



Providing Palliative Care: People Really Do Die in America

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***“Only in the U.S.
is death considered optional.”***

George Wyse M.D.
Director of Electrophysiology
University of Calgary, Canada



**"You treat a disease,
you win, you lose. You
treat a person, I
guarantee you, you'll
win, no matter what
the outcome."**

- Hunter Patch Adams

Objectives

- Define palliative care and who is eligible to receive
- Describe the role of the APRN in palliative care
- Identify components of symptom assessment and possible treatments
- Describe essential elements of advance care planning
- Discuss the elements of the Institute of Medicine Report on Dying in America

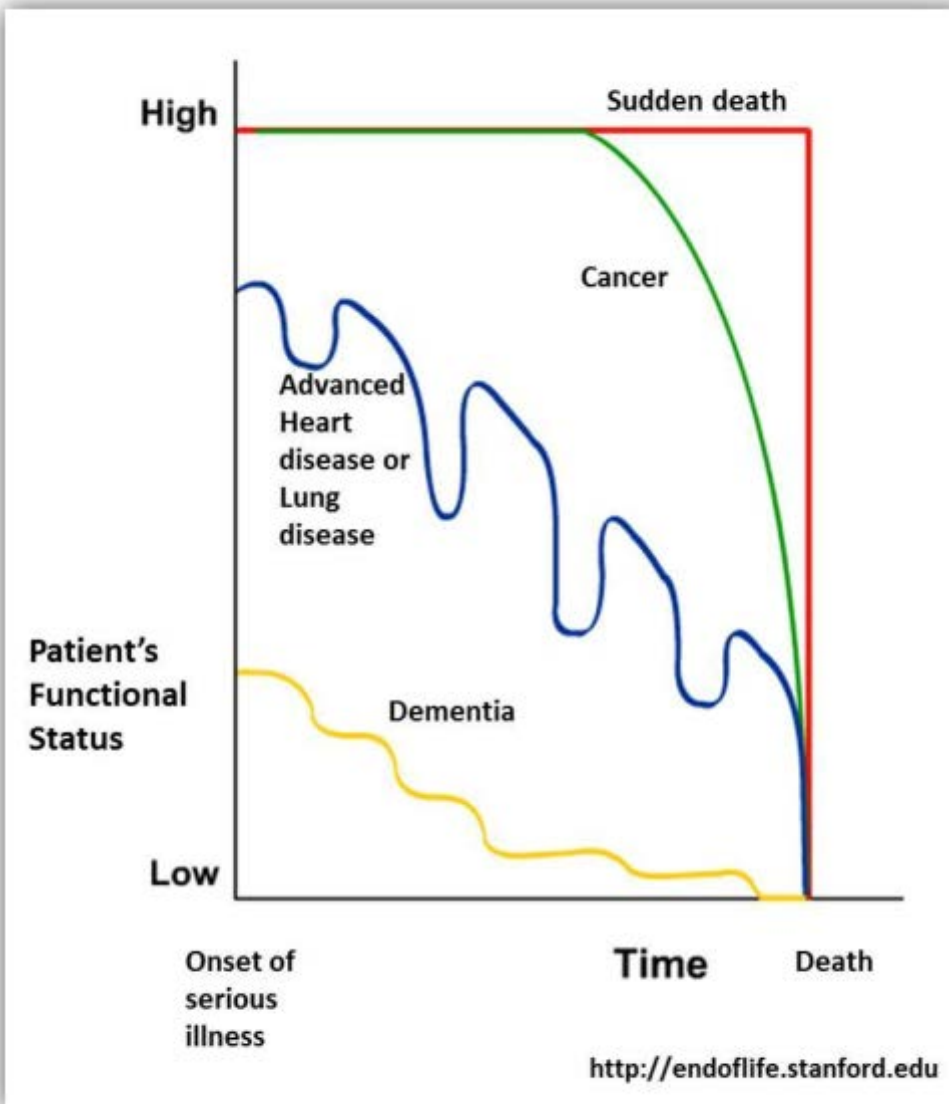
Dying in America

- >70% of those who die each year are >65 y.o.
- Majority occur after a long, progressively debilitating chronic illness, such as:
 - Cancer, cardiac disease (heart failure), renal disease, lung disease (emphysema, COPD), stroke, dementia
- Lack of understanding of prognosis
- Technology prolongs life, but does not always restore it
 - 16.7% patients stay in ICU for >7 days during last months of life

Cause of Death: Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Disease Communicable Disease	Chronic Illness
Death rate	1720 per 100,000	800 per 100,000
Average Life Expectancy	50	78
Site of Death	Home	Institutions
Caregiver	Family	Strangers/HC Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Disease Trajectories



What is a “Good Death”?

