

Best Practices in End-of-Life Care for Dialysis Patients

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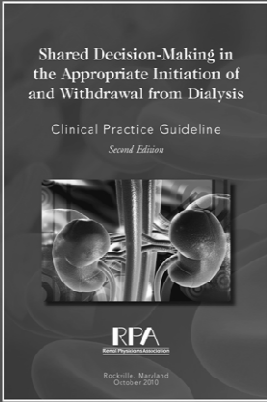
No disclosures.

Objectives

- To describe the essential components of optimum end-of-life care for dialysis patients
- To identify useful resources for end-of-life care of ESRD patients
- To discuss withdrawal from dialysis

Important Resources for EOL Care in Dialysis Patients

- Kidney End-of-Life Coalition
- Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis




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

Clinical Practice Guideline
Second Edition

RFA
Rockville, Maryland
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KIDNEY END-OF-LIFE COALITION



For additional information, including resources for patients and families, visit 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

The Kidney End-of-Life Coalition

www.kidneyeol.org

- Formed from Network 5
- Goal: To promote effective interchange between patients, families, caregivers, payers, and providers in support of integrated patient-centered end-of-life care for chronic kidney disease patients

Kidney EOL Coalition -- history

- Workgroups formed and delivered products to enhance EOL care to the target population
 - Advance care planning
 - Cardiopulmonary resuscitation
 - Patient education
 - Physician/clinician education
 - Hospice
 - Website review

Information and Tools at www.kidneyeol.org

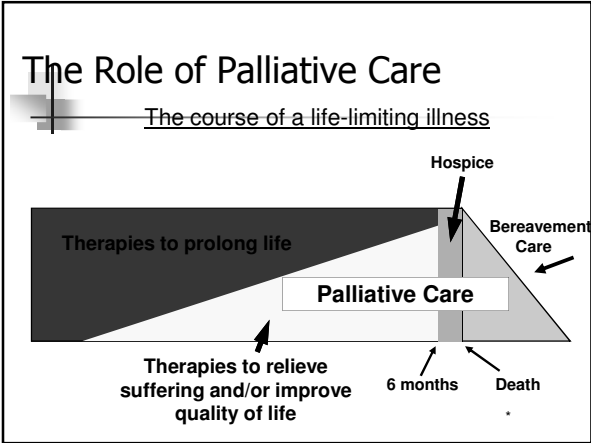
- Guides
 - CPR pt information
 - planning unit memorial svcs
 - funeral home info for units
 - pt resuscitation statement
- Model policies for dialysis units
 - DNR
 - Advance directives for DNR

Information and Tools at www.kidneyeol.org

- Links to organizations
- FAQ
- Powerpoint presentations (ACP, palliative)
- Links to Tools
- Links to patient information (NKF and Kidney Foundation of Canada)

Educational Material at www.kidneyeol.org

- Webinars symptom assessment & management
 incorporating palliative care in dial unit
 pain assessment & management
- Pain management brochure
- Powerpoint presentations
- Links to bibliography, core curriculum, learning modules (ANNA), RWJ Recommendations to the field



Components of a Renal Palliative Care Program


- pain and symptom assessment and management protocols
- systematized advance care planning
- psychosocial and spiritual support (peer counselors, SW)
- terminal care protocols (includes hospice and withdrawal from dialysis)
- bereavement program (includes memorial services)

Essential Components of EOL Care of ESRD Patients

- Advance care planning
- Withdrawal from dialysis
- Hospice referral
- Pain and symptom management
- Spiritual support
- Bereavement programs

Topics in End of Life Discussions

- **Goals of Treatment**
- **Advance Directives**
- **DNR Orders**
- **Other Life Sustaining Therapies**
- **Palliative Care**

 **Would you be surprised if this patient died within the next 12 months?**

Representative Questions for End-of-Life Discussions

- **Goals –**
 - Given the severity of your illness, what is most important for you to achieve?
 - What are your biggest fears?
 - What are your most important hopes?
 - Is it more important to you to live as long as possible, despite some suffering, or to live without suffering but for a shorter time?

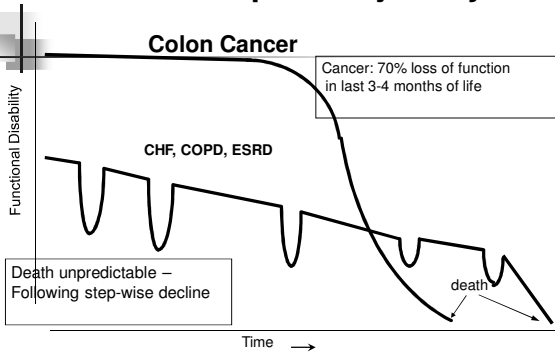
Representative Questions for End-of-Life Discussions

- Values
 - What makes life most worth living for you?
 - Are there any circumstances under which you would not find life worth living?
 - What do you consider your quality of life to be like now?
 - Have you seen or been with someone who had a particularly good (or difficult) death?

