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Palliative and End-of-Life Care in Stroke: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

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Palliative and End-of-Life Care in Stroke

A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

Endorsed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons, The American Academy of Hospice and Palliative Medicine, American Geriatrics Society, Neurocritical Care Society, American Academy of Physical Medicine and Rehabilitation, and American Association of Neuroscience Nurses

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Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology

Background and Purpose—The purpose of this statement is to delineate basic expectations regarding primary palliative care competencies and skills to be considered, learned, and practiced by providers and healthcare services across hospitals and community settings when caring for patients and families with stroke.

Methods—Members of the writing group were appointed by the American Heart Association Stroke Council's Scientific Statement Oversight Committee and the American Heart Association's Manuscript Oversight Committee. Members were chosen to reflect the diversity and expertise of professional roles in delivering optimal palliative care. Writing group members were assigned topics relevant to their areas of expertise, reviewed the appropriate literature, and drafted manuscript content and recommendations in accordance with the American Heart Association's framework for defining classes and level of evidence and recommendations.

Results—The palliative care needs of patients with serious or life-threatening stroke and their families are enormous: complex decision making, aligning treatment with goals, and symptom control. Primary palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of illness. To optimally deliver primary palliative care, stroke systems of care and provider teams should (1) promote and practice patient- and family-centered care; (2) effectively estimate prognosis; (3) develop appropriate goals of care; (4) be familiar with the evidence for common stroke decisions with end-of-life implications; (5) assess and effectively manage emerging stroke symptoms; (6) possess experience with palliative treatments at the end of life; (7) assist with care coordination, including referral to a palliative care specialist or hospice if necessary; (8) provide the patient and family the opportunity for personal growth and make bereavement resources available if death is anticipated; and (9) actively participate in continuous quality improvement and research.

Conclusions—Addressing the palliative care needs of patients and families throughout the course of illness can complement

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existing practices and improve the quality of life of stroke patients, their families, and their care providers. There is an urgent need for further research in this area. (*Stroke*. 2014;45:00-00.)

Key Words: AHA Scientific Statements ■ end of life care ■ hospice care ■ palliative care ■ prognosis ■ stroke

Considerable attention in stroke has focused on advances in emergent therapies, endovascular interventions, neuroimaging, public awareness, and risk factor control. Continued emphasis on stroke prevention and treatment is warranted, because nearly 800 000 individuals have a stroke each year. Despite advances in treating stroke, however, death and severe disability remain common outcomes, and these numbers could double as the baby boomers reach the ages of highest stroke risk.¹

In 2010, there were nearly 130 000 stroke-related deaths contributing to >5% of all deaths in the United States; of these deaths, ≈73% were attributable to ischemic stroke, 16% to intracerebral hemorrhage (ICH), 13% to sequelae of stroke, and 4% to subarachnoid hemorrhage (SAH).^{2,2a} Approximately 50% of deaths occur in hospitals (including emergency departments and acute rehabilitation facilities), 35% occur in nursing homes, and 15% occur in the home or other places.³ In addition, stroke is considered a leading cause of adult disability, because >20% of patients hospitalized for stroke are discharged to a skilled nursing facility and up to 30% of all patients remain permanently disabled.⁴ The palliative care and end-of-life needs of patients and families with stroke are enormous. According to the National Consensus Project for Quality Palliative Care⁵:

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and nonpalliative healthcare providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and death.^{5,6}

Palliative care is for all patients with serious illness that interferes with quality of life. Although there is a strong emphasis within palliative care on end-of-life care, palliative care domains are appropriate for all patients with serious illness, regardless of illness stage. For example, attention to symptom

and psychological assessment is important in improving the quality of life of patients who have had a stroke regardless of their prognosis. Diagnoses typically associated with palliative care include cancer, advanced heart disease, lung disease, AIDS, amyotrophic lateral sclerosis, and dementia. Less emphasis, however, has been given to patients and families with stroke.⁷⁻¹⁶

The field of palliative care has grown rapidly since having been granted formal specialty status by the American Board of Medical Specialties. The demand for palliative care services is growing given that consultations have been shown to improve quality, reduce costs, and for some conditions, possibly extend survival.¹⁷ Although access to specialty palliative programs and services is improving, reaching nearly 66% of all hospitals in 2010, there is still significant disparity in access to hospitals that provide specialty palliative care based on hospital size and region of country.¹⁸

The majority of palliative care provided to patients and families is not delivered by palliative care specialists,¹⁶ nor should it be. There will never be enough palliative care specialists to manage all of the palliative care needs of patients and families with stroke, and the core elements of palliative care (eg, alignment of treatment with the patient's goals, the basics of symptom management) should be routine aspects of care for any practitioner caring for patients and families with stroke. Within the field of stroke, this includes the stroke team and the various providers (neurologists, neurointensivists, neurosurgeons, physiatrists, geriatricians, primary care providers, nurses, and therapists) across the multiple settings of care (emergency department, intensive care unit, hospital, acute rehabilitation unit, nursing home, and hospice).

To optimally plan and expand palliative care services to patients and families with stroke, therefore, we distinguish between primary palliative care and specialty palliative care.¹⁹ In such a model, the primary stroke team and its various members manage many of the palliative care problems themselves (primary palliative care), initiating a specialty palliative care consultation for more complex problems.

In the present scientific statement, we delineate basic expectations regarding primary palliative care competencies and skills to be considered, learned, and practiced by providers and healthcare services across hospitals and community settings primarily responsible for caring for patients and families with stroke. We also consider an appropriate triage system for calling on palliative care specialists when necessary. We include ischemic stroke, ICH, and SAH in our definition of stroke, pointing out differences where appropriate.

Methods

Writing group members were nominated by the committee chair on the basis of their previous work in relevant topic areas and were approved by the American Heart Association (AHA)

Stroke Council’s Scientific Statement Oversight Committee and the AHA’s Manuscript Oversight Committee. The writers used systematic literature reviews, references to published clinical and epidemiology studies, morbidity and mortality reports, clinical and public health guidelines, authoritative statements, personal files, and expert opinion to summarize existing evidence and indicate gaps in current knowledge. The evidence is organized within the context of the AHA framework and is classified according to the joint AHA/American College of Cardiology Foundation and supplementary AHA Stroke Council methods of classifying the level of certainty and the class and level of evidence (Tables 1 and 2). All members of the writing group had the opportunity to comment and

approved the final version of this document. The document underwent extensive AHA internal peer review, Stroke Council Leadership review, and Scientific Statements Oversight Committee review before consideration and approval by the AHA Science Advisory and Coordinating Committee.

Primary Palliative Care for Patients and Families With Stroke

Any patient with a stroke that adversely affects daily functioning or will predictably reduce life expectancy or quality of life should have access to primary palliative care.⁵ Primary palliative care should begin at the diagnosis of an acute, serious, and life-threatening stroke, including those patients for

Table 1. Applying Classification of Recommendations and Level of Evidence.

		SIZE OF TREATMENT EFFECT			
		CLASS I <i>Benefit >>> Risk</i> Procedure/Treatment SHOULD be performed/administered	CLASS IIa <i>Benefit >> Risk</i> <i>Additional studies with focused objectives needed</i> IT IS REASONABLE to perform procedure/administer treatment	CLASS IIb <i>Benefit ≥ Risk</i> <i>Additional studies with broad objectives needed; additional registry data would be helpful</i> Procedure/Treatment MAY BE CONSIDERED	CLASS III <i>No Benefit or CLASS III Harm</i>
					Procedure/ Test Treatment
					COR III: Not Helpful No Proven Benefit
					COR III: Excess Cost w/o Benefit or Harmful Harmful to Patients
ESTIMATE OF CERTAINTY (PRECISION) OF TREATMENT EFFECT	LEVEL A Multiple populations evaluated* Data derived from multiple randomized clinical trials or meta-analyses	<ul style="list-style-type: none"> Recommendation that procedure or treatment is useful/effective Sufficient evidence from multiple randomized trials or meta-analyses 	<ul style="list-style-type: none"> Recommendation in favor of treatment or procedure being useful/effective Some conflicting evidence from multiple randomized trials or meta-analyses 	<ul style="list-style-type: none"> Recommendation's usefulness/efficacy less well established Greater conflicting evidence from multiple randomized trials or meta-analyses 	<ul style="list-style-type: none"> Recommendation that procedure or treatment is not useful/effective and may be harmful Sufficient evidence from multiple randomized trials or meta-analyses
	LEVEL B Limited populations evaluated* Data derived from a single randomized trial or nonrandomized studies	<ul style="list-style-type: none"> Recommendation that procedure or treatment is useful/effective Evidence from single randomized trial or nonrandomized studies 	<ul style="list-style-type: none"> Recommendation in favor of treatment or procedure being useful/effective Some conflicting evidence from single randomized trial or nonrandomized studies 	<ul style="list-style-type: none"> Recommendation's usefulness/efficacy less well established Greater conflicting evidence from single randomized trial or nonrandomized studies 	<ul style="list-style-type: none"> Recommendation that procedure or treatment is not useful/effective and may be harmful Evidence from single randomized trial or nonrandomized studies
	LEVEL C Very limited populations evaluated* Only consensus opinion of experts, case studies, or standard of care	<ul style="list-style-type: none"> Recommendation that procedure or treatment is useful/effective Only expert opinion, case studies, or standard of care 	<ul style="list-style-type: none"> Recommendation in favor of treatment or procedure being useful/effective Only diverging expert opinion, case studies, or standard of care 	<ul style="list-style-type: none"> Recommendation's usefulness/efficacy less well established Only diverging expert opinion, case studies, or standard of care 	<ul style="list-style-type: none"> Recommendation that procedure or treatment is not useful/effective and may be harmful Only expert opinion, case studies, or standard of care
Suggested phrases for writing recommendations	should be recommended is indicated is useful/effective/beneficial	is reasonable can be useful/effective/beneficial is probably recommended or indicated	may/might be considered may/might be reasonable usefulness/effectiveness is unknown/unclear/uncertain or not well established	COR III: No Benefit is not recommended is not indicated should not be performed/administered/other is not useful/beneficial/effective	COR III: Harm potentially harmful causes harm associated with excess morbidity/mortality should not be performed/administered/other
Comparative effectiveness phrases†	treatment/strategy A is recommended/indicated in preference to treatment B treatment A should be chosen over treatment B	treatment/strategy A is probably recommended/indicated in preference to treatment B it is reasonable to choose treatment A over treatment B			

A recommendation with Level of Evidence B or C does not imply that the recommendation is weak. Many important clinical questions addressed in the guidelines do not lend themselves to clinical trials. Although randomized trials are unavailable, there may be a very clear clinical consensus that a particular test or therapy is useful or effective.

*Data available from clinical trials or registries about the usefulness/efficacy in different subpopulations, such as sex, age, history of diabetes, history of prior myocardial infarction, history of heart failure, and prior aspirin use.

†For comparative effectiveness recommendations (Class I and IIa; Level of Evidence A and B only), studies that support the use of comparator verbs should involve direct comparisons of the treatments or strategies being evaluated.

Table 2. Definition of Classes and Levels of Evidence Used in AHA/ASA Recommendations

Class I	Conditions for which there is evidence for and/or general agreement that the procedure or treatment is useful and effective.
Class II	Conditions for which there is conflicting evidence and/or a divergence of opinion about the usefulness/efficacy of a procedure or treatment.
Class IIa	The weight of evidence or opinion is in favor of the procedure or treatment.
Class IIb	Usefulness/efficacy is less well established by evidence or opinion.
Class III	Conditions for which there is evidence and/or general agreement that the procedure or treatment is not useful/effective and in some cases may be harmful.
Therapeutic recommendations	
Level of Evidence A	Data derived from multiple randomized clinical trials or meta-analyses
Level of Evidence B	Data derived from a single randomized trial or nonrandomized studies
Level of Evidence C	Consensus opinion of experts, case studies, or standard of care
Diagnostic recommendations	
Level of Evidence A	Data derived from multiple prospective cohort studies using a reference standard applied by a masked evaluator
Level of Evidence B	Data derived from a single grade A study or one or more case-control studies, or studies using a reference standard applied by an unmasked evaluator
Level of Evidence C	Consensus opinion of experts

AHA/ASA indicates American Heart Association/American Stroke Association.

whom some reversibility is a realistic goal but for whom the stroke itself or its treatments pose significant burdens and may result in reduced quality of life. Palliative care should also be available to those stroke patients with significant functional impairments who have progressive chronic comorbidities, who are unlikely to recover, and for whom intensive palliative care is the predominant focus and goal for the remainder of their lives. Primary stroke palliative care should not be viewed as an alternative to providing access to the full range of services associated with stroke prevention, treatment, recovery, and rehabilitation but as an important component of the primary team's efforts that can optimize quality of life.

