Multiple Sclerosis Rehabilitation Interventions Across the Spectrum of Disability and Continuum of Age

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Patient Management Across Levels of Disability and the Spectrum of Age

- Mild Disability
  - EDSS 0-3.0
- Moderate Disability
  - EDSS 3.5-6.5
- Severe Disability
  - EDSS 7.0-9.5

- Pediatric MS
- Aging and MS
Outline of Today’s Content

• Discipline-specific issues through each level of disability
  – Medical issues in rehabilitation
  – Physical therapy
  – Occupational therapy
  – Speech and language pathology

• Age-related issues in rehabilitation across disciplines

The Need for Multidisciplinary Rehabilitation

• Signs and symptoms are often interdependent

• Problems cross practice areas of many professions

• Typical care should include screening by, and referral to, a multidisciplinary rehabilitation team

Adapted from Minden et al, 2006
Categorizing MS Disability

• For our purposes today
  – EDSS of 0-3.0 = Mild
  – EDSS of 3.5-6.5 = Moderate
  – EDSS of greater than 7.0 = Severe
Medical Issues for the Person with Mild MS Disability

Stephen Krieger, MD
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Topographical Model of MS: A Continuous Spectrum?

• Progression in MS, like symptom recrudescence in Uhthoff’s phenomenon and pseudoexacerbations, clinically recapitulates the form of prior relapses/lesions, incrementally revealing above the surface the underlying lesion topography as functional reserve is lost.

Krieger SC. “The Topographical Model of Multiple Sclerosis: A New Visualization of Disease Course” presented at the American Academy of Neurology 2015, p04.013
Mild/Early MS Medical Decision-Making

- Assure accurate diagnosis: RIS, CIS, McDonald MS, RRMS vs. other etiology
- Gauging prognosis based on demographic and disease factors: age, sex, race, relapse details, MRI burden of disease
- Decision making about DMT: occupies majority of discussion time
- Cormorbidities, routes of admin, side effects, risk profile, etc.

Mild/Early MS Medical Decision-Making

- Diagnostic, prognostic, and DMT decisions are all preventative and future-focused
- Symptom management and QoL affect the patient now.
- The neurologic exam is specific but insensitive to real world nuance
- The EDSS is both time consuming and cumbersome, but also misses a great deal
- Neurologists need to align their goals with that of the patient to ensure clinician-patient therapeutic relationship
- Note: evolution of quality metrics for MS care, patient evaluations of physicians (sanctioned by institutions and online)
Mild/Early MS Medical Decision-Making

• Symptom management in early/mild disease
  – Fatigue
  – Anxiety/depression/adjustment/coping
  – Subjective cognitive symptoms
  – Relapse residua: vision, balance, sensory
• Psychosocial support
  – Patient and caregiver education
  – Disclosure, employment, and insurance concerns
  – Family planning considerations
• All in 15 minutes!
  – (Plus meaningful use, full ROS, documentation...)

Mild/Early MS Medical Decision-Making

• Interdisciplinary collaborative team is necessary from the moment of MS diagnosis
• Referrals to rehabilitation/physiatry, PT/OT, SLP, social work/psychology, psychiatry can be crucial to establish a comprehensive care approach
• The neurologist or Multiple Sclerosis NP can’t – and shouldn’t! – try to do it all.
Physical Therapy for the Person with Mild MS Disability

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Hunter College, NY

Mild MS Disability

- 0-3 on the Expanded Disability Status Scale
- Occult Disability
- Infrequent referrals to PT by MD
“Herb, I don’t like to refer patients for physical therapy unless they are already falling down”

-Famous MS doctor, Name withheld

Mild MS Disability

- Patients diagnosed much earlier in the course of the disease
- Earlier and more effective treatment of disease occurs earlier
- Extended period of time at a lower period of disability
- Therapy can increase the amount of time at lower disability level
Evaluation of Mild MS Disability

• Quick tests do not uncover extent of disability
• Brief tests exclude fatigue and are therefore inaccurate means of measuring disability in this population
• More sensitive tests show abnormal mobility findings in mild MS disability
• Evidence for disability in mild MS?

Signs of Disability in Early MS Gait

• Martin et al, 2006 - MS patients with EDSS=1, no pyramidal signs, had reduced speed, reduced stride length, prolonged double support compared to controls
• Evidence of motor involvement despite absence of motor findings on the EDSS
• Unless these signs are looked for, no intervention is likely

Signs of Disability in Early MS Gait

- Benedetti et al, 1999 - patients with EDSS 0-2 without evidence of functional limitations
- Movement analysis showed reduced speed of progression, shorter strides, increased double support
- Early activation of gastrocnemius, late relaxation of ant tib.

Signs of Balance Dysfunction in Early MS

- 21 Minimally disabled MS patients (EDSS 2.1)
- Mean BBS 54.6 (low falls risk)
- COP displacement during reaching and leaning tasks less than age matched normals
- “suggests that the subjects with MS adopt a reaching strategy that allows them to stay within their reduced limits of stability”

Karst et al, 2005
Gait Evaluation

- 25-foot walk test
  Pros-short
  Cons-Not sensitive to effects of fatigue

6-Minute Walk Test

Figure 3. Differences in walking distance between INT and CONT conditions across time increments.

