Challenges in methods and availability of transport for dialysis patients

Sarah Smith, Debbie Fortnum, Marie Ludlow, Tim Mathew & Luke Toy

Submitted: 5 May 2015, Accepted: 18 September 2015

Abstract

Background
The majority of Australians with end-stage kidney disease undertake their dialysis treatment in a hospital or satellite centre. Dialysis patients are committed to having a repeating, high-frequency program and a potentially lifelong dependency on transport to survive. Existing knowledge about dialysis transport in Australia indicates a fragmented system that often does not meet the needs of those on dialysis.

Methods
Between May 2014 and July 2014, nurse managers at each of the 200 dialysis units in Australia with more than five dialysis-dependent patients were invited to complete an online survey of patient transport issues. The survey contained seven questions examining multiple aspects of patient transport and two open-ended questions to record qualitative experiences in patient transport.

Results
The national response rate was 50% (100 surveys). State-based transport arrangements were found to operate on an ad hoc basis, with 77% of units reporting inadequate transport access. Assisted transport was used for 1.7 journeys (one-way) per person per week (excluding family support). High-use transport sources were community-based transport (44%) ambulance services (39%) and subsidised taxis (28%). On average, 12% of patients experience unresolved transport difficulties in the long term. Parking cost $10–$15 each treatment for 10% of units but was free at the majority of units.

Conclusions
This survey has confirmed that the Australian dialysis transport system is inconsistent, uses expensive transport sources, and is inadequate for regular and routine dialysis attendance. The system requires systematic recognition and streamlining with the potential to save costs and to improve the quality of life for those on dialysis.

Keywords
Renal dialysis, transportation of patients, chronic kidney disease, end-stage kidney disease.

Sarah Smith Government Relations Advisor, Kidney Health Australia, Melbourne, VIC, Australia
Debbie Fortnum National Clinical Programmes Manager, Kidney Health Australia, Perth, WA, Australia
Marie Ludlow National Medical Project Manager, Kidney Health Australia, Adelaide, SA, Australia
Tim Mathew Medical Director, Kidney Health Australia, Adelaide, SA, Australia
Luke Toy General Manager Public Affairs, Kidney Health Australia, Canberra, ACT, Australia
Correspondence to: Sarah Smith, Kidney Health Australia, GPO Box 9993, Melbourne, VIC 3001, Australia
Email: sarah.smith@kidney.org.au
Introduction

There are currently close to 12,000 people in Australia undertaking dialysis treatment for end-stage kidney disease (ESKD) (ANZDATA Registry, 2015). While the uptake of home dialysis is slowly increasing, over 70% of the dialysis population undertake their dialysis treatment outside of the home, at a renal unit either situated within a hospital or at an external ‘satellite’ centre (ANZDATA Registry, 2015). Centre-based dialysis usually encompasses three times per week visits to the renal unit, for a four- to five-hour dialysis treatment per session.

Accommodating a dialysis routine into daily life presents numerous challenges for people with ESKD. For many, dialysis produces side effects such as blood pressure fluctuations, impaired concentration and executive functioning, light-headedness and nausea. These factors, along with the high prevalence of elderly people undergoing dialysis means that a large proportion of the over 8,000 people utilising centre-based dialysis are unable to drive themselves to and from their thrice-weekly treatment sessions. ESKD is strictly unique in the sense that through the provision of dialysis, it is the only condition dependent on transport to survive.

In 2011, an Australian national survey of people on dialysis found that 52% of respondents travelled more than 10 km each way to attend dialysis, equating to over 3000 km per annum (Kidney Health Australia, 2011). Approximately one-third of respondents used a form of assisted transport to attend dialysis. The associated costs of transport to and from dialysis were estimated to be greater than $20 per week for 38% of these respondents. Anecdotal feedback indicates that access and availability of transport to dialysis is an ongoing source of psychological and financial stress for people on dialysis.

The options for transport to and from dialysis include assistance by friends and family, public transport, special dialysis buses, community and volunteer agencies, hospital transport and ambulances. The preferred transport options encouraged by units are independent, relative-supported and public transport. Where these sources are not appropriate or available for all journeys, assisted transport is required. Anecdotally, this assisted transport provision is quite complex and varied, and supported by various funding structures.

