ETHICS: APPLYING PRINCIPLES IN PRACTICE & MANAGING DYSPHAGIA IN PATIENTS IN PALLIATIVE CARE AND HOSPICE

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Disclosures

- Financial
  - Received honorarium for this presentation
  - Receive royalties from Pro-Ed for The Source for Dysphagia
- Non-financial
  - Presented and written on this topic
  - Serve on Medical Advisory Board for National Foundation on Swallowing Disorders

Objectives

- Describe the impact of ethics in different contexts
- Discuss medical ethics principles
- Discuss application of ethical principles in SLP practice in health care settings
- State ASHA Code of Ethics
- Discuss case examples from Ethics Roundtable
- Discuss ethical principles as they relate to managing patients with dysphagia
- Compare case law related to dysphagia and end-of-life

Ethics

What is ethics?

"systematizing, defending, and recommending concepts of right and wrong behavior."

http://www.iep.utm.edu/ethics/

Ancient Inca ethics

The Incas had three major commandments, three principles, as the basis of their approach to life:

- search for the truth
- work hard
- respect every form of life.

Spaniards interpretation

- Spaniards adopted, but in the negative aspect:
  - Do not lie
  - Don't be lazy
  - Do not steal

Three types of ethics

- "*Metaethics* investigates where our ethical principles come from, and what they mean.
- *Normative ethics* takes on a more practical task, which is to arrive at moral standards that regulate right and wrong conduct.
- Finally, *applied ethics* involves examining specific controversial issues."

Metaethics

- Study of the origin and meaning of ethical concepts
  - *Think "metalinguistics" or "meta-analysis"*

Normative ethics

- Normative ethics involves arriving at moral standards that regulate right and wrong conduct
- The Golden Rule is an example of a normative theory that establishes a *single principle* against which we judge all actions.

What makes something an applied ethical issue?

- It's controversial (people for and against)
  - Drive by shootings: not controversial
  - Gun control: controversial
- Distinctly moral issue
  - Universally obligatory
  - Not confined to certain societies

Controversial but not moral…

- Some things can be controversial (e.g. requiring childhood immunizations) but not be a moral issue
  - Instead it is related to social policy

Normative principles in applied ethics

- ***Personal benefit****:* acknowledge the extent to which an action produces beneficial consequences for the individual in question.
- ***Social benefit****:* acknowledge the extent to which an action produces beneficial consequences for society.
- These are considered 'consequentialist'
- Appeal to the consequences of an action as it affects individual or society

Normative principles based on 'duty' we have toward others

- *Principle of benevolence:* help those in need.
- *Principle of paternalism:* assist others in pursuing their best interests when they cannot do so themselves.
- *Principle of harm:* do not harm others.
- *Principle of honesty:* do not deceive others.
- *Principle of lawfulness*: do not violate the law.

Normative principles based on moral rights

- *Principle of autonomy*: acknowledge a person's freedom over his/her actions or physical body.
- *Principle of justice*: acknowledge a person's right to due process, fair compensation for harm done, and fair distribution of benefits.
- Rights: acknowledge a person's rights to life, information, privacy, free expression, and safety.

Biomedical ethics

- Part of applied ethics, that uses ethical principles and decision making to solve actual or anticipated dilemmas in medicine and biology

  Read more: An Introduction to Biomedical Ethics http://www.medindia.net/education/familymedicine/biomedical-ethics.htm#ixzz3elYNZA00

Clinician's obligation:

- Patient-centered, value-driven ethical decisions.
  - Rather than drawing on law or religion

Bioethics and the law

- Laws stem from legislative statutes, administrative agency rules, or court decisions, and they often vary in different locales and are enforceable only in those jurisdictions where they prevail.
- Ethics incorporates the broad values and beliefs of correct conduct.

Bioethics and the law

- Significant overlap exists between legal and ethical decision making.
- Both ethical analysis (in bioethics committee deliberations) and the law (in the courts) use case-based reasoning in an attempt to achieve consistency.
- Bioethics consultations more flexible than law

Bioethics and religion

- In multicultural societies, with no single religion, a patient value-based approach to ethical issues is necessary
- Modern bioethics uses many decision-making methods, arguments, and ideals that originated from religion.
- In addition, clinicians' personal spirituality may allow them to relate better to patients and families in crisis
- Most religions have some form of the Golden Rule

Bioethics and religion

- Problems surface when trying to apply religion-based rules to specific bioethical situations.
- For example, although "do not kill" is generally accepted, the interpretation of the activities that constitute killing, active or passive euthanasia, or merely reasonable medical care vary with the world's religions, as they do among various philosophers
  Because of this, several generally accepted secular principles have emerged

