Using the KDQOL-36 to Plan Care

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Objectives

- Describe how to use two online tools available for scoring the KDQOL-36 survey
- Explain the meaning of the 5 reported survey scores
- Discuss how to share survey results with patients in order to set goals for improvement
- List clinical and psychosocial interventions that have improved outcomes
- Discuss how to plan interventions with the interdisciplinary team
Review: What HRQOL Isn’t
Review: What Health-Related QOL Is

- Patient’s *perceived mental health*¹
- Patient’s *perceived physical health*¹
- How a chronic disease *interferes with day-to-day life*¹

Unique outcome in its own right & independently predicts morbidity & mortality in ESRD—as strongly as Kt/V or serum albumin²

¹CDC - [www.cdc.gov/hrqol/index.htm](http://www.cdc.gov/hrqol/index.htm)
The interdisciplinary team must provide the necessary monitoring and social work interventions. These include counseling services and referrals for other 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.

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.
Review: Who Not to Survey Using the KDQOL-36

- Those with cognitive impairment, psychosis
- Those under age 18
  - PedsQL is only kidney-specific HRQOL survey: www.pedsqol.org
  - Other pediatric HRQOL surveys: www.proqolid.org
- Non-English speakers/readers, no translation
- Several translations on KDQOL COMPLETE
- Several translations of KDQOL-36 or longer surveys on KDQOL Working Group website “downloads” page: http://gim.med.ucla.edu/kdqol
- Patients who refuse
Review: Using the KDQOL-36

- Enter scores into the Excel workbook or KDQOL COMPLETE
- Review scores of hospitalized or deceased patients
- Track & trend looking for patterns for QAPI
- Incorporate scores & survey responses into patients’ plans of care
- Identify interventions and apply them
The KDQOL Is Not Just About Psychosocial Interventions

- It takes a team to:
  - Improve physical function
  - Improve mental function
  - Help relieve burden of kidney disease
  - Manage symptoms
  - Reduce effects of kidney disease on daily life

- Social workers can’t do it alone
Measuring HRQOL: More Than a Social Work Plan of Care

Success takes a team

Physician  Nurse  Patient  Dietitian  Social Worker
Joe Schmoe Clinic Visit

- Date of birth 1/1/1938 (age 72)
- Cause of kidney failure – diabetes
- Comorbidities – moderate CVD, mild PVD
- CAPD for 3 years
- Divorced with 2 adult children, 3 grandchildren
- Retired due to DM at 62, 10 years ago
- Ht 6’ 2”; Wt 90 kg; last BP on records 90/50
- Selected labs: Kt/V 1.6; Hgb 10.9; Alb 3.2; Ca 11.0; Phos 7.0; Glucose 150; Hgb A1c 7.8
Social Worker Administers KDQOL-36

Scales:
- Physical Component Summary
- Mental Component Summary
- Burden of Kidney Disease – 4 questions
- Symptoms & Problems – 12 questions
- Effects of Kidney Disease on Daily Life – 8 questions
KDQOL Working Group Site

- KDQOL-36 Survey, including multiple translations
- Excel scoring template
- Basic instructions
- Norms based on DOPPS data
- No report for patients
Use Excel Scoring Template Free on KDQOL Working Group Website

Raw = Joe Schmoe’s 36 responses

Use Excel Scoring Template Free on KDQOL Working Group Website

Raw = Joe Schmoe’s 36 responses

http://gim.med.ucla.edu/kdqol (register for downloads)
Use Excel Scoring Template Free on KDQOL Working Group Site

Scale = Joe Schmoe’s 5 scores

http://gim.med.ucla.edu/kdqol (register for downloads)
# Compare Scores to Norms
*(Free on KDQOL Working Group Site)*

