The Aging CKD Patient

Mark Unruh MD MS
Professor and Chair of Medicine
September 13, 2016
LSU Geriatric Nephrology Symposium
Mark Unruh MD MS

• Disclosure of relevant financial relationships
  – I have no financial relationships to disclose.

• Disclosure of off-label and/or investigative uses
  – I will not discuss off-label use and/or investigational use in my presentation.
Questions

• Higher relative QOL? Young adult or older adult on HD?
  – Both a smaller gap relative to age and a higher individualized quality of life

• Does QOL factor into patient decision making regarding renal replacement therapy?
  – Prevalent HD patients report sleep and fatigue would influence them to try frequent HD
Hypertension, diabetes, and elevated creatinine

- 81-year-old woman with long-standing hypertension and diabetes.
- Cognitively intact - Now ready for dialysis -
- How will I feel?
- Will I be independent?
- What modality, when, where, and how frequently should she undergo dialysis?
Aims for Quality of life in Older Patient with CKD

• How do we measure HRQOL?
• What have we found measuring HRQOL?
• How can we improve HRQOL in older adults with ESRD?
Health-Related Quality of Life

Multidimensional and focuses on the effects of health status of patients on their quality of life

Includes domains related to physical, mental, emotional and social functioning
### Multi-Dimensional QOL

<table>
<thead>
<tr>
<th>ITEMS</th>
<th>SCALES</th>
<th>Dimensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Vigorous activities</td>
<td>Scale 1: Physical Functioning (PF)</td>
<td>Dimension A:</td>
</tr>
<tr>
<td>4. Moderate activities</td>
<td></td>
<td>PHYSICAL HEALTH</td>
</tr>
<tr>
<td>5. Lift, carry groceries</td>
<td>Scale 2: Role-Physical (RP)</td>
<td></td>
</tr>
<tr>
<td>6. Climb several flights</td>
<td>Scale 3: Bodily Pain (BP)</td>
<td></td>
</tr>
<tr>
<td>7. Climb one flight</td>
<td>Scale 4: General Health (GH)</td>
<td></td>
</tr>
<tr>
<td>8. Bend, kneel</td>
<td>Scale 5: Vitality (VT)</td>
<td></td>
</tr>
<tr>
<td>9. Walk mile</td>
<td>Scale 6: Social Functioning</td>
<td></td>
</tr>
<tr>
<td>10. Walk several blocks</td>
<td>Scale 7: Role-Emotional (RE)</td>
<td>Dimension B:</td>
</tr>
<tr>
<td>11. Walk one block</td>
<td>Scale 8: Mental Health (MH)</td>
<td>MENTAL HEALTH</td>
</tr>
<tr>
<td>12. Bathe, dress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Cut down time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Accomplished less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Limited in kind</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Had difficulty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Pain-magnitude</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Pain-interfere</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. General health rating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Excellent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. As healthy as anyone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Sick easier</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Health worse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Pen/life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Energy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Worn out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. Tired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Social-extent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Social-time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Cut down time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Accomplished less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Not careful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Nervous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Down in dumps</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Blue/sad</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Happy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Change in reported health</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Limitations**
  - Limited vocabulary for severity
  - Domains may not reflect values of person
  - The weighting is not consistent – response shift

Kalantar-Zadeh Unruh 2005
Which definition is correct?

• Reliability- Your friend is there for you when you have a need
• Validity – You are measuring what you think you are measuring
• Responsiveness- The questionnaire changes depending on your response
• Test-retest reliability– If you don’t get the questions correct, you get to take the questionnaire over
How impaired are measures physical well-being among patients with ESRD? Similar to:

• Angina
• Arthritis
• Heart Failure
• Hypertension
HRQOL in Dialysis Patients

Why HRQOL is important?

Trend of HRQOL in Dialysis Patients

Gabbay et al. CJASN 2010;5:261-267
There is lack of improvement in overall HRQOL among dialysis patients over the past decade.
What is QOL among older adults on dialysis

- QOL impaired in domains of physical function
- QOL thought to be preserved for mental health
- Marked functional impairment in nursing home residents with ESRD (Kurella NEJM 2009)
- Older adults on dialysis have less of a QOL gap (Rebollo NDT 2001)
Associations between Schedule for the Evaluation of Individual Quality of Life (SEIQOL) and Age in advanced CKD and ESRD

Abdel-Kader K et al. CJASN 2009;4:711-718
Composite of Death and Worsening of Symptoms

Unruh et al. JAGS 2008
How to improve HRQOL in ESRD Patients?

