

# Improving Care near the End of Life:

*What Good Can Ethics Guidelines Do?*

*What Does It Mean to be Ethically  
Competent in End-of-Life Care?*

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March 20, 2010



# *Guidelines* Project: Background

- In January 2007, The Hastings Center launched a three-year project to revise and expand our 1987 ethics guidelines on end-of-life care.
- The 1987 *Guidelines* became the single most influential publication in The Hastings Center's 40-year history.



# *Guidelines* Project: Goals

- Articulate the values that constitute a vision of ethically justified, responsible end of life care.
- Recommend practices and policies that can advance this vision, with reference to evidence and consensus.
- Stay close to bedside realities, and to the needs of good professionals who may work in not-so-good systems.



# Who needs ethics guidelines?

No one turns to ethics guidelines if everyone already agrees about the right thing to do.

In drafting our *Guidelines*, we are mindful that:

“Somebody is suffering. Somebody else doesn’t know how to make the right decisions about how to relieve this suffering.” “Distress is the driver.”



# What should the ethically competent professional know about EOL care?

1. Know the **outcomes data** on end-of-life interventions.
2. Learn how to **integrate palliative care** into treatment and discharge plans.



# What should the ethically competent professional know about EOL care?

3. Learn how to **talk with and listen** to patients concerning their values and preferences. Learn how to **set, document, and use goals and plans** that reflect preferences.
4. Learn how to **collaborate** with patients and surrogates during treatment deliberations and decision-making.



# What should the ethically competent professional know about EOL care?

5. Learn how to **collaborate with other professionals** during medical conferences relevant to treatment decision-making, during handoffs and transfers, and in discharge planning.
6. Learn about the **causes of distress** experienced by patients, families, and staff in end-of-life care settings, and how these stressors may affect decision-making and care.



What should the ethically competent professional know about EOL care?

7. Learn how to **resolve interpersonal conflicts.**
8. Learn how to recognize and correct **legal myths** about end-of-life care.
9. Develop **capacities** for **personal reflection** and **ethical reflection.**





# Professional self-identity

Professionals who care for dying people but may not self-identify with “end-of-life care”:

- Hospitalists
- Intensivists and EM providers
- Primary care physicians
- Medical directors and nursing directors in nursing homes
- Senior leaders of hospitals and nursing homes



# Guidelines: formats and expectations

- **Clinical practice guidelines and related professional guidance:** journal articles or web-based
- **Clinical ethics handbooks:** books
- **Professional education curricula:** web-based



# Clinical Practice Guidelines: NCCN

NCCN®

Practice Guidelines  
in Oncology – v.1.2009

## Palliative Care

[Guidelines Index](#)  
[Palliative Care TOC](#)  
[Discussion References](#)

### PALLIATIVE CARE OVERVIEW

#### SCREENING<sup>a,b</sup>

Uncontrolled symptoms or Moderate to severe distress related to cancer diagnosis and cancer therapy or Serious comorbid physical and psychosocial conditions or Life expectancy ≤ 12 mo or Patient/family concerns about course of disease and decision-making or Patient/family requests palliative care

Present →  
Not present ↓

- Inform patients and families of role and benefits of palliative care services
  - Discuss anticipation and prevention of symptoms
  - Rescreen at next visit

#### ASSESSMENT

- Benefits/risks of anticancer therapy
- Symptoms
- Psychosocial or spiritual distress
- Personal goals/expectations
- Educational and informational needs
- Cultural factors affecting care
- Criteria for early consultation with palliative care specialist

Years  
Year to months  
Months to weeks  
Weeks to days (Dying patient)

#### PALLIATIVE CARE INTERVENTIONS<sup>b</sup>

- Anticancer therapy
- Appropriate treatment of comorbid physical and psychosocial conditions
- Promote coordination of care
- Symptom management
- Advance care planning
- Psychosocial and spiritual support
- Culturally appropriate care
- Resource management/ social support
- Consultation with palliative care specialist
- Hospice referral
- Response to request to withdraw or withhold life sustaining treatment
- Response to request for physician-assisted suicide and euthanasia
- Care of imminently dying patient
- Palliative sedation

#### REASSESSMENT

- Satisfactory:
- Patient satisfied with response to anticancer therapy
  - Adequate pain and symptom control
  - Reduction of patient/family distress
  - Acceptable sense of control
  - Relief of caregiver burden
  - Strengthened relationships
  - Optimized quality of life
  - Personal growth and enhanced meaning

Unsatisfactory

- Intensify palliative care efforts
- Consult or refer to specialized palliative care services or hospice

#### AFTER DEATH INTERVENTIONS

Death → (A "good death") →

- For family and caregivers:
- Immediate after-death care
  - Bereavement support
  - Cancer risk assessment and modification For healthcare team:
  - General support
  - After-death support

<sup>a</sup>Management of any patient with positive screening requires a care plan developed by a interdisciplinary team of physicians, nurses, mental health professionals, and chaplains.

<sup>b</sup>Oncologists should integrate palliative care into general oncology care for patients who meet screening criteria. Consultation/collaboration with a palliative care specialist/hospice team is recommended for patients with more complex issues.

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

[Palliative Care Assessment \(PAL-3\)](#)



# Clinical Practice Guidelines: NQF

 National Quality Forum

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## A Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency

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### Domain 5: Workforce Diversity and Training

- Preferred Practice 28: Recruit and hire ethnically diverse providers and staff at all levels, including management levels.
- Preferred Practice 29: Actively promote the retention of a culturally diverse workforce through organizational policies and programs.
- Preferred Practice 30: Implement training that builds a workforce that is able to address the cultural needs of patients and provide appropriate and effective services as required by federal, state, and local laws, regulations, and organizational policies.

### Domain 6: Community Engagement

- Preferred Practice 31: Engage communities to ensure that healthcare providers (individual and organizational) are aware of current and changing patient populations and cultural and communication needs and provide opportunities to share resources and information.



# Professional Guidance: NCP et al

JOURNAL OF PALLIATIVE MEDICINE  
Volume 12, Number 10, 2009  
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DOI: 10.1089/jpm.2009.0142

Special Report

## Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference

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### Abstract

A Consensus Conference sponsored by the Archstone Foundation of Long Beach, California, was held February 17-18, 2009, in Pasadena, California. The Conference was based on the belief that spiritual care is a fundamental component of quality palliative care. This document and the conference recommendations it includes builds



# Professional Guidance: Cohen et al 2003

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**PERSPECTIVES ON CARE**  
**AT THE CLOSE OF LIFE**

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## Practical Considerations in Dialysis Withdrawal "To Have That Option Is a Blessing"

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Lewis M. Cohen, MD

Michael J. Germain, MD

David M. Poppel, MD

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### THE PATIENT'S STORY

Mr D was a 78-year-old man with end-stage renal disease (ESRD) from diabetes and hypertensive nephrosclerosis. He had a prior history of multiple episodes of aspiration pneumonia. For the past 2 years Mr D resided in a convalescent home, where he was visited frequently by his daughter, son, and their families. Mr D was transferred from his skilled nursing facility to the university hospital with cough, fever, and hypoxia.

Mr D had had diabetes for 10 years, with repeated hospitalizations for nonketotic hyperosmolar state. Comorbid disorders included vascular dementia, atrial fibrillation, chronic lymphocytic leukemia, emphysema, pleural effusion, colonic diverticulosis, and tubular adenoma. Hemodialysis was begun 30 months prior to his final admission, but he became progressively more lethargic, less verbal, and physically weaker. A formal advance directive was never completed. On several

Cessation of life-support treatment is an appropriate option for situations in which the burdens of therapy substantially outweigh the benefits. Decisions to withdraw dialysis now precede 1 in 4 deaths of patients who have end-stage renal disease. Guidelines have been recently published to assist clinicians in making these complex and emotionally charged determinations, and they include: relying on shared decision making by all participants, obtaining informed consent, estimating the prognosis on dialysis, adopting a systematic approach for conflict resolution of disagreements, honoring advance directives, and ensuring the provision of palliative care. These principles are discussed in relation to an elderly man with dementia whose family decided to terminate maintenance hemodialysis.