Scores adjusted by age & gender based on DOPPS

<table>
<thead>
<tr>
<th>Variable</th>
<th>18-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>75+</th>
<th>SD</th>
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<tbody>
<tr>
<td><strong>Kidney disease-targeted Scales</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Burden of kidney disease (k=4)</td>
<td>26.64</td>
<td>41.07</td>
<td>44.11</td>
<td>40.52</td>
<td>43.55</td>
<td>42.46</td>
<td>41.85</td>
<td>29.73</td>
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<tr>
<td>Quality of social interaction (k=3)</td>
<td>64.51</td>
<td>72.27</td>
<td>74.00</td>
<td>73.98</td>
<td>77.03</td>
<td>78.90</td>
<td>81.24</td>
<td>19.24</td>
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<tr>
<td>Cognitive function (k=3)</td>
<td>67.72</td>
<td>76.84</td>
<td>78.60</td>
<td>76.37</td>
<td>77.84</td>
<td>76.73</td>
<td>77.67</td>
<td>21.32</td>
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<td>Symptoms/problems (k=12)</td>
<td>69.44</td>
<td>69.06</td>
<td>68.70</td>
<td>68.29</td>
<td>70.36</td>
<td>71.03</td>
<td>72.45</td>
<td>17.87</td>
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<tr>
<td>Effects of kidney disease (k=6)</td>
<td>56.42</td>
<td>59.69</td>
<td>60.13</td>
<td>58.49</td>
<td>63.44</td>
<td>66.71</td>
<td>69.10</td>
<td>23.83</td>
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<td>Sexual function (k=2)</td>
<td>83.93</td>
<td>77.94</td>
<td>65.18</td>
<td>66.14</td>
<td>68.97</td>
<td>74.69</td>
<td>82.14</td>
<td>36.36</td>
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<tr>
<td>Sleep (k=4)</td>
<td>63.11</td>
<td>55.59</td>
<td>57.21</td>
<td>56.86</td>
<td>57.53</td>
<td>60.91</td>
<td>61.72</td>
<td>20.50</td>
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<tr>
<td>Social support (k=2)</td>
<td>78.95</td>
<td>71.35</td>
<td>72.94</td>
<td>69.92</td>
<td>73.94</td>
<td>77.47</td>
<td>76.88</td>
<td>27.29</td>
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<td>Dialysis staff encouragement (k=2)</td>
<td>75.66</td>
<td>80.53</td>
<td>75.77</td>
<td>81.73</td>
<td>82.97</td>
<td>81.34</td>
<td>84.03</td>
<td>21.71</td>
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<tr>
<td>SF-36 physical composite T-score (NEMC)</td>
<td>38.30</td>
<td>38.42</td>
<td>34.85</td>
<td>32.39</td>
<td>30.60</td>
<td>30.53</td>
<td>28.98</td>
<td>10.40</td>
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<tr>
<td>SF-36 mental composite T-score (NEMC)</td>
<td>43.42</td>
<td>45.74</td>
<td>46.45</td>
<td>45.58</td>
<td>47.42</td>
<td>47.20</td>
<td>47.93</td>
<td>11.80</td>
</tr>
</tbody>
</table>

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[http://gim.med.ucla.edu/kdqol](http://gim.med.ucla.edu/kdqol) *(register for downloads)*
KDQOL COMPLETE
Optional Subscription Tool
Scores adjusted by age, gender, diabetes status based on DOPPS

www.kdqol-complete-org
KDQOL COMPLETE
Site Contents

- Survey (multiple languages)
- Patient report (multiple languages)
- Chart reports:
  - Individual patients
  - Facility

www.kdqol-complete.org
<table>
<thead>
<tr>
<th>PATIENT</th>
<th>KDQOL COMPLETE Responses to Each Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schmoe, Joe (003)</td>
<td></td>
</tr>
<tr>
<td>MODALITY</td>
<td>Peritoneal Dialysis</td>
</tr>
<tr>
<td>BIRTHDATE</td>
<td>01-01-1938</td>
</tr>
<tr>
<td>GENDER</td>
<td>Male</td>
</tr>
<tr>
<td>DIABETES</td>
<td>Yes</td>
</tr>
<tr>
<td>SURVEY DATE</td>
<td>12-22-2009</td>
</tr>
</tbody>
</table>

|----------|------|------|------|------|------|------|------|------|------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
Look at the scales & what they mean
- Look at color codes for risk adjustments
  - **Red** = higher risk
  - **Yellow** = average risk
  - **Green** = lower risk
- Where is score on continuum?
- Where should the IDT focus its efforts?
Joe Schmoe: 
PCS & MCS Scores

