

ADVANCED CARE PLANNING & END-STAGE KIDNEY DISEASE



RENAL SUPPORTIVE CARE TEAM
PRINCE OF WALES HOSPITAL



UNSW
AUSTRALIA

Medicine

BACKGROUND

End-stage kidney disease (ESKD) management

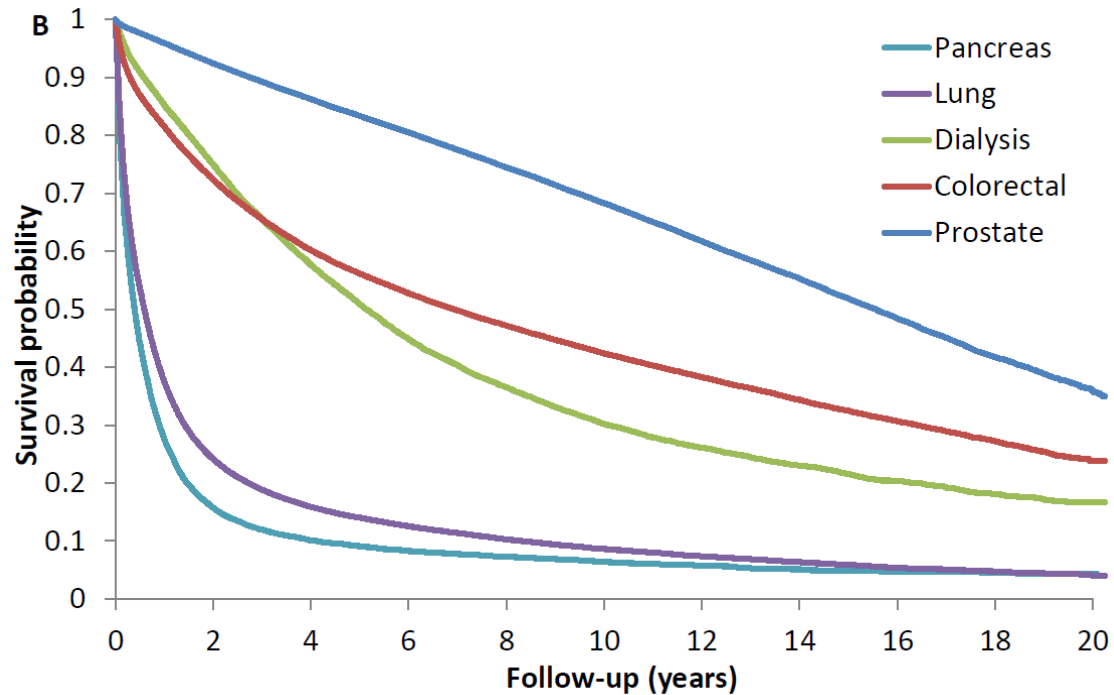
- Dismal survival
- Excessive symptom burden
- Poorly defined ceilings of care

Contextual effects of disease/treatment/psychosocial factors change over time

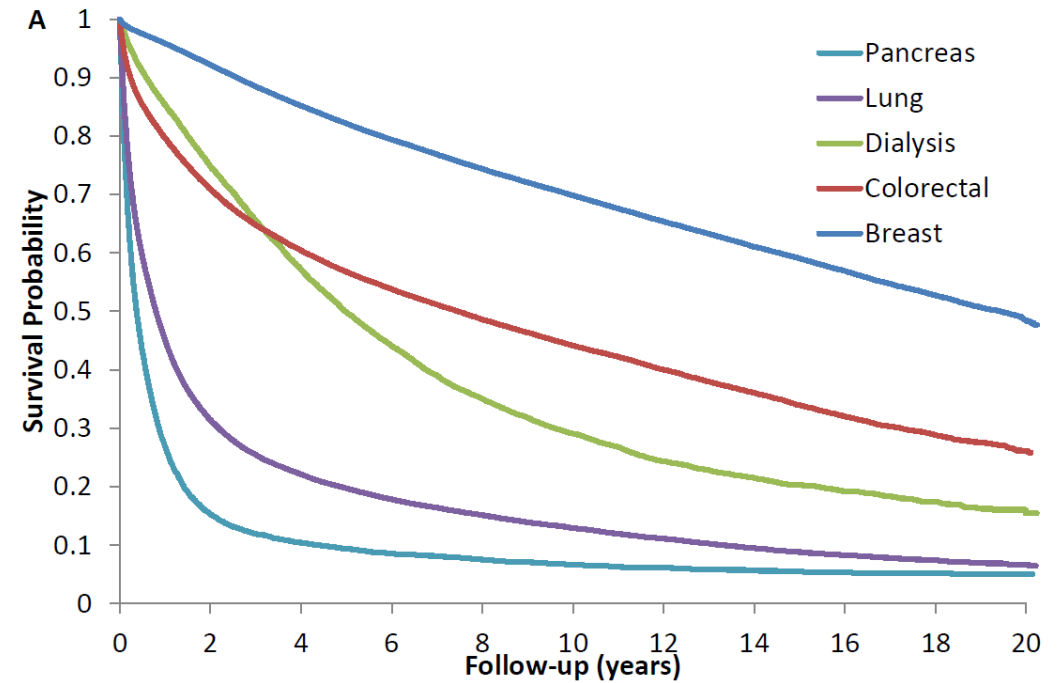
Early advanced care planning (ACP) a critical factor in decision making

ESKD: WORSE SURVIVAL THAN MALIGNANCIES

MALE SURVIVAL



FEMALE SURVIVAL



ESKD: COMPARABLE SYMPTOMS TO MALIGNANCY

| Outcomes ^c | Adjusted Proportions (%) ^b (After Propensity Weighting) | | |
|--|--|--------|-----------------------|
| | ESRD | Cancer | <i>P</i> ^d |
| Symptoms | | | |
| Often troubled by moderate/severe pain during last year of life (<i>n</i> = 1864) | 53.7 | 57.8 | 0.34 |
| Dyspnea ^f (<i>n</i> = 1466) | 61.1 | 53.5 | 0.12 |
| Frequent vomiting ^f (<i>n</i> = 1444) | 14.9 | 20.7 | 0.09 |
| Depression ^f (<i>n</i> = 1445) | 53.1 | 54.2 | 0.83 |
| Periodic confusion ^f (<i>n</i> = 1466) | 41.4 | 44.2 | 0.52 |

ESKD: INCREASED TREATMENT INTENSITY

Table. Intensity of Care During the Final Month of Life

| Intensity of Care | Medicare Beneficiaries | | |
|--------------------------------------|--------------------------------|---------------------|---------------------------------|
| | 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 |

