Quality Care to the End of Life

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Where there’s life, there’s hope.

Cicero
End-of-Life Issues

In 1997, only 4 out of 126 medical schools had a course on end of life for physicians.

www.EPEC

Only 10% of clinical guidelines for life-limiting diseases include significant information on end-of-life discussion.

Mast, 2004
Death in America

Life Completion & Closure

- Symptom management
- Allow quality remaining time
- Focus on important issues
- Complete / close lives in meaningful way
Consider your practice setting....
Hospice vs. Palliative Care

**Hospice**
- 6 months or less to live
- Comfort care focus

**Palliative Care**
- Continue treatment options
- Quality of life focus
Palliative Care

Palliatius
Latin word for “cloak or cover”

...wraps the patient with support to reduce the burden of illness

Photo courtesy of Ryan Keaveney
Palliative care is an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering.

Key is early identification & assessment & treatment of pain & other problems, physical, psychosocial and spiritual.

World Health Organization
When to Consider Palliative Care

- Disease progression, especially with functional decline.
- Pain and/or other symptoms not responding to optimal medical treatment.
- Need for advance care planning.
- Guidelines met for hospice eligibility but “not ready”
Clinical Signs of Need for Palliative Care

- > 3 chronic conditions
- Functional decline
- Patient/Family desire for “low-yield therapy”
- Increasing frequency of outpatient visits, emergency department visits, or hospitalizations
- HYHA Stage III or IV heart failure despite optimal medical management
- Oxygen dependent, O₂ saturation < 88% on RA

ICSI, 2007
Clinical Signs of Need for Palliative Care (cont)

- Unintentional weight loss
- Dyspnea with minimal exercise
- Caregiver stress—support needed
- Increased confusion
- Increased safety concerns
- Increased ascites requiring paracentesis
- Dialysis

ICSI, 2007
We frequently attempt to prolong life at all costs.....

We often succeed
"The obligation of physicians to relieve human suffering stretches back to antiquity.

Despite this fact, little attention is explicitly given to the problem of suffering in medical education, research or practice."

Eric Cassell
Theory of Unpleasant Symptoms

- Symptoms
  - Dyspnea
  - Fatigue
- Multiplicative
- Effects
Symptoms of Suffering

- Physical
- Financial pressures
- Social isolation
- Coping strategies lost
Theory of Chronic Sorrow

- Sadness or sorrow over time
- Cyclic with no predictable end
- Triggered internally or externally; brings to mind a person’s losses, fears or disappointments
- Progressive & can intensify

Eakes (1998)
Quality...

- Doing the right thing, at the right time, in the right way, for the right person, and having the best possible results.
  - Safe
  - Effective
  - Patient-centered
  - Timely
  - Efficient
  - Equitable

- AHRQ Quality indicators
Quality Indicators

Limited improved outcomes

- Symptom management
- Advanced care planning

Improved outcomes

- Communication
- Spirituality
- Family caregiver social support

National Institute of Health
Patient presents with new or established diagnosis of PAH

Assessment of goals, values, care needs.
Quality of Life
Patient presents with new or established diagnosis of PAH

Assessment of goals, values, care needs.

- Physical
- Cultural
- Psych
- Social
- Spiritual
- Ethical & legal
- Imminent dying

Develop or revise care plan

Through periodic review, is the care plan meeting the patient's needs?

Yes

Continue with current care plan.

No

Modified from ICSI, 2007
Patient presents with new or established diagnosis of PAH

Assessment of goals, values, care needs.

Physical \hspace{2em} Cultural \hspace{2em} Psych \hspace{2em} Social \hspace{2em} Spiritual \hspace{2em} Ethical & legal \hspace{2em} Imminent dying

Develop or revise care plan

Through periodic review, is the care plan meeting the patient's needs?

Yes \hspace{2em} No

Continue with current care plan.
Physical

- Dyspnea
- Fatigue
- Pain
Cultural Aspects of Care

- Avoid stereotypes
- Personalize care
- Ask what they prefer
- Use medical interpreters
Psychological

- Regular ongoing assessment
- Treatment & interventions based on goals
- Expect depression & anxiety
- Utilize screening tools
Social

- Regular care conferences
- Referrals as needed
- Financial concerns
- Caregiver coping
Spirituality

Concerned with the ultimate ends and values and search for meaning in one’s life.

How one copes, and sense of well being is directly related to spirituality.

“Hope deferred makes the heart sick.”

Proverbs 13:12
Ethical & Legal Aspects

- Informed consent
- Patient’s goals, preferences & choices are respected
- Advanced care planning
Current Recommendations

- Identify & plan early
- Improve & enhance care planning
- Address care interventions to relief suffering
- Reassess & readjust
- Document & plan
- Increase your own knowledge & skills
- Incorporate holistic guidelines
- Effective communication
Life Limiting Disease Guidelines

- Guidelines should include
  - Information on disease natural history
  - Physical and psychological symptoms
  - Supporting family caregivers
  - Spiritual issues
  - End of life goals of care
  - Other ethical & economic issues

(Mast, 2004)
Crucial Conversations

- Advance preparation
- Build the environment
- Communicate well
- Deal with reactions
- Encourage & validate emotions

ICSI, 2007
Advance Preparation

Getting started…

- Be fully aware of the situation
- Mentally rehearse the way you wish to present information
Build a Therapeutic Environment and Relationship

- Set the stage
  - Appropriate location
  - Consider tissues
  - Sit

- What does the patient/family understand

- What does the patient/family want to know
Communicate Well

- Provide “warning shot”
- Sensitive but straightforward
- Avoid medical jargon
- Allow time for silence & questions
Deal With Patient & Family Reactions

- Expect range of emotions
- Grief reactions
- Varied degrees and time frames
- Avoid defensiveness
Establish Plan

- Reassure that abandonment will not occur
- Explore plan of care
  - Tests
  - Appropriate referrals
- Establish follow-up appointment
- Ensure patient/family is safe
We Can Give Hope

- Hope for control
- Hope for resolving personal relationships
- Hope for a dignified life in the face of a life-limiting illness as PH
Always expect hopefulness.

The object of hope changes with time.

It is a true clinical skill to try to find hope for realistic goals.
References