- For Patients:

- Achieving a sense of control
- Attaining spiritual peace
- Succeeding in having finances in order
- Strengthening relationships with loved ones
- Believing their life had meaning

- For HC Team:

- Providing symptom management and discussing emotional aspects of the disease

WHO Definition



Palliative care is an approach that
improves the quality of life

for patients and their families facing 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, physical, psychosocial and spiritual.

CAPC Definition

- Palliative Care is specialized medical care for people with serious illnesses and it is focused on providing patients with relief from the symptoms, pain & stress of a serious illness—whatever the diagnosis.
- The goal is to improve quality of life for both patient and family.

General Principles of Palliative Care

- It is a philosophy of care
- Patient and family as unit of care
- Attention to physical, psychological, social and spiritual needs
- Interdisciplinary team approach
- Education and support of patient and family
- Extends across illnesses and settings, any age and any stage
- Bereavement/Grief support for families and staff

Palliative Care Is

- Evidence-Based Medicine
- Vigorous care of pain and other symptoms
- Care that patients may want at the same time as treatment to cure or prolong life

Palliative Care Does NOT

- ✗ Mean “Giving Up” on a patient nor that they will die more quickly
- ✗ Preclude curative or life-prolonging care
- ✗ Mean they are a hospice patient

Other Misconceptions

◎ Palliative Care is only for people with cancer

NOT TRUE

All hospice patients receive palliative care but not all palliative care patients are hospice candidates

◎ Hospice is only for people who are dying very soon

NOT TRUE

General Criteria for Referral

- Patients with a serious illness **and** one or more of following:
 - New diagnosis of life-limiting illness for symptom control, patient/family support
 - Progressive disease
 - Multiple hospitalizations/illness within the last 3 months
 - Difficult to control physical or emotional symptoms
 - Conflicts regarding the use of non-oral feeding/hydration in cognitively impaired, seriously ill, or dying patient
 - Impaired nutritional status indicated by involuntary weight loss >10% of body weight in past 6 months
 - Serum albumin <2.5 g/dL is helpful but not necessary
 - Functional status decline indicating considerable assistance and frequent medical care

Diseases States Appropriate for PC

- Cancers
- Heart Disease – HF and CAD
- Pulmonary Disease
- Dementia
- HIV Disease
- Liver Disease
- Renal Disease
- Stroke and coma
- Amyotrophic Lateral Sclerosis (ALS)

