The Oklahoma Academy for Palliative Care Education

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Objectives

• Describe the demographic imperative for palliative care.
• Define palliative care.
• Describe the use of palliative care for patients with a variety of serious chronic conditions as well as terminal illness.
• Describe the ethical failure in providing so little palliative care.

Objectives

• Describe the structure and function of the Oklahoma Academy for Palliative Care Education.
• Describe the development of a rural palliative care initiative.

Demographic Imperative

• More people are living longer.

![Life Expectancy Chart](http://www.uoregon.edu/~maphist/english/US/US39-01.html)

Demographic Imperative

• People who live longer are more likely to have chronic diseases.
• Chronic diseases are showing up earlier in life.
• These chronic diseases last for an extended period of time.
• Palliative care is the ethical way to provide care to these people.

![Life Curve Chart](http://www.cdc.gov/nchs/data/nvsr/nvsr53/nvsr53_06.pdf)
Definition of Palliative Care

Health care to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of the stage of disease or need for other therapies.

Goals

- Address physical, psychological, social, spiritual, and practical expectations and needs
- Anticipate and nurture individuals through the process of loss, grief, and bereavement
- Prepare for and assist with the management of self-determined life closure, the dying process, and death

Distinctions between Hospice and Palliative Care Programs

HOSPICE
- A formal medical benefit under Medicare and some commercial insurance programs.
- Participant must have a life expectancy of 6 months or less if the disease runs its usual course and be certified by a physician as terminal.
- Participant must enroll in an established program of hospice care.
- Participant must agree to care with a palliative intent and forego care that is aggressive or curative in nature.

PALLIATIVE CARE
- Currently Palliative Care programs are informal.
- Sometimes occur as a sideline to Hospice.
- May be supported by a larger institutional provider such as a hospital or university.
- Financing has to be creative.

Conventional Care to Hospice Model

Recipients of Palliative Care

- Appropriate for any patient and/or family living with, or at risk of developing a life-threatening and/or debilitating illness or condition
- Due to any diagnosis
- With any prognosis
- Regardless of age
- At any time they have unmet expectations and/or needs, and are prepared to accept care
- Best delivered by an interdisciplinary team
Interdisciplinary Team

• Physician
• Nurse
• Social Worker
• Chaplain
• Certified Nursing Assistant
• Physical Therapist
• Occupational Therapist
• Psychologist
• Lawyers
• Others

Role of Physician

• Usually does not function as the team leader for interdisciplinary team meetings
• May or may not be the medical provider for the cases being reviewed
• Contributes medical perspective and expertise
• Serves as liaison with other physicians, when necessary

Role of Nurse/Manager (RN)

• Certifies participants for eligibility to the program
• May be contracted to
  – See patients and/or conduct house calls to treat patients
  – Determine eligibility for services
  – Assess the home environment

Role of Nurse/Manager (RN)

• Commonly functions as team leader for interdisciplinary team meetings
• Manages overall care of patients either administratively or clinically
• Supervises LPNs and aides
• Coordinates care with other team members

Role of Social Worker

• Provides psychosocial support to patients and families
  – Helps patients identify and process their feelings and emotions about living with a chronic and often times debilitating disease
  – Assists the caregiver or family members in identifying ways to enhance communication surrounding the stress and strain associated with living with someone who has a chronic illness
Role of Social Worker
• Provides linkage to services and agencies in the community
• Helps patients apply for insurance or Social Security benefits, Medicare, Medicaid, food stamps, meals-on-wheels, etc.
• Works with the patient and family on financial issues, wills, advance directives, simple legal problems or concerns

Role of Social Worker
• Provides therapeutic counseling focusing on issues such as
  – Family conflicts
  – Fears and anxieties related to a chronic debilitating disease
  – Changing roles within the family unit

Role of Social Worker
• Often convenes a family conference to resolve conflicts or to discuss care needs of the patient
• Emphasizes effective communication
• Attempts to ensure that everything essential is resolved between patient, family members, and friends

Role of Chaplain
• Provides spiritual and bereavement care
  • Spiritual/bereavement care is
    – Essential – intrinsic/extrinsic
    – Personal – patient-centered
    – Permissible – dialogical/reflective
    – Palatable – affirming/reconciling
    – Team-able -- collaborative

Role of the Chaplain
• Model for spiritual/bereavement care
  – Religious tradition
  – Culture
  – Experience

Role of the Chaplain
• Method for spiritual/bereavement care
  – Attending
  – Asserting
  – Acting
Role of Lawyer

