Ethics…

We're required to have it, I sure wish everyone else was too!

Travis Camp, M.S., CCC-SLP

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Ethics is defined as:

- Merriam – Webster says:
  - The discipline dealing with what is good and bad and with moral duty and obligation a set of moral principles : a theory or system of moral values
  - The principles of conduct governing an individual or a group
  - A guiding philosophy

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ASHA Code of Ethics

Effective March 1, 2016

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Wait what???

- https://www.asha.org/Practice/ethics/
- Summary of Principals I – IV
  - Principal I: Competently treat people/animals you work with professional, in research & scholarly activities w/ respect & dignity.
  - Principal II: Keep your standards high, maintain your CCC's, comply with institutional, state and federal law.
  - Principal III: Provide accurate information in all aspects of patient care.
  - Principal IV: Accept these standards and collaborate inter/intra professionally in an appropriate way.

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State Codes and Ethical Provisions

Tennessee (Sections 1370-01-.13 & 1370-01-.15)

- http://publications.tnsosfiles.com/rules/1370/1370-01.20160622.pdf

Speech-Language Pathology

- Have at least a Master's degree in SLP from an accredited institution; AND
- Maintain your Certificate of Clinical Competence (CCC)
- Successfully complete and document:
  - Minimum 400 clock hours of supervised clinical experience with individuals having a variety of communications disorders, as required by ASHA. Through an accredited institution recognized by ASHA
  - Complete a Clinical Fellowship
  - Pass the Praxis per Rule 1370-01-.08.

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Tennessee State Codes

- The practice of SLP and AUD covered under statute T.C.A. § 63-17-103.
- Exceeding your scope of practice **or** performing procedures not adequately trained for may result in disciplinary action.
  - T.C.A. §§ 63-17-117, 63-17-126, and Rule 1370-01-.13.

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Ethical Q's and Dysphagia Management

#1: SAFETY:

How safe is the patient/resident to take foods, liquids, & meds by mouth? Choking Risk? Aspiration Risk? Remove feeding tube?

#2: PNEUMONIA POTENTIAL:

Is the patient/resident at an increased risk for developing pneumonia from aspiration?

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Ethical Q's and Dysphagia Management

#3: HYDRATION/DIET:

Are the liquid/food consistencies currently received by the patient/resident appropriate, or can they be advanced to a more normal diet consistency?

#4: IMPAIRMENT-INTERVENTION:

Are there therapies that you can use to effectively alter & improve the patient/resident's abilities to swallow safely & can we verify their effectiveness?

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Principles of Clinical Ethics & How WE can apply them to our Practice

- Principles of Clinical Ethics and Their Application to Practice By Basil Varkey. The Medical College of Wisconsin, Milwaukee, WI, USA. Medical Principles and Practice 2021;30:17–28
- Dysphagia & Diets in SNFs When Patient's Health Status Changes: The Role of Imaging Dec. 2023. Ed Bice MEd, Kristine Galek PhD, Matthew Ward PhD
- Abdelhamid et al., 2016; Alagiakrishnan et al., 2013; Anderson et al., 2013; Bassis et al., 2015; Beck et al., 2017; Bilney et al., 2003; Campbell-Taylor, 2008; Feinberg et al., 1996; Foley et al., 2008; Greeganage et al., 2012; Hanson et al., 2011; Hines et al., 2010; Jones et al., 2016; Knuijt et al., 2011; Loeb et al., 2003; Painter et al., 2017; Sakashita et al., 2014; Speyer et al., 2010; Steele et al., 2015; Thomas, 2008; Vogel et al., 2015, Begum, 2010; Cichero, 2013; Mukand, 2003; Nadel, 1980; O'Keeffe, 2018; Swann et al., 2015; Hwang, 2014; Wotton, 2008

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Principles of Clinical Ethics and Their Application to Practice

"Ethics is an inherent and inseparable part of clinical medicine"

Decisions should:

1. Benefit the patient
2. Avoid or minimize harm
3. Respect the values and preferences of the patient.

4 principles of ethics

Beneficence – Nonmaleficence – Autonomy – Justice

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Principles of Clinical Ethics and Their Application to Practice

Beneficence

The obligation of physician to act for the benefit of the patient

This supports a number of moral rules to:

1) Protect and defend the rights of others
2) Prevent harm and remove conditions that will cause harm
3) Help persons with disabilities, and rescue persons in danger

"This principle calls for not just avoiding harm, but also to benefit patients and to promote their welfare."

