

Palliative Care in Critical Access Hospitals

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The United States has 1332 critical access hospitals. These hospitals have fewer than 25 beds each and a mean daily census of 4.2 patients. Critical access hospitals are located in rural areas and provide acute inpatient services, ambulatory care, labor and delivery services, and general surgery. Some, but not all, critical access hospitals offer home care services; a few have palliative care programs. Because of the millions of patients living with serious and life-threatening conditions, the need for palliative care is increasing. As expert generalists, rural nurses are well positioned to provide care close to home for patients of all ages and the patients’ families. A case report illustrates the role that nurses and critical access hospitals play in meeting the need for high-quality palliative care in rural settings. Working together, rural nurses and their urban nursing colleagues can provide palliative care across all health care settings. (*Critical Care Nurse*. 2016;36[1]:72-78)

The media frequently portray hospitals as large facilities filled with health care professionals, including physicians, nurses, respiratory therapists, and others, who perform lifesaving interventions and surgeries in emergency departments and critical care units on a daily basis. Although this depiction of large teaching hospitals located in urban cities across the United States is true, it is not an accurate portrayal of hospitals located in rural communities, where 1 registered nurse might be the only health care professional on duty at a hospital with fewer than 25 beds and a mean daily census of 4.2 patients.¹ The United States has 1332 hospitals that fit these criteria²; these facilities are known as critical access hospitals (CAHs). The Figure shows the distribution of CAHs as of April 2015. In this article, we use a case report³ to illustrate the role that nurses and CAHs play in meeting the need for high-quality palliative care in rural settings.

Critical Access Hospitals

The Medicare Rural Hospital Flexibility (Flex) Program was created by the Balanced Budget Act in 1997 to improve access to rural health care, reduce closures of rural hospitals, and promote holistic care in rural settings. The Flex program provides grants to states to help implement a CAH program, develop rural health networks, assist with quality improvement efforts, and improve rural emergency medical services. CAHs provide rural residents local access to acute inpatient services; ambulatory care; obstetrics, with labor and delivery services; and general surgery. Some CAHs provide critical care services that “fall along a continuum, ranging from care in a unit that resembles a scaled-down version of [intensive care units] in larger hospitals to care in closely monitored medical-surgical beds.”^{4(p116)} Intensive and critical care services provided in CAHs are defined more by the nurse to patient ratio^{4,5} than by the presence of technological equipment (eg, mechanical ventilators or intra-aortic balloon pumps). Not all CAHs offer home care services, and few have palliative care programs.

