Health-Related Quality of Life Measures (HLT POL 239B)

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http://gim.med.ucla.edu/FacultyPages/Hays/



Health-Related Quality of Life (HRQOL) is

What you can <u>do</u>.

 <u>Functioning</u> Self-care Role Social

How you <u>feel</u> about your life.

 <u>Well-being</u>
 Emotional well-being Pain
 Energy



SF-36® Generic Profile Measure

- Functioning
 - Physical functioning (10 items)
 - Role limitations/physical (4 items)
 - Role limitations/emotional (3 items)
 - Social functioning (2 items)
- Well-Being
 - Emotional well-being (5 items)
 - Energy/fatigue (4 items)
 - Pain (2 items)
 - General health perceptions (5 items)

Scoring HRQOL Profile Scales

- Average or sum all items in the same scale.
- Transform average or sum to
 - 0 (worse) to 100 (best) possible range
 - z-score (mean = 0, SD = 1)
 - T-score (mean = 50, SD = 10)

SF-36 PCS and MCS $PCS_z = (PF_Z * 0.42) + (RP_Z * 0.35) +$ (BP Z * 0.32) + (GH Z * 0.25) + $(EF_Z * 0.03) + (SF_Z * -.01) +$ $(RE Z * -.19) + (EW_Z * -.22)$ MCS $z = (PF Z^* -.23) + (RP Z^* -.12) +$ $(BP Z^* -.10) + (GH Z^* -.02) +$ $(EF Z * 0.24) + (SF_Z * 0.27) +$ $(RE Z * 0.43) + (EW_Z * 0.49)$ $PCS = (PCS \ z*10) + 50$ $MCS = (MCS \ z*10) + 50$ 7

Farivar et al. alternative weights

PCS_z = (PF_z * .20) + (RP_z * .31) + (BP_z * .23) + (GH_z * .20) + (EF_z * .13) + (SF_z * .11) + (RE_z * .03) + (EW_z * -.03)

MCS_z = (PF_z * -.02) + (RP_z * .03) + (BP_z * .04) + (GH_z * .10) + (EF_z * .29) + (SF_z * .14) + (RE_z * .20) + (EW_z * .35)

•Farivar, S. S., Cunningham, W. E., & Hays, R. D. (2007). Correlated physical and mental health summary scores •for the SF-36 and SF-12 health survey, V. 1. <u>Health and Quality of Life Outcomes</u>, <u>5</u>: 54. [PMCID: PMC2065865]

Generic vs. Disease-Targeted

✓ In general, would you say your health is: Excellent/ Very good/ Good/ Fair/ Poor?

How much does kidney disease bother you in your ability to work around the house?

Not at all bothered/Somewhat bothered/ Moderately bothered/Very much bothered/ Extremely bothered

Reliability of measures

0.0 (lowest) – 1.0 (highest possible)

- ~ 0.80 for blood pressure and other clinical measures
- 0.70-0.90 for multi-item self-report measures

Hahn, E. A., Cella, D., et al. (2007). Precision of health-related quality-of-life data compared with other clinical measures. <u>Mayo Clin Proceedings</u>, <u>82</u> (10), 1244-1254.



SF-36 Physical Health Component Summary Score Predicts Mortality



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Kidney Disease Quality of Life (KDQOLTM) Instrument

Focus groups with patients and staff

Pretests on small samples

Field test with 165 persons with kidney disease at 9 dialysis centers

Thousands of administrations since

Kidney Disease Quality of Life (KDQOL) Publications

- Hays, R. D., Kallich, J. D., Mapes, D. L., Coons, S. J., & Carter, W. B. (1994). Development of the Kidney Disease Quality of Life (KDQOL[™]) Instrument. <u>Quality of Life Research</u>, 3, 329-338.
- Edgell, E. T., Coons, S. J., Carter, W. B., Kallich, J. D., Mapes, D., Damush, T. M., & Hays, R. D. (1996). A review of health-related quality of life assessment in end-stage renal disease. <u>Clinical</u> <u>Therapeutics</u>, 18(5), 887-938.
- Rao, S., Carter, W. B., Mapes, D. L., Kallich, J. D., Kamberg, C. J., Spritzer, K. L., & Hays, R. D. (2000). Development of subscales from the symptom/problems and effects of kidney-disease items in the Kidney Disease Quality of Life (KDQOL[™]) instrument. <u>Clinical Therapeutics</u>, 22, 1099-1111.

