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

Presenter: Beth Witten, MSW, ACSW, LSCSW
Moderator: Melissa Hale MSW, LCSW
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Disclosure

- Consultant with Medical Education Institute, Inc. which administers KDQOL COMPLETE & multiple other websites

- Consultant to ESRD Survey & Certification Group, Centers for Medicare & Medicaid Services & member of ESRD Training & Support Team
Objectives

- Describe why & how to measure health-related quality of life (HRQOL)
- Explain how to review scores & set goals
- List interventions that have improved scores
- State how facilities can meet surveyor expectations related to patient HRQOL
What HRQOL Is

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

¹CDC - www.cdc.gov/hrqol/index.htm
Why Use HRQOL Surveys?

- Scores independently predict hospitalization & death\(^2,3\)
- National Quality Forum recommended HRQOL for CMS clinical performance measure 4/1/2008
- Mandated in ESRD Conditions for Coverage & Interpretive Guidance

\(^3\)Mapes DL et al., *Kidney Int* 2003, 64:339-349.
The KDQOL-36™ Is Not Just About Psychosocial Interventions

It takes a team to:

- Improve physical function
- Improve mental function
- Relieve kidney disease burden
- Manage symptoms
- Limit ESRD effects on daily life

Social workers can’t do this alone!
Getting Your Team On Board for HRQOL in POC & QAPI

- Share individual patient data in POC
- Share aggregate facility-level data in QAPI
- Low scores? Share scores & responses with other team members & ask for help to address
- Ask colleagues how they got their team on board & use those techniques with your team
Who Doesn’t Need to Be Offered the KDQOL-36™

- On dialysis <3 months;
- Choose not to take the survey/refuse;
- Have cognitive impairment, dementia, active psychosis;
- Non-English speakers/readers where there is no translation or interpreter through any of these:
  - KDQOL Working Group site
  - KDQOL COMPLETE
  - Language Line
  - American Translators Assoc (includes interpreters) www.atanet.org
Who Else Doesn’t Need to be Offered the KDQOL-36™?

- Youth under 18
- However…Must offer age appropriate survey
  - PedsQL is only kidney-specific HRQOL survey: [www.pedsqql.org](http://www.pedsqql.org)
  - Find other pediatric HRQOL surveys: [www.proqolid.org](http://www.proqolid.org)
Educating/Empowering Patients Pre-Survey

To help patients see “what’s in it for me” say:

- Medicare wants us to focus on how you think you are functioning
- There are no wrong answers—no one else knows how you feel
- Your answers are important to us
- Please complete the survey while you’re here
- First 12 questions give scores that may help us help you live longer & better so please answer all of them
Self-Administration Is Best, But If You Must Assist…

- Speak clearly, confirm patient understands
  - Over last 4 weeks or current (if question states)
  - Questions about general health (1-12, 17-28)
  - Kidney-specific questions (13-16, 29-36)
- Ask patient to respond with first thought
- Do not interpret questions for patients
- Repeat as needed; avoid sounding frustrated
- Use a tip sheet for groups of questions (response options & timeframe if applicable)
Scoring KDQOL-36™ When Clinic Has No Scoring Program

**Free**
- KDQOL-36 survey (translations)
- KDQOL-36 Excel scoring template to download
- Basic instructions
- No patient report
- No norms

www.rand.org/health/surveys_tools/kdqol.html

**Subscription**
- KDQOL-36 survey (translations)
- Automatic age x gender x diabetes score adjustment (DOPPS)
- Text patient report (translations)
- Graphical clinic reports for POC & QAPI

www.kdqol-complete.org
Discussing KDQOL-36™ Results with the Patient

- Discuss scores & share patient report ASAP
- Congratulate patient on positive areas
- Focus on areas needing improvement
- Use +/- changes in responses to questions to direct plan & interventions
- Low scores? Instill hope, offer team help & support
Low Scores? Consider Factors Linked to Poor HRQOL

- Suboptimal first dialysis (hospital; with catheter; not on modality of choice)\(^4\)
- Anxiety & depression\(^5\)
- Poor sleep quality\(^6\)
- Higher malnutrition-inflammation score\(^7\)
- Longer travel times to dialysis\(^8\)

\(^4\) Mendelssohn et al., BMC Nephrol 2009 Aug 12;10:22
Physician Prescription

- Short daily or nocturnal HD reduced ↓ symptoms (cramps, headaches, hypotension, SOB, etc.), & improved HRQOL compared to standard HD\(^9,10\)

- CCPD allowed patients more time to enjoy life\(^11\)

- Icodextrin (Extraneal) PD solution ↓ symptoms\(^12\)

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Physician & Nursing Interventions

