Slide 1

Improving Care at the End of Life
Betty R. Ferrell, PhD, FAAN

Slide 2

Objectives
1. Describe the current national mandate for improved end of life care.
2. Recognize the importance of professional education in end of life care.
3. Identify strategies for education and practice for better care of the terminally ill.

Slide 3

Palliative Care - Definition
"Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure...Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs...It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them."
Institute of Medicine 1998
Slide 4

The Mandate for Improved End of Life Care

- Social Demands
- Critical Research Findings
- The Assisted Suicide Debate

Slide 5

The Mandate for Improved End of Life Care

Social Demands

Slide 6

Steady Decline, Short "Terminal Phase"

Health Status

Decline

Time

Death
Slide 7

Protracted Life - Threatening Illness

- >90%
- predictable steady decline with a relatively short "terminal" phase (cancer)
- slow decline punctuated by periodic crises (CHF, emphysema, Alzheimer's type dementia)

Slide 8

Slow Decline, Periodic Crises, Sudden Death

Health Status

Decline

Crisis

Death

Time

Slide 9

- 2.2 million deaths/year in the U.S.
- 1 in 8 Americans is > 65 years.
- Nearly half of all medical expenses are incurred in the last 6 months of an individual's life
- 80% of deaths occur in hospitals
- The median stay in hospice is 36 days; the mean is 17 days.
Slide 10

Role of Hospice, Palliative Care

- Median length of stay declining

- 36 days in 1995
- 16% died < 7 days of admission
- 20 days in 1998

Slide 11

Role of Hospice, Palliative Care

- Hospice started in US in 1970's
- Percentage of total US deaths in Hospice

- 11% in 1993
- 17% in 1995

Slide 12

The Mandate for Improved End of Life Care

Critical Research Findings
Slide 13

National data on the experience of dying in 5 tertiary care teaching hospitals

The SUPPORT Study
- Controlled trial to improve care of seriously ill patients
- Multicenter study funded by RWJ
- 9000 patients with life threatening illness, 50% died within 6 months of entry

JAMA 1995; 274:1591-98

---

Slide 14

SUPPORT: Phase I Observational Study

Determine objective measures of quality of death:
- Presence and timing of written DNR
- MD awareness of DNR preferences
- Number of 'undesirable' days
- Pain levels
- Costs of care

---

Slide 15

SUPPORT: Phase I Results

- 46% of DNR orders written within 2 days of death
- Of patients preferring DNR, <50% of their MDs were aware of their wishes
- 38% of those who died spent > 10 days in ICU
- Half of patients had moderate-severe pain > 50% of last 3 days of life
Slide 16

Pain data from SUPPORT
% of 5176 patients reporting moderate to severe pain between days 8-12 of hospitalization
- colon cancer: 60%
- liver failure: 60%
- lung cancer: 57%
- MOSF + cancer: 53%
- MOSF + sepsis: 52%
- COPD: 44%
- CHF: 43%


Slide 17

Family caregivers and the SUPPORT study
Patient needed large amount of family caregiving: 34%
Lost most family savings: 31%
Lost major source of income: 29%
Major life change in family: 20%
Other family illness from stress: 12%
At least one of the above: 55%

Slide 18

The Mandate for Improved End of Life Care

The Assisted Suicide Debate
Slide 19

Issues Regarding Assisted Suicide
- Individual Good vs Social Good
- Duty to Die
- Distraction from the Goals of Palliative Care
- Autonomy
- Separation of Roles of Health Care Providers
- Impact on Family Members

Slide 20

Issues Regarding Assisted Suicide
- Slippery Slope
- Issues of Control
- Suicide as “Prevention”
- Omission vs Commission
- Autonomy/Duty of the Health Care Providers

Slide 21

RWJ Project/Strengthening Nursing Education

Project Goals:

1. Review texts used in nursing schools for end-of-life (EOL) content.

2. Improve EOL content in the national nursing license exam.

3. Work with key nursing organizations (NCSBN, AACN, NLNAC) for improved EOL care.
Slide 22

<table>
<thead>
<tr>
<th>Summary of Content of Texts N=50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>AIDS/HIV</td>
</tr>
<tr>
<td>Amnios/Dx</td>
</tr>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Community/III</td>
</tr>
<tr>
<td>Civ Care</td>
</tr>
<tr>
<td>ER</td>
</tr>
<tr>
<td>Editor/Legal</td>
</tr>
<tr>
<td>Fundamentals</td>
</tr>
</tbody>
</table>

Slide 23

<table>
<thead>
<tr>
<th>Summary of Content of Texts N=50</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Geriatry</td>
</tr>
<tr>
<td>Med-Surg</td>
</tr>
<tr>
<td>Onc</td>
</tr>
<tr>
<td>Peds</td>
</tr>
<tr>
<td>Peds</td>
</tr>
<tr>
<td>PharmCn</td>
</tr>
<tr>
<td>Psychiatric</td>
</tr>
<tr>
<td>Nursing Research</td>
</tr>
<tr>
<td>TOTAL</td>
</tr>
</tbody>
</table>

Slides 22-23

Slide 24

<table>
<thead>
<tr>
<th>Frequency of Occurrence of End-of-Life (EOL) Care Dilemmas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dilemma</td>
</tr>
<tr>
<td>Use of advance directives</td>
</tr>
<tr>
<td>Preserving patient choice</td>
</tr>
<tr>
<td>Uncertainty about prognosis</td>
</tr>
<tr>
<td>Fear of causing death by giving</td>
</tr>
<tr>
<td>Discontinuing life-sustaining</td>
</tr>
<tr>
<td>withdrawal</td>
</tr>
</tbody>
</table>

Popp et al. 2016 JNL, JAB
Slide 25

Frequency of Occurrence of End-of-Life (EOL) Care Dilemmas, cont.

<table>
<thead>
<tr>
<th>Dilemma</th>
<th>Very Common</th>
<th>Somewhat Common</th>
<th>Not Common</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal issues of EOL</td>
<td>7%</td>
<td>39%</td>
<td>54%</td>
</tr>
<tr>
<td>Requests for assisted suicide</td>
<td>1%</td>
<td>6%</td>
<td>93%</td>
</tr>
<tr>
<td>Requests for euthanasia</td>
<td>1%</td>
<td>6%</td>
<td>93%</td>
</tr>
</tbody>
</table>

N = 2,333

Slide 26

Barriers to EOL Care

<table>
<thead>
<tr>
<th>Severe</th>
<th>Somewhat of</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Influence of managed care</td>
<td>25%</td>
<td>52%</td>
</tr>
<tr>
<td>Lack of continuity of care</td>
<td>23%</td>
<td>54%</td>
</tr>
<tr>
<td>Family members’ avoidance of death</td>
<td>19%</td>
<td>71%</td>
</tr>
<tr>
<td>Professionals’ personal discomfort with death</td>
<td>17%</td>
<td>56%</td>
</tr>
<tr>
<td>Knowledge by healthcare providers</td>
<td>15%</td>
<td>57%</td>
</tr>
<tr>
<td>Patients/families’ fears of addiction</td>
<td>13%</td>
<td>63%</td>
</tr>
</tbody>
</table>

N = 2,333

Slide 27

Barriers to EOL Care cont.

<table>
<thead>
<tr>
<th>Severe</th>
<th>Somewhat of</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased use of unlicensed personnel</td>
<td>11%</td>
<td>28%</td>
</tr>
<tr>
<td>Legal restrictions in prescribing pain medications</td>
<td>11%</td>
<td>36%</td>
</tr>
<tr>
<td>Cultural factors influencing EOL care</td>
<td>10%</td>
<td>64%</td>
</tr>
<tr>
<td>Avoidance of dying patients</td>
<td>10%</td>
<td>39%</td>
</tr>
<tr>
<td>Professionals’ fear of causing addiction</td>
<td>10%</td>
<td>34%</td>
</tr>
<tr>
<td>Patients’ avoidance of death</td>
<td>8%</td>
<td>70%</td>
</tr>
</tbody>
</table>

