TALKING TO PATIENTS AND FAMILIES ABOUT DECLINING RENAL FUNCTION

RSC Psychosocial Day 2017

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FROM EARLY TO ADVANCED CKD

- Early CKD
  - Lifestyle management
  - Blood pressure management
  - Diabetes management
  - Cardiovascular risk factors
  - Lots of numbers

- Advanced CKD
  - All of the above PLUS
  - Dialysis
  - Transplant
  - Conservative management

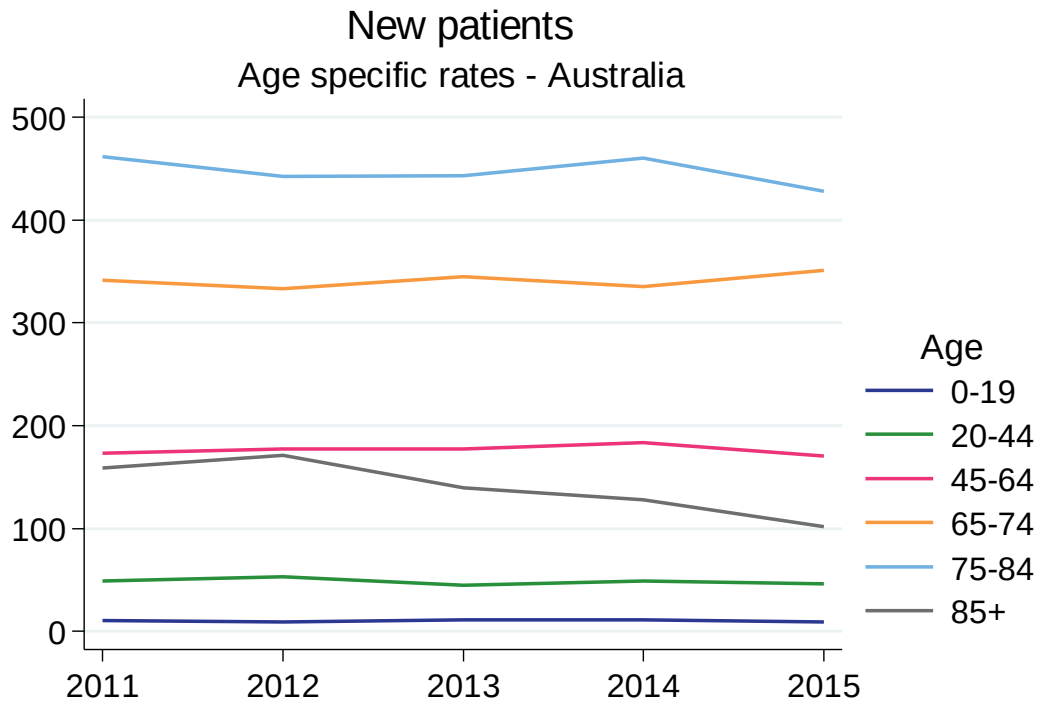
FOCUS CHANGES

- Early CKD
  - Lifestyle management
  - Blood pressure management
  - Diabetes management
  - Cardiovascular risk factors
  - Lots of numbers
- Advanced CKD
  - All of the above PLUS
  - Dialysis
  - Transplant
  - Conservative management

- Burdens of RRT
- Prognosis
- QOL

- Lots of difficult conversations!

WHO ARE OUR PATIENTS?



2016 ANZDATA Annual Report, Figure 1.3

APPROACHING ESKD

- Do patients want to know?
- Do nephrologists talk to patients about ESKD?
- What can we tell patients about their prognosis?
- How do we make ethical decisions?

APPROACHING ESKD

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DO PATIENTS WANT TO KNOW?

- Questionnaire handed out to 100 patients on their first visit to nephrologist
  - 97% would want to be given life expectancy information
  - AND for physician to do so without prompting
  - Most patients would want as much information as possible, both good and bad
- In a Canadian study of CKD patients:
  - 90% wanted to be informed about prognosis
  - 85% wanted to be informed about treatment options including withdrawing from dialysis
  - 83% thought it was important to be prepared and plan ahead in case of death

Fine et al. Nephrologists should voluntarily divulge survival data to potential dialysis patients: a questionnaire study *Perit Dial Int* 2005;25(3):269-273
Davidson SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *CJASN* 2010;5:195-204

APPROACHING ESKD

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DO NEPHROLOGIST PROVIDE INFORMATION?

