

UNIVERSITY OF BIRMINGHAM

*An investigation into the ways that nurses in dialysis sessions promote the uptake of home
haemodialysis*

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Abbreviations and Terminology

WMC	West Midlands Central
HIEC	Health Innovation and Education Cluster
CKD	Chronic Kidney Disease
HHD	Home haemodialysis
HBM	Health Belief Model
CCM	Chronic Care Management
'hospital unit'	Refers to hospital dialysis at the main renal centre that deals with long term dialysis
'satellite unit'	Refers to satellite dialysis unit not at the main renal centre
'centre'	Refers to either hospital or satellite unit
'nurse'	Staff nurse (band 5 or 6)
'manager'	Nurse manager in charge of a dialysis centre
'NHS staff' or 'clinicians'	The nurses, managers and one consultant who were interviewed
'minimal care'	patients undertake as much of their dialysis as they can manage at the centre: this is now often referred to as shared care
'self care'	patients undertake all of their dialysis whilst attending the dialysis centre
'they', 'their' etc	To strengthen anonymity, 'they' is used as a singular instead of 'he' or 'she'. 'Their', 'them' etc are used in a similar way.

Executive Summary

Introduction, aim and research questions

Available literature suggests home haemodialysis (HHD) is more clinically effective and cheaper than haemodialysis in centres. To improve uptake, many Department of Health policies have promoted HHD. In the West Midlands, there is a Commissioning for Quality and Innovation (CQUIN) payment to incentivise an increase in home therapies to 35% by 2015. In the last few years, the renal centres in West Midlands have made it a priority to increase the proportion on home therapies, particularly by focussing on pre-dialysis education and moving away from in-centre dialysis as the default modality.

Our view is that there was comparatively little research into increasing HHD from patients on long term in-centre dialysis. So the aim of this project is to evaluate how nurses enable patients undertaking long term in-centre haemodialysis to move to home therapies. The following research questions were used:

- How do haemodialysis nurses view their roles in caring for, educating and training patients to dialyse at home?
- How do haemodialysis nurses encourage patients towards self management?
- What learning facilitates patients' engagement with home haemodialysis?

Our initial hypothesis was that patients on long term centre-based dialysis may be passive with nurses adopting a caring role; but to promote HHD effectively, it may be better for nurses to be more like trainers, rehabilitating patients and encouraging them to be much more active in the understanding, monitoring and management of their condition.

Messages from the literature

A broad, light-touch, literature review provided many relevant explanatory frameworks. Regarding rehabilitation, the nurse and patient should be 'making a journey together from hospital to home' with nurses 'refraining from interventions' and so 'encouraging patient problem-solving skills'. Although nurses can find rehabilitation difficult and stressful, the therapeutic or rehabilitation alliance between the patient and nurses is crucial for this journey. The Health Belief Model urges us to consider the patient's perceived benefits and barriers to undertaking HHD. Of course, barriers are not limited to the patients; they may be due to the wider clinical, organisational, economic and political issues as well as specific details such as whether the technologies work. This literature review also considered several different approaches to individual and institutional change.

An individual undertaking HHD is entirely independent and can choose when, how often and for how long to dialyse; there is also relatively little monitoring of lifestyle, diet etc. Therefore, preparation for HHD should be patient-centred, with patients being active participants in their own treatment. Absence of patient-centeredness would involve the professional making all the decisions, seeking compliance. Complete patient-centeredness would mean the patient is making autonomous

decisions: usually health professionals are very uncomfortable with this position. However, a mid-point with genuine shared decision-making may be appropriate for some patients on in-centre dialysis. Stages required for patients to be '*activated*' are described in the literature. For long term dialysis, we might consider the stages to be: the patient understands the rules regarding diet and fluid intake → the individual understands how changes in their diet etc relate to symptoms which require altering medication and dialysis → the '*activated*' patient maintains a sensible lifestyle and is actively engaged in medication and dialysis decisions.

Data collection

Interviews were undertaken in three hospital and four satellite units across two hospital Trusts in the West Midlands. A total of 75 people were interviewed: 30 patients, 1 consultant, 6 nurse managers and 38 staff nurses. Interviews were transcribed, then coded using NVIVO software using themes identified in the literature and previous work.

Results

Most nurses see their role predominantly as a carer, and patients view them as wonderful. Close, friendly relationships between nursing staff and patients, and between patients were often described, using words like 'family'; this means that strong therapeutic alliances may develop. Dialysis units offer little privacy, but this enables patients to know each other and their conditions very well. This can be very positive e.g. by encouraging self care if they see others doing it. New patients receive both practical knowledge and emotional reassurance and they value the knowledge, experience and ordinary language of fellow patients.

Patient suitability for home haemodialysis

When asked to estimate overall, the nurses and managers interviewed suggested that nearly half their patients were too old, sick and frail for HHD and a further fifth were unable to do so, mainly due to issues with accommodation, lack of support and their own mental or physical limitations. This leaves about a third of patients currently on long term centre-based haemodialysis who may be suitable for HHD, but the majority are unwilling to do it. Reasons included: fear; social reasons; wanting to keep their illness separate from home life; and, it not being their responsibility. This substantial 'unwilling' group is the major focus of this report.

Education of patients

Nurses viewed education as a large part of their role but did not report any training on how to do this. For nurses, ongoing learning was mainly in the unit, informal, on a need-to-know basis and largely consisted of updating their clinical knowledge. They often needed high confidence in their practical understanding before sharing knowledge with patients. In many cases, 'education' was seen as dissemination of factual, clinical information. Link roles and other role demarcations were common, which often meant nurses signposting patients to specialists rather than educating them with some nurses disengaged from promoting HHD.

Patient education occurred in small bursts when they were put on and off dialysis machines. That education usually focussed on specific concerns and technical matters, pitched at the patients' level.

Minimal care

There is an important distinction between training for HHD and minimal care for all patients according to their abilities; there were very few patients undertaking minimal care training who were not intending to dialyse at home. The consensus is that dialysis is complex and likely to be overwhelming for patients, so must be taught in small steps. Several patients report wishing to be more involved in their dialysis but not being given the opportunity.

Many regarded minimal care as positive for patients to increase their confidence, feel useful and understand their illness. However, several patients were not encouraged down this path; perhaps because those not on HHD training were overlooked. This also means staff do not benefit from having independent patients in the unit. Also, there were concerns that training for minimal care: makes dialysis slower; is riskier; there is too much pressure to do it; and, some patients feel it is not their job.

Several clinicians viewed a patient's interest in treatment, undertaking minimal care and self management as mutually reinforcing. For example, learning how to programme the dialysis machine requires understanding of dry weight etc and encourages sensible fluid intake. Encouraging patients to be more independent creates a tension in some nurses as they are keen for this to happen but also wish to care for the patient. However, the majority of clinicians did not talk in these terms and used more traditional, medical descriptions, such as discussing the compliance of patients.

How decisions are made regarding the treatment of patients

Decisions were, in the main, seen as being clinically led, with patients varying in their involvement. Some were adamant they wished to be involved, others described being happy to leave it to the professionals. The patient's knowledge seemed to dictate their levels of involvement.

Attitudes to HHD policy and training

There was generally a positive view of HHD, for the right patients. It is seen as a better treatment, avoids the need to come into a centre and gives the patient independence/ control over their condition. Several staff described patients becoming healthier and more confident when they went onto HHD.

Despite this, some clinicians expressed resentment of the pressure to send patients home who were unwilling or unsuitable. Patients who had a particularly traumatic health history may need considerable time before they can consider HHD. Clearly this is a potential source of tension as 'encouragement' by one clinician may be regarded as 'undue pressure' by another. However, this was not a problem for most of the interviewed patients.

Concern was raised about the risk involved in HHD in terms of patients: dealing with emergencies; being tempted to skimp on treatment; and, being more lax regarding diet and fluids. A few staff acknowledged that it was hard for nurses to relinquish control to enable the patients to be independent. It was suggested that HHD patients should come back to the centre for 'refresher' training.

Perhaps the most difficult issues concerned which nurses trained patients for HHD. Should HHD training be by: all nurses; particular 'link' nurses in the centre assigned this role; an external HHD specialist nurse; or some combination? Some staff reported their system was working successfully. Others pointed to centre nurses not knowing enough or giving conflicting messages, and link or HHD specialist nurses being insufficiently available.

In several centres, it was suggested that patients expect to be passive and not consider HHD. Several approaches are being tried to address this, such as contact with HHD patients and initially assuming self care will be appropriate for all new patients.

Discussion

This report is based on participants' self-reported views; it does not make judgements on whether the centres generally or individually are 'doing well', rather we seek to understand what they are doing, how and why. This discussion considers how changes within dialysis centres might increase the proportion of patients undertaking minimal care, self care and HHD; it is structured round the three research questions.

Research question 1: How do haemodialysis nurses view their roles in caring for, educating and training patients to dialyse at home?

The routine care and education provided by all nurses is designed to manage patients undergoing centre-based dialysis. It is likely that with most nurses this does not promote HHD, although it may well with nurses who encourage independence or are particularly enthusiastic about HHD. Education and training specifically for HHD are not carried out by all nurses.

Research question 2: How do haemodialysis nurses encourage patients towards self management?

The majority approach was that education consists of disseminating dietary and lifestyle advice; for those training for HHD, the focus is on mastering the complex, technical activity of dialysis. However, some staff spoke of developing patient independence. Minimal care encourages self management and increases a patient's confidence, feeling of usefulness and understanding of their illness. Developing patient independence creates a tension with the caring aspect of the nurse's role. It was noted that nurses can find rehabilitation difficult and stressful, but this approach may be important to encourage self management.

Research question 3: What learning facilitates patients' engagement with home haemodialysis?

Generally, clinicians (mainly nurses) provide information and make day-to-day decisions. The patients are usually receptive to this and may actively seek further information. To promote HHD, patients should be encouraged towards shared decision making e.g. by interpreting monthly bloods before the nurse comments and by agreeing dialysis parameters with the nurse.

The Health Belief Model suggests perceived barriers are more important than perceived benefits in determining patient behaviour. Therefore, for some patients, it may be appropriate to address likely barriers prior to asking the patient to consider HHD e.g. learning to self-cannulate. In addition, genuine shared decision making regarding dialysis decisions should demonstrate that patients can self-manage their condition.

In several centres it was suggested that patients expect to be passive and not consider HHD. If HHD targets are to be met, this expectation needs to change, perhaps using ideas suggested here as well as current approaches, such as contact with HHD patients and initially assuming HHD will be appropriate for all new patients.

Conclusions and recommendations

The main finding from this study is that promoting patient independence within the dialysis centres should enable more patients to embrace full independence i.e. dialyse at home. Recommendations to encourage this:

1. Consider training to improve the way nurses facilitate patients' deeper understanding of diet, medication and dialysis.
2. Promote shared decision making between nurses and patients e.g. by jointly agreeing dialysis parameters.
3. Enable all patients to undertake as much of their dialysis as possible. This minimal care approach should involve the mechanics of dialysis, starting with weight and blood pressure **as well as** the approaches to education and decision making indicated by the first two recommendations.
4. Include spare capacity in centres: a) to permit self care patients some flexibility as to when they attend; and, b) to enable 'out-of-phase' training i.e. instead of starting at 7am, 1pm and 5 pm, one or two could start at 9am and 3pm.
5. Those suitable for HHD but unable to do so (e.g. due to accommodation issues) should be expected to undertake long term self care.
6. Those suitable and able to dialyse at home should be encouraged to self care before deciding about HHD.

Potential HHD patients might be encouraged to self care in-centre for a limited period; then once a week in-centre while doing HHD other days. They could then come in monthly to check up on technique, maintain links and have bloods done. This should be less daunting for patients, but the main aims would be to: a) enable nurses to spend more time with those who are training to self care; b) increase the centre nurses' pride in 'their' HHD patients as they would be 'making a journey together from hospital to home' and, c) create a self care expectation, as the other patients learn from the HHD patients and see how healthy and confident they are. Of course, the success of these recommendations depends on numerous factors including financial and administrative constraints.

The number of patients already on HHD suggests strong support for moves towards patient independence. However, this study indicates that some patients on long-term centre-based dialysis may be unduly passive, in part because of the nurses' caring role. To promote HHD more effectively, it may be better for nurses to be more like trainers, rehabilitating patients and encouraging them to be much more active in the understanding, monitoring and management of their condition. This study recommends that educational approaches are adopted which increase patient independence and hence the uptake of home haemodialysis.

Introduction

Recent government policies have emphasised the importance of patient-centred care, health care being offered closer to home and the promotion of self care. In Chronic Kidney Disease patients who need dialysis, there has been an emphasis on encouraging home dialysis. From the WMC-HIEC-CKD interim report on Increasing the Uptake of Home Therapies, a key issue that emerged was that “it was desirable to move the culture to a position where home therapies are the default modality of choice with alternatives considered only where there are compelling clinical, social or psychological factors, or when an individual patient exercises informed choice” (Beavan et al., 2011).

The rationale for this present study is that nurses play an important role in helping patients to move from recipients of haemodialysis care to self managed service users ideally using dialysis at home. How they perform this role, through education, training and caring is our focus.

It is anticipated that this work will provide:

- a comprehensive assessment of how nurses see their role in educating and training patients in moving towards self care and home haemodialysis;
- a better understanding of nursing practice on dialysis units and its contribution to increasing the uptake of home haemodialysis;
- an assessment of the barriers experienced by patients in considering the move to self care or home haemodialysis.

Aim and Research Questions

The aim of this project is to evaluate how nurses enable patients undertaking long term in-centre haemodialysis to move to home therapies. It will explore the learning of patients and nurses, identify best practice and recommend service improvements, if appropriate.

This project is designed to explore the following questions:

- How do haemodialysis nurses view their roles in caring for, educating and training patients to dialyse at home?
- How do haemodialysis nurses encourage patients towards self management?
- What learning facilitates patients’ engagement with home haemodialysis?

Context and literature review

Introduction

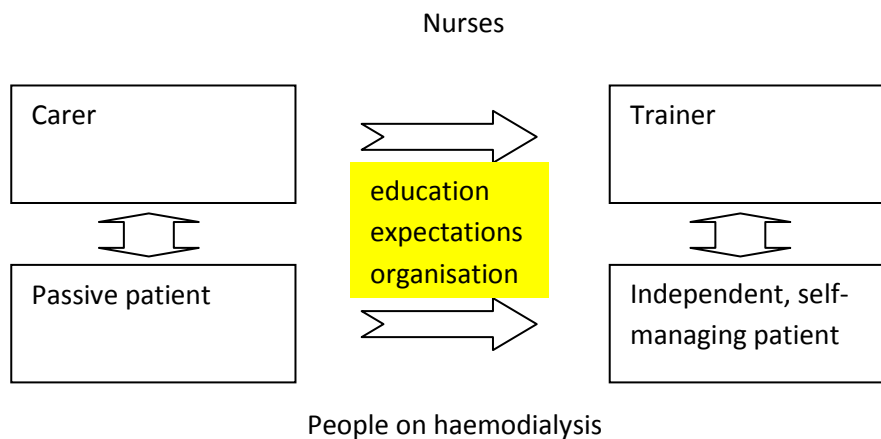
This research leads on from our first Health Innovation and Education Cluster (HIEC) report on 'Increasing the uptake of home therapies' [University of Birmingham ethics approval number ERN_10-0199] (Beavan et al., 2011). An extensive literature review in that report cited previous research that suggested home haemodialysis (HHD) may be more clinically effective and cheaper than haemodialysis in centres. HHD makes it easier for patients to work and be in control of their health and treatment, although it can put pressure on their carers. HHD is more frequent with younger, white patients living with a partner. Despite these considerable advantages, in the UK, uptake of HHD has been disappointing, perhaps due to cost of required facilities, lack of clinician awareness and insufficient staff and patient interest. Consequently, many Department of Health policies have promoted HHD, particularly a Commissioning for Quality and Innovation (CQUIN) payment to incentivise an increase in home therapies to 35% by 2015.

From our first report, a key issue that emerged was the need for home therapies to be seen as the default modality of choice (Beavan et al., 2011). Existing research and this previous work suggest that nurses play a pivotal role in helping patients to move from recipients of hospital or unit-based haemodialysis care to being self managing service users, ideally undertaking home haemodialysis. Discussion with staff at renal centres in early 2012 highlighted the importance of understanding the complex adjustments in interpersonal communication and professional behaviour required to be effective in this role. It is this that is the focus of our enquiry.