Principles of Biomedical Ethics

- Autonomy
- Non-maleficence
- Beneficence
- Justice

Autonomy

- Respect for Autonomy
- Patients have right to make independent choices about their care
- Free from controlling influences and have capacity to make independent decisions
- If the patient can't make independent choice, involve "surrogate decision makers"
  - Paternalism is in conflict with autonomy

Non-maleficence

- Above all, do no harm
- Do not cause harm or impose the risk of harm
- Closely tied to the principle of beneficence

Beneficence

- Provide positive benefits to patients
- Action done for the benefit of others
- Implies an obligation to help others
  - Paternalism sometimes necessary in order to do good

Justice

- Fairness
- Equal access to health care

ASHA Code of Ethics

How about some real examples?

Upcoming Changes to Publication of Board of Ethics Decisions

Beginning with the April 2017 issue, Board of Ethics decisions published in the printed version of *The ASHA Leader* for members found to have violated the ASHA Code of Ethics will consist of:

- full name
- city
- state
- Code of Ethics version applied
- public sanction (and length of sanction, if applicable)
- effective date of the sanction

Full details of the decisions, including the rationales and the violated principles and rules, will be located in *The ASHA Leader Online*.

Principle of Ethics I

- Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally

- Examples?

Principle of Ethics II

- Individuals shall honor their responsibility to achieve and maintain the highest level of professional competence and performance.

- Let's look at some specific rules… and give examples

Principle II: RULE 2

Individuals shall engage in only those aspects of the professions that are within the scope of their professional practice and competence, considering their level of education, training, and experience

Examples?

Principle II: RULE 4

- Individuals shall not require or permit their professional staff to provide services or conduct research activities that exceed the staff member's competence, level of education, training, and experience
- Examples?

Principle II: RULE 5

- Individuals shall ensure that all equipment used to provide services or to conduct research and scholarly activities is in proper working order and is properly calibrated
  - Examples?

Principle of Ethics III

- Individuals shall honor their responsibility to the public by promoting public understanding of the professions, by supporting the development of services designed to fulfill the unmet needs of the public, and by providing accurate information in all communications involving any aspect of the professions, including the dissemination of research findings and scholarly activities, and the promotion, marketing, and advertising of products and services.
  - Examples?

Principle of Ethics IV

- Individuals shall honor their responsibilities to the professions and their relationships with colleagues, students, and members of other professions and disciplines.
  - Examples

Common dilemmas faced by ASHA members

- Documentation lapses
  - Sign off on someone SLP did not treat
  - Sign off on student-provided services SLP did not supervise
  - Requested to alter or supplement documentation

- Heather Bupp, Esq.
- ***The ASHA Leader***, November 2012, Vol. 17, 10-13. doi:10.1044/leader.FTR1.17142012.10

Employer demands

- Productivity demands
- Overriding professional's independent judgment

Clinical fellowship mentoring/student supervision

- Mentor not providing supervision
- Careless attitude of student

Client abandonment

- Focus must stay on client
- Making adequate provision for care of client when leaving employment setting

Reimbursement…..

- Misrepresenting information to obtain reimbursement or funding, regardless of the motivation of the provider.
- Providing service when there is no reasonable expectation of significant communication or swallowing benefit for the person served.
- Scheduling services more frequently or for longer than is reasonably necessary.

Reimbursement cont'd

- Requiring staff to provide more hours of care than can be justified.
- Supervision of students or other service providers in a fee-for-service environment.
- Providing professional courtesies or complimentary care for referrals or otherwise discounting care not based on documented need

Ethics Roundtable

Topics

Our Partners

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Four examples from the Roundtable

- Recommending an employee with mixed performance reviews
- Student and supervisor disagree
- Randomized clinical trial
- Interpreting living will after stroke

Recommending an Employee With a Mixed Performance Record
Ethics Roundtable: Case Study #1

- Fran Bridgeburner recently completed a Clinical Fellowship. Although she graduated with honors just a year earlier, her work supervisor often finds her interpersonal skills with other staff members to be inappropriate.
- As a member of a multidisciplinary team, Fran often refuses to compromise on treatment plans and coworkers characterize her as "difficult." Her supervisor has counseled her many times during the past year about this issue, but it has not resolved the problem.
- Fran has indicated that she plans to seek employment elsewhere and has requested a letter of recommendation from her supervisor. How should her supervisor respond?