INCREASED TIME IN HOSPITAL



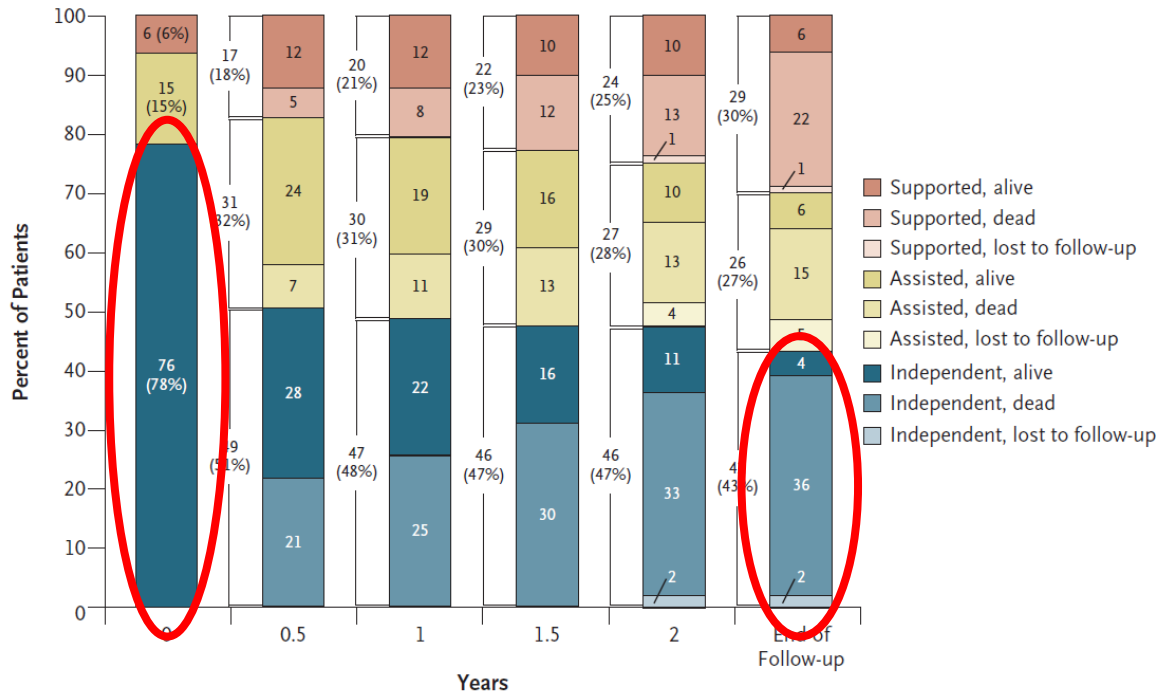
LOWER THRESHOLD FOR CRITICAL CARE TREATMENTS



REDUCED OUTPATIENT PALLIATIVE CARE SERVICES

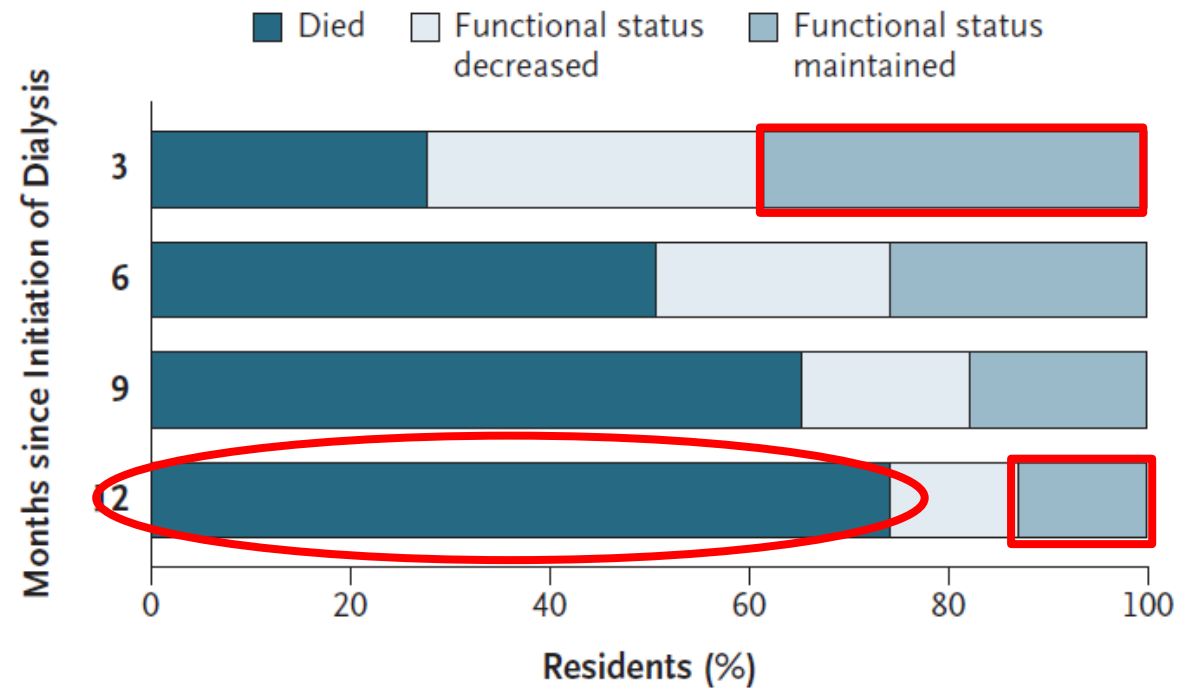


ESKD: TREATMENT EFFECTS & FUNCTIONALITY



ESKD LIVING STATUS

50% ESKD patients lose independent living status within 2-years of commencing RRT



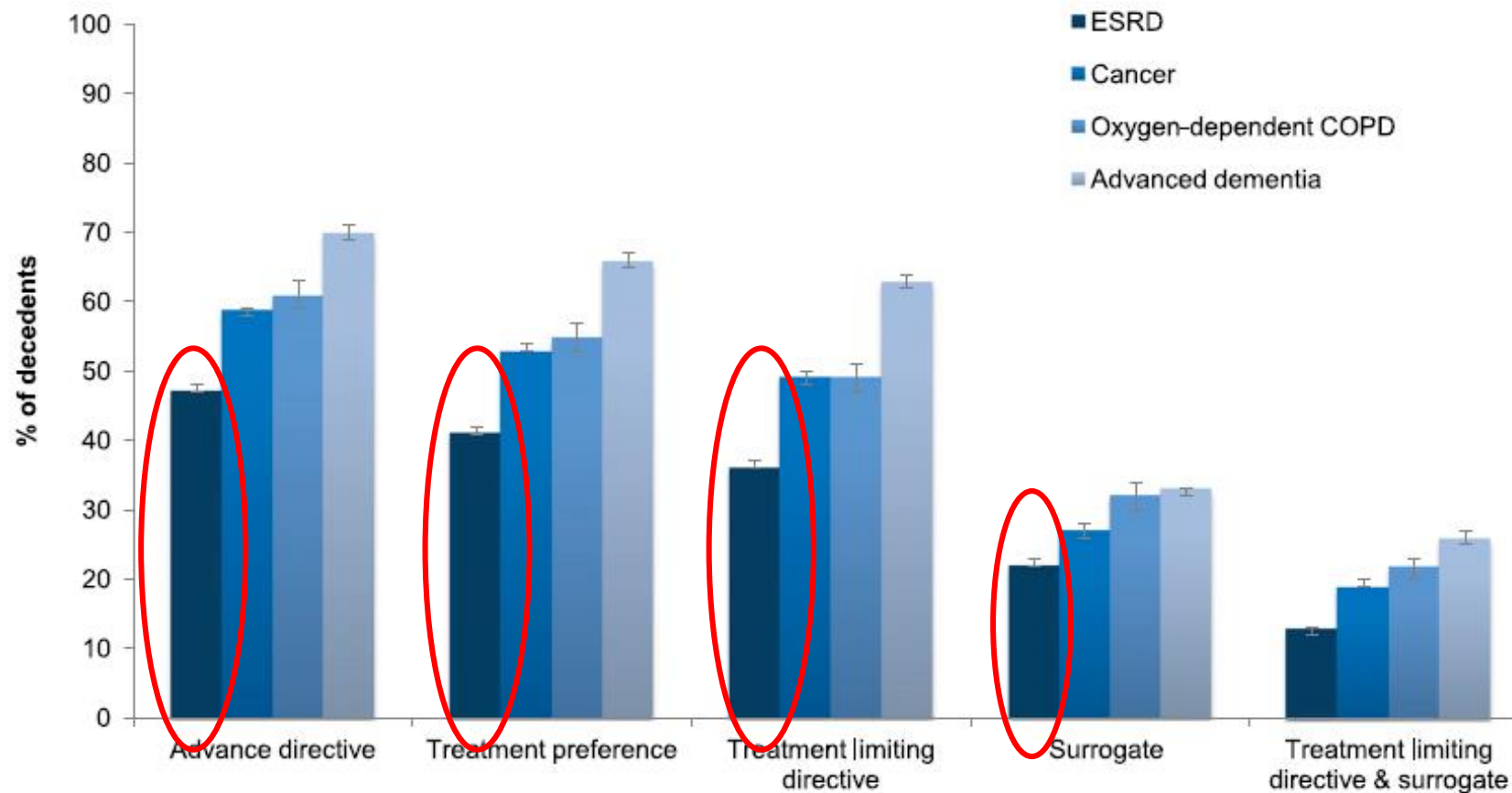
ESKD NURSING HOME FUNCTIONAL CAPACITY

Only 10-15% of nursing home patients maintain functional independence within the 1st year of RRT