- In a Canadian study of CKD patients:
  - 90% wanted to be informed about prognosis
  - 85% wanted to be informed about treatment options including withdrawing from dialysis
  - 83% thought it was important to be prepared and plan ahead in case of death

  - However, 90% of patients have not received information about their expected survival from their doctor

Davidson SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *CJASN* 2010;5:195-204

- US study
- 99 patients on maintenance dialysis
- Younger patients (most <70)

Table 3. Number (%) of patients responding 'Yes' to each informed decision-making item

Content of the item	*n* (%)
1. Condition that led to kidney failure	53 (53.5)
2. How long you would live with or without dialysis	45 (45.5)
3. Dialysis options, such as peritoneal dialysis and hemodialysis	59 (59.6)
4. Benefits and burdens associated with each type of dialysis	32 (32.3)
5. Doctor asked your values and preferences for those dialysis options	20 (20.2)
6. How your daily life might change after starting dialysis	44 (44.4)
7. Need for dialysis for the rest of your life unless you receive kidney transplantation	82 (82.8)
8. Not starting dialysis could be an option	1 (1.0)
9. Doctor tried to make sure you understood what he/she told you	74 (74.7)
10. Doctor tried to understand what was important to you	58 (58.6)

Song et al. Patient perspectives on informed decision-making surrounding dialysis initiation. *NDT* 2013;28:2815-2823

WHY ARE NEPHROLOGISTS NOT TALKING?

- In a qualitative study of US nephrologists and patients[1]
  - Nephrologists tended to avoid discussions about the future
    - Difficulty in prognosticating
    - Discussions viewed as negative, taking away hope, or unnecessary in patient stable
- In a survey of US nephrology fellows (2014)[2]
  - >90% were most comfortable writing dialysis orders or seeing an ICU consult
  - 1/3 felt most comfortable not offering dialysis to a patient in the ICU with multi-organ failure
  - 18% (almost 1/5) felt obligated to offer dialysis to every patient regardless of benefit.

1. Schell et al. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *AJKD* 2012;59:495-503
2. Shah et al. Palliative care experience of US adult nephrology fellows: a national survey. *Ren Fail* 2014;36:39-45

Comparison of Patients' and Nephrologists' Estimates of 1- and 5-Year Survival[a]

	Nephrologist Estimate of Survival, %[b]					
Patient Estimate of Survival, %	**≥90**	**61-89**	**40-60**	**11-39**	**≤10**	**Total, No. (%)**
At 1 y[c]						
≥90	13 (27)	23 (48)	12 (25)	0	0	48 (81)
75	2 (33)	2 (33)	2 (33)	0	0	6 (10)
50	0	4 (100)	0	0	0	4 (7)
25	0	0	0	0	1 (100)	1 (2)
≤10	0	0	0	0	0	0
Total	15 (25)	29 (49)	14 (24)	0	1 (2)	59 (100)
At 5 y[d]						
≥90	3 (14)	1 (5)	5 (23)	10 (45)	3 (14)	22 (42)
75	1 (9)	2 (18)	4 (36)	1 (9)	3 (27)	11 (21)
50	0	0	7 (44)	5 (31)	4 (25)	16 (31)
25	0	0	0	2 (100)	0	2 (4)
≤10	0	0	0	0	1 (100)	1 (2)
Total	4 (8)	3 (6)	16 (31)	18 (35)	11 (21)	52 (100)

Wachterman et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Intern Med.* 2013;173:1206-1214

APPROACHING ESKD

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WHAT IS THE PROGNOSIS OF PATIENTS WITH ESKD?

