Early stroke mortality, patient preferences, and the withdrawal of care bias

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ABSTRACT

Objective: Early mortality is a potential measure of the quality of care provided to hospitalized stroke patients. Whether in-hospital stroke mortality is reflective of deviations from evidence-based practices or patient/family preferences on life-sustaining measures is unclear.

Methods: All ischemic stroke mortalities at an academic medical center were reviewed to better understand the causes of inpatient stroke mortality.

Results: Among 37 deaths or discharges to hospice in 2009, 36 occurred after a patient/family decision to withdraw/withhold potentially life-sustaining interventions. An independent survey of 3 vascular neurologists revealed that some early deaths could have been delayed beyond 30 days if patients or families had agreed to more aggressive measures. From these data, we estimate the magnitude of a “withdrawal of care” bias to be approximately 40% of the observed short-term mortality.

Conclusions: Acute stroke mortality may be more reflective of patient/family preferences than the provision of evidence-based care. *Neurology*® 2012;79:941-944

GLOSSARY

AHN = artificial hydration/nutrition; **CMS** = Center for Medicare and Medicaid Services; **CPR** = cardiopulmonary resuscitation; **DNR** = do not resuscitate; **DVT** = deep vein thrombosis; **MV** = mechanical ventilation; **NIHSS** = NIH Stroke Scale; **SMH** = Strong Memorial Hospital; **tPA** = tissue plasminogen activator; **URMC** = University of Rochester Medical Center.

Mortality has increasingly been used as a measure of the quality of care provided to stroke patients.¹ However, it has been shown to be inconsistent across multiple evaluating systems and is overly reliant on proprietary risk-adjustment methods. Despite this, the Center for Medicare and Medicaid Services (CMS) is developing a 30-day risk-adjusted stroke mortality measure for public reporting purposes.

Whether inpatient stroke mortality is reflective of evidence-based practice is uncertain. Hospital-based deaths may arise from unsafe practices, deviations from standards of care, or progression of the underlying disease. Deaths also occur when patients or families elect to withhold or withdraw life-sustaining interventions, thereby allowing a natural death rather than prolonging life in a state deemed unacceptable to the patient. These choices may be guided by written advanced directives or discussions with surrogates, suggesting an informed, patient-centered decision. Research has shown that the majority of deaths on an inpatient neurology service resulted from withdrawal of life-sustaining support at the patient/family request.² In addition, involvement of palliative care services is common after stroke,³ especially among higher educated patients.⁴

We conducted a review of ischemic stroke mortalities at our institution to better describe the manner in which deaths occur after stroke, and estimate the potential impact that decisions to withhold/withdraw treatments have on short-term ischemic stroke mortality. Specifically: What are the characteristics of stroke patients who die? How do stroke patients die—are deaths due to deviations from evidence-based practices? How much could early stroke mortality be affected by decisions to withhold/withdraw life-sustaining measures?

Supplemental data at
www.neurology.org

Supplemental Data

CME

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Study funding: This study was made possible in part by grant UL1 RR024160 from the National Center for Research Resources (NCRR), a component of the NIH, and the NIH Roadmap for Medical Research. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NCRR or NIH.

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METHODS Strong Memorial Hospital (SMH) is a 765-bed hospital which serves as the primary teaching hospital of the University of Rochester Medical Center (URMC). SMH has been classified as a New York State Designated Stroke Center and Joint Commission Certified Stroke Center, and is a 3-time recipient of the Gold Plus Award, given to hospitals that sustain a high level of adherence to stroke performance measures through the Get With the Guidelines–Stroke national quality improvement program.