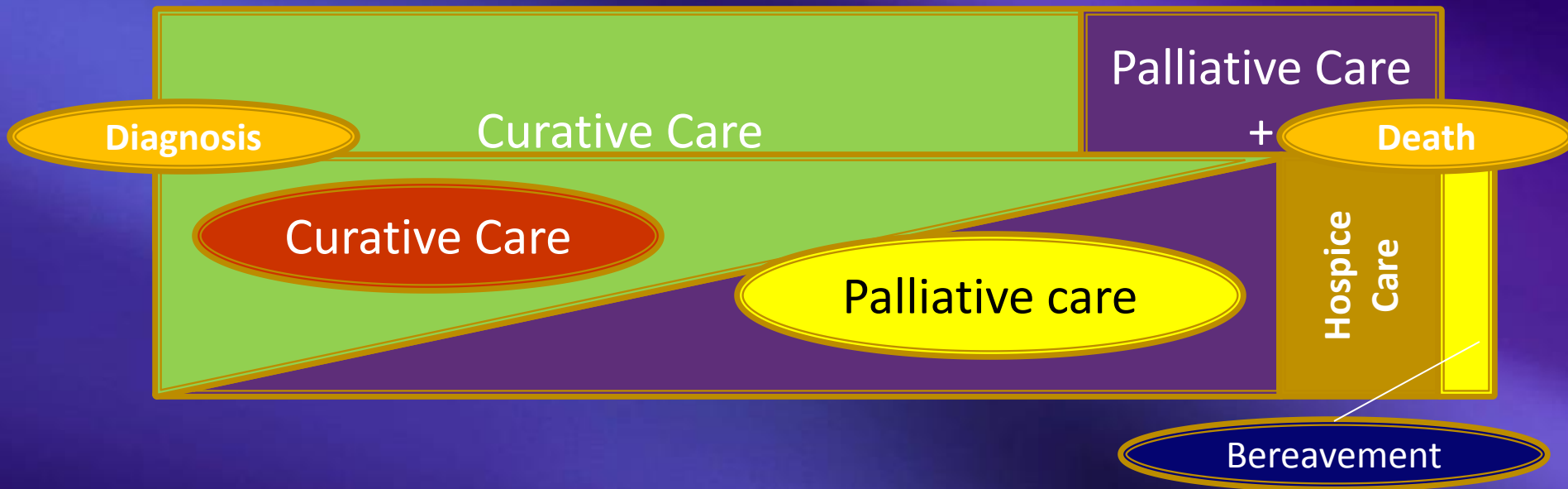
Hospital PC Teams

- Extra layer of support to address needs of the patient during their ongoing disease-specific treatments
- Often called upon to treat intractable pain and symptoms communicate with patients, families and providers to match treatment options with the patient's goals of care, or to help create care plans that enable safe discharge and minimize the risk of readmission.

Community-based PC Teams

- May be provided in patient's home, ALF, or outpatient clinic
- Includes advanced illness management and “post-acute” transitional care programs
- An effort to meet the needs of the sickest and costliest patients who must otherwise call 911, visit ED, or be re-admitted

Palliative Care Spectrum



Hospice

- Hospice care is a service delivery system that provides palliative care for patients who have a limited life expectancy of 6 months or less and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition.



Difference Between PC and Hospice

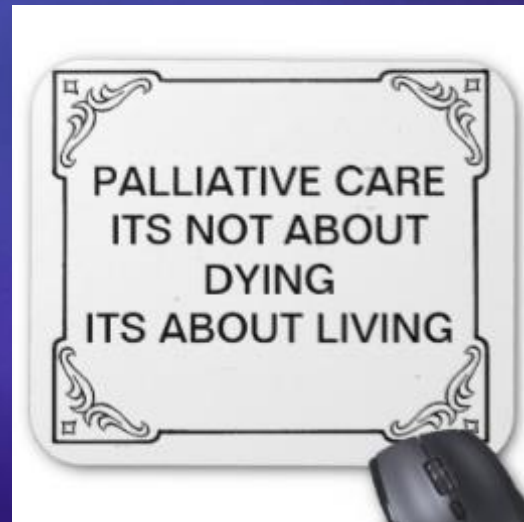
- Hospice

- Enrollment is required
- Patient must have a terminal illness
- Patient's insurance now covers all aspects of care

- Palliative Care

- Does not require enrollment or benefit choice
- No prognostic requirement
- No need to give up curative treatment

Palliative Care is not about
whether to treat or not to
treat, but about what is the
best treatment



So Many Treatment Choices

- Intubation
- Dialysis
- Do not Resuscitate
- Advanced therapies
- Hospitalization
- Curative medications
- Artificial hydration
- ICU
- Power of attorney
- Full code
- Feeding Tube
- Blood transfusions

Barriers to Quality Care at the End of Life

- Failure to acknowledge the limits of medicine
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Rules and regulations
- Denial of death



"First we'll find out if your insurance covers the magic wand treatment."



"My feeling is that while we should have the deepest respect for reality, we should not let it control our lives."

ART.
COM

Dying in America: Institute of Medicine Report (9/14)

- Improving quality and honoring individual preferences at end of life
 - Increasing number of elders with frailty, physical and cognitive disabilities, chronic illness and functional limitations
 - U.S. is more culturally diverse than ever
 - There are barriers to access for some groups
 - Mismatch of services for the needs patients and families and the services they can obtain

Dying in America

- Five areas for quality palliative care:
 - Delivery of person-centered and family focused PC
 - Clinician-patient communication and advance care planning
 - Professional education in PC
 - Policies and payment for PC
 - Public education and engagement in PC

IOM's Recommendations

● 1 Delivery of Care

- **Seamless, high quality care** that is patient centered and family oriented and available around the clock
- Consider the evolving physical, emotional, social and spiritual needs of individuals as well as family/caregivers
- Competent professionals
- Coordinated care
- Consistent with individuals' values, goals and preferences

