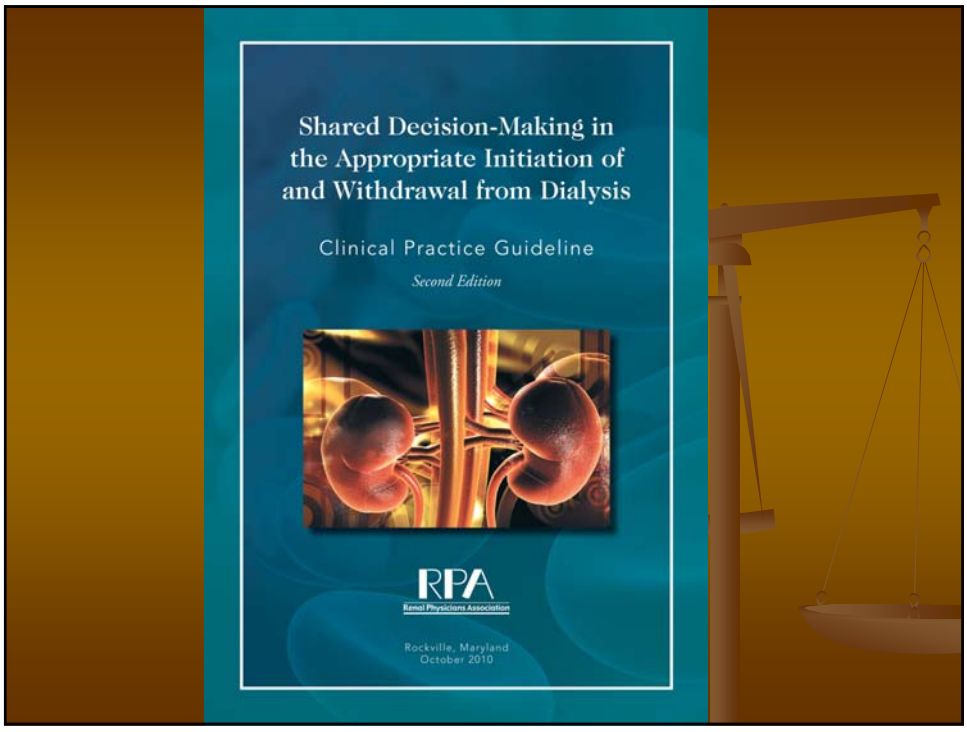
"Doctor, I want to stop dialysis": What happens next?

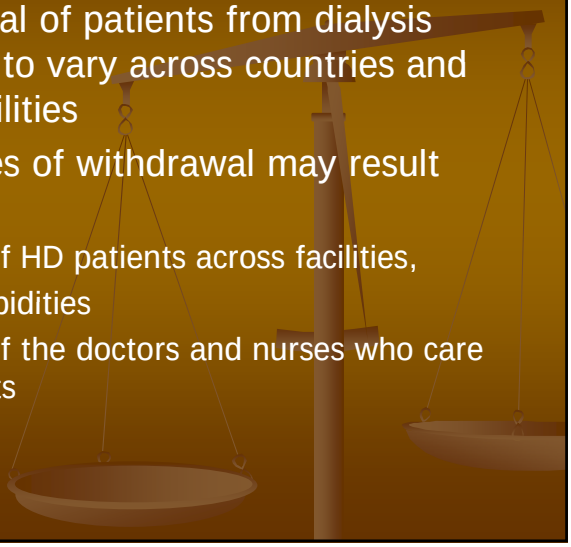
Lewis M. Cohen, MD

Director, Baystate Renal Palliative Care Initiative



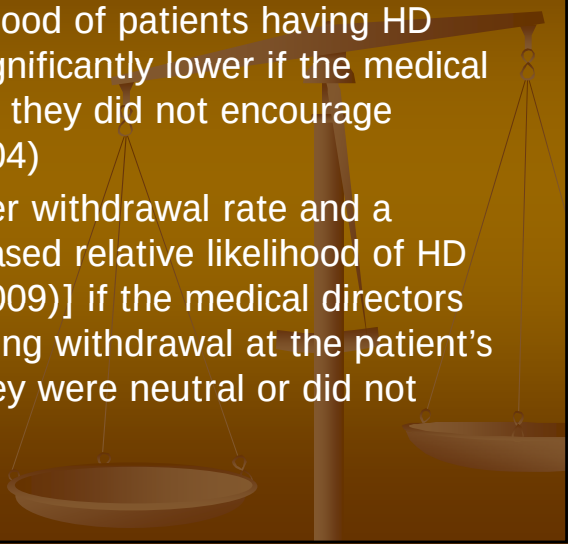
The Dialysis Outcomes and Practice Patterns Study (DOPPS)

