Objectives

- Learn what Palliative Care (PC) is, history and current trends
- Understand the difference between PC & Hospice
- Know ways to start quality of life (QOL) conversations
- Become more familiar with Advanced Care Planning (ACP)
- Recognize and support anticipatory grief and self-care
Medicine’s Shift in Focus

- Science, technology, communication
- Marked shift in values, focus of North American society
  - Value productivity, youth, independence
  - Organizational promises
  - Devalue age, family, interdependent caring

Death & Dying in America

<table>
<thead>
<tr>
<th></th>
<th>Early 1900s</th>
<th>Current</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine’s Focus</td>
<td>Comfort</td>
<td>Cure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Science, Technology, Communication</td>
</tr>
<tr>
<td>Cause of Death</td>
<td>Infectious Disease &amp; Communicable Disease</td>
<td>Chronic Illnesses</td>
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<tr>
<td>Death Rate</td>
<td>1720 per 100,000 (1900)</td>
<td>800.8 per 100,000 (2004)</td>
</tr>
<tr>
<td>Average Life Expectancy</td>
<td>50</td>
<td>77.8</td>
</tr>
<tr>
<td>Site of Death</td>
<td>Home</td>
<td>Institutions</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Family</td>
<td>Strangers/ Health Care Providers</td>
</tr>
<tr>
<td>Disease/Dying Trajectory</td>
<td>Relatively Short</td>
<td>Prolonged</td>
</tr>
</tbody>
</table>

Medicine’s Shift in Focus ...

- Death “the enemy”
- Sense of failure if patient not saved
A Brief History

Middle Ages:
religious "hospices" for travelers

1874: Our Lady's Hospice in Dublin for dying only
1966: Dr. Elisabeth Kübler-Ross publishes *On Death and Dying*. 
1974: New Haven Hospice begins hospice home care in the U.S.
1978: NHPCO founded, included PC in 2000
1979: St. Christopher’s Hospice in London
1984: Medicare adds hospice benefit.
1987: 1st US PC program, Cleveland Clinic
1989: 1st PC program, Cleveland Clinic
1999: CAPC founded
2006: Hospice & PC recognized as subspecialty by ABMS & ACCME
2006: Hospice & PC recognized as subspecialty by ABMS & ACCME
2004: 1st 1-million served by hospice in a yr
2014: 1st 1-million served by hospice in a yr

PC in Leading Health Care Organizations

The estimated number of hospitals with palliative care has dramatically increased in the past decade.

PC growth in U.S. Hospitals

The number of hospital palliative care teams in the US has grown dramatically over the past decade.

The prevalence of PC in U.S. hospitals with 50 beds or more has nearly tripled since 2000, matching 76% of all hospitals of this size

Supporting an estimated 6-million Americans!
Why Palliative Care?

- Better compliance with quality & pain standards
- Increased patient & family satisfaction
- More timely referrals to hospice & home services
- Decreased Medicare readmits

Reducing Chronic Suffering for Chronically Ill

- Multiple studies on Palliative Care have shown:
  - Seriously ill patients endure untreated and recurrent pain & other symptom crisis... they call 911, frequent ER visits and repeated lengthy hospitalizations.
  - Prolonged lifespan and lower costs

(copc 2015 report card)
What is Palliative Care? “Pal-lee-uh-tiv”

- Specialized medical care
  - People living with chronic illnesses
- Regardless of:
  - Age, stage of disease, treatment options or goals of care
- Goals:
  - Improve quality of life (QOL) for both patient and family
  - Provide relief from symptoms, physical and mental stress
  - Educate and give anticipatory guidance
- Service:
  - Programs vary from location settings, population, team members/providers, if prescribe controlled substances or not, diagnosis, insurance, and community initiatives

Common Chronic Illnesses

- Cancer
- Heart Disease, CHF
- Pulmonary Disease, COPD
- Kidney disease, ESRD, CKD
- Liver Disease, Cirrhosis
- Neurological – Dementias, Stroke, ALS, MS, Parkinson’s, TBI

When to Consider Palliative Care?

- When the chronic disease starts to impact one’s quality of life...

