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Known-Groups Validity of the Patient-Reported Outcomes Measurement Information System (PROMIS®) in Adolescents and Young Adults with Special Health Care Needs

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Abstract

Purpose—To examine known-groups validity of the Patient-Reported Outcomes Measurement Information System (PROMIS®) Short Forms (SFs) for adolescents and young adults with special health care needs (SHCN) using data collected from the PROMIS Linking Study.

Methods—292 adolescents aged 14–17.9 years and 300 young adults aged 18–20 years with SHCN from the PROMIS Linking Study were used for analyses. Presence of SHCN was classified into 3 categories (medication use, service use, and functional limitations). HRQoL was measured with the PROMIS Pediatric and Adult SFs. Differences in health-related quality of life (HRQoL) domain scores between SHCN sample and the norms of the PROMIS pediatric and adult calibration samples, respectively, were compared using t-tests. Associations of HRQoL scores with the presence of individual SHCN categories were tested using linear regression.

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No conflict of interest to all co-authors.

Ethical approval:
All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The University of Florida Institution Review Board approved the study protocol. Informed consent was obtained from all individual participants included in the study.

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Results—All HRQoL domain scores for the SHCN samples were significantly worse than the respective calibration samples. Adolescents and young adults with SHCN-related service use and functional limitations reported worse HRQoL than those without service use and functional limitations (p's<0.01).

Conclusions—PROMIS Pediatric and Adult SFs possess satisfactory known-groups validity related to SHCN status.

Keywords

Adolescents; Health-Related Quality of Life; Patient-Reported Outcomes Measurement Information System (PROMIS®); Special Health Care Needs; Young Adults

INTRODUCTION

Approximately 13% of children and youth in the US are living with special health care needs (SHCN) status [1], with 750,000 SHCN youth transitioning to adulthood each year [2]. SHCN is defined as individuals who have or are at risk for chronic physical, emotional, and developmental conditions that require health services at a rate higher than individuals without chronic conditions [3]. Health-related quality of life (HRQoL) is an important indicator to quantify outcomes of individuals with SHCN [4–6]. Patient-Reported Outcomes Measurement Information System (PROMIS®) [7] was designed to measure HRQoL and allows for tracking HRQoL changes over time including the transition from adolescence into adulthood. However, the comparative validity of the PROMIS scales between SHCN adolescents and young adults has not been established.

This study aimed to test the known-groups validity related to SHCN status for the PROMIS Pediatric and Adult Short Forms (SFs) in adolescents and young adults. Known-groups validity describes the ability of a scale to distinguish HRQoL between subgroups based on meaningful anchors [8]. First, we compared HRQoL of SHCN samples to the norms of the PROMIS pediatric [9] and adult calibration samples [10, 11]. We hypothesize that SHCN individuals will exhibit poorer HRQoL than the calibration samples. Second, we compared HRQoL in SHCN individuals by the presence of specific categories of SHCN [12]. We hypothesize that individuals with impairment in a specific SHCN category will exhibit poorer HRQoL than those without impairment.

METHODS

Study Design and Population

This study was a secondary data analysis based on the NIH-funded PROMIS Linking Study [13] that aimed to link the PROMIS Pediatric and Adult SFs to create comparable scores across adolescence and adulthood. In total, 292 adolescents and 300 young adults were recruited from the Texas Medicaid and Children's Health Insurance Program and the Opinions for Good panel. Inclusion criteria were 14–17 years of age (adolescents) and 18–20 years of age (young adults), identification with SHCN, and ability to communicate in English. SHCN status was assessed through the SHCN Screener (see below). An e-mail was sent to young adults for consent, and to parents of adolescents for consent and adolescents

for assent. Following consent, adolescents and young adults were asked to complete a 40-minute online survey. The protocol was approved by the Institutional Review Board of the University of Florida (data collection site).

