Did this patient die with hospice?

New questions in caring for patients with ESRD

Lewis M. Cohen, MD
Baystate Medical Center
Renal Palliative Care Initiative

Malene Davis, RN, MSN, MBA
Hospice Care Corporation
Arthurdale, WV 26520
Objectives

• Describe characteristics of the end-stage renal population

• List palliative care needs of the end-stage renal population

• List critical elements of a program for providing hospice care to patients and families facing end-stage renal disease

• Describe strategies for working with dialysis centers and nephrologists
Insights into renal patients and nephrologists

Lewis M. Cohen, MD
Why offer palliative care and hospice services in ESRD?

- Heavy symptom burden
- High mortality rate
- High discontinuation of dialysis rate
- Poor quality of dying
"Just when I thought things couldn’t get any worse!"
Heavy symptom burden (N=80)

- fatigue - highest endorsed
- insomnia (38%)
- cramping (36%)
- pruritis (35%)
- neuropathic symptoms (29%)
- poor spirits (24%)
- N&V (20%)

High mortality rate

• Annual rate (23%) or > 70,000 deaths

• 16%-37% life expectancy (age and sex matched)

• Risk of death of a 45 year old patient with ESRD is 20 times that of a person who is the same age and does not receive dialysis.

• 8% CPR survival to hospital discharge
A ‘GOOD DEATH’

Carmen A. Patavino spent his last day watching his beloved golf on television and talking to visitors in brief sentences, fatigue, not pain, marked his final hours.

His decision to die

Editor’s note: Soon after Carmen A. Patavino decided to stop kidney dialysis, he and his family and his doctor invited the Republican to observe his final hours in the hope that his decisions will help others.

By Patricia Moses

Death came quietly to Carmen A. Patavino. Like a whisper trailing off into air, he closed his eyes.

It was the way he chose to die. Like an increasing number of people, Patavino of Wilbraham decided to end his dialysis treatments and slip into a slumber-like peace.

He was 82.

His family, seated by his bed, had not yet noticed he was gone.

"My dad was a very precise person. Everything was neat as a pin. His ending, the end was as orderly and perfect, and his daughter, Emma Miegel of Wilbraham.

Patavino, normally a voracious man with twinkling eyes, did not welcome his own death easily, however. The man with end-stage renal disease prayed actively for a miracle before he elected to stop dialysis and ultimately hasten his end.

"We’d been hoping he would come to this decision on his own. My mother has been so tired, and we really feel like this is a gift he is giving us," daughter Ann Vincenzo said shortly after her father decided to end dialysis.

But after years on the machine that mechanically cleaned his blood three times a week, Patavino could no longer deny his small body was wearing out. The relief of coming home after treatment had been replaced by a fatigue so dense it almost always stopped him at his kitchen door. His wife of 53 years had to help him remove his jacket just so he could make it through the door.

Over the last decade, cessation of dialysis or withholding it altogether has become a more accepted option for people with end-stage renal disease. Although
High discontinuation rate

- 32% in New England
- 25% in United States
### Symptoms During Last 24 Hours Following Discontinuation (N=79)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>% present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>42</td>
</tr>
<tr>
<td>Agitation</td>
<td>30</td>
</tr>
<tr>
<td>Myoclonus/twitching</td>
<td>28</td>
</tr>
<tr>
<td>Dyspnea/agonal</td>
<td>25</td>
</tr>
<tr>
<td>Fever</td>
<td>20</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>14</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>14</td>
</tr>
<tr>
<td>Nausea</td>
<td>13</td>
</tr>
</tbody>
</table>

Cohen et al. *AJKD*, 2000;36:140-144
### All ESRD Deaths: Post Death Family Questionnaire (N=86)

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Hospital 57%</th>
<th>Nursing Home 14%</th>
<th>Home 27%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was this the preferred place of death?</td>
<td>No 38%</td>
<td>Yes 35%</td>
<td>Not sure 27%</td>
</tr>
<tr>
<td>Was the death peaceful?</td>
<td>No 12%</td>
<td>Yes 64%</td>
<td>Not sure 24%</td>
</tr>
</tbody>
</table>
### Pain in the last week of life

