Offering Conservative Care: Perceptions and Barriers

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Disclosures

- Baxter Healthcare – speaker and consultancy fees
- Fresenius Medical Care – speaker fees
- LiberDi – advisory board
- AWAK – advisory board
- Vifor – speaker fees

GOYA Y LUCIENTES, Francisco de
'I am Still Learning' ('Aún aprendo')

Kidney disease in older people

- Usually associated with other long term conditions – e.g., diabetes, vascular disease, cardiac failure
- Increased prevalence of ‘geriatric syndromes’ – frailty, cognitive impairment, falls
- Increases risk of cardiovascular events
- Increases risk of acute kidney injury
- Associated with polypharmacy, drug interactions and need to adjust drug doses for renal function
- Risk of decline in kidney function and therefore possible future requirement of dialysis
- BUT – more likely to die than reach ESRD

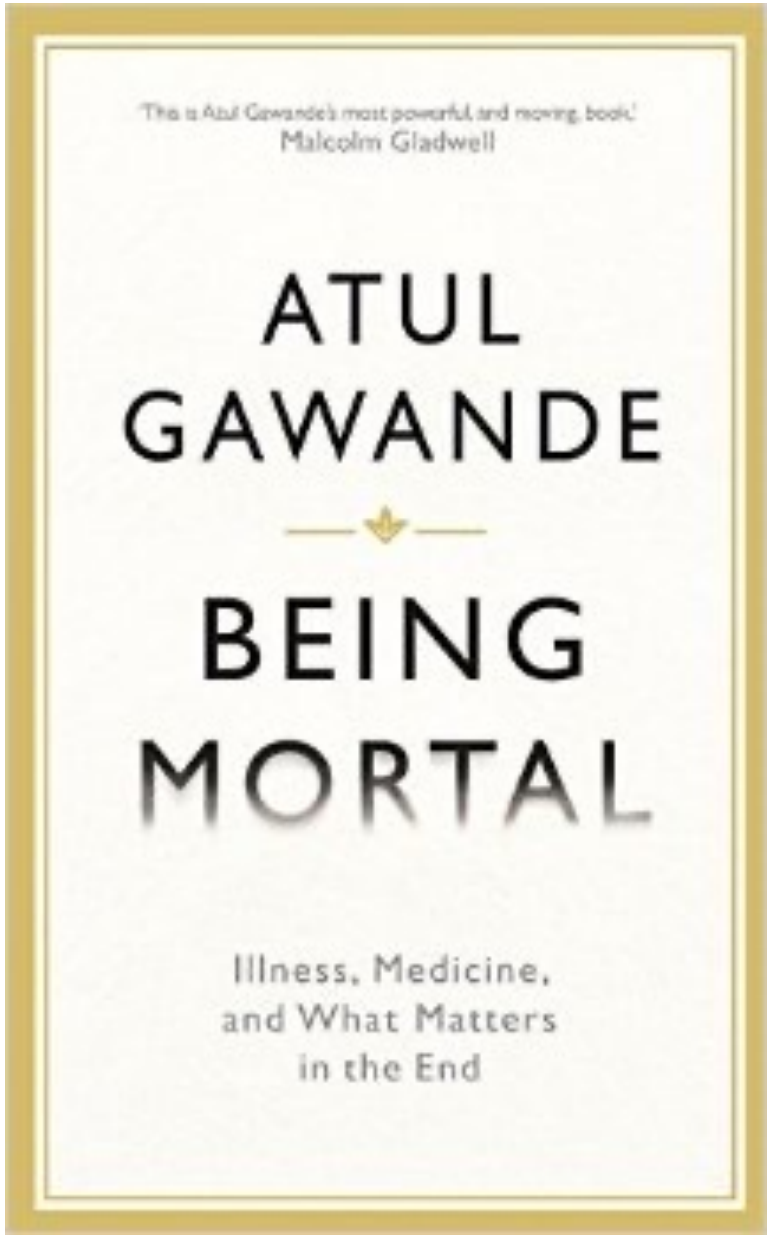
Implications of diagnosis of kidney disease: patient perspective

- Likely to have other long term conditions
  - multiple hospital / clinic visits
  - multiple symptoms
  - polypharmacy
- Accelerated ageing, particularly at lower GFRs
  - increased likelihood of frailty
  - higher risk of falls
  - higher risk of cognitive impairment and more rapid deterioration
- Anxiety about need for dialysis in future
- Impact on other medical problems and procedures
  - Need for awareness of prognosis and shared decision making round medical interventions, end of life management

Offering Conservative Care: Perceptions and Barriers

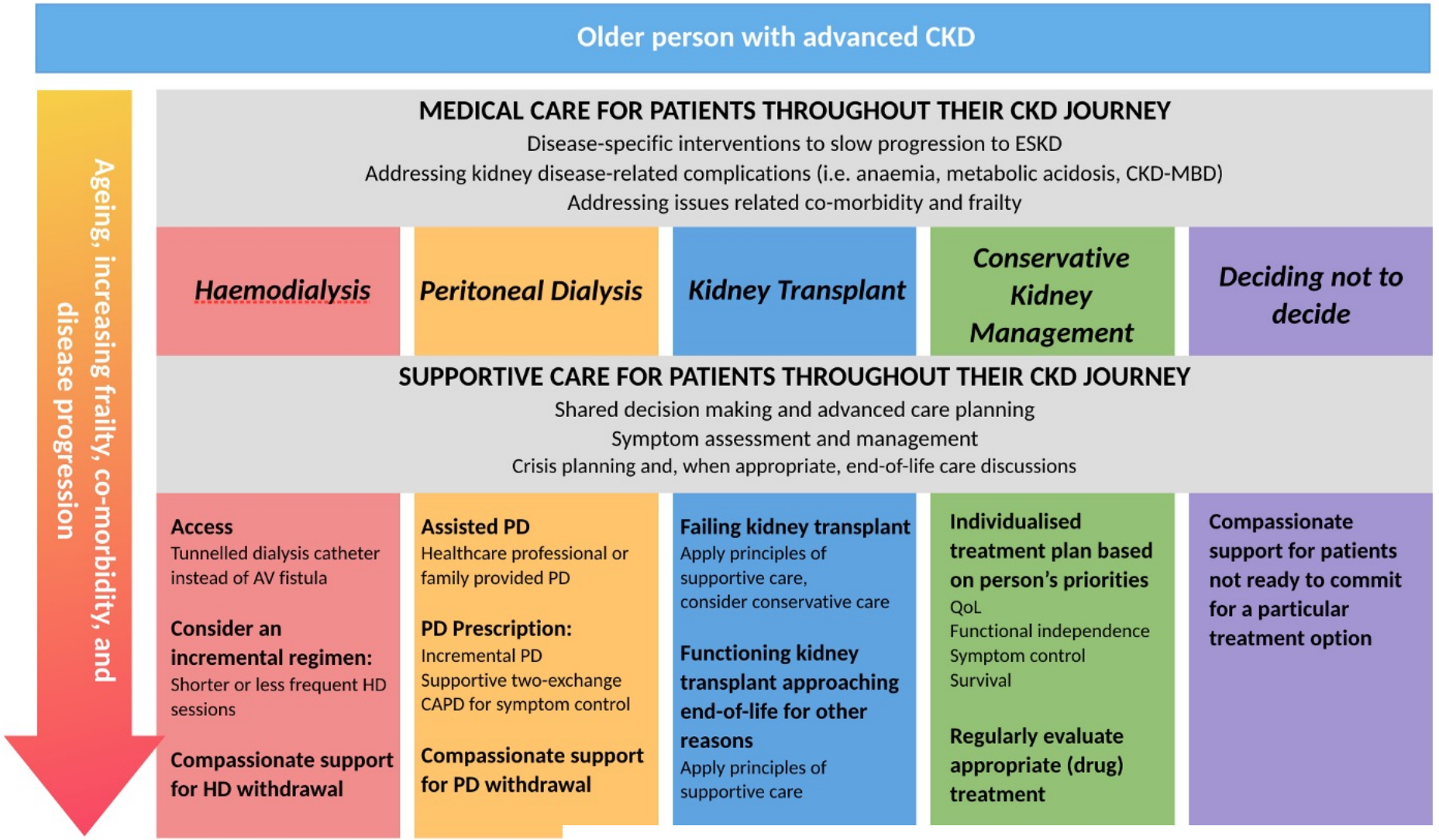
- Perceptions
  - Frailty and impact on outcomes for people with advanced kidney disease
  - Outcomes on conservative care compared to dialysis

