Dysphagia Pathways Program

Palliative dysphagia management and ethical considerations

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Ethical considerations

- The ability to eat and drink is closely linked to quality of life and psychosocial well-being (Puntil-Shelman, 2013)
- Imagine your morning coffee, your favorite desert, a family dinner
- What memories and moments come to mind, when reflecting on your favorite meals?
- Eating and drinking is inextricably bound with a person’s quality of life and is a source of happiness and comfort (Vesey, 2013)

Ethical considerations

- When managing dysphagia, SLPs form recommendations that hold potential to greatly impact patient quality of life and psychosocial well-being
- To withhold the ability to eat or drink preferred foods, or the ability to eat or drink at all, can cause unintended harm to patients
- How can SLPs continue to provide quality care, when patients do not wish to follow our dysphagia recommendations, or if our recommendations inadvertently cause harm?

Learning Objectives

After this course, the Speech-Language Pathologist should be able to:

I. Outline four key medical ethical principles and explain how they relate to dysphagia management
II. Describe informed consent and shared decision-making
III. Identify factors that indicate need for a dysphagia goals of care discussion
IV. Utilize the Dysphagia Pathways Program decision tree to navigate complex clinical scenarios
V. Conduct a dysphagia goals of care discussion
VI. Identify factors that indicate need for palliative care and/or clinical ethics referral
VII. Describe treatment techniques for palliative dysphagia care and changes to swallowing at end-of-life

Ethical considerations

Healthcare professionals have abided by ethical principles for thousands of years

- In 1847 the code of ethics was developed by the American Medical Association (AMA)
- It applies to physicians, those in law, and **other medical professions**
- We, as SLPs, follow ethical principles when treating patients with dysphagia
- We know the sensitivity our role requires, as managing dysphagia has potential to interfere with a basic human need: the need for food and water

(Puntil-Shelman, 2013)

(American Medical Association [AMA], 2016)

Medical ethical principles

Beneficence: the ability to act in the patient's best interest

- Promoting the well-being of the patient
- Treatment of pain and bothersome symptoms
- Psychosocial and spiritual support

(Puntil-Shelman, 2013)

Autonomy: respect for patient self-determination

- Recognizes the rights of a patient with decision-making capacity
- Respect for patient beliefs including cultural values, spiritual values, and life goals
- Respect for patients' decisions, even when they do not align with clinician recommendations
- Upholds patients' rights to reject any form of medical treatment
- "Such a patient has right to refuse uwanted treatment, including medically supplied nutrition/hydration and even thickened liquids." (Puntil-Shelman, p.119, 2013)

(Puntil-Shelman, 2013)

Nonmaleficence: do no harm

- The principle of preventing harm to patients
- Especially pertinent for frail and vulnerable patients
- Palliative care and hospice patients

(Puntil-Shelman, 2013)

Justice: to provide fair allocation of resources

- Equitable distribution of resources that will benefit patients
- Physicians do not have to offer treatments/resources that they believe offer no reasonable benefit to a patient

(Puntil-Shelman, 2013)

AMA Code of Medical Ethics
Opinion 1.1.3 Patient Rights

“Physicians ***(medical professionals)*** can best contribute to mutually respectful alliance with patients by serving as their patients’ advocates and respecting patient’s rights. These include rights to:

b.) "To receive information from their physician and to have the opportunity to discuss the benefits, risks, and cost of appropriate treatment alternatives, including the risks and benefits of forgoing treatment.“

d.) "To make decisions about the care the physician recommends, and to have those decisions respected. **A patient who has decision-making capacity may accept or refuse any recommended medical intervention.”**

- A note on code status

(American Medical Association [AMA], 2016)

ASHA ethical guidelines

The American Speech Hearing and Language Association (ASHA) code of ethics outlines similar considerations regarding patient rights, including:

“Individuals shall obtain informed consent from the persons they serve about the nature and possible risks and effects of services provided...this obligation also includes informing persons served about possible effects of not engaging in treatment or following clinical recommendations.”

American Speech-Language-Hearing Association. (2016). Code of Ethics [Ethics]

Decision-making capacity

“The patient’s capacity to understand specific treatment options and the consequences of accepting or refusing various options.”

(Sharp & Bryant, p.291, 2003)

The patient should have the ability to:

(1) Communicate choices
(2) Understand relevant information
(3) Comprehend risks and benefits
(4) Manipulate information rationally

(Sharp & Bryant, 2003)

- Decision-making capacity is task-specific and time limited
- A patient may have capacity to make a decision on one topic, but lack the capacity for other topics (Sharp & Bryant, 2003)
- A patient may possess decision-making capacity at some points in time, but not at others
- If a patient is found to lack decision-making capacity, a surrogate-decision maker is appointed
- In Ohio, the attending physician is responsible for determining decision-making capacity

The ethical dilemma

- For patients with decision-making capacity, it is their choice as whether to accept or decline our dysphagia recommendations
- Patients’ rights to accept or refuse clinical recommendations are widely recognized (Sharp & Bryant, 2003)
- "Such situations may be sources of moral unease or distress for health-care professionals." (Kaizer, Spiridigliozzi, Hunt, p.82, 2011)
- The compassionate SLP may worry that a patient forgoing their recommendations, will cause the patient harm

- “The clinical uncertainty coupled with professionals’ desire to protect the patient yields many ethical dilemmas.” (Sharp & Bryant, p.285, 2003)

- When a patient refuses recommendations, dysphagia specialists are left with a host of practical questions about how to continue care for the patient

- How can we, as SLPs, balance our ethical duty to respect patient autonomy and our desire to maximize patient welfare?

(Sharp & Bryant, 2003)

"Patients and families may feel responsible if negative consequences result for the patient.”

"Patients and families may feel that they are being forced to follow a dysphagia management plan they do not agree with."

(Kaizer, Spiridigliozzi, Hunt, p.82, 2011)

The issue of “non-compliance”

- Rather than referring to patients as “non-compliant”, the medical team can consider the nuances of these delicate scenarios in which psychosocial needs, autonomy, and quality of life can feel greatly threatened
- SLPs should seek to understand the reasons behind personal "non-compliance" to dysphagia recommendations
- This will add depth to management of patients with dysphagia, and guide clinical approaches to intervention

(Vesey, 2013)

- "Individuals with dysphagia and their families may **struggle** to balance safety risks with considerations of aesthetic and autonomy." (Askren & Kershner, p.1016, 2020)

- There is a great depth of emotional weight regarding decisions about eating and drinking (Vesey, 2013)

- One study suggested that as many as 40% of patients, do not follow recommendations for diet modifications (Sharp, Bryant, p.81, 2003)

- "Patients will not easily set aside their lifelong associations with food and drink when swallowing becomes difficult or even dangerous.” (Vesey, p.S14, 2013)

Holistic approaches to dysphagia care

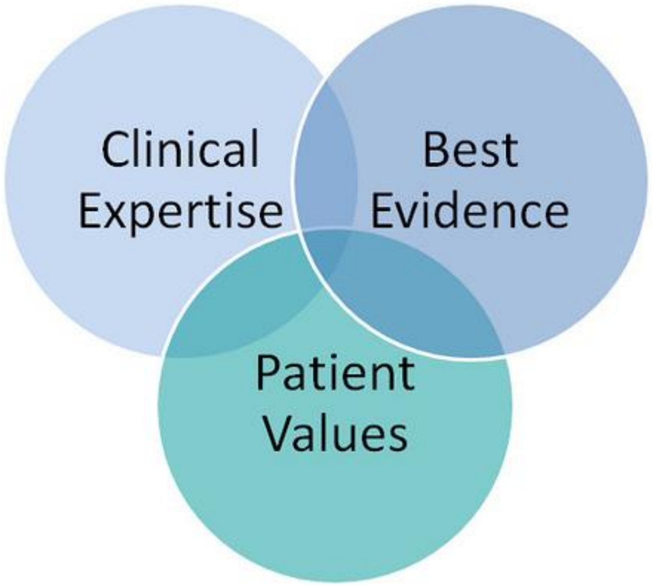
“Swallowing assessments must be holistic and take account all of the compounding factors both physical and psychosocial…” (Vesey, p.S16, 2013)

- Swallowing is more than the pharynx, and the patient is more than their dysphagia
- Evidence-based practice accounts for the whole patient

- ASHA Adult Dysphagia “Roles and Responsibilities” includes:
  - “Incorporating the patient’s dietary preferences and personal/cultural practices as they relate to food choices during evaluation and treatment services”
  - “Respecting issues related to quality of life for individuals and/or caregivers”
  - Determining the optimum supports (e.g., posture, or assistance) to reduce patient and caregiver burden while maximizing the patient’s quality of life”

("Adult Dysphagia", 2022)

How often do we ask patients about their preferences? Do we value their goals and wishes, as much as we value clinical expertise or research evidence?



Dysphagia management

Dysphagia is a life changing and often long-term health problem

- Associated with serious complications including malnutrition, dehydration, chest infections, pneumonia, choking
- Social isolation, depression, and anxiety

(Leow, Huckabee, Anderson & Beckert, 2009)

The primary conventional goals of diagnosing and treating dysphagia include:

- Helping the patient maintain adequate nutrition and hydration
- Eliminating or reducing the risk for adverse medical outcomes related to dysphagia

Balancing Act

- SLPs are challenged to form recommendations for dysphagia patients that promote safety and optional nutrition/hydration, while also considering quality of life and respect for patient wishes
- In the fast-paced hospital environment, the cascade of care can lead to dysphagia management plans, that are contrary to patient wishes
- "…There has been limited discussion of practical approaches in the literature when hospitalized patients (and their families) refuse or do not adhere to diet texture modifications."

