Improving the uptake of home dialysis in Australia and New Zealand

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Abstract

Home dialysis, incorporating both haemodialysis (HD) and peritoneal dialysis (PD), has experienced a downward trend in most Australian jurisdictions over the last 10 years. There is also considerable variation both between, and within, each state. New Zealand traditionally has high rates of home dialysis, but is also experiencing some decline. The reasons for decline are considered multifactorial. State variance is found to be inconsistent with age and race but aligns strongly with active policy implementation and the presence of home dialysis 'champions'. Many of the perceived challenges impeding home dialysis uptake are either difficult to substantiate or readily overcome. It is proposed that a combination of education, advocacy, support and policy can enhance current home dialysis rates. Positive government policy, cohesive renal unit culture and educated renal health care professionals working collaboratively with those requiring dialysis can all contribute to turning around the downward trend in home dialysis.

Keywords

Home dialysis, peritoneal dialysis, haemodialysis.

Introduction

The prevalence of end-stage kidney disease (ESKD) is slowly increasing in Australia. At the end of 2012 there were over 11,000 individuals receiving dialysis (ANZDATA, 2013), and the health system has limited human and financial resources to cope with the growing burden. Of the different dialysis treatment options, home dialysis confers considerable clinical, social and financial advantages (Fortnum *et al.*, 2012). Home dialysis includes all forms of peritoneal dialysis (PD) and haemodialysis (HD) that are performed by the individual, with or without a support person and in the comfort of their own home (or occasionally a community room). Despite the benefits of home dialysis, the percentage of people who dialyse at home in Australia has fallen from about half of all patients in 1992 (ANZDATA, 1998), to less than 30% today (Figure 1) (ANZDATA, 2012). A similar downward trend has recently been evident in New Zealand (Figure 1).

Satellite and hospital HD units are an essential component of dialysis service delivery, especially for those who need ongoing medical or nursing support. It is important, however, that the balance between home- and centre-based dialysis is appropriate and reflects personal and clinical benefits, resource implications and consumer preferences.

Personal and clinical benefits

Home dialysis has been shown to improve quality of life with benefits including increased control, freedom of daily diet and fluids, opportunities to travel, and reduced medications (Marshall *et al.*, 2011; Mowatt *et al.*, 2004). In addition, improved sexual drive and higher quality interactions with family, improved sleep patterns (Jaber *et al.*, 2010), and the ability to return to work are reported (Mowatt *et al.*, 2004).

The clinical benefits of home dialysis are most often attributed to the ability to increase frequency of home HD (HHD) sessions to a minimum of alternate days. Data analysed from 26,016 patients on the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) demonstrated a survival advantage for HHD relative to facility-based HD, even when adjusting for patient demographics and known co-morbid conditions (Marshall *et al.*, 2011). Interestingly, however, they did

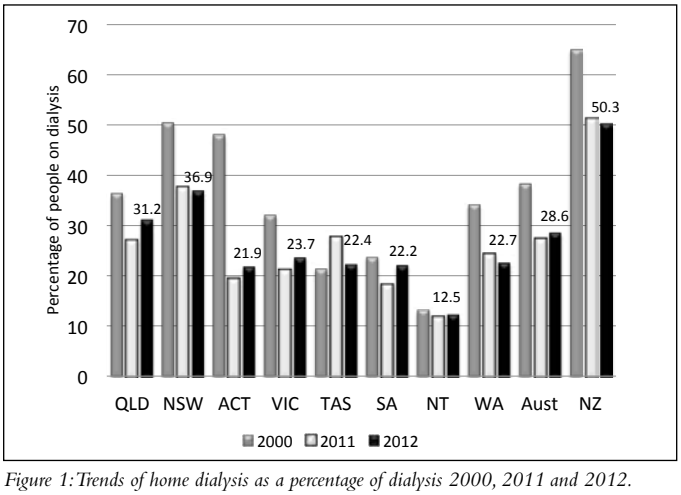

Figure 1: Trends of home dialysis as a percentage of dialysis 2000, 2011 and 2012. (Data labels are 2012.) Data courtesy of ANZDATA

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not find that the enhanced hours or any other measurable factor was associated with this difference.