- Barriers
  - Shared decision making – training, time
  - When to have the conversations
  - Patient expectations



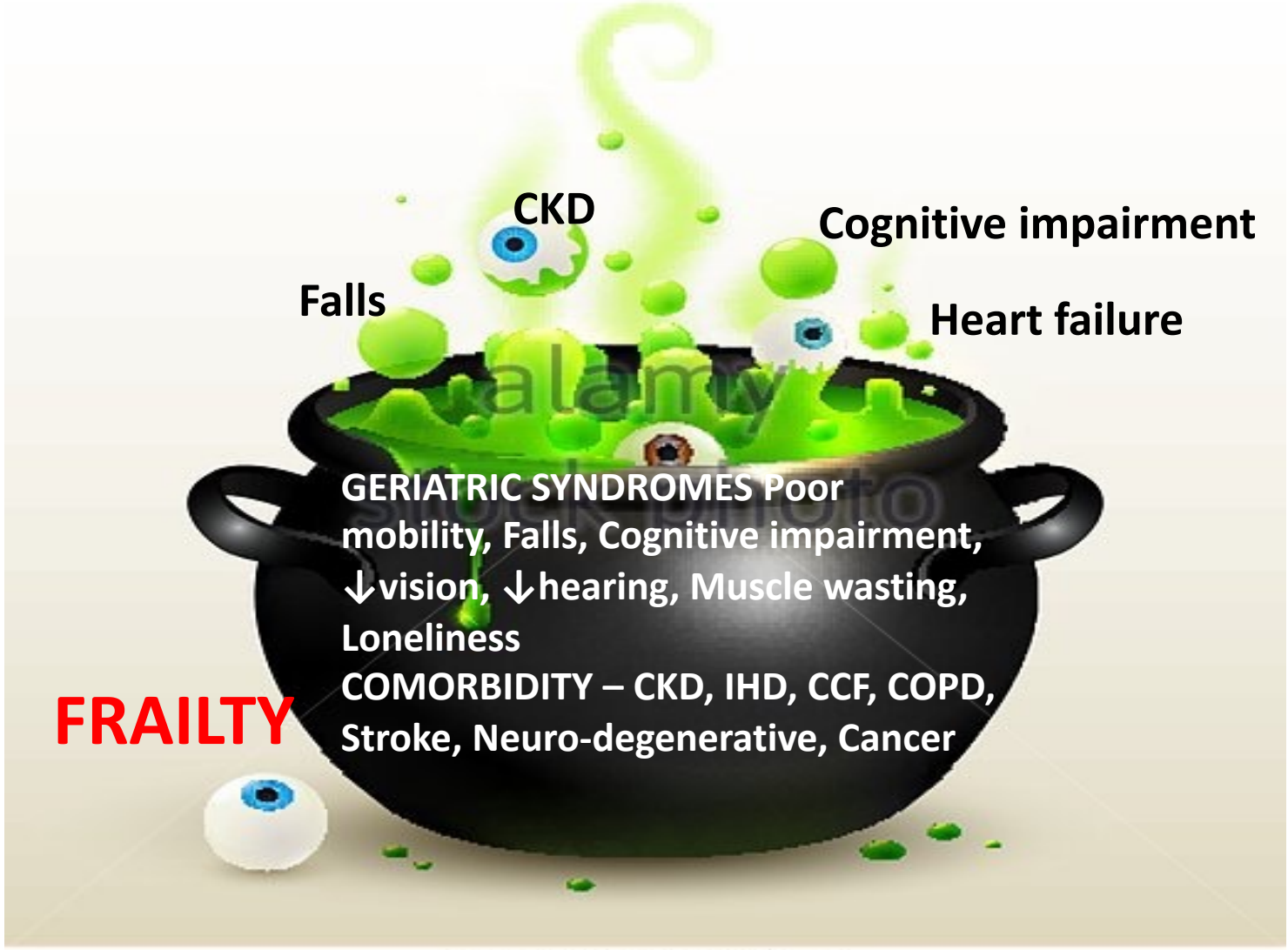
"Medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul…..For more than half a century, we have treated the trials of sickness, aging and mortality as medical concerns…That experiment has failed"

Supportive care is central to the management of all older people with progressive and advanced CKD



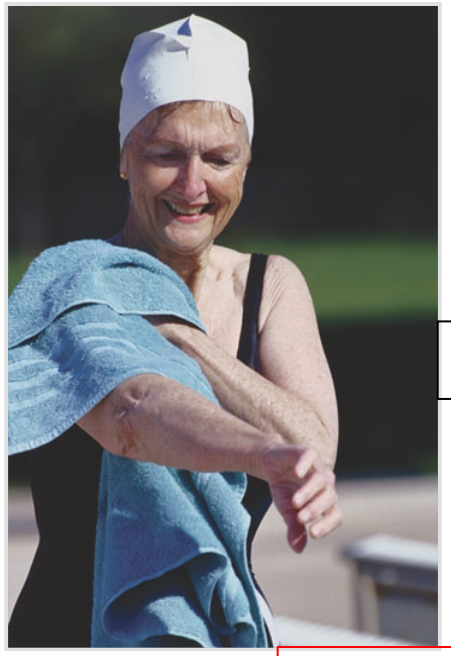
Fitzgerald TJ et al. Clin Kid J https://doi.org/10.1093/ckj/sfac256

