

# PALLIATIVE CARE IN THE END STAGE RENAL DISEASE (ESRD) POPULATION: BEYOND THE BASICS AND INTO THE FUTURE



knowledge changing life

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## CONFLICTS OF INTEREST

We have no financial or other conflicts of interest to disclose

“Palliative Care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

- WHO definition (2002)

“Palliative Care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

- WHO definition (2002)

**Patients with ESRD have a life-threatening illness that is nearly always identified very early and they have an illness course that is typically filled with a multitude of problems be they physical, psychosocial, or spiritual**

## GEORGE

George is an 68 year old male who has lived with diabetes for the past 18 years. He has developed diabetic nephropathy with chronic kidney disease. He has been following with his nephrologist and the plan was to eventually proceed with hemodialysis. Over the past three years, his renal function has declined progressively to the point of end-stage renal disease.

George meets with his nephrologist and decides to proceed with thrice weekly hemodialysis.

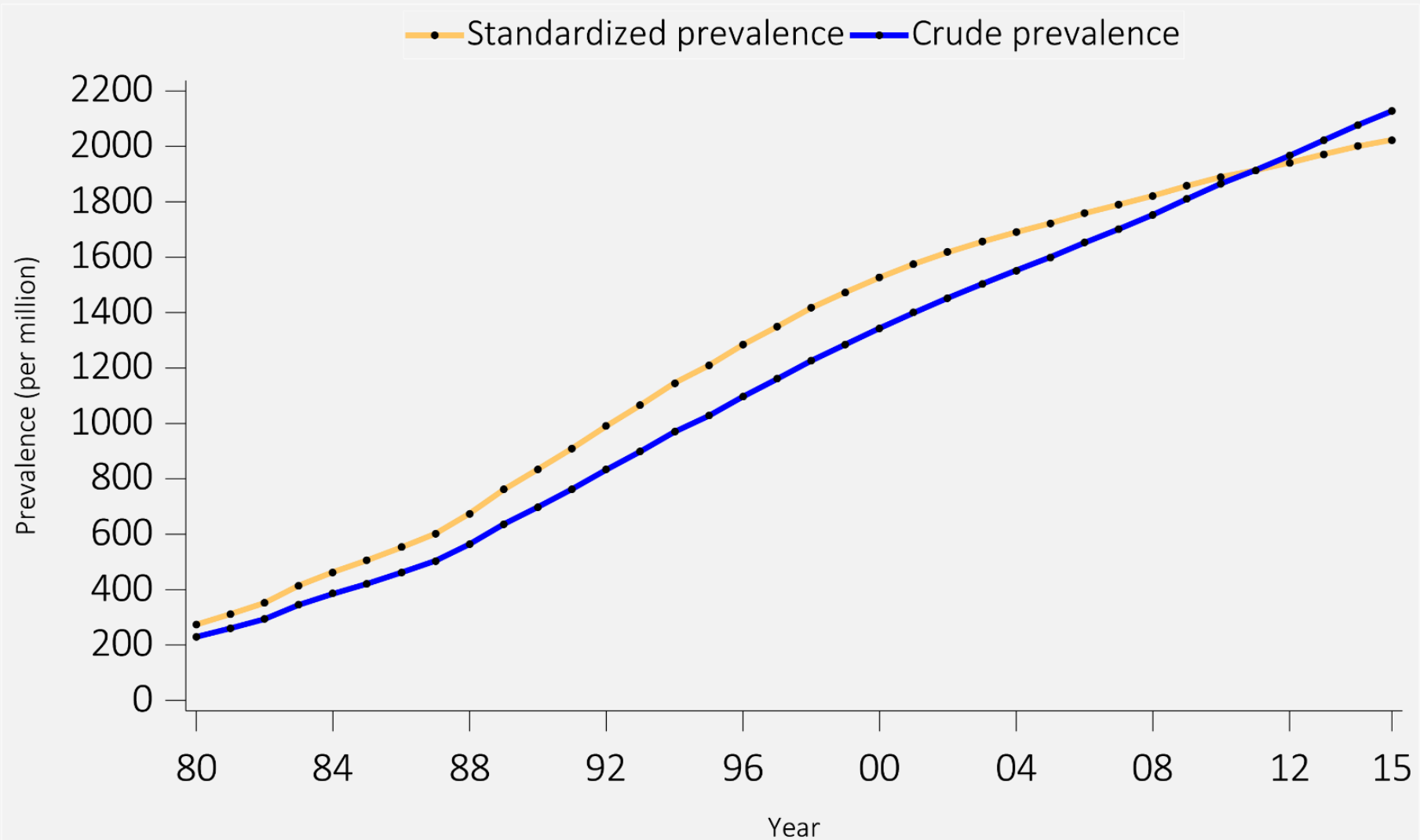
# OBJECTIVES

1. Provide background on the epidemiology of end-stage renal disease and dialysis utilization
2. Describe care models for incorporation of palliative care services for nephrology patients
3. Explore symptom management considerations in the setting of renal failure
4. Discuss hospice utilization for the ESRD patient population

# OUTLINE

1. ESRD Epidemiology
2. Changes in the ESRD population over 50 years
3. Average day for an average ESRD patient
4. Clinical course and prognosis
5. Hospice care for the ESRD patient
6. Symptom management- special considerations in the ESRD patient
7. The current (lack of) palliative nephrology approach
8. The future: models to integrate palliative medicine and nephrology care for those with ESRD

# ESRD PREVALENCE 1980-2015



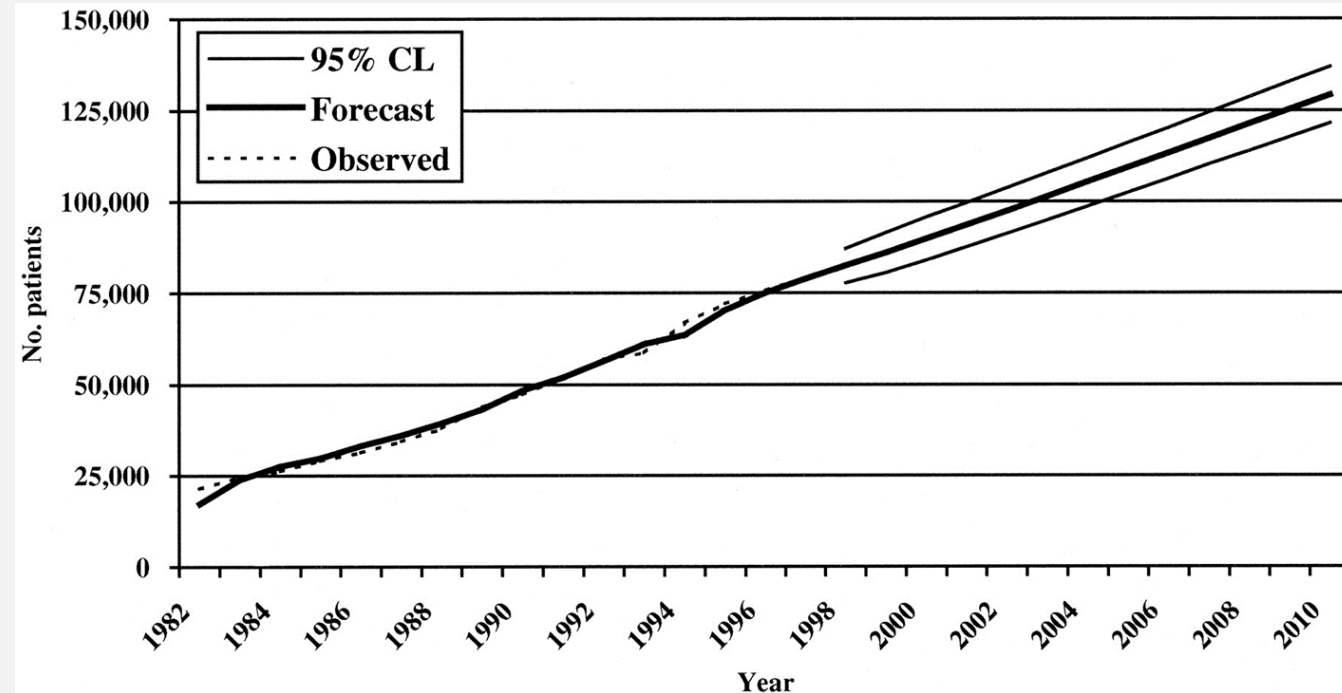


## ESRD CLINICAL COURSE AND PROGNOSIS

- Survival rates from time of dialysis initiation
  - 76% 1 year
  - 36% 5 year
- Mortality 2x that of cancer, CHF, or CVA
- Older patients with greater morbidity and mortality
  - For those >85 years old...
    - Median survival 6 months
    - 1/3 of that time spent in the hospital

# EVOLUTION OF THE “TYPICAL” ESRD PATIENT

- 1972: United States ESRD program started
  - Prior: ESRD universally fatal
- Population: Healthy → Sick
  - People are living long enough to get sick from other things
- High symptom burden<sup>1</sup>
  - Edmonton Symptom Assessment System (ESAS):
    - Mean of 7.5 +/- 2.5 symptoms
    - 4.5 are severe symptoms

