

# Principles of Medical Ethics & Professionalism

Syllabus 2012-13

M'16

This course marks the beginning of your formal ethics and professionalism curriculum, which has two primary purposes. First, as medical educators, we have a responsibility to graduate morally discerning physicians whose interactions with patients, colleagues and the public are guided by the highest standards of ethical and professional conduct. And second, we want to leave you with the ability to recognize an ethical conflict when you see one and consistently make morally defensible decisions to resolve it. We will not attempt to make you a more ethical person (even if we could) or train you to serve on a hospital's ethics committee. Rather, our intention is to engage you in the process of discovering how your own sense of right and wrong influences your decisions, attitudes and behaviors as medical students and, ultimately, as physicians.

Ethics training, like clinical training, has its greatest impact when it occurs in the context of real decisions made on behalf of real patients. Most of your ethics and professionalism education will take place unintentionally while working alongside your clinical mentors. When you reach this stage in your training, it is essential that you come prepared with sufficient insight to question what you witness and an intellectual framework to grapple with ethically controversial situations that will inevitably arise.

## **Goals**

The goals of this course are to:

- Engage in a self-reflective process of identifying personal moral values and their relevance to the medical profession
- Demonstrate how ethical considerations influence the practice of medicine and their far reaching implications for society, the profession, and the lives of individual patients
- Encourage the open, free and respectful exchange of views by challenging simple moralistic dichotomies and emphasizing the pluralism and ambiguities inherent in the ethical practice of medicine
- Foster the development of ethically competent physicians capable of, and committed to, resolving day-to-day ethical conflicts through the reasoned and balanced application of ethical principles

## Competencies

By the end of this course, students will be able to:

- Reflect on their own moral assumptions about the goals of medicine and articulate professional obligations they are expected to fulfill towards their patients, their profession, society and themselves
- Recognize that a professional community is responsible for its own standards of professionalism and that the duty to adhere to those standards is largely self-regulated
- Identify the unambiguous line (when it exists) separating professional from unprofessional attitudes and behaviors, while recognizing the ethically pluralistic nature of professional conduct
- Describe various methods of moral reasoning and explain how the most influential moral philosophers have contributed to the development of modern clinical ethics
- Recount the selected historical events that have shaped contemporary medical ethics and describe how American culture and major religions have affected ethical standards in medical practice
- Explain the major strategies used to methodically analyze morally controversial cases affecting the interests of physicians, patients and the rest of society.
- Argue a given ethical position by identifying the relevant facts, weighing the ethical principles involved, and arriving at a defensible conclusion that justly balances all competing interests at stake
- Identify circumstances where professional socialization may seriously conflict with ethical principles and propose a justifiable course of action to address them
- Recognize ethically questionable behavior wherever and whenever it occurs and make use of safe, productive and regularly available venues to express ethical misgivings without fear of retribution
- Describe and apply the ethical principles governing the rights of patients as they pertain to competency, informed consent, refusal of care, truthfulness, fidelity and confidentiality
- Demonstrate an understanding of major ethical issues involving appropriate use of medical services including medical futility, do-not-resuscitate orders and the determination of death such as that surface at the end of life including the definition of death, medical futility, euthanasia, physician-assisted dying and organ procurement
- Demonstrate an understanding of major ethical issues pertaining to the quality of life including enhancement medicine, palliative care, terminal sedation and physician-assisted dying
- Explain how physician behavior may be affected by inherent conflicts between the diverging interests of patients, physicians, insurers and the pharmaceutical industry
- Ethically weigh the opposing obligations the medical profession must uphold towards the care of individuals versus the welfare of the public
- Describe how the principles of distributive justice influence the debate over health care rationing and reform



## Student Responsibilities

### Attendance

The course consists of large group lectures and small group discussions. Attendance at **all** small group sessions is required. To receive credit for attendance, you must sign in at all small groups within the first 5 minutes of the start time. If you need to miss all or part of a session you must contact the **Office of Student Affairs** before the session begins to receive an excused absence. Two or more unexcused absences from any of the small group sessions will result in a failing grade for the course. Although attendance will not be taken at large group lectures, it is important to attend these sessions since they are designed to prepare you for the subsequent small group discussion(s).

### Reading Assignments

Reading assignments for each session are listed in the syllabus. It is essential that you do the assigned readings in advance of the relevant large or small group session. Reading materials are from two sources:

- Textbook – Jonsen A, Clinical Ethics: A Practice Approach to Ethical Decisions in Clinical Medicine, 7<sup>th</sup> Ed (2010)
- TUSK – Full-text articles and discussion cases

The textbook is available in both paper and online versions. You may purchase the paper text in the campus bookstore (or via amazon.com) or use the e-book version available through the HSL website:

<http://www.accessmedicine.com/resourceTOC.aspx?resourceID=90>

If this link fails to take you directly to the text, go to <http://www.library.tufts.edu/hsl/>. Click E-Books (in the upper right corner) > AcessMedicine (under Browse by Collections) > Textbook tab. Scroll down to *Lange Education Library*. You'll find the text under *Clinical Science*.

A few additional articles outside the text and discussion cases are also linked to the relevant session on TUSK.

### Small Group Discussion Sessions

The class will be divided into approximately 18 small groups consisting of 11-12 students and one or two facilitators each. You and your group will meet to discuss eight different ethical topics over the duration of the course. To prepare for these sessions, you will be provided with 3-4 cases to read and analyze in advance. At the start of each session, your facilitator(s) will randomly select different students to present the relevant facts of each case and identify the applicable ethical principles. ***Please take the time to read over the cases and any other***

**assigned materials prior to these sessions.** You are not required to submit anything in writing. Over the course of the year, your facilitator(s) will assess the frequency, thoughtfulness and collegiality of your contributions to the discussion. This assessment will form part of your overall score for the course (see below). You are free and encouraged to ask your facilitator(s) for individual feedback on your participation at any time following the fourth small group session.

### Ethical Analyses

On two occasions during course, you will submit a 2-page ethical analysis addressing one of 3 or 4 cases posted on TUSK. The cases, similar to those discussed in your small groups, will be available at least one week prior to the submission dates:

Analysis	Cases Posted by	Submission Due by*
1	Oct 30	Nov 6
2	Mar 1	Mar 8

\*11:59 pm

**Instructions.** After choosing your case, use the template provided on TUSK to divide your analysis into the following four sections:

- Formulation of a specific ethical question that characterizes the conflict of values in the case
- Identification of the facts in the case that are relevant to answering this ethical question
- A persuasive argument that employs ethical principles to justify your answer to the ethical question
- Practical steps you would take to gather more information and/or help resolve the conflict among stakeholders

Be sure to identify the case you have chosen to analyze in the space provided. Electronically submit your **single-spaced** analysis via TUSK by 11:59 pm on or before their respective due dates. **Note:** This is an independent assignment. You are on your honor (appropriately enough) to submit only your own work and not to discuss it with peers or anyone else until past the due date. However, you are free and encouraged to consult the syllabus, textbook and any other reference materials you wish. If you quote or paraphrase these materials, be sure to provide a brief parenthetical citation, for example: (Jonsen, *Clinical Ethics*, page 24).

Your analyses will be evaluated according to the following criteria:

- Did you formulate a specific ethical question that characterizes the conflict of values?
- Did you correctly identify the facts relevant to the ethical conflict?
- Did you apply cogent ethical reasoning to arrive at a defensible resolution to the conflict?

- Did you make practical suggestions that would be likely to clarify the appropriate ethical outcome and/or lead to a resolution of the conflict among stakeholders?

Note that while your responses to the first two parts of your analysis will be more or less correct or incorrect, a range of reasonable responses are possible for the third and fourth parts.

### Quizzes and Exam

As you probably know, the subject of ethics is characterized more by philosophical debate than by irrefutable facts. Although ethical questions always have answers, reasonable people can reasonably disagree on a particular course of action. Nevertheless, there are many situations in which the application of ethical principles clearly points in one direction. A fully competent adult, for example, disagrees with her physician's recommendation to have a malignancy surgically removed. Assuming she fully comprehends the risks and benefits involved, all would agree that forcing the patient to have surgery against her will would constitute an unacceptable violation of her right to self determination.

Since these ethically less contentious situations regularly appear in clinical practice – and as USMLE questions – we want you to have the opportunity to grapple with them during this introductory course. After each small group session, we will provide four multiple-choice questions pertaining to the topic covered for you to answer on TUSK. Quiz questions will remain available for one week from the day they are posted:

Quiz	Questions Posted*
1	Nov 26 – Dec 3
2	Dec 13 - 20
3	Jan 3 - 10
4	Feb 1 - 8
5	Feb 21 - 28
6	Apr 1 - 8
7	Apr 8 - 15
8	May 10 - 17

\*Quiz questions close at 11:59 pm on indicated dates

If you do not take the quiz within the allotted time frame, you will not receive a score. Each student must submit his or her own answers. Unlike the written ethical analyses, however, collaboration is permitted and encouraged.

The quiz questions will also serve to prepare you for an in-class final exam covering material from the entire course. The exam, consisting of 24 multiple-choice questions (similar to the quizzes) will be incorporated into the Scientific Foundations of Social & Behavioral Medicine exam at the end of the year.

## Student Evaluation

A final grade for the course will be calculated based on the total number of points earned according to this distribution:

Small group participation	20
Ethical analyses (x 2)	24
TUSK quizzes (x 8)	32
Final exam	24
<b>Total</b>	<b>100</b>

To pass the course, your score on the final exam must be 16 points or higher AND your total score for the course must be 65 points or higher.

## Faculty

### Course Director

Richard Glickman-Simon, MD  
 Department of Public Health & Community Medicine  
 Tufts University School of Medicine  
 617-636-3640  
[richard.glickman-simon@tufts.edu](mailto:richard.glickman-simon@tufts.edu)

### Associate Course Directors

Frank Chessa, PhD  
 Director, Clinical Ethics  
 Maine Medical Center  
[CHESSF@mmc.org](mailto:CHESSF@mmc.org)

## Course Schedule

Session	Venue	Date / Time	Topic	Faculty*
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5	Small group	Nov 26 / 2:30-4 pm	Medical Indications - Case Discussion 1	Facilitators
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7	Large group	Jan 3 / 1-2:20 pm	Patient Preference I	Chessa
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17	Large group	May 10 / 11-12:00 pm*	Public Health	G-S
18	Small group	May 10 / 1-3:00 pm*	Public Health – Case Discussion	Facilitators
	<b>Exam</b>	<b>May 24 / 9-12:00 pm</b>		

\*Faculty and date/time for Session 18 subject to change.

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Quiz	Sessions	Questions Posted*
<b>1</b>	4 – 5	Nov 26 – Dec 3
<b>2</b>	6	Dec 13 - 20
<b>3</b>	7 – 10	Feb 1 - 8
<b>4</b>	11 – 12	Feb 21 - 28
<b>5</b>	13 – 16	Apr 9 - 15
<b>6*</b>	17 - 18	May 15 - 17

\*Quiz questions close at 11:59 pm on indicated dates, except for Quiz 6, which opens and closes at 6 pm on its respective dates.

If you do not take the quiz within the allotted time frame, you will not receive a score. Each student must submit his or her own answers. Unlike the written ethical analyses, however, collaboration is permitted and encouraged.

The quiz questions will also serve to prepare you for an in-class final exam covering material from the entire course. The exam, consisting of 24 multiple-choice questions (similar to the quizzes) will be incorporated into the Scientific Foundations of Social & Behavioral Medicine exam at the end of the year.

### **Student Evaluation**

A final grade for the course will be calculated based on the total number of points earned according to this distribution:

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## Faculty

### Course Director

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15	Large group	Apr 8 / 1-1:50 pm	Allocation of Limited Resources	Chessa
16	Small group	Apr 8 / 2-3:30 pm	Allocation – Case Discussion	Facilitators
17	Large group	May 15 / 8:55-9:45 am	Public Health	G-S
18	Small group	May 15 / 1-2:30 pm	Public Health – Case Discussion	Facilitators
	<b>Exam</b>	<b>May 24 / 9-12:00 pm</b>		

\*Faculty and date/time for Session 18 subject to change.

# Ethics & Professionalism I

## M'16 AY 2012-13

### Assignment Due Dates

#### Analyses

Analysis	Cases Posted by	Submission Due by
1	Oct 30	Nov 6
2	Mar 1	Mar 8

#### Quizzes

Quiz	Questions Posted
1	Nov 26 – Dec 3
2	Dec 13 – 20
3-4	Feb 1 – 8
5	Feb 21 – 28
6-7	Apr 8 – 15
8	May 15 – 22

<b>Format</b>	Large group lecture
<b>Faculty</b>	Glickman-Simon
<b>Learning Objectives</b>	<p>By the end of this lecture, you will be able to:</p> <ul style="list-style-type: none"><li>• Reflect on your own assumptions about the goals of medicine and your future obligations to patients, society, your profession and yourself</li><li>• Identify attributes that distinguish a professional from a non-professional and apply this distinction to practitioners of medicine</li><li>• Discuss the connection binding professional and ethical behavior and how membership in a professional group influences standards of ethical conduct within that group</li><li>• Distinguish between professionalism and humanisms in medicine and its relevance to the care of patients</li></ul>
<b>Readings</b>	None

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# Medical Ethics & Professionalism

## Course Director

Richard Glickman-Simon, MD  
Public Health and Community Medicine  
Tufts University School of Medicine

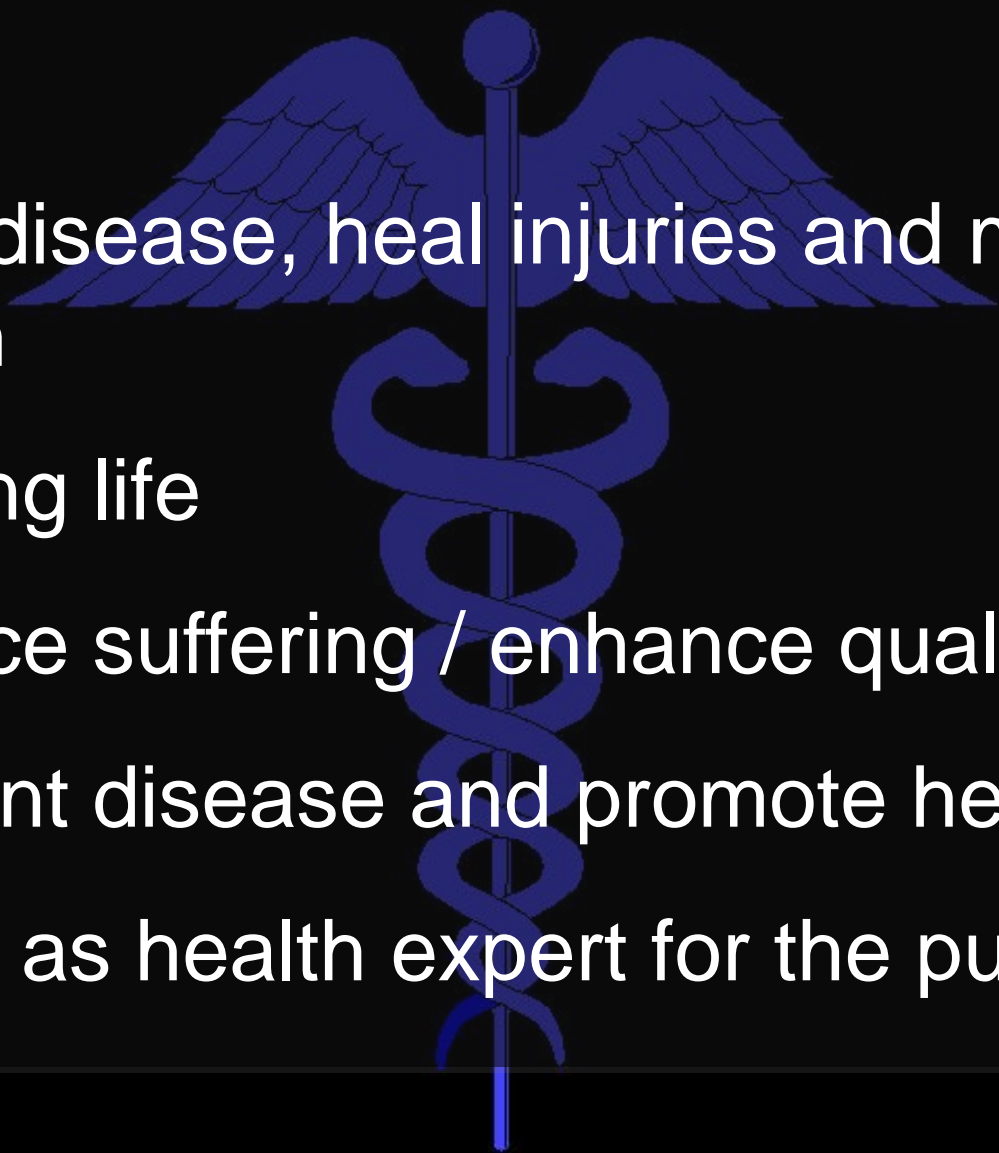
## Associate Course Director

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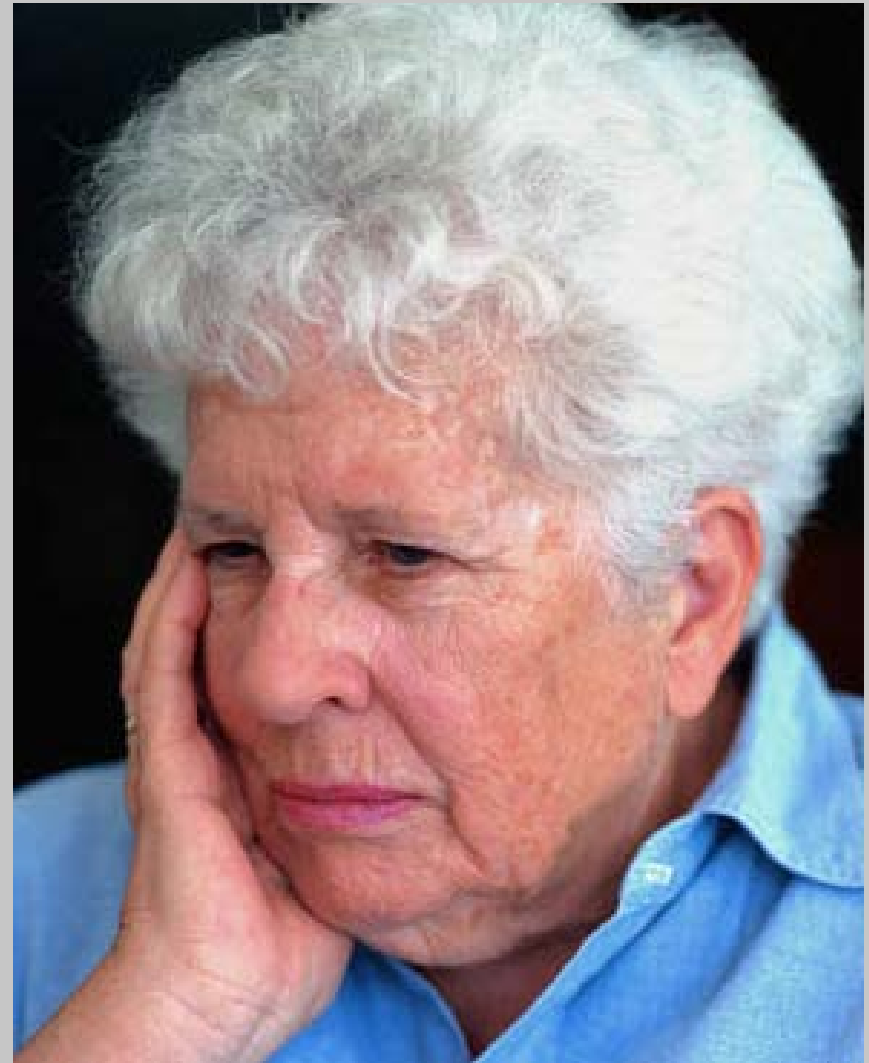
**What kind of business have you  
gotten yourself into?**



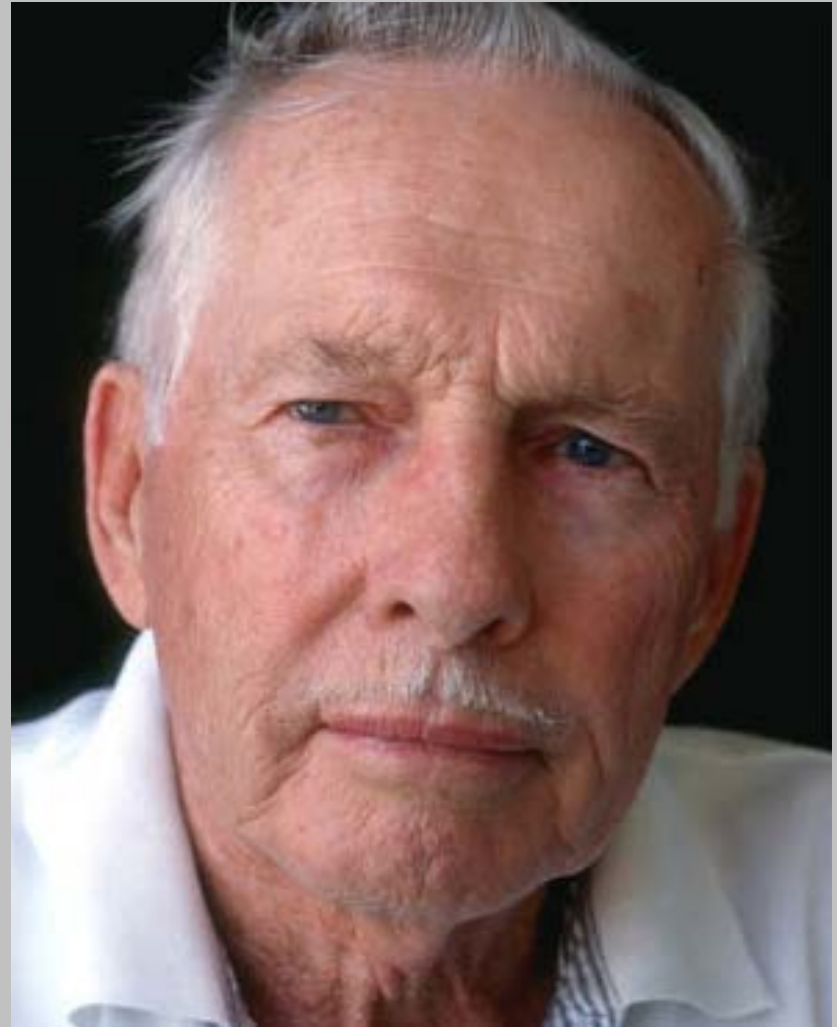
# Goals of Medicine

- 
- Cure disease, heal injuries and maintain health
  - Prolong life
  - Reduce suffering / enhance quality of life
  - Prevent disease and promote health
  - Serve as health expert for the public

You are taking care of a 75 year-old, long-term smoker with type II diabetes, congestive heart failure and chronic obstructive pulmonary disease. Today she reports bilateral lower leg pain with ambulation. You suspect worsening peripheral vascular disease and refer her for further diagnostic evaluation.



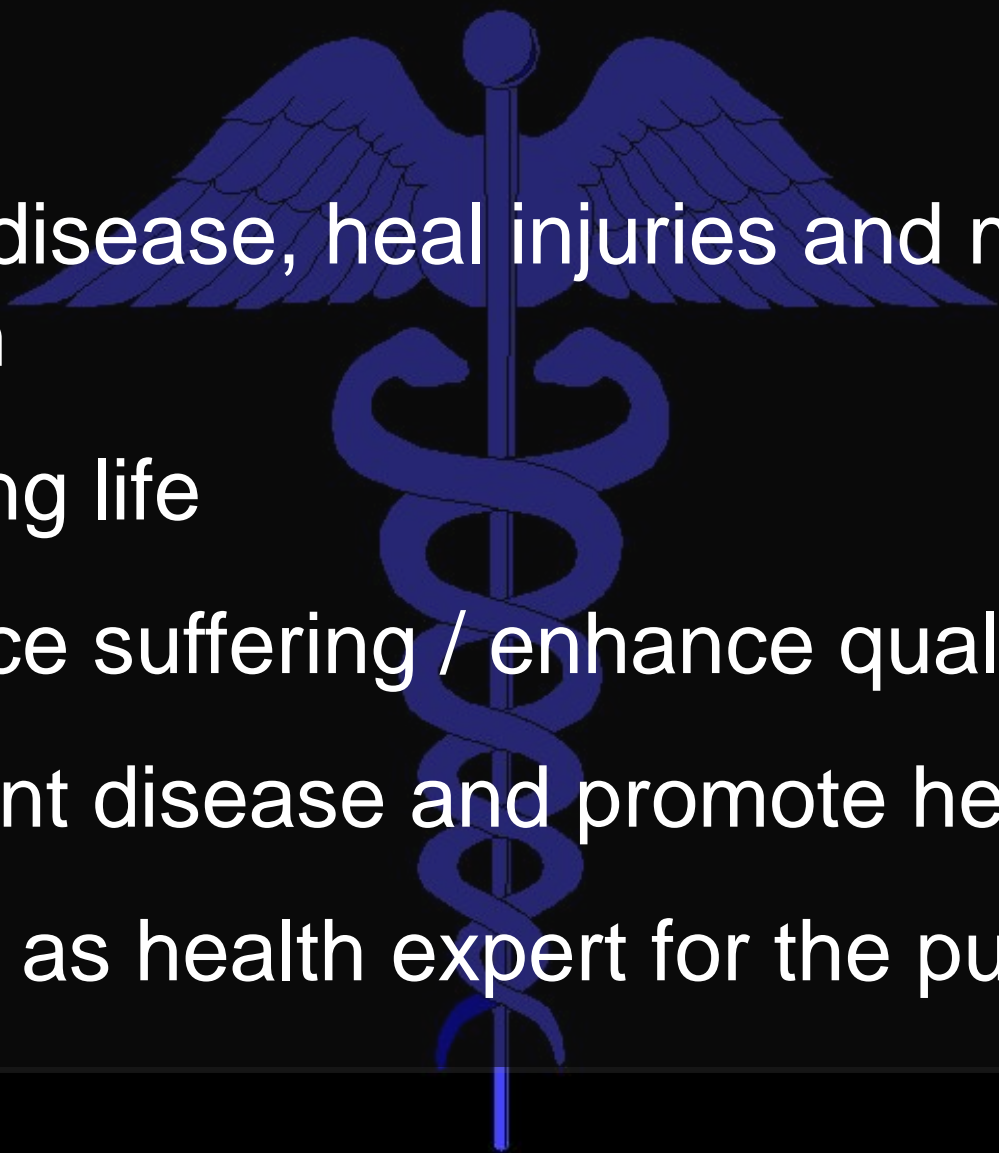
You are also taking care of another 75 year-old, smoker with type II diabetes, congestive heart failure and chronic obstructive pulmonary disease. He has been in the hospital for the past 6 weeks; most of that time in the ICU. Several recent attempts to wean him from his ventilator have failed. He remains awake but non-communicative, and periodically receives IV morphine to partially alleviate his pain and agitation.



His wife, two children and five grandchildren are frequently at his bedside. Your patient has designated his older daughter as his health care proxy, which legally authorizes her to make all medical decisions on his behalf. She repeatedly expresses her wish for you to “keep doing everything you can for my dad”. Total expenses for this hospitalization have reached roughly \$50K, which will mostly be paid by Medicare. What would do?

- A. Honor the wishes of his daughter and continue treatment**
- B. Speak privately with other family members to see if there is disagreement about continuing treatment**
- C. Remove the ventilator and allow your patient to die**
- D. Remove the ventilator and risk accelerating his death by increasing his dose of morphine to keep him comfortable**

# Goals of Medicine

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- Cure disease, heal injuries and maintain health
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# Profession Defined

A ***profession*** can be defined as a group of specialized workers whose expert knowledge and/or skills earn it the right to function as an independent semiautonomous group<sup>1</sup>.

## Rules of Membership

- Ability to achieve and maintain a certain standard of competence as defined by the group
- Willingness to embrace the collective ideology, traditions and customs of the group
- Acceptance of an identity distinct and separate from the lay community served by the group

<sup>1</sup> Freidson E. Profession of Medicine: A Study of the Sociology of Applied Knowledge. New York, NY: Dodd, Mead; 1970.

What adjectives come to mind when  
you think of a health care professional?

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Super smart

Knowledgeable

Scientific

Skillful

Scholarly

Incomprehensible

Dedicated

Driven

Overworked

Competent

What adjectives come to mind when  
you think of a health care professional?

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Competent

Sanitary

Well-Dressed

White-Coated

Detached

Exclusive

Wealthy

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Self-Important

Authoritative



What adjectives come to mind when  
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## What society wants from us

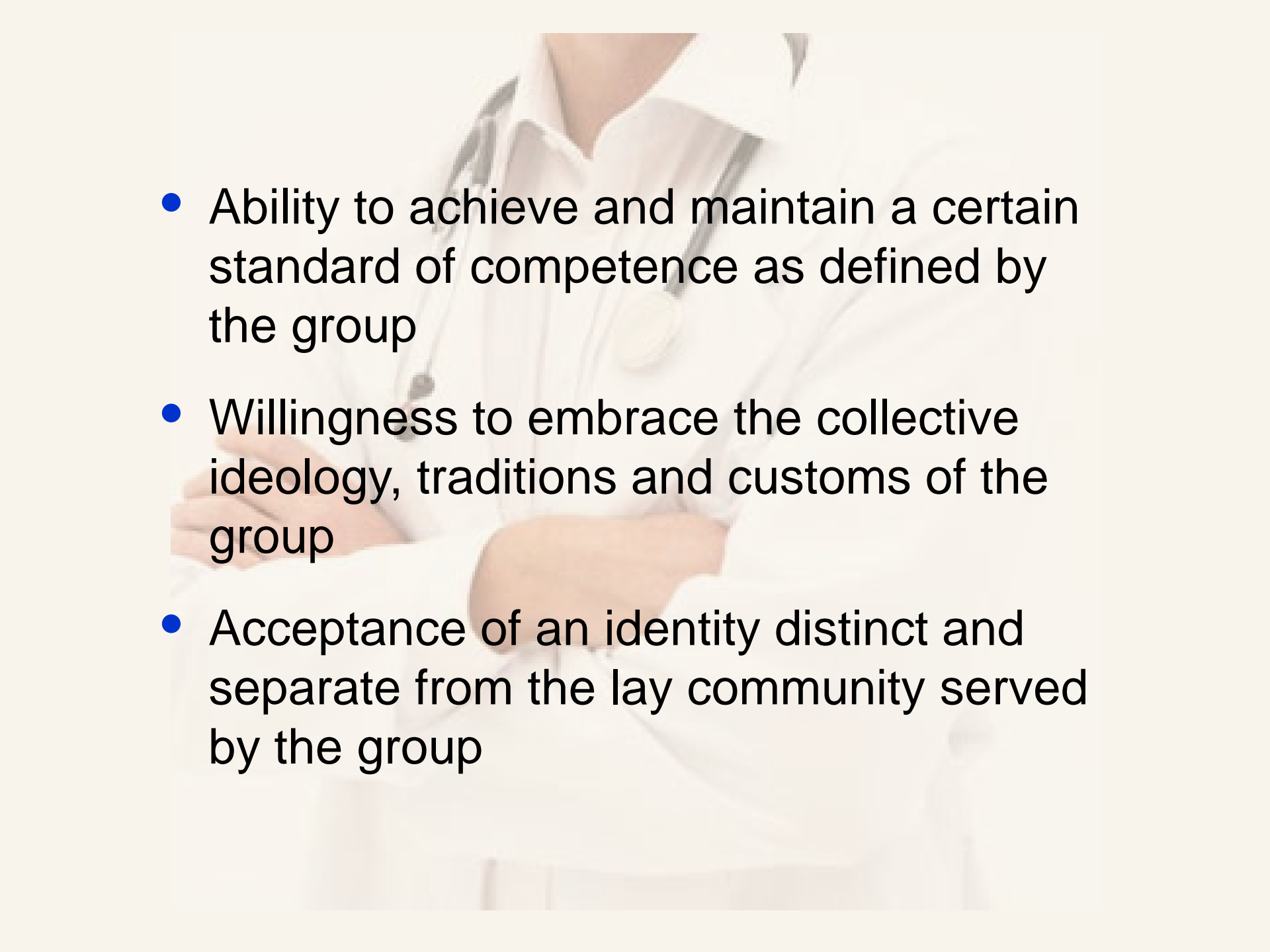
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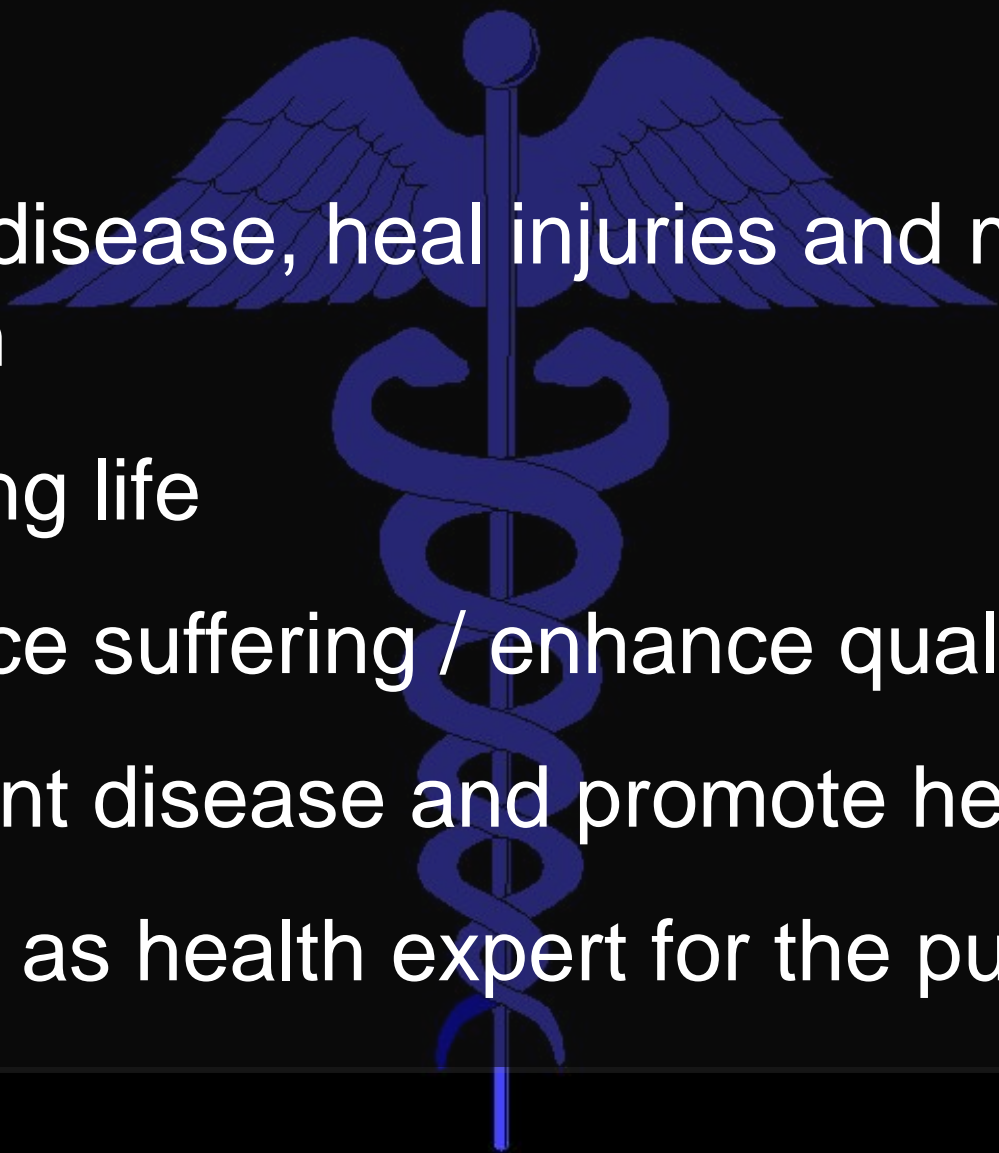
## Course Director

Richard Glickman-Simon, MD  
Public Health and Community Medicine  
Tufts University School of Medicine

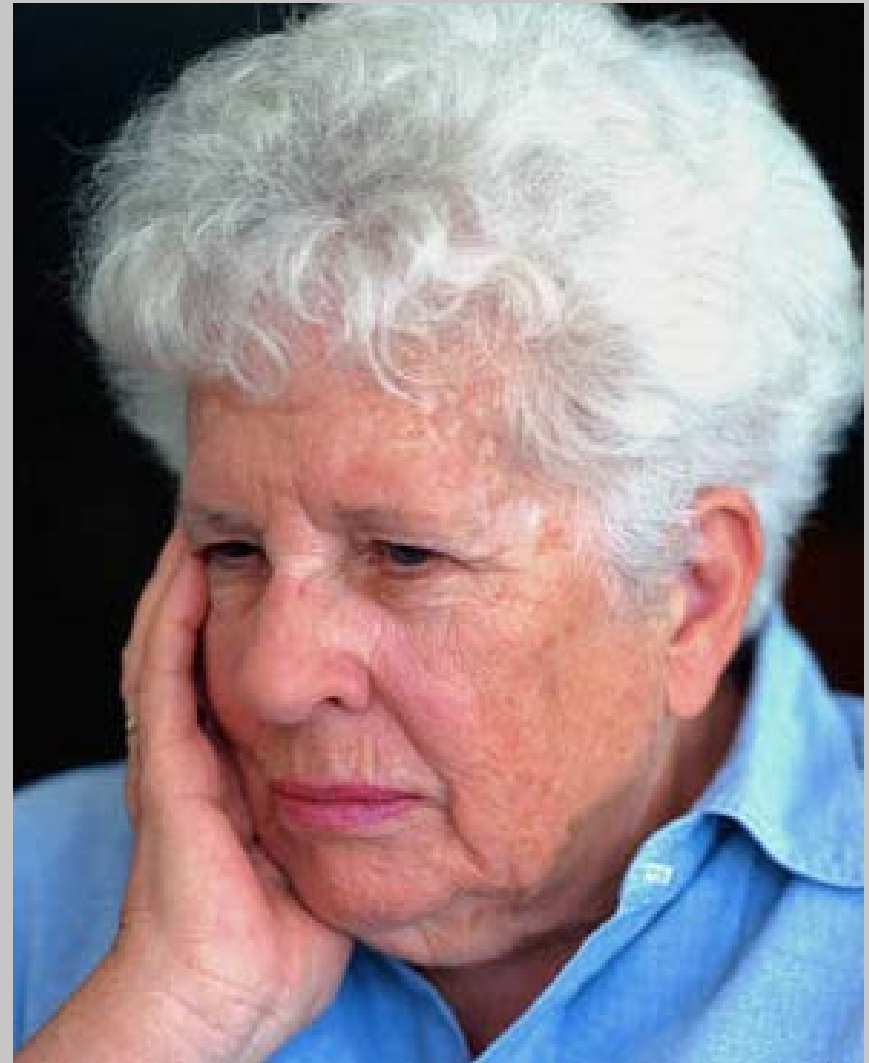
## Associate Course Director

Frank Chessa, PhD  
Director, Clinical Ethics  
Maine Medical Center

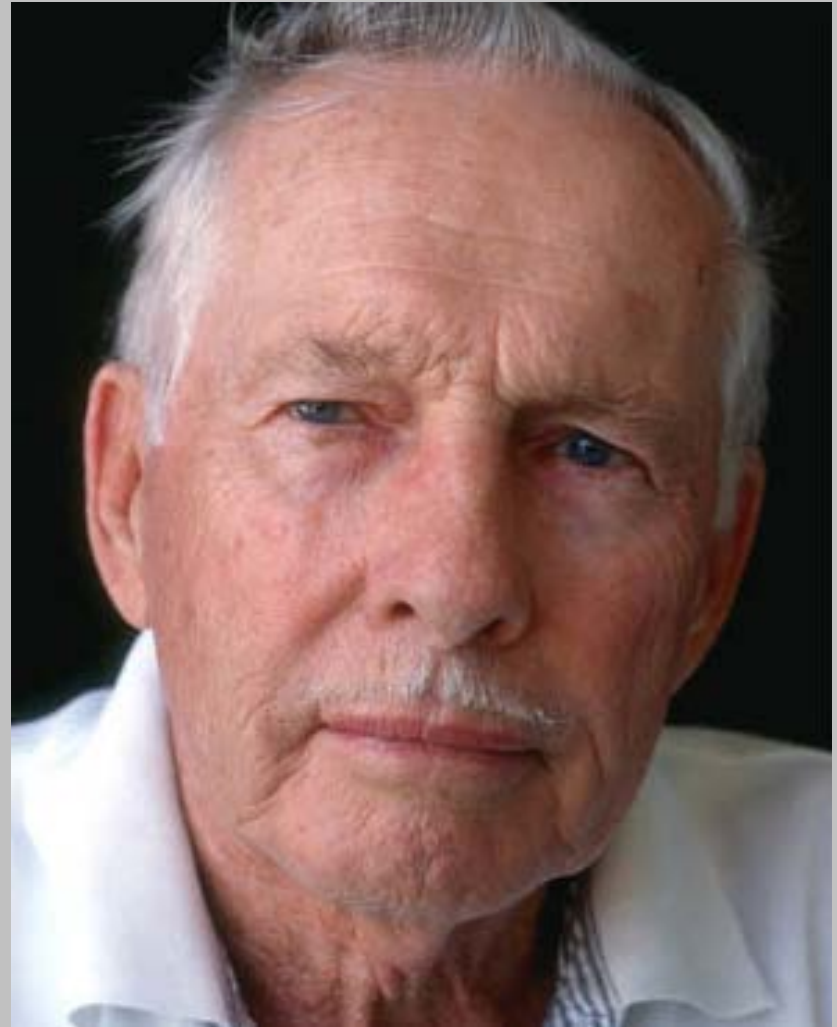
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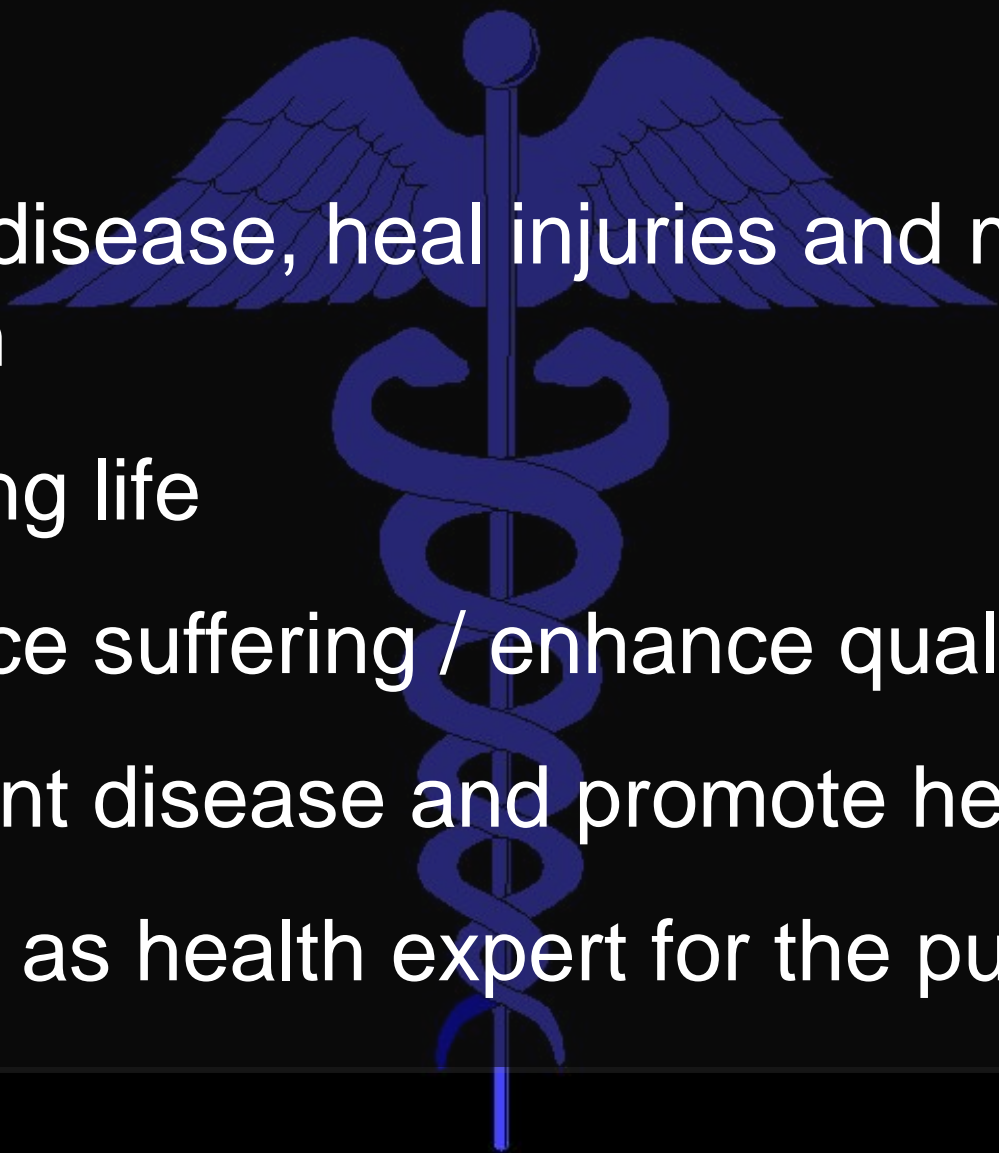
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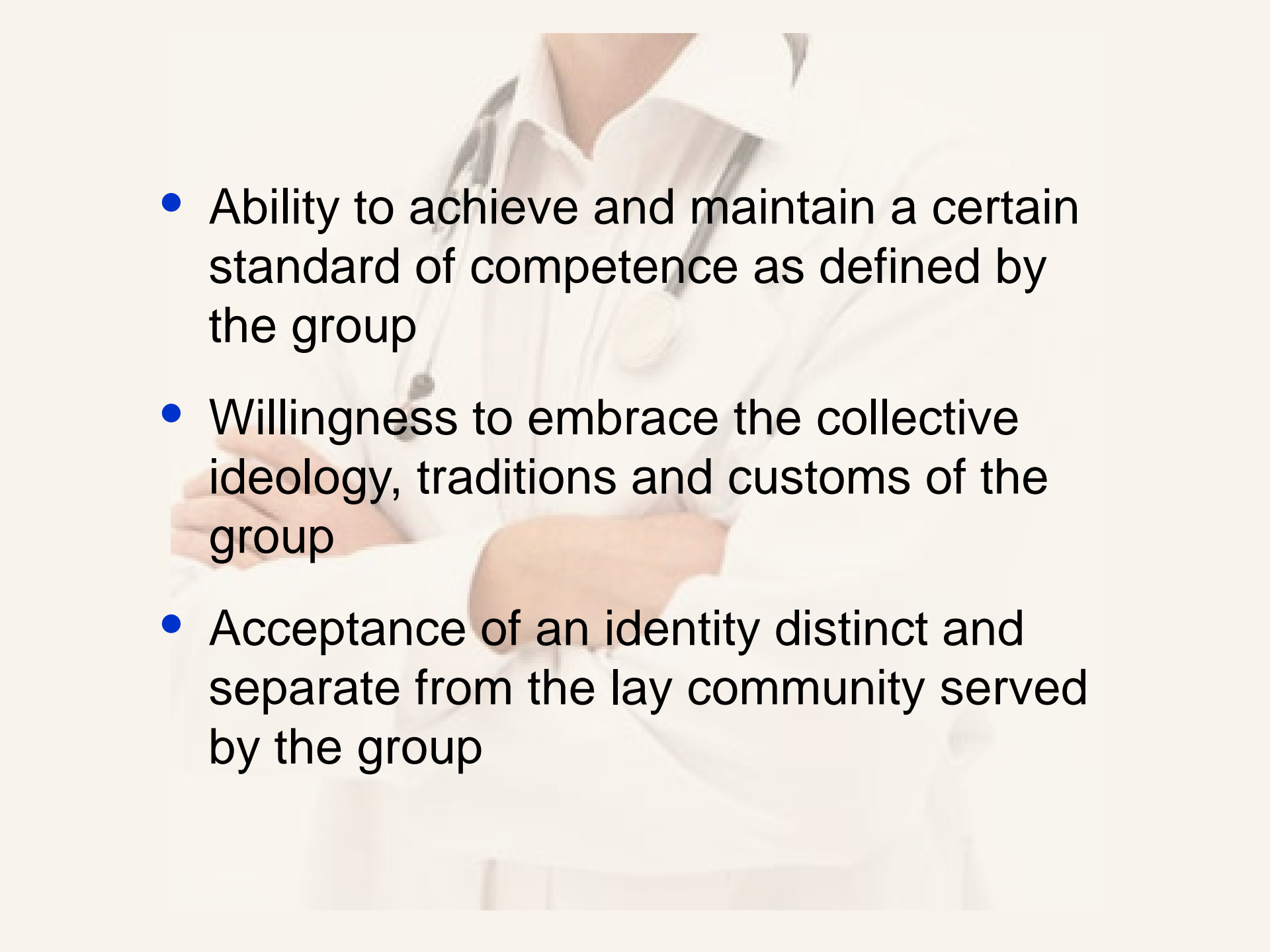
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# Medical Ethics & Professionalism

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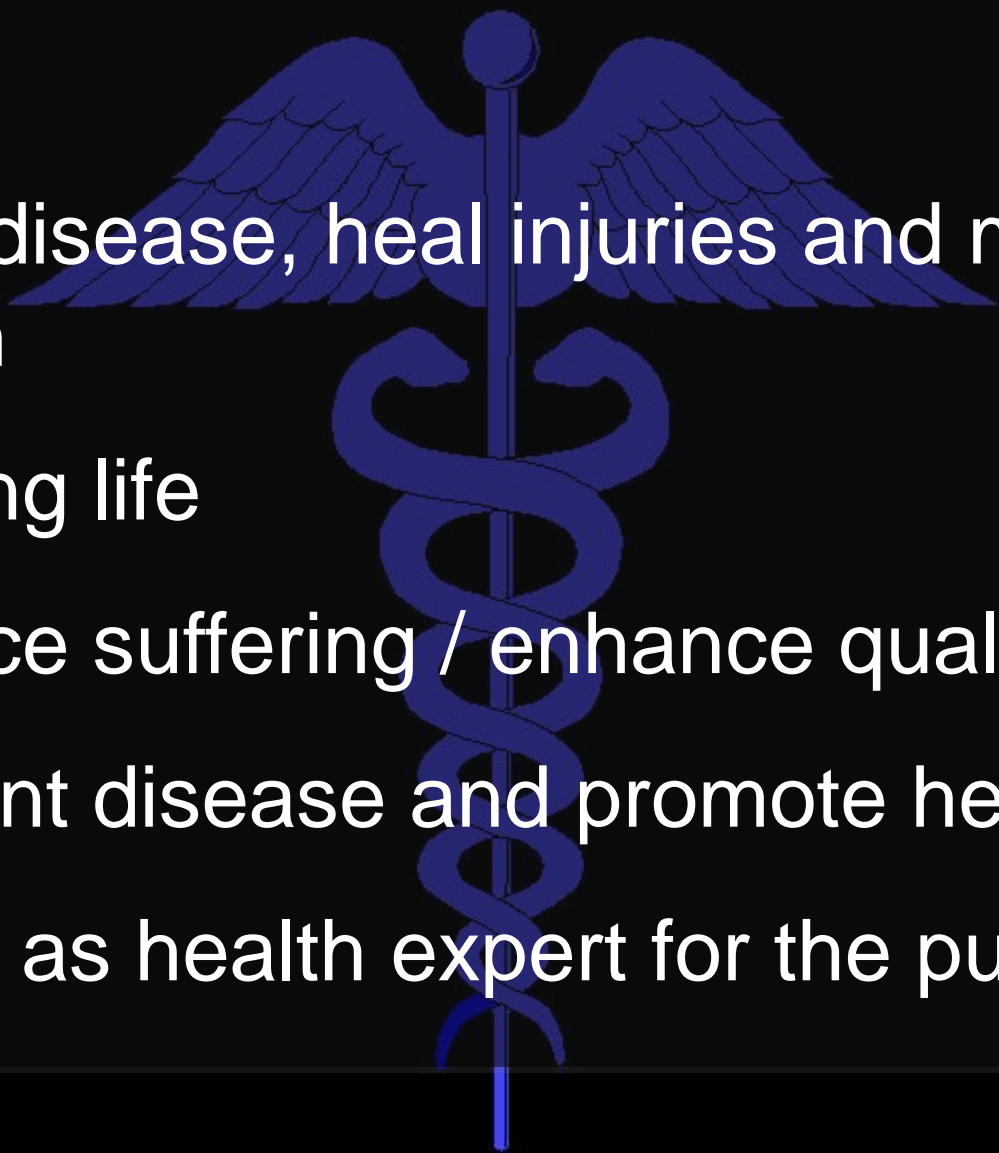
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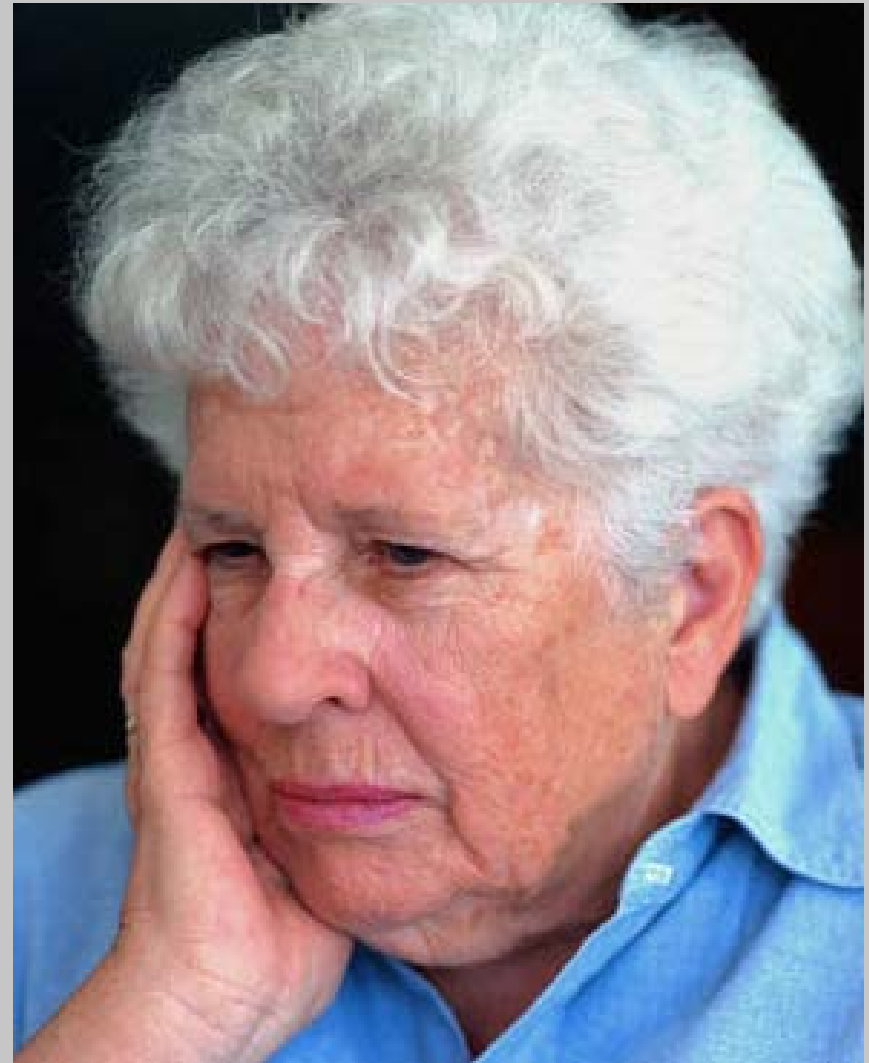
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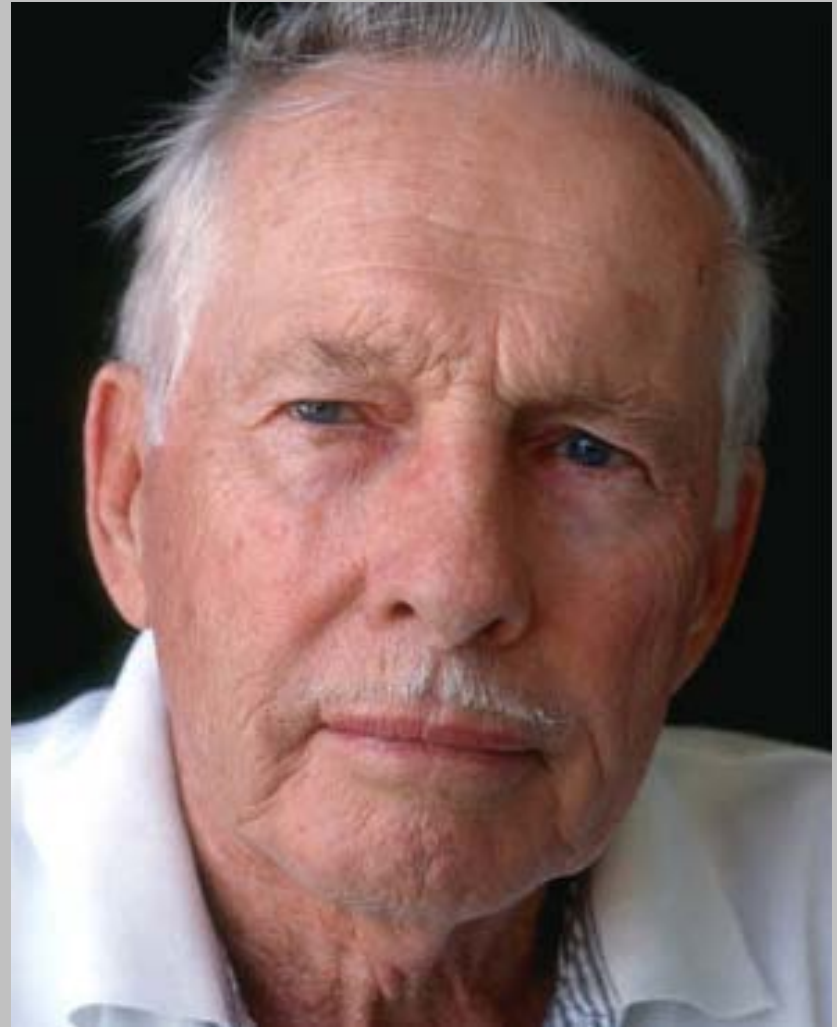
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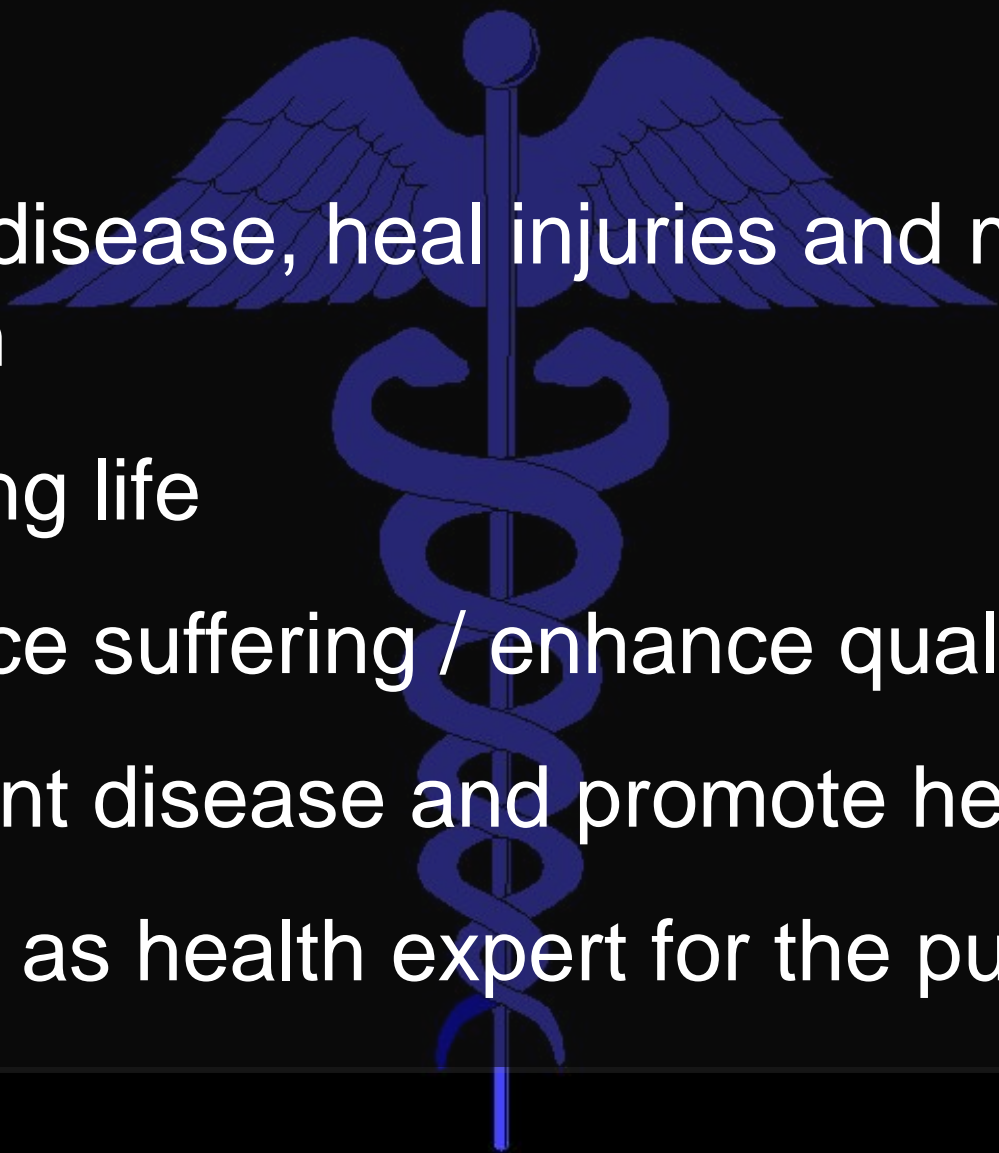


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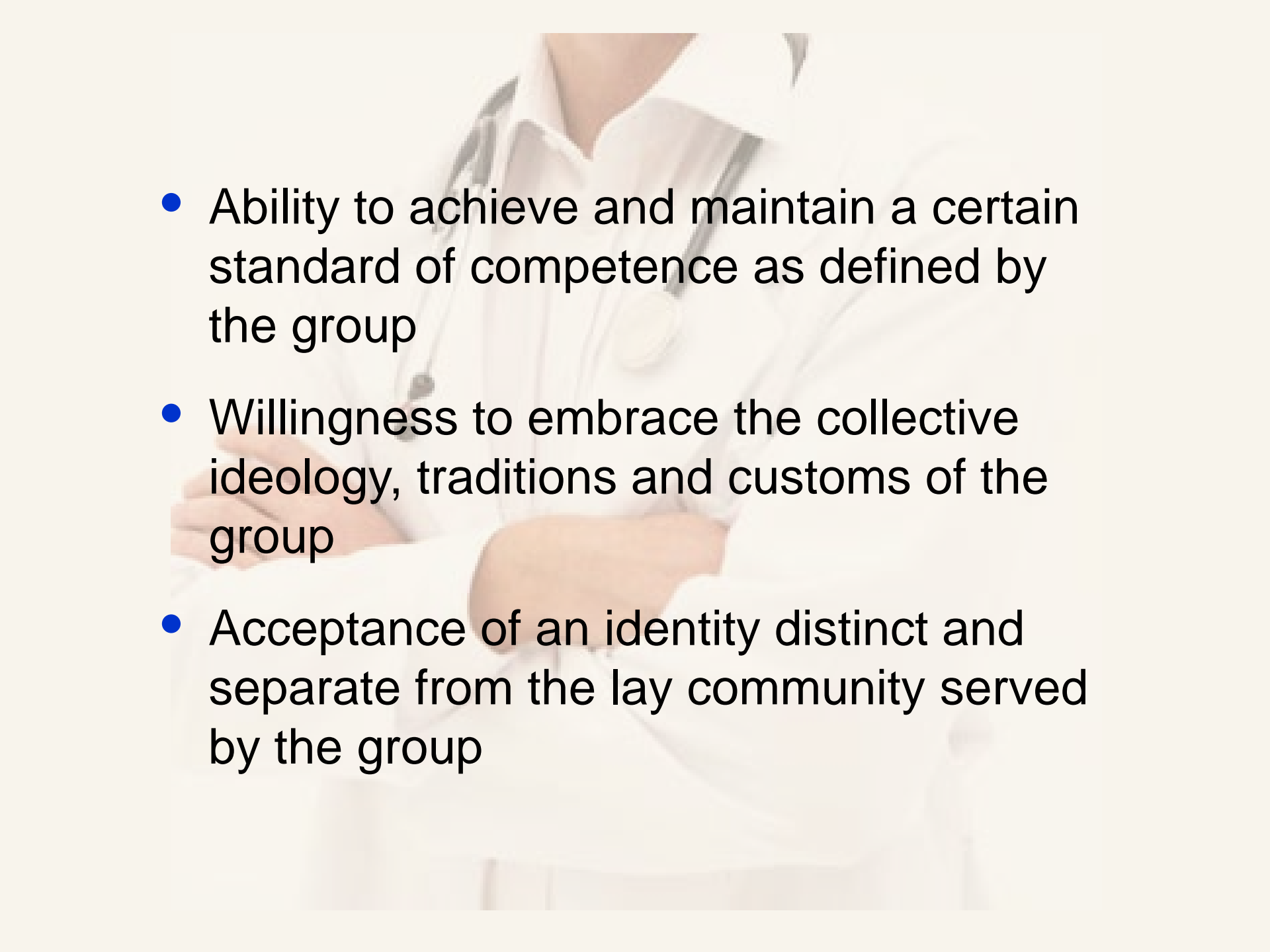
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<b>Format</b>	Large group lecture
<b>Faculty</b>	Chessa
<b>Learning Objectives</b>	<p>By the end of this lecture, you will be able to:</p> <ul style="list-style-type: none"><li>• Identify and explain the four principles of medical ethics</li><li>• Formulate a focused ethical question that characterizes the conflict of values in a clinical case in preparation for a case analysis</li><li>• Ethically analyze the Donald “Dax” Cowart case</li><li>• Describe Jonsen’s four-topics method of ethical case analysis</li></ul>
<b>Readings</b>	<ul style="list-style-type: none"><li>• Jonsen text: p 1-8</li><li>• Formulating an Ethics Question</li><li>• (Optional) Ethical Analysis – Kidney Transplant for ESRD in Prisoner</li></ul>

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# Case Analysis in Clinical Ethics

**September 14, 2012**

**Frank Chessa, Ph.D.**

Director, Clinical Ethics

Maine Medical Center

Assistant Professor Of Medicine,

TUSM



# Objectives

- Formulate a focused ethical question that characterizes the conflict of values in a clinical case (in preparation for doing a case analysis).
- Describe Jonsen's four-topics method of ethical case analysis
- Identify and explain the four principles of medical ethics
- Ethically analyze the Donald "Dax" Cowart case

# Donald Coward Case

- 25 year old burned in explosion. His father lost his life in the same explosion.
- Pilot in air force reserve; Vietnam vet; intelligent, out going, popular.
- Burns over 65% of his body; eye removed; fingers amputated
- Hospitalized for about 16 months.
- Consistent refusal of life sustaining treatment. Knowledge of burn injuries from Vietnam; Argued primarily that treatment was too painful.
- Evaluated for decision making capacity – found to have it.
- Mother and family lawyer acted as his surrogate decision makers.
- Treated against his will.

# Dax Video

# Formulating an Ethics Question

- The question should be clear, focused, specific, forward-looking, action-oriented
- Formula:

Given the conflict between value/consideration 1 and value/consideration 2, what decisions or actions are ethically justifiable?

Given the conflict between value/consideration 1 and value/consideration 2, is it ethically justifiable to decision or action ?

# Ethics Question

## ■ Conflict of Values?

- Dax's specific request to withdraw LST
- Clinician and family judgment that withdrawing LST is not in his best interest
- [Clinician and family judgment that it is not an authentic choice on his part]

## ■ Action at issue

- Withdrawing LST (probably tank treatments for burns, allowing infection to occur).

# Dax Case Ethics question

Given that the patient has consistently requested that LST be withdrawn, but that his care team expects him to survive with an acceptable quality of life, is it ethically permissible to continue to provide tank treatments and grafting?

# Quick Ethics Taxonomy Note

Actions in ethics are of three types:

Obligatory – Ethically required

Permissible – Ok, but not required

Prohibited – Ethically wrong to perform

# Two Complementary Methods for Case Analysis

- Beauchamp and Childress: *Principles of Medical Ethics*
- Jonsen, Siegler, Winslade: “Four Topics” method in *Clinical Ethics*.
- Follow the “Four Topics” format, use the principles to develop the content of the analysis.
- Ultimate Goal: Provide a method (or framework) for analyzing the ethical issues you encounter in clinical practice
- Proximate Goals: Effectively analyze the cases in your small group discussions; Write your case analysis papers for this course.



# Case Analysis Write-Up.

- **Question:** Formulation of a specific ethical question that characterizes the conflict of values in the case
- **Facts:** Identification of the facts in the case that are relevant to answering this ethical question
- **Reasoning:** A persuasive argument that employs ethical principles to justify your answer to the ethical question
- **Actions:** Practical steps you would take to gather more information and/or help resolve the conflict among stakeholders

# Caution: Additional Knowledge Required

- Neither the principles or the four topics methods are sufficient to analyze an ethical case (even when used together). Both methods require additional knowledge of particular topics in medical ethics.
- Analogy: The format for oral case presentations compared to the analysis of a particular case.
  - You need to know the format for a case presentation: cc, hpi, pmh, ros, social history, labs, etc.
  - When you present a particular case you need to know facts about patient (what is their chief complaint? SOB), and also background information about the medical conditions in question (e.g., etiology, pathophysiology, treatment, diagnostic criteria for CHF).
- The Four Topics method gives you the format (and some content), but you still need patient specific information and **background information** about the specific ethical issue.

# What do you mean by background information about ethical issues?

- *Clinical Ethics* Text is a good reference
- Laws and regulations
- Well-known prior cases
- Statements and guides from professional societies
- Research and scholarly literature

# **HRS Expert Consensus Statement on the Management of Cardiovascular Implantable Electronic Devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy**

*This document was developed in collaboration and endorsed by the American College of Cardiology (ACC), the American Geriatrics Society (AGS), the American Academy of Hospice and Palliative Medicine (AAHPM); the American Heart Association (AHA), the European Heart Rhythm Association (EHRA), and the Hospice and Palliative Nurses Association (HPNA).*

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# PEDIATRICS<sup>®</sup>

**Responding to Parental Refusals of Immunization of Children**  
Douglas S. Diekema and the Committee on Bioethics  
*Pediatrics* 2005;115:1428-1431  
DOI: 10.1542/peds.2005-0316

**This information is current as of May 13, 2005**

The online version of this article, along with updated information and services, is  
located on the World Wide Web at:  
<http://www.pediatrics.org/cgi/content/full/115/5/1428>



POLICY STATEMENT

# Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns

Committee on Fetus and Newborn

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

## ABSTRACT

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Advances in medical technology have led to dilemmas in initiation and withdrawal of intensive care of newborn infants with a very poor prognosis. Physicians and parents together must make difficult decisions guided by their understanding of the child's best interest. The foundation for these decisions consists of several key elements: (1) direct and open communication between the health care team and the parents of the child with regard to the medical status, prognosis, and treatment options; (2) inclusion of the parents as active participants in the decision process; (3) continuation of comfort care even when intensive care is not being provided; and (4) treatment decisions that are guided primarily by the best interest of the child.

# Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others

David Wendler, PhD, and Annette Rid, MD

1 March 2011 | *Annals of Internal Medicine* | Volume 154 • Number 5

*Table 3. Most Commonly Reported Stressors and Possible Ways to Mitigate Them*

Stressors	Possible Responses
Unsure of patient's preferences	Encourage previous discussion and advance directives
Uncertain prognosis	Difficult to address
Discomfort with hospital environment	Help to familiarize and adjust to environment
Logistics of making decisions	Evaluate and address challenges to decision making
Poor communication by clinicians	Establish a contact person, hold consistent meetings, and use clear language
Insufficient time	Prepare surrogates and give time to decide
Conflict with clinicians and family	Identify and address sources of conflict
Sense of sole responsibility	Share responsibility for decisions
Uncertainty or guilt over decisions	Support decisions and offer counseling





# Evidence-based guideline update: Determining brain death in adults

Report of the Quality Standards Subcommittee of the American Academy of Neurology



Eelco F.M. Wijdicks,  
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## ABSTRACT

**Objective:** To provide an update of the 1995 American Academy of Neurology guideline with regard to the following questions: Are there patients who fulfill the clinical criteria of brain death who recover neurologic function? What is an adequate observation period to ensure that cessation of neurologic function is permanent? Are complex motor movements that falsely suggest retained brain function sometimes observed in brain death? What is the comparative safety of techniques for determining apnea? Are there new ancillary tests that accurately identify patients with brain death?

**Methods:** A systematic literature search was conducted and included a review of MEDLINE and EMBASE from January 1996 to May 2009. Studies were limited to adults (aged 18 years and older).

**Results and recommendations:** In adults, there are no published reports of recovery of neurologic function after a diagnosis of brain death using the criteria reviewed in the 1995 American Academy of Neurology practice parameter. Complex-spontaneous motor movements and false-positive triggering of the ventilator may occur in patients who are brain dead. There is insufficient evidence to determine the minimally acceptable observation period to ensure that neurologic functions have ceased irreversibly. Apneic oxygenation diffusion to determine apnea is safe, but there is insufficient evidence to determine the comparative safety of techniques used for apnea testing. There is insufficient evidence to determine if newer ancillary tests accurately confirm the cessation of function of the entire brain. *Neurology*<sup>®</sup> 2010;74:1911-1918



## Should patients receive general anesthesia prior to extubation at the end of life?\*

Robert D. Truog, MD, MA; Dan W. Brock, PhD; Douglas B. White, MD, MAS

Billings has proposed that any potentially conscious and imminently dying patient who is undergoing withdrawal of ventilator support should be offered general anesthesia to fully protect against suffering. Here we examine whether his proposal is compatible with the doctrine of double effect, a philosophical construct that is generally in accord with the legal requirements for palliative care in the United States. We review the essential elements of the doctrine of double effect, and emphasize the importance of pre-medicating patients before ventilator withdrawal (anticipatory dosing) and of titrating medications to the needs of the patient. The doctrine of double effect requires physicians to balance the risk of the patient suffering against the

risk of hastening the patient's death when titrating the medications used to provide comfort. We argue that the values and preferences of the patient should determine how these risks are balanced. We therefore agree with Billings that general anesthesia may be indicated for patients who prefer to minimize the risk of suffering while accepting a greater risk of having their death hastened. This approach would not be appropriate, however, for patients who place a higher value upon avoiding the risk of hastening death, even when this involves a greater risk of potential suffering. (Crit Care Med 2012; 40:631–633)

**KEY WORDS:** double effect; end-of-life care; euthanasia; intensive care; mechanical ventilation; palliative care

# A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem

Bernard J. Hammes, PhD,\* Brenda L. Rooney, PhD, MPH,<sup>†</sup> and Jacob D. Gundrum, MS\*

**Table 2. Prevalence, Availability, and Creation Date of Advance Directives (ADs), La Crosse Advance Directive Study (LADS) I (N = 540) Versus LADS II (N = 400)**

Advance Directive Status	LADS I	LADS II	P-Value
Decedents with ADs, n (%)	459 (85.0)	360 (90.0)	.02
Of these, ADs in medical record, n (%)	437 (95.2)	358 (99.4)	<.001
Type of AD, n (%)			
Power of attorney for health care	353 (77)	324 (90.0)	<.001
Living will	46 (10)	30 (8.0)	.41
Dictated note	60 (13)	120 (33.0)	<.001
POLST, n (%)	NA	268 (67.0)	NA
Of these, POLSTs in medical record, n (%)	NA	264 (98.5)	NA
Years from AD creation to death, oldest date used, median (range)	1.3 (0–13.6)*	3.8 (0–21)*	<.001
Months from POLST creation to death, median (range)	NA	4.3 (0–114)	NA



# When Things *go* Wrong

RESPONDING  
TO ADVERSE EVENTS

*A Consensus*

*Statement of the*

*Harvard Hospitals*

MARCH 2006

# Four Topics Method

- Medical Indications
- Patient Preferences
- Quality of Life
- Contextual Features

See page 11 of your text.

# Medical Indications

- How might the patient be benefited by medical care?
  - Requires knowledge of diagnosis, treatment options, risks, benefits, chance of success, other medical knowledge
- Topics in the chapter on Medical Indications
  - Terminal illness, imminently dying patients, progressive diseases
  - Futile care
  - Foregoing (withholding or withdrawing) medical treatment
  - Do not resuscitate orders
  - Determination of Death

# Patient Preferences

- Are we allowing patients to control their own medical care?
  - When does a patient have decision making capacity (DMC)?
  - If they have DMC, what practices allow the patient to exercise choice?
  - How should medical decisions be made for patients who lack DMC.
- Topics in the chapter
  - Informed consent
  - Standards of disclosure
  - Evaluation DMC
  - Truth Telling (Errors, Placebos)
  - Advance Care Planning and Surrogate Decision Making
  - Cultural and Religious reasons for refusing recommended care

# Quality of Life

- How is a patient likely to experience their life after a medical intervention?
  - Often even successful interventions will leave patients with a reduced functional status? How is the patient likely to experience life with this reduced status?
  - Concern about bias in judgments about QOL.
- Topics in this chapter.
  - Foregoing LST because of reduced QOL.
  - Physician Assisted Suicide
  - Suicide
  - Care of the dying

# Contextual Features

- Are there factors independent of the best interest and preferences of the patient that might influence treatment decisions?
  - Clinician Conflict of Interest; Family Conflict of Interest; Money and resources; well-being of third parties; public health; attitudes and bias.
- Topics in this chapter
  - Confidentiality laws
  - Research Ethics
  - Legal and Regulator Issues
  - Allocation and economics.



# Principles of healthcare ethics

- ***Beneficence***: Doing good for a patient; Taking actions to improve a patient's health, prevent disease or otherwise enhance a patient's welfare.
- ***Respect for Autonomy***: Respecting a patient's decision-making authority; A person has a *prima facie* right to make decisions about his or her own life and body.
- ***Non-maleficence***: Refraining from harming the patient; "Primum non nocere".
- ***Justice***: Protecting one's patient from discrimination and exploitation. Balancing the interests of other parties affected by a decision.

*Principles of Biomedical Ethics*. Beauchamp, Childress, 5th Ed.





# Respect for Autonomy

- Autonomy: *autos nomos* - self-rule
- Freedom to live according to one's values
- At the heart of the American experience

## **Respect for autonomy**

- Negative prohibition to refrain from actions that remove autonomy
- Positive obligation to enhance autonomy

# Beneficence

- Doing good for others
- Acting to promote another's best interest
- Value at the heart of the helping professions

# Nonmaleficence

- One ought not to inflict evil or harm
- *Primum non nocere*
- Recognition of the power associated with the health care professions and institutions

# Justice

- Protect your patient from discrimination and exploitation
- Focus not only on a single patient, but on others as well.
  - Other Patients
  - Staff
  - Third-parties
  - One's Institution
  - Society
- Treat equals equally; treat everyone with respect.





# In case of conflict

- The principles are not lexically ordered. (No principle automatically trumps another.)
- In a case of conflict between principles, one must decide which principle is more important.
- This “balancing” is done on a case by case basis, in response to the particularities of the situation.
- **Specification:** There may already be an established (or *specified*) answer to how conflicts are resolved for specific types of cases (e.g., waiving informed consent requirements in an emergency.)

# Balancing Principles

- Balancing is not merely subjective
- Criteria for balancing
  - Reasons articulated for acting on the overriding norm
  - Moral objective for infringing a norm must have a good chance of success
  - There is no preferable alternative for infringing the norm
  - The norm is infringed to the least extent possible
  - Must seek to minimize negative effects of infringement
  - Decision reached for impartial reasons



# Case

An older woman is transferred to the critical care department from another hospital. She is ventilator dependent. She has a lower G.I. fistula and multiple co-morbidities. The patient has not been stable enough for surgery to correct the fistula. The woman has an advance directive and has officially designated her daughter as a surrogate decision-maker. The daughter is clear that her mother does not want to “live on machines.” Nursing staff and the attending physician disagree on whether treatment should be withdrawn. Nursing staff feel that the physician conveyed to the family an overly optimistic picture of the patient’s prognosis.

# Conflict between which Ethical Principles?

- Beneficence
- Respect for Autonomy
- Non-Maleficence
- Justice

# Case: Which Principles?

An older woman with end stage renal disease who requires dialysis four times a week and is non-ambulatory is refusing placement in a nursing home and wishes to return to her apartment. Because of co-morbidities and lack of 24-hour home health care, her doctor feels that if she is sent home she would have a serious adverse event and perhaps die. The woman is awake, oriented and clear about her preferences. The woman has a history of leaving nursing homes AMA. The woman is clear that she does not want to die and wishes to continue treatment.

# Conflict between which Ethical Principles?

- Beneficence
- Respect for Autonomy
- Non-Maleficence
- Justice

# Dax Video



# Conflict between which Ethical Principles?

- Beneficence
- Respect for Autonomy
- Non-Maleficence
- Justice

# Conflict between which Ethical Principles?

- Beneficence
- Respect for Autonomy
- Non-Maleficence
- Justice



What questions do you want to investigate under each of the four topics?

- Medical Indications
- Patient Preferences
- Quality of Life
- Contextual Features

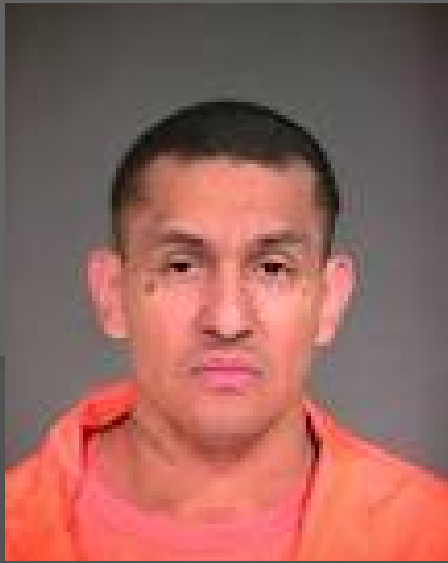
# Dax Case Ethics question

Given that the patient has consistently requested that LST be withdrawn, but that his care team expects him to survive with an acceptable quality of life, is it ethically permissible to continue to provide tank treatments and grafting?

# Case Analysis Write-Up.

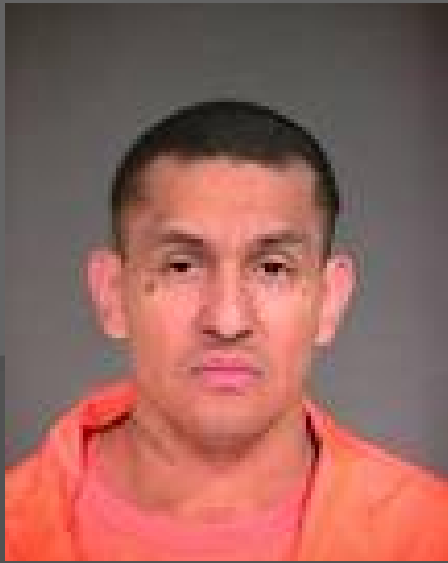
- **Question:** Formulation of a specific ethical question that characterizes the conflict of values in the case
- **Facts:** Identification of the facts in the case that are relevant to answering this ethical question
- **Reasoning:** A persuasive argument that employs ethical principles to justify your answer to the ethical question
- **Actions:** Practical steps you would take to gather more information and/or help resolve the conflict among stakeholders

# A second practice example



**James Smith is a 38 year-old male with end stage renal disease (ESRD) requiring dialysis 3 times a week.**

- His ESRD results from polycystic kidney disease.
- Initial kidney transplant 2004, rejection 2006, nephrectomy January 2007.
- The patient lost the kidney because he was not compliant with medical appointments, medications, diet and had probable controlled substance use.
- The patient is incarcerated at State Prison, convicted of felony murder for the death of a young woman. The crime was drug related.
- Sentence is 25 years, but will likely serve 13 years and 4 years probation.



- The patient's nephrologist has referred Mr. Smith to the Transplant Center for a second kidney transplant.
- The patient very much wants a second transplant.
- The patient appears to be adherent to diet and fluid restrictions required by dialysis.
- The patient does not have a living donor.
- Transplant Center physicians have little doubt that he would meet medical criteria for transplant.

Given serious disagreement among Transplant Center staff, they ask *you* for an ethics consultation.



# What is the ethics question you will consider in your consult?

Formula:

Given the conflict between value/consideration 1 and value/consideration 2, is it ethically justifiable to decision or action ?


# What is the ethics question you will consider in your consult?

Given that Mr. Smith would probably benefit from a kidney transplant, but also that Mr. Smith's past actions call into question the appropriateness of allocating a scarce, life-saving resource to him, is it ethically justifiable to evaluate him and potentially place him on the waiting list for a deceased donor kidney?


# Conflict between which Ethical Principles?

- Beneficence
- Respect for Autonomy
- Non-Maleficence
- Justice

# Conflict between which Ethical Principles?

- Beneficence
  - Respect for Autonomy
  - Non-Maleficence
  - Justice
- 
- A red rectangular box is drawn around the list items. The top and bottom horizontal lines of the box have arrows pointing to the left, specifically towards the words 'Beneficence' and 'Justice' respectively. The vertical lines on the right side of the box do not have arrows.

# Conflict between which Ethical Principles?

- Beneficence
  - Respect for Autonomy
  - Non-Maleficence
  - Justice
- 
- A red diagram consisting of a vertical line on the right side and three horizontal lines extending to the left from that vertical line. Each horizontal line ends in an arrowhead pointing towards the corresponding ethical principle listed on the left: Beneficence, Respect for Autonomy, and Justice. The Non-Maleficence principle does not have an arrow pointing to it.

What questions do you want to investigate under each of the four topics?

- Medical Indications
- Patient Preferences
- Quality of Life
- Contextual Features

# What questions do you want to investigate under each of the four topics?

- Medical Indications
  - Nature of polycystic kidney disease
  - How big a benefit would transplant be? Comparison of morbidity and mortality with transplant vs. continued dialysis
  - Wait time for patient's blood type? Sensitivity?
  - Graft survival average after second transplant?
  - More medical, psychological and social information about the patient
- Patient Preferences
  - Does the patient have capacity?
  - Is he well informed?
  - Is he likely to be adherent to medications post transplant?
  - Is secondary gain involved that may influence the patient?
- Quality of Life
  - How would the patient's QOL change after transplant?
  - Recognition of bias against felons
- Contextual Features
  - How scarce a resource are deceased donor kidneys?
    - How many people waiting for a DDK?
    - How many DDK are transplanted per year?
    - How many people die waiting for a transplant?
  - Are there special rules or laws about medical care for prisoners?
  - What is the cost of dialysis vs. cost of transplant for the state/taxpayer?
  - What does your institution, professional society, regulations say about second transplant after non-adherence?

# Case Analysis Write-Up.

- **Question:** Formulation of a specific ethical question that characterizes the conflict of values in the case
- **Facts:** Identification of the facts in the case that are relevant to answering this ethical question
- **Reasoning:** A persuasive argument that employs ethical principles to justify your answer to the ethical question
- **Actions:** Practical steps you would take to gather more information and/or help resolve the conflict among stakeholders



# Thank you

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# Kidney Transplant for ESRD in Prisoner

## Ethical Issues and Analysis

The ethics question that we have been asked to answer is whether the transplant program should evaluate and potentially offer the individual a second kidney transplant. Two ethical concerns that might argue against transplant in the current case are (1) non-compliance as a reason for loss of the first transplant and (2) the nature of the crime of which the individual has been convicted. Even though the following analysis cites court cases, it is an ethical rather than legal analysis. For legal advice clinicians should contact an attorney.

*Lack of compliance:* The loss of an initially transplanted organ because of culpable non-compliance does not generally disqualify a person from being a candidate for a second transplant. Persons who lose an initial transplant because of non-compliance may be under increased scrutiny during their second transplant evaluation to show that they will be able to be compliant. The focus on compliance for initial and subsequent transplants is justified primarily because every organ lost from culpable non-compliance means that someone else has lost an opportunity for increased survival and decreased morbidity. (A secondary justification involves the best interest of the patient herself, for whom the risks of surgery may not be justified unless there is a good chance the transplanted organ will function for some period of time.) The focus of evaluation for a second transplant is whether a patient can be successful, rather than whether the patient no longer morally *deserves* a transplant because of culpable non-compliance. Mr. Smith was reportedly non-compliant with almost all of the requirements of his first transplant. Nonetheless, this should not disqualify him from the potential to receive a second transplant. The transplant evaluation would evaluate Mr. Smith's ability to comply with post transplant requirements among other factors.

*Violent crime:* The ethical issue of whether someone who is convicted of a violent crime and incarcerated should receive an organ transplant has generated discussion in the media and in the medical, legal and ethics literature (see attached bibliography). The 1976 Supreme Court Case *Estelle v. Gamble* grants a constitutional right to a decent minimum level of health care for all prisoners. Whether *Estelle* grants a constitutional right to health care above a decent minimum is matter of debate. (Frank 2005) Further, criteria to determine whether a transplant for a particular individual is within or beyond a decent minimum are also unclear. The instances of prisoners requiring transplants are sufficiently infrequent that there seems to be no commonly accepted practice to which all transplant centers adhere. In discussions with media, at least one transplant center cited *Estelle* as evidence that it is required to consider prisoners for organ transplantation. Other transplant centers apparently have a blanket policy against offer transplants to prisoners (see *Pinkley v. Anderson*).

### Reasons against providing a transplant

- *Eighth amendment guarantee to "adequate" health care for prisoners.* The Eighth Amendment prohibits cruel and unusual punishment. In *Estelle v. Gamble* (429 U.S. 97, 1976) the Supreme Court ruled that failure to provide prisoners with adequate medical treatment constitutes cruel and unusual punishment. *Estelle* focuses on "adequate" health care and the relatively narrow condition that prison officials not show "a deliberate indifference to serious medical needs." An argument could be

made that all that is ethically owed a prisoner is a decent minimum of medical care, and that a kidney transplant goes beyond this decent minimum. Arguably, a kidney transplant could be thought to be in excess of adequate care because (a) another treatment modality (dialysis) is available, (b) kidneys are a scarce resource, (c) it is not available outside of specialized centers and (d) kidney transplant is routinely denied those without the ability to pay for it.

- *Discretion in accepting patients:* Even if the prison system has a constitutional obligation to attempt to secure medical treatments such as kidney transplant for inmates, it does not follow that individuals or private institutions must accept an inmate as a patient. Practitioners have traditionally had wide latitude in who they accept as patients.
- *Zero-sum game and an intuitive principle of fairness:* A zero sum game is one in which “reward” to one player requires taking an equal amount of benefits from another. Cadaveric kidney transplant is a zero sum game, in that giving a kidney to one person means that another person will not benefit from the kidney. Fairness in distributing the limited resource is typically managed by preset criteria to place patients at a certain place on the waiting list. (The dominant principle in the criteria for kidneys is “time on list,” which translates to “first come, first served.”) That kidney transplant is a zero sum game may have additional relevance in the current case. An intuitive principle of fairness is that those who have culpably deprived an innocent person of a life should not have an equal claim on a resource necessary to save another person’s life. Simply put, when one commits murder one forfeits an equal claim on a life-saving resource in a zero sum game. In the current situation, it is also difficult to disregard the fact that the patient lost a first kidney to non-compliance: in some sense, the patient is already “responsible” for shortening the lives of two other people, and the proposal is to allow him to benefit at the cost of shortening the life of a third person.
- *Scarcity:* The above argument relies on the claim that providing a kidney to the current patient means that someone else who needs a kidney will not get it. How scarce is the resource? There are approximately 74,000 persons waiting for kidney transplants at the current time. There will be kidneys for less than 25% of that number this year. Persons with rare blood types typically wait five years or longer for kidneys. The addition of another person to the waiting list will increase the average waiting time for those on the list, and this result in an increased mortality among those waiting. The mortality rate for patients who wait 5 years for a kidney is about 33 percent.(Schnitzler, 2005) Another way to look at the scarcity of organs is to note that every kidney that becomes available for transplant adds an average of 7.2 life years as a cumulative total for those on the waiting list. (Schnitzler, 2005)
- *Concern about the donor family:* The United Network of Organ Sharing (UNOS) rules allow UNOS to pass anonymous messages between the recipient and the donor family, sometimes culminating in disclosure of identities and meeting between the parties. Some recipients have learned the identity of the donor through the use of media sources. One concern is that the donor family may have a negative emotional reaction to learning the recipient’s identity. An additional concern is that the recipient might initiate an abusive or exploitive relationship with the donor family.

## Reasons for providing a transplant:

- *Eighth Amendment:* The Eighth Amendment prohibits cruel and unusual punishment. In *Estelle v. Gamble* (429 U.S. 97, 1976) the Supreme Court ruled that failure to provide prisoners with “adequate” medical treatment constitutes cruel and unusual punishment. *Estelle* effectively creates a right to health care for prisoners. Underlying and supporting the legal argument are the moral arguments (1) that prisoners are not free to seek out their own health care because of state action, and (2) that incarceration and other penalties established by the courts should exhaust the punishment for a crime – the morbidity and morality associated with lack of health care should not be added to the punishment.
- *United Network for Organ Sharing Ethics Committee Position Statement:* This carefully worded statement seems to favor considering convicted criminals for transplant, as indicated in this quote: “The UNOS Ethics Committee opines that absent any societal imperative, one’s status as a prisoner should not preclude them from consideration for a transplant...” Part of the Committee’s reasoning seems to be that society ought to settle the question as a matter of law or policy, rather than allowing transplant centers to use their individual discretion to disqualify someone on the basis of his or her criminal record. This latter approach would be potentially unfair to individuals because of variation in standards among transplant centers.
- *Beneficence as a central value of the health care professions:* Codes of professional ethics in health care identify promoting the health of one’s patients as the central obligation in health care. While codes also identify competing values, such as an obligation to protect the public health, the central obligation is to promote the well-being of people who present asking help with a health related issue. Making treatment decisions based on the moral judgment that a potential patient is not deserving of care adds a dimension to the role of health care professional that is in tension with the core obligation to promote the health and well-being of one’s patients. Simply put, the role of a health care professional is to help people in need, not to judge whether persons are morally deserving of care. This sentiment may also apply to institutions: the role of a medical center is to provide health care to those in need, not to act as a gatekeeper for society regarding who is morally deserving of services.
- *Slippery Slope Concerns:* Allowing the “moral worth” of class of persons to disqualify the class for one type of treatment may lead inexorably to expanding the class of persons deemed not morally worthy to receive treatment. It is frequently alleged that health care provider attitudes about social worth influences treatment decisions in patients with sexually transmitted diseases, alcohol and drug addiction, and conditions associated with smoking, obesity and pregnancy. Explicitly denying a patient a transplant because of past illegal and immoral behavior may make it easier for society and practitioners to allow social worth judgments to influence treatment decisions.

**Recommendations and Options:** The Institution’s Clinical Ethics Committee did not reach a firm consensus on which set of arguments, for or against transplant, was the stronger. The most influential argument against transplant was that those convicted of depriving an innocent person



of life should have a lower priority for a scarce, life-saving resource than those not who have not been convicted of this crime. The most influential argument for transplant was that a health care professional's core obligation of beneficence precludes practitioners from acting as "social worth gatekeepers" regarding access to their services.

Slightly more members of the committee favored evaluating the patient for transplant. Evaluating the patient for transplant is consistent with most of the advice in the ethics literature and with what appears to be the practice of most transplant centers. Finally, evaluating the patient for transplant is consistent with UNOS recommendations on the issue. For these reasons, the Committee recommends that the patient be evaluated for transplant. This vote was divided, however, with some members wishing not to provide a recommendation for or against evaluation.

The committee recognizes that evaluating the likelihood of compliance with post transplant instructions will take on enhanced importance in the case given that an initial transplant was lost due to non-compliance. The committee would like to underscore the moral importance of this evaluation: a kidney is a scarce resource that should be used for patients in whom it is highly likely to prevent mortality and morbidity; evaluating for post transplant compliance is a key component for optimizing the use of the resource.

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## ***Formulating a clear, focused and specific ethics question about a clinical case***

Formulating the ethics question can be the single most difficult, yet most important, part of ethics consultation. Formulating the ethics question in a clear way allows all participants to focus on the central ethical concern and to work efficiently toward a solution. Formulating the ethics question poorly or imprecisely can sidetrack or derail the consultation process. In addition, in some instances, the process of clarifying the ethics question may lead to the realization that the situation is not appropriate for ethics consultation after all. For these reasons, ethics consultants should formulate the ethics question early in the process and examine this formulation again at a later stage, once all the relevant information has been assembled.

In some ethics consultations there may be more than one ethical concern. When this occurs, it may be necessary to formulate more than one ethics question. At each step in the consultation process, all relevant ethics questions should be considered. Sometimes, as a consultation unfolds, the ethics question may change or additional questions may emerge. Nonetheless, formulating the central ethics question at the outset is essential, as it helps to focus subsequent steps.

### ***Formulating the ethics question***

Given the conflict between value/consideration #1 and value/consideration #2, what decisions or actions are ethically justifiable?

Given the conflict between value/consideration #1 and value/consideration #2, is it ethically justifiable to decision or action ?

In an ethics consultation, an **ethics question** asks which decisions or actions are ethically justifiable given an ethical concern. The initial formulation of the question should state the question in a way that is helpful to those who will be involved in the consultation; it shouldn't emphasize abstract concepts or attempt to display the consultant's erudition.

At the risk of reducing important issues in ethics to a formula, we suggest that an ethics question be constructed as shown above.

Consider a case in which the surrogate for a patient who lacks decision-making capacity asks that mechanical ventilation be stopped. The health care team wishes to continue providing this treatment because they believe the patient might recover the ability to breathe on his own. They ask the ethics consultation service whether they should discontinue mechanical ventilation. The ethics question in this case can be stated as:

Given ***the conflict between the surrogate's right to make health care decisions on behalf of the patient and the health care providers' obligation to act in the best interests of the patient***, what decisions or actions are ethically justifiable?

or

Given ***the conflict between the surrogate's right to make health care decisions on behalf of the patient and the health care providers' obligation to act in the best interests of the patient***, is it ethically justifiable to ***withdraw mechanical ventilation***?

Although the concern could be stated as a tension between the ethical principles of autonomy and beneficence, that formulation may be too general and abstract to be helpful to the participants at this stage.

## **Practice**

**Case 1:** Dr. Habbitt, the chief of staff, requests an ethics consultation to determine whether the facility is obligated to provide dialysis to a patient with advanced metastatic lung cancer. The patient and his family are demanding the treatment, but Dr. Habbitt and the treating team believe that this would be inappropriate because of the patient's exceedingly poor prognosis.

**Case 2:** Mrs. Steel, a veteran, has been told that her prescription for oxycodone will not be renewed unless she agrees to sign a "contract" with the facility. She has some concerns about the contract and wants to know whether she has any other recourse.



## ***Answer Key***

**Case 1:** Dr. Habbitt, the chief of staff, requests an ethics consultation to determine whether the facility is obligated to provide dialysis to a patient with advanced metastatic lung cancer. The patient and his family are demanding the treatment, but Dr. Habbitt and the treating team believe that this would be inappropriate because of the patient's exceedingly poor prognosis.

There are many ways to formulate the ethics question. For example:

**Given that** the health care providers value the patient's right to self determination, but believe that the burdens of dialysis would outweigh the benefits, **is it ethically justifiable to** deny the patient's request for dialysis?

*or*

**Given that** dialysis might prolong the patient's life but the health care providers believe that the burdens of dialysis would outweigh the benefits, **is it ethically justifiable to** offer the patient dialysis?

**Case 2:** Mrs. Steel, a veteran, has been told that her prescription for oxycodone will not be renewed unless she agrees to sign a "contract" with the facility. She has some concerns about the contract and wants to know whether she has other options.

There are many ways to formulate the ethics question. For example:

**Given that** Mrs. Steel is entitled to receive her pain medication from VA but does not wish to sign a contract she thinks is unfair, **what decisions or actions are ethically justifiable?**

*or*

**Given that** Mrs. Steel values pain relief but is reluctant to sign a contract she knows she may be unable to keep, **what decisions or actions are ethically justifiable?**

### **Materials adapted from:**

National Center for Health Care Ethics of the Veterans Affairs Administration *Integrated Ethics: Ethics Consultation Toolkit*.

Available at: <http://www.ethics.va.gov/integratedethics/ECC.asp>

## ***Formulating a clear, focused and specific ethics question about a clinical case***

Formulating the ethics question can be the single most difficult, yet most important, part of analyzing an ethics case. Formulating the ethics question in a clear way makes it possible to focus on the central ethical concern and work efficiently toward a solution. In some instances, the process of clarifying the ethics question may lead to the realization that the situation is not as controversial as originally thought. In other instances, the ethics question may change, or additional questions may emerge as more information comes to light necessitating the formulation of multiple ethics questions. Nonetheless, formulating the central ethics question at the outset is essential, as it helps to focus subsequent steps.

### **Formulating the ethics question**

Given the conflict between value/consideration #1 and value/consideration #2, what decisions or actions are ethically justifiable?

Given the conflict between value/consideration #1 and value/consideration #2, is it ethically justifiable to decision or action?

An **ethics question** asks which decisions or actions are ethically justifiable given an ethical concern. The initial formulation should state the question as plainly as possible without emphasizing abstract concepts or hinting at preemptive conclusions about the correct course of action.

### **Case Example**

Consider a case in which the surrogate for a patient who lacks decision-making capacity asks that mechanical ventilation be stopped. The health care team wishes to continue providing this treatment because it believes the patient might recover the ability to breathe on his own. It asks the ethics consultation service whether mechanical ventilation should be discontinued.

The ethics question in this case can be stated as:

Given ***the conflict between the surrogate's right to make health care decisions on behalf of the patient and the health care providers' obligation to act in the best interests of the patient***, what decisions or actions are ethically justifiable?

or

Given ***the conflict between the surrogate's right to make health care decisions on behalf of the patient and the health care providers' obligation to act in the best interests of the patient***, is it ethically justifiable to ***withdraw mechanical ventilation***?

Although the concern could be stated as a tension between the ethical principles of autonomy and beneficence, that formulation may be too general and abstract to be helpful at this stage in the case analysis.

## Practice Cases

Formulate an ethics question for each of the following cases. (Answers on next page.)

**Case 1:** Dr. Habbitt, the chief of staff, requests an ethics consultation to determine whether the facility is obligated to provide dialysis to a patient with advanced metastatic lung cancer. The patient and his family are demanding the treatment, but Dr. Habbitt and the treating team believe that this would be inappropriate because of the patient's exceedingly poor prognosis.

**Case 2:** Mrs. Steel, a veteran, has been told that her prescription for oxycodone will not be renewed unless she agrees to sign a "contract" with the facility. She has some concerns about the contract and wants to know whether she has any other recourse.

## Answers

**Case 1:** Dr. Habbitt, the chief of staff, requests an ethics consultation to determine whether the facility is obligated to provide dialysis to a patient with advanced metastatic lung cancer. The patient and his family are demanding the treatment, but Dr. Habbitt and the treating team believe that this would be inappropriate because of the patient's exceedingly poor prognosis.

There are a number of ways to formulate the ethics question. For example:

**Given that** the health care providers value the patient's right to self determination, but believe that the burdens of dialysis would outweigh the benefits, **is it ethically justifiable to** deny the patient's request for dialysis?

*or*

**Given that** dialysis might prolong the patient's life but the health care providers believe that the burdens of dialysis would outweigh the benefits, **is it ethically justifiable to** offer the patient dialysis?

**Case 2:** Mrs. Steel, a veteran, has been told that her prescription for oxycodone will not be renewed unless she agrees to sign a "contract" with the facility. She has some concerns about the contract and wants to know whether she has other options.

There are a number of ways to formulate the ethics question. For example:

**Given that** Mrs. Steel is entitled to receive her pain medication from VA but does not wish to sign a contract she thinks is unfair, **what decisions or actions are ethically justifiable?**

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National Center for Health Care Ethics of the Veterans Affairs Administration *Integrated Ethics: Ethics Consultation Toolkit*.

Available at: <http://www.ethics.va.gov/integratedethics/ECC.asp>

<b>Format</b>	Large group lecture
<b>Faculty</b>	Chessa
<b>Learning Objectives</b>	<p>By the end of this lecture, you will be able to:</p> <ul style="list-style-type: none"><li>• Define morality and moral theory</li><li>• Describe and distinguish the three moral philosophies most relevant to clinical ethics: consequentialism, deontology and virtue</li><li>• Explain how each of these philosophies relates to bioethical principles and the four topics method of ethical decision making</li><li>• Explain how religion influences moral reasoning and ethical conduct in clinical practice</li></ul>
<b>Readings</b>	Chessa F. Ethics: History & Theory. Chp 90: p. 1359-81 (Note: grayed out sections are optional)

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Who is afraid of,  
(confused or bored by,)  
Ethical Theory?

**TUSM**

**October 26, 2012**

**Frank Chessa, Ph.D.**

Director, Clinical Ethics, MMC

Assistant Professor, TUSM

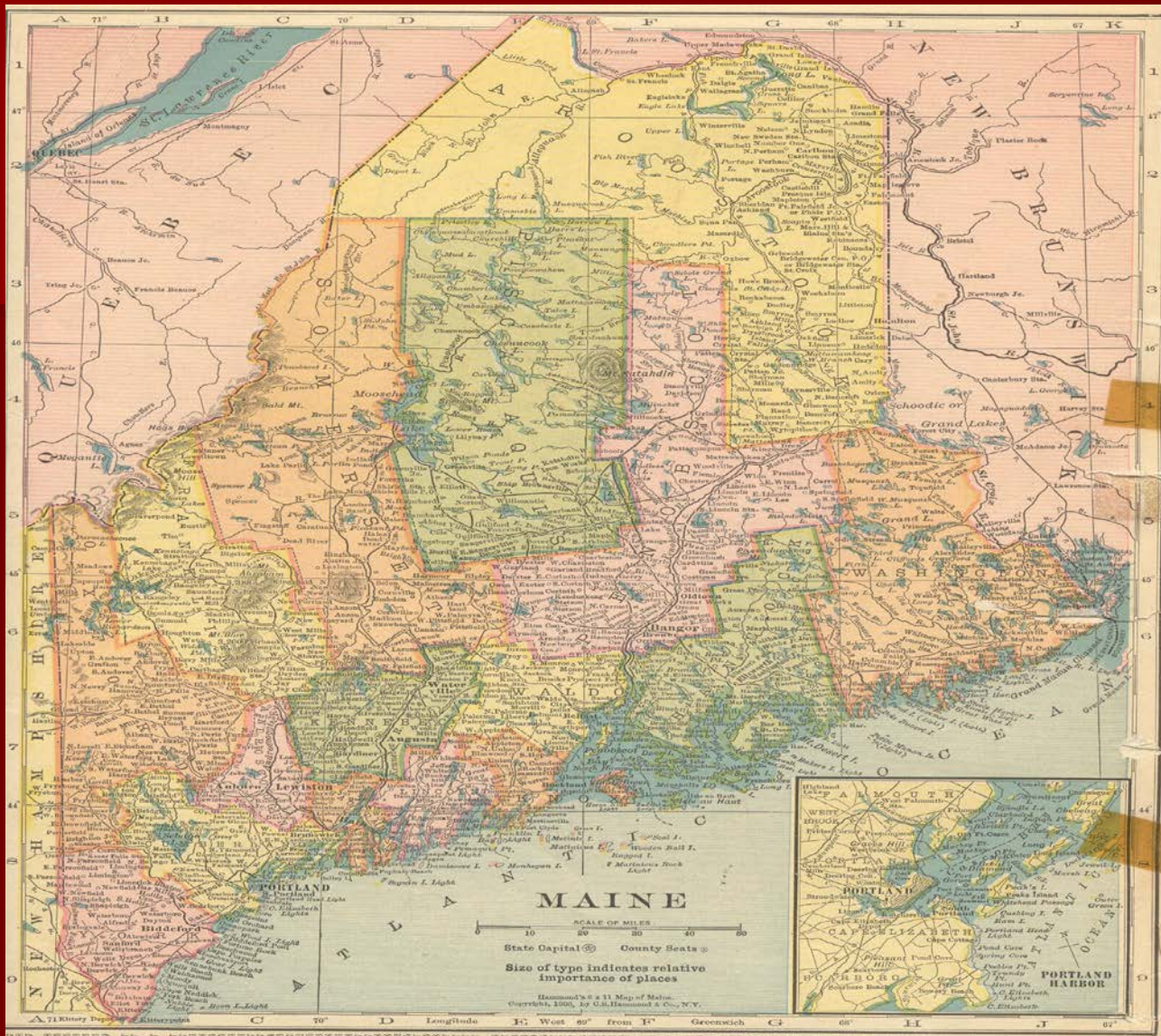


Ethics  
is like a  
**Cage**



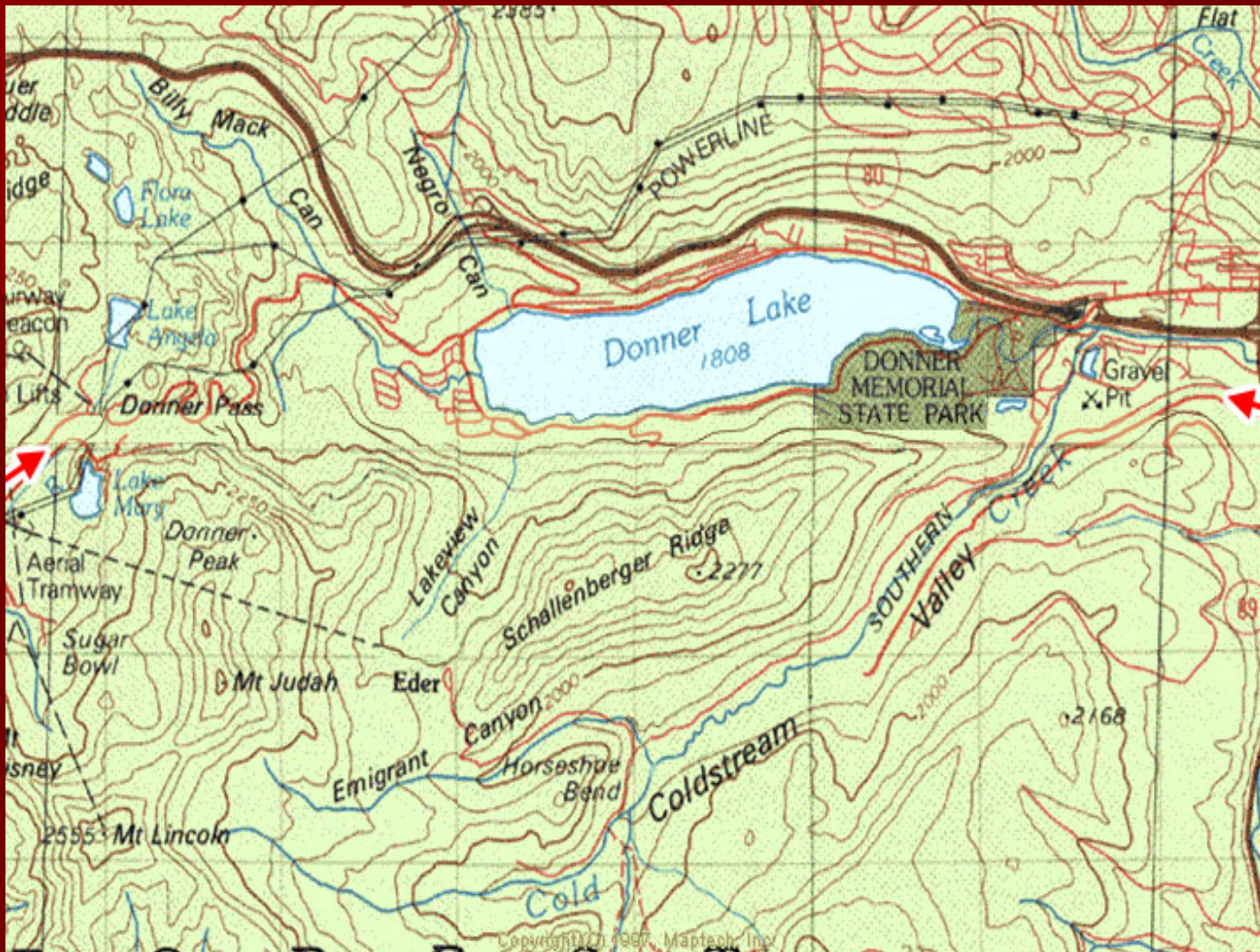


**...a cage that keeps me  
from doing what I want.**



Ethics  
is like a  
Map





...a map that helps me identify where I want to go.

# Ethical Theory

- *Science* describes the world as it is.
- *Ethics* is about the world as it should be.
- *Ethical theory* is systematic reflection about how the world should be.
  - How should society be organized?
  - What sort of person should I work to become?
  - Which actions should be performed; which should not?

# Reminders from last lecture on case analysis

# Formulating an Ethics Question

- The question should be clear, focused, specific, forward-looking, action-oriented
- Formula:

Given the conflict between value/consideration 1 and value/consideration 2, what decisions or actions are ethically justifiable?

Given the conflict between value/consideration 1 and value/consideration 2, is it ethically justifiable to decision or action ?



# Two Complimentary Methods for Case Analysis

- Beauchamp and Childress: *Principles of Medical Ethics*
- Jonsen, Siegler, Winslade: “Four Topics” method in *Clinical Ethics*.
- Follow the “Four Topics” format, use the principles to develop the content of the analysis.
- Ultimate Goal: Provide a method (or framework) for analyzing the ethical issues you encounter in clinical practice
- Proximate Goals: Effectively analyze the cases in your small group discussions; Write your case analysis papers for this course.

# Case Analysis Write-Up.

- **Question:** Formulation of a specific ethical question that characterizes the conflict of values in the case
- **Facts:** Identification of the facts in the case that are relevant to answering this ethical question
- **Reasoning:** A persuasive argument that employs ethical principles to justify your answer to the ethical question
- **Actions:** Practical steps you would take to gather more information and/or help resolve the conflict among stakeholders



# Caution: Additional Knowledge Required

- Neither the principles or the four topics methods are sufficient to analyze an ethical case (even when used together). Both methods require additional knowledge of particular topics in medical ethics.
- Analogy: The format for oral case presentations compared to the analysis of a particular case.
  - You need to know the format for a case presentation: cc, hpi, pmh, ros, social history, labs, etc.
  - When you present a particular case you need to know facts about patient (what is there chief complaint? SOB), and also background information about the medical conditions in question (e.g., etiology, pathophysiology, treatment, diagnostic criteria for CHF).
- The Four Topics methods gives you the format (and some content), but you still need patient specific information and **background information** about the specific ethical issue.