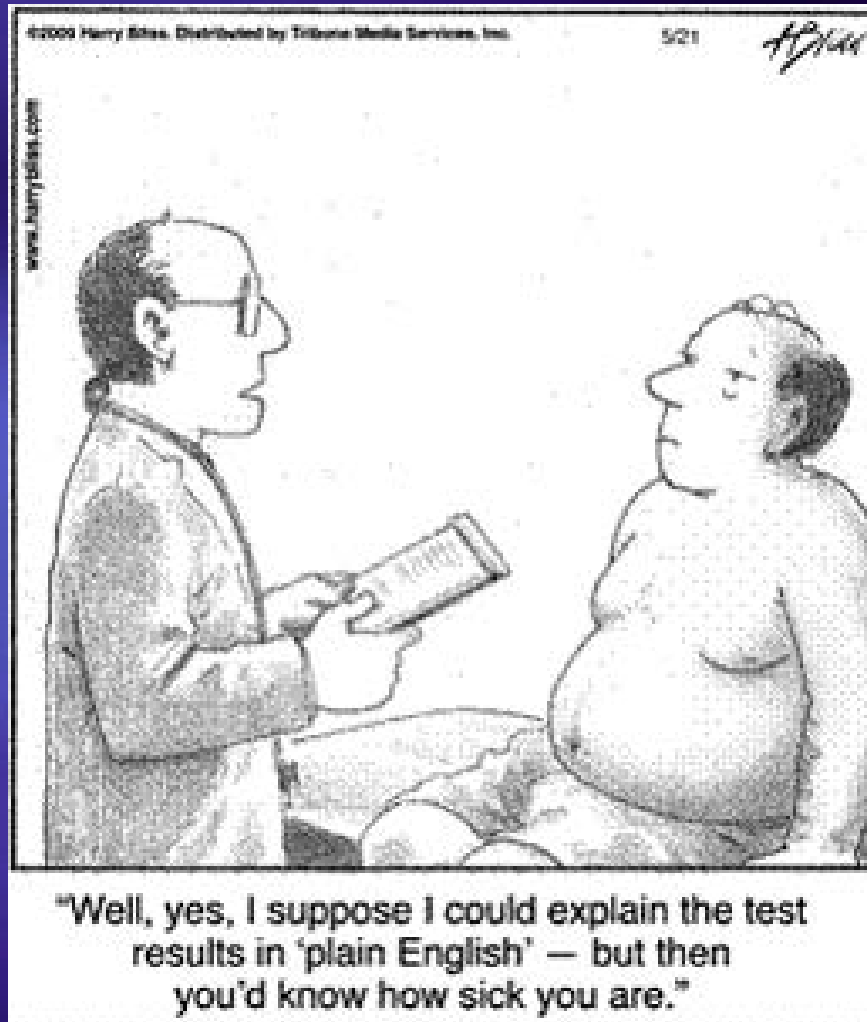
IOM's Recommendations

- **2. Clinician-Patient Communication and Advance Care Planning**
 - All individuals with capacity to do so should have the opportunity to **participate in their health decisions** throughout their life and receive care consistent with their values, goals and informed preferences
 - Clinicians should initiate high-quality conversations about **advance care planning** and communicate with other clinicians as requested
 - **Revisit** advance care planning with their patients as individuals' preferences and circumstances may change over time

Advance Care Planning

- Patient Self-Determination Act
- Advance Health Care Directives
 - DPOA
 - Living Will
 - Aging with Dignity Five Wishes
 - Respecting Choices
 - POLST

High Quality Communication?



Conversations About the Future



IOM's Recommendations

● 3. Professional Education and Development

- All clinicians across all disciplines and specialties who care for people with advance serious illness should be **competent in basic palliative care** including communication skills, interprofessional collaboration and symptom management.



IOM's Recommendations

● 4 Policies and Payment Systems

- Provide financial incentives for
 - Medical and social support services that decrease the need for the emergency room and acute care services
 - Coordination of care across settings and providers
 - Improved shared decision making and advance care planning that reduces utilization of unnecessary medical services and those not consistent with patient's goals of care

Financial Impact - Mission Hospital

- Cost reduction after PC consult = \$1167/day
- 366 patients seen in 2014
- \$243,925 saved for 108 patients from June to Oct 2014 (as determined by finance department)
- Extrapolated savings for the year on 366 consults is \$826,635
- These estimates DO NOT include another large impact which is termed Cost Avoidance, ex ER evaluation diverted from admission going on comfort care, avoiding unwanted surgeries or imaging

IOM's Recommendations

● 5. Public Education and Engagement

- Provide fact and **evidence based information** about care of people with advanced serious illness to encourage advance care planning and informed treatment choices based on the needs and values of individuals
- Encourage **meaningful dialogue** among individuals and their families and caregivers, clergy, and clinicians about values, care goals, and preferences related to advanced serious illness

Meaningful Dialogue?