Well designed randomised controlled trials comparing home dialysis versus conventional dialysis are challenging allowing the allowed 'no proof of benefit' argument to flourish. Observational research, retrospective data-analysis and non-randomised studies, however, do demonstrate benefit with over 100 peer-reviewed articles now demonstrating positive outcomes, particularly for enhanced hours or nocturnal HHD (Rosner, 2010; Ok *et al.*, 2011). Reduced left ventricular mass (Culleton *et al.*, 2007), reduced restless leg syndrome (Jaber *et al.*, 2011), and improved blood-pressure control (Rosner, 2010) are some identified benefits of HHD.

Resource implications

Increasing rates of home dialysis confers considerable resource implications. The incidence of treated ESKD patients is calculated to increase by 80% from 2009 to 2020 (AIHW, 2011). If current treatment practices continue, then facilities for centre-based HD will require massive expansion of both human and financial resources to meet this need. The different dialysis modalities are each associated with different patterns of resource utilisation, infrastructure and staffing requirements.

According to the best available data, HHD is the cheapest dialysis modality with estimated costs of A$49,137 per person per year on dialysis. This compares with A$79,072 per person per year for hospital dialysis, A$65,315 for satellite HD, and A$53,112 for PD (Cass *et al.*, 2010). Home-based dialysis requires lower infrastructure and staffing ratios than hospital or satellite dialysis. Nationally accepted ratios are one nurse for every 4–6 patients dialysing in centre per week. In comparison, one nurse would support on average of 15 HHD patients or 25 PD patients at home (NSW Health, 2007; ACT Health, 2009). Projections to 2020 estimate net cost savings of an increased home dialysis programme to be in excess of A$370 million (Cass *et al.*, 2010).

Consumer preference

Morton *et al.*, (2012) demonstrated that the majority of patients, caregivers and families prefer home-based modalities. Patients who personally anticipate a limited lifespan are influenced by the lifestyle considerations offered by home dialysis, and are willing to trade life years for improved quality of life resulting from increased freedom and the ability to travel. However, an Australian survey of dialysis consumers found that only 51% of 2,976 responding patients chose their modality of dialysis, and the rate of choice was lowest in those dialysing in HD centres (Kidney Health Australia, 2011a). Furthermore, half of 21- to 30-year-old patients not dialysing at home reported they would rather be using this treatment modality. Even in the patient population aged over 80 years, 13% indicated they would rather dialyse at home (Kidney Health Australia, 2011a).

Impact of local policy on home dialysis uptake

Despite consumer preferences, the evidence supporting improved personal and clinical outcomes, and financial advantages for increasing the uptake of home dialysis, the rate of home dialysis varies considerably within Australia. As shown in Table 1, the proportion of home dialysis patients ranges from a high of 37% in New South Wales (NSW) to 12% in the Northern Territory. The reasons for the variation are likely to be multifactorial. The following discussion highlights some of these differentiating factors, but is not intended to be exhaustive.

Currently in New Zealand 50% of people on dialysis receive their dialysis at home. Most renal units in New Zealand report a home-first policy, and patients typically commence dialysis in a home training environment. Community houses overcome some personal residence limitations, such as temporary accommodation, power and water issues. PD patients are preferentially transferred to HHD when needed. The location of HHD training within satellite centres promotes the home culture to all. The proximity of home training and satellite facilities allows extended and flexible training times, which can enhance home dialysis rates.

Table 1: Home dialysis rates for Australia and New Zealand as at 31 December 2012 (ANZDATA, 2012)

State	Dialysis population	% PD	% HHD	% Centre dialysis	No. of HD sites (average No. patients per site)
Australia	11446	19	9	71	
New South Wales	3707	25	12	63	76 (30)
Queensland	2085	19	12	69	40 (36)
Victoria	2792	17	7	76	86 (24)
Western Australia	1144	18	5	77	21 (41)
South Australia	733	20	3	77	22 (26)
Australian Capital Territory	269	10	12	78	3 (79)
Tasmania	214	15	7	78	4 (37)
Northern Territory	502	6	7	87	8 (55)
New Zealand	2469	31	19	50	12 (102)

NSW has historically reported the highest proportion of home dialysis, and currently has a target of 50% of all dialysis patients to be dialysing at home (NSW Health, 2007). Four major NSW programs are currently achieving rates of 50–70% of their dialysis patients at home. The large HHD programs were initially delivered by two central units but now other sites also have training centres. Regional areas are developing small training units, which is expanding the training opportunities for patients.