Improving symptoms to improve HRQOL?
# Provider responses - “potentially treatable” symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>K</th>
<th>Sens</th>
<th>Spec</th>
<th>PPV</th>
<th>NPV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone/joint pain</td>
<td>0.04</td>
<td>18</td>
<td>87</td>
<td>46</td>
<td>64</td>
</tr>
<tr>
<td>↓ Interest sex</td>
<td>0.01</td>
<td>6</td>
<td>98</td>
<td>50</td>
<td>77</td>
</tr>
<tr>
<td>Diff sex arousal</td>
<td>0.03</td>
<td>19</td>
<td>98</td>
<td>80</td>
<td>76</td>
</tr>
<tr>
<td>Prob fall asleep</td>
<td>0.08</td>
<td>21</td>
<td>93</td>
<td>70</td>
<td>60</td>
</tr>
<tr>
<td>Prob stay asleep</td>
<td>0.05</td>
<td>15</td>
<td>88</td>
<td>50</td>
<td>55</td>
</tr>
<tr>
<td>Swelling in legs</td>
<td>0.34</td>
<td>42</td>
<td>92</td>
<td>71</td>
<td>77</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>0.42</td>
<td>52</td>
<td>91</td>
<td>69</td>
<td>83</td>
</tr>
</tbody>
</table>

Weisbord CJASN 2007
Providers are largely unaware of symptoms

• Even symptoms that patients reported to be most severe were poorly recognized by providers.

• The severity of symptoms identified correctly by providers as being present is commonly underestimated.

• Collaborative care between nephrologists and primary care providers
No change in pain, ED, depression with nurse management

Weisbord CJASN 2013
ASCEND:
A Trial of Sertraline vs. CBT for End-stage Renal Disease Patients with Depression
Treatment Options for Depression in Patients Undergoing Hemodialysis
Symptom assessment and management is an integral component of quality care for patients with advanced chronic kidney disease. Regular global symptom screening using validated tools should be incorporated into routine clinical practice.

Symptom management requires a stepwise approach. First-line treatment includes non-pharmacological interventions and then advancing to more complex therapies. Second-line treatment is pharmacologic therapy. Consideration should be given to low-dose pharmacological therapy that may have efficacy across several symptoms.

Symptom management is a research priority in chronic kidney disease. Particular attention is required on the relative effectiveness of management strategies, including the impact on outcomes most relevant to patients such as overall symptom burden, physical function and HRQOL.
Who is responsible for treating the symptoms related to HRQOL?
Multidisciplinary team approach with effective communication between health-care providers will be beneficial to improve HRQOL and overall care of the dialysis patients.
How to manage the older patient?

• Now ready to start dialysis with AVF in place.
  – Course complicated by admission with severe AS and deemed not operable
  – Given her limited functional status with AS, the patient decided not to undergo HD

• Patient discharged to home with home hospice and passed away within one day of discharge with family at her bedside.
Key Messages

- Measurement of patient-reported outcomes may provide an opportunity to provide more patient-centered care.
- Consider targeted measurement of symptoms (pain and depression) to complement HRQOL measurement.
- Should focus on the patient-centered therapy and treat the symptoms accordingly to improve the overall quality of life and patients’ outcomes.
- Improved communication and the use of a multidisciplinary team provide mechanisms to improve HRQOL in ESRD.
Challenges in aging ESRD population

• Patients >75 have higher incidence rates of ESRD than younger patients and constitute the fastest growing segment of the ESRD population in the United States.

• \( \frac{1}{3} \) of elderly patients with ESRD have >4 chronic health conditions when they reach ESRD and many are not considered candidates for kidney transplantation.
Life expectancy for many patients with ESRD is similar or worse than that associated with common cancers, and HD does not always substantially prolong life.

USRDS 2011
Ethical Considerations

• Medical Indications for dialysis
  – Diagnosis, prognosis, treatment
• Ethical principles
  – Autonomy, Beneficence, non-maleficence, justice
• Patient Preferences
• Quality of Life
• Contextual Features
Are there differences in PCP vs. Nephrologist

<table>
<thead>
<tr>
<th>Vignette 1</th>
<th>Vignette 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undecided</td>
<td>Committed to Conservative Management</td>
</tr>
</tbody>
</table>

Mrs. Montgomery is a 78 year old woman with HTN, CAD, and COPD diagnosed with stage 4 chronic kidney disease (eGFR = 22 ml/min/1.73m²) secondary to DM II. She is capable of making decisions and is able to care for most of her personal needs herself. She adheres to medications and follow-ups.

