Palliative Care: A Focus on Person Centered Care

January 14-16, 2014  |  San Antonio, TX

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OBJECTIVES

• Identify differences between hospice and palliative care
• Describe a model for palliative care integration across the continuum of care
• Discuss the 12 Operational Domains of Palliative Care and Joint Commission Regulations as a gap analysis tool and format for program development
• Describe why patient-centered care is the core of Palliative Medicine and how this model is aligned with our Catholic health mission and practice model
It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.

William Osler
89% of inpatient discharges are from the highlighted service area.
Palliative Care: A Focus on Person Centered Care

Palliative Care

- Hospice
- Acute Palliative Care
- Community-Based
  - Consult Service
  - Acute Palliative Care Unit
Palliative Care as a Service Line

Sr VP & Chief Transformation Officer

Service Lines

Cardiovascular Services  Ortho Clinical Services

Women’s Health  Neurological Services

Palliative Care Services  Oncology Services
Palliative Care Defined

- Medicare - Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering.

  Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and facilitating patient autonomy, access to information and choice.
Trinity Health UCO Definition Palliative Care

• Specialized medical care for people with serious illnesses
• Focused on providing patients with relief from the symptoms, pain and stress of a serious illness - whatever the diagnosis
• Goal is to improve quality of life for both the patient and the family
• Provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support
• Appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment
How Does Palliative Care Differ From Hospice?

**Acute Palliative Care** - Interdisciplinary care for seriously-ill patient with *unpredictable* prognosis during acute hospitalization; spiritual/emotional support for patient/family; preparing for survival or death. It can be provided at the same time as life-prolonging treatments.

**Hospice Care** - Interdisciplinary care for dying patient with *predictable* prognosis; spiritual/emotional support for patient/family; primarily in home setting. Patients must have a 2 physician-certified prognosis of <6 months.
Community-Based Palliative Care

• Same holistic philosophy - manage symptoms through interdisciplinary care
  • Clinic
  • Nursing Home
  • Home Care
  • Hospice

• Goals of Care and addressing benefits and burdens of treatments IS central
What Does All This Mean from the Patient, Clinician, Hospital Perspective?

**Patient Perspective**
- Allow simultaneous palliation of symptoms/suffering *along with continued curative treatment*
- Navigate, coordinate a complex/confusing medical system, understand the plan of care
- Practical and emotional support for exhausted family

**Clinician Perspective**
- Promote patient and family satisfaction with the clinician’s quality of care
- Save time by handling repeated, intensive patient-family communications, coordination of care across settings, comprehensive discharge planning
- Bedside management of complex needs supporting the treatment plan of attending
What Does All This Mean from the *Patient, Clinician, Hospital* Perspective?

**Hospital Perspective**

Palliative care is a key tool to:

- Effectively address high number of patients with complex advanced illness
- Provide service excellence, patient-centered care
- Increase patient, family, staff satisfaction and retention
- Meet JC quality standards

*Increase efficiency of hospital resources, increase ICU capacity, avoid/reduce costs*
Doing Well . . .

- Documented savings of $1.0-1.5M per year through decreased LOS, decreased critical care / multiple Tx
- Increased referrals to hospice yields additional revenue for both hospice and hospital
- Patients transferred out of ICU
- Changes culture to talking about Goals of Care and coordinating care
By Doing Good

- Evidence-based
- Addresses the physical, emotional and spiritual needs of patients
- Coordinated care
- Multi-disciplinary team approach
- 95% + patient/family satisfaction
- More appropriate care for patients with chronic, multi-system conditions requiring management and symptom control rather than cure
It is … Dual Management

- Uncertainty of disease progression and preparation for both improvement or decline concurrently
  
  - Dr. Joanne Lynn

- Chronic disease management for life-limiting illness
- Care follows patient instead of patient following care
Palliative Care: A Focus on Person Centered Care
Mission and Ethics - A Fit with Palliative Care

Catholic Health Organizations

- Mission Standards
- *Ethical and Religious Directives for Catholic Health Care Services*

Ethical/Palliative Issues

When two or more values apply to a situation …

AND

these values support diverging courses of action …

an ethical conflict or dilemma exists.
In earlier times, the main job of a health care professional was to make the transition between life and death smoother, not to avoid the transition. Technology stretches the transition.

★ It does not help patients live better, just die longer.
Transition Management

- Care required to facilitate a shift from one disease stage and/or place of care to another
- Optimal transitions ensured through solid inpatient and outpatient integration
- Includes
  - Psychosocial assessment
  - Goals of Care
  - Functional status
  - Family involvement
Five **Principles** for Effective Care Transition

1. Accountability
2. Communication
3. Timely feedback and feed-forward of info
4. Pt/Family involvement
5. Respect coordination of care process
Health Care Spending NEEDS Palliative Intervention

• The highest 5% of health care users consume nearly 50% of resources.

• The steep, escalating cost of health care as people age suggests the American system overspends on end-of-life care.

• Complex ethical issues arise in providing appropriate end-of-life care that incorporates risk assessment, the patient's clinical condition and life quality considerations.
Palliating Health Care

• Doing no more than is necessary, engaging patients fully in medical choices and respecting patient preference for end-of-life care can reduce the differential in care cost between the U.S. and other developed countries.