Bubbly soup of old age



Frailty

Mrs A, 80 years old



Genetic factors

Environmental factors

Molecular and cellular damage

Reduced physiological reserve

Physical activity

Nutritional factors

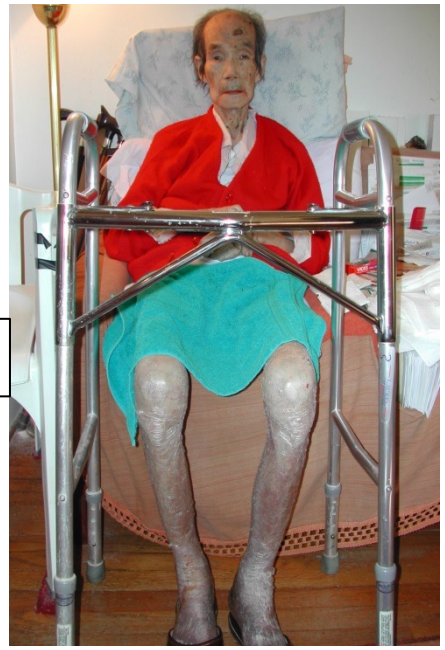
FRAILTY

Stressor event

Falls; Delirium
Fluctuating disability

Increased care needs
Hospital admissions
Long-term care

Mrs B, 80 years old



Adapted from
Clegg et al, Lancet 2013

Increased vulnerability

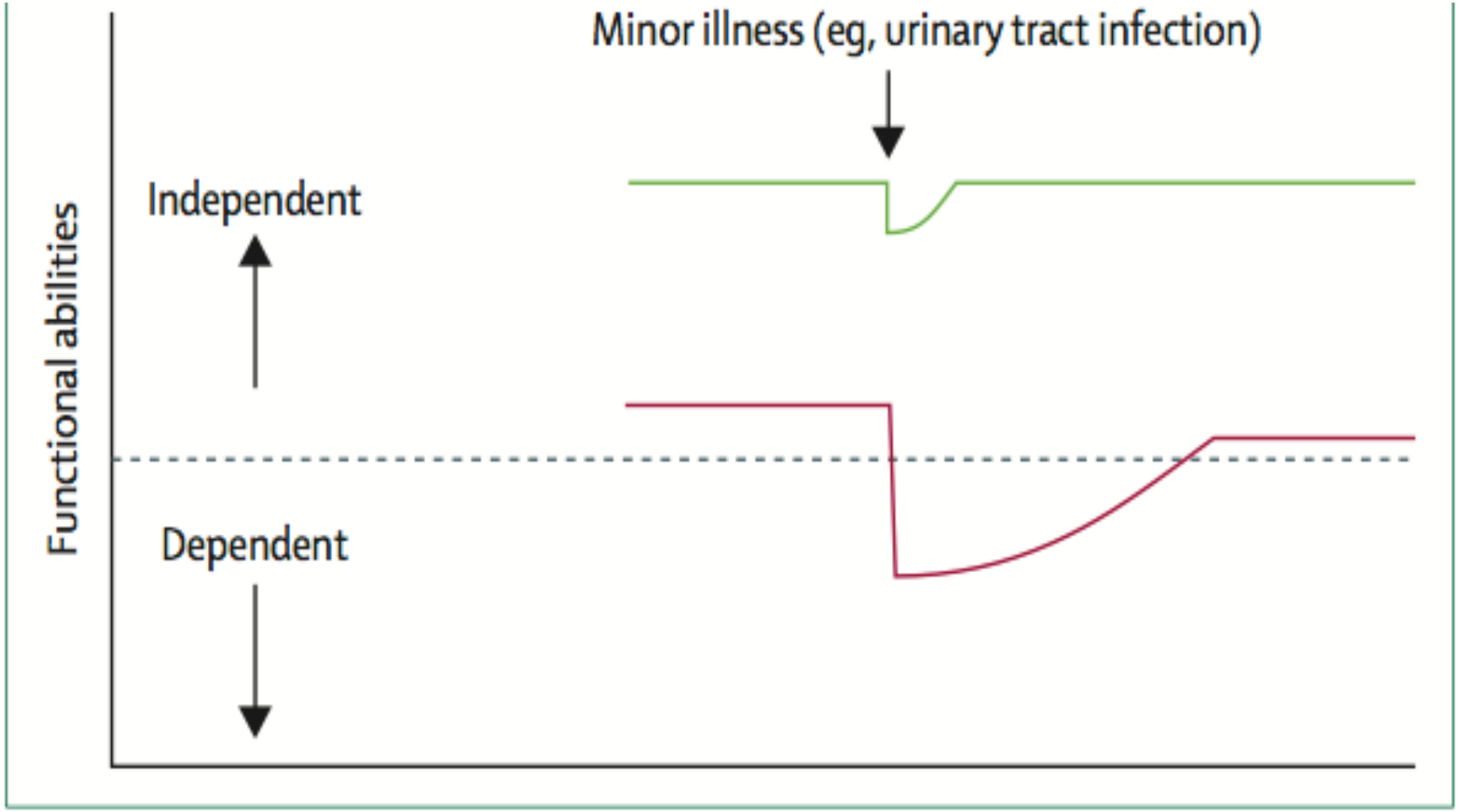


Figure 1: Vulnerability of frail elderly people to a sudden change in health

Clegg et al, Lancet 2013

Prognosis of patients with kidney disease and not on dialysis

Select univariate ORs in the derivation cohort for 12-month mortality

Covariate	*n*	OR (95% CI)	P-value
Surprise question	746		
Yes[a]		1	
No		7.457 (4.753–11.702)	<0.001
Age at visit per 10 years	749	1.818 (1.495–2.211)	<0.001
Charlson Score per unit	749	1.344 (1.214–1.489)	<0.001
KPS	737		
80–100[a]		1	
50–70		4.851 (3.042–7.736)	<0.001
<40		14.961 (6.161–36.330)	<0.001
Appetite at baseline	721		
Very good[a]		1	
Good		2.414 (1.294–4.503)	0.006
Fair		4.103 (2.042–8.244)	<0.001
Poor		6.037 (2.355–15.475)	<0.001

Multivariable regression model for 12-month mortality

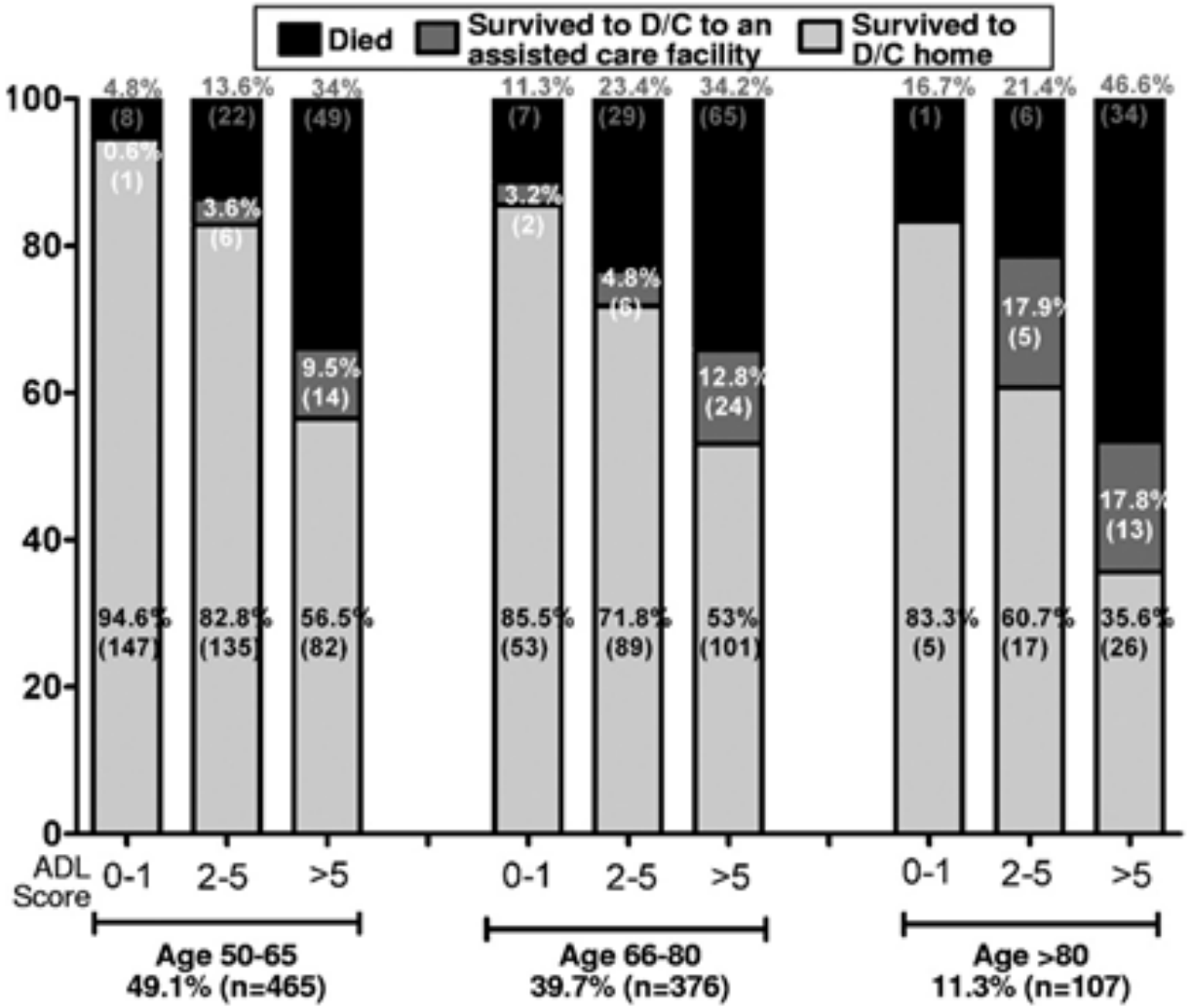
Covariate	OR (95% CI)	P-value
Surprise Question = No	3.29 (1.87–5.78)	<0.001
Baseline category = Yes		
Age per 10-year increase	1.41 (1.15–1.74)	<0.001
KPS; baseline, *n* (%)		
80–100 (good)	1	
50–70 (fair)	2.09 (1.19–3.66)	0.010
10–40 (poor)	4.69 (1.71–12.88)	0.003

