Objectives

- Highlight the need for integrating quality palliative care for patients with advanced CKD
  - Estimating life expectancy
  - Decision-making re: withholding, starting and withdrawing dialysis
  - Symptom burden

- Describe some of the barriers to establishing kidney palliative care services

- Highlight some opportunities for integrating kidney palliative care

The Dialysis Population

- 50% patients starting dialysis > 65 yrs
- Patients ≥ 75 yrs fastest group of dialysis patients.

- Significant
  - Co-morbidity (including geriatric syndromes)
  - Symptom burden
  - Mortality
Annual unadjusted mortality rate ~20%
Withdrawal from dialysis ~ 20-25% of deaths
The majority lack capacity at the time the decision to withdraw dialysis is made.

Palliative (Supportive) Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Only 6-51% of HD patients have advance directives
Address only limited treatment options (not withdrawal of dialysis)
Most do not choose a DNR
Quality of EOL care is suboptimal;
Most patients do not die in their place of choice
Most die in acute care facilities without accessing specialist palliative care services

World Health Organization

Conceptual Framework for Kidney Palliative Care/Supportive Care

Supportive Care Controversies Conference | December 6-8, 2013 | Mexico City, Mexico
TOP 10 Research Priorities
Canadian Advanced CKD Patients

1. BEST PRACTICE DECISION-MAKING
   Enhance communication between HCP & patients to maximize patient participation in decision-making, different modalities of dialysis

2. PATIENT SPECIFIC DIALYSIS MODALITY
   Impact of dialysis modalities on QOL, mortality and patient acceptability; are there specific patient factors that make one modality better for some than others?

3. TREATMENT OF TOP SYMPTOM
   Effective treatment(s) of itch

4. PSYCHOLOGICAL & SOCIAL IMPACT
   How to reduce impact of kidney failure on patients, their family and other caregivers

5. DEPARTMENT OF Nephrology
   Any patient whose primary goal is restoration of life and social functioning

6. DIET & OUTCOMES
   Impact of dietary restrictions (sodium, potassium, phosphate) separately, and when taken in combination, on important outcomes including QOL

7. SYMPTOM MANAGEMENT
   Best ways to manage symptoms

8. DEPRESSION CAUSE & TREATMENT
   Causes and effective treatment(s) of depression

9. PATIENT-CENTERED DIALYSIS & PALLIATIVE DIALYSIS
   Person-Centered Dialysis
   - Align treatment with patient preferences
   - Survival & long-term health outcomes are balanced with maximizing QOL and symptom control
   - Requires integration of supportive care

   Palliative Dialysis
   - Align treatment with patient preferences
   - Maximizing HRQOL, symptom control, and ACP for end of life care become of paramount importance

Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison, Adeera Levin, Alvin H. Moss, Vivekanand Jha, Edwina A. Brown, Frank Brennan, Fliss E. M. Murtagh, Saraladevi Naicker, Michael J. Germain, and Gregorio T. Obrador

Division of Nephrology and Immunology, Department of Medicine, University of Alberta, Edmonton, Alberta, Canada; University of British Columbia, Vancouver, British Columbia, Canada; Department of Medicine, West Virginia University, Morgantown, West Virginia, USA; Department of Nephrology, Postgraduate Institute of Medical Education and Research, Chandigarh, India; George Institute for Global Health, New Delhi, India; Imperial College Renal and Transplant Centre, Hammersmith Hospital, London, UK; Department of Palliative Care, St George Hospital, Sydney, New South Wales, Australia; King’s College London, Department of Palliative Care, Policy & Rehabilitation, Cicely Saunders Institute, London, UK; Division of Nephrology, Department of Internal Medicine, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; Division of Nephrology, Baystate Medical Center, Tufts University School of Medicine, Springfield, Massachusetts, USA; Renal Unit, Salford Royal NHS Foundation Trust, Salford, UK; School of Public Health, Sydney Medical School, University of Sydney, Sydney, New South Wales, Australia; Health Economics Research Centre, Nuffield Department of Population Health, University of Oxford, Oxford, UK and Universidad Panamericana School of Medicine, Mexico City, Mexico

http://www.kidney-international.org


International Kidney Palliative Standard
A Palliative Care Framework for Patients with Advanced CKD

Identification of patients most likely to benefit from (early) palliative care services
- High mortality risk
- High symptom burden
- Difficulty with EOL decision-making & determining goals

Palliative Care Services
May require specialist palliative care expertise and/or referral to hospice

