Using the KDQOL-36 to Improve Quality of Life (and Meet Surveyor Expectations)

Question/Comment	Answer
The KDQOL-36 Survey	
Is it mandatory to use the KDQOL-36, or are other surveys/tools allowed according to CMS?	CMS adopted assessment of health-related quality of life as a clinical performance measure (CPM) *using the KDQOL-36* in adult dialysis patients in 2008. CMS has not specified which survey should be used to assess HRQOL in *pediatric* patients but did specify that the survey must be standardized (tested for reliability and validity) and age appropriate.
Is the KDQOL adjusted for racial and cultural bias?	The original KDQOL survey was developed using focus groups with patients of different races and ethnic groups and staff to determine areas of concern. The survey is reliable and valid. The longer KDQOL has been administered to male and female patients of different races and ethnic groups in multiple countries.
Surveying Pediatric Patients	
Where can I find a survey for pediatric patients?	The PedsQL can be found at www.pedsql.org. Another website that has a database of HRQOL surveys is www.proqolid. A survey that is not kidney specific but has been used with pediatric dialysis patients is the Child Health Questionnaire (CHQ). Read about it here: www://proqolid.org/instruments/child_health_questionnaire_chq.
Is there a cost to use the peds survey from www.pedsql.org?	The PedsQL is copyrighted and licensed through MAPI in France. PROinformation@mapi-trust.org. CNSW has a subset of pediatric social workers who may be able to help you get and use the survey. CNSW has a listserv for social workers caring for pediatric patients. Subscribe at www.kidney.org/professionals/cnsw/listserv.cfm.
Availability in Other Languages	
Do you need to use a translator service or is it acceptable for staff in the facility to translate?	When any staff member, even the social worker, administers the survey, the patient may answer questions how he or she thinks the staff wants to hear them or may decline to do the survey out of privacy and confidentiality concerns. Whenever possible, it's best to use a written translation in the patient's primary language or to use a trained and certified medical interpreter. Language Line has certified medical interpreters if one can't be found locally at www.atanet.org.
Have the scores been validated with non-English speaking patients, so the scores are meaningful?	Yes. The survey has been used with thousands of patients in the Dialysis Outcomes and Practice Patterns Study (DOPPS), which is an international study.
We have a Dutch translated and validated version for the Netherlands.	There is a Dutch translation of the longer KDQOL survey at www.rand.org/health/surveys_tools/kdqol.html.
The KDQOL tool is available in Spanish. Is the results page of the KDQOL is available in Spanish?	KDQOL COMPLETE (www.kdqol-complete.org) has multiple translations of the patient survey under "Tools" and subscribers can select the language for the patient report.

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Are there any plans to offer the survey in Vietnamese?	Vietnamese is not currently one of the translations. However, a dialysis provider that has patients who speak/read Vietnamese can translate the survey following the forward-backward process: • Forward translation • Expert panel Back-translation • Pre-testing and cognitive interviewing • Final version Find more information about this process at www.who.int/substance_abuse/research_tools/translation/en/
Please make the survey available in Russian.	A Russian translation of the longer KDQOL 1.3 survey is available at www.rand.org/health/surveys_tools/kdqol.html. Compare the surveys and delete those questions that are not on the KDQOL-36.
Do you suggest that family member help a patient to complete the survey? We have many patients from Marshall Islands or Samoa. Is the survey available in these languages?	For patient confidentiality and to reduce possible bias, it is best to use an interpreter instead of a family member if the survey is not translated into the patient's native language. Currently these languages are not available. KDQOL COMPLETE (www.kdqol-complete.org) currently offers the survey and patient report in English (large font too), Spanish, Chinese (simplified), Tagalog, Korean, French-Creole, German, Italian, French and Polish. See above for information on translations and how to translate the survey.
How & When to Administer	
Is it better to give the survey in your office or on the ward (treatment floor)?	It's best if the patient self-administers. However, if you must assist the patient to complete the survey, the patient's preference should determine where to complete it.
"Cognitive impairment" has a broad range. Can you give us some examples that would impede getting valid results?	Many conditions can affect cognitive status including several kinds of dementias, mental retardation, traumatic brain injury, etc. It is important to assess whether the patient's cognitive status severely impairs his/her ability to understand the questions and answer them after the facility accommodates sensory deficits and primary language. If so, document this in the patient's medical record.
Is a consent form required to administer the KDQOL-36?	The ESRD regulations do not address this. So, it would depend on facility policy and professional ethics. Some facilities accept verbal consent while others require written consent. Many consent forms state that a patient's refusal will not affect the care he/she receives. This would not be accurate since the survey may uniquely identify problems that may help the team target specialized care to address those problems. It would be more accurate for the consent to state that if the patient chooses not to take the survey, it will not change the patient's ability to get dialysis at the facility.
Why are you supposed to wait 3 months do the KDQOL vs. at the start of dialysis?	The first 3 months of dialysis care is a period during which there may be many changes in dialysis prescription, dry weight, medications, diet, etc. any of which may confound the survey results. The application for the clinical performance measure recommended not surveying patients during this period.

