End of Life Care in the Dialysis Unit

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Outline and Objectives

• To explore the rationale for end of life care in the dialysis unit
• To review the current status of end of life care practices in dialysis patients
• To review access to hospice for the ESRD patient
• To present recommendations for improving end of life care in dialysis patients
Rationale for End of Life Care in the Dialysis Unit

• Survival continues to be poor for ESRD.
• Dialysis impacts quality of life on many levels.
• Dialysis may not be the best form of therapy for every patient.
• Elderly patients with significant co-morbidities may not benefit from dialysis.
• Conservative management may confer similar survival chances for some.
Adjusted all-cause mortality in the ESRD & general populations, by age, 2007

Figure 6.6 (Volume 2)


Deaths per 1,000 patient years at risk

<20 | 20-44 | 45-64 | 65+
---|---|---|---
ESRD | Dialysis | Transplant | General Medicare

USRDS 2009
Adjusted mortality rates, by modality & year of treatment

Figure 6.1 (Volume 2)

USRDS 2009
Adjusted cause-specific mortality in the first months of therapy

Incident dialysis patients; adjusted for age, gender, race, & primary diagnosis. Incident dialysis patients, 2005, used as reference cohort.

USRDS 2009
Adjusted cause-specific mortality in the first months of therapy: mortality due to cardiovascular disease, by age

Figure 6.13 (Volume 2)

Incident dialysis patients; adjusted for age, gender, race, & primary diagnosis. Incident dialysis patients, 2005, used as reference cohort.

USRDS 2009
Adjusted cause-specific mortality in the first months of therapy: mortality due to infection, by age

Figure 6.14 (Volume 2)

Incident dialysis patients; adjusted for age, gender, race, & primary diagnosis. Incident dialysis patients, 2005, used as reference cohort.

USRDS 2009
Expected remaining lifetimes (years) of
the U.S. population & of dialysis & transplant
patients, by age, gender, & race

Table 6.b (Volume 2)

<table>
<thead>
<tr>
<th>General U.S. population, 2004</th>
<th>ESRD patients, 2007</th>
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<tr>
<td></td>
<td>All M F</td>
</tr>
<tr>
<td>All races</td>
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<tr>
<td>All</td>
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<tr>
<td>M</td>
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<td>All</td>
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<tr>
<td>M</td>
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USRDS 2009
Predictors of mortality in Medicare patients age 66 & older, by age, gender, race, at-risk group, & comorbidity

Table 5.b (Volume 1)

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<td>66–69</td>
<td>1</td>
<td>1</td>
<td>1.33</td>
<td>1.29 - 1.38</td>
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<td>1.3 - 1.4</td>
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<td>70–74</td>
<td>2.34</td>
<td>2.28 - 2.42</td>
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<td>2.31 - 2.46</td>
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<td>85+</td>
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<td>1.13 - 1.19</td>
<td>1.15</td>
<td>1.12 - 1.18</td>
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<td>Other</td>
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<td>0.8 - 0.9</td>
<td>0.82</td>
<td>0.79 - 0.86</td>
<td>0.85</td>
<td>0.82 - 0.89</td>
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<td><strong>Comorbidity</strong></td>
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<td>No CKD, DM, or CVD</td>
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<td>1.00</td>
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<td>CKD (NDM, non-CVD)</td>
<td>1.99</td>
<td>1.83 - 2.17</td>
<td>1.60</td>
<td>1.47 - 1.74</td>
<td>1.72</td>
<td>1.6 - 1.85</td>
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<td>DM (non-CKD, non CVD)</td>
<td>1.23</td>
<td>1.19 - 1.28</td>
<td>1.22</td>
<td>1.18 - 1.27</td>
<td>1.12</td>
<td>1.08 - 1.16</td>
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<td>CVD (non-CKD, non-DM)</td>
<td>1.84</td>
<td>1.8 - 1.88</td>
<td>1.81</td>
<td>1.78 - 1.85</td>
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<td>CKD+DM</td>
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<td>1.86 - 2.37</td>
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<td>1.84 - 2.28</td>
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<td>CKD+CVD</td>
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<td>2.98 - 3.22</td>
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<td>DM+CVD</td>
<td>2.45</td>
<td>2.39 - 2.51</td>
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<td>Hypertension</td>
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<td>0.8 - 0.82</td>
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<td>0.8 - 0.83</td>
<td>0.81</td>
<td>0.8 - 0.83</td>
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<td>Liver disease</td>
<td>1.70</td>
<td>1.6 - 1.81</td>
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<td>1.69 - 1.9</td>
<td>1.84</td>
<td>1.73 - 1.95</td>
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<td>GI disease</td>
<td>1.24</td>
<td>1.21 - 1.28</td>
<td>1.26</td>
<td>1.22 - 1.3</td>
<td>1.25</td>
<td>1.21 - 1.29</td>
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<td>Cancer</td>
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<td>1.83 - 1.9</td>
<td>1.84</td>
<td>1.8 - 1.87</td>
<td>1.80</td>
<td>1.76 - 1.83</td>
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<td>COPD</td>
<td>1.98</td>
<td>1.94 - 2.01</td>
<td>1.96</td>
<td>1.93 - 1.99</td>
<td>1.95</td>
<td>1.92 - 1.99</td>
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<td>Anemia</td>
<td>1.70</td>
<td>1.67 - 1.73</td>
<td>1.71</td>
<td>1.68 - 1.74</td>
<td>1.72</td>
<td>1.69 - 1.75</td>
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</table>

