

Title: Renal unit characteristics and patient education practices that predict a high prevalence of home-based dialysis in Australia

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Key words

Pre-end stage education, home dialysis

Short Title: Factors that predict high home dialysis rates

Word count

Abstract: 232

Document including abstract 3888

Abstract:

Aim: The proportion of patients utilising home dialysis in Australia varies from 6-62% between renal units. The aim of this study was to determine if the variance is attributed to any underlying renal unit factors including pre-end stage education practices.

Methods: An online survey was distributed to all Australian units that offered home dialysis. Logistic regression was performed to estimate the effects of renal unit characteristics on the binary outcome of <30% versus ≥30% of patients utilising home dialysis, and for ≥10% of patients utilising home haemodialysis dialysis specifically. Prevalent home dialysis rates were sourced from the Australia and New Zealand Dialysis and Transplant Association registry.

Results: 33 of 43 units (77%) completed the survey. Factors shown to predict ≥30% of patients utilising home dialysis were; a metropolitan based renal unit compared to a rural or remote unit (OR 1.08, 95%CI 1.01-1.15), a New South Wales unit compared to other states (OR 1.13, 95%CI 1.04-1.22), and a unit that offered multiple group education sessions per year (OR 1.01, 95%CI 1.01-1.02). A unit that offered >1 hour of pre-end stage education per patient, compared to ≤1 hour predicted more than 10% of patients on HHD (OR 2.84, 95%CI 1.17-6.90).

Conclusion: Our data suggest certain pre-end stage education practices are significantly associated with home dialysis rates above the national average. Further research on the impact of home dialysis leadership in NSW is warranted.

Introduction:

Across the world home dialysis rates vary widely, with the uptake of home haemodialysis (HHD) ranging from 0-58.4 per million population.¹ Peritoneal dialysis (PD) rates also fluctuate and many variations are attributable to national policies. Australia has relatively high rates of home dialysis but this has declined over time. In 1992, approximately 50% of Australians on dialysis were at home but from 1994 there was a sudden decline in home dialysis with a corresponding surge in centre based dialysis, particularly at the new 'satellite' renal units, in both public and private sectors.² This trend continued into the 21st century although it has varied considerably within different States. In 2012, 11,446 patients were on dialysis with 29% on home dialysis.³

National policy in Australia favours the utilisation of home dialysis because it is acknowledged to have better health outcomes, be cost effective, and be the preference of many patients compared to centre based dialysis.^{4,5,6,7} Whilst state policies do advocate for increased home dialysis with a 'home dialysis first' policy, many renal units continue to report a low rate.

Informed patient choice has been postulated to be a contributing factor to the variable uptake of home dialysis. The recent Kidney Health Australia survey of dialysis consumer perspectives revealed that 49% of dialysis patients perceived they did not have a choice in their modality option.⁶ Pre-end stage education should be a critical component of the patient journey leading to the selection of home dialysis or a centre-based dialysis modality.

Anecdotally, the provision of education services varies widely across Australia, and is predominantly the domain of specialist nurses. Pre-end stage nurse educators report large databases of patients, late referrals, inadequate resources, cultural challenges, non-supportive renal unit policy and insufficient time as factors that limit the ability to provide comprehensive education.

This survey aimed to establish data about the delivery of pre-end stage education, focusing on treatment modality choices offered and the relationship of education to the uptake of home dialysis. In particular, as the national rate of home dialysis in Australia was 28% we were interested in the factors associated with a home based dialysis program that performed above the national average.

Method:

A 26-question online survey was developed by DF based primarily on clinical experience and discussions at national meetings (indicative of a lack of objective data about this topic). The survey was piloted by five experienced renal nurse managers. Topics included patient demographics, education workforce, content and delivery of education programmes, anticipated barriers to education and the resources that may be required to improve education. All Australian renal units with a HHD and/or a PD training program (n = 43) were invited to participate. In November 2011 the survey link was distributed to an established email network of pre-end stage educators operating in collaboration within the home training renal units. The closing date for responses was January 31 2012. One staff member central to the education service was nominated to complete the web-based survey on behalf of each renal unit. Ethics approval was not required for this study.