Stroke patients and their families need a healthcare system that is prepared for and responsive to managing both early deaths and survival with disability. Early deaths are common in stroke, and most occur as a result of brain death or in the setting of withholding or withdrawing life-sustaining therapies when prognosis for recovery is believed to be poor.^{20–25} Survivors of severe stroke often have a gradual improvement in function but may experience significant disability with loss of independence, change in role functioning, and secondary stroke symptoms, all of which may benefit from skilled

palliative care.^{7,26} The palliative care of patients and families should be individualized and tailored to the phase of illness, the patient's life stage and values, the benefits and burdens of treatment, comorbidities, and cultural attitudes.

To successfully integrate and provide primary palliative care to patients and families with stroke, providers and health systems should be knowledgeable of and responsive to the following principles and practices: (1) Promote and practice patient- and family-centered care; (2) effectively estimate prognosis; (3) develop appropriate goals of care; (4) be familiar with the evidence for common stroke decisions with end-of-life implications; (5) assess and effectively manage emerging stroke symptoms; (6) possess experience with care at the end of life; (7) assist with care coordination, including referral to a palliative care specialist or hospice if necessary; (8) if death is anticipated, provide the patient and family the opportunity for personal growth and make bereavement resources available; and (9) actively participate in continuous quality improvement and research.

Primary Palliative Care: Recommendations

- All patients and families with a stroke that adversely affects daily functioning or will predictably reduce life expectancy or quality of life should have access to and be provided with primary palliative care services appropriate to their needs (Class I; Level of Evidence B).**
- Stroke systems of care should support a well-coordinated and integrated healthcare environment that enables an informed and involved patient and family and is receptive and responsive to health professionals who can focus on both the disease process and getting to know the patient and family in making decisions that are in line with their preferences (Class I; Level of Evidence C).**

Promote and Practice Patient- and Family-Centered Care

Patient and family-centered care is “respectful of and responsive to individual patient [and family] preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”²⁷ It promotes healing relationships and demands teamwork by clinicians. Patient- and family-centered care is ultimately determined by the quality of interactions between patients, family members, and clinicians.²⁸

There are many challenges to achieving patient- and family-centered care in stroke. The compartmentalization of stroke care delivery (stroke unit, acute rehabilitation unit, nursing homes) may improve site-specific care but hinder overall care if there is fragmented communication between providers (neurologists, neurointensivists, neurosurgeons, psychiatrists, palliative care providers, geriatricians, primary care providers, nurses, and therapists) and across settings (emergency department, intensive care unit, hospital, acute rehabilitation unit, home, nursing home, and hospice). In addition, most providers receive limited training in communication skills for patient-centered care. Available data suggest that doctors often do not talk to patients about their options, risks, and benefits.²⁹

At its best, patient-centeredness is “the experience (to the extent the informed individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”³⁰ In patients and families with stroke, it has the potential to improve satisfaction, safety, and outcomes; address disparities; and provide better value.²⁸

Patient and Family-Centered Care: Recommendations

1. **The stroke community of providers, researchers, educators, payers, and policymakers should promote patient- and family-centered care as its own quality dimension that requires measurement and improvement (Class I; Level of Evidence C).**
2. **It is reasonable that the stroke community support interventions, evaluation methods, and resources to encourage providers to focus on improving and refining patient-centered communication skills throughout their careers (Class IIa; Level of Evidence C).**

Estimating Prognosis in Stroke

Recent guidelines not specific to stroke have addressed general approaches to estimating and communicating prognosis in patients with advanced illness.^{31,32} Accurately estimating and communicating prognosis is central to high-quality decision making in patients with stroke. Many studies have documented early clinical, radiographic, and laboratory variables associated with mortality and disability, and clinical practice guidelines^{33,34} and various prediction models exist for each stroke type. Prognostic estimates can be based on these prediction models or alternatively on clinician experience with prior similar cases. There are certain stroke syndromes (eg, acute basilar artery infarct with coma and apnea, and malignant middle cerebral artery infarct) with high risk for early mortality or severe disability. It is important to recognize the inherent strengths and weaknesses of various methods of formulating prognostic estimates, particularly when they are used to guide decisions about palliative and end-of-life treatments. Errors in prognostication can have significant consequences, including premature withdrawal of treatment and overtreatment causing excessive suffering, burden, and costs.

Several common challenges surrounding the determination of prognosis are worth noting. One important bias for providers to consider is the “withdrawal bias.”³⁵ Prognostic models and clinical experience for severe stroke patients may be biased by the frequent withdrawal of life-sustaining treatments, leading to a self-fulfilling prophecy in which the “true prognosis” if all life-sustaining treatment were offered is difficult to ascertain.^{36–38} Given the frequent use of early decisions to limit life-sustaining treatment in ICH, the potential for withdrawal bias is likely far greater in ICH than in other stroke types.^{39–41}

An additional challenge comes from determining what represents a “good” outcome to an individual patient. The definition of a good outcome often varies across models, with many

focusing on risk of short-term mortality. However, long-term functional outcome and quality of life are likely more important to many patients and families. Stroke survivors can report satisfying quality of life even in the face of severe functional deficits.^{42,43} The phenomenon of individuals with disabilities rating their quality of life higher than nondisabled individuals is known as the disability paradox.⁴⁴ Patients and surrogate decision makers may need to be educated about the capability of individuals to adapt to physical limitations and disease burden (“Cognitive Biases”).

The quality of existing stroke prognostic models varies widely.^{45–48} Therefore, it is important for clinicians to be confident that a selected model has been developed with appropriate methodological rigor, including adequate sample size in the development cohort and external validation of predictive accuracy in multiple diverse populations.^{45,47,49} Models derived from clinical trial populations or registries based at major stroke centers are not necessarily applicable to the broader population of all stroke patients in a community, especially when one considers diverse populations with high proportions of racial and ethnic minorities. Few if any models incorporate certain important factors shown to influence outcome after stroke, such as institutional norms on approaches to end-of-life care,³⁹ the presence of a do-not-resuscitate (DNR) order,^{36–38} provider values,⁵⁰ and communication regarding prognosis and treatment goals.⁵¹ It can often be a challenge in model development to find an appropriate balance between making a model simple enough for practical bedside use while incorporating sufficient information to account for the multiple factors that influence outcome.⁵²

In addition, there are inherent difficulties in applying probability estimates derived from a statistical model at a population level to an individual’s risk of death or disability.^{53,54} It is important to remember that assessments of model discrimination and calibration are based on the model performance at the aggregate level. Different models can lead to widely varying estimated probabilities of death for an individual, even when each individual model is well calibrated.⁵⁴ These and other difficulties have led some to suggest that model-predicted probabilities should not be used as the primary basis for decisions regarding withholding or withdrawing life-sustaining treatments.^{48,54,55} No prognostic model has been systematically evaluated in a controlled study to determine its utility in guiding decisions about end-of-life treatment.⁵⁶

An alternative to using a model-based estimate for prognosis is to base the estimate on clinician experience with prior similar cases and expected neurological deficits from knowledge of neuroanatomy. Clinicians have the ability to flexibly adapt and tailor their prognostic estimates to a variety of factors that may not be well captured in mathematical models, such as multiple comorbid illnesses, prestroke functional status, life stage, and changes in patient status over the course of hospitalization. However, clinician prognostic estimates are also imperfect, because they can vary substantially among physicians^{36,57} and are subject to both optimistic and pessimistic outcome predictions.^{58–61} Evidence from the general palliative care literature suggests that obtaining a second opinion, perhaps from an experienced colleague or a multidisciplinary

team of experts, may help to minimize the effect of individual biases on prognostic estimates.^{32,58}

Despite the potential limitations of formal prognostic models, well-validated models can have value in providing standardized estimates based on large populations with long-range outcomes. A systematic review of all available stroke prognostic models is beyond the scope of this scientific statement, although selected prognostic models for each stroke type are highlighted as a reference. Most stroke prognostic models incorporate at least the patient's age and a measure of initial stroke severity, with severity being the most important predictor of subsequent disability or death.⁶²⁻⁶⁶ Other commonly identified predictive factors for ischemic stroke include comorbid illness, especially atrial fibrillation; laboratory values such as initial glucose; and stroke subtype.^{62,66,67}

As an example for ischemic stroke, the iScore incorporates these and other elements (with the addition of prestroke functional dependence, heart failure, cancer, and dialysis) and has undergone a fairly rigorous development and external validation process for prediction of early death or severe disability at hospital discharge.^{66,68} In 1 study, the iScore has been shown to be more accurate than physician estimate alone at predicting short-term outcome.⁶⁹ For ICH, the ICH score is one of the most commonly reported models that has been associated with both 30-day mortality and 12-month modified Rankin scale.⁷⁰⁻⁷² This score incorporates age, clinical examination (Glasgow Coma Scale), hemorrhage volume, presence of intraventricular hemorrhage, and infratentorial origin. Other authors have suggested slight variations to the original ICH score that were found to improve model performance in some data sets.^{73,74} For aneurysmal SAH, the Hunt-Hess scale and the World Federation of Neurological Surgeons Scale are classically reported grading prognostic schemes, although several issues with these scales have been identified, and there is a need for additional high-quality validation studies of prognostic scales in SAH.⁴⁶ Other clinical factors commonly reported to be associated with poor outcome after SAH include hyperglycemia, aneurysm size and location, amount of blood measured by Hijdra scores, and late complications such as rebleeding and delayed cerebral ischemia.^{46,75-78}

Despite limitations to our methods for formulating a prognostic estimate, patients and families need some estimate of what the future holds to help guide decision making. As a result, the formulation of a survival and outcome prediction for patients with stroke should be individualized using the clinician's estimates based on their experience and the best available evidence from the literature, including model-based outcome predictions from well-validated studies.⁷⁹ This combined approach to formulating a prognostic estimate is supported by evidence in nonstroke patients that suggests that the combination of a model-based prediction with a clinician estimate may be superior to either individual approach.⁸⁰ Although uncertainty in prognosis can be unsettling for the clinician, the majority of family members of critically ill patients accept that prognostic estimates are uncertain and want providers to discuss prognosis even when it is unclear.⁸¹ The variability in patient self-reported outcomes at similar levels of functional

deficits suggests that an individualized approach to prognostic discussions, focused on aspects of recovery most important to the patient, may be advantageous. Clinicians should work together with patients and surrogate decision makers to find the appropriate balance between evidence available from prognostic models, patient preferences, and clinician experience to guide decision making.⁸²

Estimating Prognosis: Recommendations

- 1. Before making a prognostic statement, to the extent possible, clinicians should obtain a thorough understanding of what aspects of recovery (eg, ability to walk, communicate, tolerance for disability) are most important to the individual patient and family and then frame the subsequent discussion of prognosis in these terms (Class I; Level of Evidence C).**
- 2. Clinicians should be aware of the inherent uncertainty, limitations, and potential for bias surrounding prognostic estimates based on either clinician experience or a prognostic model (risk score) (Class I; Level of Evidence C).**
- 3. In formulating a stroke prediction of survival and the spectrum of possible outcomes, it can be useful for clinicians to use the best available evidence from the literature, including relevant model-based outcome prediction, in conjunction with their clinical impression based on personal experience (Class IIa; Level of Evidence C).**
- 4. Rigorously developed and externally validated prognostic models may be useful to inform an estimate of outcome after stroke. However, caution is advised, because the value of model-based estimates has not been established for end-of-life treatment decisions after stroke (Class IIb; Level of Evidence B).**
- 5. Providers might consider asking for a second opinion about prognosis from an experienced colleague when the range of prognostic uncertainty will impact important treatment decisions (Class IIb; Level of Evidence B).**
- 6. Explicit disclosure of prognostic uncertainty to patients and family members may be reasonable (Class IIb; Level of Evidence C).**

Establishing Goals of Care

The overall approach to care is grounded in shared decision making and based on the prognosis, the benefits and burdens of treatment choices, and the patient's values and preferences.⁸³ Initial goals of care discussions occur during the acute period when the risk of mortality and significant disability may be high and yet the ultimate outcome remains uncertain. These are not one-time discussions. Because prognosis and patient preferences change over time, the process of establishing goals of care represents an ongoing dialogue of information exchange to reaffirm and revisit the plan of care. Conversations about these issues are interprofessional and can take place formally (eg, when prognosis and treatment options are discussed with physicians) and informally (eg, at the bedside, with nurses, social workers, chaplain, and therapists, etc).

Key communication tasks include building rapport, talking about serious news, discussing prognosis, discussing treatment evidence, dealing with conflict, acknowledging loss, transitioning to end-of-life care, and talking about dying. Knowledge and use of effective communications techniques is critical for establishing the goals of care in stroke. Practical strategies including different approaches are summarized in Table 3 and have been published elsewhere.⁸⁴⁻⁸⁸ Proactive, routinely offered patient and family meetings are the means through which essential information is shared.⁸⁹⁻⁹¹ Meeting leadership requires flexibility, patience, group facilitation and counseling skills, knowledge about medical and prognostic information, and a willingness to provide guidance in decision making. Meetings should occur in a quiet, neutral place if possible. The first meeting should occur early in the course of illness, with regularly scheduled follow-up meetings.

