Palliative Care
A Core Competency for Stroke Neurologists

Claire J. Creutzfeldt, MD; Robert G. Holloway, MD, MPH; J. Randall Curtis, MD, MPH

The past 2 decades have seen remarkable advances in our abilities to treat and prevent stroke. Better vascular risk factor control has led to a decrease in stroke incidence by 50% since the early 90s. Improvements in acute stroke care, especially at specialized centers, have led to a decline in overall stroke mortality. Over the past decade, stroke death rate in the United States decreased by one third, and stroke has moved from the third to the fifth leading cause of mortality. If a patient with an acute ischemic stroke presents early enough to the hospital, systems should be in place to appropriately administer tissue-type plasminogen activator within less than an hour of arrival, thereby often doubling their chances of achieving future independence. Some patients may continue on to the angio-suite for mechanical clot retrieval; those who do are twice more likely to be independent at 3 months.

Despite these remarkable advances, only around 5% to 7% of patients with acute ischemic stroke receive tissue-type plasminogen activator. Mechanical thrombectomy is reserved for an even smaller proportion. Although community education may increase the proportion of patients calling for help sooner and mobile CT scanners and prehospital treatment may shorten the time and increase the proportion of patients receiving tissue-type plasminogen activator, for most patients, stroke remains disabling and often deadly. For these reasons, palliative care remains an important part of the stroke care that we deliver, especially for patients with severe stroke.

Here we provide a contemporary review of the literature and offer some recommendations on how stroke providers may integrate palliative care into the care of their patients with severe ischemic or hemorrhagic stroke, focusing on early interactions. Stroke palliative care is fundamental to high-quality stroke care and needs to be a core component of our research, as well as residency and fellowship training.

Palliative Care

Palliative care is an approach to medical care for patients with serious illness. It includes end-of-life and hospice care, but is much broader. Palliative care is not limited to those with a terminal prognosis, but rather is appropriate at any age and at any stage of a serious illness. Palliative care focuses on improving communication about goals of care and maximizing comfort and quality of life of patients and families through the identification, prevention, and relief of pain and suffering in body, mind, and spirit. The past decade has seen a remarkable growth in palliative care; the number of palliative care teams within US hospitals with ≥50 beds has nearly tripled to over 60% since 2000.

The broad scope of palliative care and the complex and multifaceted needs of patients and their families require an interdisciplinary team of health professionals, including physicians, nurses, therapists, pharmacists, spiritual care providers, social workers, and others. Effective communication is fundamental to this team approach.

Multiple professional societies endorse the importance of early integration of palliative care into the care of critically or seriously ill patients, and the recent American Heart Association/American Stroke Association guidelines for the management of stroke patients emphasized the importance of integrating palliative care into the general care of these patients. Early involvement of palliative care specialists in the cancer setting has been associated with improved quality of life, symptom control, increased patient and caregiver satisfaction, more appropriate health resource use, and healthcare savings and has even improved survival. However, palliative care is neither standardized nor established in the acute stroke setting, and guidance is lacking as to the best way to integrate palliative care specialists.

Palliative Care and Stroke in the Literature

Palliative care needs after stroke are common and substantial, but the literature is scarce on the exact nature and the best methods to identify and manage these needs poststroke. The literature on palliative care and stroke focuses largely on end-of-life care and dying with an emphasis on symptom control for the dying and support for family members as they grapple with difficult decisions and bereavement. Only few studies have explored palliative care needs of hospitalized stroke patients who are not actively dying, mostly by...
examining the clinical characteristics of the subset of stroke patients seen by palliative care specialists\textsuperscript{18,20,23–25}. Compared with nonstroke patients receiving palliative care consultations, stroke patients are more often referred to palliative care for end-of-life decisions and less often for symptom management.\textsuperscript{23,24} Stroke patients seen by palliative care specialists are also more functionally impaired, less likely to have decision-making capacity, and more likely to die in hospital.\textsuperscript{21} In addition, many stroke patients and their caregivers report a need for more information about prognosis.\textsuperscript{25} One narrative review identified a large knowledge gap regarding specific palliative care needs of stroke patients and calls for “collaborative research between professionals in specialist palliative care and the stroke communities.”\textsuperscript{20} Finally, the recent American Heart Association/ American Stroke Association guidelines on palliative and end-of-life care in stroke patients provides a detailed overview for stroke providers on palliative care skills, such as communication techniques, goal setting, decision-making, symptom management, and end-of-life care, and emphasizes the importance of palliative care provided at the same time as other evidence-based stroke treatments.\textsuperscript{15}