Point prevalent on January 1 of each year, age 66 & older. Comorbidities identified from claims in prior year, and exclude patients enrolled an HMO, with Medicare as secondary payor, or diagnosed with ESRD in the prior year. Followed from January 1 to December 31 of the year, censored at ESRD date and the end of Medicare entitlement. Results are from multivariable Cox regressions.
Impact of RRT Modalities on QOL

- Freedom
- Autonomy
- Convenience
- Efficacy
- Simplicity

“Choice may be based on perception regarding therapy that minimizes impact of lifestyle.”

Knowledge is Power (ful)

- Patient knowledge linked with AVF choice
- Lower scores linked with older age, lower educational status, nonwhite race
  
  Cavanaugh. CJASN 4:950, 2009

- Patients’ perception of health care system
  - Nonintegrated, insufficient info and support
  - Time trumped clinical markers

- First choice for modality based on lifestyle not clinical outcomes

Age as a Determinant in EOL Decisions

- Risk:benefit ratio especially key for elderly Stage 4 or 5 CKD patients with:
  - Significant comorbidities
  - Severe functional impairment
  - Severe malnutrition

- Age not a contraindication but age-neutral approach not always appropriate
  - Comorbidity the single most important determinant
  - Age and comorbidity additive as predictors of survival

Comparative Survival of CKD Patients over 75 Years with High Comorbidity 2 Score with and without Dialysis

Kaplan-Meier survival curves for those with high comorbidity (score=2), comparing 5 dialysis and conservative groups (log rank statistics <0.001, df 1, P=0.98.)

Informed Consent for Elderly CKD Patients

• Dialysis may not confer a survival advantage
• Patients with this level of illness more likely to die than live long enough to progress to ESRD
• Life on dialysis entails burdens likely to detract from their quality of life (access surgeries)
• The majority of patients in their condition die or succumb to significant functional decline during their first year on dialysis

Revised RPA Guideline for Shared Decision Making – personal communication (A Moss)
Conservative Management

• Survival benefit for selected sicker patients choosing dialysis over palliative care is small
  – And not uniform

• No survival benefit to dialysis in the sickest
  – Ischemic heart dz with one comorbidity
    • Murtagh 2007
  – Lower functional status with comorbidities
    • Smith. Clin Nephron Practice 2003
Current Status of End of Life Care Practices in Dialysis Patients

• Dialysis is the standard of care for ESRD, though early withdrawal not uncommon.
• Prevalence and impact of cognitive impairment in ESRD underappreciated
• End of life care discussions not universally provided
• Prognosis estimates evolving
Dialysis withdrawal & hospice status in deceased ESRD patients

Figure 6.17 (Volume 2)
Withdrawal & hospice status, by age

Figure 6.18 (Volume 2)

Dialysis Withdrawal and Hospice

(status of deceased patients, USRDS 2001 to 2002 cohort\textsuperscript{a})