When Student and Supervisor Disagree
Ethics Roundtable: Case Study #2

- Ms. Robertson, a 78-year-old is hospitalized after a hip fracture. A speech-language consultation is requested because her physician is concerned about her cognitive abilities. The evaluation is conducted by Scott, a student clinician. He observes mild cognitive deficits, but also notes that Ms. Robertson coughs immediately after taking sips of water and that she has a wet voice quality for several minutes after drinking. From the medical record, Scott notes that she had pneumonia on admission to the hospital and has been treated for pneumonia at least three times in the past nine months.

Ms. Robertson (cont'd)

- Scott discusses his observations with his supervisor. He recommends a "bedside" swallowing evaluation and possible videofluoroscopic swallow examination. His supervisor suggests that she coughs because she is recovering from pneumonia. Furthermore, they were consulted for a cognitive assessment, thus his observations about her swallowing are inappropriate to include in his report. Scott is concerned about the patient, but unsure of his role as a student and questions how to interpret his own observations

Questions to Consider

- Does the Code of Ethics provide guidance in this case?
- What is the role of a student in advocating for patients and handling disagreements with a supervisor?
- What approaches could Scott take to continue the discussion with the supervisor?

Ethical Issues in Randomized Clinical Trials
Ethics Roundtable: Case Study #3

- Immediately after a stroke, some centers provide individual speech-language therapy, while others primarily rely on group interventions. Many patients are discharged to home very quickly. Researchers propose a randomized clinical trial to study the outcomes of three treatment approaches for aphasia in the acute phase after stroke.
- Patients must be 45 to 85 years of age, must not have had prior strokes, and must have a speech-language evaluation within 10 days post-stroke. Patients with aphasia will be asked to participate in the study. All patients will continue to receive typical medical and rehabilitation services for the institution. Those who consent will be randomized to one of three treatment arms:

Clinical trials (cont'd)

- Individual therapy 5 sessions a week, minimum 14 days.
- Group therapy (no more than 6 patients per group) 5 sessions a week, minimum of 14 days.
- Family education and training, 3 sessions. Training will target individual's needs, demonstrate activities, and provide written information about aphasia, and contact numbers for the speech-language pathologist.
- Services will be given as an inpatient or outpatient, discharge will not alter the therapy plan. Patients who participate will be re-evaluated after 14 days, 30 days, 3 months, 6 months, and 1 year. The speech-language pathologists who evaluate the patients will be blinded to the treatment approach used.

Questions to consider

- Why is this kind of research important? What are the likely benefits?
- Are there any issues of concern in this protocol (e.g., consent, randomization, vulnerable population, potential harms)? What are the potential risks?
- Are there any potential conflicts for the speech-language pathologist who evaluates the patients and enrolls them in the trial in the acute setting?
- Are there any approaches or research designs that might lessen these concerns? What resources are available within institutions and nationally to assist clinician-researchers?

Interpreting a Living Will after Stroke
Ethics Roundtable: Case Study #4

- Mr. Duffy is 83 years old and is admitted to rehabilitation four weeks after a right thalamic CVA. As a result of his stroke, he has dysphagia, dysarthria, and left hemiplegia and is moderately-severely confused. When Mr. Duffy pulls out his nasogastric feeding tube, his physician decides not to re-insert it because of significant nasal tissue necrosis. The team recommends a gastrostomy tube because of his high risk for aspiration and inability to maintain nutrition and hydration with oral feeding.

- Mr. Duffy has a Living Will that states he does not wish to have his life sustained with a feeding tube. He does not have a formal Durable Power of Attorney for Healthcare. His wife has dementia and his two daughters are making decisions for both parents. They are not sure about his wishes in this particular circumstance, but report that he said of a relative who died of cancer, "things went on too long because of that feeding tube."

Mr. Duffy (cont'd)

- After three days, Mr. Duffy is more alert and during a discussion about tube feedings he says "I'll go for the works." His fluctuating alertness level makes it impossible for him to respond to this question again. His daughters feel he would not want the tube and suggest waiting to see if their father' s swallowing will improve in the next week before making a decision.

Questions to consider

- Who is the appropriate decision-maker in this case?
- What options are available to the team?
- Suggest an optimal solution in this case.

