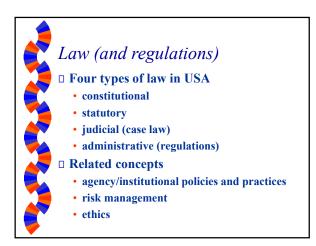
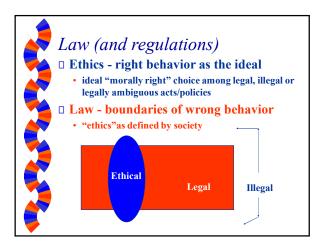


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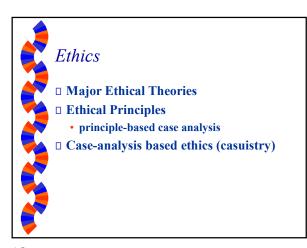














## Major Ethical Theories

- ☐ Virtue Ethics what would a virtuous person do?
  - Ancient Greeks
  - Still a worthy personal goal
  - Not especially helpful in resolving ethical dilemmas

17



## Major Ethical Theories

- □ Virtue Ethics what would a virtuous person do?
- ☐ Deontology is this an inherently right or wrong act?
  - Emphasis is on the *nature* of the action or policy being considered.
    - E.g., lying to my client is (inherently) wrong









## Ethical Principles

- ☐ Search for a more practical approach to resolving ethical dilemmas
- ☐ Commonly understood principles as the basis for making policy and resolving ethical disputes
  - · Beauchamp and Childress/Georgetown
  - Belmont Report, "Belmont Principles"
  - varied formulations (English, Veatch, etc.)

22



## Ethical Principles

- □ Beneficence/Nonmaleficence
  - doing good/not harming
    - quality
    - confidentiality
    - fidelity
- □ Autonomy (respect for persons)
  - veracity
  - candor
- ☐ Justice (treating like cases alike)

23



## Ethical Principles: Beneficence/Nonmaleficence

#### □ Problems in Implementing:

- What constitutes good?
- What constitutes harm?
- What values define good or harm?
  - RELIGION
  - SCIENCE
- Autonomy/Beneficence Conflicts
- Beneficence/Justice Conflicts



# Ethical Principles: Autonomy

- ☐ A hallowed principle in America
  - "independence", "freedom", "selfdetermination", "liberty"
  - may undermine "community"
- □ Client must consent to therapy
  - battery "unwanted touching"
  - civil liability coerced/uninformed consent

25



# Ethical Principles: Autonomy

- □ Problems in upholding autonomy
  - autonomy/beneficence conflicts
    - competence? (legal)
    - capacity? (functional)
    - relevant information?
    - idiosyncratic beliefs
    - refusal (versus compliance) as prima facie evidence of incompetence
    - cultural differences
  - autonomy/justice conflicts

26



# Ethical Principles: Justice

- ☐ Formal principle of Justice
  - "Treat like cases alike."
- □ On what basis are two cases considered to be *like cases*?



## Ethical Principles: Justice

- **□** Formal principle of Justice
  - "Treat like cases alike."
- ☐ "Material" principles of justice
  - equality
  - · ability to pay
  - need
  - merit
  - social worth
  - social contribution

28



# Ethical Principles: Justice

- ☐ Lack of a common shared understanding of justice is inherent in our nation's health care debate?
- □ What model drives:
  - state rehabilitation agencies?
  - for-profit insurance companies?
  - private rehabilitation firms?
  - Medicare/Medicaid
  - the Canadian health care financing system?

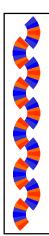
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## Ethical Principles:

## Problems in using principles to resolve ethical issues:

- Which principle matters most?
  - to whom?
  - why?
- Are there other important principles?
  - sanctity of life
  - community
  - family



A Case-Analysis Approach to Ethics (Jonsen, Siegler, Winslade, Clinical Ethics)

- ☐ Method designed for clinical settings
  - multitude of facts and values
  - need for rapid decisions
  - clinicians desire concrete, direct answers
- ☐ Four key components

31



A Case-Analysis Approach to Ethics Four key components must first be outlined

- □ Clinical Indications
- □ Client Preferences
- □ Quality of Life
- **□ Contextual Features**

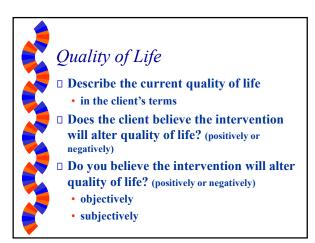
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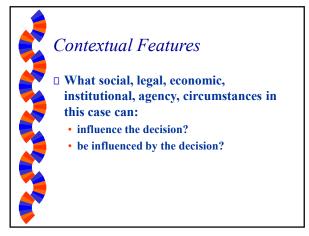


