Treatment Decisions After Severe Stroke
Uncertainty and Biases

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Stroke demands our attention because it is common, disabling, and deadly. One in 15 patients requires mechanical ventilation on admission, 1 in 20 patients is discharged from the acute care hospital with a feeding tube, and 1 in 5 patients requires institutional care at 3 months after stroke. Most patients with severe stroke who die, do so in the setting of withdrawal of life-sustaining treatment (LST), and this decision is typically made by physicians who predict a poor outcome and surrogates who are asked to articulate the patient’s preferences: "she would not want to live like that." When prognosis is certain and the outcome unacceptable, the decision to withdraw or withhold LST may be relatively straightforward, although emotionally challenging. In most severe strokes, however, decisions are made when prognosis is uncertain and when what constitutes an acceptable outcome is unknown. In this article, we explore the uncertainties and biases that influence these life-and-death decisions. Such biases can lead to errors in decision making and ultimately the overuse or underuse of LST. Hence, the need is urgent to understand better the factors that contribute to optimal decision making.

Preference-Sensitive Decisions
Surviving a severe stroke means living with disability. Treatment decisions, thus, frequently involve trade-offs. Three typical preference-sensitive decisions after severe stroke are mechanical ventilation, artificial nutrition, and surgical decompression for hemorrhagic or ischemic strokes with life-threatening mass effect. All of these LSTs reduce the risk of death but increase the chance of survival. Although one individual may choose life at all costs, even when evidence predicts severe disability, another may refuse LSTs despite a prospect of surviving with a modest deficit, trading off the possibility of survival in an undesirable health state for the more desirable outcome of death. In the acute setting, withdrawal of the ventilator commonly leads to an earlier death and may pressure decisions to withdraw LST over giving the patient time to declare herself, thereby risking either a later death from withdrawal of nutrition and hydration or being stuck with living in an unacceptable condition.

Finding the Balance
In helping stroke patients and families make treatment decisions, providers need to meld their expert knowledge with both evidence-based medicine (EBM) and preference-based medicine (PBM). Providers have learned the tenets of EBM, as well as various types of biases that may affect a study’s validity, including selection bias, measurement bias, responder bias, and others. We define PBM as the process of eliciting the preferences and values of patients and judiciously using the relevant information to help make treatment decisions. Both EBM and PBM have potential uncertainties and biases that may affect decision making, as does the provider who is called on to make an expert recommendation. Figure 1 illustrates the intersections among clinical expertise, EBM, and PBM that influence how decisions about LST are made.

Biases Affecting Decision Making

Patient Preferences
The doctrine of patient autonomy rests on the assumption that a patient knows what she would want. Patients with severe stroke are often unable to voice their own preferences, so their surrogates will act as the patient’s voice. Often times, such substituted decisions are aided by exploring who the patient was before their illness, what they enjoyed, and what they disliked. Although an empathetic method, it may have unintended consequences, because the surrogate is likely to remember a loved one as healthier, more active, and less dependent than she really was (recall bias). Translating patient preferences into treatment choices is based on predicting future quality of life or well being, a process called affective forecasting. Two important forecasting errors are the disability paradox and the focusing illusion. Many people with serious and persistent disabilities report greater quality of life compared with when healthy people are asked to imagine similar circumstances, resulting in the disability paradox. The capacity of humans to adapt to devastating experiences against all odds, be they medical or otherwise, impresses us repeatedly but remains beyond our imagination. Patients adapt to a change in their health over time by changing their internal standards, values, and self-assessment of quality of life, a process referred to as response shift or scale recalibration.
and emotional adaptation.14 People, as opposed to patients, fail to appreciate the extent to which they will accommodate because they tend to focus on the things that will change while ignoring things that will stay the same, creating a focusing illusion.15 When asked to imagine an unfamiliar situation, for example, aphasia and hemiplegia, people exaggerate the negative impact of that factor, the inability to communicate verbally, and increased dependence, while overlooking other factors that may ultimately have greater impact on their quality of life, such as nonverbal communication, social interaction, and being alive. When given a hypothetical scenario of a severe stroke, most healthy people would decline a life-saving surgery such as decompressive hemicraniectomy, because of the residual disability.16 After surviving such a severe stroke and decompressive hemicraniectomy, most disabled patients would opt to have the procedure again if in that same situation.17,18

Affective forecasting needs to account for the dynamic character of quality of life, which is shaped by what the individual patient experiences with regard to their health, disease, and disability, in relation to what she hopes and expects from life and health at any given time. Quality of life can be conceived as the gap between expectations and experience (Figure 2). This gap is particularly unstable after a stroke and during its recovery.

