

Impact of Advanced Healthcare Directives on Treatment Decisions by Physicians in Patients With Acute Stroke*

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Background: The implementation of advanced healthcare directives, prepared by almost half of the adult population in United States remains relatively under studied. We determined the impact of advanced healthcare directives on treatment decisions by multiple physicians in stroke patients.

Methods: A deidentified summary of clinical and radiological records of 28 patients with stroke was given to six stroke physicians who were not involved in the care of the patients. Each physician independently rated 28 treatment decisions per patient in the presence or absence of advanced healthcare directives 1 month apart to allow memory washout. The percentage agreement to treat/intervene per patient and proportion of treatment withheld as a group were estimated for each of the 28 treatment decision items. We also determined the interobserver reliability

between the two raters (attorneys) in interpretation of six items characterizing the adequacy of documentation within the 28 advanced healthcare directives.

Results: The percentage agreement among physician raters for treatment decisions in 28 stroke patients was highest for treatment of hyperpyrexia (100%, 100%) and lowest for ICU monitoring duration based on family-physician considerations outside of accepted criteria within institution (68%, 69%) in presence and absence of advanced healthcare directives. The physician rater agreement in choosing “yes” was highest for “routine-complexity” treatment decisions and lowest for “moderate-complexity” treatment decisions. The choice of withholding treatment in “routine-complexity,” “moderate-complexity,” or “high-complexity” treatment decisions was remarkably similar among raters in presence or absence of advanced healthcare directives. The only treatment decision that showed an impact of advanced healthcare directives was ICU monitoring withheld in 32% of treatment decisions in presence of directives (compared with 8% in the absence of directives). IV medication and defibrillation for cardiac arrest was withheld in 29% (compared with 19%) of the treatment decisions in the presence of advanced healthcare directives. The two attorney raters found the description of acceptable outcome inadequate in 14 and 21 of 28 advanced healthcare directives reviewed, respectively. The overall mean kappa for agreement regarding adequacy of documentation was modest (43%) for “does the advanced healthcare directive specify which treatments the patient would choose, or refuse to receive if they were diagnosed with an acute, terminal condition?” and lowest (3%) for “description of acceptable outcome.”

Conclusions: We did not find any prominent differences in most “routine-complexity,” “moderate-complexity,” or “high-complexity” treatment decisions in patient management in the presence of advanced healthcare directives. Presence of advanced healthcare directives also did not reduce the prominent variance among physicians in treatment decisions. (*Crit Care Med* 2013; 41:1468–1475)

Key Words: advanced healthcare directives; cardiac resuscitation; disability; intracerebral hemorrhage; ischemic stroke; patient choice; patient’s right of determination; stroke

***See also p. 1581.**

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Disabilities of various severities in United States are commonly seen in patients with stroke despite, or infrequently as a consequence of, acute treatments (1, 2). Nearly 1.1 million stroke survivors reported difficulty performing basic activities of daily life in 2005 (3). Such disability even of minor severity has been considered an unacceptable outcome by many patients with stroke or adults in the general population (4). Painless death was preferred to even a minor stroke disability in over one third of elderly individuals, while 80% would prefer painless death to severe disability; 69% of stroke patients and 82% of adults in general population ranked death as a preferable outcome over severe disability (4). In a survey of 68 young adults, almost 60% of surveyed persons were not willing to live with either mild or moderate disability (5). Up to a third of patients who survived after undergoing aggressive strategies such as decompressive hemicraniectomy or their families would not have agreed to the procedure after observing the long-term quality of survival (5–7). Patients with acute stroke face a unique challenge because of the sudden onset of incapacitation and need for rapid decision making. Advanced healthcare directives were introduced to reduce the discordance between survivors' expectation and results of and variations in treatment provided for various diseases. Such directives are prepared by a potential patient and intended to provide specific directives about the course of treatment that is to be followed by healthcare providers and caregivers in the event that the patient is incapacitated and unable to participate in the decision-making process, a scenario commonly seen in stroke patients. Therefore, such directives have particular relevance for stroke patients. We performed this study to identify the impact of existing advanced healthcare directives on treatment decisions within and between physicians involved in care of stroke patients.