Advance Care Planning
- Identify decision-maker
- Determine goals of care & preferences for EOL care
  - Conservative v. dialysis
- Withdrawal of dialysis

Suffering
- Physical symptom Rx
- Emotion/psychosocial Rx
  - Anticipatory grief
- Spiritual support

Unadjusted Survival Probabilities (%) for Incident ESRD Patients

<table>
<thead>
<tr>
<th>Age</th>
<th>1 year</th>
<th>2 years</th>
<th>3 years</th>
<th>5 years</th>
<th>10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 - 49</td>
<td>89.6</td>
<td>81.6</td>
<td>73.5</td>
<td>61.9</td>
<td>37.7</td>
</tr>
<tr>
<td>50 - 59</td>
<td>86.2</td>
<td>75.9</td>
<td>65.4</td>
<td>49.5</td>
<td>21.8</td>
</tr>
<tr>
<td>60 - 64</td>
<td>83.0</td>
<td>69.6</td>
<td>58.3</td>
<td>38.1</td>
<td>12.3</td>
</tr>
<tr>
<td>65 - 69</td>
<td>79.1</td>
<td>63.1</td>
<td>50.8</td>
<td>30.7</td>
<td>6.4</td>
</tr>
<tr>
<td>70 - 79</td>
<td>71.2</td>
<td>53.5</td>
<td>39.0</td>
<td>20.2</td>
<td>2.7</td>
</tr>
<tr>
<td>80+</td>
<td>60.5</td>
<td>40.8</td>
<td>25.7</td>
<td>9.6</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Unadjusted Survival Probabilities (ESRD v. General Population)

Unadjusted Survival Probabilities (ESRD v. General Population)

<table>
<thead>
<tr>
<th>Age</th>
<th>1 year</th>
<th>2 years</th>
<th>3 years</th>
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<td>60.5</td>
<td>40.8</td>
<td>25.7</td>
<td>9.6</td>
<td>0.9</td>
</tr>
</tbody>
</table>

Expected remaining life-years

<table>
<thead>
<tr>
<th>Age (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
</tr>
<tr>
<td>30</td>
</tr>
<tr>
<td>40</td>
</tr>
<tr>
<td>50</td>
</tr>
<tr>
<td>60</td>
</tr>
<tr>
<td>70</td>
</tr>
<tr>
<td>80</td>
</tr>
</tbody>
</table>

USRDS, 2010
Predictors of Poor Prognosis for ESRD Patients

- Age
- Nutritional status
  - Serum albumin < 35g/L
  - <50% mortality at 1 year
  - 17% at 2 years
- Comorbid Illnesses – Charlson Comorbidity Index
  - CCI ≥ 8 – 50% 1 year mortality
  - [Link](http://www.medalreg.com/qhc/medal/ch1/1_13/01-13-01-ver9.php)
- **Surprise Question**: 3.5 times more likely to die within the year
- Functional Status

Clinical Scenario

- Mrs MW: 76 year-old woman
- She has been on hemodialysis for
- ESRD due to hypertension
  Stroke 2 years ago, no apparent residual deficits
  Known CAD (stable angina), no prior MI
- Still lives in her own home with her husband
- Very knowledgeable re: politics and loves to engage in...
### Clinical Scenario

- Upon closer questioning of Mrs MW and her husband……
  - She had become forgetful (short-term memory)
  - Unable to recall what she ate the day before
- Occasional odd behaviour – found missing socks in her fridge!
- Geriatric assessment: multi-infarct dementia

<table>
<thead>
<tr>
<th>Variable</th>
<th>Enter Value</th>
<th>Predicted Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albumin</td>
<td>3.4</td>
<td></td>
</tr>
<tr>
<td>Surprise Question</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>76</td>
<td>6 months 66%</td>
</tr>
<tr>
<td>Dementia</td>
<td>1</td>
<td>12 months 84%</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>0</td>
<td>18 months 74%</td>
</tr>
</tbody>
</table>

---

Online calculator to estimate prognosis for prevalent HD patients

http://touchcalc.com/calculators/sq
I’m in bed at night… worry. I get up in the morning… I worry. Even though I’m laughing, it’s only on the inside.

Health care providers are reluctant to talk about end of life issues. I think they are afraid of how you are going to react.

I don’t think they know what to say. No, I want to talk about it, but nobody will talk to me. At least that’s how I feel… inside I am hurting like mad, but I can’t get that out.

Estimating prognosis recommendations

1. Estimate and communicate prognosis to patients and family
   a) balance biomedical facts with emotional, social, and spiritual issues.

