Mapping the Future: Innovations in Kidney Supportive Care

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Coalition for Supportive Care of Kidney Patients
Sections of Nephrology and Palliative Medicine
West Virginia University School of Medicine
Using the Chat Feature

All lines have been muted for clearer reception. We encourage you to participate and ask questions using the CHAT box on the right side of your screen. Type your comments and questions in the text box, select “All Participants,” and press “Send.” We will attempt to answer all questions.

If you are viewing the presentation in full screen mode, hover at the top of your screen, and a menu will pop up with a chat option.
Learning Objectives

- After completing this course, the learner will be able to:
  - Identify the elephant in room
  - Describe the unmet palliative care needs of patients with kidney disease
  - Appraise the value of primary palliative care to patients with kidney disease
  - Justify need for fundamental change in the disease-oriented culture of ESRD
  - Patient-centered care requires that we...
    - Talk to our patients
    - Understand what they prioritize in their care, what matters most
    - Change the system to align with what patients want
  - Make the case for CMS hospice policy changes at the federal level for ESRD
Nephrology News & Issues Series on Supportive Care in Nephrology

- December 2018: “Providing Supportive Care: Tools & Resources for the Journey” by Dale Lupu, PhD
  - December 11, 2018: companion webinar on “Providing Supportive Care: Tools & Resources for the Journey” by Dale Lupu, PhD
Audience Response Question

With regard to kidney supportive care, which ONE of the following is the elephant in the room, i.e., the biggest problem that needs to be addressed to improve patient care?

A. Underdiagnosed and treated pain
B. Lack of bereavement support to families
C. Lack of spiritual care to patients and families
D. Lack of clinician-patient communication
The Problem to Be Addressed (is a big one!)

- ~20% of patients with kidney disease are seriously ill
- Many patients do not realize they had a choice; regret decision to start dialysis
- No medical management without dialysis pathway in U.S. kidney care
- Palliative care rarely utilized to identify goals and optimize patients’ QOL
  - Many patients’ symptoms underdiagnosed and undertreated
- More patients with poor prognosis started on dialysis than in other countries
- High hospital death rate with intensive treatments
- Hospice utilization is low
- **Bottom Line: Cost is high. Quality is low!**
Definition of Serious Illness

- One that carries a high risk of death over the course of a year AND
- Has a strong negative impact on one’s QOL and functioning OR
- Is highly burdensome to a person and his or her family

Many of our CKD and ESRD patients are seriously ill!

## Disconnect between Patient/Clinician Priorities

<table>
<thead>
<tr>
<th>Patients and caregivers</th>
<th>Healthcare professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Peaceful death of the patient</strong>*</td>
<td>1. Death at the patient’s preferred place</td>
</tr>
<tr>
<td>2. Availability of a key contact person in the CKM program</td>
<td>2. Assessment of pain</td>
</tr>
<tr>
<td>3. Training of providers in symptom management</td>
<td>3. Palliative care referral</td>
</tr>
<tr>
<td>4. Avoidance of interventions not preferred by the patient</td>
<td>4. Communication with the primary care doctor</td>
</tr>
<tr>
<td>5. Presence of at least one physician in the CKM program</td>
<td>5. Discussion about patient’s wishes</td>
</tr>
<tr>
<td>6. Presence of at least one nurse in the CKM program</td>
<td>6. Percentage of patients initiating dialysis after choosing CKM</td>
</tr>
<tr>
<td>7. Delivery of knowledge and support to make health decisions</td>
<td>7. Respect of patient’s beliefs and values by the CKM team</td>
</tr>
<tr>
<td>8. Access to the clinic staff during and afterhours throughout the week</td>
<td>8. Assessment of symptoms by a validated tool</td>
</tr>
<tr>
<td>10. Receipt of a shared decision-making intervention containing knowledge about CKM</td>
<td>10. Providing anticipatory guidance</td>
</tr>
</tbody>
</table>

Harrison T. Prioritization of Quality Indicators for CKM. *AJKD* 2018. In press. 16 pts/caregivers 79 clinicians

CKM indicates conservative kidney management
Audience Response Question

Which ONE of the following would be either the first or second priority for ¾ of older adults with advanced CKD?