METHODS

We identified all patients who were admitted with a diagnosis of ischemic stroke or intracerebral hemorrhage to a comprehensive stroke center over a 12-month period. These patients were identified from a registry maintained as part of Centers for Disease Control and Prevention Paul Coverdell National Acute Stroke Registry program. Patients aged 18 years or older with documented final clinical diagnosis of stroke on hospital discharges are entered in the registry. At our site, prospective (concurrent) case identification and data abstraction method is used and supplemented by retrospective case identification. An independent audit by the Minnesota Department of Health had demonstrated that the accuracy of final diagnosis of stroke was 100% with a kappa value of 1.0 in the registry at our site. The activities pertinent to the study were conducted under an Institutional Review Board approved protocol. All patients' medical records were reviewed to identify patients who had advanced healthcare directives at the time of admission.

To identify variance in treatment decisions, we provided specific therapeutic choices that were identified based on 1) demonstrated effect on clinical outcome and 2) high frequency of use in practice. Such treatment decision items were derived

from a previous publication (8). Briefly, these treatment decisions were derived from quality care parameters and based on data derived from multicenter randomized trials and selected nonrandomized or observational clinical studies. The current guidelines from the American Heart Association and/American Stroke Association Stroke Council (9) and The European Stroke Initiative Writing Committee (10) were additionally reviewed to identify treatment decisions that met our criteria. We also reviewed the metrics for measuring quality of care in comprehensive stroke centers that provide a set of metrics and related data elements to measure the key components of specialized care for patients with ischemic stroke and intracerebral hemorrhages at comprehensive stroke centers to identify any additional items (11). A total of 28 treatment decision items were selected and categorized in three categories of decision making based on complexity and risk: 1) routine complexity—therapeutic interventions that are instituted as part of routine care and do not require any special consideration (informed consent or discussion) prior to implementation; 2) moderate complexity—therapeutic interventions for which written consent is not always required or needed, but some meaningful discussion with patient or family is needed; and 3) high complexity—therapeutic interventions that require informed consent, such as surgery, anesthesia, and other invasive procedures.

The items that were included in the “routine” complexity treatment decisions were: 1) rapid stroke team evaluation; 2) expedient acquisition of neuroimaging; 3) treatment of acute hypertensive response; 4) any ICU admission; 5) ICU monitoring for first 24 hours; 6) ICU monitoring duration based on family-physician considerations outside of accepted criteria within institution; 7) ICU monitoring for as long as patient is candidate based on accepted criteria within institution; 8) induced hypertension with IV vasopressors if appropriate candidate based on accepted criteria within institution; 9) medical treatment of clinically significant intracranial mass effect or transtentorial herniation; 10) treatment of repetitive seizures and status epilepticus (clinical or subclinical); 11) treatment of elevated serum glucose concentration; 12) treatment of hyperpyrexia; 13) deep venous thrombosis prophylaxis; 14) dysphagia screening; 15) feeding (nutrition) initiation within 72 hours; 16) treatment of persistently elevated blood pressure after first 24 hours with oral antihypertensive medication; 17) gastric ulcer prophylaxis; and 18) treatment of hospital acquired or ventilator-associated pneumonia. Items that were included in the “moderate” complexity treatment decisions were 1) IV recombinant tissue plasminogen activator if the patient is an appropriate candidate based on standard criteria; 2) intubation and mechanical ventilation for noncardiac arrest scenarios; 3) intubation and mechanical ventilation for cardiac arrest scenarios; 4) IV medication and defibrillation for cardiac arrest scenarios; and 5) therapeutic hypothermia if appropriate candidate based on accepted criteria within institution. Items that were included in the “high” complexity treatment decisions were 1) endovascular treatment if appropriate candidate based on accepted criteria within institution; 2) percutaneous gastrostomy if persistent

dysphagia is present; 3) intracranial pressure monitoring or intraventricular catheter if the patient is an appropriate candidate based on accepted criteria within institution; 4) craniectomy or craniotomy if appropriate candidate based on accepted criteria within institution; and 5) tracheostomy for persistent intubation or poor airway protection.

A summary document was prepared for each patient with three components: 1) A summary of clinical presentation, severity of neurological deficits, and presence of comorbid medical conditions; 2) one or two representative images of the initial computed tomographic scan; and 3) a copy of the patient's advanced healthcare directives. All records were deidentified consistent with the Privacy Rule (45 C.F.R. § 164.514(b)(2)(i)) (12) and met the definition of deidentified records provided by the Office of Human Research Protections (13). The summary document was independently reviewed and rated by a neurosurgeon, a neurointensivist, three vascular neurologists, and another vascular neurologist from Japan. The treatment decisions were presented as a dichotomous choice of whether or not the practitioner (rater) would or would not offer a therapeutic option based on clinical information and review of the advanced healthcare directive document. Each physician rater made the choices for each of the 28 treatment decisions for each patient twice. The first independent review was performed with (in three raters) or without (in three raters) knowledge of the advanced healthcare directives. After a minimum period of 4 weeks (memory washout period), the second review was performed by the same six physician raters using a crossover design (three with and three without knowledge of advanced healthcare directives).