   Such communication should be viewed as an integral component of shared decision-making in order to align treatment goals with patient preferences.

2. Prognostication tools have multiple purposes:
   a) administrative (resource planning)
   b) research (enrollment criteria for studies)
   c) clinician (develop care plan)
   d) patient (inform decision-making)
   e) clinician and patient: shared decision-making for patient-centered care

Research Priorities

   a) Determine international perspectives
   b) Derive and validate prognostic tools for clinical outcomes most relevant to patients using existing and future databases. This should extend beyond survival to other outcomes important to patients and families.
Decision-Making Around Dialysis Initiation

Passive decision making (pertains primarily to older patients)

- Older patients generally accept dialysis, do not choose it.
  - The imposition of health emergencies that demand quick action... and less by “choice”

- Passive acceptance generates profound questions about the meaning and worth of their life on dialysis.
  - “I regret the decision to start dialysis vs. conservative therapy.”
    - Davison CJASN 2010
  - Tremendous ambivalence about what is gained & lost with dialysis
  - Confusion about the goals of treatment: Do I really need this? Can I ever get off? What will this end?

---

Conservative Kidney Management


- Pts > 75 yrs, eGFR < 15 ml/min
- Conservatively managed patients: older (83.0 v. 79.6)

<table>
<thead>
<tr>
<th></th>
<th>Dialysis (n = 52)</th>
<th>Conservative (n = 77)</th>
<th>All patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year survival</td>
<td>84%</td>
<td>68%</td>
<td>74%</td>
</tr>
<tr>
<td>2 year survival</td>
<td>76%</td>
<td>47%</td>
<td>58%</td>
</tr>
</tbody>
</table>
... survival advantage [for dialyzed patients] was lost in those patients with high comorbidity scores, especially when the comorbidity included ischemic heart disease.

Definition of Comprehensive Conservative Care

Comprehensive conservative care is planned holistic patient-centered care for patients with G5 CKD - includes:

- Delay progression of kidney disease & minimize complications
- Shared decision-making
- Detailed communication including advance care planning
- Symptom management
- Psychological support
- Social and family support
- Cultural and spiritual domains of care

Comprehensive conservative care does not include dialysis.

Conservative care recommendations

1. Comprehensive conservative care should be provided as a viable, quality treatment option for patients unlikely to benefit from dialysis.

2. A multi-professional team should ideally deliver conservative care, will likely vary between and within countries, potentially including:
   a) nephrologist / nurse / psychosocial worker / counselor or psychologist / dietician / allied health professional / chaplain
   b) family doctors / community staff / healthcare volunteers
   c) specialist supportive care

3. Additional training in comprehensive conservative care is recommended across settings (e.g., home, hospital, hospice, and nursing homes).

Research priorities include:

a) International consensus on terminology & definition: promote shared understanding
b) Determine illness trajectories/health outcomes for those managed conservatively and how this compares with those managed with dialysis (HRQOL, symptoms, functional status, illness and care experiences, hospitalizations, survival, and quality of dying)
c) Determine effective and cost-effective models for the provision of conservative care across diverse health systems.
Most decisions do not involve active patient choice

Discussed prognosis
- No: 90%

Discussion about EOL care during the past 12 months
- No discussion: 52%
- Family member or health care proxy: 33%
- Kidney doctor (nephrologist): 10%

Older patients’ amenable participation in dialysis is construed by clinicians as a choice and “doing trumps talking”
- “Voting with their feet”
**How EOL Decisions Are Being Made**

- By family and health care providers
- Surrogates lack the knowledge of patients’ preferences
  - Includes wishes for ongoing dialysis
  - Family consistently overestimates patients’ desires to continue dialysis across hypothetical health conditions.

<table>
<thead>
<tr>
<th>Current preferences for CPR</th>
<th>Wish for dialysis in a severely demented state</th>
<th>Wish for dialysis if they had terminal cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>50%</td>
<td>44%</td>
</tr>
<tr>
<td>Physician</td>
<td>44%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Miura y et al. AJKD 2006

**Concern that Discussing Prognosis & EOL Issues may Destroy Hope**

**Patient Preferences for EOL Discussions**

- The vast majority of CKD patients want to discuss EOL care issues and prognosis (91%)
- Patients want to plan ahead in case of death (83%)
- Enhances hope, decreases fear, builds relationships......
  - ESRD patients support early ACP and are less concerned than HCP that these conversations will damage hope.

