

Title: Patients who choose not to dialyze: a prospective national observational study in Australia.

Authors and affiliations:

Rachael L Morton, MScMed (Clin Epi) (Hons),¹

Robin M Turner, PhD,²

Kirsten Howard, PhD,^{1,2}

Paul Snelling, MB,ChB,³

Angela C Webster, PhD,^{1,4}

¹ School of Public Health, The University of Sydney, Sydney, Australia

² Screening and Testing Evaluation Program, School of Public Health, The University of Sydney, Sydney, Australia

³ Department of Renal Medicine, Royal Prince Alfred Hospital, Sydney, Australia

⁴ Centre for Transplant and Renal Research, Westmead Hospital, Westmead, Australia

Corresponding author: Rachael L Morton

School of Public Health, Edward Ford building A27, The University of Sydney, Sydney, NSW 2006, Australia.

Tel: +61 2 9036 5459

Fax: +61 2 9351 5049

Email: rachael.morton@sydney.edu.au

Word counts: Abstract: 296

Body: 2862

Running head: Conservative care in stage 5 CKD

Financial conflicts of interest: None

Funding: RLM is supported by National Health and Medical Research Council (NHMRC) grants #457281 and #571372. RMT is supported by NHMRC program grants #402764 and #633003.

Abstract:

Background: It is unclear how many incident patients with stage 5 chronic kidney disease (CKD) referred to Nephrologists are presented with information about conservative care as a treatment option and how many choose not to dialyze.

Study Design: National prospective observational study with random effects logistic regression. Clinicaltrials.gov identifier: NCT01298115.

Setting and participants: Incident adult and pediatric pre-emptive transplant, dialysis and conservative care patients from public and private renal units in Australia, July-September 2009.

Predictors: Age, sex, health insurance status, language, time known to nephrologist, timing of information, presence of caregiver, unit conservative care pathway and size of unit.

Outcomes & Measurements: Information provision to incident patients about conservative care (model 1). Initial treatment, conservative care or not, (model 2).

Results: Sixty-six of 73 renal units (90%) participated. Ten (15%) had a formal conservative care pathway. Of 721 incident stage 5 CKD patients, 470 (65%) were presented with conservative care as a treatment option, and 102 (14%) chose not to dialyze, median age 80 years. Multivariate analysis for information provision (model 1) showed patients over 65 years, OR 3.40(CI 1.97-5.87) and those known to a nephrologist for more than three months, OR 6.50(CI 3.18-13.30) were more likely to receive information about conservative care. Patients with conservative care as initial treatment (model 2) were more likely over 65 years, OR 4.71(CI 1.77-12.49) and female, OR 2.23(CI 1.23-4.02) than those who commenced dialysis. Those with private health insurance were less likely to forgo dialysis OR 0.40(CI 0.17-0.98).

Limitations: Cross-sectional design prohibited longer term outcome measurement. Excluded stage 5 CKD patients managed in the community.

Conclusions: One in seven stage 5 CKD patients referred to nephrologists choose not to dialyze. Comprehensive service provision with integrated palliative care needs to be improved to meet the demands of the aging population.

Index words: end-stage kidney disease, palliative care, dialysis, chronic kidney disease, treatment options

Introduction:

The treatment options for stage 5 chronic kidney disease (CKD) include kidney transplantation, dialysis, and supportive non-dialytic therapy often referred to as palliative or conservative care. The utilization of transplantation and dialysis is well documented through country-specific registries;¹⁻³ however the uptake of conservative care for patients who choose not to dialyze is unclear. In the United States in 2008, the fastest growing cohort of patients accepted onto dialysis was in the 75+ age group, with more than 5,500 prevalent dialysis patients aged over ninety years.^{2,4} Data from single-center studies suggest that those who choose to forgo dialysis are generally older, of lower socioeconomic status, and more likely to have diabetes mellitus, than patients treated with dialysis.⁵⁻⁷

Clinical practice guidelines in the United States, United Kingdom and Australia recommend all patients approaching end-stage kidney disease (ESKD) be informed about their treatment options including the option of conservative care.⁸⁻¹¹ The rationale is that patients' treatment decisions should be based on an accurate understanding of their condition and the harms and benefits of each treatment pathway. In response to the growing number of elderly on dialysis, the US Renal Physicians Association published a specific guideline called "*Shared decision making in the appropriate initiation of and withdrawal from dialysis.*"¹² This guideline acknowledges that patients have different goals for their care, and that communication of prognostic information with the patient, their family and renal team is required to develop a consensus on these goals. In circumstances where dialysis does not offer an expectation of benefit the option of conservative care may be preferable.

The number of stage 5 CKD pre-dialysis patients that are presented with the option of conservative care is unclear. The objectives of this study were therefore to determine the national proportion and characteristics of patients approaching ESKD that are educated about conservative care as a treatment option; the characteristics of patients who choose

conservative care and the number of Australian renal units with a formalized conservative care pathway.

Methods:

We conducted a prospective national cross-sectional study including all incident stage 5 CKD patients identified during a three month period (the PINOT study). All Australian adult and paediatric renal units and private nephrology practices that contribute to the Australia and New Zealand Dialysis and Transplant Association registry (ANZDATA, www.anzdata.org.au) were invited to participate. Nephrologists and CKD coordinators completed a web-based survey detailing the initial treatment for each incident stage 5 CKD patient that presented to their unit between 1st July and 30th September 2009. Detailed methods and a copy of the survey have been reported elsewhere,¹³ and are listed on the clinicaltrials.gov database, identifier # NCT01298115. We defined the sub-group of conservative care patients for analysis *a priori*.^{13,14} The study was approved by the University of Sydney Human Research Ethics Committee (protocol #11261) and relevant hospital ethics committees.

