Ethical Dilemmas in Resource Allocation

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Learning Objectives:
- Develop an understanding of the implication of cost/risk benefit analysis in resource allocation
- Describe a summary of the philosophies behind the evolution of ethics in medicine.
1. What do we mean when we say ethics?
2. Why focus on relationship?
3. Theory
4. Ethical Relationships
5. Two Barriers to Relationship
   - Risk assessment
   - Patient responsibility
# Uses of the term “Ethics”

1. **Wrongdoing**
   - Acts that clearly violate moral norms.
   - Examples: Excessive use of restraints; Racial disparities in treatment.
   - Style of Resolution: Eliminate bad actors; Systemic analysis and reform.

2. **Dilemmas**
   - A conflict in legitimate values.
   - Examples: Should you ever conceal meds in the food of a patient with dementia?
   - Style of Resolution: Ethical analysis.

3. **Enacting our values**
   - Devising better ways to enact values.
   - Examples: Should palliative care be offered earlier in the cancer trajectory?
   - Style of Resolution: Empirical analysis; Clinical innovation.

4. **Right values**
   - Determining what values should guide professional decisions and behavior.
   - Examples: Should sanctity of life override patient choice when a terminal patient asks for assisted suicide?
   - Style of Resolution: Academic & philosophical analysis.

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## Uses of the term “ethics” in health care

<table>
<thead>
<tr>
<th>Type of problem</th>
<th>Description</th>
<th>Question needing answered</th>
<th>Examples</th>
<th>Style of Resolution</th>
</tr>
</thead>
<tbody>
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<td>Wrongdoing</td>
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<td>Enacting values</td>
<td>Devising better ways to enact values.</td>
<td>Can this be done better?</td>
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<td>What principles should guide clinical action and decisions?</td>
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<td>Academic &amp; philosophical analysis</td>
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**2. Why focus on relationship?**

The aches of others hang by a hair.
- Sancho Panza
Causes of US deaths, 2000*

- Tobacco
- Poor diet and physical inactivity
- Alcohol consumption
- Motor vehicle
- Firearm
- Illicit drug use
- Sexual behavior
- Toxic agents
- Microbial agents


The CDC estimates that if tobacco use, poor diet and physical inactivity were eliminated in it would prevent:

- 80 percent of heart disease and stroke
- 80 percent of Type 2 diabetes
- 40 percent of cancer

From: http://flcured.org/chronic_diseases.php

The burden of chronic disease

- Chronic diseases are the #1 cause of death and disability in the US
- Chronic diseases account for 75% of the US health care spending
- The vast majority of cases of chronic disease could be better prevented or managed

*From: http://www.caaccess.org/pdf/6_unhealthy_truths.pdf
- Deliberate health behaviors are a principle cause of illness.
- Chronic illnesses caused by behavior are a chief focus of treatment.
- Illnesses arising from health behavior are prevented and treated by behavior change.
- Behavior change occurs within relationships.
- Psychosocial interventions and therapeutic relationship can be learned and researched.

### Obesity by Income and Education

<table>
<thead>
<tr>
<th>Income</th>
<th>Less than $15,000</th>
<th>$15,000 to $25,000</th>
<th>$25,000 to $35,000</th>
<th>$35,000 or more</th>
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</thead>
<tbody>
<tr>
<td>Education</td>
<td>High School (HS)</td>
<td>Graduated HS</td>
<td>Enrolled in Tech Sch</td>
<td>Graduate College</td>
</tr>
<tr>
<td>Percent with BMI &gt; 30%</td>
<td>20.6%</td>
<td>10.7%</td>
<td>2.3%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

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### Average annual salary and prevalence of smoking by profession, MD, RN & LPN

<table>
<thead>
<tr>
<th>Average annual salary</th>
<th>Percent smokers</th>
</tr>
</thead>
<tbody>
<tr>
<td>$55,000</td>
<td>20.8%</td>
</tr>
<tr>
<td>$50,000</td>
<td>21.5%</td>
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<tr>
<td>$45,000</td>
<td>22.0%</td>
</tr>
<tr>
<td>$40,000</td>
<td>22.2%</td>
</tr>
<tr>
<td>$35,000</td>
<td>22.3%</td>
</tr>
</tbody>
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3. Theory

Consequences of Western perspective on clinical ethics

- Analysis structured by individual rights
  - Adversarial relations
- Emphasis on blame
  - Legitimate and illegitimate suffering
- Discomfit with influence as decreasing autonomy
- Universalizability
  - Psychological distance from decisions
Consequences of Western perspective on clinical ethics

- Assumption that rationality equals personhood
  - Near obsession with competence
- Primary concern with limitations
  - Emphasis on preventing abuse
- Dichotomous thinking
- Emotion is negative
- Particularistic relationships not relevant

Autonomy, DMC, informed consent, & responsibility are interrelated concepts

- **Autonomy**
  - Defining human attribute of great moral significance
  - Respect for autonomy

- **Decision-Making Capacity**
  - Mental functioning needed to act autonomously

- **Informed consent**
  - Technique to ensure that treatment decisions are made autonomously

- **Responsibility**
  - Conferred by autonomous decision-making

Lawrence Kohlberg (1927-1987) Carol Gilligan (1936-)

"Universal principles of justice, of the reciprocity and equality of the human rights, and of respect for the dignity of human beings as individual persons."

"To see self-sufficiency as the hallmark of maturity conveys a view of adult life that is at odds with the human condition."
Virtue ethics

- Good occurs through the actions of individuals who enact particular virtues.
- Contrasts with the dominant tradition which holds that good is achieved through the application of the correct set of a priori universally applicable principles.

