

Barriers and enablers of home haemodialysis

BASIC-HHD STUDY

(Barriers to Successful Implementation of Care in Home Haemodialysis)

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Abbreviations

ACKD	Advanced Chronic Kidney Disease
Alb	Albumin
ANZDATA	Australia and New Zealand Registry Data
CAPD	Continuous Ambulatory Peritoneal Dialysis
CCa	Corrected Calcium
CHD	Conventional Haemodialysis
CKD	Chronic Kidney Disease
CKD-V	Chronic Kidney Disease Stage V
CRF	Case Report Form
CRP	C-Reactive protein
DNA	Deoxyribo Nucleic Acid
DoH	Department of Health
EDTA	European Dialysis and Transplant Association
ESKD/ESRD	End Stage Kidney/Renal Disease
FBC	Full Blood Count
FHN	Frequent Haemodialysis Network
GCP	Good Clinical Practice
GSA	Guanidine Succinic Acid
HHD	Home haemodialysis
ICTH	Imperial College Healthcare NHS trust
IPSW	Ipswich Hospital NHS Trust
Kt/V	Measure of Dialysis Adequacy
LVMI	Left Ventricular Mass Index
MBD	Metabolic Bone Disease
MG	Methyl Guanidine
MRI	Manchester Royal Infirmary
MW	Molecular Weight
NHD	Nocturnal Haemodialysis
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NMDA	N-Methyl-D-Aspartate
P	Phosphorous level
pmp	Per Million Population
PORT	Portsmouth Hospital NHS Trust
PTH	Parathyroid Hormone
QALY	Quality Adjusted Life Years
RCT	Randomised Controlled Trial
RLS	Restless Legs Syndrome
RRT	Renal Replacement Therapy
SOP	Standard Operating Procedure
SRFT	Salford Royal NHS Trust
U/E	Urea, Creatinine and Electrolytes
UHNS	University Hospital of North Staffordshire
URR	Urea Reduction Ratio

USRDS	United States Renal Data System
UKRR	United Kingdom Renal Registry
eGFR	Estimated Glomerular Filtration Rate
ASAIO	American Society of Artificial Internal Organs
PTFE	Poly Tetra Fluoro Ethylene
SDHD	Short Daily Haemodialysis
CHD	Conventional Haemodialysis
HRQoL	Health Related Quality of Life
OSA	Obstructive Sleep Apnoea
ICHD	In Centre Haemodialysis
CCI	Charlson Comorbidity Index
API	Autonomy Preference Index
CQUIN	Care Quality and Innovation
MRSA	Methicillin-Resistant Staphylococcus Aureus
AVF	Arterio Venous Fistula
MCQ	Meta Cognition Questionnaire
3MS	Modified Mini Mental State
SF-36	Short Form -36
BASIC-HHD	Barriers to Successful Implementation of Care in Home Haemodialysis

Abstract

The University of Manchester

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PhD

Barriers and enablers of home haemodialysis

Background: Chronic Kidney Disease is a global health problem. In the United Kingdom, there is impetus for self-management of long term conditions. In 2002, the National Institute for Health and Clinical Excellence' technology appraisal guideline on haemodialysis suggested that 10%-15% of the centre's dialysis population should undertake home haemodialysis. The clinical community is yet to rise to this challenge. In this study, we seek to explore patient-related clinical and psychosocial predictors and provider beliefs and attitudes which determine the choice of self-care dialysis, particularly, home haemodialysis.

Design and methods: The design is a combined cross-sectional and longitudinal study employing an integrated mixed methodology (convergent, parallel design). Study participants include patients and multidisciplinary staff. The three patient cohorts (n = 535) include pre-dialysis (222), hospital (213) and self-care haemodialysis patients (100) from geographically distinct NHS sites, and with variable prevalence of home haemodialysis (low <3%; medium 5-8%; high >8%). The pre-dialysis patients were followed up for a period of 12 months from study entry. Quantitative data ascertained include biomarkers, clinical, psychosocial quantitative and neuropsychometric-cognitive tests in the study cohorts. Organizational attitudes and dialysis unit practices were gathered from a survey of the participating units. Semi-structured interviews were carried out for patients and care-providers. The datasets were analysed independently and the findings mixed at the stage of interpretation. Statistical tests appropriate to the specific questions were considered for the quantitative data and qualitative data was analysed using thematic analysis.

Results: Home haemodialysis has a high composite (training+home) technique survival rate of 90.2%, 87.4% & 81.5% at 1, 2 and 5-years respectively in a death and transplantation censored analysis. The key predictors of self-care dialysis, especially home haemodialysis, are self-perceived higher cognitive ability (metaconcentration), lower comorbidity score, home ownership, and white ethnicity background. There are 20% lower odds of choosing self-care dialysis over fully-assisted dialysis for every unit reduction in metaconcentration score and this is significantly associated with trails making test B, an objective test of executive brain function. Perceived inability to self-cannulate was a significant predictor of the choice of peritoneal dialysis over home haemodialysis amongst CKD-5, predialysis patients. However, approximately 1 in 3 patients from the predialysis and hospital haemodialysis groups feel able to consider self-cannulation. The centre to which the patient belonged had an impact on the choice of dialysis modality, with greater proportion opting for home haemodialysis in a centre with greater home haemodialysis prevalence. Amongst predialysis patients who made a modality choice, the experience of their interaction with healthcare teams and dialysis counselling, self-efficacy, personal fulfilment through work and social engagements, and their views of the modality's impact on their significant others, influenced the choice of home or hospital-based haemodialysis. 45% of all respondents in a survey of healthcare practitioners felt that staff knowledge and bias influenced the offer of home haemodialysis therapy. At a policy level, the tariff for home haemodialysis was not a clear incentive for its adoption due to uncertainty about operational costs.

Conclusions: There exists a perception of lack of uniformity in practice pertaining to offer of home haemodialysis across the study centres. The impact of financial incentives designed at a policy level is influenced by the understanding of cost and benefits at the local operational level. Most barriers are surmountable and patients should be able to consider self-care therapies option in all but the most limiting physical and cognitive states. There is a need locally, for units to investigate barriers to home haemodialysis therapy using a conceptual framework in order to facilitate change.

Declaration

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Dedication

I dedicate this thesis to my parents, who have always nurtured great ambitions for me. I owe you, a debt of gratitude for fostering hard work, tenacity and humility as the moral pillars of my life. I dedicate this work also to my loving husband, Krishna, and our son, Aryan, who have helped me unconditionally in realising my dreams. You have been a constant source of encouragement, practical and emotional support during the challenges of harmonising postgraduate life, professional career and home life.

Thank you!

Acknowledgements

As I approach the end of my research training tenure, I take this opportunity to thank everyone who has been instrumental in the success of this research project.

