

Identifying factors associated with the uptake of home dialysis: observational study methodology

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Abstract

Background: The use of home dialysis has been declining in Australia, despite the considerable advantages for patients. Little is known about the factors that contribute to the successful uptake of home dialysis, although increased utility costs have been identified as one possible factor affecting the decision to take up home dialysis.

Objectives: This Australian multicentre observational study will identify factors that either facilitate or inhibit the uptake of home dialysis from patients' perspectives, including the evaluation of whether the current levels of financial support impacts on their decision.

Design: Factors influencing decisions about home or hospital dialysis will be explored from the patients' perspective through survey and interviews. Initially, participants will be recruited from participating dialysis centres and invited to complete a survey. Staff will collect clinical data for all those participating. A subsection of patients will be invited to participate in an individual interview or focus group to gather more information.

Participants: Participants will be recruited from dialysis centres affiliated with the HOME Network, a national initiative to engage health care professionals in the field of home dialysis.

Measurements: Combining the analysis of individual and group data that is both reported and observed will offer an in-depth understanding of patients' perception of home dialysis that will inform policy and practice at both participating centres and in the broader clinical community.

Results: Results obtained will serve as a platform for further research of this relatively unexplored topic.

Keywords

Dialysis, home dialysis, peritoneal dialysis, home haemodialysis, barriers, facilitators.

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Introduction

Haemodialysis (HD) and peritoneal dialysis (PD) are the most common therapies available for people with end-stage kidney disease. People choosing PD often carry out dialysis at home, while HD can be done in the hospital, satellite dialysis units, or at home. Home HD (HHD) and PD therapy are cost-effective modalities, and associated with better patient outcomes. Home dialysis confers financial benefits for the health system, and clinical and social advantages for the individuals and their family (Kerr *et al.*, 2008).

Cass *et al.* (2010) estimated the annual cost of home dialysis to the health service (excluding patients' out-of-pocket costs) to be A\$49,137, compared to A\$79,072 for in-centre dialysis. Home dialysis may be associated with enhanced rehabilitation and a return to work, flexibility in dialysis schedules, time and cost savings from reduced travel to dialysis centres, and improved quality of life (Agar *et al.*, 2010; Pipkin *et al.*, 2010). Despite these considerable advantages, the use of home dialysis has been diminishing worldwide (MacGregor *et al.*, 2006) and in Australia, where the rates of home dialysis decreased from 50% in 1990 to 39% in 2000, 32% in 2005, and 29% in 2010 (Fortnum *et al.*, 2012; McDonald & Hurst, 2011).

Analysis by the Australia and New Zealand Dialysis and Transplant Registry reported for 2006–2010 (Briggs *et al.*, 2011) shows the trend away from home dialysis in Australia. Despite the introduction of innovative therapies such as nocturnal home HD in 2010 providing better lifestyle opportunities and potentially a better health outcome, the percentage of patients choosing home HD remains unchanged, being 9% in 2003 and 10% in 2010. The rates of PD dropped consistently from 24% in 2003, to 22% in 2007 and down to 19% in 2010.

The use of home dialysis therapies varies across jurisdictions in Australia. Figures from 2009, published by Kidney Health Australia in 2012 (Fortnum *et al.*, 2012) showed New South Wales to have the highest rate of use at 14% (HHD) and 28% (PD). Other states show mixed patterns of HHD and PD use. Respective uptake rates in other states are 10% and 20% (Queensland); 12% and 11% (ACT); 8% and 17% (Victoria); 3% and 21% (South Australia); 5% and 25% (Tasmania); 7% and 8% (Northern Territory); and 4% and 22% (Western Australia).

Previous studies have associated the decline of home dialysis with a growth of satellite dialysis units staffed by dialysis nurses (Agar *et al.*, 2010) and increasing age and co-morbidity of the dialysis population (MacGregor *et al.*, 2006). Additional

reasons from patients' reports include fears of and low level of motivation for HHD, lack of self-care ability and family supports, and inadequate resources available such as respite care and financial support (Agar *et al.*, 2010; Lauder *et al.*, 2010; Ludlow *et al.*, 2011; Sinclair, 2008). From health professionals' perspectives, insufficient resources in dialysis units to provide support and education to dialysis patients and lack of a culture of advocacy for home dialysis are contributing to the low uptake. Lauder *et al.* (2010) further suggest that medical staff are willing to recommend home dialysis for patients if patient-specific barriers are identified and dealt with.