Virtue in clinical care

- Virtues are those characteristics “essential to achieving the ends” of care
- Care as a moral attitude
- Maintenance of moral community
Emphasis:

**Traditional**
- Values in conflict
- Dilemmas
- Limits of clinician authority
- Honoring rights
- “Bumper car”

**Relational**
- Defining values
  - Maximizing patient dignity
  - Being worthy of patient trust
- *Clinical know-how*
- Ethical relationship
- How to best enact values
- Focus on more “good”
- Virtue

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4. The ethical relationship

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Typology of treatment goals and the significance of the clinical relationship

I. Elimination
- Strep throat, hernia, broken arm
- Relationship is minimal
- Little variation in preference and goals

II. Minimization
- Schizophrenia, rheumatoid arthritis, Crohn’s disease
- Relationship is critical because:
  - Clinician better understands the patient’s way of life
  - Patients benefit from feeling personal concern
- Significant reasonable variation in preference and goals

III. Prevention
- Heart disease from poor diet, COPD from smoking
- Relationship is critical
- Significant reasonable variation in preference and goals
Patients are vulnerable because:

- Patients are sick
- Clinicians have more power
- Clinicians have intimate knowledge of patients
- Clinicians have intimate physical contact with patients
- Clinicians control access to resources
- Clinicians make judgments about patients and control socially meaningful labels

Fiduciary relationship

A fiduciary is one in whom a person has placed special trust and confidence and who is required to watch out for the person’s best interests. It is a special relationship of loyalty based on a difference in power and knowledge.
**Trust is justified confidence:**

- That the clinician:
  - Is competent to treat
  - Has patient benefit is overriding goal
  - Will maintain confidentiality
- That the system
  - Will provide treatment fairly
  - Has patient benefit as its overriding goal

**We value trust because:**

- Patient trust in the clinician and the health care system provides the foundation of an ethical, clinical relationship.
- Trust creates a safe space:
  - To discuss clinically essential information that the patient may not want revealed
  - To allow the clinician intimate physical contact

**Trust works**

- Patients who trust their clinicians are more likely to disclose clinically essential personal information
  - (Street et al, 2008; Fuertes, et al, 2007; Lee & Lin, 2009)
- Trust increases adherence
  - (Aldoory & van Dyke, 2006; Brown & Ping, 2003; S'lachtova et al. 1998; Wakefield & Elliott, 2000; Walter et al., 2004; Lee & Lin, 2009)
Trust by race N=118*  

- Trust my physician
- Trust hospitals
- Hospitals do harmful experiments without patient knowledge


The Ethical Relationship: Dignity

Dignity is:
“...concerned with the worth and value felt by and bestowed on persons.”**

*Gallagher, 2004
5. Two barriers to therapeutic relationship

a) Divergent risk assessment

b) Perception of patient as responsible

Clinicians and patients may assess risk differently
Assessing risk of health behaviors

Patient factors decreasing perception of risk
- Sense of control over unhealthy behavior
- Familiarity with unhealthy behavior
- Active involvement
- Discounting the future
- Visceral factors
  - Healthy behavior unpleasant
  - Unhealthy behavior has increased desirability (addiction)

Clinician factors increasing perception of risk
- No control over patient behavior
- More familiar with negative consequences
- Not involved
- Future not considered
- No visceral reaction to patient behavior

Deciding to smoke or not ~ In the moment

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Cost</th>
</tr>
</thead>
</table>
| Smoke now | **FEELS REAL GOOD**  
- Take a break  
- FEELS REAL GOOD  
- Stand outside |
| Quit now | **FEELS REAL BAD**  
- Save @ 33 cents  
- Get to keep working  
- Might not get sick years from now  
- @ 33 cents  
- Might get sick years from now |

Evidence and risk perception - 1

- Increased perception of risk increases compliance (Cava, et al., 2005)
- Increased sense of risk predicted smoking cessation (Kohn, et al., 2010)
- Bias that others are more likely than self to get disease? (Riley, 2005)
  - Flu (Larwood, 1978)
  - Hepatitis (Menon et al. 2002)
- Cancer (Law et al. 2004a, 2000b; Perlloff & Fettler, 1986)
  - Smokers believe they have lower risk of cancer than other smokers (Winston, et al. 2001)
- Mental illness (Bruce 1987; Kaiser & MacDonald 1982; Perlloff & Fettler 1986)
Evidence and risk perception - 2

- Factors influencing risk perception
  - Personality
    - Trust (Aldoory & van Dyke, 2006; Brown & Poggi, 2003; S’lachtová et al., 1998; Wakefield & Elliott, 2000; Walter et al., 2004)
  - Familiarity: without knowledge (Hawkes & Rowe, 2008)
  - Emotional state (Cerully & Klein, 2010)
  - Sense of control (Kemen et al., 2003; Mgalla & Pool, 1997; Miles & Frewer, 2001; Miller, 2005; Rolham et al., 2006; Salazar et al., 2004)

- Sense of risk increased with “contemplation” & “preparation” stages in medically ill smokers (Bowtell et al., 2010)
Therapeutic connection is more difficult when patient is held responsible for the problem by the clinician.*


The judges of normality are present everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the “social worker”-judge.

From: Discipline and Punish.

Michel Foucault (1926-1984)
When Health Care Isn’t Caring. N=4,916

12.2%
23.3%
25.7%

0%
10%
20%
30%

LGB
Trans
HIV+

Perception of health behavior as determined biologically and/or genetically

Perception of health behavior as a moral issue of choice

Increases sympathy for patients with lifestyle related disease

Decreases sympathy for patients with lifestyle related disease


Jonas criteria for responsibility

1) Causality
   • The act must cause the consequence

2) Control
   • The agent must control the act

3) Foresight
   • Agent must foresee the consequence
Smoking – Lung cancer*

- **Causality** – Smoking causes lung cancer
- **Control** – Smoking is a deliberate act
- **Foresight** – The link between smoking and lung cancer is well publicized


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Smokers are responsible for getting lung cancer—

**Not so fast**

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**Causality:**

**Risk factors for lung cancer**

- Second hand smoke
- Diet
- Asbestos
- Household radon
- Genetics
- Gender
Control: Action of nicotine on neural reward system

Mu receptor upregulated by Nicotine

Ventral Tegmental Area

Nucleus Accumbens

Reward

Enkephalin

GABA

Dopamine Neuron

GABA

Dopamine Receptor

GABA

Dopamine Receptor

Mu Opiate Receptor

Enkephalin

GABA

Dopamine Neuron

GABA

Dopamine Receptor

Mu Opiate Receptor

Foresight
Some examples

1. An angry psychiatric patient threatens to leave the hospital early.
2. A patient with cancer is extraordinarily afraid of the effects of chemotherapy.
3. An obese home care patient with a decubitus ulcer on the coccyx refuses to be turned.

