

# Perceptions of Health and Relationships to Disability Measures Among People with Multiple Sclerosis

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*Researchers use various measures to assess health status, impairment, functional limitations, and disability among people with multiple sclerosis (MS). Conceptual and empirical associations among measures are not always clear, however. The purpose of this study was to examine the relationships among measures of impairment, disability, functional status, and health-related outcomes in a sample of 443 individuals with MS. A secondary purpose was to compare the self-reported health status of this sample with that of a population-based sample of individuals with and without disabilities. Although both the MS sample and a population-based sample of individuals with activity limitations indicated poorer health than did their nondisabled counterparts, the MS sample reported more days in the preceding month when their physical and mental health were not good and more days when poor health kept them from usual activities than the population-based sample of individuals with disabilities. Most measures were moderately intercorrelated, but the pattern suggests that issues such as the time frame specified may affect the relationships. Researchers should carefully consider operational as well as conceptual definitions, length of proposed measures, and appropriate time frame, in addition to the more traditional criteria of reliability and validity, when selecting study measures. *Int J MS Care*. 2009;11:57–65.*

**M**ultiple sclerosis (MS) is a chronic disabling condition estimated to affect more than 350,000 people in the United States.<sup>1</sup> People with MS experience various levels of impairment, resulting in different functional limitations. Consequently, MS research has increasingly focused on measuring key health constructs, such as disability, health status, functional limitations, and health-related quality of life (HRQL).

As researchers have adopted a broader view of health than simply morbidity and mortality, the nuances of measuring health status have gained attention. Consistent with the definition of health formulated by the World Health Organization (WHO),<sup>2</sup> the public health community now defines health as a multidimensional construct that includes physical function, symptoms and physiologic states, emotional and cognitive function, and perceptions about present and future health,

as well as premature mortality.<sup>3</sup> This broad definition has led to a proliferation of measures to assess the various components of health.

Unfortunately, the conceptual distinctions among these measures are not always clear, resulting in confusion about what each actually quantifies. For example, the Medical Outcomes Study 36-item Short Form Health Status Survey (SF-36) is often described as an HRQL measure, but its authors describe it as a health status measure. In fact, much of it assesses functional status.<sup>4</sup>

Building on the WHO's disability classification system,<sup>5</sup> Verbrugge and Jette<sup>6</sup> proposed a disablement process model that differentiates pathology, impairment, functional limitations, and disability. In their model, pathology refers to medically labeled diseases, injuries, or congenital/developmental conditions. Impairments refer to dysfunction and structural abnormalities in specific body systems, whereas functional limitations are the restrictions in daily life resulting from these impairments. Disability is a social process in which the ability to perform social role activities is lost

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or reduced because of chronic disease or impairment. To illustrate, MS destroys the myelin-insulating axons, interfering with efficient electrical conduction within the central nervous system<sup>7</sup> and leading to varying levels of weakness, gait disturbance, fatigue, visual impairment, dizziness, ataxia, bladder and bowel problems, changes in sexual functioning, pain, muscle weakness, spasm, and spasticity.<sup>8</sup> These impairments can, in turn, result in functional limitations, particularly in mobility, which may lead to disability if the environment does not provide adequate supports to enable the individual to participate in the community. Thus, pathology, impairment, functional limitation, and disability are not synonymous, but represent different concepts in the disablement process. Conceptual clarity must guide disability research, particularly in the measurement instruments used.

Recognizing that people with disabilities have historically experienced health disparities, the Centers for Disease Control and Prevention (CDC) began focusing in the 1990s on effective ways of measuring health and health-related outcomes for people with disabilities. Unfortunately, few population-based data systems could identify people with disabilities, so it was difficult to compare their health status with that of the general population. In 2000, the CDC partnered with 75 governmental and nongovernmental organizations to examine disability and secondary conditions. A key objective was to devise standardized questions to identify people with disabilities on federal surveillance instruments.<sup>9</sup> Lack of standard questions impeded measuring the nature and extent of disabling conditions and assessing their impact on participation in society, barriers to participation, and risk factors for poor health. Questions were proposed to identify the activity limitations of individuals with varying degrees of disability, so that population-based information on their health status would be available.

