Palliative Care for End Stage Renal Disease

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Objectives

1. List resources for clinicians caring for ESRD patients
2. Discuss prognosis for ESRD patients
3. Address some common questions patients might have as they contemplate their disease and compare it to evidence based literature
Stages of CKD

Glomerular Filtration Rate (GFR)
Index of overall function

<table>
<thead>
<tr>
<th>Stage</th>
<th>eGFR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>&gt;90 mL/min</td>
</tr>
<tr>
<td>2</td>
<td>60-89 mL/min</td>
</tr>
<tr>
<td>3</td>
<td>30-59 mL/min</td>
</tr>
<tr>
<td>4</td>
<td>15-29 mL/min</td>
</tr>
<tr>
<td>5</td>
<td>&lt; 15 mL/min</td>
</tr>
</tbody>
</table>

Definitions of Daily Urine Output

- Anuria < 100 ml/day
- Oliguria < 400 ml/day
- Polyuria > 3000 ml/day
Defining Durations

- Acute Kidney Injury (AKI): < 1 month
- Subacute (SKI): 1-3 mo
- Chronic (CKD): 3 or more months

“Doc, how did my kidneys become so (chronically) sick?”

Diabetic Nephropathy
Hypertension

Types of Renal Replacement

- Continuous Renal Replacement Therapy (CRRT)
- Hemodialysis
- Transplant
- Peritoneal
Complications of ESRD

Uremia
- Lethargy
- Somnolence
- Confusion
- Neuromuscular irritability
- HTN
- CHF
- Nausea
- Vomiting
- Metallic taste
- Pruritus
- Sleep disturbances
- Pericarditis
- Anorexia

Uremic Pruritus
- Unknown MOA
- Antihistamines not shown to be effective
- Doesn’t correlate with BUN
- Chronic > Acute
- Back, symmetric, continuous
- Nocturnal, dry, heat
- 17% increase mortality associated
**Uremic Pruritus**

- Skin emollients if dry, keep cooler
- Gabapentin/pregabalin
- Gamma-linolenic acid (component of evening primrose oil)
- Thalidomide
- Capsaicin cream
- Kappa-opioid receptor agonists
- UVB therapy

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**Sleep disorders**

- 75-85% of ESRD pts
- RLS, uremic pruritus, pain, iron def, etc.
- Treat underlying cause (RLS)
- Sleep hygiene
- Mild hypnotics
- Cooler dialysate (36.0-36.5 degrees)

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**Depression**

- Symptoms may overlap
- Focus on feelings of
  - Helplessness
  - Guilt
  - Worthlessness
  - Suicide
- fluoxetine, sertraline, citalopram
- Avoid bupropion
- Low employment
Calciphylaxis

- Vascular calcification
- Soft Tissue Necrosis
- Ischemic Necrosis of skin
- Extremely painful
- Lower extremities
- Unknown mechanism
- Normalize calcium-phosphate
- Meticulous wound care
- Mortality 80%

Symptoms in ESRD Patients

Yong 2009

- Average of 9.1 symptoms per patient
- Fatigue
- Difficulty sleeping
- Cold aversion
- Lower Torso Weakness
- Pruritus
- Sexual Problems
- Pain in 41%

Pain Meds with ESRD
End Stage Symptoms Compared

- Fatigue
- Sleep
- Dryness
- Pruritus
- Incontinence

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Daily symptom burden in end-stage chronic organ failure: a systematic review

John A. Jansen, Clinical Department of Treatment and Care, Prionie, Hen, IM, Sprat, Staff hospital
Chronic Renal Failure Symptom Prevalence

ESRD symptoms in Pediatrics

Symptoms in ESRD without HD

Symptoms prevalence
HD Withdrawal

Confusion/Agitation 70%
Pain 55%
Dyspnea 48%
Nausea 36%
Myoclonus/Seizures 27%
Anxiety 27%
Pruritis 24%
Edema 21%

Fast Fact #208

Does impaired Renal function impact cognition?

Normal 1.5 min (+/- 0.5 min)
CKD 2.5 min (+/- 1 min)
ESRD 3.5 min (+/- 1.5 min)
P<0.001

www.renalmd.org/End-Stage-Renal-Disease/
Prognosis

“So how long do I have, doc?”

Patient/Nephrologist Perceptions

- **Patient** - 62/80 seriously ill hemodialysis patients & 14 nephrologists in 2 Boston outpt HD units
- **Intervention** - calculated prognosis, interviewed patients and their nephrologists for perceptions, compared prognosis perceptions to goals of care
- **Comparison** - patient vs. nephrologist, predicted vs. actual survival, perception vs. goals of care
- **Outcome** - who is more accurate? How accurate? Did perception of prognosis influence GOC?
Modified Charlson Comorbidity Index

1 point each for:
- coronary artery disease, congestive heart failure, peripheral vascular disease,
- cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disorder, peptic ulcer disease, mild liver disease, diabetes
1 point for every decade over 40
2 points each for:
- hemiplegia, moderate-to-severe renal disease (including being on dialysis), diabetes with end-organ damage, cancer (including leukemia or lymphoma)
3 points for moderate-to-severe liver disease
6 points ea. for metastatic solid tumor or AIDS

