Perceived Cognitive Deficits in a Sample of Persons Living With Multiple Sclerosis

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ABSTRACT

Purpose: The aims of this study were to describe the nature and diversity of perceived cognitive deficits using the Perceived Deficits Questionnaire (PDQ), to assess the reliability of the PDQ, and to explore self-reported predictors of PDQ scores in a large community-based sample of persons with multiple sclerosis (MS). **Materials and Methods:** Persons with MS enrolled in a randomized controlled trial provided demographic data and completed the PDQ along with measures of cognitive and memory strategies, cognitive abilities, self-efficacy, and depressive symptoms and neuropsychological tests. **Results:** Most of the 183 participants were non-Hispanic white women, approximately 49 years old, and diagnosed with MS 12.5 years prior. The most frequent cognitive complaints regarded trouble remembering telephone numbers, mind drifting, and forgetting why one came into a room. The PDQ scores were significantly related to self-rated cognitive abilities, depressive symptoms, self-efficacy, and use of cognitive strategies, but not to scores on neuropsychological performance tests. When controlling for other variables, self-rated cognitive abilities was the strongest, significant predictor of perceived cognitive deficits. **Conclusion:** Persons with MS most frequently experience deficits related to short-term memory and attention. The PDQ total is a reliable measure of perceived cognitive deficits in persons with MS, is feasible for use by nurses in clinical settings—can be administered in approximately 5 minutes, and is easily scored.

Keywords: cognition, cognitive function, multiple sclerosis, perceived deficits questionnaire

Multiple sclerosis (MS) is a disease of the central nervous system that can interfere with cognitive processing, and as many as 65% of those with MS report some level of cognitive dysfunction.[1] This high prevalence of cognitive dysfunction is especially important because MS is one of the most frequent causes of disability in early to middle adulthood, and cognitive problems are barriers to maintaining employment and daily living activities.[1,2]

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The most common cognitive deficits reported by those with MS include difficulties with learning and recalling new information, attention, processing speed, and verbal fluency.[1,2] Even "mild" impairments in any of these areas can have a significant impact on daily functioning and quality of life,[3] aspects of patient care that are a large focus of nursing practice.

Despite the potential for negative impact, cognitive dysfunction is said to be underdiagnosed[4,5] because of lack of assessment and difficulty administering specific cognitive tests in clinical settings. Clinicians have expressed interest in simpler measures. Self-report measures of cognitive deficits may be of benefit because they offer valuable patient information and can be used as a quick clinical tool. Unfortunately, there is limited research regarding self-reports of cognitive function among patients with MS.

One instrument used to evaluate cognitive function is the Perceived Deficits Questionnaire (PDQ), part of a much larger instrument for those with MS.[11] Although the PDQ has been used in a number of studies as an outcome variable,[4,6–9] limited work describes this measure or participants' responses in more detail. The purposes of this study are to describe the nature and diversity of perceived cognitive deficits using the PDQ in a large community-based sample, to assess the reliability of the PDQ scale, and to explore self-reported predictors of PDQ scores in persons with MS.

Materials and Methods
Sample
The institutional review board at the University of Texas at Austin approved all study procedures. Men and women from 18 to 60 years old who had no MS-related exacerbations in the previous 3 months, were able to read and speak English, had access to the Internet, and self-reported cognitive limitations were recruited for a randomized controlled trial evaluating a cognitive rehabilitation intervention. Recruitment fliers were distributed throughout Texas at neurology clinics, self-help groups, and the National MS Society. To qualify, potential participants had to rate 5 or more of the 20 items on the PDQ as a 2 ("sometimes") or greater.

Data Collection and Analysis
Eligible participants were mailed a consent form, and after their MS diagnosis was confirmed by a physician, they completed a mailed paper survey followed by in-person cognitive testing before randomization to control or intervention groups. The paper surveys included baseline demographic variables and self-report measures. After the paper surveys were completed, neuropsychological testing was completed in person by a trained tester. Data analyses were conducted using SPSS 23.0 and included descriptive statistics for individual items, internal consistency reliability analysis of self-report instruments, simple correlational analyses, and multiple regression modeling.

Demographics
All participants were asked their date of birth, year of diagnosis, sex, race, ethnicity, highest educational degree, years of education, employment status, marital status, and MS type.

PDQ
The PDQ,[10] part of the MS Quality of Life Inventory,[11] assesses the frequency of cognitive problems that occurred during the past month. Each item is on a scale of 0 ("never") to 4 ("almost always"). Higher scores indicate greater frequency of cognitive problems. The PDQ has 4 subscales: attention, retrospective memory, prospective memory, and organization. The Cronbach α for the total score in this study was .87.

