

Palliative Care Consultations in Hospitalized Stroke Patients

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Abstract

Objective: To determine the pattern and characteristics of palliative care (PC) consultations in patients with stroke and compare them with the characteristics of nonstroke consultations.

Methods: The palliative care program at Strong Memorial Hospital (SMH) was established in October 2001. SMH is a 765-bed academic medical center with approximately 38,000 discharges. For each consult from 2005 to 2007, we collected demographic, clinical, and service-related information. We explored similarities and differences in patients with different types of stroke, including patients with ischemic stroke, intracerebral hemorrhage, subarachnoid hemorrhage, and subdural hematoma. In addition, we compared these data to the nonstroke patients who had a palliative care consultation during the same time period.

Results: Over the 3-year period from 2005 to 2007, there were a total of 101 consultations in patients with stroke (6.3% of all PC consultations). Of the 101 consultations, 31 were in patients with ischemic stroke, 26 in patients with intracerebral hemorrhage, 30 in patients with subarachnoid hemorrhage, and 14 in patients with subdural hematoma. Patients with stroke who had a PC consult were more functionally impaired, less likely to have capacity, more likely to die in the hospital, and to have fewer traditional symptom burdens than other common diagnoses seen on the PC consultation service. The most common trajectory to death was withdrawal of mechanical ventilation, but varied by type of stroke. Common treatments negotiated in these consultations included mechanical ventilation, artificial nutrition, tracheostomy, and less likely antibiotics, intravenous fluids, and various neurosurgical procedures.

Conclusions: Patients with stroke are a common diagnosis seen on an inpatient palliative care consult service. Each stroke type represents patients with potentially distinct palliative care needs.

Introduction

CONSIDERABLE ATTENTION in stroke has focused on advances in emergent therapies, endovascular interventions, neuroimaging, public awareness, and risk factor control. Continued emphasis on stroke prevention and treatment is needed, as nearly 750,000 individuals suffer a stroke each year; this number will increase as the baby boomers reach the ages of highest stroke risk.¹ Despite advances in treating stroke, death and severe disability remain common outcomes.

In 2004, there were over 150,000 stroke-related deaths in the United States (7% of all deaths). Of these deaths, 80% are due to ischemic stroke, 10%–15% are due to intracerebral hemorrhage (ICH), and 5%–10% are due to subarachnoid hemor-

rhage (SAH) or subdural hematoma (SDH). Of those who survive a stroke, up to 30% are permanently disabled and another 20% require institutional care at 3 months. Despite being the third leading cause of death and the leading cause of adult disability, the palliative care (PC) needs of patients with stroke and their families are not well defined.²

Many of the deaths occur during the acute stages of stroke and, indeed, about 50% of all stroke deaths occur in hospitals.³ It is not yet clear, however, how hospital-based palliative care programs are responding to the needs of stroke patients and their families. Prior research has shown that up to 10% of consults seen on an inpatient palliative care service are in patients with stroke. In one study, stroke was the most common diagnosis among patients with nonmalignant diseases over a 3-year period seen on a palliative medicine service.^{4–6}

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Stroke consults were more often noncommunicative and dysphagic than nonstroke consults, and referrals were often made for advice regarding symptom management, complex decision-making, and artificial nutrition and hydration.^{4,5}

These prior reports, however, either combined stroke with other neurologic conditions or did not distinguish among subtypes of stroke, a potentially important omission given their different causes, clinical pictures, clinical courses, outcomes, and treatment strategies. Here we review the palliative care consultations in patients with different types of stroke during a 3-year period at an academic medical center and compare them with patients who had nonstroke diagnoses (cancer, congestive heart failure, chronic obstructive lung disease, and dementia) during the same time period.

