Australian Nephrology Nurses Views on Home Dialysis: A National Survey

Lydia A Lauder, Marie J Ludlow, Carmel M Hawley, Elizabeth P Richardson, Timothy H Mathew and Colleen E Munro

Lauder, LA., Ludlow, MJ., Hawley, CM., Richardson, EP., Mathew, TH. & Munro, CE. (2011). Australian Nephrology Nurses views on home dialysis: A National Survey. *Ren Soc Aust J* 7(1). 6-12

Submitted August 2010. Accepted November 2010

Abstract

Background

Home dialysis has the potential for significant clinical, psychosocial and economic advantages for the patient and the health system. There is regional variation in the uptake of home dialysis in Australia, suggesting further scope for the expansion of these modalities.

Methods

Between 1 April and 5 August 2009, Australian senior nephrology nurses were invited to complete an online or hard copy survey. Thirty-four questions were asked regarding responders' experience, adequacy of facilities and support structures, attitudes to the use of home dialysis and issues impeding the increased uptake of home dialysis.

Results

Completed surveys were received and analysed from 262 respondents. There was strong support from nephrology nurses for the expansion of home dialysis therapies. The most commonly reported impediments to increased utilisation of home dialysis were: the perception that home haemodialysis patients suffer personal financial disadvantage due to out-of-pocket costs associated with dialysing at home, and an observed lack of physical infrastructure to provide the staffing and resources required to expand home dialysis programs. Nephrology nurses also identified educational, cultural and organisational impediments that are preventing the growth of home dialysis. Other areas of concern for home dialysis programs included limited access to mental health services and respite care for people dialysing at home, and a lack of support from medical administration, area health services and the federal government.

Conclusion

This survey identified support amongst Australian nephrology nurses for the expansion of home dialysis across Australia, and highlighted barriers to accessing these therapies.

Key Words

Practice patterns, health services access, home haemodialysis, peritoneal dialysis, nephrology, nursing

Introduction

The number of people requiring dialysis therapy for End Stage Kidney Disease (ESKD) in Australia is rising by approximately 6% each year (ANZDATA, 2010). A number of factors, such as an ageing population and increasing prevalence of diabetes and hypertension, have contributed to this expanding dialysis population. This increase of dialysis patient numbers has in turn had a significant financial impact on the health system. Comprehensive costing of the economic burden of dialysis in Australia (in 2004 $) indicates that the annual health care costs of ESKD in 2010 will be between $800 million and $900 million (Cass *et al.*, 2006). This represents an increase of approximately 50% from 2004. In addition, there are indirect costs associated with physical, psychosocial and economic issues, which can result in significant financial, vocational, educational, and emotional pressures for individuals, their families and for the wider community.

In recent years, there has been mounting evidence to suggest the use of home dialysis therapy (HDT) is both beneficial to patients with ESKD and cost effective for the health care system when compared to traditional in-centre haemodialysis. For patients with ESKD, advantages of these home therapies 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

Author Details: Lydia Lauder: RN, National Manager Strategic Health Projects and Publications, Kidney Health Australia
Marie Ludlow: BA (Hons) PhD, National Medical Projects Manager, Kidney Health Australia
Carmel Hawley: MBBS (Hons) M Med Sci FRACP, Clinical Director of Haemodialysis, Princess Alexandra Hospital
Elizabeth Richardson: RN BScN MScN, National Health Services Manager, Kidney Health Australia
Tim Mathew: MBBS FRACP, Medical Director, Kidney Health Australia
Colleen Munro: RN, Transplant and Chronic Kidney Disease Clinical Nurse Consultant, Liverpool Health Service

Corresponding Author: Dr Marie Ludlow, National Medical Project Manager, Level 1/25 North Terrace Hackney SA 5069 Australia. Email: marie.ludlow@kidney.org.au

locations to remain in their own homes. (Kutner *et al.*, 2005; Mowatt *et al.*, 2004; Juergensen *et al.*, 2006). Observational data from the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) suggest that undertaking longer and more frequent dialysis sessions, such as those possible with home dialysis, provides a significant survival advantage for patients (Kerr *et al.*, 2008).