We provide an overview of the goal-setting process, discuss approaches to overcome the challenges in decision making, and review common preference-sensitive decisions that confront patients and families with severe stroke.

Goal-Setting Process: Overview

Prepare and Plan

Initial steps include gathering and resolving medical facts, soliciting opinions from other specialties, and reviewing advance directives, relevant psychosocial information, important family dynamics, and any preferences for sharing of medical information. Considerations should be given as to who should be invited to meetings, including asking advice and permission from the decision maker (eg, patient, surrogate). Healthcare team members to be considered include not only physicians, nurse practitioners, and nurses but also social workers, therapists, and cultural interpreters. A premeeting team “huddle” of the healthcare professionals is recommended. At this meeting, the team aligns plans, decides on the key messages, and negotiates the role each party will have in the family meeting. The first meeting is often about sharing information regarding the medical facts, which then unfolds into discussions about options and treatment decisions, usually at subsequent meetings. One should try to adopt a mindset of curiosity and detachment and avoid preset agendas (eg,

Table 3. Communication Techniques Used in Stroke Palliative Care

Technique	Comment/Example
Strategies to build trust	Encourage patients and families to talk; acknowledge errors; be humble; demonstrate respect; do not force decisions; listen carefully before responding
“Fire a warning shot”	When initiating bad news discussions: “I am afraid I have some difficult news to share with you”
Use silence effectively	After delivering bad news, resist urge to fill silence with more medical facts
Pace information and “check-in” periodically	“Are we on track?” “What haven’t we touched upon that is important to you?”
Use “D-word” (dying) effectively	“Based on what is happening to you and how sick you have become, I believe you are (your loved one is) dying”
Cautious use of “I’m sorry”	Often misinterpreted as aloofness, pity, or admission of responsibility
“I wish” statements	Simultaneous expression of empathy and limits of treatment: “I wish we had better treatments for your condition”
Help develop coping strategies	“Where do you find your strength or support?” “In past circumstances, what has helped?”
Communication tools for addressing conflict	Active listening, self-disclosure, explaining your view, reframing, and brainstorming
Strategies to reframe hope	Lighthearted humor, life review, focus on meaningful activities
Summarize and restate your understanding	“Let me make sure I understand you correctly”
Responding to emotions	Consider the NURSE mnemonic
Name the emotion being expressed	“I can see that this is very upsetting” “You seem overwhelmed by this news”
Understand and empathize, if you genuinely feel it	“I imagine it feels overwhelming” “I would probably feel the same way” “I can’t imagine how difficult this is for you”
Respect the family’s behavior	“Anyone in your shoes would be upset” “A lot of people would feel angry right now”
Support the family by expressing a willingness to help	“We will work through this together” “Is there anyone you would like me to call?”
Explore more about what is underneath the emotion	“Tell me what is most upsetting to you” “Tell me what worries you the most”

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getting the DNR). Paying attention to the proper environment (quiet, sitting down) and the time needed can help build rapport and trust.

Find Out What the Patient and Family Know and Want to Know

The start of the meeting should begin with introductions and negotiation of the meeting agenda. Before sharing information, one should ask the family or patient what they know. This allows the clinician to know what the family knows, how other clinicians have discussed the issues, what the family's perceptions are about the issues, and where misunderstandings may be. In addition, one should ask surrogates what they want to know about their loved one's status. Although most surrogates want all possible information, good or bad, asking this shows respect for the surrogate and may allow the surrogate to control the rate of information. Most patients and families want to know prognosis, but a minority do not.⁹² In these situations, it is important to assess the reasons underlying their concerns, exploring creative solutions such as to supply limited information, designate a proxy, or allow control over how the information is shared.

Sharing Information and Communicating "What to Expect"

When sharing information, most patients want their providers to be direct yet not blunt, empathetic and willing to spend time on the topic. Basic elements of information sharing may include the nature of the injury, results of studies, and prognosis ("what to expect"). The amount, type, and pace of information shared will depend on the stage of illness, the life stage of the patient, the level of understanding, and the emotional readiness of the participants. Information should be delivered in simple language (possibly at a grade level of 6 or 7), with frequent pauses, and with periodic checking to improve understanding. Given the amount of information that could be conveyed, clinicians should think carefully about what to focus on. Some patients and families prefer to view brain images to facilitate understanding. It is also important to provide the "big picture," with the ability to delve into the details depending on the needs of the patient and family. When one communicates prognosis in stroke, it is often more important to focus on "how well" as opposed to "how long," although both are interrelated and of immense importance.⁷⁹ This involves working with the family to (1) summarize the range of medically reasonable treatments for this patient at this particular time and (2) explain the risks and benefits of each treatment option within the personalized rubric of goals and desires set by the surrogate. This will include discussions of potential complications, the degree of impairments, the remaining abilities, and the time, pace, and range of the recovery process.^{93,94} Individuals only hear a limited amount of information, and even less when stressed, so the clinician must decide the key points they want to transmit.

Responding: Attending to Emotions

Patients and families may experience a variety of emotions in response to sudden and severe stroke in a variety of ways, and providers who can anticipate, acknowledge, legitimize, explore, and support these emotions can improve satisfaction,

reduce anxiety, and lower risk of depression.⁹⁵ One useful mnemonic that has helped clinicians respond empathically in conversations is NURSE (Table 3). NURSE stands for *Naming* the emotion expressed in the conversation, *demonstrating* that you are trying to *Understand* the family's emotional reaction; *Respecting* the family's behavior; *Supporting* the family by expressing your willingness to help them deal with the information and their questions; and *Exploring* the emotion in the context of the discussion. Providers should recognize their own possible emotional blocking behaviors (interrupting, softening information, euphemistic vocabulary) and think about how their own emotions may lead them to hedge information or avoid bad news.

"Diagnosing" Patient Preferences

Misdiagnosing patient preferences can have enormous implications in stroke care.⁹⁶ Good decision making matches the treatment plan with the patient's values and preferences. When surrogate decision makers are involved, it is important that they understand their role is to help clinicians understand what the patient would want rather than to make the decision solely based on their own values. In addition to reviewing living wills or other advance care plan, the clinician and surrogate must often try to recreate the patient's values. Open-ended questions to gain insight into the patient's life and values are a useful method; for example, "If the patient was sitting here and could hear what we said about his/her medical disease, what would he/she think?" Other techniques involve asking the surrogate about the patient's daily life, what the patient liked to do or, alternatively, what the patient might worry about should the patient become sicker. After clarifying the patient's goals, it is often useful to summarize what has been expressed.

In these discussions, it is important to discuss balancing the quality and quantity of life. Elucidating from the surrogate how the patient might balance these 2 values is crucially important. When eliciting patient values, it is important to recognize that patients with disabilities tend to rate their quality of life higher than healthy patients who are asked to imagine themselves with the same disability ("Cognitive Biases").³⁵ Reasons for such a possible misestimation of the quality-of-life impact from a stroke might be that patients and surrogate overly focus on the disability rather than on the remaining cognitive and physical abilities that allow valued life activities. As a result, providers should always emphasize the remaining abilities rather than simply enumerating deficits when communicating prognosis, as well as be cognizant of the ability of patients to adapt to acquired deficits, even those that might at first seem unimaginable.⁹⁷ Thus, follow-up discussions may be required to reassess treatment goals and preferences.

Making a Recommendation: Tailoring Treatments to Goals

After the goals have been clarified, the conversation can then move to discussing the ability of specific treatments to meet desired goals.⁸² In some cases, families may want to come to a decision on their own once the treatment and probable outcomes have been presented. In other cases, they would like the physicians to make the decision, or more commonly, they want to know what the physician or other healthcare provider would recommend. Anytime a recommendation is made, it should be done in the context of the patient's and family's

values, and as much attention should be placed on what can be done as on what will not achieve the patient's goals.

Goal-Setting Process: Recommendations

1. Knowledge and use of effective communication techniques is a critical core competency to improve the quality of stroke decision making, as well as patient and family satisfaction and outcomes (Class I; Level of Evidence B).
2. Knowledge, skills, and competency in running an effective patient and family meeting are important in the management of patients and families with stroke (Class I; Level of Evidence B).
3. Providers should integrate the best available scientific evidence and the best available evidence about patient values and preferences when making a recommendation about the best course of continued care (Class I; Level of Evidence B).
4. Because patient preferences change over time, it is important to periodically revisit discussions to reaffirm or revise goals and treatment preferences as needed (Class I; Level of Evidence B).
5. A structured approach to setting patient goals in patients with stroke care may be reasonable to improve the quality of health care (Class IIb; Level of Evidence C).

Approaches to Overcome Challenges With Decision Making in Stroke

Managing Uncertainty

One approach to managing uncertainty is to acknowledge it, because most patients want their providers to acknowledge that prognosis is uncertain.^{81,92} This acknowledgement of uncertainty, however, must simultaneously be countered with a commitment to a meaningful engagement and nonabandonment during the course of one's stroke trajectory. First, this means acknowledging the difficult emotions associated with uncertainty. Second, it requires that clinicians give patients/families signposts that they can use to understand if things are getting better or worse. Finally, because many clinicians change service frequently, this requires the effective use of handoffs and information exchanges during transitions in care.

In many stroke patients, the challenge is to offer patients and families the ability to simultaneously hope for the best (explore all treatment that may help prolong life and relieve suffering) and prepare for the worst. The use of the phrase "hope for the best and prepare for the worst" can help manage and affirm both emotions.⁸⁵ Using "I wish" statements may also allow one to simultaneously manage these dual outcomes and express empathy about the limits of available options.^{85,88}

Another approach to managing uncertainty is the use of time-limited trials, which is an agreement between patient/family and clinicians to use certain medical therapies over a defined period to assess the patient's response according to agreed upon clinical outcomes that define relative successes or failures in view of the patient's goals.⁹⁸ A time-limited trial allows opportunity for (1) evaluation of trends and progress; (2) patient reflection; (3) family input; (4) goal setting; (5)

adaptation to a "new normal"; (6) palliation of symptoms and suffering; (7) building trust; (8) recruiting community resources; and (9) rehabilitation and functional improvement. In patients with stroke, time-limited trials are often structured around early swelling in ischemic strokes and ventilator or nutritional support, and the duration of the trial may be days to months depending on the outcome chosen (eg, eye opening, command following, safety of swallowing food, level of independence). Although time-limited trials can be used to facilitate a patient-centered plan, there is no prospective evidence regarding their utility in patient- or family-centered outcomes.

Surrogate Decision Makers

Because many stroke survivors lack capacity, provider skills in working with surrogate decision makers are essential. This includes effectively drawing on the hierarchy of the 3 distinct decision-making standards, including patient's known wishes, substituted judgments, and best interests.^{99,100} Although surrogate decision makers do not perfectly predict patient treatment preferences, they provide insight into the patient's prior values.¹⁰¹ It is important to keep in mind that surrogate decision makers rely on multiple sources of information when estimating their loved one's prognosis and rarely rely solely on the physician's prognostic estimate.¹⁰² In addition, like patients, surrogates are often overly optimistic in predicting how well their loved one will do over time.¹⁰³ Finally, providers need to be aware of the intense emotional burden felt by up to one third of surrogate decision makers that can linger well beyond when the decisions are made, and providers should refer to grief and bereavement services when appropriate.¹⁰⁴ As part of the goal of improving family outcomes, these should be actively shared decisions between providers and families such that providers, with their medical expertise, share the burden of these decisions with families.

Cognitive Biases

There are several well-described cognitive biases that pervade human decision making, including end-of-life treatment decision making.^{35,105} These include affective forecasting errors, focusing effects, and optimism bias. Affective forecasting errors include improperly predicting one's emotional state in the future, usually overestimating the emotional impact that a future health state will have on an individual (which results in the disability paradox). Focusing effects include anchoring too much on 1 aspect of health (usually the disability) without fully appreciating the remaining abilities. Optimism bias is pervasive to the point of likely being evolutionarily advantageous and is often found in providers, patients, and surrogates.¹⁰⁶ How these biases influence individual decision making is not yet fully elucidated, but an awareness of their potential might minimize their biasing effects. Debiasing strategies involve the explicit acknowledgement of one's own potential to be biased (eg, overly optimistic or pessimistic in one's prognostication),^{35,105} as well as the likely impact on patients and surrogates.⁷⁹ This bias "time out" forces a self-awareness of the personal, system-level, and emotional factors that may bias decision making, as well as the potential strategies to overcome these influences when establishing goals of care.

Self-Fulfilling Prophecy

A self-fulfilling prophecy is a prediction that directly or indirectly causes it to become true. Physician's prognosis of survival and poor cognitive outcome are one of the strongest predictors of withdrawal of life-sustaining therapies.^{107,108} In stroke palliative care, the risk of a self-fulfilling prophecy can occur in at least 2 contexts: the withdrawal bias and the use of early DNR orders. For a discussion of the withdrawal bias, see "Estimating Prognosis in Stroke."