The PROMIS Short Form v2.0, Cognitive Function Abilities Subset 8A
The PROMIS Cognitive Function Abilities Scale is part of the NIH PROMIS item bank for patient outcome measures (http://www.healthmeasures.net/explore-measurement-systems/promis). Respondents rate their cognitive functioning in the previous week

> ## Older individuals with MS reported cognitive problems less frequently.

on a scale from 1 ("not at all") to 5 ("very much"). Higher scores indicate higher perceived cognitive abilities. In this study, the Cronbach α was .93.

Center for Epidemiologic Studies-Depression Scale (Short Form)
The 10-item Center for Epidemiologic Studies-Depression Scale (CES-D)[12] was used to measure depressive symptoms. Total scores can range from 0 to 30, with higher scores reflecting more depressive symptoms in the previous week. This widely used scale had a Cronbach α of .81 in this study.

Memory Strategies
The 19-item Strategy Subscale of the Multifactorial Memory Questionnaire[13] was used to measure cognitive strategies related to memory. Respondents rate frequency of use for each cognitive strategy on a scale of 0 ("never") to 4 ("all the time"). Higher scores reflect more frequent strategy use. The Cronbach α in this study was .87.

Cognitive Strategies
The Compensatory Cognitive Strategy Scale, developed by the present authors,[14] measures the use of cognitive strategies related to domains other than memory, such as ways to decrease distractions and organize and sequence activities and use of newly available technologies. Respondents rate the frequency of use of each of the strategies on a scale from 0 ("never") to 4 ("all the time"). The Cronbach α for this study was .90.

Self-efficacy
The 17-item general self-efficacy subscale of Sherer et al's[15] Self-Efficacy Scale was used to measure participants' expectancies about personal mastery. Respondents rate each item on a 5-point scale from 1 ("disagree strongly") to 5 ("agree strongly"). Higher scores indicate greater self-efficacy. The Cronbach α for this study was .89.

Cognitive Performance
Five tests from the Minimal Assessment of Cognitive Functioning in Multiple Sclerosis test battery were administered at baseline. There is sufficient evidence for validity of the Minimal Assessment of Cognitive Functioning in Multiple Sclerosis in persons with

MS.[16] This battery included (*a*) the Controlled Oral Word Association Test, a measure of verbal fluency and word finding;[17] (*b*) the California Verbal Learning Test, Second Edition, a measure of verbal learning and memory;[18] (*c*) the Brief Visuospatial Memory Test-Revised, a measure of nonverbal learning and memory;[19] (*d*) the Paced Auditory Serial Addition Test, a measure of auditory information processing speed and flexibility and arithmetic;[20] and (*e*) the Symbol Digit Modalities Test, a measure of complex scanning and visual tracking.[21]

Results
Descriptives
Most of the sample (n = 183) were non-Hispanic (90.2%), white (74.9%), and women (87.4%) with a mean (SD) age of 49.35 (7.95) years. Most were diagnosed with relapsing-remitting MS (67%) 12.64 years prior (SD, 7.97 years). The mean (SD) years of education reported were 15.57 (2.44), and most were unemployed (65.7%; Supplemental Digital Content 1, available at http://links.lww.com/JNN/A99). Supplemental Digital Content 2 (available at http://links.lww.com/JNN/A100) presents all the descriptive statistics for the study variables.

Perceived Cognitive Deficits
The means and standard deviations on each of the 20 items of the PDQ were ranked in order of most to least frequently reported. The top 3 most frequently reported cognitive complaints were (1) "trouble holding phone numbers in my head" (item 17), (2) "find my mind drifting" (item 13), and (3) "forget what I came into the room for" (item 3). Table 1 presents a complete list of individual item means and standard deviations ranked in order of highest to lowest mean scores. The mean (SD) score on the PDQ was 38.18 (11.30).

