Making Choices

A Professional and Personal Perspective on Advance Care Directives and Conservative Care in CKD and ESRD

Panel:

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Disclosures

- D. Halinski has no conflicts of interest to disclose
- C. Halinski has no conflicts of interest to disclose
- M. Gedeon has no conflicts of interest to disclose

Objectives

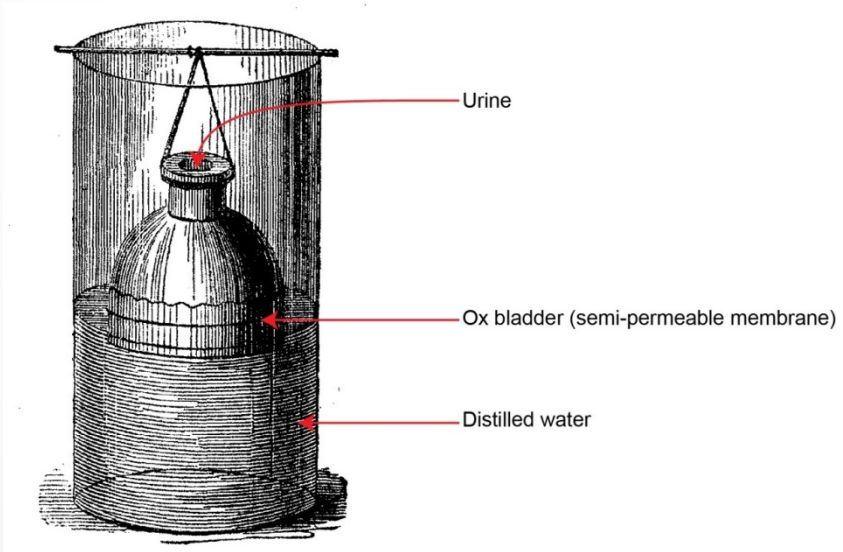
- Review history of dialysis and advance directives
- Discuss dialysis options
- Discuss role of conservative management/palliative care
- Review a case study

Technology

- What do we mean by “modern medicine or modern technology”?
- Have you thought about how dialysis therapies started?
- Where have we been?
- Where are we going?

History of dialysis

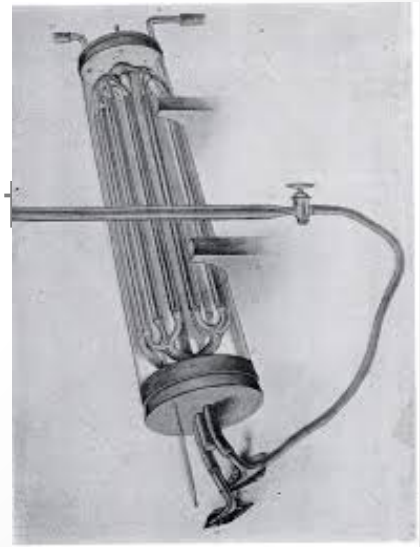
- 1854 – Thomas Graham, a chemist at Glasgow University prepared a bell shaped vessel that filtered sodium chloride and urea



Bulb dialyzer used by Graham (from Ref. 2)

More History

- Research continued with artificial membranes
- 1914, Abel, et al, developed and tested the first efficient dialysis system at Johns Hopkins University. It was called "vivi-diffusion" apparatus.
- Consisted of a filtering device and a solution obtained from leech heads that acted as an anticoagulant



History continued

- 1924 – First human hemodialysis performed by Haas at University of Giessen in Germany
- Used a tubular device made of a colloidal product immersed in dialysate solution in a glass cylinder. He showed the presence of uremic substances in the dialysate and also showed that water could be removed from the blood
- In 1928, Haas was the first to use heparin as an anticoagulant

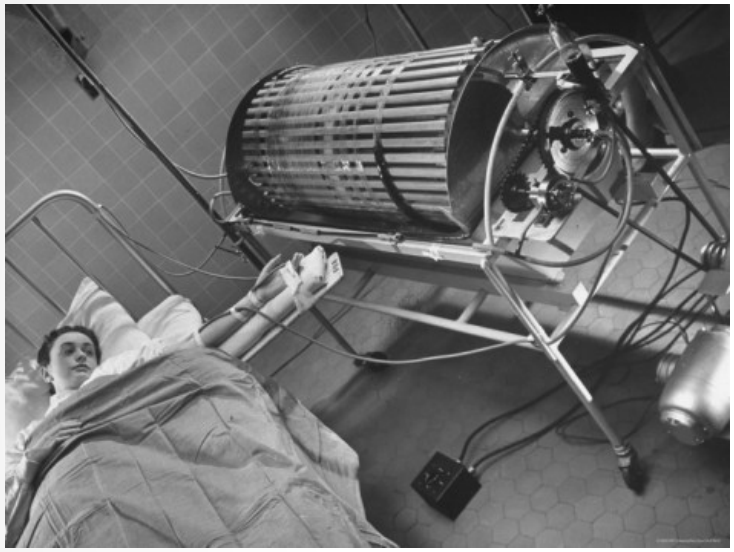
History continued

- 1940 – Willem Kolff, considered the father of dialysis. One of the first to investigate role of toxic solutes in causing uremic syndrome.
- While caring for casualties after the German invasion of the Netherlands, his interest in acute renal failure increased.

