

# Comparing Health Promotion and Quality of Life in People with Progressive Versus Nonprogressive Multiple Sclerosis

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## CME/CNE Information

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### Learning Objectives:

- 1) Describe factors associated with health and well-being among people with progressive and nonprogressive MS.
- 2) Identify differences in health-related variables between those with progressive MS and those with nonprogressive MS.

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**Background:** People with multiple sclerosis (MS) benefit from engaging in health promotion. Most studies have been conducted with those having relapsing-remitting MS; information about health promotion for those with progressive MS is more limited. In this study, health promotion and quality of life (QOL) for people with progressive versus nonprogressive MS were systematically examined and compared.

**Methods:** These data are from years 21 and 22 of an ongoing longitudinal study of persons with MS. Participants were compared on demographic, psychosocial, and health promotion factors and 36-item Short Form Health Survey (SF-36) QOL subscales. Based on the conceptual framework, barriers, symptom clusters, social supports, and health promotion activities were entered into hierarchical multivariate regressions to predict selected SF-36 subscale scores separately for those with progressive versus nonprogressive MS after controlling for variance associated with years of education and MS incapacity.

**Results:** Analyses included 72 respondents with progressive MS and 117 with nonprogressive MS. People with progressive MS reported significantly less frequent health promotion and lower scores on SF-36 physical role limitations and social functioning. Symptoms were a strong and significant predictor for all three SF-36 subscales in both groups. The explained variances in the hierarchical models differed significantly by MS course, with adjusted  $R^2$  scores ranging from 0.17 to 0.30 in progressive MS and 0.35 to 0.45 in nonprogressive MS.

**Conclusions:** Findings underscore the importance of symptom severity in relation to health promotion and QOL in people with long-standing MS. Future research should explore additional contributors to QOL for those with progressive MS. *Int J MS Care*. 2020;22:239-246.

**M**ultiple sclerosis (MS) is a chronic disabling condition that affects almost 1 million adults older than 18 years in the United States, especially women.<sup>1</sup> It is caused by abnormal immune attacks against the central nervous system.<sup>1</sup> The course of MS has been categorized in different ways, but herein we dichotomize its course as progressive versus nonprogressive. Progressive MS includes the primary progressive, secondary progressive, and progressive relapsing courses of MS; nonprogressive MS includes what has been referred to as benign sensory and relapsing-remitting MS. Although a few studies have examined differences in treatments, health behaviors, and health outcomes for people with different MS courses,<sup>2-4</sup> most studies have focused on those with nonprogressive forms of the disease, for which more disease-modifying therapies are currently available. Because up to 80% of people with MS may develop progressive MS during their lifetime and no effective treatment for progressive MS currently exists, additional research is needed to guide interventions to help those with progressive MS, as well as those with nonprogressive MS, maximize their health and well-being.<sup>5</sup>

The purpose of the present longitudinal study, which includes male and female participants, was to systematically examine the factors associated with quality of life (QOL) in people aging with long-standing (>22 years) but different MS courses (progressive vs nonprogressive). We analyzed data from two successive years (2017 and 2018) to address how health promotion and other characteristics in 2017 predicted QOL in 2018 and how the predictive models differ between those with progressive and nonprogressive MS. Specifically, we asked these research questions: 1) How did participants with progressive and nonprogressive MS courses vary in demographic and disease characteristics? 2) How did participants with progressive and nonprogressive MS courses vary in health promotion in 2017 and QOL in 2018? 3) How did the demographic, disease, psychosocial, and health promotion characteristics measured in 2017 predict QOL in 2018 in participants with progressive and nonprogressive MS?

This study was informed by Stuijbergen's model<sup>6,7</sup> to predict health promotion and QOL in people with MS (Figure S1, which is published in the online version of this article at [ijmsc.org](http://ijmsc.org)). Health promotion, in line with the goals of rehabilitation and thus improved QOL, is defined as "activities directed toward increasing the level of well-being and actualizing the health potential of individuals, families, communities and societies."<sup>8</sup> The model proposes that health promotion is influenced by

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associated barriers and social supports after controlling for demographics and disease background. Consistent with Pender's definition,<sup>8</sup> health-promoting activities can increase well-being, thereby influencing health-related QOL.