- Length of time – survival with or without dialysis
- Quality – how time is spent

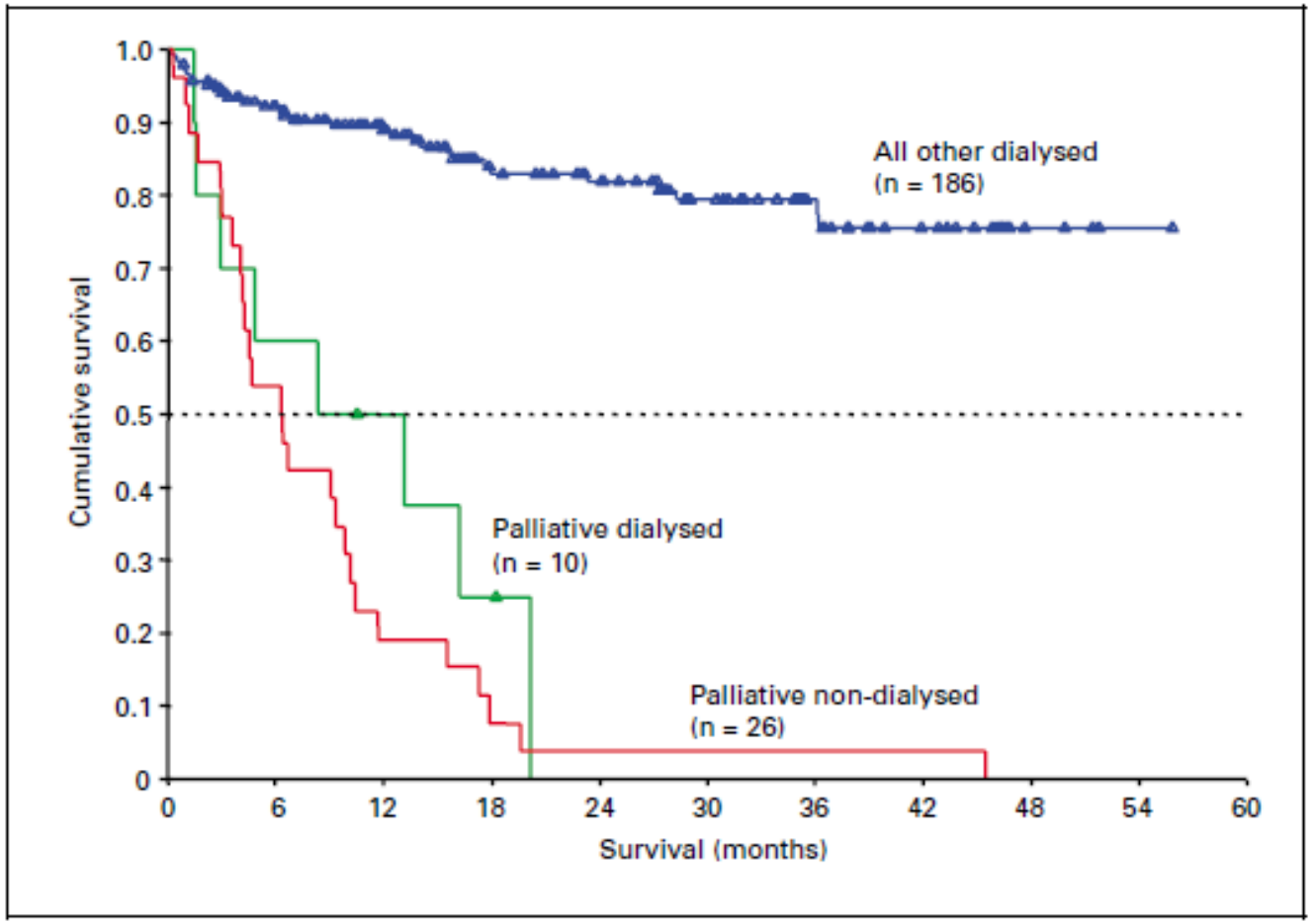


Fig. 3. Kaplan-Meier survival curves in palliative-dialysed, palliative non-dialysed, and all other dialysed patients (see text for definition of groups). Predicted survival in all other dialysed patients was significantly greater than in the other two groups. Survival in the palliative-dialysed and palliative non-dialysed groups was not significantly different.