- Rates of withdrawal of patients from dialysis have been shown to vary across countries and across dialysis facilities
- Differences in rates of withdrawal may result from variations in
  - (a) the attitudes of HD patients across facilities,
  - (b) patient comorbidities
  - (c) the practices of the doctors and nurses who care for dialysis patients



DOPPS

- The relative likelihood of patients having HD withdrawn was significantly lower if the medical directors said that they did not encourage withdrawal (P=0.04)
- There was a higher withdrawal rate and a significantly increased relative likelihood of HD withdrawal (P=0.009)] if the medical directors agreed with allowing withdrawal at the patient's request than if they were neutral or did not agree



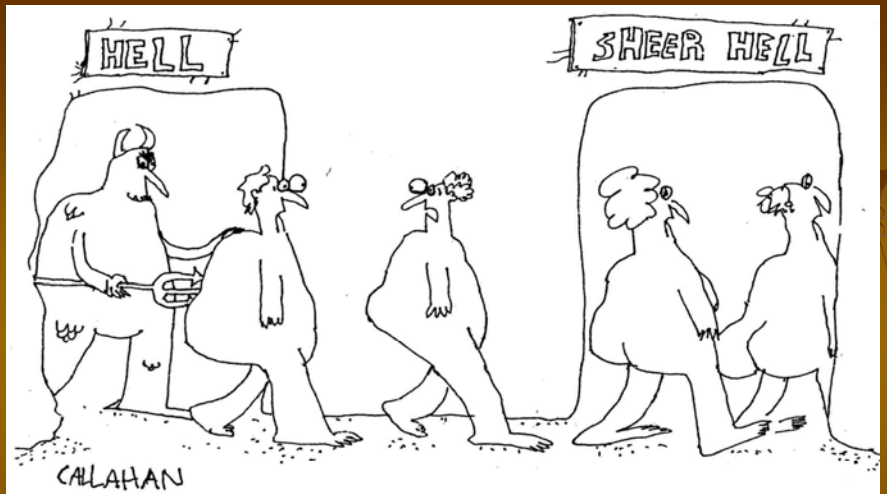
DOPPS

- Decisions regarding withdrawal of treatment are strongly influenced by ethical, religious and legal factors that vary across countries and cultures
- Higher withdrawal rates in the USA, the UK and France (6–44%) than in Italy (up to 1.1%)

United States

Increasing number of dialysis requests

- from 1990 to 1995, 20,000 deaths were preceded by dialysis withdrawal
- From 1995 to 1999, 36,000 deaths were preceded by withdrawal

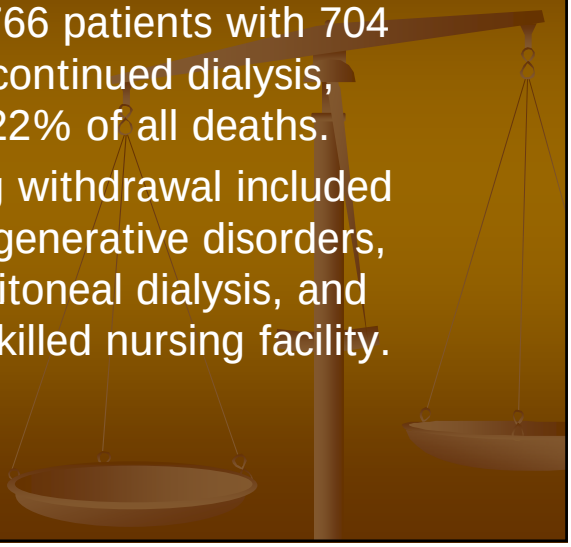


"Just when I thought things couldn't get any worse!"

Carl Kjellstrand

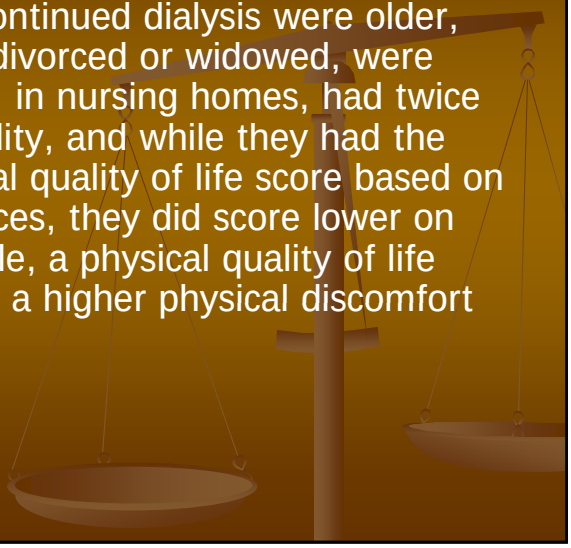
1986 Neu and Kjellstrand

- In a study of 1766 patients with 704 deaths, 155 discontinued dialysis, accounting for 22% of all deaths.
- Factors favoring withdrawal included concomitant degenerative disorders, intermittent peritoneal dialysis, and residence in a skilled nursing facility.



