The emerging partnership between palliative care and stroke

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Stroke care displays 2 truisms. First, a severe stroke is a common event often close to one's death. It unleashes a series of intense conversations among clinicians, patients, and families, rife with uncertainty, about health states with varying degrees of acceptability and what makes life worth living.¹ Second, enormous variations in clinical practice remain prevalent, including end-of-life care practices. This end-of-life practice variation has been called a hidden curriculum, providing medical students with insights into how the location of their residency training helps shape the type of physicians they will become.² It is surprising, therefore, how little we know about these important life transitions in our patients with stroke. But this ignorance is beginning to change.

In the current issue of *Neurology® Clinical Practice*, Prabhakaran et al.³ report the prevalence and predictors of an early comfort-oriented approach to care as recorded in the Get With The Guidelines–Stroke Registry. Early comfort measures only (CMO) was defined as documentation of comfort or hospice services on the day of hospital arrival or the following day. The authors found that approximately 1 in 20 strokes of all types had an early comfort-oriented approach, which was present in 3.0% of patients with ischemic stroke, 13.1% with subarachnoid hemorrhage, and 19.4% with intracerebral hemorrhage (ICH). An early CMO order was associated with older age, larger stroke, women, white race, hospital rural location, and Medicaid/self-pay. They also found enormous variations (unadjusted) in the hospital-specific rates of early CMO, particularly in patients with hemorrhages.

From a distance, the results are affirming yet unsettling. Prior studies have shown that many patient (sex, ethnicity, comorbidities, insurance status) and health system (bed size, urban/rural location, tax status) characteristics affect how stroke patients are treated at the end of life.⁴ We should accept some degree of variation in the process of shared decision-making to explain these differences. This variation may include differences in patient and surrogate preferences as well as differences in patient-centered communication skills, including clinicians' ability to prognosticate and elicit values and preferences. When the consequences of making the wrong treatment choices are so high, however, the documented variation in hospital-level early CMO rates—from less than 1% to over 35% for all strokes, and as high as 75% for ICH patients—deserves our utmost attention.

Interpreting this study, however, is like understanding quantum mechanics: the closer one looks, the more confusing it becomes. This situation is no fault of the authors, who should be commended for shining light on this topic using a large and comprehensive dataset. It more reflects the state of this field and our nascent ability to delve into the nuances of shared decision-making and unraveling the adequacy of informed choice in patients with severe stroke. Even patients and family members are taking note regarding how much better we can do in “making engagement part of the protocol.”⁵

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While the term “comfort measures” quickly conjures up a particular type of care, the process by which this decision was reached and documented is replete with ambiguity. The registry lacks detail on who participated, the setting of information exchange, and the adequacy of understanding. In addition, early CMO was explicitly distinguished from do not resuscitate orders, living wills, or orders to withhold life-sustaining interventions. Reading this study recapitulates our feelings of how decision-making happens in real time; we do our best and muddle through as we earnestly try to understand and make the right decisions. But can we do better?

The answer is a resounding yes as we usher in a new era of palliative care; one that is firmly integrated within each specialty, including neurology, which will improve the care of our seriously ill and dying patients.⁶ This integration requires at least 3 concurrent initiatives.

First, neurologists and trainees need access to renewed and improved education on skills to elicit the goals, preferences, and values of their patients, and to fine-tune their treatment recommendations to align with those aims. One example is the soon to be developed new neurology module for the Educating Physicians in End-of-Life Care program (Benzi Kluger, personal communication, March 2, 2017). In patients with severe acute brain injury, education also should include the proper role and use of time-limited trials, strategies to reduce cognitive biases, as well as the reasons for why surrogate decision-makers often have differing opinions on prognoses than physicians, and the best ways to manage such discordance.⁷

Second, more research is needed on the timing and quality of advance care planning and end-of-life decision-making in patients with stroke. Quality measures need to move well beyond the existing stroke process measures. The recently published palliative and end-of-life measure set by the National Quality Forum includes measures within the following domains: comfortable dying, symptom screening, beliefs and documentation of values, care preferences, and treatment preferences.⁸ Given recent data showing that discussions about preferences for life-limiting therapies were documented in fewer than 40% of dying stroke patients, considerable quality improvement opportunities remain.⁹

Third, federal and state agencies, payers, clinicians, and health systems all bear responsibilities for improving the integration of disease-directed and palliative care delivered to patients and families with stroke.¹⁰ This integration includes advocating for better reimbursements for comprehensive delivery of palliative care services and identification of better care and payment models, including those that align reimbursement and incentives to encourage quality.

The take-home message from this study is simple. What matters most remains the quality of the conversation—how well clinicians teach and how well we listen. We are just beginning to understand how best to measure and improve this process, which will help ensure quality care that is consistent with our patients’ goals, and to identify areas that can make our care ever better.

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