In a traditional dialysis unit, there will be many frail, extremely ill patients who will be entirely dependent upon the *care* of the nurses for their dialysis. However, there will be others who perhaps are already taking responsibility for some aspects of their dialysis and may be able to move towards greater independence. If these patients opt to dialyse at home, they will be *trained* either by a unit nurse or a 'specialist' HHD nurse perhaps during a specific session or in a separate space. In a minimal care unit, nurses are to encourage and train all patients to undertake as much of their dialysis as they can manage, depending on their clinical condition, motivation etc.

This section describes literature that may be relevant to the educational role of nurses in dialysis sessions for patients on centre-based dialysis who could be more independent. Figure 1 outlines our conception of the difference between the nurse as *carer* with passive patients and the nurse as *trainer* with more active self managing service users. Of course, in real life we do not expect the difference to be as stark as this. The centre of this figure suggests that for more capable patients in traditional units, given the right education, expectations and organisation, it may be possible for them to become self managing service users. Other factors that might affect such a change include training, severity of illnesses, age, home support and motivation. The intention of this study is to explore whether Figure 1 is a useful description of behaviour on long term dialysis centres; if so, what factors promote the development of renal nurses as trainers and people on haemodialysis to be self managing service users. Finally, is there a link between patients being more self managing and the likelihood of them undertaking HHD successfully?

Figure 1: Nurses as Carers and Trainers



The Role of the Nurse

Orem's self care deficit nursing theory suggests that nursing fills the gap when people can't care for themselves (Orem and Taylor, 2011). In Backsneider's view, patient self care is key; but if it is lacking, nurses should intervene in a way that is appropriate to the issue. So, for diabetes self care, patients are responsible for monitoring their blood sugar and symptoms, keeping a healthy lifestyle, skin care, and administering insulin. She describes the physical, mental and emotional capabilities and orientations (habits) for this self care. She also describes 4 types of nursing care: 1) supportive, educative; 2) temporary support; 3) permanent compensatory assistance; 4) environmental development (Backscheider, 1974). Unfortunately we were unable to find any literature on how nursing approaches can help this.

Bonner and Greenwood (2006) looked at how nephrology nurses develop expertise in their specialty. They stressed the value of specific, nephrology-based CPD. According to them, nurses acquired expertise in stages, moving from non-expert to experienced but still non-expert, and then on to expert, depending on their knowledge, skills, experience and focus.

Green and Thorogood (1998) describe the evolution of health policy. Previously, medicine centred on the individual who chose whether or not to see the doctor, and the doctor viewed the (sick) person holistically. With the advent of advanced scientific knowledge the focus shifted to disease, its prevention and its cure, with treatment moving into hospitals and doctors assuming more power. Now those roles are under review again with the resulting potential shifts in power. They argue:

In order to be high status the profession must lay claim to clinical and curative skills, but in order to remain as 'nursing' the practice must be centred on *caring for*, not *curing* patients (ibid. p138).

This tension between 'caring' and 'curing' matches our division between 'carer' and 'trainer'.

Models of Patient Motivation

There are several models which seek to explain differences in patient motivation, including the expectancy of improvement and self-efficacy/ internal locus of control. With a major illness, the patient may struggle to assimilate the diagnosis into their world view, which leads to stress and denial (Brennan, 2001); however, Brennan reports previous authors that "posttraumatic growth" is possible through "entirely new motivational priorities" (ibid. p10). This may be due to the patients becoming "future-oriented" with "goals around 'pleasure and mastery'"; however, it is also suggested that patients can be dominated by their disease rather than being able to 'encapsulate' it (ibid. p10-11).

The Health Belief Model (HBM) is based on the strength of people's desire to be well and their estimation of the likelihood of achieving this with specific health actions (Janz and Becker, 1984). HBM has 4 dimensions: 1) perceived susceptibility (the persons view of their chance of being ill; 2) perceived severity of the medical and social consequences; 3) perceived benefits of the recommended health action; and 4) perceived barriers to the recommended action e.g. dangerous, painful, inconvenient. Clearly all of these can be influenced by social and cultural factors. Also, a "cue to action" (ibid. p3) is usually needed to start this kind of cost-benefit analysis. This perceived threat depends on dimensions 1 and 2 plus the cues to action. Chance of taking recommended action depends on 3 minus 4 and the perceived threat (Janz and Becker, 1984). These authors suggest that the perceived barriers are probably the best predictor of compliance. However, Shanks (2009) found no prediction of cardiac rehabilitation initiation by HBM variables, and so concluded that there was either poor measurement of rehabilitation or the model is not useful.

Dimension 1 of the HBM is not relevant for those already on dialysis. Therefore our reformulation is:

A patient's desire to move to HHD from centre based haemodialysis depends on:

- Perceived benefits of dialysing at home (future orientation)
 - Medical: better dialysis -> feel better
 - Social: positive or negative?
 - Independence/ taking control of (encapsulating) the illness
- Perceived barriers regarding HHD
 - The HHD training e.g. learning to self-cannulate
 - Risks, inconvenience etc of dialysing at home

Patient centred care

The general shift towards patient-centred care described by Thompson (2007) reflects recent trends both to patient as consumer and as an active, involved participant in care. As people with long term conditions live longer their expertise about their condition increases which in turn allows for a more equal relationship between professional and patient. Thompson's typology of levels of patient involvement is useful because it describes both professional and patient-determined levels of

activation. For home therapies to succeed, it is reasonable to assert the relationship would be closer to Level 4 than to 0 (see Table 1). In this model, at Level 4 the patient is making autonomous decisions, based on information and discussion with the professional. At Level 2 the patient gives relevant information to the professional in a dialogue, the professional consulting the patient over choices. At Level 0, the professional makes decisions on behalf of the patient who is not involved in the decision making process. However, Thompson argues that even where a patient appears to be passive in the process, there may be an underlying potential for involvement and there may be specific conditions preventing them from doing so.

Table 1: Levels of patient involvement in treatment decisions

Patient desired level	Patient determined	Co-determined	Professional determined
4	Autonomous decision making		Informed decision making
3		Shared decision making	Professional as agent
2	Information giving	Dialogue	Consultation
1	Information seeking, receptive		Information giving
0	Not involved		Exclusion

Ruiz-Moral (2010) argues that patient centred care involves more than a dialogue between physician and patient over treatment options. The process involves sharing information between physician and patient and vice versa, shared deliberation over options and then a decision is arrived at by mutual consent. A more extreme version is outlined by Berwick (2009) who argues that the patient should determine their own care, even when this conflicts with health professionals' needs or opinions. He offers a definition of patient-centred care:

The experience (to the extent the informed, individual patient desires it) of transparency, individualisation, recognition, respect, dignity, and choice in all matters, *without exception*, related to one's person, circumstances, and relationships in health care (Berwick, 2009, p560, emphasis added).

However, he accepts this raises a number of issues including: the possibility of a conflict between patients' wishes and evidence-based medicine; the challenge this may pose to the role of physician as steward of the public good of health provision; and finally, the needs and wishes of the physician need to be respected. Deegan and Drake (2006) argue that shared decision making contrasts with ideas of compliance and non-compliance, where compliance may actually prove to be counter-therapeutic. Shared decision making places both the patient and the practitioner as expert. They suggest the ideal is a move towards a therapeutic alliance, or a rehabilitation alliance (Aquila, 1999).

Others describe patient activation in terms of stages to go through, highlighting the developmental process patients may need to go through before becoming fully involved. Hibbard et al (2004) argue patients move: from having basic knowledge and belief in their ability; to confidence to recognise, follow through and manage symptoms; and then being able to maintain lifestyle changes, manage their condition within acceptable patterns of daily life and feeling confident to handle changes to their care when needed. This hierarchy of activation is crucial and patients need to move through

the stages for effective activation. In doing this, four conditions are necessary: the team must value the role of the patient in managing their care; patients must possess appropriate knowledge and confidence; they must know how and be willing to take action; and to do so, persevering even under duress when inevitable setbacks are confronted.

Epstein et al (2010) discuss patient centred care in the context of a healing relationship. For them, this involves a two-way sharing relationship between patient and practitioner, acknowledging the values and preferences of both parties, putting the patient at the centre of decision making. The job of the practitioner is to facilitate behaviours and to encourage the patient to be an active participant in their care. This requires a team approach, shared information and a mindful and careful approach. The three pillars of this are: an informed and involved patient and their family; receptive and responsive health professionals; and, a coherent health care environment.

De Silva (2011) reviewed 550 papers and concluded there was evidence to support self management, particularly in relation to behaviour change and self efficacy. She identified strategies to support self management and concluded by highlighting the need to understand clinicians' skills and learning needs as well as those of the service user. However, Hibbard et al (2009) found, when they developed a measure for assessing clinicians' beliefs about patient self management, that most clinicians agreed patients should follow their advice but were less likely to endorse the suggestion that they should make independent judgements or actions, even less that they should be a full member of the care team and even fewer supporting the idea that patients should seek independent information regarding their condition. They describe a need for more research into clinicians' beliefs concerning self management.

Terry and Higgs (1993) noted the importance of understanding the patient's attitudes to, and understanding of, care needs, as well as their attitude to involvement in decision making, before agreeing any treatment plans. However, reporting on a RCT to assess the impact of nurse transition coaches, Coleman et al (2006) argue that previous studies have found patients are unprepared for self management, often get conflicting advice, are sometimes unable to contact health professionals as and when needed, and have little input into their care plans.

Several studies have discussed the benefits of greater patient involvement in decision making and care in the management of long term conditions. Despite patients often being unprepared for self management, the use of nurse transition coaches was highly effective in reducing rehospitalisation (Coleman et al., 2006). In parallel qualitative research, they found having a nurse to support the process of moving towards self care improved the knowledge and skills of patients in both medication and condition management and increased patient confidence. In a study focussing on individuals with mental illness, Cook et al (2008) found that having greater control over budget decisions as well as care led to increased quality of life and care with fewer problems and 'higher functioning'. Epstein et al (2010) argue that the reasons for increasing patient-centred care approaches include improvements to care and well-being; they tend to offer better value through these improvements and are more equitable, and therefore ethical, approaches. The reason they are more equitable lies in part in the changed relationship required between patient and practitioner, with a shift in power away from the professional (Green and Thorogood, 1998).

Models of Rehabilitation

An expert panel that considered a literature review felt that “Clinicians’ practice patterns and beliefs about patient survival, treatment effectiveness and quality of life when using each type of dialysis treatment were considered the most important factor in determining home dialysis usage” (Castledine et al., 2011, c266). Factors decreasing home therapies include the hospital dialysis capacity and financial factors to fully utilise this. In this survey of every renal centre in UK, clinicians were asked to “describe the ideal proportion of patients on each modality given current transplantation rates and levels of co-morbidity” (ibid. c263). For patients less than 65 year old, mean responses were 40% in centre HD, 25% HHD and 30% PD. For those older than 65, the means were 63% in centre HD, 10% HHD and 25% PD. The paper described 3 management styles: a) team: all patients on each modality managed by one consultant; b) overview: one consultant has an overview of all patients on the modality but other consultants managed aspects of patient care; c) named consultant regardless of dialysis modality. The team approach was thought to be best for high rates of home therapy (Castledine et al., 2011).

For rehabilitation patients with non-progressive neurological conditions, interviews suggest that goal setting was reassuring and helped coping strategies for patients and carers; also, shared goals helped staff focused and collaborate (Young et al., 2008). In Sweden, a telephone questionnaire (PaPeR, Patient Perspective on care and Rehabilitation) has been developed for use with newly discharged elderly patients about the quality on the ward regarding three factors of “‘Respect and safety’, ‘Information and participation’ and ‘Rehabilitation interventions’” (Wressle et al., 2006).

Retrospective interviews of professionals regarding home-based stroke rehabilitation of patients lead to “one main theme (‘supporting continuity’) and 4 subthemes (‘making a journey together from hospital to home,’ ‘enabling experiences of functioning,’ ‘refraining from interventions-encouraging patient problem-solving skills,’ and ‘looking for a new phase-uncertain endings’” (Wottrich et al., 2007).

With drug rehabilitation, the California Psychotherapeutic Alliance Scale (CALPAS-P) was used to show that reduced dropout was associated with higher commitment, perception of having involved and understanding therapists and the therapists’ ratings of perseverance (Cournoyer et al., 2007). This tool has 4 scales: Patient Working Capacity i.e. engagement in treatment; the Patient Commitment i.e. attitudes and commitment to therapist and treatment; the Working Strategy Consensus i.e. level of agreement with therapist on way forwards; and the Therapist Understanding and Involvement i.e. patient’s view of the therapist’s approach.

Analysing responses to 3 therapeutic alliance tools lead to 6 factors for patients: “Collaborative Work Relationship, Productive Work, Active Commitment, Bond, Non-disagreement on Goals/Tasks and Confident Progress” (Bachelor, 2011). For therapist there were 4 factors: “Collaborative Work Relationship, Therapist Confidence & Dedication, Client Commitment & Confidence, and Client Working Ability”. Perhaps the main message regarding HHD, it that patients were more concerned with “helpfulness, joint participation in the work of therapy and negative signs of the alliance” (Bachelor, 2011).

Investigating the power dynamics in a rehabilitation ward, it was concluded that nurses exercise power in terms of organising rehabilitation programmes and required activities but patients had a

say in many areas and kept their dignity (Giaquinto, 2005). Nurses found rehabilitation more stressful than other wards and a third did not feel they were participating in the rehabilitation process. However, for our purposes, the questions used seem too focused on washing, dressing etc.

Cherry-picking from the Illness Management and Recovery (IMR) resource kit by Gingerich and Mueser (2005) described in Hasson-Ohayon et al. (2008), an approach to dialysis education might include:

1. Recovery strategies that emphasize the patients' personal goals and definitions of recovery.
2. Practical information about dialysis and how to cope with CKD including diet and medication.
3. Ways to improve relationships.
4. Examining previous relapses to preventing reoccurrences.
5. Consider ways to identify and cope with stress.
6. How to get the most from the NHS.

After an 8 week exercise programme during dialysis, interviews with 7 haemodialysis patients suggested that the exercise had made them: better at undertaking normal activities; more positive about dialysis; and increased their sense of control. Therefore they said they would continue to exercise (Kolewaski et al., 2005).

In an Australian inpatient rehabilitation ward, it was reported that activities they developed led to great engagement by patients and nurses in rehabilitation and "the nurses developed a deeper appreciation of their role in rehabilitation" (Pryor and Buzio, 2010, p978). However, it is acknowledged that nurses may opt-out of rehabilitating patients due to system-based problems (Pryor and O'Connell, 2009).

Managing long term illness

There are different models of care for patients with long term illness and these relate to the degree to which the patient is involved in their care, or how *activated* they are. Achieving optimum activation is neither a linear process nor necessarily continuous but happens in *stages*, dependent on appropriate conditions. The benefits of patient activation to the healing process vary.

There is a range of models of care which might inform the move to home therapies for CKD, dominant in the literature is the Chronic Care Management (CCM) model (Wagner et al., 1996a, 1996b), subsequently adapted to care for long term illness (Jacelon et al., 2011) and chronic care at home (Suter et al., 2011). The central argument is for a reconfiguration of health care systems to reflect the different needs of patients with long term conditions, rather than systems designed to meet the needs of acute care requirements. The key differences in approach centre on regular and systematic interventions between caregiver and patient and a focus on quality of life functioning and prevention of complications. This involves a comprehensive care plan that recognises the potential for patients to manage their conditions to the limits of their ability and willingness to do so (Wagner,

1998, p2). In Wagner's original model, five criteria for health systems are identified for maximum efficacy:

- The system must be structured to both facilitate and encourage change;
- An emphasis is placed on increasing patients' capabilities such that they ultimately manage their illness;
- Team and systems are organised around the needs of chronic illness and the continuous care required;
- Use is made of evidence-based guidelines which are widely understood and adhered to by the whole care team;
- Information systems allow for appropriate patient tracking, feedback and pro-active follow-up in care.

Using chronic obstructive pulmonary disease as an example, Suter et al (2011) argue the need for greater understanding of *rehabilitation* in chronic care management. They added another four areas to Wagner's model: an identified home-care clinician; using theory based approaches to self management care (using learning and social psychology theory); acknowledging the role of specialist partners in care; and the potential use of technology, such as telehealth equipment to monitor patients and alert their carers to difficulties.

Jacelon et al (2011) proposed an adaptation of Wagner's model for use in the care of the elderly in long term care. They argue that having a pro-active and ready care team, working with an engaged, knowledgeable service user will lead to improved care outcome in both quality of life and clinical progress. Here the nurse is seen as the *advocate* for patients and their family, offering decision making and information support as well as care.

In the United States, the concept of the medical home has been widely used to reflect the need for a co-ordinated, cross-specialty practice team based upon the kind of integrated, system wide approach in Wagner's CCM model (Berwick, 2009). What these models have in common is a commitment to the principle of patient-centred care and an engaged, well-informed service user.