N = 2,333
Slide 28

<table>
<thead>
<tr>
<th>Adequacy of Basic Nursing</th>
<th>Not Adequate</th>
<th>Somewhat Adequate</th>
<th>Very Adequate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain management at EOL</td>
<td>71%</td>
<td>21%</td>
<td>8%</td>
</tr>
<tr>
<td>Overall content about EOL care</td>
<td>62%</td>
<td>31%</td>
<td>7%</td>
</tr>
<tr>
<td>Role of family caregivers in EOL care</td>
<td>61%</td>
<td>31%</td>
<td>8%</td>
</tr>
<tr>
<td>Other symptom management</td>
<td>89%</td>
<td>32%</td>
<td>9%</td>
</tr>
<tr>
<td>Grief bereavement</td>
<td>58%</td>
<td>34%</td>
<td>8%</td>
</tr>
<tr>
<td>Understanding the goals of palliative care</td>
<td>57%</td>
<td>33%</td>
<td>10%</td>
</tr>
<tr>
<td>Ethical issues of EOL care</td>
<td>56%</td>
<td>34%</td>
<td>10%</td>
</tr>
</tbody>
</table>


Slide 29

<table>
<thead>
<tr>
<th>Adequacy of Basic Nursing</th>
<th>Not Adequate</th>
<th>Somewhat Adequate</th>
<th>Very Adequate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education, Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care of patients at time of death</td>
<td>52%</td>
<td>30%</td>
<td>18%</td>
</tr>
<tr>
<td>Communication with patients and families at EOL</td>
<td>52%</td>
<td>37%</td>
<td>11%</td>
</tr>
</tbody>
</table>

N = 2233

Slide 30

End of Life Care

of

"Brink of Death" Care?
Slide 31


Slide 32

End of Life Nursing Education Consortium (ELNEC)

Robert Wood Johnson Foundation
Funded Project
2000-2003

Slide 33

Purpose

To provide a comprehensive national effort to improve end of life care by nurses.
Improving Care at the End of Life

Slide 34

Investigators

Geraldine Bednash, PhD, FAAN
Anne Rhome, MPH, RN
American Association of Colleges of Nursing

Betty Ferrell, PhD, FAAN
Marcia Grant, DNSc, FAAN
City of Hope National Medical Center

Slide 35

Consultants

Patrick Coyne, RN, MSN, CS, CHPN
Medical College of Virginia Hospitals
Virginia Commonwealth University

Kathy Egan, MA, BSN, CHPN
The Hospice Institute of the Florida Suncoast

Judy Paice, PhD, RN, FAAN
Northwestern Memorial Hospital

Joan Panke, BSN, RN
NYU Palliative Care Nurse Practitioner Program

Slide 36

Project Directors

Frances Weed, MSN, RN
American Association of Colleges of Nursing

Rose Virani, RNC, BSN, MHA, OCN
City of Hope National Medical Center
Slide 37

Affiliated Organizations

- American Medical Association, EPEC Program
- American Nurses Association
- Hospice and Palliative Nurses Association
- National Council of State Boards of Nursing, Inc.
- National Hospice and Palliative Care Organization
- National Organization for Associate Degree Nursing
- Oncology Nursing Certification Corporation
- Oncology Nursing Society
- PDIA Consortium of Specialty Nursing Groups
- Veterans Administration Health Systems

Slide 38

ELNEC Curriculum

Modules
1. Nursing Care at the End of Life
2. Pain Management
3. Symptom Management
4. Cultural Considerations in EOL Care
5. Ethical/Legal Issues
6. Communication
7. Grief, Loss, Bereavement
8. Preparation and Care for the Time of Death
9. Achieving Quality of Life at the End of Life

Slide 39

Courses

- 8 courses sponsored by COH/AACN
- 5 regional courses sponsored through Last Acts
The Importance of "Being With"

"I awoke that morning with a huge stapled wound in the center of my abdomen. Every inch of me hurt. Most of all my heart hurt with the knowledge that I had cancer. The nurse who came to bathe me was an older woman. Her hands were strong, her touch firm. As she washed my battered body, she cleansed away some fear and uncertainty and left calm and quiet in their places."