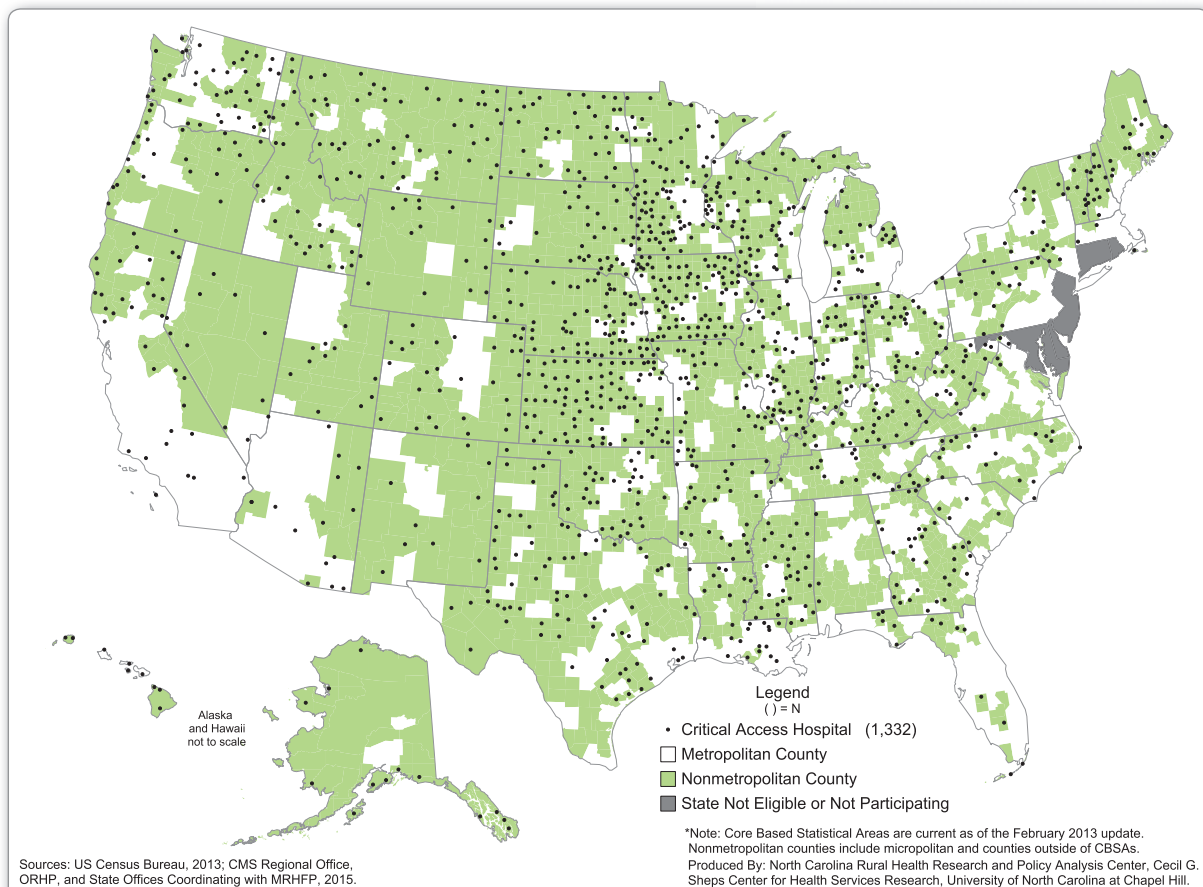


Figure Location of critical access hospitals.⁸ Information gathered through April 15, 2015. Flex Monitoring Team, <http://www.flexmonitoring.org>.

CAHs are required to provide 24-hour emergency services, with medical staff on site or on call and available on site within 30 minutes (60 minutes if certain frontier area criteria are met). If a physician is not on site 24/7, the facility must post a public notice stating that a registered nurse will provide initial treatment until a physician, physician assistant, or nurse practitioner arrives. Additional criteria for CAHs include

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maintaining an annual mean length of stay of 96 hours or less, having a maximum of 25 beds, and having established patient referral and transfer agreements in place with other acute care hospitals.⁶ Rural CAHs may apply to use some of their beds as "swing beds," a status that allows these beds to be used as needed for either acute nursing beds or skilled nursing beds.⁶ This flexibility provides benefits to rural residents, who can receive acute and postacute care services⁷ in their local community. The CAH is not just a safety net for health care, it also provides a sense of pride for rural communities.

According to the 2010 US Census,⁸ approximately 59.5 million people, or 19.3% of the US population, live in rural areas. Many rural residents are elderly and are living with 1 or more serious or life-threatening illnesses, increasing the need for palliative and end-of-life care for this vulnerable population. All health care professionals, especially nurses, are well prepared to provide palliative care in rural and remote settings where distances to

specialty health care services are great and human and fiscal resources are limited.

Case Report

Mr J, an 88-year-old man, lived independently with his wife in a rural farming area; their 4 children lived in different parts of the United States. Mr J's primary care physician was located in town near a CAH with 10 acute care beds and 15 swing beds. A 200-bed hospital with level II trauma certification was 160 miles away. Mr J's medical history included diabetes, 2 strokes, renal insufficiency, and back surgery 8 years before. Mr J's medications included insulin, warfarin sodium, potassium chloride, hydrochlorothiazide, simvastatin, and amlodipine benazepril. After a fall in the barn that injured his left hip, Mr J limited his activity for 1 week before scheduling an appointment with his physician; a radiograph showed no broken bones. Physical therapy was available at the local CAH, and Mr J attended 6 sessions of therapy during a 3-week period. Persistent pain in the left groin and buttocks continued; Mr J was scheduled for magnetic resonance imaging the next time the mobile magnetic resonance imaging truck, which provided imaging services for several CAHs across the state, was in town.

The imaging revealed avascular necrosis of the head of the left femur, and a repeat radiograph showed a crushed femur. An appointment was scheduled with an orthopedic surgeon located 165 miles away. Mr and Mrs J were not familiar with any specialists and were challenged to navigate the complex health care system in the urban center. Appointments and preoperative visits had

Registered nurses working in CAHs must be "expert generalists."

to be rescheduled as initial times were not conducive to

long-distance travel. Initially, Mr J considered surgery but reconsidered that decision when his wife expressed fears about potential complications and her ability to care for him after the surgery. Mr J's family physician assured Mr and Mrs J that surgery was necessary to meet the goal of remaining active and to prevent further disability. A nurse at the local CAH, who attended the same church as the family, provided positive feedback about the hospital where surgery was scheduled. She also encouraged Mr and Mrs J to ask 1 of their children to join them for the numerous preoperative appointments that were necessary.