<table>
<thead>
<tr>
<th>Dialysis Withdrawal and Hospice Status</th>
<th>Deceased ((N = 115,239))</th>
<th>Mean Age (yr)</th>
<th>% F</th>
<th>Race (%)\textsuperscript{b}</th>
<th>Mean Mos of Dialysis</th>
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<tr>
<td>Hospice, yes</td>
<td>15,565</td>
<td>13.5</td>
<td>73.4 ± 11.0\textsuperscript{c}</td>
<td>51.1\textsuperscript{c}</td>
<td>74.0 16.3 7.7 1.9 32.1 ± 34.7\textsuperscript{c}</td>
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<tr>
<td>Hospice, no</td>
<td>99,674</td>
<td>86.5</td>
<td>68.6 ± 13.4</td>
<td>48.1 55.3 30.7 10.0 4.0</td>
<td>37.0 ± 37.7</td>
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<tr>
<td>Withdrawal, yes</td>
<td>25,075</td>
<td>21.8</td>
<td>72.7 ± 11.8\textsuperscript{d}</td>
<td>52.4\textsuperscript{d}</td>
<td>73.1 16.4 7.5 3.0 33.1 ± 34.9\textsuperscript{d}</td>
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<td>hospice, yes</td>
<td>10,518</td>
<td>41.9</td>
<td>73.9 ± 10.6</td>
<td>51.8 76.8 13.6 7.7 1.8 32.3 ± 34.1</td>
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<td>hospice, no</td>
<td>14,557</td>
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<td>71.7 ± 12.3</td>
<td>52.8 70.4 18.5 7.4 3.8 33.7 ± 35.6</td>
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<td>Withdrawal, no</td>
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<td>70.8</td>
<td>68.0 ± 13.4</td>
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<td>71.7 ± 11.7</td>
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<td>hospice, no</td>
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<td>96.6</td>
<td>67.9 ± 13.5</td>
<td>47.4 52.2 33.0 10.7 4.1 37.5 ± 37.8</td>
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<td>Withdrawal status unknown</td>
<td>8540</td>
<td>7.4</td>
<td>71.1 ± 13.2</td>
<td>47.4 64.1 27.0 6.1 2.8 35.6 ± 44.6</td>
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</tbody>
</table>

\textsuperscript{a} Data are means ± SD. B, black; Hisp, Hispanic; O, other; USRDS, US Renal Data System; W, white.

\textsuperscript{b} Race was significantly associated with both withdrawal and hospice status.

\textsuperscript{c} Significant at \(P < 0.001\) on bivariate tests of association between variable and hospice, yes, versus hospice, no.

\textsuperscript{d} Significant at \(P < 0.001\) on bivariate tests of association between variable and withdrawal, yes, versus withdrawal, no.

Cognitive Impairment

• Common in dialysis patients
  – 30-35% prevalence overall
    • Sehgal AJKD 1997, Kurella J Am Geriatr Sco 2004

• Common in those > 55
  – Mild in 14%
  – Moderate in 36%
  – Severe in 37%
    • Murray, Neurology 2006
Cognitive Impairment

- Affects decision-making capacity
- Affects meaningful participation in care
- Affects ability to understand and accept suffering and other burdens of dialysis
- Impacts legal requirements for full disclosure and informed consent
End of Life Care Preferences
Survey of 584 Stage 4-5 CKD patients

- EOL care needs not integrated into renal care
- Patients had poor knowledge of palliative care options and illness trajectory
- Large number (61%) regretted decision to start dialysis!
- Majority of patients wanted to die at home (36%) or in inpatient hospice (29%).
- Less than 10% had discussed EOL care with nephrologist.

Prognosis

• Estimates should/will impact course of action
• Dated and documented discussions may facilitate informed decision making
• Estimates can be used to develop consensus on goals of therapy and care
• Early and continued discussion may facilitate reassessment in the event of complications that reduce survival or quality of life
Prognosis Estimates of CKD-ESRD

• Comorbidity score:
  – 3 for CHF
  – 2 for CVA/TIA, PVOD, COPD, GIB, non-ASHD cardiac, liver dz, cancer
  – 1 for ASHD, DM


• Surprise question:
  – Would I be surprised if this patient died in the next year?


• Integrated 6-month prognostic tool:
  – Older age, dementia, PVOD, decreased albumin and the surprise question

Access to Hospice for the ESRD Patient

• Barriers to hospice in ESRD patients
• Experience with hospice in ESRD
• Medicare Hospice Benefit:
  – Explanation
  – Interpretation
  – Coverage for ESRD patients
Barriers to Engaging Hospice for ESRD Patients

- Patients
- Physician providers
- Payers
- Hospice providers

Underutilization of hospice in ESRD is fostered by confusion with regard to eligibility and variability of providers and payers with regard to ESRD patients.
Barriers - 2

• Payer:
  – Variable interpretation of Medicare benefit for ESRD patients wishing hospice (federal issue)
  – Variable interpretation of terminal diagnosis requirements for hospice (local issue)

• Hospice provider:
  – Withdrawal required or encouraged on philosophical grounds
  – Hospice must pay for dialysis if terminal diagnosis is ESRD and dialysis is continued
Barriers

