Palliative Care and Stroke: An Emerging Field

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October 23, 2015
Financial Disclosures

Associate Editor, Neurology Today

Guideline Reviewer, Milliman Guidelines

Boarded in Hospice and Palliative Medicine

No relevant financial relationships exist
Outline

Palliative Care

Palliative Care and Stroke in the Literature

Integration of Primary and Specialty Palliative Care

Palliative Care Version 2.0
**Palliative Care**

*Palliative care* means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
Palliative Care Philosophy

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and nonpalliative healthcare providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and death.
Palliative Care in the U.S.

Prevalence of Palliative Care (2000–2011) in U.S. Hospitals with 50 or More Beds

- **Programs (#)**
- **Prevalence (%)**

Year | Programs | Prevalence |
--- | --- | --- |
2000 | 658 | 24% |
2001 | 805 | 30% |
2002 | 946 | 36% |
2003 | 1,082 | 40% |
2004 | 1,150 | 45% |
2005 | 1,265 | 50% |
2006 | 1,357 | 55% |
2007 | 1,373 | 55% |
2008 | 1,486 | 59% |
2009 | 1,568 | 63% |
2010 | 1,635 | 66% |
2011 | 1,692 | 67% |
2014 (projected) | 2,023 | 84% |
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Palliative Care in Stroke and the Literature

Palliative Care Consultations in Hospitalized Stroke Patients (J Palliat Med 2010)

Stroke Patients (n=1551)
- 1450 Ischemic
- ICH
- SAH
- SDH

Palliative Care Consults (n=1603)
- 1502 Cancer
- CHH/COPH
- Dementia
- Other

101
### Demographics of Stroke Patients with and without a Palliative Care Consult

|                        | PC Consult  
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td></td>
<td>n = 101</td>
</tr>
<tr>
<td>Mean age, years</td>
<td>72.4</td>
</tr>
<tr>
<td>Male, %</td>
<td>48</td>
</tr>
<tr>
<td>Non-white, %</td>
<td>11</td>
</tr>
<tr>
<td>Inpatient death, %</td>
<td>79</td>
</tr>
<tr>
<td>Median LOS</td>
<td>14</td>
</tr>
</tbody>
</table>
|                        | No Consult  
|                        | n = 1450    |
| Mean age, years        | 64.7        |
| Male, %                | 50          |
| Non-white, %           | 25          |
| Inpatient death, %     | 11          |
| Median LOS             | 5           |
Of these 101 consults, how many involved goals of care discussion around artificial nutrition and feeding tubes?

A. 5

B. 22

C. 47

D. 71

E. 94
## Goals of Care Discussion in Stroke Patients with PC Consult

<table>
<thead>
<tr>
<th>Topic Area</th>
<th>N = 101</th>
</tr>
</thead>
<tbody>
<tr>
<td>Artificial nutrition/feeding tubes</td>
<td>47</td>
</tr>
<tr>
<td>Natural nutrition</td>
<td>20</td>
</tr>
<tr>
<td>Tracheostomy</td>
<td>18</td>
</tr>
<tr>
<td>Intravenous fluids</td>
<td>14</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>12</td>
</tr>
<tr>
<td>Neurosurgical procedures</td>
<td>8</td>
</tr>
</tbody>
</table>
FIG. 1. Mode of in-hospital death of palliative care stroke patients. Other medical conditions contributing to death or discharge to hospice included cancer (4 cases), myocardial infarction (1 case), pulmonary embolism (1 case), withdrawal of hemodialysis (1 case), and chronic progressive neurologic dysfunction (1 case), multiple causes, indeterminate (8 cases).
Conclusions

Stroke patients with a PC consult differ from other consults seen on a hospital PC consult service.

Stroke patients were more often consulted for goals of care/end-of-life decisions and less for symptom management.

Inpatient stroke mortality was higher than other diagnoses seen by the PC service – and most common mode of death was compassionate extubation.

