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

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Abstract

Researchers use various measures to assess health status, impairment, functional limitations, and disability among people with Multiple Sclerosis. However, conceptually and empirically relationships among measures are not always clear. The purpose of this study was to examine the relationships among measures of impairment, disability, functional status and health related outcomes within a sample of 443 individuals with MS. A secondary purpose was to compare the reported health status of this sample to the health status of a population-based sample of individuals with and without disabilities. While both the MS sample and a population-based sample of individuals with activities limitations indicated poorer health than did their non-disabled counterparts, the MS sample reported more days in the past month when physical and mental health was 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 period specified may affect the relationships. Researchers are advised to carefully consider operational as well as conceptual definitions, length of proposed measures, and appropriate time frame, as well as more traditional criteria of reliability and validity when selecting study measures.

Multiple Sclerosis (MS) is a chronic disabling condition estimated to affect more than 350,00 people in the United States.[1] People with MS can experience various levels of impairment, resulting in different functional limitations. Consequently, MS research has increasingly focused on the measurement of key health constructs, such as disability, health status, functional limitations, and health-related quality of life.

As health researchers have increasingly adopted a broader view of health than simply morbidity and mortality, the nuances of measuring health status have gained greater attention. Consistent with the World Health Organization definition of health as " a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" [2], 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.[3] With this broader definition has come a proliferation of measures to address the various components of this multidimensional construct.

Unfortunately, the conceptual distinctions among the proliferating number of measures are not always clear, and have resulted in confusion about what is being measured. For example, the Medical Outcomes Study SF-36 (MOS) is frequently described as a health-related quality of life measure, but its authors describe it as a health status measure, and an

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examination of its content suggests much of it may be more appropriately described as a measure of functional status.[4] Verbrugge and Jette [5] described the scientific literature in this area as "bedlam vocabulary".

Building upon the World Health Organnization's International Classification of Impairments, disabilities and Handicaps[6] Verbrugge and Jette[5] 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, then, refer to dysfunction and structural abnormalities in specific body systems whereas functional limitations are the restrictions in daily life resulting from these impairments. By contrast, Verbrugge and Jette describe disability as a social process in which the ability to perform expected or specified social role activities is lost or reduced because of chronic disease or impairment. To illustrate, MS destroys the myelin-insulating axons, thereby interfering with efficient electrical conduction within the central nervous system.[7] The resulting neurological disturbance manifests itself in 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.[8] These impairments can in turn result in functional limitations, particularly in mobility, which could lead to disability, if the individuals' environment does not provide adequate supports to enable them to get around so they can participate in the community. The point here is that pathology, impairment, functional limitation, and disability are not synonymous terms, but represent different concepts in the Disablement Process and should be operationalized differently. In short, these researchers make a convincing case for the need for conceptual clarity to guide disability research, particularly in the measurement area.

Recognizing that people with disabilities have historically experienced health disparities, the Centers for Disease Control and Prevention (CDC) began focusing on more effective ways of measuring health and health related outcomes for people with disabilities. Unfortunately, few population-based data systems had previously identified people with disabilities, so it has been difficult to compare their health status to the health of the general population. To this end, in 2000, the CDC partnered with 75 organizations within and outside government to examine disability and secondary conditions. A key objective of this partnership has been to include a standardized set of questions that identify people with disabilities on federal surveillance instrument, because none of the federally funded surveys had been using the same definition of disability.[9] As this consensus group pointed out, lack of a standard set of questions has impeded the measurement of the nature and extent of disabling conditions in the United States and to assess their impact on participation in society, barriers to participation, and risk factors for poor health in this population. A set of questions were proposed to identify individuals with varying degrees of disability in terms of their activity limitations, so that population-based information on health status would be available for people with disabilities. Consequently, people with disabilities can now be identified in subgroup analyses on national health surveillance systems.

Utilizing one such data source, the 2004 Behavioral Risk Factor Surveillance System, Drum, Horner-Johnson, and Krahn [4] found that adult respondents who reported an activity limitation or use of adaptive equipment had poorer self-rated health and fewer healthy days than people without these limitations, even when controlling for demographic characteristics such as age, education, race/ethnicity, and income. Forty-five percent of the respondents with disabilities reported that their health was "fair" or "poor". They reported a mean of 11.9 days of poor physical health and 6.9 days of poor mental health in the past 30 days. Moreover, compared to non-disabled respondents, those with activities limitations reported fewer physical and mental healthy days within each health rating category. Interestingly, people with activities limitations seemed to tolerate more days when the physical and mental

health was poor when rating their health as good (11 days for persons with disabilities compared to 5 days for people without). These researchers concluded that people with disabilities may think differently than people without disabilities when asked to rate their health.

