Catastrophic Strokes: An Ethical Dilemma

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12th Annual
Gulf States Society of Hospital Medicine Conference
2016
No financial conflicts to disclose.
"First, do no harm."

Hippocrates
History at a Glance

- First described by Hippocrates between 460 and 370 BC.
- Described as sudden collapse, a loss of consciousness, a lack of movement and referred to as apoplexy.
- Caused by a humoral imbalance.
- Treatments included enemas and bloodletting.
- Nurses’ main focus was to help patients cope with and adjust to their disabilities.
Stroke Statistics

- Nearly 800,000 individuals have a stroke each year.
- In 2010: Nearly 130,000 deaths
  - Ischemic stroke: 73%
  - ICH: 16%
  - Sequelae to strokes: 13%
  - SAH: 4%
- 20% of patients hospitalized for stroke are discharged to a nursing facility.
- 30% remain permanently disabled.
A 62 year old female

- At 6AM, was at usual normal baseline when spouse went to work. Only PMHX was HTN.
- At 5PM, found by spouse minimally responsive and taken to an outside hospital.
- Noted to be aphasic and flaccid on right with CT showing early evidence of right MCA stroke.
- Not felt to be a candidate for tPA.
A 62 year old female

- Due to lack of Neurology coverage, transferred to our ICU.
- Described as somnolent, following a few commands.
- Close monitoring along with permissive hypertension continued in ICU.
48 hours later

- Mental status still fairly depressed. Would arouse and make some eye contact. Exam consistent with dense expressive and receptive aphasia.
- Noted by nursing staff to show evidence of vital sign instability with transient episodes of HR to 30’s
- NIHSS = 25 at 24 hours; 22 at 48 hours.
Shift Note Excerpt

- **13:20** Dr. Weldon notified of changes in vital signs - Brady in 40s, liable to 100 then 20.
- **13:35** Dr. Weldon at bedside.
- **13:40** Family at bedside.
- **14:05** Dr. Simeone at bedside.
- **14:20** Dr. Weldon in conference with family
- **14:45** 2.5 Versed administered
- **14:46** 2.5 Versed administered
- **14:48** ETT inserted, 24 @ Lip. Color change on c02 detector
A 91 year old female

- EMS was called after the patient had a fall at home and was poorly responsive lying face-down on the floor.
- At baseline, she was vigorous and independent for all activities.
- She had a history of atrial fibrillation and due to recent recurrent nose bleeds prompting visits to the ED, her anticoagulation had been held.
A 91 year old female

- Arrived to ED at 8:35AM on Monday.
- Exam showed severe left hemiparesis, right gaze preference, dysarthria and mildly depressed sensorium (groggy).
- Initial head CT showed NSA.
- Assessed by neurology
- Decision after discussion with family to proceed with thrombolytics.
Timeline-Monday Morning

- 8:35 Arrived to ED
- 8:36 Assessed by EDP
- 8:37 Transported to CT
- 8:55 Neurology at bedside
- 9:19 tPA initiated

- Door to thrombolytic: 44 minutes.
Subsequent Course-2 Weeks Later

- **Physical Therapy**: Mod X 2 for sitting with poor truncal control; Max X 2 for standing.

- **Occupational Therapy**: Total assistance for all ADL’s, making little progress.

- **Speech**: Able to communicate with hand gestures (thumbs up, OK), can write some phrases, oral intake limited although dysphagia flouro found profound oral phase abnormalities but no overt aspiration.
Goals of Care

- NIHSS at 14 days was 17.
- Prior wishes per patient were expressed by some family members as being strongly opposed to aggressive measures if quality of life was poor.
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Level of consciousness</td>
<td>alert</td>
<td>drowsy</td>
<td>stuporous</td>
<td>coma</td>
</tr>
<tr>
<td>2</td>
<td>LOC questions (month, age)</td>
<td>both correct</td>
<td>one correct</td>
<td>incorrect</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>LOC commands (close eyes, make a fist)</td>
<td>both correct</td>
<td>one correct</td>
<td>incorrect</td>
<td></td>
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<tr>
<td>4</td>
<td>Best gaze</td>
<td>normal</td>
<td>partial gaze palsy</td>
<td>forced deviation</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Visual fields</td>
<td>no visual loss</td>
<td>partial hemi</td>
<td>complete hemi</td>
<td>bilateral hemi</td>
</tr>
<tr>
<td>6</td>
<td>Facial palsy</td>
<td>normal</td>
<td>minor</td>
<td>partial</td>
<td>complete</td>
</tr>
<tr>
<td>7-10</td>
<td>Motor (L/R arm + leg)</td>
<td>no drift</td>
<td>drift</td>
<td>can’t resist gravity</td>
<td>no effort against gravity</td>
</tr>
<tr>
<td>11</td>
<td>Limb ataxia (Finger-Nose, Heel-Knee-Shin)</td>
<td>absent</td>
<td>present in 1 limb</td>
<td>present in 2 limbs</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Sensation (pinprick)</td>
<td>normal</td>
<td>partial loss</td>
<td>severe loss</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Best language</td>
<td>no aphasia</td>
<td>mild-mod aphasia</td>
<td>severe aphasia</td>
<td>mute</td>
</tr>
<tr>
<td>14</td>
<td>Dysarthria</td>
<td>none</td>
<td>mild-mod</td>
<td>near to unintelligible or worse</td>
<td>UN intubated/barrier</td>
</tr>
<tr>
<td>15</td>
<td>Extinction and inattention</td>
<td>no neglect</td>
<td>partial neglect</td>
<td>complete neglect</td>
<td></td>
</tr>
</tbody>
</table>
Prognosis after Ischemia Stroke