Firstly, my sincere thanks to Dr Sandip Mitra for his trust in me to start this project and see it through to completion. He has been my mentor and guide through the highs and lows of project evolution. This project would not be feasible without the support, interest and contributions from Prof. Paul Brenchley. I would also like to thank Prof. Alison Wearden, University of Manchester, for agreeing to be a co-supervisor and for having provided me with timely, prompt and useful insights into the field of health psychology. In his capacity as research advisor, Prof. Alastair Hutchison has monitored the progress of my research work and I thank him for that.

Of paramount importance, are contributions from Mr Philip Foden and Dr Julie Morris, biostatisticians. I would like to extend my sincere thanks to them for contributing to this crucial aspect of my work. I would also like to extend my sincere thanks to Ms Kate Atkinson, for database and IT support and to Mr Ian Read, who helped me set up a user-friendly system of collecting, storing and processing blood samples and has been immensely helpful in guiding me through the process of purchasing consumables essential for the study. I would like to acknowledge valuable contributions from Dr Rabiya Majeed and Ms Currie Dennington towards the qualitative arm of this study.

I would also like to acknowledge the contributions of research nurses, pre-dialysis nurses, hospital dialysis nurses, secretarial staff and community dialysis team from all five centres who have helped me with the recruitment and data acquisition process. My special thanks to Prof James Barlow, Dr Steffen Bayer and Ms Inger Abma from the Imperial College Business School, London, for accommodating me for a fortnight at their institute, whilst learning the techniques of qualitative research. I would also like to acknowledge the role Ms Haizea Moreno (Human Synergistics International, USA) who helped disseminate the centre dialysis survey to all participating centres and to Dr Alasdair Rae from the University of Sheffield for geospatial analysis. My sincere thanks to all who have helped me with data entry and transcription process.

Last, but not the least, I want to thank all patients who have participated in this research and continually help enhance our knowledge every day.

Rationale for submitting thesis in the alternative format

Alternative format for this thesis would be an appropriate manner of presenting this body of work for the following reasons-

- The study methodology is a multi-method design (Quantitative/Qualitative; Cross-sectional/Prospective) to answer the research question on barriers and facilitators of home haemodialysis.
- Each aspect of the thesis under the quantitative and qualitative branches of the study have been explored in detail. They present unique results which have added to existing literature on these specific subject areas.
- The independent results chapters also allow the bringing together of all study elements into a narrative synthesis which helps answer the overarching question.
- Quite early in the course of PhD, it was possible to write some results chapters alongside recruitment and data acquisition from the main segments of the BASIC-HHD study. This allowed some early publications in the course of work, lending credibility to the alternative format of thesis submission.

Preface

The year was 2010. I was making a considered effort as a trainee in nephrology, to undertake academic work in dialysis medicine at Manchester Royal Infirmary. I vividly remember the success of the Baxter Extramural Grant funding (2011) for my project and the joy of faring well in Dr Mitra's many tests of attitude, aptitude and fortitude, presented in his own inimitable style!

I started working on the project titled '*barriers and enablers of home haemodialysis*' at a time when there was intense focus on 'home-based' treatment of long-term conditions. The lack of increase in home haemodialysis numbers since the NICE technology appraisal guidance in 2002 and in fact, the nadir of home haemodialysis prevalence in the UK in 2006, made the case for investigating the reasons for the lack of progress. The salutary work of NHS Kidney care since 2008 brought this into sharp focus and I chose to pursue this project following the approval of its need at national fora.

It is true that the process at the outset was daunting and the scope of the project seemed boundless. As a clinical practitioner, embracing theories of social and psychological sciences, and healthcare delivery was both challenging and exciting at the same time. The learning curve was a steep one and I began enjoying the process. I defined the scope of the project dictated by the availability of resources (time, money and personnel). I am grateful to all people I have met through collaborations and who have advised me along the way. Their contribution is valued and acknowledged.

In the course of the last 4 years, I have acquired skills to conduct research and also transferable skills as most people undertaking a period of research activity would. For me personally, I am a better physician- thanks to my ability now, better than before, to reconcile knowledge of the biosciences with knowledge of the patient in front of me. In doing so, I strive to bridge the gap between best intentions and best performance; the gap between the pure science and the applied science of medicine.

Anu Jayanti
January, 2016

Key Roles and Contributions

Name/Role/Location	Contribution
Dr Anuradha Jayanti (Study Lead)	Baxter Clinical Evidence Council Extramural Grant (\$196,000) Co-author, 2010-2011 CLAHRC-NIHR grant (£53,000) Lead Author, 2012 Study design, Study protocol Ethical Approval (NRES) Networking and team building NIHR portfolio adoption application (ID12346) Renal registry contact for choice of study centres Facilitated local R&D approval at each site Induction and project review at each study site Collaboration with Imperial College Business School, London Collaboration with Human Synergistics International™, USA Recruitment into quantitative arm of the study at Manchester Royal Infirmary Input into the scope and topic guides for all arms of the study Interview of 2 hospital haemodialysis patients 2 weeks at Imperial College Business School (2013) for healthcare provider interview data analysis Data organisation, validation and cleaning Data analysis and interpretation (Quantitative + Qualitative) Thesis write-up Successful abstracts and publications Successful grant application for future work (Lead Author, \$200,000 USD, November 2014)
Dr Sandip Mitra Main Supervisor/CMFT	Periodic review of project and write-up
Prof. Alison Wearden Co-supervisor/UoM	Periodic review of project and write-up
Prof. Paul Brenchley Co-supervisor/CMFT	Periodic review of project and write-up

Prof. Alastair Hutchison Advisor/CMFT	Monitoring overall conduct of research
Mr Philip Foden Biostatistics/UoM	Statistical advice, analysis
Dr Julie Morris Biostatistics/UoM	Statistical overview and comments
Dr Rabiya Majeed Research Associate/CMFT	Conduct of most patient interviews Analysis and write-up of <i>'The anticipated and the lived experience of home and in-centre haemodialysis: is there a disconnect?'</i> In press, <i>Journal of Health Psychology</i>
Ms Currie Dennington MRes/UoM	Responsible for 8 patient interviews
Ms Inger Abma ICBS Fellow	Conduct of all healthcare professionals' interviews Analysis and write-up of <i>'Perceptions and experiences of financial incentives: a qualitative study of dialysis care in England'</i>
Dr Steffen Bayer ICBS Fellow	Analysis and write-up of <i>'Perceptions and experiences of financial incentives: a qualitative study of dialysis care in England'</i>
Prof. James Barlow Professor, ICBS	Supervision of the 'Healthcare Provider' qualitative study arm.
Dr Alasdair Rae Senior Lecturer University of Sheffield	Contribution to the paper on socioeconomic impact on home haemodialysis through geospatial analysis and maps generation
Mr Marcus Neuvonen Economic & Political studies University of Helsinki	Contribution to the paper on <i>'Healthcare decision-making in end stage renal disease-patient preferences and clinical correlates'</i> in the 'medical humanities and social sciences' segment of the discussion.