## Clinical Indications

- ☐ Consider each condition and proposed intervention and ask:
  - does it fulfill any of the goals of medicine/rehabilitation?
  - with what likelihood?
  - If not, is the proposed intervention futile?
    - Definition of futility is a challenge Wanglie case









A Case-Analysis Approach to Ethics

- ☐ Questions to be addressed after collecting information:
  - What is at issue?
  - Where is the conflict?
  - Are we aware of similar cases?
  - Is there a precedent (paradigm case)?
  - How (if at all) does this case differ from the paradigm?
  - Are these differences morally significant?

37



Dax's Case A classic medical ethics case

In 1973, Donald "Dax" Cowart, age 25, was severely burned in a propane gas explosion. Rushed to the Burn Treatment Unit of Parkland Hospital in Dallas, he was found to have severe burns over 65 percent of his body; his face and hands suffered third degree burns and his eyes were severely damaged.

38



Dax's Case A classic medical ethics case

Full burn therapy was instituted. After an initial period during which his survival was in doubt, he stabilized and underwent amputation of several fingers and removal of his right eye.



## Dax's Case A classic medical ethics case

During much of his 232 day hospitalization at Parkland, his few weeks at Texas Institute of Rehabilitation and Research at Houston, and his subsequent six months stay at University of Texas Medical Branch in Galveston, he repeatedly insisted that treatment be discontinued and he be allowed to die.

https://www.youtube.com/watch?v=M3ZnFJGmoq8

40



## Dax's Case A classic medical ethics case

- Despite this demand, wound care was continued, skin grafts performed and nutritional and fluid support provided. He was discharged totally blind, with minimal use of his hands, badly scarred, and dependent on others to assist in personal functions.
  - Jonsen, Siegler & Winslade, Clinical Ethics: Third Edition, (McGraw-Hill: New York), 1992, page 4

41



#### Dax's Case

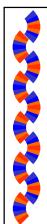
An Autonomy/Beneficence Conflict

#### ☐ Beneficence/nonmaleficence

- What "good" was accomplished?
  - Dax's life was saved
- What harm was caused?
  - Death would have avoided intensely painful treatments

#### □ Autonomy

- Were the patient's wishes respected?
- Did he have the capacity to decide?



## Dax's Case A Case Analysis

#### □ Clinical Indications

- After emergency treatment, Dax's prognosis for survival was  $\sim 20\%$ .
- After 6 months of treatment, Dax's prognosis for survival was ~100%.
- If his refusal of wound care had been respected certainty of death was ~100%.

43



### Dax's Case A Case Analysis

#### **□** Client preferences

- Initially doctors assumed that the trauma of the burn limited Dax's capacity to make decisions.
- Later, in Galveston a psychiatrist affirmed his capacity to decide.
  - Would respecting his decision constitute assisted suicide?
  - Could Dax reasonably evaluate his life postrehabilitation?

44



### Dax's Case A Case Analysis

#### □ Quality of Life

- Prior to the accident Dax was an athlete, outdoorsman, ex Viet Nam fighter pilot who worked in real estate, hoped to become an airline pilot.
- During treatment Dax's life was excruciatingly painful, and he was profoundly depressed.
- Post accident Dax would be disfigured, blind, without most fingers, and would experience mobility limitations.



### Dax's Case A Case Analysis

#### □ Contextual features

- Dax's mother urged aggressive treatment for religious reasons
- Legal implications of honoring Dax's refusal were unclear in 1973.
- Insurance or personal funds apparently covered the high cost of Dax's care.
- Dax's refusal affected staff attitudes toward his care.

46



# Thinking About Autonomy in Dax's Case

- □ Not simply respect for an abstracted principle
- □ Instead, a confluence of considerations about preferences, indications for treatment, quality of life, decisional capacity, roles of his mother, his doctors, lawyers, hospitals, legal system.

