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# Measurement of Patients' Perceptions of the Quality of Acute Stroke Services: Development and Validation of the STROKE Perception Report

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## ABSTRACT

**INTRODUCTION:** Patients' perceptions of healthcare quality have become an important part of quality measurement. We explored patients' and family's lived experiences during acute stroke hospitalization to develop a quantitative instrument. **METHODS:** Focus groups were conducted using open-ended scripted questions. Interview data were coded and analyzed using an inductive approach to thematic analysis. Symmetric patient and family instruments were developed based on qualitative domains and serially refined to a set of 30 survey items, 12 stroke knowledge test items, and 5 subject demographic fields. Scales were evaluated for internal consistency reliability using Cronbach  $\alpha$ ; construct validity with exploratory factor analysis using principal components with varimax rotation was performed to determine the extent to which items in a scale measure the same underlying factor. Feasibility of an electronic cloud-based survey was also tested. **RESULTS:** Three main themes emerged: fast action to diagnose and treat stroke, genuine caring, and education to prevent and respond to stroke. A total of 1029 subjects completed the final instrument with no differences in perception found by race, ethnicity, or length of stay.

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Scales showed satisfactory internal consistency reliability (Cronbach  $\alpha$  scores, .89–.94); factor loadings across each scale ranged from 0.55 to 0.87. Data entry by electronic pad was perceived by 77% to be more confidential than paper surveys; median score for difficulty was 4 (“easy to use”). **CONCLUSION:** The STROKE Perception Report enables understanding of patients' and family's beliefs about the quality of acute stroke care in essential new domains never explored before.

**Keywords:** acute stroke, caring, nursing, patient perception of quality care, patient reported outcomes, quality improvement

Patients' perceptions of the quality of healthcare services have become an important part of hospital quality measurement.<sup>1,2</sup> In the late 1980s and early 1990s, hospitals began exploring development of outcome-based quality measures, focusing primarily on “hospitality” indicators similar to those used by hotels.<sup>3,4</sup> However, the 1993 release of *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*<sup>5</sup> allowed providers a first glimpse of qualitative data associated with hospitalization, fueling improvement in indicators to reflect more personal patient beliefs and experiences. Over time, many of these improved measures became incorporated into the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, resulting in domains that reflect nurse and physician communication, responsiveness of hospital staff, cleanliness and quietness of hospital environment, pain management, communication about medicines, discharge information, and an overall rating of the hospital as well as hospital recommendation.<sup>2</sup> The HCAHPS survey is designed for distribution to patients after hospital discharge, resulting in returned responses from patients with diverse admitting diagnoses; the survey is a requirement for hospitals caring for patients funded by the Centers for Medicare & Medicaid Services, and the Centers for Medicare & Medicaid Services publishes findings for each hospital in relation to others in the same region and national scores on the Hospital Compare website.<sup>6</sup>

Hospitalized acute stroke patients represent a highly vulnerable group of patients with high rates of disability at discharge<sup>7–9</sup> and significant learning needs that span stroke pathogenesis and treatment, knowledge of personal stroke risk factors and their associated management, an ability to recognize stroke symptoms/warning signs, and use of emergency 911 systems.<sup>10,11</sup> The disability caused by stroke may limit return of posthospitalization surveys, and the significant burden caused by stroke may also cause caregivers to respond more negatively to hospital quality surveys or not respond at all because of increased caregiver burden once they are at home managing the reality of these disabilities.<sup>12–15</sup> In addition, research has shown that patient and family retention of learning related to stroke is poor at the time of hospital discharge,<sup>11</sup> so the HCAHPS survey items focused on

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The item domains capture what patients and family most closely relate to as genuine, authentic caring.

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the provision of written educational materials during hospitalization and explanations about medications are likely to be poor surrogates for retained stroke knowledge.

Although hospitals do not routinely measure patient perceptions until after discharge,<sup>2</sup> stroke patients and families may be an important group of patients in which to explore the hospitalization experience immediately before discharge. For example, providers could benefit from understanding the experience of emergent diagnosis and treatment from patients' and family's perspectives at a time when expectations for rapid action have become standard. In addition, knowing patients' and family members' actual knowledge of stroke warning signs and beliefs about how well they are prepared to assume self-care after discharge could be useful in driving important changes in how stroke discharge education is provided. Therefore, we aimed to explore patients' and their significant others' lived experiences during acute stroke hospitalization and, ultimately, to develop a quantitative instrument to capture this experience in an effort to foster rapid-cycle quality improvement.

## Methods

We undertook qualitative and quantitative research to understand patients' and family's perceptions of the quality of acute stroke services. Our process began with qualitative exploration of the lived experience of hospitalization for patients with an acute stroke diagnosis and their family members; we then developed and serially refined a quantitative instrument for measurement of patients' and family's perceptions of the quality of acute stroke care. All phases of the study were approved by the local and coordinating institutional review boards.