Methods

Study setting

Strong Memorial Hospital (SMH), a 765-bed teaching hospital of the University of Rochester Medical Center, employs 597 graduate medical trainees across 67 training programs. SMH treats 38,000 inpatients, 950,000 outpatients, 86,000 emergency patients, and performs 35,000 surgeries annually. The hospital-based palliative care program began at SMH in October 2001 and has grown steadily over time, providing consultations for over 850 inpatients in 2008. The palliative care team consists of 10 palliative care attending physicians, 2 nurse practitioners, palliative care fellows, social workers, clergy, massage therapist, music therapist, bereavement and research/QA coordinator. During the study period, the hospital has maintained a 12-bed inpatient mixed-use medical and palliative care unit. SMH is a New York State Designated and Joint Commission Certified Stroke Center and has an accredited cerebrovascular fellowship program. The project was approved by the University of Rochester Research Subjects Review Board.

Palliative care database

For each consult, a palliative care consult form is completed by the nurse practitioner, resident physician, fellow, or medical student who is rotating on the service. Standard information collected for each patient includes: date of consult, names of requesting and consulting physicians, reason for consult (symptom control, goals of care, end-of-life planning, other), main underlying diagnosis, symptom burden assessment (none/mild/moderate/severe), capacity to make medical decisions, and performance status as measured by the Palliative Performance Scale (PPS). The PPS is a validated measure to assess and describe a patient's functional level, and also has prognostic value.^{7,8} Reason for consult and underlying diagnosis data are not mutually exclusive and could have more than one response option.

This information has been collected since the inception of the program, and automatically entered into the database via electronically scanned forms using 100% verification beginning in 2005. The data are electronically stored in a password-protected network drive. There is routine quality control of the data including consistency algorithms to check dates and number sequences, and the patient-level data are matched with hospital administrative data to append demographic and hospital-level information to the palliative care dataset.

Defining stroke and merging with the PC database

Using hospital administrative data, we identified all patients discharged from SMH after an acute hospital stay with a principal diagnosis of stroke from January 2005 through December 2007. We defined stroke as those with an ICD-9 discharge principal diagnosis code of ischemic stroke (433.X1, 434.X1), intracerebral hemorrhage (431), subarachnoid hemorrhage (430), or subdural hematoma (432.1).⁹ We did not include patients with traumatic hemorrhages of the brain (853.0X, 853.1X, 852.2x, 852.3x, 852.0X, 852.1X, 432.9). Using patient medical record numbers common to both databases, we merged the palliative database with our hospital administrative data and identified all patients with an acute hospital admission who had a principal diagnosis of stroke and a palliative care consult. In addition, we also identified those patients with stroke as defined above during the study period who did not have a palliative care consult.

Defining the characteristics of the stroke population

We compared patients with stroke to patients with (1) cancer, (2) congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), and (3) dementia who had a palliative care consult during that time period. The nonstroke diagnoses were obtained from the main underlying diagnosis entered on the palliative care consult form. We collapsed the diagnostic categories of CHF and COPD, since significant numbers of patients had both listed as comorbid conditions. We compared demographics, length-of-stay, reason for the consult, symptom burden, performance status, and percent with capacity. In addition, we compared demographics, length-of-stay, and discharge disposition of patients with stroke who had a PC consult to stroke patients who did not have a consult.

Palliative care by stroke subtype

For patients with a stroke who had a PC consult, we stratified our analysis by stroke subtype (i.e., ischemic stroke, intracerebral hemorrhage, subarachnoid hemorrhage, and subdural hematoma). For each stroke subtype, we calculated the percent of patients who had a PC consult, and compared basic demographics, length of stay and discharge disposition.

