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Satisfaction with social role participation in adults living with chronic conditions: Comparison to a US general population sample

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Abstract: Purpose: Health-related quality of life (HRQOL) of adults living with a chronic condition or disease is an important patient-reported outcome. There is a need to better understand the social health dimension of HRQOL among adults living with a chronic condition (with or without physical/mental disability). This study examined self-reported satisfaction with participation in social roles (SPSR) in adults, grouped by different age groups, living with a chronic condition relative to the US general population.

Materials and methods: This cross-sectional survey study included a convenience sample of 1,822 community-dwelling adults living with one of four chronic conditions. Participants completed the self-report Patient Reported Outcomes Measurement Information System (PROMIS) Satisfaction with Participation in Social Roles v1.0—Short Form 7a (SPSR-SF). PROMIS SPSR-SF scores were compared with a US general population using normative data collected by PROMIS (n = 2,555).

Results: Participants self-reported significantly lower SPSR ($M = 45$, $SD = 8.3$) than the US general population ($M = 50$, $SD = 10$), $t(1821) = -25.65$, $p > .001$. A regression analysis



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ABOUT THE AUTHORS

Dr. Rozanne Wilson completed this study as part of her Advanced Training on Outcomes in Rehabilitation Research (UW-ATORR) postdoctoral fellowship at the University of Washington, under the supervision of Dr. Dagmar Amtmann. Dr. Wilson's research is focused on developing tools, guidelines, and interventions that support the social health of older adults living with a communication disorder (e.g. Alzheimer's disease, aphasia). Dr. Amtmann is an associate professor at the Department of Rehabilitation Medicine and the principle investigator at the University of Washington Center on Outcomes Research in Rehabilitation (UWCORR). This center focuses on promoting health outcomes measurement that is patient-centered, clinically relevant, appropriate for the target audience, short, but accurate, and presented in a way that facilitates patient-clinician shared decision making. Fraser Bocell has a PhD in educational measurement and statistics and is a former UW-ATORR postdoctoral fellow. Alyssa Bamer and Rana Salem are research scientists at UWCORR and work on various projects with Dr. Amtmann.

PUBLIC INTEREST STATEMENT

A rise in aging populations and an increase in people living with one or more chronic health condition is contributing to more people living with a disability. In the United States alone, an estimated 40 million people live with one or more chronic health condition that limits their usual activities¹. Perceived social health status and quality of life among adults living with a chronic condition is an important patient-reported outcome. Patient-reported outcomes measures (PROMs) are instruments that assess social function directly from patients. This paper reports findings from a study that examined self-reported satisfaction with participation in social roles (SPSR) among adults, in various age categories, living with a chronic condition relative to a general population. This study highlights that living with a chronic condition has important implications for an aspect of health and quality of life: social function. This line of inquiry is important because there is a need to better understand the impact of living with a chronic condition on social health.

indicated that physical function explained more variance of PROMIS SPSR-SF scores than age.

Conclusions: Relative to the PROMIS national sample, adults living with a chronic condition reported lower levels of SPSR. Decreased physical function was associated with lower SPSR.

Subjects: Disability; Testing, Measurement and Assessment; Gerontology/Ageing; Quality of Life; Rehabilitation Medicine

Keywords: social participation; quality of life; chronic disease; disability; aging; patient-reported outcome measures (PROMs)

1. Introduction

Adults living with a chronic condition that limits activity (physical/social/mental) and contributes to disability, face many societal and personal challenges. Importantly, living with a chronic condition has implications for an individual's perceptions of the impact of their health on everyday life. Patient-reported outcomes measures (PROMs) are instruments that assess health status directly from patients. PROMs play a crucial role in the evaluation of perceived health-related quality of life (HRQOL), or the impact of health status on daily life, among adults aging with one or more chronic condition. While health outcomes related to the physical and the mental dimensions of HRQOL have been examined in adult populations living with a chronic condition, there is a need to better understand the social health dimension of HRQOL in this population.

To respond to the need for reliable, precise, and flexible PROMs, The Patient-Reported Outcomes Measurement Information System (PROMIS) initiative, funded by the National Institute of Health (NIH), developed several standardized measures using modern psychometric techniques. A significant advantage of PROMIS measures is that they are brief tools that are all scored on the same T-score metric, with the mean of 50 that represents the mean of the PROMIS US general population, and a standard deviation of 10. These PROMs were developed for general populations, thus not disease specific, and for those living with chronic conditions. PROMIS has developed several self-report adult measures to assess for a person's perceptions of their symptoms, function, behavior, and feelings in multiple domains, including social health. PROMIS defines social health as the perceived well-being regarding social activities and relationships, including the ability to relate to individuals, groups, community, and society (Castel et al., 2008). The social health dimension of HRQOL includes the sub-domains of social function, or participation, and social relationships/support. Focusing on social function, PROMIS defines this sub-domain as the involvement in, and satisfaction, or contentment, with one's usual social roles in life's situations and activities (e.g. family/friends and work responsibilities) (Bode, Hahn, DeVellis, & Cella, 2010; Castel et al., 2008). This paper is focused on measuring adults', living with chronic conditions, self-reported satisfaction with participation in social roles (SPSR), such as work, marital and family responsibilities.²

Higher social participation has been linked to better HRQOL in aging adults (Dahan-Oliel, Gélinas, & Mazer, 2008). For example, the benefits of positive social relationships have been linked to better physical health and lower mortality (Barger, 2013, Glass, Mendes De Leon, Marottoli, & Berkman, 1999; House, Landis, & Umberson, 1988). Additionally, more social participation has been associated with significantly better self-rated health in older adults (Anderson et al., 2014; Ichida et al., 2013). Importantly, SPSR in older adults living with chronic conditions has been shown to significantly contribute to well-being, and not activity accomplishments (Anaby, Miller, Jarus, Eng, & Noreau, 2011). Generally, social function has been less studied in the aging population (Dahan-Oliel et al., 2008; Gignac et al., 2013). Therefore, it is not surprising that there is a paucity of studies that focus on SPSR in people aging with a chronic condition (Levasseur, Desrosiers, & Noreau, 2004). While a limited number of studies have examined the association between SPSR and HRQOL in adults living with a chronic condition, self-reported SPSR in adults living with a chronic condition

has yet to be described across the lifespan. Finally, an important question that needs to be addressed is whether SPSR differs in adults aging with a chronic condition compared with their contemporaries in the general population.

