



Comparative study of PROMIS[®] self-efficacy for managing chronic conditions across chronic neurologic disorders

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Abstract

Purpose Self-efficacy (SE) for managing chronic conditions is the belief that one can carry out behaviors to reach health goals. The study objective is to investigate (1) SE for managing chronic conditions across diverse neurologic conditions, (2) demographic and disease determinants of SE, and (3) SE as a predictor of health and disability.

Methods Patients with chronic neurologic conditions (epilepsy, multiple sclerosis, neuropathy, Parkinson disease, stroke; $n = 834$) completed five SE for Managing Chronic Conditions instruments (Patient-Reported Outcomes Measurement Information System[®]; PROMIS[®]). Other assessments included PROMIS depression, fatigue, physical function, and global health.

Results Two of the five SE domains showed differences across the five disorders (ANOVA; SE for Managing Daily Activities $p < .001$ and Managing Symptoms $p < .01$). The three domains with no differences were Managing Medications/Treatments, Emotions, and Social Interactions. Lowest SE was in neuropathy, and highest in epilepsy (Managing Activities) and stroke (Managing Symptoms). Multivariate regression showed SE measures to be better predictors of mental health, global health, and disability than either disease severity or diagnosis.

Conclusions SE for managing chronic conditions differs across neurologic disorders, with lowest SE for managing activities and symptoms in neuropathy, and highest in patients with epilepsy and stroke. PROMIS SE measures are better predictors of mental health, disability, and quality of life than disease severity or diagnosis.

Keywords Self-efficacy · Self-management · Chronic neurologic disorders · Neuropathy · Disability · Quality of life

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Introduction

Self-efficacy (SE) is the belief that one can carry out behaviors necessary to reach desired goals, even when situations contain unpredictable and stressful elements [1, 2]. SE is a major determinant of human behavior and a key mediator of the acquisition of self-management skills in chronic disease. SE for managing chronic conditions is associated with better health outcomes and well-being in many conditions including arthritis, diabetes, multiple sclerosis (MS), Parkinson disease (PD), and spinal cord injury [3–8]. These results support Bandura's theory that perception of capabilities may be more predictive of function than actual level of impairment [9].

We describe a new analysis of data collected during the development and validation of new measures of SE for managing chronic conditions [10]. These measures were developed for the Patient-Reported Outcomes Measurement Information System (PROMIS[®]; NIH U01AR057967-01). PROMIS measures patient-reported health status for

physical, mental, and social well-being across diverse chronic conditions [11]. The PROMIS domain, SE for Managing Chronic Conditions was defined as an individual's confidence in his/her ability to successfully perform specific tasks or behaviors related to one's health in a variety of situations.

Learning self-management skills is essential for healthy adjustment to chronic conditions [12–14]. Since many self-management skills are similar across chronic disorders, it is unclear whether the level of SE for self-management is stable across chronic conditions, or whether diverse symptom profiles affect the level of SE. When SE was measured with a 15 item version of the SE for Managing Chronic Disease Scale [15, 16] in three medical conditions (asthma, diabetes, heart failure), differences in the level of SE were seen across conditions based on two derived factors: SE *to achieve desired health outcomes* and SE in performing behaviors *to control the illness* [17]. SE for carrying out behaviors *to control the illness* was greatest in heart failure, least in asthma and intermediate in diabetes. However, the three groups were equally confident in carrying out behaviors *to achieve desired outcomes*. Depression was greatest in heart failure and least in diabetes. Diabetics reported best physical health, while those with heart failure reported the worst. These studies show that diverse features in chronic conditions are associated with different effects on SE.

The study objectives are (1) to investigate differences in SE for managing chronic conditions in diverse chronic neurologic disorders, (2) to assess differences in SE by demographic and disease-related variables, and (3) to examine the ability of SE to predict health and disability beyond measures of disease severity.