1. An angry psychiatric patient threatens to leave the hospital early

**Bumper car ethics**
- Assessed for danger
  - If yes – forcibly treated
  - If no – released whatever the need for treatment
- Assess competence
  - If yes – proceed in relation to danger
  - If no – Seek legal judgment of incompetence permanently removing right to make health care decisions

**Relational**
- Convey willingness to listen to his problems
- Encourage him to explain unmet needs
- Shows him how his needs can be met in the hospital.
- If the patient still decides to leave, this approach may increase the possibility that he will accept an outpatient plan rather than rejecting all care.
2. A patient with cancer is extraordinarily afraid of the effects of chemotherapy

**Bumper car ethics**
- Determine if the patient indicated in advance whether or not he wished such knowledge
- Cost v. Benefit analysis
  - Weighing the effect of his anxiety against his right to know in order to exercise his autonomy in consenting to or refusing the chemo
  - Therapeutic privilege

**Relational**
- Encourages the patient to define specific fears
- Address each with accurate knowledge
- Work with the patient to find supportive measures for each dreaded symptom including the anxiety.

3. An obese home care patient with a decubitus ulcer on the coccyx refuses to be turned

**Bumper car ethics**
- Assess patient’s decision-making capacity
  - If capacity
    - Disclose information needed for informed consent
    - Accept refusal
  - If without capacity
    - Turn despite patient’s protests

**Relational**
- Explore why the patient resists turning
- Look for way to turn the patient, accommodating the objections
- Or, follow a harm-reduction model to plan the best care acceptable to the patient without turning.

Final Thoughts
- Some situations will always need to be adjudicated
- Ethics as: “What’s the most good that can be achieved?”
  - “Good” is defined in terms of the individual
    - Relational ability determines the depth of understanding patient-defined good
- The goal is an organizational culture in which the virtue of relational skill can flourish
- The virtue of relational skill is more challenging and “clinical” than ethics as attention to rights and claims
Relational skill:
None lack it entirely; all can improve.
Ethics At the End of Life

Janice Firn, PhD, LMSW
Clinical Social Worker
Division of Geriatric and Palliative Medicine
Center for Bioethics and Social Sciences in Medicine

Conflict of Interest Disclosure

• Dr. Firn has no conflicts of interest to disclose.

Objectives

• Review the ethical principles that underlie clinical care for seriously ill and dying patients, illustrated by clinical cases

• Four key issues are reviewed that have direct applicability to daily patient care

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Principles

• The discipline of medical ethics has helped develop a framework for decision making that applies to care near the end-of-life.

• Four principles: Autonomy, Beneficence, Non-Maleficence, and Justice

A Warning

• Applied ethics may mask underlying philosophical assumptions

• Pluralistic society – same words but different meanings

Autonomy

• Respect for Persons: Individuals should be treated as autonomous agents able to write their own story.
  • Persons with diminished autonomy are entitled to protection.

• Autonomy = self-determination
  • Cultural differences?
  • Limits?
  • Common mistakes?
  • Informed consent and informed refusal
**Beneficence/Non-maleficence**

- **First do no harm**: Protecting people from harm.
- **Do better than no harm, help**: Make efforts to secure well-being.
- **Who identifies and defines harm and/or benefit?**
- **How should suffering be viewed?**

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**Justice**

- Who ought to receive the benefits of x and/or bear its burdens?
  - “Fairness in distribution” or “what is deserved.”
- Patient in front of you vs. system as a whole
  - Allocation of resources based on cost? Effectiveness? Combination of both?
- The return to the individual, not the return to the society, is the standard against effectiveness of an intervention is measured.
- Respect for persons not their productive capacity

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**Ethics Work-Up**

Goal: To determine the best, morally acceptable, practically realizable decision for this patient.

I. What are the ethical issues, concerns, or conflicts?

II. What are the facts of the case?

   a) Health issues, history, prognosis, options for treatment, context, legal issues, resources, financial concerns, family dynamics
   b) What is the best course of action from a medical perspective
   c) What is the best course of action overall (taking into account the patient’s preferences and values, context of that person)

III. State the ethical arguments for and against each option.

IV. Can the ethically preferable option(s) be implemented?

V. If conflicts, can they be resolved? Is it possible to compromise without loss of moral integrity?

VI. What is your final decision, how will you act?
Case-Based Approach to Ethical Decision-Making

MEDICAL INDICATIONS
2. What are the goals of treatment?
3. What are the probabilities of success of various treatment options?
4. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?
5. Are there considerations of clinical research and education that might affect clinical decisions?
6. Are there financial factors that create conflicts of interest in clinical decisions?
7. Are there biases that might prejudice the provider’s evaluation of the patient’s quality of life?
8. Are there religious issues that might affect clinical decisions?
9. Are there problems of allocation of scarce health resources that might affect clinical decisions?
10. Are there conflicts of interest within institutions or organizations (e.g., hospitals) that may affect clinical decisions?

PATIENT PREFERENCES
1. Has the patient been informed of benefits and risks, understood this information, and given consent?
2. Is the patient mentally capable and legally competent, or is there evidence of incapacity?
3. If mentally capable, what preferences about treatment is the patient stating?
4. If incapacitated, has the patient expressed prior preferences?
5. Who is the appropriate surrogate to make decisions for the incapacitated patient?
6. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

Box 1
The Principles of Beneficence and Non-maleficence
2. What are the goals of treatment?
3. In what circumstances are medical treatments not indicated?
4. What are the probabilities of success of various treatment options?
5. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

Box 2
The Principle of Respect for Autonomy
1. Has the patient been informed of benefits and risks, understood this information, and given consent?
2. Is the patient mentally capable and legally competent, or is there evidence of incapacity?
3. If mentally capable, what preferences about treatment is the patient stating?
4. If incapacitated, has the patient expressed prior preferences?
5. Who is the appropriate surrogate to make decisions for the incapacitated patient?
6. Is the patient unwilling or unable to cooperate with medical treatment? If so, why?
QUALITY OF LIFE
The Principles of Beneficence, Non-maleficence, and Respect for Autonomy
1. What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds?
2. On what grounds can anyone judge that some quality of life would be undesirable for a patient who cannot make or express such a judgment?
3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life?
4. What ethical issues arise concerning improving or enhancing a patient's quality of life?
5. Do quality-of-life measurements raise any questions regarding changes in treatment plans, such as forgoing life-sustaining treatment?
6. What are plans and rationales for forgoing life-sustaining treatment?
7. What is the legal and ethical status of suicide?