Finally, we performed a medical record review of all 101 stroke patients who had a PC consult. Two of the authors performed the chart reviews (J.R. and A.K.) and ambiguous records were resolved by consensus (J.R., A.K., and R.H.). We documented the presence or absence of discussions regarding the following treatments: feeding tubes, tracheostomy, hand feeding/natural nutrition, intravenous fluids, antibiotics, and other surgical procedures. In addition, we determined how many patients died of brain death based on hospital criteria for irreversible cessation of brain function, including the brainstem. In patients who did not die of brain death but died in the hospital or were discharged to hospice, we categorized the antecedent events as follows: terminal extubation to allow a natural death; withhold intubation based on preferences; withhold artificial nutrition based on preferences; unsuccessful attempt at cardiopulmonary resuscitation (CPR); other (e.g., clear medical error, withdrawal of dialysis); and inde-

terminate. Using the Organ Procurement Organization database, we determined how many patients were organ donors.

Statistical analysis

χ^2 was used to compare proportions and *t* tests were used to compare means. All statistical tests were two-sided and *p* values less than 5% were considered significant. All analyses were conducted using SAS software version 9.1 (SAS Institute, Cary, NC).

Results

During the 3-year period from 2005 to 2007, the palliative care service performed 101 consults on hospitalized patients with stroke, which represented about 6.3% of all palliative care consults during that time period. Consults provided during this time frame to stroke patients increased about 25% annually, with 24 patients receiving consults in 2005, 33 in 2006 and 44 in 2007. Palliative care consultations were obtained on average on day 7 (8.9 standard deviation [SD]) for stroke patients, nearly 3 days sooner than for non-stroke patients ($p < 0.001$).

Stroke patients are distinguishable from the general palliative care population in several distinct ways. Table 1 compares consults among patients with stroke to patients with selected other diagnoses including cancer, CHF or COPD, and dementia. Patients with stroke were 10 years older than those with cancer (72.4 versus 62.6, $p < 0.001$) and 10 years younger than those with dementia (72.4 versus 81.8, $p < 0.001$). Stroke patients had the lowest mean PPS scores (20 versus 44 for cancer, 37 for CHF/COPD, and 34 for dementia, $p < 0.05$ for all three comparisons) and experienced the highest inpatient mortality (80% versus 44% for cancer, 51% for CHF/COPD, and 52% for dementia, $p < 0.05$ for all three comparisons). Compared to the other diagnoses, stroke patients were more often referred for end-of-life decisions (33% versus 16% for cancer, 23% for CHF/COPD, 9% for dementia, $p < 0.05$ for all three comparisons) and less often referred for symptoms

management (10% versus 44% for cancer, 22% for CHF/COPD, and 20% for dementia, $p < 0.05$ for all three comparisons). Many stroke patients were unresponsive during the initial symptom assessment exam and thus symptoms were not rated. Palliative care patients who had suffered a stroke more frequently lacked capacity to make or participate in their own medical care decisions (83%), compared to all other diagnostic categories examined in the palliative care population, including dementia patients, some of whom retained at least some decision-making capacity (65%). Only 5 stroke patients in our sample of 101 retained full decision-making capacity.

Palliative care consultations were requested on just 6.5% of all stroke admissions during the study period (101/1551). Stroke patients with a PC consult differed from those hospitalized stroke patients without a PC consult. Stroke patients with a PC consult were 8 years older (72.4 versus 64.7, $p < 0.05$), were less likely to be non-white (11% versus 24%, $p < 0.01$), had longer median length of stays (11.5 versus 5, $p < 0.05$), and were more likely to be discharged to hospice (23/101 [22.8%] versus 52/1451 [3.6%], $p < 0.0001$).

Of the 101 stroke patients who were referred for palliative care consultations, 31 of all consults suffered ischemic stroke (30.7%), 26 experienced an intracerebral hemorrhage (25.7%), 30 were diagnosed with SAH (29.7%), and 14 had a SDH (13.9%). The frequency of palliative consultation, however, differed by stroke type being least frequent in patients with ischemic stroke and most frequent in patients with SAH: ischemic stroke, 31/976 (3.2%); SDH, 14/134 (10.4%); ICH, 26/243 (10.7%); SAH, 30/168 (15.0%).