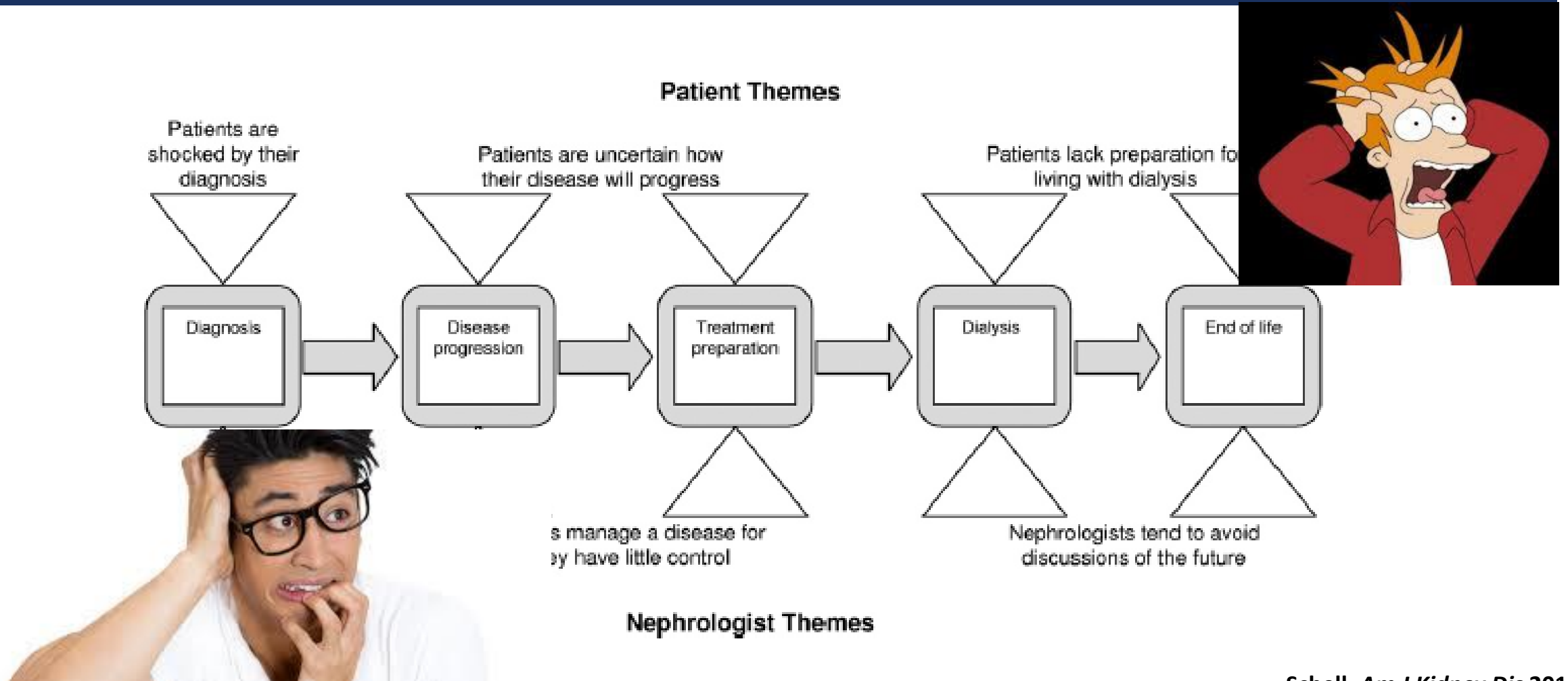
Jassal, *NEJM* 2009
 Tamura, *NEJM* 2009
 Swidler, *JASN* 2013

HOW ARE NEPHROLOGISTS AT ACP?

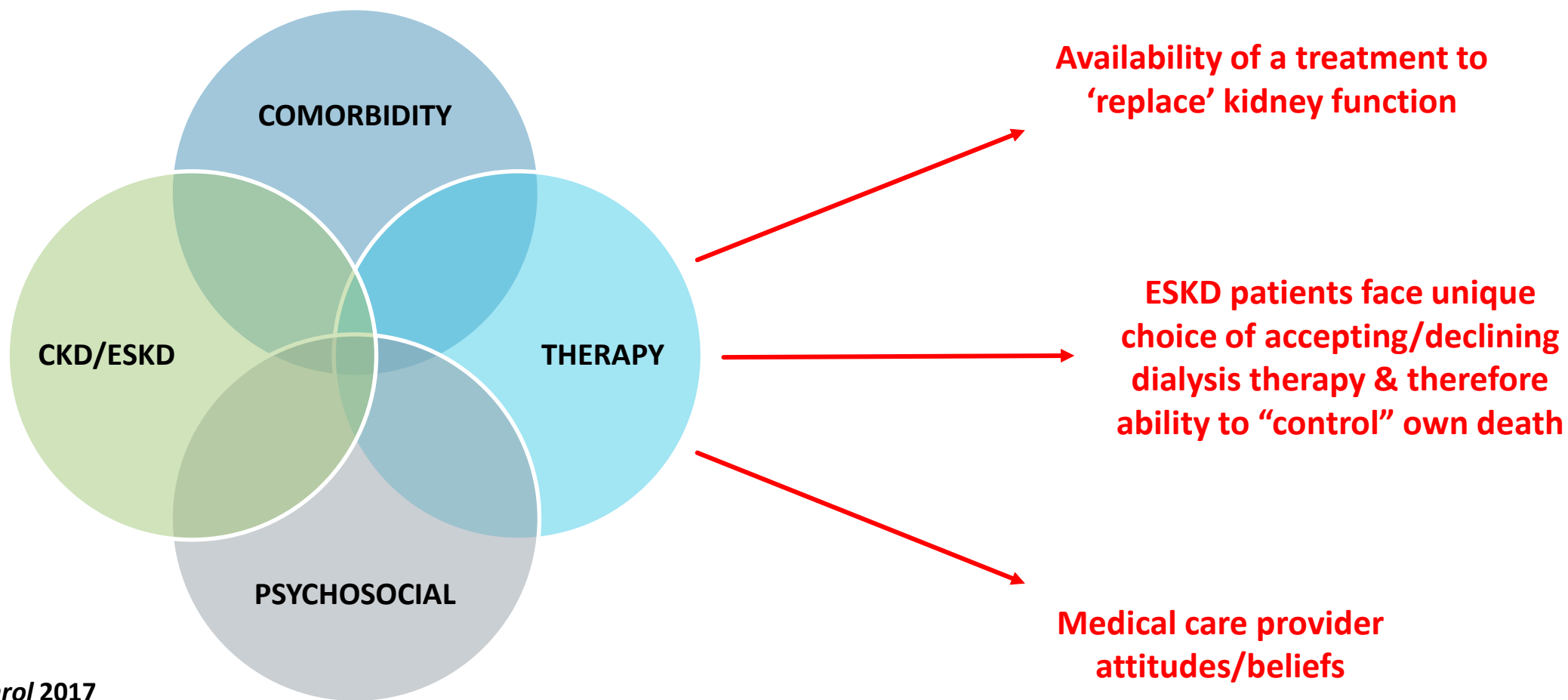
NURSING HOME RESIDENTS



ESKD: PATIENT & NEPHROLOGIST JOURNEY



ACP & ESKD : WHY IS THIS SO HARD?