From a health care system perspective, utilising HDT to treat patients limits capital expenditure necessary for in-centre and satellite dialysis facilities, reduces the numbers of medical and nursing personnel required to care for dialysis patients and minimises the exposure of patients to hospital-acquired infections. As a result, governments and health departments can achieve huge financial savings when patients undertake dialysis at home rather than in-centre (Cass *et al.*, 2006; Agar *et al.*, 2005). Using Victorian funding mechanisms, Agar *et al.* (2005) demonstrated that compared to conventional satellite HD, even 6 nights per week nocturnal HD represented an annual saving of approximately 10.75%.

Regardless of this, and in spite of the evidence supporting the use of home therapies, the number of people who dialyse at home in Australia is about one-third less than it was in 1970 and this was prior to maintenance PD being available (George, 2005; George, 2009). Although the current rate of home treatment remains greater in Australia than in many other countries (United States Renal Data System (USRDS), 2007), questions arise as to why it has declined and whether anything can or should be done to counter this. The large inter-state variation in home dialysis utilisation provides further evidence that the rate of home dialysis is Australia has scope for improvement. Whereas 14% of the dialysis population in New South Wales undertake home HD, the corresponding rates in South Australia, Western Australia and the Northern Territory are below 5%. The uptake of PD also varies around the country with 28% of New South Wales dialysis patients using this treatment in contrast to only 16% in Victoria (Integrated Care and Ageing Division of the Victorian State Government, 2010).

Individuals often speculate as to the reasons for the progressive decline and geographical patchiness in the use of home dialysis therapies in Australia. Some people may suggest that differences in funding across states for hospital dialysis capacity contribute to geographic variations in home therapy uptake, while others ponder that health professional attitudes towards, and experience with, home therapies may impact home dialysis patient numbers (George, 2005; Holley *et al.*, 1991; Bennett & Oppermann, 2006). Despite these speculations, strong evidence is lacking as to the reasons for the low HDT uptake across Australia. As a result, in late 2009 Kidney Health Australia (KHA) canvassed the opinions of all Australian nephrologists, senior dialysis nurses and dialysis patients about possible explanations for the lack of home therapy utilisation. KHA's hope was to eventually use the knowledge gained from this comprehensive series of surveys to enable health planners to overcome identifiable impediments to the expansion of home dialysis throughout the country.

Nephrology nursing has evolved as a distinct specialty area of nursing, with more and more nephrology nurses being instrumental in training home dialysis patients and setting up home dialysis programs (Bonner, 2007; Leitch *et al.*, 2003). This present publication will outline the survey responses provided by senior nephrology nurses with an interest in dialysis.

Methods

The KHA Home Dialysis Advisory Group (consisting of nephrologists, nephrology nurses, dialysis consumers and a representative of the medical technology industry) together with the Renal Society of Australasia (RSA) designed a nephrology nursing survey with 34 questions that respondents could answer anonymously. Categorical survey questions included location of unit and nursing experience. Questions regarding adequacy of existing facilities, adequacy of support for home dialysis, general renal unit philosophy regarding home dialysis, and impediments to home dialysis were presented as a 5-point Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly agree).

Free-text questions were used to identify any other potential impediments to home dialysis and to elicit opinions regarding incentives to increase the utilisation of HDTs (copies of the questionnaire available on request). The questionnaire was pre-tested by the Advisory Group and professional staff of KHA. KHA directed the survey to all dialysis nurses currently practising in Australia (identified by being members of the RSA or otherwise known to KHA). The survey was promoted through the KHA website, by media release, by direct notification in the form of flyers to all dialysis units in Australia and by word-of-mouth at national conferences. Nephrology nurses were asked to complete the survey on-line between 1st April and 5th August 2009 or to return a hard copy by mail within the same timeframe. Hard copies could be printed from the website or requested through KHA. KHA staff compiled the results and analysed them using PASW Statistics 18 (Chicago, IL, USA).