Funding can be from multiple sources including local councils, state government (directly to hospital or transport provider), federal government and a huge component of voluntary hours by drivers. While it is difficult to quantify the costs and scope of many of these schemes, transport options internally funded by the renal unit/hospital are easier to quantify. The government state-based taxi user subsidy scheme (TUSS) provides vouchers for half-price fares according to eligibility criteria. Taxi vouchers are often used by dialysis units as a last resort. They can limit distribution to those who are eligible for TUSS or choose to provide taxi vouchers to both those eligible and ineligible for TUSS. Units can usually track their taxi budget. Some hospitals use either, or both, paid and volunteer drivers for internally managed transport provision and apply eligibility criteria. Costs can be centrally absorbed by the hospital or allocated to the renal units. Some dialysis providers (usually non-government) use their transport budget to run a special ‘dialysis bus’.

External, assisted transport sources involve Indigenous organisations and multiple community groups, including councils, who are willing to support the transport needs of those in their catchment areas. Funding for these groups may be from council rates or government sources. Volunteers are often involved as drivers with some financial co-contribution from patients being common practice. Home and community care (HACC) transport is federally funded, with each state managing their own HACC provision by subcontracting to a number of local organisations to provide transport. Patients are assessed based on centrally managed eligibility criteria in each state. Ambulance transport is utilised where there are gaps in all of the provisions above or for a high dependency patient not suitable for other transport options.

At present, despite the awareness of multiple sources of dialysis transport, there is no quantifiable data about renal unit-assisted transport utilisation, how this varies between jurisdictions, and where the gaps in service provision remain.

The aim of this study was to describe and compare the dialysis transport options provided by renal units nationally, identify shortfalls in transport provision, and to outline the costs to renal units for these services.

Methods

Between May and July 2014, Kidney Health Australia used an online platform to deliver a survey to the 200 renal units in Australia with more than five dialysis patients recorded as under their care (as per the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)). The survey contained seven closed-option questions examining multiple dimensions of patient transport, including method of transport, current usage and gaps in provision of current transport methods. Questions were framed to help Kidney Health Australia determine what issues were at the forefront of dialysis units’ concerns and are causing financial implications to patients, and the health system overall. The survey also incorporated two open-ended
questions to record qualitative experiences in patient transport. The nurse manager at each dialysis unit was sent an email link inviting them to participate. This was followed up by a phone-call where initial responses were not received.

Results

Demographics

A total of 105 surveys were received; however, five of these were incomplete and therefore not included in the analysis (response rate 50%). Based on current data provided by ANZDATA, the 100 responding units dialysed a total 4,168 patients (ANZDATA Registry, 2015). Due to population differentials between jurisdictions, a high response rate — such as the 100% shown in the ACT — is due to a small population base. Other states with a lower response rate still represent a significant portion of dialysis units.

Sources of dialysis transport

The survey showed that community transport is the most common source of assisted dialysis transport offered (44% of renal units provided this service), followed by ambulance services (39%) and taxis (36% for full price and half-price combined) (Figure 1). It was more common for renal units to offer taxi vouchers to those who are eligible for the subsidised taxi voucher scheme (28% of units), with only 9% of units reporting they gave taxi vouchers to meet the full price of a taxi fare. Use of paid or volunteer hospital drivers was also infrequently reported (Figure 1).

The results demonstrate the wide variability in transport usage between the jurisdictions. Notably, while 39% of the responding Victorian renal units provided ambulances for transport, three jurisdictions (Northern Territory, South Australia and Tasmania) provided no ambulance transport at all.

There was variance between jurisdictions in the average number of transport services offered by renal units, ranging from an average of 10 different types of transport options in New South Wales and Victoria, to three or fewer options in Northern Territory and Tasmania. However, each individual renal unit typically reported offering fewer than three different types of transport.

Frequency of usage of each transport type

The responding renal units estimated they provided 2,500 patient journeys (where journey equals one-way trip) each week as a combined total. This represents an average 1.7 journeys per dialysis patient per week in this particular cohort. This does not include journeys assisted by relatives or friends.

As shown in Figure 2, most forms of transport were used by renal units up to 10 times each week. However, a small number of units reported high levels of usage (over 50 trips per week) of many forms of transport. Figure 2 shows the complexity and variability of transport usage.

Accessibility of transport

Accessibility of transport was one of the largest issues identified by the responding renal units. As shown in Figure 3, 77% of the 81 renal units who answered this question identified some level of difficulty for dialysis patients in accessing transport. The overwhelming majority of responding units also reported a level of difficulty in accessing dialysis transport.
Figure 3. One dialysis unit in Queensland indicated 31–40 people have ongoing issues accessing transport and one unit in Western Australia reported 21–30 patients with ongoing issues. Ten dialysis units from five jurisdictions reported 11–20 patients with ongoing issues (Figure 4).