Table 2 shows the demographics of patients with a PC consult by stroke type. Patients with SAH were 10 years younger than other stroke types and were less frequently female consistent with its known epidemiology. Only rarely were stroke patients who had a PC consult discharged to home or an acute rehabilitation facility (6/101). The data also show that 22.7% (23/101) of patients were discharged to hospice and that the majority of hospice admissions were to

TABLE 1. COMPARISON OF STROKE PATIENTS AND NONSTROKE PATIENTS WITH A PALLIATIVE CARE CONSULT

	Stroke (n = 101)	Cancer (n = 673)	CHF and COPD (n = 255)	Dementia (n = 56)
Mean age, years (SD)	72.4 (13.4)	63.3 (14.3)	71.5 (14.6)	81.7 (10.0)
Male, n (%)	49 (48.5)	349 (56.8)	99 (61.1)	28 (50.0)
Non-white, n (%)	11 (10.9)	129 (19.3)	19 (11.7)	11 (19.6)
Median LOS, days (IQR)	10.0 (13.0)	10.0 (14.0)	15.0 (20.0)	14.5 (16.0)
Inpatient death, n (%)	80 (79.2)	295 (43.8)	130 (51.0)	29 (51.8)
Reason for consult, ^a n (%)				
Symptom management	10 (9.9)	298 (44.3)	55 (21.6)	11 (19.6)
EOL decision-making	33 (32.7)	106 (15.8)	60 (23.5)	5 (9.1)
Moderate/severe symptoms, ^a n (%)				
Pain	5 (5.0)	326 (48.4)	53 (20.8)	11 (19.6)
Dyspnea	4 (4.0)	167 (24.8)	96 (37.6)	7 (12.7)
Nausea	0 (0.0)	93 (13.8)	11 (4.3)	1 (1.8)
Depression	3 (3.0)	106 (15.8)	34 (13.3)	4 (7.1)
Palliative Performance Scale, mean (SD)	19.8 (17.6)	44.1 (20.1)	37.3 (17.6)	33.8 (16.7)
With capacity, n (%)	5 (5.0)	329 (48.9)	87 (34.1)	2 (3.6)

^aNot mutually exclusive.

CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; SD, standard deviation; LOS, length of stay; IQR, interquartile range; EOL, end of life.

TABLE 2. DEMOGRAPHICS OF PATIENTS WITH A PALLIATIVE CARE CONSULT BY STROKE TYPE

	<i>Ischemic stroke</i> (n = 31)	<i>Intracerebral hemorrhage</i> (n = 26)	<i>Subarachnoid hemorrhage</i> (n = 30)	<i>Subdural hematoma</i> (n = 14)
Mean age, years (SD)	75.1	75.3	65.4	75.9
Male, n (%)	17 (54.8)	13 (50.0)	10 (33.3)	9 (64.3)
Non-white, n (%)	6 (19.4)	2 (7.7)	3 (10.0)	0
Median LOS, days (IQR)	10.0 (17.0)	15.0 (17.0)	10.5 (11.0)	10.5 (16.0)
Discharge Disposition, n				
Inpatient death	14	9	26	8
Inpatient hospice	6	9	1	3
Home hospice	2	2	0	0
Skilled nursing home	6	6	2	2
Other ^a	2	1	2	1

^aOther—acute rehabilitation facility, home, other facility.

SD, standard deviation; LOS, length of stay; IQR, interquartile range.

an inpatient facility (19/23) rather than to home hospice (4/23). Patients with SAH were rarely discharged to hospice (1/30) compared to patients with ischemic stroke (8/31) and ICH (11/27).