Once medical clearance was obtained from a cardiologist and a nephrologist, Mr J was scheduled to have his

left hip replaced. Because of his advanced age and frequent cardiac arrhythmias during surgery, Mr J was admitted to the intensive care unit after surgery, a step that optimized his recovery and allowed him to meet his goal of returning to live in his rural farming community.

Critical care nurses focused their care on pain management; pulmonary function; and monitoring cardiac rhythm, blood sugar level, and anticoagulant status. At night Mr J became confused, and his wife became anxious about this change. The nursing staff assured Mr J's family members that confusion was common in hospitalized elders. The nurses implemented strategies to keep him safe and provided his family with emotional support. Physical therapy started on postoperative day 1 as Mr J began to learn how to walk with his new hip. From the intensive care unit, Mr J went to a surgical step-down unit, and a social worker assisted with discharge planning when everyone became aware that Mr J would not be ready to return home to the farm directly from the hospital. Plans were made for a transfer to the local CAH for postacute nursing care.

The nurses at the urban hospital provided the CAH nurses with a well-developed plan of care for a smooth transition from one setting to another. The nursing staff at the CAH consisted of 1 registered nurse who was assisted by a licensed practical nurse and a certified nursing assistant. The director of nursing was available to provide coverage for meal breaks or when patient acuity or periods of increased census necessitated an extra nurse. While caring for Mr J, nurses at the CAH were also responsible for patients admitted to the emergency room and for delivery of medications in the adjoining long-term care unit.

In the CAH, nurses conducted ongoing pain assessments and managed medications to keep Mr J physically active; they also assessed and monitored his renal function and anticoagulant status. Mr J's family was involved in goal setting and communicated well with the nurses. Because the nurses personally knew Mr J, they encouraged him to contact his church pastor and facilitated visits with his grandchildren and his faithful best friend Scout, a border collie. The transfer to a CAH near his home community was helpful for Mrs J, who was relying on neighbors to keep up with chores at the farm while she was staying in the city to be close to her husband after surgery.

After surgery, Mr J spent 10 days recovering at the CAH and then went home and did well for several years.

Inevitably his advancing age led to a time when Mrs J was no longer able to care for him without assistance. The family consulted with their local physician and the single nurse practitioner in town to set up in-home and hospice services available from the local CAH. Mr J and his family were reassured that they would be receiving services from health care professionals who lived in the family's rural community. The family personally knew the home health nurse assigned to work with Mr J, a situation that enabled the quick development of a trusted relationship. Together the family and the home health nurse established a plan of care that focused on comfort care, specifically pain control and management of signs and symptoms. Mr J clearly expressed that he wanted to die at home, and his family members were in agreement. The home health nurse discussed the family's fears and concerns as Mr J approached the end of his life. Local health care professionals and an extended network of neighbors and friends allowed the family to keep Mr J at home until his death at age 95. In the ensuing months, Mr J's wife received bereavement support through local agencies, including a community grief support group and a rural-based mental health professional.

Rural Nurses

Registered nurses working in CAHs must be "expert generalists"; they need expertise in a wide range of general nursing areas to provide care to patients of all ages with a variety of medical conditions and different health care concerns.⁹ For example, during the course of a shift in a CAH, a nurse may be responsible for stabilizing the status of a client with an acute myocardial infarction for transfer to an urban hospital, preparing a patient for surgery, administering medications to patients in skilled nursing swing beds, and caring for a mother in labor ready to deliver a first baby.

When Mr J was admitted to the CAH, he knew his nurse. In sparsely populated communities, a nurse's patients are often the nurse's friend, relative, or neighbor. Rural nurses lack anonymity; they are easily identified as "the nurse" at the clinic or hospital when at the grocery store or local high school football game. Rural nursing practice is distinctively different from specialized urban nursing practice such as critical care, as aptly described by Scharff.^{10(p243)}

Being rural means being a long way from anywhere and pretty close to nowhere. Being

rural means being independent or perhaps just being alone. Being a rural nurse means that when a nurse saves a life, everyone in town recognizes that she or he was there; and when a nurse loses a life, everyone in town recognizes that she or he was there. Being rural means turning inward for answers, because there may be nobody to turn to outward. Being rural means that when a nurse walks into the emergency room, it may be her or his spouse or child who needs a nurse, and, at the moment, being a nurse takes priority over being anyone else. Being a rural nurse means being able to deal with what he or she has got, where she or he is, and being able to live with the consequences.