1996 Bajwa et. al.

- Patients who discontinued dialysis were older, more likely to be divorced or widowed, were more likely to live in nursing homes, had twice as much comorbidity, and while they had the same psychological quality of life score based on four separate indices, they did score lower on the Karnofsky Scale, a physical quality of life measure, and had a higher physical discomfort index.



1997 Leggat et al.

- Using the USRDS data base, they concluded that patients who are Caucasian, female, older, or die of chronic or progressive diseases are more likely to withdraw from dialysis before death. The ethnic disparity demonstrated that both African-Americans and Asians were 50% less likely to withdraw from dialysis before death as Caucasians.

Regional disparities

- in 2002, the Mid-Atlantic Network dialysis discontinuation rate was 19%, whereas in New England it was 32%
- It is now over 40% in New England

You didn't learn about it in fellowship training

- Only 22% of fellows were taught how to tell a patient he or she is dying.
- When asked a multiple choice question regarding the annual gross mortality of patients on dialysis, a full one-third of fellows chose the wrong answer.

Holley JL, et al: Am J Kidney Dis 42:813–820, 2003

Withdrawal of Dialysis: Findings from the Baystate Prospective Study

- Cohen LM, Germain MJ, Poppel DM, Pekow PS. Woods A, Kjellstrand CM: Dying well after discontinuing the life-support treatment of dialysis. Arch Intern Med 160:251-258, 2000
- Am J Kidney Dis. 36(1):140-144, 2000

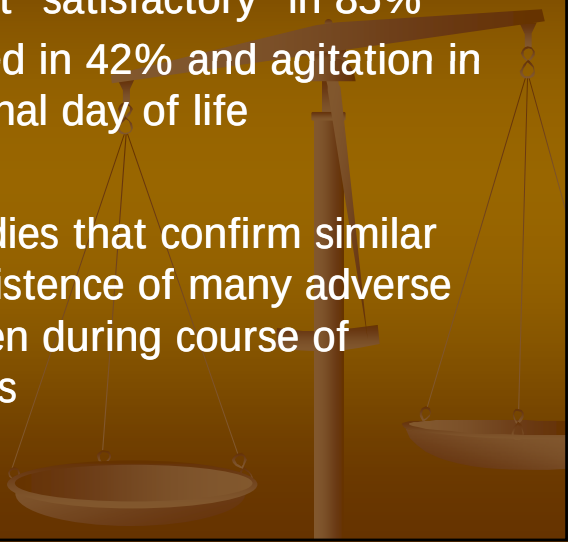
The Baystate Dialysis Discontinuation Study

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

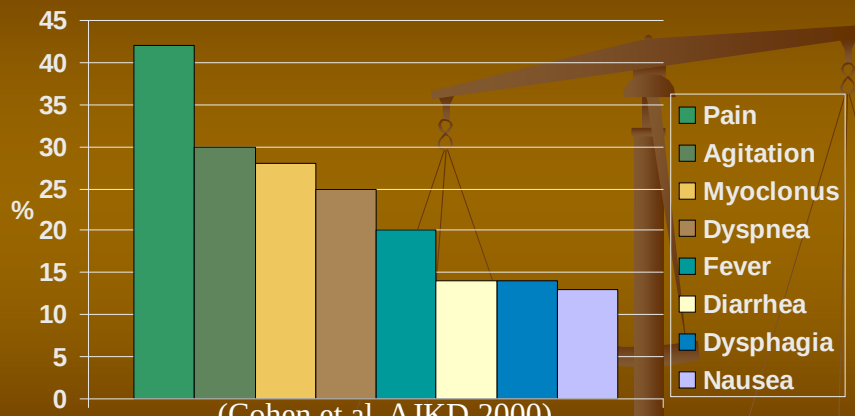
Data on How ESRD Patients Die

- 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



Symptoms During Last 24 Hours



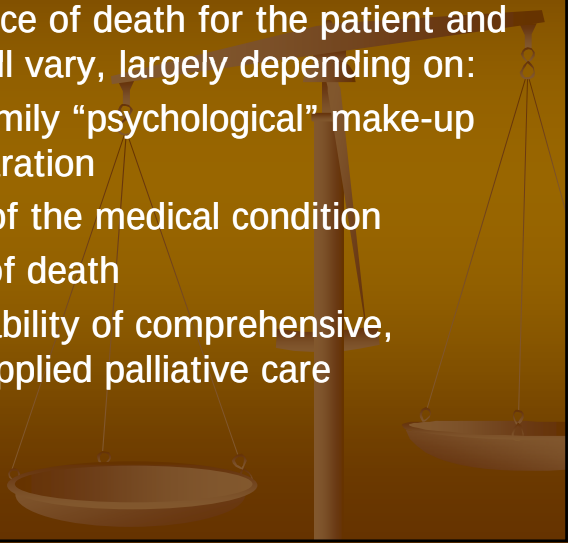
(Cohen et al. AJKD 2000)