The majority of dying stroke patients (74%) and those discharged to hospice (57%) did not have a PC consult.
Outline

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Integration of Primary and Specialty Palliative Care

Palliative Care Version 2.0
Primary versus Specialty Palliative Care
(NEJM 2013; 368:1173)

**Primary Palliative Care**

- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code Status

**Specialty Palliative Care**

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
- Assistance in addressing cases of near futility
AHA/ASA Scientific Statement

Palliative and End-of-Life Care in Stroke
A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

Endorsed by the American Association of Neurological Surgeons and Congress of Neurological Surgeons, The American Academy of Hospice and Palliative Medicine, American Geriatrics Society, Neurocritical Care Society, American Academy of Physical Medicine and Rehabilitation, and American Association of Neuroscience Nurses

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Richard D. Zorowitz, MD, FAHA; on behalf of the American Heart Association Stroke Council,
Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology

Background and Purpose—The purpose of this statement is to delineate basic expectations regarding primary palliative care competencies and skills to be considered, learned, and practiced by providers and healthcare services across hospitals and community settings when caring for patients and families with stroke.

Methods—Members of the writing group were appointed by the American Heart Association Stroke Council’s Scientific Statement Oversight Committee and the American Heart Association’s Manuscript Oversight Committee. Members were chosen to reflect the diversity and expertise of professional roles in delivering optimal palliative care. Writing group members were assigned topics relevant to their areas of expertise, reviewed the appropriate literature, and drafted manuscript content and recommendations in accordance with the American Heart Association’s framework for defining classes and level of evidence and recommendations.

Results—The palliative care needs of patients with serious or life-threatening stroke and their families are enormous: complex decision making, aligning treatment with goals, and symptom control. Primary palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of illness. To optimally deliver primary palliative care, stroke systems of care and provider teams should (1) promote and practice patient- and family-centered care; (2) effectively estimate prognosis; (3) develop appropriate goals of care; (4) be familiar with the evidence for common stroke decisions with end-of-life implications; (5) assess and effectively manage emerging stroke symptoms; (6) possess experience with palliative treatments at the end of life; (7) assist with care coordination, including referral to a palliative care specialist or hospice if necessary; (8) provide the patient and family the opportunity for personal growth and make bereavement resources available if death is anticipated; and (9) actively participate in continuous quality improvement and research.

Conclusions—Addressing the palliative care needs of patients and families throughout the course of illness can complement
<table>
<thead>
<tr>
<th>Table 1. Primary Palliative Care Skills for the Stroke Specialist</th>
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</thead>
<tbody>
<tr>
<td><strong>Primary Stroke Palliative Care Skills</strong></td>
</tr>
<tr>
<td><strong>Pain and symptoms</strong></td>
</tr>
<tr>
<td>Recognize early signs of pain, depression, anxiety, delirium</td>
</tr>
<tr>
<td>Basic symptom management skills</td>
</tr>
<tr>
<td><strong>Communication skills</strong></td>
</tr>
<tr>
<td>Communicate with empathy and compassion</td>
</tr>
<tr>
<td>Authentic and active listening</td>
</tr>
<tr>
<td>Narrative competence to elicit the patient’s story</td>
</tr>
<tr>
<td>Effectively elicit individual treatment goals (see Goals of care)</td>
</tr>
<tr>
<td>Effectively share information with the patient and family using terms they understand</td>
</tr>
<tr>
<td>Communicate prognosis for quantity and quality of life</td>
</tr>
<tr>
<td>Provide anticipatory guidance regarding illness and treatment trajectories</td>
</tr>
<tr>
<td>Develop consensus for difficult decisions in a way that is sensitive to the patient’s/family’s preferred role of decision-making</td>
</tr>
<tr>
<td>Identify and manage moral distress among interdisciplinary team members</td>
</tr>
<tr>
<td><strong>Psychosocial and spiritual support</strong></td>
</tr>
<tr>
<td>Identity psychosocial and emotional needs of patients and families</td>
</tr>
<tr>
<td>Identify needs for spiritual or religious support and provide referral</td>
</tr>
<tr>
<td>Access resources that can help meet psychosocial needs</td>
</tr>
<tr>
<td>Practice cultural humility</td>
</tr>
<tr>
<td><strong>Goals of care</strong></td>
</tr>
<tr>
<td>Help family establish goals of care based on patient and family values, goals, and treatment preferences</td>
</tr>
<tr>
<td>Willing and able to engage in shared decision-making and adapt shared decision-making approach to patient and family preferences</td>
</tr>
<tr>
<td>Incorporate ethical principles in communication and decision-making</td>
</tr>
<tr>
<td><strong>End-of-life care</strong></td>
</tr>
<tr>
<td>Emphasize nonabandonment and provide continued emotional support through the dying process for patients and their families</td>
</tr>
<tr>
<td>Provide anticipatory guidance regarding the dying process for patients and their families</td>
</tr>
<tr>
<td>Facilitate bereavement support for family members</td>
</tr>
</tbody>
</table>

