# KIDNEY END-OF-LIFE COALITION

## 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*

# 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**

# *Planning a Renal Palliative Care Program and its components*

Michael Germain
Professor Medicine Tufts University
Baystate Medical Center
Springfield MA

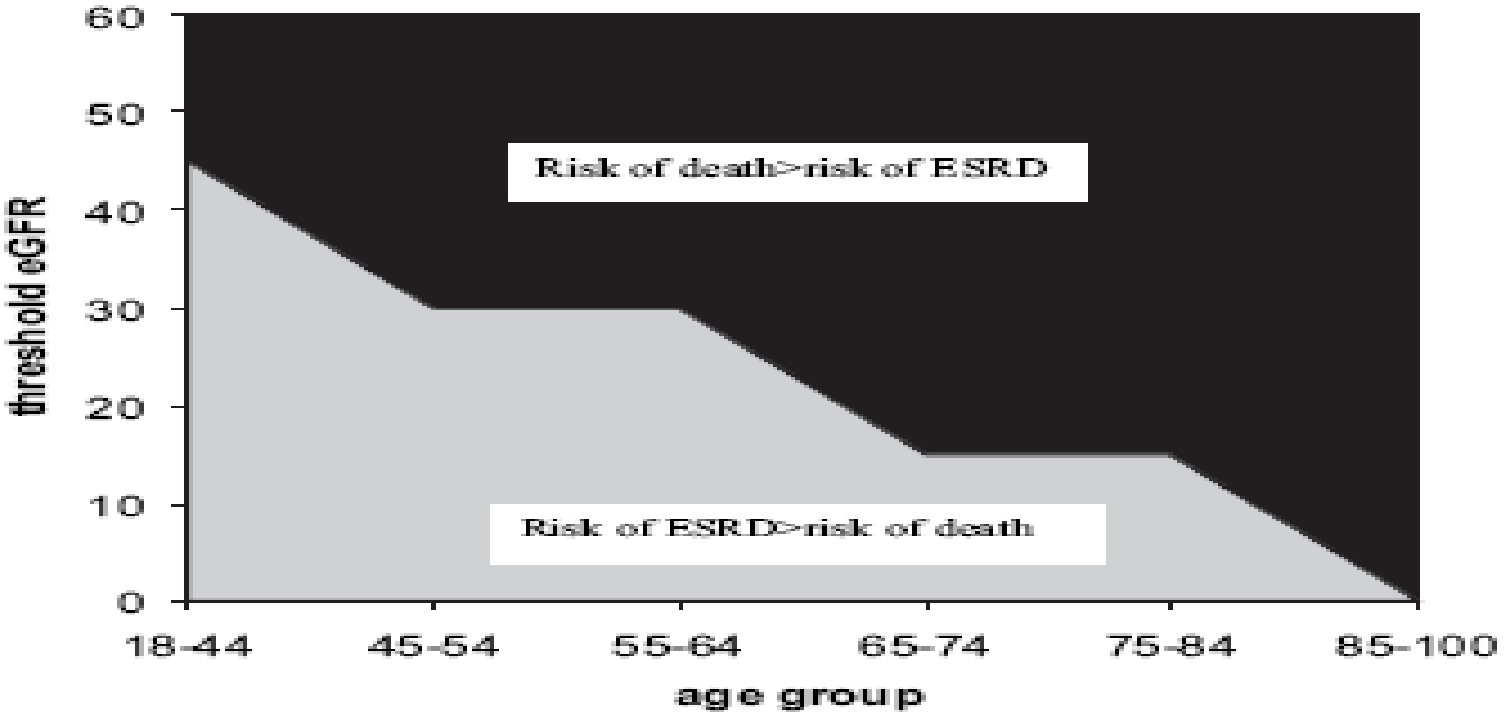
# Objectives

- 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†

*J Am Soc Nephrol* 18: 2758–2765, 2007.