Let's move the discussion to dysphagia

- Each year approximately 10 million Americans are evaluated for swallowing difficulties (Domenech, E 1999)

- Feeding/swallowing disorders are associated with high morbidity and mortality (Marik, PE 2003), significant financial burdens (Altman, KW 2010) and reduced quality of life (Ekbert, O 2002)

- *Thanks to Tammy Wigginton, M.S., CCC-SLP, BCS-S (presented some of this information to the Bluegrass Academy of Medical SLP)*

Consequences of dysphagia

Dehydration/Malnutrition

- 49% of stroke patients are malnourished when admitted to rehabilitation (Finestone, Hillel M. et al. 1995)
- 35-85% of institutionalized elderly are malnourished (Furman, 2006)

Pneumonia

- Most frequent infections cause of death (Marston, et al., 1997)
- 2nd most common nosocomial infection in hospitals (Niederman, et al., 2002)

Mortality

- 63,000 Deaths in 2003
- 40% higher incidence in the elderly with 55% fatality rate (National Center for Health Statistics, 2003)

Financial consequences

- Mean cost of an admission for an aspiration pneumonia was 17,000 thousand and increased with the number of comorbid conditions
- Conservative estimates of annual hospital costs are approximately 547 million
- The presence of dysphagia was associated with a 40% increase in length of hospital stay in all age groups

*Kenneth W. Altman, MD, PhD; Gou-Pei Yu, MD, MPH; Steven D. Schaefer, MD Consequence of Dysphagia in the Hospitalized Patient Impact on Prognosis and Hospital Resources Arch Otolaryngol Head Neck Surg. 2010;136(8):784-789

Emotional consequences

- Social and psychological impact of dysphagia has not been routinely examined in studies, however a study on 360 patients with dysphagia found:
  - 32% reported still being hungry and thirsty after their meal
  - 36% avoided eating with others
  - 41% experienced anxiety or panic during mealtime
  - 50% claimed they were eating less
  - 55% said that swallowing difficulties made their life less enjoyable

- Ekberg O, Hamdy S, Woisard V, Wuttge-Hannig A, Ortega P. Social and psychological burden of dysphagia: its impact on diagnosis and treatment. Dysphagia. 2002 Spring;17(2):139-46

Challenges to managing dysphagia

- Feeding/hydration issues are time sensitive
- Feeding/hydration issues are emotionally loaded
- Patients are often medically fragile and complex
- Multiple providers involved in care and sometimes there are competing agenda
- Uncertainty regarding medical facts and goals of care
- Misinformation about swallowing and feeding disorders even among educated medical professionals

Balancing obligations

- Manage obligations to patients, family members, institutions, professional organizations and ourselves in the context of providing optimal care to patients

Professional ethics and dysphagia

- Ethical breaches related to scope of practice, clinical competence, and current best practice can result in harm to patients particularly patients with feeding and swallowing disorders
- A thorough understanding of what constitutes “competence” should guide professional behavior and professional development:

- *“Knowledge and Skills for Speech-Language Pathologists Providing Services to Individuals With Swallowing and Feeding Disorders”*
- *“Instrumental Diagnostic Procedures for Swallowing”*
- *“Graduate Curriculum on Swallowing and Swallowing Disorders”*

Clinical ethics

- Clinical ethics involves identification, analysis and resolution of ethical dilemmas encountered in the context of providing patient care (Jonsen, Siegler and Winslade 2010)
- More challenging to navigate than professional ethical issues because one cannot refer to a “code” for an answer
- Dynamic because circumstances are unique for each patient
- “Competence” in clinical ethics depends
  - familiarity with medical ethics literature
  - a sound method for analysis

Reminder: principles of medical ethics

- 4th century BC. Hippocrates, who was a physician and a philosopher, directed physicians to "Primmum non nocere" i.e., “First, do no harm”.
- Contemporary framework used to identify ethical dilemmas is the "Four Principles approach" proposed by Tom Beauchamp and James Childress in the text book Principles of Biomedical Ethics.
- The “four principles” are:
  - Respect for Autonomy
  - Beneficence
  - Non-Maleficence
  - Justice

Systematic model for decision-making

- These “Four Topics” can be used to:
  - identify and analyze ethical dilemmas
  - facilitate a discussion of ethical issues and help the care team move toward a reasonable and practical resolution
- Four Topics:
  - Medical Indications
  - Patient Preference
  - Quality of Life
  - Contextual Features
  - *Sharp and Genesen: Ethical Decision-Making in Dysphagia Management American Journal of Speech-Language Pathology • Vol. 5 • 1058-0360/96/0501-0015) proposed by Jonsen et al., 1992*

Medical indications

- Medical history
- Acuity of the problem
- Best evidence available regarding evaluation and treatment approaches
- Potential benefits and burdens associated with treatment and overall prognosis

Patient preference

- In all medical treatment, the preferences of the patient, based on the patient's own values and personal assessment of benefits and burdens are ethically relevant. In every clinical case questions must be raised:
- What are the patient's goals?
- What does the patient want?
- Has the patient been provided sufficient information?
- Does the patient comprehend?
- Does the patient understand the uncertainty inherent in any medical recommendation and the range of reasonable options that exist?
- Is the patient consenting voluntarily?
- Has the patient coerced?

