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# Ethical Issue in Dysphagia Management

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## Learner Objectives

Participants will:

1. Identify how to discern an ethical dilemma from a clinical dilemma and moral distress
2. Describe several practical problem solving paradigms and approaches used in managing ethical dilemmas in clinical practice
3. Apply ethical problem solving strategies to several clinical vignettes



SPAULDING  
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## Ethics

**Ethical Dilemma** – choosing between 2 (or more) options, each of which may be ‘good’ or ‘bad’ options.

“Hegel, in his short essay on logic, reasoned that the headachy business of choosing between one good and another, or obversely between one evil and another, is true tragedy, whereas the simplistic collision of good and evil - black and white - is only melodrama.”

Fletcher, 1997



## Ethics

**Ethical or Moral Distress** – an individual knows, or believes she knows, the morally correct course of action but is impeded from completing that action because of varied obstacles (eg. Because one is not officially in charge of the decisions or solutions).



## Cases to consider

•A 46 yo woman with a history of mental illness has a stroke and cannot swallow thin liquids safely. She is expected to recover but refuses to drink thickened liquids. What is the role of the SLP in the case?

•A 76 yo man with moderate dementia is in a rehab hospital after a long ICU stay. He has significant generalized debility. His wife is his surrogate decision maker and told the physician that her husband would not want a feeding tube. A VFSS revealed that the patient aspirates all consistencies. What is the role of the SLP in this case?



## Case to consider

•A 60 yo man with H & N CA comes to your outpatient clinic regularly. He has had 3 bouts of pneumonia in the past 18 months – likely due to aspiration. What is the role of the SLP in this case?

•A 6 yo boy with Down Syndrome is seen in your Pediatric Feeding Clinic. His parents are divorced. Most often, Dad brings him to clinic and follows recommendations while there. Occasionally Mom comes and appears not to adhere to the child's diet texture recommendations. What is the role of the SLP in this case?



## Defining and Ethical Dilemma

“Can we ....?”

v.

“Should we ....?”



## Defining an Ethical Dilemma

**Given \_\_\_\_\_, is it ethically acceptable / unacceptable to \_\_\_\_\_?**

Or – What are we bound to? What is our **duty**? (and) What must we do *legally, regulatorily*, etc?



## Legality and Ethics

Law is rules (sometimes established through a deliberative process) by which a society is compelled to obey.

Ethics is the normative standards of right (moral) and wrong behavior and the study of why behaviors are defined as right and/or wrong.



## GENERAL ETHICAL DILEMMAS

### ■ Professional

Conflict between clinicians  
Conflict between disciplines  
Rules of comportment  
Resource constraints



## GENERAL ETHICAL DILEMMAS

### ■ Clinical

**Clinical Recommendations – who decides  
Practical aspects of assuming risk – can we or other  
clinicians opt out?**



## Ethical Decision-Making

**The Patient – Clinician Relationship and the  
Shared Decision-Making Process is  
integrally related to the practice of ethical  
care.**

**Each member of the interaction has a  
personal stake and perhaps a different  
perspective that may result in conflicting  
goals and choices.**



## Shared Decision-Making

Patients (and often families) are considered “team members” and must ‘share’ in the decision-making process. With an increase in medical technology and burgeoning treatment options, patients must weigh the risks and benefits against personal values and preferences. Our patients and their network of family/friends have the most to gain and the most to lose.



## The Ethics Committee

**Evolved to manage policy and then consultation or consultation review.**

**In 1995 the JCAHO (now The Joint Commission) required that all accredited HCOs have a mechanism to deal with ethical issues of patients, families and staff.**





## The Ethics Committee

**Developed roughly 3 decades ago – in many hospitals to deal with the new issue of the DNR order – the only order that tells clinicians NOT to do something**



## The Role of the Ethics Committee

Each institution defines its ethics committee uniquely. In many institutions the Committee encompasses all possible roles and needs for ethics assistance in the organization, namely:

- a) Consultation
- b) Education
- c) Policy Work



## The Role of the Ethics Committee

Various stakeholders have differing perceptions of the most important focus of an ethics committee.

Foglia et al. (2009) Am J of Bioethics –  
A survey of VHA hospitals – completed with focus groups of clinicians, managers, patients and ethics committee chairpersons.