Measures

SHCN Screener—The SHCN screener assesses 5 health consequences: 1) medication use; 2) use of medical, mental, and behavioral health services; 3) functional limitations that restrict individuals from participating in activities at the rate which unimpaired individuals do; 4) use of special therapy; and 5) use of treatment or counseling for emotional and developmental problems. After answering each main question, participants were asked: 1) whether the consequence is due to a specific health condition (i.e. physical, mental, behavioral) and 2) whether the condition is expected to last (or has lasted) at least 12 months. Three definitional categories of SHCN were further created: 1) medication use, 2) service use (i.e., use of medical, mental, and behavioral health services, special therapy, or treatment and/or counseling for emotional and developmental problems), and 3) functional limitations [14, 15]. The Screener possesses good psychometric properties [16] and is able to discriminate between individuals with and without chronic conditions [17].

PROMIS SFs—The PROMIS Pediatric and Adult SFs [7] were used to measure HRQoL. Adolescents completed eight pediatric SFs and young adults completed seven adult SFs (see online supplement). Both Pediatric and Adult SFs contain similar HRQoL constructs of depressive symptoms, anxiety, anger, pain interference, and fatigue; peer relationships for adolescents which is conceptually similar to social health for adults; and mobility and upper extremity for adolescents which is comparable to physical functioning for adults. A recall period of the past seven days was used for all items. Scores for each SF were summed and converted to a T-metric with a mean of fifty and a standard deviation of ten based on the original pediatric [9] and adult calibration samples [10, 11]. The PROMIS SFs have shown good psychometric properties for the Pediatric [18] and Adult SFs [19].

Statistical Methods

Overall, age-specific and gender-specific mean PROMIS SF scores of adolescent participants were compared to the norms of the PROMIS pediatric calibration sample (mean 50 and standard deviation 10) [9], and the overall and gender-specific mean PROMIS SF scores of the young adult participants were compared to the norms of the PROMIS adult calibration sample (mean 50 and standard deviation 10) [10, 11]. PROMIS adult calibration sample is representative of the US general population based on the sampling strategies and participant characteristics. Each participant was classified by presence of three definitional categories, separately. Independent sample t-tests were used to test differences in mean HRQoL domain scores by presence of individual SHCN categories. Multiple regression was performed to examine associations between presence of each SHCN category and each HRQoL domain with and without adjusting for covariates (age, gender, ethnicity, education, and chronic conditions).

RESULTS

Adolescents had a mean age of 15.5 years (SD: 1.1), and 50.3% were female. Young adults had a mean age of 19.0 years (SD: 0.8), and 50.7% were female (Table 1). All HRQoL domain scores of SHCN adolescent and young adult samples were significantly impaired compared with the norms of the pediatric calibration sample and the adult calibration sample (Figure 1). Likewise, age-specific (Figure 1) and gender-specific HRQoL of SHCN adolescent and young adult samples (Figure 2) were significantly impaired compared to the respective pediatric and adult calibration samples, except for pain interference SF in adolescent males. Adolescents and young adults with SHCN who indicated service use and functional limitations reported worse HRQoL scores on all SFs (p's<0.01) than those who did not indicate using services or having functional limitations, except for social health SF in young adults (Table 2).

Multivariate analyses reveal functional limitation category was a significant predictor of worse HRQoL scores across all SFs (p's<0.05) in both adolescents and young adults, except for social health in young adults (Model 1, Table 3). Service use was a significant predictor of worse HRQoL scores for all SFs in adolescents (p's<0.05) and for anxiety, fatigue, pain interference, and physical functioning SFs (p's<0.01) in young adults. Specifically, the magnitude of effect was higher in adolescents (vs. young adults) for service use category and higher for functional limitations category in young adults (vs. adolescents). Adolescent males reported better HRQoL scores on anxiety, fatigue, pain interference, mobility and upper extremity SFs than females (p's<0.05) (Model 2, Table 3). Hypertension was associated with worse HRQoL scores among adolescents and young adults, with greater significance and magnitudes in adolescents across all SFs. Without covariates, the status of three SHCN categories explained the most variance in adolescents in anxiety and mobility (R^2: 17% and 18%, respectively) while the three categories of SHCN explained more variance in young adults in pain interference and physical functioning (R^2: 21% and 24%, respectively) (Model 1, Table 3).