# Ethical Theorists

- Aristotle (384-322 B.C.)
- Immanuel Kant (1724-1804)
- John Stuart Mill (1806-1873)

# Ethical Theorists

- Aristotle (384-322 B.C.)
  - Primary locus of assessment is character
- Immanuel Kant (1724-1804)
  - Primary locus of assessment are actions
- John Stuart Mill (1806-1873)
  - Primary locus of assessment are actions

You and your best friend are shipwrecked on a desert island. She is dying. As she is dying, she asks you if you will see to it that all her millions are given to her country club to build another nine holes of golf for the club's golf course (making the total 27 holes). You promise her that you will. She dies. On being rescued and returned home, it comes to your attention that your town really needs a new wing on the hospital for the care of children with cancer. It is in your power to divert your friend's millions to this useful project.

Should you do it?

## You should

1. Give the money to the country club
2. Give the money to the children's hospital
3. Give the money to the country club; have them sponsor a charity tournament that funds the children's hospital

## You should

1. Give the money to the country club
2. Give the money to the children's hospital
3. ~~Give the money to the country club, have them sponsor a charity tournament that funds the children's hospital~~

# Fundamental Divide

- Deontology: Some actions are morally wrong independent of the consequences they may have.
- Consequentialism (Utilitarianism): Actions are morally right or morally wrong solely because of the consequences they have.

# Immanuel Kant

(1724-1804 )

There is no possibility of thinking of anything at all in the world, or even out of it, which can be regarded as good without qualification, except a good will.





# Kant's Good Will

Jane pauses in her walk to the market in order to help an infirm person board a bus.

Is Jane morally good in performing this action?

# Kant's Good Will

Jane pauses in her walk to the market in order to help an infirm person board a bus.

Is Jane morally good in performing this action?

It depends.

# Kant's Good Will

An act is moral only if it is done for the right reason.

And there is only one right reason:

respect for the moral law,

one does the action because  
it is the morally correct action.

# Immanuel Kant

Act in such a way that you treat humanity, whether in your own person or in that of another, always at the same time as an **end** and never simply as a **means**.

# Why treat someone as an end?

- **Respect** for a person's autonomy
  - Autonomy understood as a person's capacity to use **reason** to figure out the best thing to do.
- **Freedom** to demonstrate one's humanity.
  - To not treat person as an end is to rob them of their freedom to use reason to make decisions.

# Kantian Duties

	<i>Perfect duties</i>	<i>Imperfect duties</i>
<i>Duties to others</i>	Do not break promises	Help others in need
<i>Duties to self</i>	Do not commit suicide	Cultivate your own talents

# Problems with Kant

You are hiding people from a repressive and violent regime. Soldiers knock on your door and ask you if you are hiding anyone. You know that if you lie convincingly the soldiers will go away. But you feel that it is wrong to lie. What should you do?

What should you do?

# Kant on Lying

To be truthful in all declarations is... a sacred and unconditionally commanding law of reason that admits of no expediency whatsoever.

Kant, "On the supposed duty to lie for beneficent purposes."



# Problem with Kant

Adapted from M. Stocker

Sheila is ill and has been hospitalized. Her co-worker Bob comes to visit her. Sheila is immediately cheered: she didn't know that Bob cared about her; she is moved by Bob's compassion and friendship. She brings this up: "Bob, how nice of you to visit; it is so caring of you to go out of your way to cheer me; I am moved to have a friend such as you." Bob, ever the honest one, sets Sheila straight: "I consider it my duty to visit a coworker who is ill, and so here I am. I would rather be at home, you know, but duty calls."

Is Bob open to moral criticism?

# Kant on Moral Motivation

...there are many persons so sympathetically constituted that they find an inner satisfaction in spreading joy and they rejoice in the contentment of others. But I say that...that kind of action has no true moral worth... For it lacks the moral import of an action done not from inclination but from duty.

Kant, "Foundations of the Metaphysics of Morals" 398

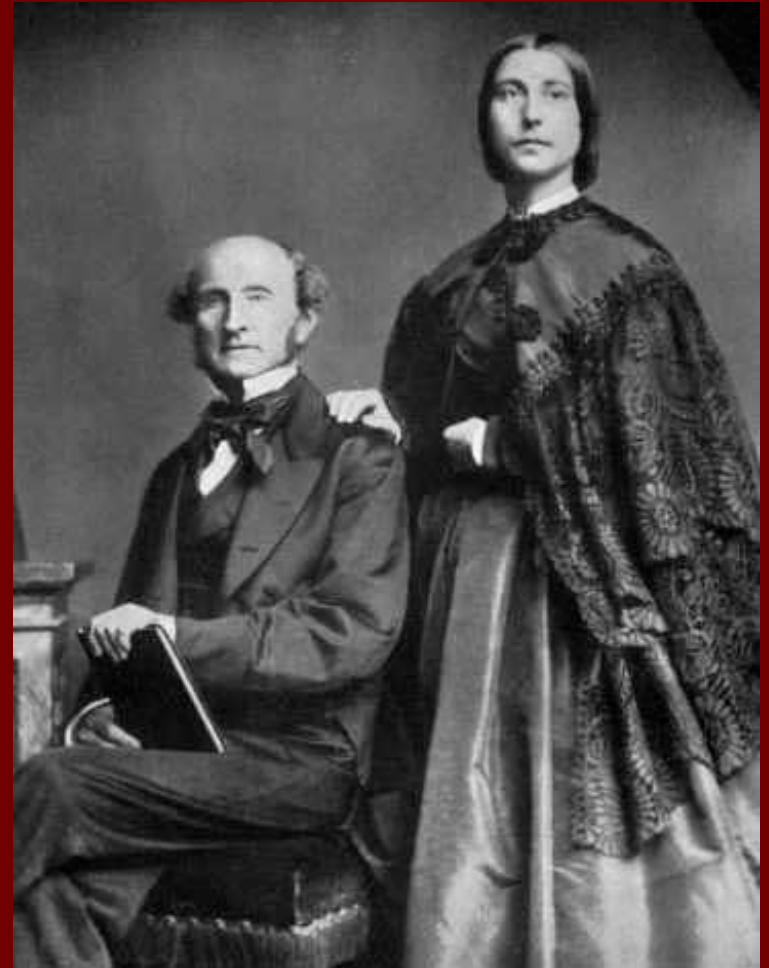
# Kant: influence on bioethics

- Informed Consent
- Positive and negative obligations regarding the autonomy of patients
- Deontological approaches to the ethics of killing

# John Stuart Mill

1806-1873

Actions are right in proportion as they tend to promote happiness; wrong as they produce the reverse of happiness.



# John Stuart Mill

- Reformer
- Old rules and institutions are antique views that maintain the status quo.
- Cut away complexity to get to the heart of ethics.
- Challenges tradition, but consistent with Christianity.

# John Stuart Mill

Actions are right in proportion as they tend to promote happiness; wrong as they produce the reverse of happiness.

By happiness is intended pleasure and the absence of pain; by unhappiness, pain and the privation of pleasure.

*Mill, Utilitarianism*

# How does it work?

- Consider the alternative actions available to you
- Figure out which creates the most happiness, remembering long-term consequences
- That action which creates the most happiness is your moral obligation

# Possible Misinterpretations

- *Not egoism* – the pleasure and pain of all people count in the calculations
- *Not hedonism* – short-term and long-term pleasures count
- *Not depravity* – “higher” pleasures are more pleasurable than “lower” pleasures



# Problem with Consequentialism

A mob is chasing a man through town. They blame him for a murder, and they plan to brutally execute him. The man happens to be innocent, as you know. However, you also know that if the mob does not kill the man, then a riot will ensue in which many persons will be killed (some of those killed will be innocent, having nothing at all to do with the situation). It is in your power to save the innocent man from being executed.

Should you do it?

# Problem with Consequentialism

Adapted from B. Williams

George has been offered a job in a research facility for chemical and biological weapons. George has been out of work for some time, and his wife and young children have suffered greatly. George does not feel he can take the job, however, because he is a committed pacifist who has always been against C and B weapons. The person offering George the job says that she, too, is against such weapons: in fact, she has offered George the job because the other candidate for the job will enthusiastically push the work along at a faster pace, while George will likely drag his feet.

Should George take the job?

# Problem with Consequentialism

On Thursday, Frank has \$10 that is uncommitted as far as his budget is concerned. Frank considers using the money to go to the movies – he would certainly enjoy this and there are no relevant constraints on his time. But, the \$10 could also be used to benefit other people – it might even save lives if contributed to Oxfam. A good utilitarian, Frank gives the \$10 to Oxfam. On Friday, Frank again has \$10. He again considers a movie, but...

# Problems with consequentialism

- Ignore special moral importance of
  - justice
  - promise-keeping
  - truth-telling
  - ownership rights
  - obligations to family
- Demands we sacrifice our integrity.
- Demands too much self-sacrifice

# Mill: influence on bioethics

- Mill focused on the badness of pain
- EOL reasoning not based on *antique* views
  - Withholding/withdrawing distinction unimportant
  - No special status for nutrition and hydration
  - Active/passive euthanasia distinction unimportant
- Liberty/autonomy also important for Mill

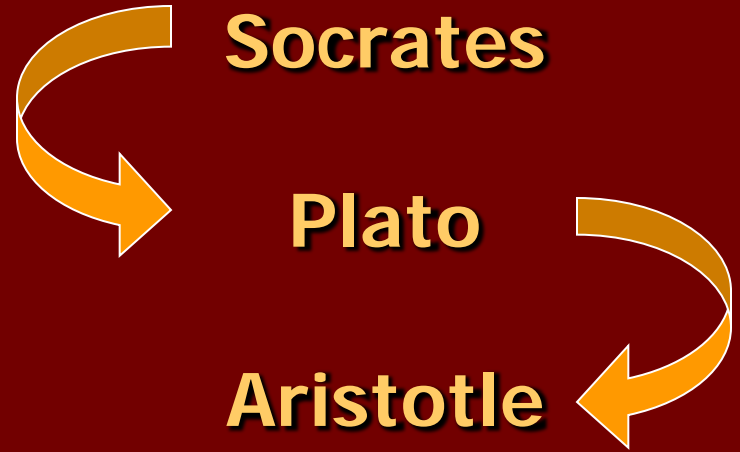
# Ethical Theories

- **Consequentialism** J.S. Mill, “*Actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness.*” (1863)
- **Deontology:** Kant, “*One must act to treat every person as a end, and never as a means only.*” (1785)
- **Virtue Theory:** Aristotle, *Virtuous actions “spring from a firm and unchangeable character.”* (NE 2.4, 330 B.C.)





**Aristotle**  
384-322 B.C.



# Aristotle

- People have a purpose.
- Moral excellence leads to a good life.
- Moral excellence is emotional.
- Ethics is a skill; practice makes perfect.



# Humans have a purpose.

- All things in nature in nature have a purpose
- Human purpose/function is to live the “active life of the element that has a rational principle.”
- The purpose of a knife is to cut. An excellent knife is one that cuts well.
- An excellent (or virtuous) human is one that performs the distinctive human function well.

# Moral excellence leads to a good life.

- When you do what is good for others, you do what is good for yourself.
- When you do what is good for yourself, you do what is good for others.
- Moderation and well-rounded life.

# Moral excellence is emotional.

Both fear and confidence and appetite and anger and pity and in general pleasure and pain may be felt both too much and too little, and in both cases not well; but to feel them at the right times, with reference to the right objects, towards the right people, with the right motive, and in the right way, is what is both intermediate and best and this is characteristic of virtue.

Aristotle, *NE* 1106b17

# Ethics is a skill; Practice makes perfect

The virtues we get first by exercising them...  
For the things we have to learn before we can do them, we learn by doing them, e.g., men become builders by building and lyre-players by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts.

*Aristotle, NE 1103b 1*

# Ethics is a skill; Practice makes perfect

Being good at ethics is not like being good at following a recipe.

Being good at ethics is more like being good at basketball.

Become the Michael Jordan of ethics.

# Aristotle and medical ethics

- Downplay strict rules for clinical-ethical decisions.
- Instead, develop skills to navigate the rich moral landscape.
- Learn from your elders.
- Be guided by the purpose of your profession.

# Ethics and You

- Ethics is a **cage** that constrains self-interested action.



- Ethics is a **map** that helps us get where we want to go.





# Questions?





# Ethics: History and Theory

*Frank Chessa*

## INTRODUCTION

Many health care providers are familiar with the basic concepts of health care ethics — surrogate decision-making, advance directives, do not resuscitate (DNR), withdrawal of treatment, confidentiality and informed consent have become need-to-know terms in the practice of medicine and nursing. Likewise, I expect many health care providers are familiar with the basic principles of health care ethics, including nonmaleficence, beneficence, respect for autonomy, veracity, and justice. What is perhaps more rare among practitioners is an awareness of how health care ethics is connected to the history of ethics and ethical theories more generally. Yet knowledge of the ethical traditions that have influenced health care ethics may help practitioners in a number of ways: (1) it may help practitioners extend well-known principles to novel cases; (2) it may help practitioners articulate why they have reached a conclusion about the ethics of a particular case; and (3) it may deepen practitioners' commitment to ethical values of their profession. This chapter seeks to bridge the gap between health care ethics and the traditions from which these ethics emerge.

This chapter also briefly surveys some ethical issues that are especially relevant to palliative care. Other chapters in this volume treat these issues in more detail. Here, the focus is on showing how the history of ethics is relevant to the ethical issues that arise with particular acuity in palliative care. It is not under the purview of this chapter to expand the discussion beyond Western ethical traditions, although non-Western traditions are increasingly important to consider as more persons from various world cultures are served by, and practice

within, health care institutions in the United States and Britain.

There is also a good deal in the history of Western ethics that could not be covered in this chapter. In part this is because many great minds who have written about ethics — including just a paragraph on each would have made this chapter too long. I have instead chosen to focus on six philosophers: Plato, Aristotle, Augustine, Thomas Aquinas, Immanuel Kant, and John Stuart Mill. Of these six, Aristotle, Kant, and Mill are given the most attention because their theories are the most relevant to health care ethics. I should also note that it is not possible to consider every facet of the theories of these philosophers. Indeed, not only have these philosophers each written thousands of pages, but each is the subject of countless books and articles. In my inevitable narrowing of this material, I have selected topics that either have had a direct influence on health care practitioners or that raise issues that may be of interest to health care practitioners. My hope is that this will serve to make the current chapter different from other surveys of the history of ethics in a way that will prove useful to the health care providers likely to read this volume.

The first section of this chapter, by far the largest, is a chronological survey of the views of the ethical theorists. For each philosopher, I have provided biographical information, a sketch of his theory, prominent criticisms of the theory, and a discussion of the ways in which the philosopher's ideas emerge in current debates in health care ethics. The second section discusses how the historical theories relate to various methodologies in contemporary health care ethics (e.g., the ethics of care, casuistry). The second section also draws some parallels between three ethical issues in palliative care and the history of ethics.

## ETHICAL TRADITIONS

### SOCRATES AND PLATO

It is appropriate to begin a discussion about the history of Western ethics with Socrates and Plato. Socrates was born in Athens around 469 B.C. and, famously, he died in 399 B.C. by drinking hemlock under order of the Athenian court. Plato (428–347 B.C.) immortalized his teacher in a series of dialogues that portray Socrates as a martyr for his ethical beliefs. Among Plato's 26 surviving dialogues are some of the first examples of extended ethical reasoning in the Western tradition. Plato's dialogues explore a range of moral (and nonmoral) issues, from the proper way to be religious (*Euthyphro*), to suicide (*Phaedo*), to civil disobedience (*Crito*), to political organization (*Republic*), to love (*Symposium*).

A good example of a Platonic dialogue focused on a moral issue is *Crito*. In *Crito*, Socrates faces the question of whether to accept death as punishment for corrupting the youth of Athens or whether to escape into exile. Escape was probably the outcome expected by Socrates's accusers, as this was a common practice and Socrates had the means to accomplish it. Socrates argues (to his friend Crito, who wishes him to escape) that although he is innocent of wrongdoing, and although the state is acting unjustly in prohibiting him from teaching philosophy, he nonetheless owes Athens a debt for raising and protecting him, and thus he should not escape (51d).<sup>\*</sup> To escape would be to weaken the state, while all of his prior activities were aimed at strengthening Athens. Socrates does not escape and soon after this dialogue takes place, he is executed, with all of his friends present and weeping openly for the loss of their great friend and philosopher. (*Phaedo*, 115b–118) Plato's *Crito* presages modern views about civil disobedience: civilly disobedient actions are morally permissible if their intention is to reform unjust laws, if the actions are performed openly, and if the actors are willing to accept punishment. What emerges in *Crito* is the idea that the aim of civil disobedience is to reform a state, not to overturn it, and that those who are civilly disobedient are among the heroes of society since they are willing to sacrifice their well-being for the good of the state. The Reverend Martin Luther King certainly fits this model.

Plato's moral reasoning sometimes relies on the conviction that there is an afterlife. In particular, Plato is explicit that how a person lives on Earth will influence his or her afterlife, so he posits "a much better future [after death] for the good than for the wicked." (*Phaedo* 63c) Plato is often interpreted as dividing the world into the

realm of appearance (the world as we experience it embodied on Earth) and the realm of reality (the world as it really is, which is accessible to us, if at all, only after we die). However, even while Plato's thought has these religious dimensions, his conclusions about particular issues rely on an astute reading of human nature as much as on theological reasoning. In *Euthyphro*, Socrates questions Euthyphro about his attempt to prosecute his father for murder. The primary moral failing of Euthyphro is not that he is attempting to prosecute his father for murder. Rather, this potentially immoral action is a symptom of a character flaw, namely, that while Euthyphro is good-hearted, he has a wildly over-inflated confidence about his knowledge of theology. Plato thus depicts the type of moral failing likely to arise from a lack of humility in otherwise praiseworthy persons.

One of the lasting legacies of Plato's thought is the idea that living ethically should be the primary goal of human life. We will also find this idea in the writings of Plato's greatest student, Aristotle, and it is to his thought that we will now turn.

### ARISTOTLE (384–322 B.C.)

Arguably, until relatively recently, the focus of modern ethics has been on the evaluation of actions. In contrast, Aristotle focused on the moral evaluation of a person's character, that is, on whether a person is virtuous or vicious. The focus on character evaluation is responsible for the popularity of virtue theory among contemporary ethical theorists (French, Uehling & Wettstein, 1988; Sherman, 1989). In particular, focusing on character has three advantages. First, action-centered theories seem not to account for the emotional dimension of our moral lives (Stocker & Hegeman, 1991). Aristotle held that feeling the correct emotion and being motivated by it are important components of having a virtuous character. Second, virtue theory is at home with particularism about right action (Dancy, 1993; McNaughton, 1991). Particularism holds that rules and general principles are not much help in determining the morally correct action because real-life situations are simply too rich to be codified by general rules. Aristotle stresses correct perception of the features of a situation and wise judgment in figuring out what to do, rather than dependence on a set of rules. Finally, the focus on character has implications for how one learns to be moral. Modern advocates of Aristotle often view morality as a type of skill that is developed in the same manner as other skills (Little, XXXX). Learning a skill primarily requires practice, although it may also involve emulation of experts, expert critique of one's performance, and reflection on theoretical issues. So Aristotle was the first in the Western tradition to deny that there is a book of rules that can teach one how to be moral. In other realms, this view is familiar. Many of us think that

<sup>\*</sup> Quotations of Plato are taken from *The Collected Writings of Plato*, Hamilton, E. and Cairns, eds., The parenthetical references for Plato refer to ..., the standard method for citing passages in Plato across various translations.

there is no book that can teach even a physically talented individual to play basketball like Michael Jordan — his split-second judgments are too rich and varied to be codified. Why then do many of us nevertheless assume that there is a book on ethics that can teach us to be moral experts in the absence of practicing ethics in the rich context of everyday life?

Aristotle was born in 384 B.C. His father was a physician at the Macedonian court. Aristotle had a lifelong association with Philip of Macedonia and his son Alexander the Great. Aristotle studied with Plato for approximately 20 years at Plato's Academy in Athens. After Plato's death in 343, Aristotle moved to Macedonia to tutor the young Alexander before returning to Athens to found his own school, the Lyceum, in 336. After the death of Alexander the Great, Aristotle left Athens to avoid the political fallout from his association with the emperor. Aristotle died in 322 at the age of 62. Aristotle's writings were extensive, and although we have perhaps lost most of his published works, we are left with thousands of pages of carefully prepared lecture notes. His writings on ethics are contained primarily in the *Nicomachean Ethics*, on which we focus.

However, our discussion of Aristotle can begin not with ethics, but by sketching the theory of causal explanation that he outline in *Physics* (194b 20) (McKeon, 1941).<sup>\*</sup> Aristotle believed that understanding how any object came to be required referring to four factors: the material cause, the efficient cause, the formal cause, and the final cause. The material cause is the raw matter that makes up an object. For example, the bronze is, in this sense, the cause of the statue. The efficient cause is the energy that has molded the matter into a certain shape. So we also say that the sculptor is the cause of the statue. The formal cause can be understood as either the blueprint for the object before it is made, or the shape and organization of the finished object. For the statue, the blueprint may exist only in the sculptor's mind, but it nonetheless lays out the shape of the object to be created. The final cause is the purpose of the object. It is the reason for which the object is created, or the action is done. So we say that the woman walks in order to improve her health and that is the final cause of her walking. For another example, consider a pitcher for holding and pouring liquid. Its material cause might be clay. The efficient cause is the potter's spinning of the wheel and movement of her hands. The blueprint (which may only exist in the potter's mind) lays out the shape of the pitcher. The final cause of the pitcher is its purpose of holding and pouring liquid. An important aspect of this theory is that the formal cause

answers to the final cause — that is, the shape of the object fits the purpose for which the object was designed. Note also that there is interplay between separate causes. In designing an object to fulfill a purpose, we need to consider whether the material has the properties that will allow it to be fashioned into the shape needed and whether the energy is available to accomplish the change. Aristotle's theory is a good fit for explaining how human-made objects came into existence. But Aristotle did not limit the theory to artifacts. Aristotle also believed that this theory of causal explanation held true for natural objects, in particular, plants, animals, and humans.

The key to Aristotle's ethics is that humans, as do all things in nature, have a final cause or purpose. He felt that careful observation of humans, including their physical bodies, their culture, and social behaviors, would yield information about humans' purpose. Living an ethical life, Aristotle then reasoned, would be living a life that achieved this purpose to the greatest extent possible. Aristotle identified the purpose or function of humans as "an active life of the element that has a rational principle" (*NE* 1098a 1). What Aristotle meant by this enigmatic phrase is much debated, but a fair interpretation is that the purpose of human life was to use reason to think about oneself and one's place in world and to perform actions as directed by the results of this reasoning — in short, to live an active life under the direction of reason. Aristotle felt that a virtuous person would be a person who did an excellent job performing the specialized human function. In fact, the word for virtue in Greek is *arête*, and this word can be equally well translated as excellence. An often-quoted illustration used by Aristotle to explain these concepts involves a knife: Aristotle says that the purpose of a knife is to cut, and an excellent knife is one that cuts excellently. So, too, with humans: an excellent or virtuous human is one that performs the function of humans excellently.

Aristotle believed that the result of a person performing the human function excellently is that the person would flourish. (The Greek word is *eudaimonia*, which can be translated as flourishing, happiness, well-being or good spirits.) Aristotle's idea was that one would reap rewards from living a virtuous life. These rewards would be both internal and external. The virtuous person would be happy, that is, she would have an internal feeling of well-being. But the virtuous person would also have some of the external trappings of success — she would be respected in her trade or craft, would have true friendships based on mutual admiration and respect, would have a loving family, and would be viewed as an upstanding member of the civic community whose counsel would be sought and trusted. These external trappings would include enough wealth to be secure and comfortable, but excessive wealth might be a sign that all is not as it should be. The virtuous person lives a well-rounded life, according to Aristotle. She enjoys good food and fine wine, but

<sup>\*</sup> Quotations for Aristotle are taken from *The Basic Works of Aristotle*, McKeon, R. ed., Random House, New York, 1941. Parenthetical citations are to the numbering in the Bekker edition of the Greek text of Aristotle, the standard method for citing passages in Aristotle across various translations. *NE* refers to the *Nicomachean Ethics*.

not to the detriment of her health. She enjoys poetry and drama, but does not live in a fantasy world. She works hard at a successful career, but also has ample time for family, friends, and fun. She is concerned with and will work to enhance the well-being of others in society, but she will not impoverish herself in the process. Finally, she is emotionally and psychologically healthy, as a result of her good relationships with others and as a result of the proper cultivation of her emotions and the appropriate expression of them at the appropriate times. Balancing these various areas of one's life, or living in the mean between excess and deficiency in each of the areas, is one of the primary skills of the virtuous person.

So, as I have reconstructed Aristotle's ethical theory, there are four primary ideas: humans have a specialized function or purpose; those who perform this function excellently are virtuous; a virtuous person flourishes in her life; and finally, a flourishing life is lived in the mean between extremes. It is worth asking why, on Aristotle's account, a person should be virtuous? The answer is that one should be moral because it is in one's self-interest, very broadly construed. Virtuous persons flourish. This is not to say that one will make decisions based on self-interested considerations. Indeed, Aristotle would say that sometimes the motivation to sacrifice a portion of one's own immediate well-being for the good of someone else is just what is required to make oneself happy. Conversely, aiming at one's own happiness in all the picky, little decisions of everyday life will have the effect of undercutting one's happiness. Nonetheless, the overarching motivation for becoming an excellent human is that benefits will rebound to oneself. As Aristotle says, the highest good is happiness (*eudaimonia*). Put differently, Aristotle was convinced that the best life for humans was the life that included moral virtue as a significant part.

This sketch of Aristotle fails to explore many of the specific topics that give his theory power and scope, for example, his account of how to deliberate about a decision, his enumeration and description of individual virtues (e.g., courage, temperance, generosity, honesty, among others), and his discussion of the nature of friendship. However, a topic I consider in more depth is his account of how one becomes virtuous, and in this context also present Aristotle's definition of virtue.

Aristotle says that humans are not by nature virtuous, for if they were it would not be possible for a human to be vicious, but we know that some persons are vicious. Instead, Aristotle says that humans have the potential to become virtuous, and this potential is realized by habituation. He writes: "Neither by nature or contrary to nature do the virtues arise in us; rather we are adapted by nature to receive them, and are made perfect by habit" (*NE* 1103a 25). Habituation is a matter of practicing virtuous behavior.

The virtues we get first by exercising them... For the things we have to learn before we can do them, we learn by doing them, e.g., men become builders by building and lyre-players by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts. (*NE* 1103b 1)

The purpose of practicing to be virtuous by performing virtuous actions is to train our emotions and desires. By performing temperate actions, one both gets used to and begins to enjoy the emotions that accompany the actions. From this enjoyment, one begins to desire to be temperate. The opposite sort of habituation can occur as well: performing intemperate actions tends to create intemperate desires and thereby an intemperate character (Sherman, 1989).

Why is it that one should train oneself to enjoy being temperate, one might ask, if one can equally well train oneself to enjoy being intemperate? As useful, if somewhat fanciful, analogy helps to answer this question. Let us say that the human body functions best on a diet of vegetables, meats, and grains. Nonetheless, a child experiences pleasure on first tasting candy. The child's untutored tastes can lead him astray. In fact, the child can eat so much candy that he no longer finds unsweetened foods at all palatable. Now, in the long term, the health of the child will suffer. So, too, the child's taste will never progress beyond the unremarkable pleasure of tasting fat and sugar. This child has not learned to love the good. Aristotle would say that it takes real effort to learn to love that which one can love most fully. So, it takes effort to forgo candy in order to eat spinach, broccoli, rice, beans, etc. One will not immediately love the taste of these foods. But over time, one's palate will be sensitized to the varied and subtle flavors of these foods. The enjoyment experienced by this trained palate will far outstrip the enjoyment of the palate desensitized by fat and sugar. Further, of course, the health of the person will benefit from eating this natural diet. Aristotle would see both the potential for the enjoyment of natural foods, and the health that results from natural foods, to be directly related to the biological characteristics of the body — human biology is such that it gets maximum benefit from natural foods. Once one is sensitized to the tastes of natural foods, staying on the diet of natural foods is effortless. In fact, any other diet tastes bad. But, it takes effort to get to this stage, and indeed it may not be possible to get to this stage if one starts down the wrong path and incorrectly trains one's sensibilities from an early age.

We should note at this point the importance of emotion to Aristotle's ethical theory. Aristotle is clear that virtue is not an emotion, but is instead a state of character (*NE* 1105b 30). Nonetheless, a virtuous character is a stable set of dispositions to have appropriate emotions and to perform right actions. A person is not virtuous until she



feels the appropriate emotions when performing the right action. Further, emotions are a guide to right action. While rational deliberation plays some role, in large part one is moved to a certain action because one feels a certain emotion. Aristotle's emphasis on the importance of emotion is one reason that his "virtue theory" experienced a resurgence in the 1980s. Historically, all moral theorists have recognized that humans are emotional creatures, but more often than not emotions were seen as a hindrance to morally correct action. Emotions were not viewed as being under the control of reason — anger, love, jealousy, even sympathy, could move one to act in ways that would be regretted later. Aristotle admitted that emotions, in the moment of their occurring, were often beyond human control. But, by beginning early to train oneself to have the appropriate emotion relative to the situation one is experiencing, it does not matter if the emotion is "out of our control" in the moment of its occurring, for it is the appropriate emotion to have, and it will move one to perform the right action.

Thus, virtue in Aristotle's view is concerned with both emotions *and* actions. One mark of a virtuous person is that she takes appropriate pleasure in doing the right actions. And a mark of someone who fails to be virtuous is that, though she may do the right action, she may not feel the right emotions. So on the battlefield (one of Aristotle's favorite examples) where standing and fighting is appropriate, a virtuous person will courageously stand and fight and feel a kind of confident pleasure in doing so, while one kind of nonvirtuous person — what Aristotle calls a continent or strong-willed person — will stand and fight but feel terrible pain and fear as he does so. Aristotle also tells us that virtue is typically destroyed by excess and defect, and preserved by the mean. To explain this he says that:

... the man who flies from and fears everything and does not stand his ground against anything becomes a coward, and the man who fears nothing at all but goes to meet every danger becomes rash. (NE 1104a21)

Extremes do not typically preserve or habituate virtue. The virtuous person is the one who rushes into battle where this is appropriate and similarly flees where this is appropriate. And the virtuous person is also the one who feels fear where appropriate and confidence where appropriate. So virtue is concerned both with passions and actions and the virtuous person is the one who finds the mean, or appropriate point, for both, feeling the right emotion and doing the right action as they are called for in particular situations. Again, Aristotle explains:

... both fear and confidence and appetite and anger and pity and in general pleasure and pain may be felt both too much and too little, and in both cases not well; but

to feel them at the right times, with reference to the right objects, towards the right people, with the right motive, and in the right way, is what is both intermediate and best and this is characteristic of virtue. Similarly with regard to actions also there is excess, defect and the intermediate. (NE 1106b17)

We now have all the components in place to understand Aristotle's definition of virtue. He says that:

Virtue ... is a state of character concerned with choice, lying in a mean, i.e. the mean relative to us, this being determined by a rational principle, and by that principle by which the man of practical wisdom would determine it. (NE 1106b36)

Virtue is a state of character that individuals cultivate through practicing virtuous actions and emotions. Both virtuous actions and emotions must find the mean between the extremes, and this is relative both to the specific circumstances the person is in (so, how much fear an individual should feel in battle depends on how well-prepared for battle one is, one's army is, how well-suited one's army is to the terrain, etc.), and it is also relative to the person herself. So if a person is attempting to cultivate the emotion anger (associated with the virtue of good temper) and she finds that she often gets too angry, she should strive to feel too little anger in this situation. That is the way in which the virtue is relative to the individual herself. And finally, the mean is determined by reason, by thinking about and assessing the practical nature of the situation. It is also determined by the moral experts, what Aristotle calls persons of practical wisdom, since moral virtue is a kind of wisdom or as we saw earlier, a kind of skill-based knowledge.

### Criticisms and Evaluation

Aristotle's claim that there were purposes in nature is at odds with the scientific world view. Aristotle did not believe that living organisms were designed with a purpose in mind in any obvious sense — for example, he did not believe that organisms were created by an intelligent God. Aristotle simply thought it was the case that things in nature had purposes since, as he saw it from his extensive botanical and zoological studies, it was obvious that living things had complex and purposeful bodily structures. However, since the publication of Darwin's *Origin of Species*, there has been an alternative explanation of how such organs, for example, the human eye, came into existence. In addition, after Darwin surviving to reproduce was recognized as the goal of living organisms — whatever worked to pass on one's genes was, from the perspective of nature, good. In Aristotle's view, an organism has a potentiality that is implicit in it and waiting to be realized. With natural selection, there is no one right way

to develop, as long as one's genes are passed on. Most contemporary philosophers of biology seek to describe the world without the teleological language of "purpose" or "goal" (or they seek to redefine these terms appealing only to concepts in the theory of evolution).

A second criticism of Aristotle is that he provides few rules that set out specific moral obligations and thus little practical advice about how to act. Instead, his most tangible advice is to act in the mean between excess and deficiency, (he does mention that committing adultery, for example, is never in the mean). Aristotle also appeals to the "person of practical wisdom" and suggests that one should act as the person of practical wisdom would act. Nevertheless, Aristotle does not provide general rules that specify our moral obligations. This can leave the novice with little guidance about how to resolve specific issues. It also tends to invest a good deal of authority in the person of practical wisdom, a "moral expert." Novices emulate moral experts as part of the process of learning to be virtuous. Moral experts, in turn, have a good deal of discretion about how to resolve ethical questions. The moral expert is supposed to be sensitized to the moral landscape such that she discerns the right action where others see only an irresolvable dispute (or worse, overconfidently insist on a vicious action) (McNaughton, 1991).\* Perhaps everyone has known someone he considers to be morally wise, but there may be little agreement about who such people are. Further, it seems somewhat dangerous to invest so much authority in a single person's power of discernment.

But what is a weakness to some, is a strength to others (Hursthouse, 1995). Aristotle is relevant to contemporary accounts of health care ethics because he views moral goodness as a skill that must be mastered rather than a set of rules that must be followed. This approach fits with the type of training received by physicians and some other health care professionals. The training of physicians in residency programs often involves mentorship by older, more experienced physicians. The training includes not only information, but also close observation and emulation of the skills involved in medicine, from communication with patients, to physician interactions with nonphysician colleagues, to skills with a scalpel. The well-respected attending physician is viewed as passing the "art of medicine" to younger colleagues. This art cannot be codified, but rather is embodied in an expert. One suggestion regarding health care ethics is to make sure that the physician (and other) leaders in an institution are not only experts in the technical side of medicine, but are also moral experts as well (Pellegrino & Thomasma, 1993). An institution with wise moral leadership would, in theory, need very few specific rules to govern the ethical conduct of its members (Beecher, 1966; Kass, 1980).

\* David McNaughton advocates moral experts. McNaughton, D., *Moral Vision*, Blackwell, Oxford, 1991, 203-5

## AUGUSTINE (A.D. 354–430)

Augustine is an influential figure in the consolidation of early Christian thought. Aurelius Augustinus was born to Roman parents in Roman-controlled North Africa. Augustine described himself as living a "lustful" and "wicked" life until about the age of 30. In *The Confessions*, he writes to God about his struggle with lust:

I in my great worthlessness had begged you for chastity, saying: "Grant me chastity and continence, but not yet." For I was afraid that you would hear my prayers too soon, and too soon would heal me from the disease of lust which I wanted satisfied rather than extinguished.\*\*

Augustine had always been a searcher for religious truth, and was for a time a member of the Manichean sect, which held that good and evil were eternal and equally powerful forces in the world. However, Augustine was profoundly influenced by the sermons of the Catholic Bishop Ambrose, who over time convinced Augustine of the intellectual merit of Catholicism. After being baptized a Catholic by Ambrose in 387, Augustine never strayed from his faith. Augustine is responsible for quite a number of works, of which the best known are *The City of God* and his autobiography, *Confessions*.

Augustine was one of the first to systematize answers to the problem of evil, which is essentially the question of why an all-good, all-knowing, and all-powerful God would allow suffering and evil to exist. Augustine advanced a number of answers, but a prominent one is that, in sin, humans freely turn away from eternal goods in order to seek inferior, temporary goods. Augustine argued that evil is simply the absence of good, so that, strictly speaking, evil is not a thing that can be said to exist. Humans' free choice of sin results in suffering and a diminishing of the good, since sin is the pursuit of inferior goods. The four cardinal virtues for Augustine are prudence, fortitude, temperance, and justice — each of these, except perhaps justice, is explained as helping humans to desire eternal goods and suppress desire for earthly goods. Augustine says that the person who desires the correct goods has "good will," and he takes this to be the most valuable possession a person can have. Augustine's ethical theory contains many prohibitions on action. Notably, Augustine presents a carefully argued, absolute prohibition of suicide in *The City of God* (the only possible exception is martyrdom at the direct command of God). Augustine also considers every lie to be sin, but his nuanced view of deception holds that some lies are clearly worse than others. (Readers familiar with the ethics of Immanuel Kant will notice some similarities between Kant and Augustine. However, it should be noted that the

\*\* Augustine, *Confessions*, Pine-Coffin, R.S., trans. Penguin Books, New York, 1961.

thinkers understand the good will in a fundamentally different way: Augustine explained it in terms of having the proper desires, while Kant felt that the good will did not depend on desires at all.)

### THOMAS AQUINAS (1224–1274)

A second great religious thinker was Thomas Aquinas, who lived approximately 800 years after Augustine. Aquinas was born to a wealthy family in southern Italy near Naples. Aquinas received religious training early, and at 20 years-old he joined the Dominican Order. His family was disappointed that he joined the newly formed order, so much so that they held him hostage for about a year in the hope he would renounce the Dominicans. He served the Dominican Order with distinction throughout his life, spending the majority of his time as a professor of theology at the University of Paris. Aquinas's writings are extensive: the best known is *Summa Theologica*, which he probably wrote while at the residence of Pope Clement IV between the years 1265 and 1268. An interesting coda to the life of Aquinas is that soon after his death many his writings were condemned by Church officials: studying the works of Aquinas was only fully sanctioned by the Catholic Church under Pope Leo XIII around the year 1900.

The thought of Aquinas is sometimes presented with the formula: Aristotle + God = Aquinas. While Aquinas's rich and extensive writings cannot be reduced to this formula, the formula does point to an organizing theme in Aquinas's thought. Aristotle held that everything in nature was imbued with a purpose (the final cause, in Aristotle's terminology). Aquinas identified God as the source of these purposes. Simply put, God designed everything in the world with a purpose in mind. With Aristotle, one can learn about an object's purpose by examining the form or organization of the object. So too for Aquinas — the study of humans and nature reveal natural laws, and these natural laws provide insight into God and God's "eternal law." One learns about the creator by studying creation. Sins are actions that conflict with natural law (and therefore also eternal law). From this guiding idea, Aquinas develops a complex taxonomy of immoral actions.

Among his specific prohibitions, Aquinas says suicide is wrong (1) because it violates the natural law of self-preservation, (2) because it harms one's community, and (3) because the power of life and death rightly belongs to God. Like Augustine, Aquinas holds that every lie is a sin, although some lies are relatively minor infractions. In this context, Aquinas defends what is known as the Pauline principle, namely, that it is not permissible to achieve a good end (no matter how great) by an evil means (no matter how minor).

Aquinas also had a good deal to say about sex and reproduction. Aquinas holds that procreation is the natural purpose of the sex act. Thus, a sexual act that does

not allow for procreation conflicts with natural law. Thus, homosexuality and masturbation are sins for Aquinas. So, too, is heterosexual sex outside of marriage, since Aquinas holds that the natural order is such that human offspring should be raised by two parents (if possible). Aquinas does not pull his punches here: any sexual act in or outside of marriage that does not allow for procreation and the proper raising of children is a mortal sin. That is, it is a sin that will result in one's damnation, unless this sin is absolved by God's grace. (Being sorry or doing penance can absolve one from venial sins, but they are powerless against mortal sins.)

The doctrine of double effect was developed by Aquinas (and others), and this doctrine plays an important role in some contemporary writings on medical ethics. The doctrine of double effect is a way to determine the moral permissibility of actions that have both good and bad effects. In essence, the doctrine holds that an action that causes a bad effect is permissible if and only if the following five criteria are met:

1. Only the good effect is intended; the bad effect may be foreseen, as long as it is not intended.
2. The action cannot be intrinsically wrong (such as lying).
3. The causal chain that leads to the good effect cannot contain the bad effect; that is, the good effect cannot be the causal result of the bad effect.
4. There are no ways to achieve the good effect without causing the bad effect (or a worse one).
5. The good effects of the action outweigh the bad effects of the action.

For example, routine surgery to remove a diseased appendix meets all of the criteria: bad effects (e.g., soreness, risks associated with anesthesia) are foreseen but not intended; removing the appendix is not intrinsically wrong; the good effect is not caused by any bad effects; there is no way to prevent a burst appendix except surgery; the badness of a burst appendix outweighs the risks and costs of surgery. A second application of the doctrine of double effect involves narcotics to relieve suffering in a terminally ill patient: the intent must be to relieve pain (this is the good effect), not cause death (this is the bad effect); providing narcotics in normal doses is not intrinsically wrong (i.e., normal doses are not tantamount to providing a deadly poison); pain relief is not achieved by death; there are no other means to relieve suffering; the good of pain relief outweighs the increased risk of premature death.

### Criticism and Evaluation

While a few isolated arguments from Aquinas and Augustine are persuasive in secular contexts, their theories as a

whole are plausible only within a religious context. This is because each of the thinkers derives ethical commitments from his theological views about the nature of God. And, of course, there are a variety of theological perspectives even within Christianity, so one cannot assume that ethical commitments of Aquinas and Augustine fit well with all Christian faiths. Nonetheless, ideas from the thinkers, especially Aquinas's view that one can use "natural law" to derive ethical rules, continue to be influential among many in society.

The doctrine of double effect has been discussed, defended, and criticized since Aquinas's time. Major criticisms include the following. Some have argued that it is impossible to foresee the bad outcome of one's action and not also intend the outcome when performing the action; that is, there is no such thing as a foreseen but unintended effect. A second criticism holds that the notion of an intrinsically wrong action is incoherent: if this is so, then one must give up criterion 2 (and maybe criterion 3), in which case the doctrine is nothing more than a form of consequentialism. (See the section on Mill for a discussion of consequentialism.) Finally, one might argue that judgments made about balancing good and bad effects (in criterion 5) are necessarily subjective. Indeed, some would argue that death is actually a good for the suffering patient for whom no relief is possible. The doctrine of double effect seems to assume that there is some noncontroversial way of identifying effects as good or bad. These criticisms are powerful when the doctrine of double effect is used in a secular context. However, the doctrine of double effect was never meant to be divorced from a religious context, which would include a substantive account of which types of actions are intrinsically wrong and a substantive account of human goods. Further, a secular theory that identified intrinsically wrong actions and which provided a substantive account of human goods could also use the doctrine.

### IMMANUEL KANT (1724–1804)

Kant invented one of the most influential deontological theories of ethics. A deontological theory takes some actions to be morally wrong regardless of their consequences. The clearest example in Kant's writing is lying. According to Kant, it is not permissible to lie even if the lie is about a relatively unimportant matter and yet would prevent great evils from occurring. Simply put, whether a lie has good or bad effects is irrelevant to whether the lie is permissible. Kant's theory is largely secular in its grounding. Nonetheless, Kantian ethics has strong affinities with religious ethics, since religious ethics also tends to identify some actions as impermissible regardless of their consequences (as our discussion of the doctrine of double effect has just illustrated). A second important aspect of Kant's ethical theory is its emphasis on auton-

omy. Kant suggests that persons' capacity for reason gives persons both freedom and responsibility. As beings with the capacity to reason, persons can rise above the instinctual, animal aspects of their natures to make informed choices about the proper course of action. The ability to make informed choices forms the basis of one's freedom. However, one is not free to make these choices willy-nilly. Rather, one has the responsibility to reason correctly about morality. This means that the choices one makes for oneself — about lying, for example — have a measure of universality, that is, all persons who reason correctly will necessarily reach the same conclusion.

Immanuel Kant was born in 1724 and he died in 1804. He lived his whole life in Königsburg, as a professor at the University of Königsburg. Kant lived the life of a quiet and not very productive professor until about the year 1776, when he read David Hume's *Enquiry Concerning Human Nature*. Kant said that Hume's book woke him from his "dogmatic slumber," meaning that Hume's work showed him that there were deep flaws in his own understanding of the world. It was quite an awakening. At the age of 56, Kant embarked on one of the most ambitious and most successful research programs in the history of philosophy. Kant published the *Critique of Pure Reason* in 1781, and followed this work with books on practical reason, aesthetics, religion, and ethics. Kant not only made original contributions in each area, but his works fit together to form a philosophical system unmatched for its subtlety and sophistication.

Kant begins the first section of the *Groundwork for the Metaphysics of Morals* with a bold statement about moral value:

There is no possibility of thinking of anything at all in the world, or even out of it, which can be regarded as good without qualification, except a good will. (GW 393)\*

Kant contrasts a good will with talents such as intelligence and wit, with virtues, such as courage and perseverance, and with calm deliberation and self-control. In contrast to Aristotle, Kant argues that none of these character traits has intrinsic value, because each of these things can be put to evil uses. What then is a good will, and why is it so valuable? Kant is clear that a good will is not good because it brings about good consequences. He writes: "a good will is good not because of what it effects or accomplishes, nor because of its fitness to attain some proposed end; it is good only through its willing, i.e., it is good in

\* Kant, I. *Groundings for the Metaphysics of Morals*, Ellington, J.W. trans., Hackett Publishing Company, Indianapolis, 1993. Parenthetical citations are to the Prussian Academy system, the standard method for citing passages in Kant across various translations. GW refers to the *Groundings for the Metaphysics of Morals*. DV refers to the *Doctrine of Virtue*.



itself" (GW 494). Indeed, Kant says that the good will "shines like a jewel" with its full value even in a person who lacks all talent and skill, and thus never succeeds in accomplishing any of his aims. Kant rules out one potential reason why a good will might be thought valuable. So, again, what is a good will and why is it valuable? Kant explicates the concept of a good will in terms of a person's motivation to perform an action. A person with a good will has the intention to do a morally correct action *because* the action is morally correct. That is, the person does the correct action out of respect for the moral law.

Kant uses a number of cases to illustrate the point. Adapting one of his cases, consider someone who goes out of her way to help an infirm person to board a bus. We can imagine any number of motivations for this kind stranger's action: she might want to impress someone she knows is watching her; she might feel guilty for snapping at a co-worker earlier in the day; she might want the satisfaction that comes from performing a good deed; the infirm person might remind her of her father, for whom she has kind feelings; she might even simply have found herself overcome by sympathetic emotions. Kant argues that none of these potential motivations for the action has any moral worth. What gives the stranger's action moral worth, if it has moral worth, is that the action is performed out of respect for the moral law. That is, the stranger intends to perform the action because the action is the right thing to do. Kant's terminology contrasts *acting from duty* with *acting according to duty*. Because this action is morally required, one acts *according to duty* no matter one's motivation. But only the correct motivation for the action yields an action *from duty*. In part, the distinction is easily understood — everyone recognizes that sometimes the morally correct action is performed for morally neutral or morally bad reasons. What is interesting is Kant's formulation of morally correct motivation: one does what is right because it is right.

It is possible to clarify what Kant means by acting from duty by considering motivations that do not count as being morally worthy. Kant's general term for such motivations is "inclination." An inclination is either a particular desire or an emotional disposition. So, one is motivated by an inclination if one helps because one *desires* to impress a potential romantic partner. Further, one is motivated by an inclination if one helps because one *desires* to feel satisfied for performing a good deed. One also is motivated by an inclination if one's emotional dispositions simply move one to act. The sympathetic person may act not because she desires something, but simply because she has a sympathetic character. (Note the contrast to Aristotle here, who would consider the sympathetically inclined person to be acting virtuously.) Kant does not view inclinations as chosen by the agent. Rather, he thinks that one finds oneself with inclinations; the inclinations arise in humans because humans are instinc-

tual creatures with bodily needs. In an important sense, when a person lets these inclinations cause his actions, then he is not free or autonomous. An autonomous choice for Kant is one that is made on the basis of reason, not on the basis of desires or emotions. Of course, Kant thinks it is often appropriate to act to fulfill one's desires — the point is that one is not demonstrating one's highest potential except when one's action is motivated by reason, in particular, when one does the morally right thing because reason shows him that it is the right thing. Kant says that we are "self-legislating." This means that we each use our reason to determine what is morally right, and we bind ourselves to doing what is right because we see that it is dictated by reason. It is in that sense that we are free — the moral rules that bind one are self-imposed.

The rules of reason are universal, according to Kant. Two people who are not making any mistakes in their reasoning will reach the same conclusion. Thus, moral rules are universal, even though each of us must reach these laws using our own reason. This allows Kant to talk about the specific moral obligations that everyone must follow, even though each person is responsible for imposing these rules on herself. Kant's core moral principle is called the categorical imperative. The categorical imperative has a number of different formulations, but the first and third are the most influential.

*Categorical Imperative, Universal Law Formulation:* Act only according to that maxim whereby you can at the same time will that it should become a universal law. (421)

*Categorical Imperative, End-in-Itself Formulation:* Act in such a way that you treat humanity, whether in your own person or in that of another, always at the same time as an end and never simply as a means. (429)

Intuitively, the universal law formulation gets at the idea that people have a tendency to make exceptions for themselves: that is, a person might rationalize that it is permissible for him to perform an action, even though he would have to admit that it would be bad if everyone acted in the same way. Kant cannot appeal to bad consequences and remain consistent with his remarks about the good will. So, Kant explains that in performing an action one is, in effect, agreeing to the principle that it is permissible for everyone to act in the same way, and reason will show one whether it is possible to embrace this principle. Kant's clearest example involves keeping promises. Kant reasons that one cannot both expect to reap the reward of breaking a promise and yet assert that it is fine for everyone to break promises: this is because in a world in which everyone breaks promises, there will be no trust, and if there is no trust, then there will be no rewards to reap from breaking a promise since no one will believe the promise in the first

place. Whether the categorical imperative “test” for the morality of actions works for all cases has been the subject of debate since Kant’s time.

The end-in-itself formulation of the categorical imperative is more straightforward. The idea is that one must respect other people as decision makers in their own right — that is to say, that one must act to respect and support other people’s autonomy. One can use other people as a means to fulfill one’s own needs (e.g., as happens in all commercial transactions), but this use of others as a means must be consistent with respecting others as persons. Note that Kant is also clear that one has to respect oneself as an autonomous being. That is, one has an obligation to respect and support one’s own autonomy.

Kant offers the following four examples to highlight the four categories of moral obligations.

	Perfect duties	Imperfect duties
Duties to others	Do not break promises	Help others in need
Duties to self	Do not commit suicide	Cultivate your own talents

Perfect duties require a person to always refrain from performing an action. They are required at all times. Imperfect duties require performing an action. Since performing an action requires time and effort, and since the effort one expends performing one imperfect duty must be balanced against one’s obligation to perform other imperfect duties, any particular imperfect duty is not required of a person at all times. One needs to perform an imperfect duty when the opportunity arises and such that one is not favoring one imperfect duty to the detriment of others. (This raises the interesting practical question of how to balance imperfect duties to self with imperfect duties to others.)

### Criticisms and Evaluation

Kant’s theory is not immune to a type of criticism that can be made against all deontological theories, namely, that some instance of an action-type identified as impermissible by the theory is considered to be permissible or even obligatory on independent grounds. Consider the following example:

You are hiding innocent people from the soldiers of a repressive regime. Soldiers knock on your door and ask you if you are hiding anyone. You know that the soldiers will torture and kill the people if you give them up. You know that the soldiers will search your house and find the people if you say nothing. You also know that if you lie convincingly the soldiers will go away. But you feel that it is wrong to lie. What should you do?

Many people have the intuition that in this case it is permissible or even morally obligatory to lie. Some will

attempt to justify the lie by saying that the soldiers do not have a right to the truth. Kant would disagree. His view is that you should tell the soldiers the truth, no matter the consequence to the innocent people. In commenting on a similar case, Kant writes: “To be truthful in all declarations is ... a sacred and unconditionally commanding law of reason that admits of no expediency whatsoever.”\* Kant’s view is that there are no exceptions to the prohibition on lying. Many people find this sort of inflexibility untenable, especially given that it will more than likely result in the death of innocents.

A second criticism of Kant involves his attitudes to the emotions. Kant is clear that an action motivated by an emotion such as sympathy has no moral worth. Rather, only actions done from duty have moral worth. Kant would say that a person who performs a compassionate act because she sees it as her duty is acting morally, and this is true whether or not the person also feels the emotion of compassion. However, a person who is motivated by the emotion, and not by duty, has not acted morally. This has led Michael Stocker to focus on the example of a person who is motivated by duty and not emotion. Here is an adaptation of his example.

Sheila is ill and has been hospitalized. Her co-worker Bob comes to visit her. Sheila is immediately cheered: she didn’t know that Bob cared about her; she is moved by Bob’s compassion and friendship. She brings this up: “Bob, how nice of you to visit; it is so caring of you to go out of your way to cheer me; I am moved to have a friend such as you.” Bob, ever the honest one, sets Sheila straight: “I consider it my duty to visit a co-worker who is ill, and so here I am. I would rather be at home, you know, but duty calls.”

Few would think that Bob is a morally praiseworthy person, even if he refrained from telling Sheila his real motivation for the visit. Rather, we generally expect morally good persons to have morally good emotional dispositions, and indeed we evaluate people based on their emotional dispositions. Sometimes we do admire people because of their strong sense of duty, but other times we admire people for their kind, compassionate, or generous emotions. Kant seems to be missing this aspect of morality.

This criticism has prompted contemporary defenders of Kant to investigate more closely Kant’s view on the moral value of emotions. Some of these defenders have suggested that focusing on Kant’s *Groundwork for the Metaphysics of Morals*, while ignoring his other works, results in a lopsided view of Kantian ethics. Kant’s *Groundwork*, it is argued, defends his conception of right action. Kant’s *Doctrine of Virtue*, on the other hand, pre-

\* Kant, I. On a supposed right to lie because of philanthropic concerns, in *Groundings for the Metaphysics of Morals*, Ellington, J.W. trans., Hackett Publishing Company, Indianapolis, 1993.

sents his conception of a virtuous person. So *The Doctrine of Virtue* may be important to balancing the overall picture of Kantian ethics.

In *The Doctrine of Virtue* Kant argues that character traits and emotional dispositions provide important support to the good will. For instance, he argues that:

... it is a duty to sympathize actively in the fate [of others]; and to this end it is therefore a duty to cultivate the compassionate natural feelings in us, and to make use of them as so many means to sympathy based on moral principles.... For this is still one of the impulses that nature has implanted in us to do what the representation of duty alone would not accomplish. (DV 457)

In this passage, Kant argues that human imperfection and weakness often prevent us from acting on duty alone. Thus we must cultivate our natural compassion, to bring it in line with the requirements of moral duty. Kant further thought that when we perform beneficent actions from duty we will, “eventually come to actually love the person [we] have helped” (DV 402). Dutiful beneficent acts will produce the emotion of sympathy in us, but it is a kind of sympathy that is obedient to and consequent upon moral duty.

But even given this defense of Kant, many non-Kantians remain unsatisfied with the Kantian view of emotions. In particular, some critics have argued that Kant’s ethical theory, at best, values emotions merely as instruments to doing one’s moral duty. Kantians cannot see the simple experience of an emotion as morally valuable in itself. Thus, a Kantian cannot hold that simply feeling sympathy for a friend in distress has moral significance, apart from the emotion’s ability to support an agent’s good will. So for those moral theorists convinced that emotions have moral value apart from their role in morally good action, the Kantian position on emotions remains inadequate even with these important defenses of Kant’s view.\*

Kant is relevant to contemporary health care ethics for a number of reasons. First, Kant was perhaps the first to develop a well-supported secular deontological theory. This makes it possible to claim in pluralistic settings that some actions are just wrong, no matter their good consequences, and to formulate public policy around the sorts of actions that are considered to be intrinsically wrong. Second, Kant championed autonomy. His view is one of the primary motivations for the Principle of Respect for Autonomy, which is discussed in the second section of this chapter. Finally, Kant’s views do much to influence theories of informed consent. Notably, informed consent procedures are designed not just to protect patients’ freedom to choose, but also to support patients in making good decisions. Kant, as we saw, connects the freedom to

choose with choosing for the right reasons: a person makes a genuinely free choice if and only if a person makes a choice based on reason. This issue is also discussed in the second section.

### JOHN STUART MILL (1806–1873)

John Stuart Mill (with Jeremy Bentham) developed consequentialism, one of the most influential modern theories of ethics. Mill’s version of consequentialism is called utilitarianism, and the great virtue of this theory is that it cuts away the complex and (Mill would say) arcane trappings of earlier ethical theories, and seeks to explain ethics in a way that is simple, direct, and that appeals to common sense. Mill’s guiding insight, which was exquisitely simple, was that those actions that cause good consequences are ethically good and those that cause bad consequences are ethically bad. Despite its apparent common sense, the theory stands in stark contrast to earlier ethical theories. In part, this is because Mill defined good consequences as pleasure and the absence of pain, and other ethical theories posited loftier goals for humans’ lives. But an even more acute point of contrast, especially to Kant, is that Mill denied that any action is wrong in and of itself, regardless of its consequences. This means, for example, that telling a lie is not necessarily wrong; whether a particular lie is morally right or morally wrong depends on the consequences of telling it. For Mill, many of the reasons why we might be tempted to say that an action is wrong “in-itself” are based on outdated traditions or suspect religious reasoning. In both cases, the moral rules that result will tend to favor the already well off in society at the expense of the common folks working in fields and factories. Mill argued that human suffering is bad wherever it is found, and that society ought to be arranged so that such suffering is minimized — if a traditional right (say, one granted to the nobility) stands in the way of minimizing suffering, so much the worse for this right. Lest Mill seem too much of a radical, it should be noted that he found that many (but not all) of the institutions of the British Empire did serve to promote the general well-being.

John Stuart Mill was born on May 20, 1806 in London. His father was James Mill, a prominent intellectual and reformer and a close associate of Jeremy Bentham. James Mill pushed John in his studies from an early age — it was said that John was reading Plato in the original Greek at age 7. John began publishing his own work at age 16. He became the editor of the *Westminster Review* and founder of the Utilitarian Society. In 1826, at age 20, Mill underwent a mental crisis, entering a 4-year period of depression the cause of which he took to be the lack of “cultivation of the feelings” in his early upbringing. The end of Mill’s depression coincided with meeting his life’s partner, Harriet Hardy Taylor, who was at the time married

\* Stark, S. “Emotions and the Ontology of Moral Value.” *Journal of Value Inquiry*, forthcoming

to someone else. Mill and Taylor remained close friends and collaborators for the next 20 years, until the death of John Taylor allowed Mill and Harriet Taylor to be married. (See the dedication of *On Liberty* for insight into Taylor's contributions to Mill's thought and writings.) Mill was elected a member of the British Parliament in 1865, although he was defeated at the next election. Mill died on May 7, 1873 in Avignon, France, apparently as the result of the exertion of a 15-mile hike he had taken 2 days previously. Throughout his life, Mill maintained his father's commitment to reforming society, particularly the sort of evils brought on common people by industrialization and urbanization. Mill was also an early defender of equality for women, publishing *The Subjugation of Women* in 1869 — which was most likely co-written with Harriet Taylor. (An interesting anecdote in this regard was that Mill was arrested and briefly jailed for obscenity in 1823, the result of distributing birth control literature in a working-class neighborhood of London.) Mill published widely in areas beyond moral philosophy, including logic (*A System of Logic*, 1843), political theory (*On Liberty*, 1859), and economics (*Principles of Political Economy*, 1848). Those interested in Mill's views on religion, God, and immortality will find his *Three Essays on Religion* (1874) to be helpful. Mill's *Autobiography* (1873) also makes fascinating reading.

Mill's moral theory is outlined in his short book *Utilitarianism* (1863). The primary idea behind the theory is that the morality of an action ought to be measured solely by the consequences, good and bad, that are produced by the action. We are obligated to perform the action that produces the most good, that is, the action that has the consequences with the highest net value. To complete the theory, Mill specifies what counts as good and bad consequences. Mill argues that the value of an action is measured by the pleasure and pain that it produces in humans. This leads to Mill's central principle, the Greatest Happiness Principle (GHP): "actions are right in proportion as they tend to promote happiness; wrong as they produce the reverse of happiness." Mill leaves no doubt as to what he means by happiness: "By happiness is intended pleasure and the absence of pain; by unhappiness, pain and the privation of pleasure" (Mill, 1966, p. 157).

Three possible misinterpretations should be headed off at the outset. First, Mill is not an egoist. That is, he is not claiming that an action is morally right for me to perform if it produces the best consequences *for me*. Rather, he is claiming that an action is morally right for me to perform if it produces the best consequences for everyone. I am allowed to consider my own well-being in calculating which action is morally right, but my well-being counts no more than the well-being of anyone else who would be affected by the action. Indeed, since my action may affect the well-being of persons yet to be born, I should also consider their well-being in my calculations.

Second, Mill is concerned with both short- and long-term consequences. Thus, the GHP does not require that I perform actions with immediately pleasurable consequences, if later consequences will cause enough pain to outweigh immediate pleasures. Finally, Mill seems only concerned with the pleasure and pain felt by humans. However, Jeremy Bentham, in developing an earlier version of utilitarianism, argued that the pleasure and pain of animals ought to be considered in the calculations. (Bentham's point is echoed by contemporary animal rights activists, notably Peter Singer, who argues that if pain is bad in humans, then it is bad in animals too [Singer, 1990].)

In refining his basic theory, Mill anticipates and answers several objections. An initial objection is that utilitarianism does not encourage what is truly valuable in human nature. So, his imagined critic might point out: "Is it not beneath the dignity of humans to chase after pleasure? We think that gluttons, drunkards, and those preoccupied with sex to be morally depraved — we certainly do not hold them up as models of right action" (Mill, 1966, p. 160). One component of Mill's answer is merely to note that some of these lifestyles will lead to painful consequences in the long term. But this answer leaves the basic thrust of the objection intact: Isn't it beneath the dignity of humans to chase after pleasure? Mill answers with a distinction between higher and lower pleasures. Lower pleasures are things like sex, drink, food, and laziness. Higher pleasures include reading literature, writing, viewing art, listening to music, contemplating philosophy, etc. Even performing moral actions can be a higher pleasure for certain individuals. A strict reading of the GHP implies that the only moral reason to prefer higher pleasures to lower pleasures is that higher pleasures are more pleasurable. Mill embraces this statement, claiming that the higher pleasures of the mind are indeed more pleasurable than the lower pleasures. As evidence for this, he claims that people who have been lucky enough to have experienced both sorts of pleasures almost invariably choose higher pleasures as the more desirable. So Mill said famously: "It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied" (Mill, 1966, p. 161). Mill's claim has fueled much debate about human nature: Is it true that people of sufficient means gravitate toward intellectual pleasure, and even if true, does this imply anything about the lesser value of lower pleasures — is reading Shakespeare really better than watching the World Wrestling Federation? At any rate, if we accept Mill's argument, then following the GHP will not require the pursuit of "swinely" pleasures, but rather the pursuit of the higher intellectual pleasures. In this sense, the GHP will promote what is dignified in human nature.

A second objection that Mill considered involves the time and effort that following the GHP would require. Mill seems to suggest that at any particular time a person



should consider all of the alternative actions that are available, should evaluate the short- and long-term consequences of these actions, and finally choose the action that has the highest net value. Even if we artificially limit the alternative actions available to three options, calculating the long-term consequences of these actions is a formidable task. Of course, there will be a good deal of uncertainty about what the likely consequences of the actions will be, but there will also be a good deal of information to sort through to attempt to trace out all the consequences of the three options. Utilitarianism, then, threatens to paralyze action in an endless fit of calculation. Mill offers a number of answers. He points out, first, that following the GHP does not require intricate calculations. Rather, most decisions about which actions will produce the best consequences involve only common sense. Second, echoing a theme from Aristotle, Mill argues that training the appropriate dispositions (such as the disposition to answer honestly when asked a question) is an important aspect of his theory. Once one has decided that being honest usually promotes the best consequences, then one trains oneself to be spontaneously honest (that is, without calculating consequences every time one is asked a question). Mill points out that most ethical theories could be interpreted in such a way that they paralyze action by requiring too much reflection — so he points out that Christians are not required to reread the Bible every time they face a decision (Mill, 1966, p. 178).<sup>\*</sup> Finally, Mill suggests that our actions will have the most of their consequences close to home. Theoretically, a decision I make today might have consequences for people in future generations and might have consequences for people I am unaware of on the other side of the world. But, generally, my decisions will have the most effect on myself, my family, my friends, and my colleagues. Also, generally, it will be easier to trace out the effects of my actions for this smaller group of people. Some of these decisions may require the careful balancing of potential good and bad consequences for this group of people, but the decisions do not require that the agent devote an extraordinary amount of time and effort to calculating how the action will affect persons in distant times and places.

Before turning to modern criticisms of Mill's *Utilitarianism*, it is important to introduce Mill's ideas from *On Liberty*, since these too have had a huge impact on political philosophy in the United States. Mill was concerned not only that a monarch would have too much power, but also that in the "democratic republic" of America the danger exists of a tyranny of the majority (to use de Tocqueville's term). In order to guard against this, Mill proposed his harm principle: "That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."

<sup>\*</sup> Mill, *Utilitarianism*, 178

Mill immediately clarifies the harm principle with an injunction against paternalism: A mature and competent person "cannot rightfully be compelled to do or forbear [any action] because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right." Mill defends these principles based on the recognition that institutions within society can be quite powerful, and that the only way to guard against inappropriate paternalism is to completely rule out all paternalism (although there is debate on this interpretation). Mill continues in *On Liberty* to further specify the types of liberties that are important to protect. There are three main categories: (1) "the inward domain of consciousness," which includes the "absolute" freedom to think, feel, and formulate opinions; (2) "liberty of tastes and pursuits," which is freedom in choice of personal lifestyles and practices as long as these do not harm anyone else; (3) freedom of association "for any purpose not involving harm to others." This "liberal argument" has been influential across the political spectrum in the United States. It also forms the core of many well-known Supreme Court decisions, including *Griswold v. Connecticut* (1965, birth control), *Roe v. Wade* (1973, abortion), and the dissent in *Bowers v. Hardwick* (1986, homosexuality).

### Criticisms and Evaluations

Despite its commonsensical nature, utilitarianism is open to a wide variety of criticism. First and most prominently, utilitarianism does not give a special status to categories of moral value that many people take to be of central moral importance. For example, utilitarianism does not seem to grant a special status to promises, to ownership rights, or to obligations arising from close relationships to family or friends, or to obligations relating to justice. For each and every category, it seems possible to imagine a situation in which utilitarianism would require that the moral value in question be overridden in the name of the common good. Consider the following example relating to justice:

A mob is chasing a man through town. They blame him for a murder, and they plan to brutally execute him if they capture him. The man happens to be innocent, as you know. However, you also know that if the mob does not capture and kill the man, then a riot will ensue in which many persons will be harmed and killed (some of those harmed and killed will be innocent, having nothing at all to do with the situation). It is in your power to save the innocent man from being stoned. Should you do it?

The gut reaction of many people to this case is that the innocent person should be saved regardless of the bad consequences — justice simply requires it. But utilitarianism seems to require that one allow the innocent person

to be killed. Utilitarians may attempt to answer the criticism by resisting the conclusion that utilitarianism requires allowing the innocent man to be killed. So, a utilitarian might argue that while the short-term consequences suggest that the innocent man should be killed, the long-term consequences of this decision include eroding society's commitment to the rule of law, which will in turn cause an increase in suffering, and these bad long-term consequences outweigh any short-term benefits of allowing the man to be killed. While this response is plausible enough, it is possible to manipulate the details of the example to exclude the possibility that the long-term bad effect of eroding the rule of law will occur — thus, in essence, painting the utilitarian into a corner in which she must admit that killing the innocent is justified by her theory. The utilitarian might then be forced into accepting the troubling result. Since it is possible to construct equally plausible counterexamples to utilitarianism about promise-keeping, truth-telling, ownership rights, obligations to family, etc., this manner of argument represents a strong challenge to utilitarianism. How persuasive such counterexamples should be is an interesting philosophical question, since the evidential authority of the counterexample ultimately relies only on the strength of one's gut reaction to the story and, one might argue, gut reactions are not to be universally trusted.

A second prominent criticism of utilitarianism is that it is too demanding. For example, utilitarianism seems to require too much personal sacrifice in order to promote the interests of other people. Consider that I have \$10 in my pocket that is uncommitted as far as my budget is concerned. I consider using the money to go to the movies tonight — I certainly would get pleasure from this, and there are no relevant constraints on my time. But, I reason, this money could also be used to benefit other people — it might even save lives if contributed to Oxfam or some other worthwhile charity. Utilitarianism seems to require that I give the money to Oxfam. Now perhaps this particular sacrifice is morally obligatory, but notice that if tomorrow I again find myself with an unencumbered \$10, I would again be obligated to donate the money, and so on, and so on. I would only be entitled to use the money for myself (or my family and friends) when it becomes the case that the happiness I can create close to home is greater than (or equal to) the happiness I can create by donating the money. Even if we lived in a world in which the inequities between rich and poor were much less pronounced, one might wonder whether a person is morally required always to spend his money (and his time) in a way that produces the most good, regardless of how it affects himself and his loved ones. These issues have led to a spirited debate about the level of self-sacrifice that can legitimately be required by an ethical theory. Notice that even minimalist ethical theories, such as libertarianism, require some self-sacrifice in the name of morality,

since libertarians hold that one must refrain from harming others even if harming another would benefit oneself. Peter Singer, inspired by utilitarianism, is at the other extreme, arguing that people in wealthy Western countries have an absolute obligation to dramatically lower their standards of living in order to benefit people in developing nations (Singer, 1977). Mill attempted to ameliorate the concern that utilitarianism demands too much personal sacrifice both by noting that one's resources are more efficiently used close to home (perhaps that was true in his day), as well as by pointing to the hedonist's paradox, which is the view that a person cannot obtain happiness by aiming directly at it, but rather truly happy people have as their goal something outside of themselves (Mill, 1966, p. 172). So it is likely that some self-sacrifice will indeed make us happier.

A third criticism of utilitarianism is that it requires a person to sacrifice his or her integrity. This criticism has been developed by Bernard Williams. Williams asks us to consider the following case, which I paraphrase:

George, a chemist, has been offered a job in a research facility for chemical and biological weapons. Despite his best efforts, George has been out of work for some time, and his young children have suffered greatly under the strain placed on the family. George does not feel he can take the job, however, given that he is a committed pacifist who has always been against chemical and biological weapons. The person offering George the job says that she, too, is against such weapons: in fact, she has offered George the job in part because of his beliefs; other candidates for the job will enthusiastically push the work along at a faster pace, while George will likely drag his feet. Should George take the job? (Williams, 1977, pp. 97–98)

Utilitarianism would seem to require that George take the job. The point of Williams' story is not merely that George is being required by utilitarianism to do something that most of us would agree is wrong. Rather, Williams is trying to show that utilitarianism is incompatible with the commitment to integrity, something central to the identities of many of us. George has identified himself with pacifism — it is part of his self-image. Maybe George initially embraced pacifism for utilitarian reasons — because he felt it brought about the most good — but being a pacifist is now George's central project; it is who he is. But whether pacifism actually causes the best consequences depends not on George, but on facts in the world, and depending on how these facts change, George at any moment could be required to act contrary to his central, defining project. At any moment, he could be required to live a lie. Williams explains:

The point is that [George] is identified with his actions as flowing from projects and attitudes which in some

cases he takes seriously at the deepest level, as what his life is about.... It is absurd to demand of such a man, when the sums come in from the utility network which the projects of others have in part determined, that he should just step aside from his own project and decision and acknowledge the decision which utilitarian calculation requires. It is to alienate him in a real sense from his actions and the source of his action in his own convictions.... It is thus, in the most literal sense, an attack on his integrity. (Williams, 1977, 132)

According to Williams, the only project that a utilitarian can be fully committed to without putting his integrity at risk is the project of being a utilitarian. But, Williams argues, this project is too thin, too formalistic, to be a central commitment or life's project. To use another of Williams' well-known examples, one should perform acts that demonstrate love for one's romantic partner out of a genuine love for one's partner, not because demonstrating love for one's partner creates, in the long run, the best consequences for all of humanity.\*

One strategy utilitarians have adopted in response to all of the criticisms mentioned is to move from act utilitarianism to some type of indirect utilitarianism. Act utilitarianism says that one should evaluate which act brings about the best consequences. Indirect utilitarianism is still interested in the best consequences, but it focuses on other mechanisms for bringing them about. For example, rule utilitarianism says that an action is morally right if and only if that action is required by a *set of rules* the adoption of which would produce the best consequences. The rule utilitarian advises that one should follow the set of rules identified, even though in isolated instances following a rule will not bring about the best consequences. Rule utilitarians think that the benefit (in good consequences) of having a stable set of rules outweighs the cost (in bad consequences) of occasionally performing non-optimal actions. Another form of indirect utilitarianism is character utilitarianism, which holds that performing an action is morally right if and only if that action promotes or is promoted by a *set of character dispositions* the inculcation of which would produce the most good or value for the members of a society. Once again, virtue utilitarianism identifies the occasional non-optimal action as morally good in order to gain the benefit of allowing persons to internalize content-rich dispositions and commitments

\* Mill considers and responds to a very similar criticism. He considers the criticism that "It is often affirmed that utilitarianism renders men cold and unsympathizing; that it chills their moral feelings towards individuals; that it makes them regard only the dry and hard consideration of the consequences of actions." *Utilitarianism*, 174. Mill argues that all moral theories sometimes require one to ignore bonds of love, and thus utilitarianism is no better or worse in this regard than other theories. Mill also draws a distinction between a standard of right action and the motivations for pursuing right action. He claims that his theory is meant to address only the former issue.

(such as George's commitment to pacifism). As a final example, rights utilitarianism holds that performing an action is morally correct if it is in accord with a scheme of *individual rights and liberties* the adoption of which would produce the most good for society. The distinction between direct and indirect utilitarianism post-dates Mill, but passages in Mill's *Utilitarianism* have been interpreted as advocating forms of indirect utilitarianism.

A second strategy for meeting the criticisms involves modifying the definition of good consequences. Utilitarianism is the name for the view that seeks to maximize pleasurable feelings and minimize painful feelings. Consequentialism is a broader category that recognizes that there are many different accounts of what "good consequences" are. So, preference satisfaction consequentialism states that one should maximize the satisfaction of preferences (whether or not such satisfaction also maximizes pleasurable feelings). A second example is objective list consequentialism, which identifies a list of goods (such as friendship, knowledge, veracity) such that persons should seek to maximize the obtaining of goods on the list (such a view requires a scheme for trading-off between the goods, as when a gain in friendship requires a loss of veracity). At the center of Mill's utilitarianism is the claim that only consequences matter in moral evaluation. It is possible to hold firm to this central claim, and yet modify significant aspects of the theory. This means that consequentialist theories of ethics may have the resources, despite first appearances, to answer the sorts of criticisms that have been leveled at them.

Many of Mill's ideas are directly relevant to health care ethics. Although Kant is more often seen as the champion of autonomy and informed consent, Mill's arguments in *On Liberty* also provide justification for these ideals. In addition, consequentialism is at base the method presupposed in cost-benefit analysis, and thus is at the heart of many policy decisions. Indeed in some ways consequentialism seems more appropriate for policy decisions made at an institutional level than it does for guiding individuals in their personal decisions.

But perhaps Mill's ideas have been most influential in debates about care at the end-of-life. Mill believed that no category of action is intrinsically morally good or bad — the morality of an action depends on its consequences, not on the type of action that it is. This has important implications for end-of-life decisions. For example, in the early 1980s a not uncommon view was that withholding treatment is permissible in certain circumstances, but withdrawing treatment is never permissible (Cugliari & Miller, 1994). The idea was that withdrawing life-sustaining treatment is a category of action that is tantamount to killing. Consequentialists, on the other hand, were less concerned about the category (withholding or withdrawing) and more concerned with the consequences of doing either in a particular situation. They argued that the cat-

egories themselves have no moral relevance: only the consequences of individual actions (or omissions) have moral relevance. As we know, the utilitarian position on this issue has been adopted in current medical practice (although there are dissents [Sulmasy & Sugarman, 1994]). A very similar debate occurred around withdrawing medical nutrition and hydration in the late 1980s, prompted primarily by the Nancy Cruzan case (Lynn & Childress, 1983). Some argued that providing food and water is a special category of action required by morality (Callahan, 1983). Others argued that if the best thing for someone is that she be allowed to die, then it did not matter whether this occurs because food and fluid is withdrawn or because another intervention such as a ventilator is withdrawn. Here, again, the position consistent with utilitarianism has been adopted.

The reader will have already surmised that the story is not over yet. Consequentialism tends to undermine the moral relevance of the distinction between killing and allowing to die. But this distinction is very important in current law and medical practice. In every jurisdiction in the United States, practitioners may allow a patient to die by withholding or withdrawing treatment. But in every jurisdiction in the United States, except Oregon, practitioners cannot kill their patients or assist patients in killing themselves. This means that extubating a terminally ill patient who is in great pain and has requested to be allowed to die is permissible, even if one knows that death will occur with extubation. But it is not permissible to kill a patient who is in identical circumstances except that he has no respirator to remove. Imagine that the consequences for the patients (and others) in each case are identical: the consequentialist would argue that if it is good to omit treatment in the first case, then it is also good to kill the patient in the second case (Rachels, 1975, 1986). But this consequentialist viewpoint has yet to be adopted, and it looks as if popular opinion is moving in the opposite direction (Emmanuel XXXX). One note of caution, here, is that there are also consequentialist arguments against active euthanasia and physician-assisted suicide, most prominently the concern that the long-term effects of legalizing active euthanasia and physician-assisted suicide will include eroding society's respect for human life in general.

## HEALTH CARE ETHICS

### PRINCIPLES IN HEALTH CARE ETHICS

The most prominent way of organizing consensus on ethical issues in health care into a usable methodology is the principles method. The principles method identifies a small number of general rules, and subsumes more particular and concrete obligations under the general rules. A number of authors use principles to develop a method-

ology for identifying and resolving ethical conflicts that arise in clinical settings (Veatch, 1981). The best-known principles method is that of Tom Beauchamp and James Childress, *Principles of Biomedical Ethics*, now in its fifth edition (Beauchamp & Childress, 2003). Beauchamp and Childress identify four principles:

1. *Beneficence: One's actions ought to benefit the patient.* Health care providers perform actions in order to improve a patient's health, prevent disease, or generally enhance a patient's welfare. This is a positive duty, that is, a duty to perform actions. Under this principle, Beauchamp and Childress discuss paternalism, suicide prevention, futility, risk-benefit assessments, quality of life, and other topics.
2. *Nonmaleficence: One's actions ought not to harm the patient,* inspired by *Primum non nocere* (First, do no harm) from the Hippocratic oath. This is a negative duty, that is, a duty to refrain from certain actions. Under this principle, Beauchamp and Childress discuss withholding and withdrawing life-sustaining treatments, physician-assisted suicide, double effect, surrogate decision making, and other topics.
3. *Respect for Autonomy: One should respect a patient's authority to make decisions about his or her health care.* Persons have a basic right to make decisions about their lives and bodies. This is both a negative and positive duty. One should refrain from actions that diminish a patient's autonomy. One should perform actions that enhance a patient's autonomy; in particular, one should provide a patient the tools and support necessary to make good decisions. Under this principle, Beauchamp and Childress discuss informed consent, competency, disclosure, coercion, and other topics.
4. *Justice: One must fairly balance the interests of all the parties affected by a decision.* Under this principle, Beauchamp and Childress discuss resource allocation, rationing, rights to health care, ageism, racism, sexism, and other topics.

A common misperception about Beauchamp and Childress's method is that they offer only general principles as guidelines for resolving clinical disputes. These general principles are viewed as being not very helpful in resolving concrete and particular disputes. In fact, Beauchamp and Childress present general principles, such as respect for autonomy, and then use the principles to derive more specific rules that provide concrete recommendations. For example, Beauchamp and Childress present a detailed set of guidelines regarding procedures for obtaining informed consent under the category of Respect for Autonomy.



A close look at the principles reveals that they are grounded in some of the ethical theories that we have discussed. Respect for autonomy has a decidedly Kantian flavor, particularly because Beauchamp and Childress understand respect for autonomy as requiring both negative and positive duties, which correspond roughly to what Kant called perfect and imperfect duties. For Kant, autonomy did not mean the mere freedom to do as one wishes, but rather the capacity to use one's reason to make good decisions. This can be seen in Kant's explanation of both perfect and imperfect duties. Kant held that we have a perfect duty to refrain from certain actions because these actions interfere with the exercise of a person's autonomy. For example, lying to an individual robs her of the opportunity to make the best decision possible by keeping relevant information from her. Kant also held that we have an imperfect duty to help individuals make good decisions. Thus, Kant explains that the reason we must help someone in need is not only to make the person happier, but also to help support the ability of the individual to make autonomous decisions (O'Neill, 1977). Likewise, for Beauchamp and Childress the purpose of the procedures for obtaining informed consent are not merely meant to protect the freedom of the patient, but also to help the patient make the decision that is best for him or her.

Benevolence is grounded in utilitarian ethics. The idea is simply that health care providers should have the best interest of the patient at heart. Indeed, this may be one of the primary reasons that people go into health care ethics, the desire to help others. Benevolence has been associated with paternalism, the view that one should do what is good for the patient regardless of whether the patient is aware of what is being done and regardless of whether the patient desires what is being done. While Mill is himself decidedly antipaternalistic, utilitarianism, theoretically at least, could justify over-riding rules meant to protect patient self-determination in the name the patient's best interest. While this may make benevolence seem like a sinister principle, one should also recognize that the desire to do good for others has motivated many noble actions.

The most important criticism of Beauchamp and Childress's methodology involves the balancing of principles in cases of conflict between principles. Beauchamp and Childress say that their principles are *prima facie* binding (Beauchamp & Childress, 2003, p. 19–24). This means that following each principle is a moral requirement unless two or more principles are in conflict. Of course, in almost all difficult cases there are at least two principles that conflict with each other — that is primarily what makes a difficult ethical decision difficult. When two principles conflict with each other, Beauchamp and Childress say that one must balance the principles. This means, in effect, that one must decide which principle is the most important in this case, and resolve the dispute in favor of this principle. Unlike some authors who adopt a principles

approach,\* Beauchamp and Childress do not set up the principles in a hierarchy such that one principle always “trumps” another principle. Rather, any of the four principles could be the most important principle in any particular case — it is up to clinicians to use their judgment to make a decision about which principle “wins” in the case.

In their treatment of many issues, Beauchamp and Childress try to do this balancing in advance. That is, they consider potential conflicts between principles, raise arguments on both sides, and then specify which principle ought to be considered most important in that case. To take a simple example, if a person shows up at an emergency room in need of medical attention, but is not competent to express a preference about receiving treatment and no other information about the person's desires are available, then the ER staff is authorized to provide medical treatment even if the treatment carries some risks with it. In this case, the principle of beneficence (to act in the patient's best interest) is more important than the principle of respecting autonomy (to not treat a patient unless she consents). A second example involves telling a patient the truth about his cancer diagnosis. A clinician might feel that telling the patient the truth will increase his depression and perhaps accelerate the disease process. Beauchamp and Childress suggest the patient needs to know the truth to freely choose a treatment and to plan for the next period of his life, and this is more important than the likely worsening of depression. Respect for autonomy is more important in this situation than beneficence (and perhaps also nonmaleficence). Just because a principle is deemed of secondary importance, however, does not mean that the principle lacks all importance and that steps cannot be taken to ameliorate any problems from the partial disregard of that principle. In the last example, the practitioner could be careful to provide the diagnosis in as gentle and reassuring a manner as possible, as well as be vigilant to treat the depression as medically indicated.

In many situations of conflict, however, it is impossible to do the balancing of principles in advance. This has led to the criticism, made by primarily by K. Danner Clouser and Bernard Gert, that Beauchamp and Childress do not provide any real help in resolving situations of conflict (Clouser & Gert, 1990; Clouser, Gert & Culver, 1997). In essence, the criticism is that all that Beauchamp and Childress have done is provide some very general labels for moral values that everyone accepts. In difficult cases these labels do little good. Rather, in difficult cases it is up to the clinician to decide which values are most important, and it is in coming to this decision that all of the substantive ethical reasoning is performed. Thus, so the criticism alleges, the Beauchamp and Childress method for identifying the correct action in difficult cases

\* For example, Veatch, R. *A Theory of Medical Ethics*, Georgetown University Press, Washington, 1981

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fails to achieve its goal, for in these cases it offers no answer at all.

Beauchamp and Childress defend themselves not by backing away from the *prima facie* nature of their principles, but by offering criteria to make balancing less “intuitive and open-ended”:

1. Better reasons must be given in favor of the overriding principle.
2. The moral objective for infringing a principle must have a realistic prospect of achievement.
3. The infringement of a principle must be the least possible commensurate with achieving the primary goal.
4. The negative effects of the infringement should be minimized.
5. The decision must be made in an impartial manner. (Beauchamp & Childress, 2003, p. 19–20)

Whether or not these steps are enough to answer the criticism raised by Clouser and Gert, their criticisms have highlighted an alternative set of methodologies for resolving ethical disputes in clinical settings.\*

## OTHER METHODOLOGIES IN HEALTH CARE ETHICS

The alternatives to principles that I discuss are virtue theory, casuistry, and the ethics of care. Interestingly, these approaches to clinical decision making do not identify moral duties that are uncontroversial in their application and thus less open to interpretation than is Beauchamp and Childress’s method of balancing. Rather, these alternatives embrace discretion and very open-ended methodologies in ethical decision making. Their common theme is that if discretion cannot be eliminated from ethical decisions, then methods for decision making ought to admit to this, rather than offering principles that promise but do not deliver definite answers. I should be clear, however, that these alternatives are not thereby accepting ethical relativism — the view that a person’s belief that an action is morally correct is sufficient for the action to be morally correct. Rather, the alternative theories hold that morality is objective, that is, there is a correct answer to a moral question that arises in a particular situation. The alternatives simply hold that principles are not the best way to identify this answer; rather, individuals should trust in other means to arrive at the objectively correct answer.

### Virtue Theory

In Aristotle’s ethics we have already examined some of the central themes of contemporary virtue theory. Virtue

theorists emphasize the importance of moral experts to discern the morally relevant features of a situation. Further, such experts use judgment and skill to respond to the moral problem, rather than reaching decisions based on rigid and overly simple sets of rules. The best-known advocates of virtue theory in health care ethics are Pellegrino and Thomasma (1988, 1993). Using a decidedly Aristotelian methodology, Pellegrino and Thomasma argue that medicine is a distinct human activity that has its own ends, goals, and purposes. From the purposes of medicine, Pellegrino and Thomasma derive the virtues required of those who would practice medicine: fidelity to trust, compassion, *phronesis* (practical wisdom), justice, fortitude, temperance, integrity, and self-effacement. The physician who embodies these character traits to a high degree is an exemplary physician, and these traits will guide him or her in her moral decisions. Again borrowing a page from Aristotle, Pellegrino and Thomasma downplay the importance of formal education in ethics, citing instead the importance of developing a virtuous character in the actual practice of medicine as a result of working “in the trenches” with senior members of the profession who are role models for virtue. Pellegrino recently appealed to some of these themes in an editorial on Iraqi physicians’ complicity in torture. Criticizing the claim that education in ethics would have helped Iraqi physicians resist complicity, Pellegrino writes:

This tendency to see education as a panacea is a common misconception. Rarely do courses in ethics make one virtuous. Nor does extensive familiarity with the intricacies of moral discourse guarantee moral wisdom.... More than education is needed. Character formation is, in the end, the surest way to inculcate the virtues. This cannot occur unless the culture of the profession is itself ethically rigorous. Even the most virtuous physicians need a supportive culture to remain virtuous. (Pellegrino, 2004, 1505–1506)

While virtue theory as developed by Pellegrino and Thomasma may rely the judgment of moral experts, virtue theory in their interpretation does not deny that there are objective moral truths by which practitioners must abide. In fact, in their emphasis on beneficence at the expense of respect for autonomy, their theory tends to underwrite a fairly conservative position on substantive moral issues such as active euthanasia and physician-assisted suicide. Simply put, Pellegrino and Thomasma argue that these actions are contrary to the ends, goals, and purposes of medicine.

### Casuistry

Casuistry is the method embraced by some leaders in the field of health care ethics, particularly Albert Jonsen (Arras, 1991; Jonsen & Toulmin, 1988; Jonsen, Siegler & Winslade, 1998). Casuistry is the view that past cases are

\* For an overview of the debate, see Davis, R.B., The Principlism debate: A critical overview, *Journal of Medicine and Philosophy* 20, 85-105, 1995.

the repository of ethical knowledge. One decides a current case by judging that it is similar in all relevant respects to an earlier case, and applying the decision from the earlier case to the current case. This is essentially the system of identifying precedents used by judges in the legal system. This type of ethical reasoning requires careful analysis of the similarities and differences between cases, and judgments about which similarities and differences are ethically relevant and which are not. Casuistry has a number of features to recommend it. First, health care providers may already use this form of reasoning in their clinical practice, comparing a current patient to earlier ones. Second, case presentation is typically an interesting and effective type of learning. Third, it is *de facto* the way in which much of health care ethics is taught. Consider Tarasoff, Quinan, Cruzan, Donald “Dax” Cowart, Timothy Quill’s patient Diane, Barney Clark, Kimberly Bergalis: each name brings to mind a set of issues and lessons learned. Casuistry has a number of limitations, however. First, knowledge of a wide range of cases in health care ethics takes some time to acquire. Second, casuistry is somewhat conservative (i.e., resistant to change and reform), since it relies on the assumption that past cases were decided correctly. Third, federal, state, and institutional policies cannot merely reference past cases, but must be written in the form of rules, thus reintroducing principles into health care ethics. Nevertheless, casuistry may be an important supplement to a methodology that also includes ethical principles (Toulmin, 1981).

### The Ethics of Care

The ethics of care is an important strand of the vibrant and growing field of feminist ethics. The term *ethics of care* was first coined in 1982 by Carol Gilligan (a clinical psychologist) in her book, *In a Different Voice*, where Gilligan argues that many women frame moral issues and problems “in a different voice” from many men (Gilligan, 1982). According to past research in moral development, many men frame moral issues as matters of conflicting rights and obligations, and questions of justice and fairness. Gilligan found, however, that many of the women she studied resisted understanding moral problems this way. Instead, the women focused on issues of caring and relationships: whether a relationship should be continued, and if it should how best to care for and meet the need of the members of the relationship. While Gilligan’s empirical findings and their connection with gender have been the subject of much controversy, it is clear that her articulation of a care-based moral outlook as an alternative to the predominant justice-based moral outlook has struck a chord with many contemporary writers on ethics (Carse, 1991; Little, 1998). Gilligan and subsequent writers on the ethics of care have argued that the justice-based view overlooks many important facets of the moral life. The

care ethic, on the other hand, brings these features sharply into focus. For example, whereas the justice ethic assumes that moral situations involve free, equal, autonomous, and independent individuals, the care ethic emphasizes that in many cases these features of a relationship do not obtain. Individuals often find themselves embedded in relationships in which the members are unequal, where some of them are not fully autonomous, or fully free, or fully independent of the other members. Surely, the care ethicist argues, morality pertains to the parent–child relationship, where the individuals are not equals, not fully independent or free of one another, and moreover one of the members of the relationship may not be autonomous. Similarly, many feminists have argued that the abortion debate has become intractable precisely because the two “individuals” involved (mother and fetus) are viewed as free, equal, autonomous, and independent individuals. Whatever position one takes on abortion, it is argued, one should not understand the involved parties as the justice framework does: the fetus is metaphysically a *relational* being — it simply cannot survive (prior to 22 weeks of age) outside of a woman’s body.

The ethics of care has made important contributions to health care ethics. For example, some ethicists of care have emphasized that the patient–provider relationship may not be best understood on the consumer model, where the consumer is a free and equal member of the relationship, contracting for a certain service in exchange for a monetary fee. Instead, some ethicists of care have reminded us that serious illness causes fear, anxiety, and some dependency, even in otherwise autonomous adults. Moreover, the relationship between patient and health care provider is necessarily a relationship among unequals: the health care provider is far more knowledgeable about medicine and disease than the patient, while the patient is far more knowledgeable about her life as a whole and the values she holds. Pointing all this out also makes it clear that the members of this relationship have special responsibilities to one another. The health care provider ought to acknowledge and respond with caring to the vulnerability and anxiety of her patient. The patient on the other hand ought to be open and honest with her care provider.

There are some limitations to the ethics of care. For one, some defenders of the justice perspective have wondered whether the care ethic represents a distinct moral perspective or simply an addition to the justice perspective. For another, it is clear that some moral problems, even ones in relationships of unequals (e.g., child abuse) are better viewed in the justice perspective. Other moral situations are better viewed through the lens of care. However, it is not always — or even often — clear which lens to use. Indeed, as I pointed out above, some feminists think that abortion should only be viewed through the lens of care. But this point is contentious, and as of the moment, there appears to be no clear way to determine

which framework to use to grapple with a particular moral problem. Nevertheless, the choice of one framework over another will often point toward one resolution or another. So the choice is a deeply normative one, but one without clear criteria to guide it.

### ISSUES IN PALLIATIVE CARE

Some ethical issues tend to arise more frequently in the context of providing palliative care. These issues include (1) the moral status of the decision to forgo life-prolonging treatment, (2) informed consent and truth-telling, and (3) the interplay of curing and caring as the goals of medicine. I want here to sketch how some of the authors we discussed would respond to these issues, although I would also caution that my sketch is brief and programmatic, and that there is significant room for disagreement in the interpretation of the historical figures on these issues.

#### The Moral Status of Decisions at the End-of-Life

Laws, codes of professional ethics, and public opinion generally draw a distinction between withholding/withdrawing life-sustaining treatment and “active” means of ending life such as physician-assisted suicide or the administration of large quantities of opiates with the intention of ending life. We have seen that a consequentialist approach to ethics would tend to undermine the moral relevance of this distinction between what has been called passive and active euthanasia. For example, Mill holds that only the consequences of an action (or omission) matter to the moral goodness of the action. As long as there were no long-term bad consequences for society, Mill might favor having the legal option of ending a terminally ill patient’s suffering more quickly than merely withdrawing life-sustaining treatment would allow. This position would also be supported by Mill’s arguments against paternalism, as expressed in *On Liberty*. Nevertheless, there are limitations to how far Mill might be willing to take this position. For example, if adequate pain management is available, it is a least theoretically possible for him to argue that the long-term costs to society (in the erosion of an ethic of respect for life) would outweigh any benefits to the particular patient. However, while this type of slippery slope argument is often mentioned in contemporary debates, I think it is unlikely that Mill would avail himself of it.

Deontologists, such as Augustine, Kant, and Aquinas, are much more likely to hold that the distinction between passive and active euthanasia is morally relevant, in part, because the distinction between intrinsically wrong and permissible types of actions is central to their theories. Each theorist also holds that suicide is intrinsically wrong. Kant seems to hold that one cannot protect autonomy by ending human life — if life is over, there is no chance to

be autonomous. It is unclear whether Kant would also hold that withdrawals of treatment that result in death also are inconsistent with protecting autonomy. Augustine and Aquinas, however, would recognize that withdrawing treatment in some circumstances is consistent with the good of the patient, since it is merely allowing the natural process of death to occur. Aquinas would invoke the principle of double effect to show that it is permissible to give pain medications, even with the risk of hastening death. The limit on this practice would be when the pain medication is given at such a dose that it constitutes a poison such that death is intended and/or the relief of pain is accomplished only by the death of the patient.

#### Informed Consent and Truth-Telling

Kant is often taken to be the inspiration for the modern doctrine of informed consent. Indeed, Kant not only believes that there is strict requirement not to lie to patients about their prognosis, but he would also hold that health care providers have an obligation to fully and truthfully provide information to patients to allow them to make decisions about care at the end of life — not to do so is to fail to respect the patient as a person. Kant would deny that a health care provider is required to follow every instruction given to her by a patient — a health care provider is not compelled to act contrary to the categorical imperative. But if a health care provider refuses to follow patient instructions as a matter of conscience, this too must be fully and truthfully disclosed to the patient. It is fair to say that Kant would require a good deal more transparency in communication between patients and care providers than is now the case in many institutions.

Theoretically, it is possible that Mill might think it best to lie to a patient to alleviate the patients’ suffering. However, given Mill’s extremely negative assessment of paternalism, it is more likely that Mill would see the potential for harm in lying to outweigh values from ameliorating depression. Indeed, Mill might worry that deceit would be likely to increase suffering as patients began to recognize inconsistency in their health care providers behaviors regarding their care.

#### Curing and Caring

Health care professionals have obligations to attempt to *cure* patients of disease (and repair their injuries), as well as to *care* for patients who are experiencing pain and suffering. Mill is the only philosopher that we have discussed that emphasizes the badness of physical pain. Indeed, rather starting with the idea that some pain is useful (e.g., to keep us from danger, to teach us fortitude) as some philosophers do, Mill is clear that pain is always bad. For Mill, an episode of avoidable pain is to be tolerated only if (1) it prevents worse pain in the future or (2)



it will produce or allow for a stronger feeling of pleasure. In this sense, Mill's philosophy fits well with the goals of palliative care, which recognizes that most if not all of a patient's pain should be ameliorated in the context of caring for those with life-threatening illnesses.

Last, Aristotle's ethics complements palliative care's emphasis on caring for the emotional needs of the patient. As we have seen, Aristotle holds that an essential part of being morally good is experiencing the appropriate emotion in response to a situation. This might mean that a care provider's laugh at a patient's joke is genuine, allowing the patient a moment of respite in an otherwise difficult day. It might mean that a care provider knows how to comfort a patient, even in the midst of a very quick and efficient visit. Aristotle is clear that feeling the appropriate emotion is important to discerning the appropriate action: unless one feels compassion, one cannot "see" the right way to be compassionate in a situation. One need not think of this as some magic new ability to see occult objects. It might only mean that one has a subtle understanding of a patient's fears, so that one is sensitive to language that might raise these fears. This sensitivity may be a physical rather than intellectual. To change examples for a moment, think of one's response to an offensive, racist joke — the first reaction is in the body, a cringing, a clenching of the stomach, and only then does one consciously think of the words of the joke and explain to oneself why it is offensive. Likewise, one might be so "tuned-in" to one's patient that the knowledge that he needs some particular object is simply felt, rather than resulting from a minute of problem-solving deliberation. Feeling (rather than feigning) emotions is important for another reason as well. Persons with life-threatening illnesses, like the rest of us, are very good at picking up subtle inconsistencies between affects, behaviors, and spoken words. Telling a patient one thing, while one believes another, is likely to raise the anxiety level of the patient as he picks up on these inconsistencies. The patient may not be able to recognize that the care provider is lying, but he will nonetheless be left with the vague feeling that "something is not right."

### CONCLUSION ON THE PERSONAL IMPORTANCE OF ETHICAL THEORY

Too many people associate ethics with a code of conduct that necessarily involves the significant sacrifice of one's own well-being in order to benefit others. People with negative views about ethics then tend to view ethics as a cage: the bars of the cage are the ethical rules that keep one from acting in one's own self-interest. I believe this view of ethics is dangerous and inaccurate. It is dangerous because it tends to drive people away from ethics. It is dangerous because even for those who would embrace

ethics, it is an ethics of self-denial and martyrdom, an ethics that encourages guilt and moralism. The ethics-as-self-sacrifice view is inaccurate because most ethical theories identify moral obligations to enhance one's own well-being, and some moral theories (such as Aristotle's and Kant's) take the enhancement of one's own well-being to be the central ethical project. A better way to understand ethics is as a tool that helps one create the sort of life of which one can be proud. Everyday each of us makes decisions that constitute who we are now and that influence what sort of person we will become. While we do not often think of decisions in these terms, it would be a tragedy to come to the end of a long life and be unable to look back with pride and pleasure at the life we have created with these decisions. And it is a rare person who would not wish to see kindness, compassion, generosity, trustworthiness, and integrity as parts of this life. A better metaphor might be that ethical theories are maps that identify desirable locations to visit and that show the best paths to these destinations. To that end, we should view Aristotle, Mill, and Kant not as providing theories that narrowly tailor our actions in the name of the rights and interests of others, but as providing theories that describe ways of life that are worth living.

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# Ethics: History and Theory

*Frank Chessa*

## INTRODUCTION

Many health care providers are familiar with the basic concepts of health care ethics — surrogate decision-making, advance directives, do not resuscitate (DNR), withdrawal of treatment, confidentiality and informed consent have become need-to-know terms in the practice of medicine and nursing. Likewise, I expect many health care providers are familiar with the basic principles of health care ethics, including nonmaleficence, beneficence, respect for autonomy, veracity, and justice. What is perhaps more rare among practitioners is an awareness of how health care ethics is connected to the history of ethics and ethical theories more generally. Yet knowledge of the ethical traditions that have influenced health care ethics may help practitioners in a number of ways: (1) it may help practitioners extend well-known principles to novel cases; (2) it may help practitioners articulate why they have reached a conclusion about the ethics of a particular case; and (3) it may deepen practitioners' commitment to ethical values of their profession. This chapter seeks to bridge the gap between health care ethics and the traditions from which these ethics emerge.

This chapter also briefly surveys some ethical issues that are especially relevant to palliative care. Other chapters in this volume treat these issues in more detail. Here, the focus is on showing how the history of ethics is relevant to the ethical issues that arise with particular acuity in palliative care. It is not under the purview of this chapter to expand the discussion beyond Western ethical traditions, although non-Western traditions are increasingly important to consider as more persons from various world cultures are served by, and practice

within, health care institutions in the United States and Britain.

There is also a good deal in the history of Western ethics that could not be covered in this chapter. In part this is because many great minds who have written about ethics — including just a paragraph on each would have made this chapter too long. I have instead chosen to focus on six philosophers: Plato, Aristotle, Augustine, Thomas Aquinas, Immanuel Kant, and John Stuart Mill. Of these six, Aristotle, Kant, and Mill are given the most attention because their theories are the most relevant to health care ethics. I should also note that it is not possible to consider every facet of the theories of these philosophers. Indeed, not only have these philosophers each written thousands of pages, but each is the subject of countless books and articles. In my inevitable narrowing of this material, I have selected topics that either have had a direct influence on health care practitioners or that raise issues that may be of interest to health care practitioners. My hope is that this will serve to make the current chapter different from other surveys of the history of ethics in a way that will prove useful to the health care providers likely to read this volume.

The first section of this chapter, by far the largest, is a chronological survey of the views of the ethical theorists. For each philosopher, I have provided biographical information, a sketch of his theory, prominent criticisms of the theory, and a discussion of the ways in which the philosopher's ideas emerge in current debates in health care ethics. The second section discusses how the historical theories relate to various methodologies in contemporary health care ethics (e.g., the ethics of care, casuistry). The second section also draws some parallels between three ethical issues in palliative care and the history of ethics.

## ETHICAL TRADITIONS

### SOCRATES AND PLATO

It is appropriate to begin a discussion about the history of Western ethics with Socrates and Plato. Socrates was born in Athens around 469 B.C. and, famously, he died in 399 B.C. by drinking hemlock under order of the Athenian court. Plato (428–347 B.C.) immortalized his teacher in a series of dialogues that portray Socrates as a martyr for his ethical beliefs. Among Plato's 26 surviving dialogues are some of the first examples of extended ethical reasoning in the Western tradition. Plato's dialogues explore a range of moral (and nonmoral) issues, from the proper way to be religious (*Euthyphro*), to suicide (*Phaedo*), to civil disobedience (*Crito*), to political organization (*Republic*), to love (*Symposium*).

A good example of a Platonic dialogue focused on a moral issue is *Crito*. In *Crito*, Socrates faces the question of whether to accept death as punishment for corrupting the youth of Athens or whether to escape into exile. Escape was probably the outcome expected by Socrates's accusers, as this was a common practice and Socrates had the means to accomplish it. Socrates argues (to his friend Crito, who wishes him to escape) that although he is innocent of wrongdoing, and although the state is acting unjustly in prohibiting him from teaching philosophy, he nonetheless owes Athens a debt for raising and protecting him, and thus he should not escape (51d).<sup>\*</sup> To escape would be to weaken the state, while all of his prior activities were aimed at strengthening Athens. Socrates does not escape and soon after this dialogue takes place, he is executed, with all of his friends present and weeping openly for the loss of their great friend and philosopher. (*Phaedo*, 115b–118) Plato's *Crito* presages modern views about civil disobedience: civilly disobedient actions are morally permissible if their intention is to reform unjust laws, if the actions are performed openly, and if the actors are willing to accept punishment. What emerges in *Crito* is the idea that the aim of civil disobedience is to reform a state, not to overturn it, and that those who are civilly disobedient are among the heroes of society since they are willing to sacrifice their well-being for the good of the state. The Reverend Martin Luther King certainly fits this model.

Plato's moral reasoning sometimes relies on the conviction that there is an afterlife. In particular, Plato is explicit that how a person lives on Earth will influence his or her afterlife, so he posits "a much better future [after death] for the good than for the wicked." (*Phaedo* 63c) Plato is often interpreted as dividing the world into the

realm of appearance (the world as we experience it embodied on Earth) and the realm of reality (the world as it really is, which is accessible to us, if at all, only after we die). However, even while Plato's thought has these religious dimensions, his conclusions about particular issues rely on an astute reading of human nature as much as on theological reasoning. In *Euthyphro*, Socrates questions Euthyphro about his attempt to prosecute his father for murder. The primary moral failing of Euthyphro is not that he is attempting to prosecute his father for murder. Rather, this potentially immoral action is a symptom of a character flaw, namely, that while Euthyphro is good-hearted, he has a wildly over-inflated confidence about his knowledge of theology. Plato thus depicts the type of moral failing likely to arise from a lack of humility in otherwise praiseworthy persons.

One of the lasting legacies of Plato's thought is the idea that living ethically should be the primary goal of human life. We will also find this idea in the writings of Plato's greatest student, Aristotle, and it is to his thought that we will now turn.

### ARISTOTLE (384–322 B.C.)

Arguably, until relatively recently, the focus of modern ethics has been on the evaluation of actions. In contrast, Aristotle focused on the moral evaluation of a person's character, that is, on whether a person is virtuous or vicious. The focus on character evaluation is responsible for the popularity of virtue theory among contemporary ethical theorists (French, Uehling & Wettstein, 1988; Sherman, 1989). In particular, focusing on character has three advantages. First, action-centered theories seem not to account for the emotional dimension of our moral lives (Stocker & Hegeman, 1991). Aristotle held that feeling the correct emotion and being motivated by it are important components of having a virtuous character. Second, virtue theory is at home with particularism about right action (Dancy, 1993; McNaughton, 1991). Particularism holds that rules and general principles are not much help in determining the morally correct action because real-life situations are simply too rich to be codified by general rules. Aristotle stresses correct perception of the features of a situation and wise judgment in figuring out what to do, rather than dependence on a set of rules. Finally, the focus on character has implications for how one learns to be moral. Modern advocates of Aristotle often view morality as a type of skill that is developed in the same manner as other skills (Little, XXXX). Learning a skill primarily requires practice, although it may also involve emulation of experts, expert critique of one's performance, and reflection on theoretical issues. So Aristotle was the first in the Western tradition to deny that there is a book of rules that can teach one how to be moral. In other realms, this view is familiar. Many of us think that

<sup>\*</sup> Quotations of Plato are taken from *The Collected Writings of Plato*, Hamilton, E. and Cairns, eds., The parenthetical references for Plato refer to ..., the standard method for citing passages in Plato across various translations.

there is no book that can teach even a physically talented individual to play basketball like Michael Jordan — his split-second judgments are too rich and varied to be codified. Why then do many of us nevertheless assume that there is a book on ethics that can teach us to be moral experts in the absence of practicing ethics in the rich context of everyday life?

Aristotle was born in 384 B.C. His father was a physician at the Macedonian court. Aristotle had a lifelong association with Philip of Macedonia and his son Alexander the Great. Aristotle studied with Plato for approximately 20 years at Plato's Academy in Athens. After Plato's death in 343, Aristotle moved to Macedonia to tutor the young Alexander before returning to Athens to found his own school, the Lyceum, in 336. After the death of Alexander the Great, Aristotle left Athens to avoid the political fallout from his association with the emperor. Aristotle died in 322 at the age of 62. Aristotle's writings were extensive, and although we have perhaps lost most of his published works, we are left with thousands of pages of carefully prepared lecture notes. His writings on ethics are contained primarily in the *Nicomachean Ethics*, on which we focus.

However, our discussion of Aristotle can begin not with ethics, but by sketching the theory of causal explanation that he outline in *Physics* (194b 20) (McKeon, 1941).<sup>\*</sup> Aristotle believed that understanding how any object came to be required referring to four factors: the material cause, the efficient cause, the formal cause, and the final cause. The material cause is the raw matter that makes up an object. For example, the bronze is, in this sense, the cause of the statue. The efficient cause is the energy that has molded the matter into a certain shape. So we also say that the sculptor is the cause of the statue. The formal cause can be understood as either the blueprint for the object before it is made, or the shape and organization of the finished object. For the statue, the blueprint may exist only in the sculptor's mind, but it nonetheless lays out the shape of the object to be created. The final cause is the purpose of the object. It is the reason for which the object is created, or the action is done. So we say that the woman walks in order to improve her health and that is the final cause of her walking. For another example, consider a pitcher for holding and pouring liquid. Its material cause might be clay. The efficient cause is the potter's spinning of the wheel and movement of her hands. The blueprint (which may only exist in the potter's mind) lays out the shape of the pitcher. The final cause of the pitcher is its purpose of holding and pouring liquid. An important aspect of this theory is that the formal cause

answers to the final cause — that is, the shape of the object fits the purpose for which the object was designed. Note also that there is interplay between separate causes. In designing an object to fulfill a purpose, we need to consider whether the material has the properties that will allow it to be fashioned into the shape needed and whether the energy is available to accomplish the change. Aristotle's theory is a good fit for explaining how human-made objects came into existence. But Aristotle did not limit the theory to artifacts. Aristotle also believed that this theory of causal explanation held true for natural objects, in particular, plants, animals, and humans.

The key to Aristotle's ethics is that humans, as do all things in nature, have a final cause or purpose. He felt that careful observation of humans, including their physical bodies, their culture, and social behaviors, would yield information about humans' purpose. Living an ethical life, Aristotle then reasoned, would be living a life that achieved this purpose to the greatest extent possible. Aristotle identified the purpose or function of humans as "an active life of the element that has a rational principle" (*NE* 1098a 1). What Aristotle meant by this enigmatic phrase is much debated, but a fair interpretation is that the purpose of human life was to use reason to think about oneself and one's place in world and to perform actions as directed by the results of this reasoning — in short, to live an active life under the direction of reason. Aristotle felt that a virtuous person would be a person who did an excellent job performing the specialized human function. In fact, the word for virtue in Greek is *arête*, and this word can be equally well translated as excellence. An often-quoted illustration used by Aristotle to explain these concepts involves a knife: Aristotle says that the purpose of a knife is to cut, and an excellent knife is one that cuts excellently. So, too, with humans: an excellent or virtuous human is one that performs the function of humans excellently.

Aristotle believed that the result of a person performing the human function excellently is that the person would flourish. (The Greek word is *eudaimonia*, which can be translated as flourishing, happiness, well-being or good spirits.) Aristotle's idea was that one would reap rewards from living a virtuous life. These rewards would be both internal and external. The virtuous person would be happy, that is, she would have an internal feeling of well-being. But the virtuous person would also have some of the external trappings of success — she would be respected in her trade or craft, would have true friendships based on mutual admiration and respect, would have a loving family, and would be viewed as an upstanding member of the civic community whose counsel would be sought and trusted. These external trappings would include enough wealth to be secure and comfortable, but excessive wealth might be a sign that all is not as it should be. The virtuous person lives a well-rounded life, according to Aristotle. She enjoys good food and fine wine, but

<sup>\*</sup> Quotations for Aristotle are taken from *The Basic Works of Aristotle*, McKeon, R. ed., Random House, New York, 1941. Parenthetical citations are to the numbering in the Bekker edition of the Greek text of Aristotle, the standard method for citing passages in Aristotle across various translations. *NE* refers to the *Nicomachean Ethics*.

not to the detriment of her health. She enjoys poetry and drama, but does not live in a fantasy world. She works hard at a successful career, but also has ample time for family, friends, and fun. She is concerned with and will work to enhance the well-being of others in society, but she will not impoverish herself in the process. Finally, she is emotionally and psychologically healthy, as a result of her good relationships with others and as a result of the proper cultivation of her emotions and the appropriate expression of them at the appropriate times. **Balancing these various areas of one's life, or living in the mean between excess and deficiency in each of the areas, is one of the primary skills of the virtuous person.**

**So, as I have reconstructed Aristotle's ethical theory, there are four primary ideas: humans have a specialized function or purpose; those who perform this function excellently are virtuous; a virtuous person flourishes in her life; and finally, a flourishing life is lived in the mean between extremes. It is worth asking why, on Aristotle's account, a person should be virtuous? The answer is that one should be moral because it is in one's self-interest, very broadly construed. Virtuous persons flourish.** This is not to say that one will make decisions based on self-interested considerations. Indeed, Aristotle would say that sometimes the motivation to sacrifice a portion of one's own immediate well-being for the good of someone else is just what is required to make oneself happy. Conversely, aiming at one's own happiness in all the picky, little decisions of everyday life will have the effect of undercutting one's happiness. Nonetheless, **the overarching motivation for becoming an excellent human is that benefits will rebound to oneself. As Aristotle says, the highest good is happiness (*eudaimonia*).** Put differently, Aristotle was convinced that the best life for humans was the life that included moral virtue as a significant part.

This sketch of Aristotle fails to explore many of the specific topics that give his theory power and scope, for example, his account of how to deliberate about a decision, his enumeration and description of individual virtues (e.g., courage, temperance, generosity, honesty, among others), and his discussion of the nature of friendship. However, a topic I consider in more depth is his account of how one becomes virtuous, and in this context also present Aristotle's definition of virtue.

**Aristotle says that humans are not by nature virtuous, for if they were it would not be possible for a human to be vicious, but we know that some persons are vicious. Instead, Aristotle says that humans have the potential to become virtuous, and this potential is realized by habituation.** He writes: "Neither by nature or contrary to nature do the virtues arise in us; rather we are adapted by nature to receive them, and are made perfect by habit" (*NE* 1103a 25). Habituation is a matter of practicing virtuous behavior.

The virtues we get first by exercising them.... For the things we have to learn before we can do them, we learn by doing them, e.g., men become builders by building and lyre-players by playing the lyre; so too we become just by doing just acts, temperate by doing temperate acts, brave by doing brave acts. (*NE* 1103b 1)

The purpose of practicing to be virtuous by performing virtuous actions is to train our emotions and desires. By performing temperate actions, one both gets used to and begins to enjoy the emotions that accompany the actions. From this enjoyment, one begins to desire to be temperate. The opposite sort of habituation can occur as well: performing intemperate actions tends to create intemperate desires and thereby an intemperate character (Sherman, 1989).