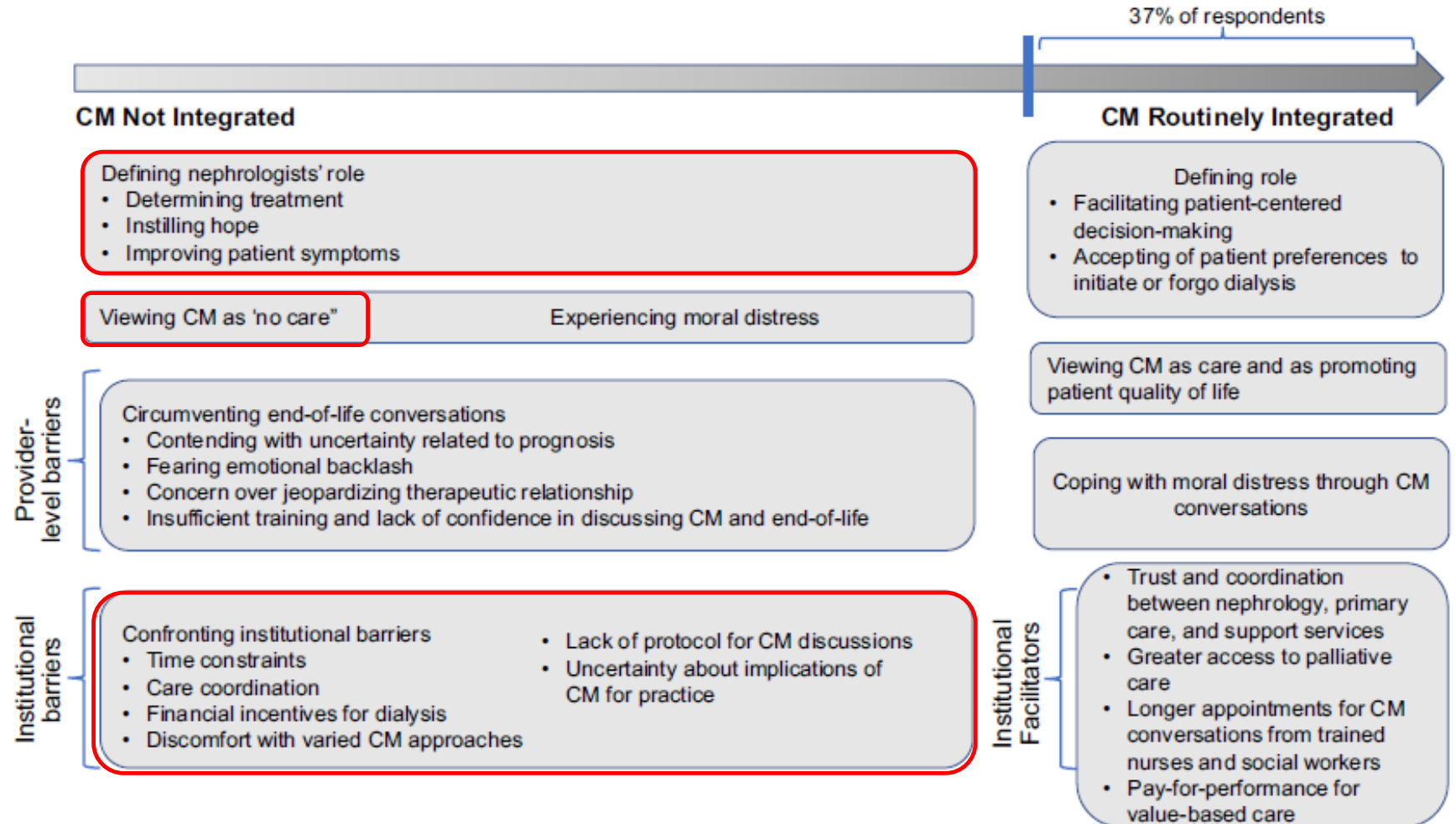
ACP & NEPHROLOGISTS: WHAT EXACTLY DO WE DO?

Health-care role perceived as treatment provider rather than to 'with-hold beneficial treatment'

Supportive care viewed as 'no treatment' option and perceived as loss of hope/giving up

"I see myself as someone who provides hope for sick people...I see enough people feel so much better after dialysis..."

Ladin, Am J Kidney Dis 2018



ACP & NEPHROLOGISTS: WHAT EXACTLY DO WE DO?

Discussions on goals of care and quality of life impeded by concern over patients' emotional response

Fear of damage to long-term therapeutic relationships and encourages 'doctor shopping'

"I can't deal with people who respond to me with...I end up saying: this is just going to happen and we'll just deal with it when they come into ED in a crisis situation"

Ladin, *Am J Kidney Dis* 2018

Provider-level barriers
Institutional barriers



37% of respondents

Continently Integrated

Defining role
Patient-centered
Involving
Patient preferences to
Go dialysis

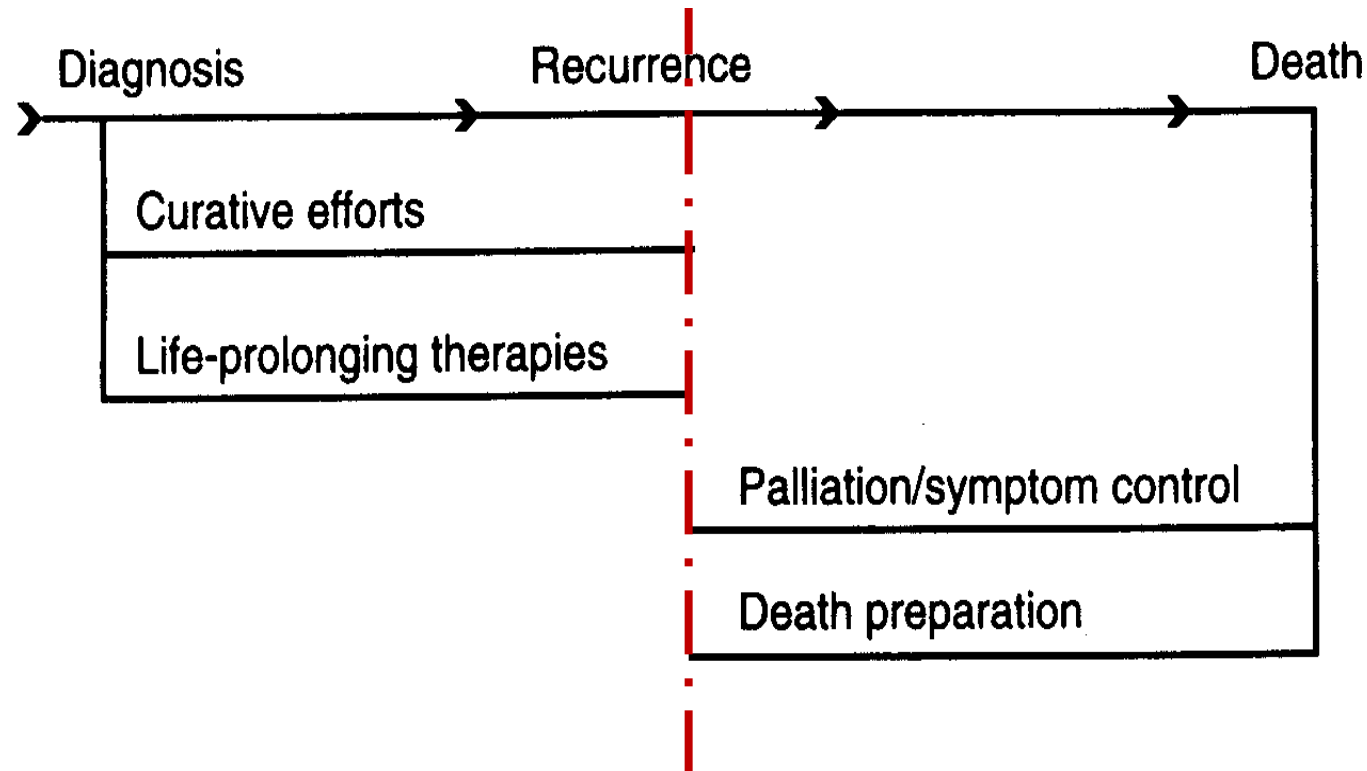
Care and as promoting
Quality of life

Reduction of patient distress through CM
Conversations

Improved coordination
In nephrology, primary
Care and support services
Access to palliative

Streamlined appointments for CM
Education from trained
And social workers
Improved performance for
Advanced care