# 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!!!

# http://touchcalc.com/calculators/sg

## 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.

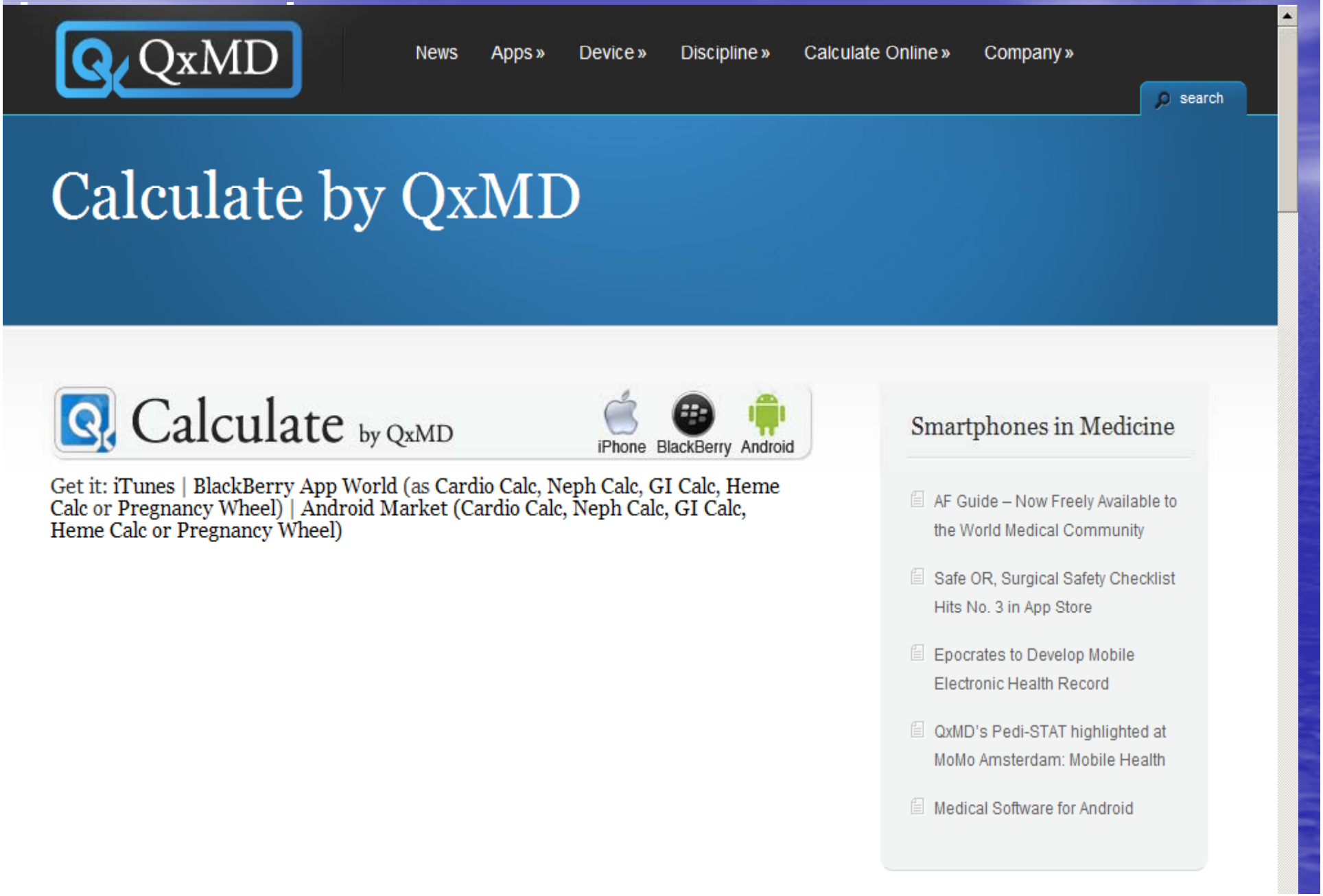
PERIPHERAL VASCULAR DISEASE
( ) My patient HAS peripheral vascular disease.
(•) My patient does NOT have peripheral vascular disease.