DISCUSSION

Both PROMIS Pediatric and Adult SFs were able to discriminate between people with and without the presence of specific SHCN categories. Adolescents and young adults with SHCN reported worse HRQoL than the norms of the PROMIS pediatric adult calibration samples, respectively, across all PROMIS SFs. Our results parallel the previous investigations where SHCN individuals reported poorer HRQoL than non-SHCN counterparts [20–22]. The differences in HRQoL between our SHCN samples and the calibration samples may be in part due to various characteristics. Compared to the calibration samples, SHCN adolescents were characterized with older ages and more chronic conditions, and SHCN young adults were characterized with racial/ethnic minorities.

The PROMIS SFs did not distinguish medication use domain within SHCN individuals and this association was not statistically significant in the regression models. Similar to a previous study [16], this finding suggests a lower discriminatory power of the medication use domain related to the underlying health status compared to service use and functional

limitations domains of the SHCN screener. This non-significant finding also implies the effective medication use on the illness and disease control that leads to better functional status and HRQoL. The PROMIS Social Health SF was not able to discriminate within SHCN young adults classified as service use or functional limitations. Although one previous study has shown acceptable known-groups validity of PROMIS Social Health SF in an older adult sample with chronic conditions [23], our findings suggest that the PROMIS Social Health SF may lack sensitivity to this dimension for younger adults with SHCN, and the contents of emotional support between younger and older adults with SHCN or chronic conditions may not be the same. Future qualitative investigation is warranted to address this issue.

SHCN explained more variance in anxiety and mobility domain scores for adolescents and more variance in pain interference and mobility domain scores for adults. This difference may be explained by developmental experiences in adolescents and young adults [24, 25]. Adolescence is an important stage of developing personality identity and independence, experiencing SHCN in adolescence can result in anxiety. In contrast, the greater association of SHCN with pain interference in adults than in adolescents may be due to pain being more prevalent and severe in young adults than in adolescents [26, 27].

In sum, HRQoL in adolescents and young adults measured by the PROMIS SFs were worse than the norms of the calibration samples. Additionally, PROMIS SFs were able to discriminate between individuals classified by specific categories of SHCN. The robust known-groups validity related to SHCN status supports the application of PROMIS SFs in future research and practice.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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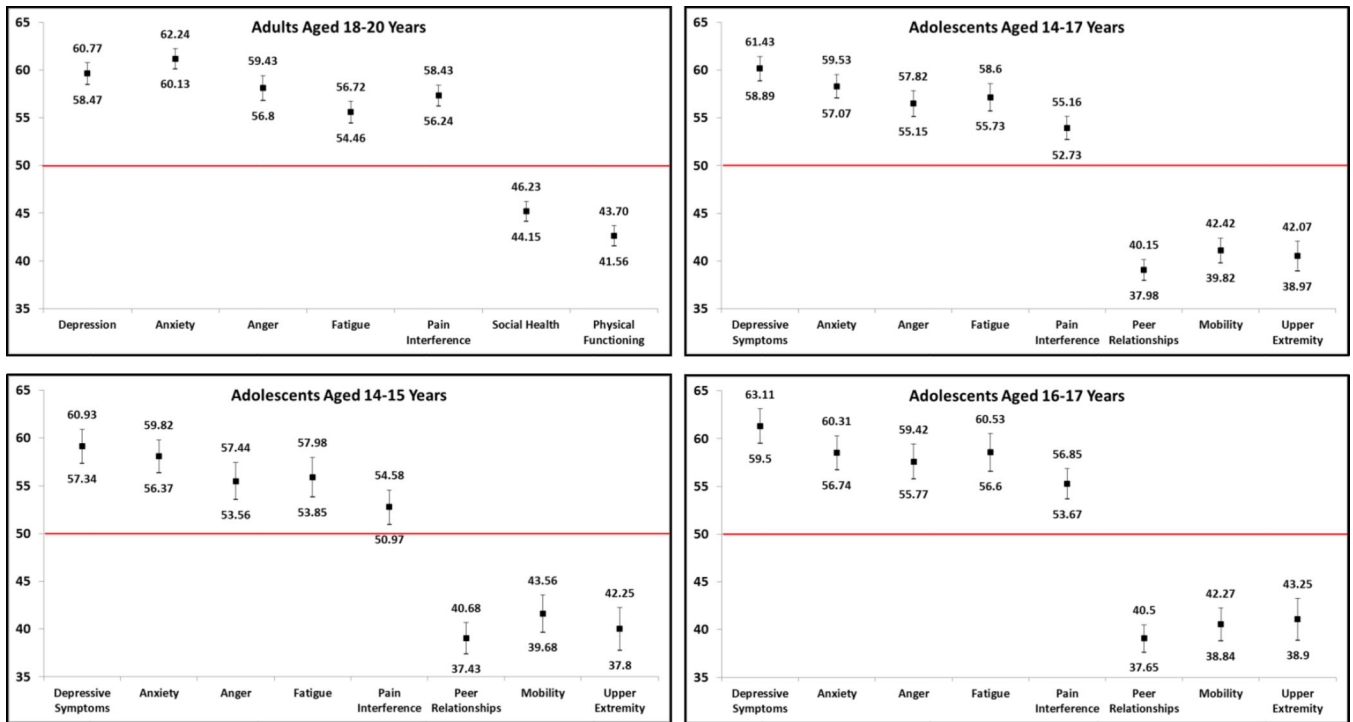
Figure 1.