<table>
<thead>
<tr>
<th>Modified CCI Score Total</th>
<th>Annual Mortality Rate</th>
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<tbody>
<tr>
<td>Low &lt;3</td>
<td>3%</td>
</tr>
<tr>
<td>Moderate 4-5</td>
<td>13%</td>
</tr>
<tr>
<td>High 6-7</td>
<td>27%</td>
</tr>
<tr>
<td>Very High &gt;8</td>
<td>49%</td>
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</tbody>
</table>

Prognosis

- N=52 pairs (patients & their nephrologist) interviewed
- Chances of living 1 & 5 yrs
- Eligibility for kidney transplant
- Actual Survival up to 23 mo.

Prognosis

- Patients much more optimistic
- Actual survival:
  - 1 yr 93%, 1½ yr 79%, 2 yr 56%
- Only 6% thought <50% survival at 5 yrs
- 60% nephrologists wouldn’t discuss any prognosis, even if patient insisted.
  - Confidence & concern for upsetting pt
“Surprise” Study

“Would you be surprised if this patient died in the next 12 months?”

PICO

- Patient: 147 Dialysis patients, 3 units
- Intervention: Applying the “would I be surprised if this patient died in the next year?” question
- Comparison: Yes vs. No
- Outcome: Does this question help identify patients with high risk for early mortality?


“Surprise” Study

- HD for 3 months
- Followed for 1 year
- N=147
- Overall mortality 15%
- “Yes” 10.6%
- “No” 29.4%
- Odds of dying 3.5 times higher


ESRD survival

18-23% 1 year mortality rate (Wellman)
20-25% 1 year mortality rate (Davidson)
24% 1 year mortality rate (Moss)
Prognosis

Illness Trajectories

A
Function

B
Function

C
Function

D
Function

New Functional Decline Trajectory in ESRD managed without dialysis

Resuscitation

“What about CPR? What are my chances”

Characterizing in-hospital CPR in ESRD maintenance dialysis

- N= 663,734 patients.
- Design—A national retrospective cohort study
- Main outcomes and measures—Incidence of CPR and survival after the first episode of CPR recorded in Medicare claims during follow-up.

Wong et al.

More post-CPR patients surviving to hospital discharge but survival shorter

Wong et al.
CPR in General Population vs. Dialysis Population

- Approximately one in five (21.9%, 95% CI 21.4–22.3)
- 14.9% (95% CI 14.8–15.1) received CPR during their terminal admission.

Nursing Home Elderly Population

**Will starting dialysis help mom get stronger? (functional status)?**

Elderly NH & ESRD

“Among nursing home residents starting dialysis, we recently demonstrated that dialysis initiation was associated with a substantial and sustained *decline* in functional status at the start of dialysis in addition to a very high mortality.”

Kurella Tamura, NEJM 10.2009
Elderly NH & ESRD

58% mortality at 12 months post HD
Pre-dialysis functional status maintained in 13%

Kruella Tamura NEJM 10.15.09

Prognosis After HD stopped in CKD

<table>
<thead>
<tr>
<th>Authors</th>
<th>Date</th>
<th>N</th>
<th>Mean Days</th>
<th>Range</th>
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<tbody>
<tr>
<td>Neu &amp; Kjellstand</td>
<td>1986</td>
<td>155</td>
<td>8.1</td>
<td>1-29</td>
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<tr>
<td>Sekkane &amp; Moss</td>
<td>1998</td>
<td>60</td>
<td>12</td>
<td>0-150</td>
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<tr>
<td>Cohen et al</td>
<td>2000</td>
<td>128</td>
<td>8.2</td>
<td>1-46</td>
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</tbody>
</table>

96% of patients died within 30 days of stopping HD

Dr. Perry Fine, 2007

“Doc I want to stop dialysis”

- Capacity? Understanding? Consequences? Depression?
  Other confounder?
- Reasons behind request: Call for help? Control?
  Attention?
- What if QOL could improve? Anything treatable?
- Encourage the patient to discuss reasons for dialysis withdrawal with family or support system.

Moss, A. "Integrating Supportive Care Principles into Dialysis Decision making: A Primer for Palliative Medicine Providers" JPSM March 2017
Approach to Decision to Withdraw Dialysis

1. Confirm wishes with patient or surrogate if patient lacks capacity
2. Advise patient with capacity to put affairs in order, median survival is ___ days, could be shorter or longer
3. Implement DNAR, end-of-life care plan, TPOPP (POLST)
4. Determine preferred site of death, feasibility?
5. Initiate Comprehensive symptom control

Moss, A. "Integrating Supportive Care Principles into Dialysis Decision Making: A Primer for Palliative Medicine Providers." JPSM March 2017

Relevant EPAs
What about Hospice?

Hospice EPA

www.usrds.org
USRD 2016

- Most patients receive hospice services only after discontinuing dialysis treatments. From 2004-2013, hospice use prior to death based on the CMS Death Notification form increased from 59% to 82% among patients who discontinued dialysis treatments, and from 5% to 8% among those who did not.