Methods

Study participants

A total of 834 subjects with chronic neurologic disorders completed the PROMIS SE for Managing Chronic Conditions instruments. Participants were recruited from the University of Maryland Neurology Care Center. Five chronic neurologic conditions were assessed: epilepsy, MS, PD, peripheral neuropathy, and stroke (data collected April 2013–April 2014). Eligibility criteria were broad to minimize bias. For inclusion, patients were greater than 18 years of age and diagnosed with one of these five neurologic conditions. The final sample of 834 patients was from a pool of 16,780 patients scheduled to visit the Neurology Care Center. Of 2860 confirmed eligible, 845 patients enrolled and 834 were analyzed. Reasons for non-participation included ineligible diagnosis, no shows, language barrier, and patient refusal.

Standard protocol approvals, registrations, and patient consents

This study was approved by the institutional review boards of the University of Maryland (#HP-000432550), the Medical University of South Carolina (#Pro00033397), and the University of Florida (#261–2010). Written informed consent was obtained from all participants or their guardians.

The self-efficacy for managing daily activities item pool

The initial item pool was developed using qualitative research methodology approved by PROMIS, including review of literature on SE scales, development of an item library, and binning and winnowing items [18]. A modified Delphi process comprised of recognized SE experts and focus groups of patients with chronic conditions was used to prioritize five SE domains. Over 1000 potential questionnaire items drawn from the literature and focus groups were reviewed by the research team and final items were reviewed in cognitive interviews with 30 patients [18, 19]. The five domains are SE for: (1) Managing Daily Activities (36 items), (2) Managing Symptoms (28 items), (3) Managing Medications and Treatments (27 items), (4) Managing Emotions (28 items), and (5) Managing Social Interactions (24 items). Item banks were developed using item response theory procedures outlined by Reeve and colleagues [19].

The SE for Managing Chronic Conditions item banks assess patient-reported, current level of confidence performing activities and behaviors involved in routine management of chronic disease. The item banks are generic rather than disease-specific, instructing the subject to consider all health conditions and all symptoms in their responses. Responses are on a five-point rating scale: 1 (I am not at all confident); 2 (I am a little confident); 3 (I am somewhat confident); 4 (I am quite confident); and 5 (I am very confident).

Since the focus of the domain is on managing chronic illness, the sample used to derive the distribution to develop the PROMIS SE item banks, was a clinical sample comprised of participants with at least one chronic condition from two sources: (1) the UM Neurology Care Center and (2) a US-based internet panel. Therefore, the theta values were converted into T-scores designated as “ T_{clin} ” with average 50 and standard deviation ten for this US clinical population.

For this study, patient-reported assessments included the five PROMIS SE item banks, the SEMCD6 [15], PROMIS version 1.0 short forms measuring depression,

anxiety, fatigue (eight items), physical function (12 items), global physical and mental health (four items each), and medical co-morbidities (number of conditions). Physician-reported assessments included disease severity (none, mild, moderate/severe), disease duration (years), time course (stable, episodic, progressive), modified Rankin Scale, and Barthel Index.

Data analysis

Overall descriptive statistics and differences across diagnostic groups for demographics were examined with chi-squares and *t* tests. ANOVAs across diagnostic group categories were conducted for each of the SE measures. Determinants of SE were investigated based on demographics, disease severity, presence of falls, medical co-morbidities and disease time course through general linear models, adjusting for disease type. Hierarchical general linear models predicting scores on the six PROMIS short forms were performed for depression, anxiety, fatigue, physical function, global physical health, and global mental health. Nesting accounted for 1) severity and diagnosis, 2a) adding PROMIS SE measures to severity and diagnosis, and 2b) adding the SEMCD6 legacy measure to severity and diagnosis. Cases with missing data were dropped from analyses, including three patients with no SE measures dropped from all analyses, and individual cases dropped in selected analyses depending on specific variables.

