Introduction to Building a Community Palliative Care Program

Lyn Ceronsky, DNP, GNP, CHPCA, FPCN
Palliative Care Consultant
Director of Palliative Care Leadership Center
Fairview Health Services
Objectives

• Gain a common understanding of key elements of palliative care
• Describe components of building palliative care programs in rural communities
• Discuss key issues in palliative care
What is Palliative Care?
Palliative care is:

• Specialized medical care for people with serious illness
• Focused on relieving symptoms, pain, stress
• Is appropriate at any age and at any stage, together with curative treatment
• Goal is to improve quality of life for pt/family
• Is provided by a team of physicians, nurses and other specialists who work with the patient’s other doctors to provide an extra layer of support
Palliative care is needed everywhere

• Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment.
• It is provided by a team of doctors, nurses, and other specialists, who work together to provide an extra layer of support.
Short Definition

Interdisciplinary care for patients and their families that improves quality of life during a serious illness; is an “extra layer of support”

Team members can use this definition as an “elevator” speech or as talking points
Eight Domains of Palliative Care

• Structure and process of care
• Physical aspects of care
• Social aspects of care
• Psychological aspects of care
• Spiritual aspects of care
• Cultural aspects of care
• Care of the patient at end of life
• Ethical and legal aspects of care

http://www.nationalconsensusproject.org/guideline.pdf
Hospice

Palliative care is not the same as hospice.

- Hospice cares for people with a six month prognosis (disease - expected course)
- Usually delivered at home; also delivered in facilities
- Medicare benefit, other insurances mirror medicare structure
Palliative Care’s Place in the Course of Illness

National Consensus Project for Quality Palliative Care
http://www.nationalconsensusproject.org/guideline.pdf

StratisHealth
What is the impact of palliative care?

• Many studies have shown that palliative care improves quality of life: reduces pain and other symptoms; patients feel better

• Helps health care teams: brings added expertise and time to work with high need patients and families

• Impacts cost of care by matching what patients want to their care plan (decreases readmissions, ICU stays)

• Improves patient and family satisfaction
Palliative Care Aligns with:

• The Value Equation: quality and cost
• Triple→ Quadruple Aim
• Patient and family-centered care
• Safety
• Care coordination
• Stewardship of resources
• Hospital mortality and readmissions
• Alternative Payment Models
Why is Palliative Care Needed?

• Advances in medical care allow people to live many years with chronic illness
• Our population is aging, especially in rural communities
• Increasing cost of medical care impacts individuals, communities, society
• A holistic approach is required to meet patients’/families’ complex needs
• Skills, processes and system improvements improve health care
A Palliative Care Story

• John Kelly is 75 years old with CHF and COPD; lives alone in own home
• Has worsening shortness of breath, anxiety, has been in/out of the hospital 6 times in last year with TCU stays
• Palliative care team is asked to see John by his primary care physician to develop a plan that meets John’s goals
A system of care?

Community

Hospitals

Physicians, NPs, PAs

Clinics

ED

Transitional Care

Nursing Facilities

Home Care

Home

Hospice
Pillars of Palliative Care

• Pain and symptom assessment and management (nausea, fatigue, anxiety)
• Psychosocial and spiritual support (patient and family)
• Information about prognosis and support to make decisions that reflect goals and values
• Continuity of care: transfer of key elements of a care plan that are documented and communicated across settings
Specialty Palliative Care and Primary Palliative Care

• Specialist providers: complete fellowships, achieve certification; almost total focus in palliative care

• Primary palliative care providers: skilled in symptom management, communication, psychosocial and spiritual support, transitions of care. Processes are in place to support their work
Developing a Palliative Care Program
Principles of Developing Community Based Palliative Care

- Assess need: talk with stakeholders
- Understand local environment
- Pilot program
- Ensure financial support
- Collect program data
- Coordinate care
- Assure quality
First Step: Needs Assessment

• Identify gap between current and needed palliative care services
• Confirms your motivation for starting a program
• Describes priorities of stakeholders to guide program development
Second Step: Decide Program Focus and Structure

• Specialty services
  – Where, what, population
• Develop processes across settings
• Determine education, resources
### Palliative Care Program Elements*

<table>
<thead>
<tr>
<th>Required element</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interdisciplinary team</td>
<td>Have regular interdisciplinary team meetings.</td>
</tr>
<tr>
<td>Assessment and management of symptoms</td>
<td>Initial &amp; ongoing, including physical and non-physical symptoms</td>
</tr>
<tr>
<td>Provider &amp; care team education</td>
<td>Staff has sufficient &amp; appropriate training relevant to roles on the team</td>
</tr>
<tr>
<td>Offer patient &amp; family centered advanced care planning and goals of care</td>
<td>Have a policy/process to support patients in creating an advance directive if they do not have one</td>
</tr>
<tr>
<td>Care is accessible</td>
<td>May include access after hours, community-based resource support and services, care coordination, and continuity of care</td>
</tr>
</tbody>
</table>

*As defined by MN Hospice and Palliative Care Network to be listed in an online registry as offering a palliative care program.*
Identifying People Appropriate for Palliative Care

- You would not be surprised if patient died within year or two
- >1 or 2 admissions in several months
- Symptom complexity
- Decline in function, i.e., failure to thrive
- Advanced disease: met cancer, chronic home oxygen use; NH + fall
Identifying People Appropriate for Palliative Care

- Advanced illness + no advance directive
- Admission to hospital from hospice
- Complex care requirements
- Limited social support in setting of serious illness
Third Step: Define Measures

