Serious Illness Care: The Roles of Palliative Care and Hospice

2023 Coming Together in Advanced Practice Nursing Conference

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Disclosures

- None

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Outcomes

- **Self-report an increase in knowledge of serious illness diagnoses/conditions frequently seen in all care settings for patients across the lifespan and the roles that palliative care and hospice may serve in the care of these patients and their families.**
- **Self-report an increase in the knowledge of the roles of palliative care and hospice in the care of patients with serious illness diagnoses, when to involve them in the care of your patients, and the obstacles to referral to their teams.**
- **Self-report an intention to integrate knowledge into current practice**

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Supportive Care and Palliative Medicine Program

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True/False

- Palliative care services are only appropriate for a patient with a poor prognosis of less than six months, based on the natural history of their disease.

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True/False

- Patients with cancer must discontinue cancer treatment (chemotherapy, radiation, etc), and patients with ESRD must discontinue dialysis, in order to receive palliative care services.

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Multiple choice

- Palliative care services may be provided at which of the following locations?
  a) Home
  b) Hospital
  c) Nursing home/SNF
  d) Assisted living facility
  e) Outpatient clinic
  f) All of the above
  g) b, c, and e only

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True/False

- Palliative care reduces a patient’s life expectancy relative to disease-directed therapies alone.

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What is Palliative Care?

- Palliative care is the relieving or soothing of symptoms of a disease or disorder while maintaining the highest possible quality of life for patients.
- Many people mistakenly believe they can receive palliative care only when they can’t be cured.
- Palliative care can be provided while one continues curative treatments.
- Palliative care may help one recover from their illness by relieving symptoms—such as pain, anxiety, or loss of appetite—as they undergo other medical treatments or procedures, such as surgery or chemotherapy.
- https://palliativedoctors.org/palliative/care

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Choosing Wisely - AAHPM

- **Don’t delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.**

- https://www.choosingwisely.org/clinician-lists/american-academy-hospice-palliative-care-dont-delay-palliative-care/ Revised January 14, 2021

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Serious Illness

- What is a serious illness and what diagnoses are considered to be serious illnesses for which patients and their families would benefit from palliative care services and/or hospice care?

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Serious Illness Diagnoses

- Cancer
- CHF
- COPD
- Cirrhosis
- ESRD
- Dementia, Parkinson’s, stroke, ALS
- Adult failure to thrive

If a person is diagnosed with any of the above, they are appropriate for referral to palliative care, regardless of other treatments they are, or will be, pursuing.

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Palliative Care

- What are the roles and benefits of palliative care services in the care of patients and their families living with serious illness?
- What obstacles exist to referral to palliative care services?

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Palliative Care

- Regardless of the <u>stage</u> of the disease
- Regardless of <u>need</u> for other therapies
  - Concurrently with life-prolonging care
    <u>OR</u>
  - the <u>main focus</u> of care (via hospice care or comfort care)
- Aim:
  - Assist patient/family in <u>coping</u> with serious illness diagnosis
  - Assist with symptoms experienced with the serious illness
  - Assist patient/family/care team in <u>making care decisions</u> that work toward treatment goals with whatever time they have remaining, including hopes for cure or life-prolongation.

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Study of Early Palliative Care

- Among patients with metastatic non–small-cell lung cancer, early palliative care led to ***significant improvements in both <u>quality of life</u> and <u>mood</u>***.
- As compared with patients receiving standard care, patients receiving early palliative care had ***less aggressive care*** (medical interventions or procedures) *at the end of life*
- **<u>and</u> longer survival (~2-3 months)**!

- Temel JS, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42. doi: 10.1056/NEJMoa1000678. PMID: 20818875.

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Journal of Clinical Oncology 2020

"Accumulating data demonstrate that early palliative care, integrated with oncology care, not only improves these key outcomes (quality of life, symptoms of depression and anxiety, illness understanding, and end-of-life care) but also enhances ***coping*** in patients with advanced cancer."

- Greer JA, Applebaum AJ, Jacobsen JC, Temel JS, Jackson VA. Understanding and Addressing the Role of Coping in Palliative Care for Patients With Advanced Cancer. J Clin Oncol. 2020 Mar 20;38(9):915-925. doi: 10.1200/JCO.19.00013. Epub 2020 Feb 5. PMID: 32023161; PMCID: PMC7082158.

