# I CHEWS: A Transformative Approach to Person-Centered Dysphagia Management Through Public Health Education

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#### Discosures

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Financial: Employed and receives a salary from University of New Hampshire

**Non-financial:** serves on the executive board of the New Hampshire Speech Language Hearing Association as the Vice President of Membership-Outreach. Volunteers through community outreach & public health education.

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Non-financial: Volunteers through community outreach & public health education with I CHEWS

#### Kate Phelps, MS, CCC-SLP

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## Learning Objectives

02 Learn the I CHEWS Framework

3 -

Apply the I CHEWS Framework

#### Poll

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# Tenets of Informed Shared Decision-Making

- 1. Clinician and patient collaborate
- 2. Best available evidence is provided & options considered
- 3. Achieve an informed, preferred choice

#### Poll

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#### The Gold Standard



Person-centered care is internationally recognized as a critical attribute of high-quality healthcare.

Shared decision-making is an essential component of person-centered care, and is considered the gold standard in patient-provider interactions.

Informed shared decision-making underscores that the decision-making process requires more than consent - it requires the best available evidence.

Principles and Models that Support ISDM

- Patient-centered care
- Informed consent
- Shared decision-making
- Evidence-based practice
- Clinical ethics:
  - autonomy, beneficence,
     nonmaleficence, equity
- Patients' rights and responsibilities
- Minimally disruptive medicine
- Values-based care

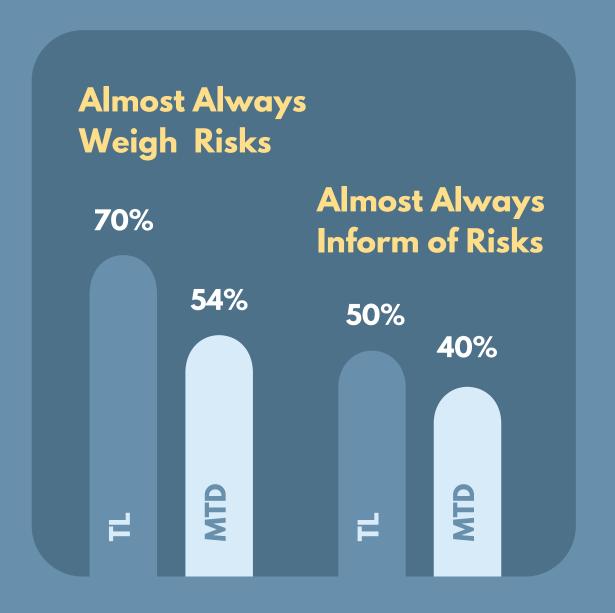


Traditional Approach to Dysphagia Management

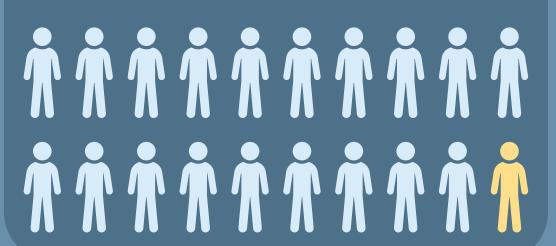
- Clinician-directed care
- Clinical experience drives recommendations
- Defensive medicine
- Suboptimal risk disclosure & patient education
- Monitor for compliance



#### ISDM and SLP Practice Patterns



93% of Irish patients diagnosed with stroke were not involved in making a decision for thickened liquids.



"There was no decision— I was just told"

"If risk feeding, why not 'risk walking' or 'anticoagulation at acknowledged risk of bleeding'? 'Risk-anything' is not how healthcare (or other) decisions are reached: instead, people need to be informed of the potential benefits and risks of any proposed interventions and can then weigh up this information in the context of their preferences and goals and decide how to proceed."