The main objectives of this study were (1) to examine self-reported SPSR in adults living with a chronic condition, (2) to compare perceived SPSR in adults living with a chronic condition to the US general population, (3) to compare perceived SPSR in people living with chronic conditions, grouped by age categories, to an age-matched US national sample, and (4) to describe the relationship between age and SPSR in this study's chronic condition sample.

2. Materials and methods

2.1. Study design

Data for this cross-sectional survey study were collected between 2009 and 2010 as part of a self-administered paper and pencil survey of community-dwelling adults living with chronic conditions (Cook, Molton, & Jensen, 2011; Molton et al., 2014). All participants who completed the survey were paid \$25.

2.2. Participants and procedure

Eligible participants were at least 18 years of age, self-reported having a definitive diagnosis of multiple sclerosis (MS), a definitive or probable diagnosis of muscular dystrophy (MD), a definitive diagnosis of spinal cord injury (SCI), or a diagnosis of post-polio syndrome (PPS), were able to read and write English, and provided written consent. Participant recruitment involved mailed invitations through registries of people who participated in previous studies at the University of Washington (UW) and indicated an interest in participating in future studies ($n = 398$), through the UW Center on Outcomes Research in Rehabilitation Medicine (UWCORR) ($n = 473$), and through disability-specific registries (Northwest Regional Spinal Cord Model Systems and the University of Rochester Neuromuscular Disease (NMD) Research Registry) ($n = 375$). Additionally, participants were recruited through print or web advertisements ($n = 661$), through friends and family referrals ($n = 90$), or through other sources ($n = 44$). A total of 2,041 interested and eligible participants were mailed the self-report survey. Of the 1,877 returned surveys, 1,822 contained a completed rating of SPSR and were included in this study (MS = 572; SCI = 483; PPS = 432; MD = 335). All respondents provided consent to participation in this study.

Overall, most participants were white (91.2%), female (62.9%), over the age of 50 years ($M = 56$, $SD = 13.4$), and had a college education (79.4%). In terms of the chronic condition sub-samples, the SCI sample had the highest percentage of males (67.7%) and was the youngest sample ($M = 50$ years, $SD = 14.1$), while the PPS sample had the highest percentage of individuals with an advanced degree (33.8%) and had been living with their condition the longest ($M = 16$ years, $SD = 10$) (Table 1).

2.2.1. Ethical approval

Procedures of this study were approved by the human subjects division of the University of Washington (UW) Institutional Review Board.

2.3. Measures

2.3.1. Demographics

Participants were asked to provide basic demographic information, including age, sex, race/ethnicity, duration of diagnosis, and education level.

2.3.2. Satisfaction with participation in social roles

SPSR was assessed using the PROMIS Satisfaction with Participation in Social Roles Version 1.0 Short Form 7a (PROMIS SPSR-SF) (see www.nihpromis.org or <http://www.healthmeasures.net/explore-measurement-systems/promis>). PROMIS SPSR-SF is a self-report assessment of contentment with one's usual social roles, including roles in marital relationships, as well as family (e.g. "I am satisfied

Table 1. Participant demographics for overall sample and for chronic condition sub-samples

Characteristics	Study sample (n = 1822)		MS (n = 572)		SCI (n = 483)		PPS (n = 432)		MD (n = 335)	
	n	%	n	%	n	%	n	%	n	%
Sex										
Male	676	37.1	100	17.5	327	67.7	109	25.2	140	41.8
Female	1146	62.9	472	82.5	156	32.3	323	74.8	195	58.2
Race (*MS, SCI, PPS, MD)										
White/Caucasian	1662	91.2	535	93.5	406	84.1	404	93.5	317	94.6
Black/African American	60	3.3	14	2.4	39	8.1	6	1.4	1	.3
Native American/Alaskan Native	10	.5	1	.2	5	1.0	2	.5	2	.6
Asian	14	.8	0	0	8	1.7	4	.9	2	.6
Native Hawaiian or Pacific Islander	1	.1	0	0	1	.2	0	0	0	0
Other	42	2.3	11	1.9	16	3.3	8	1.9	7	2.1
Ethnicity										
Hispanic/Chicano	23	1.3	7	1.2	7	1.4	6	1.4	3	.9
Education (*SCI)										
< High school	30	1.6	5	.9	14	2.9	5	1.2	6	1.8
High school or Tech school	345	18.9	93	16.3	127	26.3	54	12.5	71	21.2
Some college	450	24.7	156	27.3	122	25.3	104	24.1	68	20.3
College degree	550	30.2	189	33.0	144	29.8	123	28.5	94	28.1
Advanced degree	446	24.5	129	22.6	75	15.5	146	33.8	96	28.7
Years since diagnosis, mean (SD) (*SCI, PPS, MD)	15.4 (10.7)		15.2 (10.8)		15.5 (11.1)		16.0 (10.0)		14.7 (11.05)	
Age mean (SD), range	56.0 (13.4)	20-94	54.4 (10.8)	21-84	50.0 (14.1)	21-88	67.2 (8.3)	41-94	53.2 (13.1)	20-89