\section*{Integration of Primary and Specialist Palliative Care}

Palliative care is provided by multiple members of the interdisciplinary care team. Because the role of palliative care has expanded and the demand for early palliative care is increasing across the spectrum of serious illnesses, a model has been proposed that distinguishes primary palliative care (skills that all clinicians should have) from specialist palliative care, which is provided by clinicians who are boarded in palliative medicine and are trained in managing more complex and difficult cases.\textsuperscript{27} The coexistence of primary and specialist palliative care seems especially relevant for patients with severe stroke where palliative care needs are often influenced by highly specialized disease-specific prognostication and treatment options and where aggressive restorative therapy must often occur in close proximity with compassionate end-of-life care.\textsuperscript{28} In addition, the acuity of presentation for acute stroke may act as a barrier to specialist palliative care involvement. Primary palliative care skills that should be expected from stroke providers and therefore taught to Neurology residents and stroke fellows are listed in Table 1.\textsuperscript{29} Mastering their primary palliative care skills will serve the stroke team in several ways: it will strengthen their therapeutic relationship with the patient/family and may minimize fragmentation of care; it will sharpen the stroke team’s awareness of palliative care needs (eg, symptom management and determination of goals of care) and, in a timely manner, help them recognize unmet needs that may benefit from specialist consultation. As with any consultation service, the timing and the degree to which specialist involvement is required will depend on what the primary team is able to provide. Palliative care specialists offer an added layer of support to patients, families, and clinicians; they may be called upon to help manage complex or refractory symptoms or to assist with difficult family meetings; they may provide support with the implications of conflicting goals of care, for transitions toward end-of-life or hospice care, as well as bereavement support.\textsuperscript{27}

A simple assessment tool to identify palliative care needs specific to stroke patients\textsuperscript{18,20} may further enhance the stroke team’s primary palliative care. We have developed a daily checklist that screens for palliative care needs as perceived by the clinicians on daily work rounds (Table 2). This checklist aids the clinical team in recognizing specific needs and use family meetings or other supporting clinicians, such as palliative care specialists, psychologists, and others, to meet those needs. We were able to show that such a tool encourages the team to consider using family meetings and other supporting clinicians, including palliative care specialists, to meet patient and family needs.\textsuperscript{30}

\section*{Palliative Care Specific to Severe Stroke}

Although palliative care may be applicable to all patients and families with stroke, it is particularly relevant for those with severe stroke. With no agreed-upon definition, one way to define severe stroke is by the National Institute of Health Stroke Scale (NIHSS); for example, in the TOAST trial, 12\% of all stroke patients had an NIHSS score of ≥16.\textsuperscript{31} Alternatively, severe stroke can be defined as stroke that is not survivable without aggressive medical or surgical interventions, such as intubation and mechanical ventilation or brain surgery, or in the need for long-term institutional care. This definition includes ischemic strokes, as well as intraparenchymal and subarachnoid hemorrhages. One in 10 stroke patients require mechanical ventilation on admission,\textsuperscript{32} one in 11 patients are discharged from the acute care hospital with a feeding tube,\textsuperscript{33} and one in 5 patients require institutional care at 3 months after the stroke.\textsuperscript{2} Patients with severe stroke, by any of these definitions, are at high risk for early mortality, but also have the potential for considerable recovery and prolonged survival. Among those with prolonged survival, there is often significant disability, morbidity, and several troubling symptoms,\textsuperscript{34} suggesting a high degree of palliative care needs. In addition, severe stroke patients often lack the capacity to participate in medical decision-making, requiring the involvement of surrogate decision-makers. These surrogate decision-makers, generally family members, are often placed in the position of assisting with decision-making in the context of substantial prognostic uncertainty and often have their own palliative care needs.