IOM Report

- Inadequate number of palliative care specialists and too little palliative care knowledge among those who care for individuals with serious advanced illness
- Fragmented care delivery system with “perverse” financial incentives that contribute to lack of service coordination across programs and unsustainable growth in cost

Role of the APRN in Improving PC

- Recognize that some things cannot be “fixed”
- Use of therapeutic presence
- Maintaining a realistic perspective
- Expand the concept of healing
- Become educated
- Nurses are the constant

Role of the APRN in Assessment and Management of Symptoms

- Evaluates therapeutic and potential adverse side effects of pharmacological and non-pharmacological treatments, including integrative therapies
- Provides information about side effects of therapies

Symptom Management

- Diligent ongoing assessment and evaluation of symptoms is essential
- Management requires cohesive interdisciplinary teamwork
- Assessment includes patient/family evaluation
 - Education and support to family
- Diagnostic testing should be ordered in consideration of treatment planning or determination of intervention for symptom relief. If no change in management will result, the test should be questioned for appropriateness.

Chronic Conditions Managed by APRNs

- HIV – infections, cancers, symptoms, psycho-social
- Cancers
 - Solid tumors and hematological malignancies
 - Fatigue, resp issues, cachexia, diarrhea, N&V, pain
- Cardiac
 - Dyspnea, fatigue, chest pain, fluid retention, psych-social, mortality high, advanced therapies
- Pulmonary
 - COPD, restrictive lung disease, PH, CF
 - Dyspnea, fatigue, infections, compression fx, psych

Chronic Conditions Managed by APRNs

● Renal

- Acute and CKF
- Pain, fatigue, insomnia, pruritus, constipation, N&V, weakness

● Liver

- Alcoholic, non-alcoholic, viral
- Encephalopathy, portal HTN, varices
- Pruritus, pain , dyspnea, fatigue and malnutrition, Psych

● Neurological

- Encephalopathy,ALS, dementias, Parkinson's, brain tumor, CVA, TBI
- Cognitive impairment and function, pain, dysphagia, fatigue, seizures

● Diabetes

- Secondary conditions: renal disease, GI, PAD, retinopathy
- Pain and neuropathy

Common Symptoms in PC

- Pain
- Depression
- Dyspnea
- Anxiety
- Fatigue
- Delirium
- Insomnia
- Agitation
- Nausea/Vomiting
- Hiccoughs
- Constipation

Symptom Burden in Heart Failure

- Symptom prevalence:
 - Pain: 78%
 - Dyspnea: 61%
 - Depression: 59%
 - Insomnia: 45%
 - Anorexia: 45%
 - Anxiety: 30%
 - Constipation: 37%
 - Nausea/vomiting: 32%
 - Fatigue, difficulty ambulating, edema

Pain Considerations

- Pain is whatever the patient says it is, when they experience it Pasero & McCaffery, 2011
- Types of Pain:
 - Nocieptive, neuropathic, visceral
 - Acute, chronic, acute on chronic
 - Cardiac, pulm, ESRD, HIV/AIDS, Brain tumors, neurologic
- Memory for pain can last 48-72 hours
- Worsens when lying flat and standing

Treatment for Pain

Opioids

- Buprenorphine
- Codeine
- Fentanyl
- Hydrocodone
- Hydromorphone
- Methadone
- Morphine
- Oxycodone
- Oxymorphone

Non-Opioid

- Acetaminophen
- NSAIDS

Adjuvant Analgesics

- Anticonvulsants
- Antidepressants
- Corticosteroids
- Local anesthetics

Dyspnea Considerations

- Diagnosis: HF, PE, SVC syndrome, pulm edema, anemia, trach compression, ARF, pna, CA
- Treat symptoms or underlying cause
- Pharm: opioids, bronchodilators, diuretics, steroids, transfusion
- Non-Pharm: O2, counseling, energy conservation, fans, elevation, pursed lips
- XRT, stents

Fatigue and Insomnia Considerations

- Expert assessment
- Diagnostic: CA, anemia, Elect imbalances, malnutrition, infection, pain, organ failure, CNS injury, medications, deconditioning, hypoxia
- Treatments: treat other symptoms, stimulants, transfusion, O2, thyroid replacement, OT referral, Psychotherapy, Spiritual care
- Other: review sleep hygiene, review medication schedule, hypnotics