Mr. Suarez is an 83 year old man diagnosed with stage 5 chronic kidney disease (eGFR=9 ml/min/1.73m²) secondary to DM II and HTN. He is active and fully independent. He is adherent with medications and follow-ups. He is committed to having his CKD managed conservatively.

Parvez CJASN 2016
<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Treatment</th>
<th>PCPs (%)</th>
<th>NEPHs (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet Modification</td>
<td>85.0</td>
<td>87.5</td>
<td></td>
</tr>
<tr>
<td>Fluid Management</td>
<td>71.7</td>
<td>89.1</td>
<td></td>
</tr>
<tr>
<td>Phosphate Binders</td>
<td>37.8</td>
<td>86.8</td>
<td></td>
</tr>
<tr>
<td>EPO</td>
<td>29.1</td>
<td>88.3</td>
<td></td>
</tr>
<tr>
<td>Bicarb</td>
<td>29.9</td>
<td>87.2</td>
<td></td>
</tr>
<tr>
<td>ACEi/ARB</td>
<td>78.0</td>
<td>86.4</td>
<td></td>
</tr>
<tr>
<td>Statins</td>
<td>59.8</td>
<td>58.1</td>
<td></td>
</tr>
<tr>
<td>Pain Management</td>
<td>36.2</td>
<td>31.3</td>
<td></td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>35.4</td>
<td>32.1</td>
<td></td>
</tr>
</tbody>
</table>

**Male Characteristics**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>PCPs (%)</th>
<th>NEPHs (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet Modification</td>
<td>90.6</td>
<td>92.1</td>
</tr>
<tr>
<td>Fluid Management</td>
<td>79.5</td>
<td>94.0</td>
</tr>
<tr>
<td>Phosphate Binders</td>
<td>59.1</td>
<td>86.4</td>
</tr>
<tr>
<td>EPO</td>
<td>48.8</td>
<td>93.6</td>
</tr>
<tr>
<td>Bicarb</td>
<td>44.1</td>
<td>94.0</td>
</tr>
<tr>
<td>ACEi/ARB</td>
<td>56.7</td>
<td>44.2</td>
</tr>
<tr>
<td>Statins</td>
<td>53.5</td>
<td>41.5</td>
</tr>
<tr>
<td>Pain Management</td>
<td>37.8</td>
<td>38.5</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>34.6</td>
<td>38.5</td>
</tr>
</tbody>
</table>

Adjusted Odds Ratio (>1 Implies NEPHs More Likely)
Barriers to conservative management

<table>
<thead>
<tr>
<th>Barriers to Discussing Conservative Management</th>
<th>Nephrologists, N (%)</th>
<th>Primary Care Providers, N (%)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult to decide which patients benefit</td>
<td>96 (52.8)</td>
<td>67 (36.2)</td>
<td>0.003</td>
</tr>
<tr>
<td>Limited information about effectiveness</td>
<td>65 (24.5)</td>
<td>63 (49.6)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Too time consuming</td>
<td>80 (30.3)</td>
<td>37 (29.4)</td>
<td>0.43</td>
</tr>
<tr>
<td>Uncertainty about eligibility</td>
<td>38 (14.3)</td>
<td>38 (42.5)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Fear patient response</td>
<td>40 (15.2)</td>
<td>25 (19.8)</td>
<td>0.62</td>
</tr>
<tr>
<td>Difficult to initiate a discussion</td>
<td>36 (13.6)</td>
<td>20 (15.9)</td>
<td>0.86</td>
</tr>
<tr>
<td>Doubt patient capacity</td>
<td>21 (8.0)</td>
<td>12 (9.4)</td>
<td>0.64</td>
</tr>
<tr>
<td>Value survival over quality of life</td>
<td>18 (6.8)</td>
<td>9 (7.1)</td>
<td>0.94</td>
</tr>
</tbody>
</table>
What is conservative management

Planned holistic patient-centered care for patients with glomerular filtration rate category (G) 5 CKD that includes interventions to delay progression of kidney disease and minimize risk of adverse events or complications, shared decision making, active symptom management, detailed communication including advance care planning, psychologic support, social and family support, and cultural and spiritual domains of care.
Practice of Comprehensive CM

- Care consistent with goals and values of patient
- Do not desert your patient
- Balance risks and benefits of medications
  - Differences across providers
- Consider multidisciplinary approaches
  - Nutrition
  - Psychologist
Barriers to EOL care in CKD/ESRD

