Engaging Patients with Multiple Sclerosis to Uncover the Neuroscience of Hand Impairment

Objective

To explore how individuals with multiple sclerosis (MS) manage symptoms of their hand and arm.

Practice Points

1. In the first year of disease onset, over half of people with multiple sclerosis report having loss of manual dexterity.

2. Currently, there are no best practice guidelines for upper extremity rehabilitation.

3. There is an important need to investigate how people with MS navigate MS-related hand and arm dysfunction from a patient perspective.

Methods (PI: M. Ploughman, Author: K. Wadden)

1. 17 participants (12 females, mean age 51 years) with self-reported upper extremity dysfunction were recruited for this study. 16 individuals had relapsing-remitting MS and one secondary progressive MS.

2. In-depth interviews with questionnaire Multiple Sclerosis Impact Scale (MSIS), upper extremity assessments [Nine-hole peg test (NHPT), Box and Block Test (BBT), pinch and grip strength], and objective measures of hand and arm movement in the community (bilateral accelerometers) were performed.

3. Qualitative and quantitative data were analyzed independently (in depth interviews were analyzed using a thematic content analysis) and subsequently combined. To quantify how individuals with MS engage their limbs to complete activities of daily living in unstructured environments, such as their homes and communities, data from accelerometers were analyzed to assess magnitude and frequency of hand and arm movements.

Results

Quantitative Results

Table 1. Participants' Characteristics

Variable	Mean	SD	Range
EDSS (0–10)	2.3	1.1	(0–4)
Disease Duration (Years)	13.4	9.2	(3–28)
MOCA (0–30	26.9	2.2	(21–30)
MSIS-Physical (2–100)	50.2	17.3	(22–77)
MSIS-Psych (9–45)	23.0	10.1	(11–44)

Based on Expanded Disability Status Scale (EDSS), Montreal Cognitive Assessment (MOCA), and Multiple Sclerosis Impact Scale (MSIS)

- Two participants scored moderate and 15 participants scored mild levels of disability.

- Cognitive assessments were high, and physical and psychological impacts of MS were mid-range.

Table 2. Upper Extremity Assessments were Compared to Average Age (~50) and Sex-Matched Normative Data

Assessment	Extremity	Participant Mean (SD) Female : Male	Normative Mean (SD) Female : Male
Pinch Strength (lbs)	Affected/ Non-Dominant	12.7 (2.8): 18.9 (6.7)	16.1 (2.7): 26.1 (4.2)
	Unaffected/ Dominant	13.5 (2.7): 23.8 (2.9)	16.7 (2.5): 26.7 (4.4)
Grip Strength (lbs)	Affected/ Non-Dominant	38.0 (12.5): 67.3 (29.4)	57.3 (10.7): 101.9 (17.0)
	Unaffected/ Dominant	42.2 (13.1): 85.0 (16.2)	65.8 (11.6): 113.6 (18.1)
Nine Hole Peg Test (secs)*	Affected/ Non-Dominant	25.8 (4.8): 26.7 (7.8)	18.9 (2.3): 19.8 (3.1)
	Unaffected/ Dominant	23.7 (6.1): 23.3 (2.4)	17.4 (1.9): 18.9 (2.4)
Box and Block Test (# of Blocks)	Affected/ Non-Dominant	51.6 (12.5): 53.5 (14.6)	74.3 (9.9): 77.0 (9.2)
	Unaffected/ Dominant	54.2 (13.0): 61.6 (5.4)	77.7 (10.7): 79.0 (9.7)

*reference value >18 s = abnormal, >33 s = severe. No published references for other tests