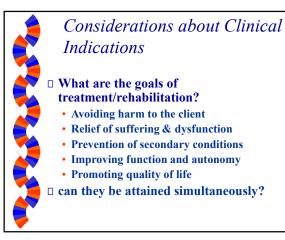
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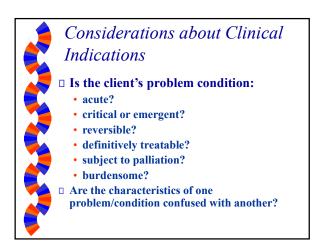


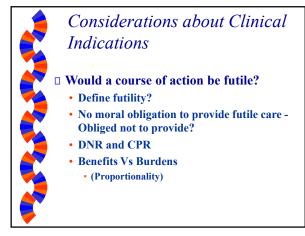
## Goal and Activities in a Case-Based Approach

#### ☐ Develop a reasonable resolution

- marshal the facts
- evaluate the facts
- project outcomes of various options
- search for precedents
- develop a nuanced understanding of the case
- · propose and defend the resolution









## Mr. J. -- Clinical Indications

□ Mr J., age 60, has terminal lung cancer. During a recent surgical hospital stay he signed a DNR order stating that if his heart should stop he did not want CPR. His surgery was uneventful and he returned home. Feeling better, he has made an appointment to discuss returning to his work as a sign painter. While in your office he complains of left arm and chest pain and then collapses.

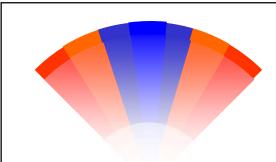
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#### Mr. J. -- Clinical Indications

- ☐ Should you use the office's portable defibrillator on Mr. J.?
- □ Does his DNR order mean anything?
  - Why or why not?
- ☐ Is his lung cancer relevant to this event?
- $\Box$  What else should be considered?
  - law?, agency policy?

53



Issues and Related Cases in Bioethics



## I. Truthtelling

#### ☐ Based upon the principle of *autonomy*

- "The truth shall set you free."
- Disinformation is a weapon.
- Is withholding the truth different than lying?
- □ What do clients want to know?
  - Studies show that 90% of medical patients want to be told about Dx like cancer, Alzheimers. 97% of physicians today would disclose (10% in 1961).

55



#### A Consequentialist Argument for Truthtelling

□ A bus load of politicians were driving down a country road, when all of a sudden, the bus ran off the road and crashed into a tree in an old farmer's field. The old farmer,after seeing what happened, went over to investigate. He then proceeded to dig a hole and bury the politicians. A few days later, the local sheriff came out, saw the crashed bus, and asked the farmer where all the politicians had gone. The old farmer said he had buried them. The sheriff then asked the old farmer, "Were they ALL dead?" The old farmer replied, "Well, some of them said they weren't, but you know how them politicians lie."

56



#### Telling and Withholding the Truth

#### □ What is the "truth"?

- The clinical facts as you best understand them:
  - Nature of the problem
  - Outcomes/with & without therapy
  - Alternative therapies with risks/benefits
  - What is unknown or uncertain
  - Other things the client wants to know
- ☐ Truthful does not mean cruel.



## Telling and Withholding the Truth

- ☐ "The client's son asked me to withhold this information from her."
  - · Generally this is inappropriate.
    - Information belongs to the client
    - Should not be revealed even to the spouse
  - There are exceptions:
    - Special characteristics of the *client* 
      - fragility
      - incapacity
    - Cultural issues/ethnicity (Navaho for example)

58



#### Telling and Withholding the Truth

- □ Therapeutic privilege withholding information when there is compelling evidence that this information will cause the client serious harm.
  - Rare event too often abused.
- What if the client asks not to be told specific information, or states he does not want to know anything?

59



### Telling and Withholding the Truth

- □ What about deceiving a client as therapy?
  - Use of *placebos* (placebos are not just inert drugs).
    - Any intervention that claims to provide clinical benefit when the best scientific evidence suggests that there is no benefit.
    - Examples in rehabilitation medicine?
      - Pain relief?
      - Mood enhancer?



## Telling and Withholding the Truth

Your 58 year old client Mr. Smith is recovering from a massive stroke and, in addition to left sided paralysis, remains somewhat confused. His medical records reveal that he also is receiving chemotherapy for a post-stroke diagnosis of prostate cancer. His wife states that he is unaware of the cancer diagnosis because she and his doctor believe that it would be too much for him to handle. He was given chemotherapy in the hospital and at home, but it was simply presented to him as "here is your medicine".

61



#### Telling and Withholding the Truth

Mr. and Mrs. J have a four year old child Jimmy who has Cystic Fibrosis (CF). They seek information from a genetic counselor about the risk of having another CF child. Genetic tests show that Mr. J does not carry the CF gene and that he is not Jimmy's biological father. What should the J's be told?