<table>
<thead>
<tr>
<th>Distressing Symptoms</th>
<th>Challenges Coping</th>
<th>Medical Planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Increased anxiety, depression, &amp; insomnia</td>
<td>Needing help understanding illness &amp; coordinating care:</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Decreased QOL</td>
<td>• Medical condition</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Increased dependence on others</td>
<td>• Treatment options</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>Complicated grief or care giver strain</td>
<td>• Things to anticipate</td>
</tr>
<tr>
<td>Constipation, Diarrhea</td>
<td></td>
<td>• May have &lt;2yr to live</td>
</tr>
<tr>
<td>Non-healing wounds</td>
<td></td>
<td>• 3+ hospitalizations or frequent ER visits &lt;1yr</td>
</tr>
<tr>
<td>Cough</td>
<td></td>
<td>• Lack of advanced care planning</td>
</tr>
</tbody>
</table>
**Common Questions**

- **Where do I receive PC?**
  - Variety of settings including the hospital, nursing homes, rehab centers, outpatient, clinic, home, community support groups

- **Does my insurance pay for PC?**
  - Most insurance plans, including Medicare and Medicaid, cover PC

- **How do I know PC is right for me?**
  - If you suffer from pain, stress or other symptoms due to a serious illness. Take the quiz [getpalliativecare.org/whatis/faq/]

- **What can I expect from PC?**
  - Improved quality of life: Relief from symptoms to help carry on with daily life. Improved ability to go through medical treatments. Better understanding of condition and choices for medical care.

**Common Questions Cont.**

- **Who provides PC?**
  - Often a team of palliative care doctors, nurses and other specialists

- **How does PC work with my own doctors?**
  - PC team works in partnership with other doctors to provide an extra layer of support. PC team provides expert symptom management, extra time for communication about goals, treatment options and help navigating the health system

- **How do I get PC?**
  - You have to ask for it! Some providers recommend or send referrals

**Change in Care Over Time**

- **Diagnosis**
  - Curative Focus: Disease-Specific Treatments
  - Palliative Focus: Comfort / Supportive Treatments

- **Illness**
  - Prevention
  - Curative Care

- **Death**
  - Hospice Care
You Are More Than Just A Diagnosis

Palliative Care vs. Hospice

- All dogs are animals, but all animals are NOT dogs!
- All Hospice is Palliative Care
- All Palliative Care is not Hospice

Relationship between PC & Hospice....

- Palliative care consultations increase earlier referrals to hospice.
- Late referrals to hospice correlate with unmanaged symptoms, lower overall family satisfaction, lower satisfaction with hospice services, more unmet needs, lack of awareness about what to expect at time of death, lower confidence in participating in patient care at home, and more concerns about coordination of care.
- In half of all cases of late referral, family members reported that physicians were a barrier to earlier hospice referral
Defining Terms

Palliative Care

Hospice

What is Hospice?
- Specialized type of Palliative Care: Caring > Curing
  - Focuses on QOL for terminally ill patients who no longer wish to intervene with natural disease progression/prolong dying process
- Life expectancy <6mo, if the disease follows its normal course
  - Physician must attest to this at admission
  - Benefit does not end at 6mo, may requalify
  - Fact: many patients live longer with hospice vs aggressive treatment
- Levels of care
  - Routine, inpatient and respite
- 24/7 support
  - Personal Hospice physician, nurses, home health aids, social worker, chaplain & volunteers
  - Bereavement support 13+ months

(www.nhpco.org)

Common Hospice Myths

Myths:  Facts:
- Hospice is a place
  - Hospice is not a place. It is a philosophy of care.
- Hospice helps you die
  - Hospice does not speed up the dying process. It accepts death as part of life.
- Hospice means giving up hope
  - Hospice does not mean giving up, but rather redefining what their hopes are about. Often, focus becomes more on fighting for quality of life vs quantity of life.
- Hospice is only for cancer patients
  - 40yrs ago hospice started by caring for people with cancer, however today more than half of patients have other end-stage chronic illnesses
- Hospice is for the very last days-weeks of life
  - Unfortunately, many people only use hospice in their final days of life although it is for people with a life expectancy of 6mo
Living Longer with Hospice

- Hospice vs non-hospice care for terminally ill patients
- Many hospice patients lived significantly longer

