The State of Palliative Care

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Objectives

- Define palliative care & differentiate primary vs specialty
- Describe how palliative care is beneficial
- Explore the growth and remaining gaps in provision of PC in the U.S.
- Define what people desire at the end of life
- Describe advance directive options in WI

U.S. Population & Health Care Facts

- Average life expectancy 78 years
- Americans with 5 or more chronic illnesses = 20% Medicare beneficiaries
- Medicare benefit payments totaled $597 billion in 2014 (23% for inpatient hospital care)
- One-quarter Medicare spending are for services in the last year of life
- 4 in 10 Americans age 65 or older do not have advance directives
- 17% of adults say they have had end of life care discussions with their doctors though 89% felt they wish for these discussions
- 7/10 Americans say they wish to die at home, only 25% actually do

What is Pall-ee-uh-tive care?

"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 and to facilitate patient autonomy, access to information and choice."

– National Consensus Project

How Has Palliative Care Evolved?

- Evolved from modern hospice care
- Need to meet gaps in care for seriously ill
- Hospital programs started late 1980's at Cleveland Clinic and Medical College of Wisconsin
- Introduced in 1990 by WHO
- Certification for CHPN started in 1999
- 2006- Palliative Medicine now a board certified sub-specialty of Internal Medicine
- 2016 APNs can sub-specialize during their graduate training for palliative care or after with residencies and fellowships

Palliative Care Is…

- Interdisciplinary and evidenced based care
- Important in optimizing quality of life
- Embedded in nursing care
- Provided alongside disease directed measures
- Inclusive of end of life & hospice but not exclusive to terminal illness

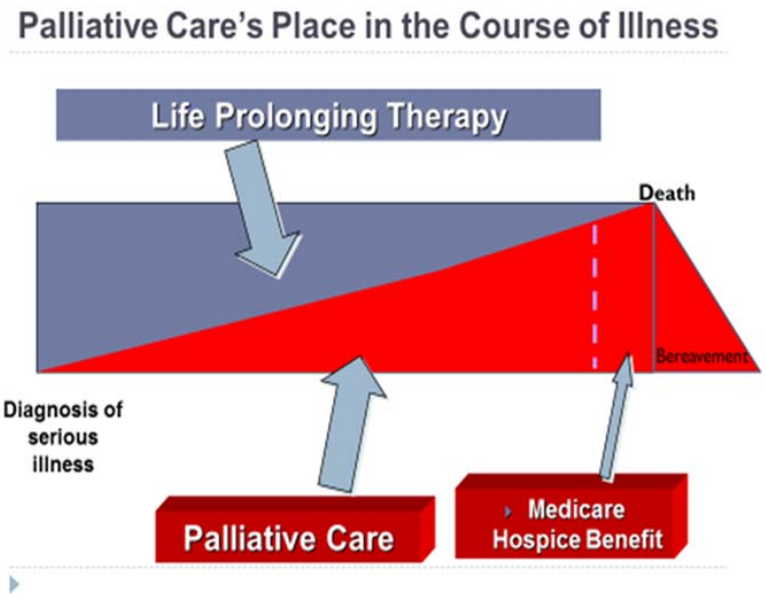
Palliative Care: Not Just End of Life

Palliative care

- For those at any stage of an illness
- No expectations that life-prolonging treatments will be avoided
- Provided mostly in the hospital and some outpatient visits

Hospice

- Insurance benefit for those with terminal condition within 6 months to end of life
- Palliation of symptoms main goal so those who enroll accept limitations in life prolonging measures
- Provides robust layer of support at home/SNF/ALF/Hospice facility



Why is Palliative Care Important?