Davison CJASN 2006, Davison CJASN 2010, Fine PDI 15 269 2005
What do Goals of Care Conversations Look Like?

- HCP do most of the talking
  - "She didn’t listen and she spent more time in kind of a social chit-chat ... She wanted to find solutions for me and I didn’t want solutions, I just wanted to be able to find my own solutions ..."
- Focus on pejorative descriptions of LST

What is not discussed?

- Prognosis
- Patients’ values, desired outcomes
- A set of positive treatment outcomes
- Treatments patients may want to forgo now v. treatment they would want to forgo if they become worse
- Spirituality (existential, religious)
- What dying may be like

Who will facilitate?

Physician Related Barriers to ACP in ESRD Care

- Belief that ACP is not needed
- Belief that patients and families do not want these discussions
  - ~90% want detailed prognostic information, EOL discussions
  - ~65% patient comfortable with EOL discussions
  - <10% patients have had EOL discussions with their renal team

- Concern that discussing EOL issues will destroy hope
- Lack of training & comfort with EOL decision-making
  - 61% of nephrologists reported feeling not very well prepared to make EOL decisions

- Time constraints
Comfort Level of US Adult Nephrology Trainees on Palliative Care Related Issues


1 = least comfortable .......................... 5 = most comfortable

End of Life Discussions with Patients

ACP is a process that involves understanding, communication and discussion between a patient, the family and staff, for the purpose of clarifying preferences for EOL care. It lays out a set of relationships, values and processes for approaching EOL decisions for individual people, including attention to ethical, psychosocial, and spiritual issues relating to starting, withholding, and stopping dialysis.

\[
\begin{array}{|c|c|c|c|c|c|}
\hline
& & & & & \\
\hline
\text{Having end-of-life discussions with patients on dialysis} & 52 & 29 & 32.8 & 27.4 & 13.7 \\
\text{Treating depression in dialysis patients} & 16.8 & 34.4 & 31.3 & 14.2 & 5.1 \\
\text{Managing pain with medications with advanced renal disease} & 11.3 & 21.6 & 34 & 23.7 & 9.4 \\
\text{Not offering dialysis} & 92.8 & 30.1 & 26.9 & 20.8 & 5.3 \\
\text{Withdrawing dialysis} & 20.8 & 28.9 & 25.8 & 19.6 & 5.3 \\
\hline
\end{array}
\]
ACP Facilitation Skills can be taught….

- Respecting Choices Program
- On-line training manual & videos
- NephroTalk (Jane O. Schell)
  - Ask-Tell-Ask: for discussing serious news
  - NURSE: recognizing & responding verbally to emotion
- Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. RPA 2010

Shared decision-making and ACP recommendations

1. Shared decision-making is recommended to align treatment with patient and family goals, values and preferences.
   a) requires a flexible approach of re-evaluation and redirection to ensure the goals of care and treatment plans remain aligned with patients’ values and preferences.

2. The treatment care team should engage in ACP.
   a) These discussions should start early
   b) Should include discussions about health states in which patients would want to withhold or withdraw dialysis.

Symptom Burden in Dialysis Patients

- Davison, et al. KI 2008, JPSM 2010
- Patients 30% to 46% in HRQL
- n = 507
- Tired
- Well-being
- Appetite
- Sleep
- Memory
- Drowsy
- Anxious
- SIB
- Nausea
**Renal Bone Disease**

- Calcium phosphate deposition in arteries, joints, soft tissues, and the viscera.
- Associated with proximal myopathy, ruptured tendons, pseudogout, and calciphylaxis.

**The Impact of Pain and Overall Symptom Burden for ESRD Patients**

<table>
<thead>
<tr>
<th>Impact</th>
<th>No – Mild pain</th>
<th>Mod – Severe pain</th>
<th>Odds Ratio</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>18%</td>
<td>34%</td>
<td>2.31</td>
<td>0.01</td>
</tr>
<tr>
<td>Insomnia</td>
<td>53%</td>
<td>75%</td>
<td>2.32</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Symptom burden accounted for 29% of the impairment in physical HRQL and 39% of the impairment in mental HRQL.

Change in symptom burden accounted for 34% of the change in physical HRQL and 46% of the change in mental HRQL.

