Palliative Care in Patients with End-Stage Renal Disease

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PGY-3
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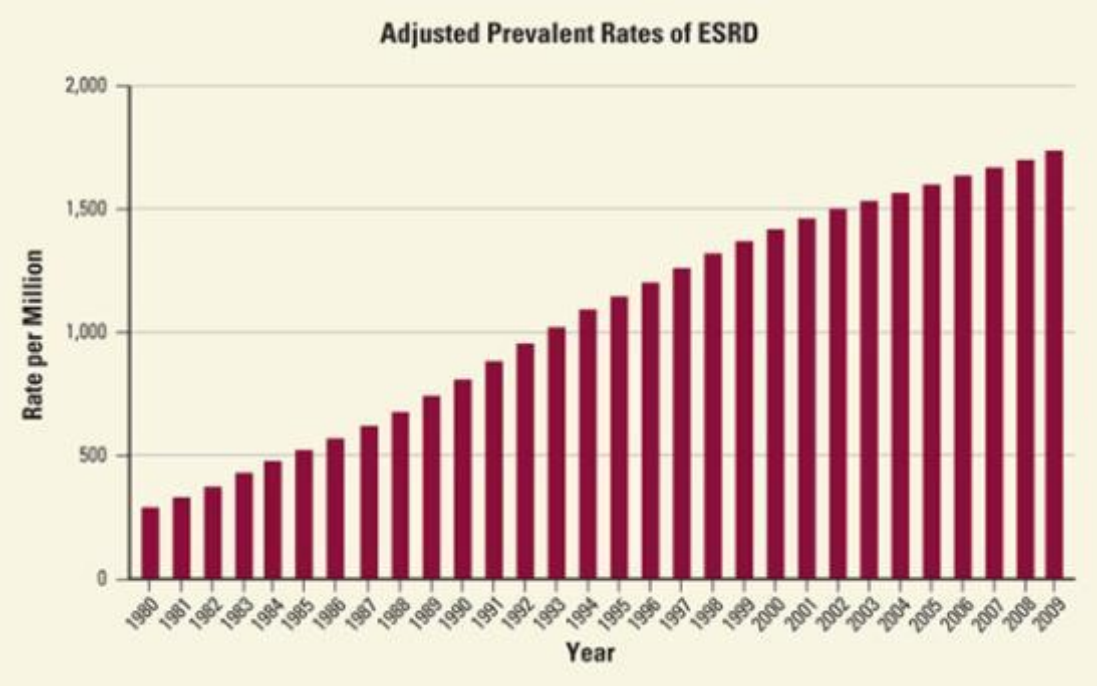
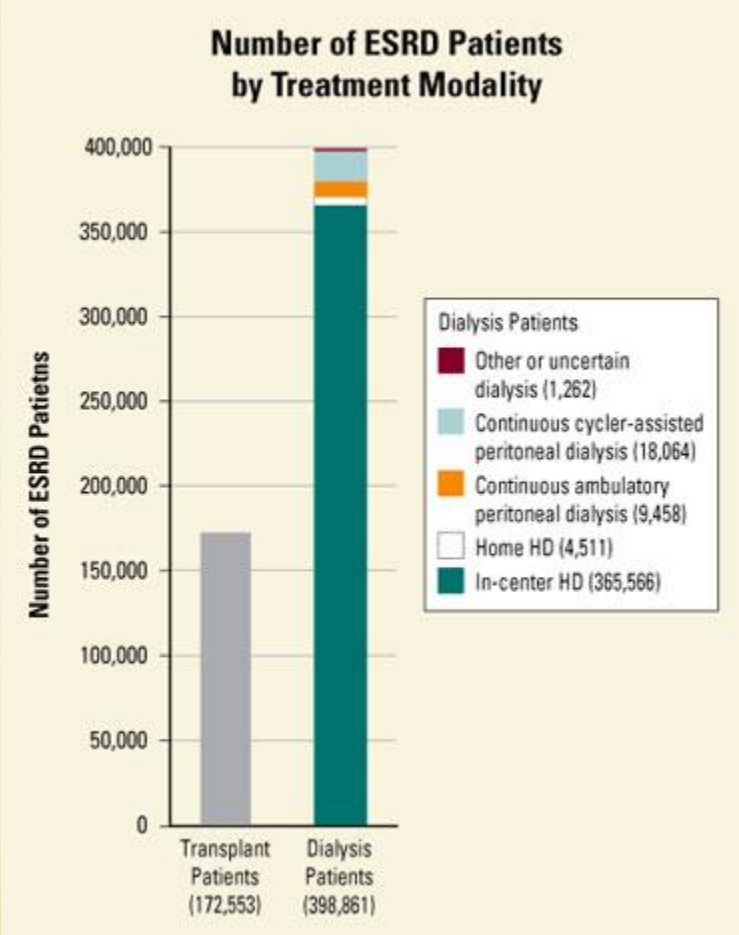
Outline

