Prognosis and Decision Making in Severe Stroke

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The trend in terminal extubation practices occurs in the broader acceptance of the “shared decision making” model of care in which the decision to continue or withdraw respiratory support is based on prognosis, benefits and burdens of treatment choices, and patient values and wishes. Indeed, promoting “patient-centered” care has emerged as a central theme in improving the nation’s health care quality. At the same time, however, striking variations in end-of-life and withdrawal-of-care practices have been documented among highly respected hospitals and individual intensive care units (ICUs).

The proportion of all ICU deaths preceded by withdrawal of life support, which include individuals with cerebrovascular disorders, ranged from 0% to 79% in one study and 1.7% to 96% in another. This marked variation has raised concern because it may reflect care decisions insensitive to patient preferences. Supporting such concerns are emerging data about the lack of evidence regarding prognosis after a stroke and that physicians inadequately communicate with families and interpret patient preferences poorly.

Unwarranted variations in the terminal extubation practices for patients with severe stroke may have true

Context An increasing number of deaths following severe stroke are due to terminal extubations. Variation in withdrawal-of-care practices suggests the possibility of unnecessary prolongation of suffering or of unwanted deaths.

Objectives To review the available evidence on prognosis in mechanically ventilated stroke patients and to provide an overall framework to optimize decision making for clinicians, patients, and families.

Data Sources Search of MEDLINE from 1980 through March 2005 for English-language articles addressing prognosis in mechanically ventilated stroke patients. From 689 articles identified, we selected 17 for further review. We also identified factors that influence, and decision-making biases that may result, in overuse or underuse of life-sustaining therapies, with a particular emphasis on mechanical ventilation.

Evidence Synthesis Overall mortality among mechanically ventilated stroke patients is high, with a 30-day death rate approximating 58% (range in literature, 46%-75%). Although data are limited, among survivors as many as one third may have no or only slight disability, yet many others have severe disability. One can further refine prognosis according to knowledge of stroke syndromes, early patient characteristics, use of clinical prediction rules, and the need for continuing interventions. Factors influencing preferences for life-sustaining treatments include the severity and pattern of future clinical deficits, the probability of these deficits, and the burdens of treatments. Decision-making biases that may affect withdrawal-of-treatment decisions include erroneous prognostic estimates, inappropriate methods of communicating evidence, misunderstanding patient values and expectations, and failing to appreciate the extent to which patients can physically and psychologically adapt.

Conclusions Although prognosis among mechanically ventilated stroke patients is generally poor, a minority do survive without severe disability. Prognosis can be assessed according to clinical presentation and patient characteristics. There is an urgent need to better understand the marked variation in the care of these patients and to reliably measure and improve the patient-centeredness of such decisions.

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“life and death” consequences. Decisions to continue treatment in situations in which the patient would prefer death can lead to errors of overuse of life-sustaining treatments, with prolongation of patient and family suffering. Decisions to withdraw treatment when the patient would prefer living can lead to errors of underuse of life-sustaining treatments and premature death because many patients with severe stroke can survive and, depending on the severity of the deficits, partially recover with continued support.

We review the available evidence on prognosis after severe stroke leading to mechanical ventilation and, using the core elements of the shared decision-making model of care, identify factors and biases that may lead to underuse or overuse of life-sustaining therapies. Finally, we conclude by suggesting an overall approach to assist physicians and families through this difficult period.

EVIDENCE ACQUISITION

To anchor the prognostic question on a common clinical situation, we focused on patients with either an ischemic stroke or intracerebral hemorrhage who were mechanically ventilated. We performed a search of MEDLINE for English-language literature from 1980 to March 2005. Search entries included the search terms stroke and mechanical ventilation. Articles were selected by using the following inclusion criteria: patients with ischemic stroke or intracerebral hemorrhage who were mechanically ventilated, were aged 18 years or older, and had an outcome assessment in the hospital or after discharge. We identified 689 possible studies, 17 of which met our inclusion criteria. In addition to foreign-language studies, we excluded studies if they did not provide mortality data by stroke type or if they included all stroke patients admitted to an ICU, including patients not mechanically ventilated. From each article, we abstracted demographic information, reasons for mechanical ventilation, losses to follow-up, number and cause of deaths, disability outcomes, and variables associated with mortality and long-term survival. We defined no or slight disability as a Barthel Index (BI) score of 90 to 100, a modified Rankin Scale (MRS) score of 0 to 2, or a Glasgow Outcome Scale (GOS) score of 5. Moderate disability was defined as a BI score of greater than 40 to less than 90, an MRS score of 3, or a GOS score of 4. Severe disability was defined as a BI score of 40 or less, an MRS score of 4 or 5, or a GOS score of 2 or 3. We also used verbal descriptions that allowed mapping into 1 of the 3 disability categories. Mortality and disability data were independently abstracted by 2 authors (R.G.H. and W.S.B.), and disagreements were resolved by discussion and consensus.

