MAXIMIZING AND MAINTAINING INDEPENDENCE WITH COMMUNICATION AND SWALLOWING IN ADVANCED MS

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Common Communication Disorders in Advanced MS

- Dysphonia (deterioration in vocal quality and volume)
- Dysarthria (reduced speech intelligibility)
- Word retrieval/aphasia
- Reading comprehension
- Written expression (including electronic)
- Cognitive-linguistic deficits
- One or more of these affect >75% TBH residents
Interdisciplinary Rehabilitation Team Approach to Intervention

• In-house PT, OT, SLP services 5 days/week
• Seating specialist PT for residents and outpatients
• 2 Rehab Aides for Functional Maintenance Program
• Consults with AT specialist
• Graduate student clinicians for OT and SLP
• Research projects with students at MIT, BU, Northeastern, Emerson, other Boston colleges

Speech Pathology Intervention

• 1:1 treatment sessions
• Monthly support groups for ongoing education and skills
• Can include behavioral exercises and approaches, low-tech assistance, and high-tech alternative communication systems
• Explore best options for residents that are functional, accessible, and customizable
Low Tech AAC Options

- Voice and speech rehabilitation
  - Text-based cues
  - Visual cues
  - Staff education signs
  - Incentive spirometry

High Tech Options

- Vocal amplifiers
- Dedicated speech generating devices
  - DynaVox and Tobii, e.g.
  - Generally covered 80-100% by insurance
  - Cost $7K-$15K+
- Tablet devices (eg iPad)
  - Mainstream tech
  - Most rapidly evolving technology
  - Not covered by insurance but cost <$500
Accessing Communication Devices

Analog Voice Amplifier

• Multiple models, including Chattervox, AddVox7, Voice Aerobics, and Radio Shack
Digital Vocal Augmentation System

- Speech Enhancer – digital processing and amplification in speech sound spectrum

Adult Female with Severe Dysphonia, Natural Voice

Adult Female with Severe Dysphonia, Enhanced
Speech Recognition Computer Access

- Dragon Naturally Speaking
  - Dialects
  - Military alphabet
  - Specific vocabulary training
  - “Code words” for public area data entry
- Windows Speech Recognition
- Siri
- Video conferencing options (eg, FaceTime, Skype) for moderate+ dysarthric speakers

Tablet Computer as AAC Device

- Capacitive stylus access
Tablet Computer as AAC Device

- Direct digital selection

Tablet Computer as AAC Device

- Switch based access
Challenges with Using Mainstream AT with People with Advanced MS

- Accessibility
- Durability
- Cost/lack of reimbursement
- Service/upgrade follow-up
- Software of unknown origin/stability

Cognitive Deficits: Why Is This Functional Area Often Overlooked?

- Later overt onset in advanced MS
- Strong human capacity for compensation
- Shame/anger from “losing one’s mind”
- Can also fluctuate or be reversible based on acute infection, med changes, fatigue, etc
- “Silent symptoms”
Potential Impacts of Cognitive Dysfunction in Advanced MS

- Loss of functional community independence
- Reduced safety with mobility and ADL’s
- Impaired capacity to make medical decisions
- Decreased ability to manage finances/medications
- Progressive visual and perceptual impairments
- Barrier to acquiring access skills for use of AT
- Increased burden/burnout for caregivers
- Lower threshold for agitation/anosognosia

Compensatory Strategies for Cognition

- Visual/auditory cues and reminders
- Lighting/ambient noise modifications
- Task analysis
- Double-sided staff ID badges
- Encouraging flexible and realistic reasoning
- Frequent caregiver education (eg, OASIS training, multimodal communication)
Dysphagia in Advanced MS

- Prevalence estimates: 30-40% (see Restivo et al, 2006)
- Can manifest in widely divergent manner even with similarly “staged” people with MS
- Usually one of final volitional motor capabilities retained
- Even without dysphagia, swallowing in advanced MS often characterized by:
  - Slowed volitional movement during oral phase
  - Increased oral residue d/t xerostomia
  - Prolonged response time prior to pharyngeal swallow onset
  - Multisensory changes in taste, smell, feeding
Consequences of Dysphagia

- Aspiration
- Hospital admission costing >$26K even 15 years ago (see Siddique et al, 2000)
- Choking
- Malnutrition
- Dehydration
- Decreased QOL
- Compromised positioning

Complicating Factors for Safe Swallowing

- Neuromuscular strength/function
- Sensation/pain
- Structural abnormalities
- Posture
- Compromised cognition
- Respiratory status
- Reduced activity tolerance
- Medication effects
- Feeding status
- Cultural considerations

Interventions for Dysphagia

- Client/caregiver education
- Postural modifications
- Texture restrictions
- Alternate means of nutrition
- NMES

Texture Restrictions

- Easiest and most controversial treatment (see Logemann et al, 2008)
- Can modify food to reduce mastication effort and promote bolus cohesion
- Can thicken liquids to increase viscosity to limit airway compromise and promote bolus cohesion (usually with modified free water protocol)
- Can ruin appetite and reduce intake
Appropriate vs Inappropriate Feeding Technique

Limitations for Effective Postural Modifications in People with MS

- Restricted cervical/facial muscle ROM
- Delayed onset of swallow reflex
- Impaired/exacerbated head/neck sensation
- Diminished proprioceptive awareness
- Pre-existing postural impairments
- Cognitive deficits
Alternate Means of Nutrition

- Needs better PR – it is not a death sentence!
- Used both in cases of chronic severe dysphagia AND chronic malnutrition/dehydration
- Can be helpful adjunct to po intake prior to or without full transfer over to NPO status
- Can still enhance QOL in some cases (eg, cocktails, less time feeding)

NMES for Dysphagia in MS

- Newer option for sensorimotor retraining of swallowing tract muscles
- FDA approved for anterior cervical placement
- Much lower current than big-muscle ES
NMES for Dysphagia in MS

- Limited study in MS population (see Bogaardt et al, 2009)
- Treatment effects are positive or neutral
- RAW DATA of serial case studies using NMES at the Boston Home:
  - September 2009-March 2012
  - \( N=13 \)
  - Average # sessions=9.5
  - Average FOIS improvement (7-point scale)=0.23

Hypotheses About Limited Progress with NMES in Advanced MS

- Poor standardization of NMES protocol
- Difficulty isolating specific muscles
- Signal deterioration transdermally vs IM
- Abnormal sensation limiting current level
- Fatigue
Statistically Significant NOMS Outcomes at TBH: September 2012 – February 2014

TBH residents make this progress with less frequent (79.1% in 3x/week sessions compared to 19.5% nationally) and fewer SLP sessions (12.9 to discharge compared to 14.7 nationally) than other SNF-based clients.

Concluding Thoughts

• Interdisciplinary treatment of communication, cognitive-linguistic, and swallowing disorders of advanced MS can enhance independence, QOL, and community participation in a chronically ill and frequently overlooked population
• Identification of appropriate approaches should consider both disabilities and residual strengths/capacities for implementation
• Both low- and high-tech assistive options should emphasize systems that are functional, accessible, and customizable based on user’s progressive disability
QUESTIONS/
FEEDBACK/
THANKS!