The process of change

The policy of increasing the uptake of home therapies represents a policy change for health care providers following the trend over recent decades to managing long term conditions through acute hospital settings. Literature focussing on the theoretical management of change is helpful as well as literature which evaluates the effectiveness of different strategies to implement change in organisations. Finally, the management of role changes (particularly for nurses) is important to consider alongside the implications of those changes.

According to the York NHS review (NHS, 1999) Effective health care: getting evidence into practice, which examined 44 systematic reviews including both empirical and theoretical models of behaviour change, there are four theoretical approaches taken: the use of learning theory; social cognition

models; models of organisational change; and ,theory within a planning framework. Learning theory is discussed, later.

In models of social cognition, the focus is on how individuals respond to change. Important influences on this response include: the balance between perceived benefits and perceived barriers; the perceived value placed on the changes by significant and powerful people; and the patients' belief in their own ability (self-efficacy). Prochaska and DiClement (1983) described the 'stages' of behaviour change as precontemplation, contemplation, preparation, action and maintained; they argue that different stages may need different interventions. Rogers (1983) on the other hand focuses on how individuals themselves perceive and are receptive to change. Individuals are described as innovators, or early adopters, early majority or late majority and finally (the most reluctant) the laggards. In this model, the emphasis is on understanding that people will respond with varying degrees of enthusiasm to change and policy needs to adapt to accommodate those differences.

Although dated, Lewin's (1958) model of organisational change is often cited. Lewin argued that organisations need to unfreeze old behaviours before it is possible to implement new methods (i.e. to change) and finally these new methods then need to be re-frozen, or cemented, into everyday practice to be effective and sustained. Shanley (2007) reports that Pettigrew et al (1992) argued that any organisational change was less clearly defined than Lewin implied. To be effective, the organisation needed to: take account of the context within which change was proposed; the process by which it would be implemented; and, the content of the change. Again often cited, Grol and Wensing (2004) argue that overlapping theories have been used, which often lack clear evidence of facilitating change. In relation to organisational theories of change, these include those focussing on: the innovativeness of the organisation; quality management processes; complexity of the organisation; how the organisation learns; and finally, the economic environment. Concluding that too little is known about what actually works, they suggest planning change requires attention being paid to: the innovation itself; the professionals involved; the patient; the social context (including working practices and cultures); the organisational context; and, the economic and political situation.

Kotler (1984) proposed a model of change described as social marketing. Here, addressing the needs and wishes of the target group are essential for change to be effective. His model describes six stages of change, all focussed on meeting those needs: planning and developing a strategy for change; designing an intervention and targeting it; developing and piloting the intervention; implementing the change; evaluating it; and finally, acting on the evaluation whereby feedback is used to refine the change. A simpler version of this often used is PRECEDE-PROCEED (Green and Kreuter, 2005) where the PRECEDE concerns problem analysis and preparation and PROCEED involves implementation and analysis. What these approaches have in common is the notion of implementing change in stages, with specific attention being paid to aspects at each stage of the change.

There is widespread agreement in the literature that the first stage in implementing any change is to understand the potential barriers to the acceptance of that change (Baker et al., 2010, Cabana et al., 1999, Grol and Grinshaw, 2003). Baker et al's systematic review of 26 studies concluded that appropriately tailored interventions can change professional practice, although evidence on large-

scale interventions was weak. They categorise the identified barriers to change into different headings with administrative constraints being the most prevalent followed by clinical uncertainties and patient expectations. Other categories included information management, sense of competence, and financial disincentives. They acknowledge that more work is needed to develop theory in this area. Cabana et al focussed specifically on physicians and their practice in following clinical guidelines. They identified a range of barriers in clinicians' behaviours including: a lack of awareness of, familiarity and agreement with the guidelines; a lack of self efficacy; lack of outcome expectancy; external contextual barriers; and, failing to building on previous, established practice. They highlight the need to consider this multiplicity of barriers in a range of settings as the lessons learnt in one place may not be applicable to another setting. Grol and Grimshaw examined 235 papers describing dissemination of guidelines and implementation of change strategies. They concluded that changing behaviour is possible but happens best with tailored, comprehensive approaches which are based on a thorough assessment of potential barriers. They suggest that some (simple) research findings get (easily) translated into practice but more complex changes are harder to implement. Adherence to guidelines was better: for acute rather than chronic care; where there was high quality, convincing evidence; change was compatible with prevailing knowledge and practice (in other words it did not contradict established wisdom); and, where the change was clearly articulated and utilised existing skills.

The York Review (NHS, 1999) identifies five important aspects to be considered in the successful implementation of change:

- Individual beliefs, attitudes and knowledge matter, but so do external and organisational conditions
- It is necessary to understand the potential barriers before implementing change
- Multi-faceted interventions, aimed at people, systems and practices work best
- Resources are needed to support the implementation of changes
- It is essential to monitor, evaluate, maintain and reinforce changes as they happen

Shanley (2007) draws attention to the power dynamics (often economic and unquestioned) and political implications (often ignored or hidden) of implementing change. Shanley also argues that change may be planned or emergent, may be led from above, below or from the side, and change may be an emotional process which requires appropriate understanding. As Oxman et al (1995) argue, 'there are no magic bullets' in translating evidence into practice, rather multi-faceted approaches which deliver more than simple dissemination are required.

Mann (2004) offers a helpful résumé of the various theoretical approaches to medical education in the literature, arguing that theory has been applied 'eclectically and episodically' (2004:S29).

Schon (1987) argues that professional practice involves more than simply the acquisition of knowledge. He uses the term 'artistry' to convey the exercise of intelligence in practice. He describes the 'arts' of problem framing, implementation and improvisation which he suggests serve to mediate the use of applied science and technology. Professionals learn artistry through 'practicum',

or through doing and talks about 'knowing-in-action' (ibid. p25). This knowing-in-action is framed within a common body of professional knowledge and its associated cultures.

Lee et al (2004) describe two paradigms of learning: what they call the 'standard' and 'emerging'. The standard paradigm includes formal learning, where the learner is taught, has to gather knowledge and changes as a result. Learning is explicit and the knowledge is seen as separate from the learner. Often seen as superior, learning is acquisition. This contrasts with the emerging paradigm which takes a more social perspective on learning. Knowledge is seen as fluid and evolves through interaction. Individuals shape both themselves and their knowledge. For Lave and Wenger, learning is participation, situated in communities of practice where learners move from 'legitimate peripheral participation' when they are new to the learning community to being central as expert (Lave and Wenger, 1991). Engeström built upon this in activity theory, arguing that learning, seen as a collective endeavour, happened through and across many inter-connected communities of practice (Engestrom, 1987).

Eraut (2007) offers a useful distinction between formal and informal learning. Like Lee et al, he describes formal learning as happening within a clear framework, as organised and taught, accredited and specified by an external body to the learner and the teacher. Informal learning on the other hand is outside a formal setting, may be intentional and incidental, experiential and crucially happens within a relationship with others. Eraut describes three learning modes: implicit, deliberative and reactive. He acknowledges that the workplace context may shape both opportunities for, and the nature of, learning. Individuals are active participants in learning and work processes.

Finally, it is important to consider issues of structure and agency in learning, particularly the influence of the organisational structure on opportunities to learn. Ashton (2004) describes how unequal access to learning opportunities in the workplace happens because of the hierarchical nature of organisations. This means that some powerful people get to control what knowledge is seen as valuable (and worthy of support) and what rewards learning will accrue. Also, people have access to different parts of organisational knowledge depending on their status and position within the organisation: Giddens (1984) calls this 'organisational structuration'. It is not just about the way the workplace is structured, as agency (individual control and action) matters too. Lee, Fuller and Unwin (2004) describe a continuum from expansive learning to restrictive learning, using the concept of 'learning territories' to describe how people view their access to learning, partly as a result of their positioning. What is important here is to recognise that what people learn at work is often within the control of others or happens within social relations.

Summary

This research stemmed from the ideas encapsulated in Figure 1. Patients on long term centre-based dialysis may be passive with nurses adopting a caring role; but to promote HHD effectively, it may be better for nurses to be more like trainers, rehabilitating patients and encouraging them to be much more active in the understanding, monitoring and management of their condition. Therefore it's also important to consider the stages required for patients to be '*activated*'. For long term dialysis, we might consider the stages of a patient's activation to be: basic understanding of diet and fluid intake

→ deeper understanding as applied to the individual so that s/he can see how changes cause symptoms → maintain lifestyle changes and the patient alters their own care as required.

The perceived role of the nurse is central to this: if this role is focussed on providing 'permanent compensatory assistance' they are then acting as carers; whereas if their roles are also to enable independence, then they are also trainers. Learning by nurses and patients happens within the social context of the unit and may be controlled by others.

Models of patient motivation urge us to consider what factors will affect a patient's desire to move to HHD from centre based haemodialysis. For example, adapted from the Health Belief Model, it might be that a patient's perceived benefits of HHD depend on: potential medical benefits (how much better may they feel); impact on their social life; and, their attitude towards increased independence/ taking control of their illness. Barriers to undertaking HHD may include: the HHD training e.g. learning to self-cannulate; and, their perception of the risks, inconvenience etc of dialysing at home.

Home-based stroke rehabilitation may have some messages relevant to HHD. It is suggested that 'supporting continuity' is key and involves 'making a journey together from hospital to home' as well as nurses 'refraining from interventions' and so 'encouraging patient problem-solving skills'. Goal setting can be reassuring and help patients cope. However, it must be noted that nurses can find rehabilitation difficult and stressful.

In moving towards HHD, we might regard the success or otherwise of this as depending on: the patient's capacity and commitment to undertake HHD; the therapeutic or rehabilitation alliance between the patient and nurses; and the consensus on the way forwards i.e. the approach used.

Patient-centred care is also about patients being active participants in their own treatment. Absence of patient-centeredness would involve the professional making all the decisions, seeking compliance. Complete patient-centeredness would mean the patient is making autonomous decisions: usually health professionals are very uncomfortable with this position. However, a mid-point with genuine shared decision-making may be appropriate for some patients on dialysis.

This literature review has also considered several different approaches to change, whether for an individual or for a whole institution. For an individual, learning can be formal such as attending courses and informal e.g. learning on-the-job. The point of this learning can be 'acquisition' (to learn information) or 'participation' (to be able to do things). Individuals vary in how willing they are to embrace change; and for major changes e.g. to re-focussing a service towards HHD, there will be several stages of behaviour change. Of course, whether such a change is successful will depend on numerous factors in addition to the professionals, patients and the proposed change; these factors will include the wider organisational, economic and political context as well as specific details such as whether the technologies work. It is important to understand potential barriers, perhaps administrative constraints, clinical uncertainties and patient expectations are most important.

Method

Lead clinicians and nurses at all renal centres in the West Midlands were offered a meeting to discuss their potential involvement in this research. We were keen to reflect centres' interests and concerns in the design of the study so we approached these meetings as shared discussions. Staff at the two Trusts which decided to be involved helped shape the design and commented on drafts.

Interviews were undertaken in three hospital and four satellite units across two hospital Trusts in the West Midlands. A total of 74 interviews were undertaken with 30 patients, 1 consultant, 6 nurse managers and 38 staff nurses i.e. there were 45 clinicians of whom 44 were qualified nurses and one was a consultant. In one of these interviews, a nurse and manager were interviewed together; some of the patient telephone interviews involved input from their partner. We endeavoured to interview all qualified nurses available on each visit to minimise interview bias. Because existing research (Chanouzas et al., 2012, Little et al., 2001, Stack, 2002) shows that some groups are under-represented in HHD patients, we asked to interview a diverse group of patients, not just the 'obvious candidates' for HHD, who might normally be identified by clinicians. The only criteria were for patients to be able to cope with a phone interview and to have been on dialysis for at least six months. In each centre, a member of staff decided which patients were suitable and made the initial enquiry.

Three interview schedules were used in this evaluation, for a) patients, b) nurses, and c) consultants and managers (see appendices 1, 2 and 3). Before an interview was agreed, potential interviewees were given a participant information sheet (see appendices 4 and 5), which described the nature and purpose of the interview. If the interviewee wished to proceed, they signed a consent form and indicated that they are happy for the interview to be recorded (see appendices 6 and 7). It was stressed before each interview, that they were entirely voluntary, questions can be unanswered without explanation and all responses are confidential to the University of Birmingham team. Ethical approval from the National Research Ethics Service (NRES) and Research Governance approval in both Trusts were obtained before work commenced.

All manager and nurse interviews were conducted in the workplace during normal working hours. Patient interviews were by phone. With appropriate permissions, all interviews were recorded, transcribed and offered to interviewees for checking and amending. Interview transcriptions were stored in NVIVO, analysed and coded according to themes identified in the literature and previous work. The two researchers working on the data analysis compared coding to ensure consistency and minimise researcher bias. Results are presented thematically to minimise identification of participants and centres. There are likely to be differences between centres e.g. when comparing a small satellite unit that has a stable, relatively healthy population with an acute hospital ward: to minimise identification, these between-centre differences were not investigated.

When analysing responses to 'Patient suitability' (see Table 3), the middle value of ranges was taken (e.g. 25% for 20 to 30%) and answers were scaled to fit 100%. Some reasonable assumptions were used to alter descriptions into numerical values, particularly: "a bit lower" and "less than" were reduced by 10% and "plus" was increased by 10%. "Already gone" = 0 for willing to go home. "Quite a lot": "not much" = 3:1; "most": "a few" = 4:1 "Main category" = 70%. Where someone didn't distinguish between categories, that amount was split equally.

Results

Patients suitability for home haemodialysis

The 7 managers and 38 nurses were asked: *Thinking about encouraging the uptake of home haemodialysis, I imagine some patients are clinically unsuitable and some may be unwilling or unable to dialyse at home for other reasons. Looking at the table below, can you describe where you might place your patients (ideally percentages in each box). Please explain your reasoning.*

Table 2: Suitability for HHD

<i>Clinically unsuitable for home haemodialysis</i>
<i>Clinically suitable but NOT able</i>
<i>Clinically suitable and able but NOT willing</i>
<i>Clinically suitable AND able AND willing to move towards home haemodialysis</i>

Of the 45 clinical interviewees, 4 didn't answer this question and 2 gave insufficient information to estimate percentages, so responses from 39 were analysed; 26 gave numerical answers that could easily be converted into percentages. For the other 13, some assumptions needed to be made (see methods). As these clinicians were asked to estimate these figures during an interview, it must be emphasized that this involves considerable guesswork, and so the figures presented below should be interpreted cautiously. As seen in Table 3, similar results were obtained by both methods: just under half the patients were judged to be clinically unsuitable with a further fifth unable to dialyse at home. This leaves about a third potentially able to undertake HHD, of which the majority were seen as unwilling. These last 2 groups are the major focus of this report, although we also explore the possible advantages of minimal care and different educational goals for the first 2 groups.

Table 3: Average percentage estimates of the suitability of home dialysis for their patients from nurses and managers

	Numerical responses (n=26)	All responses (n=39)
Clinically unsuitable for home haemodialysis?	46%	44%
Clinically suitable but NOT able?	22%	20%
Clinically suitable and able but NOT willing?	19%	24%
Clinically suitable AND able AND willing to move towards home haemodialysis?	13%	12%

The thematic coding identified 43 reasons from 27 clinicians regarding the major reasons patients were considered clinically unsuitable for HHD. As expected, the majority related to patients being too old, sick and frail (Table 4). A few referred to global reasons for this i.e. the poor catchment area, and 2 nurses declined to comment as these decisions are made by doctors.

Table 4: Reasons given by clinicians for patients being 'clinically unsuitable' to dialyse at home

Reason	Number	%
Too old	17	40%
Too ill/ comorbidities	14	33%
Too frail	4	9%
Poor catchment area	3	7%
Dialysis reasons (liable to crash)	3	7%
Unable to comment	2	5%
Total	43	100%

For those who are clinically suitable but unable to dialyse at home. The most common reasons given by clinicians are shown in Table 5. 'Accommodation issues' (37%) included lack of space and living in rented, with family (parents or children) or in a nursing home. 'Lack of support' (37%) was mainly living on their own, but included the partner not wanting home dialysis i.e. the unwillingness of the partner rather than the patient. 'Can't self dialyse' (13%) were in terms of either mental or physical reasons.

Table 5: Reasons given by clinicians for patients being 'unable' to dialyse at home

Reason	Number	%
Accommodation issues	17	37%
Lack of support	17	37%
Can't self-dialyse	6	13%
Unsafe	3	7%
Other (1 each of: cost; no machines; can't say)	3	7%
Total	46	100%

These issues were echoed by the patients with many talking about lack of space, living on their own, and not being physically able to handle a dialysis machine e.g. "me eyes are bad anyhow. Me hearing ain't too clever, you know, so I don't think that it'd do for me." In addition, problems of trying to modify their house for home dialysis were recounted in detail by several patients.

