

Evaluating an Organized Palliative Care Approach in Patients with Severe Stroke

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ABSTRACT: Background: A recent survey found few guidelines on the provision of palliative care following stroke; none examined the efficacy or results of any such process. The role of the patient's family in decision making and in conflicts with staff has not been evaluated. We sought to formally evaluate the use of locally-developed palliative care guidelines on our Acute Stroke Unit (ASU). **Methods:** We retrospectively examined records of 104 patients who died on our ASU over a two-year period to determine if our existing palliative guidelines were reflected in clinical practice, and to identify conflicts that arose. Data on medical and nursing care, palliative decisions, and medication use were compared to the ASU's existing palliative care guidelines. Family concerns about the palliative process were also reviewed. **Results:** Of patients admitted to the stroke unit, 104 (16% of total admissions) died. Ninety-four (90.4%) of these were palliated; all received routine nursing and comfort care prior to death. Median time from admission to palliation was 3.6 days; median time from admission to death was 8.5 days. Most had vital signs (98.9%), investigations (100%) and non-palliative medications (95.7%) stopped, and had nasogastric feeding (96.8%) and intravenous fluids (87.2%) withdrawn or never begun. Most were treated with morphine (93.6%) and scopolamine (81.9%). Concerns raised by family members centered around hydration and feeding (45.7%), doubts about palliative care (27.8%) and patient comfort (18.2%). **Conclusions:** A formal approach to palliation results in timely decisions regarding end of life care with relatively few conflicts. Further work to address the specific concerns of families is needed.

RÉSUMÉ: Évaluation d'une approche de soins palliatifs organisés chez les patients atteints d'un accident vasculaire cérébral sévère. Contexte : Une enquête récente a montré qu'il existe peu de lignes directrices concernant les soins palliatifs après un accident vasculaire cérébral (AVC) et qu'aucune n'en évaluait l'efficacité ou les résultats. Le rôle de la famille du patient dans la prise de décision et dans les conflits avec le personnel n'a pas été évalué. Le but de notre étude était d'évaluer formellement l'utilisation de lignes directrices mises au point localement concernant les soins palliatifs dans notre unité d'AVC aigu (UAVCA). **Méthodes :** Nous avons examiné de façon prospective les dossiers de 104 patients qui sont décédés à notre UAVCA au cours d'une période de deux ans afin de déterminer si nos lignes directrices concernant les soins palliatifs avaient un effet sur la pratique clinique et pour identifier les conflits qui étaient survenus. Les données sur les soins médicaux et infirmiers, les décisions palliatives et la médication utilisée ont été comparées aux lignes directrices actuelles concernant les soins palliatifs à l'UAVCA. Les préoccupations des familles concernant l'approche palliative ont également été revues. **Résultats :** Cent quatre (16% du total des admissions) des patients qui ont été admis à l'UAVCA sont décédés. Quarante-quatre (90,4%) de ces patients ont reçu des soins palliatifs; tous ont reçu des soins infirmiers de routine et des soins de confort avant leur décès. Le temps médian écoulé entre l'admission et le début des soins palliatifs était de 3,6 jours; le temps médian écoulé de l'admission au décès était de 8,5 jours. La plupart avaient des signes vitaux (98,9%); les évaluations (100%) et les médicaments non palliatifs (95,7%) avaient été cessés et l'alimentation par voie naso-gastrique (96,8%) et par perfusion intraveineuse (87,2%) avait été cessée ou n'avait jamais été débutée. La plupart ont reçu de la morphine (93,6%) et de la scopolamine (81,9%). Les préoccupations exprimées par les membres des familles portaient sur l'hydratation et l'alimentation (45,7%), les doutes concernant les soins palliatifs (27,8%) et le confort des patients (18,2%). **Conclusions :** Une approche formelle concernant les soins palliatifs favorise la prise de décision en temps opportun concernant les soins en fin de vie avec relativement peu de conflits. La façon de répondre aux préoccupations spécifiques des familles devra faire l'objet d'études ultérieures.