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ASCO Guideline

Recommendations:

- Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course (*within 8 weeks of diagnosis*), ***concurrent with active treatment***.
- Referral of patients to **interdisciplinary palliative care teams** is optimal, and services may complement existing programs.
- Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services.

- J Clin Oncol 35:96-112. © 2016 by American Society of Clinical Oncology

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Lack of Palliative Care Benefit

- Some studies show no benefit of palliative care
  - Single clinician, lack of interdisciplinary team
  - Late in the disease process (not enough time to help cope w/illness)

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Palliative Care & Hospice

Palliative Care = Diagnosis

Hospice = Prognosis (<6 mo)

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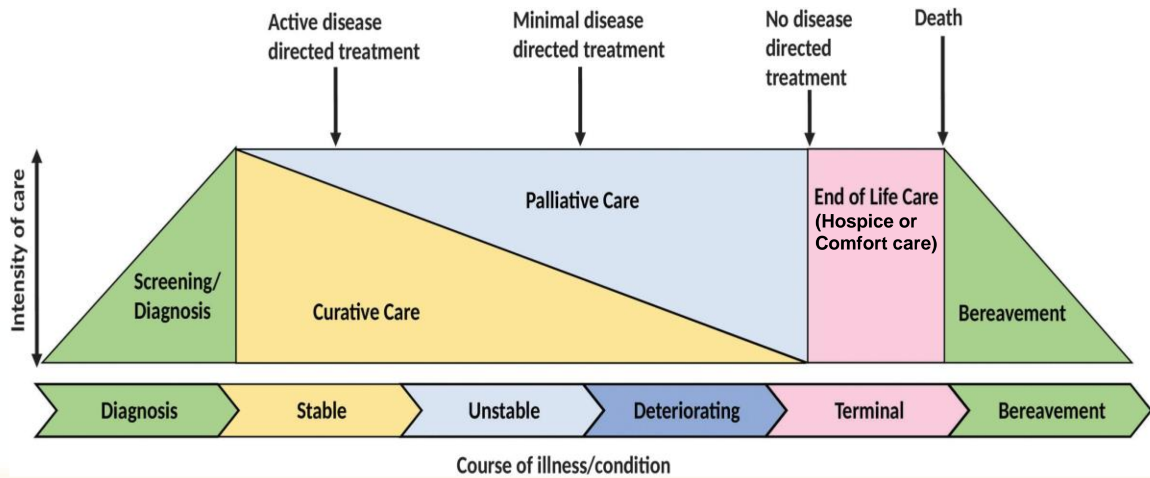

- https://pubs.asha.org/doi/10.1044/2020_PERSP-19-00032
- Kevin Craig edit (Hospice or Comfort care)

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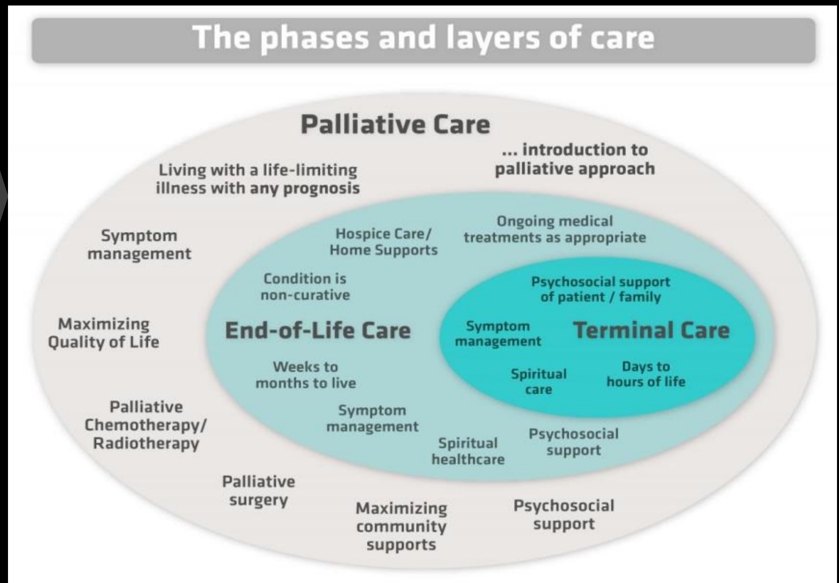

- https://hpc.providencehealthcare.org/about/what-palliative-care

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How to discuss palliative care…

"Given your diagnosis of (*serious illness*), it is the standard of care (or best practice) to involve the supportive and palliative care team.