Disability researchers have also explored the validity of generic versus disease-specific health measures. Motl, McAuley, Snook, and Gilottoni[10] compared the relationships between physical activity and quality of life for what the researchers labeled as generic versus disease-targeted instruments. They reported similar relationships between physical activity, measured by an accelerometer, and the Medical Outcomes Study SF-36, the Satisfaction with Life Scales, the Multiple Sclerosis Impact Scale-29, and the Leeds Multiple Sclerosis Quality of Life Scale among 261 individuals with multiple sclerosis. These researchers concluded that among people with Multiple Sclerosis, generic and disease-targeted instruments have similar relationships with a performance measure of physical activity.

To summarize, a variety of measures have been developed to assess health status, impairment, functional limitations, disability, and key health related outcomes, such as quality of life, secondary conditions, and depression. These measures have been utilized in multiple studies of people with chronic disabling conditions such as MS. However, the extent to which they are conceptually and operationally distinct, and the pattern of relationships among them is not always clear. To better understand the relationships among these measures and the constructs they purport to assess, we need to examine them within the same sample.

The purpose of this study was to examine empirically 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 reported health status of a group of individuals with MS to reported health status for a population-based sample of individuals with and without disabilities.

Research Questions

1. How do perceptions of individuals with MS about their health status (using the Core Healthy Days Measures) compare with perceptions of other groups of 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 upon data from a longitudinal study of health promotion and quality of life among persons with Multiple Sclerosis (MS). Data used in this analysis were taken from the 8th wave of longitudinal data collection, which was expanded to include the Core Healthy Days Measures.[11]

Following approval from the local Institutional Review Board, individuals were recruited from mailing lists provided by two National MS Society chapters.[12] 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 have continued to receive mailings approximately yearly as long as they remained eligible and

interested, and were not lost to follow-up due to death, institutionalization, or loss of address. In 2006, questionnaire packets were sent to 516 individuals, and 443 responded, yielding an 86% response to that mailing.

The measures described below were combined into a booklet, the format of which has remained consistent across the course of this longitudinal study. Participants who did not respond within 30 days were sent a second questionnaire booklet.

Data were cleaned and entered into an SPSS data-base for statistical analysis. A random sample of entries was verified by checking the computer entry against the original questionnaires; the error rate was less than 1%.

Instruments

The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984.[11] Conducted by the 50 state health departments as well as those in the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands with support from the CDC, BRFSS provides state-specific information about health concerns such as asthma, diabetes, access to services, 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 have developed the Core Healthy Days Measures consisting of four questions about perceived health status and activity limitations. These items were designed to be used to track population health status and health-related quality of life. They have been included in the Behavioral Risk Factor Surveillance System (BRFSS) telephone survey since 1993. The four questions comprising the Core Health 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 question and subtracting them from 31, 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 measure has been supported in multiple studies.[3] In particular, scores on the Core Healthy Days are moderately correlated with the Physical and Mental summary scales of the SF-36 and the CES-D, a measure of depressive symptoms. In addition, each of the four questions has been shown to predict short-term mortality.

The Charlson Comorbidity Index [13] 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 .91.[14]

The Incapacity Status Scale [15] was used to measure functional limitations related to MS. The initial structured interview format has been 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, feeding. Each item is rated on a 5-pt scale with higher scores indicating greater inability to perform activities. Scores can range from zero to 64.

Disability status was assessed using three items modified from the Disability Supplement to the National Health Interview Survey, 1994–1995.[16] 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 six months, and (3) the degree of limitation (if the respondent reported limitations in the previous two questions). Resulting scores ranged from "0" corresponding to no limitation, to "2" corresponding to a great deal of limitation. Although NHIS does not report reliability for these items, the National Center for Health Statistics tests the psychometric properties of all NHIS items.