TRADITIONAL (?FLAWED) APPROACH TO ACP



Single 'conversation'
between patient/doctor

Often occurs late in disease
trajectory

Barry, *NEJM* 2012

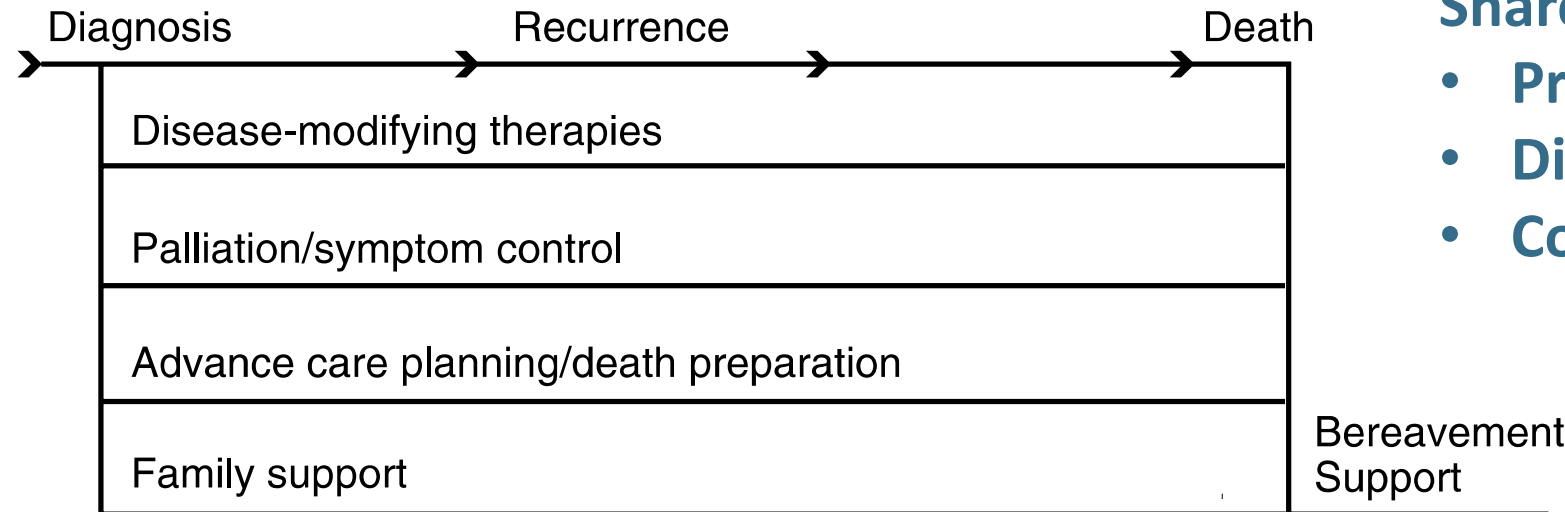
Swidler, *CJASN* 2013

Schmidt, *Semin Nephrol* 2017

Cassel, *Institute of Medicine* 1997 (Approaching Death)

NEEDS-BASED APPROACH TO ACP

Dynamic iterative process
Evolves with contextual changes in health status



Shared decision making

- Prognosis
- Dialysis trajectory
- Conservative pathway

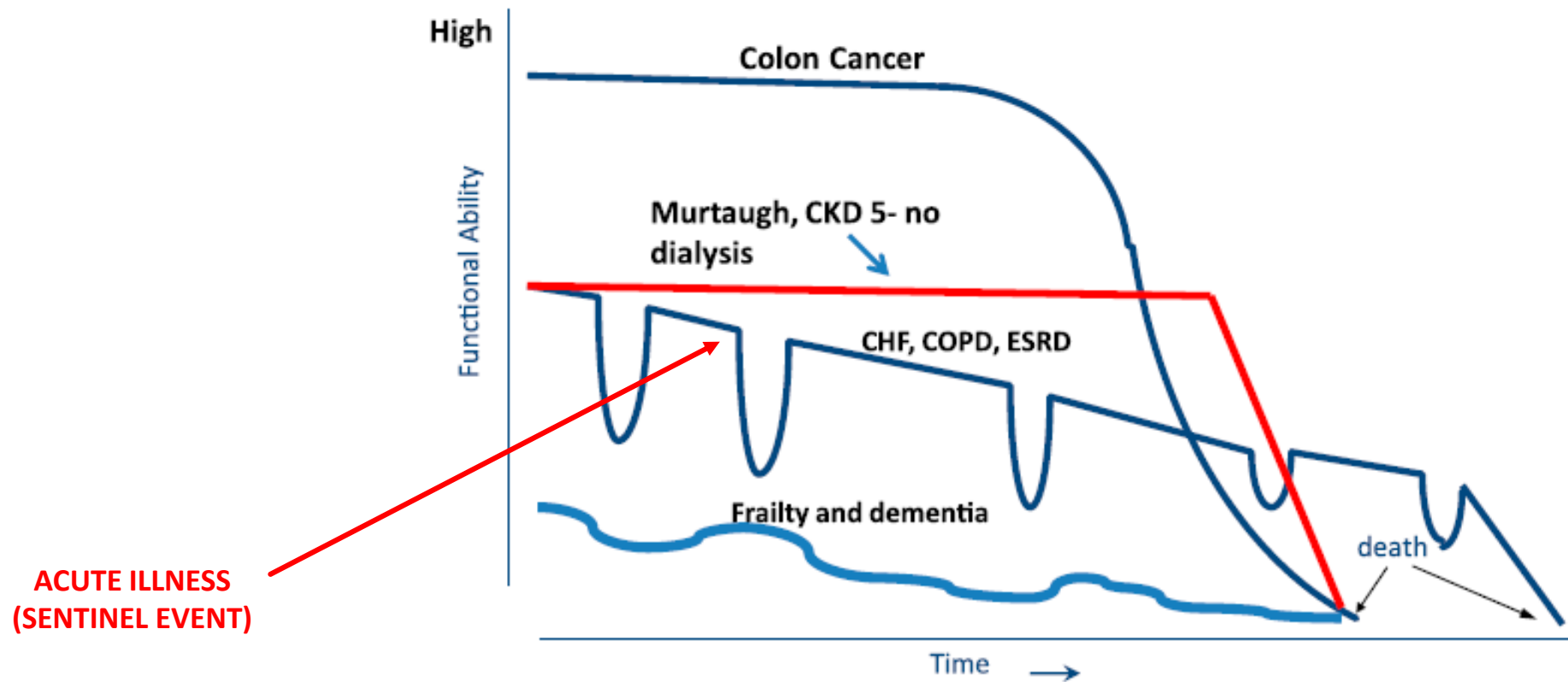
Barry, *NEJM* 2012

Swidler, *CJASN* 2013

Schmidt, *Semin Nephrol* 2017

Cassel, *Institute of Medicine* 1997 (Approaching Death)

ESKD: UNDERSTANDING TRAJECTORY OF ILLNESS

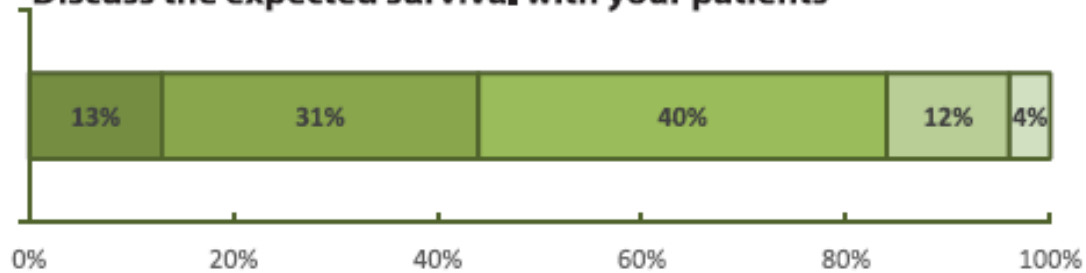


ARE NEPHROLOGISTS GOOD AT PROGNOSTICATION?

PREDIALYSIS CKD

Always Often Sometimes Rarely Never

Discuss the expected survival with your patients

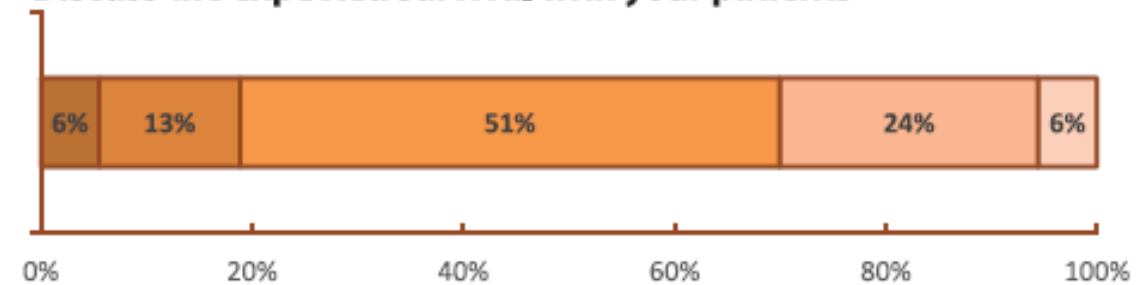


<50% discussed prognostication

ESKD/DIALYSIS

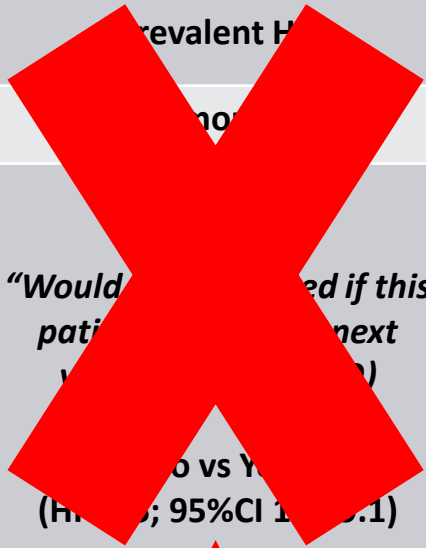
Always Often Sometimes Rarely Never

Discuss the expected survival with your patients



<20% discussed prognostication

ACP: PROGNOSTIC TOOLS & ESKD

| | MOSS (2008) | COHEN (2009) | COUCHOUD (2009) | BANSAL (2015) |
|-----------------|--|--|--|--|
| POPULATION | Prevalent HD | Prevalent HD | Incident HD | Pre-dialysis CKD (eGFR 47 ± 11) |
| OUTCOME | 6-month mortality | 6-month mortality | 6-month mortality | 5-yr mortality |
| TOOL/PREDICTORS |  <p>Age Dementia Hypoalbuminaemia Surprise question Peripheral vascular disease</p> | <p>Age Dementia Hypoalbuminaemia Surprise question Peripheral vascular disease</p> | <p>Diabetes BMI <18.5kg/m² Cardiac failure (III/IV) Peripheral vascular disease Arrhythmia Active malignancy Behavioural disorder Transfer dependent Emergency RRT</p> | <p>Age Gender (male) GFR Albuminuria Smoking Diabetes Cardiac failure Cerebrovascular accident</p> |