T1=0-2 minutes, T2=2-4 minutes, T3=4-6 minutes
* Significant higher in INT compared to CONT (between-conditions)
† Significantly higher compared to T1 (within-condition)
  There was a significant (p = <.001) interaction effect of time by condition

Karpatkin et al, 2015 (in press)
6-Minute Walk Test

- Long enough to display effects of fatigue
- Slowing of gait over time
- Slowing is accompanied by increase in gait abnormalities
- Shorter walking tests insensitive to change

Berg Balance Scale in MS: Fatigued vs Non-Fatigued Conditions

- BBS testing in persons with MS differ in fatigued vs non-fatigued conditions
- High scores (i.e. low falls risk) seen in non fatigued conditions result in false negative
- Balance test MS patients when fatigued to get true picture of falls risk
Balance Evaluation

• If tested in unfatigued state may not uncover balance loss

![Graph showing balance evaluation results](image)

Summary Thoughts

• Minimally disabled pwMS display abnormal mobility
• Evaluations need to be sensitive to changes
• Testing when fatigued may offer a more accurate picture of what persons mobility deficits are, as well as the consequences of those deficits
Occupational Therapy for the Person with Mild MS Disability

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Mild MS Disability (EDSS 0-3.0)

Occupational Therapy:
✓ Improve function in daily activities and life roles
✓ Help people become more independent
✓ Improve quality of life
  Despite MS symptoms

Education & Resources
MS Symptoms

- MS Symptoms Interdependence of MS Symptoms
  - Gait Abnormalities
  - Depression
  - Spasticity
  - Cognitive Deficits
  - Severe Pain
  - Visual Problems
  - Sexual Dysfunction
  - Emotional Changes
  - Bladder/Bowel Dysfunction
  - Debilitating Fatigue
  - Generalized Weakness
  - Numbness

Treatment Sessions

- Treatments
  - Fall Prevention
  - Energy Conservation
  - Body Mechanics
  - FM Exercises
    - Theraputty
    - Daily activities
    - Hobbies
  - UB Strengthening/Stretching
  - Stress Management Techniques/Emotional Issues
  - Medication Management
  - Money Management

- Activities of Daily Living
  - UB/LB Dressing Techniques
  - Grooming
  - Cooking
  - Dining
  - Transfers – specifically bathroom
  - Community Re-integration
  - Vocational Rehabilitation
  - Leisure/Social Isolation
  - Time Management
  - Organization Skills
  - Clutter Management
Vocational Rehabilitation

- Fatigue and Cognitive changes (specifically speed of processing information) primary reasons for unemployment in MS
- With minor adjustments/modifications we are able to keep patients at work for longer periods of time
  - Whom to tell? How to tell? When to tell?

➢ Know your rights
  • American with Disabilities Act; Rehabilitation Act of 1973; FMLA

When to Suspect Cognitive Dysfunction

- Invisible symptom - Clients can have severe cognitive impairment without signs of physical disability
- Require assistance with ADL
- Unemployment in the absence of physical disability
- Withdrawal from usual social activities
- Decreased interest in enjoyable activities (reading newspaper)
- Changes in personality (i.e. defensive)
- Inability to follow a conversation or directions
Cognitive Changes

- Cognitive abilities have a significant impact on all areas of functional performance
- Cognitive impairments present in approximately 55-70% of MS patients
- Cognitive deficits can be present at or before time of diagnosis

Cognitive Strategies

- Routines → create habits
- Reminders: electronic devices, calendars, post-it notes, checklists, alarm clocks/timers, etc
- Engage in one task at a time – avoid multitasking
- Work in a quiet, distraction-free environment
- Tackle tasks at a time of day when you are not feeling as fatigued
- Take your time
- Memorization techniques
  – Practice: grocery list
Speech and Language Rehabilitation for the Person with Mild MS Disability

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Normal Speech Production

• Speech production is a deceptively complex process dependent on the precise function of the brain, mouth, tongue, and vocal cords (larynx).

• Specifically, normal speech is created with pulmonary pressure provided by the lungs that generates sound by phonation in the glottis that then is modified by the vocal tract into different vowels and consonants.

• Any disruption, damage or disease affecting any of these underlying systems can may cause slurred speech.
The Facts on Speech + Swallowing

• Impairments in communication & swallowing have been identified in individuals with MS (Achiron et al., 1992; Kujala, Portin, & Ruutiainen, 1996; Lethlean & Murdoch, 1993).

  – 44% of the MS patients experience impairments of speech and voice in the early onset of their disease.

  – 33% of MS patients report impairments of voice, chewing and swallowing capabilities across their disease course.

Referral for Treatment

• Despite the high occurrence of communication disorders associated with MS...

  – Only 2% of MS patients are appropriately referred for treatment of speech, voice and swallowing disorders.

  – Less than 1% of patients receive appropriate cognitive intervention (Hartelius & Svensson, 1994).
Mild Disability

Mild Disability- Speech Symptoms

- Episodic slurred speech
  - Slurred speech is a symptom characterized by poor pronunciation of words, mumbling, or a change in speed or rhythm during talking.
  - Perceptually speech may sound imprecise and sloppy.

- Shortness of breath
  - Physical activities like walking or climbing stairs can cause a person to experience shortness of breath. Other people find it difficult to catch their breath when eating, talking or resting.
  - Talking can make breathing worse as the person feels as if he/she cannot get enough air.
  - Shortness of breath may be accompanied by other symptoms such as feeling dizzy or lightheaded, especially when talking.
Objective Measurements

- The Functional Communication Measures (FCMs) are a series of seven-point rating scales, ranging from least functional (Level 1) to most functional (Level 7).

- FCMs were developed by ASHA (American Speech-Language Hearing Association) to describe the different aspects of a patient’s functional communication and swallowing abilities over the course of his/her disease course.