Some staff may be more risk averse than is justified and some patients admitted home dialysis might encourage poor behaviour

I'm not sure that they would take in all the technical aspects of the machine really (nurse)

It's knowing what to do when things go wrong (nurse)

I tend to struggle with my fluids so if I was to have home dialysis and I know I can dialyse every day, I'll think "well I can drink more" (patient)

We also asked about why clinically suitable and able patients may not be willing to dialyse at home. The reasons given from 40 clinicians and 16 patients are given in Table 6. For both groups, the most common reasons related to fear of not being able to cope, particularly if there was an emergency e.g. "if you crash – I mean, who's going to bring you back?" (patient). Related to this is the fear of needling which was cited by both groups. Although, few of the clinicians saw needling as an insurmountable problem (i.e. with training, patience and motivation the most fearful patients can learn to self-needle), but many patients did: "I'm 100% sure I wouldn't be able to do me own needling" (patient).

Another frequent reason given by both groups related to the strong desire of many patients to keep their illness separate from their home. For example a patient said if he dialysed at home "you've got a constant reminder that you're a kidney patient, whether you like it or not". Three clinicians went as far as to say some patients were in a state of denial about the illness.

Table 6: reasons given for patients being 'unwilling' to dialyse at home

Reason	Clinicians		Patients	
	Number	%	Number	%
Fear/ lack of confidence	19	24%	8	29%
Needling	12	15%	4	14%
Keep separate from home	18	23%	11	39%
Social reasons	13	16%	1	4%
Not their responsibility	13	16%		
Effort to learn	3	4%		
Poor education by staff	2	3%		
Live close by			2	7%
Other			2	7%
Total	67	100%	28	100%

The view that it's 'not their responsibility' relates to later analysis in terms of whether patients are active in addressing their health needs or passive recipients of care. One clinician talking about some Asian families gave a vivid description of the passive patient role adopted

Whilst they're poorly they've got hundreds of family members and then when they're talking about going home nobody wants to take responsibility (nurse)

Two clinicians felt more could be done to educate patients of the desirability of home dialysis; but more optimistically, another said

I think 6 month ago the staff would have been one of the reasons, their influence, but I think that's changed dramatically here (manager)

There were relatively few comments about those patients able and willing to go home. It was mentioned by both clinicians and patients that those most able were already dialysing at home; they tended to be younger, have helpful family or partner and appreciate the flexibility of dialysing whenever was suitable without the need to travel to the unit. Therefore the views expressed above are primarily about those unable or unwilling to dialyse at home. However, a few interviewed patients were desperate to go home e.g. one was frustrated about waiting many months for building work to be agreed.

Summary

When asked to estimate, overall, the nurses and managers interviewed suggested that nearly half their patients were too old, sick and frail for HHD and a further fifth were unable to do so, mainly due to issues with accommodation, lack of support and their own mental or physical limitations. This leaves about a third of patients currently on long term centre-based haemodialysis who may be suitable for HHD, but the majority are unwilling to do it. Reasons included fear, social reasons, wanting to keep their illness separate from home life and it not being their responsibility.

We will return to several of these issues at the end of this results section when attitudes towards HHD are considered. In addition, risk and responsibility are important themes regarding minimal care. Now we turn to the education of patients in general terms, then to attitudes towards minimal care, then decision-making, before finishing with general attitudes towards HHD.

Education of patients

In order to understand how nurses educate patients for home haemodialysis, we first consider how their role is perceived. The processes of knowledge exchange amongst nurses will impact upon the education of patients. Therefore, interview data from nurses and patients were interrogated from two angles: how is knowledge shared amongst the nursing team and secondly, how do nurses educate patients on dialysis units? We consider learning about different modalities in greater detail in the section on Attitudes to HHD policy and training.

The role of nurses in dialysis centres

Nurses and managers were asked how they see their role. The dominant theme was as a carer.

Actually it's our role being first a care giver... my role to them is to look after their wellbeing, their health (nurse)

The role of the staff nurse is to look after the wellbeing of all our patients (nurse)

Well my first instinct when I come to work is I'm there to care for that patient, to make them comfortable, to keep them safe, to make sure they receive the correct treatment at the correct time, you know, obviously safety is paramount ... the family can feel that they're on dialysis as well as the patient. ... just referring really to the appropriate agencies... you can be sometimes you feel like a social worker, sometimes you're just a friend... I think you are closer to patients here than perhaps you would be on a general ward... it's up to you to make them feel secure (nurse)

Patients almost universally report the staff as being wonderful.

They're lovely girls, they're all ever so helpful and ever so pleasant, I can't praise them enough" (patient)

Friendly and personal and you get to know all the nurses really well (patient)

Every member of the staff, they're fantastic... It's like a work family (patient)

Even a patient who said “I don’t even think she even likes being at the hospital” still reported that “she’s a lovely person”.

Many patients value the close relationship they develop with the nurses

I mean they are professional, but they do make you feel you know that you’re sort of, you can talk to them and have a laugh... they know all the names and everything (patient)

I do think it’s important that the nurses we’ve got some good nurses, come and have a talk to you and pass the time away with everyday chit chat (patient)

Several nurses used words like “almost family”, “their second home” and “holistic care” whilst describing giving general health advice and even acting as something of a counsellor.

How do nurses learn about CKD and modality options?

You wouldn’t learn how to lay bricks from a book, would you, or fix a car from a book, you need a bit of both (manager)

All the nurses interviewed in the study reported that the main medium for learning about caring for patients on dialysis units happened primarily in the workplace, informally, as part of working practice, usually on a need to know basis. The strong consensus was that nursing is a practical role and therefore you learn best by doing, by being shown how to do something and then practising it until you perfected it. Nurses reported needing to know something properly themselves before being able to share that knowledge with patients.

I think the best way of learning is doing it hands-on, you can’t just teach somebody and stand there and talk to them because they might be taking in so much, they might be writing notes but then are they learning? (nurse)

Then we’ll show them and then we’ll just explain as and when problems arise and you know, we’ll just go from there really (nurse)

But I think a lot of the time it’s just you learn by doing, you know, it’ll be like we’ve got somebody on a single needle today, well a lot of the nurses don’t know how to do that, so we’ll make sure they go and watch and they learn how to do it (manager)

In practice, for new nurses on the unit, learning takes place through a period of shadowing more experienced staff. The standard approach seemed to include a period as a supernumerary member of staff of between three and six weeks. Subsequent education consisted of mentoring in the workplace by more experienced staff, with only occasional forays into formal, off-site education.

When we have a new member of staff they’re looked after and followed or they follow you for at least four weeks and then they’re counted – they’re supernumerary for at least four weeks and they’re always mentored by somebody. And then after that four weeks we then put them in the numbers, hopefully if we feel they’re able to be let free (nurse)

Role demarcation was a common organisational response to specialist knowledge on the unit. Certain areas of knowledge were seen as ‘specialist’, and included palliative care, transplantation, infection control, diabetes, and in some centres, HHD. This was welcomed as an opportunity to develop a particular knowledge and expertise but it also encourages the perception that specialist

knowledge may be held by 'others'. In these instances, the job of the nurse became a signposting role. In some of the units visited, there was a specialist home haemodialysis nurse role, held by a peripatetic nurse who covered several sites for education, training and support of all those patients thinking about home haemodialysis. This led to some centre-based nurses seeing education for 'going home' being the responsibility (and expertise) of someone else: this issue is discussed further under Attitudes to HHD policy and training.

Where nurses reported having been on courses away from the workplace, experience of such formal training was limited, with some reporting not having accessed it 'for years'. Opinion on the value of such courses was divided: by some it is seen as a useful time away from the stress of the workplace and as an opportunity for deep learning, for others it is seen as not being as valuable as practical experiential instruction. There was agreement that it is important to use acquired knowledge in the workplace as soon as possible after attending a course, or knowledge gets forgotten or is seen as irrelevant. Interestingly, when nurses talked about how knowledge gained in formal settings got shared with colleagues, they talked about dissemination of information. This suggests that unless knowledge is task orientated, reactive to need, the job of education is seen as dissemination: I have been on a course and I will share the information (not knowledge) with you.

A good few years back, it would be like if you go to a study day outside the Trust, like it's being funded by the Rep or anything like that, whoever goes to that study day or seminar, they bring back the information (nurse)

We try and keep each other informed of the newest things that are going on...
I think the majority of nurses are practical people so you tend to learn better as a hands-on, show me, you do it, kind of -, and I remember things better that way, I can read about it in a book and it'll -, but if I do it I remember it (manager)

There was evidence too of nurses being proactive in recognising where they needed to develop their understanding and seeking knowledge and information, most notably through "Google searches". This occurred either in nurses' own time or in quiet periods on the unit, and was often reported to be in response to specific queries from patients. Some nurses reported this was a motivating process and updating knowledge could revive an interest in treatment processes from within mundane, routine practice. Interestingly, quiet periods on the unit were reported as time for nurses to develop their knowledge, rather than providing an opportunity specifically to educate patients. However, it was reported by both nurses and patients that there is a very tight turnaround time between patient shifts so there are periods of intense activity. These are when nurses spend most time with patients, when the focus is on making sure that patients begin and end their dialysis safely and efficiently. There were reports of short-staffing on units hampering education opportunities as nurses coped with increasing numbers of patients.

Well I go on the internet, that's how I do it. I mean, I don't take a journal, because a lot of the time I just want to read about renal stuff so you just Google something and there it is, it's just so easy, isn't it, you can do it by, well just very quickly (nurse)

I think education is dead important because it just makes you feel more motivated, you're looking at your patient and think, oh gosh such and such was on about in the talk and oh how interesting, ... so it does spur you on (nurse)

Given that nurses rely so heavily on informal, workplace learning from peers, it is perhaps alarming that they report not having been taught how to teach others. Although they often see education as a crucial part of their role, both in relation to patients and other nurses, they have not been prepared for this role, instead drawing upon their own 'instincts' and practices to share their knowledge. They therefore do not have the underpinning theory of learning that might enhance this aspect of the nursing role.

I haven't had any training, I haven't got like any mentorship or anything. But I think it's one of those things that you get some of the basics of teaching just through doing things yourself (nurse)

It's recognised as a gap, that nurses are expected to teach nurses but a small percentage have done the mentorship teaching course and it's a lot of see one, do one, yeah, and yet so much is expected of us all to impart our knowledge (nurse)

Nurses therefore reported learning about CKD and treatment processes on the job, informally, from their peers, usually on a need to know basis. Practical understanding was most highly valued and gave nurses confidence in passing knowledge onto patients. Expert demarcation in the workplace was sometimes counter-productive, signally specialist knowledge as the preserve of others.

How do nurses educate patients in CKD and modality options?

One salient feature of patients on long term dialysis units is that often, patients may know more about their condition than nurses. They spend three days per week on the unit, have often experienced several modalities before arriving on the unit, and may have attended the same unit for many more years than the nurses. Therefore, the relationship between nurse and patient, and the practical knowledge accrued by the patient about their treatment, creates a different balance than the usual nurse: patient scenario. One might expect, therefore, that patients are ideally placed to take on a proactive role in their own care.

They've spent 5 years, 6 years, to get where they are to do the job they're doing. I've had 26 years of dialysis which, personally speaking, that puts me in a better frame of mind to speak about what the treatment is and what people could do (patient)

A second consideration that was highlighted in the research was the diversity in patients' capacities to understand and know about their conditions and treatment. Nurses recognised that some patients wanted to know more than others, some were more able to understand than others, and some were better placed to learn than others. This meant nurses had to be attuned to patients' capacities and tailor their advice and support accordingly.

Some patients want to know quite a bit about their treatment and conditions and you'll find that they're quite knowledgeable, they'll have researched a lot themselves and other people, they don't really want to know anything (nurse)

The patients do get very friendly and attached to us. How we educate them is very important. We have an array of different patients. Some want to be very involved, some don't want to comply or even be here. So your nursing skills come out with that range of patients. Tapping into them individually to get out of them what you can. Many don't want to be told (manager)

Despite patients being at the centre for several hours, many interviewees said the start and possibly finish of dialysis were the best times to talk. This patient education was reported to happen most often as part of treatment, by doing and asking questions. Nurses sought to explain why they were doing what they were doing, and what specific treatments were designed to achieve, as they enacted the process with the patient. Patients reported learning best by 'having a go' and by asking questions as they thought of them. What this means is that education was opportunistic, happening as and when the occasion (and staffing levels) allowed.

Well they're talking to you when they're putting you on the machine, if you want to ask them anything that's the time to tell them, ask them rather (patient).

Patients reported asking questions about different aspects of their treatment, many reporting the benefits they felt in understanding more. Relating teaching to real or potential problems was felt to be the most effective method, both by nurses and patients, as it had clear and direct relevance to improving patient health. In nurses' interviews it was evident that patient education revolved around specific, technical information about phosphates, calcium, diet, bloods. This was evident too in the testimonies from patients who concentrated on these aspects of knowledge when asked. There was a focus on detail, of aiming for specific targets around dry weights or fluid exchanges.

I only look for what I want to look for as in my phosphates and my potassium and erm, my calcium and is it the creatine? (patient)

When they tell you something's wrong, especially if they get like a problem they encounter like shortness of breath, so that's a time we can teach them the best because they will register to them (nurse)

Informal, really, and also by showing them, because you've told me this, I'm going to take this extra fluid off: look, your ankles aren't swollen, your BP's better, you're not breathless, it's almost like proving to them that when we tell us something, we can act on that and make them feel better. And Phosphates as well, if their Phosphates are high, encouraging them to take them at the right time, in the right dose so they're not itchy (nurse)

They started me off learning how to line the machine, clean the machine and doing all that for the machine part of it, you know, then I learned how to stick my own needles in and because then we used to put lignocaine in, you know, you don't do it now, and they got me through it, you know, and they let me put myself on at the hospital and line the machine and take it off and clean it until I was happy doing it (patient)

Something like especially with fluid balance with a patient yeah. And then we sort of educate that and then to take care of their access they've got, either which access they've got, fistula, lines and then medications. If however, how you know the dosages they having on how they are so because there are also patients that doesn't even, you know, they don't take their tablets, you know, there are also patients, so we have to monitor it as well (nurse)

Several interviewees regarded better understanding by the patient of their condition and the dialysis process as important in itself, regardless of whether the patient was actually involved in their treatment. Staff said that many patients were aware of how their behaviour affects their bloods and fluid retention, which is good as "it's keeping their own independence about their own care and their own medical conditions" (nurse). Another clinician said that patients "actually know how their

body reacts better than clinicians” (manager). For example a patient described that they knew “my weight needs to go up. I was told to wait until the weekend, but that’s not a good idea. And by last Friday I had crashed so I know that my weight has to go up.” Of course, this depends on the patient engaging with the process. Another who had been on dialysis for many years had a very clear idea of how to manage his diet e.g. by only having coffee during dialysis to stop spasms; but he feels many other patients do not understand enough about their condition.

I need to know what’s happening with me, so I take my own time and energy to find out ... I might be disabled, I might have a calliper on my leg, but I’m not brain dead and it certainly wouldn’t hurt me or any other person in my situation to learn... it’s taking control of your own illness which, to me, is a big part of your recovery... [other patients] when they come off the machine they may have migraine, headaches across the fronts of their eyes or feeling a bit woozy and sickly... the patient needs to play a part in their own treatment (patient)

I feel I’m looking after my condition a lot more. I mean a lot more strict on myself in terms of diet etc (patient)

This monitoring may be regarded as nagging about lack of compliance, rather than educating for understanding.

My main nurse... she’ll give me the results on my bloods and my phosphates will be high, she will question my diet... You know as if they’re moaning, they’re not, but they’re just there to help us at the end of the day (patient)

Hands on nursing care... and then giving medications... Monitoring the patients and then giving some education as well (nurse)

Both nurses and patients reported that repetition is important: patients need to hear things repeatedly and it often takes time before the knowledge is assimilated into understanding. Several nurses emphasised that education was an on-going process, highlighting the importance of re-visiting information with long-standing patients and not forgetting that they needed to be kept abreast of new developments and reminded of older, good practice.

It’s just by keep going over things each time and I think it’s just each time you say them and reiterating, kind of, the same things over and over again and then it eventually sticks in their mind (nurse)

As expected given the role demarcations described above, nurses often act as a conduit, passing questions onto other nurses, doctor or dietician

the nurses only really know the basic things it seems and they’ll pass you say “best to ask the doctor about that” (patient)

The regular, friendly relationship between nurses and patients established on dialysis units offers strong possibilities for positive education. In patient interviews, it was clear that how education was experienced, including willingness to learn, was crucially linked to patient: nurse relationships. Trust, respect and comfort were highlighted as key aspects to the relationship which provided a space for patients to learn. They needed to be in a ‘state of acceptance’ to learn, both physically and

emotionally. The supportive environment of many of the units in this research clearly enabled patient learning, together with an encouraging, nurturing approach from nurses.