Renal replacement therapy (RRT) was defined as the initiation of chronic dialysis, or pre-emptive transplantation within the three month study period. Patients were defined as receiving 'conservative care' if a confirmed decision had been made not to dialyze, their eGFR using the Modification of Diet in Renal disease (MDRD) equation was $<15\text{ml}/\text{min}/1.73\text{m}^2$ on consecutive measurements, and they did not commence dialysis within the three month study period. Patients who withdrew from dialysis were not included. Data pertaining to the presentation of treatment options and initial therapy was sourced by nephrologists, pre-dialysis and transplant coordinators using pre-existing databases. Specific encouragement was given to nephrology heads of department to report conservative care patients not routinely seen by those coordinating dialysis or transplant education.

Nephrology heads of department were also asked about the presence of a written and documented conservative care pathway in their unit.

Source data verification was undertaken by RLM in high recruiting centers in four Australian states. Additionally, completion of the surveys by a second renal unit clinician was undertaken for 20% of the total sample. Observer agreement of the proportion receiving information about their treatment options was performed by two clinicians and reported using a kappa statistic.¹⁵

Statistical methods

To measure patient and unit characteristics associated with provision of information about conservative care (model 1) we used random effects logistic regression. The characteristics assessed included initial treatment (RRT or conservative care); age (which was categorized as <65 years, 65-74 years, 75-84 years and \geq 85 years, consistent with registry cohorts); sex; health insurance status (categorized as public only, private and Department of Veterans' Affairs); language spoken at home (categorized as English speaking, non-English speaking with no interpreter; and non-English speaking with an interpreter); time known to a nephrologist, (categorized as <3 months, 3-12 months, 1-2 years and >2 years); stage of CKD when information about treatment options was first presented, (categorized as stage 5, or stages 2-4); attendance of a support person ('caregiver present'), at presentation of information about treatment options; a formal conservative care pathway in the unit; and unit size (categorized by the number of prevalent dialysis patients in the preceding year: small <100, medium 100-199 and large \geq 200). All covariates were included individually and then combined in a multivariable model. Random effects were used to account for the clustering of patients within units, whose responses may be correlated. Association was measured using odds ratios (OR) to compare the odds of being presented with conservative care information for an individual with the characteristic, to another individual without the

characteristic at the same renal unit. Likelihood ratio p-values were used to test the associations. The intraclass correlation (ρ) was estimated using the method described by Snijders.¹⁶

To assess the association between commencing conservative care compared to commencing renal replacement therapy (model 2) the same approach was used. Age, sex, insurance status, language spoken at home, time known to a nephrologist, stage of CKD, whether a caregiver was present, conservative care pathway in unit and unit size were included, both individually and in multivariable analysis. Wald tests were used to test for differences between the levels of categories within the multivariable model. Missing covariate values were included in an “unknown” category in the models. All analyses were conducted in Stata/IC 11.1 (www.stata.com).

Results:

Sixty-six of 73 (90%) Australian renal units participated. (Table 1) Ten of 66 (15%) had a formal (written and documented) conservative care pathway for CKD patients. Non-participating centers included two pediatric renal units and five small private nephrology practices with the main reason for non-participation being lack of physician time to examine patient databases. Inter-observer agreement kappa was 89%. Throughout the three month study period, 721 incident stage 5 CKD patients were identified. (Table 1) Of interest, 102 of 721 (14%) patients chose conservative care, i.e. one in 7 patients. (Figure 1) The median age for the conservative care group was 80 years, with the youngest aged 47 years and the oldest aged 94 years. (Table 1) Most did not have private health insurance and most were known to their nephrologist for longer than two years. None of the conservative patients commenced dialysis within the three month study period or had plans to commence dialysis in the foreseeable future.

Information about conservative care

All 721 incident stage 5 CKD patients were included in each analysis. Four hundred and seventy of 721 (65%) patients were presented with conservative care as a treatment option. In model 1, the multivariable analysis of characteristics associated with the presentation of conservative care as a treatment option, increasing age was a significant factor. Compared to patients less than 65 years of age, patients aged 65-74 (OR 3.40), 75-84 (OR 5.55) and patients aged 85 and over (OR 10.56) were more likely to be presented with conservative care than not. (Table 2, Figure 2) Compared to patients known to a nephrologist for less than 3 months (i.e. late referrals), patients known between 3-12 months (OR 6.50), 1-2 years (OR 5.67) and > 2 years (OR 3.14) were more likely to receive information about conservative care than not. The likelihood of receiving this information fell steadily after 12 months as the odds were significantly lower for patients known for > 2 years compared to those known for 3-12 months (Wald $p=0.02$).

The timing of information about treatment options was significantly associated with the presentation of a conservative option. Patients who were informed of their treatment options early, in stage 2-4 CKD (OR 1.01) were more likely to be presented with conservative care than those who were presented with information in stage 5, or those in whom it was unknown (OR 0.13) if they received information about treatment options prior to starting treatment. (Table 2, Figure 2) Patients without an accompanying caregiver (OR 0.62) or with caregiver unknown (OR 0.20) were less likely to receive information about conservative care. The intraclass correlation ($\rho=0.30$, 95%CI, 0.18-0.45) showed that there was considerable similarity among patients within the same renal unit regarding whether they were presented with conservative care as a treatment option.