## The Role of the Ethics Committee

Foglia et al. (2009) found that:

- Clinicians feel the most difficult ethical challenge they are faced with is restricted resources influencing their practice
- Managers say the most difficult ethical challenge they face is the fair distribution of resources
- Ethics Committee chairs are concerned about providing the best end of life care, access to palliative care, and supporting patients' wishes at the end of life



## The Role of the Ethics Committee

Foglia et al. (2009) found that:

- Patients believe the primary role of ethics services in a hospital is to support personal fair, respectful and caring treatment



## ETHICS CONSULTATION IN TEAM CARE FACILITATION

**“At the conclusion of the study, we met with physicians, nurses, and allied health professionals to discuss their views of the study and to prepare a report for administration. Anecdotal observations suggested that the staff perceived a shift in attitude, one which placed a greater value on collaboration among all members of the team.”**

Dowdy et. al., 1998



## The Role of the Ethics Committee

### **Consultation:**

#### Disability Ethics Perspective –

Ethics committees (as well as practicing clinicians and family members) may have a bias to viewing disability in a medical model rather than a social model.

This can impact the permissibility of medical options for persons with disability that would arguably never be allowed for someone without a disability (eg. The case of Ashley X)

Goering, 2010



## The Role of the Ethics Committee

**Education:** To build the “capacity” if staff or an entire organization to deal successfully with the predictable and present ethical challenges in practice.



## The Role of the Ethics Committee

**Education:**

Case consultation can and should inform the educational needs of the staff in an organization. Additionally, the ECS should actively seek out what is “bothering people”



## The Role of the Ethics Committee

**Education:**

Ladd (2009) suggests polling members of an organization at least annually to determine the educational and support needs that should be the focus of the ECS.



## The Role of the Ethics Committee

### Education:

Spaulding Rehabilitation Hospital – adopted the needs assessment survey concept formed at RIC (Kirschner et al., 1998)

Completed approximately every 5 years

- Variation by discipline
- Variation by healthcare climate and context
- Variation by geography/environment of care



## The Role of the Ethics Committee

### Education:

Spaulding Rehabilitation Hospital –

- Program Rounds
- Discipline Rounds
- Annual Grand Rounds
- E-blast education
- Patient Rights “quiz” during Quality Week



## Ethics Consultation Process

McCormick-Gendzel and Jurchak (2006) = FESOR

**Facts** – collect the facts of the case

**Ethics** – identify and apply the appropriate ethical principles

**Stakeholders** – ensure that all stakeholders are involved in the process

**Options** – identifying and implementing the ethically acceptable options

**Results** – evaluating the outcome of the ethical analysis and decision for all stakeholders



## Ethics Consultation Process

Purtilo (2005) = **Six-Step Process of Ethical Decision-Making**

**1) Getting the Story Straight** – Gather Relevant Information

**2) Identify Type of Ethical Problem** (e.g. ethical distress, ethical dilemma, question of locus of authority)



## Ethics Consultation Process

- 3) Use Ethics Theories or Approaches to Analyze the Problem(s)
- 4) Explore the Practical Alternatives
- 5) Complete the Action
- 6) Evaluate the Process and Outcome



## Ethics Consultation Process

Miller, Fletcher, and Fins (1997) =  
**Clinical Pragmatism**

Detailed ethical decision-making model in outline/checklist format that gathers information for a “Moral Diagnosis.”  
Reflective analysis is used to develop approaches for managing similar situations in the future





## Clinical Ethics Analysis

Principle or Rule-Based Approach [Deontological Approach]

- Autonomy = a capacitant individual's right to make decisions for him/herself
- Beneficence = to do good for the patient
- Non-Maleficence = to 'do no harm' to the patient
- Justice = fair and equitable treatment for each individual



## Clinical Ethics Analysis

Utilitarian Approach [Teleological Approach]

- Outcome-based approach, for the greater good of the community

Casuistic Approach

- Use of paradigm case against which similar cases are weighed to determine an acceptable and equitable response (as in law)



## Clinical Ethics Analysis

### Case-Based Approach

-A method of examination of individual cases using principles and paradigms to determine a range of ethically acceptable outcomes

-e.g. Jonsen, Siegler, Winslade (2010)



## Case-Based Ethical Analysis Paradigm *Clinical Ethics, Jonsen, Siegler and Winslade, 2010*

Clinical [Medical]  
Indications  
(Beneficence)

Patient  
Preferences  
(Autonomy)

Quality of Life  
(Non-maleficence)

Contextual  
Features  
(Justice)



## Case-Based Ethical Analysis Paradigm

■ Medical Indications - The goals of medicine, what is felt to be clinically important and efficacious taking into account the medical history, accurate diagnosis, accurate prognosis and all treatment options



## Case-Based Ethical Analysis Paradigm

■ Patient Preferences - Examination of the patient's ability to participate in decision-making must be considered. The patient's personal history, religious and personal values, communicated preferences, advance directives, and self-assessed quality of life are all relevant here.