Note: *Numbers do not add up to total sample because of missing data from identified chronic condition sub-samples. MS = multiple sclerosis; SCI = spinal cord injury; PPS = post-polio syndrome; MD = muscular dystrophy.

with my ability to do things for my family.”), household (e.g. “I am satisfied with my ability to do household chores/tasks.”), and work responsibilities (e.g. “I am satisfied with my ability to work (including work at home”) (see www.assessmentcenter.net for PROMIS SPSR-SF scoring guide). PROMIS SPSR-SF includes 7-items, each on a 5-point scale (ranging from *Not at All* to *Very Much*) and asks about SPSR over the past seven days. Higher scores on this PROM represent higher SPSR. As with all PROMIS measures, the PROMIS SPSR-SF score is transformed into a T-score with a mean (*M*) of 50 and standard deviation (*SD*) of 10. PROMIS SPSR was scored using data from a large US general population sample (*N* = 21,133) and normed using a subset of this sample (*n* = 2,555) that was matched to the 2000 US Census on age, sex, and race/ethnicity (Cella et al., 2010; Liu et al., 2010).

2.3.3. Physical function

Physical function was assessed using 10 items from the PROMIS Physical Function item bank. The selected items were deemed appropriate for users of mobility aids and were taken from the expanded PROMIS physical function item bank, which included items for mobility aid users (Amtmann, Bamer, & Cook et al., 2010; PROMIS Physical Function Scoring Manual [PDF], 2015). A total of 1,483 study participants also responded to the PROMIS physical function items (incomplete physical function data: *n* = 339).

2.4. National comparison data

2.4.1. Comparison of the overall study sample with a US national sample

A large general population sample from the United States (US) was used to complete psychometric testing for the PROMIS measures (>20, 000) (Cella et al., 2010). A sub-sample of the PROMIS national sample (*n* = 5,239) was used to establish the mean population scores for PROMIS measures (wave 1), including PROMIS SPSR. This sub-sample was matched on age, sex, and race/ethnicity to the 2000 US Census (i.e. US normative sample) (Cella et al., 2010; Liu et al., 2010). Data used for comparison in this study includes the sub-set of the PROMIS normative sample that completed the PROMIS social roles item bank (*n* = 2, 555). This paper refers to the PROMIS SPSR-SF standard scores, derived from the PROMIS US normative sample (mean = 50; *SD* = 10), as the PROMIS national sample.

2.4.2. Comparison of the study sample, grouped by age, with an age-matched US national sample

To better understand adults SPSRs and aging with a chronic condition, this study’s participants were classified into six age categories for statistical comparison with the age-matched PROMIS national sample. Age-adjusted general population means were not originally calculated for the PROMIS national sample. Therefore, the authors of this study divided the PROMIS national sample into six age categories (i.e. < 35, 35–44, 45–54, 55–64, 65–74, and 75+years). While these age categories were based on previously reported PROMIS age categories (Cook et al., 2011; Molton et al., 2014), the composition of the age categories does not correspond to the 2000 US Census. The mean T-scores, *SD*s and medians were calculated for each age category. For example, the PROMIS mean for the 55–64 age group was 51.3 (*SD* = 9.7). This paper refers to these calculated age categories as the age-matched PROMIS national sample. Of note, because of the etiology of PPS, there were no participants in the 18–34 range and only *n* = 1 in the 35–44 range; therefore, no comparisons were made for these age groups.

2.5. Statistical analysis

2.5.1. Descriptive analysis

Summary statistics (e.g. percentages, means, *SD*s, range) were calculated for all collected demographic variables (e.g. age, sex, education level) for the entire study sample and for each chronic condition sub-sample.

2.5.2. Assumption testing

To examine the normality assumption of the parametric one-sample *t*-test, a combination of graphical methods, numerical methods, and formal normality testing were used. Score distributions were assessed for the overall sample, for each of the chronic condition sub-samples, and for all chronic condition sub-samples, grouped by age categories.

In conjunction with the visual inspection of histograms and normal Q-Q plots and review of skewness and kurtosis values, the Shapiro-Wilk's test for normality (Shapiro & Wilk, 1965) was used ($p < .01$). This normality test is sensitive to small deviations from normality in larger samples, even when these small deviations would not affect parametric tests. Therefore, for larger samples ($n > 300$) in this study, graphical methods and skewness and kurtosis values, with a criterion cut-off of an absolute value less than one, were considered more heavily to help determine normality.