Thesis Synopsis

Section 1	Evolution of home haemodialysis over four decades and literature review in the area of barriers and enablers of home haemodialysis in the UK and in other healthcare systems.
Section 2	Study protocol, research methodology and its rationale with the aims and objectives of the BASIC-HHD study (Barriers to successful implementation of care in home haemodialysis).
Section 3	The results of the study have been presented in this section. The results have been presented in three parts: Technique survival, beliefs and utility of home haemodialysis (chapters 3.1-3.3); patient factors (chapters 3.4-3.9) and healthcare-system related factors (chapters 3.11-3.12).

Chapter 3.1	This chapter highlights the success of home haemodialysis technique from one large tertiary centre in the UK. It is important that this background information be established, as home dialysis technique survival data which typically includes peritoneal and haemodialysis (PD>>HHD), may not be extrapolated to home HD alone, as there are fundamental differences between the techniques and in the demographics of recipients of the two modalities.
Chapter 3.2	This chapter is the report on the outcome of a multinational survey on beliefs, attitudes and practice patterns of home haemodialysis. With majority of responses from physicians of European practice base, the findings reflect European practitioners' views to a large extent.
Chapter 3.3	Home haemodialysis is associated with several important patient-centric outcomes. I explore in this chapter if dialysis location has a bearing on a relatively new patient-reported outcome measure, namely, time to recovery from haemodialysis. I examine the bidirectional association of biopsychosocial variables on this measure.
Chapter 3.4	Having established technique success of home HD, the role of regional socio-demographics and socioeconomic factors on regional prevalence of home haemodialysis will be explored. Is the NICE recommendation of 10-15% uptake of HHD from the total dialysis cohort practicable in all regions and do centre attributes have far-reaching impact on modality uptake?
Chapter 3.5	Shared decision making is defined as "a process in which patients are involved as active partners with the clinician in clarifying acceptable medication options and in choosing a preferred course of clinical care". Here, I explore the application of Autonomy Preference Index in patients with end stage kidney disease through the decision-making and information-seeking subscales and understand this aspect underpinning their modality choices.

Chapter 3.6	<i>Self-cannulation is an integral component of self-care haemodialysis. The size of the problem is unknown, although it is widely perceived to be a deterrent to uptake of self-care haemodialysis. This paper is designed to elucidate self-cannulation in the context of patient's clinical factors and its impact on the choice of home haemodialysis.</i>
Chapter 3.7	<i>In a mixed cross-sectional and longitudinal study, I will be exploring the variability of illness perceptions across the CKD-5 and 5D trajectory. If perceptions vary, this may indicate that organised beliefs of personal illness are potentially modifiable prognostic factors and that interventions might potentially be helpful..</i>
Chapter 3.8	<i>With advancing kidney disease cognitive function gets worse. I look at cognition in the context of those who make treatment related decisions in the pre-dialysis phase. I will explore objective and subjective cognitive functions in the context of self-care modality choice.</i>
Chapter 3.9	<i>Using the quantitative variables studied thus far, in a multinomial logistic regression analysis, I look at the clinical and psychosocial predictors of self-care dialysis choice in the cohort of predialysis patients.</i>
Chapter 3.10	<i>Perceptions of treatment modalities, in the abstract, especially self-care HD vs. hospital care HD in the predialysis phase is influenced by several factors. In this chapter, I understand patient's illness beliefs, attitudes and factors which influence the choice of HD modality, in a qualitative study. This will help address the gaps in our predialysis education and preparation programme.</i>
Chapter 3.11	<i>A champion for home haemodialysis is crucial to the success of the programme. I look at the attitudes, beliefs and processes guiding the offer of home haemodialysis therapy by members of the multidisciplinary teams in the five study centres with varying prevalence of home haemodialysis.</i>
Chapter 3.12	<i>The objective of this qualitative study is to understand the extent to which financial incentives such as 'Payment by Results', 'Best Practice Tariffs', 'CQUINS' and other payment mechanisms motivate kidney centres in England to change their practices. This is especially relevant in light of the Department of Health's initiatives to promote 'care closer to home'.</i>

Section 4

In an interpretative narrative on home haemodialysis technique and therapy implementation barriers, I bring together patient-specific clinical, and psychosocial factors and organisational factors from the quantitative and qualitative observations of the aforementioned chapters. I will also look at specific subject areas of patient concern for future research.

SECTION ONE

Introduction

*Five decades of home
haemodialysis*

*Perceived adoption barriers-
patient and organizational
factors- Review of literature*

The literature review on the subject of barriers and enablers of home haemodialysis was carried out in two stages. One at the beginning of the project – in 2011/2012 and then to provide an update on the subject area. The focus in this introductory piece is limited to the examination of this overarching question, but several sub-topics required an in-depth review of literature as and when these were written.

The typical search strategy employed throughout followed the PICO format.

Population/Patient/Problem: Barriers/Enablers/Facilitators/Predictors

Intervention/Exposure: Haemo (hemo) dialysis/ Frequent/ Alternate/ Daily/ Intensive/ Extended/ Home/ Self-care/ Domiciliary

Comparison/Control: Conventional/In-centre/Facility-based/Fully-assisted/Hospital based haemodialysis

Outcome: Programme success/ failure/ adoption/ implementation/ acceptance/ quality-of-life/ self-care/ cost/ economics

Search Engines:

MEDLINE and CINAHL(Predominantly). Others- PSYCHINFO/ Cochrane Library/ References of References/ Books

Search Limits:

Study types: Primary and Secondary Research/Qualitative and Quantitative research/Mixed research Methodology

Publication Dates: Identified in the MEDLINE search builder as 01/01/1990 onwards for clinical topics. This is because, biocompatible, high-flux membranes and erythropoietin etc. were more widely available after 1990. For aspects pertaining to the history of the treatment, no such stipulation was provided. For the history, ‘History of the treatment of renal failure’ by Stewart Cameron was also reviewed.

Reference Library used: Endnote and Mendeley

A scoping review carried out initially, identified the lack of randomised trial evidence in several areas of study. Hence, observational studies, before and after studies, cross-sectional studies were all reviewed to gain the breadth of information on the overarching subject and the sub-topics.

The following is a narrative review of barriers to self-care haemodialysis and intensive haemodialysis regimens.

Once it is determined that renal replacement therapy (RRT) is required to sustain life in advanced kidney disease, there are three options available to patients for those who would like to consider treatment. These are transplantation, haemodialysis at home or in-centre and peritoneal dialysis, a home based therapy. Palliative care is an option for those who may not wish to consider any of the above.

Haemodialysis

The process of haemodialysis requires a stable vascular access with a primary arteriovenous fistula, synthetic arteriovenous graft or a tunnelled vascular catheter. Typically, this is offered three times a week and for four hours on each occasion, in-centre, more often than not. The practice of haemodialysis has evolved over the last four decades with advances in the understanding of dialysis dose, frequency, duration and technology.

