Online Dialysis Patient Webinar Presentations

Relevance of Palliative Care and Hospice

Alvin H. Moss, MD

Pain Assessment and Management

Sara Davison, MD

Symptom Assessment and Management

Steven Weisbord, MD

Incorporating Palliative Care into the Dialysis Unit

Michael Germain, MD
For additional information, including resources for patients and families, visit [www.kidneyeol.org](http://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
Planning a Renal Palliative Care Program and its components

Michael Germain
Professor Medicine Tufts University
Baystate Medical Center
Springfield MA
Objectives

- Describe a systemized approach developing a renal palliative care program.
- Awareness of resources available to assist in a strong program.
- Recognize how to improve the rate of “good deaths” in CKD patients.
- How to develop closer tie between hospice and dialysis unit.
Age Affects Outcomes in Chronic Kidney Disease

Ann M. O’Hare,* Andy I. Choi,† Daniel Bertenthal,‡ Peter Bacchetti,§ Amit X. Garg,‖ James S. Kaufman,¶ Louise C. Walter,‖ Kala M. Mehta,‖ Michael A. Steinman,‖ Michael Allon,** William M. McClellan,†† and C. Seth Landefeld†

What are the Benefits of dialysis in a 75 year old with co-morbidities?

• Does dialysis offer a Survival benefit?
• No difference in survival if a patient choose dialysis vs “conservative” management if patient has IHD or 2 co-morbids
• Does dialysis improve QOL?
• QOL and suffering is being studied in conservative vs dialysis management but antidotal evidence supports a peaceful death in most patients and “uremic” deaths are uncommon (most pts die prior to uremia)
RPCI Components of a Renal Palliative Care Program

- **A Palliative Care Focus**
  - Educational activities (in-services)
  - QI activities (M & M conferences)
  - “Would you be surprised…?”

- **Pain & Sx Assessment & Management Protocols**

- **Systematized Advance Care Planning/POLST**

- **Psychosocial and Spiritual Support (peer counselors)**

- **Terminal Care Protocol (includes hospice)**

- **Bereavement Program (includes memorial service)**
The Basics

- Estimate Prognosis-identify poor prognosis pts
- Set Default expectations of care
- Use POLST (Physician Orders for Life Sustaining Therapies)
- Have a system to communicate prognosis and make care plans with patient and family.
- Have systems in place to implement POLST and palliative protocols
To have a successful advance care planning program, it is essential to create and maintain a **system** for effective advance planning!!!
HD MORTALITY PREDICTOR

Programmed by Stephen Z. Fadem, M.D., FASN

SERUM ALBUMIN
3.5 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 65 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.

X BETA: -154.59
Predicted Six Month Survival: 89%
Predicted Twelve Month Survival: 74%
Predicted Eighteen Month Survival: 60%


Supporting data table
• Withdrawal from dialysis is not uncommon and, though often occurring in the setting of a major change and crisis in a patient’s condition, the decision may take place in the setting of more gradual and chronic changes.

• Many patients “eligible” for dialysis are refusing to start and/or are not being “offered” dialysis treatment.
Withdrawal of Dialysis: Findings from a Prospective Study

Reasons for Withdrawal

- Unacceptable quality of life or failure to thrive
- Acute complications
- Dementia
- Stroke
- Malignancy
- Other
The Baystate Dialysis Discontinuation Study

- Prospective cohort
- 6 Dialysis clinics in the US and 2 in Canada
- 131 Withdrawal deaths and 79 patients recruited along with a family member
Demographics

• 59% female
• 70±1.2 years old
• 73% white; 22% black; 6% Asian or Hispanic
• 34±2.8 months duration of dialysis
• 77% had 3-7 comorbid illnesses
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Data on How ESRD Patients Die

- Families report “satisfactory” in 85%
- BUT pain noted in 42% and agitation in 30% during final day of life
  
- Note: other studies that confirm similar data and persistence of many adverse symptoms even during course of chronic dialysis
  