Using the 2004 Behavioral Risk Factor Surveillance System (BRFSS), Drum et al.<sup>4</sup> found that adults who reported an activity limitation or used adaptive equipment had poorer self-rated health and fewer healthy days than people without these limitations, even when controlling for demographic characteristics. Moreover, compared with nondisabled respondents, those with activity limitations reported fewer physically and mentally healthy days within each health-rating category. They concluded that people with disabilities might

think differently than those without disabilities when asked to rate their health.

Researchers also explored the validity of generic versus disease-specific health measures. Motl et al.<sup>10</sup> compared the relationships between physical activity and quality of life for generic versus “disease-targeted” instruments in 261 individuals with MS. They reported similar relationships between physical activity and the SF-36, the Satisfaction with Life Scales, the Multiple Sclerosis Impact Scale-29, and the Leeds Multiple Sclerosis Quality of Life Scale.

A variety of measures have been used to assess health status, impairment, functional limitations, disability, and key health-related outcomes such as quality of life, secondary conditions, and depression in people with chronic disabling conditions. However, the extent to which they are conceptually and operationally distinct and the relationships among them are not always clear. To better understand the relationships among these measures and the constructs they purport to assess, they must be examined within the same sample.

The purpose of this study was to examine the relationships among various measures of impairment, disability, and functional status and health-related outcomes within a large sample of individuals with MS. A secondary purpose was to compare the self-reported health status of a group of individuals with MS with that of a population-based sample of individuals with and without disabilities. The following research questions were addressed: 1) How do individuals with MS perceive their health status (using the Core Healthy Days measures) compared with other adults with and without reported functional limitations? 2) What are the relationships among measures of disability, health status, functional limitations, depression, secondary conditions, and quality of life for individuals with MS?

## Methods

The analyses reported here are based on data from a longitudinal study of health promotion and quality of life among people with MS. Data used in this analysis were taken from the eighth wave of longitudinal data collection, which was expanded to include the Core Healthy Days measures.<sup>11</sup>

After obtaining study approval from the institutional review board at The University of Texas at Austin, individuals were recruited from mailing lists provided by two chapters of the National Multiple Sclerosis Society.<sup>12</sup> Surveys were mailed to the 936 individuals who

responded positively to the initial recruitment letter. Those who returned the initial survey ( $n = 834$ ) came from 110 of the 254 counties in Texas. Those who agreed to subsequent contact ( $n = 774$ ) constituted the longitudinal sample and continued to receive mailings approximately every year, as long as they remained eligible and interested and were not lost to follow-up because of death, institutionalization, or geographic moves. In 2006, questionnaire packets were sent to 516 individuals, and 443 responded, yielding an 86% response rate.

Data were cleaned and entered into an SPSS database (SPSS, Chicago, IL) for statistical analysis. A random sample of entries was verified by checking the computer entry against the original questionnaire; the error rate was less than 1%.

### Instruments

The BRFSS is the world's largest ongoing telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984.<sup>11</sup> Conducted by the 50 state health departments as well as the District of Columbia, Puerto Rico, Guam, and the US Virgin Islands with support from the CDC, the BRFSS provides state-specific information about health concerns such as asthma, diabetes, alcohol and tobacco use, hypertension, obesity, cancer screening, nutrition, and physical activity. Findings from this population-based survey are used to target public health goals, and it has become an important source of information about the health status of people with disabilities.

The CDC developed the Core Healthy Days measures consisting of four questions about perceived health status and activity limitations. These items were designed to track population health status and HRQL. They have been included in the BRFSS telephone survey since 1993. The four questions making up the Core Healthy Days measures are as follows:

1. Would you say that in general your health is excellent, very good, good, fair, or poor?
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

The summary index of unhealthy days is calculated by adding together responses to the second and third questions, to represent the number of days when the respondent indicated that either physical or mental health was not good. The reliability and validity of the Core Healthy Days measures have been supported in multiple studies.<sup>3</sup> In particular, scores on the Core Healthy Days measures are moderately correlated with the physical and mental summary scales of the SF-36 and the Center for Epidemiological Studies Depression Scale (CESD), a measure of depressive symptoms. In addition, each of the four questions has been shown to predict short-term mortality.