Comparison of SHCN adults to the norms of the PROMIS adult calibration sample overall, and SHCN adolescents to the norms of the PROMIS pediatric calibration sample overall and by age subgroups[†‡]

†: Lower scores indicate worse HRQoL for peer relationships, mobility, and upper extremity; higher scores indicate worse HRQoL for other domains

‡: Upper and lower bars indicate the 95% confidence interval range
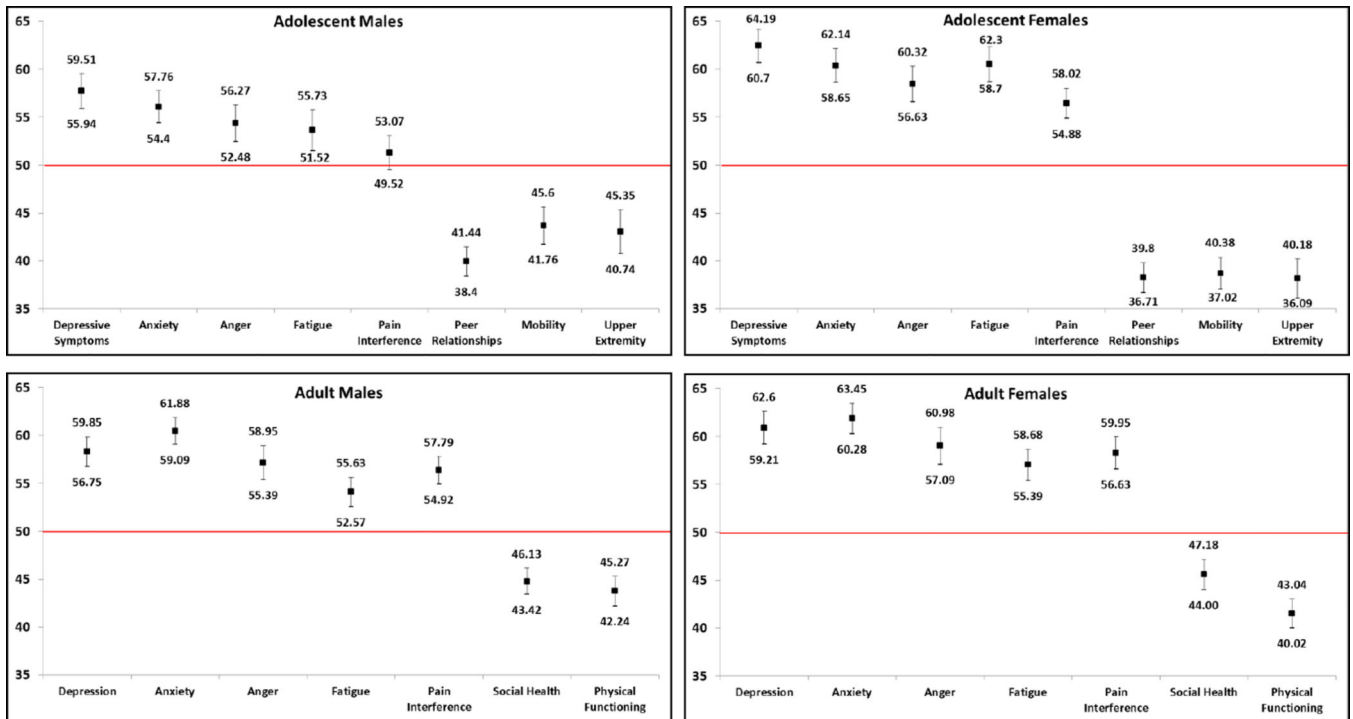
Figure 2.