- Adjusting dry weight\textsuperscript{13}
- IV iron (more than oral iron)\textsuperscript{14}
- Treating anemia with ESAs\textsuperscript{15}
- Reducing PTH with cinacalcet\textsuperscript{16}

\textsuperscript{13}Chang ST et al. *Nephron Clin Pract*. 2004;97(3):c90-7
Dietitian & Social Work Interventions

Exercise improves depression, HRQOL, stamina\textsuperscript{17-21}

\textsuperscript{17}Levendoglu F et al. *J Nephrol.* 2004 Nov-Dec;17(6):826-32
\textsuperscript{21}Molsted S et al. *Nephron Clin Pract.* 2004;96(3):c76-81
Social Work Interventions

- Adaptation training\textsuperscript{22} & group counseling\textsuperscript{23} help patients cope with stresses of ESRD & improved HRQOL more than usual care (no intervention)

- Goal setting & interdisciplinary collaboration significantly improved patients’ perception of their health status, specifically physical & emotional role functioning\textsuperscript{24}

\textsuperscript{22}Tsay SL et al. \textit{J Adv Nurs.} 2005 Apr;50(1):39-46
\textsuperscript{23}Lii YC et al. \textit{J Clin Nurs.} 2007 Nov;16(11C):268-75
\textsuperscript{24}Callahan MB et al., \textit{Nephrol News Issues} 1999 Jan; 13(1):33-7
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
  - Outcomes
Social Worker’s Lead Role in Monitoring Functioning

- Offer survey to all eligible patients within timelines
- Review scores & responses with patient quickly
  - **Good scores?** Identify & encourage ongoing efforts
  - **Scores need improvement?** Ask patient 1st priority for action
- Share survey & interview data in plan of care meetings
- Share facility-level patient data in QAPI team meetings
- Intervene with team to improve scores & outcomes
CfC Description of IDT Patient Plan of Care

- Plan must be effective & individualized to patient
- Meet in conference room or chairside, if patient agrees
- Phone participation is OK (patient, IDT member)
- Each IDT member should share assessment info
- Invite patient to offer input & participate in plan
  - Participation should be more than signing form
- Meeting substitute must promote info sharing & collaboration in developing plan
Helping Patients Set SMART Goals

“If you don't know where you are going, you'll end up someplace else.” Yogi Berra

<table>
<thead>
<tr>
<th>S</th>
<th>Your goals should be <strong>SPECIFIC</strong>. Include dates, resources, and dollar amounts you’ll need to accomplish them.</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>They should be <strong>MEASURABLE</strong> by the date, dollar, or other appropriate unit. They should also be <strong>MUTUAL</strong>. (A legal or financial goal that you share with a spouse, partner, or family members will be easier to achieve.) And, it’s best to define strategies for staying <strong>MOTIVATED</strong> towards your goals.</td>
</tr>
<tr>
<td>A</td>
<td>Your goals should be <strong>ATTAINABLE</strong> for your situation. You might even be able to complete part of your goal right now.</td>
</tr>
<tr>
<td>R</td>
<td>If your goals are <strong>REALISTIC</strong> and <strong>RELEVANT</strong> to your life, they’ll be easier to achieve. Identify the <strong>RESOURCES</strong> you’ll need to reach them, and <strong>REVIEW</strong> and <strong>REVISE</strong> them when necessary.</td>
</tr>
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<td>T</td>
<td>You’ll need a specific <strong>TIMELINE</strong> to accomplish your goals. Since there’s never enough time to complete all of your goals immediately, you’ll need to prioritize them.</td>
</tr>
</tbody>
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**Timeframes**
- **Short-term**<br>  <3 months
- **Intermediate**<br>  3-6 months
- **Long-term**<br>  ≥1 year

[www.extension.org/pages/11229/what-are-smart-goals](http://www.extension.org/pages/11229/what-are-smart-goals)
<table>
<thead>
<tr>
<th>Patient Assessment</th>
<th>Possible IDT Intervention Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sore muscles</td>
<td>Evaluate, review labs, activities,</td>
</tr>
<tr>
<td>Chest pain</td>
<td>Evaluate, educate/reinforce salt/fluid limit, refer to cardiologist, pulmonologist</td>
</tr>
<tr>
<td>Cramps</td>
<td>Review/revise dialysis Rx as needed</td>
</tr>
<tr>
<td>Itchy skin</td>
<td>Review labs, PO$_4$ intake, educate about binder, seek financial help for binders</td>
</tr>
<tr>
<td>Dry skin</td>
<td>Evaluate bathing regimen, lotion tips, refer to dermatology</td>
</tr>
<tr>
<td>Short of breath</td>
<td>Evaluate, educate/reinforce salt/fluid limit, refer to cardiology, pulmonology</td>
</tr>
</tbody>
</table>
**Symptom Relief Planning (con’t)**

