Runner’s Dystonia: The Mystery Movement Disorder

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Purpose of Lecture
• Recognize, characterize, define Runner’s Dystonia
  – Etiology
  – Risk factors
  – “Rule in” clinical diagnosis
  – “Rule out” other movement disorders
  – Outline a plan of care

Purpose of Lecture
• Problem solve/improve patient function
  – Understand medical treatment
  – Remediate secondary impairments
  – Retrain the brain
  – Create novel PT strategies
• Summarize evidence based effectiveness studies

Focal Dystonia: Challenging Problem to Diagnose and Treat

Clinical Presentation: Runner’s/ Leg Dystonia

Example of Runner’s Dystonia with Walking

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3583069/
“Runner’s Dystonia: Stair Climbing”

“Runners Dystonia”, generalized to “walking/leg dystonia”

**Leg Dystonia: Definition**
- Idiopathic, pathological, synergistic involuntary movements
- Sustained/intermittent end range, twisting postures
- Co-contraction of flexors/extensors
- Quiet at rest; worse with voluntary leg movements
- Runners dystonia (Athlete’s Dystonia): task specific to running

**Characteristics: Leg/Runners Dystonia**
- Adult onset; may or may not progress
- Involuntary movements selective
  - Usually starts with toe spasms
  - Ankle-plantar flexion/inversion
  - Knee-hyperextension
- Normal reflexes
- “Sensory tricks” temporarily improve control
- Does not spontaneously improve when stop task

**Characteristics: Leg (Runner’s) Dystonia**
- Can be bilateral at onset
- May involve lower limb and adjacent regions
  - If multiple body segments: = segmental dystonia
  - If leg and half the body = hemidystonia
- May notice abnormal jerks of other body parts (e.g. hand, lips, face, eye lids)
- Usually associated with balance dysfunction

**EMG**
- Normal nerve conduction
- Usually see contractions of agonist/antagonist
- Insertion of needle
  - Short latency high amplitude contractions
  - Amplitude even more excessive with isometric contraction
  - Cannot turn muscles off
• Frequency analysis
  – Frequency of contractions in low amplitude range (<30 Hz) Tijssen et al, 2000)
  – Median power frequency in low frequency range with simultaneous increase in The % of total power contained
  – A threshold frequency of 70 Hz in dystonic muscles with 73% sensitivity and 63% specificity (Go et al, 2014)

EMG

Drummers Dystonia of Hand: Can You imagine this in the leg/foot?

Etiology Primary Focal Dystonia: Neurophysiology

• Excessive excitation: neuronal firing too soon with high amplitude
• Insufficient inhibition: difficult to turn neurons off
• Excessive neural adaptation (CNS changes quickly)
• CNS topographically reorganized: sensory/motor
• Familial genetics, exacerbated by risk factors (Hallet, Quarterone, Jankovich)

Etiology: Primary Focal Dystonia

• PET and MRI suggest some correlation between dystonia and lesions in the thalamus or basal ganglia, but inconsistent findings (Lalli and Albanese, 2010)
• Diagnosis is usually clinical: confirmed by normal PET and MRI with characteristic clinical picture

Leg Dystonia and Brain Changes

Decreased blood flow Left and increased blood flow right in putamen-basal ganglia (a) and thalamus (b) when a patient with leg dystonia imagined walking down stairs http://link.springer.com/article/10.1007%2Fs00415-011-5989

Adult Onset Foot or Lower Limb Dystonia is Often Secondary

• Parkinsonism (Albanese 2003; Bruno et al, 2004; Jankovic and Tintner, 2001)
• Trauma (Tarsay et al, 1994)
• Stroke (Choi et al, 1993)
• Psychogenic (Michaelson 2000)
• Structural lesion/ Biomechanical limitation (Marsden et al, 1985; Leijense and Hallet)
• Paroxysmal (Bhatia et al, 1997)
• Overuse (Byl et al 1996)
**Etiology Secondary Focal Dystonia: Aberrant Learning**

- FD can develop with excessive, repetitive activities
- Repetitions lead to local tissue inflammation
- Continued repetition spreads inflammation (local, bilateral then central in spinal cord and brain)
  - Abnormal movements appear during trained tasks
  - Sensory/motor representations progressively degrade