CONTEXTUAL FEATURES
The Principles of Justice and Fairness
1. Are there professional, interprofessional, or business interests that might create conflicts of interest in the clinical treatment of patients?
2. Are there parties other than clinicians and patients, such as family members, who have an interest in clinical decisions?
3. What are the limits imposed on patient confidentiality by the legitimate interests of third parties?
4. Are there financial issues that might affect clinical decisions?
5. Are there problems of allocation of scarce health resources that might affect clinical decisions?
6. Are there religious issues that might affect clinical decisions?
7. Are there issues of public health and safety that might affect clinical decisions?
8. Are there ethical issues that might affect clinical decisions?
9. Are there ethical issues that might affect clinical decisions?
10. Are there issues of public health and safety that might affect clinical decisions?

Key Ethical Issues
1. Decision Making Capacity
2. Withdrawal/Withholding of Life Sustaining Treatments
3. Futility
4. Doctrine of Double Effect
6/19/2017

Ethics Case #1

• 67 year old man with widely metastatic lung cancer including brain involvement, which has progressed despite aggressive chemo/radiation therapy, referred to hospice by his oncologist.
  - Life-long bachelor, no close friends, estranged from family
  - Closest relationship is with his medical case manager, whom he has listed as his emergency contact.
  - Enrolled on hospice at home on Tuesday
    • No advance directive
    • Expressed a desire to be comfortable at the end of life
    • No recorded discussion of code status

Ethics Case #1 (cont.)

• Two days later, a nurse arrived to review patient's symptoms, and the patient is found in bed, confused and unable to ambulate
  - Patient is transferred to an inpatient hospice unit for management, where he continues to decline and shows clinical evidence of stroke, and appears to be close to death
    • Patient remains FULL CODE by default
    • No time to obtain an emergency guardian
    - Patient's clinical case manager, oncologist and primary care provider are contacted
    • No family is known
    • No surrogate defined

Medical Decision Making Capacity

• Capacity is a medical term:
  - Implies the capacity to provide informed consent or refusal to treatment
  - Determined by a physician
  - Decision dependent
  - May fluctuate

• To say a patient has Decision Making Capacity, the patient must be able to:
  - Understand the information (e.g. be able to relate what they have been told and what it means)
  - Evaluate the information and make a choice based on personal values
  - Communicate a choice (implies ability to communicate)
Who should participate in shared decision making when a patient is incapacitated?

- Durable Power of Attorney for Health Care, preferred document to legally authorize an agent
  - Agents legally empowered to make medical decisions
  - Agents should be familiar with patient, her values and wishes, and willing to act as a strong patient advocate
- A surrogate decision-maker, as defined by state surrogacy statutes
  - Many states have surrogacy laws that define by statute the order by which family members have legal decision making capacity
- A court appointed legal guardian

If there is no Legal Surrogate

- Decisions should be made according to the patient’s previously expressed wishes, if known
- If the patients wishes are unknown, decisions should be made in the patient’s best interest
- Physicians should include family members, and/or close friends who know patient’s wishes in the decision making discussion

Application of “Best Interest”

- People who had but are no longer capable of expressing values or preferences or individuals who never had opportunity to form values or preferences.
- Give preference to the patient’s voice if possible.
  - If wishes are not known or never articulated, then inferred wishes.
  - If no inferred wishes, then best interest
- Objective assessment of burdens/benefits of available treatment options.
Ethics Case #1 (cont.)

- Oncologist, PCP and clinical nurse manager all describe patient's previously expressed goal of focusing on his comfort at the end of life.
- Based on prior expressed wishes, a clinical decision is made that a FULL CODE status in the setting of a terminal condition is not consistent with patient's stated goals of focusing on comfort at the end of life.
  - Efforts are made to provide patient with comfort measures as he approaches death.
  - Patient expires within three hours of arrival to the in-patient hospice facility without regaining consciousness.

Ethics Case #2

- 58 year old man with severe non-ischemic cardiomyopathy eventually leading to placement of a left-ventricular assist device (LVAD).
  - Clinically doing very well; minimal symptoms, improved functional status, few reported complications or side effects.
  - Able to work and participate in the care of his 7-year-old daughter.
- Four years after his device was placed, he presents to his cardiologist's office and requests that his LVAD support be discontinued.
  - Expresses a belief that he no longer requires the LVAD support because of a religious vision he had in which God told him he was healed.

Ethics Case #2 (cont.)

- Ethics consult is placed.
  - Review of chart and discussion with patient reveals that shortly after his LVAD was placed, patient was "born again" and became an active member of a Pentecostal Church.
    - Religious tradition includes a belief in divine healing.
    - Patient expresses a belief that by continuing to have the LVAD in place, he is demonstrating a lack of faith that will risk his eternal salvation.
  - Cardiologist's office cites all available evidence suggests that patient will most likely die within minutes of discontinuation of his LVAD.
  - Weaned LVAD support in the clinic which caused patient to syncope.
    - "You do not walk into God's arms, you jump."
Time Out: Definitions

• **Euthanasia** defines a situation where a patient or surrogate decision maker requests a clinician to perform an action with the intent of ending that patient’s life.

• **Physician Assisted Death** defines a situation where a physician prescribes a lethal dose of medication which the patient can then take for the express purpose of ending his/her life.

Withholding/Withdrawing Life-Sustaining Treatments (LSTs)

• Many types: hemodialysis, ventilators, etc.