Queensland is aiming for a 40–50% home dialysis rate, and home-first is now the preferred policy. Incentivised activity-based funding models provide advantages for renal units to utilise home modalities (Queensland Government, 2007). Technology innovations are being evaluated for their potential to increase access to home dialysis and self-care units are being used for HHD to combat water and accommodation issues. In 2012 Queensland made a 4% gain in home dialysis rates to 31% (ANZDATA, 2013).

In Tasmania a commitment to increasing home dialysis has led to the opening of a new home dialysis training unit — the Karingal training centre. While the rate of home dialysis increased from 16% in 2011 to 30% in 2010, it has since declined to 22% (ANZDATA, 2012). It is worthwhile noting that small patient numbers and increased transplant rates can skew data for this jurisdiction.

Until 2007 Western Australia had an HHD programme operating in one hospital. It now has a corporate state model of home dialysis. This has created an accessible HHD programme that has increased rates from 2% to 5% of the dialysis population (ANZDATA, 2012). People of Aboriginal heritage constitute 25% of the dialysis population, many of whom live in remote regions with limited infrastructure. Community models are often used when homes are inadequate for home dialysis. Although the home dialysis model has centralised state training and care, the rates of home dialysis in Western Australia vary from 20% to 31% by parent hospital (ANZDATA, 2011).

The average rate of home dialysis varies widely between renal units in Victoria, with key individuals driving successful programs (Agar, 2010). HHD rates vary from 4% to 30% (ANZDATA, 2011). Victorians receive the highest home dialysis rebates in Australia mainly via a state payment (Kidney Health Australia, 2013). Although geographically Victoria is not a large state, it has 86 sites providing HD, resulting in a high ratio of units to patients (Table 1). Victoria is actively promoting home dialysis and reported a 3% prevalence increase from 2011 to 2012 (ANZDATA, 2013).

The Australian Capital Territory had the second highest percentage of home dialysis patients in 2000, but had decreased to become the second lowest by 2008 (ANZDATA, 2010). The PD rate is only 46% of home patients, compared to the national average of 68%, and decreasing rates coincided with changes in the contractual provision of PD. In 2009 the Renal Health Service Plan targeted increases for HHD and PD (ACT Health, 2009), and the 2012 ANZDATA figures indicate that there is currently an upward trend.

South Australia currently has a comparably low rate of home dialysis, with 22% of the dialysis population in this state dialysing at home. Of the people utilising home dialysis in South Australia, the majority (87%) perform PD, with only 12% using HHD (ANZDATA, 2012). In 2012 a review of many aspects of the HHD programme and consolidation of HHD training to one site were strategies recommended to rebalance this, and the HHD programme is now expanding (Hawley & Fortnum, 2012). The impact of transplantation on the home dialysis uptake in South Australia is a source of unresolved debate. Statistics show that the transplantation rate in South Australia is considerably higher than the national average (ANZDATA, 2013) and the median waiting time for a transplant is 1.5 years, compared with the Australian median of 2.7 years (Wright & Narayan, 2013).

The Northern Territory has recently developed a prominent and rapidly growing HHD programme centralised in Darwin. Higher staff ratios are acknowledged as necessary to support gold standard outcomes in this rural and remote population.

Commonly reported impediments to home dialysis

Patient factors

The increasing age of dialysis patients is frequently quoted as an impediment to home dialysis (Ludlow *et al.*, 2011). Projections to 2020 indicate that the highest percentage increase in dialysis uptake will be in the over-75 age group (AIHW, 2011). However, there is no correlation between the average start age and the rate of home dialysis in each Australian jurisdiction (Figure 2). Furthermore, a high percentage of patients aged less than 65 years are currently not utilising home dialysis (Figure 3).