• Communication of prognosis is a key step in EOL planning, but occurs infrequently or extremely late in the dying process among patients with CKD/ESRD.
• A lack of training in communicating has limited EOL discussions between nephrologists and CKD/ESRD patients.
• Hospice is not integrated into CKD/ESRD care
• Uncertainty regarding individual prognosis
  – Instruments to identify individuals undergoing maintenance HD who are at highest risk for death have only recently been shown to be reliable predictive models for clinical
Relationship Between the Prognostic Expectations of Seriously Ill Patients Undergoing Hemodialysis and Their Nephrologists

- Patients with end-stage renal disease (ESRD) have a mortality rate of nearly 20% despite marked improvements in dialysis technology.
- This mortality rate reflects, in part, a selection of older persons with multiple chronic health conditions.
- While patients with cancer have been shown to overestimate their likelihood of survival, little is known about whether patients with ESRD hold accurate perceptions on their prognosis.
- Patients’ understanding of prognosis is important since their perceptions may shape goals of care such as seeking evaluation for kidney transplantation or use of hospice services.

Wachterman et al. JAMA Int Med 2013
## Comparison of Patient and MD Estimates of 1-year Survival

<table>
<thead>
<tr>
<th>Patient's 1-year Survival Estimate</th>
<th>Nephrologist's 1-Year Survival Estimate</th>
<th>≥90%</th>
<th>61-89%</th>
<th>40-60%</th>
<th>&lt;40%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥90%</td>
<td></td>
<td>21%</td>
<td>37%</td>
<td>21%</td>
<td>0</td>
<td>82%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(13)</td>
<td>(23)</td>
<td>(13)</td>
<td></td>
<td>(49)</td>
</tr>
<tr>
<td>≈ 75%</td>
<td></td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>0</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2)</td>
<td>(2)</td>
<td>(2)</td>
<td></td>
<td>(6)</td>
</tr>
<tr>
<td>≈ 50%</td>
<td></td>
<td>0</td>
<td>6%</td>
<td>0</td>
<td>0</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(4)</td>
<td>(4)</td>
<td>(4)</td>
<td></td>
<td>(4)</td>
</tr>
<tr>
<td>≈ 25% or less</td>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td></td>
<td>(1)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>25%</td>
<td>48%</td>
<td>25%</td>
<td>2%</td>
<td>25%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(15)</td>
<td>(29)</td>
<td>(15)</td>
<td>(1)</td>
<td>(1)</td>
</tr>
</tbody>
</table>

Wachterman et al  JAMA Int Med 2013
Influence of prognosis on healthcare

- Of the 81% of patients reporting a 90% chance or greater of being alive at year, 44% preferred care focused on extending life, even if it meant more discomfort, compared with 9% of patients reporting a lower chance of survival (P = .05).

Table 5. Association Between Patients’ Goals of Care and Estimates of Prognosis and Optimistic Transplant Discordance

<table>
<thead>
<tr>
<th>Patient estimate of chances for 1-year survival</th>
<th>Prefer Care Focused on Life Extension</th>
<th>Prefer Care Focused on Relieving Pain and Discomfort</th>
<th>Don't Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥90%</td>
<td>18 (44)</td>
<td>20 (49)</td>
<td>3 (7)</td>
<td>41 (79)</td>
</tr>
<tr>
<td>&lt;90%</td>
<td>1 (9)</td>
<td>8 (73)</td>
<td>2 (18)</td>
<td>11 (21)</td>
</tr>
<tr>
<td>Total</td>
<td>19 (37)</td>
<td>28 (54)</td>
<td>5 (10)</td>
<td>52 (100)</td>
</tr>
</tbody>
</table>

Optimistic transplant discordance

<table>
<thead>
<tr>
<th></th>
<th>Prefer Care Focused on Life Extension</th>
<th>Prefer Care Focused on Relieving Pain and Discomfort</th>
<th>Don't Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12 (55)</td>
<td>8 (36)</td>
<td>2 (9)</td>
<td>22 (42)</td>
</tr>
<tr>
<td>No</td>
<td>7 (23)</td>
<td>20 (67)</td>
<td>3 (10)</td>
<td>30 (58)</td>
</tr>
<tr>
<td>Total</td>
<td>19 (37)</td>
<td>28 (54)</td>
<td>5 (10)</td>
<td>52 (100)</td>
</tr>
</tbody>
</table>

a Percentages have been rounded and might not total 100. Data were missing for at least 1 of the questions below for 10 patients.