Barbe et al. 2010; Coq, Byl, Blake, Merzenich

Instead of the hand/arm, the foot/leg is degraded in runner’s/leg dystonia

**Etiology Secondary: Musculoskeletal/Biomechanical Limitations**

- Involuntary dystonic movements accommodate
  - Anatomical variations
  - Unique weakness
  - Limited or excessive joint motions
- Example: focal hand dystonia of a guitarist
  - MCP joint of thumb is hypermobile/unstable
  - Cannot stabilize thumb to pluck fingers
  - Compensatory, involuntary movements of D2 and D5 to try to stabilize (Lejeinse and Hallet 2011)

**Lower Limb Dystonia: Secondary**

- Post immobilization (@ 8 wks): fixed dystonia in PD
  - Post hip and back injury
  - Transfusion therapy
  - Results in functional disability
  - Resistant to medical treatment
    - Oral medications may help to control symptoms
    - Orthopedic surgery may need to be considered

**Runner’s Dystonia: Risk Factors**

- Behavioral risk factors
  - Excessive running
  - Compulsive, obsessive
- Neurophysiological risk factors
  - Excessive plasticity
  - Hypersensitivity
  - Poor sensorimotor integration

**Leg Dystonia: Risk Factors**

- Psychosocial
  - High/chronic stress
  - Profession: athletes/musicians, programmers
  - Type A personality
  - Perfectionist
  - Perseverative
  - Phobic
- Genetic
  - Ashkenazi Jewish population
  - DYTI gene
  - Family history of movement disorder
  - Symptoms develop in presence of risk factors
Leg Dystonia

Multifactorial Etiology of Focal Dystonia

Rule Out Other Causes
- MS
- PD
- ALS
- PLS
- Stroke
- CRPS
- Severe spinal stenosis with neuropathy
- Essential tremor
- Brain atrophy
- Brain tumor
- Psychogenic dystonia
- Exertional dystonia

Ruling Out Other Diagnoses: Need for MD Referral
- Abnormal reflexes (e.g. Babinski)
- Hyper-reflexia (e.g. pasticity/increased tone)
- Resting tremor
- Tremor worse with purposeful movements
- Severe spinal stenosis by MRI
- Peripheral neuropathy (nerve conduction abnormal)
- Freezing of gait
- Hemiparesis with cardiovascular signs

Organic Vs Psychogenic Dystonia: PET
- Blood flow imaging (positron emission tomography) performed during functional tasks
  - **Organic dystonia** = abnormal *increased* blood flow in primary motor cortex and thalamus but *decreased* cerebellar activity
  - **Psychogenic dystonia** = abnormal *increased* blood flow in cerebellum and basal ganglia; *decreased* in motor cortex

R/O Paroxysmal Exercise-induced Dystonia vs Runner’s Dystonia
- Paroxysmal exercise-induced dystonia (PED)
  - PED occurs intermittently with intense exercise
  - Occurs in young individuals (2-30 years)
  - Frequently has genetic component
  - Likely to spread
  - Persists after triggering activity ends
  - Not necessarily associated with prolonged, repetitive ex

Prevalence: Leg Dystonia
- 2005: 19 cases identified at Mayo Clinic
- 2006: 17 cases reported; 5 cases reported
- 2012: 14 cases leg dystonia reported
- 2013: A case series of 7 reported
- 2014: Number tripled (48 reported in systematic review)
- 2015: Additional 9 case series reported

Cutsforth-Gregory et al, 2005; Schneider et al, 2006; Wu and Janovic, 2006; Martino et al, 2010; Katz, Byl, Ostrem, 2013; Wu et al 2012; Frucht 2015; Altenmueller 2014
**Incidence of Lower Limb Dystonia**
- Mayo clinic, retrospective search of records 1996-2000, >18 years, no neurologic findings outside affected limb
  - 36 patients (31 females)
  - 5 with PD
  - 3 with psychogenic dystonia
  - 10 post traumatic dystonia
  - 1 with stroke
- 2010: of 579 cases of diagnosed dystonia (Italy), 11 had leg dystonia
  - 4 alone
  - 7 part as part of a segmental/multifocal dystonia

**Assessment/Evaluation: Clinical Diagnosis**
- Thorough History
  - Family
  - Medical
  - Trauma
  - Occupational
  - Personality
  - Stress
  - Sleep
- Observe/videotape patient performing task
  (stair climbing, running/ walking over-ground or treadmill)
- Perform Neuro Exam
  - Reflexes
  - Rapid/slow alternating mvts
  - Neural tension
  - Posture and balance
  - Sensory exam (2 pt, Stereognosis/graphesthesia, proprioception)
- Rate dystonia severity
- Test strength
- ROM
- Pain
  - Characteristics/location
  - Severity (0-10)