Haemodialysis for advanced chronic kidney disease was started in the UK, in 1956[1]. Over the next few years, several teaching hospitals opened their own units. Belding Scribner arrived in the UK, from USA as a research fellow to the Hammersmith in 1956, originally for ‘gastro dialysis’[1]. Four years later in February 1960, Scribner designed the first usable Teflon arteriovenous shunt, which made long-term dialysis for patients a real possibility[2]. The first surgically created fistula for the purpose of haemodialysis was placed in February 1965[3].

Home haemodialysis

As early as in 1948, Bywaters and Joekes realized that for the successful development of haemodialysis, teamwork is essential[4]. The advent of chronic dialysis saw the introduction of nurse specialists. The unit at the Royal Free Hospital, London was founded by Professor Stanley Shaldon and was the hub of activity in the early days[1]. In his Presidential address to the American Society for Artificial Internal Organs, in 1961, Kirby, a cardiac surgeon stated, *‘Perhaps what we need is a home dialysis unit to be placed by the patient’s bedside, so that he can plug himself in for an 8 h period once or twice a week’*[5]. This is the earliest mention of the concept of home haemodialysis, to a professional audience and the first patient to be treated by maintenance haemodialysis at home in 1963, was trained by Scribner. In the UK, Shaldon is credited with starting long overnight home haemodialysis (nocturnal haemodialysis) three times a week, in 1964[1]. He is also one of the founding members of the European Dialysis and Transplant Association and the earliest records of successful home haemodialysis can be found in the proceedings of the meetings that began in 1964. By 1966, regular haemodialysis was the accepted treatment of choice for end stage kidney disease. Also, as the demand for this therapy increased with a general shortage of funds, trained staff and hospital accommodation home haemodialysis was explored as the alternative[6].

It is interesting to note, that home haemodialysis was perceived as a viable, safe and economical procedure, back then. In 1966, the cumulative experience derived from 9 patient

years and 1000 overnight haemodialysis sessions showed that there had been a substantial reduction in cost and reduction in technical complications compared with hospital haemodialysis. No mortality was reported in the 11 patients on home haemodialysis. Patient satisfaction surveys were conducted and patients expressed preference for home treatment[7]. The choice of patients who could enter the home haemodialysis programme was understandably restricted at the time and it was similar to the hospital dialysis programme. The capital costs were higher for home haemodialysis patients compared with hospital patients, but the running costs were 50% lower, and deemed economical[7]. The intermittent haemodialysis programme was expanding at a rapid pace, and there was an urgent need to plan for the increasing burden of dialysis at a time when the therapy was in its infancy.

Thus, the success story of home haemodialysis began. By 1971, 5 yr. survival rates of 60-90% were being achieved and home therapy with thirty hours of dialysis a week, was a big success, especially in those who were deemed unsuitable for kidney transplantation or were awaiting one[8]. For the first time in 1972, the success of home haemodialysis was measured in terms of patient's quality of life. There had been wide discrepancies between the hospital's concept of home haemodialysis and the patient's experience of it. These included the burden of concealed financial costs to the patients, loss of family income, insomnia and fatigue. Traditionally, decision-making rested solely with the medical team, without necessarily highlighting the social and economic consequences. A fundamental change in practice became essential[9]. Shaldon pointed to the benefits of home haemodialysis and mentioned of 'increased self-esteem and sense of control that these patients acquired'[10].

Another important event that also helped increase the number of home haemodialysis patients was the epidemic of hepatitis B that Britain faced in its hospital dialysis units between 1968 and 1973[11]. Overcrowding, shared dialyzers, dialyzer re-use and blood transfusions, were largely responsible for it. One of the Hepatitis outbreaks was in the Manchester unit and it killed several patients and two members of staff. The discovery of the Australia antigen in 1965[12] and tests for the same in the years after, marked the onset of a new era in the management of dialysis patients and staff.

The 1980s also witnessed new technical advances. For the first time, the word 'bioincompatibility' was used in 1980[13] and its significance became apparent in 1984. Since then, the aim has been to make membranes with higher permeability and better biocompatibility. Long term access technology, saw the introduction of PTFE as a material for implantable subcutaneous grafts[14]. Double lumen vascular access catheters made of soft silicone rubber were introduced in 1988[15]. The choice of dialysate buffer shifted from acetate to bicarbonate in the '80s and has been the standard since[16]. During the 1980s, there was no clear method available to quantify the amount of haemodialysis administered. The paper in 1985, by John Sargent and Frank Gotch, promoted the adoption of a urea-based

marker for dialysis efficiency, referred to as the Kt/V for urea[17]. URR (Urea Reduction Ratio) was another concept that gained ground, based on a reduction in urea concentration across dialysis[18]. To this date, these methods continue to be utilised in national and international guidelines.

A dramatic change in this decade was the startling reduction in the duration of dialysis, with no consideration given to residual renal function at the time. 4 hours of dialysis 3 times a week became the norm across Europe for hospital dialysis patients, probably as a result of misinterpretation of the NCDS study. Hospital dialysis units expanded across the UK in the '80s and '90s and 'satellite' units emerged- these were able to accommodate the ever increasing numbers of patients needing long term dialysis therapy. Home dialysis peaked in the mid-1980s and then for several reasons, high rate of attrition was noted in the UK and internationally- with the exception of Australia and New Zealand. Reasons for this were noted to be- steep rise in the number of patients with established ESRD, increase in the median age of dialysis population, development of PD (Automated PD, Assisted PD) and success of live donor transplant programmes, although no correlation has been described, between HHD and transplantation or the total renal replacement therapy (RRT) programme, in a study by Mac Gregor et al.[19]

In the beginning of the 21st century, in England and Wales, the average number of patients on RRT in each unit was 486pmp[20]. The one-year survival of all patients established on renal replacement therapy for at least 90 days was 83.7% for the UK. The percentage of patients on haemodialysis treated in satellite units in England & Wales was 31% compared with 17% the year before. Home haemodialysis fell from 7.5% to 5.7%[20]. These figures must be noted with the knowledge that Registry data at the time did not represent 100% of information from across the units in the country. The last decade has seen the resurgence of interest in home dialysis, after the dip of the 1990s. The reasons for the new-found interest in home haemodialysis are likely because of the increase in presentations and publications, albeit observational until very recently, suggesting clinical benefits of this treatment modality. The National Institute of Health and Clinical Excellence' technology appraisal guideline on haemodialysis in 2002, laid out ambitious targets for home haemodialysis prevalence in centres and the clinical community is yet to rise to the challenge of providing home haemodialysis to 10%-15% of the dialysis cohort[21]. This is evidenced by the renal registry report of December 2010, which suggests underutilization of a treatment type that has had a lot of research interest and several publications worldwide on its apparent benefit for both physical and mental health of patients[22]. Despite a ground swell of opinion, in favour of home haemodialysis amongst practising nephrologists within the last few years, there remain barriers which impinge upon the widespread adoption of this modality.

