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Validation of the Patient-Reported Outcomes Measurement Information System (PROMIS)-57 and -29 item short forms among kidney transplant recipients

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Abstract

Objective The Patient-Reported Outcomes Measurement Information System (PROMIS) aims to address the lack of generalizable and universal measure of patient-reported outcomes to assess health-related quality of life. It has not been validated for patients with chronic kidney disease. We aim to validate the PROMIS-57 and PROMIS-29 questionnaires among kidney transplant recipients.

Methods A cross-sectional sample of stable kidney transplant recipients was recruited. Each participant completed PROMIS-57, a 57-question instrument covering seven domains—physical function, anxiety, depression, fatigue, pain, sleep disturbance, and social functioning—alongside validated legacy questionnaires [Patient Health Questionnaire (PHQ9), General Anxiety Disorder (GAD7), Edmonton Symptom Assessment Scale revised (ESASr), and Kidney Disease Quality of Life (KDQoL-36)]. PROMIS-29, a 29-question instrument, is nested within PROMIS-57 and measures the same domains. Structural validity of PROMIS was assessed with confirmatory factor analysis, reported using the Comparative Fit Index (CFI). Construct validity was assessed with known-groups comparisons. Internal consistency was evaluated with Cronbach's α and convergent validity was assessed with Spearman's Rho. Test–retest reliability was assessed through the intraclass correlation coefficient (ICC).

Results Mean (± SD) age of the 177 participants was 50 (± 17), 57% were male and 55% Caucasian. Internal consistency of each domain was high (Cronbach's $\alpha > 0.88$). Confirmatory factor analysis showed good structural validity for most domains (CFI > 0.95, RMSEA < 0.05). Test–retest reliability indicated good agreement (ICC > 0.6). Known-groups comparisons by clinical and socio-demographic differences were found as hypothesized.

Conclusions Our results provide evidence that PROMIS-57 and PROMIS-29 are highly reliable and valid instruments among kidney transplant recipients. We propose it as a valuable tool to assess important domains of the illness experience.

Keywords PROMIS · PROMIS-57 · PROMIS-29 · Kidney transplant · Renal transplant · Patient-reported outcomes · Validation study

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Introduction

Chronic kidney disease (CKD) is a public health concern, with the prevalence increasing globally [1–4]. Patients with end-stage kidney disease (ESKD) need renal replacement therapy (RRT), either dialysis or kidney transplantation (KT), for survival. KT provides the best outcomes, including morbidity, mortality, as well as health-related quality of life (HRQOL) [5–10], and is substantially less expensive than dialysis [11–13].

However, KT recipients often experience physical symptoms, psychosocial distress, and side effects from immunosuppressive medications [7, 14]. Assessing these concerns using patient-reported outcome measures (PROMs) [15, 16] may improve communication between patients and the managing clinical transplant team [17, 18], may improve the completeness of the clinical assessment [19], and enable the prediction of the illness trajectory [20, 21]. Use of PROMs in clinical settings has demonstrated benefit, with interventions that utilized PROMs in cancer care improving health care processes, healthcare utilization, and patient survival [20, 22].

The Patient-Reported Outcomes Measurement Information System (PROMIS) of the National Institutes of Health in the United States constructed generic (not targeted toward any specific condition or treatment) PROMs that are reliable, valid, and feasible for research and clinical use across chronic disease populations [23–25]. PROMIS utilizes rigorous qualitative and quantitative methods to create item banks that measure specific patient-valued domains. This work has resulted in item banks specific for several HRQOL categories representing physical, mental, and social health (e.g., physical function, anxiety, depression, participation in social roles and activities), as well as global health measures [23–25]. Item banks have been optimized and calibrated using classical test theory [26] and item response theory [27], enabling item banks to be efficient, flexible, and precise. PROMIS item banks can be administered as fixed-length short forms (predefined or user-customized) or as computer adaptive tests (CAT) [28–30]. CAT is a method of administration that adapts to the respondent by selecting the most informative questions based on prior responses. This allows domains to be precisely measured while reducing questionnaire burden [28–30].

The PROMIS profile for adults assesses seven core domains of HRQOL: anxiety, depression, fatigue, physical function, sleep disturbance, pain interference, ability to participate in social roles and activities, and includes a pain intensity numeric rating scale (0–10). The PROMIS-29 assesses each domain with four questions and the PROMIS-57 has eight questions per domain, with PROMIS-29 nested within PROMIS-57. The PROMIS measures are generic, meaning they are applicable to an array of populations, and have been validated for use in a growing number of clinical populations [23, 24, 31–39] but have yet to be validated in KT. The goal of this study was to confirm several aspects of validity of the generic PROMIS-57 and PROMIS-29 among individuals who had received a KT. In this study, we did not assess content validity, as we felt that is has been tested extensively during item bank development [23, 24, 29, 36, 40]. We hypothesized that the PROMIS profiles will have good internal consistency, test–retest reliability, and strong construct validity, thus providing supportive evidence for the validity and reliability of these tools in KT recipients.

