A Comprehensive Overview for Treating 2 Patients with Locked-In Syndrome

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Objectives

• Describe a case of Locked-in Syndrome (LIS)
• Explain different OT treatment strategies for individuals who have Locked in Syndrome
• Explain different PT treatment strategies for individuals who have Locked in Syndrome
• Describe possible progressions in an inpatient therapy program for a patient with Locked in Syndrome
• Describe possible progression in an outpatient therapy program for a patient with Locked in Syndrome

What is Locked-In Syndrome

• Brainstem Stroke
• Awake and conscious
• Unable to produce limb movement, speech, or facial movement
• May resemble vegetative state or akinetic mutism
• Communicate via eye movement
Case 1: Inpatient PT and OT Progressions

Heather Hunt, DPT
Allyson Yukevich, MS, OTR/L, CBIS

• Past Medical History
  – 42 year old male
  – History of bilateral peripheral neuropathy, asthma, obstructive sleep apnea

• History of Present Illness
  – Presented to outside hospital on 2/2/13 with ringing in ears, lightheadedness and neurological decline
  – Head CT (+) basilar occlusion and right superior cerebellar artery occlusion
  – tPA– hemorrhagic conversion and cerebellar herniation– craniectomy/ decompression

• History of Present Illness
  – Saddle Pulmonary embolisms
  – Extensive Bilateral deep vein thromboses
  – TEE (+) Large PFO– unrepaired
  – Clostridium Difficile positive
  – Tracheostomy/PEG
  – Left eye corneal tear
  – Left ear skin breakdown
Case 1

- Social History
  - Physician
  - Wife and 3 children
  - Driver
  - Enjoys working out, TV, family, vacations, the Steelers, listening to music

Rehabilitation Team

- MD
- Nursing
- Case Manager
- OT
- PT
- SLP
- Neuropsychology
- Respiratory
- Child Life Specialist
- Family/Friends

Occupational Therapy Evaluation

- Admitted to rehab 3/23/13
- Total assist for activities of daily living
- Total assist for transfers with Hoyer lift/in-ceiling lift
- Passive range of motion (PROM) in bilateral upper extremities (UE) within normal limitations
- Increased tone in cervical spine
- GOALS: Total assist – family educated and trained in all self care/transfer tasks.
OT Treatment Strategies and Progression

OT Treatment Strategies and Progression

• Months 1-3 (March-June)
  – Cervical spine stretching
  – Lateral leans/ mat program
  – PROM to Bilateral UE
  – Electric stimulation
  – Sitting balance
  – Eye gaze
  – Communication board
  – Switch use
  – Power wheel chair mobility
  – Therapy dogs
  – Ongoing family education
  – Thumb strengthening
  – Patient/Children activities

OT Treatment Strategies and Progression

• Months 4-7 (June-October)
  – PROM/AAROM
  – Assistive technology
  – Power wheel chair mobility
  – Community integration
  – Mat program
  – Partial sit to stand transfers
  – Self feeding
  – Family training/ education
  – Neuromove
  – Fine motor coordination/ strengthening
  – Static sitting balance
  – Computer use
  – Armeo® Boom
OT Treatment Strategies and Progression

• Months 7-8 (October-November)
  – Lateral scoot transfers
  – Family training/ education
  – Sit to stand transfers
  – Power wheel chair mobility
  – AAROM/PROM
  – Core strengthening
  – Mat program

• Computer use
• Communication
• Bed mobility
• Arm bike
• Family meetings

OT Discharge Plan

• Total assist to maximal assist with activities of daily living
• Total assist to maximal assist with transfers—Hoyer lift/ lateral scoot transfers
• Discharge to home with wife and children
• Received outpatient services with an extensive home program
• Hospital bed, tilt in space shower commode chair, BFO, adaptive keyboard with key guard, universal cuff
Physical Therapy Evaluation

• Total assist for all transfers
• Total assist x 2 for wheelchair to bed transfers
• Unable to attempt stand
• Increased cervical muscle tone; head postured to left
• PROM in bilateral hips and knees normal
• PROM right ankle dorsiflexion -7 degrees
• PROM left ankle dorsiflexion 4 degrees
• Increased tone in bilateral lower extremities (LE)
  – Right > Left
• GOALS: Sitting Tolerance; power wheelchair mobility; Tolerate tilt table; Increase strength; improve quality of life; Total assist – family education and training