Patients who commenced conservative care

In model 2 the multivariable analysis compared characteristics of patients who commenced conservative care to those who commenced RRT. (Table 3, Figure 3) Compared to patients less than 65 years of age, patients aged 65-74 (OR 4.71), 75-84 (OR 23.11), and patients

aged 85 and over (OR 87.44), were more likely to be managed conservatively than start RRT. Females were twice as likely (OR 2.23) to commence conservative care than males. Patients with private health insurance (OR 0.40) were less likely to commence conservative care. Similar levels of intraclass correlation were found for this model showing that there was considerable similarity among patients within the same renal unit regarding their initial treatment. Data from the survey revealed the primary reason for not initiating dialysis in the conservative care group was patient choice (27% of cases) followed by the presence of severe co-morbid conditions. (Table 4) Ten of 102 (10%) conservative patients were referred to a palliative care team.

Discussion:

Our study showed that despite only 15% of renal units having a formal conservative care pathway, two-thirds of patients approaching ESKD were presented with information about conservative care as a treatment option. These patients were more likely to be older, have a caregiver and be well known to their nephrologist compared to patients not presented with this option. One in 7(14%) of all incident stage 5 CKD patients chose conservative care and were more likely to be older, female and have no private health insurance, compared to those who commenced RRT. Patient choice was the most common reason reported for conservative care management.

These results highlight several new findings. Firstly and most importantly, our data quantify the large national demand for renal conservative care service provision. In Australia, like many other countries, few structured conservative care pathways exist in renal units, and the referral rate of renal patients to other palliative care services is low. Our data indicate that one in 7 patients with ESKD managed in renal units choose not to dialyse, which represents a large demand on the limited existing conservative care services. Traditionally renal services have concentrated efforts and paramedical support services on the provision of renal

replacement therapy; however it would appear from this data that the focus needs to shift to include support and options for non-dialytic care.

Second, our data suggest patients who choose conservative care may be different to those who choose RRT. Females were twice as likely to commence conservative care when adjusted for all other factors. This trend has also been observed in dialysis withdrawal where females were more likely to withdraw from dialysis than males.¹⁷ Historically women in the United States and Sweden had only 70-90% chance of receiving renal replacement therapy compared to men;¹⁸ and more recently in Hong Kong a male to female renal conservative care ratio of 1 to 1.14 was reported.⁵ This association was not observed in two observational studies of conservative patients in the United Kingdom,^{19,20} however the finding is consistent with evidence from other chronic diseases suggesting that men may be more likely than women to be treated with active intervention than medical management, (for example carotid endarterectomy for stroke prevention).²¹

Patients with private health insurance (including war veterans insurance) were also less likely to commence conservative care. War veterans and war widows in Australia typically receive comprehensive health care coverage which includes subsidized transport to attend dialysis, and admission to private dialysis centres. Likewise privately insured patients have easier access to dialysis facilities used by their chosen specialist, with no out-of-pocket costs, which may make the choice to dialyze more attractive.²² If we assume that private health insurance is a proxy for higher socioeconomic status then these results are consistent with Yong et al⁵ who found conservatively managed patients in Hong Kong lived in public housing, and were financially dependent on their families, when compared to patients treated with dialysis. What is interesting is that private health insurance still has an effect on dialysis uptake, in a country where the costs of treatment are largely borne by the government.

Third, we found the longer CKD patients were known to their nephrologist (beyond 12 months) the likelihood of a conservative care discussion decreased. This association may represent patients with slow progressive CKD, particularly in the elderly, where other competing risks of death such as cancer and cardiovascular disease exceed the risk of progression to the point of requiring RRT.²³ Nephrologists might weigh up the benefits and harms of starting discussions about treatment options including conservative care, and delay such conversations until the patient becomes symptomatic. Alternatively it may reflect complacency on the part of the renal team, in assuming the patient has knowledge of their treatment options, including conservative care, related to their length of time with CKD.

International guidelines recommend conservative care or palliative services should extend to non-malignant diseases such as cardiac, liver and renal disease. However one of the practical barriers to access of palliative care services in renal units includes too few palliative care physicians. One response to this is a model of care whereby staff nephrologists are trained in aspects of palliative care including symptom assessment and symptom treatment, advance care planning, and referral of dying patients to hospice services.^{24,25,26} A second model of care integrates palliative care physicians into renal clinics, who then take the lead with management of uremic symptoms, and discussions about end of life care.^{27,28} In general, care pathways aim to ensure that the most appropriate management occurs at the most appropriate time and that it is provided by the most appropriate health professional.²⁹ For conservatively managed patients, care pathways can clarify treatment options in end-stage disease, reduce the ambiguity surrounding decision-making and reduce a sense of abandonment from the renal team.^{30,31} Benefits to clinicians include improved multidisciplinary communication and increased use of best practice.³² Whichever approach is taken, conservative care pathways for renal patients need to be well-funded, coordinated and subjected to routine evaluation and audit.