Nausea and Vomiting Considerations

- Careful assessment
 - In cancer patients, suspect brain mets and bowel obstruction
- Treatments
 - Anticholinergics
 - Antihistamines
 - Steroids
 - Prokinetic agents

Constipation Considerations

- Basic issue of care
- Preventable
- Always consider a bowel regimen with pain medications

Depression Assessment: SIG-E-CAPS

- S = sleep disorder or sexual function
- I = Interest deficit
- G = Guilt
- E = Energy deficit
- C = Concentration deficit
- A = Appetite disorder
- P = Psychomotor alteration
- S = Suicidality

Depression Assessment

- Are you depressed? Have you felt down or blue in the last month?
- How have your spirits been lately?
- How would you describe your mood today?
- How are you sleeping lately?
- What is your energy level”?
- What do you see in your future?
- What is the biggest problem you are facing?
- Can you concentrate as well as you usually could?

Depression Treatment

- Pharmacologic
 - Antidepressants
 - Stimulants
- Electroconvulsive Shock Therapy
- Cognitive Behavioral Therapy
- Spiritual Support
- Other

Anxiety Considerations

- Usually easy to detect
- Affects physical and psychiatric domains
- Can cause other secondary effects
- Treatment
 - Benzodiazepines
 - Antidepressants
 - Hypnotics for sleep
 - Stress Management
 - Counseling
 - Spiritual Support

Delirium Considerations

- Hypoactive delirium is often overlooked
- Hyperactive delirium is more visible
- Both types together can be difficult to clarify
- Medications can cause delirium
- Lack of sleep may be a factor
- Infection, particularly in the elderly, is critical to assess

Delirium Treatment

- Sedatives and antipsychotics
- Calm environment
- Familiar people such as family and caregivers
- Communication for all care and procedures

ANA Position Statement

- “the counseling a nurse provides regarding end-of-life choices and preferences for individuals facing life-limiting illness, as well as throughout the patient’s life span, honors patient autonomy, and helps to prepare individuals and families for difficult decisions that may lie ahead.”

Hospice and Palliative Nurses Association APN Competencies

- Collaborates with PC team and other HC professionals
- Creates an effective and compassionate environment
- Offers therapeutic presence
- Promotes use of verbal, nonverbal, and/or symbols
- Monitors and reflects on own emotional responses
- Elicits patient and family understanding
- Provides EB information and counseling
- Communicates treatment options, benefits and burdens

APRNs and Communication

- Information gathering
- Imparting information
- Assuring cultural competency is applied
- Skills include:
 - Delivering bad news
 - Advance care planning
 - Providing psychosocial support
 - Facilitating family meetings
 - Updating the status of an illness
 - Supporting patients/families through grief and bereavement

Why are end of life conversations so difficult?



The facts are:

- 100% guaranteed: We are all going to die.
- 60% of people say that they want to make sure their family is not burdened by tough decisions yet 56% have NOT communicated their end-of-life wishes.
- 70% of people say they prefer to die at home yet 70% die in a hospital or nursing home.
- 80% of people say that if they were seriously ill they would want to talk to their healthcare providers about end-of-life care but 7% report having that conversation with their doctor.
- 82% of people say it is important to write down their wishes but only 23% have actually done it.

Barriers and Challenges

- Lack of experience
- Sense of guilt for failure to cure
- Desire to support a perception of hope
- Fear of not knowing the answer to a question
- Disagreement in treatment choices
- Lack of cultural understanding
- Lack of understanding of patient and family's end-of-life goals, wishes
- Personal communication style

How to Overcome Barriers

- Listen, listen, listen
 - Physically, mentally, emotionally
 - Don't anticipate what may be said
 - Don't interrupt
- Be present
- Acknowledge your vulnerability
- Encourage conversation:
 - “Tell me more”
 - “So you mean that...”
 - “I can imagine...” (not “I understand...”)



Exploratory Statements

- Tell me what you know about your condition?
- How are things going for you?
- How much information do you want to know?
- What are your expectations about your condition?
- Is the treatment what you expected?
- Is there anyone else you want to know or to whom we should talk about your condition?
- If you decide you don't want to make decision, who will make them for you?

Exploratory Statements

- Are there any cultural or spiritual considerations I should know about?
- Do you have a spiritual base? Believe in a higher power?
- Is there anyone you would like me to call?
- Can you anticipate any potential areas of concern for you or your family?
- Who would you call if your started to feel sad?
- Who is your support?

