Welcome to today’s session!
Please use Chat to “All Participants” for questions
For technology issues only, please Chat to “Host”
WebEx Technical Support: 866-569-3239
Dial-in Info: Communicate / Join Teleconference (in menu)

When Chatting…
Please send your message to All Participants …NOT All Attendees
Overall Program Aim

The aim of this Expedition, Managing Advanced Disease and Palliative Care, is to help health professionals empower patients and families to make more informed choices about the use of specific life-sustaining treatments when coping with a serious illness.

Objectives of Expedition

- **Describe** the positive outcomes for all parties — patients with advanced illness, their families, health care providers, and institutions — that arise from outstanding informed consent, education, and advance care planning
- **Assess** their current system for conducting and documenting the informed consent conversation process at critical junctures in advanced illness: initiating tube feeding, kidney dialysis, or antibiotics
- **Identify** process steps and test improvements in the informed consent, documentation, and education processes for patients and families
- **Develop** a quality monitoring process for ongoing assessment of compliance with informed consent standards

This Expedition

- Certain medical interventions provide critical junctures that allow us to pause and connect with patients and their families about what the goals of care. These conversations can prevent us from being in the position of providing care that is excessive in relation to their wishes or their course of illness.
- A central tenet of palliative care is to match the right procedure for the right patient at the right time.
Introducing faculty

• Alvin H. Moss, MD
  — Professor of Medicine, West Virginia University
  — Nephrologist and Palliative Medicine Physician

• David E. Weissman, MD
  — Professor Emeritus, Palliative Care Program, Medical College of Wisconsin
  — Consultant, Center to Advance Palliative Care

Today’s Focus…

• Informed consent discussions about Kidney Dialysis

• And a quick side note… “RRT” in most IHI programs refers to Rapid Response Teams but today refers to Renal Replacement Therapy

Prior Homework: Chart Review

• Review 10 charts of hospitalized patients who started dialysis in the last six months
• Examine the documentation for the dialysis discussion:
  — Procedure description
  — Risks and Benefits including prognosis
  — Alternatives including no dialysis
  — Clinician Recommendation
Prior Homework: Chart Review

• How many of you had an opportunity to complete the chart review?
• How many of you found that 50% or more of the charts met criteria for informed consent that we spoke about at the first session?

Your Turn!

Chat in your findings from the homework
What were your “aha” moments?

Common Scenario

• 75 y/o man seven days post massive stroke with major likely permanent neuro deficits.
• History of diabetes, vascular insufficiency, coronary artery disease.
• S/p CABG, AKA for vascular disease
• Chronic kidney disease; progressive, approaching need for dialysis.
Questions?

- What are the risks and benefits of Renal Replacement Therapy (RRT) for this patient?
- What is the prognosis with and without RRT?
- What alternatives exist to RRT?
- How should the discussion be conducted?

Comments

- Questions or comments about the case?

Kidney Disease: An Opportunity

- Chronic Kidney Disease (CKD) is an opportunity for shared-decision making and goal setting.

- Goals can only be truly made in the setting of true informed consent.
  - Description of the procedure
  - Risks/benefits
  - Alternatives
  - A recommendation
Scope of the Problem

- 111,000 patients start renal replacement therapy each year
- Annual mortality for patients starting RRT is ~25%
- Morbidity for patients receiving RRT is high: more than 50% with diabetes, ASHD, and CHF; more than 25% with PVD, cardiac arrhythmias, and TIA/CVA.

Palliative Care: Relevance to ESRD

- Aging Population
- Shortened life expectancy
- Multiple comorbidities
- High symptom burden
- Nephrologists not prepared in training

High Symptom Burden

- HD patients median # of 9 symptoms
- Pain in over 50%
- Associated with impaired HRQoL
- Associated with depression

Mean Symptom severity – 1 = not bothersome to 5 = very bothersome

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest pain</td>
<td>3.63</td>
</tr>
<tr>
<td>Bone/joint pain</td>
<td>3.61</td>
</tr>
<tr>
<td>Difficulty with sex arousal</td>
<td>3.44</td>
</tr>
<tr>
<td>Trouble falling asleep</td>
<td>3.35</td>
</tr>
<tr>
<td>Muscle cramps</td>
<td>3.31</td>
</tr>
<tr>
<td>Itching</td>
<td>3.24</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>3.21</td>
</tr>
<tr>
<td>Nausea</td>
<td>3.16</td>
</tr>
<tr>
<td>Muscle soreness</td>
<td>3.14</td>
</tr>
<tr>
<td>Fatigue</td>
<td>3.12</td>
</tr>
<tr>
<td>Trouble staying asleep</td>
<td>3.10</td>
</tr>
</tbody>
</table>

Weisbord SD et al – JASN 2005;2487-94

More than somewhat bothersome

Predictors of Poor Prognosis for ESRD Patients

• Age
• Functional ability
• Nutritional status
• Comorbid Illnesses – e.g., DM, MI, CHF


The “Surprise” Question:
A Trigger for Palliative Care Evaluation and Advance Care Planning

“Would I be surprised if this patient died in the next year?”