The limitations of this study include the cross-sectional design and the non-participation of a small number of renal units which could induce selection bias. We do not have long-term follow up data to assess whether the 102 conservative patients commenced dialysis within the subsequent 12-24 month period. We know there were no plans for these patients to commence dialysis in the foreseeable future and other longitudinal studies have shown the majority of patients do not cross over from conservative care to the renal replacement therapy at the last minute, if well prepared and fully informed about their treatment options.^{5,7,33} Our study was also limited to incident stage 5 CKD patients managed conservatively by nephrologists (i.e. not in the community). Therefore the total numbers choosing conservative care are likely to be an under-estimate of the total incidence of conservative care in CKD.

Our study has many strengths. We achieved an extremely high national participation rate with 66 (90%) of all renal centers involved ensuring the study population was reflective of the Australian CKD population and likely generalizable to stage 5 patients in the United States and Europe where options for conservative treatment exist. We used robust statistical methods to assess associations, and to our knowledge are the first study to report a nationwide figure for the proportion of patients that choose not to dialyze, and the first to examine the provision of information about conservative care to incident stage 5 patients.

The number of conservative care patients seen by nephrologists is expected to increase, due to both the population increase in people with ESKD over 75 years of age, and the proportion of patients with multiple comorbidities, in whom dialysis may provide little survival benefit. Further research is needed in the area of treatment decision making and evaluation of emerging models of palliative care service provision. Large multi-centre cohort studies would help address questions of survival and quality of life in those who choose not to dialyze. In addition, the formal evaluation of patient preferences for conservative care compared to dialysis, would provide evidence to support policy in this area.

One in seven stage 5 CKD patients referred to nephrologists choose not to dialyze, which represents a large demand on the limited existing renal services. Comprehensive service provision with integrated palliative care needs to be improved to meet the demands of the aging population.

Acknowledgements:

The authors wish to express their thanks to the nephrologists and CKD coordinators from Australian renal units who participated in this study.

References:

1. Tomson CRV. UK Renal Registry Report. Chapter 1. Summary of findings in the 2009 UK Renal Registry Report. Vol 12th Annual Report. Bristol, UK: The Renal Association; 2009.
2. US Renal Data System. USRDS 2010 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States. In: National Institutes of Health, ed. Bethesda, MD: National Institute of Diabetes and Digestive and Kidney Diseases; 2010.
3. Grace B, Excell L, McDonald S. ANZDATA Registry 2010 Report. Chapter 1. Stock and Flow. Vol 33rd Annual Report: Australia and New Zealand Dialysis and Transplant Association; 2010.
4. Kurella M, Covinsky KE, Collins AJ, Chertow GM. Octogenarians and Nonagenarians Starting Dialysis in the United States. *Annals of Internal Medicine*. 2007;146(3):177-183.
5. Yong DSP, Kwok AOL, Wong DML, Suen MHP, Chen WT, Tse DMW. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care. *Palliative Medicine*. 2009;23:111-119.
6. Dasgupta I, Rayner HC. Dialysis Versus Conservative Management of Elderly Patients With Advanced Chronic Kidney Disease. *Nat Clin Pract Nephrol*. 2007;3(9):480-481.
7. Smith C, Da Silva-Gane M, Chandna S, Warwicker P, Greenwood R, Farrington K. Choosing Not to Dialyze: Evaluation of Planned Non-Dialytic Management in a Cohort of Patients with End-Stage Renal Failure. *Nephron Clin Pract*. 2003;95(2):c40-c46.
8. Royal College of Physicians. The changing face of renal medicine in the UK: the future of the specialty. Report of a Working Party. London: The Renal Association; 2007:23-24.

9. Department of Health National Service Framework Renal Team. The National Service Framework for Renal Services. Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care. London, UK: Department of Health; 2005:21-23.
10. National Kidney Foundation. Kidney Disease Outcomes Quality Initiative (K-DOQI). Clinical practice guidelines for hemodialysis adequacy. Guideline 1. Initiation of dialysis. 1.1 Preparation for kidney failure. 2006;http://www.kidney.org/Professionals/kdoqi/guideline_upHD_PD_VA/index.htm.
11. Kainer G, Fetherstonhaugh D. The CARI guidelines. Acceptance onto dialysis. Ethical considerations. *Nephrology*. 2010;15(S1):S12–S14.
12. Renal Physicians Association. Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline. Vol 2nd edition. Rockville, Maryland: Renal Physicians Association; 2010.
13. Morton RL, Howard K, Webster AC, Snelling P. Patient Information about Options for Treatment (PINOT): methods of a national audit of information provision in chronic kidney disease. *Nephrology* 2010.
14. Morton RL, Howard K, Webster AC, Snelling P. Patient Information about Options for Treatment (PINOT): a prospective national study of information given to incident CKD Stage 5 patients. *Nephrol. Dial. Transplant*. 2010;doi: 10.1093/ndt/gfq555.
15. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics*. 1977;33:159-174.
16. Snijders TAB, Bosker RJ. *Multilevel Analysis. An introduction to basic and advanced multilevel modeling*. London: Sage Publications Ltd; 1999.
17. Leggat JE, Bloembergen WE, Levine G, et al. An analysis of risk factors for withdrawal from dialysis before death. *J Am Soc Nephrol*. 1997;8:1755–1763.
18. Kjellstrand CM. Giving life - giving death. Ethical problems of high-technology medicine. *Acta Medica Scandinavica*. 1988;725(Supplement):1-88.

