Limitations of the KDQOL for Assessing Quality of Life among Patients with End-Stage Renal Disease

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Introduction

- Quality of life is a critically important outcome for patients with end-stage renal disease (ESRD).
- Since 2008, the Centers for Medicare and Medicaid Services (CMS) have mandated annual assessment of health-related quality of life as part of its conditions for coverage for ESRD facilities.[1]
  - The Kidney Disease Quality of Life (KDQOL-36) survey, published in 2000, is the most widely used tool for this assessment.[2]
  - Its 36 questions comprise 5 subscales: Physical Component Summary (PCS), Mental Component Summary (MCS), Burden of Kidney Disease (BKD), Symptoms and Problems of Kidney Disease (SPKD), and Effects of Kidney Disease (EKD)
  - Scores range from 0-100 points, with higher scores being more favorable.
- The construct validity of the KDQOL-36 among a large, nationally representative cohort of contemporary dialysis patients has not been established.

Objective

In a large, contemporary cohort of dialysis patients:

- Determine survey response rates
- Describe distribution of component scores and responses to individual items
- Determine the correlation between component scores, individual items, and objective measures of patient health
- Compare these parameters across patients treated with different dialysis modalities

Methods

- This study considered surveys offered between 01 January 2014 and 21 December 2016 to patients who, as of survey date, were ≥18 years of age, were not Veterans Affairs beneficiaries, and were receiving dialysis care at a large dialysis organization (LDO) operating in the United States.
- Patient characteristics, dialysis treatment information, and survey responses were derived from electronic records maintained by the LDO.
  - Among patients treated with in-center hemodialysis, interdialytic weight gain (IDWG) was considered with respect to treatments occuring in the 30 days prior to the survey date. Frequent excessive IDWG was defined as gain of >5% of bodyweight in >10% of treatments.
- A survey was considered completed if the patient responded to, at minimum, items 1-12 (comprising PCS and MCS).
  - If multiple surveys were offered during a given survey window (4 months, 1 year, 2 years), only the first of the surveys was considered in the analysis.
- A survey was considered declined if the patient declined the survey outright, or failed to complete items 1-12.
  - Instances in which the survey was not offered to a patient due to health or other concerns were excluded from the analysis (ie did not count as completed or declined).
- Correlations between item responses, domain scores, and IDWG were calculated using Pearson correlations computed with pairwise complete observations.

Results

Patient Characteristics and Survey Completion

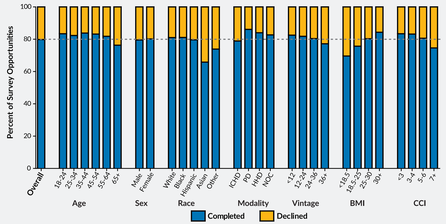
- Patients who completed KDQOL-36 surveys were, in general, younger, of shorter dialysis vintage, and had higher body mass index and lower Charlson Comorbidity Index than those who declined to complete surveys (Table 1).
- Overall survey response rate was 79.8% (Figure 1).
  - Survey response rate was lower than average among patients who were ≥65 years of age, of Asian race, patients treated with in-center hemodialysis, of ≥36 months dialysis vintage, with BMI < 25 kg/m^2 and with Charlson Comorbidity Index scores ≥ 7.

Table 1: Baseline Characteristics by Survey Completion Status

	Overall	Declined	Completed
	N = 413,951	N = 83,549	N = 330,402
Age, years, mean ± SD	61.4 ± 14.9	64.0 ± 15.2	60.7 ± 14.7
Sex, female, n (%)	183,613 (44.4)	36,323 (43.5)	147,290 (44.6)
Race, n (%)			
White	160,451 (38.8)	30,542 (36.6)	129,909 (39.3)
Black	145,729 (35.2)	27,588 (33.0)	118,141 (35.8)
Hispanic	72,769 (17.6)	14,858 (17.8)	57,911 (17.5)
Asian	17,445 (4.2)	5972 (7.1)	11,473 (3.5)
Other/unknown	17,557 (4.2)	4589 (5.5)	12,968 (3.9)
Modality, n (%)			
In-center hemodialysis	358,475 (86.6)	75,580 (90.5)	282,895 (85.6)
Peritoneal dialysis	45,903 (11.1)	6395 (7.7)	39,508 (12.0)
Home hemodialysis	6596 (1.6)	1058 (1.3)	5538 (1.7)
Nocturnal dialysis	2977 (0.7)	516 (0.6)	2461 (0.9)
Dialysis vintage, months, median [p25, p75]	29 [12, 57]	35 [15, 64]	28 [11, 56]
BMI, kg/m^2, mean ± SD	28.6 ± 7.4	27.1 ± 7.0	28.9 ± 7.4
CCI, median [p25, p75]	5 [4, 7]	6 [4, 7]	5 [4, 7]
Diabetes, n (%)	283,744 (68.5)	58,449 (70.1)	225,295 (68.2)