Smith et al. Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract* 2003;95:c40-c46

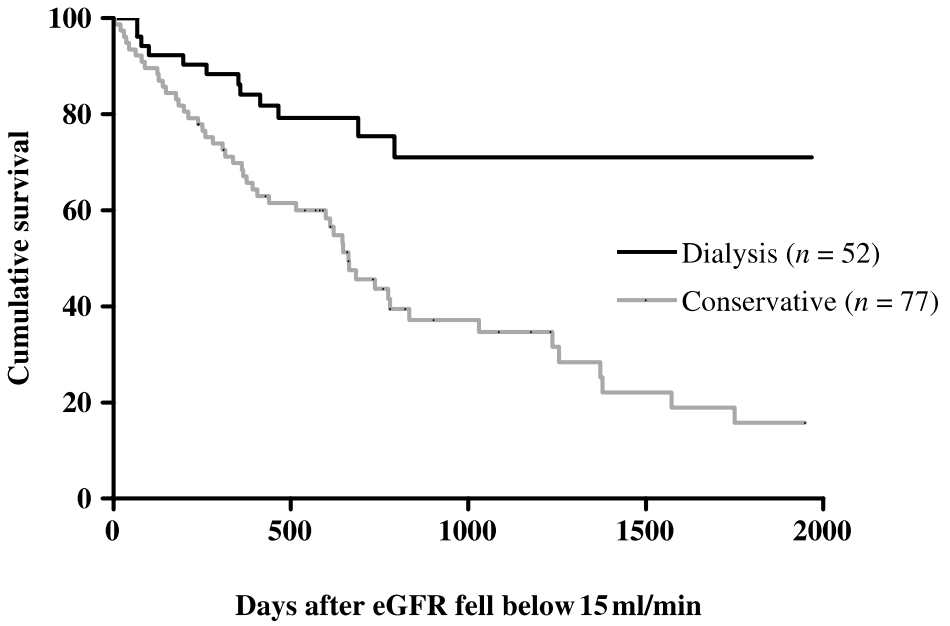


Fig. 2. Kaplan–Meier survival curves comparing the dialysis and conservative groups (log rank statistic = 13.63, $P < 0.001$).

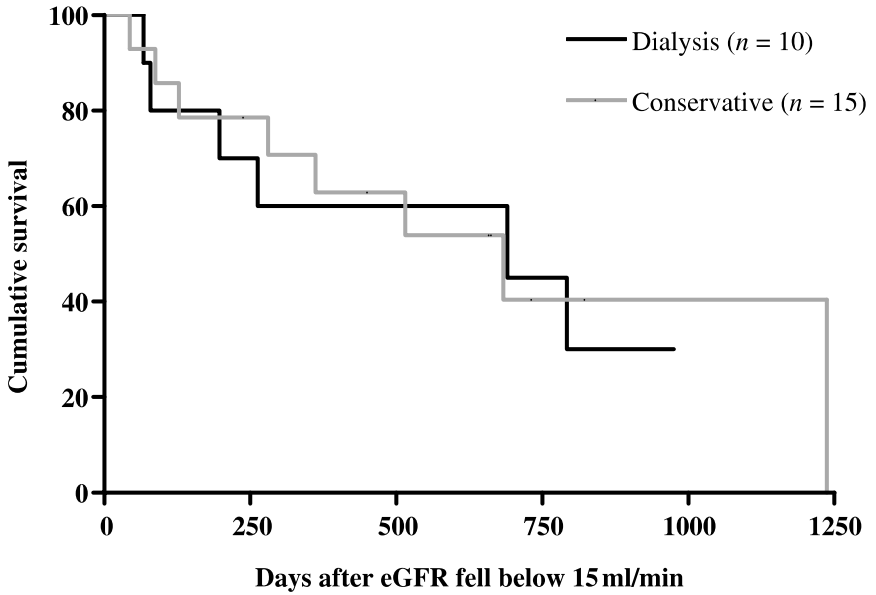


Fig. 3. Kaplan–Meier survival curves for those with high comorbidity (score = 2), comparing dialysis and conservative groups (log rank statistic <0.001, df 1, $P = 0.98$).

Murtagh et al. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *NDT* 2007;22:1955-1962