They are a team that will work with our team, and your other medical care teams, to provide an extra layer of support to you and your family in coping with your illness, including assisting us with symptom management and planning for your future care (advance care planning).

We have asked them to see you (in the hospital or clinic)."

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If you wait…

to refer a patient to palliative care services when their prognosis is poor (less than six months), then they miss the benefit of palliative care.

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Palliative Care & Hospice

Palliative Care = Diagnosis

Hospice = Prognosis (<6 mo)

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Small Group Discussion

With those sitting near you, please take 5 minutes to discuss reasons/obstacles you can think of, or know of, that prevent patients from being referred for palliative care services.

Without naming names, think of situations in the past where referral to palliative care was denied by someone.

We will then take a few minutes for members of the audience to share with the rest of the audience.

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Obstacles to Referral

- Medical team (mis)perceptions of palliative care
- Patient/family (mis)perceptions of palliative care
- Availability of palliative care
- Lack of insurance coverage of palliative care (rare)

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True/False

- Hospice is a Medicare benefit for which patient's are eligible when their prognosis, determined by two physicians, is < 6 months based on the natural history of their diagnosis/disease.

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True

- Hospice is a Medicare benefit for which patient’s are eligible when their prognosis, determined by two physicians, is < 6 months based on the natural history of their diagnosis/disease.

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Small group case discussion

- 86-year-old female
- History of Alzheimer’s dementia, fronto-parietal CVA, depression, hypertension, hypothyroidism, arthritis
- Noted to have BMI 21, weight loss (120lb 6 mo ago, now 108lb), increased confusion, non-ambulatory, able to answer yes/no questions only; dependent for all ADL
- On memantine, risperidone, ramipril, levothyroxine, gabapentin, aspirin
- CBC, CMP, TSH, b12, u/a, CXR normal except albumin 2.4 and GFR 29
- MMSE 5/30
- What hospice admission criteria does she meet?

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Case studies, cont'd

- What hospice admission criteria does she meet?
  - PPS 40% (bedbound; dependent in >3 ADLs)
  - End-stage dementia: nonverbal (<5 words), non-ambulatory
  - Weight loss >10% in past 6 months
  - BMI < 22
  - Serum albumin <2.5

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Case studies, cont'd

- Moved home from nursing home w/hospice
- Memantine discontinued – why?
- Risperidone decreased due to sedation
- Gabapentin decreased due to renal insufficiency

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Case studies, cont'd

- 5 months later – ambulatory, MMSE 15/30, gaining weight
- discharged from hospice
  - Followed in outpatient palliative care clinic
- 5 months later – non-ambulatory, MMSE 5/30, losing weight; readmitted to hospice

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Medicare Hospice Benefit

- What is the Medicare hospice benefit?
- When do patients qualify?
- What services do hospice teams provide to patients living with terminal illness, and their families?

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HOSPICE

- PROGNOSIS

  < 6 months

- Surprise question:
  - “Would I be surprised if this patient died in the next six months given the natural history of this diagnosis/disease?”

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HOSPICE

- an agency that delivers supportive care to patients at the end of life and their families
  - prognosis of <6 months required
    - opinion of 2 physicians (usually attending & hospice director)
  - wherever the patient lives: home, NH, assisted living
- General Inpatient Hospice (GIP) – hospice care that “cannot reasonably be managed outside the hospital setting” such as intractable pain/emesis or delirium

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The Medicare Hospice Benefit

- Hospice is a program of care and support for people who are terminally ill and their families.
  - Helps people who are terminally ill live comfortably.
  - Isn’t only for people with cancer.
  - Focus is on comfort, not on curing an illness.
  - A specially trained team of professionals and caregivers provide care for your physical, emotional, social, and spiritual needs.
  - Services may include physical care, counseling, prescription meds, equipment, and supplies for the terminal illness and related conditions
  - Care is generally provided in the home.
  - Family caregivers can get support.

- https://www.medicare.gov/Pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf

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What’s covered by hospice?

- Hospice care is usually given in the home, but the hospice benefit may cover care in a hospice inpatient facility. Depending on the terminal illness and related conditions, the plan of care the hospice team creates can include any or all of these services:
  - Doctor services
  - Nursing care
  - Medical equipment (like wheelchairs or walkers)
  - Medical supplies (like bandages and catheters)
  - Prescription drugs
  - Hospice aide and homemaker services
  - Social worker services

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What else is covered by hospice?