b Assessed as patient response to the question, “If you were seriously ill, would you prefer care to (a) extend life, even if it meant more pain and discomfort, or (b) relieve pain and discomfort, even if it meant not living as long?”

c Assessed as patient response to the question, “What do you think the chances are that you will be alive in 12 months?” (P = .045, Fisher exact test).

d Defined as optimistic when patients reported a greater likelihood than their nephrologists that they would receive a transplant. Numbers represent patient-nephrologist pairs (P = .054, Fisher exact test).
Implications

• Demonstrate discordance between HD patient prognosis and observed outcomes.
• Prognoses associated with aggressiveness of care in hypothetical situations.
• It would be interesting to test whether findings from this work may extend to other non-cancer chronic conditions with high mortality rates.
Prognosis in ESRD

- Integrated prognostic models may take into account laboratory values,
  - Comorbidities (Miskulin 2003)
  - changes in comorbidity score over time
  - functional status/fragility,
  - QOL(Jhamb 2009)
  - Either the patient’s or clinician’s prediction of survival (Thong 2008)
  - Changes in albumin/CRP (Kotanko 2013)

- Application of new prediction tools will help to overcome practitioner uncertainty about prognosis and increase the likelihood of meaningful EOL dialogues between clinicians, patients, and families.

Singh et al. NDT 2013
Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis

Lewis M. Cohen,* Robin Ruthazer,† Alvin H. Moss,‡ and Michael J. Germain§

*Department of Psychiatry, Baystate Medical Center, Springfield, Massachusetts; †Biostatistics Research Center, Institute for Clinical Research and Health Policy Studies, Tufts Medical Center, Boston, Massachusetts; and §Section of Nephrology, Department of Medicine, West Virginia University School of Medicine and Center for Health Ethics and Law, Robert C. Byrd Health Sciences Center, West Virginia University, Morgantown, West Virginia; and ¶Department of Medicine, Section of Nephrology, Baystate Medical Center, Springfield, Massachusetts

• Aim to develop an integrated prognostic index
• Prospective data from a total of 1026 patients divided b/w development and validation cohorts between 2006-2008.
• Patient charts for Charlson Comorbidity Index, laboratories, and collected Surprise Question
• Patients followed for up to 24 months.
• Age, Albumin, PVD, Dementia, Surprise
Hemodialysis Mortality Prediction

• At 12 months – 50% mortality of highest risk quintile
• At 18-months, the sensitivity for death in the highest quintile was 41%; specificity was 90%; PPV 53%; and NPV 85%.
• This level of specificity and sensitivity is similar to that of the MDRD equation for kidney donors and other prediction tools advocated for use in CKD care.
Prognosis in ESRD

- Missing factors - HRQOL
- What matters?
  - Disability free life-years?
  - HRQOL?
- What about advanced CKD?
- Uncertainty - maybe a good thing

Christakis BMJ 2000
Cultural Influences
How Culture Influences Withdrawal

• Language, social, or cultural barriers may hinder the completion of an advance directive leading to the patient remaining on dialysis longer
• Younger patients may not understand the need to complete advance directives
• Patients with chronic diseases more likely to withdraw dialysis than those with acute disease processes
• Females more likely than males to withdraw
• African Americans and Hispanics withdraw and approximately $\frac{1}{2}$ the rate as whites
Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients

Manjula Kurella Tamura\textsuperscript{1,2}, Mary K. Goldstein\textsuperscript{2,1} and Eliseo J. Pérez-Stable\textsuperscript{3}

\textsuperscript{1}Division of Nephrology, Center for Primary Care and Outcomes Research, Stanford University School of Medicine, \textsuperscript{2}VA Palo Alto Health Care System Geriatrics Research Education & Clinical Center, Palo Alto and \textsuperscript{3}Division of General Internal Medicine, Department of Medicine, Medical Effectiveness Research Center for Diverse Populations, University of California, San Francisco, CA, USA

\textbf{Fig. 2.} Proportion of participants ($N = 61$) who would probably or definitely withdraw from dialysis in different health states, by race/ethnicity. \textit{P}-values are for comparison across race/ethnicity groups. $N = 23$ for Blacks, $N = 7$ for Latinos, $N = 21$ for Whites and $N = 10$ for Asians.
Cultural challenges

• Autonomy
• Beliefs
• Communication
Shared Decision Making and Renal Supportive Care

• AIM 1: To improve EOL communication with a more diverse population of HD patients who are at high risk for death
• AIM 2: To determine whether enhanced renal supportive care impacts the use of hospice services, location of death, and EOL planning.
• AIM 3: To determine the effect of enhanced renal supportive care on quality of life/death and caregiver satisfaction with patient care in the last week of life.