Quality of life

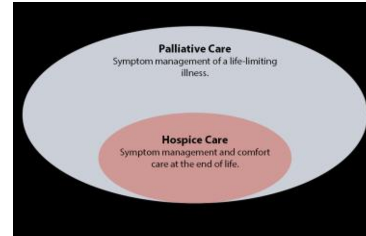
- Quality of life is a perceived assessment of health and happiness or lack of health and happiness.
- Assessment of “quality of life” should assess the impact of illness and treatment with regard to biological integrity and psychological, social and economic well-being.
- The object of any medical intervention should be to restore, maintain or improve quality of life. In the context of feeding and swallowing issues, generally the goals of care are Tammy

Contextual

- Circumstances or facts which surrounds the patients care
- Context is influenced by decisions made by or about the patient
- These decisions have psychological, emotional, financial, legal, scientific, educational and religious impact on others

Palliative and hospice

- Managing dysphagia in palliative and hospice care



Need for palliative care

- Strong correlation between aging and chronic illness
- Need to provide symptom and disease management for hospitalized patients not facing death within prescribed time
  - Not eligible for hospice services
    - Ross, Mathis & Brockopp (2008)

Cost of managing chronic illness

- Management of chronic illness that is not life-threatening accounts for approximately 75% of available health care resources in U.S.
  - *Institute of Medicine (2001)*
  - *Rice & Fineman (2004)*

Palliative or Hospice?

- Traditionally palliative care and hospice care is provided to individuals diagnosed as terminally ill
- More recently, palliative services are available to patients with chronic conditions who do not meet qualifications for hospice

Needs of patients with chronic conditions

- Management of symptoms:
  - Pain
  - Nausea
  - Fatigue
- Psychosocial issues
- Spiritual issues

Increase in palliative care programs

- In 2000, 632 hospitals reported palliative care services
- In 2005, 1,240 indicated they provided these services
  - Healthcare Quick Disk 2006

Challenges to establishing a palliative care program

- Shift in philosophy of the staff providing the care
  - Change from focus on cure to focus on management
- Fear that the program will drain resources
  - White, Stover, Cassel, Smith (2006)

Why do hospice & palliative care patients need rehabilitation?

- Multiple factors contribute:
  - De-conditioning
  - Fatigue
  - Complications from therapies
  - Under-nutrition
  - Neurologic and musculoskeletal problems
  - Pain
  - Bowel and bladder dysfunction
  - Thrombo-embolic disease
  - Depression
  - Co-existing co-morbidities
    - Multiple sources

Do hospice & palliative care patients want rehabilitation?

- Most hospice patients express desire to remain physically independent during the course of their disease
  - Wallston, Burger, Smith & Baugher 1988
  - Ebel, Langer (1993)
  - Mayer (1975)

Benefits of palliative rehabilitation

- Improved quality of life
- Improved mobility
- Better control of pain and other symptoms
- Improved mood
- Gains in motor and cognitive function
- Shorter lengths of stay
  - Various sources

Role of the SLP (Pollens 2004)

- Provide consultation to patients, families and the care team re:
  - Communication
  - Cognition
  - Swallowing
- Develop strategies in area of communication skills to support the patient’s role in decision making, maintain social closeness and assist patient in achieving fulfillment of end-of-life goals

Role of the SLP

- To assist in optimizing function related to dysphagia symptoms to improve patient comfort and satisfaction
  - Promote positive feeding interactions with family members
- Communicate with the care team related to overall care of the patient

Differences in palliative and hospice

- How does the SLP's approach differ in palliative vs. hospice
  - Use of instrumentals
  - Facilitations vs compensations
  - How conservative we are with recommendations
- Let's look at a case example

Clinical and Instrumental Results

- Clinical exam reveals patient coughing on all liquids from cup
  - Does not cough with small amounts liquid from spooon
  - Appears able to handle fork-mashed foods but c/o feels like food is sticking
- VFSS reveals:
  - Aspiration of thin liquids if taken in greater than teaspoon amounts
  - Takes nectar thick in large sips safely from cup or straw
  - Significant residue in valleculae with all solids due to reduced tongue base and pharyngeal wall squeeze

Different recommendations

Palliative

- Proceed to instrumental
- Based on instrumental, allow thin liquids in small amounts on teaspoon
- Use naturally nectar thick liquids during meals
- Multiple swallows
- Initiate exercises for tongue base/pharyngeal wall