The case for home haemodialysis

The most important reasons for consideration of home haemodialysis include low technique failure, better patient survival through intensive haemodialysis (more feasibly deployed in patients' own homes), better health-related quality-of-life, freedom, flexibility and employment potential. It is conveniently and comfortably done in the patient's own set schedule, in their own home with their own support around[23]. Irrespective of the modality of intervention, the concept of caring for one's self has definite potential to benefit patients.

Patient survival

Patients on more intensive haemodialysis, now have a cumulative survival comparable to that of some deceased-donor kidney transplant recipients in the USA. Several non-randomised studies of patients undertaking short daily HD (SDHD) or nocturnal haemodialysis (NHD) at home have been conducted. In a Canadian cohort of home NHD, unadjusted event-free survival was 95% at 1 year and 80% at 5 years[24]. In another multicentre study based in Europe and the US of patients receiving SDHD, survival was 92% at 1 year and 73% at 3 years[25]. Frequent daily haemodialysis, as compared with conventional haemodialysis, was associated with favourable results with respect to the composite outcomes of death or change in left ventricular[26]. In a comparison of the mortality hazard between the randomized groups in the frequent in-centre haemodialysis trial, over a median of 3.6 years from randomization, the authors concluded that a 12-month frequent hemodialysis intervention significantly reduced long-term mortality, suggesting that frequent hemodialysis may benefit selected patients with ESRD[27].

Improved quality of life

In a systematic review of 197 patients from 13 home HD programs, a consistent improvement in quality-of-life (Q-o-L) was demonstrated for patients receiving extended schedule dialysis versus those on standard therapy[28]. This observation was replicated in two other RCTs where improvement in Q-o-L was demonstrated in those receiving intensive HD[29, 30]. In the FHN short daily trial, frequent in-center hemodialysis compared with conventional in-center hemodialysis improved self-reported physical health and functioning but had no significant effect on objective physical performance[31]. The FHN RCT of nocturnal HD outcomes, did not show an improvement between the intensive and conventional treatment cohorts, although, it must be borne in mind that many conventional prescription recipients also received their dialysis at home. Also, the entire cohort experienced an increase in their physical health composite score after conversion to home dialysis[32, 33].

Improvement in blood pressure

Conversion from conventional HD therapy to short daily haemodialysis (SDHD) or nocturnal haemodialysis (NHD) does result in reduced use of anti-hypertensive drugs. Even greater benefit may be observed upon conversion from in-centre SDHD to home SDHD[34]. In an

observational study of 32 patients receiving SDHD, a further reduction in blood pressure (approximately 6.3/3.3 mmHg) was noted after conversion to home therapy[35]. This is also noted upon conversion to NHD from in-centre HD[36, 37]. Intensive HD brings about a lowering of BP through better control of the extracellular fluid volume control and improved peripheral resistance. The role of dialysis intensity in achieving these outcomes is also evident from the FHN trial where patients receiving NHD at home had significantly improved blood pressures compared to those receiving standard therapy at home[33].

Improvement in cardiac status

Several observational studies have addressed the issue of cardiac geometry in intensive haemodialysis recipients. The results of a meta-analysis show a 30% reduction in left ventricular mass index, with intensive haemodialysis regimens, including SDHD and NHD[38, 39]. Among patients with residual urine volumes ≥ 100 ml/day, reduction in time-integrated extracellular fluid load was associated with reduction in left ventricular mass in a secondary analysis of the FHN trials data[38].

Improved sleep-related disorders

Obstructive sleep apnoea (OSA), restless legs and poor sleep quality are often reported in patients who receive haemodialysis, these are associated with poor Q-o-L and increased mortality[40-43]. Studies show that conversion from in-centre CHD to home NHD reduces the number of apnoea or hypopnoea events for patients with obstructive sleep apnoea[41]. Conversion to home based SDHD does improve scores on surveys of sleep quality and restless legs syndrome severity[40].

Improved biomarkers

Persistently elevated serum phosphate levels, despite dietary control and use of phosphate binders, is a common problem in those who receive standard therapy. Elevated phosphate levels are associated with increased mortality[44]. Intensive haemodialysis regimens are associated with significant reductions of serum phosphate levels[45]. In the FHN trial patients receiving NHD had a mean decreased in serum phosphate level of 0.49 mmol/L at 6 months and 0.45 mmol/L at 12 months, compared with in-centre conventional therapy recipients[33].

Improvement in fertility outcomes

Gonadal and pituitary dysfunction as well as hyperprolactinaemia in ESRD are associated with male and female infertility[46]. In one cohort study of conversion from in-centre conventional therapy to home-based alternate night NHD, resulted in reduction in prolactin levels and an increase in total testosterone levels in 30 male patients[47]. The change in dialysis regimen towards increased intensity is also associated with a higher conception rate in females compared to conventional haemodialysis recipients[48].

Frequent haemodialysis-the mortality update

The conclusion of the frequent hemodialysis trials, led to several publications relating to secondary outcomes. Whilst it is true that several observational studies have reported greater survival amongst patients receiving frequent HD, the FHN Nocturnal Trial report makes for uncomfortable reading. In this analysis of post-trial follow-up data, the authors report that frequent nocturnal hemodialysis offers no survival benefit and may be associated with harm. Contrary to expectations, mortality was increased for those assigned nocturnal versus conventional dialysis (hazard ratio [HR], 3.88; 95% confidence interval [CI], 1.27-11.79) in an intention-to-treat analysis[49]. The relatively small numbers of participants (44) in this period of observation, does not lend itself to confirmatory, practice-changing belief in the findings. In the longer term (3.7-year) cohort analyses of the Frequent Daily Trial, there was increased survival among the intervention participants (HR, 0.54; 94% CI, 0.32-0.93; P 5 0.02)[27]. The contrasting findings between the FHN Nocturnal and Daily trials raise the possibility that increased frequency might have survival benefits, but that extending dialysis hours may confer risks that outweigh these benefits. This interpretation is likely to be an oversimplification. In a propensity-score matched study from the international quotidian registry on survival in daily in-centre haemodialysis recipients, those receiving daily hemodialysis had a significantly higher mortality rate than those receiving conventional hemodialysis (15.6 and 10.9 deaths per 100 patient-years, respectively: hazard ratio 1.6). Similar results were found in prespecified subgroup and sensitivity analyses[50]. Therefore, it remains that caution has to be exercised in its routine prescription. The impact on vascular access complications[51], and residual renal function reduction[52] are other clinical parameters that have raised concerns on the subject.

Having discussed the potential possible benefits of frequent haemodialysis regimens, more easily instituted in the patients' own homes, it is also important to understand the perceived barriers, precluding a higher uptake of home HD, nationally. There is wide variation between renal centres in the incidence of RRT and in the proportion of patients using a home dialysis modality, in the UK. The following figures represent the renal replacement modality trends since 1997.

