Background and Purpose—The determinants of satisfaction for families of acute stroke patients receiving palliative care have not been extensively studied. We surveyed families to determine how they perceived palliative care after stroke.

Methods—Families of patients palliated after ischemic stroke, intracerebral, or subarachnoid hemorrhage were approached. Four weeks after the patient’s death, families were administered the After–Death Bereaved Family Member Interview to determine satisfaction with the care provided.

Results—Fifteen families participated. Families were most satisfied with participation in decision making and least satisfied with attention to emotional needs. In stroke-specific domains, families had less satisfaction with artificial feeding, hydration, and communication. Overall satisfaction was high (9.04 out of 10).

Conclusions—Families of patients receiving palliative care at our institution showed generally high satisfaction with palliation after stroke; specific domains were identified for improvement. Further study in larger populations is required.

Key Words: palliative care ■ personal satisfaction ■ stroke

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roke is the fourth-leading cause of death in the United States; ≈20% of patients die within 1 month of stroke onset.2 Palliative care is comprehensive care to control pain, provide comfort, improve quality of life, and manage patients and families’ physical, social, psychological, or spiritual needs during advanced illness.3 The importance of palliative care after stroke has been increasingly recognized.4–9 After stroke, family members must make decisions about palliation in a short time, but their experiences have not been well examined. In this prospective cohort, we quantitatively studied experiences of families of patients palliated after acute stroke.

Methods

Patients were recruited from the neurology and neurosurgery services of our institution during 1 year (fiscal 2010). Patients were included if admitted with ischemic stroke or nontraumatic intracerebral/subarachnoid hemorrhage. Exclusion criteria included admission to other services, traumatic hemorrhage, and primary diagnoses other than stroke, inability of next-of-kin to communicate in English, or age <18 years. Criteria were disseminated to treating teams, who identified patients and asked families for permission to be contacted by investigators. Informed consent was obtained, after which demographic information was collected from patient records. The study protocol was approved by the local Research Ethics Board.

Four to 6 weeks after the patient’s death, next-of-kin were contacted by telephone and interviewed using the Death-in-Hospital format of the After–Death Bereaved Family Member Interview, a validated questionnaire developed for palliative research.10 The questionnaire, resource guide, and statistical methodology are available online (http://www.chcr.brown.edu/ppec/toolkit.htm). Satisfaction is evaluated across several domains (physical comfort/emotional support, provision of information/encouragement of shared decision making, focus on patient needs, encouragement of advanced care planning, attending to the family, and coordination of care). Questions are weighted by group. Each is scored from 0 to 1; higher scores represent less satisfaction. Overall satisfaction is also measured on a scale of 1 to 10; higher scores represent greater satisfaction.10 Pilot nonvalidated questions were asked about nasogastric feeding, intravenous fluids, and communication with aphasic patients, and scored similarly to validated questions (see online-only Data Supplement).

Sample size was based on an estimated 100 deaths because of stroke per year in our institution, anticipating that 50% of dying patients would be captured by the study, and a 30% to 40% response rate to the survey. Statistical analysis of the questionnaire used methods described in the initial publication.10

Results

During the study period, 80 patients died of stroke; 27 were identified as candidates and 15 families participated (55% response rate). Patient and respondent characteristics are described in the Table. Median age was 86 years, and median National Institutes of Health Stroke Scale score was 20. Power of attorney for healthcare was assigned in 80.0% of patients;...
less than half (46.7%) had an advanced care directive. Median time from admission to discussion of palliation was 28.5 hours; admission to palliative care was 68 hours. Median time from palliation to patient death was 121 hours. Most (93.3%) had intravenous hydration stopped as part of palliative care, and nasogastric feeding was avoided or discontinued in all patients.

Satisfaction was highest with treatment of pain and dyspnea, but was lower with treatment of anxiety and depression. Satisfaction with other aspects of care was consistent across all domain scores (Figure 1). Families were most satisfied with provision of information and facilitated decision making, but less satisfied with attention given to family needs and coordination of care. Families had less satisfaction with nasogastric feeding, intravenous hydration, and communication.

Satisfaction with the overall process was high (9.04/10) (Figure 2). Satisfaction was the highest with communication, provision of respectful care, and provision of dignity.

**Discussion**

To our knowledge, this is the first study that has used a validated tool to measure family satisfaction quantitatively after palliative care in acute stroke. We found that family satisfaction with palliative care was high, and most domains measured were similar in satisfaction scores. Most families were satisfied with analgesia, but less satisfied with the control of symptoms of anxiety and depression. There was less satisfaction with care given to needs as a family, privacy, and provision of information. Satisfaction with issues about parenteral nutrition, intravenous fluids, and communication with aphasic patients was low compared with other domains. On overall satisfaction scores, symptom control for patients and provision of emotional support to families were identified as areas for improvement.