Comparison of SHCN adolescents to norms of the PROMIS pediatric calibration sample, and SHCN adults to norms of the PROMIS adult calibration sample by gender subgroups[†][‡]

†: Lower scores indicate worse HRQoL for peer relationships, mobility, and upper extremity; higher scores indicate worse HRQoL for other domains

‡: Upper and lower bars indicate the 95% confidence interval range

Table 1

Participant Characteristics (N=592)

	Adolescents (N=292)	PROMIS pediatric calibration sample (N=4,129)
Age, mean (SD)	15.5 (1.1)	NA
Age group		
8–12	NA	55.4%
13–17	100%[a]	44.4%
Female, %	50.3%	50.6%
Race, %		
White	51.7%[b]	58.1%
Black	25.3%[b]	23.2%
Other	25.7%[b]	15.7%
Ethnicity, %		
Hispanic	25.0%	17.0%
Non-Hispanic	75.0%	82.1%
Chronic Conditions (Top Five), %		
Attention-deficit/hyperactivity disorder (ADHD)	36.0%[c]	4.6%[c]
Hypertension	27.1%[c]	NA
Mental Health	24.7%[c]	2.2%[c]
Allergies	19.9%[c]	1.2%[c]
Asthma	19.5%[c]	18.0%[c]

	Adults (N=300)	PROMIS adult calibration sample (N=14,128)
Age, mean (SD)	19.0 (0.8)	NA
Age group		
18–29	100%[d]	22.0%
30–44	NA	32.0%
45–59	NA	24.0%
60+	NA	22.0%
Female, %	50.7%	52.0%
Race, %		
White	52.0%[b]	74.0%
Black	25.3%[b]	11.0%
Other	26.7%[b]	4%
Ethnicity, %		
Hispanic	27.0%	11.0%
Non-Hispanic	73.0%	89.0%
Chronic Conditions (Top Five), %		

Hypertension	32.7%[c]	NA
Attention-deficit/hyperactivity disorder (ADHD)	31.3%[c]	NA
Mental Health	20.0%[c]	NA
Asthma	19.0%[c]	NA
Allergies	14.3%[c]	NA

[a]: Our sample restricted to 14–17.9 years of age

[b]: Race over 100% due to multiple choices

[c]: Chronic conditions were self-reported by parents (for SHCN adolescents) and SHCN young adults

