Rural Palliative Care: Meeting People Where They Are

By
Nancy Joyner, MS, CNS-BC, APRN, ACHPN®
Palliative Care Clinical Nurse Specialist
Outreach Specialist- Rural Palliative Care
Center for Rural Health

Objectives

1. Distinguish palliative care and its impact on rural communities.
2. Identify key barriers rural palliative care faces.
3. Determine strengths and opportunities for advancing rural palliative care.

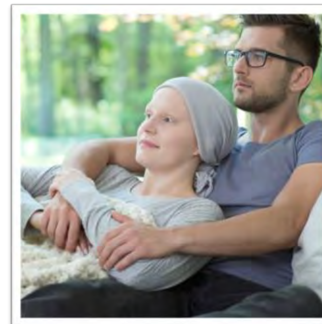
Palliative Care Definition

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

(IAHPC, 2019)

Serious Illness

A health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their caregiver.*



*Kelley, AS, Bollens-Lund, E. Identifying the population with serious illness: the "denominator" challenge. Journal of Palliative Medicine. Volume: 21 Issue S2: March 1, 2018.

Rural Palliative Care Goals

- Relieve pain and suffering
- Ensure the best possible quality of life
- Provided with curative treatments
- Addresses benefits and burdens of treatment
- Addresses the changing goals of care
- Discusses when to begin or discontinue treatments
- Care for the whole person, wherever they are
- Support for family and other staff
- Requires the support of an interdisciplinary team.

Eight Domains of Rural Palliative Care

Domain 1: Structure and Processes of Care
Domain 2: Physical Aspects of Care
Domain 3: Psychological and Psychiatric Aspects of Care
Domain 4: Social Aspects of Care
Domain 5: Spiritual, Religious, and Existential Aspects of Care
Domain 6: Cultural Aspects of Care
Domain 7: Care of the Patient Nearing the End of Life
Domain 8: Ethical and Legal Aspects of Care

(NCP Guidelines,2019)

Current Models of Palliative Care Delivery

- Hospice (since 1974)
- Hospital based palliative care (1990s)
  - interdisciplinary consultation teams
  - inpatient units

Newer Models (2000s)

- Ambulatory consultation clinics
- Interdisciplinary home care
- Palliative care teams -managed care plans
- Hospital-based teams with provider home visits
- Rural Community Based Palliative Care Teams

(Meier & McCormick, 2020)

Palliative Care Statistics

- Half of caregivers of Americans hospitalized with a serious illness report less than optimal care
- Studies have shown that 24% of health care costs can be attributed to persons living with long-term, serious illnesses.
- West & East North Central Report Card
  - A grade: Montana, North Dakota, South Dakota, Wisconsin, Illinois
  - B grade: Iowa, Minnesota, Missouri, Nebraska

(CAPC Report Card, 2020)

Problem #1

The focus of palliative care delivery has been on developing inpatient palliative care units and services in academic, tertiary care medical centers.

Question: Could offering palliative care upstream influence decision making and result in fewer patient entering the hospital at the end of life?

(Meier & McCormick, 2020)

Problem # 2: Rural Palliative Care is Different

Rural Palliative Care: What's Different

Case Study:

- Helen Johnson is an 83-year-old married lady who is Norwegian and Lutheran. She is admitted to a local critical access hospital with recurrent ovarian cancer, ascites, and dyspnea.
- She is transferred to the "academic center"-90 miles away
- Gynecology/Oncology recommends chemo. Helen has limited English language skills/ accepts treatment (because the doctor offered it)
- Family unable to visit
- Helen dies alone in the hospital from neutropenic fever and sepsis

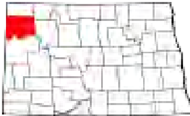
Critical Access Hospital (CAH) Criteria

- Must be rural, located within a state participating in the Medicare Rural Hospital Flexibility program
- Must be more than a 35-mile drive from any other hospital or CAH (or, in the case of mountainous terrains or in areas where only secondary roads are available, more than 15 miles from any other hospital are CAH)
- Must have 15 or fewer acute inpatient care beds (or, in the case of swing bed facilities, up to 25 inpatient beds which can be used interchangeably for acute of SNF-level care, provided no more than 15 beds are used at any one time for acute care) as reported on the cost report