Methods

Study design and population

This was a single-center, cross-sectional cohort of stable, adult (≥ 18 years) KT recipients, who had received a KT > 30 days before enrollment. Participants were recruited between April 2016 and September 2017 at the outpatient Kidney Transplant Clinic of the University Health Network in Toronto, Canada. Patients with severe acute illness, dementia, and non-English speaking patients were excluded. Approval for this study was obtained from the University Health Network Research Ethics Board (REB# 15-9645). All participants signed a written informed consent form.

Questionnaire administration

Patients were approached during regularly scheduled clinic visits. After informed consent, participants completed the study questionnaire (socio-demographic characteristics, PROMIS-57, legacy questionnaires) on an electronic data capture system (DAta Driven Outcomes System—DADOS, Techna Institute, University Health Network, Toronto) programmed on iPads. A subset of participants were invited to complete the PROMIS-29 and -57 within 2–4 weeks after the baseline visit to facilitate test–retest estimation.

Data sources and measures

Socio-demographic and clinical characteristics

Self-reported socio-demographic characteristics included age, sex, marital status, education level, employment status, and ethno-cultural background. Clinical characteristics, including etiology of kidney disease, comorbidities [evaluated using the Charlson Comorbidity Index (CCI)], and transplant vintage, were collected from medical records using a standardized data extraction form.

PROMIS-57 and -29

The PROMIS-57 measures seven domains, each with eight items, and a single-item about pain intensity, for a total of 57 items. The domains measured are anxiety, depression, fatigue, physical function, sleep disturbance, pain interference, and ability to participate in social roles and activities. Items are scored on a 5-point response scale, with each response given a value from 1 to 5; higher values indicate more of the construct being measured. The PROMIS-29 is nested within PROMIS-57 and covers the same seven domains as the PROMIS-57 but measured with 4-items each.

For both the PROMIS-57 and PROMIS-29, item responses were summed and then converted to a standardized *T* Score using suggested algorithm [41]. The *T* Score is a metric with a mean of 50 and standard deviation of 10 that has been normalized to the US general population [41].

Legacy measures

We have considered several factors when choosing the legacy questionnaires for this project, including their established validity, brevity, simplicity, and availability in the public domain.

The Kidney Disease Quality of Life-36 (KDQOL™-36) [42–45] is a 36-item profile instrument that includes the Medical Outcomes Study Short Form 12-item questionnaire (SF-12) as a generic core which can be scored into a physical component summary (PCS) and mental component summary (MCS) [46]. In addition, the KDQOL-36 includes three renal-targeted scales, including burden of kidney disease (four items), symptoms and problems of kidney disease (12 items), and effects of kidney disease (eight items). Each KDQOL-36 scale yields a score ranging between 0 and 100, with higher scores representing better quality of life [45, 47]. The KDQOL-36 has been validated in the kidney transplant population [44].

The Edmonton Symptom Assessment System revised (ESASr) [48–51] is a symptom screening tool to assess nine common symptoms including pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, and wellbeing. Each of these items is rated on a scale from 0 to 10, with 0 indicating that the symptom is not experienced and 10 indicating that the symptom is the worst possible. The ESAS has been validated in patients with ESKD on dialysis [48, 52] and has been validated in a single-kidney transplant cohort [53]. It has been endorsed by the Kidney Disease: Improving Global Outcomes (KDIGO) organization, as well [54].

We have chosen the PHQ-9 and the GAD-7 instruments, as they are brief, include simple questions and both of them are freely available (as opposed to the Hospital Anxiety and Depression Scale, for example). These tools have been widely used in general practice, i.e., in patients with various chronic medical conditions and in patients with end-stage kidney disease [55–58]. They are frequently used together and the combined score has been validated in ESKD [59]. Both tools have been recommended or endorsed for screening of depression, anxiety, or psychological distress by the American Society of Clinical Oncology [60], the Canadian Association of Psychosocial Oncology [61], and the British Columbia Renal Agency [62].

The Patient Health Questionnaire (PHQ-9) [55, 58, 63] is used to assess depressive symptoms. The scale asks whether respondents have been bothered by depressive symptoms over the previous two-week span. It contains nine items, each querying a symptom of depression, with each item rated on a scale of 0–3 (0 "not at all," and 3 "nearly every day"). The total score is a summation of the item scores and ranges from 0 to 27. The PHQ-9 has been well validated in the ESKD population [58, 59, 64].

The Generalized Anxiety Disorder 7 item scale (GAD-7) [57, 65] is a screening tool for generalized anxiety disorder. The scale asks whether respondents have been bothered by symptoms of anxiety over the previous two-week span. It contains seven items, each representing a symptom of anxiety, with responses rated on a scale of 0–3 (0 "not at all bothered" and 3 "bothered nearly every day"). The total score is a summation of the item scores and ranges from 0 to 21.