The decision to withdraw life-sustaining treatment is the most common cause of death after acute stroke.\textsuperscript{35,36} Surrogate decision-makers actively involved in shared decision-making can experience tremendous stress, and this stress—often measured as symptoms of anxiety, depression, and post-traumatic stress disorder—can be lessened by clinician communication and behaviors.\textsuperscript{37} Despite the importance of palliative care for patients with severe stroke, little guidance exists regarding best practices for integrating palliative care into the care of these patients for whom withdrawal of life-sustaining treatment is considered, resulting in dramatic variability in care.\textsuperscript{38}

\section*{Palliative Care Specific to Acute Stroke}

The time period immediately after stroke represents an important opportunity for primary palliative care. The first encounter between the stroke team and their patients is typically in the context of a crisis. For many patients, the acuity
of neurological devastation comes with a brief time window for the potential to reverse the injury, forcing an aggressive coordinated approach, and rapid treatment decisions. This fast-paced, chaotic environment is wrought with hope and disappointment, relief and anxiety. As options for thrombectomy, mechanical ventilation, craniotomy, or ventriculostomy present themselves, stroke providers need to build a trusting relationship with patients and their families before engaging in shared decisions. Some treatments in the emergency setting may not require consent, but when the optimal treatment option depends on how the patient might value the potential benefits, risks, and consequences associated with those options, effective and compassionate communication is essential. Providing information in the most accurate and sensitive way also requires an assessment of the patients’ or families’ preferred method for receiving information and making decisions. Family members vary as to how detailed they want information about prognosis. In addition, some patients and families desire an active role in the decision-making process, whereas others prefer that the physicians take more responsibility for decisions.39,40 Stroke specialists need basic skills in assessing family members’ preferences and providing sensitive patient- and family-centered communication that incorporates cultural humility and adheres to medical ethical principles (Table 1).

### Establishing Individual Treatment Goals

To identify the most appropriate, patient-centered treatment decisions, an accurate diagnosis of patient preferences is important. Different people place different values on predicted future health states and potential trade-offs. Unfortunately, however, most people do not have a predefined set of preferences specific to each possible outcome, and, even if they do, these preferences are often unknown to their family and physicians. In addition, patients with severe stroke typically lack capacity to participate in medical decision-making. Instead, a patient’s preferences need to be explored by gathering information from available sources, including through a narrative approach, that is, by developing the patient’s story.41 Neurologists are highly skilled medical detectives because they ask pertinent questions, recognize important symptoms, and identify specific syndromes. As we integrate primary palliative care into our practice, we need to refine our narrative

### Table 1. Primary Palliative Care Skills for the Stroke Specialist

<table>
<thead>
<tr>
<th>Primary Stroke Palliative Care Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain and symptoms</td>
</tr>
<tr>
<td>Basic symptom management skills</td>
</tr>
<tr>
<td>Communication skills</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>Psychosocial and spiritual support</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>Goals of care</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>End-of-life care</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>

### Table 2. Palliative Care Needs Checklist

<table>
<thead>
<tr>
<th>Unmet Palliative or Supportive Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does this patient have pain or distressing symptoms?</td>
</tr>
<tr>
<td>□ YES □ NO, details: _________________________________</td>
</tr>
<tr>
<td>Do patient and/or family need social support or help with coping?</td>
</tr>
<tr>
<td>□ YES □ NO, details: _________________________________</td>
</tr>
<tr>
<td>Do we need to (re-)address goals of care or adjust treatment according to patient-centered goals?</td>
</tr>
<tr>
<td>□ YES □ NO, details: _________________________________</td>
</tr>
<tr>
<td>What needs to be done today?</td>
</tr>
</tbody>
</table>

Data derived from Creutzfeldt et al.30
Table 3. An ASK-TELL-ASK Example for Giving Information to a Family Member of a Patient With Severe Stroke

| ASK (stroke neurologist): Before giving information, the provider explores what the patient or family understands about the illness and treatment and assesses their desire for information. This approach encourages an active dialogue, allows the patient/family to shape the direction of the conversation, and helps the provider adjust their information to the individual setting, for example: |
| “What have the doctors told you about what is going on with your loved one and what your loved one’s prognosis and treatment options are?” |
| TELL (stroke neurologist): After eliciting the patient/family’s understanding, the provider frames the information in a way the patient/family understands. Giving a warning shot (“I have difficult news for you”) allows the patient/family to prepare emotionally, for example: |
| “I’m concerned as well. I would like to tell you a little more about what I see is likely to happen down the road, and then I would like to review with you some things that we can do (pause to allow family to absorb information.) First, I am worried that she will get worse…” |
| ASK (stroke neurologist): The second Ask gives the provider the opportunity to explore how well their information was understood and which points may need more explanation. It is important that this not be perceived as testing the patient/family, but rather to avoid any misunderstandings, for example: |
| “I know that was a lot of new information. Who are you going to talk to about this meeting today? To make sure I did a good job of explaining to you, can you tell me what you are going to say to them?” |