*Cruetzfeldt C, et al. Stroke. 2015;46:2714*
Integrating Palliative Care

- Enhanced patient and caregiver understanding of disease, treatment, and prognosis
- Enhanced shared decision making based on patient values, preferences, and goals
- Improved patient and caregiver outcomes
- Enhanced patient-clinician communication
- Enhanced individual advance care planning based on benefits, risks, and burdens of care
- Enhanced preparation for end-of-life and associated care
- Bereavement support
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- *Illness trajectory research*
- *Evidence-based, “preference-based” decision making*
- *Incent and innovate goal-driven care*
The Fourth Trajectory
(BMJ 2015;351:h3904)

A. Cancer

B. Organ System Failure

C. Dementia/Frailty

D. Severe Acute Brain Injury
Chronic Stage “Resetting”

Survivors get a reset and are subsequently vulnerable to initiating any of the trajectories depending on their clinical course.

- Short period of decline
- Chronic illness with intermittent serious episodes
- Prolong dwindling
Severe Stroke

Severe Acute Brain Injury

Function

High

Building trust in crisis (1)

Prolonged survival, adaptation; Chronic illness (3)

Shared treatment decisions (2)

Low

End-of-Life Care (4)

Time

Death
Implications for Health Care Systems

• Health care systems prepared for early deaths and prolonged survival
• Measuring and improving the quality of preference-based care
• Palliative care, planning and decision making, and safety during transitions.
• As we move toward creating a high-value health care system, incentives for better informed physician and patient decision-making process must be a cornerstone of this system
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Severe Stroke

Admit to Hospital

- Effective and Safe Care
  - Get with the Guidelines
  - Therapeutic Hypothermia

- Preference-Sensitive Care

- Supply-Sensitive Care
  - No. of beds
  - Supply of physicians

Many Early Treatment Decisions

“silent epidemic of preference misdiagnosis”
Mulley AG, BMJ, 2012
# Early Treatment Decisions

<table>
<thead>
<tr>
<th>First 1-3 days</th>
<th>First 1-3 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thrombolytic agents</td>
<td>Artificial Nutrition</td>
</tr>
<tr>
<td>Intubation/Ventilation</td>
<td>PEG tube</td>
</tr>
<tr>
<td>Surgical Options</td>
<td>Tracheostomy</td>
</tr>
<tr>
<td>Advance Care Planning/DNR/DNI/Other</td>
<td></td>
</tr>
</tbody>
</table>
Variability in feeding tube insertion practices is large, 2008-11

Hospitals ordered by frequency of feeding tube use
(n = 1,540 hospitals)
... And variation remains large within specific geographies

Frequency distribution by (A) Region, and the four largest (B) States, and (C) Hospital Referral Regions within the sample
What hospital characteristic is associated with a higher risk of being discharged with a PEG tube

A. Lower stroke volume

B. Rural location

C. For profit status

D. Lower intubation use

E. Non-teaching status
Wide variability in feeding tube practices, 2008-11

Patient factors predictive of feeding tube insertion
- Age
- Gender
- Race/ethnicity
- Severity of comorbidity

Hospital factors predictive of feeding tube insertion
- Hospital ownership
- Stroke volume
- Intubation rate
- Minority admission rate

Hospitals ordered by frequency of feeding tube use
(n = 1,540 hospitals)
A Model of Optimal Care

Shared-Decision Making

Benefits/Risks
Outcome

Provider vs Patient/Surrogate

Preference/Values

Aggressive vs palliative care
Withholding/withdrawing treatment
Assist with hospice determination
Shared-Decision Making

Providers

Preference/Values

Overestimate benefits
Underestimate risks
Use of default options
Not all options presented

Patient/Surrogate

Aggressive vs palliative care
Withholding/withdrawing treatment
Assist with hospice determination
Are treatment preferences of stroke patients who die ever ever heard?