Adjusted by age, gender, diabetes status

**Physical Component Summary (PCS)**

28.829
Average

Case mix adjusted mean: 34.3193433
How the patient perceives his physical health. The lower the score, the higher the risk of hospitalization or death.

**Mental Component Summary (MCS)**

47.730
Average

Case mix adjusted mean: 50.4822684
How the patient perceives his emotional and mental health. The lower the score, the higher the risk of hospitalization or death.
Joe Schmoe: Kidney Disease Scales

Adjusted by age, gender, diabetes status

**Burden of Kidney Disease**
- Case mix adjusted mean: **45.1530612**
  - How much CKD interferes with daily life, causes frustration, and makes the patient feel like a burden.

**Symptoms and Problems**
- Case mix adjusted mean: **77.0703206**
  - How bothered the patient feels by physical symptoms associated with CKD.

**Effects of Kidney Disease on Daily Life**
- Case mix adjusted mean: **69.0322779**
  - How bothered the patient is by fluid/diet, limits on work or travel, feeling dependent, stress, sex life, and appearance.
Multidisciplinary vs. Interdisciplinary Plan of Care

**Multidisciplinary**
- Work sequentially
- Individual problem solving
- Medical record is the chief means of communication

**Interdisciplinary**
- Work collaboratively
- Collective problem solving
- Communication by regular discussions about patients & the evolving plan of care
Using the KDQOL to Set Goals with the Patient

- Review scores & responses with patients soon after survey is completed
- Focus on areas where things are going well & on areas where responses (and scores) could improve
- Ask the patient to choose an area of most concern from below average score areas to set goals & work on
Developing a Patient Plan of Care with the IDT

- Plan must be effective & individualized to patient
- Patient must be invited & encouraged to participate
- Meetings:
  - At chairside if patient agrees
  - In a conference room
- Any IDT member can participate by phone if needed
- Each IDT member shares information learned from his/her comprehensive patient assessment
- Any substitute for a meeting must promote information sharing
## Symptoms & Plan for Relief

+ Somewhat bothered; ++ Moderately bothered; +++ Very much bothered

<table>
<thead>
<tr>
<th>Patient Assessment</th>
<th>IDT Intervention Plan for Joe Schmoe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest pain +</td>
<td>Refer to cardiology, reinforce salt/fluid limit</td>
</tr>
<tr>
<td>Cramps ++</td>
<td>Review/revise dialysate Rx as needed</td>
</tr>
<tr>
<td>Itchy skin ++</td>
<td>Review diet; binder education, $ help for binders</td>
</tr>
<tr>
<td>Dry skin ++</td>
<td>Bathing regimen, lotion tips, refer to dermatology</td>
</tr>
<tr>
<td>Short of breath +++</td>
<td>Review salt/fluid limit &amp; balance, refer to cardiology</td>
</tr>
<tr>
<td>Faint/dizzy +++</td>
<td>Review BP meds, dialysate concentration use</td>
</tr>
<tr>
<td>Lack of appetite +++</td>
<td>Monitor adequacy, treat depression, resource referral</td>
</tr>
<tr>
<td>Washed out/drained +++</td>
<td>Treat anemia/depression/low BP, refer to PT</td>
</tr>
<tr>
<td>Numb hands/feet +</td>
<td>Review dialysis Rx, meds, refer to cardiology</td>
</tr>
<tr>
<td>Nausea/upset stomach ++</td>
<td>Review dialysis Rx, meds, refer to GI</td>
</tr>
<tr>
<td>Scale</td>
<td>IDT Intervention Plan for Joe Schmoe</td>
</tr>
<tr>
<td>------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>PCS</td>
<td>Treat anemia, encourage physical activity, advise about safe exercise, educate about salt/fluid, suggest protein sources</td>
</tr>
<tr>
<td>MCS</td>
<td>Build hope through mentors, encourage enjoyed hobbies, socialization, encourage step-by-step planning toward goals, treat depression &amp;/or anxiety</td>
</tr>
<tr>
<td>Burden</td>
<td>Encourage independence, questioning &amp; education about CKD &amp; treatment, discuss ways to use treatment time productively, educate &amp; evaluate ways to reduce PD burden</td>
</tr>
<tr>
<td>Effects</td>
<td>Treat anemia, provide diet education, explain why more dialysis is better, encourage physical activity, promote positive attitude, sense of humor, and joy in activities, help to set realistic goals &amp; expectations</td>
</tr>
</tbody>
</table>
Review: Documenting Surveys

