ASN DIALYSIS ADVISORY GROUP

ASN DIALYSIS CURRICULUM
Quality of Life in Dialysis

Suzanne Watnick, MD
Professor of Medicine
Training Program Director
Oregon Health & Science University
DISCLOSURES:

• None
Outline of Talk

- What is Quality of Life (Definition)?
  - What is QOL on dialysis?
- What contributes to this?
- What basic literature is important?
- How do we practically assess QOL?
- How do we improve it?
Mr M is a 73 yo caucasian gentleman, on chronic HD x 4 years due to T2 DM

• He feels constant fatigue, frequent back pain, and intermittent pruritus

• He has compression fractures, and insists on stopping treatments when in too much pain

• He wants to know 3 things:
  • ‘Doc, am I like everyone else?’
  • ‘What can you do to help me feel better?’
  • ‘Is this as good as it gets?’
What is QOL?

Active learning exercise:
• How would you define quality of life for Dialysis patients for whom you have cared?

Some other definitions:
• QOL - A complete state of physical, mental, and social well being and not merely an absence of disease in infirmity.*
• Health related QOL - The health demands that are intimately related to health or disease.**
What contributes to QOL?

Doctors may focus on: Control of:
• Acid-base status
• BP and volume status
• Cardiovascular Risk
• Diet/nutrition
• Mineral/Bone disorders
• Small/middle molecules

Patients may focus on: How do I feel !?!
What impacts a patient’s QOL?

**Global Domains**
- Happiness
- Spirituality
- Perceived health

**Physical Functioning Domains**
- Sleep Disturbance
- Pain
- Physical Activity

**Psychological Domains**
- Depression
- Anxiety
- Cognitive function

**Social Domains**
- Sexual Dysfunction
- Marital satisfaction
- Social Support
How do we assess general QOL?

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Population</th>
<th>Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Disease QOL Questionnaire</td>
<td>HD</td>
<td>QOL &amp; Symptoms</td>
</tr>
<tr>
<td>CHOICE Questionnaire</td>
<td>HD and PD</td>
<td>QOL</td>
</tr>
<tr>
<td>McGill Quality of Life Scale</td>
<td>Kidney disease</td>
<td>QOL</td>
</tr>
<tr>
<td>Illness Effects Questionnaire</td>
<td>HD</td>
<td>QOL &amp; effects</td>
</tr>
<tr>
<td>Dialysis Symptom Index</td>
<td>HD</td>
<td>P &amp; E Symptoms*</td>
</tr>
<tr>
<td>Modified Edmonton Symptom Scale</td>
<td>HD</td>
<td>P &amp; E Symptoms</td>
</tr>
<tr>
<td>Patient Symptom Form</td>
<td>CKD</td>
<td>P &amp; E Symptoms</td>
</tr>
</tbody>
</table>
## Tool Comparison for Specific Selected Symptoms Affecting QOL

<table>
<thead>
<tr>
<th>Domain</th>
<th>Validated Tools: Examples</th>
<th>Interventions include:</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>KDQOL-SF</td>
<td>Social Support Group</td>
<td>‘SS → improved compliance &amp; access to care</td>
</tr>
<tr>
<td></td>
<td>SF-36</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>MSP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>SCID-1</td>
<td>CBT</td>
<td>Check for Depression</td>
</tr>
<tr>
<td></td>
<td>PRIME-MD</td>
<td>Pharmacologic Rx</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>Bodily Pain Scale</td>
<td>Pain Management</td>
<td>Adjust meds for kidney and liver disease</td>
</tr>
<tr>
<td></td>
<td>MPG</td>
<td>WHO analgesic ladder</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exercise</td>
<td></td>
</tr>
<tr>
<td>Sexual Dysfunction</td>
<td>IIEF-5</td>
<td>PDE-5 Inhibitors</td>
<td>Minimal data for Rx in ESRD</td>
</tr>
</tbody>
</table>
Typical Symptomatology (1)

↑ symptoms with ↑age & comorbidity

• Fatigue most prevalent:
  • 82% (HD) – 87% (PD)
• Itching, muscle cramps, SOB: each >40%

Dialysis dose not associated with sx burden

Physical symptoms only ONE PART of ‘Quality of Life’
Typical Symptomatology (2)

Most prevalent symptoms
• Dry skin (72%), fatigue (69%), itching (54%), bone & joint pain (50%)

Most bothersome symptoms
• Bone & joint pain, sexual arousal
• Half of symptoms were reported as ‘more than somewhat bothersome’