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

REFERENCE:Cohen LM, Ruthhazer R, Moss AH, Germain MJ. Predicting Six-Month Mortality for Patients who are on Maintenance Hemodialysis
Clin J Am Soc Nephrol. 2009 Dec 3

Supporting data table

http://www.qxmd.com/apps/calculate-



- 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

Cohen LM, Germain MJ, Poppel DM, PekowPS.Woods A, Kjellstrand CM:

Dying well after discontinuing the life-support treatment of dialysis. Arch Intern Med160:2512518, 2000 Am J Kidney Dis. 36(1):140-144, 2000

# 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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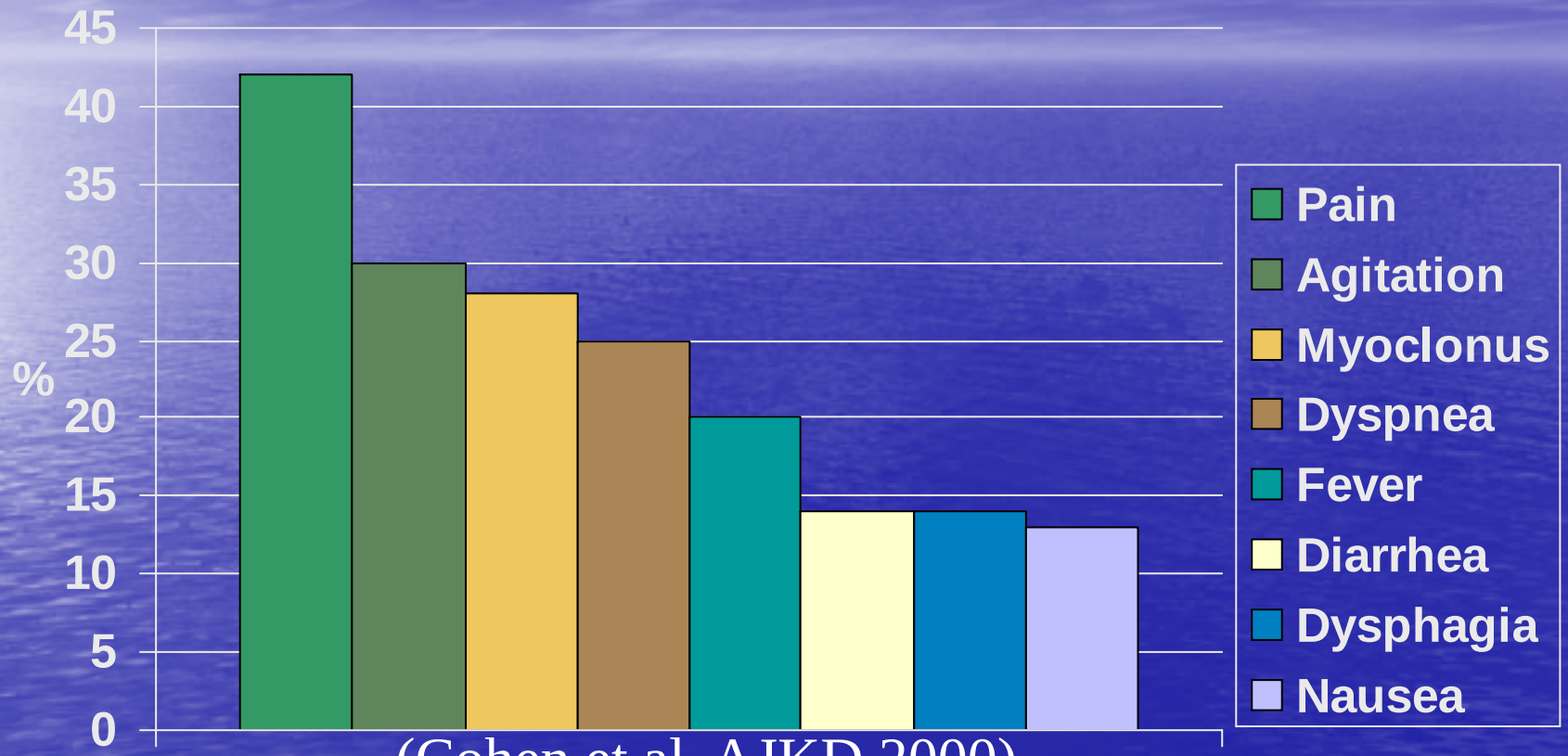
# Data on How ESRD Patients Die