*JAMA. 2003;289:2113-2119*

[www.jama.com](http://www.jama.com)

*cause they feel responsible for actively doing something that will lead to their father's death.*





# Professional Guidance: Cohen et al 2003

## CONSIDERATIONS IN DIALYSIS WITHDRAWAL

The earliest phase of the process requires the physician to sensitively broach basic end-of-life issues and to clarify goals of treatment. BOX 1 outlines steps that we have found can be helpful for the patient and family in the early stages. Ongoing discussions should include the following, which are based on the Society of Nephrology and Renal Physicians Association's 9 tenets:

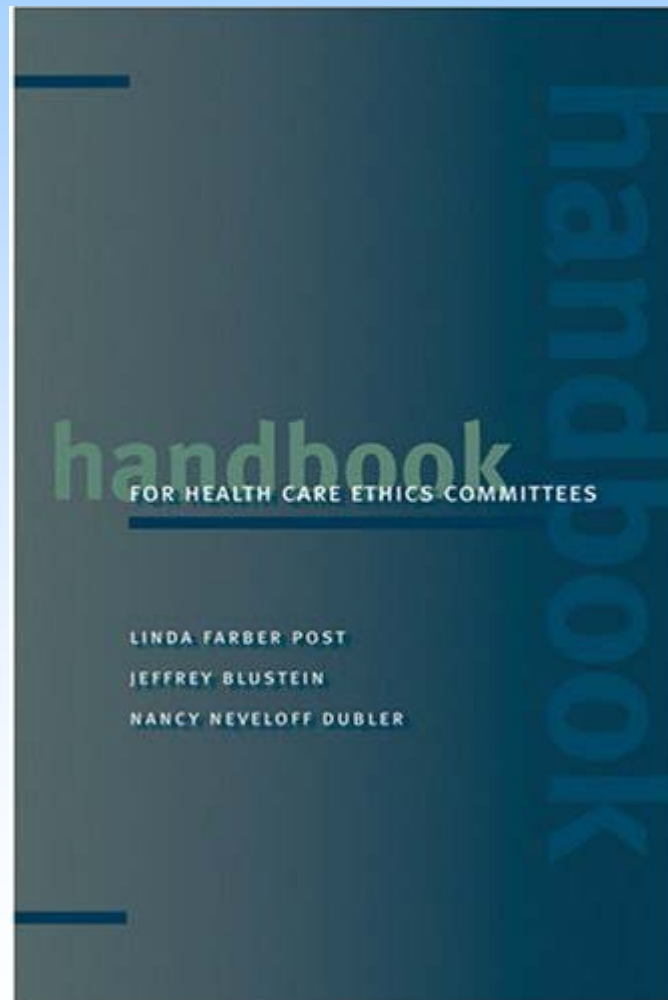
1. **Shared Decision Making.** According to the retrospective literature on dialysis discontinuation decisions, nearly half the patients lack the capacity to speak for themselves, because of dementia or other organic brain syndromes.<sup>16</sup> Even older patients who are mentally competent often defer to younger relatives and staff to help make these difficult decisions. As in the present case, family members frequently become the primary decision makers.<sup>30</sup> If the physician and family wait until the individual is too sick to participate in discussions, the default decision may be to provide aggressive care to the end; this is often futile, against the patient's values, and associated with needless suffering.<sup>37</sup> As in the present case, families can feel that the burden of arriving at a determination is almost too great for them to tolerate; they

### **Box 1. Considerations for Dialysis Withdrawal**

1. Identify patient who may benefit from withdrawal, including those with
  - Very limited estimated prognosis
  - Poor quality of life
  - Pain unresponsive to treatment
  - Progressive untreatable disease, eg, cancer, dementia, acquired immunodeficiency syndrome, peripheral vascular disease, congestive heart failure
  - Inability or unwillingness to tolerate further dialysis, or
  - Dialysis is technically difficult or impossible
2. Discuss goals of care with patient and family
3. Discuss quality of life on dialysis with patient and/or family
4. Discuss possible symptoms and their palliation
5. Clarify that dialysis withdrawal is an option
6. Reassure that it can result in a peaceful death and discuss usual course
7. Allow time for discussion
8. Make recommendations to withdraw dialysis and request family's assent
9. Provide assurance that the decision is reversible



# Ethics Handbook: Post et al 2007





# Professional Education: The EPEC Project

The screenshot shows a web browser window with the URL <http://www.epec.net/EPEC/Webpages/index.cfm>. The page features a dark red header with the text "The EPEC™ Project" and "Education in Palliative and End-of-life Care". Below the header is a navigation menu with links for "HOME", "ONLINE LEARNING", "CONFERENCES", and "MATERIALS". On the right side of the header, there are links for "SHOPPING CART" and "LOG IN".

The main content area is divided into two columns. The left column contains a red sidebar with the following text: "EPEC HOME", "ABOUT US", "FOR TRAINERS", "PARTNER INITIATIVES", "FACULTY/STAFF", "PUBLICATIONS", "RESOURCES/LINKS", "JOIN EMAIL LIST", "NEWS & EVENTS", and "10th ANNIVERSARY". Below this text is the Northwestern University logo and the text "NORTHWESTERN UNIVERSITY". At the bottom of the sidebar is a circular seal with the word "Original" and a banner that says "10th anniversary".

The right column features a "Welcome to the EPEC Project" section with the text: "Our mission is to educate all healthcare professionals on the essential clinical competencies in palliative care". Below this is a photograph of three people sitting around a table, engaged in a discussion. Underneath the photo is the text: "Learn effective approaches to adult education including interactive lecture, case-based teaching and role play." Below the photo is a "News & Events" section with two entries:

- 'Become an EPEC Trainer' Conference**  
July 10th – 12th, 2009 Chicago, IL  
[Registration](#)  
[Download Conference Brochure](#)
- 'Become an EPEC-Emergency Medicine Trainer' Conference**  
July 10th – 11th, 2009 Chicago, IL  
[Registration](#)  
[Download Conference Brochure](#)



# Professional Education: IPPC

The screenshot shows a web browser window with the URL <http://www.ippcweb.org/module2.asp>. The website header features the IPPC logo and the text "The Initiative for Pediatric Palliative Care" with the tagline "Enhancing family-centered care for children living with life-threatening conditions through education, research and quality improvement." A navigation menu on the left lists: Home, About IPPC, IPPC Curriculum, IPPC Videos, IPPC Quality Improvement Tools, Collaborating Hospitals, IPPC Team, IPPC's Funders, IPPC FAQ, Contact Us, and Site Map. The main content area is titled "IPPC Curriculum" and contains five module boxes. Module 2, "Relieving Pain & Other Symptoms," is highlighted. Below it, two activities are listed: "ACTIVITY 1: LECTURE" titled "Developmental Factors in Pain Assessment and Treatment" and "ACTIVITY 2: SEMINAR" titled "Pain Assessment in the Absence of Self Report." Each activity has a "MATERIALS" box containing links to "Facilitator's Guide" (PDF) and "PowerPoint" (PPT).

Home  
About IPPC  
IPPC Curriculum  
IPPC Videos  
IPPC Quality Improvement Tools  
Collaborating Hospitals  
IPPC Team  
IPPC's Funders  
IPPC FAQ  
Contact Us  
Site Map

## The Initiative for Pediatric Palliative Care

Enhancing family-centered care for children living with life-threatening conditions through education, research and quality improvement.

### IPPC Curriculum

<b>Module 1</b> Engaging with Children & Families	<b>Module 2</b> Relieving Pain & Other Symptoms	<b>Module 3</b> Analyzing Ethical Challenges	<b>Module 4</b> Responding to Suffering and Bereavement	<b>Module 5</b> Improving Communication & Strengthening Relationships
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#### Module 2: Relieving Pain and Other Symptoms

**ACTIVITY 1: LECTURE**  
**Developmental Factors in Pain Assessment and Treatment**  
This lecture enhances the ability of medical professionals to apply key principles and tools in the assessment of pain in children of all developmental stages and abilities. [[learn more ...](#)]

**MATERIALS**  
Facilitator's Guide [PDF](#)  
PowerPoint [PPT](#)

**ACTIVITY 2: SEMINAR**  
**Pain Assessment in the Absence of Self Report**  
This case-based seminar addresses pain assessment in children who are unable to report their pain verbally. [[learn more ...](#)]

**MATERIALS**  
Facilitator's Guide [PDF](#)



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# Funders

The *Guidelines* project is funded by a major grant from The Patrick and Catherine Weldon Donaghue Medical Research Foundation and a distribution from The Albert Sussman Charitable Remainder Annuity Trust.



