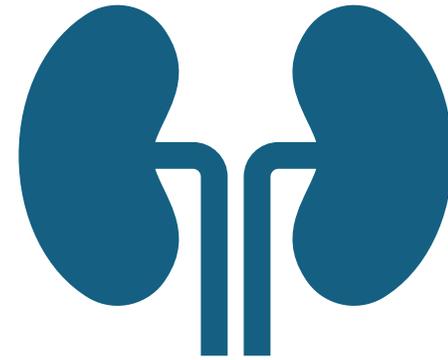


# Kidney Supportive Care and Conservative Kidney Management in Kidney Failure

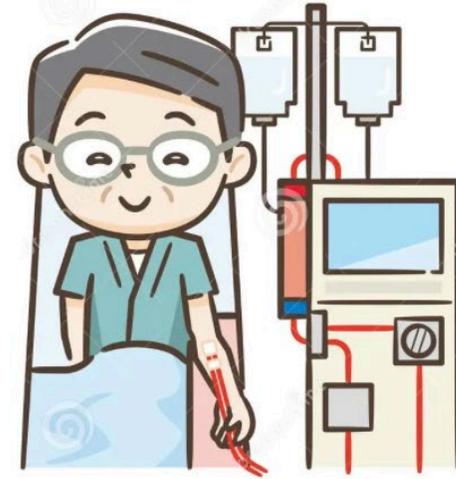
Sanjana Ramakrishnan MBBS  
Hospice and Palliative Medicine Fellow  
Virginia Commonwealth University



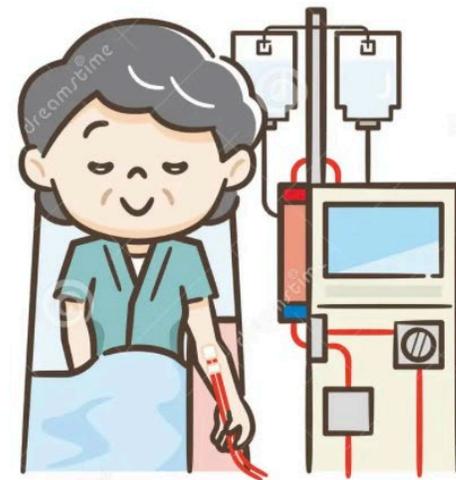
# Objectives

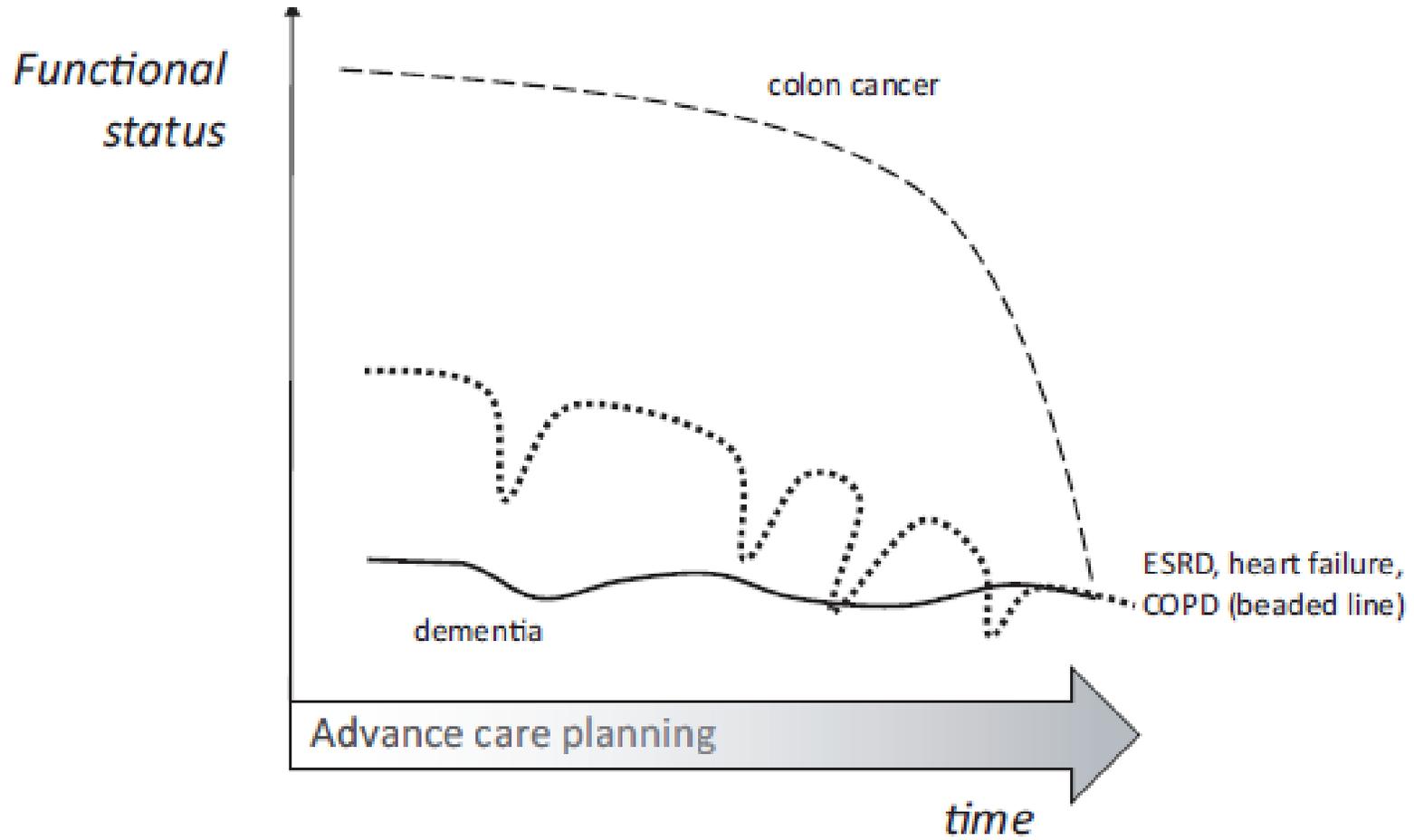
- Compare survival and illness trajectories for patients with kidney failure on dialysis vs Conservative kidney management (CKM).
- Understand the symptom burden in chronic kidney disease.
- Discuss how frailty, advanced age, and multimorbidity affect prognosis for elderly patients deciding about initiation of dialysis.
- Discuss prognostic tools in the setting chronic kidney disease.
- Describe the role of kidney supportive care and indications of CKM.
- Apply shared decision making and treatment specific goals of care discussion tools.