Results

The total sample of 834 patients comprised five chronic neurologic disorders: epilepsy ($n = 170$), MS ($n = 164$), neuropathy ($n = 165$), PD ($n = 169$), and stroke ($n = 166$). Table 1 describes the demographics for the total and individual groups. Demographics differed across the five disorders for age, gender, race, education, income, and employment. The youngest subjects were from epilepsy and MS, and the oldest from PD. The majority of the UM sample was female (58%) with only PD showing male predominance. Socioeconomic status (SES) was lowest in stroke (where racial diversity was greatest) and highest in PD (with the least racial diversity). Disease severity, disease duration, and level of disability also differed across the conditions. Greatest disability was in MS (Barthel) and PD (Rankin) while the least disability was in epilepsy (Barthel) and stroke (Barthel, Rankin). Pronounced differences in co-morbidities were seen with greatest prevalence of hypertension and heart disease in stroke, and increased diabetes and sleep disturbance in neuropathy. MS patients were most likely to report falling, while stroke patients were least likely. PD was most often rated as progressive, MS as episodic, and stroke as stable.

Comparison of PROMIS self-efficacy for managing chronic conditions across disorders

Comparing across five neurologic disorders, the level of SE differed for two domains, Managing Daily Activities and Managing Symptoms (Global $p < .0001$ and $< .01$ respectively), with no differences for three domains: Managing Medications/Treatments, Emotions, and Social Interactions (Table 2). These results remained significant when controlling for age, gender, race, and SES. For Managing Daily Activities, the lowest SE was found for neuropathy (48.0 (9.1)) and the highest for epilepsy (54.2 (8.5)). For Managing Symptoms, the lowest SE was also for neuropathy (48.7 (9.7)), and the highest was for stroke (52.3 (9.9)).

Based on the SEMCD6 [15], SE differed across the five diagnostic groups ($p < .0001$) with neuropathy patients reporting the lowest ratings (41.9 (13.6)) and epilepsy patients the highest (48.6 (10.9)). The SEMCD6 results were most similar to the PROMIS Managing Daily Activities domain.

Determinants of SE were investigated based on demographics, disease severity, presence of falls, co-morbidities, and disease time course. The strongest demographic effects on SE were seen for race, income, and employment, where significant effects were seen in all five SE domains (Table 3). Greater medical co-morbidity also had pervasive effects on all five SE domains ($p < .001$). Elderly patients (65+) reported greater SE for managing emotions and social interactions than younger patients. Greater disease severity and the presence of falls was associated with lower SE across the total sample ($p < .001$). Disease time course (stable, episodic, progressive) was associated with two SE domains: Managing Daily Activities ($p < .001$) and Symptoms ($p < .05$), with lowest SE in progressive time course. Determinants of SE by domain and diagnosis are described in Supplemental Table 1.

Comparison of PROMIS measures of depression, anxiety, fatigue, global health, and disability across neurologic disorders

Comparing the results of the PROMIS short forms (Physical Function, Depression, Anxiety, Fatigue, and Global Health; Table 2), physical function differed across the five disorders ($p < .0001$). All disorders except epilepsy (mean t-score 52.3 (9.4)) scored 0.5 SD or below (worse) than the US general population (t-scores 41.4–45.1 (8.5–12.0)). Nearly three-quarters of neuropathy patients reported poor physical function. Comparing depression, anxiety, and fatigue, only fatigue differed across the five disorders ($p < .001$). Again epilepsy is the outlier, with the only rating better than the US normative population. Depression and anxiety ratings for the five disorders were similar to the mean of the US

