PALLIATIVE CARE NETWORK OF WISCONSIN

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FAST FACTS AND CONCEPTS #3
SYNDROME OF IMMINENT DEATH

David E Weissman MD

Background Virtually all dying patients go through a stereotypical pattern of symptoms and signs in the days prior to death. This trajectory is often referred to as "actively dying" or "imminent death". Prompt recognition of this trajectory is key for clinicians to provide the most appropriate interventions for both the patient and family.

1. Stages

- ***Early***
  - Bed bound
  - Loss of interest and/or ability to drink/eat
  - Cognitive changes: increasing time spend sleeping and/or delirium (see *Fast Fact* #1)
- ***Middle***
  - Further decline in mental status to obtundation (slow to arouse with stimulation; only brief periods of wakefulness)
- ***Late***
  - Death rattle – pooled oral sections that are not cleared due to loss of swallowing reflex
  - Coma
  - Fever – usually from aspiration pneumonia
  - Altered respiratory pattern – periods of apnea, hyperpnea, or irregular breathing
  - Mottled extremities

2. Time Course The time to traverse the various stages can be less than 24 hours or as long as ~14 days. Patients who enter the trajectory who are nutritionally intact, with no infection (e.g. acute stroke), are apt to live longer than cachectic cancer patients

3. Common Family Concerns Family members present during the dying process often express the following concerns/questions. Clinicians can best help families by expecting these questions, providing education, reassurance, and responding to emotions (see also *Fast Fact* # 29; #149).

- Is my loved one in pain; how would we know?
- Aren't we just starving my loved one to death?
- What should we expect; how will we know that time is short?
- Should I/we stay by the bedside?
- Can my loved one hear what we are saying?
- What do we do after death?

4. Treatment

- Confirm treatment goals; recommend stopping treatments that are not contributing to comfort – pulse oximetry, IV hydration, antibiotics, finger sticks, etc.
- Communicate clearly to others what is going on. Write in progress notes: "patient is dying," not "prognosis is poor".
- Treat symptoms/signs as they arise: common among these are: oral secretions (see *Fast Fact* #109, #158); delirium (#1, 60); dyspnea (# 27), fever (#256) and pain (# 53, 54).
- Provide excellent mouth and skin care.
- Provide daily counseling and support to families.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #13
DETERMINING PROGNOSIS IN ADVANCED CANCER
David E Weissman MD

Background *How long do I have, Doc?* is among the most common questions asked by cancer patients, especially when informed that there are no further effective anti-neoplastic treatment options. Although prognostication is not an exact science, there are data to help clinicians provide useful information to patients and families – information critical to making realistic end-of-life decisions and referrals for home hospice service (see *Fast Fact* #30).

Performance Status The single most important predictive factor in cancer is *Performance Status* ('functional ability,' 'functional status'): a measure of how much a patient can do for themselves, their activity and energy level. Patients with solid tumors typically lose ~ 70% of their functional ability in the last 3 months of life. The most common scales used to measure functional ability are the Karnofsky Index (100 = normal; 0 = dead) and the ECOG scale (Eastern Cooperative Oncology Group), (0 = normal; 5 = dead). A median survival of 3 months roughly correlates with a Karnofsky score $\leq$40 or ECOG $\geq$ 3. Newer prognostic scales have been developed to help provide prognostic information (See *Fast Facts* #124, 125).

The simplest method to assess functional ability is to ask patients: *How do you spend your time? How much time do you spend in a chair or lying down?* If the response is >50% of the time, and is increasing, you can roughly estimate the prognosis at 3 months or less. Survival time tends to decrease further with increasing numbers of physical symptoms, especially dyspnea, if secondary to the cancer.

Other Factors Several common cancer syndromes have well-documented short median survival times:

- Malignant hypercalcemia: 8 weeks, except newly diagnosed breast cancer or myeloma (see *Fast Fact* #151)
- Malignant pericardial effusion: 8 weeks (see *Fast Fact* #209)
- Carcinomatous meningitis: 8-12 weeks (see *Fast Fact* #135)
- Multiple brain metastases: 1-2 months without radiation; 3-6 months with radiation.
- Malignant ascites (see *Fast Fact* #176), malignant pleural effusion (#209), or malignant bowel obstruction: < 6 months.
- Modified Glasgow Prognostic Score (mGPS): multiple studies have shown that an increased mGPS -- meaning an elevated serum c-reactive protein and a reduced serum albumin – is associated with a reduced cancer specific survival curve irrespective of cancer type.

Other Comments In general, a patient with metastatic solid cancer, acute leukemia or high-grade lymphoma, who will not be receiving systemic chemotherapy (for whatever reason), has a prognosis of *less than 6 months*. Notable exceptions to this are patients with metastatic breast or prostate cancer with good performance status, as these cancers may have an indolent course. In these patients additional features suggesting short prognosis are needed (declining functional status, dyspnea, weight loss).

Discussing Prognosis When discussing prognosis with patients/families, the following four step approach is recommended: *Preparation; Content; Patient's Response; Close*. Remember to:

- Confirm that the patient/family are ready to hear prognostic information.
- Present information using a range: *a few days to weeks; 2-4 months*, etc.
- Allow silence after you provide information; respond to emotion (see *Fast Fact* #29).
- Use prognostic information for eliciting end-of-life goals (see *Fast Fact* #65).

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACT AND CONCEPT #99
CHEMOTHERAPY: RESPONSE AND SURVIVAL DATA

Narendranath Epperla MD and David E Weissman MD

Background Key data in the decision process regarding chemotherapy include the response rate, median duration of response, and median survival, along with toxicity and quality of life information (see *Fast Fact* #14). The table below synthesizes data for several common cancers. The data were derived by reviewing standard oncology textbooks, along with a Medline search of recent relevant articles.

Comments on the Response and Survival Data

- All data is for patients receiving ***first-line***, commercially available, oral or IV chemotherapy and/or biological therapy (e.g. monoclonal antibodies).
- 'Response Rate' is defined as the percentage of complete and partial responders in a given trial, where 'Partial Response' = ≥ 50% reduction in measurable tumor for one month.
- Response is typically determined after 2 cycles of treatment (usually one cycle every 21-28 days). Note: patients who progress after 1 cycle will generally continue progressing after two.
- The data reflect mid-point ranges derived from the available clinical trials; most of the data represent combination chemotherapy trials. Note: for certain cancers, the benefit of combination vs. single agent therapy is not proven (e.g. pancreas, biliary, liver).
- This information is not representative of all cancer patients. The data represent the 'best case' outcome, from a population of patients who were in good enough health to participate in a clinical trial (e.g. ambulatory, good functional status). Actual responses and response durations for a non-clinical trial population will likely be poorer.
- Second-line chemotherapy, following disease progression from first-line treatment, can be expected to have a lower response rate and shorter duration of response.
- Median survival data includes both responders and non-responders. Note: patients who respond to chemotherapy typically live longer than those who do not.