Many studies in patients with ischemic stroke and ICH have shown that the presence of a DNR order compared with patients without a DNR order is associated with a higher risk of short-term mortality.^{21,37,38,40,109–113} There is concern that this association can lead to a false prognostic pessimism that may lead to premature withdrawal of life-sustaining measures and thereby to a self-fulfilling prophecy. In such studies, however, it is difficult to determine causality. On the one hand, the presence of a DNR order may influence subsequent care and treatment decisions in unintended ways that lead to less desirable outcomes. On the other hand, DNR orders are negotiated with patients and families who likely have worse underlying prognosis before the discussion and may represent appropriate matching of treatment to goals. One study showed that in the ischemic stroke patients within the veteran population, the presence of a DNR order was not associated with lower quality of care as measured on traditional process measures.¹¹⁴ To mitigate against the potential of early DNR orders causing a self-fulfilling prophecy, providers, patients, and families should be cautioned about making early DNR decisions or other limitations in treatment before fully understanding the prognosis, including the potential for recovery.

Cultural Competence

Awareness of cultural and religious preferences and practices can facilitate understanding of family choices when discussing options, particularly when families request or decline evidence-based therapy.⁸⁷ Although clinicians are not expected to be experts in various cultural or religious practices, it is important that they are respectful of and sensitive to these preferences and aware of the influence they may have in decision making. Social workers, language and/or cultural interpreters, and chaplains may provide important information about cultural and religious beliefs and practices.

Conflict Resolution

Conflicts may result from information gaps, treatment goal confusion, emotions, mistrust, and genuine value differences.⁸⁶ Conflict can occur within families, between staff and families, and among treatment teams. Because most conflict revolves around differences of opinion and interpretation of the facts and emotions, listening rather than trying to convince is often a more helpful negotiating style. In some cases, an intervention desired by a surrogate may appear discordant with the patient's stated goals or medical realities. After trying to understand why "this reasonable and loving family member is asking for something we do not believe is helpful," we as clinicians can offer to explain why we think the treatment is not going to achieve the patient's goals. This is particularly difficult in our national culture of "doing everything possible" and difficulty accepting the inevitability of impending

death.¹¹⁵ Clinicians must work with patients and their families to explain why a particular treatment is inconsistent with the overall goals of care, using patients' preferences as a rubric for why the treatment is not appropriate. These discussions can be emotionally charged and may require considerable time. However, they should not become adversarial.

Approaches to Overcome Challenges With Decision Making in Stroke: Recommendations

1. Providers should recognize that surrogate decision makers use many other sources of information in addition to the doctor's expertise in understanding their loved one's prognosis (*Class I; Level of Evidence B*).
2. Providers should recognize that making surrogate decisions has a lasting negative emotional impact on a sizeable minority of surrogates, who should be provided access to bereavement services (*Class I; Level of Evidence B*).
3. Providers should be knowledgeable and respectful of diverse cultural and religious preferences when establishing goals of care and refer to social workers and chaplains when appropriate (*Class I; Level of Evidence B*).
4. It might be useful for providers to practice self-awareness strategies (prognostic time out, self-reflection) of one's own biases and emotional state to minimize errors in prognostic estimates and goal setting recommendations (*Class IIb; Level of Evidence B*).
5. It might be reasonable for providers to recognize the existence of a possible self-fulfilling prophecy (ie, a prediction that might directly or indirectly cause itself to become true) when prognosticating and making end-of-life decisions in patients with stroke (*Class IIb; Level of Evidence B*).
6. It might be reasonable for providers to be mindful of and to educate patients and surrogate decision makers about the possible cognitive biases (affective forecasting errors, focusing effects, and optimism bias) that might exist when discussing treatment options and establishing goals of care (*Class IIb; Level of Evidence C*).
7. Providers might consider the use of time-limited treatment trials with a well-defined outcome to better understand the prognosis or to allow additional time to optimize additional aspects of decision making (*Class IIb; Level of Evidence C*).
8. If there are conflicts between the patient's goals and those of the family surrogate, providers may consider implementing strategies to help family members reconcile these differences (*Class IIb; Level of Evidence C*).

Common Preference-Sensitive Decisions in Stroke

Stroke care is dominated by preference-sensitive decisions throughout the course of the acute and chronic stage of illness. Preference-sensitive decisions are treatment decisions that largely depend on the values and preferences of the patient, informed by the available evidence regarding the benefits and risks. There are often no absolute "right" answers;

rather there are often ≥ 2 medically reasonable alternatives. In stroke palliative care, many of these treatment decisions involve significant tradeoffs that affect the patient's quality or length of life.¹¹⁶

Depending on the stage of illness, one's preexisting health, and the severity of stroke, preference-sensitive decisions may encompass the full range of available treatments from various forms of aggressive resuscitation attempts to time-limited trials of treatments not ordinarily viewed as burdensome (eg, repeated hospitalizations, course of antibiotics, artificially administered fluids and hydration). Many of these treatment decisions are captured in programs to facilitate the selective ordering of life-sustaining treatments.¹¹⁷ Here, we review common preference-sensitive decisions in stroke that involve reasonable alternatives, including the available evidence and points to consider to optimally assist patients and surrogates in making informed, value-based choices in the goal-setting process. We do not address intravenous thrombolysis, which is reviewed elsewhere.³³

Cardiopulmonary Resuscitation Versus DNR

Stroke patients are at high risk of developing myocardial infarction or cardiac arrhythmias immediately after hospitalization for the acute event.^{118,119} An ischemic infarct may result in neurogenic-induced cardiac injury and fatal arrhythmias, especially in patients with preexisting coronary artery disease.¹²⁰ This autonomic imbalance depends on the location of the ischemic injury and may gradually recover within 6 to 9 months after stroke onset.^{121–125} Cardiac monitoring may improve the awareness and early recognition of potentially fatal cardiac arrhythmias.^{33,122,126–131} In longer-term follow-up studies (up to 4 years), 2% to 6.7% of ischemic stroke patients had a fatal cardiac event.^{35,132}

During the acute hospitalization, it is important to address the patient's wishes with regard to cardiopulmonary resuscitation (CPR). The timing of such discussions can be challenging during the hyperacute phase of stroke, and judgment is needed as to the most appropriate time to initiate such a discussion. It is important to review the presence of advance directives and any existing orders restricting CPR, intubation, or other life-sustaining interventions, especially under circumstances in which the treatments would have a high burden and low chance of success.

Although precise estimates are not known as to how frequently dying stroke patients receive an attempt at CPR, the available evidence suggests that the vast majority of dying patients do not receive an attempt at CPR.¹¹⁰ What few data exist, however, suggest substantial variability in the presence of early DNR orders, ranging from 0% to 70% in 1 study in patients with ICH.³⁹ A DNR should not imply other limitations of care, unless other limitations (eg, artificial nutrition and hydration [ANH], thrombolytic therapy, or other intervention) are explicitly discussed as part of the goals of care discussion. The approach to DNR and its documentation in the medical record can vary by state and institution, and therefore, it is important for each provider to thoroughly understand applicable state laws and institutional policies.

Discussions about the overall value of CPR in patients with stroke need to occur in the context of the broader discussion

regarding goals of care, including best evidence and estimates about the outcomes in the event of a cardiac arrest. There is no direct evidence of what the outcomes would be in patients with stroke, including its subtypes. A starting point, however, should be the outcomes in reviews of patients who have an in-hospital cardiac arrest.¹³³ These data suggest that the overall survival to discharge after an inpatient cardiac arrest is $\approx 10\%$ to 20%. This estimate then needs to be tailored to the individual patient, taking into account the severity of the stroke, comorbidities, life stage, protective factors (eg, social support, community engagement), patient's values and preferences, and patient's willingness to live in different health states and circumstances. Cognitive biases ("Approaches to Overcome Challenges With Decision Making in Stroke: Cognitive Biases") and the potential for early DNR orders that result in a self-fulfilling prophecy need to be considered, and when the risk is deemed to be high (as in patients with ICH), it might be prudent to discuss postponing a new DNR order until the prognosis and goals of care are better delineated.

Intubation and Mechanical Ventilation Versus Do Not Intubate

It is important to establish goals of care and preferences surrounding the use of intubation and mechanical ventilation (MV), including preexisting advance directives that may indicate a do-not-intubate (DNI) order; however, most patients do not have such an order. Given the uncertainty often inherent in early stroke decision making, a time-limited trial is often initiated with intubation and MV when patients experience respiratory compromise ("Approaches to Overcome Challenges With Decision Making in Stroke: Managing Uncertainty"). In fact, ≈ 1 in 15 stroke patients uses MV on admission. Relative to ischemic stroke, a higher proportion of ICH patients require MV and tracheostomy.^{135,136} Risk factors for this include large hemorrhage volume, deep hemorrhage location, and development of hydrocephalus.¹³⁵ During a trial of mechanical ventilation, structured communication with surrogate decision makers is important to facilitate decision making.

Overall mortality among mechanically ventilated stroke patients is high, with a 30-day death rate ranging from 46% to 75%.^{111,136,137} Although data are limited, among survivors of mechanically ventilated stroke patients, as many as one third may have no or only slight disability, yet many others have severe disability. In ischemic stroke, as many as 40% to 70% of patients who receive prolonged MV have poor functional outcomes,¹³⁷ and this association is particularly strong in older patients (>60 years of age), those presenting in poor neurological condition (Glasgow Coma Scale score <10), and patients with preexisting brain injury.^{137,138} Those with smaller posterior circulation infarcts, younger age, or higher levels of consciousness at presentation are more likely to regain independence.¹³⁹

Establishing goals of care requires prognosticating about the likelihood of surviving and the quality of life with intubation and MV compared with noninvasive treatment approaches. These prognostic estimates need to be tailored to the individual patient based on premorbid function, comorbidities, and the details of the stroke. One should be cautious in directly using mortality estimates from the literature (see

above), because these estimates are derived from a heterogeneous mix of patients, including a portion who decided to withdraw treatment. As a result, prognostic estimates should be tailored to the individual patient assuming the particular course of treatment consistent with the goals of care.

It is equally important to discuss the benefits and risks of intubation and MV in those patients at risk for respiratory compromise. In those patients and families who elect not to pursue intubation and MV, alternatives should be offered. Several recent studies suggest that noninvasive ventilation may be safe and may avoid neurological deterioration in acute stroke patients with sleep-disordered breathing (SDB). However, this alternative may not be safe in patients with compromised airway patency and has not been tested in stroke patients with severe respiratory failure.^{140,141} For those electing a pure palliative approach, efforts to control dyspnea, anxiety, and pain should be optimized while committing to ongoing intense care aligned with the patient's goals (which may be an intensive comfort-oriented approach). Patients with a DNI order in place should receive all other appropriate medical and surgical interventions unless otherwise explicitly indicated. However, because CPR usually requires endotracheal intubation, a patient with a DNI order in place should also have a DNR order in place.

The usual time of tracheostomy after endotracheal intubation and MV is 2 to 3 weeks, which often provides a built-in time-limited trial to establish goals of care with the family. Trials of early tracheostomy compared with this 2- to 3-week delayed standard will provide data on whether complications, rehabilitation, and recovery can be enhanced by this earlier approach.^{137,142} One study of early tracheostomy (first 3 days) in a population of ischemic stroke, ICH, and SAH patients deemed to be at risk for 2 weeks of intubation suggested the possibility of decreased inpatient and 6-month mortality¹⁴³; however, this was not the primary end point of the trial, and further study is needed.

Artificial Nutrition Versus Natural Nutrition in Dysphagic Stroke

Dysphagia is common after stroke, occurring in 27% to 64% of patients.^{144,145} Complications of dysphagia include aspiration pneumonia, malnutrition, impaired rehabilitation, prolonged stays, and increased mortality.^{146,147} Approximately one half of dysphagic stroke patients will recover within 2 weeks, although 15% of patients will have persistent dysphagia at 1 month. Screening for and managing dysphagia has been shown to reduce pneumonia rates.¹⁴⁸ Although limited data are available on which patients will develop dysphagia (eg, based on localization of stroke), data are scant on reliably predicting who will recover.^{147,149} As a result, many patients are started on a time-limited trial of artificial nutrition, with assessment for recovery within the first few weeks after the stroke (“Approaches to Overcome Challenges With Decision Making in Stroke: Managing Uncertainty”).

ANH can be achieved with a nasogastric tube or more permanent access, such as percutaneous gastrostomy (PEG). From a legal and ethical perspective, ANH is a treatment like any other that can be stopped and started. However, the decision to use or forgo ANH is often an emotional one

for patients, families, and healthcare providers that requires thoughtful discussion regarding benefit and burden of these treatments. The symbolic association of death, disability, and dependency with artificial nutrition in patients with stroke is borne out by studies that show that up to 50% of patients with dysphagic stroke who require artificial nutrition do not survive to 6 months, and of those who do survive, 65% have severe disability, 20% have moderate disability, and only 15% have no or only slight disability.¹⁵⁰

Two Cochrane reviews have summarized the available evidence on interventions for dysphagia.^{145,151} The largest of the studies within this review was the FOOD (Feed or Ordinary Diet) trial, which assessed the timing and method of enteral tube feeding for dysphagic stroke patients.¹⁵⁰ The FOOD trial included 2 trials of dysphagic stroke patients, an “early versus avoid” trial that randomized patients to early enteral tube feeding or no tube feeding for >7 days and a PEG versus nasogastric tube trial that allocated patients to either of these interventions within 3 days of enrollment.