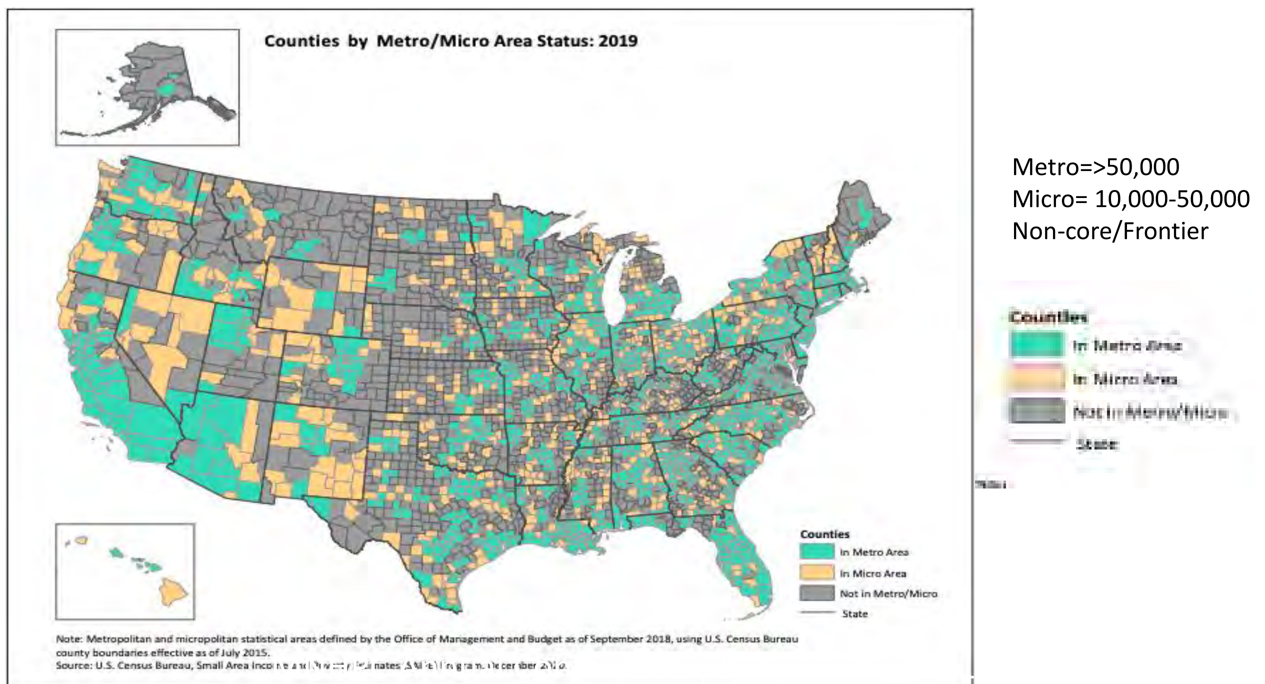
(RHIhub, 2019)

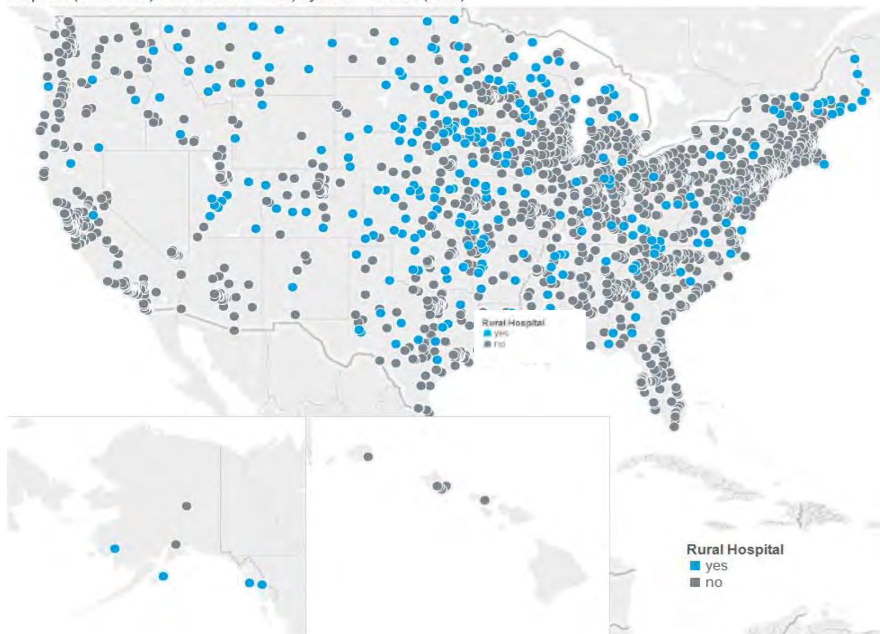
Critical Access Hospital Criteria (cont.)

