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	999 30 20 10 0	Undifferentiated dialysis Harmodialysis Outly 7	several and a se	0 ESKE	) (cost form	derly	Murtagh (SC)	carson (DX)	(1) (1) (1) (1) (1) (1) (1) (1) (1) (1)	(c) (c) (c) (c) (c) (c) (c) (c) (c) (c)	Chandra (SC)	Hussair(Dx)	()()()()()()()()()()()()()()()()()()()	(ad) unrus -20	()(25) White ()(26) ()(				

Author	Number of patients	Median age	Study design	Country	Diabetes (11)	Measure of overall comorbidity	Starting point for survival analysi	Survival
Carson <sup>sa</sup>	29	83	Prospective	England	13.8	Mean CO3.7	Threshold eGFR for dialysis initiation based on dialysis cohort	Median 13.9months (range 2-
Chandha <sup>ste</sup>	106	81.4	Retrospective	England	28.3	Co morbidity score‡ >4 in 50.9%	eGFR < 10–15 mL/min/1.73 m <sup>2</sup> with all subsequent eGFR < 15 mL/min/1.73 m <sup>2</sup>	One-year survival 80.2%
Da Silva-Gane <sup>sso</sup>	30	77.5††	Prospective	England	NR	Co morbidity score‡ >3 in 74%	Study errolment, late stage 4/5 CKD attending low clearance clinic	One-year sunival 75%, median sunival 913 days
Ellom <sup>sol</sup> t	69	80	Retrospective	England	38	NR	cGFR < 15 mL/min/1.73 m <sup>2</sup>	Median 21 months (range 1-1
Hussain <sup>56</sup>	172	NR, enrolled >70years	Prospective	England	NR	NR	eGFR < 20, eGFR < 15 and eGFR < 12 mL/min/1.73 m <sup>2</sup>	One-year survival 71% from eGFR < 15
Isaacs <sup>512</sup> ##	54	83	Retrospective	England	NR	NR	time of decision not to dialyse	Median 6 months (2.5-11)
Joly <sup>on</sup>	37	84.1††	Retrospective	France	21.6	$32.4\% \succ 3$ comorbid conditions	Suminal from decision not to perform dialysis	Median 8.9 months (95% CI 4-
Murtagh <sup>536</sup>	77	83	Retrospective	England	23.4§	18.2% Davies grade 2 score	eGFR < 15 mL/min/1.73 m²	Median 18months (range 0.1–73.1)
Seows	63	78	Prospective	Singapore	60.3§	CCI (not age adjusted) score of 5	Study enrolment, eGFR 8–12 mUmin/1.73 m <sup>2</sup>	Two-year sunival 61.9%
Shum <sup>a</sup>	42	75.3++	Retrospective	Hong Kong	66.7	CCI mean 4.6	eGFR < 15 mL/min/1.73 m <sup>2</sup>	One-year survival 80.7%
Smith <sup>ear</sup> †¶	26	71++	Retrospective	England	27	Mean comorbidity score‡ 4.7 (SD 3.0)	Putative dialysis initiation date	6.3 months
Wong <sup>sec</sup> †	73	79	Prospective	England	28^	Stoke's comorbidity grade = 1	Survival from decision not to	23.4 months



















# The JAMA Network

From: Quality of End-of-Life Care Provided to Patients With Different Serious Illnesses

# JAMA Intern Med. Published online June 26, 2016. doi:10.1001/jamainternmed.2016.1200

	No. (%)						
Dutcomes	Cancer	Dementia	ESRD	Cardiopulmonary Failure	Frailty	Other	P Value <sup>®</sup>
All veteran decedents (n = 57 728) <sup>c</sup>	23 523 (40.8)	3675 (6.4)	2265 (3.9)	13854 (24.0)	9931 (17.2)	4480 (7.8)	1
Measures of care at the end of life							
Palliative care consultation	73.5	61.4	50.4	46.7	43.7	41.5	<.001
Do-not-resuscitate order	95.3	93.5	87.0	86.3	88.6	83.9	<.001
Died in inpatient hospice	42.9	32.3	24.3	22.9	20.3	20.6	<.001
Died in the intensive care unit	13.4	8.9	32.3	34.1	35.2	37.4	<.001
Bereaved Family Survey participants (n = 34 005) <sup>d.e</sup>	40.3	6.6	3.7	24.4	17.4	7.6	
Overall rating of patient's care was excellent	59.2	59.3	54.8	54.8 <sup>9</sup>	53.7 <sup>0</sup>	55.0 <sup>8</sup>	<.001
Health care professionals always listened to concerns	73.8	75.7	68.6 <sup>4</sup>	71.5	70.5	73.0	<.001
Health care professionals always provided the medical treatment that patient and family wanted	79.1	80.4	73.4 <sup>4</sup>	76.8 <sup>9</sup>	76.5 <sup>9</sup>	77.4	<.001
Health care professionals always kept family informed about patient's condition and treatment	68.2	71.1'	63.8 <sup>h</sup>	65.99	66.6	67.5	.001
Health care professionals always gave enough emotional support prior to the patient's death	64.6	67.5	61.5	62.19	62.0	63.3	<.001
Patient had frequent uncontrolled pain <sup>4</sup>	55.0	49.49	54.3	55.9	53.3	55.3	.003