Using hospital administrative data, all patients discharged with a principal diagnosis of ischemic stroke (ICD-9 principal diagnosis code of 433.X1, 434.X1) during the 2009 calendar year were identified ($n = 474$). We chose not to use ICD-9 diagnosis code 436 since it is possible that patients with intracerebral hemorrhage may have been included under this code. Patients with a discharge status of dead, hospice-home, or hospice-medical facility were selected ($n = 37$). These charts were reviewed and data regarding basic demographics, medical history (comorbidities, presence of advanced directives), admission information (NIH Stroke Scale [NIHSS] score, stroke location), and hospital stay were collected. Using t tests for continuous variables and χ^2 tests for categorical variables, comparisons of demographic characteristics were made between the population that died or was discharged to hospice and the overall population of ischemic stroke patients admitted to SMH during calendar year 2009. During chart review, the manner in which the patient died or was transferred to hospice was categorized as one of the following predefined mechanisms: progression to death by brain criteria; attempted cardiopulmonary resuscitation (CPR) without return of spontaneous circulation; withholding of mechanical ventilation (MV) or artificial hydration/nutrition (AHN); withdrawal of MV or AHN. Patients who received even a brief trial of MV or AHN and then had this discontinued at the patient's/family's request were categorized as a withdrawal; patients never receiving these interventions were categorized as a withholding. We recorded whether hospital care adhered to 4 validated stroke process measures that might potentially affect early mortality: treatment with IV thrombolysis (tissue plasminogen activator [tPA]); administration of antithrombotic therapy by end of second hospital day; dysphagia screening before any oral intake; and prophylaxis for deep vein thrombosis (DVT).⁵

In order to better understand the effects of withdrawing or withholding potentially life-sustaining measures on hospital mortality, we conducted an independent survey of 3 vascular neurologists (2 board certified, 1 board eligible), who are members of the URMC neurology department but had no other involvement in the study. Comprehensive summaries of the hospital courses of the 30 patients who died during their hospitalization were developed (example included in appendix e-1 on the *Neurology*[®] Web site at www.neurology.org); the 7 patients discharged to hospice were excluded since their posthospital course was unavailable. Due to variability in the types of brain imaging completed, and the frequency/interval at which they were completed, we elected not to include imaging as part of these case summaries. These summaries were independently presented to the 3 neurologists, who then estimated the likelihood that patients would survive to 30 days or longer if all life-sustaining measures were provided, using a visual analog scale ranging from 0% to 100%. Using these survival estimates provided by the vascular neurologists, we calculated a “withdrawal of care bias”—the potential change in the 2009 observed hospital mortality rate if no life-sustaining measures were withdrawn or withheld.

Table	Patient population
	No. (%)
Gender	
Male	23 (62.2)
Female	14 (37.8)
Race/ethnicity	
White	32 (86.5)
Nonwhite	5 (13.5)
Stroke location	
Left MCA	20 (54.1)
Right MCA	10 (27.0)
Vertebrobasilar	5 (13.5)
Watershed	2 (5.4)
Medical comorbidities	
Hypertension	31 (83.8)
Coronary artery disease	18 (48.6)
Atrial fibrillation	14 (37.8)
Congestive heart failure	12 (32.4)
Diabetes	10 (27.0)
Prior stroke	9 (24.3)
Cancer	9 (24.3)
Dementia	9 (24.3)

Abbreviation: MCA = middle cerebral artery.

Standard protocol approvals, registrations, and patient consents. Full study evaluation by the University of Rochester Research Subjects Review Board was deemed not necessary after a preliminary review, since research was conducted on decedent patients. Data collection was done in accordance with Health Information Privacy and Portability Act standards.

THE ROCHESTER EXPERIENCE What are the characteristics of a stroke patient who dies? During 2009, the unadjusted inpatient ischemic stroke mortality rate at SMH was 7.8% (37 deaths or discharges to hospice among 474 admissions for ischemic stroke). Patients who died or were discharged to hospice typically were older (mean age 77.5 years, range 42–99), and medical comorbidities were common (table). Specifically, a preceding diagnosis of hypertension was seen in most patients (31/37, 83.8%), coronary artery disease in nearly half of patients (18/37, 48.6%), and cancer, dementia, and prior stroke seen in one-quarter of patients (9/37, 24.3%). Other data on patient demographics, stroke location, and comorbidities are summarized in the table. The mean NIHSS score in these 37 patients on admission was 20 (median 21, interquartile range 15–26, range 1–37), suggesting high stroke severity.