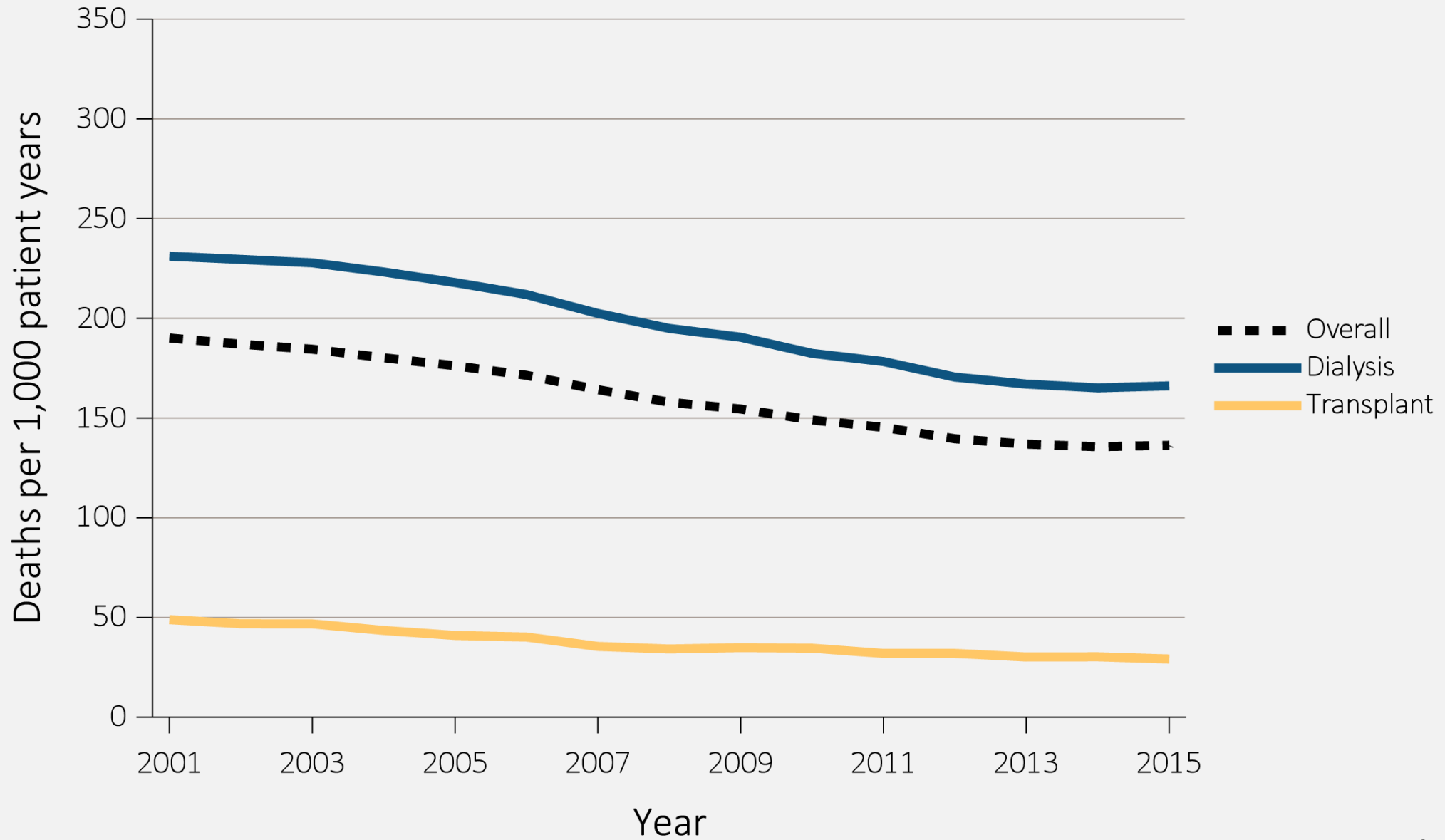


Jay L. Xue et al. JASN 2001;12:2753-2758

## HOW HAS THE ESRD POPULATION CHANGED SINCE 1972?

- Rehab or bridge to transplant —> Prolong life
- One-half of dialysis patients > 65 years-old
- 75% increase in incident ESRD over last 20 years!
- Survivorship remains poor
  - 36% 5 year survival in all patients
  - 25% 5 year survival in people > 75 years-old

# ADJUSTED ALL-CAUSE MORTALITY



# ESTIMATING 6 MONTH MORTALITY FOR PATIENTS ON MAINTENANCE HEMODIALYSIS

- Lack of clinical tools available for prognostication leads to fewer discussions about prognosis
- Cohen et al (2010)
  - Actuarial data + clinician prediction (surprise question)

*Table 3. Multivariable model of survival in the derivation cohort (n = 449 patients with complete data, 103 died)*

Variable <sup>a</sup>	HR	95% CI
SQ, not surprised <i>versus</i> surprised	2.71	1.75 to 4.17
Albumin (HR expressed for a 1-U increase)	0.27	0.15 to 0.50
Age (yr; HR expressed for a 10-yr increase)	1.36	1.17 to 1.57
PVD, yes <i>versus</i> no	1.88	1.24 to 2.84
Dementia, yes <i>versus</i> no	2.24	1.11 to 4.48

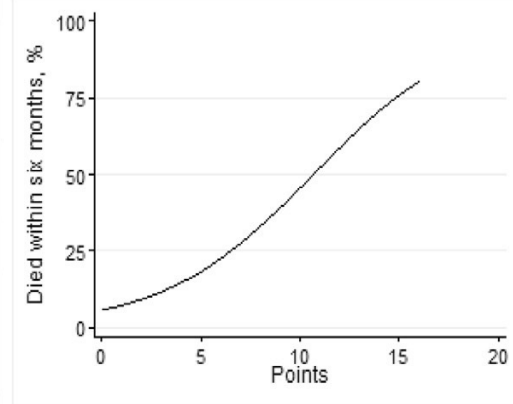
Clin J Am Soc Nephrol 5: 72-79, 2010

- Appeared to be a terrific tool for predicting mortality
  - (AUC 0.87 derivation cohort, 0.80 in validation cohort)
- Forzley et al (2017) - Cohen model overpredicted mortality in a Canadian cohort

# NEWEST MORTALITY PREDICTION MODEL

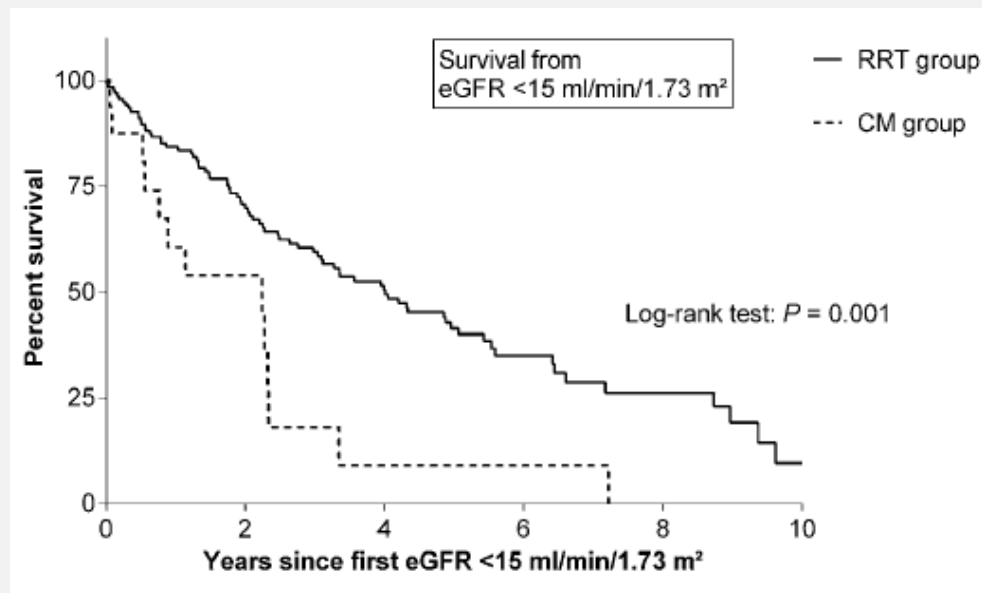
Predictors		Assigned Points
<b>Age (Years)</b>	<b>Points</b>	
65 – 69.....	0	<input style="width: 40px; height: 40px;" type="text"/>
70 – 74.....	0	
75 – 79.....	0	
80+.....	2	
<b>eGFR (mL/min/1.73m<sup>2</sup>)</b>	<b>Points</b>	
0 – 9.9.....	0	<input style="width: 40px; height: 40px;" type="text"/>
10 – 14.9.....	1	
15+.....	3	
<b>Atrial Fibrillation</b>	<b>Points</b>	<input style="width: 40px; height: 40px;" type="text"/>
	2	
<b>Chronic Heart Failure</b>	<b>Points</b>	<input style="width: 40px; height: 40px;" type="text"/>
	2	
<b>Lymphoma</b>	<b>Points</b>	<input style="width: 40px; height: 40px;" type="text"/>
	5	
<b>Metastatic Cancer</b>	<b>Points</b>	<input style="width: 40px; height: 40px;" type="text"/>
	3	
<b>Hospitalized in last 6 mos.</b>	<b>Points</b>	<input style="width: 40px; height: 40px;" type="text"/>
	2	