Coming to America

- In 1943 he introduced the rotating drum hemodialysis system, used cellophane membrane and immersion bath and treated and had recovery of an acute renal failure patient
- Kolff donated 5 artificial kidneys he'd made to hospitals around the world, one of those was Mt. Sinai Hospital in New York

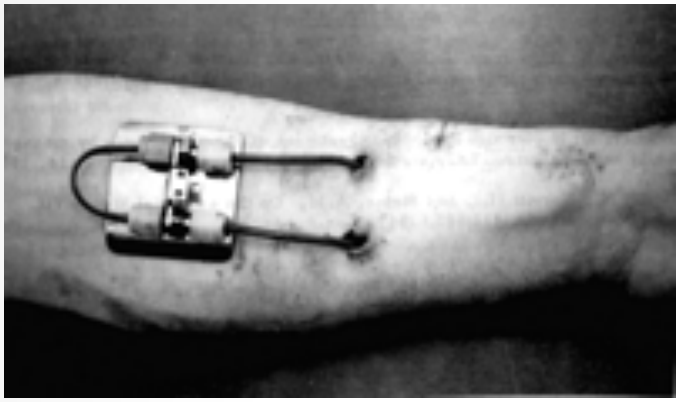
Machine Advances

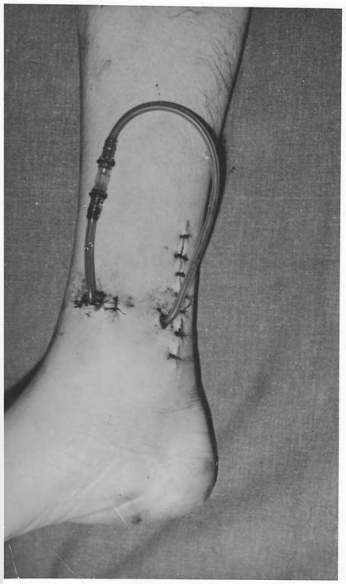


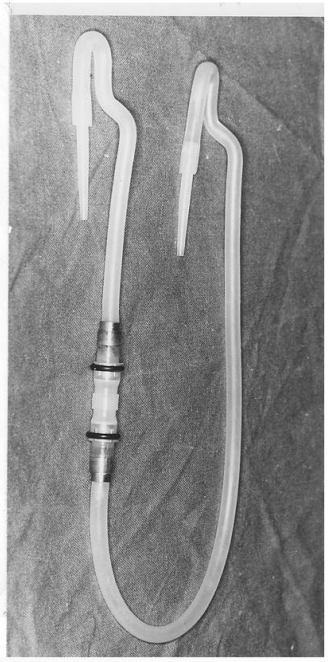
More Hemodialysis Machines

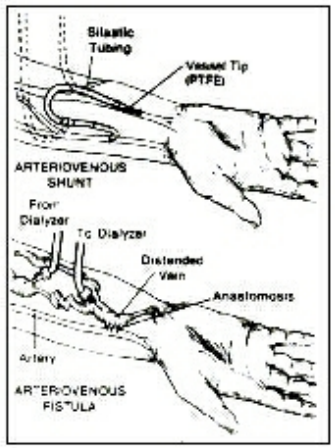
Hemodialysis and Peritoneal Dialysis

Vascular Access







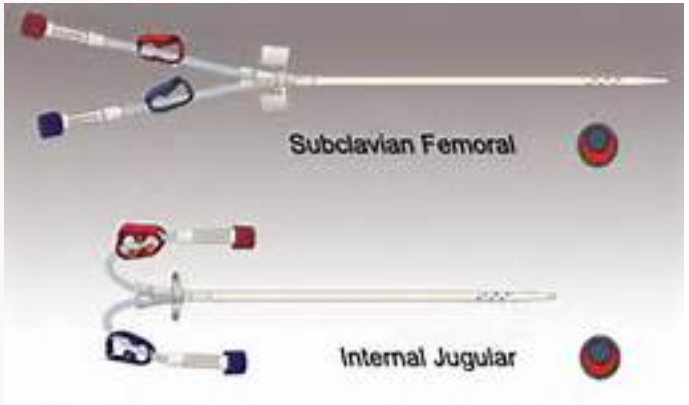


M.J. Brescia J.E. Cimino K. Appel,

In my opinion, probably the *most important contribution* to long term survival of haemodialysis patients

Brescia MJ, Cimino JE, Appel K, Hurwich BJ Chronic hemodialysis using venepuncture and a surgically created arterio-venous fistula. NEJM 1966;275;1089

Dialysis Hemodialysis Catheters



Other Advances in Care

- Stem Cell Therapies
- Researching therapies to prevent organ transplant rejection
- Renal Replacement Therapies that mimic kidney completely. For example: Human Nephron Filter, nanoelectronics for future implantable dialysis devices

In the beginning…

- Early therapies were limited
- Not as efficient
- Dangerous

But, the technology we saw on earlier slides has made dialysis as we know it today, what some people consider a routine procedure and should still be considered dangerous. The Joint Commission and Department of Health consider dialysis therapies as a "high risk" area.