Results

A total of 262 completed surveys were returned or submitted online. The demographic characteristics of the sample are displayed in Table 1. The majority of respondents were based in the Eastern States and practiced in metropolitan public hospitals. There were no respondents from the Northern Territory. While this limits the ability to generalise the survey results on a national level, the uniqueness of the predominantly Indigenous Australian dialysis population in this jurisdiction potentially warrants a separate survey. Most nurses had worked in more than one Renal Unit and had at least five years experience in the renal specialty. Although 40% of respondents reported their current Unit did not have a home HD or PD training Unit, the majority of nurses indicated they had previously worked in a Unit that trained patients for home dialysis.

Table 1: Demographic and practice characteristics (N=262)

	N (%)
State of Renal Unit	
Australian Capital Territory	6 (2%)
New South Wales	66 (25%)
Northern Territory	0 (0%)
Queensland	59 (23%)
South Australia	14 (5%)
Tasmania	12 (5%)
Western Australia	24 (9%)
Victoria	81 (31%)
Location of Renal Unit	
Metropolitan	146 (56%)
Regional (non-metropolitan city)	81 (31%)
Rural (country town)	35 (13%)
Health-care facility	
Public hospital based	212 (81%)
Private hospital based	17 (7%)
Public non-hospital based	13 (5%)
Private non-hospital based	20 (8%)
Area of current employment*	
In-centre HD	42%
Satellite HD	50%
Home HD training	29%
PD training	27%
Kidney transplantation	11%
General nephrology inpatient care	16%
General nephrology ambulatory care	21%

* Categories were not mutually exclusive

Adequacy of Facilities

Nurse Unit Managers only were instructed to answer a series of questions relating to adequacy of their existing facilities. Of the 97 Nurse Unit Manager respondents, the majority (66%) considered that the facilities available to them were inadequate to provide optimal dialysis treatment for the numbers of patients presenting for care. Nurse Unit Managers also reported high levels of dissatisfaction with the facilities provided for a range of chronic kidney disease services. The majority of respondents reported that their existing facilities were inadequate for the provision of home HD training (55%), in-centre HD (55%), palliative care (52%), and satellite HD (50%). Similarly, between 42% and 49% of Nurse Unit Manager respondents did not believe that their existing facilities were adequate for the provision of inpatient and outpatient treatment, pre-dialysis services, CKD management, training for PD, and transplant services.

Adequacy of Support for Home Dialysis

Only nurses working in home haemodialysis and peritoneal dialysis were asked to respond to this question. Most nurse respondents were satisfied with the degree of support for home dialysis they received from their Director of Nephrology, other nephrologists within their unit, maintenance technicians, water set-up and treatment advice, and supply of automated peritoneal dialysis machines (Table 2). The majority considered that adequate allied health support for home

dialysis was available from social workers and dietitians, but they were dissatisfied with the availability of mental health services. Most respondents reported that access to respite care was inadequate. Although respondents indicated they received adequate support for home dialysis from their nursing administration, they were not satisfied with the support they received from their medical administration, their area health service, and in particular, the federal government.

Renal Unit Policy

Approximately half the respondents (52%) stated their Unit gave patients free choice in relation to mode of therapy, with 68% also reporting their Unit encouraged patients to do home based therapies. Only 24% indicated their unit had a "PD first" policy, and 42% stated their Unit did not have a standard unit policy about choice of modality, but rather individual physicians adopted their own personal policy.

Impediments to Home Dialysis

The overwhelming majority of respondents (91%) agreed that Australia should be expanding the use of home therapies for dialysis patients. Figures 1 and 2 show the responses received to questions asked about perceived barriers to the uptake of home dialysis in Australia. There were two principal impediments that nurses identified. Firstly, a perception that home HD patients suffer personal financial disadvantage compared with institutionally treated patients (46%) and secondly, that a lack of physical infrastructure in their Renal Units posed a barrier to expansion of both home HD (59%) and PD (40%). The nurses expressed little support for the views that financial disadvantage to the Renal Unit, lack of support by industry, or lack of expertise by nephrologists or nurses were barriers to expanding home dialysis therapies in their Units.