2.5.3. Comparisons analyses

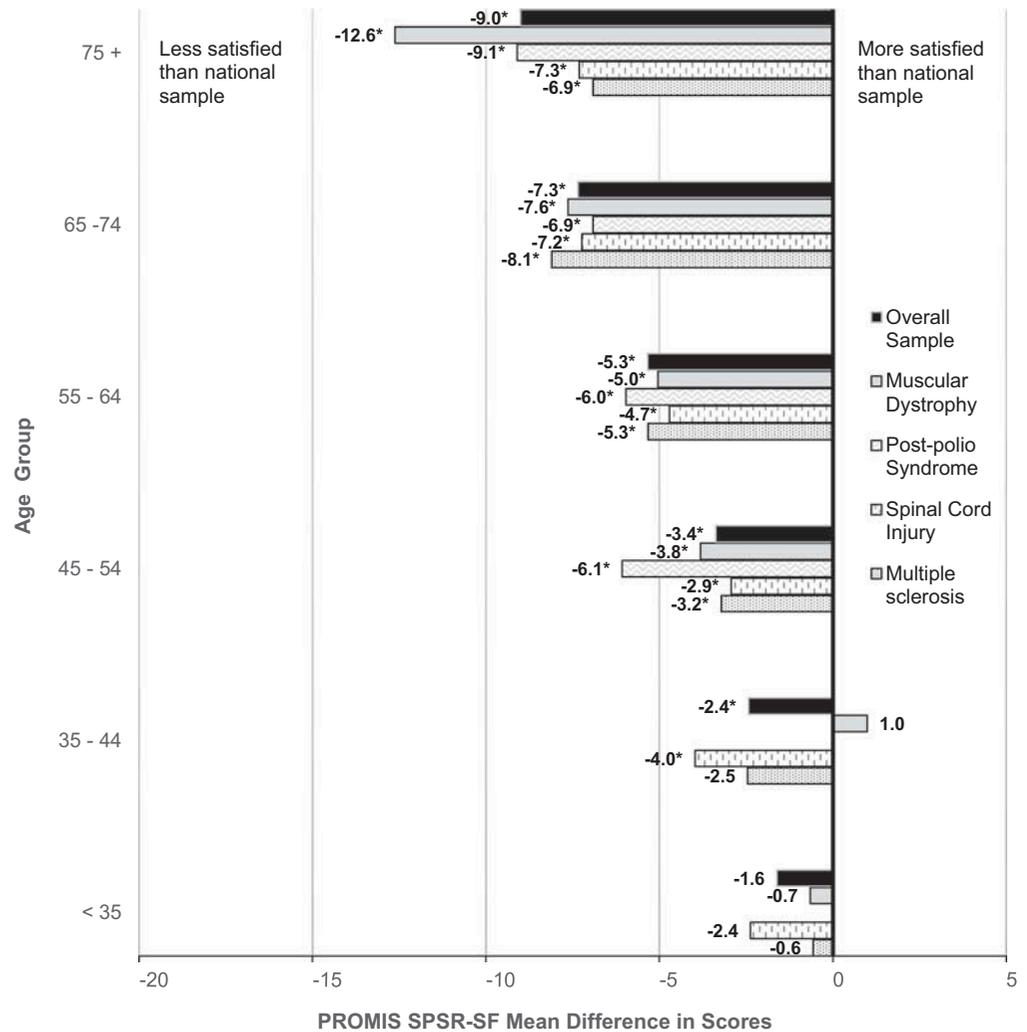
A one-sample *t*-test was performed to compare self-reported SPSR in adults living with a chronic condition to the PROMIS national sample, (T-score test value = 50). In addition, four one-sample *t*-tests were used to compare each chronic condition sub-sample (not adjusted for age) to the PROMIS national sample (T-score test value = 50). One-sample *t*-tests were also used to compare this study's sample mean T-score on the PROMIS SPSR-SF, in all age categories within each of the chronic condition sub-samples, to the age-matched PROMIS national sample means. Within each chronic condition sub-sample, 6 comparisons were conducted, with the exception of the PPS sample due to an insufficient number of participants in the two youngest age categories. For each chronic condition, grouped by age, the mean T-score was compared to the corresponding age-matched PROMIS national sample mean T-score. To show the mean differences, in points, between this study's chronic condition samples, grouped by age, and the age-matched PROMIS national sample means, a graphical profile display of the differences was created (see Figure 1).

2.5.4. Regression analysis

To better understand the differences in SPSR scores between adults living with a chronic condition and the general population, the relationship between SPSR scores and participant age (e.g. decreased SPSR with increasing age) was examined using sequential multiple regression was used. Sequential multiple regression provided a test of the effect of age on SPSR, controlling for gender, chronic condition type, and level of physical function. In step 1 of the model, age, gender, and chronic condition were entered. Physical function was added in step 2 of the model to assess the additional explanatory power. Physical function was entered into the model after age, gender, and chronic condition predictors to assess the effect on the model, in general, and then specifically on the effect of age. Raw age was used for this analysis in order to meet the assumptions of regression and to preserve information (Tabachnick & Fidell, 2007). Each chronic condition group was coded as a set of dichotomous variables, using a large community sample as a reference group. The reference group was the same PROMIS national sample comparison data ($n = 2,555$) used in the previous analysis. Only study participants with both SPSR and physical function data ($n = 1,483$) were used in the regression analysis, combining the adults with a chronic condition with the PROMIS national sample comparison sample, resulting in a sample size of 4,038.

For all statistical comparisons, significant differences were determined by setting a conservative α value: $p < 0.01$, two-tailed. All descriptive and parametric analyses were performed using PASW/SPSS Statistics (v.18). To aid in the interpretation of statistically significant results, clinical significance (i.e. practical implications of the difference) was also addressed by reporting the mean difference in scores in SD units. This study applied the conventional benchmark of a moderate effect size of 0.50 (or half an SD) (i.e. distribution-based approach), as this criterion has been previously reported to correspond to a MID that indicates a clinically meaningful change (Norman, Sloan, & Wyrwich, 2003; Wyrwich et al., 2005). In other words, a mean difference in scores of 5 points (i.e. 0.50 SD units) was considered clinically meaningful.

Figure 1. Mean difference between PROMIS SPSR-SF scores in adults living with chronic conditions and the age-matched PROMIS national sample. This figure illustrates the difference, in points, between the PROMIS SPSR-SF mean T-scores of individuals living with chronic conditions and the age-matched PROMIS US national sample mean T-scores. Age-matched PROMIS national sample PROMIS SPSR-SF mean T-scores were subtracted from the corresponding age group mean T-scores for each sub-sample. Right-facing bars indicate that the corresponding sub-sample was more satisfied with their social role participation than the age-matched PROMIS national sample, while left-facing bars indicate that the sub-sample was less satisfied with their social role participation than the age-matched PROMIS national sample. A difference in 10 points coincides with one SD and half a SD is generally considered clinically meaningful. Statistically significant differences between sub-samples and the age-matched PROMIS national sample comparison group ($p < 0.01$) are marked with *.