To determine adequacy of documentation with particular reference to clarity of expectation regarding acceptable outcomes and specific instructions to guide the treatment decisions, all deidentified advanced healthcare directives were independently reviewed by two attorneys. Both attorneys had expertise in development of training modules for patient outcome assessment and management as part of a clinical trial. The clarity of expectation was compared against the modified Rankin scale. The modified Rankin scale was chosen because of its broad use within the medical community and ability to reliably ascertain the magnitude of disability (14). Each rater graded the clarity of expectation regarding acceptable outcome as follows: inadequate, possibly adequate, and definitely adequate. Each rater also graded the advanced healthcare directives in regards to specific instructions for three domains of treatment decision making: routine, moderate, and high complexity. Each domain was graded into one of the four categories: highly specific, moderately specific, somewhat specific, and nonspecific. The two raters further categorized the clarity of instructions for treatment decisions in three categories: 1) all foreseeable treatment scenarios, 2) some scenarios, and 3) none of the foreseeable scenarios. The adequacy of documentation regarding expectations with respect to minimum acceptable quality of life was also categorized into one of three categories: 1) comprehensive, 2) subjective, and 3) poor.

The statistical analyses were predominantly descriptive. Each treatment decision was presented as a dichotomous choice, "yes" or "no." We provided the mean value of 28 values (one per patient) for each treatment decision representing proportion of physician raters choosing "yes" per patient. For example, we evaluated the proportion of raters who chose "yes" for treatment decision number 1 "rapid stroke team evaluation" for patient number 1 among all six physician raters. All six physician raters chose "yes" to rapid stroke team evaluation and the rate of "yes" for patient number 1 was 100%. Subsequently, we evaluated the agreement for treatment decision number 1 "rapid stroke team evaluation" for patient number 2 among all six physician raters. Four of six physician raters chose "yes" to rapid stroke team evaluation and the rate of "yes" for patient number 2 was 67%. Similarly, the rates of "yes" were calculated for each of the 28 patients and mean and SD values calculated to provide a single representative value for treatment decision number 1. A similar process was repeated when raters chose "yes" in the presence of advanced healthcare directives. If "no" was the predominant response (>50% of choices), the mean value was calculated representing proportion of physician raters choosing "no" per patient. We also calculated the cumulative proportion of times a treatment was withheld for each treatment decision in the presence and absence of advanced healthcare directives separately. This value was calculated for the whole group. The proportion was calculated based on number of "no" decision from a denominator of 168 treatment decisions (one treatment decision per rater made by six raters for each of the 28 patients). The questions were asked with the intention that a problem was present and choice was to treat/intervene "yes" or not "no."

We determined the interobserver reliability and the [kappa] value between the two attorney raters in interpretation of six items characterizing the "adequacy of documentation" within the 28 advanced healthcare directives. For example, for each advanced healthcare directive, the item "description of acceptable outcome" was rated by two attorneys as nonspecific, somewhat specific; moderately specific, or highly specific. The kappa value represented the agreement for categories chosen for the item "description of acceptable outcome" for the 28 directives. The analysis was performed using SAS 9.1 software (SAS Institute, Cary, NC). The sample size was based on the recommendations provided by Sim and Wright (15), which consider a sample size of 25 patients/observations appropriate to detect a kappa of 0.5 for one-tailed test at 80% power. In an exploratory analysis, we reviewed the impact of advanced healthcare directives and percentage agreement in four patients in whom both attorneys agreed that clarity of instructions in the directives was adequate for all foreseeable treatment decision scenarios.