• Patient:
  – Stigma associated with cancer and hospice
  – Magnitude of illness denied or not understood
  – Confusion about eligibility
  – Withdrawal thought to be prerequisite

• Physician provider:
  – Reticence to assert 6 month survival
  – Lack of knowledge about acceptable diagnoses
  – Withdrawal thought to be prerequisite
Medicare Coverage

Medicare (administered by CMS and local contractors)

Part A
Hospital Insurance Benefits
- Hospital inpatient services
- SNF* services
- Certain home health services
- Hospice care
- ESRD services

Part B
Medical Insurance Benefits
- Physician services
- Hospital outpatient services
- Medical equipment and supplies

Part C
Medicare Advantage (formerly Medicare+Choice)
- Medicare managed care
- Provides at least comparable benefits
- Flexible benefit structure

Part D
Prescription Drug Coverage
- Private health plans provide prescription benefits only
- At least 2 plans in each state
- Over 10 national plans
- Low-income assistance

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Medicare Coverage of Hospice
General Process

• Home Health/Hospice benefit is by National Coverage Decision (NCD)
• Interpretation of NCD made by responsible Medicare Administrative Contractor (MAC)
• Local Coverage Decisions (LCD) determining eligibility for hospice are set forth by the four A/B MACs responsible for HH/H MAC Jurisdictions A-D
• The four A/B MACs responsible for hospice include Highmark Medicare Services, now the claims processor for Jurisdiction 15 and which includes PA (HH/H MAC B)
10 - Requirements - General

(Rev. 22, Issued: 09-24-04, Effective: 12-08-03, Implementation: 06-28-04)

Hospice care is a benefit under the hospital insurance program. To be eligible to elect hospice care under Medicare, an individual must be entitled to Part A of Medicare and be certified as being terminally ill. An individual is considered to be terminally ill if the medical prognosis is that the individual’s life expectancy is six months or less if the illness runs its normal course.
Section §1814(a)(7) of the Social Security Act (the Act) specifies that certification of terminal illness for hospice benefits shall be based on the clinical judgment of the hospice physician and the individual’s attending physician if he/she has one or the medical director regarding the normal course of the individual’s illness. No one other than a medical doctor or doctor of osteopathy can certify or re-certify a terminal illness. Predicting of life expectancy is not always exact. The fact that a beneficiary lives longer than expected in itself is not cause to terminate benefits. “Attending physician” is further defined in Section 20.1 and 40.2.5.
An individual (or his authorized representative) must elect hospice care to receive it. The first election is for a 90-day period. An individual may elect to receive Medicare coverage for an unlimited number of election periods of hospice care. The periods consist of two 90-day periods, and an unlimited number of 60-day periods. If the individual (or authorized representative) elects to receive hospice care, he or she must file an election statement with a particular hospice. Hospices obtain elections from the individual and forward them to the intermediary, which transmits them to the Common Working File (CWF) in electronic format. Once the initial election is processed, CWF maintains the beneficiary in hospice status until death or until an election termination is received.
An individual must waive all rights to Medicare payments for the duration of the election/revocation of hospice care for the following services:

- Hospice care provided by a hospice other than the hospice designated by the individual (unless provided under arrangements made by the designated hospice); and

- Any Medicare services that are related to the treatment of the terminal condition for which hospice care was elected or a related condition or services that are equivalent to hospice care, except for services provided by:
  
  1. The designated hospice (either directly or under arrangement);

  2. Another hospice under arrangements made by the designated hospice; or
Chapter 9, Section 10
General Requirements for Hospice

3. The individual’s attending physician, who may be a nurse practitioner if that physician or nurse practitioner is not an employee of the designated hospice or receiving compensation from the hospice for those services. Medicare services for a condition completely unrelated to the terminal condition for which hospice was elected remain available to the patient if he or she is eligible for such care.
Medicare Benefit for ESRD

Online:

In print:
Medicare Benefit Policy Manual
Chapter 11 - End Stage Renal Disease

Medicare Benefit Policy Manual
Chapter 11 - End Stage Renal Disease (ESRD)

Table of Contents
(Rev. 67, 03-09-07)
50.6.1 - Home Health and Hospice Benefits Available for ESRD Beneficiaries

(Rev. 1, 10-01-03)

PASS Merritt004 memo

Medicare patients can receive care under both the ESRD benefit and the home health or hospice benefits. The key is whether or not the services are related to ESRD. Surgical dressing changes that are related to an ESRD condition are to be provided by the dialysis facility, but dressing changes for non-ESRD conditions may be provided under the home health benefit provided all eligibility criteria have been met.
Chapter 11, Section 50
Requirements for Hospice in ESRD

50.6.1.1 - Coverage Under the Home Health Benefit for ESRD Patients (Rev. 1, 10-01-03)

Services that are covered under the composite rate are excluded from coverage under the Medicare home health benefit.