19. Wong CF, McCarthy M, Howse ML, Williams PS. Factors affecting survival in advanced chronic kidney disease patients who choose not to receive dialysis. *Renal Failure*. 2007;29(6):653-659.
20. Murtagh FEM, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris F. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant*. 2007;22:1955–1962.
21. Simpson CR, Wilson C, Hannaford PC, Williams D. Evidence for age and sex differences in the secondary prevention of stroke in Scottish primary care. *Stroke*. 2005;36:1771–1775.
22. Harris A. The organization and funding of the treatment of end-stage renal disease in Australia. *International Journal of Health Care Finance & Economics*. 2007;7(2-3):113-132.
23. Demoulin N, Beguin C, Labriola L, Jadoul M. Preparing renal replacement therapy in stage 4 CKD patients referred to nephrologists: a difficult balance between futility and insufficiency. A cohort study of 386 patients followed in Brussels. *Nephrol Dial Transplant*. 2011;26 220–226.
24. Poppel DM, Cohen LM, Germain MJ. The Renal Palliative Care Initiative. *Journal of Palliative Medicine* 2003;6(2):321-326.
25. Karim M, Murphy-Burke D, Leung M, Chun-Yan C, Warb R, Hargrove G. Advancing end of life care provision. A provincial framework (Abstract SU313). Poster presented at the World Congress of Nephrology. Vancouver, April 8-12, 2011. 2011;URL: www.bcrenalagency.ca.
26. Davison SN. End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010;5(2):195-204.
27. Foote C, Tranter S, Jossland E, et al. Symptom burden in a palliative nephrology clinic. (Abstract 185). *Nephrology*. 2010;15(Suppl 4):5.

28. Tse DM-W. Experience of a Renal Palliative Care Program in a Hong Kong Center: Characteristics of Patients Who Prefer Palliative Care to Dialysis. *Hong Kong J Nephrol* 2009;11(2):50-58.
29. Chan R, Webster Joan. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Database of Systematic Reviews*. 2010(1):CD008006.
30. Fassett RG, Robertson IK, Mace R, Youl L, Challenor S, Bull R. Palliative care in end-stage kidney disease. *Nephrology*. 2011;16(1):4-12.
31. Ashby M, op't Hoog C, Kellehear A, et al. Renal dialysis abatement: lessons from a social study. *Palliative Medicine*. 2005;19:389-396.
32. Campbell H, Hotchkiss R, Bradshaw N, Porteous M. Integrated care pathways. *BMJ*. 1998;316(7125):133-137.
33. Carson RC, Juszczak M, Davenport A, Burns A. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol*. Oct 2009;4(10):1611-1619.

Table 1: Patient and unit characteristics of the conservative care group and renal replacement therapy (RRT) group

		Conservative care		RRT	
		n =102	(%)	n =619	(%)
Patient characteristics					
Age (years)	Mean (sd)	79 (8.7)		61 (17.3)	
	Median (IQR)	80 (9.8)		64 (24)	
Age group (years)	0-44	0	(0)	107	(17)
	45-54	2	(2)	90	(15)
	55-64	6	(6)	125	(20)
	65-74	16	(16)	149	(24)
	75-84	52	(51)	127	(21)
	≥85	26	(25)	21	(3)
Sex	Male	52	(51)	371	(60)
	Female	50	(49)	248	(40)
Type of insurance	Public only	57	(56)	418	(68)
	Private	13	(13)	136	(22)
	DVA*	5	(5)	19	(3)
	Unknown	27	(26)	46	(7)
Language spoken at home	English	83	(81)	491	(79)
	Vietnamese	6	(6)	12	(2)
	Italian	5	(5)	21	(3)
	Greek	2	(2)	11	(2)
	Arabic	1	(1)	3	(0)
	Other	5	(5)	81	(13)
Interpreter required	Yes	11	(11)	59	(10)
Time known to nephrologist	< 3 months	15	(15)	142	(23)
	3-12 months	15	(15)	111	(18)
	1-2 years	18	(18)	114	(18)
	> 2 years	54	(53)	252	(41)
Stage of CKD when information first presented	Stage 5	49	(48)	369	(60)
	Stages 2-4	40	(39)	185	(30)
	Unknown	13	(13)	65	(11)
Caregiver present	Yes	66	(65)	399	(64)
	No	16	(16)	124	(20)
	Unknown	20	(20)	96	(16)
Geographical state	NSW/ACT†	51	(50)	192	(31)
	VIC‡	16	(16)	168	(27)
	QLD§	17	(17)	106	(17)
	SA	9	(9)	49	(8)
	WA¶	6	(6)	62	(10)
	TAS**	3	(3)	19	(3)
	NT††	0	(0)	23	(4)
Unit characteristics (n=66)				n	(%)
Unit size:	small	< 100 dialysis patients		34	(51)
	medium	100-199 dialysis patients		13	(20)
	large	≥ 200 dialysis patients		19	(29)
Formal conservative care pathway	Yes		10	(15)	

* Department of Veterans' Affairs, † New South Wales / Australian Capital Territory, ‡ Victoria, § Queensland, || South Australia, ¶ Western Australia, ** Tasmania, †† Northern Territory.