The Charlson Comorbidity Index<sup>13</sup> was used to assess comorbid conditions. The 20-item index is weighted to reflect the number and seriousness of comorbid conditions, with higher scores indicating more conditions. Patient ratings on this measure were significantly related to scores derived from records review, and test-retest reliability was 0.91.<sup>14</sup>

The Incapacity Status Scale<sup>15</sup> was used to measure functional limitations related to MS. The initial structured interview format was adapted to a self-administered questionnaire designed to assess functional limitations in 16 areas, such as mobility, bowel and bladder function, sensory or cognitive impairments, bathing, dressing, and feeding. Each item is rated on a five-point scale, with higher scores indicating greater inability to perform activities. Scores range from 0 to 64.

Disability status was assessed using three items modified from the Disability Supplement to the National Health Interview Survey (NHIS), 1994–1995.<sup>16</sup> These items ask 1) if physical, mental, or emotional conditions limit daily activities in multiple domains (personal hygiene, house or yard care, work, and other things you need to do); 2) if the limitation lasted (or is expected to last) for at least 6 months; and 3) the degree of limitation (if the respondent reported limitations for the previous two questions). Resulting scores ranged from 0 (no limitation) to 2 (a great deal of limitation). Although reliability for these items was not reported, the National Center for Health Statistics tests the psychometric properties of all NHIS items.

The Social Functioning, Role Physical, and Role Emotional scales of the SF-36 were described by their developers as three of the eight dimensions of a patient-based assessment of health status.<sup>17</sup> The multi-item SF-36 scales include items measuring role limitations in work or other daily activities resulting from physical health problems (four items), role limitations due to emotional problems (three items), and interference with normal social activities due to physical and emotional problems (two items). Scores are calibrated to produce scales of 0 (least favorable) to 100 (most favorable). Extensive analyses have supported the reliability and validity of the scales among groups with various health conditions.

Secondary disabling conditions were assessed with an investigator-developed measure modified for people with MS from the measure of secondary conditions of Seekins et al.<sup>18</sup> The respondent is asked to rate the extent to which various conditions have interfered with activities and independence during the preceding 12 months: mobility, vision, speech, cognition, depression, fatigue, sexual function, bowel and bladder function, bathing, dressing, feeding, and physical health. Possible scores range from 0 to 15, with higher scores indicating greater problem frequency. In this study, those with benign sensory or relapsing-remitting MS had significantly lower scores on this measure than those reporting progressive MS.

The CESD-10 was used to measure depressive symptoms.<sup>19</sup> Respondents rate how frequently they have experienced ten depressive symptoms on a four-point scale, with higher scores indicating more depressive symptoms. The scale has shown good reliability and validity with various populations, including people with chronic and disabling conditions.<sup>20</sup>

Ferrans and Powers' Quality of Life Index (QLI-MS Version) was used to measure perceived quality of life.<sup>21</sup> The 72-item measure contains two parts: Part 1 measures satisfaction with health and functioning, socioeconomic, psychological, spiritual, and family life domains, whereas Part 2 measures the importance of these domains. Items are rated on a six-point scale, with higher scores indicating greater perceived quality of life. Total quality of life scores are calculated by weighing satisfaction responses with their paired importance ratings. Validity and reliability of the measure have been supported by previous research.<sup>22</sup>

## Results

### MS Sample Description

The sample from the eighth wave of longitudinal data collection ( $n = 443$ ) was predominantly Anglo (92%), married (71%), and female (84%). Their average age was 57 years ( $SD = 9.5$  years). Six percent had less than a high school education, 26% were high school graduates, and 69% had at least some college education. Twenty-four percent were employed at least part-time; 37% indicated that they were unemployed owing to disability. Thirty-seven percent reported having relapsing-remitting MS, while 40% reported some form of progressive MS. In 2006, the sample had been diagnosed for an average of 20 years.

Because approximately 90% of this MS sample resides in Texas, we compared our findings with the population-based sample of Texans who participated in the BRFSS in 2006 (the same year as the eighth wave of MS longitudinal data presented here). Compared with Texans in general, the MS respondents were less likely to be working, were more likely to be married and to be non-Hispanic whites, and had higher educational levels (Table 1).