FCM: Motor Speech

- LEVEL 1: The individual attempts to speak, but speech cannot be understood by familiar or unfamiliar listeners at any time.
- LEVEL 2: The individual attempts to speak. The communication partner must assume responsibility for interpreting the message, and with consistent and maximal cues words are rarely intelligible.
- LEVEL 3: The communication partner must assume primary responsibility for interpreting the communication exchange, however, the individual is able to produce short consonant-vowel combinations or automatic words intelligibly.
- LEVEL 4: In simple structured conversation with familiar communication partners, the individual can produce simple words and phrases intelligibly.
- **LEVEL 5:** The individual is able to speak intelligibly using simple sentences in daily routine activities with both familiar and unfamiliar communication partners.
- **LEVEL 6:** The individual is successfully able to communicate intelligibly in most activities, but some limitations in intelligibility are still apparent.
- LEVEL 7: The individual’s ability to successfully and independently participate in vocational and/or social activities is not limited by speech production. Independent functioning.
Intervention

- Referral to Speech-Language Pathology for an initial evaluation.
- Short-term course of therapy (~5-10 sessions) and/or development of a home exercise program (HEP).
- Yearly re-evaluation to monitor symptoms and adjust home programs as needed.
Rehabilitation Issues in Pediatric MS

Linda Csiza, PT, DSc, NCS
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Pediatric MS

• MS below 18 yo
• 2.7-10.5%
• Overall female preponderance
• Females>Males
• Higher proportion of African-Americans found
• Positive family history is seen in 6-20%
Figure 1. Distribution of patients with early onset MS according to age at onset and sex.

Pediatric MS

- 3.06% of adults with MS at MS center in NE US recall neurologic symptom consistent with MS < age 18
- Will self describe as “clumsy children, hated sports, hated summer
- Initial symptoms in children
  - Optic neuritis (52%)
  - Sensory disturbance (16%)
  - Initial presentation rapid, resulting in admission to hospital within hours to a few days (71%)

Waldman et al, 2006; Krupp, 2009
Pediatric MS

- 4 subtypes
  - Relapsing-remitting MS (most common)
  - Primary progressive MS
  - Secondary progressive MS
  - Progressive-relapsing MS

Waldman et al, 2006

Clinical Features of Pediatric MS

- History of preceding infection
- More frequent severe cognitive problems
- Seizures
- Optic nerve dysfunction
- Brainstem or cerebellar involvement
- Decreased cord involvement
- More polysymptomatic

Krone et al, 2009, MacAllister et al, 2009
Cognitive Disability

- Impairments in
  - complex attention
  - Visuomotor integration
  - Confrontation naming
  - Receptive language
  - Executive function
- Verbal fluency may be intact
- Frequency of cognitive impairment
  - 30-66% (vs 50% in adults)
  - >70% have decline in 2 years

Smerbeck et al, 2011, Montiel-Nava, 2009

Prognosis of Pediatric MS

- Children with MS develop more frequent relapses accumulating increasing disability
- Shorter span to recovery 4.3 weeks vs 6-8 weeks
- Slower disease course-less aggressive
- 50% risk for conversion from RRMS to SPMS was 23 years in children vs 10 years in adults
- Overall morbidity greater in children with MS when reach adulthood
- Persons with childhood onset have accumulated more disability than adults
- Loss of ambulation occurs earlier in the lifespan due to greater accumulation of disability

Ruggieri et al, 2004; Renoux et al, 2007; Reiber et al, 2009; Krupp, 2009
Pediatric MS: Medical Treatment

- Disease modifying drugs: DMT’s
- Medications to alleviate symptoms of fatigue, spasticity, bladder dysfunction, depression
- Steroids for acute relapses
- Neuroprotective agents being studied to prevent/repair nerve injury

Unique issues for children with MS

- Lack of awareness regarding childhood MS in the medical, educational and general public.
- “Invisible symptoms” such as fatigue, depression, memory issues.
- Feeling of isolation, not only for the child, but also the family.
- Fatigue and cognitive issues impacting the ability to fully participate in academic and recreational activities.
- Family of affected children will have to work closely with the school district in constructing an education plan specific to their child’s needs.
- Educational plans need to be modified as necessary due to the unpredictable nature of the disease
- May interfere with developing age appropriate mobility skills
5-minute break

- Mild Disability
  EDSS 0-3.0

- Moderate Disability
  EDSS 3.5-6.5

- Severe Disability
  EDSS 7.0-9.5

- Pediatric MS

- Aging and MS
Medical Issues for the Person with Moderate MS Disability

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Topographical Model of MS: A Continuous Spectrum?

- As MS evolves, new signs, symptoms, and disability can be driven both by relapses (floor effects, “activity”), and progression (surface effects).

Krieger SC. “The Topographical Model of Multiple Sclerosis: A New Visualization of Disease Course” presented at the American Academy of Neurology 2015, p04.013
2013 Revisions of Phenotype Descriptions

1996

PPMS
Progressive disability accumulation from onset with/without plateaus, remissions and improvements

SPMS
Progressive disability accumulation after initial relapsing, with/without occasional relapses and minor remissions

PPMS
Progressive disability accumulation from onset but clear acute clinical attacks with/without recovery

2013

(PP) Progressive disability accumulation from onset

Active, progressing

Active, not progressing

Not active, progressing

Not active, not progressing (stable disease)


MRI as a Potential Surrogate for Clinical Relapse

- Meta-analysis of 23 randomized clinical trials demonstrated a strong association between treatment effects on MRI lesions and relapses

23 PBO-controlled trials
63 randomized arms
40 active treatments
6,591 pooled subjects

\[ R^2 = 0.81 \]

Moderate MS Medical Decision-Making

- Gauging disease activity on DMT: number of relapses, new T2 or T1 enhancing lesions
- Disability accumulated through relapses vs gradual progression: implications for DMT change
- Escalation of DMT: risk/benefit analyses, PML concerns, risk of worsening disease vs. risk of treatment