**Why care about low incident condition?**
- Takes 2.7 (Schneider et al., 2006) to 7.2 (Wu and Janovic, 2006)
  years to make diagnosis
- Often wrongly attributed to orthopedic disorder
- Early ID may decrease severity, improve outcomes and avoid career ending situation for athletes/musicians
  - Modify poor biomechanics
  - Treat inflammation
  - Treat inflammation
  - Avoid unnecessary surgery
  - Begin counseling, mindfulness training, mental practice

**Rating Dystonia Severity: Scales**
- Leg Dystonia
  - Fahn Marsden Scale (s)
  - United Dystonia Scale
  - Twister for cervical dystonia
- Problems
  - Scales have one component for “leg” but no details included (e.g. hip, knee, ankle, toes)
  - Sensitivity for measuring change limited
Other Outcome/Diagnostic Measurements

• Medical
  – MRI
  – fMRI with imaging walking/turning
  – EMG (characteristic firing pattern)
  – Mental status
  – Depression

• Clinical Assessments
  – iTUG
  – Posturography
  – Mini Best Test
  – 10 meter/6 minute walk
  – Number falls
  – 360° turn (kinematics/time)
  – Self rated function/QOL

“Rule in” Clinical Diagnosis

<table>
<thead>
<tr>
<th>Factor</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Involuntary leg movements with target activity</td>
<td>X</td>
</tr>
<tr>
<td>2. Drags toe with running, walking and/or stairs</td>
<td>X</td>
</tr>
<tr>
<td>3. Has painful muscle cramping</td>
<td>X</td>
</tr>
<tr>
<td>4. Normal movement at rest</td>
<td>X</td>
</tr>
<tr>
<td>5. Adult onset (after 30 years of age)</td>
<td>X</td>
</tr>
<tr>
<td>6. Selective muscle imbalance (intrinsics, hip abd)</td>
<td>X</td>
</tr>
<tr>
<td>7. Normal neuro exam (reflexes, tone)</td>
<td>X</td>
</tr>
<tr>
<td>8. Normal nerve conduction</td>
<td>X</td>
</tr>
<tr>
<td>9. Leg trauma &lt; 1 year earlier</td>
<td>X</td>
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Rule in Clinical Diagnosis

<table>
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<tr>
<th>Factor</th>
<th>Present</th>
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<tbody>
<tr>
<td>10. Multi joint ROM: hypermobile/hypomobile</td>
<td>X</td>
</tr>
<tr>
<td>11. Co-contraction flexors/extensors, one dominant</td>
<td>X</td>
</tr>
<tr>
<td>12. Ashkanazi Jewish background</td>
<td>X</td>
</tr>
<tr>
<td>13. Type A Personality, perseverative/and or phobic</td>
<td>X</td>
</tr>
<tr>
<td>14. High stress/poor sleep/poor life style</td>
<td>X</td>
</tr>
<tr>
<td>15. Sensory trick (e.g. walk backwards)</td>
<td>X</td>
</tr>
<tr>
<td>16. Under stress/ history excessive repetitive practice</td>
<td>X</td>
</tr>
<tr>
<td>17. Sensory discrimination problems</td>
<td>X</td>
</tr>
<tr>
<td>18. Integrative balance problems</td>
<td>X</td>
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Benefit of Diagnostic Criteria

<table>
<thead>
<tr>
<th>Score</th>
<th>Has FD</th>
<th>Does Not have FD</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>25</td>
<td>5</td>
</tr>
<tr>
<td>≥15</td>
<td>4</td>
<td>2</td>
</tr>
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Sensitivity 25/29 = 86%
Specificity 26/31 = 84%

LR+ = sensitivity/1-specificity (high) = 5.4
LR- = 1-sensitivity/1-specificity (low) = .166
ROC plots sensitivity by 1-specificity (want combination high sens and low 1-spec)

Evidence Characterizing Runner’s Dystonia (Case Series = 5)

- Gender: 3 female
- Mean age: 44.6 (10.4)
- Mean age of onset: 37.4 (10.3)
- Mean duration of symptoms (years): 7.2 (4.4)
- Family history (DYTI Ashkenazi Jewish): 0
- Injury leg within 1 year: 2

Wu and Jancovick, 2006

Evidence Characterizing Limb Dystonia (N=17)