KEY PREDICTORS

- **Surprise question = NO**
- **Age**
- **Poor Karnofsky performance score**

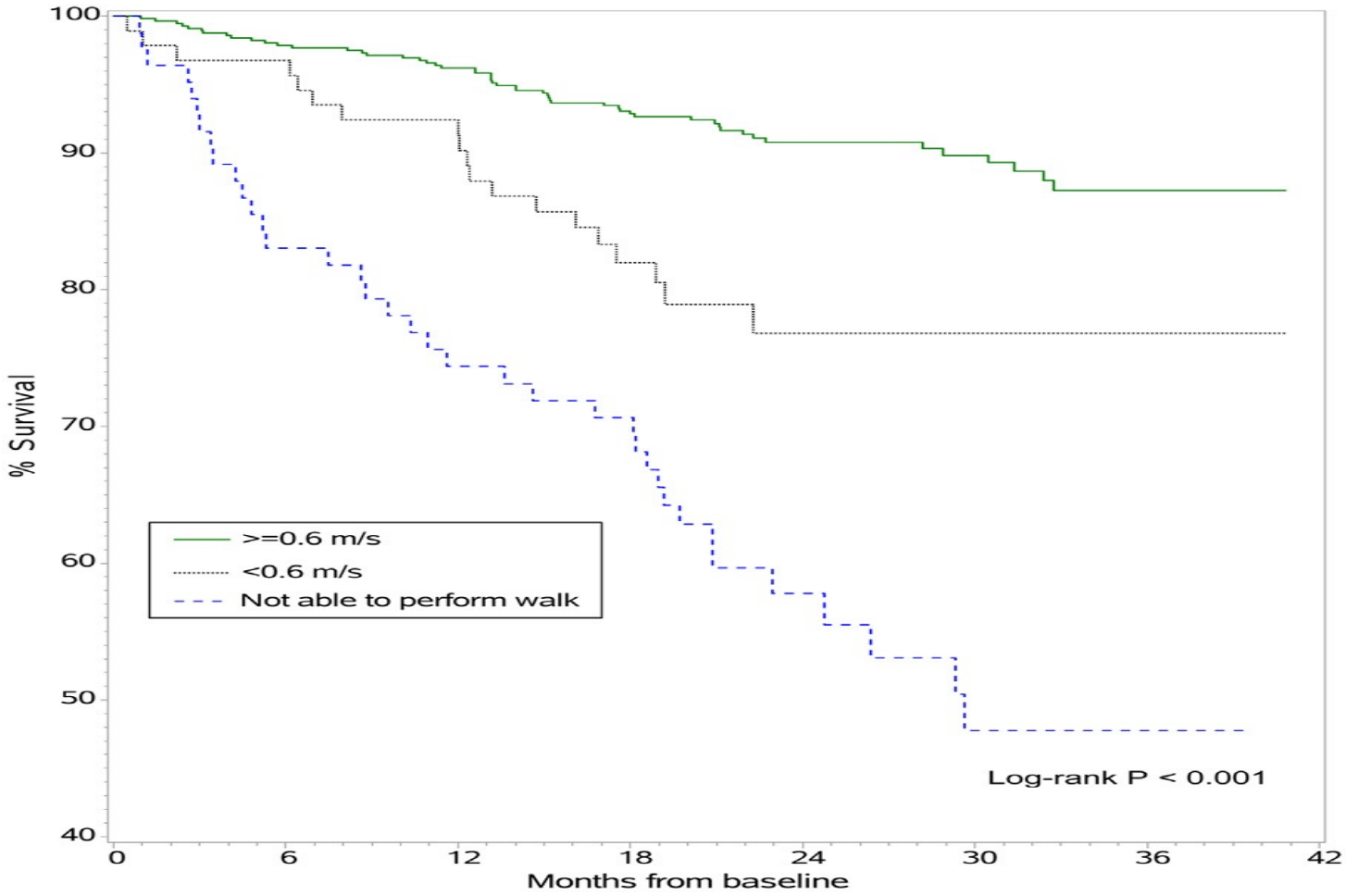
Schmidt RJ et al: Nephrol Dial Transplant (2019) 34: 1517–1525

Admission ADL score predicts death in hospital and discharge to assisted care facility in dialysis patients



Sood et al, AJKD 2011

Survival related to baseline gait speed (measured over 15 ft at usual walk speed) in 752 prevalent HD patients



Kutner NG et al, AJKD 2015

FEPOD: Frailty is principal association with outcomes and not dialysis modality. 129 assisted PD matched to 122 hospital HD requiring transport

Outcome	Predictor	Multiplicity Adjusted P-value	Effect Size (95% CI)
Illness Intrusion	Age	<0.01	0.98 (0.97 – 0.99)
SF12 PCS	Frailty	<0.01	0.90 (0.88 – 0.93)
SF12 MCS	Frailty	<0.01	0.94 (0.91 – 0.97)
Illness Intrusion	Frailty	<0.01	1.14 (1.09 – 1.24)
Barthel Index	Frailty	<0.01	0.89 (0.86 – 0.93)
Symptom burden	Frailty	<0.01	1.23 (1.13 – 1.33)
Renal Treatment Satisfaction	**HD vs PD**	**0.03**	**0.93 (0.89 – 0.98)**

Iyasere O et al: CJASN 2016; 11: 423–430

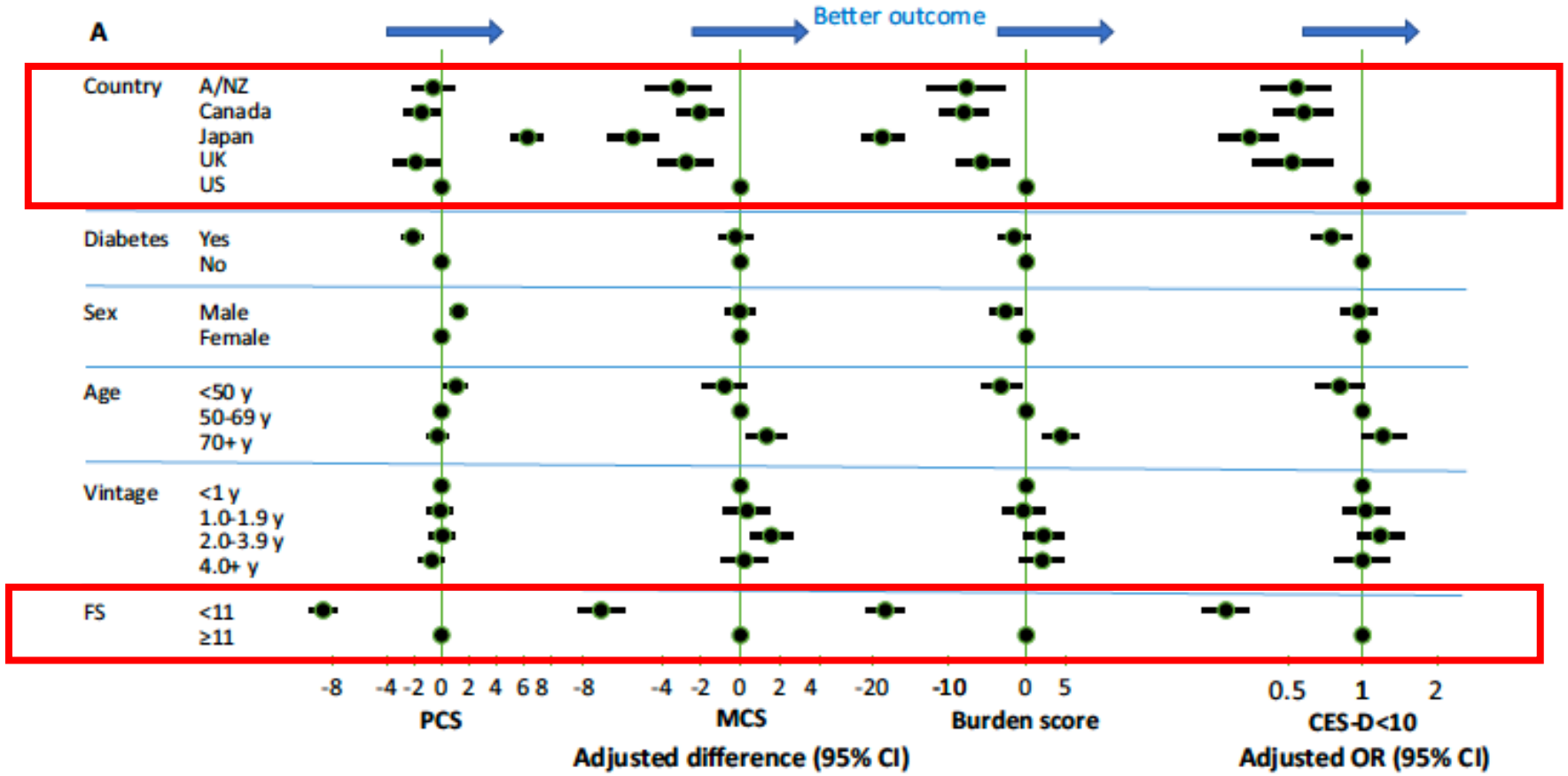
The Dunhill Medical Trust

NHS National Institute for Health Research Clinical Research Network

Baxter

Imperial NIHR Biomedical Research Centre

Impact of functional status on patient outcomes: DOPPS / PDOPPS data



Brown EA et al: AJKD 2021; 78: 489-500

HEALTH The New York Times Feb 19th, 2019

THE NEW OLD AGE

Dialysis Is a Way of Life for Many Older Patients. Maybe It Shouldn't Be.