Most previous health promotion studies have been conducted with people who have relapsing-remitting MS; research on health promotion for those with progressive MS is more limited. For example, people with relapse-onset MS who engage in more health promotion have a reduced risk of reaching an Expanded Disability Status Scale (EDSS) score of 6 (requires a cane).<sup>9</sup> A previous cross-sectional study conducted in 1996 found that women with benign sensory and relapsing-remitting MS reported more health promotion in physical activity and spiritual growth than did those with progressive MS.<sup>6</sup> Because these previous studies were cross-sectional, causal interpretations cannot be inferred. In contrast, the analysis conducted in the present longitudinal study could provide a stronger argument for the effect of the predictor variables on the QOL outcomes proposed herein, because the predictor variables were measured earlier in time than the outcome variables.

## Methods

### Recruitment and Data Collection

Data for this study are from the 21st (2017) and 22nd (2018) years of the longitudinal study Maximizing Health with MS.<sup>10</sup> The study sample was initially recruited in 1996 from a membership mailing list of two National Multiple Sclerosis Society chapters in Texas. Most of the current sample still live in Texas, but some have moved to other states. Recruitment of the initial sample is detailed elsewhere.<sup>6</sup> People were included in year 1 (1996) if they 1) had been diagnosed by a physician as having MS for at least 1 year, 2) were living in the community, and 3) were older than 18 years. This longitudinal study has continuing university institutional review board approval.

An introductory letter, a survey, and a postage-paid envelope were mailed to 336 participants in year 21 (2017) and 329 participants in year 22 (2018). Those who asked to be removed from the study or had their 2017 survey packet returned as undeliverable were not sent a survey packet in 2018. Follow-up letters were sent to individuals who did not return their questionnaires. Once the surveys had been returned, in an effort to obtain complete data, copies of pages with unanswered items were again mailed to respondents to solicit answers to missed items or reasons for leaving items blank.

In 2017, 236 surveys (70.2%) were returned. In 2018, 228 (69.3%) were returned. Only participants who responded in both years were included in the present study. Those who

reported "unable to choose one answer or don't know" for their type of MS course in 2018 were excluded. The final sample comprised 189 participants.

### Survey Data Collected

#### Background Information

Survey respondents had been asked about their age, sex, ethnicity, educational level, marital status, employment status, and diagnosis year in the first years of the study. The 2017 and 2018 surveys, therefore, collected only updated information on marital and employment status. The Self-Administered EDSS (EDSS-S)<sup>11</sup> was used to measure participants' impairments due to MS. The EDSS-S scores range from 0 (normal neurologic examination findings) to 9.5 (unable to communicate effectively or eat/swallow). The EDSS-S has shown strong correlations with physicians' ratings of MS-related disability ( $r = 0.87$ ).<sup>11</sup> The Economic Adequacy Scale<sup>12</sup> was used to evaluate the adequacy of family income to meet the needs of daily living, housing, food, health care, and recreation. The instrument's eight items are rated on a 4-point Likert scale from 1 = not at all to 4 = more than adequate. Higher mean scores indicate greater economic adequacy. The scale's validity is supported in previous research.<sup>13</sup> The Cronbach  $\alpha$  for the Economic Adequacy Scale was 0.97 for the present study.

#### MS Course

To be consistent with previous data collection categories, 2018 survey participants were provided with descriptions of five major courses of MS (benign sensory, relapsing-remitting, primary progressive, secondary progressive, and progressive relapsing) plus the option "unable to choose one answer or don't know the type of MS that best describes my experience."<sup>14</sup> The symptom patterns were described in both text and charts, and participants were asked to choose which response represented their experience with MS. In subsequent analyses, participants selecting the primary progressive, secondary progressive, and progressive relapsing categories were coded as having progressive MS; those selecting benign sensory or relapsing-remitting MS were coded as having non-progressive MS.

#### Incapacity Status Scale

A self-report version of the Incapacity Status Scale (ISS)<sup>15</sup> was used to evaluate functional impairments due to MS. The instrument's 16 items are rated on a 5-point scale, with higher scores indicating greater inability to perform activities; total scores range from 0 to 64. Previous research supports the scale's validity.<sup>15</sup> The Cronbach  $\alpha$  for the ISS in the present study was 0.86.