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

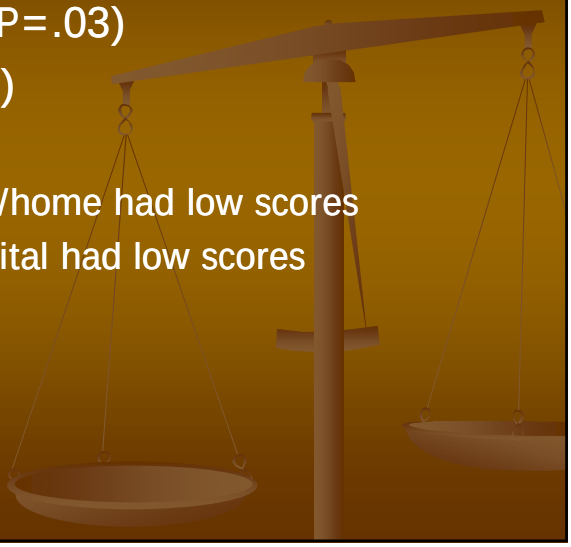
- Duration
- Psychosocial
- Symptoms

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



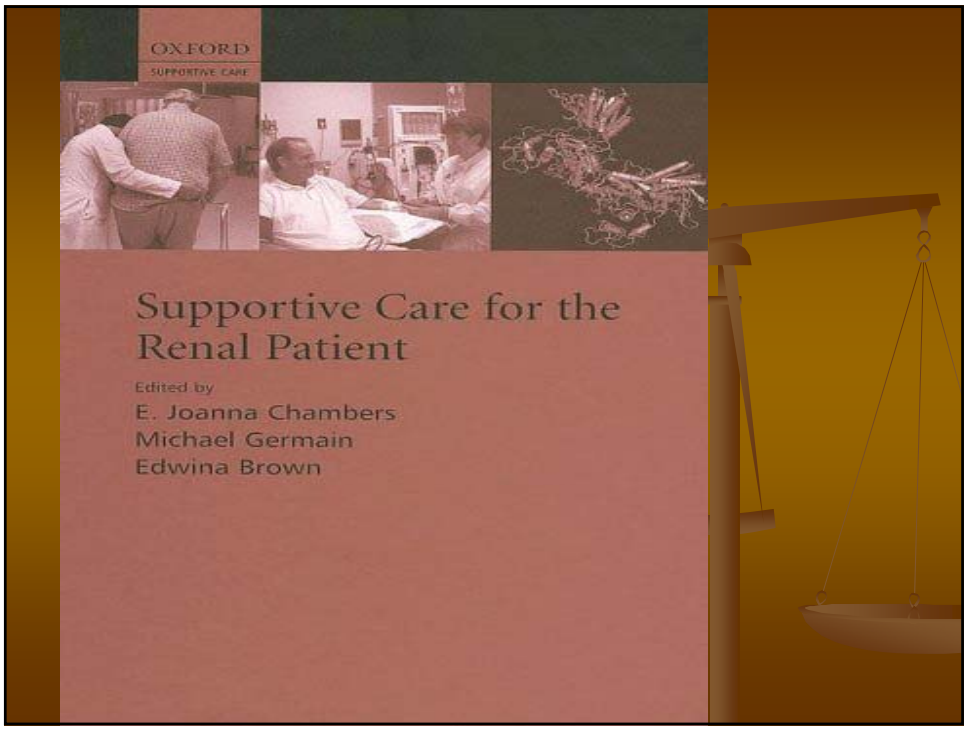
Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