So-called conservative management can ease symptoms without dialysis in some people with kidney disease. But many of them are never given the option.

Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison[1], Adeera Levin[2], Alvin H. Moss[3], Vivekanand Jha[4,5], Edwina A. Brown[6], Frank Brennan[7], Fliss E.M. Murtagh[8], Saraladevi Naicker[9], Michael J. Germain[10], Donal J. O'Donoghue[11], Rachael L. Morton[12,13] and Gregorio T. Obrador[14]

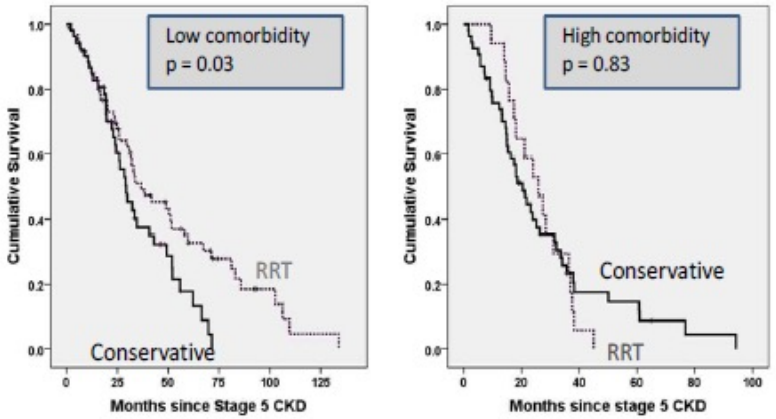
Definition of Comprehensive Conservative Care – an alternative to dialysis

- 'Comprehensive conservative care' is planned holistic patient-centred care for patients CKD 5 that includes
  - Interventions to delay progression of kidney disease and minimize risk of adverse events or complications
  - Shared decision making
  - Active symptom management
  - Detailed communication, including advance care planning
  - Psychological support
  - Social and family support
  - Cultural and spiritual domains of care
- Comprehensive conservative care does not include dialysis.

Kidney Int 2015; 88: 447-59

Outcomes on conservative care: early studies

Dialysis may not even extend life if old and multimorbid - retrospective studies from eGFR <15



Chandna et al NDT 2011

Dialysis vs CKM survival in patients >75 yrs old

Low comorbidity - dialysis longer P=0.03

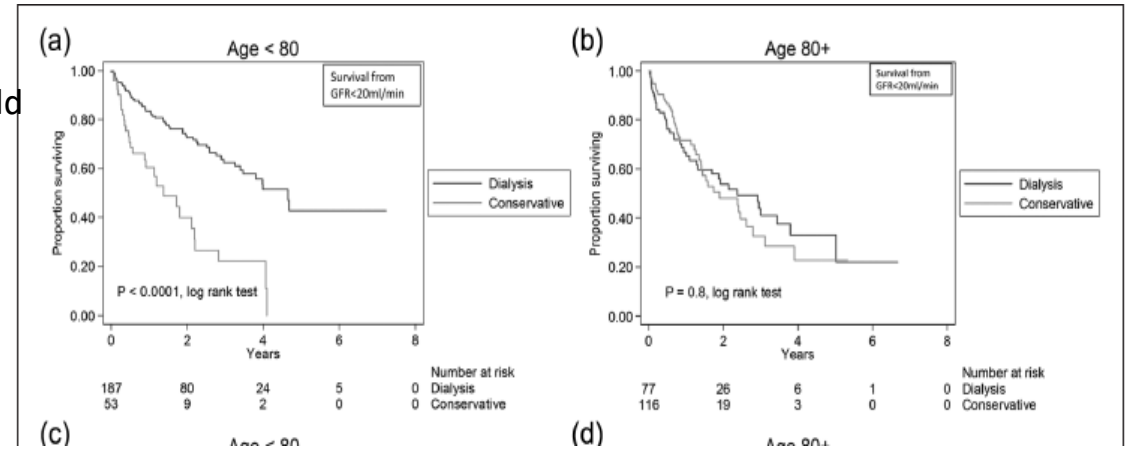
High comorbidity - no difference

Hussain et al Palliative Medicine 2013

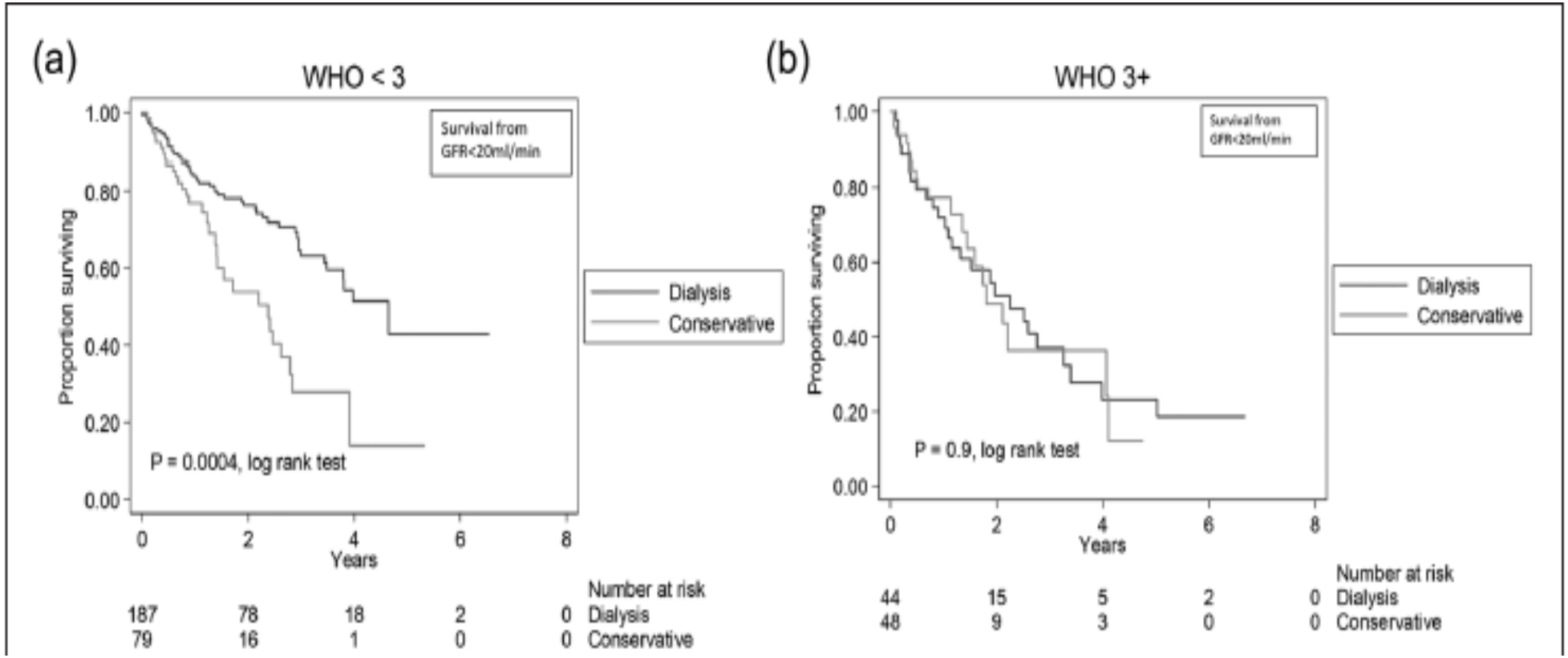
Dialysis vs CKM survival in patients >70 yrs old