Initial Demographics, Quality of Life, and Prognostic Factor Scores*

<table>
<thead>
<tr>
<th>Variable</th>
<th>All (N=150)</th>
<th>Yes (N=115)</th>
<th>No (N=35)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (yrs)</strong></td>
<td>66.6±15.83</td>
<td>64.3±15.4</td>
<td>74.1±12.6</td>
<td>0.002</td>
</tr>
<tr>
<td><strong>Serum Albumin</strong></td>
<td>3.9±0.3</td>
<td>3.9±0.29</td>
<td>3.7±0.41</td>
<td>0.01</td>
</tr>
<tr>
<td><strong>Pain Score</strong></td>
<td>2.6±3.2</td>
<td>2.6±3.3</td>
<td>2.3±2.9</td>
<td>0.601</td>
</tr>
<tr>
<td><strong>McGill Quality of Life question</strong></td>
<td>6.7±2.1</td>
<td>6.8±2.1</td>
<td>6.5±2.0</td>
<td>0.518</td>
</tr>
<tr>
<td><strong>Charlson Comorbidity Score</strong></td>
<td>6.0±2.2</td>
<td>5.8±2.1</td>
<td>7.0±2.3</td>
<td>0.003</td>
</tr>
<tr>
<td><strong>Karnofsky Performance Status</strong></td>
<td>78.7±17.1</td>
<td>81.6±15.9</td>
<td>68.7±17.7</td>
<td>0.001</td>
</tr>
</tbody>
</table>

*Values are mean ± SD. "Yes" indicates patients in the "Yes, I would be surprised" group. "No" indicates the "No, I would not be surprised" group.

Univariate logistic regression analysis to predict status at 12 months

<table>
<thead>
<tr>
<th>Predictor</th>
<th>OR (95% CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Surprise&quot; Question Response (reference = &quot;Yes&quot;)</td>
<td>3.507 (1.356 to 9.067)</td>
<td>0.01</td>
</tr>
<tr>
<td>CCI Score</td>
<td>1.417 (1.099 to 1.826)</td>
<td>0.007</td>
</tr>
<tr>
<td>Karnofsky Performance Status Score</td>
<td>0.964 (0.937 to 0.992)</td>
<td>0.012</td>
</tr>
<tr>
<td>Quality of Life Score</td>
<td>0.859 (0.693 to 1.065)</td>
<td>0.166</td>
</tr>
<tr>
<td>West Analogue Scale</td>
<td>1.109 (0.962 to 1.279)</td>
<td>0.153</td>
</tr>
<tr>
<td>Serum Albumin</td>
<td>0.329 (0.089 to 1.205)</td>
<td>0.123</td>
</tr>
<tr>
<td>Albumin Kt/V</td>
<td>1.242 (0.328 to 4.898)</td>
<td>0.729</td>
</tr>
<tr>
<td>Serum Hb</td>
<td>1.084 (0.692 to 1.699)</td>
<td>0.724</td>
</tr>
<tr>
<td>Gender</td>
<td>0.974 (0.392 to 2.420)</td>
<td>0.955</td>
</tr>
<tr>
<td>Race</td>
<td>0.324 (0.041 to 2.580)</td>
<td>0.287</td>
</tr>
<tr>
<td>Time on Dialysis (months)</td>
<td>1.006 (0.999 to 1.016)</td>
<td>0.293</td>
</tr>
<tr>
<td>Age</td>
<td>1.012 (0.999 to 1.025)</td>
<td>0.449</td>
</tr>
</tbody>
</table>

OR indicates odds ratio. For those for whom the "surprise" question was answered "No," the odds of dying within a year were 3.507 times the odds of dying for those for whom the "surprise" question response was "Yes." CCI indicates Charlson Comorbidity Index. Kt/V indicates the dialysis index. Hb indicates serum hemoglobin.


Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis

Lewis M. Cohen,* Robin Rutvitz,' Alvin H. Moss, and Michael J. Germaine5

**Results:** In a Cox multivariate analysis of the derivation cohort (N=449), five variables were independently associated with early mortality: Older age (hazard ratio [HR] for a 10-yr increase 1.35; 95% confidence interval [CI] 1.17 to 1.57), dementia (HR 1.88; 95% CI 1.24 to 2.84), peripheral vascular disease (HR 2.24; 95% CI 1.11 to 4.48), decreased albumin (HR for a 1-U increase 0.27; 95% CI 0.15 to 0.50), and CCI (HR 2.71; 95% CI 1.76 to 4.17). Area under the curve for the resulting prognostic model predictions of 6-mo mortality were 0.87 (95% CI 0.82 to 0.92) in the derivation cohort and 0.80 (95% CI 0.73 to 0.86) in the validation cohort.

**Conclusions:** An integrated 6-mo prognostic tool was developed and validated for the HD population. The instrument may be of value for researchers and clinicians to improve end-of-life care by providing more accurate prognostic information.
The model successfully predicted which patients had worse and better survival over time with patients in quintile 5—the highest risk quartile—having the poorest survival (P < 0.001).


Comments

- Questions or comments about the relevance of palliative care to ESRD and the use of the “surprise” question?

