

Original Article

Australian consumer perspectives on dialysis: First national census

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SUMMARY AT A GLANCE

The percentage of home dialysis in Australia has steadily decreased over the past 40 years. Consumer factors related to the delivery of pre-dialysis education do not support all options of dialysis for all individuals. State variances indicate that local policy and health professional teams significantly influence the operation of dialysis programs.

ABSTRACT:

Aim: The percentage of people in Australia who undertake home dialysis has steadily decreased over the past 40 years and varies within Australia. Consumer factors related to this decline have not previously been determined.

Methods: A 78-question survey was developed and piloted in 2008 and 2009. Survey forms were distributed to all adult routine dialysis patients in all Australian states and territories (except Northern Territory) between 2009 and 2010. Of 9223 distributed surveys, 3250 were completed and returned.

Results: 49% of respondents indicated they had no choice in the type of dialysis and 48% had no choice in dialysis location. Respondents were twice as likely to receive information about haemodialysis (85%) than APD (39%) or CAPD (41%). The provision of education regarding home modalities differed significantly between states, and decreased with increasing patient age. Additional nursing support and reimbursement of expenses increased the proportion of those willing to commence dialysis at home, from 13% to 34%. State differences in the willingness to consider home dialysis, the degree of choice in dialysis location, the desire to change current dialysis type and/or location, and the provision of information about dialysis were identified.

Conclusion: The delivery of pre-dialysis education is variable, and does not support all options of dialysis for all individuals. State variances indicate that local policy and health professional teams significantly influence the operation of dialysis programs.

Chronic kidney disease (CKD) is a significant and growing public health problem responsible for a substantial burden of illness and premature mortality. Based on data from the Australian Diabetes, Obesity and Lifestyle Study (AusDiab) study, it is estimated that approximately 6 million individuals have one or more of the major CKD risk factors and that about 1.7 million Australian adults have at least one clinical sign of existing CKD, such as protein in the urine or reduced kidney function.^{1,2}

At the end of 2010, 10 603 Australians were undergoing dialysis for the management of end-stage kidney disease.³ CKD progresses at a rate that currently requires approximately 2400 individuals each year to commence dialysis or undergo kidney transplantation.⁴ There are two forms of dialysis, peritoneal dialysis (PD) or haemodialysis (HD). PD is

a home therapy. HD can be performed at home (HHD), at a satellite dialysis unit, or at a hospital renal unit.

Increasing evidence suggests that undertaking dialysis at home (either PD or HD) confers substantial clinical and social benefits for patients.^{5–7} The advantages of home dialysis include ease of increasing the duration and/or frequency of treatment, enhanced opportunities for rehabilitation and return to employment, improved satisfaction and quality of life, and an ability for those residing in remote locations to remain in their own homes. Observational data derived from the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) also supports a survival advantage for home HD.⁸ In an Australian survey of nephrologists, the majority responded that existing evidence justifies recommending HHD, and there is no disadvantage to PD.

In addition, home dialysis has cost benefits. A recent economic analysis demonstrated that the cumulative cost, in 2009 dollars, of treating all current and new cases of ESKD from 2009 to 2020 is estimated to be up to \$12.3 billion.⁹ Increasing the use of home dialysis over this period would lead to estimated net savings of between \$378 and \$430 million.⁹

Despite the cost, and the clinical and social benefits of home dialysis, the percentage of home dialysis patients in Australia has fallen from about half of all patients in the 1970s (even before maintenance PD was available), to less than one-third now.¹⁰ The declining rate of home dialysis is variable within Australian. Of the New South Wales (NSW) dialysis population, 39% use home dialysis, compared with 21% in Victoria (Vic) and Western Australia (WA) and 18% in South Australia (SA).⁴

Kidney Health Australia canvassed the opinions of all Australian nephrologists,¹¹ dialysis nurses¹² and dialysis consumers about possible explanations for the progressive decline and geographical patchiness in the use of home dialysis in Australia, to enable health planners to overcome identifiable impediments to the expansion of home dialysis throughout the country. The present publication outlines the responses to this survey given by the dialysis consumers.