**Total Score**

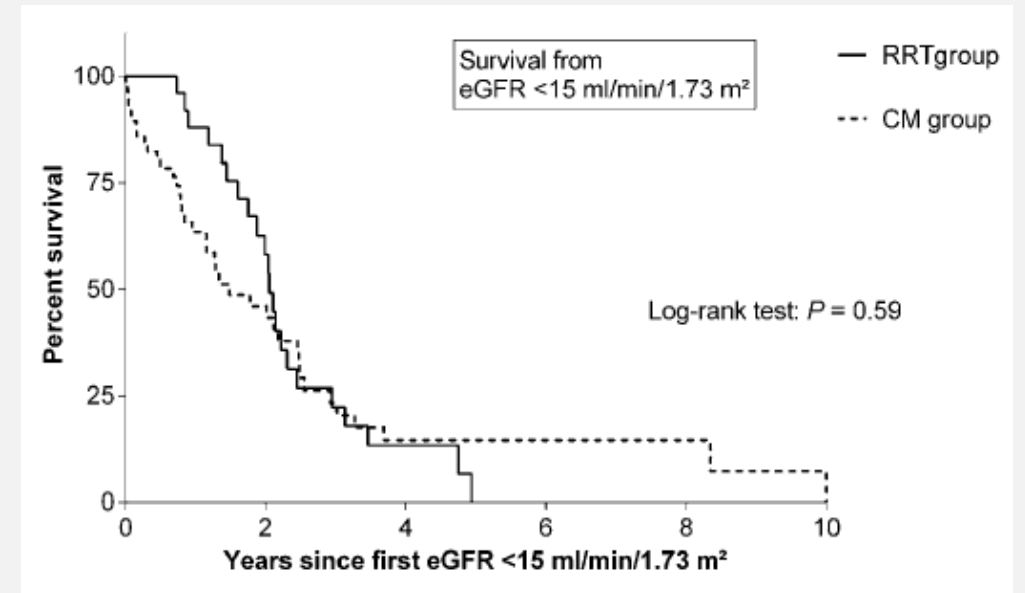


# COUNSELING ELDERLY PATIENTS REGARDING DIALYSIS INITIATION

70-79 Years Old



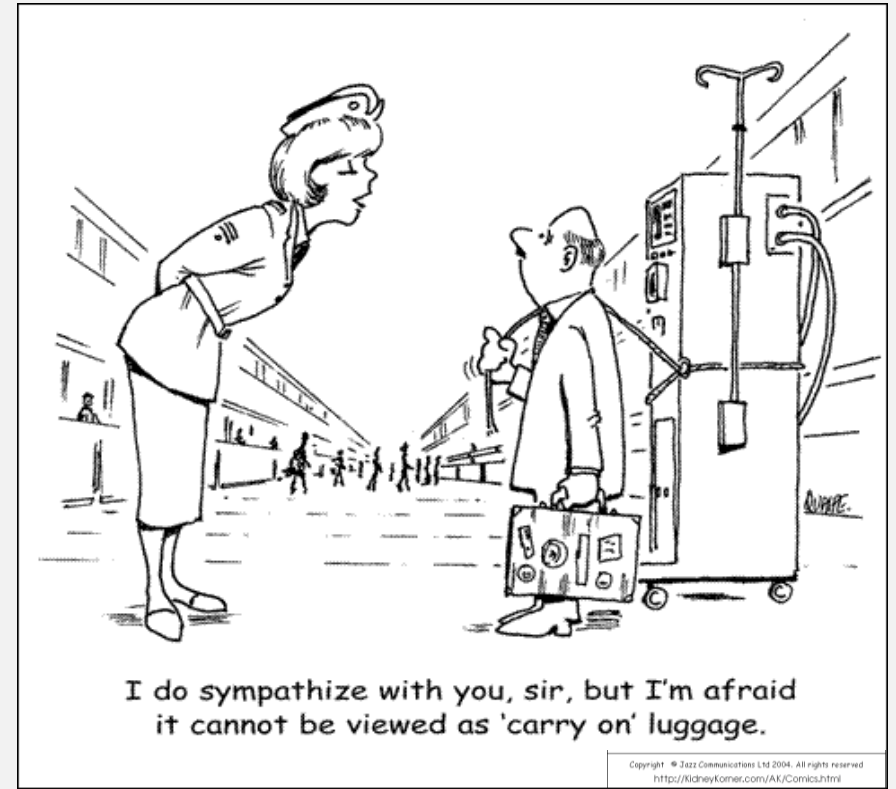
>80 Years Old



\*\* No survival advantage among patients age >80 choosing dialysis over conservative management

# DIALYSIS JOB DESCRIPTION

- Full time
- No vacation
- Expected to work from home
  - 7.5 symptoms - 4.5 severe  
(Edmonton Symptom Assessment System)
- Business trips - several weeks per year





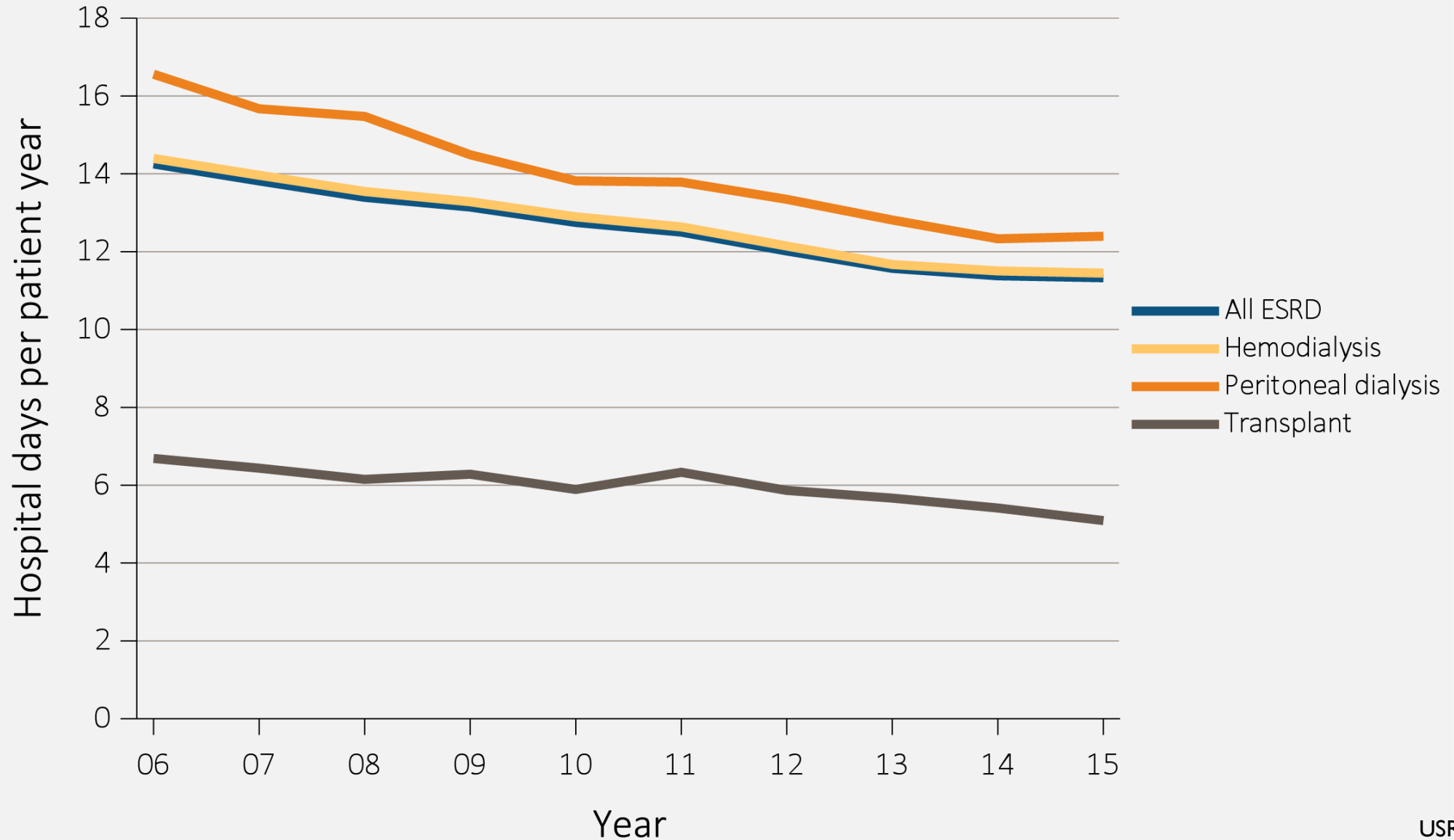
# A DAY IN THE LIFE...

