

Home haemodialysis: a literature review

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Abstract

Background: The number of people with end stage kidney disease is growing rapidly in Australia and health care resources are strained due to fiscal limitations and a changing workforce. One strategy to cope with the strain on health resources is to increase the number of patients performing self-care dialysis at home.

Aim: A literature review was conducted to answer the question: Why do patients who have achieved self-care status in the community haemodialysis setting choose not to undertake home haemodialysis?

Methods: A literature search was carried out in Medline, Cinahl, Proquest dissertation and thesis database, PsycINFO and the Cochrane library (1990 – December, 2007) using text words for hemodialysis (HD), home haemodialysis (HHD), barriers, intervention, education, socialisation, socialization, self efficacy, attitude, culture, community, satellite, self care ability, limited care, modality choice, personality traits, transition and patient experience

Results: The core body of literature concerning home haemodialysis can be categorised by: Prevalence, trends/variations, determinants of modality selection, benefits of home haemodialysis and interventions to promote self-care dialysis.

Conclusion: Further research is required to describe the experiences and opinions of patients who perform HD independently in community satellite units and why they choose not to undertake HHD. Affording them this opportunity will circumvent the natural tendency of clinicians to assume that they know what these patients need. With this understanding, quantitative studies could then be initiated that would evaluate interventional programs which support the transition to HHD, based on identified patient needs, not researcher assumptions.

Introduction

This paper reports a literature review that was conducted to answer the question: Why do patients who have achieved self-care status in the community haemodialysis setting choose not to undertake home haemodialysis (HHD)? While there is a vast amount of

literature in this field, it exists mainly in a quantitative form. There is an under representation of qualitative studies within the literature, with consideration only being given to incident end stage kidney disease (ESKD) patients or prevalent patients already performing self-care dialysis (SCD) modalities. The current

Key Words

Home haemodialysis, dialysis, chronic kidney disease, end stage kidney disease, review, culture, self care

body of literature concerning HHD can be sub-categorised by: prevalence, trends/ variations, determinants of modality selection, comparative benefits of HHD, interventions to promote SCD, aspects of patient experiences of HHD, and anecdotal evidence/review articles. This paper considers key research in these areas and makes recommendations for further research that may facilitate an increase in the number of prevalent limited care patients transitioning to HHD.

Background

A glomerular filtration rate below 15ml/min is incompatible with maintaining homeostasis within the body (Cass et al. 2006). It is at this stage that a person is classed as having ESKD and must choose either a renal replacement therapy or to withdraw from treatment. Renal replacement therapy consists of three modalities, peritoneal dialysis, haemodialysis (HD) or kidney transplantation. HD can be further stratified to include HHD and in this instance, along with peritoneal dialysis, is classified as SCD. Patients are further described as being either incident or prevalent, these classifications serve to describe whether they are starting a dialysis modality for the first time or are currently on a form of renal replacement

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therapy respectively. Using the terms incident or prevalent affords the opportunity to describe a person within the context of their dialysis trajectory. In Australia, excluding renal transplant, satellite HD is the most prevalent form of renal replacement therapy followed by hospital based HD, peritoneal dialysis and HHD respectively (ANZDATA, 2008).

The number of individuals with renal insufficiency in Australia is increasing progressively and nephrology departments are under a great deal of pressure to deal with these increases with a finite level of resources available (ANZDATA, 2008; Cass et al. 2006; Hawthorne, 2001). These increases can be directly attributed to the aging of the population, better screening techniques for kidney disease and the increasing incidence of diabetes and hypertension both of which can lead to ESKD (Cass et al. 2006; NSW Health, 2006; Zimmet et al. 2001).