Table 2: Univariate and multivariable analyses for receiving information about conservative care as a treatment option versus not presented or unknown

Characteristic	Univariate (unadjusted) association			Multivariable (adjusted) association		
	OR	95%CI	p-value*	OR	95% CI	p-value*
Treatment			0.013			0.567
RRT [†]	1.00	(referent)		1.00	(referent)	
Conservative care	2.10	1.14-3.85		1.26	0.57-2.76	
Age (years)			<0.001			<0.001
< 65	1.00	(referent)		1.00	(referent)	
65-74	2.91	1.83-4.64		3.40	1.97-5.87	
75-84	4.08	2.53-6.56		5.55	3.08-10.02	
≥ 85	9.95	3.49-28.36		10.56	2.96-37.68	
Sex			0.717			0.596
Male	1.00	(referent)		1.00	(referent)	
Female	0.94	0.66-1.33		0.89	0.59-1.35	
Insurance			0.132			0.700
Public only	1.00	(referent)		1.00	(referent)	
Private	1.41	0.87-2.27		1.13	0.65-1.99	
DVA [‡]	3.03	0.95-9.66		2.14	0.50-9.09	
Unknown	0.93	0.46-1.90		1.28	0.53-3.08	
Language spoken at home			0.001			0.077
English	1.00	(referent)		1.00	(referent)	
Non-English, no interpreter	1.83	1.02-3.31		1.70	0.85-3.39	
Non-English, interpreter	4.60	2.09-10.14		2.24	0.95-5.25	
Time known to a nephrologist			<0.001			<0.001
< 3 months	1.00	(referent)		1.00	(referent)	
3-12 months	5.70	3.07-10.60		6.50	3.18-13.30	
1-2 years	5.83	3.22-10.57		5.67	2.83-11.37	
> 2 years	3.09	1.93-4.96		3.14	1.78-5.54	
Stage of CKD when info presented			<0.001			<0.001
Stage 5	1.00	(referent)		1.00	(referent)	
Stages 2-4	1.51	1.00-2.29		1.01	0.61-1.64	
Unknown	0.15	0.07-0.33		0.13	0.05-0.34	
Caregiver present			<0.001			<0.001
Yes	1.00	(referent)		1.00	(referent)	
No	0.54	0.34-0.86		0.62	0.37-1.06	
Unknown	0.13	0.08-0.23		0.20	0.11-0.37	
Unit has conservative care pathway			0.273			0.663
Yes	1.00	(referent)		1.00	(referent)	
No	1.61	0.69-3.80		1.27	0.44-3.69	
Unit size (dialysis patients)			0.393			0.851
< 100	1.00	(referent)		1.00	(referent)	
100-199	1.13	0.46-2.78		1.00	0.34-2.89	
≥200	0.66	0.30-1.43		0.78	0.30-2.03	

Intraclass correlation $\rho=0.30$, 95%CI (0.18-0.45)

*Likelihood ratio, [†]Renal replacement therapy, [‡]Department of Veterans' Affairs.

Table 3: Characteristics of patients commencing conservative care versus renal replacement therapy; results of univariate and multivariable analyses

Characteristic	Univariate (unadjusted) association			Multivariable (adjusted) association		
	OR	95%CI	p-value*	OR	95% CI	p-value*
Age (years)			<0.001			<0.001
< 65	1.00	(referent)		1.00	(referent)	
65-74	4.23	1.66-10.78		4.71	1.77-12.49	
75-84	18.35	7.91-42.59		23.11	9.46-56.47	
≥ 85	53.02	18.34-153.23		87.44	26.77-285.60	
Sex			0.076			0.007
Male	1.00	(referent)		1.00	(referent)	
Female	1.55	0.96-2.51		2.23	1.23-4.02	
Insurance			0.081			0.021
Public only	1.00	(referent)		1.00	(referent)	
Private	0.54	0.25-1.16		0.40	0.17-0.98	
DVA†	1.61	0.50-5.20		0.23	0.05-0.96	
Unknown	2.08	0.85-5.08		1.76	0.60-5.17	
Language spoken at home			0.185			0.740
English	1.00	(referent)		1.00	(referent)	
Non-English, no interpreter	1.05	0.45-2.48		0.74	0.27-2.02	
Non-English, interpreter	2.20	0.97-4.98		1.19	0.47-3.01	
Time known to a nephrologist			0.625			0.982
< 3 months	1.00	(referent)		1.00	(referent)	
3-12 months	1.15	0.49-2.67		1.19	0.39-3.23	
1-2 years	1.66	0.74-3.75		1.21	0.45-3.25	
> 2 years	1.36	0.67-2.74		1.14	0.49-2.65	
Stage of CKD when info presented			0.049			0.112
Stage 5	1.00	(referent)		1.00	(referent)	
Stages 2-4	1.86	1.08-3.19		1.99	1.04-3.80	
Unknown	2.05	0.79-5.34		1.30	0.40-4.21	
Caregiver present			0.431			0.376
Yes	1.00	(referent)		1.00	(referent)	
No	1.05	0.54-2.06		1.68	0.75-3.77	
Unknown	1.54	0.81-2.95		1.44	0.62-3.37	
Unit has conservative care pathway			0.558			0.721
Yes	1.00	(referent)		1.00	(referent)	
No	1.42	0.44-4.59		1.25	0.36-4.36	
Unit size (dialysis patients)			0.205			0.176
< 100	1.00	(referent)		1.00	(referent)	
100-199	1.49	0.51-4.37		0.91	0.27-3.07	
≥200	0.56	0.21-1.48		0.36	0.12-1.12	

Intraclass correlation $\rho=0.29$, 95%CI (0.13-0.51)

*Likelihood ratio, † Department of Veterans' Affairs.