And now…

- Healthcare, in particular, renal replacement therapies have seen many discoveries and innovations
- Those discoveries and innovations impact patients lives and how we provide care
- With those discoveries come the added challenge of preventing and diagnosing correctly and ensuring that patients and families are selecting appropriate treatments

Beginning of Advanced Directives

- Began to be developed in the late 1960's
- What are advance directives? Term that refers to treatment preferences and designation of a surrogate to make decisions in the event that a person becomes unable to make medical decisions on their own behalf
- Three categories: living will, health care proxy and durable power of attorney
- More recently, a document called "5 Wishes"

Advance Directive Categories

- Living Will: written document, specifies types of medical treatment desired if person becomes incapacitated, can be general or specific
- Health Care Proxy: legal document that designates another person to make health care decisions
- Durable Power of Attorney: individual executes legal documents that provide power of attorney to others in the case of incapacitating medical conditions, allows individual to make bank transactions, sign social security checks, apply for disability or write checks to utilities while person incapacitated

History of Advance Directives (State level)

- 1967 – First living will suggested by an attorney, Luis Kutner, to facilitate the "rights of dying people to control decisions about their own medical care."
- 1968 – First living will legislation presented to Florida legislature. Bill would allow patients to make decisions regarding the future of life-sustaining equipment.
- Not until 1976 did first state legally sanction living wills, that was California

Other States

- By 1977, 43 states had considered living will legislation and 7 states passed bills.
- By 1992, all 50 states and the District of Columbia has passed legislation to legalize some form of advance directive
- In the early 1990s, growing concern of unwanted resuscitations of terminally ill patients living at home or in hospice care, having medical crisis without an out of hospital DNR. States began enacting legislation for use of out-of-hospital DNRs

Federal Government and Advance Directives and RPA Guidelines

- 1991 – U.S. House of Representatives enacted the Patient Self- Determination Act. All hospitals receiving Medicaid or Medicare reimbursement needed to ascertain whether patients have or wish to have advance directives.
- 2000, RPA published Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis- clinical practice guidelines

POLST Paradigm

- Physician Orders for Life-Sustaining Treatment: requires a discussion between the health care practitioner and the patient or authorized surrogate about key end-of life options.
- Objective of POLST is to discern the patients wishes and discuss available care options
- New York State version is MOLST (Medical Orders for Life-Sustaining Treatment. Enacted in 2010

Technology and Advance Directives

- Renal Replacement therapies had limited capabilities
- Vascular access was a challenge, in some cases, still is
- Advance Directives sheds a new light on selection of treatment modality, or does it?

Healthcare Providers Committment

- "I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug." (Excerpt from Hippocratic Oath)

- "I will do all in my power to maintain and elevate the standard of my profession, and will hold in confidence all personal matters committed to my keeping and all family affairs coming to my knowledge in the practice of my calling. With loyalty will I endeavor to aid the physician in his work, and devote myself to the welfare of those committed to my care." (Excerpt from Florence Nightingale Pledge)
- Do these statements elude to our role as patient advocate?

The Dilemma

- We have a plethora of treatment options available
- We also have an aging population
- Patients with multiple co-morbidities
- Insufficient education of the public, in general, regarding advance directives, etc

Case #1: Meet Roberta

- 81 y/o F. PMHx CKD III, spinal stenosis, & COPD. "Stable" CRT baseline 1.4
- Mother, mother-in-law, grandmother, great grandmother
- "Irish Catholic" firm beliefs
- Written Advance Directive in the form of HCP
- Recent insidious onset of dementia

The Presentation

- Altered mental status: changes in cognitive abilities
- Increasing confusion
- Decreased appetite: poor albumin
- Difficulty with ADLs
- Change in hygiene practices
- Hx of falls at home
- Unable to manage medication regime
- Generalized weakness, limited mobility

The Turning Point

- Fall at home following multiple falls; unable to safely ambulate with R.W.
- Progressively declining appetite with minimal fluid intake
- Increased confusion
- E.R. to evaluate fall
- Rising CRT noted on intake

The Diagnosis

- C-Diff
- Acute SOB; pulmonary edema
- "AKI": "Her CRT was stable"
- "Cognitive impairment"

The "Conversation"

- "Your mother needs dialysis. If she does not have it in the next two days she will die."
- What conversation existed?
- What real options existed?
- What explanation existed?
- What about the Advance Directives?
- "Lets ask her what she wants."
- **REALLY ?!**

The Dynamics

- 1 Nephrologist: explained the need for dialysis in "medical terms"
- 1 patient "cognitively impaired"
- Husband present: no medical experience. Passive recipient of medical care. What the doctor says goes.
- Family present:
  - 1 Nurse with extensive dialysis experience
  - 1 retired cop with dialysis experience: technician
  - 1 retried state trooper with no medical background
  - 1 daughter in law "home maker"
- Was the conversation reasonably thought out ?
- Was the conversation patient specific?

The Decision

- Dialysis via I.J. cath urgently for acute SOB and pulmonary edema
- Initiation of dialysis with family approval since it was possible "the kidneys will open up" and her CRT was so stable
- Placement of subclavian cath for out-patient treatment
- "Trial" of dialysis: Plans for duration?

The "Aftermath"

- Uncertainty for family regarding dialysis: Honeymoon period following acute incident. Non medical family members noted the drop in acuity.
- Frailty continued to advance
- Appetite worsened
- Falling at home
- Progressive dementia
- "Do I have to do this forever?"