Increased utility costs are one known, previously identified factor contributing to the low uptake of home dialysis (Agar *et al.*, 2010). These costs result from elevated water usage, electricity requirements for using dialysis machines and other costs related to travel. State governments and some utility providers offer some financial support for home dialysis patients (Lauder *et al.*, 2010). Financial schemes and subsidies for home dialysis patients vary widely from state to state, between jurisdictions and by concessional status. In 2011, the Finance Taskforce of the HOME Network, an Australian national network for home therapies, in partnership with Kidney Health Australia developed financial fact sheets that provide concise information of the reimbursements available for home dialysis patients. Concessions and rebates are available for eligible patients that fulfil certain criteria. The concessions criteria vary between suppliers and state and territory governments, meaning that many marginal patients may miss out.

A recent survey conducted between October 2014 and June 2015 by Kidney Health Australia (Fortnum & Grennan, 2015) reported that 55% (n=540) of respondents on dialysis are affected financially by their treatment. Twenty-nine per cent of people (1 in 3) rated the effect as moderate or extreme. Financial strain is associated with being less satisfied on dialysis ($p < 0.001$). There was no variance between those on home dialysis and centre-based dialysis. To what extent current levels of available financial support meet patients' needs is not known, and the complexity of rules for concessions suggests that many who are economically disadvantaged may easily miss out on available financial support because they have not accessed the support available.

The extent to which financial/cost factors explained above coexist or interact with other identified influences on dialysis decisions such as fear or low motivation, has not been fully explored to date.

Research question

The methodology explained here outlines a study that will identify factors that facilitate or inhibit the uptake of home dialysis from the perspective of dialysis patients. Experienced clinicians in the research team anticipate that out-of-pocket costs for home dialysis may be the most important contributing factor associated with the low uptake of this modality. Provision of financial support is expected by these clinicians to be identified as essential to improve patients' quality of life and clinical outcomes. In order to avoid bias in data interpretation, a qualitative researcher with no prior clinical experience in renal care (the second author) will be responsible for the initial analysis of the data, which will subsequently be presented to the clinical research team for their comment and further interpretation.

The adequacy of current levels of financial support available to home dialysis patients will be considered in the light of how financial support impacts on their decision to perform home dialysis along with any other factors that may be identified. The study seeks to uncover, for the first time, whether patients in Australia reduce their dialysis hours or frequency due to their inability to manage utility costs. Engaging participants through surveys, followed by semi-structured interviews, will help us understand the place of any financial constraints within the context of other considerations.

As a multicentre site across Australia, where each individual state and territory offers different forms of financial support to dialysis patients, concerns reported by participants will be interpreted in light of the financial support they have had access to, with some comparison between different funding models being possible.

The study is designed as the first multicentre, Australia-wide, observational examination of patients' decision making in light of information about home dialysis and financial support available. The findings will be extremely valuable to inform policies and practices, ensuring relevance to the home dialysis population across Australia.

Objectives

The objectives of the study are as follows:

1. Identify what financial supports may be available to each individual patient and document their access to those supports.
2. Identify the out-of-pocket costs that patients incur during home dialysis.

3. Describe and analyse all factors from the patients' perspective that inhibit the uptake of home dialysis.
4. Identify what relationship exists (if any) between out-of-pocket expenses and the factors that participants report influence the uptake of home dialysis.
5. Examine the relationships (if any) between out-of-pocket expenses, financial support, quality of life as assessed by patients, biological parameters, duration of home/hospital dialysis and dialysis-related complications.

The findings will offer experiential evidence to the team of health professionals and consumer groups working in renal care so that advice can be offered to those deciding between different forms of dialysis treatment.

Methods

Study design

A multicentre, observational, descriptive cohort study using mixed research methods (combined qualitative and quantitative) will be undertaken. Both qualitative and quantitative data will be collected concurrently, thereby triangulating the data set with multiple data sources. The data sources will be biochemical parameters, survey responses and recorded semi-structured interviews. Participant types will be both home and hospital dialysis patients. Participants will be recruited from urban, regional and rural areas across Australia. The data analysis will allow for a shift from description (quantitative data and main themes) to interpretation (examining interrelationship between themes and narratives from the qualitative interview data).

