SWALLOWING, COGNITION, AND DIGNITY: A CLINICAL PATHWAY FOR DYSPHAGIA IN PERSONS WITH DEMENTIA

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OBJECTIVES

• Identify steps to implement a systematic protocol for dysphagia in persons with dementia
• Describe the rationale for use of the Dysphagia–Dementia Scale
• Develop functional, measurable, patient-focused goals for patients with dual diagnosis of dysphagia and dementia

QUALITY OF LIFE

“Where there is life ... we must provide quality of life.” –Paul Raia

• Cognition, nutrition, and hydration are a significant part of our quality of life
  – We give directions by using restaurants as landmarks
  – We use executive functions to plan, organize, and sequence our meal preparations
  – We look forward to enjoying meals with friends and family

PURPOSE OF THE PROTOCOL

• 1st choice – To sustain nutrition and hydration needs via eating by mouth
• 2nd choice – Safely and effectively tolerate quality of life, recreational/plasure PO intake
• Provide an alternative to enteral and parenteral nutrition and hydration due to their contraindications in persons with advanced dementia

THE COGNITIVE–COMMUNICATION HIERARCHY

Executive functions
Judgement, insight
Reasoning, organization
Problem solving, sequencing
Short- and long-term memory
Core/foundational-level cognitive skills: arousal, alertness, consciousness, awareness, attention, concentration
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THE NORMAL AGING SWALLOW
• What has been described as swallowing dysfunction in young persons may not be abnormal in very elderly persons. It is difficult to distinguish the effect of normal aging from the effects of specific diseases or gradual degenerative changes.
  (Tracy et al., 1989)
• Five measures were significantly changed with increasing age:
  1. Duration of pharyngeal swallow delay (increased)
  2. Duration of pharyngeal swallow response (decreased)
  3. Duration of cricopharyngeal opening (decreased)
  4. Peristaltic amplitude (decreased)
  5. Peristaltic velocity (decreased)

EARLY-STAGE DEMENTIA: SWALLOWING, NUTRITION, AND HYDRATION
• Mild cognitive impairment (MCI)
• Depression
• Taste and smell dysfunction
• Awareness of cognitive deficits
• Attention – mildly impaired
  • Distracted intermittently throughout the meal
• Medications and polypharmacy
• Decreased nutrition and hydration due to MCI and depression

MIDDLE-STAGE DEMENTIA: SWALLOWING, NUTRITION, AND HYDRATION
• Mild cognitive impairment (MCI)
• Depression
• Taste and smell dysfunction
• Awareness of cognitive deficits
• Attention – mildly impaired
  • Distracted intermittently throughout the meal
• Medications and polypharmacy
• Decreased nutrition and hydration due to MCI and depression

ADVANCED/LATE/END-STAGE DEMENTIA: SWALLOWING, NUTRITION, AND HYDRATION
• Cognitive-based dysphagia
• Dependence on oral care
• Oral apraxia
• Oral acceptance deficits
• Oral preparatory deficits
• Attention – mod-severely impaired – often distracted
  • Texture aversion
• Medications and polypharmacy
• Pharyngeal phase deficits and aspiration
  • Over chewing, severe myoclonus
  • Twitching in oral musculature
  • Self-feeding ability is lost
  • Become dependent on others for meal consumption

Assessment Tools for Swallowing and Cognition to Facilitate a Quality Mealtime Experience

Crescent Pillow Mate – cervical alignment w/o forward flexion
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Dementia – Dysphagia Assessment Tools

- Successful Eating
- Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q)
- Environment & Communication Assessment Toolkit for Dementia Care
- Dementia Mealtime Assessment Tool (DMAT)

Evaluating Cognitive Skills

- Alertness as a prerequisite to safe PO consumption
- Awareness of mealtime task
- Attention
- Visual perception

Cognitive-based Dysphagia Assessment

- Sensory function
- Oral motor changes in dementia
- Oral apraxia
- Oral acceptance
- Oral acceptance differential diagnosis cognition and behavior
- Oral preparatory

Mealtime Routine History Inventory

- Describe the mealtime routines characteristic of person with dementia’s preferences throughout his/her life (for all mealtimes): Location of meals
- Family/friends typically shared meals with
- Sequence of eating and drinking during meals
- Meals regularly skipped
- Condiments/spice preferences and dislikes
- Temperature preferences
- Typical external stimuli during meals
- Snacks before and/or after
- Food/drink likes and dislikes
- Cultural rituals
- Religious beliefs
- Social interaction during meals
- Favorite, familiar mug, plate (may be brought in from home)