In the trial of early versus no enteral tube feeding, patients randomized to the early enteral feeding group had a non-significant decrease in death, a nonsignificant increase in disability, and a small but significant increase in the risk of gastrointestinal hemorrhage at 6 months, although low power and other methodological concerns limit the conclusions that can be drawn from this study. In the PEG versus nasogastric tube trial, early PEG was associated with a significant risk of death and poor outcome. For long-term management, PEG tubes are better tolerated than nasogastric tubes with fewer failures, although there were no significant differences in complications.¹⁵¹

Several interventions have been suggested to treat dysphagia after stroke.¹⁴⁵ Behavioral interventions and acupuncture may reduce the proportion of patients with persistent dysphagia.¹⁴⁵ Electrical stimulation of the pharynx may result in slower transit time; however, it is unclear whether these interventions have an impact on nutritional status or outcome.¹⁴⁵

Before artificial nutrition is started, measurable goals should be identified that are reviewed on a periodic basis. These goals might include regaining the ability to swallow, regaining consciousness, prolonging life, or minimizing the burdens of treatment (eg, restraints during nasogastric feeding, surgical interventions). These goals should be documented and follow the patient when the patient is transferred to other providers or facilities. The development of a systematic approach to evaluating patients, meeting with families, and time-limited trials can decrease unwarranted variations in care and improve patient- and family-centered care.¹⁵² The eliciting of patient preferences regarding the use of feeding tubes and the negotiation of alternatives such as hand feeding (the true risks and benefits of which are unknown in this population) require intense discussions with concepts, language, and words that most find uncomfortable but are critical for establishing the proper goals of care. In those patients who do not elect to have artificial nutrition or a PEG, depending on the goals of care, efforts to restore swallowing should continue. Because many stroke patients lack capacity, it is important to know the laws of one's state and institutional policies regarding surrogate

decision making in the absence of a designated healthcare proxy, particularly with regard to AHN.

Surgical Options for Severe Stroke

The value of invasive treatments for patients with massive ischemic stroke of the cerebral hemisphere and cerebellum, intraparenchymal hematomas, and intraventricular and SAH are reviewed in the specific AHA/American Stroke Association guidelines devoted to these topics.^{33,34,153} However, a brief discussion of these invasive interventions is pertinent to the present scientific statement.

The benefits and risks of these invasive treatments, although they usually demand emergent decisions, need to be discussed with patients, when possible, and families before proceeding with the intervention. The chances of survival with severe disability should be understood. These invasive therapies may be inappropriate for patients who had previously expressed clear wishes to avoid aggressive treatments if confronted with the prospect of survival with disability.

Decompressive craniectomy is a lifesaving treatment for selected patients with hemispheric strokes that cause massive ischemic brain edema.¹⁵⁴ This benefit was demonstrated in a pooled analysis of 3 randomized controlled trials in which early decompressive surgery (within 48 hours of stroke onset) decreased the mortality of these massive strokes (from 71% with conservative treatment to 22% with surgery) and also significantly increased the chances of survival with only moderate disability (from 21% with conservative treatment to 43% with surgery).¹⁵⁵ On the basis of the available data, decompressive craniectomy results in improved quality-adjusted life years¹⁵⁶; however, the benefit of decompressive surgery has only been shown for patients aged ≤ 60 years. This caveat is particularly relevant because prognosis after decompressive craniectomy has been reported to be highly dependent on age.¹⁵⁷ The ongoing trial DESTINY 2 (Decompressive Surgery for the Treatment of Malignant Infarction of the Middle Cerebral Artery II) is being conducted to answer the question whether decompressive craniectomy may also be valuable in patients aged >60 years. Further research is also necessary concerning the prevention of cerebral edema and optimization of the timing of surgery.

Surgical evacuation is not superior to conservative treatment for patients with spontaneous cerebral hematomas¹⁵⁸; however, it may be an effective strategy in selected patients. A subgroup analysis of STICH (Surgical Trial in Intracerebral Hemorrhage), the largest randomized trial comparing medical versus surgical treatment for ICH, suggested that noncomatose patients with superficial hematomas (ie, hematomas with margins within 1 cm of the brain surface) might benefit from craniotomy for evacuation.¹⁵⁹ This specific population was recently evaluated in STICH II, which suggested early surgery has similar rates of death or disability at 6 months as initial conservative treatment.¹⁶⁰ Stereotactic approaches, which can be combined with the injection of a thrombolytic agent to enhance the aspiration of the hematoma, have been reported to result in good outcomes in some cases, but experience with these techniques is limited, and this technique remains investigational.¹⁶¹ Ongoing trials specifically exclude comatose patients because surgery has not been effective for

the treatment of comatose patients in previous randomized trials.^{158,159} However, in daily practice, there are some rapidly deteriorating patients with marked tissue shift who may achieve favorable recovery after emergency surgery.¹⁶² More research is needed to identify which selected patients may benefit from emergency evacuation.

Suboccipital craniotomy for evacuation of large cerebellar hematomas and suboccipital craniectomy for large cerebellar infarctions are recommended for patients who deteriorate from brainstem compression and obstructive hydrocephalus. Although the evidence for these interventions is limited to case series,^{163,164} the improvement in outcomes with surgery and the ominous prognosis with conservative management indicate that these interventions can be beneficial in selected patients. Treatment of obstructive hydrocephalus caused by a massive cerebellar stroke or hematoma with ventriculostomy alone is generally considered inadequate because of the risk of worsening upward tissue herniation and insufficient decompression.^{34,164} The value of surgery for elderly patients with massive cerebellar lesions and severe comorbidities has never been examined formally; in these cases, the decision to proceed with surgery needs to be individualized with consideration of the overall prognosis for recovery and the patient's wishes. The best timing for decompressive surgeries after cerebellar stroke is not clear and deserves further study.

Patients presenting with poor-grade SAH (ie, stuporous and comatose) may improve markedly after initial stabilization in the intensive care unit. Necessary treatments may include artificial ventilation, vasopressors and inotropes, osmotic agents for amelioration of brain edema, and ventriculostomy for hydrocephalus.¹⁵³ Early improvement in motor responses is associated with better outcome.¹⁶⁵ Even a substantial proportion of those patients who remain in poor-grade status after these initial measures can achieve a favorable outcome; functional recovery with no more than moderate cognitive and physical disability has been documented in as many as half or more of all poor-grade SAH patients treated intensively in a dedicated neurocritical care unit after coiling of the ruptured aneurysm.^{166,167} Patients initially discharged to a nursing home can regain function over time if rehabilitation services are provided.¹⁶⁸ Although elderly, comatose patients with poor-grade SAH have a high likelihood of a poor outcome, it still may be reasonable to attempt a limited trial of aggressive treatment for some patients given the potential for considerable recovery. This should include early treatment of the ruptured aneurysm to reduce the devastating consequences of rebleeding.

Symptomatic hydrocephalus from intraventricular hemorrhage can only be treated effectively with emergent ventriculostomy.¹⁶⁹ Intraventricular administration of recombinant tissue-type plasminogen activator can be beneficial by accelerating the clearance of the clot,¹⁷⁰ but the efficacy of this intervention is being further evaluated in a phase 3 trial.

Common Preference-Sensitive Decisions in Stroke: Recommendations

- 1. The decision to pursue life-sustaining therapies or procedures, including CPR, intubation and MV, artificial nutrition, or other invasive procedures, should be**

based on the overall goals of care, taking into account an individualized estimate of the overall benefit and risk of each treatment and the preferences and values of the patient (*Class I; Level of Evidence B*).

2. DNR orders should be based on a patient's prestroke quality of life and/or the patient's view of the risks and benefits of CPR in hospitalized patients. In patients with acute ischemic stroke, ICH, or SAH (with no pre-existing DNR orders), providers, patients, and families should be cautioned about making early DNR decisions or other limitations in treatment before fully understanding the prognosis, including the potential for recovery (*Class I; Level of Evidence B*).
3. Patients with a DNR order in place should receive all other appropriate medical and surgical interventions unless otherwise explicitly indicated (*Class I; Level of Evidence C*).
4. Patients with a DNI order in place should receive all other appropriate medical and surgical interventions unless otherwise explicitly indicated (*Class IIa; Level of Evidence C*). Because CPR usually requires endotracheal intubation, providers should explain why a patient with a DNI order should also consider a simultaneous DNR order and encourage patients (or their surrogates) to execute a DNR order if they have a DNI order in place.
5. Patients who cannot take solid food and liquids orally should receive nasogastric, nasoduodenal, or PEG tube feedings to maintain hydration and nutrition while undergoing efforts to restore swallowing (*Class I; Level of Evidence B*).³³
6. In selecting between nasogastric and PEG tube routes of feeding in patients who cannot take solid food or liquids orally, it is reasonable to prefer nasogastric tube feeding until 2 to 3 weeks after stroke onset (*Class IIa; Level of Evidence B*).³³
7. To maintain nutrition over the longer term, PEG tube routes of feeding are probably recommended over nasogastric routes of feeding (*Class IIa; Level of Evidence B*).
8. Patients who elect to not have ANH based on discussion of the goals of care should be provided with the safest method of natural nutrition and educated about the potential risks and benefits of this approach (*Class I; Level of Evidence B*).
9. Decompressive craniectomy for hemispheric infarctions with malignant edema can be effective in reducing mortality and increasing the chances of survival with moderate disability (*Class IIa; Level of Evidence B*).
10. Patients with large cerebellar hematomas or massive cerebellar infarctions who develop neurological deterioration, brainstem compression, or obstructive hydrocephalus should undergo emergent decompressive surgery (*Class I; Level of Evidence B*).
11. Initial aggressive treatment is recommended for most patients with poor-grade aneurysmal SAH, including ventilatory assistance, vasopressors, ventriculostomy if hydrocephalus is present, and early occlusion of the aneurysm if the patient can be stabilized (*Class I; Level of Evidence B*).

Symptom Detection and Management

Palliative care seeks to improve the quality of life of patients and families through the identification, prevention, and relief of pain and suffering in body, mind, and spirit. Because the ability of stroke survivors to offer details or describe their concerns is commonly impaired, clinicians need to be aware of the prevalence of these symptoms and attentive to their presence. The following sections discuss the epidemiology, importance, and management options of common and disabling poststroke symptoms and review the role of caregivers and ways to support them, patient's spiritual needs, and the management of terminal symptoms.

Several themes are evident. First, troubling symptoms are common and occur in all stroke patients, including those with minimal deficits, those with severe deficits, and those who are actively dying. Second, stroke symptoms have a profound impact on recovery, quality of life, and mortality. Third, many patients continue to have poor symptom control and unmet care needs long after the onset of the stroke.¹⁷¹ Fourth, particular attention is needed for older adults and patients with impaired communication because they are less likely to be prescribed medications for pain, depression, and other troubling symptoms.¹⁷² Fifth, we have limited information on the epidemiology of many symptoms, including prevalence, risk factors, and prognostic significance, and the evidence to guide treatment and management is scarce.

Pain

Freedom from pain is one of the most important issues to patients and families facing the end of life.¹⁷³ Although physical pain is not as common in the acute stroke setting, almost half of stroke survivors report newly developed pain 6 months after stroke.¹⁷⁴ Some factors associated with pain include younger age, female sex, higher National Institutes of Health Stroke Scale score, and higher hemoglobin A_{1c}.¹⁷⁵ In vulnerable populations (older adults and impaired communication), there should be enhanced strategies for detection and monitoring, including verbal descriptor scales, caregiver report, and knowledge of pain behaviors. Two of the most commonly reported stroke-specific pain syndromes, central poststroke pain (CPSP) and hemiplegic shoulder pain (HSP), as well as painful spasticity, are discussed in more detail below.