• Implementing true informed consent results in more satisfied patients (and families), better outcomes and less intensive treatment.
“It is thornlike in appearance, but I need to order a battery of tests.”
Why is Palliative Care Important?

- Palliative care addresses both Catholic health mission and margin
- Positions us to move into the new phase of health care delivery
- Holistic
- Person centered
- Crosses the continuum
Palliative Care is the Answer

- There is no ability to reduce costs of health care without integrating palliative care.

- Instead of approaching a patient as a “checklist of problems” based on organ systems and diseases, palliative care ASKS about Goals of Care and total system issues and needs.

- Care is driven by the patient’s agenda, not the system checklist.

- Whole person, not a collection of organs
Physician Training

No formal training, physicians feel ill equipped ...

“They said there was ‘nothing to do’ for this young man who was ‘end stage.’ He was restless and short of breath; he couldn’t talk and looked terrified. I didn’t know what to do, so I patted him on the shoulder, said something inane, and left. At 7 am he died. The memory haunts me. I failed to care for him properly because I was ignorant.”
### Gaps

<table>
<thead>
<tr>
<th>Fears</th>
<th>Desires</th>
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<tr>
<td>Die on a machine</td>
<td>Die without machines</td>
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<tr>
<td>Die in discomfort</td>
<td>Die in comfort</td>
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<tr>
<td>Be a burden</td>
<td>Die with family/friends</td>
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<tr>
<td>Die in institution</td>
<td>Die at home</td>
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Comparison of Models

- **Curative**
  - **Primary goal** is cure
  - **Object** is disease process
  - **Symptoms** are clues to diagnosis
  - **Primary value** is measurable data

- **Palliative**
  - **Primary goal** is relief of suffering
  - **Object** is patient and family
  - **Symptoms** are entities unto themselves
  - Measurable and subjective data are valued
Comparison of Models

• **Curative**
  – *Therapy* is indicated if it affects disease progression
  – *Patient’s* body is differentiated from the mind
  – *Death* is the ultimate failure

• **Palliative**
  – *Therapy* indicated if it controls symptoms and relieves suffering
  – *Patient* has physical, emotional, social and spiritual dimensions
  – A *death* that occurs after suffering has been alleviated is a success
Merging the Gap

- Early symptom management interventions
  - While everything else is going on, are we doing a good job of keeping you comfortable?”

- Honoring Advance Directives and using them to establish Goals of Care
  - Objective benefits and burdens of treatment options
Trinity Health Palliative Care Definition & Organizational Scope

The Palliative Care 12 Operational Domains are:

- Domain 1: Program Administration
- Domain 2: Types of Services
- Domain 3: Availability
- Domain 4: Staffing
- Domain 5: Measurement
- Domain 6: Quality Improvement
- Domain 7: Marketing
- Domain 8: Education
- Domain 9: Bereavement Services
- Domain 10: Patient Identification
- Domain 11: Continuity of Care
- Domain 12: Staff Wellness
Patient-Centered Care
## Patient-Centered and Person-Focused Care

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<tr>
<th>Patient-Centered Care</th>
<th>Person-Focused Care</th>
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<tr>
<td>Generally refers to interactions in visits</td>
<td>Refers to interrelationships over time</td>
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<tr>
<td>May be episode oriented</td>
<td>Considers episodes as part of life-course experiences with health</td>
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<tr>
<td>Generally centers around management of diseases</td>
<td>Views diseases as interrelated phenomena</td>
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<tr>
<td>Generally views comorbidity as number of chronic diseases</td>
<td>Often considers morbidity as combinations of types of illnesses (mutimorbidity)</td>
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<tr>
<td>Generally views body systems as distinct</td>
<td>Views body systems as interrelated</td>
</tr>
<tr>
<td>Uses coding systems that reflect professionally defined conditions</td>
<td>Uses coding systems that also allow for specification of people’s health concerns</td>
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<td>Is concerned primarily with the evolution of patients’ diseases</td>
<td>Is concerned with the evolution of people’s experienced health problems as well as with their diseases</td>
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Patient Centered - Ask, Talk, Presence

Let me know if you want to know why I am here.
National Consensus Project Domains for Palliative Care

- Domain 1: Structures and Processes of Care
- Domain 2: Physical
- Domain 3: Psychological
- Domain 4: Social
- Domain 5: Spiritual, Religious, Existential
- Domain 6: Cultural
- Domain 7: Care of the Imminently Dying
- Domain 8: Ethical & Legal
Joint Commission – Advanced Certification for Palliative Care Patient Care Standards