# End-of-Life Vigne The Symptoms Prevalence, Medical Interventions, and Health Care Service Needs for Patients With End-Stage Renal Disease in a Renal Palliative Care Program Annie O. Kwok, MBBS, MRCP, FHKCP, FHKAM<sup>1</sup>, Sze-kit Yuen, MBChB, MRCP, FHKCP, FHKAM<sup>1</sup>, David S. Yong, MBBS, MRCP, FHKCP, FHKAM, FRCP (Edin)<sup>1</sup>, and Doris M. Tse, MBBS, FHKAM, FHKCP, FRCP (Lond, Edin)<sup>1</sup> <sup>1</sup>Department of Medicine & Geriatrics, Caritas Medical Centre, Kowloon, Hong Kong SAR Retrospective study; Last 2 weeks of life; CM non-dialysis pathway Structured RSC team 2006 to 2011 average of 3.1 acute admissions . 335 patients with ESKD; mean eGFR 12; age 77 • 2/3 diabetes; 30% IHD Median survival 15.5 months; 87% had DNR order and received no CPR 8% still received CPR even with DNR order 65% families responded to support urvey about death

55%	lannies	responded	to st

- 93% totally satisfied
- Most helpful : symptom control; psychosocial support - NONE regretted decision to forgo dialysis

	All	Male	Female	Ρ
Dyspnea	144 (63.7%)	74 (65.5%)	70 (61.9%)	.684
Fatigue/weakness	117 (51.8%)	56 (49.6%)	61 (54%)	.705
Edema	109 (48.2%)	47 (41.6%)	62 (54.9%)	.128
Pain (including angina)	100 (44.2%)	42 (37.2%)	58 (51.3%)	.094
Anorexia	86 (38.1%)	41 (36.3%)	45 (39.8%)	.746
Cough	70 (31.0%)	44 (38.9%)	26 (23%)	.026 <sup>a</sup>
Nausea and vomiting	60 (26.5%)	25 (22.1%)	35 (31%)	.287
Bowel problem	47 (20.8%)	23 (20.4%)	24 (21.2%)	.838
Confusion	43 (19%)	20 (17.7%)	23 (20.4%)	.754
Fever/chills/rigor	40 (17.7%)	20 (17.7%)	20 (17.7%)	.844
Bed sores/wounds	27 (11.9%)	11 (9.7%)	16 (14.2%)	.511
Urinary problem	24 (10.6%)	9 (8%)	15 (13.3%)	.376
Mouth problem	18 (8.0%)	7 (6.2%)	11 (9.7%)	.531
Convulsion	14 (6.2%)	4 (3.5%)	10 (8.8%)	.220
> Pruritus	11 (4.9%)	4 (3.5%)	7 (6.2%)	.557
Sleep problem	9 (4.0%)	6 (5.3%)	3 (2.7%)	.495
Distended abdomen	5 (2.2%)	4 (3.5%)	I (0.9%)	.332
Cold intolerance	3 (1.3%)	0 (0%)	3 (2.7%)	.187
Anxiety	I (0.4%)	0 (0%)	I (0.9%)	.513
Depressive mood	2 (0.9%)	I (0.9%)	I (0.9%)	.845
Suicidal thoughts	I (0.4%)	0 (0%)	I (0.9%)	.513
Median (IQR) number	4 (3-6)	4 (3-5)	5 (3-6)	.072
of symptoms		_		
No. (%) of patients with				.302
Substant Sector Sect	21 (9.3%)	14 (12.4%)	7 (6.2%)	
2-3 symptoms	65 (28.8%)	33 (29.2%)	32 (28.3%)	
4-5 symptoms	77 (34.1%)	39 (34.5%)	38 (33.6%)	
≥6 symptoms	63 (27.9%)	27 (23.9%)	36 (31.9%)	

Event	ts in last 2 weeks	that need p	lanning for
	Coexisting acute event	s	
	in last 2 weeks of life	2	
	Congestive heart	53 (23.5%)	
	failure		
	Pneumonia	44 (19.5%)	
	Other sepsis	37 (16.4%)	
	Gastrointestinal	34 (15.0%)	
	bleeding		
	Hypoglycemia	31 (13.7%)	
	Acute coronary	28 (12.4%)	
	syndrome		
	Arrhythmia	26 (11.5%)	

# Conclusions

- High uptake of a RSC program in HK
- Median survival 15-16 months
- High symptom prevalence
  - Predominantly SOB; pain; fatigue; anorexia
- Cardiac, infectious & GI bleeding common in last 2 weeks
- · Families very satisfied with such a program





# Exploring the interface between 'physician-assisted death' and palliative care: cross-sectional data from Australasian palliative care specialists

L. Sheahan<sup>1,2,3,4</sup>

<sup>1</sup>St George and Calvary Hospitals, <sup>2</sup>Centre for Values Ethics and the Law in Medicine, University of Sydney, and <sup>4</sup>School of Medicine, University of New South Wales, Sydney, New South Wales, Australia, and <sup>3</sup>Joint Centre for Bioethics, University of Toronto, Toronto, Ontario, Canada

- · some form of legalised assisted death exists in:
  - Netherlands, Belgium, Luxembourg, Switzerland, and the states of Oregon, Washington State, Vermont and Montana (USA).