KDQOL Targeted Domains (97 items and 43 items)

 Symptoms/problems Effects of kidney disease Burden of kidney disease 		34 20 4	12 8 4
 Sleep Cognitive function Quality of social interaction Work status 		9 6 4 4	4 3 3 2
Sexual function		4	2
 Social support Dialysis staff encouragement Patient satisfaction 	4	2 6 2	2 1

KDQOL-36

- **Ttems 1-12:** SF-12
- Items 13-16: Burden of Kidney Disease (4)
- Items 17-28: Symptoms/Problems (12)
- Items 29-36: Effects of Kidney Disease (8)

Glover, C. et al. (2011). Understanding and assessing the impact of end-stage renal disease on quality of life: A systematic review of the content validity of self-administered instruments used to assess health-related quality of life in end-stage renal disease. <u>Patient</u>, <u>4</u>(1), 19-30.

Burden of Kidney Disease

- My kidney disease interferes too much with my life.
- Too much of my time is spent deading with my kidney disease.
- I feel frustrated with my kidney disease
- I feel like a burden on my family.

Symptom/Problems--To what extent were you bothered by ...

- Soreness in your muscles?
- Chest pain?
- Cramps?
- Itchy skin?
- Dry skin?
- Shortness of breath?
- Faintness or dizziness?
- Lack of appetite?
- Washed our or drained?
- Numbness in hands or feet?
- Nausea or upset stomach?
- Problems with access (catheter) site?

Effects of Kidney Disease— How much does kidney disease bother you in ...

- Fluid restrictions?
- Dietary restriction?
- Your ability to work around the house?
- Your ability to travel?
- Being dependent on doctors and other medical staff?
- Stress or worries caused by kidney disease?
- Your sex life?
- Your personal appearance?

Scoring

Higher score = better health
Transform linearly to 0-100 range
Average items in each scale together

KDQOL-36 Translations

Comparison KDOOL-SE1 3 and KDOOL-36

Chinese Czech Danish Dutch English French 🄹 German Greek Hebrew

KDQOL-SF 1.3	KDQOL-36
1	1
3 b	2
3 d	3
4 b	4
4 c	5
5 b	6
5 c	7
8	8
9 d	9
9 e	10
9 f	11
10	12
12 a	13
12 b	14
12 c	15
12 d	16
14 a	17
14 b	18
14 c	19
14 d	20
14 e	21
14 f	22
14 g	23
14 h	24
14 i	25
14 j	26
14 k	27
14	28 a (HD only
14 m	28 b (PD only
15 a	29
15 b	30
15 c	31
15 d	32
15 e	33
15 f	34
15 g	35
15 ĥ	36

- Hungarian
- Italian
- Malay
- Polish
- Portuguese
- Russian
- Spanish
- Swedish
- Turkish

http://gim.med.ucla.edu/kdqol (register for downloads)

Dialysis Outcomes and Practice Patterns Study (DOPPS)

- Longitudinal study of hemodialysis patients and unit practices
 - Goal is to identify practice patterns associated with improved patient outcomes
- Uniform international data collection
 - Mortality
 - Health-related quality of life
 - Hospitalization
 - Vascular access
- Coordinated by Arbor Research Collaborative for Health

DOPPS Data

- 308 dialysis facilities in DOPPS I
 - 12,465 patients from 7 countries
 - France, Germany, Italy, Japan, Spain, UK, US
- 320 dialysis facilities in DOPPS II
 - 10,551 patients from 12 countries
 - Same 7 above plus Australia, New Zealand, Belgium, Canada and Sweden
- 297 facilities in DOPPS III
 - 9,316 patients from the same 12 countries

KDQOLTM Scores Compared to National Sample of Patients



Dialysis Outcomes and Practice Patterns Study (DOPPS) 55-64 year old age group

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Means and Standard Deviations for $KDQOL^{M}$ Scales by Age Group in Dialysis Outcomes and Practice Patterns Study (Females, n = 2265)