• Ethics principle: *respect for autonomy*
  – Rights to refuse, or request the withdrawal of, unwanted interventions even if doing so results in death; should not impose treatments
  – No ethical or legal differences between withholding and withdrawing
  – Informed refusal

W/W LSTs

<table>
<thead>
<tr>
<th>Case</th>
<th>Year</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quinlan</td>
<td>1975</td>
<td>WD ventilator</td>
</tr>
<tr>
<td>Salkewicz</td>
<td>1977</td>
<td>WH chemotherapy</td>
</tr>
<tr>
<td>Dinnerstein</td>
<td>1978</td>
<td>WH CPR</td>
</tr>
<tr>
<td>Spring</td>
<td>1980</td>
<td>WD hemodialysis</td>
</tr>
<tr>
<td>Barber</td>
<td>1983</td>
<td>WD IV fluids</td>
</tr>
<tr>
<td>Bouvia</td>
<td>1985</td>
<td>WH, WD feeding tube</td>
</tr>
<tr>
<td>Cruzan</td>
<td>1990</td>
<td>WD feeding tube</td>
</tr>
<tr>
<td>Schiavo</td>
<td>2005</td>
<td>WD feeding tube</td>
</tr>
</tbody>
</table>

WD = withdrawal; WH = withhold
Karen Quinlan
70 N.J. 10 (1976), Supreme Court of New Jersey

- Found unresponsive; PVS
- The family wanted to withhold LST; the institution did not

Court decision:
- Patients have the right to refuse treatment
- Surrogates may exercise the patient’s right
- Such decisions are best made by families, not courts
- The state’s interest in preserving life can be overridden by the patient’s right to refuse treatment

Elizabeth Bouvia
179 Cal App 3d 1127, 225 Cal Rptr 297, 1986

- Born with cerebral palsy
- Quadriplegic and in constant pain
- At 28, she announced her intent to no longer eat or drink
- She was competent and understood risks
- Received a feeding tube against her will
- Court ordered tube removed; barred replacement without consent
- The right to refuse treatment is not limited to terminally-ill patients

Nancy Cruzan
1983: in a motor vehicle accident; never regained consciousness (PVS)
1988: parents sought removal of feeding tube
Hospital refused without court order
Trial court ordered removal of tube
Nancy Cruzan
Missouri Supreme Court
• Must have clear and convincing evidence of a patient's wishes (e.g., an advance directive) before removing a feeding tube
• The state's interests in preserving life outweigh the patient's interests
• Artificially administered hydration and nutrition are not medical treatments

Nancy Cruzan
US Supreme Court, 1990
• Competent adults have a constitutional right to refuse unwanted treatments
  — 14th Amendment “liberty interest”
• This right extends to incompetent persons through their surrogates
• Artificially administered hydration and nutrition are medical treatments

Precedence of Landmark Cases
Not a right to die, but a right to be left alone
• A competent patient has the right to refuse or request the withdrawal of LSTs
• The incompetent patient has the same right (exercised through a surrogate)
• No difference between withholding and withdrawing LSTs
• Artificial fluid and nutrition are medical treatments
• No physician liability for granting such requests
Ethics Case #2 (cont.)

- Ethics:
  - Recommended spiritual care consult
  - Clarified patient’s goals: “I’d rather die a saved man than live a life of damnation”
  - Consulted with leaders of the Pentecostal faith, who discussed with the patient and supported his decision
  - Supported the patient's decision to withdraw life-sustaining treatments if it does not support his goal of care (religious salvation)
- With hospice present at the home, LVAD support was withdrawn while patient was surrounded by his friends and family
- Died shortly thereafter

Ethics Case #3

- 58 year old female with widely metastatic breast cancer, is brought to the emergency room by her family after being told by an outside hospital that no further chemotherapy or radiation therapy options existed for her
  - In addition to breast cancer, patient also has a small bowel obstruction, worsening kidney function, and is diagnosed with peritonitis
- Over the next several days, despite aggressive measures to stabilize patient’s medical state, patient continues to worsen

Ethics Case #3 (cont.)

- Family demands that additional chemotherapy be provided
  - Cite their cultural values which, per family, demand that the patient be allowed “to fight” the cancer until her last day
  - This belief was supported by the patient, when she was able to speak
- Medical team states that further chemotherapy would shorten patient's dying process and likely worsen her symptoms (pain, nausea, etc.).
  - Ethical question: Are they obligated to provide the care requested?
Futility

- An intervention is considered futile when it cannot accomplish the intended physiologic goal.
- The concept of how to define futility and when to invoke it is controversial.
  - Judgments are often mistaken or problematic
  - Futility applies to few patients
  - Unilateral decisions polarize parties
  - Value judgments may be masked as scientific expertise

Potentially Inappropriate and/or Non-Beneficial Treatments

- Non-Beneficial Treatment - Treatments that the health care team believes have no reasonable medical chance of achieving the outcome sought beyond minor physiologic changes are outweighed by the danger to the patient, and/or would not achieve a medically appropriate goal are considered to be non-beneficial treatments.
  - Under this definition, futile interventions may be considered a type of non-beneficial treatment.
- Potentially Inappropriate Treatment - Treatments that, while they may achieve a certain goal, are outside the standard of care.
  - Use of broad-spectrum antibiotics to treat a simple bacterial infection or use of high-dose narcotics to treat chronic, non-terminal pain.

Michigan Medicine Withdrawal and Withholding of Medical Treatments (Non-Beneficial Treatment/Intervention) Policy

- When a medical intervention is futile, the attending physician is under no obligation to initiate, or to continue such treatment, even though it may have been requested by the patient, or the patient's family or representative(s).
- An intervention may be considered futile when it satisfies all of the following conditions:
  - The attending physician has determined that the patient's condition is terminal and incurable;
  - The attending physician has determined that the intervention in question is not required for relieving the patient's discomfort;
  - The attending physician has determined that the intervention in question offers no reasonable medical benefit to the patient, and that such intervention could serve only to postpone the moment of death.

Note: The issue of futility has not been considered under Michigan law so this section of the Policy sets forth the Hospital's ethical position.

http://eduserv.hscer.washington.edu/bioethics/topics/futil.html

Futility - Resolution

• Many cases of invoking futility involve significant barriers or breakdown in trust and communication, between the patient/surrogate and the health care team.

• Resolution can be best achieved by mediation with staff trained in conflict mediation (palliative care, patient relations etc.)