- Must restrict patient length of stay to no more than 96 hours unless a longer period is required because of inclement weather or other emergency conditions, or a physician review organization (PRO) or other equivalent entity, on request, waives the 96-hour restriction
- Must offer 24-hour emergency services
- Must be owned by a public or nonprofit entity
- If a hospital does not meet the above conditions, it may be designated by other state criteria as a critical access hospital



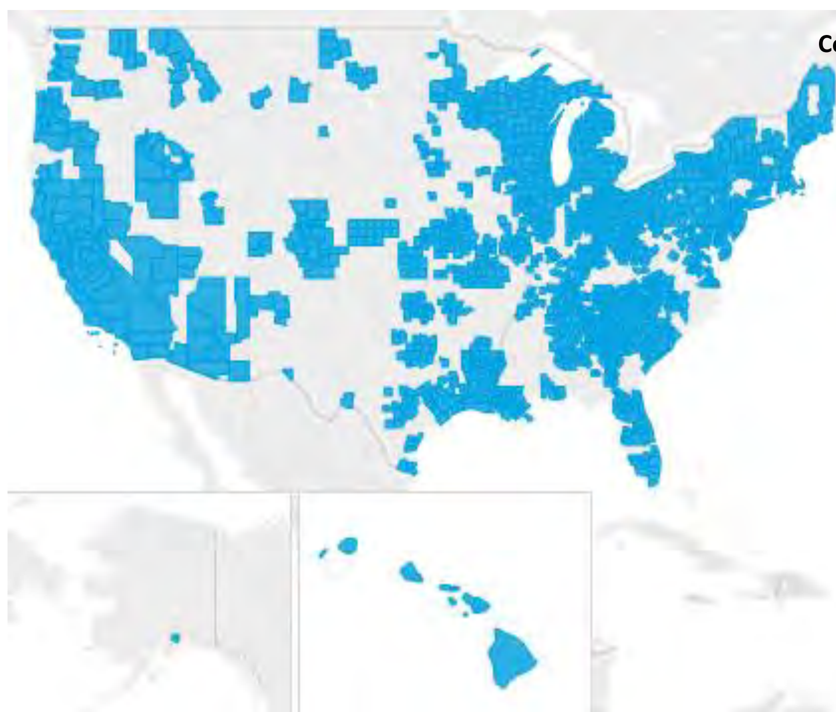
(RHIhub, 2019)





Hospital Based Palliative Care CAPC, 2021

Rural Hospitals are Teal dots



Community Palliative Care Programs

Update: July 2020
Results based on program self-report
653 in-home palliative care programs, providing some level of care in 51.8% of US counties (n=1627)

(CAPC, 2021)

Rural Palliative Care Challenges

- Service gaps
- Cost of services in relation to the population
- Sustainability
- Difficulty in demonstrating improvements in outcomes
- Geographic isolation
- Nature of palliative health care services
- Nature of rural relationships
- Competencies required for rural palliative care

Barriers/Challenges to Rural Palliative

used with permission of the Center to Advance Palliative Care, Diane E. Meier, MD, Director

- **Patient Barriers**
  - Patient preference to stay in home community for care
  - Lack of transportation & long distances to palliative care centers (for patients or visitors)
  - Patient/clinician concerns that they will lose touch with community providers if they seek care at centers far from home
- **Provider Barriers**
  - Limited access to palliative care experts (only 22% of hospitals with <50 beds have PC)
  - Limited exposure to palliative patients in rural practices (1-2 deaths/year)
  - Limited availability of palliative care education for clinicians
- **Practice/System Barriers**
  - Poor communication/coordination of care between academic and rural community settings
  - Lack of availability of technology/techniques used for complex patient problems (e.g. pain pumps)
  - Few studies to identify 'best practices' or models for rural palliative care (e.g. no mention of rural in 3rd edition of National Consensus Guidelines; Limited mention in IOM "Dying in America" report
  - Few (reimbursement) incentives to keep patients in local community (e.g. critical access hospitals)

14 UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM Knowledge that will change your world

Data From: Fink et. al. JPM 2013; Ceronsky et al. 2013; CAPC Report Card 2011

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Other Barriers

- Understanding/misunderstanding of palliative care vs. hospice
- Multiple stakeholders
- Financial constraints
- Different settings and disciplines
- Lack of prior experience working
- Relationships among the participating organizations

Palliative Care or Hospice Care?

