

# Conservative Management and End-of-Life Care in an Australian Cohort with ESRD

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## Abstract

**Background and objectives** We aimed to determine the proportion of patients who switched to dialysis after confirmed plans for conservative care and compare survival and end-of-life care among patients choosing conservative care with those initiating RRT.

**Design, setting, participants, & measurements** A cohort study of 721 patients on incident dialysis, patients receiving transplants, and conservatively managed patients from 66 Australian renal units entered into the Patient Information about Options for Treatment Study from July 1 to September 30, 2009 were followed for 3 years. A two-sided binomial test assessed the proportion of patients who switched from conservative care to RRT. Cox regression, stratified by center and adjusted for patient and treatment characteristics, estimated factors associated with 3-year survival.

**Results** In total, 102 of 721 patients planned for conservative care, and median age was 80 years old. Of these, 8% (95% confidence interval, 3% to 13%), switched to dialysis, predominantly for symptom management. Of 94 patients remaining on a conservative pathway, 18% were alive at 3 years. Of the total 721 patients, 247 (34%) died by study end. In multivariable analysis, factors associated with all-cause mortality included older age (hazard ratio, 1.55; 95% confidence interval, 1.36 to 1.77), baseline serum albumin <3.0 versus 3.7–5.4 g/dl (hazard ratio, 4.31; 95% confidence interval, 2.72 to 6.81), and management with conservative care compared with RRT (hazard ratio, 2.18; 95% confidence interval, 1.39 to 3.40). Of 247 deaths, patients managed with RRT were less likely to receive specialist palliative care (26% versus 57%;  $P<0.001$ ), more likely to die in the hospital (66% versus 42%;  $P<0.001$ ) than home or hospice, and more likely to receive palliative care only within the last week of life (42% versus 15%;  $P<0.001$ ) than those managed conservatively.

**Conclusions** Survival after 3 years of conservative management is common, with relatively few patients switching to dialysis. Specialist palliative care services are used more frequently and at an earlier time point for conservatively managed patients, a practice associated with better symptom management and quality of life.

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## Introduction

In the United Kingdom and Australia, up to 20% of patients with stage 5 CKD who are referred to a nephrologist and informed of their treatment options choose conservative care (1–3). Comprehensive conservative care is defined as planned holistic patient-centered care for people with stage 5 CKD that includes interventions to delay progression of kidney disease and minimize risk of adverse events; shared decision making; active symptom management; detailed communication, including advance care planning; psychologic, social, and family support; and cultural and spiritual care, but it does not include RRT (4,5). The focus of conservative care incorporating palliative care principles is to prioritize comfort and quality of life aligned with patients' goals of care rather than a conventional disease-orientated focus on RRT (particularly dialysis) as rehabilitative treatment (6). It has been reported that patients initially

choose conservative care but may change their minds and commence dialysis after their kidney function deteriorates and they feel unwell (7–9). However, it is unclear what proportion of patients switch to dialysis after an initial plan for conservative care.

Palliative care service provision and access to hospice care are variable in Australia and other countries for people with nonmalignant conditions. Several studies (10–12) report limited access to specialist palliative care for patients with ESRD. Some reasons for this include a workforce shortage of palliative care clinicians, lack of recognition of the need for palliative care symptom management for patients managed with dialysis, poor education and training in palliative care for nephrologists, and nephrologists feeling reluctant to discuss that patients are near the end of their life (13–15). There is also a recognition that the nephrologists' role in provision of palliative care is evolving; however, questions remain about

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optimal models of care and the best time for referral to palliative care services. There are new initiatives looking at different models of renal supportive care that include palliative care. For example, the Agency for Clinical Innovation in Australia has funded a pilot program of specialist nurses to provide renal supportive care (<http://www.aci.health.nsw.gov.au/about-aci/e-news/newsletter/february-2015/sections/renal2>).

The Patient Information about Options for Treatment (PINOT) Study was a prospective national cohort of patients on incident dialysis, patients with transplants, and conservatively managed patients enrolled between July and September of 2009 and followed for 3 years (3,16). The PINOT Study was designed to investigate the information about treatment options that incident patients with ESRD received before starting treatment and then, follow the cohort to assess renal and palliative care service provision and mortality outcomes over a 3-year period. This cohort from Australian renal units provides a nationally representative sample in which to assess changes in type of treatment and patterns of end-of-life care. We aimed to determine the proportion of patients who commenced dialysis or a time-limited trial of dialysis within 3 years after confirmed plans for conservative care and compare survival and end-of-life care among patients choosing conservative care with those initiating RRT. In addition, we were interested in documenting the prevalence of advance care directives, the use of the surprise question in

prognostication (17,18), and the location of participants' place of death.