The Social, Physical and Emotional Role Functioning Scales of the Medical Outcomes Study SF-36 were described by their developers as three of the eight dimensions of a patient-based assessment of health status.[17] The multi-item MOS SF-36 scales include items measuring role limitations in work or other daily activities resulting from physical health problems (4 items), role limitations due to emotional problems (3 items), and interference with normal social activities due to physical and emotional problems (2 items). Scores are calibrated to produce 0 (least favorable) to 100 (most favorable) scales. Extensive analyses with various samples 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 Seekins, Clay, and Ravesloot's measure of secondary conditions.[18] The respondent is asked to rate the extent to which various conditions interfere with activities and independence during the past 12 months: mobility, vision, speech, cognition, depression, fatigue, sexual function, bowel and bladder function, bathing, dressing, feeding, and physical health. Scores range from zero to 15 with high 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 Center for Epidemiological Studies Depression Scale -10 (CESD-10) was used to measure depressive symptoms.[19] Respondents rate how frequently they have experienced 10 depressive symptoms on a 4-pt. scale, such that higher scores indicate more depressive symptoms. The Scale has shown good reliability and validity with various populations, including people with chronic and disabling conditions.[20]

Ferrans and Powers' Quality of Life Index (QLI-MS Version) was used to measure perceived quality of life.[21] The 72-item measure contains two parts: Part 1 measures satisfaction with health and functioning, socioeconomic, psychological, spiritual, and family life domains while Part 2 measures the importance of these domains. Items are rated on a 6 pt. 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 in previous research.[22]

Results

MS Sample description

The sample from the 8th wave of longitudinal data collection (n=443) was predominantly Anglo (92%), married (71%), and female (84%). Their average age was 57 years old (S.D. = 9.5). Six percent had less than a high school education; 25% were high school graduates, and 69% had at least some college education. Twenty-four percent were employed at least part-time; 37% indicated they were unemployed due to disability. Thirty-seven percent reported having relapsing-remitting multiple sclerosis, while 40% reported some form of progressive M.S. In 2006, the sample had been diagnosed 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 8th wave of MS longitudinal data presented here). Compared with Texans in general, or Texans who reported poor or fair health, the MS respondents were less likely to be working, more likely to be married and non-Hispanic Whites, and had higher educational levels (see Table 1).

Reliability

Cronbach alpha coefficients were computed as measures of internal consistency for all scales. Alpha coefficients ranged from .68 for the 5-item Secondary Conditions measure to .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 co-morbidities.

Core Healthy Days Measure Comparisons

In the BRFSS Texas sample, respondents were categorized as disabled or non-disabled 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 they did have activities limitations and therefore constitute the "Disabled" group, while 77% were classified as non-disabled.

Table 2 compares responses to the CORE Healthy Day 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 past month when physical and mental health were not good, and more days when poor health kept respondents from usual activities than did non-disabled Texans. Thirty-seven percent of the MS sample rated their health as fair or poor, compared with 41% of Texans with activities limitations, and 12% percent of the nondisabled Texans. While 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 for Texans with disabilities. However, the percent of the MS sample reporting 5 or more days of poor physical health (57%) was above the 95% confidence interval for disabled Texans (46%, C.I., 40.9 – 50.2).

We also analyzed responses to the Core Healthy Days questions for those individuals in the MS sample who indicated (n=260) that physical, mental, or emotional condition limited their daily activities (i.e., the same question used to determine disability status in the 2006 Texas cohort on the BRFSS). That subset of the MS sample was more likely to report fair or poor health (48%) than either the MS sample as a whole or the disabled Texans (see Table 2). They also reported considerably more days when physical health was not good (69%) and mental health was not good (48%) or activity limitations in the previous 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 are moderately correlated with each other, and the patterns are what might be expected. Incapacity Status, a measure of functional limitations, was most highly correlated with the 3-item Activity Limitation composite from the Disability Supplement to the National Health Interview Survey (NHIS) (r=.65), followed by the Secondary Conditions, which like the Incapacity Status Score is a MS specific measure (r=.60). All the Core Healthy Days items are moderately correlated with the MOS Role Physical, Role Emotional, and Social Functioning subscales, with the highest correlations between the summary of poor physical and mental days and MOS Role Physical (r=−.52), MOS Role Emotional (r=−.52) and Social Functioning (r=−.60). (Note that high scores on the MOS scales reflect better functioning, so the negative correlations between Core Healthy Days items and the MOS indicate that the more days of poor health or activity limitations, the lower the MOS scores, as expected.) The number of days when mental health was not good correlates more highly with the CESD depressive symptoms score (r=.68) and the MOS Role Emotional score (r=−.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=.30).