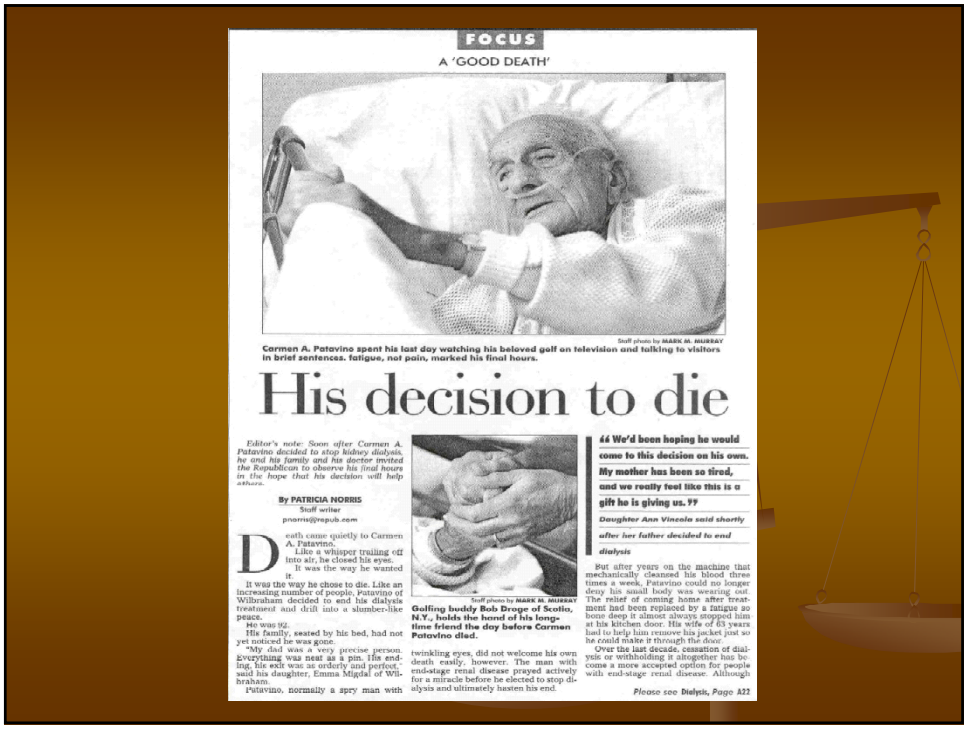
RPA
Renal Physicians Association

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





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 Vincola said shortly after her father decided to end dialysis

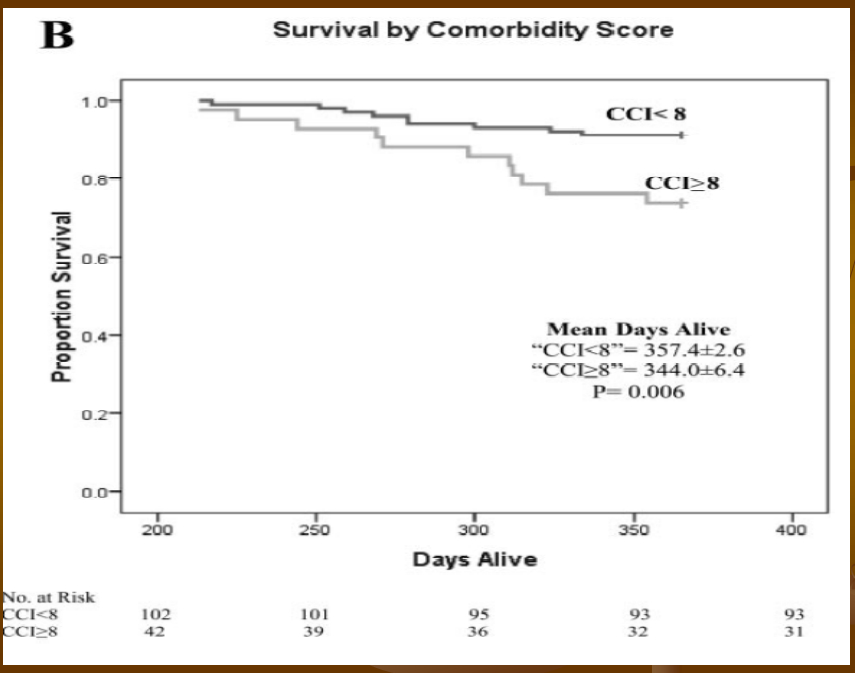
But after years on the machine that mechanically cleansed his blood three times a week, Patavino could no longer deny his small body was wearing out. The relief of coming home after treatment had been replaced by a fatigue so bone deep it almost always stopped him at his kitchen door. His wife of 63 years had to help him remove his jacket just so he could make it through the door.

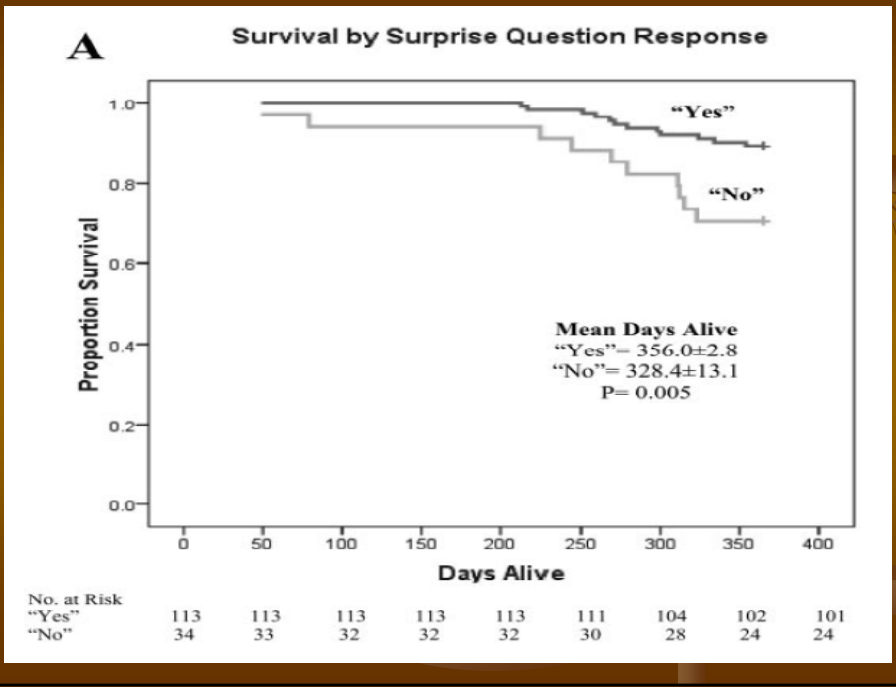
Over the last decade, cessation of dialysis or withholding it altogether has become a more accepted option for people with end-stage renal disease. Although