Moderate MS Medical Decision-Making

- Symptoms and signs of accumulated disability
- Multifocal myelopathy: spasticity, ambulatory dysfunction, sensory loss, sensory ataxia, bladder dysfunction
- Cerebellar and brainstem: imbalance, frank ataxia, tremor, diplopia/smearing of vision, nystagmus
- Cerebral: cognitive dysfunction, dysexecutive function, worsened fatigue (medication refractory), language deficits
• Pharmacologic Approaches
  – Treatments shown to be effective in randomized, double-blind, placebo-controlled trials
    • amantadine (symmetrel)-antiviral, dopamine agonist, antiglutamate
    • About 1/3 of patients with mild to moderate fatigue report significant short-term improvement
      – Dosage: 100mg bid, a drug holiday for 2 days/wk prolongs effect
      – Nausea, lightheadedness, insomnia, follow LFT, confusion, hallucination, dry mouth, livedo reticularis, peripheral edema


– Modafinil (Provigil)
  • FDA-approved in 1999 as a “wake-promoting” agent for the treatment of excessive daytime sleepiness in patients with narcolepsy
  • In a crossover study by Rammohan et al, MS patients treated with 200 mg/day modafinil for 2 weeks showed a significant improvement in fatigue vs placebo
    – like CNS stimulant, promoting daytime wakefulness with fewer adverse effects and less abuse potential
    – Up to 200mg bid
    – If a second daily dose is required, administer before 1:00 PM to prevent adverse effect on nocturnal sleep
    – Interference with BCPs may necessitate use of alternative forms of birth control
    – Drug Holidays maintain sensitization


– Other agents for fatigue

- Methylphenidate (Ritalin/Concerta) and dextroamphetamine (Adderall, Adderall XR)
- Vyvanse (lisdextroamphetamine) (pro-drug)
- Atomoxetine (Straterra)
- 4-aminopyridine (4-AP) (Ampyra)
  - K channel blocker, improve nerve impulse-prolongs APD
  - 4AP: 5mg tid up to 10mg tid; paresthesias, abdominal pain, confusion and seizure

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Mobility Impairment:
Pharmacologic Treatment: Dalfampridine

- Two Phase III clinical trials demonstrated significant improvements walking ability of patients with four primary forms of MS
  - Consistent improvement in walking in 35-43% of patients using the Timed 25-Foot Walk Test
  - Generally well tolerated within the recommended dose of 10 mg twice daily
  - Common side effects: mild dizziness, GI discomfort, and some agitation or wakefulness
  - The risk for more serious and intolerable adverse events such as seizures increases at higher doses (20 to 30 mg twice daily)

Hayes KC. Neuropsychiatr Dis Treat. 2011;7:229-239.
Physical Therapy for the Person with Moderate MS Disability

Linda Csiza, PT, DSc, NCS
Texas Woman’s University, TX
Rehabilitative Techniques

- MS patients usually referred to PT when disability is moderate
- Patients show up with a significant disability “load”
- Rehab becomes more reactive then proactive

Evaluation-Task specific assessments

Gait- evaluate in multiple settings, under multiple conditions: over ground, varied surfaces, dual tasks, fatigued vs unfatigued

Balance- Task specific evaluations- BBS, MiniBesTest, Dynamic Gait Index, fatigued vs unfatigued

Transfer/mobility tasks
  - sit to stand, bed mobility activities, floor to stand

ADL’s/IADL
  - Dressing, hygiene

Endurance-Task specific vs cardiovascular fitness
Gait Limitations

- Becomes less occult
- Occurs earlier in the walking period
- Slowdown in 6MWT becomes more overt
- Deviations may become falls risks (i.e. foot drag) or lead to musculoskeletal damage (extension thrust/genu recurvatum)
- Overall walking decreases

Balance limitations

- Multifactorial- multiple system dysfunction may contribute to falls
- More frequent falls
- Voluntary activity restrictions to prevent falls
- Familiar vicious circle of decreasing activity leading to decreasing balance skills
Assess underlying impairments

- Flexibility
- Strength
- Sensation
- Vestibular
- Spasticity
- Vision

- Fatigue: Assess in fatigued and unfatigued state
- What is relationship between impairment and functional limitation?
- What is relationship between impairments (i.e. does spasticity lead to contractures)

Interventions

- Task specific: what is the task the patient is struggling with? That is the task to be practiced
- What are the underlying impairments? Intervene upon those impairments
Interventions

• Gait: Practice in multiple settings: TM, indoors, outdoors, varied terrain, with cognitive interference
• Balance- what tasks did the evaluation(s) show as impaired? Practice those
• Rest breaks allow for a greater volume of practice

Interventions-Impairments

• Flexibility- most MS patients don’t stretch enough, especially if spasticity is present
• Sensory loss- can be secondary as well as primary
• Vestibular- can be peripheral or central
• Fatigue- intermittent exercise, cooling modalities, energy conservation
Weakness in MS

- Lack of force output- inability to produce sufficient force output for a particular task(s)
- Lack of endurance- strength sufficient to do specific task once, but insufficient to perform task for several repetitions or period of time
- Motor Control-strength may test normally on MMT, but unable to coordinate the force to perform specific functional tasks
- Range limitation- due to contracture, unable to perform a task due to inability to access full range of motion
- Cognition-able to produce sufficient force in a quiet environment, but unable in a highly distracting environment
- Secondary causes-Learned Disuse, medication, sleep disturbance, depression

Maximal Strength Training (MST)?