PD is utilised more in the elderly than HHD. Currently 46% and 10% of PD and HHD patients respectively are aged over 65. Peritonitis rates and survival on PD are comparable across age groups (ANZDATA, 2010). As a treatment for the elderly, PD is a continuous and gentle treatment that does not have the biochemical and fluid shifts of a standard HD regime, has better cardiovascular stability and allows independence (Ho-dac-Pannekeet, 2006; Chesterton & Fluck, 2012). Longer HHD hours could also potentially have the same effect. Innovative and supportive models of home dialysis care can overcome age-related issues including reduced mobility (Oliver *et al.*, 2007). Functional and cognitive ability rather than age should determine home dialysis suitability.

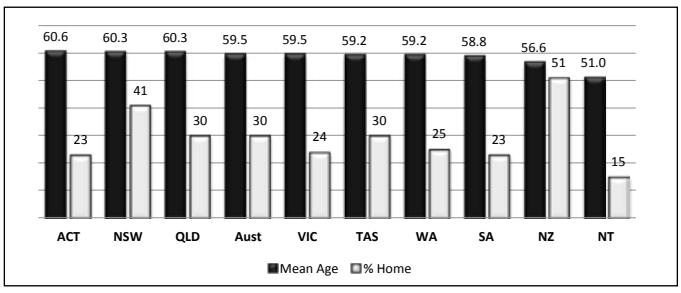

Figure 2: Mean age for starting dialysis compared to percentage of patients using home dialysis (ANZDATA, 2010)

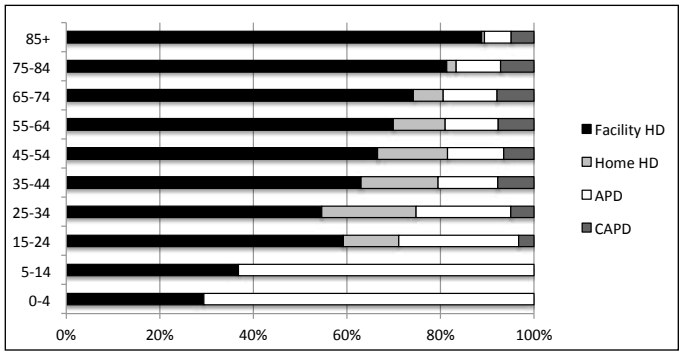

Figure 3: Percentage of dialysis patients using each dialysis modality by age group in Australia (ANZDATA, 2010)

The prevalence of people of non-Caucasian origin varies by jurisdiction. One-quarter of Australian renal units have over 50% of patients from culturally and linguistically diverse (CALD) backgrounds. Interpreters should be an integral part of the health system to assist in overcoming communication issues. In Australia, the Asian population has a lower than average uptake of home dialysis (ANZDATA, 2011). Comparatively, in Hong Kong there is a PD-first culture leading to 80% on PD with 76% of patients being peritonitis-free annually, and good technique survival (Li & Szeto, 2008).

People of Aboriginal and Torres Strait Islander origin utilise HHD in only four states in Australia (Figure 4). The housing environment and mobile carer population can be challenging issues to overcome. Despite this, for those determined to return to their home for dialysis, obstacles can be addressed with the support of dedicated home dialysis nurses and community supports.

Distance from a specialist health care team also raises its own challenges. It is often considered that PD has poor clinical outcomes in rural regions but Gray, Grace and McDonald (2013) found that rural non-Indigenous PD patients have technique survival outcomes and peritonitis rates comparable to their metropolitan counterparts.

An additional patient factor is the status quo bias. The Australian survey of dialysis patients showed that the majority of patients are generally unwilling to change dialysis modalities once they are established. Therefore, exposure to home therapies needs to occur early to avoid patient-led resistance to change. However,