#### Perceived Stress Scale

Self-perceived stress was measured using the Perceived Stress Scale.<sup>16</sup> Its validity has been supported in individuals with MS.<sup>17</sup> The scale's ten items are rated from 0 = never to 4 = very often; total scores range from 0 to 40. The Cronbach  $\alpha$  for the Perceived Stress Scale in this study was 0.91.

#### Center for Epidemiologic Studies Depression Scale-10

The Center for Epidemiologic Studies Depression Scale-10<sup>18</sup> was used to measure levels of depressive symptoms. This

scale has been found to be reliable and valid in various populations, including those with MS.<sup>19</sup> Items are rated from 0 to 3, representing the frequency with which patients have experienced the scale's ten depressive symptoms in the past week. For this study, the Cronbach  $\alpha$  was 0.86.

### **Patient-Reported Outcomes Measurement Information System Version 1.0 Short Form**

The Patient-Reported Outcomes Measurement Information System (PROMIS) version 1.0 short form measures for Pain Interference (six items), Pain Intensity (three items), Fatigue (seven items), Sleep Disturbance (seven items), and Applied Cognition–Abilities (six items) were used to evaluate those symptoms. Higher scores represent greater levels of the measured symptoms or abilities.<sup>20</sup> The PROMIS scales' reliability and validity have been supported in different populations.<sup>21</sup> In the present study, the Cronbach  $\alpha$  ranged from 0.87 to 0.97.

### **Functional Comorbidity Index**

The Functional Comorbidity Index, which includes 18 diagnoses, was used to collect participants' self-reported comorbidities. This scale has shown higher associations with physical function than are found with the Charlson and Kaplan-Feinstein indexes.<sup>22</sup> It can be scored as a simple (yes/no) count of diagnoses.

### **Barriers to Health-Promoting Activities for Disabled Persons Scale**

The Barriers to Health-Promoting Activities for Disabled Persons Scale (Barriers henceforth in this article)<sup>23</sup> was used to measure barriers to health promotion. The scale's 18 items are rated on a 4-point scale from 1 = never to 4 = routinely. Total scores thus range from 18 to 72, with higher scores indicating greater barrier levels. The scale's validity is supported by the results of previous studies.<sup>10,23</sup> In the present study, the Cronbach  $\alpha$  for Barriers was 0.87.

### **Personal Resource Questionnaire**

The Personal Resource Questionnaire (PRQ)<sup>24</sup> was used to measure situational and perceived social support, such as with the item "There is someone I feel close to who makes me feel secure." The PRQ's validity has been supported in various populations.<sup>25</sup> Its 25 items are scaled from 1 = strongly disagree to 7 = strongly agree, with total scores ranging from 25 to 175. Higher scores indicate higher perceived social support. The Cronbach  $\alpha$  in the present study was 0.92.

### **Health-Promoting Lifestyle Profile II**

The Health-Promoting Lifestyle Profile II (HPLP II)<sup>26</sup> measures the frequency of health promotion activities. It consists of 52 items on six subscales (physical activity, health responsibility, spiritual growth, interpersonal relations, nutrition, and stress management). An example of the items is "Follow a planned exercise program." Participants are asked how often they have performed each activity on a scale from 1 to 4, where 1 = never, 2 = sometimes, 3 = often, and 4 = routinely. The scale's reliability and validity have been supported in previous MS research.<sup>9</sup> For the present study, the Cronbach

$\alpha$  ranged from 0.76 to 0.89 for the subscales and was 0.94 for the total score.

### **36-Item Short Form Health Survey**

The 36-item Short Form Health Survey (SF-36) (version 2) is a form developed to evaluate health status in clinical practice and research, health policy evaluations, and general population surveys.<sup>27</sup> Used to represent QOL in this study, three subscales were included. Role limitations due to physical problems, role limitations due to emotional problems, and social functioning are measured with four, three, and two items, respectively, thus representing QOL. These three subscales were chosen because they align well with Verbrugge and Jette's definition of disability outcomes.<sup>28</sup> These 5-point Likert scales are rated from 1 = all of the time to 5 = none of the time or from 1 = not at all to 5 = extremely. Transformed scores were calculated based on the developers' instructions. Higher scores mean better physical role, emotional role, and social functioning. The scale's validity is supported by a previous MS study.<sup>3</sup> In the present study, the Cronbach  $\alpha$  for the subscales ranged from 0.78 to 0.94.