It Addresses Quality & Value

- Treats people and not just disease
- Strengthens patient-family-provider relationships
- Ensures well-coordinated care across health care settings
- Helps to define a patient's goals in context of his/her **evolving** medical conditions (Doing things for a person and not to him/her)
- Increases patient satisfaction
- Reduces health care costs as product of above

Cost Savings

- Study of 8 diverse US hospitals
- PC consult = reduction in direct hospital costs of almost $1,700 per admission for patients discharged alive and of almost $5,000 per admission for patients who died
- For avg. 400-bed hospital containing interdisciplinary palliative care team seeing 500 patients a year, these figures could translate into net savings of $1.3 million a year

Providing Palliative Care Means Having…

- Knowledge of disease state, prognosis, pharmacology, evidenced based practice
- Communication skills used for assessment of a patient's beliefs/values/coping skills, eliciting goals of care, navigating relationships, education of condition and illness trajectory, collaboration, coordination of care, active listening/presence
- Symptom management: acute and chronic symptoms

Primary vs Specialty Palliative Care

- Primary palliative care = basic day to day management of serious illness including…
  - Illness trajectory
  - Code status
  - Basic symptom mgmt.
  - Advance care planning
  - Aligning treatments with patient goals
- Specialty palliative care = consultation for complex palliative needs such as…
  - Management of refractory pain/symptoms
  - Management of complex grief and existential distress
  - Conflict resolution regarding goals of care with patients, their families and amongst health care providers

What Does A Specialty Palliative Care Consult Include?

- Focus on patient and his/her family
- Symptom assessment and mgmt.
- Coordination of family medical conference including patient's interdisciplinary team if necessary
- Discussion of medical conditions and choices for medical care
- Collaborating with other health care providers involved in patient's care including outpatient providers
- Communicating patient's goals

Meet Anne…

- Anne is a 72 year old retired librarian and grandmother of two who loves to sew and cook. She has been married to Tom for over 50 years. She walks 2 miles every day and loves to travel with her family.
- She has a past medical history of mild and controlled COPD, compensated CHF, controlled HTN, esophageal motility disorder, GERD, and thyroid cancer in her 30s that was treated with radiation to the neck.

Anne…

- She started to have headaches and weight loss
- Due to weakness & double vision she is hospitalized
- A CT of the head revealed a large brain lesion
- A neurosurgeon states it is an inoperable glioblastoma
- Oncology consults and steroids/radiation and symptom mgmt. recommended due to Anne's weakened functional status
- Anne and her family consider second opinion at Mayo Clinic

Anne Without Adequate Discussion of Diagnosis, Prognosis, and Goals of Care

- Anne and her family travel to Mayo Clinic for a second opinion and radiation is recommended. Providers there recommend follow up with local oncologist for further goals of care discussions.
- Though they have met and discussed the situation with multiple providers they continue to believe radiation will cure Anne's cancer
- Tom provides increasing amounts of cares in the home and takes her to the hospital when she can no longer get out of bed and has a fever
- She is diagnosed with pneumonia and as Tom and her family hope for her to improve she dies in the hospital

Oncology Consults Palliative Care For Assistance with Goals of Care Communication

- Meet with Anne, family, neurosurgery, & oncology
- Anne shares she has inoperable brain tumor
- Prognosis shared as short months
- Radiation and symptom mgmt discussed as well as reaching out to oncology at Mayo Clinic
- Anne shares her main wish is to spend time with family at home
- Hospice discussed and Anne requests their cares at home after radiation
- Code status of DNR recommended

Primary Palliative Nursing Care for Anne

- Assessing if patient has advance directives
- Does she have questions about code status?
- Assessing symptoms such as headache, nausea, weakness, etc
- Provide careful listening to assess Anne's understanding and coping
- Summarizing care plan as it evolves

So, Do People Have Access to Palliative Care When Needed?

National Palliative Care Facts

Strengths:

- 148% increase in palliative care programs in hospitals >50 beds since 1998
- 90% of hospitals with 300 or more beds have PC teams
- Palliative care certified APNs increasing: 50.9% programs in 2014 report having certified APN. Up from 33.2% in 2008.
- Palliative Care and Hospice Education and Training Act
- Hospice benefit helping to provide quality end of life care

National Palliative Care Facts

Room for improvement:

- One-third of U.S. hospitals with fifty or more beds report no palliative care services in 2015
- Recent study of 410 hospitals show only 39% have funded fully staffed PC teams (MD, NP/RN, SW, chaplain)
- Lack of robust community based palliative care (hospice level of support)