- CHF
- Lung cancer
- Pancreatic cancer
- Colon cancer

Montgomery Hospice (published in the Journal of Pain and Symptom Management)

US Hospice Average LOS, 2016

The Statistics Portal, Distribution of U.S. hospice patients based on length of stay

Dispelling Hospice Care Myths

- Removing the stigma surrounding hospice and redefining end-of-life care is essential to the future of healthcare.
- By 2060, the number of people age 65 or older in the United States is projected to reach 98.2 million, which will be roughly one in four Americans.
- That means more people will be living with chronic, life-limiting illnesses and require expert end-of-life care.
- Dispelling these four hospice myths can help bring us closer to providing high quality, skilled care to all patients who need it at the end of life.

Barriers to End-of-Life Care

- Disparity between desired and actual death
- Fragmented care
  - Multiple care providers and locations, less time with doctors, electronic medical records
- Psychosocial
  - Age, socioeconomic, education
- Health care providers lack of training
  - Unaware of EOL care options, what hospice is
  - Discomfort discussing end of life
  - Skills negotiating goals of care, treatment priorities, and advance care planning and true understanding of hospice

Evolving Beyond the “Either-Or”

CONVENTIONAL MODEL

- Clinical onset of serious illness
- Death
- Aggressive Care
- Palliative Care or Hospice
- Time
- Bereavement

IMPROVED MODEL

- Clinical onset of serious illness
- Disease-modifying, “curative” care
- Living well with disease; “palliative care”
- Hospice Care
- Time
- Bereavement

Source: Sick to Death and Not Going to Take it Anymore, Lynn and Adamson, 2003.

How to Choose?

- Curative Focus: Disease-Specific Treatments
- Palliative Focus: Comfort / Supportive Treatments
- EOL / Dying Life Closure
- Bereavement

Focus of Care
- Cure
- Life Prolonging
- Life Closure
- Comfort

Attitude vs. Condition
- Beat it
- Fight it
- Live with it
- Embrace it

Suffering Tolerance
- Very high
- High
- Low
- Very low
Helpful Questions

- What do you understand about your chronic illness?
- How has it impacted your quality of life? What changes have you experienced this past year?
- What do you anticipate as your disease progresses?
- What scares you most about your medical condition and your future health?
- What is important for you to maintain control over as your disease progresses?
- Do you have anything you hope for or want to accomplish before you die?
- What will be important to you when you are dying?

Case Study: PC vs Hospice?

- 86yo male with end stage heart disease
- CAD, CHF with EF 20%, arrhythmias, AICD with shocks, recurrent syncope episodes and 3 admissions past 6mo
- Anticipated <6mo with natural disease course

No Cure Does NOT Mean No Care

- Choosing PC does not mean stop fighting or give up hope
  - A person may give up on medical interventions that are no longer helping or causing more burden than benefit
  - PC may reframe what the person wishes to fight for and what hopes are about
  - Fighting harder for greater quality of life!
Empowering Patients, Reducing Family Stress

- Identify barriers
- Normalize, validate
- Active listening, touch, silence, reassurance
- Identify support system
- Be present

**Prognosis**

<table>
<thead>
<tr>
<th>Karnofsky Performance Status Scale</th>
<th>Definitions Rating (%) Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Normal; no complaints; no evidence of disease</td>
</tr>
<tr>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease</td>
</tr>
<tr>
<td>70</td>
<td>Cared for self, unable to carry on normal activity or to do usual work</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most personal needs</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care</td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated although death not imminent</td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary</td>
</tr>
<tr>
<td>10</td>
<td>Moribund; terminal illness progressing</td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
</tr>
</tbody>
</table>