The Outcomes

- Increased confusion
- Increased falls at home
- Discontinuation of dialysis
- Initiation of hospice in the home
- Mortality within the 90 day period
- Hospitalization and decreased QOL
- Conflicting advice; confused family

What Went Wrong Here?

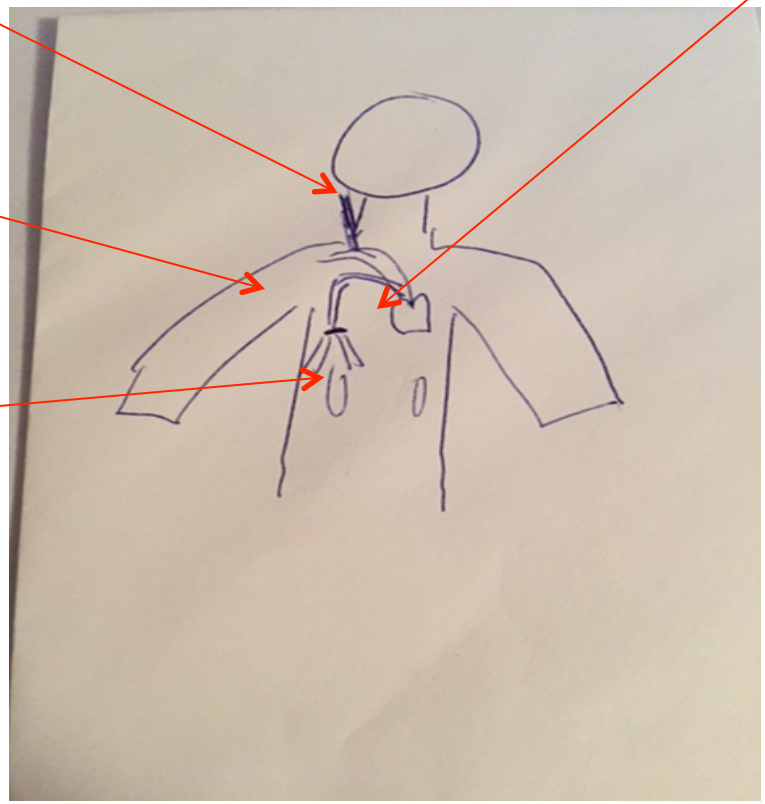
- Lack of provider initiated conversation surrounding status and QOL
- Lack of education about dialysis and options
- Disregard for written HCP
- Private family conversation
- Transparency in diagnosis
- Planning after initiation of H.D.

Debbie's Educational Drawing

Internal jugular vein

Tesio catheter

The kidneys or "boobs"



The Heart

What could have been taken into account?

Recommendations	Description
1. Shared decision making	Participant should at minimum involve patient and provider. If patient lacks capacity, their agent.
2. Informed consent or refusal	Physicians should fully inform patients about diagnosis, prognosis, and ALL treatment options
3. Estimating prognosis	Discussions should occur about life expectancy and QOL. Documented and dated
4. Conflict resolution	Systematic approach for conflict resolution if there is disagreement regarding benefits of dialysis between the pt. or legal guardian and a member of the renal care team. This approach should review the process for conflict from miscommunication or misunderstanding about prognosis, intrapersonal or interpersonal issues, or values.

- RPA guidelines revised in 2010
- "Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis"
- Are we following our own advice?

RPA Guidelines Con't

Recommendations	Description
5. Advance Directives	The renal team should attempt to obtain written advance directives from ALL dialysis patients
6. Withholding or withdrawing dialysis	This is appropriate for: those making the voluntary choice to discontinue or refuse dialysis, patients who no longer posses decision making capacity who previously refused in written format, patients who no longer posses decision making capacity and whose properly appointed agents refuse dialysis, patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior
7. Special Patient Groups	It is reasonable to consider not initiating or withdrawing dialysis for patients with ARF or ESRD who have a terminal illness from a non-renal cause or whose medical condition precludes the technical process of dialysis
8. Time limited trials	For pts requiring dialysis , but who have an uncertain prognosis, or form whom a consensus cannot be reached about providing dialysis providers should consider
9. Palliative care	All patients who decide to forego dialysis or for whom such a decision is made should be treated with continued palliative care. With the patient's consent experts should be involved in such care.

Let's say it Again….

- Recommendation No. 6: Withholding or Withdrawing Dialysis

"Patients who no longer possess decision making capacity who have previously indicated refusal of dialysis in an oral or written advance directive"

A Promise of Education…

Case Study #2

- 86 year old AA male presented to ER with c/o cold symptoms x past few days & fluid draining from right ear.

- PMHx: HTN, CVA 2001 w/residual right-sided weakness, COPD, CKD stage IV, Prostate CA, ASHD, Dementia, Hyperlipidemia, early stages Parkinson's Disease.