There can be personality issues with some patients preferring other nurses; although we should just be providing what's needed (manager)

It can take time for a new patient to get into that stage of acceptance (nurse)

You obviously have to gauge how receptive they are to information you're going to give them (nurse)

Both nurses and patients described informal, opportunistic education based around practical treatment issues in small windows of time as patients were put onto and taken off dialysis machines. That education is most effective when it centred on immediate issues of concern, on very specific technical matters, pitched at a level appropriate to the patients' physical and emotional state at the time. There were very few instances of taking time away from treatment to discuss treatment options or to address broader understandings of CKD.

How do patients educate patients about CKD and modality options?

Throughout the interviews with patients, a common theme emerged of the importance of patient to patient education. The value of such education was grounded in the social relationships built between patients, the common shared experience of the condition and the knowledge acquired across years of treatments.

The satellite units in particular had well established social relationships as the same patients attended sessions with the same nurses. The relaxed atmosphere on units meant that patients had time to talk to one another and built up a camaraderie that was conducive to sharing knowledge. Patients commented that there was little privacy on the units, but this meant they were encouraged to talk to one another. In one case this camaraderie even manifested itself as light-hearted competition between patients to see who could 'get the best results'.

We have like a competition you know, what's your potassium oh I beat you, you know, and phosphate and I've got a problem with this and a problem with that. You know and if someone says you want to try eating this and eating that. Which is good but I don't know if they do that on a bigger ward...We were more talkative or watching the telly. When we do get our bloods we're looking to see who's' names on the board for, you know, so it's quite fun...We talk about it all the time. Even when the dieticians there we all have like a cross talk and you know nothing's really private. We're all family (patient)

We do try and pass information around, you know, if somebody's got to have something done we say 'oh well I've had that done, you're OK, they do this, they do that, you'll be alright' (patient)

The informal, relaxed setting was reported to be helpful in building trust between patients, adding credibility to their shared stories. The open space arrangements of the units also meant that patients observed how other patients managed their treatments. They watched as other patients engaged in

minimal care and for some patients this served to motivate them to think that they might do more for themselves as well. They were learning by example.

Yes we laugh and talk with each other. It's a little family at [Name of unit]. Laugh when talking with staff and patients (patient)

There is a culture of 'oh what have you done?' and trying to learn off each other, or wanting to, you know, seeing somebody else do something and think 'oh that would be good if I knew how to knock myself out of UF or do that then, you know, I might not have such a bad headache post dialysis' (nurse)

Patients reported knowing that someone had shared the experiences of the condition added authenticity to advice and meant that sensitive areas could be explored in a safe relationship of trust. For example, it was reported that emotional aspects of the patient experience could be shared with fellow patients more easily than with nurses who did not have the same direct experience. The use of 'ordinary' language by other patients was valued as patients reported the use of 'jargon' by nurses and doctors was sometimes off-putting. The shared experience lent credibility to the advice other patients offered.

[Name of main unit] do have a very good education programme, because they actually invited us in and they had patients talking to us rather than the consultant saying oh this is this and this is that. They actually had patients and they had 3 patients there. They had somebody who was doing peritoneal dialysis, somebody who was doing home dialysis and somebody who had a transplant as well. So it really gave us a good opportunity to ask the people at the sharp end, you know, it's different when a consultant talks about it and he's talking about it in a medical manner. Whereas somebody's talking about their feelings and what they underwent etc, I think you learn a lot more (patient)

I used to go in [centre] and answer question to some people, new people come over there and some are frightened to go to the machine because some are refusing. Only fortnight ago one man he comes here, you not coming to the machine? And one of the members of staff bring him to me, come to me, I give him to and I have tubes on me. I look you can't refuse because you don't know how long your life (patient)

The long term nature of CKD meant that some patients on the unit had accrued many years experience, often of multiple modalities of treatment. New patients coming on to the unit reported they learnt from more established members of the dialysis unit community, learning which encompassed both practical knowledge and emotional reassurance. It was also recognised that sometimes patients knew more than the nurses and this, together with direct experience, enabled them to speak to newer patients with some authority.

However, there was a suggestion that being amongst patients with significantly more experience than yourself could be intimidating. Listening to other patients who seemed to be coping better than you could be disempowering and one patient reported that this made him feel inadequate, as if he should be able to cope as others did.

He made it seem as though it was going to be so easy... He said ... you could be draining out and putting in you know while eating your sandwiches or your meal. He said he also went to work and he worked on a building site...I didn't sort of pick up straight away and I literally

thought I was just a failure. And then one day when I was talking to my main nurse, '[name] she says 'he does go to work' she says 'but he's a boss. He works on a building site, but he walks around for a while' ... I was thinking he was humping bricks around. And also she says 'his wife gets all his meals ready.' ...So basically he was sort of walking in, plugging in, she was giving him a sandwich which she'd made or whatever. He was sitting down and he was unplugging himself and she was sorting the rest out. But he hadn't said that. So as I say that made me feel that I was a total failure (patient)

The other note of caution to be added is that although patient to patient education was clearly valued and prevalent, there was no control over what was shared and therefore no guarantee of its validity. Nevertheless, patients' educating each other was a powerful medium through which knowledge and experiences could be shared with integrity and authenticity.

Summary

For nurses, ongoing learning was mainly in the unit, informally, on a need to know basis; they often needed high confidence in their practical understanding before sharing knowledge with patients. Link roles and other role demarcations were common, and in many cases 'education' was seen as dissemination of information. This meant nurses may signpost patients to specialists rather than educating them, and some nurses disengaged from promoting HHD. Nurses viewed education as a large part of their role but did not report any training on how to do this.

There are periods of intense activity in dialysis centres interspersed with quiet periods when nurses reported developing their knowledge more than educating patients. Therefore patient education occurred in small bursts when patients were put on and off dialysis machines. That education usually focussed on specific concerns and technical matters, pitched at the patients' level.

Most nurses see their role predominantly as a carer, and patients view them as wonderful. Close, friendly relationships between nursing staff and patients, and between patients were often described, using words like 'family'; this means that strong therapeutic alliances may develop. Dialysis units offer little privacy, but this enables patients to know each other and their conditions very well. This can be very positive e.g. by encouraging minimal care if they see others doing it. New patients receive both practical knowledge and emotional reassurance and they value the knowledge, experience and 'ordinary' language of fellow patients.

Minimal care

What was happening in practice

All interviewees were told that: *Minimal care is where patients are trained to undertake as much of the dialysis process as they can*; they were asked if they were involved in minimal care and about their attitudes towards it.

There was a very wide range of responses from patients who had never heard of it, to examples where patients undertake all aspects of their dialysis in the centre (complete self care). The most common situations are that the patient does not play any part in their dialysis: “The norm now is you sit down and let the nurses do everything for you” (patient) or they weigh themselves and perhaps take their blood pressure. Several nurses said they ask some patients to help; for example to collect blankets, tidy round the bed, hold needles etc for the nurse or hold the patch to stop bleeding when the needles are removed. Less common aspects of minimal care reported were taking out the needles and working out their dry weight. The least frequent elements seem to be to strip, line and programme the machine and inserting the needles.

As expected, the sicker, frailer patients are less able to be involved in their care: these are often in the middle shift of the day. Whereas in.

Evening shifts you often get people who are working so they're quite positive anyway, aren't they, they're motivated to not let dialysis rule their life really, they want to be in control of it and they want it to work around their lives (nurse)

Many clinicians said they gently “encourage them, of course we do” (nurse) to be involved even if only in a very minor way. It was suggested that encouragement was all that was needed.

I haven't encountered anyone that doesn't want to be involved as well... if you ask them, they're willing to help” (nurse)

I don't at the moment, but would be happy to self care, if shown, except needling (patient)

One clinician said they would only start minimal care for a suitable person e.g. reasonably young with sufficient English. A patient who has never seen any minimal care said: “Well I don't know whether I could take it all in! It seems rather a puzzle to put all the tubing on, to me. I've watched them do it but I've always thought there's too many ends! Well I wouldn't mind if I had a little tuition on this...” Clearly this patient would be happy to engage with minimal care if given very small tasks to gradually take on over time. Several clinicians agreed with this approach of taking one step at a time: “if you throw it all at them in one hit, it's so overwhelming, isn't it, I think that puts them off. So it is just judging the pace that different people want to go” (nurse). Also a huge amount of encouragement is required: “just have to keep persuading them” (nurse).

In a centre where a considerable amount of minimal care is reported, one patient said she's not been allowed: “I have asked, but to date I haven't got anywhere with it” (patient). For others the set-up makes it unlikely: “I could get everything out erm, in preparation, but that's all done when I get there” (patient).

For a longstanding patient: "I do feel I am the patient sat on the ward and I do feel really it's the patient's responsibility really to find out what their care is." This patient was keen to learn how to line the machine etc, but didn't feel they could ask as "you know don't want to impose on their responsibilities". He went on to say: "we're never asked to needle ourselves... I think I'd be able to do it". Another patient indicated how easy it is to be passive regarding dialysis: "I do understand what's going on, you know, I'm interested in point of view, but I'm quite happy to arrive, sit down and let them do it for me." However, this patient later said the staff were encouraging them to take their weight etc and is gradually becoming involved in their own care.

Opinion was divided as to whether there should be a minimal care area separate from the others or spread across the centre. An advantage of minimal care patients being together is "they talk about what's going on" (nurse).

Several patients have a partner or carer actively involved in their dialysis. Opinions were divided as to whether the patient should also learn to dialyse.

A few clinicians have worked overseas where self care was the norm: "they came in, they did everything. We might have just had to put in the needles in that's it" (nurse). Similarly, a nurse who had worked in intensive care said that experience makes them much more determined to encourage patients to do things for themselves.

Changes over time were described in both directions. Some nurses and patients explained that patients used to operate the machines but that has now stopped: "nowadays nobody's doing it" (nurse). Several possible explanations for this were given: the patients remaining at the centre being more elderly; staff being too busy to train the patients; the attitude of patients, including that they now just wait for a transplant. As increasing numbers of fit, able patients are dialysing at home, there are fewer who are likely to undertake self care in the long term.

There is an important distinction between training for HHD and minimal care for all patients according to their abilities. The consensus is that dialysis is complex and likely to be overwhelming for patients, so must be taught in small steps. Several patients report wishing to be more involved in their dialysis but not being given the opportunity.

Positive aspects of minimal care

A significant proportion of the clinicians were positive about minimal care regardless of whether it lead to HHD.

Self care is even good if they don't go home... it can give them confidence (manager)

They will have the pride in doing it (nurse)

It's just feeling useful, I think, just feeling they've got some sort of grip on their treatment (manager)

Some patients just help you make the bed ... that is all contributing to making them feel more involved so it's really, really important (nurse)

[Even just weighing themselves] gives them a certain amount of power over their treatment (nurse)

The more the patient takes ownership, the more likely to have less admissions and I think the mortality rate is lower (nurse)

Similarly taking their own blood pressure can help patients make the connection between fluid intake and their blood pressure.

Perhaps they might, you know, adhere to things a bit more, because sometimes the blood pressure's high or they've got too much fluid on. I think probably if they know a bit more it's got to help them in looking after themselves... don't get me wrong we do tell them anyway, but I think a lot of the time it goes over their head (nurse)

Independence and keeping mentally active were also seen as positive aspects of minimal care. "I quite like being trusted to stop myself bleeding, even if it is just holding a swab" (patient), "you know I want them to get involved... audience participation is always a good thing" (nurse). At a more practical level, "it does help us a lot" (nurse), "they know that we're short staffed so they've been ever so good and they do do what they can" (nurse) and "if we are busy we can concentrate more on the elderly patient" (nurse). Also in practical terms, patients can see it as a way to leave earlier: "she wants to learn to take off herself from the machine because she doesn't want to wait here" (nurse) were frequently expressed views.

"Just writing it [your own blood pressure] down in the book, you know, it sort of makes you more aware of what's happening." This patient's partner is learning to operate the machine for HHD, but they're now keen the machine is always facing them so they can see their pressures. However, not everyone agrees, with one patient saying: "well the only advantage is to the nurses" explaining that they were in the centre longer due to being slower to set up the machine and needing to clean up afterwards.

A patient said they were very concerned about wasting nurses' time by accidentally setting off the alarm: "I'd like to understand the machine a little bit" to understand the warning signals, and what I'm doing wrong to set them off. Similarly another patient has learnt to adjust the pump speed so as not to set off the alarm while dialysing at a reasonable rate: this patient happy to do this, but has no desire to do more.

Staff said that the self-needling by the patient should keep the access better and have less pain; a patient that self cares was very positive about the buttonhole needling which they used.

Lack of these opportunities was noted by some patients: "But we're never asked to needle ourselves...I think I'd be able to do it" (patient). Another patient was clearly frustrated by this: "nobody seems to be helping me to become independent. You know they say we want people to be independent, but nobody sort of helping me to become independent". For this patient, lack of independence included access to knowledge such as explanation of their monthly blood results as well as dialysis. This last point is slightly surprising as most patients were very happy with the information received from the nurses: "they'll explain to you as best they can" (patient) and "they are very good... they always tell you what they're doing" (patient). This difference may be due to a particularly busy unit or less helpful nurse; however, it might be that the level of detail sought by the patient seeking independence is much greater and so harder for the nurses to provide.

Several clinicians talked about patients going straight into the centre without waiting when on minimal care; this was seen as a perk to encourage them and others. Another perk offered in some places was to be able to dialyse at any time i.e. not have a fixed time slot: “they can walk in from any time from six o’clock in the morning till midnight” (manager). However, several patients were angry in one centre because they say this didn’t happen, despite being promised.

Given the purpose of the interviews, it’s not surprising that many clinicians saw minimal care as a stepping stone to home therapy; in many interviews, this seemed to be the sole purpose: “fewer suitable patients should be unwilling to go home” (manager). In some centres, a complete divide was noted between these potential HHD patients who were always encouraged to do more for themselves and the other patients who were not asked to do anything. A distinction should be made between self care and training for HHD. With self care, once trained, the staff would have less to do as the patients would be doing much of the work. However, with HHD training, this easier time never arrives as the patients go home once they are able to look after themselves.

Many regarded minimal care as positive for patients to increase their confidence, feel useful and understand their illness. However, several patients were not encouraged down this path; perhaps because those not on HHD training were overlooked: this also means staff don’t benefit from having independent patients in their unit.

Negative aspects of minimal care

The biggest issue seems to be “the time pressure: they want to get on and off, and we need them all through in time” (manager). Several clinicians explained how rushed they are when putting people on and off and that patients complained bitterly if the nurses are late. Even those who encourage minimal care say “when the ward is busy, it reverts back to it’s a lot quicker for the nurse to do it than to teach the patient” (nurse). However, some staff said that once patients were doing self care, it saved them time considerable time: “It’s a big help, really... We will just watch them for complications on dialysis... If in one unit and they’re all self care, maybe you can have, like, ten, fifteen patients in a row with only one of you there” (nurse). However, this lack of contact means “you don’t really go and have a chat with them because you’re already focusing on those patients who really need your care” (nurse).

A manager indicated that initially “more work when you were short staffed” was a problem, but now that there are some independent patients in the unit, this frees up time in the centre so they can use that time to train more, leading to “a positive change in attitude from both staff and patients” (manager).

Several clinicians said that patients refuse, saying “you’re being paid to do that!” (nurse). However, another recounted that a patient was very angry saying it was outrageous when asked, but after a few weeks had “started doing his own blood pressure, he’s doing this, doing that, we put his needles in but he takes himself off” (nurse).

Several patients and some staff complained about the pressure put on them to agree to minimal care and to self-needle: “when I started I said I only want to go so far, but then the boundaries were pushed further and further. We were made a lot of promises that weren’t true. We were told that we could go in early so we could set up our machines.” This patient is now doing self care, but is

unhappy that help often isn't there when they're feeling ill or has forgotten something. However another patient in this centre said "When you do call out they are there."

Nurses seem very aware of potential risks of minimal care both in terms of procedures and whether patients might be devious.

You don't just leave him (nurse)

I don't know now [whether they support minimal care] because with all this infection control we stop patient doing it (nurse)

They'll say "well it's the weekend coming and that means I can have an extra drink" [to justify taking off extra fluid] (nurse)

Conversely, some patients felt they needed to check the staff were doing things correctly.