- 1972 ESRD Medicare Entitlement program



- ESRD became a manageable chronic condition.





# Disease based illness trajectory

# Case 1

79-year old male with CKD -5 with proteinuria secondary to diabetes and recurrent AKIs due to cardiorenal syndrome.

## **Other comorbidities:**

- HFrEF (10-15%) ,aortic stenosis, p-Afib s/p CRT-D placement, CAD s/p CABG
- COPD, HTN, OSA

## **Social/ Personal history:**

- Served in Army
- Lives at home with wife, has one daughter
- Worked night shifts at a 7x11 store

# Case 1, continued

## **Symptoms:**

- Exertional fatigue and SOB
  - Loss of appetite and weight
- He was emergently started on HD when he developed kidney failure and progressive fluid overload in the setting of heart failure with severely reduced ejection fraction to 10-15% and moderate –severe aortic stenosis (deemed to be a poor candidate for valve replacement)

# Case 1, continued

## **Functional status :**

Prior to dialysis: PPS 70%

- independent of ADLS and IADLS at home
- spends time doing repairs at home.

After starting dialysis :PPS 50%

- Can only walk up to 13 steps, with considerable effort, ambulates with cane assistance.
- Continued to have shortness of breath on any minimal exertion, decreased appetite.  
+ constipation.

## **What matters most:**

- Participate in church activities.
- Live as long as he is able to be aware of his surroundings

# Symptom Burden in Kidney Failure

~12  
symptoms per dialysis patient

Symptom	All sample (n = 236)
Dry mouth	216 (91.5)
Itching	196 (83.1)
Dry skin	194 (82.2)
Feeling tired or lack of energy	192 (81.4)
Trouble staying asleep	178(75.4)
Worrying	168 (71.2)
Feeling anxious	159 (67.4)
Trouble falling asleep	158 (66.9)
Feeling irritable	147 (62.3)
Muscle cramps	129 (54.7)
Difficulty becoming sexually aroused	129 (54.7)
Decreased interest in sex	129 (54.7)

Older patients had significantly higher total symptom counts, higher severity scores, and higher palliative care needs scores.

# Symptom Burden in Kidney Failure (contd..)

**r=0.88**

correlation: reduced QOL

**r=0.62**

correlation: depression

**r=0.78**

correlation: anxiety

r 0.5-0.7= strong;  
>0.8= very strong

## Factors Increasing Symptom Burden

- ▲ **Older age** -- physiological decline, more comorbidities
- ▲ **Female sex** -- greater symptom expression
- ▲ **Longer dialysis duration** -- vascular calcification, neuropathy
- ▲ **Poor sleep quality** -- affects 85% of dialysis patients
- ▲ **Malnutrition** -- electrolyte imbalance, organ decline
- ▲ **Comorbidities** -- additive symptom effects
- ▲ **Lower income / unemployment** -- dual financial-disease burden

## Protective Factors (Lower Burden)

- ▼ **Social support** -- feeling respected, understood
- ▼ **Good self-management** -- adherence, structured lifestyle
- ▼ **Married status** -- family support, disease engagement

## Common Symptoms (ESAS-Renal / IPOS-Renal)

- Fatigue, pruritus, restless legs, pain
- Nausea, insomnia, dyspnea, anxiety, depression
- Bidirectional relationship with depression and QOL

***Clinical implication:** High symptom burden predicts poor QOL independent of dialysis status -- reinforcing the need for routine symptom screening in all kidney failure patients*

Nephrol Dial Transplant (2006) 21: 3189–3195  
doi:10.1093/ndt/gfl380  
Advance Access publication 6 September 2006

*Original Article*

**Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in haemodialysis patients**



**ESAS**

Tired  
Well-being  
Itching  
Pain  
Appetite  
Drowsy  
Depressed  
Shortness of breath  
Anxious  
Nauseated  
Total symptom distress score  
Number of symptoms  
Moderate/severe symptoms

# Does dialysis improve symptoms in older adults?

## European QUALity (EQUAL) study



456 Europeans  
age  $\geq$  65 years



eGFR  
 $\leq$  20 ml/min/1.73m<sup>2</sup>

Patients surveyed every 3-6 months on 30 symptoms using the dialysis symptom index (DSI)

One year pre-dialysis

Symptom number

**+3.6**

(95%CI: +2.5 to +4.6)

Symptom burden

**+13.3**

(95%CI: +9.5 to +17.0)

At start of dialysis



77 Years old, 75% Men  
eGFR 8 ml/min/1.73m<sup>2</sup>  
44% Diabetes, 46% CVD

81% Fatigue  
69% Decreased interest  
in sex  
68% Difficulty becoming  
sexually aroused

One year post-dialysis

Symptom number

**+0.9**

(95%CI: -3.4 to +1.5)

Symptom burden

**-5.9**

(95%CI: -14.9 to -3.0)

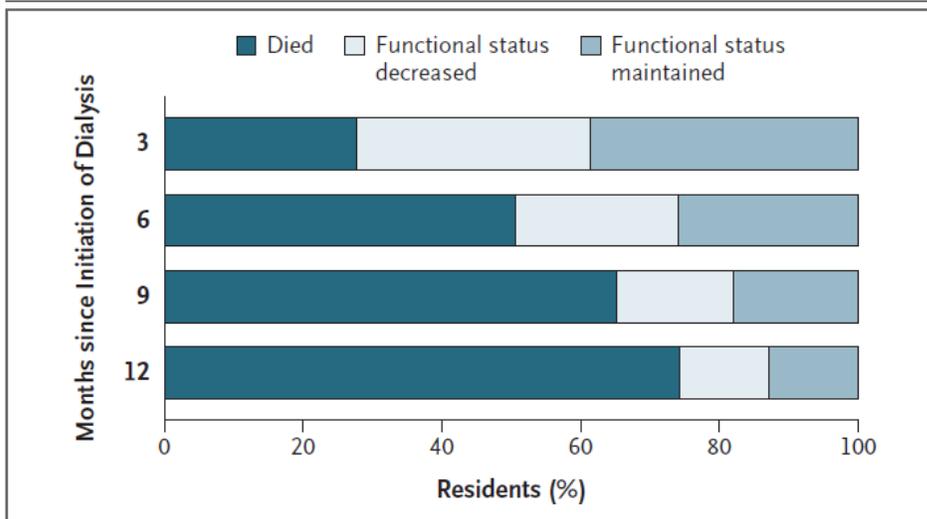
**Conclusions:** Symptom burden worsened considerably before and stabilized after dialysis initiation. "Fatigue," "decreased interest in sex," and "difficulty becoming sexually aroused" were considered most burdensome, of which only "fatigue" somewhat improved after dialysis initiation.