Case Study # 2

- Standard work-up in ER was performed
- Pt diagnosis revealed Right ear infection, dehydration, ARF
  - Initial bloodwork: BUN 122/ Creatinine 7
- ID & Renal consults were called
- Discussion with pt's family ensued
- Plan: Administer ABT; Hydrate with IV fluids; watch bld work daily

Case Study # 2

- Trend of bloodwork

INITIAL	BUN = 122	CREATININE = 7
DAY 1	BUN = 128	CREATININE = 6.6
DAY 5	BUN = 86	CREATININE = 5.8
DAY 14	BUN = 43	CREATININE = 4

- Daily consults with Nephrologists – Family wishes vs. Medical Advice
- Meanwhile, pt's hospital stay further complicated by aspiration pneumonia, failure of swallow eval, g-tube placement, immobility, progression of dementia
- Finally, mutual decision reached and pt discharged to skilled rehab facility

Case Study # 2

- Once admitted to skilled rehab facility, Medical Director called pt's family upon return of pt's initial bloodwork
- Lack of communication between hospital and rehab facility –MD would not listen to family and insisted pt be seen by nephrologist immediately
- Pt readmitted to hospital few days later for diagnosis of dehydration

Case Study # 2

- Discussions with Nephrology team continued
- Meanwhile, pt's health continued to further decline
- Quality of Life Discussion Point:
  - Would initiating hemodialysis be appropriate for this pt?
  - Review of quality indicators –
    - Pt's frail state
    - Pt's medical history in conjunction with advanced age
    - Pt stopped speaking to family or anyone in his presence – progression of dementia
    - Pt unable to eat food – dependent on g-tube for nutrition
    - Pt immobile – unable to walk/ Hoyer transfer
    - Pt incontinent

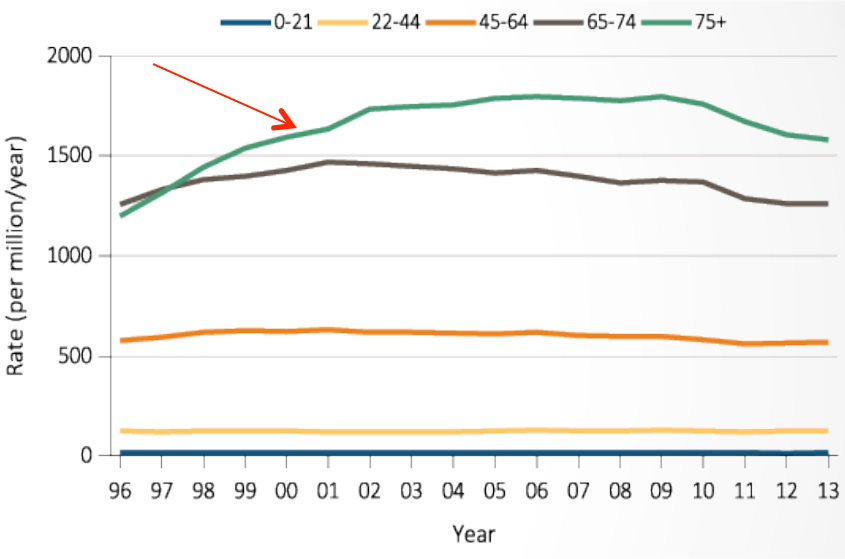
Case Study # 2

- After meeting with patient's family and Hospital's Care Team, it was decided to place pt on Hospice Care.
- Pt was transferred to Hospice Care that day within 2 hours
- Pt expired in Hospice Care within 8 hours of transfer

Case Study # 2

The Aging Dialysis Population

- CKD patients
  - largest group: >60 years old
- 2010
  - >110,000 incident dialysis patients
  - 49.5% : > 65 years old
  - Fastest growing group was patients >75 years old
  - Now stabilizing



U.S. Renal Data System, USRDS 2014 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2014.

The Reality of Dialysis After Age 75

- Elderly persons > 75 Y/O compromise about 12% of the population
- By 2050 it is expected to increase to 25% of the world population.
- Fastest growing segment of elderly are those > 85 Y/O
- Between 1996 and 2003 initiation of dialysis in the elderly increased by 57%

Murea & Burkart, 2016

What about survival?

