ESRD Network Meeting
What's New in Renal Palliative Care

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Baystate Renal Palliative Care Initiative

The rationale for expanding palliative care

- One of the rationales for providing universal health insurance coverage for this single category of disease was the hope and expectation that dialysis therapy would not only extend life, but enable many patients disabled by ESRD to return to work or their normal activities.

Reality in the US

- Patients over the age of 75 have higher incidence rates of ESRD than younger patients and constitute the fastest growing segment of the ESRD population in the United States
- Only 19% of patients under the age of 55 are employed
- Dialysis may not substantially prolong life for some patients

Conservative Management

- In two studies, median survival was similar among elderly patients receiving non-dialytic management of ESRD as compared to elderly patients who started dialysis with coexisting ischemic heart disease, or elderly patients who started dialysis after emergency referral

Despite Poor Survival

- Advance care planning occurs infrequently
- Rates of hospice use before death among patients with ESRD are less than half that seen among patients dying of cancer, even among patients with ESRD who choose to withdraw from dialysis before death
- Most patients with ESRD die in the hospital, often in an intensive care setting after undergoing expensive and invasive medical tests and therapies, while suffering with pain or other distressing symptoms

Weakness of Current Management

- Half of all hemodialysis patients report pain symptoms which are often inadequately controlled with medication
- One-third have severe cognitive impairment
- In Kurella's sample of Nursing Home patients begun on dialysis, after one year 58% had died, 29% had a decrease in functional status, only 13% maintained functional ability, and there were no data suggesting function had improved for any subjects

More Bad News

- In a recent survey of Canadian ESRD patients, 60% said they regretted beginning dialysis; just over half of these patients indicated that they began the treatment because of the urging of their physician

Therefore….

- The question is not *whether* palliative care should play an expanded role in ESRD management – clearly it should. The question is *how* to expand palliative care in a way that is appropriate for an individual patient's stage of disease and congruent with his or her preferences and values

NON SEQUITUR
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Palliative or Supportive Care

- WHO defines palliative care as treatment that strives to improve quality of life and relieve suffering for patients with life-threatening illness and their families
- Focus on relieving pain and other distressing symptoms rather than curing disease or delaying disease progression

Palliative or Supportive Care

- Integration of psychosocial and spiritual needs with medical care
- Coordination of medical and social services
- Creation of a support system to help the patient and family cope with illness and prepare for death
- Delivered at any point during the course of an illness and can be provided in conjunction with curative or life-extending therapy

Delivery Steps

- (1) Estimation of prognosis and explanation of treatment options
- (2) Advance care planning
- (3) Symptom assessment and management
- (4) Timely hospice referral and bereavement support

Physicians Hesitate to Communicate Prognosis

- Patients and families want the information
- Staff concern about loss of hope is unfounded
- New prognostic instruments
- Training in communication
- Value of relying on the dialysis team

Communicating Bad Prognosis Think of the patient and family as one unit

- Trained surrogate communicator with the MD (social worker?)
- Empathetic listening- what does the patient already know
- Give an "aggressive" plan; symptom relief, palliative services, more care - not less
- Shared decision making but ultimately an MD order (POLST).
- Make the default palliative care

Reasons for ACP

- Studies of patients with other life-limiting illnesses, patients who had end-of-life discussions with a health care provider accrued fewer health care costs, used less invasive or burdensome procedures, and entered hospice care earlier and more frequently
- Davison's patient-centered ACP model for ESRD ensures that end-of-life care is consistent with patient preferences