Table 1 Demographics by diagnostic group

	Total	Epilepsy	MS	Neuropathy	PD	Stroke
Sample size	834	170	164	165	169	166
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age	54.5 (14.7)	43.8 (14.9)	48.2 (11.5)	58.4 (12.2)	66.3 (9.7)	55.6 (13.2)*
Disease duration	10.0 (10.6)	19.6 (16.2)	11.4 (7.2)	5.9 (6.7)	8.5 (5.0)	4.6 (6.3)*
Modified Rankin	2.0 (1.3)	1.7 (1.3)	2.2 (1.4)	2.1 (1.2)	2.5 (1.0)	1.4 (1.1)*
Barthel Index	19.3 (2.1)	19.9 (0.5)	18.4 (3.3)	19.3 (1.8)	19.2 (2.1)	19.6 (1.3)*
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Gender						
Male	358 (43.0)	72 (42.4)	28 (17.1)	86 (52.1)	107 (63.3)	65 (39.6)*
Female	474 (57.0)	98 (57.7)	136 (83.0)	79 (47.9)	62 (36.7)	99 (60.4)
Disease severity						
No impairment	184 (22.0)	53 (31.2)	38 (23.3)	28 (17.5)	12 (7.1)	53 (32.1)*
Mild impairment	372 (45.4)	75 (44.1)	55 (33.7)	73 (45.6)	87 (51.8)	82 (49.7)
Mod/severe impairment	272 (32.5)	42 (24.7)	70 (42.9)	59 (36.9)	69 (41.1)	30 (18.2)
Education						
≤ High school	170 (21.1)	36 (22.6)	32 (19.8)	36 (22.2)	16 (9.6)	50 (31.6)*
Some college+	637 (78.9)	123 (77.4)	130 (80.2)	126 (77.8)	150 (90.4)	108 (68.4)
Race						
White	597 (71.8)	109 (65.3)	110 (67.1)	126 (76.4)	154 (91.7)	98 (59.4)*
Non-white	232 (28.2)	58 (34.7)	54 (32.9)	39 (23.6)	14 (8.3)	67 (40.6)
Marital status						
Married	484 (59.8)	72 (44.7)	87 (54.0)	103 (63.6)	138 (81.7)	84 (52.8)*
Not married	325 (40.2)	89 (55.3)	74 (46.0)	59 (36.4)	28 (16.9)	75 (47.2)
Employment						
Employed	334 (39.9)	92 (54.1)	88 (53.7)	52 (31.5)	44 (26.0)	58 (34.9)*
Not employed	500 (60.1)	78 (45.9)	76 (46.3)	113 (68.5)	125 (74.0)	108 (65.1)
Household income						
≤ \$60k	333 (43.7)	80 (54.8)	72 (46.5)	72 (46.2)	35 (21.6)	74 (51.7)*
> 60k	429 (56.3)	66 (45.2)	83 (53.5)	84 (53.8)	127 (78.4)	69 (48.3)
Co-morbidities						
Average #	3.9 (2.5)	3.2 (2.5)	3.1 (2.1)	5.2 (2.8)	3.4 (2.0)	4.7 (2.6)*
1	148 (18.0)	49 (29.2)	38 (23.2)	11 (6.7)	33 (19.5)	17 (10.2)
2–3	266 (31.8)	59 (25.1)	69 (42.1)	39 (23.6)	60 (35.5)	39 (23.5)
4–5	224 (26.8)	37 (22.0)	36 (22.0)	40 (24.2)	51 (30.2)	58 (34.9)
6	196 (23.4)	23 (13.7)	21 (12.8)	75 (45.5)	25 (14.8)	52 (31.3)
Faller						
No	620 (76.8)	129 (81.7)	108 (66.7)	126 (77.8)	124 (74.7)	133 (83.7) (<i>P</i> = .003)
Yes	187 (23.2)	29 (18.4)	54 (33.3)	36 (22.2)	42 (25.3)	26 (16.4)
Time course						
Stable	371 (44.8)	40 (23.5)	74 (45.4)	90 (56.3)	17 (10.1)	151 (91.0)*
Episodic	217 (26.1)	130 (6.5)	68 (41.7)	9 (5.6)	0	10 (6.0)
Progressive	239 (29.0)	0	21 (12.9)	61 (38.1)	152 (89.9)	5 (3.0)