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Hospitalization is a moment to assess, but what are "major life events" that should trigger the test?	The ESRD Conditions for Coverage state that the test should be given at regular intervals or as needed. The Interpretive Guidance defines "regular intervals" as with the first reassessment (during the 4th month of dialysis) and defines "as needed" as when the patient has a "significant life changing event (e.g., loss of a spouse, loss of job, recent move to a nursing home) or a change in health status."
Should the survey be offered to unstable patients?	The ESRD regulations require the survey to be offered on an "as needed" basis, which the Interpretive Guidance defines as when the patient experiences a significant life changing event or health status change. Offering an unstable patient the chance to complete the survey may identify problems the team could work on to stabilize the patient's status faster.
Can the KDQOL be given at the predialysis stage to provide a baseline?	Omit questions 28a and 28b related to dialysis access when using the survey with CKD (non-ESRD) or transplant patients.
Can the questions on moderate activities and climbing steps be reworded for patients with amputations or obvious mobility issues? Sometimes the questions upset them.	The survey was tested for reliability and validity *as written*. Tell patients with mobility limitations or amputations that these may be limiting, but you need patients to answer the questions honestly so you and the team can help them function as well as possible in spite of any limitations.
How can we make this survey relevant for patients in nursing homes?	The goal of the survey is to identify problems that adversely affect a patient's health-related quality of life. Therefore, when offering the survey to any patient, including those in nursing homes, assure the patient that the survey results can identify areas where improvement is possible to help him/her stay as active and independent as possible.
Do you know of patient peer support groups that use this survey?	Studies of group adaptation training found improvement in health-related quality of life using the KDQOL or SF-36. More study is needed of effectiveness of interventions in improving scores. 1) Tsay SL, Lee YC, Lee YC. Effects of an adaptation training programme for patients with end-stage renal disease. J Adv Nurs. 2005 Apr;50(1):39-46. 2) Lii YC, Tsay SL, Wang TJ. Group intervention to improve quality of life in haemodialysis patients. J Clin Nurs. 2007 Nov;16(11C):268-75.