Table 2. Support for Home Dialysis

	Percentage of respondents who strongly agree or agree they receive adequate support	
Do you receive adequate support from:	**HD***	**PD#**
Director of Nephrology	74%	65%
Other renal physicians within your Unit	77%	68%
Access surgeons	50%	57%
Social work	74%	73%
Psychology/psychiatry	34%	35%
Dietitians	80%	81%
Maintenance technicians	89%	-
Water set-up/treatment advice	76%	-
Business staff with regards to purchasing dialysis equipment	48%	-
Supply of automated peritoneal dialysis machines	-	87%
Home visits	79%	79%
Respite care	41%	30%
Nursing administration	60%	60%
Medical administration	51%	48%
Area health service	44%	40%
Federal government	22%	19%
Industry	49%	63%

* Only home HD staff responded. Due to missing responses, N ranged from 85 to 101
# Only PD training staff responded. Due to missing responses, N ranged from 83 to 94

Table 3. Other reported impediments to home dialysis in Australia

Patients	Increased age
	Increased number of co-morbid conditions
	Lack of self-motivation
	Patient abilities – cognition, dexterity, physical strength
Staff	Inadequate number of staff trained in home HD
	Patients not being referred
	Nurses not aware of benefits of home dialysis
	Limited access to surgical time and trained surgeons for catheter insertion
System	Limited pre-dialysis education regarding home dialysis
	Lack of psychosocial support for patients and carers
	Lack of clinical and/or technical support
	Late referral leading to acute initiation if in-centre dialysis – then hard to move patient home

Figure 1. Barriers to home HD uptake in Australia

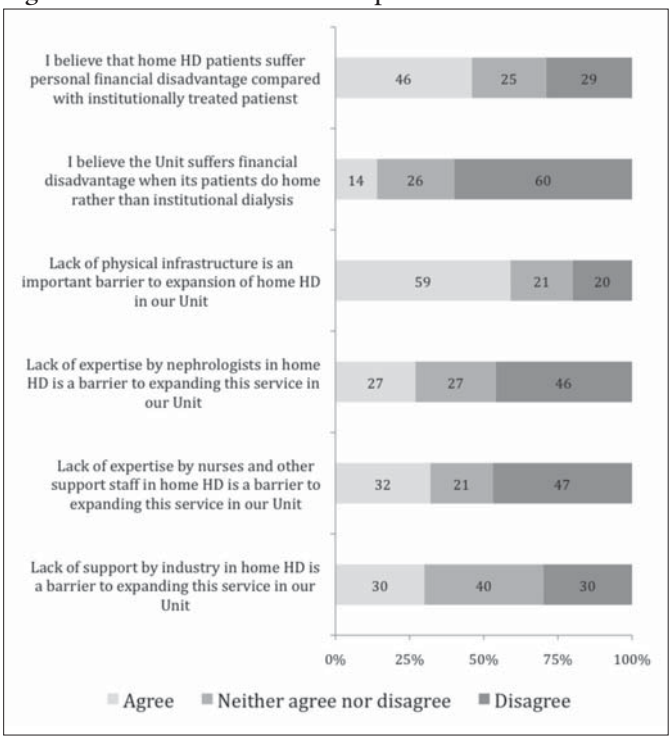
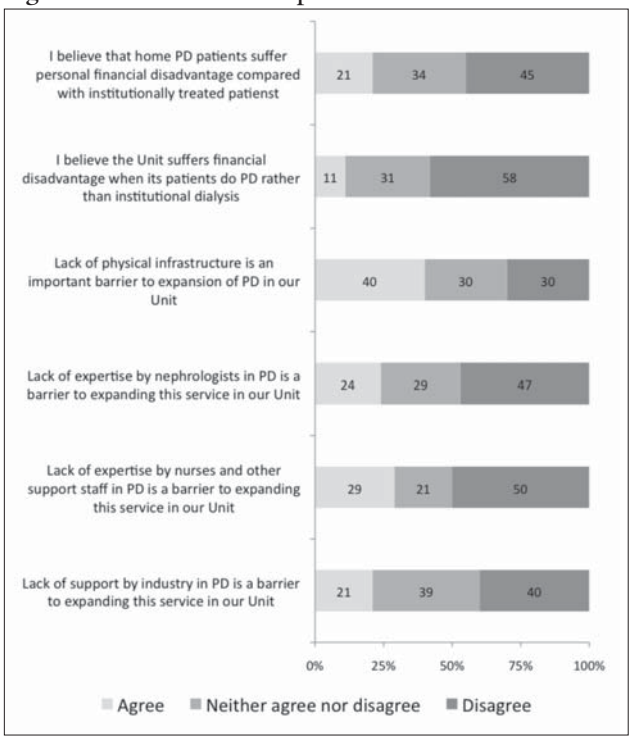