[d]: Our sample restricted to 18–20 years of age

Table 2

Association between SHCN status by Screener definitional domains and HRQoL

	SHCN Category								
	Medication Use			Service Use			Functional Limitations		
	No	Yes	T-Score	No	Yes	T-Score	No	Yes	T-Score
Adolescents	N=29	N=245		N=31	N=243		N=82	N=192	
Depressive Symptoms	60.1	60.2	<−0.1	51.1	61.3	−5.3***	55.5	62.2	−5.0***
Anxiety	58.9	58.2	0.8	48.6	59.5	−5.9***	53.1	60.5	−5.7***
Anger	58.7	56.2	1.1	46.5	57.7	−5.6***	53.2	57.9	−3.2**
Fatigue	59.4	56.9	1.1	48.8	58.2	−4.2***	51.6	59.6	−5.3***
Pain Interference	54.9	53.8	0.5	47.7	54.8	−3.7***	49.4	55.9	−5.1***
Peer relationships†	38.4	39.2	−0.4	44.2	38.4	3.4***	41.8	37.9	3.3**
Mobility†	40.4	41.2	−0.4	49.0	40.1	4.4***	47.4	38.4	6.8***
Upper Extremity†	38.8	40.7	−0.8	48.9	39.4	3.9***	45.9	38.2	4.7***
	No	Yes	T-Score	No	Yes	T-Score	No	Yes	T-Score
Adults	N=21	N=279		N=27	N=273		N=104	N=196	
Depression	55.6	59.9	−1.9	53.3	60.2	−3.5***	55.1	62.0	−5.9***
Anxiety	58.5	61.4	−1.4	54.0	61.9	−4.3***	56.8	63.5	−6.3***
Anger	55.9	58.3	−0.9	50.8	58.8	−3.5***	52.9	60.9	−6.0***
Fatigue	52.1	55.9	−1.7	47.8	56.4	−4.4***	51.5	57.8	−5.5***
Pain Interference	57.8	57.3	0.2	48.6	58.2	−5.2***	51.6	60.4	−8.4***
Social Health†	41.3	45.5	−2.0*	46.9	45.0	1.0	46.0	44.7	1.2
Physical Functioning†	42.3	42.7	−0.2	51.4	41.8	5.3***	48.7	39.4	9.1***

*
p<0.05;

**
p<0.01;

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***
p<0.001

†: Lower scores indicate worse HRQoL for the domains with symbol; otherwise higher scores indicate worse HRQoL

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Table 3

Multivariable linear regression testing association between SHCN definitional domains and PROMIS Mean Domain Scores for Adolescents and Adults

Adolescents

	Depressive Symptoms		Anxiety		Anger		Fatigue		Pain Interference		Peer Relationships[†]		Mobility[†]		Upper Extremity[†]	
	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2
	β	β	β	β	β	β	β	β	β	β	β	β	β	β	β	β
Medication use	−0.6	−0.9	−1.4	−0.9	−2.6	−3.4	−3.7	−3.1	−2.0	−1.9	1.2	0.7	2.3	0.7	3.0	0.7
Service Use	8.3***	5.9**	8.8***	6.9***	10.0***	8.5***	6.7**	6.0**	4.9*	4.1*	−4.6**	−4.1*	−5.9**	−5.5**	−6.9***	−6.3**
Functional Limitations	5.4***	5.4***	6.0***	5.8***	3.2*	3.2*	7.2***	6.5***	5.9***	5.5***	−3.2**	−3.0*	−8.2***	−7.3***	−6.8***	−5.5***
Age	-------	0.5	-------	−0.3	-------	0.8	-------	0.8	-------	0.5	-------	<0.1	-------	<0.1	-------	1.1
Male	-------	−2.4	-------	−3.3**	-------	−2.1	-------	−5.1***	-------	−3.6**	-------	0.6	-------	3.3*	-------	3.5*
Hispanic	-------	3.7*	-------	2.6	-------	2.6	-------	2.3	-------	1.8	-------	−3.1*	-------	−4.4**	-------	−6.0**
Black[a]	-------	1.4	-------	−0.6	-------	1.9	-------	<0.1	-------	−0.6	-------	−1.4	-------	0.7	-------	0.2
Other race[a]	-------	0.5	-------	−0.9	-------	<0.1	-------	−0.4	-------	1.5	-------	−2.8	-------	−1.4	-------	−2.6
Middle School[b]	-------	−4.7	-------	−0.6	-------	−5.0	-------	1.6	-------	−3.5	-------	0.1	-------	−1.3	-------	−1.6
ADHD	-------	−0.8	-------	0.2	-------	1.9	-------	−0.3	-------	−0.2	-------	<0.1	-------	2.4*	-------	2.2
Hypertension	-------	3.3*	-------	2.2	-------	3.0*	-------	5.5***	-------	3.7**	-------	−0.7	-------	−5.1***	-------	−6.5***
Mental Health	-------	5.2***	-------	3.3*	-------	1.9	-------	1.6	-------	0.5	-------	0.1	-------	1.1	-------	1.8
Allergies	-------	1.2	-------	−0.3	-------	1.5	-------	3.3	-------	3.3*	-------	−0.3	-------	−0.5	-------	1.8
Asthma	-------	−2.2	-------	−1.8	-------	−1.1	-------	−0.4	-------	−1.2	-------	1.4	-------	0.8	-------	1.3
R²	14%	28%	17%	26%	12%	20%	13%	26%	11%	22%	7%	10%	18%	30%	11%	25%

