Autonomy at the Table:
Case Studies in Diet Texture Modification

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1

Disclosures

- Financial:
  - Owner, North Louisiana Swallow Solutions (receives salary, ownership interest)
  - Faculty, McDaniel College (receives salary)
- Non-Financial:
  - President & Co-founder, Dysphagia Outreach Project
  - Doctoral Candidate, Baylor University
  - Member of Simucase Advisory Board
  - 2024-2025 Treasurer, Council for State Association Presidents (CSAP)
  - Past President, Louisiana Speech-Language Hearing Association (LSHA)

2

Time-Ordered Agenda

0-5 Minutes	Introduction
5-15 Minutes	Foundations of Informed Consent
15-25 Minutes	Framework for IC Conversations
25-35 Minutes	Informed Consent Tools & Resources
35-75 Minutes	Case Studies in Informed Consent
75-90 Minutes	Q&A

3

Learner Objectives

1. Participants will be able to identify 3 essential components of informed consent discussions related to diet texture modifications.
2. Participants will be able to apply an informed consent framework to real-world scenarios using case studies.
3. Participants will be able to utilize three tools to facilitate the informed consent process.

4

Disclaimer

I am not a lawyer. The information contained within this webinar is NOT to be construed as a replacement for legal advice.

Prior to implementation of changes in your medical setting that may have legal ramifications, I STRONGLY recommend that you or your facility consult with an attorney who is experienced in healthcare law.

Laws vary by state or country. It is important to be knowledgeable about the laws regarding documentation of informed consent that may be specific to your state (or country).

5

Notice

The scope of the work presented in this webinar is intended for use with the ADULT DYSPHAGIA population.

Materials and research provided in this webinar was NOT designed for the pediatric or adolescent population.

6

Notice

Please only download any resources provided in this webinar directly from the Dysphagia Outreach Project website. This is for quality control and to be sure we can notify you if we make changes to the handouts.

Please **do not** reproduce any slides or handouts without my permission. Changing certain handouts may impact their legal validity.

7

Dysphagia: A Legal Definition

"...the impairment of the emotional, cognitive, sensory, and/or motor acts involved with transferring a substance from the mouth to stomach, resulting in failure to maintain hydration and nutrition, and posing a risk of choking and aspiration."

(Tanner, 2010, p. 42)

8

Texture-Modified Diets in Clinical Practice

9

TMDs in Clinical Practice

Oropharyngeal dysphagia (OD) affects ~6% of adults and nearly 50% of long-term care residents

(Hong et al., 2024; Rajati et al., 2022; Rivelsrud et al., 2023)

10

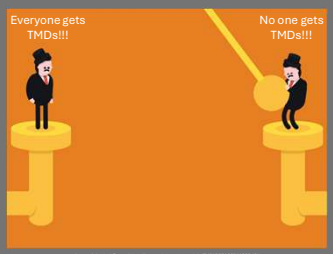
TMDs in Clinical Practice

Texture-Modified Diets (TMDs) and feeding tubes are widely used tools for preventing aspiration and choking

(McCurtin et al., 2024)

11

TMDs in Clinical Practice



12

TMDs in Clinical Practice

13

TMDs in Clinical Practice

The evolution of TMD use is reflected in advances in safety, ethics, and patient autonomy

(Atkinson, 2022; O'Keeffe et al., 2023)

14

Risks & Benefits of Texture-Modified Diets

15

Risks & Benefits of TMD

- Thes charts are organized by risks and benefits of texture-modified liquids and solids.
- Since research in this area is constantly growing, this is intended to be a living document.
- I'll update as new evidence emerges or articles are brought to my attention.
- Be sure to download it directly from the Dysphagia Outreach Project website so we can notify you when updates are made.
  - We're not going to spam you.

16

Handouts for Risks & Benefits of Texture Modified Diets

Available FREE at
www.dysphagiaoutreach.org/shop

17

Tour of Handout for Risks & Benefits of Texture Modified Diets

Available FREE at
www.dysphagiaoutreach.org/shop

18

Principles of Biomedical Ethics: A Brief Review

19

Principles of Biomedical Ethics

Autonomy

Beneficence

Nonmaleficence

Justice

(Beauchamp & Childress, 2001)

20

Principles of Biomedical Ethics

Autonomy

- "Self rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice." (p. 58)
- Essential conditions for autonomy:
  1. Liberty – independence from controlling influences
  2. Agency – capacity for intentional action

(Beauchamp & Childress, 2001)

21

Principles of Biomedical Ethics

Beneficence

- "Morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare. (p. 165)
- Two types of beneficence:
  1. Positive beneficence – agents must provide benefits
  2. Utility – agents must balance benefits and drawbacks to produce the best overall results

(Beauchamp & Childress, 2001, p. 165)

22

Principles of Biomedical Ethics

Nonmaleficence

- "In medical ethics it has been closely associated with the maxim *Primum non nocere*: 'Above all[or first] do no harm'" (p. 113)
- Examples of nonmaleficence include: (p. 117)
  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

(Beauchamp & Childress, 2001)

23

Principles of Biomedical Ethics

Nonmaleficence

- Doctrine of Double Effect:
  - Understanding that a treatment may have BOTH positive and negative effects
- "[W]e justifiably allow a harmful effect only if we will probably bring about a proportionately weighty good one."

(Beauchamp & Childress, 2001, p. 132)

24

Principles of Biomedical Ethics

Justice

- The right to a decent minimum of health care
- In the realm of dysphagia management, this means equitable access to evidence-based therapy interventions (Leslie et al., 2020) as well as access to necessary supplies (such as thickeners or adaptive equipment) to facilitate those interventions.

(Beauchamp & Childress, 2001)

25

What is Shared Decision-Making?

26

Shared Decision Making (SDM)

"[A]n approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences."

(Elwyn et al., 2010)

27

Shared Decision-Making (SDM)

- SDM = collaborative process between provider and patient
- Emphasizes patient values, preferences, and autonomy
- Informed consent is a minimum standard, not the goal
- True SDM is ongoing, not one-time

28

Coercive SDM

- Provider nudges patient toward a "preferred" option
- Language or tone may imply risk, guilt, or urgency
- Power imbalance is unaddressed
- Consent may be technically obtained — but not freely given

29

Characteristics of Non-Coercive SDM

- Presents risks, benefits, and uncertainties neutrally
- Encourages questions, reflection, and discussion
- Respects patient autonomy.
  - Even if choice differs from provider's preference
- Builds trust and long-term rapport

30

Times When SDM May Not Be Required

- Emergency medical decisions need to be made to save a life or prevent injury
- The patient (or representative) cannot collaborate in the process
- A Living Will or Durable Power of Attorney document is in place which establishes the patient's choices
- There is no decision to be made

(Theriault et al., 2020)

31

Why It Matters in TMD Recommendation?

- Dysphagia care often involves emotionally and functionally complex decisions
- Clients and families may feel pressure to agree with provider recommendations
- Autonomy and dignity should guide our communication
- Ethical SDM = clinical expertise + client values and lived experiences

32

Informed Consent: A Vital Part of Shared Decision-Making

33

Patient Self-Determination Act of 1990

Defines patient rights, including:

- The right to facilitate their own health care decisions
- The right to accept or refuse medical treatment
- The right to make an advance health care directive

(Kelley, 1995)

34

Patient Self-Determination Act of 1990

This legislation gives our patients the right to refuse treatment based on their personal values and beliefs

As a result, we are **legally** obligated to consider the patient's wishes when making medical recommendations and document accordingly when they refuse

(Horner, et al., 2016)

35

Patient Self-Determination Act of 1990

- Facilities and providers must inquire as to whether the patient already has an advance health care directive and make note of this in their medical records.
- Facilities and providers must provide education to their staff and affiliates about advance health care directives.
- Health care providers are not allowed to discriminately admit or treat patients based on whether or not they have an advance health care directive.

(Horner, et al., 2016; Kelley, 1995)

36

Essential Components of Informed Consent

37

Essential Components of Informed Consent

Capacity Assessment

Disclosure of Information

Voluntariness of Decision

Demonstration of Understanding

38

Essential Components of Informed Consent

- Yes, there's a FREE handout for that too.
- Visit: www.dysphagiaoutreach.org/shop for the Informed Consent Process Checklist, Capacity Assessment Review, and More

39

How to Discuss Informed Consent with Patients & Staff

40

Discussing Informed Consent

Tip #1:
It's a menu, not a mandate.

41

Discussing Informed Consent

Tip #2:
Avoid coercive language.

42

Discussing Informed Consent

Tip #3:
Use visual aids.

43

Discussing Informed Consent

Tip #4:
Talk TO the patient, event when family is present.

44

Discussing Informed Consent

Tip #5:
Use teach-back often.

45

Discussing Informed Consent

Tip #6:

Failure to give them an option because YOU don't like it is failure to give informed consent.

46

Discussing Informed Consent

Tip #7:

Separate your *recommendation* from their *decision*.

47

Discussing Informed Consent

Tip #8:

Ensure they know they can change their mind whenever they want.

48

Discussing Informed Consent

Tip #9:
Don't rush because *you* are uncomfortable.

49

Discussing Informed Consent

Tip #10:
Document the *conversation*, not just the diet.

50

Case Discussions

51

Case 1 Description

- **Client age range & care setting:**
  - Mid 60s female
  - Acute care hospital, neuro ICU unit
- **Primary diagnosis & relevant medical history:**
  - Admitted for left hemisphere hemorrhagic stroke with craniotomy. Was intubated for 5 days.
  - Mild expressive aphasia; fluctuating attention/alertness but follows 1-2 step commands
  - Hypertension, hyperlipidemia, recent breast cancer w/mastectomy & radiation
  - No prior history of dysphagia
- **Swallowing concern(s) & current diet recommendation(s):**
  - Post-extubation FEES shows frank, silent aspiration with thin liquids by cup and straw, silent aspiration with nectar thick by straw, safe/efficient with nectar thick by cup, and very poor mastication
  - Oral phase inefficiency & anterior loss with solid textures
  - Right true vocal fold paresis noted
- **Recommended diet:**
  - IDDSI Level 5 (minced & moist) solids and Level 2 (mildly thick) liquids

52

Case 1 Description

- **Key risk factors, preferences, or values influencing decision-making**
  - Patient communicates frustration with modified textures, stating (with support):
    - "This food tastes wrong. I want real food."
  - Spouse is highly anxious and repeatedly requests the "safest possible diet"
  - Family expresses fear of aspiration and having her get sicker
  - Spouse described food enjoyment as a major quality-of-life factor for his wife, who loved to cook for others at her church. Food is a large part of her life.
  - The patient did not have a living will. She is full code.

53

Case 1 Description

- **Conflict, uncertainty, or SDM challenge**
  - Questionable decision-making capacity due to aphasia and cognitive fatigue
  - Patient's health status remains quite fragile, with the patient being in the ICU
  - Family's risk tolerance is significantly lower than the patient's expressed values
  - Care team defaults to "safer diet" language without clearly discussing trade-offs, uncertainty, or evidence limitations
  - Unclear how much the patient understands versus how much the family is driving the decision
  - Challenge in distinguishing best interest decisions from risk-averse substitutions for consent

54

Case 1 Discussion

1. Capacity

55

Case 1 Discussion

1. Capacity
2. Disclosure of Information

56

Case 1 Discussion

1. Capacity
2. Disclosure of Information
3. Voluntariness

57

Case 1 Discussion

1. Capacity
2. Disclosure of Information
3. Voluntariness
4. Demonstration of Understanding

58

Let's Discuss Cases Together!

59

Case 2 Description

- **Client age range & care setting**
  - Late 70s male
  - Acute care hospital, med/surg floor
- **Primary diagnosis & relevant medical history**
  - Admitted for bilateral pneumonia
  - History of right CVA (3 years prior) with mild residual left facial weakness & history of dysphagia with aspiration
  - COPD, atrial fibrillation (on anticoagulation), type 2 diabetes, and is edentulous
  - Lives independently; cognitively intact and oriented ×4
- **Swallowing concern(s) & current diet recommendation(s)**
  - Bedside swallow evaluation reveals overt coughing with thin liquids, & poor oral control
  - Instrumental study pending radiology scheduling
- **Recommended diet:**
  - IDDSI Level 4 (puree) solids and thin water only until imaging is obtained. Recommend meds whole in puree.

60

Case 2 Description

- **Key risk factors, preferences, or values influencing decision-making:**
  - Recent pneumonia raises concern for aspiration-related complications
  - Patient strongly values independence and quality of life, stating:
    - "I've eaten regular food my whole life and I'm not giving that up now."
  - Expresses dislike of thickened liquids and texture-modified solids based on prior experience after stroke
  - Prioritizes returning home quickly and maintaining normal routines
  - The patient does not have a living will, but is DNI/DNR.

61

Case 2 Description

- **Conflict, uncertainty, or SDM challenge**
  - Medical team emphasizes aspiration risk and pneumonia recurrence
  - SLP is concerned about liability and patient safety without instrumental data
  - Patient appears to understand risks but questions why he needs to eat "that dog food"
  - Tension between temporary "medical necessity" framing and the patient's expressed preferences

62

Case 2 Discussion

1. Capacity
2. Disclosure of Information
3. Voluntariness
4. Demonstration of Understanding

63

Case 3 Description

- **Client age range & care setting**
  - Mid 90s female
  - Admitted back to skilled nursing facility after a prolonged hospital stay, where a feeding tube was placed due to patient not being alert enough to eat
- **Primary diagnosis & relevant medical history**
  - Long-term resident of the SNF
  - PMHX includes: metabolic encephalopathy, UTI, sepsis, advanced dementia, severe dysphagia, gastrostomy status, pressure ulcers, DMII, protein calorie malnutrition, moderate hearing loss, blindness
  - Moderate-severe cognitive impairment was noted with patient inconsistently following 1-step directions with repetition
- **Swallowing concern(s) & current diet recommendation(s)**
  - FEES revealed silent aspiration of secretions and frank, silent aspiration with thin, nectar, and puree. The study was terminated after meeting "bail out" criteria.
- **Recommended diet:**
  - NPO with ice chips. Oral suctioning for secretion management and oral care. Alternative nutrition/hydration.

64

Case 3 Description

- **Key risk factors, preferences, or values influencing decision-making:**
  - The patient was noted to have oral thrush
  - Tube feeding has resulted in the patient having nausea/vomiting, and diarrhea
  - During the FEES, the patient exhibited reluctance to engage in oral intake, stating "I'm not hungry" and "just leave me alone – I'm tired"
  - Director of rehab, director of nursing, and Nurse Practitioner recommended hospice or palliative care, as the patient cannot tolerate skilled rehab
  - The patient's family expressed that they want all interventions for their family's matriarch "so she can strengthen up and be her old self again". They refused hospice or palliative care and want to continue PEG tube use.

65

Case 3 Description

- **Conflict, uncertainty, or SDM challenge**
  - Medical team is concerned that patient has a poor prognosis due to her advanced age and significant debility.
  - The family feels like the patient has the potential to eat, walk, and socialize again if therapy works with her.
  - SLP is concerned about the liability of attempting aggressive dysphagia therapy with this patient
  - The MPOA is the daughter, who lives out of state

66

Case 3 Discussion

1. Capacity
2. Disclosure of Information
3. Voluntariness
4. Demonstration of Understanding

67

Let's Hear YOUR Cases!

68

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69

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70

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71

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72

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73