  (Germain et al. ASN 2000)
Symptoms During Last 24 Hours

(Cohen et al. AJKD 2000)
Death

- 8.2±2.8 days (range 1-46 days)
- 61% in hospital, 24% in nursing home, 15% in home/hospice
Quality of Dying

- The experience of death for the patient and the family will vary, largely depending on:
  - Patient-family “psychological” make-up and preparation
  - Specifics of the medical condition
  - Location of death
  - The availability of comprehensive, skillfully applied palliative care
Good Death

• Painless or largely pain-free
• Happening in the company of loved-ones
• Peaceful
• Asleep
• At home
• Mentally alert
Three Domains of QOD

- Duration
- Psychosocial
- Symptoms
Baystate QOD Measure

- 15% bad deaths
- 47% good deaths
- 38% very good deaths
QOD Analysis

- Older patients (P=.03)
- Females (P=.03)
- Location
  - 1/11 in hospice/home had low scores
  - 41% from hospital had low scores
The Long-Term Impact of Dialysis Discontinuation on Families

- 26 of 39 (66%) Western New England subjects from dialysis termination study
- 55 months (44-64 months)
- Deceased patient characteristics (65% female, 74 years old, 3 years dialysis, survived 8 days (1-34)
- Respondent characteristics (spouses (27%), adult children (42%), siblings (12%), other relatives (19%), primary caretaker (58%))
Dialysis Discontinuation Follow-up Study

- Impact of Event Scale administered to 26 (66% of convenience sample) at 55 months following patient deaths
- Low overall level of distress
- Intrusiveness highest for spouses and primary caregivers
- More comfortable with decision than originally

The Long-Term Impact of Dialysis Discontinuation on Families

- Location of deaths (hospital (42%), nursing home (31%), or the patient’s home (27%))
- ACP (69% had health care proxies, 46% living wills)
- ACP instruments were helpful in 45% of cases and of no benefit in 45% (the rest were undecided)
Figure 1. Comparison of IES between the Tilden and Baystate samples.

Y-Axis is the IES score, X-Axis is the time elapsed after the deaths, “1-2 months” is Tilden’s sample, “6 months” is also Tilden’s sample, and “55 months” is the Baystate long-term follow-up sample.
Renal Palliative Care in USA

- RPCI
- Sharing the Caring-NIH study of hospice use
- Syllabus for nephrology training program
- RPA/ASN: statement on quality care at EOL.
- RPA/ASN: Guidelines “Initiation and Withdrawal from Dialysis: Shared Decision Making”
- RWJ workgroups-work products
  http://www.promotingexcellence.org/
- **Kidney End-of-Life Coalition**
  http://www.kidneyeol.org/index.htm
KIDNEY END-OF-LIFE COALITION

Dedicated to End-of-Life Care for Kidney Patients

Mission: To promote effective interchange between patients, families, caregivers, payers, and providers in support of integrated patient-centered end-of-life care of chronic kidney disease (CKD) patients.

There are over 320,000 people receiving dialysis therapy in the United States and over 45% are over the age of 60. Despite many dialysis patients having significant co-morbid conditions that affect their care, they have a high quality of life and can be expected to enjoy extra years of life afforded by dialysis. However, this is not true for all patients. About 20% of patients withdraw from dialysis prior to death, and many die from heart disease, infections, and other causes while continuing dialysis. For these patients, end-of-life care is an important part of their treatment plan.

This website is dedicated to those patients and to all the caring staff in hospitals, dialysis units, and hospice organizations who are committed to helping patients with death, the final stage of growth. (1)

This website has been developed by the Kidney End-of-Life Coalition and is intended to be a dynamic site with links to many other websites and resources addressing end-of-life concerns. Contact us with questions; your feedback is always appreciated.