Figure 2. Barriers to PD uptake in Australia



Over half of respondents volunteered other impediments that they considered limited the uptake of home dialysis, focusing on patient, staff and system issues (see Table 3). Most nurses indicated that they would recommend increasing the proportion of patients in their Unit receiving home dialysis (HD 76%, PD 67%) if these impediments could be overcome.

Incentives to increase home dialysis

Respondents suggested several incentives they believed would increase the uptake of home dialysis. The most commonly reported were financial incentives, including reimbursement of out-of-pocket costs for training and setting up, payments for dialysis carers, and direct payments to Renal Units. Enhanced support for people dialysing at home such as improved access to respite care and holiday dialysis, and clinical and technical support (including access to surgeons for PD catheter insertion) were also reported as incentives to increase home dialysis. Respondents also frequently indicated that improved infrastructure such as training Units closer to patients' homes and an increased number of dedicated home dialysis nurses would also encourage more adoption of home dialysis.

Discussion

This paper presents the results of the nephrology nursing component of a four-part assessment in which the opinions of dialysis patients, nephrology nurses, nephrologists and the medical directors of renal Units were canvassed. According to the surveyed nephrology nurses, the most commonly reported barriers to expanding home dialysis programs were out-of-pocket costs for patients using home HD as compared to in-centre HD, and a lack of physical infrastructure to support the execution of home dialysis programs. This finding is consistent with the results of the nephrologists and medical director's survey (Ludlow *et al.*, 2010). Additionally, several issues relating to patients, culture and organisational systems were identified by nephrology nurses as being possible barriers to the uptake of home dialysis in Australia.

Surveyed nurses expressed the view that reimbursement of patient's out-of-pocket costs for training and set-up would increase the uptake of home dialysis. It is disappointing that a therapy that could potentially save the health care system millions of dollars annually (Cass *et al.*, 2006) is perceived to come at a financial cost to the patient, and the reasons for these perceptions should be further explored. Provision of a simple reimbursement of legitimate out-of-pocket costs could provide a solution to overcoming such problems for patients.

A recently implemented Victorian government funding model which provides incentive payments to hospitals for each patient they put on home dialysis, in addition to annual lump sum reimbursements to patients for out-of-pocket home dialysis expenses, may prove effective in positively impacting home dialysis utilisation rates (Integrated Care and Ageing Division of the Victorian State Government, 2010).

Nurses surveyed in the current study also identified several perceived and/or real demographic, geographical and clinical contraindications to undertaking home dialysis. These factors all relate to enhancing the capacity for self-care, and should not automatically preclude a patient from being offered home dialysis. As affirmed by Lynn and Buttimore (2005), renal staff should adopt the approach that the more patients can do for themselves the better the outcome. This often requires flexible solutions for individual patients and adaptation of traditional education and training methods. Examples include offering training outside of the conventional Monday to Friday routine, modifying the dialysis equipment so that lifting is not an issue, adapting educational resources to suit different populations, and training nursing home staff to assist with PD (King, 1999).