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Consequences of Dysphagia

- Aspiration pneumonia – food/prandial, infected saliva, gastric stomach contents/vomit.
- Prevalence from food/liquid is only about 1-11%
- Feeding tubes do not prevent pneumonia
  - Increase pneumonia frequency from:

1.3% (major aspirators –oral intake to 4.4% (major aspirators – tube feeding)
(Feinberg et al., 1996; Robbins, 2001)

- The use of thickened liquids and altered diet textures alone will not prevent pneumonia
- Altered diet textures and thickened liquids have serious side effects that include malnutrition and dehydration aiding in the development of pneumonia & other iatrogenic health conditions

(Abdelhamid et al., 2016; Alagiakrishnan et al., 2013; Andersson et al., 2013; Bassis et al., 2015; Beck et al., 2017; Bilney et al., 2003; Campbell-Taylor, 2008; Feinberg et al., 1996; Foley et al., 2008; Greeganage et al., 2012; Hanson et al., 2011; Hines et al., 2010; Jones et al., 2016; Knuijt et al., 2011; Loeb et al., 2003; Painter et al., 2017; Sakashita et al., 2014; Speyer et al., 2010; Steele et al., 2015; Thomas, 2008; Vogel et al., 2015)

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Principles of Clinical Ethics and Their Application to Practice

Nonmaleficence

The obligation of a physician not to harm the patient.

This simply stated principle supports the moral rules to:

1) Do not kill 2) Do not cause pain or suffering
3) Do not incapacitate 4)Do not cause offense
5) Do not deprive others of the goods of life

Practical application:

To weigh the benefits against burdens of all interventions and treatments, To eschew those that are inappropriately burdensome To choose the best course of action for the patient.

"This is particularly important and pertinent in difficult end-of-life care decisions on withholding and withdrawing life-sustaining treatment, medically administered nutrition and hydration, and in pain and other symptom control."

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Consequences of Dysphagia

Known complications – *Iatrogenic*

- Malnutrition
  - *Dehydration, poor recovery from illness, debilitation, prone to infections*
- Dehydration
  - *Renal failure, constipation, UTI, impaired mental status, respiratory infection, hypotension, delirium, poor recovery from illness, fever*
- Interfere with medication absorption
- Slowed digestion/delayed gastric emptying – exacerbate reflux
- Increase economic cost – $2000-$3000+/yr for thickened liquids alone
- Significantly reduced quality of life – patients describe as "vile"& "awful."

(Begum, 2010; Fishgro, 2013; Mukand, 2003; Nadel, 1980; O'Keeffe, 2018; Swann et al., 2015; Hwang, 2014; Wotton, 2008)

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Principles of Clinical Ethics and Their Application to Practice

Autonomy

All persons have intrinsic and unconditional worth, and therefore, should have the power to make rational decisions and moral choices, and each should be allowed to exercise his or her capacity for self determination

This principle was affirmed by court decision

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body" –Justice Cardozo in 1914

How do we deal with this?

"The principle of autonomy does not extend to persons who lack the capacity (competence) to act autonomously; examples include infants and children and incompetence due to developmental, mental or physical disorder."

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Consequences of Dysphagia

"Modified diets are a more intrusive intervention than any medication and are widely used in the absence of a high-quality evidence base." – O'Keeffe, 2018

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Principles of Clinical Ethics and Their Application to Practice

Informed Consent

For a medical/surgical procedure or research, The patient or subject

1. Must be competent to understand and decide,
2. Receives a full disclosure,
3. Comprehends the disclosure,
4. Acts voluntarily,
5. Consents to the proposed action.

"Each one of the 4 principles of ethics is to be taken as a prima facie obligation that must be fulfilled, unless it conflicts, in a specific instance, with another principle."

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Principles of Clinical Ethics and Their Application to Practice

"One of the basic and not infrequent reasons for disagreement between physician and patient on treatment issues is their divergent views on goals of treatment."

As goals change in the course of disease, the physician must communicate with the patient in clear and straightforward language with the aim of defining the goal(s) of treatment under the changed circumstance

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Principles of Clinical Ethics and Their Application to Practice

Table 3. Physicians obligations

• Cure of disease when possible
• Maintenance or improvement of functional status and quality of life (relief of symptoms and suffering)
• Promotion of health and prevention of disease
• Prevention of untimely death
• Education and counseling of patients (condition and prognosis)
• Avoidance of harm to the patient in the course of care
• Providing relief and support near time of death (end-of-life care)

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How do WE stack up?

- Accuracy = Truth – Susan Langmore
- Assessment of oropharyngeal dysphagia at bedside is essentially a screen & over diagnosed ~70% of the time (Leder, 2002)
- The reason SASS provides a thorough & comprehensive assessment reviewing patient history, medications, prior level, analysis of 22 trials with imaging?
  a. To optimize the nutrition-hydration of the patient vs. focus on preventing PNA primarily
- 2009 SASS Data: <3% of patients were recommended thickened liquids & 75% of NPO patients were recommended an oral diet.
- 15 yrs later…

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How do WE stack up?

- 25 Skilled Nursing Facilities – (East, Middle, & West region of the US) retrograde review of 120 patients referred for FEES; including SASS FEES Data
- Why?
  a. Research shows inconsistency w/ assessing-treating dysphagia poses potential harm to patients.
- 67% on a modified diet or NPO did not have dysphagia.
- 33% of patients did not have dysphagia but were receiving therapy for dysphagia.
- 61% of patients with feeding tube had no dysphagia.
- 45% of NPO patients had an instrumental evaluation in their acute setting.
- Only 5% of NPO patients originally recommended NPO, remained NPO post FEES

Dysphagia & Diets in SNFs When Patient's Health Status Changes: The Role of Imaging Dec. 2023
Ed Bice MEd, Kristine Galek PhD, Matthew Ward PhD

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Ethics:
A Review of literature

Patient Wishes Before Risk

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Wishes Over Risks

- **Patient Wishes Before Risk**
  - "How do we honor patients' decisions about their swallowing treatment when they have dementia–and there's aspiration risk?"
  - by Elizabeth Thompson Beckley
  - The ASHA Leader 1 May 2017 Volume 22, Issue 5, Pages: 40 – 47
  - https://doi.org/10.1044/leader.FTR1.22052017.40

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Wishes Over Risks

Consider the Scenario:

A speech-language pathologist examines a person with dementia and finds that they aspirate on thin liquids, but if the liquid is thickened to a nectar consistency, they do not. The patient, however, refuses to drink the thickened liquids and becomes dehydrated. This raises the question: Is this really the most appropriate consistency for this person?

DISCUSSION!!!

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Wishes Over Risks

The Article Asks...

1. Are those patients capable of making an informed choice?
2. Who is liable for adverse outcomes based on that choice?

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Wishes Over Risks

What does the article say about this?

- Require Person Centered Care Practices
  - CMS says this will provide more safety for residents!
  - Step further, 2013 Provide better food choices
- Person Centered Care is complicated because…
  - LTC's consists of over 50% dementia or other cognitive difficulties

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Wishes Over Risks

What does the article say about this?

- SLP's may:
  - Have apprehension over being sued.
- That Fear over being held liable may override patient preferences and the effort it takes to determine those preferences

Lawsuits related to
swallowing treatments are rare

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Wishes Over Risks

What does the article say about this?

- It is often that very process to determine those preferences that is the care provider's best protection.
- The patient may not want to give up the enjoyment of eating or the social aspects of it.
- Ultimately!
  - "Dysphagia treatment needs to involve shared decision-making among patient, clinicians and, in many cases, patients' families."
  - That requires "a clear, deliberate process of open, ongoing communication and informed consent for treatment."

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Ethics: A Review of literature

Ethical Dilemmas in Providing Nutrition

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Ethical Dilemmas in Providing Nutrition

- **Ethical Dilemmas in Providing Nutrition**
  - By Michael E. Groher, Ph.D.
    - Department of Veterans Affairs Medical Center, New York, New York, USA
  - Dysphagia 5:102-109 (1990)

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Ethical Dilemmas in Providing Nutrition

- This paper asks…
  - Should nutritional support be provided or discontinued?
  - If it is to be provided, what route of feeding is in the patient's best interest?
  - Is the route acceptable to the patient and/or surrogate.

"These questions cross the intersection of individual and societal morals, ethics, and precedents in law."

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Ethical Dilemmas in Providing Nutrition

- **"Courts have upheld that a competent person maintains the right to refuse any medical treatment, including artificial feeding and this issue is not different than provisions for respiratory support."**
  - The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Deciding to forego life-sustaining treatment. Washington, D.C. : Government Printing Office, 1983
  - The American Medical Association: Statement of the Council on Ethical and Judicial Affairs: Withholding or with- drawing life prolonging medical treatment. Chicago, Illinois, 1986
  - In re: Rodas, No. 86PR 139 (Colo. Dist. Ct. Mesa County Jan. 22, 1987)

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Ethical Dilemmas in Providing Nutrition

- Patients who fail to or refuse PO intake should undergo a complete and thorough evaluation, including:
  - "Imaging with a variety of textures, bolus sizes, and consistencies."
    - Jones B, Donner MW: How I do it: examination of the patient with dysphagia. Radiology167:319-326, 1988
  - "Physical inspection of the mouth, pharynx, upper airway, and esophagus"
  - "Dynamic/still radiographic recording of the entire GI tract"
- The evaluation should take into account the patient's prognosis
  - "If the patient feels that the health care team's wishes run contrary to his or her own, he or she may choose to execute a living will."

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Ethical Dilemmas in Providing Nutrition

- The most common argument for alternative methods of nutrition, hydration and medication administration:
  - "It may benefit the patient by reversing malnutrition and prolonging life"

"Neither of these assertions have been supported scientifically for patients in a chronic care setting."

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Ethical Dilemmas in Providing Nutrition

- Insertion of a feeding tube in chronically ill elderly individuals did not prevent death, but seemed only to defer it.
  - Quill TE: Nasogastric feeding tubes in a group of chronically ill elderly patients in a community hospital. Arch Intern Med 149:1937–1941, 1989
- However:
  - There are well established benefits for younger and older patients with reversible illness.

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Ethical Dilemmas in Providing Nutrition

"Guidelines should be framed around the focal ethical principle that the patient has a basic right to determine the course of his or her medical care, and that the patient has the right to be able to avoid care that he or she sees as painful, meaningless, or undignified."

"It is imperative that the guidelines reflect the fact that this discussion be documented in the medical record"

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Ethics:
A Review of literature

Promoting Shared Decision-Making in Rehabilitation

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Promoting Shared Decision – Making in Rehabilitation

- **Promoting Shared Decision-Making in Rehabilitation: Development of Framework for Situations When Patients with Dysphagia Refuse Diet Modifications Recommended by the Treating Team**
  - By Franceen Kaizer et. al.
  - Dysphagia 27:81–87 (2012)

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Promoting Shared Decision – Making in Rehabilitation

What's the article about?

- We need an algorithm to promote shared decision making with dysphagia.
  - It needs to be "clear, concise, readily accessible, and relevant for the clinical teams."
  - It should facilitate team discussions in a structured and guided manner, promote improved dysphagia management, enhance support amongst the team, and promote effective communication

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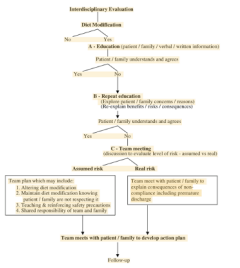
Promoting Shared Decision – Making in Rehabilitation



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Ethics: What's already been published

Consent, Refusal, and Waivers

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Consent, Refusal and Waivers in Patient – Centered Dysphagia Care

- **Consent, Refusal, and Waivers in Patient–Centered Dysphagia Care: Using Law, Ethics, and Evidence to Guide Clinical Practice**
  - By Jennifer Horner, Maria Modayil, Laura Roche Chapman and An Dinha
  - American Journal of Speech–Language Pathology (AJSLP) November 2016 Volume 25 Pages 453–469

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Consent, Refusal and Waivers in Patient –Centered Dysphagia Care

The short of the article?

As Speech – Language Pathologists we "have fiduciary and other ethical and legal obligations to patients."

"Waivers try to shift liability for substandard care from health care providers to patients"

"Courts usually find waivers of liability in the medical context unenforceable as a matter of public policy."

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Ethics:
A Review of literature

Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Meaghann S. Weaver MD, PhD, MPH , Cynthia M.A. Geppert MD, MA, MPH, MSBE, DPS, MSJ

Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat, Journal of Pain and Symptom Management (2022)

doi: https://doi.org/10.1016/j.jpainsymman.2022.10.007

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Case Description

Mr. J is an 82-year-old retired farmer with a preexisting diagnosis of moderate vascular
dementia who recently suffered a stroke resulting in a new diagnosis of dysphagia and a loss of complex decision-making capacity. He is admitted to a hospital rehabilitation unit for a course of speech, physical and occupational therapy. His wife, Mrs. J, is his surrogate and has made clear that the couple's shared goals of care are for him to regain as much function as possible so he can return to his own home. Consonant with those goals, his medical record documents preference for full resuscitation. A swallowing study determined he is more likely to choke on thin liquids.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Based on this evaluation:

1. Recommended Mr. J's diet be restricted to a soft pureed texture.
   a. Mr. J has started each day since he began working on the farm at 14 with eggs, bacon, and toast.
   b. He expresses anger and frustration toward the staff at the skilled nursing facility for "giving me gruel for breakfast."
   c. He becomes frustrated, refusing to eat the puree and once even knocking the bowl off the table.
2. Worried about her husband's behavior, Mr. J's wife started to bring a daily breakfast sandwich which she cuts into pieces for him.
3. Mr. J's bedside nurse is concerned that Mr. J "sputters and coughs" even with small bites and worries that allowing Mr. J to eat it places him at risk of aspiration resulting in pneumonia or even asphyxiation resulting in a cardiopulmonary event.
4. The nurse was distressed because she had obtained a large bolus of pocketed food after a finger sweep the other morning after breakfast.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

In response to the nurse's concerns, Mr. J's wife says she cannot bear to see him upset about not getting to eat as food has always been something he enjoyed.

The nurse speaks to her nurse manager who says:
If Mrs. J wants to disregard the dietary recommendations, then she must "change her husband's resuscitation preference as staff cannot be expected to initiate CPR in the rehabilitation unit any time Mr. J chokes."

Mrs. J feels distressed she must make such a difficult choice between two of her husband's preferences and asks to speak to the unit chaplain who recommends an ethics consultation.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Defining Issues

- This case represents a values conflict between the staff's professional obligation to protect Mr. J from harm and their duty to respect the surrogate's preferences to honor the desires of the patient to eat.
  - Data on the benefits of a soft pureed diet for patients with dementia remains "soft" even as the diet change imposes a negative impact on quality of life.
- A shared decision-making approach may help to address the challenges of supporting autonomy, making Mr. J's rehabilitation a more positive experience, clarifying the gaps in evidence of harm, and reducing the risk associated with eating.

A shared decision-making approach entails sharing the best available evidence in a way that supports the consideration of options to then achieve an informed preference.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Ethical Analyses

The case reveals a values conflict between:

A. Prioritizing the competing values of doing no harm and
B. Respecting the surrogate's preferences and values.

As a Therapist and Health Care Provider

1. A robust informed consent conversation should occur. This should include informing the patient and surrogate
   a. Potential risks
   b. Offering alternatives to a regular diet
   c. Education regarding rationale for dietary modifications

"Informed consent engages a summary of risk-benefit ratio"

- Allowance of a regular diet should not be contingent upon Mrs. J changing her husband's medical order to DNR as this would represent coercion.
- Efforts should then be made to agree on a diet order that balances Mr. J's safety and food preferences.
- The patient's surrogate may choose a diet that increases his risk of aspiration or choking based on her understanding of his lifelong values and his prioritization of quality of life.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Information Gathering

- Ensure there has been due clinical diligence in the form of an actual swallow study
  - This will identify the physiologic risk of a regular diet

Things to Remember

- Evidence-base for a modified diet is lacking but it may lead to dehydration or malnutrition.
- A large retrospective study of patient with documented aspiration found no difference in the time to first pulmonary event (pneumonia, pneumatosis, or pulmonary infection) or survival between those allocated to modified texture diets and NPO status.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Clarification of Surrogate and Family Caregiver Role

"A meta-analysis suggests over 70% of caregivers of adults with dysphagia experience some degree of burden."