- Average age (years):
  – Onset: 48.4
  – Saw MD: 50
- Average time (years):
  – To diagnosis: 2.7
- Side affected (2 bilateral):
  – One: 15
  – Left: 8
- Foot involvement:
  – Toe flexion: 9
- Plantar flexion ankle: 6
- Family hx tremor: 1
- Family hx of dystonia: 1

Schneider et al, 2009
Evidence Characterizing Leg Dystonia Case Series / Case Studies (21)

- Female: 13
- Range: age of onset (years) 27-57.7
- Time with leg dystonia (years) 3-7
- Avg time to diagnosis (years) 4 (9.5 SD)
- Pain 3
- History of specific trauma: 3
- *Trigger: running/walking/hiking, dancing, drumming, kickboxing, cycling (only I had dystonia at rest)

Evidence Characterizing Leg Dystonia in Musicians (Drummers)

- Task-specific; does not impact walking
- Presents at older age than FHD (> 50yrs)
- More common females vs males*
- Hx of intense prolonged practice
- Less progressive than FHD

(=Katz et al, 2013)

Evidence Characterizing Medications for Leg Dystonia

- Case Series N=5 (Wu & Jancovick, 2006)
  - Botox 2
  - Anticholinergic 1
  - Levadopa 1
  - Anticholinergic 1

- Case Series N=17 (Schneider et al 2009)
  - Other drugs 15
  - Dopa-responsive 8
  - Treated with botox 8
  - (6 improved)

Effectiveness of Treatment

- Cutsforth-Gregory et al, 2005 (19 patients)
- After a F/U of 4.8 years (0.4-23 years)
  - All patients still symptomatic
  - Effective treatment rare
  - Most achieving only partial return to predystonia activity
  - Beneficial treatments: botox 3/5, PT 6/15, clonazepam (2/5), carbidopa/levodopa (3/8) trihexyphenidyl (1/3)

Goal for Intervention

- Manage signs and symptoms; cure is uncommon
  - Decrease pain and cramping
  - Minimize dysfunction on ADL
  - Minimize secondary impairments
  - Maximize quality of life
  - Stop progression
  - Modify ergonomics to enable task performance

Objectives for Intervention

- Involve family and establish consensus of objectives: patient, therapist, family, physician
- Educate patient and family
  - Etiology of focal dystonia
  - Science of neuroplasticity and retraining
  - Positive expectations
- Stop abnormal movements
- Be willing to change life style
Objectives for Focal Dystonia

- Prepare CNS for learning with quality lifestyle
  - Regular exercise
  - Strengthen weak muscles
- Decreased stress
  - Normalize ROM
- Decrease neural sensitivity
  - Improve sleep
- Manage pain and neural tension
- Improve trunk stabilization, posture, and balance
- Counseling for depression

Objectives: Focal Leg Dystonia

- Follow principles of neuroplasticity to retrain the brain
  - Improve sensory, sensory-motor, sensorimotor integration
  - Improve voluntary control/quality movement
    - Initiation and controlled movements
    - Assistive devices
    - Electrical modalities (FES, Biofeedback)
    - Robotic assisted movements

(Jabusch et al, 2005; Leijense, 2009; Altenmueller et al, 2013)

Prognosis: Limited by Severity and Personal Traits

- Negative expectations
- Low self-esteem
- Habitual activities; reluctant to change
- Continued stress
- Behaviors near simultaneous in time
- Reduced repertoire of motor movements
- Continue repetitive abnormal movements
- Repetition of erroneous neural signals
- Continued repetitive practice

Establish a Team

- Find a physician familiar with dystonia and can do botulinum toxin injections
- Identify a coach who understands running biomechanics
- Identify programs or individuals who can help with
  - Stress and anxiety management
  - Massage
  - Imagery
  - Self healing
- Find individuals who have recovered or are effectively managing FD

(Schuel et al 2005)

Medical Intervention

- Education re dystonia
- Referrals
  - Diagnostic W/U
  - PT
  - Psych counseling
  - TMS, ICTS, DBS
- Fatigue therapy
- Limb immobilization

- Medications
  - Muscle relaxants
  - Levadopa
  - Anticonvulsants (Carbamazepine)
  - Inject botulinum toxin
  - Inject Phenol
  - Anti depressants
- Orthopedic surgery

Physical Therapy

- Modify life style
  - Stress management
  - Nutrition
  - Stop smoking
  - Eliminate drugs and ETOH
  - Sleep
  - Exercise
**Stress management: Mindfulness**

- Personal training or online training in stress management
  - Example of 6 week online training course (Florence Meleo-Meyer and Saki Santorelli)
  - Oasis Institute for Mindfulness-Based Education and Training
  - Center for Mindfulness in Medicine, Health Care, Society

