

Table S2. Instrument validity and reliability testing.^a

| Instrument | Content validity | Construct validity ^b | Internal consistency reliability | Test-retest reliability | Responsiveness ^c |
|--|--|---|--|--|---|
| <i>Developed in dialysis populations</i> | | | | | |
| 100 Category Checklist ^{61, 72} | Patient review ♦ Expert review | r= -0.24- -0.32 (p<0.05) for 9 of 40 body function categories and KDQOL kidney disease-targeted scales ♦■ Higher body function scores in patients with anemia (p<0.01) and higher body structure scores in patients with secondary hyperparathyroidism (p=<0.01) vs. in patients without ♦■ [known groups validity] | Cronbach's α=0.78 for body function, 0.50 for body structure, and 0.86 overall ♦■ | NR | NR |
| CHOICE Health Experience Questionnaire (CHEQ) ^{13, 73} | Structural literature review Patient focus groups ♦ Patient review ♦ Expert review ¹³ | Symptoms score=76 for PD and 78 for HD patients (p=NS) Symptom scores=79 for ICED= 0-1, 75 for ICED=2, and 77 for ICED=3 (p=NS) Sex score=67 for HD and 58 for PD patients (p≤0.01) ¹³ ♦■ [known groups validity] | Cronbach's α>0.7 for all multi-item scales except for time and quality of life ♦ ICC=0.81 (symptoms) ⁷³ ♦■ | ICC= 0.55-0.79 (baseline, 1 year) ⁷³ ♦ | NR |
| Curtin, et al. ⁶³ | Literature review Patient interview ⁶³ ♦ | r= -0.061- -0.460 (p<0.05) for >75% of instrument symptoms and MOS SF-36 PCS ⁶³ ♦■ | Cronbach's α=0.78 for fatigue/sleep sub-index and 0.89 for sexual concerns sub-index ⁶³ ♦■ | NR | NR |
| Dialysis Symptom Index (DSI) ¹⁹ | Patient focus group ♦ Provider focus group Existing instrument review Patient review ♦ Expert review ¹⁹ | NR | NR | Kappa= 0.06-0.90 (mean 0.48 ± 0.22) ¹⁹ ♦■ | NR |
| Fluid Management Survey ⁵³ | Patient focus group ♦ Expert review Patient review ⁵³ ♦ | NR | Cronbach's α 0.72 (fluid-related symptoms) ⁵³ ♦■ | Kappa= 0.53-0.88 (baseline, 2 weeks) ⁵³ ♦ | NR |
| Hemodialysis Quality of Life Questionnaire (HQL) ^{14, 64} | Patient interviews ♦ Expert interviews Patient review ¹⁴ ♦ | NR | NR | ICC 0.91-0.95 (p<0.001 for all) for 5 domains (baseline, 6-8 weeks) ¹⁴ ♦■ | RR= 7.94 (Z=2.07) ^d for boredom; other symptoms non-significant (Kt/V <0.8, improve to Kt/V >1.0) ¹⁴ ♦■ |

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| Kidney Disease Quality of Life Instrument (KDQOL) ^{12, 74-77} | Literature review Patient focus groups ♦ Expert focus groups ¹² | F=22.5 for energy/fatigue and F=17.8 for symptom/problems scale displaying sensitivity to differences in the number of good days reported in a typical week ^f ⁷⁸ ♦■ <i>[known groups validity]</i> r=0.62 for KDQOL symptoms/ problems and EuroQOL overall health rating; r=0.76 for KDQOL overall health rating and EuroQOL overall health rating (p<0.05 for both) ⁷⁴ ♦■ p<0.05 for symptoms/problems correlation with serum albumin (r=0.14) and change in GFR (r=0.17) (3m, 12m after dialysis initiation) ⁷⁴ ♦■ | Cronbach's α 0.80 for symptom/ problems scale ⁷⁴ ♦■ Cronbach's α 0.69 for dialysis-related symptoms; 0.79 for cardiopulmonary symptoms; 0.82 for sleep; 0.92 for energy; 0.73 for cramps; 0.66 appetite ⁷⁵ ♦■ | NR | ANOVA p<0.05 for dizziness, nausea, chest pain; other symptoms non-significant (conventional vs. high-flux dialysis) ⁶⁴ ♦■ X ² p>0.20 for differences in sexual questions baseline to 6 months for nocturnal HD (vs. conventional HD) ⁷⁶ ♦■ Wilcoxon rank test p=0.50 for symptom score change and paired t-test p=0.03 for energy/fatigue from baseline to weeks 7 and 11 among HD patients treated with acupuncture ⁷⁷ ♦■ |
| Kidney Disease Questionnaire (KDQ) ^{11, 15, 65, 66} | Patient interviews ♦ Expert interviews ¹⁵ | r= -0.31 (p<0.01) for KDQ physical symptoms with Sickness Impact Profile physical component ¹⁵ ♦■ | reliability scores ^e >0.70 for all 5 dimensions ⁶⁶ ♦■ | ICC 0.85 (physical symptoms and fatigue) (baseline, 2 months) ¹⁵ ♦■ | ANOVA p<0.001 improvement in physical symptoms and fatigue in ESA-treated (vs. placebo) ^{11, 15} ♦■ ANOVA p<0.005 improvement in weakness, low energy, felt worn out, sluggish, and difficulty because of little strength in ESA-treated group (vs. placebo) ⁶⁵ ♦■ |
| Modified Edmonton | Patient survey ⁷⁹ ♦ | r= -0.69 (p<0.01) for overall symptom distress and KDQOL-SF symptom list | Cronbach's α 0.61-0.81 ⁴⁸ ■ | ICC= 0.53-0.71 (baseline, 1 week) ⁵ ♦■ | r= -0.73 (p<0.01) for change in overall symptom distress |

