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End of Life Care:
Listening to the Patient

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Learning Objectives

• To enhance the clinician’s ability to engage in discussion related to end-of-life decision making
• To identify modalities of therapy within palliative and hospice care
• To value the importance of listening to the patient in providing end of life care

Advance Directives

• Two types
  – Durable Power of Attorney or Health Care Proxy
  – Living Will

Advance Directive —
Durable Power of Attorney

• Durable Power of Attorney
  • Allows individuals to appoint someone, a health care proxy, to make health care decisions for them should they lose the ability to make decisions or communicate their wishes

Advance Directive

• Living Will
  – Provides specific instructions to health care providers about kinds of treatment an individual would or would not want to prolong life
Advance Directive Discussions: Challenges

- What we do in theory often differs from what we do in reality.
- Family wishes may trump individual preferences.
- Reconciling advance directives into appropriate medical decision making may be difficult.

Advance Directives — Little Effect on Actual Decisions

- Empirical evidence that presence of advance directives have little effect on actual decisions
  - Seminal Study: SUPPORT
    - Study to Understand Prognoses & Preferences for Outcomes and Risks of Treatments (SUPPORT) Study

Advance Directives — Little Effect on Actual Decisions

- Other studies
  - Without intensive, community wide efforts, few people have advanced directives
  - In hypothetical cases of seriously ill patients, with each case containing an explicit advance directive, internal medicine faculty & residents were not consistent with the advance directive in 65% of cases
  - Minimal impact on end-of-life care

Advance Directives — Autonomy of Person

- Criticism of Advance Directive:
  - When patients are at their most vulnerable, our primary responsibility should be to protect them from harm
- Counterpoint:
  - Respect for autonomy is central to health care ethics.
  - Therefore, disregarding the expressed wishes of an autonomous person for paternalistic reasons is not acceptable.

Advance Directive versus Advance Care Planning

- Advanced Directive:
  - Document that formally conveys an individual’s wishes about medical decision to be made in the event that the person loses decision-making capacity.
- Advance Care Planning
  - Process that involves preparing for future medical decisions in hypothetical event that individuals are no longer able to speak for themselves
  - Often culminates in creation of an advance directive

Advance Care Planning

Opportunity to:

- Educate to better understand conditions not yet personally experienced — “informed consent”
- Educate to better understand treatment options in terms of the individuals’ own values & priorities
- To reflect to help overcome inaccurate forecasting
- To initiate discussions with loved ones & health care providers about wishes & desires
Advance Care Planning: Where Is the Time?

- An alternative to one-on-one clinician patient discussions
  - Computerized Program
    - Doesn’t work for all. For some, uncomfortable working with computers and/or without access
    - However, evidence that computers are widely accepted by people regardless of socioeconomic status, education background & age
  - www.makingyourwishesknown.com

Advance Care Planning

- Outcomes
  - Not yet known: whether computerized advance care planning will have effect on clinical outcomes in end-of-life care
  - Perhaps “success” of outcome measured too narrowly; rather measures of success may include:
    - Opportunity to better understand one’s goals & wishes
    - May help to communicate more effectively with family, friends & healthcare providers
    - Makes end-of-life experience better than it otherwise would have been

Palliative Care

- Focus on improving overall quality of life for patients and families facing serious illness
- Emphasis on
  - Communication
  - Pain & symptom management
  - Coordination of care
- Appropriate at any point in serious illness
- Can be provided at same time as curative treatments

Benefits of Palliative Care

- Among patients with metastatic non-small-cell lung cancer, early palliative care led to:
  - Significant improvements in both quality of life and mood as compared with patients receiving standard care
  - Less aggressive care at the end of life
  - Longer survival


Structure & Processes of Palliative Care

- Interdisciplinary approach
- Patient & family centered

Physical Aspects of Care

- Symptom Control
- Education
- Referral to specialist
- Backup resources
Psychological Aspects of Care

• Patient & family
  response to serious illness
• Grief & bereavement
• Referral to specialists

Social Aspects of Care

• Social needs of patient & family
• Particular attention to the developmental social needs of children
• Referral to specialists – e.g. social workers

Spiritual, Religious & Existential Aspects of Care

• Assessment of spiritual & existential concerns common to both children & adults
• Facilitation of contact with spiritual/religious communities as desired
• Referral to specialists

Life Meanings at End-of-Life

• Among adults with cancer diagnosis at end-of-life, qualitative study that examined life meanings
  – Two interviews
    • 1st interview: Participants asked about important people and events in their lives and current situation
    • 2nd interview: Sharing of life story and reflection on meaning of life


Life Meanings at End-of-Life

– Participants described their experiences in relation to four themes
  • Suffering
  • Coping and hope
  • Priority of love, cherished values, spirituality and religion
  • Value and meaning of reflecting on the whole of their lives

Cultural Aspects of Care

• Cultural background elicited
• Cultural sensitivity
• Care provided in language of patient & family
• Recruitment & hiring practice reflective of cultural diversity of community
Care of the Imminently Dying Patient

- Recognizing symptoms of impending death
- Post-death care
- Bereavement plan

Comfort Pack

- Morphine: Breakthrough pain or shortness of breath
- Lorazepam: Anxiety
- Prochlorperazine for nausea/vomiting
- Haloperidol: Delirium
- Acetaminophen: fever
- Atropine: Dry up upper airway rattle

Ethical & Legal Aspects of Care

- Awareness of legal & regulatory aspects of palliative care
- Patient’s goals respected within limits of state & federal law
- Awareness of complex ethical issues in care of persons with life-threatening, debilitating illness

Hospice Care

- Hospice care always provides palliative care – Emphasis on symptom management & comfort measures
- Curative treatments are no longer being sought
- Supportive care for individuals with a life expectancy of six months or less in final phase of terminal illness

End-of-Life Discussions

- “But our responsibility . . . is to deal with human beings as they are. People die only once. They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come – and to escape a warehoused oblivion that few really want.”


Patient Desires at End of Life

People have concerns beyond prolonging life:

- To avoid suffering
- To be with family
- To have the touch of others
- To be mentally aware
- To not become a burden to others
Guidelines for Discussions

• Sit down
• Make time
• Learn what’s important to the person under the circumstances
  – Can then provide information & advice on the approach that gives the person the best chance
  of achieving what is important to them.
• Requires as much listening as talking
  – If you’re talking more than ½ the time, you’re talking too much

Specific Questions

• “What are you hoping for?”
  – Clinician can provide balance between hope & reality
  – Continue to ask about hope
    • What one hopes for changes
    • What are your worries?
    • What is important to you?

What Not to Say

“There is nothing more that we can offer.”

What Can be Said

• Perhaps no curative therapies to offer
• But always caring with absolute commitment to:
  – Comfort
  – Symptom relief

Loss of a Child

• Concern of many parents who have lost children; their child will be forgotten
• In role of primary care provider
  – Talk with the parent(s) about their child
  – Use the child’s name
  – How is the family doing?
    • Parents
    • Siblings
    • Extended family
  – How are friends doing?

Living with Dying On Our Own Terms
Moyers on Dying