• Lewis Cohen MD
• Michael Germain MD
• Sarah Goff MD MS
• John Griffith PhD
• Lisa Marr MD
• Nwamaka Eneanya MD
Communication of prognosis is a key step in EOL planning, but occurs infrequently or extremely late in the dying process among patients with ESRD

- The most valued components are being informed about prognosis, treatment options and planning for death
- 95% and 97% of patients with ESRD preferred to be given life-expectancy information—even if their prognosis was poor—and patients specifically wanted their physician to disclose this information without prompting
Both uncertainty and a lack of training in communicating has limited EOL discussions

- Instruments to identify individuals undergoing maintenance HD who are at highest risk for death have only recently been shown to be reliable predictive models for clinical use.
- Communication has been highlighted as a barrier in a qualitative study of elderly ESRD patients and nephrologists
Now is the time to test SDM-RSC

• prognostic instrument to identify subjects
• train staff to apply a communication protocol in family meetings on EOL issues and through follow-up contacts
• share responsibility for communication between the nephrologists and SW
• facilitate cooperation between dialysis and hospice staff
AIM 1: To improve EOL communication with a more diverse population of HD patients who are at high risk for death

• A total of 21 participants were interviewed:
  • 5 female patients, 8 male patients and 8 family members/friends (7 female and 1 male)
    – Black (1)
    – Hispanic (2)
    – Navajo (1)
    – Pacific Islander (1)
    – White (8).

Goff et al. CJASN 2015
Qualitative findings

• Most patients reported that they had not discussed prognosis or ACP with their nephrologist or other members of the dialysis team.
  – 2 preferred not to have such discussions
  – majority said they would welcome them and/or desired them.

• Some patients reported having filled out paper work for “DNR”, but many had never handed the paperwork back in to their dialysis team; those that had were unsure of who on the dialysis team had this information or knew of their preferences.

Goff et al. CJASN 2015
Theme 1: Patients’ prior experiences with ACP and prognostic discussions with dialysis team

• **Belief that the doctor knows best**
  – “I don’t question a lot. I feel that they [doctors] know more about what they’re doing than what I know... if it’s going OK, if it’s not too painful, I’m good.”

• **Pragmatic arrangements**

• **Family discussions**
  – “Between her [daughter], her baby and her oldest [patient’s grandchildren] there’s going to be a war [over stopping patient’s life support] and I don’t want it to be...”

Goff et al.  CJASN 2015
Theme 2: Factors that may impact patients’ perspectives regarding ACP and prognostic discussions

• *Dialysis experience* “The dialysis just drains me down to nothing. It just zaps me. I’ll be good for a couple of hours afterwards and then I just sit in a chair and stare.” [UNM 5 patient, male, White]

• Patients described specific *Positive* and *Negative* aspects of their dialysis experience.

• “I don’t worry about it [ACP]... adjust it [dialysis] and run day by day and work with these nice people. I’ve been very happy here – never consider making a change.” [BMC 5, patient, male, White]

• “Right now I have a doctor that I basically haven’t ever been introduced to.” [BMC 3, patient, male, White]

Goff et al. CJASN 2015
SMD-RSC

- Patient Advisory Group
- Stakeholder Advisory Group
- Qualitative Interviews
- Data Use Agreements
- Feed forward qualitative findings to advisory groups and revise protocol
Study Approach

• The design for the primary outcome of hospice usage rates consisting of a prospective intervention period among 210 participants in 16 HD units and a retrospective control period at the same dialysis units was selected to balance efficacy, power, and accuracy.

• The design avoids the contamination effect and inadvertent cross-overs that would be present with a participant randomization design.
Figure 2 RSC Addresses Barriers to End of Life Care in ESRD

- Maintenance Hemodialysis Patients at high risk for death
  - Demographic
  - Personal attributes
  - Social/Environment
  - Cultural

Awareness of prognosis and hospice resources

Renal Supportive Care

Patient/provider communication

- End of life planning
- Use of hospice
- Death at home
- Reduced Costs
- Improved QL and quality of death
- Family Satisfaction

Eneanya et al, BMC Palliative 2015
PATIENT-CENTERED CARE
“The best measure of quality is not how well or how frequently a medical service is given, but how closely the result approaches the fundamental objectives of prolonging life, relieving distress, restoring function, and preventing disability.”

P.A. Lembcke, 1952