EVIDENCE SYNTHESIS

Prognosis in Mechanically Ventilated Stroke Patients

Of 17 studies identified, 7 were prospective and 10 were retrospective, with representation from 4 countries: United States (9), Germany (4), France (3), and Israel (1). Eight studies enrolled ischemic strokes and intracerebral hemorrhages, 7 enrolled only ischemic strokes (3 of which focused on carotid territory strokes and 1 on basilar occlusion), and 2 enrolled only intracerebral hemorrhages. One study provided disability data after mechanical ventilation requiring tracheostomy. Most studies included patients who developed ventilatory failure for neurologic or respiratory reasons while excluding patients primarily intubated for elective procedures. Two studies focused on patients requiring intubation for neurologic deterioration not thought to be due to other reasons. The mean age of intubated patients was 64 years, with a range from 59 to 75 years. All studies had greater than 93% follow-up, except 2 with 89% and 74%. Two studies collected long-term quality-of-life data.

TABLE 1 shows published mortality rates by stroke type and length of follow-up. Excluding the basilar occlusion study and the 2 studies that enrolled patients exclusively in the 1980s, the observed inpatient mortality rate was 55% (range, 48%-70%). The 30-day mortality rate increased to approximately 58% (range, 46%-75%). By 1 to 2 years, mortality rates increased to approximately 68% (range, 59%-80%).

Table 2 shows disability by stroke type and length of follow-up among early survivors. Although data are limited, among survivors as many as a third may have no or only slight disability, yet many others have severe disability. This pattern appears to hold for all ischemic strokes, carotid territory strokes, intracerebral hemorrhages, and individuals older than 65 years. Even more limited data, however, are available for other outcomes. In one study, the quality-of-life scores of individuals with no or minimal disability were similar to population norms except for slight decreases in role limitations because of physical problems, and of 27 ischemic stroke patients who survived up to 3 years, 63% had no or minimal cognitive impairment (Mini-Mental State Examination score >24).

Other Sources of Prognostic Information

Current evidence suggests that one can further refine prognosis according to knowledge of stroke syndromes, early patient characteristics, use of clinical prediction rules, and the need for continued interventions.

Knowledge of Stroke Syndromes. Certain stroke syndromes are associated with higher mortality, including stroke resulting in pontine herniation, pontine hemorrhage with hyperthermia, and basilar artery occlusion with coma and apnea. Strokes that result in severe disability include large middle cerebral artery infarcts and pontine strokes resulting in locked-in syndrome (ie, quadriplegia and anarthria with preserved consciousness and vertical eye movements).

Early Patient Characteristics. The strongest predictor of long-term outcome is initial stroke severity, including coma depth. Similar to anoxic-
ischemic encephalopathy, the most powerful predictors of death and poor outcome are persistent coma and absent pupillary or corneal reflexes at day 2 or 3. Predictive variables specific for intracerebral hemorrhage include volume of blood, intraventricular hemorrhage, hydrocephalus, and hypertension. Factors associated with a more favorable outcome include intubation for seizures or pulmonary reasons rather than neurologic reasons, younger age, minimal other comorbidities, presence of spouse at home, early neurologic recovery, and lower body temperature.