Hospice

- Likely make recommendations based on clinical exam:
  - Soft foods
  - Second dry swallow
  - Thin liquids in small sips

Tube feeding and end of life

- History of PEG (Wall Street Journal December 8, 2005)
- On June 12, 1979, two physicians inserted the first modern feeding-and-hydration tube to save a sick infant
  - Gauderer & Ponsky at University Hospitals of Cleveland
- One dubbed it the "percutaneous endoscopic gastrostomy" nozzle
- Before this, a gastrostomy tube required major surgery

- http://vimeo.com/32507507

History of PEG

- Ponsky adapted it in the early 1980s for use with adults
- Used with stroke patients initially
- Use quickly spread to patients with terminal cancer and elderly with dementia
- Device generally low cost ($200-$600)
- Short recovery time meant patients could be discharged quickly

Increase in PEG use

- Embraced by nursing homes b/c it was a quick way to feed patients who couldn't feed themselves
- Is it easier for the physician to order a PEG placed than to have a difficult conversation with the family?

PEGs in nursing homes

- In 1999, nearly 34% of patients with severe dementia who were residents of U.S. nursing homes were living with PEG
    - Mitchell, DL, Tetroe, JM. Survival after percutaneous endoscopic gastrostomy placement. J. Gerontol A Biol Sci Med 2000; S5A:M735-M739
- A recent five-state survey found that 11% of persons dying with dementia had a feeding tube
  - Teno, Mitchell, Kuo et al (2011)

PEGs and economics

- Medicare considers PEGs to be skilled nursing
  - Hand feeding is not skilled
- Nursing homes get more money for patients with PEG and they also do not have the cost of paying someone to feed
  - CNA making $8/hr can hand-feed perhaps 2 patients in an hour
  - Can hook up 10 feeding tubes in same amount of time

PEGs and economics

- Tube-fed residents in nursing homes generate a higher daily reimbursement rate from Medicaid, but require less expensive care
  - Mitchell, Buchanan, Littlehale & Hamel 2003)
- Nursing home industry reports that patients with feeding tubes result in increased cost of care
  - *Are feeding tubes cost-driven?*

Case law related to nutrition and hydration

- Karen Ann Quinlan case – 1976
- April 15, 1975 –July 11, 1985

- A significant outcome of her case was the development of formal ethics committees in hospitals, nursing homes and hospices

Case law

- Nancy Beth Cruzan (1990)
- January 11, 1983 – December 26, 1990

- Justices determined that the choice of a person in a persistent vegetative state to decline life support is a protected liberty interest under the 14th amendment, and that this right is exercisable by a lawful surrogate
- Supreme Court determined that death after surrogate refusal of AHN is neither euthanasia nor assisted suicide, but simply the natural consequence of the exercise of the patient's right to refuse unwanted treatment

Patient Self Determination Act

- Took effect December 1, 1991
- Direct result of Cruzan case
- Requires all hospitals and nursing homes receiving federal Medicare or Medicaid funding to inform patients of their rights to provide *advance directives* like living wills, healthcare surrogates, and durable power of attorney.

Advance directive

- Legal, written statement of medical choices or the way the patient wants medical choices to be determined
- Written prior to need for such decisions
- Goes into effect when patient can no longer decide for him/herself or can no longer tell others of decision
- Cannot be required to have advance directive

Living wills may include:

- Directions that life-prolonging treatment not be provided, or once started, that such treatment be stopped
- Directions that food (nutrition) and water (hydration) not be provided through artificial means like tubes, or once started, that they be stopped
- A choice of one or more persons to act as your surrogate and make decisions for you

Healthcare surrogate

- Person you appoint in your living will or in another written document to make medical decisions for you if you are not able to speak for yourself

Durable power of attorney

- Advance directive that lets you name someone (attorney-in-fact) to make medical decisions for you if you're unable to speak for yourself
- Similar to healthcare surrogate, but may also give attorney-in-fact power to make decisions about personal and financial affairs

Terry Schiavo

February 25, 1990- March 31, 2005

Schiavo case raised the question: should AHN be considered medical therapy that lawful surrogated can refuse based on preferences the patient had expressed orally while competent

Arguments for distinguishing artificial nutrition and hydration from other life-sustaining medical treatments

- Ordinary care - now there is no distinction between ordinary and extraordinary care
- "Basic sustenance vs. medical procedure"
- NG tubes "minimally invasive"
- "Causation - dying of starvation rather than underlying disease process"
- "Allowing physicians to withhold or stop AHN is step on slippery slope to euthanasia for devalued human lives"