- Increased “neural drive” following MST
- 7 patients with EDSS 3.5
- 2x week MST
  - 4 x4 reps at 85-90% of 1RM for eight weeks
  - unilateral leg press
  - significant improvements in BBS and 6MWT
  - No adverse events, no change in fatigue
Occupational Therapy for the Person with Moderate MS Disability

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New York University School of Medicine, NY

Moderate MS Disability (EDSS 3.5-6.5)

Focus on symptoms interfering with functioning and QOL
Transition from remedial to compensatory techniques to improve daily functioning
*Fatigue
  Cognition
  ADL
A brief video...

MS Fatigue

• “A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities”
• Most common MS symptom affecting 75%-95% of individuals with MS
• Many report it to be the most debilitating symptom
• Invisible symptom
• Lassitude – “An overwhelming sleepiness that may come on abruptly and severely at any time of day”
Cause of MS Fatigue

- Underlying disease process
- Sleep disturbance
  - Specific symptoms or insomnia
- Infection
- Heat and humidity
- Medication side effects
  - Keep track of your medications
- Stress
- Depression & anxiety
- Poor nutrition
- Deconditioning
- Respiratory issues

Energy Conservation

- Adaptive equipment, activity modifications, cooling strategies, and proper exercise regimen
- Every person is unique, everyone's fatigue is different
- Plan, Prioritize, and Pace
- In general:
  - Do not reach the point of exhaustion
  - Incorporate rest breaks (no longer than 30 minute nap)
  - Utilize your best time in the day
**Moderate MS Disability (EDSS 3.5-6.5)**

Focus on symptoms interfering with functioning and QOL

Transition from rehabilitative to compensatory techniques to improve daily functioning

*Fatigue  
Cognition  
ADL

http://www.magnaready.com/shop/home.php

**MS Fatigue**

- “A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities”
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## Energy Conservation

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Speech and Language Rehabilitation for the Person with Moderate MS Disability

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Moderate Disability - Dysarthria

Dysarthria
- A neurological, motor speech disorder characterized by slow, weak, or uncoordinated movements of the speech musculature.
  - Speech musculature: lungs, vocal folds, velum, tongue, lips, nose and jaw.

- Often respiratory and articulatory muscles become weak resulting in significantly impaired speech production.

- Dysarthria results in reduced speech intelligibility (clarity) and communicative function.
  - It is a common cause of social isolation & depression in MS.
Dysarthria

− Dysarthria can occur in two contexts in MS:

• **Episodic dysarthria** - dysarthria lasts for a few minutes to an hours and recurs several times during the day, during periods of high fatigue.

• **Consistent dysarthria** - symptoms of dysarthria persist throughout the day, day after day.

Cause of Dysarthria

• Changes in respiration occur due to deconditioning.
  − Deconditioning is a result of ...
    • Sedentary lifestyle (relatively common in MS)
    • Underused respiratory system
    • Disuse atrophy of respiratory muscles

• Interference along the upper motor neurons and lesions within the cerebellum.
Dysarthria

Perceptually, speech sounds...
- sloppy
- imprecise
- uncoordinated
- effortful

Vocal quality can sound...
- harsh
- hoarse
- breathy
- nasal

Dysarthria

- Vocal weakness paired with reduced respiratory support causes significantly reduced vocal volume in MS.

- Endurance for conversation and “running out of air” when communicating is frequently reported.

- On average, individuals with MS on have a vocal volume 8 dB SPL less than the average adult.
FCM: Motor Speech

• LEVEL 1: The individual attempts to speak, but speech cannot be understood by familiar or unfamiliar listeners at any time.
• LEVEL 2: The individual attempts to speak. The communication partner must assume responsibility for interpreting the message, and with consistent and maximal cues words are rarely intelligible.

• LEVEL 3: The communication partner must assume primary responsibility for interpreting the communication exchange, however, the individual is able to produce short consonant-vowel combinations or automatic words intelligibly.
• LEVEL 4: In simple structured conversation with familiar communication partners, the individual can produce simple words and phrases intelligibly.

• LEVEL 5: The individual is able to speak intelligibly using simple sentences in daily routine activities with both familiar and unfamiliar communication partners.
• LEVEL 6: The individual is successfully able to communicate intelligibly in most activities, but some limitations in intelligibility are still apparent.
• LEVEL 7: The individual’s ability to successfully and independently participate in vocational and/or social activities is not limited by speech production. Independent functioning.

Intervention

• Referral to Speech-Language Pathology for an initial evaluation.
• Course of therapy (16-24 sessions) and the development of a home exercise program (HEP).
• Re-evaluation every 6 months to monitor functional gains and and adjust home programs as needed.
LSVT® LOUD: Sustained “ah”

• #1 exercise to improve vital lung capacity (Hixon & Hoit, 2005)
• Increases breath support for speech and vegetative purposes
• Control of expiratory flow-focus on intercostal muscles
• Improves vocal volume (loudness) and intelligibility (speech clarity)
• Also, improves swallowing by mimicking laryngeal excursion.

Let’s Try!

1. Take a deep breath.

2. Now, “Open your mouth wide”

3. Lastly, say “Ahh” for as long and loud as you can until you have no more air left in your lungs.
Normative Values

- Males- 20-40 seconds
- Female- 15-35 seconds
- Children- 10-18 seconds

(Duffy, 2005; Hixon & Hoit, 2005)

Incentive Spirometer  cost  ~$35.00

- Incentive spirometer has been shown to:
  - improves respiratory support for speech articulation, and swallowing.
  - aid in both inspiratory and expiratory resistive breathing training (RBT),
  - increase resistive pressure and duration over time.
Dysphagia

- Dysphagia is difficulty swallowing.
- Normal swallowing occurs ~1000 times per day.
- Over 40% of individuals with Multiple Sclerosis experience swallowing difficulty within 15 years of their initial diagnosis (ASHA 2008).
- Serious medical condition that requires skilled SLP intervention.
- Consequences can be aspiration pneumonia and/or death.