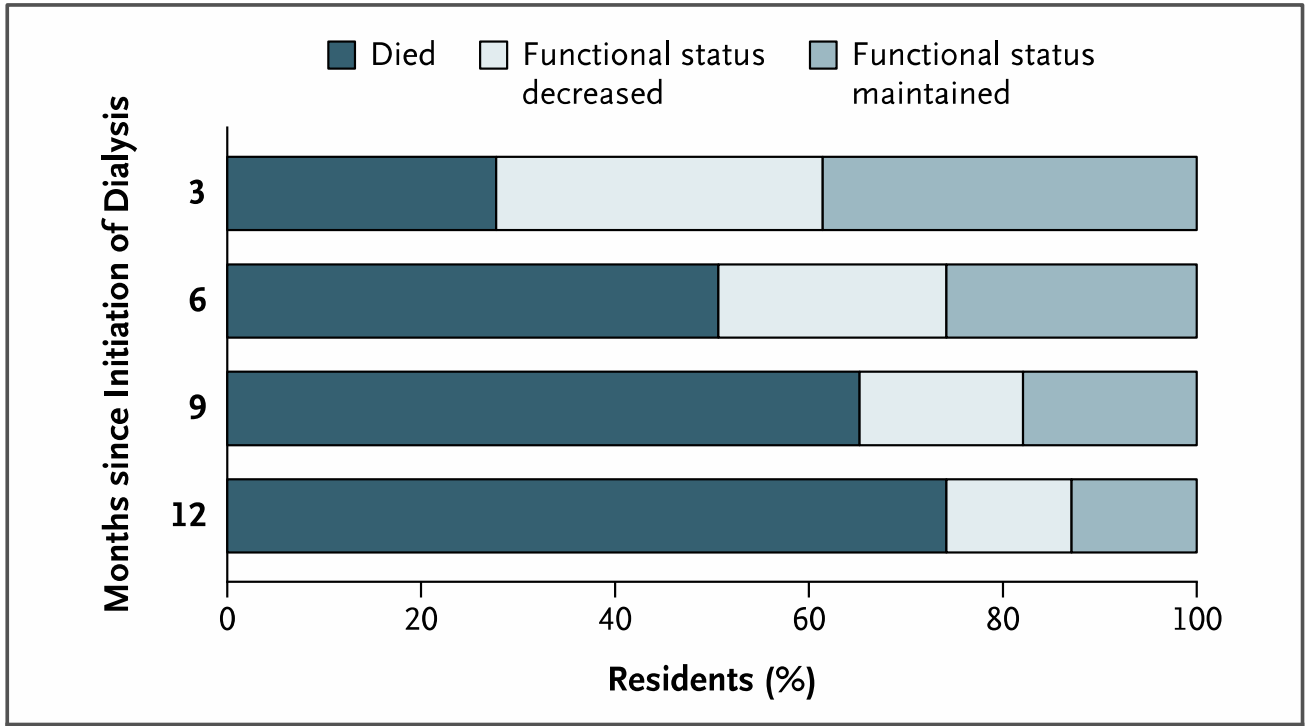


Figure 2. Change in Functional Status after Initiation of Dialysis.

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.

Kurella et al. Functional status of elderly adults before and after initiation of dialysis. *NEJM*. 2009;361:1539-1547