Why is it that one should train oneself to enjoy being temperate, one might ask, if one can equally well train oneself to enjoy being intemperate? As useful, if somewhat fanciful, analogy helps to answer this question. Let us say that the human body functions best on a diet of vegetables, meats, and grains. Nonetheless, a child experiences pleasure on first tasting candy. The child's untutored tastes can lead him astray. In fact, the child can eat so much candy that he no longer finds unsweetened foods at all palatable. Now, in the long term, the health of the child will suffer. So, too, the child's taste will never progress beyond the unremarkable pleasure of tasting fat and sugar. This child has not learned to love the good. Aristotle would say that it takes real effort to learn to love that which one can love most fully. So, it takes effort to forgo candy in order to eat spinach, broccoli, rice, beans, etc. One will not immediately love the taste of these foods. But over time, one's palate will be sensitized to the varied and subtle flavors of these foods. The enjoyment experienced by this trained palate will far outstrip the enjoyment of the palate desensitized by fat and sugar. Further, of course, the health of the person will benefit from eating this natural diet. Aristotle would see both the potential for the enjoyment of natural foods, and the health that results from natural foods, to be directly related to the biological characteristics of the body — human biology is such that it gets maximum benefit from natural foods. Once one is sensitized to the tastes of natural foods, staying on the diet of natural foods is effortless. In fact, any other diet tastes bad. But, it takes effort to get to this stage, and indeed it may not be possible to get to this stage if one starts down the wrong path and incorrectly trains one's sensibilities from an early age.

We should note at this point the importance of emotion to Aristotle's ethical theory. **Aristotle is clear that virtue is not an emotion, but is instead a state of character (*NE* 1105b 30). Nonetheless, a virtuous character is a stable set of dispositions to have appropriate emotions and to perform right actions. A person is not virtuous until she**



feels the appropriate emotions when performing the right action. Further, emotions are a guide to right action. While rational deliberation plays some role, in large part one is moved to a certain action because one feels a certain emotion. Aristotle's emphasis on the importance of emotion is one reason that his "virtue theory" experienced a resurgence in the 1980s. Historically, all moral theorists have recognized that humans are emotional creatures, but more often than not emotions were seen as a hindrance to morally correct action. Emotions were not viewed as being under the control of reason — anger, love, jealousy, even sympathy, could move one to act in ways that would be regretted later. Aristotle admitted that emotions, in the moment of their occurring, were often beyond human control. But, by beginning early to train oneself to have the appropriate emotion relative to the situation one is experiencing, it does not matter if the emotion is "out of our control" in the moment of its occurring, for it is the appropriate emotion to have, and it will move one to perform the right action.

Thus, virtue in Aristotle's view is concerned with both emotions *and* actions. One mark of a virtuous person is that she takes appropriate pleasure in doing the right actions. And a mark of someone who fails to be virtuous is that, though she may do the right action, she may not feel the right emotions. So on the battlefield (one of Aristotle's favorite examples) where standing and fighting is appropriate, a virtuous person will courageously stand and fight and feel a kind of confident pleasure in doing so, while one kind of nonvirtuous person — what Aristotle calls a continent or strong-willed person — will stand and fight but feel terrible pain and fear as he does so. Aristotle also tells us that virtue is typically destroyed by excess and defect, and preserved by the mean. To explain this he says that:

... the man who flies from and fears everything and does not stand his ground against anything becomes a coward, and the man who fears nothing at all but goes to meet every danger becomes rash. (NE 1104a21)

Extremes do not typically preserve or habituate virtue. The virtuous person is the one who rushes into battle where this is appropriate and similarly flees where this is appropriate. And the virtuous person is also the one who feels fear where appropriate and confidence where appropriate. So virtue is concerned both with passions and actions and the virtuous person is the one who finds the mean, or appropriate point, for both, feeling the right emotion and doing the right action as they are called for in particular situations. Again, Aristotle explains:

... both fear and confidence and appetite and anger and pity and in general pleasure and pain may be felt both too much and too little, and in both cases not well; but

to feel them at the right times, with reference to the right objects, towards the right people, with the right motive, and in the right way, is what is both intermediate and best and this is characteristic of virtue. Similarly with regard to actions also there is excess, defect and the intermediate. (NE 1106b17)

We now have all the components in place to understand Aristotle's definition of virtue. He says that:

Virtue ... is a state of character concerned with choice, lying in a mean, i.e. the mean relative to us, this being determined by a rational principle, and by that principle by which the man of practical wisdom would determine it. (NE 1106b36)

Virtue is a state of character that individuals cultivate through practicing virtuous actions and emotions. Both virtuous actions and emotions must find the mean between the extremes, and this is relative both to the specific circumstances the person is in (so, how much fear an individual should feel in battle depends on how well-prepared for battle one is, one's army is, how well-suited one's army is to the terrain, etc.), and it is also relative to the person herself. So if a person is attempting to cultivate the emotion anger (associated with the virtue of good temper) and she finds that she often gets too angry, she should strive to feel too little anger in this situation. That is the way in which the virtue is relative to the individual herself. And finally, the mean is determined by reason, by thinking about and assessing the practical nature of the situation. It is also determined by the moral experts, what Aristotle calls persons of practical wisdom, since moral virtue is a kind of wisdom or as we saw earlier, a kind of skill-based knowledge.

### Criticisms and Evaluation

Aristotle's claim that there were purposes in nature is at odds with the scientific world view. Aristotle did not believe that living organisms were designed with a purpose in mind in any obvious sense — for example, he did not believe that organisms were created by an intelligent God. Aristotle simply thought it was the case that things in nature had purposes since, as he saw it from his extensive botanical and zoological studies, it was obvious that living things had complex and purposeful bodily structures. However, since the publication of Darwin's *Origin of Species*, there has been an alternative explanation of how such organs, for example, the human eye, came into existence. In addition, after Darwin surviving to reproduce was recognized as the goal of living organisms — whatever worked to pass on one's genes was, from the perspective of nature, good. In Aristotle's view, an organism has a potentiality that is implicit in it and waiting to be realized. With natural selection, there is no one right way

to develop, as long as one's genes are passed on. Most contemporary philosophers of biology seek to describe the world without the teleological language of "purpose" or "goal" (or they seek to redefine these terms appealing only to concepts in the theory of evolution).

A second criticism of Aristotle is that he provides few rules that set out specific moral obligations and thus little practical advice about how to act. Instead, his most tangible advice is to act in the mean between excess and deficiency, (he does mention that committing adultery, for example, is never in the mean). Aristotle also appeals to the "person of practical wisdom" and suggests that one should act as the person of practical wisdom would act. Nevertheless, Aristotle does not provide general rules that specify our moral obligations. This can leave the novice with little guidance about how to resolve specific issues. It also tends to invest a good deal of authority in the person of practical wisdom, a "moral expert." Novices emulate moral experts as part of the process of learning to be virtuous. Moral experts, in turn, have a good deal of discretion about how to resolve ethical questions. The moral expert is supposed to be sensitized to the moral landscape such that she discerns the right action where others see only an irresolvable dispute (or worse, overconfidently insist on a vicious action) (McNaughton, 1991).\* Perhaps everyone has known someone he considers to be morally wise, but there may be little agreement about who such people are. Further, it seems somewhat dangerous to invest so much authority in a single person's power of discernment.

But what is a weakness to some, is a strength to others (Hursthouse, 1995). Aristotle is relevant to contemporary accounts of health care ethics because he views moral goodness as a skill that must be mastered rather than a set of rules that must be followed. This approach fits with the type of training received by physicians and some other health care professionals. The training of physicians in residency programs often involves mentorship by older, more experienced physicians. The training includes not only information, but also close observation and emulation of the skills involved in medicine, from communication with patients, to physician interactions with nonphysician colleagues, to skills with a scalpel. The well-respected attending physician is viewed as passing the "art of medicine" to younger colleagues. This art cannot be codified, but rather is embodied in an expert. One suggestion regarding health care ethics is to make sure that the physician (and other) leaders in an institution are not only experts in the technical side of medicine, but are also moral experts as well (Pellegrino & Thomasma, 1993). An institution with wise moral leadership would, in theory, need very few specific rules to govern the ethical conduct of its members (Beecher, 1966; Kass, 1980).

\* David McNaughton advocates moral experts. McNaughton, D., *Moral Vision*, Blackwell, Oxford, 1991, 203-5

## AUGUSTINE (A.D. 354–430)

Augustine is an influential figure in the consolidation of early Christian thought. Aurelius Augustinus was born to Roman parents in Roman-controlled North Africa. Augustine described himself as living a "lustful" and "wicked" life until about the age of 30. In *The Confessions*, he writes to God about his struggle with lust:

I in my great worthlessness had begged you for chastity, saying: "Grant me chastity and continence, but not yet." For I was afraid that you would hear my prayers too soon, and too soon would heal me from the disease of lust which I wanted satisfied rather than extinguished.\*\*

Augustine had always been a searcher for religious truth, and was for a time a member of the Manichean sect, which held that good and evil were eternal and equally powerful forces in the world. However, Augustine was profoundly influenced by the sermons of the Catholic Bishop Ambrose, who over time convinced Augustine of the intellectual merit of Catholicism. After being baptized a Catholic by Ambrose in 387, Augustine never strayed from his faith. Augustine is responsible for quite a number of works, of which the best known are *The City of God* and his autobiography, *Confessions*.

Augustine was one of the first to systematize answers to the problem of evil, which is essentially the question of why an all-good, all-knowing, and all-powerful God would allow suffering and evil to exist. Augustine advanced a number of answers, but a prominent one is that, in sin, humans freely turn away from eternal goods in order to seek inferior, temporary goods. Augustine argued that evil is simply the absence of good, so that, strictly speaking, evil is not a thing that can be said to exist. Humans' free choice of sin results in suffering and a diminishing of the good, since sin is the pursuit of inferior goods. The four cardinal virtues for Augustine are prudence, fortitude, temperance, and justice — each of these, except perhaps justice, is explained as helping humans to desire eternal goods and suppress desire for earthly goods. Augustine says that the person who desires the correct goods has "good will," and he takes this to be the most valuable possession a person can have. Augustine's ethical theory contains many prohibitions on action. Notably, Augustine presents a carefully argued, absolute prohibition of suicide in *The City of God* (the only possible exception is martyrdom at the direct command of God). Augustine also considers every lie to be sin, but his nuanced view of deception holds that some lies are clearly worse than others. (Readers familiar with the ethics of Immanuel Kant will notice some similarities between Kant and Augustine. However, it should be noted that the

\*\* Augustine, *Confessions*, Pine-Coffin, R.S., trans. Penguin Books, New York, 1961.

thinkers understand the good will in a fundamentally different way: Augustine explained it in terms of having the proper desires, while Kant felt that the good will did not depend on desires at all.)

### THOMAS AQUINAS (1224–1274)

A second great religious thinker was Thomas Aquinas, who lived approximately 800 years after Augustine. Aquinas was born to a wealthy family in southern Italy near Naples. Aquinas received religious training early, and at 20 years-old he joined the Dominican Order. His family was disappointed that he joined the newly formed order, so much so that they held him hostage for about a year in the hope he would renounce the Dominicans. He served the Dominican Order with distinction throughout his life, spending the majority of his time as a professor of theology at the University of Paris. Aquinas's writings are extensive: the best known is *Summa Theologica*, which he probably wrote while at the residence of Pope Clement IV between the years 1265 and 1268. An interesting coda to the life of Aquinas is that soon after his death many his writings were condemned by Church officials: studying the works of Aquinas was only fully sanctioned by the Catholic Church under Pope Leo XIII around the year 1900.

The thought of Aquinas is sometimes presented with the formula: Aristotle + God = Aquinas. While Aquinas's rich and extensive writings cannot be reduced to this formula, the formula does point to an organizing theme in Aquinas's thought. Aristotle held that everything in nature was imbued with a purpose (the final cause, in Aristotle's terminology). Aquinas identified God as the source of these purposes. Simply put, God designed everything in the world with a purpose in mind. With Aristotle, one can learn about an object's purpose by examining the form or organization of the object. So too for Aquinas — the study of humans and nature reveal natural laws, and these natural laws provide insight into God and God's "eternal law." One learns about the creator by studying creation. Sins are actions that conflict with natural law (and therefore also eternal law). From this guiding idea, Aquinas develops a complex taxonomy of immoral actions.

Among his specific prohibitions, Aquinas says suicide is wrong (1) because it violates the natural law of self-preservation, (2) because it harms one's community, and (3) because the power of life and death rightly belongs to God. Like Augustine, Aquinas holds that every lie is a sin, although some lies are relatively minor infractions. In this context, Aquinas defends what is known as the Pauline principle, namely, that it is not permissible to achieve a good end (no matter how great) by an evil means (no matter how minor).

Aquinas also had a good deal to say about sex and reproduction. Aquinas holds that procreation is the natural purpose of the sex act. Thus, a sexual act that does

not allow for procreation conflicts with natural law. Thus, homosexuality and masturbation are sins for Aquinas. So, too, is heterosexual sex outside of marriage, since Aquinas holds that the natural order is such that human offspring should be raised by two parents (if possible).

Aquinas does not pull his punches here: any sexual act in or outside of marriage that does not allow for procreation and the proper raising of children is a mortal sin. That is, it is a sin that will result in one's damnation, unless this sin is absolved by God's grace. (Being sorry or doing penance can absolve one from venial sins, but they are powerless against mortal sins.)

The doctrine of double effect was developed by Aquinas (and others), and this doctrine plays an important role in some contemporary writings on medical ethics. The doctrine of double effect is a way to determine the moral permissibility of actions that have both good and bad effects. In essence, the doctrine holds that an action that causes a bad effect is permissible if and only if the following five criteria are met:

1. Only the good effect is intended; the bad effect may be foreseen, as long as it is not intended.
2. The action cannot be intrinsically wrong (such as lying).
3. The causal chain that leads to the good effect cannot contain the bad effect; that is, the good effect cannot be the causal result of the bad effect.
4. There are no ways to achieve the good effect without causing the bad effect (or a worse one).
5. The good effects of the action outweigh the bad effects of the action.

For example, routine surgery to remove a diseased appendix meets all of the criteria: bad effects (e.g., soreness, risks associated with anesthesia) are foreseen but not intended; removing the appendix is not intrinsically wrong; the good effect is not caused by any bad effects; there is no way to prevent a burst appendix except surgery; the badness of a burst appendix outweighs the risks and costs of surgery. A second application of the doctrine of double effect involves narcotics to relieve suffering in a terminally ill patient: the intent must be to relieve pain (this is the good effect), not cause death (this is the bad effect); providing narcotics in normal doses is not intrinsically wrong (i.e., normal doses are not tantamount to providing a deadly poison); pain relief is not achieved by death; there are no other means to relieve suffering; the good of pain relief outweighs the increased risk of premature death.

### Criticism and Evaluation

While a few isolated arguments from Aquinas and Augustine are persuasive in secular contexts, their theories as a

whole are plausible only within a religious context. This is because each of the thinkers derives ethical commitments from his theological views about the nature of God. And, of course, there are a variety of theological perspectives even within Christianity, so one cannot assume that ethical commitments of Aquinas and Augustine fit well with all Christian faiths. Nonetheless, ideas from the thinkers, especially Aquinas's view that one can use "natural law" to derive ethical rules, continue to be influential among many in society.

The doctrine of double effect has been discussed, defended, and criticized since Aquinas's time. Major criticisms include the following. Some have argued that it is impossible to foresee the bad outcome of one's action and not also intend the outcome when performing the action; that is, there is no such thing as a foreseen but unintended effect. A second criticism holds that the notion of an intrinsically wrong action is incoherent: if this is so, then one must give up criterion 2 (and maybe criterion 3), in which case the doctrine is nothing more than a form of consequentialism. (See the section on Mill for a discussion of consequentialism.) Finally, one might argue that judgments made about balancing good and bad effects (in criterion 5) are necessarily subjective. Indeed, some would argue that death is actually a good for the suffering patient for whom no relief is possible. The doctrine of double effect seems to assume that there is some noncontroversial way of identifying effects as good or bad. These criticisms are powerful when the doctrine of double effect is used in a secular context. However, the doctrine of double effect was never meant to be divorced from a religious context, which would include a substantive account of which types of actions are intrinsically wrong and a substantive account of human goods. Further, a secular theory that identified intrinsically wrong actions and which provided a substantive account of human goods could also use the doctrine.

### IMMANUEL KANT (1724–1804)

Kant invented one of the most influential deontological theories of ethics. A deontological theory takes some actions to be morally wrong regardless of their consequences. The clearest example in Kant's writing is lying. According to Kant, it is not permissible to lie even if the lie is about a relatively unimportant matter and yet would prevent great evils from occurring. Simply put, whether a lie has good or bad effects is irrelevant to whether the lie is permissible. Kant's theory is largely secular in its grounding. Nonetheless, Kantian ethics has strong affinities with religious ethics, since religious ethics also tends to identify some actions as impermissible regardless of their consequences (as our discussion of the doctrine of double effect has just illustrated). A second important aspect of Kant's ethical theory is its emphasis on auton-

omy. Kant suggests that persons' capacity for reason gives persons both freedom and responsibility. As beings with the capacity to reason, persons can rise above the instinctual, animal aspects of their natures to make informed choices about the proper course of action. The ability to make informed choices forms the basis of one's freedom. However, one is not free to make these choices willy-nilly. Rather, one has the responsibility to reason correctly about morality. This means that the choices one makes for oneself — about lying, for example — have a measure of universality, that is, all persons who reason correctly will necessarily reach the same conclusion.

Immanuel Kant was born in 1724 and he died in 1804. He lived his whole life in Königsberg, as a professor at the University of Königsberg. Kant lived the life of a quiet and not very productive professor until about the year 1776, when he read David Hume's *Enquiry Concerning Human Nature*. Kant said that Hume's book woke him from his "dogmatic slumber," meaning that Hume's work showed him that there were deep flaws in his own understanding of the world. It was quite an awakening. At the age of 56, Kant embarked on one of the most ambitious and most successful research programs in the history of philosophy. Kant published the *Critique of Pure Reason* in 1781, and followed this work with books on practical reason, aesthetics, religion, and ethics. Kant not only made original contributions in each area, but his works fit together to form a philosophical system unmatched for its subtlety and sophistication.

Kant begins the first section of the *Groundwork for the Metaphysics of Morals* with a bold statement about moral value:

There is no possibility of thinking of anything at all in the world, or even out of it, which can be regarded as good without qualification, except a good will. (GW 393)\*

Kant contrasts a good will with talents such as intelligence and wit, with virtues, such as courage and perseverance, and with calm deliberation and self-control. In contrast to Aristotle, Kant argues that none of these character traits has intrinsic value, because each of these things can be put to evil uses. What then is a good will, and why is it so valuable? Kant is clear that a good will is not good because it brings about good consequences. He writes: "a good will is good not because of what it effects or accomplishes, nor because of its fitness to attain some proposed end; it is good only through its willing, i.e., it is good in

\* Kant, I. *Groundings for the Metaphysics of Morals*, Ellington, J.W. trans., Hackett Publishing Company, Indianapolis, 1993. Parenthetical citations are to the Prussian Academy system, the standard method for citing passages in Kant across various translations. GW refers to the *Groundings for the Metaphysics of Morals*. DV refers to the *Doctrine of Virtue*.



itself" (GW 494). Indeed, Kant says that the good will "shines like a jewel" with its full value even in a person who lacks all talent and skill, and thus never succeeds in accomplishing any of his aims. Kant rules out one potential reason why a good will might be thought valuable. So, again, what is a good will and why is it valuable? Kant explicates the concept of a good will in terms of a person's motivation to perform an action. A person with a good will has the intention to do a morally correct action because the action is morally correct. That is, the person does the correct action out of respect for the moral law.

Kant uses a number of cases to illustrate the point. Adapting one of his cases, consider someone who goes out of her way to help an infirm person to board a bus. We can imagine any number of motivations for this kind stranger's action: she might want to impress someone she knows is watching her; she might feel guilty for snapping at a co-worker earlier in the day; she might want the satisfaction that comes from performing a good deed; the infirm person might remind her of her father, for whom she has kind feelings; she might even simply have found herself overcome by sympathetic emotions. Kant argues that none of these potential motivations for the action has any moral worth. What gives the stranger's action moral worth, if it has moral worth, is that the action is performed out of respect for the moral law. That is, the stranger intends to perform the action because the action is the right thing to do. Kant's terminology contrasts *acting from duty* with *acting according to duty*. Because this action is morally required, one acts *according to duty* no matter one's motivation. But only the correct motivation for the action yields an action *from duty*. In part, the distinction is easily understood — everyone recognizes that sometimes the morally correct action is performed for morally neutral or morally bad reasons. What is interesting is Kant's formulation of morally correct motivation: one does what is right because it is right.

It is possible to clarify what Kant means by acting from duty by considering motivations that do not count as being morally worthy. Kant's general term for such motivations is "inclination." An inclination is either a particular desire or an emotional disposition. So, one is motivated by an inclination if one helps because one *desires* to impress a potential romantic partner. Further, one is motivated by an inclination if one helps because one *desires* to feel satisfied for performing a good deed. One also is motivated by an inclination if one's emotional dispositions simply move one to act. The sympathetic person may act not because she desires something, but simply because she has a sympathetic character. (Note the contrast to Aristotle here, who would consider the sympathetically inclined person to be acting virtuously.) Kant does not view inclinations as chosen by the agent. Rather, he thinks that one finds oneself with inclinations; the inclinations arise in humans because humans are instinc-

tual creatures with bodily needs. In an important sense, when a person lets these inclinations cause his actions, then he is not free or autonomous. An autonomous choice for Kant is one that is made on the basis of reason, not on the basis of desires or emotions. Of course, Kant thinks it is often appropriate to act to fulfill one's desires — the point is that one is not demonstrating one's highest potential except when one's action is motivated by reason, in particular, when one does the morally right thing because reason shows him that it is the right thing. Kant says that we are "self-legislating." This means that we each use our reason to determine what is morally right, and we bind ourselves to doing what is right because we see that it is dictated by reason. It is in that sense that we are free — the moral rules that bind one are self-imposed.

The rules of reason are universal, according to Kant. Two people who are not making any mistakes in their reasoning will reach the same conclusion. Thus, moral rules are universal, even though each of us must reach these laws using our own reason. This allows Kant to talk about the specific moral obligations that everyone must follow, even though each person is responsible for imposing these rules on herself. Kant's core moral principle is called the categorical imperative. The categorical imperative has a number of different formulations, but the first and third are the most influential.

*Categorical Imperative, Universal Law Formulation:* Act only according to that maxim whereby you can at the same time will that it should become a universal law. (421)

*Categorical Imperative, End-in-Itself Formulation:* Act in such a way that you treat humanity, whether in your own person or in that of another, always at the same time as an end and never simply as a means. (429)

Intuitively, the universal law formulation gets at the idea that people have a tendency to make exceptions for themselves: that is, a person might rationalize that it is permissible for him to perform an action, even though he would have to admit that it would be bad if everyone acted in the same way. Kant cannot appeal to bad consequences and remain consistent with his remarks about the good will. So, Kant explains that in performing an action one is, in effect, agreeing to the principle that it is permissible for everyone to act in the same way, and reason will show one whether it is possible to embrace this principle. Kant's clearest example involves keeping promises. Kant reasons that one cannot both expect to reap the reward of breaking a promise and yet assert that it is fine for everyone to break promises: this is because in a world in which everyone breaks promises, there will be no trust, and if there is no trust, then there will be no rewards to reap from breaking a promise since no one will believe the promise in the first

place. Whether the categorical imperative “test” for the morality of actions works for all cases has been the subject of debate since Kant’s time.

The end-in-itself formulation of the categorical imperative is more straightforward. The idea is that one must respect other people as decision makers in their own right — that is to say, that one must act to respect and support other people’s autonomy. One can use other people as a means to fulfill one’s own needs (e.g., as happens in all commercial transactions), but this use of others as a means must be consistent with respecting others as persons. Note that Kant is also clear that one has to respect oneself as an autonomous being. That is, one has an obligation to respect and support one’s own autonomy.

Kant offers the following four examples to highlight the four categories of moral obligations.

	Perfect duties	Imperfect duties
Duties to others	Do not break promises	Help others in need
Duties to self	Do not commit suicide	Cultivate your own talents

Perfect duties require a person to always refrain from performing an action. They are required at all times. Imperfect duties require performing an action. Since performing an action requires time and effort, and since the effort one expends performing one imperfect duty must be balanced against one’s obligation to perform other imperfect duties, any particular imperfect duty is not required of a person at all times. One needs to perform an imperfect duty when the opportunity arises and such that one is not favoring one imperfect duty to the detriment of others. (This raises the interesting practical question of how to balance imperfect duties to self with imperfect duties to others.)

### Criticisms and Evaluation

Kant’s theory is not immune to a type of criticism that can be made against all deontological theories, namely, that some instance of an action-type identified as impermissible by the theory is considered to be permissible or even obligatory on independent grounds. Consider the following example:

You are hiding innocent people from the soldiers of a repressive regime. Soldiers knock on your door and ask you if you are hiding anyone. You know that the soldiers will torture and kill the people if you give them up. You know that the soldiers will search your house and find the people if you say nothing. You also know that if you lie convincingly the soldiers will go away. But you feel that it is wrong to lie. What should you do?

Many people have the intuition that in this case it is permissible or even morally obligatory to lie. Some will

attempt to justify the lie by saying that the soldiers do not have a right to the truth. Kant would disagree. His view is that you should tell the soldiers the truth, no matter the consequence to the innocent people. In commenting on a similar case, Kant writes: “To be truthful in all declarations is ... a sacred and unconditionally commanding law of reason that admits of no expediency whatsoever.”\* Kant’s view is that there are no exceptions to the prohibition on lying. Many people find this sort of inflexibility untenable, especially given that it will more than likely result in the death of innocents.

A second criticism of Kant involves his attitudes to the emotions. Kant is clear that an action motivated by an emotion such as sympathy has no moral worth. Rather, only actions done from duty have moral worth. Kant would say that a person who performs a compassionate act because she sees it as her duty is acting morally, and this is true whether or not the person also feels the emotion of compassion. However, a person who is motivated by the emotion, and not by duty, has not acted morally. This has led Michael Stocker to focus on the example of a person who is motivated by duty and not emotion. Here is an adaptation of his example.

Sheila is ill and has been hospitalized. Her co-worker Bob comes to visit her. Sheila is immediately cheered: she didn’t know that Bob cared about her; she is moved by Bob’s compassion and friendship. She brings this up: “Bob, how nice of you to visit; it is so caring of you to go out of your way to cheer me; I am moved to have a friend such as you.” Bob, ever the honest one, sets Sheila straight: “I consider it my duty to visit a co-worker who is ill, and so here I am. I would rather be at home, you know, but duty calls.”

Few would think that Bob is a morally praiseworthy person, even if he refrained from telling Sheila his real motivation for the visit. Rather, we generally expect morally good persons to have morally good emotional dispositions, and indeed we evaluate people based on their emotional dispositions. Sometimes we do admire people because of their strong sense of duty, but other times we admire people for their kind, compassionate, or generous emotions. Kant seems to be missing this aspect of morality.

This criticism has prompted contemporary defenders of Kant to investigate more closely Kant’s view on the moral value of emotions. Some of these defenders have suggested that focusing on Kant’s *Groundwork for the Metaphysics of Morals*, while ignoring his other works, results in a lopsided view of Kantian ethics. Kant’s *Groundwork*, it is argued, defends his conception of right action. Kant’s *Doctrine of Virtue*, on the other hand, pre-

\* Kant, I. On a supposed right to lie because of philanthropic concerns, in *Groundings for the Metaphysics of Morals*, Ellington, J.W. trans., Hackett Publishing Company, Indianapolis, 1993.

sents his conception of a virtuous person. So *The Doctrine of Virtue* may be important to balancing the overall picture of Kantian ethics.

In *The Doctrine of Virtue* Kant argues that character traits and emotional dispositions provide important support to the good will. For instance, he argues that:

... it is a duty to sympathize actively in the fate [of others]; and to this end it is therefore a duty to cultivate the compassionate natural feelings in us, and to make use of them as so many means to sympathy based on moral principles.... For this is still one of the impulses that nature has implanted in us to do what the representation of duty alone would not accomplish. (DV457)

In this passage, Kant argues that human imperfection and weakness often prevent us from acting on duty alone. Thus we must cultivate our natural compassion, to bring it in line with the requirements of moral duty. Kant further thought that when we perform beneficent actions from duty we will, “eventually come to actually love the person [we] have helped” (DV 402). Dutiful beneficent acts will produce the emotion of sympathy in us, but it is a kind of sympathy that is obedient to and consequent upon moral duty.

But even given this defense of Kant, many non-Kantians remain unsatisfied with the Kantian view of emotions. In particular, some critics have argued that Kant’s ethical theory, at best, values emotions merely as instruments to doing one’s moral duty. Kantians cannot see the simple experience of an emotion as morally valuable in itself. Thus, a Kantian cannot hold that simply feeling sympathy for a friend in distress has moral significance, apart from the emotion’s ability to support an agent’s good will. So for those moral theorists convinced that emotions have moral value apart from their role in morally good action, the Kantian position on emotions remains inadequate even with these important defenses of Kant’s view.\*

Kant is relevant to contemporary health care ethics for a number of reasons. First, Kant was perhaps the first to develop a well-supported secular deontological theory. This makes it possible to claim in pluralistic settings that some actions are just wrong, no matter their good consequences, and to formulate public policy around the sorts of actions that are considered to be intrinsically wrong. Second, Kant championed autonomy. His view is one of the primary motivations for the Principle of Respect for Autonomy, which is discussed in the second section of this chapter. Finally, Kant’s views do much to influence theories of informed consent. Notably, informed consent procedures are designed not just to protect patients’ freedom to choose, but also to support patients in making good decisions. Kant, as we saw, connects the freedom to

choose with choosing for the right reasons: a person makes a genuinely free choice if and only if a person makes a choice based on reason. This issue is also discussed in the second section.

### JOHN STUART MILL (1806–1873)

John Stuart Mill (with Jeremy Bentham) developed consequentialism, one of the most influential modern theories of ethics. Mill’s version of consequentialism is called utilitarianism, and the great virtue of this theory is that it cuts away the complex and (Mill would say) arcane trappings of earlier ethical theories, and seeks to explain ethics in a way that is simple, direct, and that appeals to common sense. Mill’s guiding insight, which was exquisitely simple, was that those actions that cause good consequences are ethically good and those that cause bad consequences are ethically bad. Despite its apparent common sense, the theory stands in stark contrast to earlier ethical theories. In part, this is because Mill defined good consequences as pleasure and the absence of pain, and other ethical theories posited loftier goals for humans’ lives. But an even more acute point of contrast, especially to Kant, is that Mill denied that any action is wrong in and of itself, regardless of its consequences. This means, for example, that telling a lie is not necessarily wrong; whether a particular lie is morally right or morally wrong depends on the consequences of telling it. For Mill, many of the reasons why we might be tempted to say that an action is wrong “in-itself” are based on outdated traditions or suspect religious reasoning. In both cases, the moral rules that result will tend to favor the already well off in society at the expense of the common folks working in fields and factories. Mill argued that human suffering is bad wherever it is found, and that society ought to be arranged so that such suffering is minimized — if a traditional right (say, one granted to the nobility) stands in the way of minimizing suffering, so much the worse for this right. Lest Mill seem too much of a radical, it should be noted that he found that many (but not all) of the institutions of the British Empire did serve to promote the general well-being.

John Stuart Mill was born on May 20, 1806 in London. His father was James Mill, a prominent intellectual and reformer and a close associate of Jeremy Bentham. James Mill pushed John in his studies from an early age — it was said that John was reading Plato in the original Greek at age 7. John began publishing his own work at age 16. He became the editor of the *Westminster Review* and founder of the Utilitarian Society. In 1826, at age 20, Mill underwent a mental crisis, entering a 4-year period of depression the cause of which he took to be the lack of “cultivation of the feelings” in his early upbringing. The end of Mill’s depression coincided with meeting his life’s partner, Harriet Hardy Taylor, who was at the time married

\* Stark, S. “Emotions and the Ontology of Moral Value.” *Journal of Value Inquiry*, forthcoming

to someone else. Mill and Taylor remained close friends and collaborators for the next 20 years, until the death of John Taylor allowed Mill and Harriet Taylor to be married. (See the dedication of *On Liberty* for insight into Taylor's contributions to Mill's thought and writings.) Mill was elected a member of the British Parliament in 1865, although he was defeated at the next election. Mill died on May 7, 1873 in Avignon, France, apparently as the result of the exertion of a 15-mile hike he had taken 2 days previously. Throughout his life, Mill maintained his father's commitment to reforming society, particularly the sort of evils brought on common people by industrialization and urbanization. Mill was also an early defender of equality for women, publishing *The Subjugation of Women* in 1869 — which was most likely co-written with Harriet Taylor. (An interesting anecdote in this regard was that Mill was arrested and briefly jailed for obscenity in 1823, the result of distributing birth control literature in a working-class neighborhood of London.) Mill published widely in areas beyond moral philosophy, including logic (*A System of Logic*, 1843), political theory (*On Liberty*, 1859), and economics (*Principles of Political Economy*, 1848). Those interested in Mill's views on religion, God, and immortality will find his *Three Essays on Religion* (1874) to be helpful. Mill's *Autobiography* (1873) also makes fascinating reading.

Mill's moral theory is outlined in his short book *Utilitarianism* (1863). The primary idea behind the theory is that the morality of an action ought to be measured solely by the consequences, good and bad, that are produced by the action. We are obligated to perform the action that produces the most good, that is, the action that has the consequences with the highest net value. To complete the theory, Mill specifies what counts as good and bad consequences. Mill argues that the value of an action is measured by the pleasure and pain that it produces in humans. This leads to Mill's central principle, the Greatest Happiness Principle (GHP): "actions are right in proportion as they tend to promote happiness; wrong as they produce the reverse of happiness." Mill leaves no doubt as to what he means by happiness: "By happiness is intended pleasure and the absence of pain; by unhappiness, pain and the privation of pleasure" (Mill, 1966, p. 157).

Three possible misinterpretations should be headed off at the outset. First, Mill is not an egoist. That is, he is not claiming that an action is morally right for me to perform if it produces the best consequences for me. Rather, he is claiming that an action is morally right for me to perform if it produces the best consequences for everyone. I am allowed to consider my own well-being in calculating which action is morally right, but my well-being counts no more than the well-being of anyone else who would be affected by the action. Indeed, since my action may affect the well-being of persons yet to be born, I should also consider their well-being in my calculations.

Second, Mill is concerned with both short- and long-term consequences. Thus, the GHP does not require that I perform actions with immediately pleasurable consequences, if later consequences will cause enough pain to outweigh immediate pleasures. Finally, Mill seems only concerned with the pleasure and pain felt by humans. However, Jeremy Bentham, in developing an earlier version of utilitarianism, argued that the pleasure and pain of animals ought to be considered in the calculations. (Bentham's point is echoed by contemporary animal rights activists, notably Peter Singer, who argues that if pain is bad in humans, then it is bad in animals too [Singer, 1990].)

In refining his basic theory, Mill anticipates and answers several objections. An initial objection is that utilitarianism does not encourage what is truly valuable in human nature. So, his imagined critic might point out: "Is it not beneath the dignity of humans to chase after pleasure?" We think that gluttons, drunkards, and those preoccupied with sex to be morally depraved — we certainly do not hold them up as models of right action" (Mill, 1966, p. 160). One component of Mill's answer is merely to note that some of these lifestyles will lead to painful consequences in the long term. But this answer leaves the basic thrust of the objection intact: Isn't it beneath the dignity of humans to chase after pleasure? Mill answers with a distinction between higher and lower pleasures. Lower pleasures are things like sex, drink, food, and laziness. Higher pleasures include reading literature, writing, viewing art, listening to music, contemplating philosophy, etc. Even performing moral actions can be a higher pleasure for certain individuals. A strict reading of the GHP implies that the only moral reason to prefer higher pleasures to lower pleasures is that higher pleasures are more pleasurable. Mill embraces this statement, claiming that the higher pleasures of the mind are indeed more pleasurable than the lower pleasures. As evidence for this, he claims that people who have been lucky enough to have experienced both sorts of pleasures almost invariably choose higher pleasures as the more desirable. So Mill said famously: "It is better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied" (Mill, 1966, p. 161). Mill's claim has fueled much debate about human nature: Is it true that people of sufficient means gravitate toward intellectual pleasure, and even if true, does this imply anything about the lesser value of lower pleasures — is reading Shakespeare really better than watching the World Wrestling Federation? At any rate, if we accept Mill's argument, then following the GHP will not require the pursuit of "swinely" pleasures, but rather the pursuit of the higher intellectual pleasures. In this sense, the GHP will promote what is dignified in human nature.

A second objection that Mill considered involves the time and effort that following the GHP would require. Mill seems to suggest that at any particular time a person



should consider all of the alternative actions that are available, should evaluate the short- and long-term consequences of these actions, and finally choose the action that has the highest net value. Even if we artificially limit the alternative actions available to three options, calculating the long-term consequences of these actions is a formidable task. Of course, there will be a good deal of uncertainty about what the likely consequences of the actions will be, but there will also be a good deal of information to sort through to attempt to trace out all the consequences of the three options. Utilitarianism, then, threatens to paralyze action in an endless fit of calculation. Mill offers a number of answers. He points out, first, that following the GHP does not require intricate calculations. Rather, most decisions about which actions will produce the best consequences involve only common sense. Second, echoing a theme from Aristotle, Mill argues that training the appropriate dispositions (such as the disposition to answer honestly when asked a question) is an important aspect of his theory. Once one has decided that being honest usually promotes the best consequences, then one trains oneself to be spontaneously honest (that is, without calculating consequences every time one is asked a question). Mill points out that most ethical theories could be interpreted in such a way that they paralyze action by requiring too much reflection — so he points out that Christians are not required to reread the Bible every time they face a decision (Mill, 1966, p. 178).<sup>\*</sup> Finally, Mill suggests that our actions will have the most of their consequences close to home. Theoretically, a decision I make today might have consequences for people in future generations and might have consequences for people I am unaware of on the other side of the world. But, generally, my decisions will have the most effect on myself, my family, my friends, and my colleagues. Also, generally, it will be easier to trace out the effects of my actions for this smaller group of people. Some of these decisions may require the careful balancing of potential good and bad consequences for this group of people, but the decisions do not require that the agent devote an extraordinary amount of time and effort to calculating how the action will affect persons in distant times and places.

Before turning to modern criticisms of Mill's *Utilitarianism*, it is important to introduce Mill's ideas from *On Liberty*, since these too have had a huge impact on political philosophy in the United States. Mill was concerned not only that a monarch would have too much power, but also that in the "democratic republic" of America the danger exists of a tyranny of the majority (to use de Tocqueville's term). In order to guard against this, Mill proposed his harm principle: "That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."

<sup>\*</sup> Mill, *Utilitarianism*, 178

Mill immediately clarifies the harm principle with an injunction against paternalism: A mature and competent person "cannot rightfully be compelled to do or forbear [any action] because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right." Mill defends these principles based on the recognition that institutions within society can be quite powerful, and that the only way to guard against inappropriate paternalism is to completely rule out all paternalism (although there is debate on this interpretation). Mill continues in *On Liberty* to further specify the types of liberties that are important to protect. There are three main categories: (1) "the inward domain of consciousness," which includes the "absolute" freedom to think, feel, and formulate opinions; (2) "liberty of tastes and pursuits," which is freedom in choice of personal lifestyles and practices as long as these do not harm anyone else; (3) freedom of association "for any purpose not involving harm to others." This "liberal argument" has been influential across the political spectrum in the United States. It also forms the core of many well-known Supreme Court decisions, including *Griswold v. Connecticut* (1965, birth control), *Roe v. Wade* (1973, abortion), and the dissent in *Bowers v. Hardwick* (1986, homosexuality).

### Criticisms and Evaluations

Despite its commonsensical nature, utilitarianism is open to a wide variety of criticism. First and most prominently, utilitarianism does not give a special status to categories of moral value that many people take to be of central moral importance. For example, utilitarianism does not seem to grant a special status to promises, to ownership rights, or to obligations arising from close relationships to family or friends, or to obligations relating to justice. For each and every category, it seems possible to imagine a situation in which utilitarianism would require that the moral value in question be overridden in the name of the common good. Consider the following example relating to justice:

A mob is chasing a man through town. They blame him for a murder, and they plan to brutally execute him if they capture him. The man happens to be innocent, as you know. However, you also know that if the mob does not capture and kill the man, then a riot will ensue in which many persons will be harmed and killed (some of those harmed and killed will be innocent, having nothing at all to do with the situation). It is in your power to save the innocent man from being stoned. Should you do it?

The gut reaction of many people to this case is that the innocent person should be saved regardless of the bad consequences — justice simply requires it. But utilitarianism seems to require that one allow the innocent person

to be killed. Utilitarians may attempt to answer the criticism by resisting the conclusion that utilitarianism requires allowing the innocent man to be killed. So, a utilitarian might argue that while the short-term consequences suggest that the innocent man should be killed, the long-term consequences of this decision include eroding society's commitment to the rule of law, which will in turn cause an increase in suffering, and these bad long-term consequences outweigh any short-term benefits of allowing the man to be killed. While this response is plausible enough, it is possible to manipulate the details of the example to exclude the possibility that the long-term bad effect of eroding the rule of law will occur — thus, in essence, painting the utilitarian into a corner in which she must admit that killing the innocent is justified by her theory. The utilitarian might then be forced into accepting the troubling result. Since it is possible to construct equally plausible counterexamples to utilitarianism about promise-keeping, truth-telling, ownership rights, obligations to family, etc., this manner of argument represents a strong challenge to utilitarianism. How persuasive such counterexamples should be is an interesting philosophical question, since the evidential authority of the counterexample ultimately relies only on the strength of one's gut reaction to the story and, one might argue, gut reactions are not to be universally trusted.

A second prominent criticism of utilitarianism is that it is too demanding. For example, utilitarianism seems to require too much personal sacrifice in order to promote the interests of other people. Consider that I have \$10 in my pocket that is uncommitted as far as my budget is concerned. I consider using the money to go to the movies tonight — I certainly would get pleasure from this, and there are no relevant constraints on my time. But, I reason, this money could also be used to benefit other people — it might even save lives if contributed to Oxfam or some other worthwhile charity. Utilitarianism seems to require that I give the money to Oxfam. Now perhaps this particular sacrifice is morally obligatory, but notice that if tomorrow I again find myself with an unencumbered \$10, I would again be obligated to donate the money, and so on, and so on. I would only be entitled to use the money for myself (or my family and friends) when it becomes the case that the happiness I can create close to home is greater than (or equal to) the happiness I can create by donating the money. Even if we lived in a world in which the inequities between rich and poor were much less pronounced, one might wonder whether a person is morally required always to spend his money (and his time) in a way that produces the most good, regardless of how it affects himself and his loved ones. These issues have led to a spirited debate about the level of self-sacrifice that can legitimately be required by an ethical theory. Notice that even minimalist ethical theories, such as libertarianism, require some self-sacrifice in the name of morality,

since libertarians hold that one must refrain from harming others even if harming another would benefit oneself. Peter Singer, inspired by utilitarianism, is at the other extreme, arguing that people in wealthy Western countries have an absolute obligation to dramatically lower their standards of living in order to benefit people in developing nations (Singer, 1977). Mill attempted to ameliorate the concern that utilitarianism demands too much personal sacrifice both by noting that one's resources are more efficiently used close to home (perhaps that was true in his day), as well as by pointing to the hedonist's paradox, which is the view that a person cannot obtain happiness by aiming directly at it, but rather truly happy people have as their goal something outside of themselves (Mill, 1966, p. 172). So it is likely that some self-sacrifice will indeed make us happier.

A third criticism of utilitarianism is that it requires a person to sacrifice his or her integrity. This criticism has been developed by Bernard Williams. Williams asks us to consider the following case, which I paraphrase:

George, a chemist, has been offered a job in a research facility for chemical and biological weapons. Despite his best efforts, George has been out of work for some time, and his young children have suffered greatly under the strain placed on the family. George does not feel he can take the job, however, given that he is a committed pacifist who has always been against chemical and biological weapons. The person offering George the job says that she, too, is against such weapons: in fact, she has offered George the job in part because of his beliefs; other candidates for the job will enthusiastically push the work along at a faster pace, while George will likely drag his feet. Should George take the job? (Williams, 1977, pp. 97–98)

Utilitarianism would seem to require that George take the job. The point of Williams' story is not merely that George is being required by utilitarianism to do something that most of us would agree is wrong. Rather, Williams is trying to show that utilitarianism is incompatible with the commitment to integrity, something central to the identities of many of us. George has identified himself with pacifism — it is part of his self-image. Maybe George initially embraced pacifism for utilitarian reasons — because he felt it brought about the most good — but being a pacifist is now George's central project; it is who he is. But whether pacifism actually causes the best consequences depends not on George, but on facts in the world, and depending on how these facts change, George at any moment could be required to act contrary to his central, defining project. At any moment, he could be required to live a lie. Williams explains:

The point is that [George] is identified with his actions as flowing from projects and attitudes which in some

cases he takes seriously at the deepest level, as what his life is about.... It is absurd to demand of such a man, when the sums come in from the utility network which the projects of others have in part determined, that he should just step aside from his own project and decision and acknowledge the decision which utilitarian calculation requires. It is to alienate him in a real sense from his actions and the source of his action in his own convictions.... It is thus, in the most literal sense, an attack on his integrity. (Williams, 1977, 132)

According to Williams, the only project that a utilitarian can be fully committed to without putting his integrity at risk is the project of being a utilitarian. But, Williams argues, this project is too thin, too formalistic, to be a central commitment or life's project. To use another of Williams' well-known examples, one should perform acts that demonstrate love for one's romantic partner out of a genuine love for one's partner, not because demonstrating love for one's partner creates, in the long run, the best consequences for all of humanity.\*

One strategy utilitarians have adopted in response to all of the criticisms mentioned is to move from act utilitarianism to some type of indirect utilitarianism. Act utilitarianism says that one should evaluate which act brings about the best consequences. Indirect utilitarianism is still interested in the best consequences, but it focuses on other mechanisms for bringing them about. For example, rule utilitarianism says that an action is morally right if and only if that action is required by a *set of rules* the adoption of which would produce the best consequences. The rule utilitarian advises that one should follow the set of rules identified, even though in isolated instances following a rule will not bring about the best consequences. Rule utilitarians think that the benefit (in good consequences) of having a stable set of rules outweighs the cost (in bad consequences) of occasionally performing non-optimal actions. Another form of indirect utilitarianism is character utilitarianism, which holds that performing an action is morally right if and only if that action promotes or is promoted by a *set of character dispositions* the inculcation of which would produce the most good or value for the members of a society. Once again, virtue utilitarianism identifies the occasional non-optimal action as morally good in order to gain the benefit of allowing persons to internalize content-rich dispositions and commitments

\* Mill considers and responds to a very similar criticism. He considers the criticism that "It is often affirmed that utilitarianism renders men cold and unsympathizing; that it chills their moral feelings towards individuals; that it makes them regard only the dry and hard consideration of the consequences of actions." *Utilitarianism*, 174. Mill argues that all moral theories sometimes require one to ignore bonds of love, and thus utilitarianism is no better or worse in this regard than other theories. Mill also draws a distinction between a standard of right action and the motivations for pursuing right action. He claims that his theory is meant to address only the former issue.

(such as George's commitment to pacifism). As a final example, rights utilitarianism holds that performing an action is morally correct if it is in accord with a scheme of *individual rights and liberties* the adoption of which would produce the most good for society. The distinction between direct and indirect utilitarianism post-dates Mill, but passages in Mill's *Utilitarianism* have been interpreted as advocating forms of indirect utilitarianism.

A second strategy for meeting the criticisms involves modifying the definition of good consequences. Utilitarianism is the name for the view that seeks to maximize pleasurable feelings and minimize painful feelings. Consequentialism is a broader category that recognizes that there are many different accounts of what "good consequences" are. So, preference satisfaction consequentialism states that one should maximize the satisfaction of preferences (whether or not such satisfaction also maximizes pleasurable feelings). A second example is objective list consequentialism, which identifies a list of goods (such as friendship, knowledge, veracity) such that persons should seek to maximize the obtaining of goods on the list (such a view requires a scheme for trading-off between the goods, as when a gain in friendship requires a loss of veracity). At the center of Mill's utilitarianism is the claim that only consequences matter in moral evaluation. It is possible to hold firm to this central claim, and yet modify significant aspects of the theory. This means that consequentialist theories of ethics may have the resources, despite first appearances, to answer the sorts of criticisms that have been leveled at them.

Many of Mill's ideas are directly relevant to health care ethics. Although Kant is more often seen as the champion of autonomy and informed consent, Mill's arguments in *On Liberty* also provide justification for these ideals. In addition, consequentialism is at base the method presupposed in cost-benefit analysis, and thus is at the heart of many policy decisions. Indeed in some ways consequentialism seems more appropriate for policy decisions made at an institutional level than it does for guiding individuals in their personal decisions.

But perhaps Mill's ideas have been most influential in debates about care at the end-of-life. Mill believed that no category of action is intrinsically morally good or bad — the morality of an action depends on its consequences, not on the type of action that it is. This has important implications for end-of-life decisions. For example, in the early 1980s a not uncommon view was that withholding treatment is permissible in certain circumstances, but withdrawing treatment is never permissible (Cugliari & Miller, 1994). The idea was that withdrawing life-sustaining treatment is a category of action that is tantamount to killing. Consequentialists, on the other hand, were less concerned about the category (withholding or withdrawing) and more concerned with the consequences of doing either in a particular situation. They argued that the cat-

egories themselves have no moral relevance: only the consequences of individual actions (or omissions) have moral relevance. As we know, the utilitarian position on this issue has been adopted in current medical practice (although there are dissents [Sulmasy & Sugarman, 1994]). A very similar debate occurred around withdrawing medical nutrition and hydration in the late 1980s, prompted primarily by the Nancy Cruzan case (Lynn & Childress, 1983). Some argued that providing food and water is a special category of action required by morality (Callahan, 1983). Others argued that if the best thing for someone is that she be allowed to die, then it did not matter whether this occurs because food and fluid is withdrawn or because another intervention such as a ventilator is withdrawn. Here, again, the position consistent with utilitarianism has been adopted.

The reader will have already surmised that the story is not over yet. Consequentialism tends to undermine the moral relevance of the distinction between killing and allowing to die. But this distinction is very important in current law and medical practice. In every jurisdiction in the United States, practitioners may allow a patient to die by withholding or withdrawing treatment. But in every jurisdiction in the United States, except Oregon, practitioners cannot kill their patients or assist patients in killing themselves. This means that extubating a terminally ill patient who is in great pain and has requested to be allowed to die is permissible, even if one knows that death will occur with extubation. But it is not permissible to kill a patient who is in identical circumstances except that he has no respirator to remove. Imagine that the consequences for the patients (and others) in each case are identical: the consequentialist would argue that if it is good to omit treatment in the first case, then it is also good to kill the patient in the second case (Rachels, 1975, 1986). But this consequentialist viewpoint has yet to be adopted, and it looks as if popular opinion is moving in the opposite direction (Emmanuel XXXX). One note of caution, here, is that there are also consequentialist arguments against active euthanasia and physician-assisted suicide, most prominently the concern that the long-term effects of legalizing active euthanasia and physician assisted suicide will include eroding society's respect for human life in general.

## HEALTH CARE ETHICS

### PRINCIPLES IN HEALTH CARE ETHICS

The most prominent way of organizing consensus on ethical issues in health care into a usable methodology is the principles method. The principles method identifies a small number of general rules, and subsumes more particular and concrete obligations under the general rules. A number of authors use principles to develop a method-

ology for identifying and resolving ethical conflicts that arise in clinical settings (Veatch, 1981). The best-known principles method is that of Tom Beauchamp and James Childress, *Principles of Biomedical Ethics*, now in its fifth edition (Beauchamp & Childress, 2003). Beauchamp and Childress identify four principles:

1. *Beneficence: One's actions ought to benefit the patient.* Health care providers perform actions in order to improve a patient's health, prevent disease, or generally enhance a patient's welfare. This is a positive duty, that is, a duty to perform actions. Under this principle, Beauchamp and Childress discuss paternalism, suicide prevention, futility, risk-benefit assessments, quality of life, and other topics.
2. *Nonmaleficence: One's actions ought not to harm the patient,* inspired by *Primum non nocere* (First, do no harm) from the Hippocratic oath. This is a negative duty, that is, a duty to refrain from certain actions. Under this principle, Beauchamp and Childress discuss withholding and withdrawing life-sustaining treatments, physician-assisted suicide, double effect, surrogate decision making, and other topics.
3. *Respect for Autonomy: One should respect a patient's authority to make decisions about his or her health care.* Persons have a basic right to make decisions about their lives and bodies. This is both a negative and positive duty. One should refrain from actions that diminish a patient's autonomy. One should perform actions that enhance a patient's autonomy; in particular, one should provide a patient the tools and support necessary to make good decisions. Under this principle, Beauchamp and Childress discuss informed consent, competency, disclosure, coercion, and other topics.
4. *Justice: One must fairly balance the interests of all the parties affected by a decision.* Under this principle, Beauchamp and Childress discuss resource allocation, rationing, rights to health care, ageism, racism, sexism, and other topics.

A common misperception about Beauchamp and Childress's method is that they offer only general principles as guidelines for resolving clinical disputes. These general principles are viewed as being not very helpful in resolving concrete and particular disputes. In fact, Beauchamp and Childress present general principles, such as respect for autonomy, and then use the principles to derive more specific rules that provide concrete recommendations. For example, Beauchamp and Childress present a detailed set of guidelines regarding procedures for obtaining informed consent under the category of Respect for Autonomy.



A close look at the principles reveals that they are grounded in some of the ethical theories that we have discussed. Respect for autonomy has a decidedly Kantian flavor, particularly because Beauchamp and Childress understand respect for autonomy as requiring both negative and positive duties, which correspond roughly to what Kant called perfect and imperfect duties. For Kant, autonomy did not mean the mere freedom to do as one wishes, but rather the capacity to use one's reason to make good decisions. This can be seen in Kant's explanation of both perfect and imperfect duties. Kant held that we have a perfect duty to refrain from certain actions because these actions interfere with the exercise of a person's autonomy. For example, lying to an individual robs her of the opportunity to make the best decision possible by keeping relevant information from her. Kant also held that we have an imperfect duty to help individuals make good decisions. Thus, Kant explains that the reason we must help someone in need is not only to make the person happier, but also to help support the ability of the individual to make autonomous decisions (O'Neill, 1977). Likewise, for Beauchamp and Childress the purpose of the procedures for obtaining informed consent are not merely meant to protect the freedom of the patient, but also to help the patient make the decision that is best for him or her.

Benevolence is grounded in utilitarian ethics. The idea is simply that health care providers should have the best interest of the patient at heart. Indeed, this may be one of the primary reasons that people go into health care ethics, the desire to help others. Benevolence has been associated with paternalism, the view that one should do what is good for the patient regardless of whether the patient is aware of what is being done and regardless of whether the patient desires what is being done. While Mill is himself decidedly antipaternalistic, utilitarianism, theoretically at least, could justify over-riding rules meant to protect patient self-determination in the name the patient's best interest. While this may make benevolence seem like a sinister principle, one should also recognize that the desire to do good for others has motivated many noble actions.

The most important criticism of Beauchamp and Childress's methodology involves the balancing of principles in cases of conflict between principles. Beauchamp and Childress say that their principles are *prima facie* binding (Beauchamp & Childress, 2003, p. 19–24). This means that following each principle is a moral requirement unless two or more principles are in conflict. Of course, in almost all difficult cases there are at least two principles that conflict with each other — that is primarily what makes a difficult ethical decision difficult. When two principles conflict with each other, Beauchamp and Childress say that one must balance the principles. This means, in effect, that one must decide which principle is the most important in this case, and resolve the dispute in favor of this principle. Unlike some authors who adopt a principles

approach,\* Beauchamp and Childress do not set up the principles in a hierarchy such that one principle always “trumps” another principle. Rather, any of the four principles could be the most important principle in any particular case — it is up to clinicians to use their judgment to make a decision about which principle “wins” in the case.

In their treatment of many issues, Beauchamp and Childress try to do this balancing in advance. That is, they consider potential conflicts between principles, raise arguments on both sides, and then specify which principle ought to be considered most important in that case. To take a simple example, if a person shows up at an emergency room in need of medical attention, but is not competent to express a preference about receiving treatment and no other information about the person's desires are available, then the ER staff is authorized to provide medical treatment even if the treatment carries some risks with it. In this case, the principle of beneficence (to act in the patient's best interest) is more important than the principle of respecting autonomy (to not treat a patient unless she consents). A second example involves telling a patient the truth about his cancer diagnosis. A clinician might feel that telling the patient the truth will increase his depression and perhaps accelerate the disease process. Beauchamp and Childress suggest the patient needs to know the truth to freely choose a treatment and to plan for the next period of his life, and this is more important than the likely worsening of depression. Respect for autonomy is more important in this situation than beneficence (and perhaps also nonmaleficence). Just because a principle is deemed of secondary importance, however, does not mean that the principle lacks all importance and that steps cannot be taken to ameliorate any problems from the partial disregard of that principle. In the last example, the practitioner could be careful to provide the diagnosis in as gentle and reassuring a manner as possible, as well as be vigilant to treat the depression as medically indicated.

In many situations of conflict, however, it is impossible to do the balancing of principles in advance. This has led to the criticism, made by primarily by K. Danner Clouser and Bernard Gert, that Beauchamp and Childress do not provide any real help in resolving situations of conflict (Clouser & Gert, 1990; Clouser, Gert & Culver, 1997). In essence, the criticism is that all that Beauchamp and Childress have done is provide some very general labels for moral values that everyone accepts. In difficult cases these labels do little good. Rather, in difficult cases it is up to the clinician to decide which values are most important, and it is in coming to this decision that all of the substantive ethical reasoning is performed. Thus, so the criticism alleges, the Beauchamp and Childress method for identifying the correct action in difficult cases

\* For example, Veatch, R. *A Theory of Medical Ethics*, Georgetown University Press, Washington, 1981

fails to achieve its goal, for in these cases it offers no answer at all.

Beauchamp and Childress defend themselves not by backing away from the *prima facie* nature of their principles, but by offering criteria to make balancing less “intuitive and open-ended”:

1. Better reasons must be given in favor of the overriding principle.
2. The moral objective for infringing a principle must have a realistic prospect of achievement.
3. The infringement of a principle must be the least possible commensurate with achieving the primary goal.
4. The negative effects of the infringement should be minimized.
5. The decision must be made in an impartial manner. (Beauchamp & Childress, 2003, p. 19–20)

Whether or not these steps are enough to answer the criticism raised by Clouser and Gert, their criticisms have highlighted an alternative set of methodologies for resolving ethical disputes in clinical settings.\*

### OTHER METHODOLOGIES IN HEALTH CARE ETHICS

The alternatives to principles that I discuss are virtue theory, casuistry, and the ethics of care. Interestingly, these approaches to clinical decision making do not identify moral duties that are uncontroversial in their application and thus less open to interpretation than is Beauchamp and Childress’s method of balancing. Rather, these alternatives embrace discretion and very open-ended methodologies in ethical decision making. Their common theme is that if discretion cannot be eliminated from ethical decisions, then methods for decision making ought to admit to this, rather than offering principles that promise but do not deliver definite answers. I should be clear, however, that these alternatives are not thereby accepting ethical relativism — the view that a person’s belief that an action is morally correct is sufficient for the action to be morally correct. Rather, the alternative theories hold that morality is objective, that is, there is a correct answer to a moral question that arises in a particular situation. The alternatives simply hold that principles are not the best way to identify this answer; rather, individuals should trust in other means to arrive at the objectively correct answer.

#### Virtue Theory

In Aristotle’s ethics we have already examined some of the central themes of contemporary virtue theory. Virtue

theorists emphasize the importance of moral experts to discern the morally relevant features of a situation. Further, such experts use judgment and skill to respond to the moral problem, rather than reaching decisions based on rigid and overly simple sets of rules. The best-known advocates of virtue theory in health care ethics are Pellegrino and Thomasma (1988, 1993). Using a decidedly Aristotelian methodology, Pellegrino and Thomasma argue that medicine is a distinct human activity that has its own ends, goals, and purposes. From the purposes of medicine, Pellegrino and Thomasma derive the virtues required of those who would practice medicine: fidelity to trust, compassion, *phronesis* (practical wisdom), justice, fortitude, temperance, integrity, and self-effacement. The physician who embodies these character traits to a high degree is an exemplary physician, and these traits will guide him or her in her moral decisions. Again borrowing a page from Aristotle, Pellegrino and Thomasma downplay the importance of formal education in ethics, citing instead the importance of developing a virtuous character in the actual practice of medicine as a result of working “in the trenches” with senior members of the profession who are role models for virtue. Pellegrino recently appealed to some of these themes in an editorial on Iraqi physicians’ complicity in torture. Criticizing the claim that education in ethics would have helped Iraqi physicians resist complicity, Pellegrino writes:

This tendency to see education as a panacea is a common misconception. Rarely do courses in ethics make one virtuous. Nor does extensive familiarity with the intricacies of moral discourse guarantee moral wisdom.... More than education is needed. Character formation is, in the end, the surest way to inculcate the virtues. This cannot occur unless the culture of the profession is itself ethically rigorous. Even the most virtuous physicians need a supportive culture to remain virtuous. (Pellegrino, 2004, 1505–1506)

While virtue theory as developed by Pellegrino and Thomasma may rely the judgment of moral experts, virtue theory in their interpretation does not deny that there are objective moral truths by which practitioners must abide. In fact, in their emphasis on beneficence at the expense of respect for autonomy, their theory tends to underwrite a fairly conservative position on substantive moral issues such as active euthanasia and physician-assisted suicide. Simply put, Pellegrino and Thomasma argue that these actions are contrary to the ends, goals, and purposes of medicine.

#### Casuistry

Casuistry is the method embraced by some leaders in the field of health care ethics, particularly Albert Jonsen (Arras, 1991; Jonsen & Toulmin, 1988; Jonsen, Siegler & Winslade, 1998). Casuistry is the view that past cases are

\* For an overview of the debate, see Davis, R.B., The Principlism debate: A critical overview, *Journal of Medicine and Philosophy* 20, 85-105, 1995.

the repository of ethical knowledge. One decides a current case by judging that it is similar in all relevant respects to an earlier case, and applying the decision from the earlier case to the current case. This is essentially the system of identifying precedents used by judges in the legal system. This type of ethical reasoning requires careful analysis of the similarities and differences between cases, and judgments about which similarities and differences are ethically relevant and which are not. Casuistry has a number of features to recommend it. First, health care providers may already use this form of reasoning in their clinical practice, comparing a current patient to earlier ones. Second, case presentation is typically an interesting and effective type of learning. Third, it is *de facto* the way in which much of health care ethics is taught. Consider Tarasoff, Quinan, Cruzan, Donald “Dax” Cowart, Timothy Quill’s patient Diane, Barney Clark, Kimberly Bergalis: each name brings to mind a set of issues and lessons learned. Casuistry has a number of limitations, however. First, knowledge of a wide range of cases in health care ethics takes some time to acquire. Second, casuistry is somewhat conservative (i.e., resistant to change and reform), since it relies on the assumption that past cases were decided correctly. Third, federal, state, and institutional policies cannot merely reference past cases, but must be written in the form of rules, thus reintroducing principles into health care ethics. Nevertheless, casuistry may be an important supplement to a methodology that also includes ethical principles (Toulmin, 1981).

### The Ethics of Care

The ethics of care is an important strand of the vibrant and growing field of feminist ethics. The term *ethics of care* was first coined in 1982 by Carol Gilligan (a clinical psychologist) in her book, *In a Different Voice*, where Gilligan argues that many women frame moral issues and problems “in a different voice” from many men (Gilligan, 1982). According to past research in moral development, many men frame moral issues as matters of conflicting rights and obligations, and questions of justice and fairness. Gilligan found, however, that many of the women she studied resisted understanding moral problems this way. Instead, the women focused on issues of caring and relationships: whether a relationship should be continued, and if it should how best to care for and meet the need of the members of the relationship. While Gilligan’s empirical findings and their connection with gender have been the subject of much controversy, it is clear that her articulation of a care-based moral outlook as an alternative to the predominant justice-based moral outlook has struck a chord with many contemporary writers on ethics (Carse, 1991; Little, 1998). Gilligan and subsequent writers on the ethics of care have argued that the justice-based view overlooks many important facets of the moral life. The

care ethic, on the other hand, brings these features sharply into focus. For example, whereas the justice ethic assumes that moral situations involve free, equal, autonomous, and independent individuals, the care ethic emphasizes that in many cases these features of a relationship do not obtain. Individuals often find themselves embedded in relationships in which the members are unequal, where some of them are not fully autonomous, or fully free, or fully independent of the other members. Surely, the care ethicist argues, morality pertains to the parent–child relationship, where the individuals are not equals, not fully independent or free of one another, and moreover one of the members of the relationship may not be autonomous. Similarly, many feminists have argued that the abortion debate has become intractable precisely because the two “individuals” involved (mother and fetus) are viewed as free, equal, autonomous, and independent individuals. Whatever position one takes on abortion, it is argued, one should not understand the involved parties as the justice framework does: the fetus is metaphysically a *relational* being — it simply cannot survive (prior to 22 weeks of age) outside of a woman’s body.

The ethics of care has made important contributions to health care ethics. For example, some ethicists of care have emphasized that the patient–provider relationship may not be best understood on the consumer model, where the consumer is a free and equal member of the relationship, contracting for a certain service in exchange for a monetary fee. Instead, some ethicists of care have reminded us that serious illness causes fear, anxiety, and some dependency, even in otherwise autonomous adults. Moreover, the relationship between patient and health care provider is necessarily a relationship among unequals: the health care provider is far more knowledgeable about medicine and disease than the patient, while the patient is far more knowledgeable about her life as a whole and the values she holds. Pointing all this out also makes it clear that the members of this relationship have special responsibilities to one another. The health care provider ought to acknowledge and respond with caring to the vulnerability and anxiety of her patient. The patient on the other hand ought to be open and honest with her care provider.

There are some limitations to the ethics of care. For one, some defenders of the justice perspective have wondered whether the care ethic represents a distinct moral perspective or simply an addition to the justice perspective. For another, it is clear that some moral problems, even ones in relationships of unequals (e.g., child abuse) are better viewed in the justice perspective. Other moral situations are better viewed through the lens of care. However, it is not always — or even often — clear which lens to use. Indeed, as I pointed out above, some feminists think that abortion should only be viewed through the lens of care. But this point is contentious, and as of the moment, there appears to be no clear way to determine



which framework to use to grapple with a particular moral problem. Nevertheless, the choice of one framework over another will often point toward one resolution or another. So the choice is a deeply normative one, but one without clear criteria to guide it.

## ISSUES IN PALLIATIVE CARE

Some ethical issues tend to arise more frequently in the context of providing palliative care. These issues include (1) the moral status of the decision to forgo life-prolonging treatment, (2) informed consent and truth-telling, and (3) the interplay of curing and caring as the goals of medicine. I want here to sketch how some of the authors we discussed would respond to these issues, although I would also caution that my sketch is brief and programmatic, and that there is significant room for disagreement in the interpretation of the historical figures on these issues.

### The Moral Status of Decisions at the End-of-Life

Laws, codes of professional ethics, and public opinion generally draw a distinction between withholding/withdrawing life-sustaining treatment and “active” means of ending life such as physician-assisted suicide or the administration of large quantities of opiates with the intention of ending life. We have seen that a consequentialist approach to ethics would tend to undermine the moral relevance of this distinction between what has been called passive and active euthanasia. For example, Mill holds that only the consequences of an action (or omission) matter to the moral goodness of the action. As long as their were no long-term bad consequences for society, Mill might favor having the legal option of ending a terminally ill patient’s suffering more quickly than merely withdrawing life-sustaining treatment would allow. This position would also be supported by Mill’s arguments against paternalism, as expressed in *On Liberty*. Nevertheless, there are limitations to how far Mill might be willing to take this position. For example, if adequate pain management is available, it is a least theoretically possible for him to argue that the long-term costs to society (in the erosion of an ethic of respect for life) would outweigh any benefits to the particular patient. However, while this type of slippery slope argument is often mentioned in contemporary debates, I think it is unlikely that Mill would avail himself of it.

Deontologists, such as Augustine, Kant, and Aquinas, are much more likely to hold that the distinction between passive and active euthanasia is morally relevant, in part, because the distinction between intrinsically wrong and permissible types of actions is central to their theories. Each theorist also holds that suicide is intrinsically wrong. Kant seems to hold that one cannot protect autonomy by ending human life — if life is over, there is no chance to

be autonomous. It is unclear whether Kant would also hold that withdrawals of treatment that result in death also are inconsistent with protecting autonomy. Augustine and Aquinas, however, would recognize that withdrawing treatment in some circumstances is consistent with the good of the patient, since it is merely allowing the natural process of death to occur. Aquinas would invoke the principle of double effect to show that it is permissible to give pain medications, even with the risk of hastening death. The limit on this practice would be when the pain medication is given at such a dose that it constitutes a poison such that death is intended and/or the relief of pain is accomplished only by the death of the patient.

### Informed Consent and Truth-Telling

Kant is often taken to be the inspiration for the modern doctrine of informed consent. Indeed, Kant not only believes that there is strict requirement not to lie to patients about their prognosis, but he would also hold that health care providers have an obligation to fully and truthfully provide information to patients to allow them to make decisions about care at the end of life — not to do so is to fail to respect the patient as a person. Kant would deny that a health care provider is required to follow every instruction given to her by a patient — a health care provider is not compelled to act contrary to the categorical imperative. But if a health care provider refuses to follow patient instructions as a matter of conscience, this too must be fully and truthfully disclosed to the patient. It is fair to say that Kant would require a good deal more transparency in communication between patients and care providers than is now the case in many institutions.

Theoretically, it is possible that Mill might think it best to lie to a patient to alleviate the patients’ suffering. However, given Mill’s extremely negative assessment of paternalism, it is more likely that Mill would see the potential for harm in lying to outweigh values from ameliorating depression. Indeed, Mill might worry that deceit would be likely to increase suffering as patients began to recognize inconsistency in their health care providers behaviors regarding their care.

### Curing and Caring

Health care professionals have obligations to attempt to cure patients of disease (and repair their injuries), as well as to care for patients who are experiencing pain and suffering. Mill is the only philosopher that we have discussed that emphasizes the badness of physical pain. Indeed, rather starting with the idea that some pain is useful (e.g., to keep us from danger, to teach us fortitude) as some philosophers do, Mill is clear that pain is always bad. For Mill, an episode of avoidable pain is to be tolerated only if (1) it prevents worse pain in the future or (2)

it will produce or allow for a stronger feeling of pleasure. In this sense, Mill's philosophy fits well with the goals of palliative care, which recognizes that most if not all of a patient's pain should be ameliorated in the context of caring for those with life-threatening illnesses.

Last, Aristotle's ethics complements palliative care's emphasis on caring for the emotional needs of the patient. As we have seen, Aristotle holds that an essential part of being morally good is experiencing the appropriate emotion in response to a situation. This might mean that a care provider's laugh at a patient's joke is genuine, allowing the patient a moment of respite in an otherwise difficult day. It might mean that a care provider knows how to comfort a patient, even in the midst of a very quick and efficient visit. Aristotle is clear that feeling the appropriate emotion is important to discerning the appropriate action: unless one feels compassion, one cannot "see" the right way to be compassionate in a situation. One need not think of this as some magic new ability to see occult objects. It might only mean that one has a subtle understanding of a patient's fears, so that one is sensitive to language that might raise these fears. This sensitivity may be a physical rather than intellectual. To change examples for a moment, think of one's response to an offensive, racist joke — the first reaction is in the body, a cringing, a clenching of the stomach, and only then does one consciously think of the words of the joke and explain to oneself why it is offensive. Likewise, one might be so "tuned-in" to one's patient that the knowledge that he needs some particular object is simply felt, rather than resulting from a minute of problem-solving deliberation. Feeling (rather than feigning) emotions is important for another reason as well. Persons with life-threatening illnesses, like the rest of us, are very good at picking up subtle inconsistencies between affects, behaviors, and spoken words. Telling a patient one thing, while one believes another, is likely to raise the anxiety level of the patient as he picks up on these inconsistencies. The patient may not be able to recognize that the care provider is lying, but he will nonetheless be left with the vague feeling that "something is not right."

### CONCLUSION ON THE PERSONAL IMPORTANCE OF ETHICAL THEORY

Too many people associate ethics with a code of conduct that necessarily involves the significant sacrifice of one's own well-being in order to benefit others. People with negative views about ethics then tend to view ethics as a cage: the bars of the cage are the ethical rules that keep one from acting in one's own self-interest. I believe this view of ethics is dangerous and inaccurate. It is dangerous because it tends to drive people away from ethics. It is dangerous because even for those who would embrace

ethics, it is an ethics of self-denial and martyrdom, an ethics that encourages guilt and moralism. The ethics-as-self-sacrifice view is inaccurate because most ethical theories identify moral obligations to enhance one's own well-being, and some moral theories (such as Aristotle's and Kant's) take the enhancement of one's own well-being to be the central ethical project. A better way to understand ethics is as a tool that helps one create the sort of life of which one can be proud. Everyday each of us makes decisions that constitute who we are now and that influence what sort of person we will become. While we do not often think of decisions in these terms, it would be a tragedy to come to the end of a long life and be unable to look back with pride and pleasure at the life we have created with these decisions. And it is a rare person who would not wish to see kindness, compassion, generosity, trustworthiness, and integrity as parts of this life. A better metaphor might be that ethical theories are maps that identify desirable locations to visit and that show the best paths to these destinations. To that end, we should view Aristotle, Mill, and Kant not as providing theories that narrowly tailor our actions in the name of the rights and interests of others, but as providing theories that describe ways of life that are worth living.

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inction between a standard of right action and the motivations for pursuing right action. He claims that his theory is meant to address only the former issue.

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citation





<b>Format</b>	Large group lecture
<b>Faculty</b>	Glickman-Simon
<b>Learning Objectives</b>	<p>By the end of this lecture, you will be able to:</p> <ul style="list-style-type: none"><li>• Distinguish between beneficent and non-malificent acts</li><li>• Define medical futility and describe under what circumstances medical interventions are not indicated</li><li>• Identify the appropriate indications for cardio-pulmonary resuscitation and orders not to resuscitate</li><li>• Explain the medical and ethical implications of an evolving definition of death</li></ul>
<b>Readings</b>	Jonsen text: p 9 - 45

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## MEDICAL ASPECTS OF THE PERSISTENT VEGETATIVE STATE

### (First of Two Parts)

#### THE MULTI-SOCIETY TASK FORCE ON PVS\*

**Abstract** This consensus statement of the Multi-Society Task Force summarizes current knowledge of the medical aspects of the persistent vegetative state in adults and children.

The vegetative state is a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brain-stem autonomic functions. In addition, patients in a vegetative state show no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; show no evidence of language comprehension or expression; have bowel and bladder incontinence; and have variably preserved cranial-nerve and spinal reflexes. We define persistent vegetative state as a vegetative state present one month after acute traumatic or nontraumatic brain injury or lasting for at least one month in patients with degenerative or metabolic disorders or developmental malformations.

THE term "persistent vegetative state" was coined by Jennett and Plum in 1972 to describe the condition of patients with severe brain damage in whom coma has progressed to a state of wakefulness without detectable awareness.<sup>1</sup> Such patients have sleep-wake cycles but no ascertainable cerebral cortical function. Jennett and Plum thought that patients in a persistent vegetative state could be distinguished clinically from those with other conditions associated with prolonged unconsciousness.

In 1983 the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research accepted the definition of persistent vegetative state proposed by Jennett and Plum and defined unconsciousness as the inability "to experience the environment." In the commission's

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This statement has been approved by the American Academy of Neurology, Child Neurology Society, American Neurological Association, American Association of Neurological Surgeons, and American Academy of Pediatrics. The results of the literature search, as well as correspondence and other documents generated by the task force, are available through the American Academy of Neurology in Minneapolis.

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The clinical course and outcome of a persistent vegetative state depend on its cause. Three categories of disorder can cause such a state: acute traumatic and nontraumatic brain injuries, degenerative and metabolic brain disorders, and severe congenital malformations of the nervous system.

Recovery of consciousness from a posttraumatic persistent vegetative state is unlikely after 12 months in adults and children. Recovery from a nontraumatic persistent vegetative state after three months is exceedingly rare in both adults and children. Patients with degenerative or metabolic disorders or congenital malformations who remain in a persistent vegetative state for several months are unlikely to recover consciousness. The life span of adults and children in such a state is substantially reduced. For most such patients, life expectancy ranges from 2 to 5 years; survival beyond 10 years is unusual. (N Engl J Med 1994;330:1499-508.)

judgment, a persistent vegetative state is only one form of permanent unconsciousness.<sup>2</sup> The others include coma after a traumatic or nontraumatic injury, with death occurring before the recovery of sufficient brain-stem function to allow a stable vegetative state; the end stages of degenerative neurologic conditions, such as Alzheimer's or Creutzfeldt-Jakob disease; coma from untreatable mass lesions such as neoplasms or vascular masses; and anencephaly in infants.

Because of the diagnostic, prognostic, and therapeutic uncertainties concerning the persistent vegetative state, several professional medical organizations began a comprehensive examination of their standards of medical care for patients with this condition.<sup>3-7</sup> In 1989, the American Academy of Neurology published a position paper that defined persistent vegetative state, classified artificial nutrition and hydration as forms of medical treatment, and stated that patients or their surrogates could decide to terminate treatment and that there were no medical or ethical distinctions between withholding and withdrawing treatment.<sup>8</sup> A 1990 survey by the American Neurological Association found that 88 percent of responding members agreed with this document.<sup>9</sup> In a 1991 survey by the Child Neurology Society, 92 percent of respondents agreed with the position paper as it related to adults, but only 72 percent thought that it was applicable to infants and children.<sup>10</sup> In addition, 75 percent of the respondents to this survey indicated that they would not withdraw nutrition and hydration from children in a persistent vegetative state.

In 1990, the Council on Scientific Affairs and the Council on Ethical and Judicial Affairs of the American Medical Association issued a report that provided

clinical criteria for the diagnosis of a persistent vegetative state and discussed ethical and legal implications of decisions to withhold or withdraw life-prolonging medical treatment — matters that were receiving widespread attention at the time.<sup>11-15</sup> In 1991, the United Kingdom's Institute of Medical Ethics Working Party on the Ethics of Prolonging Life and Assisting Death published a position statement indicating that a diagnosis of persistent vegetative state could usually be made with confidence three months after the acute insult but that in young children, the extent of damage and period of recovery were less predictable.<sup>16</sup> More recently, the British Medical Association's Medical Ethics Committee and the American Neurological Association have published position papers that define criteria for the clinical diagnosis of a persistent vegetative state and address several of the ethical issues concerning the care of patients in such a state.<sup>17,18</sup>

Because of the acceptance of recent consensus statements concerning guidelines for determining brain death in children<sup>19</sup> and the medical aspects of anencephaly in infants,<sup>20</sup> the Multi-Society Task Force on PVS was established in 1991 and charged with the creation of this document. Two representatives were appointed from each of the five societies, and an advisory panel of consultants was selected from the related fields of medicine, ethics, and law. The document was approved by the executive committee of each society.

Data reviewed by members of the task force were obtained from several sources, including a comprehensive literature review of all Medline references to the terms "vegetative state" and "persistent vegetative state," a "request for information" published in medical journals supported by the five sponsoring societies, a review of stories in the popular media concerning unexpected recovery from prolonged coma, and data from the National Institute of Neurological Disorders and Stroke Traumatic Coma Data Bank.

This statement by the task force summarizes the medical facts about the persistent vegetative state; it does not address associated ethical, legal, or other issues. The statement is divided into two parts. The first defines persistent vegetative state and related terms and conditions and discusses the epidemiology, causes, and pathological features, as well as ancillary diagnostic studies. The second part addresses the prognosis for recovery and long-term survival of patients in a persistent vegetative state and discusses issues related to pain and suffering and treatment.

#### DEFINITION AND CLINICAL ASPECTS

The vegetative state is a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain-stem autonomic functions. The condition may be transient, marking a stage in the recovery from severe acute or chronic brain damage, or permanent,

as a consequence of the failure to recover from such injuries. The vegetative state can also occur as a result of the relentless progression of degenerative or metabolic neurologic diseases or from developmental malformations of the nervous system.

The vegetative state can be diagnosed according to the following criteria: (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculocephalic, corneal, vestibulo-ocular, and gag) and spinal reflexes.

The distinguishing feature of the vegetative state is an irregular but cyclic state of circadian sleeping and waking unaccompanied by any behaviorally detectable expression of self-awareness, specific recognition of external stimuli, or consistent evidence of attention or intention or learned responses. Patients in a vegetative state are usually not immobile. They may move the trunk or limbs in meaningless ways. They may occasionally smile, and a few may even shed tears; some utter grunts or, on rare occasions, moan or scream. Some patients have acquired, nonhabitual startle myoclonus. Such activities are inconsistent, nonpurposeful, and coordinated only when they are expressed as part of a subcortical, instinctively patterned, reflexive response to external stimulation. These motor activities may misleadingly suggest purposeful movements, yet these responses have been observed in patients in whom careful study has disclosed no evidence of psychological awareness or the capacity to engage in learned behavior.

As a result of the relative preservation of brain-stem functions, most patients in a vegetative state retain good to normal reflexive regulation of vision and eye movement. Some patients have unequal or irregular pupils or limited responses to vestibulo-ocular stimulation. A few patients may have signs of mild internuclear ophthalmoplegia or other oculomotor abnormalities related to the brain stem. Occasionally, one or both third nerves are paralyzed.

Sustained visual pursuit is lacking in most patients in a vegetative state. They do not fixate on a visual target, track moving objects with their eyes, or withdraw from threatening gestures. When patients undergo a transition from the vegetative state to a state of awareness, one of the first and most readily observable signs of this transition is the appearance of sustained visual pursuit. However, patients in a vegetative state often have inconsistent primitive auditory or visual orienting reflexes, characterized by a turning of the head and eyes toward peripheral

sounds or movements. In rare cases, patients who have no other evidence of consciousness over a period of months to years have some degree of briefly sustained visual pursuit or fixation, which is believed to be mediated through brain-stem structures. Nevertheless, one should be extremely cautious in making a diagnosis of the vegetative state when there is any degree of sustained visual pursuit, consistent and reproducible visual fixation, or response to threatening gestures.

The capacity for survival in a persistent vegetative state requires preservation of hypothalamic and brain-stem autonomic functions. Most patients who survive for a long time maintain normal body temperature, the ability to breathe spontaneously, and a functioning cardiovascular system. The prognosis is worse if there are hypothalamic disturbances producing central fever, excess sweating, disturbances in salt and water metabolism, and refractory pulmonary problems. In most patients, the gag, cough, sucking, and swallowing reflexes are preserved. Except for a lack of coordination in chewing and swallowing, gastrointestinal function remains nearly normal. As the prolonged survival of some patients in a persistent vegetative state suggests, autonomic function is sufficient to maintain long-term internal regulation so long as external needs receive constant attention.

#### RELATED TERMS AND CONDITIONS

##### Unconsciousness, Coma, and the Vegetative State

The term "consciousness" was defined by William James in 1890 as awareness of the self and the environment. Consciousness has two dimensions: wakefulness and awareness. Normal consciousness requires arousal, an independent, autonomic-vegetative brain function subserved by ascending stimuli from the pontine tegmentum, posterior hypothalamus, and thalamus that activate wakefulness. Awareness is subserved by cerebral cortical neurons and their reciprocal projections to and from the major subcortical nuclei. Awareness requires wakefulness, but wakefulness can be present without awareness.

Unconsciousness implies global or total unawareness and is characteristic of both coma and the vegetative state. Patients in a coma are unconscious because they lack both wakefulness and awareness. Patients in a vegetative state are unconscious because, although they are wakeful, they lack awareness. In this report we use the terms awareness and consciousness interchangeably.

##### *Persistent as Compared with Permanent Vegetative States*

As originally defined by Jennett and Plum in 1972, the term "persistent," when applied to the vegetative state, meant sustained over time; "permanent" meant irreversible.<sup>1</sup> Notwithstanding Jennett and Plum's precise use of language, confusion has arisen over the exact meaning of the term "persistent." The adjective "persistent" refers only to a condition of past and continuing disability with an uncertain future, whereas

"permanent" implies irreversibility. Persistent vegetative state is a diagnosis; permanent vegetative state is a prognosis.

A wakeful unconscious state that lasts longer than a few weeks is referred to as a persistent vegetative state. We define such a state operationally as a vegetative state present one month after an acute traumatic or nontraumatic brain injury or a vegetative state of at least one month's duration in patients with degenerative or metabolic disorders or developmental malformations. A permanent vegetative state, on the other hand, means an irreversible state, which like all clinical diagnoses in medicine, is based on probabilities, not absolutes. A patient in a persistent vegetative state becomes permanently vegetative when the diagnosis of irreversibility can be established with a high degree of clinical certainty — that is, when the chance that the patient will regain consciousness is exceedingly small. We believe there are sufficient data on the prognosis for neurologic recovery to allow us to distinguish between persistent and permanent vegetative states. These data, in conjunction with other relevant factors in an individual patient, can be used by a physician to determine when the persistent vegetative state becomes permanent — that is, when a physician can tell the patient's family or surrogate with a high degree of medical certainty that there is no further hope for recovery of consciousness or that, if consciousness were recovered, the patient would be left severely disabled.

##### *Diagnostic Factors and the Limits of Certainty*

By definition, patients in a persistent vegetative state are unaware of themselves or their environment. They are noncognitive, nonsentient, and incapable of conscious experience. There is, however, a biologic limitation to the certainty of this definition, since we can only infer the presence or absence of conscious experience in another person.<sup>21</sup> A false positive diagnosis of a persistent vegetative state could occur if it was concluded that a person lacked awareness when, in fact, he or she was aware. Such an error might occur if a patient in a locked-in state (i.e., conscious yet unable to communicate because of severe paralysis) was wrongly judged to be unaware. Thus, it is theoretically possible that a patient who appears to be in a persistent vegetative state retains awareness but shows no evidence of it. In the practice of neurology, this possibility is sufficiently rare that it does not interfere with a clinical diagnosis carefully established by experts.

Several individual signs of unconsciousness, as well as a small number of laboratory tests, are very closely correlated with the diagnosis of the condition of unconsciousness that characterizes a persistent vegetative state. At present, three lines of evidence based on careful clinical and laboratory studies support the conclusion that patients in a persistent vegetative state are unaware of themselves or their environment.<sup>8,11,21</sup> First, motor or eye movements and facial expressions

in response to various stimuli occur in stereotyped patterns that indicate reflexive responses integrated at deep subcortical levels rather than learned voluntary acts. The presence of these responses is consistent with complete unawareness. Second, positron-emission tomographic studies of regional cerebral glucose metabolism show levels far lower than those in patients who are aware or in a locked-in state. These low metabolic rates are comparable to those reported during deep general anesthesia in normal subjects whom all would agree are unaware and insensate.<sup>22</sup> Finally, all available neuropathological examinations of the brains of patients with a clinical diagnosis of a persistent vegetative state show lesions so severe and diffuse that awareness would have been highly improbable, given our biologic understanding of how the anatomy and physiology of the brain contribute to consciousness.<sup>23,24</sup>

An accurate diagnosis is critical. Errors in diagnosis have occurred because of confusion about the terminology used to describe patients in this condition, the inexperience of the examiner, or an insufficient period of observation.<sup>25</sup> Physicians caring for such patients should be aware of these potential problems and be as precise and careful as possible when applying the suggested clinical criteria.<sup>26</sup>

#### Related Conditions

Other conditions of severe neurologic disability or altered consciousness include coma, brain death, the locked-in syndrome, and dementia (Table 1).

Coma is deep, sustained pathologic unconsciousness that results from dysfunction of the ascending reticular activating system in either the brain stem or both cerebral hemispheres. The eyes remain closed,

and the patient cannot be aroused. To be clearly distinguished from syncope, concussion, or other states of transient unconsciousness, coma must persist for at least an hour.

Brain death is the permanent absence of all brain functions, including those of the brain stem. Brain-dead patients are irreversibly comatose and apneic and have lost all brain-stem reflexes and cranial-nerve functions. The standard clinical criteria for the diagnosis of brain death in adults, children, and newborn infants are outlined elsewhere.<sup>14,19,27-30</sup>

The locked-in syndrome refers to a state in which consciousness and cognition are retained but movement and communication are impossible because of severe paralysis of the voluntary motor system.<sup>28,31</sup> This condition may result from abnormalities in the descending corticospinal and corticobulbar pathways at or below the pons. In such cases, breathing is possible. The locked-in syndrome can also be associated with diseases of the peripheral motor nerves or paralysis produced by the administration of neuromuscular blocking agents. Patients with this syndrome can usually establish limited communication through eye-movement signals. Diagnosis of the locked-in syndrome is established by clinical examination. Brain imaging may show isolated ventral pontine infarction, and nerve-conduction studies may demonstrate severe peripheral neuropathy. Positron-emission tomographic scans have shown higher metabolic levels in the brains of patients in the locked-in state than in patients in a persistent vegetative state. Electroencephalograms, evoked responses, and single-photon-emission computed tomograms do not distinguish reliably between the locked-in and vegetative states.

Dementia is a condition of progressive, multidimen-

Table 1. Characteristics of the Persistent Vegetative State and Related Conditions.\*

CONDITION	SELF-AWARENESS	SLEEP-WAKE CYCLES	MOTOR FUNCTION	EXPERIENCE OF SUFFERING	RESPIRATORY FUNCTION	EEG ACTIVITY	CEREBRAL METABOLISM†	PROGNOSIS FOR NEUROLOGIC RECOVERY
Persistent vegetative state	Absent	Intact	No purposeful movement	No	Normal	Polymorphic delta or theta, sometimes slow alpha	Reduced by 50% or more	Depends on cause (acute traumatic or nontraumatic injury, degenerative or metabolic condition, or developmental malformation)
Coma	Absent	Absent	No purposeful movement	No	Depressed, variable	Polymorphic delta or theta	Reduced by 50% or more (depends on cause)	Usually recovery, persistent vegetative state, or death in 2 to 4 weeks
Brain death	Absent	Absent	None or only reflex spinal movements	No	Absent	Electrocerebral silence	Absent	No recovery
Locked-in syndrome	Present	Intact	Quadriplegia and pseudobulbar palsy; eye movement preserved	Yes	Normal	Normal or minimally abnormal	Minimally or moderately reduced	Recovery unlikely; persistent quadriplegia with prolonged survival possible
Akinetic mutism	Present	Intact	Paucity of movement	Yes	Normal	Nonspecific slowing	Unknown	Recovery very unlikely (depends on cause)
Dementia	Present but lost in late stages	Intact	Variable; limited with progression	Yes but lost in late stages	Normal	Nonspecific slowing	Variably reduced	Irreversible (ultimate outcome depends on cause)

\*This table provides a general overview of the persistent vegetative state and related neurologic conditions. Because of the overlap between clinical and laboratory findings, these characteristics will not apply to every patient. Neuroimaging studies (magnetic resonance imaging or computed tomography) may be useful in the clinical evaluation of patients but may not always be helpful in differentiating among these conditions. EEG denotes electroencephalographic.

†Determined by positron-emission or single-photon-emission computed tomography.

sional loss of cognitive functions in which arousal mechanisms are usually normal. Advanced dementia can progress until patients lose their self-awareness and all evidence of learned behavior. At this point, such patients are in a vegetative state.

Three other conditions deserve mention. Akinetic mutism is a rare syndrome characterized by pathologically slowed or nearly absent bodily movement and loss of speech.<sup>28</sup> Wakefulness and self-awareness may be preserved, but the level of mental function is reduced. The condition characteristically accompanies gradually developing or subacute bilateral damage to the paramedian mesencephalon, basal diencephalon, or inferior frontal lobes. Neocortical death is a term used by some authors to refer to a persistent vegetative state, but in addition to the characteristics of a persistent vegetative state, neocortical death is marked by an absence or substantial slowing of electrocortical activity on electroencephalography. Others equate neocortical death with the ostensible death of all neurons of the cerebral cortex. It is not clear, therefore, whether this term denotes a clinical syndrome or its electrical, pathologic, or anatomical features. Apallic syndrome is an archaic term for a condition that is now considered equivalent to a persistent vegetative state.<sup>32</sup> The terms "neocortical death" and "apallic state" have limited usefulness and should be abandoned, because they do not represent distinct clinical entities.

### EPIDEMIOLOGY

The prevalence of persistent vegetative state is not known because of the lack of accepted diagnostic criteria and the fact that, until recently, neither the *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM), nor most health agencies included persistent vegetative state as a codable diagnosis. According to estimates, however, in the United States there are 10,000 to 25,000 adults and 4,000 to 10,000 children in a persistent vegetative state.<sup>6,10,11,15,16,33-47</sup>

### CAUSES AND CLINICAL COURSE

The clinical course of a persistent vegetative state depends on the particular underlying disease process.

#### Acute Traumatic and Nontraumatic Injuries

The most common acute causes of the vegetative state in adults and children are head trauma and hypoxic-ischemic encephalopathy (Table 2). The clinical course after the acute insult usually begins with coma (with eyes closed) for several days to weeks, during which time the acute illness stabilizes and the stunned but ultimately viable brain stem and lower diencephalon resume function.<sup>43-45</sup> By this time, most patients are able to breathe spontaneously and no longer require ventilatory assistance. After the interval of coma, spontaneous opening of the eyes, random eye movements, blinking, and limb movements occur, along with sleep-wake cycles. In a few patients,

Table 2. Causes of the Persistent Vegetative State in Adults and Children.\*

<b>Acute injuries</b>
<i>Traumatic</i>
Motor vehicle accidents
Gunshot wound or other form of direct cerebral injury
Nonaccidental injury in children
Birth injury
<i>Nontraumatic</i>
Hypoxic ischemic encephalopathy
Cardiorespiratory arrest
Perinatal asphyxia
Pulmonary disease
Prolonged hypotensive episode
Near-drowning
Suffocation or strangulation
Cerebrovascular injury
Cerebral hemorrhage
Cerebral infarction
Subarachnoid hemorrhage
CNS infection
Bacterial meningitis
Viral meningoencephalitis
Brain abscess
CNS tumor
CNS toxins or poisoning
<b>Degenerative and metabolic disorders</b>
<i>In adults</i>
Alzheimer's disease
Multi-infarct dementia
Pick's disease
Creutzfeldt-Jakob disease
Parkinson's disease
Huntington's disease
<i>In children</i>
Ganglioside storage disease
Adrenoleukodystrophy
Neuronal ceroid lipofuscinosis
Organic aciduria
Mitochondrial encephalopathy
Gray-matter degenerative disorders
<b>Developmental malformations</b>
Anencephaly
Hydranencephaly
Lissencephaly
Holoprosencephaly
Encephalocele
Schizencephaly
Congenital hydrocephalus
Severe microcephaly

\*Includes only the most common disorders that have been reported to cause a persistent vegetative state in each of the three categories. CNS denotes central nervous system.

the vegetative state occurs immediately after the insult, without an initial period of coma.

A persistent vegetative state develops in approximately 1 to 14 percent of patients in prolonged traumatic coma and in 12 percent of those in prolonged nontraumatic coma.<sup>46-51</sup> Although numerous studies have examined a wide variety of clinical and laboratory variables, no well-established criteria applied during the period of coma can, with certainty, predict a vegetative outcome.<sup>52-54</sup> Some evidence suggests a direct correlation between a post-traumatic vegetative outcome and the presence of ventilatory dysfunction, decorticate posturing, and extraneural trauma soon after the insult.<sup>55</sup> Other variables that are correlated with a poor outcome include an advanced age, pupillary abnormalities, and a low score on a test of motor responses.<sup>47</sup> In patients with nontraumatic coma, im-

pairment of eye opening, the presence of abnormal oculocephalic or motor responses, and the inability to obey commands at two weeks are all correlated with a vegetative outcome.<sup>56</sup>

### Degenerative and Metabolic Disorders

Many degenerative and metabolic nervous system disorders in adults and children inevitably progress to an irreversible vegetative state. The early stages of such disorders are marked by progressive impairment of intellect, memory, language, motor skills, and social behavior, yet many patients retain some degree of awareness of themselves and their environment. In later stages, awareness disappears, marking the start of a vegetative state.

In patients with degenerative diseases, a persistent vegetative state usually evolves over a period of several months or years.<sup>57</sup> Those who remain in a vegetative state may die of a superimposed infectious illness. Those who survive such an illness remain in a vegetative state or go into a coma. Patients with degenerative diseases who have severe impairment but retain some degree of awareness may lapse briefly into a vegetative state from the effects of medication, infection, superimposed medical or surgical illnesses, seizure activity, or decreased fluid and nutritional intake.<sup>57</sup> The possibility of such a temporary metabolic or toxic encephalopathy must be eliminated before establishing that the patient is in a persistent vegetative state.<sup>21</sup>

### Developmental Malformations

Severe congenital malformations of the nervous system in infants and children may prevent the development of awareness or cognition. Among the malformations associated with the developmental vegetative state are anencephaly and hydranencephaly (Table 2). Diagnosis of the vegetative state in infants and children poses several problems related to the immaturity of the developing brain and the ongoing influences of development on the potential for reorganization of structure and function.<sup>58</sup>

On the basis of our understanding of development, the diagnosis of the vegetative state may be difficult to make in infants younger than three months, except in the case of infants with anencephaly. Newborns and young infants have a limited ability to show higher cognitive functions before this age.<sup>59,60</sup> Although they are capable of a variety of social responses, including visual and auditory orientation, cuddling, the ability to be consoled, and self-quieting behavior, these responses may be tenuous, inconsistent, and unsustainable until three months of age.<sup>61,62</sup> The concept of the vegetative state cannot be applied to preterm infants because of developmental immaturity and, to a lesser extent, the lack of consistently recognizable sleep-wake cycles.<sup>63,64</sup>

Recognition of the vegetative state in infants and young children also depends on the ability to distinguish between voluntary and involuntary responses.

<sup>65,66</sup> Differentiation of voluntary from involuntary responses may be unreliable until approximately three months of age. Voluntary behavior that can be elicited includes a consistent and sustained response of turning to or following visual or auditory stimuli, a growing awareness of social stimuli, cuddling in response to interactions experienced as comforting, and a preference for a specific behavior when several choices are presented. Involuntary behavior includes blinking or wandering, nonpurposeful eye movements; nonspecific sounds and grimace-like expressions in reaction to noxious stimuli; and primitive reflexes, including grasp, postural, startle, and alerting responses.

Some newborn infants with severe developmental malformations, such as hydranencephaly, have a minimal cerebral cortex or none. Such infants usually remain in a developmental vegetative state. Because some brain tissue is developing, these infants may have a limited awareness of their environment and minimal purposeful motor activity within the first several months of life.<sup>67,68</sup> However, only limited improvement has been reported in such children. Those with less extensive malformations (such as certain types of holoprosencephaly or lissencephaly) may appear to be in a vegetative state as infants but eventually show some evidence of awareness and responsiveness. Such infants generally continue to have severe disabilities. There are few reports describing the clinical course of such patients, but some degree of consciousness may emerge.

### PATHOLOGIC FEATURES

The anatomical basis for a persistent vegetative state differs somewhat from case to case, for several reasons. The interval between brain injury and death affects the nature and severity of pathologic changes. Patients in a vegetative state who die early of medical complications are unlikely to undergo neuropathologic changes that would be sufficient to cause chronic unconsciousness in long-term survivors. Furthermore, in patients with chronic neurologic conditions, other complicating factors, such as severe atherosclerotic disease, may independently injure the brain. In such patients, it may be difficult to determine at autopsy exactly which neuropathologic changes accompanied the initial failure to recover consciousness.

Allowing for the above limitations, two major patterns have characterized most detailed reports on the neuropathology of a persistent vegetative state due to acute traumatic or nontraumatic brain injury. We are not aware of any systematic investigation of the neuropathologic characteristics of patients in whom a persistent vegetative state was due to degenerative, metabolic, or developmental disorders.

### Diffuse Laminar Cortical Necrosis

This pattern follows acute, global hypoxia and ischemia. The principal finding is extensive multifocal or diffuse laminar cortical necrosis with almost invari-

able involvement of the hippocampus. These abnormalities may be accompanied by scattered small areas of infarction or neuronal loss in the deep forebrain nuclei, hypothalamus, or brain stem.<sup>23,69</sup> Relatively selective thalamic necrosis may also follow acute global ischemia, although the specific anatomical boundaries for this uncommon pattern have not been well described<sup>70</sup> (and see the report, elsewhere in this issue of the *Journal*, on studies of the brain of Karen Ann Quinlan).<sup>71</sup>

#### Diffuse Axonal Injury

This abnormality is usually due to a shearing injury after acute trauma. An extensive subcortical axonal injury virtually isolates the cortex from other parts of the brain.<sup>41</sup> Sometimes a diffuse axonal injury is accompanied by small primary brain-stem injuries, as well as secondary damage to the brain stem that results from transtentorial herniation soon after the injury.<sup>72-74</sup> In patients with an axonal injury complicated by acute circulatory or respiratory failure, diffuse laminar necrosis may also be present.

Only a few pathological reports on the persistent vegetative state describe severe abnormalities of the brain stem. Those that do mainly concern patients in whom severe paramedian mesencephalic damage developed secondary to acute downward or upward transtentorial herniation during the early stage of illness. Lesions confined to the brain stem seldom, if ever, cause long-term unconsciousness, although there has been a report of four patients with severe secondary brain-stem damage in whom coma persisted for as long as six weeks before death.<sup>75</sup> We have found no well-described autopsy studies of patients in a persistent vegetative state who had severe damage confined to the hypothalamus.

#### ANCILLARY DIAGNOSTIC STUDIES

Neurodiagnostic tests alone can neither confirm the diagnosis of a vegetative state nor predict the potential for recovery of awareness.<sup>53</sup> However, when used in conjunction with a clinical evaluation, laboratory tests may provide useful supportive information.

#### Electroencephalography

In most patients in a persistent vegetative state, electroencephalograms (EEGs) show diffuse generalized polymorphic delta or theta activity.<sup>76,77</sup> This pattern is usually not attenuated by sensory stimulation, except occasionally by noxious stimulation.<sup>78,79</sup> In most patients, the transition from wakefulness to sleep is accompanied by some desynchronization of the background activity.<sup>80</sup> In some patients, very-low-voltage EEG activity is all that can be detected. In others, persistent alpha activity is the most remarkable feature. In approximately 10 percent of patients in a vegetative state, the EEG is nearly normal late in the course of illness but without evidence of vision-induced alpha blocking.<sup>77</sup> There have been occasional reports of isoelectric EEGs in patients in a vegetative

state.<sup>37,58,76,81,82</sup> Most investigators have not reported this finding, however, nor has it been confirmed by reviews of the initial EEG records by other investigators. Typical epileptiform activity is unusual in patients in a persistent vegetative state, as is seizure activity.

The transition from coma to the vegetative state is not accompanied by notable changes in the EEG. However, clinical recovery from the vegetative state may be paralleled by diminished delta and theta activity and the reappearance of a reactive alpha rhythm.<sup>76,78</sup> This phenomenon is inconsistent and does not predict future recovery.<sup>37,78</sup>

Compressed spectral analysis of the EEG has been used to study patients with prolonged unconsciousness. Preliminary data suggest that patients with changeable or desynchronized spectrograms and abnormal evoked responses remain in a vegetative state.<sup>83</sup>

Infants and children have abnormalities on the EEG that are similar to those reported in adults, although in infants and children the EEG activity may be somewhat more discontinuous and of lower voltage.<sup>66,84</sup>

#### Evoked-Response Studies

Evoked-response testing is useful statistically, but not always clinically, in trying to assess the risk of a vegetative outcome in patients who are in a coma as a result of an acute neurologic injury.<sup>85</sup> Somatosensory evoked responses are the most sensitive and reliable markers in both adults and children.<sup>86-91</sup> The bilateral absence of such responses one week after the insult is highly predictive of failure to regain consciousness (i.e., of death or survival in a vegetative state). Patients without somatosensory evoked responses, however, may recover at least minimal cognitive activity, especially if the coma is traumatic rather than anoxic.<sup>92,93</sup> In contrast, patients with normal somatosensory responses may enter a vegetative state and remain in it.<sup>88</sup> Prolongation of the central conduction time of an evoked response is a less reliable finding than the absence of a response in predicting a poor outcome.<sup>78,94,95</sup>

Other evoked potentials, such as the brain-stem auditory evoked response, are of limited value. Numerous studies have shown that the brain-stem auditory evoked response is preserved when the somatosensory evoked response is absent, and the outcome is either survival in a vegetative state or death.<sup>78,86,87</sup> Multimodal evoked-response testing may be used to determine the outcome, but whether the results are of greater predictive value than the somatosensory evoked response alone remains uncertain. The presence of P<sub>300</sub> evoked responses is not necessarily correlated with the outcome.<sup>96</sup>

#### Neuroimaging

Computed tomographic or magnetic resonance imaging in patients in a persistent vegetative state often



reveals diffuse or multifocal cerebral disease involving the gray and white matter. Although there are no established correlations between the results of neuroimaging studies and the development of the vegetative state or the potential for recovery, most patients who do not recover consciousness have abnormal scans.<sup>49,57,67,97,98</sup> When studied during the first several months after a traumatic or nontraumatic brain injury, patients in a persistent vegetative state are more likely to recover consciousness yet remain severely disabled if serial neuroimaging scans are normal than if they are abnormal. Serial scanning usually documents progressive brain atrophy, which reduces the likelihood of neurologic recovery.

### Cerebral Metabolic Studies

A substantial reduction in the cerebral metabolic rate has been reported in approximately 20 adults in a persistent vegetative state.<sup>22,99-101</sup> A 40 to 60 percent reduction in global cerebral oxidative metabolism was observed in six patients in a vegetative state after trauma or diffuse anoxia.<sup>99</sup> Positron-emission tomographic (PET) studies showed a 50 to 60 percent decrease in the glucose metabolic rate in the cerebral cortex, basal ganglia, and cerebellum in seven adults; no overlap in metabolic impairment was noted when these patients were compared with three patients who had the locked-in syndrome.<sup>22</sup> Using the same method, other investigators found a 50 percent reduction in cerebral glucose metabolism in patients in a vegetative state, as compared with a 25 percent reduction in metabolic activity in patients who had regained consciousness after anoxic cerebral injuries.<sup>100</sup> The parieto-occipital and mesiofrontal regions had the most consistent reduction in metabolic activity, whereas Levy et al. reported consistently low metabolic rates in all cortical areas.<sup>22</sup>

Although these studies demonstrate substantial reductions in the metabolism of glucose, there is not yet sufficient information to warrant the use of PET scanning to determine prognosis. Likewise, the lack of experience with cerebral metabolic studies in infants and children in a vegetative state precludes the use of such studies to assess prognosis in infants and children. Normal cerebral metabolic activity in this age group is substantially lower than that reported in adults.<sup>102</sup> Questions have been raised about the validity of cerebral metabolic studies to determine whether patients in a vegetative state are conscious or can experience pain and suffering. These questions remain unanswered and require further systematic investigation. Whether patients are conscious and have the potential to experience pain and suffering can best be assessed by careful and repeated neurologic examinations.

### Cerebral Blood Flow

Measurement of cerebral blood flow immediately after an acute neurologic injury does not predict a

vegetative outcome in either adults or children.<sup>84,103-105</sup> Once a vegetative state exists, however, cerebral blood flow is likely to be reduced. An early study using xenon-133 in four patients in a vegetative state found that cerebral blood flow was 10 to 20 percent of normal.<sup>106</sup> PET studies in seven patients in a persistent vegetative state who were studied 3 weeks to 68 months after acute injury showed a 50 percent decrease in cerebral blood flow.<sup>22</sup> More recent radio-nuclide-imaging studies using HM-PAO—single-photon-emission computed tomography showed a global reduction in cerebral blood flow 2 to 12 months after a head injury, as well as 3 years later.<sup>107</sup> Some studies, however, have found normal cerebral blood flow in patients in a persistent vegetative state.<sup>108</sup>

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## SPECIAL ARTICLE

## MEDICAL ASPECTS OF THE PERSISTENT VEGETATIVE STATE

## (Second of Two Parts)

## THE MULTI-SOCIETY TASK FORCE ON PVS\*

## PROGNOSIS FOR RECOVERY

There are two dimensions of recovery from a persistent vegetative state: recovery of consciousness and recovery of function. Recovery of consciousness can be verified by reliable evidence of awareness of self and the environment, consistent voluntary behavioral responses to visual and auditory stimuli, and interaction with others. Recovery of function is characterized by communication, the ability to learn and to perform adaptive tasks, mobility, self-care, and participation in recreational or vocational activities. Recovery of consciousness may occur without functional recovery, but functional recovery cannot occur without recovery of consciousness. In some instances, during the early stages of recovery of consciousness, external manifestations may not be immediately apparent. Repeated examinations over time are necessary to ensure the consistency and accuracy of signs of recovery.

The prognosis for cognitive and functional recovery depends on the cause of the underlying brain disease. The Glasgow Outcome Scale classifies outcome in five categories: good recovery, moderate disability, severe disability, persistent vegetative state, and death.<sup>108</sup> Patients with a good recovery have the capacity to resume normal occupational and social activities, although there may be minor physical or mental deficits or symptoms. Patients with moderate disability are independent and can resume almost all activities of daily living. They are disabled to the extent that they can no longer participate in a variety of social and work activities. Patients with severe disability are no longer capable of engaging in most previous personal, social, and work activities. Such patients have limited

communication skills and abnormal behavioral and emotional responses. They are partially or totally dependent on assistance from others in performing the activities of daily living.

## Acute Traumatic and Nontraumatic Injuries

Recovery of consciousness after 12 months is unlikely in adults and children who have had traumatic injuries. Recovery of consciousness after three months is rare in adults and children with nontraumatic injuries (Fig. 1 and Tables 3 and 4).

## Traumatic Injuries in Adults

For patients in a vegetative state as a result of traumatic brain injury, the prognosis for recovery remains unfavorable. Recovery of consciousness and function was determined by reviewing data from previously described series of patients rather than individual case reports. Data were available on 434 patients in a vegetative state one month after a severe head injury (Fig. 1 and Table 3)<sup>47,49,50,106,109,110</sup> (and Tillet JA: personal communication). Recovery of consciousness varied with time. Three months after injury, 33 percent of the patients had recovered consciousness; 67 percent had died or remained in a vegetative state. Recovery had occurred in 46 percent of the patients at 6 months and in 52 percent at 12 months. Recovery after 12 months was reported in only 7 of the 434 patients.<sup>47,49</sup> One patient recovered consciousness 30 months after injury and remained severely disabled.<sup>47,111</sup> The Traumatic Coma Data Bank study reported that 6 of 93 adult patients in a vegetative state recovered consciousness one to three years after injury.<sup>49</sup> Four of these six patients had severe disability, and one had moderate disability; the status of the sixth patient could not be determined. Five of the six patients were under 30 years of age. There have been no other well-documented reports of recovery of consciousness in patients in a persistent vegetative state more than 12 months after a traumatic injury.

Good recovery of function is also unlikely. Among the 434 patients in a vegetative state, the outcome at one year, according to the Glasgow Outcome Scale, was as follows: 33 percent had died, 15 percent were in a persistent vegetative state, 28 percent had severe disability, 17 percent had moderate disability, and 7 percent had a good recovery. Of the 7 percent of patients who had a good recovery, over half showed signs of improvement within three months after injury, and almost all within six months after injury. For the entire group of 434 patients, the incidence of a good recovery beginning 6 to 12 months after injury was less than 0.5 percent. No patient had a good recovery that began after 12 months. Among patients

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This statement has been approved by the American Academy of Neurology, Child Neurology Society, American Neurological Association, American Association of Neurological Surgeons, and American Academy of Pediatrics. The literature search, correspondence, and other documents generated by the task force are available through the American Academy of Neurology in Minneapolis.

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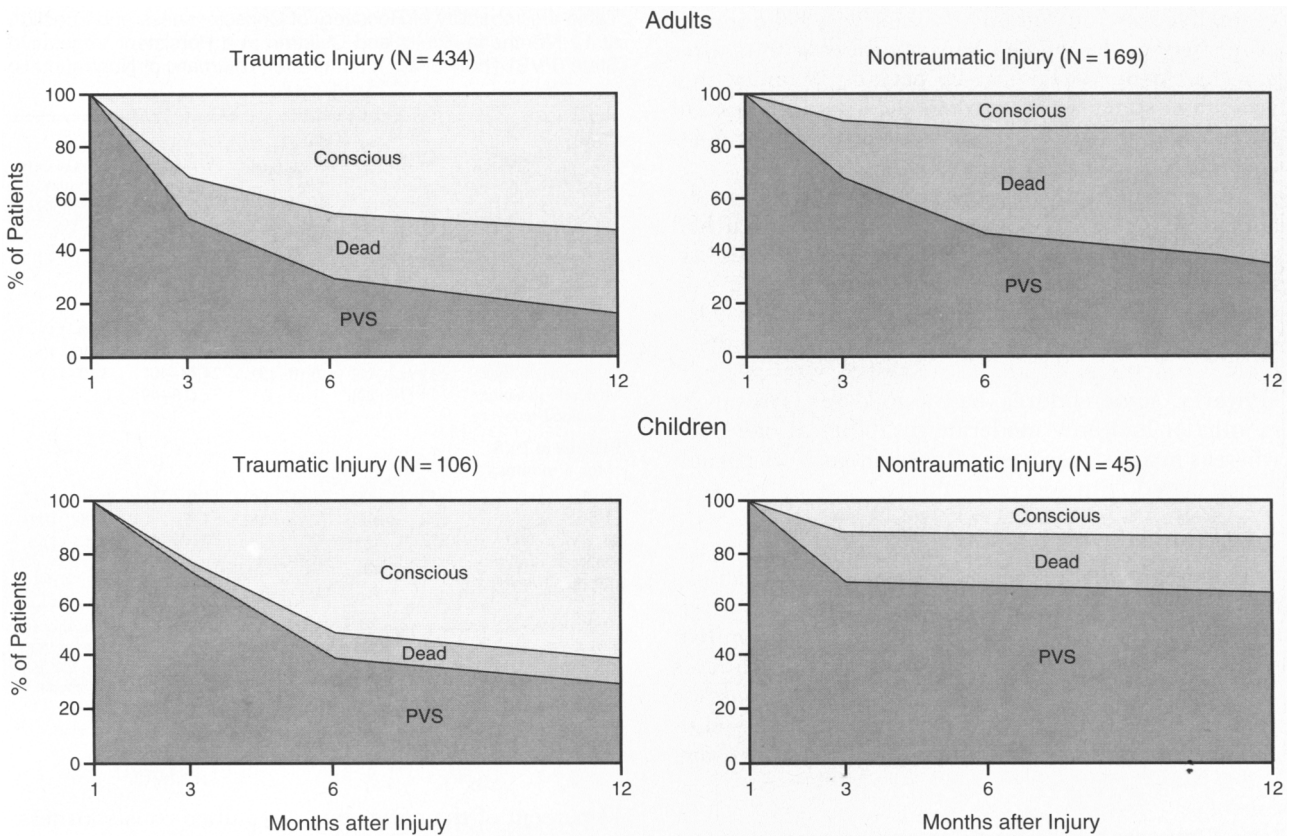


Figure 1. Outcome for Patients in a Persistent Vegetative State (PVS) after a Traumatic or Nontraumatic Injury.