# For more information

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Current research on EOL care and palliative care:

- Project Director, *Guidelines* Project
- Co-PI, The Chaplain's Role in Pediatric Palliative Care





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**THE VALUES & HEALTH REFORM  
CONNECTION**

The Values & Health Reform Connection

<http://valuesconnection.thehastingscenter.org>



# LOUISIANA'S DECLARATION CONCERNING LIFE- SUSTAINING PROCEDURES *and* DISASTER LEGISLATION OF 2008

Presented by

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END OF LIFE REVISITED  
MARCH 20, 2010

# DECLARATIONS CONCERNING LIFE-SUSTAINING PROCEDURES

La.R.S. 40:

§1299.58.1.

A. ...all persons have the fundamental right to control the decisions relating to their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn... where...diagnosed as having a terminal and irreversible condition.

(3)...the State of Louisiana shall recognize:

(a) The right of such a person to make a declaration instructing his physician to withhold or withdraw life-sustaining procedures or designating another to make the treatment decision and make such a declaration for him,

# DECLARATION

I, \_\_\_\_\_, willfully and voluntarily make known my desire that my dying shall not be artificially prolonged

....

I direct (initial one only):

\_\_\_ That all life-sustaining procedures, including nutrition and hydration, be withheld or withdrawn (food and water will not be administered invasively).

\_\_\_ That life-sustaining procedures, except nutrition and hydration, be withheld or withdrawn (food and water can be administered invasively.)

I further direct that I be permitted to die naturally with only the administration of medication... deemed necessary to provide me with comfort care.

# DNR ID BRACELETS

- D.(1)(a) The secretary of state shall establish a declaration registry in which a person, or his attorney,... **may** register ...the declaration.
- (b) The secretary of state shall issue a do-not-resuscitate identification bracelet to qualified patients listed in the registry. The ...bracelet must include the patient's name, date of birth, and the phrase "DO NOT RESUSCITATE".

## §1299.58.8. Immunity from liability

A.(1) Any health care facility, physician, or other person acting under the direction of a physician shall not be subject to criminal prosecution or civil liability or be deemed to have engaged in unprofessional conduct as a result of the withholding or the withdrawal of life-sustaining procedures from a qualified patient who has made a declaration or is wearing a do-not-resuscitate identification bracelet in accordance with the provisions of this Part.

# WORLD MEDICAL ASSOCIATION STATEMENT ON MEDICAL ETHICS IN THE EVENT OF DISASTERS (1994)

- 3. TRIAGE
  - e. patients whose condition exceeds the available therapeutic resources...may be classified as "beyond emergency care".
- 4. ...treatment beyond emergency care:
  - a. It is ethical for a physician not to persist, at all costs, in treating individuals "beyond emergency care"...., It is justified when it is intended to save the maximum number of individuals. However, the physician must show such patients compassion and respect for their dignity, for example by separating them from others and administering appropriate pain relief and sedatives.

# COMMITTEE FOR DISASTER MEDICINE REFORM





# Louisiana Disaster Legislation

- **Act 538**
  - La.R.S. 29:735.3 (Amendment to Good Samaritan Statute)
- **Act 539**
  - La.R.S. 37:1731.1 (Disaster Medicine Protocol, Civil Immunity)
- **Act 758**
  - La. R.S. 29: 7353
  - La. R.S. 40: 1299.3 (Disaster Medicine Review Panel/Criminal Cases)

*For Language of Acts, see links within [www.cdmr.org](http://www.cdmr.org)*

**Do not protect against intentional acts**

# ALL THREE ACTS

## ACT 538/ACT 539/ACT 758

- Who is Covered?
  - Persons listed in the existing Good Samaritan Statute R.S. 37:1731 (i.e. physicians, surgeons, physician assistant, nurses, medical professionals from other states, veterinarians, dentists and emergency medical technicians.)
- Who is Not Covered?
  - Not all “healthcare providers” are covered. The focus is on the individuals and not corporations or entities.
- Applicable only during State of Emergency declared by Governor
- Effective August 15, 2008

## ACT 538 SENATE

La.R.S. 37:1731.1

- ***Amendment to Good Samaritan Statute***
  - Services rendered in disaster area during declared disaster
  - Covered “**regardless of compensation**” (anyone on call or paid employee are now covered)
  - **Simple negligence law suits are prohibited** (not actionable)



# Question

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- If government or military **orders** civilian doctors to evacuate hospital using disaster medicine protocol, ***why should physicians' conduct be subject to different liability rules than government officials?***

# ACT 538

La.R.S. 29: 7353  
STATUTE DEFINITIONS

- (1) “**Disaster medicine**” means the art and science of patient care when the number of patients exceeds the normal medical capacities, facilities and personnel.
- (2) “**Disaster medicine protocol**” means the order of evacuation and treatment of persons by priority in accordance with recognized triage process applicable when disastrous conditions prevent evacuation or treatment of *all* patients.

# **ACT 538**

## **La.R.S. 29: 735.3--DISASTER MEDICINE PROTOCOLS**

- **PROTECTION AGAINST Civil damages** to patients as a result of evacuation or treatment
- In accordance with **disaster medicine protocol** (cannot treat all patients) **and** **at the direction of Government or military**

\*Medical Community needs to eliminate “direction of Government” by developing well-defined “disaster medicine protocols” that are widely accepted \*

# ACT 758

DISASTER MEDICINE REVIEW (CRIMINAL)

La. R.S. 29:7353; La. R.S. 40: 1299.3

- **Opinion by Independent Body** (Disaster Medicine Review Panel)  
Three member panel consists of: Coroner; Member of LSMS; Expert in Disaster Medicine (appointed by Governor or other two members)
- Input from Medical Community on Medical Judgment
- Scientifically Reliable Evidence
- Standard: “**Good Faith Medical Judgment under the circumstances.**”
- **Advisory Opinion** to Prosecution
- Statement of Legislative Intent – Prosecution “*shall refrain from arrest* of respondent medical personnel until panel opinion” (except: Risk of Flight).

# UNIQUE PROVISIONS OF THE STATUTES

- “**Regardless of compensation**” amendment to Good Samaritan statute
- Definitions of “**Disaster Medicine**” and “**Disaster Medicine Protocol**”
- Criminal Standard—“**Good Faith Medical Judgment** under the Circumstances”
- **Disaster Medicine Review Panel** to protect medical judgment from criminal charges
- Requires **Scientifically Reliable Evidence**
- Statement of **Legislative Purpose** and **Intent**



# Ochsner Health System

## Establishing Competence in Palliative Care



**David E. Taylor, M.D.**  
**ICU Medical Director**  
**Chairman, Pulmonary/Critical Care**  
**Palliative Care**



*"There's no easy way I can tell you this, so I'm sending you to someone who can."*

# Domains of Palliative Care

- Patient and Family-Centered Decision Making
- Communication within Team and with Patient / Family
- Continuity of Care
- Emotional and Practical Support for Patient / Family
- Symptom Management and Comfort Care
- Spiritual Support for Patient / Family

# Domains of Palliative Care

## Patient and Family-Centered Decision Making

- Assess patient competence
- Identify family spokesperson
- Pre-existing advance directives
  - ⊙ Living Will
  - ⊙ Healthcare Power of Attorney
- Establish parameters of care (DNR status)
- Share plan of care with patient / spokesperson daily
- Formal family conference within 48 hours of admit
- Provider care conference to determine care plan

# Domains of Palliative Care

## Communication within Team

## Communication with Patient / Family

- Interdisciplinary approach to care
- Formal family conference within 48 hours of admit
  - Format
  - Goals
  - Participants
  - Setting
  - Documentation
- Provider care conference to determine care plan

# Patient / Family Conference

- Change in patient status or goals of care
- Provider / family miscommunication or conflict
- Long length of stay without clear discharge plan
- “Blanket” family directions – “Do everything”
- Differing messages from various family members
- Need for further cultural and spiritual insight
- Family conflict or mistrust of medical caregivers
- Uninvolved family members – “Relative from Alaska”
- Alternative sites of care to be considered

# Provider Care Conference

- No clear physician leader – MD coordinator of care
- Disagreement among healthcare team members
- Inconsistent assignments of nurse to patient
- Nurses request different patient assignments
- Patient / family reported as “difficult” or “challenging”
- Co-morbid acute or chronic mental health condition
- Debriefing after a death

# Domains of Palliative Care

## Continuity of Care

- Shift to shift transfer of care
- Transfer of care to alternative provider
- Transfer of care to alternative setting





*"As you can see, we've transferred your husband from intensive to casual care."*

