

KDQOL ASSESSMENTS: Expectations & Challenges

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HRQOL—What is it?

- Per the CDC website (www.cdc.gov/hrqol/index.htm), a Health-Related QOL:
 - Refers to a person or group's perceived physical and mental health over time.
 - Is used to measure the effects of chronic illness to better understand how an illness interferes with a person's day-to-day life.

AND

- Tracking health-related quality of life can help guide policies or interventions to improve patient health.

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And why do we do it?

- The CMS Conditions for Coverage mandate it.
- The State of Texas mandates it.
- The Clinical Performance Measurements mandate it.

So let's take a look at what they all have to say...

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Conditions for Coverage:

- 494.90(a)(6) states:
- “The interdisciplinary team must provide the necessary monitoring and social work interventions, including counseling and referrals for social services, to assist the patient in achieving and sustaining an appropriate psychosocial status **as measured by a standardized mental and physical assessment tool** chosen by the social worker, at regular intervals, or more frequently on an as-needed basis.”

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Or, simply put, per the Interpretive Guidance (V552):

- “The social worker must have a system for routine use of the assessment survey, evaluation of the results, and incorporation of the survey results into the development and updating of the psychosocial portion of the plan of care.”

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And the Clinical Performance Measures (CPM) weigh in:

- As downloaded from www.cms.gov/cpmproject/, the CMS document entitled “Phase III ESRD Clinical Performance Measures in effect April 1, 2008” states that centers need to report the “percentage of dialysis patients who receive a **quality of life assessment using the KDQOL-36** (36-question survey that assesses patients’ functioning and well-being) at least once per year.”

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And what about the great State of Texas?

- The proposed rules slated to go into effect shortly specify in §117.44 (h) (2) The social worker shall be responsible for:
 - (A) conducting psychosocial evaluations, **which include health-related quality of life surveys; ...**

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Sooooooooo.....Why should we REALLY administer the KDQOL?

- Because it's good patient care!
- It allows us to find out how our patients feel about their quality of life.
- It shows us how we can help them feel better, inside and out, mentally and physically.
- It helps us treat the WHOLE patient.

And isn't that what social work is all about???

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So where did the KDQOL Survey come from?

- Initial tool was developed in 1994 for research purposes by the Kidney Disease Quality of Life Working Group. (134 items)
- Provided a means of measuring health-related quality of life specifically for kidney patients.
- KDQOL-SF (2002)– 80 items.
- KDQOL-36 (2002) – 36 items.

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How is it organized and what does the document tell us?

- Measures physical and mental functioning (PCS & MCS) with questions related to general health, limitations, accomplishing desired tasks, depression, anxiety, energy level, and activities. (1-12)
- Burden of Kidney Disease—how much does kidney failure cause frustration and interfere with life? (13-16)
- How bothersome are symptoms & problems? (17-28)
- Effects of kidney disease on daily life. (29-36)

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Physical Component Score

- Measures self-care, level of bodily pain, fatigue
- Should be greater than 40
- Patients with low PCS scores (less than 34) are twice as likely to be hospitalized
- A 5 point improvement in the PCS score improves survival 10.4% and reduces hospital days 5.8%
- Low PCS as compared to low kt/v

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Mental Component Score

- Measures level of psychological distress, affect and limitations of social role activities.
- Should be greater than 50.
- An MCS score of less than 42 is correlated with a diagnosis of clinical depression.
- Patients aged 55 to 75 years of age rated their mental health better than 35-55 year old patients.

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Burden of Kidney Disease

- Measures patient perception of how much kidney disease is affecting their life
 - Is it taking up too much time?
 - How frustrating is it?
 - Is it making the patient feel like a burden on others?

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Symptoms & Problems:

- Measures patient perception of how much they are bothered by day to day symptoms
 - Chest pain
 - Cramps
 - Itching
 - Shortness of breath
 - Loss of appetite
 - Feeling washed out
 - Etc....

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Effects of Kidney Disease on Daily Life:

- Measures patient perception of the impact of kidney disease on an average day.
 - Impact of fluid and diet restrictions
 - Ability to work around the house
 - Freedom to travel
 - Stress
 - Dependence on doctors
 - Sex life
 - Self-image

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What about scoring?

- The maximum score for each domain is 100.
- The higher the score for each domain, the better.
- A standard deviation is 10 points.
- Scoring should be averaged with other patients of same gender, age bracket, and diabetic category.

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BUT it's not ALL about the patient. What can the KDQOL mandates can do for you?

- Facilitate a patient-centered approach.
- Can save time in the assessment process.
- Great communication tool for patient & IDT.
- It can help with relationship building.
- Can help identify you as the helper you're meant to be.
- Requires you be given the time to counsel.