(Kaizer, Spiridigliozzi and Hunt, p.82, 2011)

Dysphagia Pathways Program

- The need was identified for hospitalized patients to receive holistic dysphagia care and for SLPs to have a framework to navigate these complex clinical situations
- The program was started with the intent to create a framework for:
  - How we provide care for patients who do not wish to follow our primary dysphagia recommendations
  - How we provide care for patients with adverse medical or psychological outcomes due to primary dysphagia recommendations
  - How we approach patients who are choosing to forgo conventional or “common” dysphagia management for a more comfort-focused or "palliative" approach

- ASHA SIG 13: Swallowing and swallowing disorders
- Interviewed SLPs at Cleveland Clinic, Kansas University Hospital, and Vanderbilt Medical Center
- Collaboration with the palliative care team at Riverside Methodist Hospital
  - Palliative medical directors: Dr. Matthew Brown, DO and Dr. Kerry Bertke, DO
  - Dr. Tommy Petros, MD
- Collaboration with RMH clinical ethicist
  - Alexandria Lesher, D.Be.
  - Gavin Enck, Ph.D., HEC-C

- There are often two different courses, or ***pathways***, a patient can choose when considering how to manage their dysphagia
- There is variable terminology for how we discuss these two different courses:
  - "Aggressive management", "conservative management"
  - "Comfort diet", "Pleasure diet", "Palliative diet", "Pleasure feeds"

Common dysphagia management

- The primary recommendation provided by an SLP, felt to be most beneficial to the patient’s safety and nutrition
- Primary goal is to maintain nutrition and reduce adverse medical outcomes of dysphagia including the risks of aspiration, subsequent illnesses, and mortality
  - Pneumonia
  - Respiratory failure
  - Fibrotic lung changes
  - Intubation
  - Malnutrition
  - Death
- When patient safety or nutrition is threatened, this management method often includes recommendations for the patient to be fed using alternative means or a modified diet
- Often these patients have a good prognosis for restoration of swallow function

Palliative dysphagia management

- The secondary recommendation provided by an SLP (if at all)
- Primary goal is to promote patient quality of life, comfort, and wishes, but not necessarily to extend length of life or prevent adverse medical outcomes of dysphagia
- Generally recommendation is for a regular diet, with patient and/or surrogate-decision maker acceptance towards known risks of dysphagia
- Avoids NPO status
- Generally avoids use of modified diets (although may be implemented for patient comfort if preferred)
- Often these patients have a poorer prognosis for restoration of swallow function
- Commonly implemented for dysphagia patients at end-of-life
- The term “palliative” does **not** indicate a patient needs to be a palliative care patient to manage their dysphagia in this way. The term is used to indicate the goals of this type of management: decreasing bothersome symptoms and improving quality of life.

Summary

We have now discussed:

- Ethical considerations for dysphagia management
- The importance of a holistic approach to dysphagia care
- The balancing act SLPs face when providing dysphagia care
- Introduction to the Dysphagia Pathways Program

Coming up

- General risks of dysphagia
- Risks/benefits of common dysphagia management approaches
- Risks/benefits of palliative dysphagia management approaches

Risks of dysphagia

- Aspiration pneumonia can lead to death, which is especially a risk in elderly patients (Mandell and Niederman, 2019)
- A study of patients hospitalized for aspiration pneumonia showed that:
  - About 1 in 9 patients > 65 years old died while hospitalized
  - Approximately 1 in 20 patients < 65 years old died while hospitalized

(Wu, Chen, Wang & Pinelis, 2017)

- Another study of patients hospitalized for aspiration pneumonia, found that approximately 1 in 6 died while in the hospital (Yoon, 2019)
- Aspiration pneumonia accounts for 5-15% of pneumonias in hospitalized populations (DiBardino and Wunderink, 2015)
- It is associated with higher mortality rates than other forms of pneumonia (Mandell and Niederman, 2019)

Risks of dysphagia

- Aspiration pneumonia is the leading cause of death among older patients
- However, a study by Yoon, 2019 found that long-term prognosis of aspiration pneumonia was poor as a result of underlying morbidity rather than the aspiration pneumonia itself
- Yoon concluded that underlying conditions should be included when considering prognosis for patients with aspiration pneumonia

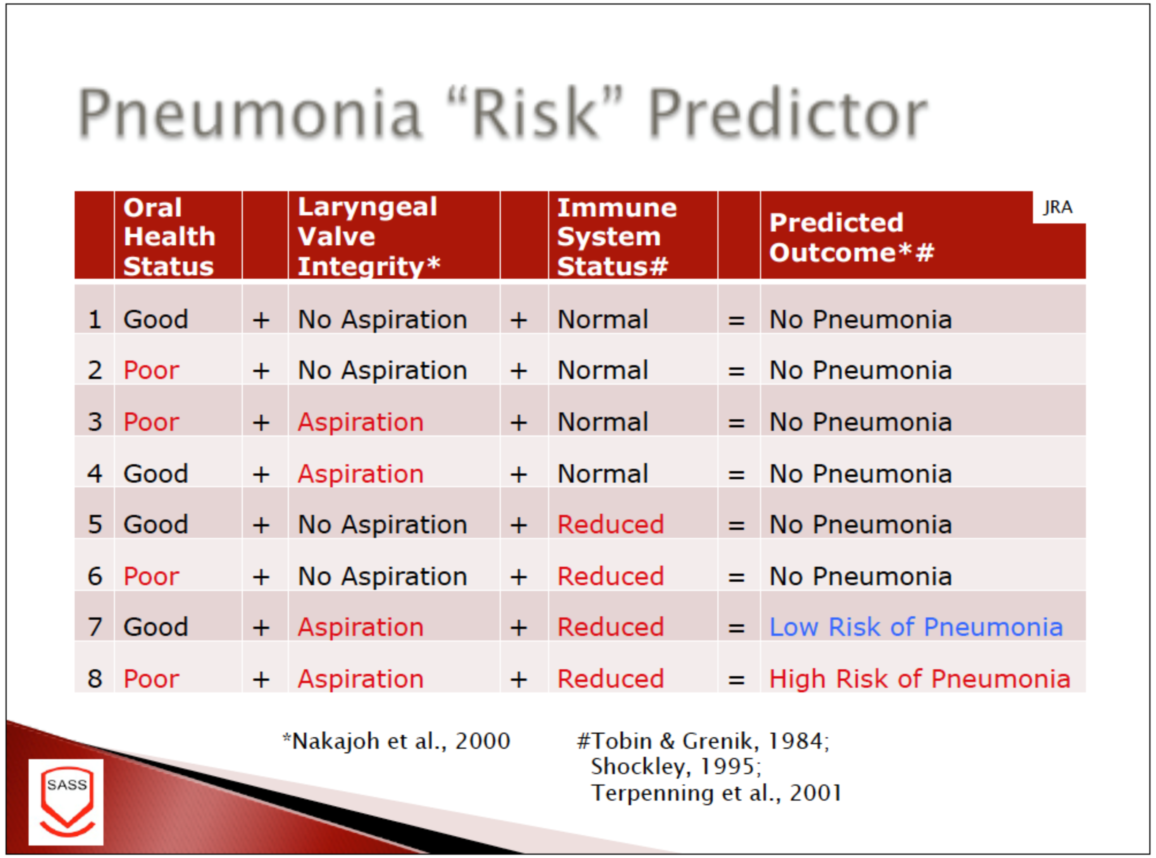
(Yoon, 2019)

Risks of dysphagia

- Research supports that aspiration pneumonia is serious and can be fatal, especially in elderly patients
- However, the pathogenesis between aspiration visualized on instrumental swallow testing and aspiration pneumonia is poorly understood
- We know not every patient who aspirates, is at risk for aspiration pneumonia or will develop aspiration pneumonia
- “There are no studies in humans that have been able to link the amount or type of an aspirant to the development of aspiration pneumonia.” (Groher & Groher, 2012)

Three Pillars of Aspiration Pneumonia

"Clinicians should be aware of the complexity of serious illness and how the alterations to major systems of the body can lead to dysphagia and pneumonia. Assessment and treatment should move beyond observations of potential aspiration events and their causes and place these findings within the context of the patient's total medical condition."
(Ashford, p.14, 2005)



Pneumonia "Risk" Predictor

JRA

	Oral Health Status		Laryngeal Valve Integrity*		Immune System Status#		Predicted Outcome*#
1	Good	+	No Aspiration	+	Normal	=	No Pneumonia
2	Poor	+	No Aspiration	+	Normal	=	No Pneumonia
3	Poor	+	Aspiration	+	Normal	=	No Pneumonia
4	Good	+	Aspiration	+	Normal	=	No Pneumonia
5	Good	+	No Aspiration	+	Reduced	=	No Pneumonia
6	Poor	+	No Aspiration	+	Reduced	=	No Pneumonia
7	Good	+	Aspiration	+	Reduced	=	Low Risk of Pneumonia
8	Poor	+	Aspiration	+	Reduced	=	High Risk of Pneumonia

*Nakajoh et al., 2000

#Tobin & Grenik, 1984;
Shockley, 1995;
Terpenning et al., 2001

Assumed vs. real risks

	Defined as:	Examples:
Assumed Risk	Situations in which there is potential for dysphagia to have a serious, negative impact a patient's health.	• Visualized aspiration on instrumental swallow study • Visualized pharyngeal/esophageal obstruction
Real Risk	Situations in which there are measurable, clinical signs that dysphagia is negatively impacting a patient's health.	• Hx of aspiration PNA • Chronic respiratory problems • Signs of dehydration • Fever • Reduced oxygen saturations

(Kaizer, Spiridigloiozzi, Hunt, 2011)

Psychological risks

- Social isolation
- Depression
- Anxiety

“Social and psychological consequences of dysphagia are under researched despite reports that social isolation associated with dysphagia can have a profound impact on a person’s quality of life.”

(Leow, Huckabee, Anderson & Beckert, p.216, 2009)

Common Dysphagia Management

- To review: this involves what we consider conventional treatment methods for dysphagia
- The goal is to keep the patient safe, medically stable, and well nourished
- We are seeking to prevent risks of dysphagia including respiratory compromise, pulmonary compromise, choking, and death
- Often these patients have a good prognosis for recovery of dysphagia

Modified diets

- The belief that altering consistencies can help patients with dysphagia is widely held
- Should we believe this?