	Response Rate	Median Duration of Response	Median Survival
Breast	25-55%	8-12 months	24-36 months
Lung (Non-Small Cell) NSCLC, squamous NSCLC, non-squamous	 20-36% 20-35%	 4-6 months 4-6 months	 6-11 months 10-12 months
Esophagus	30-50%	4-6 months	6-9 months
GEJ	40-60%	6-8 months	9-12 months
Gastric HER2 negative HER2 positive	 20-40% ~50%	 4-7 months 6-7 months	 6-11 months 12-14 months
Pancreas	20-32%	4-6 months	8-11 months
Liver (Hepatocellular-HCC) Non Hepatitis C related HCC Hepatitis C related HCC	25-40%	2-5 months	 6-10 months 14 months
Biliary (Cholangiocarcinoma)	20-35%	4-8 months	9-14 months
Colon	30-45%	8-10 months	16-21 months

Melanoma	15-40%	4-14 months	6-15 months

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #125

THE PALLIATIVE PERFORMANCE SCALE (PPS)

L Scott Wilner MD and Robert Arnold MD

Background Accurate prognostic information is important for patients, families and physicians. This *Fast Fact* reviews the **Palliative Performance Scale (PPS)**; see *Fast Fact* #124 The Palliative Prognostic Score for another prognostic tool used in palliative care patients.

The **PPS** uses five observer-rated domains correlated to the Karnofsky Performance Scale (100-0). The PPS is a reliable and valid tool and correlates well with actual survival and median survival time for cancer patients in outpatient and ambulatory settings. It has been found useful for purposes of identifying and tracking potential care needs of palliative care patients, particularly as these needs change with disease progression. Large validation studies are still needed, as is analysis of how the PPS does, or does not, correlate with other available prognostic tools and commonly used symptom scales.

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days (a)	(b)	(c)
100	Full	Normal *No Disease*	Full	Normal	Full	N/A	N/A	108
90	Full	Normal *Some Disease*	Full	Normal	Full			
80	Full	Normal with Effort *Some Disease*	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work *Some Disease*	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework *Significant Disease*	Occasional Assistance Needed	As above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work *Extensive Disease*	Considerable Assistance Needed	As above	Full or Confusion	30	11	41
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	As above	Total Care	Reduced	As above	8	5	
20	Bed Bound	As above	As above	Minimal	As above	4	2	

10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma	1	1	6
0	Death	-	-	-	--			

(a) Survival post-admission to an inpatient palliative unit, all diagnoses (Virik 2002).
(b) Days until inpatient death following admission to an acute hospice unit, diagnoses not specified (Anderson 1996).
(c) Survival post admission to an inpatient palliative unit, cancer patients only (Morita 1999).

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #141
PROGNOSIS IN END-STAGE COPD

Julie Wilson Childers MD, Robert Arnold MD, and J Randall Curtis MD

Background Prognostic variables in COPD patients are not well described, thus decision making regarding when to move away from aggressive life-sustaining treatments is challenging. This *Fast Fact* will review prognostication in patients with advanced COPD.

Ambulatory COPD Patients The forced expiratory volume in one second (FEV_1) has traditionally been used to assess COPD severity. A FEV_1 of less than 35% of the predicted value represents severe disease; 25% of these patients will die within two years and 55% by four years. A number of other studies have shown that age, low body mass index (BMI), serum inflammatory biomarkers (such as C-reactive protein, IL-6, and fibrinogen) and low PaO_2 were independent predictors that correlated to reduced survival time. The BODE scale, consisting of BMI, exercise capacity, and subjective estimates of dyspnea, has been shown to help predict survival over 1-3 years (2).

Variable	**Points on BODE Index**			
	0	**1**	**2**	**3**
FEV1 (% predicted)	≥65	50-64	36-49	≤35
Distance walked in 6 min (meters)	>350	250-349	150-249	≤149
MMRC dyspnea scale*	0-1	2	3	4
Body-mass index (BMI)	>21	≤21		

*MMRC dyspnea scale range from 0 (none) to 4 (4 dyspnea when dressing or undressing).

BODE Index Score	**One year mortality**	**Two year mortality**	**52 month mortality**
0-2	2%	6%	19%
3-4	2%	8%	32%
4-6	2%	14%	40%
7-10	5%	31%	80%

Note: these variables do not appear to help predict prognosis within six months of death.

Hospitalized COPD Patients Mortality statistics vary for patients admitted with COPD exacerbations depending on age, functional status, co-morbidities, and physiological variables such as hypoxia and hypercarbia. Roughly 10% of patients admitted with a $PaCO_2$ >50 mmHg will die during the index hospitalization, 33% will die within six months, and 43% die within one-year (3). Patients with less severe COPD have lower in-hospital mortality rates (4). COPD patients who require mechanical ventilation have an-hospital mortality of ~25% (5,6). Poor prognostic factors include: co-morbid illnesses, severity of illness (APACHE II score), low serum albumin, and/or low hemoglobin. Previous mechanical ventilation, failed extubation, or intubation for greater than 72 hours all increase mortality (5). In one study, patients ventilated more than 48 hours had a 50% one year survival; functional status and severity of illness were associated with short term mortality while age and co-morbidities were associated with one year mortality (2).

National Hospice and Palliative Care Organization Criteria NHPCO guidelines for hospice admission in COPD include factors such as cor pulmonale and pO2 <55 mmHg while on oxygen, albumin < 2.5 gm/dl, weight loss of > 10%, progression of disease, and poor functional status. However, a study showed when using these factors, 50% of the patients were still alive at six months, implying that the NHPCO

criteria have a limited role in predicting six month mortality and thus should be used with caution in determining hospice eligibility under the Medicare Hospice Benefit (7).