# Domains of Palliative Care

## Emotional and Practical Support

- Social services
- General information
  - Advance directives
  - Palliative care
  - Hospice
- Bereavement services
- Strengthen family relations and communication
- Liberal patient visitation
- “Nobody dies alone in my ICU”

# Domains of Palliative Care

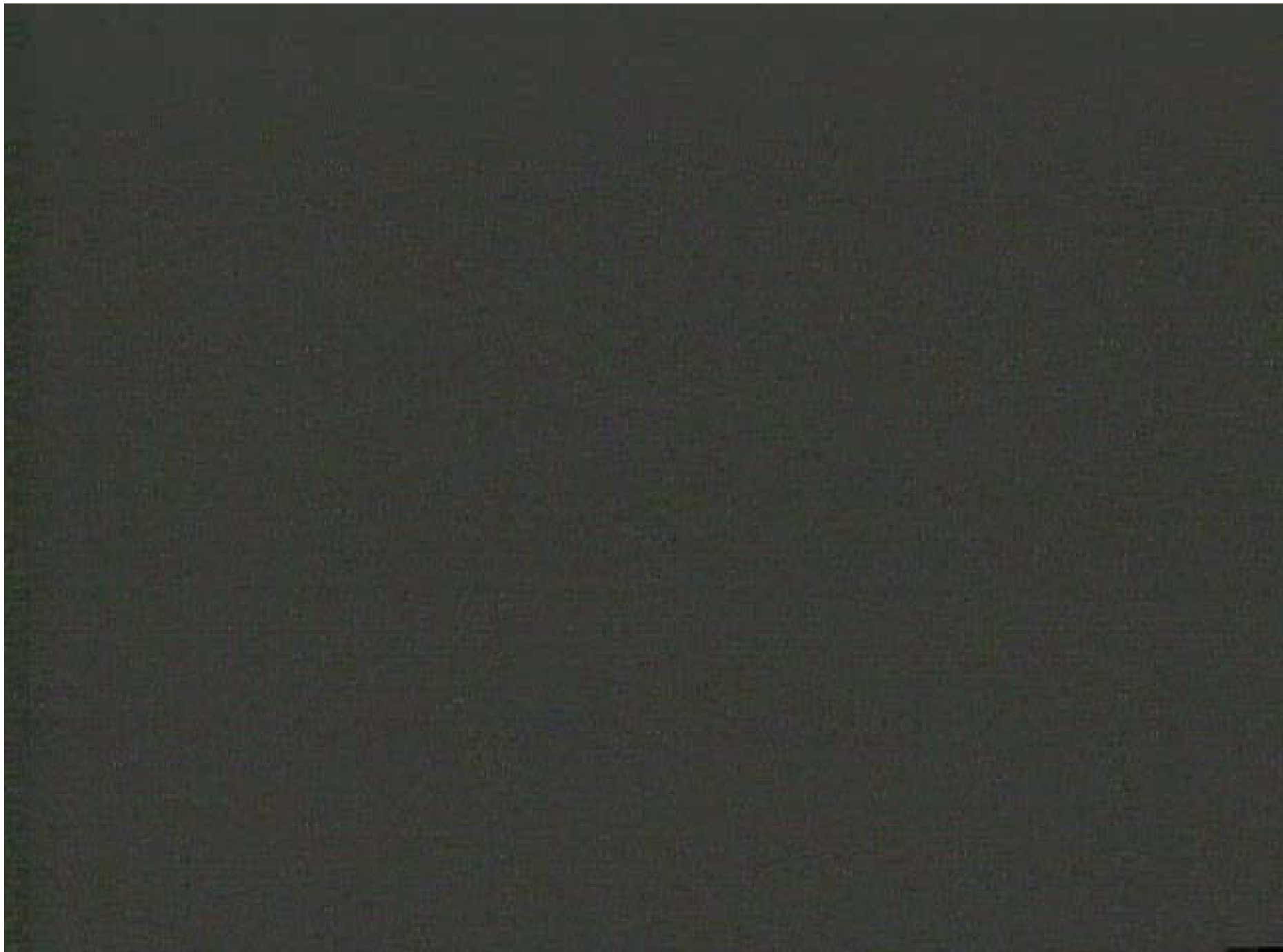
## Symptom Management and Comfort Care

- Identify symptoms of discomfort and distress
- Standard (but flexible) comfort care orders
- Anticipate side effects of medications
- Establish best practices for withdrawal of aggressive interventions (ventilator)
- Create a checklist

# Domains of Palliative Care

## Spiritual Support for Patient / Family

- Incorporate pastoral care provider as team member
- Establish spiritual needs early in the course of care
- Cultural and spiritual sensitivity
- Offer spiritual support as requested by patient / family



# A SyMPLE Approach to Palliative Care

- Symptoms
- Medical Problems / Prognosis
- Psychosocial (Spiritual)
- Legal
- Ethical

# Palliative Care

## The Quest for Goal Alignment

	Patient	Family	Provider	
Knowledge “Think”				Prognosis
Emotion “Feel”				Suffering
Action “Do”				Plan of care









Facultad de Medicina

Clínica Alemana - Universidad del Desarrollo

Centro de Bioética

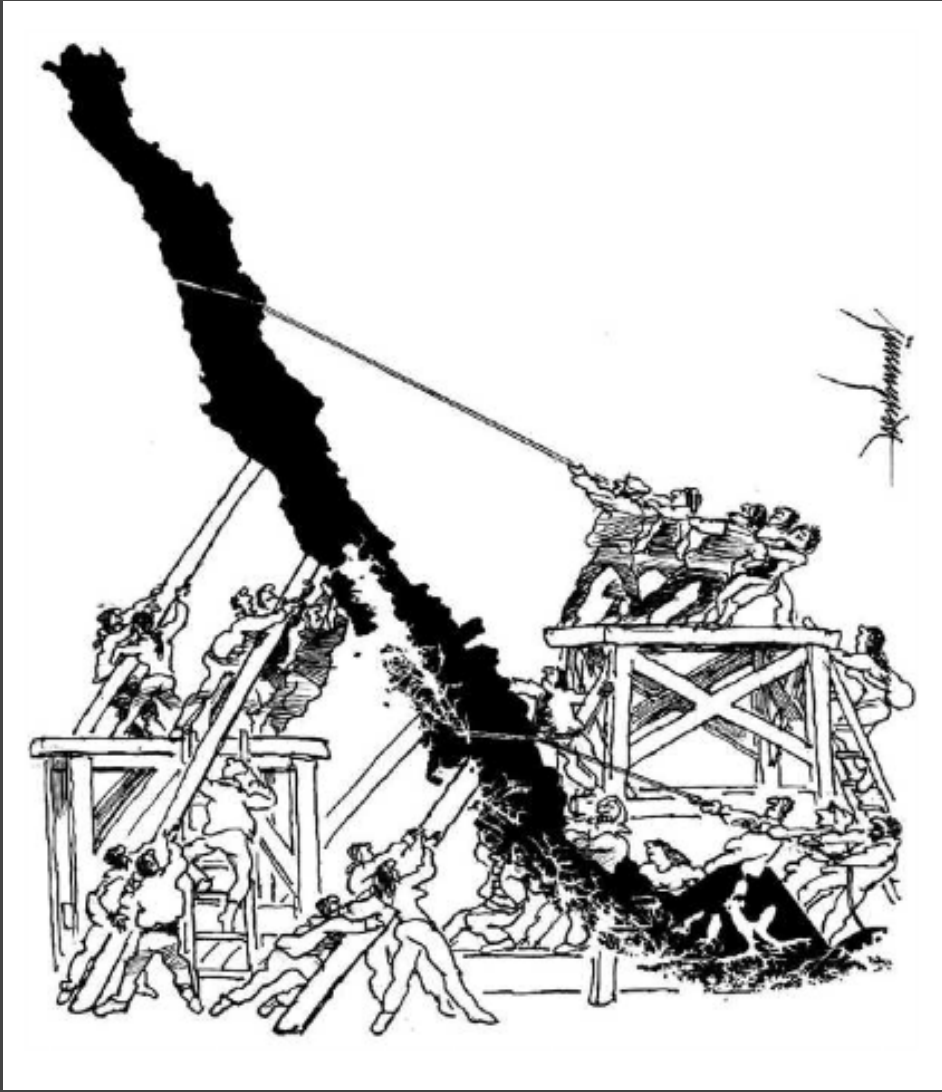
# The End of Life Revisited

March 20th, 2010

## Building competencies in pediatric end of life care

Dr. Juan Pablo Beca





# Competencies in pediatric end of life care

- Background / goals of medicine
- Our understanding of children's death
- How can we improve end of life care
- Pediatric EOL care as a professional responsibility