## Materials and Methods

### Setting

The PINOT Study was conducted among 66 Australian renal units, including each state and territory. The PINOT Study cohort represented 95% of all patients commencing RRT for the 3-month intake period and included all known incident patients with an eGFR of <15 ml/min per 1.73 m<sup>2</sup> and a confirmed plan for conservative care. Additional details are described in Supplemental Appendix.

### Methods of Follow-Up for the PINOT Study Cohort

In 2012, a detailed questionnaire was sent to each participating renal unit to confirm the patient's baseline demographics, document dialysis and/or conservative care activity between July 1, 2009 and September 30, 2012, and confirm survival status as of September 30, 2012 (Supplemental Appendix). The Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry was used to confirm changes in RRT, and both this and the Ryerson Death Index were used to confirm notification of deaths. The study was approved by relevant health research ethics committees, with a waiver for informed consent, and it was prospectively registered as an observational study on Clinicaltrials.gov (NCT01768624).

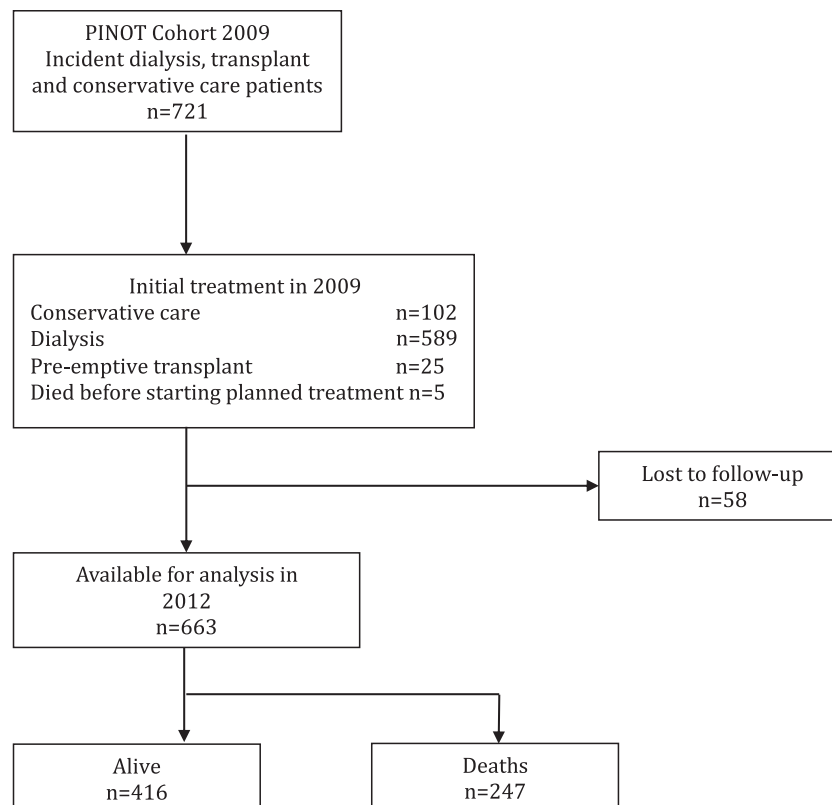


Figure 1. | Patient Information about Options for Treatment (PINOT) cohort participant flow chart.

## Outcomes

The primary outcome was the proportion of conservatively managed patients who switched to dialysis or commenced a time-limited trial of dialysis during follow-up (July of 2009 to September 30, 2012). We hypothesized that, nationally, this proportion would be <15% on the basis of available small or single-center studies from the United Kingdom and Australia that reported a switch to dialysis of between 2% and 16% (7–9). The secondary

outcomes of the follow-up study included 3-year survival among patients who initially commenced conservative care at study baseline compared with patients who commenced RRT at baseline. Survival was verified through hospital and primary care records, ANZDATA Registry records, and when unknown, the Ryerson Death Index, an organization that reviews death notices and obituaries in Australian newspapers (19). To determine the prevalence of a documented advance directive (a legal