A. Reducing pain
B. Maintaining independence
C. Staying alive
D. Reducing other symptoms
Health Outcome Priorities of Older Adults with Advanced CKD and Concordance with Their Nephrology Providers’ Perceptions

Table 5. Absolute agreement and weighted κ values for patient-provider concordance for health outcome priorities

<table>
<thead>
<tr>
<th>Health Outcome Priority</th>
<th>Absolute Agreement, % (95% CI)</th>
<th>Weighted κ (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining independence</td>
<td>31 (26 to 37)</td>
<td>−0.02 (−0.23 to 0.19)</td>
</tr>
<tr>
<td>Staying alive</td>
<td>26 (21 to 31)</td>
<td>0.01 (−0.20 to 0.21)</td>
</tr>
<tr>
<td>Reducing pain</td>
<td>30 (24 to 35)</td>
<td>0.01 (−0.18 to 0.20)</td>
</tr>
<tr>
<td>Reducing other symptoms</td>
<td>27 (22 to 33)</td>
<td>−0.07 (−0.47 to 0.32)</td>
</tr>
</tbody>
</table>

*Calculated by treating patients as one rater and providers as another rater.

¾ of patients’ top or second priority-independence
½ of patients’ third or fourth priority-staying alive

Providers’ agreement on their patients’ top priority-Cohen’s $K = .10$
Core Outcome Measures for HD

Evangelidis N. AJKD 2017
Clash of Cultures: ESRD Disease-oriented vs Patient-centered* Culture

Disease-oriented
Kt/V
Hb-Calcium-Phos
Access

Patient-centered
QOL-Symptoms-ICH
CAHPS
SDM-ACP
What matters most

*Respectful of and responsive to individual patient preferences, needs, and values
The Role of High-quality Communication

1. Aligns treatment with patients’ values and goals
2. Enables goal-concordant care
3. *A sine qua non*, essential element, prerequisite for improving serious illness care
   A. Serious illness requires complex decision-making with strong communication
   B. Serious illness heightens emotions which makes communication more challenging
   C. Serious illness decisions dicey as may impact length of remaining life
Clinician–Patient Communication Improves Patient/Caregiver Experience and Overall Care

Positive Outcomes of Communication

- Better respect for patients’ end-of-life wishes for treatment
- Better patient QOL
- Better patient understanding of seriousness of illness
- Completion of advance directives and DNR and POST orders
- Lower rate of ICU admission in the last week of life
- Lower rate of CPR and mechanical ventilation
- Higher hospice referral rate ≥ 1 week before death
- Bereaved caregivers report better QOL and less regret and depression
- Decreased costs of care

Unmet Supportive Care Needs in US Dialysis Centers (N=487)

- Only 4.5% reported providing high-quality supportive care
- Top 5 least well met needs
  - Bereavement support
  - Spiritual support
  - End-of-life care discussions—provider, patient, and family
  - Pain control
  - Caregiver support to family

Audience Response Question

- With regard to access to kidney supportive care for patients with kidney disease, which ONE of the following is true?

  A. There is an adequate supply of specialist palliative care clinicians and nephrology clinicians readily refer.
  B. There is an adequate supply of specialist palliative care clinicians but nephrology clinicians fail to refer.
  C. There is a shortage of specialist palliative care clinicians but enough to meet the needs of patients with kidney disease if referrals were made.
  D. There is a shortage of specialist palliative care clinicians and consequently nephrology clinicians will need to provide palliative care to patients with kidney disease.
Estimated nationwide shortage of 5,000 to 10,000 palliative care physicians.

There are not enough palliative care clinicians to treat our patients. We need to learn how to do it ourselves!

Representative Skill Sets for Primary and Specialty Palliative Care.

**Primary Palliative Care**
- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

**Specialty Palliative Care**
- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

Undertreatment of Symptoms

Renal Provider Recognition of Symptoms in Patients on Maintenance Hemodialysis

“Renal providers are largely unaware of the presence and severity of symptoms in patients who are on maintenance hemodialysis. Implementation of a standardized symptom assessment process may improve provider recognition of symptoms and promote use of symptom-alleviating treatments.”

Weisbord SD. CJASN 2007

Original Article

Under treatment of Symptoms in Patients on Maintenance Hemodialysis

René N. Claxton, MD, Leslie Blackhall, MD, Steven D. Weisbord, MD, and Jean L. Holley, MD
Age Differences in Treatment Decision and Practices Stratified by Comorbidity Score

Survival by Age and Quintile of Intensity


### A

<table>
<thead>
<tr>
<th>Group</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Outpatient</td>
</tr>
<tr>
<td>2</td>
<td>&lt;2 weeks hospitalized, no intensive procedure</td>
</tr>
<tr>
<td>3</td>
<td>&lt;2 weeks hospitalized, at least one intensive procedure</td>
</tr>
<tr>
<td>4</td>
<td>&gt;2 weeks hospitalized, no intensive procedure</td>
</tr>
<tr>
<td>5</td>
<td>&gt;2 weeks hospitalized, at least one intensive procedure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Years of Survival (median, interquartile range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>67-74 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
<tr>
<td>75-79 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
<tr>
<td>80-84 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
<tr>
<td>≥85 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
</tbody>
</table>