- Facility policy determines where to file survey (medical record or file cabinet)

- Chart notes should include:
  - Scores & how they compare to mean (average)
  - Risk for hospital/death (low, average, high)
  - Patient-reported factors contributing to low scores
  - Patient & team goals & roles
  - Timelines

- Some ideas for QAPI
  - Track & trend number patients by risk level, contributing elements, success of interventions
Interventions That Have Improved Health-Related Quality of Life Scores
Peritoneal Dialysis

- **APD vs. CAPD** – 6 month study. Gave patients more time to have a life.
- **Icodextrin PD fluid** – 13 week study. Caused fewer symptoms than glucose-based fluid.

More Hemodialysis Is Better

- Short daily or nocturnal HD reduced cramps, headaches, hypotension, shortness of breath, and other symptoms, and improved HRQOL vs. standard HD.\(^3,4\)

Using echocardiograms to adjust dry weight by measuring the inferior vena cava improved HRQOL vs. usual care.\textsuperscript{5}

\textsuperscript{5}Chang ST et al. \textit{Nephron Clin Pract.} 2004;97(3):c90-7
Treating Anemia

- Compared to oral iron, IV iron significantly increased hemoglobin levels and KDQOL scores.\(^6\) Use of ESAs to treat anemia was associated with increased HRQOL.\(^7\)


Maintaining Bone Mineral Balance

- Use of cinacalcet to reduce PTH significantly reduced parathyroidectomies, cardiac hospitalizations, and fractures — and improved HRQOL.\(^8\)

Exercise Training

- Improves depression, HRQOL, and stamina$^{9,10,11,12,13}$

Adaptation Training & Group Counseling

- Helping patients cope with the stresses of ESRD improved HRQOL over usual care

15 Lii YC et al. J Clin Nurs. 2007 Nov;16(11C):268-75
I have made the KDQOL the center of the work I do with patients. I spend a lot of time on the KDQOL with patients, and make it the cornerstone of what I discuss in care plan meetings, and I find that this makes most other processes quicker. With a thorough QOL discussion, I find assessments and care plans go faster, make more sense and are truly patient centered. QOL helps us identify patient goals that we can work together as a team to help them achieve.

-- Megan Prescott, LCSW
University of Colorado Hospital Chronic Dialysis Unit
Plan Well & Your Team May Help Patients Live Longer and Better

1 Point ↑ in PCS
- RR mortality ↓ 2%
- RR hosp. ↓ 2%

1 Point ↑ in MCS
- RR mortality ↓ 2%
- RR hosp. ↓ 1%

Questions or Comments

- For questions or comments about this presentation or the KDQOL, please email Beth at beth@wittenllc.com
- For questions or comments about obtaining copies of the presentation or about the Heartland Kidney Network, please email Anne at akaranja@nw12.esrd.net