Increasing Peace:
Spiritual Aspects of Palliative Care

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Objectives

- Describe the role of spiritual care in integrated palliative care.

- Identify interpersonal, intra-psychic and spiritual tasks essential to effective end of life care.

- Describe barriers to palliative care and peaceful dying.
Palliative Care

“...comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a [serious, chronic, or] terminal illness and for their families...assuring physical comfort [and] psychosocial support. [It is provided simultaneously with all other appropriate medical treatments]”

Billings, J Pall Med, 1999; 1:73-81
Goals of Palliative Care

- Not restricted to end-of-life care
- Is appropriate for any patient with a serious chronic illness
  - regardless of prognosis.
- Prevent and relieve suffering
- Support the best quality of life for individual and their families
  - regardless of the stage of the disease or the need for other therapies
- Optimize function
- Help with decision making
- Providing opportunities for personal growth
- Can be delivered concurrently with life-prolonging interventions or as the main focus of care

National Consensus Project
8 Domains of quality palliative care

- Structure and processes of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care
- Spiritual, religious and existential aspects of care
- Cultural aspects of care
- Care of the imminently dying patient
- Ethical and legal aspects of care

National Consensus Project
Life Expectancy at Birth

Past and projected female and male life expectancy at birth, United States, 1900 – 2050.

(Source: U.S. Department of Commerce, Bureau of the Census)
Sudden Death

Time

Death

MI, Accident <10%

FURTHER READING:
Progressive Disease with a Terminal Phase

Pancreatic Cancer <10%

Time

Death
Chronic, Eventually Fatal Illness, “Sudden” Death

CHF, COPD
DM, AIDS
Neuro
~80%

Death
Chronic, Eventually Fatal Illness

FURTHER READING:
Shift in Thinking

Curative model
- Condition-specific goal of cure
- Symptoms as clues, efforts directed at the disease entity
- Death, lack of cure = failure

Palliative model
- Manage symptoms, maximize quality
- Symptoms are manifestations of the underlying disease
- Death is part of the normal clinical course
Quality Domains for Patients

- Receive adequate pain and symptom management
- Avoid inappropriate prolongation of dying
- Achieve a sense of control
- Relieve burden
- Strengthen relationships with loved ones

FURTHER READING:
### Realms of Suffering

#### Physical
- Functional Ability
- Strength/Fatigue
- Sleep & Rest
- Nausea
- Appetite
- Constipation
- Pain

#### Psychological
- Anxiety
- Depression
- Enjoyment/Leisure
- Pain Distress
- Happiness
- Fear
- Cognition/Attention

#### Social
- Financial Burden
- Caregiver Burden
- Roles and Relationships
- Affection/Sexual Function
- Appearance

#### Spiritual
- Hope
- Suffering
- Meaning of Pain
- Religiosity
- Transcendence

Adapted from Ferrell, et al. 1991
Family Needs

- Frequent communication
- Information and understanding
- Review the life story
- Maintain family role & relationships
- Illness as part of the story
- Honoring the person
- Unfinished business

FURTHER READING:
Swigart. Letting go: Family willingness to forgo life support. 
Spirituality

A way of being and experiencing that comes about through awareness of a transcendental dimension.

Characterized by certain identifiable values in regard to self, others, nature, life, and whatever one considers to be the Ultimate.

That which gives one purpose, meaning and hope and provides a vital connection

- David Elkins
Spiritual Integration

- A healing process...
- An integrative process…
- A parallel process…
  for individual, family and staff.
Integrative Tasks

- Coming to terms with limits
- Enhanced sense of self
- Defining purpose, meaning, and hope
- Belonging
- Putting the pieces together
“It’s more important to know who has the disease than to know the disease the person has.”