3. Results

3.1. Assumption testing

The score distributions for the overall sample ($n = 1,822$) and all the chronic condition sub-samples were approximately normally distributed (Table 2). The Shapiro-Wilk's test indicated that nearly 70% of the chronic condition samples, grouped by age, were approximately normally distributed ($p > .01$) (Table 2) on PROMIS SPSR-SF scores. However, with the exception of the two younger age groups, the Shapiro-Wilk's test indicated that the MS samples were non-normally distributed. Additionally, the SCI sample that was below the age of 35 years and two PPS samples (55–64; 65–74) also had non-normal distributions. That said, caution should be taken when interpreting the Shapiro-Wilks test for scale data due to lower score variations and because larger sample sizes with small deviations from normality are likely to produce significant results (Field, 2009). For instance, the MS sample was larger across all age groups except the very old (75+). Therefore, to make an informed decision about the normality of the sample distributions, significant normality test results were interpreted in conjunction with the review of skewness and kurtosis values (Table 2) and visual inspection of histograms and normal Q-Q plots. Non-normal distributions were

Table 2. Skewness, kurtosis, and normality test for each chronic condition sample, grouped by age, on PROMIS SPSR-SF score

Age Range	Chronic Condition Group	Skewness (SE)	Kurtosis (SE)	Shapiro-Wilk			
				n =	Statistic	df	p -value
All ages	Overall	1822	0.338 (.057)	0.145 (.115)	0.979	1822	0.000
	MD	335	0.325 (.133)	-0.154 (.266)	0.973	335	0.000
	MS	572	0.422 (.102)	-0.003 (.204)	0.974	572	0.000
	SCI	483	0.262 (.111)	0.144 (.222)	0.984	483	0.000
	PPS	432	0.378 (.117)	0.422 (.234)	0.984	432	0.000
< 35	MD	33	0.244 (.409)	-0.356 (.798)	0.968	33	0.437
	MS	26	-0.122 (.456)	-0.352 (.887)	0.929	26	0.073
	SCI	79	0.133 (.271)	-0.284 (.535)	0.956	79	0.009*
35-44	MD	43	-0.059 (.361)	-0.364 (.709)	0.968	43	0.280
	MS	77	0.115 (.274)	-0.245 (.541)	0.972	77	0.092
	SCI	89	0.187 (.255)	0.073 (.506)	0.994	89	0.962
45-54	MD	100	0.328 (.241)	-0.042 (.478)	0.976	100	0.059
	MS	172	0.253 (.185)	0.181 (.368)	0.976	172	0.005*
	SCI	122	0.365 (.219)	0.059 (.435)	0.984	122	0.157
	PPS	13	-0.546 (.616)	1.72 (1.19)	0.961	13	0.763
55-64	MD	92	0.392 (.251)	0.153 (.498)	0.969	92	0.025
	MS	200	0.502 (.172)	0.000 (.342)	0.975	200	0.001*
	SCI	123	0.012 (.218)	0.157 (.433)	0.989	123	0.468
	PPS	167	0.561 (.188)	0.134 (.374)	0.974	167	0.003*
65-74	MD	53	0.449 (.327)	0.555 (.644)	0.943	53	0.014
	MS	82	0.829 (.266)	0.731 (.526)	0.940	82	0.001*
	SCI	54	0.563 (.325)	-0.020 (.639)	0.955	54	0.041
	PPS	164	0.485 (.190)	0.885 (.377)	0.976	164	0.005*
75+	MD	14	1.36 (.597)	1.78 (1.15)	0.864	14	0.034
	MS	15	1.27 (.580)	0.590 (1.12)	0.828	15	0.009*
	SCI	16	-0.636 (.564)	-0.507 (1.09)	0.925	16	0.206
	PPS	87	-0.009 (.258)	0.027 (.511)	0.986	87	0.447

Note. SE = standard error. MS = multiple sclerosis; SCI = spinal cord injury; PPS = post-polio syndrome; MD = muscular dystrophy PPS sample for age categories < 35 and 35-44 was omitted from this analysis. * Indicates non-normal distribution $p < .01$.

identified for five of the chronic condition samples by age categories: MS (55-64, 65-74, 75+); PPS (55-64, 65-74).

The majority of sample distributions in this study had values that were acceptable for performing the parametric one-sample *t*-test. Because parametric tests can perform well for non-normal distributions if the sample sizes are not small ($n > 20$) and have more statistical power than non-parametric tests, both the Sign *M* test of medians and the one-sample *t*-test was calculated for the non-normally distributed samples. Both statistical tests yielded similar statistically significant results. Therefore, to support the interpretation of all the comparisons, the parametric one-sample *t*-test findings were reported in this paper.

Table 3. One-sample t-test comparisons of the PROMIS SPSR-SF scores between study sample and the PROMIS national sample (mean = 50)

Study sample	n	Mean (SD)	t	df	Probability (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
							Lower	Upper
Overall	1822	45 (8.3)	-25.6	1821	< 0.001*	-5.0	-5.4	-4.6
MS	572	45.1 (8.7)	-13.7	571	< 0.001*	-4.9	-5.6	-4.2
SCI	483	45.6 (8.1)	-12.1	482	< 0.001*	-4.4	-5.2	-3.7
PPS	432	43.9 (7.0)	-18.2	431	< 0.001*	-6.1	-6.8	-5.5
MD	335	45.5 (9.3)	-8.8	334	< 0.001*	-4.5	-5.5	-3.3

Note. MS = multiple sclerosis; SCI = spinal cord injury; PPS = post-polio syndrome; MD = muscular dystrophy. *Indicates significance at $p < .01$.