Data derived from Back et al.47

Prognosis Communication

Decision-makers appreciate prognostic information early in the course of serious or critical illness, even if this prognostic information is framed with a statement of a high degree of uncertainty,42 yet physicians are often reluctant to provide this information.43 Because prognostic uncertainty is the rule after stroke rather than the exception,44 stroke providers need to communicate effectively and provide anticipatory guidance regarding possible trajectories and issues that patients and family members may soon experience. Anticipatory guidance helps patients and family prepare for anticipated developments, expect complications and plan for potential decisions that may ensue. It is also important to realize that many surrogate decision-makers rely on multiple sources of information to inform their own view of prognosis, not just the physicians’ estimates.45

Observational studies and expert opinion provide some guidance for talking about prognosis. It can be helpful to describe the anticipated best case and worst case scenarios at 3 or 6 months after stroke to help frame the potential outcomes. This is congruent with the palliative care model of balancing a hope for the best with preparing for the worst.46 When communicating prognosis, the stroke provider needs to customize the amount and type of information to what is relevant and meaningful to this particular patient and family member. By effectively assessing the decision-maker’s understanding and exploring the patient’s values, the good communicator shares information in a way that encourages participation. The Ask-Tell-Ask approach involves asking what the patient or family member understands (Ask) before giving the news and information (Tell) and then assessing what the patient or family member understood (Ask) from the information given47 (Table 3). Genuinely shared decisions develop from curiosity and consensus, rather than negotiation and consent.48 The skill of the clinician then lies in developing this consensus and being prepared to provide a corresponding treatment recommendation.

Conclusions

The palliative care needs of patients with severe stroke are immediate and consist of psychosocial support for patient and family, shared decision-making for preference-sensitive treatment decisions, determination of patient-centered goals of care, and pain and symptom management. Early stroke palliative care should be integrated with acute lifesaving and neuro-restorative treatments and should be provided by stroke providers, drawing on the skills of the interdisciplinary palliative care team when these specialists can provide additional support for patients, family members, or clinicians. A narrative approach in the acute setting can be challenging given time constraints, but is essential given the impact that treatment decisions will have on the lives of the patient and their family. Vascular Neurology fellowships need to include palliative care competencies to ensure all providers are proficient in primary palliative care skills (Table 1), as well as effective in triaging identified needs to consulting specialties. Rigorous, multisite evidence-based research is needed to determine best methods for prognosis communication, identifying patient treatment preferences and patient- and family-preferred roles in decision-making and individualizing treatment decisions.

Disclosures

Dr Creutzfeldt received support for article research from the Cambia Health Foundation and the National Institutes of Health (NIH), NINDS Stroke Trials Network Regional Coordinating Stroke Center U10 NS08652501 (PI: David Tirschwell). Dr Holloway consulted for Milliman Guidelines (Reviewer of neurology guidelines) and Neurology Today (Associate Editor). His institution received grant support from the NIH. Dr Curtis has no conflicts of interest specific to this work. His institution received grant support from the Cambia Health Foundation and the National Institute of Nursing Research (R01 NR005226).

References


**Key Words:** acute care ■ end-of-life care ■ ethics ■ prognosis ■ stroke
Palliative Care: A Core Competency for Stroke Neurologists
Claire J. Creutzfeldt, Robert G. Holloway and J. Randall Curtis

Stroke. 2015;46:2714-2719; originally published online August 4, 2015;
doi: 10.1161/STROKEAHA.115.008224
Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2015 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/46/9/2714

Data Supplement (unedited) at:
http://stroke.ahajournals.org/content/suppl/2016/04/07/STROKEAHA.115.008224.DC1