The 3-item NHIS composite assessing limitations in activities of daily living was more highly correlated with the Core Healthy Days when physical health was not good than days when mental health was not good. While we might expect responses to the 3-item NHIS composite and the Core Healthy Days activity limitation days item to be highly related, the correlation was only .49; both of these measures were more highly correlated with other variables in this analysis, such as the MOS Role Physical measure (r=−.69 and r=−.59, respectively).

Quality of Life was most highly correlated in a negative direction with the CESD measure of depressive symptoms (r=−.69), followed by the sum of poor physical and mental health days (r=−.63), General Health (r=−.61) and the MOS Social Functioning Scale (r=.61). While the MS-specific Seconday Conditions measure is most highly correlated with the MSspecific Incapacity Status Score (r=.60), it is moderately correlated with the MOS 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 of individuals with and without disabling conditions provides important information about health-related concerns for people with disabilities. The fact that all samples are responding to the same questions facilitates comparisons among groups. Our total 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 (78%). However, the MS sample reported more days when physical or mental health limited their activities than did Texans with disabilities. And, when we select only those individuals in the MS sample who indicated that their physical, mental, or emotional condition limited daily activities (i.e., the same question used to determine disability status on the BRFSS), this subset of our total MS sample reported poorer heath on all four of the Core Healthy Days measures than any of the other samples compared here. These findings underscore the variability in functional status among people with MS.

There could be various explanations for the discrepancies in self-reported health status between the MS sample as a whole and the two population-based samples of individuals with disabilities. While both the Texans with disabilities and the Drum, et al sample were population-based samples, the MS sample was drawn from individuals willing to participate in a research study on an ongoing basis. The latter sample was recruited through mailing lists from chapters of the MS society and therefore reflects individuals who choose to join such groups. Moreover, the demographic characteristics of the two samples of people with disabilities differed. The MS sample was better educated, more likely to be female and non-Hispanic Whites, although less likely to be employed than the Drum et al sample.[4] The better education of the MS sample may have provided them with greater resources (e.g., financial, adaptive coping skills) than the less educated sample of people with disabilities, and these resources may enable them to perceive their impairment as less detrimental to their general health status. However these factors do not appear to have the same buffering effects on their reports of the actual number of days when their physical or mental health was not good or interfered with their ability to do usual activities.

The general Texas sample is more likely to be male and working, has a higher percentage of individuals who have not completed high school, and is more diverse racially and ethnically than the MS sample. Again, these demographic differences may contribute to the differences in health status variables observed here.

In interpreting these findings, 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 and results in a very heterogeneous group of individuals labeled as "disabled". Without more specific information about when the disability was acquired and the nature of the disabling condition, it may be difficult to interpret the resulting analyses. Because the BRFSS is administered by phone, individuals who are deaf or who have difficulty answering the telephone within the number of rings allowed in the typical research protocol may not be able to participate.[23] Individuals living in institutional settings are not represented. Those with cognitive impairments may require prompts to clarify questions and the response alternatives, and self-report bias is also possible. Nonetheless, these surveys begin to fill the void of information we have had about people with disabilities and their health status.

Finally, differences observed here may reflect differences in the underlying disabling conditions experienced by respondents in the various samples. The disability screening questions used on the BRFSS are quite broad. Anyone who reports activities limitations because of physical, mental, or emotional problems or uses adaptive equipment is considered disabled. Consequently, individuals with a broad range of disabling conditions would be included in the population-based samples. The MS sample itself is heterogeneous with some experiencing few, if any, functional limitations or disabilities and other 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, we observed that they reported poorer general health and more days of poor health and activity limitations than the disabled Texans sample.

As expected, the results of the bivariate correlation analyses show relationships among many of the variables studied here. Given the large sample size, virtually all these relationships were statistically significant at p<.05. Moreover, the vast majority of correlations also meet Cohen's[24] criteria for moderate to large correlations (r .30).