Finally, the Social Difficulties Inventory (SDI) is a tool for screening and monitoring the social impact of diagnosis and treatment [66]. It has been developed and validated using rigorous psychometric methodology, it is shorter and more comprehensive than many of the tools available to measure everyday social problems [67, 68]. The tool contains 21 items, each querying an area of social functioning, with each item rated on a scale of 0–3 (0 "no difficulty" and 3 "very much difficulty"). It is a comprehensive measure of the impact of chronic illness on the social domain [67, 68], and is shorter and more comprehensive than many of the tools available to measure everyday social problems. The SDI also offers a validated cut-off score to identify patients with potentially clinically significant social distress. Although it has not been validated in patients with chronic kidney disease, our preliminary findings support its use in this patient population [69, 70].

Statistical analysis

Descriptive statistics

Baseline characteristics were examined using frequencies, means, and standard deviations. Floor and ceiling effects were reported for each domain as the proportion of patients with the minimum or maximum theoretically possible score on each respective measure. Internal consistency was

estimated by computing Cronbach's alpha. Alpha values > 0.90 are considered excellent, 0.80–0.89 are considered good, and 0.70–0.89 are considered acceptable [71, 72]. Test–retest reliability was assessed using the intraclass correlation coefficients (ICC), with values > 0.90 indicating excellent reliability, and values between 0.75 and 0.89 indicating good reliability [73].

The dimensional structure of each of the PROMIS domains was examined with confirmatory factor analysis (CFA) models. Each CFA model tested a single-factor structural equation using a maximum likelihood estimation for each domain measure. Model fit was assessed with the Comparative Fit Index (CFI) and the root mean square error of approximation (RMSEA). CFI values above > 0.95 and RMSEA values < 0.05 indicate good model fit [74, 75].

Construct (convergent) validity was examined using Spearman's rank correlations between the PROMIS-57 and -29 scores and key legacy measures. For each PROMIS domain, the following legacy measures were principal validity targets: PROMIS Anxiety: GAD-7; PROMIS Physical Function: SF-12 PCS; PROMIS Depression: PHQ-9; PROMIS Fatigue: ESAS Tiredness item; PROMIS Pain Interference: ESAS Pain item; PROMIS Sleep Disturbance: PHQ Sleep item; and PROMIS Ability to Participate in Social Roles and Activities: SDI Score. Correlation coefficients 0.7–0.9 are considered large, and 0.5–0.7 are considered moderate [76]. Moderate or large correlations were considered to indicate construct validity.

Construct validity was also examined using known-groups analysis, which determined whether PROMIS scores were different between pre-defined socio-demographic and clinical groups that were expected to have different levels of HRQOL based on clinical experience and previous research. Known-groups differences in PROMIS scores were examined with independent samples *t* tests or Mann–Whitney U test when non-parametric tests were required. In addition, effect sizes were calculated as Cohen's *d* (mean difference in PROMIS score divided by the pooled standard deviation). Values > 0.8 are considered a large effect size, 0.50–0.79 considered a medium effect size, and 0.20–0.49 considered a small effect size [77, 78]. For all statistical analyses, *p* values < 0.05 were considered statistically significant, and all statistical tests were performed using Stata, version 13.0 (StataCorp, College Station, Tx).

Results

Study participants

Of the 298 patients invited to participate in the study, 91 patients declined and 30 did not fully complete the measures. The final study cohort included 177 patients (Fig. 1).

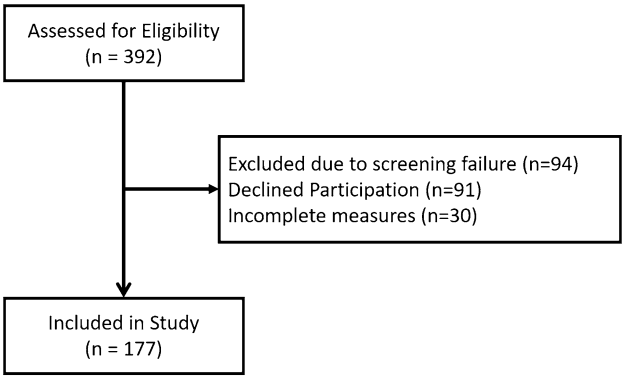

Fig. 1 Patient flow diagram

Table 1 Patient characteristics at baseline ($N = 177$)