### **Data Analysis**

Surveys were proofed for completeness and entered into IBM SPSS Statistics for Windows, version 25.0 (IBM Corp, Armonk, NY). Data entry was first checked for out-of-range values and then double checked with a random 10% of the sample. The error rate was less than 1%. Mean substitution was used to account for missing data on scales when a respondent left less than 15% missing items. Marital status was recoded as married/significant other or unmarried. Employment status was recoded as employed or unemployed.

Data for the predictor variables were taken from the 2017 survey. Data for MS course (so that MS categorization would reflect the most recent information available) and QOL outcome were taken from the 2018 survey. Independent two-tailed  $t$  tests and  $\chi^2$  tests were used to compare the sample characteristics by MS course. Listwise bivariate correlations were used to compare the associations between predictor variables and SF-36 subscale scores, separately for each MS course. Principal component factor analysis was used to create one standardized symptom cluster score to represent all measured symptoms, which included pain intensity and interference, fatigue, sleep disturbance, cognitive abilities, perceived stress, and depressive symptoms. This procedure avoided multicollinearity because these factors correlated among themselves with  $r > 0.3$ . The standardized Cronbach  $\alpha$  for the single symptom cluster was 0.89. Multivariate hierarchical regressions were then used to predict each SF-36 subscale outcome using selected predictor variables for the two MS course groups. Because of the sample size, the number of predictors was limited. The selection of predictor variables was based on the following: 1) the conceptual model,<sup>29</sup> 2) minimal missing data, and 3) good scale reliabilities. As is shown in Figure S1, demographic and disease trajectory variables, including years of education and MS ISS score in 2017, were input in the first step of the regression. Barriers score, symptom cluster score,



and social support (PRQ scores) in 2017 were input in the second step. The HPLP II total score in 2017, representing health promotion, was added in the third step. The SF-36 subscale scores for physical role limitations, emotional role limitations, and social functioning in 2018 were the outcome variables. Separate models were created for each of these three outcome variables. *T* tests were then used to compare parameter estimates and  $R^2$  between the models for those with progressive and nonprogressive MS. Alpha was set at  $P < .05$  for all analyses. Assumptions such as multicollinearity were not violated.

## Results

### Sample Description and Comparison by MS Course

Table S1 presents demographic characteristics for all the participants with MS and for the two MS courses separately. Most participants were female (88.4%), were older than 65 years (62.4%), had more than a high school education (59.9%), and had long-standing MS (mean time since diagnosis, 31.1 years). The participants had four comorbid conditions on average, and their EDSS scores were 6.8 and 4.9 for those with progressive and nonprogressive MS, respectively. Comparisons using *t* tests and  $\chi^2$  tests showed that participants with progressive MS were more likely to be male, with a significantly longer time since diagnosis, and had significantly higher EDSS total scores. Those with progressive MS reported significantly lower health promotion on the subscales for health responsibilities, physical activity, and spiritual growth, as well as on SF-36 Role Physical and Social Functioning (Table S2).

### Correlations with QOL by MS Course

Table S3 presents the correlations between the predictors and SF-36 subscale scores for the progressive and nonprogressive groups. Generally, the SF-36 Role Physical and Social Functioning subscale scores were significantly correlated with MS ISS, symptom experience, Barriers, PRQ, and HPLP II total scores for both groups. Greater MS incapacity, disabling symptom experience, and Barriers scores were associated with worse Role Physical, Role Emotional, and Social Functioning scores. The correlation values ranged from  $\pm 0.15$  to  $0.59$  and thus were weak to moderate for the progressive MS group. The correlations ranged from  $\pm 0.31$  to  $0.68$  (moderate to strong) for the nonprogressive MS group. Greater PRQ and HPLP scores were associated with better Role Physical and Social Functioning scores in both groups; PRQ and HPLP scores were associated with Role Emotional scores for those with nonprogressive MS. The correlation values ranged from  $0.30$

to  $0.42$  and thus were moderate for the progressive MS group. The correlations ranged from  $0.19$  to  $0.33$  (weak to moderate) for the nonprogressive MS group.