Compared to the overall population of ischemic stroke patients admitted to SMH in 2009, patients who died or were discharged to hospice were significantly older (77.5 vs 68.0 years, $p < 0.0001$). There were no

differences between these 2 groups regarding gender ($p = 0.23$) or race/ethnicity (white vs nonwhite, $p = 0.52$).

How do stroke patients die? No patients underwent CPR without return of spontaneous circulation. A single patient met criteria for brain death on the fifth hospital day. The 36 remaining patients died or were discharged to hospice following a patient or family decision to limit life-sustaining interventions: withdrawal of MV (15/37 cases, 40.5%); withholding of MV (10/37, 27.0%); withdrawal of AHN (10/37, 27.0%); and withholding of AHN (1/37, 2.7%). Among patients where MV was withdrawn, this occurred an average of 3.2 days after hospital admission (range 1–16 days). In the population of patients where AHN was withdrawn, this occurred an average of 9.7 days after admission (range 2–26 days).

Advanced directives in the form of do-not-resuscitate (DNR) orders were present in 11 patients at the time of hospital admission. DNR orders were ultimately present in all remaining patients; this order occurred within the first 2 hospital days in 7/26 (26.9%) patients without a DNR order on admission.

Are deaths a result of deviations from accepted standards of care? IV tPA was administered to all 7 eligible patients; all other patients had at least 1 warning/contraindication to tPA use. An additional 6 patients underwent some form of intra-arterial stroke treatment without previously receiving IV tPA therapy; in all, 13/37 patients (35.1%) underwent some form of acute reperfusion therapy. All 37 patients received DVT prophylaxis and underwent dysphagia screening prior to any oral intake. Antithrombotic therapy was administered by the second hospital day in 35/37 patients. The aggregate adherence to these 4 measures was 98.3%.

How many deaths could be prevented if no interventions were withdrawn or withheld? Of the 30 case scenarios, all 3 neurologists agreed that 7 patients had at least a 50% chance of surviving to 30 days or beyond, assuming no life-sustaining interventions were withdrawn/withheld. Estimates of $\geq 80\%$ survival were seen in 4 cases; in 9 cases, at least 1 of the neurologists estimated 30-day survival at 0%. If all patients with $\geq 50\%$ estimated survival were provided with life-sustaining measures and did survive to 30 days, the SMH mortality rate for 2009 would decrease from the observed rate of 7.8% to 6.3%. All 3 neurologists also agreed that an additional 8 patients had at least a 20% chance of surviving to 30 days or beyond, assuming no interventions were withdrawn/withheld. If the 15 patients with $\geq 20\%$ estimated survival were provided with all life-sustaining measures and did survive to 30 days, the SMH mortality rate would decrease to 4.6%. Therefore, the magnitude of a “withdrawal of care bias” in

this population is estimated as up to 3.2%, or roughly 41% of the observed short-term mortality.

DISCUSSION In this study, inpatient ischemic stroke mortality was highly sensitive to patient and family preferences, and deaths occurred almost exclusively after limitations on potentially life-sustaining measures. Decisions to withdraw/withhold interventions that might prevent or postpone mortality may have considerable effects on hospital-based mortality rates; our estimates suggest that inpatient stroke mortality may be affected by more than 40%. These mortalities occurred in the setting of high adherence to stroke process measures, suggesting that deaths can occur despite the provision of high-quality, evidence-based care. This is consistent with previous data showing that adherence to performance measures correlates poorly with short-term mortality after myocardial infarction.⁶

IV tPA or other attempts at reperfusion therapy were used in over one-third of patients in this study, well above the average reported treatment rates of 3% to 5%.⁷ Less than 30% of patients had early limitations of care as evidenced by DNR orders prior to the second hospital day, which has been considered a possible proxy of less aggressive care in prior studies.^{8,9} In addition, withdrawal of MV or AHN was much more common than withholding these treatments (25 patients vs 11, respectively), so the majority of patients received at least a trial of life-sustaining interventions to allow for potential neurologic recovery. Therefore, in this population, deaths are unlikely to be explained by an overall lack of urgency or aggressiveness in the early care of stroke patients.