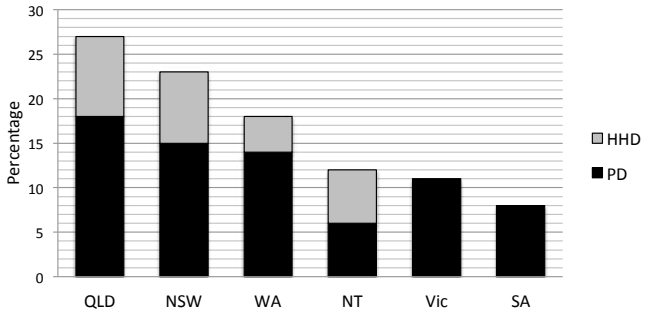

Figure 4: Percentage of Indigenous patients utilising home dialysis in each Australian state in 2009 (ANZDATA, 2010)

the younger age cohorts showed greater willingness to change to home and there are also opportunities to revisit established centre-based patients to provide education regarding dialysing at home (Kidney Health Australia, 2011a).

Learning, technology and support

PD technology is simple enough to be learned by most individuals in one or two weeks unless they are very frail or cognitively impaired. HHD training averages up to three months, although simplified technology can decrease training times (Blagg, 2005). Learning cannulation skills with or without needle phobias is a challenge, but supportive education can overcome this hurdle for the majority of patients (Mott, 2011). Multiple case histories prove that 'the difficult patient who insisted on home' has achieved this goal, despite the odds, but there is no doubt that HHD training times are onerous. Historically Australia and New Zealand have used similar machine types, indicating that technology is not a key influential variance in HHD rates (Agar, 2008).

Carer burn-out, lack of respite or assisted dialysis and isolation issues, however, are regularly identified as barriers to going or staying home on PD (Oliver *et al.*, 2007). The Australian dialysis consumer perspectives survey revealed that a proportion of patients were willing to consider home dialysis if paid carer support and expense reimbursement were available (Kidney Health Australia, 2011a).

Surveys of both nephrologists and renal nurses in Australia identified out-of-pocket costs as potential impediments to increasing home dialysis uptake (Lauder *et al.*, 2011; Ludlow *et al.*, 2011). Home dialysis equipment and consumables are provided by state programs. Reimbursements vary between states, leaving patients in some jurisdictions out of pocket, particularly for electricity and water costs (Kidney Health Australia, 2011b).

Clinical outcomes

Australian data shows that patient three-year survival rates are comparable for PD and HD (73% and 70% respectively) (ANZDATA, 2010). The Caring for Australasians with Renal Impairment (CARI) guidelines do not recommend PD over HD, but do acknowledge a preservation of renal function advantage for CAPD (CARI, 2005). In a recent survey, Australian nephrologists did not rate PD as an inferior therapy (Ludlow *et al.*, 2011).

Twenty-one per cent of patients with PD technique failure are due to infection, with peritonitis the primary cause (ANZDATA, 2010). Peritonitis rates are 1 per 22 patient months in Australia and 1 per 19.4 patient months in New Zealand (ANZDATA, 2010). With a benchmark of 1 per 73.5 months in Japan, the reasons cited for variable rates are multifactorial (such as appropriate patient selection, prophylaxis and treatment of infectious complications, investigation of social causes of technique failure and a greater focus on patient education and clinical governance) and with close attention may be preventable (Jose *et al.*, 2011).

Health professionals and the health system influence on choice

Patient decision making is influenced by information presented, and is strongly influenced by their physicians and renal nurse opinions (Morton *et al.*, 2010). Australian nephrologists acknowledge their perceptions of home dialysis are influenced by a lack of availability of: respite care, home visits, financial support, simple technology, and government and medical administrative support (Ludlow *et al.*, 2011). Similarly, Australian renal nurses identified educational, cultural and organisational impediments to the expansion of home dialysis in their respective renal units (Lauder *et al.*, 2011). Some of the inter-unit variability in home dialysis uptake may be attributed to the presence of home dialysis 'champions' who advocate strongly for the cause. For example, in one Victorian unit dedicated support for nocturnal dialysis has led to over one-third of dialysis patients utilising this modality (Agar, 2010).

Strategies to increase home dialysis rates

Australian home dialysis rates fluctuate by jurisdiction, with factors such as funding policies, availability and ease of access to home dialysis training units, accessibility of satellite dialysis units and health professional opinions affecting the trend both positively and negatively.