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Stroke can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Stroke is online at:
http://stroke.ahajournals.org//subscriptions/
지난 20년 동안 뇌졸중을 치료하고 예방하는데 필요한 능력에 있어 상당한 발전이 있었다. 뇌졸중의 위험인자에 대한 조절이 잘 이루어지면서, 90년대 초반 이래로 뇌졸중의 발생이 50% 감소하였다.1 특수화된 센터와 같은 급성뇌졸중 치료의 향상으로 뇌졸중의 전체 사망률이 감소하였다. 지난 10년 동안 미국에서 뇌졸중으로 인한 사망률은 1/3으로 감소하였고, 뇌졸중은 주요 사망원인의 세 번째 순위에서 다섯 번째로 변동되었다.2 급성허혈뇌졸중을 보인 환자가 병원에 충분히 일찍 도착할 경우 조직플라스미노겐활성제가 도착 이후 30분 이내에 적절히 투여되어야 하는데, 이는 향후의 뇌졸중으로 인한 독립성의 기회를 배가시켜 줄 수 있다.3,4 몇몇 환자들은 기계적인 혈전제거를 위한 혈관시술을 시행받을 수 있는데, 이를 시행받은 환자의 경우 3개월째의 독립성을 배가시킬 수 있다.5-7

이러한 주목할 만한 발전에도 불구하고 급성허혈뇌졸중을 보인 환자들의 약 5-7% 정도만이 조직플라스미노겐활성제를 투여받고 있다.8,9 기계적 혈전제거술은 혈관 내 혈전을 제거하는 수단으로 만성 뇌졸중 환자에게 적합하지만, 완화의료를 이용할 수 있는 환자들에게 적합하다고 할 수 있다.10,11 완화의료는 치료 목표에 대한 의사소통을 향상시키고, 신체, 정신과 마음의 존재하는 통증 및 고통을 인지하고 예방하고 경감시키고, 환자들과 보호자들의 안락과 삶의 질을 최대화하는 데에 초점을 맞추고 있다. 지난 10년간 완화의료는 괄목한 만한 성장을 보였는데, 미국 내 병원에서 50병상 이상을 갖춘 완화의료팀의 숫자는 2000년 이래로 3배 가까이 증가하여 전체 의료기관의 60%가 이러한 의료팀을 갖추게 되었다.12

완화의료는 과학적인 접근의 지원을 가진 환자들에 의한 의학적 치료에 대한 접근법의 하나이다. 이것은 시간을 보는 환자들의 간호 및 호스피스 의료를 포함하고 있으나, 더 광범위하다. 완화의료는 말기 환자들에게만 국한되는 것이 아니라, 심각한 질환을 가지고 있거나, 단계에 상관 없이 가능할 수 있다.13 완화의료는 치료 목표에 대한 의사소통을 향상시키고, 신체, 정신과 마음의 존재하는 통증 및 고통을 인지하고 예방하고 경감시키며, 환자들과 보호자들의 안락과 삶의 질을 최대화하는 데에 초점을 맞추고 있다. 지난 10년간 완화의료는 괄목한 만한 성장을 보였는데, 미국 내 병원에서 50병상 이상을 갖춘 완화의료팀의 숫자는 2000년 이래로 3배 가까이 증가하여 전체 의료기관의 60%가 이러한 의료팀을 갖추게 되었다.13

완화의료는 의학적 접근의 지원 및 환자들과 보호자들의 복잡하고 다면적인 수요에 대응하여 완화의료는 의사, 간호사, 치료사, 약사, 종교인, 사회사업가 등과 같은 다학제적인 건강관련 전문가들을 요구한다. 효율적인 의사소통은 이러한 팀 접근법에 있어 필수적인 요소이다.

다양한 전문가 및 학회들에서도 이러한 심각한 질병에 걸린 환자들에 의한 의료에 대한 중요성을 강조하고 있으며, 미국심장학회 및 미국뇌졸중학회의 뇌졸중 환자들의 치료에 대한 지침은 이러한 환자들에게 완화의료를 일반적인 치료에 통합하는 것에 대한 중요성을 강조하고 있다.
뇌졸중은 선천적인 위험인자에서 완화의료 전문가의 초기 개입이 삶의 질 향상, 증상조절 향상, 환자 및 보호자의 만족도 증가, 적절한 보건재정의 사용 및 보건해치의 정량적 결과의 상승을 시각시킬 수 있다고 보고되었다. 그러나 완화의료는 극심한뇌졸중과 같은 상황에서의 표준화되어 있지 않고 확립되어 있지 않으며, 완화의료 전문가를 통합할 수 있는 체계적 방법에 대한 안내도 제대로 되어 있지 않다.