Short-term mortality rates can be improved by the more routine provision of life-sustaining interventions,¹⁰ but at the cost of patients being left in disabled states that might be against their wishes. Conversely, choosing a palliative approach early after stroke may prevent the opportunity for significant recovery and adaptation of patients and families to neurologic deficits. This decision process is further complicated by the relative lack of early prognostic signs (clinical or radiographic) in ischemic stroke that are highly predictive of a universally poor outcome.¹¹

This study analyzes outcomes from a single large academic medical center. There is likely to be some variation in the rate of withdrawal/withholding decisions across different institutions, depending on patient case mix, hospital size, academic status, geographic location, economic considerations (from the patient/family and medical center perspective), and other factors. We challenge other centers to critically evaluate their early stroke mortalities to further increase data in this area.

Our attempt to quantify a “withdrawal of care bias” is dependent on the opinions of 3 neurologists with

clinical expertise in caring for stroke patients. Estimates of surviving to 30 days if no interventions were withdrawn/withheld might be considerably different if other providers (e.g., neurointensivists, internal medicine hospitalists) had been surveyed instead. Therefore, the effect of withdrawal/withholding of care on early stroke mortality may be greater than or less than our estimate. The variability in how different providers offer prognoses after ischemic stroke warrants further study, especially since patients and families may be deciding to withhold or withdraw interventions based, at least in part, on these predictions.¹² Given the retrospective nature of our study, the specific manner in which details regarding prognosis for recovery, likelihood of disability, and other critical elements in the decision-making process cannot be determined.

Current attempts by the Center for Medicare and Medicaid Services to develop a hospital-based, 30-day stroke mortality measure are ongoing. The proposed measure has come under scrutiny during a public comment period¹³ for 1) the inability to account for initial stroke severity, which is the strongest predictor of early stroke mortality¹⁴; and 2) the inability to discern deaths due to deviations in standards of care from those deaths that occur after withdrawing or withholding life-sustaining measures in a palliative care setting. The results of our study substantiate these concerns; nearly all deaths occurred after a decision to withdraw/withhold interventions in a population with high initial stroke severity (as measured by the NIHSS).

The goal of the proposed CMS measure, like most publicly reported measures, is to improve transparency and hospital accountability in order to improve outcomes. But will it improve the actual care that is being provided to stroke patients? There are well-reported unintended consequences of publicly reported outcomes data,¹⁵ and one could argue that providers might be more apt to suggest MV or AHN to stroke patients or their families in fear of “failing” the CMS measure. If providers allow their personal or other motivations (consciously or unconsciously) to intrude on patient-centered decisions regarding life-sustaining interventions, therein lies the true failure.

Short-term stroke mortality is highly dependent on patient/family preferences regarding goals of care, and this sensitivity should give us pause in using short-term stroke mortality as a primary marker of quality of care. Measures of decisional quality (accounting for personal preferences) should be developed to ensure that the provision of care is patient and family-centered, even under circumstances where there is little or no hope for recovery.¹⁶ We recommend that time-limited trials be utilized in situations where the clinical outcome or patient preferences are uncertain.

AUTHOR CONTRIBUTIONS

Design and conceptualization of the study (Drs. Kelly, Hoskins, and Holloway), analysis and interpretation of the data (Drs. Kelly, Hoskins, and

Holloway), drafting and revising the manuscript for content (Drs. Kelly, Hoskins, and Holloway).

DISCLOSURE

A. Kelly and K. Hoskins report no disclosures. R. Holloway serves as an associate editor for *Neurology Today* and reviews neurology guidelines for Milliman Guidelines, Inc. **Go to Neurology.org for full disclosures.**

Received November 23, 2011. Accepted in final form March 21, 2012.

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