Table 4: Primary reason given by participating units as to why dialysis was not undertaken in the conservative care sub-group

Primary reason	n=102	(%)
Frail / elderly	19	(19)
Suitable but patient declined	27	(26)
Co-morbid conditions (eg. metastatic malignancies, dementia)	25	(25)
No dialysis access (vascular or peritoneal) possible	2	(2)
No dialysis close to home and unable to perform a home therapy	1	(1)
Not stated	28	(27)

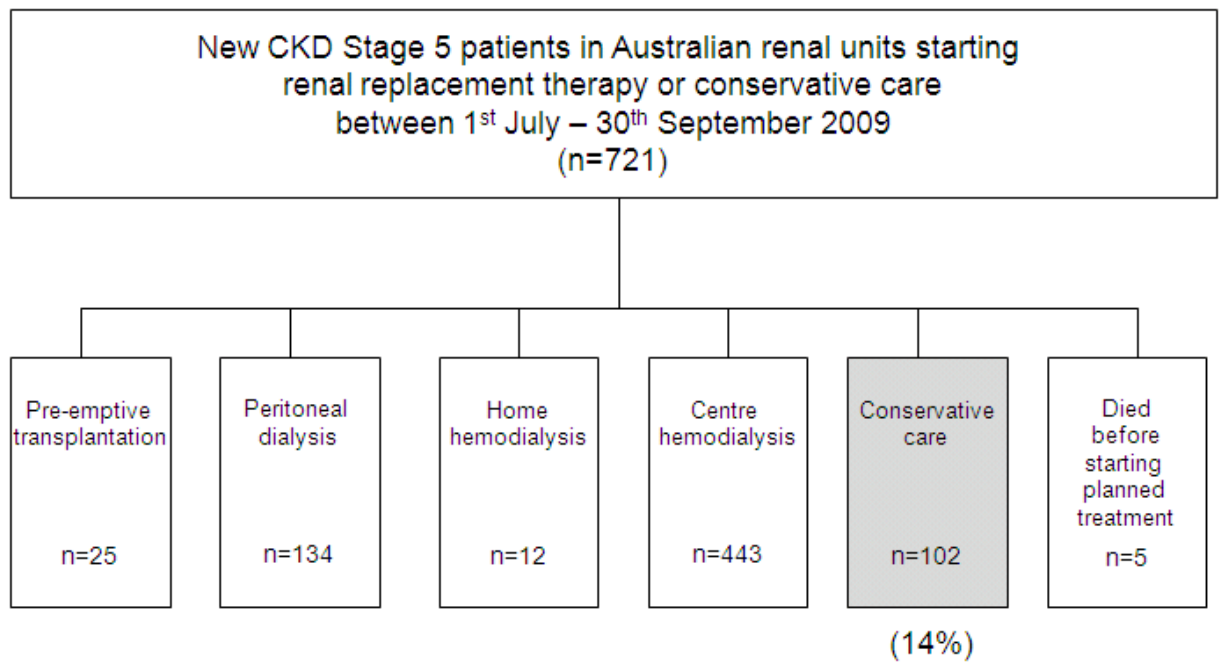


Figure 1.
 Title: Study enrolment. Incidence of conservative care patients among Australian renal units over a three-month period