Characteristic	
Sex [*n* (%)]	
Male	102 (58)
Female	75 (42)
Age, mean (SD)	50.6 (17.0)
Ethnicity[*n* (%)]	
Caucasian	98 (55)
Black	19 (11)
East Asian	8 (5)
South Asian	33 (19)
Other/unknown	19 (11)
Education [*n* (%)]	
Less than high school	14 (8)
High school and/or some college	71 (40)
College/university degree	83 (47)
Marital status [*n* (%)]	
Single	45 (25)
Married or common-law	106 (60)
Divorced, widowed, or separated	24 (14)
Income (in CAD/year) [*n* (%)]	
30,000 or below	25 (14)
30,001 to 70,000	57 (32)
> 70,000	55 (31)
Prefer not to answer	42 (24)
CCI score [*n* (%)]	
2 or less	72 (41)
3–4	54 (31)
5+	37 (21)
Diabetes mellitus [*n* (%)]	
Yes	50 (28)
No	127 (72)
eGFR (in mL/min/1.73 m^2), mean (SD)	59 (24)
Serum albumin (in g/L), mean (SD)	42 (3)
Hemoglobin (in g/L), mean (SD)	126 (16)
Transplant vintage (years), mean (SD)	9 (9)

The majority of the cohort were male (57%) and Caucasian (55%), and the mean (SD) age was 50 (+/− 17) years. The mean estimated glomerular filtration rate was 59 (24), 28% had diabetes mellitus as the etiology of ESKD, and the median CCI was 3 (range 2–9; IQR 2–4). The average time from transplant was 9 years (SD 9; median 6.5; IQR 1.3–12.8) years (Table 1).

Distribution of PROMIS and legacy measures

The mean scores for individual domain means for PROMIS-57 and -29 ranged between 46 and 53, and between 47 and 53, respectively (Table 2). Ceiling and floor effects were noted for both the PROMIS and the legacy measures, with the greatest floor effect seen in pain interference (ESAS Pain: 49%, PROMIS-29: 48%, PROMIS-57: 46%) (Table 3). Notably, for most domains, floor effects were smaller for PROMIS scales than for the legacy measures (Fig. 2).

Reliability

Internal consistency for each of the PROMIS domains was most often excellent or approaching that threshold (≥ 0.90), with Cronbach's alpha for PROMIS-57 (8-item short forms) between 0.93 and 0.98 and for PROMIS-29 (4-item short forms) between 0.88 and 0.95 (Table 2).

Of the 177 participants that completed the baseline questionnaires, 55 of them completed the PROMIS profiles retest within an average of 27.0 (7.0) days. The test and retest values did not differ significantly, and ICCs were good (> 0.70); with the exception of the anxiety short form (PROMIS 57: mean difference [MD] = 2.4, $p = 0.02$, ICC = 0.73; PROMIS 29: MD = 3.0, $p = 0.007$, ICC = 0.62) (Table 3).

Structural validity

Most domains within PROMIS-57 demonstrated good model fit, with CFI values ranging from 0.86 to 0.97 and RMSEA values ranging between 0.042 and 0.087 (Table 4). The PROMIS-57 anxiety, depression, and fatigue domains evidenced good fit (CFI > 0.95, RMSEA < 0.05), while pain interference (CFI = 0.95, RMSEA = 0.061), sleep disturbance (CFI = 0.89, RMSEA = 0.061), ability to participate in social roles (CFI = 0.86, RMSEA = 0.087), and physical function (CFI = 0.93, RMSEA = 0.058) fell somewhat below this threshold. Most domains within PROMIS-29 demonstrated good model fit with CFI values > 0.95 and RMSEA values ranging from 0.036 to 0.078 (Table 4). The PROMIS-29 anxiety, depression, fatigue, pain interference, and ability to participate in social roles and activities domains evidenced good fit (CFI > 0.95, RMSEA ≤ 0.05), while the physical function (CFI = 0.99, RMSEA = 0.051)

Table 2 Distribution of PROMIS scores by domain

	n	Mean	SD	Median	25%	75%	Min	Max	α[a]	ICC[b]
Anxiety										
PROMIS-57	169	49.21	10.32	49.4	37.1	57.4	37.1	78.2	0.96	0.73
PROMIS-29	170	51.07	9.7	51.2	40.3	57.7	40.3	81.6	0.92	0.62
Depression										
PROMIS-57	168	47.38	9.51	44.7	38.2	53.7	38.2	81.3	0.96	0.85
PROMIS-29	167	48.24	8.70	41.0	41.0	53.9	41.0	79.4	0.92	0.80
Sleep disturbance										
PROMIS-57	168	47.62	10.53	47.3	40.4	54.3	30.5	77.6	0.93	0.83
PROMIS-29	168	47.54	9.76	48.4	41.1	54.2	32.0	73.3	0.88	0.82
Fatigue										
PROMIS-57	169	49.61	10.94	49.2	41.0	57.5	33.1	77.8	0.97	0.77
PROMIS-29	169	49.22	10.68	48.6	43.1	57.0	33.7	75.8	0.94	0.72
Pain interference										
PROMIS-57	166	50.32	10.24	49.9	40.7	55.8	40.7	77.0	0.99	0.75
PROMIS-29	164	50.52	9.91	49.6	41.6	56.4	41.6	75.6	0.93	0.76
Physical function										
PROMIS-57	171	46.78	9.60	46.4	39.4	59.7	27.9	59.7	0.95	0.89
PROMIS-29	170	48.24	9.39	48.0	40.4	56.9	26.9	56.9	0.91	0.93
Ability to participate in social roles and activities										
PROMIS-29	168	52.97	9.26	51.6	44.8	64.1	29.0	64.1	0.95	0.70
PROMIS-57	167	52.46	9.73	52.7	44.0	60.2	25.9	65.4	0.97	0.76