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| Symptom Scale (mod-ESAS) ^{5, 48, 49, 79, 80} | | r= -0.19 - -0.56 (p<0.01) for ESAS-listed symptoms and KDQOL-SF physical health composite and r= -0.22 - -0.62 (p<0.01) for KDQOL-SF mental health composite ⁵ ◆■ | Overall Cronbach's α 0.79 ⁴⁹ ■ [both for non-modified Edmonton symptom scale] | | score and change in KDQOL-SF symptom list (baseline, 6m) ⁸⁰ ◆■ |
| National Kidney Dialysis and Kidney Transplantation Study (NKDKTS) ^{16, 67} | Patient review ◆ Patient interviews ¹⁶ ◆ | ANOVA p=0.02 across patients with different hemoglobin levels at different time-points, patients with lower hemoglobin had lower scores ⁶⁷ ◆■ [known groups validity] | Cronbach's α 0.86 at baseline, 0.89 at 48 hours, 0.90 at 7 days; Cronbach's α decreased if any item was removed ⁶⁷ ◆■ | ICC 0.59-0.82 (p<0.001) (baseline, 2 days) ⁶⁷ ◆■ | NR |
| Parfrey Symptom Assessment ¹⁷ | Patient interviews ◆ Patient review ¹⁷ ◆ | ANOVA p=0.004 for symptom score difference between transplant and dialysis patients ¹⁷ ◆■ [known groups validity] | NR | NR | Symptom scores improved post-transplant (p=0.007) ¹⁷ ◆■ |
| Physical Symptom Distress Scale ⁶⁸ | Literature review Expert review ⁶⁸ | r= -0.46 (p<0.0001) for overall scale and the KPS ⁶⁸ ◆■ | Cronbach's α 0.87 ⁶⁸ ◆ | ICC= 0.82 (baseline, 2 weeks) ⁶⁸ ◆■ | |
| Short-Version Checklist ⁶² | Patient review ◆ Expert review | r= 0.23- 0.43 (p<0.05) for 8 of 17 body function categories and KDQOL kidney disease-targeted scales ◆■ Higher body function scores in patients with carpal tunnel syndrome (p<0.05) and patients with anemia (p<0.01) and higher body structure scores in patients with carpal tunnel syndrome (p<0.01) and patients with anemia (p<0.05) vs. in patients without ◆■ [known groups validity] | Cronbach's α =0.79 overall ◆■ | NR | NR |
| Developed in non-dialysis populations | | | | | |
| Bowel Disease Questionnaire ^{81, 82} | Expert review Patient review ⁸² | NR | NR | Kappa= 0.56-0.86 (baseline, 1 week, and 7 weeks) ⁸¹ | NR |
| European Organization for Research and | Expert consensus ⁸³ | r= 0.05- 0.35 (0.22, p<0.05 for fatigue and 0.35 for sleep disturbance, p<0.01) for EORTC-QLQ symptoms and HADS | Cronbach's α 0.86 (fatigue, pain, nausea/vomiting) ⁸⁴ ■ | NR | NR |