-Sir William Osler, MD
Understand the Patient

How do they make sense of life?
- Role in the family
- Employment
- Social factors
- Cultural factors
- Spiritual factors
Sources of Suffering…

- Isolation
- Denial
- Estrangement
- Unfinished business
- Age
  - Perception of completion of life’s tasks
- Conflict
- Failure of enduring myths
  - Why
  - GOD questions
  - Afterlife
- Guilt
- Sense of
  - Worthlessness
  - Impending disintegration
...suffering

- Loss of
  - Faith
  - Future
  - Hope
  - Control
  - Dignity
  - Meaning and purpose
  - Independence

- Fear of
  - Being a burden
  - Abandonment
  - Pain
  - Dying
  - Death
Working towards peace: Patient

- Unique needs
- Sources of support
  - Strength, hope
- Feelings
  - Acknowledge
  - Normalize
  - Facilitate grief/loss
- Loss history
  - Validate relationships, losses
- Identify causes of suffering

- Frankl: Find “meaning”
- Give control where possible
- Respect your efforts to care may be rejected
  - Die as live
- Develop healing relationships
  - Connective practice
  - Compassionate presence
Identify goals, wishes, hopes
  - Facilitate advance care planning
Identify opportunities for fulfillment/healing
Encourage addressing unfinished business/conflict
  - Reconciliation
Facilitate telling of stories
  - Participate in life review
  - Help with a “legacy”
  - Share wisdom
Address pain and suffering
  - Physical, psychological, social, spiritual
With dying patients
  - Encourage saying goodbye
Identifying & Accessing Resources

Spiritual
- Prayer
- Scripture
- Sacraments
- Hymns
- Other spiritual practices
- Clergy
- Cultural beliefs and practices

Relational
- Family
  - Who is it?
  - Surrogate
  - Dynamics
- Other sources of support
- Pets
Working towards peace: Family

- Identify nature of significant relationships
  - Who? Close, distant, enmeshed? Conflicts?
- Make decisions consistent with patient’s wishes
  - “If mom could speak what would she want?”
- Advocate for the patient
- Participate in planning
- Encourage story telling
  - “Tell me about your mom as a person.”
  - Identify milestones
- Facilitate reconciliation
  - Unfinished business
...peace

- Maintain connection with patient
- Inform family about what to expect
- Provide comfort
  - Touch
- Encourage grieving what is lost
- With dying patients
  - Vigil keeping
  - Foster awareness family will go on
    - It will be different
  - Helps patient and family find peace boldly
Identifying & Accessing Resources

- **Spiritual**
  - Sources of strength
  - Faith community
  - Significant practices
  - Hymns
  - Faith sharing
  - Enduring hopes
- **Cultural beliefs and practices**

- **Relational**
  - Children
  - Friends
  - Neighbors
  - Co-workers
  - Sunday school class
“Tools”

- On going relevant information
- Family conferences
- Access to appropriate supports
  - Pastoral care
  - Ethics
  - Social work
  - Financial counselors
  - Community resources
- Access to each other
  - Patient and family
Barriers to Quality Palliative and End of Life Care

- Societal
- Organizational
- Professional
- Personal
Barriers

- Death as failure
  - Illness and death are bad, not normal
- Death denying culture
- Cure orientation
- Technology
- Biomedical model
- Fragmentation of care
- Uncertainty
- Flawed information about prognosis
- Discomfort with vulnerability/mortality
...Barriers

- Role and relevance questions
- Lack of
  - Skill
  - Time
- Conflict
  - Team, interpersonal, intra-psychic
- Belief “doing everything” a sign of faithfulness
- Closeness/Identification
- Focus on miracles
- Unrealistic expectations
“Sorry I’m late, but they had me on a life support system for two months.”
FURTHER READING:
“Little Deaths”

- Frequent communication
- Information and understanding
- Review the life story
- Maintain family role & relationships
- Illness as part of the story
- Honoring the person
- Unfinished business

FURTHER READING:
Foundations of Taskwork

- Patient focus—always
- Develop effective, healing relationships
  - Trust, time, compassion, presence
- Whole person assessment
  - “What is most important thing I can do for you today”
- Respect diverse needs
- Care when can’t cure
- Support the family unit
- Appropriate referrals
- Courage
Telling Their Stories