**Objective:** To quantify the extent of documentation of preferences for life-sustaining interventions (LSI) in a population-based cohort of ischemic stroke patients who died within 30 days post-stroke in California.

**Design/Methods:** We used the California Office of Statewide Health Planning Patient Discharge Database to identify all adults with ischemic strokes at all California acute care hospitals from December 2006 to November 2007.

**Results/Conclusion:** Among a representative sample of California patients who died within 30 days after an ischemic stroke, less than half (93/198, 47%) had documented discussions about life sustaining interventions.

Maisha Robinson 2015, work in progress
What percent of surrogates rely exclusively on physicians as a source of prognostic information?

A. 2%
B. 10%
C. 25%
D. 40%
E. 60%
F. 80%
What percent of surrogates rely exclusively on physicians as a source of prognostic information?

A. 2%
B. 10%
C. 25%
D. 40%
E. 60%
F. 80%

Crit Care Med. 2010;38:1270-75

The majority of surrogates cited other factors including:

1. Perceptions of the patient's strength of character and will to live
2. Patient’s unique history of illness and survival
3. Surrogate’s observations of the patient’s physical appearance
4. Surrogate’s belief that their bedside presence improves prognosis
5. Surrogate’s own optimism, intuition and faith
Shared-Decision Making

Benefits/Risks
Outcome

Aggressive vs palliative care
Withholding/withdrawing treatment
Assist with hospice determination

Providers

Preference/Values

Patient/Surrogate
Shared-Decision Making

Providers
Structure and Process
Patient/Surrogate
Outcome
Shared-Decision Making

- Feel informed about the options and about the risk, benefits and consequences of the options
- Be clear about what matters most to them for this decision
- Discuss goals, concerns, and preference with their health care providers
- Be involved in decision making

- Informed patient
- Concordance between what matters most to patient and the chosen option
Decision Aids in Serious Illness
Moving what works into practice

- 17 RCTs: 6 for advance care planning and 11 for current treatment options
- Decision aids are acceptable and feasible and can modify patients’ expressed preferences.
- Increase ease of decision making reduce decisional conflict and modify the decisions made.
- No study answered the most important question – are patients who complete such interventions more likely to receive the care that they actually prefer?

JAMA Intern Med 175; 2015:1213
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CMS began publicly reporting 30-day risk standardized stroke mortality in **December 2014**

Mary Rowan

Died May 29, 2010

“....In lieu of flowers, contributions may be made to the Sussman Palliative Care Unit at Strong Memorial Hospital...”

Temporal changes in survival after cardiac surgery are associated with the thirty-day mortality benchmark

Health Services Research 49:5 (October 2014): 1659
An Evolving Measurement Framework

**Existing Measures**
- Dysphagia screen
- Time to thrombolytics – 60
- IV rt-PA by 3.5, treat by 4.5
- VTE prophylaxis
- Antithrombotics
- Anticoag for afib/flutter
- NIHSS reported
- Stroke education
- Rehab considered
- LDL documented
- Statin

**Palliative Care v2**
- Priorities/values documented
- Timing of goals of care discussion
- Informed about decision
- Level of conflict/agreement
The QI Approach

- Design electronic health record changes to facilitate documentation of preferences
- Train clinician in appropriate communication skills
- Provide tools that support patient-centered goals of care discussion
- Develop policies to ensure that these discussions occur with the appropriate clinicians at appropriate time points
Summary

(AHA/ASA Palliative Care Policy Recommendations, forthcoming)

- Provide patients with access to continuous, coordinated, comprehensive, high-quality palliative care provided \textit{concurrently} with specialist-level stroke care;
- Promote well-prepared, empowered individuals and families;
- Customize care to reflect patient and family preferences, as well as the unique situation of each individual;
- Develop and support a skilled, compassionate and responsive healthcare workforce;
- Embed and actualize continual structure and performance assessment based on these principles.
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