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Stroke is the third-leading cause of death in Canada. Approximately 20% of people who have a stroke will die within one month from direct consequences of the stroke or its complications¹. Most patients with severe stroke will die within one month; a significant number will die within ten days of the onset of symptoms^{2,3}. However, few approaches to palliative care have been established in centres which care for these patients, and many of these have not been formally examined⁴. It has been estimated that 8% of hospital inpatients admitted with cerebrovascular disease have some need for palliative care, and

that up to 9.4% of referrals to inpatient palliative care services are for patients who have had a stroke⁴.

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Palliative care models suggest that multiple aspects of the patient's social, spiritual and cultural context be considered when asking the family to make decisions about palliative care⁵. Physical issues and parameters of care must be discussed, including pain control, the role of artificial nutrition and intravenous fluids, and the treatment of complications arising from the stroke⁵. Due to the sudden nature of the event and the need for swift decision-making, families experience high levels of stress, which may lead to conflicts with caregivers due to such issues as feelings of inadequate symptom management or misunderstanding of the goals of palliative care^{4,6}. Studies have suggested that the primary concerns of families during palliative care following acute stroke are the provision of information by health-care staff, management of pain and symptoms, and provision of nasogastric feeding and intravenous fluids⁶. Removing these is often a source of great conflict and disagreement among the family and between the family and caregivers⁷⁻⁹. However, various studies have suggested that artificial feeding and hydration are not beneficial and should be discontinued^{7,10,11}.

In this study, we examined locally-developed palliative care guidelines utilized by the Acute Stroke Unit (ASU) of the QEII Health Sciences Centre (QEII HSC) in Halifax, Nova Scotia, which treats all patients admitted with ischemic stroke or intracerebral hemorrhage, approximately 350 patients annually. By retrospectively examining the charts of patients who died while admitted to the ASU, we hope to understand how the guidelines are translated into clinical management, and to show that an organized approach to management of patients with devastating stroke leads to better end of life care.

MATERIALS AND METHODS

Demographic data was obtained from the acute stroke registry concerning patients who had died while admitted to the Acute Stroke Service of the QEII HSC during the years 2003 and 2004 (n=104). The charts of these patients were examined, and

Table 1: Characteristics of patients

Characteristic	N (total=104)	% of total
Female gender	63	60.6%
Age (median)	80	n/a
Palliative goals of care established	94	90.4%
Stroke type		
Total anterior circulation	34	32.7%
Partial anterior circulation	26	25.0%
Posterior circulation	3	2.9%
Lacunar stroke	5	4.8%
Intracerebral hemorrhage	27	26.0%
Transient ischemic attack	1	1.0%
Uncertain	8	7.7%
Stroke Severity (FSSS)		
0-6	13	12.5%
7-10	90	86.5%
Unknown	1	1.0%

FSSS = functional stroke severity scale. FSSS >7 were classed as severe stroke according to QEII Health Sciences Centre Stroke registry.

information was collected on stroke characteristics including stroke severity as measured by the Functional Stroke Severity Scale (FSSS)¹², physician's orders, investigations, vital signs and nursing care, nasogastric feeding and intravenous fluids, and family discussions and concerns around patient care, as detailed in the medical and nursing progress notes. The ASU makes use of a formalized approach to end of life care, and has developed standardized 'palliative care orders' that deal with all aspects of patient care. The documented time interval and rationale for decisions to move to palliative care were recorded, and the administration of medications, the cessation of feeding and intravenous fluids, and family conflicts (defined as interactions with documented conflict, anger, or hostility as perceived by health-care staff, as judged by the reviewer) and concerns about the provision of palliative care were noted. Charts where no explicit discussions with family were noted were retained in the analysis. Data were stored in tabular form, and descriptive statistics were performed on all quantitative measures to determine trends.