- Epidemiology of ESRD
- Current limitations of palliative care in ESRD
- Prognosis in ESRD
- Decision to stop dialysis
- Advanced care planning
- Symptom burden and quality of life
- Hospice

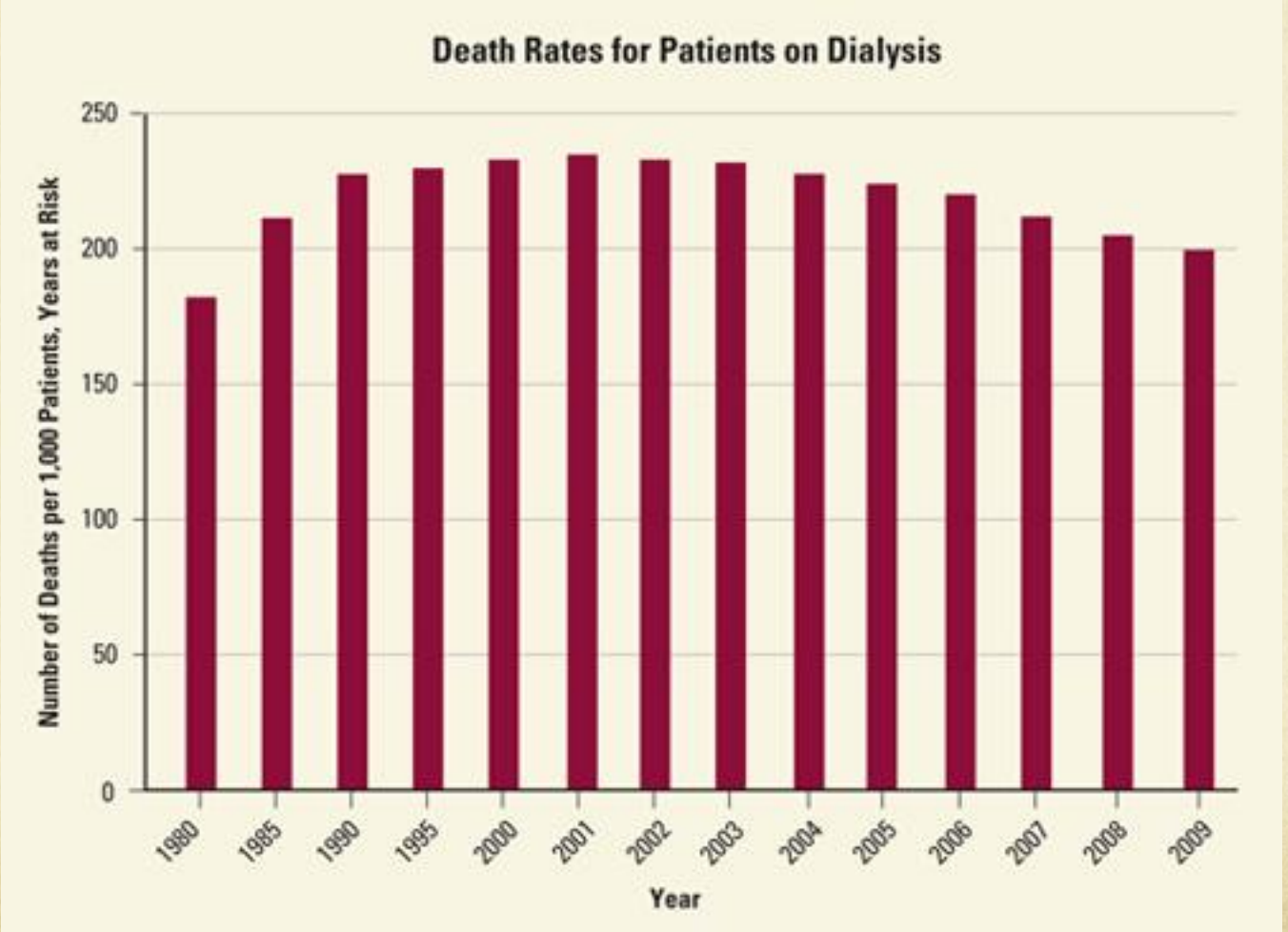
Prevalence of Patients with ESRD





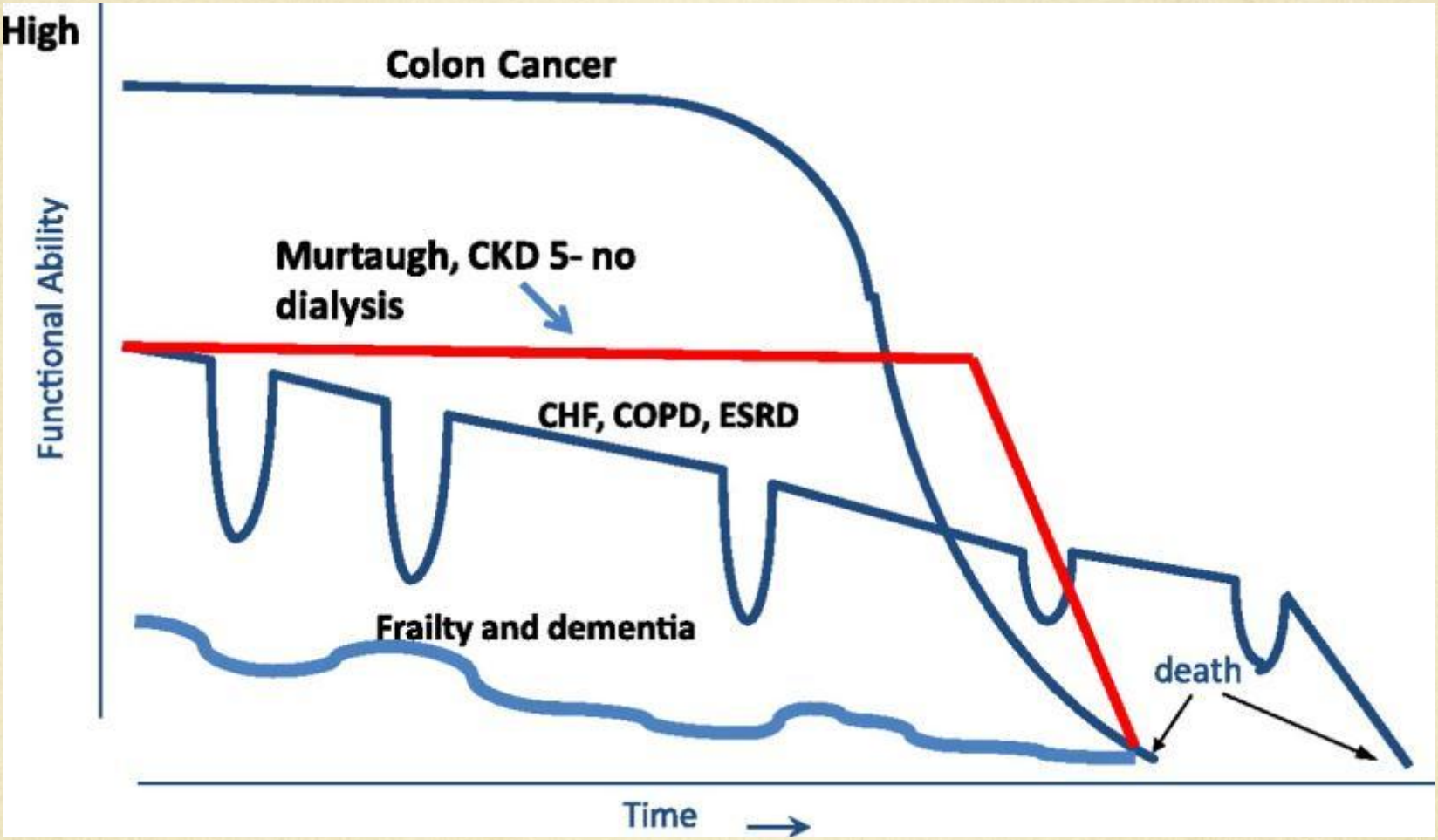
http://kidney.niddk.nih.gov/kudiseases/pubs/kustats/#1