For the optimal levels of home dialysis to be realised, the overarching government policies and funding mechanisms need to support and promote home dialysis as a preferred therapy. Current federal and state government initiatives are working to address these issues. For example, the Kidney Health Australia End-Stage Kidney Disease Education Project is a federally funded national initiative to improve access to, and quality of, pre-ESKD patient education. In addition, Victoria and Queensland have both committed funding for committees and ongoing projects since 2011 to find solutions to perceived home dialysis impediments such as technology and home support. Whilst outcomes from these initiatives are yet to be published, both of these states have recently demonstrated an increase in home dialysis rates. Data analysis with benchmarking is important, and should incorporate health outcomes, programme performance and costs. Where outcomes do not meet national or international benchmarks, quality improvement programs should be developed. Victoria now has a statewide key performance indicator programme that has collated data for this purpose since 2012.

The lead should be taken by health departments and government by reimbursing cost-neutral home dialysis, investing in home dialysis programs, and rewarding renal units for a cost-effective approach to meeting the burden of the dialysis population. Realistically, targets can be set for 1–2% of an additional prevalent home dialysis population per year. Identification of the barriers in the local programme that prevent optimal home dialysis utilisation are critical, and development of strategies and pathways to achieve it are needed (Fortnum *et al.*, 2012). Victoria and Queensland health departments have implemented a number of strategies to increase home dialysis and have seen positive increases in 2012, demonstrating that policy can alter practice (ANZDATA, 2013).

Locally, a renal health care team who are comprehensively educated and who advocate for home dialysis are essential. This must include all nephrologists, the pre-ESKD education team, all renal nursing staff including the HD unit staff, allied health and the administration staff. All relevant health professionals must be educated in the facts regarding home dialysis, including clinical and personal lifestyle outcomes (Lee *et al.*, 2008). To this end, the HOME Network, a group of health professionals whose mission is to empower patients to gain access to home dialysis, has also recently produced a myth-busting fact sheet for health professionals (Nurse Education Taskforce, 2013).

Decision making and education should be supported in a non-biased way (Lancsar & Louviere, 2008). To meet this strategy for Australia/New Zealand education practice the *My Kidneys, My Choice Decision Aid* was developed in 2012 by an Australian and New Zealand multidisciplinary working group who advocated for shared decision making and unbiased education about all treatment options (Smolonogov *et al.*, 2012). Additionally a structured pathway for education of late referrals and re-education of those patients dialysing in-centre is also essential to avoid the status quo bias, and to reach patients ready to change modality.

Managers and heads of renal units have an important role to ensure that the unit philosophy, funding and overarching mission supports home dialysis. The preferred culture of the renal unit should be home dialysis-first, with referrals to unit-based HD only if home is ruled out, or transplant is imminent (Oreopoulos *et al.*, 2009). This would be enhanced by a culture and staff that support a patient self-management approach throughout the renal journey. Positive actions to reduce HHD training times include creative and innovative use of patient time in satellite units, more flexible rostering schedules and advanced teaching methods. The peripheral team who also play a role in optimising uptake of home dialysis include support agencies such as Kidney Health Australia, industry and, importantly, consumer organisations who can advocate for national change.

Recruitment of staff from CALD backgrounds and the use of international access to education and training materials via the internet could contribute to reducing the culture barriers. The models of successful practice utilised by those jurisdictions with a higher proportion of Indigenous patients could be modelled in those jurisdictions with less experience. Social workers, Aboriginal health care workers and occupational therapists are experts in overcoming individual barriers to undertaking medical treatment at home, but they are often under-resourced or simply not available. To overcome consumer barriers, the health care team should look for creative solutions to support home dialysis (Oliver *et al.*, 2007).

Conclusion

Utilisation of home dialysis has an unjustified wide variance within Australia. Satellite dialysis is currently widely utilised with

no proof of better outcomes, and at a higher cost. Home dialysis models are fiscally responsible, produce at least equal if not better medical outcomes and have been shown to improve many consumer lifestyle factors. Autonomy, control, positive outcomes and community care can become the norm for dialysis patients, including many of those with health concerns. Turning around the home-dialysis trend requires a multifaceted and long-term approach. This is required not only because consumers deserve choice, but before both financial and human resources are exhausted.

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