Patients receiving HD in community satellite units in one sector of the Hunter New England Area Health Service (HNEAHS) are classified as either 'high dependent' or 'limited-care'. High dependent patients require full assistance with their HD procedure, whereas limited care patients undertake HD with minimal or no intervention by the nursing team, they are essentially 'self-caring'. The only assistance that may be required by these patients is with cannulation of vascular access. SCD is under utilised within the HNEAHS. The total number of patients undertaking SCD is estimated at 42% of which 25% of people perform peritoneal dialysis and 17% perform HHD (ANZDATA, 2008). These estimates place HNEAHS slightly above the state average for SCD distribution. In New South Wales, the Department of Health has established a target benchmark for all SCD modalities of 50%, which would be distributed 30% for peritoneal dialysis and 20% for HHD (NSW Health, 2006).

Search strategy

A literature search was carried out in Medline, Cinahl, Proquest dissertation and thesis database, PsycINFO and the Cochrane library (1990 - December, 2007) using text words for home hemodialysis, home haemodialysis, barriers, intervention, education, socialisation, socialization, self efficacy, attitude, culture, community, satellite, self care ability, limited care, modality choice, personality traits, transition and patient experience. The use of Australian and American English spelling variations in addition to reviewing reference lists of identified key papers afforded additional reliability to the literature search.

In 1960 Scribner et al. (cited in MacGregor et al. 2006) reported the first ever HHD treatment which occurred in Seattle, USA. Due to the rapid changes in renal care and technology, however, papers were only included in this review if they were published after 1990 to ensure relevance to today's practice. To date, research has largely considered the barriers of SCD (Little et al. 2001; McLaughlin et al. 2003; Mehrotra et al. 2005), how to overcome them (Goovaerts et al. 2005; Manns et al. 2005), and the benefits to incident patients choosing SCD (McGregor et al. 2000; Mowatt et al. 2003). The primary focus has been on modality choice at the predialysis stage of the chronic kidney disease continuum. This literature search revealed a paucity of evidence on interventions to overcome these barriers. No published studies exist on this transition of patients from either hospital or satellite based HD to HHD. Finally, the literature review revealed few qualitative studies which considered the experiences of patients currently performing HHD.

Considerations when reviewing renal literature

The technology associated with the delivery of renal replacement therapy has progressed rapidly over the years. As such, any review of the renal literature

needs to consider the context of the study in relation to its year of publication and the technologies being utilised. For example McGregor et al. (2000) discussed the use of mercury sphygmomanometers and acetate based dialysate when discussing the New Zealand experience with HHD. Advances in dialysate technology have seen the emergence of bicarbonate based dialysates due to the complications associated with acetate use. To further illustrate, the majority of studies reviewing the cost effectiveness and efficacy of HHD, poorly report dialysis duration, frequency and types of equipment used (Mowatt et al. 2003). As a result any generalisations from some studies must be made with extreme caution. Additional difficulties exist when comparing results of studies for efficacy of HHD due to the variations in treatment protocols that are utilised internationally. These protocols include slow daily, nocturnal, or short daily dialysis, which provide a higher dialysis dose and have been shown to provide better outcomes (Mowatt et al. 2004). It is well known that HHD provides more flexibility in the frequency and duration of HD, which is generally not feasible in conventional hospital or satellite units (Agar, 2005). This, in addition to patient selection bias for HHD, must also be considered when evaluating reported patient mortality, morbidity and quality of life data. Finally the international variations that exist in modality distribution, case mix and reimbursement schemes must also be taken into consideration when reviewing and comparing research results.

Comparative benefits of home haemodialysis

Renal transplantation is the most cost effective form of renal replacement therapy, followed by HHD, peritoneal dialysis, satellite HD and hospital HD respectively, but is restricted due to limited organ availability (Cass et al. 2006). The fiscal benefits afforded by HHD provide a cost effective solution to

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a cost inhibited health economy (Lynn & Buttimore, 2005). HHD can support the projected increase in the numbers of patients requiring renal replacement therapy which is unlikely to be associated with a parallel increase in the nephrology work force (Gardner et al. 2007).

Mowatt et al. (2003) conducted a systematic review of the literature to assess the effectiveness of HHD versus other forms of HD. They concluded that patients receiving HHD were more likely to work, have lower mortality rates, experience less hospitalisation, less intradialytic complications and have a better quality of life than satellite or hospital based HD patients. Additionally, after adjusting for confounding variables, they found that individuals who chose HHD tended to be younger in age and have less co-morbid complications than those dialysing in other settings.