Central Poststroke Pain

Chronic pain in those body areas that have lost part of their sensory innervation occurs in 1% to 12% of stroke patients.¹⁷⁶ Although the precise mechanism is unknown, it is thought to result from partial deafferentation of the spinothalamic tract or its cortical projections. The most common site of involvement is the thalamus, but other areas involving the spinothalamic tract may be responsible, including the brain stem and spinal cord.¹⁷⁶ A number of antidepressant and anticonvulsant agents have been studied specifically in CPSP.¹⁷⁷ Only amitriptyline^{178,179} and lamotrigine¹⁸⁰ have been shown to relieve pain, but the studies were small (n=15 and 30, respectively). Levetiracetam (n=42),¹⁸¹ pregabalin (n=219),¹⁸² and carbamazepine (n=14)¹⁷⁸ have not been found to have meaningful pain relief in CPSP. Opioids are not effective for CPSP.¹⁸³ In a randomized clinical trial of gabapentin for neuropathic pain

syndromes, only 9 people in the study population (3%) had CPSP.¹⁸⁴ Similarly, although venlafaxine has been found to be effective for a variety of neuropathic pain syndromes, its benefit in CPSP is unknown.¹⁸⁵

Hemiplegic Shoulder Pain

HSP occurs in approximately half of patients with hemiparesis.¹⁸⁶ The highest incidence is in those with complete plegia of the arm (>80%),¹⁸⁷ but sensory deficits also appear to be associated with the development of HSP.¹⁸⁶ Local causes include adhesive capsulitis, rotator cuff disorders, subluxation of the glenohumeral joint, and tendonitis. Causes related to the nervous system include cervical radiculopathies, visceral referred pain, and CPSP. Because of the variety of pathogenesis that play into HSP, treatment needs to be tailored individually. Several nonpharmacological measures to prevent or treat HSP have been suggested, including electrical stimulation, shoulder strapping, physical therapy with passive range of motion, and shoulder girdle strengthening.¹⁸⁸ Evidence regarding the impact of physical therapy on stroke outcome is lacking.¹⁸⁹ Ice, heat, and soft tissue massage, as well as oral analgesics (NSAIDs), all can produce temporizing pain relief. Several interventions have been studied for HSP, but more research is needed to better define optimal treatment and directly compare specific treatment options. Intra-articular steroid injection is used commonly, but studies evaluating this intervention are small and vary in diagnostic criteria, and results are conflicting.¹⁹⁰⁻¹⁹³ Intramuscular botulinum toxin A injection was the subject of a Cochrane review that suggested a benefit but urged caution concerning the interpretation of the results because of small sample sizes and high risk of bias in each of the randomized controlled trials.¹⁹⁴ Intramuscular electrical stimulation may reduce pain better than the use of a shoulder sling.¹⁹⁵ Overall, the prognosis of HSP is good, with 80% of patients improved or pain free at 6 months with usual treatment (including physiotherapy and simple analgesics in all patients and shoulder steroid intra-articular injection and amitriptyline in some).¹⁸⁶

Poststroke Spasticity

Poststroke spasticity is common and becomes symptomatic in one third of stroke survivors.¹⁹⁶ Although oral antispastic agents have been suggested,^{188,197} side effects such as sedation, confusion (tizanidine), and hepatotoxicity (dantrolene and tizanidine) may limit their use. Local injections of botulinum toxin may improve dexterity (in the upper extremity).^{198,199} Nonpharmacological treatment such as physical therapy, splints and orthoses, range of motion exercises, and electrical stimulation can be used in combination with pharmacological treatment.^{200,201}

Pain: Recommendations

- 1. For the treatment of CPSP, pharmacological treatment with amitriptyline or lamotrigine is reasonable, although studies have been small. In older adults, given the side effects associated with amitriptyline, nortriptyline may be a reasonable substitute (Class IIa; Level of Evidence B). Venlafaxine and gabapentin may be considered on the basis of their efficacy in**

other neuropathic pain syndromes (Class IIb; Level of Evidence C). Treatment with pregabalin, carbamazepine, levetiracetam, or opioids is not effective (Class III; Level of Evidence B).

- 2. For patients with poststroke HSP, ice, heat, soft tissue massage, and NSAIDs before or after exercise are reasonable for temporizing pain relief (Class IIa; Level of Evidence C). For patients with persistent HSP, interventions that may be reasonable to perform include intra-articular steroid injections (Class IIb; Level of Evidence C), intramuscular Botox injections in the case of local spasticity (Class IIb; Level of Evidence A), intramuscular electric stimulation (Class IIb; Level of Evidence B), aromatherapy (Class IIb; Level of Evidence B), and slow-stroke back massage (Class IIb; Level of Evidence B).**

Nonpain Physical Symptoms

In addition to the traditional stroke symptoms, such as loss in motor function and trouble with vision, language, and speech, stroke patients commonly experience other physical symptoms, including fatigue, incontinence, seizures, sexual dysfunction, and SDB, which are discussed below.

Fatigue

Fatigue is a common poststroke symptom, with >50% of stroke survivors reporting fatigue after 1 year.²⁰² Fatigue may be more common in patients with brainstem or subcortical/thalamic strokes than in those with cortical strokes. Its occurrence in the absence of depression, obstructive sleep apnea, or other medical conditions has led to the concept of primary poststroke fatigue. One theory of poststroke fatigue posits an attention deficit that results from damage to the reticular formation and related structures involved in the subcortical attentional network. Currently, there is little evidence-based advice that can be offered to people with stroke to help manage their fatigue.²⁰³ Modafinil was studied in 23 young patients (aged <70 years) with mild strokes 12 to 48 months from the acute event; the study was limited by a high dropout rate, and treatment was found to be effective only in a subgroup of stroke patients.²⁰⁴ Amantadine and methylphenidate have been used to treat cancer fatigue or fatigue in other neurological conditions²⁰⁵ but have not been studied for fatigue in the stroke population.

Incontinence

Approximately 50% of stroke patients experience incontinence during the initial hospitalization, but this number is reduced to 20% for urinary and 10% for fecal incontinence by 6 months after the event.²⁰⁶ Older age, increased stroke severity, and diabetes mellitus and other disabling comorbidities increase the risk of urinary incontinence in stroke patients.²⁰⁶ Incontinence can be embarrassing to patients and a major burden on their caregivers once they are discharged home. Incontinence after stroke is not always central in origin but may be the result of immobility and impaired ability to communicate. Although there is insufficient evidence regarding the treatment of incontinence after stroke,²⁰⁷ general continence care includes early removal of indwelling catheters to

avoid urinary tract infection, bladder training programs, and prompted voiding and bowel programs.¹⁸⁸

Constipation is also common after stroke, particularly when mobility is reduced, and requires regular monitoring, bowel programs, and appropriate medical treatment. Despite its frequency, little evidence exists to guide the approach to constipation. A reasonable bowel regimen in bedridden patients includes a stimulant laxative, such as bisacodyl or senna, along with an osmolar agent, such as milk of magnesia, lactulose, or polyethylene glycol.²⁰⁸ Stool softeners, such as docusate, have limited clinical efficacy.²⁰⁹

Poststroke Seizures and Epilepsy

Between 5% and 12% of patients will experience ≥ 1 epileptic seizures after an ischemic stroke, and the incidence increases with cortical location and greater stroke severity.²¹⁰⁻²¹² Most studies distinguish between early and late (within versus after the first 2 weeks of stroke) poststroke seizures. Antiseizure medications for the primary prevention of poststroke seizures are not recommended.^{33,34} Patients with late poststroke seizures have a higher risk of developing epilepsy (ie, ≥ 2 unprovoked seizures). Once patients develop poststroke epilepsy, antiseizure medications should be given.³³ The choice of the specific agent needs to take into consideration comorbidities, concomitant medications, preferences, and cost. Providers may want to consider electroencephalographic monitoring in stroke patients with a change in mental status or those with depressed mental status out of proportion to the degree of brain injury.^{33,34}

Sexual Dysfunction

A noticeable decline in sexual activity happens after stroke, even in patients with mild or no residual deficit.²¹³ Sexual disorders are rarely a consequence of the stroke alone but rather are associated with a variety of psychosocial factors, medication side effects, and medical comorbidities. Practical advice to patients and their partners include spending time together doing activities both enjoy, or just sitting quietly holding hands or embracing each other, and in the dysphasic patient, establishing a method of saying, "I love you."²¹⁴ Health providers need to acknowledge the effect of stroke on intimacy and sexuality and should provide the necessary resources, such as the [article in Stroke Connection that can be found at http://www.nxtbook.com/nxtbooks/aha/strokeconnection_200903/#/14](http://www.nxtbook.com/nxtbooks/aha/strokeconnection_200903/#/14) ("Sex and Intimacy after Stroke") or the fact sheet at www.stroke.org ("Recovery After Stroke: Redefining Sexuality"). The safety and efficacy of medications for erectile dysfunction such as phosphodiesterase inhibitors (eg, sildenafil) in stroke patients are unknown. Although a small study of 12 patients with mild to moderate stroke suggested it was safe,²¹⁵ sildenafil is a vasoactive drug and should be used cautiously in patients with vascular disease.

Sleep-Disordered Breathing

SDB is defined as ≥ 10 breathing pauses (apneas) per hour, each lasting >10 seconds (apnea-hypopnea index of $\geq 10/h$) and occurs in more than half of stroke survivors, regardless of type of stroke.²¹⁶ SDB is more common in men, in patients with recurrent strokes, and in patients with cryptogenic stroke than in those with a cardioembolic pathogenesis.²¹⁶ The most common

form of SDB is obstructive sleep apnea, which is caused by collapse of the upper airway.²¹⁷ The presence of obstructive sleep apnea increases the risk for incident hypertension, and continuous positive airway pressure therapy may reduce that risk.²¹⁸ The effect of continuous positive airway pressure therapy on cardiovascular events is less clear in nonsleepy patients with obstructive sleep apnea.²¹⁹ Research is still needed to determine whether the treatment of SDB in stroke patients will prevent recurrent stroke, vascular events, or death.²²⁰

Nonpain Physical Symptoms: Recommendations

1. In patients with primary poststroke fatigue, the usefulness of pharmacological treatment such as modafinil, amantadine, or methylphenidate is not well established (Class IIb; Level of Evidence C).
2. Poststroke epilepsy should be treated similarly to epilepsy from any other pathogenesis (Class I; Level of Evidence B). Prophylactic administration of anti-convulsants to patients with stroke but who have not had seizures is not recommended (Class III; Level of Evidence C).
3. Poststroke sexual dysfunction should be acknowledged and periodically screened for, and when present, a referral to necessary resources should be provided (Class I; Level of Evidence C).
4. Patients with stroke who have excessive daytime somnolence should be referred to an accredited sleep center for an evaluation (Class I; Level of Evidence B).

Psychological Symptoms

Stroke patients and their family members are commonly unprepared for the psychological impact of stroke. Although delirium commonly occurs during hospitalization, depression, anxiety, and emotional lability may not be evident until weeks or months later. From the beginning, clinicians may want to acknowledge, look for, and if appropriate, educate patients and families about the prevalence and management of psychological problems after stroke.

Poststroke Depression

Poststroke depression occurs in at least one third of patients but is often underdetected and undertreated.²²¹ Providers should be particularly vigilant of the possibility of depression in stroke patients with prior history of depression, physical disability, cognitive impairment, and low social support.²²² Screening measures for poststroke depression include the Patient Health Questionnaire 2 and Patient Health Questionnaire 9²²¹ or even a simple questions such as, "Do you often feel sad or depressed?"²²³ This line of questioning may also provide an opportunity to educate patients about abnormal mood, reassure them that depressive symptoms are common after stroke, and encourage them to seek help if their symptoms are persistent and interfere with their usual daily activities.²²⁴ Several controlled trials have demonstrated beneficial effects of antidepressant therapy, such as selective serotonin reuptake inhibitors, in the treatment of poststroke depression.²²⁵⁻²²⁹ Psychotherapy alone has not been shown to be effective in treating depression after stroke.²³⁰ For the prevention of poststroke depression, a Cochrane review suggested no benefit of antidepressant

therapy but a possible benefit of psychotherapy.²³⁰ A subsequent literature review that used some overlapping studies also concluded that selective serotonin reuptake inhibitors may reduce the odds for developing poststroke depression.²³¹ Lastly, treatment of chronic pain or other physical symptoms, as described in previous sections, may also result in improvement in concomitant depressive symptoms.

Poststroke Anxiety

Anxiety after stroke is common and long-lasting, interferes with social relationships, and worsens functional outcome.²³² During the first 3 years after a stroke, ≈20% of survivors experience generalized anxiety disorder.²³³ Anxiety may accompany depression (in two thirds of patients with generalized anxiety disorder)²³³ or delirium or may result from other distressing physical symptoms. Antidepressant medications may effectively treat poststroke anxiety symptoms in patients with comorbid depression.^{232,234} If anxiety is severe and lifespan is limited, however, benzodiazepines are the drugs of choice.