Scientific Evidence

When trying to make treatment recommendations in severe stroke, traditional tenets of EBM can only bring us so far. Prognostic models are an attempt to predict future health state and are developed by associating presenting characteristics with future outcome. However, both characteristics and outcome are subject to interpretation and statistical error. First, a prognostic model can only be useful if all clinically relevant patient characteristics were tested for inclusion. Presenting characteristics that may lead to a poor outcome, but are rarely included, are institutional norms on approaches to end-of-life care,21 the presence of a Do-not-attempt-resuscitation order,22 physician values,23 and communication with the patient regarding prognosis and treatment goals.24

An important bias that we call the withdrawal bias results from the inclusion of a heterogeneous patient population with a mix of treatment options, from all aggressive measures possible to comfort measures only. Because most patients with a survivable stroke die because of withdrawal or withholding of LSTs, the reported mortality estimates are generally higher than what would be expected in the setting of full, aggressive care. In ischemic stroke patients, this withdrawal bias may account for ~40% of the observed mortality.23 Second, outcome is a broadly defined term and people place different values on relevant outcomes. Clinical trials evaluating the effect of stroke-related treatments commonly use the modified Rankin Scale

![Figure 1](image1.png)

**Figure 1.** Balancing different kinds of evidence in decision making after severe stroke.

![Figure 2](image2.png)

**Figure 2.** A model of quality of life (QoL). One hypothesis of quality of life describes it as the gap between our expectations (hopes, aspirations) and experience (reality), depending on what period in our lives an illness may occur and on what resources we may have to cope.19 We show a modification of this gap for a patient with stroke who has 3 potential trajectories (models A, B, and C) of experiences and expectations.20 Each of the models begins with a baseline QoL gap, where expectations and experience run parallel. When the stroke occurs (▼), experience falls below expectations and the gap widens, adversely affecting quality of life. If symptoms completely resolve, the gap may narrow again implying a return to the patient’s previous QoL (model A). If no functional recovery occurs and her expectations do not change, the gap persists or widens and the QoL is worse than before (B). In model C, after some time, the patient learns to accept her disability and recalibrate her expectations: the gap narrows, thus reestablishing a homeostasis. In this situation, the QoL may eventually be no different in the patient who recovers from their stroke (A) and the patient who is left with permanent disability (C). The grey arrow in model C suggests a subsequent change in experience, whereby experience may even exceed expectations. Most current measures of QoL refer only to the time period before adaptation, when the illness has a negative impact on a patient’s QoL (modified from Reference 20).
(mRS) as their standard clinical outcome measure. The mRS is a 7-point scale ranging from 0 (no symptoms) to 6 (dead) and is typically dichotomized into good and poor outcomes, but no consensus exists on where to draw the line. Moreover, the mRS as an ordinal scale may not proportionally reflect quality of life and implies that death (mRS 6) is worse than severe disability (mRS 5), whereas many might argue the opposite. More and more, health-related quality of life instruments are finding their way into clinical trials. The challenge with these instruments remains how to incorporate the various facets of quality of life that vary by person, by disease, and over time (Figure 2).

**Physician Decisions**

Physician decisions should be based on the 4 ethical principles of beneficence, nonmaleficence, patient autonomy, and justice. Sometimes, beneficence and nonmaleficence may be in conflict with patient autonomy. Sometimes, acting in the patient’s best interest may conflict with a fair distribution of scarce resources. Physician’s decisions can be driven by institutional norms such as those regarding the use of orders not to resuscitate and financial incentives that often lead to overutilization. Physicians’ decisions are also influenced by their own personal values and professional characteristics and by their estimation of prognosis. Many physicians have a disposition toward optimism when making survival predictions. Yet, when it comes to treatment recommendations after severe stroke, in particular intraparenchymal hemorrhage, physicians tend to be overly pessimistic. Nurses may be more pessimistic than physicians when predicting survival or quality of life in a medical intensive care unit, and neither is always correct. Nurses and physicians with specialty training in critical care are rarely given the privilege to follow patients after hospital discharge and to see what their outcome is 6 months and further down the road. Just like patients, health providers often undervalue future health states, and forecasting biases, such as the disability paradox and the focusing illusion, apply equally to patients, families, and healthcare providers.

**Implications for Clinical Care**

Patient-centered care and practicing high-quality PBM start with a partnership among healthcare providers, patients, and their families. A mutual decision is reached by sharing knowledge, engaging in shared deliberation, and creating a shared mind. When educating the patients and surrogates about a patient’s condition and medical prognosis, we need to be frank about the uncertainties that lie within scientific prognostication as well as their own affective forecasting. Future quality of life is not determined solely by premorbid statements and values but by the ability to recalibrate and accommodate. In addition to exploring what the patient specifically enjoyed or disliked, providers should explore certain patient characteristics such as their optimism, resilience, or their reaction to previous experiences to help predict their ability to adapt. We should explore and acknowledge biases that may be misleading. We should consider a time-limited trial, which may reduce both uncertainties and biases. Until then, utterances such as, "she would not want to live like that," should be interpreted with caution.

**Implications for Research**

It is high time for an aggressive research agenda on decision making in stroke, particularly in the setting of choosing life-sustaining interventions. We need to better understand existing practices and the extent of and influences contributing to variation in end-of-life treatment practices in stroke care. We need more research on how quality of life, experiences, and expectations change over time, and which factors influence these changes. To optimize decision making, more research is needed on how to reliably estimate and communicate prognosis, as well as the most effective and efficient means of eliciting preferences from both patients and surrogates, accounting for the known and unknown biases. To improve on the quality of decision making in stroke, we need measures of decision quality, accounting for the adequacy of shared decision making, managing uncertainty and decisional conflict, and ultimate concordance of the outcome with the underlying preferences of the patient and family. Information gained from such research should help develop aids for patients, families, and care providers to assist with making life-and-death decisions tailored for the individual patient.

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References


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