**Table 1. Patient characteristics categorized by baseline treatment modality**

| Characteristic at Study Baseline     | Conservative Care,<br><i>n</i> =102 (14%) |         | RRT, <i>n</i> =619 (86%) |         | <i>P</i> Value for Difference<br>Between Groups <sup>a</sup> |
|--------------------------------------|---|---------|--------------------------|---------|--|
|                                      | <i>n</i>                                  | Percent | <i>n</i>                 | Percent |  |
| <b>Age, yr</b>                       |   |         |                          |         | <0.001   |
| Mean (SD)                            | 79  | (9)     | 61                       | (17)    |  |
| Median (IQR)                         | 80  | (75–85) | 64                       | (50–74) |  |
| <b>Sex</b>                           |   |         |                          |         | 0.09   |
| Men                                  | 52  | 51      | 371                      | 60      |  |
| Women                                | 50  | 49      | 248                      | 40      |  |
| <b>Marital status</b>                |   |         |                          |         | <0.001   |
| Married/ <i>de facto</i>             | 43  | 44      | 308                      | 52      |  |
| Single                               | 5   | 5       | 82                       | 14      |  |
| Separated/divorced/widowed           | 41  | 40      | 100                      | 16      |  |
| Unrecorded                           | 13  | 11      | 129                      | 18      |  |
| <b>Area deprivation index</b>        |   |         |                          |         | 0.74   |
| High SES, deciles 8–10               | 20  | 20      | 158                      | 26      |  |
| Mid-SES, deciles 4–7                 | 38  | 37      | 267                      | 43      |  |
| Low SES, deciles 1–3                 | 28  | 27      | 174                      | 28      |  |
| Unrecorded                           | 16  | 16      | 20                       | 3       |  |
| <b>ARIA remoteness index</b>         |   |         |                          |         | 0.17   |
| Major city                           | 55  | 54      | 348                      | 56      |  |
| Inner regional                       | 24  | 23      | 145                      | 24      |  |
| Outer regional                       | 5   | 5       | 69                       | 11      |  |
| Remote or very remote                | 2   | 2       | 37                       | 6       |  |
| Unrecorded                           | 16  | 16      | 20                       | 3       |  |
| <b>Type of health insurance</b>      |   |         |                          |         | 0.19   |
| Public only                          | 57  | 56      | 418                      | 68      |  |
| Private                              | 13  | 13      | 136                      | 22      |  |
| Veterans Affairs                     | 5   | 5       | 19                       | 3       |  |
| Unrecorded                           | 27  | 26      | 46                       | 7       |  |
| <b>Language spoken at home</b>       |   |         |                          |         | 0.80   |
| English                              | 82  | 80      | 491                      | 79      |  |
| Other <sup>b</sup>                   | 20  | 20      | 128                      | 21      |  |
| <b>Interpreter required</b>          |   |         |                          |         | 0.69   |
| Yes                                  | 11  | 11      | 59                       | 10      |  |
| <b>Time known to a nephrologist</b>  |   |         |                          |         | 0.10   |
| >2 yr                                | 54  | 52      | 252                      | 41      |  |
| 1–2 yr                               | 18  | 18      | 114                      | 18      |  |
| 3–12 mo                              | 15  | 15      | 111                      | 18      |  |
| <3 mo                                | 15  | 15      | 142                      | 23      |  |
| eGFR, ml/min per 1.73 m <sup>2</sup> | <15                                       | —       | On dialysis              | —       |  |
| <b>Serum albumin, g/dl</b>           |   |         |                          |         | 0.68   |
| <i>n</i> , Mean (SD)                 | 82, 3.25                                  | (0.57)  | 513, 3.28                | (0.63)  |  |
| <b>Hemoglobin, g/dl</b>              |   |         |                          |         | 0.99   |
| <i>n</i> , Mean (SD)                 | 82, 10.68                                 | (1.57)  | 513, 10.68               | (1.56)  |  |

Percentages presented are row percentages. IQR, interquartile range; SES, socioeconomic status; ARIA, Accessibility/Remoteness Index of Australia.

<sup>a</sup>Pearson chi-squared test for difference between groups, excluding the unrecorded group.