MacGregor et al. (2000) in a retrospective single unit analysis conducted in New Zealand concluded that HHD afforded better rehabilitation and blood pressure control, in addition to longer treatment times which combined may contribute to better survival rates than those seen in hospital based patients. These studies are consistent with Woods et al. (1996) earlier observations that, after adjusting for confounding variables of age, diagnosis and comorbidities, survival rates for HHD patients remained higher than for hospital based HD patients.

International trends and variations in self care dialysis modalities

Marked variation exists in the prevalence of HHD internationally with additional variation also seen within countries. State variation alone in Australia varies from a low of 5.1 per million population (pmp) in the Northern Territory to a high of 74.5pmp in New South Wales/ Australian Capital Territory (MacGregor et al. 2006). In a retrospective analysis of 33 national and regional renal registries, MacGregor et al. (2006) found that

variations existed in the prevalence of HHD which could not be attributed to healthcare expenditure, prevalence of diabetic nephropathy or population density. This may, in part, be explained by local practice variations. Despite a global decline in HHD prevalence, Australian, New Zealand, Finish and French renal registries show an increase in HHD prevalence (MacGregor et al. 2006).

Despite lower population densities, Australia and New Zealand have the highest rates of HHD pmp in the world (MacGregor et al. 2006). This has been born out of necessity due to the geographical isolation of regional patients who do not have access to mainstream city dialysis services (Agar 2005). In a report on global modality utilisation, Grassman et al. (2005) reported the worldwide prevalence of HHD to be a mere 0.4%. In Australia and New Zealand there is a 9% and 15% prevalence of patients utilising HHD respectively (ANZDATA, 2008). Whereas countries like Canada (2%) and the United States (0.4%) report significantly lower usage (MacGregor et al. 2006). Nesrallah and Mendelssohn (2006) attributed the global decline to a lack of infrastructure and clinical experience with HHD. Nissenson et al. (1997) argued very early that the way HHD is reimbursed is a major contributor to its decline in the United States. This argument is not the situation in Australia. In November 2005, the Australian Federal Government introduced a financial incentive for managing nephrologists through Medicare item 13104 which aims to reward managing nephrologists for sustaining patients on HHD (MacGregor et al. 2006). The effects of this initiative remain to be seen due to the one year delay in data reporting from the ANZDATA registry.

The advent of improved peritoneal dialysis and renal transplantation techniques, increases in community

satellite dialysis units, an aging population coupled with patients who have multiple co-morbid conditions have all contributed to the decline in HHD (George, 2005; MacGregor et al. 2006:1934; Nesrallah & Mendelssohn, 2006). From an American perspective, Blagg (2000) attributed the increase in 'for profit' units and insufficient financial reimbursement to cover HHD training and support. He additionally blamed the passivity of staff and the genesis of production line HD mentalities as contributors towards the decline in HHD.

Moran and Kraus (2007) maintained that it is unrealistic to expect the prevalence of HHD returning to the early 1970's peak of 40% seen in the United States. The deteriorating trend in HHD is not isolated to the United States where most of the HHD literature is generated. Australia has experienced a decline in HHD prevalence from >35% in 1979 to 9% in 2005 with HHD being notably replaced by satellite HD (Agar, 2005; ANZDATA, 2008). Blagg (2005) asserted that a culture change is required to arrest the international decline in HHD suggesting this can be done by ensuring earlier referral to nephrologists, the timely placement of vascular access (thus avoiding emergency hospital based HD), and by incorporating a SCD focus into chronic kidney disease programs.

Culture change

In conducting a review of the history of HHD in Australia, George (2005) argued that renal physicians might also be partly to blame for contributing to the poor uptake of HHD. He suggested that nephrologists may find it is easier and less time consuming to refer a patient to limited care, HD than to resolve complex 'non-renal' psychosocial difficulties associated with assisting patients to overcome natural fears and assume personal responsibility for their health management.