### Reliability

Cronbach  $\alpha$  coefficients were computed as measures of internal consistency for all scales. Alpha coefficients ranged from 0.68 for the five-item secondary conditions measure to 0.96 for the 36-item quality of life measure. In terms of score distributions, only the Charlson Comorbidity Index manifested a markedly skewed distribution, with most people reporting few if any comorbidities.

### Core Healthy Days Measure Comparisons

In the BRFSS Texas sample, respondents were categorized as disabled or nondisabled based on their response to the following question: Are you limited in any way in any activities because of physical, mental, or emotional problems? Approximately 23% of the sample indicated that they did have activity limitations and therefore constitute the "disabled" Texas group, while 77% were classified as nondisabled.

Table 2 compares responses to the Core Healthy Days measures for this MS sample with data from the 2006 BRFSS conducted with Texas respondents. Both the MS sample and the disabled Texans reported poorer health, more days in the preceding month when physical and mental health were not good, and more days

**Table 1. Demographic characteristics of the MS sample and the population-based sample of Texans**

Characteristic	MS sample, % (n = 443)	General Texans, % (n = 6854)
Sex		
Male	16	49
Female	84	51
Education		
Less than high school	6	16
High school/GED	26	27
Some post-high school	31	25
College degree or higher	38	33
Race/ethnicity		
White	87	60
Black	4	7
Hispanic	3	28
Other/multiracial	6	4
Marital status		
Married/partnered	74	67
Never married	6	16
Divorced/widowed/separated	20	17
Employment		
Part-time/full-time employed	24	60

Abbreviations: GED, general equivalency diploma; MS, multiple sclerosis.

Note: Data for the Texas sample are from the 2006 Texas Behavioral Risk Factor Surveillance System Survey.

when poor health kept respondents from usual activities than did nondisabled Texans. Thirty-seven percent of the MS sample rated their health as fair or poor, compared with 41% of Texans with activity limitations and 12% of nondisabled Texans. Although the MS sample reported slightly better general health than the population-based sample of Texans with disabilities, the percentage fell within the 95% confidence interval (CI) for Texans with disabilities. However, the percentage of the MS sample reporting 5 or more days of poor physical health (57%) was above the 95% CI for disabled Texans (46%; CI, 40.9%-50.2%).

We also analyzed responses to the Core Healthy Days questions for those individuals in the MS sample

who indicated that physical, mental, or emotional conditions limited their daily activities (ie, the same question used to determine disability status in the 2006 Texas cohort on the BRFSS). That subset of the MS sample (n = 260) was more likely to report fair or poor health (48%) than either the MS sample as a whole or the disabled Texans (Table 2). They also reported considerably more days when physical (69%) and mental (48%) health were not good and more activity limitations in the preceding 30 days (56%) than either the Texans with disabilities or the total MS group.

### Interrelationships Among Measures

As shown in Table 3, many of these measures were moderately correlated with each other, and the patterns were what might be expected. Incapacity status, a measure of functional limitations, was most highly correlated with the three-item activity limitation composite from the Disability Supplement to the NHIS ( $r = 0.65$ ), followed by secondary conditions, which, like the incapacity status score, is an MS-specific measure ( $r = 0.60$ ). All the Core Healthy Days items were moderately correlated with the SF-36 physical, emotional, and social subscales, with the highest correlations between the summary of poor physical and mental days and SF-36 Role Physical ( $r = -0.52$ ), Role Emotional ( $r = -0.52$ ), and Social Functioning ( $r = -0.60$ ). (Note that high scores on the SF-36 scales reflect better functioning, so the negative correlations between Core Healthy Days items and the SF-36 indicate that the more days of poor health or activity limitations, the lower the SF-36 scores.) The number of days when mental health was not good correlates more strongly with the CESD depressive symptoms score ( $r = 0.68$ ) and the SF-36 Role Emotional score ( $r = -0.56$ ) than do the other functional measures, such as the NHIS or the MS incapacity measure. The Charlson Comorbidity Index had only modest correlations with all the measures here, except the MS secondary conditions scale ( $r = 0.30$ ).