### Predicting QOL in Progressive and Nonprogressive MS

Tables 1 and 2 present the results of the hierarchical multivariate regressions to predict the SF-36 subscale scores separately for the two MS course groups. For physical role limitations measured in 2018, MS incapacity and symptom cluster measured in 2017 were significant predictors for both groups. Incapacity of MS was a stronger predictor for people with progressive MS, whereas symptom cluster was a stronger predictor for those with nonprogressive MS. Symptom cluster added significantly to the prediction of Role Emotional scores for both groups after entering education and ISS scores, and the Barriers total score was an additional significant predictor for people with nonprogressive MS. For the 2018 Social Functioning score, the Barriers total score was the only significant predictor for people with nonprogressive MS, and symptom cluster was the only significant predictor for those with progressive MS. The adjusted  $R^2$  values were all relatively higher (eg,  $0.45$  vs  $0.26$ ) for the nonprogressive group than for the progressive group. Although the Barriers, PRQ, and HPLP II total scores did not emerge as significant predictors for most SF-36 subscales for both groups in the multivariate regressions, they were mostly highly associated in the bivariate correlations. Because of multicollinearity, the shared variance of the Barriers, PRQ, and HPLP II total scores could be explained by other predictors in the same or previous steps in the hierarchical regressions.

$R^2$  comparisons showed that the variance explained by the models for the SF-36 subscale scores varied significantly by MS course. The models explained significantly more QOL variances for those with nonprogressive MS than for those with progressive MS (data not shown).

## Discussion

In this study, we explored health, health promotion, and QOL differences in relation to MS course in people aging with long-standing MS. People aging with different MS courses differed in their physical and social health as well as health responsibility, physical activity, and spiritual growth. The variance explained by health promotion in predicting QOL after controlling years of education, MS incapacity, barriers, symptom experiences, and social support also differed by MS course. Consistent with previous research, however, there was

**Table 1. Hierarchical multivariate regressions for SF-36 subscale scores for progressive MS ( $n_1 = 68$ )**

Final model estimate	<i>B</i>	<i>SE</i>	$\beta$	<i>t</i>	<i>P</i>	Adj <i>R</i> <sup>2</sup>
<b>Year 22 (2018) SF-36 Role Physical</b>						0.26
Constant	21.62	42.14		0.51	.61	
Years of education	0.47	1.26	.04	0.37	.71	
Year 21 (2017) MS incapacity	-1.16	0.43	-.34	-2.68	.01 <sup>a</sup>	
Year 21 (2017) Barriers total score	0.55	0.54	.15	1.03	.31	
Year 21 (2017) symptom cluster	-10.36	4.43	-.33	-2.34	.02 <sup>b</sup>	
Year 21 (2017) PRQ total score	-0.09	0.23	-.07	-0.42	.68	
Year 21 (2017) HPLP II total score	0.28	0.21	.20	1.36	.18	
<b>Year 22 (2018) SF-36 Role Emotional</b>						0.17
Constant	102.15	43.33		2.36	.02 <sup>b</sup>	
Years of education	1.62	1.29	.15	1.25	.22	
Year 21 (2017) MS incapacity	-0.43	0.44	-.13	-0.96	.34	
Year 21 (2017) Barriers total score	-0.40	0.55	-.11	-0.72	.47	
Year 21 (2017) symptom cluster	-11.03	4.56	-.36	-2.42	.02 <sup>b</sup>	
Year 21 (2017) PRQ total score	-0.23	0.23	-.17	-1.00	.32	
Year 21 (2017) HPLP II total score	-0.01	0.21	-.01	-0.03	.98	
<b>Year 22 (2018) SF-36 Social Functioning</b>						0.30
Constant	27.44	43.62		0.63	.53	
Years of education	-0.19	1.30	-.02	-0.15	.88	
Year 21 (2017) MS incapacity	-0.86	0.45	-.24	-1.93	.06	
Year 21 (2017) Barriers total score	0.34	0.56	.08	0.60	.55	
Year 21 (2017) symptom cluster	-12.45	4.59	-.37	-2.71	.01 <sup>a</sup>	
Year 21 (2017) PRQ total score	0.21	0.24	.14	0.87	.39	
Year 21 (2017) HPLP II total score	0.13	0.21	.09	0.61	.54	

Note: Listwise deletion.