Organisational and cultural impediments, such as lack of referral of patients, limited access to surgeons and inadequate number of staff trained in HD, were also raised by surveyed nurses as issues which are limiting the uptake of home dialysis in Australia. Nurses also reported that deficiencies currently exist in the provision of psychosocial support for patients dialysing at home and their carers. These impediments were similarly identified by Bennett and Opperman (2006) in their discussion of literature relating to nursing barriers to nocturnal home haemodialysis. It is evident that these barriers are not insurmountable and, as previously reported, can be remedied by the implementation of multidisciplinary teams comprising nephrologists, nurses and clinical technicians who are skilled in training patients for home dialysis and are certain of their roles (Lynn & Buttimore, 2005).

Consistent with these cultural/organisational barriers, the nurses also reported a perceived lack of support from medical administration, from the local level to the federal government, to appropriately fund and resource home dialysis programs. This reflects a counter-productive approach by administrators as there is a great potential for financial savings if home-based dialysis therapies were more widely utilised, especially with the prospective increase of 8% per year of patients requiring dialysis therapies (Cass *et al.*, 2006; Agar *et al.*, 2005; Mowatt *et al.*, 2004; Bennett & Oppermann, 2006). Enhanced engagement of nephrology nurses with clinical and hospital networks may assist in identifying these perceived barriers and potentially garnering support for home therapy from medical administration and health policy makers.

The survey also identified a current lack of patient education regarding home dialysis, particularly in the pre-dialysis phase. Pre-dialysis education has been shown to have a pivotal role in influencing the dialysis decision-making process (Manns *et al.*, 2005; Goovaerts *et al.*, 2005; Little *et al.*, 2001; Marron *et al.*, 2005; Wuerth *et al.*, 2002; Ahlmen *et al.*, 1993). Limited knowledge regarding home dialysis not only increases the likelihood of declining home dialysis as an initial treatment option (McLaughlin *et al.*, 2003), but also reduces the probability of changing to home dialysis once dialysis has been initiated. However, there is evidence from a randomised controlled trial that active participation in a pre-dialysis education program designed to improve self-efficacy in undertaking dialysis at home results in an increased likelihood of choosing a home dialysis modality (McLaughlin *et al.*, 2003).

The overwhelming majority of nurse respondents agreed that Australia should be expanding the use of home therapies in Australia. Nurses have a privileged role to play in increasing the uptake of home dialysis. They are highly influential in helping patients choose a dialysis modality (Holley *et al.*, 1991), and are effective patient advocates (Bennett & Oppermann, 2006). Nurses need to be trained, supported and encouraged to support patients to undergo home dialysis therapies (Bennett & Oppermann, 2006; George, 2005).

Conclusion

We believe this is the first survey of nephrology nurses' opinions on home dialysis undertaken in Australia. Previous research into barriers to home dialysis is limited and differences in health care systems hinder international comparisons. The overwhelming majority of nurse respondents agreed that Australia should be expanding the use of home therapies. The survey suggests that nurses believe reimbursing patients for out-of-pocket costs for set-up and training for home dialysis therapies, and more appropriate resourcing of renal teams who train and maintain these patients at home will overcome some of the barriers to the uptake of home dialysis therapies in Australia.

Reference

Agar, J. W. M., Knight, R. J., Simmonds, R. E., Boddington, J. M., Waldron, C. M., & Somerville, C. A. (2005). Nocturnal haemodialysis: An Australian cost comparison with conventional satellite haemodialysis. *Nephrology, 10,* 557-570.

Ahlmen, J., Carlsson, L., & Schonborg, C. (1993). Well-informed patients with end-stage renal disease prefer peritoneal dialysis to hemodialysis. *Peritoneal Dialysis International, 13,* S196-S198.

ANZDATA (2010). *The 32nd ANZDATA Registry Report* Australia and New Zealand Dialysis and Transplant Registry, Adelaide, South Australia.

Bennett, P. N. & Oppermann, W. (2006). Are nurses the key to the increased uptake of frequent nocturnal home haemodialysis in Australia? *Renal Soc Aust J, 2,* 22-29.

Bonner, A. (2007). Understanding the role of knowledge in the practice of expert nephrology nurses in Australia. *Nursing and Health Sciences, 9*, 161-167.