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Some patients see their dialysis schedules as a precious form of social interaction and view SCD as a modality choice that would push them into social isolation (Collins, 2003). Patients appreciate the sense of community and the development of friendships which occurs in HD units (Collins, 2003; Stack, 2002). Agar (2005, p227), when discussing the uptake of nocturnal HHD, suggested that the socialisation patients experience within satellite units may be too strong for them to be realistically “shaken free” from their hold. This statement perhaps reflects the passivity of health professionals Blagg (2000) alluded to. On the contrary, Feraud and Wauters (1999, p254) argued that it is the patients who experience passivity and psychological regression and that staff must “fight continuously” to prevent this.

The renal team has a responsibility to reliably inform patients about the benefits afforded by HHD modalities, and not place them in the ‘too-hard’ basket. Patients who are socialised into the culture of satellite units may become reliant on nursing staff and experience a shift in their locus of control. As a result, patients begin to discard their responsibility of self-management and develop learned helplessness (Blagg, 2005). This may be averted if units have an underlying culture of independence that is fostered within all facets of the nephrology department, beginning with the pre-dialysis chronic kidney disease programs. As Schatell (2005) argued, the fundamentals of self-management and self-efficacy are associated with advanced functioning and well being which may predict lower hospitalisation and mortality rates. Nursing staff play an integral role in nurturing and developing these principles (Blagg, 2005). Nephrology departments need to champion the values of self-efficacy and autonomy, which are integral to transferring the locus of control back to the patient (Bevan, 2000; Lynn & Buttimore, 2005).

Determinants of modality choice

The debate continues within the literature over patient suitability for HHD and is largely based on anecdotal evidence. Whereas studies reporting the clinical and social predictors that influence dialysis modality selection, have essentially reached agreement. Moran and Kraus (2007) suggested that patients who are motivated, less than 55 years of age, are healthy with no significant comorbidities are most suited to HHD. Alternatively, Young et al. (2004) reported that patients in the 50–65 year age bracket were less likely to experience HHD modality failure than younger patients. Others suggest that willingness to accept a modality is a more appropriate predictor than age (McGregor, 2000). Some conjecture also exists as to whether or not a support partner is required. This is largely dependent on the degree of support required, and as such, decisions should be made on a case by case basis (Lindley, 2006; Moran & Kraus, 2007). These selection criteria arguments may resolve after Chow (2005) reported that a piloted pre-training assessment tool for home dialysis had sufficient validity and reliability to successfully assess patient suitability for SCD. However, the literature to date has not reported its use and it remains to be seen if the international renal community adopts this tool.

Several studies have reported variables that influence the uptake of peritoneal dialysis over HD, with little to no mention of HHD (Jager et al. 2004; Little et al. 2001; Miskulin et al. 2002; Stack, 2002). In fact, some of these landmark studies excluded HHD patients from the study or reported no HHD patients in their sample selection (Little et al. 2001; Miskulin et al. 2002; Stack, 2002). This represents the low prevalence of HHD despite the benefits that have been reported. McLaughlin et al. (2003) conducted a multi-centre cross sectional survey of 173 Canadian patients treated in hospital based HD units to determine

why prevalent HD patients do not choose SCD modalities. To date, this is the only study that has considered the opinions of prevalent HD patients. McLaughlin et al. (2003) found that the lack of explanation of techniques, fear of failure and social isolation were significant knowledge and attitudinal barriers contributing to the unwillingness of patients to perform SCD. In addition, they found needle phobia, fear of substandard care/change, age and lack of space at home to further impede the uptake of SCD.