## Case-Based Ethical Analysis Paradigm

- Quality of Life - Third-party assessment (Whose responsibility is it to decide when the patient cannot?)
- Contextual Features - External issues to consider such as economic constraints, family preferences, burdens on caregivers, other psychosocial parameters, and legal issues. Is it prudent to consider these features 'at the bedside?'



Galli R. *Rescuing Jeffrey*. Chapel Hill, NC: Algonquin Books, 2000

**“When you go to sleep, do you want to stay asleep and never wake up, or do you want to wake up again?” His eyes widened, “Wake up,” he said. (p. 52)**

**“Jeffrey,” I said, “you are not your legs. Jeffrey is not in your legs. Jeffrey is up here.” I tapped his head. “Jeffrey is up here, and that means you are still here, all of you.” (p. 44)**



## Quality of Life Considerations

Healthcare providers and others tend to rate the quality of life of a person with a disability or chronic illness as lower than their own and lower than the person with the lived experience of disability would rate their own quality of life

- Gerhard et al., 1994
- Bach et al., 1994
- Albrecht and Devlieger, 1999



## Who Decides?

How do we proceed with shared decision making if we are not certain the patient can fully participate (is competent) in making choices at this time?



## Assessment of DMC

THE PATIENT SELF-DETERMINATION ACT (1990) -  
All health care facilities receiving Medicare and Medicaid reimbursement are required to ask patients if they possess formal advance directives. This act also directs these facilities to provide patient education regarding their rights in relation to these documents



## Competence

- Legal term
- Incompetence is adjudicated [competence is assumed]
- Global description



## Decision Making Capacity (DMC)

- Clinical definition
- Task-specific
- Requires
  1. Ability to understand information presented
  2. Understand the consequences of the options available
  3. Ability to express a preference
  4. Evidence of reasoning

Appelbaum & Grisso, 1988



## How is DMC Assessed?

TASK specific or rather, QUESTION specific.

- Does the patient have the capacity to understand and name a HCP and a POA?
  - Does the HCP need to be invoked at this time?

Once this question is answered, the team can often move forward with a framework for making choices on the patient's behalf when necessary.



## Assessing Decision-Making Capacity (DMC)

Tunzi, 2001, American Family Physician

Aid to Capacity Evaluation (ACE) – ‘formalized’ but not standardized

“Physicians are called upon to make decisions about patients’ capacity, not competency, which is a legal issue.”



## From Tunzi, 2001

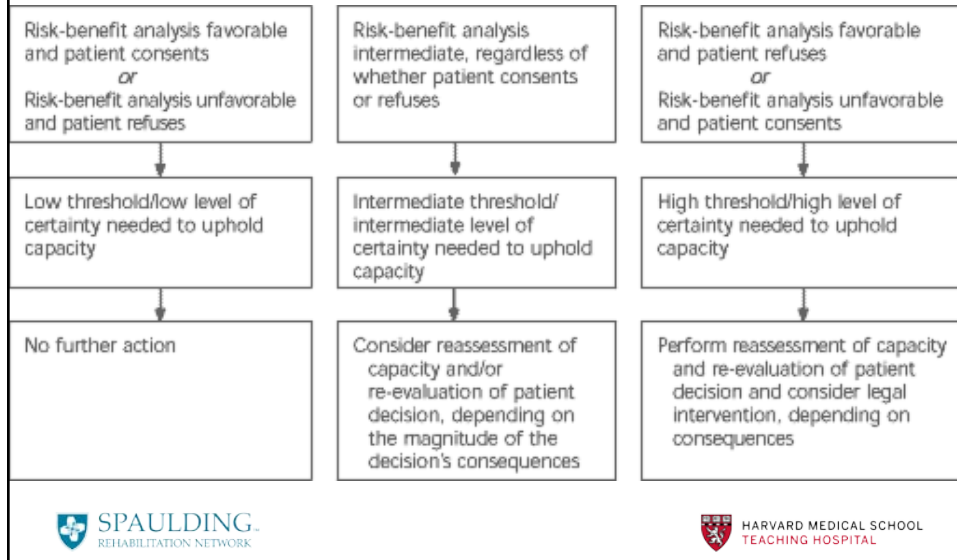
### Formal Assessment Tools

**The ACE (*Figure 2*) is a short, more clinically oriented tool that can be administered and scored in five to 10 minutes. The ACE can also be found on the Web site of the University of Toronto Joint Centre for Bioethics: [http://www.utoronto.ca/jcb/\\_ace](http://www.utoronto.ca/jcb/_ace). General instructions are simple: clinicians are directed to address communication barriers, discuss treatment information and answer patient questions before administering the assessment.**





## From Tunzi, 2001



## Advance Directives

Advance Directive - a legal document that allows an individual to state his/her wishes for future medical decisions under certain qualifying conditions.