• Due process approach to cases involving ongoing conflicts about continued 'futile' treatment
  • Negotiate disagreements
  • 2nd opinion by consultant if appropriate
  • Ethics consultation
  • Seek transfer of care
  • MD has no obligation to provide futile treatment (AMA Code of Ethics § 2.037)

Ethics Case #3 (cont.)

• Ethics Consult
  • Supports physicians in not providing care they deem to be inappropriate or futile
  • Recommended a good faith effort be made to seek second opinion from other clinician and other institutions
  • Recommend reframing the role of chemotherapy
    • In this case, further chemotherapy would limit the patient's natural ability to 'fight' the cancer
    • Recommended Palliative Care Consult
  • After much discussion and psychosocial support to the family, they expressed understanding and acceptance of the decision to not provide further chemotherapy
    • Patient expired 48 hours after ethics consult was placed

Ethics Case #4

• 87 year old man with end-stage COPD, admitted to the hospital after a fall results in a broken hip; not deemed a surgical candidate because of his compromised pulmonary status, and during his hospitalization develops severe multi-focal pneumonia
  • DNR status is clearly stated in his advance directive and this is supported by family
  • Over 48 hours, he worsens despite aggressive care and appears to be approaching the end of his life.
    • After much discussion, the decision is made to transition to a comfort focused plan of care
      • Includes morphine for pain and dyspnea
Ethics Case #4

- Overnight, patient appears to be in great distress related to his known hip fracture
- Overnight nurse refuses to administer morphine given his respiratory status
- Family very distressed by patient’s apparent suffering as he approaches the end of life

Doctrine of Double Effect

- States that clinicians can institute a therapy that may cause a bad effect if the intention is to provide a good effect
- The bad effect can be foreseen, tolerated, and permitted but it must not be intended
- The good effect must outweigh the bad effect
- The bad effect must not be a means to the good effect (i.e., I intend to kill this patient so he/she no longer feels pain). If the good effect were the direct causal result of the bad effect, the agent would intend the bad effect in pursuit of the good effect.
- Often cited in end-of-life care, when aggressive symptom control risks shortening a life
- At its heart, the idea that intentions matter

Conclusion

- End of life care is an emotional time for all involved, and can be fraught with conflict, ethical or otherwise
- The general concepts of medical ethics (autonomy, beneficence, non-maleficence, justice) apply
- Other ethical concepts can guide appropriate care for those at the end of life
References

- EPEC curriculum; www.EPEC.net
Navigating the Fear of Litigation

Legal Ramifications of End Of Life Decisions

Randy Hackney, JD

We Live in a Society Permeated by Litigation

- Advanced directives have not yet become the norm.
- Hospitals have standard forms.
Succession of Responsibility

- Who has the final say;
- May not be the closest "next of kin".

Substituted Judgment vs. Best Interest of the Patient

- These are NOT the same thing.

Substituted Judgment

- How the patient would decide if he or she were able;
- The decision maker puts themselves in the patient's "shoes"
Best Interest

- Decision makers use their own values to make their best decision on behalf of the patient.

Implementing End of Life Decisions

- THE 4 “C’s”
  - Communication
  - Consent
  - Charting
  - Consistency

Communication

- Patients who lack the capacity to make decisions have the same rights as those who have the capacity to make decisions.
- May refuse unwanted medical treatment even if this may result in their death;
- 14th Amendment;
- Cruzan vs Director of Missouri Department of Health;
- Cruzan Family wanted to only remove their daughter’s food and water rather than more advanced artificial life support.
An individual has a constitutional right to refuse treatment.

This extends to patients who do not have life threatening illnesses.

Distinctions that make a difference

- The treatment option being suggested must not be considered homicide or suicide;
- There is a difference between intentionally causing or hastening a patient’s death versus allowing a patient to die as a result of withdrawing life sustaining treatment.

Withdrawing and Withholding Treatment is Justifiable

- Court have upheld the validity of DNR;
- There is no limitation on the type of treatment that may be withheld or withdrawn;
- Recently courts have rejected the distinction between ordinary and extraordinary treatment;
- Ventilator withdrawal which may directly result in death is permissible;
- Parenteral nutrition and hydration may be withheld or withdrawn.
Information Physicians MUST Provide

- Complete and accurate information about the patient’s situation;
- Complete and accurate description of all choices of treatment (including non-treatment);
- Description of all reasonable methodologies of care;
- Consequences of reasonable methodologies of care.

Informed Consent

- The patient has the ultimate ability to decide how he/she will be treated;

Defeating Informed Consent Allegations and Arguments

- Patients and/or decision makers may not have been fully informed of the risks and benefits of therapy at the time it was begun and this complicates the decision to withhold or terminate treatment or therapy;
- Patients and/or decision makers may not have been told that the treatment would be withdrawn if the treatment was no longer deemed effective;
- Patients and/or decision makers may not have been advised of the burdens of continued treatment (both physically, mentally, emotionally and financially).
The Decision Maker Must be Told of the Consequences Regarding Continuation and/or Discontinuation of Treatment

- This discussion must be as accurate, complete and pertinent as a discussion of the risks and benefits of intervention.
- Consent must be given voluntarily and free of coercion.

The Criteria for Judging the Propriety of the Information Given to the Patient or Decision Maker

- What any good professional would do;
- What any reasonable person would want;
- What this specific patient has expressed he or she would want under these circumstances.

Charting: All Decisions Relative to Treatment Options Must Be Clearly and Consistently Charted.

- This includes:
  - Who the decision maker is;
  - If it is not an "obvious" choice state why this person is the decision maker;
  - A complete description of the treatment alternatives provided to the decision maker;
  - A description that the decision maker is able to appreciate the impact of the condition and the consequences of the various options;
  - Charting of the decision maker's ability to evaluate the options and make a decision.
Consistency: Once a Determination has been made, that Determination has to be Followed in a Consistent Manner

- If there are changes in circumstances that effect the original decision this must be communicated to the decision maker for any change or alteration they may wish to make.

The Appearance of inconsistency in End of Life Decisions will be Subject to Close Scrutiny

- The standard that is most often utilized to determine the reasonableness of end of life decisions is the "preponderance of evidence" standard.
- This is not beyond a shadow of the doubt;
- This is more probable than not.