- Strongest predictors are stroke severity and age of patient.
- NIHSS Score > 22 at 24 hours assoc. with poor prognosis.
- NIHSS Score > 16 at 7-10 days assoc. with high probability of death or severe disability.
- Initial infarct volume on CT or MRI within 72 hours was independent predictor of outcome at 90 days.

Stroke 2012; 43: 2071.
Will she get well?
What are we looking at, Doc?
Is she going to ___________ again?
Trajectory
Source: Murray, S.A. et al

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)
Bio-medical Ethical Principles

- Beneficence-Moral obligation to promote goodness or benefit to the patient.
- Nonmaleficence-Obligation not to harm patients- *Primum non nocere*.
- Justice-What is most fair to the patient and to society. Often difficult to define.
How decisions are made in the absence of directives.

- **Best Interests**
  - Ideally based on patient’s values.
  - Conveyed by family to physicians, but only if the physician asks.
  - Frequently colored by family members emotional needs.
  - “If Mom was sitting in that chair, what would she tell us to do?”

- **Substituted Judgement**
  - Should represent what had actually been said by the patient.
  - Often gets colored by family members interpreting what they thought was meant.
  - “Dad always said not to put him on machines if he was brain dead.”
Errors in Prognostication and Perception
“Withdrawal Bias”

- An early decision to limit treatment or withdraw from aggressive treatment based on an impression that the prognosis is very poor.
- May easily be viewed as a self-fulfilling prophesy.
- Most patients with a survivable stroke die because of withdrawal or withholding of life-sustaining therapy.
- May account for ~40% of observed mortality.
- Remember: “Primum non nocere”.

“Disability Paradox”

- That the definition of a good or acceptable outcome may not be what is expected. Some stroke survivors report satisfying quality of life even in the face of relatively severe functional deficits.
- Patients adapt over time by changing their standards, values and definition of quality of life.
Model of Quality of Life

“Recall Bias”

- Asked to provide substituted judgement, a family member may remember the patient in more optimistic terms:
  - Healthier
  - More Active
  - Less dependent
“Inappropriate Optimism”

- Delay in providing prognostic comments due to reluctance to “give up”.
- A steadfast tendency to “keep going” even when available data suggest a poor prognosis.
- A failure of exploring and fully understanding the patient’s or family’s goals of care.
What defines a poor prognosis?

- A very high probability of death within 3 months.
- In surviving patients, total dependence on others for ADL’s with a lack of meaningful communication 3 months after the stroke.

What are the hard decisions?

- Mechanical ventilation: To withhold it or to withdraw it.
- Placement of tracheostomy.
- Artificial nutrition including surgical placement of a PEG tube.
- Surgical decompression for hemorrhagic or ischemic strokes with life-threatening mass effect.

What do their words mean?

“I want her to get well.”

“I want her to be the way she was before.”
## TABLE 2. IES Scores and Rate of Occurrence of PTSD in Family Members of ICU Patients