**Chronic Inflammation**

- Excessive repetition can lead to
  - Chronic pain
  - Chronic soft tissue inflammation (muscle, nerve fascia)

- Critical to minimize injury behavior
  - Protect area and minimize unnecessary forces
  - Retrain quality biomechanical movements
  - Mobilize tissue (e.g. neural mobilization)
  - Treat inflammation (e.g. meds/non inflammatory foods)

**Nutrition: Reducing Inflammation**

- Probiotics (Lipski, 2012; Dickerson, 2014; Giardina, 2014; Xiao, 2014; Voghef-Mehrabany, 2014)
- Antioxidants (nuts, variable colored fruits and vegetables) (San Miguel, 2013; Urios, 2007; Kim, 2014; Demirkol, 2012; Part, 2016; Grieger, 2014)

**Nutrition: Reducing Inflammation**

- Vitamin D (sunshine, liver, grass fed dairy) (Angelina, 2014; Park, 2014; Santini, 2013; Baggerly, 2015; Park, 2015)
- Gelatin/Collagen (healing of gut lining) (Han, 2015; Atiba, 2011; Ao, 2012)
- Curcumin (Turmeric) (Shakibaei, 2011; Somchit, 2014; Ganjali, 2014)

**Nutrition: Reducing Inflammation**

- Eat whole nutrient rich food when hungry
- Eat in a calm manner
- Stop eating when full
- Do intermittent fasting (extend the interval between meals)

**Nutrition: Reducing Inflammation**

- Remove
  - Refined flour, refined sugar, refined vegetable oils, processed foods,
  - Unnecessary medications (under a physicians guidance)

- Replace
  - Eat whole organic produce, meats, fish and healthy fats.
  - Drink 8 glasses H2O

- Restore
  - Healthy inflammatory response
  - Better health

**Sleep is Essential**

- Most individuals need 7-8 hours of sleep with a good period of deep sleep
  - Consolidate learning
  - Allow recovery from stressful life events

- Behaviors to improve quality of sleep
  - Dine early
  - Relax before going to bed
  - Warm shower helps relax muscles before sleep
  - Review positive and challenging aspects of day
  - Review for activities for next day
**Improve Sleep**

- Do not go to bed until you are sleepy
- Use bedroom only for sleep
- Get out of bed if you are unable to sleep after 15 min (avoid stimulating activities)
- Get up each day at the same time every day

**Exercise**

- Do not take naps late in the day
- Participate in regular physical activities
- Reduce evening caffeine, nicotine and alcohol
- Reduce fluid intake in the evenings

**Aerobic exercise 5x/week 30 minutes**
- Strengthening, balance/posture exercise, 2x/wk, 30 min
- Be physically active everyday
  - Use stairs instead of elevator
  - Walk or bike instead of taking the car
  - Take breaks from sitting with brief walks or ROM activities

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**Stop Abnormal Movements**

- Have the individual capture the image of the past when no leg dystonia present
  - Look at personal running videos when no dystonia and imagine restoring normal running
  - Watch videos of different people running/walking
    - imagine it is "you" running
    - imagine correcting the dysfunction

**Stop Abnormal Movements**

- Substitute mental practice for physical practice
  - Mental imagery (Page etc)
  - Guided imagery (Marten Rossman, MD)
  - Mirror imagery (noigroup.com; JHT 2012; Ramashandran)
  - Graded motor imagery (noigroup.com; JHT 2012)

**Stop Abnormal Movements**

- Perform running/jogging/walking movements in different, unusual postures/positions
  - Lie supine and cycle legs like walking/running
  - Lie on side (support upper leg) and cycle
  - Walk backwards (flat, up hill, down hill)
  - Walk with arms on treadmill; crawl on floor
- Perform task in unusual environment (water, high altitude)

**Stop Abnormal Movements**

- Perform parts of the task that are normal
  - Unweight affected leg and walk with unaffected leg letting affected leg swings normally
  - Glide Trak over a treadmill or over ground
  - Use crutches: nonweight bearing
  - Use BWST (AlterG, Biodex, Mobility Research) to walk over a treadmill or over ground
Stop Abnormal Movements

- Use orthotics to correct biomechanical problems
  - Toe spreaders
  - Metatarsal pads/bars
  - Medial wedge hind foot
  - Lateral wedge forefoot
  - Hammer toe options
- Strengthen intrinsic muscles of foot