- Families report “satisfactory” in 85%
- BUT pain noted in 42% and agitation in 30% during final day of life

  (Cohen et al. Archives Int Med 2000)
- 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 care taker (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

*Phillips JM, Brennan M, Schwartz CE, Cohen LM: The long-term impact of dialysis discontinuation on families. J Palliative Med, Vol. 8(1), 2004, In Press.*

# 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)

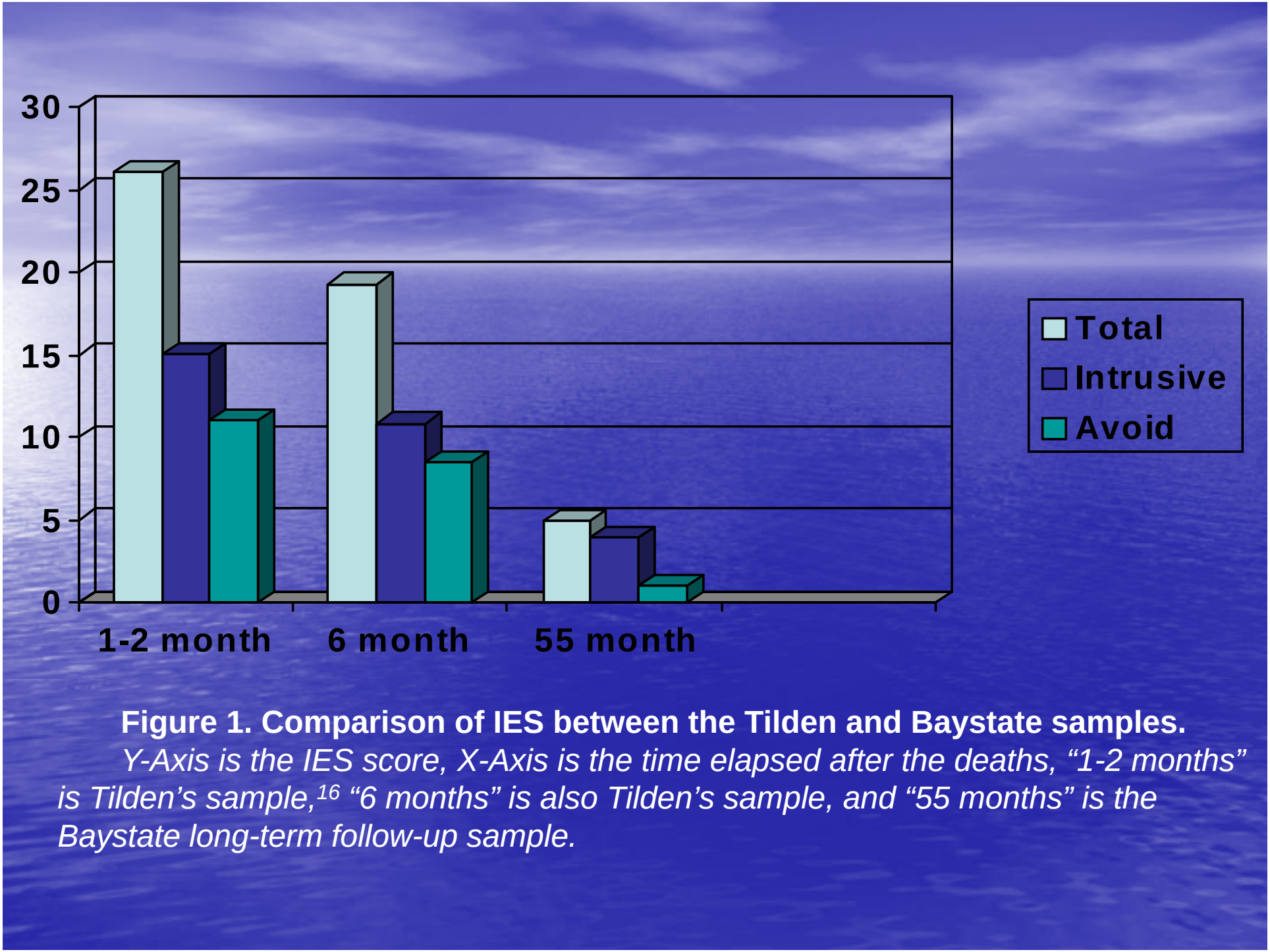



**Figure 1. Comparison of IES between the Tilden and Baystate samples.**
*Y-Axis is the IES score, X-Axis is the time elapsed after the deaths, "1-2 months" is Tilden's sample,[16] "6 months" is also Tilden's sample, and "55 months" is the Baystate long-term follow-up sample.*

# 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, paye
providers in support of integrated patient-centered end-of-life care of chronic kidney di
(CKD) patients.


vance Care Planning

-of-Life Decisions in the Dialysis Unit

Access to Hospice

hysician Education

atient and Family Education

dditional Resources

Coalition History

Presentations

Home


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.

# www.Kidneyeol.org
# 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
RENAL PHYSICIANS ASSOCIATION

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 patients 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 i**f 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.**