RESULTS

A total of 73 of 241 consecutive patients (30.3%) admitted within a 12-month period with ischemic and hemorrhagic strokes had advanced healthcare directives. We included 28 consecutive patients from 73 patients with advanced healthcare directives pursuant to our sample size calculation. These

TABLE 1. Treatment Decisions and Agreement Among Independent Physician Raters in Presence or Absence of Advanced Healthcare Directives

Treatment Decisions	In the Presence of Advanced Healthcare Directives		In the Absence of Advanced Healthcare Directives	
	Percentage Agreement Per Patient to Choose "Yes" (Mean % \pm SD)	Proportion of Times Withheld in 168 Treatment Decisions	Percentage Agreement Per Patient to Choose "Yes" (Mean % \pm SD)	Proportion of Times Withheld in 168 Treatment Decisions
Routine-complexity treatment decisions				
Rapid stroke team evaluation	96.4 \pm 9.5	3.5	97.0 \pm 6.5	2.9
Expedient acquisition of neuroimaging	99.4 \pm 3.1	0.6	98.2 \pm 5.2	1.7
Any ICU monitoring	86.9 \pm 11.4	13.1	89.8 \pm 10.4	10.1
ICU monitoring for first 24 hr	88.6 \pm 12.0	11.3	88.6 \pm 11.2	12.5
ICU monitoring duration based on family-physician considerations outside of accepted criteria within institution	67.8 \pm 10.1	32.1	69.1 \pm 9.8	32.1
ICU monitoring for as long as patient is a candidate based on accepted criteria within institution	92.2 \pm 10.6	31.5	91.6 \pm 13.9	8.3
Treatment of acute hypertensive response	92.2 \pm 11.5	7.7	92.8 \pm 10.5	7.1
Induced hypertension with IV vasopressors if appropriate candidate based on accepted criteria within institution	75.5 \pm 16.6	25.6	77.9 \pm 18.7	22.0
Medical treatment of clinically significant intracranial mass effect or transtentorial herniation	78.5 \pm 13.5	25.0	79.7 \pm 17.7	21.4
Treatment of repetitive seizures and status epilepticus (clinical or subclinical)	97.6 \pm 5.9	2.3	98.8 \pm 6.3	1.2
Treatment of elevated serum glucose concentration	98.8 \pm 4.3	1.1	99.4 \pm 3.1	0.6
Treatment of hyperpyrexia	100 \pm 0	0	100 \pm 0	0
Deep venous thrombosis prophylaxis	100 \pm 0	0	98.8 \pm 4.3	1.2
Dysphagia screening	98.8 \pm 4.3	1.2	97.0 \pm 10.2	2.9
Feeding (nutrition) initiation within 72 hr	90.4 \pm 13.2	9.5	96.4 \pm 8.3	4.7
Gastric ulcer prophylaxis	97.0 \pm 7.9	2.9	96.4 \pm 6.9	3.5
Treatment of persistently elevated blood pressure after first 24 hr with oral antihypertensive medication	96.4 \pm 8.3	3.5	96.4 \pm 8.3	3.5
Treatment of hospital acquired or ventilator-associated pneumonia	94.0 \pm 9.3	5.9	97.0 \pm 9.1	2.9
Moderate-complexity treatment decisions				
IV tissue plasminogen activator if appropriate candidate based on standard criteria ^a	71.1 \pm 17.2	45.2	66.6 \pm 21.8	48.2
Intubation and mechanical ventilation for noncardiac arrest scenarios	78.5 \pm 18.0	21.4	86.3 \pm 15.1	13.6
Intubation and mechanical ventilation for cardiac arrest scenarios	75.5 \pm 15.3	29.1	77.4 \pm 14.5	25.0
IV medication and defibrillation for cardiac arrest scenarios	74.4 \pm 16.6	29.1	80.9 \pm 15.5	19.1
Therapeutic hypothermia if appropriate candidate based on accepted criteria within institution	67.8 \pm 13.5	38.1	72.0 \pm 16.4	31.5

(Continued)

TABLE 1. (Continued). Treatment Decisions and Agreement Among Independent Physician Raters in Presence or Absence of Advanced Healthcare Directives

Treatment Decisions	In the Presence of Advanced Healthcare Directives		In the Absence of Advanced Healthcare Directives	
	Percentage Agreement Per Patient to Choose “Yes” (Mean % ± SD)	Proportion of Times Withheld in 168 Treatment Decisions	Percentage Agreement Per Patient to Choose “Yes” (Mean % ± SD)	Proportion of Times Withheld in 168 Treatment Decisions
“High-complexity” treatment decisions				
Endovascular treatment if appropriate candidate based on accepted criteria within institution ^a	80.0 ± 19.1	31.5	83.3 ± 14.0	26.7
Percutaneous gastrostomy if persistent dysphagia	79.2 ± 16.7	22.0	84.5 ± 13.5	16.6
Intracranial pressure monitoring or intraventricular catheter if appropriate candidate based on accepted criteria within institution	77.3 ± 13.0	27.3	76.7 ± 14.5	24.4
Craniectomy or craniotomy if appropriate candidate based on accepted criteria within institution	74.4 ± 12.4	31.5	71.4 ± 14.2	29.7
Tracheostomy for persistent intubation or poor airway protection	77.3 ± 13.7	33.3	78.4 ± 16.5	25.6

^aOnly assessed for patients with ischemic stroke.