Home dialysis prevalence by renal unit was sourced from the Australia and New Zealand Dialysis and Transplant Association registry (ANZDATA) 2011.³⁸ Renal unit characteristics included size of total dialysis population (≤ 100 , 101-300, 301-500, >500); number of CKD stage 4-5 patients (≤ 100 , 101-300, 301-500, >500 , not stated); the Accessibility/Remoteness Index of Australia (ARIA) indicating geographical remoteness (continuous variable with a scale of 1= major Australian city to 5= very remote area); formalised 'home first' policy (always or usually, sometimes, rarely or never, not stated or unsure); and referral of centre-based patients for home training (regular, occasional, never, unsure/not stated). Workforce characteristics included pre-end stage nurse hours per week (none, 1-10 hours, 11-20 hours, 21-30 hours, 31-40 hours); and educator position appointed at nurse practitioner level (yes/no). Education program characteristics included number of pre-end stage group education sessions per year (0, 2-3, 4-6, >6 , not stated); average time spent per patient on pre-end stage education (<30 minutes, 30-60 minutes, 1-2 hours, 2-3 hours, >3 hours, not stated); and use of a formal dialysis modality matching tool (yes/no).

Logistic regression was performed to estimate the effects of the above renal unit characteristics on the binary outcome of $<30\%$ versus $\geq 30\%$ of their patients utilising home dialysis, and on the outcome of $\geq 10\%$ of patients using home haemodialysis specifically. These outcomes were selected *a priori* and represent a home dialysis rate and home haemodialysis rate higher than the Australian national average, (i.e. 29% and 9% respectively). Odds ratio estimates with 95% confidence intervals were reported for characteristics that showed a statistically significant association ($p < 0.05$). Analyses were performed using SAS version 9.2 statistical software (www.sas.com).

Results

Responses were received from 33 of the 43 of home training renal units (77%), representing all States and Territories, with both metropolitan and rural renal units represented equally (table 1). Approximately 8000 patients, (76%) of Australian dialysis patients were managed by the participating renal units.

Renal unit Characteristics (table 1)

The responding Australian dialysis renal units varied in size from less than 100 (12%) to over 500 patients (12%). In addition, 76% of units managed over 100 stage 3 CKD patients, and 88% managed over 100 stage 4-5 patients. The majority of the renal units (82%) were ranked on the ARIA remoteness index as highly accessible, reflecting the centralisation of education and home training services, not the residency of patients in the cohort. The range of patients in each renal unit dialysing at home varied from 6% to 62%, with a mean of 28%.

Home first policy

Home first was the recognised policy for 77% of renal units. Renal units reporting 'always having a home first treatment option policy' achieved a mean of 34% of patients dialysing at home, decreasing to 26% for renal units who 'usually had a home first policy'. The seven renal units that sometimes, rarely or never had a home first policy averaged 21%.

Workforce Characteristics

Education is managed by a wide range of staff positions ranging from no specific educator (9%), pre-end stage educator (27%), shared role of pre-end stage and early CKD educator (33%) and shared education role with another role, e.g. vascular access coordinator (30%). In 30% of renal units these roles were also designated nurse practitioner positions. For every one fulltime equivalent (FTE) educator employed there were 456 pre-end stage patients on the renal unit database with a ratio of 12 patients (range 2-31) for every hour per week that a pre-end stage nurse was employed.

Population Characteristics

English was the first language for the majority of patients from 26 units but seven renal units (21%) had less than 50% of an English speaking population. Nineteen renal units (73%) reported having non-English speaking Europeans, 20 (77%) had non-English speaking Asians and 21 renal units (81%) managed Aboriginal and Torres Strait Islander peoples. The languages spoken were varied and included Cantonese, Mandarin, Italian, Vietnamese, Greek, Arabic and Hindi.

Timing of pre-end stage education

Education referrals were predominantly in stage 4-5 CKD, and 97% of renal units reported a formal referral process. Only one third of renal units estimated that 91-100% of patients received comprehensive education, prior to starting dialysis (including late referrals). The rate of delivery of comprehensive education was not significantly associated with the staff to patient ratios. In renal units reporting the highest pre-end stage comprehensive education rates, 22% of patients were on PD compared to only 11% in the renal units where less than half of the patients received comprehensive education. Two thirds of renal units reported that they

continued to assess and educate those patients utilising satellite dialysis about home dialysis. The renal units with formal re-evaluation and referral processes for further education had on average, one and a half times the rate of HHD compared to those that did not (11% versus 7%).

Delivery of Education

Four renal units from different States and Territories reported spending less than one hour per patient providing education and only averaged 20% of patients on home dialysis. Thirteen renal units (39%) provided education for 1-2 hours. 13 renal units (39%) indicated education was more than two hours which was associated with a prevalence of home dialysis averaging 36%. Increased use of group education sessions was associated with more hours of education. The preference for group education sessions was higher where high patient to staff ratios existed. Only half of the renal units reported that more than 75% of their patients attended education with a family member or close person.

Analyses of factors predicting $\geq 30\%$ uptake of patients utilising home dialysis

As shown in table 2, only three explanatory variables (metropolitan renal unit, NSW renal units, and frequent group education sessions) were statistically associated with an increased likelihood of $\geq 30\%$ of patients in the renal unit utilising home dialysis.