- Wake up at 05:00 Monday/Wednesday/Friday
- Either drive self or receive transportation
- 10-15 minutes in waiting room
- 4 hours of dialysis\*
- Either drive self or receive transportation
- Fatigue post-dialysis and recover remainder of day
- Feel well the next day
- Repeat



\*The process works with industrial efficiency at hemodialysis units

# HOSPITAL DAYS FOR ESRD PATIENTS 2006-2015



# ESRD AND HOSPICE UTILIZATION

- 20% of dialysis patients utilize the hospice benefit
  - Compared with....
    - 55% of those with cancer
    - 39% of those with heart failure
  - Utilization is generally in the last days of life
- 18% of maintenance hemodialysis patients preferred to live as long as possible even if it meant suffering
- 45% of dialysis patients die in the hospital
  - Versus 35% of Medicare beneficiaries with other severe illness (CHF, ESKD, dementia, COPD)
  - 9.8 days in hospital in last month of life

# ESRD HOSPICE CRITERIA

## **CMS hospice criteria for kidney failure as a terminal diagnosis**

- Serum creatinine 8 mg/dL or greater (6 mg/dL or greater in patients with diabetes)
- or
- Creatinine clearance <10 mL/min/1.73 m<sup>2</sup> (<15 mL/min/1.73 m<sup>2</sup> for individuals with diabetes)
- or
- Symptoms

## **CMS hospice benefits and eligibility specific for kidney failure**

Home Health and Hospice Benefits Available for ESRD Beneficiaries, tagline 50.6.1.

- “Medicare beneficiaries can receive care under both ESRD benefit and the home health or hospice benefits. The key is whether or not the services are related to ESRD.”
- “If the patient’s terminal condition is not related to ESRD, the patient may receive covered services under both ESRD benefit and the hospice benefit. A patient does not need to stop dialysis treatment to receive care under the hospice benefit.”

## GEORGE

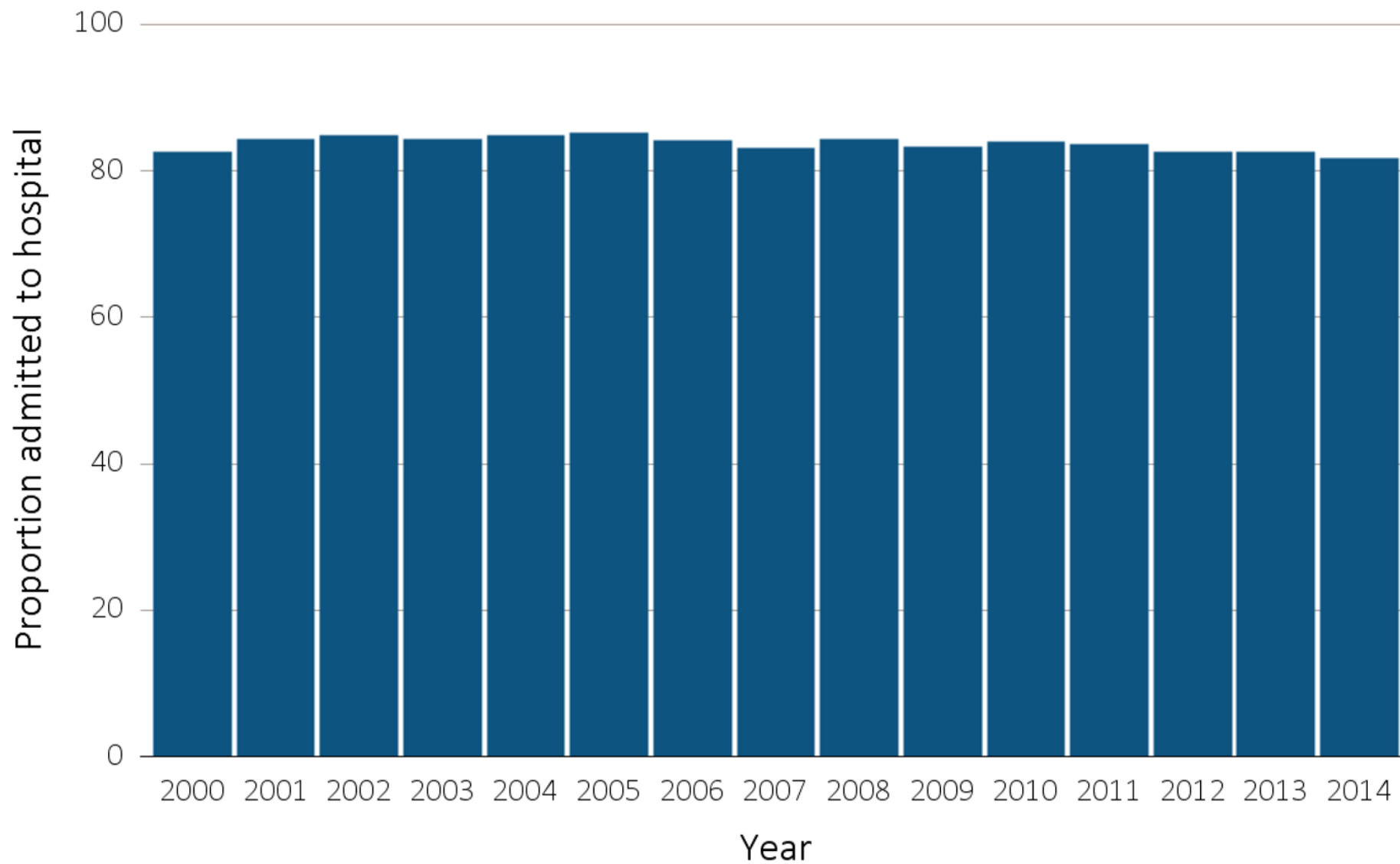
George underwent arteriovenous fistula placement and was able to initiate dialysis in the outpatient setting. He has remained on hemodialysis for the past two years.

Over the last week, he developed shortness of breath and presented to the ER. He was found to have what looks like an infiltrate on his chest x-ray.

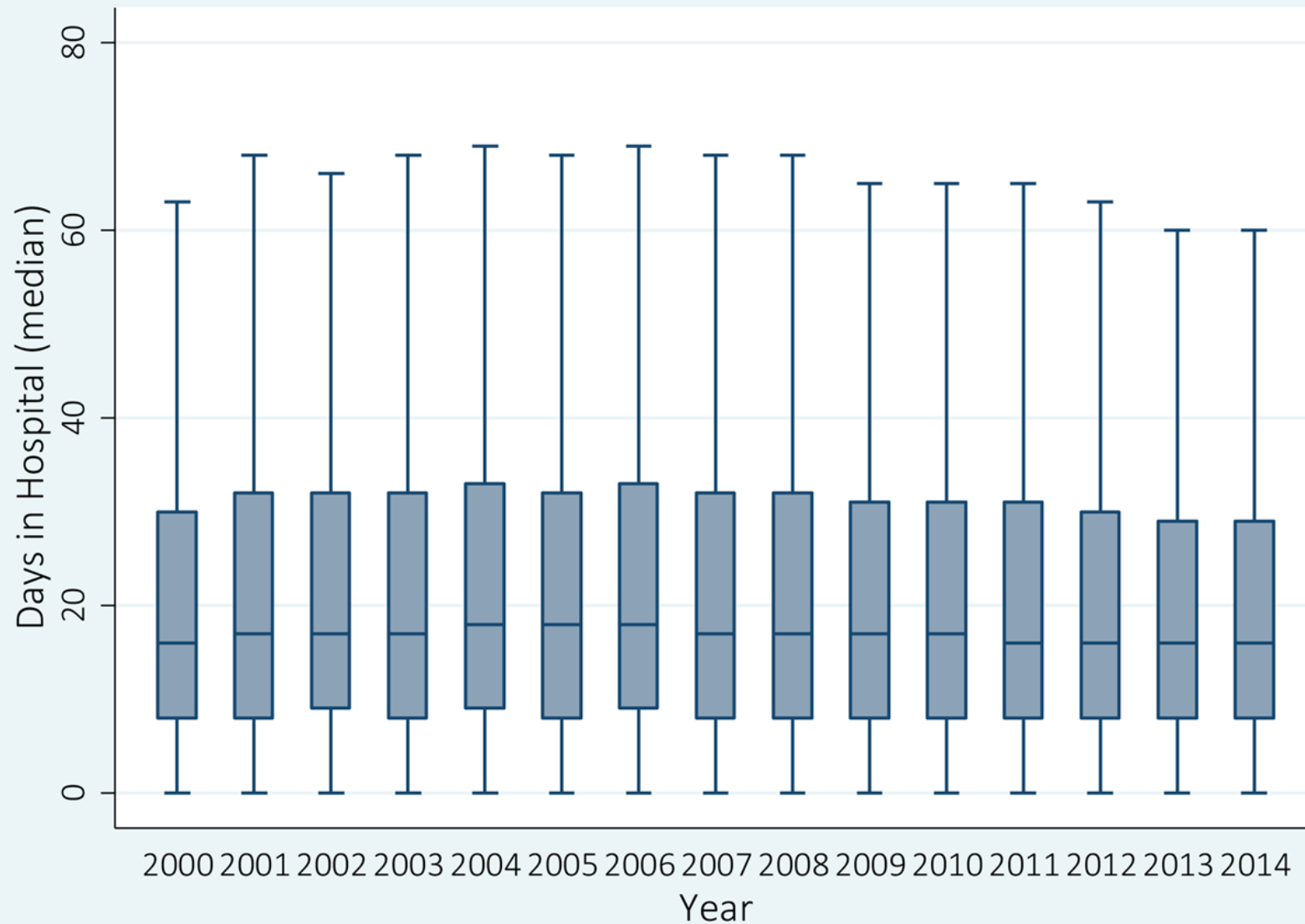
He was admitted to the hospital for IV antibiotics for pneumonia.