Summary COPD is a heterogeneous disease without a simple prognostic trajectory. For ambulatory patients, age, degree of dyspnea, weight loss (BMI), functional status, and FEV_1 are relevant prognostic factors for predicting 1-3 year survival. For hospitalized patients, the same factors are relevant. In addition, the need for prolonged or recurrent mechanical ventilation is predictive of a shorter prognosis.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #143
PROGNOSTICATION IN HEART FAILURE

Gary M Reisfield MD and George R Wilson MD

Background This *Fast Fact* reviews prognostication data in Heart Failure (HF). Although the Framingham Heart Study (1990-1999) showed a 5-year mortality rate of 50% for newly identified cases, providing accurate prognostic data for 6-12 month mortality in HF has been nearly impossible. Reasons cited include: 1) an unpredictable disease trajectory with high incidence (25-50%) of sudden death; 2) disparities in the application of evidence-based treatment guidelines; 3) inter-observer differences in New York Heart Association (NYHA) classification; and 4) heterogeneous study populations

NYHA Classification The NYHA classification remains the major gauge of disease severity. Based on data from SUPPORT, Framingham, IMPROVEMENT, and other studies, 1-year mortality estimates are:

- Class II (mild symptoms): 5-10%.
- Class III (moderate symptoms): 10-15%.
- Class IV (severe symptoms): 30-40%.

General Predictors of Shorter Prognosis:

- Cardiac hospitalization (triples 1-year mortality; nearly 1 in 10 die within 30 days of admission).
- Intolerance to neurohormonal therapy (i.e. beta-blockers or ACE-inhibitors) is associated with high 4 month mortality
- Elevated BUN (defined by upper limit of normal) and/or creatinine ≥1.4 mg/dl (120 µmol/l).
- Systolic blood pressure <100 mm Hg and/or pulse >100 bpm (each doubles 1-year mortality).
- Decreased left ventricular ejection fraction (linearly correlated with survival at LVEF ≤ 45%).
- Ventricular dysrhythmias, treatment resistant.
- Anemia (each 1 g/dl reduction in hemoglobin is associated with a 16% increase in mortality).
- Hyponatremia (serum sodium ≤135-137 mEq/l).
- Cachexia or reduced functional capacity.
- Orthopnea.
- Co-morbidities: diabetes, depression, COPD, cirrhosis, cerebrovascular disease, and cancer

Hospice Eligibility Guidelines The National Hospice and Palliative Care Organization's 1996 guidelines for heart disease admission criteria include: a) symptoms of recurrent HF at rest (NYHA class IV) *and* b) optimal treatment with ACE inhibitors, diuretics, and vasodilators (*contemporary optimal treatment now includes β-blockers, aldosterone antagonists, and device therapies*). The NHPCO guide indicates that an ejection fraction ≤ 20% is "helpful supplemental objective evidence," but not required. The NHPCO guidelines also assert that each of the following further decreases survival: treatment resistant ventricular or supraventricular arrhythmias, history of cardiac arrest in any setting, history of unexplained syncope, cardiogenic brain embolism, and concomitant HIV disease.

Prognostic Models Since publication of the NHPCO's guidelines, several models have been developed for predicting short- and/or long-term mortality among HF patients. Two recent models purport to predict mortality among patients *hospitalized with acutely decompensated HF.* Fonarow et al (2005), using a model based on admission BUN (≥ 43 mg/dl), creatinine (≥ 2.75 mg/dl), and systolic BP (< 115 mmHg), identified in-hospital mortality rates ranging from about 2% (0/3 risk factors) to 20% (3/3 risk factors). Lee et al (2003), using a model based on admission physiologic variables and co-morbidities (almost all from above list of indicators) identified 30-day mortality and 1-year mortality rates ranging from <1% and <10%, respectively, for the lowest risk patients to >50% and >75%, respectively, for the highest risk patients. While both models are applicable to bedside use, neither has been applied prospectively or in independent patient samples, nor do they address HF treatments as predictive variables. More recently, Levy et al (2006) developed a 24-variable risk model using the PRAISE1 (*n*=1125) database and

validated it on preexisting ELITE2, ValHeFT, UW, RENAISSANCE, and IN-CHF (*n*=9942) databases. The model purports to accurately estimate mean 1-, 2-, and 3-year survival and, importantly, *dynamically* incorporates clinical and laboratory variables, HF medications, and device therapies. It awaits independent, prospective evaluation in unselected HF patients. A web-based interactive calculator can be accessed at http://www.seattleheartfailuremodel.org.

Bottom Line Meticulous application of medication and device therapies can and will continue to change HF prognosis. HF follows an unpredictable disease trajectory, one which is highly mutable by application of evidence-based therapies, yet still marked by a high incidence of sudden death. The 1996 NHPCO criteria are not accurate predictors of 6-month mortality. Several models have recently been developed to aid in determining short- and long-term mortality in HF patients. These models await independent, prospective validation in unselected ambulatory HF patients and will need periodic updating to control for continually evolving standards of HF care. At present, accurate prognostication remains problematic.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #150
PROGNOSTICATION IN DEMENTIA

Sing Tsai MD and Robert Arnold MD

Background Dementia is a syndrome of acquired and persistent impairment in cognition and intellectual functioning (1). When caused by certain diseases or injury, dementia is irreversible, leading to progressive brain failure and death. This *Fast Fact* reviews issues of prognostication in dementia.

Natural history of dementia Olson (2003) classifies dementia into four functionally defined categories: mild, moderate, severe, and terminal. 'Terminal dementia' is defined as loss of communication, ambulation, swallowing, and continence. Others use the term "end-stage" or "advanced" making interpretation of prognostic data challenging. Many prognostic factors have been associated with shortened survival: male gender, age, diabetes mellitus, CHF, COPD, cancer, cardiac dysrhythmias, peripheral edema, aspiration, bowel incontinence, recent weight loss, dehydration, fever, pressure ulcers, seizures, shortness of breath, low oral intake, not being awake for most of the day, low Body Mass Index, and recent need for continuous oxygen. A 2012 systematic review found that malnutrition, feeding issues, and dysphagia were the strongest associated factors with 6 month mortality in elderly patients with advanced dementia. Simply being admitted to the hospital with acute illness and end-stage or terminal dementia is associated with a particularly poor prognosis: the six month mortality after hospitalization for pneumonia was 53% compared with 13% for cognitively intact patients. For patients with a new hip fracture, 55% of end-stage dementia patients died within 6 months compared with 12% for cognitively intact patients (Morrison 2000).