Abbreviations: BMI, body mass index; CCI, Charlson Comorbidity Index; SD, standard deviation

Figure 1: Survey Completion by Patient Characteristics

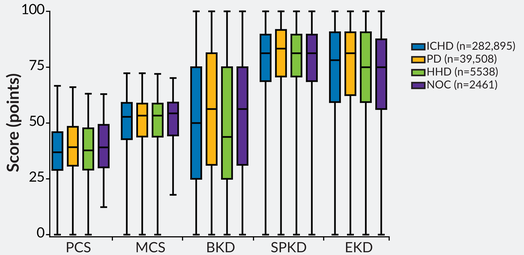


Abbreviations: BMI, body mass index; CCI, Charlson comorbidity index; HHD, home hemodialysis; ICHD, in-center hemodialysis; NOC, nocturnal hemodialysis; PD, peritoneal dialysis

Distribution of Domain Scores and Individual Item Responses

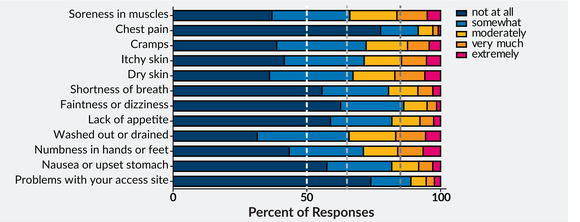
- Scores on the 5 domains of the KDQOL-36 were similar across treatment modalities (Figure 2).
  - Some differences were observed across modalities with respect to BKD, SPKD, and EKD; differences were modest.
- Scores on the SPKD were markedly skewed, with median scores above 80 points in all modalities .
  - For 3 of 12 items in this subscale, >85% of patients were "not at all" or only "somewhat" bothered.
  - For all 12 items, >65% of patients were "not at all" or "somewhat" bothered; <10% of patients were "extremely" bothered (Figure 3).

Figure 2: Domain Scores by Dialysis Treatment Modality



Plots indicate minimum, bottom quartile, median, top quartile, and maximum scores for each score and modality.
Abbreviations: HHD, home hemodialysis; ICHD, in-center hemodialysis; NOC, nocturnal hemodialysis; PD, peritoneal dialysis

Figure 3: Item Responses for Symptoms and Problems of Kidney Disease

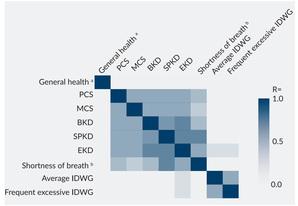


Stem: During the past 4 weeks, to what extent were you bothered by each of the following? Data represent patients treated with in-center hemodialysis only (n=282,895); similar results were obtained for patients using other treatment modalities (not shown).
White dashed line = 50%; light grey = 65%; dark grey = 85%

Correlation between KDQOL Components and Health Measures

- Patient perceptions of their general health (item 1) were not correlated (R<0.05) with any of the 5 KDQOL component scores (Figure 4).
- Correlation between KDQOL subscales was moderate (R=0.35-0.63).
  - Interdialytic weight gain was not correlated with any domain score, or with patient-reported shortness of breath (R=0.00-0.10).

Figure 4: Correlation between KDQOL Components and Health Measures



[a] Item 1: In general, would you say your health is (range: excellent - poor)
[b] Item 22: During the past 4 weeks, to what extent were you bothered by...(range: not at all - extremely).

Interdialytic weight gain (IDWG) was considered over the 30 days prior to survey administration. Excessive IDWG was considered as >5% of target weight in >10% of treatments. Data represent patients treated with in-center hemodialysis only (n=282,895). Similar results were observed for patients treated with peritoneal dialysis (data not shown).

Summary and Conclusions

- KDQOL-36 survey completion rates are high, although specific patient subgroups may be under-represented.
- Scores on the KDQOL-36 are similar across treatment modalities.
- Distribution of scores on the SPKD was high, particularly considering the low scores on PCS.
  - Some symptoms queried by the KDQOL-36 may only be relevant to a minority of contemporary dialysis patients.
- New measures of quality of life are needed that focus on factors that affect a considerable proportion of contemporary dialysis patients, and that can be addressed by modifiable clinical practices.

References

1. Centers for Medicare & Medicaid Services. Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule. *Federal Register* 73: 20370-20484, 2008.
2. https://www.rand.org/content/dam/rand/www/external/health/surveys_tools/kdqol/kdqol36.pdf

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