PT Treatment Strategies and Progression

• Months 1-3 (March-June)
  – Seat edge of bed balance
  – Lateral leans/ mat program
  – PROM to bilateral lower extremity
  – Standing Frame
  – Power wheelchair mobility with head array
  – Ongoing family education
  – Patient/Children activities

PT Treatment Strategies and Progression

• Months 4-7 (June-October)
  – PROM/AAROM
  – Power wheelchair mobility
  – Mat program
  – Partial sit to stand transfers
  – Family training/ education
  – Static sitting balance
  – Lokomat® Trial (7/29)
  – Guldman^TM Lift for standing and ambulation training (starting 8/13)
  – Use of bilateral knee ankle foot orthoses (KAFOs)
### PT Treatment Strategies and Progression

- **Months 7-8 (October-November)**
  - Lateral scoot transfers
  - AAROM/PROM of lower extremity
  - Core strengthening with edge of bed sitting and standing frame without table
  - Mat program for bilateral lower extremity
  - Bed mobility
  - Ambulation over ground with use of KAFO’s and body weight support system
  - Ambulation over treadmill with use of KAFO’s and body weight support system
  - Family training/education

### PT Discharge Plan

- **Total assist to maximal assist for transfers—Hoyer lift/lateral scoot transfers**
- **Family able to make a bedroom on the 1st floor**
- **Family equipped the bedroom with an in ceiling lift**
- **Equipment for home included:**
  - Power wheelchair with sit to/from stand capability
  - Manual tilt in space wheelchair
  - Bilateral custom stretch splints
- **Received out patient services with an extensive home program**

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**Case 2: An Inpatient and Outpatient PT Progression**

Amy Greaney, PT, DPT
Hallie Zeleznik, PT, DPT, NCS
### Past Medical History and Medical Course

- 62 y/o male
  - PMH: MI s/p stenting, hypothyroidism, hyperlipidemia
- 2/9/13: bilateral medial pontine infarcts and locked in syndrome (LIS)
  - Occluded vertebral artery and basilar filling from the posterior communicating arteries
- Intra-ventricular and intra-arterial thrombectomy at Georgia Medical Center
- Tracheostomy and PEG
- Transferred from GA to UPMC Presbyterian Hospital

### Past Medical History and Medical Course

- UPMC Presbyterian → Skilled Nursing Facility with "Road to Rehab"
  - Decannulated
- Seen in neurology clinic for follow-up on 4/16/13
- Admitted to inpatient rehabilitation on 4/19/13
  - Diagnosis: bilateral pontine infarcts with *incomplete locked in syndrome*
- *Incomplete Locked In Syndrome*
  - Voluntary movement of muscle groups other than the eyes is possible

### Background Info

- Husband, father, grandfather
- Recently retired (since January 2013)
- On vacation with his wife at time of stroke
- Enjoys:
  - Spending time with family
  - Dancing
  - Woodworking
  - Wine making
  - Camping
  - Biking
  - Reading
  - Playing on computer
Physical Therapy Evaluation

- Motor Exam - LEFT
  - Sh abd: 1/5
  - Elbow flex: 2/5
  - Elbow ext: 2/5
  - Wrist ext: 2/5
  - Grp: 2/5
  - Interossi: unable to test 2’ tone in finger flexors
  - Hip flex: 2/5
  - Knee ext: 3+/5
  - DF: 4/5
  - PF: 4/5

- Motor Exam – RIGHT
  - 0/5 throughout
  - Trace movement at ankle and thumb – not testable

- Bilateral sublux

- Sensation: intact to light touch

- Speech
  - Able to nod Y/N
  - Using letter board created by family

Physical Therapy Evaluation (cont.)

- Transfers
  - Total assist
    - 2 person lat scoot vs use of hoyer for bed <> wc
  - Unable to come to full stand

- Mobility
  - Unable to attempt amb 2’ weakness and safety concerns
  - Unable to perform wc mobility 2’ LUE/LLE weakness

Treatment Strategies...Evidence...What works?