완화의료와 뇌졸중에 대한 문헌고찰

뇌졸중 이후의 완화의료에 대한 요구는 흔하고 상당하지만, 이러한 요구가 정확히 어떤 것이 있는지 그리고 이러한 요구를 확인하고 해결하기 위한 가장 좋은 방법은 어떤 것이 있는지에 대한 문헌은 부족하다. 완화의료와 뇌졸중에 대한 문헌은 대부분 임상에 대한 증상조절을 강조하면서 시한부 환자 간호 및 증상에 대한 상담을 강조하고 있으며, 어려운 결과나 사별에 대한 고심이 많은 보호자들에 대한 지원을 중요하게 다루고 있다. 몇 안 되는 연구는 전문가들에 의해 공통된 뇌졸중 환자들 일부에 대한 상담적인 특징들을 조사한 것이다. 완화의료 전문가들은 환자, 가족 및 임상 의료자들에게 한층 더 나은 지원을 제공해 주는데, 이것은 복잡하거나 급성 관리가 어려운 환자들에게 적절한 지원을 제공할 수 있는 기회를 제공하기도 한다. 완화의료 전문가들은 환자, 가족 및 임상 의료자들에게 한층 더 나은 지원을 제공해 주는데, 이것은 복잡하거나 급성 관리가 어려운 환자들에게 적절한 지원을 제공할 수 있는 기회를 제공하기도 한다.

뇌졸중 환자들에게 특수한 완화의료의 수요를 확인하기 위한 단순한 평가 도구도, 여러 연구는 뇌졸중 환자들의 완화의료의 수요를 조사하였다. 이러한 연구들은 뇌졸중 환자들에 대한 요구와 가족들의 요구를 조사한 것이다. 또한 많은 연구들은 뇌졸중 환자 및 보호자들은 환자들에 대한 예후에 대해 더 많은 정보를 필요하다고 보고하였다. 이러한 연구는 뇌졸중 환자들에 대한 요구와 가족들의 요구를 조사한 것이다. 또한 많은 연구들은 뇌졸중 환자 및 보호자들은 환자들에 대한 예후에 대해 더 많은 정보를 필요하다고 보고하였다.

심각한 뇌졸중에 특수한 완화의료

뇌졸중과 완화의료는 암과 같은 임상상황에서 완화의료 전문가의 초기 개입이 삶의 질 향상, 증상조절 향상, 환자 및 보호자의 만족도 증가, 적절한 보건재정의 사용 및 보건해치의 정량적 결과의 상승을 시각시킬 수 있다고 보고되었다. 그러나 완화의료는 극심한뇌졸중과 같은 상황에서의 표준화되어 있지 않고 확립되어 있지 않으며, 완화의료 전문가를 통합할 수 있는 체계적 방법에 대한 안내도 제대로 되어 있지 않다.
아니라 뇌실질내 출혈 및 지주막하 출혈을 포함한다. 10명의 뇌졸중 환자 중에서 한 명의 환자가 입원 시에 기계환기를 필요로 하며, 31개월 중의 한 명이 급성기 병원으로부터 뇌실질내 출혈을 거쳐 11명 중의 한 명이 뇌졸중 발생 3개월 이후에도 입원치료가 필요하다. 퇴원중 환자 중에서 심각한 뇌졸중은 초기에 사망할 확률이 낮은 동시에 상당한 희생의 장기적인 생존 못지 않은 장애로 각각 가지고 있다. 장기 생존 환자들 중에서 도 고도의 환자치료를 필요로 하는 상당한 환자, 이환율 및 다양 한 고통스러운 증상들이 있다. 또한 심각한 뇌졸중 환자들은 종 종 의학적인 의사결정에 참여할 수 있는 능력이 결여되어 잠재적 인 의사결정자의 관여가 필요한 경우가 있다. 이러한 잠재적인 의사결정자는 일반적으로는 가족 구성원들이 되는데, 이들은 상당 한 예후관련 불확실성이라는 환경에서 의사결정을 도와야 하는 위치에 있게 되고 또한 스스로에 대한 환자치료 요구도 있을 수 있다.