The three-item NHIS composite assessing limitations in activities of daily living was more strongly correlated with the Core Healthy Days when physical health was not good than when mental health was not good. Although we might expect responses to the three-item NHIS composite and the Core Healthy Days activity-limited days item to be highly related, the correlation was only 0.49; both of these measures were

**Table 2. Responses to Core Healthy Days questions for the MS sample and Texans with and without disabilities**

Core Healthy Days question	MS sample, % (CI) (n = 442)	MS with impairment, % (CI) (n = 260)	Disabled Texans, % (CI) (n = 1587)	Nondisabled Texans, % (CI) (n = 5180)
Self-reported fair or poor general health	37.1 (±4.5)	48.1 (±6.1)	40.9 (±4.4)	11.8 (±1.6)
≥5 days of physical health not good	56.5 (±4.6)	69.4 (±5.6)	45.5 (±4.7)	9.9 (±1.7)
≥5 days of mental health not good	40.9 (±4.6)	48.2 (±6.1)	35.3 (±4.8)	12.5 (±1.6)
≥5 days kept from usual activities by poor physical/mental health	40.5 (±4.6)	55.6 (±6.1)	32.1 (±4.1)	6.0 (±1.5)

Abbreviations: CI, confidence interval; MS, multiple sclerosis.

Note: Data for disabled and nondisabled Texans are from the 2006 Texas Behavioral Risk Factor Surveillance System Survey. Disability status was determined by response to a question about limitation of activities because of physical, mental, or emotional problems.

more strongly correlated with other variables in this analysis, such as the SF-36 Role Physical measure ( $r = -0.69$  and  $r = -0.56$ , respectively).

Quality of life was most strongly correlated in a negative direction with the CESD measure of depressive symptoms ( $r = -0.69$ ), followed by the summary of poor physical and mental health days ( $r = -0.63$ ), general health ( $r = -0.61$ ), and the SF-36 Social Functioning scale ( $r = 0.61$ ). Whereas the MS-specific secondary conditions measure was most strongly correlated with the MS-specific incapacity status score ( $r = 0.60$ ), it was moderately correlated with the SF-36 scales and the other physical health and activity limitations measures.

## Discussion

The ability to compare large groups of individuals who have disabling conditions, such as MS, with population-based samples with and without disabling conditions provides important information about health-related concerns. Our MS sample ( $n = 443$ ) was more likely to perceive their health as good, very good, or excellent (63%) than either Texans with disabilities (59%) or Drum et al.'s 2004 national sample of individuals with disabilities (55%), although their average health rating was lower than that of Texans without disabilities (88%). However, the MS sample reported more days when poor physical or mental health limited their activities than did Texans with disabilities. When we selected only those in the MS sample who indicated that their physical, mental, or emotional condition limited daily activities (ie, the same question used to determine disability status on the BRFSS), this subset report-

ed poorer health on all four of the Core Healthy Days measures than any of the other samples. These findings underscore the variability in functional status among people with MS.

There are several explanations for the discrepancies in self-reported health status between the MS sample and the two population-based samples of individuals with disabilities. Whereas the Texans with disabilities and Drum et al. samples were population-based, the MS sample was drawn from individuals willing to participate in an ongoing research study. The MS sample was also recruited through mailing lists obtained from the MS society and therefore reflects individuals who join such groups. Moreover, the demographic characteristics of the two samples differed. The MS sample was better educated, more likely to be female and non-Hispanic whites, and less likely to be employed than the Drum et al. sample.<sup>4</sup> The better education of the MS sample may have provided them with greater resources (eg, financial, adaptive coping skills) than the less-educated sample with disabilities. These resources may enable them to perceive their impairment as less detrimental to their general health status. However, these factors did not have the same buffering effects on their reports of the actual number of days their physical or mental health was not good or interfered with their ability to do usual activities.

The general Texas sample was more likely to be male and working, contained a higher percentage of individuals who had not completed high school, and was more racially and ethnically diverse than the MS sample.

Again, these demographic differences may contribute to the observed differences in health status variables.