Renal units offering more group sessions per year had significantly higher levels of home dialysis, $p=0.008$ (OR 1.013, CI 1.01-1.02). Large renal units showed a tendency to have a higher home dialysis ratio although this was not statistically significant ($p= 0.086$). Being in the State of NSW was associated with having above 30% of home dialysis patients $p= 0.011$, (OR

1.130, CI 1.04-1.22). The impact of remoteness was found to significantly impact on the ratio of patients at home $p=0.043$ (OR 0.928, CI 0.86-1.00).

Factors preventing optimum education

Renal units were asked to choose any factors that they felt prevented optimum education delivery (figure 1). The system factors of untimely referrals affected 82% of renal units and workforce factors affected 27%, predominantly in rural renal units. Specific patient factors including reluctance to attend education and difficulty in doing so, also affected 82% and 78% of renal units respectively. Lack of interpreter services was more prevalent at small renal units. Whilst it was not possible to calculate the individual effect of these factors, the renal units reporting the highest number of factors preventing optimal education also reported lower percentages of patients attending education and an average of only 6% of patients' utilising HHD. Those reporting the least number of issues averaged 10% HHD.

Methods of Education

A varied combination of education methods were reported, incorporating many members of the health care team. Involvement of the home training team (75%) was more likely to be from a PD than HHD staff member. The renal units who did not use a member of the HHD team for education averaged only a 3% rate of HHD, compared to an average of 10% on HHD overall. The education process involved dietitians (79%) and social workers (69%). Although HHD was presented to 97% of patients, variations in HHD regimens, for example enhanced hours and nocturnal dialysis were only discussed in 65% and 80% of renal units respectively (figure 2).

Use of Formal assessment tools or decision aids

Formal assessment tools or decision aids were not reported as standard practice for pre-end stage education. Only 20% of renal units reported consistent use of any assessment tool, but 70% of renal units would support possible future use of decision making or assessment tools. Two thirds of renal units identified that an Australian home dialysis website to support education would also be of benefit.

Discussion:

The findings of this online survey of Australian renal units suggest that a number of education and non-education factors are associated with an increased utilisation of home dialysis. The provision of multiple group education sessions throughout the year significantly increases the rate of home dialysis. Non-education factors that were associated with home dialysis rates above 30% were metropolitan-based home training units, and being in the State of NSW. Wide variance both between States, and within States was found in many aspects of pre-end stage education, including the ratio of staff employed to educate patients, the education delivery methods and the treatment modalities discussed during education. There were many factors such as a PD first policy or involvement of the home dialysis team in education that were not significantly associated with high rates of home dialysis across all units, however within individual units these factors appeared to produce favourable outcomes. Overall the results suggest that the predictors of home dialysis utilisation are multi-factorial, and therefore a comprehensive approach covering the spectrum of home dialysis service delivery is recommended.

Home dialysis is more cost effective than centre based dialysis and therefore current healthcare systems operating within economic and resource restraints need to prioritise the modifiable factors that can maximise home dialysis rates.⁹ The high ratio of patients per pre-end stage educators indicates that patient education has a low priority in hospital budgets. Funding in Australia does not specifically support the delivery of education practice whereas in the USA pre-end stage education is considered mandatory and attracts a Medicare rebate item for both doctors and nurses.¹⁰

The State of NSW has been committed to home dialysis and has achieved benchmark rates for multiple decades.³ Whilst a current 'home dialysis first' policy was not significantly associated with a home dialysis rate above 30%, those renal units with the most commitment to this policy usually were amongst the ones with the higher home dialysis rates. Tradition and leadership by both individual educators and nephrologists is recognised for promoting home dialysis within their units. This leadership factor may be a confounder that contributes to some programmes that appear poorly resourced having high rates of home dialysis and vice versa.

In this study late referrals were the most frequently reported limitation for education indicating that there are opportunities for many units to modify referral practices. Use of timely comprehensive education before dialysis commencement showed a tendency towards enhancing PD uptake, which has previously been demonstrated.¹¹ The average timing of education delivery was during stage 4-5, with a reported 82% of patients receiving education prior to treatment. PINOT similarly found that the average eGFR of patients receiving education was 13.3mmol/l and that 84% of patients received information prior to treatment, 72% of incident patients were documented to have received PD, and 52% HHD education.⁷

The CARI pre-end stage education guideline (Caring for Australians with Renal Impairment) states that every patient with ESKD should receive comprehensive education about their treatment options to inform decision making.¹² Comprehensive education fulfils the criteria of informed consent and has the potential to enhance home dialysis rates.^{11,13} The results of this survey of Australian renal units demonstrate that comprehensive and unhurried education is not occurring in many regions with some renal units having no dedicated education staff, some delivering less than one hour of education, and many not providing information about all modalities of dialysis that are available. This was more prevalent in smaller units in rural and regional areas which may contribute to their lower home dialysis rates.