Age <80yrs - dialysis longer

Age ≥80 yrs - no difference

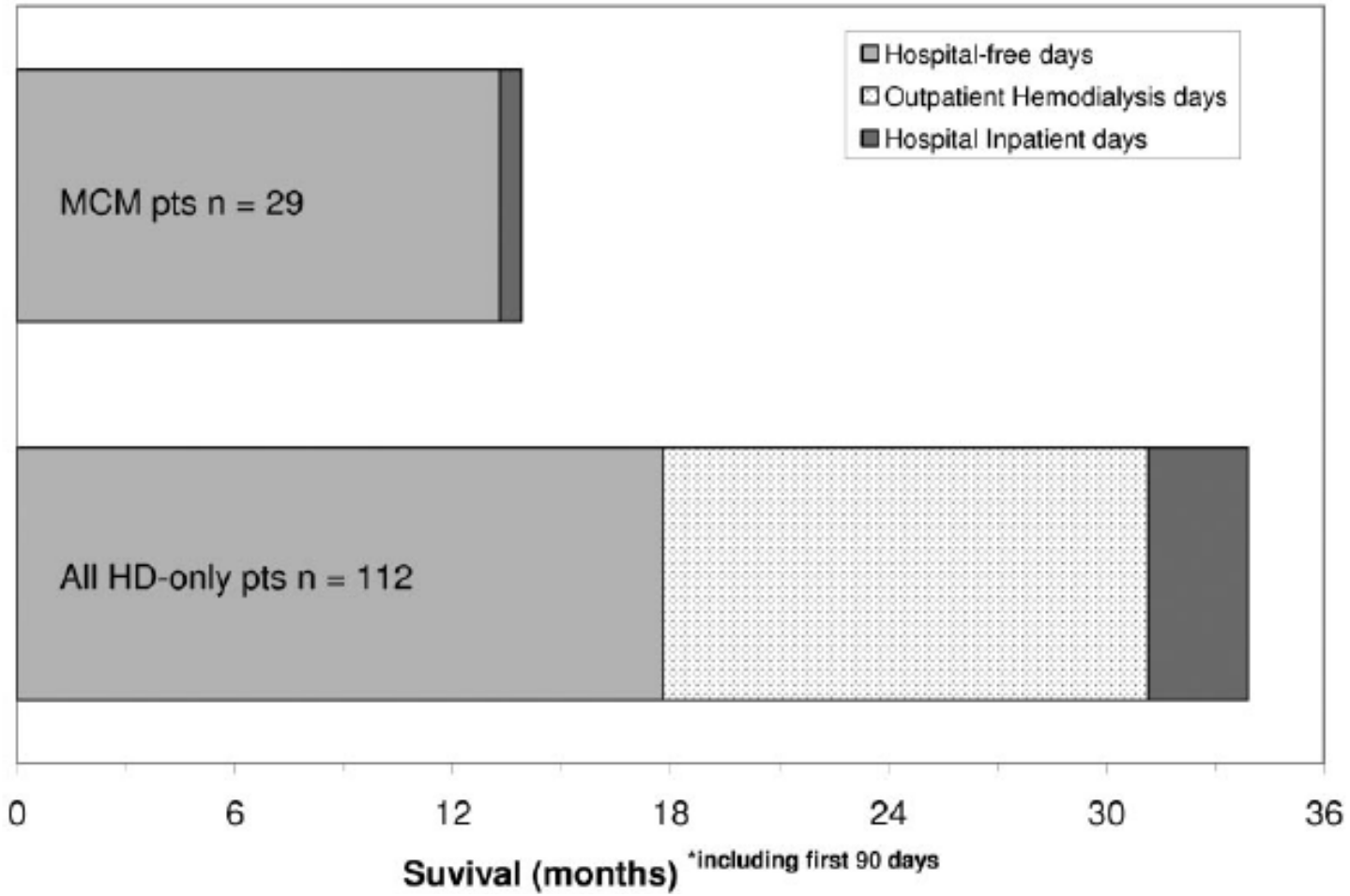


Survival from eGFR 20ml/min on Conservative Management cf Dialysis for WHO performance status <3 and 3+



Hussain et al, Palliative Medicine: epub 2013

Distribution of days survived: hospital-free days, outpatient HD days and hospital inpatient days in patients >70yrs old from start of dialysis or eGFR 10.8ml/min/1.73m^2



Carson RC et al, CJASN 2009

Outcomes on conservative care: recent publications

2 systematic reviews of outcomes conservative care published so far in 2022

JAMA Network Open

Original Investigation | Nephrology

Long-term Outcomes Among Patients With Advanced Kidney Disease Who Forgo Maintenance Dialysis

A Systematic Review

Susan P. Y. Wong, MD, MS; Tamara Rubenzik, MD; Leila Zelnick, PhD; Sara N. Davison, MD; Diana Louden, MLib; Taryn Oestreich, MPH, MCHES; Ann L. Jennerich, MD, MS

Nephrol Dial Transplant (2022) 37: 1529–1544
https://doi.org/10.1093/ndt/gfac010
Advance Access publication date 23 February 2022

Survival of patients who opt for dialysis versus conservative care: a systematic review and meta-analysis

Carlijn G.N. Voorend[1,*], Mathijs van Oevelen[1,*], Wouter R. Verberne[1,2,3], Iris D. van den Wittenboer[2], Olaf M. Dekkers[4], Friedo Dekker[4], Alferso C. Abrahams[3], Marjolijn van Buren[1,5], Simon P. Mooijaart[6] and Willem Jan W. Bos[1,2]

Wong SPY et al. JAMA Netw Open. 2022;5(3):e222255.
Voorend CGN et al, Nephrol Dial Transplant. 2022;37:1529-1544

Long-term Outcomes Among Patients With Advanced Kidney Disease Who Forgo Maintenance Dialysis

- 41 cohort studies comprising 5102 patients (range, 11-812 patients) included (5%-99% men; mean age range, 60-87 years)
- Substantial heterogeneity in study designs and measures used to report outcomes
- Median survival 1-41 months measured baseline mean eGFR 7-19 ml/min
- 1-2 hospital admissions, 6-16 in-hospital days, 7-8 clinic visits, and 2 emergency visits per person-year
- Over 8-24 months, mental well-being improved, physical well-being and overall quality of life were largely stable until late in illness course

Wong SPY et al. JAMA Netw Open. 2022;5(3):e222255

Survival of patients who opt for dialysis versus conservative care: a systematic review and meta-analysis

Background

Conservative care (CC) has been proposed as a treatment alternative to dialysis in vulnerable patients.

Aim: to compare survival outcomes among patients explicitly choosing dialysis versus CC.

Methods

Electronic databases:
PubMed, Embase, Cochrane, CINAHL Plus, PsycINFO

Inclusion criteria:
CKD stage G4–5
Explicit choice for dialysis vs. CC

Outcome:
All-cause mortality

Results

22 observational cohort studies

At baseline, 'choice for dialysis' group had:
↓ lower age, less comorbidity, frailty, functional status

Median survival (unadjusted)

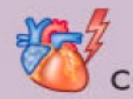
Dialysis choice
20–67 months

CC choice
6–31 months

Pooled mortality risk (age/sex adjusted)

aHR 0.47 (0.39–0.57)

Subgroup analysis



Severe comorbidity — RR 0.66 (0.56–0.78)