Prognostic Systems (see table below):

I. The National Hospice and Palliative Care Organization (NHPCO) recommends the *Functional Assessment Staging* (FAST), a 7-step staging system, to determine hospice eligibility. The FAST identifies progressive steps and sub-steps of functional decline. NHPCO guidelines state that a FAST stage 7A is appropriate for hospice enrollment, based on an expected six month or less prognosis, if the patient also exhibits one or more specific *dementia-related co-morbidities* (aspiration, upper urinary tract infection, sepsis, multiple stage 3-4 ulcers, persistent fever, weight loss >10% within six months). Luchins (1997) studied the relationship of FAST to survival in 47 patients enrolled in hospice with advanced dementia and one or more dementia-related co-morbidities. The median survival for all patients was 6.9 months; 38% survived beyond six months. Of note, 41% of patients did not demonstrate dementia progression in a manner that allowed for assigning a FAST stage. For those patients who could be assigned a FAST stage (n = 12), and who were at stage 7C or greater, mean survival was 3.2 months. The generalizability and clinical relevance of this data are greatly compromised by this very low patient number.

II. The *Mortality Risk Index* (MRI), a composite score based on 12 risk factor criteria obtained from using the MDS (Minimum Data Set), has been suggested as an alternative to FAST. Mitchell (2004) developed and then validated the MRI by examining data from over 11,000 newly admitted nursing home patients. Among patients with a MRI score of ≥ 12, 70% died within 6 months (mean survival time not reported). Compared to FAST Stage 7C, the MRI had greater predictive value of six month prognosis. The MRI as only been evaluated in newly admitted nursing home residents; it has yet to be validated in the community setting or for previously established long-term nursing home residents.

Medical Interventions Estimation of prognosis in severe/terminal dementia is in part dependent on the goals of care and decisions regarding the level of intervention that will be provided to treat acute medical problems such as urosepsis and malnutrition.

Summary Although many prognostic risk factors have been identified there is no gold standard to help clinicians determine a less than six months prognosis with any degree of certainty. The criteria adopted by NHPCO for hospice eligibility is based on very limited research and lacks important studies to determine FAST scale reliability and validity among referring physicians and hospice staff. The MRI is a promising new scale but more research is needed. Physicians can best help their patients by working with families to help them establish goals of care and levels of medical intervention that are most consistent with current medical research and family/patient preferences.

Functional Assessment Staging (FAST)

Stages

1. No difficulties
2. Subjective forgetfulness
1. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7. A. Ability to speak limited to six words
   B. Ability to speak limited to single word
   C. Loss of ambulation
   D. Inability to sit
   E. Inability to smile
   F. Inability to hold head up

Mortality Risk Index Score (Mitchell)

Points	Risk factor
1.9	Complete dependence with ADLs
1.9	Male gender
1.7	Cancer
1.6	Congestive heart failure
6.	O_2 therapy needed w/in 14 day
1.5	Shortness of breath
1.5	<25% of food eaten at most meals
1.5	Unstable medical condition
1.5	Bowel incontinence
1.5	Bedfast
1.4	Age > 83 y
1.4	Not awake most of the day

Risk estimate of death within 6 months

Score	Risk %
0	8.9
1-2	10.8
3-5	23.2
6-8	40.4
9-11	57.0
≥ 12	70.0

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content. The full set of *Fast Facts* are available at Palliative Care Network of Wisconsin with contact information, and how to reference *Fast Facts.*

Disclaimer: *Fast Facts and Concepts* provide educational information for health care professionals. This information is not medical advice. *Fast Facts* are not continually updated, and new safety information may emerge after a *Fast Fact* is published. Health care providers should always exercise their own independent clinical judgment and consult other relevant and up-to-date experts and resources. Some *Fast Facts* cite the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.

PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #189
PROGNOSIS IN DECOMPENSATED CHRONIC LIVER FAILURE

Brigid Dolan MD and Robert Arnold MD

Background In 2009, chronic liver disease and cirrhosis resulted in approximately 30,000 deaths, making it the twelfth leading cause of death in the United States. Patients with compensated chronic liver failure (without ascites, variceal bleeding, encephalopathy, or jaundice) have a median survival of 12 years. After decompensation, median survival drops to ~ 2 years. This *Fast Fact* reviews prognosis in chronic liver failure, focusing on two validated prognostic indices. Of note, these indices predict prognosis for patients without liver transplantation.

The ***Child's-Turcotte-Pugh (CTP)*** score includes 5 variables, each scored 1-3:

	Numerical Value		
Variable	1	2	3
Ascites	None	Slight	Moderate/Severe
Encephalopathy	None	Grade 1-2	Grade 3-4
Bilirubin (mg/dL)	< 2.0	2.0-3.0	>3.0
Albumin (mg/L)	> 3.5	2.8-3.5	<2.8
Increase in seconds from normal Prothrombin time	1-3	4-6	>6.0

Patients are grouped into three classes based on the total CTP score, which is simply the sum of the scores for each of the 5 variables. Patients scoring 5-6 points are considered to have *'Class A'* failure*;* their 1 and 2 year median survivals are 95% and 90%, respectively. A score of 7-9 is considered *Class B* with median survivals of 80% at 1 year and 70% at two years. *Class C* patients (10-15) have far greater mortality: 1-year median survival is 45% and 2-year is 38%. Variations in the timing and subjectivity inherent in the scoring of the CTP (e.g. in grading ascites or encephalopathy) are its major limitations. In addition, the scale does not include renal function, an important prognostic factor in liver failure.

The ***Model for End-stage Liver Disease (MELD)*** score was developed in 2000 to overcome the above-mentioned limitations and determine survival benefit from transjugular intrahepatic portosystemic shunting. It is currently used to help determine organ allocation for liver transplantation, and there is increasing evidence that it can also be used generally to predict survival in patients with chronic liver failure. The MELD score relies on laboratory values alone (serum creatinine, total bilirubin, and INR). An additional benefit over CTP is that it can predict prognosis on the order of months with more precision – making it helpful for determining hospice eligibility in the US. The formula to calculate MELD score is complex, and a calculator can be found at: http://reference.medscape.com/calculator/meld-score-end-stage-liver-disease.