# HOSPITAL ADMISSIONS IN LAST 90 DAYS OF LIFE

## 2000-2014

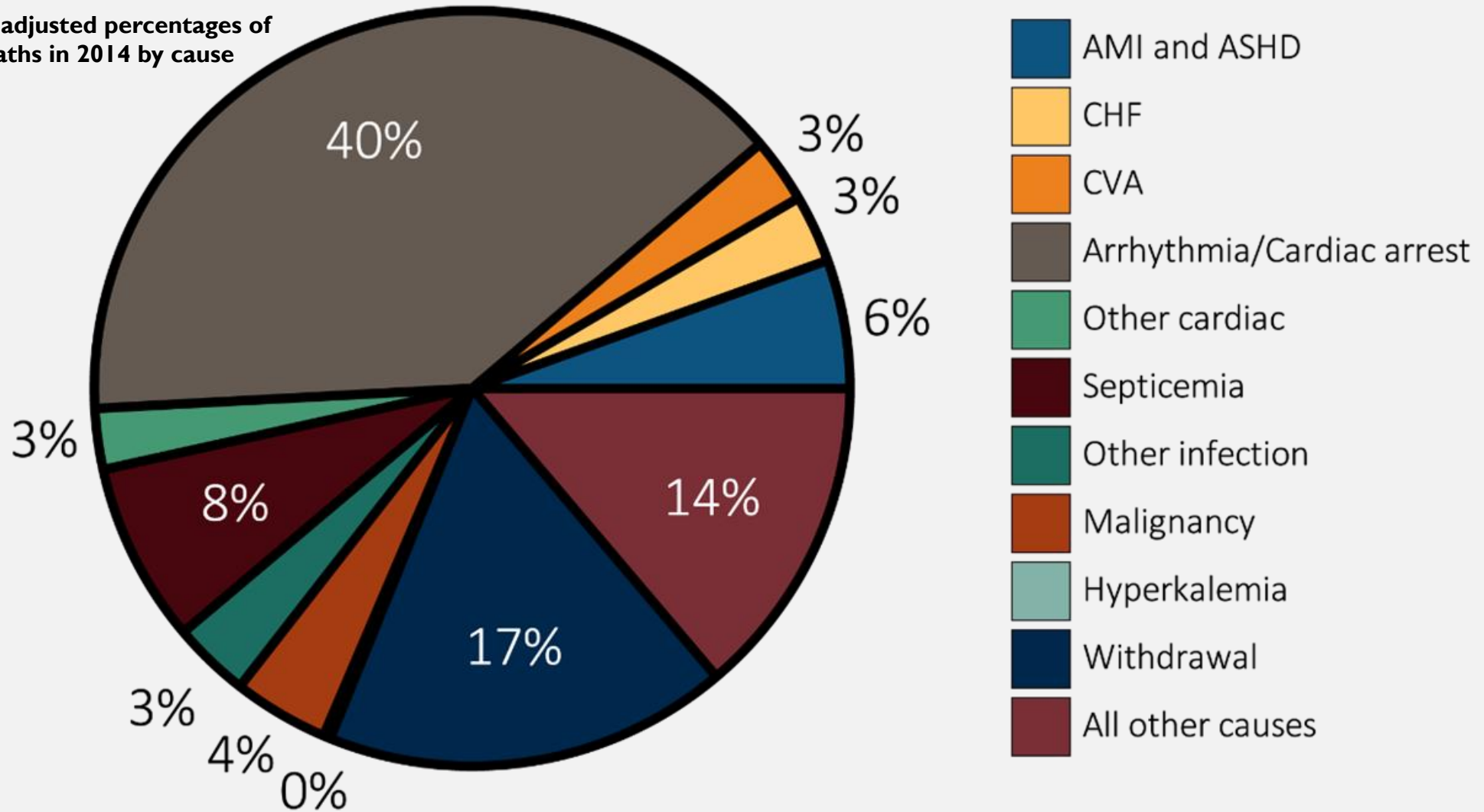


# HOSPITAL ADMISSIONS WITH PROLONGED STAYS



# HOW DO ESRD PATIENTS DIE?

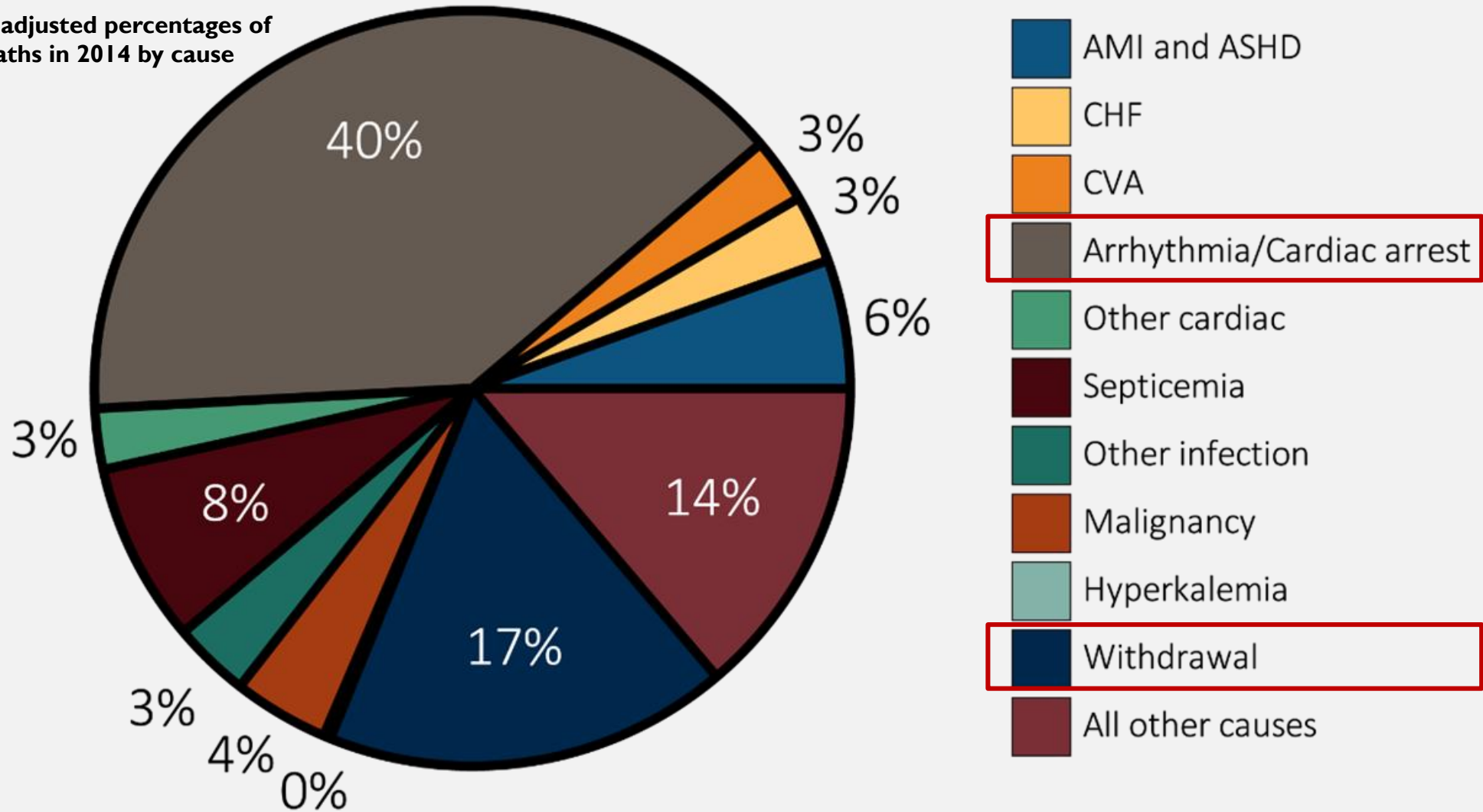
Unadjusted percentages of deaths in 2014 by cause