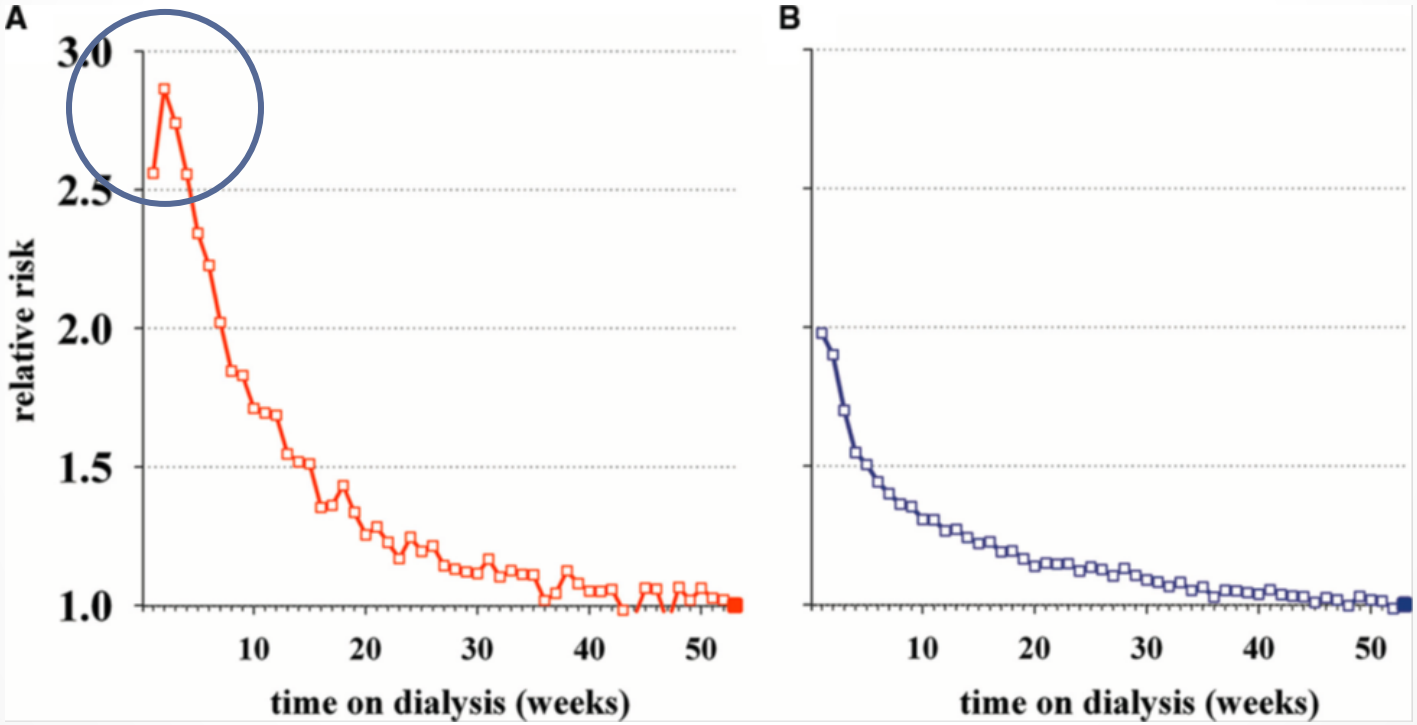
	ESRD patients, 2013				General U.S. population, 2012	
	Dialysis		Transplant			
Age	Male	Female	Male	Female	Male	Female
0-14	24.1	22.4	59.2	61.2	70.7	75.4
15-19	20.9	19.3	46.8	48.6	59.7	64.4
20-24	18.1	16.5	42.5	44.2	55.0	59.5
25-29	15.8	14.3	38.6	40.2	50.3	54.6
30-34	14.1	13.0	34.7	36.4	45.7	49.7
35-39	12.5	11.7	30.8	32.4	41.0	45.0
40-44	10.8	10.3	26.9	28.6	36.4	40.3
45-49	9.1	8.8	23.2	24.8	31.9	35.6
50-54	7.7	7.7	19.8	21.3	27.7	31.1
55-59	6.5	6.6	16.6	18.1	23.7	26.8
60-64	5.5	5.7	13.8	15.2	19.8	22.6
65-69	4.5	4.8	11.4	12.7	16.2	18.5
70-74	3.8	4.0	9.4	10.4	*12.8*	*14.7*
75-79	3.2	3.5	7.7a	8.6a	9.8	11.3
80-84	2.6	2.9			7.1	8.4
85+	2.1	2.4			4.9	5.8

Table 6.4 Expected remaining lifetime (years) by age, sex, and treatment modality of prevalent dialysis patients, prevalent transplant patients, and the general U.S. population (2012), based on USRDS data and the National Vital Statistics Report (2013)

The First 90 Days

Mortality

Hospitalization



- (Chan,et. Al., 2011)

Can We Offer Conservative Management?

- 2010 Renal Physicians Association Guidelines (RPA)
  - Recognized as acceptable and **active** treatment
    - Right to **forego** vs. withhold or withdraw dialysis

- Medically manage Stage 4 CKD (CrCl <30ml/min)
  - Targeted treatments of
    - anemia
    - volume status
    - mineral bone disease
    - cardiovascular risk factors
    - electrolyte abnormalities

Conservative Management

- Palliative Care Model:
  - Simultaneous medical care to help match care with patient goals
  - Prevention and relief of suffering by ***early*** identification, assessment and treatment of pain and symptoms
  - Providing physical, psychosocial and spiritual care
  - Advance Care Planning
  - Identification of increasing care needs and hospice eligibility

Conservative Management

- For most, dialysis will offer a survival advantage.
- Consideration of QOL
- Median Survival ranges from 6.2-13.4 months.
- Longer survival associated with:
  - Female
  - Lower co-morbidity Score
  - Albumin > 3.5
  - Early referral to nephrology (prior to CKD Stage 5)

- Patients ≥ 75 years with CKD Stage 5 AND ≥2 of the following criteria
  - Clinicians response of "NO" to the surprise question
  - High co-morbidity score (Charleston)
  - Impaired functional status (Karnofsky score < 40)
  - Severe chronic malnutrition (albumin < 2.5g/dL)

Charleston Co-Morbidity

Scoring	Positive Indicators
1	• CAD • CHF • PVD • CVA • Dementia • Chronic Pulmonary Disease • PUD • Mild liver disease • Diabetes
2	• Hemiplegia • Diabetes with end organ damage • Moderate or severe renal disease • Any tumor, leukemia, or lymphoma
3	• Moderate or sever liver disease • Advancing Renal disease
6	• Metastatic solid tumor • AIDS

- Based on age and co-morbidity
- 1 point for every 10 years over 40.
- **Scores**: Low $\leq$ 3; Moderate 4-5; High 6-7 ; Very High $\geq$ 8

Karnofsky Performance Status Scale

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

- Patients are classified according to functional impairment
- Can be used to evaluate effectiveness of therapies or aid in prognosis
- The lower the number, the worse the survival

QOL Considerations

- Time
- Symptoms
- Surgery
- Hospitalizations
  - >400,000 Medicare beneficiaries (≥67 years old)
  - **64.5%** initiated dialysis as inpatient
  - **36.6%** hospitalized for ≥2 weeks

- Courtesy of H. Koncicki, M.D.