Logemman, 2008

- Examined immediate effect of modification of fluid viscosity during MBSS
- Found that honey thick liquids were most effective in immediately eliminating aspiration

Leonard, White, McKenzie & Belafsky, 2014

- Compared the effect of thin liquid barium, starch thickened barium, and gum thickened barium in patients with dysphagia
- Involved 100 patients at the Center for Voice and Swallowing at University of California
- One SLP and two investigators independently reviewed and evaluated MBS results
- Study revealed significantly less aspiration of gum thickened barium than thin barium
- PAS scores were significantly lower for gum thickened than thin barium

Bock, Varadarajan, Brawley & Blumin, 2017

- Reviewed 2,616 inpatient and outpatient swallowing studies over a 2-year period
- 564 patients (21.5%) scored PAS >5 or higher during MBS
- These patients were followed retrospectively and measured time to “first pulmonary event”
  - Defined as pneumonia, pneumonitis, or other life-threatening pulmonary infection based on clinical imaging

Bock, Varadarajan, Brawley & Blumin, 2017

- There were no statistically significant differences from time to first pulmonary event and dietary recommendation at time of MBS, on univariate analysis
- Diet modification or NPO status, did not show statistical significance when compared to a regular diet for time to first pulmonary event
- Severity of aspiration as defined by PAS or dietary recommendations were not associated with development

  of pulmonary events or survival

Kaneoka et al., 2016

- Completed a systematic review and meta-analysis of pneumonia associated with thin liquid vs. thickened liquid intake in patients who aspirate
- Reviewed seven research studies involving 650 patients
- All seven studies excluded patients with more than one known risk factor for pneumonia
- Compared whether drinking thin liquids with safety strategies increased the risk for pneumonia as compared to thickened liquids, in patients with known aspiration of thin liquids
- Results: *no significant difference* in the risk of pneumonia in aspirating hospitalized patients who took thin liquids with safety strategies, as compared with those who took thickened liquids only
- The short-term effect of thickened liquids has been proven to eliminate aspiration in instrumental examination in some patients
- However, efficacy of this intervention to prevent dysphagia-related complications remains unknown

Use of modified diets to prevent aspiration in oropharyngeal dysphagia: is current practice justified? (O’Keeffe, 2018)

- 30-45% of older people in acute care and rehabilitation wards receive modified texture food
- They found no convincing evidence to suggest that texture modified foods and thickened fluids benefit adults with dysphagia by preventing pneumonia and its consequences

Robbins, 2008

- Studied the effectiveness of chin-down posture and 2 consistencies (nectar/honey) thickened liquids on the 3-month cumulative incidence of pneumonia in participants with dementia or Parkinson’s Disease
- No definite conclusions about superiority of any tested treatment could be made

Maeda et al., 2019

- Followed 3,594 adults age >65 years old, admitted to the hospital between December 2017 and March 2018
- 110 were consuming a modified diet prior to hospitalization
- Minced, pureed, or liquid food
- Patients were sorted in two groups: those consuming modified diets and those consuming regular diets
- Investigated association between daily premorbid modified diet consumption, nutritional status at time of hospitalization and the burden on hospitalization outcomes

Maeda et al., 2019

- Patients consuming a modified diet on admission were overall: older, had a poorer nutritional status, more prevalent ASPEN defined malnutrition at time of hospital admission (61.8% v. 14%)
- They also had a higher mortality rate (7.3% v 2.9%) and length of stay (19 days v 8 days)
- Multivariate analysis showed that being on a modified diet was independently associated with poor nutritional status and prolonged length of stay, but not mortality

Maeda et al., 2019

- Modified food is often cooked with a large amount of water which can result in low density of nutrition per volume
- Many modified diets contain a poor amount of nutrients, and older inpatients often are unable to eat the full amount on their plate at meal time
- Patients on modified diets show less skeletal muscle mass
- Older adults consuming modified diets are more likely to be diagnosed with sarcopenia
- Older adults with sarcopenia have decreased pharyngeal/laryngeal muscle strength

Modified diets: Summarized benefits

- Reduction of real-time airway events (penetration/aspiration) during modified barium swallow studies (Logemman, 2008)
- Some clinical evidence shows that increasing bolus viscosity reduces risk for airway invasion (C. Gallegos et al., 2017)
- Possibly reduced risk for aspiration and dysphagia-related illness, though this is poorly understood in the literature
  - It may be most reasonable for patients with high risk for development of aspiration PNA, who are known to aspirate via an instrumental swallow study
- Increased comfort or nutritional intake for some patients in special circumstances
  - I.e. A patient who overtly coughs/chokes with thin liquids, but can manage nectar thickened liquids without overt s/sx
  - I.e. A patient who is unable to masticate due to facial trauma, and is consuming a pureed diet

Modified diets: Summarized risks

- Questionable efficacy in reducing risk for aspiration pneumonia; poor understanding in the literature regarding pathogenesis of aspiration pneumonia in dysphagia patients
- Greater difficulty clearing airway with more viscous fluid interventions
- May increase post swallow risk, by increasing pharyngeal retention (C. Gallegos et al., 2017)
- Dehydration, UTI, fever (Robbins, 2008)
- Poor nutrition
- Delayed medication absorption (even a minimal increase in viscosity can delay medication dissolution and bioavailability)
- Cost of for thickened liquids, estimated to be 174-289 dollars per month (O'Keeffe, 2018)
- Caregiver burden
- Lack of standardization of modified diets (variability of consistency of thickened fluids and foods prepared by staff within/between hospitals and rehabilitation facilities)
- Poor quality of life and depression
  - Significant psychological and social consequences (Flynn, Smith, Walsh & Walshe, 2014)
- Overall, the use of thickened liquids as a management strategy for airway protection remains controversial (Groher & Groher, 2012)

“The disconnect between the limited evidence base and widespread use of modified diets suggests the need for more careful consideration as to when modified diets might be recommended to patients. Patients (or their representatives) have a choice as to whether or not to accept a modified diet and must receive adequate information, about the potential risks and impact on quality of life as well as the possible benefits, to make that choice. There is an urgent need for better quality evidence regarding this intervention.”

(O’Keeffe, p.1, 2018)

Alternative nutrition and hydration (ANH)

- Enteral feeding tubes are typically indicated for patients who have a functional GI tract, but are unable to meet nutritional needs by mouth
  - Short-term: NG
  - Long-term: PEG tube, J- tube
- According to American Gastroenterological Association guidelines (1994) , tube feeding should be considered when a patient cannot eat, the gut is functional, and the patient can tolerate placement of the device
- Indication for ANH should not just be determined by dysphagia diagnosis but also:
  - Medical status (acute v chronic, progressive v reversible, diagnoses)
  - Nutritional status (projected needs, baseline status)
  - Behavioral and cognitive status

(Krival, McGrail & Kelchner, 2021)

“Nonoral feeding is recommended with the intent of reducing aspiration, increasing nutrition, and/or maintaining patient comfort, yet recent studies and reviews of the literature find little evidence that these goals are met by enteral tube feeding.”

(Sharp & Bryant, p. 288, 2003)

- PEG tube placement does not always prevent development of aspiration pneumonia, especially in patients with dementia
- Individuals with dysphagia remain at risk for aspiration of saliva and gastric content
- PEG tubes may increase risk for aspiration pneumonitis

(Krival, McGrail & Kelchner, 2021)

Murphy & Lipman, 2003

- Received 41 consultations for PEG tube placements in patients with dementia
- Patients all had advanced dementia, documented dysphagia, expected life expectancy of at least 30 days, no contraindication to conscious sedation, and no disease other than dementia contributing to dysphagia
- PEG tube placement was performed in 23 patients
- The other 18 patients had surrogates who declined PEG tube placements
- Kaplan-Meier survival curve was used to compare median survival between patients with and without PEG placement
- Median survival for patients with PEG placement was 59 days
- Median survival for patients without PEG placement was 60 days
- Conclusion: There is no survival benefit in patients with dementia who receive artificial nutrition by a PEG tube

“The percutaneous endoscopic gastrostomy tube medical and ethical issues in placement” (Angus, 2003)

- Argued that PEG tubes are often placed inappropriately because of unrealistic and inaccurate expectations of what they can accomplish
- Reviewed literature on PEG tube placements in oncology, neurology, and geriatric patients

Appropriate indications for PEGs included:	Inappropriate indications for PEGs included:
• Esophageal obstruction (I.e. Cancer) • Neurologic etiology of dysphagia without obstruction (I.e. CVA, pseudobulbar palsy) • Prolonged refusal to swallow without evidence of concomitant terminal illness (e.g. protracted pseudo dementia due to severe depression) • Supplemental nutrition for patients undergoing chemotherapy or radiation therapy with impaired nutrition • Chronic gastric decompression in patients with benign/malignant obstruction who do not wish or cannot have an NG placed (Angus, 2003)	• Patients with anorexia-cachexia syndromes (e.g. terminal cancer/end stage AIDS) • Permanent vegetative state • **Patients with dysphagia and medical complications**: it is appropriate to discuss the risks and benefits of a PEG versus no PEG, with patient/caregiver

- If no physiologic benefit is expected with PEG placement, health care team has no obligation to offer or perform the intervention
- The same applies if intervention improves physiologic state but has no effect on QOL (e.g. permanent vegetative state)
- The decision to place a PEG, as with all medical care, should be determined on the basis of whether or not it will benefit the patient
- Economic considerations of PEG should also be considered but are often not discussed
- In patients with only temporary interference for oral intake, the decision for a PEG is often made inappropriately when a small-bore feeding tube can provide adequate nutritional support

(Angus, 2003)

ANH: Summarized risks

- Major/minor infections
- Major/minor bleeding
- Diarrhea
- Nausea/vomiting
- Tube dislodgement/blockage
- Bowel perforation
- Death

(Mitchell, Tetroe & O'Connor, 2001)

- Does not improve nutritional status in all patients
- Can cause pressure sores
- Can reduce functional status and patient comfort
- May lead to an increase in urine/fecal incontinence, and increased pulmonary secretions
- Use of physical or chemical restraint, which may be a violation of patients’ dignity

(Murphy & Lipman, 2003)

- Risk for aspiration pneumonia/pneumonitis (One of the most common complications, per Sharp & Bryant, 2003)
- Decreased human contact during meals
- Increased care needs
- May limit placement options after discharge from hospital

(Sharp & Bryant, 2003)

ANH: Summarized benefits

- Can provide necessary nutrition and hydration, for patients who have a temporary inability to swallow or to use their gastrointestinal tract due to reversible conditions
  - Acute stroke or neurological condition
  - Esophageal obstruction
  - Head and neck cancer
- In patients with head and neck cancer, PEG tubes are commonly placed at the outset of treatment in anticipation of swallowing difficulties severe enough to prevent adequate p.o. nutrition or increase aspiration risk (Krival, McGrail & Kelchner, 2021)
- ANH may prolong life in appropriate scenarios and may allow for a more accurate assessment of a patient’s chance of recovery
- At times, ANH can provide physical and psychological relief from dysphagia, by reliving the burden of trying to meet all p.o. needs by mouth and improve QOL (Groher & Groher, 2012)
- “Some patients with progressive disorders report improved personal, health, and social outcomes with tube feeding because they expend less effort to maintain adequate nutrition.” (Sharp & Bryant, p.288, 2003)

Review: Common dysphagia management

- There are known risks and benefits to modified diets and alternative means of nutrition and hydration
- In the hospital setting, these recommendations are made frequently for acutely ill patients with dysphagia
- Given the limited quality evidence to support use of modified diets, and the risks of alternative nutrition and hydration in certain patient populations:

How can SLPs make well-informed recommendations for their patients using the available evidence, while also considering patient goals and preferences?