Abbreviations: Adj, adjusted; Barriers, Barriers to Health-Promoting Activities for Disabled Persons Scale; HPLP II, Health-Promoting Lifestyle Profile II; MS, multiple sclerosis; PRQ, Personal Resource Questionnaire; SF-36, 36-item Short Form Health Survey.

<sup>a</sup> $P < .01$ .

<sup>b</sup> $P < .05$ .

generally a moderate relationship between health promotion and QOL.<sup>6</sup> Although this was an observational study, the inferences that could be drawn about the relationships with QOL measured the following year are stronger in such a longitudinal study than what could be inferred from a cross-sectional design.

The higher proportion of men in the progressive group was consistent with previous findings that the course of MS proceeds faster in men than in women.<sup>30</sup> Differences in time since diagnosis and EDSS total scores could be explained by differences between progressive and nonprogressive MS course. People with progressive MS in the study by Rooney et al<sup>2</sup> also reported significantly more time since diagnosis. Otherwise, demographic differences between those with progressive and those with nonprogressive MS were not statistically significant. In year 22 (2018), people with nonprogressive MS also reported significantly higher health responsibility than did those with progressive MS. Perhaps people with nonprogressive MS are more likely to be taking disease-modifying medications, so they

see their providers more often and are more attuned to monitoring their bodies' reactions to those medications. Differences in physical role limitations and social functioning were consistent with previous research.<sup>3</sup> Perhaps the more similar emotional scores could be explained by similar levels of support from interpersonal relationships and personal resources, which were seen herein (data not shown).

Symptom cluster was a general predictor for QOL subscales except for the social functioning of people with progressive MS, indicating a need for better symptom management in both groups. The different strengths of the symptom cluster and MS incapacity in predicting physical functioning in the two groups could be explained by the different scale content foci and emphases. For example, sleep disturbance was measured only within the symptom cluster, and vision was measured only by the MS ISS. The MS ISS mainly captured the limitations in function due to the symptoms of MS, whereas the symptom cluster captured general daily symptom experience. People with nonprogressive MS

**Table 2. Hierarchical multivariate regressions for SF-36 subscale scores for nonprogressive MS ( $n_2 = 107$ )**

Final model estimate	B	SE	$\beta$	t	P	Adj R <sup>2</sup>
<b>Year 22 (2018) SF-36 Role Physical</b>						0.45
Constant	101.17	27.74		3.65	.00 <sup>a</sup>	
Years of education	0.70	0.86	.06	0.82	.42	
Year 21 (2017) MS incapacity	-0.86	0.40	-.23	-2.14	.04 <sup>b</sup>	
Year 21 (2017) Barriers total score	-0.01	0.39	-.00	-0.03	.98	
Year 21 (2017) symptom cluster	-15.31	3.13	-.60	-4.89	.00 <sup>a</sup>	
Year 21 (2017) PRQ total score	-0.10	0.14	-.08	-0.76	.45	
Year 21 (2017) HPLP II total score	-0.15	0.13	-.12	-1.12	.27	
<b>Year 22 (2018) SF-36 Role Emotional</b>						0.35
Constant	90.10	30.05		3.00	.00 <sup>c</sup>	
Years of education	0.47	0.93	.04	0.50	.62	
Year 21 (2017) MS incapacity	-0.19	0.44	-.05	-0.44	.66	
Year 21 (2017) Barriers total score	-0.89	0.42	-.24	-2.09	.04 <sup>b</sup>	
Year 21 (2017) symptom cluster	-9.67	3.39	-.38	-2.85	.01 <sup>c</sup>	
Year 21 (2017) PRQ total score	0.20	0.15	.15	1.34	.18	
Year 21 (2017) HPLP II total score	-0.16	0.14	-.13	-1.11	.27	
<b>Year 22 (2018) SF-36 Social Functioning</b>						0.38
Constant	103.34	26.66		3.88	.00 <sup>a</sup>	
Years of education	-0.04	0.82	-.00	-0.05	.96	
Year 21 (2017) MS incapacity	-0.55	0.39	-.16	-1.41	.16	
Year 21 (2017) Barriers total score	-1.14	0.38	-.34	-3.03	.00 <sup>c</sup>	
Year 21 (2017) symptom cluster	-4.62	3.01	-.20	-1.54	.13	
Year 21 (2017) PRQ total score	0.11	0.13	.09	0.86	.39	
Year 21 (2017) HPLP II total score	-0.04	0.13	-.03	-0.30	.76	

Note: Listwise deletion.