Hospice Enrollment after HD D/C

- 7.4 days mean survival
- Independent predictors of earlier mortality
  - Male gender
  - Referral from a hospital
  - Lower fx status (PPS)
  - Presence of peripheral edema
“Is there ANY chance I might survive if I stop my chronic dialysis?”

**Chronic Dialysis Discontinuation**

- **Patient** - CKD started on dialysis for at least 3 months without perceived chances of functional recovery
- **Intervention** - search strategy for publications 2000-2013 which included renal function recovery (n=24 studies)
- **Comparison** - had renal function recovery vs. not
- **Outcome** - identify incidence of RFR + predictors
Incidence of Renal Function Recovery for Chronic ESRD patients on dialysis

• Roughly 1% (Piccoli)
• 1-2.4% (Chu)

Underlying etiology of ESRD is the most important predictor of RFR

Diseases with highest RFR rates
• atheroembolic renal disease
  – Cholesterol emboli
• systemic autoimmune disease
• renovascular diseases
  – Hypertensive crises
• scleroderma (10%)

Diseases with lowest RFR rates
• diabetic nephropathy
• cystic kidney disease

Additional Resources Worth Knowing
Calculating Prognosis

http://touchcalc.com/calculators/sq
Neph Fellowship End-of-life care training

- National survey compared their 2003 peers, N= 204 US neph fellows 65% response rate.
- Significantly more thought it was moderately to very important to learn to provide care at end of life (95% vs 54%, \( P < 0.001 \)).
- 99% fellows believed physicians have responsibility to pls at EOL.
- Neph Fellowship QOT (teaching) scale of 0-5 (0, poor; 5, excellent).
  - All areas (mean, 4.1 ± 0.8) vs. end-of-life care (mean, 2.4 ± 1.1).
- MK: knew annual gross mortality rate for dialysis patients 57% (current) vs 67% (2003) \( P = 0.05 \).
- What would most improve your end-of-life care education?
  - Answer: Required palliative medicine rotation during fellowship.
- Conclusion: Palliative care training should be integrated into nephrology fellowship curricula.

To do dialysis or not?
4 choices, not 2!!
1. Available dialysis and kidney transplant
2. Not starting dialysis and continuing medical management
3. Time-limited trial of dialysis
4. Stopping dialysis and receiving end-of-life care
RPA Guideline Recommendation #6

Consider forgoing dialysis for patients who have a very poor prognosis or when HD cannot be provided safely:
- Advanced dementia, pulls out needles
- Hypotension
- CKD stage 5, older than 75 who meet two or more:
  - "NO" to surprise question
  - High comorbidity
  - Significantly impaired functional status (KPS <40)
  - Severe chronic malnutrition* (<2.5 g/dL)

www.renalmd.org/End-Stage-Renal-Disease/

RPA Guideline Recommendation #7

Consider a time-limited trial of dialysis for patients requiring dialysis but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis.

www.renalmd.org/End-Stage-Renal-Disease/

RPA Toolkit (Section Nine)

- Sample questions to facilitate communication
- Quick Depression Assessment Tool
- Montreal Cognitive Assessment Tool
- Decision Making Capacity Assessment Tool
- Advanced Care Planning
- Prognosis Tools
- Preparation for Dying Checklist

www.renalmd.org/End-Stage-Renal-Disease/
Decision-Making Capacity Assessment Tools
RPA Shared Decision Making

1. Able to understand medical problem?
2. Able to understand proposed treatment?
3. Able to understand alternative(s)?
4. Able to understand option of refusal?
5. Able to appreciate foreseeable consequences of accepting/refusing treatment?
6. Decision affected by major depression?
7. Decision affected by delusion/psychosis?

www.renalmd.org/End-Stage-Renal-Disease/

“there's an app for that”…

2014 Palliative care made the USRDS Annual Report!
Up and Coming: NCT02405312

- Multi-center study to systematically elicit high risk patient’s EOL care preferences (pt and caretaker), prognosis delivery, coordinate care concordant with GOC.
- Prospective cohort with a retrospective cohort serving as the comparison group.
- Nephrologist + SW
- Outcomes: frequency/timing of hospice referrals, patient/caretaker satisfaction, quality of EOL discussions, and QOD.
Palliative Care Fast Facts

- mypcnow.org

Fast Fact #161 “Opioid Use in Renal Failure”
Fast Fact #191 “Prognostication in Patients’ Receiving Dialysis”
Fast Fact #207 “Withdrawal of Dialysis: Decision Making”
Fast Fact #208 “Clinical Care Following Withdrawal of Dialysis”

www.Kidneyeol.org
http://www.kidneysupportivecare.org/Home.aspx

Treating Pain in Advanced CKD & Dialysis Patients
Clinical Algorithm & Preferred Medications

http://www.kidneysupportivecare.org/Home.aspx
Summary

• Many great resources available
• ~20% of ESRD patients on HD die each year
• Avoid Morphine in renal failure. Fentanyl, Methadone are preferred in ESRD
• Anuric ESRD chronic dialysis dependent patient, stopping therapy, average prognosis is 8-12 days

References

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