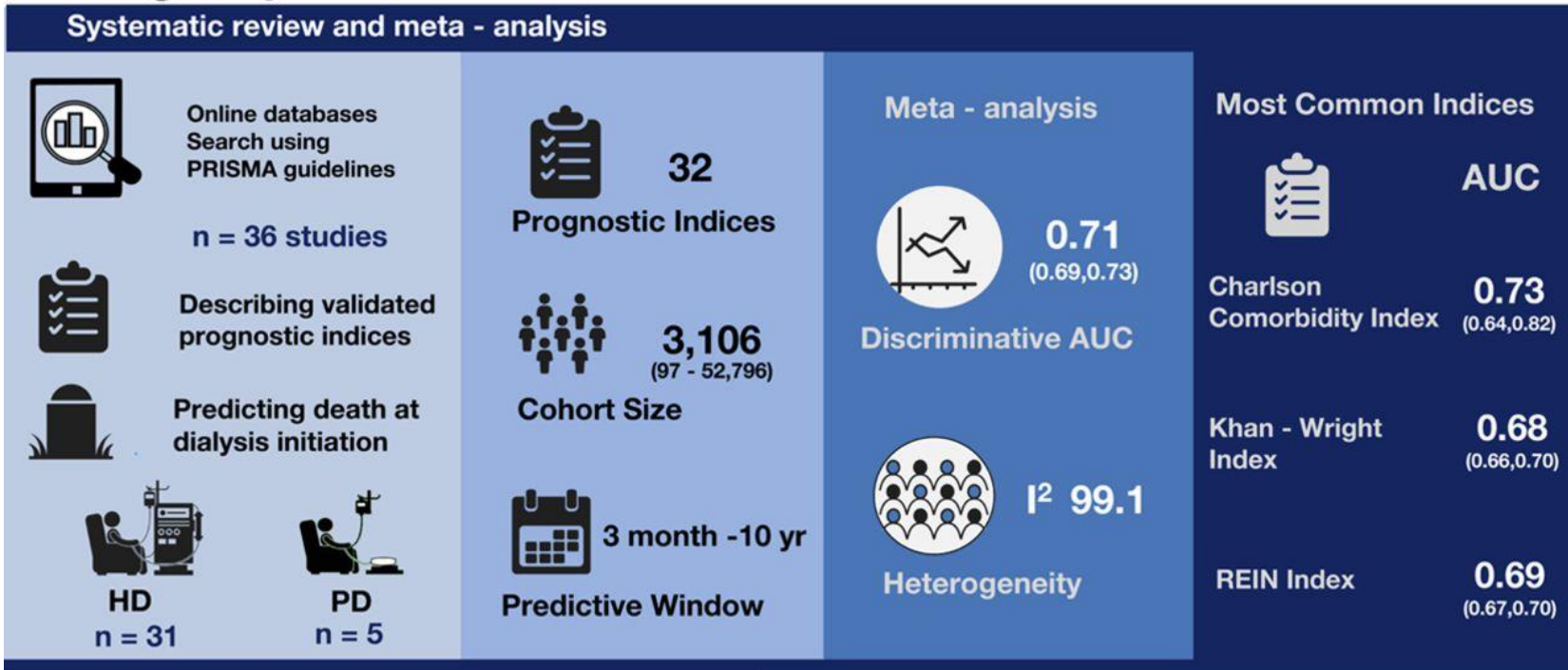
Clinical utility questionable
Only 'modest' changes in care in advanced CKD
 (Salat, *CJASN* 2017)

Moss, *CJASN* 2008
 Cohen, *CJASN* 2009
 Bansal, *CJASN* 2015
 Couchoud, *Nephrol Dial Transplant* 2009

ACP & MORTALITY PREDICTION: NO EASY TASK

How well do we predict the risk of death for patients starting dialysis?

CJASN
Clinical Journal of American Society of Nephrology



Retrospective studies

Lack of evidence demonstrating beneficial effects of prognostication upon 'shared decision making'

Fear that overly pessimistic prognostic estimates leads to loss of patient hope

Conclusions: Several well validated indices with good discrimination are available for predicting survival at dialysis start.

Ryan T. Anderson, Hailey Oeek, Atieh Pejrouhi, M. Fernanda Baldoia, et al. *Prediction of Risk of Death for Patients Starting Dialysis: A Systematic Review and Meta-Analysis.* CJASN DOI: <https://doi.org/10.2215/CJN.00050119>. Visual Abstract by Divya Bajpai, MD, PhD

ACP: BENEFITS OF EARLY INITIATION

PREVENT IMPORTANT DECISION
MAKING DURING SITUATIONS
WHEREBY OVERWHELMING
SYMPTOMS AND FEAR OF DEATH
CLOUD OBJECTIVITY

POTENTIAL IMMINENT DEATH
TO OVERRIDE ANY
CONSIDERATION

PA... FOR
CONS... CONSERVATIVE
... CARE PATHWAY

MULTIPLE DISCUSSIONS
(WITH FRIENDS + FAMILY/CAREGIVERS)

**WHEN IS THE OPTIMAL "EARLY"
TIME TO INITIATE ACP??**



ACP: WHAT IS THE EVIDENCE?

Benefits of ACP remain unproven

- ?align treatment with patient preferences
- ?prevent intensive interventions
- ?reduce hospital admissions
- ?economic savings



**Cochrane
Library**

Cochrane Database of Systematic Reviews

Advance care planning for haemodialysis patients (Review)

Lim CED, Ng RWC, Cheng NCL, Cigolini M, Kwok C, Brennan F

Authors' conclusions

We found sparse data that were assessed at suboptimal quality and therefore we were unable to formulate conclusions about whether advance care planning can influence numbers of hospital admissions and treatment required by people with ESKD, or if patients' advance care directives were followed at end-of-life. Further well designed and adequately powered RCTs are needed to better inform patient and clinical decision-making about advance care planning and advance directives among people with ESKD who are undergoing dialysis.

Sellars, *PLOS One* 2019

Sellars, *Nephrology* 2019

Lim, *Cochrane Database Sys Rev* 2016

ACP: WHAT IS THE EVIDENCE?

