Nursing’s Role in Addressing Palliative Care Needs of Stroke Patients

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Although patient survival after stroke has improved, stroke remains a leading cause of death and severe disability. It is the second leading cause of death globally\(^1\) and fifth in the United States.\(^2\) The risk of death in the first 5 years after stroke is \(\approx50\%\), with the greatest risk in the first year.\(^3\) With advances in acute stroke treatment, stroke survivors and their family members are faced with making potentially life-altering decisions in both acute and chronic phases of stroke. Patient and family engagement in decision-making is critical, especially when faced with treatment decisions that may include transitioning from active treatment to a palliative approach to care. Palliative care is an emerging focal area and an important part of stroke treatment to a palliative approach to care. Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems” (WHO Definition of Palliative Care,\(^4\) paragraph 1). Palliative care throughout the illness continuum involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.\(^5,6\) Table 1 includes key elements of palliative care.\(^5\)

Palliative care may be appropriate at any stage of serious or life-limiting illness, regardless of current goals of care. According to an American Heart Association scientific statement, palliative care should be considered for all patients who have suffered a stroke that interferes with daily functioning or will predictably reduce life expectancy or quality of life (Holloway et al,\(^7\) p 1890). Quality of life preferences may be predicated on multiple factors, including prognosis, comorbidities, age, culture, social support, and resources.

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**Essential Aspects of Stroke Palliative Nursing Care**

When interacting with patients and families living with stroke, providing a family-centered approach that optimizes quality of life by anticipating, preventing, and treating distressing symptoms and emotional distress becomes the goal of nursing care.\(^8\) Family-centered care begins with understanding what matters most to patients and their loved ones and, with the palliative care team, building a care plan to achieve the goals they articulate.\(^9,10\) At the heart of the palliative care team are the patient and family; the team should also include physicians, nurses, and other clinicians with expertise in palliative care and stroke, as well as social workers, chaplains, massage therapists, pharmacists, nutritionists, and others as needed for each patient.

Patient and family-centered communication across care settings requires active engagement among patients, families, and the healthcare team\(^11\) and is imperative in the palliative care process.\(^9\) Nurses have a pivotal role in integrating a palliative approach to care for people with advancing chronic, life-limiting conditions, such as stroke, through interpersonal relationships and therapeutic communication with patients and families.\(^12\) Understanding what matters most to patients and their loved ones requires engaging in sensitive conversations. Because they are providing care at the bedside, nurses have opportunities for initiating these focused discussions in the moment that may not be available to other healthcare providers.

Within the growing body of nursing research focused on palliative care and stroke, there are consistent key messages about palliative care needs of stroke patients.\(^13–17\) This research provides suggestions aimed at enhancing quality of life, including relieving pain and other distressing symptoms, integrating psychological and spiritual aspects of patient care, and providing a support system to help patients and caregivers. For example, researchers assessing the palliative care needs of 191 primarily white, acute stroke patients reported moderate to major fatigue and symptom-related problems (eg, pain and headache) or psychological distress (eg, anxiety, low mood, confusion, and loneliness) in over 50% of study participants. Higher levels of dependence, being female, and more comorbidities were predictors of increased palliative care needs. Approximately 25% worried about death and dying, while over 50% were concerned with dependence and disability and expressed significant concern over the burden their stroke
sadness), delirium, and sleep disorders. Research indicates the most common symptoms are dyspnea and pain, while other issues include management of nausea, depression (anxiety/sadness), delirium, and sleep disorders.13,18

Symptom management is one of the most commonly requested services from the palliative care team. The palliative care needs of acute stroke patients and families should be addressed.23 There are several validated tools (eg, Sheffield Palliative Care Profile for Assessment and Referral to Care, 24 Palliative Care Association published a scientific statement on stroke-specific care.7

Table 1. WHO Key Elements of Palliative Care5

| Providing relief from pain and other distressing symptoms |
| Affirming life and regarding dying as a normal process |
| Intending neither to hasten or postpone death |
| Integrating psychological and spiritual aspects of patient care |
| Offering a support system to help patients live as actively as possible until death |
| Providing support to help the family cope during the patient’s illness and in their own bereavement |
| Using a team approach to address the needs of patients and their families, including bereavement counseling |
| Enhancing quality of life, which may positively influence the course of illness |
| Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life |

might place on their support network of family and friends,14; a concern expressed by many stroke survivors.

Most research specifically examining palliative care needs of stroke patients and families focuses on the final hours or days of life and encompasses those whose conditions are advanced, progressive, and incurable. Over the past decade, researchers have identified several prevalent themes related to care of the dying stroke patient, regardless of the care setting. Symptom management is one of the most commonly requested services from the palliative care team. The most common symptoms are dyspnea and pain, while other issues include management of nausea, depression (anxiety/sadness), delirium, and sleep disorders.13,18 Research indicates that patient and family members’ satisfaction with treatment of psychosocial symptoms is lower than that for the treatment of physical symptoms,19 highlighting the need for evidence-based interventions to address this unmet need.