Accidents do happen, you know, nurses don't put the gloves on, sometimes you'll type in your wrong weight or the wrong flow or put your wrong needles in. So you know it's up to patients to be aware of that really (patient)

A nurse said: "I think for them it gives independence" as it means that patients stop abdicating responsibility to staff. Another felt minimal care gave them a new role but another resented it.

It helps with the pressure of us looking after so many patients and it gives us something to do where we're also educating patients, it gives us a new role that we probably never probably thought we're going to get the opportunity to do, unless you did the mentorship course or unless you were given a student, so it gives you a good insight and then you realise actually that patient knows more or less everything that you know, so it makes you think OK I should know my stuff and we can talk more among ourselves (nurse)

I think our issue here is when we have gone ahead and done it [trained patients for HDD], when we've been asked to do it with this patient and that patient we've started the ball rolling but then the nurses that are employed and paid to do that we very rarely see them and it ends up we take on their, ninety percent of their work but they're being paid for that job and we're taking on that extra workload so then that makes us not want to do it if I'm being brutally honest (nurse)

There were concerns that training for minimal care: makes dialysis slower; is riskier; there is too much pressure to do it; and some patients feel it is not their job.

Summary

Minimal care really starts with interest in treatment.

Some patients are much more involved with the treatment, are interested to know their monthly blood results for instance and things like that (nurse)

When you step back you see how it would benefit them. Doing more themselves might give some who are reluctant to go home the insight then the confidence to go home... Patient and nurse trust is important for minimal care. You are reliant on the patients being competent: but it's their life (manager)

Taking responsibility for their dialysis helps patients take better care of themselves e.g. in terms of dietary and fluid control.

You're not just teaching them the machine, you're teaching them the mentality of, you know, going about fluid restriction, dry weight (nurse)

Part of the acknowledged tension in the nurses is that they want to take care of the patients but realise they need to train them to be more independent; this requires a change in expectations in dialysis centres.

Some nurses are more discerning of the type of patient who is more perhaps able to do self care and then there's other nurses who haven't got that level of discernment and just automatically do everything for them (manager)

There's a conflict within us as I do want patients to look after themselves, but also want to care for them (manager)

I'm the sort of nurse who mollycoddles my patients really! So it is quite hard for me. But I suppose if you're a bit more proactive and think well you could do that yourself and a bit more pushy then, you know, perhaps they would do more for themselves... it's up to us, isn't it, to change the culture, the nurses to change the culture (nurse)

This relates to the view expressed earlier that "a lot of them just accept what we say and just try and do" (nurse); so there is potential for nurses to change the overall attitude of patients to minimal care.

In addition, several clinicians clearly felt the system should change: "it makes me feel uncomfortable thinking about minimal care; yes we should be promoting it more" (manager). In one place, there is going to be a move to a new location where it is intended that the default is that patients take their own weight and blood pressure and will be given much more encouragement to look after themselves. "We'll start by assuming 100% and see how far they will go" (manager). Here the feeling is that a culture change is required and a new location offers this opportunity. This requirement for a difficult cultural shift means that it's much easier to work with new patients: [with existing patients] "I think because they've had it done for so long that it goes against their grain and I think the best way to tackle this is when they come in to get them to ... start from the word go" (nurse). On the positive side, once minimal care is established, "they almost don't want to miss out" (manager).

Several clinicians viewed a patient's interest in treatment, undertaking minimal care and self management as mutually reinforcing. So learning how to operate the dialysis machine requires understanding of dry weight etc and encourages sensible fluid intake. Encouraging patients to be more independent creates a tension in many nurses as they are keen for this to happen but also wish to be the carer. However, the majority of clinicians did not talk in these terms.

How decisions are made regarding the treatment of patients

Despite a dominant discourse amongst nurses and patients of 'informed choice', interview data suggested that clinical decisions about day-to-day treatment were largely consultant or nurse-led. Patients varied in their desire to be involved in decision-making and there were no reports from patients who were excluded from decisions against their will. Heavy reliance on nurses' and doctors' professional knowledge was evident, despite some patients reporting knowing more about their condition than their nurses.

Some nurses described the decision-making process as one of negotiation, recognising the benefits to patients of having some control over their condition. However, this was often framed in pragmatic terms.

It's a bit of a negotiation, it's a two way street. We try and get them involved because they need to be responsible (nurse)

We sort of encourage the patients to take some ownership of their medical health needs, because otherwise you're just fighting a losing battle (nurse)

The theme of hierarchy was apparent in other descriptions where nurses and managers confirmed that ultimately it was the consultant or the nurse who decided treatment and where they talked about how they saw the relationship between nurses and patients, using language of behaviour, compliance and 'sorting out'.

We would inform the doctor who's on-call ... and we would sort things out ourselves and liaise with the doctors ourselves to sort the patients out (nurse)

What we normally experience is non-compliance in terms of the fluid intake, non-compliance in terms of the tablets (manager)

You do get to know the patients that are compliant. I mean some people have an off day and they will admit that 'oh I was a bit naughty this week' (nurse)

Although nurses recognised the benefits of patient involvement in decisions, the patients varied greatly in their attitudes to that involvement. Some were adamant they did not wish to be involved, preferring to leave it to the professionals who, they felt, had appropriate knowledge, while others felt it was important they understood what their options were.

I leave it to them because they're the experts. They know what they'll do (patient)

I just think sometimes patients just perhaps sign things blindly (patient)

I do find a lot of patients don't seem to, although they see a doctor in the clinic, you know, once every 3 months, I don't think they, they come away and sometimes not taking in what he's said or they misunderstand something he said and they seem to be a bit wary of asking more questions (patient)

I wanted to know as soon as and I made it very clear to my doctors, such as my medical records, I look at my medical records when they're put in front of me, now obviously when I speak to Doctor [name] or Professor [name] or different ones, I'll speak my mind, I want to know in my language, fair enough you have to put it down on paper in the medical terms,

but I want to know what's happening to me and what I can do to help that process and to keep me here a bit longer (patient)

I can understand why he's doing it and, I mean it's explained and that's why I can understand it. I wouldn't know necessarily just out of the blue, but yes I understand what he's doing, what he's saying... it depends how much faith you've got in your consultant (patient)

Despite the understanding that professionals possessed expert knowledge and that patients need to defer to them, nurses recognised that patients could contribute to discussions and often had practical, personal knowledge to share.

It kind of can be, kind of, a culmination of professional and patient, because some of them have been on it so long that they know it as well as if not better than some of the newer staff in particular, so it's kind of like a -, the ones that have been on it a long time, it's more a discussion and they give their input as well as professionally as well (nurse)

They know about their body more than us actually. We are here to give them more like advice: as a medical professional this is not right, but when they go out of the building they know that's going on with their own body (nurse)

Summary

Therefore, the data suggested that decisions were, in the main, seen as being clinically led, with patients varying in their involvement. Some were adamant they wished to be involved, others described being happy to leave it to the professionals. Knowledge seemed to dictate levels of patient involvement.

Attitudes to HHD policy and training

As indicated in the section on Patient suitability for home haemodialysis, clinicians believed the majority of patients are clinically unsuitable or otherwise unable to dialyse at home. Even so, perhaps a third of patients are suitable for HHD, although most of these are unwilling: this section is concerned with these 'suitable' patients.

All clinicians and many patients were aware of the drive for HHD, and most clinicians were clear and positive about it, but not everyone as some nurses said HHD isn't really discussed.

I am passionate about HHD (manager)

I think we all feel that it's the way forward, especially myself (nurse)

It's better for the patient (nurse)

Positive, I think positive, yeah (nurse)

In my team I think it is a positive view of home haemo (nurse)

I'm not sure if it was like a proper policy... I've just heard that they're trying to increase the number of patients to go on home haemodialysis (nurse)

At the moment what they're trying to do is encourage us to go home (patient)

Key patient benefits of HHD were increased patient independence, more free time and better quality of life; most staff were confident that it wouldn't be detrimental to their centre.

[No concern over work in the centres as there's] a long list of patients waiting (nurse)

Paid more for HHD which is the main driver (nurse)

More frequent, hence better dialysis (manager)

Won't get hospital infections (nurse)

They can have their independence back and especially their self-motivation, their confidence and their responsibilities. They are more responsible with their health (nurse)

I think the consensus really is it's got to be better for patients who have that ability to look after themselves (nurse)

It gives them control of their own health and their families can get involved in that treatment as well with them (nurse)

Several staff reported the positive effects of the patients who had gone onto HHD. Once dialysing at home, some centre staff say they never see the patient again. Elsewhere, they come in for monthly bloods, talk with their friends and still feel a social bond.

The people we've got at home they look really well and they are doing well (nurse)

We're here on the phone [for HHD patients] (nurse)

They pop by with a box of chocolate and still keep in touch... I mean, patients have gone home, you know, they certainly has changed their qua-, you know, these patients would never, ever come back here, that's not because, you know, there's no place like home. Even if they are poorly, they hate to be in hospital, these are the experience you get from the home dialysis patients, once they're home, they're settled, they enjoy (manager)

I have seen the both sides. The patient who been empowered and doing their care by themselves at home, I can actually see the difference in the patient. They are much more, how do I put it? Not better, they are very confident, they are taking control of their life. They are changing their time of dialysis and fitting their life around it, rather than the clinic different patients comes here, they're worried about their time, worried about their transport. That's why probably they see same faces every time they moan at the staff, the transport system and they are not quite happy with anything (nurse)

I think what drives you on is how you see them developing. Because when they first start say oh I couldn't do that and you think, you know, 3 months down the line, you know, they're lining, they're needling and don't need us anymore. And in one respect it is sad to see them go, but in another you just think, you know, they've got more power and control over their life... I went home with a patient. I did their first dialysis session and it was quite euphoric really, because you're sitting there in their kitchen and they're dialysing chatting away ... some

people don't like coming in here because again as I say they feel dialysis rules them, but when they're in their own setting I can't dictate to them. They can dictate to me which is, you know, it's just about that control which is, you know, and the patients have gone home and they come and see us now and you just think they look better, they feel better in themselves (nurse)

Most patients interviewed were positive about HHD even if they didn't consider it for themselves e.g. because they have arthritis or enjoyed meeting people at the centre: "I do believe it's very good, you know, if my life was different", this patient said they would consider HHD if had the space and was working or looking after children. Another patient said they were now considering HHD as their wife/ husband had just retired; similarly others have partners who are carers. Many mentioned flexible dialysis times and no travel time as benefits. One patient wants nocturnal "because that frees up my whole day then" and another said: "the positives are of course like you can, because you're going on it more frequently you do get a better dialysis." However, one patient who had been on HHD had fluid and access problems, so they came back into the centre and doesn't want to go back to HHD.

Some clinicians and patients felt undue pressure or coercion in relation to home haemodialysis. One manager, although positive about HHD "for the appropriate people" felt the staff greeted the HHD policy "in general, I think with scepticism." This was because they believed their remaining patients were either unsuitable or unwilling to dialyse at home and "sure there isn't meant to be too much pressure, but it feels like it to many of the patients" (manager). There is clearly a delicate balance to be struck between encouraging, nurturing and over emphasising the benefits of a move home.

They came, they two girls came in my bedside and they were thingmy and I says 'oh I says are you selling double glazing here?' They were trying to talk me in to thingmy and they were saying what do you feel? I says 'yeah it's maybe something I might think in the future'...Then I got a letter, I got a few letters actually and I was a bit upset because I felt under pressure as if they were pressurising me... because I feel at first I thought I was letting people down, not doing home dialysis or taking a space up for somebody that needs dialysis, but they come and a couple of the senior nurses says don't think like that they always pressure you like that (patient)

I think going home is brilliant if the patient is capable and able to go home. I think that's fantastic if they can do that. I don't think patients should be pressured into going home. I don't believe in so many having to go out because the hospital gets so much money if you get so many out. I'm afraid I'm totally against all of that (nurse)

However, this wasn't the dominant view. Almost all patients remembered being asked about HHD: "Yes I was informed by the unit;" they were not unhappy about it; for example, another patient elsewhere said.

Just to check, you know, when you have a new influx of people they'll come round and talk to them, 'have you changed your mind?', 'no thanks' and they'll leave you alone (patient)

Several staff said it's up to the patient to choose, but if they think they will benefit, they are likely to encourage more strongly e.g. with "a young gentleman here now and he's perfectly fit and able to go home, but he's needle phobic" (nurse).

Concern was expressed that some patients may agree to HHD without knowing all that it involves, then back out later. A more frequently expressed issue was the 'risk' involved in HHD as it is dialysis without immediate clinical support. There was a suggestion for training updates for HHD patients.

I just think like the job that we do here on the unit, that there's all these rules, regulations and boundaries that we must follow because it's dangerous if we don't, but then to allow patients to go home and do all of that and not know the rules, regulations and boundaries, I just think it contradicts what they're making us practice here but then allowing patients to go home on their own" (nurse)

The only disadvantage when they're home is the risk of them not being too careful and we're struggling at the moment with one of our very well-educated patients who's training up to do home haemo who thinks he can bleed back right to the bag" (nurse)

I think it would be very tempting to just to finish you know a little bit earlier (patient)

When you know you can dialyse every day I think it makes it easier for you to drink more (patient)

They have no update on, you know a refresher of troubleshooting with the machine. So they get stuck into their routine even though it might not be the right way (nurse)

Some patients gave long detailed accounts of their medical histories involving multiple comorbidities and numerous treatments e.g. difficult, failed transplants. Although we weren't exploring this area, we felt their sense of relief in being settled into in-centre dialysis. It is not surprising that many of these patients do not wish to consider a change in treatment modality.

Some staff were aware that wanting the best for their patients in terms of care and HHD are not the same and that there is a need for nurses to step back to allow the patient to gain independence.

I don't think they [the nurses] are always so passionate about getting them home, necessarily, but I think they are all there to try and give them as good care as they can (manager)

It gives them their independence. There's always the issue with home haemodialysis and non-compliance but that's just part and parcel of it. When they go home to do home haemo you trust these patients that they will do it. Trust is placed in them... They have power over their treatment (nurse)

In a centre where 'standard' renal nurses do the training, phrases like 'ad hoc' were used to describe the system. HHD training had to be fitted round dialysing everyone else e.g. by giving a nurse relatively 'easy' patients to hook up before spending more time training a patient for HHD. Elsewhere, patients training for HHD are encouraged to come in early to be given more attention. Also, it may be desirable for the same nurse to train a patient to ensure consistency e.g. for buttonhole needling.

The sections on education and minimal care included concern over role demarcations; this was even more evident here with the view that encouraging HHD was someone else's responsibility i.e. the HHD nurse, technician, link nurse or consultant. Consequently, some nurses had not developed knowledge or confidence in training for HHD and may even begrudge doing it. However, there were also positive examples of working together.

If they are interested we arrange the proper staff who can speak to them and explain to them (nurse)

I'm an experienced renal nurse but from the inpatient unit, I really would like some training on home haemo, on understanding the basics of home haemo (nurse)

the main complaint ... was that we had one person who was never here, though she would teach some today, never see them for 6 weeks and then come back and we'd see her and then not see her the gap was too long. They weren't getting consistent erm, and the knowledge base was a bit airy fairy... Before we used to teach the patients, not necessarily if they wanted to go home, but we used to teach them if they want to sort of know to set up the machine do whatever... Used to be each nurse would be able to teach that person. So every single time they came they would have less so that would be obviously be compacting a lot quicker. But waiting for one person to come and teach several people and it took several months and quite a few people dropped out saying we're not interested because they don't see the person and they're going back and forth, back and forth with the same thing (nurse)

Well [name] is in charge of the home haemo programme and she's definitely mainly involved in signing the patient off, the going home stage, but all of us are encouraged to take part, because there are, like, particularly the priming, there are very minute changes in priming with home haemo than there is with the standard renal machines, so we're encouraged to all know so that we are -, we don't end up confusing the home haemo patients by showing them something that's slightly different. So we are encouraged to be involved from the beginning really so that we're all singing off the same hymn sheet (nurse)

Anybody can teach the patient. That's the rule here (nurse)

The reason many patients deemed suitable for HHD are unwilling to consider it may be due to centre or wider societal factors. Several staff suggested that unsuitable and unwilling patients are being trained for HHD.

The unwilling patients are the main block but this might be because we've not educated or given adequate information (manager)

I know a few of us think a lot of the patients now are inappropriate to be at home. There's not enough staff to do it. We end up teaching a lot of our patients if they go home from here so it's not always possible for the one nurse to come over and train them (nurse)

They grew up in this culture that they are very dependent or they just don't want to do anything but just sit there and do everything for them, so home dialysis is a no-no for them. But in a group where they're used of having their independence and they like to do their own

thing in their own time or they want to be, to feel as normal as possible, that kind of thing is open to them (nurse)

However in another centre, the manager explained that a previously passive culture in the centre could be overcome: “2 of them or 3 of them [who have gone onto HHD] have been on dialysis more than 5/7 years. So, you know, it is doable.”