Delirium

Delirium is common in the acute phase after stroke, with a prevalence of 10% to 48%.²³⁵ It is associated with a higher mortality, a longer hospital stay, and an increased risk of institutionalization.²³⁵ Older age, preexisting cognitive deficits, higher National Institutes of Health Stroke Scale score, infection, and a right hemispheric location increase the risk for delirium after stroke.²³⁶ According to 1 study that involved hospitalized older patients (not specific to stroke), up to one third of delirium cases may be preventable. As a result, a proactive approach to prevent delirium is warranted.²³⁷ Drugs with sedative or neuroactive effects should be avoided, dehydration should be prevented, and regulation of sleep/wake cycle and a calming, stable sensory environment should be maintained with day/night orientation, cognitive stimulation, reminder of date, and early mobilization. This may include having a family member stay with the patient to promote orientation, sense of security, and safety. The management of delirium starts with identification of the underlying cause, which could include infectious, metabolic, or toxic pathogenesis. Short-term use of antipsychotic agents may be reasonable for the treatment of delirium,²³⁸ although studies specific to stroke are lacking. The chronic use of antipsychotic agents has been associated with a higher risk of stroke²³⁹ and severe cardiovascular events,²⁴⁰ particularly in elderly patients. In the face of very few controlled trials, benzodiazepines cannot be recommended for the treatment of delirium unless the patient is undergoing sedative or alcohol withdrawal.²³⁸ Dexmedetomidine may be beneficial in the management of delirium in the intensive care unit, but studies specific to stroke are lacking.²⁴¹

Emotional Lability

Exaggerated crying or laughing, or the pseudobulbar affect, can be distressing to both patients and their families and occurs in one fifth of stroke survivors in the first 6 months.²⁴² As with many other symptoms, acknowledgement and education can defuse potentially uncomfortable situations. Although antidepressant medication may reduce the frequency of crying or laughing episodes, it is difficult to recommend use on these grounds alone.²⁴² Dextromethorphan/quinidine was recently

approved by the FDA for the treatment of pseudobulbar affect; studies supporting its effectiveness have been performed only on patients with multiple sclerosis and ALS.²⁴³ Its effects on stroke patients are unknown.

Psychological Symptoms: Recommendations

- 1. Stroke survivors should be periodically screened and evaluated for the presence of depression and, if present, treated with antidepressant therapy, especially selective serotonin reuptake inhibitors (Class I; Level of Evidence B).**
- 2. In patients with stroke and generalized anxiety, antidepressant medications can be useful (Class IIa; Level of Evidence B). Benzodiazepines are recommended only for short-term treatment, particularly in patients receiving end-of-life measures, or if symptoms are severe (Class I; Level of Evidence C).**
- 3. All stroke patients with delirium should be evaluated for reversible causes, such as toxic and metabolic derangements; specific treatment of the causes and behavioral approaches are recommended for management (Class I; Level of Evidence C). Antipsychotic agents may be considered for short-term treatment (Class IIb; Level of Evidence B), but benzodiazepines are not recommended (Class III; Level of Evidence B).**
- 4. In stroke patients with emotional lability, the use of antidepressants may be considered if symptoms are troubling or coexist with depression (Class IIb; Level of Evidence B).**

Social and Existential Suffering

Care Giving and Receiving

Stroke requires adjustments in the lives of everyone it touches. Stroke patients struggle to adapt to their new disability and their new roles within their social environment. Caregivers try to cope with the physical, emotional, and cognitive changes of their loved one, while demands of everyday life and financial concerns are increased. Fatigue, depression, and anxiety are common among caregivers (caregiver strain/burnout), in particular women, younger caregivers, those with poor physical health, and those caring for patients with severe cognitive, behavioral, and emotional changes.²⁴⁴ In contrast to caregivers of people with other chronic conditions such as dementia or cancer, caregivers of stroke survivors are thrust into their role with little time to learn or grow into the necessary skills. Common fears are caused by the uncertainty of prognosis, with the fear of another stroke, and the feeling of abandonment, especially when their loved one is unable to communicate.³⁵ Caregivers' needs include information provision, management of emotions, social support, health maintenance, practical problem solving, and respite. Training caregivers in their new roles may reduce burden while improving psychosocial outcomes in both caregivers and patients.²⁴⁵

Anticipatory, Acute, and Complicated Grief

Grief reactions are common in patients and families with stroke but remain insufficiently studied.²⁴⁶ Providers need to recognize and help manage the anticipatory grief of the

loved ones of patients who are dying by encouraging open discussion, clarifying future plans, assisting in life review, and involving them in the patient's care to the extent they wish. It is equally important to address the grief and loss experienced by patients and families even if the patient does not die of the stroke. The stroke impacts future life plans for both the patient and caregiver, and the experience of grief and loss that is felt is often not addressed. Providers should acknowledge the sense of loss, provide time and permission to grieve, and offer follow-up support, including bereavement counseling. The spectrum of normal grief is difficult to define, but complicated grief or depression usually begins 1 to 2 months after significant loss or after the death occurs and may be more severe when death is sudden. In the case of death, a condolence contact to a family member by either a short phone call or a personalized letter may be helpful.

Provider Self-Care and Preventing Burnout

Many factors in providing care to patients and families with stroke can lead to burnout, a "state of mental and/or physical exhaustion caused by excessive or prolonged stress."²⁴⁷ These include work overload, family and work imbalance, exposure to intense suffering, and insufficient resources. Symptoms of burnout can be both mental and behavioral, which can lead to neglect of self and family, depression, reduced productivity, depersonalization, anger, and cynicism.²⁴⁸ Healthcare providers of patients and families with stroke should self-monitor with periodic self-reflection and debriefing with trusted colleagues. Other methods of self-care include proper work-life balance, hobbies, exercise, and spiritual practices, as well as referral to more formal mental health services if necessary.

Social Suffering: Recommendations

- 1. To prevent caregiver burnout, education about the nature of the stroke, stroke management, and outcome expectations, including the caregiver's roles in that process, is useful. Caregivers should be provided information on supportive resources (Class I; Level of Evidence C). Caregiver training may be considered (Class IIb; Level of Evidence C).**
- 2. Providers should try to anticipate, recognize, and help manage grief in patients and families with stroke (Class I; Level of Evidence C).**
- 3. Providers should develop self-care strategies to monitor for symptoms and to manage burnout while providing care to patients with serious and life-threatening stroke (Class I; Level of Evidence C).**

Addressing Spiritual Needs

A stroke can shatter one's meaning and purpose in life, either as a patient or a family member. Although there are few data on prevalence, our experience suggests that spiritual or existential crises are common after a stroke. As providers, we should identify and manage spiritual pain. In the broadest sense, spiritual care is the emotionally sensitive, empathetic care of the human "spirit" and is not specific to religion. Patients and families often welcome such discussions, and open-ended questions may facilitate dialogue. Examples of

questions include, "Is faith (religion, spirituality) important to you?" "What thoughts do you have about why you had this stroke at this time?" and "Would you like to explore religious matters with someone?"²⁴⁹ Empathetic listening and acknowledgment of suffering are important, not providing "correct answers." Spirituality helps people find hope in despair and can help restore purpose.

Other strategies for fostering hope include relief of suffering, developing caring relationships, setting attainable goals, involving the patient in the decision-making process, affirming the patient's worth, using lighthearted humor (when appropriate), and reminiscing.²⁵⁰ It is important, however, to know one's professional boundaries and refer to other members of the care team as appropriate. Pastoral care providers, who are trained in spiritual care and counseling, can help patients and families to explore issues of meaning, reconcile suffering, and draw strength from values and beliefs.²⁵¹

Spiritual Needs: Recommendations

- 1. It is reasonable for providers caring for stroke patients and their families to consider asking their patients about possible spiritual or religious beliefs and to offer referral to a chaplain or spiritual care provider (Class IIa; Level of Evidence C).**

Addressing Requests for Hastened Death

Occasionally, stroke patients express a wish to die.²⁵² These requests need to be taken seriously and should not be minimized ("Everyone would feel the same way") or considered necessarily psychopathological ("This is clear psychopathology"). It is important to develop a systematic approach in evaluating such requests to clarify the request, support the patient, evaluate for decision-making capacity, explore the dimensions of suffering, respond to emotions, intensify treatment where appropriate, and respond to the request only after a full multidimensional evaluation.²⁵³ Exploring such requests with statements such as, "Can you tell me what you mean by that?" will often uncover one of the following underlying reasons: (1) unrecognized or undertreated physical symptoms, (2) psychosocial crisis (fear of being a social or financial burden), (3) spiritual crisis, or (4) clinical depression. Although poststroke depression is common, such requests in the acute setting are often cries for help that indicate emergent psychosocial or spiritual crises. In these situations, a palliative care consultation is often helpful. Responding to persistent requests for hastened death is beyond the scope of this review but should involve reflecting on one's personal feeling about the request and discussing it with other professionals, seeking out a consultation or second opinion, learning of the possibilities, and balancing integrity with nonabandonment. We do not address voluntarily stopping eating and drinking or physician-assisted dying, but reviews on these topics are available.²⁵⁴

Addressing Requests for Hastened Death: Recommendations

- 1. Providers may consider developing a strategy for evaluating and responding to requests for hastened**

death in patients with stroke, including assessment of suicide and searching for remedies for the underlying problem (Class IIb; Level of Evidence C).

Palliative Treatments and Options at the End of Life

State-of-the-art palliative care includes responding appropriately to patients who are actively dying or who have died and finding the least harmful solution to often morally complex situations while keeping in focus the values of the patients, the surrogate decision makers, and the providers. Here we review common palliative treatments at the end of life in patients with stroke.²⁵⁴

Foregoing Life-Sustaining Therapy

Most patients who die of stroke do so after a decision is made to forego life-sustaining therapies. These decisions should be made after a systematic process of establishing goals of care (“Establishing Goals of Care”).²⁵⁵ Limiting treatments in stroke patients usually involves decision making concerning CPR, intubation and MV, cranial surgery, cerebrospinal fluid diversion, vasoactive support, osmotic therapy, antibiotic treatment, ANH, and occasionally dialysis. After a decision is made to forego life-sustaining therapy, it is important to reaffirm to the patient and family an ongoing commitment to continue care through the dying process.

Although difficult to estimate precisely, withdrawal of MV occurs in up to 35% to 60% of all deaths in patients with stroke, which makes it one of the most common modes of death in the country.^{256–258} Existing data are largely derived from observational studies in ischemic stroke and ICH; there are fewer available data in SAH. There is considerable variation in rates of withdrawal of life-sustaining therapies that is not completely explained by disease severity and patient preferences.^{258,259} There are important racial or ethnic variations in the decision to limit certain treatments, but a full appreciation of the physician and hospital factors that may influence withdrawal practices has not yet been achieved.^{40,257,260,261}

Providers should offer to counsel family members about anticipated signs and symptoms after extubation (changes in breathing, color, and urine output; agitation; breathing noises [“death rattle”]), as well as the available treatments, and prepare family members for the fact that death may or may not occur shortly after extubation. Although >50% to 70% patients survive <24 hours after extubation,^{255,257} up to 60% of patients may exhibit labored breathing after extubation.²⁵⁷ General guidelines are available to make this transition as comfortable as possible for the patient and family.⁸⁴

Treating Severe Terminal Symptoms

Patients who have survived the acute stage of stroke, are not comatose, but have made the choice to withhold or withdraw life-sustaining therapies such as MV or ANH are at risk for developing severe symptoms such as pain, dyspnea, or agitation (as can be seen in terminal delirium). With the primary intent of treatment being relief of suffering, not all patients will require continuous infusion of sedatives or opiates, particularly if that would prevent meaningful interaction with family

members. This requires close observation, careful attention, and prompt treatment of any signs of suffering, including increased respiratory rate, heart rate, muscle tension, or grimacing. The first approach should be to use intermittent medications (with dose escalations) such as morphine, midazolam, or fentanyl. It is extremely important to counsel families on what to prepare for in terms of changing signs and symptoms (decreased food and fluid intake, decreased ability to cough, breathing noises, reduced circulatory and renal function, decreased levels of consciousness, agitation, and changes in breathing). Pooling of saliva in the posterior oropharynx can occasionally cause breathing noises (death rattle). Suctioning is generally not indicated, because most of the time, simple measures such as repositioning and oral glycopyrrolate/scolamine patches will suffice.²⁶² Continuous monitoring of cardiac, oxygen, or hemodynamic parameters, however, may be more disconcerting to the family than it is helpful. During the dying process, it is important to educate the family on what to expect regarding changing signs or symptoms. It is important to assure the family that their loved one’s pain or other discomfort will be treated aggressively and that clinical care will be continued throughout the dying process.

Brain Death and Organ Donation

Each year, the predicted number of donors after brain death is between 10500 and 13800, and stroke accounts for a large proportion of patients declared brain dead who become potential organ donors.^{263,264} In the United States, hospitals are mandated by law to involve organ procurement agencies in the evaluation of these cases for possible organ donation and to offer the option to the families of appropriate candidates. Available estimates indicate that >50% of families provide the consent for organ donation,²⁶³ but donation rates indicate that donation only occurs in one third of suitable cases.²⁶⁵ This gap can be reduced by separating (decoupling) the communication of brain death from the discussion of organ donation,²⁶⁶ optimizing the identification of potential donors,²⁶⁷ and ensuring timely communication with the organ procurement agency.²⁶⁸ Programs that incorporate an in-house presence of the coordinator from the organ procurement agency can be effective in achieving these goals.²⁶⁹ In addition, although the concept of brain death is widely accepted, policies and procedure to determine brain death are highly variable across states, and even across leading hospitals in the same region.²⁷⁰ It is likely that the unification of criteria for brain death determination would have a positive impact on donation rates by avoiding unnecessary delays.²⁷¹

Organ donation after cardiac death has emerged as an alternative to diminish the shortage of organs by allowing organ procurement from patients who die within 60 minutes of cessation of MV. After extubation in this setting, a 2-minute observation period before the declaration of death has been reported to be sufficient,²⁷² but protocols in many centers require an observation period of 5 minutes. In patients with severe brain damage, the neurological examination is crucial to identifying the best candidates for this type of donation; absent cough and corneal reflexes and absent or extensor motor response to pain in addition to a poor oxygenation

index have been shown to reliably predict death within 60 minutes of withdrawal of life-sustaining therapy. However, protocols vary among hospitals.²⁷³ The decision to explore donation after cardiac death should be clearly separated from the decision to withdraw life-sustaining treatment. Protocols for donation after cardiac death require close collaboration among neurologists, neurosurgeons, intensivists, palliative care and ethics consultants, and organ procurement personnel.

