Navigating the Landscape: Decision Making and Palliative Care for the Older Patient with ESRD

Vanessa Grubbs, MD, MPH
Associate Professor
Division of Nephrology
University of California, San Francisco/Zuckerberg San Francisco General Hospital

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Disclosures

- HarperCollins Publishers
By the end of this talk, the audience will be able to…

- Describe the current dialysis population and usual path of care for older patients with end-stage renal disease.
- List alternative paths to “usual care” for older patients with end-stage renal disease.
- Understand when alternative paths should be considered and the barriers to them.
Why I do this work:
The story of Mrs. Lee
End-Stage Renal Disease

- Dialysis
- DEATH
- Transplant
“In England people believe death is imminent, in Canada people believe death is inevitable…

but in America people believe death is optional.”

--- Ian Morrison, health care futurist
End-Stage Renal Disease

Dialysis

Transplant

DEATH
Audience Response Question

Which of the following factors may suggest no survival difference between starting dialysis and foregoing dialysis?

A. Age > 75 years
B. Dementia
C. Ischemic heart disease
D. All of above
E. None of above
Audience Response Question

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Dialysis offers survival advantage

- 18-year follow-up
- 844 patients
  - Dialysis
    - n=689 (82%)
    - mean age 58.5 (11.2% >75)
    - 17.3% high comorbidity
  - Conservative
    - n=155 (18%)
    - mean age 68.4 (68.4% >75)
    - 49.7% high comorbidity

67.1 months vs. 21.2 months
p<0.001

Unless you’re old and sick

Much of time gained is spent at dialysis or in hospital

生存（月）
0 5 10 15 20 25 30 35 40
Hospital-free days Outpatient hemodialysis days Hospital inpatient days

Supportive Care n=29

Hemodialysis n=112

[Chart showing hospital-free days, outpatient hemodialysis days, and hospital inpatient days for Supportive Care and Hemodialysis groups.]

Reproduced from Carson et al. CJASN, 2009.

CVD, cardiovascular disease
Most frail patients decline soon after starting dialysis

The frail older patient has very limited life expectancy after starting dialysis

Paths

- The usual
- Time-limited trial
- Forego dialysis
- Withdraw dialysis
- Palliative approach to dialysis care
Paths

- The usual
- Time-limited trial
- Forego dialysis
- Withdraw dialysis
- Palliative approach to dialysis care
All for all

- In-center hemodialysis
  - Thrice weekly
  - Four hours
  - Fistula first
- Kinetics
- Diet restrictions
- Average eGFR 10ml/min at initiation
- Intensive care

eGFR, estimated glomerular filtration rate
Our approach hasn’t changed with the changing demographic

1967
- Only 7% over age 55
- Otherwise healthy
- Goal survival AND rehabilitation

2011
- Half over age 62
- Prevalence of age 75+ doubled over last 20 years
- Comorbid conditions
- High morbidity & mortality
- Goal survival

Evan et al. JAMA, 1981
USRDS Atlas 2014
Grubbs et al. CJASN, 2014
Particularly in the U.S. for older patients

Wong SPY et al. CJASN, 2016.
Regardless of how sick even among oldest

Low comorbidity

High Comorbidity

Age at cohort entry (years)

Wong SPY et al. CJASN, 2016.
Almost all older patients start with in-center hemodialysis

Incident ESRD patients 75+ years in 2015

Older dialysis patients get more intense care in the final month of life

Despite having similar symptom burden

PPS, Palliative Performance Scale

Paths

- The usual
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Audience Response Question

Which of the following is an appropriate length of a time-limited trial of in-center hemodialysis?

A. 6 months  
B. 1 month (12 treatments)  
C. 1 week (3 treatments)  
D. 1 day (1 treatment)  
E. None of above
Audience Response Question

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E. None of above
A real time-limited trial

- Discuss concept and prognosis over 2-3 family meetings
- Define goals—e.g. improved symptoms, improved mentation, full participation in activities daily living, interactive with environment
- Limit to 1 month—“What you see at the end of the month is what you get.”
- Weekly bedside/chair-side family meetings to review progress (or lack thereof)
Paths

- The usual
- Time-limited trial
- Forego dialysis
- Withdraw dialysis
- Palliative approach to dialysis care
What makes foregoing/stopping dialysis difficult?