# Existing Frameworks and Tools



#### **EDAR Decision-Making Flowchart**



Eating and drinking with acknowledged risks: Multidisciplir team guidance for the shared decision-making process (adults)

#### Engage in Process of Shared Decision-Making 1. Provide clear information of the person's swallowing ability:

- - a. a clear summary and explanation of the assessment results
  - b. include information on the severity of their presentation
- 2. Describe all treatment options available to the person
- 3. Talk through all risks and consequences associated with each treatment option
- 4. Determine a plan for eating/drinking (inc. strategies)

#### **Document Shared Decision-Making**

1. Document the above discussion and final decision in the person's official medical record

# Existing Frameworks and Tools



#### PARTNERS© Framework

- 1. Prognosis
- 2. Advance Directives
- 3. Risk
- 4. Talk
- 5. Nonoral Feedings
- 6. Expectations
- 7. Recommendations
- 8. Summary and Support

## ISDM Practice Patterns in Healthcare

### Information About Benefits & Risks

- More discussion of benefits vs. risks with medications and tests
- Patient had minimal discussion of either

## Provider Asked Patient Preferences

- Situational
- Ranged from 37%(medication) to 78%(surgery)

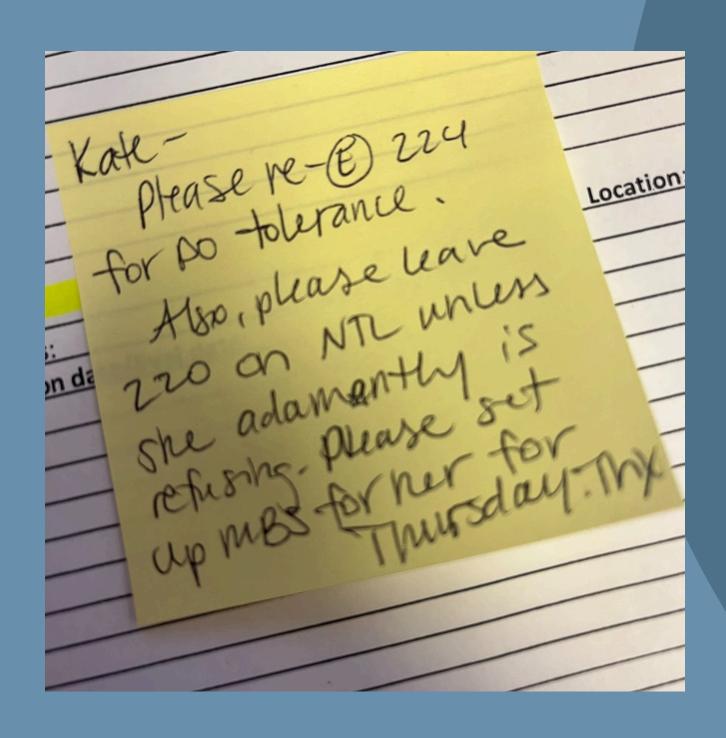
#### **OPTION Scale**

- 12-item observational tool
- 5-point rating (0-4)
- Raw score: 0-100 (higher =
   better patient involvement)
- low (5 23)

(Fowler et al., 2013; Dierckx et al., 2013; Jones et al., 2013; Mertyz et al., 2018; Couet et al., 2013)



