End of Life Care

“There is no greater gift of charity you can give then helping a person to die well”

-Sogyal Rinpoche
The Tibetan Book of Living and Dying

End of Life Care

Those who are dying are more than objects of medical attention. They remain human beings with wide variety of needs they experienced over the course of their life - Practical Emotional Spiritual as well as Medical.
End of Life/Bereavement Support: Partners in Care

Overview of Presentation
- Sociocultural Aspects of Dying/Death/Grief
- Personal Aspects of Dying/Death/Grief
- Grief and Loss in Illness/End of Life
- Existential/Spiritual Challenges at End of Life
  - Anticipatory Grief
  - Cultural/Religious Implications
  - Program Models

End of Life Care

Death is Universal....

Grief Responses that Death Elicits is Cultural/Personal

Sociocultural Aspects of Death/Grief

Personal Aspects of Death and Grief

The mystery of life and death is found everywhere.
No one can escape the mystery of life and death.

Sociocultural Aspects of Death/Grief

Dying in America
Institute of Medicine

- Improving Quality Patient Centered Care
- Honoring Individual Preferences
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<td>Resulting Form – Medical Orders (POLST)</td>
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Sociocultural Aspects of Death/Grief

What is POLST?
Health Care Agent or Surrogate Role - Can Engage in Discussion if Patient Lacks Capacity
Portability – Provider Responsibility
Periodic Review – Provider Responsibility

National POLST Paradigm Programs*

Endorsed Programs
Mature Programs
Developing Programs
Regionally Endorsed Program
No Program (Contacts)
Programs That Do Not Conform to POLST Requirements

Four Questions about Treatment at the End of Life
• Will Treatment Make a Difference?
• Do the Burdens of Treatment Outweigh its Benefits?
• Is There Hope of Recovery? If So, What will Life be Like Afterward?
• What Does the Patient Value? What is the Patient’s Goal for His/Her Care?

Palliative Care
• Affirms Life, Regards Dying as a Normal Process
• Neither Hastens nor Postpones Death
• Provides Relief from Pain, other Symptoms
• Integrates Psychological and Spiritual Care
  • Interdisciplinary Team
  • Support System for the Family
Hospice Care
Loss/Grief in Illness and End of Life

- Loss of Health
- Loss of Future
- Loss of Physical Abilities
- Loss of Roles
- Loss of Relationships/Isolation
- Loss of Control

Loss/Grief in Illness and End of Life

- Changes in Self Perception
  - Distress
  - Quality of Life
  - Transformation

Grief Reactions

- Shock, Denial, Numbness, Disbelief
- Disorganization, Confusion, Searching, Yearning
  - Anxiety, Panic, Fear
  - Physiological Changes
  - Explosive Emotions
- Guilt and Regret

“There is No Right Way to Grieve, Just Your Way”
Loss/Grief in Illness and End of Life

• Relief-Guilt Syndrome
• Joy-Guilt Syndrome
• Loss, Emptiness, Sadness
  • Relief, Release
  • Time Distortion
• Grief Attacks or Memory Embraces
• Powerlessness and Hopelessness

Existential/Spiritual Challenges at End of Life

• Maintaining a Sense of Continuity with One’s Self
• Maintaining and Enhancing Relationships
  • Forgive Me
  • I Forgive You
  • Thank You
  • I Love You
  • Good-bye

Existential/Spiritual Challenges at End of Life

• Making Meaning
• Legacy and Leave Taking
  • Achieving a Sense of Control
  • Confronting and Preparing for Death

Implication for Practice

• Recognition of Partnership with Psychosocial Oncology Team/Pastoral/Spiritual Care
• Listening - Non Verbal/Verbal Messages
  • Life Stories
• Assessments to Include Body/Mind and Spirit
### Families and Caregivers

"I was scared by my husband’s cancer. He had always taken care of me and we did everything together. I was afraid I would not be strong enough to help him through recovery. I was afraid that he might not recover. I was afraid to talk about my fears with him because I did not want to upset him."

-National Cancer Institute

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<th>Caregivers Roles Expands as Patient Roles Contracts.</th>
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<td>- Greater Financial Responsibility</td>
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<td>- Emotional Support for Patient/Family</td>
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<td>- The “Public” Face of the Patient/Family</td>
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<td>- Nursing Care for the Patient</td>
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<td>- Caregiver Loss- Emotional/Physical/Sexual Intimacy</td>
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<td>- Anticipatory Grief</td>
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### Anticipatory Grief

**Dying Person’’s/Caregiver’’s Experience of Grief with Past, Present and Future**

**Purpose**
- Is not Merely Conventional Grief Begun Early but allows for
- Absorbing the Reality of the Loss Gradually Over Time
- Finishing Unfinished Business
- Making Restitution for Past Transgressions

**Withdrawing Slowly, Some of the Emotional Energy Invested**
- Assuming, Gradually, the Responsibilities of the Dying Person Among Themselves
- Redefining the Family Roles in Relationship to the Dying Person.
### Anticipatory Grief

#### Potential Difficulties Faced by Families

- Physical Strain
- Engrossed as Caregiver/Loses Individual Identity
- Social Isolation
- Stress Increase/Family Dynamics Intensifies
  - Communication Shut Down
  - Uncertainties/Triggers Fears
- Difficulty Witnessing the Progressive Debilitation of a Loved One
  - Visioning the future
  - Maintaining Hope

#### Factors Affecting the Anticipatory Process

- Family Members Past Experience with Loss and Grief
- Circumstances Surrounding the Illness
  - Age
  - Personality
- Family Conditioning/Role Expectations
  - Relationship to Patient

### Cultural and Religious Implications

#### Culture/Religion/Spirituality

- Indigenous Traditions
- Eastern Traditions
- Western Traditions
**Cultural and Religious Implications**

- **Indigenous Traditions - All of Life and Death**  
  Interconnected

- **Eastern Traditions - Karma/Reincarnation**  
  Respect for Family Lineage/Bond Continues

- **Western Traditions - One Life/Judgement**  
  • Respect for Life  
  • Relationship with God

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**Cultural and Religious Implications**

Religions Provide Answers to the Questions of

- **Meaning**
- **Suffering**
- **Afterlife**

Through Beliefs/Practices/Social Community

Rituals Portray Understanding

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**Programs/Outreach End of Life/Bereavement**

- Community Conversations on Compassionate Care  
  • National Healthcare Decisions Day

- P2 Collaborative Initiative in Western New York  
  Clergy Luncheon  
  8 Week Course

- End of Life/Bereavement Support Program RPCI

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**Tools and Resources**

- IOM Report Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life
  Released September 17, 2014
  Report available: [www.nap.edu](http://www.nap.edu)

- National POLST Paradigm Program
  POLST.org

- CompassionAndSupport and New York State’s MOLST
  CompassionAndSupport.org
Tools and Resources

New York’s eMOLST
NYSeMOLSTregistry.com

CompassionAndSupport YouTube Channel
https://www.youtube.com/user/CompassionAndSupport?feature=mhee

Community Conversations on Compassionate Care
https://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning/community_conversations