Clinical Indications for Discussing End-of-Life Care --Routine

- **Discussing prognosis**
- **Discussing treatment with low probability of success**
- **Discussing hopes and fears**
- **Physician would not be surprised if the patient died in 6-12 months**

Illness Impact Trajectory



Factors Predicting Increased Risk of Death Summary

- sentinel events
 - **acute myocardial infarction:** 38 – 44% survival at 1 year post event
 - **amputation:** BKA survival 49% at 1 year
AKA survival 27% at 1 year
 - **bacteremia:** 7.1 X risk in first 6 months, 1.6 x risk at 48 months
 - **bone fracture:** 2.5 – 5 X higher at 6 months depending on gender, comorbid conditions

Concepts of ACP: Traditional vs Contemporary (from Singer, AJKD 1999;33:980)

| | <u>traditional</u> | <u>contemporary</u> |
|-----------------|------------------------|--|
| <u>purpose:</u> | prepare for incapacity | prepare for death achieve control relieve burdens strengthen relat. |
| <u>focus:</u> | written AD | AD only 1 aspect |
| <u>context:</u> | physician-patient | patient-family |

Contemporary Advance Care Planning

- To prepare patients and surrogates to participate with clinicians in making the best possible in-the-moment decisions Sudore, Fried Ann Int Med 2010;153:256
- A relational patient-centered process that focuses on broader goals of care for a particular patient and serves as a guide to help health care professionals explore ACP discussions with patients and their families Davison, Torgunrud AJKD 2007;49:27

Patient Participation is central to ACP and requires

Davison, Torgunrud, AJKD 2007

- patient's ability to be involved
- patient's interest in participating
- perception of level of control and power
- perceived benefits of participation
- resources to participate
- identification of individuals the patient wants to be included in the process

Representative Questions for End-of-Life Discussions

- Advance directives
 - If you are unable to speak for yourself in the future, who would be best able to represent your views and values? Proxy
 - Have you given any thought to what kinds of treatment you would want or not want if you become unable to speak for yourself in the future? Living will

Useful Advance Directives

- DNAR or DNR
- POLST or POST (Physician Orders for Life-Sustaining Treatment)

Outcomes of CPR

- On television: 75% survived CPR, 67% to hospital discharge (Diem et al NEJM 334:1578, 1996)
- Medical literature: 30-40% survived CPR, 15% to hospital discharge
 - Pulseless electrical activity 1-4% survival to discharge
 - Asystole near 0% survival to discharge

Survival after CPR: dialysis and control patients

Moss et al, JASN 3; 1993 (n = 74 dialysis, 247 controls)

| Survival Stage | Dialysis pts (%) | Control pts (%) |
|-------------------|------------------|-----------------|
| after CPR | ~35 | ~35 |
| to hosp discharge | ~10 | ~15 |
| at 6 mos | ~5 | ~10* |

Use of POLST (Physician Orders for Life-Sustaining Treatment) Nationally

Sept 2010

Legend:

- Endorsed Programs
- Developing Programs
- No Program (Contacts)

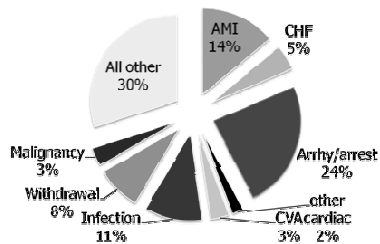
Frequency of Death in Dialysis Units

- Average of 17 deaths per dialysis unit/yr
- 78% of units withdrew at least 1 patient (1990)
- Mean # withdrawn: 3 (0-20)
- Most nephrologists withdraw at least one patient/yr
- Mean # withdrawn/nephrologist/yr: 5

Frequency of Death in Dialysis Units USRDS 2011

- Adjusted rates all cause mortality 6.4 – 7.8 times higher in dialysis patients vs general pop
- 5 yr probability of survival 0.39 in incident patients 1999-2003

Causes of Death prevalent dialysis patients 2006 – 2008, USRDS



**Risk Factors for Withdrawing from Dialysis --
Literature Overview**

- older age, ethnicity (white), diabetic, women
- comorbidity, severe pain
- divorced or widowed
- nursing home resident
- ? modality Home HD (Leggat, Roberts)
 PD (DM only, Bloembergen)

Characteristics of Death from Withdrawal of Dialysis

**Death in 1-2 weeks; progressive impairment of
consciousness with little associated
suffering**
(Golden, 1993)

- average survival 8-10 days (1-134, Neu)

**Hospice enrollment requires. . . . Lynn, JAMA
2001;285:925**

- Decision-makers confront the prognosis and their uncertainties about it
- Consider desirability of other services
- Recognize hospice program variations
- Address financial issues
- Weigh the distress of patients and loved ones at being labeled as "dying"

Hospice and ESRD

- Requires prognosis \leq 6 months
- ESRD pts who withdraw from dialysis accepted by hospice programs
- Require nonrenal terminal diagnosis for hospice if dialysis continued
- Variability among hospice programs