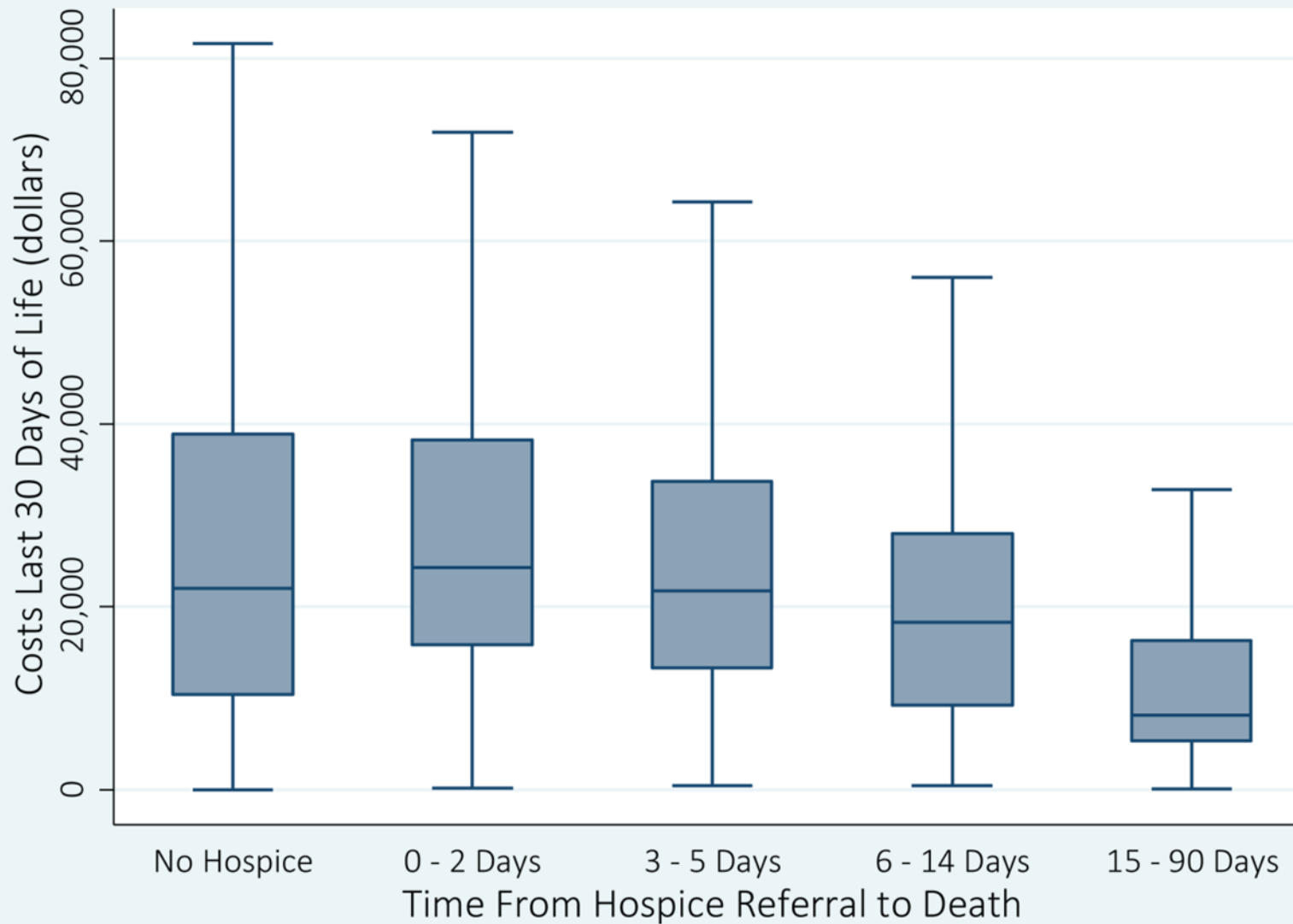


# HOW DO ESRD PATIENTS DIE?

Unadjusted percentages of deaths in 2014 by cause



# UTILIZATION OF HOSPICE RESULTS IN COST REDUCTION



## GEORGE

George remains admitted for three days without improvement in his respiratory status.

A CT scan is performed and demonstrates a large lung mass concerning for malignancy with evidence of widely metastatic disease in the liver, lymph nodes, and bones.

Palliative care is consulted to discuss goals of care with George and his family. George is considering a transition to a comfort plan of care, including consideration of stopping dialysis, but is worried about what symptoms may arise from his renal failure...

## SYMPTOM MANAGEMENT CONSIDERATIONS

1. Pain
2. Dyspnea
3. Pruritis
4. Agitation
5. Secretions
6. Nausea and Vomiting

# PAIN MANAGEMENT GENERAL CONSIDERATIONS

- Utilize a step-wise approach based on the WHO ladder
  - Similar to non-ESRD patients
- Non-opioid analgesics
  - Acetaminophen is the non-narcotic choice
  - Limit NSAIDs
    - Further renal impairment, hypertension, edema, hyperkalemia can result
- Consider opioid pharmacokinetics
  - Morphine metabolites are renally cleared
    - Use can result in opioid toxicity
    - Avoid in ESRD patient

## PAIN MANAGEMENT OPIOID CONSIDERATIONS

Tramadol	- Maximum dose 50 mg BID
Oxycodone	- Safer than morphine due to hepatic metabolism - Excreted in urine → start at lower dose and frequency
Morphine	- Metabolites accumulate and can cause toxicity
Hydromorphone	- Metabolite (hydromorphone-3-glucuronide) can accumulate - Fewer side effects than morphine, however anecdotal evidence with safety concerns - Use with caution in ESRD patients
Fentanyl	- Dose similar to patients with normal renal function - Shortest acting
Methadone	- Metabolism may be impacted by renal impairment, dose reduce 50-75% - Recommend specialist involvement

## PAIN MANAGEMENT ADJUVANTS

Gabapentin	<ul style="list-style-type: none"><li>- Adjunct for neuropathic pain</li><li>- Elimination directly related to GFR</li><li>- 35% removed during hemodialysis</li></ul>
Anticonvulsants	<ul style="list-style-type: none"><li>- Adjuncts for neuropathic pain</li><li>- Data limited in ESRD patients, therefore consider specialized dosing for ESRD patients</li></ul>
Antidepressants	<ul style="list-style-type: none"><li>- Tricyclics: significant adverse effects (sedation, anticholinergic) despite hepatic metabolism</li></ul>
Corticosteroids	<ul style="list-style-type: none"><li>- Same considerations as patients with normal renal function</li></ul>

# DYSPNEA

- Multifactorial etiology
  - Inflammation associated with the active dying process
  - Volume overload associated with renal disease
- Opioid considerations same as those described for pain
- Utility of diuretics?
  - Can have efficacy in volume removal if patient making urine
  - Requires a high dose (can estimate 20 x creatinine)
  - Remind patients about stopping lab monitoring



# PRURITIS

- Secondary symptom with multifactorial etiology
  - 2° hyperparathyroidism, hyperphosphatemia, calcium deposition, dry skin
- Primary management:
  - Xerosis: Emollients
  - Anti-histamines
  - UVB light (2-3 times per week)
- Alternative interventions without clear evidence base
  - Gabapentin: Dosing limited in ESRD
  - Capsaicin: Burning may be problematic
  - Cholestyramine: May impact absorption of other medications

# TERMINAL AGITATION AND ANXIETY

- Evidence base limited, therefore based on expert consensus
- Benzodiazepines: More unbound medication available and can cause drowsiness
  - If utilized would require dose reduction
- Most benefit from antipsychotic medications
  - [Haloperidol](#) recommended

# TERMINAL SECRETIONS

- Treat only if causing patient discomfort
  - Loud secretions can be distressing for care providers and family
- Recommend utilization of medications that do not cross the blood brain barrier
  - Can cause paradoxical agitation in the setting of uremia
- Medication options similar to other patients
  - Atropine drops
  - Glycopyrrolate
    - Can accumulate in the setting of renal impairment
    - Start at 50% normal starting dose

# NAUSEA AND VOMITING

- Uremia induced nausea due to stimulation of chemoreceptor trigger zone
- Recommended first line drug: [Haloperidol](#)
  - Metabolites may accumulate
  - Start at 50% of normal dose
- Second line: Chlorpromazine
- Avoid use of Metoclopramide
  - Increased incidence of extrapyramidal reactions

# DOES USE OF ERYTHROPOIETIN STIMULATING AGENTS CONTRIBUTE TO COMFORT?

- Retrospective cohort study in Hong Kong – 2011-2013
  - Non-dialysis palliative care
  - ESA versus non-ESA control over 6 months
  - Baseline: 91% patients fatigued, 83% moderate-severely fatigued
  - ESA group (6 months)
    - Improvement in fatigue ( $P < 0.05$ )
    - Reduced hospitalizations per patient year (4.4 versus 9.2,  $P < 0.001$ )
- Expensive – Medicare spends \$2B annually (10% of ESRD spending)

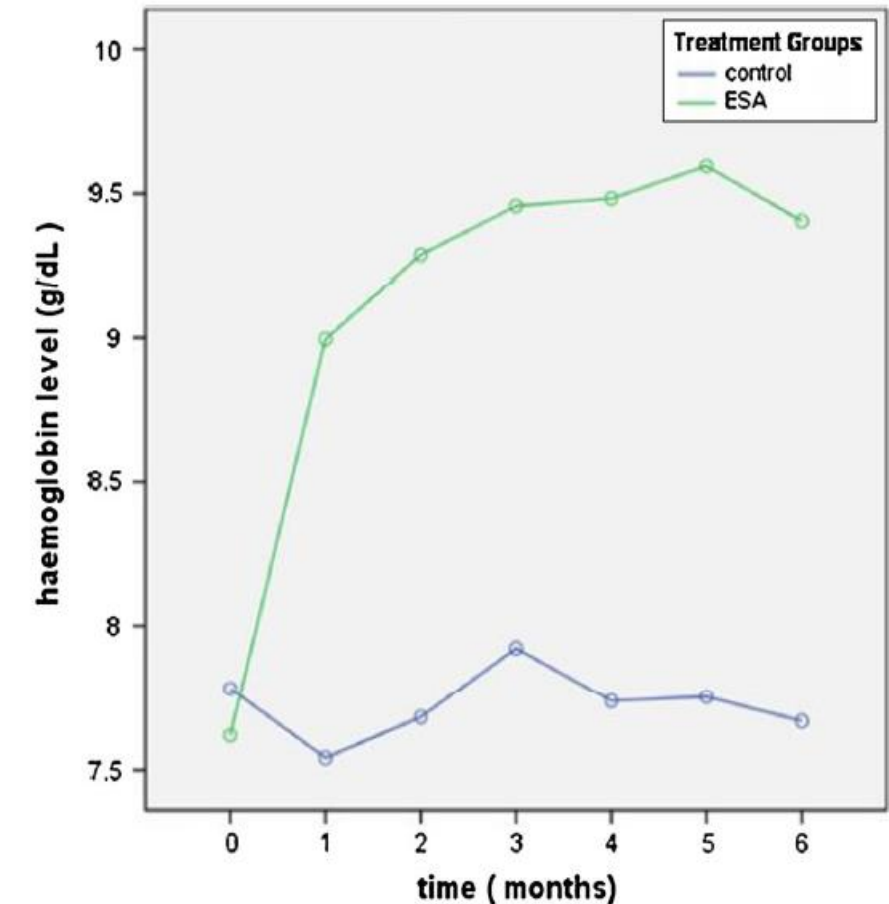


Fig. 1 Temporal change of Hb levels in palliative ESRD patients on ESA versus control

## GEORGE

George elects to transition to a comfort plan of care and enrolls in home hospice.