Previous studies show that palliative care helps families feel that patient needs are met.11 In 1 study, excellent care was associated with adequate nursing assistance, family involvement with decision making, respecting patient dignity, and being told when death was imminent.7 Other areas of concern include providing adequate information to families, and control of patient symptoms.3,5 Our study confirms these findings; most were satisfied, but areas for improvement were identified, including symptom control and care for the family, with these domains being identified as areas for improvement.

| Table. Demographic/Clinical Data for Patients/Respondents (N=15) |
|-----------------|-----------------|
| Patient age (median) | 86 |
| Men | 8 (53.3%) |
| Ethnicity |
| White | 14 (93.3%) |
| Inuit | 1 (6.67%) |
| Educational level |
| Less than high school | 4 (26.7%) |
| High school or above | 11 (73.3%) |
| Estimated annual household income |
| <$50,000 | 2 (13.3%) |
| >$50,000 | 10 (66.7%) |
| Unknown | 3 (20.0%) |
| Independent before hospitalization | 8 (53.3%) |
| Power of attorney (healthcare) assigned | 12 (80.0%) |
| Advanced care planning before stroke | 7 (46.7%) |
| Stroke type |
| Ischemic | 10 (66.7%) |
| ICH/SAH | 5 (33.3%) |
| Median NIHSS | 20 |
| Median time for care milestones, d |
| Admission to discussion of palliation | 1.2 |
| Admission to palliation | 2.8 |
| Stroke onset to death | 9.9 |
| Palliation to death | 5.0 |
| IV fluids stopped | 14 (93.3%) |
| NG feeding stopped/never started | 15 (100%) |
| Respondent relation to patient |
| Child | 13 (86.67%) |
| Spouse | 1 (6.67%) |
| Friend | 1 (6.67%) |

ICH indicates intracerebral hemorrhage; IV, intravenous; NG, nasogastric; NIHSS, National Institutes of Health Stroke Scale; and SAH, subarachnoid hemorrhage.
The cessation of artificial hydration and feeding are contentious, coinciding with our finding in this cohort of lowered satisfaction with these issues. The discussion of artificial feeding and nutrition with family requires balancing emotional concerns with evidence and guidelines concerning end-of-life care after stroke.

Limitations of our study include the small sample size, the lack of validity of the stroke-specific questions in the questionnaire, and the uncertainty of the generalizability of the study instrument to patients with stroke because it was originally designed for general palliative care research. Nevertheless, this study suggests areas to improve palliative care after stroke. Future studies should develop validated tools to measure satisfaction with care specific to stroke in a broader sample of patients. In the meantime, caregivers can use these findings to help guide their interactions with families while caring for patients dying from acute stroke.

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Disclosures

None.

References

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Supplemental Methods: Non-validated Stroke Specific Questions

These questions were asked in addition to the Death-in-Hospital Format of the After-Death Bereaved Family Member Interview. The questionnaire, resource guide and statistical methodology are available online at the following web address: (http://www.chcr.brown.edu/pcoc/toolkit.htm).

(In that last week/while under care of the hospital), was [PATIENT] receiving tube feeding, though a tube down their nose or directly inserted into their stomach?

[ ] YES  
[ ] NO  
[ ] DON’T KNOW

(In that last week/while under care of the hospital), did (his/her) doctor or the medical staff who cared for (him/her) tell you about tube feeding in a way that you could understand?

[ ] YES  
[ ] NO

(In that last week/while under care of the hospital), did [PATIENT] receive too much, too little, or just the right amount of food to keep them comfortable?

[ ] TOO MUCH  
[ ] TOO LITTLE  
[ ] RIGHT AMOUNT

(In that last week/while under care of the hospital), was [PATIENT] receiving fluids through an intravenous line?

[ ] YES  
[ ] NO  
[ ] DON’T KNOW

(In that last week/while under care of the hospital), did (his/her) doctor or the medical staff who cared for (him/her) tell you about intravenous fluids in a way that you could understand?

[ ] YES  
[ ] NO

(In that last week/while under care of the hospital), did [PATIENT] receive too much, too little, or just the right amount of fluids to keep them comfortable?
[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

(In that last week/while under care of the hospital), was [PATIENT] able to communicate verbally with other people?

[ ] YES
[ ] NO
[ ] DON’T KNOW

(In that last week/while under care of the hospital), did (his/her) doctor or the medical staff who cared for (him/her) tell you about communication in a way that you could understand?

[ ] YES
[ ] NO

(In that last week/while under care of the hospital), how often did [PATIENT]’s doctors make the effort to communicate with (him/her) verbally – always, usually, sometimes or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER