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Ethical and Legal Issues in Dysphagia Management - Part 2

Denise Dougherty, MA, SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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Ethical and Legal Issues in Dysphagia Management – Part 2

Denise Dougherty, MA, CCC-SLP

CONTINUED

Disclosures

Financial Disclosures

- Private Practice
- Honorarium SpeechPathology.com

Non-financial Disclosures

- Governing Body – Anew Home Health
- Quality Insights of Pennsylvania

CONTINUED

- Speech-language pathologist involved in dysphagia evaluation and therapy face many challenges including how to handle a patient/family that does not agree with the recommendations.
- This seminar will cover ethical and legal considerations we face in working with this type of client including ethical concerns with waivers and patient centered plan of care.

CONTINUED

Learning Outcomes

After this course, participants will be able to:

- Describe the differences between skilled and unskilled care.
- Describe how to develop a plan of care that facilitates safe swallowing on the highest level appropriate diet.
- Explain how to honor resident choices and mitigate risks when patients choose to opt out of the recommended dysphagia plan of care.

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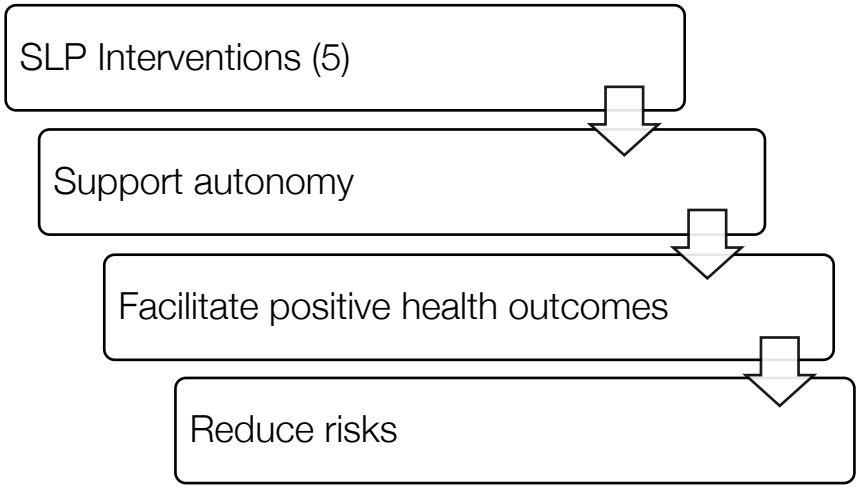


Should you treat? (27)

- Reasonable: appropriate amount, frequency, duration of tx in accordance w/ accepted standards of practice
- Necessary: appropriate tx for diagnosis & condition
- Specific: targeted to particular treatment goals
- Effective: expected to yield improvement in reasonable time
- Skilled: requires knowledge, skills, judgment of SLP, that is complex & sophisticated

Autonomy

SLPs duty to ensure patients understand:

- nature
- costs
- benefits of different approaches
- including that of no treatment (12)

- Person presumed competent unless shown by evidence not to be competent
- Irrationality of decision does not justify conclusion pt. is incompetent in legal sense
- Law protects right to make own decision to accept/reject treatment, whether that decision is wise or unwise (20) (21)

Decision Making Capacity

SLPs can contribute to clinical capacity assessment (20)

MacArthur Competence Assessment Tool-Treatment (MacCAT-T) guides providers through detailed dialogue w/ pt: addresses 4 functional abilities of decision making incorporating process of informed consent. Uses pt's own unique decision to be made, rather than hypothetical situation. (13)

Ethically & Legally Defensible Standards for Care (20)

- Education about risks is important!
- Could help refute later claim by pt. that SLP was negligent in failing to properly inform him

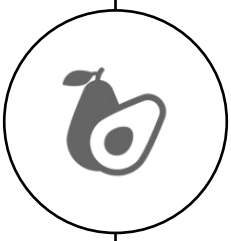
- Beneficence - requires SLPs to think beyond short-term & specific intervention for a small aspect of patient's condition.
  - Chin tuck w/ each swallow removes harm but does it do good if pt. avoids social events because they're embarrassed/won't use it? (12)
  - Waste what little energy pt. has doing a strategy - less energy left for chew/swallow?
  - With constant cueing for strategy, risk of patient becoming combative?

Nonmaleficence— would never deliberately do harm? Good evidence that altered diets result in dehydration and malnutrition

Reducing aspiration risk w/ thickened liquids following VFSS (good evidence) is not appropriate if pt. gets dehydrated d/t refusing to drink thickened liquids

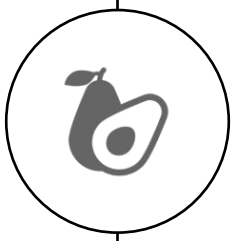
Justice rests upon what people need. ASHA supports this w/ Principle I Rule I of the Code of Ethics (12)

- Balance duty of pt. benefit vs. obligations to minimize unnecessary harm and uphold autonomy
- Prevention of harm weighs heavily in intervention planning & management
- Harm minimization approaches
  - modified diet textures
  - thickened liquids
  - avoidance of unsafe foods/liquids
  - enteral feeding for pts. w/ severely impaired oral/pharyngeal swallow functions (5)



Ethical considerations of texture of diet receive less attention

- Pts. attach strong values to eating/drinking
- Conflict when preferred or culturally significant foods become risky
- Importance of retaining individual's food choices plus health benefits assoc. w/ exercising food preferences (5)



Eating

- Alters mood & emotional predisposition, reducing irritability, increasing calmness, positive effect
- Positive effects depend on meal size, habits, expectations & needs
- Presenting "wrong" food or meal time experience negatively affect mood when adult is experiencing physical, emotional distress during acute or chronic illness (5)

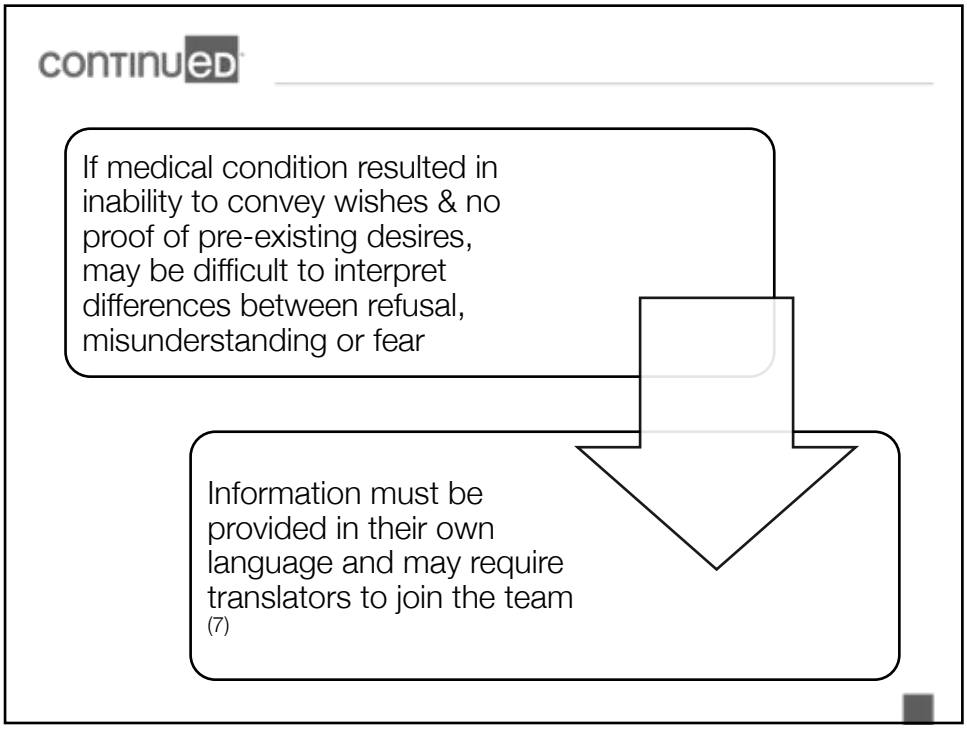
CONTINUED

Food preferences

- Signatures of personal & cultural identity, group membership, influenced by gender w/ specific foods assoc. w/ masculine or feminine roles, community, meat eating or vegetarian cultures
- Links between food preferences, culture and individual/group identity have ethical implications
- Dietary restrictions may challenge professional relationships, reduce pt. compliance
- Impacts of limiting food preferences are important consideration for adult w/ dysphagia (5)

CONTINUED

- Must look at pts values, attitudes re: food preferences
- Negative attitudes re: textured modified meals especially if friends present at meals
- Modified textures may be seen as sign of weakness – especially w male pts.
- Re-education may not result in agreement between pt., family, caregivers
  - Conflict w/ upholding pts. right to make informed choice vs. responsibilities placed on family, spouse to purchase/prepare safe vs. risky meals (5)



Dysphagia treatment w/ artificial hydration/nutrition is accepted medical intervention

- Enteral feeding provides calories, frees time, improves QOL when feeding is a chore/takes too much time/energy
- Is intervention w parenteral/enteral nutrition appropriate?
- Legitimately be withheld if risks, judged according to pts values, outweigh benefits
- Applies to known or documented values – frequently not the case! (7)

CONTINUED

Importance of Culture & Religion re: Recommendations

- Handbook of Patients' Spiritual and Cultural Values for Health Care Professionals – HealthCare Chaplaincy – Updated March 2013
- Consult this resource!

CONTINUED

- Pts. have right to receive info about benefits, risks of harm, probability & magnitude of possible harm assoc. w/ recommended treatment <u>&</u> reasonable alternative treatments before deciding to choose/refuse recommended treatment
- <u>Whether or not medical practitioners agree the decision is wise or unwise, or rational or irrational</u> (20)

Strategies (20)

Engage and educate	Pts. during informed consent process using creative multimodality and individualized approaches
Facilitate	Shared decision making between pt. and multidisciplinary medical team
Judiciously Apply	Published clinical evidence
Integrate	Knowledge of ethics, law and public policy into daily practices

ASHA's (2016) Code of Ethics

- Principe of Ethics 1
- "to hold paramount the welfare of persons served professionally both empowers and obligates SLPs to avoid both positive and negative or assurance and avoidance defensive practices and to advocate for their patients" (20)

If relevant information needed for informed, autonomous decision was adequately disclosed, can we accurately label pt. “noncompliant” if they chose to refuse?????

To effectively participate in informed consent process, SLP should be equipped w/ relevant, current field knowledge regarding decision to be made (13)

Comfort feeding (28)

Continued attempts w/ careful hand feeding & stopping point if pt. appears distressed

Feedings are goal oriented to provide comfort & aren’t invasive compared w/ tube feeding

Continued interaction for meticulous mouth care, socialization, therapeutic touch w/ pt., not just feeding attempts

PEG and Advanced Dementia Pt.

American Geriatrics Society published formal position in 2014

- Feeding-tube use associated with:
  - increased risk for agitation
  - use of physical/chemical restraints
  - tube-related complications
  - development of new pressure ulcers

Careful hand feeding judged to be at least as good as enteral feeding when it came to survival, aspiration pneumonia, functional status, and comfort. (13)

End of Life

- Not unusual for pts. to stop eating, drinking
- Right to refuse is no different than right to refuse other forms of treatment, intervention
- Factors influencing reduced food intake in elderly -
  - Ethnicity, geographical area, living alone, health problems, mobility, age, difficulty swallowing, loss of appetite
  - Instances where nutrition does not add to comfort of pt.
- Further intervention provides no benefit, is futile, becomes unethical or causes distress to pt. and caregivers (7)

SLPs

- May adopt procedures d/t inexperience or institutional practices:
  - Without knowing the current literature
  - Uncertain how to apply current evidence
  - Automatically apply established practice protocols rather than tailoring them to individual patients
  - Lack a full appreciation of their ethical and legal responsibilities (16)

SLPs (20)

- Feel they are under obligation to follow waiver practice of their employers

- Adopt defensive practices using waivers of liability EVEN if they do not fully understand legal significance of waivers in clinical settings

Waivers and Courts

Unenforceable when they are against public policy of holding health professionals responsible for care they provide & for impropriety of shifting risk to pt. who is less knowledgeable, more vulnerable & not in a position to manage or avoid it

Tunkl factors influence many jurisdictions to deem waivers of liability unenforceable in the medical context (20)

Immunize professional from his/her own carelessness by asking pt. to assume the risk of substandard care

Tunkl Factors (20)

Medical care is a matter of public interest and concern therefore is suitable for public regulation

Members of the public need health care – need arises out of practical necessity not choice

Service provider offers specific types of health care to whoever needs it

Tunkl Factors (20)

Service provider has a "decisive advantage of bargaining strength over the person seeking the service

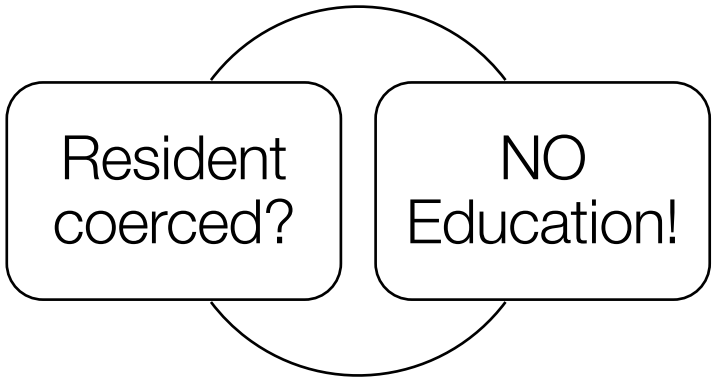
When service provider presents waiver of liability to pt. there is no room for negation – take or leave it basis

Party signing waiver places himself/herself "under the control of" the service provider and subjects himself/herself "to the risk of carelessness" by the service provider

Waivers (20)

- Standard of care is common law and **cannot be modified by contract**
- Undermine relationship of trust that is essential to pt. – practitioner relationship by placing professional's interests above best interest of pt. – **violation of ASHA first principle**

Waivers



Waivers
Not Enforceable Contract! (20)

1. Parties don't have equal bargaining strength
   - Pt. has limited knowledge of dysphagia & not in position to suggest changes, modifications to POC

2. SLP states signing waiver is condition to receive thin liquids
   - "contract" becomes "take it or leave it" agreement

CONTINUED

Waivers
Not Enforceable Contract (20)

3. Release is ambiguous
   - Promise not to sue for current existing claims OR promise not to sue for claims in the future?

4. Legal contract includes something of value from both parties
   - Pt. gives up legal right to sue to affirm his independent right to refuse medical recommendation; facility gave up nothing
   - Facility gained something of great value – agreement not to bring legal action

CONTINUED

Shared Decision Making Algorithm

1. Education
2. Repeat Education

- Address noncompliance w reeducation
- Explore pt./family concerns & reasons behind decisions to refuse recommended diets
- Challenges in community setting
  - Time, logistics required for education w/ caregivers employed fulltime
  - Pts. communication may be impacted for intelligibility which affects ability to express opinions
  - Complexity of caregivers relationships, who prepares meals – family, spouse/significant other & conflict between children, spouse, significant other (5)

Shared Decision Making Algorithm

3. Team Meeting – healthcare team & family

- SLP has leadership role
- Distinguish risks w clinical data, evidence vs attitudes, beliefs
- Risks: independence & QOL, safety, economic risks
- Explain diagnostic info, potential risks assoc. w/ refusal to accept modified diet, intervention options
- Potential negative outcome - hospital readmission (5)

Two Difficult Issues

- Pt. wants to eat/drink but swallow unsafe w/ high aspiration risk
  - If cognitively intact w/ mental capacity, they should be allowed to eat and drink after all risks explained
  - If capacity is issue, discuss w rep/advocate
- Pt. capable of swallow, able to meet needs but refuses to swallow
  - If restraint – physical or chemical – required to keep feeding tube in, benefits should be questioned
  - If goal is for pt. to conform, needs to be predefined definition as to what is to be assessed, how QOL is improved? (7)

CONTINUED

- Education efforts/meetings w/ informed choice
- Be sure pt. makes informed decisions/informed choice
- Meeting individuals involved in pt. care allows all voices to be heard, perspectives to be considered
- SLP must share concerns
- Intervention plans, decisions clearly documented following meeting (5)

CONTINUED

- Pt. may decide importance of choice outweighs potential risks assoc. w/ his food preferences
- May agree to work w/ SLP to select relatively less risky menu, cooking options that aren't texture modified
- Some family members may refuse to cook/purchase unsafe food but may accept pts. decision to consume these foods at home or social gatherings (5)

Loss of License? (13)

- SLPs concerned loss of license to practice if they don't recommend a particular diet consistency having seen aspiration on instrumental assessment or when pt. chooses different course than "best" professional recommendation.
- ASHA's Preferred Practice Patterns for Swallowing Intervention in Adults includes guidance for the SLP:
  - When SLP includes pt. in formulation of treatment plan and documents process then licensee should be protected.

Rothschild Person Centered Care Planning Process (22)

Guides staff & clearly demonstrate to residents, state surveyors, family members, & others care community has done due diligence:

- Assessed pt's functional abilities & relevant decision-making capacity
- Weighed w/ pt. & representative, potential outcomes (+/-) of both respecting & aiding pt. in pursuit of her/his choices
- Reviewed potential outcomes (+/-) of preventing pt. from acting on his/her choices.

Rothschild Process (22)

I. Identifying and clarifying resident's choice

II. Discussing the choice and options w/ resident

III. Determining how to honor choice (& which choices are not possible to honor)

IV. Communicating the choice through care plan

V. Monitoring and making revisions to plan

Examples include diet modification issues & consumption of alcohol, w/ completed forms to show process & template for use

Rothschild Process (22)

I. Identifying and clarifying resident's choice

- What is resident's preference that is of concern?
  - Prefer to eat regular texture than recommended puree – would rather risk choking than to eat purees rest of her life
- Why is this important to resident?
  - Texture and taste of puree is unappealing – healthy, nicely prepared and presented meals are a high priority
- What is safety/risk concern?
  - Choked once – needed Heimlich maneuver, long time to chew, often coughs after swallowing
- Who representing the resident was involved?
- Who on care team was involved in these discussions?

CONTINUED

Rothschild Process (22)

II Discussing the choice and options w/ resident

- What are potential benefits to honoring resident's choice?
  - Increased caloric consumption, greater satisfaction, QOL, liberalization conforms to current standards of practice
- What are potential risks to honoring resident's choice?
  - Risk of choking during meals
- What alternative options were discussed?
  - Improve flavor/presentation of meals, try modified diet texture, work w/ SLP & Dietitian to identify safer preferred foods without pureeing; foods unsafe if not modified and foods resident prefers from these options
  - Teach universal sign for choking to get help quickly
  - Participate in dysphagia tx to improve chewing/swallowing
  - Always have at least one soft "preferred" food available

CONTINUED

Rothschild Process (22)

II Discussing the choice and options w/ resident

- What education about the potential consequences of choice alternative actions/activities was provided?
  - Discuss risks of eating textured foods so resident understands
  - SW explains to family resident is still capable of making decisions
  - Care community has responsibility to determine/meet resident's own preferences
  - Explain to family that resident is working w staff to identify diet that honors most choices while eliminating most dangerous foods
- Who was involved in these discussions?

Rothschild Process (22)

III Determining how to honor choice (& which choices are not possible to honor)

- Of all options considered, is there one that is acceptable to the resident/representative and staff? Which one?
  - Identify foods considered high risk – offer alternative when those foods are served that have less risk
  - Make plate more appealing in presentation (should do for EVERYONE)
  - Family bring in some of her favorite foods that are naturally soft
- If no option is acceptable to both resident/representative and staff, what is reason for denial of resident choice? AND what is/are the consequences or actions that will be taken?
- Who was involved in these discussions/decisions?

Rothschild Process (22)

IV Communicating the choice through care plan

- What specific steps will be taken to assure both the resident and staff follow the agreed to option?
- Document a brief summary of the plan here and put the detailed goal and approaches in the care plan
- Was care plan updated?

Rothschild Process (22)

V. Monitoring and making revisions to plan:

- How often will this decision be formally reviewed (recognizing that informal monitoring may take place on a daily basis)?
  - 1 wk. reviewing menus to identify high risk foods and acceptable alternates
  - SLP & Dietitian will meet w/ resident and CNA each week of menu rotation to see how new menu is working
  - SLP tx plan
- Who has primary responsibility for monitoring implementation?
  - CNA tracks residents comments, Dietitian tracks consumption
- Was there another option considered to be the "next best step" that would be implemented next?

Model Medical Review Guidelines for Dysphagia Services (24)

- Skilled level of care
  - Documentation:
    - should support ongoing need for skilled services
  - Suggests NONSKILLED or maintenance level of care routine, repetitive observation or cuing
    - only observing meal, reporting on amt. consumed, providing verbal reminders in absence of other skilled assistance or observations
  - Establishment of maintenance program covered for a brief period
  - Usually included during final visits

Skilled vs. Unskilled (23)

SKILLED

- Evals & re-evals
- Designing plan of care
- Ongoing assessment & analysis
- Therapeutic services
- Compensatory skills training
- Selection of devices to replace or augment function
- Establishing maintenance program & training staff
- Pt. & caregiver training

UNSKILLED

- Repetitive tasks w/ no variation in complexity, level of cueing or independence
- Observing pt.'s or caregivers' performance w/ no feedback****
  - "pt. tolerated diet or treatment well" (25)
- General activities to promote overall fitness, provide diversion or general motivation

Diet and Liquid Consistency

National Dysphagia Diet

- Phasing out

IDDSI

- Framework
- EASY Criteria for bite size
- EASY Testing liquids to identify accurate consistencies

FAQ includes studies, rationale for recommendations (26)

Therapy

- Aim for safe swallow on highest appropriate diet/liquid level or least restrictive diet/liquid level
- ****Remember! Highest appropriate diet/liquid level MAY NOT be thin liquids and regular diet!
- ALL diet and liquid upgrades tax the swallow system and muscles
- May not have strength, ROM, tongue pressure, mastication to warrant an upgrade
- Trials can be misleading
  - May not allow adequate evaluation of fatigue level
  - BIG difference w/ ability to tolerate trials vs. entire meal
  - May do well w/ upgrade at breakfast but increased difficulty as day goes on
  - Suggest trials of upgraded diet over course of several meals to document what works vs. doesn't work before ordering upgraded diet

Improve Documentation
Be careful what you say, how you say it!

With trials:

- What diet level?
- What food – meat, veg, bread, dessert?
- When – snack? Which meal?
- Vary meal – assess impact of fatigue
- Bites or entire meal?
- Pt. self feed or fed?
- Amt. of cues vs. self monitoring?
- Performance?
- Overt s/s observed?

Improve Documentation

Pt./staff will utilize safe swallow strategies during oral intake	EDUCATE STAFF/CAREGIVERS AND DOCUMENT!
WHAT strategies? ▪DON'T assume everyone knows what they are! ▪Patient specific! (chin tuck etc.)	Write out as Dr.'s order? ▪Staff Inservice w/ documentation? Initial staff communication book? ▪Need copy of strategies - where can they be found? ▪ Place strategies in ▪ ADL book, chart, dining room? Where else?

Improve Documentation

Compensatory swallow training	Who? Written? Verbal? Demonstrate comprehension?
Pt./caregiver education	Who? Written? Verbal?
# of "trials" to determine safety w/ upgrade?	1? 2?
	Sips, bites or meals?

Functional Maintenance Program?

Established after initial evaluation and reasonable period of tx; determine FMP would be suitable

Qualified SLP designs program

Once established, & instructions DOCUMENTED for carrying out program, SLP services are no longer covered (ASHA, 2004b).

Documentation!

- Detail important!
  - SLP's covering caseload
  - Dropdown boxes often lack detail
  - EVERY pt. sounds the same!
  - Potential litigation!!!!!!
  - FAMILIES SUE!
- If you didn't WRITE it, you didn't DO it!***
- Don't forget about documentation of pt., family, staff education
- Strategies/precautions – what exactly ARE they?

Take Aways

- Importance of providing information necessary for pt. to make INFORMED, EDUCATED decision
- Importance of religion & culture in making decisions
- Pt. has right to choose or refuse even if we believe the choice is unwise
- Accurate documentation of skilled treatment, education efforts
- Waivers vs. Shared Decision Making Algorithm vs. Rothschild Process

Q & A

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