Clinical Prediction Rules. Despite the availability of many prognostic models for stroke, few are routinely used to inform end-of-life decision making. Existing models vary in terms of outcomes being predicted (eg, short-term mortality, survival, independent survival, alive and at home), often include ambiguous or impractical predictor variables, lack sufficient predictive accuracy, and have limited external validity. Of 18 models focusing on short-term outcome in patients with intracerebral hemorrhage (eg, death or poor outcome at 30 days), the most commonly included predictor variables were poor clinical condition on admission, hematoma size, and presence of intraventricular extension. Indeed, a subset of models could identify patients with a greater than 95% probability of death or a poor outcome at 30 days, but the lower bounds of the observed confidence intervals (30% to 80%) limit the models’ usefulness as a sole criterion for treatment decisions on the day of admission. Validated and easily applied models that include predictor variables at various points (eg, stroke severity on day 3 of admission) will be most useful to inform end-of-life decision making in patients with severe stroke.

Interventions as Prognostic Markers. For stroke patients requiring a percutaneous endoscopic gastrostomy (PEG),

<table>
<thead>
<tr>
<th>Table 1. Mortality in Mechanically Ventilated Stroke Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Source</strong></td>
</tr>
<tr>
<td>-------------</td>
</tr>
<tr>
<td><strong>Ischemic Stroke</strong></td>
</tr>
<tr>
<td>Wijdicks and Scott[34]</td>
</tr>
<tr>
<td>Gujjar et al[22]</td>
</tr>
<tr>
<td>Grotta et al[23]</td>
</tr>
<tr>
<td>Berroushcot et al[27]</td>
</tr>
<tr>
<td>Wijdicks and Scott[28]</td>
</tr>
<tr>
<td>Foerch et al[29]</td>
</tr>
<tr>
<td>Santoli et al[31]</td>
</tr>
<tr>
<td>Schelke et al[33]</td>
</tr>
<tr>
<td><strong>Intracerebral Hemorrhage</strong></td>
</tr>
<tr>
<td>Gujjar et al[22]</td>
</tr>
<tr>
<td>Roch et al[23]</td>
</tr>
<tr>
<td>Foerch et al[26]</td>
</tr>
<tr>
<td>Lessire et al[27]</td>
</tr>
<tr>
<td>Burtin et al[28]</td>
</tr>
<tr>
<td>Steiner et al[29]</td>
</tr>
<tr>
<td><strong>Mean mortality, total No. (%)</strong></td>
</tr>
</tbody>
</table>

Abbreviation: NA, not available.
*Excludes basilar occlusion study[24] and studies that exclusively enrolled in the 1980s.[30]
6-month mortality is nearly 50% and increases to 80% by 3 years. In one series of 162 patients, of the 50% of patients with PEG who survived to 6 months, 11% had no or slight disability, 11% had moderate disability, and 78% had severe disability. Similarly, in a study of 97 mechanically ventilated stroke patients who required a tracheostomy and survived 1 year, 18% had no or minimal disability, 26% had moderate disability, and 56% had severe disability.

Factors Influencing Preferences for Life-Sustaining Treatment in Severe Stroke

Up to 50% of healthy adults and those with a variety of medical conditions view the prospect of a severe stroke as "worse than death." It is not surprising, therefore, that many individuals and families have strong preferences for or against life-sustaining therapies under such circumstances. In one study of 341 people, after a hypothetical severe stroke, 77% of respondents would refuse long-term mechanical ventilation, 67% would refuse a feeding tube, 63% would refuse dialysis, 65% would refuse CPR, 41% would refuse short-term mechanical ventilation, and 28% would refuse antibiotics. Emerging data are beginning to unravel what aspects of severe stroke interfere with valued life activities to such an extent that it drives preferences for death over life.

Pattern and Severity of Outcome. Although mortality (ie, "inevitable death") is important, disability outcomes may well play an even greater role in patient preferences for or against life-sustaining treatments, with cognitive issues appearing more important than functional (ie, cognitive-dependent treatment pattern). Although it is rare for strokes to result in significant disorders of consciousness (ie, permanent vegetative state, minimally conscious state), they can result in dementia, aphasia, and other cortical syndromes (eg, neglect). It is not yet clear, however, what dimensions of cognition are considered most important to patients.