# RPA/ASN Statement on Quality Care at the End of Life

**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.**

# RPA/ASN Statement on Quality Care at the End of Life

**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.**

# RPA/ASN Statement on Quality Care at the End of Life

**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.**

# RPA/ASN Statement on Quality 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.**

OXFORD
SUPPORTIVE CARE

# Supportive Care for the Renal Patient

Edited by
E. Joanna Chambers
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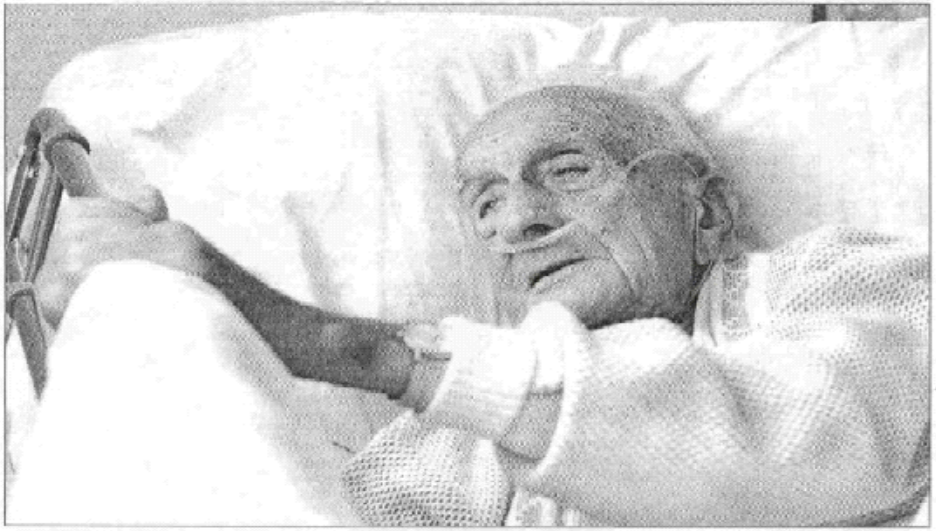
FOCUS

A 'GOOD DEATH'



Staff photo by MARK M. MURRAY

**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 decision will help others.*


**By PATRICIA NORRIS**
Staff writer
pnorris@repub.com


Death came quietly to Carmen 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, Patavino of Wilbraham decided to end his dialysis treatment and drift into a slumber-like peace.

He was 92.

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 Migdal of Wilbraham.

Patavino, normally a spry 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.

Staff photo by MARK M. MURRAY

**Golfing buddy Bob Droge of Scotia, N.Y., holds the hand of his longtime friend the day before Carmen Patavino died.**

**"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 Vinciola said shortly after her father decided to end dialysis***

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 relief of coming home after treatment had been 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 accepted option for people with end-stage renal disease. Although

*Please see* **Dialysis,** *Page* **A22**

# KIDNEY END-OF-LIFE COALITION

## For Further Information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