Current Mealtime Preferences

- Which mealtime is the person with dementia most alert and aware? Adapt and compromise
- Medications - adjust dosage around meals
- Pain treatment - coordinate around meals
- Meet basic comfort needs before meals
- Resolve anxiety prior to meals
- Sensory aids in place - hearing aids, glasses, dentures - capitalize on all senses to increase appetite

Successful Eating

- Assessment of General Cognitive and Language Skills
- Assessment of Environment, Approach, Texture

Eula Boylston and Carol O’Day, 1999
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**Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) (Watson & Dreary, 1997a)**

- Valid and reliable 11 item observational instrument for persons with late stage dementia
- Nurses can use to identify eating and feeding difficulties and determine the level of assistance needed and appropriately refer to SLP
- Developed and tested extensively with nurses in psychogeriatric units and nursing homes

Score answers to questions 1-10: never (0), sometimes (1), often (2)

1. Does the patient require close supervision while feeding? _______
2. Does the patient require physical help with feeding? _______
3. Is there spillage while feeding? _______
4. Does the pt tend to leave food on the plate at the end of the meal? ___
5. Does the patient ever refuse to eat? _______
6. Does the patient turn his head away while being fed? _______
7. Does the patient refuse to open his mouth? _______
8. Does the patient spit out his food? _______
9. Does the pt leave his mouth open allowing food to drop out? _______
10. Does the patient refuse to swallow? _______

Total Score = _______

(Total scores range from 0 to 20, with 20 being the most serious.)

11. Indicate appropriate level of assistance required by patient: supportive-educative; partly compensatory; wholly compensatory

**Environment & Communication Assessment Toolkit for Dementia Care**

- Evaluation of person spaces
  - Activity Performance
  - Environmental Measures – Circulation, Toilet, Bathtub / Shower, Signage, Sink-Grooming, Clothes Storage, Time/Location Cues, Controls for Ambient Conditions, TVs, Radios and Telephones, Conversation Areas, Display of Personal Items, Social Environment
- Evaluation of public spaces
  - Activity Performance
  - Environmental Measures – Circulation, Signage, Time/Location Cues, Restroom, Dining Room, Leisure and Social Areas

REFERENCE: Environment & Communication Assessment Toolkits (ECAT) for Dementia Care (with meters). By Jennifer Brush, M.A., CCC/SLP; Margaret Calkins, Ph.D., CAPS, EDAC; Carrie Bruce, M.A., CCC/SLP; and Jon Sanford, M. Arch.

**The Dementia Mealtime Assessment Tool – DMAT**

- British software based on research evidence, best practice guidelines, clinical and caring experience
- The DMAT system helps to create a dementia friendly mealtime care plan - www.thedmat.com
- The DMAT system includes:
  - ‘Initial Measurement Form’ - 37 common mealtime eating difficulties
  - An extensive range of practical and cost effective strategies and interventions
  - The ability to generate an unlimited number of individualized care plans
- 7 day free trial then $50 subscription annually

**Grind Dining, Atlanta, GA**

- Grind Dining™ is an innovative food services process designed to restore the dignity and enjoyment of mealtime for individuals with cognitive, neuromuscular and chewing disorders.
- We come to you. We learn your menu. We understand your resident population and their needs. And we train your staff – not just in how to transform meals, but how to provide the best dining experience for everyone they proudly serve.
- http://www.grinddining.com/contact-us/

**Tardive Dyskinesia**

- Middle to late stage dementia and other diagnoses
- Older antipsychotic medications taken for a minimum of 6 weeks to extended periods
  - Chlorpromazine
  - Fluphenazine
  - Haloperidol
  - Trifluoperazine
- Newer antipsychotic medications are less harmful
  - Tongue thrust
  - Repetitive chewing
  - Disorganized tongue movements
  - Pharyngeal pooling, aspiration
  - Facial grimacing
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SENSORY CONSIDERATIONS
- Oral acceptance, bolus formation, bolus control, and retropulsion are primary challenging areas for persons with moderate and moderate-to-severe dementia
- Sensory information received from bolus texture, temperature, taste, and smell is transferred to the trigeminal sensory nuclei
- Window of opportunity we must capitalize on to compensate for diminished sensory interpretation and resulting motor response

ENVIRONMENTAL CONSIDERATIONS
- Media stimulation during mealtime
  - TV, radio, music amount and type
- Lighting
- Visual organization of the environment
  - Level of clutter