Esther N.M. de Rooij, Yvette Meuleman, Johan W. de Fijter, et al.  
**Symptom Burden before and after Dialysis Initiation in Older Patients.** CJASN doi: 10.2215/CJN.09190822.  
Visual Abstract by Joel Topf, MD, FACP

- Fatigue, cardiopulmonary symptoms improved after dialysis initiation.
- Sexual dysfunction, itching did not improve with dialysis.
- Symptoms induced dialysis

# Functional Status of Elderly Adults before and after Initiation of Dialysis

Manjula Kurella Tamura, M.D., M.P.H., Kenneth E. Covinsky, M.D., M.P.H., Glenn M. Chertow, M.D., M.P.H., Kristine Yaffe, M.D., C. Seth Landefeld, M.D., and Charles E. McCulloch, Ph.D.



**Figure 2. Change in Functional Status after Initiation of Dialysis.**

Data were missing for 549 nursing home residents at 3 months, 696 residents at 6 months, 823 residents at 9 months, and 787 residents at 12 months from the full analytic cohort of 3702 residents.



The study looked into whether functional status before dialysis is maintained after the initiation of this therapy in elderly patients with end-stage renal disease (ESRD).



Evaluated 3702 nursing home residents in the United States who were starting treatment with dialysis between June 1998 and October 2000

# How is functional status and caregiver burden affected by initiation of maintenance dialysis?

## Methods and Cohort



Mean age  
75 ± 7



ESKD  
N = 187



Geriatric assessment +  
Fried Frailty Index +  
Groningen Frailty Indicator



Functional  
status



Caregiver  
burden

assessed at baseline and 6m  
of starting dialysis

## Definitions



Decline  
Loss of ≥ 1 domains in  
functional status



Stable  
No difference



Improvement  
Gain of ≥ 1 domains in  
functional status

## At baseline



79% care dependent

## At 6 months



40%  
decline



34%  
stable



18%  
improvement



8%  
died



Prevalence caregiver burden increased from 25  
to 38% (p=0.04).



Age (OR 1.05)  
(95% CI 1.0-1.1/year older at baseline)



High Groningen Frailty  
Indicator score (OR 1.97)  
(compared to score <4, 95% CI 1.05-  
3.68)



was  
associated  
with



Functional  
decline



Death

**Conclusions** In patients ≥65 years, functional decline within the first 6 months after initiating dialysis is highly prevalent. The risk is higher in older and frail patients. Loss in functional status was mainly driven by decline in instrumental activities of daily living. Moreover, the initiation of dialysis seems to be accompanied with an increase in caregiver burden.

N.A. Goto, I.N. van Loon, F.T.J. Boereboom, M.H. Emmelot-Vonk, et al. **Association of Initiation of Maintenance Dialysis With Functional Status and Caregiver Burden.** CJASN doi: 10.2215/CJN.13131118. Visual Abstract by Michelle Lim, MBChB

# Kidney supportive care (KSC)

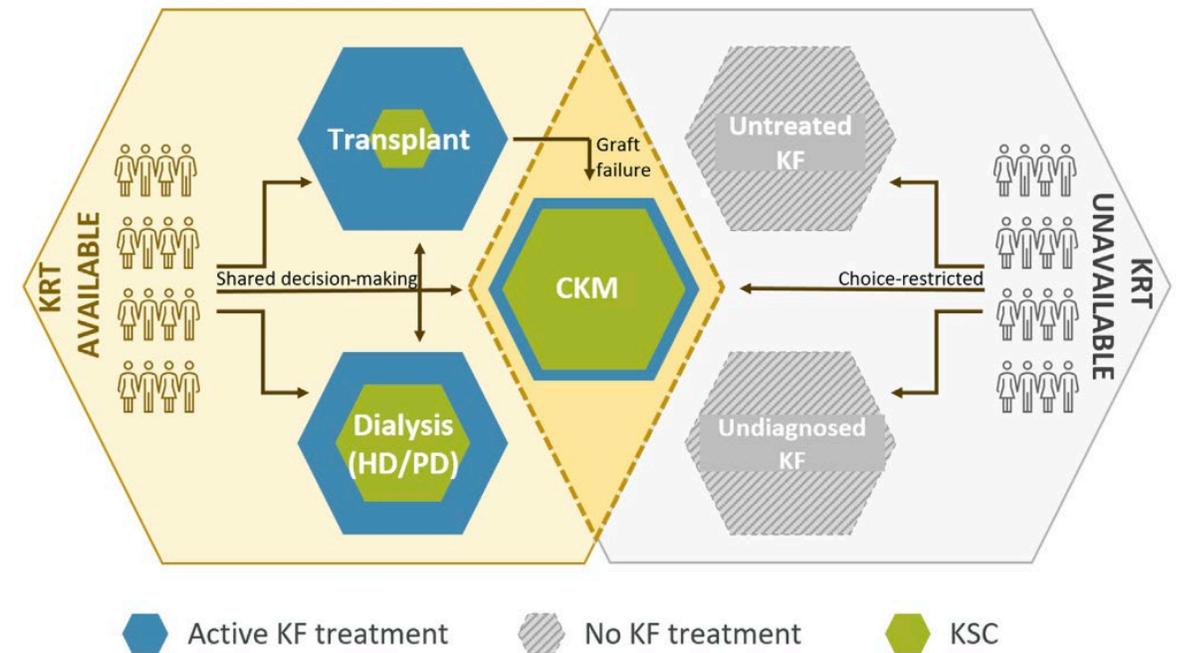
**KSC** -Care that helps patients with advanced CKD to improve QOL, based on individual supportive care needs