## Advance Directives

### Living Will

- Typically a written request to forgo specific treatments in the event that the person is
  - Terminally or irreversibly ill
  - Permanently unconscious
- NOT VALID IN SOME STATES, but does provide evidence of what the patient would have wanted to assist surrogate decision maker in making substituted judgment (but such judgment rests with Surrogate Decision Maker even if in conflict with Living Will).

### Durable Power of Atty for Healthcare (Health Care Proxy)

- Written identification of surrogate decision-maker
- Only in the event that the person is unable to make a given health care decision

PSDA, 1990 & Uniform  
Health Care Decisions  
Act, 1993



## Advance Care Planning

- Pain and symptom management
- Previously stated wishes
- Values statements



## Advance Care Planning Options

Aging with Dignity – FIVE WISHES

[www.agingwithdignity.org/fivewishes.php](http://www.agingwithdignity.org/fivewishes.php)

- Who do you want to make decisions for you?
- Kind of medical treatment you would choose
- How comfortable do you want to be?
- How you want people to treat you
- What you want your loved ones to know



## Advance Care Planning Options

Gunderson Lutheran – Medical System in LaCrosse, WI  
Respecting Choices

[www.respectingchoices.org](http://www.respectingchoices.org)

- Nursing training modules to help facilitate conversations between patients and family members
- Hammes BJ, Rooney BL, Death and end-of-life planning in one midwestern community. Arch Intern Med. 1998; 158: 383-390



## Advance Care Planning Options

Center for Practical Bioethics  
Caring Conversations®  
[www.practicalbioethics.org](http://www.practicalbioethics.org)

- Can obtain free copies of Caring Conversations.
- Translated into Spanish as well.
- Caring Conversations for Young Adults®



## Advance Directives

As of 2007, thirty-eight States and the District of Columbia have formal State surrogate statutes that provide guidance on naming the appropriate surrogate decision-maker. Usually this follows a “next of kin” hierarchy and the person highest on the list who is available and willing to serve in this capacity is the default legal surrogate.

MA, for example, does not have such a surrogacy statute.



## Surrogate Decision-Makers

Surrogate (Proxy) Decision-Maker - One who has the moral and legal authority to make decisions for an individual who cannot make decisions for him/herself. The proxy can be assigned through a health care proxy, guardianship proceedings or informally in certain circumstances.



## Surrogate Decision-Makers

Substitute Judgment - Making decisions the patient would have, based on his/her values and preferences

Best Interest Standard - In the absence of knowledge of what decision the patient would have made, making a decision that is felt to be in the patient's 'best interest'



## Guardian

One who is given legal responsibility by a court for the care of a minor child or an adult who has been deemed to lack capacity in a court of law.



## Dealing with Conflict Among Family and Interested Parties

**Gaining consensus among interested parties is in the patient's best interest. This may require a significant amount of education and processing with the involved parties – often the role of an ethics committee or consultation.**



## Refusal of Treatment in the Context of Rehabilitation and Chronic Illness

- Adults who possess DMC have the right to refuse medical treatment; even life-sustaining treatment
- A surrogate decision-maker has the right to refuse medical treatment for a non-capacitant individual provided the decision is made based on the patient's values, expressed wishes, or (lastly) on what is considered to be in the patient's 'best interest'



## Refusal of Treatment in the Context of Rehabilitation and Chronic Illness

- Powell and Lowenstein (1996) posit that the evaluation of DMC in the context of catastrophic illness and chronic disability may include a more in-depth analysis of the circumstances surrounding the refusal - physical, psychological, social limitations that may influence a person's decision



## Refusal of Treatment in the Context of Rehabilitation and Chronic Illness

- Educational Model - Caplan et. al. (1987) suggest that persons in rehabilitation require a period of 'education' to the possibilities of independence before a true self-determining decision can be made



## Alternative Feeding

Ethical discussions regarding medical appropriateness for placement of percutaneous endoscopic gastrostomy (PEG) tube

What are the CLINICAL INDICATIONS/RECOMMENDATIONS?