#### • Aims:

 to identify current attitudes and experiences of palliative care specialists in Australasia regarding requests for PAS and VE

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#### Exploring the interface between 'physician-assisted death' and palliative care: cross-sectional data from Australasian palliative care specialists L. Sinshan<sup>1,24</sup>

#### <sup>1</sup>St Deorge and Calvary Hospitals, <sup>2</sup>Centre for Values Bhics and the Law in Medicine, University of Sydney, and <sup>4</sup>School of Medicine, University of Seath Wales, Sydney, New South Wales, Australia, and <sup>1</sup>School calments, Canada

### 156 Palliative Care specialists (40% response rate)

- 18 multiple-choice questions, addressing the following six areas:
  - 1. General demographic information.
  - 2. Frequency of requests for assisted death, and type of response given.
  - 3. Initial understanding of the term 'voluntary euthanasia'.
  - 4. Opinion regarding legalisation of PAS and/or VE in an Australasian
  - context, as well as willingness to participate if legal.
  - Identification of the most important and relevant values guiding this opinion.
    Anticipated impact that legalisation of assisted death would have on
  - Anticipated impact that regarsation of assisted death would have o palliative care practice and services in Australasia.







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## Conclusions

- · Reasons for opposition largely secular
  - Professional obligation to do no harm (28%)
  - Community interest in not taking life (26%)
  - Spiritual beliefs (16%)
  - (Presumed) belief that symptoms can be controlled with best practice palliative Care.

# PATIENTS' UNDERSTANDING OF **DIALYSIS & CONSERVATIVE CARE**

# Older patients' understanding of dialysis & conservative care for ESKD

- . 9 renal units across UK; 42 patients – dialysis, CM, pre-dialysis with eGFR <15; Age <275 2/3 male;
- Interviews & thematic analysis
- Previous studies on why choose CM
  - Too old: dialysis too burdensome: too much a problem on family:
  - Felt well without dialysis; travel to dialysis a problem
- Themes identified
  - 1. Patients' understanding of options All knew about dialysis: iable knowledge of CM
  - 2. Patients' perception of their own CKD
  - Feeling well led to reduced understanding of disease
  - Patients' experiences about making a decision re dialysis or CM
    Conflicting views & knowledge about survival & QOL with or without dialysis

Tokin-Crine et al. American Journal of Kidney Diseases 2015 65, 443-450DOI: (10.1053/j.ajkd.2014.08.011)

# Comments

#### Theme 1

"It was presumed that dialysis would work for me.... I can't remember [staff] ever suggesting or saying that there is a third option-of not having dialysis." (Male, 82, predialysis, unit 5)

#### Theme 2

"[The GFR] was about 8.1 but I feel ok, my appetite is good and I sleep well. I still drive my car and so forth so there's no problem there." (Male, 76, conservative management, unit 1).

Theme 3 – conflicting information

"I decided that I didn't want dialysis. I'm told that's not terribly unusual and I was told that if you say yes to dialysis, you don't necessarily live any longer anyway." (Male, 84, conservative management, unit 9)

"The staff small 'it's up to you, you've got the choice. You can have dialysis or you can have the other thing...if you wann not to have dialysis it's you choice but you've got to realize that it is going to kill you...but if you're on dialysis you could last for ten, fifteen, twenty years'." (Male, 76, dialysis, uni 2)







Reason	Number of doctors citing reason	Proportion of tota sample (n=96) (%)
Doctor-related factors	92	96
Trained to treat	81	84
Inexperience with death and dying	42	44
Don't want to give up hope	38	40
Aversion to death	37	39
Worries about legal risk	29	30
Poor communication	28	29
Doing everything possible	23	24
Emotional attachment to patients	19	20
Personality, personal experiences or religion	12	13
Patient-related factors	87	91
Family or patient request	63	66
Prognostic uncertainty	47	49
Lack of information about patient wishes	36	38
Hospital-related factors	65	68
Specialisation	27	28
Medical hierarchy	26	27
Hospitals designed to provide acute care so it does	25	26
Hard to stop once started	22	23
Time pressure	18	19
After-hours care	10	10



# Summary

- Renal Supportive Care is underpinned by better research
- We are learning more about:
  - Survival with and without dialysis
  - Uptake of RSC options
  - Symptom management
  - What patients understand
  - ACP