Shared decision-making

- At least part of the answer to these questions, is to give the patient with decision-making capacity a choice and a voice
- We have already established that all patients with decision-making capacity can make choices about their medical care, and should be provided options as appropriate
- But how often do we actively decide to involve the patient in the decision-making process?
- Given the complexity of the trade-offs involved in the decision to initiate tube feeding or a modified diet, the patient's preference should weigh heavily in determining the plan of care (Sharp & Bryant, 2003)
- Groher & Groher (2012) offer the concept of *"shared decision-making"*

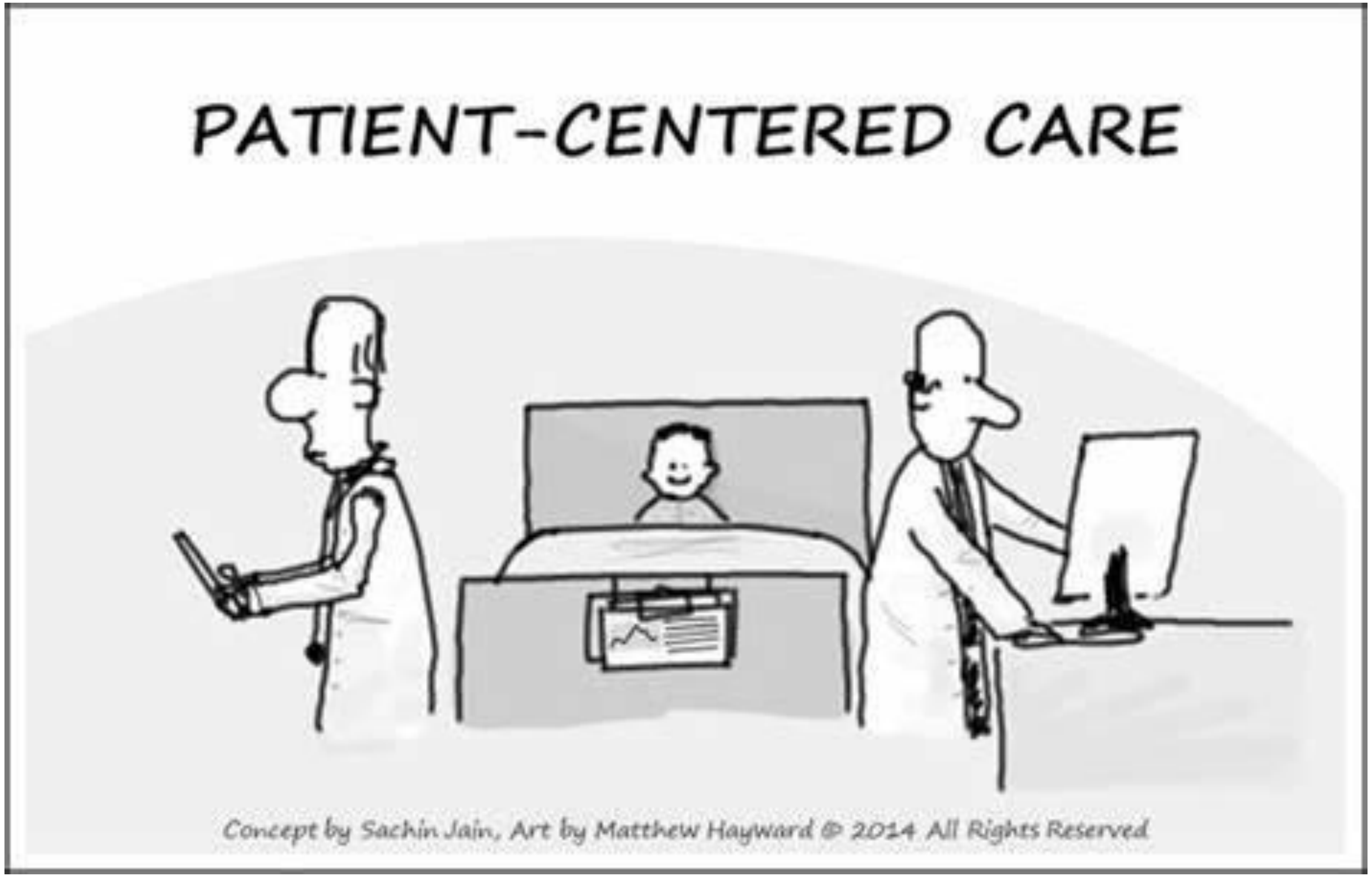
Shared decision-making

Legislative changes have shifted views on medical decision-making from a paternalistic view of a physician-patient relationship to informed consent and shared decision-making models (Groher & Groher, 2012)

Paternalism model	Informed consent model	Shared decision-making model
Clinician makes what they believe to the best decision for the patient, but without the patient's consent.	Clinician provides treatment options to the patient and the patient is responsible for choosing.	Clinicians provides treatment options. The patient provides their goals, values, and preferences as well as acceptable quality of life. They come to a conclusion together, based on the patient's goals.

Shared decision-making

"This model may be best used when decisions have a high degree of uncertainty and importance…and when available treatments are controversial, have similar outcomes, or evidence directing optimal treatment is lacking." (Groher & Groher, p.157, 2012)



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Palliative dysphagia management

- To review: this involves what we consider to be less common dysphagia management methods
- The goal is to keep the patient comfortable, avoid distress, and promote quality of life
- Generally recommendation is for a regular diet, with patient and/or surrogate-decision maker acceptance towards known risks of dysphagia
- Avoids NPO status
- Generally avoids use of modified diets
- Often these patients have a poorer prognosis for recovery of swallow function, but not always
- Can still involve dysphagia treatment, often compensatory in nature but can be rehabilitative, pending the patient’s overall goals and prognosis
- May still involve instrumental swallow assessments, with the specific goal of identifying postures, compensatory strategies, or diet modifications that will enhance oral intake
- Instrumental swallow assessments are contraindicated though, at end-of-life (Palliative Care Network of Wisconsin Fast Facts and Concepts #128)

Palliative dysphagia management

Regarding palliative management of dysphagia, the role of the SLP includes:

“To assist in optimizing function related to dysphagia symptoms in order to improve patient comfort and eating satisfaction, and promote positive feeding interactions for family members, to communicate with members of the interdisciplinary...team, to provide and receive input related to overall patient care.” (Pollens, p.696, 2004)

The patient’s perception of comfort and ease of swallowing is what guides the therapeutic recommendations (Pollens, 2004)

Palliative dysphagia management: Benefits

- Improves patient quality of life and psychosocial well-being
- “Maintains the normalcy and pleasure of eating and socialization, costs less, and eliminates the morbidity associated with surgery.” (Sharp & Bryant, p.288, 2003)
- Reduces caregiver anxiety and sense of hopelessness regarding their loved one with dysphagia (Pollens, 2004)
- Promotes a patient’s sense of autonomy and agency
- Allows for consumption of food and drink of cultural/familial significance (Pollens, 2004)
- Promotes feelings of social closeness, decreasing feelings of isolation
- Avoids use of chemical/physical restraints, utilized for some patients who are receiving alternative means of nutrition and hydration

Palliative dysphagia management: Risks

- Some dysphagia patients may struggle to maintain sufficient nutrition and hydration orally
- This may burden caregivers, lead to weight loss, and poor nutrition, which can increase risk for confusion (Groher & Groher, 2012)
- Aspiration
- Choking
- Pneumonia and other respiratory and pulmonary illnesses
- Possibly, hastened death

Summary

We have now discussed:

- Ethical considerations to dysphagia management
- The importance of a holistic approach to dysphagia care
- The balancing act SLPs face when providing dysphagia care
- Introduction to the Dysphagia Pathways Program
- Risk of dysphagia
- Risks/benefits of common dysphagia management approaches
- Risks/benefits of palliative dysphagia management approaches

Coming up

- Dysphagia Pathways Program: Decision Tree
- Goals of care discussions
- Case Study
- Documentation
- Providing palliative dysphagia care and swallowing at end-of-life