---

**KDIGO Pain Scoping Review**

- Limited data in PD & conservatively cared for patients: prevalence & severity appear similar
- Cause of pain is NOT predictive of severity

<table>
<thead>
<tr>
<th>Studies</th>
<th>Patient Pop</th>
<th># Patients</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>36</td>
<td>Prevalent HD</td>
<td>5244</td>
<td>58.6% (21%-81%)</td>
</tr>
<tr>
<td>6</td>
<td>Moderate/ severe pain</td>
<td>1701</td>
<td>48.8% (41%-68.6%)</td>
</tr>
<tr>
<td>11</td>
<td>Prevalent HD</td>
<td>3215</td>
<td>No clinically significant association with gender, age, race, biochemical parameters</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>2086</td>
<td>Decreased QOL</td>
</tr>
</tbody>
</table>

Davison SN Semin Dial 2014
### Prevalence of Analgesic Use in CKD

<table>
<thead>
<tr>
<th>Analgesic</th>
<th>Prevalence of Prevalent HD Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Patients (n = 25725) 13</td>
</tr>
<tr>
<td>Any analgesic</td>
<td>27% (n=6025)</td>
</tr>
<tr>
<td>Any narcotic</td>
<td>15.2% (n=2568)</td>
</tr>
<tr>
<td>Any NSAID</td>
<td>4.9% (n=6000)</td>
</tr>
<tr>
<td>Any acetyaminophen</td>
<td>8.9% (n=6000)</td>
</tr>
</tbody>
</table>

### Barriers to Effective Pain Rx in ESRD
- Complicated pharmacokinetics and pharmacodynamics
- Uremic symptoms may mimic opioid toxicity
- Treatment algorithms for cancer may not apply to ESRD
- Elderly
- Limb preservation
- Pain experienced in complex clusters & EOL issues
- Lack of recognition of the problem
- Implementation of systematic approaches to pain assessment & management improves provider recognition & treatment of symptoms.
Pain Algorithms & Preferred Analgesics for Chronic Pain in Patients with Chronic Kidney Disease Stages 4 and 5 (GFR < 30 ml/min/1.73m²)

Developed by the Northern and Southern Alberta Renal Programs (NARP & SARP)
July 2010

Chronic Pain Management Guidelines
Chemically Sensitive Patients

A. Normal 'window of comfort'
B. Small 'window of comfort' in sensitive pts
Symptom assessment and management recommendations

1. Routine symptom screening using validated tools (ESAS-r:Renal, POS-renal) should be incorporated into routine clinical practice.

2. Symptom management requires a step-wise approach.
   a) Basic non-pharmacological interventions - advancing to more complex therapies.
   b) Pharmacologic therapy.
   c) Consideration should be given to therapies that may have efficacy across several symptoms.

4. Develop clinical guidelines to aid in the stepwise approach to uremic pruritus, sleep disturbances, restless legs syndrome, pain and depression in CKD.

Research priority: relative effectiveness of management strategies, impact on outcomes most relevant to patients such as overall symptom burden, physical function, and HRQL.
### Costs Associated with Hospice Use

**USRDS 2001-2002 Cohort**

<table>
<thead>
<tr>
<th>Dialysis Withdrawal and Hospice Status</th>
<th>Patients (N)</th>
<th>Mean cost last 6 months of life (US$)</th>
<th>Mean cost last week of life (US$)</th>
<th>Mean hospital days last week</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 month cohort</td>
<td>91,687</td>
<td>64,461</td>
<td>6,885</td>
<td>3.0</td>
</tr>
<tr>
<td>Patients who withdrew Hospice Yes</td>
<td>8,200</td>
<td>60,261</td>
<td>3,324</td>
<td>1.4</td>
</tr>
<tr>
<td>Hospice No</td>
<td>11,317</td>
<td>66,253</td>
<td>6,257</td>
<td>3.7</td>
</tr>
<tr>
<td>Withdrawal No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice Yes</td>
<td>2,165</td>
<td>64,979</td>
<td>4,318</td>
<td>1.8</td>
</tr>
<tr>
<td>Hospice No</td>
<td>65,868</td>
<td>65,345</td>
<td>7,588</td>
<td>3.1</td>
</tr>
</tbody>
</table>

**Overarching recommendations for supportive care in CKD populations**

1. **Primary supportive care should be available to all patients with advanced CKD and their families:**
   a) Fundamental component of quality kidney care
   b) Based on need rather than solely an estimation of survival
   c) Normalize EOL discussions
   d) Develop and Implement clinical policy and guidelines to support integrated palliative care

2. **Education:**
   a) Palliative care should be recognized as a core clinical competency
   b) Needed early in training with ongoing CME

3. **The nephrology community should actively support and participate in kidney palliative care research to address knowledge gaps and advocate for policy change.**