## Qualitative Phase

The primary aim of the qualitative phase of the study was to identify key patient-derived themes perceived as essential to the provision of high-quality acute stroke

care. A focus group approach was used to understand the patient/family experience of being hospitalized with an acute stroke event and to unveil perceptions of indicators of high-quality acute stroke hospital services. Patient eligibility for participation in a focus session included ability to speak, read, and write in English; current hospitalization for a primary diagnosis of acute stroke; National Institutes of Health Stroke Scale (NIHSS) scores of 0 on items 1A, 1B, 1C, and 9 and a score of less than 1 on item 10; and hemodynamically stable and physically capable of joining a focus group located within the hospital but outside the stroke unit. Family focus group eligibility included status as next of kin and/or family spokesperson for a patient with a significant neurologic disability incapable of speaking for himself or herself and greater than 3 days of lived experience with the reference stroke admission.

The same focus group leader and two recorders were used for all sessions, with none of these investigators involved in the provision of patient/family care for any invited study participants. During a 6-month period, a convenience sample of acutely hospitalized stroke patients, or family members of patients with a severe neurologic disability, were recruited to participate in 1 of 5 focus groups (2 family-only group sessions, 2 patient-only group sessions, and 1 combined patient/family group session). Written consent was obtained from all study participants. All focus groups were conducted in two parts: part I consisted of interviews using open-ended scripted questions, with all information simultaneously tape- and hand-recorded; part II consisted of completion of a brief questionnaire that asked patients and family members to rank from most important to least important a variety of hospital quality indicator categories derived from a review of existing hospital quality measures and content expert consensus.

De-identified data from the scripted interviews were later transcribed verbatim from tape recordings and supplemented by notes taken by the 2 hand-recorders. The interview data were subsequently coded and analyzed using an inductive approach to thematic analysis to allow for independence of theory and epistemology while promoting emergence of a detailed, complex account of the stroke hospitalization experience. The first step in this process entailed careful reading to identify meaningful text units relevant to the study topic. Next, units of text detailing similar issues were grouped together in analytic categories, and provisional definitions were applied. The data were then systematically reviewed to ensure an exhaustive set of data were defined to support each category, and a descriptive name for each theme was identified. Ranked hospital quality indicator categories from part II of the study were analyzed using descriptive statistics to provide further support for the importance of candidate themes to acute stroke patients and their families.

### **Quantitative Phase**

The major aim of the quantitative phase was to assemble an instrument from the qualitative findings and analyze its psychometric properties and overall performance as a measure of patient/family perception of the quality of acute stroke care. The secondary aim of the study was to embed a participant knowledge test within the instrument, derived from stroke center certification required stroke education elements,<sup>10,11</sup> to examine patients' and family's acquired knowledge alongside their perceived quality of the inpatient stroke education received.

Symmetric patient and family instruments were developed based on the domains identified in the qualitative phase of the study and serially refined by content experts to a set of 30 survey items, 12 stroke knowledge test items, and 5 subject demographic fields; no identifying information was collected. The instrument was titled "STROKE (Stroke Treatment, Risk, Outcome Knowledge, Education) Perception Report" to represent survey content. Items overlapping with the HCAHPS survey were removed to prevent concerns related to duplicative reporting. A benchmark reporting system was developed to test the value of comparing participating sites' responses on the instrument similar to that used by existing commercial hospital quality instruments but limited exclusively to findings from acute stroke patients or their families. Surveys were coded by study site for the assembly of quarterly benchmark performance reporting to support rapid-cycle program improvement efforts.

A diverse sample of US-certified stroke center academic and community hospitals was recruited for patient/family enrollment. Subject inclusion criteria for these participating sites were a convenience sample of consecutive patients, 18 years or older with a hospital admission greater than 24 hours for ischemic stroke, transient ischemic attack, or hemorrhagic stroke. Patients were excluded if they were admitted with a primary diagnosis other than stroke, even if they subsequently developed a stroke during their hospital stay. Patients completed a "patient version" of the instrument if their NIHSS items 1A, 1B, 1C, and 9 were scored as 0 and the patient expressed a willingness despite other disabilities to participate in the study. A "family version" was completed by willing family members or significant others designated as a spokesperson and/or legally authorized next of kin when neurologic disabilities prohibited direct patient participation. At the time of hospital discharge, patients/families were given the instrument, an envelope in which to seal their completed surveys, and access to a hospital unit mailbox for survey submission. Surveys were filled out after all nursing and medical interaction was complete, immediately before the patient/family leaving

the hospital to ensure high return rates with the best possible recall of the hospital experience; no physical contact with surveys was allowed by hospital employees once the instrument was distributed to patients/families.