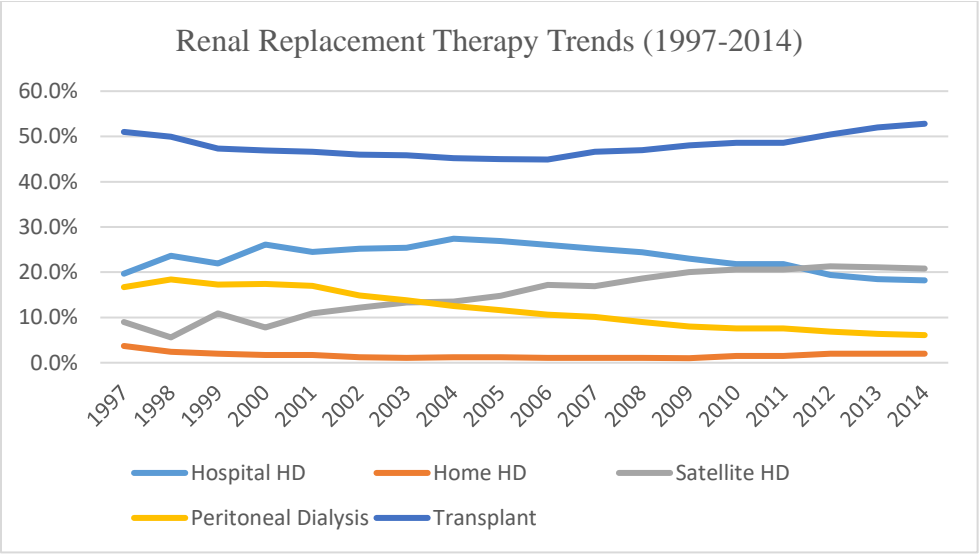


Figure 1: Prevalent RRT patients by treatment modality at the end of each year 1997–2014

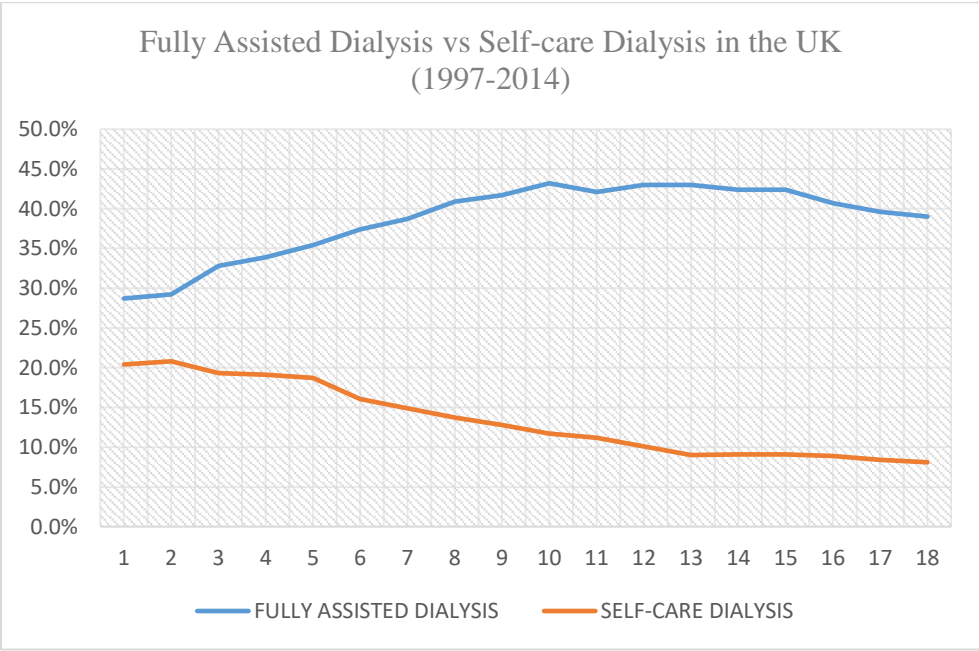


Figure 2: Prevalence trend of fully assisted dialysis (Hospital + Satellite dialysis) and self-care dialysis (home haemodialysis + peritoneal dialysis)

Perceived adoption barriers- Patient related factors

The lack of awareness of the availability of home HD could restrict the patient's choice of dialysis modality. The type of therapeutic patient education, may also well contribute to being an important determinant of patient's ultimate choice. This does need to be fairly comprehensive and over an extended period of time. Some uniformity of information on a nation-wide scale may help the situation too. Multidisciplinary education and counselling should form a part of the management of patients with ESRD. A USRDS report from 1997, revealed that 84% of PD patients, but only 47% of HD patients believed they had even been

involved in choice of modality (USRDS, 1997). In the US, 88% of patients in another report, were unaware of home HD as an option[53].

A prospective study of patient's choice of dialysis modality was done in Birmingham, UK, and it revealed that up to half of the patients counselled would accept a home based, in this instance, CAPD therapy. The quality and quantity of pre-dialysis education and the level of support, in the form of a team of specialist nurses, does influence the number of patients choosing a home modality[54, 55]. This was demonstrated in another study, where in over 3000 patients attending an options class pre-dialysis was associated with more frequent selection of home dialysis, fewer tunnelled HD catheters, and lower mortality risk during the first 90 days of dialysis therapy[56]. The impact of in-hospital pre-dialysis education program has been positive on unplanned dialysis starts with increased uptake of home dialysis therapies in a study cohort from Canada[57]. The impact of education on pre-dialysis patients has been the subject of one randomised controlled trial, where, one CKD study cohort of 35 patients received a two-phase patient-centred educational intervention (phase 1 included educational booklets and a 15-minute video on self-care dialysis; phase 2 included a 90-minute small group interactive educational session on self-care dialysis) in addition to their regular multidisciplinary care, and the second cohort of 35 CKD patients, received on-going standard care and education in the multidisciplinary pre-dialysis clinic[58]. The availability of adequate staff to deliver this information may be variable across different centres.

The association between social deprivation and survival on RRT in England and Wales between 1997 and 2004 reported inequitable access to RRT of individuals from deprived areas, using the Townsend index[59]. Late referral of patients from these areas was also highlighted. These could potentially have an impact on uptake of home dialysis. Patients who presented within 3 months of requiring dialysis were less likely to receive a home dialysis treatment in a survey[60]. An unpublished abstract by Ebah et al (Manchester, 136 patients over 7 years), presented at the Renal Association, UK (2010), reported that socio demographic deprivation did not impact upon successful completion of training and commencement of self-care haemodialysis.