ENVIRONMENTAL CONSIDERATIONS
- Color contrast of utensils, cups, dishes
- Overall dining area
- Place setting
- Visual world shrinks
  - Early-stage dementia - 14–24"
  - Middle-stage dementia - 7–14"
  - Late-stage dementia - 7" from the midline
- Significantly diminished visual perceptual processing

ENVIRONMENTAL CONSIDERATIONS
- Number of staff and residents/patients in the immediate dining area
- Pre-meal wait time
- Contextual cues to comprehend mealtime setting (cooking smells, sounds, mealtime supplies, use “paid receipts” for concerned residents/patients)
- Participation in mealtime setup
- Differentiate place settings (use of square tables, name place cards)

DEMENTIA AND DYSPHAGIA INTERVENTIONS
- The degree to which sensory information activates motor response remains uncertain
- SLPs are encouraged to probe the effects of heightened sensory input with strong smell and taste (as well as texture and temperature) information to increase the opportunity for persons with dementia to recognize, interpret, and react to the bolus
- 1000s of sensory receptors in the anterior oral mucosa
  - Chemoreceptors (taste, smell, pain)
  - Mechanoreceptors (touch, kinesthesia)
  - Thermoreceptors (temperature, pain)

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DEFINING “EFFECTIVENESS”

• Success...Validity... Capable... Performance
• Adequate to accomplish a purpose; producing the intended or expected result
• After trialing a technique, was it effective enough for the individual person with dementia to recommend for caregivers to use?
• Will the technique assist the person with dementia to safely sustain nutrition and hydration needs? If not, will the technique assist in preserving an aspect of quality of life through consumption of recreational/pleasure PO intake?
• If you have answered “yes”, then the technique makes “the cut” and should be recommended!

ALERTNESS APPROACHES FOR SAFE EATING

• Determining satisfactory alertness criteria for safe meal consumption:
  • Are questions being answered contingently?
  • Does patient follow one-step commands?
  • Are eyes open – not 100% necessary if other criteria are met
• Consider the etiology of reduced alertness
• Give extra helpings when alert
• Nutritional supplements
• Flexibility within the feeding routine

Attention Considerations During Meals

• Types of stimulation that most readily sustain attention
• Which staff members and familiar objects are most likely to sustain patient attention?
• What is the length of time that the patient can sustain attention?
• What environmental factors affect arousal and ability to sustain attention?
• Distinguish between poor initiation of activity versus poor motivation or volitional refusal

ATTENTION APPROACHES

• Establish mealtime schedule simulating lifetime meal routines
• Caregiver sits at eye level, makes eye contact when providing physical assist and verbal cues
• Limit number of food/beverage items presented simultaneously - 1-2 items as appropriate
• Limit choice of utensils
• Provide familiar mug, plate from home
• Provide choices when feeding - chicken or potato next?
• Allow adequate time to eat
• For visual and sustained attention challenges:
  • Offer 5-6 smaller meal/day
  • Provide double portions when alert

Attention

• Finger foods – when difficult to use utensils
• Ambulate and eat simultaneously with finger foods
  • Includes food that are easy to eat without a utensil
  • Purpose is to allow persons to retain or increase independence in dining
  • Can be combined with a mechanical soft diet if an altered texture is needed
    • Most meals are ground
    • Gravy or sauce planned when appropriate
    • Raw fruits/vegetables generally excluded unless modified consistency & appropriate
    • All other foods are regular consistency

ORAL APRAXIA/ORAL ACCEPTANCE/ORAL PREPARATORY

• Thermal-gustatory stimulation – cold sour stim before and intermittently throughout meals
• Why does lemon Italian ice work?
• Neuroreceptors and motor response
• Alternate extreme tastes – e.g., sweet versus sour – capitalize on taste receptors to facilitate motor response
• Alternate temperature – hot versus cold
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**ORAL APRAXIA/ORAL ACCEPTANCE/ORAL PREPARATORY**

- Carbonated beverages
- Coated spoon
- Cold, metal spoon
- Iced toothette prior to and during meals

**ORAL APRAXIA/ORAL ACCEPTANCE/ORAL PREPARATORY**

- Cup versus spoon presentation
- Nourishing full liquid diet/blenderized or pourable pureed diet
- Appropriate for end-stage, cognitive-based dysphagia after exhausting all appropriate treatment interventions
- Patients responding better to cup versus spoon presentation due to oral apraxia and oral acceptance deficits