**P* < .001 from ANOVA for continuous variables (age, disease duration, modified Rankin, and Barthel Index); and from chi square for all others

Table 2 Comparison of PROMIS SE, mental health, global health, and function across five neurologic conditions

	Total sample <i>N</i> =834	Epilepsy <i>N</i> =170	MS <i>N</i> =164	Neuropathy <i>N</i> =165	PD <i>N</i> =169	Stroke <i>N</i> =166
SE managing daily activities	50.5 (9.5)	54.1 (8.5)	49.1 (10.5)	48.0 (9.1)	50.6 (9.6)	50.8 (8.9)**
SE managing symptoms	50.6 (9.5)	51.5 (9.5)	50.6 (9.5)	48.7 (9.7)	49.6 (8.4)	52.3 (9.9)*
SE managing meds/treatments	50.6 (8.9)	51.2 (8.5)	50.4 (8.8)	50.6 (9.4)	50.5 (9.4)	50.4 (8.4)
SE managing emotions	51.3 (9.6)	52.2 (9.7)	50.7 (10.1)	50.6 (9.9)	52.0 (9.0)	51.2 (9.5)
SE managing social interactions	51.6 (8.8)	51.9 (8.3)	50.9 (9.1)	50.7 (9.4)	51.4 (8.7)	53.0 (8.5)
Anxiety	50.3 (9.7)	50.5 (10.1)	51.2 (9.4)	49.5 (10.1)	49.8 (9.0)	50.6 (9.8)
Depression	48.0 (9.4)	49.1 (9.7)	48.8 (10.2)	47.7 (9.2)	46.6 (8.1)	47.9 (9.6)
Fatigue	51.7 (10.2)	47.5 (9.5)	53.3 (10.7)	54.5 (11.4)	52.4 (8.9)	50.9 (8.7)**
Global mental health	46.9 (10.5)	46.9 (10.8)	46.6 (11.6)	46.4 (10.5)	48.3 (9.2)	46.1 (10.4)
Global physical health	49.6 (8.3)	53.6 (7.8)	48.7 (8.8)	45.9 (8.3)	50.2 (7.3)	49.7 (7.3)**
Physical function	45.1 (10.5)	52.3 (9.4)	42.7 (12.0)	41.4 (8.5)	43.9 (9.0)	45.2 (9.7)**

PROMIS SE scores are T_{clin} scores (US chronic conditions sample); all other PROMIS measures are T-scores (US population sample)

* $p < .01$ and ** $p < .001$ for ANOVA across neurologic conditions

population (all $< \frac{1}{2}$ SD). Comparing global health across the disorders, global physical health but not mental health differed ($p < .001$); epilepsy had the best global physical health (53.77 (7.8)) and neuropathy the worst (45.9 (8.3)). Global mental health was similar for all disorders, ranging from 46.1 (10.4)–48.3 (9.2).

Self-efficacy as a determinant of mental health, global health, and disability

Multivariate regression analyses (Supplemental Table 2) showed the PROMIS SE measures to be better predictors of mental health, global health, and disability than either disease severity or diagnosis. Severity and diagnosis predicted 3–27% of the variance (Model 1), while models with PROMIS SE measures predicted 40–71% of the variance, adding 31–47% to the overall explained variance (Model 2a). Among all PROMIS SE measures, the domain Managing Emotions predicted all outcomes, including function and mental health. Fatigue was the only outcome predicted by all SE domains, and was the only outcome where SEMCD6 slightly outperformed the PROMIS measures in explaining the variance (Model 2b).

Discussion

This study investigated differences in SE for managing chronic conditions across diverse neurologic disorders. Differences in levels of SE were found for two of the five SE domains, SE for Managing Daily Activities and Managing Symptoms. Differences in SE were not found for Managing Medications/Treatments, Emotions, and Social Interactions. Disease-related differences in treatments such as

anticoagulation (stroke), IV infusions (MS), and frequent dosing (PD) did not result in differences in patient confidence to manage treatments. Similarly, differences in symptoms including tremor, ataxia, paresis, seizure, and pain, did not result in differences in confidence in managing social interactions or emotions.