Other factors associated with self-care haemodialysis, include fear of self-cannulation, fear of isolation or handling complex medical technology. In most industrialised countries, the use of complex medical technology in the home environment is increasing. With increasingly miniaturised versions of the machines and the user-friendliness of upcoming technology, the choice may well be in favour of promoting home therapies. In the USA, NxStage machines are in maximum use, due to its portability and short set-up time, drop-in cartridge, automated prime and rinse back and wipe-down disinfect[61]. The user-friendliness of technology is vital to its wide-spread adoption and will influence its integration into the private lives of patients. A qualitative study of different home care interventions- intravenous antibiotic therapy,

parenteral nutrition, peritoneal dialysis and oxygen therapy at home has been done in Canada. All four interventions had both positive and negative impact on lives of both patients and carers. Although, each technology provided patients with relative freedom from hospital, none of them were seen as being user-friendly. For some conditions accepting this outcome becomes the only one alternative to hospital-based therapies. Effective patient education strategies and better design of the home care devices were identified as being crucial to achieve the best balance for the patient[62].

Processes of learning, which are multidimensional, can be a stressful experience, especially in the context of illness and heightened levels of anxiety. Another qualitative study from Canada explored patients' experiences with learning a complex medical device for self-administration of nocturnal home haemodialysis. It emerged from this study that technology-related fears were not the most important barrier; in fact, the fears were of a psychosocial nature. Patient education to operate technology in combination with psychosocial counselling may help adapt to the training process for home self-treatment[63]. In a review by Aujoulat et al, outcomes associated with the process of patient empowerment in a provider-patient relationship, were found to relate to self-management of disease and treatment[64]. The main features of an 'empowering' relationship are continuity, patient-centeredness, mutual acknowledgement and relatedness. Discounting experiential knowledge and providing inadequate resources, particularly, time and continuity, are main features of a disempowering relationship[64, 65]. Morton et al carried out a systematic review to synthesise the views of patients and carers in decision making regarding treatment for chronic kidney disease, and to determine which factors influence those decisions. 18 studies that reported the experiences of 375 patients and 87 carers were included. 14 studies focused on preferences for dialysis modality.' Four major themes were identified as being central to treatment choices: confronting mortality (choosing life or death, being a burden, living in limbo), lack of choice (medical decision, lack of information, constraints on resources), and gaining knowledge of options (peer influence, timing of information), and weighing alternatives (maintaining lifestyle, family influences, maintaining the status quo).' They concluded that the experiences of other patients greatly influenced the decision making of patients and carers. The timing of information about treatment options and synchronous creation of vascular access seemed to predetermine haemodialysis and inhibit choice of other treatments, including palliative care[66].

Perceived barriers- Provider related factors

Nephrologists form an important part of the team who help patients decide the choice of modality. Their own educational gaps may be contributing to inadequate spread of the message and consequently poorer uptake. Poor exposure to PD during training[53, 67, 68] and in one US study less recent completion of training[69] were found to bias clinicians against

home dialysis therapies, whereas belief in a superior quality of life associated with home dialysis[70] will result in the choice of home dialysis therapies. Golper and colleagues have eloquently described a different paradigm of patient information, wherein, the PD versus HD decision is the fourth in line after consideration of renal replacement vs. conservative care, pre-emptive transplantation vs. dialysis, and home vs. in centre dialysis[71]. Clinician’s bias to one or the other modality also may have an important role to play.

The survey by the Renal Registry demonstrated a broad range of opinions about dialysis modality related survival and quality of life amongst UK nephrologists. The UKRR has also looked at the physical limitations that may influence the uptake of home therapies. Twenty-one (33%) of the centres responded that space within patients’ homes was ‘never/ almost never’ a factor preventing home HD and 8 centres (12%) that space was at least ‘frequently’ a factor preventing home HD. Twenty-five centres (39%) highlighted that funding restrictions prevented a patient receiving home HD in at least some cases.

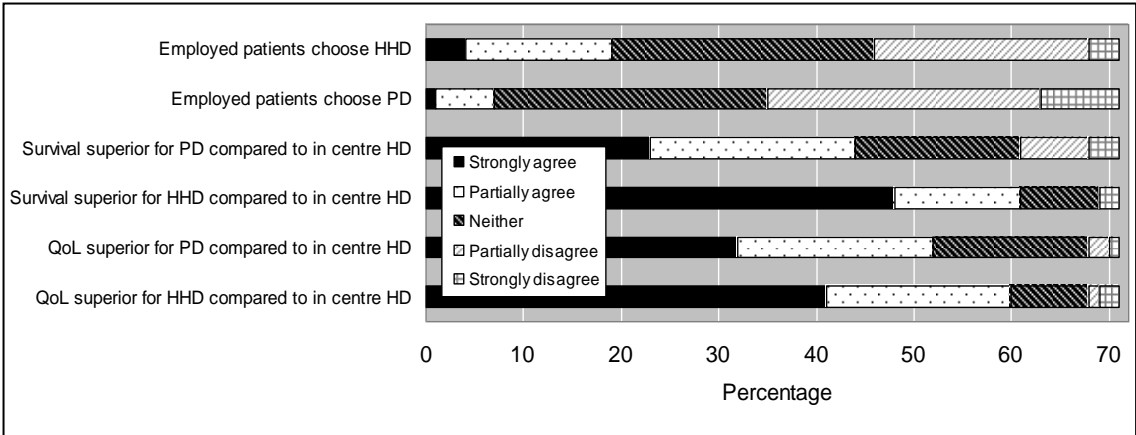


Figure 3: Clinician’s views on patient’s choice of modality (UKRR, 2010)

In the USA, a systematic study of the barriers to uptake of home dialysis was published[71]. The authors have highlighted the current under-usage of home dialysis and identified problem areas including, limited and unmandated home dialysis training of nephrology fellows, lack of synchronised education of ESRD care providers, Medicaid services’ poor reimbursement policies which dis-incentivises home based therapy, business policies and philosophy of dialysis providers, eg., because of restrictive-use policies of some dialysis providers, not all PD solutions and HD equipment are available to US patients. The restrictions are financially motivated rather than reflecting concern over the efficacy and benefit of the interventions. A number of action plans have been suggested, with a view to overcoming the barriers to expansion of home dialysis in the United States systematically and thus will require rigorous attention to detail, changes in attitudes and philosophies, and major legislative or regulatory changes.

In Australia, a survey was conducted[72], to obtain the view of nephrologists about the barriers to the expansion of HHD. There was a strong agreement amongst nephrologists that HD with long hours was advantageous and that this was most easily accomplished in the home. PD was not considered to be an inferior therapy. A 'PD first' policy existed in 34% of Renal Units. The most commonly reported impediments to expanding home dialysis services were financial disadvantage for home HD patients, and lack of physical infrastructure for training, support and education. Areas of concern for included psychiatric support, access to respite care and home visits, and lack of support from medical administration and government. The majority of nephrologists would recommend home dialysis to more patients if these impediments could be overcome.