3.2. Comparing the overall study sample and the chronic condition sub-samples to the PROMIS national sample

The PROMIS SPSR-SF T-score for the study's overall sample ($M = 45$, $SD = 8.3$), as well as for each chronic condition sub-group, were significantly lower than the PROMIS national sample norm ($M = 50$, $SD = 10$) ($p < .001$) (Table 3). The overall study sample ($N = 1,822$) presented a mean difference that was 0.50 SD units below the PROMIS national sample norm. The mean differences for each chronic condition sub-sample ranged from 0.44 SD (MD, SCI) to 0.61 SD (PPS) units below the PROMIS national sample (Table 3).

3.3. Comparing the overall study sample, grouped by age categories, to the age-matched PROMIS national sample

For all age-matched PROMIS national samples, the PROMIS SPSR-SF mean T-scores hovered around 50 and ranged from 48.6 ($SD = 10.3$) in the 45–54 year age category to 51.7 ($SD = 9.4$) in the 75+years age category (Table 4). The PROMIS SPSR-SF mean T-scores for the overall study sample, grouped by age, ranging from 42.7 ($SD = 7.6$) in the 75+years age category to 48.5 ($SD = 9.9$) for the < 35 year age category. When compared with each age-matched PROMIS national sample mean T-score, all age categories in this study had statistically significantly lower PROMIS SPSR-SF scores (all $p < .001$) except for the < 35-year group, which had a mean difference of only 1.6 points. The largest mean difference in scores between the overall study sample, grouped by age categories, and the age-matched PROMIS national sample was for the 75+age category (9 points or 0.90 SD unit) (Table 3).

3.4. Comparing the study chronic condition sub-samples, grouped by age categories, to the age-matched PROMIS national sample

When comparing the PROMIS SPSR-SF scores for each chronic condition sub-sample, in each age category, to the age-matched PROMIS national sample, all sub-samples 45 years and older reported statistically significantly lower PROMIS SPSR-SF scores (all $p < .01$) (Table 4), with mean differences ranging from 3 points (0.3 SD units) lower in the SCI 45–54 age category to 12.7 points (1.27 SD units) lower in people living with MD in the 75+age category. Mean difference, in points, between this study's chronic condition sub-samples, grouped by age, and the age-matched PROMIS national sample indicates that all sub-samples appeared increasingly less satisfied with their social role participation with advancing age (Figure 1). One exception to this general trend was in people living with MD in the 35–44 age category, which was 1 point higher (0.10 SD units) higher (i.e. more satisfied) than the age-matched PROMIS national sample mean. For the two youngest age categories, only individuals with SCI (35–44 years) reported significantly lower PROMIS SPSR-SF mean T-score than the age-matched PROMIS national sample.

Table 4. One-sample t-test comparisons of PROMIS SPSR-SF scores between chronic condition sub-samples and age-matched PROMIS national sample means

Age group	PROMIS national sample (N = 2,555) Mean (SD)	Chronic condition	n	Mean (SD)	t	df	Probability	Mean difference	Lower	Upper
< 35	n = 585 50.1 (9.3)	Overall	138	48.5 (9.9)	-1.9	137	0.06	-1.6	-3.3	0.05
		MS	26	49.5 (10.7)	-2.7	25	0.79	-0.6	-4.9	3.7
		SCI	79	47.8 (10.1)	-2.1	78	0.04	-2.3	-4.6	-0.08
		PPS	-	-	-	-	-	-	-	-
35-44	n = 448 49.0 (10.2)	MD	33	49.5 (8.5)	-0.44	32	-0.66	-0.7	-3.7	0.05
		Overall	210	46.6 (8.7)	-4.0	209	< 0.001*	-2.4	-3.6	-1.2
		MS	77	46.6 (9.6)	-2.2	76	0.03*	-2.4	-4.6	-0.28
		SCI	89	45.0 (7.1)	-5.3	88	< 0.001	-4.0	-5.5	-2.5
45-54	n = 430 48.6 (10.3)	PPS	1	-	-	-	0.49	-	-	-
		MD	43	50.0 (9.5)	0.69	42		1.0	-1.9	3.9
		Overall	407	45.2 (8.4)	-8.1	406	< 0.001*	-3.4	-4.2	-2.6
		MS	172	45.3 (8.7)	-4.9	171	< 0.001*	-3.3	-4.5	-1.9
55-64	n = 428 49.8 (10.9)	SCI	122	45.6 (7.5)	-4.3	121	< 0.001*	-3.0	-4.3	-1.6
		PPS	13	42.5 (6.8)	-3.2	12	0.007	-6.1	-10.2	-2.0
		MD	100	44.7 (9.0)	-4.2	99	< 0.001*	-3.9	-5.6	-2.0
		Overall	582	44.5 (7.9)	-16.4	581	< 0.001*	-5.3	-6.0	-4.7
		MS	200	44.5 (8.1)	-9.4	199	< 0.001*	-5.3	-6.5	-4.2
		SCI	123	45.1 (7.4)	-7.1	122	< 0.001*	-4.7	-6.0	-3.4
		PPS	167	43.8 (7.2)	-10.7	166	< 0.001*	-6.0	-7.1	-4.9
		MD	92	44.8 (9.2)	-5.3	91	< 0.001*	-5.0	-6.9	-3.1

(Continued)

Table 4. (Continued)

