

# Measuring Dialysis Patients' Health-Related Quality of Life with the KDQOL-36

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## New Clinical Performance Measure (CPM)

Effective April 1, 2008, the Centers for Medicare and Medicaid Services (CMS) adopted 26 new clinical performance measures to assess the quality of dialysis care in the United States. They include a new requirement for annual measurement of health-related quality of life (HRQOL) in most patients.

The new CPM for HRQOL will measure the **number of patients who complete a KDQOL-36 with or without assistance at least once/year** out of the **number of eligible prevalent dialysis patients (peritoneal dialysis, in-center hemodialysis, home hemodialysis)**<sup>1</sup>, with exclusions for:

- Patients under age 18
- Those who cannot complete a KDQOL-36 due to cognitive impairment, dementia, active psychosis
- Non-English speakers/readers (for whom there is no native language translation or interpreter)
- Patients under the facility's care for less than 3 months
- Patients who refuse to complete the KDQOL-36

When CROWNWeb is set up to collect data (est. early 2010), this CPM will officially take effect. At this time, clinics that use another tool to measure HRQOL will also need to administer the KDQOL-36 once per year.

## Why Assess Health-Related Quality of Life

Dialysis is both live-saving and life-altering. It changes patients' patterns of eating, sleeping, medication use, and daily tasks at home, in the community, or in the workplace for the 50% of incident patients each year who are working-age. The degree of lifestyle change needed—adherence to diet and medications and the symptom burden in particular—depends on the choice of treatment modality, and affects patients' day-to-day health-related quality of life. Per the U.S. Centers for Disease Control and Prevention, **health-related quality of life is the impact of a chronic disease and its treatment on patients' perceptions of their own physical and mental function.**<sup>2</sup>

Among people on dialysis, HRQOL scores are both a critical outcome *and* a predictor of morbidity and mortality. A prospective study of 1,000 patients on standard in-center hemodialysis (HD) first linked low HRQOL scores, hospitalizations, and death more than a decade ago.<sup>3</sup> Patients with SF-36 scores below the center's median were twice as likely to be hospitalized as those above it. In this study, each 5-point increase in physical component summary (PCS) score—a measure of patients' perceptions of their physical health—was associated with a 10% improvement in the chance of survival, and a 6% reduction in hospital days.

An analysis of nearly 14,000 Fresenius patients on standard in-center HD also found that HRQOL scores predicted hospitalizations and mortality.<sup>4</sup> PCS scores below 43 and mental component summary (MCS) scores—a measure of patients' perceptions of their mental health—below 51 correlated with a higher risk of death. Each 1-point increase in PCS was associated with a 2% reduction in the relative risk of both death and hospitalization. Each 1-point increase in MCS was associated with a 2% reduction in the relative risk of death and a 1% reduction in the relative risk of hospitalization.

The **Dialysis Outcomes and Practice Patterns Study (DOPPS)** is a prospective observational study in Europe, Canada, the U.S., New Zealand, and Japan, of lab values, demographics, co-morbidities, dialysis parameters, and HRQOL data. Among 10,030 patients, low HRQOL scores were associated with a higher risk of death and hospitalization, *independently of demographic factors and co-morbidities.*<sup>5</sup> As PCS and MCS scores fell, the risks of death and hospitalization rose significantly. 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. Researchers concluded that *low PCS, MCS scores were as powerful an independent predictor of hospitalization and death as serum albumin.*

HRQOL is a unique dimension of chronic disease care—one whose data source is *patient perceptions* captured via a valid, reliable tool.

### About the KDQOL-36

The Kidney Disease Quality of Life (KDQOL) survey was developed in 1994 by the Kidney Disease Quality of Life Working Group as a kidney disease-specific measure of HRQOL. The first version contained the Medical Outcomes Study 36 (MOS SF-36) as a generic chronic disease core, and added items relevant to patients with kidney disease, such as symptoms, burden of illness, social interaction, staff encouragement, and patient satisfaction.<sup>6</sup>

The KDQOL-36, available since 2002, is a 36-item HRQOL survey with five subscales:

- ❑ **The SF-12 measure of physical (PCS) and mental (MCS) functioning (1-12)**, with items about general health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities.
- ❑ **Burden of Kidney Disease subscale (13-16)**, with items about how much kidney disease interferes with daily life, takes up time, causes frustration, or makes the respondent feel like a burden.
- ❑ **Symptoms and Problems subscale (17-28<sup>b</sup>)**, with items about how bothered a respondent feels by sore muscles, chest pain, cramps, itchy or dry skin, shortness of breath, faintness/dizziness, lack of appetite, feeling washed out or drained, numbness in the hands or feet, nausea, or problems with dialysis access.
- ❑ **Effects of Kidney Disease on Daily Life subscale (29-36)**, with items about how bothered the respondent feels by fluid limits, diet restrictions, ability to work around the house or travel, feeling dependent on doctors and other medical staff, stress or worries, sex life, and personal appearance.

### KDQOL-36 Online Scoring

Scores are reported separately for each of the five KDQOL-36 subscales. Arbor Research Collaborative for Health supplied KDQOL-36 data from 1,282 U.S. prevalent in-center hemodialysis patients. Arbor statisticians determined that **gender** (M/F), **diabetes** (Y/N), and **age** (<45, 45-64, 65-74, 75+) were the

demographic characteristics associated with the greatest variability in KDQOL-36 scores. (NOTE: Race was examined, but did not contribute as much variation as the others).

Arbor provided means and standard deviations (SD) for each of the 16 cells a given respondent can belong to (2 cells for sex • 2 cells for diabetes • 4 cells for age). Based on these data, KDQOL-36 Online reports individual patient subscale scores by tertiles (thirds):

1. More than one SD *above* the mean is the “above average” tertile
2. The mean +/- one SD is “average”
3. More than one SD *below* the mean is the “below average” tertile

In this way, patients are compared to others who are like themselves in terms of age, gender, and presence/absence of diabetes.

### Administering the KDQOL-36

The survey takes ~10-15 minutes. Provide pencil or pen. If patients are not sure how to answer, advise them to choose their *first response*. Verify that all items have been completed prior to scoring. Print and provide the score report to the patient ASAP: rapid feedback improves future participation.

When possible, patients should *self-administer* the survey. Those who were interviewed for HRQOL in the HEMO study had higher PCS scores—despite multiple and more severe co-morbidities than self-administerers. This suggests that response bias (telling the interviewer what he/she might want to hear) can occur with staff administration of the survey.<sup>7</sup>

If you must complete the KDQOL-36 for a patient:

- Speak loudly and clearly and verify that the patient can hear you.
- Do not interpret items. Ask the patient to respond to what he or she believes it asks.
- Repeat response options as often as needed, keeping any frustration out of your voice.

### Interventions that Improve HRQOL

Certain interventions have been found to improve HRQOL scores among people with chronic kidney disease (most often on dialysis) in randomized, controlled trials. These include:

- ❑ **Automated (vs. manual) peritoneal dialysis.**<sup>8</sup> After 6 months, APD patients had higher SF-36 scores. Nighttime treatments allowed time for work, family, and social life.
- ❑ **Icodextrin peritoneal dialysis fluid.**<sup>9</sup> After 13 weeks, patients using icodextrin had fewer dialysis symptoms and higher mean change scores on the KDQOL than those on usual care.
- ❑ **More frequent hemodialysis.**<sup>10,11</sup> Short daily or long nocturnal HD reduced cramping, headaches, hypotension, shortness of breath and other common dialysis symptoms and improved SF-36 scores in patients switched from standard in-center HD.
- ❑ **Goal-setting.**<sup>12</sup> An intervention with interdisciplinary collaboration and support, significantly improved two PCS domains.
- ❑ **Help with coping.** Adaptation training to help patients cope with the stresses of ESRD significantly improved SF-36 scores vs. usual care,<sup>13</sup> as did group psychosocial counseling.<sup>14</sup>
- ❑ **Exercise training.** Exercise programs have significantly improved exercise duration and peak workload, reduced depression, and improved both PCS and MCS on the KDQOL-36 in people on standard in-center HD<sup>15,16,17,18,19</sup> and peritoneal dialysis.<sup>20</sup>
- ❑ **Use of intravenous iron.** Compared to oral iron in 75 non-dialysis CKD patients, IV iron use was associated with significant increases in hemoglobin levels and KDQOL scores.
- ❑ **Anemia treatment.** Significant improvements in SF-36 scores were found in dialysis patients whose anemia was treated with ESAs<sup>21</sup> or IV (vs. oral) iron.<sup>22</sup>
- ❑ **Echocardiogram adjustment of dry weight.**<sup>23</sup> Reaching ideal dry weight as measured by the size of the inferior vena cava (n=68) was associated with SF-36 score improvements compared to usual care (n=51).
- ❑ **Improving bone mineral metabolism.**<sup>24</sup> Compared to placebo, use of cinacalcet to reduce parathyroid hormone levels was associated with significantly lower risk of parathyroidectomy, hospitalization for cardiac reasons, fracture, and significantly higher PCS scores on the KDQOL.
- ❑ **Treatment of Restless Legs Syndrome with Gabapentin.**<sup>25</sup> Treatment with gabapentin significantly relieved RLS symptoms and improved several subscales of the SF-36.
- ❑ **Treatment of carnitine deficiency with carnitine.**<sup>26</sup> Patients randomized to receive carnitine for 24 weeks showed significant SF-36 score improvements over placebo.