What causes swallowing dysfunctions?

- Dysphagia may be a result of multiple contributing factors:
  - Decreased neural drive (energy) to the swallowing muscles.
  - Insufficient sensory feedback
  - Jaw restrictions
  - Disruption of air-flow
  - Anatomical changes to the swallowing muscles
  - Muscle atrophy as a result of disuse.
S/S of Swallowing Dysfunction

- Coughing/clearing of throat
- Abnormal volitional cough
- Decreased voice quality (wet, hoarse, weak)
- Recurring chest infections
- Multiple swallows/special maneuvers needed to clear the throat
- Long mealtime (30+ mins)
- Feeling of food being stuck in the throat (globus sensation)
- Diet modification (e.g., thickening, pureed food, soft solids)
- Difficulty initiating a swallow
- Spillage of food/liquid from lips and/or drooling

FCM: Dysphagia

- LEVEL 1: Individual is not able to swallow anything safely by mouth. All nutrition and hydration is received through non-oral means (e.g., nasogastric tube, PEG).
- LEVEL 2: Individual is not able to swallow safely by mouth for nutrition and hydration, but may take some consistency paired with alternative method of feeding.
- LEVEL 3: Alternative method of feeding required as individual takes less than 50% of nutrition and hydration by mouth.
- LEVEL 4: Swallowing is safe, but usually requires moderate cues to use compensatory strategies, and/or the individual has moderate diet restrictions.
- LEVEL 5: Swallowing is safe with minimal diet restriction and/or occasionally requires minimal cueing to use compensatory strategies. All nutrition and hydration needs are met by mouth at mealtime.
- LEVEL 6: Swallowing is safe, and the individual eats and drinks independently and may rarely require minimal cueing. May need to avoid specific food items or require additional time.
- LEVEL 7: The individual’s ability to eat independently is not limited by swallow function. Swallowing would be safe and efficient for all consistencies
Intervention

• Referral to Speech-Language Pathology for a Videofluoroscopic Swallowing Study (VFSS).
• Development of a “safe food” program.
• Diet modifications to ensure swallowing safety.
• Course of therapy (16-24 sessions) and the development of a home exercise program (HEP).

Thickening Products
5-minute break
Medical Issues for the Person with Severe MS Disability

Stephen Krieger, MD
Mt. Sinai School of Medicine, NY

Topographical Model of MS: A Continuous Spectrum?

- In late-stage or severe MS, there has been loss of functional reserve, loss of neurons and axons, and a gradual accumulation of severe disability as a consequence of multifocal damage that is now clinically apparent. Disease activity, or new lesions, form far less frequently.

Krieger SC. “The Topographical Model of Multiple Sclerosis: A New Visualization of Disease Course” presented at the American Academy of Neurology 2015, p04.013
Severe MS Medical Decision-Making

- Loss of brain and spinal cord volume, correlative with accumulated disability
- Very little efficacy data for our DMTs at this stage of disease: exclusion criteria for trials, little long term cohort data

Brain atrophy images courtesy of R. Zivadinov. Unpublished data.

Reduction in All-Cause Mortality: Effect of DMTs?

Time From Study Randomization to Death

Proportion of Patients Who Are Still Alive

Emergency Medical Care of MS Patients

![Graph showing number of visits for EDSS<6 and EDSS>6 categories.]

Most Common Diagnoses by Category

- **Unrelated to MS**
  - Gastrointestinal issues
    - Abdominal pain, diarrhea, etc.
  - Viral infections (URI, gastroenteritis, etc.)
  - Respiratory issues (asthma, SOB, etc.)
  - Cardiac issues (chest pain, etc.)
  - Psychiatric issues (panic disorder, etc.)

- **Indirectly Related to MS**
  - Sepsis/Fever
  - Pneumonia
  - UTI/Urosepsis
  - Falls
  - Cellulitis/decubitus/ulcers
  - Hardware malfunction (i.e., urinary catheter)
  - DVT

- **Directly Related to MS**
  - MS exacerbation
    - (i.e., Optic Neuritis, etc.)
  - Worsening of chronic MS


CASE STUDY: Leslie is a 47-year-old African American woman who is seeing a new neurologist for the first time after last neurologist said “there’s nothing I can do for you.”

**History:** Diagnosed with MS in 1990, and subsequently had a series of attacks that included ON, myelopathy with paraparesis, and brainstem symptoms, followed by a progressive course. In 1996, she started treatment with IFN β-1a, but also started using a wheelchair outside of the house and had to stop working as an accountant.

**Recent Symptoms:** Hospitalized for presumed aspiration pneumonia and UTI/urosepsis that required a prolonged stay in subacute rehab.

**Current Condition:** Uses a wheelchair outside of the house; no function in left arm; legally blind. Has a 7-hr-per-day home health aide.

**Current Complaint:** Significant lower extremity pain and daytime somnolence and fatigue. Previously prescribed modafinil, which did not help and makes her nauseated. She has transferred to you after her previous neurologist said there was nothing else he could do for her.