Limitations of large population-based surveys, such as the BRFSS, must also be considered. The activity limitations question used to determine disability status is quite broad, such that a very heterogeneous group of individuals is labeled as “disabled.” Without specific information about when the disability was acquired or the nature of the condition, the resulting analyses may be difficult to interpret. Because the BRFSS is administered by phone, individuals who are deaf or have difficulty answering the telephone within the number of rings used in the typical research protocol may not be able to participate.<sup>23</sup> Individuals living in institutional settings are not represented. Those with cognitive

impairments may require prompts to clarify questions and response alternatives, and self-report bias is possible. Nonetheless, these surveys have begun to fill the void of information about the health status of people with disabilities.

Finally, observed differences may reflect differences in the underlying disabling conditions of respondents in the different samples. The disability screening questions used on the BRFSS are quite broad. Anyone who reports activity limitations because of physical, mental, or emotional problems or uses adaptive equipment is considered disabled. Consequently, individuals with a broad range of disabling conditions were included in the population-based samples. The MS sample, however, was also heterogeneous, with some experiencing few,

**Table 3. Bivariate correlations among health, functioning, disability, and quality of life measures (n = 443)**

	SF-36 Social	SF-36 Role Emotional	SF-36 Role Physical	Secondary conditions	Incapacity status	Charlson comorbidity	NHIS composite	CESD	Quality of life	Summary of bad days <31	Activity-limited days	Mental bad days	Physical bad days
General health	-0.48	-0.47	-0.49	0.41	0.50	0.23	0.37	0.52	-0.61	0.61	0.49	0.43	0.60
Physical bad days	-0.55	-0.42	-0.54	0.42	0.43	0.21	0.42	0.45	-0.56	0.89	0.66	0.49	
Mental bad days	-0.49	-0.56	-0.35	0.26	0.28	0.13	0.22	0.68	-0.53	0.70	0.49		
Activity-limited days	-0.59	-0.48	-0.56	0.39	0.43	0.18	0.49	0.48	-0.57	0.66			
Summary of bad days <31	-0.60	-0.52	-0.52	0.40	0.43	0.18	0.40	0.62	-0.63				
Quality of life	0.61	0.54	0.51	-0.42	-0.50	-0.08	-0.45	-0.69					
CESD	-0.54	-0.55	-0.46	0.30	0.36	0.09	0.31						
NHIS composite	-0.52	-0.35	-0.69	0.48	0.65	0.11							
Charlson comorbidity	-0.16	-0.16	-0.11	0.30	0.20								
Incapacity status	-0.55	-0.45	-0.65	0.60									
Secondary conditions	-0.48	-0.42	-0.50										
SF-36 Role Physical	0.67	0.53											
SF-36 Role Emotional	0.61												

Abbreviations: CESD, Center for Epidemiological Studies Depression Scale; NHIS, National Health Interview Survey; SF-36, 36-item Short Form Health Status Survey.

Note: Correlation coefficients greater than 0.10 are significant at  $P < .05$ ; coefficients greater than 0.13 are significant at  $P < .01$ .

if any, functional limitations or disabilities and others experiencing major limitations in their daily functioning. When we examined only those individuals with MS who reported that their daily activities were limited by physical, mental, or emotional conditions, they reported poorer general health and more days of poor health and activity limitations than the disabled Texans sample.

As expected, our analyses showed relationships among many of the variables studied. Given the large sample size, virtually all of these relationships were statistically significant at  $P < .05$ . Moreover, the vast majority of correlations also met Cohen's<sup>24</sup> criteria for moderate-to-large correlations ( $r \geq 0.30$ ).

The observed strong relationships among the Core Healthy Days measures, the CESD, and the SF-36 Social Functioning, Role Physical, and Role Emotional subscales are consistent with previously reported studies.<sup>3</sup> These relationships are not surprising given the similarity in content among many of the measures. For example, items on the SF-36, the NHIS, and the Core Healthy Days ask the respondent to consider the relationship between their health and activities of daily living. However, the time frame varies from 1 week to 30 days. This difference may partially explain the different pattern of relationships observed with other measures. For example, the CESD, which asks about depressive symptoms experienced over the preceding week, is more strongly correlated with scores on the SF-36 Role Physical ( $-0.46$ ) and the Core Healthy Days activity limitations item (0.48) than with scores on the NHIS (0.31), which does not specify such an immediate time frame. Researchers should carefully consider the time frame of interest when selecting measures.