### Interpretation of KDQOL-36 Scores

PCS and MCS scores from the KDQOL-36 or other HRQOL surveys are associated with aggregate hospitalization and mortality for *groups* of patients—not for individuals. However, on the presumption that scores *more than one standard deviation below the mean* may signify a degree of health risk that could perhaps be preventable, the patient scoring language in the KDQOL- Online is deliberately cautionary for those with lower scores.

Where possible, suggested “tips to feel better” were based on available evidence cited above. Others were based on known contributors to dialysis morbidity and mortality, such as serum albumin levels,<sup>27</sup> interdialytic weight gains,<sup>28</sup> hemodialysis catheters,<sup>27</sup> serum phosphate control,<sup>27</sup> and dialysis dose.<sup>27</sup> Finally, the remaining tips were based on factors known to contribute to health-related quality of life and derive directly from items in the KDQOL-36, such as sexual function, sleep, symptoms, etc.

### Talking with Patients About Low Scores

Key points to remember about the KDQOL-Online scoring are:

- The range of average scores is very broad, so someone who falls in the “below average” tertile is at *significantly higher risk of hospitalization and/or death*.
- The predictive value of these scores has been proven in multiple studies among tens of thousands of dialysis patients.
- Patients who respond to questions with the low options *know* that they don't feel good: We are not telling them anything they didn't already know.
- *There is hope.* There are interventions that have been shown through research to be effective in improving scores.

Knowing the truth may help motivate patients to do something different, and we should not be afraid to share this difficult truth with patients. If we shy away from delivering this news, we need to consider whether we are protecting our patients—or ourselves. Certainly a doctor would tell a patient that he/she has kidney failure (or cancer) or some other frightening but treatable illness. We owe our patients the truth.

Social workers who use the KDQOL-Online have found that when the report is presented in a positive way, it can have a positive outcome in behavior change. One way to present the information to patients is to say something like:

*“I looked at your survey and notice that you marked several survey questions low. Can we talk about that? What affected how you marked your survey (probe for reasons)?”*

*My concern is that the way you marked your survey lowered your scores in these areas (describe).*

*Research has shown that low scores are linked to higher risk of hospitalizations and even death. We want to help you avoid those things. There are a number of things you can do that research has shown to improve scores. [Discuss these with the patient and personalize them if you know behaviors the patient has that may be contributing—skipping/shortening treatments, not taking medications as prescribed, being sedentary, avoiding people because of depression, etc.]*

*What goals would you be willing to set to improve these scores? How can our team help you do that? We'll be planning for your care at a meeting on (date) and we'd like you to attend to help us help you. Would you be willing to be there?”*

You can take the survey and the scores to a care planning meeting, explain the scores and the risks, and point out the symptoms or problems the patient reported and other areas where the patient marked negatively. This should help individual

team members brainstorm things they can do and how the team as a whole can work together.

Patients need to be more involved in planning than just signing a form, as some of the team goals may not be patient goals and patients may not be willing to do some of the interventions staff may consider. Interventions must be workable and goals achievable to help patients achieve the best possible outcomes.

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