Fifty-two percent of adults and 62 percent of children who are in a PVS one month after a traumatic injury recover consciousness within one year. The majority recover within the first six months; recovery after six months is unusual. In contrast, for patients in a PVS one month after a nontraumatic injury, recovery of consciousness is much less frequent (15 percent of adults and 13 percent of children) and is extremely unlikely after three months. Approximately 5 percent of patients in a PVS 1 month after injury were lost to follow-up at 12 months.

who recovered with moderate or severe disability, almost all showed signs of improvement within six months after injury. A later recovery was almost invariably associated with severe disability.

Age is an important factor affecting outcome. Among patients who have had traumatic injuries, those over the age of 40 years have a smaller chance of improvement than those who are younger; recovery without severe disability is rare, especially after three months.<sup>47</sup> Ventilatory dysfunction, lack of early motor reactivity, late-onset epilepsy, or the development of hydrocephalus may also indicate a poorer prognosis for recovery of awareness.<sup>55,112</sup>

#### Nontraumatic Injuries in Adults

Adults in a coma immediately after a nontraumatic injury have a poorer prognosis than those in a coma after a traumatic injury, with 85 percent or more dying within the first month after the insult or remaining in a vegetative state.<sup>52,56</sup> Later recovery of consciousness and function was determined by reviewing data from previously described series consisting of 169 patients who were in a vegetative state one month after a nontraumatic injury (Fig. 1 and Table 3).<sup>37,42,43,51</sup> Recovery of consciousness after a nontraumatic injury is unlikely. Of the 169 patients with such injuries, only 11 percent had recovered consciousness three months

after injury; 89 percent remained in a vegetative state or had died (Fig. 1 and Table 3). Six months after injury, only two additional patients had recovered consciousness. One year after injury, 15 percent of the 169 patients had recovered consciousness, 32 percent were in a persistent vegetative state, and 53 percent had died.

Recovery of function in the 15 percent of patients who regained consciousness was extremely poor. Only one patient had a good recovery. Two additional reports of individual patients with good functional recovery after nontraumatic injury have been published. In both patients, improvement began within two months after a hypoxic injury.<sup>78,113</sup> There have been reports of five other patients who began to recover from a vegetative state more than six months after a nontraumatic injury. Two had moderate disability, and three had severe disability (Table 5).

#### Traumatic Injuries in Children

Recovery of consciousness and function in children after a traumatic injury was determined by reviewing data on 106 patients in previously reported series (Fig. 1 and Table 3)<sup>49,110,117-119</sup> (and Tillet JA: personal communication). The prognosis for recovery of consciousness after a traumatic injury is slightly better in children than in adults (Fig. 1). Of the 106 children in a

vegetative state one month after a severe head injury, 24 percent had regained consciousness within three months. At one year, only 29 percent remained in a vegetative state, 9 percent had died, and 62 percent had recovered consciousness. None of the children recovered consciousness after 12 months.

Recovery of function was comparable to that in the adults. At one year, 35 percent of the children had severe disability, 16 percent had moderate disability, and 11 percent had made a good recovery. As in adults, if recovery of consciousness from the post-traumatic vegetative state began before six months, a higher functional grade of recovery was likely.<sup>118</sup> However, some children had a good recovery at six months or had only moderate disability at one year, whereas in adults recovery after six months was usually associated with severe disability.

#### Nontraumatic Injuries in Children

The prognosis for recovery after nontraumatic injuries in children appears to be similar to the prognosis for adults. However, the available data are limited, since previously described series total only 45 patients (Fig. 1 and Table 3).<sup>44,66,86</sup> Recovery of consciousness in children, as in adults, was primarily observed within the first three months after injury. By that time,

**Table 3. Incidence of Recovery of Consciousness and Function in Adults and Children in a Persistent Vegetative State (PVS) after Traumatic or Nontraumatic Brain Injury.\***

OUTCOME AND FUNCTIONAL RECOVERY†	3 MONTHS	6 MONTHS	12 MONTHS
	% of patients		
<b>Adults</b>			
Traumatic injury (n = 434)			
Death	15	24	33
PVS	52	30	15
Recovery of consciousness	33	46	52
Severe disability			28
Moderate disability			17
Good recovery			7
Nontraumatic injury (n = 169)			
Death	24	40	53
PVS	65	45	32
Recovery of consciousness	11	15	15
Severe disability			11
Moderate disability			3
Good recovery			1
<b>Children</b>			
Traumatic injury (n = 106)			
Death	4	9	9
PVS	72	40	29
Recovery of consciousness	24	51	62
Severe disability			35
Moderate disability			16
Good recovery			11
Nontraumatic injury (n = 45)			
Death	20	22	22
PVS	69	67	65
Recovery of consciousness	11	11	13
Severe disability			7
Moderate disability			0
Good recovery			6

\*Data were collected from series of patients in a PVS one month after injury and do not include individual case reports. Some patients who recovered consciousness died within 12 months after injury or were lost to follow-up. The data for nontraumatic injuries reflect all causes, not just postanoxic injury; for this category alone, the prognosis is poorer than that suggested by the data.

†Data on functional recovery are for patients who had recovered consciousness within 12 months after injury.

**Table 4. Probability of Recovery of Consciousness and Function at 12 Months in Adults and Children in a Persistent Vegetative State (PVS) Three or Six Months after Traumatic or Nontraumatic Injury.\***

OUTCOME	ADULTS		CHILDREN	
	TRAUMATIC INJURY (N = 434)	NONTRAUMATIC INJURY (N = 169)	TRAUMATIC INJURY (N = 106)	NONTRAUMATIC INJURY (N = 45)
	% of patients (99% confidence interval)			
<b>Patients in PVS for 3 months†</b>				
Death	35 (27–43)	46 (31–61)	14 (1–27)	3 (0–11)
PVS	30 (22–38)	47 (32–62)	30 (13–47)	94 (83–100)
Severe disability	19 (12–26)	6 (0–13)	24 (8–40)	3 (0–11)
Moderate disability or good recovery	16 (10–22)	1 (0–4)	32 (15–49)	0
<b>Patients in PVS for 6 months‡</b>				
Death	32 (21–43)	28 (12–44)	14 (0–31)	0
PVS	52 (40–64)	72 (56–88)	54 (30–78)	97 (89–100)
Severe disability	12 (4–20)	0	21 (1–41)	3 (0–11)
Moderate disability or good recovery	4 (0–9)	0	11 (0–26)	0

\*Conditional probabilities were determined from data in Table 3. The numbers of patients given in parentheses refer to the numbers of patients who were in a vegetative state one month after injury.

†A total of 218 adults with traumatic injuries, 77 adults with nontraumatic injuries, 50 children with traumatic injuries, and 31 children with nontraumatic injuries.

‡A total of 123 adults with traumatic injuries, 50 adults with nontraumatic injuries, 28 children with traumatic injuries, and 30 children with nontraumatic injuries.

11 percent of the patients had regained consciousness; by one year, only an additional 2 percent had recovered consciousness. At one year, the majority of the children remained in a vegetative state (65 percent) or had died (22 percent). Apparent recovery of consciousness after one year has been reported in several children in a vegetative state after a hypoxic-ischemic injury.<sup>119</sup> However, these children recovered a level of function described as socially responsive, meaning that they smiled in response to the presence of other people but without other evidence of awareness. The prognosis for recovery from a vegetative state in young infants with birth injuries and perinatal asphyxia is more variable than in older infants and children.<sup>3,4,58,66</sup>

The prognosis for recovery of function in children with a nontraumatic injury is somewhat better than that for adults. Of the 13 percent of children who recovered consciousness, 6 percent had a good recovery, and the other 7 percent had severe disability; there were no reports of moderate disability.

#### Degenerative and Metabolic Diseases

Patients in a vegetative state due to degenerative or metabolic diseases have no possibility of recovery. Some patients may temporarily lapse into a vegetative state when systemic illness causes a reversible depression of neurologic function. This possibility must be considered before determining that a patient's vegetative state is irreversible.

#### Developmental Malformations

Infants and children with brain malformations severe enough to cause a developmental vegetative state are unlikely to become conscious; those who do are in

**Table 5. Verified Reports of Five Patients with a Late Recovery from a Persistent Vegetative State (PVS).\***

REPORT	AGE (YR)/SEX OF PATIENT	CAUSE OF PVS	DURATION OF PVS (MO)	OUTCOME
Arts et al. <sup>111</sup>	18/F	Trauma	30	Severe disability
Rosenberg et al. <sup>115</sup>	43/M	Anoxia	17	Severe disability
Higashi et al. <sup>42</sup>	61/F	Subarachnoid hemorrhage	36	Moderate disability
	26/M	Anoxia	8	Moderate disability
Snyder et al. <sup>116</sup>	36/M	Anoxia	22	Severe disability

\*These are published cases in which sufficient information was available to conclude that late recovery of awareness occurred. Late recovery from a PVS was defined as recovery of consciousness more than 12 months after a traumatic injury or more than 3 months after a nontraumatic injury. The exact duration of the vegetative state in the patients reported by Higashi et al. is uncertain. An additional patient reported by Tanheco and Kaplan<sup>114</sup> was said to be in a PVS for six years; the clinical data were insufficient to include in this table.

most cases severely disabled. Anencephaly is the only malformation for which it is clear at birth that there is no possibility of recovery of consciousness. The complete absence of the cerebral cortex in anencephalic infants precludes consciousness.<sup>20</sup>

Other malformations diagnosed at birth may result in a vegetative state. If the patient remains in a vegetative state at three months of age, the prognosis for any improvement is quite poor.<sup>10,66</sup> Lack of evidence of consciousness in such infants by the age of six months almost completely precludes the potential for future improvement.

#### Verified and Unverified Late Recovery

Few patients in a persistent vegetative state have undergone a verified recovery of consciousness more than 12 months after a traumatic injury or more than 3 months after a nontraumatic injury (Table 5). One patient recovered 30 months after a traumatic brain injury; four patients recovered 8 to 22 months after a hypoxic-ischemic or cerebrovascular injury. An additional six patients, described in the study by the Traumatic Coma Data Bank, were reported to have recovered consciousness beginning one to three years after injury. Further investigation of these six patients suggests that only half recovered awareness after one year; one was moderately disabled, and the others had severe disabilities.<sup>49</sup> Two recent studies in adults and children have also reported that a few patients with traumatic and nontraumatic injuries recovered consciousness after the expected intervals.<sup>119,120</sup> The task force knows of no other cases of verified late recovery.

Several reports in the popular media have described dramatic recovery from a persistent vegetative state. In most reports, recovery of consciousness and function occurred within the time frames noted above.<sup>121</sup> Unusual cases in the medical literature or popular media are poorly documented, the nature of the patients' neurologic condition is unclear, or the timing of the entry into the vegetative state is extremely atypical.<sup>114,122</sup> A tabular summary of these cases is available from the task force. Several of these reports have been investigated by members of the task force, and it appears likely that, although the patients were not directly examined, a late recovery of consciousness did occur. The total number of such patients is extremely

small, however, considering the estimated prevalence of the persistent vegetative state, and all were apparently left with severe disability.

#### Probability of Recovery

On the basis of the data in the series noted above, we have estimated the probability of recovery of consciousness in adults and children who were in a vegetative state one month after an acute traumatic or nontraumatic injury (Table 4). The outcome probability at 12 months was determined in patients who remained in a vegetative state at 3 months and at 6 months. In addition, the probability of functional recovery was determined for two possible outcomes: good recovery or recovery with moderate disability, and recovery with severe disability. On the basis of these probabilities, a persistent vegetative state can be judged to be permanent 12 months after a traumatic injury in adults and children; recovery after this time is exceedingly rare and almost always involves a severe disability. In adults and children with nontraumatic injuries, a persistent vegetative state can be considered to be permanent after three months; recovery does occur, but it is rare and at best associated with moderate or severe disability.

#### SURVIVAL

Despite the preservation of hypothalamic and brain-stem function, the severe neurologic injury necessary to produce the vegetative state in adults and children reduces the average life expectancy to approximately two to five years. Survival beyond 10 years is unusual. As shown in Figure 1 and Table 3, within one year after a traumatic injury, 33 percent of adults in a vegetative state had died, and 53 percent of those in a vegetative state after a nontraumatic injury had died. Among children with traumatic and nontraumatic injuries, 9 and 22 percent, respectively, had died within one year.

Overall, the available data (based on 251 patients in four large series) indicate that the mortality rate for adults in a persistent vegetative state after an acute brain injury is 82 percent at three years and 95 percent at five years<sup>33,42,51,112</sup> (tabular data are available from the task force). In a study of 110 patients, the mortality rate increased from 65 to 73 percent between 3 and 5 years, and 90 percent of the patients had died within 10 years; the average life expectancy of the 71 patients who died was 38.4 months.<sup>42</sup> Another study of 53 patients in a persistent vegetative state six months after an acute injury reported a mortality rate of 47 percent at three years, 76 percent at six years, and 78 percent at eight years.<sup>33</sup> The mean duration of survival was 4.4 years; five patients survived longer than 10 years.

Other investigators studying somewhat different populations of patients in a persistent vegetative state have reported similar estimates of survival. For example, in a study by Tresch and colleagues, the mean ( $\pm$ SD) survival of 51 patients in a persistent vegetative state in nursing homes was  $3.3 \pm 0.5$  years.<sup>39</sup> Among adults with degenerative diseases who enter a



vegetative state, survival ranges from 3.5 to 7 years.<sup>57</sup> In all these, a few patients lived for periods as long as 10 to 16 years.

Estimates of the survival of infants and children in a persistent vegetative state, based on the clinical experience of pediatric neurologists, were published recently.<sup>10</sup> These estimates range from  $4.1 \pm 0.7$  years, for infants up to 2 months of age, to  $7.4 \pm 1.8$  years, for children 7 to 18 years old. A large population-based study examining 847 children and adults considered to be in a persistent vegetative state reported approximately the same duration of survival among older children but a much shorter survival among children under the age of one year.<sup>40</sup> Rare cases of survival as long as 10 to 20 years were also noted in the survey of pediatric neurologists.<sup>10</sup>

A very small number of well-described patients in a persistent vegetative state have survived for more than 15 years (data available from the task force), including three patients who survived for more than 17, 37, and 41 years.<sup>29,123,124</sup> Considering the small total number of patients in a persistent vegetative state, the probability that an individual patient will have such a prolonged survival (i.e., over 15 years) is exceedingly low, probably less than 1 in 15,000 to 75,000 (calculations available from the task force).

The shortened life expectancy of patients in a persistent vegetative state is due to several factors. Reported causes of death (based on data from 143 patients) include infection, usually of the pulmonary or urinary tract (in 52 percent of patients); generalized systemic failure (in 30 percent); sudden death of unknown cause (in 9 percent); respiratory failure (in 6 percent); and other disease-related causes, such as recurrent strokes or tumors (in 3 percent).<sup>23,37,112</sup> Age is also an important factor; both young infants and children and the elderly have a shorter life expectancy than do young or middle-aged adults. Whether this is related to the cause of the vegetative state or to the risks of subsequent medical complications is unknown. In addition, there have been no formal studies of the effect of the level of care on the life expectancy of patients in a persistent vegetative state.

The costs of caring for patients in a persistent vegetative state are difficult to estimate. The cost of hospital care for the first three months is estimated to be \$149,200.<sup>125</sup> The estimated cost of long-term care in a skilled nursing facility ranges from approximately \$350 per day (\$126,000 per year) to approximately \$500 per day (\$180,000 per year).<sup>124</sup> For children in a persistent vegetative state, the estimated annual cost of care at home is \$129,000 ( $\pm$ \$51,000) for the first year and \$97,000 for subsequent years.<sup>126</sup> A rough approximation of the total annual costs in the United States for the care of adults and children in a persistent vegetative state is \$1 billion to \$7 billion.

#### PAIN AND SUFFERING

The question has been raised whether patients in a persistent vegetative state can experience pain and suffering. These terms refer to the unpleasant experi-

ences that occur in response to stimulation of peripheral nociceptive receptors and their peripheral and central afferent pathways or that may emanate endogenously from the depths of human self-perception.<sup>127</sup>

The term "nociceptive" refers only to the response to noxious stimuli, not to the experience of pain. Nociceptive responses, which can be elicited at every level of the nervous system, from the spinal cord to the thalamus, are behavioral responses governed by functional motor systems. Such responses consist of flexor spasms at the spinal level, flaccid lower extremities and extended upper extremities at the lower level of the brain stem, extensor spasms of all extremities at the upper level of the brain stem, and flexor responses in the upper extremities and extensor responses in the lower extremities at the thalamic level. None of these responses necessarily reflect the perception of pain. Nociceptive stimulation elicits well-known, unconscious postural responses, as well as other motor, autonomic, and endocrinologic reflexive responses. None of these, however, can evoke the experience of pain and suffering if the brain has lost its capacity for self-awareness. The perceptions of pain and suffering are conscious experiences: unconsciousness, by definition, precludes these experiences.

Four levels of neurologic responses to nociceptive stimuli, from unconscious responses to the experience of pain and suffering, can be recognized on the basis of current anatomical knowledge. First, monosynaptic reflex responses occur at the level of the spinal cord through synapses connecting incoming nociceptive impulses with motor responses programmed at that level. Second, simple nociception occurs at the level of the thalamus with the reception of nociceptive impulses. Third, subcortical nociceptive responses produce patterned behaviors, such as grimace-like or crying-like behavior similar to that accompanying conscious emotional responses. These responses, commonly seen in patients in a persistent vegetative state, are probably mediated at subcortical levels through synaptic connections between the thalamus and limbic system. Finally, conscious awareness of pain or the experience of suffering occurs at a cortical level through synapses connecting parietal cortical neurons with other areas of the cerebral cortex. Conscious (i.e., learned) responses to pain differ measurably from the reflexive decorticate or decerebrate postural responses that usually characterize a persistent vegetative state.

As noted in the first part of this article, extensive clinical experience, the results of positron-emission tomographic (PET) studies, and neuropathologic examination support the belief that patients in a persistent vegetative state are unaware and insensate and therefore lack the cerebral cortical capacity to be conscious of pain. Almost all such patients have some degree of motor activity and eye movement that would be capable of signaling conscious perception of pain or suffering if such existed. In rare cases, it may be difficult to distinguish a persistent vegetative state from a severe locked-in state. Under such unusual cir-



cumstances, a patient may not be able to express behavioral responses to painful stimuli or the responses may be extremely difficult to detect; the absence of a response cannot be taken as proof of the absence of consciousness.<sup>21,128</sup>

Because the pain response is functional at all levels up to the cerebrum, but not necessarily the cortex, at birth, children of all ages are capable of responding to noxious stimuli.<sup>129,130</sup> Newborns may have the potential to experience pain and suffering. Infants over several months of age are consciously aware and capable of suffering. Children in a vegetative state may react to noxious stimuli, but for the same reason as in adults, they cannot experience pain or suffering. Such children may have involuntary responses to noxious stimuli, including alerting behavior, grunting, or grimace-like or crying-like behavior. The elicitation of these responses is unlikely to be evidence of conscious awareness of pain or suffering unless they are consistent, sustained, and definitive in nature.

### TREATMENT

Therapy aimed at reversing the persistent vegetative state has not been successful.<sup>131,132</sup> There have been occasional reports of a benefit from dopamine agonists or dextroamphetamine, but the benefit has been modest at best, and there have been no placebo-controlled or double-blind studies.<sup>133</sup> Direct electrical stimulation of the mesencephalic reticular formation, nonspecific thalamic nuclei, or dorsal columns has been attempted experimentally in patients in a vegetative state, with claims of recovered consciousness in a few instances.<sup>134-136</sup> The quality of the recovered state was not described in detail, however, and these approaches remain experimental. Reports of improvement with coma stimulation programs have been published, but there are no verified controlled studies reported in peer-reviewed journals.<sup>132,137-142</sup> Overall, there is no published evidence that coma sensory stimulation improves the clinical outcome in patients in a persistent vegetative state.

#### Determining the Level of Treatment

When the diagnosis of a persistent vegetative state has been properly established, physicians have the responsibility of discussing with the family or surrogate decision makers the probability that the patient will recover or remain in a vegetative state. Physicians should also work closely with the family to determine the appropriate level of medical treatment. There are four levels of treatment: high-technology "rescue" treatments, such as mechanical ventilation, dialysis, and cardiopulmonary resuscitation; medications and other commonly ordered treatments, including antibiotics and supplemental oxygen; hydration and nutrition; and nursing or home care to maintain personal dignity and hygiene.<sup>143</sup>

When there is agreement on the appropriate level of treatment, the physicians should provide nurses, family members, or others caring for the patient with explicit written instructions about which treatments can

be administered and which should be withheld. At all times, the patient's dignity and hygiene must be maintained.

If the decision is to treat the patient aggressively, diligent medical treatment and nursing care are required to prevent and treat the complications that are likely or inevitable in states of severe brain damage.<sup>131</sup> The survival of patients in a persistent vegetative state is, to some degree, related to the quality and intensity of the medical treatment and nursing care that they receive.

Preventive care is foremost. Daily exercises in a range of movements slow the formation of limb contractures, which otherwise become particularly severe in patients in a persistent vegetative state. Daily skin care and frequent repositioning of the patient prevent decubitus ulcers. A tracheostomy may be required to maintain airway patency and prevent aspiration pneumonia. Bladder and bowel care is desirable for hygienic reasons. Since pulmonary and urinary tract infections are common, appropriate monitoring and, if necessary, treatment with antibiotics are required. Placement of nasogastric, gastrostomy, or jejunostomy feeding tubes is usually necessary to maintain adequate nutrition and hydration.

Several medical societies and interdisciplinary bodies have asserted that surrogate decision makers and patients acting through advance directives have the right to terminate all forms of life-sustaining medical treatment, including hydration and nutrition, in adult patients in a persistent vegetative state.<sup>2,8,11,16-18,41</sup> These organizations include the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983), the Hastings Center (1987), the American Academy of Neurology (1989), the American Medical Association (1990), and the United Kingdom Institute of Medical Ethics Working Party on the Ethics of Prolonging Life and Assisting Death (1991). Surrogates and families should be given appropriate psychosocial and religious counseling as they face decisions about termination of treatment. Specific clinical guidelines are available for physicians terminating treatment in adult patients in a persistent vegetative state.<sup>8,14,18,143</sup> There are no well-accepted clinical guidelines for withdrawing nutrition and hydration from children in a persistent vegetative state or from adults in such a state who have never been competent. It should be emphasized that confirmation of a persistent vegetative state is not the only criterion that can or should be considered in decisions concerning life support in newborns, infants, children, or adults. Numerous judicial decisions over the past two decades have also addressed this issue, and the process of surrogate decision making may be limited or affected by the statutes of a particular state.<sup>11,12,144-149</sup>

Few data have been collected concerning the care given to patients in a persistent vegetative state and whether the care they receive affects the incidence of medical complications or their life expectancy. An epidemiologic study of patients in a persistent vegetative

state living in nursing homes found that each received an average of 3.7 prescribed medications daily and had an average of 1.2 hospitalizations during their stay in the nursing home.<sup>39</sup> Less than half the patients had do-not-resuscitate orders written in their charts.

#### Withdrawing Artificial Nutrition and Hydration

When artificial nutrition and hydration are withdrawn, patients in a persistent vegetative state usually die within 10 to 14 days.<sup>150</sup> The immediate cause of death is dehydration and electrolyte imbalance rather than malnutrition; patients in a persistent vegetative state cannot experience thirst or hunger.<sup>151</sup> Some patients die from intercurrent acute illnesses, such as pneumonia. Others may die from underlying cardiac or renal disease when medications are also discontinued.

Appropriate nursing care can prevent the most common signs of acute dehydration, such as dryness of the skin and mucous membranes of the mouth and eyes.<sup>152</sup> Facial swelling from prolonged administration of artificial nutrition and hydration decreases as the patient becomes progressively dehydrated; during the last few days of life, facial features may assume a more normal appearance. When dehydration leads to systemic hypotension, some patients in a vegetative state slip into a coma, whereas others continue to have periods of wakefulness and sleep-wake cycles until they die. Except for dryness of the skin and mucous membranes, it is not readily apparent to family or health care professionals that a patient in a vegetative state is dying of acute dehydration. Such patients also do not manifest the characteristic signs of malnutrition after depletion of nutrients over a prolonged period.

#### FUTURE DIRECTIONS

Although investigators have learned much about the persistent vegetative state over the past two decades, several areas deserve additional study. In the area of epidemiology, improved data on the incidence, prevalence, and natural history of the persistent vegetative state would be available if health authorities recorded such a state in patients, in addition to its underlying cause. More careful clinical studies of individual patients could provide data to determine which clinical findings are critical for the diagnosis of a persistent vegetative state. Future PET studies should measure regional cerebral blood flow or glucose metabolism in response to visual, auditory, and somatosensory stimulation, to determine whether depressed cortical regions in patients in a persistent vegetative state can be activated by peripheral sensory stimuli. A confirmation of the absence of evoked activity on the PET scan would help defend the assertion that patients in a persistent vegetative state are completely unaware and insensate.<sup>21</sup> Single-photon-emission computed tomography (SPECT) may be used to study changes in blood flow. SPECT findings generally parallel PET findings, but SPECT units are less expensive and more widely available. Finally, studies

should include larger numbers of patients in a persistent vegetative state to establish clinical predictors of recovery of consciousness, other neurologic functions, and survival based on age, cause of the vegetative state, and other comorbid factors. Outcome studies should determine the degree of disability in patients with a late recovery of consciousness. Studies of children with developmental disorders causing a persistent vegetative state may show how they differ from patients in a vegetative state as a result of injuries or degenerative or metabolic disorders.

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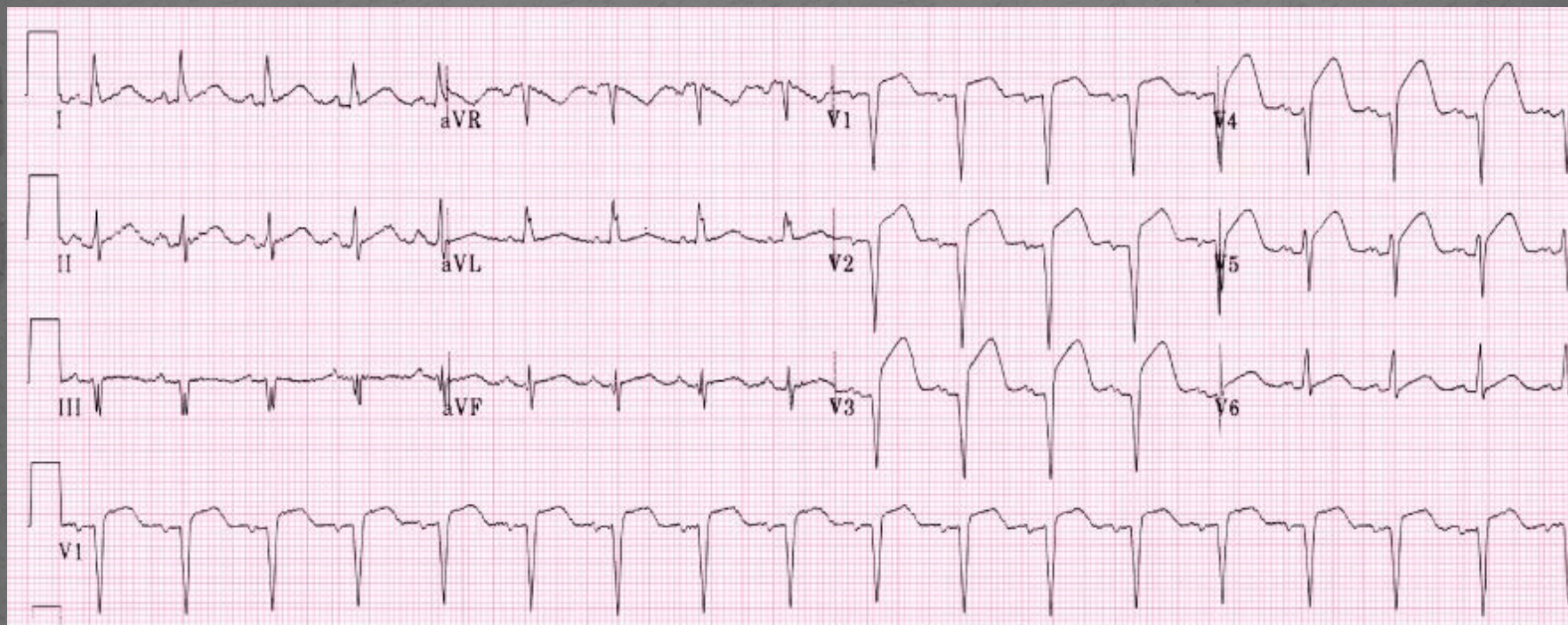
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The Patient with a  
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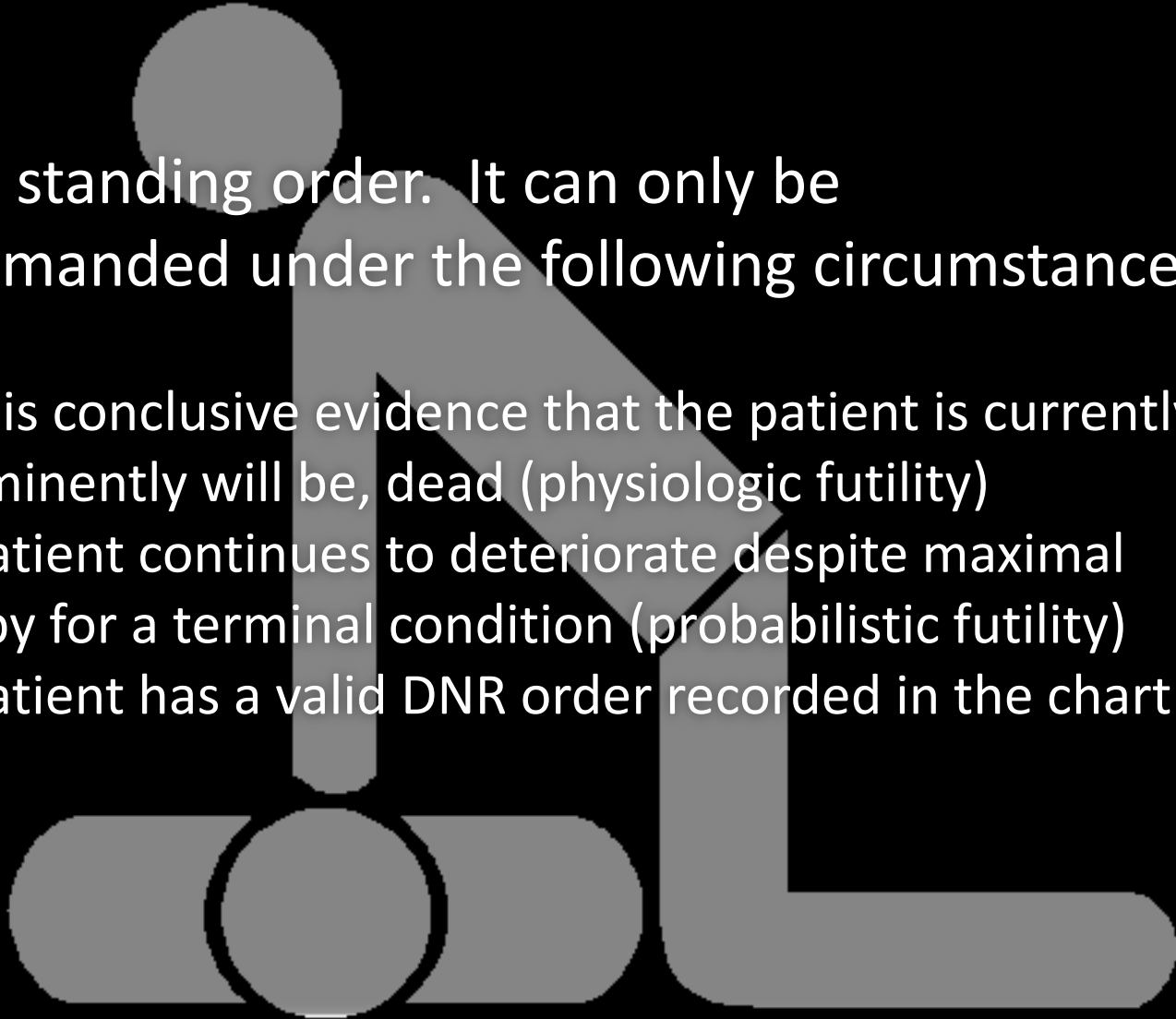
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# What is the likelihood of survival to discharge following CPR?

Hospitalized patients 10 – 17%

Non-hospitalized citizens 3 – 14%

Soap actors 67%

- A. 5%
- B. 15%
- C. 30%
- D. 50%
- E. 75%

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# Cardiorespiratory Criteria





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Mechanical Ventilation





# Brain Criteria





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And...

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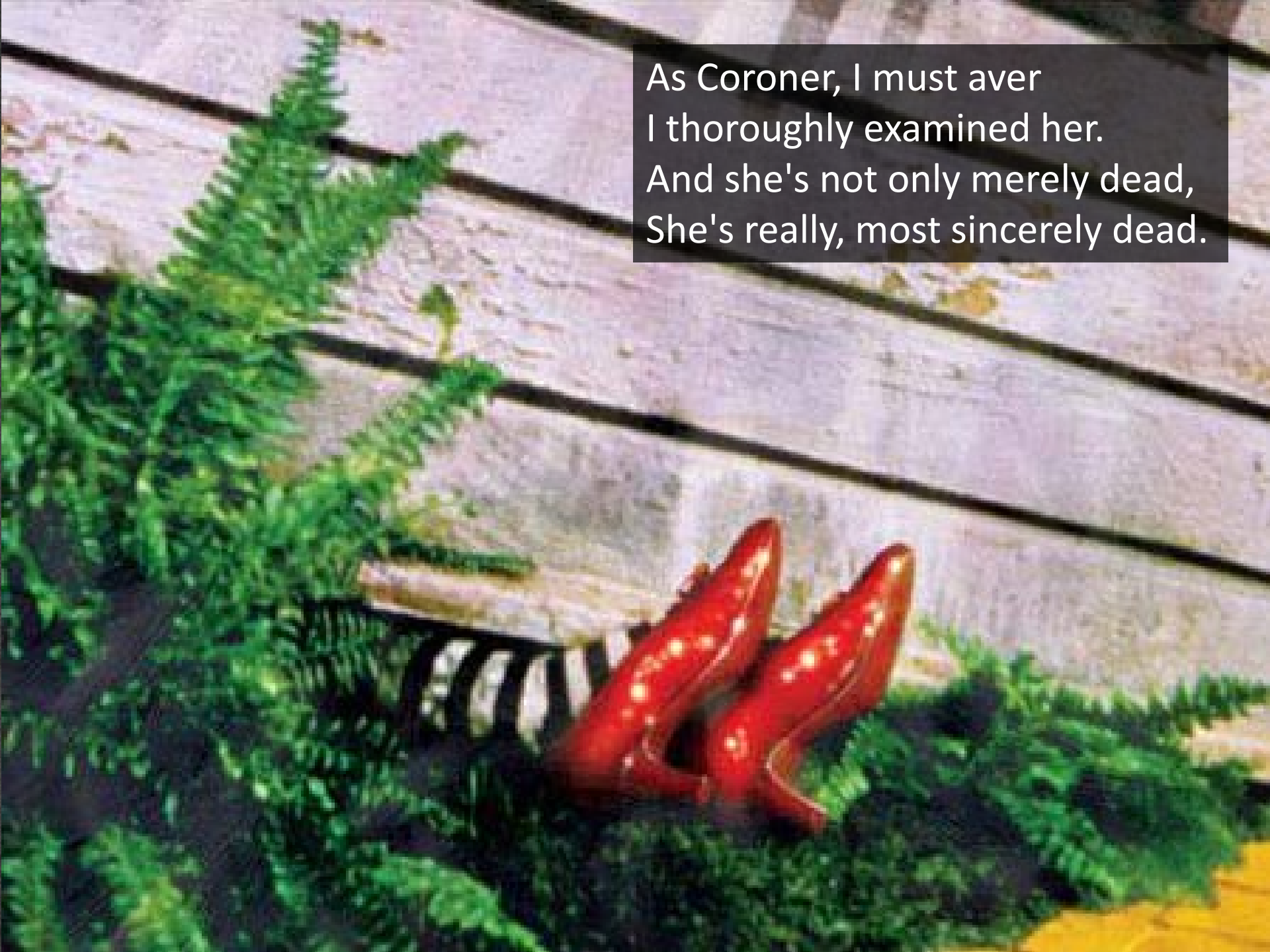
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- Apnea with hypercapnia occurs with temporary cessation of mechanical ventilation

Absence of EEG activity (which measures cortical function only) is insufficient to establish death and may be omitted when the above criteria are present

As Coroner, I must aver  
I thoroughly examined her.  
And she's not only merely dead,  
She's really, most sincerely dead.





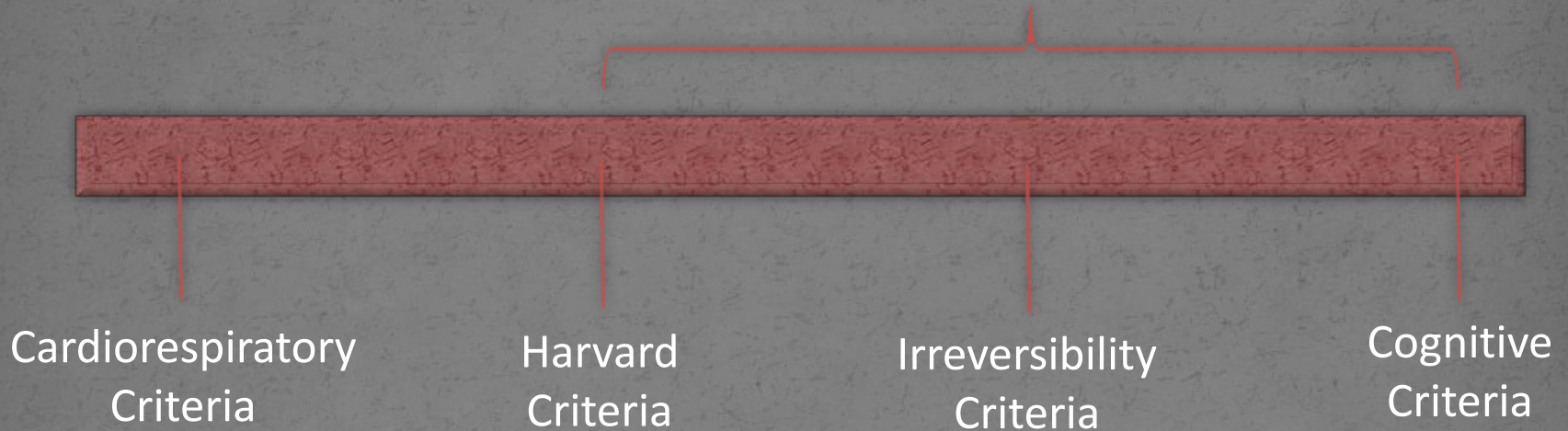
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Is it possible to die more than once?

No. If you're brain dead, you're dead.

# Defining Death

Brain Death



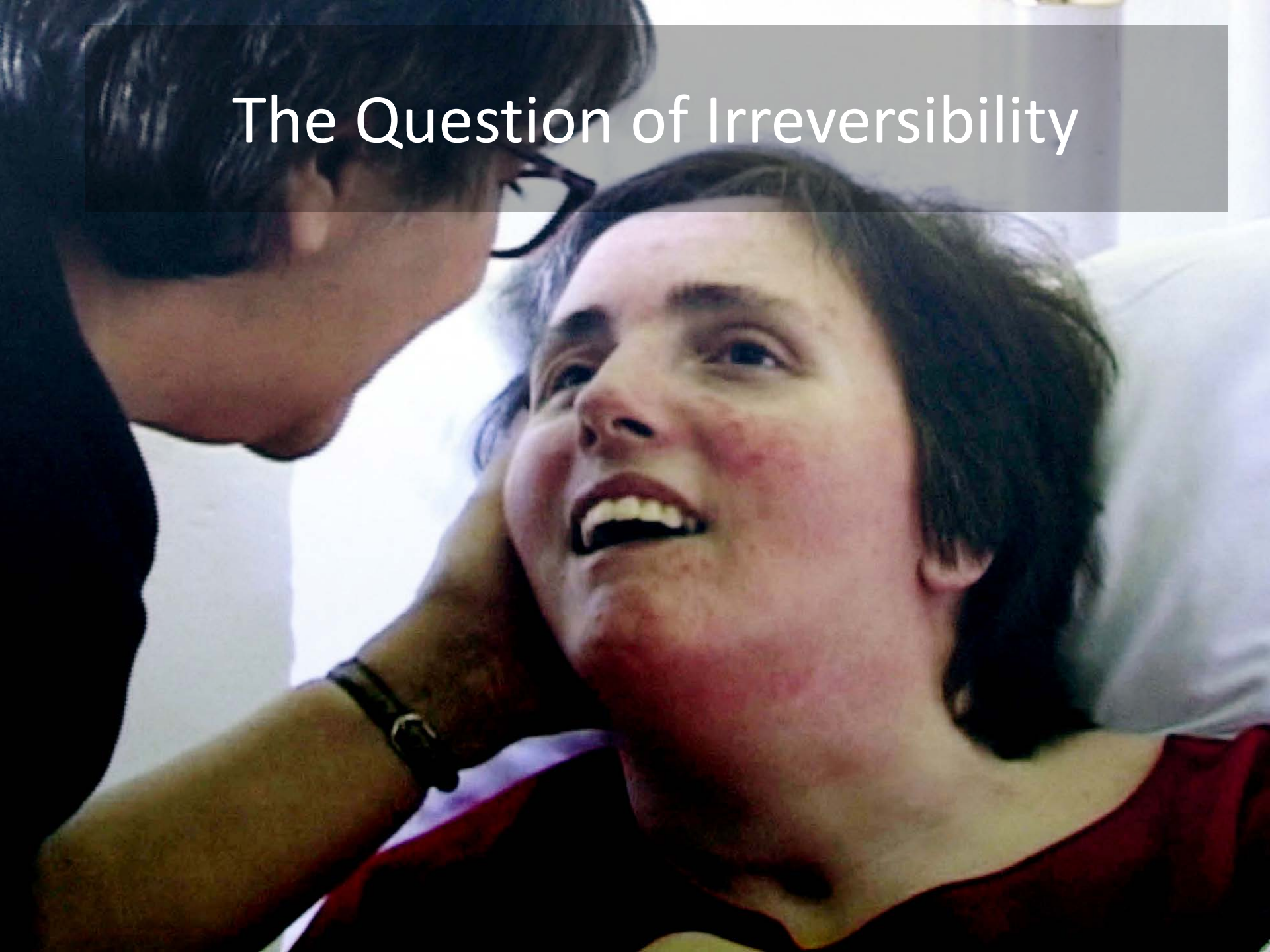


# Cognitive Criteria

Death is equivalent to the end of personhood. An individual dies with his or her loss of:

- Reason
- Memory
- Agency
- Self-awareness

# The Question of Irreversibility





# Case 4

A 21 year-old woman lapses into a coma after drinking alcohol and taking barbiturates and/or benzodiazepines on an empty stomach. Severe respiratory depression leads to anoxic encephalopathy. She is immediately intubated and 5 months later a feeding tube is placed. Around this time, her parents determine that their daughter is never going to regain consciousness and ask her doctors to disconnect the ventilator, a request that leads to considerable medical and legal wrangling. Thirteen months following her admission, she was successfully weaned off mechanical ventilation and, soon thereafter, was transferred to a nursing home. She died nine years later.



Karen Ann Quinlan  
March 29, 1954 – June 11, 1985



# Case 5



Nancy Cruzan

July 20, 1957 – December 26, 1990

A 24 year-old woman loses control of her car on an isolated, icy country road and is thrown 35 feet landing face down in a water-filled ditch. Arriving on the scene at least 15 minutes later, the paramedics manage to restart her asystolic heart. By that time she has suffered profound anoxic encephalopathy and is comatose. A feeding tube is placed to keep her alive. Four years later her parents decide that any hope of recovery has passed and ask that the feeding tube be removed, a request that eventually reaches the US Supreme Court. Almost 18 years after her accident, her feeding tube is removed and she dies.

## Case 6

A 27 year-old woman with a history of anorexia nervosa suffers a coma presumably due to a sustained arrhythmia leading to anoxic encephalopathy. A percutaneous endoscopic gastrostomy (PEG) tube is placed to keep her alive. For nearly 5 years she receives intensive rehabilitative care in an effort to regain consciousness. Eight years into her coma, the patient's husband asked that her PEG tube be removed, a request that leads to considerable legal battling, medical controversy, and extraordinary public rancor. When it finally ends, the PEG tube is removed and the patient dies 13 days later after 15 years of existence in a persistent vegetative state.



Terri Schiavo

December 3, 1963 – March 31, 2005



Normal  
Normal



Terri Schiavo 2002



# Characteristics of Persistent Vegetative State and Related Conditions

	Self Awareness	Sleep-Wake Cycle	Motor Function	Suffering (?)	Respiratory Function	EEG Activity
<b>PVS</b>	Absent	Intact	No purposeful movement	No	Normal	Polymorphic
<b>Coma</b>	Absent	Absent	No purposeful movement	No	Depressed; variable	Polymorphic
<b>“Brain Death”</b>	Absent	Absent	None or only reflex spinal movement	No	Absent	Electro-cerebral silence
<b>Locked In Syndrome</b>	Present	Intact	Quadriplegia; eye movement preserved	Yes	Normal	Normal or minimally abnormal
<b>Dementia</b>	Present but lost in late stages	Intact	Variable; limited with progression	Yes until late stages	Normal	Non-specific slowing

# How many adults in PVS eventually wake up?

OUTCOME AND FUNCTIONAL RECOVERY†	3 MONTHS	6 MONTHS	12 MONTHS
	<i>% of patients</i>		
<b>Adults</b>			
<b>Traumatic injury (n = 434)</b>			
Death	15	24	33
PVS	52	30	15
Recovery of consciousness	33	46	52
Severe disability			28
Moderate disability			17
Good recovery			7
<b>Nontraumatic injury (n = 169)</b>			
Death	24	40	53
PVS	65	45	32
Recovery of consciousness	11	15	15
Severe disability			11
Moderate disability			3
Good recovery			1

# How many children in PVS eventually wake up?

OUTCOME AND FUNCTIONAL RECOVERY†	3 MONTHS	6 MONTHS	12 MONTHS
	<i>% of patients</i>		
<b>Children</b>			
<b>Traumatic injury (n = 106)</b>			
Death	4	9	9
PVS	72	40	29
Recovery of consciousness	24	51	62
Severe disability			35
Moderate disability			16
Good recovery			11
<b>Nontraumatic injury (n = 45)</b>			
Death	20	22	22
PVS	69	67	65
Recovery of consciousness	11	11	13
Severe disability			7
Moderate disability			0
Good recovery			6



# Issues Raised

- Beneficence and non-maleficence
- Medical futility
- Extraordinary vs. ordinary care
- Withdrawing vs. forgoing treatment
- Passive vs. active euthanasia
- Advance directives and surrogate decision-makers





# Medical Indications

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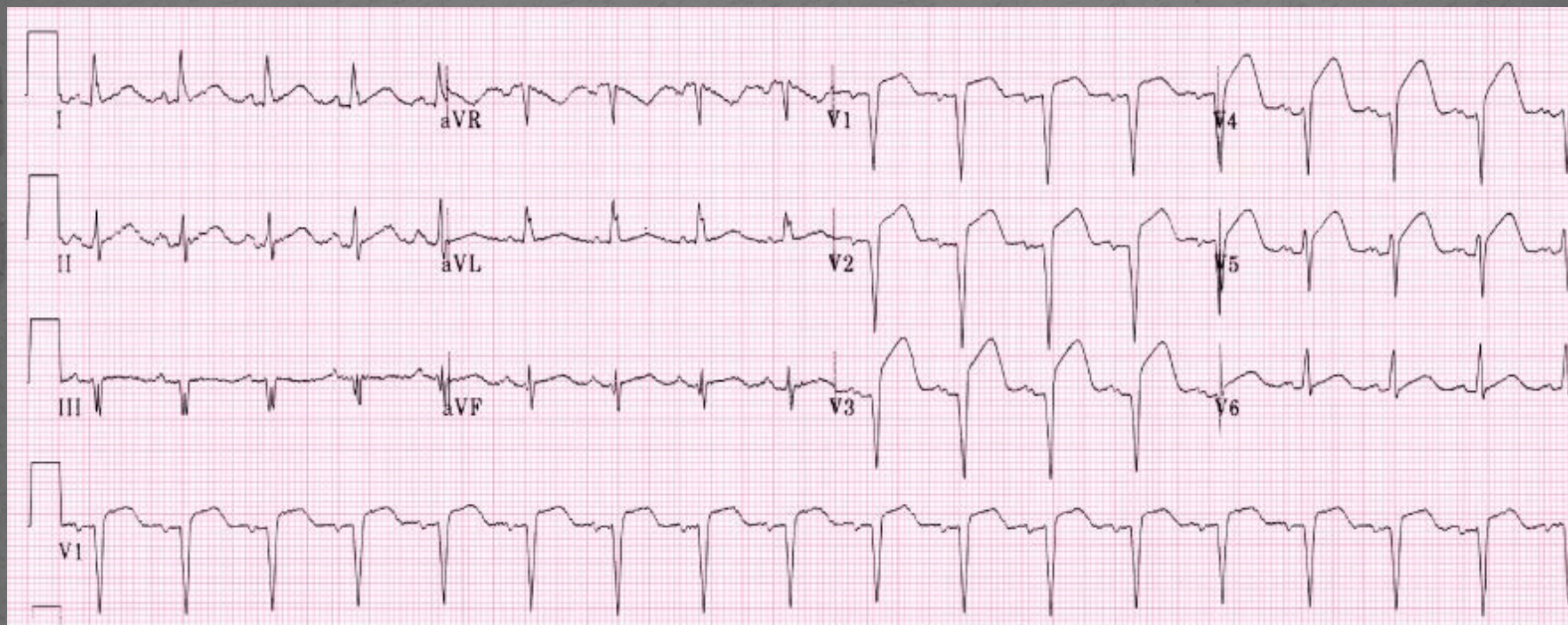
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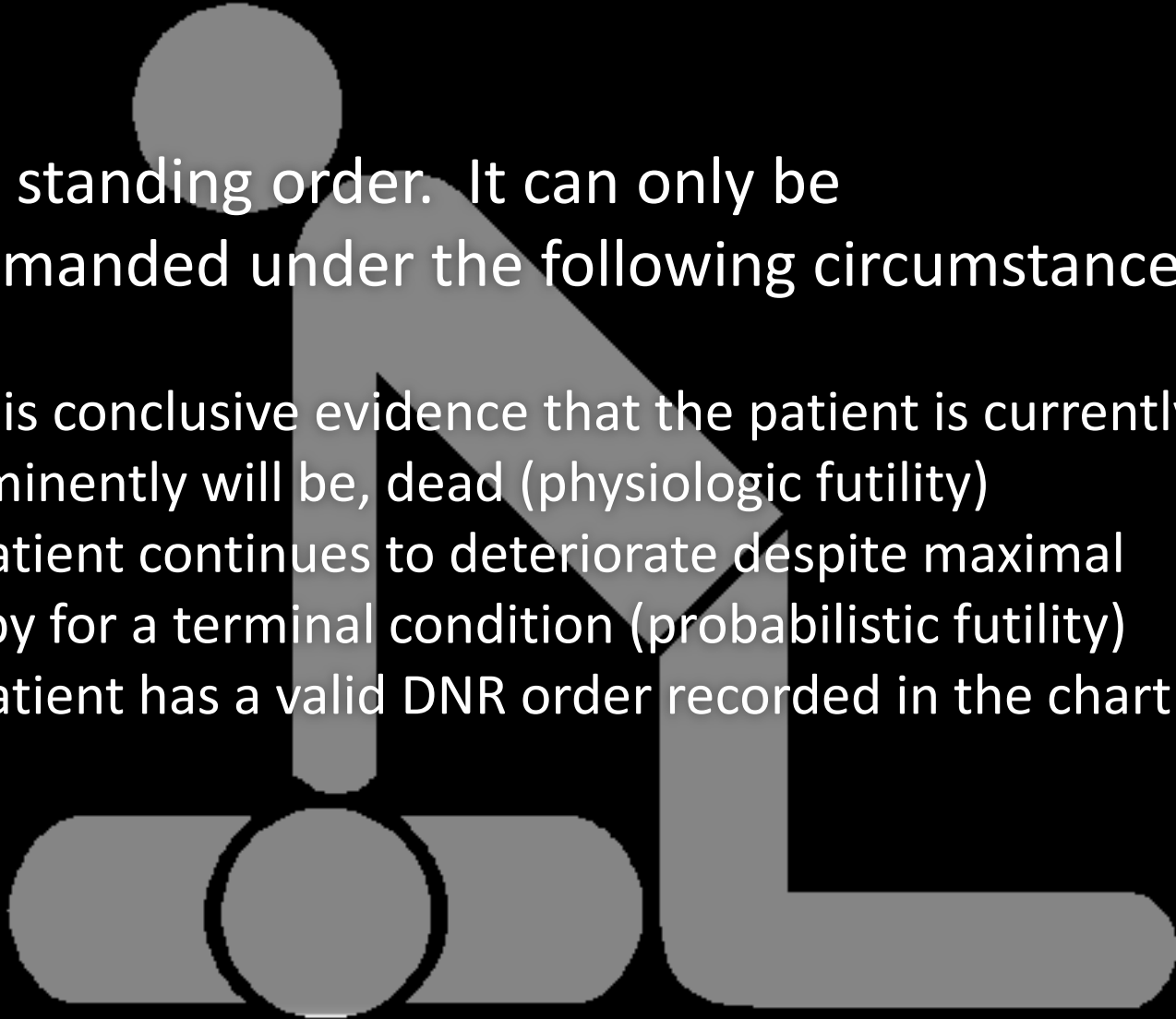
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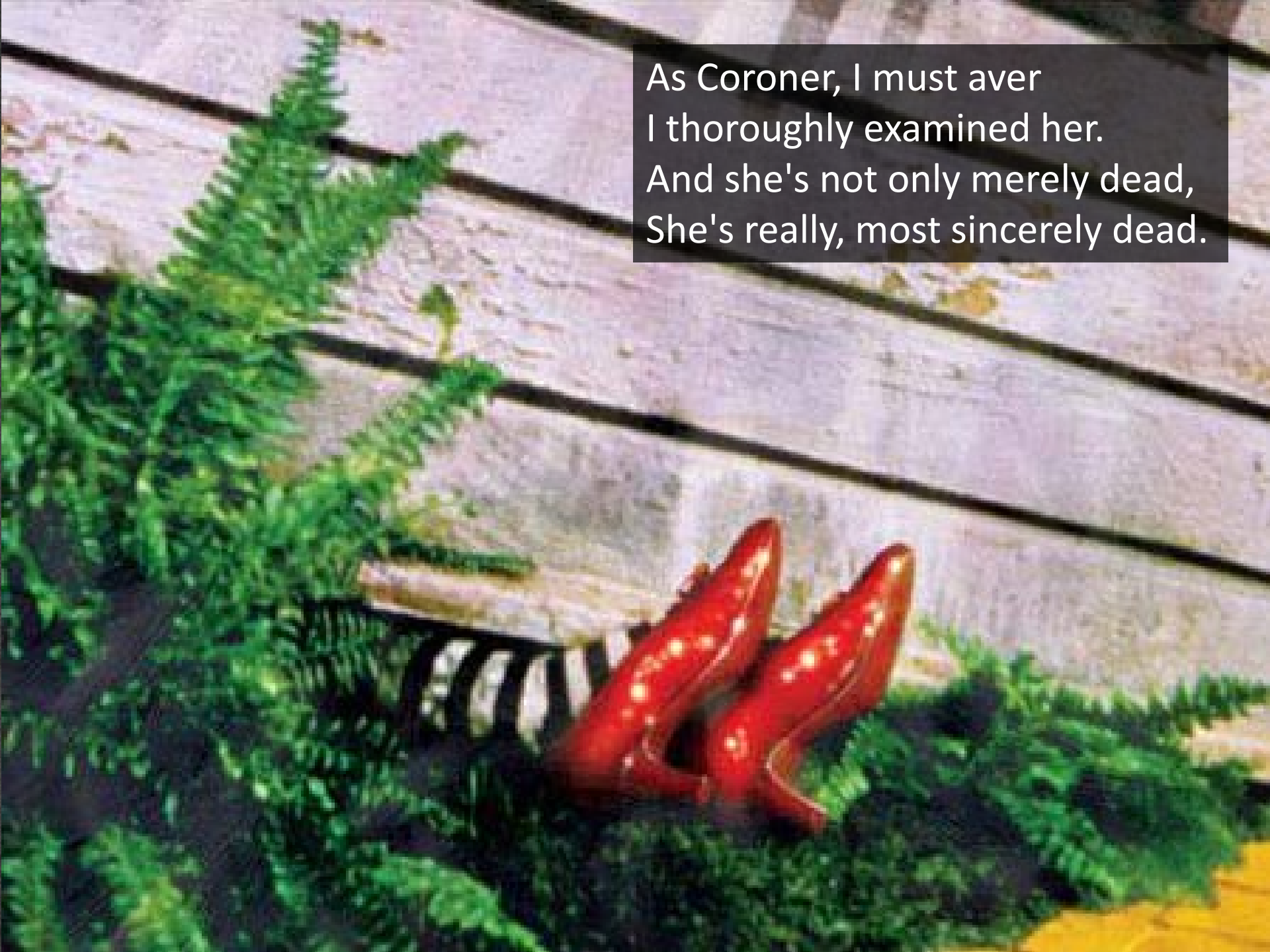
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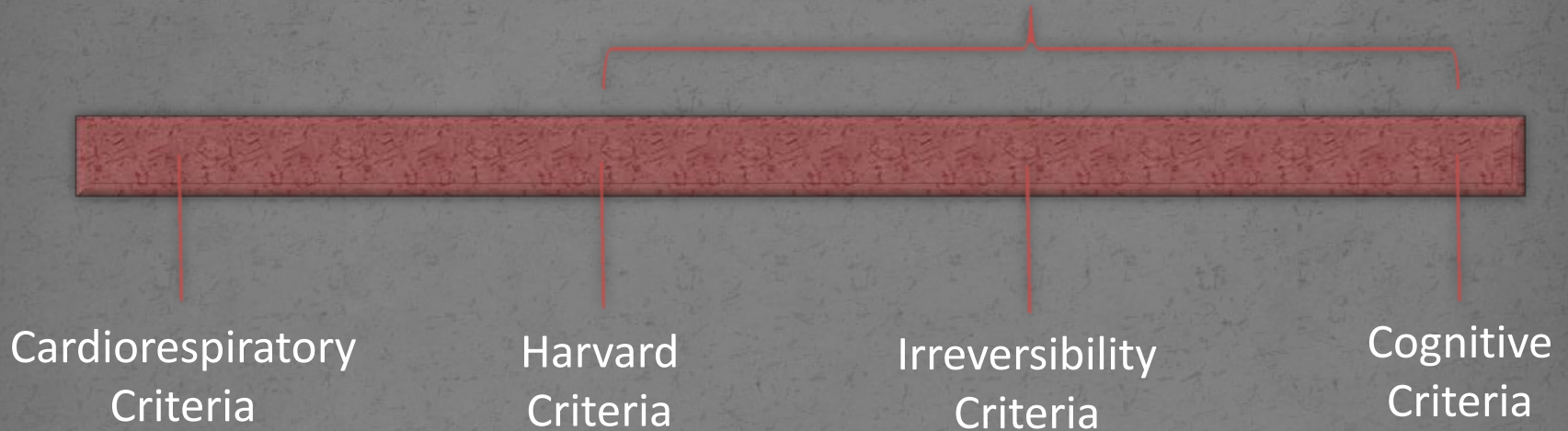
Is it possible to die more than once?

No. If you're brain dead, you're dead.



# Defining Death

Brain Death



Cardiorespiratory  
Criteria

Harvard  
Criteria

Irreversibility  
Criteria

Cognitive  
Criteria

Availability of transplantable organs

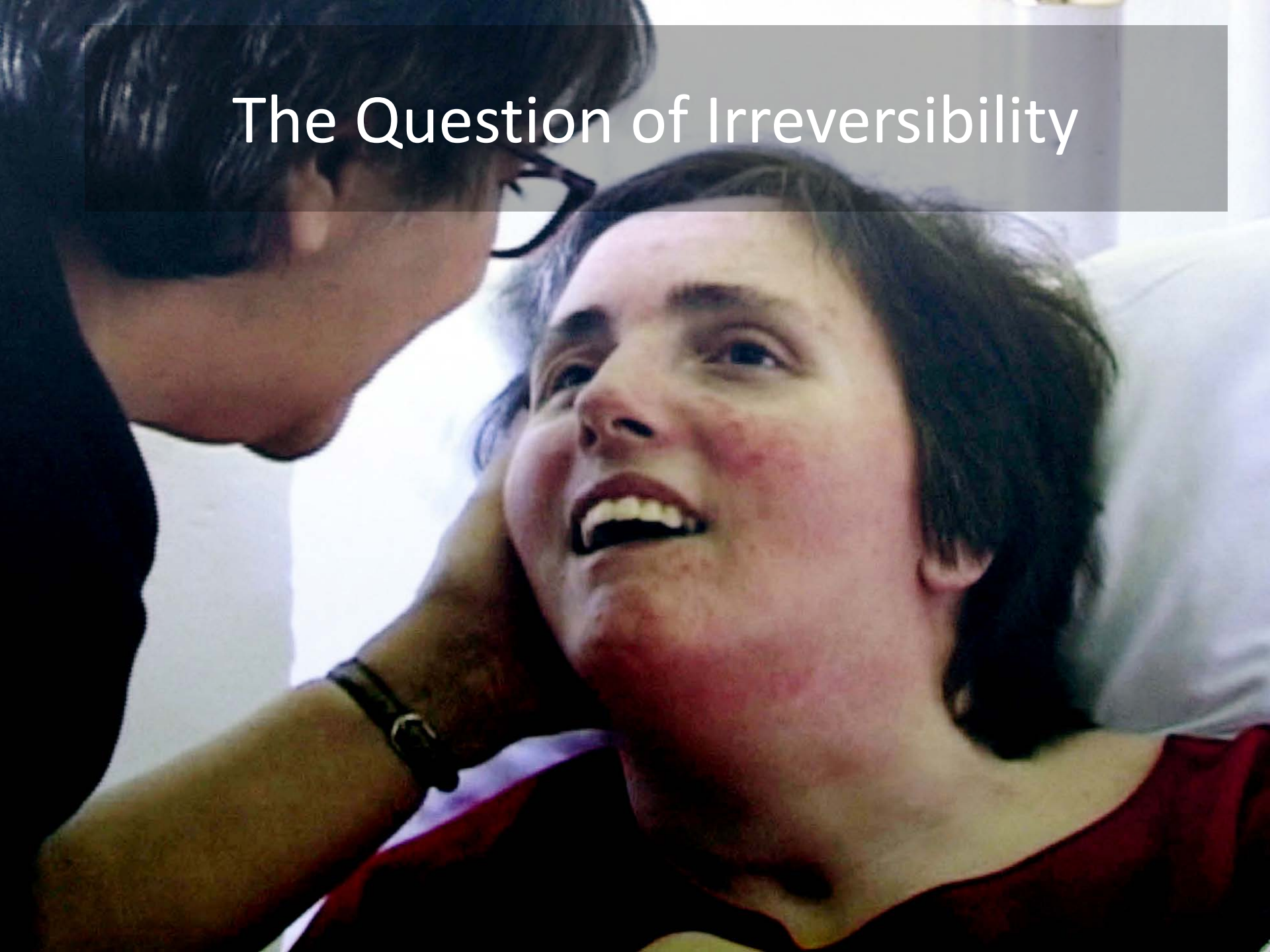
# Cognitive Criteria

Death is equivalent to the end of personhood. An individual dies with his or her loss of:

- Reason
- Memory
- Agency
- Self-awareness



# The Question of Irreversibility



# Case 4

A 21 year-old woman lapses into a coma after drinking alcohol and taking barbiturates and/or benzodiazepines on an empty stomach. Severe respiratory depression leads to anoxic encephalopathy. She is immediately intubated and 5 months later a feeding tube is placed. Around this time, her parents determine that their daughter is never going to regain consciousness and ask her doctors to disconnect the ventilator, a request that leads to considerable medical and legal wrangling. Thirteen months following her admission, she was successfully weaned off mechanical ventilation and, soon thereafter, was transferred to a nursing home. She died nine years later.



Karen Ann Quinlan  
March 29, 1954 – June 11, 1985



# Case 5



Nancy Cruzan

July 20, 1957 – December 26, 1990

A 24 year-old woman loses control of her car on an isolated, icy country road and is thrown 35 feet landing face down in a water-filled ditch. Arriving on the scene at least 15 minutes later, the paramedics manage to restart her asystolic heart. By that time she has suffered profound anoxic encephalopathy and is comatose. A feeding tube is placed to keep her alive. Four years later her parents decide that any hope of recovery has passed and ask that the feeding tube be removed, a request that eventually reaches the US Supreme Court. Almost 18 years after her accident, her feeding tube is removed and she dies.

## Case 6

A 27 year-old woman with a history of anorexia nervosa suffers a coma presumably due to a sustained arrhythmia leading to anoxic encephalopathy. A percutaneous endoscopic gastrostomy (PEG) tube is placed to keep her alive. For nearly 5 years she receives intensive rehabilitative care in an effort to regain consciousness. Eight years into her coma, the patient's husband asked that her PEG tube be removed, a request that leads to considerable legal battling, medical controversy, and extraordinary public rancor. When it finally ends, the PEG tube is removed and the patient dies 13 days later after 15 years of existence in a persistent vegetative state.



Terri Schiavo

December 3, 1963 – March 31, 2005





Normal  
Normal



Terri Schiavo 2002

# Characteristics of Persistent Vegetative State and Related Conditions

	Self Awareness	Sleep-Wake Cycle	Motor Function	Suffering (?)	Respiratory Function	EEG Activity
<b>PVS</b>	Absent	Intact	No purposeful movement	No	Normal	Polymorphic
<b>Coma</b>	Absent	Absent	No purposeful movement	No	Depressed; variable	Polymorphic
<b>“Brain Death”</b>	Absent	Absent	None or only reflex spinal movement	No	Absent	Electro-cerebral silence
<b>Locked In Syndrome</b>	Present	Intact	Quadriplegia; eye movement preserved	Yes	Normal	Normal or minimally abnormal
<b>Dementia</b>	Present but lost in late stages	Intact	Variable; limited with progression	Yes until late stages	Normal	Non-specific slowing

# How many adults in PVS eventually wake up?

OUTCOME AND FUNCTIONAL RECOVERY†	3 MONTHS	6 MONTHS	12 MONTHS
	<i>% of patients</i>		
<b>Adults</b>			
<b>Traumatic injury (n = 434)</b>			
Death	15	24	33
PVS	52	30	15
Recovery of consciousness	33	46	52
Severe disability			28
Moderate disability			17
Good recovery			7
<b>Nontraumatic injury (n = 169)</b>			
Death	24	40	53
PVS	65	45	32
Recovery of consciousness	11	15	15
Severe disability			11
Moderate disability			3
Good recovery			1

# How many children in PVS eventually wake up?

OUTCOME AND FUNCTIONAL RECOVERY†	3 MONTHS	6 MONTHS	12 MONTHS
	<i>% of patients</i>		
<b>Children</b>			
<b>Traumatic injury (n = 106)</b>			
Death	4	9	9
PVS	72	40	29
Recovery of consciousness	24	51	62
Severe disability			35
Moderate disability			16
Good recovery			11
<b>Nontraumatic injury (n = 45)</b>			
Death	20	22	22
PVS	69	67	65
Recovery of consciousness	11	11	13
Severe disability			7
Moderate disability			0
Good recovery			6



# Issues Raised

- Beneficence and non-maleficence
- Medical futility
- Extraordinary vs. ordinary care
- Withdrawing vs. forgoing treatment
- Passive vs. active euthanasia
- Advance directives and surrogate decision-makers





<b>Format</b>	Small group discussion
<b>Faculty</b>	Facilitators
<b>Learning Objective</b>	Identify the relevant facts and use the appropriate ethical principles to argue a position in cases pertaining to clinical genetics and medical indications.
<b>Readings</b>	<u>Cases for Discussions</u> <ul style="list-style-type: none"><li>• Duty to Warn At-Risk Family Members of Genetic Disease</li><li>• Turning Off an Implanted Life-Saving Device</li><li>• End of Life and Sanctity of Life</li><li>• The Hard Case of Palliative Sedation</li></ul>

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# Defining Death

Medical, Legal and  
Ethical Issues in the  
Determination of Death



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President's Commission for the Study of  
Ethical Problems in Medicine and  
Biomedical and Behavioral Research

**\*Special note:** In creating an electronic version of this document, every attempt was made to replicate the original. However, some of the footnote symbols in this electronic version do not match the footnote symbols in the original (both versions use a numbering system to symbolize the footnotes). This change only affects the way the footnotes are symbolized, but does not affect the correspondence of each particular footnote to the text as it is in the original document.

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# Defining Death

A Report on the  
Medical, Legal and  
Ethical Issues in the  
Determination of Death

July 1981

President's Commission for the Study of  
Ethical Problems in Medicine and  
Biomedical and Behavioral Research

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## President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

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President's Commission for the Study of Ethical Problems  
in Medicine and Biomedical and Behavioral Research

Suite 555, 2000 K Street, NW., Washington, DC 20006 (202) 653-8051

July 9, 1981

The Honorable Thomas P. O'Neill, Jr.  
Speaker  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Mr. Speaker:

On behalf of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, I am pleased to transmit our report concerning the "definition" of death. This is one of several subjects which Public Law 95-622 directs the Commission to study and regarding which we are to report to the President, the Congress and the relevant Departments of government.

We have concluded that, in light of the ever increasing powers of biomedical science and practice, a statute is needed to provide a clear and socially-accepted basis for making determinations of death. We recommend the adoption of such a statute by the Congress for areas coming under federal jurisdiction and by all states as a means of achieving uniform law on this subject throughout the Nation.

We are grateful for the opportunity to assist in resolving this issue of public concern and importance.

Respectfully,

A handwritten signature in black ink, appearing to read "Morris B. Abram". The signature is fluid and cursive, with a long horizontal flourish extending to the right.

Morris B. Abram  
Chairman





President's Commission for the Study of Ethical Problems  
in Medicine and Biomedical and Behavioral Research

Suite 555, 2000 K Street, N.W., Washington, DC 20006 (202) 653-8051

July 9, 1981

The Honorable George Bush  
President  
United States Senate  
Washington, D.C.  
20510

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Chairman





President's Commission for the Study of Ethical Problems in  
Medicine and Biomedical and Behavioral Research

Suite 555, 2000 K Street, N.W., Washington, DC 20006 (202) 653-8051

July 9, 1981

The President  
The White House  
Washington, D.C. 20500

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Morris B. Abram  
Chairman



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# Summary of Conclusions and Recommended Statute

The enabling legislation for the President's Commission directs it to study "the ethical and legal implications of the matter of defining death, including the advisability of developing a uniform definition of death."<sup>1</sup> In performing its mandate, the Commission has reached conclusions on a series of questions which are the subject of this Report. In summary, the central conclusions are:

1. That recent developments in medical treatment necessitate a restatement of the standards traditionally recognized for determining that death has occurred.
2. That such a restatement ought preferably to be a matter of statutory law.
3. That such a statute ought to remain a matter for state law, with federal action at this time being limited to areas under current federal jurisdiction.
4. That the statutory law ought to be uniform among the several states.
5. That the "definition" contained in the statute ought to address general physiological standards rather than medical criteria and tests, which will change with advances in biomedical knowledge and refinements in technique.
6. That death is a unitary phenomenon which can be accurately demonstrated either on the traditional grounds of irreversible cessation of heart and lung functions or on the basis of irreversible loss of all functions of the entire brain.
7. That any statutory "definition" should be kept separate and distinct from provisions governing the donation of cadaver organs and from any legal rules on decisions to terminate life-sustaining treatment.

---

<sup>1</sup> 142 D.S.C. §1802 (1978).

To embody these conclusions in statutory form the Commission worked with the three organizations which had proposed model legislation on the subject. the American Bar Association, the American Medical Association, and the National Conference of Commissioners on Uniform State Laws. These groups have now endorsed the following statute, in place of their previous proposals:

**Uniform Determination of Death Act**

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

The Commission recommends the adoption of this statute in all jurisdictions in the United States.

# Introduction

Death is the one great certainty. The subject of powerful social and religious rituals and moving literature, it is contemplated by philosophers, probed by biologists, and combatted by physicians. Death, taboo in some cultures, preoccupies others. In this Report the President's Commission explores only a small corner of this boundless topic.

The question addressed here is not inherently difficult or complicated. Simply, it is whether the law ought to recognize new means for establishing that the death of a human being has occurred. The accepted standard for determining death has been the permanent absence of respiration and circulation. A question arises about continued reliance on the traditional standard because advances in medical technique now permit physicians to generate breathing and heartbeat when the capacity to breathe spontaneously has been irretrievably lost. Prior to the advent of current technology, breathing ceased and death was obvious. Now, however, certain organic processes in these bodies can be maintained through artificial means, although they will never recover the capacity for spontaneous breathing or sustained integration of bodily functions, for consciousness, or for other human experiences.

Such artificially-maintained bodies present a new category for the law (and for society), to which the application of traditional means for determining death is neither clear nor fully satisfactory. The Commission's mandate is to study and recommend ways in which the traditional legal standards can be updated in order to provide clear and principled guidance for determining whether such bodies are alive or dead.

Although it is in most respects straightforward, "the matter of defining death" seemed troublesome enough to be included in the Commission's statutory mandate for several



reasons. Most important, consideration of the new approaches to the determination of death has resulted in attention being paid to underlying questions about the meaning of life and death. Concerns about diagnosing death by measuring the presence or absence of brain functions has occasioned a reexamination of the traditional techniques. Consequently, questions have been posed about the scientific and clinical bases for the traditional standard for death and about the understanding of human life upon which that standard rests.

Furthermore, other changes in medical abilities have contributed to the concern about the "definition" of death. For example, the importance customarily accorded to a person's beating heart in differentiating the living from the dead is challenged when a "dead" person's heart can beat in the chest of a "living" person whose own heart has not merely stopped but has been removed from his or her body.

Finally, confusion arises—which can only be dispelled by the application of accepted medical standards in each individual case—because the same technology not only keeps heart and lungs functioning in some who have irretrievably lost all brain functions but also sustains other, less severely injured patients. Inexact medical and legal descriptions of these two categories of cases have led to a blurring of the important distinction between patients who are dead and those who are or may be *dying*. This Report on "Defining Death" does *not* address the medical, legal and ethical problems concerning dying patients. Issues in the treatment of dying patients will be the subject of a later study by the Commission. This Report focuses solely on the determination that death has occurred.

Although it is possible—indeed, in the Commission's view, necessary—to treat "determination of death" and "allowing to die" separately as matters for public policy, both arise from common roots in society. These roots not only grow in the soil of newly developed medical capabilities but are also nourished by the flood of popular attention to "death and dying." The "movement" that they have generated is now a staple of the popular media.<sup>1</sup> The portrayals in news stories, dramas and documentaries of vignettes and dilemmas about dying touch deep ethical and existential chords and reflect broader concerns about the physician-patient relationship, personal autonomy and control of treatment, and the myriad consequences of modern,

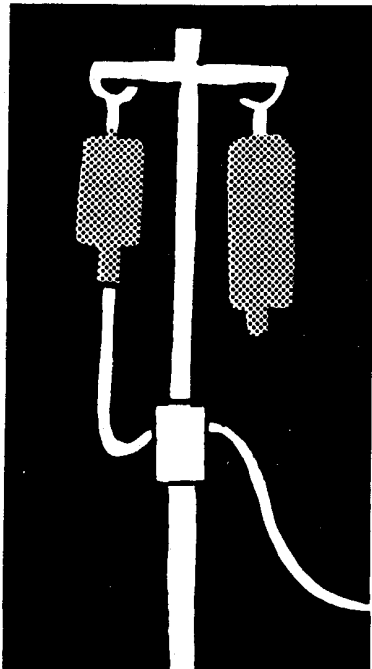
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<sup>1</sup> George Gerbner, "Death in Prime Time: Notes on the Symbolic Functions of Dying in the Mass Media," 447 *Ann. Am. Acad. Polito &- Soc. Sci.* 64 (1980); Michel Vovelle, "Rediscovery of Death Since 1960," 447 *Ann. Am. Acad. Polito &- Soc. Sci.* 89 (1980).

high-technology medicine. All of these areas are matters for continuing study by the Commission, illuminated by, but not limited to, the special setting of death and dying.

### Overview of the Report

Traditionally, the cessation of heartbeat and of breathing were regarded by the lay and medical communities alike as the definitive signs of death. The law, through the judgments of courts in deciding individual cases, articulated this general view. In the oft-quoted words of *Black's Law Dictionary*, the common law mirrored the physician's "definition" of death "as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc."<sup>1</sup>



Developments in medical technology and practice, which are reviewed in Chapter One, have prompted an examination of the adequacy of the traditional view of the proper way to determine whether death has occurred. Since respiration is controlled by brain centers, the loss of function in those centers used to mean that breathing (and consequently heartbeat) would never return. Mechanical respirators and related therapy now enable physicians to reverse the failure of respiration and circulation in many victims of conditions such as cardiac arrest or trauma. If blood flow to the

brain is restored quickly enough (usually this must be within several minutes), these victims may eventually recover unassisted breathing. But the brain cannot regenerate neural cells to replace ones that have permanently stopped metabolizing. Hence, longer periods without blood flow (ischemia) or oxygen (anoxia) may cause complete and irreversible loss of all brain functions. When the entire brain

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<sup>1</sup> *Black's Law Dictionary*, (4th ed.) West Publishing Co., St. Paul, Minn. (1968) at 488: DEATH. The cessation of life; the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc.

*But see Black's Law Dictionary* (5th ed.) West Publishing Co., St. Paul, Minn. (1979) at 170, which now includes an entry under the heading "brain death," citing recent statutes and court cases.

has been so severely damaged, spontaneous respiration can never return even though breathing may be maintained by artificial means for some time (typically, several days).

Although physicians find themselves unable to rely on respiration and circulation as a means of diagnosing death in artificially-maintained, comatose patients, they have developed means of detecting the existence or nonexistence of brain functions and the potential for reversibility in such patients. These tests are intended to measure the organic functioning of the brain, not the mere existence of cellular activity which may continue in some brain cells—as in cells of other organs, such as the heart and lungs—for varying lengths of time after the organ has lost the ability to fulfill any of its functions in an organized manner. From the evidence presented at the Commission's July 11, 1980, meeting and in the biomedical literature, the Commission concludes in Chapter Two that proof of an irreversible absence of functions in the entire brain, including the brainstem, provides a highly reliable means of declaring death for respirator-maintained bodies.

The diagnosis of death has, of course, significance beyond its role as a physiological concept. Therefore in Chapter Three several different explanations of the "meaning" of human life and death are examined. Formulations based upon the functions of the whole brain include those that focus on the integrated functioning of brain, heart and lung and on the primacy of the brain among organs as the body's regulator. Some people have argued for a "higher brain" formulation, such as one which attempts to enumerate the characteristics essential to "personhood" or one that bases death on the loss of "personal identity," viewed here as a consequence of discontinuity in certain mental processes. Finally, several explanations of death not oriented to brain functions are also reviewed, such as those which hold death to occur when the soul leaves the body or which equate life with the flow of air and blood through the body. The Commission had some points of disagreement with all of the formulations. Nevertheless, without resolving all the conceptual issues, the Commission found that all the formulations, except perhaps the last, were consistent with the public policy recommendations of this Report.

If death were entirely a medical matter, the process of "redefinition" might have been left in the hands of the health professions, as the Commission notes in Chapter Four. But, as the Congress and the President signified in referring this task to an interdisciplinary, broadly-based public body for study, the standards by which death is determined have significance and consequences that are not limited to medical ones. Accordingly, the standards by

which death is to be recognized should be arrived at publicly, although it will remain for physicians to continue to develop criteria and tests and to apply them in reaching individual diagnoses.

Chapter Four examines ways to effect this public response. Traditionally, the law on the determination of death was found in the common law decisions of judges ruling on individual cases rather than in the statute books.<sup>1</sup> One could, of course, remain in that tradition and await judicial reformulation of the standard. Yet this method of law reform has serious drawbacks-among them, delay, uncertainty, and lack of consistency in the rules applicable in different jurisdictions. Consequently, in the past decade half the states have adopted statutes incorporating the cessation of total brain functions as a ground for declaring death.

Having concluded that change should be effected publicly and through legislation, the Commission next addresses several basic policy issues. First, how specific- socially or scientifically-should this legislation be? After considering the alternatives, from the basic concept of death to the precise clinical procedures for diagnosis, the Commission concludes that what is required is the promulgation of general physiologic standards for recognizing that death has occurred.

Second, a statute ought to meet several objectives. Most important, any law should treat like cases alike and provide consistency among jurisdictions when an issue is as important as determining that a human being has died. As a practical matter, alternative standards may be necessary and appropriate. But the use of two standards in a statute should not be permitted to obscure the fact that death is a unitary phenomenon.

It is also desirable, in the Commission's view, to limit change in the law on death to the minimum necessary for the problem at hand, *Le.*, ambiguity about the status of cases of coma with respirator-assistance. Extending the "definition" of death beyond those lacking all brain functions to include, for example, persons who have lost only cognitive functions but are still able to breathe spontaneously would radically change the meaning of death. Furthermore, in language as well as content, any legislation ought to make personal sense to lay people and to reflect scientific knowledge and clinical reality.

Certainty and clarity about the standards for determining death are equally matters of concern in the making of public policy throughout the country. Practically, patients are transported across state lines for treatment; if neighboring states had different definitions, confusion would proba-

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<sup>1</sup>See Appendix D, *infra*.

bly result, and abuse become possible. State-by-state variation is not justified on a matter that is so fundamental and that rests on biological facts of universal applicability. Accordingly, in Chapter Five, the Commission recommends that all states adopt a uniform statute on determining death to replace existing judicial or statutory formulations. Expecting that uniform law will emerge from this process, the Commission concludes that this topic remains an appropriate subject for state rather than federal legislation, except as to those areas where the federal government exercises jurisdiction. The chapter also provides a point-by-point examination of the proposed statute and the reasons favoring its adoption.

Finally, Chapter Five concludes with brief comments on several ethical aspects of the proposed statute. The purpose in changing the law is to regularize its administration and to permit more prudent and humane medical care. These improvements will better protect life and respect the fact of its end. Plainly, any standard for determining death must be capable of certain and consistent application.

### **The Process of the Commission's Study**

At its first meeting, in January 1980, the Commission decided to make the "matter of defining death" one of its first studies. Discussion centered on four points: (1) whether a federal commission is an appropriate body to formulate a position regarding a matter traditionally left to state law, (2) whether problems of uniformity or implementation had arisen with the statutes on death already adopted by many States, (3) whether one or more of the existing "model statutes" should be endorsed or a new one proposed, and (4) whether to enlarge on the Commission's statutory mandate to study with the "definition of death" the related but distinct issues presented by decisions to forego life-sustaining therapy.

At its next meeting, in May, the Commission heard philosophical and political testimony on the determination of death. Professor Daniel Wikler, a University of Wisconsin philosopher, proposed a concept of "personal identity" to supplant the common understanding of "whole brain" functioning as the basis for "brain death." Nevertheless, he urged the Commissioners to focus on the legal issue of whether those who are "brain dead" should be ruled legally dead. He noted that it may be possible to agree on policy without achieving full consensus on the purely conceptual issues. Professor Wikler's points are considered in Chapter Three.

Professor Robert Veatch of the Kennedy Institute of Ethics at Georgetown University cautioned against using the term "brain death" because it has two distinct but

confusing meanings-cessation of brain functions and the death of a person based on that cessation. He noted that the latter phenomenon is the one of concern to public policy. Two basic issues identified by Professor Veatch are considered in this Report: (1) Should society stay with heart-lung criteria for death, since some people still doubt that a person is dead while a respirator keeps lungs and heart working, or, at the other extreme, should death be based solely on the loss of "higher" brain functions? and (2) Is diversity in the public definition of death (by society, physicians, patients, or their agents) possible? Can such diversity be tolerated on so fundamental a matter?

During May the Commission's Executive Director met with representatives of the American Bar Association (ABA), the American Medical Association (AMA), and the National Conference of Commissioners on Uniform State Laws (NCCUSL). Those attending this meeting prepared a statute on the determination of death which they recommended for approval by their organizations in place of the organizations' preexisting statutory proposals. During the summer, the Director served as a special consultant to the NCCUSL during its deliberations about the proposed statute, which was approved. Subsequently, the new uniform statute was also approved by the AMA (October 19, 1980) and the ABA (February 10, 1981).



The Commission devoted a day of testimony and discussion to the medical and theological aspects of "defining" death at its next meeting, in July 1980. During the morning, the Commission heard from five expert witnesses: Dr. Frank Veith, Chief of Vascular Surgery at the Montefiore Hospital in New York City; Dr. Ronald Cranford,



Director of the Neurological Intensive Care Unit at the Hennepin County Medical Center, and Chairman of the Ethics Committee of the American Academy of Neurology; Dr. Gaetano Molinari, Professor and Chairman of the Department of Neurology at the School of Medicine and Health Services at George Washington University, who had served as the principal NIH officer for the Collaborative Study of Cerebral Death; Dr. Earl Walker, Adjunct Professor Neurosurgery and Neurology at the University of New Mexico School of Medicine, Coordinator of the Collaborative Study; and Dr. Julius Korein, Professor of Neurology at the New York University Medical Center.

The witnesses agreed that the technological advances which have made artificial respiration possible also spawned criteria for determining irreversible cessation of brain functions. The physicians all concurred that a statutory definition of death should encompass irreversible loss of brain functions. They cited a number of reasons:

- (1) Such a law would establish the legality of pronouncing death based on brain criteria;
- (2) The use of the brain-based standard when the heart-lung standard is not applicable would protect patients against ill-advised, idiosyncratic pronouncements of death;
- (3) Legal recognition of the brain-based standard would remove the doubt that exists in some states over the use of patients without brain functions as organ donors;
- (4) A single set of standards for death pronouncements is appropriate for all legal purposes (encompassing inheritance, taxes and criminal trials, as well as medical treatment); and
- (5) Maintaining a dead body on artificial support systems consumes scarce medical resources and may unnecessarily deplete the family's emotional and financial resources.

Because the medical testimony indicated that the epidemiology of total and irreversible brain cessation (including the frequency of its occurrence, its effects on the medical management decisions, and the relative proportion of survivals and death among comatose patients placed on respirators) was not well documented, the Commission embarked during the Fall of 1980 on a small empirical study. A full description of this project is in Appendix B; some of its findings are highlighted in relevant sections of the Report.

The Commission also considered religious viewpoints. Testimony was received from Rabbi J. David Bleich, Associate Professor of Talmudic and Jewish Law at Yeshiva University in Union of Orthodox Jewish Congre-

gations of America; Rabbi Moses Tendler, Professor of Biology and of Talmudic Law at Yeshiva University; Father Paul M. Quay, Associate Professor in the Departments of Theological Studies and Physics at St. Louis University; Father Kevin O'Rourke, Director of the Center for Health Care Ethics at St. Louis University; and Professor Paul Ramsey, a leading Protestant theologian who is the Harrington Spear Paine Professor of Religion at Princeton University.

Jewish writings do not deal directly with "brain death" but contain passages susceptible to opposing readings. Rabbi Bleich interpreted Jewish law to require a cessation of corporal blood flow, whether or not spontaneous, as a prerequisite for determining death; Rabbi Tendler said that the Jewish tradition would recognize complete cessation of brain function as "physiological decapitation" and hence accept it as a basis for declaring death.

Catholic and Protestant theological doctrines do not directly address the method of determining death. The belief that the human essence or soul departs at the moment of death is not inconsistent with the establishment, through neurological examination, of the time when death occurs.<sup>1</sup> The religious concern is, rather, with according proper respect to the deceased (which may include the termination of unnecessary procedures) while also avoiding premature termination of helpful treatment under the guise of declaring death.

The views of leaders in the "right to life" movement were also reviewed. In their published statements there is support for the enactment of statutes incorporating "total brain death" as a basis for determining death. As stated by Dennis Horan, President of American Citizens United for Life,

Legislation limiting the concept of brain death to the irreversible cessation of total function of the brain, including the brain stem, is beneficial and does not undermine any of the values we seek to support.<sup>2</sup>

Indeed, by drawing a clear line between the living and the dead, legislation of this sort is supported as a means of relieving- "some of the pressure for legalizing euthanasia"<sup>3</sup> according to a leading pro-life philosopher, Christian Eth-

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<sup>1</sup> "[I]t remains for the doctor to give a clear and precise definition of 'death' and the 'moment of death' of a patient who passes way in the state of unconsciousness." Pope Pius XII, "The Prolongation of Life," 4 *The Pope Speaks* 393, 396 (1957).

<sup>2</sup> Dennis J. Horan, "Definition of Death: An Emerging Consensus," 16 *Trial* 22,26 (1980). *See also* pp. 81-84 *infra*.

<sup>3</sup> "[A] correct definition of death, if it would eliminate some false classifications of dead individuals [as being] among the living, could relieve some of the pressure for legalizing euthanasia-in this case, pressure arising from a right attitude toward individuals really dead and only considered alive due to conceptual confusion." Germain Grisez & Joseph M. Boyle, Jr., *Life and Death with Liberty and Justice: A Contribution to the Euthanasia Debate*, University of Notre Dame Press, Notre Dame, Indiana (1979) at 61. Dennis Horan also concludes that "total brain death legislation enhances those values [we seek to support] by prohibiting euthanasia and allowing only those to be declared dead who are really dead." *Gp. cit.* at 26.

ics Professor Germain Grisez of Mount Saint Mary's College.

The theological witnesses stated that it is neither necessary nor appropriate for public policy to resolve matters of religious belief. The Commission agrees; the statute recommended in this Report rests on secular foundations and does not purport to dictate religious beliefs. Necessarily, however, in reforming the legal standards governing a physician's determination that someone's biological life has ended, the proposed statute will have implications for secular legal and medical conduct with respect to the dead, while permitting accommodation of religious views and practices.<sup>1</sup>

Testimony from several of the religious leaders emphasized that death is an absolute phenomenon, so that terms such as "brain dead" or "virtually dead" are misleading. Father Quay and Professor Ramsey, in particular, warned that a statutory definition should not be construed as inviting premature organ transplantation. The Commissioners agree that since the determination of death is irrevocable, extreme caution must be exercised in the process of making public policy and law as well as each individual diagnosis. The medical information reviewed in Chapter Two of this Report and the guidelines for diagnosis developed concurrently by a group of medical experts (see Appendix F) respond to the concern for certainty.

The staff's first draft report was briefly considered at the September 1980 meeting. A second draft was discussed at the November meeting, at which time the Commissioners endorsed the general presentation and the model statute. Following that meeting, the draft Report was revised and circulated. The Commissioners discussed that revised draft at their June 1981 meeting. Final consideration of the subject occurred at the meeting of July 9, 1981, at which time the Commissioners present unanimously gave formal approval to the Uniform Determination of Death Act and to this Report, subject to several editorial corrections.

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<sup>1</sup> See pp. 80-81 *infra*.

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# Why "Update" Death?

# 1

For most of the past several centuries, the medical determination of death was very close to the popular one. If a person fell unconscious or was found so, someone (often but not always a physician) would feel for the pulse, listen for breathing, hold a mirror before the nose to test for condensation, and look to see if the pupils were fixed. Although these criteria have been used to determine death since antiquity, they have not always been universally accepted.

## **Developing Confidence in the Heart-Lung Criteria**

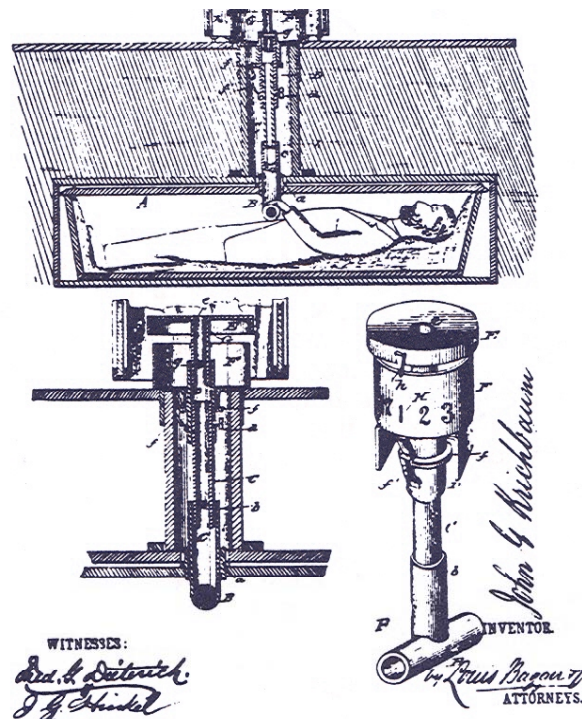
In the eighteenth century, macabre tales of "corpses" reviving during funerals and exhumed skeletons found to have clawed at coffin lids led to widespread fear of premature burial. Coffins were developed with elaborate escape mechanisms and speaking tubes to the world above (Figure 1), mortuaries employed guards to monitor the newly dead for signs of life, and legislatures passed laws requiring a delay before burial.<sup>1</sup>

The medical press also paid a great deal of attention to the matter. In *The Uncertainty of the Signs of Death and the Danger of Precipitate Interments* in 1740, Jean-Jacques Winslow advanced the thesis that putrefaction was the only sure sign of death. In the years following, many physicians published articles agreeing with him. This position had, however, notable logistic and public health disadvantages. It also disparaged, sometimes with unfair vigor, the skills of physicians as diagnosticians of death. In reply, the French surgeon Louis published in 1752 his influential *Letters on*

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<sup>1</sup> Marc Alexander, "The Rigid Embrace of the Narrow House: Premature Burial and the Signs of Death," 10 *Hastings* Ctr. Rpt. 25 (1980); John D. Arnold, Thomas F. Zimmerman and Daniel C. Martin, "Public Attitudes and the Diagnosis of Death," 206 *I.A.M.A.* 1949 (1968).

*the Certainty of the Signs of Death.* The debate dissipated in the nineteenth century because of the gradual improvement in the competence of physicians and a concomitant increase in the public's confidence in them.



**Figure 1.** Kirchbaum's device for indicating life in buried persons, Patent sketch, 1882.

Physicians actively sought to develop this competence. They even held contests encouraging the search for a cluster of signs—rather than a single infallible sign—for the diagnosis of death.<sup>1</sup> One sign did, however, achieve prominence. The invention of the stethoscope in the mid-nineteenth century enabled physicians to detect heartbeat

<sup>1</sup> Alexander, *op. cit.* at 30, citing, Orifila, *A Popular Treatise on the Remedies to be Employed in Case of Poisoning and Apparent Death; Including Means of Detecting Poisons, of Distinguishing Real From Apparent Death, and of Ascertaining the Adulteration of Wines*, trans. from French, Philadelphia, (1818) at 154; G. Tourdes, "Mort (Medicine legat)," *Dictionnaire Encyclopedique des Sciences Medicales*, Ser. II, X (1875) at 579-708, 603.

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with heightened sensitivity. The use of this instrument by a well-trained physician, together with other clinical measures, laid to rest public fears of premature burial. The twentieth century brought even more sophisticated technological means to determine death, particularly the electrocardiograph (EKG), which is more sensitive than the stethoscope in detecting cardiac functioning.

### **The Interrelationships of Brain, Heart, and Lung Functions**

The brain has three general anatomic divisions: the cerebrum, with its outer shell called the cortex; the cerebellum; and the brainstem, composed of the midbrain, the pons, and the medulla oblongata (Figure 2). Traditionally, the cerebrum has been referred to as the "higher brain" because it has primary control of consciousness, thought, memory and feeling. The brainstem has been called the "lower brain," since it controls spontaneous, vegetative functions such as swallowing, yawning and sleep-wake cycles. It is important to note that these generalizations are not entirely accurate. Neuroscientists generally agree that such "higher brain" functions as cognition or consciousness probably are not mediated strictly by the cerebral cortex; rather, they probably result from complex interrelations between brainstem and cortex.

Respiration is controlled in the brainstem, particularly the medulla (Figure 2). Neural impulses originating in the respiratory centers of the medulla stimulate the diaphragm and intercostal muscles, which cause the lungs to fill with air. Ordinarily, these respiratory centers adjust the rate of breathing to maintain the correct levels of carbon dioxide and oxygen. In certain circumstances, such as heavy exercise, sighing, coughing or sneezing, other areas of the brain modulate the activities of the respiratory centers or even briefly take direct control of respiration.

Destruction of the brain's respiratory center stops respiration, which in turn deprives the heart of needed oxygen, causing it too to cease functioning. The traditional signs of life-respiration and heartbeat-disappear: the person is dead. The "vital signs" traditionally used in diagnosing death thus reflect the direct interdependence of respiration, circulation and the brain.

The artificial respirator and concomitant life-support systems have changed this simple picture. Normally, respiration ceases when the functions of the diaphragm and intercostal muscles are impaired. This results from direct injury to the muscles or (more commonly) because the neural impulses between the brain and these muscles are interrupted. However, an artificial respirator (also called a ventilator) can be used to compensate for the inability of the thoracic muscles to fill the lungs with air. Some of these



machines use negative pressure to expand the chest wall (in which case they are called "iron lungs"); others use positive pressure to push air into the lungs. The respirators are equipped with devices to regulate the rate and depth of "breathing," which are normally controlled by the respiratory centers in the medulla. The machines cannot compensate entirely for the defective neural connections since they cannot regulate blood gas levels precisely. But, provided that the lungs themselves have not been extensively damaged, gas exchange can continue and appropriate levels of oxygen and carbon dioxide can be maintained in the circulating blood.

Unlike the respiratory system, which depends on the neural impulses from the brain, the heart can pump blood without external control. Impulses from brain centers modulate the inherent rate and force of the heartbeat but are not required for the heart to contract at a level of function that is ordinarily adequate. Thus, when artificial respiration provides adequate oxygenation and associated medical treatments regulate essential plasma components and blood pressure, an intact heart will continue to beat, despite loss of brain functions. At present, however, no machine can take over the functions of the heart except for a very limited time and in limited circumstances (e.g., a heart-lung machine used during surgery). Therefore, when a severe injury to the heart or major blood vessels prevents the circulation of the crucial blood supply to the brain, the loss of brain functioning is inevitable because no oxygen reaches the brain.

### **Loss of Various Brain Functions**

The most frequent causes of irreversible loss of functions of the whole brain are: (1) direct trauma to the head, such as from a motor vehicle accident or a gunshot wound, (2) massive spontaneous hemorrhage into the brain as a result of ruptured aneurysm or complications of high blood pressure, and (3) anoxic damage from cardiac or respiratory arrest or severely reduced blood pressure.<sup>1</sup>

Many of these severe injuries to the brain cause an accumulation of fluid and swelling in the brain tissue, a condition called cerebral edema. In severe cases of edema, the pressure within the closed cavity increases until it exceeds the systolic blood pressure, resulting in a total loss of blood flow to both the upper and lower portions of the brain. If deprived of blood flow for at least 10-15 minutes, the brain, including the brainstem, will completely cease func-

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<sup>1</sup> Ronald E. Cranford and Harmon L. Smith, "Some Critical Distinctions Between Brain Death and Persistent Vegetative State" 6 *Ethics in Sci. and Med.* 199, 201 (1979).

tioning.<sup>1</sup> Other pathophysiologic mechanisms also result in a progressive and, ultimately, complete cessation of intracranial circulation.

Once deprived of adequate supplies of oxygen and glucose, brain neurons will irreversibly lose all activity and ability to function. In adults, oxygen and/or glucose deprivation for more than a few minutes causes some neuron loss.<sup>2</sup> Thus, even in the absence of direct trauma and edema, brain functions can be lost if circulation to the brain is impaired. If blood flow is cut off, brain tissues completely self-digest (autolyze) over the ensuing days.

When the brain lacks all functions, consciousness is, of course, lost. While some spinal reflexes often persist in such bodies (since circulation to the spine is separate from that of the brain), all reflexes controlled by the brainstem as well as cognitive, affective and integrating functions are absent. Respiration and circulation in these bodies may be generated by a ventilator together with intensive medical management. In adults who have experienced irreversible cessation of the functions of the entire brain, this mechanically generated functioning can continue only a limited time because the heart usually stops beating within two to ten days. (An infant or small child who has lost all brain functions will typically suffer cardiac arrest within several weeks, although respiration and heartbeat can sometimes be maintained even longer.<sup>3</sup>)

Less severe injury to the brain can cause mild to profound damage to the cortex, lower cerebral structures, cerebellum, brainstem, or some combination thereof. The cerebrum, especially the cerebral cortex, is more easily injured by loss of blood flow or oxygen than is the brainstem. A 4-6 minute loss of blood flow—caused by, for example, cardiac arrest—typically damages the cerebral cortex permanently, while the relatively more resistant brainstem may continue to function.<sup>4</sup>

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<sup>1</sup> H. A. H. van Till-d'Aulnis de Bourouill, "Diagnosis of Death in Comatose Patients under Resuscitation Treatment: A Critical Review of the Harvard Report," 2 *Am. J. L. & Med.* 1,21-22 (1976).

<sup>2</sup> One exception to this general picture requires brief mention. Certain drugs or low body temperature (hypothermia) can place the neurons in "suspended animation." Under these conditions, the neurons may receive virtually no oxygen or glucose for a significant period of time without sustaining irreversible damage. This effect is being used to try to limit brain injury in patients by giving them barbiturates or reducing temperature; the use of such techniques will, of course, make neurological diagnoses slower or more complicated.

<sup>3</sup> Julius Korein, "Brain Death," in J. Cottrell and H. Turndorf (eds.) *Anesthesia and Neurosurgery*, C.V. Mosby & Co., St. Louis (1980) at 282, 284, 292-293.

<sup>4</sup> Cranford and Smith, *op. cit.* at 203.

When brainstem functions remain, but the major components of the cerebrum are irreversibly destroyed, the patient is in what is usually called a "persistent vegetative state" or "persistent noncognitive state."<sup>1</sup> Such persons may exhibit spontaneous, involuntary movements such as yawns or facial grimaces, their eyes may be open and they may be capable of breathing without assistance. Without higher brain functions, however, any apparent wakefulness does not represent awareness of self or environment (thus, the condition is often described as "awake but unaware"). The case of Karen Ann Quinlan has made this condition familiar to the general public. With necessary medical and nursing care—including feeding through intravenous or nasogastric tubes, and antibiotics for recurrent pulmonary infections—such patients can survive months or years, often without a respirator. (The longest survival exceeded 37 years.<sup>2</sup>)

### **Conclusion: The Need for Reliable Policy**

Medical interventions can often provide great benefit in avoiding *irreversible* harm to a patient's injured heart, lungs, or brain by carrying a patient through a period of acute need. These techniques have, however, thrown new light on the interrelationship of these crucial organ systems. This has created complex issues for public policy as well.

For medical and legal purposes, partial brain impairment must be distinguished from complete and irreversible loss of brain functions or "whole brain death."<sup>3</sup> The President's Commission, as subsequent chapters explain more fully, regards the cessation of the vital functions of the entire brain—and not merely portions thereof, such as those responsible for cognitive functions—as the only proper neurologic basis for declaring death. This conclusion accords with the overwhelming consensus of medical and legal experts and the public.

Present attention to the "definition" of death is part of a process of development in social attitudes and legal rules stimulated by the unfolding of biomedical knowledge. In the nineteenth century increasing knowledge and practical skill made the public confident that death could be diagnosed reliably using cardiopulmonary criteria. The ques-

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<sup>1</sup> Bryan Jennett and Fred Plum, "The Persistent Vegetative State: A Syndrome in Search of a Name," 1 *Lancet* 734 (1972); Fred Plum and Jerome B. Posner, *The Diagnosis of Stupor and Coma*, F. A. Davis Co., Philadelphia (1980 3rd. ed.) at 6-7.

<sup>2</sup> See Norris McWhirter (ed.) *The Guinness Book of World Records*, Bantam Books, New York (1981) at 42, citing the case of Elaine Esposito who lapsed into coma following surgery on August 6, 1941 and died on November 25, 1978, 37 years and 111 days later.

<sup>3</sup> Original has footnote indicated in text, but no footnote at bottom of page.

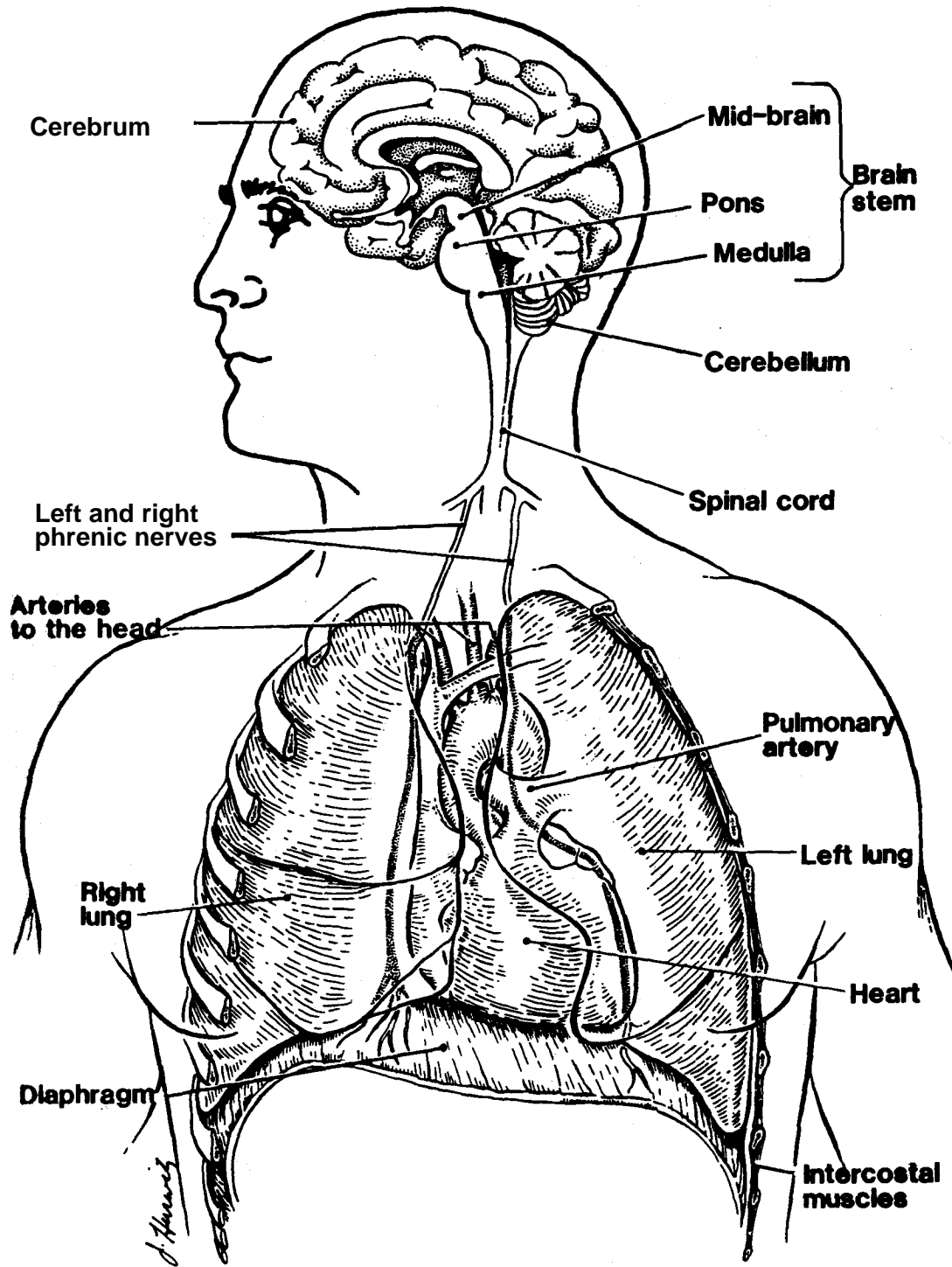


Figure 2. Anatomic Interrelationships of Heart, Lungs and Brain

tion now is whether, when medical intervention may be responsible for a patient's respiration and circulation, there are other equally reliable ways to diagnose death.

The Commission recognizes that it is often difficult to determine the severity of a patient's injuries, especially in the first few days of intensive care following a cardiac arrest, head trauma, or other similar event. Responsible public policy in this area requires that physicians be able to distinguish reliably those patients who have died from those whose injuries are less severe or are reversible. In the next chapter, medical evidence on these points is examined. Ascertaining the medical facts is only a part of the process of framing a "definition," however. Therefore, the third chapter examines concepts of death at a more basic, albeit not technical level.

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# The "State of the Art" in Medicine

# 2

Until the past few decades, comatose patients fairly rapidly either improved or died. If no other complication supervened and the patient did not improve, death followed from starvation and dehydration within days; pneumonia, apnea, or effects of the original disease typically brought on death even more quickly. Before such techniques as intravenous hydration, nasogastric feeding, bladder catheterization and respirators, no patient continued for long in deep coma.

With the aid of modern medicine, some comatose patients can be kept from a rapid death. Many, however, become permanently and totally unresponsive. In other words, their appearance resembles that of the dead as traditionally perceived: they no longer respond to their environment by sensate and intellectual activity. But their appearance also differs from that traditionally associated with the dead because mechanical support generates breathing, heartbeat, and the associated physical characteristics (e.g., warm, moist skin) of life.

The ever more sophisticated capabilities developed by biomedical practitioners during the past quarter century to support or supplant certain vital functions have thus created new problems in diagnosing death. If these diagnostic problems were the only consequence of medicine's new capabilities, those who developed and employed them might well be criticized for having opened a Pandora's Box of troubles for physicians and for society. But, as witnesses told the Commission, in a portion of the cases the armamentarium of resuscitative medicine brings comatose patients back from the brink of death by supporting their breathing and blood flow during a period of acute need.

Since the witnesses and existing medical literature lacked information on the relative proportion of comatose,



respirator-assisted patients who survive versus those who die (as determined by either brain-based or heart/lung-based tests), the Commission sponsored a small study. This study was not intended to generate definitive data on the incidence of such outcomes but rather to provide a rough estimate of the extent of the various outcomes. The study examined the experience over a period ranging from two months to one year at seven hospitals serving major metropolitan areas. (A full description of the study and its results appears in Appendix B.) At the four acute care centers from which such data were available, 2-4 cases of irreversible loss of all brain functions arose each month, a figure consistent with other data.<sup>1</sup> These figures convey a useful, if limited, perspective on the frequency with which the medicolegal dilemma of determining death in comatose, respirator-assisted cases arises at such hospitals.

The social and legal as well as medical consequences attached to a determination of death make it imperative that the diagnosis be incontrovertible. One must be certain that the functions of the entire brain are irreversibly lost and that respiration and circulation are, therefore, solely artifacts of mechanical intervention. Indeed, though suspicious that their interventions may be doing nothing more than masking what would otherwise manifestly be death by the traditional measures, physicians are concerned about doing anything—such as removing a respirator—that would hinder the recovery of a patient whose loss of brain functioning might be only partial or reversible.<sup>2</sup>

### **Development of the Concept of "Brain Death"**

The concept of "brain death" and efforts to refine criteria to identify that condition have been developing during the last two decades, concomitant with the spread of life support systems in clinical medicine. In 1959, several French neurophysiologists published results of research they had conducted on patients in extremely deep coma receiving respirator assistance, a condition they termed "coma dépassé."<sup>3</sup> Multiple tests showed these patients

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<sup>1</sup> Ake Grenvik, David J. Powner, James V. Snyder, Michael S. Jastremski, Ralph A. Babcock and Michael G. Loughhead, "Cessation of Therapy in Terminal Illness and Brain Death," 6 *Critical Care Med.* 284 (1978).

<sup>2</sup> Accordingly, in the procedures for diagnosing death set forth by the Commission's medical consultants in Appendix F infra, the test for apnea involves elevating the level of circulating oxygen before turning off the respirator and allowing the level of carbon dioxide to rise as a stimulus for spontaneous respiration. The high level of oxygen protects the brain cells (if any remain active) from further damage.

<sup>3</sup> P. Mollaret and M. Goulon, "Le Coma Depasse," 101 *Rev. Neural.* 3(1959).

lacked reflexes and electrophysiologic activity. The investigators concluded that the patients had suffered permanent loss of brain functions—they were, in other words, "beyond coma." Postmortem examinations of those patients revealed extensive destruction (necrosis and autolysis) of the brain—a phenomenon that has since been called the "respirator brain."<sup>1</sup>

With the advent of transplant surgery employing cadaver donors—first with kidney transplantation in the 1950's and later, and still more dramatically, with heart transplantation in the 1960's—interest in "brain death" took on a new urgency.<sup>2</sup> For such transplants to be successful, a viable, intact organ is needed. The suitability of organs for transplantation diminishes rapidly once the donor's respiration and circulation stop. The most desirable organ donors are otherwise healthy individuals who have died following traumatic head injuries and whose breathing and blood flow are being artificially maintained. Yet even with proper care, the organs of these potential donors will deteriorate. Thus, it became important for physicians to be able to determine when the brains of mechanically-supported patients irretrievably ceased functioning.

Yet, the need for viable organs to transplant does not account fully for the interest in diagnosing irreversible loss of brain functions. The Commission's study illustrates this point; of 36 comatose patients who were declared dead on the basis of irreversible loss of brain functions, only six were organ donors. Other studies also report that organs are procured in only a small percentage of cases in which brain-based criteria might be applied.<sup>3</sup> Thus, medical con-

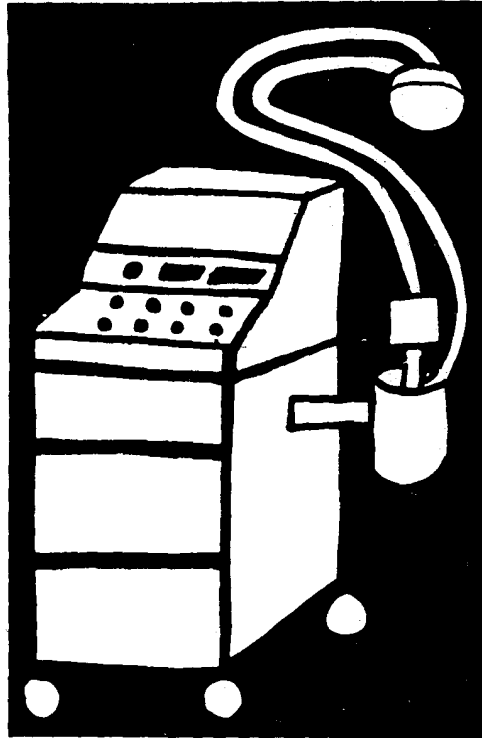
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<sup>1</sup> A. Earl Walker, E. L. Diamond and John Moseley, "The Neuropathological Findings in Irreversible Coma; A Critique of the Respirator Brain," 34 *J. Neuropath. Exp. Neurol.* 295 (1975); John I. Moseley, Gaetano F. Molinari and A. Earl Walker, "Respirator Brain: Report of a Survey and Review of Current Concepts," 100 *Arch. Pathol. Lab. Med.* 61 (1976).