Several studies (Mehrotra et al. 2005; Stack, 2002; Winkelmayer et al. 2001) have found similar results in incident American dialysis patients to those of the prevalent HD population studied by McLaughlin et al. (2003). These studies concluded that, in the United States, an incomplete presentation of the available treatment modalities for ESKD, increasing age, educational qualifications, socioeconomic status, educational qualifications, comorbidities, delayed referral, patient choice, ethnic differences and the geographical distance from treating units were major factors behind the decreased uptake of home based dialysis modalities (Mehrotra et al. 2005; Stack, 2002; Winkelmayer et al. 2001). The only anomaly within this cluster of findings was that Winkelmayer et al. 2001, contrary to Mehrotra et al. (2005) and Stack, (2002), found that the timing of referral was not likely to influence modality choice.

Bass et al. (2004) used a novel approach when investigating the strengths of patient modality preferences. Except with patients living alone, they found no association between patient characteristics and a willingness to switch modalities despite alternative therapy offering a proposed ‘hypothetical 20%’ increase in survival. Bass et al. (2004) suggested that these strong preferences may be attributed to the success of health service decision making strategies. The study sample had a high percentage of

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African American (88%) participants and did not report previous modalities experienced by the patients. With ethnic differences being shown previously to influence modality selection (Stack, 2002; Winkelmayer et al. 2001) and previous experiences likely to influence preferences it would be difficult to generalise these findings. Regardless of study limitations, Bass et al (2004) findings typify the difficulty faced by nephrology departments in encouraging patients to switch modalities.

Several studies conducted in the United Kingdom, Canada and the United States surveyed nephrologist opinions on factors that contributed to patient modality selection. All reported that nephrologists believed SCD modalities were under utilised (Jassal et al. 2002; Jung et al. 1999; Mendelssohn et al. 2001; Thamer et al. 2000). These studies represent a cross section of nephrologist opinions and may not actually reflect or be representative of their current practice or true opinions. Since the publication of these studies, there has been little to no change in the numbers of patients undertaking SCD in these countries. This suggests that the studies have had no influence in stimulating the uptake of home based therapies through raising awareness in the renal community. This cluster of similar surveys reported a relatively low response rate, which may have suggested that respondents were those most concerned about SCD. However, Mendelssohn et al. (2001) suggested that this bias may be limited due to similar findings in these studies.

Interventions to influence uptake of self care dialysis

The majority of studies reporting pre-dialysis educational interventions to increase the prevalence of SCD have utilised retrospective and observational designs. To date, Manns et al. (2005), have conducted the only randomised control trial investigating strategies to overcome the barriers of SCD. They found that a two phase pre-dialysis educational

intervention was more likely to influence patients choosing SCD over hospital based modalities when compared to ongoing standard care in a multidisciplinary clinic. However the study was limited by a small sample size (n=70) and the primary outcome being the patient's intention to initiate SCD, not whether patients subsequently took up SCD.

Pre-dialysis education programs have been shown to play an influential role in modality choice and enhancing patient outcomes (Goovaerts et al. 2005; Jager et al. 2004; Klang et al. 1999; Little et al. 2001; Manns et al. 2005; Mehrotra et al. 2005; Winkelmayer et al. 2001). However the findings of these interventions were uncontrolled, lacked standardisation, and were potentially influenced by biased representation of modality choice or did not include HHD as a treatment option. Despite methodological limitations there remains no doubt as to the importance patient education, autonomy and pre-dialysis care plays in improving the uptake of SCD modalities.

Aspects of patient experiences of HHD

The experiences of patients performing SCD at home have been revealed in two studies undertaken by a single researcher in New Zealand (Polaschek, 2003; Polaschek, 2006; Polaschek, 2007a; Polaschek 2007b). In these qualitative studies, Polaschek used a critical interpretive methodology to reveal the differences between professional assumptions and patients' reality. Three papers (Polaschek, 2006; Polaschek, 2007a p21; Polaschek, 2007b p51) were generated from interview data gathered with the same set of 20 participants with the aim to "describe characteristic attitudes towards their treatment [regimen]". Regardless of the potential confusion of multiple papers reporting findings from the same study, these papers argued that from the patient perspective, the need for treatment and hence compliance was viewed as a process of