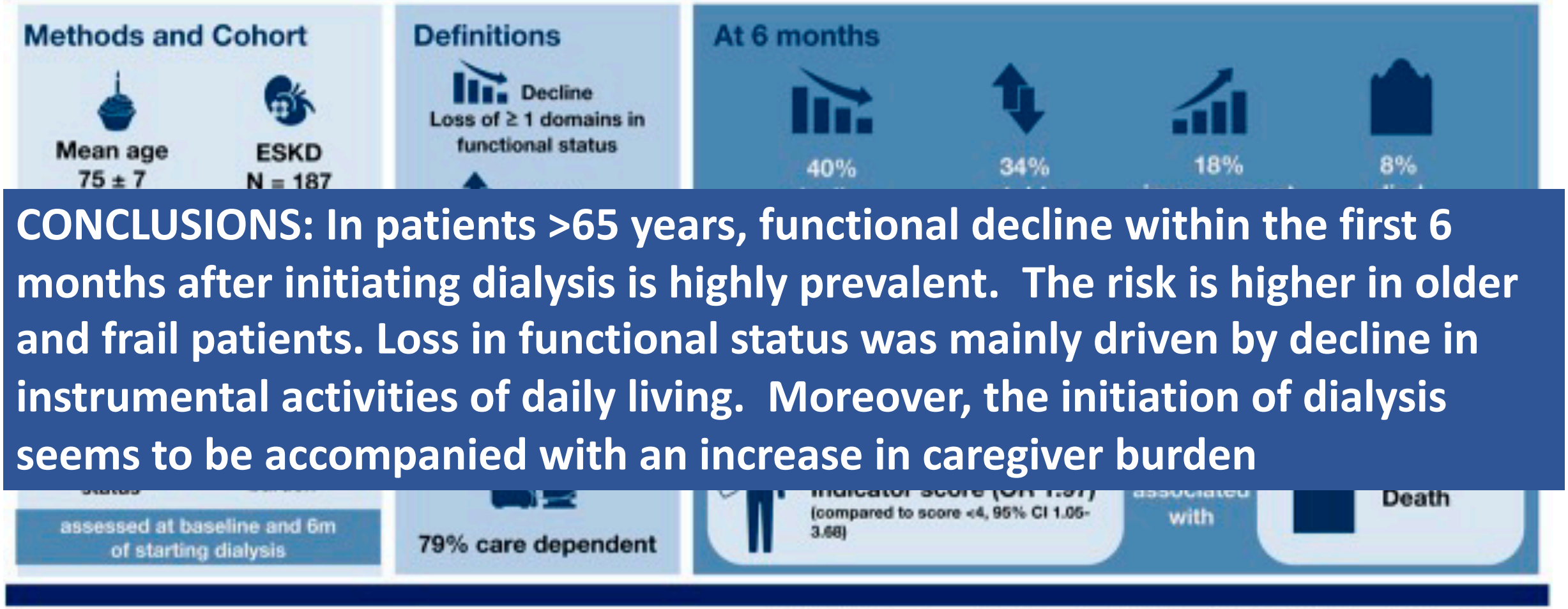
Conclusion

Patients opting for dialysis have an overall lower mortality risk compared to patients opting for CC. Data were limitedly comparable and with high risk of bias.

Voorend CGN et al, Nephrol Dial Transplant. 2022;37:1529-1544

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

CJASN
Clinical Journal of American Society of Nephrology



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

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

N.A. Goto, L.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**

Goto NA et al. Clin J Am Soc Nephrol. 2019;14:1039-1047.

Does dialysis improve symptoms in older adults?

CJASN
Clinical Journal of the American Society of Nephrology

European QUALity (EQUAL) study

456 Europeans
age ≥ 65 years

eGFR
≤ 20 ml/min/1.73m²

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

One year pre-dialysis	At start of dialysis	One year post-dialysis
Symptom number		**Symptom number**
+3.6	77 Years old, 75% Men	**+0.9**
(95%CI: +2.5 to +4.6)	eGFR 8 ml/min/1.73m²	(95%CI: –3.4 to +1.5)
	44% Diabetes, 46% CVD	
Symptom burden	**81% Fatigue**	**Symptom burden**
+13.3	**69% Decreased interest in sex**	**–5.9**
(95%CI: +9.5 to +17.0)	**68% Difficulty becoming sexually aroused**	(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

Does dialysis improve symptoms in older adults?

CJASN
Clinical Journal of the American Society of Nephrology

European QUALity (EQUAL) study

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

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age ≥ 6

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≤ 20 ml/min/1.73m²

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–3.0)

sexually aroused

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

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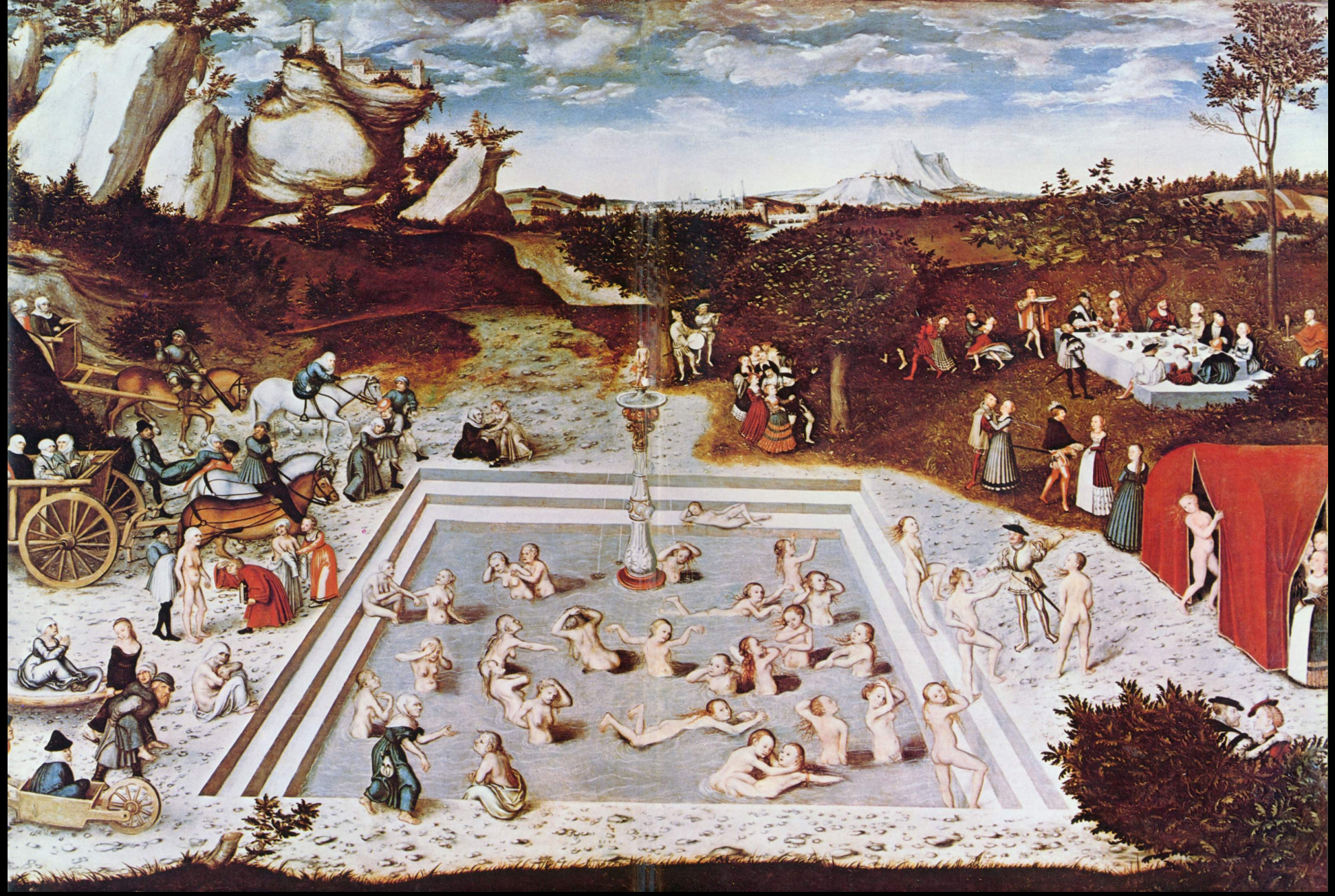
Offering Conservative Care: Perceptions and Barriers

- Perceptions
  - Frailty and impact on outcomes for people with advanced kidney disease
  - Outcomes on conservative care compared to dialysis

- Barriers
  - Shared decision making – training, time
  - When to have the conversations
  - Patient expectations



Cranach: Fountain of Youth

Shared decision making exchange

Person

Lifestyle: functional status, social activities, employment, travel, housebound or out and about

Social support: informal and formal caregivers

Goals: symptom control, optimized quality of life, survival, avoiding excessive interaction with healthcare services, survival to reach specific life events

Healthcare team

Kidney function prognosis: expected time to ESKD (i.e. need for dialysis or CKM)

Dialysis: realistic and unbiased information on the benefits and burdens of *all* dialysis modalities

CKM: description of what CKM involves and how it compares with dialysis

Survival: provide the person with honest information on their life expectancy (insofar as this is possible) if they ask or if you feel it is likely to have an impact on their decisions

EoL: most people with advanced CKD fear what might happen at the EoL if they decide to forego dialysis

Fitzgerald TJ et al. Clin Kid J https://doi.org/10.1093/ckj/sfac256

Barriers to conservative care (CC): the CKD-REIN study

- 1204 patients, eGFR <30ml/min at 40 French clinics (2013-2016) completed questionnaire about information received, treatment choices, including CC
- 137 nephrologists reported on clinic resources and practices regarding CC
- Only 37% clinics had written protocol and 5% person or team primarily responsible for CC
- 6% patients estimated to use CC
- 82% nephrologists comfortable with discussing, but only 28% routinely offered CC to patients >75 years old
- Among patients >75 years old, 5% reported receiving information and 2% preferred CC

Hamroun A et al. Nephrol Dial Transplant. 2022: doi: 10.1093/ndt/gfac009.

