Hospice and Palliative Care
What's the right choice for my patient?

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Providence Hospice

Learning objectives
• Participants will be able to
  – Describe the relationship between hospice and palliative care
  – Identify patients appropriate for palliative care
  – Identify patients appropriate for hospice care
  – Explain the benefits of incorporating palliative care and early discussion of hospice into their practice

My palliative care education
• 28 years as a registered nurse; 15 specializing in Hospice
• 4 years as a hospice nurse practitioner
• Patients and families
• Hospice teams
  – Aides
  – Nurses
  – Social workers
  – Chaplains
  – Medical staff
• Formal training
• Medical literature
What is palliative care?

People with serious illness

Provide relief from the symptoms and stress of serious illness

Improve quality of life

Center to Advance Palliative Care (CAPC)
https://www.capc.org/about/palliative-care/

Palliative care vision

Best possible quality of life to the end of life

Chronic Life Limiting Illness Trajectory

Advance Care Planning / Advance Directive

Active Disease Modifying Treatment and Intervention

Palliative Care

Reduce the symptoms and stress of serious illness and help through decision making

Provider Office, Acute Care Inpatient & Outpatient, Home, Hospice Inpatient & Outpatient, Long Term Care
Life limiting illnesses

- Cancer
- Heart failure
- COPD
- Pulmonary fibrosis
- CKD
- Debility

- Dementia
- Parkinson’s disease
- ALS
- Other degenerative neurologic diseases
- Other conditions

Goal of palliative care

Relieve suffering

Impact of serious illness

<table>
<thead>
<tr>
<th>Stress</th>
<th>Symptoms</th>
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<tbody>
<tr>
<td>Anxiety</td>
<td>Dyspnea (88%)</td>
</tr>
<tr>
<td>Depression</td>
<td>Pain (61%)</td>
</tr>
<tr>
<td>Spiritual distress</td>
<td>Terminal delirium (42%)</td>
</tr>
<tr>
<td>Existential distress</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Dysfunctional family coping</td>
<td>Depression (25-77%)</td>
</tr>
<tr>
<td>Financial stress</td>
<td>Nausea</td>
</tr>
<tr>
<td>Caregiver burnout</td>
<td>Bowel obstruction</td>
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<td></td>
<td>Adverse effects of medications</td>
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</table>
What is palliative care?

**Reduce stress**
- Listening and discussion
  - The illness, prognosis, and what to expect
  - Patient’s and family’s values
  - Relationship of goals and values to treatment options
- Reduce symptoms
- Provide emotional support for patients and families

**Reduce symptoms**
- Work with primary treating providers*
  - In-depth evaluation of symptoms and causes
  - Apply advanced symptom management tools and approaches to develop an effective plan
  - Provide access to medications not usually prescribed by PCPs

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A palliative care approach can accomplish more than just reduce day-to-day suffering

**Crisis Avoidance**

Where is palliative care provided?

- Clinical office
- Home
- RCF, ALF, AFH
- Nursing home
- Hospital
Who can provide palliative care?

- Physicians
- Nurse Practitioners
- Nurses
- Aides
- Social Workers
- Chaplains
- Physical therapists
- Complementary therapists
- Volunteers

* Hospice providers are available in or near most communities however palliative care providers and other staff may not be available outside the hospice setting

Barriers for primary providers

Talking with patients and families about serious illness can take a lot of time and it’s stressful…

so providers often avoid these important discussions and when they provide a prognosis, it’s overly optimistic


Prognosis and the crystal ball

Highly predictable
- Cancer
- Dehydration
- Active dying
- End Stage Renal Disease

Somewhat predictable
- Advanced Alzheimer’s disease

“Up for grabs”
- Most everything else
Most crystal balls are cracked… so

- Hospice eligibility: must attest to prognosis <6 months.
  - No good models for many conditions
  - Medicare criteria based on condition-specific “best medical evidence” and overall gestalt

Poor prognosis indicators*

**Nutritional status**
- >10% weight loss over 6 months
- Albumin <2.5 mg/dL
- Dysphagia with insufficient fluid intake
- Dehydration

**General factors**
- Infection history
  - Aspiration pneumonia
  - Pyelonephritis
  - Sepsis any cause
  - Recurrent fever
- Multiple stage 3-4 pressure sores
- Rapid decline over 3-6 months

* See Medicare LCDs for additional disease-specific criteria
  http://www.nhpco.org/sites/default/files/public/InfoCenterAccess/CAHABA_LCD.pdf
Your patient with ES COPD

He’s only 60 but he’s
- been intubated twice in the past 5 months
- recovering from acute exacerbation and almost ready for discharge
- lost 30 pounds over 6 months
- O2 sat 90% on 2L oxygen at “baseline”
- only able to walk to the bathroom with several stops to catch his breath

Patient and family might say…

- “Being on the ventilator was really awful. I don’t know if I want to do this again.”
- “I don’t know why he got sick but Dad’s a real fighter and he always beats it.”
- “We’ve been talking about moving Dad in with us so that we can make sure that he gets his medicines regularly and doesn’t get sick again.”