One approach to addressing this unwillingness is with contact from HHD patients as they are viewed as excellent for promoting the benefits of HHD. An issue is whether patients training for HHD should all be separate to facilitate training or in the middle of the centre

We have home haemo patients that come here for their bloods and that, so if they're thinking about it we'll get one of them to speak to them. And we'll also ask, get the patient's consent and say 'well can we bring them out to your house to show them the set up that you've got' so that they've got it in their mind? (manager)

The patients are coming in and they're looking so much better. And they're feeling better. So because they know patients on the shift so they'll go round and talk to them and then they'll say 'he's looking really well', 'that's what you can do when you go on home haemo' (same manager)

[With HHD training in the middle of the centre] “then other patients can see that you're having training for HHD and they can also see well, they've managed to do it, so maybe I could (manager)

We initially started with one patient going home and then his mate saw him, saw how well he was looking, so he decided he'd go for it and then we had a guy who worked days who didn't want to spend his nights here when he could be sitting at home, so he saw the set up these people had got and he's gone (manager)

Several practical barriers to HHD were noted where patients are waiting to dialyse at home, but require house needs modification, staff to train them or suitable machines. In some places, this lack of machines means they stop training; elsewhere

Once you can learn one machine, it's not difficult to operate another machine (manager)

To address isolation when home, one centre reports that the HHD team now visits patients as they are dialysing to offer support and encouragement. A patient agrees that in the past it felt very isolated dialysing at home

Once it was done and I was at home I never saw a soul; that was the down part (patient)

Several centres are making many changes to encourage home dialysis e.g. by being able to self care (not need a partner at home); having a central line; introducing assisted HHD to start patients at home, and using a tray system instead of major modification of the patient's home as it's much cheaper and quicker, especially as the patient may later have a transplant. One centre explained they are starting to use their HHD education material with all new patients. However, it was suggested that it's important to give patients a chance to settle into dialysis in the centre first: “probably it will stress them up if we just push them soon” (nurse).

Summary

There was generally a positive view of HHD, for the right patients. It is seen as a better treatment, avoids the need to come into a centre and gives the patient independence/ control over their condition. Several staff described positive changes in patients when they went onto HHD in terms of being healthier and more confident.

Despite this, there was some resentment of the pressure to send patients home who were unwilling or unsuitable. Patients who had a particularly traumatic health history may need considerable time before they can consider HHD. Clearly this is a cause of great tension as clinicians may vary in their assessment of patients: 'encouragement' by one may be regarded as 'undue pressure' by another. However, this was not a problem for most of the interviewed patients.

Concern was raised about the extra risk involved in HHD in terms of dealing with emergencies and being tempted to skimp on treatment or being more lax regarding diet and fluids. A few staff acknowledged that it was hard for nurses to relinquish control to enable the patients to be independent. It was suggested that HHD patients should come back to the centre for 'refresher' training.

Perhaps the most difficult issues concerned which nurses should train patients for HHD; should it be: all nurses; particular 'link' nurses in the centre assigned this role; an external HHD specialist nurse; or some combination? Some staff reported their system was working successfully. Others pointed to centre nurses not knowing enough or giving conflicting messages, and link or HHD specialist nurses being insufficiently available.

In several centres it was suggested that patients expect to be passive and not consider HHD. Several approaches are being tried to address this, such as contact with HHD patients and initially assuming HHD will be appropriate for all new patients.

Discussion

This report is based on interviewing 75 patients and NHS staff. The interviewees appeared to be extremely honest and helpful, but it is important to consider possible biases. Almost all the managers were interviewed as were most available nurses in the smaller centres, so there would have been little selection bias with them. However, with nurses in the larger centres and all patients, it is possible that people were asked who were more positive about the centre. Regarding response bias, interviewees knew they would be asked about HHD, so may have been more positive about this aspect, and possibly said less about other aspects such as general education. We recognise this report represents the views of participants at a particular point in time under interview conditions.

This report is not intended to make judgements on whether the centres generally or individually are 'doing well'. This is partly because self-report is not a reliable way to make such judgments; but mainly because our purpose was to understand what they are doing, how and why. We must emphasise that the comments and suggestions below are not at all critical of any of the centres.

Although guided by theoretical considerations, we have endeavoured to be as objective as possible in describing the results, above. In this section and the next, we offer our opinions and interpretations in an attempt to integrate the results with ideas from the literature to make positive recommendations.

There was generally a positive view of HHD as being desirable for suitable patients. It is seen as a better, more convenient treatment, enabling the patient to be healthier, more confident and independent. However, there was some clinician resentment of the pressure to send home 'inappropriate' patients.

The NHS staff interviewed estimated that nearly half their patients were too old, sick and frail for HHD; so we might infer that the other half would be capable of minimal care. A further fifth were judged to be unable to do HHD, mainly due to issues with accommodation and lack of support. This leaves about a third of patients currently on long term centre-based haemodialysis who may be suitable for HHD, but the majority are unwilling to do it. Reasons included fear, social reasons, wanting to keep their illness separate from home life and it not being their responsibility. This discussion considers how changes within dialysis centres might increase the proportion of patients undertaking both minimal care and HHD, structured round the three research questions.

Research question 1: How do haemodialysis nurses view their roles in caring for, educating and training patients to dialyse at home?

Nurses did not report any training on how to educate patients. Caring was seen as the principal nursing role; very strong positive bonds with patients were described and patients held nurses in high regard. Patient education was also seen as central to the nurse's role. This education tended to be dissemination of information regarding specific concerns and technical matters (e.g. regarding fluid intake and medication) and usually occurring in small bursts when patients were put on and taken off dialysis. Nurses often felt the need to be very confident in their own understanding to discuss topics with patients and, where this was not the case, some signposted patients to specialists (e.g. dietician, doctor, HHD nurse) rather than educating them, and so disengaging from the

promotion of HHD. Another manifestation of this 'signposting' approach is that link roles and other role demarcations were common.

It should also be noted that patients know each other and their conditions very well; they provide each other with practical knowledge and emotional reassurance. Staff are well aware of this and often make use of it e.g. by bringing in HHD patients.

Who trains HHD patients is clearly a difficult and complex issue which appears to be problematic in some centres. All nurses care for their patients in dialysis centres, which may promote HHD or, alternatively, may encourage patients to stay in the centre. Some nurses promote HHD enthusiastically and so are happy to encourage patients to consider it; other nurses feel insufficiently trained to discuss HHD and do not see this as part of their role. Once a patient has chosen HHD, this training may be provided in a variety of ways: by all nurses; particular 'link' nurses in the centre assigned this role; an external HHD specialist nurse; or some combination.

In summary, the routine care and education provided by all nurses is designed to manage patients undergoing centre-based dialysis. It is likely that with most nurses this does not promote HHD, although it may well with nurses who encourage independence or are particularly enthusiastic about HHD. Education and training specifically for HHD are not carried out by all nurses.

Research question 2: How do haemodialysis nurses encourage patients towards self management?

As indicated above, the majority approach was that education consists of disseminating knowledge; many staff talked in terms of 'compliance'. Within this approach, training for HHD is to master the complex, technical activity of dialysis. This is usually overwhelming for patients, so must be taught in small steps. Training for HHD can also be seen as burdensome to staff: it makes dialysis slower; is riskier; and, there may be pressure to do HHD with inappropriate patients. Several patients wished to be more involved in their dialysis, so there is potential for greater encouragement of self management. This might be due to time constraints or because self management is not seen as desirable, except as a step towards HHD.

A minor but not uncommon discourse was around developing patient independence, although several staff indicated that while this was desirable it did not happen regularly. With this approach, minimal care is an excellent way to encourage self management and increase a patient's confidence, feeling of usefulness and understanding their illness. This is desirable in its own right, rather than only as a path towards HHD. In this view, a patient's self management, understanding of their condition, and undertaking minimal care are mutually reinforcing. For example, learning how to programme the dialysis machine requires understanding of dry weight etc and encourages sensible fluid intake.

Developing patient independence creates a tension with the caring aspect of the nurse's role. We conceptualised patient independence as requiring nurses to change from beings 'carers' to 'trainers' (see Figure 1 in the introduction to the Context and literature review section). The literature on home-based stroke rehabilitation suggests rehabilitation involves patients and nurses 'making a journey together from hospital to home' as well as nurses 'refraining from interventions' and so 'encouraging patient problem-solving skills'. It was noted that nurses can find rehabilitation difficult and stressful, but this approach may be important to encourage self management.

None of this is easy. To re-iterate our initial comments in this discussion, there is no suggestion that nurses are not doing a thoroughly professional job. Also to return to the introduction to this report, in developing this project, staff at renal centres indicated that complex adjustments in interpersonal communication and professional behaviour would be required to further promote HHD. We agree and believe the issues raised here suggest some areas where these 'complex adjustments' may be required.

Research question 3: What learning facilitates patients' engagement with home haemodialysis?

Day-to-day decisions were generally clinically led, with patients varying in their involvement. Some wished to be involved and often were happy with the answers given by the clinicians; however there was some disquiet e.g. delays in being able to see and discuss their monthly bloods. Others patients described being happy to leave it to the professionals; perhaps due to their limited understanding of dialysis. In terms of Thompson's typology, this means that level 1 is the norm i.e. clinicians (mainly nurses) provide information. The patients are usually receptive to this and may actively seek further information. Our argument here is that to encourage HHD, patients should first be encouraged towards shared decision making (level 3 of Thompson's levels of patient involvement) e.g. by being encouraged to interpret monthly bloods before the nurse comments and by agreeing dialysis parameters with the nurse.

In the introduction we said we'd make an *assessment of the barriers experienced by patients in considering the move to self care or home haemodialysis*. Tables 5 (at the beginning of the Results section) lists reasons given by clinicians why some patients are 'unable' to dialyse at home such as accommodation and support issues and Table 6 lists reasons for 'unwillingness' such as fear of needling and wishing to keep dialysis separate from home. We will not discuss these further as they are covered in greater detail by other research. However, it may be useful to consider the suggestion of the Health Belief Model that perceived barriers are more important than perceived benefits in determining patient behaviour. Therefore, it may be advantageous to address some of the likely barriers to undertaking HHD before asking the patient to consider it. That is to say, using minimal care, patients could learn to self-cannulate and deal with some problems during dialysis themselves; if this is done before being asked about HHD, it would reduce their fear and perception of the risks of HHD making them more likely to want to dialyse at home. It is also important to address the perceived barriers expressed by staff. For example, concern was raised about the extra risk involved in HHD in terms of dealing with emergencies and being tempted to skimp on treatment or being more lax regarding diet and fluids. Once again, a longer period of minimal care may help to allay these fears; in addition, genuine shared decision making regarding dialysis decisions should demonstrate that patients can self-manage their condition.

In several centres it was suggested that patients expect to be passive and do not consider HHD. This expectation needs to change if targets for HHD are to be met, perhaps using ideas suggested here as well as current approaches, such as contact with HHD patients and initially assuming self care will be appropriate for all new patients.

Conclusions and recommendations

The aim of this project is *to evaluate how nurses enable patients undertaking long term in-centre haemodialysis to move to home therapies*. In all the centres visited, some patients had successfully moved onto HHD, so nurses are at least partially successful at this. The main finding from this study that may be used to increase HHD is that promoting patient independence within the dialysis centres should enable more patients to embrace full independence i.e. dialyse at home. Possible ways to encourage patient independence are described below and these are recommendations for dialysis centres to consider.

1. Two concerns regarding the education of patients by nurses were evident: first, nurses may avoid providing more than basic education to patients by forwarding questions too readily to the dietician, doctor, HHD nurse etc.; second, education appears to consist frequently of providing information, rather than developing a patient's understanding of their condition. Presumably nurses should be confident explaining diet, medication and dialysis in quite some depth. However, the education from nurses centres on what blood levels should be, what to eat and not, rather than on broader considerations about the disease or condition itself. So education is specific and in relation to targets set by the doctor, not about why those targets are set, how they might influence the patient's quality of life etc. We doubt that these issues relate to nurses' clinical knowledge or that time constraints are the major barrier. Our view is that it is that some nurses may lack the communication skills and confidence, but it is more that many nurses do not regard it as part of their role. The absence of training for nurses regarding approaches to the education of patients was noted. Doubtless, many nurses are excellent at this aspect of their role, but some could improve the way they support the learning of patients. Recommendation 1: consider training to improve the way nurses facilitate patients' deeper understanding of diet, medication and dialysis.
2. Recommendation 2 is that shared decision making (level 3 of Thompson's levels of patient involvement) between nurses and patients should be promoted e.g. by encouraging patients to interpret monthly bloods before the nurse comments or by them jointly agreeing dialysis parameters. The goal, here, is to encourage patient independence and control over their condition. The first step could be to debate this issue and raise awareness about the benefits of encouraging patients to be involved with decisions about their diet, medication and dialysis. There should be an assumption of involving the patient in all decisions e.g. by asking the patients (who are able) to say how much fluid should come off. On-going nurse training and discussion would be required to embed this change as different techniques would need to be employed; for example, thinking aloud protocols may be useful in moving towards shared decision making.
3. Recommendation 3 recognises that minimal care is good in itself, so dialysis centres should be organised to enable all patients to undertake as much of their dialysis as possible. This approach should involve the mechanics of dialysis, starting with weight and blood pressure **as well as** the approaches to education and decision making indicated by the first two recommendations.

We are aware that at least one centre in this study has embarked on this since our data collection finished. Elsewhere it is being promoted as Shared Haemodialysis Care (The Yorkshire and the Humber Renal Network, 2011, p41).

For nurses to train patients for maximum independence, whether as minimal care, self care or HHD, recommendations 1, 2 and 3 all need to be followed.

4. Recommendation 4 is that centres should be organised so that there is some spare capacity for two reasons: a) to permit self care patients some flexibility as to when they attend; and, b) to enable out-of-phase dialysis to train patients i.e. instead of starting at 7am, 1pm and 5 pm, one or two could start at 9am and 3pm to make educational use of nurses' quiet periods.
5. Recommendation 5: those suitable for HHD but unable to do so e.g. due to accommodation issues should be expected to undertake long-term self care.
6. Recommendation 6: those suitable and able but potentially unwilling to dialyse at home should be encouraged to self care before any decision about HHD is made.

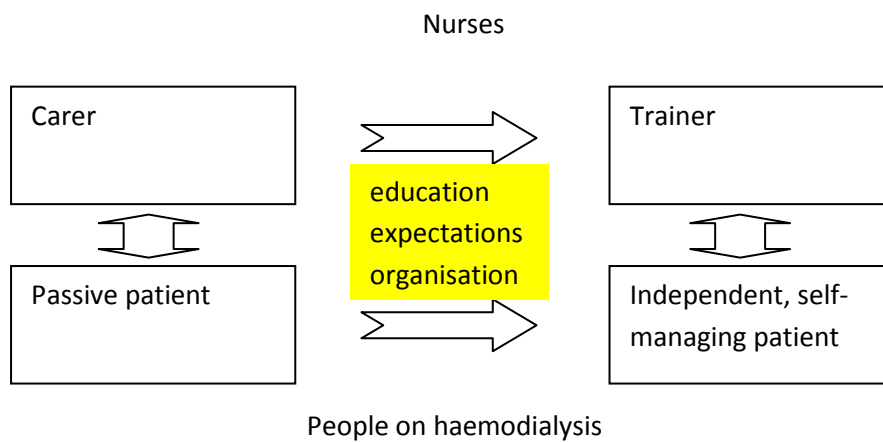
Potential HHD patients might be encouraged to self care in-centre for a limited period such as three months; then once a week in-centre while doing HHD other days. They could then come in once a month to check up on technique, maintain links and have bloods done. This ideal would probably be less daunting for patients, but the main aims would be: a) so nurses benefit from the time taken to train i.e. less input is needed for those doing self care, which enables them to spend time with those who are training to self care; b) increasing the centre nurses pride in 'their' HHD patients as they would be 'making a journey together from hospital to home' and, c) other patients would interact with a substantial number of self care patients: this would be good for changing expectations, for learning from the HHD patients, and for seeing how healthy and confident they are. The recent experience from Yorkshire and the Humber is that after initial high levels of self care, despondency can creep in as patients go to HHD or other units. For example, they noted that it was difficult "to maintain their own personal motivation in relation to SHC [shared haemodialysis care, i.e. minimal care], when they have commenced training with a patient who is then transferred to another unit." (Campbell et al., 2012, p37). We do not have a clear recommendation about the roles of link and HHD nurses; however, our recommendations are intended to improve the way all nurses encourage independence in their patients. This leads us to suggest that self care patients are dialysed alongside the more passive patients.