Correlations
The relationships between perceived cognitive deficits, demographic variables, and other self-report instruments were examined and are presented in Table 2. The *P* value of .05 was adjusted using a Bonferroni correction to account for multiple comparisons. A moderate negative relationship was found between the PDQ and scores on perceived cognitive abilities scale ($r = -0.53$, $P < .003$). A moderate positive relationship was found between the PDQ and the CES-D ($r = 0.38$, all *P*s $< .003$) and memory strategies ($r = 0.34$, $P < .003$). No significant relationships

TABLE 1. PDQ Item Ranked Scores (N = 183)

Items	Mean	SD
13. Find mind drifting	2.55	0.959
17. Trouble holding phone numbers in head	2.48	1.27
3. Forget what you came into the room for	2.39	1.036
1. Lost train of thought (speaking)	2.34	0.964
11. Forget the date unless look it up	2.34	1.107
4. Trouble getting things organized	2.26	1.156
12. Trouble getting started, lots to do	2.23	1.08
18. Forget what did last weekend	2.15	1.132
16. Feel like mind went blank	2.14	0.984
20. Trouble making decisions	2.06	1.091
6. Forget you already did something	2.03	1.01
5. Trouble concentrating in conversations	2.02	1.176
10. Forget what you did the night before	1.9	1.044
9. Trouble concentrating—TV or reading	1.86	1.152
14. Forget what talked about after phone	1.8	1.045
8. Difficulty planning what to do in a day	1.61	1.143
19. Forget to take medication	1.17	1.06
7. Miss appointments and meetings	1.07	0.964
15. Forget turn off stove, on alarm	0.96	0.928
2. Difficulty remembering names of people	0.81	0.421

Note. PDQ individual items were ranked in order from highest to lowest mean scores. The higher the score, the more the problem. PDQ = Perceived Deficits Questionnaire.

Measures	PDQ
Cognitive abilities	−0.53[a]
CES-D depressive symptoms	0.38[a]
Self-efficacy	−0.27[a]
Memory strategy score	0.34[a]
Cognitive strategy score	0.24
Age	−0.10
Years since diagnosis	−0.27[a]
Ethnicity (1, Hispanic; 0, non-Hispanic)	0.22[a]
Years of education	−0.20
CVLT	−0.02
CVLT delayed	−0.04
BVMT	0.11
BVMT-delayed	0.14
PASAT 3 s	−0.03
PASAT 2 s	−0.06
SDMT	0.05
COWAT	−0.002

Note. Pearson *r* was used for interval level variables, all categorical variables were dummy coded, and Kendall τ correlations were used. BVMT = Brief Visuospatial Memory Test; CES-D = Center for Epidemiologic Studies-Depression Scale; COWAT = Controlled Oral Word Association Test; CVLT = California Verbal Learning Test; PASAT = Paced Auditory Serial Addition Test; PDQ = Perceived Deficits Questionnaire; SDMT = Symbol Digit Modalities Test.
[a]$P < .0029$ (2-sided); *P* values were adjusted using Bonferroni correction (.05/17).

between PDQ scores and any of the neuropsychological measures were found.

Multiple Regression Analysis

A stepwise multiple regression was run using the demographic and self report measures as predictors of PDQ scores; the results are displayed in Supplemental Digital Content 3 (available at http://links.lww.com/JNN/A101). Demographic variables related to cognitive function were entered in step 1 (age, years since diagnosis, years of education). In step 2, total scale scores for the 10-item CES-D, Self-efficacy Scale, cognitive abilities, cognitive strategies, and memory strategies were entered and explained additional variability in cognitive deficits (adjusted $R^2 = 0.28$, $\Delta R = 0.28$, $F_{5,104}$, $P < .001$) above and beyond the demographic variables. When controlling for the other self-report measures, the only significant predictor of PDQ scores was cognitive abilities ($\beta = -0.36$, $t = -3.79$, $P < .001$).

Discussion

This study contributes to our understanding of self-reported cognitive deficits by providing descriptive data for the PDQ, other self-report measures, and neuropsychological measures that are relevant to clinical settings in a large, diverse, community-based sample of persons with MS.

This is one of the largest samples for evaluating the PDQ in persons with MS, and this study provides a more in-depth examination of the PDQ scale by examining the individual item scores, which previously mentioned studies did not.[6–8,22,23] The PDQ total score reported in this sample was similar to previously reported findings[6,8,22] and lower than the means in 2 studies, by approximately 5 to 16 points.[7,23] The results of this analysis support the internal consistency reliability of the PDQ total scale.

Each PDQ item asks about specific cognitive problems, and this scale could be used as a clinical tool for guiding cognitive rehabilitation, although more research is needed such as studies of which items are most sensitive to change after a cognitive rehabilitation intervention. In a statewide community sample of persons with MS, we found a mean of 2 ("sometimes") or greater on 8 of the 20 PDQ scale items. The most frequent cognitive complaint among these participants was having trouble holding phone numbers in one's head, even for a few seconds, closely followed by finding one's mind drifting and forgetting why one has come into a room.