Dysphagia Pathways Program: Decision Tree

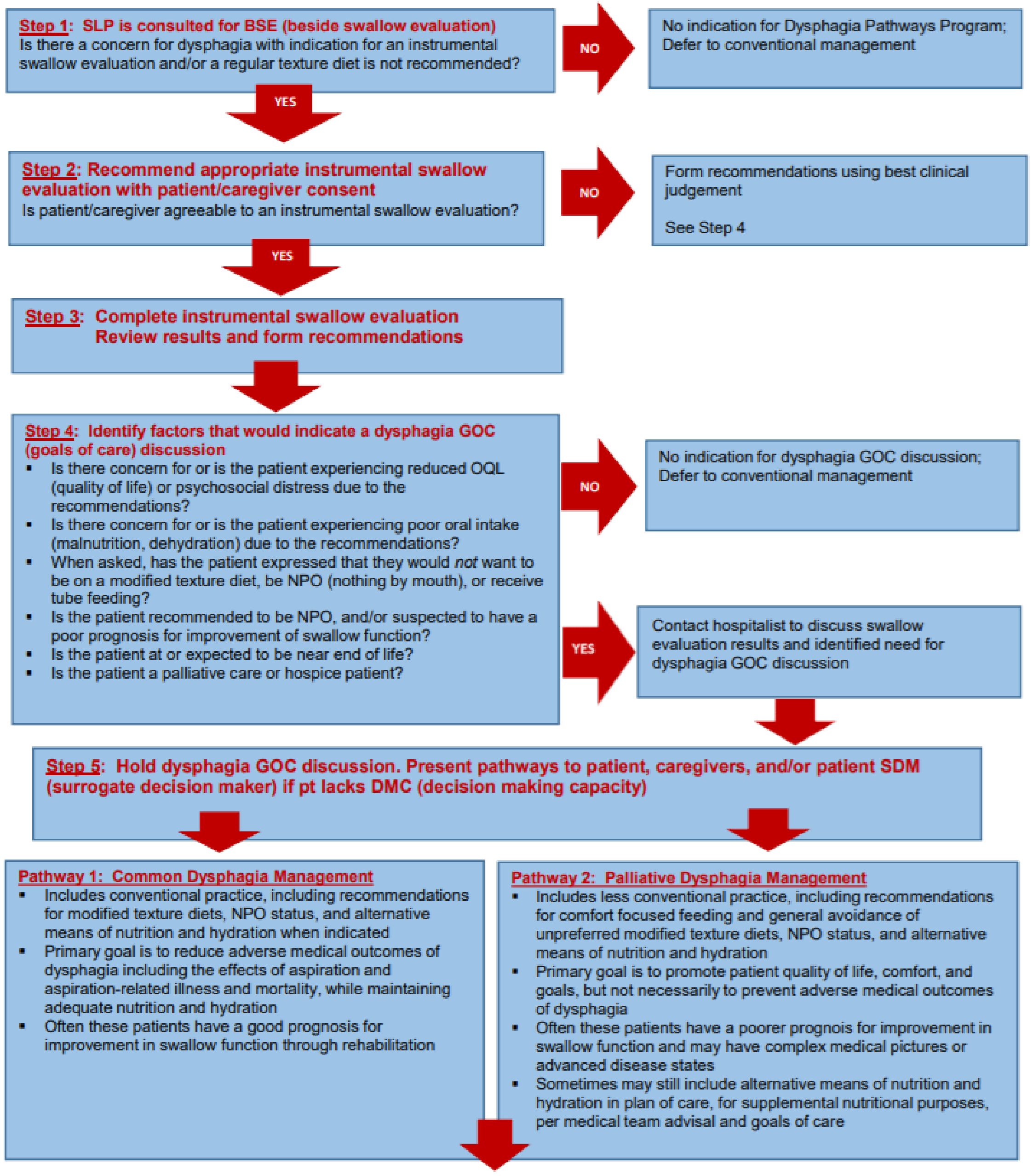
- This decision tree was developed to be a guide for these complex clinical situations
- The goal of this tool is to guide SLPs and other medical team members involved in dysphagia care, through a decision-making process with the patient, in order to develop recommendations and a plan of care, that aligns with the patient's goals and preferences
- The decision tree designates procedural steps and concludes in two plan of care pathways: Common Dysphagia Management and Palliative Dysphagia Management

If not us, who?

“The SLP should consider and integrate the patient’s wishes and advocate on behalf of the patient to the health care team, the family, and other relevant individuals.”

-ASHA Adult Dysphagia

- As SLPs, we have a responsibility, to advocate for our patients, regarding their wishes surrounding dysphagia management
- If we do not advocate for our patients, who will?
- Physicians often feel too busy and burdened with other types of patient care, to have these conversations
- We are the experts in dysphagia; and we have in-depth knowledge of communication and counseling skills
- This decision tree is led by the SLP, and is meant to empower us to practice at the top of our license and use our full scope of practice, to assist the patient in meeting their goals and to educate the medical team in the process



Step 1: SLP is consulted for BSE (beside swallow evaluation)
Is there a concern for dysphagia with indication for an instrumental swallow evaluation and/or a regular texture diet is not recommended?

NO: No indication for Dysphagia Pathways Program; Defer to conventional management

YES:

Step 2: Recommend appropriate instrumental swallow evaluation with patient/caregiver consent
Is patient/caregiver agreeable to an instrumental swallow evaluation?

NO: Form recommendations using best clinical judgement

See Step 4

YES:

Step 3: Complete instrumental swallow evaluation
Review results and form recommendations

Step 4: Identify factors that would indicate a dysphagia GOC (goals of care) discussion

- Is there concern for or is the patient experiencing reduced OQL (quality of life) or psychosocial distress due to the recommendations?
- Is there concern for or is the patient experiencing poor oral intake (malnutrition, dehydration) due to the recommendations?
- When asked, has the patient expressed that they would *not* want to be on a modified texture diet, be NPO (nothing by mouth), or receive tube feeding?
- Is the patient recommended to be NPO, and/or suspected to have a poor prognosis for improvement of swallow function?
- Is the patient at or expected to be near end of life?
- Is the patient a palliative care or hospice patient?

NO: No indication for dysphagia GOC discussion; Defer to conventional management

YES: Contact hospitalist to discuss swallow evaluation results and identified need for dysphagia GOC discussion

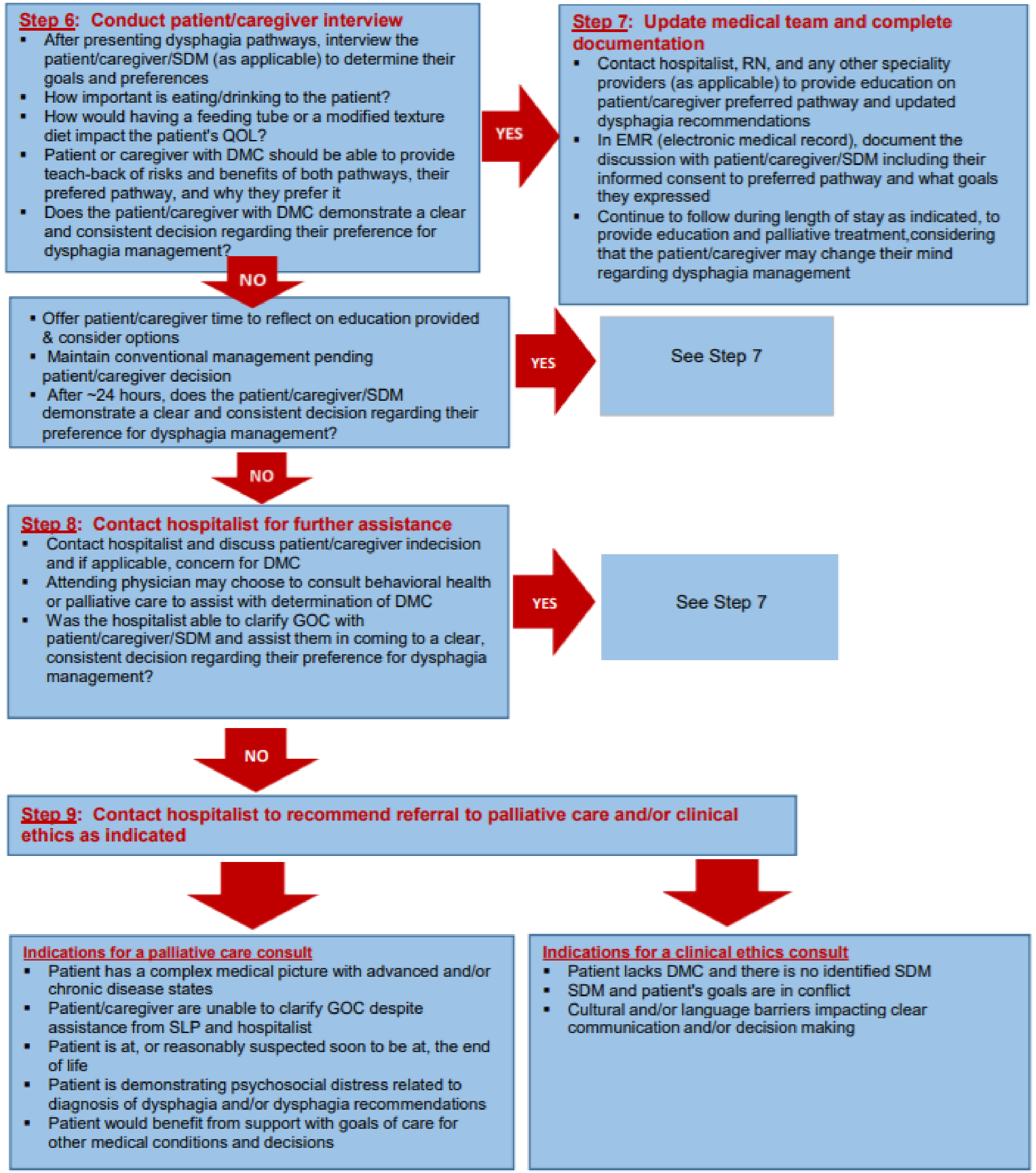
Step 5: Hold dysphagia GOC discussion. Present pathways to patient, caregivers, and/or patient SDM (surrogate decision maker) if pt lacks DMC (decision making capacity)

Pathway 1: Common Dysphagia Management

- Includes conventional practice, including recommendations for modified texture diets, NPO status, and alternative means of nutrition and hydration when indicated
- Primary goal is to reduce adverse medical outcomes of dysphagia including the effects of aspiration and aspiration-related illness and mortality, while maintaining adequate nutrition and hydration
- Often these patients have a good prognosis for improvement in swallow function through rehabilitation

Pathway 2: Palliative Dysphagia Management

- Includes less conventional practice, including recommendations for comfort focused feeding and general avoidance of unpreferred modified texture diets, NPO status, and alternative means of nutrition and hydration
- Primary goal is to promote patient quality of life, comfort, and goals, but not necessarily to prevent adverse medical outcomes of dysphagia
- Often these patients have a poorer prognosis for improvement in swallow function and may have complex medical pictures or advanced disease states
- Sometimes may still include alternative means of nutrition and hydration in plan of care, for supplemental nutritional purposes, per medical team advisal and goals of care



Step 6: Conduct patient/caregiver interview

- After presenting dysphagia pathways, interview the patient/caregiver/SDM (as applicable) to determine their goals and preferences
- How important is eating/drinking to the patient?
- How would having a feeding tube or a modified texture diet impact the patient's QOL?
- Patient or caregiver with DMC should be able to provide teach-back of risks and benefits of both pathways, their prefered pathway, and why they prefer it
- Does the patient/caregiver with DMC demonstrate a clear and consistent decision regarding their preference for dysphagia management?