He initially develops nausea and agitation which is effectively managed with haloperidol. Over the subsequent days, he also develops dyspnea and requires initiation of IV hydromorphone.

He dies 9 days after enrolling in home hospice.

**THE IDEAL:  
SHARED DECISION-MAKING IN ESRD**

## IS THIS AN ISSUE OF IMPROVING THE INFORMED CONSENT PROCESS FOR DIALYSIS?

- Study of patients on maintenance dialysis:
  - 30% said risks/benefits of HD were described to them
  - 1% recalled option of conservative therapy
- Boston study of dialysis patients:
  - Zero patients reported having a discussion of prognosis
- Canadian study:
  - 61% of patient regretted dialysis
  - One half reported starting dialysis because it was the nephrologist's wish
- National survey of nephrology fellows: 1 in 5 felt obligated to offer dialysis to every patient, regardless of benefit (or lack thereof)



# THE DISCONNECT

**Table 1.** Findings from the patient experience survey.

71% [95% CI: 64, 77]	Felt confident enough to ask questions and discuss concerns with the team.
50% [95% CI: 42, 57]	Felt that their concerns were taken seriously.
65% [95% CI: 58, 72]	Felt that their treatment options had been clearly explained to them.
48% [95% CI: 41, 55]	Felt that they had been sufficiently involved in treatment decisions.

**Table 2.** Mean confidence scores for training participants.

No.	Question	Pre-training (95% CI)
1	Discussing psychological problems with patients with ESKD?	6.8 (5.8–7.7)
2	Providing information to patients who ask about the efficacy of treatment?	7.1 (6.0–8.2)
3	Giving the complex information to patients who have a limited ability to understand?	6.7 (5.7–7.7)
4	Discussing prognosis with patients with ESKD?	6.6 (5.5–7.8)
5	Discussing death and dying with patients with ESKD?	5.9 (4.9–6.8)
6	Informing the relatives of patients with ESKD that death is imminent?	6.3 (5.1–7.4)
	Mean overall confidence score	6.6 (5.7–7.4)

# THE CURRENT (DEFICIENCY OF) PALLIATIVE NEPHROLOGY

## Questions to ask your nephrologist (kidney doctor)

- What should I expect from CKD treatment?
- When should I expect to feel better?
- Will I be on dialysis for the rest of my life?
- How can I get the most out of my treatment?
- Is there anything I may experience that I should contact you about?
- Do I need to make changes to any other medications I'm taking?
- Am I a candidate for transplant? If so, what do I need to do?
- What do I need to know about over-the-counter medications or vitamins?

## Planning for End-of-Life Decisions

Many people put off end-of-life preparations, but it's an important step to protect your wishes—and your family's best interests. If you don't already have documentation of your plans and preferences, take steps to put them in place.

Though end-of-life planning isn't the easiest thing to talk about, discussing your wishes openly with your spouse and family can help them understand what's really important to you. Handling your legal paperwork as soon as possible can give you added peace of mind.

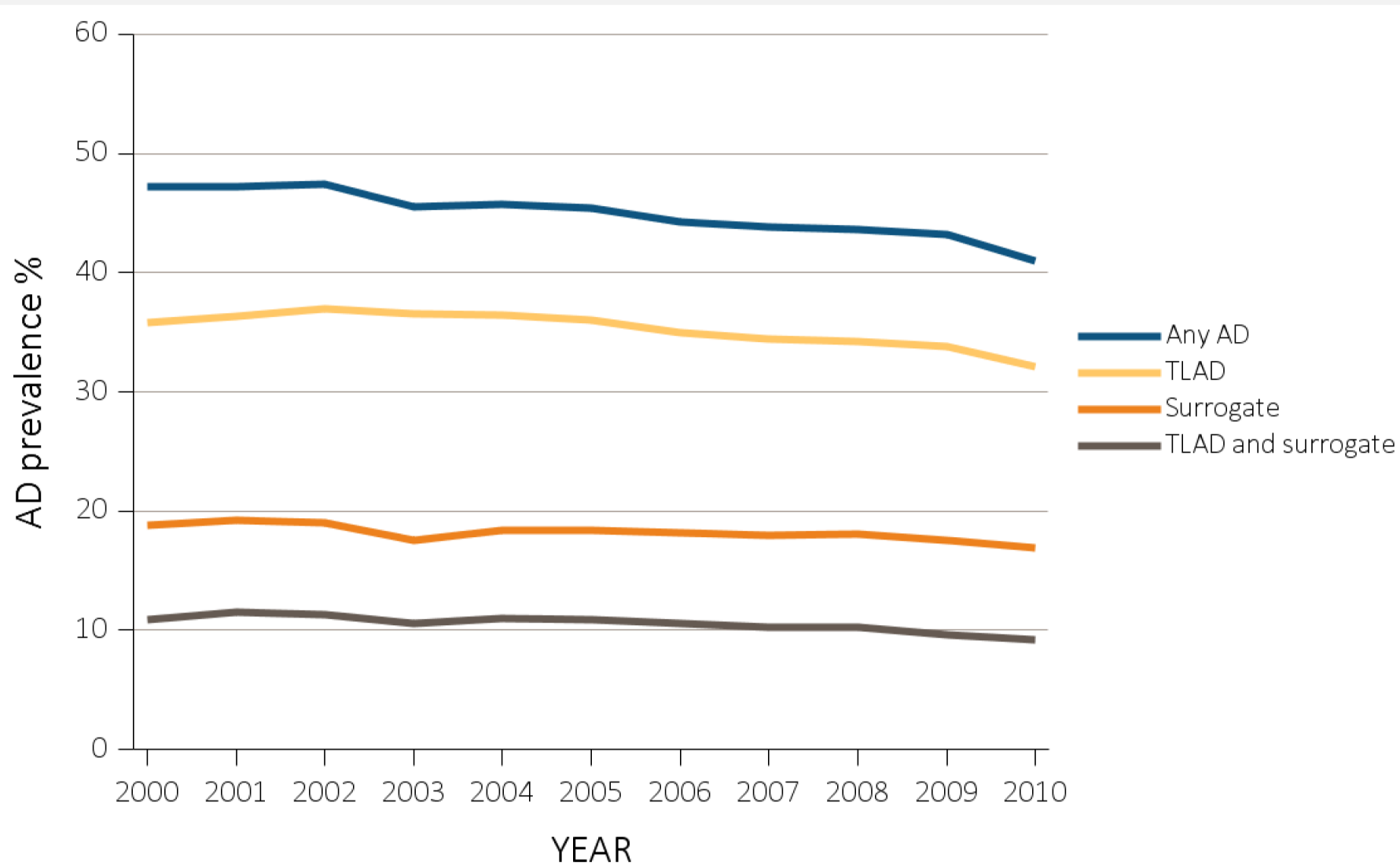
## Plans to make and documents to complete

There are different approaches and documents for ensuring your end-of-care wishes are followed. Your doctor, lawyer or a private advisor can help you make the right choices for your situation. If you complete a living will, advance directives or durable healthcare power of attorney, make a copy and share it with your doctor.

Some terms to know:

- **Living Will**—a document of your end-of-life care wishes if you are unable to speak for yourself.
- **Advance Directives**—this term simply refers to written instructions that let others know the type of care you want if you are unable to communicate them. Advance directives may include a living will and a durable healthcare power of attorney.
- **Durable Healthcare Power of Attorney**—a document that names a healthcare proxy or representative to make care decisions for you in the case that you're unable. Giving healthcare power of attorney to a spouse, family member or friend allows him or her to evaluate your health situation as it unfolds and make decisions in accordance with your wishes, beyond the dictates of your living will. If you don't have this document in place, the state you live in may dictate who is allowed to make healthcare decisions on your behalf, based on family relationship.