Figure 1 illustrates that nearly 50% of all stroke deaths in the palliative care population were due to withdrawal of mechanical ventilation and other life sustaining interventions, most commonly occurring in patients with SAH. Deaths due to withholding of interventions (either mechanical ventilation or artificial nutrition) were most common in patients with ischemic stroke (8/22) and ICH (6/20). Brain death only occurred in two patients, one of whom was an organ donor. No patient who received a PC consult underwent an attempt at cardiopulmonary resuscitation. Deaths were occasionally due

to other identifiable causes including withdrawal of dialysis, myocardial infarction, and pulmonary embolus. Review of medical records on patients undergoing PC consultations demonstrated that issues regarding nutrition and hydration were the most commonly discussed topics: artificial nutrition/feeding tubes (47/101), natural nutrition (20/101), and intravenous fluids (14/101). Less common discussion topics included tracheostomy (18/101), antibiotics (12/101), and neurosurgical procedures (8/101).

Discussion

Our data show that stroke patients who had a PC consult differ from other common diagnoses seen on a busy, inte-

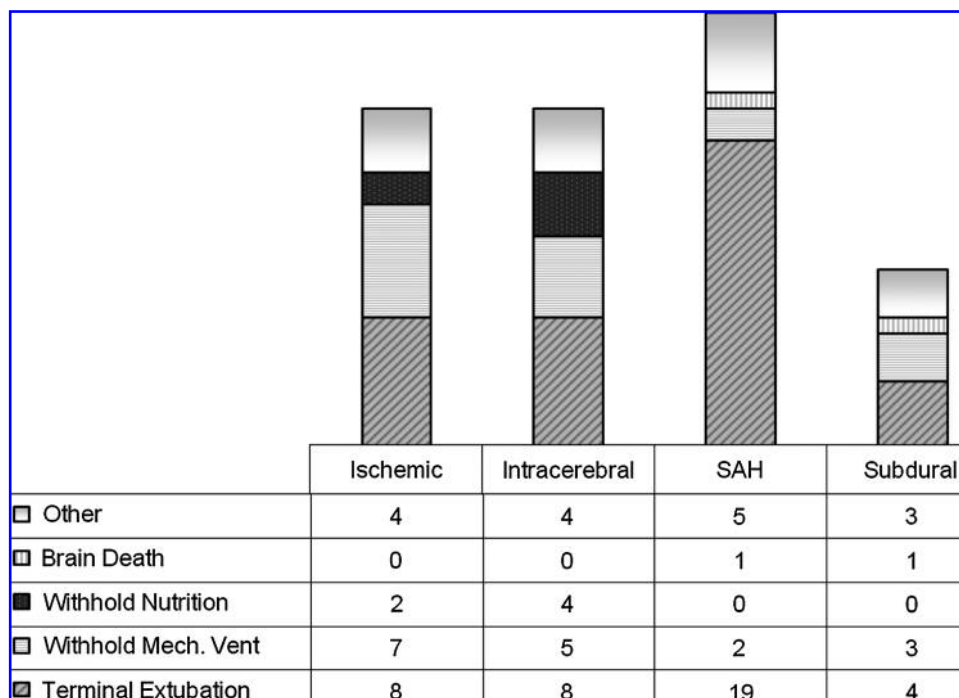


FIG. 1. Mode of in-hospital death of palliative care stroke patients. Other medical conditions contributing to death or discharge to hospice included cancer (4 cases), myocardial infarction (1 case), pulmonary embolism (1 case), withdrawal of hemodialysis (1 case), and chronic progressive neurologic dysfunction (1 case), multiple causes, indeterminate (8 cases).

grated hospital-based palliative care consultation service. Patients with acute stroke were more functionally impaired, less likely to have capacity, more likely to die in the hospital, and to have fewer physical and psychological symptom burdens than in patients with CHF, COPD and dementia. In addition, our findings underscore the palliative care needs of this population, as the majority of stroke deaths and discharges to hospice during the study period were not seen by the PC service (74% and 57%, respectively).