Adults

	Depression		Anxiety		Anger		Fatigue		Pain Interference		Social Health[†]		Physical Functioning[†]	
	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2
	β	β	β	β	β	β	β	β	β	β	β	β	β	β
Medication use	4.0	3.5	2.6	2.4	1.9	1.3	3.6	3.0	−0.9	−1.3	4.2*	4.1	0.8	1.0
Service Use	3.8	3.9	4.9**	4.6*	4.2	4.5	5.9**	5.9**	5.3**	5.4**	−1.1	−2.2	−5.1**	−5.8**

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Functional Limitations	6.0[***]	6.1[***]	5.6[***]	5.7[***]	7.1[***]	7.0[***]	5.1[***]	5.2[***]	7.8[***]	7.8[***]	-1.2	-1.0	-8.2[***]	-8.1[***]
Age	-------	0.3	-------	0.1	-------	0.6	-------	-0.4	-------	-0.6	-------	-1.6[*]	-------	0.4
Male	-------	-2.3[*]	-------	-1.4	-------	-2.0	-------	-2.6[*]	-------	-1.9	-------	-0.5	-------	1.8
Hispanic	-------	0.7	-------	0.8	-------	0.1	-------	0.9	-------	0.2	-------	-0.4	-------	-1.1
Black[a]	-------	-1.8	-------	-2.6	-------	-2.0	-------	-1.5	-------	-0.8	-------	0.7	-------	0.3
Other race[a]	-------	-2.6	-------	-2.3	-------	-0.8	-------	-1.0	-------	-1.5	-------	1.4	-------	0.7
Less than High School[c]	-------	2.3	-------	-0.3	-------	-2.7	-------	2.2	-------	-0.4	-------	<-0.1	-------	-1.0
High School[c]	-------	<-0.1	-------	-0.8	-------	-2.4	-------	-0.6	-------	0.1	-------	-1.8	-------	0.6
ADHD	-------	0.8	-------	0.4	-------	1.5	-------	0.9	-------	-0.1	-------	-0.9	-------	1.6
Hypertension	-------	1.7	-------	1.7	-------	2.7[*]	-------	0.5	-------	1.7	-------	-2.1	-------	-2.5[*]
Mental Health	-------	2.8[*]	-------	2.9[*]	-------	1.6	-------	1.7	-------	-1.3	-------	0.5	-------	2.7[*]
Allergies	-------	1.5	-------	2.5	-------	2.9	-------	2.2	-------	3.7[*]	-------	0.5	-------	-1.9
Asthma	-------	1.4	-------	-0.3	-------	1.0	-------	0.1	-------	-0.8	-------	-3.5[*]	-------	-2.0
R^2	12%	18%	14%	20%	12%	17%	17%	17%	21%	25%	2%	7%	24%	31%

[*] p<0.05;

[**] p<0.01;

[***] p<0.001

[†]: Lower scores indicate worse HRQoL for the domains with symbol; otherwise higher scores indicate worse HRQoL

[a]: Reference group = White

[b]: Reference group = High school

[c]: Reference group = College or above

M1: Model 1 included SHCN domains (medication use, service use, and functional limitations)

M2: Model 2 included SHCN domains (medication use, service use, and functional limitations), age, gender, race, ethnicity, education, and top 5 chronic conditions for each group