Qualitative answers revealed that when trying to utilise a service, return home journeys have been identified as more difficult to obtain. One-quarter of dialysis units identified the unpredictability of ambulance arrivals and departures for transport to be an ongoing issue. The same issue was identified for community transport outside business hours. The availability of transport in the evening is a particular concern if after 5 pm, or if a dialysis appointment falls on a public holiday. Community transport and volunteer drivers were an important
part of the transport provision, which leads to uncertainty for patients. These services are often not available outside business hours, on public holidays or at weekends. Three units specifically identified that the availability of transport can be unreliable and the waiting time can be long. Lack of transport availability is felt more acutely in rural areas. The lack of subsidised transport for regional and rural patients was mentioned by 46% of dialysis units as a concern.

Parking
The survey identified that 10% of dialysis units reported patients pay $10–$15 for parking during dialysis treatments. Survey respondents indicated that parking is free for dialysis patients in 80% of renal units. The highest cost for parking was recorded in New South Wales, where two dialysis units cited more than $15 per visit, while both Victoria and Western Australia reported one unit each where the cost was above $15 per visit.

The qualitative answers also found that 66% of all the dialysis units who identified free parking was available on site also indicated there were not enough spaces to meet demand. Where free parking was available, there was often no dialysis-specific parking, meaning often the spots are taken on a first-come, first-served basis. One-quarter of renal units reported they had no dedicated on-site parking for dialysis patients. Parking close to the hospital was reported as an issue for at least three dialysis units, all in different states/territories.

Cost of transport to dialysis units
There are significant costs associated with providing transport as a service to dialysis patients. However, this cost is typically not directly borne by the dialysis units. This survey confirmed that less than 20% of units were able to provide any information related to cost and even these responses were incomplete.

Dialysis centres did identify significant ebbs and flows in access to both hospital and community transport, during periods such as school holidays and public holidays. This incurred direct cost increases, which are due to more use of either hospital transport or taxi vouchers. Difficulties in rural transport provision are compounded by low availability of taxis compared to metropolitan areas.

Discussion
Dialysis is a unique treatment — the only treatment for which there is both a lifelong dependency and high frequency of travel required to survive. Assisted transport is a key support strategy for approximately 30% of this population. An understanding of who the key providers of transport are, and the associated barriers in accessing transport, is critical if changes are to be implemented to enhance this service to meet the needs of all eligible patients. Assisted transport systems should provide equitable and easy access to cost-effective transport that is simple for patients and renal units to utilise and navigate.

The aim of this survey was to quantify the national utilisation of assisted transport and parking for dialysis. The findings have identified a high variance in both transport provision and

How many patients still have difficulties getting to dialysis?

<table>
<thead>
<tr>
<th>State/Metropolitan Area</th>
<th>0</th>
<th>5</th>
<th>10</th>
<th>15</th>
<th>20</th>
<th>25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western Australia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tasmania</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Australia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Queensland</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern Territory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New South Wales</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 4: Percentage of patients reporting ongoing issues accessing dialysis transport
parking, with a lack of equity across the various jurisdictions in Australia.

Transport is acknowledged as a factor that impacts on patient treatment choices and quality of life. An Australian consumer perspectives survey found that 67% of unit-based patients chose a unit because it was easy to get to, 30% of home dialysis patients chose their dialysis type to avoid burdening their family with travel commitments and 15% choose a particular location because transport is provided (Kidney Health Australia, 2011). Burden of treatment on dialysis is high, illustrated by the fact that in 2013, 43% of 495 patients who withdrew voluntarily from dialysis did so for psychosocial reasons (ANZDATA, 2014). In the current survey one unit specified that outside of clinical costs, transport is one of the single biggest burdens on both dialysis units and patients. A study of close to 21,000 dialysis patients enrolled in the Dialysis Outcomes and Practice Patterns Study demonstrated that the time required to travel to dialysis therapy adds considerable burden to haemodialysis patients, such that longer travel time is associated significantly with increased mortality risk and decreased health-related quality of life (Moist, et al., 2008). Furthermore, a recent study into factors that influence patient choice of dialysis identified a cohort of patients preparing for treatment who were significantly more likely to choose dialysis over conservative care, if transport subsidies were provided (Morton, et al., 2012).

The current survey identified that, despite various resources, 14% of patients (half of those seeking assisted transport) are estimated to have difficulty getting to or from dialysis treatments after all options have been exhausted. The survey also identified that many patients are required to pay for parking or transport, in addition to all the out-of-pocket costs associated with a diagnosis of a chronic condition. There is evidence to show that lower socio-economic status is associated with a higher prevalence of kidney disease (Kidney Health Australia, 2014), and these transport issues undoubtedly add to the psychological and cost burden on the patient and their family. For those people who are able to drive themselves to dialysis (or have others drive them) the costs of car parking at the renal unit can be prohibitive, and ease of access is not guaranteed. It is recommended that a combination of reduced parking fees and increased access to dialysis-specific parking bays be provided to alleviate cost and access issues.