Question/Comment	Answer
Scoring the Survey & Interpreting Results	
Is the social worker the only member of the team that can score the KDQOL or can other team members share these responsibilities?	Anyone who can accurately enter data can score the survey and provide the results to the social worker to discuss with the patient.
My facility has 40% of patients over 75 years of age. How can I expect this factor to affect my over-all facility results?	KDQOL COMPLETE (www.kdqol-complete.org) risk adjusts scores based on age, gender, and diabetes status. The ESRD Network of New England posts the average (mean) score based on a patient's age, gender and diabetes status but does not include what scores are 1 standard deviation above (lower risk) or below (higher risk) the mean. www.networkofnewengland.org/Patient&Community/KDQOLavgscores.pdf.
Where can I find the scoring tool for the KDQOL?	Some corporations have their own scoring tool. The research version of the survey in multiple languages and a scoring template can be downloaded from www.rand.org/health/surveys_tools/kdqol.html. The KDQOL COMPLETE (www.kdqol-complete.org) subscription site has the survey in multiple languages, risk-based scoring (age, gender, and diabetes), and English and translated reports for patients and reports for plan of care and QAPI.
How do we capture aggregate clinic data from the KDQOL surveys?	Both KDQOL COMPLETE (www.kdqol-complete.org) and the free scoring template at www.rand.org/health/surveys_tools/kdqol.html provide individual scores for plan of care and aggregate scores quality assessment and performance improvement (QAPI) for each of the 5 scales. KDQOL COMPLETE (www.kdqol-complete.org) automatically risk adjusts scores. The QAPI team should decide what data would be most helpful so you can compile those data before meeting.
Is a 1 point change most predictive with the PCS & MCS scores?	The PCS and MCS scales have been studied the most. The SF-36 and questions 1-12 on the KDQOL-36 yield PCS and MCS scores and a 1 point difference reduces the risk of hospitalization and death.
What is the rate of mortality or hospitalization with lower scores?	The Dialysis Outcomes & Practice Patterns Study (DOPPS) of over 10,000 patients in Europe, Japan, and the U.S. used the longer KDQOL SF survey from which the KDQOL was derived and found these increased risks: • **PCS**: for death **93%** and hospitalization **56%** comparing patients in the lowest quintile (<25) to highest (>46) • **MCS**: for death **46%** and hospitalization **21%** comparing patients in the lowest quintile (<34) to highest (>56) • **KDCS** (symptoms/problems, burden, effects composite): for death **51%** and hospitalization **30%** comparing patients in the lowest quintile (<52) to highest (>75)

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Is a score drop of ≥10 points predictive of hospitalization/death on all five scales?	The DOPPS research found each 10 point lower score increased these risks: • **PCS**: for death **25%** and hospitalization **25%** • **MCS**: for death **13%** and hospitalization **9%** • **KDCS**: for death **11%** and hospitalization **10%**
Care Planning	
We are not having plan of care meetings, only rounds. The patients are not discussed in detail. How do we address this if it is not happening?	All members of the interdisciplinary team (including the patient, as desired) must be involved in developing the plan based on a recent comprehensive assessment. Any alternative to a meeting must facilitate discussion of data from all assessments and provide an opportunity to develop an effective, coordinated, individualized plan. If this is not happening alert your team that the facility could be at risk of citation.
What was the website which you can find the goal sheet?	You can find the Goal Setting Worksheet at www.lifeoptions.org/catalog/pdfs/worksheets/Goalsheet.pdf
I have a patient who scores below average in a couple of areas. I think the issue is more his expectations. He complains travel is difficult yet is leaving for Europe soon, complains re: sexual function yet is in a long distance relationship. Can you provide suggestions on how to craft a plan?	The patient's perception is his reality and crafting the plan should start "where the patient is." Ask the patient to describe his specific concerns in these two areas and reflect back to him what you hear him saying. This should let him know you're listening, taking his concerns seriously, and will work with him and the team to address concerns. Traveling to Europe on dialysis is a challenge, but his willingness to do that demonstrates an adventurous spirit. Provide education and encouragement to travel, and remind him that making plans to travel to Europe indicates that he's not allowing dialysis to limit his enjoyment of a full life. His concerns about sexual functioning may be heightened because he is in a long distance relationship. Help him identify his fears and encourage him to seek further assessment. Difficulties with sexual functioning may have a physical or psychological basis. Share resources about sexuality and intimacy like Kidney School Module 11. Encourage him to discuss his concerns with his nephrologist who can order screening blood tests and refer the patient to a specialist.
If patient's illness has nothing to do with ESRD, for example, cancer patients. What do we do with the low scores re PCS and MCS?	The PCS and MCS scales are not kidney specific but *generic* scales so they reflect the patient's perception of his/her physical and mental functioning based on his/her current status, *including* other conditions. The expectation would be that the team would monitor the patient's responses, recognize the low scores, and take action which should include collaborating with others treating the patient for other conditions to maximize the patient's functioning.