The time frame may be particularly relevant in intervention studies, in which participants' time of reference should fit the structure of the intervention. We might not expect to see as much change on the Core Healthy Days measure from week to week as we might detect on the SF-36 or CESD, both of which specify a shorter time frame.

The weakest observed correlations involved the Charlson Comorbidity Index. This index, a weighted compilation of various health conditions, was skewed, because few in the MS sample had multiple comorbid conditions. Thus, it may not be a particularly meaningful health indicator for people with MS, unless a particular sample is known to have other health conditions.

Although quality of life and CESD scores were negatively related ( $r = -0.69$ ), scores on secondary conditions were only moderately related to these two measures ( $r = -0.42$  for quality of life;  $r = 0.30$  for CESD). The secondary conditions measure exhibited the lowest internal consistency reliability and asks participants about conditions affecting activities over a 12-month time frame, possibly contributing to the lower associations with other measures in this study. As might be expected, the SF-36 Role Emotional score was most strongly related to depressive symptoms on the CESD ( $r = -0.55$ ), whereas the secondary conditions measure was most strongly related to incapacity status ( $r = 0.60$ ). In contrast, the summary of physically and mentally unhealthy days was most strongly related to perceived quality of life ( $r = -0.63$ ). Notably, the single-item general health self-rating and the single-item activity-limited days measure from the Core Healthy Days were each more strongly correlated with the quality of life measure ( $r = -0.61$  and  $r = -0.57$ ) than was the Incapacity Status Scale ( $r = -0.50$ ), the Charlson Comorbidity Index ( $r = -0.08$ ), or the secondary conditions measure ( $r = -0.42$ ), each of which has multiple items. Verbrugge et al.<sup>25</sup> also found that a global disability item was more strongly related to chronic conditions and physical limitations than detailed disability measures.

Although the MS-specific Incapacity Status Scale and the secondary conditions were related to each other ( $r = 0.60$ ), these MS-specific measures were also at least moderately correlated with many other health measures. In fact, incapacity status was more strongly correlated with the three-item NHIS composite measure ( $r = 0.65$ ) and the SF-36 Role Physical scale ( $r = -0.65$ ) than with secondary conditions. Consistent with the finding of Motl et al.,<sup>10</sup> we recommend that MS researchers not limit themselves to MS-specific measures when assessing health outcomes. Utilizing MS-specific measures enables researchers to compare their findings with results from other MS studies, but limits comparisons with functional status or quality of life studies that utilize broader-based measures with extensive psychometric evaluation, such as the SF-36. Therefore, what the study purports to measure should be carefully considered. When progression of disease is the focus, MS-specific measures may be most appropriate, but when exploring functional status or quality of life, other measures may be more suitable.

## Practice Points

- Pathology, impairment, functional limitation, and disability are not synonymous terms, but represent different concepts in the disablement process and should be measured differently.
- Just as in other disabled groups, people with MS were more likely to rate their health as fair or poor than were people without disabilities. Compared with other disabled groups, people with MS reported more days when their physical and mental health were not good and more days when their health kept them from usual activities.
- Criteria such as participant burden and appropriate time frame, as well as the more traditional criteria of reliability and validity, should be considered when selecting data-collection measures for people with MS.

The principle of parsimony suggests that a shorter, more reliable measure valid for the intended purpose is more desirable than a longer one. Thus, if the CDC's summated rating of the number of physically and mentally unhealthy days correlates with key outcomes, such as quality of life, as well as or better than longer health status measures, such as the SF-36, then researchers may want to consider the shorter measures. This may be particularly important when fatigue in MS research participants is an important factor.

What measure to use should be driven by the research question and the constructs therein. Thus, we urge researchers to look beyond a measure's title to what the items actually assess. Our understanding of the constructs of "impairment," "functional limitations," "quality of life," and "disability" have evolved, and the tools we select should reflect the conceptual and theoretical definitions we wish to address. This study provides a starting point for examining relationships among many of these measures in a large sample of individuals with MS. □

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