RESULTS

A survey of patients admitted to the ASU in 2003-04 showed that 16% died while in hospital. The majority of these were female; the median age of these patients was 80 years (Table 1). A majority (90.4%) had been placed under palliative care, while 9.6% were receiving active treatment at the time of death. Of the strokes that these patients experienced, most were total anterior

Table 2: Documented interventions and cessation of treatment for patients receiving palliation

Intervention	N (total=94)
Vital signs	
Discontinued	89 (94.7%)
Never ordered	4 (4.3%)
Total	93 (98.9%)
Investigations	
Discontinued	83 (88.3%)
Never ordered	11 (11.7%)
Total	94 (100%)
Non-palliative medications	
Discontinued	90 (95.7%)
Never ordered	0 (0.0%)
Total	90 (95.7%)
Nasogastric feeding	
Discontinued	38 (40.4%)
Never started	53 (56.4%)
Continued until death	3 (3.2%)
Intravenous fluid	
Discontinued	80 (85.1%)
Never started	2 (2.1%)
Continued until death	11 (11.7%)
Medication	
Morphine (regular : 1-10 mg sc q4h prn)	88 (93.6%)
Morphine (breakthrough: 1-5 mg sc q1h prn)	28 (29.8%)
Scopolamine (0.4-0.6 mg sc q4-6h prn)	77 (81.9%)
Acetaminophen (650 mg po/pr q4-6 h prn)	34 (36.2%)
Lorazepam (0.5-2 mg sl q4-6h prn)	20 (21.3%)

Table 3: Families with documented interactions and conflicts with staff regarding specified topics surrounding provision of palliative care

Topics	Interactions (total=104)	Conflicts (total=104)	% of interactions designated conflicts
Provision of information	60 (57.7%)	8 (7.7%)	13.3%
Prognosis of stroke	51 (49.0%)	1 (1.0%)	2.0%
Changing to palliative care	72 (69.2%)	20 (19.2%)	27.8%
Provision of comfort	44 (42.1%)	8 (7.7%)	18.2%
Provision of medication	36 (34.6%)	5 (4.8%)	13.9%
Cessation of feeding/fluids	46 (44.2%)	21 (20.2%)	45.7%

circulation strokes partial anterior circulation strokes or intracerebral hemorrhage. Most strokes tended to be of greater severity, measured as 7 or greater on the FSSS scale¹². This measurement reflects stroke resulting in loss of independence with impairment in three of: swallowing, self-care, ambulation, communication, and comprehension.

Most (93.3%) of patients' families had discussions with staff regarding palliative care, with the median time being 2.2 days after admission (range: 0.0-53.5 d). The change to palliation occurred at a median time of 3.6 days (range 0.0-53.5 days). Patients were charted as unresponsive at a median time of 5.5 days after admission (range 0.0-52.5 days). Death occurred at a median time of 8.5 days from admission (range 0.7-54.2 days) and 2.6 days from the beginning of palliation (range 0.1-25.4 days).

Most patients had vital sign monitoring, investigations, and non-palliative medications discontinued by staff (Table 2). In addition, the majority of patients either were never begun on nasogastric feeding or intravenous fluids, or had them removed as part of their palliative care. The families of a notable minority of patients, however, chose to keep these measures in place after palliative management was begun.

The majority of patients received morphine for control of pain. Most did not use breakthrough morphine for further pain control; however, some required further pain management in addition to regularly scheduled morphine. As well, most patients received scopolamine as part of the management to control bronchial secretions. Acetaminophen and lorazepam were provided as needed to patients requiring antipyretics or anxiolytics; the majority of patients did not require these medications.

Families had interactions with staff most often about concerns over the switch to palliative management, information concerning their loved one's care, and the prognosis for the stroke (Table 3). However, those families who had conflicts and disagreements with the staff had them most often over the issue of cessation of feeding and hydration. Other conflicts concerned disagreement over the change to palliative management, a perceived lack of information, and concern over patient comfort.

DISCUSSION

We believe this is the first study to retrospectively examine a cohort of people who died from acute stroke in order to examine trends in their palliative management. Previous research has examined smaller groups of people in a focused setting. These data agree with previous findings in that those who died of stroke while admitted to the ASU tended to be older people with large ischemic strokes or intracerebral hemorrhages. The clinical management of these patients should take into account the possibility of switching to a palliative care model, particularly as topics such as resuscitation status are discussed with the family.

A high percentage of patients had vitals monitoring and investigations discontinued, in keeping with suggested guidelines for palliative care. It is interesting to note the high number of families who ceded to this advice with little disagreement. It may be that families feel a relative certainty with the diagnosis and prognostic information that is given to them; it is therefore important to quickly give the family an adequate summary of the clinical picture and the rationale for ceasing to monitor vitals and blood variables.