Question/Comment	Answer
How does home dialysis affect KDOOL scores?	There have not been many studies comparing health-related quality of life in patients on different modalities. Some studies have shown higher scores for PD patients and patients on more frequent home HD on some scales. Depression adversely affects health-related quality of life scores and patients who switched from in-center HD to daily home HD reported fewer depression symptoms. More study is needed in this area.
What constitutes "one level up?"	On the survey, one level up relates to responses on the survey. If there are 5 response choices and the patient marks the lowest response, "one level up" would be a response that was one step higher. In some questions 1 is better than 5 (reversed scored) and in others 5 is better than 1.
What can I do as a social worker to help an elderly person who scores below average on PCS due to multiple health conditions that limit mobility/ function? In some situations, PT may not help.	The KDQOL norms on the DOPPS and KDQOL COMPLETE (www.kdqol-complete.org) risk adjust scores by age so if scores are low (higher risk), the patient is compared to others like him/her. Review how the patient answered questions 1-12 for questions where the patient reported deficits. Report these to the team to help develop a plan to help the patient function as well as possible physically. The plan could involve one or many team members.
If transportation worked better, many patients will be less depressed and score higher for "burden."	Research has shown that patients who must travel farther for dialysis have lower HRQOL scores. Burden scores could be improved by advocating for higher quality transportation services. In addition, burden scores could be improved by educating and encouraging patients to consider home dialysis options and assessing all patients for home dialysis candidacy as required in the ESRD regulation.
QAPI	
What is the meaning of QAPI?	This stands for the Condition of *Quality Assessment and Performance Improvement* in the ESRD regulation. The QAPI team (medical director, nurse, dietitian, social worker, and others as need) must evaluate facility-level data, prioritize major problems that threaten patients' health and safety, and take actions to address identified problems.
Why don't we also report scores that have improved by >10 points since last assessment?	A one point improvement reduces the relative risk of death and hospitalization. A decline of ≥10 points increases the relative risk of hospitalization and death. The percent of eligible patients taking the survey annually is the clinical performance measure. Surveyors also look at percent of patients with a 10 point decline, although you could also look at the percent of patients whose scores improve.
Are there social workers among surveyors on the state or federal level?	Although most surveyors are nurses, surveyors come from many different backgrounds, including social work.

Question/Comment	Answer
Resources	
Can we get slides from this lecture?	The slides and webinar are posted at www.lifeoptions.org. (see Webinar in left frame).
Where can I find info about the symptom targeted intervention?	The Symptom Targeted Intervention DVD and manual, including tools, can be found at www.stiinnovations.com.
What are the citations for the *Nephrology News & Issues* articles on Symptoms Targeted Intervention?	The following articles reported a successful pilot in which multiple U.S. social workers measured outcomes of the Symptom Targeted Intervention technique with dialysis patients using the KDQOL, CES-D (depression screener), and a severity scale. • McCool M, Johnstone S, Sledge R, Witten B, Contillo M, Aebel-Groesch K, Hafner J. The promise of symptom-targeted intervention to manage depression in dialysis patients. Nephrol News Issues. 2011 May;25(6):32-3, 35-7. • Sledge R, Aebel-Groesch K, McCool M, Johnstone S, Witten B, Contillo M, Hafner J. Part 2. The promise of symptom-targeted intervention to manage depression in dialysis patients: improving mood and quality of life outcomes. Nephrol News Issues. 2011 Jun;25(7):24-8, 30-1.
Where can activities patients can do on dialysis be found?	You can find what patients do on dialysis using Google and searching for "activities on dialysis." Patients watch movies or TV, play video games, play solitaire, use computers, read books or magazines, listen to music, do crossword or word puzzles, do work activities, exercise, do arts and crafts, volunteer for organizations, and talk with nearby dialysis "neighbors" and staff. Some dialysis teams organize competitions among dialysis patients to increase physical fitness and improve outcomes.
Helpful Comments	
Education and empowerment of those closest to patients is underestimated indeed!	
The tendency to give information to patients is not the same as educating patients. Social workers assess to find out if the message came across!	
I just use the word intimacy with my patients instead of asking about their sex life. That helps sometimes because that kind of closeness can be described as intimacy.	