<sup>b</sup>Other language includes predominantly Greek, Italian, Arabic, Chinese, Vietnamese, and Indigenous languages.

document intended to record or instruct a patient's preference for future health and personal care should decision-making capacity become impaired) (20), patient's medical records and renal care plans were searched. The presence of an advance directive included either a copy of the advance directive in the patient's notes or a documented acknowledgment in the patient's notes that the individual did, indeed, have an advance directive that stated his/her wishes. Similarly, medical records were searched for the documented use of the surprise question for prognostication (17) (that is, "Would I be surprised if this patient died in the next year?") The provision and timing of specialist palliative care services that were used for patients who died during the follow-up period and the location of patients' place of death (*i.e.*, hospital, hospice, or home) were sourced through hospital and hospice records, doctors' letters, and primary care records. Regular palliative care medical services were defined as hospital- or community-appointed palliative care specialist physicians rather than a joint nephrology/palliative care service that included a nephrologist.

### Statistical Methods

Differences between groups were assessed using Pearson chi-squared or Fisher exact test for categorical variables and two-sample *t* test for continuous variables. A two-sided binomial test was performed to assess the proportion of patients who switched from conservative care to RRT from a hypothesized value of <15%. Cox proportional hazards models were used to estimate factors associated with 3-year mortality. The hazard ratios (HRs) and their 95% confidence intervals (95% CIs) for each factor are presented both unadjusted and stratified by center and adjusted for age, sex, home language, marital status, socioeconomic status, remoteness, health insurance, late referral to a nephrologist, serum albumin, and hemoglobin. Missing data for baseline biochemistry and deaths were addressed by using complete case analysis. The number of participants who were lost to follow-up and the reasons for loss to follow-up were reported by initial

treatment modality. All analyses were performed using STATA, version 13.1 (StataCorp., College Station, TX). We followed the Strengthening the reporting of observational studies in epidemiology (STROBE) statement (21).

## Results

### Participants

In total, 721 participants, mean age of 63 years old (SD=17.5), were enrolled in the study in 2009 (Figure 1). Of these, five (1%) died before starting planned treatment. At the time of enrolment, 102 (14%) planned for conservative care, 589 (82%) commenced dialysis, and 25 (3%) received a preemptive kidney transplant. For the 3-year follow-up study, 64 of 66 renal units agreed to participate; the two that declined did so because of inadequate staffing to complete the follow-up questionnaires. After 3 years of follow-up, 247 (34%) patients were deceased, 416 (58%) were alive, and 58 (8%) were lost to follow-up. All remaining patients (*n*=663) were included in the analyses for survival and end-of-life care outcomes (Figure 1).

Patients who elected for conservative care at baseline were, on average, older (median age of 80 versus 64 years old) and more likely to have lost a partner (40% versus 16%) than those who commenced RRT (Table 1). There was no significant difference between the groups for area-based socioeconomic status (*P*=0.74), geographic remoteness (*P*=0.17), home language (*P*=0.80), time known to a nephrologist (*P*=0.10), baseline serum albumin (*P*=0.68), or hemoglobin (*P*=0.99) (Table 1).

### Main Results

Of the 102 patients who planned for conservative care, eight (8%) switched to dialysis within the 3-year follow-up (95% CI, 3% to 13%; *P* value for difference from hypothesized value of 15% =0.04) (Table 2). The primary reason for commencement of dialysis was symptom management, primarily uremic symptoms and/or fluid overload. The outcomes of these eight patients are described in Table 3. Three of the eight patients were started on a time-limited

**Table 2. Dialysis access creation and initiation during the 3-year follow-up period among 102 patients who chose conservative care at study baseline**

| Characteristic                                     | <i>n</i> | Percent | 95% Confidence Interval, % |
|--|----------|---------|----------------------------|
| <b>First dialysis access created<sup>a</sup></b>   |          |         |                            |
| Fistula/vascular catheter                          | 7        | 7       | 2 to 12                    |
| Peritoneal dialysis catheter                       | 3        | 3       | 1 to 8                     |
| No access  | 85       | 83      | 76 to 90                   |
| Unknown  | 7        | 7       | 2 to 12                    |
| <b>Dialysis commenced</b>                          |          |         |                            |
| Yes  | 8        | 8       | 3 to 13                    |
| No   | 87       | 85      | 77 to 91                   |
| Unrecorded   | 7        | 7       | 2 to 12                    |
| <b>Primary reason for commencement of dialysis</b> |          |         |                            |
| Symptom management                                 | 4        | 50      | 22 to 78                   |
| Time-limited trial of dialysis                     | 3        | 38      | 14 to 69                   |
| Emergency/intensive care unit admission            | 1        | 12      | 2 to 47                    |

<sup>a</sup>Dialysis access was created for ten of 102 patients; eight of these patients commenced dialysis.