What Is Palliative Care?

Palliative care is specialized medical care for people with serious illnesses. It is appropriate at any age at any stage in a serious illness and can be provided together with curative treatment. Palliative care promotes quality of life by addressing the physical, psychological, emotional, cultural, social, and spiritual needs of patients and families. It offers treatment of pain and other symptoms; relief from worry and distress of illnesses; close communication about goals of care; and well-coordinated care during illness transition. It also provides care across treatment settings and support for family/caregivers and offers a sense of safety in the healthcare system. Palliative care is delivered by a team of physicians, nurses and other specialists who work with the patient's other doctors to provide an extra layer of support.

What Is Hospice Care?

Hospice care is a team approach to expert medical care for individuals who face a life-limiting illness. With a focus on comfort, the team develops a plan of care tailored to each individual's needs and goals. It includes pain and symptoms management, personal care, emotional and spiritual support, and grief support for the each individual's loved ones. All of hospice is palliative care, but not all of palliative care is hospice.

For more information:
Nancy Joyner, MS, CNS-BC, APRN, ACHPN
(218) 779-5037 • Nancy.Joyner@und.edu

ruralhealth.und.edu • (701) 777-3848

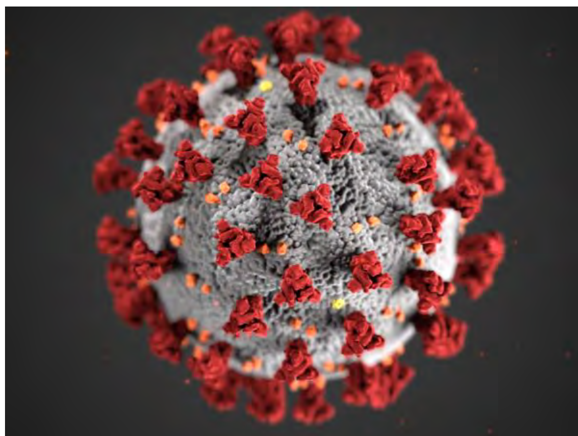
Palliative Care Continuum Diagram modified from:
- Lynn, J. 2005. Living Long in Fragile Health: The New Demographics Shape End of Life Care. Hastings Report. November-December 2005, S14-18
- American Cancer Society/Cancer Action Network. 2016 North Dakota Palliative Care Presentation. Bismarck, ND.
- Center to Advance Palliative Care. 2016. Diane E. Meier, Director

Created by the ND Palliative Care Task Force.

January 2020

Rural Health – What's one more hat to wear?!

….And then there's COVID-19



A new hat for our collection

P is for Pandemic now

- **P**alliative **p**ause- CAH “all hands-on-deck”
- Economic downturn- loss of employment and insurance
- LTC and inpatient visitation issues
- Vulnerable population to bring into the clinic
  - Tele health options: virtual visits, remote monitoring
  - Aging in place? LTC “heated topic” in pandemic
  - Home based care program development in conjunction with Medicaid
  - Younger population facing their own and their family mortalities

Strengths & Opportunities

- Awareness and education
- Training rural primary health care professionals for implementation
- Community EMS
- Community representatives
- Community–academic partnerships

2021

Innovative Solutions

- Project ECHO
- UND Center for Rural Health/ Stratis Health Training
- Center to Advance Palliative Care (CAPC) -Tipping Point Challenge
- Telehealth
- Community lay navigators

Conclusion-
Palliative Care Is Needed Everywhere

- Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment.
- People may need palliative care in hospitals, in the community, in nursing facilities, and rural homes- meeting people wherever they are
- **Integration of Palliative Care Into All Serious Illness Care as A Human Right** (Ross, Ferrell & Mason, 2021)

Questions?

For More Information, contact:

Nancy Joyner, Clinical Nurse Specialist
Palliative Care
Outreach Specialist – UND Center for Rural Health
nancy.joyner@und.edu

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