WI Palliative Care Facts

Strengths:

- > 80% of WI hospitals report having a palliative care team (50/57)
- UW, Medical College of Wisconsin & Marshfield Clinic Palliative Care medical fellowships
- > 300 certified hospice and palliative care RNs
- PCNOW
- Advanced care planning initiatives (Respecting Choices, Honoring Choices)
- Participating in Medicare Care Choices Model

WI Palliative Care Facts

Room for improvement:

- Most palliative care teams in Madison are understaffed and unable to capture all consults
- Lack of specialty palliative care in outpatient clinics
- Currently only have palliative care visits provided by hospice and home health agencies with limited follow up
- Majority of certified hospice and palliative care nurses working only in hospice care

So What Can Nurses Do to Advance Palliative Care?

- Seek education to strengthen palliative care skills
  - Fast Facts via PCNOW
  - Browse https://getpalliativecare.org
  - ELNEC
  - PalliTALK
  - *End-of-Life Care* by Barry M. Kinzbrunner & Joel S. Policzer
  - *Being Mortal* by Atul Gawande
  - Primary Palliative Care course for RNs at UW Hospital
  - National Consensus Project – Clinical Practice Guidelines for Quality Palliative Care Third Edition

What Can Healthcare Organizations and our Country Do?

- Healthcare systems/agencies: invest in creating or strengthening existing palliative care programs in both inpatient and outpatient realms. Continue to strengthen advanced care planning initiatives.
- As a country: support Palliative Care and Hospice Education and Training Act (PCHETA), CMS needs to provide palliative care benefit

Advance Care Planning

- Process of understanding, reflecting on, and discussing future medical decisions, including end-of-life preferences.
- Response to increasing sophistication in medical technology
- Includes documents (known as advance directives) to specify wishes
- Patient Self Determination Act 1991 - health care institutions required to provide information about advanced health care directives upon admission
- Not just a document. Requires conversation.

Respecting Choices: La Crosse, WI

- Initiative that provides framework for discussions to ensure patients receive medical management that is in line with their identified goals
- 90% of decedents have an advance directive
- 99.4% of those decedents' advance directives were found in the medical record where they died.
- 99.5% of treatment decisions were found consistent with instructions
- Dramatic effect on family satisfaction

  (LADS 2007-08, Detering et al. 2012)

Honoring Choices Wisconsin

- Initiative by Wisconsin Medical Society
- For health care organizations and community associates to design and embed comprehensive approach to advance care planning
- Provides training of health care workers to be facilitators for the advance care planning discussion
- Based on Respecting Choices First Step program

Other Advance Care Planning Initiatives

- Aging with Dignity-Five Wishes
- The Conversation Project
- Death over Dinner
- Death Cafes

Advance Directive Documents

- Durable Power of Attorney for Healthcare
- Financial Durable POA
- Living Will
- POLST/MOST
- Find directives from each state at Caring Connects/NHCPO

POWER OF ATTORNEY FOR HEALTH CARE

Document made this_________day of _______________(month),______(year).

CREATION OF POWER OF ATTORNEY FOR HEALTH CARE

I, ____

____

(print name, address, and date of birth), being of sound mind, intend by this document to create a power of attorney for health care. My executing this power of attorney for health care is voluntary. Despite the creation of this power of attorney for health care, I expect to be fully informed about and allowed to participate in any health care decision for me, to the extent that I am able. For the purposes of this document, "health care decision" means an informed decision to accept, maintain, discontinue, or refuse any care, treatment, service, or procedure to maintain, diagnose, or treat my physical or mental condition.

In addition, I may, by this document, specify my wishes with respect to making an anatomical gift upon my death.

DESIGNATION OF HEALTH CARE AGENT

If I am no longer able to make health care decisions for myself, due to my incapacity, I hereby designate ____

____

print name, address and telephone number) to be my health care agent for the purpose of making health care decisions on my behalf. If he or she is ever unable or unwilling to do so, I hereby designate ____

ADMISSION TO NURSING HOMES OR COMMUNITY-BASED RESIDENTIAL FACILITIES

My health care agent may admit me to a nursing home or community-based residential facility for short-term stays for recuperative care or respite care.