**Table 3. Survey details for the eight conservative care patients who commenced dialysis within the 3-year follow-up period**

| Treatment Summary   | Survival Status at 3 yr | Survival Duration After Initiation of Dialysis, d |
|---|-------------------------|---|
| 47-yr-old Woman: initially chose conservative care; started APD and then HD; continues on HD  | Alive                   | 1067  |
| 71-yr-old Man: initially chose conservative care; however, after several hospital admissions, family insisted on dialysis; changed to center HD   | Alive                   | 797   |
| 60-yr-old Woman: bipolar disorder; refused all treatment initially but did not want discussions about end-of-life care; had PD catheter inserted but later commenced center HD (time-limited trial) | Alive                   | 638   |
| 80-yr-old Woman: physician started APD; patient withdrew from therapy (time-limited trial)  | Deceased                | 3   |
| 75-yr-old Woman: started acute HD in ICU for symptom management   | Deceased                | 7   |
| 71-yr-old Man: commenced HD when he became unwell; cognitively impaired but adamant about wanting dialysis (time-limited trial)   | Deceased                | 118   |
| 85-yr-old Man: admitted from ICU; commenced center HD for symptom management; commenced dialysis  | Deceased                | 426   |
| 74-yr-old Woman: commenced HD for symptom management; MI on dialysis  | Deceased                | 536   |

APD, automated peritoneal dialysis; HD, hemodialysis; PD, peritoneal dialysis; ICU, intensive care unit; MI, myocardial infarction.

trial of dialysis that continued for 3 days, continued for 118 days, and in one patient, was ongoing at study end after 638 days (Table 2). Dialysis access was created for ten conservatively managed patients, and this was unused in two patients (Table 2). Of 102 patients who initially commenced conservative care, 23% (95% CI, 15% to 31%) were alive at 3 years, including those who switched to dialysis (Supplemental Table 1). Of those who did not commence dialysis ( $n=94$ ), 17 (18%) were still alive at 3 years. The survival status of ten conservatively managed patients was unable to be ascertained; however, there was no evidence from the ANZDATA Registry that they commenced dialysis.

Among the entire cohort of 721 patients, there were 247 deaths. Higher 3-year mortality was associated with older age (HR, 1.55; 95% CI, 1.36 to 1.77), serum albumin at

baseline  $<3.0$  versus  $3.7$ – $5.4$  g/dl (HR, 4.31; 95% CI, 2.72 to 6.81), and management with conservative care compared with RRT (HR, 2.18; 95% CI, 1.39 to 3.40). (Supplemental Figure 1, Supplemental Table 2). Of the 247 deaths, 77 were within 6 months (26 conservative and 51 RRT), 121 were within 1 year (41 conservative and 80 RRT), and 180 were within 2 years (59 conservative and 121 RRT); 46 of 721 patients had a documented advance directive, with conservatively managed patients more likely to have one than patients on RRT (21% versus 4%;  $P<0.001$ ) (Table 4). The main themes related to the presence or absence of an advance directive are tabulated in Supplemental Table 3. The surprise question was infrequently identified in the patients' medical records; however, it was more likely to be documented among conservative care patients than among patients

**Table 4. Use of advance care directives and the surprise question for prognostication at any time during the 3-year follow-up period**

| Characteristic   | Conservative Care, $n=102$ (14%) |         | RRT, $n=619$ (86%) |         | Difference, % | 95% CI for Difference, % | $P$ Value for Difference Between Groups <sup>a</sup> |
|--|----------------------------------|---------|--------------------|---------|---------------|--------------------------|--|
|  | $n$                              | Percent | $n$                | Percent |               |                          |  |
| <b>Advance care directive documented at any time</b>         |                                  |         |                    |         |               |                          | $<0.001$   |
| Yes (documented)   | 21                               | 21      | 26                 | 4       | 17            | 9 to 25                  |  |
| No (including not documented or unknown)                     | 81                               | 79      | 593                | 96      |               |                          |  |
| <b>Surprise question used in prognostication at any time</b> |                                  |         |                    |         |               |                          | $<0.001$   |
| Yes (documented)   | 9                                | 9       | 17                 | 3       | 6             | 2 to 13                  |  |

Percentages presented are column percentages. 95% CI, 95% confidence interval.