Clear, concise, timely advanced directives continue to be the best and most effective device in assisting healthcare providers in making decisions relative to end of life care and treatment.
When an Advance Directive or Living Will is NOT Available

- The Following Steps Should be Applied:
  - The physician should clearly, concisely and competently advise the family/decision maker of the prognosis;
  - A determination should be made on how an end of life treatment decision is going to be made before the actual decisions are made;
  - Identification of the individual who has the “final say”;
  - Discuss all choices and the ramifications both positive and negative;
  - Do not hesitate to utilize second and even third opinions when necessary.

End of Life Decisions are Often Painful and Fraught With High Emotions. Following a Clear and Consistent Protocol will ease the Potential for Post-Decisions Ramifications if the Four “C’s” are followed

Communication  Consent
Charting  Consistency
Traumatic Grief and Loss at End of Life

Judy C Wheeler, MSN, GNP-BC
Palliative Care Nurse Practitioner
Detroit Medical Center
Co-Chair, Medical Ethics Committee
Detroit Receiving Hospital

Objectives

- Recognize criteria that indicate that a patient would benefit from palliative care or hospice care referral
- Provide patients with information and questions to help them determine “readiness” for palliative and hospice care
- Identify resources to help with grieving

World Health Organization Definition of Palliative Care

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Unlike hospice, PC is appropriate early in illness, and patients can receive concomitant treatment, including life prolonging therapies.
Definition of Hospice Care

End of life care to assist with medical, psychological and spiritual support to help the dying and their families to have peace, comfort and dignity.

- Concentration is on comfort, not disease abatement.
- Generally death is expected within six months of admission to program, with two physicians certifying this.
- Requires formal “enrollment”.
- Covered by Medicare and most insurances.

Benefits of Palliative Care Consultation

67% of health care institutions have some sort of Palliative Care team. Results include:

- Increased rates of formalized advanced directives
- Increased use of hospice
- Decreased use of non–beneficial life sustaining therapies
- Increased families discussion and decreased misconceptions about the withdrawal of medical equipment
Benefits of Palliative Care Consultation

- Minimizes patient and caregiver distress
- Ensures better quality of life by relieving
  - Insurmountable physical distress
  - Inadequate coping patterns
  - Unanswered spiritual issues
- Provides an appropriate venue for end of life care
- Reduced exposure to chemotherapy and radiation
- Reduced health care costs
- Reduced length of stay
- Reduced admission and readmission rates

Begum, A. 2013 BMJ of Qual Improvement 3(1)714-732

More Specifically....

Palliative Care consultations facilitate discussion of goals of care, which are associated with reduced rates of 30 day admissions.

O'Connor, Moyer, Behta, Casarett J. Palliative Med 2015, Nov 18 (11) 956-61

There is data to support that referral to Palliative Care and Hospice can actually increase life expectancy for some.

A 2014 meta-analysis of the literature demonstrates that palliative care consults can reduce hospital costs by lowering average daily costs between 9 and 25%.

Barriers to Palliative Care Consultation

- Prognostication can be difficult
- Clinicians may not consider potential life expectancy or quality of life past the acute care phase
- The culture of health care may be focused on rescuing patients and denying death—the "technological imperative"
- Belief that Palliative Care is end of life care, and separate from other medical treatment
Barriers to Palliative Care Consultation

- Clinicians are not comfortable to initiate the discussion
- Many clinicians believe they can “handle it themselves”
- National healthcare policies may not include palliative care
- Cultural and social values may interfere
- Fear of opioid addiction and prescribing
- Belief that palliation/hospice mean “giving up” and hastening death

Palliative Care Screening Tools

- Screen select patients using predetermined criteria to “trigger” a palliative care consult
- Use of a trigger tool provides an objective basis for initiating conversation
- Increases consultations and decreases 30 day rehospitalizations

The Project Impact Study

Retrospective study of ICU admissions from 2001-2008 (385,770 admissions, with 53,124 meeting trigger) indicated that 14% met at least one trigger for palliative care consultation, and when multiple sets of triggers were used, nearly 20% met triggers

- ICU admission after hospital stay of ten days or more
- Age greater than 80 with two or more life threatening comorbidities
- Diagnosis of active stage IV malignancy
- Status post cardiac arrest
- Intracerebral hemorrhage requiring mechanical ventilation

Screening within 72 hours of admission
- Patients were likely to be older, male, African American, less functional at baseline
- Estimated need for 1.1 to 1.5 million consults per year (8 million ICU admissions annually)
- Missing triggers include high risk of hospital death, refractory pain or other symptoms, other needs for support, such as psychological, emotional or spiritual distress, family/care team conflict

Hua, Li, Blinderman and Wunsch. 2014, American Journal of Respiratory and Critical Care Medicine, 189(4) 428-436
The “Surprise” Question

Would you be surprised if this person were to die within the next year?

Weissman and Meier found that when the answer is “not surprised” 85% of the patients did die within the year, and would have benefited from a palliative care consult.

The DMC Palliative Care Screening Tool

- Measures six items:
  - From ECF/home with chronic failure in ADL
  - End stage illness/organ failure
  - Advanced or metastatic cancer
  - Uncontrolled distressing symptoms
  - Post cardiopulmonary arrest
  - Readmission within 30 days
- One trigger should result in request for PCC
- Early Palliative Care Consult (by day 4) was associated with more frequent DNR code status and hospice referrals, but not with 30 day readmissions nor hospital utilization. Early PCC associated with deceased LOS and direct cost reductions.

Helping Families Seek Help

- Does your loved one have untreated fatigue, thirst, nausea, anxiety, depression, delirium or pain?
- Do you or your loved one have spiritual or emotional pain that you need help with?
- Do you need help with decision making, advance directives, or setting goals for this part of your life?
People have bad outcomes.

People die.

People have outcomes “worse than death”.

We aren’t always well prepared to deal with difficult issues.

Let’s Talk about Outcomes

So We Need to Get Real About It

It’s not like on TV.

Studies have shown a relationship between watching medical fiction on TV and overestimating in-hospital survival rates after CPR.

What happens on TV?

Between 1994 and 1995, researchers from Duke University watched 97 episodes of “ER,” “Chicago Hope” and “Rescue 911,” taking note of when CPR was administered during each show.