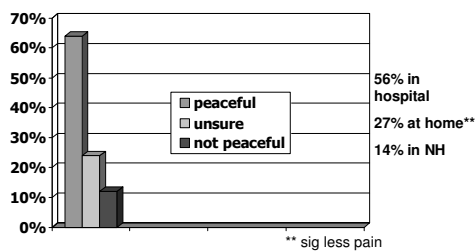
Hospice and ESRD

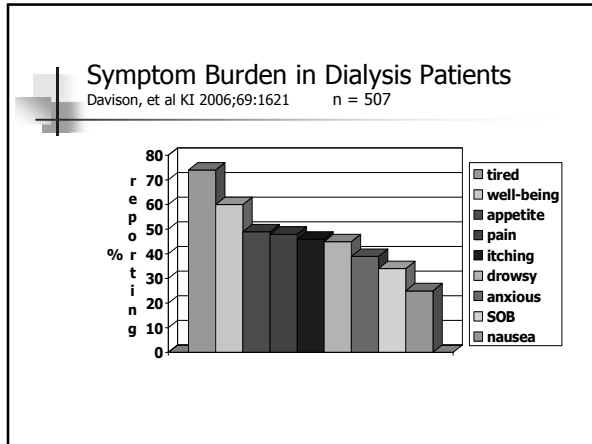
Murray et al CJASN 2006;1:1248 2001-2002 cohort of 115,239 ESRD deaths

- Low utilization: 13.5% died in hospice; 42% who withdrew died with hospice (22% withdrew)
- Assoc with hospice use among withdrawing pts: age, race, reason for withdrawal, ability to walk at dial initiation, state of residence
- Died in hospital: 23% hospice, 69% nonhospice

Family perspective of ESRD deaths

Cohen et al AJKD, 2005;45:154 86 completed surveys of 188 deaths



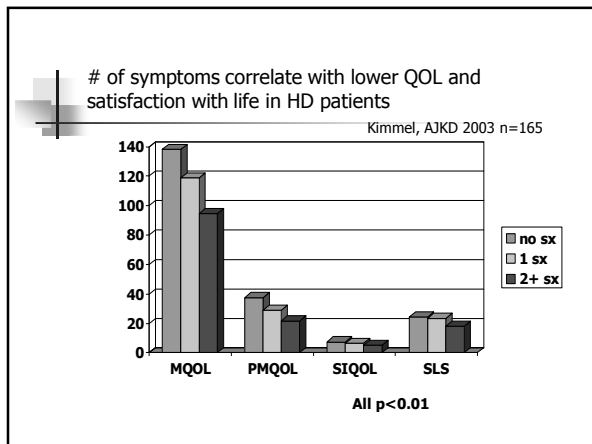


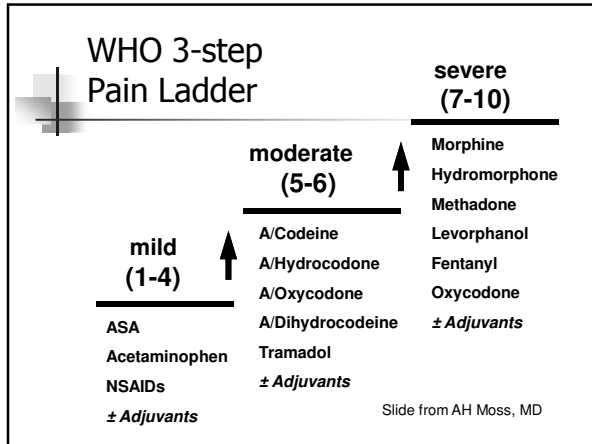
Symptom Burden in Chronic Dialysis Patients

Davison, KI 2006 n = 507

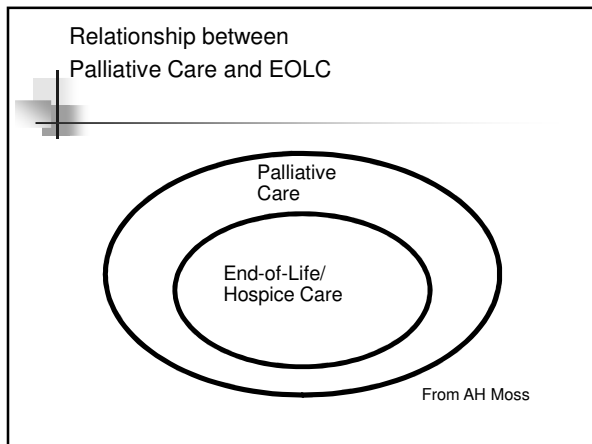
- Mean # symptoms 7.5 ± 2.5
- # moderate or severe symptoms 4.5 ± 2.9

Mean age 63.5 yrs, 73% Caucasian, 37% diabetic, 90% HD, mean 3.4 yrs on dialysis





- ### Bereavement Programs
- Included in hospice care
 - Dialysis unit initiated
 - Family
 - Support staff
 - Dialysis unit staff
 - Other patients



End-of-Life Care and Palliative Care in the Dialysis Unit A Collaborative Effort

- identify patients appropriate for a palliative care focus [estimate prognosis, be aware of sentinel events]
- identify and manage symptoms [especially pain]
- incorporate palliative care issues in unit quality initiative activities [morbidity & mortality, advance care planning as part of overall patient care plan]
- involve the multidisciplinary dialysis unit team

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