<table>
<thead>
<tr>
<th>Category</th>
<th>Patients n (%)</th>
<th>Median IES Score (25–75%)</th>
<th>Patients With PTSD n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All family members</td>
<td>284 (100)</td>
<td>22 (11–34)</td>
<td>94 (33.1)</td>
</tr>
<tr>
<td>Family members involved in patient care</td>
<td>71 (25)</td>
<td>20 (10–29)</td>
<td>17 (24)</td>
</tr>
<tr>
<td>Family members of patients discharged alive from the ICU</td>
<td>228 (80.3)</td>
<td>21 (10–32)</td>
<td>66 (28.9)</td>
</tr>
<tr>
<td>Family felt that not enough time was allowed for information</td>
<td>43 (15.1)</td>
<td>29 (20–39)</td>
<td>20 (46.5)</td>
</tr>
<tr>
<td>Family felt that information was not easy to understand</td>
<td>45 (15.8)</td>
<td>33 (21–39)</td>
<td>24 (53.3)</td>
</tr>
<tr>
<td>Family felt that information was incomplete</td>
<td>95 (33.4)</td>
<td>29 (15–37)</td>
<td>46 (48.4)</td>
</tr>
<tr>
<td>Family members involved in everyday decisions about the patient</td>
<td>69 (24.3)</td>
<td>30 (15–36)</td>
<td>33 (47.8)</td>
</tr>
<tr>
<td>Family members of patients who died in the ICU</td>
<td>56 (19.7)</td>
<td>30.5 (18–38)</td>
<td>28 (50)</td>
</tr>
<tr>
<td>Family members of patients who died in the ICU after end-of-life decisions</td>
<td>50 (17.6)</td>
<td>33 (22–39)</td>
<td>30 (60)</td>
</tr>
<tr>
<td>Family members involved in end-of-life decisions</td>
<td>22 (7.7)</td>
<td>35.5 (31–39)</td>
<td>18 (81.8)</td>
</tr>
</tbody>
</table>

**Definition of abbreviations:** ICU = intensive care unit; IES = Impact of Event Scale; PTSD = post-traumatic stress reaction.

PTSD was defined as an IES score > 30, indicating a high risk of developing post-traumatic stress disorder. Family involvement in decisions about the patient included consent to research, decision to perform tracheotomy, discussions about the appropriate level of care, and discussions about the patient preferences and values and about the patient’s quality of life.

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**Post-traumatic Stress Symptoms**

Risk of Post-traumatic Stress Symptoms in Family Members of Intensive Care Unit Patients

*Am J Respir Crit Care Med; Vol 171. pp 987–994, 2005*
Horns of a dilemma

While ethicists and lawyers contend that withholding and withdrawing treatment have the same moral significance, most family members feel the weight of responsibility differently.

SPIKES

- S = SETTING up the family conference.
- P = Assessing the family’s PERCEPTION.
- I = Obtaining the family’s INVITATION.
- K = Giving KNOWLEDGE and information.
- E = Addressing the family’s EMOTIONS.
- S = SUMMARY and STRATEGY.

The Oncologist 2000; 5: 302-311.
The surprise question

Would I be surprised if this patient died within the next 6 months?
Another Important Question:

How do you see the future?
Suggestions for Approach

- Go very slowly.
- Spend time getting to know the family and letting them get used to you.
- Make sure that you include all of the stakeholders.
- Make recommendations by increment.
- If the discussion is very uncomfortable, back down and don’t keep hammering away at it. You risk losing their trust.
Perceptions of CPR Success

- Respondents prediction of a patient’s survival following in-hospital cardiac arrest with CPR: 72%
- Chance of survival to discharge after in-hospital cardiac arrest treated with CPR:
  - All comers - 18%
  - Neurologically intact – 9%

Code Status Orders and Goals of Care in the Medical ICU. *Chest* - Volume 139, Issue 4 (April 2011)
CPR Outcomes In Hospitalized Patients

Please Note:
We can only show averages. It is impossible to predict whether your results will be positive or negative.

Living to Discharge Neurologically Intact
Living to Discharge Neurologically Impaired
A 62 year old female

- Intubated & on vent for a week.
- PEG placed.
- Sent to LTAC and from there to inpatient rehab unit and from there to SNF.

2 Months after stroke:
- PEG out and eating well.
- Receptive aphasia much improved.
- Expressive aphasia still severe.
- Right arm paralyzed and right leg very weak.
- Stands and pivots but little walking.
- Very frustrated and husband not sure what to do next.
A 91 year old female

- Never on ventilator.
- PEG placed on day 15.
- To inpatient rehab on day 22.
- Discharged home with family and HH and paid caregivers on day 39.
  - Dysphagia still severe but can tolerate some pleasure feeding carefully. Uses PEG.
  - Speech limited usually to single word answers and occasional familiar phrases.
  - Complete left paralysis and transfers to WC require total assistance. Truncal control very poor, cannot sit unassisted.
Concept of time-limited trial (TLT)

- An agreement between clinician and patient/family to use certain medical therapies over a defined period.
- If patient gets better, therapy may continue.
- If patient doesn’t improve or gets worse, may choose to withdraw and palliate.
- If patient outcome is unclear, may renegotiate TLT.

::The END::

Thank you for your Attention!