Age group	PROMIS national sample (N = 2,555) Mean (SD)	Chronic condition	n	Mean (SD)	t	df	Probability	Mean difference	Lower	Upper
65-74	n = 342	Overall	353	44.2 (7.8)	-17.7	352	< 0.001*	-7.4	-8.2	-6.5
	51.6 (9.7)	MS	82	43.5 (8.5)	-8.6	81	< 0.001*	-8.1	-10.0	-6.2
		SCI	54	44.4 (8.2)	-6.5	53	< 0.001*	-7.2	-9.5	-5.0
		PPS	164	44.7 (6.8)	-13.1	163	< 0.001*	-6.9	-8.0	-5.9
		MD	53	44.0 (9.3)	-6.0	52	< 0.001*	-7.6	-10.2	-5.1
75+	n = 322	Overall	132	42.7 (7.6)	-13.5	131	< 0.001*	-9.0	-10.2	-7.6
	51.7 (9.4)	MS	15	44.7 (9.2)	-2.9	14	0.011*	-7.0	-12.0	-1.8
		SCI	16	44.4 (9.6)	-3.1	15	0.008*	-7.3	-12.4	-2.2
		PPS	87	42.6 (7.0)	-12.1	86	< 0.001*	-9.1	-10.6	-7.6
		MD	14	39.0 (5.9)	-8.0	13	< 0.001*	-12.7	-16.0	-9.2

Note. MS = multiple sclerosis; SCI = spinal cord injury; PPS = post-polio syndrome; MD = muscular dystrophy. *Significance at p < .01

The MD 75+age category ($n = 14$) reported the lowest PROMIS SPSR-SF mean T-score ($M = 39.0$, $SD = 5.9$) and this was significantly different from the mean T-score of the age-matched PROMIS national sample ($M = 51.7$, $SD = 9.4$) ($t(13) = -8.0$, $p < .001$) (Table 4). The MS sample showed a general pattern of lower satisfaction with increasing age, with the exception of the 75+year age category, which had a slightly lower difference in mean score (7 points) than the 66–74 years age category (8 points). Except for the 35–44 years age range showing lower SPSR (0.40 SD units) than the 45–54 years age range (0.29 SD units), the SCI sub-sample displayed a general pattern of decreasing SPSR with age. SCI sub-sample mean differences ranged from 0.23 SD units lower in the < 35 years age range to 0.73 SD units lower in the 75+years age range than the age-matched PROMIS national sample means. Across age categories that were 45 years and older, the PPS sub-samples PROMIS SPSR-SF mean T-scores remained relatively consistent, with mean differences ranging from 0.61 SD units in the 45–54 years age range to 0.91 SD units in the 75+years age range.

3.5. Regression analysis

Table 5 presents the results from the final model after including physical functioning in step 2. In step 1 of the model, age had a non-significant effect on accounting for SPSR scores ($\beta = -0.01$, $p > 0.05$) while gender ($\beta = -1.30$) and chronic condition type ($\beta = -5.52$ to -6.90) had a significant, negative effect ($p < 0.00625$). After including physical functioning in the model, gender, and diagnosis of MD or PPS were not significant predictors of SPSR. Age had a modest positive effect on SPSR ($\beta = 0.16$, $p < 0.00625$), after gender, chronic condition type, and physical functioning were taken into account. Adults with MS experienced significantly lower satisfaction ($\beta = -0.07$, $p < 0.00625$), while those with SCI reported significantly higher SPSR than the PROMIS national sample ($\beta = 0.12$, $p < 0.00625$). Finally, physical functioning had a significant, positive effect on SPSR scores ($\beta = 0.67$, $p < 0.00625$). In the absence of physical function, the model (age, gender, and chronic condition type) accounted for 12% of the total variance in SPSR; however, the addition of physical function to the model increased the R^2 to explain 38% of the variance.

4. Discussion

Results indicated that adults living with a chronic condition, on average, reported significantly lower levels of SPSR when compared to the PROMIS national sample. In all sub-samples of people living with a chronic condition 45 years of age or older, participants were significantly less satisfied with their social role participation than the age-matched PROMIS national sample. Interestingly, the PROMIS SPSR-SF mean T-scores in the age-matched PROMIS national sample ($M = 51.7 - 48.6$) hovered around the PROMIS national sample mean ($M = 50$, $SD = 10$), suggesting that SPSR may remain relatively constant over time in the US general population. This finding has important implications for adults below 65 years of age living with a chronic condition. For instance, working-age adults are typically expected to be involved in a variety of important and often demanding social roles, such as marital and work relationships; however, living with a chronic condition, that limits physical function, has been associated with limitations in role engagement and lower satisfaction with role participation (Gignac et al., 2013) and quality of life (Levasseur et al., 2004). Moreover, aging with a chronic condition that limits daily activities has negative implications on several HRQOL domains for aging adults (Rothrock et al., 2010). For example, older adults living with one or more chronic conditions reported poorer physical function and lower SPSR compared with individuals living with no chronic condition. Further, those who reported limitation in daily activities scored worse in physical and social health domains compared to those who indicated that they did not experience limitations in daily activities due to a chronic condition.

The largest mean differences were observed in chronic condition sub-samples above 65 years of age, with the difference in scores ranging from 6.9 – 12.7 points (i.e. more than half an SD) lower than the age-matched PROMIS national sample. Notably, adults 65 years and older experience typical life transitions that are accompanied by changes in social roles (Cornwell, Laumann, & Schumm, 2008). For example, retirement, divorce or death of a spouse, and grown children leaving the home can impact opportunities for social participation in older adults, thus influencing SPSRs. Interestingly, while lower perceived SPSR was reported by MD, MS, and PPS sub-samples, the SCI

Table 5. Sequential multiple regression of PROMIS SPSR-SF

Model	R ² change	F change	R ² total	R ² Adj	F total	b	(SE)	t	β
Step 1	-	-	.12	.12	94.4(6,4031)***	52.10	(0.50)	103.78***	-
Intercept						-0.01	(0.01)	-0.75	-0.01
Age						-1.30	(0.28)	-4.65***	-0.07
Female gender						-5.52	(0.49)	-11.37***	-0.17
MD						-5.61	(0.39)	-14.24***	-0.22
MS						-6.90	(0.46)	-15.00***	-0.24
PPS						-5.85	(0.42)	-13.86***	-0.22
SCI									
Step 2	0.26	1710.9(1,4030)***	0.38	0.38	359.6(7,4030)***	21.52	(0.85)	25.32***	-
Intercept						0.09	(0.01)	12.14***	0.16
Age						-0.16	(0.24)	-0.67	-0.01
Female gender						0.18	(0.43)	0.42	0.01
MD						-1.73	(0.34)	-5.05***	-0.07
MS						-0.70	(0.41)	-1.69	-0.03
PPS						3.38	(0.42)	8.08***	0.12
SCI						0.51	(0.01)	42.83***	0.67
Physical functioning									