**ORAL APRAXIA/ORAL ACCEPTANCE/ORAL PREPARATORY**

- Timing, readiness, latency techniques – present bolus at regular time intervals to capitalize on oral motor and oral prep follow-through
- Self-feeding to facilitate natural, automatic oral acceptance and prep
- Use of distraction to facilitate oral acceptance, oral prep functions, and retropulsion of bolus (change activity/attention/focus to gain reacceptance)

**ORAL APRAXIA/ORAL ACCEPTANCE/ORAL PREPARATORY**

- Diet texture modifications – solid and/or liquid – to alleviate oral acceptance and oral prep difficulties
- Provide multi-modality and multi-sensory cues – tactile, visual, verbal cues and modeling to improve oral phase functions

**ORAL APRAXIA/ORAL ACCEPTANCE/ORAL PREPARATORY**

- Beckman Oral Motor – compensatory handling techniques for:
  1. Impaired oral acceptance
  2. Tonic biting on an item
  3. Delayed oral transit
  4. Anterior spillage of solids/liquids

  [http://www.beckmanoralmotor.com](http://www.beckmanoralmotor.com)
  (Course is mandatory for technique use)

**ADAPTIVE EQUIPMENT**

- High-top table
- Utensils that compensate for impaired motor control
- Adaptive cups
- Adaptive spoons
ENTERAL FEEDING

- Appropriate use of PEG
- Advanced dementia population
  - Contraindicated – risk of tube removal by patient, painful, GERD, artificial nutrition and hydration (ANH) not beneficial at end of life
- End-of-life population
  - Specific MD orders for recreational PO
  - Documentation should support inability to meet nutritional needs by mouth
- AAHPM – American Academy of Hospice and Palliative Medicine
  - Position statement on ANH at end of life

AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

Position Statement on Artificial Nutrition and Hydration at End of Life

ENTERAL FEEDINGS AND SMALL AMOUNTS OF PO

- Enteral nutrition is included in the all-inclusive room and board rate for Medicare A patients
- Enteral nutrition is eligible for Medicare Part B reimbursement for an individual with Part B benefits not currently using Med A benefits or using a Medicare/Managed Care benefit
- Coverage guidelines indicate:
  - "The patient must require tube feedings to maintain weight and strength commensurate with the patient’s overall health status. Adequate nutrition must not be possible by dietary adjustment and/or oral supplements. Coverage is possible for patients with partial impairments – e.g., a patient with dysphagia who can swallow small amounts of food or a patient with Crohn’s disease who requires a prolonged infusion of enteral nutrients to overcome a problem with absorption."
- Refer to:
  - www.cms.gov/mcd/viewarticle.asp?article_id=53636&article_version=5&show=all

ENVIRONMENTAL MODIFICATION ANALYSIS

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MIDDLE STAGE DEMENTIA – USING TASK SEGMENTATION DURING MEALS

- Complete personal interest inventory
- Establish rapport with pre-activity and post-activity conversation
- Minimize refusal, anxiety and agitation
- Modify verbal & non-verbal communication style
- Shorten verbal phrases as the person with middle stage dementia has shortened attention and memory
- Strive for simple 1-step directions
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MIDDLE STAGE DEMENTIA – USING TASK SEGMENTATION DURING MEALS

- Example of shortening verbal instruction:
- Instead of saying, “Millie, I would like you to stand up and walk over to the closet to pick out a nice outfit for this beautiful day. Do you know it is 75 degrees and sunny today?”
- Simplify this to: “Millie, please lean forward.” [STOP] “Stand up.” [STOP] “Walk with me.” [STOP] “Open the closet.” [STOP] “Would you like to wear the red or yellow outfit?” [STOP]

MIDDLE STAGE DEMENTIA – USING TASK SEGMENTATION DURING MEALS

- When verbal instruction in shortened phrases generates no response or incomplete response:
  - Allow 10-15 seconds for verbal or motor response at each step
  - Minimize overstimulation
  - Pair visual and/or tactile cues with each verbal instruction step
  - Touch and redirect to the task of eating

LATE STAGE DEMENTIA MEALTIMES

- Hand under hand assist
- Mirroring/visual modeling
- Do not force feed more than accepted
- Oral care is a must even for persons at end of life stage who may not be able to eat or drink much

COMMUNICATION APPROACHES DURING MEALS

- Use multi-sensory cueing with frequent gestures
- Lift the item away from the table or food up from the plate to regain attention
- Use verbal encouragement, “This is a new recipe I want to cook for my daughter. Would you please try it for me and tell me what you think?”
- When asking questions about food choices, use “either/or” questions rather than “yes/no” questions, which could lead to, “no’s” and reduced PO intake
- Inability to communicate thirst can lead to or at least contribute to dehydration which can increase agitation or combativeness