Variable	18-24	25-34	35-44	45-54	55-64	65-74	75+	SD
Kidney disease-targeted Scales								
Burden of kidney disease (k=4)	26.64	41.07	44.12	40.52	43.55	42.46	41.85	29.73
Quality of social interaction (k=3)	64.91	72.27	74.00	73.98	77.03	78.90	81.24	19.24
Cognitive function (k=3)	67.72	76.84	78.60	76.37	77.34	76.73	77.67	21.32
Symptoms/problems (k=12)	69.44	69.06	68.70	68.29	70.36	71.03	72.45	17.87
Effects of kidney disease (k=8)	56.42	58.69	60.13	58.49	63.44	66.71	69.10	23.83
Sexual function (k=2)	83.93	77.94	65.18	68.18	68.87	74.69	82.14	36.36
Sleep (k=4)	63.11	55.59	57.21	56.86	57.53	60.91	61.72	20.50
Social support (k=2)	78.95	71.35	72.94	68.92	73.84	77.47	76.88	27.29
Work status (k=2)	26.32	21.88	21.26	15.37	14.72	19.56	24.94	29.32
Dialvsis staff encouragement (k=2)	75.66	80.53	75.77	81.73	82.97	81.34	84.03	21.71
Pt satisfaction rating	62.28	71.62	68.72	68.51	72.92	73.16	74.75	22.06
Overall health rating	58.42	59.64	57.48	53.91	53.58	56.38	54.63	21.74
SF-36 Scales								
Physical functioning	57.38	62.14	50.49	41.95	33.96	32.67	26.66	28.70
Role limitationsphysical	31.25	45.69	38.24	30.13	29.81	28.45	24.52	38.93
Pain (NEMC scoring)	62.00	54.95	55.26	53.81	53.31	53.77	54.72	28.41
General health (NEMC scoring)	39.60	47.26	41.11	39.05	38.60	41.01	41.44	22.09
Emotional well-being	58.32	66.28	67.47	64.53	66.73	67.43	68.59	21.40
Role limitationsemotional	51.67	61.61	55.35	51.58	53.02	49.86	50.33	44.43
Social function	67.50	64.02	62.89	60.85	61.82	59.89	60.03	29.35
Energy/fatigue	49.12	47.45	45.80	41.38	42.20	40.87	38.53	23.04
SF36 physical composite T-score (NEMC)	38.30	38.42	34.85	32.39	30.60	30.53	28.98	10.40
SF36 mental composite T-score (NEMC)	43.42	45.74	46.45	45.58	47.42	47.20	47.93	11.80

Hemo. vs. Peritoneal Dialysis



Future Directions in HRQOL http://www.nihpromis.org/

- Item banks to assess HRQOL and allow for computer-adaptive testing (CAT)
- Reliability = 1 SE² = **0.90**
- SE = 3.2 for T-score (mean= 50 & SD = 10)

Anger CAT^1 (In the past 7 days)

I was grouchy

- -Never
- -Rarely
- Sometimes
- Often
- Always

• Theta = 56.1 SE = 5.7

²In the past 7 days ...

- I felt like I was ready to explode
 - -Never
 - -Rarely
 - Sometimes
 - Often
 - Always

• Theta = 51.9 SE = 4.8

³In the past 7 days ...

I felt angry

- -Never
- Rarely
- Sometimes
- Often
- Always

• Theta = 50.5 SE = 3.9

4In the past 7 days ... I felt angrier than I thought I should

- -Never
- -Rarely
- Sometimes
- -Often
- Always

• Theta = 48.8 SE = 3.6

⁵In the past 7 days ...

I felt annoyed

- -Never
- Rarely
- Sometimes
- Often
- Always

• Theta = 50.1 SE = 3.2

⁶In the past 7 days ...

I made myself angry about something just by thinking about it.

- Never
- Rarely
- Sometimes
- Often
- Always

• Theta = 50.2 SE = 2.8

Theta and SE estimates

- Item 1: 56 and 6
- Item 2: 52 and 5
- Item 3: 50 and 4
- Item 4: 49 and 4
- Item 5: 50 and 3
- Item 6: 50 and <3

Thank you. http:// gim.med.ucla.edu/kdqol/