MELD Score	**Predicted 6 month survival**	**Predicted 12 month survival**	**Predicted 24 month survival**
0-9	98%	93%	90%
10-19	92%	86%	80%
20-29	78%	71%	66%
30-39	40%	37%	33%

Other important prognostic variables The hepatorenal syndrome (HRS) – renal failure from renal arterial under-filling due to decompensated liver failure – portends a particularly poor prognosis. Most patients with type-1 HRS (rapid and severe renal failure) die within 8-10 weeks even with therapy. Median survival with type-2 HRS (chronic, less severe renal failure with serum creatinine usually 1.5-2 mg/dL) is around 6 months. Both older age and hepatocellular carcinoma also adversely affect survival. While the CTP and MELD systems provide objective guidance to prognostication in liver failure, clinical judgment, patient comorbidities, the rate of decompensation, and the likelihood of transplantation all should additionally affect the assessment and communication of a patient's prognosis in liver disease.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #191
PROGNOSTICATION IN PATIENTS RECEIVING DIALYSIS

Matthew Hudson, Steven Weisbord MD, Robert Arnold MD

Background End stage renal disease (ESRD) is a highly prevalent and rapidly increasing condition. While dialysis prolongs life in patients with ESRD, life expectancy remains only a third to a sixth as long as similar patients not on dialysis. The overall one and five year mortality rates are 25% and 60%, respectively. Approximately 20% of ESRD patient deaths occur after a decision to stop dialysis, highlighting the importance of discussions of prognosis and goals of care with this chronically ill population. This *Fast Fact* reviews the current data regarding prognostication in patients receiving chronic hemo- and peritoneal dialysis. **Note:** renal transplantation reduces mortality and the following data do not consider patients with functioning kidney transplants.

Prognostic Factors Several patient-specific factors influence prognosis:

- *Age:* For 1-year increments beginning at age 18, there is a 3 to 4% increase in annual mortality compared to the general population. 1 and 2 year mortality rates go from 10 and 12% at 25-29 years of age, to 25% and 42% at 65-69 years, to 39% and 61% at 80-84 years of age.
- *Functional status:* the relative risk of dying within 3 years of starting dialysis is 1.44 for those with Karnofsky Performance Status scores of <70 compared to a score ³70 (see *Fast Fact* #13).
- *Albumin:* a low serum albumin level, both at baseline and during the course of dialysis treatment, is a consistent and strong predictor of death. For example, the 1 and 2 year survival of patients with an albumin of >3.5 g/dL is 86% and 76% respectively, compared to 50% and 17% if less than 3.5.
- *Surprise question*: in a multivariate analysis, the likelihood of death in 6 months was significantly greater when nephrologists answered no to the question "*would I be surprised if this patient died within 6 months*?"

Prognostic Tools It has long been recognized that patient comorbidity is strongly correlated with prognosis in ESRD. An age-modified Charlson Comorbidity Index (CCI), which stratifies patients based on medical comorbidities and age, has been successfully used to predict mortality in dialysis-dependent patients (8):

Modified Charlson Comorbidity Index: Total score is the sum of the comorbidity points

Comorbidity Points				
1 point each for coronary artery disease, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disorder, peptic ulcer disease, mild liver disease, diabetes **1** point for every decade over 40 (e.g. a 65 year old would receive 3 points).				
2 points each for hemiplegia, moderate-to-severe renal disease (including being on dialysis), diabetes with end-organ damage, cancer (including leukemia or lymphoma)				
3 points for moderate-to-severe liver disease				
6 points each for metastatic solid tumor or AIDS				
Modified CCI Score Totals	Low score (£3)	Moderate (4-5)	High (6-7)	Very High (³8)
Annual mortality rate	0.03	0.13	0.27	0.49

For example, a 66 year old male on dialysis with a history of CHF, COPD, and diabetes with retinopathy would have a CCI score of 9 and a nearly 50% chance of dying within a year. Using this, a provider could discuss with the patient his prognosis and use this to facilitate further discussion regarding planning for

the future, including end-of-life decisions. The Index of Coexistent Disease (ICED), a general illness severity index, has also shown predictive power in ESRD. The scale's complexity and length however (it entails asking over 100 questions) limit its clinical usefulness.

Summary The age-modified CCI, in conjunction with other prognostic factors such as serum albumin and functional status, can be used to help facilitate discussions with dialysis-dependent patients and their families regarding goals of care and end-of-life planning.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #234
PROGNOSIS OF ANOXIC-ISCHEMIC ENCEPHALOPATHY 3RD EDITION

James Fausto MD

Introduction Cardiac arrest, experienced by approximately 450,000 Americans annually, has a very poor survival rate (see *Fast Fact* #179). Some patients who initially survive cardiopulmonary resuscitation remain comatose, demonstrating obvious impairments in consciousness and neurologic function. This syndrome, called anoxic-ischemic encephalopathy (AIE, also known as 'anoxic brain injury,' or 'hypoxic-ischemic coma'), can result in outcomes ranging from full recovery to permanent unconsciousness to death. This *Fast Fact* discusses prognostic factors in adults with AIE after cardiac arrest.

"Neurologic Outcome" A challenge in interpreting the literature on AIE is the use of variable or imprecise definitions of a 'poor neurologic outcome.' The American Academy of Neurology practice parameter paper defines poor outcome as: death, persistent unconsciousness (such as a vegetative state), or severe disability requiring full nursing care after 6 months (6). This is the definition used in this *Fast Fact*.

Predictors of Neurologic Outcome A review of the current literature reveals that data obtained by careful neurologic exam, electrophysiologic studies, and biochemical markers are most predictive of outcome (see below). Other factors not strongly predictive of outcome include: age, sex, cause of arrest, type of arrhythmia, total arrest time, duration of CPR, geographic location of arrest, elevated body temperature, elevated intracranial pressure, concurrent respiratory failure, and early brain imaging findings (3,6,7,8).

Note: the data below assume patients are not receiving medications which would significantly confound their neurologic examination such as high-dose barbiturates. In all cases, specialist neurologic examination and input is advised.

Strong Indicators of Poor Outcome (false positive rates of 0% based on current literature):

- Absent pupillary light reflexes 24 hours after CPR, or 72 hours after CPR for those who initially had intact papillary light reflexes (3,6,7).
- Absent corneal reflexes 72 hours post-CPR (6,7).
- Short-latency Somatosensory Evoked Potentials (SSEP, an electrophysiologic study): bilateral absence of the N20 potentials on SSEP of the median nerve in AIE patients greater than 24 hours post-CPR (1,6,7,8).
- Neuron-Specific Enolase (NSE, a blood test): serum NSE > 33 mcg/L on day 1 to 3 (6,7,8). While this biomarker is promising, it has not been studied in large trials, nor is the assay itself standardized, so its current clinical role remains undefined (7).

