The authors have no conflicts to report.
Learner Objectives

✓ The learner will be able to:

✓ Discuss the most common cognitive deficits experienced by persons with MS

✓ Critique the measurement of cognitive deficits using the Perceived Deficits Questionnaire
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Collaborators

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Millions of persons worldwide live with some type of chronic and/or disabling condition
Multiple Sclerosis (MS)

- Most common neurological disease in young adults
- Affects more than 2.3 million people worldwide – more common in women
- Unpredictable and generally progressive disease of central nervous system
MS is characterized by...

- Destruction of the myelin insulating the axons, thus interfering with the efficiency of electrical conduction within the central nervous system and the brain; axon damage and death can also occur
- Wide differences in symptoms, impairments and functional limitations
- Unpredictable disease course
Cognitive Problems in MS

✓ Thought to occur in 40-75% of those with MS
✓ Numerous studies have demonstrated deficits in tasks assessing
  ✓ recent memory,
  ✓ attention,
  ✓ information processing (including processing speed),
  ✓ executive functions (including verbal learning) and
  ✓ visuospatial abilities
Compared to those without cognitive problems, persons with MS with cognitive dysfunction are:

- Less likely to be employed
- Require greater personal assistance
- Less likely to engage in social activities
- Report more difficulties with parenting
- Perform significantly worse on tests of driving skills and have higher rates of motor vehicle crashes
✓ Cognitive deficits may occur at any point in the disease and are only weakly associated with physical impairment.
✓ No approved medications for cognitive impairment in MS and almost no clinical trials to determine treatment efficacy.
Cognitive Impairment

✓ Likely the most disabling symptom of multiple sclerosis – has received much less attention than the physical and emotional symptoms
✓ Controversy regarding how best to measure cognitive symptoms in clinical settings
Issues

✓ Standard neuropsychological tests require substantial resources and may not be sensitive to change

✓ Self-reports are easy and quick to use but have failed to correlate with performance tests

✓ Reports and performance may be confounded by depression and fatigue
Key Question…

✓ Does the weak correlation between self-reports of cognitive symptoms and performance on neuropsych tests mean that self reports are inaccurate or do they represent a different aspect of cognition?
Increasing interest in self-reports due to:

✓ Reflection of individual’s perspective (gap between demand and ability)
✓ Evidence showing that self-reported deficits in memory are correlated with structural alterations in the hippocampus of persons with MS (Pardini et al., 2014)
✓ New evidence that self-reports may be early predictors of subsequent cognitive decline
Perceived Deficits Questionnaire (PDQ) (Sullivan, Edgley & DeHoux, 1990)

✓ One tool used to measure self-reports of cognitive problems in persons with MS

✓ 20 items that assess the frequency of cognitive problems that occurred over the last month
Purpose:

✓ Explore cognitive deficits reported by a community-based sample of persons with MS

✓ Explore relationships between the PDQ and other measures of cognitive function in persons with MS
Methods

✓ Data collected at screening and baseline for a multi-site RCT of a cognitive rehabilitation intervention for persons with MS

✓ Study received IRB approval prior to recruitment
Self-Report Measures

✓ Perceived Deficits Questionnaire (PDQ)
✓ PROMIS – Cognitive Abilities (Short Form)
✓ CES-D (depression)
✓ Memory Strategies Scale
✓ Compensatory Cognitive Strategies Scale
Neuropsychological Tests

- Controlled Oral Word Association Test (COWAT) – measure of verbal fluency and word finding
- California Verbal Learning Test (CVLT) – measure of verbal learning and memory
- Brief Visuospatial Memory Test – Revised (BVMT-R) – measure of nonverbal learning and memory
Paced Auditory Serial Addition Test (PASAT) – measure of auditory information processing speed and flexibility and arithmetic

Symbol Digit Modalities Test (SDMT) – measure of complex scanning and visual tracking
Findings
Sample (N=183)

✓ Average age 49.35 (SD 7.96)
✓ Diagnosed for a mean of 12.64 years
✓ Well-educated with an average of 15.57 years of education
✓ Over-half (58%) were college graduates
✓ Majority of the sample was
  ✓ White (75%)
  ✓ Female (87%)
  ✓ Unemployed (66%)
  ✓ Married or living with a significant other (63%)
Perceived Deficits Questionnaire (PDQ) (Sullivan, Edgley & DeHoux, 1990)

✓ Administered as part of phone screening
✓ Each item rated on a scale ranging from “0” (never) to “4” (almost always)
✓ Higher scores on the summated score indicate greater cognitive problems
✓ Cronbach alpha in this sample = .87
PDQ Mean Item Scores

✓ Find my mind drifting 2.55
✓ Trouble holding phone numbers in my head 2.48
✓ Forget what I came in the room for 2.39
✓ Lost my train of thought 2.34
✓ Forget the date 2.34
✓ Trouble getting things organized 2.26
✓ Trouble getting started 2.23
✓ Forget what I did last weekend 2.15
✓ Feel like mind went blank 2.14
✓ Trouble making decisions  2.06
✓ Forget what I already did  2.03
✓ Trouble concentrating in conversations  2.02
✓ Forgot what I did the night before  1.90
✓ Trouble concentrating on TV or reading  1.86
✓ Forget what I talked about on the phone  1.80
✓ Difficulty planning day’s activities  1.61
✓ Forget medication  1.17
Least troublesome...

✓ Miss appointments and meetings  1.07
✓ Forget to turn off stove or alarm  0.96
✓ Difficulty remembering names of people  0.81
Correlation of PDQ with Self-Reports

✓ PROMIS Cognitive Abilities $r = -0.53^*$
✓ CESD Depressive Symptoms $r = 0.38^*$
✓ Memory Strategies Scale $r = 0.34^*$
✓ Cognitive Strategy Scale $r = 0.24$

*p<.0029; p values adjusted using Bonferroni’s correction*
Correlations of PDQ with performance tests:

<table>
<thead>
<tr>
<th>Test</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>COWAT</td>
<td>$r = -0.02$</td>
</tr>
<tr>
<td>CVLT</td>
<td>$r = -0.02$</td>
</tr>
<tr>
<td>BVMT-R</td>
<td>$r = 0.11$</td>
</tr>
<tr>
<td>PASAT-3 sec</td>
<td>$r = -0.03$</td>
</tr>
<tr>
<td>PASAT – 2 sec</td>
<td>$r = -0.06$</td>
</tr>
<tr>
<td>SDMT</td>
<td>$r = 0.05$</td>
</tr>
</tbody>
</table>
Conclusion

✓ Detection of cognitive dysfunction is essential in MS treatment and management
✓ Largest and most diverse sample for evaluating the PDQ in persons with MS
✓ This study contributes to our understanding of self-reported cognitive deficits with descriptive ‘item-level’ data from PDQ
✓ The PDQ can be administered and scored in approximately 5 minutes
✓ Use of the PDQ in clinical settings could be useful for guiding cognitive rehabilitation efforts
✓ Significant correlations were seen between self-reports of cognitive problems and other self-report measures but not with neuropsychological performance tests
Likely that self-reports and performance tests are capturing differing or complementary aspects of the complex phenomenon of cognition.
✓ Assessment of perceived cognitive function is important as it provides an understanding of the individual’s perspective and is a significant predictor of perceived quality of life
✓ PDQ can be useful for screening and for capturing trends over time