#### In Practice



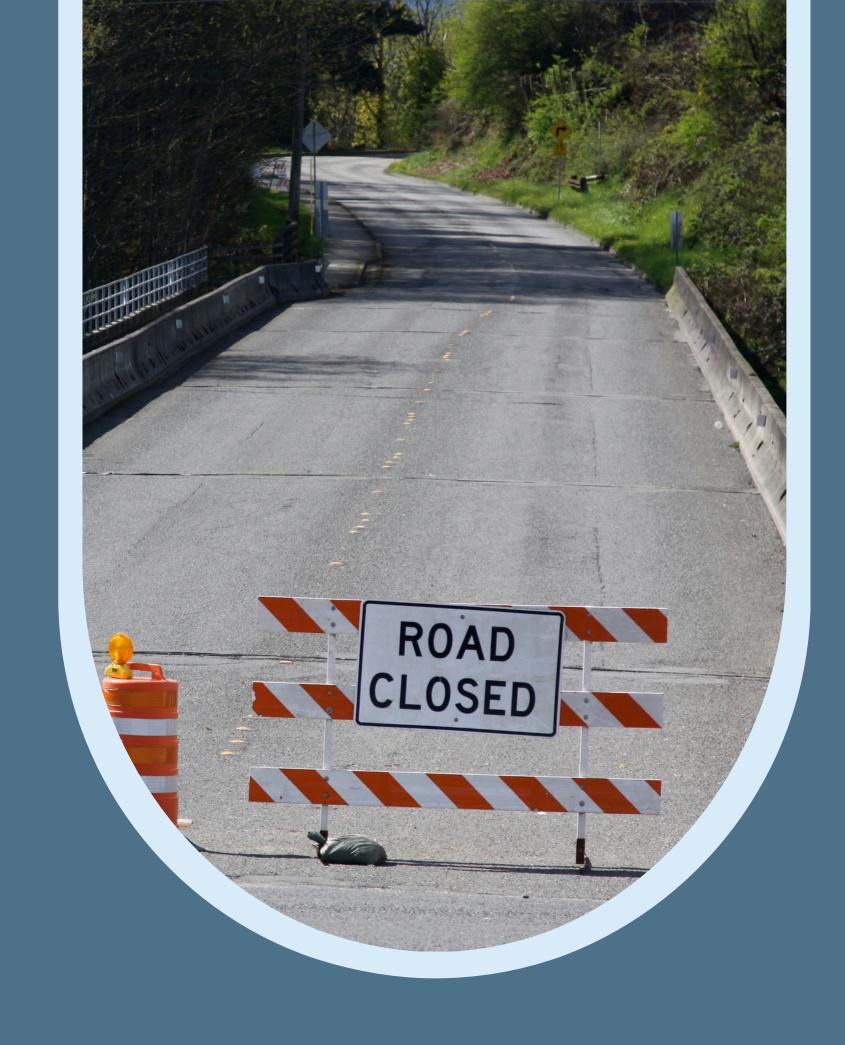
"Open discussion/education provided re: prior MBS results, current respiratory status, s/sx of aspiration, progressive swallowing difficulty, past esophageal deficits, treatment/diet options and clinical recommendations.

Pt amenable to repeat MBS for re-eval of swallow function and to consume nectar thick liquids in the interim as a precaution. MBS will be completed 12/26/24 due to tomorrows' holiday.

Dietary Recommendations: Diced Meats, Regular Solids, Close Supervision, Nectar Thick Liquids"

#### Barriers

- Insufficient education & training
- Misunderstandings about ethical clinical practices
- Evidence knowledge gaps
- Productivity standards
- Time constraints
- Systemic issues
- Assumed metrics of success
- Patient attitudes and practices



## Patient Attitudes and Practices

- Passive participation
- Deference to providers
- Overtrust clinical recommendations
- Low question asking
- Unvoiced concerns, limited disclosure, polite compliance



(Bynum et al., 2015; Gaffney & Hamiduzzaman, 2022)

Clinical and patient practices need to change....



### The Solution

Educate and empower patients to drive their own health care through a public health campaign promoting informed shared decision-making





Community-based public health campaigns reliably facilitate health behavior change in older adults.

#### **Core components:**

- Community-based programs
- Multiple components
- Peer-based
- Social support strategies
- Tailored, culturally appropriate messaging

# Effective Public Health Campaigns





of hip fractures are caused by older adult falls.

Keep your patients #STEADI.



stroke.org/en/fast-experience cdc.gov/still-going-strong cdc.gov/steadi

Learn more at stroke.