생명유지치료를 철회하는 결정은 급성뇌졸중 이후에 사망에 이르게 하는 가장 흔한 원인이다. 공동 의사결정에 능동적으로 관여한 대리 의사결정자의 경우 극도의 스트레스를 경험할 수 있는데, 불안, 우울 및 외상후스트레스 장애와 같은 증상으로 습득되는 메커니즘은 임상의와의 의사소통과 행동을 통하여 경감될 수 있다. 심각한 뇌졸중을 가진 환자들에 대한 완화의료의 중요성이 상당함에도 불구하고 퇴원중 환자들 중에서 수술적 치료 환자들이 있으며, 그러한 환자들은 여러 반도의 적용력이 더 나아질 수 있는 환자들이다. 이와 같이 뇌졸중후의 환자들을 위한 정체성의 의료는 결국 환자들에게 간접적으로 전체가 되는데, 이들은 상당한 잠재적 인 의료자에게 의존하게 되며, 또한 스스로의 의료를 요구하고 있다.

급성뇌졸중에 특수한 완화의료

뇌졸중 발생 바로 직후의 기간의 기간은 일차 완화의료에 대한 중요한 기회에 해당할 수 있다. 뇌졸중 치료팀과 그들의 환자들 사이의 첫 만남은 전형적으로 어떠한 위기의 전개에 있다. 많은 환자들에게 있어 신경학적 위기와 환자에 대한 예민한 손상을 회복시킬 수 있는 잠재적이 있는 시간대에 원인인 경우가 많는데, 이러한 시간대에서는 적극적 협동 치료 및 빠른 치료 결정을 요구하게 된다. 이와 같이 빠르게 진행되는 환경은 희망과 실망, 안도와 불안을 동시에 초래할 수 있다. 뇌졸중 후의 케어, 기계환기, 개 두술 및 뇌실조류술과 같은 치료의 선택으로서 뇌졸중을 치료하 는 사람들은 공동의의결정에 참여하기 이전에 환자 및 보호자들 과의 신뢰관계를 쌓아야 한다. 응급상황에서 어떠한 치료의 경우

Table 1. Primary Palliative Care Skills for the Stroke Specialist

<table>
<thead>
<tr>
<th>Primary Stroke Palliative Care Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain and symptoms</td>
</tr>
<tr>
<td>Recognize early signs of pain, depression, anxiety, delirium</td>
</tr>
<tr>
<td>Basic symptom management skills</td>
</tr>
<tr>
<td>Communication skills</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>Psychosocial and spiritual support</td>
</tr>
<tr>
<td>Identify 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>Goals of care</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>End-of-life care</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>
예후에 대한 의사소통

의사결정자들은 '예후에 대한 정보가 상당한 불확실성에 대한 진술이된다'라는 것을 알고 있다고 할지라도 심각한 질병의 초기에 듣는 예후 정보들은 높이 평가하지만,65 임상 의사들은 종종 이로운 정보를 제공하는 것을 거부한다.66 예후의 불확실성은 예외가 아니라, 뇌졸중이 아니다.67 예후 정보들은 환자와 가족들로 이는 정보를 제공하는 것이 중요하다.68 예후지침은 항상 및 가족들에 대해 상당히 많은 수와 문제들에 대하여 예상하는 지침들을 효과적으로 의사소통할 수 있고 전달할 수 있어야 한다. 예상지침은 환자와 보호자들이 기대되는 호전에 대해 준비할 수 있도록 도움을 주고, 합병 증상을 예상하고 대응할 수 있는 잠재적인 결과에 대한 계획을 세우는데 있어 도움이 되어야 한다. 또한 많은 잠재적인 의사결정 자들이 의사결정의 예상뿐만 아니라 그들 자신들이 가진 예후에 대한 관점을 알기 위해서라도 다양한 종류의 정보들에 상당히 의존적이라는 것을 인식하는 것도 중요하다.69

관찰연구 및 전문가 의견들은 예후에 대한 정보를 수집하고자 합의적으로, 임상 의사들은 종종 이러한 정보를 제공하는 것을 거부한다.66 예후의 불확실성은 예외가 아니라, 뇌졸중이 아니다.67 예후지침은 항상 및 가족들에 대해 상당히 많은 수와 문제들에 대하여 예상하는 지침들을 효과적으로 의사소통할 수 있고 전달할 수 있어야 한다. 예상지침은 환자와 보호자들이 기대되는 호전에 대해 준비할 수 있도록 도움을 주고, 합병 증상을 예상하고 대응할 수 있는 잠재적인 결과에 대한 계획을 세우는데 있어 도움이 되어야 한다. 또한 많은 잠재적인 의사결정 자들이 의사결정의 예상뿐만 아니라 그들 자신들이 가진 예후에 대한 관점을 알기 위해서라도 다양한 종류의 정보들에 상당히 의존적이라는 것을 인식하는 것도 중요하다.69