The observed strong relationships among the Core Healthy Days measures, the CESD, and the SF-36 Social, Physical and Role Emotional subscales are consistent with previously

reported studies in other samples.[3] These relationships are not surprising, given the similarity in content among many of the measures. For example, compare the following items from the 1) MOS, 2) the National Health Interview Survey, and 3) the Core Healthy Days:

1. During the past week, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (MOS)

2. Because of a physical, mental, or emotional condition, are you limited in doing your daily activities like personal hygiene, house or yard care, shopping, your work, or other things you need to do?(NHIS)

3. 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? (BRFSS)

All the items ask the respondent to consider the relationship between their health and activities of daily living. However, the time period to be considered does vary from 1 week on the MOS to 30 days on the Core Healthy Days. While this NHIS item does not specify a time frame, a subsequent question on the NHIS does ask if the limitation lasted at least 6 months, and this difference in time perspective may help explain the different pattern of relationships with other measures observed here. For example, the CESD, which queries depressive symptoms experienced over the past week is more highly correlated with scores on the MOS Role Physical (−.46) and the Core Healthy Days activity limitations item (.48) than with scores on the NHIS (.31), which does not specify such an immediate time frame. Researchers should consider carefully the time period of interest when selecting their measures.

The time frame targeted may be particularly relevant in intervention studies, where it is important to have participants' time of reference fit the structure of the intervention. We might not expect to see as much change on the CORE Healthy Days measure from one week to the next as we might detect on the MOS or CESD, both of which in this study specified a shorter time frame.

The lowest correlations observed in this study involved the Charlson Comorbidity Index. The Index, which is a weighted compilation of various health conditions, was skewed, because few people in the MS sample had multiple co-morbid conditions. As such, it may not be a particularly meaningful health indicator for people with MS, unless a particular sample is known to have other health conditions.

While Quality of Life and CESD scores were highly related to each other in a negative direction (r= −.69), scores on Secondary Conditions were only moderately related to these two measures (r=.30 for CESD and r= −.42 for Quality of Life). The fact that the Secondary Conditions measure exhibited the lowest internal consistency reliability as well as asking participants about conditions affecting activities over a 12 month time frame may contribute to the lower associations with other measures in this study. As might be expected, the MOS Role Emotional score was most highly related to depressive symptoms on the CESD (r=−.55), while Secondary Conditions was most highly related to Incapacity Status (r=.60). By contrast, the sum of unhealthy physical and mental days was most highly related to perceived quality of life (r=−.63). Of particular note, the 1-item general health self-rating and the 1-item activity limitations day from the CORE Healthy Days were each more highly correlated with the quality of life measure (r=−.61 and r=−.57) than was the Incapacity Status Scale (r=−.50), the Charlson Comorbidity Index (r=−.45), or the Secondary Conditions measure (r=−.42), each of which has multiple items. To this end, Verburgge,

Merrill, and Liu[25] have found that a global disability item is more strongly related to chronic conditions and physical limitations than detailed disability measures.

Of particular note, the 3-item NHIS composite measure was consistently more highly related to other measures of physical health than to other measures of mental health, despite the fact that the activity limitations specified physical, mental, or emotional conditions limit daily activities in multiple domains. The finding points to the importance of carefully describing the outcome of interest and finding a measure that most closely fits that definition.

While we observed the MS specific Incapacity Status Scale and the Secondary Conditions were related to each other (r=.60), these MS specific measures were also at least moderately correlated with many other health measures in this study. In fact, Incapacity Status was actually more highly correlated with the 3-item NHIS composite measure (r=.65) and the MOS Role Physical Scale (r=−.65) than with Secondary Conditions. Consistent with Motl, McAuley, Snook, and Gilottoni's finding[10], 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 form other MS studies using these measures, but limits comparisons with studies examining functional status or quality of life that utilize broader-based measures with a long history of psychometric evaluation, such as the MOS. Therefore, it is important to carefully consider what the study purports to measure. If progression of disease is the focus, then MS specific measure may be most appropriate, but when exploring functional status or quality of life, then other measures may be more suitable.

The principle of parsimony suggests that a shorter measure that is both reliable and valid for the intended purpose is more desirable than a longer one. Given this criteria, then if CDC's summated rating of number of unhealthy mental and physical days correlates with key outcomes, such as quality of life at least as well as, or even better than, longer health status measures, such as the MOS, then researchers may want to seriously consider the shorter measure. This may be particularly important to take into account when dealing with MS research participants for whom fatigue may be an important factor.