28 patients were selected by a review of consecutively admitted patients with advanced healthcare directives from start of study period including those in whom a full copy of the actual directives document was available within the medical records until the a priori set number of ischemic stroke and intracerebral hemorrhage patients were identified. The percentage agreement among physician raters for choosing “yes” to a treatment decision for 28 stroke patients was highest for treatment of hyperpyrexia (100%, 100%) and deep venous thrombosis prophylaxis (100%, 99%) and lowest for ICU monitoring duration based on family-physician considerations outside of accepted criteria within institution (68%, 69%) in the presence and absence of advanced healthcare directives, respectively (Table 1). Other treatment decision items such as therapeutic hypothermia if the patient was an appropriate candidate based on accepted criteria within institution also had low agreement among physician raters. The rater agreement for choosing “yes” was highest for “routine-complexity” treatment decisions and lowest for “moderate-complexity” treatment decisions. The rater agreement remained relatively low for “high-complexity” treatment decisions.

The treatment decisions or choice of withholding treatment was remarkably similar among raters in the presence or absence of an advanced healthcare care health directives. Subjectively, the only treatment decision item that showed an impact of the presence of advanced healthcare directives was ICU monitoring for as long as patient is a candidate based on accepted criteria within institution: withheld in 32% compared with 8% of patients in the presence of advanced healthcare directives, respectively. IV medication and defibrillation for cardiac arrest was withheld

in 29% (compared with 19%) of the treatment decisions in the presence of advanced healthcare directives. Presence of advanced healthcare directives did not affect decision choices for either “routine-complexity,” “moderate-complexity,” or “high-complexity” treatment decisions. The treatment decision to withhold intracranial pressure monitoring or intraventricular catheter (if the patient was an appropriate candidate) and performance of craniectomy or craniotomy based on accepted criteria within institution demonstrated minimal variation in the presence of advanced healthcare directives.

A determination of adequacy of documentation by the two attorney raters found that description of acceptable outcome was inadequate in 14 and 21 of 28 advanced healthcare directives reviewed, respectively (Table 2). The specific instructions were considered highly specific in 11 and ten of the directives reviewed for “routine-complexity” treatment decisions making but only in two and two for “moderate-complexity,” and four and three for “high-complexity” treatment decisions. Whether the advanced healthcare directives specify which treatments the patient would choose or refuse to receive if they were diagnosed with an acute, terminal condition was considered specific for all scenarios in six and nine of the 28 advanced healthcare directives by the two raters. The overall mean kappa for agreement regarding adequacy of documentation was highest (43%) for “does the advanced healthcare directive specify which treatments the patient would choose or refuse to receive if they were diagnosed with an acute, terminal condition?” and lowest (3%) for “description of acceptable outcome.”

The presence of an advanced healthcare directive affected several decision items after limiting the analysis to the four

TABLE 2. Results of Review of Quality and Characteristics of Documentation of Advanced Healthcare Directives by Two Independent Attorney Raters