Probability of Outcomes. Both the probability of enduring in a "worse than death" health state and the probability of having "meaningful" recovery appear to matter. In one study of 226 people who were aged 60 years or older, for example, individuals began to reject all treatments and prefer death when the probability of severe cognitive impairment was 50% or greater. In another study of 50 elderly adults, only 4% wanted artificial nutrition/hydration in severe stroke with "no chance of recovery" compared with 24% with "very slight chance of recovery." Burdens of Treatment. In the setting of severe stroke in which outcomes are undesired or marginally desired, treatment burdens may begin to

### Table 2. Disability in Mechanically Ventilated Stroke Patients Who Survived 3 Months or Longer

<table>
<thead>
<tr>
<th>Source</th>
<th>Enrollment Dates</th>
<th>Survived to Follow-up, %</th>
<th>Disability, No. of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 mo</td>
</tr>
<tr>
<td></td>
<td></td>
<td>None/ Slight</td>
<td>Moderate</td>
</tr>
<tr>
<td>Ischemic Stroke</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Berrouschot et al</td>
<td>1994-1997 (Carotid only)</td>
<td>19</td>
<td>2</td>
</tr>
<tr>
<td>Wijdicks and Scott</td>
<td>1976-1994 (Carotid only)</td>
<td>29</td>
<td>5</td>
</tr>
<tr>
<td>Leker and Ben Hur</td>
<td>1992-1998</td>
<td>31</td>
<td>2</td>
</tr>
<tr>
<td>Foerch et al</td>
<td>1998-2001</td>
<td>39</td>
<td>2</td>
</tr>
<tr>
<td>Grotta et al</td>
<td>NA (Carotid only)</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>Burtin et al</td>
<td>1984-1989</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Santoli et al</td>
<td>1990-1995</td>
<td>27</td>
<td>7</td>
</tr>
<tr>
<td>Schieke et al</td>
<td>1996-1999*</td>
<td>24</td>
<td>9</td>
</tr>
<tr>
<td>Intracerebral Hemorrhage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foerch et al</td>
<td>1998-2001</td>
<td>50</td>
<td>1</td>
</tr>
<tr>
<td>Burtin et al</td>
<td>1984-1989</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Lessire et al</td>
<td>1990-1994</td>
<td>27</td>
<td>1</td>
</tr>
<tr>
<td>Roch et al</td>
<td>1997-1999</td>
<td>30</td>
<td>15</td>
</tr>
<tr>
<td>Ischemic and Hemorrhagic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mayer et al</td>
<td>1993-1996†</td>
<td>27</td>
<td>1</td>
</tr>
<tr>
<td>Steiner et al</td>
<td>1992-1993‡</td>
<td>33</td>
<td>22</td>
</tr>
</tbody>
</table>

Abbreviation: NA, not available.
* Dichotomized modified Rankin Scale as 0-2 (no/slight disability) and 3-5 (moderate/severe disability).
† Includes patients with subarachnoid hemorrhage.
‡ Dichotomized Barthel Index as >60 (no/slight/moderate disability) and ≤60 (moderate/severe disability). Includes patients with subarachnoid hemorrhage.
trump their benefits and dictate preferences for life-sustaining therapies. In addition, treatments not ordinarily viewed as burdensome (eg, course of antibiotics, blood transfusions, temporary procedures, repeated hospitalizations) may become so as illness progresses, health outcomes become less desirable, and the benefits of treatment become less clear. Aspects of treatment burden include invasiveness and how long the treatment is expected to last. Potentially burdensome therapies in severe stroke include the need for prolonged ventilation, tracheostomy, feeding tubes, and prolonged nursing or custodial care.

Other Factors. Other factors that influence an individual’s preference for life-sustaining therapies include age and life stage, cultural and spiritual beliefs, preexisting comorbidity, caregiver burden, and future financial consequences of care.59

**Biases That May Result in Overuse or Underuse of Life-Sustaining Therapies**

Physicians’ personal characteristics have been shown to be associated with their preferences and practices on the use of life-sustaining treatments.60-63 Factors associated with being more willing to withdraw life-sustaining therapies include younger age, white race, practicing in tertiary settings, and more time spent in clinical practice, whereas factors associated with being less willing include being Catholic or Jewish.60 Other factors associated with preferences for life-sustaining treatment include physician specialty, sex, and degree of “burnout.”61-63 Different “practice styles” may influence 1 or more of the core elements of shared decision making, with the potential consequence of overuse or underuse of life-sustaining technologies. Table 3 summarizes biases that may affect end-of-life decision making in severe stroke, their potential causes, and suggested strategies to minimize their occurrence.