**Palliative Performance Scale (PPS)**

<table>
<thead>
<tr>
<th>% Ambulation</th>
<th>Activity and Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Full</td>
<td>Full</td>
<td>Full</td>
<td>Full</td>
</tr>
<tr>
<td>90</td>
<td>Full</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80</td>
<td>Full</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70</td>
<td>Reduced</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60</td>
<td>Reduced</td>
<td>Occasional Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50</td>
<td>Very Sick/Dead</td>
<td>Considerable Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40</td>
<td>Totally Bed Bound</td>
<td>Total Care</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>30</td>
<td>As Above</td>
<td>Total Care</td>
<td>Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>20</td>
<td>As Above</td>
<td>Total Care</td>
<td>Minimal Signs</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>10</td>
<td>As Above</td>
<td>Total Care</td>
<td>Moderately Confused</td>
<td>Death or Confusion</td>
</tr>
<tr>
<td>0</td>
<td>Death</td>
<td>Total Care</td>
<td>Inefficient</td>
<td>Death or Confusion</td>
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</table>
PC Proactive Measures

- Advanced Care Planning
- Disease Education & Anticipatory Guidance
- Goals of Care
- Symptom Management
- Referrals & Community Resources
- Ways to minimize sense of loss:
  - Mobility: Adaptive equipment
  - Control: Advance directives, Head to Toe
  - What to expect: Reframing experiences, open discussion
  - Ways to continue: the patient’s story

Advanced Care Planning (ACP)

- It is impossible to provide good disease management without conversations addressing what to anticipate as the disease progresses
- Knowledge creates opportunities to be proactive, thus provide a sense of control in an otherwise incurable condition or state that knowingly will decline
- Help continue the conversation to re-evaluate what QOL means to the individual throughout the disease progression; ask questions, involve loved ones and providers

ACP Cont.

- The conversation is more important than the document
- Know your local laws
- Health Care Representative
- Code Status
- POST, Living Will

- It is impossible to provide good disease management without conversations addressing what to anticipate as the disease progresses
- Knowledge creates opportunities to be proactive, thus provide a sense of control in an otherwise incurable condition or state that knowingly will decline
- Help continue the conversation to re-evaluate what QOL means to the individual throughout the disease progression; ask questions, involve loved ones and providers
A POLST form is a **medical order** that tells emergency health care professionals what to do in case of a medical crisis when patient cannot speak for themselves.

An advanced directive is a **legal document** that tells who the patient wants making medical treatment decisions if they can't and generally, what treatments patient wants or does not want.

The POLST does **not** replace an advance directive — but they work together. While all adults should have an advance directive, not all should have a POLST form.

**Who needs one:** seriously ill or frail (any age) for whom health care professional wouldn’t be surprised if died within 1 year

---

**Code Blue, CPR vs DNR**

- Decision if you want CPR when your heart or lungs stop working...
- Time to choose is when you feel well and have the facts you need
- CPR has side effects
- Age and health make a difference
CPR Facts

- **Does CPR work?**
  - Not as much as most of us think
  - Works best if health with no illness and given to you within minutes
  - CPR does not work as well if:
    - You have chronic health problems or an illness that can no longer be treated, or older and weak

- **What else can happen?**
  - Lungs weakened, on breathing machine, cared for in an ICU, risk of brain damage, and damage to ribs

- **If you want to try CPR**
  - Talk about what results you would expect, goals and would make you no longer want to be alive

- **If you do not want CPR**
  - You will still get the care you need. There are many choices to help with comfort and live as well as possible

(www.gundersenhealth.org/respecting-choices)

PC & Communication

- Talking to patients is to PC what surgery is to a surgeon

  **Barriers to exploring & impacting patient’s QOL:**
  - Fragmentation of health care
  - Staff stress
  - Time constraints
  - Patient/family not feeling empowered
  - Patient/family own anticipatory grief

Communication is Crucial

- PC spends time talking and listening
  - Active listening, open-ended questions, reflective statements, clarification, normalize, validation, being present (2min rule)

- Assuring understanding of treatment options and choices

- Deeply exploring personal goals

- Coordinate with other providers

- SPIKES (Setting, Perception, Invitation, Knowledge, Summarize & Strategies)
BIAS: Our Own & Patient/Family Understanding & Acceptance of Disease Process
- Professional Education & Experience
- Experience with Death & Loss
- Unresolved Issues
- Personality & History of Coping
- Mindfulness & Self Care
- Spiritual & Culture Beliefs
- Compassion Fatigue
- Systems of Support