<sup>2</sup> See, e.g., Renée C. Fox and Judith P. Swazey, *The Courage to Fail: A Social View of Organ Transplantation and Dialysis*, University of Chicago Press, Chicago, (1978); Francis D. Moore, *Give and Take: The Biology of Tissue Transplantation*, W.B. Sanders, Co., Philadelphia, Pa. (1964).

<sup>3</sup> See e.g., Howard H. Kaufman, John D. Huchton, Megan M. McBride, Carolyn A. Beardsley and Barry D. Kahan, "Kidney Donation: Needs and Possibilities," 5 *Neurosurg.* 237 (1979); K. J. Bart, "The Prevalance of Cadaveric Organs for Transplantation" in S.W. Sell, U.P. Perry and M.M. Vincent (eds.) *Proceedings of the 1977 Annual Meeting of American Association Tissue Banks*, American Association of Tissue Banks, Rockville, Md. (1977) at 124-130; A. Earl Walker, "The Neurosurgeon's Responsibility for Organ Procurement," 44 *J. Neurosurg.* 1 (1976).

cern over the determination of death rests much less with any wish 'to facilitate organ transplantation than with the



the need both to render appropriate care to patients and to replace artificial support with more fitting and respectful behavior when a patient has become a dead body. Another incentive to update the criteria for determining death stems from the increasing realization that the dedication of scarce and expensive intensive care facilities to bodies without brain functions may not only prolong the uncertainty and suffering of grieving families but also preclude access to the facilities for patients with reversible conditions.<sup>1</sup>

### The Emergence of a Medical Consensus

Medical concern over making the proper diagnosis in respirator-supported patients led to the development of criteria which reliably establish permanent loss of brain functions. A landmark in this process was the publication in 1968 of a report by an *ad hoc* committee of the Harvard Medical School which became known as the "Harvard criteria."<sup>2</sup> The Committee's report described the following characteristics of a permanently nonfunctioning brain, a condition it referred to as "irreversible coma":

<sup>1</sup> B.D. Colen, "Medical Examiner's Solution to Life and Death Problem," January 28, 1978, *Wash Post* §A at 8, col. 1, describing the attempts of Dr. Ron Wright, deputy chief medical examiner for Dade County Florida, to have medical interventions ceased for bodies declared dead on the basis of brain-oriented criteria. (Florida did not enact a statute on the subject until 1980.) "Wright was able to get a judge to hold a special Sunday morning hearing at the hospital-with reporters and photographers in attendance-at which he successfully argued that the family was being forced to pay \$2,000 a day to keep a dead body in the intensive care unit." Patricia H. Butcher, "Management of the Relatives of Patients with Brain Death" in Ronald V. Trubuhovich (ed). *Management of Acute Intracranial Disasters*, Little, Brown and Company, Boston, Mass. (1979) at 327.

<sup>2</sup> Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma," 205 *J.A.M.A.* 337 (1968).

1. *Unreceptivity and unresponsivity*. The patient shows a total unawareness to externally applied stimuli and inner need, and complete unresponsiveness, even when intensely painful stimuli are applied.

2. *No movements or breathing*. All spontaneous muscular movement, spontaneous respiration, and response to stimuli such as pain, touch, sound or light are absent.

3. *No reflexes*. Among the indications of absent reflexes are: fixed, dilated, pupils; lack of eye movement even when the head is turned or ice water is placed in the ear; lack of response to noxious stimuli; and generally, unelicitable tendon reflexes.

In addition to these three criteria, a flat electroencephalogram (EEG), which shows that there is no discernible electrical activity in the cerebral cortex, was recommended as a confirmatory test, when available. All tests were to be repeated at least 24 hours later without showing change. Drug intoxication (e.g., barbiturates) and hypothermia (body temperature below 90°F), which can cause a reversible loss of brain functions, also had to be excluded before the criteria could be used.

The "Harvard criteria" have been found to be quite reliable. Indeed, no case has yet been found that met these criteria and regained any brain functions despite continuation of respirator support. Criticisms of the criteria have been of five kinds. First, the phrase "irreversible coma" is misleading as applied to the cases at hand. "Coma" is a condition of a living person, and a body without any brain functions is dead and thus beyond any coma. Second, the writers of these criteria did not realize that the spinal cord reflexes actually persist or return quite commonly after the brain has completely and permanently ceased functioning. Third, "unreceptivity" is not amenable to testing in an unresponsive body without consciousness. Next, the need adequately to test brainstem reflexes, especially apnea, and to exclude drug and metabolic intoxication as possible causes of the coma, are not made sufficiently explicit and precise. Finally, although all individuals that meet "Harvard criteria" are dead (irreversible cessation of all functions of the entire brain), there are many other individuals who are dead but do not maintain circulation long enough to have a 24-hour observation period. Various other criteria have been proposed since 1968 that attempt to ameliorate these deficiencies.<sup>1</sup>

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<sup>1</sup> David J. Pawner, James V. Snyder, and Ake Grenvik, "Brain Death Certification: A Review," 5 *Crit. Care Med.* 230 (1977); Julius Korein, "Brain Death," in J. Cottrell and H. Turndorf (eds.) *Anesthesia and Neurosurgery* (1980) at 282; Peter McL. Black, "Brain Death" 299 *N.E.J.M.* 338 & 393 (1978).

As the Harvard Committee noted, permanent loss of brain functions can also be confirmed by absence of circulation to the brain. The brain necessarily ceases functioning after a short period without intracranial circulation, unless it is protected by hypothermia or drug induced depression of neuronal metabolism. In recent years, several procedures have been developed to test for absence of intracranial blood flow, including radioisotope cerebral angiography by bolus or static imaging and four vessel intracranial contrast angiography.<sup>1</sup>

Clinical research has emphasized the development of procedures that can be performed reliably at a patient's bedside, so as to interfere as little as possible with treatment and not to risk harming the patient when recovery may still be possible. The aim of the tests is to reduce mistaken diagnoses that a patient is still alive, without incurring risks of erroneous diagnoses that a patient lacks all brain functioning when such functions actually remain or could recur. This is achieved by establishing first that all brain functions have ceased and then ascertaining that the cessation is irreversible. To do this, the cause of coma must be established and this may require, in addition to history and physical examination, such tests as computerized axial tomography, electroencephalography and echoencephalography.<sup>2</sup> The cause of the cessation of functions must be sufficient to explain the individual's clinical status and must be demonstrated to be permanent during a period of observation.<sup>3</sup>

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<sup>1</sup> See, e.g., Julius Korein (ed.), *Brain Death: Interrelated Medical and Social Issues*, 315 *Ann. N.Y. Acad. Sci.* 62-214 (1978); Julius Korein, Phillip Braunstein, Ajax George, Melvin Wichter, Irving Kricheff, Abraham Lieberman and John Pearson, "Brain Death: I. Angiographic Correlation with the Radioisotopic Bolus Technique for Evaluation of Critical Deficit of Cerebral Blood Flow," *2 Ann. Neural.* 206 (1977); Andrew J.K. Smith and A. Earl Walker, "Cerebral Blood Flow and Brain Metabolism as Indicators of Cerebral Death: A Review," 133 *Johns Hopkins Med. J.* 107 (1973); Julius M. Goodman and Larry I. Heck, "Confirmation of Brain Death by Bedside Isotope Angiography," 238 *J.A.M.A.* 966 (1977).

<sup>2</sup> See, e.g., Gian Emilio Chatrian, "Electrophysiologic Evaluation of Brain Death: A Critical Appraisal," in M. J. Aminoff (ed.) *Electrodiagnosis in Clinical Neurology*, Churchill Livingstone, New York (1980); Donald R. Bennett, Julius Korein, John R. Hughes, Jerome K. Merlis and Cary Suter, *Atlas of Electroencephalography in Coma and Cerebral Death*, Raven Press, New York (1976); Fred Plum and Jerome B. Posner, *op. cit.*; Stuart A. Schneck, "Brain Death and Prolonged State of Impaired Responsiveness," 58 *Denver L. J.* 609, 612-613 (1981).

<sup>3</sup> See, e.g., U.S. Department of Health and Human Services, *The NINCDS Collaborative Study of Brain Death*, N.I.H. Publication No. 81-2286, U.S. Government Printing Office (1980), reported in, "An Appraisal of the Criteria of Cerebral Death. A Summary Statement. A Collaborative Study," 237 *J.A.M.A.* 982 (1977); Peter McL. Black, *op. cit.*; Pamela F. Prior, "Brain Death" 1980(i) *Lancet* 1142.

The studies that document the adequacy of criteria have followed one of two general formats. Some define a group of subjects who have met the proposed criteria and demonstrate that in all such cases the heart soon stopped beating despite intensive therapy.<sup>1</sup> Other studies identify a group of subjects who met the proposed criteria and demonstrate widespread brain necrosis at autopsy, providing the body has remained on a respirator for sufficient time for necrosis to occur.<sup>2</sup> All the studies focus on patients with deep coma including absence of spontaneous breathing (apnea): in addition, some require known and sufficient cause for the absence of brain functions, isoelectric electroencephalogram, dilated pupils, or absent circulation shown by angiography. The published criteria for determining cessation of brain functions have been uniformly successful in diagnosing death. The differences among criteria often arise from differing assessments of the technical skill and instrumentation available to the physician. Experts now generally agree that careful clinical assessment (including identification of a cause of the damage to the brain which is sufficient to explain the clinical findings) is the *sine qua non* of a diagnosis.

The role of confirmatory tests such as electroencephalography or circulation tests beyond such bedside judgments in establishing either the cessation of brain functions or the irreversibility of such cessation has been the subject of considerable discussion.<sup>3</sup> For example, the Conference of Royal Colleges and Faculties in Britain focused on the function of the brainstem alone to diagnose death.<sup>4</sup> Since the brainstem's reticular activating formation is essential to generating consciousness and its transmittal of motor and sensation impulses is essential to these functions, loss of brainstem functions precludes discernable functioning of the cerebral hemispheres. In addition, the brainstem is the locus of homeostatic control, cranial nerve reflexes, and control of respiration. Thus, if the brainstem

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<sup>1</sup> See, e.g., Bryan Jennett, John Gleave and Peter Wilson, "Brain Death in Three Neurosurgical Units" 282 *Brit. Med. J.* 533 (1981).

<sup>2</sup> See, e.g., U.S. Department of Health and Human Services, The NINCDS Collaborative Study of Brain Death, *op. cit.*

<sup>3</sup> Peter McL. Black, *op. cit.*

<sup>4</sup> Conference of Royal Colleges and Faculties of the United Kingdom, "Memorandum on the Diagnosis of Death" (January 1979), in Working Party of the United Kingdom Health Departments, *The Removal of Cadaveric Organs for Transplantation: A Code of Practice* (1979) at 32-36.



completely lacks functions, the brain as a whole cannot function. American physicians, however, judge the reliability of brainstem testing to be incomplete. Therefore they endorse the appropriate use of cerebral blood flow testing or electroencephalography in order to confirm the completeness of injury and the irreversibility of conditions that have led to cessation of brain functions.<sup>1</sup> The published data support the reliability of both approaches.

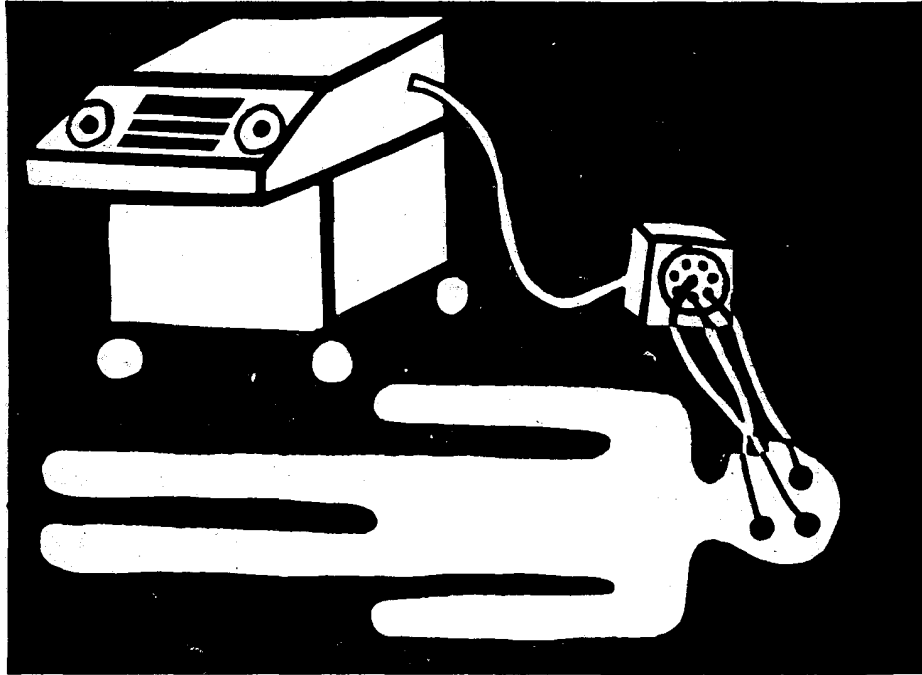
The prevailing British viewpoint on the neurologic diagnosis of death is closer to a *prognostic* approach (that a "point of no return"<sup>2</sup> has been reached in the process of dying), while the American approach is more *diagnostic* in seeking to determine that all functions of the brain have irreversibly ceased at the time of the declaration of death. Also, the British diagnose brain death almost entirely where irremediable structural injury has occurred while the American concept has encompassed all etiologies that may lead to irreversible loss of brain functions in respirator--maintained patients.

The British criteria resemble the American, however, in holding that death has been established when "all functions of the brain have permanently and irreversibly ceased."<sup>3</sup> In measuring *functions*, physicians are not concerned with mere *activity* in cells or groups of cells if such activity (metabolic, electrical, etc.) is not manifested in some way that has significance for the organism as a whole. The same is true of the cells of the heart and lungs; they too may continue to have metabolic and electrical activity after

<sup>1</sup> See Appendix F, *infra*; Peter McL. Black *op. cit.*; Julius Korein, "Brain Death" *op. cit.*

<sup>2</sup> Conference of Royal Colleges and Faculties, *op. cit.* at 35. "Medicine and the Media," 281 *Brit. Med. J* 1064 (1980). See also A. Mohandas and Shelley Chou, "Brain death: A Clinical and pathological study," 35 *J. Neurosurg.* 211, 215 (1971) (authors of so-called "Minnesota criteria" hold that "the state of irreversible damage to the brain-stem... is the point of no return"). The more typical contrast between the American and British approaches is illustrated by the criteria employed at the University of Pittsburgh School of Medicine where "brain death" is defined as the "irreversible cessation of all brain function," as demonstrated by coma of established cause, absence of movements and brain stem reflexes, and an isoelectric EEG. David J. Powner and Ake Grenvik, "Triage in Patient Care: From Expected Recovery to Brain Death," 8 *Heart & Lung* 1103 (1979). The British rely instead on another observation, confirmed by the University of Pittsburgh, that "*prognosis* appears to be *similarly hopeless* for those patients who have clinical findings consistent with brain death but who have a nonisoelectric EEG." *Id.* at 1107 (emphasis added) (cited by British neurologist Christopher Pallis in lecture at Conference on Brain Death, Boston, Mass., April 4, 1981).

<sup>3</sup> Conference of Royal Colleges and Faculties, *op. cit.* at 36.



death has been diagnosed by cardiopulmonary standards.<sup>1</sup> Tests that measure cellular activity are thus relevant to the determination of death only when they forecast whether missing functions may reappear.

### **Translating Medical Knowledge into Policy**

Knowledgeable physicians agree that, when used in appropriate combinations, available procedures for diagnosing death by brain criteria are at least as accurate as the customary cardiopulmonary tests. Indeed, medical experts testified to the Commission that the risk of mistake in a competently performed examination was infinitesimal. Plainly, the results depend on the personal knowledge, judgment and care of the physicians who apply them. Expert witnesses before the Commission pointed out that many physicians (including some neurologists and neurosurgeons) are not sufficiently familiar with the criteria (much less the detailed tests) by which the cessation of total brain functions is assessed. As one step toward professional education, a group of physicians, working with the encouragement of the Commission, has developed a summary of currently accepted medical practices. (The statement appears as Appendix F to this Report.) Such criteria—particularly as they relate to diagnosing death on neurological grounds will be continually revised by the biomedical community in light of clinical experience and new scientific knowledge.

At present, the accepted norm is that the tests will be employed by a physician who has specialized knowledge of

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<sup>1</sup> See also pp. 75-76 *infra*.

their use. Consultation with another appropriately trained physician is typically undertaken to confirm a brain-based diagnosis in an artificially supported individual before any decisions are made on whether to discontinue support.

Particular care must be exercised to establish the cause of the patient's condition and especially to rule out conditions (such as drug intoxication or treatable brain lesions) that can give the misleading appearance that brain functions have stopped irreversibly. (Research is currently underway to test whether hypothermia and large doses of barbiturates might be used to reduce brain injury after trauma or surgery. This will complicate the diagnosis of death in these patients.)

The Commission concludes that reliable means of diagnosis are essential for determinations of death and that the medical community has developed such means. Insistence that determinations of death accord with "accepted medical standards" would thus, in the opinion of the Commission, bring to bear all the usual stimuli for assuring accuracy in medical diagnosis: the testing of practices through biomedical research and the dissemination of the results of such research; the continuing education of physicians and other health care personnel; the conscientious application of professional skills and knowledge; and the encouragement of due care provided by professional standards and by state civil and criminal laws. In the Commission's view, it is not necessary—indeed, it would be a mistake—to enshrine any particular medical criteria, or any requirements for procedure or review, as part of a statute.

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# Understanding the "Meaning" of Death

# 3

It now seems clear that a medical consensus about clinical practices and their scientific basis has emerged: certain states of brain activity and inactivity, together with their neurophysiological consequences, can be reliably detected and used to diagnose death. To the medical community, a sound basis exists for declaring death even in the presence of mechanically assisted "vital signs." Yet before recommending that public policy reflect this medical consensus, the Commission wished to know whether the scientific viewpoint was consistent with the concepts of "being dead" or "death" as they are commonly understood in our society. These questions have been addressed by philosophers and theologians, who have provided several formulations.<sup>1</sup>

The Commission believes that its policy conclusions, including the statute recommended in Chapter 5, must accurately reflect the social meaning of death and not constitute a mere legal fiction. The Commission has not found it necessary to resolve all of the differences among the leading concepts of death because these views all yield interpretations consistent with the recommended statute.

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<sup>1</sup> See, e.g., Robert M. Veatch, *Death Dying and the Biological Revolution: Our Last Quest for Responsibility*, Yale University Press, New Haven, Conn., (1977) at 21-76; Douglas N. Walton, *Defining Death: An Analytic Study of the Concept of Death in Philosophy and Medical Ethics*, McGill-Queen's University Press, Montreal, Que. (1979); William C. Charron, "Death: A Philosophical Perspective on the Legal Definitions," 4 *Wash. U.L.Q.* 797 (1975); Dallas M. High, "Death: Its Conceptual Elusiveness," 55 *Soundings* 438 (1972); Paul Ramsey, *The Patient as Person: Explorations in Medical Ethics*, Yale University Press, New Haven, Conn. (1971) at 59-112; Stanley Hauerwas, "Religious Concepts of Brain Death and Associated Problems," 315 *Ann. N.Y. Acad. Sci.* 329 (1978).

Three major formulations of the meaning of death were presented to the Commission: one focused upon the functions of the whole brain, one upon the functions of the cerebral hemispheres, and one upon non-brain functions. Each of these formulations (and its variants) is presented and evaluated.

### The "Whole Brain" Formulations

One characteristic of living things which is absent in the dead is the body's capacity to organize and regulate itself. In animals, the neural apparatus is the dominant locus of these functions. In higher animals and man, regulation of both maintenance of the internal environment (homeostasis) and interaction with the external environment occurs primarily within the cranium.

External threats, such as heat or infection, or internal ones, such as liver failure or endogenous lung disease, can stress the body enough to overwhelm its ability to maintain organization and regulation. If the stress passes a certain level, the organism as a whole is defeated and death occurs.

This process and its denouement are understood in two major ways. Although they are sometimes stated as alternative formulations of a "whole brain definition" of death, they are actually mirror images of each other. The Commission has found them to be complementary; together they enrich one's understanding of the "definition." The first focuses on the integrated functioning of the body's major organ systems, while recognizing the centrality of the whole brain, since it is neither revivable nor replaceable. The other identifies the functioning of the whole brain as the hallmark of life because the brain is the regulator of the body's integration. The two conceptions are subject to similar criticisms and have similar implications for policy.

**The concepts:** The functioning of many organs—such as the liver, kidneys, and skin—and their integration are "vital" to individual health in the sense that if any one ceases and that function is not restored or artificially re-placed, the organism as a whole cannot long survive. All elements in the system are mutually interdependent, so that the loss of any part leads to the breakdown of the whole and, eventually, to the cessation of functions in every part.<sup>2</sup>

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<sup>2</sup> Germain Grisez & Joseph M. Boyle, Jr., *Life and Death with Liberty and Justice: A Contribution to the Euthanasia Debate*, University of Notre Dame Press, Notre Dame, Ind. (1979) at 59- 61.

If death is understood in theoretical terms as the permanent termination of the integrated functioning characteristic of a living body as a whole, then one can see why death of higher animals is usually grasped in factual terms by the cessation of the vital functions of respiration and circulation, which correlates so well with bodily decomposition. Breathing is the minimum in "social interaction." However, considering the role of the brain in the maintenance of the dynamic equilibrium of any system which includes a brain, there is a compelling reason for defining death in factual terms as that state of affairs in which there is complete and irreversible loss of the functioning of the entire brain. To accept this definition is not to make a choice based on one's evaluation of various human characteristics, but is to assent to a theory which fits the facts.

*Id.* at 77.

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Three organs—the heart, lungs and brain—assume special significance, however, because their interrelationship is very close and the irreversible cessation of anyone very quickly stops the other two and consequently halts the integrated functioning of the organism as a whole. Because they were easily measured, circulation and respiration were traditionally the basic "vital signs." But breathing and heartbeat are not life itself. They are simply used as signs-as one window for viewing a deeper and more complex reality: a triangle of interrelated systems with the brain at its apex. As the biomedical scientists who appeared before the Commission made clear, the traditional means of diagnosing death actually detected an irreversible cessation of integrated functioning among the interdependent bodily systems. When artificial means of support mask this loss of integration as measured by the old methods, brain-oriented criteria and tests provide a new window on the same phenomenon.

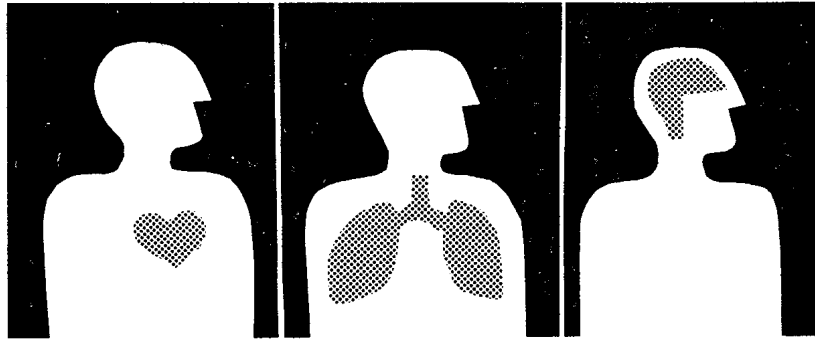
On this view, death is that moment at which the body's physiological system ceases to constitute an integrated whole. Even if life continues in individual cells or organs, life of the organism as a whole requires complex integration, and without the latter, a person cannot properly be regarded as alive.

This distinction between systemic, integrated functioning and physiological activity in cells or individual organs is important for two reasons. First, a person is considered dead under this concept even if oxygenation and metabolism persist in some cells or organs. There would be no need to wait until all metabolism had ceased in every body part before recognizing that death has occurred.

More importantly, this concept would reduce the significance of continued respiration and heartbeat for the definition of death. This view holds that continued breathing and circulation are not in themselves tantamount to life. Since life is a matter of integrating the functioning of major organ systems, breathing and circulation are necessary but not sufficient to establish that an individual is alive. When an individual's breathing and circulation lack neurologic integration, he or she is dead.



The alternative "whole brain" explanation of death differs from the one just described primarily in the vigor of its insistence that the traditional "vital signs" of heartbeat and respiration were merely surrogate signs with no significance in themselves. On this view, the heart and lungs are not important as basic prerequisites to continued life but rather because the irreversible cessation of their functions shows that the brain had ceased functioning. Other signs customarily employed by physicians in diagnosing death, such as unresponsiveness and absence of pupillary light response, are also indicative of loss of the functions of the whole brain.



This view gives the brain primacy not merely as the sponsor of consciousness (since even unconscious persons may be alive), but also as the complex organizer and regulator of bodily functions. (Indeed, the "regulatory" role of the brain in the organism can be understood in terms of thermodynamics and information theory.<sup>3</sup>) Only the brain can direct the entire organism. Artificial support for the heart and lungs, which is required only when the brain can no longer control them, cannot maintain the usual synchronized integration of the body. Now that other traditional indicators of cessation of brain functions (i.e., absence of breathing), can be obscured by medical interventions, one needs, according to this view, new standards for determining death—that is, more reliable tests for the complete cessation of brain functions.

**Critique:** Both of these "whole brain" formulations—the "integrated functions" and the "primary organ" views—are subject to several criticisms. Since both of these conceptions of death give an important place to the integrating or regulating capacity of the whole brain, it can be asked whether that characteristic is as distinctive as they would suggest. Other organ systems are also required for life to continue—for example, the skin to conserve fluid, the liver to detoxify the blood.

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<sup>3</sup> Julius Korein, "The Problem of Brain Death: Development and History," 315 *Ann. N.Y. Acad. Sci.* 19 (1978).

The view that the brain's functions are more central to "life" than those of the skin, the liver, and so on, is admittedly arbitrary in the sense of representing a choice. The view is not, however, arbitrary in the sense of lacking reasons. As discussed previously, the centrality accorded the brain reflects both its overarching role as "regulator" or "integrator" of other bodily systems and the immediate and devastating consequences of its loss for the organism as a whole. Furthermore, the Commission believes that this choice overwhelmingly reflects the views of experts and the lay public alike.

A more significant criticism shares the view that life consists of the coordinated functioning of the various bodily systems, in which process the whole brain plays a crucial role. At the same time, it notes that in some adult patients lacking all brain functions it is possible through intensive support to achieve constant temperature, metabolism, waste disposal, blood pressure, and other conditions typical of living organisms and not found in dead ones. Even with extraordinary medical care, these functions cannot be sustained indefinitely—typically, no longer than several days—but it is argued that this shows only that patients with nonfunctional brains are dying, not that they are dead. In this view, the respirator, drugs, and other resources of the modern intensive-care unit collectively substitutes for the lower brain, just as a pump used in cardiac surgery takes over the heart's function.

This criticism rests, however, on a premise about the role of artificial support vis-a-vis the brainstem which the Commission believes is mistaken or at best incomplete. While the respirator and its associated medical techniques do substitute for the functions of the intercostal muscles and the diaphragm, which without neuronal stimulation from the brain cannot function spontaneously, they cannot replace the myriad functions of the brainstem or of the rest of the brain. The startling contrast between bodies lacking all brain functions and patients with intact brainstems (despite severe neocortical damage) manifests this. The former lie with fixed pupils, motionless except for the chest movements produced by their respirators. The latter can not only breathe, metabolize, maintain temperature and blood pressure, and so forth, on their *own* but also sigh, yawn, track light with their eyes, and react to pain or reflex stimulation.

It is not easy to discern precisely what it is about patients in this latter group that makes them alive while those in the other category are not. It is in part that in the case of the first category (i.e., absence of all brain functions) when the mask created by the artificial medical support is stripped away what remains is not an integrated organism but "merely a group of artificially maintained sub-

systems."<sup>4</sup> Sometimes, of course, an artificial substitute can forge the link that restores the organism as a whole to unified functioning. Heart or kidney transplants, kidney dialysis, or an iron lung used to replace physically-impaired breathing ability in a polio victim, for example, restore the integrated functioning of the organism as they replace the failed function of a part. Contrast such situations, however, with the hypothetical of a decapitated body treated so as to prevent the outpouring of blood and to generate respiration: continuation of bodily functions in that case would not have restored the requisites of human life.

The living differ from the dead in many ways. The dead do not think, interact, autoregulate or maintain organic identity through time, for example. Not all the living can always do all of these activities, however; nor is there one single characteristic (e.g., breathing, yawning, etc.) the loss of which signifies death. Rather, what is missing in the dead is a cluster of attributes, all of which form part of an organism's responsiveness to its internal and external environment.

While it is valuable to test public policies against basic conceptions of death, philosophical refinement beyond a certain point may not be necessary. The task undertaken in this Report, as stated at the outset, is to provide and defend a statutory standard for determining that a human being has died. In setting forth the standards recommended in this Report, the Commission has used "whole brain" terms to clarify the understanding of death that enjoys near universal acceptance in our society. The Commission finds that the "whole brain" formulations give resonance and depth to the biomedical and epidemiological data presented in Chapter Two. Further effort to search for a conceptual "definition" of death is not required for the purpose of public policy because, separately or together, the "whole brain" formulations provide a theory that is sufficiently precise, concise and widely acceptable.

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<sup>4</sup> James L. Bernat, Charles M. Culver and Bernard Gert, "On the Definition and Criterion of Death," 94 *Ann. Int. Med.* 389, 391 (1981).

...When the respirator maintains the organism, it is questionable whether there is complete and irreversible loss of the functioning of the entire brain. But this is a question to be settled by empirical inquiry, not by philosophy. Philosophically, we answer the objection by saying that if the functioning of the brain is the factor which principally integrates any organism which has a brain, then if that function is lost, what is left is no longer as a whole an organic unity. If the dynamic equilibrium of the remaining parts of the system is maintained, it nevertheless as a whole is a mechanical, not an organic system.

Grisez & Boyle, *op. cit.* .at 77

**Policy Consequences:** Those holding to the "whole brain" view—and this view seems at least implicit in most of the testimony and writing reviewed by the Commission—believe that when respirators are in use, respiration and circulation lose significance for the diagnosis of death. In a body without a functioning brain these two functions, it is argued, become mere artifacts of the mechanical life supports. The lungs breathe and the heart circulates blood only because the respirator (and attendant medical interventions) cause them to do so, not because of any comprehensive integrated functioning. This is "breathing" and "circulation" only in an analogous sense: the function and its results are similar, but the source, cause, and purpose are different between those individuals with and those without functioning brains.

For patients who are not artificially maintained, breathing and heartbeat were, and are, reliable signs either of systemic integration and/or of continued brain functioning (depending on which approach one takes to the "whole brain" concept). To regard breathing and respiration as having diagnostic significance when the brain of a respirator-supported patient has ceased functioning, however, is to forget the basic reasoning behind their use in individuals who are not artificially maintained.

Although similar in most respects, the two approaches to "whole brain death" could have slightly different policy consequences. The "primary organ" view would be satisfied with a statute that contained only a single standard—the irreversible cessation of all functions of the entire brain. Nevertheless, as a practical matter, the view is also compatible with a statute establishing irreversible cessation of respiration and circulation as an alternative standard, since it is inherent in this view that the loss of spontaneous breathing and heartbeat are surrogates for the loss of brain functions.

The "integrated functions" view would lead one to a "definition" of death recognizing that collapse of the organism as a whole can be diagnosed through the loss of brain functions as well as through loss of cardiopulmonary functions. The latter functions would remain an explicit part of the policy statement because their irreversible loss will continue to provide an independent and wholly reliable basis for determining that death has occurred when respirators and related means of support are not employed.

The two "whole brain" formulations thus differ only modestly. And even conceptual disagreements have a context; the context of the present one is the need to clarify and update the "definition" of death in order to allow principled decisions to be made about the status of comatose respirator-supported patients. The explicit recognition of

both standards-cardiopulmonary and whole brain-solves that problem fully. In addition, since it requires only a modest reformulation of the generally-accepted view, it accounts for the importance traditionally accorded to heartbeat and respiration, the "vital signs" which will continue to be the grounds for determining death in the overwhelming majority of cases for the foreseeable future. Hence the Commission, drawing on the aspects that the two formulations share and on the ways in which they each add to an understanding of the "meaning" of death, concludes that public policy should recognize both cardiopulmonary and brain-based standards for declaring death.

### **The "Higher Brain" Formulations**

When all brain processes cease, the patient loses two important sets of functions. One set encompasses the integrating and coordinating functions, carried out principally but not exclusively by the cerebellum and brainstem. The other set includes the psychological functions which make consciousness, thought, and feeling possible. These latter functions are located primarily but not exclusively in the cerebrum, especially the neocortex. The two "higher brain" formulations of brain-oriented definitions of death discussed here are premised on the fact that loss of cerebral functions strips the patient of his psychological capacities and properties.

A patient whose brain has permanently stopped functioning will, by definition, have lost those brain functions which sponsor consciousness, feeling, and thought. Thus the higher brain rationales support classifying as dead bodies which meet "whole brain" standards, as discussed in the preceding section. The converse is not true, however. If there are parts of the brain which have no role in sponsoring consciousness, the higher brain formulation would regard their continued functioning as compatible with death.

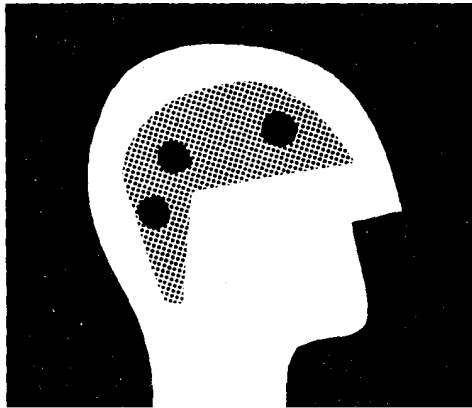
**The Concepts:** Philosophers and theologians have attempted to describe the attributes a living being must have to be a person.<sup>5</sup> "Personhood" consists of the complex of activities (or of capacities to engage in them) such as thinking, reasoning, feeling, human intercourse which make the human different from, or superior to, animals or things. One higher brain formulation would define death as the loss of what is essential to a person. Those advocating the personhood definition often relate these characteristics to

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<sup>5</sup> H. Tristram Englehardt, Jr., "Defining Death: A Philosophical Problem for Medicine and Law," 112 *Ann. Rev. Respiratory Dis.* 587 (1975); Robert M. Veatch, "The Whole-Brain Oriented Concept of Death: An Outmoded Philosophical Formulation," 3 *J. Thanatology* 13 (1975).

brain functioning. Without brain activity, people are incapable of these essential activities. A breathing body, the argument goes, is not in itself a person; and, without functioning brains, patients are merely breathing bodies. Hence personhood ends when the brain suffers irreversible loss of function.

For other philosophers, a certain concept of "personal identity" supports a brain-oriented definition of death.<sup>6</sup> According to this argument, a patient literally ceases to exist as an individual when his or her brain ceases functioning, even if the patient's body is biologically alive. Actual decapitation creates a similar situation: the body might continue to function for a short time, but it would no longer be the "same" person. The persistent identity of a person as an individual from one moment to the next is taken to be dependent on the continuation of certain mental processes which arise from brain functioning. When the brain processes cease (whether due to



decapitation or to "brain death") the person's identity also lapses. The mere continuation of biological activity in the body is irrelevant to the determination of death, it is argued, because after the brain has ceased functioning the body is no longer identical with the person.

**Critique:** Theoretical and practical objections to these arguments led the Commission to rely on them only as confirmatory of other views in formulating a definition of death. First, crucial to the personhood argument is acceptance of one particular concept of those things that are essential to being a person, while there is no general agreement on this very fundamental point among philosophers, much less physicians or the general public. Opinions about what is essential to personhood vary greatly from person to person in our society—to say nothing of intercultural variations.

The argument from personal identity does not rely on any particular conception of personhood, but it does require assent to a single solution to the philosophical prob-

<sup>6</sup> Michael B. Green and Daniel Wikler, "Brain Death and Personal Identity," 9 *Phil. and Pub. Affairs* 105 (1980); Bernard Gert, "Personal Identity and the Body," *Dialogue* 458 (1971); Roland Puccetti, "The Conquest of Death" 59 *The Monist* 252 (1976); Azriel Rosenfeld, "The Heart, the Head and the Halakhah," *N.Y. State J. Med.* 2615 (1970).



lem of identity. Again, this problem has persisted for centuries despite the best attempts by philosophers to solve it. Regardless of the scholarly merits of the various philosophical solutions, their abstract technicality makes them less useful to public policy.

Further, applying either of these arguments in practice would give rise to additional important problems. Severely senile patients, for example, might not clearly be persons, let alone ones with continuing personal identities; the same might be true of the severely retarded. Any argument that classified these individuals as dead would not meet with public acceptance.

Equally problematic for the "higher brain" formulations, patients in whom only the neocortex or subcortical areas have been damaged may retain or regain spontaneous respiration and circulation. Karen Quinlan is a well-known example of a person who apparently suffered permanent damage to the higher centers of the brain but whose lower brain continues to function. Five years after being removed from the respirator that supported her breathing for nearly a year, she remains in a persistent vegetative state but with heart and lungs that function without mechanical assistance.<sup>7</sup> Yet the implication of the personhood and personal identity arguments is that Karen Quinlan, who retains brainstem function and breathes spontaneously, is just as dead as a corpse in the traditional sense. The Commission rejects this conclusion and the further implication that such patients could be buried or otherwise treated as dead persons.

**Policy Consequences.** In order to be incorporated in public policy, a conceptual formulation of death has to be amenable to clear articulation. At present, neither basic neurophysiology nor medical technique suffices to translate the "higher brain" formulation into policy. First, as was discussed in Chapter One, it is not known which portions of the brain are responsible for cognition and consciousness; what little is known points to substantial interconnections among the brainstem, subcortical structures and the neocortex. Thus, the "higher brain" may well exist only as a metaphorical concept, not in reality. Second, even when the sites of certain aspects of consciousness can be found, their cessation often cannot be assessed with the certainty that would be required in applying a statutory definition.

Even were these difficulties to be overcome, the adoption of a higher brain "definition" would depart radically from the traditional standards. As already observed, the new standard would assign no significance to spontaneous

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<sup>7</sup> "Karen Ann Quinlan: A Family's Fate," May 26, 1981, *Wash. Post*, A at 1, col. 1.

breathing and heartbeat. Indeed, it would imply that the existing cardiopulmonary definition had been in error all along, even before the advent of respirators and other life-sustaining technology.

In contrast, the position taken by the Commission is deliberately conservative. The statutory proposal presented in Chapter Five offers legal recognition for new diagnostic measures of death, but does not ask for acceptance of a wholly new concept of death. On a matter so fundamental to a society's sense of itself—touching deeply held personal and religious beliefs—and so final for the individuals involved, one would desire much greater consensus than now exists before taking the major step of radically revising the concept of death.

Finally, patients declared dead pursuant to the statute recommended by the Commission would be also considered dead by those who believe that a body without higher brain functions is dead. Thus, all the arguments reviewed thus far are in agreement that irreversible cessation of all brain functioning is sufficient to determine death of the organism.

### The Non-Brain Formulations

**The Concepts:** The various physiological concepts of death so far discussed rely in some fashion on brain functioning. By contrast, a literal reading of the traditional cardiopulmonary criteria would require cessation of the flow of bodily "fluids," including air and blood, for death to be declared. This standard is meant to apply whether or not these flows coincide with any other bodily processes, neurological or otherwise. Its support derives from interpretations of religious literature and cultural practices of certain religious and ethnic groups, including some Orthodox Jews<sup>8</sup> and Native Americans.<sup>9</sup>

Another theological formulation of death is, by contrast, not necessarily related to any physiologic phenomenon. The view is traditional in many faiths that death occurs the moment the soul leaves the body.<sup>10</sup> Whether this

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<sup>8</sup> J. David Bleich, "Neurological Criteria of Death and Time of Death Statutes," in Fred Rosner and J. David Bleich (eds.) *Jewish Bioethics*. Hebrew Publishing Co., New York (1979) at 303-316.

<sup>9</sup> Telephone conversation with Richard E. Grant, Assistant Professor of Nursing, Arizona State University, July 17, 1981.

<sup>10</sup> Milton McC. Gatch, "Death: Post-Biblical Christian Thought" in Warren T. Reich (ed.), *Encyclopedia of Bioethics* (v.1), MacMillan Publishing Co., N. Y., N.Y. (1976) at 249, 250; Saint Augustine, *The City of God*, Vernon H. Bourke (ed.) Image Books, Garden City, N. Y. (1958) at 269, 277; J. David Bleich, "Establishing Criteria of Death," in Fred Rosner and J. David Bleich (eds.), *Jewish Bioethics*, Hebrew Publishing Co., New York (1979) at 285.

happens when the patient loses psychological capacities, loses all brain functions, or at some other point, varies according to the teachings of each faith and according to particular interpretations of the scriptures recognized as authoritative.

**Critique.** The conclusions of the "bodily fluids" view lack a physiologic basis in modern biomedicine. While this view accords with the traditional criteria of death, as noted above, it does not necessarily carryover to the new conditions of the intensive care unit—which are what prompts the reexamination of the definition of death. The flow of bodily fluids could conceivably be maintained by machines in the absence of almost all other life processes; the result would be viewed by most as a perfused corpse, totally unresponsive to its environment.

Although the argument concerning the soul could be interpreted as providing a standard for secular action, those who adhere to the concept today apparently acknowledge the need for a more public and verifiable standard of death. Indeed, a statute incorporating a brain-based standard is accepted by theologians of all backgrounds.<sup>11</sup>

**Policy Consequences:** The Commission does not regard itself as a competent or appropriate forum for theological interpretation. Nevertheless, it has sought to propose policies consistent with as many as possible of the diverse religious tenets and practices in our society.

The statute set forth in Chapter Five does not appear to conflict with the view that the soul leaves the body at death. It provides standards by which death can be determined to have occurred, but it does not prevent a person from believing on religious grounds that the soul leaves the body at a point other than that established as marking death for legal and medical purposes.

The concept of death based upon the flow of bodily fluids cannot be completely reconciled with the proposed statute. The statute is partially consistent with the "fluids" formulation in that both would regard as dead a body with no respiration and circulation. As noted previously, the overwhelming majority of patients, now and for the foreseeable

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<sup>11</sup> Bernard Haring, *Medical Ethics*, Fides Publishers, Inc., Notre Dame, Ind. (1973) at 136; Charles J. McFadden, "The Dignity of Life: *Moral Values* in a *Changing Society*, Our Sunday Visitor, Inc. Huntington, Ind. (1976) at 202; Paul Ramsey, *op. cit.* at 59-112; Seymour Siegel, "Updating the Criteria of Death," 30 *Conservative Judaism* 23 (1976); Moses D. Tendler, "Cessation of Brain Function: Ethical Implications In Terminal Care and Organ Transplant," 315 *Ann. N.Y. Acad. Sci.* 394 (1978). *See also* pp. 13-14 *supra* and accompanying notes for a summary of the religious views presented to the Commission.

future, will be diagnosed on such basis. Under the statute, however, physicians would declare dead those bodies in which respiration and circulation continued *solely* as a result of artificial maintenance, in the absence of all brain functions. Nonetheless, people who believe that the continued flow of fluids in such patients means they are alive would not be forced by the statute to abandon those beliefs nor to change their religious conduct. While the recommended statute may cause changes in medical and legal behavior, the Commission urges those acting under the statute to apply it with sensitivity to the emotional and religious needs of those for whom the new standards mark a departure from traditional practice. Determinations of death must be made in a consistent and evenhanded fashion, but the statute does not preclude flexibility in responding to individual circumstances after determination has been made. A fuller discussion of the implications of the proposed statute for decisions about the dead is presented in Chapter Five.<sup>12</sup>

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<sup>12</sup> See pp. 80-84 *infra*.



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# Who Ought to "Redefine" Death?

# 4

The developments in medical technology that permit maintenance of respiration and circulation have engendered broad social concern over unnecessary or inappropriate use of that technology. This, in turn, has provoked the call for new standards by which to determine that death has occurred. To respond, we must ask two questions: What sort of standards, and by whom devised and promulgated? The first question is easier to answer than the second.

As described in the preceding chapter and elaborated in Appendix F, the medical profession has generally accepted the new brain-based criteria as one means for diagnosing death. Yet medical criteria alone cannot meet the public concern, which arose not only because of advances that complicated the decisions of physicians, but also because the public perceived a departure from long-accepted social standards for differentiating life and death. This departure seemed to have momentous implications for many social practices and institutions. Criminal prosecution, inheritance, taxation, treatment of the cadaver, and mourning are all affected by the way society draws the dividing line between life and death.<sup>1</sup>

That the definition of death can touch social life so profoundly, explains why the need for law is perceived. Legal standards for determining when death occurs evolved over the years. They sanctioned the "all bodily functions" view traditionally accepted by the public and practiced by physicians. Any newly formulated standard should attain equal recognition by the public and physicians before being adopted. One must turn, then, to the second question: Who ought to devise and announce the law "defining" death?

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<sup>1</sup> See, e.g., Harold L. Hirsh, "Brain Death" 12 *Med. Tri. Tech. Q.* 377, 391 (1975); Kathleen Price, "Defining Death and Dying: A Bibliographic Overview," 71 *L. Library J.* 49, 59-63 (1978).



**The Scope of Medical Authority**

Traditionally, great deference has been paid to medical expertise in the making of diagnoses of death. As long as the standards employed by the profession were stable and basically congruent with opinion in the community at large, there was little reason for public scrutiny. The law simply reflected the common opinion about death and largely let the physicians—once their techniques and skills had risen to the necessary level of reliability—formulate and apply the tests to measure vital human functions. Yet the movement toward ever more sophisticated medical science, which produced treatments that interfered with the efficacy of the accepted tests, led medicine to new tests that were less comprehensible to the public. This made clear that a *choice* about the "definition" of death was at issue, a choice that ought to involve people beyond the biomedical community.

Furthermore, even the customary deference of the common law—which regarded the moment of a person's death as a "question of fact" for determination at trial largely on the basis of expert testimony<sup>2</sup> should not obscure the public choices that have been, and must be, made. For despite that deference, the standards applied to give legal effect to the testimony about death (medical as well as lay) were established by the courts "as a matter of law."<sup>3</sup>

Biomedical knowledge ought to continue to inform public policy in revising the legal standards concerning death. Physicians have taken the lead in reconsidering the criteria used in diagnosis. They now know what evidence is needed to attest the cessation of brain functions to be complete and irreversible. Furthermore, they can explain what this irreversible cessation means for various human capabilities and biological activities. But, in the end, the society as a whole must judge that these technical standards and the opinions they reflect conform to the society's settled values and accepted conceptions of human existence and personal rights.<sup>4</sup> This judgment will be most clearly ex-

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<sup>2</sup> See, e.g., *Thomas v. Anderson*, 96 Cal. App. 2d 371, 375, 215 P.2d 478, 482 (1950).

<sup>3</sup> See, e.g., *Smith v. Smith*, 229 Ark. 579, 587, 317 S.W.2d 275, 279 (1958); *In re Estate of Schmidt*, 261 Cal. App. 2d 262, 273, 67 Cal. Rptr. 847,854 (1968).

<sup>4</sup> In light of the challenges that have been mounted to any professional prerogative in *establishing* the standards for determining that a human being has died, it may seem surprising that the traditional role of physicians in *applying* the standards has not been challenged. The difference in the tasks probably explains the lack of controversy in the latter situation. Application of an agreed-upon standard is a matter for technical expertise, and it is not doubted that competent physicians (among others) possess the necessary proficiency in diagnosis.

pressed through the medium of the law of the land.

### **Judicial Revision of the Common Law**

The medical profession itself has come to recognize the need for official action on the definition of death.<sup>5</sup> Litigation involving physicians as defendants or as key witnesses has been largely responsible for this recognition. These cases made it clear that, surface appearances notwithstanding, the standards by which death is declared are not left to medical discretion alone. There may have been no statutes on death, but the "common law", which is to be found in the decisions of judges in prior cases, had established a legal standard.

It might appear simplest to change the common law on death—if change is needed—the same way it was made. Confronted with new biomedical developments—in the form of respirators that make comatose patients without brain functions appear "alive" and tests that show that they are really "dead"—judges might be expected to bring the judicially established standards into line. Predictably, however, while some courts adhered to existing law, others cautiously moved away from it.<sup>6</sup> No clear pattern emerged. This is one of several reasons for doubting that judicial revision of the common law presents a promising route to death policy reform, although it does not counsel against appropriate rulings by judges as cases are presented in which the need to "update" the "definition" arises.

A judge's unwillingness to alter the common law on death does not necessarily mean that the judge adheres unthinkingly to tradition or unreasonably resists new knowledge. Anglo-American jurisprudence is based on precedents. It places great value on evenhandedness among litigants and on assuring everyone that the rules by which they conduct themselves will "not be changed in the middle of the game."<sup>7</sup> Allowing judges to decide every rule of law anew in every case would jeopardize the impartiality of the judicial process and place an impossible burden on the courts.

Nonetheless, precedents must be rethought; such rethinking may occasionally lead to bold statements of new rules of law, rather than the incremental (indeed, often imperceptible) modifications favored in judge-made law. Some judges have made sweeping changes regarding the "redefinition" of death (these are discussed in detail in

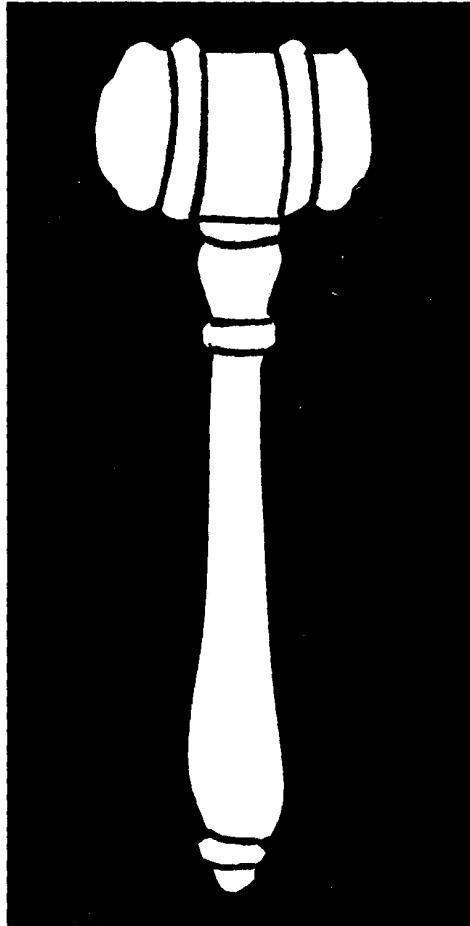
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<sup>5</sup> Frank J. Veith, Jack M. Fein, Moses D. Tendler, Robert M. Veatch, Marc A. Kleiman and George Kalkines, "Brain Death: II. A Status Report of the Legal Considerations" 238 *I.A.M.A.* 1744 (1977).

<sup>6</sup> The judicial rulings on the "definition" of death appear in Appendix D.

<sup>7</sup> *Woods v. Lencet*, 303 N.Y. 349, 354, 102 N.E. 2d 691, 695 (1951).

Chapter Five). More can be expected over time. Additional reasons militate, however, against relying on common law revision as the primary route to revising the standards for declaring that a person has died.



First, the judicial route would extend the period of uncertainty. This could be unfortunate since the application of some standards could cause unwarranted prolongation of treatment (for bodies that have died) while the application of others could cause premature termination of useful treatment (for patients still alive by "whole brain" criteria). A period of legal uncertainty arises because courts cannot simply "declare" law whenever they decide to do so; revision of the common law awaits litigation in which the parties contend over a particular rule of law in the context of a factual dispute. The parties usually identify the issues, articulate the scope and nature of the dispute, provide the le-

gal reasoning and expert testimony, and propose outcomes. The parties to a dispute may present differing views of an issue without presenting all views or even the true polar positions. A judge may not know enough about a field to recognize the need for expert witnesses to supplement the litigants' positions. Anglo-American courts have neither authority nor personnel to conduct independent investigations.

Furthermore, even when courts rule on cases, they do not always "make law." The outcome of a jury trial, for example, is the verdict, usually a simple conclusion to an often complex and secret process. Unless appeal is taken to a higher court, that part of the trial process which is public—namely, the judge's rulings on evidence and instructions to the jury—will not emerge in a form that would give them value as a precedent. In most states the appellate process has multiple levels; proceeding through the court system to the highest court involves much time and expense. Only the latter court can promulgate law binding on

all the lower courts in the jurisdiction. Finally, even when a case has been decided by the highest court, the "holding" which the case establishes is, strictly speaking, limited to the facts of that case. Courts sometimes state their conclusions in broad terms, of course. But the "obiter dicta"—that is, the court's comments incidental rather than necessary to its decision—are often disregarded. Moreover, the standard declared in a homicide case involving the victim's having been disconnected from the respirator that the defense maintains was keeping him "alive" might be disregarded in a later inheritance case involving the time of death.<sup>8</sup> Also, if the facts of two cases—even those in the same field of law—are sufficiently distinguishable, the ruling of one might not be applied in the second.

Beyond differences in the resulting rules supposedly rooted in the particular (and perhaps peculiar) facts of each case, other variations are likely to arise from the difficulties judges have in stating their conclusions about a specialized field that is probably unfamiliar to them. Further, judges may be quite tempted to "improve" on the decisions of courts that have dealt previously with the subject. Thus, although general rules may emerge from judicial decisions, they emerge slowly and somewhat roughly—despite the pains taken.

In some areas of the law, piecemeal modification of rules is rightly seen as a great strength of the common law. A federal system, such as that of the United States, magnifies this process by greatly increasing the number of appellate courts ruling on an issue in a "binding" fashion. As desirable as this step-by-step process may seem, a persistent diversity of standards on a matter as fundamental as the "definition" of death does not seem desirable. There is nothing to applaud in the prospect that small, and perhaps inadvertent, differences in the opinions of the highest courts in two neighboring states might make a "live" patient "dead" as the ambulance carrying him or her crosses their border.

### **Legislative Reform**

Judicial revision of the common law is too dilatory to dispel public confusion and professionals' doubts. Its tardiness and conservatism may fail to capture the movement of public values, frustrating the norms of participation and pluralism that are important in our society.

Legislative modification—the adoption of a statute to supplement or supplant the common law on death—could include public hearings through which members of the general public would both become more familiar with the issue

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<sup>8</sup> See Chapter 5, n.42 and accompanying text, and Appendix D at 137 -38. *infra*

and have their views taken into account in the framing of policy. Legislators, acting directly through legislative committees or with the aid of special purpose study commissions, can investigate both public views and the full range of expert opinion. The views of many groups—representing patients, religious bodies, professional groups, and the general public—should be heard on the "definition" of death. The legislative process easily accommodates the full range of views, unlike the more closed and formal judicial process. (The Commission, in considering the statute recommended in this Report, was likewise able to hear a wide range of professional and lay opinion.)

Legislative reform also has its risks, one of the most prominent being poor drafting. This is a particular danger when issues appear highly technical, uninteresting to legislators, and unlikely to generate passionate feelings. None of these factors should characterize the process of "defining" death, accurately assessed. Though the question has technical aspects, the task of the legislature is not to do the work of physicians in developing medical criteria for diagnosis but to establish the general standards to which society will give legal significance. Similarly, although the attention of the legislature is not likely to be focused on the task of "defining" death the way it is on issues involving economic and political matters that provoke powerful interest groups, there is no question that the subject is one of basic importance to any society: who is alive and who is dead? Finally, the subject is most likely to engender passion when misunderstood, particularly when it becomes confused with the distinct but related question of terminating treatment of respirator-supported patients who still have brain functions although they may not be conscious. With a little care, discussion can be confined to the topic at hand—the recognition of a new formulation of the standards for determining death—standards on which there appears to be general professional and public consensus.

A statute on death ought to guide physicians and others in decision-making about respirator-maintained patients; it ought also to educate those who must make legal and policy decisions. "Legislation will not remove the need for reasoned interpretation—first by physicians and perhaps then by judges—but it can restrict the compass within which they make their choices to one which has been found acceptable by the public."<sup>9</sup> Furthermore, if legislators are guided by a single model bill the likelihood of statutory law that is uniform in language and intent is greatly increased.

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<sup>9</sup>Alexander M. Capron and Leon R. Kass, "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal," 121 *U. Pa. L. Rev.* 87, 101 (1972).

In sum, while the Commission believes that courts should update the standards for declaring death as the issue arises in litigation, it does not think the formulation of new standards should have to await judicial decision. Besides the uncertainty engendered, litigation (civil or criminal) involves time, expense and psychological trauma; it would be unfortunate for society to have to rely on retrospective determination of the basic rules concerning such a fundamental problem as the "definition" of death. The legislative alternative may have drawbacks; still the Commission concludes that (subject to the guidance provided in the next chapter) it is the better course.

### **The Federal Role**

The articulation of standards for determining that a human being has died has traditionally been a matter for state rather than federal law. Necessarily, this allocation of lawmaking responsibility gives rise to the possibility of variations among the laws of the several states. In the field of concern here, just such variation has come about over the past decade, as some states have made statutory or judicial changes in their "definition" of death and others have not.



For reasons set forth more fully in the next chapter, the Commission believes that uniformity on this matter is a desirable goal. One would expect the same basic rule about who is dead, and who is not, to apply everywhere in the United States. Moreover, since certainty and clarity are



highly valuable in this area, uniformity of statutory language would be preferable lest differences in words seem to open the door to differences in substance.

The federal government could respond to the harm that is risked by diversity in the states' legal rules for determining death by passing a statute intended to preempt the field. The Commission believes that such action would be premature, before seeing whether the states all adopt the Uniform Determination of Death Act and secure uniformity that way. Until this is tried, there is no justification for disturbing the traditional allocation of state and federal responsibilities on this subject.

The federal government may have two constructive (and non-coercive) roles to play in defining death, however. First, the federal government can usefully bring together experts and representatives of different streams of thought on the matter, seek to clarify the issues at stake, and facilitate cooperative formulation of a statute and medical criteria. The Commission has attempted to perform precisely this role through its hearings, its participation in law reform efforts, its encouragement of medical groups to examine the reliability of criteria for diagnosing death, and its publication and distribution of this Report.

Second, the federal government should "define death" for matters under direct federal jurisdiction. When legal disputes arise in such places—for example, military installations (including military hospitals), Indian reservations, and other federal preserves<sup>10</sup>—governing law may be either that of the state within which the place is located or special federal law applicable to such places.

Federal law arises in some instances from Congressional enactment and in others from the decisions of federal judges, who have on occasion created a "federal common law" rule different from existing state law.<sup>11</sup> A federal judge faced with an issue turning on the "definition" of

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<sup>10</sup>U.S. CONST. Art. 1, § 8, cl. 17, "The Congress shall have Power. . . . To exercise exclusive Legislation in all Cases whatsoever. . . over all Places purchased by the Consent of the Legislature of the State in which the Same shall be, for the Erection of Forts, Magazines, Aresenals, dock-Yards, and other needful Buildings," U.S. CONST, Art. 4, § 3, cl. 2, "The Congress shall have Power to dispose of and make all needful Rules and Regulations respecting the Territory or other Property belonging to the United States,"; 18 U.S.C. 7 (statute defining special maritime and territorial jurisdiction of the United States for the purpose of federal criminal law.)

<sup>11</sup> The "international rule" of *Chicago, Rock Island & Pacific Ry. v. McGlinn*, 114 U.S. 542 (1885), under which the rules of state law existing at the time the federal enclave was acquired continue to apply until the federal government imposes a new rule has been substantially weakened by *Howard v. Commissioners*, 344 U.S. 14 (1953) and its progeny, which accept coexisting state authority over federal enclaves provided that state law does not interfere with federal jurisdiction. Some relief from the problems faced by individuals who reside on federally owned land which "are especially acute where the litigation arises from acts occurring upon the enclave itself," Richard T. Altieri, "Federal Enclaves: The Impact of Exclusive Legislative Jurisdiction upon Civil Litigation," 72 *Military L. Rev.* 55 (1976), is provided by federal statutes making state law governing, for example, wrongful death, 16 U.S.C. 457 (1970), and criminal law, 18 U.S.C., 14 (1970), applicable to federal enclaves. See generally U.S. Attorney General, *Report of the Interdepartmental Committee for the Study of Jurisdiction over Federal Areas Within the States* (1957); Note, "The Federal Common Law," 82 *Harv. L. Rev.* 1512 (1969).

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death applicable in a federal preserve would probably rely upon the standard for determining death in force in the state where the federal land was located. If that state has failed to update its legal standard to reflect the developments discussed in this Report, the Commission believes that it would be appropriate for the court to take account of the material discussed in this Report and to employ a legal standard that includes irreversible cessation of total brain functions as well as irreversible cessation of heart and lung functions. To promote uniformity, the court ought to establish the more inclusive standard as a matter of federal common law.

It would be both simpler and more certain, however, were the federal rule to follow the route the Commission as endorsed for state law, namely the adoption of a statute. Accordingly, the Commission recommends that the Congress adopt the Uniform Determination of Death Act proposed in this Report as the governing rule in instances falling within federal jurisdiction. (The statute should be enacted as a definitional provision of general application, probably as an amendment to Title 1 of the United States Code.)

The Commission believes that federal adoption of the statute recommended herein for use in only these matters already under direct federal jurisdiction would be salutary in its own right. Furthermore, without in any way coercing the States, federal adoption would offer useful encouragement to the States to place this matter on their legislative agendas.

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# What "Definition" Ought to be Adopted?

# 5

The Commission has concluded that legislatures ought to set the rules for determining human death and that those rules should recognize brain-oriented techniques of establishing death because traditional standards often cannot be employed with patients whose respiration and circulation are artificially maintained. This chapter asks: by what principles should the drafting of a statute on death be guided, how does the law stand at present, and what would a good statute provide?

## **The Specificity of Public Policy**

A statute on death should guide those who will decide whether (and if so, when) a person has passed from being alive to being dead. Such guidance can be general or specific. An initial question for legislative drafters is what level of detail should be incorporated within a statute and what supporting concepts or details can be drawn from other sources. Four levels of generality for such a "definition" have been suggested:<sup>1</sup>

The *basic concept* of death is fundamentally a philosophical matter. Examples of possible "definitions" of death at this level include "permanent cessation of the integrated functioning of the organism as a whole," "departure of the animating or vital principle," or "irreversible loss of personhood." These abstract definitions offer little concrete help in the practical task of

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<sup>1</sup> Alexander M. Capron and Leon R. Kass, "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal," 121 *U. Po. 1. Rev.* 87, 102-104 (1972); See also Robert M. Veatch, *Death, Dying and the Biological Revolution: Our Last Quest for Responsibility*, Yale University Press, New Haven, Conn. (1977) at 68; Task Force on Death and Dying of the Institute of Society, Ethics and the Life Sciences, "Refinements for the Determination of Death: An Appraisal," 221 *J.A.M.A.* 48, 52 (1972).

determining whether a person has died but they may very well influence how one goes about devising standards and criteria.

In setting forth the *general physiological standard(s)* for recognizing death, the definition moves to a level which is more medico-technical, but not wholly so. Philosophical issues persist in the choice to define death in terms of organ systems, physiological functions, or recognizable human activities, capacities, and conditions. Examples of possible general standards include "irreversible cessation of spontaneous respiratory and/or circulatory functions," "irreversible loss of spontaneous brain functions," "irreversible loss of the ability to respond or communicate," or some combination of these.

*Operational criteria* further define what is meant by the general physiological standards. The absence of cardiac contraction and lack of movement of the blood are examples of traditional criteria for "cessation of spontaneous circulatory functions," whereas deep coma, the absence of reflexes, and the lack of spontaneous muscular movements and spontaneous respiration are among criteria proposed for "cessation of spontaneous brain functions" by the Harvard Committee.

Fourth, there are the *specific tests and procedures* to see if the criteria are fulfilled. [Measurement of] pulse, heart beat, and blood pressure, electrocardiogram, and examination of blood flow in the retinal vessels are among the specific tests of cardiac contraction and movement of the blood. Reaction to painful stimuli, appearance of the pupils and their responsiveness to light, and observation of movement and breathing over a specified time period are among specific tests of the "brain function" criteria enumerated above.

The Commission has concluded that legislation should be formulated at the second level, that of general standards. Broader formulations would lead down arcane philosophical paths which are at best somewhat removed from practical application in the formulation of law. To truly redefine the very concepts of life and death, such a course might be necessary; but that is not the Commission's objective. Physicians, applying the traditional procedures that corresponded to societal expectations, were not maintaining that death is the irreversible loss of heart and lung functions. They were affirming only that the loss of those functions *indicated* that a person had died. Modern treatments that interfere with these indicators do not necessitate a change in concepts, provided that alternative indicators of the current

concept are available. As discussed in Chapters Two and Three, the brain-oriented indicators provide such an alternative. Thus, it seems proper to proceed on the assumption that the widespread agreement in traditional understanding of death (i.e., that it is manifested by cessation of spontaneous cardiopulmonary functioning) would apply equally for alternative procedures congruent with the traditional concept.

The third and fourth levels of specificity have problems opposite to those of the first. Agreement might be reached about the details, but this agreement would be fleeting, since new criteria and tests—unlike new concepts—will be repeatedly generated by changes in biomedical knowledge and clinical abilities. It would seem more realistic to leave the technical details to physicians and other biomedical scientists. Once the public has set its goal, specialists in the field can be delegated the responsibility of elaborating the means toward it.

The distinction between general standards (which a statute ought to articulate) and operational criteria (which are better left to medical bodies to establish) is not always recognized. The term "criteria" reflects the usage of the *ad hoc* Harvard committee whose 1968 report on "the definition of irreversible coma" brought the issue to the fore.<sup>2</sup> In the years since that group made its recommendations, the criteria by which an irreversible cessation of total brain functioning is detected have been repeatedly revised.<sup>3</sup> Were a statute to incorporate such criteria, its inflexibility might chill the development of more accurate criteria and of faster, more precise, and more economical tests. By remaining at a slightly greater level of generality—e.g., "irreversible cessation of all functions of the entire brain"—a statute may be able to remain valid indefinitely and not to require repeated amendments.

### **The Objectives to be Sought**

General principles of drafting—such as clarity and brevity—apply as well to a statute on the standards for death determination as to any legislation. But there are also certain objectives particular to the subject at hand.

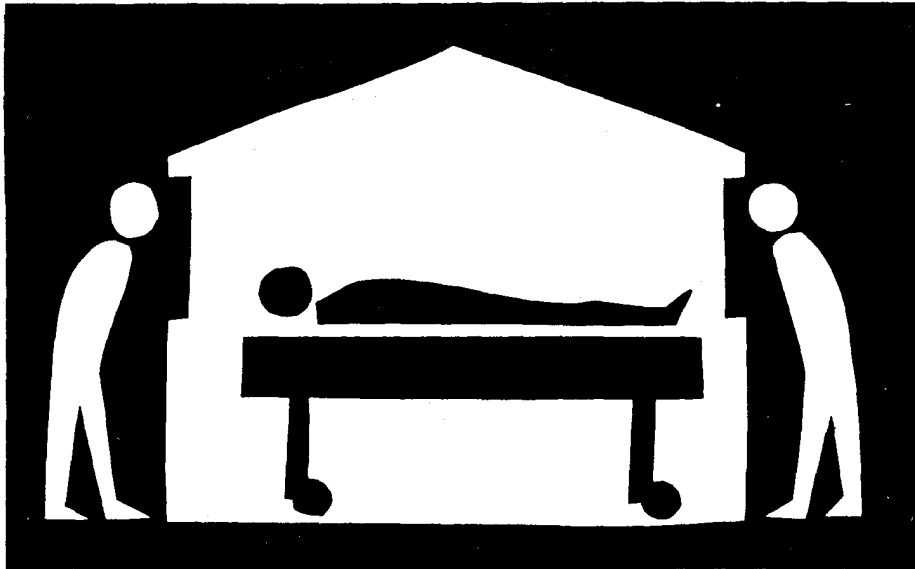
**Death is a Single Phenomenon:** The statute must address the right question. The Commission conceives the question to be, "how, given medical advances in cardiopulmonary support, can the evidence that death has

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<sup>2</sup> Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma," 205 *I.A.M.A.* 337 (1968).

<sup>3</sup> Black, *op. cit.*: Ronald E. Cranford, "Minnesota Medical Association Criteria: Brain Death: Concept and Criteria," 61 *Minn. Med.* 600 (1978).

occurred be obtained and recognized 1" When the presence of a mechanical ventilator precludes the use of traditional vital signs (*i.e.*, respiration and heartbeat) to ascertain whether a person is alive, the use of brain-based criteria provides another means of making such a determination. Thus, brain-based criteria do not introduce a new "kind of death", but rather reinforce the concept of death as a single phenomenon—the collapse of psycho-physical integrity. The statute merely allows new ways to recognize that this phenomenon has occurred.



**Death of the Organism as a Whole:** The death of a human being—not the "death" of cells, tissues or organs—is the matter at issue. The cessation of vital bodily systems provides the basis for broad standards by which death can be judged to have occurred. But such functional cessation is not of interest in and for itself, but for what it reveals about the status of the person. What was formerly a person is now a dead body and can be socially and legally treated as such. Although absence of breathing and heartbeat may often have been spoken of as "defining" death, review of history and of current medical and popular understanding makes clear that these were merely evidence for the disintegration of the organism as a whole, as discussed in Chapter Three.

**Incremental (Not Radical) Change:** Two advantages of the traditional vital signs were their accessibility to measurement (not only by the medically-trained) and their obvious connection to the reality of death as perceived in everyday life. Although fewer and fewer people actually witness death (how many children, for example, today are gathered with their families around the death bed of an elderly relative?), most Americans still feel they recognize the manifest signs of death, at least through the arts and the communications media, if not first-hand. The "whole brain" signs of



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life and death are less well comprehended by nonspecialists, and they measure functions that are less clearly manifest. The heart and the lungs move when they work; the brain does not. Thus, since any incorporation of brain-oriented standards into the law necessarily changes the type of measures permitted somewhat, a statute will be more acceptable the less it otherwise changes legal rules.

Conservatism seems justified in articulating a rule that will not only be applied within the legal system but will also guide the beliefs and behavior of physicians and the public. People's attitudes toward death evolve, and changes in medical capabilities certainly come to be reflected in public as well as professional circles: heart transplantation, for example, cannot help but alter the romantic notion of the heart as the seat of soul or personality. Change does not occur overnight, however, and there seems to be no reason to force it by statute when wrenching change is not necessary. Any statute on death should, therefore, supplement rather than supplant the existing legal concept.

The conservative nature of the reform here proposed will be more apparent if the statute refers explicitly to the existing cardiopulmonary standard for determination of death. The brain-based standard is, after all, merely supplementary to the older standard, which will continue to be adequate in the overwhelming majority of cases in the foreseeable future. Indeed, of all hospital deaths at four acute hospitals in the Commission's survey, only about 8 percent could have been declared dead by neurologic criteria prior to cardiac arrest. The study clearly illustrates that the use of cardiopulmonary criteria predominates. In the first place, the brain-based criteria are relevant only to a limited patient population (*i.e.*, comatose patients on respirators). Even among this population, only one-fourth of those who died at the four acute care centers in the Commission's study met brain-based criteria before meeting the cardiopulmonary standard. Moreover, among those in that population who are likely to *meet* the criteria, cardiac standstill sometimes intervenes (*i.e.* cardiopulmonary criteria are met) prior to completion of the waiting period necessary to confirm the irreversibility of the loss of brain functions. In addition, as the Commission's study illustrates, physicians who conclude that still living patients have no chance for recovery sometimes forego extraordinary treatment; as a result, patients who might have met brain-based criteria if placed on respirators die instead from cardiac standstill or collapse. Thus, although brain-based criteria are needed in those cases where traditional criteria cannot be applied, these instances at present represent, and will in all probability continue to represent, a small percentage of all determinations of death.

**Uniformity Among People and Situations:** Besides moving slowly, the law ought to move evenhandedly. The statute, ought not to reinforce the misimpression that there are different "kinds" of death, defined for different purposes, and hence that some people are "more dead" than others.

In many contexts, definitions are handmaidens to other purposes lawmakers are seeking to achieve. Rather than asking "what is death"? one might ask, "what difference does it make whether somebody is dead"?<sup>4</sup> That question has many answers, most of them familiar to everyone. Criminal law (murder v. aggravated assault), tort law (wrongful death), family law (the status of spouse and children), property and estate law, insurance law (payment of life insurance benefits and termination of health insurance payments), and tax law, as well as some actions and culturally determined behaviors of family members, physicians, clerics and undertakers are all initiated by the determination that a death has occurred. Were there good reason for one branch or another of the law or one or another cultural institution to employ a different "definition" of death, logic would not preclude such a step. But in fact, society has found it desirable to employ a single standard for declaring death in all these circumstances and no special-purpose definitions have been seriously advanced. Calling the same person "dead" for one purpose and "alive" for another would engender nothing but confusion.<sup>5</sup> Thus, in setting forth the law in statutory form, the wisest and most cautious course (furthering the principle of incrementalism as well) would be to adopt a rule recognizing the unity of the concept of death. Such a "definition" of death can be applied in all appropriate circumstances; if a special need is identified for acting on a different basis, a separate status—other than that of being "dead"—could be defined for that purpose.<sup>6</sup>

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<sup>4</sup> Roger B. Dworkin, "Death in Context," 48 *Ind. L. J.* 623, 629 (1973).

<sup>5</sup> See, e.g. Fred Fabro, "Bacchiochi vs. Johnson Memorial Hospital" 45 *Conn. Med.* 267 (1981) chronicling the troublesome case of Melanie Bacchiochi. On February 11, 1981 after repeated clinical examinations confirmed by electroencephalography, physicians found she had suffered irreversible loss of total brain function. Her physician was unwilling to remove her from the respirator because of legal uncertainty since Connecticut's statute on "brain death" applies only to organ transplantation. "It is ironic that if the patient had been a donor, she could have been pronounced dead on February 11 and the respirator could have been withdrawn. Dead for transplantation, but not dead otherwise!" *Id.* at 268.

<sup>6</sup> Alexander M. Capron, "The Purpose of Death: A Reply to Professor Dworkin," 48 *Ind. L.J.* 640, 643-45 (1973); Capron and Kass, *op cit.* at 107-08.

**Adaptability to Advances in Technique:** Some, particularly in the medical community, have voiced a fear of statutory "inflexibility". A statute should apply uniformly at anyone time, but it need not fix at the current level of scientific sophistication or biomedical technology the means by which it is to be implemented. In the terms used earlier, a statute should be confined to the standards by which death is to be determined and leave to experts in biomedicine the continuing development of criteria and specific tests that fulfill them.

### **The Legal Changes That Have Occurred**

The gap between the common law definition of death and the skills of modern medicine has not gone unnoticed by lawmakers. Spurred initially by the interest in trans plantation,<sup>7</sup> later by the widely publicized tragedy of Karen Ann Quinlan,<sup>8</sup> and finally by a recognition of the perplexities in the civil and criminal law processes, legislators in twenty-seven states<sup>9</sup> have enacted statutes that permit reliance on brain-oriented criteria for determining death. Moreover, in several states where legislators had not yet acted, judges have given some recognition to similar standards.<sup>10</sup> (Statutory and common law developments are discussed at greater length in Appendices C and D of this Report; the international trends are surveyed in Appendix E.)

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<sup>7</sup> David Sanders and Jesse Dukeminier, Jr., "Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation," 15 *U.C.L.A. L. Rev.* 357,410 (1968).

<sup>8</sup> Although the *Quinlan* case focused public attention on the capabilities of intensive medical care to resuscitate comatose individuals, legislation of the type recommended in this Report and already adopted in some states would not hold Karen Quinlan to be dead. As this Report has repeatedly emphasized, situations like Ms. Quinlan's do not involve determinations of death but rather decisions about whether to cease treatment of patients with no prospect of recovery to consciousness. This is a distinct bioethical and legal issue receiving separate attention from the President's Commission. Joseph Quinlan and Julia Quinlan (with Phyllis Battelle), *Karen Ann: The Quinlans Tell Their Story*, Doubleday and Co., Garden City, N. Y. (1977); *In the Matter of Karen Ann Quinlan: The Complete Briefs, Oral Arguments and the Opinion of the New Jersey Supreme Court*, Washington, D.C., University Publications of America, Inc. (1975) (2v.); *In Re Quinlan*, 70 N.J. 10 (1976).

<sup>9</sup> See Appendix C, Parts I and III, *infra*.

<sup>10</sup> See Appendix D, *infra*.

**Legislative Developments:** The statutes proposed or adopted fall into seven basic groups (see Figure 3).

*The Kansas-Inspired Statutes:* In 1970 the Kansas legislature took the first legal action in an American jurisdiction recognizing brain-based criteria for the determination of death. The Kansas Supreme Court had shortly before then reiterated its adherence to the common law standard of "complete cessation of *all* vital functions... even if artificially maintained."<sup>11</sup> The statute, proposed by a physician-legislator and adopted without substantial debate, provides alternative "definitions" of death, one based upon traditional heart-lung functions and the other upon brain functions.

A person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice, there is the absence of spontaneous respiratory and cardiac function and, because of the disease or condition which caused, directly or indirectly, these functions to cease, or because of the passage of time since these functions ceased, attempts at resuscitation are considered hopeless; and, in this event, death will have occurred at the time these functions ceased; or

A person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice, there is the absence of spontaneous brain functions; and if based on ordinary standards of medical practice, during reasonable attempts to either maintain or restore spontaneous circulatory or respiratory function in the absence of aforesaid brain function, it appears that further attempts at resuscitation or supportive maintenance will not succeed, death will have occurred at the time when these conditions first coincide. Death is to be pronounced before artificial means of supporting respiratory and circulatory function are terminated and before any vital organ is removed for purposes of transplantation.

These alternative definitions of death are to be utilized for all purposes in this state, including the trials of civil and criminal cases, any laws to the contrary notwithstanding.<sup>12</sup>

With slight variations, in 1972 Maryland,<sup>13</sup> and in 1973

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<sup>11</sup> United Trust Co. v. Pyke 199 Kan. 1,4,427 P.2d 67,71 (1967).

<sup>12</sup> Kan. Stat. Ann. §77-202 (Supp. 1971).

<sup>13</sup> Md. Code Ann., Art. 43, §54F (1972).

New Mexico<sup>14</sup> and Virginia,<sup>15</sup> enacted statutes patterned on the Kansas model. (In 1975 Oklahoma adopted a statute drawn solely from the second "alternative definition" of the Kansas prototype.<sup>16</sup>)

The dual nature of the Kansas statute is its most troublesome feature. The alternative standards are set forth in two separate, complex paragraphs without a description of how they were to be related to the single phenomenon, death. When the statute was enacted, transplantation was very much in the news. The two-pronged statute seems to create one definition of death for most people and another, apparently more lenient standard for "harvesting" organs from potential donors.

*The Capron-Kass Proposal:* To overcome the confusion of the "two deaths" problem, Professor Alexander Morgan Capron and Dr. Leon R. Kass proposed a model statute in a 1972 law review article.<sup>17</sup> Substantially shorter than the Kansas version, it spelled out how the two standards for death were related. It also avoided language in the Kansas statute about "hopeless" treatment that may have implied that the statute had to do with terminating treatment for dying patients rather than defining when death occurs. As subsequently revised by Professor Capron, it states:

A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an irreversible cessation of respiratory and circulatory functions, or in the event that artificial means of support preclude a determination that these functions have ceased, he has experienced an irreversible cessation of total brain functions. Death will have occurred at the time when the relevant functions ceased.<sup>18</sup>

Seven states have adopted versions of the Capron-Kass model. Alaska, Iowa, Louisiana and Michigan enacted the statute with only minor modifications,<sup>19</sup> while other states

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<sup>14</sup> N. M. Stat. Ann. §12-2-4 (1978).

<sup>15</sup> Va. Code §54.325.7 (1979).

<sup>16</sup> Okla. Stat. Ann. tit. 63, §1-301(g) (West 1975).

<sup>17</sup> Capron and Kass, *op. cit* at 111.

<sup>18</sup> Alexander M. Capron, "Legal Definition of Death," 315 *Ann. N.Y. Acad. Sci.* 349,356 (1978).

<sup>19</sup> Alaska Stat. §09. 65. 120 (Cum. Supp. 1979); Iowa Code Ann. §702.8 (West 1979); La. Rev. Stat. Ann. §9:111 (West Cum. Supp. 1980); Mich. Stat. Ann. §§14.15 (1021) to (1024) (1979).

have made more substantial modifications,<sup>20</sup> which are discussed at length in Appendix C.

*The American Bar Association Proposal:* The ABA proposed its own model statute in 1975. It resembled a California law enacted in the previous year.<sup>21</sup> The ABA statute states:

For all legal purposes, a human body, with irreversible cessation of total brain function, according to usual and customary standards of medical practice, shall be considered dead.<sup>22</sup>

Some version of the ABA model statute can be found on the books of five states.<sup>23</sup> Montana and Tennessee adopted the proposal verbatim.<sup>24</sup> Illinois employed largely the same language but, regrettably, inserted it as an amendment to the state's Uniform Anatomical Gift Act, thus creating the impression that it applies only to organ donors.<sup>25</sup> Because it ignores determinations of death based on the traditional cardiopulmonary criteria, a "single standard" statute of the ABA-type might appear to be irrelevant to most patients. To avoid this problem, several states, including California, amended the statute to permit determinations to be made based on "other usual and customary procedures"—unfortunately, without explicating these terms or their relationship to the brain-based standards. The inclusion of this second undefined alternative resurrects—indeed, magnifies—the "two (unrelated) deaths" problem of the Kansas statute.

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<sup>20</sup> Ala. Code § §22-31-1 to 22-31-4 (Cum. Supp. 1979) (accepts other, unspecified procedures; provides for "independent confirmation of death" by a second doctor when brain criteria are used or transplantation is planned; excludes liability for actions in accordance with statute); Hawaii Rev. Stat. §327 C-1 (Supp. 1979) (requires opinion of a consulting physician for brain-based determinations; provides for biennial review of subject by committee appointed by director of health); Tex. Rev. Civ. Stat. Ann. art. 4447t (Vernon Cum. Supp. 1980) (adds "no liability" provisions of AMA model bill).

<sup>21</sup> Cal. Health and Safety Code §7180 (West 1975).

<sup>22</sup> 100 *A.B.A. Ann. Rprt.* 231-232 (1978) (February 1975 Midyear Meeting).

<sup>23</sup> In addition to the states mentioned in the text, Ga. Code Ann. §88-1715.1 (1979) requires "independent confirmation," provides "no liability" for good faith actions in accordance with the statute, and permits use of "other medically recognized criteria" which are not specified.

<sup>24</sup> Mont. Rev. Code Ann. § 50-22-101 (1977); Tenn. Code Ann. §53-459 (1976).

<sup>25</sup> Ill. Ann. Stat. ch. 3, §552(b) (Smith-Hurd Supp. 1975).



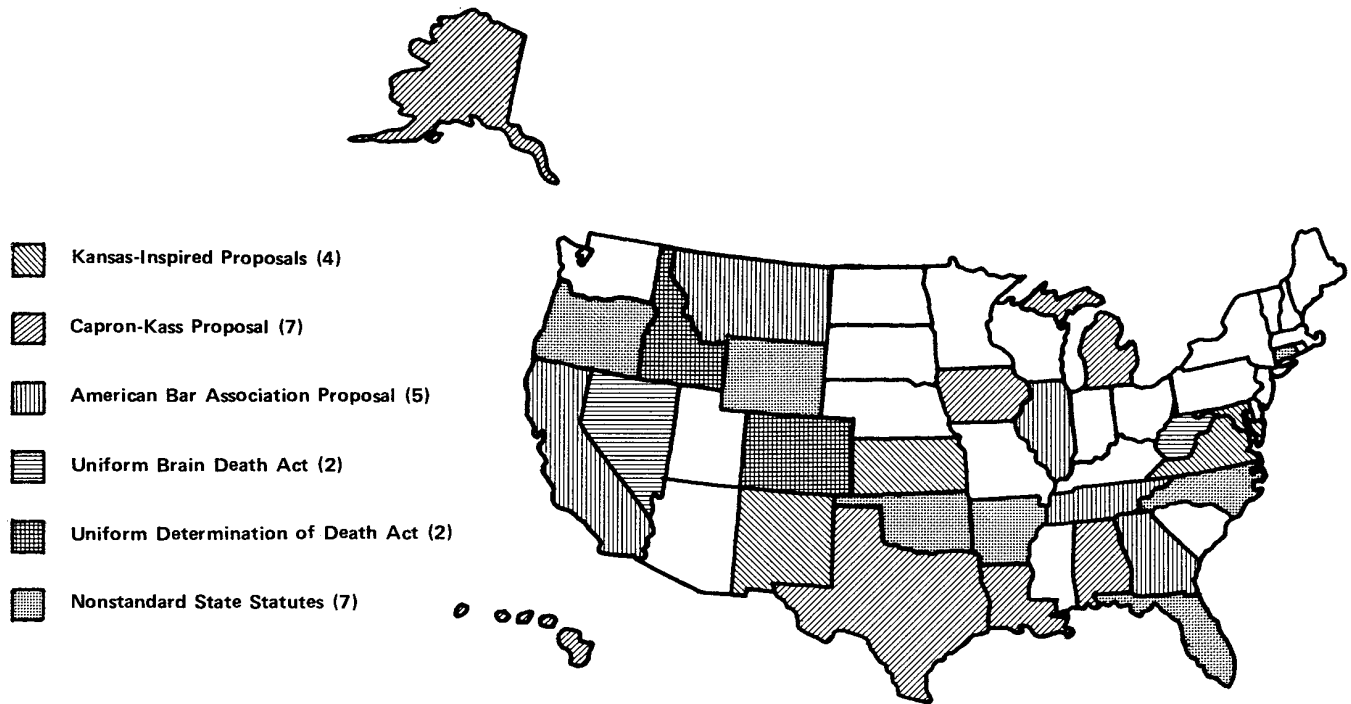


Figure 3. State Statutes on the Determination of Death

*The Uniform Brain Death Act:* A third model statute received the approval in 1978 of the National Conference of Commissioners on Uniform State Laws.<sup>26</sup> The Uniform Brain Death Act, adopted verbatim by Nevada,<sup>27</sup> and in part by West Virginia,<sup>28</sup> provides:

For legal and medical purposes, an individual who has sustained irreversible cessation of all functioning of the brain, including the brain stem, is dead. A determination under this section must be made in accordance with reasonable medical standards.

*The American Medical Association Proposal:* Most recently, the American Medical Association proposed a model bill, which no jurisdiction has yet adopted. As amended at the December 1979 Interim Meeting of the AMA, the proposal incorporated cardiopulmonary and brain-based alternatives for declaring death. Unlike most other statutes, it contained extensive provisions to limit liability for people making or taking actions pursuant to declarations as authorized by the state.

*Individual State Statutes:* Seven states have adopted statutes that do not closely track any of the model proposals. In 1975, Oklahoma adopted the "brain death" half of the Kansas statute, as mentioned previously, and Oregon enacted a law with alternative definitions that is much shorter than the Kansas statute.<sup>29</sup>

In recent years, states have turned increasingly to nonstandard statutes. North Carolina originally adopted a rather confusing statute in 1977 incorporating both "braindeath" and "living wills" provisions.<sup>30</sup> It recently substituted a somewhat clearer statute, an amalgam of the American Bar Association and Capron-Kass approaches. Its central provision reads: "Brain death may be used as the sole basis for the determination that a person has died, particularly when brain death occurs in the presence of artificially maintained respiratory and circulatory functions."<sup>31</sup>

<sup>26</sup> 12 *Uniform Laws Ann.* 15 (Supp. 1981).

<sup>27</sup> Nev. Rev. Stat. §451, as amended by S.B. 5 (Laws 1979).

<sup>28</sup> W. Va. Code §16-19-1 (Supp. 1980). The West Virginia provision came as a partial amendment to an earlier statute on the Capron-Kass model, see W. Va. Code §16-19-1(c) (Cum. Supp. 1977) (adopted March 9, 1975).

<sup>29</sup> Okla. Stat. Ann. tit. 63 §1-301(g) (West 1975); Or. Rev. Stat. §146.087 (1977).

<sup>30</sup> N.C. Adv. Legis. Servo Ch. 815, § 90-320 (1977).

<sup>31</sup> N.C. Gen. Stat. § 90-323, as amended by S.B. 771 (1979).

In 1979, three states enacted idiosyncratic statutes. The provisions in Arkansas<sup>32</sup> and Connecticut<sup>33</sup> essentially elaborate a brain-only standard. Connecticut, like Illinois, placed its law as an amendment to the state's Uniform Anatomical Gift Act. Wyoming's law amalgamates the basic structure of the ABA model with several features of the Uniform Brain Death Act, specifically the inclusion of explicit reference to the brainstem and the replacement of "shall be considered dead" by "is dead."<sup>34</sup> Most unusually, Wyoming drew on the NCCUSL's "Comment" for additional statutory language defining brain functions as "purposeful activity of the brain as distinguished from random activity."

Finally, Florida in 1980 became the twenty-sixth state with a statutory "definition" of death.<sup>35</sup> Its statute also draws on the ABA model and Uniform Brain Death Act in only explicitly recognizing "irreversible cessation of the functioning of the entire brain," but draws on the Capron-Kass approach by implicitly acknowledging the cardiopulmonary standard. It provides that the brain-based standard is to be used 'where respiratory and circulatory functions are maintained by artificial means of support so as to preclude a determination that these functions have ceased.' The Florida statute also specifically requires that determinations of death be made by two physicians, including one specialist, and that the family be notified of the procedures used to determine death; the statute also draws on Sections 2 and 3 of the AMA model in insulating from liability those acting in accordance with its terms.

*Uniform Determination of Death Act:* Legislative response to the statute recommended in this Report began shortly after the President's Commission, the Uniform Law Commissioners and other sponsors of the proposal had officially acted. While this Report was being prepared, Colorado<sup>36</sup> and Idaho<sup>37</sup> (the latter in place of its existing statute) became the first states to enact the Uniform Determination of Death Act, bringing to 27 the states with statutory "definitions" of death.

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<sup>32</sup> Ark. Stat. Ann. § §82-537 and 538 (Cum. Supp. 1979).

<sup>33</sup> Conn. Gen. Stat. Ann. §19-139i (West Cum. Supp. 1980).

<sup>34</sup> Wyo. Stat. §35-19-101 (Cum. Supp. 1979).

<sup>35</sup> Fla. Stat. §382.085 (1980).

<sup>36</sup> Colo. Rev. Stat. §12-36-136 (1981). In a 1979 decision accepting "brain death" in a criminal case, the Colorado Supreme Court had encouraged the legislature to enact a statute. *Lovato v. District Court*, 601 P.2d. 1072 (Col. 1979) (*en banc*).

<sup>37</sup> Idaho Code §54-1819 (Cum. Supp. 1981) (defines "accepted medical standards" as "the usual and customary procedures of the community")

**Judicial Developments:** Over the past decade, courts as well as legislatures have attempted to "redefine" death. While courts adhered for a time to the traditional cardiopulmonary standards, the recent trend has been to recognize the brain-based standard, even in the absence of an explicit statute. Nonetheless, as described more fully in Appendix D, the courts have not all been willing to "update" the common law nor have their rulings established consistent standards of universal application. More fundamentally, the court cases that persistently arise hint at the uncertainty about legal standards that pervades the medical community in states without statutes.

Cases have also arisen in jurisdictions having a statute on death. The cases have mostly involved after-the-fact rulings concerning determinations of death. Generally, the statutes have been upheld by the courts, although in one case the ambiguity of the statutory language led to a "hung jury" and in another the judge refused to apply an "organ donor" statute in a nontransplant case.<sup>38</sup>

The court cases have arisen in a variety of legal contexts. Some defendants charged with murder have argued that they could not be guilty of homicide because their victims were alive when physicians—who should bear the responsibility for the deaths—removed them from the respirators.<sup>39</sup> Doctors have also been sued for removing organs for transplantation from a patient declared dead on the basis of brain-oriented criteria.<sup>40</sup> A third category of cases has involved petitioning a court for permission to terminate life-support systems for bodies without functioning brains.<sup>41</sup>

While the courts have generally recognized brain-oriented criteria, they have often limited their rulings to the context of the particular type of case before the court, (e.g.,

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<sup>38</sup> See Sandra Saperstein, "Maryland Law on Brain Death Was Unclear to Jurors," March 21, 1979, *Wash. Post*, §C at 1, col. 1; Sandra Saperstein, "Md. Nurse to be Freed of Charges: Law Defining Death Held Too Ambiguous," Mar. 29, 1979, *Wash. Post*, §B at 1, col. 6; *Bacchiocchi v. Johnson Memorial Hospital*, No. 256126 (Hartford/New Britain, Conn., Super. Ct., March 13, 1981).

<sup>39</sup> See, e.g., *People v. Saldana* 47 Cal. App. 3d 954, 121 Cal. Rptr. 243 (1975); *State v. Brown*, 8 Ore. App. 72, 491 P.2d 1193 (1971).

<sup>40</sup> *Tucker v. Lower*, No. 2231 (Richmond, Va. L. & Eq. Ct., May 23, 1972).

<sup>41</sup> *Bacchiocchi v. Johnson Memorial Hospital*, No., 256126 (Hartford/New Britain, Conn., Super. Ct., March 13, 1981) (judge declined officially to "update" common law "definition" of death but provided informal assurances to physicians that no liability will follow discontinuation of treatment in patient without brain functions).

explicitly stating that the precedential value of a decision is limited to criminal cases).<sup>42</sup> Moreover, some of the most widely discussed cases did not reach the appellate level, limiting their actual impact to the particular court that decided them.<sup>43</sup>

One case involving the question of whether a respirator-supported patient lacking all brain functions is dead or alive which reached the highest court of a state warrants particular mention because of the relationship of the court's ruling to the policy proposed in this Report. In the case of *In Re Bowman*, the Washington Supreme Court late in 1980 affirmed a lower court ruling that a person without any brain function is dead.<sup>44</sup> The trial court in *Bowman* had ruled that five-year-old Matthew Bowman was dead, having suffered massive physical injuries. The court enjoined the removal of the "extraordinary measures" sustaining respiration and heartbeat, however, pending an appeal. The case was set for argument before the state's highest court a week later, but the day before the argument was scheduled, all of Matthew's bodily functions ceased irretrievably. Although this event made the case moot, the court decided to rule upon the case nonetheless. The Washington Supreme Court observed in its ruling:

An electroencephalogram (EEG) gave no reading and a radionucleide scan, which shows whether blood is getting to and through the brain, found a total absence of blood flow. No cornea reflex was present and Matthew's pupils were dilated and nonreactive to any stimuli. There were also no deep tendon reflexes or other signs of brain stem action, nor responses to deep pain or signs of spontaneous breathing. Body temperature and drug intake had been controlled to avoid adverse influence on these tests. The testifying physician indicated that he believed Matthew's brain was dead under the most rigid criteria available, called the "Harvard criteria," and that his cardiovascular system would, despite the life support systems, fail in 14 to 60 days. [The physician] ... recommended that he be removed from the ventilator, a recommendation consented to by his mother.<sup>45</sup>

The Washington Supreme Court was able to consider the model statute recommended in this Report (it had been

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<sup>42</sup> See, e.g., *Commonwealth v. Golston*, 373 Mass. 249, 366 N.E. 2d 744 (1977); *State v. Johnson*, 395 N.E.2d 368 (Ohio 1977).

<sup>43</sup> *Tucker v. Lower*, No. 2831 (Richmond, Va. L. & Eq. Ct., May 23, 1972, New York Health & Hospitals Corp. v. Sulsona, 81 Misc.2d 1002 (N.Y. Sup. Ct. 1975).

<sup>44</sup> *In re Bowman*, 94 Wash: 2d 407,617 P.2d 731 (1980).

<sup>45</sup> *Id.* at 733.

approved by the Uniform Law Commissioners in August of 1980, in place of the Uniform Brain Death Act discussed above). The court "adopted" the provisions of the new uniform bill, while explicitly leaving to the medical profession the definition of "acceptable diagnostic tests and medical procedures... taking into account new knowledge of brain function and new diagnostic procedures."<sup>46</sup>

**International Developments:** The interference of increasingly sophisticated medical technology with determining death by traditional heart-lung criteria is also a matter of concern outside the United States as well. Indeed, an international body broached the issue as early as 1968 when, a few days after the publication of the seminal Harvard criteria, the 22nd Congress of the World Medical Assembly (WMA) adopted its "Declaration of Sydney."<sup>47</sup> This statement, framed in general terms, recognized that, although physicians will usually be able to meet their legal responsibility in diagnosing death by relying on classical heart-lung criteria, artificial respirators and transplantation of cadaver organs posed problems for which these criteria seem insufficient. The WMA concluded that "no single technological criterion is entirely satisfactory in the present state of medicine nor can anyone technological procedure be substituted for the overall judgment of the physician." A determination of death should, the WMA declared, "be based on clinical judgment supplemented *if necessary* by a number of diagnostic aids of which the electroencephalograph is currently the most helpful."<sup>48</sup>



The Declaration of Sydney went on to recommend that, where transplantation is involved, the determination of death should be made by two or more physicians, who must not be "immediately concerned with the performance of transplantation." This recommendation remains the most frequent common denominator in statutes found in other countries, as death is most often defined in the context of rules relating to organ transplantation.

<sup>46</sup> *Id.* at 738.

<sup>47</sup> Reprinted in "Declaration of Sydney," 2 *Med. J. Aust. Supp.* 58 (1973).

<sup>48</sup> *Id.*



Questions raised by the new resuscitative technology have also received some, albeit not entirely satisfactory, attention in international legal bodies. In 1976 the Parliamentary Assembly of the Council of Europe issued a "Report on the Rights of the Sick and Dying" which included a recommendation on the prolongation of life.<sup>49</sup> Unfortunately, the report seems to confuse patient participation in decisions about medical care with legal rules on the irreversible cessation of brain function.

In model legislation on transplantation in 1978, the Council of Europe dealt obliquely with the "definition" of death. Like the model American statute on transplantation (the Uniform Anatomical Gift Act), the European proposal did not state the basis on which death could be declared in so many words. It went somewhat further than the American provision, however, implying that cessation of brain functions is a ground for pronouncing death, at least when organs are to be removed. The 1978 Council of Europe proposal stated that "[d]eath having occurred, a removal [of organs or tissues for transplantation] may be effected even if the function of some organ other than the brain may be artificially preserved."<sup>50</sup>

A number of countries have taken up these issues through national medical societies or law reform commissions. As a result at least 13 countries have statutes of national force and effect that allow for the determination of death based on brain-oriented criteria. At least ten countries require specific tests (usually electroencephalography and/or cerebral angiography) as part of their statutes or regulations promulgated pursuant to statutory authority.

Two countries, Canada and Australia, have a legal situation that parallels the United States; a few provinces have enacted statutes, while the others have not. In 1977 the Law Reform Commission of Australia recommended, in the context of human tissue transplants, a statute declaring death to occur upon "irreversible cessation of all functions of the brain" or "irreversible cessation of circulation of blood in the body."<sup>51</sup> The Law Reform Commission of Canada recently proposed amending the federal "Interpretation Act" to add a brain-based "definition" to the law "for all pur-

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<sup>49</sup> Parl. Ass., 27th Sess. Resolution 613, adopted Jan. 29, 1976. Parl. Ass. 27th Sess. Recommendation 779, adopted Jan. 29, 1976.

<sup>50</sup> Council of Europe, On Harmonisation of Legislations of Member States Pertaining to Removal, Grafting and Transplantation of Human Substances, Resolution of the Committee of Ministers, 287th Sess., No. 29 (May 11, 1978) at ch. 1, art. 11, § 1.

<sup>51</sup> Law Reform Commission of Australia, *Human Tissue Transplants* (Report No.7) Australian Government Publishing Service, Canberra (1977) at 63.

poses within the jurisdiction of the Parliament of Canada."<sup>52</sup> Other countries, such as Great Britain, rely on codes of medical practice drafted by nationally recognized bodies with quasi-legal status and accepted by the relevant executive branch departments.<sup>53</sup> A recently published survey of the international situation identifies fifteen countries where the medical profession has officially recognized brain-based criteria in determining death in the absence of statutory or case law, and five countries where it has not, although physicians in some of these countries may in fact employ the criteria in declaring death in appropriate cases.<sup>54</sup>

### The Proposal For a Uniform Statute

**The Language and Its History:** The array of "model laws" and state variations reveals two major problems: first, their diversity, and second, the overly complex or inexact wording that characterizes many of them. Diversity is a problem for several reasons. In the case of enacted statutes, diversity means nonuniformity among jurisdictions. In most areas of the law, provisions that diverge from one state to the next create, at worst, inconvenience and the occasional failure of a finely honed business or personal plan to achieve its intended result. But on the subject of death, nonuniformity has a jarring effect. Of course, the diversity is really only superficial; all the enacted statutes appear to have the same intent. Yet even small differences raise the question: if the statutes all mean the same thing, why are they so varied? And it is possible to think of medical situations—and, even more freely, of legal cases that would be unlikely but not bizarre—in which the differences in statutory language *could* lead to different outcomes.<sup>55</sup>

<sup>52</sup> Law Reform Commission of Canada, *Criteria for the Determination of Death*, Report, No. 15), Minister of Supply and Service, Canada (1981).

<sup>53</sup> Working Party of the United Kingdom Health Departments, *The Removal of Cadaveric Organs for Transplantation: A Code of Practice* 11 (1979), accepting the views of the Conference of Royal Colleges and Faculties of the United Kingdom, "Diagnosis of Death," 1979(i) *Lancet* 261, and "Diagnosis of Brain Death," 1976 (ii) *Lancet* 1069-70.

<sup>54</sup> Frank P. Stuart, Frank J. Veith and Ronald E. Cranford, "Brain Death Laws and Patterns of Consent to Remove Organs for Transplantation from Cadavers in the United States and 28 Other Countries," 31 *Transplantation* 238 (1981).

<sup>55</sup> For example, the Kansas statute might be (mis)applied to declare dead a patient who still has some brain functions but who is experiencing repeated and apparently terminal respiratory difficulties, because the first paragraph of Kan. Stat. Ann. § 777-02 states that a person is dead when "Attempts at resuscitation [of respiratory and cardiac function] are considered hopeless." Disputes could arise under the Oregon statute over the propriety of a physician declaring a person dead after a severe trauma to the heart and lungs without attempting resuscitation; Or. Rev. Stat. §146.087 treats a person as alive only if "spontaneous respiration and circulatory function" can be restored.

More fundamental is the obstacle that diversity presents for the process of statutory enactment. Legislators, presented with a variety of proposals and no clear explanation of the significance of their differences, are (not surprisingly) wary of *all* the choices. Proponents of each of the models (and other critics) compounded this difficulty by objecting to the language of the other statutes along the lines discussed in the preceding section of this Chapter.

A uniform proposal that is broadly acceptable would significantly ease the enactment of good law on death throughout the United States. To that end, the Commission's Executive Director met in May 1980 with representatives of the American Bar Association, the American Medical Association and the National Conference of Commissioners on Uniform State Laws. Through a comparison of the then existing "models" with the objectives that a statute ought to serve, they arrived at a proposed Uniform Determination of Death Act:

§ 1. [*Determination of Death.*] An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

§ 2. [*Uniformity of Construction and Application.*] This act shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this Act among states enacting it.

This model law has now been approved by the Uniform Law Commissioners, the ABA, and the AMA as a substitute for their previous proposals. It has also been endorsed by the American Academy of Neurology and the American Electroencephalographic Society.

**Construction of the Statute:** As recommended at the outset of this Chapter, the proposed statute addresses the matter of "defining" death at the level of general physiological standards rather than at the level of more abstract concepts or the level of more precise criteria and tests. The proposed statute articulates alternative standards, since in the vast majority of cases irreversible circulatory and respir-

atory cessation will be the obvious and sufficient basis for diagnosing death. When a patient is not supported on a respirator, the need to evaluate brain functions does not arise. The basic statute in this area should acknowledge that fact by setting forth the basis on which death *is* determined in such cases (namely, that breathing and blood flow have ceased and cannot be restored or replaced).

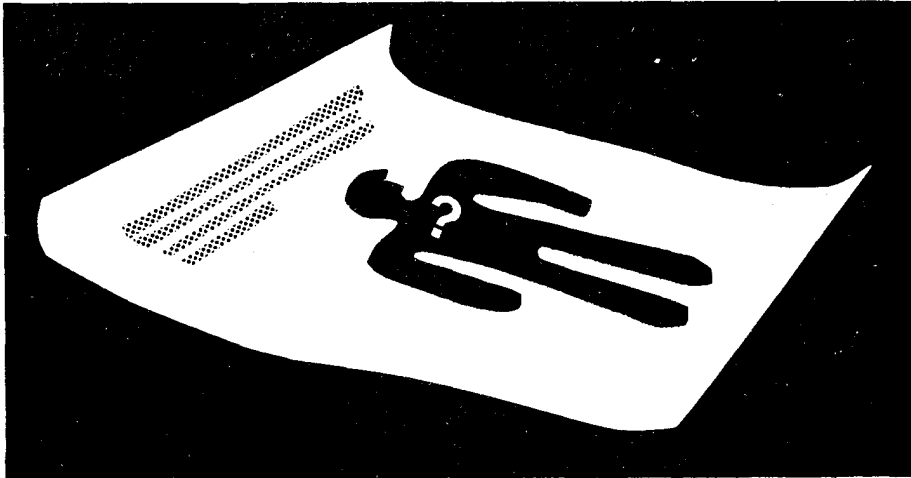
It would be possible, as in the statute drafted by the Law Reform Commission of Canada, to propound the irreversible cessation of brain functions as *the* "definition" and then to permit that standard to be met not only by direct measures of brain activity but also "by the prolonged absence of spontaneous cardiac and respiratory functions."<sup>56</sup> Although conceptually acceptable (and vastly superior to the adoption of brain cessation as a primary standard conjoined with a nonspecific reference to other, apparently unrelated "usual and customary procedures"<sup>57</sup>), the Canadian proposal breaks with tradition in a manner that appears to be unnecessary. For most lay people—and in all probability for most physicians as well—the permanent loss of heart and lung function (for example, in an elderly person who has died in his or her sleep) clearly manifests death. As previous chapters in this Report recount, biomedical scientists can explain the brain's particularly important and vulnerable role in the organism as a whole and show how temporary loss of blood flow (ischemia) becomes a permanent cessation because of the damage it inflicts on the brain. Nonetheless, most of the time people do not, and need not, go through this two-step process. Irreversible loss of circulation is recognized as death because—setting aside any mythical connotations of the heart—a person without blood flow simply cannot live. Thus, the Commission prefers to employ language which would reflect the continuity of the traditional standard and the newer, brain-based standard.

*"Individual"*: Other aspects of the statutory language, as well as several phrases that were intentionally omitted, deserve special mention. First, the word "individual" is employed here to conform to the standard designation of a human being in the language of the uniform acts. The term "person" was not used here because it is sometimes used by the law to include a corporation. Although that particular confusion would be unlikely to arise here, the narrower term "individual" is more precise and thus avoids the possibility of confusion.

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<sup>56</sup> Law Reform Commission of Canada, *op. cit.* at 7-20.

<sup>57</sup> See, e.g., Cal. Health and Safety Code §7180 (West 1975).



*"Irreversible Cessation of Functions"*: Second, the statute emphasizes the degree of damage to the brain required for a determination of death by stating "all functions of the *entire* brain, including the brain stem" (emphasis added). This may be thought doubly redundant, but at least it should make plain the intent to *exclude* from application under the "definition" any patient who has lost only "higher" brain functions or, conversely, who maintains those functions but has suffered solely a direct injury to the brain stem which interferes with the vegetative functions of the body.

The phrase "cessation of *functions*" reflects an important choice. It stands in contrast to two other terms that have been discussed in this field: (a) "loss of activity" and (b) "destruction of the organ."

Bodily parts, and the subparts that make them up, are important for the functions they perform. Thus, detecting a loss of the ability to function is the central aim of diagnosis in this field. After an organ has lost the ability to *function* within the organism, electrical and metabolic *activity* at the level of individual cells or even groups of cells may continue for a period of time. Unless this cellular activity is organized and directed, however, it cannot contribute to the operation of the organism as a whole. Thus, cellular activity alone is irrelevant in judging whether the organism, as opposed to its components, is "dead."

At the other pole, several commentators have argued that organic *destruction* rather than cessation of functions should be the basis for declaring death.<sup>58</sup> They assert that until an organ has been destroyed there is always the *possibility* that it might resume functioning. The Commission

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<sup>58</sup> Paul A. Byrne, Sean O'Reilly and Paul M. Quay, "Brain Death: An Opposing Viewpoint," 242 *J.A.M.A.* 1985 (1979).

has rejected this position for several reasons. Once brain cells have permanently ceased metabolizing, the body cannot regenerate them. The loss of the brain's functions precedes the destruction of the cells and liquefaction of the tissues.

Theoretically, even *destruction* of an organ does not prevent its functions from being restored. Any decision to recognize "the end" is inevitably restricted by the limits of available medical knowledge and techniques.<sup>59</sup> Since "irreversibility" adjusts to the times, the proposed statute can incorporate new clinical capabilities. Many patients declared dead fifty years ago because of heart failure would have not experienced an "irreversible cessation of circulatory and respiratory functions" in the hands of a modern hospital.

Finally, the argument for using "brain destruction" echoes the proposal about "putrefaction" made two centuries ago and overcome by advances in diagnostic techniques. The traditional cardiopulmonary standard relies on the vital signs as a measure of heart-lung function; the declaration of death does not await evidence of destruction. Since the evidence reviewed by the Commission indicates that brain criteria, properly applied, diagnose death as reliably as cardiopulmonary criteria, the Commission sees no reason not to use the same standards of cessation for both. The requirement of "irreversible cessation of functions" should apply to both cardiopulmonary and brain-based determinations.

*"Is Dead"*: Most of the model statutes previously proposed state that a person meeting the statutory standards "will [or shall] be considered dead." This formulation, although probably effective in achieving the desired clarification of the place of "brain death" in the law, is somewhat disconcerting since it might be read to indicate that the law will consider someone dead who by some other, perhaps wiser, standard is not dead. The President's Commission does not endorse this view. It favors stating more directly (as had the Uniform State Law Commissioners in their 1978 proposal) that a person "is dead" when he or she meets one of the standards set forth in the statute.

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<sup>59</sup> Already, a hand "destroyed" in an accident can be reconstructed using advanced surgical methods. The functions of the kidney can be artificially restored through extracorporeal devices; an implantable artificial heart has been tested in animals and is now proposed for human trials. It is impossible to predict what other "miracles" biomedical science may some day produce in the restoration of natural functions or their substitution through artificial means.



In declaring that an individual "is dead," physicians imply that at some moment prior to the diagnosis the individual moved from the status of "being alive" to "being dead." The Commission concurs in the view that "death should be viewed not as a process but as the event that separates the process of dying from the process of disintegration."<sup>60</sup> Although it assumes that each dead person became dead at some moment prior to the time of diagnosis, the statute does not specify that moment. Rather, this calculation is left to "accepted medical practices" and the law of each jurisdiction.

Determining the time of passage from living to dead can be troublesome in certain situations; like all aspects of assessing whether a body is dead, it relies heavily on the clinical skills and judgment of the person making the determination. In most cases, it appears to be the custom simply to record the time when a diagnosis of death is made as the time of death. When precision is important for legal purposes, the scientific basis for determining the time of death may be reexamined and resolved through legal proceedings.

A determination of death immediately changes the attitudes and behavior of the living toward the body that has gone from being a person to being a corpse. Discontinuation of medical care, mourning and burial are examples of customary behavior; people usually provide intimate care for living patients and identify with them, while withdrawing from contact with the dead. In ordinary circumstances, the time at which medical diagnosis causes a change in legal status should be synchronous with the time that social behaviors naturally change.

In some cases of death determined by neurologic criteria, however, it is necessary to allow for repeated testing, observation, or metabolism of drugs. This may interpose hours or even days between the actual time of death and its confirmation. Procedures for certifying time of death, like those for determining the status of being dead, will be a matter for locally "accepted medical standards," hospital rules and custom, community mores and state death certificate law. Present practice in most localities now parallels

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<sup>60</sup> James L. Bernat, Charles M. Culver and Bernard Gert. "On the Definition and Criterion of Death," 94 *Ann. Int. Med.* 389 (1981):

If we regard death as a process then either the process starts when the person is still living, which confuses the "process of death" with the process of dying, for we all regard someone who is dying as not yet dead, or the "process of death" starts when the person is no longer alive, which confuses death with the process of disintegration.

the determination of death by cardiopulmonary criteria: death by brain criteria is certified at the time that the fact of death is established, that is, after all tests and confirmatory observation periods are complete.

When the time of "brain death" has legal importance, a best medical estimate of the actual time when all brain functions irreversibly ceased will probably be appropriate. Where this is a matter of controversy, it becomes a point to be resolved by the law of the jurisdiction. Typically, judges decide this on the basis of expert testimony—as they do with a contested determination of unwitnessed cessation of cardiopulmonary functions.

*"Accepted Medical Standards"*: The proposed statutes variously describe the basis on which the criteria and tests actually used to diagnose death are to be selected and employed. The variations were:

Capron-Kass (1972):	"based on ordinary standards of medical practice"
ABA (1975):	"according to usual and customary standards of medical practice"
NCCUSL 1978):	"in accordance with reasonable medical standards"
AMA (1979):	"in accordance with accepted medical standards"

Despite their linguistic differences, the Capron/Kass, ABA and AMA models apparently intend the same result: to require the use of diagnostic measures and procedures that have passed the normal test of scrutiny and adoption by the biomedical community. In contrast, the 1978 Uniform proposal sounded a different note by proposing "reasonableness" as the standard. The problem is: whose reasonableness? Might lay jurors conclude that a medical practice, although generally adopted, was "unreasonable"? It would be unfair to subject a physician (and others acting pursuant to his or her instructions) to liability on the basis of an after-the-fact determination of standards if he or she had been acting in good faith and according to the norms of professional practice and belief. Even the prospect of this liability would unnecessarily disrupt orderly decision-making in this field.

The process by which a norm of medical practice becomes "accepted" varies according to the field and the type of procedure at issue. The statutory language should eliminate wholly idiosyncratic standards or the use of experimental means of diagnosis except in conjunction with ade-



quate customary procedures). On the other hand, the statute does not require a procedure to be universally adopted; it is enough if, like any medical practice which is later challenged, it has been accepted by a substantial and reputable body of medical men and women as safe and efficacious for the purpose for which it is being employed.<sup>61</sup>

The Commission has also concluded that the statute need not elaborate the legal consequences of following accepted practices. The model statute proposed earlier by the AMA contained separate sections precluding criminal and civil prosecution or liability for determinations of death made in accordance with the statute or actions taken "in good faith in reliance on a determination of death."<sup>62</sup> It is not necessary to address this issue in a statute because the existing common law already eliminates such liability.

*Scope of Application:* The Kansas statute specified that it established when a person is considered "medically and legally dead."<sup>63</sup> Although this unnecessary language was deleted in the 1972 model statute, it partially resurfaced in the 1975 ABA proposal which begins "for all legal purposes."<sup>64</sup> Three years later it was back in full flower in the Uniform Brain Death Act, whose scope includes all "legal and medical purposes."<sup>65</sup>

Besides being unnecessary, the broader provisions are misleading. A law setting a general standard without explicit limitations would be assumed to apply for *all* legal purposes; to say so in the statute, however, only raises needless questions (e.g., what does "all *legal* purposes" leave out? For example, proceedings in equity?).