METHODS

Participants

The intended survey population was all adult patients receiving routine dialysis services in Australia. Ethics approval for this study was sought from adult renal units via the appropriate Hospital Research Ethics Committees. Private renal units in SA and WA were included as they were covered by their relevant state ethics applications. Only two private units from the other states/territories were included. Ethics applications were not processed in a timely manner for 25 renal Units/satellite centres in NSW, 9 in Queensland (QLD), and 13 in Vic. These units were excluded. Renal units in Northern Territory were not invited to participate in the survey due to the uniqueness of the predominantly Indigenous Australian dialysis population in this jurisdiction.

Questionnaire

The Kidney Health Australia Home Dialysis Advisory Group (HDAC) designed a survey with 78 questions that respondents could answer anonymously (see Appendix S1). Multiple-choice questions were included that related to demographics of the individual, current modality of dialysis, education process and reasons for dialysis choice, intent or willingness to change dialysis modality and barriers to home dialysis. The survey was provided in English.

Data analysis

Survey forms were scanned using a HP Scanjet N9120. Images were processed using Kofax Capture Software package. Kidney Health

Australia staff compiled the results and analysed them using PASW Statistics 18 (Chicago, IL, USA). *P*-values < 0.05 were considered statistically significant.

RESULTS

A total of 9223 surveys were distributed and 3250 were returned (response rate of 35%). The response rate varied from 22% in WA to 63% in Tasmania (Tas).

Demographics

The demographics of the survey respondents and the prevalent dialysis population at a similar time-point are compared in Table 1. Respondents were typically Australian-born men, aged over 60 years. Over 80% had completed secondary school education, and most were currently either retired or not actively looking for work. HD was used by 81%, 50% had been on dialysis for over 3 years, 32% for 1–3 years, and 18% for less than one year. Ten per cent of survey respondents were previous kidney transplant recipients.

As shown in Table 1, the age group of the respondents demonstrated a similar pattern to the known prevalence of dialysis treatment by age group. The age varied significantly by state/territory, with the proportion over 70 years highest in SA (54% of all SA respondents) and lowest in QLD (33%) and Tas (29%).

The survey sample was underrepresented by satellite dialysis (25% of respondents but 47% of dialysis patients) and overrepresented by hospital dialysis (42% of respondents and 23% of patients). There was a statistically significant association between age and dialysis type/location. Use of HD at a public hospital was lowest in respondents aged between 31 and 60 years (30–36% of this age group) and highest in those aged over 70 years (49–53%). Conversely, the uptake of home HD was highest in those aged 31–60 years (23–26%), and lowest in respondents aged over 70 years (1–5%).

Dialysis choice

Forty-nine per cent of respondents reported that they were not provided with a choice of dialysis type and 41% of this group reported that they were not informed of why they did not have an option. Similarly, 48% of respondents were not given a choice in their location for dialysis, and 53% of this group were unaware why they did not have a preference.

Individuals using PD were more likely to report they had a choice in their type of dialysis (78%) compared with those on HD (46%). Individuals dialysing at home were also more likely to report having an option in their dialysis location (68%) compared with those dialysing in a public hospital (40%). The state of residence significantly impacted on choice of dialysis location. The proportion of respondents

Table 1 Characteristics of survey respondents and comparison with ANZDATA dialysis data