## When to provide KSC:

- Alongside ALL treatments, including dialysis
- NOT just for end-of-life or CKM

## Core Principles:

- Patient priorities guide clinical decisions
- Culturally sensitive shared decision-making
- Addresses physical, psychosocial, and spiritual need:



# Case 2

- 92-year male with **CKD-5** secondary to long history of hypertension, status post left nephrectomy, status post ablation of right kidney, history of AKI and aging, s/p L AV fistula creation for potential HD initiation

## Other comorbidities:

- HTN, CAD s/p MI and stenting, HFpEF, bradycardia
- hyperparathyroidism, primary aldosteronism, hypercalcemia
- Hx of upper GIB, GERD, s/p R hemicolectomy w/ ileocolic anastomosis, cholelithiasis, BPH
- MGUS, anemia of chronic disease, breast cancer, glaucoma, cataracts, OSA, gout

## Social/Personal History:

- Served in Army
- Widowed , 2 sons
- Retired teacher
- Jehovah's Witness

## Baseline function status:

- PPS 80%
- Living alone
  - Independent of ADL
  - Ambulatory

## Symptoms:

- LE edema
- Fatigue
- Limited appetite
- Loss of taste

# Case 2, continued

## What matters most:

- Ministry work as a Jehovah's Witness.
- Children
- Staying at home and remaining as independent as long as possible are two priorities that inform his care decisions

## Care plan:

- Continue with **conservative kidney management.**
- If opted to initiate HD, **a time limited trial** might be a useful way to monitor if intervention were yielding benefits in line with his care goals and allow for early creation of clearly defined plan for transitioning off HD to focus on symptom management if goals are not met.

# Conservative Kidney Management (CKM)

## Box 3 | Indicators to help identify people with kidney failure who might benefit from CKM

- Poor quality of life, including irremediable physical or psychosocial suffering, where dialysis may extend life, but prolong suffering
- Frailty: cognitive and physical domains with poor functional status
- High comorbidity, especially if severe heart failure and/or advanced age (>80 years)
- Severe malnutrition
- Clinician's response of "No, I would not be surprised" to the question ("Would I be surprised if this patient died in the next year?")
- Those whose medical condition precludes the technical process of dialysis because the patient is
  - Unable to cooperate (e.g., advanced dementia)
  - Unstable medically (e.g., profound hypotension)
  - Experiencing another life-limiting illness (e.g., advanced stage cancer)

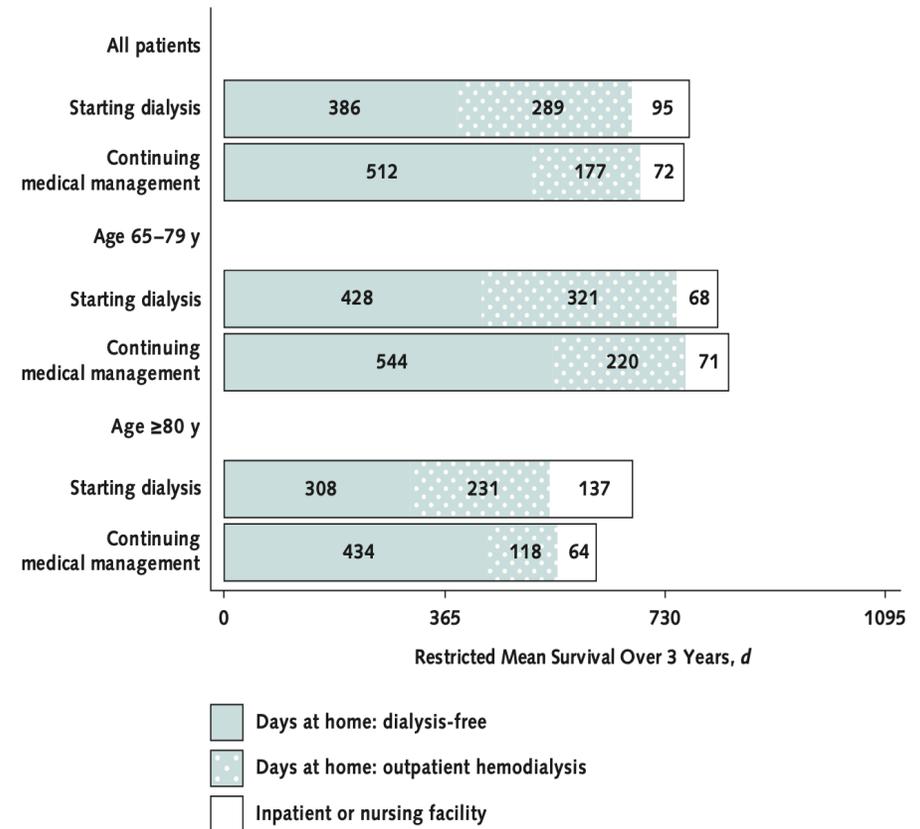
- **CKM** : Care for people with kidney failure that focuses predominantly on providing KSC (kidney supportive care) to promote quality of life but does not include dialysis

## Effect of Starting Dialysis Versus Continuing Medical Management on Survival and Home Time in Older Adults With Kidney Failure

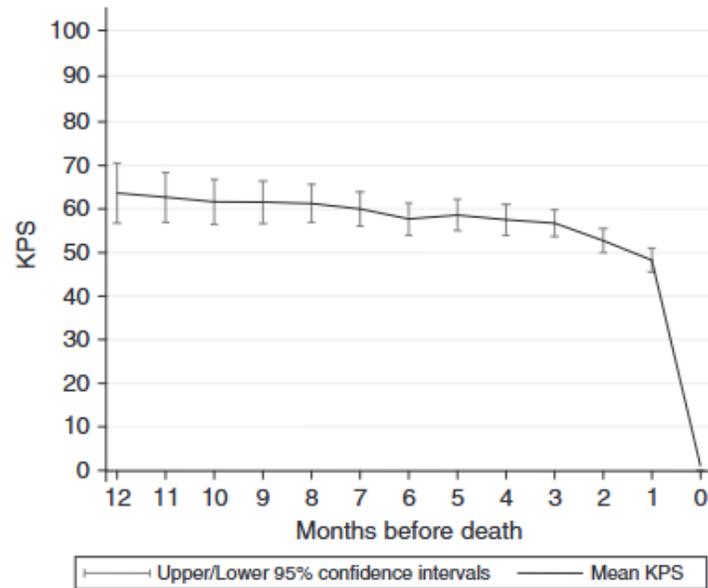
A Target Trial Emulation Study

- While starting dialysis may offer a **slight increase in life expectancy**, it significantly **reduces the number of days spent at home**.
- The modest gains in longevity are often offset by the **increased time spent in hospitals** or nursing facilities.