## A Work in Progress

- 1. Literature review and synthesis
- 2. Informal interviews
- 3. Content development
- 4. Community partnerships
- 5. Pilot groups in the community
- 6. Feedback from stakeholders
- 7. Adjust messaging
- 8. Impact stories



#### when it comes to my health ...

## CHEMS "I choose"

# Introducing the ICHEWS Framework

A guide to informed shared decision-making in dysphagia care



Involve yourself



Choose wisely



Honor your values



**E**ducate yourself



Work together



Speak up

#### From Passive to Empowered Patients

#### Traditional Clinical Approach

Clinician-directed care

Defensive medicine

Clinical expertise

Suboptimal risk disclosure

Monitor for compliance

## Common Patient Behaviors

Passive participation

Overtrust clinical recommedations

Deference to providers

Low-question asking

Unvoiced concerns, limited disclosure, polite compliance

## Reframing with I CHEWS

Involve yourself

Choose wisely

Honor your values & Work together

Educate yourself

Speak up



## I - Involve yourself

Patient-centered care, Autonomy

Actively participate in your health care decisions and clearly express your wants and needs.



## I - Involve yourself

Patient-centered care, Autonomy

# ISDM-Aligned Clinical Approach

Empowered Patients

- Explain roles, responsibilities, and rights
- Seek patient participation, justify self-management (multiple choices, different impacts, uncertainty)
- Teach I CHEWS framework

- Actively participate in their care
- Drive the conversation



## C - Choose wisely

Beneficence, nonmaleficence

When making decisions, think about your health and well-being, including your enjoyment and quality of life.



## C - Choose wisely

Beneficence, nonmaleficence

#### ISDM-Aligned Approach

Empowered Patients

- Consider health (nutrition, hydration, pulmonary health) and quality of life outcomes
- Consider the impact, effort, and burden
- Provide all options in patient-friendly language
- Promote autonomy

- Thoughtfully weigh options with their values in mind
- Consider both their health and quality of life



## H - Honor your values

Person-centered care, values-based care, minimally disruptive medicine

Share what you value most at this time with your clinicians and providers.



## H - Honor your values

Person-centered care, values-based care, minimally disruptive medicine

#### ISDM-Aligned Approach

**Empowered Patients** 

- Engage in a goals of care discussion
- Facilitate reflection on their values
- Relate treatment options to the patient's values and preferences

- Engage in self-reflection
- Share their values and preferences



## E - Educate yourself

Informed decision-making, Information disclosure, Informed consent

Take time to understand all of your options, including the risks and benefits.



## E - Educate yourself

Informed decision-making, Information disclosure, Informed consent

#### ISDM-Aligned Approach

**Empowered Patients** 

- Discuss options including all components of BRAN
- Encourage and answer questions
- Acknowledge uncertainties
- Check for understanding via teachback

- Request resources to learn
- Ask questions



## W - Work together

Shared decision-making, interprofessional practice

Work together with everyone on your care team

including clinicians and providers as well as your loved ones and support system.



## W - Work together

Shared decision-making, interprofessional practice

#### ISDM-Aligned Approach

Empowered Patients

- Involve all key stakeholders (family and care team)
- Provide support in decision-making

Include their family, care partners, and care team



## S - Speak up

Participation in treatment decisions, autonomy, self-determination

Ask questions so you can make informed decisions about your eating, drinking, and swallowing health care.



## S - Speak up

Participation in treatment decisions, autonomy, self-determination

#### ISDM-Aligned Approach

**Empowered Patients** 

- Promote self-monitoring, and self-modification to POC
- Create opportunities to re-assess and make changes

- Provide honest feedback
- Voice their concerns
- Continuously re-evaluate



Involve yourself

when it comes to my health ...