<sup>a</sup>Pearson chi-squared test for difference between groups.

**Table 5. Cause of death, place of death, and utilization of specialist palliative care services among 247 deceased patients**

| Characteristic   | Conservative Care |         | RRT |         | P Value for Difference Between Groups <sup>a</sup> |
|--|-------------------|---------|-----|---------|--|
|  | n                 | Percent | n   | Percent |  |
| <b>Cause of death</b>  |                   |         |     |         | <0.001   |
| Cardiovascular   | 24                | 34      | 57  | 33      |  |
| Infectious   | 1                 | 1       | 25  | 14      |  |
| Cancer   | 3                 | 4       | 11  | 6       |  |
| Renal failure  | 21                | 29      | 0   | 0       |  |
| Withdrawal of RRT  | 1                 | 1       | 45  | 26      |  |
| Other <sup>b</sup> or unrecorded   | 22                | 31      | 37  | 21      |  |
| <b>Place of death</b>  |                   |         |     |         | <0.001   |
| Hospital   | 30                | 42      | 115 | 66      |  |
| Hospice  | 10                | 14      | 6   | 3       |  |
| Nursing home   | 9                 | 13      | 6   | 3       |  |
| Main residence/home  | 9                 | 12      | 23  | 13      |  |
| Unknown  | 14                | 19      | 25  | 15      |  |
| <b>Received specialist palliative care</b>   |                   |         |     |         | <0.001   |
| Yes (documented)   | 41                | 57      | 45  | 26      |  |
| No   | 16                | 22      | 57  | 42      |  |
| Unknown  | 15                | 21      | 73  | 32      |  |
| <b>Among 86 patients receiving palliative care</b>   |                   |         |     |         |  |
| <b>Context of initial palliative care consultation</b>   |                   |         |     |         | <0.001   |
| <i>Inpatient acute care episode</i>  | 12                | 29      | 33  | 73      |  |
| <i>Outpatient referral</i>   | 29                | 71      | 11  | 25      |  |
| <i>Unrecorded</i>  | 0                 | 0       | 1   | 2       |  |
| <b>Palliative care service type</b>  |                   |         |     |         | 0.03   |
| <i>Joint nephrology/palliative care service</i>  | 7                 | 18      | 7   | 16      |  |
| <i>Existing regular palliative care service</i>  | 33                | 80      | 29  | 64      |  |
| <i>Other<sup>b</sup>/unknown</i>   | 1                 | 2       | 9   | 20      |  |
| <b>Palliative care personnel involved in delivering care (more than one can be selected)<sup>c</sup></b> |                   |         |     |         |  |
| <i>Palliative care physician</i>   | 36                | 88      | 27  | 60      | <0.001   |
| <i>Palliative care nurse (hospital)</i>  | 19                | 46      | 22  | 49      | 0.004  |
| <i>Palliative care nurse (community)</i>   | 17                | 41      | 12  | 27      | <0.001   |
| <i>GP</i>  | 7                 | 17      | 7   | 16      | 0.07   |
| <i>Other<sup>d</sup></i>   | 8                 | 20      | 5   | 11      | <0.01  |
| <i>Unknown</i>   | 6                 | 15      | 6   | 13      |  |
| <b>Duration of palliative care from first consultation to death</b>                                      |                   |         |     |         | 0.001  |
| <i>&lt;1 wk</i>  | 6                 | 15      | 19  | 42      |  |
| <i>1 wk to 1 mo</i>  | 11                | 27      | 18  | 40      |  |
| <i>1–3 mo</i>  | 10                | 24      | 4   | 9       |  |
| <i>3–6 mo</i>  | 8                 | 19      | 3   | 7       |  |
| <i>&gt;6 mo</i>  | 6                 | 15      | 1   | 2       |  |

Percentages presented are column percentages. GP, general practitioner (primary care physician).

<sup>a</sup>Fisher exact test or Pearson chi-squared test for difference between groups.

<sup>b</sup>Other causes of death include respiratory; other services include nephrology team and medical/nursing team in regional hospital.

<sup>c</sup>Percentages add to >100, because multiple categories can be selected.