### B

<table>
<thead>
<tr>
<th>Age Group</th>
<th>% Remaining follow-up spent hospitalized (median, interquartile range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>67-74 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
<tr>
<td>75-79 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
<tr>
<td>80-84 years</td>
<td><img src="image" alt="Graph" /></td>
</tr>
<tr>
<td>≥85 years</td>
<td><img src="image" alt="Graph" /></td>
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</tbody>
</table>
### Table. Intensity of Care During the Final Month of Life

<table>
<thead>
<tr>
<th>Intensity of Care</th>
<th>Medicare Beneficiaries</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dialysis (Present Study)</td>
<td>Cancer</td>
<td>Heart Failure</td>
</tr>
<tr>
<td>Hospitalization, %</td>
<td>76.0</td>
<td>61.3</td>
<td>64.2</td>
</tr>
<tr>
<td>Days hospitalized, mean</td>
<td>9.8</td>
<td>5.1</td>
<td>NA</td>
</tr>
<tr>
<td>Intensive care unit admission, %</td>
<td>48.9</td>
<td>24.0</td>
<td>19.0</td>
</tr>
<tr>
<td>Days in an intensive care unit, mean</td>
<td>3.5</td>
<td>1.3</td>
<td>NA</td>
</tr>
<tr>
<td>Any intensive procedure, %</td>
<td>29.0</td>
<td>9.0</td>
<td>NA</td>
</tr>
<tr>
<td>Hospice use, %</td>
<td>20.0</td>
<td>55.0</td>
<td>39.1</td>
</tr>
<tr>
<td>Death in a hospital, %</td>
<td>44.8</td>
<td>29.0</td>
<td>35.2</td>
</tr>
</tbody>
</table>

Abbreviation: NA, not available.
## Measures of Quality of EOLC: ESRD vs General Medicare Population

<table>
<thead>
<tr>
<th>Quality Measure</th>
<th>ESRD Population</th>
<th>General Medicare Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalization in the last 30 days of life</td>
<td>73%</td>
<td>40%</td>
</tr>
<tr>
<td>Out-of-hospital death</td>
<td>54.3%</td>
<td>79%</td>
</tr>
<tr>
<td>Referral to hospice</td>
<td>20%</td>
<td>47%</td>
</tr>
<tr>
<td>Hospice referral &gt; 3 days prior to death - Referral ≤ 3 days prior to death</td>
<td>41.5%</td>
<td>25%</td>
</tr>
<tr>
<td>Cost of the last week of life</td>
<td>$10,900</td>
<td>$3,000</td>
</tr>
</tbody>
</table>
Wachterman MW. Hospice LOS, Utilization, and Medicare Costs at the End of Life Among Patients Who Received Maintenance Hemodialysis. 
Patient-Centered: Why Patients May Value CCC* over Dialysis

- Freedom to travel, not being tied down to a schedule
- Willing to trade longer survival for independence
- Quality of life
- Lower symptom burden
- Hospital-free days
- Less impact on caregivers-do not want to be a burden


*comprehensive conservative care=medical management without dialysis
Audience Response Question

- Based on the literature from abroad and the US, what percentage of older patients with advanced CKD are likely to choose medical management without dialysis if offered that option?

  A. 5%
  B. 10%
  C. 15%
  D. 20%
  E. 25%
“Pearls” from Literature Review of Comprehensive Conservative Care (CCC)

- About 15% of patients choose CCC for “lifestyle-related outcomes.”
- CCC patients may live longer than a year and need to be treated with primary palliative care.
- Geriatric syndromes (including frailty), old age, and high comorbidities predict patients who may not benefit from dialysis.
- Patients respond well to CCC when pathway is established and presented as “natural ageing” or “holistic care.”
- Risk algorithms for patients with high 90-day mortality after starting dialysis can inform decisions about initiating dialysis (Couchoud C. *Kidney Int* 2015)
Comprehensive Conservative Care—Active Medical Management w/o Dialysis

- Control hypertension
- Preserve kidney function
- Maintain fluid balance with diet and diuretics
- Treat acid-base imbalance
- Manage anemia
- Address calcium, phosphorous, bone metabolism
- Advance care planning with documentation of goals
- Pain and symptom assessment and management
- Refer to hospice when appropriate
Discussing Conservative Management With Older Patients With CKD: An Interview Study of Nephrologists

Nephrologist Attitudes toward Medical Management without Dialysis

N=35

CM=conservative management

AJKD 2018;71(5):627-6

Institutional Facilitators

- Trust and coordination between nephrology, primary care, and support services
- Greater access to palliative care
- Longer appointments for CM conversations from trained nurses and social workers
- Pay-for-performance for value-based care