DINING, DIGNITY AND DEMENTIA

- Additional information with regards to interventions can be found on the handout. “Dining Interventions for Individuals with Alzheimer’s – Dementia”
- Key points:
  - Encourage dining in the dining room
  - Use square or 4 person tables of appropriate height; sit in chair (instead of wheelchair)
  - Provide adequate lighting without glare
  - Minimize distractions
  - Seat compatible residents together
  - Provide input to facility based on your evaluation and knowledge of the resident
  - Arrange food to facilitate self-feeding

DINING, DIGNITY AND DEMENTIA

- Key points:
  - Patient out of bed, seated in chair that promotes good posture & comfort, if possible
  - Properly position to see and reach food
  - Assess for and provide appropriate utensils, plates, cups as clinically indicated
  - Provide appropriate level cues to initiate and continue with self feeding
  - Consult with family regarding food preferences
  - Choice dining
  - Instrumental music
  - Balance place setting, visual attention, fine motor
Dining, Dignity and Dementia

- Involve in mealtime preparations
- Talk about smells and tastes before and during the meal
- Homelike meals
- Assess and palliate pain
- Use aromatherapy to stimulate appetite - bread maker
- Discontinue or reduce medications that increase drowsiness and decrease appetite
- Refer to Speech Pathology for oral and pharyngeal swallow difficulties
- Refer to Occupational Therapist for self feeding and adaptive dining equipment
- Refer to Physical Therapist for positioning at mealtime
- Refer to Dentist for dentition, denture issues, dry mouth
- Refer to Dietitian when there is a need for supplements

The Dual Diagnosis Protocol

- Benefits of protocol use
  - Clear, systematic toolbox protocol for management of dysphagia in persons with dementia
  - ASHA Noms-stabilized scores supported by the Training/Consultation Model
  - Improved scores post-protocol implementation on clinical swallowing and quality-of-life measures
  - Comprehensive skilled evaluation and treatment plans for dual diagnosis
  - Comprehensive documentation supporting medical necessity
  - Reduction of denials

Criteria for protocol implementation

- MDS - Section K - Swallowing and Nutritional Status responses indicating triggers for concern
- Positive signs/symptoms of a swallowing disorder
- Unplanned significant weight loss
- Reduced PO intake
- Past or current medical history of: malnutrition, dehydration, failure to thrive
- Sarcopenia - loss of muscle mass and function with aging
- Middle-stage dementia - moderate cognitive impairment, moderate-severe cognitive impairment per Global Deterioration Scale or similar
- Late-stage dementia - severe cognitive impairment per Global Deterioration Scale or similar
- End-of-life-stage - per medical team

Screening

- Observation of current meal or snack within typical environmental and feeding conditions
- Medical record review and medical team consultation to include two or more criteria above

Evaluation

- Standardized bedside swallowing assessment MAY include:
  - Global Deterioration Scale (GBS)
  - Mann Assessment of Swallowing Ability (MASA)
  - Swallowing Ability and Function Evaluation (SAFE)
  - Functional Oral Intake Scale (FOIS)
  - Eating Assessment Tool (EAT-10) - Will require intact family/caregiver input to complete
  - Quality of Life Measures: Selected sections of the SWAL-QOL - Will require intact family/caregiver input to complete
  - Outcome Measurements: ASHA Noms Swallowing FCM

Categories of dysphagia - dementia compensatory techniques

- Alertness level during mealtime
- Mealtime environmental modifications
- Oral apraxia/oral acceptance/oral preparatory techniques
- Attention and behavioral modification
- Adaptive equipment

Pilot Study Framework

- 3-month pilot April-June 2015
- 23 patients
- 8 skilled nursing facilities
- 8 speech-language pathologists
- 1 training
- States represented
  - Massachusetts, Tennessee, Florida, Texas, Wisconsin, Kentucky, North Carolina
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THE DYSPHAGIA – DEMENTIA SCALE

- Components/sections of analysis
- Dementia stage
- Cognitive impairment
- Oral phase swallow impairment
- Pharyngeal phase swallow impairment
- Sustains nutrition and hydration needs by mouth
- Quality of life – food/drink
- Alertness/awareness/attention
- Compensatory techniques and environmental modifications required

REFERENCES


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- References 82
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CLOSING THOUGHTS

Thank you!