Surveys were submitted within their sealed envelopes to the coordinating center where they were entered into SPSS (IBM v. 23), cleaned by an independent researcher not affiliated with any study site, and subsequently analyzed by an independent psychometrician. All scales were evaluated for internal consistency reliability using Cronbach  $\alpha$  with a finding of .70 deemed satisfactory for a new instrument.<sup>16,17</sup> Construct validity with exploratory factor analysis using principal components with varimax rotation was performed to determine the extent to which items making up a scale measure the same underlying construct or factor, and a shared variance of 50% or greater was considered excellent.<sup>18,19</sup> Data were analyzed descriptively for the overall sample, and tests of difference were used to evaluate whether patient and family findings differed by race, age, education, ethnicity, or hospital length of stay (LOS). Data from participating sites were analyzed in relation to other sites to provide a snapshot of site-specific patient and family responses, with data assembled into a report card that presented site aggregate findings alongside that of all other participating sites.

### *Cloud-Based, Electronic Pad Feasibility*

Study sites were invited to participate in a final feasibility study to test the implementation of a cloud-based, password-protected, electronic version of the survey accessible by an electronic pad. Additional items were included relating to subjects' perceptions about confidentiality and privacy security with electronic cloud-based responses, as well as subjects' perceptions of ease of use for survey completion by an electronic pad. Similar patient and family inclusion criteria were used to recruit consecutive acute stroke patients or their next of kin/family spokesperson for electronic pad survey completion. Data were downloaded from the cloud and included in the quantitative analyses previously described, with separate descriptive analyses of the items relating to confidentiality/privacy and ease of use.

## **Results**

### *Qualitative Phase*

A total of 18 subjects were recruited, consisting of 10 family members (age,  $49 \pm 7$  years; 60% female; 50% African American and 50% white; 100% non-Hispanic) and 8 acute stroke patients (age,  $52 \pm 8$  years; 50% female; 57% white, 30.5% African American, and 12.5% Asian; 100% non-Hispanic). The inductive thematic

analysis resulted in 19 categories that were grouped into 3 key themes: (1) fast action to diagnose and treat stroke, (2) genuine caring, and (3) education to prevent and respond to future strokes.

### *Fast Action to Diagnose and Treat Stroke*

All participants described the importance of what they perceived as "rapid" or "fast actions" on the part of physicians and nurses to their stroke symptoms. The "fast action" theme comprised 7 categories: rapid physical response, clarity of options, partnering in treatment choice, fast treatment, feelings of safety, confidence in the team, and "determined knowing" why the stroke occurred. Transcribed interview content capturing the "fast action" theme included the following excerpts from 2 subjects:

Excerpt 1: "I think you just want to be sure that everything that can be done is done and is done quickly.... I just want them to tell me what they are going to do and this is why we are doing it. 'If you don't do this, then this is going to happen...if you do this, then this is what we expect to happen.' I got that; I was given options. No one here drags their feet or delays, they just get it done."

Excerpt 2: "They do one test and if it is negative, they quickly order more tests until they find the problem. That's a good thing...the last hospital we went to didn't do this, they just gave up and said 'nothing could be done.' Being very thorough and not settling for 'no treatment options' is something we really appreciate; it makes us feel very safe."

### *Genuine Caring*

Text aligned with the "genuine caring" theme constituted the greatest number of all coded sections at more than 50% of coded text, illustrating its relative importance to patients and family members. A total of 6 categories fell within this theme consisting of unique needs; patience, respect, and kindness; engaged listening; trusting my caregivers; authentic caring; and "top priority" caring. Examples of focus group dialogue illustrating the importance of this theme include the following excerpts from 3 separate participants:

Excerpt 1: "I feel somewhat helpless. There is nothing I can do; I can pray, but there is nothing I can do...it happened. I don't feel hopeless, but I feel helpless. They really identified with me on a personal level, it's like they don't even have other patients. They never look at their watches, they just let me talk and really make me feel like I am the center of their world. I feel very cared for, and I need that right now."

Excerpt 2: “The staff might not have gone through it themselves, but they should sympathize with you...they should know how you feel deep inside and want to really support you.”

Excerpt 3: “I need them to take their time, be patient, kind and understand how I feel...what I’m going through...not rush, because rushing around scares you, and it makes you feel like you are in the way...that what has happened is not important.”

### *Education to Prevent and Respond to Stroke*

All patients and family members identified the importance of being well educated and prepared to prevent future strokes, recognize warning signs, and respond to future stroke events. A total of 6 categories emerged within this theme: stroke defined, my risk factors, warning signs, teaching with patience, emergency systems activation, and self-care preparation. Transcribed excerpts from 3 separate participants illustrate the importance of the education theme:

Excerpt 1: “I know the definition of what a stroke is, but as far as understanding exactly what happened, you know, I didn’t get it. Both the doctors and nurses understood this, and they were patient with me. They explained what happened to Dad, why it happened, and they spent a great deal of time making sure that I really got it. They didn’t want me to be unprepared if it happened again, and they wanted me to work with them to prevent Dad from having another stroke.”