The PDQ scale was significantly related to scores on measures of related concepts such as feelings of depression, perceived cognitive abilities, self-efficacy, use of cognitive strategies, use of memory strategies, and years since diagnosis. The finding that as perceived deficits increase so do feelings of depression is consistent with other studies,[4,6–8] suggesting that self-reported cognitive difficulties are related to depressive symptoms. Importantly, these are correlations that show associations, not causality. A bidirectional relationship between cognitive difficulties and depressive symptoms would also be logical.

The relationship found between self-efficacy and PDQ supports similar findings recently presented by Strober et al[6] and Schmitt et al[7] that self-efficacy significantly predicted perceived cognitive functioning (measured by the PDQ) after controlling for depressive symptoms. The largest correlations found in this study were between the PDQ and the PROMIS Cognitive Abilities scale, suggesting that a person's general perceived capabilities are associated with his or her cognitive complaints and may be important

factors to consider when designing interventions to bolster cognitive abilities in persons with MS. We also found that greater use of memory strategies was related to greater perceived deficits.

Interestingly, we found no significant relationships between advancing age and perceived cognitive problems. In fact, the minimal relationship that does exist suggests that older individuals reported cognitive problems less frequently. This is contrary to findings that age is associated with increased neuropsychological decline in persons with MS.[24] This might be because our inclusion criteria restricted age to 18 to 60 years, so that age-related cognitive complaints were not as pronounced in this population. Another unexpected finding was that, as time since diagnosis increased, cognitive complaints decreased. It is possible that, as time passes, people adjust to their cognitive changes not "perceiving" that they are as severe or they consider these cognitive problems more normal because their same-age peers start experiencing them as well.

No significant relationships between the PDQ and any of the neuropsychological performance measures were found, congruent with other reports in the literature.[6,23,25] Some might therefore conclude that self-reports are not a valid representation of cognition. It is more likely that these 2 types of measures capture differing, or complementary, aspects of the complex phenomenon of cognition. We would argue that both perceived and performance-based cognitive measures have clinical significance. For example, Honan et al[26] found that both perceived and performance-based cognitive measures significantly predicted employment outcomes in persons with MS. In addition, findings from Pardini et al[27] suggest that the PDQ may serve as a proxy measure of subtle structural damage to the memory network of the hippocampus.

The multiple regression analysis allowed for a better understanding of the unique contributions of each self-report variable to perceived deficits. Interestingly, the relationship between depressive symptoms and PDQ scores became smaller and no longer significant when controlling for the other variables. This goes against the argument that perceived cognitive deficits are largely influenced by mood and affect.[4,6] The only significant predictor for PDQ scores was self-rated cognitive abilities, which is logical because someone's perceptions of his/her abilities should be related to perceptions of his/her deficits.[28]

Certain limitations should be noted. First, the sample was self-selected—a convenience sample of those interested in possibly participating in a cognitive rehabilitation study. Only participants who scored 2 or more on 5 or more PDQ items were included in the study, thus reducing variability in PDQ total scores that might have impacted the results of the correla-

tion analyses. Finally, the study's data were cross-sectional, so causality between variables could not be determined.

Conclusion

Despite the limitations of this study, its findings have important nursing implications. The detection of cognitive dysfunction is essential in MS treatment and management, especially because perceived cognitive function is a significant predictor of quality of life.[9] Clinicians and researchers alike have acknowledged that traditional measures of function, such as the Extended Disability Status Scale, are not sensitive to the MS sequelae of neurological disability.[5] The PDQ shows relationships with depressive symptoms, self-efficacy, perceived cognitive abilities, and use of cognitive strategies. It may provide a more accurate reflection of the complex neurological sequelae in persons with MS than neuropsychological test scores. The PDQ is a reliable, valid measure of perceived cognitive difficulties and can be easily administered and scored by nurses in approximately 5 minutes. Although not intended to replace comprehensive neurocognitive assessments, it can be used to screen for specific cognitive difficulties and trends over time or to quickly assess whether a patient needs a referral for more extensive testing. In addition, understanding the relationships between perceived cognitive deficits and other symptoms common in persons with MS, such as feelings of self-efficacy and the use of compensatory strategies, can help nurses develop comprehensive care plans for persons with MS. Nurses are in a unique position to help improve perceived cognitive function for persons with MS, which could potentially improve their quality of life and ability to function in social roles.

Acknowledgments

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