Making decisions

Patient with serious illness and family
- Goals?
  - Best Choices?

Palliative Care in hospice
Palliative Care outside of hospice
Your patient with ES COPD

- He’s eligible for hospice and home health
  - bed-to-chair existence
  - hypoxia at rest and despite oxygen
  - hospitalizations for respiratory failure
  - weight loss
  - not yet medically stable

COPD trajectory

He is here

What should you do now?
Making decisions

Patient with serious illness and Family

He’s eligible for Hospice or HH

TBD

Best Choice?

TBD

Advanced Palliative Care in hospice

Advanced Palliative Care outside of hospice

A patient with Alzheimer’s

He’s sweet but he’s
• speaking only 5-6 words/day
• lost 20 pounds (10%) over the past 6 months
• choking on liquids
• just recovering from aspiration pneumonia
• suffering severe back pain

The patient

• He’s eligible for hospice
  – Advanced dementia with significant decline
    • loss of ability to manage his ADLs
    • loss of speech
    • weight loss >10% in 6 months
    • aspiration pneumonia

• But is the family ready for comfort care?
His son might say...

I can’t understand why my father has lost his appetite and is losing weight. How can we get him to gain weight? And what can we do about his pain?

Several years ago my Dad and our whole family talked about dementia and what would happen as his dementia got worse. He told us that he wanted to die at home without heroics.

We never talked with Dad about his dementia and dying, but I think he’d want us to do everything?

Providence Palliative Care
Chronic Life Limiting Illness Trajectory

Don’t offer a plan until you understand what the family knows, hear their concerns, fears and family issues!
• Meet with the family to learn about the patient, family and their understanding of the illness*
• Learn about their values, hopes, and goals

Best practice is for a clinical person to partner with a social worker or someone with similar skills at picking up on psychosocial issues and other cues. Best options: a PCP with an MSW, a palliative care team, or an experienced individual alone.

• Correct misunderstandings
• Provide information about prognosis and options
• Reduce stress

Choices will sort themselves out

Prognosis and Treatment Options

Palliative Care outside of hospice
Hospice

Eligibility criteria include 6 months prognosis
Hope for the best

Plan A: Treatment will produce a cure

* Patient and family often has been advised that there is no possibility of cure

Starting to prepare for the worst

Plan A: Treatment will extend life*

* Patient and family often has been advised that there is no possibility of cure
Benefits of choosing hospice

- Financial benefits
  - Covers all symptom management medicines, DME, and oxygen
  - Includes all nursing care, bath aides, hospice physician oversight and 24/7 nurse triage
- Intensive psychosocial and spiritual support for patients and families
  - Includes services of chaplains, social workers, volunteers
  - One year bereavement support

Beliefs that create barriers

Active treatment = hope
Hospitals = rescue
Choosing hospice = giving up
Hospice = dying
Life not shortened by hospice

- Analysis of Medicare end-of-life claims data on nearly 4,500 adults (≈4000 with cancer)
  - 29 days average survival benefit for those receiving hospice at end-of-life
  - Benefit with cancer limited to lung, pancreas and colon cancer
  - Benefit greatest for people with heart failure


Cochrane review of SCLC

- Limited data comparing chemotherapy to "best supportive care" for small cell lung cancer
  - 1st line chemotherapy including platinum produced response but no significant difference in survival
  - 2nd line chemotherapy at relapse or progression may prolong survival for some weeks in relation to best supportive care


Primary hospice diagnoses

2013 National Hospice Data

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Cancer</td>
<td>36.5%</td>
</tr>
<tr>
<td>Dementia</td>
<td>15.2%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>13.4%</td>
</tr>
<tr>
<td>Lung disease</td>
<td>9.9%</td>
</tr>
<tr>
<td>All others</td>
<td>25%</td>
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2013 National Hospice Data

Median days on hospice 18.5 days
Mean days on hospice 71.8 days
Died or discharged within 7 days 34.5%
Died or discharged within 14 days 38.8%


Is continued treatment with limited benefit worth the outcome of delaying the opportunity to benefit from the robust support that hospice provides?

Symptoms and suffering

Suffering:
- Pain
- Anxiety
- Low Energy
- Dyspnea
- Poor appetite

No possibility of cure, little or no potential benefit from palliative chemotherapy, or no wish for further treatment.
Prepare for the worst— positively

Plan B: Control symptoms, support patient and family, and optimize quality of life

Palliative care outside hospice

Comfort, Pain, Anxiety, Energy, Dyspnea, Hope

Hospice Care

Plan B: Control symptoms, support patient and family, and optimize quality of life

Palliative care outside hospice

Comfort, Pain, Anxiety, Energy, Dyspnea, Hope

Hospice Care

Options when death is expected

Palliative care outside hospice vs Palliative care in Hospice

- Prognosis may be days to a year (or so)
- Wish may include ability to return to ED or inpatient care

- Prognosis must be less than 6 months
- Wish is to remain at home with support until natural death

* Palliative care at end of life not provided in hospice is usually delivered by a PCP in collaboration with a home health agency. Palliative care consultations are available in some communities.