"Personal and professional caregivers may experience fear that the individual with dysphagia will choke, and feel frustration or guilt at the inability to adequately maintain the patient's weight or hydration."

"Despite the way dysphagia alters family mealtime, family caregivers often desire to maintain dietary options to honor their loved one's preferences and to cling to prior mealtime normalcy."

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Patient Perspective

A patient lacking the ability to recognize aspiration as a feeding risk may be the same patient who then lacks the ability to understand the treatment team's reasons for withholding desired foods and fluids.

This may result in increased anxiety, anger and lead to distrust of the care team that interferes with other aspects of care like not participating in therapy.

Expecting a patient with dementia to accept without protest a food restriction when the patient experiences hunger or food cravings from that restriction as a deprivation or even punishment seems unrealistic and even inhumane.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Retaining Connection and Culture

- Due to the intimate interplay between food and personal, familial, and communal memory the idea of retaining access to favorite foods and liquids may amount to retaining a sense of connection not only to other people but also to oneself.
- The human brain maintains synaptic engagement with personal memories through taste, particularly for patients with dementia.

Proportionality, Pleasure, and Prognosis

- Qualitative interviews with patients with dysphagia revealed food access expanded perception of quality of life
- Whereas denying access to food negatively impacted self-perceived quality of life
- The ethical principle of proportionality acknowledges that sustained oral intake should be proportional to the good that can be achieved and the harm that may be caused

"Sustaining oral intake may help to further sustain the patient's sense of daily enjoyment and identity beyond diagnosis or illness."

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Staff Perspective

- The nurse manager believed that nursing professional integrity included protecting Mr. J from harm even if this meant denying his access to his preferred foods contrary to the wishes of his surrogate.
- **An important role in the ethics consult is to recognize what may be a real fear for staff members (in this case, a respiratory arrest) and to provide empathetic education.**
- The ethical focus should then be on the duty of all staff to provide patient-centered care in a way that maximizes swallowing safety to the extent possible while also honoring food preferences
- Bedside staff experiencing moral distress from caring for patients with an increased risk of choking should be offered ongoing education and support.
- Staff who after these interventions, feel that participating in Mr. Js' feeding contravenes their moral beliefs, may need to be reassigned or recused from care in accordance with the facility policy on conscientious objection.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Conclusion of the Case

- The ethics consultants advised the medical team to discuss and carefully document the discussion with Mr. and Mrs. J about the risks of declining the modified dietary recommendations as well as risk mitigation strategies
- The ethics consultants along with the primary treatment team met with rehabilitation unit staff to explain their analysis and recommendations, respond to concerns from staff about the plan, and provide resources for care providers wanting to learn more about the ethical issues.

Duty to Plan

- We should consider proactive approaches to patient's values and preferences for food and liquid intake early in a disease course rather than waiting until loss of swallowing function
- Clarify the priority a patient places on maintaining a regular diet and the level of risk a patient is willing to accept over time while documenting wishes to then inform care plans.
- Goals of care documentation and advance directive forms should include not only artificial nutrition and hydration preferences but also oral feed preferences.

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Sometimes a Difficult Decision to Swallow: Ethical Dilemmas When Patients with Dysphagia who Lack Capacity Want to Eat

Feeding Not Fatalism

- Patients with dysphagia and their surrogates have the right to choose if the pleasure and relief they receive from PO intake outweigh risks.
- Upholding patient-centric care regarding dysphagia management requires coordinating care among all disciplines with ongoing and clear communication with bedside staff.

Final Thoughts

"Due diligence and respect for patient dignity warrants attentiveness to maximizing both the pleasure of feeds for patients and the safety of feeds through staff and patient education and inclusion of swallow specialists."

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