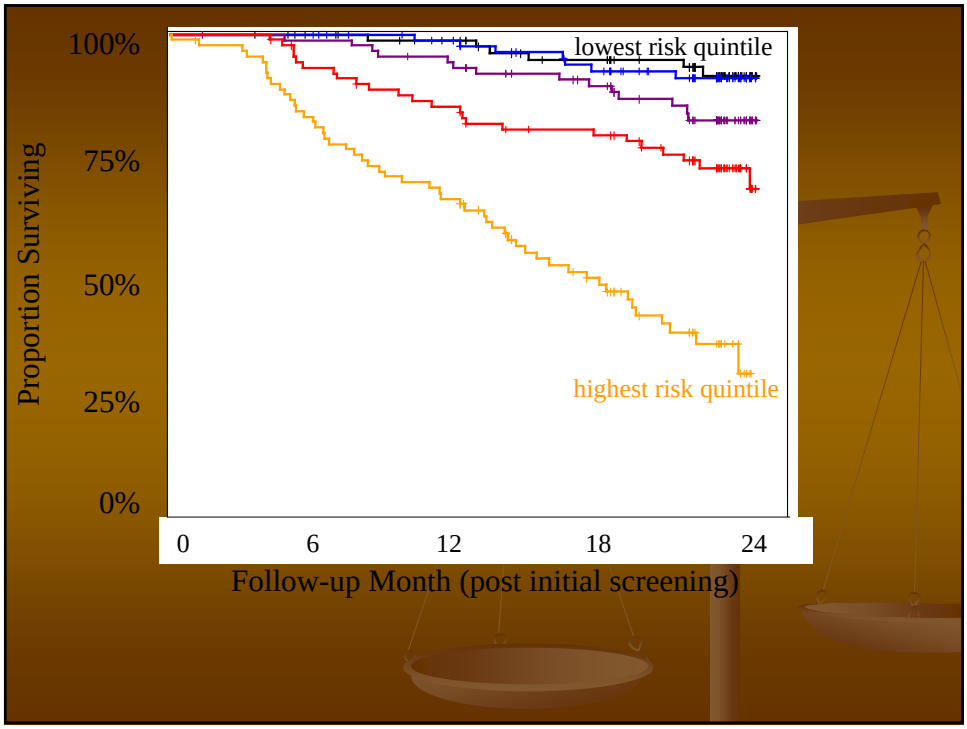
Please see Dialysis, *Page* A22

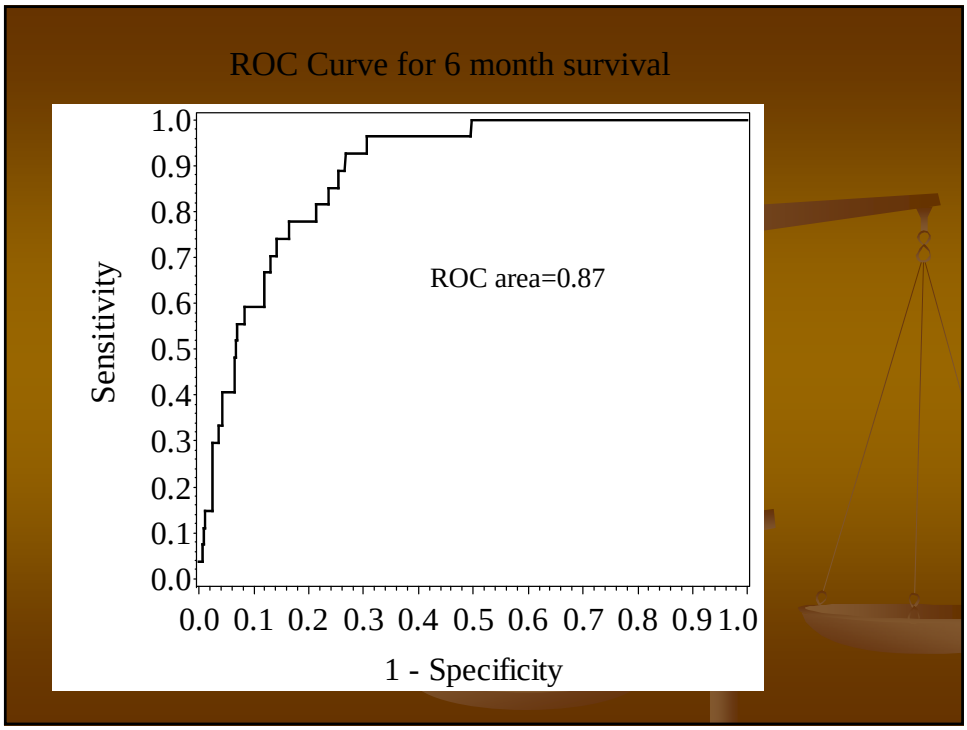
Communicating Prognosis

- Patient overwhelmingly want to know their prognosis, good or bad
- They want to hear it from the MD
- MDs are uncomfortable giving prognosis: uncertain of accuracy, poor skills at breaking bad news, feel the pt will give up hope and the MD should be positive
- Giving bad prognosis information does not result in harm and has positive outcomes


B
Survival by Comorbidity Score
CCI< 8
CCI≥8
Proportion Survival
1.0
0.8
0.6
0.4
0.2
0.0
Mean Days Alive
"CCI<8"= 357.4±2.6
"CCI≥8"= 344.0±6.4
P= 0.006
200
250
300
350
400
Days Alive
No. at Risk
CCI<8 102 101 95 93 93
CCI≥8 42 39 36 32 31