62



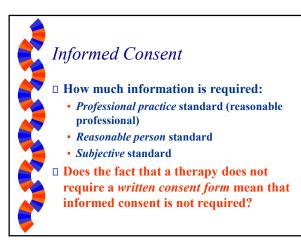
## II. Informed Consent

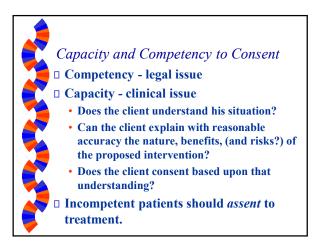
□ Informed consent is a process

- based upon self-determination
- allows autonomous choices
- closely related to truthtelling

☐ Elements of informed consent

- information
  - · nature of process, risks, benefits, alternatives
- capacity to understand
- freedom from coercion









## Informed Consent?

Mr. B age 58 is hospitalized with MS. The team feels he needs a feeding tube to assure adequate nourishment. He agreed yesterday morning to a feeding tube, but then at 7:00 p.m. appeared disoriented and confused and told the team he did not want it. Now at 8:00 a.m. he again agrees to the procedure.

67



## III. Confidentiality

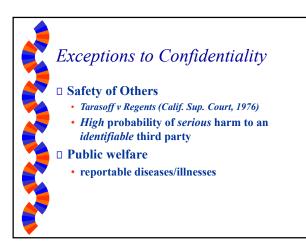
- ☐ A Professional duty:
  - respect for persons/beneficence/autonomy
  - challenged by law
  - challenged by technology
  - challenged by third party payment
  - upheld by professionals
- □ Requires
  - prudence, caution, security, care, concern

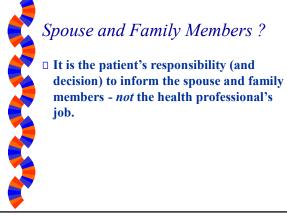
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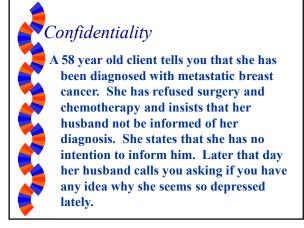


## Confidentiality

- ☐ What constitutes inappropriate disclosure?
  - Public conversations
  - Careless handling of documents
  - Inadequately protected electronic records
  - Visible VDTs
  - Teaching materials that identify patients unnecessarily









## Confidentiality

A 28 year old man paralyzed by a gunshot wound is in therapy when he learns that he is HIV positive. He states that he has no intention of telling his wife because she will dump him and leave him without support if she learns about his condition.

73



## IV. End of Life Issues

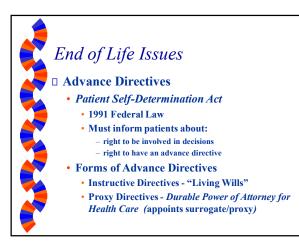
- ☐ Life "a death-defying act".
- ☐ Deaths can't be "prevented" only postponed.
  - For how long
  - What are the costs?
    - pain & suffering
    - medically managed death
    - financial burden
- ☐ Goals of medicine... curing vs. healing

74



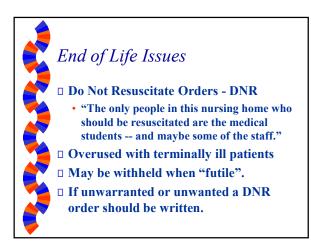
## End of Life Issues

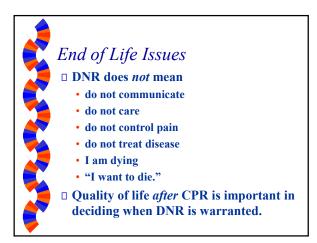
- ☐ Goals in working with the dying:
  - Listen, listen, listen
    - cultural values
    - individual preferences
    - experience of living --- "the story"
    - · experience of dying
  - Prevent suffering
  - Help with living
    - family issues
    - help "tie up loose ends"
    - friendships/support

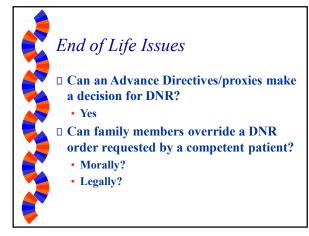


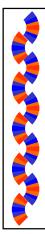












## End of Life Issues

- ☐ Withholding and Withdrawing Life-Sustaining Treatments
  - When can life-sustaining treatments be withdrawn?
    - When the patient (or surrogate) requests it.
    - When it is no longer of benefit
  - · How do I know what "benefit" is?
    - Medical futility
    - Patient's values/directives

82



## End of Life Issues

- $\ \square$  Is nutrition & Hydration "different"?
  - Symbolic meaning of food and water
  - Feeding and hydrating is not always more humane!
  - Legally, no (in most venues).
  - Schiavo case in Florida.
- □ Can patients demand life-sustaining treatments that physicians perceive as *futile*?