- Positive indicators of stroke recovery:
  - Thrombolysis
  - Early rehab/mobilization
  - Repeated practice
  - Early neurological recovery

- Preferred treatments:
  - Repetitive gait training
  - Static/dynamic standing balance

- Based on patient presentation:
  - Standing frame
  - Postural awareness activities in sitting

Treatment Progression

• So much to do…So little time…
  – Bed Mobility
  – Sitting Balance
  – Transfers
    • Bed <> chair
    • Sit <> stand
  – Wheelchair Mobility
  – Standing Frame
  – Standing Balance
  – Pre-gait Activities
  – Family Training

Gait Trials

• Initiated 5/1/13
• Setup
  – Right knee immobilizer
  – Right ankle ace wrapped into dorsiflexion/eversion
  – Bilateral platform wheeled walker
  – Started from edge of mat table
  – PT assist from behind once upright
    • Assist for full upright posture; dependent to advance RLE; cues to increase step with LLE
  – Second person assist to stabilize/advance walker
  – Wheelchair pickup
  – Distance: 10 feet x1; 20 feet x1

Motor Imagery

• Initiated visualization technique of walking to improve gait
  – Motor Imagery Practice
• Initiated technique in low stimulation room; lights dimmed
  – Eyes closed
  – Focus on the ‘feel’ of walking; visualize self walking
  – Progressed to patient and wife completing in evenings as “homework”
• Evidence support:
  – Case study; potential contribution of motor imagery practice to gait speed
  – “Task-oriented circuit class training with Motor Imagery produced statistically significant and clinically relevant improvements in the gait and the gait-related activities.”
### Progression of Gait

<table>
<thead>
<tr>
<th>Date</th>
<th>Device</th>
<th>Bracing</th>
<th>Distance</th>
<th>Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/3/13</td>
<td>(B) PFWW</td>
<td>(R) knee immobilizer; (R) ankle ace wrap</td>
<td>50-60 feet</td>
<td>Assist x3</td>
</tr>
<tr>
<td>5/8/13</td>
<td>(R) PFWW</td>
<td>(R) ankle ace wrap</td>
<td>4 feet</td>
<td>Assist x3</td>
</tr>
<tr>
<td>5/18</td>
<td>(R) PFWW</td>
<td>(R) knee immobilizer; (R) ankle ace wrap</td>
<td>70 feet</td>
<td>ModA x1 plus standby</td>
</tr>
<tr>
<td>5/19/13</td>
<td>(R) PFWW</td>
<td>(R) ankle ace wrap</td>
<td>50 feet</td>
<td>ModA x1</td>
</tr>
<tr>
<td>5/20/13</td>
<td>(R) PFWW</td>
<td>(R) KAFO – locked</td>
<td>60 feet</td>
<td>ModA – ModA x1</td>
</tr>
<tr>
<td>5/24/13</td>
<td>(R) PFWW</td>
<td>(R) KAFO – unlocked</td>
<td>50 feet</td>
<td>ModA x1 plus wc follow; required assist to block knee but quick tugging</td>
</tr>
<tr>
<td>5/25/13</td>
<td>(R) PFWW</td>
<td>(R) KAFO – locked</td>
<td>150 feet</td>
<td>ModA x1</td>
</tr>
<tr>
<td>5/28/13</td>
<td>(R) PFWW</td>
<td>(R) KAFO – unlocked</td>
<td>150 feet</td>
<td>ModA x1; req assist to block knee</td>
</tr>
<tr>
<td>6/1/13</td>
<td>None</td>
<td>None</td>
<td>30 feet</td>
<td>Min-modA x1 plus wc follow</td>
</tr>
<tr>
<td>6/4/13</td>
<td>(R) PFWW</td>
<td>(R) KAFO – unlocked</td>
<td>150 feet</td>
<td>Min-modA x1</td>
</tr>
</tbody>
</table>

### Discharge from Inpatient Rehab

- **Length of Stay**
  - 4/19/13 to 6/5/13
- **Discharged home with his wife**
  - Daughter also trained and assisted once pt was home
  - Wife modified home to provide FFSU and stair-glide
- **Equipment**
  - Bilateral platform wheeled walker
  - Right KAFO
  - Manual wheelchair
- **Therapy**
  - Home care with transition to outpatient