Excerpt 2: “They started explaining and teaching things to me right from the beginning...in the emergency room. That was good because I didn’t know what to do and I was scared...I needed to know what was going on.”

Excerpt 3: “There’s a lot of information that you have to digest...what caused the stroke, what you can do about it, how you have to change your life to keep it from happening again. It’s a lot of information, and they need to keep telling you about it, otherwise you’ll never understand...you’ll never know what to do to stay safe from stroke.”

Participants concluded this phase of the study by ranking elements of care that they perceived to be the most and least important during an acute stroke hospitalization. Consistent with the qualitative findings, the 3 highest ranked responses were “rapid response to treat stroke symptoms,” “authentic caring about my unique needs, fears and concerns,” and “teaching me about warning signs, risk factors, and ways to modify lifestyle to prevent a future stroke.” The lowest ranks

were held by access to ancillary support personnel (ie, social workers and spiritual support), with custodial indicators, namely, “the comfort of the hospital room” and “the quality of the hospital food,” receiving the lowest ratings for perceived importance.

## *Quantitative Results*

### *Part I: Sample*

A total of 35 sites were recruited for participation from the United States, enrolling 1029 patients in total. Patient versions of the STROKE Perception Report were completed by 761 participants (74%), and the overall complete response rate for the sample was 99.8%. Racial characteristics and ethnicity for the overall sample were 72% white, 19% African American, 6% Asian, 2% Native Hawaiian/Pacific Islander, and 1% American Indian/Alaska Native; 7% indicated Hispanic ethnicity. Most participants (87%) graduated from high school (HS), and of these, 28% had earned a 4-year college degree or higher. LOS averaged  $5 \pm 4.3$  days (range, 1–59 days), and the odds of family members acting as the survey responder were significantly associated with an increased LOS (odds ratio, 1.14; 95% confidence interval, 1.098–1.192;  $P < .0001$ ).

There were no differences in perception of care quality by race, ethnicity, or LOS. Overall, the lowest rated hospital quality rankings were in the “education to prevent and respond to stroke” subscale, whereas the highest quality rankings were in the “genuine caring” scale. Patients were more likely to state that their nurses ( $P = .015$ ) and physicians ( $P = .0009$ ) did not teach them about the warning signs for a stroke, as compared with family member perceptions. Overall, participants with higher levels of education were more likely to state that the nurses ( $P = .0014$ ) and doctors ( $P = .012$ ) did not educate them about posthospitalization care.

### *Part II: Instrument Psychometrics*

Psychometric results are described separately by sample type (patient or family) and presented in Tables 1 and 2.

**Patient sample.** Sample size differed for each scale because of missing values: (Fast Action to Diagnose and Treat Stroke,  $n = 676$ ; Genuine Caring,  $n = 701$ ; Education to Prevent and Respond to Stroke,  $n = 642$ ) (Table 1). Cronbach  $\alpha$  scores ranged from .89 to .94 showing satisfactory internal consistency reliability. The Fast Action to Diagnose and Treat Stroke scale exhibited a single underlying factor, which explained 18.5% of shared variance, with factor loadings ranging from 0.56 to 0.79. The second scale, Genuine Caring, exhibited two underlying factors that explained 27.8% of shared variance; 6 items about physician caring behaviors loaded on 1 factor, and 4

