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Improving Care at the End of Life

Betty R. Ferrell, PhD, FAAN

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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.**

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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

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The Mandate for Improved End of Life Care

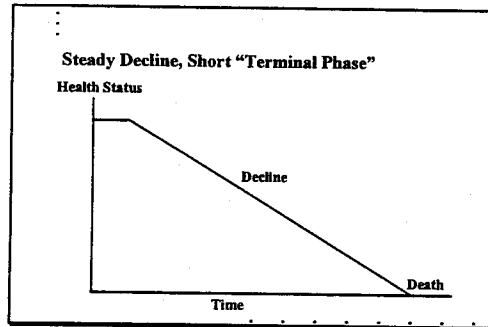
- Social Demands
- Critical Research Findings
- The Assisted Suicide Debate

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The Mandate for Improved End of Life Care

Social Demands

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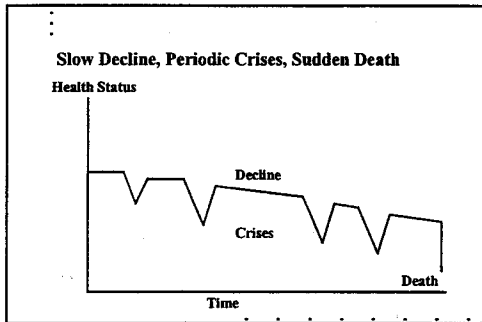


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Protracted Life - Threatening Illness

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

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- 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.

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Role of Hospice, Palliative Care

- Median length of stay declining
- 36 days in 1995
 - 16% died < 7 days of admission
- 20 days in 1998

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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

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The Mandate for Improved End of Life Care

Critical Research Findings

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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

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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

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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

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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%
Desbiens & Wu. JAGS 2000; 48: S183-186.	

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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%
<i>At least one of the above</i>	55%

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The Mandate for Improved End of Life Care

The Assisted Suicide Debate

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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

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Issues Regarding Assisted Suicide

- Slippery Slope
- Issues of Control
- Suicide as "Prevention"
- Omission vs Commission
- Autonomy/Duty of the Health Care Providers

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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.

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Summary of Content of Texts N=50

Category	#	%	#	# EOL	# chps	# EOL
	Txts	Txts	pgs	pgs	chps	chps
AIDS/HIV	1	2	526	20	16	0
Assmnt/Dx	3	6	1783	15.3	80	0
Communication	2	4	767	38	35	0
Community/HH	4	8	3108	21.3	116	0
Crit Care	4	8	4116	80.8	181	2
ER	2	4	1006	14.5	69	1
Ethics/Legal	5	10	2018	143	88	4
Fundamentals	3	6	4353	114.9	140	3

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Summary of Content of Texts N=50

Category	#	%	#	# EOL	# chps	# EOL
	Txts	Txts	pgs	pgs	chps	chps
Gerontology	3	6	2515	84.8	72	2
Med-Surg	5	10	9969	146.3	298	2
Onc	2	4	3264	107.5	149	7
Pt Ed	2	4	636	8.0	26	0
Peds	3	6	2599	33.5	70.0	2
Pharmacology	4	8	3476	22.0	236	0
Psychiatric	3	6	2886	35.3	127	1
Nursing Review	4	8	2661	17.0	47	0
TOTAL	50	100	45,638	901.9	1750	24 (1.4%)

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Frequency of Occurrence of End-of-Life (EOL) Care Dilemmas

Dilemmas	Very Common	Somewhat Common	Not Common
Use of advance directives	37%	32%	31%
Preserving patient choices	23%	48%	29%
Uncertainty about prognosis	13%	44%	43%
Fear of causing death by giving pain medication	11%	34%	55%
Discontinuing life-sustaining therapies	11%	48%	41%
Withholding/withdrawing nutrition/hydration	8%	42%	50%

Forrell et al. ONE 27(3), 2898

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

Dilemmas	Very Common	Somewhat Common	Not Common
Legal issues of EOL	7%	39%	54%
Requests for assisted suicide	1%	6%	93%
Requests for euthanasia	1%	6%	93%

N = 2,333

Ferrell et al. *ONE* 27(3), 2000

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Barriers to EOL Care

Barriers to EOL Care	Severe Barrier	Somewhat of Barrier	Not a Barrier
Influence of managed care	25%	52%	23%
Lack of continuity of care	23%	54%	23%
Family members' avoidance of death	19%	73%	8%
Professionals' personal discomfort with death	17%	56%	27%
Knowledge by healthcare providers	15%	57%	28%
Patient/families' fears of addiction	12%	63%	25%

N = 2,333

Ferrell et al. *ONE* 27(3), 2000

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Barriers to EOL Care, cont.

Barriers to EOL Care, cont.	Severe Barrier	Somewhat of Barrier	Not a Barrier
Increased use of unlicensed personnel	11%	28%	61%
Legal restrictions in prescribing pain medications	11%	36%	53%
Cultural factors influencing EOL care	10%	64%	26%
Avoidance of dying patients	10%	39%	51%
Professionals' fear of causing addiction	10%	34%	56%
Patients' avoidance of death	8%	70%	22%

N = 2,333

Ferrell et al. *ONE* 27(3), 2000

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Adequacy of Basic Nursing Education	Not Adequate	Somewhat Adequate	Very Adequate
Pain management at EOL	71%	21%	8%
Overall content about EOL care	62%	31%	7%
Role/needs of family caregivers in EOL care	61%	31%	8%
Other symptom management	59%	32%	9%
Grief/bereavement	58%	34%	8%
Understanding the goals of palliative care	57%	33%	10%
Ethical issues of EOL care	56%	34%	10%

Ferrell et al. ONF 27(3), 2000.

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Adequacy of Basic Nursing Education, Cont.	Not Adequate	Somewhat Adequate	Very Adequate
Care of patients at time of death	52%	36%	12%
Communication with patients/families at EOL	52%	37%	11%

N = 2333

Ferrell et al. ONF 27(3), 2000.

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End of Life Care
 or
“Brink of Death” Care?

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Field MJ, Cassel CK. (Eds.): Approaching death: Improving care at the end of life (Report of the Institute of Medicine Task Force). Washington, DC: National Academy Press, 1997.

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End of Life Nursing Education Consortium (ELNEC)

**Robert Wood Johnson Foundation
Funded Project
2000-2003**

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Purpose

To provide a comprehensive national effort to improve end of life care by nurses.

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Investigators

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City of Hope National Medical Center

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Northwestern Memorial Hospital

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NYU Palliative Care Nurse Practitioner Program

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Project Directors

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American Association of Colleges of Nursing

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

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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

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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

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Courses

- 8 courses sponsored by COH/AACN
- 5 regional courses sponsored through Last Acts

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The Importance of "Being With"

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"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."

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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

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Non-Abandonment

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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

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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

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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

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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

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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.

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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

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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, "Death is a series of preventable diseases."

-Callahan, 2000

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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

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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

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“Too Many Words. . .
Let Them Just See What We Do.”
-Mother Teresa

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City of Hope Pain Resource Center
(COHPRC)
Ph: 626/359-8111, x 63829
Website: <http://prc.coh.org>