- Patients know how to access and use the program’s care, treatment and services.
- The program communicates with and involves patients in decision making.
- The program tailors care, treatment, and services to meet the patient’s lifestyle, needs, and values.
- The interdisciplinary program team assesses and reassesses the patient’s needs.
- The program provides care, treatment, or services according to the plan of care.
- The patient’s care is coordinated.
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<th>National Consensus Project Guidelines Spiritual Domain</th>
<th>National Quality Forum Preferred Practices</th>
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<tr>
<td>• Guideline 5.1&lt;br&gt;• Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied.</td>
<td>• DOMAIN 5.&lt;br&gt;• SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE</td>
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<tr>
<td>• DEVELOPED PRACTICE 20&lt;br&gt;Develop and document a plan based on assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.</td>
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<tr>
<td>• DEVELOPED PRACTICE 21&lt;br&gt;Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual counseling or through the patient’s own clergy relationships.</td>
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<tr>
<td>• DEVELOPED PRACTICE 22&lt;br&gt;Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.</td>
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<tr>
<td>• DEVELOPED PRACTICE 23&lt;br&gt;Specialized palliative and hospice spiritual care professional should build partnerships with community clergy and provide education and counseling related to end-of-life care.</td>
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Improving the Quality of Spiritual Care as a Dimension of Palliative Care:

A Consensus Conference Convened
February 2009

Principal Investigators
Christina Puchalski, MD, MS, FACP
Betty Ferrell, PhD, MA, FAAN, FPCN

Supported by the Archstone Foundation, Long Beach, CA. as a part of their End-of-Life Initiative.

Executive Summary published in the Journal of Palliative Medicine, October 2009
A Consensus Definition of Spirituality was Developed:

“Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”
Conference Recommendations

Recommendations for improving spiritual care are divided into seven keys areas:

I. Spiritual Care Models
II. Spiritual Assessment
III. Spiritual Treatment/Care Plans
IV. Interprofessional Team
V. Training/Certification
VI. Personal and Professional Development
VII. Quality Improvement
“Be near me when my light is low.”

Tennyson

The one who is dying wants to know they’re not alone. Our goal is to connect and reassure them

• Connect by listening = sacred gift
• Connect by respecting & focusing on their needs
• Connect by simply being present = “I won’t desert you,” “I enjoy being w/you,” “I care.”
• Connect by touching: if it’s a comfort to them
• Connect by talking: only as needed; always as equals
Spiritual Care at the End Of Life

- **The patient**
  We recognize that a patient’s inner life often comes to the fore as death comes near, &
  We extend our support for this realm of the person’s experience.

- **The family**
  Families need to feel that their loved one is cared for, not only in a medically competent way, but in a way that honors & even celebrates that person.
  The family’s spiritual needs are as much the focus of care as are the patient’s.
From Mike Harlos MD, CCFP, FCFP
Professor and Section Head, Palliative Medicine, University of Manitoba
Palliative Care

• Reduces high levels of suffering and distress
• Improves communication and understanding of disease and treatment and Px
• Addresses the entire family unit
• Reduce unwanted, unnecessary and painful interventions
• Improve Survival - *New England Journal of Medicine* article – early Palliative Care advanced lung cancer, increased mood and quality of life, 2.7 month longer life expectancy
• Improve patient and family satisfaction
• Reduces costs
Palliative Care is the Answer

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Most people are not afraid of dying, they are afraid of dying alone and in pain.

We give them hope and promise that we will not let this happen.
HOPE
Expectation, Trust, Anticipation, Faith, Planning

• Is different for each individual … depends on their world view and definition of quality of life

• Absence of hope is hopelessness or despair—when you find no meaning or purpose

• Ask the patient or family what gives them hope, faith, how you can help plan
Instilling Hope

- Controlling the uncontrollables
- Defining quality of life
- Take away the “prolonging death” – modern technology does not always extend life, but it prolongs death
Reframe the Message

- Health care professionals – message is pathology, call a patient by their Dx, talk about the “problems” needing fixed

- Importance of positive thinking – intentionally lift people up, making a difference, focus on strengths
Is it really HOPELESS?

- Even a chronic condition, a severe limitation, impending death can be reframed to find the positives, the quality and the HOPE still left.
- Staff feeling “there is nothing else that can be done” or a situation is hopeless, or feel discouraged – look inward
- How are your perceptions clouding this sense?
Case Example

“there’s nothing else we can do”
There is ALWAYS something that can be done …
Being Patient Centered

Patient Dignity Question (PDQ): “What do I need to know about you as a person to give you the best care possible?”

The responses ranged from practical to spiritual:

• “Afraid of dying alone in a hospital”
• “Difficulty trusting doctors, and that they aren’t telling me everything”
• “That I will be unable to make my own decisions”
• “To be served food on the right side of the tray” because of a visual field defect
• “My children will try to keep me alive even as a ‘vegetable’ … don’t let me be that way.”
SUMMARY

- Palliative Care and Hospice - Mission Services, Volunteers, “ADD ON” roles and a “nice thing” to do
- No evidence-based practice, regulations, standards
- Despite the “noise” going on around us, listen to our patients, focus on their needs, and be in their space
- PERSON CENTERED – across the continuum
- PATIENT CENTERED – across the encounter
- Palliative care and mission are integrated
- Move away from “fee for service,” siloed practices, “cure cure cure,” “treat treat treat,” to more person-centered continuum. Thanks to Health Care Reform, new payment models, ACO, Medical Home
Everything Old is New Again

The model adapted by Palliative Care and Hospice will guide us to do the right thing for right reason … the PATIENT