Decrease Neural Hypersensitivity: Quiet the Nervous System

- Wrap tightly in a blanket
  - Rock in a rocking chair
  - Nap while wrapped up
- Swing on a swing
- Get up a battery operated porch swing to swing at different speeds
- Have friend gently stroke your head, neck or foot
- Listen to relaxing music
- Play calming sounds (breaking waves, birds)
- Laugh
- Participate/imagine doing pleasurable activities
- Go to a special relaxing place (e.g. mountains)

Improve Posture

- Stand tall with chin tucked in
- Keep the ears midline of the shoulder
- Improve postural righting reflexes
  - Look up; reach up
  - Scan environment
  - Step over objects
  - Walk in Kangoo boots
  - Respond to quick and prolonged perturbations (eyes closed, someone perturbs or rope tug)

Improve Posture

- Use roller for trunk stabilization
- Strengthen lower abdominals
- Strengthen scapular stabilizers hip extensors

Maximize Experience Dependent Plasticity: Principle of Brain Retraining

- Use it or lose it
- Use remap and improve it
- Have adequate but not excessive repetitions
- Make training intense (2-8 hrs/day, 2-5 days/wk)
- Attend to activities
- Vary training sequence
- Progress difficulty
- Be specific

Kleim and Jones, 2008; Byl and Merzenich, 2012; 2013 Section on Neurology, Neuroplasticity Course; Merzenich 2012, Woodsen and Faller
**Principles of Neuroplasticity**

- Make learning **fun**
- Space practice over time (8-12 weeks)
- Make training salient
- Adjust training to age
- Reinforce learning with feedback/accuracy
- Transfer learning
- Strengthen learning with interference/surprise

**Improve Sensory Discrimination**

- Eliminate vision
- Incorporate all sensory modalities (tactile, proprioception, sound, vibration, gravity, temperature)
- Use active and passive stimuli
- Make all tasks a forced choice
- Dol training activities positions
- Have sensory objects
- Add time as a variable

**Improve Sensory Discrimination (Stereognosis): Feet**

- Feel and match objects with eyes closed
- Learn to read large Braille letters
- Paste buttons on cards and match buttons by feel
- Put stickers on cards, and match stickers
- Feel and spell words with small alphabet letters
- Sort by size, surface coarseness

**Sensorimotor training (LBSMT)**

- Think about sensory aspects of performing functional tasks with leg; let object texture guide the foot
- Use a mirror image to facilitate normal sensory information and movement
- Progress non-target task to completion with normal movements and good sensory awareness; progress difficulty
- Begin performance of part of the target task

**Mirror Imagery**

Affected hand is behind the mirror and tries to move just like the mirror image Do the same thing with the foot

The image of the unaffected hand looks like the affected hand in the mirror (translate this to the leg/foot)
**Somatosensory Training:**

**Recognise** | ipham e app 8.99 |

**Laterality**
- Place foot on scale at different weights
- Use smooth movements to tap foot
- Use limb in stress free way (ex hand or foot)
  - Use limb in good biomechanical alignment
  - Use sensory information to guide movement (rough, sticky, vibratory)
  - Strengthen the intrinsic muscles
  - Emphasize proximal movements

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**Practice Grading Movements**

- Place one foot on treadmill (ex. Hand)
  - Keep the normal arches of palm and digits
  - Let belt move under foot with no toe grabbing
- Touch fan blades with toes; do not stop blades
- Let weight of foot drop on keyboard at slow and fast speed

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**Improve Dynamic Balance**

- Wear ankle weights
- Wear weighted vest
- Perform dynamic balance activities
  - Eyes closed, head turning
  - Dual tasking (e.g. reading, catching, throwing and kicking balls, crossword puzzles,)
  - Bosu ball  - Swivel Board
  - Rocker board  - Unstable surface (foam/ball)

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**Improve Voluntary Motor Control**

- Functional Electrical Stimulation (FES)
- Gait timed electrical stimulation/gait devices
  - Common devices: Walk aid; Bioness; Bioness L 300
  - Surface electrode placement
    - Peroneal nerve (Ant tibialis; peroneus brevis)
  - Training time
    - Daily
    - Months (up to 20 months)

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**Improve Voluntary Motor Control**

- Use biofeedback to
  - Inform about errors
  - Positive reinforcement
  - Quiet muscle spindles
  - Recruit muscles
- Types of biofeedback
  - Electrical
  - Auditory
  - Visual
  - Tactile
  - Virtual reality
### Improve Voluntary Control