	Survey respondents, n (%)	ANZDATA (as at 31 December 2009)
Total	3250	10 341
State of residence		
ACT	77 (2%)	239 (2%)
NSW	1173 (36%)	3 374 (33%)
NT	–	418 (4%)
Qld	479 (15%)	1 944 (19%)
SA	209 (6%)	670 (6%)
Tas	128 (4%)	194 (2%)
Vic	923 (28%)	2 513 (24%)
WA	261 (8%)	989 (10%)
Demographics		
Male	1970 (61%)	6 197 (60%)
30 years or less (ANZDATA: 34 years or less)	48 (1%)	382 (4%)
31–40 years (ANZDATA: 35–44 years)	143 (4%)	854 (8%)
41–50 years (ANZDATA: 45–54 years)	301 (9%)	1 638 (16%)
51–60 years (ANZDATA: 55–64 years)	591 (18%)	2 233 (22%)
61–70 years (ANZDATA: 65–74 years)	856 (27%)	2 538 (25%)
71–80 years (ANZDATA: 75–84 years)	893 (28%)	2 155 (21%)
Over 80 years (ANZDATA: 85 years or more)	388 (12%)	360 (3%)
Married	1960 (61%)	–
Aboriginal or Torres Strait Islander origin	111 (3%)	1 174 (11%)
Born in Australia	1999 (66%)	–
Speak only English at home	2356 (77%)	–
Education and employment		
Completed secondary school	2573 (81%)	–
Employed (working more than 15 h per week)	299 (9%)	–
Retired or not looking for work	2428 (77%)	–
Current treatment type/location†		
Hospital HD	1281 (42%)	2 351 (23%)
Hospital PD	7 (0.3%)	13 (0.1%)
Home HD	411 (13%)	963 (9%)
Home PD	584 (18%)	2 157 (21%)
Satellite HD	753 (25%)	4 850 (47%)

†n = 3068 (182 respondents missing data). ACT, Australian Capital Territory; ANZDATA, the Australian and New Zealand Dialysis and Transplant Registry; HD, haemodialysis; NSW, New South Wales; NT, Northern Territory; PD, peritoneal dialysis; Qld, Queensland; SA, South Australia; Tas, Tasmania; Vic, Victoria; WA, Western Australia.

who reported a choice in dialysis location was lowest in NSW (46%) and highest in SA (62%) and Vic (61%).

The most frequently reported reasons for choosing PD included less interference with lifestyle (55%), preference to be independent (50%), wanting to dialyse at night (42%), and less requirement for travel for dialysis (41%). The most frequently reported reasons for choosing HD were dislike of PD (32%), wanting someone else to perform dialysis for them (31%), not feeling comfortable in doing dialysis themselves (29%), and believing the best level of care is available at the hospital (28%). Of the respondents who preferred their home as their location for dialysis, 34% reported this was because they wanted to dialyse at night. For those respondents who chose a satellite centre or a public hospital as their location for dialysis, proximity to home was the most commonly reported reason behind this decision (71% and 67% for satellite dialysis and public hospital dialysis respectively).

Changing dialysis modality

Only 7% of respondents reported they currently wished to change their dialysis type, and 9% indicated they wanted to change their location for undertaking dialysis. As shown in Figure 1, of the 201 respondents who indicated they wished to change their dialysis location, they most frequently wished to change to a home-based modality.

There was a statistically significant association between state of residence and whether someone wanted to change their dialysis type and/or dialysis location. The proportion was lowest in the ACT (3%), and highest in Western Australia (16%) and Qld (14%). There was also a significant association between respondent age and whether someone wanted to change their dialysis type and/or location. The proportion was highest for those aged between 21 and 30 years (18%), and lowest for respondents aged over 70 years (8%).

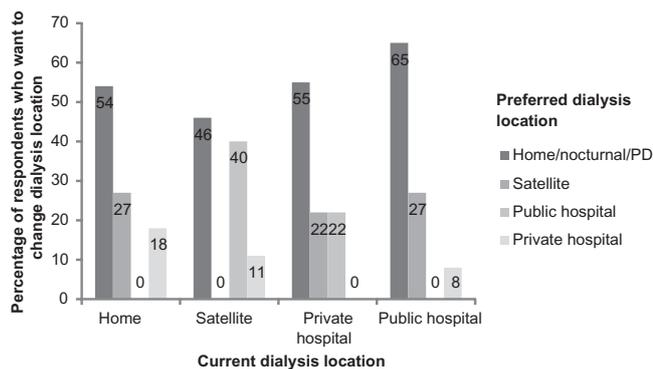


Fig. 1 Where dialysis currently takes place compared with preferred dialysis location ($n = 201$). PD, peritoneal dialysis.