**Figure 1.** Mean survival time, in days, for older adults with eGFR <12 mL/min/1.73 m<sup>2</sup> starting thrice-weekly hemodialysis within 30 d and older adults who continued medical management, partitioned by dialysis-free days at home, outpatient hemodialysis days, and inpatient or nursing facility days.



# Trajectory in ESRD managed on CKM



Time before death (months)	12	11	10	9	8	7	6	5	4	3	2	1	0
Mean KPS	63.9	64.4	62.8	63.3	62.9	62.6	61.1	61.2	59.6	59.0	56.6	52.2	0
Standard Deviation	9.16	9.61	9.60	9.59	9.57	9.64	9.48	9.40	9.60	9.59	9.91	10.91	0
Minimum	50	50	50	50	50	50	40	40	30	30	40	30	0
Maximum	80	80	80	80	80	80	80	80	80	80	80	80	0
N	11	14	18	19	23	25	26	29	32	37	40	46	0
Not yet recruited	38	35	31	29	25	23	20	19	15	11	7	0	0
Missing	0	0	0	1	1	1	3	1	2	1	2	3	0

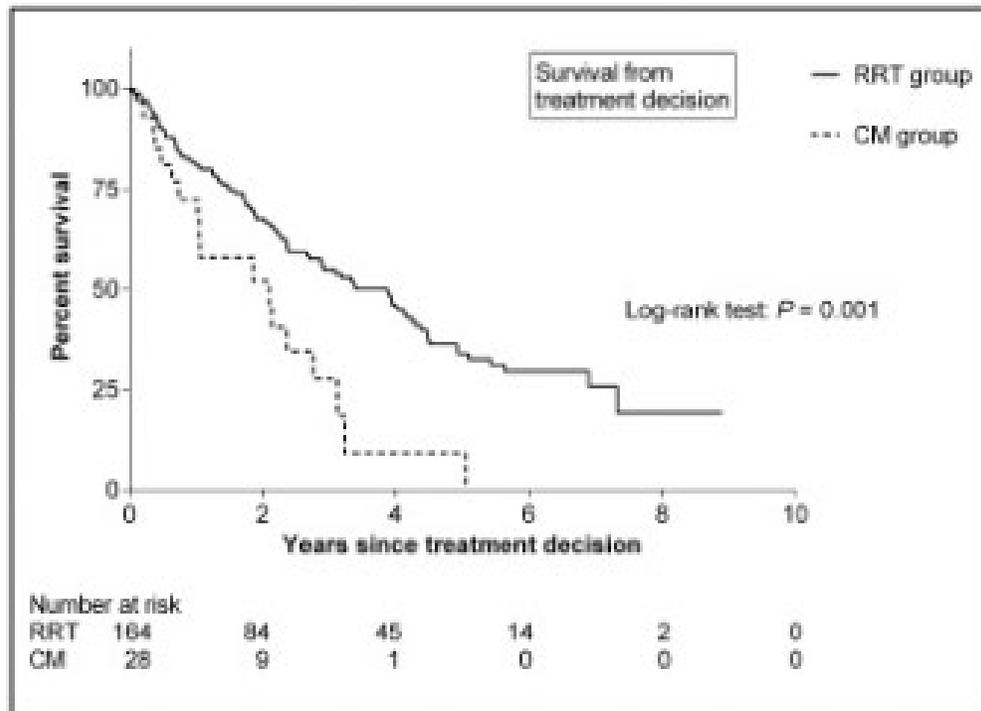
**Figure 2.** Trajectory of mean Karnofsky Performance Scale (KPS) score over the last year of life for those who died (N = 46).

**Table 1. Brief Criteria to Define Each Point on the Karnofsky Performance Scale**

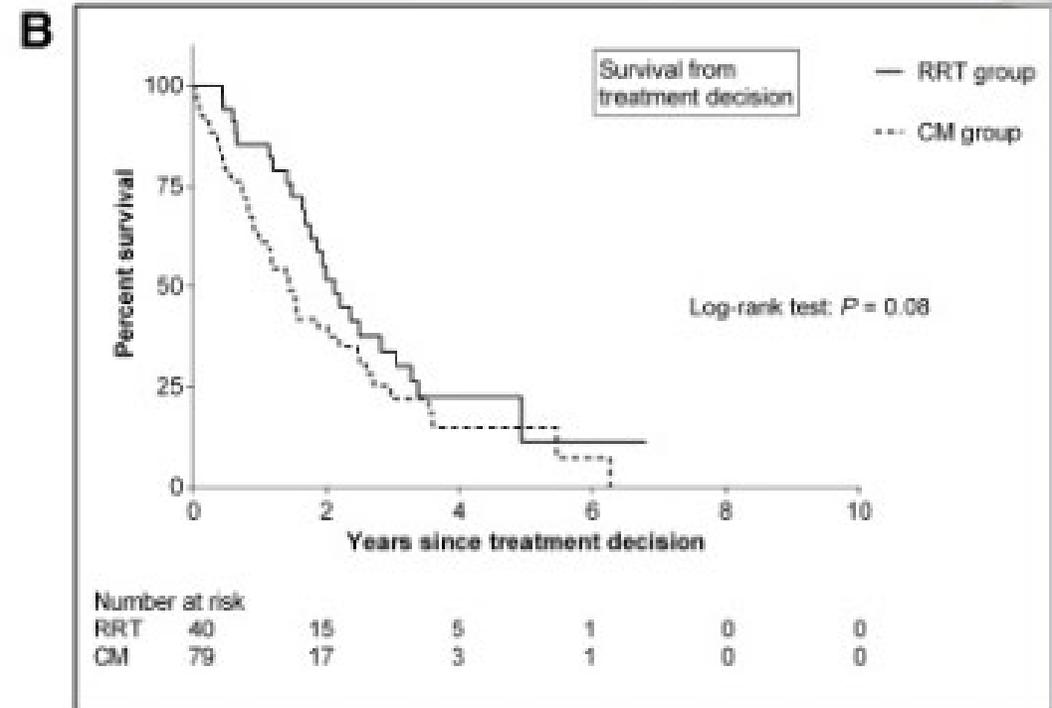
Score %	Criterion
100	Normal, no complaints; no evidence of disease
90	Able to carry on normal activity; minor symptoms or signs of disease
80	Normal activity with effort; some symptoms or signs of disease
70	Cares for self; unable to carry on normal activity or do normal work
60	Requires occasional assistance but is able to care for most needs
50	Requires considerable assistance and frequent medical care
40	Disabled; requires special care and assistance
30	Severely disabled; hospitalization is indicated, although death is not imminent
20	Very sick; hospitalization necessary; active supportive treatment is necessary
10	Moribund, fatal processes progressing rapidly
0	Dead