By mentioning "medical purposes," the Kansas act and 1978 Uniform proposal compounded the confusion. Without this language, a statute would certainly reach the prac-

<sup>61</sup> *Edwards v. United States*, 519 F.2d 1137 (5th Cir. 1975); *Price v. Neyland*, 320 F.2d 674 (D.C. Cir. 1963).

<sup>62</sup> 243 *J.A.M.A.* 420 (1980) (editorial).

<sup>63</sup> Kan. Stat. Ann. §77-202 (Supp. 1971).

<sup>64</sup> 100 *A.B.A. Ann. Rpt.* 231-232 (1978) (February 1975 Midyear Meeting).

<sup>65</sup> Uniform Brain Death Act §1. 12 *Uniform Laws Annot.* 15 (Supp. 1980).

tice of medicine and its consequences for patients. The only additional area that might be encompassed by the phrase "medical purposes" is medical theory, a plane which a statute cannot reach whatever it may proclaim. Society cannot legislate the laws of nature, nor is there any reason to think that in this case it should want to try to do so. Thus, the language proclaiming a "definition" of death "for all medical purposes" is at best unnecessary and at worst foolish.

Finally, since the proposed statute is intended to apply in all situations, it ought not to be incorporated into a state's Uniform Anatomical Gift Act (UAGA). Placing it there would create the mistaken impression that a special "definition" of death needs to be applied to organ transplantation, which is not the case. (As a matter of fact, most of the respirator-supported cases in which the brain-oriented standard would be applicable are not potential donors, as noted in Chapter 2.) Section 7(b) of the UAGA makes the time of death a matter to be determined by the attending physician; the proposed Uniform Determination of Death Act specifies the grounds on which such a determination are made. Some people have expressed concern that a determination of death in a potential organ donor might be made by a physician with a conflict of interest, but the UAGA specifies that the physician who determines that death has occurred "shall not participate in the procedures for removing or transplanting a part."<sup>66</sup>

*Personal Beliefs:* Should a statute include a "conscience clause" permitting an individual (or family members, where the individual is incompetent) to specify the standard to be used for determining his or her death based upon personal or religious beliefs?<sup>67</sup> While sympathetic to the concerns and values that prompt this suggestion, the Commission has concluded that such a provision has no place in a statute on the determination of death. Were a non-uniform standard permitted, unfortunate and mischievous results are easily imaginable.<sup>68</sup>

If the question were what actions (*e.g.*, termination of treatment, autopsy, removal of organs, etc.) could be taken, there might be room for such a conscience clause. Yet, as the question is one of legal *status*, on which turn the rights and interests not only of the one individual but also the

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<sup>66</sup> Uniform Anatomical Gift Act § 7(b), 8 *Uniform Laws Annot.* 608 (1972).

<sup>67</sup> Veatch, *Death, Dying and the Biological Revolution*, *op. cit.* at 72-76; Michael T. Sullivan, "The Dying Person-His Plight and His Right," 8 *New Eng. L. Rev.* 197, 216 (1973).

<sup>68</sup> Capron, "Legal Definition of Death," *op. cit.* at 356-357.

other people and of the state itself, the subject is not one for personal (or familial) self-determination.<sup>69</sup>

The statute specifies that death has occurred if either cardiopulmonary or brain criteria are met. Although, as a legal matter, there is no personal discretion as to the *fact* of death when either criteria is met, room remains for reasonable accommodation of personal beliefs regarding the actions to be taken once a determination of death has been made. Such actions, whether medical (*e.g.*, maintaining a dead body on a respirator until organs are removed for transplantation) or religious (*e.g.*, withholding religious pronouncement of death until the blood has ceased flowing), can vary with the circumstances. Some subjects in the Commission's hospital survey, for example, were maintained on ventilators for several hours after they were dead, in deference to family wishes or in order for the family to decide whether to donate the deceased's organs.

### **Ethical Aspects of the Proposal**

In addition to the issues discussed earlier, particularly in Chapter Three, two further ethical issues deserve mention: (a) concerns about the certainty of diagnosis and (b) concerns about the medical steps that may be taken after death is pronounced.

**Certainty of Diagnosis:** Part of the public concern over employing a brain-based standard to determine death seems to arise from fear that this may cause medical treatment to be withdrawn from some patients who might have "recovered," that is, regained consciousness or at least the ability to breathe without the aid of a respirator. This fear is ex-

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<sup>69</sup> Physicians have recognized the need for sensitivity and good communication on this point:

Before and during the diagnostic evaluation of brain death, the patient's family is informed not only of the patient's medical condition but also of the concept of brain death, its diagnosis, and the consequences of death certification in these cases. Because the declaration of death is the legal responsibility of the medical practitioner, the family's permission for this procedure is not sought but their questions and concerns must be answered honestly and with the necessary education and communication regarding the events following discontinuation of cardiopulmonary support... When transplantation is not planned, family members may request to be at the bedside when the ventilator is removed. This is permitted but the family is advised that peripheral muscle movements may be observed during the ensuing anoxia and that these are not dependent on remaining brain function.

David J. Pawner & Ake Grenvik, "Triage in Patient Care: From Expected Recovery to Brain Death," 8 *Heart & Lung* 1103, 1107 (1979).

pressed in anecdotes about patients who have resumed normal lives after long periods of coma or even after having been pronounced dead.<sup>70</sup> The ethical question is whether a new, brain-oriented definition of death would lead to abandonment of patients who might have responded to continued medical care. Those who press this objection to "redefinition" of death insist that death should not be pronounced until it is certain that recovery is impossible.<sup>71</sup>

The moral gravity of the concern over premature cessation of care cannot be questioned. It is important, however, to be clear on the relation of this Concern to the proposed brain-oriented standard. Under that standard, death will be pronounced in cases in which there is an irreversible loss of brain functions while respiration is artificially supplied. Such bodies might have been regarded as alive if only heart-lung tests for death were permissible. Yet ethical concern over the accuracy of the criteria used to establish a standard and the certainty of the resulting diagnosis can be expressed about both standards—brain or heart-lung—or indeed about any standard. The certainty issue, then, is not peculiar to a brain-oriented standard.

It is true that public attention has not recently focused on the certainty of the diagnosis of death under the heart-lung formulation. But this has not always been so. From time to time in centuries past, the public questioned the ability of doctors to determine when a person had suffered irreversible cessation of life functions. Writers were able to excite the public imagination with tales of buried people awakening and escaping from coffins.<sup>72</sup> The prospect of premature burial has been eliminated by the practice of embalming. Increased public confidence in the diagnostic ability of physicians has laid the remaining fears largely to rest, although reports of occasional "mistakes" (for example, by paramedics in battle) continue to circulate.

The ethical concern over certainty, then, is addressed to a relatively narrow and technical question: with what assurance can a physician state that the relevant organs will

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<sup>70</sup> Bethia S. Currie, "The Redefinition of Death," in S.F. Spieker (ed.) *Organism, Medicine, and Metaphysics*, D. Reidel Publishing Co., Dordrecht, Holland (1978) at 177, 184-191. Review of the cases cited established that in none was a patient who subsequently recovered spontaneous functioning ever dead according to the standard of "irreversible cessation of all functions of the brain" or by the detailed medical guidelines set forth in Appendix F to this Report.

<sup>71</sup> Bryne, O'Reilly & Quay, *op. cit.*

<sup>72</sup> See pp. 13-15 *supra*; Edgar Allan Poe, "Fall of the House of Usher," David Galloway (ed.) *Edgar Allan Poe: Selected Writings*, Penguin Books, New York (1979) at 138.



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not resume functioning in a person diagnosed to have lost certain vital functions? This question cannot be answered by any moral or philosophical argument; it requires empirical evidence. Since experts testified before the Commission that determinations of death based on the irreversible cessation of total brain functioning are today no more, and perhaps less, subject to error than those based on irreversible cessation of heart and lung functions, this ethical question can be satisfactorily answered: a statute establishing a whole-brain standard for determining death would not lead to an increase in the number of patients declared dead who actually possessed the capacity for recovery. Both standards contained in the proposed statute provide the basis for accurate and reliable determinations, when proper criteria and tests are used with due care by qualified people.

**Terminating Medical Interventions on Dead Bodies:** A patient correctly diagnosed as having lost brain functions permanently and totally will never regain consciousness. He or she will experience no pleasure or pain, enjoy no social interaction, and be unable to pursue or complete his or her life's projects. Why, then, is there an ethical issue over discontinuing medical interventions? For many, there will be none. As with all dead bodies, it is appropriate to discontinue interventions—indeed, it is usually inappropriate, on both practical and moral grounds, to continue to intervene,<sup>73</sup> except under closely circumscribed conditions (as when a dead person's organs are kept functioning briefly while preparations for organ removal and transplantation are completed.)

For some people, however, the withdrawal of treatment from a mechanically respirated patient diagnosed as dead because of loss of all brain functions is difficult and perhaps ethically questionable. Such corpses after all, typically have some appearance of life, such as a moving chest, pulsing blood vessels, and bodily warmth. It is these factors, of course, that make the status of such bodies ambiguous and present the issues for biomedical professionals and the public discussed in this Report.

Ceasing to intervene medically in such cases should be compared with the appropriate behavior in regard to other dead bodies. For example, medical personnel may labor vigorously over a patient with a cardiac arrest. If they are

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<sup>73</sup> Cf. Markku Kaste, Matti Hillbom & Jorma Palo, "Diagnosis and Management of Brain Death," 1 *Brit. Med J.* 525, 527 (1979): "As soon as it is obvious that the patient cannot recover, lifesupporting measures should perhaps be withdrawn, since continued support may increase reluctance to embark on resuscitative measures generally. "

not able to restore spontaneous circulation, they know that the patient is dead and treatment ceases.

The use of the respirator—and the decision to withdraw it from a patient who has been declared dead on the basis of an irreversible cessation of all brain functions—only appears to be different. The superficial difference arises because of differences in the clinical situations. An attempt at cardiac resuscitation is acute and dramatic (typically involving numerous people who labor vigorously, shouting orders and employing ever more Draconian measures). By comparison, an attempt at brain resuscitation is chronic (taking hours or days, not minutes) and typically peaceful (the loudest noise may be the quiet "woosh" of air from a mechanical respirator and the rhythmic beeping of a cardiac monitor). At the moment of cardiac failure, one can almost see the life pass from a patient, while from the other it has slipped away so stealthily that its image lingers on. Although undeniably disconcerting for many people, the confusion created in personal perception by a determination of "brain death" does not, in the Commission's view, provide a basis for an ethical objection to discontinuing medical measures on these dead bodies any more than on other dead bodies.

Indeed, it is quite important to be clear on this matter because of the attention paid in recent years to the ethical issues in decisions to forego treatment of *dying*—but still living—patients. That is a separate issue, and one which the Commission will address in a subsequent report. Mechanical respirators and associated treatments are applied to two groups of patients: those whom they are helping to keep alive and those who have died despite such treatment. Failure to recognize the distinctness of those two situations will only obscure and exaggerate the difficulties of framing policy. The statute recommended in this Report aids in that process of recognition by providing a legal standard to distinguish the dead from the dying.

# Defining Death

## Appendices

<b>Appendix A:</b>	Glossary of Terms
<b>Appendix B:</b>	Studies of Outcome in Comatose, Artificially-Respirated Patients
<b>Appendix C:</b>	Statutes on the Determination of Death I: Analysis of Statutes II: Model Legislation III: State Legislation Adopted 1970-1981
<b>Appendix D:</b>	Judicial Developments in the Definition of Death
<b>Appendix E:</b>	International Rules
<b>Appendix F:</b>	Guidelines for the Determination of Death

*These documents are attachments to the Report and were not formally adopted by the Commission. Appendices A – E were prepared by the staff and Appendix F is a statement endorsed by a group of medical consultants to the Commission.*



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# Glossary of Terms

# A

**Anoxia** is the absence of oxygen supply to the tissues.

**Apnea** denotes an absence of the impulse to breathe which leads to an inability to breathe spontaneously.

**Asystole** is the absence of contraction (systole) of the heart. Cephalic reflexes require some intact brainstem. Most important in the discussion of "brain death" issues are the light reflex (constricting the pupils when a light is shined in the eyes), the corneal reflex (blinking when the cornea is touched), the oculocephalic reflex or doll's head reflex (maintaining the position of the eyes when the head is turned), and the vestibular reflex (turning of the eyes when an ear is irrigated with cold liquid).

**Hypoxia** is the reduction of oxygen supply to the tissues below physiologic levels.

**Infarction** is a localized area of necrosis in response to ischemia.

**Irreversible coma** has been used by some authors as a synonym for persistent vegetative state and by others as a synonym for brain death. Although a patient without any brain functions on respirator support may still appear to be in a deep sleep, by generally accepted medical criteria such a patient would not be in a coma or any other living state. Nevertheless, the term is used as an umbrella term for a variety of comatose states including brain death, persistent vegetative state, and locked-in state (consciousness without movement).

**Ischemia** denotes a loss of blood supply to a tissue, and thus includes not only hypoxia or anoxia but deprivation of nutrients and waste accumulation.

**Necrosis** is the mortification of cells or tissue.

**Persistent vegetative state** or **persistent noncognitive state** describes a syndrome of diverse etiologies including cerebral, cortical, or brainstem lesions. Patients in this condition are often described as awake but not aware: they often can breathe, chew, swallow and even groan but show no signs of consciousness, perception, cognition, or other higher functions.

**Spinal reflexes**, which include the knee jerk, ankle jerk, and so forth, require an intact spinal cord segment but not an intact brainstem. A person in deep coma and a person whose entire brain is dead may both have spinal reflexes.

**Systolic blood pressure** is the force of the blood in a major artery at the time of maximum force, resulting from cardiac contraction (systole).



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# Studies of Outcome in Comatose, Artificially- Respirated Patients

B

The mechanical respirator is a life-saving technology, facilitating the recovery of patients whose capacity for spontaneous respiration is temporarily lost or seriously impaired. But not all patients receiving respirator support recover; the technology also generates medico-legal dilemmas.

The Commission was unable to locate any data on the number of patients who have permanently lost all brain functions, despite ventilator-maintained respiration and circulation, or on the relative proportion of this and other outcomes among comatose patients receiving respirator support. Although time and budget constraints prevented the Commission from embarking on a large-scale study which would yield national statistics or widely generalizable data, several small hospital surveys were commenced in the fall of 1980 to shed some light on the implications of respirator use.

## Methodology

The Commission's work had two components: in part I, the Commission arranged for a retrospective review of medical records at four hospitals; in part II, the Commission made use of three existing computerized data bases collected for purposes independent of the Commission's work. The data bases in Part II included four hospitals, none of which were included in Part I. In both parts of the Commission's study, the same entrance criteria were applied, namely coma<sup>1</sup> for at least six hours and simultaneous respirator

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<sup>1</sup>Coma was defined as inability to 1) open the eyes, 2) obey verbal commands and 3) utter recognizable words, (*i.e.*, maximum scores of 1-5-1 on the Glasgow Coma Scale). G. Teasdale and B. Jennett "Assessment of Coma and Impaired Consciousness. A Practical Scale," 2 *Lancet* 81 (1974).

support. A detailed description of the methodology for each portion of the study follows.

### Part I: Record Review

The Commission arranged for investigators at four acute care hospitals<sup>2</sup> (hereafter referred to as Centers 1-4) to review the medical records of comatose patients who received respirator assistance during a two-month period in 1980. The centers were not selected randomly and are not "representative" of the range of hospitals in the United States. On the contrary, they were chosen because there were likely to be more cases of coma with respirator support at this type of hospital and, therefore, the attendant medico-legal issues were especially likely to arise. Among the reasons for selecting the particular hospitals were: a reasonable number of cases could be expected because these centers were acute care facilities in large metropolitan areas; the medical records were likely to contain information which the Commission sought; participating neurologists at the institutions were knowledgeable about the use of brain-based criteria for diagnosing death; and the centers were geographically dispersed. Table 1 presents an overview of Centers 1 – 4.

Table 1:

Overview of Centers in Part I (Record Review)

		Number of Patients	Number of
	Approximate	Receiving Respirator	Patients Meeting
Center	Number Beds	Support 4/1/80.5/31/80	Study Criteria
1	350	99	30
2	425	121	35
3	900	242	36
4	850	152	32

Medical records were reviewed in the following way: Each investigator obtained a list of patients over one year of age who had received respirator assistance at his or her center between April 1, 1980 and May 31, 1980. The patient records were then screened to determine which patients met the entrance criteria, namely coma for at least six hours and simultaneous respirator assistance during the two-month period. The record of each subject who met the entrance criteria was then reviewed to determine whether 30 days after meeting the criteria the subject had died, was discharged or remained in the hospital. The condition of patients who remained in the hospital 30 days after onset of coma and respirator support was abstracted from the chart,

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<sup>2</sup> One of the four hospitals actually includes two facilities: a center primarily serving adults and an associated children's hospital.

as was the discharge diagnosis of those who left the hospital within the month. Any subject who died after having been discharged was to be included as a discharge, not a death. Additional information about the neurological status and medical management of those who died and their organ donor status was also obtained. The questionnaire used in the study is reprinted at pages 102-05 of this appendix.

The research review committee at each of the participating centers gave prior approval to the study. Confidentiality of the subjects was preserved.

### **Part II: Computerized Data Bases**

The second part of the Commission's empirical work involved secondary analysis on the following existing computerized data bases on critically ill patients: (1) all patients with severe head trauma between April 1979 and March 1980 at an acute care center in a large metropolitan area (hereafter Center A); (2) all patients in deep coma of *nontraumatic* origin between April 1976 and March 1977 at Center A and at a university-based tertiary care facility (hereafter Center B); (3) all patients admitted to the Intensive Care Unit between April 1979 and March 1980 at a second university-based hospital that provides both acute and tertiary care (hereafter Center C). Center C is not the primary trauma center in its locale and thus the majority of its coma cases are of nontraumatic origin.

Investigators responsible for the data bases determined which of their patients met the criteria of coma and simultaneous respirator assistance during the year indicated. The type of data solicited about subjects at Centers A, B and C is shown on the forms at pages 106 -07 of this appendix. The information requested was not uniformly available from each of these centers.

The data available on head *trauma* subjects at Center A included: the one-month and six-month status of subjects; the number and management of patients who met neurologic criteria for death (irreversible cessation of all functions of the entire brain, including the brainstem); and whether those declared dead on the basis of such criteria were organ donors.<sup>3</sup>

Less complete information was available on subjects in coma of *nontraumatic* origin at Centers A and B. The one-month and six-month status of subjects in this data base was provided to the Commission. No data on the number of subjects meeting neurologic (i.e. brain-based) criteria were available.

At Center C, the one-month outcome of subjects meeting the Commission study criteria was available. The

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<sup>3</sup> Some of these data were obtained by also reviewing medical records of subjects identified in the computerized data base.

neurologic status, medical management and organ donor status of subjects was available on about two-thirds of the subjects who died; the charts on the remaining dead subjects were not available.

Because some data from Centers A, Band C were not available, not all centers are represented in each of the analyses presented.

## **RESULTS**

Hospitals 1 – 4 in the record review ranged in size from 350 to 900 beds, and the total number of patients receiving respirator support (both comatose and not comatose patients) varied with the size of the facility. The number meeting the study criteria of coma and simultaneous respirator support was very similar at each of the four centers, however, ranging from 30 to 36 patients (Table 1). The results from the four centers are aggregated in some of the analyses that follow.

A description of the subjects in Parts I and II of the study is provided in Table 2. A total of 133 subjects met the study criteria at Centers 1 – 4 in Part I of the study, 93 of these with coma of nontraumatic origin and 40 with a traumatic coma. In Part II, there were 79 patients in the severe head injury data base at Center A who were entered in the study; 57 subjects in the nontraumatic data base from Centers A & B; and 47 subjects at Center C who met the study criteria.

### **1. Status of subjects one and six months after entering study**

Table 3 presents the functional categories of the 133 patients at Centers 1 – 4 one month after being entered in the study. About two-thirds (89/133) of all subjects at Centers 1 – 4 were dead within one month of the onset of coma with respirator support. Among the 40 survivors<sup>4</sup> were eight subjects in a persistent vegetative state (PVS) and 16 who suffered severe disability at the end of the month. The remaining 16 survivors—12 percent of all subjects—achieved a good to moderate recovery within 30 days. Those who achieved a good outcome were usually in a coma due to drug intoxication. The overall rates convey the experience with comatose respirator-assisted patients at the acute care hospitals. The mortality rate of a population of comatose, respirator-supported patients depends, in part, however, on the relative proportion of patients with various types of nontraumatic causes of coma and those in coma resulting from a severe head injury. The results from Centers 1 – 4 broken down by type of coma (nontraumatic/traumatic) and the data from the specialized data bases in Part II of the

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<sup>4</sup> The one-month outcome of four subjects discharged within three weeks of entering the study is not known.

Table 2:  
Subjects in Part I and Part II

	Type of Center/Sample	Dates	Number of Subjects	Etiology of Coma			Total Deaths		Total Deaths that Occurred According to Neurologic Criteria	No. Deaths Declared by Neurological Criteria
				Trauma	Nontrauma	Unknown	1 mo.	6 mo.		
Part I: Record review	4 acute care hospitals	4/1/80-5/31/80	133	40	93	--	89	unk.	23	12
Part II: Computerized data bases										
Center A	severe head trauma	4/79-4/80	79	79	--	--	46	50	11	10
Centers A & B	nontraumatic coma	4/76-4/77	57	--	57	--	42	46	unk.	unk.
Center C	ICU data base	4/79-4/80	47	6	35	6	42 <sup>a/</sup>	unk.	b/	b/

a/ Of the 42 deaths, 33 were among those with nontraumatic coma; 4 with traumatic coma; and in 5 cases the etiology is unknown.

b/ Data were available on only 26 of the 42 subjects who died; of these 26, there were 14 who met neurologic criteria, all of whom were declared dead on that basis.

Table 3:  
Functional Status of Subjects at Centers 1 – 4 One Month After Entering Study<sup>a/</sup>

	Trauma	Nontrauma	All Cases
	(40)	(93)	(133)
<b>Dead</b>	<b>17 (42.5%)</b>	<b>72 (77.4%)</b>	<b>89 (66.9%)</b>
<b>Persistent Vegetative State</b>	<b>4 (10.0)</b>	<b>4 (4.3)</b>	<b>8 (6.0)</b>
<b>Severe Disability</b>	<b>9 (22.5)</b>	<b>7 (7.5)</b>	<b>16 (12.0)</b>
<b>Moderate Disability</b>	<b>2 (5.0)</b>	<b>1 (1.0)</b>	<b>3 (2.2)</b>
<b>Mild Disability</b>	<b>4 (10.0)</b>	<b>0</b>	<b>4 (3.0)</b>
<b>Good Recovery</b>	<b>2 (5.0)</b>	<b>7 (7.5)</b>	<b>9 (6.7)</b>
<b>Unknown</b>	<b>2 (5.0)<sup>b/</sup></b>	<b>2 (2.1)<sup>c/</sup></b>	<b>4 (3.0)</b>

a/ Table includes patients who died in hospital, remained hospitalized at the end of the 30-day follow-up period and who were discharged within 30 days. This latter group are reported as follows: discharge diagnosis was used if patient was discharged between day 22 and day 30 of the follow-up period; patients discharged within the 30 day period with normal function are included under "good recovery", 1 patient discharged with mild disability 12 days after entry (had mild disability 3 months later) is included as mild disability; all other discharges are called "unknown" outcome and additional information, when available, is provided in the footnotes.

b/ One patient discharged to another hospital in a PVS. considered "terminal" 8 days after meeting criteria; one patient with moderate disability 16 days after entry (had mild disability 7 months later).

c/ One patient discharged to another hospital "in coma, no response to pain," 6 days after meeting criteria; one patient discharged with moderate disability 1 week after meeting criteria.

study provide more detailed information about the relative proportion of comatose patients who recovered and who died following respiratory support.

#### a. Nontraumatic

About 75 percent of subjects in coma of nontraumatic origin at Centers 1 – 4 and at Centers A & B died within a month (Table 2). Centers A & B, however, exclude comas caused by drugs. Eliminating drug cases-which tended to recover-from analysis of the data from Centers 1 – 4, the mortality rate was about 80%. The one-month mortality among the 35 nontraumatic coma patients exclusive of drug-induced comas at Center C was 94'percent (Table 2).

The functional status at six months of the 15 subjects who were alive one month after onset of a coma of nontraumatic origin and respirator support at Centers A & Bare shown in Table 4. In six months almost all subjects in a persistent vegetative state or severely disabled had died, while those with better one-month outcomes generally stayed the same or improved. The six-month status of only one of the



two nontraumatic coma survivors at Center C is known; a PVS patient at one month remained in that state at six months.

### **b. Traumatic**

About 40 percent of trauma patients at Centers 1 B 4 died within a month (Table 3). Mortality among traumatic coma patients at Center A was higher—58 percent at one month and 63 percent at six months (Table 2). Age is a significant factor in the outcome of coma resulting from a head injury and the older age of patients at Center A may well explain the increased mortality. Table 5 shows the functional status at six months of the 33 subjects at Center A who were alive one month after onset of traumatic coma and artificial respiration. Most subjects remained in the same functional category or improved slightly at six months. One-month and six-month mortality rates of traumatic coma subjects at Center C were not calculated separately since there were only six such subjects and data about them were limited.

## **2. Neurologic deaths and declarations of death**

In the Part I record review, between five and seven subjects each center met brain-based criteria of death over the two-month period.<sup>5</sup> The total of 23 such subjects at the four centers represents one-quarter of the 89 subjects who died, and 17 percent of the 133 comatose, respirator-supported subjects in Part I of the study. During April, May and June of the year under study, the total number of hospital deaths in the four centers was 453, or an estimated 299 per two-month period. The ratio of patients with irreversible cessation of total brain functions within 30 days of onset of respirator-assisted coma to total hospital deaths is thus 23/299 or eight percent.

Centers 1 B 4 differed markedly in the extent to which brain-based criteria were used to declare death (Table 6). Every time a subject at Center 2 suffered irreversible cessation of brain functions, death was declared on that basis. In contrast, at Center 4 such subjects were never declared dead until the cardiopulmonary standard was met.

In Part II (Table 2), records from Center A on the 46 traumatic coma subjects who died showed that 11 (24 percent) fulfilled brain-based criteria prior to cardiac standstill. In all but one case, death was declared on that basis and support of the body was discontinued. Data were avail-

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<sup>5</sup> A chart review of this sort is dependent on the notes in the medical record being sufficiently complete to document a retrospective diagnosis. The neurologists abstracting data for the study at each center categorized a subject as having been "brain dead," if 1) the chart specifically stated that "brain death" had occurred, and/or 2) on the basis of the chart notes the neurologist concluded that an irreversible loss of all brain functions had occurred.

Table 4:  
One Month and Six Month Outcome of Nontraumatic Coma at Centers A and B

		Six Month Outcome				
		Death (50)	PVS (0)	Severe Disability (0)	Moderate Disability (2)	Good Recovery (5)
One Month Outcome	Death (42)	42				
	PVS (4)	4				
	Severe Disability (4)	3			1	
	Moderate Disability (3)				1	2
	Good Recovery (4)	1				3

Cases on the dashed line showed no change;  
those above improved, below worsened.

able on 26 of the 42 subjects at Center C who died. Fourteen of these 26 subjects met brain-based criteria and in all cases death was declared on that basis and support discontinued. Data on the number of nontraumatic coma subjects at Centers A & B who suffered irreversible cessation of all brain functions were unavailable. All subjects in the Commission's study who met brain-based criteria, but were maintained on respirators and not declared dead by these criteria, subsequently met cardiopulmonary criteria of death.

The determination that a subject had suffered a permanent loss of all brain functions did not always—or even usually—trigger *immediate* termination of support and declaration of death. The amount of time support was continued after a diagnosis of irreversible loss of all brain functions varied considerably among, and in some cases within, centers. At Center A, for example, where ICU beds are scarce, respirators were consistently disconnected from dead bodies as soon as the family was apprised of the determination. This often occurred in less than an hour and, with one exception, within a few hours after the determination had been made, which itself followed a period of vigorous medical support of hours or even days. In the one ex-

Table 5:  
One Month and Six Month Outcome of Traumatic Coma at Center A

		Six Month Outcome					Unknown (1)
		Death (50)	PVS (0)	Severe Disability (12)	Moderate Disability (5)	Good Recovery (11)	
One Month Outcome	Death (46)	46					
	PVS (4)	2		2			
	Severe Disability (17)	2		10	5		
	Moderate Disability (8)					7	1
	Good Recovery (4)						4
	Unknown (0)						

Cases on the dashed line showed no change; those above improved, below worsened.

ceptional case, respirator support was continued for 12 hours after death occurred while the family attempted to decide whether to donate the deceased's organs. After 12 hours the family had still not reached a decision and the need for the ICU bed led the physicians to discontinue support. In contrast, at Center C, several dead bodies were maintained on respirators for 24, 48, and in one case 72 hours, before death was declared on the basis of brain criteria. As a general practice, families at participating centers were consulted before death was declared and support terminated.

### 3. Organ donation and use of brain-based criteria

The use of neurologic criteria has been linked in popular understanding with organ transplantation.<sup>6</sup> Data were obtained from centers in the Commission's study, to ascertain whether organ donation was the primary reason for use of brain criteria. Of the 36 subjects found by the study to have been *declared* dead on the basis of neurologic criteria, only six were organ donors; in the vast majority of cases brain criteria were applied independently of organ donation considerations.

<sup>6</sup> Peter McL. Black, "Brain Death II" 299 *J.A.M.A.* 393, 396 (1978); "Are Some Patients Being Done In?" 116 *Time* 54 (1980).

**Table 6:**  
**Use of Brain-Based Criteria at Centers 1 – 4**

Center	Number of subjects	Number who died in hospital within 30 days	Number who met brain-based criteria <sup>a</sup>	Number who met criteria who were declared dead on that basis
1	30	16 (53.3%)	6 (20% of sample) (37.5% of dead)	5 (83.3% of those who met brain-based criteria)
2	35	25 (71.4)	5 (14.3) (20.)	5 (100)
3	36	23 (63.9)	5 (13.9) (21.7)	2 (40)
4	32	25 (78.1)	7 (21.9) (28.)	0 (0)
total all centers	133	89 (66.9)	23 (17.3) (25.8)	12 (52.2)

a. Either as reported in chart or on basis of abstractors' review of notes.

At centers 2 – 4 official criteria at that hospital was applied; at center 1 where no official criteria exist the neurologist reviewing charts made the determination.

## Discussion

The Commission's study provides data on several questions relating to the role of respirators and the incidence and medical management of respirator-supported comatose patients who irreversibly lose all brain functions. Discussion of the Commission's findings are organized around the following questions:

- 1) What are the relative proportions of comatose, respirator-supported patients who survive and who die?
- 2) What proportion of comatose, respired patients experience an irreversible cessation of all brain functions?
- 3) What actions are taken when a patient is found to have permanently lost all brain functions?
- 4) What proportion of patients declared dead by brain-based criteria are organ donors?

### **1. What are the relative proportions of comatose, respirator-supported patients who survive and who die?**

Death, and specifically death determined by brain-based criteria, is a common outcome among comatose, respirator-supported patients. In some cases in which respirator support is provided to comatose patients, however, the patient survives, sometimes in a persistent vegetative

state or with another severe disability and other times with less serious or no residual damage. In the Commission's study, about two-thirds of the 133 subjects (in traumatic and nontraumatic coma) at Centers 1 – 4 died within a month. At the other end of the spectrum, about 12 percent of the subjects achieved a good to moderate recovery.<sup>7</sup>

The cause of coma, early clinical signs and, at least in the case of traumatic coma, the age of the victim affect the patient's prognosis. About 20 percent of subjects in coma due to nontraumatic causes survived one month after onset of coma and respiratory support. The progress reported at one month appears to be a meaningful indicator of longer term outcome. Levy *et al.* found that patients in coma of nontraumatic origin who survived for one year made most of their improvement during the first month.<sup>8</sup> Most patients in their series of 500 nontraumatic coma patients who were alive one year after onset of coma were in the same functional category as at one month; some improved slightly.

Unlike nontraumatic coma, in which one-month status is a strong predictor of longer term outcome, the six month status of traumatic coma patients is a much better indicator of longer term outcome. Heiden *et al.* report that of 184 patients who survived for a year, 90 percent achieved their best outcome by six months.<sup>9</sup> At Center A about 40 percent of the comatose respirator-assisted subjects survived six months; however, 12 of those 29 survivors were in a persistent vegetative state or severely disabled.

## **2. What proportion of comatose, respirated patients experience an irreversible cessation of all brain functions?**

At each of the four acute care hospitals in Part I of the Commission's study, 2 – 4 cases of permanent loss of all brain functions occurred each month among patients receiving aggressive medical support (including artificial respiration) for comas of traumatic and nontraumatic origin. It is interesting to note that the proportion of

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<sup>7</sup> Although the study was not designed to test the accuracy of the brain-based criteria for determining death but rather to assess the outcome of respirator support for a range of comatose patients it bears noting that none of the subjects who survived ever met those criteria.

<sup>8</sup> David E. Levy, David Bates, John J. Caronna, Niall E.F. Cartlidge, Robin P. Knill-Jones, Robert H. Lapinski, Burton H. Singer, David A. Shaw and Fred Plum, "Prognosis in Nontraumatic Coma," 94 *Ann. Int. Med.* 293 (1981). This series includes 57 subjects in the Commission's study.

<sup>9</sup> James S. Heiden, Richard Small, William Caton, Martin H. Weiss and Theodore Kurze, "Severe Head Injury and Outcome: A Prospective Study," in A.J. Popp et al. (ed.) *Neural Trauma* Raven Press, New York (1979).

respirator-supported comatose patients who suffered neurologic death was similar (about 15 percent) at each center. The incidence of 2 – 4 cases per month is consistent with a report by Grenvik *et al.* of 48 cases of "brain death" over a two-year period at Presbyterian-University Hospital in Pittsburgh.<sup>10</sup> Although the data available on the incidence of "brain death" are from only five hospitals, the recurring finding of 2 – 4 cases per month is suggestive of the frequency with which these cases may be expected to arise at acute care centers in major metropolitan areas.

The Commission's investigations focused on respirator-assisted comatose patients—the population in which it is possible to meet brain-based criteria prior to fulfilling cardiopulmonary criteria of death. Even among this population, most fulfilled the cardiopulmonary standard for declaring death before a diagnosis of irreversible loss of all brain functions was or could have been made. The 23 cases of neurologic death at Centers 1 – 4 comprised only one-fourth of the 89 deaths among respirator-supported comatose patients. Similarly, among subjects with traumatic injury at Center A, brain-based criteria were met in only one-fourth of the deaths. Clearly, cardiopulmonary criteria remain the predominant basis for determining that death has occurred, even in patients on respirators.

The number of deaths diagnosed by neurologic as compared to cardiopulmonary criteria can reflect medical management decisions. For example, a patient who might have met brain-based criteria while on a mechanical respirator will instead be declared dead on cardiopulmonary grounds if artificial support is not initiated or maintained. A few such instances occurred in the Commission's study.

Another factor affecting the relative proportion of deaths declared by cardiopulmonary criteria and neurologic criteria is the systemic condition of the subjects receiving support. Older patients, for example, are more likely to succumb to cardiac standstill before suffering an irreversible loss of all brain functions because, in general, their systems are weaker and more difficult to maintain. In some cases in the study an initial diagnosis of loss of brain functions was made, but before that determination could be confirmed, cardiac standstill intervened, despite mechanical respiration.

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<sup>10</sup> Ake Grenvik, David J. Pawner, James V. Snyder, Michael S. Jastremski, Ralph A. Babcock and Micheal Loughhead, "Cessation of Therapy in Terminal Illness and Brain Death," 6 *Critical Care Med.* 284 (1978).



### **3. What actions are taken when a patient is found to have permanently lost all brain functions?**

The Commission's data illustrate the wide variation in the extent to which brain-based criteria are used to *declare* death when irreversible loss of all brain functions occurs. One center declared all subjects who met brain-based criteria dead and discontinued support, while another always supported such bodies until cardiac arrest. Practice at other centers fell between these extremes: Sometimes a body without brain functions was supported and sometimes such a body was declared dead and support discontinued.

Some of the disparities in use of neurologic criteria within and among centers may reflect variations in knowledge about and/or acceptance of the brain-based standard by physicians and the public. Since the practical consequence of failing to cease treatment and pronounce death when brain functions cease irreversibly is support of a dead body for a brief period (usually less than a week) until cardiac standstill occurs, evaluation of whether such continued treatment is a major problem or, on the other hand, not a matter of concern at all probably varies from individual to individual.

Incentives to make an appropriate diagnosis and declare death do not always seem compelling when professional or public understanding is lacking. A climate of public acceptance of the neurologic basis for determining death, general legal adoption of that standard, and medical recognition of the social and legal acceptance as well as of a unified set of reliable medical criteria should result in more consistent management of dead bodies.

### **4. What proportion of patients declared dead by brain-based criteria are organ donors?**

Clearly, advances in organ transplantation were a major impetus in the early development of brain-based criteria for death. Nevertheless, the Commission's findings that only six of 36 subjects in the Commission's surveys who were declared dead by neurologic criteria were organ donors illustrates that the criteria are being applied primarily outside the context of organ donation. Indeed, considerations such as respect for the dead and a desire to make scarce resources available to those whom they might benefit are today more important incentives for the use of brain-based criteria when traditional criteria for determining death cannot be applied.

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## Questionnaire for Record Review at Centers 1–4

Hospital \_\_\_\_\_ Abstracter \_\_\_\_\_

Subject Number \_\_\_\_\_

### Part I

1. **Date of Birth:** \_\_\_\_\_

2. **Sex:**    \_\_\_ female \_\_\_ male

3. **Race:** (if available)

   \_\_\_ White    \_\_\_ American Indian    \_\_\_ Hispanic    \_\_\_ Asian

   \_\_\_ Black    \_\_\_ Other, please specify \_\_\_\_\_

   \_\_\_ not reported in chart

4. **Date of Entry into Study:** \_\_\_\_\_

5. Is this the second time this patient has entered the study (i.e. did the subject first meet the entrance criteria more than 30 days previously)?

   \_\_\_ Yes (previous subject number    \_\_\_\_\_)    \_\_\_ No

6. **Score on Glasgow Coma Scale:** (see attachment)

Indicate the score at the time patient entered study. (Note entrance criteria is a maximum of 1–5–1 on the eye opening, motor response and verbal response scores respectively)

eye opening    \_\_\_    motor response    \_\_\_    verbal response    \_\_\_

7. **Brainstem Reflexes:**

Indicate whether the following brainstem reflexes were present or absent at the time the patient met the entrance criteria. If the information is not available in the chart, check “unknown.”

	Present	Absent	Unknown
a) pupillary	___	___	___
b) corneal	___	___	___
c) doll's eye movement	___	___	___
d) calorics	___	___	___
e) spontaneous respirations	___	___	___
f) other: Please specify			

\_\_\_\_\_

\_\_\_\_\_

8. **Etiology of Coma:** (Mark most appropriate response)

   \_\_\_ cardio respiratory (e.g., cardiac arrest, hypovolemic shock)

   \_\_\_ subarachnoid hemorrhage

   \_\_\_ cerebrovascular

   \_\_\_ hepatic

   \_\_\_ metabolic

   \_\_\_ CNS infection

   \_\_\_ drugs

\_\_\_ trauma

\_\_\_ other: Please specify \_\_\_\_\_

Describe any unusual circumstances

\_\_\_\_\_

\_\_\_\_\_

9. **Last Date of 30-day Follow-up Period** (i. e. date 30 days after date entered in question 4): \_\_\_\_\_

10. **Readmission to Participating Hospital During Follow-up Period:**

Complete this question only if the subject was discharged *and* readmitted to the participating hospital (whether or not they again meet the entrance criteria) during the 30-day follow-up period.

a) date of discharge: \_\_\_\_\_

b) date of readmission: \_\_\_\_\_

c) was readmission related to condition leading to entry into the study?

\_\_\_ yes \_\_\_ no

Please explain \_\_\_\_\_

\_\_\_\_\_

11. **Brain Functions**

a) Does the chart report that the patient satisfied criteria for "brain death"?

\_\_\_ Yes \_\_\_ No

b) If yes, describe the criteria used \_\_\_\_\_

\_\_\_\_\_

c) In your opinion, did the patient satisfy criteria for brain death?

\_\_\_yes \_\_\_ no \_\_\_ unable to determine from chart because

\_\_\_\_\_

d) If you answered "yes" to c), explain the basis of your answer, including the criteria you are using and the relevant findings on the patient.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

12. **Donor Status**

Was the patient a kidney donor? \_\_\_ Yes \_\_\_ No

\_\_\_ Unable to determine from chart

If no, was the patient considered for donation and rejected?

\_\_\_ Yes \_\_\_ No

If rejected, explain \_\_\_\_\_

\_\_\_\_\_

**Part II: Outcome****A. Death in Hospital**

(Complete Section A only if the record reveals that subject died within the 30-day follow-up period)

1. **Date of Death:** \_\_\_\_\_

2. Death was declared based on

\_\_\_ brain criteria

\_\_\_ cardiopulmonary criteria

\_\_\_ unable to determine because \_\_\_\_\_

3. If the chart reports that there was a determination that the patient was "brain dead", (i.e. you answered "yes" to 11a)

a) how much time elapsed between the determination of "brain death" by the attending physician (after any confirmatory period) and the declaration of death \_\_\_\_\_

b) describe the management from the time the physician determined that the patient met brain death criteria and the patient was declared dead

4. If, in your opinion, the patient was "brain dead" although not noted in the chart or met criteria at a time other than that identified in the chart

a) how much time elapsed between the time the patient met your criteria for "brain death" and death was declared \_\_\_\_\_

b) describe the management from the time the patient met your criteria and the patient was declared dead

**B. Discharged**

(Complete this section only if the subject was discharged during the 30-day follow-up)

1. **Date of Discharge from Hospital:** \_\_\_\_\_

2. **Functional Status:**

**Prior to this Hospitalization:**      **On discharge:**

Persistent Vegetative State

\_\_\_

\_\_\_

Severe Disability:  
dependent on others for all  
activities of daily living  
(ADL)

Moderate Disability:  
dependent on others for  
some ADL

\_\_\_

\_\_\_

Mild Disability: residual damages but independent ADL	_____	_____
Normal Function	_____	_____
Not Reported in Chart	_____	_____
<b>3. Living Condition:</b>	<b>Prior to this Hospitalization:</b>	<b>Discharged to:</b>
Other hospital	_____	_____
Custodial facility	_____	_____
Rehabilitation facility	_____	_____
Home or other non-institu- tional setting	_____	_____
Not reported on chart	_____	_____

**C. Hospitalized**

(Complete this section only if the subject was in the hospital 30 days after entering the study).

**1. 30-day and Last Reported Outcome**

Indicate the 30-day outcome and last reported outcome.

	<b>30 day outcome</b>	<b>Last reported outcome</b>
Death	N.A.	_____
Persistent Vegetative State	_____	_____
Severe Disability (dependent on others for all ADL)	_____	_____
Moderate Disability (dependent on others for some ADL)	_____	_____
Mild Disability (residual damages but independent ADL)	_____	_____
Good Recovery	_____	_____
Not Reported in Chart	_____	_____
Date of chart note on which 30-day outcome based	_____	
Date of last reported outcome	_____	

In the space below, please provide any additional explanations or comments about responses in Part I or Part II.

## Format for Data Transmission—From Computerized Data Sets at Centers A-C

### Simultaneous Criteria for Inclusion:

Motor response no better than localizing (i.e., less than or equal to 5)  
and Eye opening of none to any stimulus (i.e. score of 1)  
and on ventilator.

### Provide the Following in this Order:

Columns	Information	Codes
1-4	Ident. Number	
5	Hospital	1= 2= 3=
6-7	Age	
8	Sex	1=Male, 2=Female
9-14	Date qualifies	Month (2 digits), Day * (2 digits), Year (2 digits)
15	Period after coma onset for qualification <sup>t</sup>	Period * *
16	Qualifying motor score	1=none, 2=extensor, 3=flexor, 4=withdrawal, 5=localizing
17	Corresponding verbal score	1=none, 2=sounds, 3=words, 4=phrases, 5=oriented, 9=intubated
18	Actual 1 month outcome	1=dead, 2=vegetative, 3=severe disab, 4=mob disab, 5=gd rec
19	Actual 6 month outcome	as for 18
20	Cause of coma	1=hyp-isch, 2=subarach, 3=other cerebrovasc, 4=hepatic, 5=misc, 6=drug, 7=trauma
21	Best pupillary reactivity at time of qualification	1=absent, 2=present, 9=unk
22	Best corneal reflex at time of qualification	1=absent, 2=present, 9=unk
23	Best oculovestibular response at time of qualification	1=absent, 2=present, 9=unk
24	Best oculocephalic response at time of qualification	1=absent, 2=present, 9=unk
25	Spontaneous eye movements at time of qualification	1=absent, 2=present, 9=unk
26-29	Best pupils, corneals, oculocephalics, spontaneous eye movements, and motor responses all unreactive or any reactive at onset, 1, 3, 7 days * * *	1 = all absent, 2=any present, 9=unk
30-33	Oculovestibulars at onset, 1, 3, 7 days	1 =absent, 2=present, 9=unk
34	Time to death	Period * *
35-38	Ventilator used at adm, 1, 3, 7 days	1=no, 2=yes, 9=unk



39-42	Steroid used at adm, I, 3, 7 days	1=no, 2=yes, 9=unk
43	Brain dead in chart	1=no, 2=yes, 9=unk
44	Kidney donor	1=no, 2=yes, 9=unk
45	EEG	1=isoelectric, 2=abnormal, 3=normal, 9=unk
<b>Columns</b>	<b>Information</b>	<b>Codes</b>
46-50	Worst pupils, corneals, oculocephalics, spontaneous eye movements and motor responses all unreactive or any reactive at onset, I, 3, 7 days * * *	1=all absent, 2=any present, 9=unk
51	Outcome at discharge from hospital	1=vegetative, 2=severe disability, 3=moderate disability, 4=good recovery
52	Time from onset until discharge from rcu (specify categories you have)	
53	Time from onset until discharge from hospital (specify categories you have)	
54	Death declared by	1 = brain-based criteria 2 = cardiopulmonary criteria 3=unknown,9=not dead

\*Omit if unknown

"qualifies" refers to meeting entrance criteria

\*\*O=adm, 1=0-24 hrs, 2=1-3 days, 3=3-7 days, 4=7-14 days,  
5=14d-1m, 6=1-3 m, 7=3-6ni, 8=6-12m

\* \* \*This reflects best/worst reactivity during intervals: onset-1 day; 1-3 days; 3-7 days.



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# Statutes on the Determination of Death

# C

## I. ANALYSIS OF STATUTES

### A. Degree of Uniformity

Prior to the recommendation of the Uniform Determination of Death Act, five prototype statutes were employed by legislatures: The Kansas law adopted in 1970,<sup>11</sup> the model statute prepared by A.M. Capron and L.R. Kass in 1972,<sup>12</sup> the proposal put forward in 1975 by the American Bar Association,<sup>13</sup> the Uniform Brain Death Act, recommended in 1978 by the National Conference on Commissioners on Uniform State Laws,<sup>14</sup> and the American Medical Association's 1979 proposal.<sup>15</sup> Of the 25 statutes adopted prior to 1981 that are still on the books,<sup>16</sup> 18 were based on the first four models (no state having directly followed the AMA proposal). But in many instances the statutes as enacted depart in significant ways from the prototypes; in addition to the seven states with original legislation not cut to any of the model patterns, almost all of the other 18 contain some verbal variations (from minor to major). Thus, if anything, the patch-

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<sup>11</sup> Kan. Stat. Ann. ' 77-202 (Cum. Supp. 1979).

<sup>12</sup> Alexander M. Capron and Leon R. Kass, "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal," 121 *U. Pa. L. Rev.* 87 (1972), as modified in Alexander M. Capron, "Legal Definition of Death," 315 *Ann. N.Y.Acad. Sci.* 349, 356 (1978).

<sup>13</sup> 100 *A.B.A. Ann. Report* 231-232 (February 1975 Midyear Meeting).

<sup>14</sup> 12 *Uniform Laws* 5 (Supp. 1980).

<sup>15</sup> 243 *J.A.M.A.* 420 (1980) (editorial).

<sup>16</sup> More than 25 statutes were actually adopted prior to 1981 on the determination of death, since several states (e.g., Idaho, North Carolina and West Virginia) have replaced one statute with another.

work appearance of the map in the Report (Figure 3 at page 65) *overstates* the degree of uniformity achieved thus far.

The prospects for true uniformity are not as bleak as this picture might suggest, however. In the first place, the state adoptions seem to come in groups. For several years immediately after the first statute was adopted in Kansas in 1970,<sup>17</sup> other legislatures used that law as their starting point: Maryland in 1972,<sup>18</sup> and New Mexico and Virginia in 1973.<sup>19</sup> Similarly, four of the five states that now have on their books a statute resembling the ABA proposal acted between 1974 and 1976; the fifth, Wyoming, adopted its law in 1979.<sup>20</sup> The two adoptions of the Uniform Brain Death Act came in 1979 and 1980,<sup>21</sup> and both states that have thus far accepted the Uniform Determination of Death Act did so within a few months time in 1981.<sup>22</sup> Second, several states that had enacted statutes, then amended those statutes when "uniform" proposals were put forward.<sup>23</sup> It is reasonable to expect that legislators in the twenty-five states that have accepted the brain-based standard as at least one basis for declaring death would be amenable to adopting the Uniform Determination of Death Act, which recognizes the brain-based standard in the context of a uniform law that also incorporates the cardiopulmonary standard.

Finally, the greatest impediment to uniformity has been the multiplicity of proposals. Nonstandard laws accounted for nearly a third of the total number of 25 state statutes prior to the recent adoption by two states of the new law recommended in the Commission's Report. The increasing number of "models" seems to have caused a flood rather than an ebb in the tide of idiosyncratic bills. Five of the seven nonstandard statutes were enacted since 1977. Moreover, in the absence of a single, uniform proposal, the states turned increasingly to nonstandard statutes; the five adopted in 1977-80 represent nearly half of all the statutes adopted (other than "Uniform" proposals) during this period.

## **B. Scope of Statutes**

**1. Single or Multiple Bases for Diagnosis:** All of the enacted statutes depart from the common law rule that death

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<sup>17</sup> Kan. Stat. Ann. ' 77-202 (Cum. Supp. 1979).

<sup>18</sup> Md. Code Ann., Art. 43, ' 54F (1972).

<sup>19</sup> N.M. Stat. Ann. ' 12-2-4 (1978); Va. Code ' 54.325.7 (1979).

<sup>20</sup> Wyo. Stat. ' 35-19-101 (Cum. Supp. 1979).

<sup>21</sup> Nev. Rev. Stat. ' 451.007 (1979); W. Va. Code ' 16.10-1 (Supp. 1980).

<sup>22</sup> Colo. Rev. Stat. ' 12-36-136 (1981); Idaho Code ' 54-1819 (Cum. Supp. 1981).

<sup>23</sup> Idaho Code ' 54-1819 (Cum. Supp. 1981).

occurs only when blood flow and breathing have ceased. The statutes divide, however, into several groups regarding the grounds for determining death that they *do* recognize. One third of the 27 laws presently in force articulate a single, brain-based standard for determining death; they are silent on the relationship between this statutory, neurological "definition" and the common law, cardiopulmonary "definition."

In contrast are the laws of 13 states which explicitly provide for determinations of death by either the newer, neurological standards or the traditional, cardiopulmonary standards. (In some instances the statute spells out the relationships between the two standards, in others it is left to readers to deduce the relationship.)

Halfway between these poles are the statutes in four states that specify cessation of brain functions as a standard for determining death but also accept other, *unspecified* criteria. Rather than being a happy medium, this approach contains the worst of both worlds. On the one hand, it seems intended to recognize that the diagnosis of death in most cases will not be made by physicians directly measuring brain functions. But the means chosen by these statutory drafters to go beyond the single, neurological standard creates an impression that there may be any number of phenomena called death, of which "brain death" is only one. The statutes open up the grounds for determining death to an unspecified range of medical (or even nonmedical) criteria; the Connecticut statute, for example, recognizes brain-based criteria "[w]ithout limiting any other method of determining death."<sup>24</sup> On the other hand, these statutes lack the elegance of the single-standard statutes. The additional, vaguer language was plainly added (sometimes, as in the first of these statutes to be adopted, in California,<sup>25</sup> through legislative amendment to a bill containing only the single, brain-based standard) out of a recognition that death is diagnosed in most cases through cardiopulmonary tests rather than those that are typically thought of as tests of brain functions. But it replaces the elegance of a "brain only" standard (which rests on the equation of an absence of spontaneous respiratory and circulatory functions with a lack of brain functions) with an open-ended recognition of standards of no specified relationship to "brain death." Finally, the statute adopted in Oregon<sup>26</sup> carries the process of expansion one step further. It recognizes irreversible cessation *both* of respiratory/circulatory functions

<sup>24</sup> Conn. Gen. Stat. Ann. ' 19-139i (West. Cum. Supp. 1981).

<sup>25</sup> Cal. Health & Safety Code ' ' 7180-7182 (Deering Supp. 1980).

<sup>26</sup> Or. Rev. Stat. ' 146.087 (1977).

and of brain function. But, in addition, it also accepts without limitation "criteria customarily used by a person to determine death."

The proposed Uniform Determination of Death Act specifies both cardiopulmonary and brain standards as alternative bases for declaring death. These standards exhaust the grounds for such a determination and no unspecified, open-ended language is needed or employed.

**2. "Whole" versus "Higher" Brain:** The statutes' diversity in accepting one or more standards is matched by the range of wording used to describe the brain standard. All the laws were apparently intended to cover only loss of functioning in the whole brain, not merely in a part. This is clearly expressed in about half the states, in terms that vary somewhat, including "total and irreversible cessation of brain function" (2 states), "irreversible cessation of total brain function" (6 states), "irreversible cessation of all functioning of the brain" (1 state), and "irreversible cessation of the functioning of the entire brain, including the brain stem" (2 states). Some of the statutes state merely "no spontaneous brain function" or "an irreversible cessation of brain function," which by their failure explicitly to *exclude* some parts of the brain imply cessation of functioning in the entire organ. A few of these statutes make this requirement more explicit by linking loss of brain functioning with other signs. Virginia's statute, for example, speaks of "the absence of spontaneous brain functions and spontaneous respiratory functions."<sup>27</sup> Spontaneous respiration does not occur in the absence of a functioning brain stem.

The Uniform Determination of Death Act is explicit on this point: it requires irreversible cessation of *all* functions of the *entire* brain, *including the brain stem*.

**3. Functions:** Despite these elements of diversity in their explicit scope, the enacted statutes have one important point in common: they all provide *standards* for determining whether death has occurred, not the medical criteria or tests for diagnosing whether such standards have been met, and they do so by speaking of the "functions" (or "functioning") of organ systems, not in terms of any cellular *activity* occurring within those organs. The Uniform Determination of Death Act continues this pattern.

### C. Applicability

**1. Purpose:** About half the statutes include some language intended to frame their purpose: for example, "a person is considered medically and legally dead" (4 states), or "for legal and medical purposes" (3 states), or simply "for all legal purposes" (4 states). None of these except for the

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<sup>27</sup> Va. Code § 54.325.7 (Cum. Supp. 1981).



two statutes that are amendments to the Uniform Anatomical Gift Act, those of Florida<sup>28</sup> ("for purposes of the Act") and Connecticut (which speaks only of potential organ "donors" and not of general "individuals"), seems intended to limit the normal application of the statute.<sup>29</sup>

The other states avoided possible confusion by not stating a "purpose" for a law intended to be generally applied. The Uniform Determination of Death Act likewise contains no such statement of "purposes" or range of application. It applies to all determinations of death.

**2. Definition versus Permission:** Only a few of the statutes are actually written as "definitions" in the usual sense. The Oklahoma statute is perhaps the best example. It begins straightforwardly: "The term 'dead body' means a human body in which there is irreversible total cessation of brain function."<sup>30</sup> Most of the other statutes—including a few, such as those of New Mexico<sup>31</sup> and Iowa<sup>32</sup> that have the appearance of a "definition"—are actually statements of conditions which, when found upon physical examination to be met, establish that an individual has died.

It is important to note, however, that with only a few exceptions the statutes are declaratory and not merely permissive. That is, they establish that an individual who has lost X functions irreversibly (alternatively, one who has lost X or Y functions irreversibly) has died. Several of the nonstandard statutes, however, announce that "a person may be pronounced dead" (Georgia),<sup>33</sup> that "brain death. . . may be used as a sole basis for the determination that a person has died" (North Carolina),<sup>34</sup> or that "a physician... may make such a determination 'if [X] exists" (Oregon).<sup>35</sup> These statutes are responsive to medical needs. They provide a way out of the dilemma created for physicians and families who wish to use vigorous resuscitative measures while also seeing the need to be able to pronounce death when these artificial means produce breathing and blood flow but the individual has lost all brain functions and hence all ability to regain *spontaneous* respiration. But the statutes do not fulfill the need for legal certainty about an individual's *status*, since they make the determination of death permissive.

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<sup>28</sup> Fla. Stat. ' 382.085 (1980).

<sup>29</sup> Conn. Gen. Stat. Ann. ' 19-139i (West Cum. Supp. 1981).

<sup>30</sup> Okla. Stat. Ann. tit. 63, ' 1-301(g) (West Cum. Supp. 1981).

<sup>31</sup> N.M. Stat. Ann. " 12-2-4 and 5 (1978).

<sup>32</sup> Iowa Code Ann. ' 702.8 (West 1980).

<sup>33</sup> Ga. Code Ann. ' 88.1715.1 (Cum. Supp. 1980) (emphasis added).

<sup>34</sup> N.C. Gen. Stat. ' 90-323 (Cum. Supp. 1979) (emphasis added).

<sup>35</sup> Or. Rev. Stat. ' 146.087 (1977) (emphasis added).

The Uniform Determination of Death Act avoids this pitfall. It sets forth alternative standards for determining death; when either is met, the individual *is* dead. (This also avoids the awkwardness of many existing statutes which state that a person "*will be considered dead.*") In most instances, such a determination would be accompanied by an explicit declaration of death by a physician or other qualified observer. But when such a contemporaneous determination is for some reason impossible, not undertaken or actually withheld, the determination could be made after the fact (for example, in a legal proceeding where the time of a particular death is a matter of importance) based upon all the evidence, including the medical records and any postmortem examination.

#### **D. Miscellaneous**

**1. Standard for Action:** Four variations appeared in the model bills to describe the basis on which the criteria and tests used to diagnose death are to be selected and employed. The enacted statutes are almost evenly divided between "ordinary standards of medical practice" and "usual and customary standards of medical practice." These two formulae appear to be synonymous.

Several states require "reasonable medical standards," which is the formula of the Uniform Brain Death Act. Florida blends this with the notion of acceptability and expects determinations to "be made in accordance with currently accepted reasonable medical standards."<sup>36</sup> The Florida provision highlights the problem with "reasonableness" in this context. The latter standard invites lay (jury) evaluation after-the-fact and for this reason it is seldom used in judging the performance of professionals. Instead, the competence of professionals is usually measured by whether they came within the boundaries of the theories and practices accepted by their professional groups.

The Uniform Determination of Death Act requires that determinations of death be based upon "accepted medical standards." Idaho, one of the first two states to adopt the new statute, defined accepted medical standards as "the usual and customary procedures of the community in which the determination of death is made."<sup>37</sup>

**2. Authority to Act:** Most of the existing statutes are framed in terms of a determination by a "medical doctor" or "physician." The Uniform Determination of Death Act does not explicitly require a physician because in some instances (for example, in the case of a death occurring in a remote area) actions may have to be taken based upon a lay deter-

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<sup>36</sup> Fla. Stat. ' 382.085 (1980).

<sup>37</sup> Idaho Code ' 54-1819 (Cum. Supp. 1981).

mination that breathing and heartbeat have ceased and cannot be revived. Protection against inappropriate action by a lay person under the statute arises from the requirement mentioned above, that all determinations "must be made in accordance with accepted medical standards." Such standards would not countenance a nonphysician diagnosing that all functions of the entire brain had ceased irreversibly for an individual with respirator-supported cardiopulmonary functions but lacking consciousness.

Similarly, the Uniform Determination of Death Act leaves to current medical standards to establish the number and specialized expertise of the physicians who should perform any particular tests. Some of the existing statutes—particularly those that pay direct attention to organ transplantation—specify that *two* physicians must participate in determining death under the brain-based standard. Some even specify the physician's professional qualifications (e.g., Florida: "board-eligible or board-certified neurologist, neurosurgeon, internist, pediatrician, surgeon, or anesthesiologist,"<sup>38</sup> and Virginia: "a consulting physician, who shall be duly licensed and a specialist in the field of neurology, neurosurgery, or electroencephalography"<sup>39</sup>). The protection against conflict of interest—that a physician diagnosing death ought not to participate in the transplantation of organs from the deceased—is spelled out in several statutes.<sup>40</sup> Such provisions are duplicative of § 7(b) of the Uniform Anatomical Gift Act, which has been adopted in all jurisdictions in the United States.<sup>41</sup>

**3. Personal Beliefs:** None of the existing statutes provide for a "conscience clause" for individuals or their families to "opt out" of the law's provisions. This absence is not surprising in a law intended to establish every individual's status in society (as "alive" or "dead"). The Florida statute does provide, however, for notification of the deceased's next of kin "as soon as practicable of the procedures [used] to determine death" and for the recording in the medical record of such notice or "the attempts to identify and notify the next of kin."<sup>42</sup> This provision seems intended to avoid or reduce misunderstanding. The need for such a provision is not immediately apparent if physicians are following ac-

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<sup>38</sup> Fla. Stat. ' 382.085 (1980).

<sup>39</sup> Va. Code ' 54.325 (Cum. Supp. 1981).

<sup>40</sup> See e.g. Cal. Health & Safety Code ' ' 7180-7182 (Deering Supp. 1980); Hawaii Rev. Stat. ' 327C-1 (Supp. 1980).

<sup>41</sup> Uniform Anatomical Gift Act, see 8 *Uniform Laws Annat.* 608 (1972) at ' 7(b); Annot. 76 A.L.R. 3d 890.

<sup>42</sup> Alexander Morgan Capron, "The Development of Law on Human Death," 315 *Ann. N.Y. Acad. Sci.* 45, 52 (1978).

cepted medical procedures in dealing with patients' relatives and maintaining medical records; the provision may have resulted from a particular controversy in Florida. In any event, it does not authorize the next of kin to insist that any particular diagnostic approach be employed in preference to another; such matters are left by the statute to medical judgment.

**4. Living Will:** In a number of jurisdictions bills have been introduced that combine provisions "defining" death with those permitting the use of "living wills" or similar directives to physicians to cease treatment should a person become incompetent while suffering from a terminal illness. In North Carolina a "Natural Death Act" combining these features was adopted in 1977.<sup>43</sup> That statute was criticized as "a virtual invitation to litigation, so many are the problems and ambiguities it create[d]."<sup>44</sup> The statute was subsequently rewritten and reenacted as two separate provisions, with most of the problems in the "definition" of death section removed.<sup>45</sup>

**5. Liability:** The model statute formulated by the American Medical Association insulated from civil liability or criminal prosecution (i) any physician (or "other person authorized by law to determine death") who acted in accordance with the statute, or (ii) any person "who act[ed] in good faith reliance on [such] a determination."<sup>46</sup> Such preclusion of liability provisions appear in the statutes adopted in five states.<sup>47</sup> They are redundant of the protection already provided by the common law and by accepted rules of statutory interpretation. The Uniform Determination of Death Act does not include any preclusion of liability provisions.

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<sup>43</sup> N.C. Adv. Legis. Servo Ch. 815, ' 90-322.

<sup>44</sup> Alexander Morgan Capron, "The Development of Law on Human Death" 315 *Ann. N.Y. Acad. Sci.* 45, 52 (1978).

<sup>45</sup> N.C. Gen. Stat. ' 90-323 (Cum. Supp. 1979).

<sup>46</sup> 243 *J.A.M.A.* 420 (1980) (editorial).

<sup>47</sup> Ala. ' 22-31-4 (Cum. Supp. 1979); Conn. Gen. Stat. Ann. ' 19-139i(c) (West Cum. Supp. 1981); Fla. Stat. ' 382.085(4) (1980); Ga. ' 88-1715.1(b) (Cum. Supp. 1980); Tex. Rev. Civ. Stat. Ann. art. 447t ' 3 (Vernon Cum. Supp. 1980).

## II. MODEL LEGISLATION

### ABA

The following is the text of the model statute proposed by the American Bar Association in 1975:

For all legal purposes, a human body with irreversible cessation of total brain function, according to usual and customary standards of medical practice, shall be considered dead.

100 *A.B.A. Ann. Rprt.* 231-32 (1978) (February 1975 midyear meeting)

### AMA

The following is the amended model state determination of death bill approved at the December 1979 Interim Meeting of the American Medical Association:

IN THE GENERAL ASSEMBLY  
STATE OF \_\_\_\_\_

An Act

To Provide for Determination of Death

Be it enacted by the People of the State of  
represented in the General Assembly:

*Section 1.* An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, shall be considered dead. A determination of death shall be made in accordance with accepted medical standards.

(COMMENT: This section is intended to provide a comprehensive statement for determining death in all situations, by clarifying and codifying the common law in this regard. The two bases set forth in the statute are the only medically accepted bases for determining death, and the statute is therefore all inclusive. "All functions" of the brain means that purposeful activity of the brain, as distinguished from random activity in the brain, has ceased. "Entire brain" includes both the brain stem and the neocortex and is meant to distinguish the concept of neocortical death, which is not a valid medical basis for determining death.

It is recognized that physicians may determine death. It is also recognized that in some jurisdictions

non-physicians i.e. coroners) are empowered to determine death. It is the intent of this bill to recognize that under accepted medical standards a determination of death based on irreversible cessation of brain function may be made only by a physician.)

*Section 2.* A physician or any other person authorized by law to determine death who makes such determination in accordance with Section 1 is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his acts or the acts of others based on that determination.

*Section 3.* Any person who acts in good faith in reliance on a determination of death is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act.

(COMMENT: While Section 1 is intended to remove legal impediments relating to a declaration of death based on medically accepted principles, sections two and three are intended to remove inhibitions from making a declaration of death based on either of the two standards and also to remove inhibitions of hospital personnel from carrying out the direction of a physician in this regard by removing the threat of liability. These sections do not absolve from liability a person who acts negligently or contrary to accepted medical standards.)

*Section 4.* If any provision of this Act is held by a court to be invalid such invalidity shall not affect the remaining provisions of the Act, and to this end the provisions of this Act are hereby declared to be severable.

### **Capron-Kass**

The following is the modified text of a model bill proposed in 1972 by Professor Alexander M. Capron and Dr. Leon Kass in an article in Volume 121 of the *University of Pennsylvania Law Review* at pages 87-118:

A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an irreversible cessation of respiratory and circulatory functions, or in the event that artificial means of support preclude a determination that these functions have ceased, he has experienced an irreversible cessation of total brain functions. Death will have occurred at the time when the relevant functions ceased.

A.M. Capron, "Legal Definition of Death," 315 *Ann. N.Y. Acad. Sci.* 349, 356 (1978).

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## Uniform Brain Death Act

The following is a proposal approved and recommended for enactment by the National Conference of Commissioners on Uniform State Laws at its Annual Conference on July 28-August 4, 1978:

*Section 1. [Brain Death.]* For legal and medical purposes, an individual who has sustained irreversible cessation of all functioning of the brain, including the brain stem, is dead. A determination under this section must be made in accordance with reasonable medical standards.

### Comment

This section legislates the concept of brain death. The Act does not preclude a determination of death under other legal or medical criteria, including the traditional criteria of cessation of respiration and circulation. Other criteria are practical in cases where artificial life-support systems are not utilized. Even those criteria are indicative of brain death.

"Functioning" is a critical word in the Act. It expresses the idea of *purposeful* activity in all parts of the brain, as distinguished from random activity. In a dead brain, some meaningless cellular processes, detectable by sensitive monitoring equipment, could create legal confusion if the word "activity" were substituted for "functioning."

*Section 2. [Short Title.]* This Act may be cited as the Uniform Brain Death Act.

## Uniform Determination of Death Act

The following is the text of the statute approved by the National Conference of Commissioners on Uniform State Laws at its Annual Conference on July 26-August 1, 1980, by the American Medical Association on October 19, 1980, by the President's Commission on November 7, 1980, and by the American Bar Association on February 10, 1981 to supersede the existing "model" bills:

*Section 1. [Determination of Death.]* An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

*Section 2. [Uniformity of Construction and Application.]* This Act shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this Act among states enacting it.

*Section 3. [Short Title.]* This Act may be cited as the Uniform Determination of Death Act.



### **III: STATE LEGISLATION ADOPTED 1970-1981**

#### **Alabama**

##### **§ 22-31-1. Standards and procedures for determination of death generally.**

(a) A person is considered medically and legally dead if, in the opinion of a medical doctor licensed in Alabama, based on usual and customary standards of medical practice, in the community, there is no spontaneous respiratory or cardiac function and there is no expectation of recovery of spontaneous respiratory or cardiac function.

(b) In the case when respiratory and cardiac function are maintained by artificial means, a person is considered medically and legally dead if, in the opinion of a medical doctor licensed in Alabama, based on usual and customary standards of medical practice in the community for the determination by objective neurological testing of total and irreversible cessation of brain function, there is total and irreversible cessation of brain function. Death may be pronounced in this circumstance before artificial means of maintaining respiratory and cardiac function are terminated. In the case described in this subsection, there shall be independent confirmation of the death by another medical doctor licensed in Alabama. (Acts 1979, No. 79-165, § 1.)

##### **§ 22-31-2. Use of other methods.**

Nothing in this chapter shall prohibit a physician from using other procedures based on usual and customary standards of medical practice for determining death as the exclusive basis for pronouncing a person dead. (Acts 1979, No. 79-165, §1.)

##### **§ 22-31-3. Procedure where part of body to be used for transplantation**

(a) When a part of a donor is proposed to be used for transplantation pursuant to article 3 of chapter 19 of this title and the death of the donor is determined as set forth in section 22-31-1, there shall be an independent confirmation of the death by another medical doctor licensed in Alabama. Neither the physician making the determination of death nor the physician making the independent confirmation shall participate in the procedures for removing or transplanting a part.

(b) When a part of a donor is proposed to be used for transplantation pursuant to article 3 of chapter 19 of this title and the death of the donor is determined as set forth in

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section 22-31-1, complete patient medical records shall be kept, maintained and preserved. (Act 1979, No. 79-165, §§3,4.)

§ 22-31-4. Liability for acts.

A person who acts in accordance with the terms of this chapter is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act. (Acts 1979, No. 79-165, § 5.)

Ala. Code § § 22-31-1 through 22-31-4 (Cum. Supp. 1979)  
(Effective June 5, 1979).

## **Alaska**

Sec. 09.65.120. Definition of death. A person is considered medically and legally dead if, in the opinion of a medical doctor licensed or exempt from licensing under AS 08.64, based on ordinary standards of medical practice, there is no spontaneous respiratory or cardiac function and there is no expectation of recovery of spontaneous respiratory or cardiac function or, in the case when respiratory and cardiac functions are maintained by artificial means, a person h. considered medically and legally dead, if, in the opinion of a medical doctor licensed or exempt from licensing under AS 08.64, based on ordinary standards of medical practice, there is no spontaneous brain function. Death may be pronounced in this circumstance before artificial means of maintaining respiratory and cardiac function are terminated. (§ 1 ch 8 SLA 1974)

Alaska Stat. § 09.65.120 (Cum. Supp. 1980)

## **Arkansas**

82-537. Death defined. -A person is legally dead when the brain has irreversibly ceased to function and there is an absence of spontaneous breath. [Acts. 1979, No. 99, § 1]

82-538. Standard of medical practice. -The diagnosis of death as defined in this ACT [§ § 82-537, 82-538] shall be made using ordinary standards of medical practice. [Acts 1979, No. 99, § 2]

Ark. Stat. Ann. §§ 82-537-82-538 (Cum. Supp. 1981) (Effective February 11, 1979)

## **California**

§7180. Pronouncement on determining cessation of brain  
function: Confirmation: Other procedures.

A person shall be pronounced dead if it is determined by a physician that the person has suffered a total and irreversible cessation of brain function. There shall be independent confirmation of the death by another physician.

Nothing in this chapter shall prohibit a physician from using other usual and customary procedures for determining death as the exclusive basis for pronouncing a person dead.

§ 7181. Confirmation in event of transplantation under Uniform Anatomical Gift Act: Restriction on physician's participation in removal and transplantation.

When a part of the donor is used for direct transplantation pursuant to the Uniform Anatomical Gift Act (Chapter 3.5, commencing with Section 7150) and the death of the donor is determined by determining that the person has suffered a total and irreversible cessation of brain function there shall be an independent confirmation of the death by another physician. Neither the physician making the determination of death under Section 7155.5 nor the physician making the independent confirmation shall participate in the procedures for removing or transplanting a part.

§ 7182. Patient medical records.

Complete patient medical records required of a health facility pursuant to regulations adopted by the department in accordance with Section 1275 shall be kept, maintained, and preserved with respect to the requirements of this chapter when a person is pronounced dead by determining that the person has suffered a total and irreversible cessation of brain function.

Cal. Health & Safety Code § § 7180-7182 (Deering Supp. 1980)

(Added Stats. 1974 ch 1524 § 1, effective September 27, 1974).

## **Colorado**

12-36-136. Determination of death.

(1) An individual is dead if:

(a) He has sustained irreversible cessation of circulatory and respiratory function; or

(b) He has sustained irreversible cessation of all functions of the entire brain, including the brain stem.

(2) A determination of death under this section shall be in accordance with accepted medical standards.

SECTION 2. *Safety clause.* The general assembly hereby finds, determines, and declares that this act is necessary for the immediate preservation of the public peace, health, and safety.

Colo. Rev. Stat. § 12-36-136 (1981).

(Approved May 21, 1981)

**Connecticut**

§ 19-139i. Acceptance and rejection of gift. Determination of time of death. Civil and criminal liability. Approved by medical examiner or coroner.

(b) The time of death shall be determined by two physicians who attend the donor at his death, or if none, two physicians who certify death, who shall use generally recognized and accepted scientific and clinical means to determine such time of death. Without limiting any other method of determining death, a donor may be pronounced dead if two physicians determine, in accordance with the usual and customary standards of medical practice, that the donor has suffered a total and irreversible cessation of all brain function. A total and irreversible cessation of all brain function shall mean that the heart and lungs of the donor cannot function, and are not functioning, without artificial supportive measures. The physicians who so certify shall not participate in the procedures for removing or transplanting a part. No organ shall be removed for transplantation until death has been pronounced.

(c) A person who acts in good faith in accordance with the terms of sections 19-139a and 19-139c to 19-139j, inclusive, shall not be liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act.

Conn. Gen. Stat. Ann. § 19-139i (West Cum. Supp. 1981) (1979, P.A. 79-556 amended subsec. (b) by inserting the second, third and fifth sentences.)

**Florida**

§ 382.085. Recognition of brain death under certain circumstances

(1) For legal and medical purposes, where respiratory and circulatory functions are maintained by artificial means of support so as to preclude a determination that these functions have ceased, the occurrence of death may be determined where there is the irreversible cessation of the functioning of the entire brain, including the brain stem, determined in accordance with this section.

(2) Determination of death pursuant to this section shall be made in accordance with currently accepted reasonable medical standards by two physicians licensed under chapter 458 or chapter 459. One physician shall be the treating physician, and the other physician shall be a board-eligible or board-certified neurologist, neurosurgeon, internist, pediatrician, surgeon, or anesthesiologist.

(3) The next of kin of the patient shall be notified as soon as practicable of the procedures to determine death under this section. The medical records shall reflect such notice; if such notice has not been given, the medical records shall reflect the attempts to identify and notify the next of kin.

(4) No recovery shall be allowed nor shall criminal proceedings be instituted in any court in this state against a physician or licensed medical facility that makes a determination of death in accordance with this section or which act in reliance thereon, if such determination is made in accordance with the accepted standard of care for such physician or facility set forth in s. 768.45. Except for a diagnosis of brain death, the standard set forth in this section is not the exclusive standard for determining death or for the withdrawal of life-support systems. (Added by Laws 1980, c. 80-216, § 1)

Fla. Stat. § 382.085 (1980).  
(Effective October 1, 1980).

## **Georgia**

### §88-1715.1 Determination of death

(a) A person may be pronounced dead if it is determined that the person has suffered an irreversible cessation of brain function. There shall be independent confirmation of the death by another physician.

(b) A person who acts in good faith in accordance with the provisions of subsection (a) shall not be liable for damages in any civil action or subject to prosecution in any criminal proceeding for such act.

(c) The criteria for determining death authorized in subsection (a) shall be cumulative to and shall not prohibit the use of other medically recognized criteria for determining death.

(Acts 1975. p. 1629)

Ga. Code Ann. § 88-1715.1 (Cum. Supp. 1980)  
(Adopted April 28, 1975)

## **Hawaii**

### § 327C-1. Determination of Death.

(a) Except as provided in subsection (b) of this section, a person shall be considered dead if in the announced opinion of a physician licensed under chapter 453, based on ordinary standards of current medical practice the person has

experienced irreversible cessation of spontaneous respiratory and circulatory functions. Death will have occurred at the time when the irreversible cessation of the functions first coincided.

(b) In the event that artificial means of support preclude a determination that respiratory and circulatory functions have ceased, a person shall be considered dead if, in the opinion of an attending physician licensed under chapter 453, and of a consulting physician licensed under chapter 453, based on ordinary standards of current medical practice, the person has experienced irreversible cessation of brain function. The opinions of the physicians shall be evidenced by signed statements. Death will have occurred at the time when the irreversible cessation of brain function first occurred. Death shall be pronounced before artificial means of support are withdrawn and before any vital organ is removed for purposes of transplantation.

(c) When a part of a donor is used for direct organ transplantation under chapter 327, and the donor's death is established by determining that the donor experienced irreversible cessation of brain function, the determination shall only be made under subsection (b) of this section. The physicians making the determination of death shall not participate in the procedures for removing or transplanting a part, or in the care of any recipient.

(d) All death determinations in the State shall be made pursuant to this section and shall apply to all purposes, including but not limited to civil and criminal actions, any laws to the contrary notwithstanding, provided that presumptive deaths under the Uniform Probate Code shall not be affected by this section.

(e) The director of health shall convene in every odd-numbered year, a committee which shall be composed of representatives of appropriate general and specialized medical professional organizations, licensed attorneys, and members of the public. The committee shall review medical practice, legal developments, and other appropriate matters to determine the continuing viability of this section and shall submit a report of its findings and recommendations to the legislature, prior to the convening of the regular session held in each even-numbered year. [1978, c 248, § 1; am L 1979, C 193; § 1]

Hawaii Rev. Stat. § 327 C-1 (Supp. 1980)

(L 1979 substituted "person" for "human body" in subsections (a) and (b), deleted reference to neurologist and neurosurgeon from subsection (b), and rephrased last sentence of subsection (c).)

**Idaho**

54-1819. Definition and procedure for determination of death.

(1) An individual who has sustained either (a) irreversible cessation of circulatory and respiratory functions, or (b) irreversible cessation of all functions of the entire brain, including the brain stem, is dead.

(2) A determination of death must be made in accordance with accepted medical standards which mean the usual and customary procedures of the community in which the determination of death is made. [I.C., § 54-1819, as added by 1981, ch. 258, § 2, p. 549.]

Former § 54-1819 (1977, ch. 130, § 1, p. 276) was repealed by S.L. 1981, ch. 258, § 1.

**Illinois**

§ 302 Definitions

(b) "Death" means for the purposes of the Act, the irreversible cessation of total brain function, according to usual and customary standards of medical practice.

Ill. Ann. Stat. ch. 1101/2 §302 (Smith-Hurd Cum. Supp. 1978)  
(Effective October 1, 1975)

**Iowa**

702.8 Death.

"Death" means the condition determined by the following standard: A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, that person has experienced an irreversible cessation of spontaneous respiratory and circulatory functions. In the event that artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of two physicians, based on ordinary standards of medical practice, that person has experienced an irreversible cessation of spontaneous brain functions. Death will have occurred at the time when the relevant functions ceased.

Acts 1976 (66 G.A.) ch. 1245, ch. 1 § 208

Iowa Code Ann. § 702.8 (West 1980)  
(Effective January 1, 1978)



**Kansas**

77-202. Definition of death.

A person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice, there is the absence of spontaneous respiratory and cardiac function and, because of the disease or condition which caused, directly or indirectly, these functions to cease, or because of the passage of time since these functions ceased, attempts at resuscitation are considered hopeless; and, in this event, death will have occurred at the time these functions ceased; or

A person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice, there is the absence of spontaneous brain function; and if based on ordinary standards of medical practice, during reasonable attempts to either maintain or restore spontaneous circulatory or respiratory function in the absence of aforesaid brain function, it appears that further attempts at resuscitation or supportive maintenance will not succeed, death will have occurred at the time when these conditions first coincide. Death is to be pronounced before any vital organ is removed for purposes of transplantation.

These alternative definitions of death are to be utilized for all purposes in this state, including the trials of civil and criminal cases, any laws to the contrary notwithstanding.

Kan. Stat. Ann. § 77-202 (Cum. Supp. 1979)

(K.S.A. § 77-202; L. 1979, ch. 199, § 11; July 1. Deleted the provision requiring the pronouncement of death before artificial means of supporting respiratory and circulatory functions are terminated.)

(Enacted  
1970)

**Louisiana****§111. Definition of death.**

A person will be considered dead if in the announced opinion of a physician, duly licensed in the state of Louisiana based on ordinary standards of approved medical practice, the person has experienced an irreversible cessation of spontaneous respiratory and circulatory functions. In the event that artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of a physician, duly licensed in the state of Louisiana based upon ordinary standards of approved medical practice, the person has experienced an irreversible total cessation of brain function. Death will have occurred at the time when the rel-

evant functions ceased. In any case when organs are to be used in a transplant, then an additional physician, duly licensed in the state of Louisiana not a member of the transplant team, must make the pronouncement of death.

La. Rev. Stat. Ann. § 9:111 (West Cum. Supp. 1981) (Added by Acts 1976, No. 233, §1)

### **Maryland**

§ 54F. When person considered medically and legally dead.

(a) A person will be considered medically and legally dead if, based on ordinary standards of medical practice, there is the absence of spontaneous respiratory and cardiac function and, because of the disease or condition which caused, directly or indirectly, these functions to cease, or because of the passage of time since these functions ceased, attempts at resuscitation are considered hopeless; and, in this event, death will have occurred at the time these functions ceased; or

(b) A person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice and because of a known disease or condition, there is the absence of spontaneous brain function; and if based on ordinary standards of medical practice, during reasonable attempts to either maintain or restore spontaneous circulatory or respiratory function in the absence of spontaneous brain function, it appears that further attempts at resuscitation or supportive maintenance will not succeed, death will have occurred at the time when these conditions first coincide. Death is to be pronounced before artificial means of supporting respiratory and circulatory function are terminated and before any vital organ is removed for purposes of transplantation.

(c) These alternative definitions of death are to be utilized for all purposes in this State, including the trials of civil and criminal cases, any laws to the contrary notwithstanding. (1972, ch. 693).

Md. Ann. Code art. 43, § 54F (1980)  
(Effective July 1, 1972)

### **Michigan**

§14.15(1021) Determination of death; means; time of death.

SEC. 1. A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice in the community, there is the irreversible cessation of spontaneous respiratory and circu-

latory functions. If artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice in the community, there is the irreversible cessation of spontaneous brain functions. Death will have occurred at the time when the relevant functions ceased. (MCL

§333.1021.)

§14.15(1022) Pronouncement of death before termination  
of life support systems.

SEC. 2. Death is to be pronounced before artificial means of supporting respiratory and circulatory functions are terminated. (MCL § 3333.1022.)

§14.15(1023) Means of determining death, use.

SEC. 3. The means of determining death in section 1 shall be used for all purposes in this state, including the trials of civil and criminal cases. (MCL §333.1023.)

Statutory reference. Section 8b of Act No. 343 of 1925, above referred to, is § 14.228 (2).

Mich. Stat. Ann. § 14.15 (1021 to 1024) (Cum. Supp. 1981)

## **Montana**

50-22-101. Definition of death.

A human body with irreversible cessation of total brain function as determined according to usual and customary standards of medical practice, is dead for all legal purposes.

Mont. Rev. Codes Ann. § 50-22-101 (1978)

(Enacted 69-7201 by Sec. 1, Ch. 228, L. 1977, R.C.M. 1947, 69-7201.)

(Adopted April 4, 1977)

## **Nevada**

§ 451.007. Definition of death for legal, medical purposes.

1. For legal and medical purposes, a person who has sustained irreversible cessation of all functioning of the brain, including the brain stem, is dead. A. determination under this section must be made in accordance with reasonable medical standards.

2. This section may be cited as the Uniform Brain Death Act.

Nev. Rev. Stat. § 451.007 (1979)

(Added to NRS by 1979, 226)

(Approved, April 20, 1979)

## New Mexico

### 12-2-4. Death defined.

A. For all medical, legal and statutory purposes, death of a human being occurs when, and "death," "dead body," "dead person" or any other reference to human death means that:

(1) based on ordinary standards of medical practice, there is the absence of spontaneous respiratory and cardiac function and, because of the disease or condition which caused, directly or indirectly, these functions to cease, or because of the passage of time since these functions ceased, there is no reasonable possibility of restoring respiratory or cardiac functions; in this event death occurs at the time respiratory or cardiac functions ceased; or

(2) in the opinion of a physician, based on ordinary standards of medical practice:

(a) because of a known disease or condition there is the absence of spontaneous brain function; and

(b) after reasonable attempts to either maintain or restore spontaneous circulatory or respiratory functions in the absence of spontaneous brain function, it appears that further attempts at resuscitation and supportive maintenance have no reasonable possibility of restoring spontaneous brain function; in this event death will have occurred at the time when the absence of spontaneous brain function first occurred. Death is to be pronounced pursuant to this paragraph before artificial means of supporting respiratory or circulatory functions are terminated and before any vital organ is removed for purposes of transplantation in compliance with the Uniform Anatomical Gift Act [24-6-1 to 24-6-9 NMSA 1978].

B. The alternative definitions of death in Paragraphs (1) and (2) of Subsection A of this section are to be utilized for all purposes in this state, including but not limited to civil and criminal actions, notwithstanding any other law to the contrary.

### 12-2-5. Death defined; presumptive decedents.

Presumptive decedents under Section 31-41-1 NMSA 1953 shall not be affected by this act [12-2-4, 12-2-5 NMSA 1978].

N.M. Stat. Ann. § 12-2-4 (1978)

(1953 Comp., § 1-2-2.2, enacted by Laws 1973, Ch. 168, §§ 1-22)

(Laws 1973, Ch. 168 contains no effective date provision, but was enacted at a session which adjourned on March 17, 1973.)

**North Carolina**

§ 90-323. Death; determination by physician.

The determination that a person is dead shall be made by a physician licensed to practice medicine applying ordinary and accepted standards of medical practice. Brain death, defined as irreversible cessation of total brain function, may be used as a sole basis for the determination that a person has died, particularly when brain death occurs in the presence of artificially maintained respiratory and circulatory functions. This specific recognition of brain death as a criterion of death of the person shall not preclude the use of other medically recognized criteria for determining whether and when a person has died. (1979, c. 715, s. 3.)

N.C. Gen. Stat. § 90-323 (Cum. Supp. 1979)

**Oklahoma**

§ 1-301. Definitions. As used in this article:

(g) The term "dead body" means a human body in which there is irreversible total cessation of brain function; and if, based upon ordinary standards of medical practice, during reasonable attempts to either maintain or restore spontaneous circulatory or respiratory function in the absence of aforesaid brain function, it appears that further attempts at resuscitation or supportive maintenance will not succeed, death will have occurred at the time when these conditions first coincide. Death is to be pronounced before artificial means of supporting respiratory and circulatory function are terminated and before any vital organ is removed for purposes of transplantation.

Okla. Stat. Ann. tit. 63, § 1-103 (g) (West Cum. Supp. 1981)  
(Effective April 28, 1975)

**Oregon**

146.087 Criteria for determination of death.

In addition to criteria customarily used by a person to determine death, when a physician licensed to practice medicine under ORS chapter 677 acts to determine that a person is dead, he may make such a determination if irreversible cessation of spontaneous respiration and circulatory function or irreversible cessation of spontaneous brain function exists. [1975 c. 565 § 1]

Or. Rev. Stat. § 146.087 (1977)

**Tennessee 53.459.**

Death Defined.

For all legal purposes, a human body, with irreversible cessation of total brain function, according to the usual and

customary standards of medical practice, shall be considered dead.  
[Acts 1976 (Adj. S.), ch. 780, § 1.]

Tenn. Code Ann. § 53-459 (Cum. Supp. 1980)  
(Adopted March 18, 1976)

### **Texas**

Art. 4447t. Determination of death.

Section 1. (a) A person will be considered legally dead if, based on ordinary standards of medical practice, there is the irreversible cessation of spontaneous respiratory and circulatory functions.

(b) If artificial means of support preclude a determination that spontaneous respiratory and circulatory functions have ceased, a person will be considered legally dead if in the announced opinion of a physician, based on ordinary standards of medical practice, there is the irreversible cessation of all spontaneous brain function. Death will have occurred at the time when the relevant functions ceased.

(c) Death is to be pronounced before artificial means of supporting respiratory and circulatory functions are terminated.

Section 2. A physician who determines death in accordance with the provisions of Section 1(b) of this Act is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his or her acts or the actions of others based on that determination.

Section 3. A person who acts in good faith in reliance on a determination of death by a physician is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his or her act.

Act 1979, 66th Leg., p. 368, ch. 165.

Tex. Rev. Civ. Stat. Ann. art. 4447t (Vernon Cum. Supp. 1980)  
(Effective May 15, 1979)

### **Virginia**

§ 54-325.7. When person deemed medically and legally dead.

A person shall be medically and legally dead if, (a) in the opinion of a physician duly authorized to practice medicine in this Commonwealth, based on the ordinary standards of medical practice, there is the absence of spontaneous respiratory and spontaneous cardiac functions and, because of the disease or condition which directly or indirectly caused these functions to cease, or because of the passage of time since these functions ceased, attempts at resuscitation

would not, in the opinion of such physician, be successful in restoring spontaneous life-sustaining functions, and, in such event, death shall be deemed to have occurred at the time these functions ceased; or (b) in the opinion of a consulting physician, who shall be duly licensed and a specialist in the field of neurology, neurosurgery, or electroencephalography, when based on the ordinary standards of medical practice, there is the absence of spontaneous brain functions and spontaneous respiratory functions and, in the opinion of the attending physician and such consulting physician, based on the ordinary standards of medical practice and considering the absence of spontaneous brain functions and spontaneous respiratory functions and the patient's medical record, further attempts at resuscitation or continued supportive maintenance would not be successful in restoring such spontaneous functions, and, in such event, death shall be deemed to have occurred at the time when these conditions first coincide. Death, as defined in subsection (b) hereof, shall be pronounced by the attending physician and recorded in the patient's medical record and attested by the aforesaid consulting physician.

Notwithstanding any statutory or common law to the contrary, either of these alternative definitions of death may be utilized for all purposes in the Commonwealth, including the trial of civil and criminal cases.

(Code 1950, § 32-364.3:1; 1973, c. 252; 1979, c. 720)

Va. Code § 54-325.7 (Cum. Supp. 1981)

(Effective March 13, 1973)

## **West Virginia**

### 16-19-1. Definitions.

(c) "Death" means that a person will be considered dead if in the announced opinion of the attending physician, made in accordance with reasonable medical standards, the patient has sustained irreversible cessation of all functioning of the brain.

W. Va. Code § 16-19-1 (Supp. 1980)

(Effect of amendment of 1980.- The amendment, in subsection (c), substituted the language beginning "made in accordance with reasonable medical standards" for "based on ordinary standards of medical practice, the patient has experienced an irreversible cessation of spontaneous respiratory and circulatory function; or, in the event that artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, the patient has experienced an irreversible cessation of spontaneous brain functions,"



and deleted the former second paragraph, which read: "Death will have occurred at the time when the relevant functions ceased.")

### **Wyoming**

§ 35-19-101. Brain death; determination in accordance with medical standards.

For all legal purposes, a human body, with irreversible cessation of total brain function, including the brain stem, according to the usual and customary standards of medical practice, is dead. Total brain function shall mean purposeful activity of the brain as distinguished from random activity.

(Laws 1979, ch. 101, § 1.)

Wyo. Stat. § 35-19-101 (Cum. Supp. 1979) (Effective February 22, 1979)

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# Judicial Developments in the "Definition" of Death

# D

Judicial decisions "defining" death are of three types: those that adhere to the cardiopulmonary standard, those that updated the cardiopulmonary standard prior to any legislative "modernization," and those that interpret recent statutes which include brain-based language.

## I. Traditional Rulings

The courts long ago established that "the cessation of life" was to be judged primarily by "a total stoppage of the circulation of the blood," in the words of *Black's Law Dictionary*.<sup>1</sup> *Black's* which is not usually a leading legal authority is associated with this "definition" because the dictionary language was repeated *in haec verba* in a number of judicial opinions. Indeed, this interpretation was reiterated despite the development of medical techniques that could revive respiration and circulation in a corpse. Though medical evidence was presented in litigation contradicting the old "definition," courts into the 1970's favored consistency over modernity in the law. The most recent example of this is *State v. Johnson*:

There are presently no statutory provisions in the Ohio Revised Code which define death. . . . [W]hile the present trend is toward adoption of some phase of the general "brain death" theory, most states, including Ohio, have not yet altered the traditional common law approach that death means the permanent cessation of all vital functions and the fact and time of its occurrence are questions for the jury.<sup>2</sup>

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<sup>1</sup> *Black's Law Dictionary*, (4th ed.) West Publishing Co., St. Paul, Minn., (1968) at 488, but see *Black's Law Dictionary* (5th ed.) West Publishing Co., St. Paul, Minn. (1979) at 170, which now includes an entry under the heading "brain death."

<sup>2</sup> *State v. Johnson*, 395 N.E.2d 368, 371-72 (Ohio 1977).

Nevertheless, courts of late have generally -been willing either to "update" the "definition" of death or to avoid the incongruous results that would follow from applying cardiopulmonary standards in determining death for individuals on respirator support.

## **II. Judicial Revisions of the Law**

### **A. Criminal Cases Updating the Common Law**

Opportunities to update the common law in the absence of a statutory definition have arisen in two major contexts. The first is in murder trials where defendants have maintained that the victim of their act was still "alive" when artificial life-support systems were removed. This defense has (with one reported exception at the trial level, which was thereafter reversed<sup>1</sup>) been uniformly rejected by the judiciary.<sup>2</sup> Courts have articulated three reasons for regarding the defendant as responsible for the victim's death: "proximate cause," "cause in fact," and a judicial recognition of a new standard of death. Only the last group of cases explicitly updates the common law rules.

The "proximate cause" argument relies upon the well accepted legal principle that a criminal defendant is liable for the natural consequences of his act.<sup>3</sup> Even negligent care by physicians attending the victim of an alleged criminal act does not relieve the defendant from responsibility for the consequences. Thus, even if the defendants in these cases were correct that their victims had still been legally alive when artificial respiratory support systems were removed, their indictments and convictions would not thereby be invalid. "The state is only required to prove beyond a reasonable doubt that the defendant's acts were 'a substantial factor in producing the death'."<sup>4</sup> (Moreover, in the case that emphasized this view most clearly, *People v. Olson*,<sup>5</sup> the Illinois court found the physicians' decision to withdraw heart-lung support measures to be reasonable.)

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<sup>1</sup> *People v. Flores*, No. 7246-C (Sonoma County, Cal., Super. Ct. 1974). After Flores' indictment was reinstated, he was tried and convicted of vehicular manslaughter and felony drunk driving. The light sentence he received (less than five months) was attributed by the prosecutor to "the uncertain state of the case and statutory law on the subject of brain death." Frank J. Veith, Jack M. Fein, Moses D. Tendler, Robert M. Veatch, Marc A. Kleiman & George Kalkines, "Brain Death: II. A Status Report of Legal Considerations," 238 *I.A.M.A.* 1744, 1746 (1977).

<sup>2</sup> See e.g. *People v. Saldana*, 47 Cal. App. 3d 954, 121 Cal. Rptr. 243 (1975); *State v. Brown*, 8 Or. App. 72,491 P.2d 1193 (1971).

<sup>3</sup> *Johnson v. State*, 64 Fla. 321, 59 So. 894 (1912); *Hamblin v. State*, 81 Neb. 148,115 N.W. 850 (1908).

<sup>4</sup> *Cranmore v. State*, 271 N.W.2d 402, 428 (Wis. App. 1978).

<sup>5</sup> *People v. Olson*, 377 N.E.2d 371 (Ill. 1978).

In a similar "proximate cause" case, *State v. Fierro*,<sup>1</sup> the Arizona Supreme Court held that although the common law cardiopulmonary standard is still sufficient to establish death, the medical criteria of the *ad hoc* Harvard Committee or the legal standard put forward by Uniform Brain Death Act (which are not in actuality comparable documents) are also valid bases for declaring death, when properly supported by medical testimony. The removal of the respiratory-support systems was thus found not to be the proximate cause of the victim's death. It was not error for the trial court to have found that the gunshot wound inflicted by the defendant caused the victim's death.

Other courts have relied on "cause in fact." Under this approach, the courts do not explicitly revise the "definition" of death, but they accept the physicians' conclusions about the occurrence of death as matters of fact. For instance, in a case involving a gunshot wound to the head, *State v. Brown*,<sup>2</sup> the Oregon appellate court held that the victim's life was terminated by the bullet wound that caused "damage to the vital centers of the brain which control respiration and other body activities."<sup>3</sup>

In *People v. Saldana*<sup>4</sup> the doctor testified that death is "a failure of part of that organism such that the total organism is no longer functioning in a manner which a reasonable, intelligent person would recognize as the purpose of that organism."<sup>5</sup> In the absence of evidence to contradict the doctor's testimony that the victim suffered brain death, the court held that the victim's death was caused by the defendant's act. "Given the current state of medical science . . . we cannot say as a matter of law that the victim was not dead when he reached the hospital, much less when the artificial life-support systems were-removed."<sup>6</sup>

The third ground on which homicide defendants' claims have been rejected is the most sweeping, namely, judicial revision of the common law standard for deciding when death has occurred. In upholding criminal convictions, the highest courts of both Massachusetts and Colorado have explicitly adopted a "brain death" standard.

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<sup>1</sup> *State v. Fierro*, 124 Ariz. 182,603 P.2d 74 (1979).

<sup>2</sup> *State v. Brown*, 8 Or. App. 72,491 P.2d 1193 (1971).

<sup>3</sup> *Id.* at 1195.

<sup>4</sup> *People v. Saldana*, 47 Cal. App. 3d 954, 121 Cal. Rptr. 243 (1975).

<sup>5</sup> *Id.* at 245.

<sup>6</sup> *Id.* at 244.

The first state supreme court case was that of *Commonwealth v. Golston*,<sup>1</sup> a 1977 Massachusetts case. The trial judge had instructed the jury "as a matter of law, the occurrence of a brain death, if you find it, satisfies the essential element of the crime of murder requiring proof beyond a reasonable doubt of the death of the victim."<sup>2</sup> Borrowing from the language of the recent statutes, the judge stated that, "Brain death occurs when, in the opinion of a licensed physician, based on ordinary and accepted standards of medical practice, there has been a total and irreversible cessation of spontaneous brain functions and further attempts at resuscitation or continued supportive maintenance would not be successful in restoring such functions."<sup>3</sup>

The Supreme Court of Massachusetts held the trial judge had acted correctly in accepting the medical concept of brain death. (Alternatively, the court held any error in this respect to be harmless beyond a reasonable doubt.) The court limited its holding to criminal cases, however.

In the Colorado case of *Lovato v. District Court*<sup>4</sup> the trial judge had held "[A]s the rule of this case. . . to be followed until otherwise changed legislatively or judicially, we adopt the provisions of the proposed Uniform [Brain Death] Act. . . Our recognition of this concept of brain death does not preclude continuing recognition of the standard of death as determined by traditional criteria of cessation of respiration and circulation."<sup>5</sup> The effect of the decision was to provide alternative determinations of death.

The Supreme Court of Colorado upheld the District Court. In doing so, the court explicitly addressed two important issues: the relationship between judicial and legislative revision of the common law, and the grounds on which established precedent may sometimes be abandoned:

We recognize the authority of, and indeed encourage, the General Assembly to pronounce statutorily the standards by which death is to be determined in Colorado. We do not, however, believe that in the absence of legislative action we are precluded from facing and resolving the legal issue of whether irretrievable loss of brain function can be used as a means of detecting the condition of death. Under the circumstances of this case we are not only entitled to resolve

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<sup>1</sup> *Commonwealth v. Golston*, 373 Mass. 249, 366 N.E.2d 744 (1977), *cert. denied*, 434 U.S. 1039 (1978).

<sup>2</sup> *Id.* at 747.

<sup>3</sup> *Id.* at 747-8.

<sup>4</sup> *Lovato v. District Court*, 601 P.2d 1072 (Colo. 1979) (*en banc*).

<sup>5</sup> *Id.* at 1081.

the question, but have a duty to do so. To act otherwise would be to close our eyes to the scientific and medical advances made worldwide in the past two or three decades.<sup>1</sup>

### **B. Civil Cases Updating the Common Law**

The second major legal context affording judges the opportunity to update the common law has been in civil actions. These cases have addressed directly the issue of organ transplantation based upon the "definition" of death.

The 1972 Virginia case of *Tucker v. Lower* has received considerable attention although it did not progress beyond the trial level.<sup>2</sup> Following a workplace accident, the plaintiff's brother had been taken unconscious to a hospital where surgery for severe head injuries was performed. After the treating physicianAs decided the victim was "brain dead," he was taken off the respirator and his heart and kidneys were removed for transplantation. The victim's brother brought suit against the physicians and surgeons under the Virginia wrongful death act.<sup>3</sup> One of his grounds for recovery was that the operation had been commenced before death had occurred. To support this contention, the plaintiff established that the brother's heart was still beating as a result of the respiratory treatment at the time death was declared.

The trial judge refused the defendants' motion to dismiss the case or to grant summary judgment in their favor. He held that the "definition" of death was the "all vital bodily functions" test established by the common law. Yet at the last minute, the judge apparently reconsidered his decision and instructed the jury that:

You shall determine the time of death in this case by using the following definition of the nature of death. Death is a cessation of life. It is the ceasing to exist. Under the law, death is not continuing, but occurs at a precise time, and that time must be established according to the facts of each specific case. In determining the time of death, as aforesaid, under the facts and circumstances of this case, you may consider the following elements, none of which should necessarily be considered controlling, although you may feel under the evidence, that one or more of these con-

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<sup>1</sup> *Id.* at 1081.

<sup>2</sup> *Tucker v. Lower*, No. 2831 (Richmond, Va. L. & Eq. Ct., May 23, 1972); See, e.g., Robert M. Veatch, *Death, Dying and the Biological Revolution: Our Last Quest for Responsibility*, Yale University Press, New Haven, Conn., (1977) at 21-24; Alexander Morgan Capron, "Legal Definition of Death," 315 *Ann. N.Y. Acad. Sci.* 349,351 (1978).

<sup>3</sup> Va. Code § 8-633 *et seq.* (1970).

ditions are controlling: the time of the total stoppage of the circulation of the blood; the time of the total cessation of the other vital functions consequent thereto, such as respiration and pulsation; the time of complete and irreversible loss of all function of the brain; and, whether or not the aforesaid functions were spontaneous or were being maintained artificially or mechanically.<sup>1</sup>

The jury acquitted the defendants. Because there was no appeal, higher courts did not have occasion to rule on the soundness of the trial judge's revision of the standards for determining death. Thus, the case did not establish a new rule on the legal standard to be used in Virginia for determining when death occurs. It did, however, prompt the Virginia medical society to support a statute which was adopted by the legislature the year after *Tucker v. Lower* recognizing brain cessation as one ground for declaring death.<sup>2</sup> (Indeed, in most of the states in which cases illuminating the inadequacies of the common law "definition" have arisen, the legislature has reacted by enacting a statute on the subject.<sup>3</sup>)

The "definition" arose in a narrower but more conclusive fashion in *New York City Health and Hospital Corp. v. Sulsona*,<sup>4</sup> another organ transplant case. The petitioner sought a declaratory judgment to construe the time of death provisions in New York's Anatomical Gift Act.<sup>5</sup> Section 7(b) of the Uniform Anatomical Gift Act merely provides that "The time of death shall be determined by a physician who attends the donor at his death or, if none, the physician who certifies death."

The controversy in *Sulsona* arose because of the difficulty, under the common law and the policies of the Chief Medical Examiner of New York City, in carrying out organ transplants from suitable donors who were determined to be dead on neurological grounds. The trial judge held: "The context in which the term 'death' is used in Sections 4301 and 4306 of Article 43 of the Public Health Law implies a definition consistent with the generally accepted medical practice of doctors primarily concerned with effectuating the purposes of this statute."<sup>6</sup> The judge noted that this

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<sup>1</sup> *Tucker v. Lower*, No. 2831 (Richmond, Va. L. & Eq. Ct., May 23, 1972).

<sup>2</sup> Va. Code § 54.325.7 (Cum. Supp. 1981).

<sup>3</sup> See e.g., Cal. Health & Safety Code §§ 7180-7182 (Deering Supp. 1980) Or. Rev. Stat. § 146.087 (1977).

<sup>4</sup> *New York City Health and Hospital Corp. v. Sulsona*, 81 Misc. 2d 1002, 367 N.Y.S.2d 686 (Sup. Ct. 1975).

<sup>5</sup> N. Y. Pub. Health Law Article 43, §§ 4301-4307 (1977).

<sup>6</sup> *New York City Health & Hosp. Corp. v. Sulsona*, 81 Misc. 2d 1002, 367 N.Y.S.2d 686, 691 (Sup. Ct. 1975).



definition was applicable in her court only; furthermore, it would be limited to potential donors from whom organs were to be removed upon death, under the procedures defined in the anatomical gift law. The judge urged the legislature to remedy the situation immediately.

The "definition" of death has also arisen in civil cases not involving organ transplantation. For example, a large body of law concerning the time of death in inheritance cases has provided a major focus of the "existing law" defining death. Recently, the question of whether respiratory support is being given to a live patient or a dead body has been presented a number of times<sup>1</sup> but has been decided by the highest court of a state in only one case, *In re Bowman*.<sup>2</sup> Late in 1980, the Supreme Court of Washington affirmed a lower court's ruling that a person without any brain functions is dead. Five year-old Matthew Bowman had suffered massive physical injuries from a nonfamily member who was caring for him. He was admitted to the hospital in critical condition and placed under the guardianship of the Department of Social and Health Services. When his natural parents were located, Matthew's court-appointed guardian objected to being dismissed on the ground that the parents would order the withdrawal of the respirator and other medical care supporting Matthew.

Although it ruled that Matthew was dead, the trial court enjoined the removal of the "extraordinary measures" sustaining respiration and heartbeat, pending an appeal. The case was set down for argument before the state's highest court a week later, but a day before the argument was scheduled all of Matthew's bodily functions ceased irretrievably.

Since the issue was of such importance, the Washington Supreme Court decided to rule on it even though the particular case had become technically moot upon Matthew Bowman's death.<sup>3</sup> The Washington Supreme Court reviewed the medical findings and the attending physician's conclusion that "Matthew's brain was dead under the most rigid criteria available, called the 'Harvard criteria,' and that his cardiovascular system would, despite the life support systems, fail in 14 to 60 days."<sup>4</sup> The physician also cited the

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<sup>1</sup> *People v. Lyons*, 15 Crim. L. Rptr. 2240 (Cal. Super. Alameda Co. 1974); *Cranmore v. State*, 271 N.W.2d 402 (Wis. App. 1978).

<sup>2</sup> *In re Bowman*, 617 P.2d 731 (Wash. Sup. Ct. 1980).

<sup>3</sup> *Id.* at 734; *Sorenson v. Bellingham*, 80 Wash. 2d 547, 496 P.2d 512 (1972).

<sup>4</sup> *In re Bowman*, 617 P.2d 731, 733 (Wash. Sup. Ct. 1980).

agreement of "all physicians in the Children's Orthopedic Hospital intensive care unit. . . that Matthew was no longer alive"<sup>1</sup> at the time of the hearing, and conveyed their recommendation, to which Matthew's mother consented, that he be removed from the ventilator.

As in the Colorado decision,<sup>2</sup> the Washington court decided that the failure of the state legislature to adopt the new standard did not pose a barrier to judicial recognition of such a formula. In the year that had passed since the *Lovato* decision in Colorado, the statute recommended in the present Report had been taken for approval to the uniform law commissioners. The Commissioners approved it in August 1980 in place of the Uniform Brain Death Act embraced in *Lovato*.<sup>3</sup> Accordingly, the Washington court in *Bowman* "adopted" the provisions of the Uniform Determination of Death Act while explicitly leaving to the medical profession the definition of "acceptable diagnostic tests and medical procedures. . . taking into account new knowledge of brain function and new diagnostic procedures."<sup>4</sup>

### **III. Statutory Construction**

Finally, a few cases have arisen in states having a statutory "definition" of death, in which the courts have had to interpret the meaning of the statutes as applied to a particular set of facts. For the most part the statutes have fared well: they have been upheld and have been interpreted in a straightforward and biomedically appropriate fashion. Peculiarities of the statutes in two states led to odd outcomes in two cases, however, and point to conclusions that ought to enter into the thinking of those who draft statutes.

#### **A. Cases Upholding Statutes**

In *State v. Shaffer*,<sup>5</sup> the landmark Kansas statute was challenged. *Shaffer*, convicted of first degree murder, claimed the statute was never intended to apply to criminal homicide trials and that the instruction given to the jury pursuant to the statute was thus erroneous. The court held that it is proper in a criminal trial to instruct the jury on the statute as the basis for determining when death occurs. The court also held that the Kansas statute when applied to murder in the first degree is not unconstitutionally vague in allowing either of two standards to be applied to determine death. The Court found the alternative brain-based standard to the traditional cardiopulmonary standard to be grounded

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<sup>1</sup> *Id.*

<sup>2</sup> *Lovato v. District Court*, 601 P.2d 1072 (Colo. 1979) (en banc).

<sup>3</sup> Colo. Rev. Stat. § 12-36-136 (1981).

<sup>4</sup> *In re Bowman*, 617 P.2d 731, 738 (Wash. Sup. Ct. 1980).

<sup>5</sup> *State v. Shaffer*, 223 Kan. 244, 574 P.2d 205 (1977).

on sound considerations in keeping with advanced medical technology. It found no constitutional requirement that a single standard be used. Nor was the statute unconstitutionally vague for failure to enumerate procedures for determining when death has occurred. A determination based on the "ordinary standards of medical practice" was held sufficient.

The court also relied upon the "proximate cause" theory of criminal responsibility. It held that if the defendant has caused wounds to be inflicted on the victim, and if the jury found that those wounds contributed to the death of the victim, the defendant could not avoid responsibility by showing that the treating physicians had turned off the respirator and transplanted the victim's kidneys.

Similarly, in *People v. Vanderford*,<sup>1</sup> the Capron-Kass statute adopted in Michigan<sup>2</sup> withstood challenge by a criminal defendant. Convicted of involuntary manslaughter, the appellant challenged the Michigan statute as unconstitutionally vague or not sufficiently rigorous. He claimed that death might have been caused by the respirator having been *prematurely* terminated (*i.e.*, because a patient who was actually alive had been incorrectly declared dead under the statute).

The Michigan court held the defendant was not in a position to challenge the statute. First, he had no personal interest in the constitutionality of the statute since, even if it were found unconstitutional, his conviction would stand because Michigan also employs the usual legal rule that intervening medical error is not a defense when the accused has inflicted a mortal wound upon another. Second, Vanderford was held not to have standing to attack the statute on the ground that its application might deny the constitutional rights of another.

The defendant's claim that the trial court should have instructed the jury that death must be pronounced before artificial life support systems are terminated was found by the Michigan court to be without merit, since the time at which death was pronounced, either before or after the life support system is terminated, is not material to his guilt.

In *North Carolina v. Holsclaw*<sup>3</sup>, the court held the "brain death" provisions of the state's 1977 Natural Death Act irrelevant to a homicide case where a determination had to be made as to the proximate cause of death. In a

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<sup>1</sup> *People v. Vanderford*, 77 Mich. App. 370, 258 N.W.2d 502 (1977).

<sup>2</sup> Mich. Stat. Ann. § 14.15 (1021 to 1024) (Cum. Supp. 1981).

<sup>3</sup> *North Carolina v. Holsclaw*, 42 N.C. App. 696, 257 S.E.2d 650 (1979).

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criminal prosecution, the North Carolina court held, an intervening cause of death must be the sole cause in order to release the criminal defendant from responsibility for murder. It was held to be a jury function to resolve the issue of proximate cause involved in the determination of "brain death" and termination of life supports.

### **B. Cases Demonstrating Some Problems with the Statutes**

The first serious problem with a statutory "definition" of death arose in a 1979 Maryland case interpreting a statute patterned on the original legislation in Kansas. In *State v. Robaczynski*<sup>1</sup> a Baltimore nurse was tried for murdering a 48 year-old comatose cardiac patient by disconnecting his respirator.

Although the case initially appeared to be one of "mercy killing," at trial the defense contended that the patient was actually "brain dead" before Ms. Robaczynski "pulled the plug." The state's evidence, supplied by the victim's cardiologist and by the medical examiner who conducted the autopsy, was that his brain was functioning (and his general condition was improving) at the time the respiratory support was withdrawn, causing his heart to fail completely within 25 minutes.<sup>2</sup>

After three days of deliberation the jury was unable to reach a verdict and a mistrial was declared.<sup>3</sup>

Reports revealing the trouble the jurors had in reaching a verdict are instructive. In Maryland the jury is the arbiter of the law as well as the facts in criminal cases and thus was left on its own to interpret the statute.<sup>4</sup> Interviews with the jurors revealed that their inability to reach a verdict hinged on the interpretation of the word "spontaneous" in the Maryland law which lists the "irreversible cessation of *spontaneous* brain function" as one standard for determining death.<sup>5</sup>

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<sup>1</sup> *State v. Robaczynski*, No.5 78-23001 (Criminal Court of Baltimore, 1979).

<sup>2</sup> Alexander Morgan Capron, "Death and the Law: A Decade of Change," 63 *Soundings* 290, 304-05 (1980).

<sup>3</sup> Sandra Saperstein, "Maryland Law on Brain Death Was Unclear to Jurors," March 21, 1979, *Wash. Post*, § C at 1, col. 1; Sandra Saperstein, "Md. Nurse to be Freed of Charges: Law Defining Death Held Too Ambiguous," March 29, 1979, *Wash. Post*, § B at 1, col. 6.

<sup>4</sup> Md. Const. art. 23.; *Wyley v. Warden*, 372 F.2d 742 (4th Cir.), *cert. denied*, 389 U.S. 863 (1967).

<sup>5</sup> Md. Ann. Code art. 43, § 54F(a)(b) (1980); Millard Bass, "Definition of Brain Death," (letter to editor) 242 *J.A.M.A.* 1850 (1979).