Alternatives to RRT

- Rehabilitative dialysis-life prolongation and optimization of function
- Palliative dialysis-life prolongation with goal of comfort and reduction of suffering for patient with SQ answer of “No”
- Active disease management without dialysis
  — Advance care planning and goals implementation
  — Treatment of anemia, acidosis, hypertension, bone disease, fluid balance, and pain/symptoms
  — Referral to hospice when appropriate
Patients for Whom Dialysis May Not Confer a Survival Advantage

Patients with two or more of the following…

• Advanced age (>75 years in one study)
• Multiple severe comorbidities
• Impaired functional status
• Low serum albumin (<2.5 g/dL ~ 50% 1-year survival)

Patients in Whom Dialysis Is Not Recommended

• Patients who lack capacity who have previously indicated refusal of dialysis
• Patients whose legal agent refuses dialysis
• Patients with profound neurological impairment who lack purposeful behavior and awareness of self and environment

Comments

• Questions or comments about the alternative of active disease management without dialysis?
Starting the Discussion

• As you understand it, what is your major medical problem?
• How serious is it?
• What is most important to you in the treatment of your illness?

Definition of Advance Care Planning

“ACP is a process that involves understanding, reflection, communication, and discussion between a patient, family/health care proxy, and staff for the purpose of prospectively
1) identifying a surrogate (health care proxy),
2) clarifying preferences, and
3) developing individualized plans for care near the end of life.”


Goals of Care and ACP

“Goals of care are inextricably linked with patient and family understanding of illness and expectations. In the context of facilitated ACP, it is clear that goals must reflect expectations that are in balance with adequate knowledge.”

Patients’ Desires for Treatments in Various Health States (%)

<table>
<thead>
<tr>
<th></th>
<th>Current Health</th>
<th>Sev CVA</th>
<th>Sev Dementia</th>
<th>Term Illness</th>
<th>Perm Coma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tube feeding</td>
<td>100</td>
<td>50</td>
<td>30</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>MV</td>
<td>90</td>
<td>40</td>
<td>20</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>CPR</td>
<td>80</td>
<td>30</td>
<td>15</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Dialysis</td>
<td>70</td>
<td>20</td>
<td>10</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Discussing RRT

- Shared decision-making
- Estimation of prognosis
- Goals of care discussion based on health state and patient’s wishes
- Documentation of wishes in advance directive and POLST form
- System to respect wishes

Improving the System of Care

- What steps can hospitals take to systematize care so that patients are more likely to get true informed consent where all options are presented?
Components of the System

- Standardized practices and policies
  - RRT discussion checklist
  - Identification of patients with poor prognosis
- Timely discussions prompted by prognosis
  - Use of the “surprise” question to identify patients
  - Trained advance care planning facilitators
    - Respecting Choices
    - Nephrologist and ...
      - Dialysis nurse or social worker or palliative care nurse
Components of the System

- Clear, specific language on an actionable ACP form
  - Bright form easily found among paperwork
  - POLST/MOLST
  - Orders honored throughout continuum
- Patient/Family education material
  - Reading level appropriate
- QI activities for continual refinement
  - Percent of charts with appropriate documentation

KIDNEY END-OF-LIFE COALITION

For additional information, including resources for patients and families, visit www.kidneyeol.org

Advance care planning information
Do not resuscitate orders in the dialysis unit
Access to hospice
Clinician educational resources

Contact the Kidney End of Life Coalition at kidneyeol@nw5.esrd.net

Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

rpa@renalmd.org
301.468.3515
Conclusions

- Guidelines exist for who should be dialyzed.
- There is a recommended process for making decisions about dialysis.
- Patients who will do poorly can be predicted with reasonable accuracy, and for them, dialysis may not confer a survival advantage.
- Discussion and documentation within a system is necessary to ensure that patients' wishes are respected.

Comments

- Any reactions? Questions?

Leaving in Action… start testing!

THE PDSA CYCLE

- Act: What changes are to be made? Next cycle?
- Plan: Objective, Questions and predictions (why) Plan to carry out the cycle (who, what, where, when)
- Study: Complete the analysis of the data Compare data to predictions Summarize what was learned
- Do: Carry out the plan Document problems and unexpected observations Begin analysis of the data
Leaving in Action – Ideas for Testing

AT NEXT INFORMED CONSENT FOR KIDNEY DIALYSIS you could...

• Use educational material that Dr. Moss referenced with one family and get their feedback and then revise for further testing
• Use the “surprise question” to screen for palliative care consult
• Hold a family meeting using a couple elements from Dr. Weissman’s presentation (don’t want to test too many things at once – can add others in during future PDSA cycles)
• Test documenting family meeting process and outcome using guidelines in Dr. Weissman’s presentation

Next Sessions

• May 12th 1-2pm ET
• Teams report out about testing for kidney dialysis informed consent processes

Then:

• May 26th 1-2pm ET
• Carol Montelioni will be our guest speaker re: feeding tubes

References

• Renal Physicians Association Shared Decision-Making clinical practice guideline. 2000
• United States Renal Data System. 2009 Annual Data Report. www.usrds.org