Mortality in ESRD



http://kidney.niddk.nih.gov/kudiseases/pubs/kustats/#1

Trajectory in Patients with ESRD



Holley J L CJASN 2012;7:1033-1038

CJASN

Life Expectancy in Patients with ESRD

- About 1/3 of patients have 4 or more comorbidities at diagnosis of ESRD and are not transplant candidates
- Longer survival among elderly patients starting dialysis may be explained by additional days in the hospital when compared to non-dialyzed patients

End-of-Life Care in Patients with ESRD

- US Renal Data System: 99,329 Medicare patients older than 65
  - Initiated dialysis between January 2004 and December 2007
  - Died before January 2009

Table. Intensity of Care During the Final Month of Life

	Medicare Beneficiaries		
Intensity of Care	Dialysis (Present Study)	Cancer[7]	Heart Failure[8,9]
Hospitalization, %	76.0	61.3	64.2
Days hospitalized, mean	9.8	5.1	NA
Intensive care unit admission, %	48.9	24.0	19.0
Days in an intensive care unit, mean	3.5	1.3	NA
Any intensive procedure, %	29.0	9.0	NA
Hospice use, %	20.0	55.0	39.1
Death in a hospital, %	44.8	29.0	35.2

Abbreviation: NA, not available.

Wong SPY, Kreuter W, O'Hare AM. Treatment Intensity at the End of Life in Older Adults Receiving Long-term Dialysis. Arch Intern Med 2012;172:661-663

Palliative Care-Definition

- Definition: An approach to treatment that aims to improve quality of life and relieve suffering for patients (and families) with life-threatening illnesses
- Palliative care can be integrated at any point during disease course and in conjunction with life-prolonging treatment
- Role:
  - Estimation of Prognosis
  - Explanation of treatment options
  - Advanced care planning
  - Symptom assessment and management
  - Hospice referral
  - Bereavement support

Current State of Palliative Care

- Coalition for Supportive Care of Kidney Patients
- Barriers to palliative care:
  - Low health literacy among patients
  - Nephrologists are uncomfortable discussing dialysis as a life-prolonging, not life-saving modality in patients with significant comorbidities and high mortality rate
  - Lack of formal assessment of patients who are nearing end of life
  - More patients "dying on dialysis" with dementia and other cognitive or medical conditions limiting decision-making capacity
  - Medicare billing for hospice

Estimation of Prognosis

- Clinical risk score by Couchoud et al. predicting 6-month mortality in patients older than 75
- Modified Charlson Comorbidity Index gives annual mortality rate
- Prognostic factors: Age, functional status, Albumin
- Patient preference to know prognosis
  - 97% of patients want to know life expectancy with dialysis
  - 88% said information on life expectancy affects decision to start dialysis
  - 96% want information on life expectancy from physician without being prompted for it
  - 95% said information on life expectancy better prepares them to accept what happens
  - 99% want to know limitation to QOL with dialysis

Decision to Stop Dialysis

- A leading cause of death among dialysis patients
- In setting of Acute illness or from fatigue of physical/emotional symptom burden
- Patient Characteristics: Older age, female, White, Longer duration on dialysis, higher education level, living along, severe pain, other serious comorbidities
- Average length of survival: 7 days (Range 0 -150 days)
- Predictors of Mortality after Cessation: PPS <20, Presence in hospital or inpatient facility, White, Male, Peripheral edema, Oxygen

Decision to Stop Dialysis

- Nephrologist identify physical and cognitive functional limitations as most important factor

- For patients not close to death, identify factors that may be treated
  - Undertreated depression, anxiety, pain, or other symptoms
  - Difficulties with dialysis (e.g. modality, access, time commitment, setting of treatment)
  - Lack of social support, feeling of burdening family members

Process of Dialysis Withdrawal

- For patients close to death
  - Address larger goals of care, Patient/family assessment of QOL
  - Prognosis after withdrawal
  - Counseling about symptoms
  - Counsel about site of care
  - Review other comorbidities and treatments and d/c those not contributing to QOL, DNR discussion
  - Psychological/Spiritual/Emotional support and Bereavement

