

POLICY ISSUES IN END-OF LIFE CARE

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NEW JERSEY HEALTH DECISIONS

- **Promote informed health care decision-making**
- **Improve end-of-life care**
- **Professional education**
- **Community outreach**
- **Public Policy**
- **Research**

**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**
- **Increase in chronic & life-threatening disease**
- **Cultural shifts and new awareness**
- **Doctor's focused on curing, not caring**
- **Doctor's 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

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 length 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 less than 6 months**
 - **May be renewed**
- **Provides range of health care & support services**
 - **MD, RN, MSW, in-patient, medications**

BARRIERS TO PAIN MANAGEMENT

■ *Physician-related*

- **Lack of knowledge regarding pain care**
- **Reluctance to prescribe narcotics due to concerns re 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 to burden doctor**
 - **Not to distract from treating condition**
- **Fear of side effects (addiction, tolerance, confusion)**
- **Cultural/religious beliefs**

PREDICTING UNDER-TREATMENT

- **Gender – Females**
- **Education – Less**
- **Substance use as risk factor**
- **Higher levels of pain intensity**
- **Physician / patient-related barriers**
- **Disability – Pre-existing**

PAIN TERMINOLOGY

■ Tolerance

- Need to increase drug dosages to maintain analgesic effects**

■ Physical dependence

- Signs and symptoms of withdrawal if narcotics are abruptly stopped**

PAIN TERMINOLOGY

■ **Addiction / Abuse**

- **Psychological dependence**
- **Behavioral syndrome with drug craving, compulsive use, hoarding, and relapse after abstinence**

■ **Pseudo-addiction**

- **Showing behaviors like addiction, but due to uncontrolled pain and inadequate pain care**

HOW N.J. COMPARES?

- ***Means to a Better End: A Report on Dying in America***

Last Acts (A Project of the Robert Wood Johnson Foundation), November 2002

HOW N.J. COMPARES?

- **Hospitals reporting pain management programs—B (60 < 80%)**
- **Hospitals reporting hospice programs – D (20 < 40%)**
- **Hospitals reporting palliative care programs – D (20 < 40%)**

HOW N.J. COMPARES?

- **Deaths at home – D (15 < 30%)**
- **Median number of days in hospice – D (15 < 30 days)**
- **People over 65 who used hospice in last year of life – D (13 < 25%)**

HOW N.J. COMPARES?

- **People over 65 with 7 or more ICU days during last 6 months of life – E (> 14%, bottom 5 states)**
- **Nursing home residents in persistent pain – C (35 < 45%)**
- **Strength of state pain policies – D**

HOW N.J. COMPARES?

- **Physicians certified in palliative medicine – D**
- **Nurses certified in palliative care
- C**

HOSPICE DATA

- **New Jersey Health Decisions/Rutgers CSHP - 1999 data**
- **Services Used**
 - **Routine home care**
 - **Hospice directed care in nursing home**
- **Services Little Used**
 - **Inpatient care**
 - **Respite care**
 - **Continuous care**
- **Patients with Cancer – 72%**

HOSPICE DATA

- **Gender: 53% Female**
- **Race**
 - **White – 87%**
 - **African American / Black – 9%**
 - **Asian – 2%**
 - **Hispanic – 2%**
- **Location**
 - **City (>50,000) – 25%**
 - **Suburbs – 75%**

HOSPITAL/PALLIATIVE CARE DATA

- **New Jersey Health Decisions/Rutgers CSHP 2002 data**
- **Reporting palliative care services**
 - **Pain consultation – 23 hospitals**
 - **Palliative care consultation – 9**
 - **In-patient – 1**
 - **Out-patient – 4**
 - **Facility-based hospice – 5**

HOSPITAL/PALLIATIVE CARE DATA

- **Hospitals reporting palliative care program – 6**
- **Factors in establishing pall care**
 - **Strong leadership**
 - **Identification of services**
 - **Strategic plan**
 - **Financial plan**
 - **Business plan**
- **Interest in establishing pall. care**
 - **Next year – 10**
 - **Next 2 years – 7**
 - **Next few years - 9**

HEALTH CARE PLANNING

- **New Jersey Advance Directives for Healthcare Act
(L. 1991, NJSA 26:2H-53)**

“Competent adults have the fundamental right to control decisions about their health care.”

HEALTH CARE PLANNING

- **Authorized use of:**
 - **Health Care Proxy**
 - **Living Will (Instruction Directive)**
 - **Do-Not-Resuscitate Order (Physician's order)**
 - **Out-of-Hospital DNR Order – by consensus (NOT statutory) guidelines of Medical Society of N.J.**

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