83



## End of Life Issues - Futility How do we define futility?

- ☐ *Quantitative* there is little chance it will change the patient's condition.
- ☐ *Qualitative* even if it works, the quality of life will be exceedingly poor
  - Which of these is more a question of values?
- □ Experimental treatment is not futile
  - If it is known in advance to be futile it shouldn't be instituted!!



## End of Life Issues - Futility

- ☐ Is a physician obligated NOT to provide care that is *quantitatively* futile?
- ☐ Is a patient entitled to care that the physician views as *qualitatively* futile?

85



## End of Life Issues

- ☐ Hospice movement
  - alternative to medicalization
  - Goals are:
    - pain control
    - symptom control
    - psychological support/therapy
    - spiritual/existential help

86



## End of Life Issues

Ms. W is a 27 year old who has been placed in a skilled nursing facility for rehabilitation from a cervical spine injury. She has quadriplegia, no problems with respiration, and normal cognitive function. She develops pneumonia and is transferred to the local hospital. Upon admission the resident says "She should be DNR based on medical futility."



## End of Life Issues

Mr. R.W., age 87, has end-stage emphysema and appears at the emergency room short of breath. He is discovered to have pneumonia. Over the next 3 hours his condition deteriorates, though he remains awake and alert. His chart from a previous admission contains a signed and witnessed Living Will that stipulates he wants no "invasive" medical procedures "that will serve only to prolong my death".

Should mechanical ventilation be instituted?

88



## End of Life Issues

J.D., a 37 year old fundamentalist minister had a massive cerebral hemorrhage and is dependent on a ventilator. His neurologist states that his cerebral cortex has been destroyed and that there is no hope that he will regain consciousness. His family says that they know God will produce a miracle if the hospital keeps Mr. D. alive. The church had no health insurance. The physician believes that continued ventilator support is futile. The family is suing the hospital to continue support. Medicaid is paying for Mr. D's intensive care.

89



### V. Advance Care Planning

- ☐ Refers to the process that *may* lead to an advance directive
- □ Purposes
  - fit care to patient's goals
  - minimize under/over treatment
  - reduce family conflicts over future care
  - minimize burden of decision-making on family



## Advance Care Planning

- ☐ Should occur with patients at elevated risk of *decisional incapacity* based on:
  - medical indications (poorly controlled hypertension, early stage dementia)
  - behavioral indications(head trauma risks behaviors)
  - recurrent psychiatric illnesses
  - · terminal illness

91



## Advance Care Planning

- ☐ Should determine:
- Who should speak for you?
  - Do you have specific preferences?
  - Are there specific treatments you would never want?
  - What are your views on death/dying?
  - Should your *current* preferences be *strictly applied*, or be a general guide?

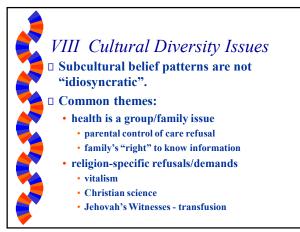
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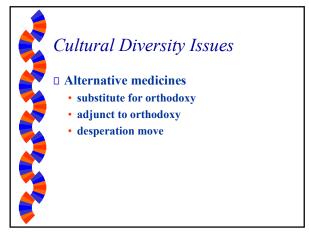


#### VI: HIV & AIDS

- ☐ Special ethical issues because of the combination of:
  - communicability
  - · lack of definitive treatment
  - stigma/discrimination
  - · changing nature of disease
  - populations affected
  - · fears and prejudices of providers









## Cultural Diversity Issues

A 45 year old steel worker has fallen and broken his leg severely. He has been dicharged from the hospital with a rehabilitation plan that includes physical and exercise therapy. He refuses and states that he will return to the Onondoga reservation where his medicine man will restore function to his leg.

97



### Cultural Diversity Issues

Your client's fourteen year old daughter has had a severe headache and high fever for several days. Your client, a Christian Scientist, shows great concern and has contacted elders in her church who assure her that her daughter's devotion to Christian Science will remove the apparent symptoms.

What should you do/say?

98



## Summary

- ☐ Theories, principles and case analysis skills are all necessary
- ☐ Communication is essential to resolving ethical disputes
- **□ Ethics Committees** 
  - Educate professionals
  - · Set and evaluate policy
  - Review cases