관찰연구 및 전문가 의견들은 예후에 대한 정보를 수집하고자 합의적으로, 임상 의사들은 종종 이러한 정보를 제공하는 것을 거부한다.66 예후의 불확실성은 예외가 아니라, 뇌졸중이 아니다.67 예후지침은 항상 및 가족들에 대해 상당히 많은 수와 문제들에 대하여 예상하는 지침들을 효과적으로 의사소통할 수 있고 전달할 수 있어야 한다. 예상지침은 환자와 보호자들이 기대되는 호전에 대해 준비할 수 있도록 도움을 주고, 합병 증상을 예상하고 대응할 수 있는 잠재적인 결과에 대한 계획을 세우는데 있어 도움이 되어야 한다. 또한 많은 잠재적인 의사결정 자들이 의사결정의 예상뿐만 아니라 그들 자신들이 가진 예후에 대한 관점을 알기 위해서라도 다양한 종류의 정보들에 상당히 의존적이라는 것을 인식하는 것도 중요하다.69

관찰연구 및 전문가 의견들은 예후에 대한 정보를 수집하고자 합의적으로, 임상 의사들은 종종 이러한 정보를 제공하는 것을 거부한다.66 예후의 불확실성은 예외가 아니라, 뇌졸중이 아니다.67 예후지침은 항상 및 가족들에 대해 상당히 많은 수와 문제들에 대하여 예상하는 지침들을 효과적으로 의사소통할 수 있고 전달할 수 있어야 한다. 예상지침은 환자와 보호자들이 기대되는 호전에 대해 준비할 수 있도록 도움을 주고, 합병 증상을 예상하고 대응할 수 있는 잠재적인 결과에 대한 계획을 세우는데 있어 도움이 되어야 한다. 또한 많은 잠재적인 의사결정 자들이 의사결정의 예상뿐만 아니라 그들 자신들이 가진 예후에 대한 관점을 알기 위해서라도 다양한 종류의 정보들에 상당히 의존적이라는 것을 인식하는 것도 중요하다.69
결론

심각한 뇌졸중을 가진 환자들의 완화의료에 대한 요구는 즉각적이고 환자와 가족들에 대한 정서적인 지지, 선호도에 민감한 치료결정에 대한 공동의사결정, 환자 중심의 치료목표 결정, 통증 및 증상조절 등으로 구성된다. 뇌졸중 환자들에 대한 조기의 완화의료가 급성기의 목숨을 살릴 수 있고 신경을 회복할 수 있는 치료에 통합되어야 하고, 환자, 가족 구성원 및 임상 의사들에 대한 추가적인 지지를 제공할 수 있는 다학제적인 완화의료팀들이 뇌졸중 치료자들에 의한 조기완화의료가 제공되어야 한다. 응급 상황에서의 서술적인 접근법이 시간적 제약과 관련해서는 문제가 될 수도 있으나, 치료결정이 환자들과 가족들의 삶으로부터 영향을 받을 수 있다는 중요성을 감안한다면 이러한 방법은 반드시 필요하다. 신경과 혈관전문 페로우들은 모든 의료제공자들이 일차 완화의료기술(Table 1)에 능숙하고 전문가들과의 상담 시에 필요한 것들을 효율적으로 전달하기 위해서 완화의료에 대한 역량을 향상해야 한다. 예후에 대한 의사소통, 환자의 치료에 대한 선호도 확인, 환자의 치료에 대한 선호도 파악 및 의사결정과 치료에 대한 결정을 개별화함에 있어 환자 혹은 가족들이 신경증으로부터 가능한 최적의 방법을 결정하기 위해 철저하고 다양한 근거중심의 연구가 필요하다.

Disclosures

Dr Creutzfeldt received support for article research from the Cambia Health Foundation and the National Institutes of Health (NIH), NINDS Stroke Trials Network Regional Coordinating Stroke Center U10 NS08652501 (PI: David Tirschwell). Dr Holloway consulted for Milliman Guidelines (Reviewer of neurology guidelines) and Neurology Today (Associate Editor). His institution received grant support from the NIH. Dr Curtis has no conflicts of interest specific to this work. His institution received grant support from the Cambia Health Foundation and the National Institute of Nursing Research (R01 NR005226).

References


---

Key Words: acute care ■ end-of-life care ■ ethics ■ prognosis ■ stroke