Referrals for consultations may be requested to provide patient and family support and advice on complex clinical decision-making, often related to use of artificial hydration and nutrition toward end of life.19,20 These decisions may cause considerable anxiety for the family if there is inadequate discussion with clinicians about the meaning attributed to withdrawing these care supports.21 To help reduce anxiety associated with withdrawal of active interventions, it is imperative that nurses assure families that core nursing care (eg, oral care, turning, bathing, oxygen therapy, symptom/pain management, comfort, and support) will be maintained. Issues related to communication and information provision between family members and health professionals are also key elements in reducing uncertainty and anxiety in preparing for the end of life.22

Palliative care should be considered early in the care trajectory, but published guidelines and evidence tend to focus on care at the end of life, suggesting a gap in evidence about how palliative care needs of acute stroke patients and families should be addressed.23 There are several validated tools (eg, Sheffield Profile for Assessment and Referral to Care,24 Palliative Care Assessment Tool, and NEST13+25) used to identify palliative care needs, but there is insufficient evidence that their use results in improved patient outcomes.24 Contributing factors may be that results of the assessments are not systematically integrated into the treatment plan or that needed services may not be available.24 Similarly, implementing end-of-life care pathways for patients with stroke is widely recommended as best practice even though efficacy has not been established.21 Research shows that engaging palliative and spiritual care specialists supports high-quality patient-centered services, including decision-making and symptom management for patients and their families at the end of life after stroke.26 Taken together findings suggest that more research is needed on addressing palliative care needs for stroke patients and their families, including understanding the needs of diverse populations.

One way to help minimize questions and anxiety when dealing with uncertain prognoses and complex decisions is to encourage patients and families to engage in advance care planning (ACP), ideally before stroke or other life-threatening illness occurs. Research suggests that <50% of adults have had these conversations with family members and that ACP discussions more frequently occur when patients and families are faced with a serious or life-threatening illness.6,19 During the initial time after stroke, patients and families often struggle with uncertainty around recovery and prognosis. Nurses are ideally situated to provide support in maintaining hope for optimal recovery while identifying and taking advantage of cues, indicating that families may be receptive to initiating ACP conversations.27 Websites, including The Jonas Center for Nursing (http://dyinginamerica.org/) and Begintheconversation.org, provide more information about talking with patients and families about ACP.

Although the evidence base is limited, palliative and end-of-life care standards are being integrated into best practices in many countries, including Canada, Australia, the United Kingdom, and the United States. For example, the Institute of Medicine proposed 12 components for quality palliative and end-of-life care in their report, “Dying in America” (http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx), and the National Consensus for Quality Palliative Care developed “Clinical Guidelines for Palliative Care” (http://www.nationalconsortiumproject.org/guideline.pdf). The American Heart Association published a scientific statement on stroke-specific palliative care, which includes over 50 recommendations in 11 areas (Table 2) for providers and stroke care systems.7

Nurses working directly with stroke patients and their families can promote family-centered palliative care by (1) including patients and families in discussions and decisions about treatments; (2) identifying potential palliative care needs; (2) carefully assessing patients for distress and making recommendations to the care team about symptom management; (3) advocating for referrals to counseling, social services, and spiritual care; (4) updating goals as needs and preferences change; and (4) helping patients and families engage in ACP. The boxed text includes key take-home messages.

It is critical for nurses caring for stroke patients and their families to be familiar with best practice recommendations as well as the emerging body of research on stroke palliative care. These steps can help improve quality of care, optimize
quality of life, and allow patients to live as actively and as well as possible until the end of life.

Table 2. American Heart Association Stroke Palliative Care Recommendation Categories

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<tr>
<th>Recommendation Categories</th>
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<tbody>
<tr>
<td>Provide primary palliative care</td>
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<tr>
<td>Promote and practice patient- and family-centered care</td>
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<tr>
<td>Effectively estimate prognosis</td>
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<tr>
<td>Develop appropriate goals of care</td>
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<tr>
<td>Understand the evidence for common stroke decisions with end-of-life implications</td>
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<tr>
<td>Assess and effectively manage distressing symptoms</td>
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<tr>
<td>Develop experience in palliative treatments</td>
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<tr>
<td>Assist with care coordination, including referrals to appropriate palliative care services</td>
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<tr>
<td>Provide patients and families opportunities for personal growth</td>
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<tr>
<td>Provide bereavement resources if death is anticipated</td>
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<tr>
<td>Actively participate in continuous quality improvement and research</td>
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**Recommendations**

- Consider palliative care early in the care trajectory when indicated.
- Implement family-centered care, including identifying and integrating patient/family preferences into care plan.
- Enhance quality of life by managing distressing symptoms, providing emotional support, integrating spiritual care, and providing a support system for patients and caregivers.
- Assure families that core nursing care (eg, oral care, turning, bathing, oxygen therapy, symptom/pain management, comfort, and support) will be maintained.

**Disclosures**

None.

**References**


**Key Words:** advance care planning • palliative/end-of-life care • nursing • stroke
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Stroke. 2016;47:e263-e265; originally published online November 8, 2016;
doi: 10.1161/STROKEAHA.116.013282
Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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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/47/12/e263

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