## Alternative Feeding

### ALTERNATIVE NUTRITION AND HYDRATION (ANH):

1. Is considered a medical treatment (legally)
2. Can be seen as providing comfort and 'basic care'
3. Can be seen as a disability accommodation (like a prosthesis)



## Clinical Efficacy

### Dysphagia and Artificial Nutrition and Hydration (ANH) at the End-Of-Life

**Consider the known clinical efficacy:  
eg. Advanced dementia; cachexia  
syndrome; esophageal CA; etc**



## Informed Consent

- Patients must comprehend and must give their consent **voluntarily**
- If a patient does not possess formal (legal) ability to make decisions for him/herself, should pursue gaining the patient's **assent** – an 'informal' agreement or cooperation



## Involving Patients in Health Care Decisions

Assent - The informal agreement obtained from a person who is unable to fully participate in the informed consent process, but who can provide a preference related to medical care



## Informed Refusal

- The corollary of informed consent is informed refusal. To respect an autonomous individual's right to accept, we must also accept their right to refuse
- Often our sense of what is beneficent care clashes with a patient refusal [even when a patient want to continue treatment and we believe it would be futile].



## The Question of Clinician Refusal

**Is it a professional right (conscientious objection) or is it abandonment?**



## Treatment Alternatives

Time Limited Trials - Often, a time limited trial can be negotiated. Time limited trials give the patient some control in having the option to stop treatment after an agreed upon length of time. The time limit should be reasonable in relation to the goals discussed

Combination Treatment - The patient may agree to treatment that includes a combination of P.O. intake with supplemental tube feeding



## Documentation

**Documentation of how recommendations are shared and what the decision-making process was/is for all aspects of care (even those considered routine) is important . . .**



## When Patients Refuse – Exploration and documentation are critical

### Should document:

- **Rationale for the recommendation**
- **Patient's capacity for decision-making**
- **Patient's response, preferences and reasons**
- **Patient's desires for continued treatment and how they wish potential complications for their condition to be managed**
- **Follow-up plan**



## Conclusions

- Understand your ethical (professional, clinical institutional) as well as legal and regulatory duties
- Keep a client/patient-clinician relationship at the heart of a shared decision-making model. Be problem and solution oriented
- Ensure supervisory and team acknowledgment
- Document well
- Foster open, productive and blameless communication for effective problem solving with the team



## Discussion

### CASE Considerations



## The Case of D

D is a young girl in the United States from Haiti – being treated for a brain tumor. Has surpassed her rehabilitation needs.

Nursing team members believe that D's mother is not engaged and cannot safely manage D's care (including swallowing recommendations) – do not believe D can have a safe discharge plan.

Therapists believe that nursing is not addressing mom's education needs, but "cannot" be involved because the patient does not have skilled therapy needs.



## Were the Needs of the Stakeholders in the Case of D

How can issues of Moral Distress for the caregivers solved?

Ethics Consultation Meeting – a lengthy team discussion included all healthcare team members.

Members had the opportunity to safely share their viewpoints. The team agreed to a trial of interdisciplinary education with mom and all necessary interpreter and community supports with diligent documentation of response.

Team members publically recognized and validated each other's stress



## Moral Distress

Addressing the realities of Moral Distress in healthcare can be facilitated by using the experience of prevalent case consultation and staff-identified educational needs (often specific to a unit or team).

Thoughtful inclusion of all team members and concrete, practical, well publicized plans for accountable follow-up aid in alleviating Distress.



## Moral Distress

Organizational ethics education and policy development efforts can assist in preventing a sense of Moral Distress by setting a tone in an organization for attention and commitment to the moral needs of all stakeholders.



## The Case of S

Susan is a 46 yo woman with a h/o mental illness and is admitted to the hospital for complications of an acute left lateral medullary stroke.

A VFSS revealed severe dysphagia with limited ability to trigger a swallow. S was admitted to the rehab hospital with an NG tube.

The SLP prognosticates that it will take weeks to months for the patient to regain a functional/safe swallow. The team recommends a PEG, and S refuses. S's NG tube becomes dislodged later that evening.





## The Case of J

Joseph is a 76 yo man with moderate dementia is in a rehab hospital after a long ICU stay. He has significant generalized debility. His wife is his surrogate decision maker and told the physician that her husband would not want a feeding tube.

A VFSS revealed that the patient aspirates all consistencies. After discussion with the patient to the extend possible, his wife and the MD, the SLP makes a recommendation for eating and drinking in the safest way based on the exam.

In tears, the nurse tells the SLP she is afraid to feed J. She is worried that she may harm or even kill J if he aspirates.



## The Case of A

Adam is a 6 yo boy with Down Syndrome is seen in your Pediatric Feeding Clinic. His parents are divorced. Most often, Dad brings him to clinic and follows recommendations while there.

Occasionally Mom comes and appears not to adhere to the child's diet texture recommendations. In fact, A tells his team that Mom gives him foods that are not recommended for him.

Dad tells the team at the next visit that they are not allowed to communicate with Mom re A's treatment.