Abbreviations: Adj, adjusted; Barriers, Barriers to Health-Promoting Activities for Disabled Persons Scale; HPLP II, Health-Promoting Lifestyle Profile II; MS, multiple sclerosis; PRQ, Personal Resource Questionnaire; SF-36, 36-item Short Form Health Survey.

<sup>a</sup> $P < .001$ .

<sup>b</sup> $P < .05$ .

<sup>c</sup> $P < .01$ .

have relatively less impairment than do those with progressive MS, so the general symptom cluster could have weighed more heavily in influencing their QOL.

The increase in impairment that characterizes progressive MS can affect the individual's ability to promote their health in multiple ways. For example, being physically active may become more difficult as mobility impairment increases, and the challenges of carrying out activities of daily living may increase depression and stress. Providers need to be particularly proactive and creative in helping their patients with progressive MS find the supports and resources they need to maximize their health.

Stuifbergen's model predicted the QOL scores better for those with nonprogressive MS than for those with progressive MS. This is similar to the findings from previous research in which health promotion reduced the risk of reaching EDSS scores of 6 for people with relapsing onset, but in which no significant associations were found for progressive-onset MS.<sup>9</sup> However, the

definition and categorization of MS onset courses in that study were different from the progression courses in the present study. Future examination of the present longitudinal data using similar survival analysis<sup>8</sup> could explore whether health promotion reduces the progression of functional limitations by MS courses. In addition, future research should examine the relative contribution of different aspects of health promotion to the prediction of QOL in such hierarchical models. A need also remains for further exploration of other factors that may influence QOL in people with progressive MS.

## PRACTICE POINTS

- People with progressive versus nonprogressive MS courses may experience differences in health promotion and quality-of-life outcomes.
- Symptom management should be a key focus of health providers and others working with people with MS.

This study has certain limitations. First, we used a convenience sample recruited primarily through the MS Society in one state, although some participants have moved to other states. Most participants were non-Hispanic White and relatively well-educated, with 59.6% having some postsecondary education, which may limit generalizability to other people with MS. Future studies will require more diverse samples recruited from other states using other recruitment methods. Second, the potential biases of self-report measures are present. Due to recall bias, annual data collection may not accurately represent the disease's progression throughout an entire year. Future studies could include more frequent measures of MS symptoms. In addition, if participants had not recently discussed their MS course with physicians, they may not have been able to report their MS course accurately. Finally, the participants in this 23-year longitudinal study were "survivors." They might, therefore, report greater health promotion and QOL than would other groups of individuals with MS.

In conclusion, one of the characteristics of MS is the variability of the symptom experience.<sup>1</sup> People with long-standing MS also experience different courses. Differences between these courses may have contributed to the differences in health promotion and QOL outcomes observed in this study. Because symptom cluster was generally a significant predictor of QOL in both groups, symptom management should be a key focus of health providers and others working with people with MS. The scope of symptom management for people with progressive MS should be broader and not limited only to symptoms typically associated with MS. Nonpharmaceutical therapies targeting symptoms such as fatigue could be considered and are being addressed in several ongoing studies of MS.<sup>31</sup> Our study finding supports these many ongoing studies. □

