

PATIENT PERSPECTIVES ON DIALYSIS

FIRST NATIONAL CENSUS



Chronic Kidney Disease (CKD) occurs when a person suffers from gradual and usually permanent loss of kidney function over a period of months to years. End-Stage Kidney Disease (ESKD) occurs when the kidneys are no longer able to function at a level needed for daily life, usually when CKD has worsened to the point at which kidney function is less than 10% of normal¹.

The most common causes of ESKD are:

- Diabetes
- Nephritis (inflammation of the kidney)
- High blood pressure²

People who have reached this stage need dialysis or a kidney transplant. It is estimated that approximately 6 million Australians have one or more of the major CKD risk factors and that about 1.4 million Australian adults have at least one clinical sign of existing CKD, such as protein in the urine or reduced kidney function^{3,4}.

Why undertake the census?

Kidney Health Australia conducted a census to investigate the experience, perceptions and preferences of people currently undertaking dialysis in Australia. The census attempts to better understand why patients use certain types of dialysis in certain locations and what the barriers may be for undertaking dialysis in the home.

Every day, 6 Australians start dialysis⁵. The increase in numbers is being fuelled by Australia's ageing population, obesity and diabetes in the community. Research into patient perspectives on dialysis is vital, if Australia wishes to improve its dialysis services in line with the rising numbers of potential dialysis patients.

Treatment for ESKD in the form of dialysis is expensive. The annual cost of dialysis per patient per year is:

- Hospital Haemodialysis \$79,072
- Satellite Haemodialysis \$65,315
- Home Haemodialysis (HHD) \$49,137
- Home Peritoneal Dialysis (PD) \$53,112⁶

Research suggests that home dialysis (HHD and PD) is not only more cost effective for the Australian health-care system, but it can also positively impact on the patient's life, enabling increased mobility and independence. The percentage of patients undertaking home haemodialysis has fallen from about half of all dialysis patients in the 1970s⁷ to approximately 9% in 2009⁸.

Methodology

In 2010, Kidney Health Australia conducted an Australia-wide census of all adult patients receiving routine dialysis services - the first of its kind. The survey included 78 questions relating to:

- Dialysis treatment type and location
- Dialysis and transplantation
- Dialysis choice
- Preferred dialysis type and location
- Changing dialysis type or location
- Satisfaction with dialysis
- Travel to and from dialysis
- Holidays on dialysis
- Dialysis information and education
- Clinical support
- Psychosocial support
- Home dialysis treatment

For the majority of hospital and satellite patients, survey forms were handed out to them by nurses at their Renal Unit as they came in for their dialysis. Alternatively, survey forms were posted directly to hospital and satellite patients in Western Australia and a smaller number of patients in New South

Wales and Victoria. For home-based patients, surveys were posted by Renal Units to patients' homes. Reply-paid envelopes were supplied for the return of the surveys to Kidney Health Australia. The survey received a 35% response rate – of the 9,223 surveys distributed, 3,250 surveys were completed.



¹ Medline Plus, U.S. National Library of Medicine. End-stage kidney disease. Available at: <http://www.nlm.nih.gov/medlineplus/ency/article/000500.htm> [Accessed October 2010].

² Medline Plus, U.S. National Library of Medicine. End-stage kidney disease. Available at: <http://www.nlm.nih.gov/medlineplus/ency/article/000500.htm> [Accessed October 2010].

³ Chadban SJ, Brigganti EM, Kerr PG et al. Prevalence of kidney damage in Australian adults: The AusDiab kidney study. *J Am Soc Nephrol* 2003; 14: S131-S138.

⁴ White SL, Polkinghorne KR, Atkins RC, Chadban SJ. Comparison of the prevalence and mortality risk of CKD in Australia using the CKD Epidemiology Collaboration (CKD-EPI) and Modification of Diet in Renal Disease (MDRD) Study GFR estimating equations: The AusDiab (Australian Diabetes, Obesity and Lifestyle) Study. *Am J Kidney Dis* 2010; 55: 660-670.

⁵ The 32nd ANZDATA Registry Report. McDonald, S., Excell, L., and Livingston, B. 2010. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, South Australia.

⁶ Cass A, Chadban S, Gallagher M et al. The economic impact of end-stage kidney disease in Australia: Projections to 2020. 2010. Kidney Health Australia, Melbourne, Australia.

⁷ George CRP. History of home haemodialysis in Australia. *Nephrology* 2005; 10: 215-221.