**TABLE 1. Reliability and Construct Validity for Patient Perceptions of Stroke Care**

Subscale	Component			
	1	2	3	4
Action to diagnose and treat ( $\alpha = .93$ , explained variance = 18.5%)				
Physicians respond	0.123	<b>0.728</b>	0.232	0.050
Nurses respond	0.161	<b>0.731</b>	0.143	0.178
Rapid treatment	0.218	<b>0.699</b>	0.250	0.188
Physicians safe	0.208	<b>0.788</b>	0.245	0.072
Nurses safe	0.224	<b>0.755</b>	0.100	0.296
Physicians confident	0.201	<b>0.757</b>	0.328	0.141
Nurses confident	0.185	<b>0.738</b>	0.123	0.304
Physicians determined	0.250	<b>0.561</b>	0.443	0.227
Nurse caring ( $\alpha = .89$ , explained variance = 11.4%)				
Nurses unique	0.221	0.303	0.202	<b>0.701</b>
Nurses trust	0.136	0.280	0.165	<b>0.762</b>
Nurses cared	0.176	0.157	0.279	<b>0.822</b>
Nurses' priority	0.301	0.164	0.277	<b>0.778</b>
Physician caring ( $\alpha = .91$ , explained variance = 16.4%)				
Physicians unique	0.248	0.334	<b>0.686</b>	0.255
Physicians trust	0.146	0.307	<b>0.726</b>	0.311
Physicians cared	0.155	0.172	<b>0.793</b>	0.369
Physicians' priority	0.248	0.196	<b>0.774</b>	0.368
Physician info	0.224	0.336	<b>0.696</b>	0.067
Physician participate	0.283	0.342	<b>0.547</b>	0.016
Education to prevent and respond ( $\alpha = .94$ , explained variance = 22.1%)				
Nurses teach	<b>0.737</b>	0.214	0.160	0.302
Physicians teach	<b>0.648</b>	0.150	0.517	0.125
Nurses' risk factors	<b>0.838</b>	0.179	0.074	0.246
Physicians' risk factors	<b>0.737</b>	0.113	0.446	0.108
Lifestyle changes	0.382	0.148	0.034	0.269
Nurses' warning signs	<b>0.839</b>	0.180	0.093	0.199
Physicians' warning signs	<b>0.766</b>	0.126	0.392	0.053
Nurses hospital quickly	<b>0.769</b>	0.172	0.052	0.111
Physicians hospital quickly	<b>0.707</b>	0.124	0.342	0.016
Nurse discharge	<b>0.681</b>	0.365	0.100	0.173
Physician discharge	<b>0.623</b>	0.302	0.443	0.052

Note. Factor loadings are in bold.

items about nurse caring behaviors loaded on the second, with all factor loadings ranging from 0.55 to 0.82. The third scale, Education to Prevent and Respond to Stroke, exhibited a single underlying factor that explained 22.1% of shared variance, with factor loadings ranging from 0.62 to 0.84. One item, “likeliness to modify lifestyle,” did not load on any factor.

Family sample. Sample size differed for each scale because of missing values (Fast Action to Diagnose and Treat Stroke,  $n = 247$ ; Genuine Caring,  $n = 251$ ; Education to Prevent and Respond to Stroke,  $n = 227$ ) (Table 2). Cronbach  $\alpha$  scores ranged from .88 to .93 showing excellent internal consistency reliability. The Fast Action to Diagnose and Treat Stroke subscale

**TABLE 2. Reliability and Construct Validity for Family Perceptions of Stroke Care**

Subscale	Component			
	1	2	3	4
Action to diagnose and treat ( $\alpha = .93$ , explained variance = 18.5%)				
Physicians respond	.067	.189	<b>.829</b>	.064
Nurses respond	.137	.015	<b>.851</b>	.008
Rapid treatment	.116	.204	<b>.790</b>	.021
Physicians safe	.162	.314	<b>.750</b>	.126
Nurses safe	.204	.133	<b>.790</b>	.219
Physicians confident	.100	.435	<b>.730</b>	.111
Nurses confident	.181	.201	<b>.748</b>	.298
Nurse caring ( $\alpha = .88$ , explained variance = 10.8%)				
Nurses unique	.100	.333	.220	<b>.715</b>
Nurses trust	.218	.167	.195	<b>.777</b>
Nurses cared	.195	.172	.050	<b>.833</b>
Nurses' priority	.273	.236	.098	<b>.759</b>
Physician caring ( $\alpha = .92$ , explained variance = 19.0%)				
Physicians determined	.250	<b>.624</b>	.470	.091
Physicians unique	.143	<b>.730</b>	.329	.255
Physicians trust	.085	<b>.758</b>	.286	.175
Physicians cared	.218	<b>.834</b>	.066	.193
Physicians' priority	.219	<b>.792</b>	.193	.317
Physicians teach	.407	<b>.658</b>	.094	.266
Physician info	.204	<b>.666</b>	.415	-.003
Physician participate	.203	<b>.544</b>	.272	.176
Education to prevent and respond ( $\alpha = .93$ , explained variance = 20.7%)				
Nurses teach	<b>.658</b>	.330	.127	.274
Nurses' risk factors	<b>.778</b>	.309	.073	.201
Physicians' risk factors	<b>.685</b>	.497	.041	.172
Lifestyle changes	.244	.364	.047	.074
Nurses' warning signs	<b>.867</b>	.042	.123	.180
Physicians' warning signs	<b>.778</b>	.304	.063	.167
Nurses hospital quickly	<b>.844</b>	.026	.154	.098
Physicians hospital quickly	<b>.767</b>	.169	.118	.158
Nurse discharge	<b>.728</b>	.123	.296	.052
Physician discharge	<b>.697</b>	.373	.286	.010

Note. Factor loadings are in bold.

exhibited 1 underlying factor, which explained 18.5% of shared variance with factor loadings ranging from 0.73 to 0.85. The second scale, Genuine Caring, exhibited 2 underlying factors that explained 29.8% of shared variance; 8 items about physician caring behaviors loaded on 1 factor, and 4 items about nurse caring behaviors loaded on the second, with factor loadings ranging from 0.54 to 0.83. The third scale, Education to Prevent and Respond to Stroke, exhibited a single underlying factor that explained 20.7% of shared variance, with factor loadings ranging from 0.66 to 0.87. One item, "likeliness to modify lifestyle," did not load on any factor.