### Transition to Outpatient

- **Outpatient Physical, Occupational and Speech Therapies**
  - 8/5/13
- **Progression with home therapists**
  - Reduce assistive device to wheeled walker/no platforms
  - Cut down right KAFO to an AFO
  - Using right neoprene knee brace (osteoarthritis)
- **Physical Therapy Evaluation:**
  - Transfers: Minimal Assistance x1
  - Gait: 100 feet with wheeled walker and knee brace Supervision to Minimal Assistance x1
  - Gait speed 0.06 m/sec
  - Unable to rise from a chair without assistance and without UE use
  - Berg Balance Scale Score (day 2): 18/56
Locked In Syndrome Part II: Occupational and Physical Therapy Management: 2 Case Studies

Transition to Outpatient

- Impairment based exam
  - Moderate spasticity right upper/lower extremities
  - Impaired coordination right upper/lower extremities
- MMT:

<table>
<thead>
<tr>
<th>Muscle Group</th>
<th>Left</th>
<th>Right</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hip flexion</td>
<td>4+</td>
<td>3+</td>
</tr>
<tr>
<td>Hip abduction</td>
<td>4</td>
<td>2+</td>
</tr>
<tr>
<td>Knee extension</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Ankle dorsiflexion</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Ankle inversion</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Ankle eversion</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

Theoretical Framework: Application of Evidence to Practice

- 1,000-3,000 steps per day necessary to drive change post stroke in the lower extremity (Chu, 2007)
  - Observational studies have shown significantly less repetitions in therapy sessions
  - Average total steps per session
    - 200-300 (TBI and Stroke) (Kimberly, 2010)
    - Approximately 350 (Lang, 2009)
  - >1,000 steps in a PT session is achievable
  - High intensity step program: 2,887 steps/session (Holleran, 2014)

- Error enhancement/increased challenges (Holleran, 2014)
- Intensity
  - Not necessarily number of steps or time of activity
  - Intensity= workload (cardiovascular and musculoskeletal)

Video Examples of Treatment Strategies
### Outcomes

<table>
<thead>
<tr>
<th>Metric</th>
<th>Initial</th>
<th>8 weeks</th>
<th>14 weeks</th>
<th>22 weeks</th>
<th>26 weeks</th>
<th>30 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gait</td>
<td>Wheeled walker</td>
<td>Minimal Assist</td>
<td>Wheeled walker</td>
<td>Minimal Assist</td>
<td>Standard cane</td>
<td>Standard cane</td>
</tr>
<tr>
<td>Speed</td>
<td>0.05 w/w</td>
<td>0.24 w/w</td>
<td>0.38 w/w</td>
<td>0.47 w/w</td>
<td>0.60 w/w</td>
<td>0.76 w/w</td>
</tr>
<tr>
<td>6 MWT</td>
<td>Unable</td>
<td>150 feet w/w</td>
<td>265 feet w/w</td>
<td>500 feet w/w</td>
<td>600 feet w/w</td>
<td>725 feet w/w</td>
</tr>
<tr>
<td>Stairs</td>
<td>Unable</td>
<td>12, bilateral HR</td>
<td>Supervision</td>
<td>12, bilateral HR</td>
<td>Supervision</td>
<td>12, unilateral HR Min A</td>
</tr>
<tr>
<td>SXSTS</td>
<td>Unable</td>
<td>Unable</td>
<td>Unable</td>
<td>Mod A</td>
<td>25 sec Sup Min A</td>
<td></td>
</tr>
<tr>
<td>BBS</td>
<td>18</td>
<td>22</td>
<td>36</td>
<td>44</td>
<td>43</td>
<td>48</td>
</tr>
<tr>
<td>Total # Visits</td>
<td>N/A</td>
<td>14</td>
<td>26</td>
<td>39</td>
<td>45</td>
<td>49</td>
</tr>
</tbody>
</table>

### References

- Cha, J, Hong C, Reinkensmeyer DJ, Roy RR, Edgerton VR, de Leon RD. Locomotor ability in spinal rats is dependent on the amount of activity imposed on the hind limbs during treadmill training. J Neurotrauma 2007;24:1000-1012.