Advanced Care Planning

- Should be addressed early and throughout disease course
  - As part of routine care, with acute illnesses, when initiating dialysis, when patient/family questions, answering NO to "surprise" question
- Less than half of Nephrologist feel very prepared to address end-of-life care, Fellows report inadequate training
- More often discussed within patient-family context
- Focus on health states as opposed to medical interventions
- Role of physician as facilitator and to engage patients and families in this discussion

Advanced Care Planning

- Patient/Family-centered goals
  - To prepare for death
  - To strengthen relationships
  - To achieve control over medical care
  - To relieve the burden of loved ones
  - To prepare for future decisions
- Physician-centered goals
  - Clarify goals of medical care
  - Identify health-care proxy
  - To complete DNR and other forms

Symptom Prevalence, Quality of Life, and Depression

- 162 patients receiving HD rated symptoms and severity, HRQOL, Depression
  - Most common symptoms: dry skin (72%), fatigue (69%), pruritis (54%), bone/joint pain (50%)
  - Other symptoms: numbness/tingling, trouble sleeping, dry mouth, decreased sexual desire/arousal
  - Most severe symptoms: bone/joint pain (3.6), chest pain (3.6), vomiting (3.5), decreased sexual arousal (3.4), muscle pain (3.3)
  - HRQOL: 22% moderate to severe distress

Symptom Prevalence, Quality of Life, and Depression, cont

- Depression: 25.9% moderate to severe depression
- Relationship between symptoms and HRQOL was independent of depression
- Symptom burden not affected by age, ethnicity, time on dialysis and prior failed transplant

Symptom Burden, Depression and Quality of Life: ESRD vs CKD

- 70 ESRD patient and 87 CKD patients
  - No differences in number of symptoms or severity
  - Most common: fatigue (79%), trouble falling asleep/staying asleep (60%/56%), pruritis (51%)
  - Common: dry skin, sadness, irritability, worrying, difficulty with sexual arousal, bone/joint pain, muscle cramps, dry mouth, restless legs, muscle soreness, lightheadedness
  - Most severe symptoms: trouble falling asleep, difficulty with sexual arousal, decreased sexual interest, vomiting

Symptom Burden, Depression and Quality of Life: ESRD vs CKD, cont

- No difference in prevalence or severity of Depression
  - 11% moderately depressed, 7% severely depressed
- No overall difference in composite QOL scores
  - Physical functioning domain: Patients with ESRD had significantly lower scores than those with CKD

Symptoms in patients with ESRD Not on Dialysis

- 66 patients with ESRD managed conservatively
- 75% of patients: fatigue and itching
- 50% of patients: drowsiness, dyspnea, swelling of legs, pain, dry mouth, muscle cramps
- 30% of patients: difficulty concentrating, difficulty sleeping, constipation, skin changes, dizziness.
- Most Severe: fatigue, itching, pain
- Scores for global distress and average distress similar for cancer

Symptoms after Withdrawal of Dialysis

Symptom	Prevalence (%)
Pain	55
Confusion/agitation	70
Dyspnea	48
Nausea	36
Twitching/seizures	27
Anxiety/psychological distress	27
Pruritis	24
Diarrhea/stool incontinence	21
Peripheral edema	21

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Chater S, Davison SN, Germain MJ, Cohen LM: Withdrawal from dialysis: a palliative care perspective. Clin Nephrol 66:364–372, 2006

Symptom Management

- Pain: Acetaminophen, tramadol, fentanyl, methadone
  - Caution with use: Oxycodone, hydromorphone
  - Not Recommended: Morphine, diamorphine, meperidine, gabapentin, pregabalin
- Pruritis: Emollients including hydrourea, ondansetron, anti-histamine
- Dyspnea: Oxygen, fans, positioning, opiates, diuretics

Symptom Management, cont

- Anxiety/Agitation: Pain control (fentanyl IV/SC), Psychosocial support, benzodiazepines, haldol, Atypical anti-psychotics
- Restless legs: Benzodiazepines (clonazepam)
- Nausea: Metaclopramide, haldol, prochlorperazine, ondansetron
- Muscle Cramps: Benzodiazepines (clonazepam)

Hospice in ESRD

- Less than half of patients with ESRD withdrawing from dialysis use hospice, but hospice use increases with age
- Factors associated with hospice use: older age, white, failure to thrive
- Patients using hospice were more than 4x more likely to die at home
- Median days in the hospital in the last week of life was 4 for non-hospice patients and 0 for hospice patients
- Median cost in last week of life for hospice patients was 1/3 that of non-hospice patients

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