# Goals of Medicine

(Hastings Center Report; Nov/Dec96, Vol. 26 Issue 6, pS9, 6p)

1. The prevention of disease and injury, and the promotion and maintenance of health
2. The relief of pain and suffering caused by maladies
3. The care and cure of those with a malady, and the care of those who cannot be cured
4. The avoidance of premature death, and the pursuit of a peaceful death

**INCONSISTENCY BETWEEN OUR  
CLINICAL SKILLS AND OUR  
SUPPORTING COMPETENCIES**

# Clinical situations that need end of life care:

Pediatric intensive care

Neonatology

Oncology

Chronic diseases

Primary care

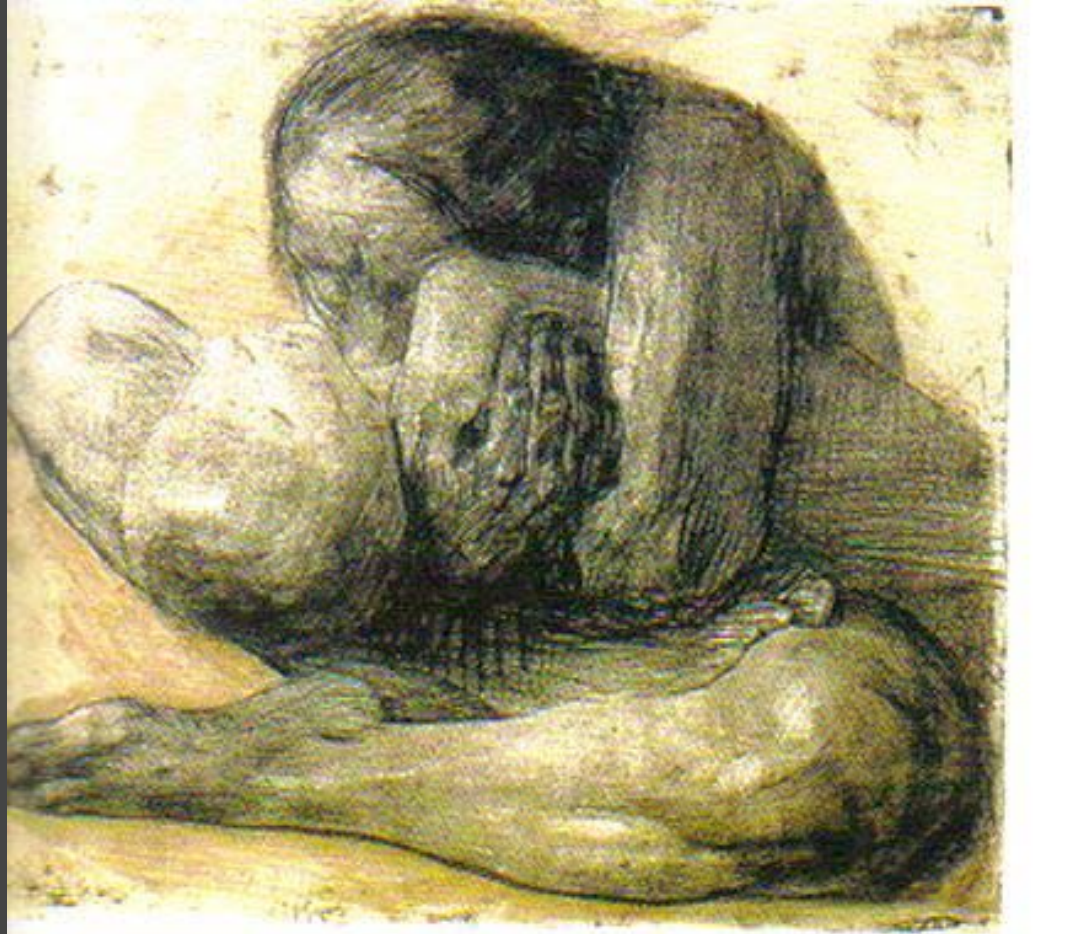
ETC.

- All pediatricians need to develop competencies to improve end of life care of their patients
- Other professionals in the health team
- Not a duty for separate teams



# Which competencies do we need?

1. Clinical skills
2. Supportive competencies
3. Bioethical competencies
4. Personal attitudes



Kathe Kollwitz (1867-1945), *Woman with her Dead Child* (1903)

- We need to understand death
- If we deny and hide adult's death, when it occurs in children we are left with no answers at all: only questions and mystery



Velorio del angelito. Arturo Gordon (1883-1944)



*Pearl Born July 7, 1895  
Died December 26, 1895*

- What is the meaning of such short lives?
- We are left with no answers: Their lives are a mystery
- Responses come from poetry and faith

- Mystery ....
- The deep meaning and transcendence of each human life is not age dependent
- We need a personal learning:
  - We have to understand and work out the death of children in a professional way
  - to be able to identify the child's and parents' needs and to respond to them

# The health professional and a child's death

We have responsibilities with:

- The child
- The family
- Our working team
- Scientific issues



# Responsibilities with the child

- Support for coping, according to age
- Balance between intensive treatment and palliative care
- Analgesia and sedation
- Personalized plan for end of life care
- Treatment limitation decisions
- No patient abandonment

# Children's comprehension of death?

- Newborns and infants: no comprehension
- Preschool children: different sense of time, death is not definitive, they recognize adult's sadness, helplessness and grief

- School age children: recognize death as definitive, they fear their own death
- Adolescents: comprehend death depending on their experiences. They feel anger and may go into personal crisis

**THEY ALL NEED SUPPORT ACCORDING  
TO THEIR AGE,**

**BOTH FOR THEIR OWN PROXIMITY TO  
DEATH AND FOR THEIR GRIEF**

# Responsibilities with families

- Support to admit the probability of their child's death
- Good communication
- Shared decisions
- Emotional and spiritual support
- Assistance in last moments and for bereavement

- **Parents' priorities:**
  - Complete and honest information
  - Fluent access to medical staff
  - Harmonization of information and decisions
  - Staff's emotional expressions
  - Encouragement of parent's and child bonding
  - Faith expressions facilitated

*(Meyer EC, Pediatrics 2006; 117:649-657)*

# Responsibilities with families

- What parents value most in communication:
  - Truthful, gradual and continuous
  - Reporting biological analysis and systemic organ functions does not ease comprehension of child's disease
  - Less talking and more listening !!!
  - They value silence time and companionship from physicians and health professionals

# Responsibilities with our own working team

- Enhance their understanding of a child's death
- Multidisciplinary team decisions
- Separate professional work from personal life
- Need to care of ourselves



# Scientific responsibilities

## Scientific point of view:

Final diagnosis

Post mortem exams

Causes of death

Critical analysis

Review of similar cases and issues



**How can we improve our  
management of a child's death?**

# Support experiences for bereavement in pediatrics

- Good communication and support during disease
- Definition of the best place for dying
- Favor family and child relationship and attachment
- Detailed information of final procedures
- Post mortem meetings

# Our experience in Neonatal Unit at Clínica Alemana in Santiago

- **Post mortem meetings:**
  - Analysis of clinical history and unavailability of death
  - Results of postmortem exams
  - Clarify any possible doubts
  - Explaining emotional phases of grief
  - Analysis of parent's coping process
  - Assure them that they'll overcome to their child's lost
  - Reproductive counseling
  - Directing to specific professional assistance

# The experience in Neonatal Unit at Hospital Regional de Temuco: Analysis of 141 neonatal deaths 2000-2002

- Grief committee
- Staff's training program
- Procedure handbook
- Imminent death was informed in 96%
- Parents' visits were authorized at any time
- 77% of parents were with their baby at death
- Post mortem meetings with 50% of parents









# Conclusions ?

1. We should improve our understanding of death and its meaning in our pediatric patient
2. Avoid denying death and hiding it as a clinical issue

3. There is a need for improvement in its knowledge and for developing clinical, supportive and bioethical competencies, altogether with personal attitudes
4. End of life care in pediatrics is a responsibility of the entire professional team

***Thank you***





***Thank you***

The Practice of Voluntary Active Euthanasia  
and PAS in the Netherlands and Oregon  
Its Impact on Patients, Families, Physician-  
Patient Relationship, society?