Presented with conservative care treatment option

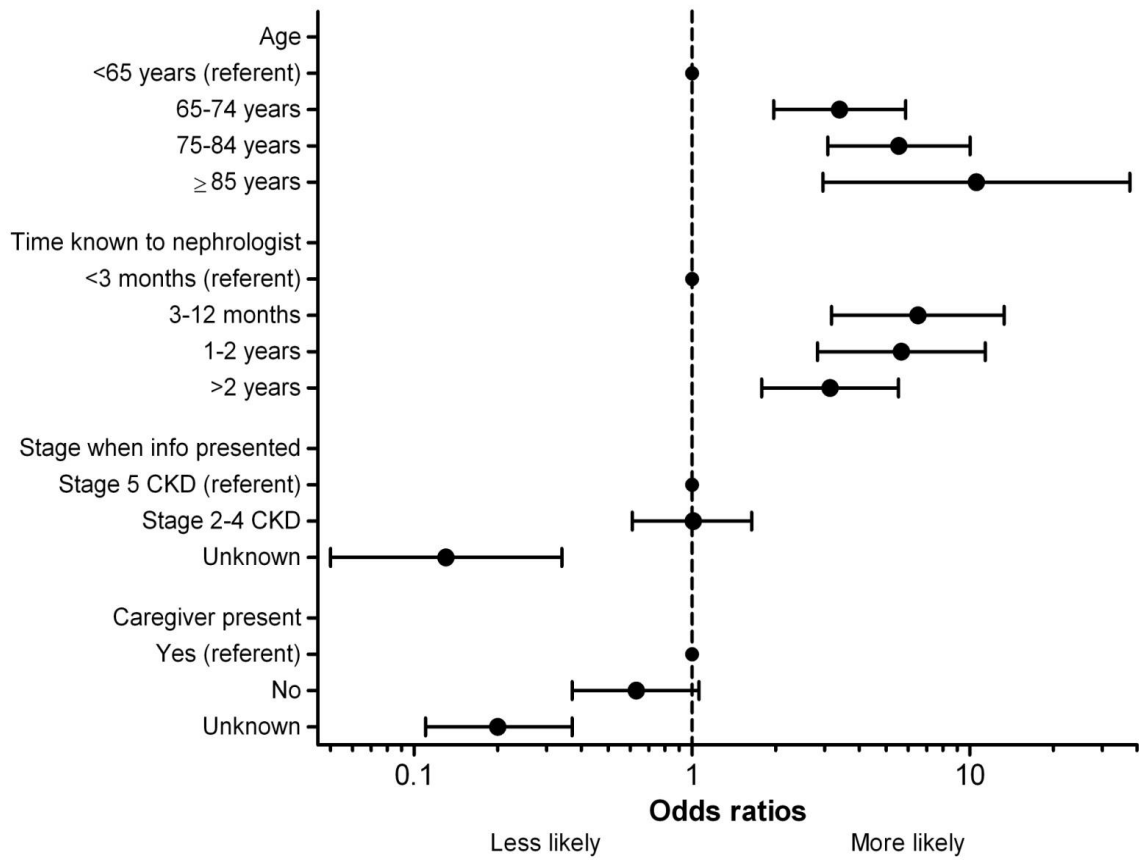


Figure 2.

Title: Forest plot for odds of being presented with a conservative care treatment option.

Legend: Characteristics from multivariable model 1 with $p < 0.05$ included. The dot represents the odds ratio and the bars represent the 95% confidence interval. The null has a value of 1 (central dotted line) and the scale is logarithmic.

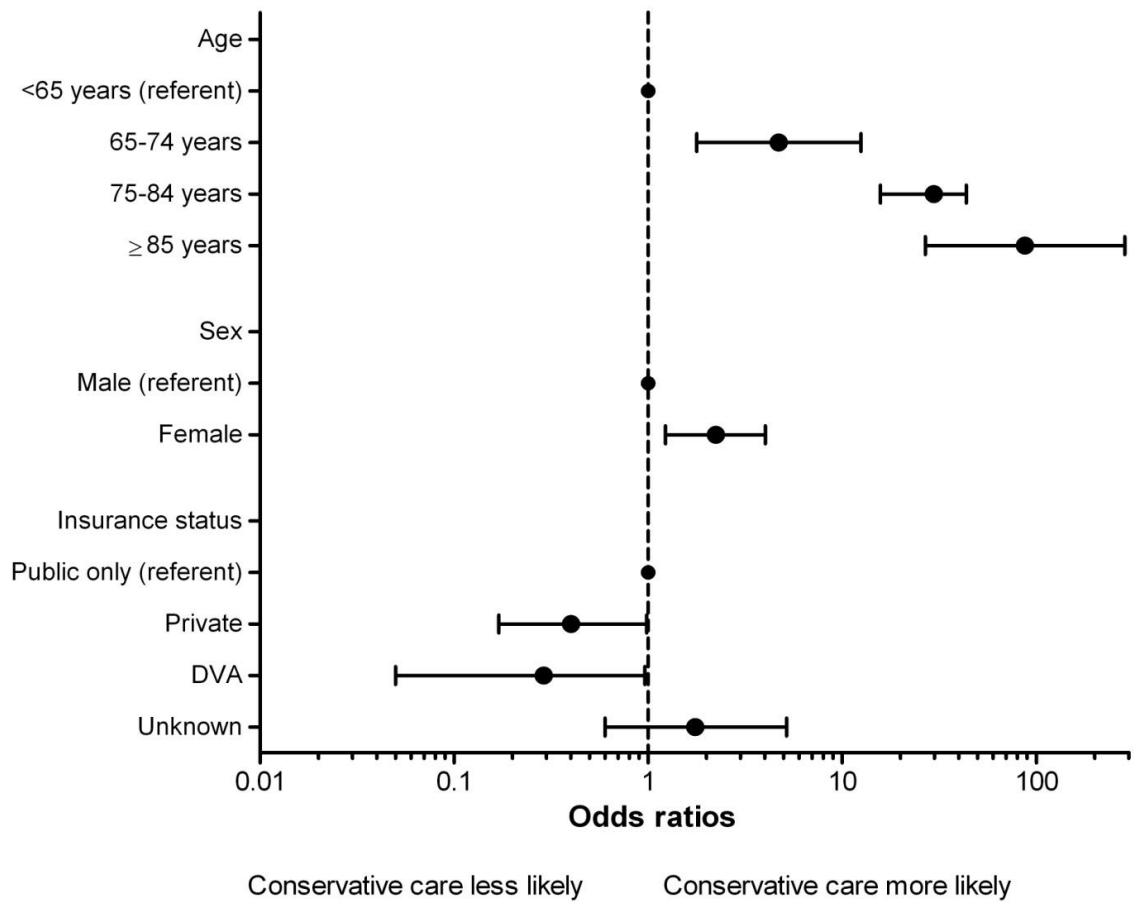


Figure 3.

Title: Forest plot for odds of commencing conservative care compared to renal replacement therapy.

Legend: Characteristics from multivariable model 2 with $p < 0.05$ included. The dot represents the odds ratio and the bars represent the 95% confidence interval. The null has a value of 1 (central dotted line) and the scale is logarithmic.