Family Discussions

- What is your understanding of your family member's condition?
- How much do you want to know?
- Permission to speak frankly and honestly?
- Focus on the family member's wishes
 - If your family member were sitting right here, how would they answer these questions about treatment options, end-of-life care, code status?
- Remind families they are not making decisions for themselves, but for their family member in accordance with their wishes

End-of-Life Discussions

- Use words like death and dying
- Maintain hope for pain and symptom control, a good death, chance to resolve issues with family
- Clarify benefits and burdens of treatment options
- Ensure consistent information is being given



Exploratory Statements

- I'd like to talk with you about possible health care decisions in the future
- I would like to discuss something I discuss with all my patients admitted to the hospital
- I want to be sure that I understand your wishes and preferences for aggressive care when there may be changes in your condition.

Hope

- Hope for the Best...Prepare for the worst
- Encourage patient/family to reminisce – gives meaning to their lives
- Review treatments that may prolong life and relieve suffering
- What would be left undone?
 - Some want to die with things on their “bucket list”
 - Some want to die with their “bucket list” completed
- Aggressive treatments, such as CPR

Code Status

- Unrealistic expectations
- Less than 8% survive CPR
- Begin with brief review about patient's condition
- “Given the progression of your disease and the focus on quality and comfort, CPR would unlikely support either of those goals.”
- “I hear that you want more time, but I wonder if you understand that CPR may not allow you meaningfully interact with your family.”

Case Study

- 76 yo man with HF, PVD, CKD, COPD, DM
- Lives at home with wife who has early dementia
 - Daughter lives in town but works FT
- Retired postal worker who enjoys tinkering with old cars
- Catholic who hasn't attended mass for 3-4 years and feel guilty about it
- Living well means having his mind and independence; not being a burden to his family
- Dying well means going in his sleep, comfortable, at home

January 4th, 1st Hospitalization for HF

- Fluid balance restored with IV furosemide
- Cardiologist wouldn't be surprised if patient died in the next year
- Tires and feels short of breath with activity
- Worries about wife's slipping memory and safety

March 28, 2nd Hospitalization

- Moderately symptomatic with max medical management
 - Dyspnea and palpitations with daily activity
 - Moderate to severe leg pain from PVD
- Renal function worsening
- Cardiologist wouldn't be surprised if patient died in next 6 months
- Decreasing function/mobility, increasing isolation and caregiver fatigue (daughter)

May 9, 3rd Hospitalization

- Highly symptomatic
 - Dyspnea at rest
 - Severe leg pain
 - Cachexia/weakness
 - Delirium
- Hemodialysis started

June 1, 4th Hospitalization

- Intubated, sedated/restrained, CRRT
- Necrotic foot
- Multiple specialists
- Daughter drops mom off at hospital before work and picks her up after 6pm

What if...In the Beginning

- Diagnosis of heart failure
- “HF is a chronic illness that we are going to work hard to control. Part of good medical care is to talk about what to expect.”
- “One of the most important things for us to know is who could best speak for you if you could not.”
- “At some point, your illness might cause some symptoms and stress. We work with a team called Palliative Care that can help.”

First Hospitalization - Redo

- Fluid balance restored with IV furosemide
- Cardiologist wouldn't be surprised if patient died in the next year
- Tires and feels short of breath with activity
- Worries about wife's slipping memory and safety

- Confirmed discussion about future wishes
 - Discussed Palliative Care vs. hospice
 - Confirmed DNAR/DNI

March 28, 2nd Hosp. - Redo

- Moderately symptomatic with max medical management
 - Dyspnea and palpitations with daily activity
 - Moderate to severe leg pain from PVD
 - Renal function worsening
- Cardiologist wouldn't be surprised if patient died in next 6 months
- Decreasing function/mobility, increasing isolation and caregiver fatigue (daughter)
- Again, confirmed his wishes
- Discharged on Hospice and passed away comfortably at home with family around him

The focus of Palliative Care is to give the best evidenced-based treatment that conforms with the wishes of each individual