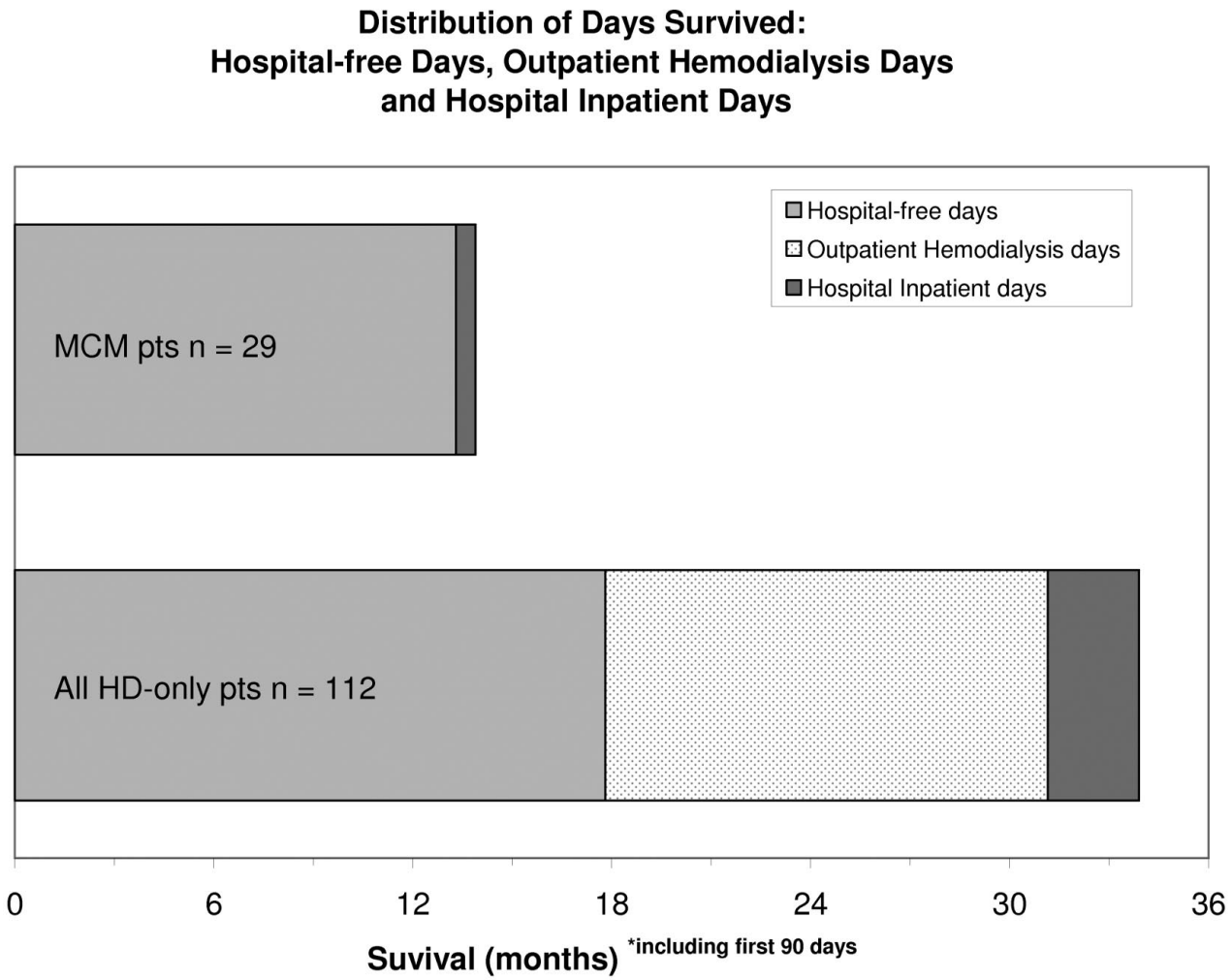


Figure 3. Median survival for MCM cohort and the hemodialysis-only subgroup in the RRT cohort. Data shown are how many days were spent hospital-free, compared with in-patient stays in hospital and outpatient hospital attendances for dialysis.

Carson et al. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *CJASN*. 2009;2009:1611-1619

RENAL PHYSICIANS ASSOCIATION GUIDELINES:

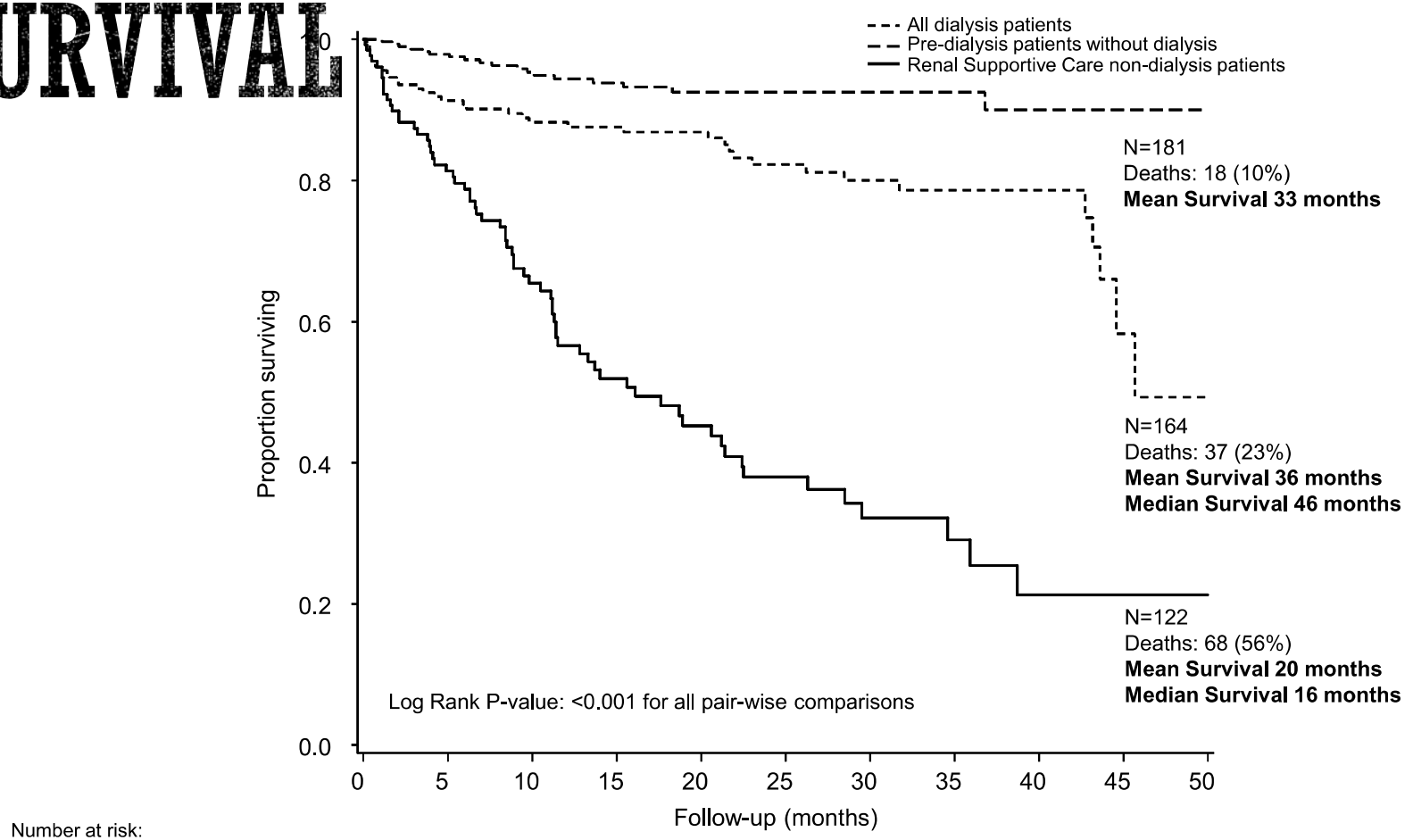
- It is reasonable to consider forgoing dialysis in the following
  - Medical condition precluding dialysis eg
    - Patient unable to cooperate due to dementia
    - Profound hypotension
  - Those with a terminal illness from non-renal causes
  - Those aged over 75 with 2 or more of
    - Clinician response of "no, I would not be surprised" to the surprise question
    - High comorbidity score
    - Significantly impaired functional status
    - Severe chronic malnutrition

Renal Physicians Association. *Shared Decision Making in the Appropriate Initiation and Withdrawal From Dialysis.* 2nd ed. Washington, DC: Renal Physicians Association; 2010

WHAT CAN WE TELL PATIENTS ABOUT CONSERVATIVE MANAGEMENT?

- Survival
- Symptoms
- Function

SURVIVAL



Number at risk:

Pre-dialysis without dialysis	181	151	125	97	66	49	40	32	20	8	0
All dialysis	164	124	110	98	79	61	51	37	23	6	0
RSC non-dialysis	122	90	63	45	33	24	17	12	5	2	0