Step 7: Update medical team and complete documentation

- Contact hospitalist, RN, and any other speciality providers (as applicable) to provide education on patient/caregiver preferred pathway and updated dysphagia recommendations
- In EMR (electronic medical record), document the discussion with patient/caregiver/SDM including their informed consent to preferred pathway and what goals they expressed
- Continue to follow during length of stay as indicated, to provide education and palliative treatment,considering that the patient/caregiver may change their mind regarding dysphagia management

- Offer patient/caregiver time to reflect on education provided & consider options
- Maintain conventional management pending patient/caregiver decision
- After ~24 hours, does the patient/caregiver/SDM demonstrate a clear and consistent decision regarding their preference for dysphagia management?

See Step 7

Step 8: Contact hospitalist for further assistance

- Contact hospitalist and discuss patient/caregiver indecision and if applicable, concern for DMC
- Attending physician may choose to consult behavioral health or palliative care to assist with determination of DMC
- Was the hospitalist able to clarify GOC with patient/caregiver/SDM and assist them in coming to a clear, consistent decision regarding their preference for dysphagia management?

See Step 7

Step 9: Contact hospitalist to recommend referral to palliative care and/or clinical ethics as indicated

Indications for a palliative care consult

- Patient has a complex medical picture with advanced and/or chronic disease states
- Patient/caregiver are unable to clarify GOC despite assistance from SLP and hospitalist
- Patient is at, or reasonably suspected soon to be at, the end of life
- Patient is demonstrating psychosocial distress related to diagnosis of dysphagia and/or dysphagia recommendations
- Patient would benefit from support with goals of care for other medical conditions and decisions

Indications for a clinical ethics consult

- Patient lacks DMC and there is no identified SDM
- SDM and patient's goals are in conflict
- Cultural and/or language barriers impacting clear communication and/or decision making

Steps 1-3

- SLP is consulted for a beside swallow evaluation
- After completing the BSE:
  - Is there a concern for dysphagia with indication for instrumental swallow assessment and/or a regular texture diet is not recommended?
- Recommend an instrumental swallow assessment
- Assuming patient/SDM are agreeable to the instrumental swallowing assessment, complete assessment and form recommendations

Step 4

- Identify if a dysphagia goals of care discussion is needed
- If patient/SDM are agreeable to the primary recommendations provided, defer to common dysphagia management
- However, let’s discuss what factors may be present that would indicate need for further discussion

Indications for a goals of care discussion

- Patient reports they do not want to be on a modified texture diet, be NPO, or have a feeding tube
- Reduced quality of life or psychosocial distress caused by primary recommendations
- Reduced nutritional status or dehydration due to primary recommendations
- Any patient recommended to be NPO with suspected poor prognosis for recovery of swallow function
- Any patient receiving palliative care, hospice care, or at/near end-of-life

- These factors may be identified along the continuum of a patient’s care
- We might identify them during an initial BSE, after an instrumental swallow assessment, or later in the patient’s course of treatment
- Some patients may initially be agreeable to trial a modified diet or NPO status, and then later develop some of the discussed factors that would indicate a change to the initial plan of care
- Discussing goals of care is a continuum and as patients and caregivers adjust to what it looks like to manage dysphagia, their outcomes and goals may change

Step 4 continued

- After identifying these factors, the next step is to contact the patient’s hospitalist to notify of them of the identified need for a dysphagia goals of care discussion

“Hello Dr. Long, I am calling from speech pathology. Do you have a moment to talk about Mr. Roberts? He is having poor oral intake due to his modified diet and is now at risk for dehydration. He reports he does not want to be on thickened liquids any longer. I am planning to have a further conversation with him and his wife regarding their goals of care for dysphagia management. We will discuss the idea of initiating a regular diet, if the patient is comfortable accepting the risks of dysphagia.”

Step 5

Conduct a goals of care discussion

- When holding these discussions ensure that:
  - The patient and any requested family members, friends, or caregivers are present
  - If the patient lacks their own decision-making capacity, ensure the surrogate decision-maker is present
  - Some of these discussions may be formal and some may be casual, depending on the severity of the patient’s difficulty swallowing, if risks are real or assumed, the prognosis, and how the patient/caregivers perceive the situation
  - During the discussion, the SLP presents the 2 differing plans of care to the patient/caregivers: Common Dysphagia management and Palliative dysphagia management and discusses risks and benefits of both
  - We do not necessarily have to use these terms with the patients, we may just say “Option 1” and “Option 2” but I find the terms valuable for use with the rest of the medical team and in documentation

Step 6

Conduct patient/SDM interview regarding goals

- After presenting the dysphagia pathways, interview the patient/caregivers (as applicable) to determine goals, values, and preferences
- How important is eating/drinking to the patient?
- How would having a feeding tube or a modified diet impact the patient's quality of life?

Step 6 continued

- The interview portion of the decision tree, may be brief or extended, depending on the patient/SDM needs
- Some patients are keenly aware of what their acceptable quality of life involves and what their wishes are for eating and drinking
- Other patients and SDMs may feel torn and overwhelmed by the weight of the decision
- We never want to pressure a patient or caregiver into a decision
- Offer time to process and reflect on the information presented, for those who are finding the decision to be difficult
- For those who are able to come a decision during the initial discussion, the next step will be to confirm their understanding and informed consent

Step 6 continued

- For a patient/SDM to demonstrate informed consent regarding dysphagia management, they should be able to:

  - Teach-back the details of both pathways
  - Teach-back basic risks and benefits of both pathways
  - Verbalize which pathway they prefer, and why (i.e. state their goals)
  - Demonstrate this choice clearly and consistently

Step 7

Update medical team and complete documentation

- Contact hospitalist, RN, and any other specialty providers (as applicable) to provide education on the pathway chosen and updated recommendations
- In the electronic medical record, document the discussion with the patient/SDM including their informed consent to their preferred pathway and what goals they expressed
- Continue to follow with the patient, during length of stay to provide education and treatment as indicated, considering that the patient/caregiver may change their mind regarding dysphagia management once they experience the reality of it

Step 8

- For patients and SDMs who required extended time to make a decision, re-visit the topic with them the following day if possible
- After time to process and reflect, does the patient/SDM demonstrate a clear and consistent decision regarding their preference for dysphagia management?
- If patient/SDM are still unsure or inconsistent regarding a choice, contact their hospitalist for further assistance
- At this point, often the hospitalist will discuss goals with the patient themselves
- Was the hospitalist able to with the patient/SDM and assist them in coming to a clear, consistent decision regarding their preference for dysphagia management?

Step 9

Recommend referral to palliative care and/or clinical ethics as indicated

- Indications for palliative care referral
  - Patient with complex medical picture, multiple advanced/chronic diseases
  - Patient/SDM unable to clarify goals of care despite assistance from SLP and hospitalist
  - Patient near or at end-of-life
  - Patient would benefit from support with other goals of care/decision-making (non-dysphagia related)

Step 9 continued

- Indications for clinical ethics referral
  - Patient lacks DMC and hospitalist is unable to identify a SDM
  - SDM and patient goals in conflict
  - Cultural and/or language barriers impacting clear communication for GOC

Goals of Care Discussions

Support for the SLP role in goals of care discussions:

- Evidence shows that therapeutic professionals may understand patients and their goals, better than their physicians
- SLPs have a unique position to facilitate and document (end of life) wishes
  - SLPs may facilitate conversations with patients about decisions relating to nutrition and hydration, ventilation, and tracheostomies
  - SLPs may address patient's priorities, fears, worries, and goals
  - We can provide valuable support in communicating and documenting (end of life) preferences

(Stead & McDonnell, 2015)

- When discussing goals of care for dysphagia management with our patients, we are often discussing serious news
- The importance of these conversations, cannot be underestimated as the result of forgoing these discussions is often a patient receiving care that is inconsistent with their wishes
- Patients who receive the opportunity to discuss goals with their physicians (or clinicians) are shown to:
  - Experience less psychological distress
  - Have a better quality of life
  - Receive end of life care most consistent with their preferences

(Jain & Bernacki, 2020)

- Physicians (or clinicians) who implement a systematic approach to these discussions with patients, report feeling more comfortable during the conversations and report that they find them more rewarding
- This is a skill, like any other, that requires practice

(Jain & Bernacki, 2020)

Framework for a GOC discussion

Step 1: Prepare for the discussion

- Review the patient’s electronic medical record
- Consider the acuity of the patient’s dysphagia
- Consider what the prognosis may be
- Review plans of care that will be presented
- Provide notice to patient and caregivers as applicable about the GOC discussion
- Set a time for the meeting as applicable ensuring all who wish to be included can be present

(Jain & Bernacki, 2020)

Step 2: Introduce the purpose of the discussion

- Discussion should begin with an introduction of all individuals present and their relationship to the patient or role in the patient’s care
- The SLP should clearly convey the purpose of the meeting

“We are meeting today to talk about management options for Mr. Robert’s difficulty swallowing”

(Jain & Bernacki, 2020)

Step 3: Assess patient/caregiver understanding of the problem

- Before you provide any further information, you want to know what the patient/caregiver understand about the patient's dysphagia
- This will help guide what information you provide and at what depth you provide it

"What have you already heard from the medical team about your swallowing?"

"Do you know the results from your swallow assessment?"

- Keep in mind patients and caregivers often will have an overly optimistic or unrealistic sense of illness trajectory

(Jain & Bernacki, 2020)

Step 4: Deliver information about the patient’s dysphagia and suspected prognosis

- Verbally teach-back what patient/caregivers have expressed thus far

“So what I am hearing, is you are all aware Mr. Roberts is having difficulty swallowing. You are disappointed by this news and were hoping for better results after his last swallow assessment”

- Share MBS/FEES results, limiting information provided based on patient/caregiver previous knowledge and health literacy
- If results are severe, it can be helpful to prepare the patient/caregivers with supportive statements such as:

“Unfortunately, I do not have good news about Mr. Robert’s swallowing”

“I am afraid the results were not what you were hoping for”

(Jain & Bernacki, 2020)

Step 4 continued:

- As possible, share suspected etiology and prognosis for the dysphagia

“As you all know, Mr. Robert’s has ALS and with progressive diseases like this, we cannot anticipate that his swallowing will get better”

- General tips for delivering information:
  - Avoid medical jargon
  - Deliver information succinctly
  - Utilize supportive but direct statements

“I hope your swallowing will improve with time, but I worry that it will not.”