How Palliative Care Helps

<table>
<thead>
<tr>
<th>Proactive Measures</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Education &amp; Anticipatory Guidance</td>
<td>Improved patient QOL</td>
</tr>
<tr>
<td>Goals of Care</td>
<td>Greater patient understanding of disease</td>
</tr>
<tr>
<td>Symptom Management</td>
<td>Reduced caregiver strain</td>
</tr>
<tr>
<td>Referrals &amp; Community Resources</td>
<td>Enhance continuity of care</td>
</tr>
<tr>
<td>Advanced Care Planning</td>
<td>Earlier referrals to hospice</td>
</tr>
<tr>
<td>Enhance continuum of care with other providers</td>
<td>Understanding &amp; respecting patient wishes</td>
</tr>
<tr>
<td></td>
<td>Advanced care planning</td>
</tr>
</tbody>
</table>

Key Messages for Providers, How PC can help:

- Devoting extra time to intensive family meetings,
counseling education & collaboration with providers/continuity of care
- Resolving questions & conflicts to obtain desired Goals of Care
- Assist/recommendations with expertise in pain & symptom management
- Direct impact on reducing healthcare cost & Medicare readmissions

(CAPC/ACS-CAN Public Opinion Research Focus Groups, Conducted by POS 2011)
Common Phrases

- I don’t want that morphine—it killed my mom.
- But, I can’t just starve my husband.
- He told me he would never want to be in a nursing home, have a feeding tube, be on a ventilator, but...
- Nobody ever told me that my CHF/COPD/Parkinson’s/Stage 4 cancer wasn’t curable...
- What are you doing here? He is not ready for Palliative Care yet.

Talking to a Patient About Palliative Care

- Whatever you do...
  - DON’T use the words hospice or end of life when describing PC!

  ![Red x icon]

- Focus on words/topics of:
  - QUALITY OF LIFE
  - CHRONIC DISEASE MANAGEMENT
  - HOPES, GOALS
  - RESPECTING WISHES
  - PROACTIVE, REDUCING STRESS
  - MANAGING SYMPTOMS
  - SUPPORT COPING WITH ILLNESS

How Not to Communicate Recommendations

![Cartoon image of a doctor and patient]

“What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?”
Language to Avoid

- DO NOT use the following phrases regarding end of life decisions:
  - There's nothing we can do
  - Do you want us to stop everything?
  - It's time to think about withdrawing care
  - You've failed treatment
  - I think it's time for hospice

Loss.... We all experience it

- **Loss** may be a person, thing, relationship, situation, or role
- **Anticipatory grief** occurs before an actual loss or fear of potential loss
- **Grief** is an emotional response to a loss
- **Mourning** is the outward, social expression of loss which is strongly influenced by culture
Relaxation Tips

- Deep breathing
- Progressive muscle relaxation
- Meditation techniques
- Guided imagery
- Massage therapy
- Aromatherapy
- Acupressure & reflexology
- Stretching

Support Options

- Ask for help—Make specific request
- Routine "Me time"
- Support groups
  - In person and online
- Talk to your doctor & PC team about care giver demands and coping
- Explore care options
  - Private care givers or get paid
  - Adult day care, ALF, SNF
- Utilize mental health services

Elizabeth Kübler Ross’s five stages of grief:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

Self Care
EVERYONE CAN PROVIDE PALLIATIVE CARE!

- You know yourself, patients and loved ones better - health changes, likes, dislikes, behaviors, and things that bring pleasure to the day
- Talk about advance care planning, disease education & discuss end of life options
- Explore options & opportunities at home and work to increase conversations about wishes
- Recognize your own fears and be aware of bias

Resources

- www.getpalliativecare.org
- www.caringinfo.org
- www.capc.org
- www.nhpco.org
- www.homecareinformation.net
- ELNEC core curriculum
  - http://palliative.info/teaching_material/EffectiveCommunication.pdf
  - http://www2.latech.edu/~jenna/seminar-presentations/non-verbal_communication.pdf
  - https://www.youtube.com/watch?v=Kh6zVzWozk
  - https://www.capc.org
  - https://getpalliativecare.org/whatis/
  - http://www.oktodie.com/blog/when-dying-should-not-be-an-emergency/

Andrea Lantz, MSW, LICSW
Deaconess PC:
Inpt: 812-450-3201
Outpt: 812-450-3241
Email: andrea.lantz@deaconess.com