[a]Cronbach's alpha

[b]Intra-class correlation coefficient

Table 3 Ceiling and floor effects of PROMIS and legacy measures

	PROMIS-57		PROMIS-29		Legacy questionnaires		
	Floor (%)	Ceiling (%)	Floor (%)	Ceiling (%)		Floor (%)	Ceiling (%)
Anxiety	32	1	36	1	GAD7	43	1
Physical function	3	26	1	50	SF-12 PF	1	1
Depression	21	1	31	1	PHQ9	31	1
Fatigue	15	1	18	2	ESAS tiredness	29	1
Pain interference	46	2	48	2	ESAS pain	49	1
Sleep disturbance	13	1	14	2	PHQ sleep	52	11
Ability to participate in social roles and activities	1	23	1	33	SDI score	33	1

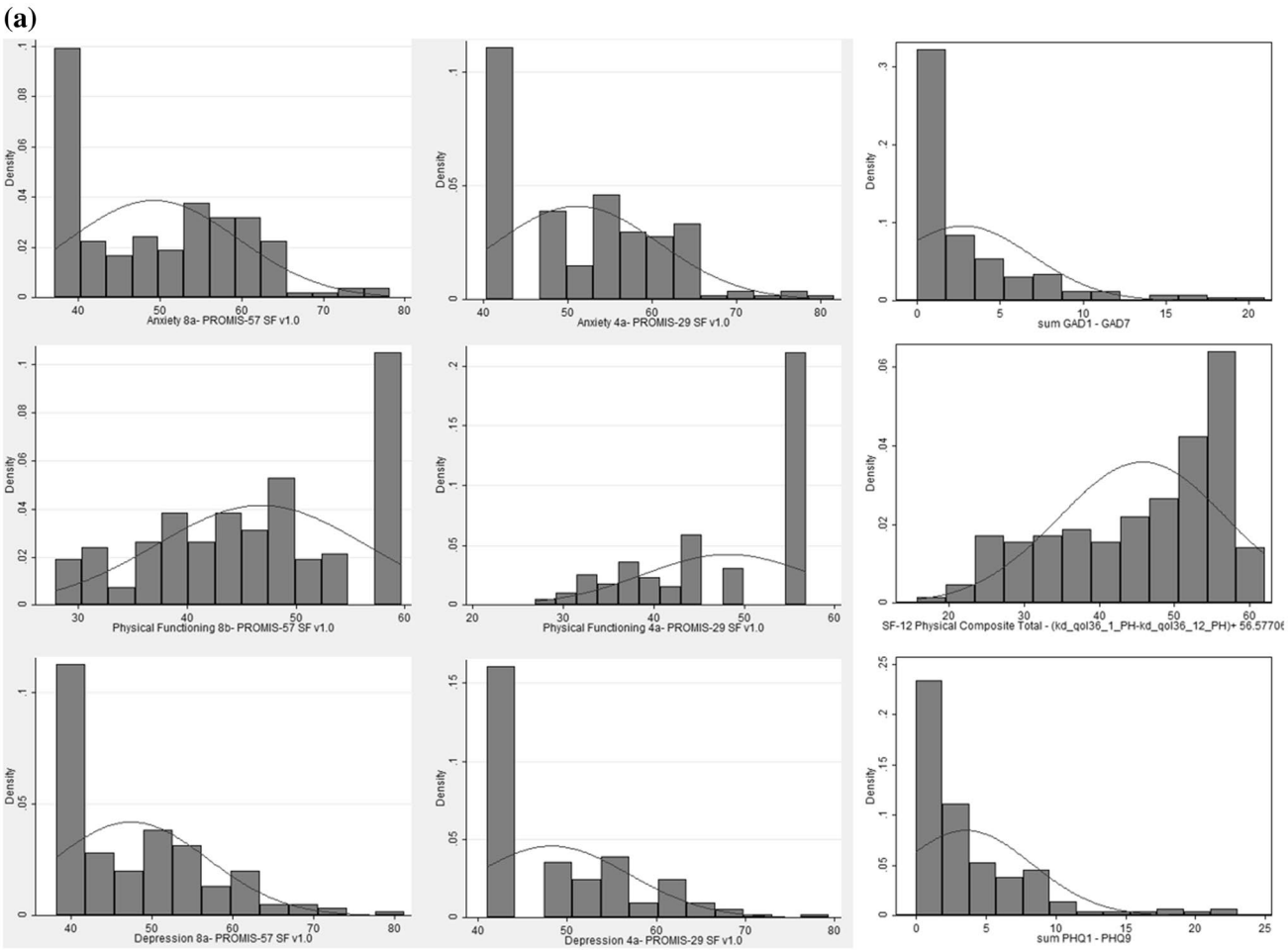

Fig. 2 Distribution of PROMIS and legacy measure scores

and sleep disturbance (CFI = 0.95, RMSEA = 0.078) domains had adequate fit.