- Lack of training
- Lack of time
- Financial incentives
- Uncertainty about prognosis/ what being on dialysis will mean
- Palliative care and hospice capacity
Training: Hasn’t changed over a decade

Holley et al. AJKD 2003
Combs et al. AJKD 2015
Time & Money

- 69% seen 4+ times
  - <1% explained by patient factors
  - 15-36% pre-2006

- Drive-by visits

- Patients of nephrologists with large caseloads
  - higher mortality
  - lower dialysis adequacy
  - lower receipt of kidney transplant

Erickson et al. CJASN, 2013.
Harley et al. JASN, 2013.
Uncertainty: Can predictors ever be precise enough?

Not validated for CKD patients not yet on dialysis

HD MORTALITY PREDICTOR
Programmed by Stephen Z. Fadem, M.D., FASN and Joseph Fadem
DOWNLOAD IPHONE APP

SERUM ALBUMIN
2.8 g/dL

SURPRISE QUESTION
☒ I would NOT be surprised if my patient died in the next 6 months.
☒ I would be surprised if my patient died in the next 6 months.

AGE 79 years

DEMENTIA
☒ My patient HAS dementia.
☒ My patient does NOT have dementia.

PERIPHERAL VASCULAR DISEASE
☒ My patient HAS peripheral vascular disease.
☒ My patient does NOT have peripheral vascular disease.

XBETA: 42.16
Predicted Six Month Survival: 43%
Predicted Twelve Month Survival: 12%
Predicted Eighteen Month Survival: 3%

http://touchcalc.com/calculators/sq

A different approach: Best Case/Worst Case

Gretchen Schwarze, MD
University of Wisconsin

youtube.com
Time to recast our approach for older patients with ESRD: The best, the worst, and the most likely.

Dialysis & palliative care

**Best Case**
- Tired but some good days in between
- Over time more complications
- Live 1-3 years

**Most Likely**
- Sleep on HD days
- Health declines
- More hospitalizations
- Live ~1 year

**Worst Case**
- Rough going
- Complications, hospital time
- Health declines quickly
- Time is short

Palliative care to control symptoms and quality of life concerns

No dialysis & palliative care

**Best Case**
- Medicines/diet
- Regular office visits
- Health declines slowly
- Symptoms worsen
- Live 1-2 years

**Most Likely**
- Short of breath, some good days
- Few hospital stays
- Live 3-9 months

**Worst Case**
- More tired uncomfortable
- Go to hospital
- Time is short

Audience Response Question

Do your patients with ESRD have access to outpatient palliative care where you are?

A. Yes, embedded or does home visits
B. Yes, separate clinic
C. No
Palliative care consultation is good

% code status at initial consult and discharge

% with symptom improvement from 1st to 2nd assessment

<table>
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<tr>
<th></th>
<th>Renal disease</th>
<th>Other serious illness</th>
<th>p-value</th>
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<tbody>
<tr>
<td>Pain</td>
<td>67</td>
<td>77</td>
<td>0.9</td>
</tr>
<tr>
<td>Anxiety</td>
<td>92</td>
<td>66</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Nausea</td>
<td>71</td>
<td>78</td>
<td>0.5</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>69</td>
<td>68</td>
<td>0.9</td>
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Capacity is limited

- **Palliative Care**
  - 20% institutions with outpatient palliative care
  - 1 palliative care specialist for every 20,000 adults with serious illness
  - Sometimes lack renal specificity

- **Hospice**
  - Dialysis inconsistent with traditional hospice philosophy
  - Dual hospice & ESRD benefit only if ESRD not terminal illness
  - Private health care insurers (Medicare Administrative Contractors, MACs) determine dual eligibility
  - Hospice formulary does not include erythropoietin stimulating agents
  - In-center hemodialysis is expensive

Paths

- The usual
- Time-limited trial
- Forego dialysis
- Withdraw dialysis
- Palliative approach to dialysis care
A Palliative Approach to Dialysis Care: A Patient-Centered Transition to the End of Life

Vanessa Grubbs, Alvin H. Moss, Lewis M. Cohen, Michael J. Fischer, Michael J. Germain, S. Vanita Jassal, Jeffrey Perl, Daniel E. Weiner, and Rajnish Mehrotra on behalf of the Dialysis Advisory Group of the American Society of Nephrology

Goal: Achieving standard dialysis care metrics
Focus: Rehabilitation

Goal: Achieving patient-centered metrics
Focus: Symptom control and goals of care

Conventional approach to dialysis care
Palliative approach to dialysis care

Dialysis initiation
Prognosis less than 1 year
Death

Grubbs et al. CJASN, 2014.
What is a palliative approach to dialysis care?