Assessment Considerations

- Falls
  - > 45% of elderly dialysis patients have ≥ 1 fall per year
- Functional Status
  - Assistance with ADLS?
- Cognitive Impairment & Dementia
  - Declining levels of renal function associated with increased rates of cognitive decline and mortality

Assessment Considerations

- Frailty (≥3)
  - Unintentional weight loss
  - weakness
  - Poor endurance/exhaustion
  - slowness
  - Low activity

  - Majority of incident dialysis patients display indicators

- Patients with cognitive impairment and frailty are started on dialysis earlier
  - Johansen *JASN* 2007
  - Boa, Y et al 2012

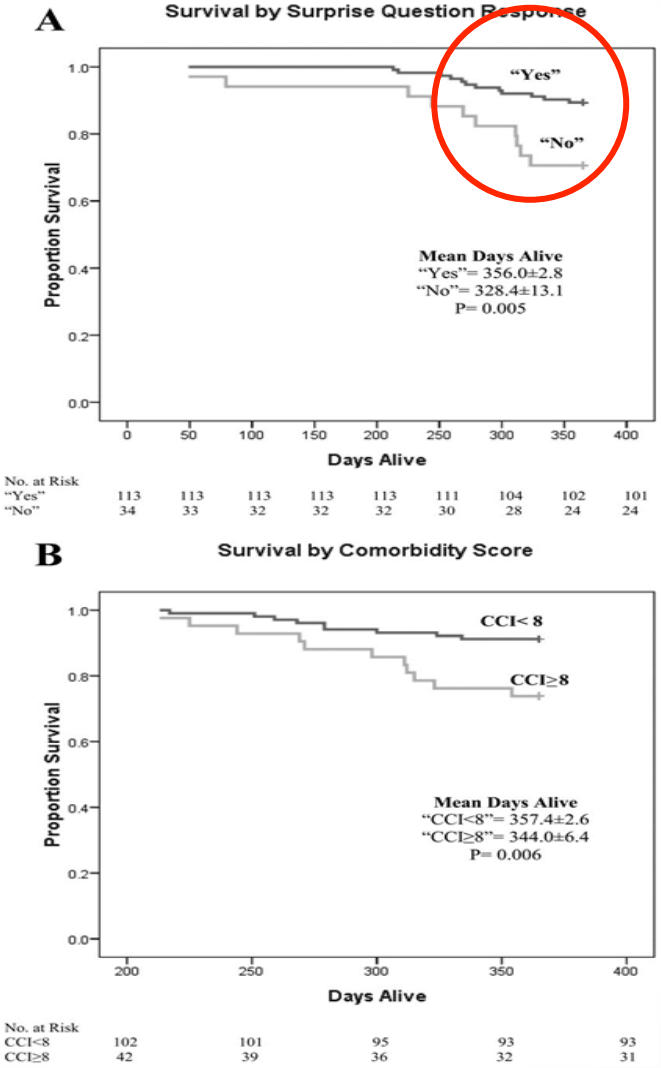
The Surprise Question…..

- Validated in primary care
- Simple to attain an answer and more time sensitive than other forms and tools.
- It has **not** been validated in the dialysis population however has been proven to be a useful clinical tool in primary care.
- Found to be effective in helping physicians identify patients in a primary care population who are terminally ill and for whom palliative care referral is appropriate

The Surprise Question

"Would I be surprised if this patient died in the next year?"

The Surprise Question as a Tool…..



Alvin H. Moss et al. CJASN 2008;3:1379-1384

CJASN

Consider the "Big Picture"

- Patient centered care does not mean we should blindly follow patients' wishes
- Understand the reasons behind the patients request. Consider all factors.
  - Misconception of survival benefit or quality of life?
  - Family or financial reasons? (Contextual – non clinical factors)
- Explore hopes and expectations: Wishes as a tool
- Identify patient and family concerns

"What Do You Want Out of Treatment?"

Some people want to live as long as possible and choose dialysis even at the risk of frequent hospitalizations and less independence. Other people wish to focus on the quality of their lives and prefer treatments that are focused on their symptoms without dialysis even if this meant life could be shorter. Do you have a sense of how you feel about this?"

- Courtesy of: H. Koncicki, MD

How Do You Know a Patient is Declining?