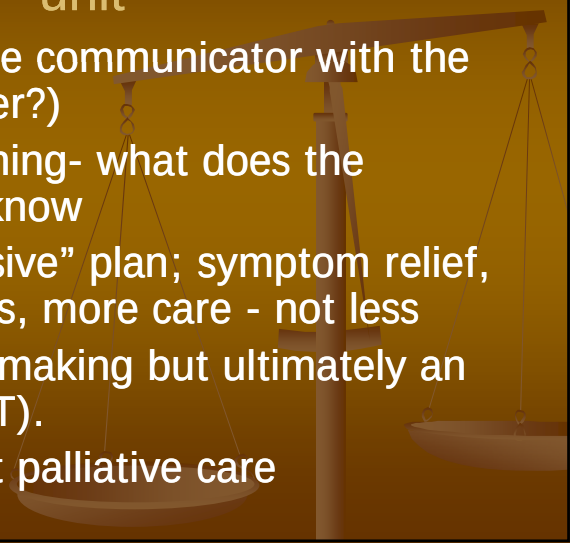

A
Survival by Surprise Question Response
"Yes"
"No"
Proportion Survival
1.0
0.8
0.6
0.4
0.2
0.0
Mean Days Alive
"Yes"= 356.0±2.8
"No"= 328.4±13.1
P= 0.005
0
50
100
150
200
250
300
350
400
Days Alive
No. at Risk
"Yes" 113 113 113 113 113 111 104 102 101
"No" 34 33 32 32 32 30 28 24 24


100%
75%
50%
25%
0%
Proportion Surviving
lowest risk quintile
highest risk quintile
0
6
12
18
24
Follow-up Month (post initial screening)


ROC Curve for 6 month survival
1.0
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0.0
Sensitivity
ROC area=0.87
0.0 0.1 0.2 0.3 0.4 0.5 0.6 0.7 0.8 0.9 1.0
1 - Specificity

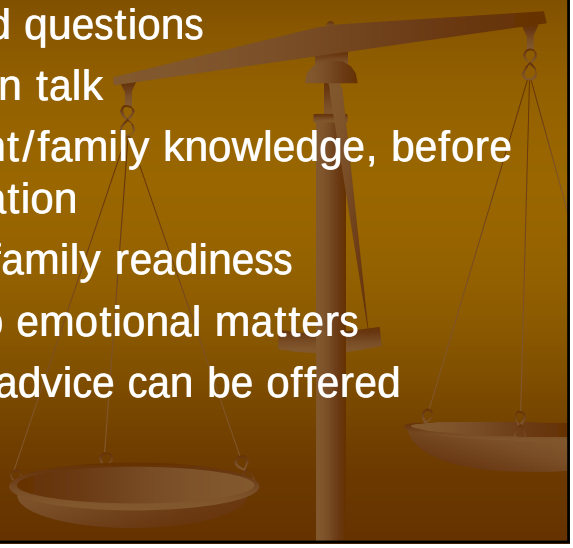
Communicating Bad Prognosis
Think of the patient and family as one unit