Items Reviewed	Rater Number 1	Rater Number 2	Kappa
Description of acceptable outcome ^a	Inadequate (<i>n</i> = 14); possibly adequate (<i>n</i> = 9); definitively adequate (<i>n</i> = 5)	Inadequate (<i>n</i> = 21); possibly adequate (<i>n</i> = 6); definitively adequate (<i>n</i> = 1)	3.3%
Specific instructions for "routine-complexity" treatment decision making ^b	Nonspecific (<i>n</i> = 3); somewhat specific (<i>n</i> = 3); moderately specific (<i>n</i> = 11); highly specific (<i>n</i> = 11)	Nonspecific (<i>n</i> = 1); somewhat specific (<i>n</i> = 10); moderately specific (<i>n</i> = 7); highly specific (<i>n</i> = 10)	17.8%
Specific instructions for "moderate-complexity" treatment decision making ^b	Nonspecific (<i>n</i> = 7); somewhat specific (<i>n</i> = 10); moderately specific (<i>n</i> = 9); highly specific (<i>n</i> = 2)	Nonspecific (<i>n</i> = 10); somewhat specific (<i>n</i> = 8); moderately specific (<i>n</i> = 8); highly specific (<i>n</i> = 2)	9.9%
Specific instructions for "high-complexity" treatment decision making ^b	Nonspecific (<i>n</i> = 1); somewhat specific (<i>n</i> = 10); moderately specific (<i>n</i> = 13); highly specific (<i>n</i> = 4)	Nonspecific (<i>n</i> = 10); somewhat specific (<i>n</i> = 5); moderately specific (<i>n</i> = 10); highly specific (<i>n</i> = 3)	15.2%
Do the advanced healthcare directives specify which treatments the patient would choose, or refuse, to receive if they were diagnosed with an acute, terminal condition? ^c	All scenarios (<i>n</i> = 6); some scenarios (<i>n</i> = 17); no scenarios (<i>n</i> = 5)	All scenarios (<i>n</i> = 9); some scenarios (<i>n</i> = 14); no scenarios (<i>n</i> = 5)	43.2%
Does the advanced healthcare directive articulate what the patient would consider to be the minimum acceptable quality of life? ^d	Comprehensive (<i>n</i> = 10); subjective (<i>n</i> = 11); poor (<i>n</i> = 7)	Comprehensive (<i>n</i> = 1); subjective (<i>n</i> = 11); poor (<i>n</i> = 16)	12.9%

^aInadequate, the advanced healthcare directives specified acceptable outcome cannot be used to determine the disability on modified Rankin scale; possibly adequate, the advanced healthcare directives specified acceptable outcome do not contain terminology that is similar to modified Rankin scale but contains terminology that can be extrapolated to determine the disability; definitively adequate, the advanced healthcare directives acceptable outcome contains terminology that is similar to modified Rankin scale.

^bHighly specific, specific instructions were available for all decision items; moderately specific, specific instructions were available for two or more decision items; somewhat specific, specific instructions were available for at least one decision items; nonspecific, specific instructions were available for none of the decision items.

^cAll scenarios, the advanced healthcare directive provides clear instructions regarding all foreseeable treatments; some scenarios, the advanced healthcare directive provides some instructions regarding some treatments; no scenarios, the advanced healthcare directives does not provide clear instructions regarding all foreseeable treatments.

^dComprehensive, the advanced healthcare directives clearly articulated what they considered to be the minimum acceptable quality of life; subjective, the advanced healthcare directives discussed minimum acceptable quality of life in subjective terms; poor, the advanced healthcare directives did not discuss minimum acceptable quality of life.

patients with advanced healthcare directives that both attorney raters determined as providing clear instructions regarding all foreseeable treatments (Supplemental Table 1, Supplemental Digital Content 1, <http://links.lww.com/CCM/A609>). The decision items that were affected by advanced healthcare directives included ICU monitoring, treatment of acute hypertensive response, induced hypertension with IV vasopressors (if appropriate candidate based on accepted criteria within institution), feeding (nutrition) initiation within 72 hours, treatment of hospital acquired or ventilator-associated pneumonia, intubation and mechanical ventilation for noncardiac arrest scenarios, IV medication and defibrillation for cardiac arrest, percutaneous gastrostomy if persistent dysphagia, and tracheostomy for persistent intubation, or poor airway protection. The percentage agreement among raters for care item choices for these four stroke patients was high for several decision items but was relatively similar in the presence and absence of advanced healthcare directives.

DISCUSSION

In 1990, the Council on Scientific Affairs and the Council on Ethical and Judicial Affairs of the American Medical Association issued a report that highlighted ethical and legal implications of decisions to withhold or withdraw life-prolonging medical treatment (16). In 1991, the Patient Self-Determination Act enacted by the United States Congress went into effect in all healthcare facilities receiving Medicare or Medicaid funding (17). In 1992, the Joint Commission on Accreditation of Healthcare Organizations published a section on advanced healthcare directives for healthcare facilities directly related to the care of the dying patient (18). After receiving official recognition, advanced healthcare directives were increasingly used among persons with or without chronic terminal diseases to provide specific directives about the course of treatment when they were incapacitated and unable to participate in the decision-making process. In theory, advanced healthcare directives would provide an ideal surrogate for in-person decision

making and ensuring that treatment decisions are made under well-defined parameters in patients such as those suffering from acute stroke where incapacitation is very common in the early part of the disease.