However, services can be provided to dialysis patients under the home health benefit as long as the condition that necessitates home health care is not included in the composite rate. A beneficiary, entitled to Medicare under the ESRD program, is eligible for home health benefits as is any other Medicare beneficiary if coverage conditions are met provided the patient’s condition is not covered by the composite rate. This is true even where the primary condition is related to kidney failure.

A beneficiary may receive covered services under both the home health benefit and the ESRD benefit. Therefore, when ESRD patients meet all the eligibility criteria for coverage of home health services, Medicare will pay for home health care, such as decubitus care or for severe hypotension that is not included in the composite rate. See 42 CFR 409.49(e).
50.6.1.4 - Coverage Under the Hospice Benefit

(Rev. 1, 10-01-03)

If the patient’s terminal condition is not related to ESRD, the patient may receive covered services under both the ESRD benefit and the hospice benefit. A patient does not need to stop dialysis treatment to receive care under the hospice benefit. Consequently, hospice agencies can provide hospice services to patients who wish to continue dialysis treatment.
Current Benefit for ESRD Patients

• CMS provides hospice benefit for ESRD patients
• ESRD may be used as the terminal diagnosis for hospice benefit in those patients:
  – who withdraw from dialysis
    » OR
  – for whom hospice agrees to cover the ESRD benefit
• A non-ESRD terminal diagnosis is required for ESRD patients choosing to continue dialysis, retain their ESRD benefit, AND be covered with hospice benefit
Current Benefit – cont.

ESRD diagnosis may be used if patient is not seeking dialysis or transplant and:

– Cr clearance < 10 ml/min (15 for DM)
– Serum creatinine > 8 (6 for DM)
– Signs/symptoms of renal failure
Explanation of Benefit

• A beneficiary with ESRD may be covered under the Medicare hospice benefit for services related to the terminal diagnosis.

• Services not related to the terminal diagnosis are not covered under the hospice benefit.

• When a beneficiary with ESRD has a terminal diagnosis other than ESRD, the beneficiary may elect the hospice benefit and continue dialysis for palliative reasons.
ESRD beneficiaries with a non-ESRD terminal diagnosis who elect the hospice benefit but wish to continue dialysis may be covered under both the hospice benefit and the ESRD benefit.

– Services related to the terminal (non-ESRD) diagnosis would be covered under the hospice benefit.

– Services related to ESRD (eg. dialysis) would be covered under the ESRD benefit.
Bottom Line

• ESRD patients wishing to engage hospice and withdraw from dialysis may use ESRD as the terminal diagnosis for the hospice benefit.

• ESRD patients wishing to engage hospice without withdrawal from dialysis must:
  – Have a terminal diagnosis other than ESRD to qualify for the hospice benefit AND retain their ESRD benefit.
  
  OR

  – Forego their ESRD benefit and engage a hospice willing to cover pay for ESRD services (dialysis) as part of the hospice benefit.
Bottom Line

• Withdrawal from dialysis not a prerequisite for ESRD patients wishing to engage the hospice benefit.

• Individual hospice entities have the option to choose NOT to accept ESRD patients.
Recommendations for Improving EOL Care of CKD Patients

- Identify patients likely to benefit from palliative care interventions
- Screen for and manage pain and physical sx routinely
- Screen for and manage emotional, psychosocial and spiritual distress
- Assess patients’ desire for prognostic information
- Enhance dialysis education and include conservative care and available palliative care services
- Routine advance care planning
- Increase access to specialist palliative care
- Provide bereavement support to patients’ families
Conclusions

• Practice shared decision making
• Evaluate patient and family values
• Discuss diagnosis and estimate prognosis
• Fully disclose all treatment options including associated risks and benefits
• Recognize special considerations of the elderly
• Consider propriety of conservative approach
References and Resources

• End of Life Coalition – ESRD Network 5
  – http://www.kidneyeol.org/advanced.htm

• Medicare and Coverage
  – http://www.cms.gov/MedicareContractingReform

• Medicare and Hospice
  – http://www.cms.hhs.gov/providers/hospiceps/

• Renal Physicians Association Clinical Practice Guideline on Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis
  – http://renalmd.org