# Comparing survival between dialysis and CKM

## Age 70-79 years



## Age $\geq 80$ years



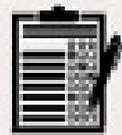
## Methods and cohort



Cleveland, OH  
7 dialysis units



Maintenance  
dialysis



Completed 41-item  
questionnaire  
n = 397



“Do you regret  
your decision  
to start dialysis?”

## Adjusted for:



Attitudes  
toward medical  
decision-  
making and  
care



Attitudes  
towards future  
care



Modifiable care  
process

## Outcomes



82/397 (21%) reported  
decisional regret



Regret more  
likely if



Choosing  
dialysis to  
please doctors/  
family members

Adjusted odds ratio (AOR) 2.34 (1.27, 4.31)



Regret less  
likely if



Prognostic discussions  
about life expectancy  
with doctor occurred

AOR 0.42 (0.18, 0.98)



A living will  
was completed

AOR 0.45 (0.25, 0.85)

**Conclusions** Dialysis regret was common in this sample. Demographic factors (age, gender, marital status, race or educational attainment) were not

Fahad Saeed, Susan Ladwig, Ronald M. Epstein, Rebeca D. Monk, and Paul R. Duberstein. *Dialysis Regret: Prevalence and Correlates*. CJASN doi: 10.2215/CJN.13781119. Visual Abstract by Michelle Lim. MRCHE, MRCP

# Challenges with communication

- **Themes identified:**

- Viewing CKM as “no care”
- Prognostic uncertainty
- Manage emotions
- Navigate family dynamics

→ Reframe

→ Address limitations, relate prognostic data to the patient’s goals.

→ Acknowledge

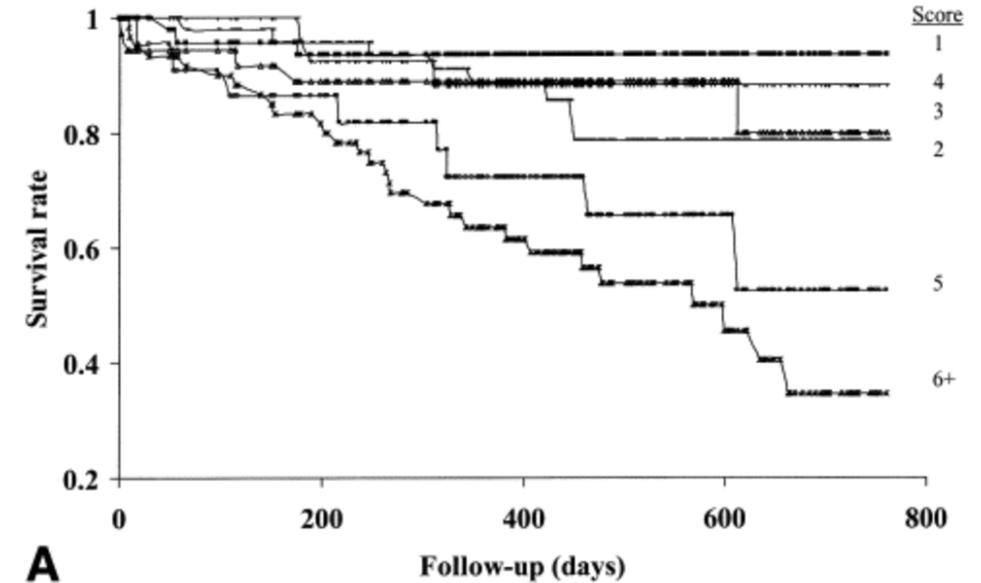
→ Family meetings

# Prognostication tools

## 1) Charlson Comorbidity Index:

- valid predictor of survival in patients with ESRD.
- identifies subpopulation of sicker dialysis patients with approximately a 50% 1-yr mortality rate.

Myocardial infarction	1
Congestive heart failure	1
Peripheral vascular disease	1
Cerebral vascular disease	1
Dementia	1
Chronic lung disease	1
Rheumatological	1
Peptic ulcer disease	1
Mild liver disease	1
Diabetes without complications	1
Hemiplegia	2
Diabetes with complications	2
Neoplasia	2
Moderate/severe liver disease	3
Metastatic disease	6
Leukemia	2
Lymphoma	2
Human immunodeficiency virus	6
Renal disease	2



# Prognostication tools

## 2) Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis:

**“Would I be surprised if this patient died in the next year?”**

The odds of dying within 1 yr for the patients with ESRD in the “No, I would not be surprised” group was 3.5 times higher than for patients in the “Yes” group

Variables in the prognostic model to predict 6-month survival for patients undergoing maintenance hemodialysis

“Surprise” question<sup>a</sup> (yes or no)

Dementia (yes or no)

Peripheral vascular disease (yes or no)