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Importance of KDQOL Surveys:

- Facilitates communication about what matters most to the patient.
- Overcomes significant differences in perceptions of QOL between patients and caregivers at home and clinic.
- Provides clinical indicators which can serve as predictors of "incidents".

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Predictor of Hospitalization & Mortality

- Patients with PCS scores in the lowest quintile had a 56% higher risk of hospital stays and a 93% higher risk of death than those in the highest quintile.
- PCS scores below 43 and MCS scores below 51 correlated with a higher risk of death. Each 1 point increase in PCS was associated with measurable decreases in risk of death (2%) and hospitalization (1%)

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MCS and PCS Findings. Things that make you go, "hmmmm."

- Chronic no-showers had a higher Physical Component Score and lower Mental Component Score than non no-showers
- Both PCS and MCS tend to decline in the initial months of dialysis
- Females reported lower scores
- A strong association was found between sf-36 scores and serum albumin levels
- Significant differences in perceptions between patients and their care-givers

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When do I give it?

- Complete the QOL survey with the 90-day reassessment, at least annually, and PRN.
 - It's part of the psychosocial assessment and plan of care process.
- Re-administer QOL survey after major life events:
 - Divorce
 - Amputation
 - Medical Crisis
 - Unplanned change of modality
 - Death of loved one
 - Change of caregiver or living situation

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OK, I think I'm ready. Now where do I get it?

- KDQOL Working Group Website
<http://gim.med.ucla.edu/kdqol>
- KDQOL Complete Website
<http://www.kdqol-complete.org/>
- Corporate Program

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KDQOL Working Group Website
<http://gim.med.ucla.edu/kdqol>

- Tools available for download: survey, instructions, and scoring tools in Excel format.
- Survey in numerous languages.
- Downloads are free but require registration.
- Does not generate a results report for patient or chart.
- Requires manual scoring.
- Developed for research purposes. Requires you to formulate patient introduction document.

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KDQOL Complete Website
<http://www.kdqol-complete.org/>

- Survey including patient intro available for download.
- Survey and patient reports available in numerous languages.
- Non-profit service requires paying subscription fee.
- Upon survey input, scores are instantly generated.
- Generates an in-depth results report for patient including intervention activities to consider.
- Generates a results summary for chart.
- Tracks and trends individually & for clinic at large.

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Administering the Survey:

- Does EVERYONE have to take it?
- Patients who are exempt from survey process
- Patients who need help
- Avoiding bias
- Reporting scores back to patients
- Taking the next step with patients who decline to take the survey

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Make it count!

- Make it the most meaningful time you spend with your patients all year, because this is the stuff that matters to the THEM!
- Explain why you're giving the survey, and why it's so important.
- Make sure patient understands that this document will be impacting their care for the next year.
- Score it promptly and report back to the patient.
- Go over the responses and results in detail.
- Make a plan with the patient.
- Take it to the team!

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What do I do now? Interventions for Improving QOL Scores:

- Suggestions include empowerment, time management, problem solving, cognitive/behavioral and illness schema, educational support, self care, treatment options...
- What are the patient's goals?
- Decide on a few intervention choices with patient and incorporate into Plan of Care process.

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Beyond the QOL: Indications for practice.

- Taking assessment a step further
- Depression Identification
- Rehabilitation Needs
- Behavior Modification
- Using the survey as a catalyst for change

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Resources:

- KDQOL Complete Website
- KDQOL Working Group Website
- NKF -- Council of Nephrology Social Workers Website
 - Quality of Life Assessment Tools
- Lit Review
 - *DOPPS: Making the Case for Using Functioning and Well-Being Surveys to Assess Risk and Improve Outcomes.* Beth Witten, JNSW, 2007.
 - *A Model for Patient Participation in Quality of Life Measurement to Improve Rehabilitation Outcomes.* Callahan, LeSage, and Johnstone, NN&I, 1999.

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Why Should I Take the KDQOL™-36?

The KDQOL™-36 survey lets you rate your quality of life with kidney disease. Hundreds of studies have found that how you view your physical and mental function is vital. People who had a poor view of their lives were more likely to need hospital care and less likely to live a long time.

You are the only one who can tell us how you feel about your life.

In fact, how you rate your quality of life is one of the best ways to know how you are doing. The *Dialysis Outcomes and Practice Patterns Study (DOPPS)* looks at people who are on dialysis around the world. The DOPPS found a strong link between how people feel, their quality of life, and how well they do on dialysis.

We ask you to take this survey so you can share things that may affect how well you feel while you receive dialysis treatment. At the end of the survey, we will provide a report that will tell you information about:

- Your scores on each of 5 subtests
- How your scores compare to others like you with regard to age, sex, and diabetic status
- Things you can do to improve your scores

Over time, tracking your scores will help you learn how taking care of yourself affects how you feel.
Help us to help you feel your best with kidney failure.

Ready? Let's begin!

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