The medications noted in this study were those specifically set out as part of the palliative care protocol in the ASU; in most cases, these are the medications that would be considered for use for pain control, bronchial secretions, agitation, and fever. The number of patients who received these medications may be used to infer that pain control and bronchial secretions are the most common symptoms requiring pharmaceutical management following acute stroke. Agitation and fever, while not occurring in a majority of patients, were notable events requiring symptomatic management. It should be noted that these drugs were only one part of the comfort care received by patients, and that frequent nursing care with a focus on patient comfort was a priority, as was oral and airway care to control excessive secretions.

Of those patients who were switched to palliative care, most had either never had nasogastric feeding started, or had it removed as part of palliation. In a similar fashion, most had intravenous fluids withdrawn or never started. However, nutrition and hydration were one of the topics of greatest conflict

to families; nearly half of all recorded interactions between family and staff described some conflict in this area. It has been suggested that such interventions do little more than prolong the death process with little effect on reducing symptoms or affecting outcome, and that patients with decreased levels of consciousness are for the most part unaware of hunger or thirst⁸. Dehydration, in particular, has been suggested to have an analgesic effect¹¹. It has been suggested that families and caregivers have more difficulty with removing nutrition and fluids because their provision is a highly symbolic act; however, it may be better to stress physical and social contact with the patient as a means of connection, and to pursue adequate oral care and mouth hygiene, rather than continuing to provide nutrition and hydration^{8,11,12}. Although many families had great concern with provision of nutrition and fluids, most families eventually chose to end these interventions. It should be noted that, as per the ASU palliative care protocol, many of the patients for whom these interventions were stopped continued to receive small amounts of food or fluid as requested; these were not enough to provide adequate nutrition or hydration, but they were a means of allowing a measure of support and comfort.

Other conflicts among families included questions about the palliative care model, and in symptom management. There appeared to be a recurring idea that "palliative care" meant "no care", and that pain and discomfort would not be addressed by the staff. All patients received the same standard of nursing care with regards to oral care, turning, bathing, and oxygen therapy, and staff routinely noted their observations concerning the patient's comfort and pain management. This should be communicated to the families at the time of palliative discussion to ensure that the families are clear on what the concept of palliation means and what measures will be taken to improve patient comfort.

The retrospective nature of this study is a limitation in that there was no way to ask the families what their opinions were concerning the care their loved ones received. Details were taken from progress notes and clinical data from the patient charts; while these give a broad picture of the management of these cases, they do not give a complete understanding of the details and emotions surrounding the case. A better way to obtain an accurate picture of the care received by patients with acute stroke would be to speak with the people involved with care and with the families to discuss care and concerns in a prospective study. In the interim, we would suggest that adopting an organized approach toward palliative care in devastating stroke may help to alleviate suffering, and improve the end of life care for these patients, while at the same time provide families with much-needed support and guidance during troubling times. This research identifies areas where conflicts may be anticipated, and where focused discussions with families may be helpful.

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APPENDIX

Standard orders for palliative care on the ASU, QEII Health Sciences Centre, Halifax, Nova Scotia

- These orders may be carried out on any nursing unit.
- No Code.
- Maximum care and comfort.
- Move patient to private room.
- Family may room in with patient.
- May have food and drink by mouth ad lib for comfort.
- Activity as tolerated for comfort.
- Discontinue monitoring vital signs.
- Discontinue all bloodwork and investigations.
- Discontinue all previous medication orders.
- Cancel any outstanding consultations.
- Remove intravenous fluids.
- Remove nasogastric tube.
- Insert subcutaneous needle for morphine and scopolamine.
- Morphine 1 – 10 mg s/c q 2 to 4 hours prn.
- Morphine 1 – 5 mg s/c q 1 hour prn.
- Versed 0.5 – 1 mg s/c q 1 hours prn.
- Ativan 0.5 – 2mg s/l q 4 to 6 hours prn.
- Scopolamine 0.4 – 0.6 mg s/c q 4 to 6 hours prn.
- Tylenol suppository 650 mg pr q 4 to 6 hours prn.

Orders are checked as applicable and a standardized form is placed on the chart. Other medications/interventions may be ordered as felt appropriate.

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