- **Lazars for retraining**
- **Robotic devices**
  - Passive assistive
  - Progressive assistive
  - Functional activities
  - ROM
- **Assistive devices**
  - AFO (traditional, noodle, spring loaded)
  - Knee scooter
  - Walking poles
  - Canes, crutches

### Use of Lazars

**Movement Training**

Wendy Simpson PT: Innovative Lazer Training

### Improve Voluntary Control: Mechanical/Robotic Devices

- **Mechanical devices**
  - Kickstart- Cadence
  - Up and Go walker
- **Robotic devices**
  - Bionic Leg (After G)
  - Ekso Bionics
  - Rewalk
  - C Brace
  - Smart Shoe

### Biomechanics/Kinematics at Home

- **Improve stride symmetry**
  - Put lines on floor equal distance for usual/stride
  - Change line spacing for different stride length
  - Walk at different speeds
  - Put down electronic keyboard and step to keys with each foot, reaching different distances
- **Decrease excessive ground reaction forces**
  - Step one foot up on scale to estimate force
  - Walk lightly on feet (less, \( > \) scale force)
  - Walk on different surfaces (uneven, soft, hard, uncomfortable)

### Improve Kinematics of Gait: At Home

- **Increase foot clearance**
  - Actively increase dorsi, knee and hip flexion
  - Put up ropes to step over (increase height of rope as successful)
  - Practice jumping over lines
  - Practice stepping over objects (e.g. paper plates, books)
**Improve Kinematics at Home**

- Improve proprioception
  - Wear ankle weights
  - Walk on uneven surfaces
- Improve time on affected leg
  - Swing unaffected leg
  - Kick balls of different size at different targets
  - Hold single leg squat while playing catch

**Improve Kinematics of Gait: At Home**

- Improve forefoot roll off/heel off by putting unaffected leg forward, affected leg back
  - Roll off forefoot, bending knee and stepping forward
  - Let heel come up followed with knee flexion
  - Step up on stair with affected leg
  - Rise on toes, both feet/come down slowly
  - Rise up on affected foot/come down slowly

**Improve Kinematics of Gait: At Home**

- Strengthen weak muscles
  - Hip abduction + extension
  - Ankle dors flex/eversion
  - Eccentric quadriceps
- Increase range of motion
  - Hip extension
  - Ankle dors flexion

- Dynamic, integrative strengthening
  - Descend stairs with affected (increase stair height)
  - Practice walking lunges with increasing weights and increasing R for abduction
  - Do concentric and eccentric exercises (e.g. Practice letting heel down slowly from up on toes)

**Control Knee Bending**

- Descend stairs with affected leg
- Practice walking lunges with increasing weights and increasing R for abduction
- Do concentric and eccentric exercises (e.g. Practice letting heel down slowly from up on toes)

**Exoskeleton without Robotics**

*Kickstart from Cadence*

**Other Examples of Motor Retraining**

- Integrate normal gait with unweighting systems (e.g. AlterG, GlideTrak, Biodex, Mobility Research)
- While un-weighted, change speed and
  - Emphasize walking forwards and backwards
  - Add eccentric exercises by walking down hill
  - Increase challenge and walk up hill
- Crawl to simulate unweighting and reciprocal mvts
Retrain with Unweighting

Glide Trak Training
Unweighting to Stride

Swinging Affected Leg Without Weight Bearing

Power Knee: Enables Reciprocation

Smart Shoe: Dynamic Kinematic Feedback

Smart Shoe: Kinematic Feedback
Leg Dystonia: Use of Low Cost Technology to Stop Abnormal Movement

Sensory Tricks

Stop abnormal movement

Weight limbs and trunk to increase proprioception

Improvement with practice

Impact of Assistive and Dynamic Orthoses

Integrate Functional Activities

Make relearning fun
- Competitive
- Include youthful activities such as skipping, hopscotch, ball games)

Walk Backwards and Forwards

Improve Proprioception and Movement With Weights
Evidence of Effectiveness: Focal Dystonia

- Patients generally self-report improvement but objective measurements do not confirm change
- Individuals do best when they
  - Take time off to retrain do best in recovery
  - Periodically can successfully perform the target task
  - Are positive about recovery
  - Continue to teach or coach but not perform

Evidence Based Effectiveness

- Level of evidence of effectiveness - “poor”
  - Based on case studies and case series
  - Small number of subjects in any one location
  - No randomized controlled comparative trials with usual care/age matched control group vs brain retraining
  - No good systematic reviews on effectiveness