**Exam:** Alert with severe dysarthria, some drooling. Bilateral INOs with facial weakness. Visual: Can read with right eye. Motor: Triplegic with residual strength in RUE ~4/5; increased tone in all extremities; LEs stiff with decreased ROM and clonus at ankles. Sensory: Painful, dysesthetic loss of all modalities in legs. **Bladder/Bowel:** Incontinent; currently using pads.
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**GETTING FROM “I CAN’T HELP YOU” TO “WHERE DO I START?”**

1. **Mobility / triplegia:** Need for increased care at home; motorized wheelchair
2. **Spasticity:** PT eval; ROM exercises; consider pharmacologic intervention/LE botox/baclofen pump evaluation
3. **Drooling / aspiration pneumonia:** Address siallorhea; consider botox to parotids
4. **Pain:** Consider pain from spasticity and dysesthesia; both can be addressed
5. **Fatigue and somnolence:** Consider interrupted sleep due to pain; spasticity; urinary frequency or immobility. Address these and reassess daytime somnolence. Without this, modafinil won’t help!
GETTING FROM “I CAN’T HELP YOU” TO “WHERE DO I START?” (CONT’D)

6. **Bladder**: Urinary retention and incontinence are likely; urology evaluation; may benefit from Foley (administered by HHA); consider suprapubic cath

7. **Polypharmacy**: Does she need to be on IFN β-1a SC? How would you evaluate the risk–benefit ratio here?

8. **Stress/Depression and psychosocial issues**: Pursue this; consider social work involvement, supportive psychotherapy, refer patient to the resources of professional societies like NMSS

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**Physical Therapy for the Person with Severe MS Disability**

Evan Cohen, PT, MA, PhD, NCS
Rutgers, The State University of New Jersey, NJ
A Shift in Priorities

• The person with severe disability from a PT’s perspective
  – Is unable to walk, or can walk only very short distances with assistance
  – May require assistance with functional mobility
  – May have significant restrictions in flexibility, or have an elevated risk of developing these restrictions
  – May have poor posture/postural control and their associated problems
    • Impact of communication, feeding, swallowing, bathing, dressing, etc.
  – May have some aspects of function that are not limited
  – Will be unlikely to have substantial functional recovery

The Focus of PT Interventions

• Rehabilitative strategies for deficits that have not yet become severe to maintain maximum function

• Activities and equipment that maximize independence
  – Wheelchair seating and positioning
  – Adaptive equipment to assist with any standing

• Maintain adequate flexibility even in the absence of strength
  – Function, pain control/prevention, cosmesis, skin safety
  – Consider the use of positioning aids in bed/chair

• Maximize/maintain respiratory function/hygiene

• Caregiver training
  – In bed mobility and transfer for patient/caregiver safety
  – Home exercise/stretching program
The Goals of PT Intervention

- Minimize secondary complications and maximize quality of life
- Caring for the person with severe MS related disability requires a reframing of practice for the rehabilitation therapist (Pizzi & Briggs, 2004).
- This should include a shift in mindset to help the person with MS live with the greatest amount of dignity and hope (Doyle, 1998), maximizing quality of life by addressing patient and/or family identified goals that are of the highest priority.

This might sound familiar...it is the philosophy of palliative care

How Can the PT Apply Palliative Care?

- Rehabilitation in Reverse Model
- Case Management Model
- Supportive Care Model
- Applying existing decision-making frameworks (e.g. HOAC II)

Briggs, 2011; Cohen & Briggs, 2011
Occupational Therapy for the Person with Severe MS Disability

Jennifer Kalina, MS, OTR/L, CCRC, MSCS
New York University School of Medicine, NY

Severe MS Disability (EDSS 7-9.5)

* Improve quality of life
Support system (though important throughout the disease course, essential when becoming more dependent)
Task modification
Role reversals
ADL – adaptive equipment and assistive technology
Speech and Language Rehabilitation for the Person with Severe MS Disability

Marissa Barrera, MS, MPhil, MSCS, TSHH, CCC-SLP
New York Neurogenic Speech-Language Pathology, NY

Severe Disability- Dysarthria

• Profound dysarthria and the inability to reliably orally communicate needs/wants.
• Inability to generate the necessary breath support to achieve an audible conversational volume.
• Need to supplement oral communication with AAC methods.
FCM: Motor Speech

- **LEVEL 1:** The individual attempts to speak, but speech cannot be understood by familiar or unfamiliar listeners at any time.
- **LEVEL 2:** The individual attempts to speak. The communication partner must assume responsibility for interpreting the message, and with consistent and maximal cues words are rarely intelligible.
- **LEVEL 3:** The communication partner must assume primary responsibility for interpreting the communication exchange, however, the individual is able to produce short consonant-vowel combinations or automatic words intelligibly.
- **LEVEL 4:** In simple structured conversation with familiar communication partners, the individual can produce simple words and phrases intelligibly.
- **LEVEL 5:** The individual is able to speak intelligibly using simple sentences in daily routine activities with both familiar and unfamiliar communication partners.
- **LEVEL 6:** The individual is successfully able to communicate intelligibly in most activities, but some limitations in intelligibility are still apparent.
- **LEVEL 7:** The individual's ability to successfully and independently participate in vocational and/or social activities is not limited by speech production. Independent functioning.

Intervention - AAC

- **Augmentative and alternative communication (AAC)** is an term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production of language.
- **AAC systems** are diverse:
  - Unaided communication uses no equipment and includes signing/gesturing.
  - Aired approaches use external tools.
  - These can include communication methods ranging from paper and pencil to communication books, boards, voice output devices (speech generating devices or SGD's) and/or voice amplifiers.
Intervention:  
Manual Diaphragmatic Support

• What is manual diaphragmatic support?
  • Manual application of pressure beneath the diaphragm to assist in respiration/phonation.
  • May be applied to one’s self/therapist/caregiver

• Why it is useful? Case example:
  • YS is 57-y-o female with MS; was in emergency situation where she needed to identify herself to police/EMTs
  • YS manually applied diaphragmatic support to increase vocal volume: was able to be understood in emergency
Severe Disability- Dysphagia

- Unable to eat/drink without s/s of aspiration.
- If dysphagia is associated with aspiration of food into the lungs, aspiration pneumonia may occur with all of the symptoms of pneumonia (fever, chills, and respiratory distress)
- Concern if solid food becomes lodged in the lower throat, it may induce choking/gagging interfering with breathing.
- If food stuck in the lower esophagus regurgitates at night, individuals may awaken coughing and choking due to food entering the throat, larynx, or lungs.
- Insertion of a PEG or NG tube is deemed medically necessary.