### Part III: Knowledge Testing

Instrument item 27 asked subjects to identify common stroke warning signs from a list of 11 symptoms; Table 3 (Supplemental Digital Content 1, available at <http://links.lww.com/JNN/A188>) provides the percentage of correct responses submitted by patients and family members. Significantly more white family members recognized facial droop as a warning sign for stroke ( $\chi^2 = 17.4, P = .02$ ), and that both chest pain ( $\chi^2 = 9.6, P = .048$ ) and nausea/vomiting/diarrhea ( $\chi^2 = 16.9, P = .02$ ) were not stroke warning signs. Hispanic family members more commonly believed that chest pain was a warning sign for stroke ( $\chi^2 = 6.2, P = .013$ ) compared with non-Hispanic family members, whereas Hispanic patients more commonly believed that an irregular heart beat was a warning sign for stroke ( $\chi^2 = 4.1, P = .042$ ) compared with non-Hispanic patients.

Item 28 asked subjects what the best first response would be when stroke symptoms were identified (Table 4, Supplemental Digital Content 2, available at <http://links.lww.com/JNN/A189>). There were no differences by education, race, or ethnicity to what both family and patients believed would be the "best" first action to take if stroke warning signs occurred, with both patients (90%) and family members (94%) identifying activation of emergency (911) systems as the preferred response.

### Part II: Electronic Pad Feasibility Testing

A total of 153 surveys were collected by an electronic pad, with 101 (67%) collected from stroke patients averaging  $62 \pm 14$  years (median, 62 years; range, 19-94 years). Subjects were 74% white, 14% African American, 6% Asian, 2% Native Hawaiian/Pacific Islander, and 4% Native American/Alaskan Native; 17% of the sample indicated Hispanic ethnicity. Education was as follows: 37% HS graduates, 26% some college, 20% 4-year college graduates, 12% graduate degree, and 5% some HS. The median score for difficulty was 4 ("easy to use"), and only 2% of the

patients rated data entry "difficult," whereas no family members indicated difficulty with data entry by an electronic pad. No participants rated their entries as concerning for "confidentiality/privacy loss," and 77% perceived entries as "more confidential/more private" than paper entries. Of note, 62% indicated that, if the survey was mailed to their house, they would not respond to it. There was no difference in "ease of use" or "confidentiality protection" by patients, families, or race; however, higher levels of education were associated with perceptions of improved confidentiality ( $\chi^2 = 16.3, P = .039$ ). Interestingly, as patient age increased, perceptions of difficulty of use decreased ( $r = -0.29, P = .029$ ).

### Site Satisfaction With Benchmarked Report Cards

A report card template (Figure 1, Supplemental Digital Content 3, available at <http://links.lww.com/JNN/A190>) was developed to promote benchmarking between sites. Participating sites agreed unanimously that the report card was beneficial in facilitating rapid improvement processes. In addition, of 12 sites that presented their report cards to Stroke Center Certification Reviewers as evidence of their measurement of patient perception of care quality, all were provided with reviewer feedback that the instrument and benchmarking methods were considered an excellent quality monitoring process.

### Discussion

The STROKE Perception Report<sup>20</sup> is a valid and reliable measure of patients' and family surrogates' perceptions of the quality of acute stroke hospital services. The survey is meant for distribution to patients or family caregivers immediately before hospital discharge to ensure high rates of return that will enable acute stroke providers and administrators to understand areas for improvement as well as providing opportunities to celebrate key aspects of stroke care perceived to be of high quality. Mazurenko and colleagues<sup>21</sup> have shown that differences in perceptions of HCAHPS quality scores can be driven by patient characteristics such as race and ethnic minority status. Interestingly, we have shown that race, ethnicity, and patient LOS do not create differences in perceptions of stroke care quality. We have also shown that an electronic version of the instrument is not only easy to use regardless of age and education but also perceived to provide a more confidential and private method than paper instruments to collect hospital quality data. To the best of our knowledge, no other work has described patients' and family members' perceptions of data confidentiality by use of an electronic cloud-based survey to capture their beliefs about hospital quality. This finding of "improved

confidentiality/privacy” is important because we collected survey data immediately before the patient/family leaving the hospital; this method has been discouraged<sup>2</sup> because of concerns for subject pressure by hospital staff to respond positively, as well as the risk of data tampering by hospital staff. Our methods ensured that neither of these risks could intervene with survey completion as patients and family accessed the electronic survey and submitted their responses fully independent of hospital staff involvement.