**Erroneous Prognostic Estimates.** Physician estimations of prognosis have a profound impact on decisions for life-sustaining therapies. In one study, the decision to withdraw mechanical ventilation in a neurological ICU was based primarily on the severity of the acute neurologic injury.64 These decisions were likely based, in part, on the physicians’ prediction of a low likelihood of survival or a high likelihood of poor cognitive function.65,66 Physicians have been shown, however, to be overly pessimistic in their prediction of survival and quality of life of survivors of critical illness, including patients with intracerebral hemorrhage,67,68 which contrasts with the situation in cancer, in which physicians have a tendency to be overly optimistic in their assessment of prognosis.69 Lacking or misinterpreting clinical information, not appreciating the best available published evidence, or allowing one’s own values to excessively influence subjective estimates may lead to erroneous prognostic estimates.

**Method of Communicating Evidence.** Patient and surrogate-based perception of prognosis and treatment evidence influences preference for life-sustaining therapies, and these perceptions are likely shaped by how evidence is presented.70,71 We know that relative expressions of benefit may exaggerate treatment benefits compared with absolute expressions (eg, “If we attempt a surgical evacuation of the hemorrhage, he will have a 50% better chance of an improved outcome” vs “If we attempt a surgical evacuation of the hemorrhage, he will have an increase in his chances of an improved outcome from 5% to 7.5%”).72 People also

**Table 3. Biases That Could Affect Decision Making in Severe Stroke**

<table>
<thead>
<tr>
<th>Decision-Making Domain</th>
<th>Causes</th>
<th>Consequence on Use of Life-Sustaining Treatments</th>
<th>Strategies to Minimize</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Erroneous prognostic estimate</strong></td>
<td>Optimistic prognosis (overuse)</td>
<td>Overuse or underuse</td>
<td>Explicitly estimate prognosis based on existing literature and/or clinical prediction rules</td>
</tr>
<tr>
<td></td>
<td>Pessimistic prognosis (underuse)</td>
<td></td>
<td>Seek a second opinion</td>
</tr>
<tr>
<td></td>
<td>Wanting to provide hope (overuse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lacking clinical information</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Misinterpreting clinical information</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Personal beliefs</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Inappropriate or selective communication of evidence</strong></td>
<td>Misuse of 1 or more of the following evidence presentation styles:</td>
<td>Overuse or underuse</td>
<td>Consider type of evidence, characteristics of the patient and family, and characteristics of the clinician and health care team</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Create conducive environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Use nontechnical language</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Tailor amount and pace of information</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Check for understanding</td>
</tr>
<tr>
<td></td>
<td>Numeric translation of evidence</td>
<td></td>
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<tr>
<td></td>
<td>Graphic presentation of evidence</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Use of decision-aid programs</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unbalanced/unilateral focus on mortality, neglecting morbidity</td>
<td>Overuse</td>
<td>Complete data presentation</td>
</tr>
<tr>
<td></td>
<td>Framing effects</td>
<td>Overuse or underuse</td>
<td>Present data in negative and positive frames</td>
</tr>
<tr>
<td><strong>Misunderstand patient values and expectations</strong></td>
<td>Incomplete health state descriptions</td>
<td>Overuse or underuse</td>
<td>Active listening</td>
</tr>
<tr>
<td></td>
<td>Too little time spent listening</td>
<td></td>
<td>Build partnership</td>
</tr>
<tr>
<td></td>
<td>Ignoring cultural values</td>
<td></td>
<td>Acknowledge emotions</td>
</tr>
<tr>
<td><strong>Undervalue future patient health state</strong></td>
<td>Failure to appreciate extent to which a patient can physically and psychologically adapt</td>
<td>Underuse</td>
<td>Adaptation exercise: inform decision makers that it exists</td>
</tr>
</tbody>
</table>
interpret proportions (1 out of 10 chances) and probabilities (10% chance) differently and respond to graphic presentations of data differently than spoken numeric presentations. Which presentation style is most effective likely depends on the type of evidence (risk vs benefit), the certainty of the evidence, the outcomes associated with the evidence, the characteristics of the patient and family, and the characteristics of the provider. Clinicians need to learn to communicate evidence by using a variety of techniques and be able to adjust to different settings and learning styles of patients and families.