Construct validity

All PROMIS-57 domain measures had strong correlations with the corresponding legacy instrument. The strongest correlation was observed between PROMIS-57-PF and SF-12 PCS ($r = 0.806$, 95% CI 0.745–0.853) and the weakest correlation was between PROMIS-57-Pain Interference and ESAS Pain ($r = 0.666$, 95% CI 0.568–0.746). Similarly, all PROMIS-29 domain measures had strong correlations with the corresponding legacy instruments. The strongest correlation was seen between PROMIS-29-PF

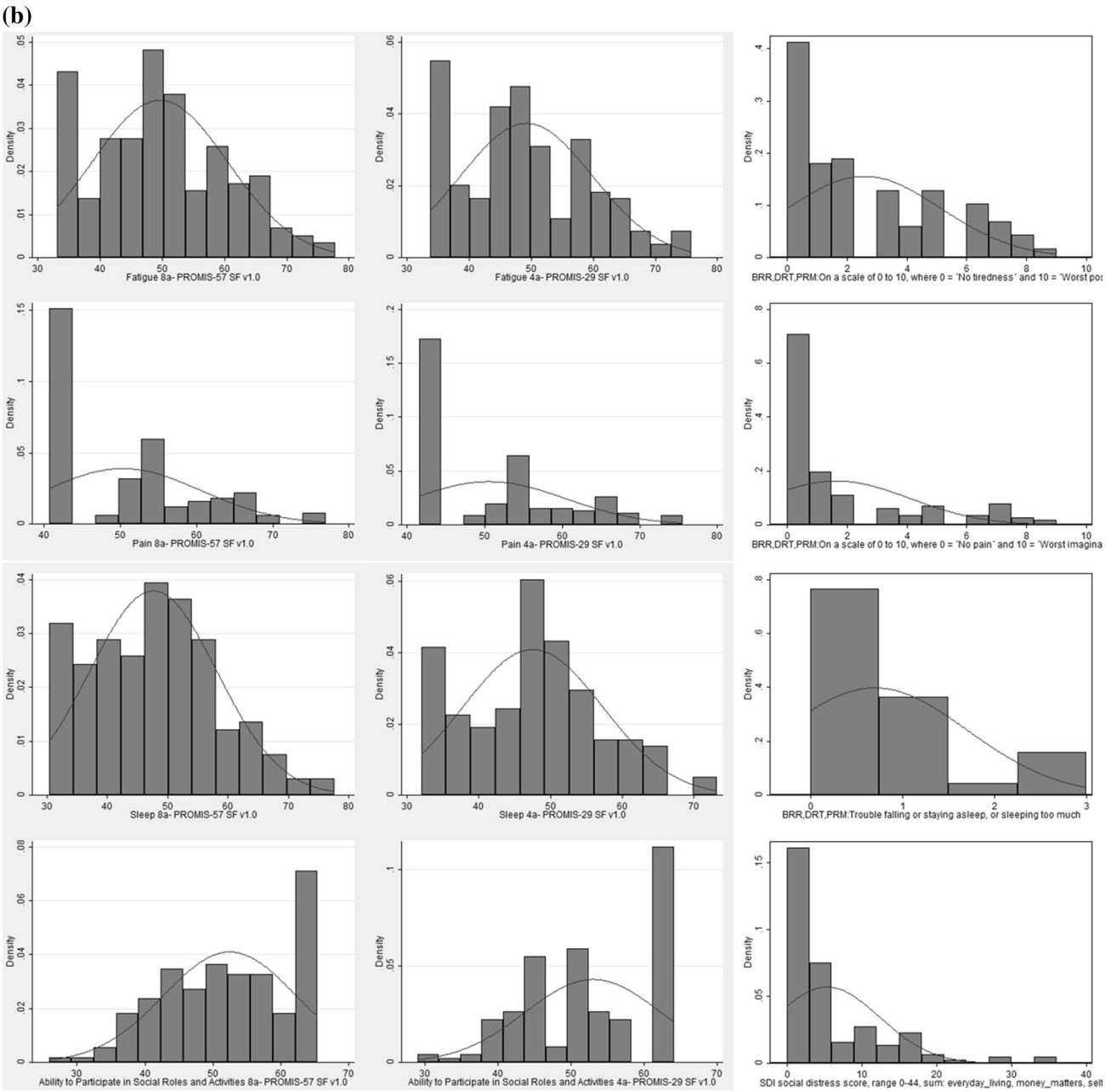

Fig. 2 (continued)

and SF-12 PCS ($r = 0.789$, 95% CI 0.723–0.840) and the weakest correlation was between PROMIS-29-Depression and PHQ-9 Score ($r = 0.634$, 95% CI 0.526–0.721). The correlations of PROMIS-57 and PROMIS-29 domain measures against the legacy measures are shown in Table 4.