The analysis will begin with a description of the quantitative data collected, followed by the identification of themes in the qualitative survey results, comparing those themes with themes identified from interview data, and, lastly, examining interview data for insights into interrelationship between themes and factors. The design may be described as convergent mixed methods (Creswell, 2014), whereby the quantitative and qualitative analyses will both be carried out and the results of both will be combined to build an understanding of factors affecting the uptake of dialysis treatment methods.

Incorporating both quantitative and qualitative data allows for both succinct descriptions and summaries of factual data integrated with the same participants' reports of their personal experience, which requires qualitative data and qualitative methods of analysis. Findings may indicate the need for either more extensive quantitative or qualitative investigations.

Data

Clinical data — quantitative

Quantitative clinical data will be extracted from patients' medical records by the researchers at the participating centres, using a data extraction form developed by the research team.

Clinical data to be collected include biochemical parameters (haemoglobin, creatinine, urea, potassium, calcium and phosphate), complications of dialysis (infection on dialysis access, hospitalisation due to fluid overload and other dialysis-related), and duration of dialysis treatment. Clinical data will be extracted at two time points over six months (three months prior to and three months after questionnaire completion).

Survey data — quantitative and qualitative

Survey questions will cover the following:

Quantitative

- Demographic information (age, location, language, employment status, concession status, income per week).
- Dialysis treatment and preferences (transport, dialysis method, treatment history).
- Out-of-pocket expenses (consumables, financial assistance received, other costs).
- Barriers and facilitators of treatment method (information, assistance, caring, flexibility, transport, monetary).

Qualitative

- Participants will be asked to provide their own account of their experiences on dialysis and their treatment.
- Participants will be asked to identify barriers and facilitators to home dialysis.

Interview data — qualitative

Participants will be invited to participate in an interview at selected participating centres. Centres will be chosen to be inclusive of urban, rural and regional dialysis populations. Interviews will be conducted to suit patient availability and convenience. Semi-structured interviews, conducted according to a pre-designed template, will deliver consistency, allowing for comparison of content. Interviews will probe reasons for choosing home dialysis. Topics will include:

1. Experience (to date) of the health care system in relation to renal care.

2. Identifying positive aspects of health care.
3. Identifying what has not worked well and offering constructive criticism.
4. Describing perceived burden and barriers to choosing home dialysis.
5. Expenses incurred directly related to dialysis treatment over the previous 12 months.
6. Identifying strategies which may facilitate choosing home dialysis.

Data handling and analysis

Quantitative data (survey responses and clinical data) will be entered into an Excel spreadsheet. Summary statistics and exploration of relationships between survey responses and clinical data will be conducted within Excel as the first step in describing and exploring the data. Summary statistics (means, standard deviations, maximum and minimum values) will be used to describe the health of participants during a six-month period in which they were surveyed and interviewed (if applicable), demographic characteristics, renal care history and expenses incurred.

The quantitative data in the Excel spreadsheet data will be transferred to SPSS for any statistical analysis to be conducted by a biostatistician. This may include t-tests and chi square analysis to examine differences between participants on home versus hospital dialysis and correlation coefficients between survey responses and clinical data.

Qualitative data from the survey will be entered into an Excel spreadsheet so that responses can be tracked back to survey questions answered by each participant. Qualitative data from interviews will similarly be summarised and documented as responses to each of the prompt questions listed above, allowing for comparison between participants as well as retaining the narrative theme for each individual interviewee.

Themes that emerge from within the qualitative data will be identified and examined in terms of their range, similarity across participants, and interrelationship with other themes. How themes relate to each other (for example how financial considerations and employment interrelate) will be examined. Within identified themes, accounts from those on home versus hospital dialysis will be compared and contrasted. Similarly, themes will be examined in terms of whether they emerge differently for those from urban, regional and rural areas. Selected recorded interviews will be transcribed in full following

standard orthographic convention to allow for individual case studies to illustrate interrelationships between themes.

Research sites

The study will be conducted over a two-year period. Data collection will occur in multiple home dialysis centres across Australian states and territories. Researchers at each site will be core members of the HOME Network. Hence it is likely that the investigators will be highly committed to the recruitment and retention of study participants.

Up to eight sites that provide a home dialysis program will be invited to participate. Each dialysis centre will be asked to recruit 30 patients to participate in the study, totalling a maximum number of 240 survey responses. At least 10 of the participants who complete the survey will be invited to be interviewed. All interviews will be recorded. All interview data from each participant will be analysed. Selected interviews will be transcribed verbatim and used as case illustrations.