Given the known effects of framing bias, information should be presented in a positive (eg, “She has a 30% chance of surviving”) and negative frame (eg, “She has a 70% chance of dying”). In addition, given the known importance of disability outcomes, one should not exclusively focus on mortality but should also include aspects of cognitive and functional outcomes if a patient should survive. Selective presentation of the potential outcomes may influence preferences for life-sustaining treatments, as has been shown for the degree of detail provided for different treatment options.

Misunderstanding of Patient Values and Expectations. In one study, a physician’s perception of the patient’s preferences for life support was the strongest determinant of withdrawal of ventilation. Therefore, any misperceptions may result in wrong decisions. Even if living wills are present, they rarely provide the level of detail needed to confidently direct withdrawal decisions. We believe one of the most effective ways to develop a profile of a patient’s valued life activities is to ask surrogate decision makers, using open-ended questions, and to listen. Although studies have shown that patient and caregiver agreement on valuation of health states and treatment preferences is relatively poor, agreement is better for outcomes such as severe cognitive impairment, often the focus of discussion in severe stroke.

Undervaluing Future Patient Health States. Nonpatients tend to think that an illness such as a severe stroke will affect a patient’s quality of life significantly more than it actually does, and this overestimation of impact is particularly large for new-onset disabilities, such as a sudden severe stroke. One explanation for this overestimation is that nonpatients fail to predict the extent to which patients can successfully adapt, tending to focus on the negative aspects of the health states (eg, unable to walk, difficulty speaking) rather than on the positive aspects that may endure (eg, enjoying relationships, maintaining sense of humor). In fact, some stroke patients can find meaning in new health states that most non–stroke patients find unfathomable (eg, “locked-in” syndrome). If decision makers undervalue future patient health states (ie, overestimating the stroke’s impact), it may bias toward underuse of life-sustaining therapies. It is not yet clear what preferences are most important to consider (preadaptation vs adaptation health states), but decision makers should be informed that adaptation exists, with an emphasis on the possible ways patients can find new meaning in their lives with their projected future deficits.

**DECISION MAKING IN SEVERE STROKE: A SUGGESTED APPROACH**

The Box suggests a shared decision-making approach to care, customized to the needs of patients and families with severe stroke. Almost all discussions must be with surrogate decision makers, and one should anticipate the need to manage the value conflicts that often arise (physician vs family, physician vs physician, physician vs other health care provider).

Part of the preparation, including providing structured interactions, is being mindful of the many biases that may influence the decision-making process. When prognosis for mechanically ventilated stroke patients is assessed and communicated, the data from Tables 1 and 2 can help. These estimates, however, need to be refined by the particulars of each case and bounded by an upper and lower range, depending on the specifics and uncertainties of each case. One of the greatest challenges in the acute setting is to estimate, given a sufficient recovery time of up to 6 to 12 months, the degree to which the disability estimates will interfere with a patient’s valued life activities and knowing when such severe disruption is viewed as “worse than death.” This estimate requires gentle probing of positions on “life worth living,” as well as the degree and acceptance of conditions considered “not worth living,” with the recognition that even for health states that are consensually abhorred, patients and families may have drastically different views on what represents “worse than death” (eg, depending on religious beliefs).

When families appear prepared or receptive for further discussion, it is appropriate to explain the alternatives to continued treatment, including no further escalation of treatments (eg, CPR), as well as the potential for withdrawal of treatments. Withdrawal options include a “bundled withdrawal” in which all active treatments, including artificial hydration and nutrition, are withdrawn or “partial withdrawals,” in which only selected treatments are withdrawn (eg, mechanical ventilation). In addition, physicians should consider presenting a detailed discussion of the withdrawal-of-care process, including estimated survival times if a bundled withdrawal is appropriate and comfort measures to be provided while allowing for a natural death. It is important to keep in mind that survival may be days to weeks; in one study of primarily stroke patients, the median time of survival after extubation was 7.5 hours, and although 25% of patients died within 1 hour, 31% lived longer than 24 hours.

