

**THE PALLIATIVE CARE APPROACH
TO END-OF-LIFE CARE**

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**ITS NOT ABOUT DEATH, IT'S REALLY
ABOUT LIVING WITH A DISEASE
THAT'S GOING TO KILL YOU, ABOUT
GOOD LIVING ON THE WAY TO
DEATH**

Joanne Lynn, MD
TIME Magazine, 2000

THE BACKGROUND

- People are living longer
- Increases in chronic & life-threatening illness
- Significant under-treatment of pain
- Cultural shifts and new awareness
- Doctors often focused on curing, not caring
- Doctors not well-trained in pain & comfort care

PALLIATIVE CARE: Definition

Palliative care seeks to improve the quality of life of patients with life-threatening illness and their families, through the early prevention and relief of suffering ... by treating pain and other problems – physical, psychosocial, and spiritual.

WHO, 2002

Palliative care may be provided simultaneous with all other treatment for patients with advanced illness.

Center to Advance Palliative Care, 2003

COMPONENTS OF PALLIATIVE CARE

- **Relieve suffering**
 - Physical (pain & symptoms)
 - Psychosocial (bereavement)
 - Spiritual

INTERDISCIPLINARY CARE

- **Physician**
- **Nurse**
- **Social worker**
- **Pastoral care**

PALLIATIVE CARE: Background

- Assists patient & family/caregiver
- Any diagnosis/Life-threatening illness
- Any age
- Complements disease-modifying therapy
- Best when started at time of diagnosis
- May become total focus of care (Hospice)

HOSPICE: Background

- Form of palliative care
 - Focus on comfort care
 - Patients agree to forego curative treatment
- Program, place, form of care
- Started in U.S. in late 1970s
 - Only 17% of total us deaths in 1995
 - Decreasing lengths of stay – 20 days in 1998

HOSPICE: Background

- Designed on cancer model
 - Predictably steady decline, short terminal phase
- Available for diagnosis with terminal illness
 - Prognosis < 6 months
 - May be renewed
- Provides range of health care & support services
 - MD, RN, MSW, in-patient, medications

PALLIATIVE CARE IN PRACTICE

- Expert control of pain & symptoms.
- Uses the crisis of hospitalization to improve communication & decisions about goals of care with patient & family.
- Coordinates care across fragmented healthcare system.
- Provides practical support for patient, family, & professional caregivers.

STATE END-OF-LIFE CARE REGULATIONS

- BGS acts as public guardian
- Palliative care / hospice may be provided when life-threatening illness
- DNR orders, withholding/withdrawal of LSMT permissible
- New advisory role for ethics committees
- Oversight by NJ P&A
- Final decisions by BGS

MAKING DECISIONS: COGNITIVE LIMITATIONS

- Issue: Balance protection from harm with right to self-determination
- Never-competent or having no ability to process information
- Marginal or transient capacity
- Sufficient cognitive understanding to provide consent

**SURROGATE DECISION-
MAKING STANDARDS**

- **Previously capacitated**
 - **Substituted Judgment**
- **Never-capacitated**
 - **Best Interests**

SUBSTITUTED JUDGMENT

- What decision would be made if capacitated
- Evidence of wishes / life values
- Written documents: Advance directives
- Oral directives
- Religious beliefs
- Prior medical decisions

BEST INTERESTS

- Prior preferences cannot be determined
- Quality of life criterion
- Highest benefit among options
- Evaluate treatment risks / benefits / alternatives
- Consider pain and suffering
- Likelihood of restoring functioning

BARRIERS TO PAIN MANAGEMENT

• *Physician-related*

- Lack of knowledge regarding pain care
- Reluctance to prescribe narcotics due to concerns regarding addiction
- Fears of regulatory oversight & prosecution

BARRIERS TO PAIN MANAGEMENT

• *Health care system-related*

- Lack of access to services
- Excessive regulation of pain medications
- Inability to afford pain medications

BARRIERS TO PAIN MANAGEMENT

• *Patient-related*

- Not being a “good” patient
- Not being a burden to doctor
- Not to distract from treating condition
- Fear of side effects (addiction, dependence, tolerance, confusion)
- Cultural/religious beliefs

PREDICTING UNDER-TREATMENT

- Gender – Females
- Age – Older
- Education – Less
- Substance use as risk factor
- Site of care – nursing home
- Higher levels of pain intensity
- Physician / patient-related barriers
- Disability – Pre-existing

DEMAND FOR PALLIATIVE CARE: What Patients & Families Want for Their Care

- Pain & symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

Singer, et al. *JAMA*, 1999

A GOOD DEATH

- Interviews & focus groups with patients, families, and providers
- Key attributes of a “good death”:
 - Symptom control
 - Effective communication
 - Clear, shared decision-making
 - Preparation

Steinhauser et al., *Ann Intern Med*, 2000

HOSPICE DEMONSTRATION PROJECT

- **Develop partnerships**
 - Hospice, community homes, institutional residence, hospital, State guardians, Medicaid & community care waiver programs
- **Formalize linkages**
- **Educate staff**
 - Hospice
 - Disabilities services
- **Assure provision of care**
- **Provide ethics consults**
- **Assure reimbursement for care**
- **Evaluate**

CONCLUSIONS

- **Promote access to palliative care**
- **Professional training critical**
 - Promote awareness
 - Understand population
 - Overcome communications barriers
 - Encourage comfort
- **Inform families & guardians**

CONCLUSIONS

- **Address policy barriers**
 - Encourage hospice & palliative care
 - Permit DNR orders
 - Permit withholding or withdrawing of life-prolonging care
 - Encourage use of ethics committees
- **Develop services models**
- **Research quality of end-of-life care & impact of new policies**
