Advancing Quality Palliative Care for Patients with Chronic Kidney Disease in BC

2017 Canadian Hospice Palliative Care Conference
Friday, September 22, 2017

Dr. Gaylene Hargrove & Helen Chiu
Territorial Acknowledgement

We would like to acknowledge the Algonquin nation whose traditional and unceded territory we are gathered upon today.
Disclosure

• Nothing to disclose
Overview

• Patient case
• Chronic kidney disease: a life-limiting illness
• Mortality and morbidity in BC
• Provincial renal network in BC
• Where we have been in CKD care in BC
  o Advance care planning
  o Symptom assessment & management
• Lessons learned
• Summary
Patient case: ‘Ernie’

• 76 year old retired electrical engineer; married with two children
• Diagnosed with multiple myeloma April 2017; presented with severe anemia, pathologic vertebral compression fractures, stage 5 CKD requiring initiation of hemodialysis
• Chemotherapy ‘successful’, but no renal recovery, severe pain/symptom burden despite palliative care consultant’s efforts to optimize therapy
• Re-admission to hospital July 2017—intolerable pain, dyspnea, progressive vertebral and rib fractures
• Decision to stop dialysis late July, but death not imminent; patient decides to pursue MAiD
• Peaceful death with all family members at bedside mid-August
• Follow up: “Thank you for being honest, for being a friend, for being you.”
Chronic kidney disease (CKD): a life-limiting illness

- High mortality and morbidity in advanced stage
  - 5-year survival of older patients after starting dialysis is comparable to metastatic cancer
- Journey in transitions
- Prognostic uncertainty

A Palliative Approach to Dialysis Care: A Patient-Centered Transition to the End of Life

Vanessa Grubis, 4 Alvin H. Moss, 4 Lewis M. Cohen, 5 Michael J. Fischer, 1 Michael J. Germain, 5 S. Vania Jassal, 2 Jeffrey Perl, 17 Daniel E. Weiner, 13 and Rajnish Mehrotra 10 on behalf of the Dialysis Advisory Group of the American Society of Nephrology

Abstract
As the importance of providing patient-centered palliative care for patients with advanced illnesses gains attention, standard dialysis delivery may be inconsistent with the goals of care for many patients with ESRD. Many dialysis patients with life expectancy of <1 year may desire a palliative approach to dialysis care, which focuses on aligning patient treatment with patients’ informed preferences. This commentary elucidates what comprises a palliative approach to dialysis care and describes its potential and appropriate use. It also reviews the barriers to integrating such an approach into the current clinical paradigm of care and existing infrastructure and outlines system-level changes needed to accommodate such an approach.
Chronic kidney disease: Mortality in BC
Patients with end-stage kidney disease have multiple co-morbidities
Provincial renal network in BC

- Collaborations with health authority renal programs
- Active provincial multi-disciplinary committees
  - Cross health authority representation
  - Annual work plans with clear deliverables
  - Research, evaluation and continuous quality improvement
Where we have been in CKD care in BC

• **2004—2005:** Formal engagement and discussion around renal palliative and EOL care in the BC renal community

• **2006—2007:** Development of guidelines and plans within health authority renal programs by an “EOL working group”

• **2008—2009:** Publication of the End-of-Life Framework: Recommendations for a Provincial EOL Care Strategy
Framework for palliative approach to CKD care in BC
Where we have been in CKD care in BC (con’t)

- **2010—2011**: Development and implementation of education strategies for the four pillars of renal palliative care that make up the EOL Framework

- **2012—2013**: Publication of protocols and algorithms for symptom management and launch of online training module for symptom assessment

- **2014—2015**: Environmental scan to review progress for strategizing improvement in renal palliative care and develop 3-year goals and objectives going forward

- **2016—2017**: Development and implementation of a set of quality metrics to aid strategic planning and continuous quality improvement efforts
Advance care planning (ACP)

- **Goal:** To enhance patient and family understanding of their health issues and identify their key priorities in care
- Led by local champions
  - Initial funding to develop process with multidisciplinary teams to integrate the process into existing workflow
- Sharing lessons learned → spread in BC
- Provincial support:
  - Alignment with provincial and health authority efforts
  - ACP videos guide for MDs and staff to initiate the conversation with patients and their families
  - ACP module for process data capture
Advance care planning (ACP): Progress

- Social worker: key facilitator in ACP discussions in all health authority renal programs
- Timing of initiation varies
- 28 service units have started using the ACP module since 2015
Symptom assessment & management

- **Goal:** To relieve symptom burden that are generally under-reported in patients with kidney disease, thereby improving their quality of life
- **Led by local champions**
  - Initial funding to develop process with multidisciplinary teams to integrate the process into existing work flow
- **Sharing lessons learned → spread in BC**
- **Provincial support:**
  - Symptom assessment module for process and outcome data capture
  - Algorithms for symptom management
  - Online training module and information sheet for MDs and staff
  - Symptom guides for patients
## Symptom assessment & management: Progress

<table>
<thead>
<tr>
<th>Health authority renal program</th>
<th>Fraser</th>
<th>Interior</th>
<th>Island</th>
<th>Northern</th>
<th>Vancouver Coastal-Providence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Targeted populations</td>
<td>HD</td>
<td>Non-dialysis, HD, PD, HHD</td>
<td>Non-dialysis, HD, PD, HHD</td>
<td>Non-dialysis, HD, PD</td>
<td>Non-dialysis, HD, PD</td>
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<tr>
<td>Frequency</td>
<td>every 6 months and post-hospitalization</td>
<td>every 3 months or as needed</td>
<td>every 6</td>
<td>at entry, post-hospitalization,</td>
<td>every 3 or 6</td>
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<td>Trigger for review</td>
<td>medical reconciliation</td>
<td>clinic visit</td>
<td></td>
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<td></td>
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<tr>
<td>Modified ESAS presented to patient by</td>
<td>Nurse</td>
<td>Nurse</td>
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</tbody>
</table>
Symptom assessment & management: Process and outcome measures
Lessons Learned

• Culture change takes time
• Focus on a common goal to improve care and quality of life
• Integration with existing workflow is key
• Successful implementation is contingent on engaging the multi-disciplinary teams at the frontline
• Including voices of patients and other key stakeholders from the planning to evaluation

“The Committee’s accomplishments to date have set the foundation for alleviating some of the challenges faced by kidney patients. We, the Committee’s patients and health care professionals, are working together to deal with the important patient issues that haven’t received sufficient focus in the past.”

• Data capture enables monitoring of progress over time
Summary

- A series of provincial strategies enabled the culture change
- Success and progress are made possible with provincial renal network and champions in ACP and palliative care
- Collaborations across modalities and sub-specialities are possible and mutually beneficial
- Collaborations across CKD modalities can be challenging but integral to the culture change and equitable access to a palliative approach in the continuum of chronic care
Thank you!

• BCPRA Palliative Care Committee

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