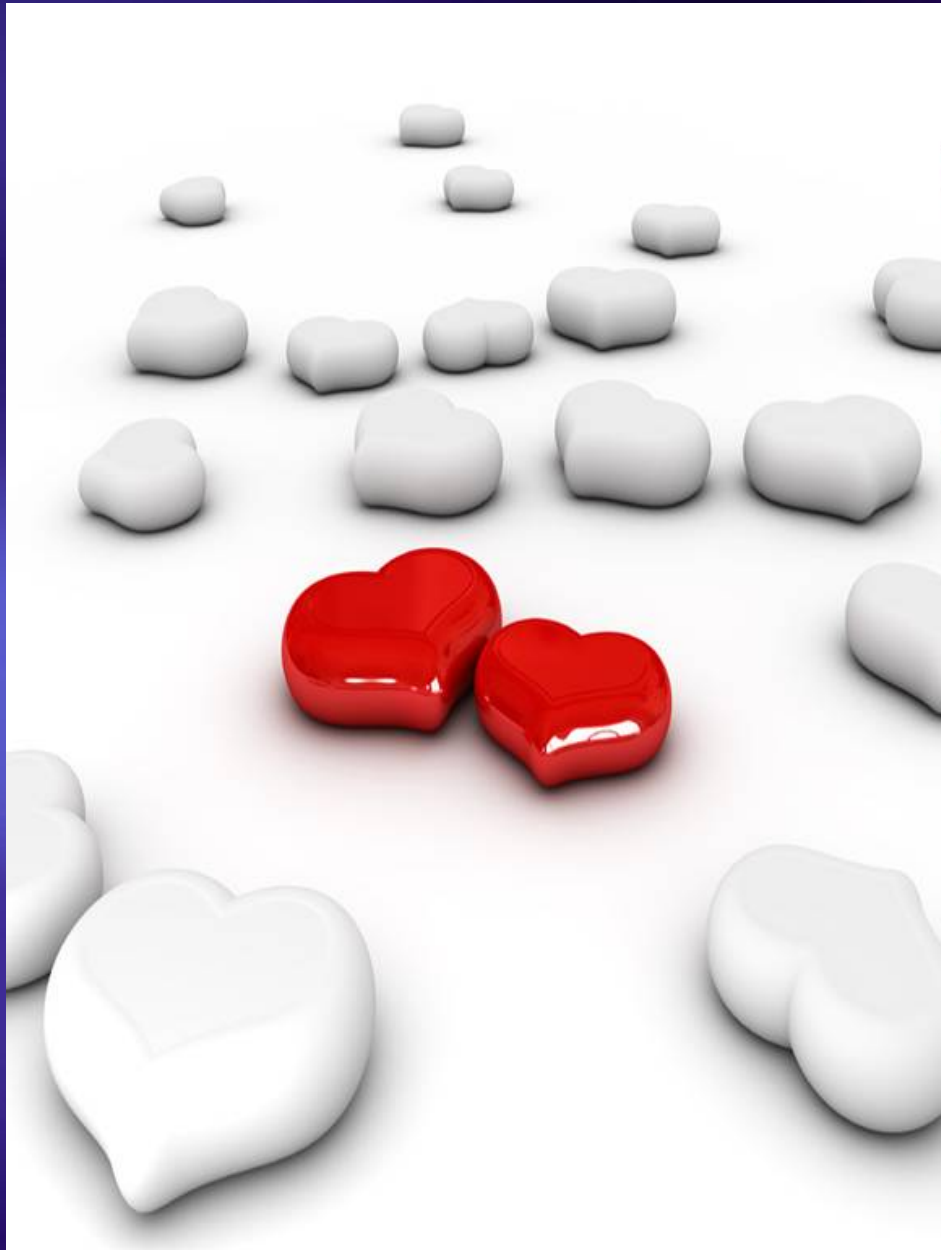
~ Dignity ~

*We never stop being human
through the last stages of life.*

*We never stop experiencing
the full range of human emotions.*

*Palliative care is about dignity
and respect. It is about quality
of life in the final stages.*

Source Unknown



If ever there is tomorrow when we're not together... there is something you must always remember. you are braver than you believe, stronger than you seem, and smarter than you think. But the most important thing is, even if we're apart...

I'll always be with you
~ Winnie The Pooh

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www.spreading-joy.org

References

- Center to Advance Palliative Care, Retrieved from <http://www.capc.org>
- **Institute for Healthcare Improvement (www.ihp.org)**
- Paulus, S.C. (2013). Palliative care: an ethical obligation. Retrieved from <http://www.scu.edu/ethics/practicing/focusareas/medical/palliative.html>
- The Conversation Project www.TheConversationProject.org
- Wessel, E.M., & Garon, M. (2005, August). Introducing reflective. Home healthcare nurse, 23, 516-522.
- ELNEC - <http://www.aacn.nche.edu/elneec>
- Hospice and Palliative Nursing Association- <http://hpna.advancingexpertcare.org/>

Thank you

Questions??