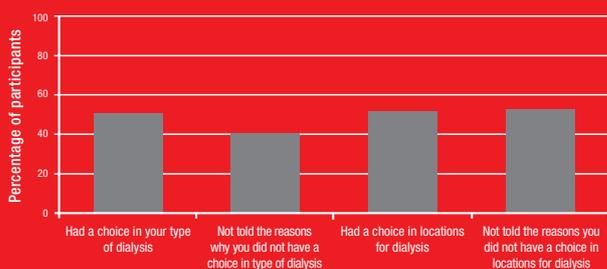
⁸ ANZDATA Registry, 2010, Summary 1-Jan-2009 to 31-Dec 2009.

Results

Patient Choice

The results of the survey show that many patients (49% of respondents) were not given a choice as to the kind of dialysis they were about to begin, and that many patients were also not informed by specialists or renal nurses why they did not have such a choice. 41% of those that say they didn't have a choice were not told why they didn't have a choice.

48% of respondents noted that they did not have a choice in the location of their dialysis. Of this percentage, 53% were not informed why they did not have a choice. The proportion of patients who reported a choice in dialysis location was lowest in New South Wales (46%) and highest in South Australia (62%).



The survey also clearly showed that once patients have been established in their particular type and location of dialysis, they are less likely to want to change their type or location. Such resistance to change illustrates the need for patients to be told about home dialysis options early in their treatment, and perhaps even before the patient has commenced dialysis. Only 4% of respondents were shown a home dialysis set-up.

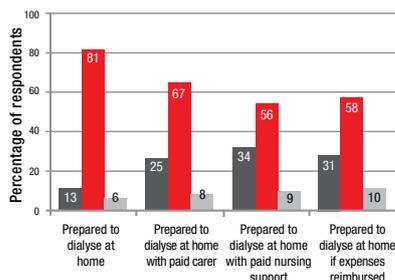
Home Dialysis

Overall, only 13% of patients not currently dialysing at home were prepared to do so. However, 25% were prepared to do so if there was a paid carer, 34% if there was paid nursing support and 31% if expenses were reimbursed.

There was a strong link between age and willingness to dialyse at home. The proportion of patients willing to dialyse at home was higher for respondents aged between 21 and 50 years, and was lower for respondents aged more than 71 years.

Level of support for home dialysis among respondents who are not currently using home dialysis

- Yes
- No
- Don't know



The proportion of patients willing to dialyse at home varied between States and Territories:

SA 13%	ACT 22%	WA 26%	TAS 30%
VIC 16%	NSW 25%	QLD 28%	

Patient Education

Patient education prior to beginning dialysis is extremely important. Three months or more is considered long enough to begin teaching patients about their forthcoming dialysis treatment. However, survey results indicate that 64% of patients were not receiving information three months or more prior to their first treatment. Furthermore, 34% received information less than two weeks before starting dialysis.

The most commonly reported sources of information about dialysis were nephrologists, specialist renal nurses, education days at Renal Units and general practitioners. Patients were twice as likely to receive information about haemodialysis (85%) than automated peritoneal dialysis (APD) (39%) or continuous ambulatory peritoneal dialysis (CAPD) (41%).

Despite renal nurse specialists being highly trained and informed on the specifics of dialysis, they appeared to not be the key source of information and education for patients. This is in spite of them having the ability to give in-depth, detailed and hands-on educational information to patients regarding their particular kind of dialysis.

Interesting to note was the considerable variability in the amount of time spent with a health professional discussing dialysis as indicated in the above chart.

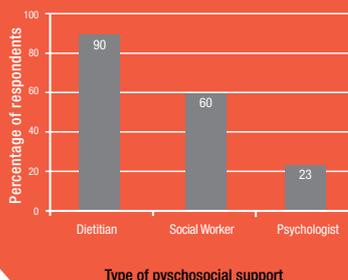


Average time the health professionals spend explaining dialysis

Psychosocial support

The proportion of patients who had seen a psychologist was lower for patients who dialysed at a satellite centre or at a private hospital, compared to patients who dialysed at home or at a public hospital.

The proportion of patients who had seen dietitians, social workers or psychologists varied considerably.



To read the full version of the survey, or to find out more, visit www.kidney.org.au

To become part of our Kidney Community and receive our monthly newsletter, please contact Kidney Health Australia on 1800 4543 639 or info@kidney.org.au

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