The five neurologic disorders are chronic conditions with a mixture of similarities and differences that are likely to result in different perceptions of SE. All conditions require adherence to treatment regimens, but vary in terms of symptoms, age of onset, medical co-morbidities, time course, and prognosis. Neuropathy results in subjective symptoms of pain and discomfort, while PD patients experience observable symptoms including tremor. Patients with epilepsy, stroke and MS often improve over time and may return to baseline function following diagnosis. In contrast, PD and neuropathy are generally partially treated with current therapy.

There are few studies comparing SE across chronic conditions. In a comparison of MS and spinal cord injury (SCI), MS resulted in lower SE and greater depression and helplessness than SCI; the authors concluded this was related to greater variability of MS symptoms and differences in time course [4]. There was no difference in SE between cancer and general chronic conditions, although both groups scored relatively low [20]. When SE in PD was compared with psychogenic movement disorders, psychogenic patients reported worse SE on all domains [21].

The gravity of the patient experience of neuropathy may be unexpected to clinicians and other health specialists. Neuropathy patients described the poorest physical function and global physical health, and greatest fatigue. These experiences are likely to underlie neuropathy patient reports of lowest SE for Managing both Activities and Symptoms. Neuropathy was associated with greatest medical co-morbidity (greater than stroke), including highest proportion of

Table 3 Determinants of PROMIS SE for managing chronic conditions measures by domain

	Sample size <i>N</i>	Self-efficacy for managing daily activities	Self-efficacy for managing symptoms	Self-efficacy for managing medications & treatments	Self-efficacy for managing emotions	Self-efficacy for managing social interactions
Age		ns	*	ns	***	***
18–49	282	51.6 (9.4)	50.7 (10.1)	50.4 (8.5)	50.6 (9.7)	51.4 (8.8)
50–64	314	49.4 (10.0)	49.8 (9.4)	50.2 (9.0)	50.5 (9.9)	50.6 (9.2)
65	225	50.9 (8.9)	51.4 (8.7)	51.4 (9.3)	53.4 (8.8)	53.3 (8.1)
Race		***	*	***	**	**
Non-white	232	47.5 (9.8)	48.8 (10.6)	48.0 (9.3)	49.3 (10.2)	50.0 (9.5)
White	597	51.8 (9.2)	51.1 (9.0)	51.8 (8.5)	51.8 (9.4)	52.1 (8.5)
Gender		***	ns	ns	*	ns
Men	358	51.9 (9.3)	50.5 (8.8)	50.6 (9.1)	52.4 (9.2)	52.0 (8.5)
Women	474	49.5 (9.6)	50.6 (10.0)	50.6 (8.8)	50.5 (9.9)	51.3 (9.1)
Education		***	<i>P</i> = .07	***	*	ns
HS Grad or less	170	47.9 (9.5)	49.6 (10.6)	48.0 (9.8)	49.9 (10.5)	51.5 (9.7)
Some college+	637	51.5 (9.4)	50.9 (9.2)	51.5 (8.5)	51.9 (9.4)	51.7 (8.6)
Income		***	*	***	***	**
> 60 k	429	53.3 (9.2)	51.3 (8.9)	52.3 (8.2)	52.7 (9.1)	52.4 (8.6)
≤ 60 k	333	47.8(9.1)	49.8 (10.0)	49.0 (9.4)	50.0 (10.2)	50.7 (9.2)
Marital status		***	ns	*	ns	*
Unmarried	325	49.1 (9.3)	50.3 (10.1)	50.1 (8.8)	51.1 (9.7)	50.7 (9.5)
Married	484	51.9 (9.5)	50.9 (9.1)	51.5 (8.9)	51.9 (9.6)	52.4 (8.4)
Employment		***	***	***	***	***
Unemployed	503	47.2 (8.9)	48.9 (9.2)	49.1 (9.3)	49.8 (9.7)	50.6 (8.9)
Employed	334	54.7(8.5)	52.7 (9.4)	52.7 (7.8)	53.6 (9.2)	53.0 (8.5)
Medical co-morbidities (# conditions)		***	***	***	***	***
1	148	52.9 (9.8)	53.1 (10.4)	51.3 (9.5)	53.4 (9.6)	53.2 (9.2)
2–3	266	52.9 (9.7)	51.8 (8.7)	52.2 (8.5)	53.4(9.3)	53.2 (8.1)
4–5	224	49.4 (9.2)	50.9 (9.6)	50.4 (8.8)	50.8(9.6)	51.2 (9.0)
6+	196	46.3 (7.7)	47.3 (8.9)	47.4 (8.7)	46.7 (9.0)	48.6 (8.8)
Disease severity		***	***	***	***	***
No	184	55.9 (8.6)	54.1 (10.2)	51.7 (8.5)	52.4 (9.7)	54.3 (9.1)
Mild	372	51.9 (8.5)	51.2 (9.1)	51.9 (8.4)	51.6 (9.5)	52.0 (8.5)
Moderate-severe	272	44.9 (8.7)	47.3 (8.6)	48.2 (9.4)	49.3 (9.3)	49.5 (8.6)
Falls		***	***	***	***	***
Fallers	187	44.7 (7.4)	46.3 (8.4)	47.6 (8.5)	47.4 (8.8)	48.4 (8.7)
No falls	620	42.5 (9.3)	51.9 (9.4)	51.8 (8.7)	52.7 (9.5)	52.8 (8.6)
Time course		***	*	<i>P</i> = .08	ns	ns
Stable	372	50.9 (9.2)	51.5 (9.8)	51.2 (8.6)	51.8 (9.8)	52.5 (8.7)
Episodic	217	52.5 (9.1)	51.2 (9.6)	50.7 (8.8)	51.3 (9.6)	51.7 (8.6)
Progressive	241	48.4 (10.0)	48.7 (8.7)	49.9 (9.5)	50.9 (9.5)	50.4 (9.1)