Known-groups comparisons were conducted comparing PROMIS scores between subgroups of the sample where a difference was expected based on clinical or socio-demographic characteristics (Table 5). Compared to males, females had higher mean PROMIS-57 anxiety scores (Cohen's d [d] = 0.54; $p < 0.001$), Depression scores ($d = 0.36$; $p = 0.02$), and sleep disturbance scores ($d = 0.43$; $p = 0.01$). Relative to older patients (> 65 years old), younger patients (< 50 years old) had higher mean PROMIS Anxiety scores ($d = 0.49$; $p = 0.02$), and depression scores ($d = 0.51$; $p = 0.02$). Patients with a high CCI score (5+) had a lower mean PROMIS Physical Function score ($d = 0.51$; $p = 0.01$).

Table 4 Correlation of PROMIS scores with legacy kidney transplant measures

Domain	Principal legacy	PROMIS-57			PROMIS-29		
		CFI	RMSEA	Correlation coefficient	CFI	RMSEA	Correlation coefficient
Anxiety	GAD7	0.97	0.042	0.760 (0.683 to 0.820)	0.99	0.050	0.730 (0.645 to 0.798)
Physical function	SF-12 PF	0.93	0.058	0.806 (0.745 to 0.853)	0.99	0.051	0.789 (0.723 to 0.840)
Depression	PHQ9	0.97	0.045	0.676 (0.578 to 0.755)	0.99	0.036	0.634 (0.526 to 0.721)
Fatigue	ESAS tiredness	0.97	0.044	0.722 (0.636 to 0.790)	0.99	0.045	0.725 (0.640 to 0.792)
Pain interference	ESAS pain	0.95	0.061	0.666 (0.568 to 0.746)	0.99	0.050	0.671 (0.573 to 0.750)
Sleep disturbance	PHQ sleep	0.89	0.066	0.682 (0.585 to 0.759)	0.95	0.078	0.683 (0.587 to 0.760)
Ability to participate in social roles and activities	SDI score	0.86	0.087	− 0.700 (− 0.774 to − 0.606)	0.99	0.039	− 0.695 (− 0.771 to − 0.601)

CFI Comparative fit index, *RMSEA* Root mean square error of approximation

Discussion

Results of this study provide new information about the validity of the PROMIS-57 and PROMIS-29 short forms among KT recipients. These two instruments were selected as they represent key domains affecting health-related quality of life within the KT population [79–82]. Our results suggest that both PROMIS-57 and PROMIS-29 have strong evidence of reliability and validity in KT recipients as evidenced by strong internal consistency, test–retest reliability, convergent validity, and known-groups validity.

Scores on the two profiles that we tested correlated highly with the legacy instruments. While the PROMIS-29 has the advantage of reducing responder burden and improving ease of administration, the PROMIS-57, which uses eight items to assess each domain, offers greater precision and reliability of the scores.

Similar to legacy scales, some evidence of ceiling and floor effects was noted, an observation that has been consistent in other PROMIS validation studies [31, 83]. Most PROMIS domains demonstrated a smaller such effect when compared to legacy instruments. These effects can be, in part, explained by the fact that our participants were stable KT recipients, who were generally doing well which was reflected in mean scores close to the general population. These effects may also be attributed to the relative shortness of the instruments (4 or 8 questions), which can limit the breadth of measurement [84–86]. Shorter scales have the advantage of reducing responder burden and improving ease of administration, an important consideration for clinical implementation. Alternatives to fixed short forms may come in the form of computer adaptive testing or optimizing instruments with additional questions [87].

Overall, there was strong evidence of internal consistency and test–retest reliability of the PROMIS profiles. One exception was the stability of the Anxiety scores. However, it is likely that this can be attributed to the longer-than-ideal period between the baseline administration and the follow-up. It is also likely that anxiety levels can change within short periods of time and are more sensitive to variations in everyday life or non-health-related factors [10, 88, 89].

Likewise, the findings for known-groups comparisons also supported the validity of these measures in KT populations. We hypothesized that younger patients would report more stress and depressive symptoms compared to older patients [90–92]; our results confirmed this hypothesis. We also hypothesized that as compared to older participants, younger individuals would report higher physical function [93]. While a trend was seen in the hypothesized direction, it did not reach statistical significance. Furthermore, we expected females to have higher depression and anxiety scores [90, 94], that was confirmed by the results, providing further evidence to support the validity of these measures. When assessing by comorbidity, we hypothesized that a higher comorbidity (CCI > 3) would be associated with lower physical function scores [95]. In our results, physical function followed the expected trend.