- Grief and loss counseling for patient and family (until 13 months after death)
- Physical and occupational therapy
- Speech-language pathology services
- Dietary counseling
- Short-term inpatient care (for pain and managing symptoms)
- Short-term respite care
  - If usual caregiver (like a family member) needs a rest, patient can get inpatient respite care in a Medicare-approved facility (like a hospice inpatient facility, hospital, or nursing home). The hospice provider will arrange this.
- Any other Medicare-covered services you need to manage your pain and other symptoms that are part of your terminal illness and related conditions, as your hospice team recommend.

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Core Hospice IDT

- The hospice interdisciplinary team includes physicians, nurses, hospice aides, social workers, counselors, chaplains, therapists, and trained volunteers.
- National Hospice & Palliative Care Organization (NHPCO)

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Small group case discussion

- 54 year old male, history of schizophrenia
- Found to have advanced squamous cell carcinoma of neck
- Has tracheostomy, gastrostomy tubes
- Admitted to skilled nursing home for care
- 1st visit for surgical evaluation, he declines surgical, chemotherapy and radiation therapies

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Discuss

- Is he a hospice candidate? Why or why not?
- What issues must be addressed?

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Conclusion

- Determined to lack decisional capacity (physicians)
- Deemed incompetent (courts)
- Appointed guardian by courts
- Procedures again explained to guardian and patient, with risks and benefits of options
- He declines treatment, guardian and court agree
- Admitted to hospice for palliative/comfort care

False

- Palliative care services are only appropriate for a patient with a poor prognosis for whom you would not be surprised, based on the natural history of their disease, if they died in the next six months.

False

- Patients with cancer must discontinue cancer treatment (chemotherapy, radiation, etc), and patients with ESRD must discontinue dialysis, in order to receive palliative care services.

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All of the above

- Palliative care services may be provided at which of the following locations?
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False

- Palliative care reduces a patient's life expectancy relative to disease-directed therapies alone.

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Resource

- Fast Facts in Palliative Care
  - Free website (mypcnow.org) and smart-phone app
  - Evidence-based w/citations, one-pagers (460 to date)
    - #1 Diagnosis and treatment of terminal delirium
    - #460 Cognitive-based Pain Self-Management Strategies in Serious Illness

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Why discuss prognosis?

- How can a patient/family make an informed decision if they don't have all of the information needed to make that decision?
- What is the risk/benefit/burden of this intervention, and what is the risk/benefit/burden without?
- What is the patient's most likely prognosis with the intervention, and what is the likely prognosis without?
- How much will the intervention cause additional suffering for how much benefit?

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Quote

"When healthcare professionals provide their patients with the honesty, expertise, advocacy, compassion, and commitment they would want for themselves and their families,

they provide the highest quality of medical care possible."

Initiating End-of-Life Discussions With Seriously Ill Patients Addressing the "Elephant in the Room" Timothy E. Quill, MD *JAMA.* 2000;284:2502-2507

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Thank you!

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Questions?

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Resources: Organizations

- **Center to Advance Palliative Care: https://www.capc.org/training/an-in-depth-look-at-palliative-care-and-its-services/**
- **Fast Facts in Palliative Care: https://www.mypcnow.org/wp-content/uploads/2019/03/Core-Palliative-Hospice.pdf**
- **Palliative Doctors: https://palliativedoctors.org/palliative/care**
- **Choosing Wisely: https://www.choosingwisely.org/clinician-lists/american-academy-hospice-palliative-care-dont-delay-palliative-care/ Revised January 14, 2021.**
- **Medicare.gov https://www.medicare.gov/Pubs/pdf/11361-Medicare-Hospice-Getting-Started.pdf Revised April 2022**

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Peer-Reviewed Journal Article

Temel JS, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42. doi: 10.1056/NEJMoa1000678. PMID: 20818875.

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Clinical Guidelines

ASCO Guidelines

https://old-prod.asco.org/practice-patients/guidelines/supportive-care-and-treatment-related-issues#/9671

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Expert Resources

American Academy of Hospice and Palliative Medicine

National Hospice and Palliative Care Organization

Center to Advance Palliative Care

Fast Facts in Palliative Care

Palliative Doctors.org

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