Patient transport is also a critical enabler — the step without which dialysis and, therefore, treatment — would not occur. The average patient requires around two assisted journeys per week. From the health care system perspective, inadequate patient transport means higher administration costs with potential problems to the delicate scheduling required for rolling dialysis appointments, particularly when capacity is strained. For example, one of the surveyed renal units identified that community transport or taxi services not running on time can cause significant delays for future dialysis appointments. Also, a renal unit identified that not having adequate parking at a hospital can cause great concern for health care workers watching elderly or frail post-dialysis patients being forced to walk long distances back to their vehicle.

Providing dialysis transport as a regular service comes at a significant cost. The renal units included in this survey reported they provided an estimated total of 2,500 patient journeys each week. A United States survey estimated that transportation for dialysis costs $3.0 billion per annum, of which 50% of costs were ambulance (Stephens, et al., 2013). This was despite the fact that ambulance only accounted for 5% of journeys. Furthermore, it was calculated that one-third of costs could be saved with a reduction in ambulance use from 5% to 1%. The current survey identified a wide variance in ambulance utilisation around Australia. While 38% of surveyed renal units reported they use ambulances for dialysis transport, this form of transport was not used at all in Tasmania, Northern Territory and South Australia. It is unlikely that patient demographics are solely responsible for these wide discrepancies, and more research is needed to decipher the sources of this variation. New South Wales is currently tackling this with a new system for non-emergency patient transport (NEPT) which aims to improve system efficiencies and reduce costs (NSW Government, 2014).

The cost-effectiveness of dialysis transport in Australia is compounded by the wide range of stakeholders funding different transport types. This potentially reduces the system capacity to understand and standardise transport using the most cost-effective methods. Costing per kilometre of each method is not readily available and is an area for future analysis. Alternative policy solutions could be considered, such as redirecting ambulance transport costs to community transport, or allowing community transport providers to ‘pool’ the funds made available for their patients who are eligible for assisted transport and use that to subsidise community transport instead. New dialysis units should always be planned with patient transport access and parking at ‘front of mind’. Proximity to road/transport/community links will reduce the burden and difficulties for renal units and patients. One model worth further consideration applies in Western Australia where there is a private dialysis facility that has been allowed to use its state government funds (for subsidised taxis) to purchase a vehicle, and employ a part-time driver and deliver a much more flexible, reliable and successful transport solution. This strategy
is also being used in some Indigenous communities.

This survey is the first attempt to quantify and compare the dialysis transport options provided by renal units nationally, to identify shortfalls in transport provision, and to outline the costs to renal units for these services. While the findings are limited by the low response rates in some jurisdictions, we believe the results are an accurate portrayal of the current status of dialysis transport service provision in Australia. Future endeavours by states/territories should focus on determining the most cost-effective model for local delivery of dialysis transport. It is recommended that renal units should establish databases of the transport services their patients are utilising, and record issues surrounding equity and access (Stephens, et al., 2013).

Conclusion
Australian renal units confirmed that the assisted transport system for dialysis is inconsistent, with wide variations in service provision both between and within jurisdictions. There are still many patients struggling to find transport, particularly to return home, out of hours and for those living in rural and remote areas. Providing transport in a cost-effective way is compounded by the current diversity of transport options, which potentially reduces the system capacity to quantify and standardise service provision. There is little evidence of work by governments to ensure national consistency in the area of dialysis patient transport. This survey has outlined scope for future opportunities for streamlining policy in order to pursue both health care system cost savings and improved outcomes for those on dialysis.

References


Renal nursing care is evolving.
Are your skills and knowledge up to date?

Do you have the knowledge and skills required to move to the next level of your nursing career? ACN offers a selection of courses to help you excel in your area of specialty.

The Graduate Certificate in Acute Care Nursing (renal stream) will enhance your knowledge, and clinical expertise within this specialised field. It focusses on adults experiencing alterations in renal function (acute and chronic) and provides a structured theoretical platform which will optimise practical application of renal nursing skills.

ACN also offers a range of distance education single subjects, including:
• (115) Principles of renal nursing
  (Also available in January, pre req. for 233)
• (233) Principles of renal replacement therapy

Next intake for GC courses and single subjects: July 2016
Visit www.acn.edu.au/postgraduate or call 1800 265 534 to find out more about all courses on offer and enrol today!