<table>
<thead>
<tr>
<th>Patient Assessment</th>
<th>Possible IDT Intervention Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Faint/dizzy</td>
<td>Evaluate, review BP meds &amp; timing, fluid removal rate (HD, PD)</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>Monitor adequacy, treat depression, promote socialization, refer for meal help</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>Monitor adequacy, labs, meds, refer to neurology, educate to control DM (if applicable)</td>
</tr>
<tr>
<td>Nausea/upset stomach</td>
<td>Monitor dialysis adequacy, meds, refer to GI</td>
</tr>
<tr>
<td>Problems with access site (HD)</td>
<td>Evaluate &amp; treat infection, educate about access care, evaluate &amp; correct flow problems</td>
</tr>
<tr>
<td>Problems with catheter site (PD)</td>
<td>Evaluate &amp; treat infection, educate about access care, use prophylactic antibiotic cream, evaluate &amp; correct flow problems</td>
</tr>
</tbody>
</table>
## IDT Interventions to Maintain/Improve Scores

<table>
<thead>
<tr>
<th>Scale</th>
<th>Possible IDT Intervention Plan</th>
</tr>
</thead>
<tbody>
<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 instruction, explain why more dialysis is better, encourage physical activity, promote positive attitude, sense of humor, &amp; joy in activities, help to set realistic goals &amp; expectations</td>
</tr>
</tbody>
</table>
Tracking KDQOL-36™ Scores in Plan of Care

- What were the scores & how were individual questions marked this time & last?
  - What scores should be maintained?
  - What scores are worse on this survey?
  - What scores are better on this survey?
Tracking KDQOL-36™ Scores in Plan of Care (cont.)

- What does team think the patient should work on?
- What is patient’s highest priority to work on?
- What interventions have been attempted?
- How effective were interventions attempted?
- How does the plan need to be adjusted?

Goal ► Action ► IDT Member ► Start Date ► Check Date ► End Date ► Outcome
Measures You Could Report in QAPI (V627)

- % of eligible patients taking survey on time (initial reassessment in 4th month & annually) per CMS clinical performance measure (minimum)
- % of patients excluded & reasons why
- % of patients who refused & later took survey
- % surveyed whose low score improved ≥1 point
- % surveyed whose score declined ≥10 points

Problem ➤ Goal ➤ Action ➤ QAPI Member ➤ Target Dates ➤ Outcome ➤ Monitor
More Measures You Could Report in QAPI (V627)

- Did KDQOL scores of patient’s’ exhibiting risky behaviors show certain pattern
  - ↑PCS + ↓MCS → skipping or shortening treatment
- Did patients who were hospitalized or died have low or declining scores on recent surveys? What scale(s)?
- What interventions improved facility level patient scores? What scale(s)?
- What were the cost-benefits of time spent on actions?
What Do Surveyors Look For?

- Is there documentation of the KDQOL-36 or other age appropriate survey or...
  - Did patient meet exclusion criteria?
  - If patient refused, what was the follow-up?
- Was survey scored & results reported:
  - To patient?
  - To interdisciplinary team?
- Was survey used by IDT in plan of care?
Where Do Surveyors Look for Evidence of Compliance?

- Did staff adhere to CfC, facility P&P?
- Does the record include scores & plans to address or valid reason to exclude
- Do interviews confirm POC & QAPI notes:
  - Patients?
  - Social worker?
  - Other members of interdisciplinary team?
V552 Psychosocial Status

- One of the top 25 citations in FY 2010 & 2011
- This citation is for failure to do any of these:
  - Psychosocial counseling
  - Referrals for other social services
  - Helping to achieve & sustain appropriate psychosocial status using HRQOL survey
- POC is a team responsibility & citation is for IDT
- Avoid citation by administering, sharing, & using survey in plan of care
"I have made the KDQOL-36 ™ the center of the work I do with patients. I spend a lot of time on the KDQOL-36™ 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
Improving These Scores 1 Point Helps Patients Live Longer & Better

**PCS Score**
- RR mortality ↓ 2%
- RR hospitalization ↓ 2%

**MCS Score**
- RR mortality ↓ 2%
- RR hospitalization ↓ 1%

Additional Resources for Improving Health-Related Quality of Life

www.kidneyschool.org
www.homedialysis.org
www.lifeoptions.org
Learn About Treatment Options & Living with Kidney Disease

- ALL dialysis options
- 6th grade reading level
- Indexed, illustrated
- Evidence-based

www://lifeoptions.org/help_book
Thank You and Questions
We’d Love to Hear from You…

- Send ideas for future topics &/or speakers to mhale@meiresearch.org
- “Like” MEI for a chance to win free CE credits www.facebook.com/MedicalEducationInstitute