Dialysis education

Respondents reported a wide range of multiple sources of education regarding dialysis. The most commonly reported sources of information were nephrologists (80%), specialist renal nurses (36%), education days at renal units (33%), and general practitioners (23%). A further 25% of respondents indicated they performed their own searches of the Internet and written materials for information about dialysis. Fourteen per cent of respondents reported they had received information from people currently on dialysis.

The time devoted to dialysis education varied from less than 30 min (16%), between 30 min and 1 h (31%), one to 2 h (22%), and more than 2 h (23%), of education. The results indicated that 46% of respondents received information at least 1 month before starting dialysis, but 34% received information about dialysis less than 2 weeks before their first treatment.

Respondents reported disparities in the provision of information about each dialysis type. More than twice as many people received information about HD (82%) than PD (40%). Respondents reported they were predominantly provided with information about dialysing in a public hospital (64%), with other locations such as home (47%) or satellite centres (39%) less frequently discussed. As shown in Figure 2, there were statistically significant state differences in the provision of information about dialysing at home, in a satellite centre, and in a public hospital. Respondents from ACT, SA and WA were less likely to receive information about dialysing at home. Age also influenced the delivery of information about locations for undertaking dialysis (Fig. 3). Respondents aged between 31 and 40 years or between 51 and 60 years were more likely to receive information about dialysing at home, whereas respondents aged over 70 years were less likely to have home dialysis discussed with them.

Converting to home dialysis

Respondents who were not already using home dialysis ($n = 2170$) answered questions about receiving dialysis at

home. Of these respondents, 27% reported they had someone who could assist with dialysis at home, and 27% indicated their home was suitable for home HD. Of the respondents not currently dialysing at home, 13% were prepared to do so (Fig. 4). This willingness to undertake home dialysis increased to 34% when paid carers or nursing support was offered, and 31% if expenses were to be reimbursed. Support for home dialysis was highest when the option of a community dialysis house was provided (36%).

There was a statistically significant association between state of residence and willingness to dialyse at home. This was highest in Tas (30%) and Qld (28%), and lowest in SA (13%) and Vic (16%). There was a statistically significant association between age and willingness to dialyse at home. This was highest for respondents aged between 21 and 30 years (50%), and was lowest for respondents aged more than 70 years (14%).

DISCUSSION

This survey is the first national census of dialysis consumers in Australia. This is one component of a four-part assessment in which the opinions of patients, of senior nurses,¹² of nephrologists,¹¹ and of the medical directors of renal units¹¹ were canvassed. The results from the nephrologists and renal nurses indicated general support for home dialysis, but also identified issues such as infrastructure, patient reimbursement, renal unit culture and organizational systems which impede the increased use of home dialysis. Similarly, the consumer survey results showed a willingness of dialysis consumers to undertake home dialysis, but also identified inequities in pre-dialysis education, patient choice and the ability to move between dialysis modalities.

These findings also complement the PINOT study, a prospective Australian study that detailed education of incident dialysis patients over a three-month period. Renal unit staff participating in the PINOT study reported that 75% of 721 patients were educated regarding home dialysis.¹³ This contrasts with 47% of consumer respondents in this study indicating they had received information about home dialysis. Potential reasons for this disparity include recall bias in relation to pre-dialysis education, particularly as 50% of respondents in this consumer survey had been on dialysis for over three years. Similarly, as only 18% of respondents in this consumer survey had received pre-dialysis education in the past year, any conclusions from the current study regarding the state of pre-dialysis education are diluted with those educated throughout the last decade.