Given the inherent uncertainties in stroke prognoses and, at times, knowledge of patient preferences, we recommend the judicious use of time-limited trials to improve estimates of prognosis, better understand the ben-
First, there is an urgent need to better understand unwarranted variation in end-of-life stroke care and to reliably measure the patient-centeredness of such decisions. Ideally, quality of care should be judged by the degree of concordance between the patient values and care received, with recognition that a comfortable death may be a sign of exemplary quality. This judgment should be informed by research on the process, content, and biases of the 2-way information exchange of prognosis from provider to patient or family and values from patient or family to provider, including the use of evidence-based tools to facilitate the process (eg, patient/family decision aids). Second, we need to continue to develop a credible evidence base of prognostic information with outcomes that are meaningful to patients, including the various

**Box. Decision Making in Severe Stroke: A Suggested Approach**

**Provide structured interactions**
- Health care proxy and advance directive clarification
- Identify key decision makers and meet in quiet
- Build partnership with patient and family
- Identify decision points in advance: feeding tubes, tracheostomy, posthospital care
- Establish clear follow-up plans/communication times

**Be mindful of potential decision-making biases**
- Optimistic or pessimistic prognoses
- Inadequate communication of treatment evidence
- Selective presentation of information (eg, framing effects)
- Misunderstanding patients values and expectations
- Undervaluing future patient health states

**Expect and manage conflicts**
- Agonizing with families is part of the process
- Physician vs family, physician vs physician, physician vs other team members

**Communicate prognosis with continued treatment**
- If mechanically ventilated, approximate 1-year mortality is 70%
- Among survivors, no/slight disability may be possible
- Modify estimate based on patient details
- Provide range and avoid being vague
- Include elements of treatment burden

**Elicit patient’s valued life activities**
- Time with family and friends, autonomy, recreation, other
- Probe positions on “life worth living” and states considered “worse than death”
- Include spiritual and ethical dimensions of these values

**Will deficits and treatment burdens interfere with future valued life activities?**
- If yes, estimate probability and ranges

**If appropriate, explain alternatives to continued treatment**
- Withholding from further escalation of treatment (eg, CPR)
- Withdrawal of life-sustaining therapies
- Explain process of withdrawal, estimated survival and comfort measures

**Consider use of time-limited trials**
- To improve estimates of prognosis
- To better understand the benefits and burdens of therapies
- To provide time to achieve consensus about the goals of care
- To allow families to work through grief and let go of loved ones

**Be familiar with state laws and institutional policies**
- Particularly with regard to artificial nutrition and hydration

Adapted from references 80-86.
dimensions of cognition (eg, level of alertness, level of consciousness, delirium, aphasia), which needs to include standards for defining patient populations, predictor variables, follow-up times, cause of death, and outcome measures, as well as methods to account for “withdrawal of care” bias. Although research is needed on the epidemiology and proper role and use of time-limited trials in the setting of advanced illnesses in which prognosis is uncertain, treatment burdens are high, and the evidence base for benefit is scant. Finally, despite being the third leading cause of death and one of the most disabling of all human conditions, stroke has received little attention in the palliative-care literature and palliative care has received little attention in the stroke literature. Additional areas of research include better defining the palliative-care needs of patients and families who survive a severe stroke, the detection and management of stroke-specific symptoms, ways to optimize donation after brain and cardiac death, and the proper role of palliative care and hospice.

**CONCLUSIONS**

As baby boomers reach the age of high-stroke risk, the need for better understanding the emotionally intense and ethically complex choices surrounding life-sustaining therapies in severe stroke will likely more than double. Although overall prognosis is poor, with high mortality and disability rates, a moriety of mechanically ventilated stroke patients survive without severe disability. Failure to accurately assess prognosis, communicate treatment expectation, or elicit patient preferences can result in a substantial probability of overuse or underuse of life-sustaining therapies. Patients with severe stroke and their families, as well as all those at risk for severe stroke, need more assurances that current end-of-life stroke practices minimize unwanted deaths and unnecessary prolongation of suffering.

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**REFERENCES**


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