Moderate Predictors of Poor Outcomes (these all predict a poor outcome, but not as invariably as the above factors based on current literature):

- Clinical exam findings: no spontaneous eye movements or absent oculocephalic reflexes at 72 hours post-arrest (3,6,7). No, or extensor-only, motor response to painful stimuli at 72 hours also implies a very poor chance of recovery (3,6).
- Electroencephalogram findings: certain findings can be strongly associated with poor outcomes but are highly subject to institutional/technician variability. Myoclonic status epilepticus within 1 day of cardiac arrest is the most predictive of a poor outcome (3,6,7,8).

The Therapeutic Hypothermia Protocol The majority of the evidence for prognosis in the comatose patient after CPR predates the widespread use of therapeutic hypothermia in patients after cardiac arrest. It remains unclear how this intervention will change prognostication. While the above factors will likely still indicate poor prognosis, the timing of when the evaluations should be done, as well as if they will predict a *uniformly* poor outcome is uncertain. One European study advises that patients have an initial

neurological assessment as soon as possible, but that the second assessment occurs *no earlier* than 48-72 hours after the return of normal blood temperature and not 48-72 hours after the discontinuation of active cooling (2). Zandbergen et al suggest that serum NSE >33 mcg/L occurring while hypothermic still consistently predicts poor outcomes accurately (8). Initial data (4,8) on the predictive value of SSEPs in patients who underwent hypothermia confirmed that bilateral absent N20 responses is highly predictive of a poor outcome. There has been a case report of an isolated patient with absent N20 responses who made a full recovery, highlighting the importance of ongoing investigation into the impact of the hypothermia protocol on the prognosis of AIE (4).

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Author Affiliation: Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, NY.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #235
PROGNOSTIC MODELS IN CRITICALLY ILL ADULTS

René Claxton MD, Derek Angus MD, and Robert Arnold MD

Background Prognostication for ICU patients is challenging. Grieving families, trying to make informed decisions about their loved ones care, often ask *What are the chances he or she will get through this?* Several prognostic models have been developed to predict survival for groups of patients stratified by severity of illness. These are used in outcomes research to compare patient groups, assess and compare ICU performance and help guide resource allocation. Anecdotally, data from these models is sometimes used in discussing prognosis with family members of critically ill patients. This *Fast Fact* discusses common ICU prognostic models and their role in guiding patient care and communication.

Widely used ICU prognostic models Common models for predicting mortality in medical-surgical ICU patients include the Acute Physiologic and Chronic Health Evaluation (APACHE) score, the Mortality Probability Model (MPM), the Simplified Acute Physiology Score (SAPS) and the Sequential Organ Failure Assessment (SOFA) score (1-4). The SOFA score can be calculated at the bedside based on laboratory and physiologic data; however, this model has not been widely used in either clinical or research practice by the critical care community to predict mortality. The APACHE, MPM, and SAPS models are more widely used and require computer software to calculate a score based on multiple variables including type of admission, the patient's underlying diseases, physiologic data, and – in the case of APACHE – laboratory data. The APACHE score is based on the worst values available during ICU Day 1 whereas MPM and SAPS scores are calculated based on data obtained within one hour of ICU admission. The models require re-validation over time as ICU interventions and outcomes change. The APACHE score is currently in its fourth version. MPM and SAPS are in their third versions. Although APACHE IV and MPM III require proprietary software to calculate a score, the SAPS3 score can be computed using a downloadable calculator (5). Individual institutions may use a model for all ICU admissions for purposes of quality monitoring, outcome reporting, or research, and so some clinicians may have these scores readily available to them.

Accuracy of the prognostic models The discrimination and calibration ability of ICU prognostic models determine their predictive accuracy (6). Discrimination is the ability of a model to predict a mortality rate similar to the observed rate; calibration reflects a model's ability to predict an outcome at multiple levels (mortality rates). The most recent versions of APACHE, MPM, AND SOFA show both high discrimination and calibration. All three models report a score based on the above variables that correlates with a predicted in-hospital mortality rate. For example, a SAPS3 score of 73 correlates with a hospital mortality rate of 62%. The other two models work similarly.

Clinical use of ICU prognostic models All of these models accurately predict *rates of in-hospital mortality in a population* of critically ill patients. This is different than predicting survival for an individual patient (7), let alone using them to guide individual treatment decisions. None of the models alone can, for instance, predict 100% mortality, a standard that some families and clinicians may require in order to limit life-sustaining treatments. Also, as these models focus solely on in-hospital mortality as the outcome measure, a patient's functional status, quality of life, and long-term prognosis are not predicted. These considerations can be equally as important as short-term survival for families and clinicians in determining appropriate treatment goals. Practically, then, the clinical use of the models is best limited to three uses:

1. *As a single 'data point' among many to guide patient-centered decision-making.* Clinicians can use outcome data from the tools, along with patient co-morbidity, long-term prognosis, baseline and anticipated functional status and quality of life, etc., to guide discussions (see *Fast Facts* 222-227). *Chances are your loved one is not going to survive this illness. She might, and currently we are doing everything we can to get her through this. However, even if she does, her emphysema is severe enough that we will not be able to improve her breathing or ability to take care of herself any more than before she became this ill, and it is very likely another event like this will happen again in the near future.*
2. As a screening tool to identify those ICU patients uniquely 'in need' of palliative care evaluation.
3. As a research tool to look at the impact of interventions on mortality, morbidity and quality of life.

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Author Affiliations: University of Pittsburgh Medical Center, Pittsburgh, PA.

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PALLIATIVE CARE NETWORK OF WISCONSIN

FAST FACTS AND CONCEPTS #239
PROGNOSTICATION IN SEVERE TRAUMATIC BRAIN INJURY IN ADULTS

Stacy M Kessler MD and Keith M Swetz MD

Background Traumatic brain injury (TBI) is defined as brain injury caused by an external force – most commonly falls, struck by/against events, motor vehicle collisions, and assaults. The vast majority of patients with mild to moderate TBIs have substantial recoveries; this is not true of severe TBIs. This *Fast Fact* discusses prognostication in severe TBI in adults.

Initial TBI severity TBI severity is most commonly graded by the initial Glasgow Coma Scale (GCS) score. The GCS rates the patient's best verbal response, best motor response and the stimulus needed to elicit eye opening. Scores range from 3-15, with score ≤ 8 representing coma. 'Mild' TBI (accounting for ~80% of cases) is manifest by a 30 minute post-injury GCS of 13-15. 'Moderate' TBI consists of immediately altered or loss of consciousness for > 30 minutes and 6 hour post-injury GCS of 9-12. 'Severe TBI' involves immediate loss of consciousness for > 6 hours with residual GCS of 3-8.