Why those arguments don't work

- Artificial nutrition and hydration = medical procedure
- Virtually every reported appellate case has rejected these objections
- Nutrition and hydration may be forgone according to same standards as any other medical treatment
- AMA classifies artificial nutrition and hydration as "life-prolonging medical treatment"

Medicare and Medicaid requirements

- For long-term care facilities - recognize that competent residents have unqualified right to refuse treatment, including artificial nutrition and hydration when state law permits
- Cause of death is patient's inability to eat, brought about by disease or injury, and cannot be characterized as starvation

Artificial nutrition and hydration carries own set of risks, discomforts and drawbacks

- Courts view PEG as highly intrusive
- NG can contribute to progression of disease
- Persistent vegetative state -- continuing artificial nutrition and hydration denies dignity

Dehydration and starvation

- "It may not result in more pain than the termination of any other medical treatment"
  - In conscious patients, if adequate analgesic medication is provided, death should be painless
  - In persistent vegetative state, will certainly be painless

Martha Sue DeGrella

- Kentucky case
- February 22, 1983-August 18, 1993
- Mother of patient in vegetative state as result of severe beating brought suit against guardian, seeking court authorization to order medical personnel to discontinue nutrition and hydration by tube
- Supreme Court upheld that mother could order life-sustaining treatments d/c
  - irreversible
  - patient's prior statement

State statutes and appellate cases Sieger, et al 2002

- Twenty-seven states (39%) have one or more explicit statutory provisions delineating a separate and more stringent standard for ANH refusal with a higher evidentiary standard
  - Requirement for specific preauthorization
  - Qualifying medical conditions
  - Second medical opinion
  - Judicial review, etc

Professional malpractice

- "Delivery of patient care that falls below the standard expected of ordinary reasonable practitioners of the same profession acting under the same or similar circumstances" Scott, 1994, p. 20

Professional malpractice

- Now more broadly defined to include:
  - Potential for liability if there is a breach of patient-clinician contractual promise
  - Liability for defective treatment-related products that cause harm to the patient
  - Liability for abnormally dangerous treatment activities

Criteria that must be met to be found guilty of malpractice (Ohliger, 1996)

- Existence of duty of care
  - Agreement by the clinician to enter a patient/client relationship
  - Not bound to provide care to every patient, but once patient is accepted, clinician has duty to protect the patient from foreseeable harm

Legal implications

- Standard of care
  - healthcare providers have duty to exercise "the reasonable degree of skill, knowledge, and care ordinarily possessed and exercised by members of the same profession under the same or similar circumstances"
  - May be compared to peers not in the same community

Legal implications

- Foreseeable harm
  - If reasonable clinician could not have foreseen that harm would have resulted from actions, no liability for negligence
    - e.g. patient placed on pureed + thick liquids secondary to aspiration; SLP gives patient glass of water
    - probably considered below standard of care, and found liable for negligence

Legal implications

- Causation
  - Clinician's actions must be the "cause in fact" of the injury
    - have to show that "but for" the health care provider's actions, the injury would not have occurred
  - Proximate cause
    - was there an intervening act not reasonable foreseen *

Legal implications

- Proximate cause (e.g. Huckabee & Pelletier, 1999)
- SLP instructs nursing assistant to supervise patient and NOT give water
- Assistant leaves patient unattended and unexpectedly, family member visits and gives water
- Would this be considered foreseeable?

Informed consent to treat

- Providing patient with sufficient information about proposed treatment and its reasonable alternatives to allow patient to make a knowing, intelligent, and unequivocal decision regarding whether to accept or reject the proposed treatment (Scott, 1994, p. 219)

Informed consent to treat should include:

- Description of diagnosis and evaluation, proposed treatment, presented to patient in terms they can understand
- Discussion of "material" risks
- Reasonable alternatives
- Expected benefits and prognosis
- Solicit questions from the patient about proposed treatment plan

Risk of aspiration with tubes

- Aspiration pneumonia most common cause of death after PEG placement
- Feeding tubes (NG & PEG) actually increase the risk of aspiration pneumonia
  - GERD?
  - Oropharyngeal colonization?
    - Plonk, 2005

Aspiration and tubes

- Non-randomized prospective study
  - Orally fed patients with dysphagia had fewer major aspiration events than those tube fed
- Non-randomized, retrospective observation of SNF residents found no survival advantage with tube feeding
  - Reported in Finucane et al 1999

Burdens and complications of PEG

- Pain at site of tube
- Diarrhea
- Nausea
- Hematoma
- Fistula
- Peritonitis
- Abdominal abscess
- Loss of dignity
  - Plonk 2005

Poor prognostic factors for PEG placement (Plonk)

- Older than 75 years
- Male
- Diabetes Mellitus
- COPD
- Advanced cancer
- Previous aspiration
- NPO x 7 days
- UTI
- Low BMI
- Hospitalized
- Bedridden
- Pressure sores
- Confusion
- Cardiac disease

Number of patients who can't eat will increase

- Council on Bioethics (2005) warned that number of patients with Alzheimer's, estimated then at 4.5 million, will triple in the next 45 years

How do families make decisions?