The key issue of what measure to use should be driven by the research question and the constructs therein. To that end, researchers are urged to look beyond the title of the measures they select to what the items actually assess. For example, the Expanded Disability Status Scale has "disability" in the title, but the tool really focuses on neurological impairments. Our understanding of the constructs of "impairment", "functional limitations", "disability", and "quality of life" have evolved, and the tools we select need to reflect the conceptual and theoretical definition 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.

In conclusion, MS researchers confront an ever-increasing number of potential health and disability-related measures. Many appear to overlap in wording, and as demonstrated in this study, many measures appear to be at least moderately correlated with each other. Researchers are advised to carefully consider criteria, such as length with respect to participant burden, or appropriate time frame, as well as the more traditional criteria of reliability and validity when selecting study measures. In addition, the actually wording of items, as well as proposed conceptual definitions, must be critiqued as part of the selection process.

Acknowledgments

of Il Park and the Center on Health Statistics at the Texas Department of State Health Services for their assistance with data analysis.

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Key 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 with 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 was not good and more days when their health kept them from usual activities.

Consider criteria such as length with respect to participant burden, or appropriate time frame, as well as the more traditional criteria of reliability and validity when selecting data collection measures for people with MS.

Table 1

Comparison of Demographic Characteristics Between MS Sample and Population-Based Sample of Texans[*]

	MS Sample (n=443)	General Texans (n=6854)
Gender : Male	16%	49%
Female	84%	51%
Education		
< less than high school	6%	16%
High School/GED	26%	27%
Some post-H.S.	31%	25%
College graduate 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/Full Time Employed	24%	60%

[*] Data for Texas sample from the 2006 Texas Behavioral Risk Factor Surveillance System Survey.

Table 2

Comparison of Percentage Responses to Core Healthy Days Questions Between MS Sample and Texans With and Without Disabilities [*]

Core Healthy Days Questions	MS Sample (n=442)	C.I.	MS with Impair (n=260)	C.I.	Disabled Texans (n=1,587)	C.I.	Non-Disabled Texans (n=5,180)	C.I.
Self-Reported Fair or Poor	37.1%	± 4.5	48.1%	± 6.1	40.9%	± 4.4	11.8%	± 1.6
5 or more Days of Physical Health Not Good	56.5%	± 4.6	69.4%	± 5.6	45.5%	± 4.7	9.9%	± 1.7
5 or more 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

[*] Data for Disabled and Non-Disabled Texans taken from 2006 Texas Behavioral Risk Factor Surveillance System Survey. Disability status determined by response to question about any limitation in activities because of physical, mental, or emotional problems.

Table 3

Bivariate Correlations Among Health, Functioning, Disability, and Quality of Life Measures (n=443)

	MOS Social	MOS RE	MOS RP	Second	Incapac Status	Charlson Co-morbid	NHIS Disab	CESD	Quality of Life	Sum	Activity Limit	Mental Bad Days	Physical Bad Days
General Health	−.48	−.47	−.49	.41	.50	.23	.37	.52	−.61	.61	.49	.43	.60
Physical Bad Days	−.55	−.42	−.54	.42	.43	.21	.42	.45	−.56	.89	.66	.49	
Mental Bad Days	−.49	−.56	−.35	.26	.28	.13	.22	.68	−.53	.70	.49		
Activity Limit Day	−.59	−.48	−.56	.39	.43	.18	.49	.48	−.57	.66			
Sum Bad Days <31	−.60	−.52	−.52	.40	.43	.18	.40	.62	−.63				
Quality of Life	.61	.54	.51	−.42	−.50	−.08	−.45	−.69					
CESD Depressive	−.54	−.55	−.46	.30	.36	.09	.31						
NHIS Act. Limit	−.52	−.35	−.69	.48	.65	.11							
Charlson Co Morbidity	−.16	−.16	−.11	.30	.20								
Incapacity Status	−.55	−.45	−.65	.60									
Secondary Conditions	−.48	−.42	−.50										
MOS Role Physical	.67	.53											
MOS Role Emotional	.61												

Note: Correlations coefficients greater than .10 are significant at p<.05; coefficients greater than .13 significant at p<.01.