Long-term outcomes The Glasgow Outcome Scale (GOS) is a five-point scale used widely in brain injury research. An eight-point Extended Glasgow Outcome Scale (GOS-E) is available with more sensitivity to change in function, but most outcome studies reference the GOS. The GOS range is (1) death, (2) persistent vegetative state (unconscious and unable to interact), (3) severe disability (conscious; cannot live independently; requires daily assistance due to physical or mental impairment), (4) moderate disability (able to live independently; able to work in a supported environment), and (5) good recovery (minimal or no deficits; able to work and socialize normally). In addition to global functional impairments, survivors of severe TBIs often have impairments in memory, executive functioning, impulse control, sensory processing, and communication skills. Mental health problems are common.

Predicting outcomes Overall 30-day mortality following TBI is estimated to be 20% with the highest mortality corresponding to the worst initial GCS scores. For patients with reliable initial GCS scores of 3-5, only 20% will survive and less half of those survivors will have what is often referred to in the research literature as a 'good outcome' (GOS 4-5). Older age, lower initial GCS score, abnormal initial pupil reactivity, longer length of coma and duration of post-traumatic amnesia, and certain computed tomography findings all indicate a smaller chance of recovery to GOS 4-5. Kothrari proposed the following prognostic guidelines, based on a comprehensive review of studies that looked at outcome in adults 6 months or later after severe TBI [8]:

- Favorable outcome (GOS 4-5) likely when the time to follow commands is less than 2 weeks after injury, and the duration of post-traumatic amnesia is less than 2 months.
- Poor outcome (GOS <4) is likely when the patient is > 65 years old, the time to follow commands is longer than 1 month, or the duration of post-traumatic amnesia is greater than 3 months.
- Notably, 10% of patients will not have the outcome predicted by the guidelines above.

A multinational collaborative trial developed a prognostic model (referred to as the CRASH prognostic mode) which has been validated to predict outcomes in TBI (9,10). The model is available online and uses age, GCS, pupil reactivity, presence of major extracranial injury, and (optional) computed tomography findings to give rates of death at 14 days post-injury and GOS at 6 months for survivors (11).

Helping families make decisions Families of patients with severe TBIs may be confronted with decisions about medical care (e.g. gastrostomy tube placement, chronic ventilatory support, dialysis). Such decisions often depend on a family's understanding of a patient's long-term functional outcome. The above-mentioned prognostic indicators can help clinicians provide objective information for families about the likelihood of recovery after a TBI. As with all prognostic tools, however, clinicians can only predict what would happen to a population of patients with a similar injury (e.g. 'only 10% of patients would recover such that they could live independently'); this is different from predicting any particular patient's course. It is important to communicate the uncertainty that accompanies most prognostic estimations. Counseling families about long-term functional prognosis, as well as the expected treatment course (what rehabilitation would involve) is important. While the research literature often defines a 'good recovery' as GOS 4-5, that may not constitute a 'good' recovery for an individual patient. Clinicians

should avoid such language at the bedside and instead use detailed descriptive language of expected functional and cognitive outcomes. Early and frequent family meetings can facilitate communication, built rapport, and are vital in expectation setting and establishing goals of care. If life sustaining treatments are initiated, framing the treatments in the context of time-limited trials is helpful. This empowers family members to discontinue certain cares after a specified period of time if the prognosis remains unchanged or if the treatment is not meeting the goals of care (e.g. helping to restore a patient to a functional status which is acceptable to the patient). Interdisciplinary team members including speech, occupational, and physical therapists, physiatrists, neurologists, palliative care clinicians, and neurosurgeons can be important in letting family members more fully understand a patient's likely future. See *Fast Fact* #226 about helping surrogates make decisions.

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Author Affiliations: Mayo Clinic, Rochester, MN.

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FAST FACTS AND CONCEPTS #360
THE SURPRISE QUESTION AS A PROGNOSTIC TOOL
Kate S. Jennings, MD[1], Sean Marks, MD[2], and Hillary D. Lum, MD, PhD[1,3]

Background: Clinicians have been encouraged to utilize the surprise question (SQ) -- "*Would I be surprised if this patient died within 12 months*?" – to identify patients at high 1-year mortality risk. When clinicians answer "No – I would NOT be surprised if this patient died within 12 months," the SQ may help clinicians identify patients with unmet palliative care needs who could benefit from advance care planning discussions and/or a palliative care referral (1). This *Fast Fact* reviews the clinical utility of the SQ.

Rationale of the SQ: As difficult as it is for clinicians to prognosticate accurately, multiple studies have shown that patients with incurable disease desire more prognostic information the sicker they get and prognosis is a major factor in preferences for rehospitalizations, life support, and CPR (2-4). Although, patients and surrogates often want *temporal prognostic predictions* (the clinician's estimated length of time he or she predicts the patient will live), clinicians are more accurate and willing to offer *probabilistic predictions* (the clinician's estimate, often in a percentage, of the chance of death in a set time frame, such as 1 year) (4-6). The SQ was designed as a clinical tool that generalist clinicians would utilize willingly and routinely to identify patients at risk of death in a year and thereby lead to more appropriate advance care planning, goals of care discussions, symptom management, and hospice referrals.

Effectiveness of the SQ: Although variations on the SQ have been described in the published literature including "*Would I be surprised if this patient died this hospitalization*?" or "*Would I be surprised if this patient died in 3 months*?", the SQ most commonly referred is "*Would I be surprised if this patient died within 12 months*?" This SQ has been studied in diverse populations, including a general inpatient setting (7), high-risk primary care clinic (8), pediatric patients (9), advanced kidney disease (10-12), cancer (13,14), acute surgical patients (15), emergency department settings (1,16), and nursing home settings (17). In general, the SQ has performed modestly well in identifying patients with a prognosis of < 1 year across these various patient populations (18,19). Notable findings from these studies include:

- A meta-analysis of the SQ among 26 studies across these patient populations found that it had a pooled accuracy of 75%, a sensitivity of 67% and specificity of 80% (18).
- "Yes" answers appear to be much more accurate than "No" answers. The predictive value of a "Yes" answer was 93%, while only 37% for a "No" answer (18). This means that the SQ is likely better designed to identify patients who will live more than a year vs the patients who live less a year. It also suggests that there is "false positives" are relatively common when clinicians answer "No" to the SQ.
- The SQ may be slightly more accurate for cancer patients (pooled accuracy 79%) and renal patients (76%) vs other disease groups (72%) (18). This may reflect a more predictable illness trajectory in cancer and renal disease. See *Fast Fact* #326 for more information on illness trajectories.
- In most studies, the SQ was utilized as one aspect of a broad prognostic assessment which included clinician gestalt and/or other prognostic tools. Hence, used in isolation, its accuracy is unclear (18).

