Patient and Family Perceptions of the Key Indicators for Measurement of Stroke Center Quality: Qualitative Support for an Acute Stroke-Specific Instrument

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Disclosures

• Anne W. Alexandrov, PhD, RN, CCRN, FAAN  
  – Nothing to disclose
• April Sisson, BSN, RN  
  – Nothing to disclose
• Loretta T. Lee, MSN, RN, ANP  
  – Nothing to disclose
• Damon E. Patterson, MD  
  – Nothing to disclose
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  – Nothing to disclose
Background

• The Joint Commission (TJC) requires measurement of patient perception of the quality of acute stroke services.

• Currently, there are no valid/reliable instruments specifically constructed for use in acute strokes.
  – Existing instruments are often more focused on “hospitality indicators.”
  – Existing implementation methods often depend on return of a mailed sample of surveys.

• Purpose: As the first phase in the development of an acute stroke-specific instrument, we aimed to understand patient and family perceptions of the most valued indicators of quality Stroke Center services.
Methods

- Five focus group sessions were conducted:
  - 2 family sessions
  - 2 patient sessions
  - 1 combined patient/family session

- Eligibility for participation in a focus session:
  - English speaking
  - Currently hospitalized for acute stroke
  - Zero scores on NIHSS items 1ABC, 9, and 10
  - Hemodynamically stable and physically capable joining a focus group
  - Family focus group members had to be the next of kin/spokesperson for a patient with significant neurologic disability unable to speak for him/herself.
All focus groups were conducted in two parts:

- **Part 1** = Interviews with open ended questions.
  - The same scripted questions were used in all groups.
  - Information was recorded, and data were later transcribed, coded and themes identified.

- **Part 2** = Patients and family members completed a brief questionnaire that asked them to rank a variety of Stroke Center quality indicator items on a scale from 1 (most important) to 10 (least important).
Results

• Participant Sample:
  – 18 participants agreed to be interviewed
    • 10 family members designated as next of kin/spokespersons
      – Mean age 49±7; 60% female
      – 50% African American; 50% White
    • 8 acute stroke patients
      – Mean age 52±8; 50% female
      – 57% White; 30.5% African American; 12.5% Asian/Pacific Islander

• Thematic analysis revealed 3 key themes, with patient responses paralleling family responses.
Theme #1

• **Fast action to diagnose and treat stroke**
  – Rapid, intensely focused, efficient physical action by physicians and nurses.
  – Concurrent clear, honest communication about what has occurred.
  – Non-paternal, dialogue about emergency treatment options.

“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. ‘And if you don’t do this, then this is going to happen. If you do this, then this is what we expect to happen.’ And, I got that; I was given options. No one here drags their feet or delays, they just get it done.”
“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.”
Theme #2

**Genuine Caring**
- An ability to see and accept “my unique needs.”
- To authentically care for patients/families.

“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, its 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.”
“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.”

“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.”
Theme # 3

- **Education to prevent and respond to future strokes**
  - Interdisciplinary staff taking “every opportunity” to teach, test and reinforce new knowledge related to stroke

“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.”
“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.”

“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.”
Part 2: Ranked Responses

1. Stroke nurses and doctors rapidly responding to treat stroke symptoms
2. Having stroke nurses, doctors and therapists take time to listen to you to understand your fears and concerns
3. Having the stroke nurses, doctors and therapists be truthful with you about your condition
4. Having the stroke nurses, doctors and therapists take time to teach you about stroke, its warning signs, risk factors and ways to modify your life style to prevent a future stroke
Part 2: Ranked Responses (continued)

5. Being able to have input into the decisions made about your health care
6. Allowing family members to stay at the bedside whenever they want to be there day or night
7. Having a social worker available to assist you with planning for hospital discharge
8. Having spiritual support during your time in the hospital
9. The comfort of the hospital room
10. The quality of the hospital’s food
Truth – Beliefs

Knowledge

Epistemology

Truth:
- Rapid / efficient treatment required
- Authentic caring is valued.
- Complex disease to prevent and treat

Beliefs:
- Fast action to diagnose / treat stroke
- Genuine caring
- Education to prevent / respond to future strokes
Conclusions

- Patients, and families of disabled acute stroke patients, value Stroke Centers capable of providing acute stroke care with involvement in decision making, provided by practitioners that genuinely/authentically care for them, delivered in an environment that fosters ongoing learning about stroke.

- These elements form the basis of a new instrument for measurement of patient/family perception of Stroke Center quality that is undergoing testing at this time.

STROKE Perception Report (Stroke Treatment, Risk, Outcome, Knowledge, & Education)

Recruiting sites for psychometric testing; if interested, contact: annealex@uab.edu