Timing of dialysis or no dialysis conversation

- Too early (GFR >15, stable or slow decline kidney function)
  - Increases anxiety, depression in patients and families
  - May increase choice of conservative care as natural to say ’no’ to dialysis or not want to make decision
  - Can result in unnecessary vascular access procedures as high chance of death before dialysis
- Too late (dialysis needed imminently)
  - Worse prognosis with acute start
  - Default of in-centre HD rather than planning for PD
  - People wanting conservative care pressurised by families on to dialysis as very symptomatic

Edward Hopper: Approaching a City

Enabling Patient Choice: The "Deciding Not to Decide" Option for Older Adults Facing Dialysis Decisions

Fahad Saeed,[1] Alvin H. Moss,[2] Paul R. Duberstein,[3] and Kevin A. Fiscella[4] *JASN* 33: 880–882, 2022.

- ADVANTAGES
  - Allows more time to fully appreciate options and contemplate choices.
  - Recognizes choices may be revisited, particularly if preferences change.
  - Delays and/or prevents unwanted disruption in day-to-day life.
  - Patient-centred and focuses on quality of life
- DISADVANTAGES
  - May increase potential for more emergency dialysis initiations
  - May increase the number of patients who initiate dialysis with a catheter with attendant risks.
  - May result in a missed opportunity to have subsequent decision-making conversations if the patient unexpectedly becomes overtly uremic.

NDT Advance Access published August 30, 2016

Nephrol Dial Transplant (2016) 0: 1–8
doi: 10.1093/ndt/gfw307

ndt
Nephrology Dialysis Transplantation

Original Article

Engagement in decision-making and patient satisfaction: a qualitative study of older patients' perceptions of dialysis initiation and modality decisions

Keren Ladin[1,2], Naomi Lin[1,2], Emily Hahn[2], Gregory Zhang[2], Susan Koch-Weser[3] and Daniel E. Weiner[4]

[1]Department of Occupational Therapy, Tufts University, Medford, MA, USA, [2]Research on Aging, Ethics, and Community Health, Tufts University, Medford, MA, USA, [3]Department of Public Health and Community Medicine, Tufts University School of Medicine, Boston, MA, USA and [4]Department of Medicine, Tufts Medical Center, Boston, MA, USA

Shared-decision making and patient satisfaction

- Many older patients do not perceive dialysis as their choice and do not actively engage in decision-making
  - ‘I was in the hospital and they discovered that all of the sudden out of the blue I had a kidney problem. The kidney doctor is the one that said I should have dialysis, and I don’t know…lying on a bed three hours a day is not my way of living’ (80–90-year-old woman, HD)

Ladin et al, NDT 2016

Potential barriers to shared decision-making and possible solutions

	Potential barrier	Possible solution
Older person with advanced kidney disease	Denial Cognitive impairment Limited health literacy Depression Anxiety Different culture to primary national one Acute event so limited time	Small amount of information at a time Avoidance of jargon Access to different methods to give information Psychosocial support Training healthcare team to be culturally aware and determine whether patient or family is primary decision maker Provide opportunity for decision making once patient is stable

Adapted from **Blake PD, Brown EA, Perit Dial Int 2020**

Potential barriers to shared decision-making in PD and possible solutions

	Potential barrier	Possible solution
Health-care team related	Discomfort with sharing bad news Lack confidence to talk about PD, palliative care and so on Unrealistic expectations of treatment efficacy or prognosis	Communications skills training Appropriate training Multidisciplinary meetings to discuss individual people on PD
Health-care system related	Limited time with people on PD in clinics Lack of privacy in outpatient and inpatient settings Lack of continuity – people seen by multiple teams and members	Use of tools to measure patient experience overall and with decision-making Development of electronic registers to record conversations and decisions

Adapted from **Blake PD, Brown EA, Perit Dial Int 2020**

My own practice for older people with advanced kidney disease

- Discuss with frail /multimorbid patients with stable or slowly declining kidney function that very low risk of dialysis
- Leave dialysis discussion to when dialysis looks like a possibility – GFR<15 and declining (can stay stable at 10-15 for years)
- Always mention choice of ‘no dialysis’
- Availability of assisted PD enables older frail individuals to choose PD
- Supportive assisted 2-exchange CAPD programme enables ‘trial of dialysis’

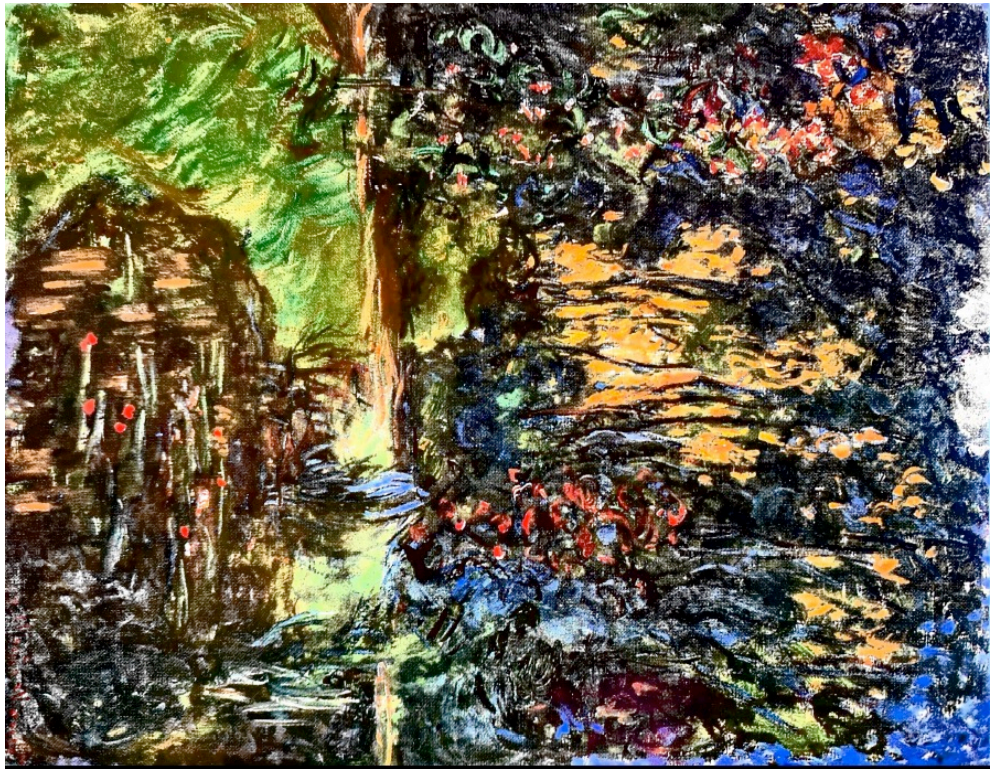
Shared-decision making

Thank you for organising the meeting to allow me, my wife Elisabeth and my three daughters Suzanne, Denise and Madeline to meet you both to pool our knowledge and the resources available to get to the bottom of all the issues that I am likely to face shortly. I trust you will see the choice of this card as apposite

Shared-decision making

- Admitted end June 2020 – increasing drowsiness and R sided weakness
- Advance care planning noted on admission – not for dialysis, not for resuscitation
- Infection and deteriorating kidney function
- Referred to palliative care day after admission
- Died 10 days later

Shared-decision making



11th July 2020

As you probably know, T died last Tuesday. I just wanted to thank you for all the times we have seen you over the past years….I found this card amongst T's papers. We took a granddaughter to Monet's garden many years ago which proved a delight