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| Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ-C30) ^{20, 83, 84} | | anxiety composite and $r=0.02-0.38$ (0.34 for fatigue, 0.28 for dyspnea, 0.38 for sleep disturbance, all $p<0.01$) for HADS depression composite ⁸⁴ ■ | | | |
| McGill Quality of Life Questionnaire (MQOL) ^{18, 85, 86} | Literature review Expert experience Patient interviews ¹⁸ | $r=0.56$ ($p=0.0005$) for physical symptom subscale and Spitzer's health item ¹⁸ ■ | Cronbach's α 0.70 ¹⁸ and 0.62 ⁸⁵ for physical symptom subscale ■ | ICC 0.69 for physical symptom subscale (baseline, 2 days) ⁸⁶ ■ | NR |
| Memorial Symptom Assessment Scale (MSAS) ^{23, 87} | Literature review ²³ | $r=0.87$ for distress scores, $r=0.85$ for frequency scores, and $r=0.84$ with validation measures- FLIC, RAND distress, RAND well-being, KPS and mood VAS ²³ ■ $r=-0.66$ for MSAS-GDI (4 psychological and 6 physical symptoms) and RAND well-being; $r=0.79$ for RAND distress; $r=-0.60$ for KPS ²³ ■ MSAS-GDI scores= 0.93 for outpatients and 1.53 for inpatients ($p<0.001$) ²³ ■ [known groups validity] | Cronbach's α 0.88 (12 physical symptoms), 0.84 (pain symptoms), 0.75 (gastrointestinal distress), 0.58 (15 physical symptoms distinguished from other symptoms based on low frequency) ²³ ■ Cronbach's α 0.84 (all questions); 0.65-0.75 (subscales) ⁸⁷ ◆■ | NR | NR |
| Nottingham Health Profile (NHP) ^{21, 45, 88} | NR | $r>0.7$ for energy (NHP) and physical symptoms and fatigue from KDQ ⁴⁵ ◆■ | Cronbach's α 0.64-0.79 ⁴⁵ ◆ | $r=0.61-0.84$ (baseline, 2 weeks) ⁴⁵ ◆■ | McNemar $p=0.001$ for energy, $p=0.25$ for pain, and $p=0.12$ for sleep between baseline and 2 nd follow-up among HD patients treated with ESA ⁸⁸ ◆■ |
| Palliative Care Outcome Symptom Scale-Renal (POS-S Renal) ⁶⁹ | Literature review Patient interviews Expert interviews Patient review ⁶⁹ | $r=0.51$ ($p=0.005$) POS and EORTC QLQ-C30 physical symptoms ⁶⁹ | Cronbach's α 0.65 ⁶⁹ | Kappa= 0.10-0.43 for symptom-related items (consecutive visits, interval time not specified) ⁶⁹ ■ | NR |
| Quality of Life at the End of Life (QUAL-E) ^{89, 90} | Patient interviews ◆ Family interviews Patient review ◆ | $r=0.23$ ($p<0.01$) QUAL-E symptoms and FACIT physical well-being subscale ⁹⁰ ◆ | Cronbach's α 0.87 for symptom impact ⁹⁰ ◆■ | ICC=0.23 for symptom impact (baseline, 1 week) ⁹⁰ ◆■ | NR |

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| | Family member review Expert review ^{89, 90} | r= -0.12 (p=NS) QUAL-E symptoms and Missoula-VITAS QOL Index symptom subscale ⁹⁰ ♦ | | | |
| Quality of Well Being Self-Administered Scale (QWB-SA) ^{70, 91-94} | NR | r= -0.45 (p<0.01) QWB-SA and Sickness Impact Profile total score ⁷⁰ | NR | r=0.77 (baseline, 1 month) ⁹² r=0.80-0.97 (day 1, day 2) ⁹⁴ | NR |
| Rotterdam Symptom Checklist (RSCL) ^{22, 71, 95, 96} | Literature review Expert review ⁷¹ | r= -0.67 (p=0.001) RSCL physical symptom distress and Medical Outcome Study (MOS-20) physical function ⁷¹ | Cronbach's α 0.82 for physical distress scale ²² ■ Cronbach's α 0.68-0.85 at baseline ⁹⁵ | NR | NR |
| Symptom Distress Scale (SDS) ^{23, 44, 97-100} | Literature review Patient interviews ⁹⁷ | r=0.60 (p==x) SDS and Sickness Impact Profile ⁹⁹ ■ r=0.65 (p=x) SDS and KPS ¹⁰⁰ ■ p<0.002: more symptom distress in hospitalized vs. non-hospitalized patients and p<0.0001 in low vs. high performance status ²³ ■ <i>[known groups validity]</i> | Cronbach's α 0.70-0.92 in over 40 studies in different populations ⁴⁴ ■ | ICC=0.78 (baseline, 1 month) ⁴⁴ ■ | NR |

^a Results for symptom-specific domains and questions reported when available. ESRD population specific data reported when available.

^b Construct validity reported as congruent validity unless otherwise noted.

^c Responsiveness to change reported only when tested in a dialysis population.

^d Relative risk of an increase of 1 unit for patients with an increase in Kt/V from <0.8 to >1.0 compared to those with stable Kt/V >1.0.

^e Type of reliability score not characterized.

^f F-ratios from 1-way ANOVA with KDQOL subscales for 6 different known group classifications.

♦ = tested in a dialysis population

■ = specifically evaluated for the symptom domain/ questions

Abbreviations: ESRD, end stage renal disease; PD, peritoneal dialysis, NS, non-significant; ICED, index of coexistent disease; MOS SF-36 PCS, Medical Outcomes Study Short Form Physical Component Summary; HADS, Hospital Anxiety and Depression scale; RAND well-being, Revised Rand Mental Health Inventory- positive affect; RAND distress, Revised Rand Mental Health Inventory- psychological distress; KPS, Karnofsky Performance Status Scale.