Options when death is expected

Palliative care outside hospice vs Palliative care in Hospice

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* Hospice General Inpatient Care is "comfort care" provided for hospice patients whose symptoms can't be managed in the “home setting”. It is provided in a hospital or skilled nursing facility.
Options when death is expected

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<tr>
<td>• Wish may include ability to return to ED or inpatient care</td>
<td>• Wish is to remain at home with support until natural death*</td>
</tr>
<tr>
<td>• Care plan may still include active, life extending treatment, palliative chemotherapy, or rehabilitation</td>
<td>• Care plan does not include active, life-extending treatment</td>
</tr>
</tbody>
</table>

The POLST

Full code is the default option unless a POLST exists indicating DNR.
EMTs will attempt resuscitation and transfer the patient to hospital if 911 is called.

New videos available in English: [http://www.or.polst.org/resources/](http://www.or.polst.org/resources/) and Spanish: [http://www.or.polst.org/espanol/](http://www.or.polst.org/espanol/)

POLST & Advanced Directives

Natural death ≠ Cardiac arrest
POLST & Advanced Directives

Have you ever asked a patient

“What should we do if your heart stops or you stop breathing?”

Instead, assist patients and families in understanding how their goals and care options align with POLST and Advanced Directive choices.

Access to specialized palliative care services in your community.
Hospice

Available throughout the state

Carve out Medicare benefit: funded on a per diem basis through Medicare FFS, Medicaid or private insurance

Comprehensive: covers all nursing care, aides, social work, chaplain, and complementary services, equipment, and medications until death so long as prognosis remains <6 months, goals are aligned and patient shows evidence of ongoing decline

Care oversight: a hospice physician oversees all care and can provide management if requested by the PCP, patient or family

Exception: Symptom management visits provided by a hospice physician or PCP are billed separately

* Hospice physicians and nurse practitioners may or may not be Hospice and Palliative Medicine certified providers

Home Health (HH)

Available throughout the state

Carve out Medicare benefit: A program funded by Medicare for benefit periods, by Medicaid or private insurance

Benefit: Nursing care, bath aides, OT, PT, speech therapy, and social work with limit on number of days. Chaplain and dietitian services may be provided at no charge. Mental health nurses are available in some agencies

Other: Medications covered under Part D, DME, and provider services are covered under Part B

Care oversight/management: primary care provider with palliative care providers and social workers available for consultation in some communities

HH Palliative Care*

Available in some communities

Not a formal Medicare program: Services provided for patients with a limited prognosis who are enrolled in a home health program

Palliative nursing care: provided by home health nurses

Palliative care consultations: Palliative care physicians, nurse practitioners, social workers, and chaplains available in some communities to assist patients and families in determining goals of care and primary providers with symptom management (patients can be receiving active treatment)

* HH Palliative Care is not provided by all HH agencies
** Patients may also be eligible for hospice but have chosen not to enroll in hospice
Palliative Care Consultation Service

- Available in many hospitals but few outpatient programs
- A professional consultation service rather than a formal Medicare program
- Defined by service offerings: Palliative care physicians, nurse practitioners, social workers, and chaplains are available in some communities to assist patients and families in determining goals of care and primary providers with symptom management (patients can be receiving active treatment)
- Population served: patients with a limited prognosis who are not enrolled in a hospice program
- Settings: services can be provided in hospital, setting, hospital, SNF, ICF, or any “home” setting (e.g., ALF, RCF, AFH)

Palliative care programs summary

<table>
<thead>
<tr>
<th></th>
<th>Patient can continue to receive active treatment and rehabilitation</th>
<th>Unlimited duration based on prognosis &lt;6 months</th>
<th>Intensive comprehensive care benefit</th>
<th>Palliative care (PC) provider oversees or manages care</th>
<th>Palliative care (PC) staff provide psychosocial support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>HH Palliative Care</td>
<td>X</td>
<td>PC consultation support available in some communities</td>
<td>PC staff or consultants available in some communities</td>
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<td>Palliative Care consultations</td>
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* Hospice co-pays limited to physical symptom management visits. All patients must have regular visits from chaplains and must have a psychosocial/spiritual evaluation within 5 days of electing hospice.
** Some HH agencies have mental health nurses and/or nurse practitioners available.
Back to where we started

- You should be able to
  - Describe the relationship between hospice and palliative care
  - Identify patients appropriate for palliative care
  - Identify patients appropriate for hospice care
  - Explain the benefits of incorporating palliative care and early discussion of hospice into their practice

Thank you for your participation!

I hope you understand more about how palliative care and hospice teams can assist you in making your patients' end-of-life as comfortable and meaningful as possible.

Sharon Benjamin, ANP