Outcome Effectiveness

(Cutsforth-Gregory et al, Minn Med, 2015)

- Mayo Clinic follow-up of 19 patients (4.8 years from dystonia onset and 2.1 years from diagnosis
  - All patient still symptomatic
  - Effective treatment rare with only partial return to pre dystonia state
  - Botulinum 3/5
  - Clonazepam 2/5
  - PT 6/15
  - Carbidopa/levodopa 3/8

Effectiveness: Medical Intervention

- Medications for anxiety: helpful for performance
- Levadopa: usually no benefit (none of patients developed PD in 2.5 yrs) (Katz et al, 2013)
- Botulinum toxin injections (A or B): Positive
  - Decrease cramping severity and increase use of limb
  - Improve quality of response: 20-90%
  - Of 17 patients, 8 treated with botulinum and 6 improved (Schneider et al, 2006)

Effectiveness of Medications

- Botulinum toxin injections (A or B): Negative
  - Temporary (lasts @ 3 mo) and may not fully recover
  - No change sensory processing, motor control or topographical maps on cortex or brain stem
  - Weakness may be excessive
  - Strength may not return

Effectiveness: Medical Treatment

- Surgery
  - Types: trigger toe release, release of fascia, extensor hallucis or anterior tibialis
  - Split anterior tib transfer
  - Surgery
    - Most: no change dystonia
    - Several case studies improved equinovarus deformity
- Immobilization in cast
  - Early onset patients improved
  - Chronic cases worse
- Cooling with stretching
  - Temporarily decreases severe cramping episodes
  - No long term changes
### Effectiveness of Medical Treatment

- Repeated TMS/tDCS (Kimberly 2009; Quartarone, 2010)
  - not curative but may set stage for retraining
  - exact repetitions/ stimulation unknown
- Fatigue training
  - temporary improvement
  - prepares for retraining
- Nutrition (e.g. gluten free diet) positive case reports Perlmutter Grain Brain

### Effectiveness of Rehabilitation

- Electrical stimulation (timed with swing phase and heel strike)
  - guide retraining but not curative
  - may need to be used for up to a year (Barret et al, Letter to Editor 2012)
- Biofeedback
  - increases awareness
  - challenges patient to change

### Effectiveness of Rehabilitation

- Body unweighting to 40% of bodyweight
  - decreased intensity of abnormal firing of extensor hypertonicity
  - Increased gait speed
  - Did not improve integrative balance


### Effectiveness of Rehabilitation

- Stress management
  - Patients self report improvement
  - Objective evaluation of dystonia unchanged
- Improved life style
  - Increases telomere length
  - Improves sense of well being
- Multidisciplinary intervention (team) best

### Outcome: 21 Leg Dystonia Cases

- 17 treated: 1 patient returned to work with no tx
- 11/17 treated returned to walk/run after therapy (65%)
  - 6/7- effective return to exercise/running with: AFO, knee brace, physical therapy; body-weight supported treadmill training, FES of peroneal nerve; Benzodiazepines, BoTox
  - 2/5 - returned to walking following Carbamezapine Levodopa Trihexyphenidyl, Botulinum toxin

### Outcome: 21 cases Continued

- 2/3 - returned to exercise when supplemented with leg brace, botulinum toxin, clonazepam or nortryptylene,
- 1/7 - returned to exercise when treated with clonazapen
Future Rehabilitation Research

• Evaluate similarities in topographical sensory and motor maps: leg vs hand/arm dystonia
• Carry out prospective, randomized clinical trials on effectiveness of medical interventions
  – TMS with/without botox
  – tCTR with/without botox
  – DBS with/without botox and learning based training
  – Learning based gait training with and without botox

Future Research: Rehabilitative Interventions

• Multi site RCT’s comparing different strategies
  – Manual mobilization (hip, knee, ankle, foot) and strengthening
  – Timed ES (dorsifexion) during walking/running
  – Mental imagery and virtual reality gait training
  – Biofeedback/neurobiofeedback with learning based gait training
  – Body un-weighted gait training: regular vs split belt treadmill

Summary

• Runner’s dystonia: uncommon/difficult to diagnose/treat
  – Best to diagnose early
  – Can be managed with high patient motivation and a comprehensive team approach
  – Rare for focal limb dystonia to be cured
  – Patients interpret more improvement than is objectively documented
  – Botulinum toxin and creative brain retraining is best management strategy

There is still a lot to learn about Runner’s Dystonia

Thank You

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