- 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



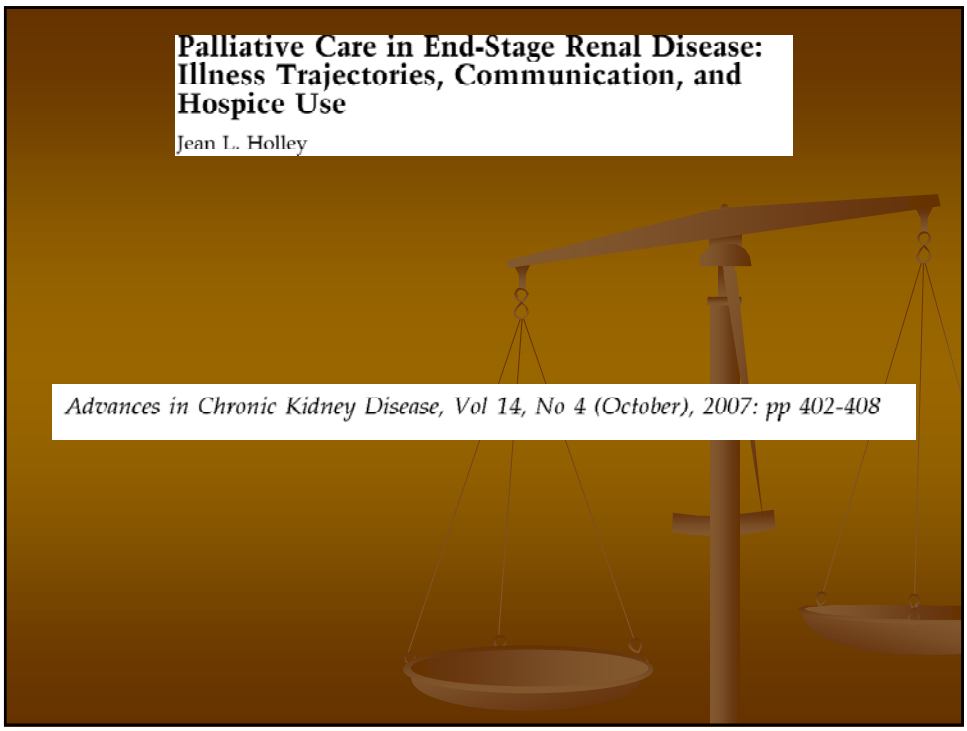
Basic Communication Skills

- Use open-ended questions
- Listen more than talk
- Ascertain patient/family knowledge, before offering information
- Assess patient/family readiness
- Pay attention to emotional matters
- Suggestions or advice can be offered



Palliative Care in End-Stage Renal Disease: Illness Trajectories, Communication, and Hospice Use

Jean L. Holley



Advances in Chronic Kidney Disease, Vol 14, No 4 (October), 2007: pp 402-408

Addressing goals of care when prognosis is uncertain

What are your most important hopes?
What concerns you most about your illness?
What is your quality of life like now?
How do you think about balancing quality of life with length of life?
Is it more important for you to live as long as possible, despite some suffering, or to live without suffering but for a shorter time?
What are your biggest fears?
Given the severity of your illness, what is most important to you to achieve?
What do you understand about your illness?
How much do you want to know?

Advance-care planning and end-of-life issues

Values

- What makes life most worth living for you?
  - Are there circumstances in which you would find life not worth living?
- Have you seen or been with someone who had a particularly good (or difficult) death?
  - What have been the worst and the best things about this illness for you?

Directives

- If you are unable to speak for yourself in the future, who would be best able to represent your views and values? (proxy directive)
- 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? (instruction directive or living will)
- Have you considered circumstances in which you would want to stop dialysis?
- Where would you like to be and who would you like to be there when you die?

Conclusions

- Patients and families need to understand that not having dialysis does not equate to not having care
- It is a shift in care to prioritize management of different symptoms
- Ongoing open, honest communication with all team members giving the same message is crucial and allows families, and patients, to acknowledge and express their fears and concerns as well as their preferences

Conclusions

- Outcomes are no longer being equated to survival alone
- The nephrology team has a responsibility to assist patients with the best possible living, or if appropriate, the best possible death
- What we need to learn is that it is not about the dying, it is about the living beforehand

References

- Hackett AS, Watnick SG: Withdrawal from dialysis in end-stage renal disease: medical, social, and psychological issues. *Semin Dial* 20(1):86-90, 2007
- Cohen LM, Germain MJ: The psychiatric landscape of withdrawal. *Semin Dialysis* 18:147–153, 2005
- Lambie, Rayner HC, et al: Starting and withdrawing haemodialysis—associations between nephrologists' opinions, patient characteristics and practice patterns (data from DOPPS). Nephrol Dial Transplant 21:2814–2820, 2006
- Jassal SV, Watson D: Doc, don't procrastinate . . . Rehabilitate, palliate, and advocate. *Am J Kidney Diseases* 55(2):209-212, 2010