The survey results highlighted differences in the willingness to consider home dialysis, the degree of choice in dialysis location, the desire to change current dialysis type and/or location, and the provision of information about the various dialysis locations by States. It is reasonable to expect that these differences translate into uptake of home dialysis. For example, SA has one of the lowest rates of home dialysis in

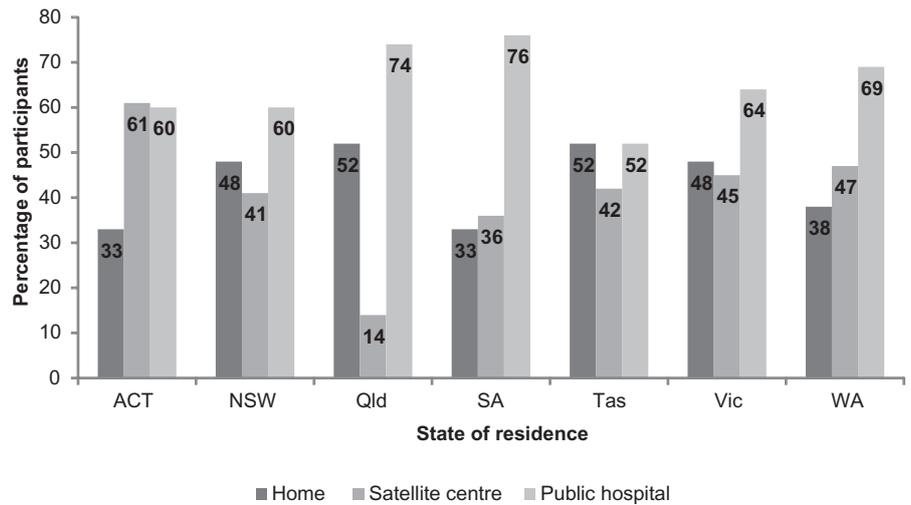


Fig. 2 State comparison of the percentage of respondents provided with information about each location for dialysis.

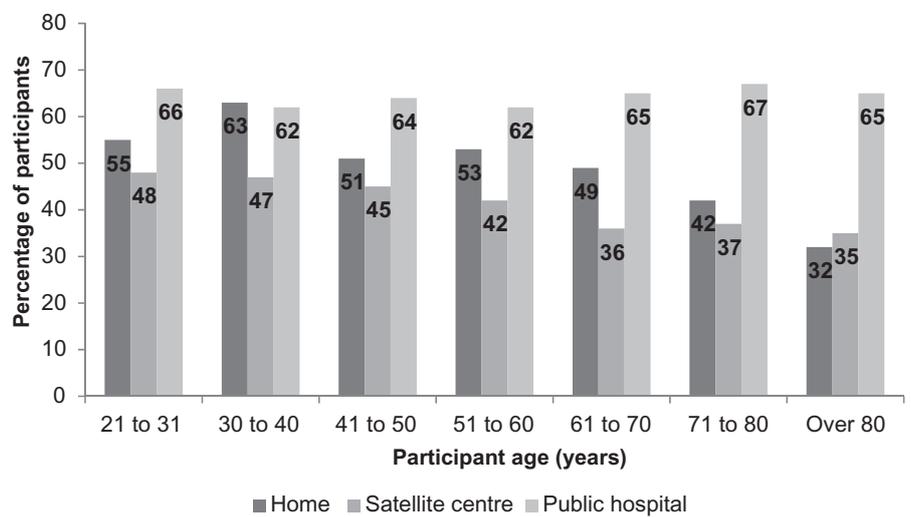


Fig. 3 Age comparison of the percentage of respondents provided with information about each location for dialysis.