# PATIENT-BASED CHALLENGES: LOW ADVANCE DIRECTIVE COMPLETION RATE



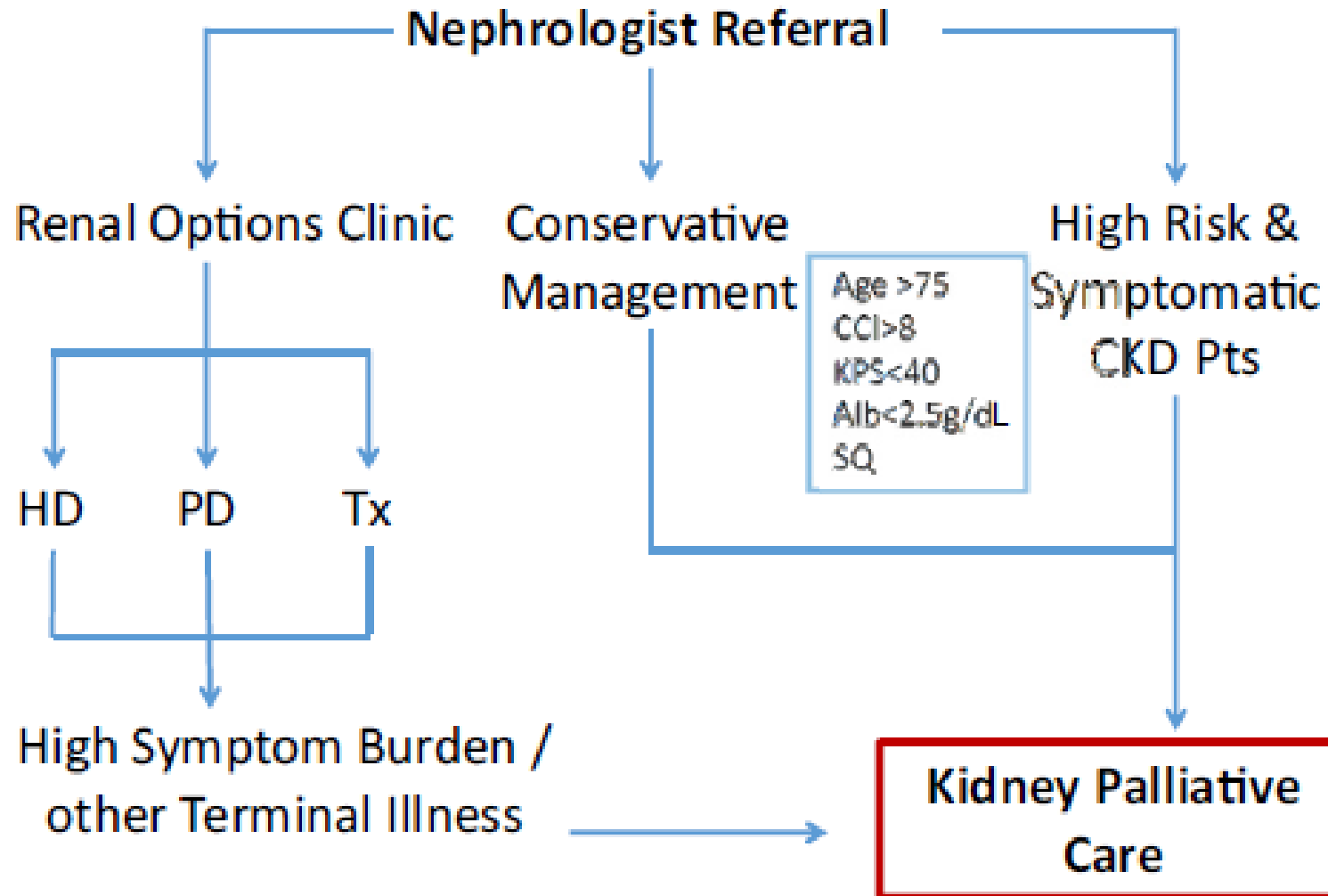
## PROVIDER-BASED CHALLENGES

- “Patient is not ready for palliative care,”  
“Doesn’t need palliative care”
  - Nephrologist
- “We thought every patient would be dying,”
  - Office staff
- Apprehension toward practice changes
- Operational challenges
  - (\$\$\$)

## A PALLIATIVE NEPHROLOGY CLINIC MODEL

- Renal Supportive Care (RSC) Clinics in Sydney, Australia
- Palliative physician or APP, nephrologist, social worker
- 30 minute time slots
- Innovative model comprehensive care with focus on QOL, conservative (non-dialytic) management
- Improved symptom control, QOL

# AUSTRALIAN OUTPATIENT KIDNEY PALLIATIVE CARE MODEL



## BUILDING AN OUTPATIENT PROGRAM

- Implement Australian model in the USA
- Stakeholder needs:
  - “Symptom management is low hanging fruit”
    - Nephrologist
  - “Normalize palliative services for HD patients”
    - Dialysis RN
  - “What are these patients told when HD is started? They seem unprepared”
    - Palliative nurse practitioner
- Determining work flow

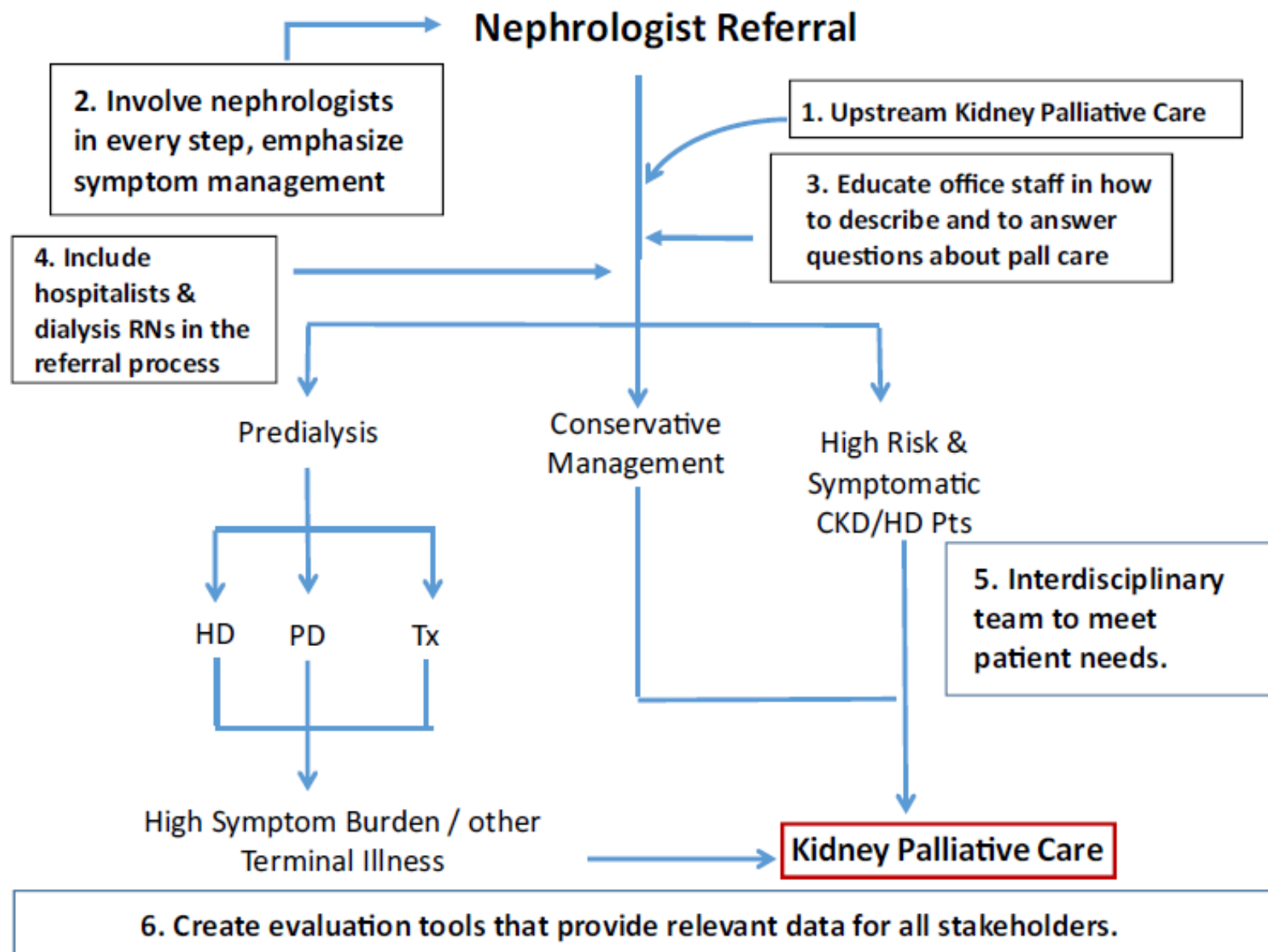


Fig. 3. Incorporation of stakeholder feedback in iterative adaptation of the Australian model of care. RNs = registered nurses; HD = hemodialysis; PD = peritoneal dialysis; Tx = transplant; CKD = chronic kidney disease.



**Manage physical & emotional symptoms of serious kidney disease.**

**Facilitate shared decision-making concerning dialysis decision-making and advance care planning. Elicit patient goals.**

**Patient-Centered Care**

**Collaborate with the primary nephrologist to care for conservative management patients.**

**Work with community providers (hospice & home care) to allow for smooth transitions of care, particularly at end of life.**

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QUESTIONS?