Choose wisely

CHEMS "I choose"



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Speak up

## Overcoming the Barriers with I CHEWS



Promote active patient participation



Optimize efficiency and your time



Increase patients' understanding and knowledge



Achieve patient and clinician partnership

## Pratical Application

#### Self

- Self-audit using 10-item checklist from SDM toolkit
- Build values talk skills with tools and courses: VitalTalk, ICAN
- Use I CHEWS to embed ISDM into your workflow
- Teach I CHEWS to your patients
- Use decision aids
- Assess ISDM in real time using SDM-Q-9 or collaboRATE
- Practice with a virtual AI patient
- Hang a poster in your office
- Give pocket cards to patients

#### Team

- Teach ISDM and I CHEWS to your students and team
- Dialogue about ISDM with a colleague
- Discuss in a journal club
- Facilitate ISDM training using the SDM toolkit

#### Community

- Share I CHEWS with existing
   SLP community groups
- Present at your facility
- Present to your community (e.g., senior centers, library)
- Publicly disseminate
   materials (e.g., flyers,
   newsletters, dysphagia
   awareness month)

## Case Studies

#### Case Study A

52 y/o L-handed male, 1 year post L CVA PEG-dependent and NPO (FOIS 1) for 1 year. Presents for OP MBSS following 9 months of therapy w/ prior SLP. No prior hx of PNA. 25% underweight, R hemiparesis, mild apraxia of speech, dysarthria, and anomic aphasia, no cog-comm deficits, and independent with IADLs. Lives alone, cousin is involved. Imaging reveals trace flash penetration (PAS 2) with thin liquids only, mild pharyngeal residue with liquids, puree, and soft solids in 5mL amounts. Absent pharyngeal constriction and impaired UES opening. Minimal improvement with R head turn.

#### **Traditional Approach:**

Clinician recommends least restrictive diet (mildly thick liquids and soft solids) with aspiration precautions. Brief education of results and diet to patient. Follow-up with OP SLP.

#### Case Study A

#### ISDM-Alligned Approach:

Thoroughly discuss all clinically acceptable options (e.g., initiate PO with or without compensatory maneuvers, bolus-driven therapy, exercise therapy, modified texture diets, education only, no intervention) without suggesting one is superior. Educate in benefits, risks, and burdens associated with each. Include cousin in the conversation, consult with dietician and PT. Patient's values, lifestyle, and preferences are central to the joint decision.

#### Case Study B

56 y/o female 4 months s/p CRT for laryngeal cancer, PEG-dependent with inconsistent PO (FOIS 2). Presents with new onset URI symptoms and cachexia. Pt is receiving IV fluids intermittently. PMH includes substance use disorder, multiple mental health conditions. Sister is actively involved in care.

#### **Traditional Approach:**

Chest CT reveals consolidation in RLL concerning for aspiration pneumonia. Bedside swallow eval unremarkable. Clinician-driven decision for strict NPO, oral care 4x/day, orders MBSS. Notifies team.

Imaging reveals chronic gross deep penetration of thin and mildly thick liquids (PAS 5) but no aspiration. Does not improve with chin tuck. No pharyngeal residue.

Upgrade to mildly thick liquids and puree at discharge. Education in alternatives is brief and described as unsafe. Education to sister on how to purchase thickeners and how to thicken liquids. F/u with OP SLP to monitor.

#### Case Study B

#### ISDM-Alligned Approach:

Following bedside swallow eval, patient and sister participate in education on all medically acceptable options (e.g., PO w/ or w/o imaging and/or diet modifications), as well as the benefits, risks, and burdens associated with each. Together, they weigh options against their health goals and values

Following imaging, they use a decision aid to compare all options (e.g., NPO, FFW protocol, unlimited PO with oral care, outpatient dysphagia therapy after d/c, no intervention) including the benefits and risks of each. They weigh the pros and cons based on their values, health priorities, financial means, geographic limitations. Education provided in patient-friendly language, verbally and in writing. Collaborate with other disciplines including dentist for ill-fitting dentures and dietian.



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Involve yourself



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Work together



Speak up



Use these ideas as a guide to support conversations with you family, care partners, doctors, and entire health care tear about your eating, drinking, and swallowing

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