Implementing the SQ Into Clinical Practice: The SQ can be helpful in identifying patients at risk of medical decline and death in a certain time frame when used as part of a larger prognostic assessment (19). Yet, considering the relatively high false positive rate of a "No" answer, it is not established if the SQ is a cost-effective tool nor an effective way to trigger a palliative care consultation on its own. A consensus panel of experts suggested that a "No" answer trigger generalist clinicians to perform a primary palliative care assessment or screening for unmet palliative care needs (20). Sentinel medical events like hospitalization, decline in performance status, or disease progression are reasonable triggers to implement the SQ into clinical practice. Note templates, medical rounding tools, and electric medical record prompts are potential system-based approaches to accomplish this. Reasonable components of the primary palliative care assessment triggered by a "No" include (20):

- Assessment for distressing physical, psychological, social, or spiritual concerns.
- Identification of whether the patient completed an advance directive such as a health care power of attorney that is available in the medical records.
- Assessment of patient, family, and/or surrogate's understanding of the underlying illness, treatment options, and prognostic trajectory.
- Assessment of decision-making capacity.
- Engagement in honest conversations about prognosis and medical expectations.
- Elicitation of the patient's care preferences and values.
- Consideration of whether a hospice referral would be appropriate.
- Consideration of whether a palliative care consultation may be beneficial.

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Author Affiliations: [1]University of Colorado School of Medicine, Aurora, CO, USA; [2]Medical College of Wisconsin, Milwaukee, WI; [3]Veterans Affairs Eastern Colorado Geriatric Research Education and Clinical Center, Denver, CO, USA

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FAST FACTS AND CONCEPTS #374
PROGNOSIS AFTER STROKE
Lily Kosminsky, Nidhi Shah MD, Philip Chang DO

Background Patients who suffer from an acute stroke often cannot make informed medical decisions and may not have advance directives. The rapidity of its onset often means that the burden of whether to pursue placement in a nursing home and/or life-prolonging measures such as artificial feeding, falls on unprepared loved ones. This *Fast Fact* reviews clinical factors and tools which could help in prognostication and medical-decision-making for stroke patients.

Accuracy of Clinician Predictions Stroke-related morbidity and mortality improved significantly between 1995 and 2010 (2). Still, prognostication following stroke, even when done by neurologic specialists, remains overly optimistic (1). In general, predictions of a poor outcome (death or severe disability meaning a life of complete dependence) remain relatively reliable (90% accurate in one study), but <1/2 of the predictions for a good outcome were accurate (3). One unanswered and debated clinical question is whether a clinician's prediction of a poor outcome, especially if made early after the stroke, increase the likelihood that families will withdraw life-sustaining treatment (4,5), and thereby becomes a self-fulfilling prophecy. To our knowledge, there are no studies which have assessed the prognostic accuracy of palliative care clinicians for post-stroke patients.

Early Prognostic Factors Stroke scales and other prognostic factors have been recognized to help predict morbidity and mortality in the first few days of a hospitalization. This data is often utilized to triage and guide immediate post-stroke decisions by neurologists, generalist clinicians, or intensive-care clinicians. The most commonly used and studied is the National Institute of Health Stroke Scale (NIHSS) which is also used as a gold standard (6). The Modified NIHSS (mNIHSS) and the Scandanavian Stroke Scale (SSS) are similarly notable scales which have been shown to have comparable reliability to the NIHSS yet may be easier to use and have better interrater reliability (7,9). Unfortunately, all these scales (including the NIHSS) are similarly optimistic and likely less accurate than clinician gestalt (6-9). While high scores (e.g. an NIHSS score >16) reliably predict poor outcomes at 3 months, low or intermediate scores are of minimal value. Other "early" prognostic factors correlated with poor outcomes include age > 75, female gender, embolic stroke type, hemorrhagic conversion, onset to treatment > 2 hours, ED stay > 8 hours, failure to receive tPA, failure to receive treatment in a dedicated stroke unit, low income (except in universal healthcare systems), and poor social support.

Late Prognostic Factors Often times palliative care specialists are not consulted until several days after an acute stroke at which point these "later" prognostic factors take on greater importance in the decision-making process. Dysphagia that persists 3-7 days after a stroke is associated with worse 1-year functional outcomes (11). Additionally, data suggest that only 10-15% of post-acute stroke patients who require a gastric feeding tube ever make it home. Post-stroke coma lasting > 3 days and an absent response to verbal stimuli at 3 days or later have been associated with poor outcomes as well (15), while active finger extension (at least able to resist gravity) at 7 days is correlated with a more favorable functional outcomes at 6 months (16). For surrogates considering withdrawal of ventilatory support for post-stroke patients and a transition to comfort as the primary goal of care, survival times generally range between 10 minutes to 11 days with a median survival of 7.5 hours (13). Multiple studies suggest the greatest neurologic recovery from a stroke occurs in the first 6 months (13-16).

Palliative Care Considerations For clinicians and surrogates faced with these challenging post-stroke decision-making situations, exploring the patient's values and identifying things that matter most to the patient should guide treatment choices. The common dilemma surrogates face is taking a small chance for meaningful functional recovery while a patient remains in what is often a completely dependent state for potentially months to years vs deciding to forgo or discontinue nutritional support which will invariably result in death. Evidence suggests that 75% of families prefer a shared or collaborative decision-making model in stroke care vs unilateral physician or surrogate decision making (13). Decision-making tools such as the best case-worst case scenario may be helpful methods to achieve informed and collaborative value-based decisions for both patients and surrogates of post-stroke patients (17). Considering that survey data suggest that clinicians may be prone to disability biases in post-stroke patients (meaning clinicians who are not disabled predict poorer life satisfaction and poorer resiliency than is reported by individuals disabled by the illness) (1,12), in certain circumstances it may be reasonable to give a trial of nasogastric feedings for 3-7 days immediately after a stroke. If there is no significant neurologic recovery at that point and surrogates are still having significant difficult deciding, a 3-6-month time-limited trial of skilled nursing facility placement with artificial nutrition via a more permanent feeding tube could be reasonable if there is adequate follow up to readdress goals of care if quality of life has not improved to an acceptable level.

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Author Affiliations: Drexel University College of Medicine, Philadelphia, PA; Montefiore Medical Center, New York, NY.

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