Palliative Care

Palliative care is a form of specialized care for patients with serious, life-threatening, or incurable conditions. Signs and symptoms are managed, pain is relieved, quality of life is improved, and grief and bereavement are supported.¹¹ In contrast to the belief that palliative care is used only when a patient is dying, palliative care actually has a broader application and is ideal for patients with serious and incurable illnesses and the patients' family members. Palliative care is recognized as a national priority by several health professional organizations, including the American Association of Critical-Care Nurses,¹² which recognizes that critical care and palliative care should no longer be viewed as polar opposites. The "science and skills of both disciplines are needed to provide optimal care for critically ill or injured patients and their families."^{13(para 4)}

The American Association of Critical-Care Nurses recognizes that critical care and palliative care should no longer be viewed as polar opposites.

Palliative care includes providing relief of physical and emotional distress, facilitating communication and decision making with health care providers, and coordinating care across health care settings.¹⁴ The most common model of palliative care delivery is the consultative model.¹⁵ Specialists in palliative care are called in to consult on cases that require management of complex signs and symptoms, have challenging decision-making needs, and/or are characterized by unusual family dynamics.

Table Palliative care: definition, domains, clinical implications, and tenets^a

Definition

Palliative care means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information, and choice.^{16(p9)}

Domains of care	Clinical implications	Tenets
1. Structure and processes	Palliative care occurs across health care settings; care includes physical, psychological, and social aspects of care; best practices are used; and health care providers engage in quality and performance improvement activities	Patient and family centered
2. Physical aspects	Compassionate care is provided by health care providers; pain and symptoms of patients and patients' families are managed to promote quality of life	Comprehensive palliative care with continuity across health care settings
3. Psychological and psychiatric aspects	Assessment of psychological and psychiatric aspects is ongoing; grief and bereavement services are provided for patients, patients' families, and staff members	Early introduction of palliative care at diagnosis of a serious disease or life-threatening condition
4. Social aspects	Health care providers assess social structure of patients and patients' families, including culture, values, strengths, goals, and preferences of family system	Interdisciplinary collaborative palliative care
5. Spiritual, religious, and existential aspects	All health care providers assess spiritual needs of patients and patients' families; health care providers are aware of their own spirituality and how it may influence the care provided	Clinical and communication expertise among palliative care team members
6. Cultural aspects	Health care providers should be culturally competent and provide appropriate cultural care to patients and patients' families	Relief of physical, psychological, emotional, and spiritual suffering of distress of patients and patients' families
7. Care of the patient at the end of life	Health care providers promote a peaceful and honorable death, with awareness of the values, preferences, beliefs, culture, and religion of patients and patients' families	A focus on quality
8. Ethical and legal aspects	Health care providers need awareness of ethical principles and access to legal and ethical expertise to support palliative care practice	Equitable access to palliative care services

^a Based on information from Dahlin.¹⁶

This model is consistent with secondary (medical specialists) or tertiary (advanced level care) levels of palliative care.¹⁵ Because of the tremendous increase in the number of patients living, and dying, with multiple serious and life-threatening illnesses, health care providers now recognize the need to move away from only using the consultative model of care. Ideally, palliative care should be provided by frontline staff, including physicians, nurses, and others (social workers, chaplains, and so on), who are involved in the routine care of patients with serious and life-threatening illnesses, reserving consultations with palliative care specialists for the

most complex cases. In either instance, health care providers are challenged to implement palliative care in rural settings such as the one where Mr J lived.

The *Clinical Practice Guidelines for Quality Palliative Care* were recently updated¹⁶ to emphasize continuity, consistency, and quality of care (see Table). Although some CAHs provide palliative care services to patients and patients' family members, the hospitals often face challenges in meeting national guidelines, such as having a multidisciplinary palliative care team available around the clock or providing bereavement services to surviving families for up to 1 year after a patient's death. In

addition, rural areas have prominent barriers that may limit access to health care, including long distances, unpredictable weather, lack of public transportation, limited health care resources, shortages in the number of health care providers, few certified specialists, and limited opportunities for training in palliative care.¹⁷ Providing palliative care services can be especially challenging in rural settings because of personal and professional role strain, including lack of anonymity and role diffusion,¹⁸ which is common among health care providers in rural environments.¹⁹

Nurses' Role in Palliative Care

All patients with serious and life-threatening illnesses deserve access to high-quality palliative care. The tenets of palliative care¹⁶ include being patient and family centered, providing continuity across health settings, working with patients with serious disease or life-threatening conditions, collaborating with other disciplines, using excellent communication skills, providing relief of suffering and distress, focusing on quality, and providing equitable access to care (see Table). The Hospice and Palliative Nurses Association promotes the importance of the professional nurse in palliative care, stating that “nursing care is critical to achieving healthcare goals of patients, families, communities, and populations through the end of life.”^{20(p2)} Patients and patients’ families benefit when nursing care includes both the science (assessment, management of signs and symptoms, critical thinking) and the art (compassion, empathy, and excellent communication) of nursing. Nurses are well positioned to provide support and promote quality of life for vulnerable patients and families facing serious or life-threatening illnesses.