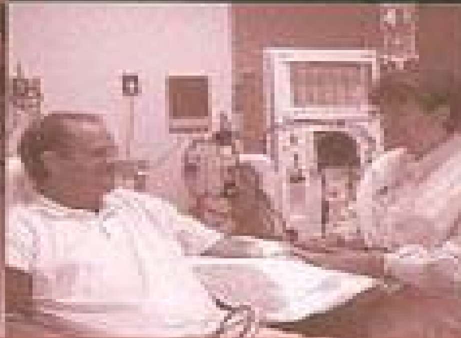
Hospice

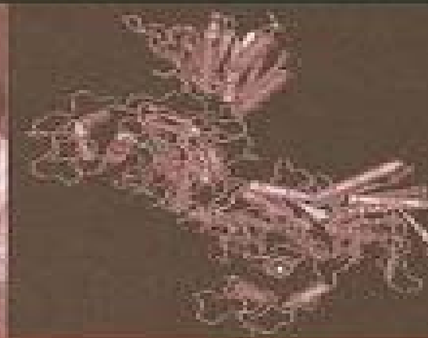
- ESRD patients spend an average of only 14 days in hospice, in contrast to the average of 59 days for patients with other diseases, suggesting that they are referred late in the dying process
- Only one-in-five dying dialysis patients currently receive hospice care—about half that of national figures for overall deaths in the United States and one-fourth that of people dying from cancer

Recent Advances

- Second edition of the textbook on Supportive Care for the Renal Patient
- Second iteration of the Guidelines for the Initiation and Discontinuation of Dialysis
- Recognition for inadequate training in fellowships and creation of syllabus with the publication of the Geriatric Nephrology Curriculum

OXFORD
SUPPORTIVE CARE





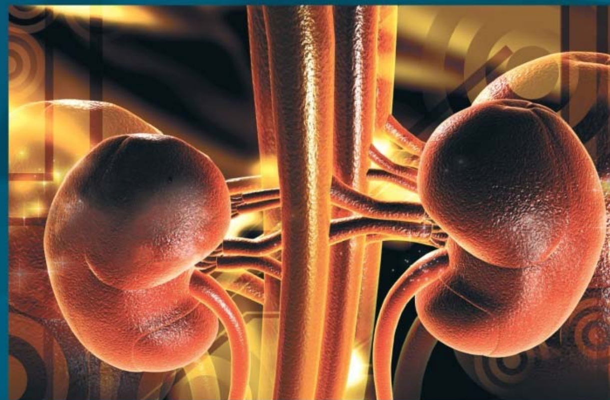
Supportive Care for the Renal Patient

Edited by
E. Joanna Chambers
Michael Germain
Edwina Brown

Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Clinical Practice Guideline

Second Edition



RPA
Renal Physicians Association

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Thanks to Dr. Woody Moss for his slides on the new guidelines!

What's New in the Guideline

- Recognition of advance care planning as the preferred approach for decision-making for patients who lose decision-making capacity
- The under treatment of pain in dialysis patients
- The underutilization of hospice in dialysis patients
- Strategies to assist nephrologists with communication challenges regarding prognosis and treatment options
- Recommendations with regard to pediatric dialysis decision-making

What's New in the Guideline

- The poor prognosis of some elderly stage 4 & stage 5 chronic kidney disease patients, many of whom are likely to die prior to initiation of dialysis or for whom dialysis may not provide a survival advantage over medical management without dialysis
- An online calculator to estimate prognosis in ESRD patients http://touchcalc.com/calculators/sq
- The frequent prevalence of cognitive impairment in dialysis patients
- The identification of distinctly different treatment goals for ESRD patients based on their overall condition and preferences

Different Treatment Goals for ESRD Patients

New in the guideline is the identification of distinctly different treatment goals for ESRD patients based on their overall condition and preferences:

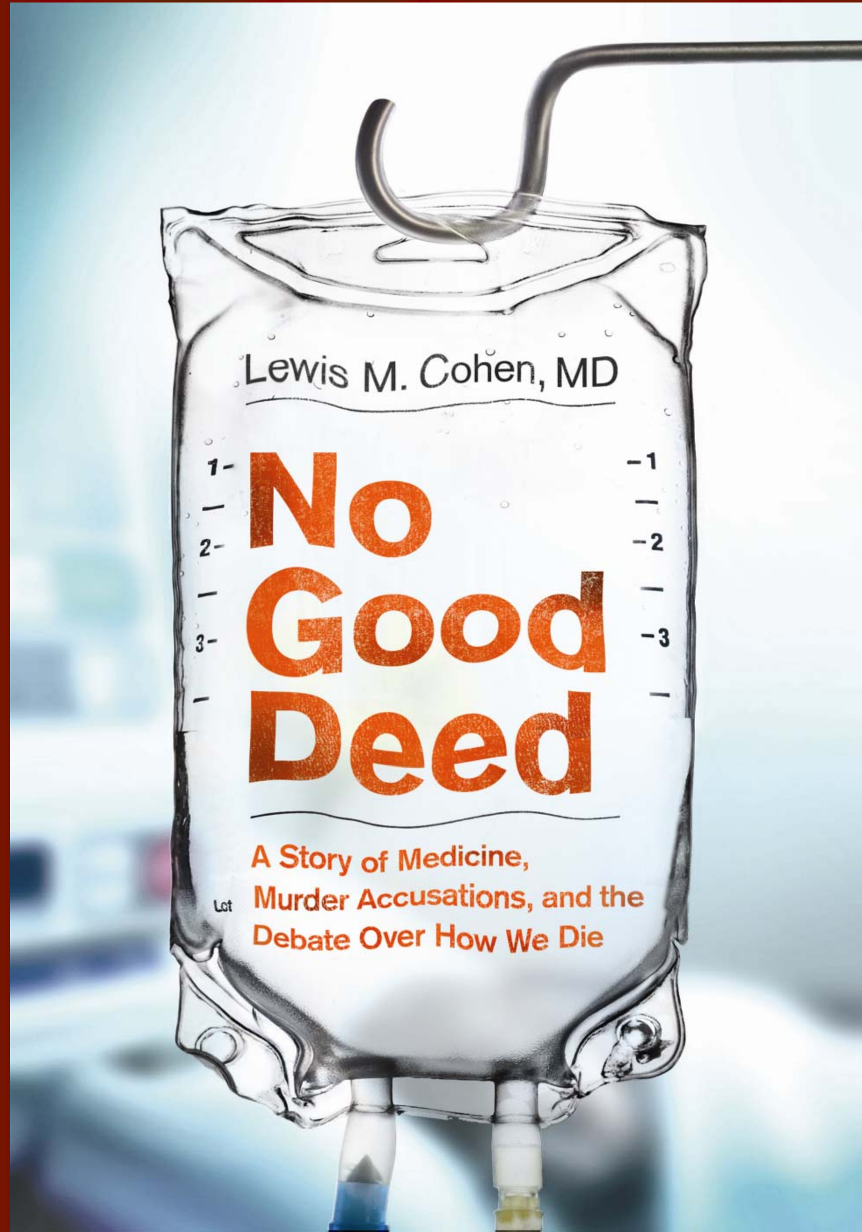
1. Patients who choose aggressive therapy with dialysis without limitations on other treatments
2. Patients with a poor prognosis who choose dialysis but with limitations on other treatments such as cardiopulmonary resuscitations, intubation, and mechanical ventilations because they want to balance life prolongation and comfort
3. Patients who decline dialysis and prefer that the primary goal of care be their comfort

The Guideline Recommends

- Establishing a shared decision-making relationship
- Informing patients
- Facilitating advance care planning
- Making a decision to initiate or discontinue dialysis
- Resolving conflicts about what dialysis decision to make
- Providing effective palliative care

Conclusion

- Over the last few years, great strides have been made in illuminating the need for palliative care in patients with ESRD, and in identifying the outlines of a palliative care model. Testing, refining and disseminating these models into clinical practice will not be easy, but these are challenges that we must meet.



Lewis M. Cohen, MD
No Good Deed
A Story of Medicine, Murder Accusations, and the Debate Over How We Die

Thanks!

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