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## References

- National Multiple Sclerosis Society website. <https://www.nationalmssociety.org/>. Accessed June 19, 2019.
- Rooney S, Wood L, Moffat F, Paul L. Prevalence of fatigue and its association with clinical features in progressive and non-progressive forms of multiple sclerosis. *Mult Scler Relat Disord*. 2019;28:276-282.
- Chow HH, Schreiber K, Magyari M, et al. Progressive multiple sclerosis, cognitive function, and quality of life. *Brain Behav*. 2018;8:e00875.
- Zhang Y, Taylor BV, Simpson S Jr, Blizzard L, van der Mei I. Patient-reported outcomes are worse for progressive-onset multiple sclerosis than relapse-onset multiple sclerosis, particularly early in the disease process. *Eur J Neurol*. 2019;26:155-161.
- International Progressive MS Alliance website. <https://www.progressivemsa.org/progressive-ms/the-condition/>. Accessed June 15, 2020.
- Stuifbergen AK, Roberts GJ. Health promotion practices of women with multiple sclerosis. *Arch Phys Med Rehabil*. 1997;78(suppl 5):S3-S9.
- Stuifbergen AK, Rogers S. Health promotion: an essential component of rehabilitation for persons with chronic disabling conditions. *Adv Nurs Sci*. 1997;19:1-20.
- Pender NJ. *Health Promotion in Nursing Practice*. Appleton & Lange; 1987.
- D'hooghe MB, Nagels G, De Keyser J, Haentjens P. Self-reported health promotion and disability progression in multiple sclerosis. *J Neurol Sci*. 2013;325:120-126.
- Stuifbergen AK, Blozis S, Becker H, Harrison T, Kullberg V. Selected health behaviors moderate the progression of functional limitations in persons with multiple sclerosis: eleven years of annual follow-up. *Disabil Health J*. 2016;9:472-478.
- Bowen J, Gibbons L, Gianas A, Kraft GH. Self-administered Expanded Disability Status Scale with functional system scores correlates well with a physician-administered test. *Mult Scler*. 2001;7:201-206.
- Lobo ML. *Mother's and Father's Perceptions of Family Resources and Marital Adjustment and Their Adaptation to Parenthood* [dissertation]. Seattle: University of Washington; 1982.
- Becker H, Kang SJ, Stuifbergen A. Predictors of quality of life for long-term cancer survivors with pre-existing disabling conditions. *Oncol Nurs Forum*. 2012;39:E122-E131.
- Schapiro RT. *Multiple Sclerosis: A Rehabilitation Approach to Management*. Demos Publications; 1991.
- Kurtzke JF. A proposal for a uniform minimal record of disability in multiple sclerosis. *Acta Neurol Scand*. 1981;64:110-129.
- Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav*. 1983;24:385-396.
- Strober LB, Arnett PA. Unemployment among women with multiple sclerosis: the role of coping and perceived stress and support in the workplace. *Psychol Health Med*. 2016;21:496-504.
- Radloff LS. The CES-D Scale: a self-report depression scale for research in the general population. *Appl Psychol Meas*. 1977;1:385-401.
- Zhang W, Becker H, Stuifbergen AK, Brown A. Predicting health promotion and quality of life with symptom clusters and social supports among older adults with multiple sclerosis. *J Gerontol Nurs*. 2017;43:27-36.
- PROMIS. Northwestern University HealthMeasures website. <http://www.healthmeasures.net/explore-measurement-systems/promis>. Updated 2019.
- Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Med Care*. 2007;45(suppl 1):S3-S11.
- Groll DL, To T, Bombardier C, Wright JG. The development of a comorbidity index with physical function as the outcome. *J Clin Epidemiol*. 2005;58:595-602.
- Stuifbergen AK, Becker H, Sands D. Barriers to health promotion for individuals with disabilities. *Fam Community Health*. 1990;13:11-22.
- Brandt PA, Weinert C. The PRQ—a social support measure. *Nurs Res*. 1981;30:277-280.
- Weinert C, Brandt PA. Measuring social support with the Personal Resource Questionnaire. *West J Nurs Res*. 1987;9:589-602.
- Walker SN, Sechrist KR, Pender NJ. Health Promoting Lifestyle Profile II. <https://www.unmc.edu/nursing/faculty/health-promoting-lifestyle-profile-ii.html>.
- Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I: conceptual framework and item selection. *Med Care*. 1992;30:473-483.
- Verbrugge LM, Jette AM. The disablement process. *Soc Sci Med*. 1994;38:1-14.
- Stuifbergen AK, Seraphine A, Roberts G. An explanatory model of health promotion and quality of life in chronic disabling conditions. *Nurs Res*. 2000;49:122-129.
- Bergamaschi R. Prognostic factors in multiple sclerosis. *Int Rev Neurobiol*. 2007;79:423-447.
- Byrnes KL, Whillier S. Effects of nonpharmaceutical treatments on symptom management in adults with mild or moderate multiple sclerosis: a meta-analysis. *J Manipulative Physiol Ther*. 2019;42:514-531.