Mr J’s case report illustrates how he and his family benefited from the care he received in a rural community. Mr J’s serious illnesses were managed, but not cured, and his injury was surgically repaired so he could regain a level of physical functioning that allowed him to return home to his rural community. Consistent with the domains and tenets of palliative care (see Table), Mr J’s physical, emotional, social, and spiritual needs were addressed by a small number of local health care providers and the support of neighbors and family members. Mr J’s autonomy was maintained when local health care providers provided information necessary for him and his family to make choices about what was important at

the end of his life. Mr J’s local physician knew that Mr J wanted to remain active and explained that surgery would allow Mr J to regain mobility. A nurse familiar with Mr J and his family provided encouragement about the care provided at the large urban hospital. Emotional support was provided by a friend in town, who suggested Mrs J ask the children to assist with preoperative appointments. Coordination of care took place as surgical and critical care nurses in the urban hospital facilitated Mr J’s transfer back to the local CAH after surgery (domain 1). Mr J’s signs and symptoms were well managed, and assessments of his pain and anticoagulant status continued in his rural community (domain 2). Staff at the CAH involved Mr J’s family in the plan of care and provided emotional and spiritual support (domain 3). Health care professionals in the rural community were known to Mr J and his family and supported his social, spiritual, and cultural connections in the community (domains 4, 5, and 6). Home health and palliative care services from the local CAH enabled Mr J’s family to accommodate his wish to die at home (domains 7 and 8). After Mr J’s death, his family received bereavement support (domain 3) from local providers in the family’s rural community.

Shadd et al²¹ provide an important differentiation between palliative care provided by a specialized team and a palliative approach to care, stating that as an approach to care, “palliative care appreciates death as a normal life event, emphasizes good communication and clarification of goals of care, and focuses on quality of life including symptom

A palliative approach provides patients with life-threatening illnesses an opportunity to receive primary palliative care on a daily basis from frontline health care providers.

management.”^{21(p1149)} A palliative approach provides patients with serious and life-threatening illnesses an opportunity to receive primary palliative care on a daily basis from frontline health care providers, thus leaving specialty palliative care for more complex cases that cannot be handled by primary level palliative care providers. A palliative approach is a model that works especially well in rural settings.²²

The model of distinguishing palliative care provided by specialized teams from a palliative approach of care provided by all health care providers affirms nurses’ ability to provide palliative care to patients in all settings. Furthermore, because of the close link between

nursing care and the tenets of palliative care, all nurses, whether intentionally or not, often use a palliative approach to provide care. Rural nurses often do not have a palliative care team to consult and yet instinctively resort to a palliative approach to care: advocating for patients and implementing work-arounds for rules and policies that do not support the needs of patients and patients' family members. The differences between a model of specialist-promoted palliative care teams, which exist in urban settings, and the model of a palliative approach to care, which is common in rural settings, are important. These differences may lead to tensions, which in turn, weigh heavily on rural nurses and lead to adverse effects on the nurses' emotional well-being. Rural health care providers are often supported by colleagues and professional networks, as well as the inherent sense of connectedness found between friends and neighbors in rural communities.¹⁹

Conclusion

Because millions of patients are living with serious, complex, and potentially life-threatening conditions, the need for palliative and end-of-life care for patients and patients' families is increasing. Because of limited fiscal and human resources in all health care settings, health care providers can no longer rely on specialized palliative care teams as the only clinicians to provide palliative care. A palliative approach, which requires all health care providers to provide palliative care, is especially suited for rural settings. As expert generalists, rural nurses are well positioned to provide care close to home for patients of all ages and the patients' families. Rural nurses' familiarity with community members and knowledge of available resources allow these nurses to work with their urban counterparts to overcome challenges when providing compassionate palliative care to rural residents and the residents' families. **CCN**

Financial Disclosures
None reported.

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To learn more about palliative care, read "Negotiating Transitions: Involvement of Critical Care Outreach Teams in End-of-Life Decision Making" by Pattison et al in the *American Journal of Critical Care*, May 2015;24:232-240. Available at www.ajconline.org.

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