Age

Serum albumin

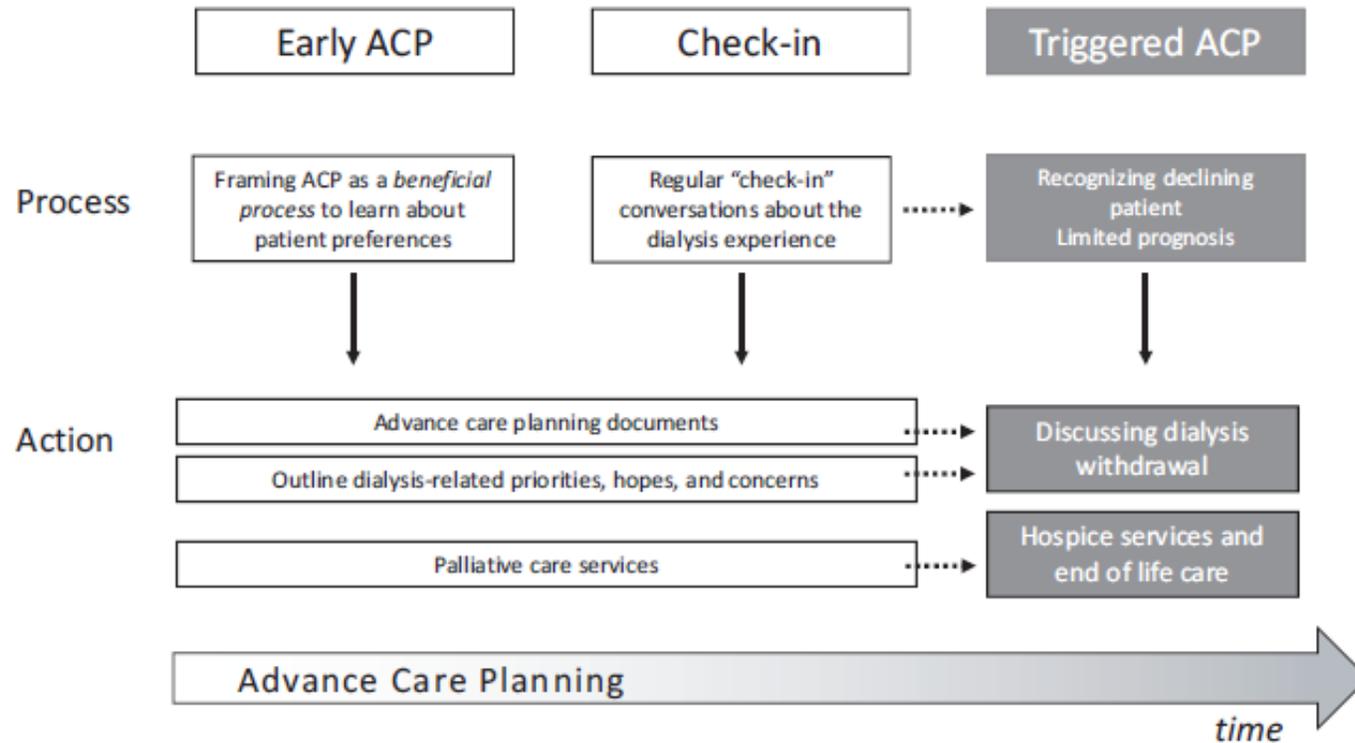
Cohen et al CJASN  
2010

3) First prognostic score **for predicting early death** (6 months) after starting dialysis in in elderly ESRD patients.

Risk Factors	Points		Total Score	6-Month Mortality Rate
Total dependence for transfers	3	}	0	8%
BMI <18.5 kg/m <sup>2</sup>	2		1	8-10%
Peripheral vascular disease stage 3 or 4	2		2	14-17%
Congestive heart failure stage 3 or 4	2		3-4	21-26%
Severe behavioral disorder	2		5-6	33-35%
Unplanned dialysis initiation	2		7-8	50-51%
Active malignancy	1		≥9	62-70%
Diabetes mellitus	1			
Dysrhythmia	1			

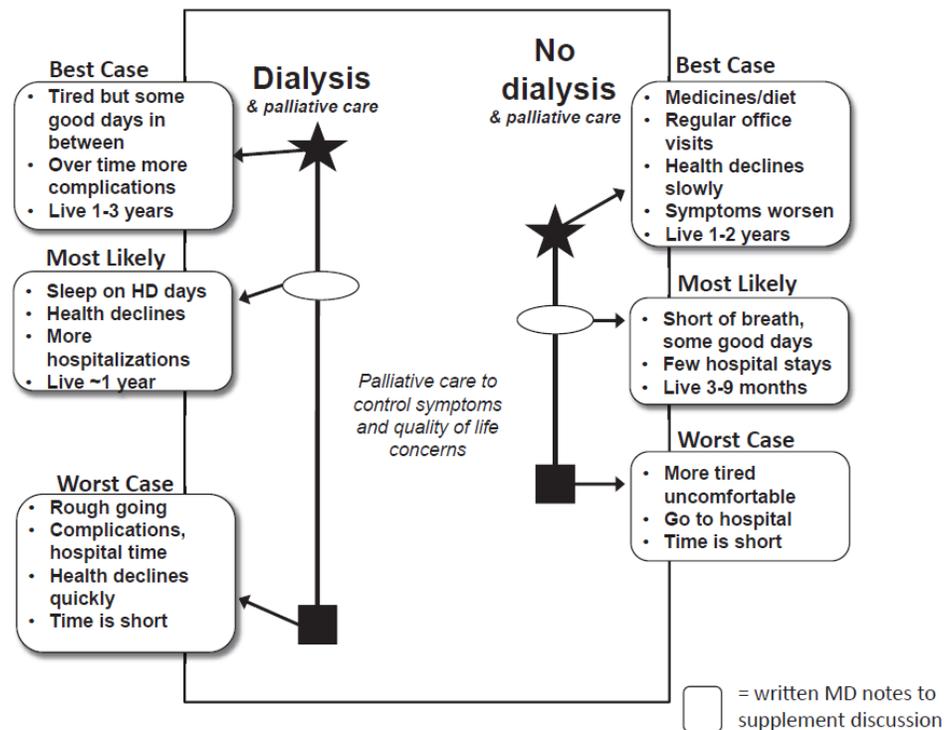
Berger et al, CJASN 2012

# Advance Care Planning



**FIGURE 2** Framework for advance care planning that includes early, check-in, as well as triggered conversations. Although the tools are not limited to specific phases of chronic illness, for simplicity, they are shown as discrete tools over the course of time. ACP; advance care planning