- Provides legal counsel to the team in such areas as:
  - State and federal laws
  - End-of-life legal documents
  - Risk assessments of conflict situations

Inadequacy of Our Current Health Care System

- Geared toward acute, curative care
- Geared toward hospital based care
- No reimbursement for a team approach to chronic needs
- Many with serious, chronic illness driven into poverty and isolation from family and society
- Lack of understanding of end-of-life laws and documents which ensure patients’ wishes are honored post-capacity

Ethical Failure

- “...the lack of palliative care programs in American hospitals is a complete ethical failure – a failure on the part of hospitals to attend to the needs, and to relieve the pain and suffering, of their patients when it is entirely possible to do so.” (Paulus, 2008)
- We would extend that to include nursing homes and community settings.

Why We Have Failed

- Failure to commit resources to hospice units in hospitals
- Failure to educate physicians and staff about palliative care and hospice
- Failure to educate physicians and staff about end-of-life laws and documents
- Tendency to treat families and not the patient

Why We Have Failed

- Misunderstanding that pain and other symptoms are expected with acute care
- Misunderstanding that palliative care is synonymous with hospice care
- Misunderstanding that hospice care has no place in an acute care setting

End-of-Life Legal Documents

- Do-not-resuscitate Consent
- Advance Care Directive
- Durable Power of Attorney for Healthcare
  - POA vs DPOA vs DPOAHC
  - Witnesses and notarization
- Guardianships
- Last Will and Testament
- Trusts
Oklahoma Academy for Palliative Care Education

Current Consortium Members
- Marcia Howland, M.R.E. - Chaplain/Bereavement Coordinator, Cornerstone Hospice
- Audrey McCraw, LCSW - Vice President of Support Services, Sojourn Care of Tulsa
- Richard Perry, M.A. - Director, Oklahoma Area Health Education Center, Oklahoma State University Center for Health Sciences
- Jean Root, D.O. - Retired Associate Professor of Geriatrics, University of Oklahoma - Tulsa
- Jan Slater, J.D. - Chief Executive Officer, Oklahoma State University Medical Center
- Angie Temple, RN - Director of Business Development, Select Specialty Hospital
- Patricia Turner, M.A. - Director, Northeast Area Health Education Center, Tulsa Community College
- Nancy Van Winkle, Ph.D. - Professor of Behavioral Sciences, Oklahoma State University Center for Health Sciences

Oklahoma Academy for Palliative Care Education

Vision
A culture and infrastructure of health care delivery that recognizes palliative care as a distinctive blend of curative and supportive medical care that is determined by the best interest of the patient and is incorporated into the knowledge base of all health care professionals.

Purpose
To further palliative care education in Oklahoma by establishing a philosophical, ethical, legal, and clinical dialogue regarding persons with serious chronic conditions and terminal illness.

Goals
- Utilize an interdisciplinary, case-based model of education anchored in adult learning theory
- Explore the scientific evidence of "Best Practices" for delivery of palliative care
- Create a new standard of care for persons with serious chronic conditions and terminal illness

History
- First meeting in February, 2006
- Online survey of health care professionals in June, 2006: Interest in palliative care education, format, and topics
- First workshop in October, 2007: A Workshop on Palliative Care: An Interdisciplinary Approach to Medical Care for Chronically and Terminally Ill Patients in Tulsa and Tahlequah
- Second workshop in January, 2009: A Workshop on Palliative Care: The Palliative Care Team for Chronic Disease in Tulsa and Grove
Minnesota Rural Palliative Care Initiative

A learning collaborative that is working with 10 rural communities to help them begin or strengthen palliative care programs in their communities.

Partners
- Stratis Health – non-profit organization that leads collaboration and innovation in health care quality and safety
- Fairview Health Services – nationally recognized palliative care program
- UCare – non-profit health plan
- MDH – Office of Rural Health and Primary Care

Minnesota Rural Palliative Care Initiative

- Community teams composed of
  - Interdisciplinary health care providers – e.g., physicians, nurses, therapists, social workers, chaplains
  - From multiple sites – e.g., hospitals, hospices, home health agencies, nursing homes

Minnesota Rural Palliative Care Initiative

- 18 month program began in Fall, 2008 and includes:
  - Workshops for the community teams
    - Pain and symptom management
    - Family-clinician relationships
    - Transitions between health care providers
  - Webinars, conference calls
  - Individual technical support to teams
  - Outcomes Congress where teams will share their experiences and accomplishments