- A response of "no" to the surprise question
- Multiple hospital admissions and complications
- Worsening symptom burden
- Unable to tolerate dialysis treatments.
- Missing treatments or requesting to stop.
- Dialysis access complications
- Unintentional weight loss
- Withdrawing from people, treatments, or hobbies
- Declining functional status, unable to complete ADLs
- Dysphagia (can

Last 90 days of life

Medicare patients with ESRD (2000-2012)

- Hospitalized: 84%
  - 28.2% had 3 admissions in 90 days prior to death
  - Average LOS: 17 days

The Events of The last 90 days of life: (2000-2012)

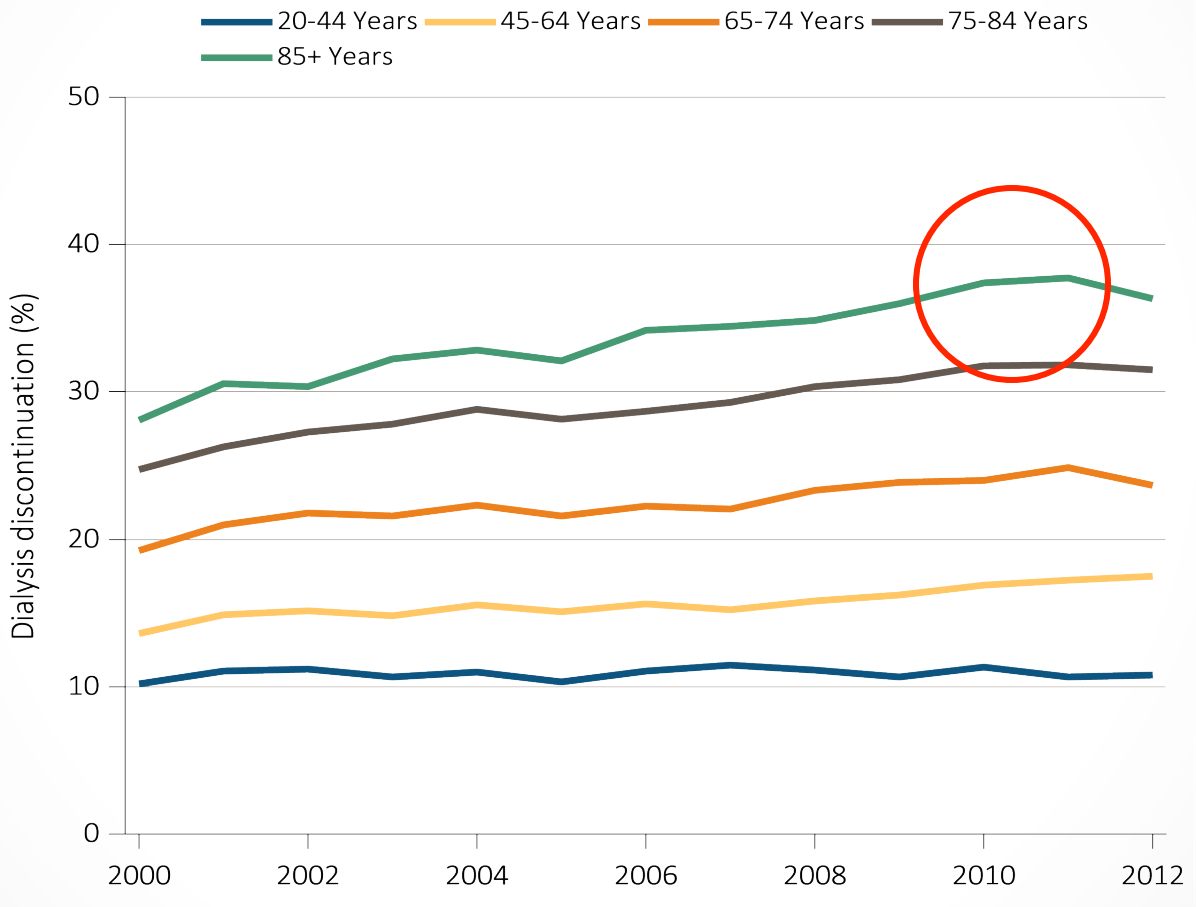
- Admittance to CCU: 50% → 63%
- Intensive procedure:27% → 35%
- Discontinued dialysis prior to death: 19 → 25%

- Less patients died in the hospital (41%) and more are utilizing hospice care (25%)

USRDS 2015

Dialysis Withdrawal

(b) Dialysis discontinuation by age



Data Source: Special analyses, USRDS ESRD Database. Denominator population is all patients with complete data on dialysis discontinuation from the CMS Death Notification form (CMS 2746).

Conclusions

- The advent of technology and medical innovation has made it possible for us to dialyze nearly every complicated case of ESRD
- As healthcare providers we must consider the efficacy of this treatment as it relates to patient status and QOL.
- We need to take time to consider the individual characteristics of our patients and carefully construct a plan of care that is in line with our patient's wishes.

Thank You

- Acknowledgment to Holly Koncicki, MD Northwell Health who provided me with much of the content in the slides and has taught me so much about conservative care in CKD and ESRD.

Final Thought

- There are very few things certain in life except for these two:
- We were all born and we will all die
- What truly matters is the journey that takes us between these two points in time, the lives we touch and the changes we can make.

Resources

- Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, Clinical Practice Guidelines, Second Edition- RPA-Renal Physicians Association
- Five Wishes – www.agingwithdignity.org
- Being Mortal by Atul Gawande, M.D.
- The Conversation –A Revolutionary Plan for End of Life Care by Angelo E. Volandes, M.D.
- The Good Death – An exploration of Dying in America by Ann Neumann
- https://www.ag.ny.gov/sites/default/files/pdfs/publications/Planning_Your_Health_Care_in_Advance.pdf