The word "spontaneous" as related to brain function apparently was intended to have a meaning analogous to its use in the context of circulation and respiration—that is, an inherent rather than artificially maintained function. But since the heart and lungs can be maintained artificially by a respirator, while brain activity cannot likewise be supported with artificial technology, the use of "spontaneous" as a modifier of "brain functions" was unnecessary and, as it turned out, confusing. Defense testimony was introduced to show that under the accepted medical tests upon which the prosecution was relying to show that the victim had still been alive, his brain activity was not manifested *spontaneously* but would have had to be evoked by the application of external stimuli. Thus, confusion was established between the legal meaning of the word spontaneous (*i.e.* inherent v. artificially maintained) and the medical use of the word (manifested without intervention v. apparent only upon stimulation). Unable to reconcile the two, the jury was stymied.

After the mistrial, the prosecuting attorney, William A. Swisher, declined to retry Ms. Robacynski. The initial charge and three similar ones were dropped in exchange for the return of her Maryland nurse's license and her promise to forego the practice of nursing. Newspaper accounts quoted Swisher as saying, "The law should be clarified. We need an acceptable universal definition of death."<sup>1</sup>

The second serious problem in statutory interpretation appeared in a Connecticut case. Commentators on statutes "defining" death have long argued against attaching such statutes to special purpose legislation—such as the laws on organ transplantation—lest a special category of "death" be created. In enacting statutes on the determination of death, state legislatures have overwhelmingly heeded this advice. The unfortunate consequences of a special transplantation-only "definition" of death manifested themselves earlier this year in a case in Connecticut, one of the two states to have made its statute on death a part of its organ transplantation law.

On January 30, 1981, Melanie Bacchiochi suffered a cardiac arrest while having her wisdom teeth removed under general anesthesia.<sup>2</sup> After resuscitation she was admitted to a Stafford, Connecticut hospital. By February 11, her physician and consultants found her to have suffered

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<sup>1</sup> T. Humphrey, "Md. Drops Euthanasia Charges," March 30, 1979, *Phila. Inquirer* at 7 A, col. 1.

<sup>2</sup> Fred Fabro, "Bacchiochi vs. Johnson Memorial Hospital," 45 *Conn. Med.* 267 (1981); Fred Fabro, "The Bacchiochi Case-Continued" 45 *Conn. Med.* 334 (1981).

total, irreversible loss of the functions of her entire brain, including the brain stem. In the physician's view, his patient had died. Thus, it was no longer appropriate to continue treatment (estimated to cost \$1,000 per day) that should be made available instead for those whom it might benefit.

Nevertheless, Ms. Bacchiochi's doctor refused to remove her from the respirator unless he was granted immunity from prosecution by the Chief State's Attorneys Office. His request was supported by the hospital's attorney. Since Connecticut's statute recognizing "brain death" had been adopted in 1979 as part of the State's Uniform Anatomical Gift Act, its application is limited to potential organ donors—a group into which Ms. Bacchiochi did not fall.

Ms. Bacchiochi's family brought suit to have her removed from the respirator. Four days of court hearings, attended by attorneys representing at least eight different parties, were held before Judge Harry Hammer of the Hartford/New Britain Superior Court.

Although Judge Hammer declined to bring the general common law on death into line with the statutory law on organ donors or, indeed, to issue any formal ruling in the case, the Assistant State's Attorney stated informally that he had no intention of prosecuting. Reassured, Ms. Bacchiochi's doctor removed her respirator on March 13, 1981, and the artificially-supported cardiopulmonary functions ceased. The irony of the Bacchiochi case is that had she been an organ donor, she could have been declared dead under Connecticut law and removed from the respirator on February 11. Furthermore, the prosecutor stated that his position in *Bacchiochi* was limited to the facts of that case and would not preclude prosecution of physicians or others for actions they take in any future "brain death" cases.

## **Argentina**

The law on determination of death in Argentina is found in a 1977 statute<sup>1</sup> related to the donation and transplantation of organs. It provides for a determination of death when "all brain functions have totally and irreversibly ceased." Certification of death of a transplant donor is to be made by a team of experts consisting of a general practitioner, a neurologist or neurosurgeon and a cardiologist, none of whom are members of the team that will perform the operation on either the donor or recipient.

Regulations pursuant to the 1977 statute require that all of the following confirmatory tests be performed:<sup>2</sup>

1. Total absence of response of any kind to external stimuli, especially to those of a nociceptive nature applied above the occipital orifice.

2. Electroencephalographs on patients not intoxicated and those not affected by hypothermia, with the observance of the following requirements:

- a) Flat lineal reading with no bioelectrical response to several sensitive-sensorial stimuli applied during the test.

- b) Utilization of at least eight electrodes at a minimum interelectrode distance of at least eight centimeters.

- c) Setting of the equipment at its maximum capacity of amplification (up to 25 microvolts per 1 centimeter).

- d) Time constant of 0.3.

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<sup>1</sup> Law 21, 541 of March 2, 1977, *Boletín Oficial* [B.D.] March 18, 1977, art. 21.

<sup>2</sup> Decree 30011 of October 3, 1977, *Boletín Oficial* [B.D.] October 13, 1977, art. 21.



e) Registry of a minimum duration of fifteen minutes with repetition after six hours.

3. Lack of spontaneous breathing, with the absolute necessity of an artificial respirator.

4. Fixed mydriatic pupils or pupils in an intermediate position despite the use of intense photic stimuli to observe pupilar reactivity.

5. Lack of oculocephalic reflexes during the passive cephalic rotations.

6. Vestibular caloric tests. After otological examination, irrigate with a clyster tube each external duct with 200 cubic centimeters of iced water in an alternated manner, and with a ten-minute interval between each irrigation. There should be no ocular movements during and at the end of the test.

7. Atropine test. Inject two to four milligrams of atropine intravenously observing for possible changes on the electrocardiogram. There should be no acceleration of the cardiac frequency during the test. This observation should last no less than six minutes.

8. When tests 4, 5, and 6, above, may not be conducted because of severe ocular lesions, it shall be required that tests leading to a certification of the total lack of cerebral circulation be conducted for no less than thirty minutes.

## **Australia**

In an extensive 1977 report entitled "Human Tissue Transplants"<sup>1</sup> the Law Reform Commission of Australia recommended a statute which was adopted in the following fashion by the Northern Territory of Australia and the Australian Capital Territory.

For the purpose of the law of the Territory, a person has died when there has occurred—

(a) irreversible cessation of all function of the brain of the person; or

(b) irreversible cessation of circulation of blood in the body of the person.

The following recommendations accompanied the Law Reform Commission's statute:

The Commission offers a number of comments on the recommended provision. Flexibility to allow adoption of criteria to accord with the best current professional procedures is preferable to verbose legislation. The brevity of the recommended statutory provision, and the deliberate omission of detailed criteria, may be taken as a reflection and

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<sup>1</sup> The Law Reform Commission of Australia, *Human Tissue Transplants* (Report No.7) Australian Government Publishing Service, Canberra (1977).

confirmation of the Australian community's general confidence in the medical profession. The creation and prescription of techniques of diagnosis should be the responsibility of the medical profession. Thirdly, although appearing in this context of transplantation, the recommended statutory definition of death is intended to have general application. It should not be limited in its legal effect to any particular kind of patient, nor to patients maintained by support machinery (although, in practice it will no doubt principally, if not exclusively, affect only such patients), nor to transplantation. The inclusion in the statutory provision of references both to "brain death" and to traditional criteria serves a useful purpose. Despite the greater accuracy of determining death by reference to cessation of brain function, it is clear that in most cases, death will be certified or determined according to the traditional respiratory-circulatory-cardiac standards. There will not be a great number of cases in which the need and facilities for, and opportunity of, employing the necessary "brain death" criteria will be present.

## **Canada**

There is no Canadian federal case or statutory law on the subject of the use of brain-oriented criteria to determine death. However, in response to a 1974 report by the Manitoba Law Reform Commission, the Province of Manitoba enacted the following statute (the only province to do so):

For all purposes within the legislative competence of the Legislature of Manitoba, the death of a person takes place at the time at which irreversible cessation of all that person's brain function occurs.

More recently, as part of a series of reports in its "Protection of Life Project" which began in 1976, the Law Reform Commission of Canada issued a report, the "Criteria for the Determination of Death" (Working Paper No. 23). The Commission recommended that the following statute be adopted as federal statutory law by way of an amendment to the Interpretation Act of 1970:

- (1) A person is dead when an irreversible cessation of all that person's brain functions has occurred.
- (2) The cessation of brain functions can be determined by the prolonged absence of spontaneous cardiac and respiratory functions.
- (3) When the determination of the absence of cardiac and respiratory functions is made impossible by the use of artificial means of support, the cessation of the brain functions may be determined by any means recognized by the ordinary standards of current medical practice.

In drafting the statute the Commission noted the following series of objectives:

- (1) The proposed legislation must avoid arbitrariness and give greater guidance to doctors, lawyers and the public, while remaining flexible enough to adapt to medical changes.
- (2) The proposed legislation must not attempt to solve all the problems created by death, but only the problem of establishing criteria for its determination.
- (3) The one proposed piece of legislation must apply equally in all circumstances where a determination of death is at issue.
- (4) The proposed legislation must recognize only the standards and criteria of death; it must not define the medical procedure to be used, nor the instruments or procedures by which death is to be determined.
- (5) The proposed legislation must recognize standards and criteria generally accepted by the Canadian public.
- (6) To remain faithful to the popular concept, the proposed legislation must recognize that death is the death of an individual person, not of an organ or cells.
- (7) The proposed legislation must not in practice lead to wrong or unacceptable situations.
- (8) The proposed legislation must not determine the criteria of death by reference only or mainly to the practice of organ transplantation.

## **Czechoslovakia**

Criteria for the determination of death can be found in a directive entitled "Extraordinary Removal of Tissues and Organs from Dead Bodies" which was promulgated by the Ministry of Health of the Czech Socialist Republic and took effect on April 1, 1978.

Artificial respiration support may be given up after diagnosis of death of the brain when the following criteria are complied with:

- a) deep coma with total unreceptivity to internal or external stimuli
- b) no muscular reflexes
- c) no vegetative reflexes
- d) lack of spontaneous respiration
- e) angiography by contrast material which does not penetrate to the brainstem, visualizing only the extra cranial sections of those arteries that supply blood to the brain [angiography is to be done twice with a thirty minute interval; or an isoelectric electroencephalogram is to be done three times within twenty four hours]

## **Finland**

Act Number 260 of July 8, 1957 entitled "The Use of Tissues of a Dead Person for Therapeutic Purposes," includes the following provisions:

The removal of tissues must not be begun until the corpse shows unmistakable signs of death. The National Board of Health decides how death shall be determined before the removal of tissues referred in this act.

Regulations pursuant to the above act were promulgated in 1971 by Finland's national board of health. (Reg. No. 10063. 1969. S).

### **I Place of venue**

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### **II Ascertaining death**

Death has to be ascertained by the appropriate chief physician, or by another hospital physician, who has a written authorization from the chief physician. The physician who has ascertained the death shall not participate in the transplantation of tissues.

#### **III The grounds for ascertaining death**

Before tissues are removed, the following signs of death, as referred to in subsection 2 of section 1 of the above Act, must be present:

—permanent cessation of the activity of the brain or of the heart; as specified in detail in subsections 1) and 2) below. It is assumed that all therapy required by the patient under the circumstances has been carried out. A person is dead when his or her brain is so damaged that the vital functions of the brain have ceased regardless whether the heart has stopped or not;

or:

—secondary signs of death such as postmortem lividity, cooling of the body and rigor mortis (subsection 3).

#### **1) Permanent cessation of functions of the brain**

The underlying cause of brain death must be known with absolute certainty. If the cause of the brain damage is a condition leading to raised intracranial pressure (e.g. a severe brain injury, an intracranial hemorrhage, a brain tumor), the permanent cessation of the functions of the brain is ascertained as follows:

- a) the pupils are permanently dilated, with no reaction to light;
- b) spontaneous breathing has stopped and does not start after  $\frac{1}{2}$  – 1 hour of efficient artificial respiration;
- c) cranial nerves show no reaction.

In other cases, and if there remains the slightest doubt about brain death, further examinations must be carried

out, such as electroencephalogram, cerebral angiography, etc. For the electroencephalogram, at least a 6-channel recording with needle electrodes is required. The electroencephalogram must be isoelectric, nor must there be noise impairing the assessment of isoelectricity, nor must there be any response to any stimuli. In childhood, in hypothermia and in acute intoxication the lack of electrical activity of the brain is not a reliable sign of death.

2) Permanent cessation of the heart beat

The absence of the heart beat is not in itself a sign of death. If all therapeutic and resuscitating measures required by the condition of the patient and by the circumstances have been carried out, the patient is considered dead when the vital functions of the brain have irrevocably stopped. If the asystolic heart cannot be made to function effectively after ½ – 1 hour of resuscitation, the signs of death apply as set out in subsections 1), a to c.

3) Secondary signs of death,

such as post mortem lividity, cooling of the body and rigor mortis are not applicable if organs are to be removed for transplantation. However, tissues such as skin and cornea may still be removed. In the latter case it is sufficient that the physician in charge has certified the death.

## France

French law contains no legal definition of death as such; however, there are several provisions establishing the occurrence of death which are given by the Decree of October 20, 1947, and the Law of July 7, 1949. These two provisions stipulate that death must be established by two physicians who must use all the means which are recognized to be valid by the Ministry of Public Health to make certain that death has, indeed, occurred.<sup>1</sup>

France recognizes the criteria adopted by the Scientific Conference of the World Health Organization held in Geneva from June 13-14, 1968.

1. loss of all vital signs of life;
  2. complete areflexy and atony of the muscles;
  3. complete halt of spontaneous breathing;
  4. complete pulse arrest, if not artificially stimulated;
- and
5. an absolutely linear electroencephalographic drawing.<sup>2</sup>

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<sup>1</sup> Repertoire de droit penal Medicine, 21 (Paris, Dalloz, 1978).

<sup>2</sup> *Id.*

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The memoranda issued by the French Ministry of Public Health on February 3, 1948, September 19, 1958, and April 25, 1968, also require, besides and in addition, the use of the following direct examinations:

1. arteriotomy;
2. a fluorescein test; and
3. an absolutely linear electroencephalogram for a sufficient time.<sup>1</sup>

Documents published by the Ministry of Health in April 1968 endorsed criteria close to those adopted by the Harvard school.<sup>2</sup>

## Great Britain

Although there is no official legal definition of death in Great Britain the issue has been addressed in an October 1979 pamphlet entitled "The Removal of Cadaveric Organs for Transplantation: A Code of Practice." This code was drafted by a working party under the the aegis of the Health Department of Great Britain and Northern Ireland as a guide for hospital practice. It states:

There is no legal definition of death. Death has traditionally been diagnosed by the irreversible cessation of respirator and heart beat. This working party accepts the view held by the Conference of Royal Colleges that death can also be diagnosed by the irreversible cessation of brains stem function—"brain death." In diagnosing brain death the criteria laid down by the Colleges should be followed.

It is sometimes necessary to carry out the diagnostic tests on more than one occasion. As a patient must be presumed to be alive until it is clearly established that he is dead, the time of death should be regarded as the time when death was conclusively established, not some earlier or a later time when artificial ventilation is withdrawn, or the heartbeat ceases.

The following are some excerpts from the paper produced by the Conference of Royal Colleges and Faculties of the United Kingdom which is included by reference in the Working Party document<sup>3</sup> (Some explanatory notes have been deleted.)

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<sup>1</sup> *Id.*

<sup>2</sup> Law Reform Commission of Canada Working Paper 23 Criteria for the Determination of death, 1979.

<sup>3</sup> Conference of Medical Royal Colleges and Faculties of the United Kingdom "Diagnosis of Brain Death" ii Lancet 1069 (1970).

**Conditions under which the Diagnosis of Brain Death should be considered**

1. The patient is deeply comatose.
  - (a) There should be no suspicion that this state is due to depressant drugs.
  - (b) Primary hypothermia as a cause of coma should have been excluded.
  - (c) Metabolic and endocrine disturbances which can be responsible for or can contribute to coma should have been excluded.
2. The patient is being maintained on a ventilator because spontaneous respiration had previously become inadequate or had ceased altogether.
  - (a) Relaxants (neuromuscular blocking agents) and other drugs should have been excluded as a cause of respiratory inadequacy or failure.
3. There should be no doubt that the patient's condition is due to irremediable structural brain damage. The diagnosis of a disorder which can lead to brain death should have been fully established.

**Diagnostic tests for the confirmation of Brain Death**

All brainstem reflexes are absent:

- (i) The pupils are fixed in diameter and do not respond to sharp changes in the intensity of incident light.
- (ii) There is no corneal reflex.
- (iii) The vestibulo-ocular reflexes are absent.
- (iv) No motor responses within the cranial nerve distribution can be elicited by adequate stimulation of any somatic area.
- (v) There is no gag reflex or reflex response to bronchial stimulation by a suction catheter passed down the trachea.
- (vi) No respiratory movements occur when the patient is disconnected from the mechanical ventilator for long enough to ensure that the arterial carbon dioxide tension rises above the threshold for stimulation of respiration.

**Other considerations****1. Repetition of Testing**

It is customary to repeat the tests to ensure that there has been no observer error. The interval between tests must depend upon the primary pathology and the clinical course of the disease. The interval between tests depends upon the progress of the patient and might be as long as 24 hours. This is a matter for medical judgement and repetition time must be related to the signs of improvement, stability, or deterioration which present themselves.

It is now widely accepted that electroencephalography is not necessary for the diagnosis of brain death. Electroen-



cephalography has its principal value at earlier stages in the care of patients, in whom the original diagnosis is in doubt. When electroencephalography is used, the strict criteria recommended by the Federation of E.E.G. Societies must be followed.

Other investigations such as cerebral angiography or cerebral bloodflow measurements are not required for the diagnosis of brain death.

## Greece

The law establishing the definition of death in Greece is found in Article 9 of Law No. 821 of October 14, 1978, a statute entitled "Concerning the Removal and Transplantation of Biological Substances of Human Origin."

(1) Any activity undertaken on the corpse for the removal of biological material is forbidden as long as it has not been previously established that the individual is dead. For the purpose of implementation of the provisions of the present law, an individual is considered dead when doctors establish, according to the provisions of paragraph two and through established and indisputable scientific methods, that there exist signs indicating the definite (irrevocable) termination of the functioning of the central nervous system, independently of the time of appearance and duration of presence of such signs and including indispensably all of the following signs:

- a) Termination of automatic and provoked movements.
- b) Termination of reflexes, and especially of the cornea.
- c) Mydriasis and lack of any reaction of the eye pupil.
- d) The lack of appearance of respiratory motion after an experimental interruption of the operation of the resuscitation apparatus, provided that the individual is connected to one, for a period of time sufficient to cause automatic respiratory motion as a result of the accumulation of carbon dioxide.
- e) Electroencephalographic silence.

(1) Artificial prolongation of the functioning of certain isolated organs of systems cannot place in doubt the ascertainment of death according to the above criteria, nor does it suspend the undertaking of removal of biological material.

(2) The ascertainment of death according to the previous paragraph is done by two doctors practicing medicine for at least five years; one of these two doctors must be a neurology specialist.

Neither of the ascertaining doctors is allowed to have a relationship with any scientific team interested in and occupied with transplantation.

## Norway

Regulations regarding the definition of death were promulgated by Royal Decree in June of 1977 pursuant to Act No. 6 of February 1973, "Transplantation, Hospital Autopsies and Donation of Bodies."

It is the cessation of brain function which decides that continued life is not possible. A universally valid definition of death must therefore be based on the fact that brain function has ceased.

The following definition shall be the basis of the diagnosis of death:

*Death has taken place when there is total destruction of the brain with complete and permanent cessation of all functions in the cerebrum, the cerebellum and the brainstem (mesencephalon, pons and medulla oblongata).*

This definition of death is of universal validity and covers all causes of death.

The signs of the total destruction of the brain are either permanent cessation of heartbeat and respiration or the following criteria which must be satisfied if heartbeat and respiration are artificially maintained.

### **Recognized intracranial pathological process**

Total destruction of the brain occurs if the pressure inside the cavity of the skull rises to the same level as the blood pressure, so that the blood supply to the brain ceases. The rise of pressure in the cavity of the skull is caused by space-consuming pathological processes and/or swelling of the brain (i.e. brain edema or an increase of fluid content in the brain).

The destruction of the brain may be due to disease or injury inside the cavity of the skull itself, such as hemorrhages, abscesses, inflammations and head injuries (primary causes) or disease or injury outside the cavity of the skull which lead to lack of oxygen in the brain (secondary causes).

### **Total unconsciousness**

Here there must be failure to react to light, sound, touch and pain-producing stimuli. The spinal cord—which lies outside the cavity of the skull—may have reflex functions even if the brain in its entirety has been destroyed. Spinal cord reflexes (i.e. muscle contractions in response to tapping of the sinews) may therefore be present, even if death has occurred.

### **Cessation of own respiration**

This is an absolute requirement for the diagnosis of death.

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**Cessation of all brain nerve reflexes**

Reflexes which pass the brain stem—which lies in the cavity of the skull—must not be able to be obtained: the pupils must not react to light, the corneal reflex (movement of the eyeball following the injection of cold water into the auditory canal) must not be able to be produced.

**Cessation of the electrical activity of the brain**

An isoelectrical or "flat" electroencephalogram is usually an indication of the total destruction of the brain. On its own the EEG examination is not sufficient proof that the brain has been totally destroyed, because in cases of poisoning by soporific drugs and narcotics, of low body temperature (hypothermia) or of acute lack of oxygen patients may temporarily have an isoelectrical electroencephalogram. If radiological examination (cerebral angiography, see under next heading) has already shown that the blood supply to the brain has ceased, the EEG examination may be omitted.

**Cessation of blood supply to the brain demonstrated by cerebral angiography**

Confirmation by angiography that the blood supply to the brain has ceased is the decisive indication of total destruction of the brain. The injection of contrast medium must be made into all four arteries which carry blood to the brain, namely both arteries of the neck (the carotid arteries) and both arteries of the cervical vertebrae (the vertebral arteries).

If the injection of contrast medium in both the carotid arteries has shown that neither of these is carrying blood to the brain, it is sufficient to make an injection of contrast medium into one of the vertebral arteries if the contrast medium flows back in the other without the veins in the cavity of the skull being filled with contrast medium.

The blood pressure must be measured before, during and after the radiological examination, so that it is certain that the absence of contrast medium in the veins in the brain is not due to a fall in blood pressure during the actual examination. If the blood pressure falls while the examination is being carried out, it must be repeated with a stabilized blood pressure.

**CONCLUSION**

If all the criteria 1-6 are satisfied, the patient shall be declared dead.

**Spain**

Spain recognized brain-based criteria for determining death in its Law 30 of October 27, 1979<sup>1</sup>

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<sup>1</sup> *Boletín Oficial* [B.O.], November 6, 1979.

**Art. 5.** The extraction of organs or of any other anatomical parts of deceased persons may be made after the death of that person has been attested to. When the attestation is based on the existence of data concerning the irreversibility of cerebral damage, and therefore, incompatible with life, the death certificate shall be subscribed by three doctors, among whom will be one neurologist or neurosurgeon and the chief of the corresponding medical unit, or his or her substitute. None of these physicians may favor part of the team that will use the organ(s) or make the transplant.

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# Guidelines for the Determination of Death

# F

## Report of the Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research \*

\* The guidelines set forth in this report represent the views of the signatories as individuals; they do not necessarily reflect the policy of any institution or professional association with which any signatory is affiliated. Although the practice of individual signatories may vary slightly, signatories agree on the acceptability of these guidelines: Jesse Barber, M.D., Don Becker, M.D., Richard Behrman, M.D., J.D., Donald R. Bennett, M.D., Richard Beresford, M.D., J.D., Reginald Bickford, M.D., William A. Black, M.D., Benjamin Boshes, M.D., Ph.D., Philip Braunstein, M.D., John Burroughs, M.D., J.D., Russell Butler, M.D., John Caronna, M.D. Shelley Chou, M.D., Ph.D., Kemp Clark, M.D., Ronald Cranford, M.D., Michael Earnest, M.D., Albert Ehle, M.D., Jack M. Fein, M.D., Sal Fiscina, M.D., J.D., Terrance G. Furlow, M.D., J.D., Eli Goldensohn, M.D., Jack Grabow, M.D., Phillip M. Green, M.D., Ake Grenvik, M.D., Charles E. Henry, Ph.D., John Hughes, M.D., Ph.D., D.M., Howard Kaufman, M.D., Robert King, M.D., Julius Korein, M.D. Thomas W. Langfitt, M.D., Cesare Lombroso, M.D., Kevin M. McIntyre, M.D., J.D., Richard L. Masland, M.D., Don Harper Mills, M.D., J.D., Gaetano Molinari, M.D., Byron C. Pevehouse, M.D., Lawrence H. Pitts, M.D., A. Bernard Pleet, M.D., Fred Plum, M.D., Jerome Posner, M.D., David Powner, M.D., Richard Rovit, M.D., Peter Safar, M.D., Henry Schwartz, M.D., Edward Schlesinger, M.D., Roy Selby, M.D., James Snyder, M.D., Bruce F. Sorenson, M.D., Cary Suter, M.D., Barry Tharp, M.D., Fernando Torres, M.D., A. Earl Walker, M.D., Arthur Ward, M.D., Jack Whisnant, M.D., Robert Wilkus, M.D., and Harry Zimmerman, M.D.

The preparation of this report was facilitated by the President's Commission but the guidelines have not been passed on by the Commission and are not intended as matters for governmental review or adoption.

## Foreword

The advent of effective artificial cardiopulmonary support for severely brain-injured persons has created some confusion during the past several decades about the determination of death. Previously, loss of heart and lung functions was an easily observable and sufficient basis for diagnosing death, whether the initial failure occurred in the brain, the heart and lungs, or elsewhere in the body. Irreversible failure of either the heart and lungs or the brain precluded the continued functioning of the other. Now, however, circulation and respiration can be maintained by means of a mechanical respirator and other medical interventions, despite a loss of all brain functions. In these circumstances we recognize as dead an individual whose loss of brain functions is complete and irreversible.

To recognize reliably that death has occurred, accurate criteria must be available for physicians' use. These now fall into two groups, to be applied depending on the clinical situation. When respiration and circulation have irreversibly ceased, there is no need to assess brain functions directly. When cardiopulmonary functions are artificially maintained, neurologic criteria must be used to assess whether brain functions have irreversibly ceased.

More than half of the states now recognize, through statutes or judicial decisions, that death may be determined on the basis of irreversible cessation of all functions of the brain. Law in the remaining states has not yet departed from the older, common law view that death has not occurred until "all vital functions" (whether or not artificially maintained) have ceased. The language of the statutes has not been uniform from state to state, and the diversity of proposed and enacted laws has created substantial confusion. Consequently, the American Bar Association, the American Medical Association, the National Conference of Commissioners on Uniform State Laws, and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research have proposed the following model statute, intended for adoption in every jurisdiction:

### **Uniform Determination of Death Act**

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

This wording has also been endorsed by the American Academy of Neurology and the American Electroencephalographic Society.

The statute relies upon the existence of "accepted medical standards" for determining that death has occurred. The medical profession, based upon carefully conducted research and extensive clinical experience, has found that death can be reliably determined by either cardiopulmonary or neurologic criteria. The tests used for determining cessation of brain functions have changed and will continue to do so with the advent of new research and technologies. The "Harvard criteria" (JAMA, 205:337, 1968) are widely accepted, but advances in recent years have led to the proposal of other criteria. As an aid to the implementation of the proposed uniform statute, we provide here one statement of currently accepted medical standards.

## **Introduction**

The criteria that physicians use in determining that death has occurred should:

- (1) Eliminate errors in classifying a living individual as dead,
- (2) Allow as few errors as possible in classifying a dead body as alive,
- (3) Allow a determination to be made without unreasonable delay,
- (4) Be adaptable to a variety of clinical situations, and
- (5) Be explicit and accessible to verification.

Because it would be undesirable for any guidelines to be mandated by legislation or regulation or to be inflexibly established in case law, the proposed Uniform Determination of Death Act appropriately specifies only "accepted medical standards." Local, state, and national institutions and professional organizations are encouraged to examine and publish their practices.

The following guidelines represent a distillation of current practice in regard to the determination of death. Only the most commonly available and verified tests have been included. The time of death recorded on a death certificate is at present a matter of local practice and is not covered in this document.

These guidelines are advisory. Their successful use requires a competent and judicious physician, experienced in clinical examination and the relevant procedures. All periods of observation listed in these guidelines require the patient to be under the care of a physician. Considering the responsibility entailed in the determination of death, consultation is recommended when appropriate.

The outline of the criteria is set forth below in capital letters. The indented text that follows each outline heading explains its meaning. In addition, the two sets of criteria (cardiopulmonary and neurologic) are followed by a pre-



sentation of the major complicating conditions: drug and metabolic intoxication, hypothermia, young age, and shock. It is of paramount importance that anyone referring to these guidelines be thoroughly familiar with the entire documents, including explanatory notes and complicating conditions.

### **The Criteria for Determination of Death**

An individual presenting the findings in either section A (cardiopulmonary) or section B (neurologic) is dead. In either section, a diagnosis of death requires that both cessation of functions, as set forth in subsection 1, and irreversibility, as set forth in subsection 2, be demonstrated.

**A. AN INDIVIDUAL WITH IRREVERSIBLE CESSATION OF CIRCULATORY AND RESPIRATORY FUNCTIONS IS DEAD.**

**1. CESSATION IS RECOGNIZED BY AN APPROPRIATE CLINICAL EXAMINATION.**

Clinical examination will disclose at least the absence of responsiveness, heartbeat, and respiratory effort. Medical circumstances may require the use of confirmatory tests, such as an ECG.

**2. IRREVERSIBILITY IS RECOGNIZED BY PERSISTENT CESSATION OF FUNCTIONS DURING AN APPROPRIATE PERIOD OF OBSERVATION AND/OR TRIAL OF THERAPY.**

In clinical situations where death is expected, where the course has been gradual, and where irregular agonal respiration or heartbeat finally ceases, the period of observation following the cessation may be only the few minutes required to complete the examination. Similarly, if resuscitation is not undertaken and ventricular fibrillation and standstill develop in a monitored patient, the required period of observation thereafter may be as short as a few minutes. When a possible death is unobserved, unexpected, or sudden, the examination may need to be more detailed and repeated over a longer period, while appropriate resuscitative effort is maintained as a test of cardiovascular responsiveness. Diagnosis in individuals who are first observed with rigor mortis or putrefaction may require only the observation period necessary to establish that fact.

**B. AN INDIVIDUAL WITH IRREVERSIBLE CESSATION OF ALL FUNCTIONS OF THE ENTIRE BRAIN, INCLUDING THE BRAINSTEM, IS DEAD.**

The "functions of the entire brain" that are relevant to the diagnosis are those that are clinically ascertainable. Where indicated, the clinical diagnosis is subject to confirmation by laboratory tests as described below. Consultation with a physician experienced in this diagnosis is advisable.

1. *CESSATION* IS RECOGNIZED WHEN EVALUATION DISCLOSES FINDINGS OF a AND b:

a. CEREBRAL FUNCTIONS ARE ABSENT, AND . . .

There must be deep coma, that is, cerebral unreceptivity and unresponsivity. Medical circumstances may require the use of confirmatory studies such as EEG or blood flow study.

b. BRAINSTEM FUNCTIONS ARE ABSENT.

Reliable testing of brainstem reflexes requires a perceptive and experienced physician using adequate stimuli. Pupillary light, corneal, oculocephalic, oculovestibular, oropharyngeal, and respiratory (apnea) reflexes should be tested. When these reflexes cannot be adequately assessed, confirmatory tests are recommended.

Adequate testing for apnea is very important. An accepted method is ventilation with pure oxygen or an oxygen and carbon dioxide mixture for ten minutes before withdrawal of the ventilator, followed by passive flow of oxygen. (This procedure allows PaCO<sub>2</sub> to rise without hazardous hypoxia.) Hypercarbia adequately stimulates respiratory effort within thirty seconds when PaCO<sub>2</sub> is greater than 60 mmHg. A ten minute period of apnea is usually sufficient to attain this level of hypercarbia. Testing of arterial blood gases can be used to confirm this level. Spontaneous breathing efforts indicate that part of the brainstem is functioning.

Peripheral nervous system activity and spinal cord reflexes may persist after death. True decerebrate or decorticate posturing or seizures are inconsistent with the diagnosis of death.

2. *IRREVERSIBILITY* IS RECOGNIZED WHEN EVALUATION DISCLOSES FINDINGS OF a AND b AND c:

a. THE CAUSE OF COMA IS ESTABLISHED AND IS SUFFICIENT TO ACCOUNT FOR THE LOSS OF BRAIN FUNCTIONS, AND. . .

Most difficulties with the determination of death on the basis of neurologic criteria have resulted from inadequate attention to this basic diagnostic prerequisite. In addition to a careful clinical examination and investigation of history, relevant knowledge of causation may be acquired by computed tomographic scan, measurement of core temperature, drug screening, EEG, angiography, or other procedures.

b. THE POSSIBILITY OF RECOVERY OF ANY BRAIN FUNCTIONS IS EXCLUDED, AND . . .

The most important reversible conditions are sedation, hypothermia, neuromuscular blockade,

and shock. In the unusual circumstance where a sufficient cause cannot be established, irreversibility can be reliably inferred only after extensive evaluation for drug intoxication, extended observation, and other testing. A determination that blood flow to the brain is absent can be used to demonstrate a sufficient and irreversible condition.

c. THE CESSATION OF ALL BRAIN FUNCTIONS PERSISTS FOR AN APPROPRIATE PERIOD OF OBSERVATION AND/OR TRIAL OF THERAPY.

Even when coma is known to have started at an earlier time, the absence of all brain functions must be established by an experienced physician at the initiation of the observation period. The duration of observation periods is a matter of clinical judgment, and some physicians recommend shorter or longer periods than those given here.

Except for patients with drug intoxication, hypothermia, young age, or shock, medical centers with substantial experience in diagnosing death neurologically report no cases of brain functions returning following a six hour cessation, documented by clinical examination and confirmatory EEG. In the absence of confirmatory tests, a period of observation of at least twelve hours is recommended when an irreversible condition is well established. For anoxic brain damage where the extent of damage is more difficult to ascertain, observation for twenty-four hours is generally desirable. In anoxic injury, the observation period may be reduced if a test shows cessation of cerebral blood flow or if an EEG shows electrocerebral silence in an adult patient without drug intoxication, hypothermia, or shock.

Confirmation of clinical findings by EEG is desirable when objective documentation is needed to substantiate the clinical findings. Electrocerebral silence verifies irreversible loss of cortical functions, except in patients with drug intoxication or hypothermia. (Important technical details are provided in: American Electroencephalographic Society, *Guidelines in EEG 1980*, Section 4: "Minimum Technical Standards for EEG Recording in Suspected Cerebral Death," pp. 19-24, Atlanta, 1980.) When joined with the clinical findings of absent brainstem functions, electrocerebral silence confirms the diagnosis.

Complete cessation of circulation to the normothermic adult brain for more than ten minutes is incompatible with survival of brain tissue.

Documentation of this circulatory failure is therefore evidence of death of the entire brain. Four-vessel intracranial angiography is definitive for diagnosing cessation of circulation to the entire brain (both cerebrum and posterior fossa) but entails substantial practical difficulties and risks. Tests are available that assess circulation only in the cerebral hemispheres, namely radioisotope bolus cerebral angiography and gamma camera imaging with radioisotope cerebral angiography. Without complicating conditions, absent cerebral blood flow as measured by these tests, in conjunction with the clinical determination of cessation of all brain functions for at least six hours, is diagnostic of death.

## Complicating Conditions

### A. Drug and Metabolic Intoxication

Drug intoxication is the most serious problem in the determination of death, especially when multiple drugs are used. Cessation of brain functions caused by the sedative and anesthetic drugs, such as barbiturates, benzodiazepines, meprobamate, methaqualone, and trichloroethylene, may be completely reversible even though they produce clinical cessation of brain functions and electrocerebral silence. In cases where there is any likelihood of sedative presence, toxicology screening for all likely drugs is required. If exogenous intoxication is found, death may not be declared until the intoxicant is metabolized or intracranial circulation is tested and found to have ceased.

Total paralysis may cause unresponsiveness, areflexia, and apnea that closely simulates death. Exposure to drugs such as neuromuscular blocking agents or aminoglycoside antibiotics, and diseases like myasthenia gravis are usually apparent by careful review of the history. Prolonged paralysis after use of succinylcholine chloride and related drugs requires evaluation for pseudocholinesterase deficiency. If there is any question, low-dose atropine stimulation, electromyogram, peripheral nerve stimulation, EEG, tests of intracranial circulation, or extended observation, as indicated, will make the diagnosis clear.

In drug-induced coma, EEG activity may return or persist while the patient remains unresponsive, and therefore the EEG may be an important evaluation along with extended observation. If the EEG shows electrocerebral silence, short latency auditory or somatosensory evoked potentials may be used to test brainstem functions, since these potential are unlikely to be affected by drugs.

Some severe illnesses (e.g., hepatic encephalopathy, hyperosmolar coma, and preterminal uremia) can cause

deep coma. Before irreversible cessation of brain functions can be determined, metabolic abnormalities should be considered and, if possible, corrected. Confirmatory tests of circulation or EEG may be necessary.

### **B. Hypothermia**

Criteria for reliable recognition of death are not available in the presence of hypothermia (below 32.2 °C core temperature). The variables of cerebral circulation in hypothermic patients are not sufficiently well studied to know whether tests of absent or diminished circulation are confirmatory. Hypothermia can mimic brain death by ordinary clinical criteria and can protect against neurologic damage due to hypoxia. Further complications arise since hypothermia also usually precedes and follows death. If these complicating factors make it unclear whether an individual is alive, the only available measure to resolve the issue is to restore normothermia. Hypothermia is not a common cause of difficulty in the determination of death.

### **C. Children**

The brains of infants and young children have increased resistance to damage and may recover substantial functions even after exhibiting unresponsiveness on neurological examination for longer periods than do adults. Physicians should be particularly cautious in applying neurologic criteria to determine death in children younger than five years.

### **D. Shock**

Physicians should also be particularly cautious in applying neurologic criteria to determine death in patients in shock because the reduction in cerebral circulation can render clinical examination and laboratory tests unreliable.

<b>Format</b>	Small group discussion
<b>Faculty</b>	Facilitators
<b>Learning Objective</b>	Identify the relevant facts and use the appropriate ethical principles to argue a position in cases pertaining to medical indications.
<b>Readings</b>	<u>Cases for Discussions</u> <ul style="list-style-type: none"><li>• It's Over Debbie</li><li>• Balancing Parental Wishes with Medical Judgment</li><li>• Disagreement over Resuscitation</li><li>• Faith-Based Decisions: Parents Who Refuse Appropriate Care for Their Children</li></ul>

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<b>Format</b>	Large group lecture
<b>Faculty</b>	Chessa
<b>Learning Objectives</b>	<p>By the end of this lecture, students will be able to:</p> <ul style="list-style-type: none"><li>• Explain the historical context that gave rise to standards for informed consent</li><li>• Identify the elements of informed consent as they relate to protecting patient autonomy</li><li>• Describe the necessary and sufficient conditions for having decisional capacity</li><li>• Describe the principles that govern how much and what type of information to disclose during the informed consent process.</li></ul>
<b>Readings</b>	Jonsen text: p 47 – 107
<b>Additional Readings (Optional)</b>	<ul style="list-style-type: none"><li>• Berdik C. The nocebo effect: How health warnings cause health troubles. Boston Globe; 2012 Sept 09</li><li>• Applebaum P, Grisso T. Assessing Patients Capacity to Consent to Treatment. NEJM 1988; 319:1635-8</li><li>• Ethicists of The National Catholic Bioethics Center. Preaching Points on Nutrition and Hydration. Ethics &amp; Medics January 2008</li></ul>

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# Outline

- Respect for Patient Autonomy
  - A little from the history books
  - Bottom Line
- Informed Consent
  - Five elements: Capacity, Voluntariness, Disclosure, Understanding, Consent.
  - Placebos and nocebos
- EOL Ethics, Briefly

# Veracity vs. Therapeutic Privilege

A Little History

“Speak to the patient carefully and adroitly,  
concealing most things.”

“Life is short, the Art long, opportunity  
fleeting... The physician must be ready  
not only to do his duty himself, but also to  
secure the cooperation of the patient.

*Hippocrates*

Yield to patients in matters of little consequence, but maintain an inflexible authority. . . in matters essential to life.

*Benjamin Rush, 1786*

“The only point at issue is, whether the practitioner shall sacrifice that delicate sense of veracity, which is so ornamental to, and indeed forms a characteristic of excellence of the virtuous man, to this claim of professional justice and social duty.”

“To a patient who makes inquiries which, if faithfully answered, might prove fatal to him, it would be a gross and unfeeling wrong to reveal the truth. His right to it is suspended, and even annihilated.”

Thomas Percival, *Medical Ethics*, 1803

# Contrary View

The physician . . . is invariably bound never to represent the uncertainty or danger as less than he actually believes it to be.

*Rev. Thomas Gisborne 1794*



# Case from Jonsen

Mr. S.P., a 55-year-old teacher, has had chest pains and several fainting spells during the past 3 months. He reluctantly visits a physician at his wife's urging. He is very nervous and anxious and says to the physician at the beginning of the interview that he abhors doctors and hospitals. On physical examination, he has classic signs of tight aortic stenosis, confirmed by echocardiogram. The physician wants to recommend cardiac catheterization and probably cardiac surgery. However, given his impression of this patient, he is worried that full disclosure of the risks of catheterization would lead the patient to refuse the procedure.

Should the physician explain the diagnosis and risks?  
Who will you follow? Percival or Gisborne

## Contemporary view, from Jonsen

“Communications between physicians and patients should be truthful; that is, statements should be in accord with facts. If the facts are uncertain, that uncertainty should be acknowledged. Deception, by stating what is untrue or by omitting what is true, should be avoided.”

More history  
Deception in Research

# Tuskegee Syphilis Study

- 1930 until 1972
- US Public Health Service
- Poor, African-American men in Macon County Alabama
- “Study in nature” of syphilis.
- Prevented subjects from seeking treatment in order to study untreated syphilis.
- Little disclosure; deceptive language



# Tuskegee Syphilis Study



Dear Sir:

Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment if it is believed you are in a condition to stand it. ...

**REMEMBER THIS IS YOUR LAST CHANCE FOR SPECIAL FREE TREATMENT. REMEMBER TO MEET THE NURSE.**

-Letter sent encouraging subjects to continue participation in the study



# Willowbrook Hepatitis Research



- Institution for mentally retarded children
- Over 5000 residents; 1 attendant/50 residents.
- Hepatitis and other diseases prevalent.
- Director of research intentionally exposed new residents to hepatitis in order to learn about different types of hepatitis and test gamma globulin as a protective therapy.





# Willowbrook Hepatitis Research

- Saul Krugman became very well known for his discoveries
  - Identification of Hepatitis A and B
  - Immunoglobulins confer passive immunity
- During some periods, children denied admission to Willowbrook unless they consented to the study.
- Disclosure about the study was misleading.
- Defense of Research: Although children were intentionally infected, they probably would have been infected anyway, and they received good clinical care because they were part of the study.

# Letter to Willowbrook Parents

We are studying the possibility of preventing epidemics of hepatitis on a new principle. Virus is introduced and gamma globulin given later to some, so that either no attack or only a mild attack of hepatitis is expected to follow. This may give the children immunity against this disease for life. We should like to give your child this new form of prevention with the hope that it will afford protection.

Permission forms are enclosed for your consideration. If you would like your child given the benefit of this new preventive, will you so signify by signing the form.

-Letter sent to parents asking for consent

Who made Willowbrook famous?



# Respect for Patient Autonomy

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.”

Justice Benjamin Cardozo, 1914: *Schloendorff v. NY Hospital*

*\*Mary Schloendorff did not consent to removal of tumor.*

*\*Legal basis for IC is found in battery and negligence.*

# Autonomy for patients and physicians

“When there are medical indications for treatment, a physician should propose a treatment plan that a patient may accept or refuse .

“As a moral principle, respect for autonomy is a "two-way street": the autonomy of physicians to act only on their best judgment about how best to benefit a patient medically, must also be respected. Therefore, respect for patient autonomy does not imply that patients have the right to demand inappropriate treatment, or that a physician must accede to any and every request of a patient if it conflicts with the physician's best judgment.”

# Informed Consent for Medical Care

# Informed Consent

- Procedures for obtaining informed consent are the primary tools used in health care to insure that a person remains in control of what happens to his or her body.
- The basic idea is that a person's body is her own and she should be in control of what happens to it.
- A person who gives her informed consent to a medical treatment is in control because she understands the treatment being offered and freely accepts it.



# Philosophical reflection on genuine choice

- What is it to be “in control” of a choice?
  - Choices made free of coercion, after rational deliberation, with a good understanding of the consequences of the choice, are generally considered to represent the authentic preferences of the chooser.
- Can we say anything more substantive about what it is to be “in control”?
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# Elements of Informed Consent

- Competency/Capacity
- Voluntariness
- Disclosure
- Understanding
- Consent

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- Capacity is a medical determination.
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(These can come out of sync: a patient can regain decision capacity but still be declared incompetent under a court order.)

- Capacity can be evaluated by any physician. A psychiatrist has specialized training to make determinations in tough cases.
- That a patient has a mental illness (such as depression, schizophrenia, etc.) does not entail that the patient lacks capacity.

# Determining Capacity

- Applebaum and Grisso (*NEJM*, 1988) necessary and jointly sufficient conditions for decisional capacity:
  - the ability to communicate choices;
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  - the ability to rationally manipulate information; and
  - the ability to appreciate the situation and its consequences.
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Applebaum criteria



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  - "Incapacitated person" means any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause except minority to the extent that he *lacks sufficient understanding or capacity to make or communicate responsible decisions* concerning his person

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- Free from threat of force or harm
- Controversy: Free from excessive reward
- Physician abandonment vs. appropriate referral and end of physician-patient relationship
- Family pressure

# Disclosure of Information

## Three issues

- **What?** What is the content that needs to be provided?
- **How Much?** At what level of detail?
- **When?** Under what circumstances, what triggers a requirement for the discussion.

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*It is widely agreed that disclosure should include*

*(1) the patient's current medical status, including the likely course if no treatment is provided;*

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*Jonsen, Clinical Ethics, Chapter 2*

# What Information? (CMS CoP 2007)

- Health status, diagnosis, prognosis
- Potential short and longer term risks and benefits of proposed intervention
- Treatment alternatives, including doing nothing
- Care after discharge
- Resident or trainee participation in surgery

# What Information?

## Controversial Questions

- A physician's experience with a procedure
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  - “What is your rate of central line infections?”
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# How Much? Level of Detail

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- Informed consent is a process spread throughout the care of the patient.
  - Right to “be informed of health status, *being involved in care planning and treatment*, being able to request or refuse treatment.” (CMS, 2007)
- Formal documented session and signed form prior to major interventions; Surgery, Anesthesia, Blood transfusion, Chemotherapy, Radiation Therapy, and others.

# Understanding

- Practitioner assesses the patient's understanding of information
- “Teach back” method

# Consent – Not just a form

- Mental action on the part of the patient – They have made a decision.
- Signature on form indicates the mental action has occurred.
- More people are recommending documentation in the MR in addition to signed form.

# Placebos

A 73-year-old widow lives with her son. He brings her to a physician because she has become extremely lethargic and often confused. The physician determines that, after being widowed 2 years earlier, she had difficulty sleeping, had been prescribed hypnotics, and is now physically dependent on them. The physician determines the best course would be to withdraw her from her present medication by a trial on placebos.

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Is it permissible to prescribe the patient a placebo?

No. Placebos involve deception and this is discouraged. Many physicians still use placebos. The AMA is generally against their use. (The AMA says you can use a placebo if you tell the patient about it.)

# The Nocebo Effect

## The nocebo effect: How health warnings cause health troubles

Doctors grapple with the moments when 'do no harm' and informed consent collide

By Chris Ziegler | Boston.com 09/08/12

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# End of Life Ethics, Briefly

## Life Imitates Work

**P**ATRICIA HAYDEN POWELL, THE MOTHER FOR WHOM I was named, died early one morning last October. As a middle-aged person and a physician, I can claim no surprise at the loss of an elderly parent. Many of my friends and contemporaries have recently faced the same loss, a natural consequence of the passage of time. As a bioethicist I have shepherded many families through discussions of impending loss and medical decision-making in the context of grief and uncertainty. I was in some ways better prepared than many other health care proxies. I was also a bewildered daughter, more like than unlike any other.

My mother died *with* dementia, but *of* heart disease. Her dementia progressed gradually over the last decade, and more obviously after the death of my father three years ago. My mother at the end knew some of her six children by name some of the time, though she might also mistake one of us for a relative from another generation—a son became a brother or a husband. She needed substantial help in all activities of daily living. In earlier phases of dementia my mother was anxious and

ner at which my demented grandmother was rattling away in a nonsense version of French. She told me not to do it a few years ago when we talked about her mother, and my father also reminded me not to give my mother a pacemaker. As far as advance directives went, my mother did everything right. She had a child who is a physician and appointed that child as health care proxy. She formed a specific opinion about a treatment and expressed that opinion in unambiguous terms to many people on more than one occasion.

And yet because the cardiologist had been called, along he came. An earnest, thoughtful, and respectful young man, he spent a lot of time talking with my family. He told my siblings that “No one is allowed to die of heart block.” He further opined that no palliative care could be offered, since any symptom would come without warning and would be untreatable. He supposed that her death would feel “like drowning.” He noted that most cardiologists would refuse to turn off a pacemaker once it was installed. He himself would consider stopping the pacemaker, but only if all six of my mother’s children agreed in

# My mother died with dementia, but of heart disease.

Patient: Patricia Hayden Powell

- Older woman (assume 80s)
- Moderate dementia (QOL acceptable now)
- Episode of shaking and LOC. R/O brain hemorrhage; R/O seizures; diagnosed heart block.
- Heart block – pacemaker recommended
- Six children, husband deceased

Patient wishes

- Had specifically said she would not want pacemaker. Why? Because she watched her mother languish for 12 years with Alzheimer's after receiving a pacemaker
- Had filled out an Advanced Directive, appointed POA, and talked to all her children about her wishes.

# My mother died with dementia, but of heart disease.

## Cardiologist Recommendations

- “No one is allowed to die of heart block”
- “Death would feel like drowning”
- Palliative care not possible
- Admitted many cardiologists would not remove pacemaker; he would, if all six children agreed.

## Decision-making

- When patient asked about pacemaker: “Whatever the doctor thinks is best.”
- Children divided.
- POA (physician-daughter) urged for pacemaker hoping it could be withdrawn if QOL deteriorated.
- Pacemaker authorized.

# End of Life Ethics

## Three dimensions

- Active vs. Passive (How death occurs)
- Prognosis
- Knowledge of patient's preferences

# End of Life Ethics

## Active vs. Passive

- The more active the means of providing death, the more controversial and (generally) the less ethically acceptable.
- *Allowing to die* is permissible under the right conditions.
- *Killing* a patient is never permissible.

# Active vs. Passive

- Withholding LST
- Withdrawing LST
- DNR
- Withdrawing Food and Fluids
- Withdrawing ICD
- DNR during surgery
- Double effect of pain medication
- Palliative Sedation
- PAS
- Active Killing



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# End of Life Ethics

- Active vs. Passive
- Prognosis
  - Good prognosis: withdrawing life-sustaining care from a patient with a good prognosis is suspect.
  - Very bad prognosis: not withdrawing futile care wastes resources and increases suffering.

## *Three dimensions of EOL decision Making*

- Active vs. Passive
- Prognosis
- Knowledge of patient's preferences
  - The more certain that you are do what the patient wants (or would want) the less controversial the decision.
  - The less certain you are, the more controversial the decision

# Patient Preferences

- Patient has capacity. Ask the patient.
- Patient lacks capacity.
  - **Substituted Judgment:** Determine what the patient would have wanted were they able to understand relevant information and make a choice.
  - Search for **evidence**
    - POA
    - Family
    - Living Will
    - Medical Record
    - Other providers (PCP)
  - If sufficient evidence from these sources of evidence is not available, move to **best interest** standard

# Who makes decisions for a patient who lacks capacity?

In order of priority:

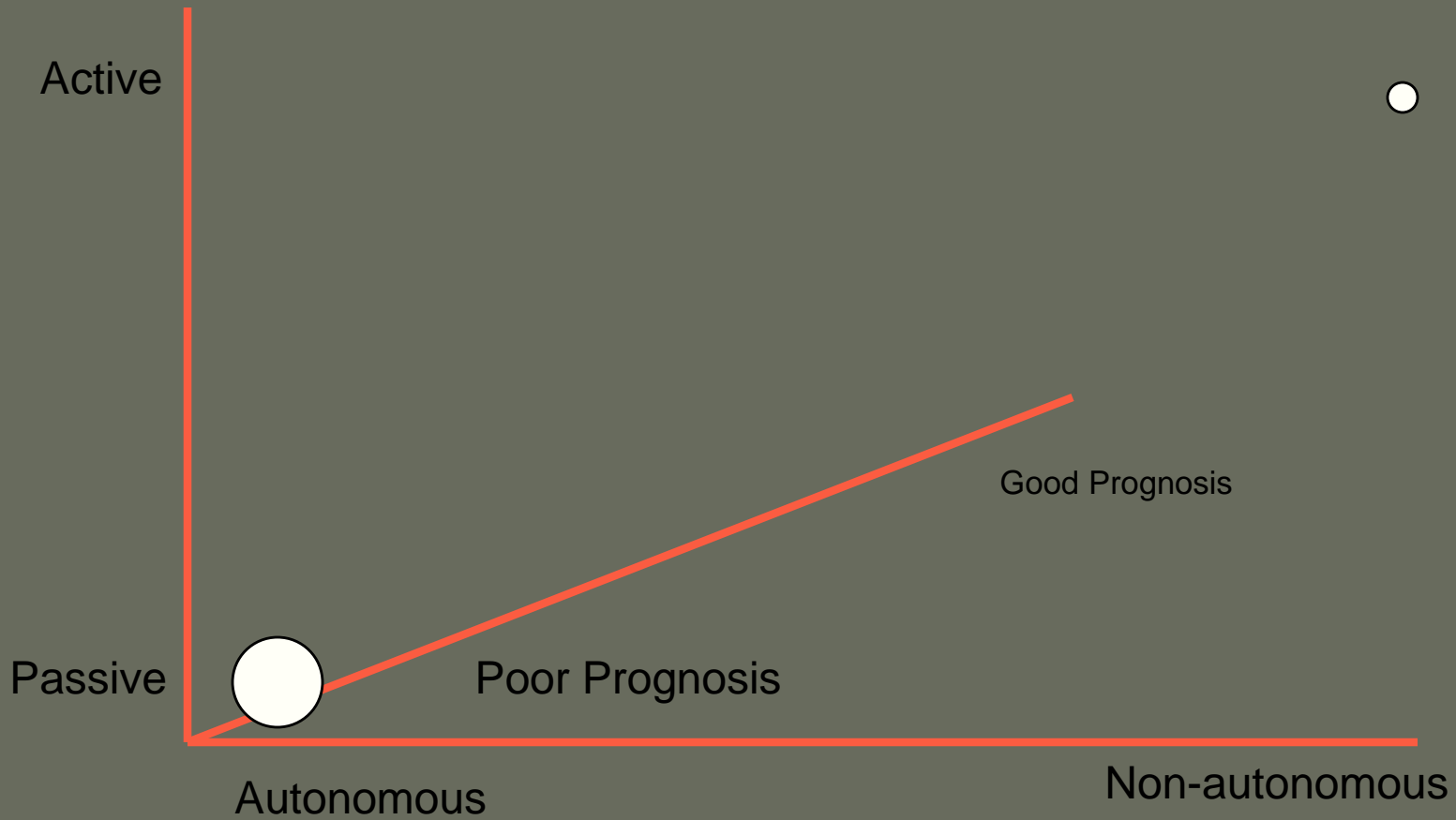
1. Power of attorney (unless revoked)
2. Court appointed guardian
3. Family member acting as surrogate.
4. Others who know the patient

# **Maine Law: Surrogacy** (Title 18A §5-805)

## *Priority of surrogates*

- (1) The spouse, unless legally separated;**
  - (1-A) An adult who shares an emotional, physical and financial relationship with the patient similar to that of a spouse;**
  - (2) An adult child;**
  - (3) A parent;**
  - (4) An adult brother or sister;**
  - (5) An adult grandchild;**
  - (6) An adult niece or nephew, related by blood or adoption;**
  - (7) An adult aunt or uncle, related by blood or adoption; or**
  - (8) Another adult relative of the patient, related by blood or adoption, who is familiar with the patient's personal values and is reasonably available for consultation.**
- (c) If none of the individuals eligible to act as surrogate under subsection (b) is reasonably available, an adult who has exhibited special concern for the patient, who is familiar with the patient's personal values and who is reasonably available may act as surrogate.**





# Catholic Church View on AN&H

- <http://ncbcenter.org/document.doc?id=9>



## THE NATIONAL CATHOLIC BIOETHICS CENTER

6399 Drexel Road, Philadelphia, PA 19151 Tel. 215-877-2660 Fax. 215-877-2688 [www.ncbcenter.org](http://www.ncbcenter.org)

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*Ethics & Medics* enjoys a broad circulation to bishops, parish priests, and others engaged in pastoral ministry. It is our intent to provide occasional practical inserts that you will find useful in preparing homilies and ministering to individuals in clinical and pastoral settings.

*"Preaching Points on Nutrition and Hydration," prepared by the NCBC Ethicists, is the second of these.*

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Thank You

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# Outline

- Respect for Patient Autonomy
  - A little from the history books
  - Bottom Line
- Informed Consent
  - Five elements: Capacity, Voluntariness, Disclosure, Understanding, Consent.
  - Placebos and nocebos
- EOL Ethics, Briefly

# Veracity vs. Therapeutic Privilege

A Little History

“Speak to the patient carefully and adroitly,  
concealing most things.”

“Life is short, the Art long, opportunity  
fleeting... The physician must be ready  
not only to do his duty himself, but also to  
secure the cooperation of the patient.

*Hippocrates*



Yield to patients in matters of little consequence, but maintain an inflexible authority. . . in matters essential to life.

*Benjamin Rush, 1786*

“The only point at issue is, whether the practitioner shall sacrifice that delicate sense of veracity, which is so ornamental to, and indeed forms a characteristic of excellence of the virtuous man, to this claim of professional justice and social duty.”

“To a patient who makes inquiries which, if faithfully answered, might prove fatal to him, it would be a gross and unfeeling wrong to reveal the truth. His right to it is suspended, and even annihilated.”

Thomas Percival, *Medical Ethics*, 1803

# Contrary View

The physician . . . is invariably bound never to represent the uncertainty or danger as less than he actually believes it to be.

*Rev. Thomas Gisborne 1794*

# Case from Jonsen

Mr. S.P., a 55-year-old teacher, has had chest pains and several fainting spells during the past 3 months. He reluctantly visits a physician at his wife's urging. He is very nervous and anxious and says to the physician at the beginning of the interview that he abhors doctors and hospitals. On physical examination, he has classic signs of tight aortic stenosis, confirmed by echocardiogram. The physician wants to recommend cardiac catheterization and probably cardiac surgery. However, given his impression of this patient, he is worried that full disclosure of the risks of catheterization would lead the patient to refuse the procedure.

Should the physician explain the diagnosis and risks?  
Who will you follow? Percival or Gisborne

## Contemporary view, from Jonsen

“Communications between physicians and patients should be truthful; that is, statements should be in accord with facts. If the facts are uncertain, that uncertainty should be acknowledged. Deception, by stating what is untrue or by omitting what is true, should be avoided.”

More history  
Deception in Research

# Tuskegee Syphilis Study

- 1930 until 1972
- US Public Health Service
- Poor, African-American men in Macon County Alabama
- “Study in nature” of syphilis.
- Prevented subjects from seeking treatment in order to study untreated syphilis.
- Little disclosure; deceptive language





# Tuskegee Syphilis Study



Dear Sir:

Some time ago you were given a thorough examination and since that time we hope you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination. This examination is a very special one and after it is finished you will be given a special treatment if it is believed you are in a condition to stand it. ...

**REMEMBER THIS IS YOUR LAST CHANCE FOR SPECIAL FREE TREATMENT. REMEMBER TO MEET THE NURSE.**

-Letter sent encouraging subjects to continue participation in the study



# Willowbrook Hepatitis Research



- Institution for mentally retarded children
- Over 5000 residents; 1 attendant/50 residents.
- Hepatitis and other diseases prevalent.
- Director of research intentionally exposed new residents to hepatitis in order to learn about different types of hepatitis and test gamma globulin as a protective therapy.



# Willowbrook Hepatitis Research

- Saul Krugman became very well known for his discoveries
  - Identification of Hepatitis A and B
  - Immunoglobulins confer passive immunity
- During some periods, children denied admission to Willowbrook unless they consented to the study.
- Disclosure about the study was misleading.
- Defense of Research: Although children were intentionally infected, they probably would have been infected anyway, and they received good clinical care because they were part of the study.

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A 73-year-old widow lives with her son. He brings her to a physician because she has become extremely lethargic and often confused. The physician determines that, after being widowed 2 years earlier, she had difficulty sleeping, had been prescribed hypnotics, and is now physically dependent on them. The physician determines the best course would be to withdraw her from her present medication by a trial on placebos.

Is it permissible to prescribe the patient a placebo?

No. Placebos involve deception and this is discouraged. Many physicians still use placebos. The AMA is generally against their use. (The AMA says you can use a placebo if you tell the patient about it.)

# The Nocebo Effect

## The nocebo effect: How health warnings cause health troubles

Doctors grapple with the moments when 'do no harm' and informed consent collide

By Chris Ziegler | BOSTON GLOBE | 09/08/12

ARTICLE COMMENTS SUBSCRIBE

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2012: What ended

Mom, what was happening?

How to talk like a doomsday gripper

The art (literally) of espionage

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Free legal advice—but does it work?

I saw paranormal Santa Claus

Did an invisible run on banks kill the economy?

What Scotland's public bikes tell us about the city

How lights define a city

Think yourself full

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Breaking news of the Revolutionary War

And 2012's word of the year is...



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# End of Life Ethics, Briefly

## Life Imitates Work

**P**ATRICIA HAYDEN POWELL, THE MOTHER FOR WHOM I was named, died early one morning last October. As a middle-aged person and a physician, I can claim no surprise at the loss of an elderly parent. Many of my friends and contemporaries have recently faced the same loss, a natural consequence of the passage of time. As a bioethicist I have shepherded many families through discussions of impending loss and medical decision-making in the context of grief and uncertainty. I was in some ways better prepared than many other health care proxies. I was also a bewildered daughter, more like than unlike any other.

My mother died *with* dementia, but *of* heart disease. Her dementia progressed gradually over the last decade, and more obviously after the death of my father three years ago. My mother at the end knew some of her six children by name some of the time, though she might also mistake one of us for a relative from another generation—a son became a brother or a husband. She needed substantial help in all activities of daily living. In earlier phases of dementia my mother was anxious and

ner at which my demented grandmother was rattling away in a nonsense version of French. She told me not to do it a few years ago when we talked about her mother, and my father also reminded me not to give my mother a pacemaker. As far as advance directives went, my mother did everything right. She had a child who is a physician and appointed that child as health care proxy. She formed a specific opinion about a treatment and expressed that opinion in unambiguous terms to many people on more than one occasion.

And yet because the cardiologist had been called, along he came. An earnest, thoughtful, and respectful young man, he spent a lot of time talking with my family. He told my siblings that “No one is allowed to die of heart block.” He further opined that no palliative care could be offered, since any symptom would come without warning and would be untreatable. He supposed that her death would feel “like drowning.” He noted that most cardiologists would refuse to turn off a pacemaker once it was installed. He himself would consider stopping the pacemaker, but only if all six of my mother’s children agreed in

# My mother died with dementia, but of heart disease.

Patient: Patricia Hayden Powell

- Older woman (assume 80s)
- Moderate dementia (QOL acceptable now)
- Episode of shaking and LOC. R/O brain hemorrhage; R/O seizures; diagnosed heart block.
- Heart block – pacemaker recommended
- Six children, husband deceased

Patient wishes

- Had specifically said she would not want pacemaker. Why? Because she watched her mother languish for 12 years with Alzheimer's after receiving a pacemaker
- Had filled out an Advanced Directive, appointed POA, and talked to all her children about her wishes.

# My mother died with dementia, but of heart disease.

## Cardiologist Recommendations

- “No one is allowed to die of heart block”
- “Death would feel like drowning”
- Palliative care not possible
- Admitted many cardiologists would not remove pacemaker; he would, if all six children agreed.

## Decision-making

- When patient asked about pacemaker: “Whatever the doctor thinks is best.”
- Children divided.
- POA (physician-daughter) urged for pacemaker hoping it could be withdrawn if QOL deteriorated.
- Pacemaker authorized.



# End of Life Ethics

## Three dimensions

- Active vs. Passive (How death occurs)
- Prognosis
- Knowledge of patient's preferences

# End of Life Ethics

## Active vs. Passive

- The more active the means of providing death, the more controversial and (generally) the less ethically acceptable.
- *Allowing to die* is permissible under the right conditions.
- *Killing* a patient is never permissible.

# Active vs. Passive

- Withholding LST
- Withdrawing LST
- DNR
- Withdrawing Food and Fluids
- Withdrawing ICD
- DNR during surgery
- Double effect of pain medication
- Palliative Sedation
- PAS
- Active Killing

# Active vs. Passive

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  - Withdrawing LST
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- Withdrawing ICD
- DNR during surgery
- Double effect of pain medication
- Palliative Sedation
- PAS
- Active Killing

# End of Life Ethics

- Active vs. Passive
- Prognosis
  - Good prognosis: withdrawing life-sustaining care from a patient with a good prognosis is suspect.
  - Very bad prognosis: not withdrawing futile care wastes resources and increases suffering.

## *Three dimensions of EOL decision Making*

- Active vs. Passive
- Prognosis
- Knowledge of patient's preferences
  - The more certain that you are do what the patient wants (or would want) the less controversial the decision.
  - The less certain you are, the more controversial the decision



# Patient Preferences

- Patient has capacity. Ask the patient.
- Patient lacks capacity.
  - **Substituted Judgment:** Determine what the patient would have wanted were they able to understand relevant information and make a choice.
  - Search for **evidence**
    - POA
    - Family
    - Living Will
    - Medical Record
    - Other providers (PCP)
  - If sufficient evidence from these sources of evidence is not available, move to **best interest** standard

# Who makes decisions for a patient who lacks capacity?

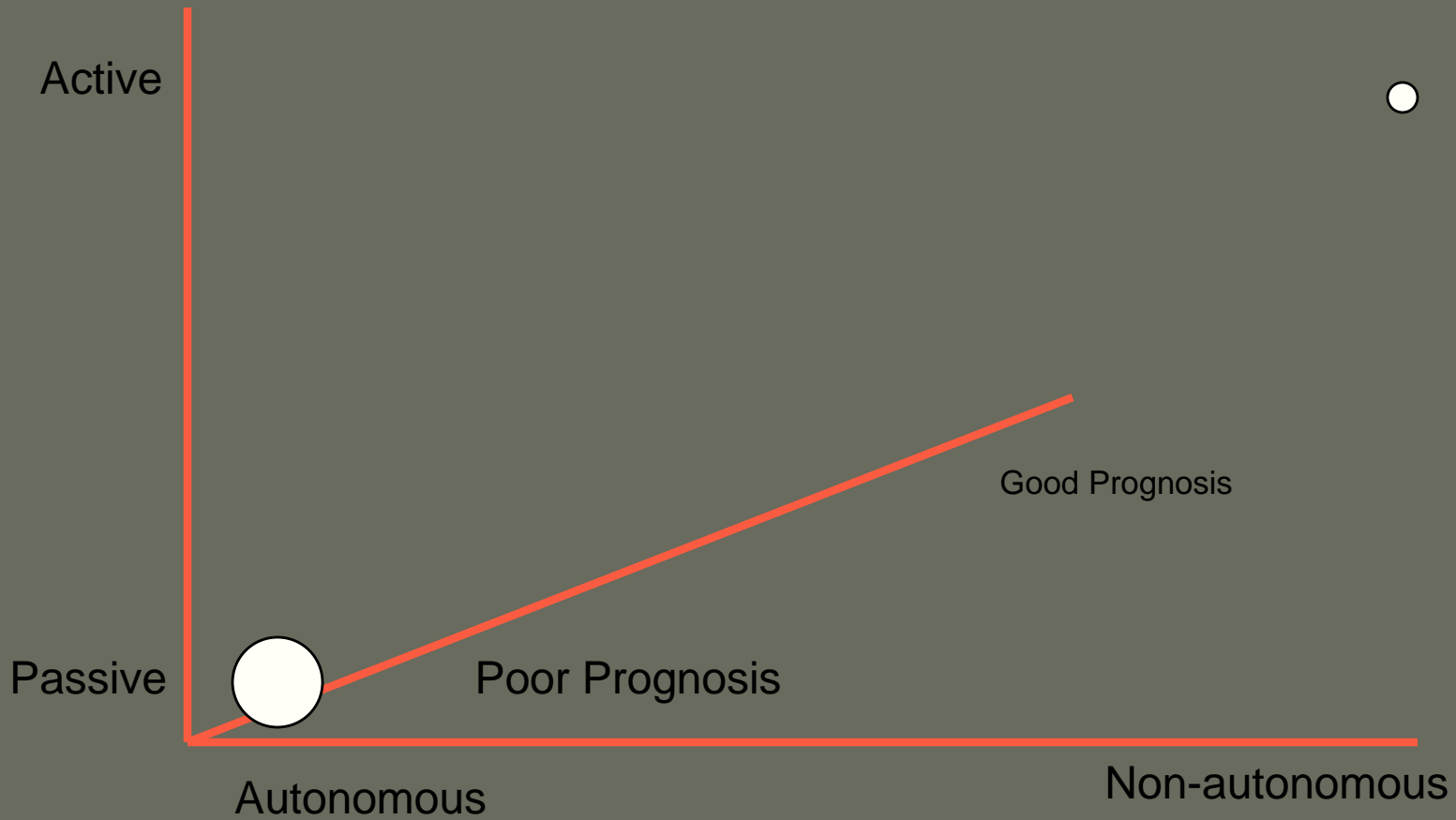
In order of priority:

1. Power of attorney (unless revoked)
2. Court appointed guardian
3. Family member acting as surrogate.
4. Others who know the patient

# **Maine Law: Surrogacy** (Title 18A §5-805)

## *Priority of surrogates*

- (1) The spouse, unless legally separated;**
  - (1-A) An adult who shares an emotional, physical and financial relationship with the patient similar to that of a spouse;**
  - (2) An adult child;**
  - (3) A parent;**
  - (4) An adult brother or sister;**
  - (5) An adult grandchild;**
  - (6) An adult niece or nephew, related by blood or adoption;**
  - (7) An adult aunt or uncle, related by blood or adoption; or**
  - (8) Another adult relative of the patient, related by blood or adoption, who is familiar with the patient's personal values and is reasonably available for consultation.**
- (c) If none of the individuals eligible to act as surrogate under subsection (b) is reasonably available, an adult who has exhibited special concern for the patient, who is familiar with the patient's personal values and who is reasonably available may act as surrogate.**



# Catholic Church View on AN&H

- <http://ncbcenter.org/document.doc?id=9>



## THE NATIONAL CATHOLIC BIOETHICS CENTER

6399 Drexel Road, Philadelphia, PA 19151 Tel. 215-877-2660 Fax. 215-877-2688 [www.ncbcenter.org](http://www.ncbcenter.org)

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*Ethics & Medics* enjoys a broad circulation to bishops, parish priests, and others engaged in pastoral ministry. It is our intent to provide occasional practical inserts that you will find useful in preparing homilies and ministering to individuals in clinical and pastoral settings.

*"Preaching Points on Nutrition and Hydration," prepared by the NCBC Ethicists, is the second of these.*

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Thank You

Frank Chessa, Ph.D.  
[chessf@mmc.org](mailto:chessf@mmc.org)

<b>Format</b>	Small group discussion
<b>Faculty</b>	Facilitators
<b>Learning Objective</b>	Identify the relevant facts and use the appropriate ethical principles to argue a position in cases pertaining to patient preferences.
<b>Readings</b>	<u>Cases for Discussion</u> <ul style="list-style-type: none"><li>• Is Artificial Nutrition And Hydration Extraordinary Care?</li><li>• Taking No for an Answer—Refusal of Life-Sustaining Treatment</li><li>• Psychiatrist's Role in Involuntary Hospitalization</li><li>• Can Parents of a Child with Autism Refuse Treatment for Him?</li><li>• Can a Minor Refuse Assent for Emergency Care?</li></ul>

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<b>Format</b>	Large group lecture
<b>Faculty</b>	Chessa
<b>Learning Objectives</b>	<p>By the end of this lecture, students will be able to:</p> <ul style="list-style-type: none"><li>• Describe the historical context that gave rise to the substituted judgment standard for patients without decisional capacity</li><li>• Define contemporary tools and techniques (e.g., Durable Power of Attorney, Advance Directives and POLST) that are used in advanced care planning for adults</li><li>• Explain the ethical standards that guide parental decision making for children (and other dependents), including the right of parents and/or children to refuse life saving care</li><li>• Describe ethical challenges in caring for patients who express a desire to accept treatment but demonstrate non-adherent or disruptive behavior</li><li>• Justify how the rights of patients to medically indicated care may be balanced against the rights of providers to conscientiously object to the provision of such care</li></ul>
<b>Readings</b>	Jonsen text: p 47 – 107

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# Outline

- EOL Ethics, super quick review
- Patient's without capacity
  - Surrogate Decision Makers
  - Advance Directives and POLST
  - Palliative Care
  - Ethics and Economics
- Decision making for children
- Patient choice, physician integrity



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- (c) If none of the individuals eligible to act as surrogate under subsection (b) is reasonably available, an adult who has exhibited special concern for the patient, who is familiar with the patient's personal values and who is reasonably available may act as surrogate.**

# Are surrogate accurate?

- Since 1966, there have been 16 studies that tested the accuracy of surrogate decision-makers
- Compare surrogate and patient responses to hypothetical end-of-life scenarios
- 151 scenarios; 2595 surrogate-patient pairs; 19,526 responses.
- Overall accuracy?
- 68%

Shalowitz et.al., The Accuracy of Surrogate Decision Makers, *Archives Internal Medicine* 166 (Mar 13, 2006)

# Is 68% good or bad?

- What sort of error are surrogates making?
  - 12 studies evaluated this question
  - 3 found surrogates tend to provide interventions patients don't want; 1 found surrogates tend to withhold interventions patients want; 8 found no consistent trend.
- Are surrogates more accurate than physicians?
  - Yes (4 studies)

# Can we make it better?

- Suggestion #1: Trust POAs over next-of-kin surrogates
  - POA and next-of-kin surrogates are roughly equally accurate (69 vs 68%).
  - Specific familial relationship not predictive of accuracy.
- Suggestion #2: Prior discussion between patient and surrogate increase accuracy of surrogate.
  - 7 studies (5 uncontrolled) show no consistent trend; one controlled study showed accuracy decreased with a prior discussion.

# Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others

David Wendler, PhD, and Annette Rid, MD

**Conclusion:** Making treatment decisions has a negative emotional effect on at least one third of surrogates, which is often substantial and typically lasts months (or sometimes years). Future research should evaluate ways to reduce this burden, including methods to identify which treatment options are consistent with the patient's preferences.

# FIVE WISHES<sup>®</sup>

## MY WISH FOR:

The Person I Want to Make Care<sup>1</sup> Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want<sup>2</sup>

How Comfortable I Want to Be<sup>3</sup>

How I Want People to Treat Me<sup>4</sup>

What I Want My Loved Ones to Know<sup>5</sup>

print your name

# Maine's Advanced Directive

Taking Charge  
of Your Health



## Maine Health Care Advance Directive Form

You may use this form now to tell your physician and others what medical care you want to receive if you become too sick in the future to tell them what you want. You may choose to fill out the whole form or any part of the form and then sign and date the form in Part 6. These are the parts:

<b>Part 1</b>	Fill this out if you want to choose someone to make all your health care decisions for you, either right away or if you become too sick to tell others what you want. This person is called your agent. <b>Directives</b>
<b>Part 2</b>	Fill this out if: (1) you did not name an agent in Part 1 and now want to choose whether you want certain treatments or, (2) you did name an agent in Part 1 and want to tell your agent your wishes about certain treatments, knowing that your agent must follow your directions. <b>POA</b>
<b>Part 3</b>	Fill this out if you want to give the name of your primary physician, physician assistant or nurse practitioner.
<b>Part 4</b>	Fill this out if you want to make decisions about donating your organs, body or tissues after your death.
<b>Part 5</b>	Fill this out if you want: (1) to choose someone to make all funeral and burial decisions after your death, or (2) to tell your family any wishes you have about funeral and burial decisions.
<b>Part 6</b>	You must sign and date your Advance Directive form on this page. Have two witnesses sign the form at the same time you sign it. Tell others about your decisions and give copies to your physician, other health care providers, family and hospital.
<b>Part 7</b>	If you do not wish to be revived by ambulance crews should your heart or breathing stop, then you <b>and</b> your physician (or nurse practitioner or physician assistant) need to sign this Do Not Resuscitate (DNR) form.



# Older Maine Form

I **do** or **do not** want my life prolonged if

- (1) I have an incurable and irreversible condition that will result in my death within a relatively short time;
- (2) If I become unconscious and to a reasonable degree of medical certainty I will not regain consciousness; or
- (3) The likely risks and burdens of treatment would outweigh the expected benefits

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- (3) The likely risks and burdens of treatment would outweigh the expected benefits

# New Maine Form

I **do** not want treatment to keep me alive if my physician decides any of the following is true

- (1) I have an illness that will not get better, cannot be cured, and will result in my death quite soon (sometimes referred to as a terminal condition),
- (2) I am no longer aware (unconscious) and it is very likely that I will never be conscious again (sometimes referred to as a persistent vegetative state).

# Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD

## Problems with Advance Directives

- Have not been effective (after 20 years experience)
- Values change over time
  - Adaptation with declining health
- Too general for specific treatment decisions.
- *Terminal* and *Irreversible* are vague concepts
- Context matters – clinical, social, emotion
- Surrogates need leeway

# Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD

We propose that the main objective of advance care planning be to prepare patients and surrogates to participate with clinicians in making the best possible **in-the-moment** decisions. Preparing patients for such decisions shifts the focus away from premature treatment decisions based on incomplete or hypothetical information and ensures that complex health care decisions are based on a more comprehensive set of considerations, including the current clinical context, shifting and evolving goals, and patients' and surrogates' needs.



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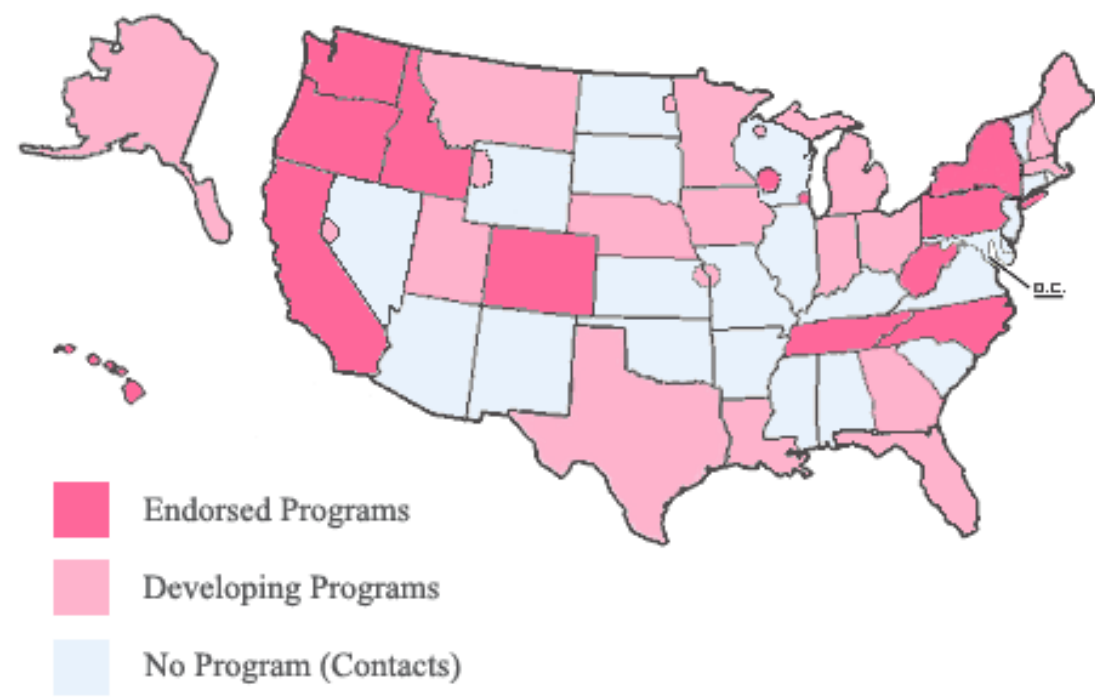
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## POLST State Programs

Please click on your state to learn if there is a POLST Paradigm Program in your state or community.



# Physicians Orders for Life Sustaining Treatment

(Generally, for people with less than one year of life)

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT 4/2009  
**Physician Orders for Life-Sustaining Treatment (POLST)** Maine

First follow these orders, then contact physician, NP or PA. These medical orders are based on the patient's **current** medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section.

Last Name / First / Middle Initial	
Address:	
City / State / Zip:	
Date of Birth:	Gender: M F

**A** **CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.**  
 Check One Attempt Resuscitation/CPR Do Not Attempt Resuscitation/DNR (Allow Natural Death)  
 When not in cardiopulmonary arrest, follow orders in B, C and D.

**B** **MEDICAL INTERVENTIONS: Patient has pulse and/or is breathing.**  
 Check One **Comfort Measures Only:** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Do Not Transfer to Hospital for life sustaining treatment. Transfer if comfort needs cannot be met in current setting.*  
**Limited Additional Interventions:** Includes all care described above. Use medical treatment and monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). **Transfer to hospital if indicated. Avoid intensive care.**  
**Full Treatment:** Includes all care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer to hospital if indicated. Includes intensive care.**  
**Additional Orders:**

**C** **ANTIBIOTICS**  
 Check One No antibiotics. Use other measures to relieve symptoms.  
 Determine use or limitation of antibiotics when infection occurs.  
 Use antibiotics if medically indicated.  
**Additional Orders:**

**D** **ARTIFICIALLY ADMINISTERED NUTRITION / HYDRATION: Offer food / liquids by mouth if feasible.**  
 Check One for part 1 **Part 1 – Nutrition:** No artificial nutrition by tube  
 Trial period of artificial nutrition by tube.  
 Goal: \_\_\_\_\_  
 Long-term artificial nutrition by tube.  
 Check One for part 2 **Part 2 – Hydration:** No artificially administered fluids  
 Trial period of artificial hydration.  
 Goal: \_\_\_\_\_  
 Full treatment with artificially administered fluids.  
**Additional Orders:**

**E** **BASIS FOR ORDERS**  
 My signature below indicates to the best of my knowledge that these orders are consistent with the patient's **current** medical condition and preferences as indicated by:

<b>Basis for determining patient's preferences</b> (check all that apply) Advance Directive (on file) Patient's current statement to Physician /NP/ PA Patient's statement to authorized representative Best interest determined by authorized representative (no advance directive / preferences known)	<b>Discussion with:</b> (check all that apply) Patient Parent of a minor Guardian Health Care Agent Other
--	--

Print Name of Primary Care Professional Phone:  
 Print Name of Signing Physician / PA / NP Phone:  
 Signature of Physician / PA / NP (required) Date:

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT 4/2009

**F** **Signature of Patient or Authorized Representative**  
 This form records your preferences for life-sustaining treatment in your **current** state of health. It can be reviewed and updated by your health care professional at any time if your preferences or condition change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by the authorized representative named below.

Signature	Name (print)	Relationship (write 'self' if patient)
Name of Authorized Representative	Relationship	Address & Phone

Health Care Professional Preparing Form Title Phone Date

**Directions for Health Care Professionals**

**Completing POLST**

- Should reflect patient's preferences based on **current** medical condition. Encourage completion of an advanced directive.
- POLST must be signed by a physician, nurse practitioner or physician assistant to be valid. Verbal orders are acceptable with follow up signature by the physician/NP/PA in accordance with facility /community policy.
- Use of original form is strongly encouraged. Photocopies and faxes are legal and valid.
- Patient should sign this form if (s)he is able to make his/her own health care decisions. If unable to sign, an authorized representative should sign.
- An Authorized Representative includes, in order of priority, a health care agent (same as durable health care power of attorney or agent named in advance directive), court appointed guardian, parent of minor, or surrogate as defined in 18-A MRS § 5-801.

**Using POLST**

- Section A**
- No defibrillator (including AED's) should be used on a person who has chosen "Do Not Attempt Resuscitation."
- Section B**
- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort Measures Only", should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- IV medication to enhance comfort may be appropriate for a patient who has chosen "Comfort Measures Only."

**Reviewing POLST**  
 This POLST should be reviewed periodically and if:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

Draw a line through sections A through F and write "VOID" in large letters if POLST is replaced or becomes invalid.

**SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED**



# Section B: Medical Interventions

<p><b>B</b> <i>Check One</i></p>	<p><b>MEDICAL INTERVENTIONS: Patient has pulse <u>and/or</u> is breathing</b></p> <p><b>___ Comfort Measures Only:</b> Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Do Not Transfer to Hospital for life sustaining treatment.</i> <i>Transfer if comfort needs cannot be met in current setting.</i></p> <p><b>___ Limited Additional Interventions:</b> Includes all care described above. Use medical treatment and monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). <b>Transfer to hospital if indicated.</b> <i>Avoid intensive care.</i></p> <p><b>___ Full Treatment:</b> Includes all care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <i>Transfer to hospital if indicated.</i> <i>Includes intensive care.</i></p> <p><b>Additional Orders:</b></p>
--------------------------------------	---

# Section C: Antibiotics

**C**

## **ANTIBIOTICS**

*Check  
One*

- No antibiotics. Use other measures to relieve symptoms.
- Determine use or limitation of antibiotics when infection occurs.
- Use antibiotics if medically indicated.

***Additional Orders:***

# A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem

*Bernard J. Hammes, PhD,\* Brenda L. Rooney, PhD, MPH,† and Jacob D. Gundrum, MS\**

**CONCLUSION:** A system for ACP can be managed in a geographic region so that, at the time of death, almost all adults have an advance care plan that is specific and available and treatment is consistent with their plan. *J Am Geriatr Soc* 58:1249–1255, 2010.

- All adults have a plan
- It is specific
- It is available at the point of care
- It is followed

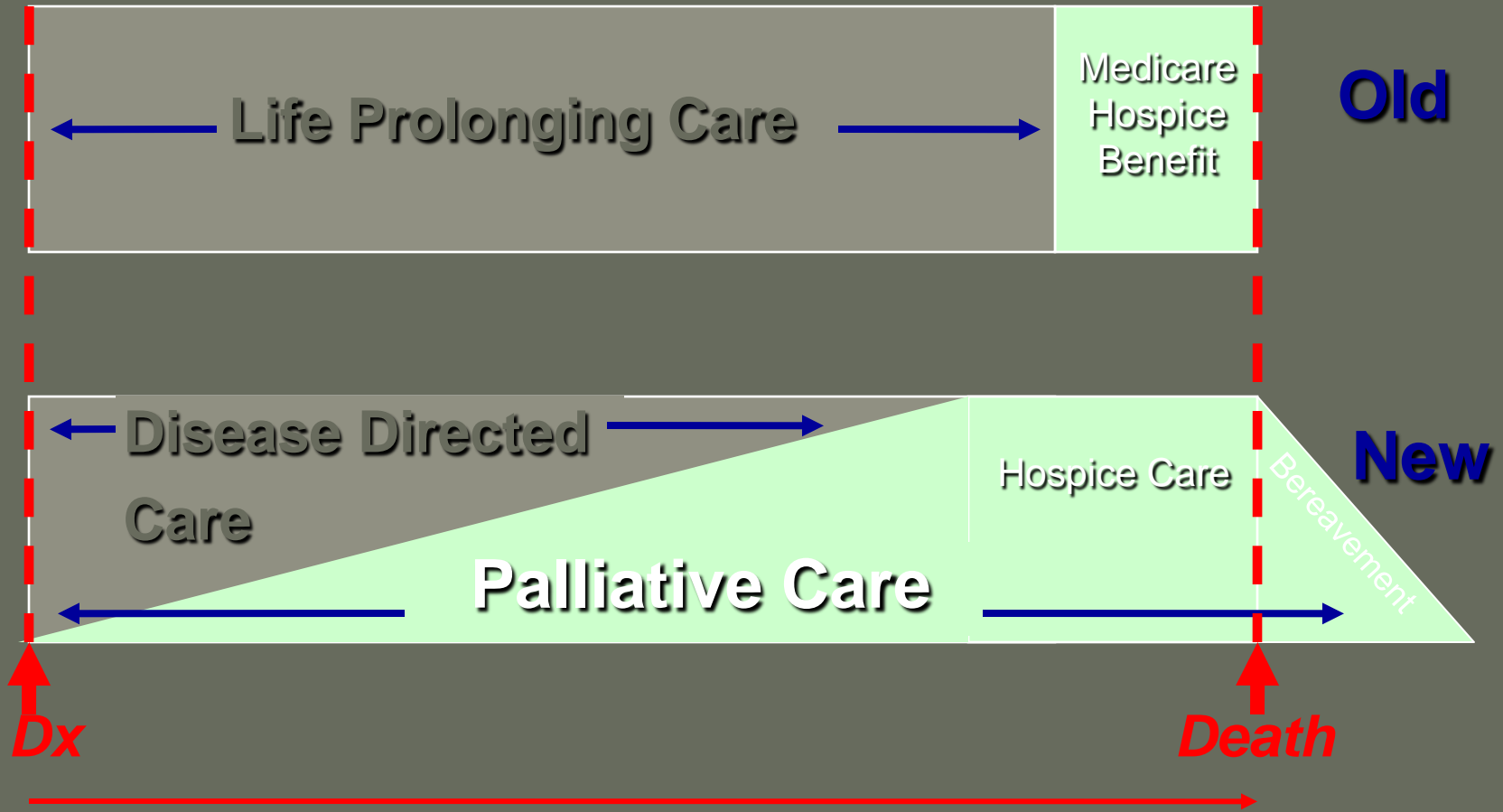
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Bernard J. Hammes, PhD,\* Brenda L. Rooney, PhD, MPH,<sup>†</sup> and Jacob D. Gundrum, MS\*

**Table 2. Prevalence, Availability, and Creation Date of Advance Directives (ADs), La Crosse Advance Directive Study (LADS) I (N = 540) Versus LADS II (N = 400)**

Advance Directive Status	LADS I	LADS II	P-Value
Decedents with ADs, n (%)	459 (85.0)	360 (90.0)	.02
Of these, ADs in medical record, n (%)	437 (95.2)	358 (99.4)	<.001
Type of AD, n (%)			
Power of attorney for health care	353 (77)	324 (90.0)	<.001
Living will	46 (10)	30 (8.0)	.41
Dictated note	60 (13)	120 (33.0)	<.001
POLST, n (%)	NA	268 (67.0)	NA
Of these, POLSTs in medical record, n (%)	NA	264 (98.5)	NA
Years from AD creation to death, oldest date used, median (range)	1.3 (0–13.6)*	3.8 (0–21)*	<.001
Months from POLST creation to death, median (range)	NA	4.3 (0–114)	NA

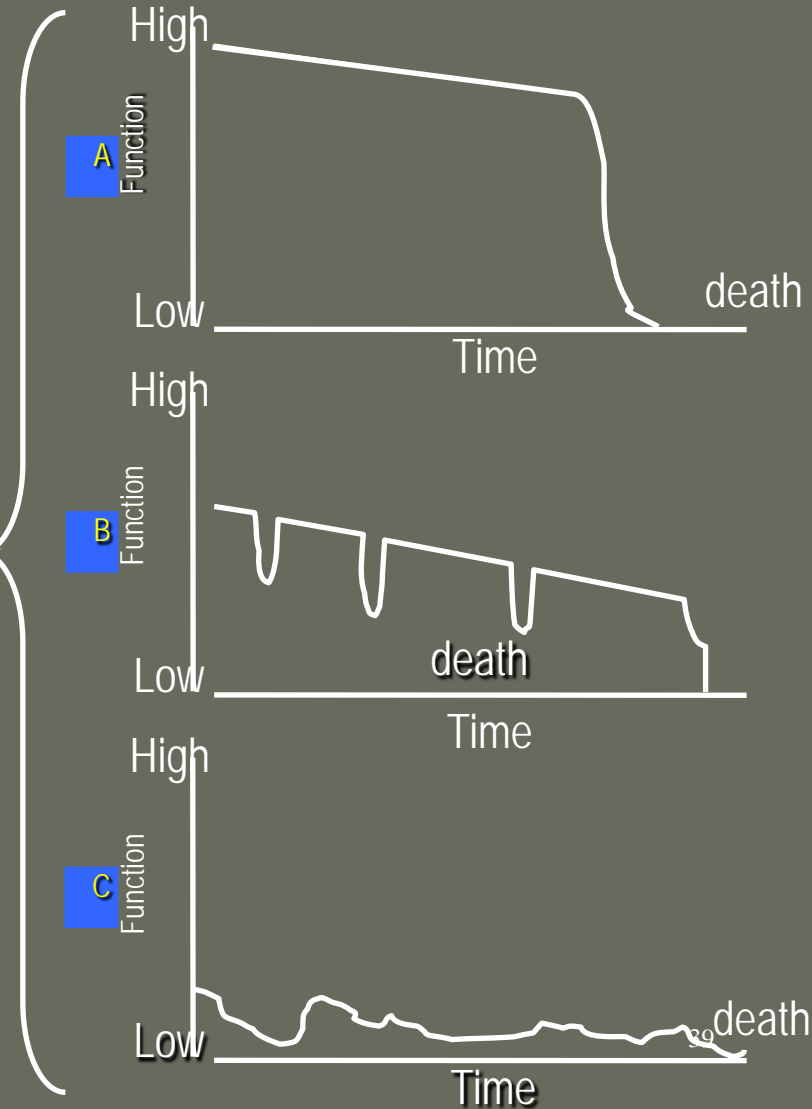
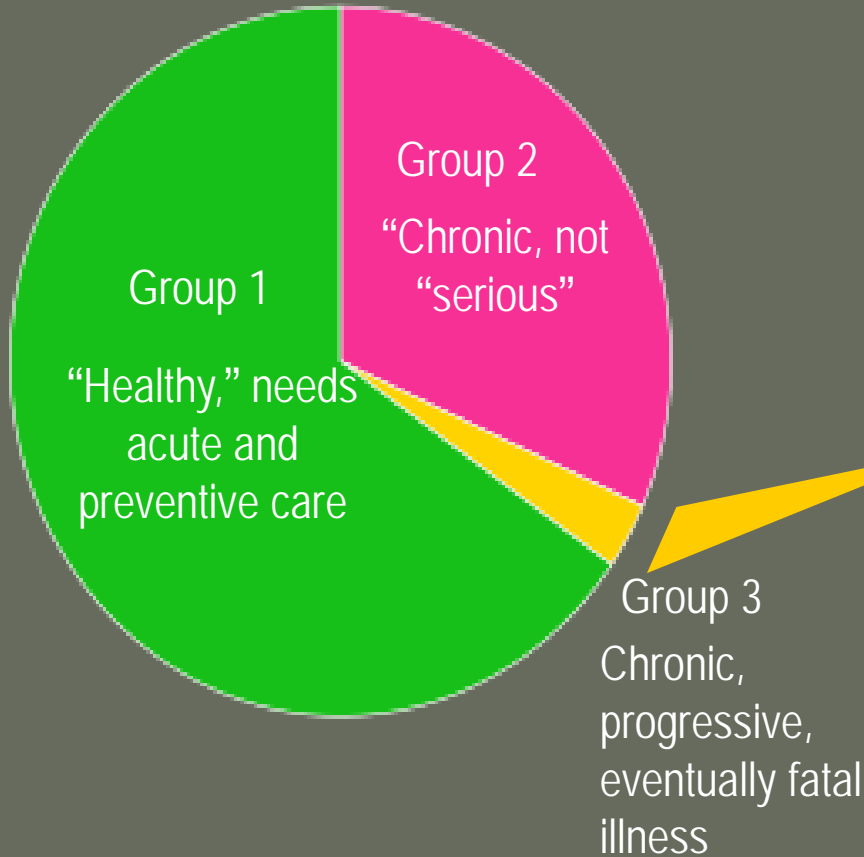
# Modern US Palliative Care



# Divisions by Health Status in the Population and Trajectories of Eventually Fatal Chronic Illnesses

Divisions in the Population

Major Trajectories near Death





# Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction\*

Jonathan R. McDonagh, MD; Tricia B. Elliott; Ruth A. Engelberg, PhD; Patsy D. Treece, RN, MN; Sarah E. Shannon, PhD, RN; Gordon D. Rubenfeld, MD, MSc; Donald L. Patrick, PhD, MSPH; J. Randall Curtis, MD, MPH

**Objective:** Family members of critically ill patients report dissatisfaction with family-clinician communication about withdrawing life support, yet limited data exist to guide clinicians in this communication. The hypothesis of this analysis was that increased proportion of family speech during ICU family conferences would be associated with increased family satisfaction.

**Design:** Cross-sectional study.

**Setting:** We identified family conferences in intensive care units of four Seattle hospitals during which discussions about withdrawing life support were likely to occur.

**Participants:** Participants were 214 family members from 51 different families. There were 36 different physicians leading the conferences, as some physicians led more than one conference.

**Interventions:** Fifty-one conferences were audiotaped.

**Measurements:** We measured the duration of time that families and clinicians spoke during the conference. All participants were given a survey assessing satisfaction with communication.

**Results:** The mean conference time was 32.0 mins with an SD of 14.8 mins and a range from 7 to 74 mins. On average, family members spoke 29% and clinicians spoke 71% of the time. Increased proportion of family speech was significantly associated with increased family satisfaction with physician communication. Increased proportion of family speech was also associated with decreased family ratings of conflict with the physician. There was no association between the duration of the conference and family satisfaction.

**Conclusions:** This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. Future studies should assess the effect of interventions to increase listening by critical care clinicians on the quality of communication and the family experience. (Crit Care Med 2004; 32:1484–1488)

**KEY WORDS:** end-of-life care; family satisfaction; communication; death; dying; critical care



## ORIGINAL ARTICLE

## Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,  
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,  
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,  
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,  
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

### CONCLUSIONS

Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

DOI: 10.1377/hlthaff.2010.0929  
 HEALTH AFFAIRS 30,  
 NO. 3 (2011): 454–463  
 ©2011 Project HOPE—  
 The People-to-People Health  
 Foundation, Inc.

By R. Sean Morrison, Jessica Dietrich, Susan Ladwig, Timothy Quill, Joseph Sacco, John Tangeman, and Diane E. Meier

## THE CARE SPAN

# Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries

### EXHIBIT 2

Comparison Of Palliative Care And Usual Care Costs For A Single Hospitalization Of Adult Medicaid Enrollees, 2004–07

	Discharged alive			Died in hospital		
	Usual care	Palliative care	Net change	Usual care	Palliative care	Net change
Average total cost per admission	\$36,741	\$32,643	-\$4,098**	\$68,804	\$61,241	-\$7,563**
Average total cost per day	\$2,744	\$2,254	-\$490****	\$3,503	\$3,187	-\$316***
Average intensive care cost per admission	\$6,452	\$3,774	-2,678****	\$29,706	\$28,420	-\$1,286
Average intensive care length-of-stay (days)	5.8	5.3	-0.5	13.8	10.2	-3.6**
Average laboratory cost per admission	\$1,801	\$1,519	-\$282	\$4,885	\$4,777	-\$108
Average imaging cost per admission	\$1,697	\$1,478	-\$219	\$2,661	\$2,676	\$25
Average pharmacy cost per admission	\$2,719	\$2,705	-\$14	\$10,392	\$8,168	-\$2,224**
Percent discharged to hospice	1%	30%	29%****	— <sup>a</sup>	— <sup>a</sup>	— <sup>a</sup>
Percent dying in intensive care	— <sup>a</sup>	— <sup>a</sup>	— <sup>a</sup>	58%	34%	-24%**

# Ethics, Economics and End of Life Care

# The Dartmouth Atlas

## **“Unwarranted Variation in Care”**

### Three Categories of Care

1. Effective Care
2. Preference Sensitive Care
3. Supply Sensitive Care

# Dartmouth Atlas EOL Report

April 12, 2011

- Analyses Medicare Data 2003-2007
- Widespread regional variation in EOL care
- Good News
  - Fewer days in hospital at the end of life
  - Less likely to die in hospital
  - More likely to die in Hospice
- Bad News
  - Saw more physicians near end of life
  - Referred to more specialists in last six weeks of life
  - More time in ICU in last six weeks of life

# Comparative Cost of Care: Last 2 Years of Life

Hospital	Reimbursement per deceased pt (2-yr total)	Reimbursement per day	Hospital days per deceased pt
Gundersen	\$18,359	\$1,355	13.5
Marshfield/St. Joseph's	\$23,249	\$1,126	20.6
US Nat'l Average	\$25,860	\$1,096	23.6
University of WI	\$28,827	\$1,462	19.7
Cleveland Clinic	\$31,252	\$1,307	23.9
Mayo Clinic	\$31,816	\$1,497	21.3
UCLA	\$58,557	\$1,871	31.3

# Ethical Framework for Medical Decision Making for Children



# Jacob

- Jacob is a 10 year old with aplastic anemia. He was admitted with increased bruising and petechial rash and found to be pancytopenic.
- There was not a HLA compatible bone marrow donor in Jacob's family, so immunosuppressive therapy was recommended.
- Jacob's parents declined immunosuppressive therapy, which is the standard therapy when no related donor is available. Instead, Jacob's parents decided to pursue CAM therapies, primarily Chinese herbal medicine guided by a local practitioner.

# Jacob

- Jacob's parents are pleasant, articulate people who are open to discussing their decision-making. There has been a good deal of cooperation between the family, his physicians and CAM providers.
- The parents hope for a cure for Jacob. They believe that Chinese medicine offers a better chance of cure with fewer side effects. However, they say they are giving Chinese medicine a "trial run." If it does not work, they will try standard therapy.
- The trial run has now lasted five months. Jacob's parents have continued to bring him to clinic for blood tests and transfusions. Jacob continues to be severely pancytopenic, but has not yet had a serious infection.

# Jacob: Ethical Questions

- Is it permissible (or obligatory) to take steps to limit parental decision-making authority given the parent's refusal of the recommended treatment?
- Is it permissible to continue to see Jacob in clinic and provide “non-standard” management of his disease, e.g., blood transfusions?

# Primary duties to pediatric patients

- Beneficence (Best Interest)
- Respect for autonomy *commensurate with development of decision making capacity in the child*

# Primary duties to pediatric patients

- Beneficence
- Respect for autonomy *commensurate with development of decision making capacity in the child*

*“Decision-making involving the health care of older children and adolescents should include, to the greatest extent feasible, the assent of the patient as well as the participation of the parents and the physician.”*

*(AAP Committee on Bioethics, 1995)*

# AAP Policy Statement, 1995

- *Informed Consent, Parental Permission, and Assent in Pediatric Practice*
  - “Informed Consent” is inappropriate terminology
  - “Parental Permission” is favored
  - Should include the “assent” of patients to the greatest extent feasible
  - Recognizes that pediatricians face potentially conflicting duties.

# Arguments for priority of parental decision making?

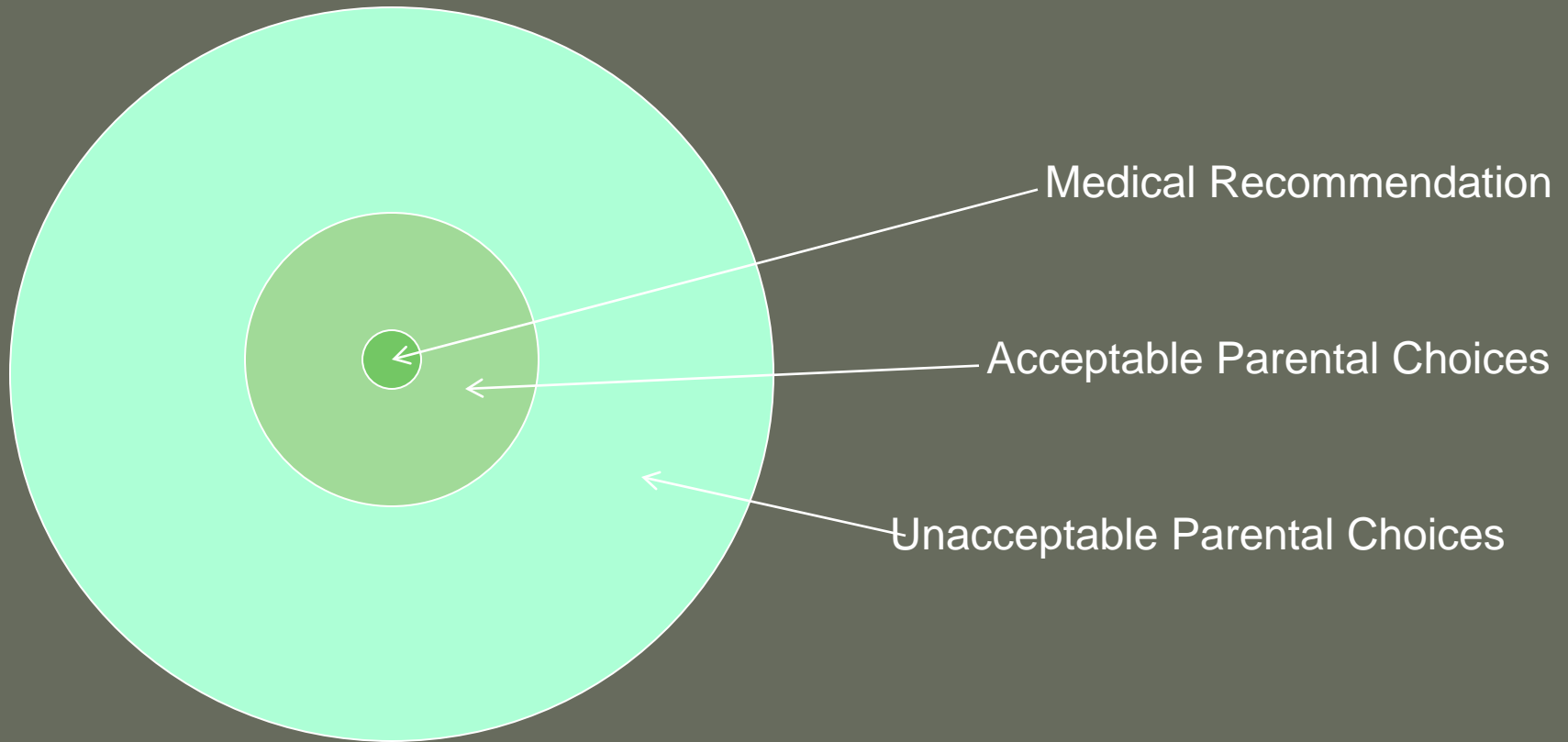
- Parents, given their knowledge and concern, are the most capable of making a decision that promotes the interests of the child.
- Parents bear the consequences, financial and otherwise, of treatment decisions.
- Parents have a right, within limits, to foster their own standards and values in their children.
- Families need freedom from state intrusion and control to foster close bonds between family members.



# AAP Policy Statement, 1995

“[P]roxy consent” poses serious problems for pediatric health care providers. Such providers have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses. Although impasses regarding the interests of minors and the expressed wishes of their parents or guardians are rare, the pediatrician's responsibilities to his or her patient exist independent of parental desires or proxy consent.

# Limits to Parental Authority



# Patient Choice and Physician Integrity

Sub-optimal Care  
Unhealthy Behaviors  
Non-Adherence  
Disruptive Behaviors  
Moral Conflicts

# Autonomy for patients and physicians

“When there are medical indications for treatment, a physician should propose a treatment plan that a patient may accept or refuse .

“As a moral principle, respect for autonomy is a "two-way street": the autonomy of physicians to act only on their best judgment about how best to benefit a patient medically, must also be respected. Therefore, respect for patient autonomy does not imply that patients have the right to demand inappropriate treatment, or that a physician must accede to any and every request of a patient if it conflicts with the physician's best judgment.”

# What is the physician's responsibility to patients who

- desire suboptimal care
- engage in risky or unhealthy behaviors
- are non-adherent to treatment plans
- have disruptive behaviors
- desire morally-contested services

# Clinician Integrity and Limits to Patient Autonomy

John Lantos, MD

Ann Marie Matlock, RN, MSN

David Wendler, PhD

**R**ESPECT FOR PATIENT AUTONOMY plays a central role in modern clinical ethics,<sup>1</sup> and clinicians today are trained to provide care based on patients' preferences and requests.<sup>2-4</sup> However, patients occasionally request treatments that their clinicians think are inappropriate. In these cases, respect for patient autonomy can conflict with clinicians' professional integrity, forcing clinicians to decide to what extent their professional integrity places limits on the types of care they should agree to provide.

This dilemma arises because the physicians and nurses who provide medical care have rights and obligations of

A 28-year-old man with chronic granulomatous disease developed worsening respiratory status in the setting of chronic bacterial and fungal infections. The attending physician recommended transfer to the intensive care unit (ICU), but the patient declined. The patient understood that the nurses in the ICU have expertise in caring for patients with poor respiratory function. He also understood that he faced an increased risk of dying if he remained on the medical ward. At the same time, the patient was familiar with the nurses on the medical ward and felt comfortable there. Unsure of whether it was appropriate for clinicians to agree to provide less than optimal care for a critically ill patient, the clinicians on the medical ward requested a bioethics consultation. This article reviews the ethical issues that arise when patients ask clinicians to provide less than optimal care. Although it is well established that clinicians ought to respect patient autonomy, that obligation conflicted, in the present case, with the clinicians' sense of professional integrity. Future research on this vital but underexplored topic is needed to determine the extent to which clinicians' professional integrity places limits on the types of patient requests to which they should agree.

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- Patient goal is to prolong life and improve function.
- Yet, some of the patients choice are at odds with this goal.
- How should we deal with this?



# Non-Adherence

Ms. Cope is admitted for inpatient treatment of obesity with a protein-sparing modified fasting regimen. She was found repeatedly in the cafeteria cheating on the diet. Clinicians made reasonable efforts to persuade her to change her behavior. A decision was made to discharge her. She protested vigorously.

- Was the discharge ethically permissible?
- Was it the best option?
- If you were her PCP, would you discharge her from your outpatient practice?

# Non-Adherence and Disruptive Behavior

- Ron, an IV drug addict, is admitted for the third time with a diagnosis of infective endocarditis. He is on his second prosthetic valve.
- After 1 week of antibiotic therapy, he continues to have positive blood culture results. One cardiac surgeon refuses to operate, saying that correcting his drug addiction is futile. Another surgeon agrees to operate. Mr. R.A. consents to surgery to replace the valve. Postoperatively, for 10 days he is cooperative, afebrile with negative cultures. Plans is for discharge, with venous access for antibiotics.
- He begins to behave erratically. He leaves his room and stays away for hours, missing some meds. Urine screening demonstrate the presence of opiates and quinine, revealing that he is using illicit narcotics. Two cultures now grow *S. aureus*.
- He verbally abuses two nurses. Several patients complain that he threatened them. Nurses suspect he is dealing drugs within the hospital.
- Despite the fact that the patient's infective endocarditis has not been treated optimally, the physician asks him to leave the hospital immediately.

» Adapted from Jonsen, *Clinical Ethics*, Chapter 2, section 6

# Questions

- Is the discharge ethically permissible?
- Would it have been ethically permissible not to operate to replace the valve?
- Would it have been ethically permissible not to treat the patient with antibiotics when he presented?

Use the principles  
to organize your thoughts.

- Beneficence
- Respect for Patient Autonomy
- Non-maleficence
- Justice

# Physician Moral Beliefs and Patient Care

- Male presents to urologist requesting a penile implant for the purpose of
  - having sex with his wife
  - having sex with his girlfriend
  - having sex with his mistress (he is married)
  - having sex with a male partner
- The urologist believes that sex outside of marriage is immoral.
- Is he ethically required to perform any of the above procedures?
- If not, what steps should he take?

# Abortion and Sterilization Conscience Clauses in the Law

- **The Church Amendments**
- **Public Health Service Act § 245**
- **The Weldon Amendment**


An institution that receives federal funds may not

- require a clinician to participate in sterilization or abortion;
- discriminate against any physician or health care personnel in employment or staff privileges because the individual participated in or refused to participate in sterilization or abortion
- deny admission to any program applicant (including applicants for internships or residencies) because of the applicant's reluctance or willingness to participate in sterilization or abortion.

- **The Affordable Care Act**

- “No qualified health plan offered through an Exchange may discriminate against any individual health care provider or health care facility because of its unwillingness to provide, pay for, provide coverage of, or refer for abortions.”

# Conscience clauses not just about abortion anymore

Posted 10/24/2009 9:00 AM | Comment  | Recommend 

E-mail | Print | **RSS**



 Enlarge

By H. Darr Beiser, USA TODAY

Should doctors be allowed to deny a birth control prescription for moral, not medical, reasons?

By Adelle M. Banks, Religion News Service

WASHINGTON — Faced with a request to give an unmarried female patient a prescription for birth control pills, Dr. Michele Phillips looked to her conscience for the answer.


"I'm not going to give any kind of medication I see as harmful," said Phillips of San Antonio. The drugs would not protect her patient from "emotional trauma from multiple partners," Phillips reasoned, or sexually transmitted diseases. "I could not ethically give that type of medication to a single woman."


After the evangelical Christian refused to write the prescription, she resigned her position. She now does contract work at a faith-based practice that permits her to "prescribe according to my ethical values."


Medical technology has surged forward in recent years, leading to many life-saving and life-giving procedures. At the same time, legal

and ethical remedies haven't kept pace, and officials at the state and federal level are still working out how to address the sometimes competing needs and values of doctors and patients.

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- Refer to another provider?
  - Assumes one is available
  - Considered by some providers to be immoral
  - Right *not to refer* is the new battleground
- Is a person other than the patient harmed?
  - People generally have the right to make unwise or immoral decisions for themselves.
  - Is an embryo or fetus a person?
  - What is the extent of the harm to another person?
- Deep issues in political philosophy
  - We live in a pluralistic, free society that asserts both positive and negative rights.
  - Given that the law establishes rights, it is not possible for public policy to be neutral on all substantive ethical questions.
  - Given pluralism, some people will believe that their natural (not legal) rights are violated no matter the particular arrangement of institutions and laws.
- Conscience cuts both ways
  - Some pro-choice providers argue that their conscience tells them that making abortion available is morally required of them.
- Conscience should always play a role in the practice of medicine
  - Remember that epistemic humility is a virtue.
  - Remember that the patient is at the center – their control of their body and your promise to promote their best interest



**Thank You**

Frank Chessa, Ph.D.  
[chessf@mmc.org](mailto:chessf@mmc.org)

**Format** Small group discussion

**Faculty** Facilitators

**Learning Objective** Identify the relevant facts and use the appropriate ethical principles to argue a position in cases pertaining to patient preferences.