Key Measurement Areas:
• Operational
• Clinical
  – Symptom management
  – Goals of care
  – Support to patient/caregiver
  – Transition management
• Satisfaction
Operational Measures

Operational

• Who are our patients?
• Who refers to our program?
• What happens after our intervention?
• Costs and revenue
Clinical Measures: Symptom management

- Assessment on initial visit
- Plan for symptom reduction
- Reassessment for moderate-severe symptoms
- Changes in symptom scores over time
Clinical Measures: Goals of Care/Treatment Discussions

- Diagnosis, prognosis, treatment options reviewed
- Goals of care identified
- Plans to meet goals documented
- Preferred setting for care
- Advance care plan; shared decision making
Clinical Measures: Psychosocial, Spiritual Support

- Needs identified
- People important to patient
- Coping strategies and support
- Plan to meet needs with follow-up actions
Clinical Measures: Transitions and Anticipatory Guidance

- Define what should be communicated across care settings
- Patients understanding of prognosis
- ADs, SDM with contact information
- Symptom management plans
- Community services
- Recommendations for next steps
Satisfaction Measures

- Patient and family
- Referring clinicians
- Health system
- Stakeholders
- Philanthropists
Palliative care programs have been developed in

- Hospitals, palliative care clinics, home programs, nursing homes
- Clinicians equipped with palliative care primary palliative care skills is essential for ongoing success
Hospital Palliative Care

- Review of patients at time of admission and daily for unmet palliative needs
- ICU family meetings
- Document discussion of prognosis and goals of care
- Bereavement
Clinic and Home Palliative Care

- Pain and symptom assessment and management
- Care planning
  - Advance directives, POLST
- Care management
- Linking to community resources
- Specialized palliative care education for home care staff
Nursing homes

• Pain and symptom assessment and management
• Advance care planning; identifying goals of care; POLST
• End of life care: care of the dying patient, comfort care orders, bereavement, staff support
Community Focus Areas

- Volunteers for practical and social needs
- Parish nurses; Aging organizations
- Collaboration with Alzheimer's or cancer initiatives
- Advance care planning
- Education
What does a rural palliative care program look like?

- Wide variation in structure and focus for the teams that have developed formal programs
- Process and system improvements are key component:
  - Process for supporting and documenting discussions of prognosis and goals of care
  - Shared order sets/care plans across settings
  - Professional and community education
### Variables in program structure

<table>
<thead>
<tr>
<th>Methods of service delivery</th>
<th>Interdisciplinary team</th>
<th>Patient focus</th>
<th>Coordinating staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home visits</td>
<td>All teams included physician, social work, nursing</td>
<td>Hospice eligible but refused</td>
<td>Nurse practitioner</td>
</tr>
<tr>
<td>Clinic appointments</td>
<td>Other disciplines vary:</td>
<td>Infusion therapy</td>
<td>Registered nurse</td>
</tr>
<tr>
<td>Nursing home visits</td>
<td>• Rehabilitation services</td>
<td>Home care with complex illness</td>
<td>Social worker</td>
</tr>
<tr>
<td>Inpatient consultation</td>
<td>• Volunteers</td>
<td>Inpatient consult when requested</td>
<td>Certified nurse Specialist</td>
</tr>
<tr>
<td>Telephonic case management</td>
<td>• Nurse practitioner</td>
<td>Physician referred with complex illness</td>
<td>Advance practice nurse</td>
</tr>
<tr>
<td>Volunteer support visits/services</td>
<td>• Chaplain</td>
<td>Nursing home residents – triggered by minimal data set (MDS) criteria</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Pharmacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Advance practice nurse in psychiatry</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Examples of Palliative Care Models in Rural Communities

- Build a team around the patient, primary physician/APP and family
- Nurse Practitioners offer consults, pulling in other member of the care team
- Triaging patient needs to identify frequency of visits and team member. May also include connections to social services supports or volunteer visitors.
- In some areas, telemedicine plays a role.
Key Issues in Palliative Care
Key Issues in Palliative Care: Finances

- MD/APN Provider revenue (like any consult or follow up in any setting)
- Cost avoidance: less resource use with alignment of care plan with patient goals
- Possible increased LOS in hospice
- Potential for alignment with Chronic Care Management billing codes
Financial sustainability

• As your program grows, consider opportunities for estimating program costs and generating revenue:
  – Provider billing
  – Advance care planning codes
  – Complex care management
  – Contracts with payers
  – Administrative support for improving quality, decreasing readmissions (metrics others care about)
Key issues in Palliative Care: Language Matters

- When we try to sell dying, we turn away the majority of patients who need our help
- For patients: improving concerns as they perceive them
- For health care agencies: quality, less resource use
- For physicians, NPs, PAs: time, help with pain and communication
Marketing

- A key part of program development is to create access to quality care for patients with serious illness and their families
- Explain the who-what-why-where
- Important to use language that talks about benefits to patients and families, stories work great
- Target information to what audience cares about: different messages to different audiences
Key issues in Palliative Care: Education

• For your team
  – Options: self study, on line courses, conferences, ELNEC, Fast Facts, APRN Externship program

• For your community

• For your colleagues
Education and Certification in Palliative Care

- Medicine: EPEC, other conferences in palliative care
- Fellowships: Clinical Scholars (one week)
- Certification: AAHPM: ([www.aahpm.org](http://www.aahpm.org))
Start where you are, use what you have, do what you can.

- Arthur Ashe