(Jain & Bernacki, 2020)

Step 5: Expect and respond to patient/caregiver emotion

- A strong emotional response from a patient/caregiver, can be a positive sign that the information conveyed was appropriately received
- Therapeutic silences and compassionate statements can be helpful in this space

“I wish I had better news to tell you”

“I can see this wasn’t what you were expecting”

“I am so sorry to have to tell you this”

- When patient/SDM appears ready, ask them to provide teach-back of the information presented to assess for understanding

“So that I can ensure we are all understanding each other, can you please summarize what I’ve told you so far?”

(Jain & Bernacki, 2020)

Step 6: Present treatment options (pathways) and assess patient/caregiver preferences

- Present the dysphagia pathways as appropriately tailored to the individual patient and assess the patient’s preferences based on their goals, wishes, and acceptable quality of life
- Explain common and palliative dysphagia management, similarities and differences, risks and benefits, and any alternative treatment options if applicable

  (E.g., PEG with comfort feeds, Frazier Free Water Protocol, etc.)

- Questions to ask to assess goals and preferences:

“Have you ever known anyone who had trouble swallowing, how did that affect them? How would that affect you?”

“Have you or anyone you know ever needed a special diet or a feeding tube?”

“Would your quality of life be acceptable if you couldn’t eat or drink?

(Jain & Bernacki, 2020)

“Part of the clinicians responsibility in the decision making process is to emphasize importance of individual preference while also acknowledging the extent of uncertainty regarding projected treatment outcomes.”

(Jain & Bernacki, p.384, 2020)

- Clinicians can offer a recommendation, but this must be based only on the patient’s reported goals and preferences, not personal opinion or liability.

(Jain & Bernacki, 2020)

- At this point in the discussion, the patient/SDM may come to a decision, and the SLP will again ask for confirmation of understanding by asking the patient/SDM for teach-back of information discussed

- If patient/SDM are unable to come to a decision, we again offer time for reflection and re-visit the topic at a later time, involving the hospitalist and other specialty services as indicated

Step 7: Follow up with the multidisciplinary medical team

- Communicate the outcomes and decisions made in the discussion, to all pertinent medical team members
- Document the discussion and update the treatment plan and orders as indicated

(Jain & Bernacki, 2020)

Case Study 1

- Mrs. Garcia
- 65 year-old female with PMH: atrial fibrillation, hypothyroidism, chronic pain, thrombocytopenia, anemia, advanced COPD, and multiple admissions over the past few months for malnutrition, bacteremia, and respiratory failure requiring previous intubations
- The patient presented to our hospital as transfer from an outlying hospital with encephalopathy, septic shock, GI Bleed, and right pneumothorax
- The patient was admitted to the MICU and palliative care was consulted

- SLP was consulted for a BSE on hospital day 4
- Patient was NPO with NGT prior to SLP consult due to poor alertness and altered mentation x4 days
- Pt had no reported history of dysphagia
- Clinical s/sx of dysphagia during BSE: immediate and delayed coughing with thin liquids, effortful swallowing, and odynophagia
- Predictors for aspiration pneumonia: multiple medical diagnoses, current smoker, high number of medications, tube fed
- Chest imaging: Left lower lung consolidation, persistent bilateral pleural effusions, lesion concerning for malignancy

- SLP performed a FEES the same day in the MICU for further pharyngeal diagnostics
- FEES Results: moderate pharyngeal dysphagia
  - Physiological deficits: reduced supraglottic closure, partial epiglottic inversion, reduced tongue base retraction, reduced cough strength
  - Deep laryngeal penetration observed with thin and nectar thick liquids with immediate cough response
  - Cough was judged to be ineffective to clear material from laryngeal vestibule; aspiration of residue was observed inconsistently after the swallow
- FEES Recommendations: chopped solids, honey thick liquids, with plan for ongoing dysphagia intervention and repeat FEES within the next 5-7 days to assess for improvement following daily rehabilitative swallowing treatment
- Following presentation of the FEES results and recommendations, the patient informed the SLP that she did not wish to be on a modified diet

- The Dysphagia Pathways Program decision tree was utilized to guide further discussion and intervention
- The need for a goals of care discussion was identified
- Indicators:
  - Patient voiced preference for a regular diet
  - Palliative care patient
  - Multiple recent hospitalizations
  - Advanced disease state (COPD)
  - Suspected poor prognosis regarding recovery of swallow function, given patient's overall decline in functional status with progressive weakness and advanced COPD

Goals of care conversation

- SLP contacted intensivist and discussed indication for goals of care conversation
- SLP met with patient and patient’s son in the MICU
- Patient’s son was deemed her surrogate decision maker, due to patient’s waxing/waning alertness and mentation limiting her capacity during hospital stay

- Patient/SDM education was provided regarding FEES results and options for dysphagia management
- Education provided regarding the patient's personal risk factors for development of dysphagia and subsequent illness
  - Progressive weakness
  - Advanced COPD
  - History of respiratory failure/intubations
  - Suspected poor prognosis for improvement in dysphagia
- Patient expressed sadness regarding her condition, but that her QOL would not be maintained without her normal foods and drinks. She expressed hope for improvement in her swallowing and overall medical condition, but acknowledged her prognosis
- The patient’s son expressed that he would respect his mom’s wishes regardless of the risks
- The patient’s son was able to demonstrate informed consent to the risks of dysphagia, and verbalized his wish to proceed with palliative dysphagia management to support his mom’s wishes and QOL
- SLP updated the intensivist, RN, and palliative care team on the outcomes of the discussion
- SLP completed documentation and updated orders and patient’s plan of care

Documentation

- In many circumstances, it will be appropriate to provide 2 separate recommendations (pathways) in the EMR, which support differing plans of care, dependent upon the patient’s overall goals and preferences
- This may be especially useful when the SLP observes factors that might indicate a future need for a goals of care discussion
  - E.g. A patient who tells the SLP they would never want a feeding tube or to drink thickened liquids
  - E.g. A patient with a progressive etiology of dysphagia
  - E.g. A patient with advanced age or suspected to be near end-of-life

.PALLIATIVEPENDING

{MMMBSFEES:43156} recommendations are advised, pending pt/caregiver goals of care. Treating SLP and medical team may consider factors including patient quality of life, prognosis, goals of care, risks and benefits of recommended and alternative treatment, and pt/caregiver wishes surrounding oral intake. A dysphagia management GOC discussion should be initiated if patient/caregiver are not agreeable to below recommendations, or if they negatively impact patient quality of life or nutritional status.

.PALLIATIVEPATHWAYSBASIC

Pathway 1: Common dysphagia management with goal to reduce risk for aspiration and aspiration-related illness would include {MMDIET:43157} with plan for ongoing dysphagia rehabilitation and repeat instrumental swallow study in the future to assess for improvement in dysphagia. Benefits may include: reduced risk for aspiration and aspiration-related illness including respiratory compromise, pulmonary compromise, pneumonia, choking, and death; Risks may include: dehydration, malnutrition, reduced quality of life, and psychosocial impact including depression, anxiety, and social isolation.

Pathway 2: Palliative dysphagia management with goal to continue oral intake and avoid NPO status/alternative means of nutrition/hydration, would include {MMDIET2:43158}. SLP to provide ongoing support for dysphagia management. Risks may include: aspiration, aspiration-related illness including respiratory compromise, pulmonary compromise, pneumonia, choking, and death. Benefits may include: increased nutrition and hydration, increased quality of life, and increased psychosocial health and well-being.

Case Study Example: Mrs. Garcia

FEES recommendations:

Pathway 1: Common dysphagia management with goal to reduce risk for aspiration and aspiration-related illness would include diet of honey thick liquids and chopped soft solids with plan for ongoing dysphagia rehabilitation and repeat instrumental swallow study in the next 5-7 days, to assess for improvement in dysphagia. Benefits may include: reduced risk for aspiration and aspiration-related illness including respiratory compromise, pulmonary compromise, pneumonia, choking, and death; Risks may include: dehydration, malnutrition, reduced quality of life, and psychosocial impact including depression, anxiety, and social isolation.

Pathway 2: Palliative dysphagia management with goal to continue oral intake and avoid NPO status/alternative means of nutrition/hydration, would include a regular diet. SLP to provide ongoing support for dysphagia management. Risks may include: aspiration, aspiration-related illness including respiratory compromise, pulmonary compromise, pneumonia, choking, and death. Benefits may include: increased nutrition and hydration, increased quality of life, and increased psychosocial health and well-being.

.PALLIATIVEGOC

A meeting was held today to discuss goals of care for dysphagia management. Pt was found to have {DYSPHAGIASEVERITY:43212} dysphagia following {SLP instrumentation:32314} and was recommended {MMDIET:43157}. The need for GOC discussion was identified given: {GOCINDICATION:43213}. The individuals present were: ***. Pt has been deemed to have DMC OR Pt has been deemed to lack DMC and *** is acting as their SDM. The purpose of the GOC discussion was introduced to patient/caregiver. Education provided regarding {SLP instumentation:32314} results, and severity of dysphagia, suspected etiology, and suspected prognosis was explained. Introduced the dysphagia pathways.

Discussed that Pathway 1: Common dysphagia management with goal to reduce risk for dysphagia, aspiration, and dysphagia-related illness would include {MMDIET:43157} with plan for ongoing dysphagia rehabilitation and repeat instrumental swallow evaluation in the future to assess for improvement. Benefits may include: reduced risk for aspiration and dysphagia-related illness including respiratory compromise, pulmonary compromise, choking, and death; Risks may include: dehydration, malnutrition, reduced quality of life, and psychosocial impact including depression, anxiety, social isolation, and side effects of tube feeding (if applicable) including infection, nausea, vomiting, diarrhea, tube falling out, repeat hospitalizations, pressure sores, and use of restraints and/or sedatives. Discussed that Pathway 2: Palliative dysphagia management with goal to continue oral intake and avoid NPO status/alternative means of nutrition/hydration, would include patient consuming {MMDIET2:43158}. SLP to provide ongoing support for dysphagia management. Risks may include: aspiration, dysphagia-related illness including respiratory compromise, pulmonary compromise, choking, and death. Benefits may include: increased nutrition and hydration, increased quality of life, and increased psychosocial health and well-being.