negotiation. Rather than completely follow their prescribed regimen, this cohort of patients experimented with and modified their therapeutic prescriptions in order to integrate HHD into their normal lifestyle (Polaschek, 2006; Polaschek, 2007a; Polaschek, 2007b). In another study Polaschek (2003) also sought to describe the experience of six males who undertook HHD. He described four concerns that characterised the perspectives of this cohort: symptom management, limitations on lifestyle, ongoing uncertainty and increased dependence. As with all qualitative methodologies the findings of Polaschek (2003; 2006) remain exclusive to those participants studied. Regardless, understanding the experience and perspectives of people undertaking HHD can be used to improve the discourse between the renal team and patients. Additionally these findings can be used to assist prevalent patients who currently undertake HD independently in satellite units to transition to HHD.

Suggestions for further research

Clearly further research describing the experiences and opinions of patients who perform HD independently in community satellite units and why they choose not to undertake HHD is required. To date the majority of studies have used quantitative closed question survey instruments to determine patient preferences of modality choice and barriers to SCD. The nature and use of these surveys, potentiates bias because the researcher's perception of what is relevant to patients may misrepresent or overlook potentially significant patient responses (Babbie, 2007; Polit & Beck, 2006). SCD patients in community satellite units have complex inter-related realities that require investigation beyond quantitative study. Affording them the opportunity to share their fears and experiences will circumvent the natural tendency of clinicians to assume that they know what the patient needs. With

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this understanding, quantitative studies could then be initiated that would evaluate interventional programs which support the transition to HHD, based on identified prevalent patient needs, not researcher assumptions. While Polaschek's (2003; 2006) research has provided an insight into the experience and concerns of some people on SCD modalities, there remains a need to undertake similar studies in other renal settings to further explore the meaning of HHD to these people.

Randomised controlled trials are still required to evaluate standardised educational and psychological interventions aimed at the increased uptake of SCD modalities. These should not be limited to incident patients. A local question still remains to be answered: Are the factors preventing Australian limited care patients transitioning to HHD the same as the pre-dialysis population? The first part of the larger question is why do prevalent patients chose not to undertake HHD? The second is how do renal clinicians facilitate their transition to HHD?

Conclusion

A literature review was conducted to answer the question: Why do patients who have achieved self care status in the community haemodialysis setting choose not to undertake home haemodialysis? The literature to date does not reveal definitive answers to this question.

The current body of literature has examined regional, national and international trends and variations of SCD modalities. In addition to reporting their incidence and prevalence, the benefits of HHD versus other forms of renal replacement therapies have been identified. HHD has been shown to provide better patient outcomes when compared to satellite and hospital based haemodialysis. It is utilised by a highly selective patient cohort who are generally younger and have less

comorbidities than those undergoing satellite or hospital based HD. Patients who select HHD are also reported to experience less hospitalisations and intradialytic complications, have better haemodynamic stability and health related quality of life, live longer and are more likely to be engaged in full-time work. In fiscal terms, HHD is more cost effective than hospital or satellite HD. Despite these benefits the trend in HHD usage has seen a decline internationally. This decline has been attributed to the increasing age and comorbidities of incident patients, the improvement in renal transplantation and peritoneal dialysis techniques and the increasing prevalence of community based satellite units.

Current workforce trends and fiscal restraints necessitate prevalent patients who are capable of safely performing HD to transition to HHD in order to ease institutional burdens and resource usage. The barriers to this transition have not been given due consideration within the literature.

The literature has largely considered uncontrolled interventions to support the uptake of SCD modalities in incident patients. This focus on the pre-dialysis population is nonetheless valid. With an increasing number of patients expected to commence the renal replacement therapy pathway, the nephrology community is becoming increasingly aware that a culture change is required. Nephrology departments need to develop and sustain a culture of self-efficacy and self-management in their entire patient population and not neglect the large cohort of patients who perform SCD in community dialysis settings. These patients may additionally provide solutions to area health service key performance indicators of increased utilisation of SCD modalities and ease the expected patient congestion in satellite dialysis units.

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