There appears to be reasonable support for some of these recommendations, but the argument is not yet won. Substantial development work would be required with most nurses and it is envisaged that there would be challenges from many quarters. For example, Trust financial managers will need convincing, as investing time and resources in minimal care for those not expected to go onto HHD could be regarded as an unaffordable luxury. Individuals vary in how willing they are to embrace change; and for major changes such as these, there would need to be substantial work to enable people to go through several stages of behaviour change. Of course, whether such changes are successful would depend on numerous factors in addition to the professionals, patients and the proposed change; these factors will include the wider organisational, economic and political context as well as specific details such as whether the technologies work. It is important to understand these potential barriers: perhaps administrative constraints, clinical uncertainties and patient expectations are most important.

Finally, we reconsider Figure 1 as a description of behaviours in long-term dialysis centres. We were impressed by the strength of the bond (therapeutic alliance shown by double-headed arrows)

between nurses and their patients. The number of patients already on HHD indicates that there already are important factors that support moves towards patient independence i.e. to the right of Figure 1. However, this study suggests many patients on long-term centre-based dialysis may be unduly passive, in part because of the nurses caring role i.e. stay unnecessarily on the left of the figure. To promote HHD more effectively, it may be better for nurses to be more like trainers, rehabilitating patients and encouraging them to be much more active in the understanding, monitoring and management of their condition. This study recommends that educational approaches are adopted which increase patient independence and hence the uptake of home haemodialysis.

Figure 1 (repeated): How nurses can encourage patient self management



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Appendices

How do nurses in dialysis sessions promote the uptake of home haemodialysis?

I am a researcher from the University of Birmingham working with the hospital to look at treatment choices of patients on dialysis. Thank you for agreeing to take part in our study. We talked about the study before and you had the chance to ask some questions.

- Before we start, have you got any more questions about the study?
- Are you comfortable that you understand what the study is about and what we are asking you to do?

I must emphasise that nothing you say will be discussed with nurses or doctors (except where you specifically ask me to) and this interview will have no effect on your treatment or your treatment options.

What you say will be seen only by the research team and if we use any quotes no-one will know who said them. I'll send you a copy of my notes to correct or add to, if you wish. All records will be stored securely.

You can withdraw from the study at any time. I have questions, but hope the discussion will be informal and that you will say anything you like. If you do not wish to answer a question we will move onto the next one.

Please sign the consent form and say if you're happy for the interview to be recorded.

Interview questions (omit if already covered)

1. To start, can you please say a little about yourself, such as your age, where you live and whether you work.
2. Thinking about the treatment you receive from the renal team:
 - a. Can you tell me who do you see, and when?
 - b. Do you always see the same consultant/nurse?
 - c. Who decides, and how, what happens to you?
3. Thinking about yourself as a dialysis patient:
 - a. How long have you been on haemodialysis?
 - b. Have you ever had any other form of dialysis or a transplant?
4. Finding out about treatment options:
 - a. How much do you know about your treatment options?
 - b. How and when have you found these out?
 - c. How much do you want to know?
5. What do you know about dialysing at home?
 - a. Have you ever considered it?
 - b. What are the factors which make this more or less likely for you?

Patient Interview Schedule

6. Minimal care is where patients are trained to undertake as much of the dialysis process as they can. Has anyone discussed minimal care as an option for you?
 - a. If no: would you want to do it? Why?
 - b. If yes: how are you getting on? Please explain

7. Finally, are there any other questions or comments that you think are important?

Thank you for giving up your time to take part in our study.

We would like to send you the notes from this conversation so you can add or change anything you want to after we have finished talking. Would you like to see notes of this interview? If so, do you have an email address I can send them to or should I post them to your home address?

We will spend some time writing up this study and when we have finished our final report we will send you a copy if you would like to see it. Would you like us to send you a copy?

Just to remind you, you can contact us on our work telephone numbers or via email:

Dr Ian Davison, i.w.davison@bham.ac.uk 0121 414 4808

Sandra Cooke, s.cooke@bham.ac.uk 0121 458 2596

Before we finish, have you got any more questions or comments for me?

Thank you once again for taking part in our study and I wish you all the best with your continued treatment.

Goodbye.

UNIVERSITY OF
BIRMINGHAM

How do nurses in dialysis sessions promote the uptake of home haemodialysis?

I'm a researcher from the University of Birmingham working on this project which is funded by the West Midlands HIEC. We are working with Trusts to support them in increasing the uptake of home dialysis. Previous research suggests that nurses can play a key role in encouraging patients to become more independent in the management of their conditions: this is the focus of our work.

We talked about the study before and you had the chance to ask some questions.

- Before we start, have you got any more questions about the study?
- Are you comfortable that you understand what the study is about and what we are asking you to do?

What you say will be confidential to the university team and if we use anything you have said in our report, it will be reported anonymously. I'll send you a copy of my notes to correct or add to, if you wish. All records will be stored securely.

You can withdraw at any time. I have questions, but hope the discussion will be informal and that you will say anything you like.

Please sign the consent form and say if you're happy for the interview to be recorded.

Interview questions (omit if already covered)

1. To start, can you please describe this unit?
 - a. How many staff (their role) & patients?
 - b. What are the links to other units (main renal units/satellites)?
2. Can you tell me a little bit about your patients?
 - a. What are the likely next steps for your patients? When?
3. Please say a bit about the patterns of consultations for patients on this unit?
 - a. Who does the patient see, when? Do they always see the same consultant/nurse?
 - b. Who decides, and how, what happens to patients?
4. How do you see your role as a nurse?
5. Can you describe your role in educating patients?
 - a. How does this help your patients?
 - b. What educational processes do you think are most effective?
 - c. Is there a focus to move patients home? If so, how does this work in practice?
6. For you and your patients, what do you think patient-centred care really means?
 - a. How does this influence what you do?
 - b. Is it a good thing?

Nurse Interview Schedule

7. Are you involved with educating colleagues? Being educated/ trained on-the-job?
 - a. How does knowledge get shared between colleagues?
8. How is the policy to increase the uptake of home therapies viewed in the unit?
9. Thinking about encouraging the uptake of home haemodialysis, I imagine some patients are clinically unsuitable and some may be unwilling or unable to dialyse at home for other reasons. Looking at the table below, can you describe where you might place your patients (ideally percentages in each box)? Please explain your reasoning.

<i>Clinically unsuitable for home haemodialysis</i>
<i>Clinically suitable but NOT able</i>
<i>Clinically suitable and able but NOT willing</i>
<i>Clinically suitable AND able AND willing to move towards home haemodialysis</i>

10. Thinking of patients who could move towards home haemodialysis, what do you think are the factors holding them back?
11. Minimal care is where patients are trained to undertake as much of the dialysis process as they can. Is minimal care practised here?
 - a. If no: do you think minimal care would work here? Why?
 - b. If yes: how is it going?
 - c. For both: what are the pros and cons of minimal care? What are the main things needed for it to succeed?
12. Finally, are there any other questions or comments that you think are important?

Nurse Interview Schedule

Thank you for giving up your time to take part in our study.

We would like to send you the notes from this conversation so you can add or change anything you want to after we have finished talking. Would you like to see notes of this interview? If so, do you have an email address I can send them to or should I post them to your home address?

We will spend some time writing up this study and when we have finished our final report we will send you a copy if you would like to see it. Would you like us to send you a copy?

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Before we finish, have you got any more questions or comments for me?

Thank you once again for taking part in our study and I wish you all the best in your valuable work.

Goodbye.

How do nurses in dialysis sessions promote the uptake of home haemodialysis?

I'm a researcher from the University of Birmingham working on this project which is funded by the West Midlands HIEC. We are working with Trusts to support them in increasing the uptake of home dialysis. Previous research suggests that nurses can play a key role in encouraging patients to become more independent in the management of their conditions: this is the focus of our work.

We talked about the study before and you had the chance to ask some questions.

- Before we start, have you got any more questions about the study?
- Are you comfortable that you understand what the study is about and what we are asking you to do?

What you say will be confidential to the university team and if we use anything you have said in our report, it will be reported anonymously. I'll send you a copy of my notes to correct or add to, if you wish. All records will be stored securely.

You can withdraw at any time. I have questions, but hope the discussion will be informal and that you will say anything you like.

Please sign the consent form and say if you're happy for the interview to be recorded.

Interview questions (omit if already covered)

1. To start, can you please describe this unit?
 - a. How many staff (their role) & patients?
 - b. What are the links to other units (main renal units/satellites)?
2. Can you tell me a little bit about your patients?
 - a. What are the likely next steps for your patients? When?
3. Please say a bit about the patterns of consultations for patients on this unit?
 - a. Who does the patient see, when? Do they always see the same consultant/nurse?
 - b. Who decides, and how, what happens to patients?
4. How do you see your role as the consultant/ manager in charge of the ward/ unit?
 - a. What are the different elements to your job?
5. What is the role of nurses in educating patients?
 - a. How does this help your patients?
 - b. What educational processes do you think are most effective?
 - c. Is there a focus to move patients home? If so, how does this work in practice?

Manager or Senior Clinician Interview Schedule

6. What do you think patient-centred care really means for this ward/ unit?
 - a. How does this influence what nurses do?
 - b. Is it a good thing?
7. How are the nurses involved with educating colleagues? Being educated/ trained on-the-job?
 - a. How does knowledge get shared between colleagues?
8. How is the policy to increase the uptake of home therapies viewed in the unit?
9. Thinking about encouraging the uptake of home haemodialysis, I imagine some patients are clinically unsuitable and some may be unwilling or unable to dialyse at home for other reasons. Looking at the table below, can you describe where you might place your patients (ideally percentages in each box)? Please explain your reasoning.

<i>Clinically unsuitable for home haemodialysis</i>
<i>Clinically suitable but NOT able</i>
<i>Clinically suitable and able but NOT willing</i>
<i>Clinically suitable AND able AND willing to move towards home haemodialysis</i>

10. Thinking of patients who could move towards home haemodialysis, what do you think are the factors holding them back?
11. Minimal care is where patients are trained to undertake as much of the dialysis process as they can. Is minimal care practised here?
 - a. If no: do you think minimal care would work here? Why?
 - b. If yes: how is it going?
 - c. For both: what are the pros and cons of minimal care? What are the main things needed for it to succeed?

12. Finally, are there any other questions or comments that you think are important?

Thank you for giving up your time to take part in our study.

We would like to send you the notes from this conversation so you can add or change anything you want to after we have finished talking. Would you like to see notes of this interview? If so, do you have an email address I can send them to or should I post them to your home address?

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Before we finish, have you got any more questions or comments for me?

Thank you once again for taking part in our study and I wish you all the best in your valuable work.

Goodbye.

UNIVERSITY OF BIRMINGHAM

How do nurses in dialysis sessions promote the uptake of home haemodialysis?

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **We will go through the information sheet with you and answer any questions you have.** We'd suggest this should take about 10 minutes. Please talk to others about the study if you wish.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

Please ask us if there is anything that is not clear.

PART ONE

1 What is this study about?

Evidence suggests that patients who are able to receive dialysis therapy at home often like the freedom and control this gives them. Health is often improved too. Therefore, hospitals are being asked to increase the number of patients who treat themselves at home. Not all patients want this, and for many this will not be possible. We aim to find out a bit more about this with our research. We are also looking at how nurses help patients look after themselves, through education, training and caring.

2 Why have I been asked to take part in the study?

We are asking you to take part in the study because we want to hear about the experiences of patients who have been using hospital or unit based dialysis services for a while. This work will help your NHS Trust to develop its practice in the treatment of chronic kidney disease. A report with recommendations will be produced that will inform Trust activity.

3 Do I have to take part in the study?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

4 What will happen to me?

Once you are sure you are happy to take part in the study, we will ask you to sign a consent form. We will then ask you for a home telephone number so we can contact you in a few days time. We will ring you and ask to arrange a time when it would suit you for us to ring you at home. At that agreed time we will ring you again and ask you a number of questions about your treatment. We will ask you if we can record the conversation to help us to remember what you say. The telephone call should last no more than half an hour. During

the call, if you do not want to answer any questions, or you change your mind and want to stop the conversation, you can just tell us that and we will not ask any more questions. After the call, we will send you a written copy of the conversation for you to read. If you wish to change anything at that point you will be able to do so. We will speak to you just once unless you wish to add something later.

5 Are there any costs involved?

Taking part will not cost you anything apart from your time. We are unable to pay you anything for taking part in the study.

6 Why should I take part in the study?

We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with Chronic Kidney Disease.

7 Will the information I share be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART TWO

8 Who will my information be shared with?

The only people to see your information will be the researchers at the University of Birmingham. The information will be kept securely in password protected computer storage. When we report on the project we may use things you have said but no one will know that you said it.

9 What happens if I have a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [see below]. At any point if you want to withdraw from the study please just say so and we will not use any of the information you have given us: it will be destroyed.

10 Who is doing this work?

We are researchers from the University of Birmingham and we are happy to talk to you more about the project or answer your questions. You can contact us by telephone or via email:

Dr Ian Davison, i.w.davison@bham.ac.uk 0121 414 4808

Sandra Cooke, s.cooke@bham.ac.uk 0121 458 2596

11 Who is funding this work?

This work is being funded by the West Midlands Central Health Innovation and Education Cluster (HIEC) on behalf of the Department of Health.

12 Who has approved this work?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed by the North Wales Research Ethics (Central & East) Proportionate Review Sub-Committee. It has also been approved by the NHS Trust.

UNIVERSITY OF BIRMINGHAM

How do nurses in dialysis sessions promote the uptake of home haemodialysis?

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **We will go through the information sheet with you and answer any questions you have.** We'd suggest this should take about 10 minutes. Please talk to others about the study if you wish.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

Please ask us if there is anything that is not clear.

PART ONE

1 What is this study about?

Evidence suggests that patients who are able to receive dialysis therapy at home often like the freedom and control this gives them. Health is often improved too. Therefore, hospitals are being asked to increase the number of patients who treat themselves at home. Not all patients want this, and for many this will not be possible. We aim to find out a bit more about this with our research. We are also looking at how nurses help patients look after themselves, through education, training and caring.

2 Why have I been asked to take part in the study?

We are asking you to take part in the study because we want to hear about the experiences of NHS staff who are responsible for hospital or unit based dialysis services. This work will help your NHS Trust to develop its practice in the treatment of chronic kidney disease. A report with recommendations will be produced that will inform Trust activity.

3 Do I have to take part in the study?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

4 What will happen to me?

Once you are sure you are happy to take part in the study, we will ask you to sign a consent form. We will then arrange a time when it would suit you for us to ask you a number of questions about your work with patients on dialysis. We will ask you if we can record the conversation to help us to remember what you say. The interview should last no more than one hour. During the interview, if you do not want to answer any questions, or you change your mind and want to stop the conversation, you can just tell us that and we will not ask any

more questions. After the interview, we will send you a written copy of the conversation for you to read. If you wish to change anything at that point you will be able to do so. We will speak to you just once unless you wish to add something later.

5 Are there any costs involved?

Taking part will not cost you anything apart from your time. We are unable to pay you anything for taking part in the study.

6 Why should I take part in the study?

We think that the information we get from this study will help improve the treatment of people with Chronic Kidney Disease.

7 Will the information I share be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART TWO

8 Who will my information be shared with?

The only people to see your information will be the researchers at the University of Birmingham. The information will be kept securely in password protected computer storage. When we report on the project we may use things you have said but no one will know that you said it. However, in the unlikely event of a disclosure of malpractice concerning colleagues, we will be obliged to share this with Senior Clinical staff in the department.

9 What happens if I have a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [see below]. At any point if you want to withdraw from the study please just say so and we will not use any of the information you have given us: it will be destroyed.

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How do nurses in dialysis sessions promote the uptake of home haemodialysis?

Researchers: Sandra Cooke and Dr Ian Davison

Please initial box

1. I confirm that I have read and understood the information sheet dated 07.03.12 (Version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason, without my medical care or legal rights being affected.

3. I understand that data collected during the study may be looked at by individuals from the University of Birmingham, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I understand that my name and any distinguishing features will not be in any reports.

5. I agree to this interview being recorded.

6. I agree to the researcher ringing me at home to conduct a telephone interview and my contact telephone number is:

.....
6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking Consent

Date

Signature

Copy One for Patient, Copy Two for Researcher

How do nurses in dialysis sessions promote the uptake of home haemodialysis?

Researchers: Sandra Cooke and Ian Davison

Please initial box

1. I confirm that I have read and understood the information sheet dated 07.03.12 (Version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.

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4. I understand that my name and distinguishing features will not be in any reports.

5. I agree to this interview being recorded

5. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking Consent

Date

Signature

Copy One for Member of staff, Copy Two for researcher