**Readings** Cases for Discussion

- Honoring an Advance Directive
- A Disruptive Dialysis Patient
- Reproductive Rights
- Prescribing Placebos

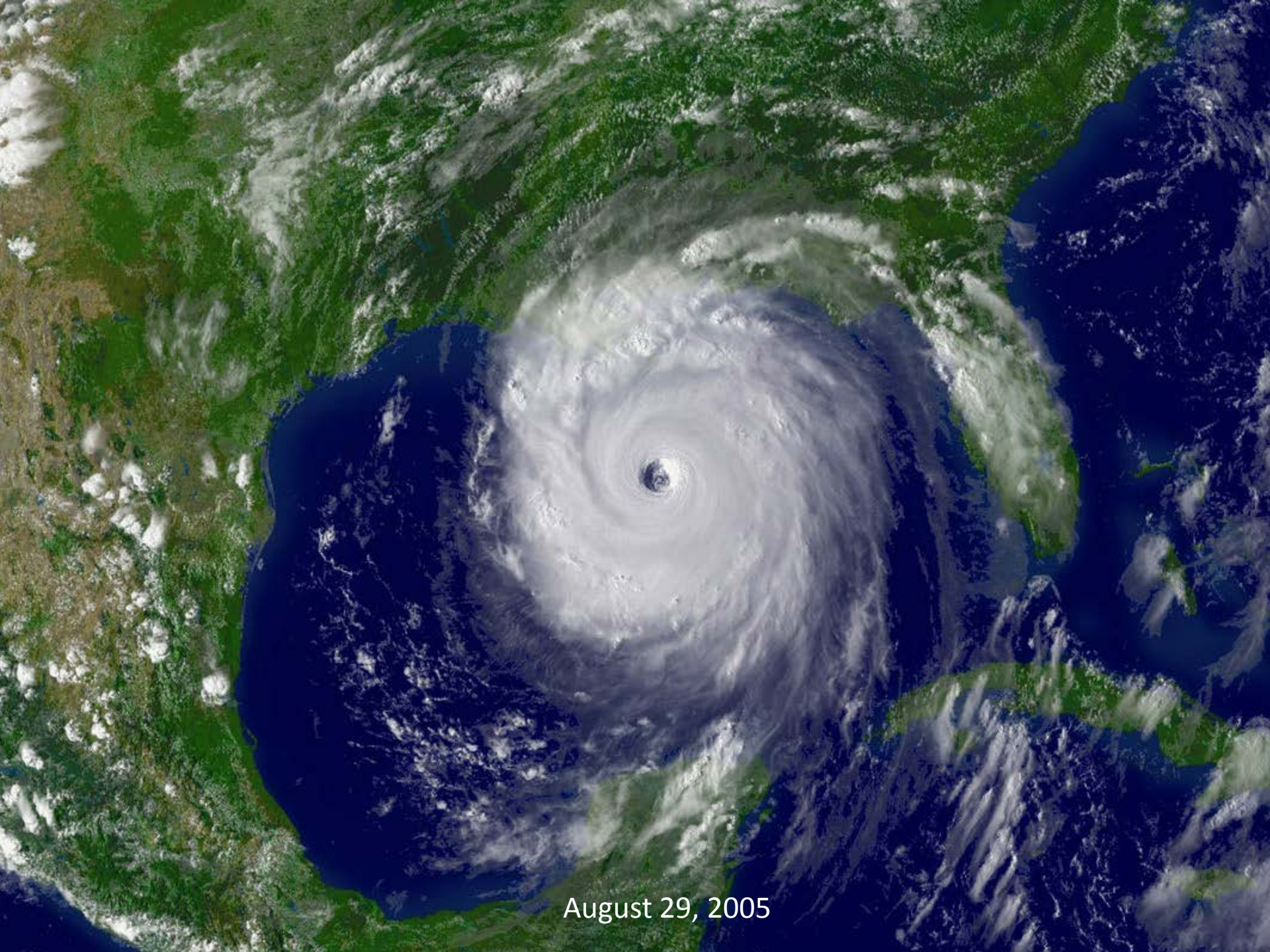
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<b>Format</b>	Large group lecture
<b>Faculty</b>	Glickman-Simon
<b>Learning Objectives</b>	<p>By the end of this lecture, students will be able to:</p> <ul style="list-style-type: none"><li>• Define quality of life and describe its relativistic nature</li><li>• Explain how quality of life considerations relate to principle-based clinical ethics</li><li>• Explain the relationship between quality of life, medical futility and palliative care</li><li>• Consider at what point medical treatment crosses the line to become medical enhancement</li><li>• Argue positions on both sides of the debate over physician-assisted dying</li></ul>
<b>Readings</b>	Jonsen text: p 109 – 159

---

# Quality of Life





August 29, 2005











Anna Pou, MD

# What constitutes a quality life?

- Ability to think and feel
- Ability to communicate thoughts and feelings
- Freedom from pain and suffering
- Opportunity to pursue happiness

# Ethical Controversies Pertaining to Quality of Life

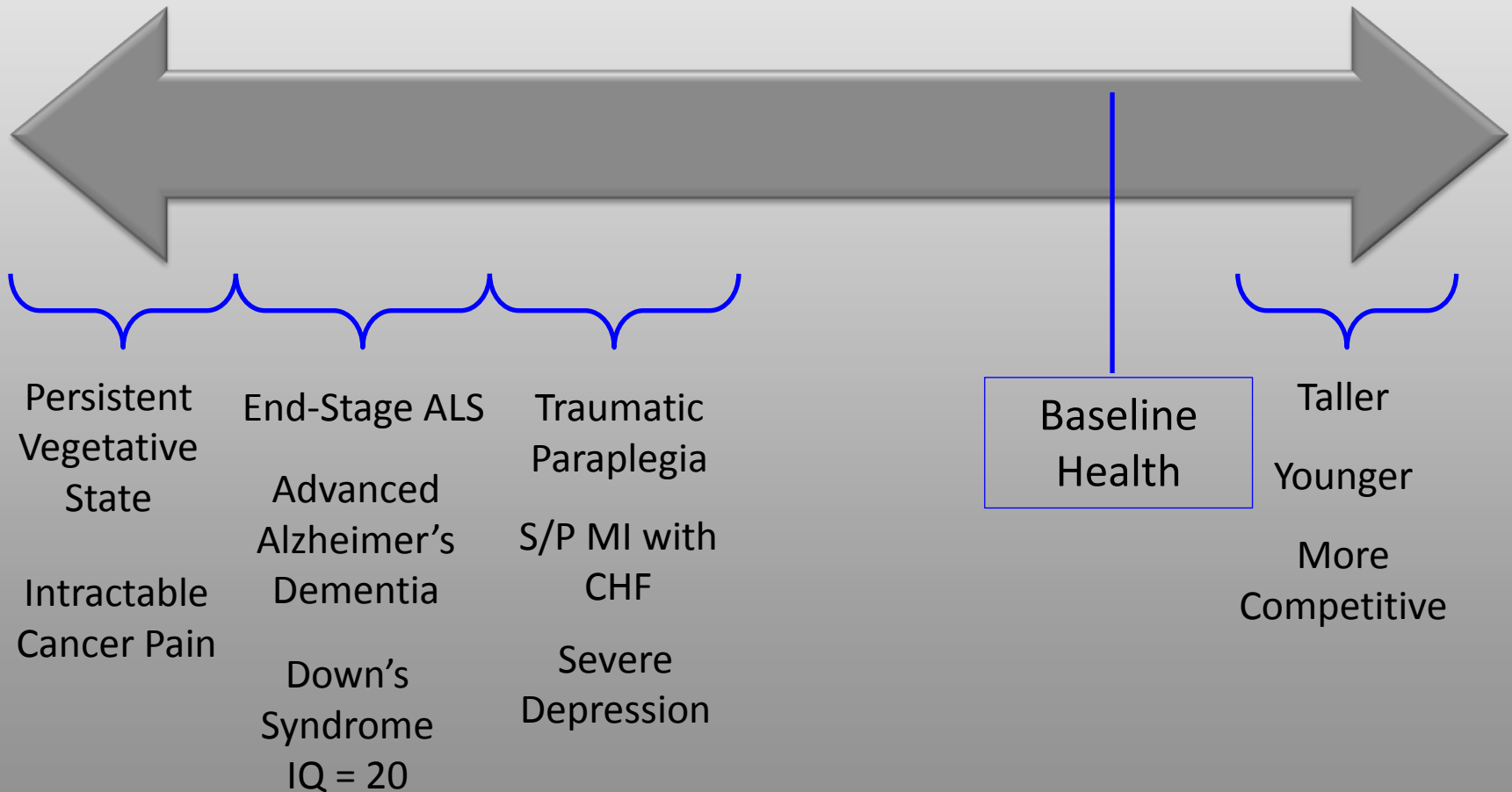
- When physicians and patients disagree about what constitutes a life worth living
- When patients are unable to express their view of the quality of the life they are facing
- When quality of life seems to have been entirely lost (quality of life vs. sanctity of life)
- When enhancement of normal qualities is sought as a goal of medicine
- When quality of life is used as an objective standard for the distribution of scarce resources

# Physicians & Quality of Life

- Physicians consistently rate the quality of their patients' lives lower than the patients' themselves
- Physicians' quality of life assessments strongly influence their clinical decisions, including resuscitation and life-support
- Physicians are not above basing their quality of life judgments on race, gender, age, disability, lifestyle and social worth

The Golden Rule does not  
always apply in clinical  
medicine

# Quality of Life Continuum



# Killing and Dying in Medicine

- Active vs. passive euthanasia
- Omission vs. commission
- Withholding vs. withdrawing
- Ordinary vs. extraordinary

***Principle of Proportionate Treatment** – a medical treatment is mandatory to the extent that it is likely to confer greater benefits than burdens on the patient*

– From Jonsen 2010







10 mL Single-dose  
Preservative-Free **Rx only** Discard

**MORPHINE** **(II)**  
Sulfate Inj., USP

WARNING: MAY BE ABUSIVE FORMING

5 mg/10 mL (0.5 mg/mL) **Fluor**

For IV, Epidural or Intrathecal Use

HOSPINA, INC., LAKE FOREST, IL 60045 USA



Flip-top Vial

**Midazolam** **(II)**  
Injection, USP

10 mg / 10 mL (1 mg/mL)

Sterile. FOR IM or IV Use.

Hospira, Inc., Lake Forest, IL 60045 USA



Jack Kevorkian, MD



The "Mercitron"



Janet Adkins





Kevorkian's "Death" Van

# Principle of Double Effect

Applies to a clinical situation in which two foreseeable outcomes – one good or neutral and the other bad – are inextricably linked. The following criteria must be present for an act to be considered ethically acceptable under this principle:

- The action itself is ethically good or neutral
- The agent must intend the good effects and not the bad effects even though both are foreseen
- The ethically impermissible effect must not be the means to the ethically permissible effect



# Palliative vs. Terminal Sedation

## Palliative Sedation

- The use of potent analgesics at the end of life for the purpose of pain relief that increases the risk of death from excessive sedation
- Principle of double effect applies
- Widely practiced and accepted

## Terminal Sedation

- The use of medications at the end of life to sedate a patient to unconsciousness in an attempt to relieve otherwise intractable suffering followed by the withholding or withdrawing of life sustaining treatment
- No lethal dose of analgesic or sedative is administered
- Principle of double effect does not apply
- Ethically controversial

# 2012 Massachusetts “Death With Dignity” Ballot Proposal

Would allow a physician licensed in Massachusetts to prescribe medication, at a terminally ill patient’s request, to end that patient’s life.

---

## Patient Qualifications

- Capacity to make and communicate health care decisions
- Diagnosed by attending and consulting physicians with an incurable, irreversible disease that will cause death within 6 months
- Voluntarily expresses a wish to die and has made an informed decision

## Patient Requirements

- Communicate the request on 2 occasions separated 15 days apart
- Sign a standard form in the presence of 2 witnesses

# 2012 Massachusetts “Death With Dignity” Ballot Proposal



## Physicians Requirements

- Determine if the patient is qualified
- Inform the patient of his or her medical diagnosis and prognosis, potential risks and probable result of ingesting the medication, and feasible alternatives, including comfort care, hospice care and pain control
- Refer the patient to a consulting physician for diagnosis and prognosis, and confirmation that the patient is acting voluntarily and is capable of making an informed decision
- Refer the patient for psychiatric or psychological consultation if he or she believes the patient may have a disorder causing impaired judgment
- Inform the patient that he or she may rescind the request at any time, and again verify that the patient is making an informed decision at the time the prescription is written
- Arrange for the medicine to be dispensed directly to the patient, or the patient’s agent, but not by mail or courier

# 2012 Massachusetts “Death With Dignity” Ballot Proposal

## Additional Stipulations

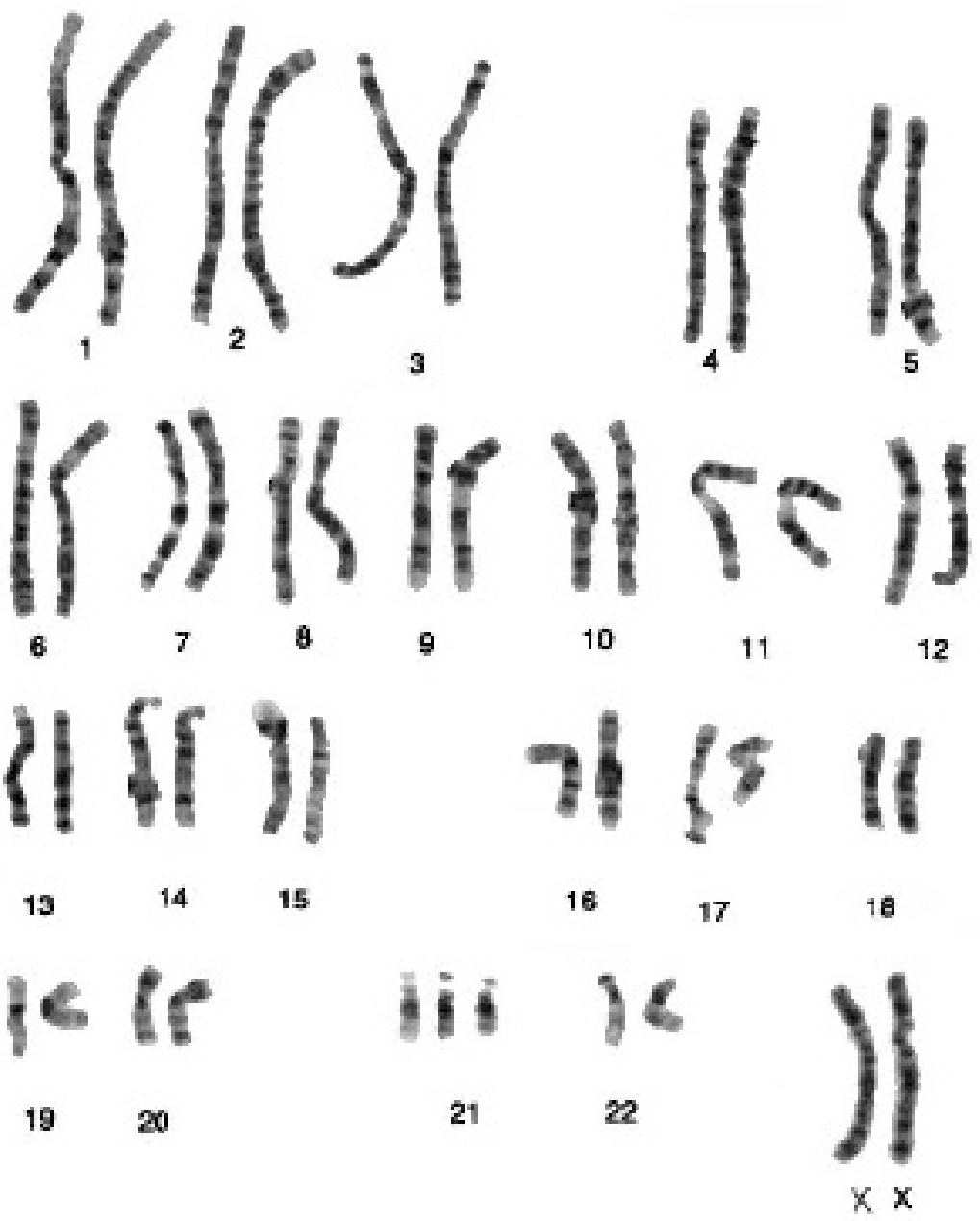
- Coercing a patient to request medication, forging a request, or concealing a rescission would be punishable by imprisonment and/or fines
- Ending a patient’s life by lethal injection, active euthanasia, or mercy killing would remain illegal
- The death certificate would list the underlying terminal disease as the cause of death
- Physician participation would be voluntary

	1,534,757	51.9%
	1,466,866	48.1%

If I end up practicing in a state where  
PAD is legal, I would

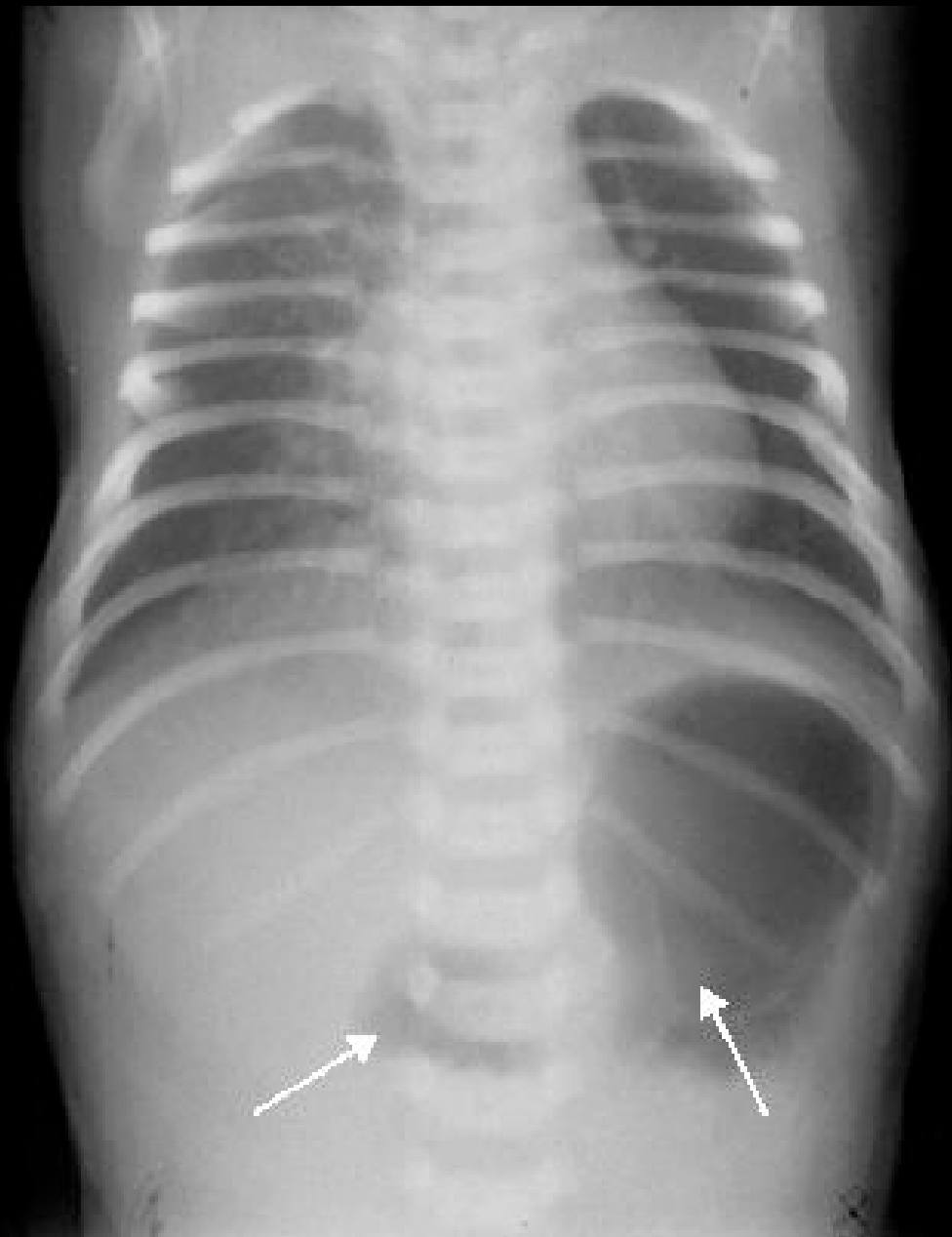
- A. Prescribe medications to help my patients die
- B. Not prescribe medications to help my patients die
- C. Don't know what I would do

# Future Quality of Life









Duodenal Atresia

**Baby Jane Doe**

**Born: October 11, 1983**





# Enhancement Medicine

# Single Women Only

I prefer to date and eventually marry someone

- A. Who is on the tall side
- B. Who is on the short side
- C. Doesn't matter

# Single Men Only

I prefer to date and eventually marry someone

- A. Who is on the tall side
- B. Who is on the short side
- C. Doesn't matter





Manute Bol (7 feet 7 inches)  
Muggsy Bogues (5 feet 3 inches)



Before

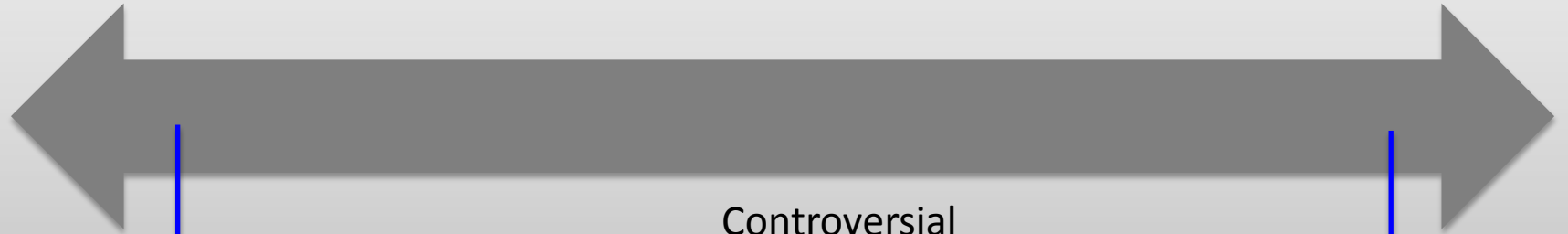


After



LIVESTRONG

# Goals of Medicine



## Controversial

- Assist patients in their deaths
- Enhance patients' natural traits
- Accept patients based solely on their ability to pay

## Universally Accepted

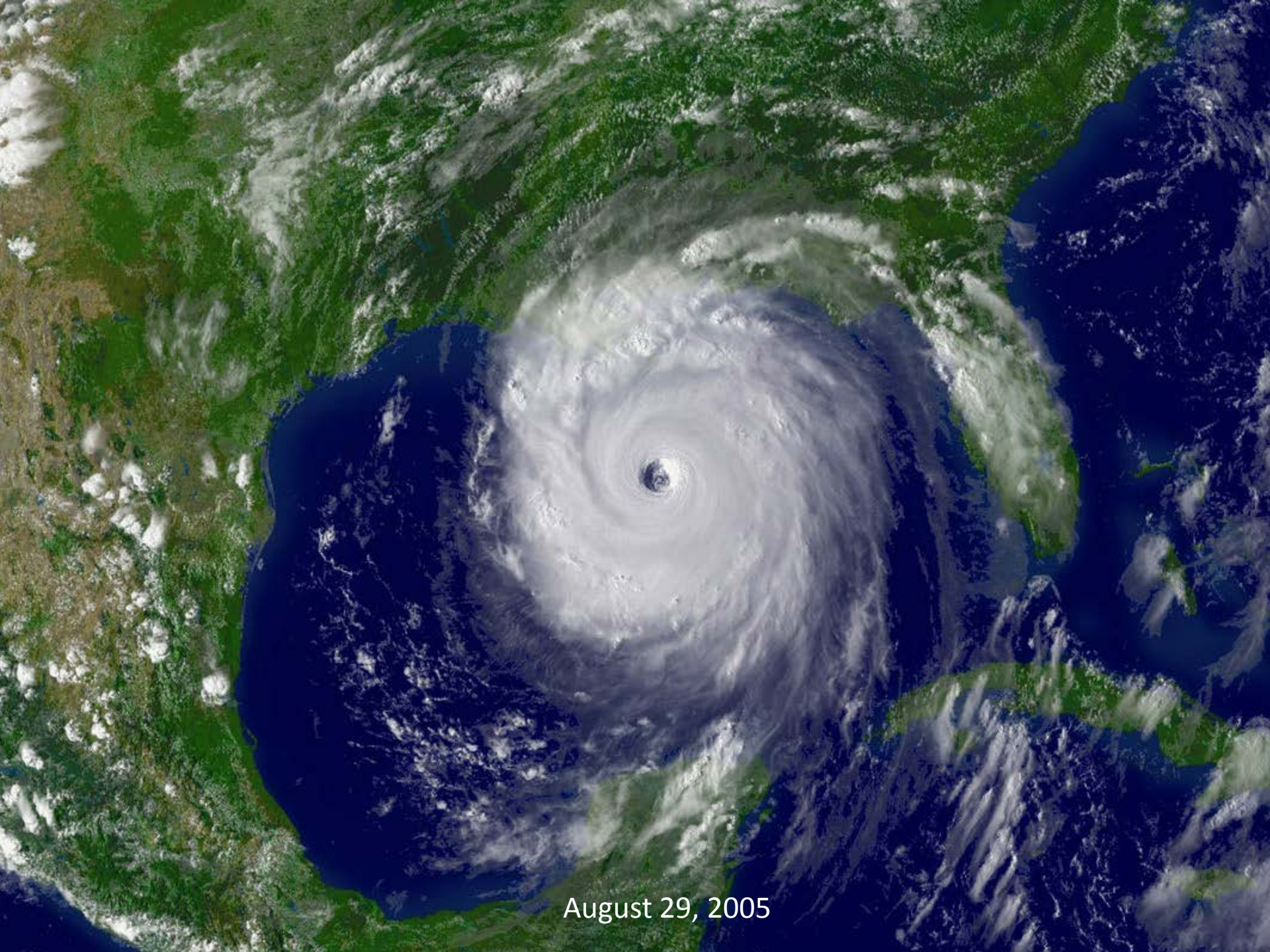
- Cure disease and heal injuries
- Reduce pain and suffering
- Promote health and prevent disease
- Avoid excess harm in the course of care

## Universally Condemned

- Execute convicted criminals
- Experiment on patients without informed consent
- Make life saving care contingent on ability to pay
- Supply narcotics to addicted patients

# Quality of Life





August 29, 2005











Anna Pou, MD

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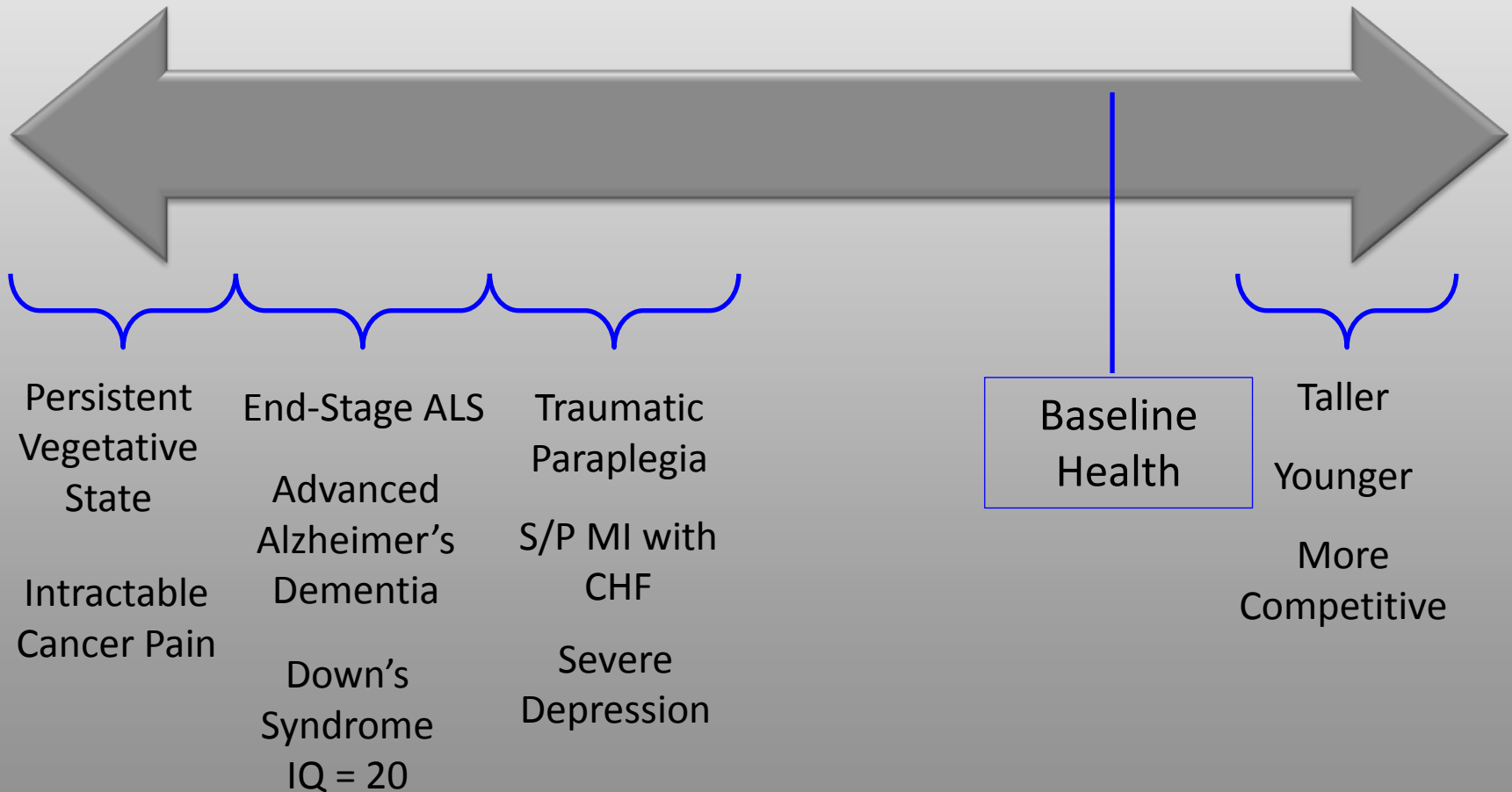
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- Principle of double effect does not apply
- Ethically controversial

# 2012 Massachusetts “Death With Dignity” Ballot Proposal

Would allow a physician licensed in Massachusetts to prescribe medication, at a terminally ill patient’s request, to end that patient’s life.

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## Patient Qualifications

- Capacity to make and communicate health care decisions
- Diagnosed by attending and consulting physicians with an incurable, irreversible disease that will cause death within 6 months
- Voluntarily expresses a wish to die and has made an informed decision

## Patient Requirements

- Communicate the request on 2 occasions separated 15 days apart
- Sign a standard form in the presence of 2 witnesses

# 2012 Massachusetts “Death With Dignity” Ballot Proposal

## Physicians Requirements

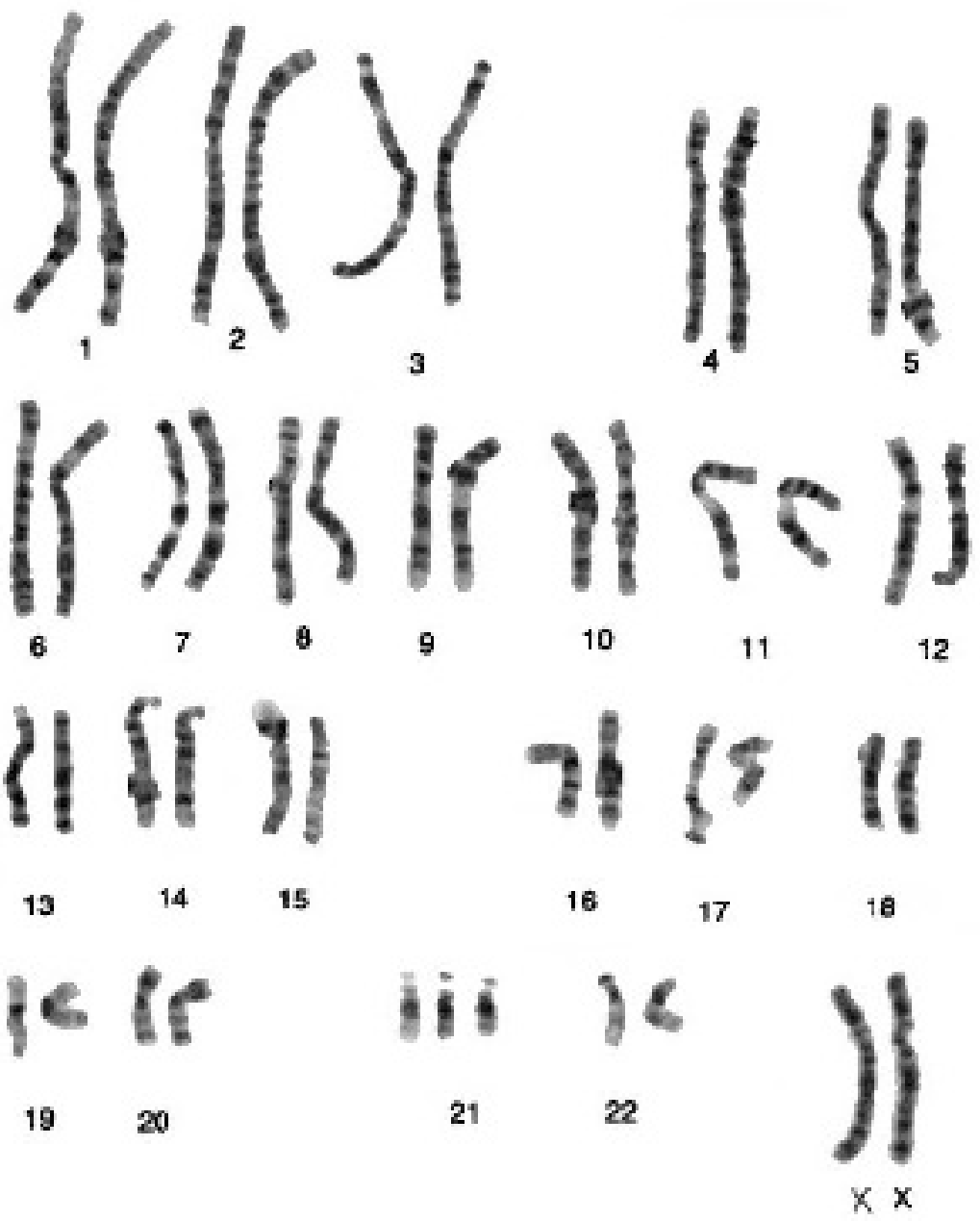
- Determine if the patient is qualified
- Inform the patient of his or her medical diagnosis and prognosis, potential risks and probable result of ingesting the medication, and feasible alternatives, including comfort care, hospice care and pain control
- Refer the patient to a consulting physician for diagnosis and prognosis, and confirmation that the patient is acting voluntarily and is capable of making an informed decision
- Refer the patient for psychiatric or psychological consultation if he or she believes the patient may have a disorder causing impaired judgment
- Inform the patient that he or she may rescind the request at any time, and again verify that the patient is making an informed decision at the time the prescription is written
- Arrange for the medicine to be dispensed directly to the patient, or the patient’s agent, but not by mail or courier

# 2012 Massachusetts “Death With Dignity” Ballot Proposal

## Additional Stipulations

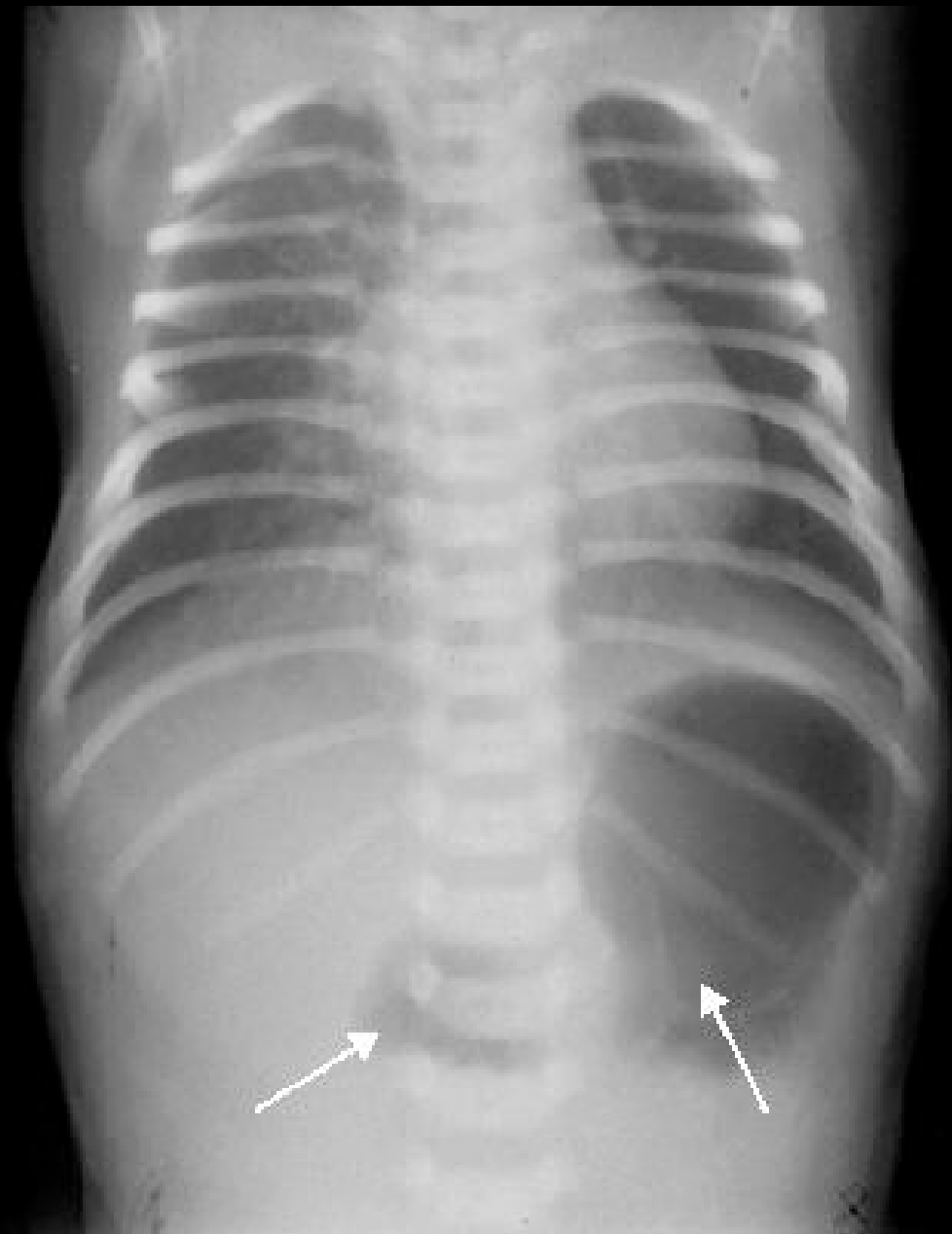
- Coercing a patient to request medication, forging a request, or concealing a rescission would be punishable by imprisonment and/or fines
- Ending a patient’s life by lethal injection, active euthanasia, or mercy killing would remain illegal
- The death certificate would list the underlying terminal disease as the cause of death
- Physician participation would be voluntary

# Future Quality of Life









Duodenal Atresia

**Baby Jane Doe**

**Born: October 11, 1983**





# Enhancement Medicine



Manute Bol (7 feet 7 inches)  
Muggsy Bogues (5 feet 3 inches)



Before



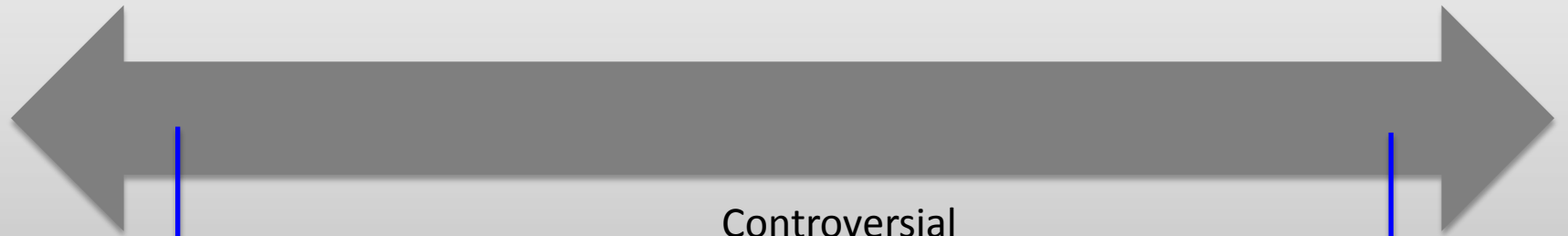
After



LIVESTRONG



# Goals of Medicine



## Controversial

- Assist patients in their deaths
- Enhance patients' natural traits
- Accept patients based solely on their ability to pay

## Universally Accepted

- Cure disease and heal injuries
- Reduce pain and suffering
- Promote health and prevent disease
- Avoid excess harm in the course of care

## Universally Condemned

- Execute convicted criminals
- Experiment on patients without informed consent
- Make life saving care contingent on ability to pay
- Supply narcotics to addicted patients

<b>Format</b>	Small group discussion
<b>Faculty</b>	Facilitators
<b>Learning Objective</b>	Identify the relevant facts and use the appropriate ethical principles to argue a position in cases pertaining to quality of life.
<b>Readings</b>	<u>Cases for Discussion</u> <ul style="list-style-type: none"><li>• Helping the Patient Achieve Quality-of-Life Goals</li><li>• Physicians' Role in Assisted Suicide</li><li>• Treating Short Stature with Growth Hormone</li><li>• “Doc, I Need a Smart Pill”—Requests for Neurologic Enhancement</li></ul>

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Cases for Discussion  
Session 12 – Quality of Life  
Student Version

### **Helping the Patient Achieve Quality-of-Life Goals**

Mrs. McGoldrick was admitted to the hospital from a local nursing home with a urinary tract infection (UTI) and multiple chronic diseases including diabetes and a history of heart attacks. Mrs. McGoldrick is 81 years old, has an adult daughter, Regan, and an elderly sister, Emily. During the admission process, Mrs. McGoldrick reported that she could walk only with pain and therefore spent most of her day sitting in a chair. She was evaluated by a psychiatrist immediately after admittance and was prescribed antidepressants to combat symptoms of clinical depression. She was also observed to have indications of moderate dementia.

After spending 3 days in the hospital, Mrs. McGoldrick appeared to have been successfully treated for the UTI but remained weak and lethargic. In an effort to elevate her mood, the anti-depressant dosage was increased, but after several days there were no marked signs of improvement. One of the most distressing trends noted by the clinical staff was Mrs. McGoldrick's intake of foods and liquids. Several tests revealed that she was suffering from hypoprotein anemia, which suggested that she had not been properly nourished for a sustained period of time. The hospital staff, however, observed Mrs. McGoldrick eating and drinking well when Emily fed her during one of her regular visits.

Prior to Mrs. McGoldrick's release from the hospital, her primary care physician, Dr. Misenti, spoke privately with Mrs. McGoldrick's daughter, Regan, who stated that her mother had expressed a "wish to die," believing that there was nothing more that she wanted from this life. After considering Regan's information, Dr. Misenti suggested continuing the anti-depressants and giving Mrs. McGoldrick the option of a percutaneous endoscopic gastrostomy (PEG), which might help raise her mood and nutritional status and, hence, her quality of life. It was Dr. Misenti's hope that by improving the quality of Mrs. McGoldrick's life, he would also encourage her to want to live. Regan believed that this was an idea that should be explored and implemented, but Mrs. McGoldrick refused to consider the option.

Virtual Mentor. February 2005, Volume 7, Number 2

### **Physicians' Role in Assisted Suicide**

Four years ago, Jonathan Witlaw's internist referred him to neurologist Bob Ferris for a work up. At the time, Mr. Witlaw reported having stumbled on several occasions over the span of 6 or 8 weeks. At first, he paid no attention, thinking he was just being careless or not looking at the pavement, but then he stumbled in his own apartment and knew he needed to check it out. The work-up, including nerve conduction and electromyographic studies confirmed that Mr. Witlaw had amyotrophic lateral sclerosis (ALS). When Dr. Ferris called Mr. Witlaw to the office

to discuss the test results, he had much information to share about support services—physical, psychological, and social. He told Mr. Witlaw that the disease progressed a little differently in each patient, but he was honest about the stages of the disease, what Jonathan could expect, and what would, eventually, cause death. Dr. Ferris explained the sorts of interventions that could help—physical therapy, speech and swallowing therapy, counseling, and the pharmacologic agents that together would help him manage his illness.

It turned out that the rate of Jonathan Witlaw's ALS progress was on the slow end of the continuum, and he fought it with all he had. A computer applications designer who lived alone, Mr. Witlaw was able to continue going to work for many months. When his leg strength deteriorated but his arm control still allowed him to type, he worked from home for a few more months. About 2 years after confirmation of his diagnosis, Mr. Witlaw went on long-term disability. He received a portion of his pay, and his medical bills were mostly covered. He had been working with his therapists and counselors and had consulted a lawyer to "get his affairs in order." His living will stated that he does not want to be put on a ventilator or to receive a feeding tube when he was no longer able to swallow.

Dr. Ferris sees Jonathan every few weeks. A home nursing agency provides someone to accompany Jonathan in his wheelchair to the neurology clinic. On one visit, Mr. Witlaw asks Dr. Ferris to prescribe a barbiturate and tell him how best to use it "just in case." He wants to be able to commit suicide before he loses the ability to do it on his own.

"I don't have any family," Jonathan says. "No one's pleading for me to stay alive for those last few months of deterioration. And my decision is not influenced by depression—you know me well enough to know that, Doc," Mr. Witlaw says. "What I'm suggesting is pretty sane, under the circumstances, isn't it?"

Not comfortable with participating in Mr. Witlaw's plan, Dr. Ferris said, "Well, I'm told you can get information from many of those death with dignity organizations. Is that true?"

"Yeah, probably, but you've been my doctor through all this and I trust you. Tell me what's the best thing to take and then give me a prescription. I'll save them up from several prescriptions, if necessary. I won't make you look bad, I promise."

"Jonathan," Dr. Ferris said, compassionately, "I can't argue with anything you say, but, as a physician, I just can't participate in helping you commit suicide."

"Patient's best interest, Doc. Remember that?" was Jonathan's final attempt.

Virtual Mentor. August 2004, Volume 6, Number 8.

### **Treating Short Stature with Growth Hormone**

Mr. and Mrs. Malcolm are worried about the growth of their 5-year-old son, David.

David was the shortest child in his preschool classes, and his parents worry that, as he enters kindergarten, he may be teased for his shortness. Looking ahead, they fear all kinds of other consequences; competitive sports could be closed to him, and dating and job finding could be more difficult than for his taller contemporaries. Mrs. Malcolm is 5 ft tall, and Mr. Malcolm is 5 ft 4 in. They have expressed their concerns over the course of David's last few pediatrician visits. The pediatrician, noting in David's chart that he has been approximately 3 standard deviations below the mean for height since 18 months of age, refers the Malcolms to Dr. Tyson, a pediatric endocrinologist.

Dr. Tyson orders several tests to determine whether David's short stature is due to an underlying pathology (e.g., Turner's syndrome, renal insufficiency) or growth hormone deficiency. All tests come back negative. After a radiological evaluation, Dr. Tyson concludes that David has idiopathic short stature (ISS), specifically, familial short stature; he is short because his parents are short. The Malcolms are relieved that David does not have a serious illness, but their fears and concerns are not abated by Dr. Tyson's diagnosis. Mr. Malcolm recalls the pain of being a short teen and still feels that people look at him awkwardly when they first meet him. A lawyer, he prefers to do most of his initial client interviews by telephone. Mrs. Malcolm doesn't want her son to be shorter than girls his own age, and she fears that he could be psychologically scarred as he gets closer to puberty.

The Malcolms tell Dr. Tyson that they have read on the Internet that human growth hormone therapy (hGH) is safe and effective for children like their son. They are eager to get David's therapy started as soon as possible and ask Dr. Tyson to prescribe the treatment for him. When Dr. Tyson begins to tell them that most insurance companies do not cover GH therapy for ISS cases, Mr. Malcolm declares that they have decided to look at the therapy as an investment in David's future, as important as private school education, if not more so.

Virtual Mentor. November 2005, Volume 7, Number 11

### **"Doc, I Need a Smart Pill"—Requests for Neurologic Enhancement**

Dr. Warren, the only neurologist in a hardscrabble town of 7,000 residents, looked at his new patient and chewed his lip. They were sitting in a small examining room at Dr. Warren's clinic. The patient, Mr. Conway, was a soft-spoken 28-year-old unemployed sales clerk who had just explained the reason for his visit: recently laid off, and with no other job prospects in sight, he wanted to attend graduate school. This would require him to take the Graduate Record Examination (GRE), but Mr. Conway said he would have "extreme difficulty" remaining focused for the full 4-hour length of the exam. He wanted Dr. Warren to prescribe something to help him stay focused and think better.

"Just temporarily, Dr. Warren," the polite Mr. Conway said. "Just so I can do my best on the exam."

Dr. Warren had listened to his patient's story with great sympathy. Mr. Conway needed a

scholarship to attend graduate school, and a low score on the test would spoil his chances. Based on a growing literature, modafinil might help Mr. Conway focus during the long test. Dr. Warren had explained to Mr. Conway that, because he did not have symptoms of attention deficit disorder (ADD) or other neurological problems, prescribing a cognitive-enhancement drug would be hard to justify.

Virtual Mentor. November 2010, Volume 12, Number 11: 849-853.

**Format** Large group lecture

**Faculty** Boumil

**Learning Objectives**

- Define conflicts of interest in the clinical setting
- Identify and describe conflicts of interest resulting from relationships between physicians and their employers or health insurers
- Similarly, identify and describe conflicts of interests resulting from relationships between physicians and health care industries
- Explain how patients are protecting from conflicts of interest that may actually or potentially harm their right to equitable care

**Reading Assignment** Jonsen text: p 161-170, 181-7



# Conflicts of Interest

## Conflicts of Interest in Clinical and Academic Medicine

Tufts University School of Medicine

April 1, 2013

# What is a Conflict of Interest?

What kinds of issues raise fCOIs in medicine?

Where do we find them?

Although this presentation will focus on the pharmaceutical and medical device industries, COI are everywhere!

# Case Study

A 6-year old child is seen in the ENT Clinic by a 1<sup>st</sup> -year resident. The child has symptoms of an ear infection and is diagnosed with otitis media.

The 1<sup>st</sup> year resident presents the patient to the 3<sup>rd</sup> year resident who agrees with the diagnosis.

# Industry Conflicts of Interest

The 3<sup>rd</sup> year resident asks 1<sup>st</sup> year for a treatment recommendation.

“I suggest Augmentin ... it is unsurpassed in the treatment of otitis media.”

Augmentin prescribed; pt leaves w mom

# Industry Conflicts of Interest

- Mom goes to pharmacy to fill rx. She has no insurance. The rx is \$140. (She has \$22 in her wallet.)
- Pharmacist suggests mom return to the clinic and ask about Ampicillin which, he opines, is usually the first line of treatment for ear infections.
- Ampicillin is a generic (i.e. off patent), and costs \$4.

# Industry Conflicts of Interest

- Mom is embarrassed by her \$\$ situation and does not return to clinic.
- Child gets worse and mom eventually takes to the ER.
- Child is diagnosed with ruptured ear drum and is admitted for treatment.

# Industry Conflicts of Interest

- Why Augmentin?
- Both the 1<sup>st</sup> and 3<sup>rd</sup> year residents had attended a industry-sponsored lunch earlier that day.
- *Do you think this influenced either doc?*



# Industry Conflicts of Interest

- They returned from lunch with literature and a coffee mug flaunting the slogan:

*“Augmentin is unsurpassed in the treatment of otitis media...”*

*Do you think they were influenced?*

# Industry Conflicts of Interest

- Why Augmentin?
- In fact, at that time Ampicillin and another generic were considered the first line of treatment for otitis media, with Augmentin reserved for treatment refractory cases ...

# Industry Conflicts of Interest

- Why was Augmentin prescribed?
- What went wrong?

# Industry Conflicts of Interest

What is a financial Conflict of Interest?

- A conflict of interest exists when an individual or organization has a financial relationship with one entity that might reasonably appear to influence one's actions with respect to one or more professional responsibilities.

# Industry Conflicts of Interest

- In clinical medicine, there is a credible body of literature suggesting that free food, free pens, mugs, etc., including free drug samples and other perks from industry influences medical practice including the prescribing of drugs.

# Industry Conflicts of Interest

- Did the physicians here have a “financial relationship” with the pharmaceutical company that produced Augmentin?

# Industry Conflicts of Interest

- In academia physicians have an array of relationships with pharmaceutical and medical device companies.
- What are they?



# Is this a fCOI?

- Example: a physician receives compensation from a drug company for consulting on, or speaking about, the company's drug – and thereafter is invited to conduct drug trials to determine the safety and efficacy of that drug.

# Industry Conflicts of Interest

- The term “conflict of interest” has come to encompass a wide array of physician-industry relationships, ranging from collaborations that discover and test new pharmaceutical products - to promotional events that are intended to influence physician prescribing habits.

# The “Dilemma”

- On the one hand.....
  - (a) Industry needs physicians to help discover and test new drug products on their (willing) patients; and (b) physicians need industry to produce and commercialize new products.

# The “Dilemma”

➤ On the one hand.....

(c) and, of course, Industry needs to be able to “tell” physicians about their new products and their proposed uses in order to get the word out...

# The “Dilemma”

➤ On the other hand.....

(a) Physicians’ first and foremost duty is to act in the best interest of their patients, uninfluenced by other factors (such as \$\$ they might receive from a pharmaceutical company); and

# The “Dilemma”

➤ On the other hand.....

(b) Pharmaceutical companies primary obligation is to maximize the economic return on their shareholders’ investments – the so-called “bottom line”.

# The “Dilemma”

➤ And these are inconsistent ...

(a) Not because pharmaceutical companies want patients to be injured (or benefit from patient injuries)...

(b) But because given choices among classes of drugs (or no-drug options), a pharmaceutical company’s priority is to have its drug be prescribed.



# The “Dilemma”

- And these are inconsistent ...
- The physician priority is supposed to be the best interest on the patient, based only on which drug product (or no product) is best for that patient, given the available options.

# The “Dilemma”

- A company pays physicians (and provides other perks) to be in its corner – as a spokesperson, researcher, advisor, etc. – on behalf of a particular drug, because...
- Docs like to hear from other docs (instead of detailers) about new products coming onto the market.

# The “Dilemma”

- And what do you think happens when a company pays a physician (or showers the doc with other perks) to be in its corner – as a spokesperson, researcher, advisor, etc. – on behalf of a particular drug?
- Does the doc give an unbiased presentation ...?

# The “Dilemma”

- And just to complicate matters further ... approximately 50% of all new drugs coming onto the market are pulled off by the FDA within one year because they are found to be unsafe or ineffective.

# The “Dilemma”

- Why did the physicians prescribe them?
- Physicians prefer to learn from other docs, don't have a lot of time to read up on new products...
- So they rely upon marketing pitches instead of clinical data on experience with the drug.

# The “Dilemma”

- Do the docs in the audience “get” that it’s a marketing pitch, even though it’s delivered by a doc instead of a detailer?
- When these talks are delivered, a representative from the company is always present in the audience.
- How does that affect the presentation?

# The “Dilemma”

- Tufts and most academic medical centers value legitimate (unconflicted) faculty-industry collaborations intended to discover, develop, test, produce and commercialize new pharmaceutical products.



# The “Dilemma”

- And Tufts ... like most academic medical centers “gets” that there is substantial value to legitimate faculty-industry collaborations.
- And, of course, everyone of us has benefited from the good work of the pharmaceutical world.

# The “Dilemma”

- At the same time, not a single year has gone by in more than a decade when some pharmaceutical company has not paid at least hundreds of millions of dollars in gov't fines due to *illegal promotion of a pharmaceutical product*.

# The “Dilemma”

What kind of behavior?

- Off-label marketing (and who does this?)
- Incentives (a/k/a kickbacks) to formularies to purchase drugs
- Illegal “tying” schemes
- Etc.

# The “Dilemma”

- And therein lies the dilemma ... medicine and industry cannot function without each other – but the constant drum beat of illegal pharma behavior requires medicine to be vigilant about not being drawn into these very different “bottom-line” obligations that differentiates the two professions.

# The “Dilemma”

- Do such perks as “free lunches” influence prescribing behavior ...
- The most compelling research data comes from pharma itself: it spends more on marketing than R&D because its own marketing research show it works – big time!

# The TUSM View of fCOIs

- Tufts (and most medical schools) prohibit physicians from accepting free food or any other gifts of any value (e.g. free CME) from pharma - since the primary purpose is to market products or influence the prescribing practices of other physicians.

# The Tufts View of fCOIs

- Tufts also prohibits industry relationships wherein physicians use Tufts faculty credentials to speak on behalf of industry products solely for the purpose of marketing, promoting or influencing the prescribing practices of other physicians.



# Are fCOIs a problem of particular concern to the medical profession?

- “Conflicts of interest are ubiquitous and inevitable in academic life, indeed, in all professional life. The challenge for academic medicine is not to eradicate them, which is fanciful and would be inimical to public policy goals, but to recognize and manage them sensibly and effectively.”

David Korn *JAMA* 284, 2234-2236, 2000

# Background:

## The Need for Collaboration

- Prior to 1980 the federal government sponsored research that led to hundreds of valuable patents.
- However, many sat idle for years because the federal government, which owned the patent rights, lacked the resources and relationships with industry needed to develop and market the inventions.

# Background: Bayh-Dole Act of 1980

- Federal legislation known as the Bayh-Dole Act was enacted in 1980 to respond to this issue by passing a law that would promote the commercialization of funded research.

# Bayh-Dole Act of 1980

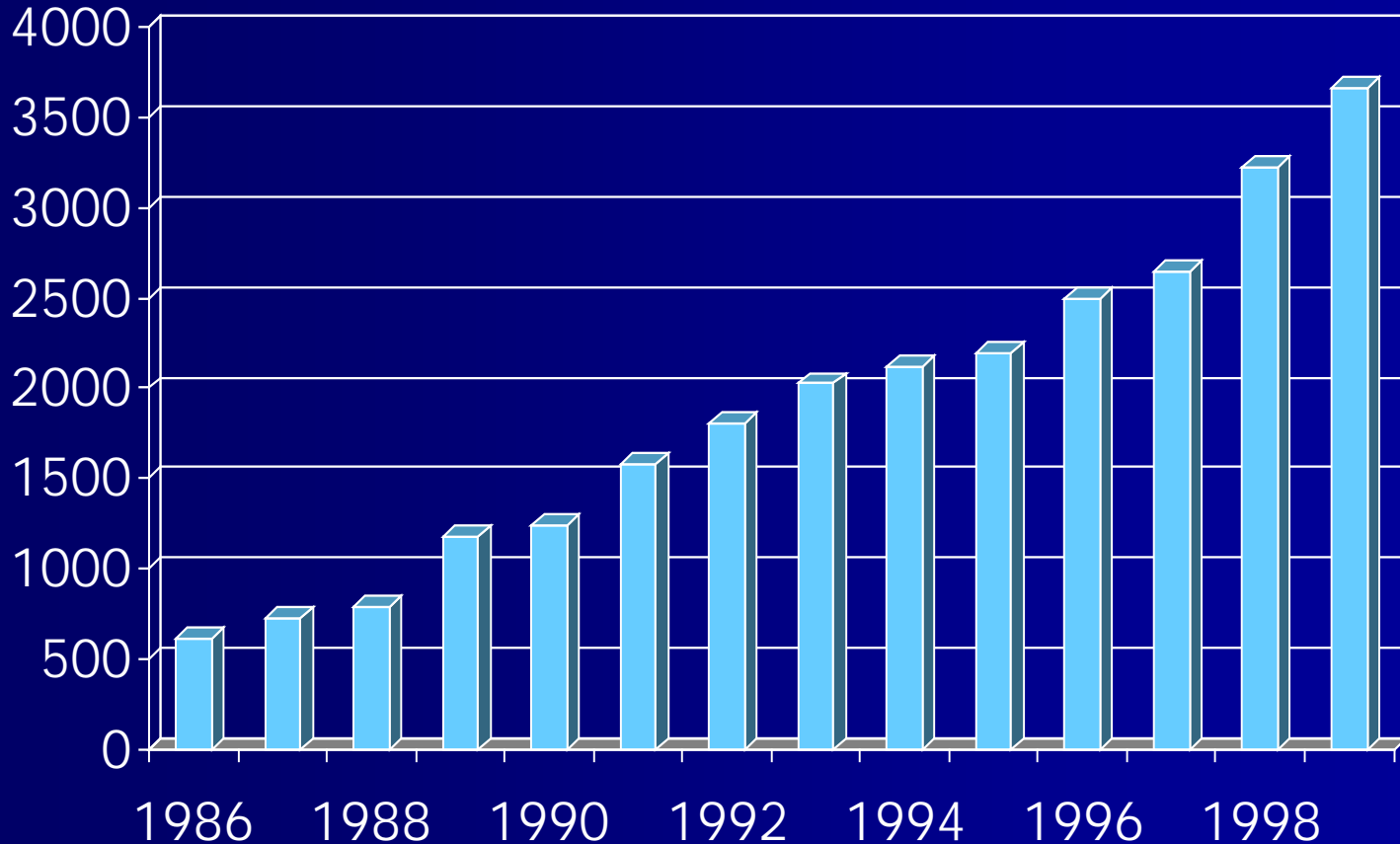
- The Bayh-Dole Act created a uniform patent policy among federal agencies that fund research enabling non-profit organizations and small businesses, including universities, to retain titles to inventions made pursuant to federally-funded research programs.
- The Bayh-Dole Act was thus designed to promote the use, development and promotion of technology invented with federal funding.

# Bayh-Dole Act of 1980

- Recipients of federal funding now have the right to retain ownership of inventions developed with federal funding.
- Recipients of funds must also share royalties and other income derived from the invention with the inventor(s).
- Result: Investigators and institutions are encouraged to seek technology transfer (commercial) opportunities – *i.e., bring inventions to market.*

# Patents to Universities 1986-1999

Source: Association of University Technology Managers



# Industry Conflicts of Interest

Many organizations, incl. Tufts, encourage legitimate industry relationships and have policies that address:

- Educating faculty and students about fCOIs that can arise from industry relationships;
- How to “manage” conflicted relationships;
- How to protect the integrity of research (including human subjects);
- Compliance with national standards for proper disclosure of industry relationships;
- Discouraging improper marketing relationships.



# Where else is COI regulated?

- Massachusetts law (Chapter 111N) regulates pharmaceutical Conflicts of Interest within Massachusetts;
- Some other states have similar laws;
- The new federal Patient Protection and Affordable Care Act has COI “Sunshine” provisions.

# Gifts

- The provision of gifts from industry to physicians does not serve to further legitimate physician-industry collaborations.
- Gifts of every nature -- pens, mugs, complimentary lunches or industry-funded expenses for educational events -- are intended solely to market industry products.

# TUSM Policy: Hospitality

- Hospitality, on or off-campus (*e.g.*, complimentary tickets to sporting, theatre or other events), is prohibited.

# How much does the “free lunch” cost?

- Industry spends ~\$12 billion per year on marketing, or approximately \$12,000 per physician per year.
- Industry spends \$3.5 million per year on free lunches.
- Why?

# Tufts Policy on Meals

- Industry-funded meals to physicians are prohibited.
- Exceptions: Modest meals provided in conjunction with approved on- or off-campus CME or other educational activities;
- Meals pursuant to consulting contracts

# NB: Mass Meals Law Flip-Flop

- 2009 Mass flip: Physicians could not accept a free meal during the course of a promotional pharma event – unless it is held in a hospital or physicians' office *and* it is accompanied by an educational presentation.

# NB: Mass Meals Law Flip-Flop

- 2012 Mass Flop: Physicians can accept a free meal during the course of a promotional pharma event – even if held in a restaurant – if the meal is modest *and* it is accompanied by an educational presentation.
- What's the difference?



# Is this is free lunch?

Are following activities OK?

- Coffee and donuts, courtesy of ABC Corp., brought into a physicians' lounge in the Department of X.
- Chinese food provided by an XYZ Corp. representative for a luncheon talk in the Department of Y.

# Tufts Policy: Travel \$\$

- Industry likes to offer free CME. Why?
- Industry-funded travel is only allowed in conjunction with a consulting contract or for a CME presenter.
- Industry can give unrestricted gifts (including travel) to a development office – but it cannot control how the gift is distributed.
- Why?

# Tufts Policy: Travel \$\$

Are the following travel funds permitted for TUSM physicians:

- ABC Corp, maker of new drug to treat condition Q, offers to pay the admission fee for certain members of the Unnamed Medical Center to attend a conference on the treatment of Q.

# Tufts Policy: Speaking for Industry

- Tufts faculty are not permitted to participate in industry-sponsored speaking activities, whether or not compensated, if the content and materials (e.g. slides) are prepared or controlled by the industry sponsor.
- Why?

# Tufts Policy: Speaking for Industry

- Note that the FDA requires its pre-approval of pharmaceutical companies' marketing slides. Why?
- And as a result, pharma often insists that speakers use the slides as approved by the FDA.
- So what's the issue?

# Tufts Policy: Speaking for Industry

- These so-called “speakers’ bureaus” are promotional, not educational, particularly when industry prepares the slides.
- The job of the speaker is to emphasize the favorable features and obfuscate the rest.
- But – they are effective?

# Tufts Policy: Speaking for Industry

- Physicians are 4 times more likely to prescribe a drug promoted by a physician colleague than a drug rep.
- Speakers bureaus are funded through the company's marketing department.
- 94% of physicians have some sort of relationship with pharmaceutical companies.

# Tufts Policy: Speaking for Industry

- Academic investigators may present results of their own industry-sponsored studies only when there is full opportunity to present balanced research and a forum for critical exchange with the audience is afforded to the speaker.



# Tufts Policy: Ghostwriting

- Ghostwriting occurs when Industry prepares written materials (promotional or not) in whole or in substantial part and such materials are attributed to a non-industry author.
- Ghostwriting is prohibited at TUSM.

# Tufts Policy: Consulting Relationships

- Tufts permits “Consulting” on behalf of industry as long as the tasks are legitimate and they are not just being paid to be a cheering squad.
- E.g. payment to sit on a scientific advisory boards that rarely meets is tantamount to a “gift” and thus prohibited.

# Tufts Policy: Industry Access to TUSM

- Tufts does not allow industry reps to interact with students except under the direct supervision of a faculty in a structured learning environment.
- Industry reps are not be provided with student mailing or email addresses.
- Why?

# TUSM Policy: Industry Access to TUSM

- On-campus exhibits intended to showcase Industry products are permitted only with prior approval of the Dean. Why?
- On-campus demonstrations of research equipment prior to purchase are permitted, consistent with TUSM purchasing policies.
- Exhibitors are not be permitted to distribute free drug samples, meals, raffle tickets or other gifts to attendees.

# Complimentary Drug Samples

- What about complimentary drug samples at Tufts training hospitals?
- What are their functions?

# Complimentary Drug Samples

- They are sometimes given to patients who otherwise cannot afford medicine.
- More likely they are intended for patients to start a course of treatment and then continue it.

# Complimentary Medical Devices

- What about complimentary medical devices at Tufts or Tufts hospitals?
- Sometimes they are loaned for a period of time to see if physicians or researchers like them, to eventually be purchased.
- Is this a COI?

# Tufts Policy: Look for it!

- All Course Directors who teach Tufts students must disclose all relevant relationships with industry.
- Course directors are responsible for full disclosure by their guest speakers.
- Disclosure may be done verbally but should also occur on the course syllabus, TUSK or on the lecturer's slide presentation.
- Disclosure should occur at the beginning of the course and when relevant to the content of the course materials.



# Example of Disclosure: Look for it!

Jonathan Smith, M.D.

Associate Professor, Dept. of X, TUSM

## Consultancies:

Major Pharmaceuticals, Inc.

Specialty Products Corp.

## Funded Research

Major Pharmaceuticals, Inc.

## Founding Partner and Shareholder

ABC Start-up Corp.

# TUSM Policy: Continuing Medical Education

- All physicians are required to attend CME.
- CME funded by pharma is likely to focus on narrow topics treatable with drugs for which the company has a product to promote.
- And although 88% of docs think pharma-sponsored CME is biased, less than half reported willingness to pay more to eliminate pharma sponsorship!

# The Accreditation Council for Continuing Medical Education (ACCME)

- All CME events hosted or sponsored by Tufts comply with the ACCME Standards for Commercial Support of educational activities, whether or not CME credit is awarded.
- ACCME-certified educational activities specifically address and eliminate the bias of industry.

# How?

- Industry may not designate CME program faculty, participants or content.
- Industry cannot pay for attendees to come.
- CME speakers and planners disclose any industry relationships and commercial support – and if the COI is significant, they may not participate.

# Tufts Policy:

## Continuing Medical Education

- Tufts faculty and students who attend off-campus, non-ACCME educational activities are urged to evaluate the potential for undue industry influence using the guidelines set forth by Tufts.
- Payment for attendance (only) at industry-sponsored events is prohibited.

# Direct-to-Physician Advertising

- Over 90% of physicians report receiving free samples; 60% receive free meals, entertainment or travel.

Debate about extent of influence:

- Does a free meal influence prescribing?
- Does a free sample affect prescribing?
- Does free travel affect prescribing?
- Does hospitality affect prescribing?

# Direct-to-Consumer Advertising

Do ads to consumers work?

- Patients pressure docs to prescribe the advertised drugs.
- Increased emphasis on drug therapies.
- Time is required to dissuade patients.
- Interferes with physicians practice.
- BUT ... 1<sup>st</sup> amendment, free speech

# COI in Research

IRBs evaluate all COIs and do not approve research with significant conflicts.

- All financial relationships must be disclosed to research subjects.
- Research subjects must be free to decline after learning of relationships.
- Research subjects must be able to change their minds at any time.



# Contact US:

- The Office of COI Administration makes every effort to assist the TUSM community in fostering and managing industry relationships.
- Email: [med-coi@tufts.edu](mailto:med-coi@tufts.edu) or [marcia.boumil@tufts.edu](mailto:marcia.boumil@tufts.edu)

# Visit the COI website!

- *Frequently Asked Questions* is posted on the COI Website.
- A list of *Resources* is posted on the COI website.
- Specific inquiries can be emailed to: [med-coi@tufts.edu](mailto:med-coi@tufts.edu).

<b>Format</b>	Small group discussion
<b>Faculty</b>	Facilitators
<b>Learning Objective</b>	Identify the relevant facts and use appropriate ethical principles to argue a position in cases pertaining to conflicts of interest in clinical settings.
<b>Readings</b>	<u>Cases for Discussion</u> <ul style="list-style-type: none"><li>• Drug Company Sponsorship of Clinical Conferences</li><li>• Hidden costs of free samples</li><li>• Is the Surgery Necessary Now? The Surgeon's Conflict of Interest</li><li>• Duty to Treat versus Personal Safety</li></ul>

---

**Format** Large group lecture

**Faculty** Chessa

**Learning Objectives**

- Identify and describe various contexts in which limited medical resources may need to be allocated by criteria other than medical need (e.g., battlefield triage, local resource limitations, solid organ transplantation)
- Distinguish between relative vs. absolute scarcity of health care resources
- Define “beside rationing” and discuss the ethical implications of making clinical decisions for individual patients on the basis of societal needs
- Apply ethical principles to the problem of solid organ transplantation in the US and internationally (i.e. transplant tourism)

**Reading Assignment** Jonsen text p 187 - 98

---

# Allocation of Limited Resources

**April 8, 2013**

**Frank Chessa, Ph.D.**

Director, Ethics, MMC  
Assistant Professor, TUSM

How should the healthcare delivery system be organized to distribute resources fairly?

How should the healthcare delivery system be organized to distribute resources fairly?

What ethical principles should guide my resource allocation decisions in clinical care?

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Fee for service



More procedures

Capitation



Fewer procedures

Capitation + Outcomes



Better clinical decisions (?)



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Better clinical decisions

IHI Triple Aim:  
Patient Experience  
Population Health  
Per Capita Cost

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Better clinical decisions

**IHI Triple Aim:**

Patient Experience  
Population Health  
Per Capita Cost

**ACA:**

Expanded access

- Mandate &Subsidies
- Insurance Reform

Accountable Care Organizations

# Flu.gov

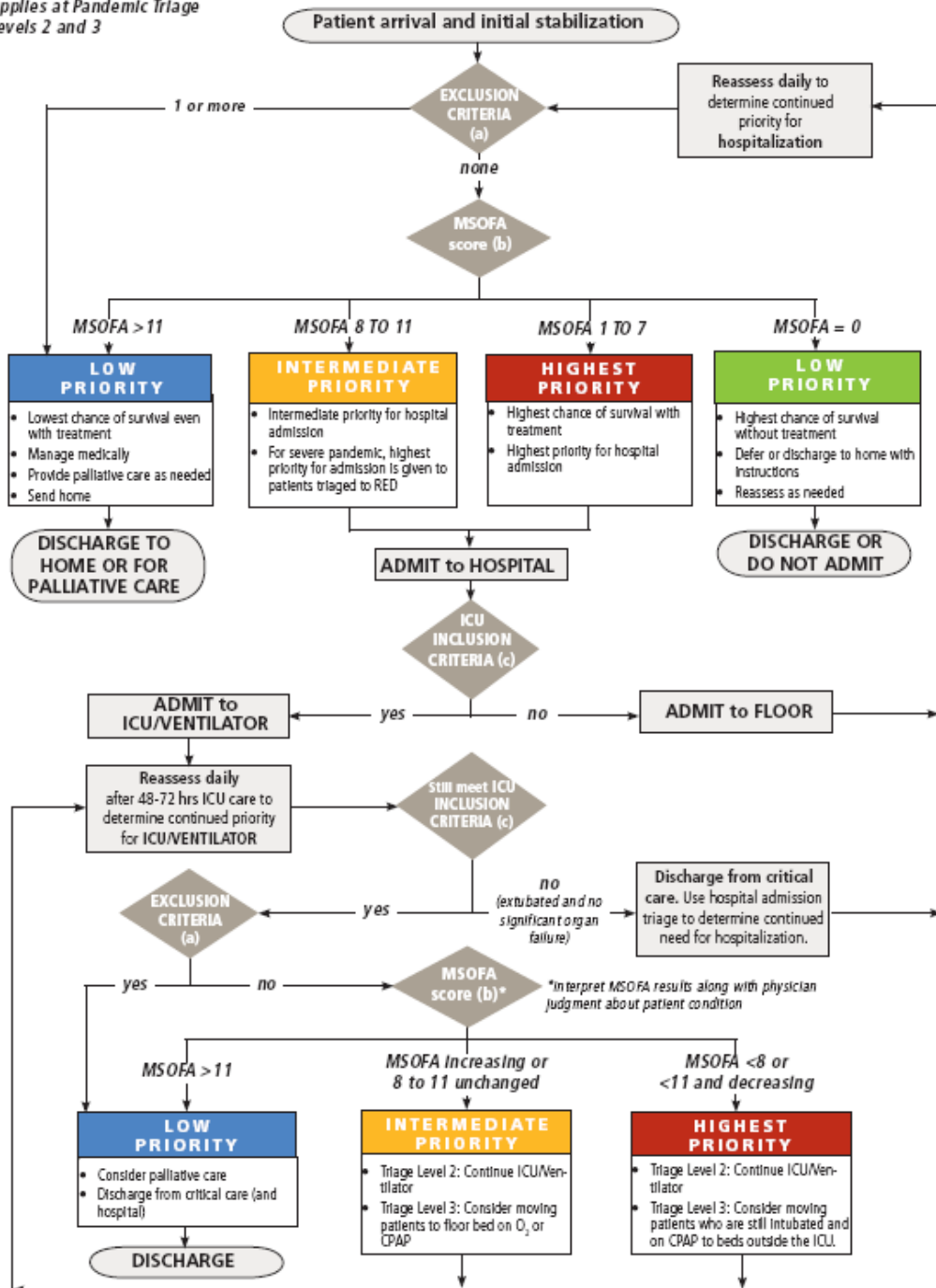


## Characteristics and Challenges of a Flu Pandemic

1. Rapid Worldwide Spread
2. Overloaded Health Care Systems
3. Inadequate Medical Supplies
4. Disrupted Economy and Society

# ALGORITHM: HOSPITAL AND ICU/VENTILATOR ADMISSION TRIAGE

Applies at Pandemic Triage Levels 2 and 3



## (b) Modified Sequential Organ Failure Assessment (MSOFA)

The MSOFA requires only one lab value, which can be obtained using bedside point-of-care testing (creatinine obtained through ISTAT). MSOFA has not been validated in children, but is currently under study.

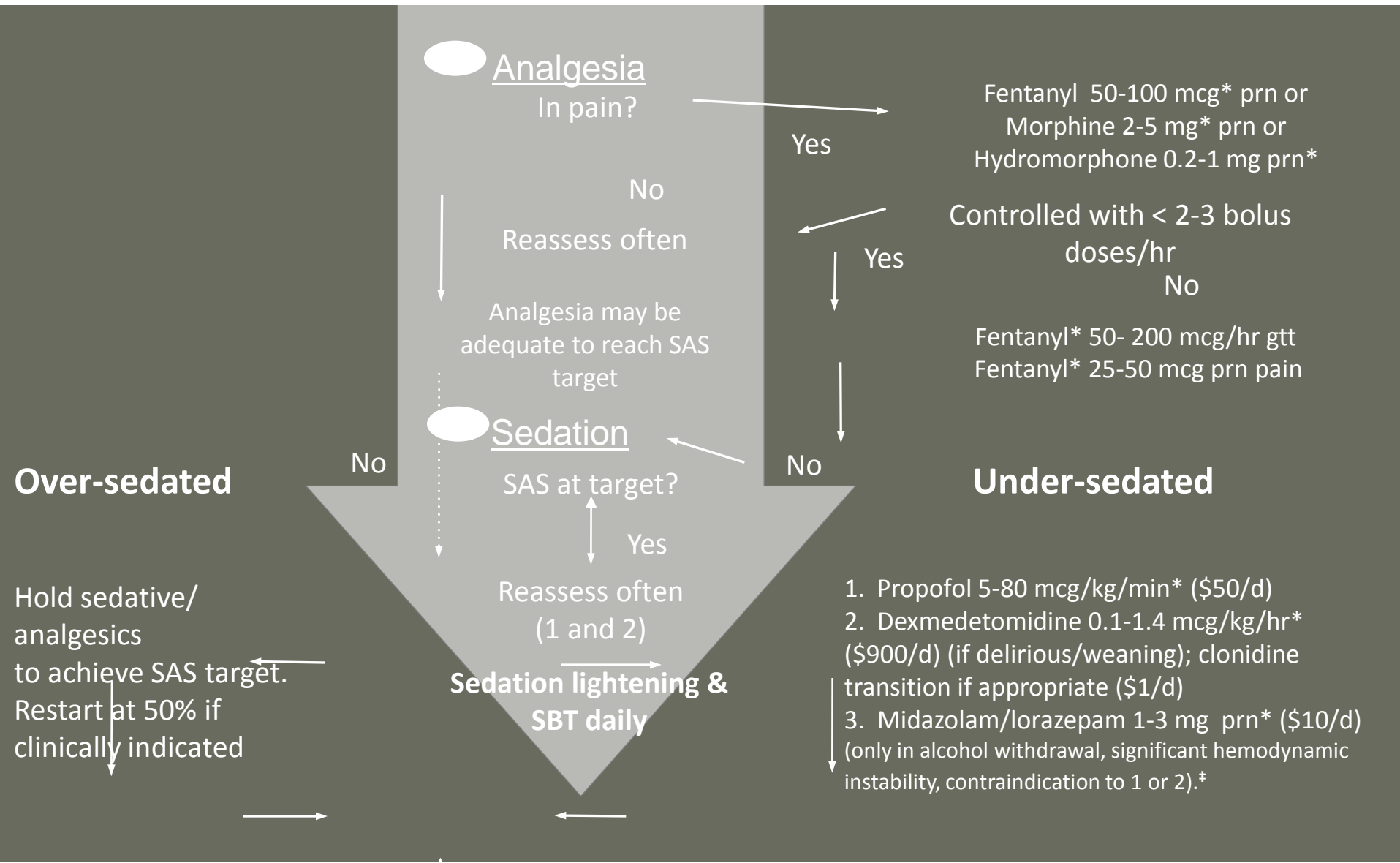
MSOFA scoring guidelines						
Variable	Score 0	Score 1	Score 2	Score 3	Score 4	Score for each row
SpO <sub>2</sub> /FIO <sub>2</sub> ratio* or nasal cannula or mask O <sub>2</sub> SpO <sub>2</sub> >90% required to keep SpO <sub>2</sub> >90%	SpO <sub>2</sub> /FIO <sub>2</sub> >400	SpO <sub>2</sub> /FIO <sub>2</sub> 316-400 or SpO <sub>2</sub> >90% at 1-3 L/min	SpO <sub>2</sub> /FIO <sub>2</sub> 231-315 or SpO <sub>2</sub> >90% at 4-6 L/min	SpO <sub>2</sub> /FIO <sub>2</sub> 151-230 or SpO <sub>2</sub> >90% at 7-10 L/min	SpO <sub>2</sub> /FIO <sub>2</sub> ≤150 or SpO <sub>2</sub> >90% at >10 L/min	_____
Jaundice	no scleral icterus			clinical jaundice/ scleral icterus		_____
Hypotension†	None	MABP <70	dop <5	dop 5-15 or epl ≤0.1 or norepl ≤0.1	dop >15 or epl >0.1 or norepl >0.1	_____
Glasgow Coma Score	15	13-14	10-12	6-9	<6	_____
Creatinine level, mg/dL (use ISTAT)	<1.2	1.2-1.9	2.0-3.4	3.5-4.9 or urine output <500 mL in 24 hours	>5 or urine output <200 mL in 24 hours	_____
MSOFA score = total scores from all rows:						_____

## (a) EXCLUSION CRITERIA for Hospital Admission:

The patient is excluded from hospital admission or transfer to critical care if ANY of the following is present:

- (1) Known "Do Not Resuscitate" (DNR) status.
- (2) Severe and irreversible chronic neurologic condition with persistent coma or vegetative state
- (3) Acute severe neurologic event with minimal chance of functional neurologic recovery (physician judgment). Includes traumatic brain injury, severe hemorrhagic stroke, and intracranial hemorrhage.
- (4) Severe acute trauma with a REVISED TRAUMA SCORE  $< 2$  (see (d) and (e))  
GCS: \_\_\_\_\_ SBP: \_\_\_\_\_ RR: \_\_\_\_\_  
Revised trauma score: \_\_\_\_\_
- (5) Severe burns with  $< 50\%$  anticipated survival (patients identified as "Low" or worse on the TRIAGE DECISION TABLE FOR BURN VICTIMS (f)). Burns not requiring critical care resources may be cared for at the local facility (e.g., burns that might have been transferred to the University of Utah Medical Center Burn Center under normal circumstances). Score: \_\_\_\_\_
- (6) Cardiac arrest not responsive to ACLS interventions within 20-30 minutes.
- (7) Known severe dementia medically treated and requiring assistance with activities of daily living.
- (8) Advanced untreatable neuromuscular disease (such as ALS or end-stage MS) requiring assistance with activities of daily living or requiring chronic ventilatory support.
- (9) Incurable metastatic malignant disease.
- (10) End-stage organ failure meeting the following criteria:
  - Heart: NEW YORK HEART ASSOCIATION (NYHA) FUNCTIONAL CLASSIFICATION SYSTEM Class III or IV (g). Class: \_\_\_\_\_
  - Lung (any of the following):
    - Chronic Obstructive Pulmonary Disease (COPD) with Forced Expiratory Volume in one second (FEV<sub>1</sub>)  $< 25\%$  predicted baseline, PaO<sub>2</sub>  $< 55$  mm Hg, or severe secondary pulmonary hypertension.
    - Cystic fibrosis with post-bronchodilator FEV<sub>1</sub>  $< 30\%$  or baseline PaO<sub>2</sub>  $< 55$  mm Hg.
    - Pulmonary fibrosis with VC or TLC  $< 60\%$  predicted, baseline PaO<sub>2</sub>  $< 55$  mm Hg, or severe secondary pulmonary hypertension.
    - Primary pulmonary hypertension with NYHA class III or IV heart failure (g), right atrial pressure  $> 10$  mm Hg, or mean pulmonary arterial pressure  $> 50$  mm Hg.
  - Liver: PUGH SCORE  $> 7$  (h), when available. Includes bill, albumin, INR, ascites, encephalopathy.  
Total score: \_\_\_\_\_
- (11) Age:
  - Triage Level 1:  $> 95$  years
  - Triage Level 2:  $> 90$  years
  - Triage Level 3:  $> 85$  years

# Analgesia/Sedation Protocol for Mechanically Ventilated Patients



\*Detailed dosing information available in SCM: "SCU Sedation, Analgesia, and Delirium"

Is it ethically appropriate to consider cost as a factor in treatment decisions?

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**Yes**



Is it ethically appropriate to consider cost as a factor in treatment decisions?



Yes

But this means I am not guided solely by my patient's best interest.

Can I avoid a social worth bias in my microallocation decisions

Is the money I save really doing good elsewhere?

Is it ethically appropriate to consider cost as a factor in treatment decisions?



**Yes**



**No**

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Is the money I save really doing good elsewhere?



No

The system could be quickly bankrupted.

There is persistent marketing of \$\$\$ options as better options. Can I avoid this bias?

Paradoxically plays into a "maximize profit" free market system.

# Is it ethically appropriate to consider cost as a factor in treatment decisions?



**Yes**

Some physicians say that...their only allegiance is to individual patients; societal or institutional costs are not relevant to clinical decisions. Whatever is required by medical indications and personal preferences should be provided. Noble as it is, this view is highly unrealistic. Physicians must consider not only the benefits and safety of an intervention and the patient's preferences, but also its financial implications.

Jonsen, Siegler, Winslade, *Clinical Ethics*, Chap 4, Economics of Clinical Care

But this means I am not guided solely by my patient's best interest.

Can I avoid a social worth bias in my microallocation decisions

Is the money I save really doing good elsewhere?

What are we aiming at, when we aim at the just distributions of scarce resources?

# Formal and Material Principles

- Equals must be treated equally – Aristotle
  - What characteristics matter for what goods?
    - Tallness should not matter in respect to college admissions
    - IQ should matter in respect to college admissions.
    - Minority status should/should not matter for college admissions.

# Formal and Material Principles

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- Material Principles give content to the formal principle.
  - To each an equal share
  - To each according to need
  - To each according to merit (skill, intelligence)
  - To each according to effort
  - To each according to likely contribution to society
  - To each according to fair market exchange (to each who can pay)
  - To each in redress for past harms

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- No one of these principles seem to fit all circumstances.
- All must be limited by available goods.



# Rejection of Social Worth Criteria

- 1943. Willem Kolff (Netherlands) invents hemodialysis machine.
- 1960, Belding Scribner develops in-dwelling shunt.
- 1961, Swedish Hospital, Seattle, Committee on Policy and Admissions
  - Committee decides who gets dialysis.
  - Appointed by King County Medical Association
  - Minister, lawyer, housewife, labor leader, state government official, banker, surgeon
  - Anonymous, no pay, never meet patients



# The God Committee's Criteria

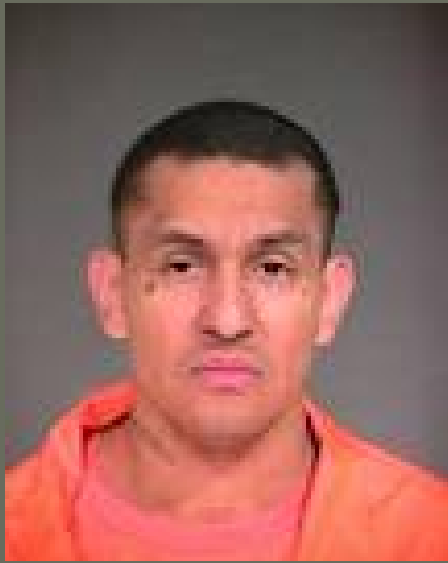
- *First level criteria:* Patients had to be residents of the state of Washington that were less than 45 years old and able to afford dialysis treatment (whether through insurance or other means).
- *Second level criteria:* employment status, parent of dependent children, levels of education, motivation, history of personal achievements, potential to help others.
- *Third level criteria:* ability to tolerate anxiety, independently manage medical care, personality, personal merit, strengths and weaknesses of the candidate's family, family's emotional support of the patient.

# Public Reaction

- “They decide who lives, who dies.” Shana Alexander, *Life Magazine*, 1962
  - “Will These Patients Have to Die?” *Seattle Times*, 1963
  - Scribner, Presidential Address, Am Soc Artificial Internal Organs, 1964
  - “*Who Shall Live?*” NBC Documentary, 1965
  - *BMJ* Symposium “Selection of Patients for Hemodialysis” 1968
  - “Who has a right to live?” *Good Housekeeping*, 1968
  - “The Allocation of Exotic Medical Lifesaving Therapy” Rescher, *Ethics*, 1969
- 
- 1963 – Boeing Corporation subsidizes dialysis in Washington state
  - 1967 – approximately 120 patients world-wide are get out-patient dialysis
  - 1968 – approximately 1000 patients accommodated in the US
  - 1972 – U.S. Congress pay for dialysis for all Americans through Medicare.
  - 1972 – God Committee Disbands

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**James Smith is a 38 year-old male with end stage renal disease (ESRD) requiring dialysis 3 times a week.**

- His ESRD results from polycystic kidney disease. Initial kidney transplant 2004, rejection 2006, nephrectomy January 2007.
- The patient lost the kidney because he was not compliant with medical appointments, medications, diet and had substance abuse.
- The patient is incarcerated at State Prison, for drug related murder of convenience store clerk. The crime was drug related.
- Sentence is 25 years, but will likely serve 13.
- Presented to transplant center for inclusion on wait list for deceased donor kidney

# What is the ethics question you will consider in your consult?

Given that Mr. Smith would probably benefit from a kidney transplant, but also that Mr. Smith's past actions call into question the appropriateness of allocating a scarce, life-saving resource to him, is it ethically justifiable to evaluate him and potentially place him on the waiting list for a deceased donor kidney?

# Ethical Issues in Organ Donation

## Donor Issues

### Dead Donors (Dead Donor Rule)

Definition of Death

- Neurological Death
- Cardiovascular Death

└───▶ DCD

Consent Issues



Full Understanding  
Family Role  
Advance Consent  
Process

## Recipient Issues

### Allocation of Dead Donor Organs

Heart	Short Supply
Lungs	
▶ Pancreas	Waiting List
▶ Kidney	
Liver	
Intestines	
Skin	
Cornea	
Bone	
Bone Marrow	

### Living Donors

Harming a healthy person  
How much risk can a donor accept?  
Donor-recipient confidentiality  
Family coercion  
Directed, unrelated donation  
Should we reward living donors?

Independent Living Donor Advocate

### Allocation of Living Donor Organs

Kidney	Bone Marrow
Liver Lobe	Lung Lobes

Should allocation be by directed by donor?  
Tourism    Payment    Swaps  
Donor responsibility to care for gift?

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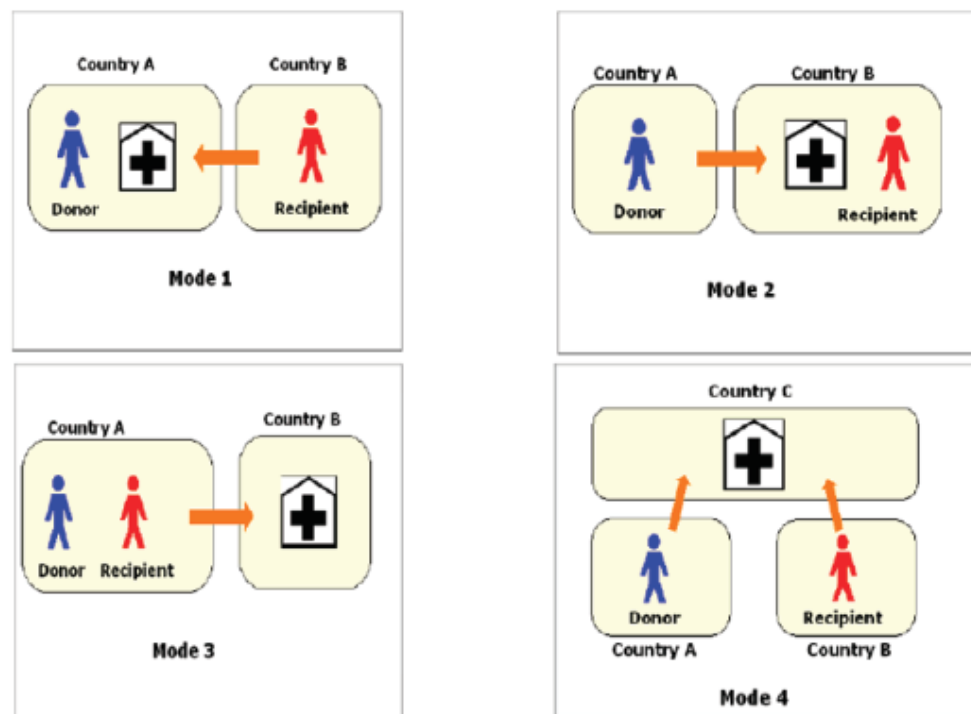
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## Ethics Corner

# Organ Trafficking and Transplant Tourism: A Commentary on the Global Realities

## Modes of international organ trade and organ trafficking



**Figure 1:** In this figure, Shimazono (2007) illustrates four modes of transplant tourism. Mode 1 entails a recipient traveling from Country B to Country A where the donor and transplant center are located, Mode 2 entails a donor from Country A traveling to Country B where the recipient and transplant center are located, Mode 3 entails a donor and recipient from Country A traveling to Country B where the transplant center is located, and Mode 4 entails a donor from Country A and a recipient from Country B traveling to Country C where the transplant center is located.

## Ethics Corner

# Organ Trafficking and Transplant Tourism: A Commentary on the Global Realities

D. A. Budiani-Saberi <sup>a,\*</sup> and F. L. Delmonico <sup>b</sup>

<sup>a</sup>Center for Bioethics, University of Pennsylvania,  
Philadelphia, PA

<sup>b</sup>Harvard Medical School at the Massachusetts General  
Hospital, Boston, MA

\*Corresponding author: Debra A. Budiani-Saberi,  
debra@cofs.org

The extent of organ sales from commercial living donors (CLDs) or vendors has now become evident. At the Second Global Consultation on Human Transplantation of the World Health Organization's (WHO) in March 2007, it was estimated that organ trafficking accounts for 5–10% of the kidney transplants performed annually throughout the world. Patients with sufficient resources in need of organs may travel from one country to another to purchase a kidney (or liver) mainly from a poor person. Transplant centers in 'destination' countries have been well known to encourage the sale of organs to 'tourist' recipients from the 'client' countries.

<a href="#">Welcome</a> Friday, March 30	<a href="#">Home</a> <a href="#">Advanced Search</a>	<a href="#">Patient Desktop Home</a> <a href="#">Potential Donor Home</a>	<a href="#">Patient Login</a> <a href="#">Potential Donor Login</a>	<a href="#">Sign Up As A New Patient</a> <a href="#">Sign Up As A New Potential Donor</a>
---	---	--	--	--

Patient Keyword Search (e.g., Kidney)

There are currently **10638** registered Potential Donors on MatchingDonors.com.

[Text too Small? Zoom Site.](#)

[Advertise with MatchingDonors.com Advertising](#)

*Sign-up for our newsletter.*

Name:

E-mail:

» [Press here to view our newsletter - updated weekly.](#)



**New Video Contest !**



**Press Here To Sign Up As A New Patient**

Feel free to call us at 1-800-385-0422.

**Many patients get their transplant through MatchingDonors.com within six months of signing up on this website.**

Nineteen people die every day in the United States waiting for a kidney transplant, most waiting 7 to 9 years. The team at MatchingDonors.com is working hard to make sure that doesn't happen by finding altruistic living organ donors for people needing kidney transplants.

MatchingDonors has become the most successful nonprofit organization that is finding living altruistic organ donors for patients needing transplants. The MatchingDonors.com website can get over 1.5 million hits in a month.

You can always call us to give you references of past and present patients that you can talk to about their great success with MatchingDonors.com.

*Organs that can be transplanted*

- » [Kidney](#)
- » [Kidney & Pancreas](#)
- » [Liver](#)
- » [Liver & Lung](#)
- » [Lung](#)
- » [Pancreas](#)
- » [Bone Marrow](#)
- » [Intestine](#)

*\* All organ donations on this site are only from living donors. \* MatchingDonors is a 501(c)3 nonprofit organization supported by memberships, advertisements and donations.*



**BBB Rating: A+**

as of 3/30/2012

[Click for Review](#)



**Need Assistance?  
Call 1-800-385-0422**

Press here to advertise on

# Living Donor Allocation Issues

- **Why allow non-related directed donation?**
  - Because it will attract more donors.
  - Donor-Recipient Chains
  - Because donors have a right to the decision.
- **Internet solicitation**
  - Payment possibility
  - Possible exploitation of recipients
  - Inappropriate motivations of donors
  - Benefits “cute” people.
- **Transplant Tourism**
  - Exploitation of the poor by the rich

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Font Size:

Page 1 of 1

**Waitlist : Organ by Age**  
 Current U.S. Waiting List  
 For Count = Registrations, Format = Portrait  
 Based on OPTN data as of March 29, 2013

[Create a New Report](#)

**Change Report (Optional) :**

**Format**      **Count**

Portrait  Registratio

Add Field to Report :

count flip cols rows both graph graph print

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Heart / Lung	Intestine
All Ages	127,725	102,409	16,446	1,198	2,196	3,488	1,677	48	263
< 1 Year	77	2	39	0	0	29	2	1	4
1-5 Years	593	180	160	32	1	103	12	2	103
6-10 Years	390	164	98	11	0	70	15	2	30
11-17 Years	877	535	171	8	1	99	37	4	22
18-34 Years	11,871	9,981	770	167	414	323	183	10	23
35-49 Years	31,956	26,829	2,293	609	1,258	682	235	14	36
50-64 Years	57,483	44,065	10,065	361	509	1,569	860	14	40
65 +	24,478	20,653	2,850	10	13	613	333	1	5

Font Size:

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	2012	2011
All Organs	28,052	28,537
Kidney	16,486	16,813
Liver	6,256	6,342
Pancreas	242	287
Kidney / Pancreas	801	795
Heart	2,378	2,322
Lung	1,754	1,822
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 #  ↺  %▼  %▶  #%  ▶  ↴  ↻

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**127,725    Needed today**  
**28,052    Transplanted 2012**



Who gets the available organs?

**Hearts**

# 5 Steps of Matching Process

- 1. An organ is donated.** When the organ becomes available, the OPO managing the donor sends information to UNOS. The OPO procurement team reports medical and genetic information, including organ size, and condition, blood type and tissue type by entering this information into UNet.
- 2. UNOS generates a list of potential recipients.** The UNOS computer generates a list of potential transplant candidates who have medical and biologic profiles compatible with the donor. The computer ranks candidates by this biologic information, as well as clinical characteristics and time spent on the waiting list.
- 3. The transplant center is notified of an available organ.** Organ placement specialists at the OPO or the UNOS Organ Center contact the centers whose patients appear on the local list.
- 4. The transplant team considers the organ for the patient.** When the team is offered an organ, it bases its acceptance or refusal of the organ upon established medical criteria, organ condition, candidate condition, staff and patient availability and organ transportation. By policy, the transplant team has only one hour to make its decision.
- 5. The organ is accepted or declined.** If the organ is not accepted, the OPO continues to offer it for patients at other centers until it is placed

# Match Run Criteria

(Not Ranked)

- tissue match
- blood type
- length of time on the waiting list
- immune status
- distance between potential recipient and donor
- degree of medical urgency (for heart, liver, lung and intestines)
- Organ size in relation to recipient

**3.7.10** **Sequence of Adult Heart Allocation.** Donor hearts recovered from donors age 18 and older shall be allocated in the following sequence in accordance with Policies 3.7.3, 3.7.4, 3.7.5, 3.7.7, 3.7.8, and 3.7.9:

**Local**

1. Status 1A candidates
2. Status 1B candidates

**Zone A**

3. Status 1A candidates
4. Status 1B candidates

**Local**

5. Status 2 candidate s

**Zone B**

6. Status 1A candidates
7. Status 1B candidates

**Zone A**

8. Status 2 candidates

**Zone B**

9. Status 2 candidates

**Zone C**

10. Status 1A candidates
11. Status 1B candidates
12. Status 2 candidates

**Zone D**

13. Status 1A candidates
14. Status 1B candidates
15. Status 2 candidates

**Zone E**

16. Status 1A candidates
17. Status 1B candidates
18. Status 2 candidates

## **UNOS Policy Adult Heart Allocation Ranking Criteria**

- 1. ABO Typing**
- 2. Geography**
- 3. Urgency**
- 4. Wait Time**

**\*Exception for sensitized candidates: If all centers and OPO agree, a compatible organ for a highly sensitized candidate may be used regardless of other criteria.**

# Medical Urgency, Hearts

- **Status 1A**
  - Mechanical circulatory support with acute hemodynamic instability (LVAD, RVAD, TAH, Balloon Pump, ECMO)
  - Mechanical circulatory support with device related complications
  - Mechanical Ventilation
  - Continuous infusion IV inotrope plus continuous of LV filling pressures
  - By application to Regional Review Board
- **Status 1B**
  - LVAD and/or RVAD
  - Continuous infusion IV inotrope
  - By application to Regional Review Board
- **Status 2**
  - Candidate not meeting 1A or 2A criteria
- **Status 7**
  - Temporarily Unsuitable

# Questions about Ranking Criteria

## Why should distance matter?

- Shouldn't people in rural areas have an equal chance at transplant? (Assuming most organ retrieval occurs in major urban areas.)
- Do shorter distances have an increased utility?
  - Keep travel time for organs short
  - Increase likelihood of donation (locals want to give to locals)
  - Incentive for local transplant program to expend resources to increase local donor pool
- Is the utility of these factors sufficient to override fairness concerns.

# Wait Time vs. Urgency

- A person disadvantaged by distance, blood type and relative health may have an extraordinarily long wait time.
- His quality of life will remain poor throughout this time.
- Why should he be penalized for his relative health?

Is there an ethical justification for “first come, first served?”

# Non-List Fairness Issues

- “Social support” criteria for getting on the list
- Access to health care determinant of getting listed.
- “Loose criteria” for medical urgency.
  - “continuous infusion of inotropes”? Put someone in the ICU with 3 mg of Dopamine to up their status?
- No UNOS defined counterindications to transplant
  - Wasting organs by transplanting them into someone too sick to benefit or with a much less likely chance of benefiting.



# Thank you

Questions?

**Frank Chessa, Ph.D.**

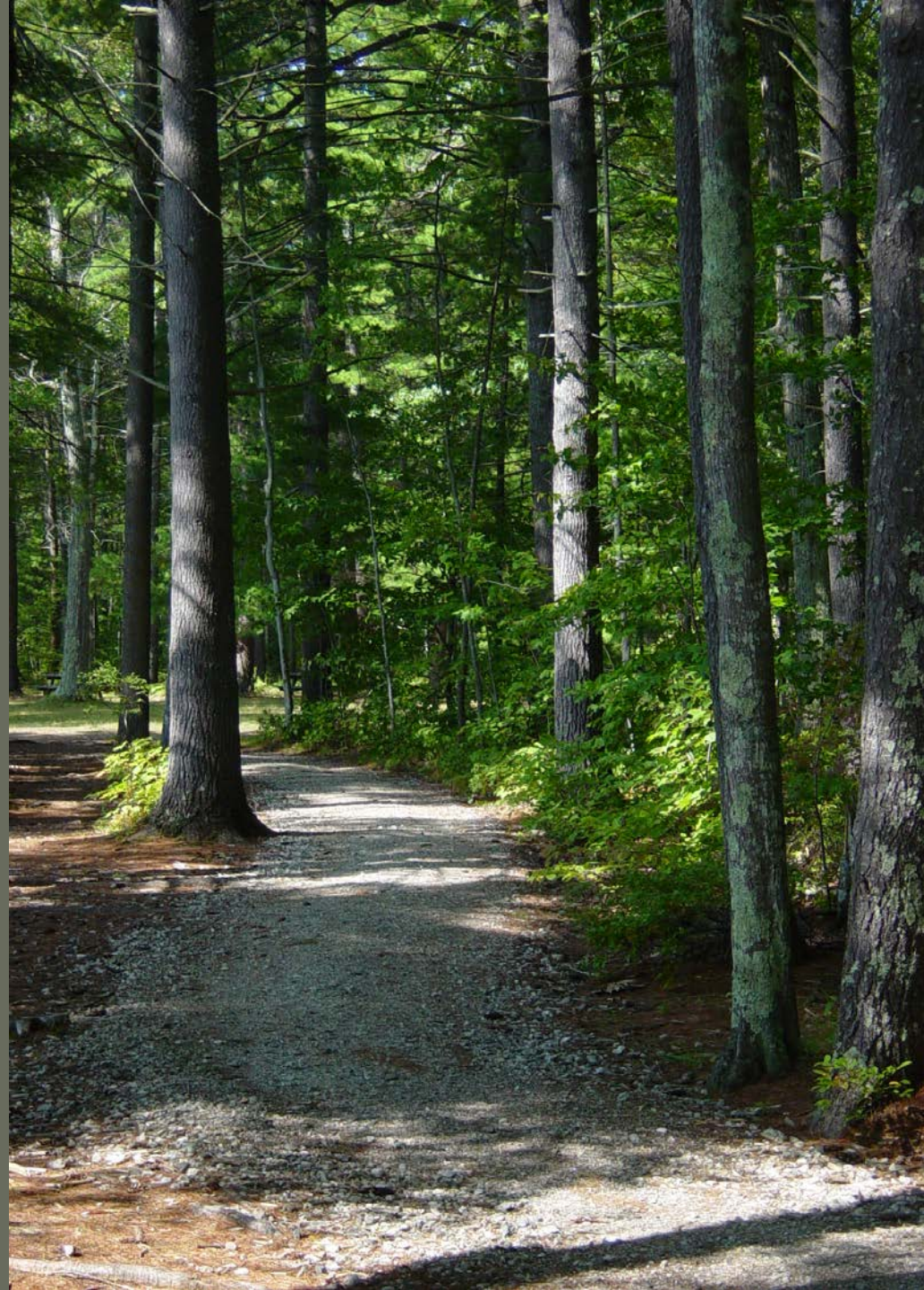
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**Format** Small group discussion

**Faculty** Facilitators

**Learning Objective** Identify the relevant facts and use appropriate ethical principles to argue a position in cases pertaining to allocation of limited resources in clinical settings.

**Readings** Cases for Discussion

- Is Understaffing a Unit a Form of Rationing Care?
  - Should a Prisoner Be Placed on the Organ Transplant Waiting List?
  - Transplant Tourism: Treating Patients when They Return to the U.S.
  - Assessing the Motives of Living, Non-Related Donors
-

**Format** Large group lecture

**Faculty** Glickman-Simon

**Learning Objectives**

- Explain the concept of dual agency as it pertains to the responsibility of clinicians to the welfare of other individuals besides their patients
- Identify under what circumstances it may be permissible to waive privacy regulations contained in the Health Insurance Portability and Accountability Act (HIPAA)
- Describe when it is ethically permissible to restrict the liberty of some individuals for the sake of other individuals, identified or unidentified
- Discuss the ethical tensions that may arise for physicians when the interests of their patients conflict with those of the state

**Reading Assignment** Jonsen text p 170 – 181, 214 - 218

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<b>Format</b>	Small group discussion
<b>Faculty</b>	Facilitators
<b>Learning Objective</b>	Identify the relevant facts and use appropriate ethical principles to argue a position in cases pertaining to public health ethics.
<b>Readings</b>	<u>Cases for Discussion</u> <ul style="list-style-type: none"><li>• Communicable Disease and Immigration Fears</li><li>• Maintaining Medical Neutrality in Conflict Zones</li><li>• Physician Activism and Civil Disobedience</li><li>• Treating Children Whose Parents Refuse to Have Them Vaccinated</li></ul>

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Cases for Discussion  
Session 18 – Public Health  
Student Version

**Communicable Disease and Immigration Fears**

Joseph had been feeling sick for a few weeks, with a severe cough and poor appetite. He even started losing weight. Despite his condition, Joseph did not seek medical care because if he called in sick at the construction company where he worked (either to visit the doctor or to stay home after being diagnosed) his paycheck would be docked. Joseph had a family of five to support: himself, his wife, and three small boys. A few years earlier with the help of some distant relatives, the family had managed to cross the border from Mexico—where Joseph had worked as a farmer and earned a few dollars a day—to California.

In America Joseph was earning nearly 10 times the amount of money he made in Mexico. Still, he couldn't afford a loss in his daily pay. One morning, Joseph woke up coughing violently and eventually spit up blood. He decided to go to work anyway. When he arrived at work, his condition drew the attention of his boss, who sent him to the community health clinic where he saw Dr. Monroe. After hearing how long Joseph had had the cough, Dr. Monroe ordered a chest X-ray, which showed that Joseph had active tuberculosis (TB).

When Dr. Monroe talked to Joseph about the test results, he cautioned him that his tuberculosis was highly infectious, imposing special restrictions on his life. He would have to isolate himself to limit the exposure of others. The public health department would also have to be notified, an idea which terrified Joseph. He pleaded with the doctor not to take this step, citing fears that he would be arrested and sent back to Mexico. Dr. Monroe assured Joseph that deportation would be a highly unlikely outcome, although he was unable to guarantee it would not happen. Dr. Monroe added that the health care system in the United States operated outside of immigration law enforcement. Still, Joseph was not reassured. He tried to bargain with Dr. Monroe, repeatedly promising to isolate himself voluntarily so long as neither he nor anyone else alerted the authorities.

American Medical Association Journal of Ethics  
December 2007, Volume 9, Number 12: 799-805

**Maintaining Medical Neutrality in Conflict Zones**

Asher is a fourth-year medical student doing an international elective in northern Uganda. The clinic he's stationed in serves primarily the local

community, and he's seen everything from routine ear infections to advanced AIDS, encephalitis, parasitic infections, and disseminated tuberculosis.

As one of the few Westerners the villagers have ever seen, Asher has created quite a stir. Although he's starting to feel more at home in the village, he knows that his actions are watched closely by the townspeople, and he's scrupulous about his interactions with them, always respectful and deferential to local customs and values.

The organization he's working with can only staff the clinic for eight months out of the year, so when an American medical team is there, news travels fast to neighboring communities, and occasionally people come from quite a distance to seek care.

One evening, Asher heard a commotion outside the clinic. Several men and women had gathered, and there was shouting. Asher asked a nurse what was causing the upset, and she explained that men thought to be affiliated with a group of rebel fighters from the north were approaching town, and some had been wounded. Asher moved to send for the local physicians and ready the procedure suites, but the nurse stopped him. "We've worked for years to establish trust among the local people here—trust that's enabled us to dramatically improve the health in these communities. It would be a grave insult if we offered care to their violent enemies, and that would surely result in a huge setback for all our hard work. We should shut down the clinic before the rebels arrive because they're not welcome here."

American Medical Association Journal of Ethics  
October 2007, Volume 9, Number 10: 681-687

### **Physician Activism and Civil Disobedience**

Dr. Garrison is a family physician who has been practicing at a health center in a high-poverty urban neighborhood for 20 years. She finds her work at the health center challenging and often frustrating, but she thinks it is important because the community is plagued by serious health and social problems. In the last 5 years, for example, Dr. Garrison and her colleagues have observed a steady increase in communicable diseases such as hepatitis and human immunodeficiency virus (HIV). The county public health department has also recognized this trend and has attributed this increase largely to high rates of intravenous drug use in the community.

Dr. Garrison's clinical experience supports the findings of the health department. In addition to her work at the health center, each week she conducts patient outreach visits at social service organizations and community centers. She also goes on street outreach to provide health care to the homeless. In each setting, Dr. Garrison has been told of—and in some cases even witnessed—IV drug users sharing needles.

Each time Dr. Garrison sees or hears about needle-sharing, she sees an opportunity for education. She has told her patients about the risks involved and provided them with information about treatment centers for drug addiction. Despite her efforts, Dr. Garrison sees no progress; more of her patients and their friends are contracting HIV and hepatitis.

In a meeting at the county health department to address this public health problem, she learns of an approach that might be effective in the neighborhood. Evaluations of some programs that provide IV drug users with clean needles and syringes, she is told, have had promising results in reducing the spread of communicable disease in some communities. Intrigued, she reads and assesses some of available literature. She finds that indeed, providing IV drug users with clean needles and syringes can be an effective means for combating the spread of hepatitis and HIV.

Stunned and inspired, Dr. Garrison thinks a needle exchange program would be effective in the neighborhood where she practices. She wonders, however, whether the program is legal. In researching the effectiveness of needle exchange programs, she had learned that they are illegal in many communities.

Dr. Garrison calls one of her friends on the city council to talk about whether local ordinances forbid such programs and, in doing so, learns that both local and state laws prohibit the distribution of needles. Her initial enthusiasm turns to anger, and she makes an appointment to discuss the issue with her state representative.

Dr. Garrison's state representative is sympathetic to her cause but tells her that the legislature's priorities right now are to manage the budget deficit and revive the state's economy. Besides, he says, many state legislators think that needle exchange programs encourage drug use and that there are better and more appropriate ways to reduce the spread of disease.

Frustrated with the legislator's response, Dr. Garrison decides it is time to take matters into her own hands and create a needle exchange program on her own time and with her own money. She knows that in doing so she is engaging in an illegal act that could endanger her career and reputation. She believes that this risk is worth taking, however, because providing her patients and others in the community with clean needles could help reduce the transmission of disease. She also hopes that the program and publicity it receives will draw more attention to the problem and will prompt local and state policymakers to address the issue.



## **Treating Children Whose Parents Refuse to Have Them Vaccinated**

Dr. Feyn, a Denver pediatrician, mentions to his colleague Dr. Manning that parents' refusal of vaccines for their children has become more popular among parents in his patient panel in the last 5 years. "Most of these parents have similar reasons for choosing not to vaccinate their children. They cite alternative vaccination schedules, celebrity campaigns against vaccine side effects, even online forum discussions with other parents."

Dr. Manning responds, "The CDC has recommended schedules for vaccination, but I know you would like to respect the discretion of patients and parents of patients as much as possible. So what are you going to do?"

"In the past I have documented the vaccine refusal and moved on, but I'm considering changing my approach," Dr. Feyn responds. "As the number of unvaccinated children in my practice increases, I wonder if I am creating a risky environment for vaccine-preventable infections in my community. We recently witnessed an outbreak of pertussis nearby in Boulder because the percentage of immunized kids at a certain school was below threshold necessary for herd immunity."

"I'm thinking of insisting that my patients receive vaccinations according to the standard schedule, unless, of course, there is a specific health-related reason why an individual child should not be vaccinated. I am also considering not treating children in my practice unless they are vaccinated. What do you think of that?"