- Families of individuals with dementia engage in choices about feeding more often than any other treatment, but report quality of decision-making is poor
  - Givens et al 2009

Decision aids

- Provide patients and families with structured information about a clinical choice
- Used to enhance clinical decision-making
- Present balanced, evidence-based information about risks, benefits, and alternatives to a particular decision
  - Elwyn, O'Connor, Stacey, et al 2006

A Decision Aid for Long-Term Tube Feeding in Cognitively Impaired Older Adults (Mitchell, Tetroe & O'Connor 2001)

- Substitute decision-makers for 15 cognitively impaired inpatients being considered for placement of PEG
- Questionnaires used to compare the decision-makers' knowledge, decisional conflict and predisposition regarding feeding tube placement before and after exposure to the decision aid

A Decision Aid for Long-Term Tube Feeding in Cognitively Impaired Older Adults (Mitchell, Tetroe & O'Connor 2001)

- Results: Increased their knowledge and decreased their decisional conflict regarding long-term tube feeding after using the decision aid
- Impact of the decision aid on predisposition toward the intervention was greatest for those who were unsure of their preferences at baseline

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- Randomized, Controlled Trial
- 24 nursing homes in NC
- Residents with advanced dementia and feeding problems and their surrogates
- Surrogates received audio or print decision aid on feeding options
- Controls received usual care

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- Primary outcome was Decisional Conflict Scale measured at three months
- Other main outcomes: surrogate knowledge, frequency of communication with providers and feeding treatment use

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- Surrogates in both groups experienced the same level of decisional conflict at time of study enrollment
- After three months, surrogates who received the decision aid had significantly lower scores on each subscale

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- After review of the decision-aid, intervention surrogates had higher mean knowledge scores than controls and expected fewer benefits from the tube feeding
- Over the next 3 months, surrogates in intervention group were more likely than controls to have discussed feeding treatments with MD, APRN,PA

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- Decisional regret was low and satisfaction high at 3 months for both groups
- After 3 months, residents in the intervention group:
  - had greater use of some assisted oral feeding techniques than those in the control group
  - Were more likely to receive a dysphagia diet
  - Trend towards greater use of specialized assistance for feeding
- Mortality similar for both groups

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- At 3 months, explicit choices for or against tube feeding were rare, so performed chart review at 9 months:
  - 3 controls vs. 1 intervention resident had feeding tube
  - 2 control vs. 4 intervention residents had orders not to tube feed
  - Weight loss less common at 9 months for intervention group

Decision aid

- Making Choices: Long Term Feeding Tube Placement in Elderly Patients
  - Mitchell, Tetroe, O'Connor, Rostom, Villeneuve, Hall (2001; 2008)

Resources for professionals

- Several organizations have developed position statements on ANH
  - American Academy of Hospice and Palliative Medicine Statement on Artificial Nutrition and Hydration Near the End of Life
  - American Dietetic Association: Ethical and Legal Issues in Nutrition, Hydration, and Feeding
  - AMA Statement on End-of-Life Care
  - American Society for Parenteral and Enteral Nutrition Statement on Ethics of Withholding and/or Withdrawing Nutrition Support Therapy

Have the medical and legal communities reached consensus?

- Some religious groups have actively challenged living wills that call for patients to die without having a tube placed
  - Agudath Israel case re: Lee Kahan
- February 2005 New York State Supreme Court Judge ordered patient's daughter to keep her mother alive as long as medically possible
  - *Note: living will was incomplete*

Have the medical and legal communities reached consensus?

- Some groups treat the PEG as an issue similar to stem-cell research and abortion
- Burke Balch, director of National Right to Life Committee's Robert Powel Center for Medical Ethics:
  - Their interest in end-of-life care is equivalent to its concern over abortion

Have the medical and legal communities reached consensus?

- Lawmakers in dozens of states have sought changes that would make it harder to remove feeding tubes
- Right to Life Committee has won sponsors in more than 10 states for legislation requiring courts to presume a mentally handicapped patient would want to live