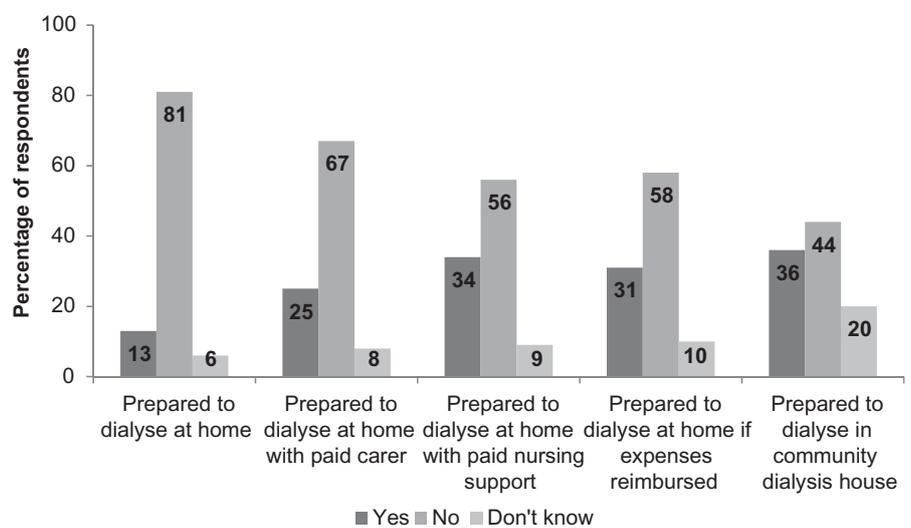


Fig. 4 Level of support for home dialysis among respondents who are not currently using home dialysis ($n = 2170$).

Australia (18% of all dialysis patients). The census showed that while surveyed SA dialysis patients were offered more choice in their dialysis location, they were less likely to receive information about home dialysis, and were less likely to consider using home dialysis. These findings support previous studies linking comprehensive education and the uptake of home dialysis.^{14,15}

Interestingly, the survey also suggests that while many patients are generally comfortable once they are established on dialysis, some have the desire to change dialysis modality. This implies that to improve home dialysis rates patients need to be exposed to home dialysis therapies early to avoid the 'status quo' bias against changing to these therapies once dialysis is established, but also should be offered the opportunity regularly, as their life and experiences change.

The census also provided valuable information regarding incentives for increasing the uptake of home dialysis in Australia. Consistent with the views of nephrologists¹¹ and renal nurses,¹² options such as providing paid nursing support for people dialysing at home, and reimbursing establishment and maintenance expenses were all associated with increased willingness to undertake home dialysis. Nursing support could have particular effect in making home an option for those over 70 years, a group who demonstrated limited interest in home dialysis.

Several limitations of the survey are acknowledged. Providing the survey exclusively in English led the study population to be underrepresented by individuals from culturally and linguistically diverse backgrounds. Similarly, as the survey was not distributed in the NT, the percentage of survey respondents of Aboriginal and Torres Strait Islander origin (3%) was less than the known prevalence (11%). The low response rate (35%), while not unexpected from a hard copy survey,¹⁶ raises questions as to whether the respondents are a representative sample of the larger dialysis population. Comparisons with ANZDATA revealed the census respondents were more likely to be older, and also more likely to be using public hospital dialysis. Furthermore, the response rate varied state-by-state, from 63% in Tas to 22% in WA. This may be a result of a difference in survey distribution techniques. In WA the survey forms were not distributed by renal unit staff, but were mailed to all dialysis patients (including hospital and satellite centre patients). In all other states/territories the survey forms were primarily distributed by hand to dialysis patients when they attended the renal unit/satellite centre for dialysis, with only home dialysis patients receiving their surveys by mail. Finally, the comprehensive nature of the survey, although very useful, may have also led to responder fatigue, both in terms of the proportion of those who responded as well as limiting the attention to questions towards the end of the questionnaire. There are plans to conduct a follow-up survey, which would reduce the number of questions to focus on modifiable factors, focus on representative sites rather than the entire country, and provide a web-based version.

Overall, the results indicate a clear need to review and benchmark pre-dialysis education programmes, using appropriate methods of education and incorporating all modalities. State variances indicate that local policy and the health professional teams significantly influence the operation of the dialysis programs. This in turn influences choice options, education programmes, location of dialysis units and the percentage of patients that have access to home modalities. Employment of key staff, or up-skilling of existing staff to become home dialysis champions has the potential to increase the home dialysis rate. Importantly, the *status quo* effect implies that in order to increase home dialysis patients need to be encouraged to go home as their initial therapy.

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SUPPORTING INFORMATION

Additional Supporting information may be found in the online version of this article:

Appendix S1 Australian Dialysis Consumer Survey.