Our data also show that the demographics, prognoses, care patterns, and outcomes differ by stroke type. Although ischemic stroke represents 80% of all strokes and was the most commonly consulted stroke type in this study, the relative frequency of consultations was more common in patients with ICH and SAH. Hospitalized patients with hemorrhagic strokes are known to have higher 30-day mortality rates compared to patients with ischemic stroke (as high as 40% versus up to 15%).¹⁰ Therefore, hemorrhagic stroke patients likely have a greater acute palliative care and end-of-life needs than patients with ischemic stroke.

Inpatient stroke mortality was higher than other diagnoses seen by the PC service. The most common trajectory to death was withdrawal of mechanical ventilation and other life support. Prior studies have shown that predictors of withdrawal of mechanical ventilation include physician prediction of high likelihood of cognitive dysfunction, a potential outcome in severe stroke of all types.^{11,12} The frequency of terminal extubations, however, varied by stroke type and was most common in patients with SAH. It is not yet clear if this is due to differences in the presentation and prognosis of the different stroke subtypes or differences in the patterns of triage in requesting a PC consult.

Our study also showed that of the 23 patients enrolled on hospice, 19 were enrolled on inpatient hospice indicative of a 2-week or less prognosis. Only 1 patient with SAH, however, was enrolled on hospice. This might reflect the short survival often associated with terminal extubation in the neuro-intensive care unit (ICU). For example, in one study of terminal extubations in patients in a neuro-ICU, including patients with stroke, the median time of survival after extubation was 7.5 hours (25% of patients died within 1 hour and 31% lived longer than 24 hours).¹³ Another study showed that of patients with ischemic stroke who died within 30 days of admission, predictors of hospice enrollment were older age, length-of-stay greater than 3 days, female gender, HMO enrollment, and dementia.¹⁴

Stroke is the most common cause of the 15,000 brain-dead potential donors per year. Brain death causes about 0.5% of all deaths, up to 10% of all hospitalized stroke deaths, and up to 20% of deaths in patients admitted to a neuro-ICU.¹⁵ However, only 2 patients fulfilled criteria for brain death in our series, one of whom was an organ donor. Much work remains in defining the proper role of the PC provider at the interface between brain death procedures and organ donation practices (including donation after cardiac death). If one considers organ donation another "last resort option", the PC provider may be in a unique position to assist in such discussions and decisions.

This study has several limitations. First, it is limited to one academic medical center and is mainly exploratory in nature. Thus, the majority of conclusions may not be generalizable to other settings, especially those where palliative care is not

well-integrated into the facility. Second, there are well-recognized limitations in using hospital administrative data but prior research has shown good accuracy of the ICD-9 codes for stroke type compared with medical record abstraction.^{9,16} Finally, the interrater reliability of symptom burden and performance status measurement has not been established in this dataset.

Population demographics and the high case-fatality rates of stroke point to an urgent need for research at the intersection of stroke and palliative care. More descriptive research is needed on current practice patterns, including how those stroke patients who died or were discharged to hospice who did not have a PC consult differed from those stroke patients who did have a PC consult. Well-designed qualitative research is needed on how best to clarify treatment goals when mortality risk is high, impairments are severe, yet both are expected to improve. This should include the further development and validation of stroke clinical prediction rules, as well as methods to assess for the presence and magnitude of various biases that can enter into the decision-making process, including prognosticating illness, estimating benefits and burdens of procedures, and valuation of health states.¹⁷⁻²⁰ Finally, more research is needed on the emerging palliative care needs in those patients and their families who survive the acute event but remain with significant disability and at heightened risk of mortality.

Integrating palliative care in the management of stroke should not be viewed as an alternative to providing treatment and services associated with stroke prevention, treatment, and rehabilitation. Rather, palliative care should be viewed as an important supplement that can optimize preference-sensitive decision-making, minimize the suffering patients and families may experience, and when needed, provide a guide and partner through the dying process. As the numbers of patients with stroke are projected to double with the aging of the baby boomers, there is an urgent need to better understand and optimally integrate palliative care in the management of patients and families.

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Author Disclosure Statement

No competing financial interests exist.

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