Across total sample

P value indicates differences by the overall variable (e.g., age) even when controlling for diagnostic groups

PROMIS SE scores are T_{clin} scores (US chronic conditions sample)

p* < .05 *p* < .01 ****p* < .001

arthritis (55%), anxiety (40%), sleep disorder (37%), and diabetes (33%). Conversely, epilepsy reported best SE for Managing Activities, and stroke reported best SE for Managing

Symptoms. Epilepsy and stroke had lowest disability and disease severity ratings (physician-reported) and best physical function (patient-reported). Lower SE for Managing

Activities and Symptoms were seen in disorders with progressive symptoms including neuropathy, MS and PD.

The demography of patients with neurologic conditions seen in urban tertiary care centers is diverse in age, gender, SES, and disability. Epilepsy patients were young with less disability, MS-young, but among the most disabled, stroke-older, with relatively mild disability, and PD-oldest with greater disability. This study shows demographic disparities in SE for managing conditions, with lower SE associated with low SES and non-white race. Greater SE was reported by men than women for Managing Daily Activities and Emotions. Previous studies of gender show conflicting results with men rating SE greater than woman post-stroke [22], but women reporting greater SE than men in MS [23]. Previous studies show employment and income correlated with SE in chronic pain [24, 25]. A longitudinal study compared SE in morbid obesity vs. COPD following a patient education course; obese patients increased their SE over 1 year, while COPD patients initially increased SE followed by a decrease [26]. This may reflect differences in time course, with episodic symptoms in COPD. Our results show lower SE associated with progressive disease course. Bandura described controllability and predictability as two components of SE [9].