There was also a low prevalence of renal units utilising formal decision making processes, despite research suggesting that supported shared decision making is an important part of patient centred care.^{14,15} This identified need for a relevant tool for the Australian market has led to the recently released Australian 'My Kidneys, My Choice Decision Aid' which aims to fill this gap.¹⁶

Factors that enhance education and home dialysis rates

This survey suggests that offering regular group education has a positive effect on home dialysis rates. Patient narratives are a regular feature of group education; a factor shown previously to influence choices.¹² Group sessions are often up to three hours and utilise a number of speakers which also increase the related positive factor of time spent on education, a factor found to be associated with increased HHD uptake. Patients receiving group education also receive follow-up at individual appointments. Patients are known to value home

treatment¹⁷ and this study suggests that acceptance for performing complex treatments at home benefits from time. Group education also enhances the opportunity to establish rapport with dietitians and social workers which should be beneficial for future care.

This study found that some units do not revisit dialysis option education. The Australian consumer perspectives survey found whilst 90% of dialysis patients were happy with their current modality up to 39% were willing to consider home dialysis if they were offered appropriate support.⁶ To ensure that late referrals and those whose circumstances have changed are encouraged to transfer to home dialysis a formal system for re-evaluation is recommended.

Despite all renal units placing a high value on the presence of significant others to support the patient with ESKD, many patients attended education alone. The PINOT study found that only 20% of patients started on home dialysis, but 80% of these had a care-giver present at education, compared to only 56% of those who started at a centre.⁷ Care-givers and future patients in Italy reported they were concerned about the potential burden of home dialysis.¹⁷ Care-givers who attend education potentially have the opportunity to learn about support mechanisms for their role, which may increase the likelihood of home dialysis being initiated.

Factors to increase education effectiveness

Lack of interpreters and translated materials for people with culturally and linguistically diverse backgrounds indicates a barrier for home dialysis education and training. This was frequently reported in rural or small units. This may contribute to the lower rates of home

dialysis in people from culturally and linguistically diverse backgrounds.³ Addressing the needs for culturally specific information is one component, although the strategies to fully attend to cultural needs are anticipated to extend beyond education.

Smaller rural units appear disadvantaged in terms of pre-end stage education services and delivery, and therefore funding and up-skilling of rural staff is critical. Integration of modern technologies to overcome the tyranny of distance could be used to enhance rural home dialysis and education programmes.

Limitations

The cross-sectional survey method means the data is observational and establishes associations rather than causality. Other factors that may be associated with high rates of home dialysis e.g. technique survival on home dialysis, costs to patients and access to home training were not investigated. Australia only has 43 major renal units and therefore outlier responses created wide deviations in results, particularly within States.

Confounding factors not accounted for were the variance and quality of the educational materials utilised, the focus of the educational materials and the involvement or influence of individual nephrologists or specialist educators. Furthermore, ANZDATA classifies home patients by the training renal unit rather than the parent renal unit. This affected the results for NSW, where three country renal units refer their home patients to metropolitan renal units.

Future recommendations

It would be worthwhile to re-survey renal units at either end of the home dialysis rate spectrum, to determine the positive characteristics of, or beliefs about dialysis modalities held by the nurse educators or nephrologists. It would also be beneficial to determine and compare the patient's viewpoint regarding the factors that contributed to whether they and their caregivers attended pre-end stage education. As recommended by PINOT, quantitative or qualitative evaluation of education and whether utilising adult learning principles, patient centred approaches or focusing on life-style considerations improves learning would also shed more light on what is successful about education delivered.⁷

Australia does not yet have a national KPI or database to evaluate the delivery of pre-end stage education. Addition of an educational variable to the national ANZDATA renal data collection could be a future strategy to monitor and increase education rates and increase the accountability of renal units regarding the delivery of education.

Conclusion:

Pre-end stage education is a uniquely renal unit driven process, with no observed consistency between renal units. Metropolitan renal units with strong education programmes, home first policies, good staffing ratios, a wide array of educational options, group education and who use the multidisciplinary team are more likely to succeed in timely comprehensive education and to achieve the highest rates of home dialysis. Renal units without these qualities on average have lower home dialysis rates but there were obvious exceptions to both groups in the data. NSW home dialysis rates indicate that there could be a strong influence by State policy or leadership of the pre-end stage educator and nephrologists.

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