G.K.Kimsma, MD MPh

Radboud University Medical Center  
Nijmegen

Vrije Universiteit Medical Center  
Amsterdam, The Netherlands

# Aims of presentation

- Describe
  - the Dutch and Oregonian □ legal position /numbers/ diseases/physicians
  - the requests and the suffering
  - the role and role perception of Dutch doctors
  - the effect of E/PAS on patients, physicians and families
  - if dangers for a ‘slippery slope’ are realistic?
- Formulate conclusions



# definitions

- Dutch: euthanasia: ending the life of a patient *after a request, by injection*
- Other forms: death through stopping treatment (NTD), death as unintended effect of treatment, alleviating pain and suffering (APS), life ending without an explicit request (LAWER)
- PAS: helping a patient die after a request through handing a potion
- USA: this is voluntary active euthanasia: VAE
- Other forms: passive E, voluntary/ involuntary, direct/indirect
- PAS: helping a patient die after a request through handing a potion

## VAE and PAS, when allowed: conditions

- Conditions in the *Law on Review Procedures for the Termination of Life, 2002*
  - Voluntary and carefully considered *request*
  - Unbearable and hopeless *suffering*
  - Full *information* on the medical position
  - No reasonable *alternative*
  - Independent collegial *consultation*
  - *Life ending with due medical care*
- Mandatory reporting: Euthanasia Review Committees (5) : lawyer, physician, ethicist, binding decisions
- 2008: 2321 cases/'80%'

# When is PAS allowed? (O)

- Conditions of the ODDA 1997:
  - >18 yr, resident Oregon
  - Patient must be *capable*
  - *Physician and consultant* confirm diagnosis and prognosis
  - Determination of *terminal illness*, 2 physicians
  - 2 oral *requests*, 15 days apart, one written
  - In case of *doubt* of competence, referral to mental health
  - Full *information* on alternatives in care and comfort
  - Request to notify the *patient's next of kin*
  - *Mandatory report* of prescription to Oreg dept health services
  - Pharmacies are *required* to report prescriptions

# Differences between N and O (1)

- Euthanasia and PAS, 1:60
- Not limited to terminal patients: ‘unbearable and hopeless suffering’
- Phys ends life by injection or hands potion: duty to be *present*
- Prior phys consultation
- Mandatory reporting to Euthanasia Review Cie, for review
- PAS, 1:800
- Terminal patients, life expect < 6 months
- Phys writes prescription, is *absent* at ingestion
- Prior consultation by 2 physicians
- Mandatory reporting, for statistics

# Differences N and O (2)

- Jurisprudence allowed PAD since the seventies
- Broad public support, >80%
- Support of the medical profession since 1984
- Cooperation between the legal and medical profession: *focus of the law is on medical science and medical ethics*
- Parliamentary passage in 2002
- Only allowed after the law was voted on 1997
- Divided public support, narrow majority
- No support of the medical profession
- No cooperation between law and medicine
- Passage by popular vote

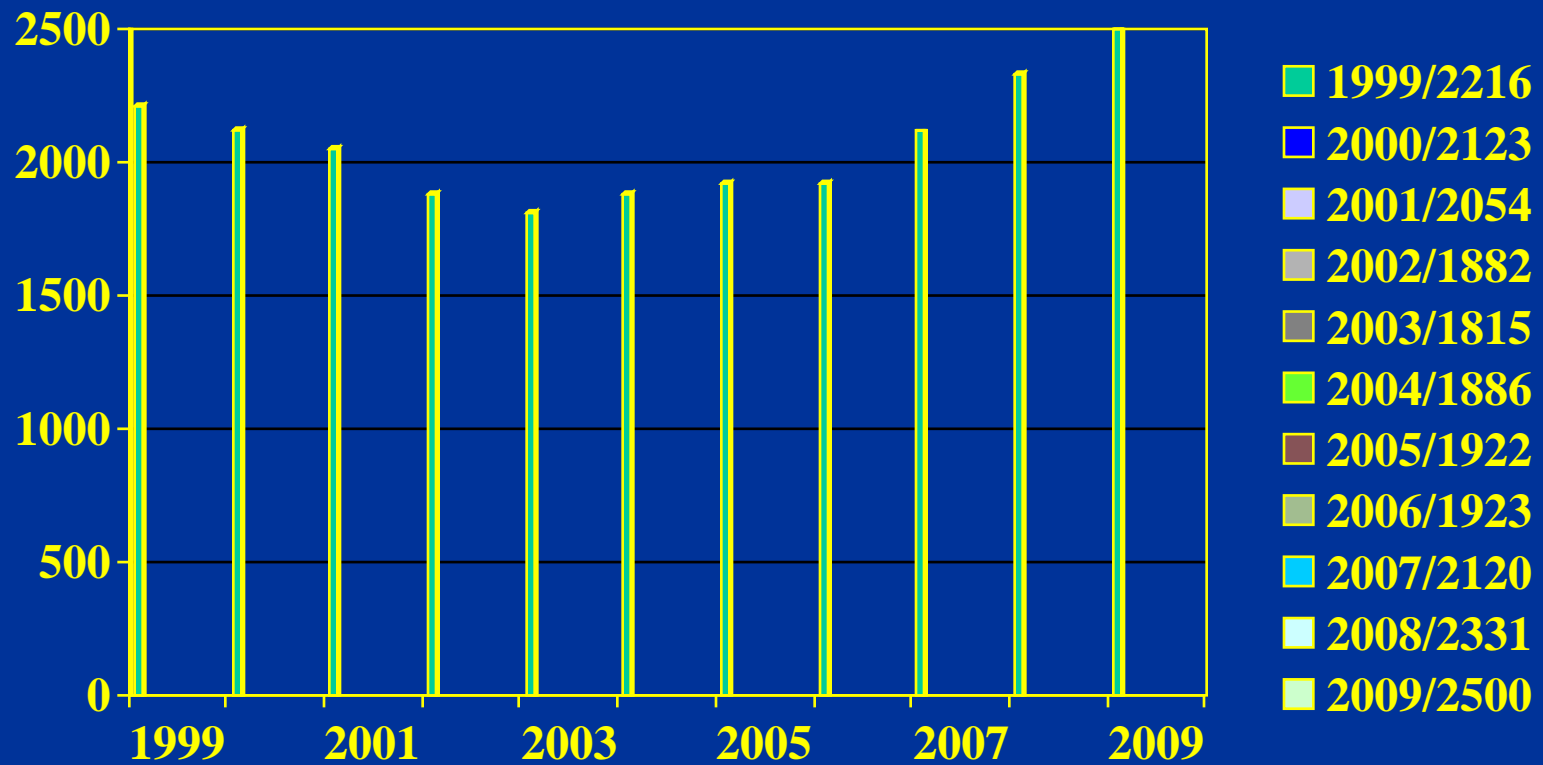
# How often does 'it' happen? Does any request do it? 2005

- Roughly 10x more requests for 'the future' than actual cases (~34000 vs 3600)
- Roughly 3x more requests for the immediate future than actual cases (9700 vs 3600)
- 80% family physicians, 2-3 requests a year, VAE and PAS about once every two years

Numbers 2005 (N): 138.000 deaths in 16  
million inhab/ USA 2006: 2.426.264

- VAE: 1,7% : 2325: ~ USA 41.000
- PAS: 0,1%: 100 Or: 97/07: 341
- APS: 25% ~ USA 600.000
- NTD: 16% ~ USA 390.000
- LAWER: 0,4%: 550 ~ USA 9.700
- Reporting VAE/PAS : 80 % ~USA ? %?

# Numbers of E and PAS: Netherlands





# PAS in Oregon

QuickTime™ en een  
TIFF (ongecomprimeerd)-decompressor  
zijn vereist om deze afbeelding weer te geven.

# Comparing cases 2008(N) and 2007(O)

- Diseases: 81% cancer
  - 19%: CLRD, ALS, HIV/AIDS, heart dis
  - 80% died at home, with GP care, 20% hospital, longterm care, nursing homes, hospices
- Diseases: 86% cancer
  - 7%: ALS, CLRD, HIV/AIDS
  - 90% died at home, 88% with hospice care

# Why do patients want to die?

- Netherlands
  - To prevent:
    - further suffering,
    - meaningless suffering
  - Further deterioration
  - Pain
  - Death without dignity
  - Loss of independence
  - Fatigue, suffocation
  - Being a burden
- Oregon
  - Loss of autonomy  
100%
  - Decreasing abilities  
86%
  - Loss of dignity 86%
  - Inadequate pain  
control 33%

# Observation and interpretation: Physician and Patient

- Actual suffering: symptoms, loss of function
- Future suffering: what symptoms, which loss?
- What is unbearable for this patient?
- How has the patient reacted to 'threats'?
- Context of care, burdens for others?
- What does this mean for this patient?
- How does the patient experience loss of function, increased dependence?
- How does the patient look at more loss of functions
- What loss is unacceptable?
- When does care become no longer acceptable?