Patient/caregiver stated their goals include ***. Patient/caregiver were able to demonstrate informed consent by teaching-back the risks and benefits of presented dysphagia pathways. Patient/caregiver verbalized they would like to proceed with Pathway 1: Common dysphagia management/Pathway 2: Palliative dysphagia management. Discussed outcome of GOC discussion with RN and MD, and updated orders and plan of care to reflect this.

A meeting was held today to discuss goals of care for dysphagia management. Pt was found to have **moderate pharyngeal dysphagia** following **FEES** and was recommended **a modified diet of honey thick liquids and chopped soft solids**. The need for GOC discussion was identified given **pt expressing wishes for a regular diet, established palliative care patient, concern for poor prognosis for recovery in swallow function.**

The individuals present were: **Mrs. Garcia, her son Juan Garcia, and this SLP.** Pt has **been deemed to lack DMC and Juan Garcia is acting as her SDM.** The purpose of the GOC discussion was introduced to patient/caregiver. Education provided regarding FEES results, and severity of dysphagia, suspected etiology, and suspected prognosis was explained. Introduced the dysphagia pathways.

Discussed that Pathway 1: Common dysphagia management with goal to reduce risk for aspiration and aspiration-related illness would include diet of **honey thick liquids and chopped soft solids with plan for ongoing dysphagia rehabilitation and repeat instrumental swallow study in the next 5-7 days**, to assess for improvement in dysphagia. Benefits may include: reduced risk for aspiration and aspiration-related illness including respiratory compromise, pulmonary compromise, pneumonia, choking, and death; Risks may include: dehydration, malnutrition, reduced quality of life, and psychosocial impact including depression, anxiety, and social isolation. Discussed that Pathway 2: Palliative dysphagia management with goal to continue oral intake and avoid NPO status/alternative means of nutrition/hydration, would include **a regular diet.** SLP to provide ongoing support for dysphagia management. Risks may include: aspiration, aspiration-related illness including respiratory compromise, pulmonary compromise, pneumonia, choking, and death. Benefits may include: increased nutrition and hydration, increased quality of life, and increased psychosocial health and well-being.

SDM (Juan Garcia) was able to demonstrate informed consent by teaching-back the risks and benefits of presented dysphagia pathways. Mrs. Garcia stated her goals include consuming a regular diet for QOL purposes. Juan verbalized he would like to proceed with Pathway 2: Palliative dysphagia management to support his mother’s wishes for a regular diet.

Discussed outcome of GOC discussion with RN and MD, and updated orders and plan of care to reflect this.

- The field of speech-language pathology is an art and a science
- There is gray area, and subjectivity, when it comes to forming dysphagia recommendations
- SLPs may feel pressure from the medical team to provide black and white recommendations for our patients, but that is often not possible
- It may be an adjustment to write multiple recommendations, or write recommendations that are pending further discussion with consideration for goals of care
- However, as SLPs we have a unique opportunity in this space to be advocates for our patients and examples to the rest of the medical team, to pause the cascade of care, and ask important questions before it becomes too late

Case Study 2

- Mr. Brajot
- 80 year-old male with PMH: hypertension, CVA, and right vocal fold paralysis
- The patient presented to our hospital following a fall with associated left knee pain
- Pt was found to have a left femur fracture and septic shock due to urosepsis

- SLP was consulted for a BSE on hospital day 1 given RN observing overt s/sx of dysphagia during patient’s meal time
- Pt had a history of dysphagia and dysphonia secondary to right vocal fold paralysis from a stroke 5 years prior
- Pt had been evaluated by SLP in the past. Pt reported he was told he aspirates liquids following an MBS several years ago, trialed thickened liquids but was never able to tolerate them due to poor taste and texture
- Pt also reported he was told a chin tuck would help to reduce his risk for aspiration, but was also unable to tolerate this strategy due to the burden it placed on oral intake intake.
- Most recently, the patient reported he was consuming a regular diet at home without associated respiratory or pulmonary complications but with frequent coughing during meals

- Clinical s/sx of dysphagia during BSE: immediate strong coughing episodes with liquids, reddened face and increased respiratory rate when drinking
- Predictors for aspiration pneumonia: multiple medical diagnoses, h/o visualized aspiration on instrumental swallow testing, impaired immune system due to urosepsis
- Chest imaging: “No acute cardiopulmonary abnormalities”
- Pt on room air

- Following the BSE, an instrumental swallow assessment was recommended for further laryngeal/pharyngeal diagnostics
- However, Mr. Brajot declined any further swallow assessments
- Pt stated that he would not follow recommendations for diet modifications or compensatory strategies given his history of trying them and being unable to tolerate the burden it placed on oral intake and QOL

- The Dysphagia Pathways Program decision tree was utilized to guide further discussion and intervention
- The need for a goals of care discussion was identified
- Indicators:
  - Patient voiced he would not consume a modified texture diet
  - Patient declined further instrumental swallow assessment
  - Suspected poor prognosis regarding recovery of swallow function, given history of chronic dysphagia (~5 years) due to unilateral vocal fold paralysis
  - Of note, patient did undergo vocal fold medialization several years after his stroke but this did not improve his dysphagia

Goals of care conversation

- SLP contacted hospitalist and discussed indication for goals of care conversation
- SLP met with patient and patient’s wife (via telephone call)
- Patient possessed DMC

- Patient/caregiver education was provided regarding BSE results and options for dysphagia management
- Education provided regarding the patient's personal risk factors for development of dysphagia and subsequent illness
    - Unilateral vocal fold paralysis
    - Hx of visualized aspiration of instrumental swallow assessments
    - Impaired immune system with urosepsis
- Patient expressed excellent insight into diagnosis and risks of dysphagia. Patient expressed he had been living with the dysphagia for 5 years, with only one known occurrence of PNA
- The patient and his wife were able to demonstrate informed consent to the risks of dysphagia, and verbalized wish to proceed with palliative dysphagia management and continue a regular diet
- SLP updated the hospitalist and RN, and on the outcomes of the discussion
- SLP completed documentation and updated orders and patient’s plan of care

Providing palliative dysphagia care

- Much of what seems like common sense to us as SLPs, is new information for patients and caregivers
- Education and instruction may include:
  - Teaching patient and caregivers the signs and symptoms of dysphagia
  - Training in compensatory swallow strategies
  - Teaching patients/caregivers how to modify their diet, what foods to eat, what food to avoid, as appropriate
  - Teaching caregivers how to carefully-hand feed patients
    - Rate of oral intake
    - Positioning
    - Reading a patient's non-verbal cues
    - Assessing appropriate alertness/mentation for p.o. intake
    - How to palpate for a swallow reflex
    - How to check the oral cavity for residue and clear it as necessary
  - Training caregivers how to provide oral care
    - This also gives caregivers something tangible they can provide directly to the patient that is a caring task that can help take the place of feeding the patient, when swallowing becomes more difficult or uncomfortable

- Another part of providing palliative dysphagia management, may include a multidisciplinary effort of monitoring the patient for any expected concerns
  - Nutritional intake, hydration
  - Weight
  - Temperature
  - Evidence of pneumonia
  - Quality of life
- Patients (and SDMs) maintain the right to change their plan of care, once they experience the reality of it
- Example: A patient was recommended ANH and decided to eat by mouth. If burden of swallowing or medical complications are unmanageable, or risks are found to outweigh benefits, the patient may change their mind and request a feeding tube

(Sharp & Bryant, 2003)

- Continued consultation and defining of goals of care, to ensure that the patient’s initial preferences and goals are being met through the selected plan of care

Swallowing changes at end-of-life

- For some patients, including hospice patients or those with suspected progressive dysphagia (i.e. ALS), it can be helpful to educate the patient and caregiver on what to expect
- Dysphagia is a common symptom at end-of-life and swallowing safety is often compromised (Groher & Groher, 2012)
- In a retrospective study, dysphagia was one of the seven most common reported symptoms in the last 48 hours of life (Pollens, 2004)

- Fatigue and poor appetite are signs of a person entering the active dying phase
- Loss of appetite is natural and expected when the body (digestive tract) begins to shut down
- Reduced food and drink intake at the end of life does not cause suffering as long as oral care and small amounts of water are provided
  - Many caregivers feel that their loved ones are “starving” at end-of-life, because they stop a normal pattern of eating and drinking
  - It may provide reassurance to explain that this is a natural process, and that their loved one is actually likely not experiencing hunger
  - Train in oral care as a substitute for providing oral intake
- Consider that food/drink may no longer be enjoyable at the end of life, and this is acceptable, anticipated, and part of the dying process

(Askren & Kershner, 2020)

Cool Water

Benjamin W. Frush, M.D

- Writes a thought provoking story, centered around a dying patient asking for water
- The patient keeps asking his doctor for water, his doctor keeps saying no, as he is only allowed 1 liter of fluid per day
- The doctors suspects the patient is dying, although he fears saying this aloud, and he continues with an aggressive plan of care including the fluid restriction

“And I look at the dying man on the bed, who is turgid and desperate and thirsty, so thirsty, can he please have something to drink? I am this man’s Doctor, it is time to assert myself, and I say, “No, remember we talked about this, you need to do your part. We said one liter yesterday, did we not?”

(Frush, 2021)

“Here, here is your Nurse,” I say, “she has the small sponge on a stick, that should do it for you; no, please don’t chew the ice — the ice will melt and it is part of that one liter. Your Nurse, she says you tried to drink from the sink yesterday, is this true?” And the dying man looks up, and his eyes are sunken and his lips are cracked and his breath is rancid..”

- Later that day, the man decompensates, and the doctor recognizes his initiation was right- the man indeed is dying
- The doctor quickly enters comfort orders, and stops the aggressive plan of care
- He wants to allow the patient as much water as he wants, but he finds it is now too late

(Frush, 2021)

" I ask the Nurse, "Do you think we could give him some of that cool water?" "I think we are past that point," she says, "and besides, he looks very peaceful." I nod and I squeeze his tumid hand and I leave…But what I would give to go back and to say yes, yes, you are right, you are dying, and it is OK, and here is that cool water, here, I will have some, too."

(Frush, 2021)

Questions?

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