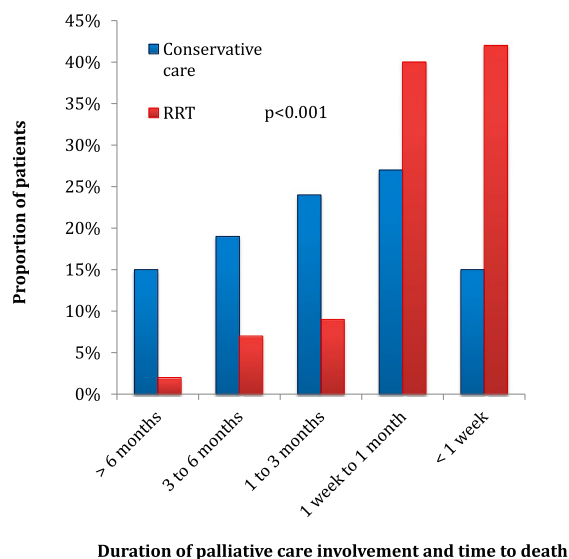
<sup>d</sup>Other personnel includes renal supportive care clinical nurse consultant, general medical/nursing staff from medical ward in regional hospital, and palliative care social worker.

on RRT (difference of 6%; 95% CI for difference, 2% to 13%) (Table 4).

Of 247 deaths, patients on RRT were more likely to die in the hospital and less likely to die in hospice than patients managed conservatively (Table 5); 86 of 247 patients received specialist palliative care. A greater proportion of conservative care patients received specialist palliative care than patients on RRT (57% versus 26%;  $P<0.001$ ) (Table 5). Patients managed with RRT were more likely

to receive palliative care only during the last week of life (42% versus 15%;  $P<0.001$ ) than patients managed conservatively (Figure 2, Table 5). Of the five patients who switched from conservative care to RRT and died within the study period, two were referred for palliative care. Of those with advance directives ( $n=21$ ), nine (43%) were treated with inpatient acute palliative care, and 12 (57%) were treated with outpatient care. Two (10%) patients were managed within a joint nephrology palliative care





**Figure 2. | Time between palliative care utilization and death by initial treatment modality for 86 of 247 participants.**

service, and 17 (81%) were managed with existing regular palliative care services. Of those who died in hospice ( $n=16$ ), equal numbers (eight each) were treated with inpatient acute palliative care for those admitted to the hospital and outpatient care and those at home. Three (19%) patients were managed in a joint nephrology palliative care service, and 12 (75%) were managed in existing regular palliative care. The major themes regarding advance directives and the location of patient deaths are outlined in Supplemental Tables 3 and 4.

## Discussion

Our national follow-up study suggests that <10% of patients who initially choose conservative care switch to dialysis within 3 years. One in five patients with ESRD who commenced conservative care (mean age of 80 years old) was still alive at 3 years, and this number may be larger, because there were no death records identified for the ten participants whose survival status was unknown. Among the whole cohort, factors associated with all-cause mortality included older age, low serum albumin at study baseline, and management with conservative care compared with RRT. Of patients who died during the 3-year follow-up period, those managed with RRT were less likely to receive specialist palliative care and more likely to die in the hospital than at home or in hospice. Patients managed with RRT were more likely to receive palliative care only within the last week of life than patients managed conservatively.

Referral to hospice and deaths in hospice are low for patients with ESRD globally and very low for Australian patients with ESRD compared with the United States patients with ESRD (10). However, the rate identified in our study is not dissimilar to population-based reports of hospice deaths for Australian patients with cancer. For example, in 2003 in New South Wales (Australia's most populous state), only 7.5% of cancer deaths were in a dedicated palliative care

institution (*i.e.*, hospice) compared with 55.5% of deaths in public hospitals, 10% of deaths in private hospitals, 10% of deaths in nursing homes, and 17% of deaths at home (22). This is likely a result of a low number of hospice facilities overall, the creation of palliative care beds within public hospitals, and restrictions of hospice services to particular local area health districts.

## Limitations

Despite our best efforts to follow all patients in the PINOT Study cohort, 58 (8%) were lost to follow-up, and their survival status could not be ascertained. Forty-five (87%) of these patients came from the two renal units that were unable to participate in the follow-up study and were initially managed with dialysis; ten of 102 conservatively managed participants were lost to follow-up. A review of ANZDATA Registry records did not find evidence that these patients commenced dialysis within the follow-up period, and they were, therefore, most likely managed in the community. In addition, comorbid conditions were not systematically recorded for the PINOT Study cohort, and therefore, we were unable to include these data in the analyses in a meaningful way.