The drains, the tubes, the staples didn't deter her from seeing me as a frightened, hurt human being. I don't know if she said much, but her hands spoke volumes."

The Octopus and Me by Susan G. Jaquette, BA, MATS. AJN, April 2000
Slide 43

Non-Abandonment

Slide 44

Pass Me the Blue
A little girl died today. She was 7 years old, liked cheese pizza, frozen yogurt, and macaroni, and loved dancing to Broadway hits. Her favorite color was purple although she had reconsidered and announced it to be "lavender"). And like other 7 year-olds, she was quite wise about what really matters.

Pamela Hinds, RN, PhD, DS; J of Ped Onc Nsg, 11(2), 1994

Slide 45

Pass Me the Blue
She was first diagnosed with acute lymphocytic leukemia when she was an infant; she had a first relapse when she was 5 and a second relapse several months ago. Shortly after her first relapse, we were coloring together and sharing the same package of crayons.

Pamela Hinds, RN, PhD, DS; J of Ped Onc Nsg, 11(2), 1994
Pass Me the Blue

"Pass me the yellow," she said. I did.
"Do you think I'm going to die?" she asked. I swallowed.
"This is serious," I said. "But I'm concentrating on you getting well again."

Pamela Hinds, RN, PhD, DS; J of Ped Onc Nsg, 11(2), 1994

---

Pass Me the Blue

"Pass me red," she commanded. I did.
"I figured out it's serious," she said.
"And I'm thinking the same thing you are. But if I die, will you be there?"
"Yes, for sure," I said.
"O.K., good," she said. "Pass me the blue."

Pamela Hinds, RN, PhD, DS; J of Ped Onc Nsg, 11(2), 1994

---

We estimate that it will cost $1.4 million per year to provide universal access to hospice for terminally ill Oregonians who remain uninsured. Ironically, those for and against Oregon's assisted suicide initiative spent a total of $4.6 million in advertising for the intensely debated November 1997 election to retain or eliminate Oregon's assisted suicide law. That is enough money to fund access to hospice for every dying Oregonian for 3 years.
Slide 49

If so much money can be found to fight battles over differing moral views, it seems reasonable to expect that, as a society, we can agree to fund access to high-level end-of-life care, including hospice care for all terminally ill Americans, thereby ensuring a true choice about end-of-life treatment.

-Susan Tolle, MD (1998)
Oregon Health Sciences University

-------------------

Slide 50

Eliminating Death, Disease by Disease
The tacit message of the research agenda is that if death itself cannot be eliminated - no one is so bold as to claim that it can - then at least all the diseases that cause death can be done away with. As William Haseltine, chairman and chief executive officer of Human Genome Sciences, has put it it, "Death is a series of preventable diseases."

-Callahan, 2000

-------------------

Slide 51

Eliminating Death, Disease by Disease
From this perspective, the researcher is like a sharpshooter who will pick off the enemy one by one: cancer, then heart disease, then diabetes, then AIDS, then Alzheimer's disease, and so on. The human-genome effort, the latest contender in the battle against death, will supposedly get to the genetic bottom of things, radically improving the aim of the sharpshooter.

-Callahan, 2000

-------------------
Slide 52

For every birth, someone long ago happened to notice, there is one death. We cannot and will not change that fact. But we can change the way people are cared for at the end of life, and we can substantially reduce the burden of illness. It is not, after all, death that people seem to fear the most, and certainly not in old age, but a life poorly lived. Something can be done about that. —Callahan, 2000

Slide 53

"Too Many Words... Let Them Just See What We Do."

-Mother Teresa

Slide 54

City of Hope Pain Resource Center (COHPRC)

Ph: 626/359-8111, x 63829
Website: http://prc.coh.org