- Maintenance dialysis patients in last year of life
- Shift from conventional disease-oriented to patient-centered approach
- Prioritizes comfort and alignment with patient preferences and goals of care
- Goal to improve quality of life and reduce symptom burden
Understands that dialysis is not all bad…

- Life extension
- Symptom relief
- Improved quality of life
- Social aspects

…but it ain’t all good either

- Procedures for access
- Time spent undergoing dialysis
- Increased hospitalizations and setbacks
- Symptoms related to dialysis or its complications

Which of the following is most consistent with a palliative approach to dialysis care?

A. Maintaining statin
B. Achieving minimum dialysis adequacy
C. No binder for phosphorus of 6mg/dL
D. Fistula first, catheter never
E. All of above
F. None of above
Audience Response Question

Which of the following is most consistent with a palliative approach to dialysis care?

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C. No binder for phosphorus of 6mg/dL
D. Fistula first, catheter never
E. All of above
F. None of above
A new standard of care

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<th>Conventional Disease-Focused Approach</th>
<th>Patient-Centered Approach to Dialysis Care</th>
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</thead>
<tbody>
<tr>
<td>Fistula First</td>
<td>Catheter OK</td>
</tr>
<tr>
<td>Minimum kt/V</td>
<td>Lower clearance OK</td>
</tr>
<tr>
<td>Treating cardiovascular risk factors</td>
<td>Hypertension, but not statins, OK</td>
</tr>
<tr>
<td>Dietary restrictions and binders</td>
<td>Limited restrictions</td>
</tr>
<tr>
<td>Routine monthly lab tests</td>
<td>Minimal/No lab tests</td>
</tr>
<tr>
<td>In-center hemodialysis if dependent</td>
<td>Staff-assisted home dialysis</td>
</tr>
</tbody>
</table>

Grubbs et al. CJASN, 2014.
When to consider changing course

- Patient develops severe illness that changes life expectancy
- Patient started on dialysis in setting of AKI with unclear life expectancy/goals of care
- Patient with progressive functional or cognitive decline
- When answer to the “surprise question” is NO

Grubbs et al. CJASN, 2014.
Moss et al. CJASN, 2008.
An easier pill to swallow than foregoing or withdrawal?

- Fear of quick death
- Uncertainty about what lies ahead if abrupt withdrawal
- Equating *foregoing* with *giving up*
- Patient goals
- Cultural expectations
- Nephrologist uncertainty about prognosis
Audience Response Question

What is the “Elephant in the Room” when it comes to ESRD decision-making for older patients?

A. Poverty  
B. Race  
C. Unaddressed symptoms  
D. Access to hospice
What is the “Elephant in the Room” when it comes to ESRD decision-making for older patients?

A. Poverty
B. Race
C. Unaddressed symptoms
D. Access to hospice
“I’m right there in the room, and no one even acknowledges me.”
What is the “Elephant in the Room” when it comes to ESRD decision-making for older patients?

A. Poverty
B. Race
C. Unaddressed symptoms
D. Access to hospice
Maslow’s Hierarchy of Needs, 1943.

- **Physiological needs:** food, water, warmth, rest
- **Safety needs:** security, safety
- **Belongingness and love needs:** intimate relationships, friends
- **Esteem needs:** prestige and feeling of accomplishment
- **Self-actualization:** achieving one’s full potential, including creative activities

Self-fulfillment needs
Psychological needs
Basic needs
Dealing with the elephant

"I suppose I’ll be the one to mention the elephant in the room."

Try: If you were my ______, I would recommend the same.
How can we do better?

- Actively address
- Nephrologist-led
- Conversations over time
- Consider a new path/approach
- Advocate for system change
- Collaborate, not delegate
- Grow workforce
The best path for the person in front of us may not be straight ahead
QUESTIONS?

vanessa.grubbs@ucsf.edu

www.thenephrologist.com

@thenephrologist

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