Overall, our results did not support the value of advanced healthcare directives as means to influence treatment decisions in stroke patients. The crossover design allowed differentiation between treatment decisions based on patient-related factors and those related to presence of advanced healthcare directives. Our study was unable to demonstrate any major change in treatment decisions pertaining to various facets of care among stroke patient in the presence of advanced healthcare directives. Surprisingly, even decision making for “moderate-complexity” and “high-complexity” treatment decisions was not noticeably influenced by the presence of advanced healthcare directives. We also identified prominent variance among physicians in treatment decisions even in the presence of advanced healthcare directives. There are two possible explanations for these findings. First, advanced healthcare directives in the current format do not provide adequate or specific information to influence medical decision making. It is possible that physician decisions were more likely to be affected if advanced healthcare directives were more explicit. Second, physicians do not make treatment decisions based on advanced healthcare directives but rather on clinical factors supplemented by feedback from patients’ families. The choice of treatment decisions, such as endovascular treatment for ischemic stroke or performance of craniectomy or craniotomy is influenced to a greater extent by physicians’ clinical assessment. We included 28 consecutive patients from 73 patients with advanced healthcare directives pursuant to our sample size calculation. A larger sample size would have increased our ability to determine minor differences. However, the number of treatment decisions in the review or the number of reviewers would have to be reduced for practical reasons. We chose to provide an in-depth analysis which we thought was more appropriate for an initial study.

We explored the adequacy of documentation using an independent review by two attorney raters who found that the description of acceptable outcome was inadequate in half of the advanced healthcare directives reviewed, and the specific instructions were considered “not specific” in regards to treatment decisions in a large proportion of directives for “moderate-complexity” and “high-complexity” decisions. The agreement between interpretations of the two attorney raters was poor for most items assessed for determining adequacy of documentation. While it appears that several items in the current format of advanced healthcare directives can be improved upon, it remains unclear whether such improvement will result in a larger impact on medical decision making and ensure greater uniformity in interpretation among physicians. In an exploratory analysis limited to advanced healthcare directives that both attorneys determined that directives provide clear instructions, several decision items showed an impact of presence of advanced healthcare directives. We need to acknowledge that advanced healthcare directives are not disease specific and may lose generalizability if more specific terms are used in the document. The number of

raters was too small to assess the differences between physicians and attorneys and the impact of physician specialty in interpretation of the document.

It is important to understand the consequences of treatment decisions evaluated in our study and whether such treatment decisions can lead to unnecessarily prolonged, painful, expensive, and emotionally burdensome care and unacceptable outcomes for both patients and their families. Our study did not look at the impact of such variations in treatment decisions on patient outcome in this patient sample. There are sample data that presence of do-not-resuscitate orders and advanced healthcare directives leads to variation in care and premature withdrawal of care in certain situations (19–23). There is also evidence that intensity of ICU care reduces mortality among stroke patients (24) and even decisions regarding institution of feeding (25–27), blood pressure monitoring and intervention (28, 29), intubation and mechanical ventilation (30), medical treatment of intracranial hypertension and transtentorial herniation (31), management of hyperglycemia (32), IV antibiotics for treatment of pneumonia (33, 34), and gastric ulcer prophylaxis (35) lead to alteration in cost of hospitalization, length of stay, and patient outcomes. Certain treatment choices, such as endovascular treatment for ischemic stroke and craniectomy/craniotomy for mass effect are likely to result in lower mortality but higher disability (5–7). The low threshold exhibited by patients, families, and healthy population in the community for accepting disability instead of death (4, 5) would support the assumption that the limited impact of advanced healthcare directives in modifying care and reducing variation in decision making increases the likelihood of “unacceptable outcomes” among patients.

In conclusion, our results mandate steps to provide a clear understanding among patients and attorneys involved in the preparation of advanced healthcare directives regarding the expected impact of the document on actual treatment decisions. Steps such as involvement of physicians in providing professional opinion at the time of preparation of advanced healthcare directives may assist in preparation of a document that guides treatment decisions consistent with patients’ expectations. A greater level of awareness and collaboration among patients, families, legal parties, and physicians may result in implementation of advanced healthcare directives during management of diseases, such as stroke which is associated with high rates of surrogate decision making and variation in magnitude of disability and quality of life subsequent to such decisions.

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