The 3 domains identified by patients and family members in our qualitative work informed our development of quantitative survey items, with 2 domains (Fast Action To Diagnose And Treat Stroke, and Education to Prevent and Respond to Stroke) emerging that have never been identified or developed into survey items before. As stroke programs work toward shortening their arrival/door to tissue plasminogen activator and thrombectomy times, it is interesting to note that both patients and families identified that “fast action” is indeed essential to quality stroke treatment. The survey items in this domain will prove to be important in helping stroke centers improve their actions as well as their patient/family communication about the importance of rapid diagnosis and treatment.

Understanding patients’ and family’s knowledge of stroke at discharge, after education has been provided, is yet another essential component of quality monitoring. Our survey knowledge test items are the first to be validated and found reliable as outcome measures in this important domain. In addition, the configuration of our report card to show knowledge scores in relation to other users and to present these data alongside patients’ and family’s perceptions of adequacy of teaching about the pathophysiology, risk factors, and warning signs of stroke provides a powerful look at ways to improve the delivery of stroke education before discharge. Because patient and family knowledge retention associated with hospital stroke teaching is poor,<sup>11</sup> ongoing feedback provided to stroke center hospitals is essential to improvement. One item asking about intent to modify lifestyle based on new knowledge about risk factors did not load on any factors; however, this single item provides insight into how effective our teaching is at getting patients to adopt healthier ways of living after a stroke, an important area for future research.

Our survey also includes content within a “genuine caring” domain; however, our items differ considerably from those represented in the HCAHPS survey that focus on courtesy, respect, and careful listening. Evidence of our qualitative findings’ impact on our survey items in this domain is clear, including content evaluating whether patients believed staff recognized them as individuals with full lives that have been

significantly affected by stroke disability, as well as staff authenticity in caring about what patients and family are experiencing, confidence and trust in nurses and physicians, and perceptions that their care and well-being were a “top priority” of the stroke center staff. Items such as these provide a clear picture of the depth of patients’ actual lived experience during a stroke hospitalization, which includes their fear and recognition of new limitations in the face of what can be a devastating neurologic disability. We believe that, although courtesy, respect, and careful listening are important hospitality measures, our items in this domain capture what patients and family most closely relate to as genuine, authentic caring. Of interest are the differences in item loadings between patients and family members. Two of the physician items, one asking about the stroke doctor’s determination to find the cause of the stroke and another asking about stroke education provided by the stroke doctor, loaded on the physician Genuine Caring scale for family members completing the survey, whereas for patients completing the survey, the first item loaded as expected with the other Fast Action to Diagnose and Treat Stroke subscale, but the second item loaded as expected with the Education to Respond and Prevent Stroke subscale. This difference may indicate subtle differences between patients’ and family members’ perceptions regarding physician actions. One reason for this may be that physicians interacting with family members of highly disabled patients may take extra care in using highly empathetic approaches to provision of care and education given the devastated state of the patient. Further testing will need to be performed to see whether this difference was sample related versus a systematic difference between patients and families in their beliefs about physician behaviors.

The HCAHPS survey is here to stay, and our work should by no means be interpreted as offering a replacement of the HCAHPS tool. We deliberately removed overlap with HCAHPS items focused on nurses and physician courtesy, respect, careful listening, and provision of understandable explanations. Interestingly, we did include a question to patients and families about whether they would be likely to complete surveys mailed to their home after discharge, finding that most would be unlikely to follow through with mailed survey completion. This may explain why hospitals commonly receive very small numbers of returned HCAHPS results specifically from stroke patients, and this small return rate significantly limits the ability to understand and improve the stroke patient experience. In addition, at the core of disease-specific care principles is an intent to use instruments that are specific to a patient population.<sup>10</sup> The STROKE Perception Report aligns with these important disease-specific principles, while also

contributing to the important work of measure discovery as described by the National Quality Forum<sup>1</sup> and the American Academy of Neurology.<sup>22</sup> With very few well-designed studies showing the potential impact of disease-specific care certification,<sup>23</sup> work in the area of instrument development for discrete disease populations is important to support rapid-cycle quality improvement and better care for vulnerable patients and families.

Our work does have limitations that are tied to methods associated with both qualitative and survey research. First, it is likely that other important domains exist that are associated with the hospitalization experience after an acute stroke admission. As is typical of qualitative work, our focus groups consisted of small numbers of patients and family members, and therefore the findings of our subjects may not fully represent the beliefs of all stroke patients. However, we were cautious not to lead our qualitative subjects in any specific direction, and despite this, each group articulated similar important experiences and beliefs that are compelling. Second, as is true with all survey research, we must assume that the opinions and knowledge test responses are truthful on the part of participating subjects. The fact that our findings were able to load consistently across both patients and family members is representative of the validity of our work, with very reasonable reliability further supporting the instrument.