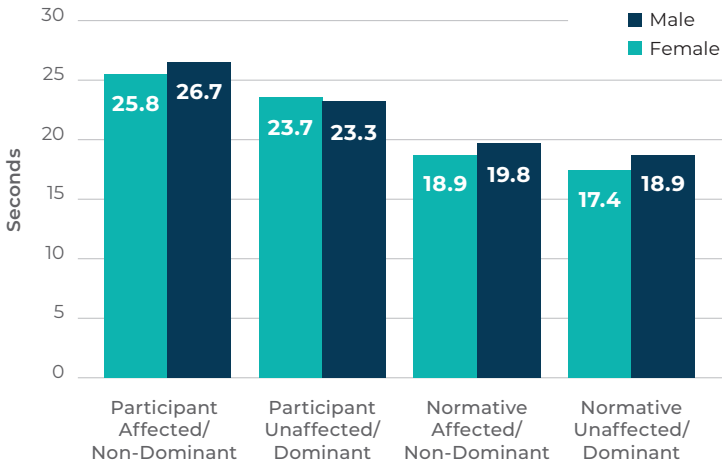
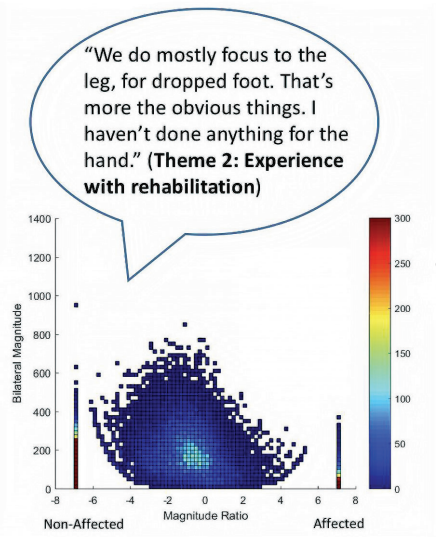


Figure 1. Nine Hole Peg Test (seconds) in Affected and Unaffected Upper Extremities in Female and Male Patients with MS Compared to Normal

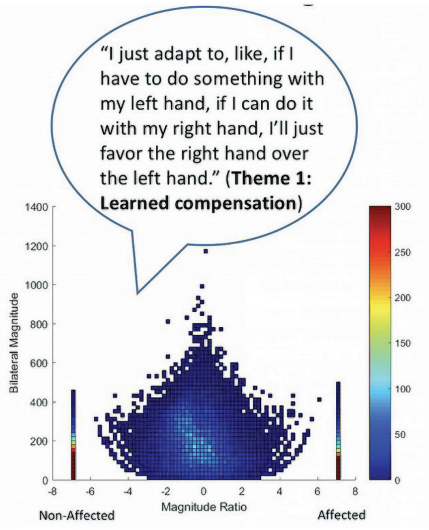
- All assessment means were below normal data. For NHPT, two participants scored in the severe impairment range (> 33.3 s) and 15 scored in the mild impairment range (18 – 33.3 s). Of the 15 within the mild range, 13 participants discussed significant hand dysfunction limiting independence.



- Nine hole peg test for affected limb: 39/s (severe); Grip strength for affected limb: 15 lbs (below normal).

Figure 2. Accelerometry Diagram in a Participant Showing Asymmetrical, Low Frequency and Magnitude of Bilateral Upper Limb Movements in the Community Over 24hrs

- On the y-axis, the bilateral magnitude quantifies the intensity of movement in both upper limbs. On the x-axis, the magnitude ratio indicates the contribution of each limb to activity. The large color bar scale on the right side of the figure represents frequency, where brighter colors indicate greater frequencies of movement. The affected limb represents the hand and arm that was self-reported by the patient as more symptomatic. The non-affected limb represents the hand and arm that was self-reported by the patient as less symptomatic.



- NHPT for affected limb: 30s (mild); Grip strength for affected limb: 48 lbs (below normal)

Figure 3. Accelerometry Diagram in a Participant Showing Asymmetrical, Low Frequency and Magnitude of Bilateral Upper Limb Movements in the Community Over 24hrs

- **Accelerometry Figures:** Participants' accelerometry data aligned with their accounts of learned compensation and priority of the lower versus upper extremity in rehabilitation settings.

- Most patients did not receive rehabilitation for the management of their upper extremity symptoms.

Qualitative Results

1. Qualitative Theme 1: Self-learned compensation – Participants responded to their physical limitations by developing strategies to help them live independently. For example, "I would just work around it. I got used to using my left. But I manage to get it done. Whichever hand." (NHPT affected hand: 20 s (mild), Accelerometry plots: Symmetry, moderate frequency and magnitude).

2. Qualitative Theme 2: Priority of lower versus upper extremity – Described by most participants as their experience in rehabilitation. For example, “The exercises at home were mostly for legs. I don’t remember anything there for arms.” (NHPT affected hand: 38 s (severe), Accelerometry plots: N/A).

Conclusions

1. Patients described creating their own compensatory strategies to perform tasks, which was detected by asymmetrical bilateral accelerometry data.

2. Most participants scored in the mild impairment range on Nine Hole Peg Test, which did not align with qualitative data.

3. Upper extremity rehabilitation in multiple sclerosis appears to be inconsistent, and not prioritized.