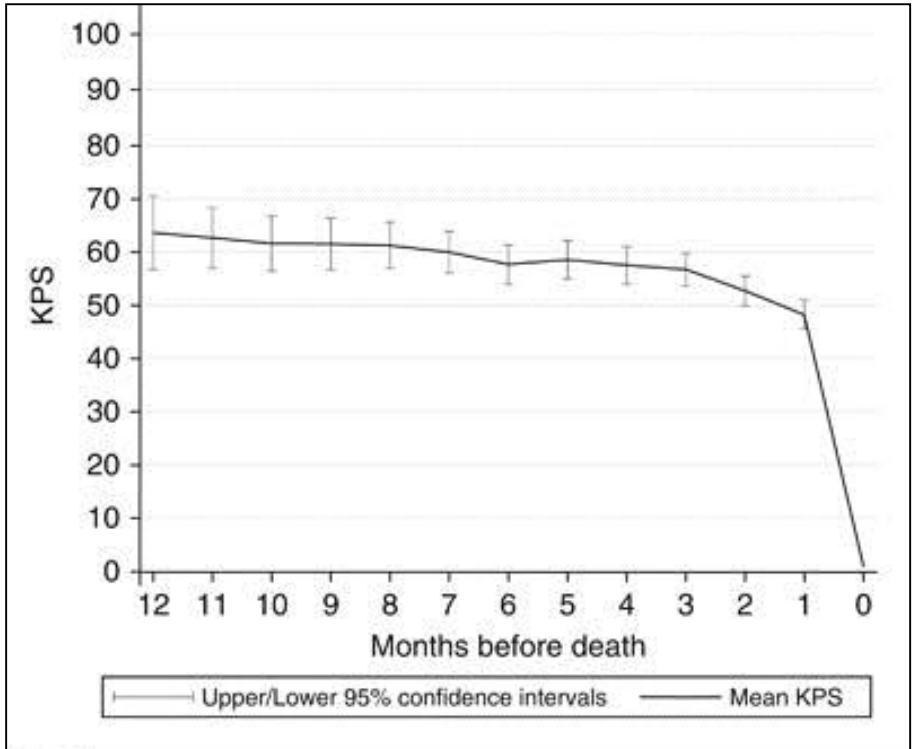
Brown et al. CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *CJASN* 2015;10:260-268

SYMPTOMS

POS-S symptom status	78
Change of POS-S (renal) score over 6 mo	
Stable	3 (4%)
Improved	48 (62%)
Worse	27 (35%)
Change of POS-S (renal) score over 12 mo	69
Stable	3 (4%)
Improved	49 (71%)
Worse	17 (25%)

Brown et al. CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *CJASN* 2015;10:260-268

FUNCTION



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).

Murtagh et al. End-stage renal disease: a new trajectory of functional decline in the last year of life. *J Am Geriatr Soc*. 2011;59:304-308

APPROACHING ESKD

- Do patients want to know?
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- ***How do we make ethical decisions?***

ETHICAL DECISION-MAKING

- Medical indication
- Patient preference
- Quality of life
- Context

Renal Physicians Association. *Shared Decision Making in the Appropriate Initiation and Withdrawal From Dialysis.* 2nd ed. Washington, DC: Renal Physicians Association; 2010

MEDICAL INDICATIONS

ETHICAL PRINCIPLES OF BENEFICENCE & NONMALEFICENCE

- Ethical duty to provide treatment that benefit patients and do no harm

- "Professional integrity requires physicians to refrain from providing dialysis when the burdens of treatment substantially outweigh the benefits."
- "In circumstances in which dialysis is not medically indicated, a patient or family preference to receive dialysis does not justify its provision."

Renal Physicians Association. *Shared Decision Making in the Appropriate Initiation and Withdrawal From Dialysis.* 2nd ed. Washington, DC: Renal Physicians Association; 2010

PATIENT PREFERENCES

RESPECT FOR AUTONOMY

- If treatment is medically indicated, physicians and family members have an ethical duty to accept decisions of competent patients

- If patient is incompetent
  - To respect patient's wishes, if known
  - To act in the best interest of the patient, if wishes are not known

Renal Physicians Association. *Shared Decision Making in the Appropriate Initiation and Withdrawal From Dialysis.* 2nd ed. Washington, DC: Renal Physicians Association; 2010

- Quality of life
  - Medical interventions aim to restore, maintain or improve QOL
  - QOL need to be perceived by the patient

- Context
  - External factors which may be institutional, social, or financial

Renal Physicians Association. *Shared Decision Making in the Appropriate Initiation and Withdrawal From Dialysis.* 2nd ed. Washington, DC: Renal Physicians Association; 2010

COMMUNICATION

- Incorporating patient goals and values to outline a treatment plan
  - Explore hopes and expectations (quantity vs quality)
  - Explore concerns (physical, psychological, family)
  - Explore limitations (situations where life is not worth living)
  - Re-evaluating goals over time

- Allows us to see the "big picture" and make recommendations

Koncicki et al. Communication skills and decision making for elderly patients with advanced kidney disease: a guide for nephrologists. *AJKD*. 2016;67(4):688-695

- Nephrologists love numbers

THE BIG PICTURE

NAZCA LINES

- Nephrologists love numbers