# How do Dutch physicians see their roles in helping die? (Norwood, 2005)

- In general : helping people die is normal medicine, *ending life is part of medical ethos*, even when legally it is not normal medicine
- *Non abandonment*: guide, witness and facilitator
- Making *death as acceptable* as possible for the individual patient
- *Helping families* in accepting death of a patient
- Euthanasia is only possible with a deeper, mutual, reciprocal relationship

# The effect on physicians after helping patients die 'in all forms' 1

- Haverkate (2001): interviews 405 phys after E and other med dec at the end of life (MDEL)
- Both feelings of satisfaction/relief (52%) and discomfort/emotional drain (42%) , esp GPs
- *Surprise finding: discomfort increased with E/PAS, even higher than with 'illegal' hastening of death without request (LAWER)*
- *Explanation: with E/PAS the closer relationship causes the deeper 'hurt'*

# The effect on physicians 2

- *No routine*: 110 physicians with more experience, next case perceived: 45% just as difficult, 26% less difficult, 29% more difficult
- *No withdrawal*: 95% indicated a willingness to participate again if need be
- *Little regret*: 5% had regrets but no doubts about the appropriateness of the E
- *Satisfaction*: 85% reported an increase in the quality of dying through E, 12% reported a 'somewhat' increase
- *Conclusion*: a good death was realized, even under lingering doubts.

# What happens after a request? Changes in the physician-patient relationship

- *Hightened awareness of the limits of the medical role and the ethos of helping patients die*
- *Intenser emotions: experiencing anxieties/ambivalence, including the confrontation of one's own mortality*
- *Intenser involvement with the patient and the family: a need for more intimacy, to come closer, to bond*
- Evaluating constantly whether the stage of unbearable suffering becomes a shared experience, beyond the subjective patients' feelings
- Experiencing ambivalence between the illegality of helping someone die and the duty not to abandon



# ‘Medical friendship’ as a condition for E/PAS (Clark/Kimsma)

- A mutual need for closeness by patients, families and physicians
- The need for a more personal relationship within the limits of professional distance
- Coupled with the need to know about a patient’s endurance/biography in the face of unbearable suffering (against subjectivism)
- With the aim to prevent suffering and not to abandon
- Qualifies as *friendship as virtue*, hence: ‘medical friendship’

## Effects of E on the grieving of families/friends (Swarte 2003)

- Comparison grieving of 189 persons who lost a E patient, with 316 persons who lost a patient after 'natural death', gynecological tumors
- Group A has less traumatic grief symptoms, less current feelings of grief and less post-traumatic stress reactions, independent of other risk factors
- Possible explanations: possibility to say goodbye, anticipatory grief, the possibility to talk open about death and dying: 'euthanasia discourse'

## Dangers, slippery slopes in the Netherlands?

- No increase in numbers of E/PAS
- Pressure groups aim at the option to end life in case of loss of meaning, 'ready with life'
- No political inclination to expand the law
- 'Refinements' for special groups through ERC's: psychiatric patients, early Alzheimer's patients, more stress on a prior advance directive in case of loss of communication
- 'unbearable suffering' remains difficult to assess
- The status of patients' refusal of available care as 'reasonable alternatives'

## Dangers in Oregon? Effects on vulnerable groups?

- No slippery slope for:
  - The elderly, over 85 years
  - Women: 46% in O, N: slightly more males
  - Uninsured: 16,9% uninsured, 1% of prescriptions
  - Education: more college grads, 7.6x higher
  - Poverty: rather higher educated, insured
  - Race: 97% white, no African Americans
  - Disabilities, chronic diseases: no evidence
  - Minors and mature minors: no evidence
- Overrepresentation of HIV/AIDS patients

## Conclusions: N/O: much anecdotal and few empirical studies on the effect of E on the PP relationship

- N/O: More attention during the process of E
- N/O: A deeper relationship between physician and patient and families
- Both unsettling for physicians and gratifying
- No research on the appreciation of the medical profession in the area of E except anecdotal
- N: Anecdotal information is overwhelmingly appreciative and positive
- N: The effect seems to be respect and appreciation for individual physicians and the medical profession

# Thank you

- G.K.Kimsma

# Theory of Conflicts: moral/legal and professional (Clark/Kimsma)

- Moral: ending vs protecting life
- Legal: protection of life vs duty to alleviate suffering
- Professional: the necessary basis of a treatment relationship (no euthanasia tourism)
- Paradox: the perceived need for a closer relationship as a condition to be able to end life

# Why do physicians refuse in two out of three cases? Resistance?

- Alternatives present, including pain treatment
- Suffering was not unbearable
- Request was not really well considered
- Absence of a correct view on the disease
- Request was withdrawn
- Objections in a particular case or in general against VAE/PAS of the physician



# Patients, physicians and diseases

## Review Committees' Report 2008

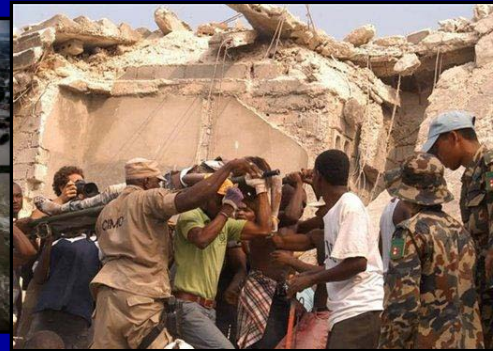
- Of 2331 reported cases
- 81% suffered from terminal cancer
- Other 19%: CVD, Nerv Syst, COPD, AIDS
- 80% died at home, helped by a family phys
- Usually after a longterm relationship, after a longer process of discussion, initiated mainly by patients
- Other 20%: hospital 6%, nursing home 4%, care institutions for elderly and hospice 10 %

# The assessment of suffering: the theory

- Suffering: actual/future suffering
  - Synchronic: complaints/symptoms
  - loss of function
  - Diachronic: changes over time, which symptoms will increase, what functional loss will increase?
- Suffering and personality: why unbearable for this person?
- Suffering and biography: what coping mechanisms are part of the biography?
- Suffering and surrounding: what care is available and how does the patient feel about it? Nursing homes as an option or not?

# Phases in the *process* of euthanasia/pas

- *Initial requests*, for some time in the future, no terminal/serious disease in sight
- When sick: actual request for the near or immediate future
- Balancing (palliative) care versus the desire to die
- Asking for an independent consultation
- Setting a date and time
- Checking the veracity of the request
- Ending life through i.v. injection or oral barbiturate
- Reporting to a local municipal MD and a Euthanasia Review Committee



# Public Health Emergencies and

# The Duty to Care: Medico-Legal Implications

Anna Maria Pou, MD

LSU Health Sciences Center



hurricane  
earthquake  
flood  
mudslide  
pandemic  
nuclear incident  
chemical spill  
terrorist attack  
whatever

***This CAN happen to you!***



# Prelude

- Aug 28<sup>th</sup>-Mandatory evacuation Orleans parish
  - No mandatory evacuation for hospitals
  - Superdome refuge of last resort
- Patients still being admitted
- Hospital Lockdown 5pm
- 2,000 people inside
- 110 pets
- **Mass chaos**

August 29<sup>th</sup>, 2005



- Hurricane Katrina makes landfall in Louisiana early am with 135mph winds
- Levees breached
- Hospital on generator power



# Tuesday August 30th



Citizens trying to break into hospital  
had to deputize medical personnel

- 6 Orleans Parish hospitals underwater
- Triage: *critical go first*
- Generators later failed
- **Communications failed**  
(*cut off from outside world & each other*)
- No running water
- Limited food, water, supplies
- **Hospital in survival mode**
- **“Reverse” triage**



# Outside.....



Citizens on roof tops



KATRINA: THE STORM WE'VE ALWAYS FEARED

## The Times-Picayune

THURSDAY, SEPTEMBER 8, 2005

# 'HELP US, PLEASE'

AFTER THE DISASTER, CHAOS AND LAWLESSNESS RULE THE STREETS



**Local leaders call relief efforts too little, too late**

**Blanco demands thousands of troops**

**Man pleads for help**

**Blanco demands thousands of troops**

**Man pleads for help**



# Hospital Conditions

***“Special Needs” Shelter***  
***3<sup>rd</sup> world***



# Thursday September 1st

- No security at hospital/s
- Volunteer airboats were told to leave
- People would not evacuate without pets
- Families wanted to leave together
- Afraid of what laid ahead-many could not swim
- National Guard and helicopters later arrived





Charity Hospital ER Ramp



University Hospital



Memorial Hospital



Lindy Boggs (Mercy) Hospital



# Evacuation



# Disaster Medicine



- “The art and science of patient care under circumstances of stress when the number of patients exceeds the normal medical capacities, in which a sudden concentration of causalities overwhelms existing medical facilities and personnel.”