NEPHROLOGY

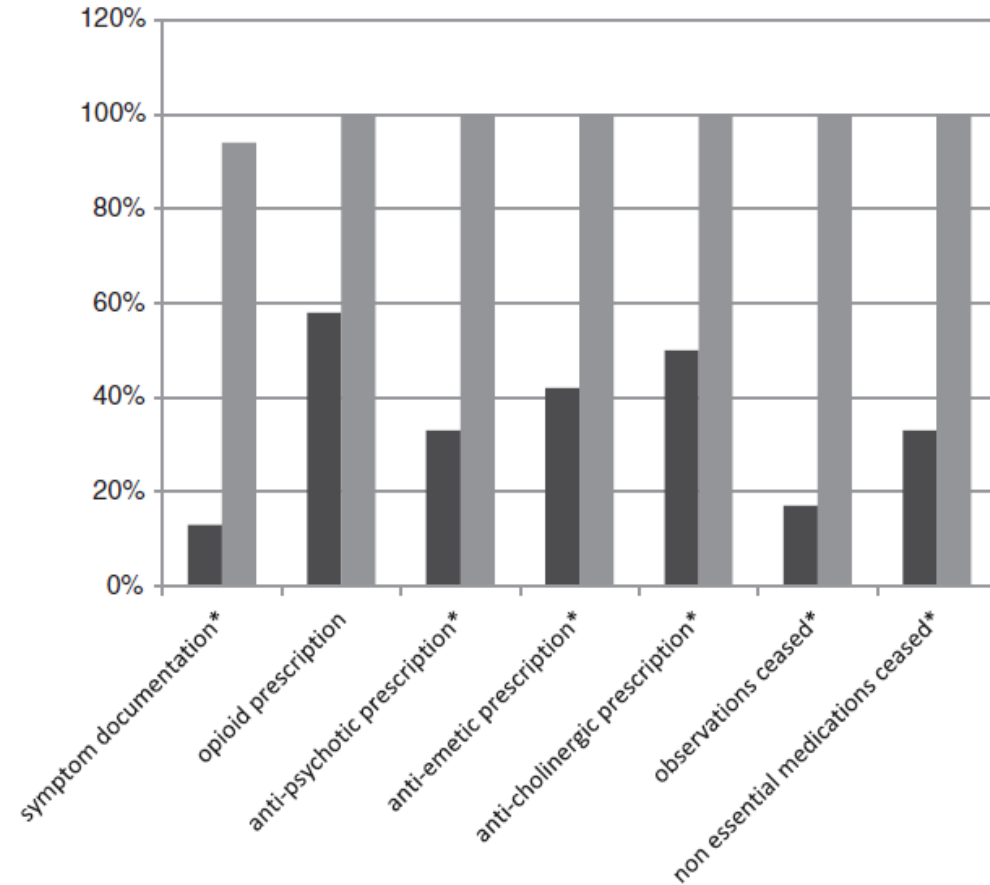
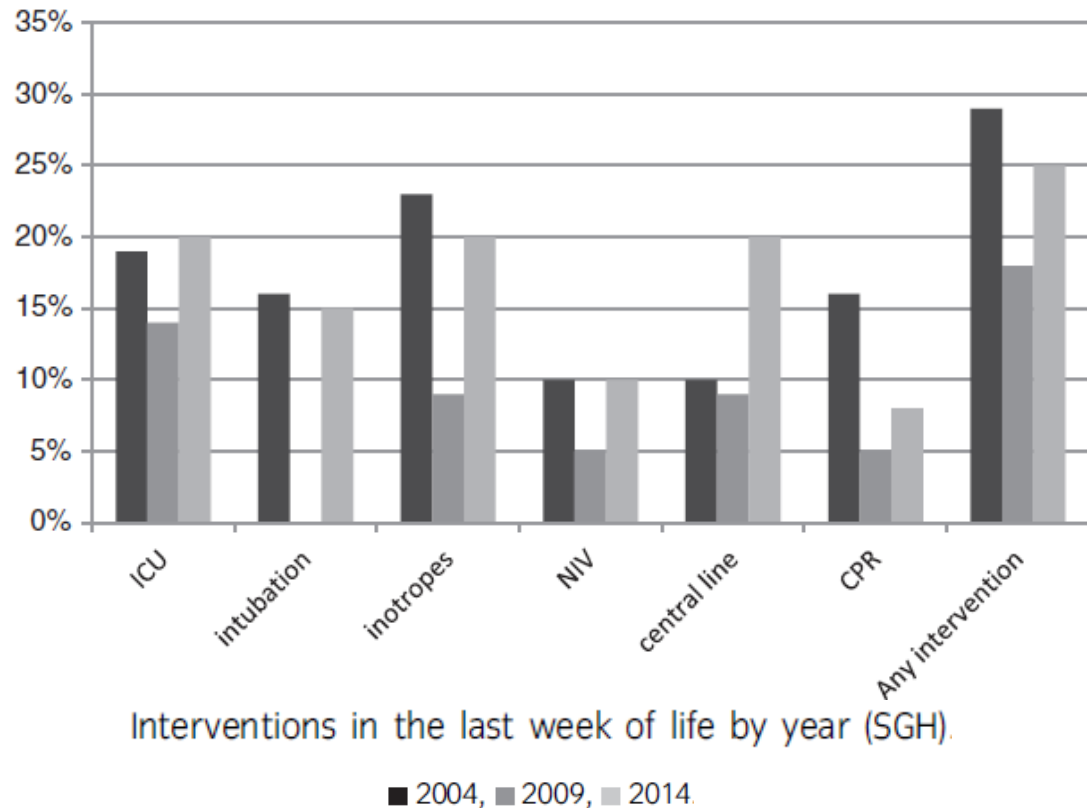


Fig. 7 Significant differences in quality indicators by use of EOLCP. EOLCP, end of life care plan. * Indicates statistically significant result. ■ No EOLCP, ■ EOLCP.

SUMMARY

ACP is a dynamic iterative process involving shared decision making/patient centered outcomes

Early (timely) initiation with appears crucial for successful outcomes

Multiple barriers to establishing ACP as standard-of-care

- **Physician-based**
- **Difficulties with prognostication**
- **Other medico-psychosocial factors (frailty/cognition)**
- **Lack of definitive evidence base**

TIME LINE

-Referral to Neph
eGFR 33

Sept 2015

<3yrs

Hosp Admission
eGFR 9

May 2018

-Family Meeting re Dx
-Referral to RSC
RSC initiate ACP
discussions w Dtr

June 2018
July 2018

6m

eGFR 5
Dies at home after
unsuccessful CPR

Dec 2018

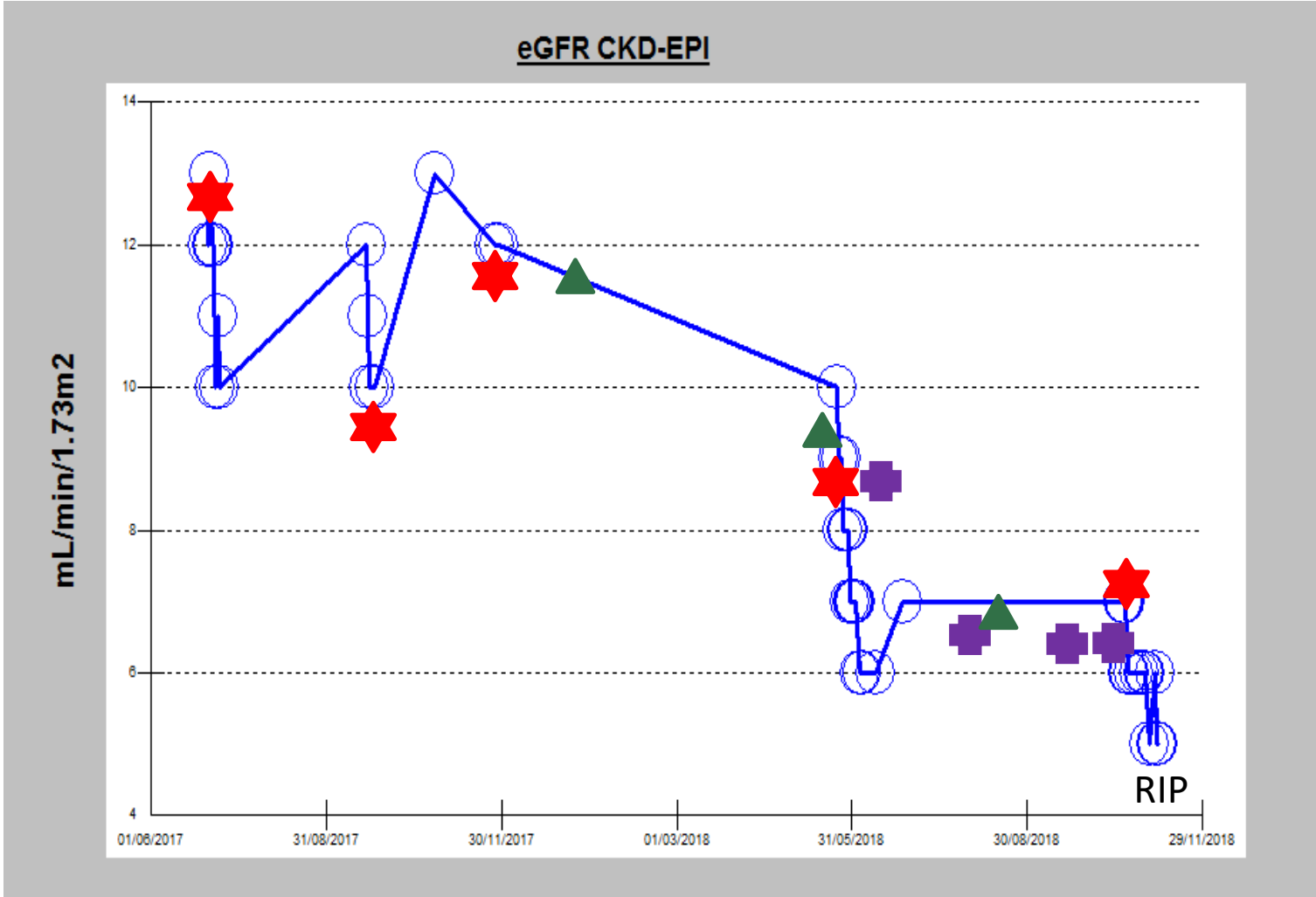
Mrs AD, 80yrs

-Greek, NESB, widow

-Supportive Daughter and Son

-CKD 2° Type 2 DM, insulin dependant, Retinopathy,
Thalassaemia, previous GI bleed and uterine cancer