## Conclusions

The STROKE Perception Report enables stroke center staff to understand patients' and family's beliefs about the quality of acute stroke care in 3 essential new domains never explored before that are key to the responsibilities of vascular neurologists and nurses working in this fast-paced, rapidly evolving specialty. By understanding these important perceptions of acute stroke services through the eyes of stroke survivors and caregivers, stroke center hospitals are well positioned to improve and celebrate the care they deliver in support of this vulnerable patient population.

## References

1. Roundtable on Value & Science-Driven Health Care; Institute of Medicine. *Core Measurement Needs for Better Care, Better Health, and Lower Costs: Counting What Counts: Workshop Summary*. Washington, DC: National Academies Press; 2013: ISBN-13: 978-0-309-28522-3.
2. Centers for Medicare & Medicaid Services. HCAHPS Hospital Consumer Assessment of Healthcare Providers and Systems. Available at <https://www.hcahpsonline.org/>. Accessed July 6, 2019.
3. Ellwood PM. Shattuck lecture—outcomes management. A technology of patient experience. *N Engl J Med*. 1988;318(23):1549–1556.
4. Wojner AW. *Outcomes Management: Application to Clinical Practice*. St Louis, MO: Mosby; 2001.
5. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. San Francisco, CA: Jossey-Bass; 1993.
6. Centers for Medicare & Medicaid Services. Hospital Compare. Available at [www.medicare.gov/hospitalcompare](http://www.medicare.gov/hospitalcompare). Accessed July 6, 2019.
7. Jauch EC, Saver JL, Adams HP Jr., et al. Guidelines for the early management of patients with acute ischemic stroke: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2013;44(3):870–947.
8. Hemphill JC III, Greenberg SM, Anderson CS, et al. Guidelines for the management of spontaneous intracerebral hemorrhage: a guideline for Healthcare Professionals from the American Heart Association/American Stroke Association. *Stroke*. 2015;46(7):2032–2060.
9. Connolly ED Jr., Rabinstein AA, Carhuapoma JR, et al. Guidelines for the management of aneurysmal subarachnoid hemorrhage: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2012;43(6):1711–1737.
10. The Joint Commission. *2019 Comprehensive Certification Manual for Disease-Specific Care Including Advanced Programs for DSC Certification*. Oakbrook, IL: The Joint Commission; 2018.
11. Johnson B, Handler D, Urrutia V, Alexandrov AW. Retention of stroke education provided during hospitalization: does provision of required education increase stroke knowledge? *Interv Neurol*. 2018;7(6):471–478.
12. Ganapathy V, Graham GD, DiBonaventura MD, Gillard PJ, Goren A, Zorowitz RD. Caregiver burden, productivity loss, and indirect costs associated with caring for patients with post-stroke spasticity. *Clin Interv Aging*. 2015;10:1793–1802.
13. Rigby H, Gubitz G, Eskes G, et al. Caring for stroke survivors: baseline and 1-year determinants of caregiver burden. *Int J Stroke*. 2009;4(3):152–158.
14. Jessup NM, Bakas T, McLennon SM, Weaver MT. Are there gender, racial or relationship differences in caregiver task difficulty, depressive symptoms and life changes among stroke family caregivers? *Brain Inj*. 2015;29(1):17–24.
15. Pound C, Greenwood N. The human dimensions of post-stroke home care: experiences of older carers from diverse ethnic groups. *Disabil Rehabil*. 2016;38(20):1987–1999.
16. Nunnally JC, Bernstein IH. *Psychometric Theory*. 3rd ed. Philadelphia, PA: McGraw-Hill; 1994.
17. Price LR. *Psychometric Methods: Theory Into Practice*. New York, NY: Guilford Press; 2017.
18. Pett MA, Lackey NR, Sullivan JJ. *Making Sense of Factor Analysis: The Use of Factor Analysis for Instrument Development in Health Care Research*. Thousand Oaks, CA: Sage; 2003.
19. Fabrigar LR, Wegener DT. *Exploratory Factor Analysis*. Oxford, England: Oxford Press; 2012.
20. Health Outcomes Institute. STROKE Perception Report. Available at [www.strokeperceptionreport.org](http://www.strokeperceptionreport.org). Accessed July 6, 2019.
21. Mazurenko O, Collum T, Ferdinand A, Menachemi N. Predictors of hospital patient satisfaction as measured by HCAHPS: a systematic review. *J Healthc Manag*. 2017;62(4):272–283.
22. Latorre JGS, Flanagan S, Phipps MS, Shenoy AM, Bennett A, Seidenwurm D. Quality improvement in neurology: Stroke and Stroke Rehabilitation Quality Measurement Set update. *Neurology*. 2017;89(15):1619–1626.
23. Musallam E, Johantgen M, Connerney I. Hospital disease-specific care certification programs and quality of care: a narrative review. *Jt Comm J Qual Patient Saf*. 2016;42(8):364–368.