# Disaster Medicine Protocol:

## ***Not Business as Usual***

- “The order of evacuation and treatment of patients by priorities in accordance with the recognized triage process applicable ***when disastrous conditions may prevent evacuation or treatment of all patients.***
- ***Greatest good for greatest number***
  - ***Population based***
  - ***War-like situations***

# Physician's Role During a Disaster

- “...individual physicians have an obligation to provide urgent medical care during disasters. The ethical obligation *holds even in the face of greater than usual risk to their own safety, health or life*...physicians should balance immediate benefits to individual patients with ability to care for patients in the future.” (AMA 2004, E-9.067)




# Triage

- S.T.A.R.T. model (Simple Triage and Rapid Treatment)
- Immediate: threat to life or limb
- Delayed: medical attention within 6 hours
- Minimal: “walking wounded”
- Expectant: survival not expected

Triage is accepted as preferred model for the ethical distribution of scarce medical resources—no alternative proposed to date

# Applied Values of Medical Ethics

- Beneficence: act in the best interest of the patient
- Non-maleficence: " first do no harm "
- Autonomy: right to refuse or choose treatment
- Justice - concerns the distribution of scarce health resources, who gets what treatment (fairness and equality)
- Truthfulness and honesty: the concept of informed consent
- Dignity
- Transparency: open and publicly debated

- 
- Ethical dilemma: when moral values are in conflict; sometimes, no good solution exists
    - The values of the medical community conflict with the values of the individual patient, family, or larger non-medical community
    - Conflicts can also arise between health care providers, or among family members

# Pandemic Flu

- Protocols:
  - New York; Indiana; Ontario Health Plan
  - Task force on mass critical care :“ *Definitive Care for the Critically Ill During a Disaster: A Framework for Allocation of Scarce Resources in Mass Critical Care*” (*Devereaux et al, Chest 2008;133:51S-66S*)
- **Objective exclusion criteria** (some use age; SOFA score)
- Palliative care team for those who will not receive a ventilator



# Ethical Framework for Allocating Resources/Disaster Triage

- Duty to care: obligation to care for patients
- Duty to steward resources:
  - Balance obligation to save greatest number of lives vs. the obligation to care for each patient
- Duty to plan:
  - Planning is an obligation
- Distributive justice:
  - Same allocation system should be used across the state and authorized by the state; equal access
- Transparency
  - **Public input and education**

# Ethical Principles at Risk

- Autonomy/Decision Making: patients may want care, but may not receive care
- Autonomy/Informed consent:
  - Patients and their family members will not be actively participating in consent when resources are scarce (i.e. to withhold care or to withdraw care—to be removed from vent)
  - Often impractical/unrealistic to have patients sign a written consent form during a disaster depending on patient (unconscious) and hospital conditions, time constraints (WMA, 2006)

**A just rationing system must support ethical principles when possible**

# Criteria

- Justice/allocation of resources:
- **Pandemic:** Sequential Organ Failure Assessment (SOFA) score; severity of chronic illness
  - **Hurricane Katrina:**
    - IVF's: Open eyes and state name (used by a downtown hospital)
    - Food/water: Patient, employee, young pregnant female?

**SOFA score not applicable**

- Beneficence
- Non-maleficence
- Dignity






# Ethical Issues

- **Hurricane Katrina order of evacuation:**
  - Evacuation:
    - Are family members evacuated with patients?
    - Pregnant women/young people evacuated before elderly patients?
    - Are mothers separated from children?
    - What to do with those who won't evacuate without pets?
    - Critically ill/DNR

# Ethical Issues

- **How long are physicians/nurses expected to stay with dying patients?**
- **What do you do with patients who can't be evacuated? (Lindy Boggs Hospital)**

**“Duty to serve”**



# Hope Turns to Anguish at Intensive-Care Unit

*(Robert Davis, USA Today, 9/2005)*

***“There was no good solution. There were only bad choices.”***

*(James Riopelle, MD; Lindy Boggs Hospital)*

*...not everyone going to make it out*

# “Missing” Pieces

- **Mass Casualty Events:**
  - **NO standard triage** at present in U.S. for mass casualty events
  - “Standard” triage not applicable to chronically/critically ill patients (hospital/shelter)
  - No triage system to provide reliable distinction among similar patients
  - **State/National guidelines needed: medical protocols (care during altered conditions)**
  - **Legal standard of care: there is none**



# Legal Issues

- Liability protection for health care workers who adhere to the rationing criteria/guidelines
- Legislation
- Defense and/or indemnification



# Preparation

- Know your plan
  - Know the “key players”: Do they have advanced training?
  - Physicians are at the mercy of those who planned— **be proactive!**
  - Protection for healthcare workers and families
- \* National Disaster Life Support Education Consortium (NDLSEC): educates med students, residents and practicing physicians in disaster medicine



# Resource Allocation & the Cost of Care Near the End of Life

*Promoting Discussion, Developing Policy, and  
Building Consensus  
in Health Care Institutions*

The Hastings Center  
*Guidelines Project*

© 2010





# Cost is an ethical challenge in end-of-life care

- Equity requires health care institutions to grapple with the moral and fiscal dimensions of resource allocation and the cost of care, including end-of-life care.
- It is difficult to talk about such issues in a structured and productive way.



# Talking about the ethics of cost

Developing an institutional practice of talking about the ethical dimensions of the cost of care:

- supports policy development concerning the equitable allocation of limited resources
- helps professionals learn how to talk with patients and families about treatment burdens that are economic as well as physiological.



# Discussion strategy 1

Provide an appropriate forum for discussing resource allocation.



# Discussion strategy 2

Provide accurate institutional data on costs to support discussions of resource allocation.



# Discussion strategy 3

Describe the different levels at which health care resource allocation takes place. Support ethical reflection appropriate to each level while clarifying which levels are actionable within the institution.



# Discussion strategy 4

Identify known problems, shared goals, and viable options.



# Discussion strategy 5

Develop a working vocabulary of concepts and definitions relevant to resource allocation.



# Discussion strategy 6

Provide information and training for physicians concerning the economic implications of treatment plans for patients and families.





# Discussion strategy 7

- Conduct a staff survey or interviews to identify the resource allocation and cost issues that are most troubling to staff.
- Address these issues in ongoing discussions.
- Develop ethics education programs that respond to specific needs.



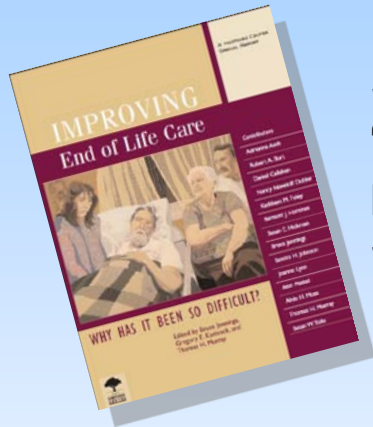
# Discussion strategy 8

- Discuss resource allocation and the cost of uncompensated care for patients without insurance.



# For more information

Nancy Berlinger, The Hastings Center  
berlingern@thehastingscenter.org



Special Report (2005):

“Improving End of Life Care: Why Has it Been So Difficult?”

<http://www.thehastingscenter.org/Publications/SpecialReports/Detail.aspx?id=1344>

Current research projects on end-of-life care and palliative care:

- *Ethics Guidelines for Decision-Making About Life-Sustaining Treatment and Care Near the End of Life*  
(revision of 1987 Hastings Center *Guidelines*)
- The Chaplain’s Role in Pediatric Palliative Care:  
Mapping Model Programs  
(empirical study with Rush University Medical Center)



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