CM=Routinely Integrated

Defining role
- Facilitating patient-centered decision-making
- Accepting of patient preferences to initiate or forgo dialysis

Viewing CM as care and as promoting patient quality of life

Coping with moral distress through CM conversations

37% of respondents
Best Case/Worst Case Decision Aid for Dialysis vs Medical Management

Time to Recast Our Approach for Older Patients With ESRD: The Best, the Worst, and the Most Likely
Vanessa Grubbs. AJKD 2018;71(5):605-607
This Change Package was adapted from work funded by the Gordon and Betty Moore Foundation through grant 5397 to Quality Insights to support the Pathways Project Phase I.
Key Evidence-Based Recommendations

Supportive Care Capacity

Create the System
Assemble an interdisciplinary team for setting with a day-to-day leader and champion(s)

Just Right Care

The Right Care to the Right Person at the Right Time
Prioritize seriously ill patients with CKD and ESRD for primary and specialty supportive care interventions

Values Guide Care

Elicit & Respect Patient Values and Preferences
Implement shared decision-making for current and advance care planning for future options

Throughout the Continuum

Enhanced Support at the End of Life
Coordinate care and care transitions with specialty palliative care and hospice
Audience Response Question

- In multivariate logistic regression analysis, which ONE of the following has consistently been found to be the most predictive of a poor prognosis in patients with kidney disease?

  A. Age
  B. Nutritional status
  C. “No” response to the surprise question
  D. Functional status
  E. Comorbidity score
Identifying the Seriously III CKD/ESRD Patient

With a “No” response to the “surprise” question—“Would I be surprised if this patient died in the next 6-12 months?”—nephrologists and nephrology nurse practitioners identify CKD and ESRD patients who are **3.5 times more likely to die in the next year** and who are appropriate for advance care planning and other supportive care interventions.

Why Use the “Surprise” Question

- In multiple studies of CKD and dialysis patients, the “surprise” question has been the strongest predictor (compared to comorbidities, functional status, nutritional status, or age) in multivariate logistic regression analysis of a high risk of mortality.

- Use of objective variables (age, comorbidities, functional status, and nutritional status) in addition to the subjective intuitive “surprise” question in an integrated prognostic model for CKD and ESRD patients creates a more accurate model with a C-statistic of ≥.78.
Shared Decision-Making in Informed Consent

- A process of communication between patients and physicians **based on patient’s overall condition**
- Reach agreement on a specific course of treatment
  - After patients describe their values and preferences
  - Physicians present dx, px, and treatment alternatives with their attendant benefits and risks
- Each participant better understands the relevant factors
- And shares responsibility in the decision

CollaboRATE: A Fast, Frugal Measure of Shared Decision-Making

- How much effort was made to help you understand your health issues?
- How much effort was made to listen to the things that matter most to you about your health issues?
- How much effort was made to include what matters most to you in choosing what to do next?

Patient responds on 0-10 scale; 0=No effort was made to 10=Every effort was made

Elwyn G. Patient Education and Counseling, 2013
Measuring Quality of Communication

9. Talking to you about how long you might have to live.

10. Talking to you about what dying might be like.

11. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself.

12. Asking about the things in life that are important to you.

### Serious Illness Conversation Guide

#### CLINICIAN STEPS

- **Set up**
  - Thinking in advance
  - Is this okay?
  - Hope for best, prepare for worst
  - Benefit for patient/family
  - No decisions necessary today

- **Guide** (right column)

- **Act**
  - Affirm commitment
  - Make recommendations about next steps
    - Acknowledge medical realities
    - Summarize key goals/priorities

#### CONVERSATION GUIDE

<table>
<thead>
<tr>
<th>Understanding</th>
<th>What is your understanding now of where you are with your illness?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information preferences</td>
<td>How much information about what is likely to be ahead with your illness would you like from me?</td>
</tr>
<tr>
<td></td>
<td>FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prognosis</th>
<th>Share prognosis as a range, tailored to information preferences</th>
</tr>
</thead>
</table>

| Goals | If your health situation worsens, what are your most important goals? |
Take-home Messages

- High-quality communication is the elephant in the room, the thing that most needs to be improved for patients with kidney disease to receive patient-centered care.
- Clinicians need to learn patients’ priorities to provide them with goal-concordant, patient-centered care.
- Nephrology clinicians will need to learn and use primary palliative care skills to improve their patients’ quality of life.
- Systematic identification of seriously ill patients is a first step in implementing primary palliative care.
Join the Coalition!

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@kidneycoalition