If I have checked "Yes" to the following, my health care agent may admit me for a purpose other than recuperative care or respite care, but if I have checked "No" to the following, my health care agent may not so admit me:

1. A nursing home - - ☐ Yes ☐ No
2. A community-based residential facility - - ☐ Yes ☐ No

If I have not checked either "Yes" or "No" immediately above, my health care agent may admit me only for short-term stays for recuperative care or respite care.

PROVISION OF FEEDING TUBE

If I have checked "Yes" to the following, my health care agent may have a feeding tube withheld or withdrawn from me, unless my physician has advised that, in his or her professional judgment, this will cause me pain or will reduce my comfort. If I have checked "No" to the following, my health care agent may not have a feeding tube withheld or withdrawn from me.

My health care agent may not have orally ingested nutrition or hydration withheld or withdrawn from me unless provision of the nutrition or hydration is medically contraindicated.

Withhold or withdraw a feeding tube - - ☐ Yes ☐ No

If I have not checked either "Yes" or "No" immediately above, my health care agent may not have a feeding tube withdrawn from me.

HEALTH CARE DECISIONS FOR PREGNANT WOMEN

If I have checked "Yes" to the following, my health care agent may make health care decisions for me even if my agent knows I am pregnant. If I have checked "No" to the following, my health care agent may not make health care decisions for me if my health care agent knows I am pregnant.

Health care decision if I am pregnant - - ☐ Yes ☐ No

If I have not checked either "Yes" or "No" immediately above, my health care agent may not make health care decisions for me if my health care agent knows I am pregnant.

STATEMENT OF DESIRES, SPECIAL PROVISIONS OR LIMITATIONS

In exercising authority under this document, my health care agent shall act consistently with my following stated desires, if any, and is subject to any special provisions or limitations that I specify. The following are any specific desires, provisions or limitations that I wish to state (add more items if needed):

1. ____
2. ____
3. ____

DEPARTMENT OF HEALTH SERVICES — STATE OF WISCONSIN

PLEASE BE SURE YOU READ THE FORM CAREFULLY AND UNDERSTAND IT BEFORE YOU COMPLETE AND SIGN IT

DECLARATION TO PHYSICIANS (WISCONSIN LIVING WILL)

1. If I have a TERMINAL CONDITION, ...

2. If I am in a PERSISTENT VEGETATIVE STATE, ...

3. If I am in a PERSISTENT VEGETATIVE STATE, ...

Physician Orders for Life-Sustaining Treatment (POLST)

ANY SECTION NOT COMPLETED INDICATES FULL TREATMENT FOR THAT SECTION.

Section A — Treatment options when the patient/resident is not breathing and has no pulse.

Section B — Treatment options when the Patient/Resident has pulse and/or is breathing. ☐ Comfort Measures Only. ☐ Limited Additional Interventions. ☐ Aggressive Treatment. Other Instructions:

Section C — Antibiotics. Other Instructions:

Section D — Artificially Administered Fluids and Nutrition. Other Instructions:

Section E — Discussed with: ☐ Patient/Resident ☐ Health Care Agent ☐ Court-appointed Guardian ☐ Other (specify). THE BASIS FOR THESE ORDERS IS:

ORIGINAL FORM MUST ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED.

End of Life Care: What Do People Want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

What is Needed to Provide This End of life Care?

- Patient & family centered care
- Trained providers (primary and specialty levels of PC)
- Societal change: normalize discussion surrounding end of life
- Timely referrals to palliative care and hospice
- Access to quality care

In Summary…

- There are and will continue to be increasing palliative care needs in the community, in clinics, and in hospitals.
- There are only so many specialists in palliative care and all health care providers, including every nurse, should be have the necessary training to be able to provide primary palliative care.
- End-of-life care should be discussed before the end of life through advance care planning which includes ongoing conversations about goals of care and completion of advance directives.

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