We acknowledge that we considered several pragmatic factors when choosing the legacy questionnaires for this project, in addition to established validity. Accordingly, we considered brevity, simplicity, and availability in the public domain. Finally, we also considered endorsement or recommendation by relevant professional organizations.

This study has several strengths. Our sample was sociodemographically and ethno-culturally diverse, with 45% of the sample representing minorities and less than half having a college degree. Patients completed the questionnaires while receiving routine care, illustrating the feasibility of using the measures in real-world KT settings. However, there are also limitations that need to be considered when interpreting the results. We did not assess content validity of the item banks, as we felt that had been tested extensively

Table 5 Known-groups comparison of PROMIS profile scores

	Age (mean, ± SD)				Gender (mean, ± SD)				CCI Score (mean, ±SD)			
	Young (< 50)	Old (> 65)	*p* value	*d*	Male	Female	*p* value	*d*	Bottom tertile (< 3)	Top tertile (5+)	*p* value	*d*
Anxiety	50.5 ± 11.1	45.4 ± 8.9	0.02	0.49	46.9 ± 9.3	52.4 ± 10.9	0.00	0.54	49.8 ± 9.8	48.3 ± 10.6	0.46	0.16
Depression	48.8 ± 10.2	44.1 ± 7.7	0.02	0.51	45.9 ± 8.5	49.4 ± 10.5	0.02	0.36	47.4 ± 8.6	46.2 ± 9.2	0.50	0.14
Sleep disturbance	47.1 ± 10.7	43.8 ± 9.5	0.14	0.32	45.7 ± 9.6	50.2 ± 11.2	0.01	0.43	47.7 ± 11.6	46 ± 9.9	0.44	0.00
Fatigue	49.3 ± 10.3	46.3 ± 10.8	0.17	0.26	48.2 ± 10.6	51.5 ± 11.2	0.06	0.27	48.4 ± 11.5	50.3 ± 10.8	0.39	0.05
Pain	47.3 ± 9.1	48.6 ± 9.7	0.51	0.14	50 ± 10.1	50.8 ± 10.5	0.62	0.07	48.3 ± 9.9	51.1 ± 9.8	0.18	0.22
Physical function	50.4 ± 8.9	47.1 ± 9.3	0.08	0.37	47.6 ± 9.9	45.7 ± 9.1	0.19	0.19	50 ± 9.3	45.2 ± 9.6	0.01	0.51
Ability to participate in social roles and activities	54.5 ± 9.2	54.2 ± 9.2	0.86	0.04	53.3 ± 9.5	51.4 ± 10	0.22	0.19	54.6 ± 10.1	51.4 ± 9	0.11	0.27

CCI Charlson comorbidity index, *d* Cohen's *d* effect size

during item bank development, and we felt it reasonable to assume content validity in patients with advanced kidney disease. We do believe, however, that well-developed and validated generic measures can be regarded as "fit for purpose" in specific clinical settings where content validity has not been previously documented [40]. We used a convenience sample of patients seen in the largest kidney transplant center in Canada who were stable post-transplant and administered English versions of PROMIS. To assess responsiveness, longitudinal studies with administration of the questionnaires prior to KT and during recovery and long-term follow-up are needed. T scores were calibrated to the US general population mean [41] and there are no norms available for Canadian patients. Test–retest scores should be compared over a shorter time period to assure respondents are clinically stable. Future studies also should assess the responsiveness of the PROMIS instruments to changes in clinical status. In addition, defining clinically meaningful cut-offs will facilitate clinical implementation of these tools.

Conclusion

This study provides new evidence offering support for the validity and reliability of PROMIS profiles (PROMIS-57 and PROMIS-29) measures in KT patients. Future studies confirming the content validity of the PROMIS item banks in patients with chronic kidney disease will further strengthen the confidence in the validity of the PROMIS item banks for use in patients with chronic kidney disease.

PROMIS tools, which can be completed in a few minutes, can offer a reliable and precise assessment of multiple aspects of physical, emotional, and social health in patients with KT. In our sample of stable post-transplant patients, most participants reported relatively few symptoms and were able to function well in day-to-day life. Importantly, PROMIS profiles can be easily reviewed by clinicians to help quickly identify patients who experience clinically significant symptoms and functional impacts that have negative impact on their health-related quality of life.

Compliance with ethical standards

Conflict of interest The author(s) have no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval Ethical approval for this study was obtained from the University Health Network (REB# 15-9645). All study procedures were conducted in accordance with the standards of the University Health Network research ethics board and with the 1964 Helsinki declaration and its later amendments.

Informed consent All participants signed a written informed consent form.

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