Ethics

This study will be approved and authorised by the local research governance bodies at each participating site. Participating centres will display a poster advising study details.

Participant recruitment

The site investigator and supporting staff will make a list of centre patients who may be suitable to participate in the study. Participants will need to meet the following criteria:

- Over eighteen years of age.
- Preferred language is English, Chinese or Arabic (surveys will be available in all three languages).
- Clinical records indicate that the potential participant is not pregnant during the data collection period, to avoid confounding results with complex medical conditions that may arise for renal patients who are pregnant.
- Clinical records do not indicate any intellectual or mental health concerns.

The site investigator or their representative will approach potential participants in person or by telephone or email, and briefly explain the study. If the participant is willing to read the information about the study, a package, including the patient information sheet and consent form, will be provided. Once the participant has signed the informed consent form, the survey will be distributed. The investigator will follow up with the participant to collect the completed survey.

Researchers in each site will assign a participant a number, ensuring that the identity of each participant is not revealed to those handling the data.

Once the survey data has been collected, sites suitable to represent a subset of participants will be identified and researchers at those sites will invite participants who have completed the survey to be interviewed. Interviews will be scheduled. Only names of interviewees will be made available to the interviewer. Medical records and other personal details will not be shared with the interviewer.

Study oversight and guidance

This study is a collaborative study between a number of the renal units in Australia and a research consultant from a university. Representatives from each renal unit and the consultant have been aligned to form the study's steering committee. The Dialysis Uptake Factor Steering Committee purview includes:

1. Scientific and operational oversight in conjunction with feedback from the national investigators.
2. Approval of research and manuscripts intended for peer-reviewed publication, as guided by the study's publication policy.
3. Review and approval of new site participation in the study by evaluating funding support, operational feasibility and alignment with overall study goals.
4. Promotion of the findings of the study as a resource for diverse stakeholders across the home dialysis community.

Discussion and clinical practice implications

The impact of kidney disease is felt by individuals, families, co-workers and communities. Improving understanding of treatment decisions from the patient's perspective will ensure that health care providers offer appropriate support and information. By doing so, all those affected, not only the individual patient, will benefit from informed decision making.

Dialysis requires lifestyle changes that can alter work and family life. Financial burdens of altered work arrangements plus the financial burden of ongoing dialysis interact in a complex way. If, as hypothesised, these costs are a significant factor influencing a patient's treatment decisions, decision making needs to focus on financial matters. Understanding how patients balance up potential financial burdens for families against the impact on lifestyle and convenience will provide

extremely valuable information to guide patients' decision making. It is essential that health care providers understand factors affecting decisions from the perspective of patients, not only from the perspective of the health care service. To date, this information has not been gathered in Australia.

Decision aids are currently presented to patients that very broadly refer to costs as mostly being covered by the health service. This leaves many questions unanswered for individual patients. The information gained from this study will enable far more specific information to be included in those decision aids, based on the lived experience of dialysis patients. This will help to prepare patients and their families for any financial costs and raise awareness of available financial support. Knowledge of financial support available to families may remove the financial burden as a major decision-making factor, which will allow for decisions to be made based on clinical and lifestyle factors, rather than cost.

The data will be able to provide information that includes how much home dialysis actually costs the patient:

- In what areas are patients out of pocket?
- Are the subsidies in each state/territory accessed by the patients?
- What are the other key concerns for those choosing home dialysis?
- How do patients overcome potential barriers?
- Which barriers are patients not able to overcome but choose to live with?
- Information for health professionals and government about the key areas of concern that require intervention in order to increase the uptake of home dialysis.

Understanding the overall cost and the implications for the individual patient, rather than understanding cost as only the cost to the health service will inform clinical practice. This will improve efficiency, ensuring that decisions are made that are suited to the circumstances of each patient.

This improvement in service delivery based on improved understanding of financial factors will offer direct savings to the health service. Patients will be more likely to opt for home dialysis (which is less costly to the health service than hospital dialysis) if financial implications can be better explained and if any available financial support can be accessed efficiently. The results of this study will be ideally placed to inform future policy

amendments in the area of dialysis provision and health care planning for those suffering from chronic kidney disease.

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