<table>
<thead>
<tr>
<th>Percentage of patients in pain</th>
<th>73.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency</strong></td>
<td></td>
</tr>
<tr>
<td>All of the time</td>
<td>27.4%</td>
</tr>
<tr>
<td>Most of the time</td>
<td>35.5%</td>
</tr>
<tr>
<td>Half of the time</td>
<td>8.1%</td>
</tr>
<tr>
<td>Occasionally</td>
<td>29.0%</td>
</tr>
</tbody>
</table>
### All ESRD Deaths: Post Death Family Questionnaire

#### Pain in the last week of life

<table>
<thead>
<tr>
<th>Percentage of patients in pain</th>
<th>73.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity</strong></td>
<td></td>
</tr>
<tr>
<td>Extreme</td>
<td>35.6%</td>
</tr>
<tr>
<td>Moderate</td>
<td>55.9%</td>
</tr>
<tr>
<td>Not severe</td>
<td>8.5%</td>
</tr>
<tr>
<td><strong>Distress level</strong></td>
<td></td>
</tr>
<tr>
<td>Very much</td>
<td>59.7%</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>20.8%</td>
</tr>
<tr>
<td>Somewhat</td>
<td>19.5%</td>
</tr>
<tr>
<td><strong>Told family member about pain directly</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>70.7%</td>
</tr>
<tr>
<td>No</td>
<td>29.3%</td>
</tr>
</tbody>
</table>
Barriers to the Provision of Hospice Services for ESRD Patients

- Financial disincentives
- Lack of patient awareness of life-limiting nature of ESRD resulting in many not wanting to discuss end-of-life issues
- Nephrologists and dialysis staff lack of familiarity with hospice
- Hospice providers lack of familiarity with ESRD patients and their issues
Who are the Nephrologists? Fellowship Survey

• N=171

• Almost all in 2\textsuperscript{nd} year of Nephrology Fellowship

• 73\% characterized themselves as more inclined towards the technological and scientific, rather than the social and emotional aspects of medical care.
## Fellows Exposure to Palliative Care

**Holley et al.**

<table>
<thead>
<tr>
<th></th>
<th>Geriatric</th>
<th>Critical Care</th>
<th>Nephrol.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed Rotation Focused on Palliative Care</td>
<td>71%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Had Contact with Palliative Care Specialist</td>
<td>80%</td>
<td>46%</td>
<td>45%</td>
</tr>
<tr>
<td>Quality of teaching with respect to end-of-life care rated ‘very good’ or ‘excellent’</td>
<td>53%</td>
<td>34%</td>
<td>15%</td>
</tr>
</tbody>
</table>
During your fellowship, were you explicitly taught to:

- Determine when to refer to hospice
- Respond to request to stop dialysis
- Help with reconciliation and goodbyes
- Assess and manage depression at eol
- Tell patient he/she is dying
- Treat pain

% fellows who received explicit teaching on topic
Lessons from the field: ESRD patients in hospice

Malene Davis, RN, MSN, MBA
Elements of a successful strategy

- Management considerations
- Developing criteria
- Developing service line
- Education
- Outreach
- Data
- Costs
Management considerations

• Open access
• Cost
• Counseling staff
• Staffing issues
Developing Criteria

• Is the renal problem the ‘terminal’ dx?

• Do other co-morbidities exist?

• Major symptoms

• Documentation

• Identifying patients
Building the bridge

- Transportation
- Team – community, health process
Medicare Hospice Benefit

- Covers core services – nurses, social workers, nursing assistants, chaplain
- DME, Rx, Supplies
- All related to the terminal illness
- Volunteers and Bereavement
- Per diem rate based on MSA
Education

• Renal physicians

• Health care professionals

• Community
Outreach

• Marketing strategy
• Dialysis providers
• Nephrologists
Data

• Team effort: Dialysis center and hospice
• Numbers in hospice
• Peritoneal dialysis
• Cost analysis
• Documentation issues
Costs

• Transportation

• Administration

• Dialysis costs

• Staffing issues
Case study

• Referral

• Patient and family assessment

• Goals for care

• Role of team members

• Interventions and outcomes
Summary/ Q&A

• Refer to list of resources for Promoting Excellence presentations

• Additional resources on the website www.promotingexcellence.org

• Questions for presenters