Treatment - examples
• Dry Skin & Pruritus: Emollients, dermatology referral, dietary counseling
• Fatigue: Can assess and treat for OSA (obstructive sleep apnea)
• Bone & Joint Pain: WHO analgesic ladder, CKD-MBD treatment
Physical Functioning Domains
Pain

Etiologies:
• Treatment related - needles, fluid & electrolyte shifts
• Renal bone disease
• Comorbidity related

Common (25-50%) & severe
Associated with:
• depression, low QOL scores, insomnia, anxiety, dialysis withdrawal
Physical Functioning Domains
Sleep Disturbances

Etiologies include:
• Sleep apnea, Restless leg syndrome (RLS), altered sleep-wake cycles

Common (41-83%) & associated with:
• Pain, depression, poor Global QOL, adverse cardiovascular outcomes

Consider sleep hygiene assessment before pharmacologic Rx
Polysomnography +/- CPAP, RLS therapy
• Including d/c antidopaminergic agents
Social Domains: Sexual Dysfunction

Etiologies include:
- Vascular disease, hormonal changes, medications, psychological concerns

Range of reported sxs from 33-83%
- including ED, decreased interest, poor arousal
- One of the most bothersome symptoms

Treatment -
- 18% of those w/sxs received therapy
- medications effective vs placebo
- Phosphodiesterase inhibitors have been used:
  - caution for use in population with high burden of cardiovascular disease
Social Domains: Social Support

Types: support via:
- Cognitive - information/knowledge
- Emotional - concerns & feelings
- Materials - goods & services

Improvements in:
- aid and access to care
- symptoms of depression and anxiety
- adherence, direct physiologic effects.

Demonstrated relationships between social supports and:
- Items listed above, also
- quality of life and survival
Psychological Domains

Depression

Most common psychiatric disorder in chronic dialysis patients
• Prevalence estimates ~20% of MDD
• Dx via DSM-IV criteria
• Screening tools include BDI, PHQ-9, CES-D

Therapies: non- and pharmacological
• SSRIs with few side effects, low dose & titrate
• Counseling (eg CBT), exercise, Rx anxiety
• Understudied
Psychological Domains
Cognitive Impairment (1)

**Definition of cognitive impairment:**
- new deficit in 2 areas of cognitive functioning
  - Memory, executive function, attention/processing, perceptual motor, language
  - Diagnosis: 3MS score < 80 or MMSE < 24

**Prevalence not well documented**
- Chart dx - 2.9% but with formal testing:
  - 37% severe impairment
  - 36% moderate
  - 14% mild
Psychological Domains

Cognitive Impairment (2)

Etiologies (risk factors) include:

• Traditional vascular: large & small vessel vascular disease (HTN, DM, age, smoking)
• Nontraditional vascular (hypercoagulable, hemostatic, inflammatory, oxidative stress)
• Nonvascular (Anemia, hyperparathyroidism, polypharmacy, sleep, age, education)

Treatment should focus on above etiologies

Associated with:

• increase risk of death, decreased quality of life, increased hospitalization/healthcare utilization
Global Domains

Important to address general issues related to:
• Spirituality
• Perception of health
• Overall happiness
Our Patient...

Physical Function domains
• Sleep disturbance & pain addressed

Social domains
• Family and friends spent more time with him

Psychological domains
• Patient was depressed, started therapy

Global domains
• Patient assured that he was not ‘alone’ (major fear of his), ensured presence of spiritual support, daily activities
Easy Recipe: Quality of Life Assessment

Input patient’s subjective assessment of QOL

Input objective measures of QOL

Are goals being achieved

Yes → Continue what you are doing

No → Change something
Future Needs Assessment: Shaping the Research and Policy Agenda

Identification of broad themes to improve patient-centered outcomes

- Decrease morbidity and mortality
- Enhance Quality of Life
- From Kidney Research National Dialogue
“Several said the government is making a crucial mistake by rating performance [of dialysis clinics] by lab tests, not outcomes or measures that reflect patients’ quality of life. ‘Mortality, morbidity, and infection—that’s the bottom line,’ said [a former dialysis-clinic owner]. ‘It’s easy to adjust the labs. What good is it if you have good numbers, but everyone’s dying or in the hospital?’”

- Robin Fields, in “God Help You. You’re on Dialysis.” The Atlantic, December 2010
Quality of Life is...

What is important to the patient

• Thus an essential component of what we should consider when we care for those around us

Composed of Global, Psychological, Social, and Physical functioning domains

Assessable in the dialysis unit

Impacted by looking, listening and feeling with your patients