# Shared decision making



**Figure 1.** “Best Case/Worst Case” tool involves the drawing of a pen-and-paper diagram by the physician. Each treatment option is depicted by a vertical bar; the length of the bar represents the range of possible outcomes. The “best case” is represented by a star; the “worst case,” by a box; and the “most likely” outcome, by an oval. The physician describes each “case” using narrative derived from clinical experience and relevant evidence and writes key points on the diagram. Abbreviation: HD, hemodialysis. Adapted from Kruser et al<sup>11</sup> with permission of John Wiley and Sons.

# Dialysis specific care goals discussions

**TABLE 2** Phrases that can be useful for asking about dialysis-specific hopes and concerns

Values and priorities	Open-ended questions to outline dialysis goals
Explore patient hopes	What do you hope dialysis will help you do? or How do you think dialysis can improve your life?
Explore patient concerns	Are there situations when you would not want to continue treatments like dialysis? or What concerns about dialysis do you have?
Check-in on patient experience	Now that you have been on dialysis for a while, is there anything you are worried about?

# Dialysis cessation

**TABLE 4** Phrases that can be useful for bringing up dialysis withdrawal and responding to requests to stop dialysis

Rationale and framing	Useful phrases
Gain patient perspective. This step helps to determine whether they are also worried.	<ul style="list-style-type: none"><li>• How are things going on dialysis?</li><li>• Are your other doctors worried about your condition?</li><li>• How are you doing this month compared to, let's say, six months ago?</li></ul>
Gently frame your own concerns and explore further.	<ul style="list-style-type: none"><li>• Given the setbacks you've experienced, what's most important to you?</li><li>• I am concerned you have declined in the past few months. Do you think so also?</li><li>• I am worried dialysis is not making your life better. Do you see it this way?</li></ul>
Suggest how dialysis may not be optimizing quality of life based on patient's stated goals.	<ul style="list-style-type: none"><li>• When you started dialysis, it helped you recover and regain strength. That was important to you. Now I believe it could be making you weaker. (Expect and acknowledge emotion)</li></ul>
Responding to a request for dialysis withdrawal.	<ul style="list-style-type: none"><li>• I am grateful you brought this up with me. Can you tell me more about why you want to stop dialysis?</li></ul>
For patients at risk for dying in weeks to months, flexibility is important. <sup>a</sup>	<ul style="list-style-type: none"><li>• Many people in your condition would say that dialysis may not be helping them anymore.</li><li>• Do you feel this is true for you? You are very sick. It is ok for you not to come to dialysis if you feel too weak.<sup>b</sup></li></ul>

# Kidney Supportive Care (KSC) - Core Components

## Shared Decision-Making

- Ask: 'What are you hoping for? What concerns you most?'
- Explore support needs for patient and family
- Focus on values and priorities

## Symptom Management

- Routine screening with validated tools (ESAS-Renal, IPOS-Renal)
- Address: pruritus, restless legs, fatigue, pain, nausea, insomnia, anxiety, depression
- Ensure access to treatment algorithms

## Crisis Planning

- Educate about common symptoms
- Establish action plans
- Identify who to call for help
- Anticipatory prescribing

## Advance Care Planning

- Start conversations early
- Discuss end-of-life care preferences and location
- Identify substitute decision-maker
- Ensure decision-maker understands wishes

## Spiritual Care

- Screening: 'Are there spiritual concerns you'd like addressed?'
- Gateway to deeper assessment
- Connect with spiritual care team

## Integration with Community

- Anticipate declining self-care ability
- Support for activities of daily living
- Arrange nursing care as needed

## End-of-Life Care & Bereavement

- Anticipate symptoms with prescriptions ready
- Alternative routes to oral medications
- Support for dying patient and family

## Box 2 | KSC skill sets for nephrology and specialty palliative care teams

### Nephrology

- Basic assessment and management of pain and other physical symptoms
- Basic assessment and management of depression and anxiety
- Communication skills to discuss:
  - i. Prognosis
  - ii. Shared decision-making regarding kidney failure treatment options
  - iii. Goals of care and advance care planning, including wishes for resuscitation
  - iv. Conflict resolution regarding goals of care or treatment options
  - v. Relief of suffering: physical, psychosocial, and spiritual domains

### Specialty palliative care

- Comanagement of refractory pain and other physical symptoms
- Comanagement of complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals of care, treatment options, or advance care planning
  - i. Within families
  - ii. Between staff and families
  - iii. Among multidisciplinary care teams

# Conservative Kidney Management (CKM) - Specific Components

**FOUNDATION: Meticulous and timely attention to ALL core elements of KSC**

## Kidney Supportive Care Integration

- All 7 KSC components apply
- Shared decision-making
- Symptom management
- Advance care planning
- Spiritual care
- Crisis planning
- Community integration
- End-of-life care

## Disease Progression Management

- Avoid nephrotoxins (NSAIDs, contrast)
- Preserve residual kidney function
- Consider oral alkali therapy for severe metabolic acidosis ( $\geq 16$  mmol/L)
- Align interventions with patient goals

## Medical Complications Management

- That aligns with the individual's priorities
- Liberalize diet to optimize nutrition,
- Dietary restrictions ONLY to minimize symptoms

**CKM Does NOT Include Kidney Replacement Therapy (KRT)**

Exception: Failed kidney transplant patients unable or unwilling to transition to dialysis or receive another transplant

# Key Take aways

- Although dialysis has symptom benefit to an extent, may not improve many patients' overall quality of life or help them achieve their goals for care. (increase in hospital stays, reduced home time).
- Role of KSC and CKM
- Opportunities to integrate palliative care to kidney disease
- Identify patient priorities, choose treatment pathway that meet patient goals through shared decision making.
- Importance of advance care planning and check-in

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Questions?



THANK YOU