Palliative Treatments and Options at the End of Life: Recommendations

1. In patients with severe brain injury, withdrawal of life-sustaining treatments and the institution of intensive comfort measures is an appropriate treatment plan that should be made in collaboration with identified surrogate decision makers. The decision should be individualized, as well as patient and family centered (*Class I; Level of Evidence C*).
2. Patients undergoing palliative extubation should be monitored closely for symptoms of discomfort and air hunger and treated appropriately with opioids or benzodiazepines (*Class I; Level of Evidence C*).
3. Patients who have intractable physical symptoms (eg, dyspnea and pain) at the end of life should be provided with the minimally effective amount of sedation necessary to relieve refractory symptoms (proportionate palliative sedation). Only rarely will patients require progressive increases in sedation to the point of unconsciousness to achieve this goal (*Class I; Level of Evidence B*).
4. Physicians should work closely with representatives from the local organ procurement agency to ensure that the option of organ donation is offered to the family of every patient declared brain dead (*Class I; Level of Evidence C*).

Role of Palliative Care Specialists

Typically, a palliative care physician works with an interdisciplinary team that consists of nurse practitioners, physician assistants, nurses, social workers, and spiritual providers. Unlike hospice, the application of palliative care is based on need rather than prognosis or life expectancy.

Although data on palliative care in patients with strokes are limited, data from a single center suggest that most consultations are for help with conversations about goals. In 1 study, 6.3% of all palliative care consultations were for patients with strokes (31% ischemic, 26% intracerebral bleeds, 30% subarachnoid bleeds, and 14% with subdural hematomas).¹⁶ Compared with their other palliative care patients, patients with stroke were more functionally impaired at the time of consultation, more likely to die in the hospital, and had fewer traditional symptom burdens than other diagnoses.

In a recent randomized controlled trial of patients with newly diagnosed non-small cell lung cancer, the intervention of an early palliative care consultation (compared with routine involvement) resulted in improved quality of life, less depression, less healthcare resource use, and improved survival.¹⁷ In

patients with stroke, it is not yet known whether and under what circumstances there would be improved quality with earlier involvement of a formal palliative care consult. This deserves further study.

Role of Palliative Care Specialists: Recommendation

1. Although not an exhaustive list, in patients with stroke, a formal palliative care consultation may be reasonable in the following situations: (1) management of refractory pain, dyspnea, agitation, or other symptoms, particularly near the end of life; (2) management of more complex depression, anxiety, grief, and existential distress; (3) any requests for hastened death; (4) assistance with goals and methods of treatment, particularly pertaining to options for long-term feeding and methods of ventilation; (5) assistance with managing the process of palliative extubation; (6) assistance with addressing cases of near futility and in families who “want everything”; (7) assistance with conflict resolution, whether it be within families, between staff and families, or among treatment teams; and (8) introduction and transition to hospice care (*Class IIb; Level of Evidence B*).

Role of Hospice

For patients approaching the end of life, hospice may be a viable option to provide symptom care and supportive services for patients and their families while promoting patients' ability to die in their preferred environment. In 2009, 6% of hospice enrollees had a terminal diagnosis of stroke.^{273a} To be eligible for the Medicare hospice benefit, 2 physicians (1 of whom is generally the hospice medical director) must certify that the patient has ≤ 6 months to live if the disease follows its usual course, and the patient is willing to forego medical services aimed at curing the underlying terminal diagnoses. Most private insurers have a hospice benefit similar to that provided under Medicare. In addition, hospices may also have different policies regarding the use of antibiotics or ANH.

Criteria for hospice eligibility exist to assist in determining whether survival prognosis is < 6 months for both stroke and coma²⁷⁴ (Table 4). These criteria include clinical signs after 3 days of coma in the acute setting, functional status and nutritional indicators for the more chronic stages of stroke, and additional clinical and imaging factors that can support a poor prognosis. These criteria, however, should be used with caution, because they have not been updated or validated in contemporary healthcare settings. The same challenges as described in “Estimating Prognosis in Stroke” apply.

Inpatient hospice (in a hospital, a stand-alone hospice unit, or a long-term care institution) is an option for many acute-stage patients and families, primarily those who have life-sustaining treatments withdrawn with symptoms that are difficult to control. Although some patients and families are able to go home with hospice support, they should be counseled that hospice typically provides support for only 2 to 4 hours per day. Thus, home care often requires that families have additional support, either by paid or informal caregivers.

Table 4. Hospice Criteria for Stroke and Coma*

Patients will be considered to be in the terminal stages of stroke or coma (life expectancy of ≤ 6 mo) if they meet the following criteria:

Acute stage of stroke

1. Comatose patients with any 3 of the following on day 3 of coma:
 - a. Abnormal brainstem response
 - b. Absent verbal response
 - c. Absent withdrawal response to pain
 - d. Serum creatinine >1.5 mg/dL

Chronic stage of stroke

1. Karnofsky Performance Status $<50\%$ or Palliative Performance Scale $<40\%$.
2. Inability to maintain hydration and caloric intake with 1 of the following:
 - a. Weight loss $>10\%$ in the past 6 mo or $>7.5\%$ in the past 3 mo
 - b. Serum albumin <2.5 g/dL
 - c. Current history of pulmonary aspiration not responsive to speech language pathology intervention
 - d. Sequential calorie counts documenting inadequate caloric/fluid intake
 - e. Dysphagia severe enough to prevent patient from continuing fluids/foods necessary to sustain life, and patient does not receive artificial nutrition and hydration

Documentation of the following factors will support eligibility for hospice care:

1. Medical complications, in the context of progressive clinical decline, within the previous 12 mo that support a terminal prognosis
 - a. Aspiration pneumonia
 - b. Upper urinary tract infection (pyelonephritis)
 - c. Refractory stage 3–4 decubitus ulcers
 - d. Fever recurrent after antibiotics

Documentation of diagnostic imaging factors that support poor prognosis after stroke includes the following:

1. For nontraumatic hemorrhagic stroke:
 - a. Large-volume hemorrhage on CT
 - (1) Infratentorial: 20 mL
 - (2) Supratentorial: 50 mL
 - b. Ventricular extension of hemorrhage
 - c. Surface area of involvement of hemorrhage equal to 30% of cerebrum
 - d. Midline shift $=1.5$ cm
 - e. Obstructive hydrocephalus in patient who declines, or is not a candidate for, ventriculoperitoneal shunt
2. For thrombotic/embolic stroke:
 - a. Large anterior infarcts with both cortical and subcortical involvement
 - b. Large bihemispheric infarcts
 - c. Basilar artery occlusion
 - d. Bilateral vertebral artery occlusion

CT indicates computed tomography.

*This list is meant to provide standardized criteria for scenarios in which hospice may be considered. However, it is important for providers to develop and communicate an individualized prognostic estimate for each patient when setting a treatment plan (“Estimating Prognosis in Stroke” and “Establishing Goals of Care”).

The amount of support that any particular hospice provides varies by the hospice. For patients who have symptoms that cannot be managed at home, hospices can admit the patient to either a nursing home or a stand-alone hospice unit or provide

in-home care 24 hours per day. The availability of each of these different options also varies by the situation and the hospice. Hospice enrollment provides families with bereavement services as well.

In 1 study, up to 25% of patients who died within 30 days of an ischemic stroke were enrolled in hospice.²⁷⁵ Older age, female sex, and a diagnosis of dementia were associated with increase hospice use, and black race and use of gastrostomy and MV were associated with decreased use. Hospice services have been shown to improve patient and family satisfaction with care. Families of those dying with hospice services are more likely to rate the dying experience as more favorable than those who die in an institution or at home with only home health services.^{276,277} There are also data on decreased adverse bereavement and psychological sequelae in families who have used hospice.^{278,279}

Initiating hospice discussions, however, can be challenging and uncomfortable for everyone. Hospice discussion are often viewed as “bad news,” and therefore, it is useful to develop a structured strategy for discussing hospice based on techniques of effective communication and goal setting when bad news (eg, poor prognosis) is discussed.²⁸⁰ Many of the recommendations provided in the “Goal Setting Process: Overview” should be adopted to establish and discuss the benefits and risks/burdens associated with the option of transitioning to hospice for the individual patient and family.

Role of Hospice: Recommendation

1. In patients with stroke, referral to hospice should be considered if survival is expected to be ≤ 6 months and when the patient’s goals are primarily palliative (*Class I; Level of Evidence B*).
2. When introducing and discussing hospice with patients and families, providers may consider adopting strategies of communication used in other “bad news” settings and frame the discussions around the benefits and burdens of hospice in achieving the patient’s and family’s overall goals of care (*Class IIb; Level of Evidence C*).

Education Agenda

There are educational opportunities for all providers who care for patients and families with stroke. Palliative care providers could benefit from additional stroke education, and stroke providers could benefit from additional palliative care education. Training opportunities exist to develop and improve effective patient-centered communication skills, including prognostication skills, across various trainee groups (students, residents, fellows, providers, and nurses).²⁹ Examples of approaches include standardized patients, immediate feedback, role modeling, and coaching, which can be incorporated into residency and fellowship training programs, as well as continuing medical education offerings. A novel training program for oncologists called “Oncotalk” can be easily adapted to create stroke vignettes (eg, “Stroketalk”).²⁸¹ Providers caring for stroke patients and families should also practice self-care techniques to minimize the risk of burnout, including the possibility of self-reflection activities, which may also help providers

become and stay more empathic when communicating with patients and families.^{248,282}

Education: Recommendation

- 1. The teaching of critical core competencies in palliative and end-of-life care should be integrated within training programs and continuous educational offerings for all professionals who care for patients with stroke and their families (Class I; Level of Evidence C).**

Quality Improvement and Research Agenda

The lack of evidence in support of optimal palliative care practices in patients with stroke and families is striking. We need better intermediate and long-term prognostic data for symptoms and outcomes that are frequent among and meaningful to patients. This should include additional high-quality research into external validation of prognostic scales, as well as specific testing of the utility of these scales in the context of end-of-life decision making. More research is also needed on the proper role and use of time-limited trials in the setting of stroke, where prognosis is uncertain and possibly expected to improve over time. Future studies should address optimal symptom management, as well as optimal organization and financing of care to maximize patient and family outcomes.

We need more research on optimal communication strategies, including decision aids, to enhance decisional quality and reduce decisional conflict and regret, including methods to formulate a prediction, communicate prognosis, and establish goals of care both with patients and with surrogate decision makers. We know relatively little about the presence and magnitude of cognitive biases that can influence end-of-life and withdrawal-of-treatment decisions. This research should also attempt to assess the true risk of the self-fulfilling prophecy and approaches to mitigate that risk.

Research is necessary to determine the causes of variation in withdrawal-of-treatment practices, including a better understanding of social and cultural influences, and the accuracy of diagnosing patient preferences.⁴⁰ Furthermore, observational data that are both patient centered (labored breathing, tachycardia) and family centered (short- and long-term anxiety, depression) are needed to establish benchmarks for palliative interventions in stroke patients undergoing withdrawal of life-sustaining therapies. Continued efforts are needed to improve uniformity in the declaration of brain death and to optimize opportunities for organ donation.²⁸³ Finally, effort should be focused on development of performance measures that address optimal approaches to delivering high-quality patient- and family-centered care.

Quality Improvement and Research: Recommendation

- 1. Stakeholders with an interest in improving the quality of care and quality of life for patients and families with stroke should develop and implement an aggressive palliative and end-of-life research and quality improvement agenda for this population (Class I; Level of Evidence C).**

Summary and Conclusions

Stroke care is dominated by clinically challenging, emotionally intense, and ethically complex medical choices. Most patients when acutely ill or dying want relief of suffering, help in minimizing the burden on families, closer relationships with loved ones, and a sense of control.²⁸⁴ Palliative care has much to offer in the provision of stroke care. It should be viewed not as an alternative to offering life-sustaining therapies or other evidence-based stroke treatments but as an important supplement that can enhance care delivery for patients, families, and providers alike.

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*Modest.

†Significant.

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