**Disability Bioethics: How Faith**

**and Ethics influence Health Care**

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Objectives

* 1. Understand the role of clinical ethicists

and the history behind their existence

* 2. Review the continuing controversies

between bioethics and disability rights

* 3. Practice resolving ethical dilemmas in health care using the methods of clinical ethics consultants

What is Bioethics?

* Bioethics is an activity; it is a shared, reflective examination of ethical issues in health care, health science, and health policy. These fields have always had ethical standards, of course, handed down within each profession, and often without question. About forty years ago, however, it became obvious that we needed a more public, and more critical, discussion of these standards.


## What does an ethics committee

do?

* 1. Recommends ways to resolve ethical

dilemmas as they occur in health care

* 2. Educates hospital staff
* 3. Authors policies and procedures to ensure ethical decision making occurs

Who is on the ethics committee?

* Clinicians and hospital staff (mostly volunteers) interested in promoting ethical practice at their institution

– Physicians, nurses, risk managers, hospital

lawyers, PT, OT, ect.

* Community Members
* Employed or contracted clinical ethics

consultants


## Defining clinical ethics consultation

"Health care ethics consultation (HCEC or “ethics consultation”) is a set of services provided by an individual or a group to help patients, families, surrogates, health care providers, or other involved parties address uncertainty or conflict regarding value-laden concerns that emerge in health care."

ASBH Core Competencies for Health Care Ethics Consultation, 2nd ed. 2011.


## What is the role of a clinical ethics

consultant?

* To promote an ethical resolution of the case

at hand

* To establish comfortable and respectful communication among the parties involved
* To help those involved learn to work through ethical uncertainties and disagreements on their own
* To help the institution recognize ethical patterns that require attention


# Why do these services exist?

* Theologians interested in health care
* The “God Committee” (1962)
* Karen Quinlan (1976)
* Baby Doe (1986)

Bioethics, Disability Rights, and

Religion

* Why the 3 diverged
* The status of disability advocacy and religion in bioethics today
* Points of intersection and continuing

debates

Continuing Controversies

* Prenatal Screening/PGD/Abortion
* Physician Assisted Suicide
* Institutionalization PID
* Development of prosthetics
* The biomedical model/ “species typical

functioning”

* Quality of life determinations – who gets to decide?


# Group Reflection

* What would you like clinicians and bioethicists to know about your “disability experience”
* What would you like clinicians and bioethicists to know about your “religious experience”

Considering ethical implications

* Mr. D was admitted through the ED with cough, fever, and difficulty breathing. X-rays showed lung infiltrates. He was admitted with a presumptive diagnosis of pneumonia, and treated with broad-spectrum antibiotics. Two days later his symptoms had worsened. Bronchoscopy was recommended, and the possible need for ventilatory support was discussed. Mr. D adamantly refused both. Although in some distress, he was alert and oriented. He appeared to understand the information provided, but would not explain the reasons for his refusals.

Key Ethical Considerations

* Autonomy: the right to make medical decisions for yourself
	+ Right to refuse medical treatment
	+ Decisional capacity: your ability to make decisions for yourself
		- If you do not have DC, your surrogate has an obligation to make choices as you would have made them OR to act in your best interest
* Beneficence/Non-Maleficence: the clinicians’ obligation to help and not harm you
	+ Clinicians have an obligation to prevent an avoidable death
* Justice: Clinicians are obligated to distribute resources fairly and not discriminate against certain patients

Do not

intubate


### Options

He has decisional capacity


### Reasoning

He’s refusing Tx

Right to refuse treatment

### Moral

**Considerations**

Do not

intubate Intubate


### Options

Other evidence of his values?

He has

capacity (?)

He’s

refusing Tx

He doesn’t have capacity (?)

### Reasoning

Right to refuse treatment

### Moral Considerations

Do not

intubate

## Ethical Diagnosis for Mr. D

Intubate


### Options

He’s got

Prognosis

poor

Prognosis

good ?? **Reasoning**

capacity; or

not

He’s

refusing Tx

Right to refuse treatment

Prevent avoidable death

### Moral Considerations

Small Group Exercise: The Ashley

Case

* Ashley is born with severe developmental disabilities due to static encephalopathy of unknown origin. Physicians predict that mentally she will remain at the infant level. At 6, she begins to show early signs of puberty. Her parents are worried that if she grows too large they will not be able to take care of her at home. Her parents ask doctors to help attenuate her growth with estrogen therapy, give her a hysterectomy, remove her breast buds, and give her an appendectomy.


# Ethical Diagnosis for Ashley


### Options

**Reasoning**

**Moral**

**Considerations**