(1) DEATH, The Final Stage of Growth by Elizabeth Kubler Ross, Touchstone, 1997.
The Kidney EOL Coalition

**Mission:** To promote effective interchange between patients, families, caregivers, payers, and providers in support of integrated patient-centered end-of-life care of chronic kidney disease (CKD) patients

- Funded through the ESRD networks-CMS
- Workgroups have: MD, RN, SW, RD, patients, family, network administrators
- Please email feedback if you view the website
Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

rpa@renalmd.org
301.468.3515
Recommendations from the RPA Guidelines

- Shared Decision making
- Informed consent or refusal
- Estimate Prognosis
- Conflict Resolution
- Advanced Directives
- Withholding or withdrawal from dialysis: a patient and or family’s right. Patients with profound irreversible neurological impairment, pts terminally ill and illness that technically precludes dialysis
- Time-limited trial of dialysis
- Palliative care
Downloadable tools for a PDA from the Guideline “Initiation and Withdrawal from Dialysis: Shared Decision Making” (www.renalmd.org)

The following documents have been optimized for use on the Palm Platform with Documents to Go if you have an m series or newer Palm this program is standard. Otherwise click here to download.

- Prognostic Tables 5-9
- Prognostic Tables 10-15
- Mini-Mental State Exam
- Karnofsky Performance Status Scale
- Suggested Steps for Implementing Advance Directive Recommendation Checklist Regarding Shared Decision Making
- Evaluation of Patient or Family Request to Stop Dialysis
- Examples of Questions to Help Discuss End of Life Care
- I&WCPG Recommendations Summary
- Assessing Decision Making Capacity
RPA/ASN Statement on Quality Care at the End of Life

6. Nephrologists should explicitly include in their advance care planning...information about the outcomes of CPR for patients with ESRD and a discussion of patients’ preferences regarding CPR if cardiac arrest were to occur while patients are undergoing ...dialysis... The RPA/ASN encourages dialysis facilities to develop policies and procedures for respecting the wishes of dialysis patients with regard to CPR in ... the dialysis unit.
3. After a decision is made to forgo dialysis, the renal team should refer the patient to a hospice or adopt a palliative care approach to patient care. In either case, the nephrologist and other members of the renal team should remain active in the patient’s care to maintain continuity of relationships and treatment.
4. Nephrologists and other members of the renal team should obtain education and skills in advance care planning so that they are comfortable addressing end-of-life issues with their patients.
5. Dialysis facilities should develop protocols, policies, and/or programs to ensure that advance care planning is conducted with their patients.
RPA/ASN Statement on Quality Care at the End of Life

**Recommendations**

1. All members of the renal health care team including nephrologists, nephrology nurses, nephrology social workers, and renal dietitians should obtain education and skills in the principles of palliative care to ensure that ESRD patients and families receive multidimensional, compassionate, and competent care at the end of life.
2. In responding to an ESRD patient/surrogate decision to forgo dialysis, the nephrologist is obligated to determine, if possible, why the patient/surrogate has decided to forgo dialysis ... Once the nephrologist is satisfied that the patient’s decision to forgo dialysis is informed and not coerced, the nephrologist should respect the wishes of the patient/surrogate.
Supportive Care for the Renal Patient

Edited by
E. Joanna Chambers
Michael Germain
Edwina Brown
His decision to die

Editor's note: Soon after Carmine 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 decision will help others.

BY PATRICIA MORRIS
Staff writer
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Death came quietly to Carmine A. Patavino. Like a whisper trailing off into air, he closed his eyes. It was the way he wanted it.

It was the way he chose to die. Like an increasing number of people, knowing Carmine was nearing the end, the family decided to end dialysis treatments and drift into a manner-like peace.

He was 74.

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, his exit, was as orderly and perfect," said his daughter, Emma Migdel of Wilbraham.

Patavino, normally a very private man, in brief sentences. Fatigue, not pain, marked his final hours.

His mother has been so tired, and we really feel like this is a gift he is giving us," said Daughter Ann Vincenzo about shortly after her father decided to end dialysis.

"I'd been hoping he would come to this decision on his own.

But after years on the machine that mechanically cleansed his blood three times a week, Patavino could no longer deny his small body was wearing out. The ordeal of coming home after treatment and being replaced by a fatigue so bone deep it almost always stopped him at his kitchen door. His wife of 63 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 acceptable option for people with end-stage renal disease. Although
For Further Information

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