N = 4,038. MD = muscular dystrophy; MS = multiple sclerosis; PPS = post-polio syndrome; SCI = spinal cord injury.
 Step 1 results not shown. Physical function was entered at Step 2, while all other predictors were entered at Step 1. *p < .05, **p < .01, ***p < .001

sub-sample did not appear to show lowered SPSR with advancing age. This finding may reflect the variability in the progressive nature of the different chronic condition sub-samples. For instance, SCI typically occurs as a result of an acute injury (Wyndaele & Wyndaele, 2006), while MS is an autoimmune disease that typically presents itself as relapsing-remitting or progressive types (Kremenchtzky, Rice, Baskerville, Wingerchuk, & Ebers, 2006). In sum, there appears to be a general lowered satisfaction with SPSR in older adults living with a chronic condition and this may be partly due to transitions in social roles that occur post-retirement or to the nature of the chronic condition that people are living with.

Age was a modest predictor of SPSR after controlling for gender, chronic condition type, and physical function. However, the relationship between age and SPSR was positive, indicating that, once other factors were accounted for, including physical function, SPSR scores increased slightly with age. Therefore, the difference in SPSR found among older age groups living with chronic conditions is associated with decreasing physical function rather than with increasing age. Specifically, a positive association was found between PROMIS SPSR-SF T-scores and physical function scores, with nearly thirty percent of the variance accounted for by physical functioning. While other variables are likely influencing SPSR, age, and physical function needs to be controlled for when evaluating SPSR. Taken together, age and having poorer physical function accounted for lower SPSR. That said, 74 percent of the variation observed in this study cannot be explained by the model as a whole; therefore, there are other variables that influence SPSR in older adults living with a chronic condition. Findings from this study indicate that the relationship between age and SPSR warrants further examination.

To facilitate interpretation of the statistically significant mean effects reported, this study examined minimal important difference (MID), or the criteria that need to be met when determining if a mean difference in scores on a PROM is clinically meaningful (Wyrwich, Norquist, Lenderking, & Acaster, 2013). The mean difference in scores (study sample—PROMIS national sample) on the PROMIS SPSR-SF were compared to the threshold value of 0.50 SD (i.e. mean difference of 5 points). Mean differences for the overall sample were clinically meaningful for all age categories 55 years and older. In this study, the overall sample presented a mean difference that was 0.50 SD units below the PROMIS national sample. In terms of the chronic condition sub-samples, observed differences for all groups were 4–6 points lower than the PROMIS national sample. The PPS group reported the largest mean difference of 0.61 SD units while SCI group differed by 0.44 SD units. For participants in this study, grouped by age category, clinically meaningful differences were observed for all chronic condition sub-samples that were 55 years and older, with differences in T-scores ranging from 0.47 SD (SCI)—0.60 SD (PPS) units for the 55–64 age category to 0.70 SD (MS) to 1.27 SD (MD) units for the 75+age category.

This study had a few limitations. First, this was a cross-sectional study; therefore, a longitudinal study would be necessary to draw causal conclusions about changes in self-reported SPSR. Second, the participants in this study were a convenience sample of people living with chronic conditions. Thus, the samples of people with chronic conditions included in this study are not representative of the US population of individuals with MS, SCI, PPS, and MD. Some age categories included small sample sizes, which limits interpretation and generalizability beyond this study. For example, sample sizes were small for MS, SCI, and MD ($n = 14$ to 16) for the oldest age range (75+), limiting statistical power to detect differences between the chronic condition sub-samples and the age-matched PROMIS national sample means. Finally, criteria for clinical meaningfulness for PROMIS SPSR has not been published. This study applied general MID, which is a criterion that is considered to be a conventional benchmark (Norman et al., 2003); however; it is important to note that, to the author's knowledge, MID criteria of half SD has yet to be established for PROMIS SPSR-SF.

5. Conclusion

This study found that living with a chronic condition has important implications for the HRQOL, specifically social function. Findings indicate that individuals living with a chronic condition

experience, on average, lower perceived levels of SPSR than adults who are not living with a chronic condition and this finding is both statistically and clinically significant. However, physical functioning explained this difference and not age. Across all chronic condition sub-samples, participants reported approximately half SD lower levels of SPSR compared to the age-matched PROMIS national sample. More research is needed to understand the role of age in SPSR in adults with chronic conditions and how the effects of age and/or physical function differ among people with chronic conditions and the general adult population. Some caution is advised in interpreting the results for the youngest and oldest age groups because the sample sizes for these groups were small.

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Disclosure Statement

The authors report no conflicts of interest.

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Notes

1. National Center for Health Statistics, Centers for Disease Control and Prevention. (2013) Summary

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2. PROMIS Wave 1 data (2005–2007) resulted in the development of two item banks: (1) Satisfaction with Participation in Social Roles (v1.0) and (2) Satisfaction with Participation in Discretionary Social Activities (v1.0). Revised item pools were developed based on supplemental data collection (2009–2010), resulting in the development of one overall item bank: Satisfaction with Social Roles and Activities (v2.0). This study collected data using PROMIS Satisfaction with Participation in Social Roles v1.0—Short Form 7a.

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