In these dramas, 75% of patients survived immediate cardiac arrest, and two-thirds were discharged from the hospital with full brain function.

CPR Survival Rates Meta-Analysis

Non-community dwelling elder has 1–2% chance of surviving in-hospital CPR, those who do survive only briefly or with severe disability.

Overall likelihood of immediate survival of CPR is 2 out of 5, and surviving to discharge is 1 in 3 for those who survive CPR.

Overall roughly 1 out of 8 (13.4%) receiving CPR in-hospital survive to discharge.

Factors associated with failure to survive overall—sepsis on the day prior to CPR, metastatic cancer, African American, serum creatinine of 1.5 or greater, CAD, resuscitation in the ICU.


Results: 18.3% of these patients survived to discharge.

The rate of survival did not change substantially during the period from 1992 through 2005.

The overall incidence of CPR was 2.73 events per 1000 admissions; the incidence was higher among black and other nonwhite patients. The proportion of patients undergoing in-hospital CPR before death increased over time and was higher for nonwhite patients.

Survival rate was lower among patients who were men, were older, had more coexisting illnesses, or were admitted from a skilled-nursing facility.

Adjusted odds of survival for black patients were 23.6% lower than those for similar white patients.

Among patients surviving in-hospital CPR, the proportion of patients discharged home rather than to a health care facility decreased over time.

Conclusions: Survival after in-hospital CPR did not improve from 1992 through 2005. The proportion of in-hospital deaths preceded by CPR increased, whereas the proportion of survivors discharged home after undergoing CPR decreased. Black race was associated with higher rates of CPR but lower rates of survival after CPR.


Retrospective review of Level I Trauma Center database (n = 588)
- 40% survived to hospital admission
- 4% survived to hospital discharge
- Penetrating injuries had lower survival than drowning or hanging (<1% vs. 6% vs. 13%)
- Victims of penetrating trauma with cardiac arrest should be declared “dead at the scene”

Stockinger and McSwain, J Am College of Surgeons, 2004
Do Not Resuscitate Decisions

We should all do this, right?

Illness Trajectories

Complicated Grief

- Death/loss is traumatic when it is sudden and unexpected, and may include additional trauma, such as facing life threatening situations or witnessing horror or devastation.
- It can be argued that all death is traumatic.
Higher risk of adverse health outcomes, should be assess for suicide risk and other conditions such as depression and PTSD, and should be treated.

Pre-loss Risk Factors include:
- Female
- Preexisting trauma
- Prior loss
- Insecure attachment
- Preexisting mood and anxiety disorders
- Nature of the relationship

Loss–Related Risk Factors include:
- Relationship and caretaker roles
- Nature of the death itself

Peri-loss Risk Factors include:
- Social circumstances
- Resources available following the death
- Poor understanding of circumstances of death
- Interference with natural healing process (alcohol abuse, inability to follow cultural practices, etc)

Simon, N. N. 2013 Treating complicated grief. JAMA 310(4) 416–423
Survivors Experiences of Traumatic Death

Studies indicate that those who experience a “traumatic” death have higher rates of PTSD, complicated grief (CG) and depression as compared to those who experience a “natural” death.

Violent death is associated with higher rates of PTSD and complicated grief than non-violent traumatic deaths.

- CG rates in general 2.4–6.7%
- CG rates in violent death 12.5 5–78%


Grief Experiences after Violent Death

- Sudden and unexpected
- Difficult to “make sense” of
- Difficult to see as part of life
- Negative self appraisal
- Exposure to media and criticism
- Effects of legal processes
- Intrusive symptoms of PTSD

Complicated Grief after ICU Death

Study of relatives of 475 adults who expired in 41 ICUs.

52% of relatives surveyed had complicated grief at 6 months, essentially unchanged at 12 months.

Factors related to complicated grief included

- Relative living alone
- Relative of female patient
- Patient died while intubated
- Relative present at time of death
- Relative not having said goodbye to patient
- Suboptimal communication with intensivist

Kentish-Barnes, et al. 2015 Complicated grief after death of a relative in the ICU. Eur Respir J, 45, 1341–1352
Prolonged Grief Disorder

- Core symptoms include:
  - Intrusive preoccupation
  - Denial/avoidance
  - Failure to adapt—enduring feelings of loneliness or emptiness, difficulty with new intimacy
- Considered a stress response syndrome
- 19 item Inventory of Complicated Grief
- Normal grief is widely variable, but allows for both painful and positive feelings, and becomes integrated over time
- PGD includes difficulty in accepting death, repetitive loop of yearning (intrusive wishes that the deceased person be present) and longing, intense, unending pain
- Must last more than six months


Strategies for Treatment

- Antidepressants
- Cognitive behavioral therapy
- Exposure therapy—revisiting the loved one and traumatic memories
Treating Prolonged Grief

- Randomized study of 80 people with prolonged grief
- Weekly 2-hour cognitive behavioral therapy sessions
- Four individual sessions, randomized to either exposure therapy to memories of the death, or supportive counseling.
- Measures included depression, cognitive appraisal and functioning at 6 month follow-up.
- Exposure therapy seemed to facilitate changes in appraisal of the loss, which was associated with symptom reduction.


Case Study

- The Church Lady
  - 71 year old AA female with history of COPD, HTN, hypothyroidism presents to the ED in cardiac arrest from church with total downtime approximately 15 minutes, EMS provided immediate CPR.
  - Anoxic brain injury after cardiac arrest
  - Myoclonic status
  - 26 day LOS
  - Palliative Care and Ethics were consulted
“There was a tunnel and a bright white light and a souvenir shop. I bought back T-shirts for the kids!”
Beyond Diagnosis and Treatment
The Emotional Journey Behind the Patient Experience
Katie Gott, RN
• Communicate
  - Tell the patient what you know
  - Show the patient their entire team is on the same page
• Address every problem, even if you can't fix it
• Don't make the patient wait unnecessarily
• Tell the patient when you will be back

• Be patient
• Include the patient's family
• Be consistent
  - Predictability is a good thing
• Follow through
  - Give the patient a reason to trust you
• Pay attention to details

FINAL TAKEAWAY