Cass, A., Chadban, S., Craig, J., Howard, K., McDonald, S., Salkeld, G. *et al.* (2006). *Economic Impact of End-Stage Kidney Disease in Australia* Kidney Health Australia.

George, C. R. P. (2005). History of home haemodialysis in Australia. *Nephrology, 10,* 215-221.

George, C. R. P. (2009). The development of home dialysis in Australia. *Renal Society of Australasia Journal, 5*, 97-101.

Goovaerts, T., Jadoul, M., & Goffin, E. (2005). Influence of a pre-dialysis education program (PDEP) on the mode of renal replacement therapy. *Nephrology Dialysis Transplantation, 20,* 1842-1847.

Holley, J. L., Barrington, K., Kohn, J., & Hayes, I. (1991). Patient factors and the influence of nephrologists, social workers, and nurses on patient decisions to choose continuous peritoneal dialysis. *Advances in Peritoneal Dialysis, 7,* 108-110.

Integrated Care and Ageing Division of the Victorian State Government (2010). Victorian Maintenance Renal Dialysis Program. *http://www.health.vic.gov.au/renaldialysis/funding.htm* [accessed 01/08/10].

Juergensen, E., Wuerth, D., Finkelstein, S. H., Juergensen, P. H., Bekui, A., & Finkelstein, F. O. (2006). Hemodialysis and peritoneal dialysis: patients' assessment of their satisfaction with therapy and the impact of the therapy on their lives. *Clin J A Soc Nephrol, 1*, 1191-1196.

Kerr, P. G., Polkinghorne, K. R., & McDonald, S. P. (2008). Home hemodialysis in Australia: Current perspective. *Hemodialysis International, 12,* S6-S10.

King, M. (1999). Nursing Application: Unique peritoneal dialysis nursing practices in Australia. *Peritoneal Dialysis International, 19,* 394-395.

Kutner, N. G., Zhang, R., Barnhart, H., & Collins, A. J. (2005). Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant, 20,* 2159-2167.

Leitch, R., Ouwendyk, M., Ferguson, E., Clement, L., Peters, K., Eidenheim, P. *et al.* (2003). Nursing issues related to patient selection, vascular access, and education in quotidian hemodialysis. *American Journal of Kidney Disease, 42,* 56-60.

Little, J., Irwin, A., Marshall, T., Rayner, H., & Smith, S. (2001). Predicting a patient's choice of dialysis modality: Experience in a United Kingdom renal department. *American Journal of Kidney Diseases, 37,* 981-986.

Ludlow, M. J., George, C. R. P., Hawley, C. M., Mathew, T. H., Agar, J. W. M., Kerr, P. G. *et al.* (2010). How Australian Nephrologists View Home Dialysis: Results of a National Survey. *Nephrology, In press.*

Manns, B. J., Taub, K., Vanderstraeten, C., Jones, H., Mills, C., Visser, M. *et al.* (2005). The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney International, 68,* 1777-1783.

Marron, B., Martinez, O., Salgueira, M., Barril, G., Lamas, J. M., Martin, M. *et al.* (2005). Analysis of patient flow into dialysis: Role of education in choice of dialysis modality. *Peritoneal Dialysis International, 25,* S56-S59.

McLaughlin, K., Manns, B., Mortis, G., Hons, R., & Taub, K. (2003). Why patients with ESRD do not select self-care dialysis as a treatment option. *Am J Kidney Diseases, 41,* 380-385.

Mowatt, G., Vale, L., & Macleod, A. (2004). Systematic review of the effectiveness of home versus hospital or satellite unit hemodialysis for people with end-stage renal failure. *Int J Technol Assess Health Care, 20,* 258-268.

United States Renal Data System (USRDS) (2007). *2007 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States.*

Wuerth, D. B., Finkelstein, S. H., Schwetz, O., Carey, H., Kliger, A. S., & Finkelstein, F. O. (2002). Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or hemodialysis. *Peritoneal Dialysis International, 22*, 184-190.