FCM: Dysphagia

- **LEVEL 1:** Individual is not able to swallow anything safely by mouth. All nutrition and hydration is received through non-oral means (e.g., nasogastric tube, PEG).
- **LEVEL 2:** Individual is not able to swallow safely by mouth for nutrition and hydration, but may take some consistency paired with alternative method of feeding.
- **LEVEL 3:** Alternative method of feeding required as individual takes less than 50% of nutrition and hydration by mouth.
- **LEVEL 4:** Swallowing is safe, but usually requires moderate cues to use compensatory strategies, and/or the individual has moderate diet restrictions.
- **LEVEL 5:** Swallowing is safe with minimal diet restriction and/or occasionally requires minimal cueing to use compensatory strategies. All nutrition and hydration needs are met by mouth at mealtimes.
- **LEVEL 6:** Swallowing is safe, and the individual eats and drinks independently and may rarely require minimal cueing. May need to avoid specific food items or require additional time.
- **LEVEL 7:** The individual’s ability to eat independently is not limited by swallow function. Swallowing would be safe and efficient for all consistencies.
Intervention: Assistive Swallowing Device

The Bionix Safe dysphagia straw allows only a small amount of liquid to enter the mouth per suck, freeing the patient/caregiver from manually controlling volume intake by squeezing the straw.

Two different versions available:
• one for thick, nectar sweetened liquids; and
• one for thin liquids.

Intervention: NMES

• What is NMES?
  – Neuromuscular Electrical Stimulation (NMES)
  – Use of a small, carefully calibrated electrical current delivered to the submandibular triangle.
  – NMES elicits neuroplasticity and strengthen the muscles responsible for hyolaryngeal excursion via surface electrodes.
  – The electrical current causes the muscles responsible for initiation of swallowing to contract.
  – NMES® therapy can lead to improved quality of the muscle contractions, thereby, improving the brains representation for swallowing at the cortex.
NMES: Typical Treatment Session

- Prepare skin, attach electrodes.
- Achieve therapeutic dosage.
- Stimulation remains on for 30 minutes in most cases.
- During stimulation the patient swallows with the onset of stimulation.
- Progress patient with different foods/liquids as per tolerance.

Intervention: NMES
What makes NMES for swallowing innovative?

NMES elicits brain plasticity which enables the recovery/relearning of swallowing function.

It targets and stimulates muscles that otherwise could not be treated with “traditional” swallowing intervention.

Clinical treatment is NOT dependent on having intact cognition.
Rehabilitation Issues in Aging and MS

Evan Cohen, PT, MA, PhD, NCS
Rutgers, The State University of New Jersey, NJ

Aging with MS

• What are we talking about here?
  – Persons previously diagnosed with MS who are living to older adulthood
  – Older adults who are diagnosed with MS later in life
    • Late onset MS: 2.7-12% of people with MS (Awad & Stüve, 2010)

• Estimated worldwide prevalence of persons with MS over the age of 65: 225000-350000 (Awad & Stüve, 2010)
Aging with MS

Can we differentiate age-related change from MS-related change?

A Summary of Relevant Age-Related Changes

Kane et al, 2013; Halter et al, 2009
Cardiovascular
- Reduced exercise tolerance
- Changes in blood pressure including orthostatic hypotension
- Arrhythmias

Neurologic
- Slower nerve conduction
- Alteration in short-term memory
- Changes in ability to perform ADLs

Respiratory
- Reduced respiratory volumes and efficiency
- Increased risk of aspiration

Integumentary
- Reduced ability to regulate body temperature
- Loss of bone protecting fat pads

Musculoskeletal
- Decreased muscle strength
- Limitations in ADL performance

Vision
- Diminished acuity
- Limitations in visual fields
- Slower light/dark adaptation
- Distorted depth perception
Genitourinary
- Reduced bladder capacity
- Increased PVRV
- Increased urgency

Hearing
- Decreased auditory acuity and isolation

Smell, Taste, Touch
- Inability to smell noxious odors
- Decreased food intake
- Safety risk (e.g. fire alarms/tripping obstacles, etc).

Endocrine
- Altered temperature regulation
- Weight gain

What are the Implications?

- Reduced cardiovascular and respiratory function contribute to diminished endurance and activity tolerance
- Alterations in thermoregulation may impact heat/cold tolerance
- Peripheral and central neurologic changes compound already altered neurologic function
- Decreased muscle strength and contractility further impact ADL and IADL functions
What are the Implications?

- Changes in sensation, skin and fat/muscle mass may increase risk of skin breakdown in persons with limited mobility.
- Alterations in vision worsen preexisting visual dysfunction.
- Declining GU function compounds continence issues.
- Other sensory system changes may have safety and/or health implications (e.g. altered senses of smell and taste).
- Age-related weight-gain may increase workload and alter biomechanical demands of ADLs.

Factors Influencing Healthy Aging with MS

- Proximal factors
  - Factors identified as invaluable and critical to maintaining a high quality of life.
- Foundational factors
  - Establish the basis for achievement of proximal factors.

Figure reproduced with permission from the authors.

Ploughman et al, 2012
Acknowledgements and Questions & Answers