Since the PACE model of care has all the essential elements for quality palliative medicine and end-of-life care: an interdisciplinary team, a person-centered holistic approach, comprehensive care planning and care delivery that meets a participant’s needs and supports family and caregivers. PACE programs have an opportunity to provide excellent palliative care and end-of-life care to the participants and families. This will allow participants to remain living safely in the community throughout their lives and disease trajectories.
Learning Objectives

- Understand the Philosophy of Palliative and end-of-Life care in PACE
- Define Palliative and End-of-Life Care in PACE
- Introduce Key topics in providing high quality palliative and end-of-life care in PACE.
Currently in the U.S. over 50% of people die in hospitals. Often with their wishes not being honored. In a place that is foreign to them surrounded by medical professional that don’t know them and sometimes family not there or making decisions with out knowing the persons wishes truly are.

The US health care system is one that focuses on aggressive medical treatment until the very end. In the last few years of person’s life they are in and out of the hospital, trips to and from PCP, ER, to hospitalist, to specialist, having medications changed all over and usually No discussion about medical wishes or any other
wishes. Even when they are not known the are often not followed. (no clear MPOA, disagreements between family, Medical community erroring on etc)

• This is for several reasons: a culture that worships youth and is very uncomfortable talking about and will ignore the very natural process of death and dying. Lack of education in the medical field on end of life care and death is considered a failure. False hope about cure instead of death is a natural process.
• **PACE Organizations:** We are set up to work with this population. With the average LOS in a PACE organization around 2.5 years- Providing palliative and EOL care is a big part of what we do. But there is no guidance in the regulations on specifically on how that should be done.

• **CMS guidelines:** “Since comprehensive care is provided to PACE participants, those participants who need end-of-life care will receive the appropriate medical, pharmaceutical, and psychosocial services through the PACE organization. If the participant specifically wants to
elect the hospice benefit from a certified hospice organization, then the participant must voluntarily disenroll from the PACE organization.”

• **Education and structure:** As a PACE organizations we have the responsibility provide high quality palliative and end-of-life care to our participants and their families.
As a participant transitions across the care continuum, the IDT changes its focus of care to meet the needs of the individual. A participant whose care plan is curative focused will look different than one whose is palliative focused. PACE is an excellent model to support our participants along that continuum.
Palliative Care

- Palliative care in PACE is participant and family-centered care coordinated by the IDT which is directed toward improving quality of life and relieving suffering.
- It may be provided concurrently with curative strategies.
- Palliative care addresses physical, psychological, social, and spiritual needs of the participant and family in the setting of serious illness.
- Focus is clarified through the alignment of goals of care.

- Definition created by the NPA Palliative and End-of-Life Work group 2016
End-of-Life Care

• End-of-life Care in PACE is participant and family-centered care coordinated by the IDT which is directed toward improving quality of life and relieving suffering in the last months, weeks, days of life when the goal of care is no longer curative.

• It addresses physical, psychological, social, and spiritual needs of the participant and family in the setting of advanced life-limiting illness.

• Focus is clarified through the alignment of goals of care.

• Definition created by the NPA Palliative and End-of-Life Work group 2016
1. Can not be enrolled in PACE and the Medicare Hospice Benefit at the same time.
   • Pros: Hospice agencies have a history of expertise in providing end-of-life care. The PACE organization may not.
   • Cons: No longer being able to care for a participant that has been in the program. Loss of relationship and financial reimbursement.
2. Collaboration with Hospice
   1. Pros: working with an hospice agency can provide support and expertise that the PACE organization may not be able to provide.
   • Cons: communication between entities can become difficult. There may be philosophical differences. Decrease in relationship and financial reimbursement.
3. In-house Palliative and End-of-Life Program
   1. Pros: All-inclusive. PACE staff can continue caregiving relationship and be the ones provided care through death and bereavement. Increased cultural acceptance to death and dying issues.
   2. Cons: If a PACE organization does not have structure and education in place to provide this type care quality may suffer.
Circle of Care

- Registered Dietician
- Physical Therapist
- Occupational Therapist
- Recreation Therapist
- Speech Therapist
- Massage Therapist
- Beautician
3 Common Death Trajectories

- Cancer
  - Rapid Decline

- Organ Failure
  - Decline with Exacerbations

- Dementia/Neurological
  - Slow & Inexorable
• Total Pain
  • Another concept in EOL care that is very important to be aware of is total pain.
  • so often we conceptualize pain as just physical, and though it is an important component...there is a bigger picture.
  • Pain is what the ppt says it is!
  • We also need to be aware of the multidimensional aspect of pain and these can include:

• Physical
  • Pain is what aggressively and accurately addressing phial pain. We must follow the lead of the ppt with input from family, and all staff involved.
  • Those staff members tasked with phsycial pain must become experts in pain management.
  • Medications

• Psychological
  • Loss, grief, anticipatory grief, and chronic mental illness-
  • Loss of independence, frustration, pain
  • Withdrawing pulling away from things they used to like to do (reading paper, fly fishing, etc), their loved ones,
  • Pulling more inside

• Social
  • Social activities may diminish because of the ppt’s decline.
  • Regular communication/phone calls, etc.
  • There may be a pulling more inside to focus on internal things and they not as social
  • The ppt may naturally begin to pull away from social engagements, go inward, pull away

• Spiritual
  • Very personal
  • Unfinished business- Chaplain/others can create a safe environment to let it out...address forgiveness-
  • Self/ God/ Higher power
  • Ppts may have regrets in their lives at the end of their lives these regrets may become more prominent.
  • Did I live a good life?, Where am I going? It can be a natural thing to question one’s faith and how they lived their life.

• It is not always our job with pain to “Fix it” or take it away. Certain aspects or pain are better served but staff members being a witness to the suffering and being present to honour the process and offer support if appropriate.
Palliative and End-of-life programing is set up to promote high quality care and a Good Death.

• The concept of a "good death" is not a just a nice idea.
• There are quantifiable aspects

• **Most important: Control over the process**-
  • Participant has the say, direction, and their wishes should be honored.

**Caution/ Language**-
• A good death is not a cookie cutter experience or a list you check off.
• It is driven by participant and family preferences and wishes.
NPA EOL Education Series Modules
Topic Areas

1. Palliative and End-of-Life care in PACE
2. Advanced Care Planning
3. Trajectories and Symptoms
4. Self-Exploration
5. Communication and Difficult Conversations
<table>
<thead>
<tr>
<th>Topic Areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Family Dynamics</td>
</tr>
<tr>
<td>7. Cultural Considerations</td>
</tr>
<tr>
<td>8. Loss, Grief, and Bereavement</td>
</tr>
<tr>
<td>9. Ethical Issues</td>
</tr>
<tr>
<td>10. Final Hours</td>
</tr>
</tbody>
</table>
Bibliography/Resources


• End-of-Life Nursing Consortium (ELNEC)

• National Hospice and Palliative Care Organization (NHPCO)

• Center to Advance Palliative Care (CAPC)
Contact Information:

Tom Smith, LCSW

Regional Palliative and End-of-Life Care Coordinator

Volunteers Of America Western Slope Colorado

ThoSmith@voa.org

970-240-2706 Ext 27