Both patients and physicians reported that epilepsy was associated with mildest disability, but there was less agreement on conditions associated with greatest disability. Neurologists rated PD and MS patients as most disabled, however neuropathy patients reported the lowest ratings on physical function and global physical health. Neuropathy had more medical co-morbidity, while PD had relatively low co-morbidity given their greater age. Our study showed that disease severity and falls were associated with lower SE managing chronic conditions. Previous studies show that seizure severity and self-management skills were determinants of SE for managing epilepsy [27], pain was associated with low SE in neuropathy, stroke and SCI [28–30], and fatigue, depression, and anxiety correlated with lower SE in epilepsy and back pain [20, 24, 27].

Similar to previous studies showing SE as a predictor of health outcomes and well-being, our study shows the PROMIS SE measures to be major determinants of mental health, disability, and global health. The five SE measures were better predictors of mental health, disability and global health than either disease severity or the neurologic diagnosis. Notably, a single domain, SE for Managing Emotions predicted all outcomes of mental health, fatigue, physical functioning, and global health. SE's definition includes patient confidence to complete necessary tasks *in stressful situations*. This may explain the key role of the Managing Emotions SE domain as a predictor of outcomes- regardless of disease severity. At its core, living successfully with

chronic conditions depends upon one's sense of control. This is captured by the definition of SE.

Following stroke, SE for balance and falls were more powerful predictors of function than actual walking or balance performance [22, 31]. In MS, SE predicted disability, QoL, and activity (measured by a community-based accelerometer) [32–34]. SE was a better predictor of disability than pain intensity in chronic musculoskeletal pain [35], a better predictor than disease severity in COPD [36] and an independent predictor of future asthma control [37]. A study of predictors of immunosuppressant medication adherence after kidney transplant showed low medication SE to be the only predictor of non-adherence [38].

Study limitations include recruitment of patients from a tertiary care center at a single urban site. This results in selection bias including race, ethnicity and SES. The low disability in stroke is partially explained by referral bias, since greater disability following stroke results in admission to rehabilitation. Also, stroke specialists are less likely to provide long-term follow-up, in contrast to epilepsy, MS, neuropathy, and PD. Notably, the T_{clin} scores used in the SE measures compare ratings across chronic conditions, not with the general population. Therefore, when ratings are similar, it is possible that all chronic condition groups have similarly low (or high) scores.

In summary, differences in SE for managing chronic conditions are seen across neurologic patients seen in a neurology ambulatory setting, with lowest SE (for managing activities and managing symptoms) in patients with neuropathy, and highest in patients with epilepsy and stroke. This study shows that the PROMIS SE measures are better predictors of mental health, disability and QoL than either disease severity or the specific neurologic diagnosis. Demographic disparities were present, with minority race, low income, and unemployment all associated with lower SE. Greater disease severity, greater co-morbidities, and falls are generally associated with lower SE. This study supports previous evidence that SE for Managing Chronic Conditions is a major determinant of health outcomes and demonstrates the value of assessing SE to identify patients at risk for poor health outcomes.

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Compliance with Ethical Standards

Conflict of interest Dr. Shulman received funding as PI of NIH Grants U01 AR057967-01 and R01 AG059651-0. She has also received funding as site PI for clinical trials supported by U01NS0808-01A1, the Parkinson Study Group, the Michael J. Fox Foundation, and Biotie, for an observational study funded by Pfizer and as consultant for PCORI Grant ME-1306-01511. She receives royalties for patient-centered books published by Oxford University Press and Johns Hopkins University Press. Dr. Shulman's research is supported by endowments as the Eugenia Brin Professor of Parkinson Disease and from the Rosalyn Newman Foundation. Drs. Gruber-Baldini received funding as PI of R21 AG054143 and R01 AG059651-0, co-Investigator on NIH Grants U01 AR057967-01, R01 AG035009 (Magaziner), UH2 AG056925 (Orwig), T32 AG000262 (Magaziner) and from Pluristem Therapeutics. Dr. Romero and Vellozo received funding as co-Investigators on NIH Grant U01AR057967-01.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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