KEY
 Hospital Adm
 Neph appt
 RSC appt



TIME LINE

| | |
|---|--------------|
| Referral to Neph <i>eGFR 27</i> | 2010 |
| <i>eGFR 12</i> | Nov 2015 |
| Referral to RSC <i>eGFR 8</i> <i>RSC initiate ACP discussions</i> | June 2016 |
| Ambulance PCP signed <i>eGFR 5-7</i> | 2017-2018 |
| Hosp Admission Family meeting re EOLC | 8 June 2019 |
| Dies in Wolper | 28 June 2019 |

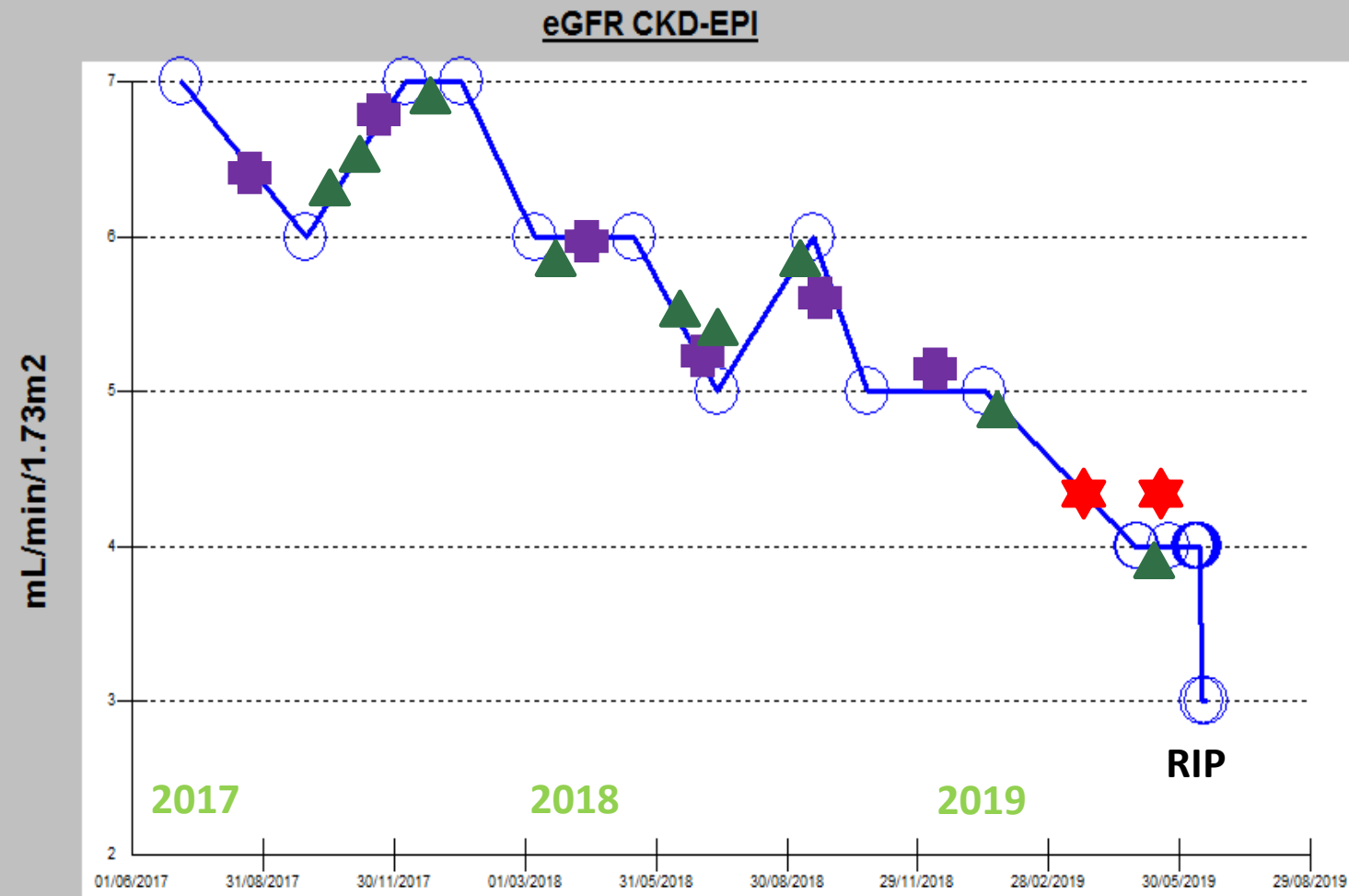
6yrs

36m

Mrs ML, 81yrs
 -Lebanese, NESB, widow
 -Large, supportive family
 -CKD 2° obstruction, HT, AF/?IHD

KEY

- ★ Hospital Adm
- ▲ Neph appt
- RSC appt



MORAL OF THE STORY

TIME IS OF THE ESSENCE...

**Increasingly so if an initial discussion about
advance care planning has not commenced in patients NFD
at the time of referral to RSC**

BARRIERS TO ACHIEVING POSITIVE PATIENT OUTCOMES

CASE 1

R/F to RSC to death = 6m*

Charlson Comorbidity Index = 11

CALD B/G: Difficulty coordinating family w each other/Pall Care/Interpreter (finite resources)

No documented ACP

No decision re EOLC

Pt dies at home after failed CPR- futile and undignified, traumatic for pt and family

CASE 2

R/F to RSC to death = 36m*

Charlson Comorbidity Index = 6

CALD B/G: Achieving family consensus protracted but accomplished due to extended time frame

Documented ACP

Decision made re EOLC

Pt dies in hospice as planned, a peaceful death surrounded by family

POWH RSC DEATHS (2018-2019)

**10 pts (>30%) referred to RSC in 2018-2019 died without an ACP
(31 deaths of 86 R/Fs)**

| RSC referral eGFR | Number | Time from RSC referral to death |
|-------------------|-----------|---------------------------------|
| ≤ 8 | 12 | All 9 deaths within 6m |
| 9 - 14 | 22 | 8 of 14 deaths within 6m |
| 15 - 20 | 18 | |
| > 20 | 12 | |

REFERRALS TO RSC 2018-2019

iPOS surveys were performed and collected at the satellite HD unit (Feb 2020)

45 of 48 forms returned

3 questions added to evaluate patient awareness regarding ACP

Important considerations

- Health literacy
- English fluency
- Cognition

| 45 PARTICIPANTS | YES | NO | NO COMMENT |
|--|-----|----|------------|
| Do you know what advanced care planning is? | 15 | 28 | 2 |
| Do you have an advanced care plan? | 4 | 36 | 5 |
| Would you like to find out about advanced care planning? | 17 | 21 | 7 |

POWH NEPHROLOGY & ACP: CURRENT SITUATION

Ad-hoc implementation

ACP conversations frequently initiated by RSC (rather than long-term nephrologist)

RSC referral timing can leave insufficient time to develop adequate relationships with patient/family

Poor documentation of ACP discussions with primary nephrologist (self-reported by dialysis cohort)

ACP DILEMMA: WHO SHOULD INITIATE DISCUSSION

?primary nephrologist (2013 ANZSN RSC guidelines)

?other treating medical practitioners (GP/geriatrician/...

?nephrology team members at 'opport...

- Acute sentinel events/h...
- Nephrology trainees (with ACP checklist)
- Allied health professionals (e.g. dialysis/HD nurses)

COMMENTS WELCOME PLEASE!!!!