Furthermore, our study relied on the presence of documented medical records, which may not be complete, and therefore, any estimates of palliative care service provision or presence of documented advance directives may have been underestimated. In the majority of Australian renal units, an advance directive is usually highlighted in an electronic record or color coded in patients' medical notes to facilitate rapid identification, and hence, the chance of missing a documented record was likely very low.

## Interpretation

Few patients switched to dialysis after a confirmed plan for conservative care, consistent with other studies (7–9). The low rate of crossover from conservative management to RRT may indicate more anticipatory discussions among those with structured and early access to palliative care. Our results suggest that structured access to palliative care may avoid emergent dialysis in the emergency department or intensive care unit for those who have decided to not pursue RRT but end up starting in a catastrophic situation. Of the eight patients in our study who did switch to dialysis, five died within a mean of 218 days (range =3–536 days), and three were still alive after 3 years of follow-up. These numbers are too small for any meaningful interpretation, and our data did not include measures of quality-adjusted survival that might inform assessment of the value of any survival benefit. We are unable to know whether the survival time would have been different for these three patients had they remained on conservative care. Until we better understand what makes some patients satisfactorily manage dialysis, nephrologists are limited in how they can advise their patients.

Patients on RRT are significantly more likely to die in the hospital and less likely to die in hospice. This finding is echoed in two single-center studies in the United Kingdom (2,23). The proportion of patients on dialysis who died in hospital in our study (66%) is higher than the Australian average for hospital deaths of 54% (24), and may reflect

deaths because of withdrawal of dialysis. Although systematic reviews commonly report that the general public has a preference for dying at home (25,26), it is possible that dialysis withdrawal may be preferred on a renal ward, where the patients and their family members are well known to the renal staff. Additional research in this area is needed, because in many places, Australian nephrologists cannot access palliative care for people on dialysis until treatment is withdrawn. Therefore, although our finding is not surprising, it reflects the lack of access to palliative care services from a health system that regards RRT as ongoing treatment and not as representing a palliative care context. It is important that people with ESRD are recognized as needing specialist palliative care services, regardless of whether they are on dialysis or managed conservatively.

The low rate and late involvement of palliative care and the low rate of advance directives in the RRT group may signal that nephrologists and/or family members are not broaching the subject of end-of-life care among a population with high mortality rates. Similarly, the low prevalence of documentation of the surprise question, validated in patients on dialysis (17,18), may mean the question is not used or if used, not documented. This might also suggest that prognosis is communicated to patients infrequently. A recent survey found that 97% of Australian and New Zealand nephrology fellows over the last 10 years reported conservative care being a very important skill, but only 43% reported being well trained in it (27). This represents an area for clinical improvement, and education programs for nephrology trainees have begun to address this need. Quality metrics for palliative care suggest that palliative care involvement within days of death is considered a marker of poor care in other specialties (28). Additional research is needed to determine the outcomes for those patients who have advanced kidney disease and receive palliative care.

Specialist palliative care services were used more frequently in end-of-life care among people managed conservatively; however, this was still only for 57%. Similarly, the prevalence of advance directives was relatively low among those with planned conservative care. The prevalence of advance directives among adults with ESRD is not well understood. One small study of 19 patients on dialysis in the United States reported that 32% had advance directives (29), and another single-center study of 182 patients on dialysis reported that 41% had stated their advance directives either verbally or in writing (30).

### Generalizability

There are very little national data available on conservatively managed patients, because long-term follow-up often occurs in the community and is not routinely recorded in a registry. Our study provides 3-year follow-up data for a representative cohort of national incident patients with ESRD including all age groups, ethnicities, socioeconomic status, and those from metropolitan, rural, and remote geographic locations. Our outcomes are likely to be similar to those of other countries that offer dialysis, transplantation, and comprehensive conservative care. The

end-of-life care results, however, may differ from those of other countries with alternate financing and structures of palliative care services and/or streamlined access to hospice for people with ESRD. Although the Australian population with ESRD is culturally and linguistically diverse, results may differ among populations with different cultural or religious beliefs about death and dying.

Our study suggests that survival after 3 years of conservative care is common, with relatively few patients switching to dialysis. Specialist palliative care services are used more frequently and at an earlier time point for conservatively managed patients, a practice that is associated with better symptom management and quality of life.

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### Disclosures

None.

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