Canada has a well-established PD programme [73] and a prospective observational study looking into impacts that contraindications and barriers to self-care have on incident PD use, where, home care assistance was available. Barriers of physical (decreased strength, manual dexterity, vision) and cognitive nature (language barrier, history of non-compliance, poor memory, psychiatric condition) were recognized, the former being more prevalent. These patients were generally older and were likely to have a history of vascular disease, cardiac disease and cancer. This study demonstrates that, even when home care assistance for PD is available, family support was an important driver of PD eligibility, choice and use among patients with barriers to self-care PD. Barring medical contraindications to PD, barriers were considered modifiable and in the generally older population, uptake of PD in incident ESRD population could be promoted. This highlights another potential limiting factor to PD utilization. Another cross-sectional study from Canada looked at reasons behind prevalent in-centre haemodialysis patients, choosing not to perform self-care dialysis[74]. The survey showed that, the variables that were associated with a negative attitude towards self-care dialysis included, fear of change, fear of social isolation, not prepared to stay awake on dialysis, time constraints, needle phobia and age/fear of reduced interaction.

In one of the largest opinion surveys, over 7000 nephrology health-care professionals were given questionnaires at five major international dialysis conferences in 2006. This survey has identified patient motivation as one of the strongest drivers of self-care dialysis at home. The need for dedicated resources for the staff to devote time to developing such motivation is given as one of the major reasons for the slow adoption. Under ideal conditions, it is felt that one-third of all patients starting dialysis can be trained to perform self-care dialysis[75]. The gap between patient's and nephrologist's reasons for not choosing self-care dialysis was highlighted in a survey published in 2015. According to the authors, reasons that nephrologists believe patients are hesitant to pursue self-care or home hemodialysis do not correspond in parallel or by priority to reasons reported by patients[76].

Most published analyses from the UK have been limited by examining factors in isolation, or studies based on opinions, questionnaires and surveys which may lack consensus. Registry data collection is limited to clinical dataset and does not incorporate delivery aspects, patient reported outcomes and factors that define treatment preference and pathways of this modality. The report from NHS Kidney care workshop [77]conducted at the Symposium on Home Dialysis, Manchester, UK in 2009 highlighted the participant’s views on adoption barriers. Responses from about 70 participants is outlined below:

Table 1-Barriers to uptake of Home HD; NHS Kidney Care, 2009

CLINICIANS	PATIENTS	RESOURCES
Lack of leadership	Lack of genuine choice especially if English not first language	Perceived high capital costs- especially for units with no or limited HHD programme
Lack of knowledge especially amongst junior staff	Lack of knowledge or awareness of benefits/potential	Monitoring and support of home therapy
Inertia, historical practice limits	Lack of suitable role models or advocates locally	Availability of new technologies
Physician Bias	Fear of machines	Home conversion costs/ installations and uncertain true costs
Preconceptions about ability of patient/carer to cope	Fear of self-cannulation	Uncertain demand
Perceived lack of demand	Concerns regarding risks of adverse events at home	Potential negative impact on new satellite units
Difficulties identifying suitable patients	In-centre exposure- negative impact	Limited training capacity
	No suitable homes or carers	Perceived need for carer at home, lack of support for carers
		Lack of resources

In addition to personal benefits to patient’s health, the true cost benefits of self-care therapies have been analysed in different health care settings. The cost to a nation’s economy through improved patient productivity and reduction of carbon footprint through reduced transport use are very relevant today. The true cost benefits can be seen to involve therapy related costs and other costs such as those due to infections, hospitalisations due to comorbidities etc. The wider implications on the society through employment or the lack of it and taxation or receipt of benefits are to be factored in for the true estimation of economic consequences. A systematic review of 27 studies undertaken between 1978 and 2001were included, 18 of which considered cost effectiveness. Mowatt et al, concluded, in 2003, that the evidence was very much in favour of low costs for home haemodialysis[78]. Even switching from hospital based to home based haemodialysis would optimise cost effectiveness. This was demonstrated in an Australian study in 2009[79]. In a recent study from the UK, although high dose HD was acknowledged to have beneficial clinical effects, under the 2015 payment tariffs, it would be only cost-effective, if the therapy was offered at home[80]. The implications of broader

economic benefits of home dialysis cannot be overemphasized. The available evidence points to better full time employment of home and nocturnal dialysis patients[81].

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SECTION TWO

*Barriers to Successful
Implementation
of Care in Home Haemodialysis –
Study design, methods and rationale
Data analysed and presented
in this thesis*

Quantitative and Qualitative methods in medical research have had a long and successful history. The beginning of the new millennium saw a huge expansion in the understanding and use of qualitative methods in healthcare research. These research methods are finding increased acceptance in clinical and biomedical arenas. The choice of a research methodology is typically informed by a research strategy. The study of adoption barriers to uptake of home haemodialysis should ideally involve research in clinical and biomarkers with psychosocial influences on health of these individuals concerned and health services research simultaneously. It is also important to understand these together as there is little point in developing services or measuring patients' outcome of health care, without an understanding of how people's beliefs and expectations about health, illness and treatment regimens on offer may conflict with those of health professionals, and thereby influence uptake of services and adherence to therapy.

The choice of methodology to evaluate our research question is one of mixed methods. This choice evolves from a 'pragmatist' world-view which embraces paradigms that influence and underlie the conduct of qualitative and quantitative research methods, through a social science theoretical lens. The BASIC-HHD study will adopt a synergistic approach to the design process. This implies that, the sum of quantitative and qualitative research is greater than either approach alone.

In the ensuing pages of the chapter, the 'protocol paper' has been presented and the scope of the project pertinent to this thesis has been identified after the protocol paper.

Barriers to Successful Implementation of Care in Home Haemodialysis (BASIC-HHD): study design, methods and rationale

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INTRODUCTION

Burden of ESRD

Chronic kidney disease (CKD) is a global public health problem[1, 2]. The tip of the CKD ‘iceberg’ is manifest in end stage renal disease (ESRD), when, to sustain life, some mode of renal replacement therapy (RRT) becomes necessary. Typically, there are three options available to patients who would like to consider treatment. These are transplantation (Tx), home-based dialysis (home haemodialysis-HHD and peritoneal dialysis-PD) or hospital-based /In-Centre haemodialysis (ICHD). The global explosion in uptake of dialysis in the 80s and 90s, due to lack of availability of donor organs to meet demands for transplantation, is a testimony to the success of dialysis technology. However, patient outcomes on dialysis have been poor, and in this context, extended haemodialysis at home has delivered the best results. Management of ESRD with haemodialysis began in the 1960s. The use of HHD modality was at its peak in the early 1980s (up to 2,200 patients), representing 61% of haemodialysis patients. Hospital dialysis units expanded across the UK in the 80s and 90s and ‘satellite’ hospital units emerged trying to meet the demand - as they were able to accommodate the ever increasing numbers of patients needing long term dialysis therapy. High rates of attrition from home HD were noted in the 90s. The prevalence of HHD modality dropped, to its usage in just 445 HD patients (2.4%) in 2006[3]. The evolution of dialysis therapies has resulted in a gradual diminution of home based therapies to be largely replaced by ICHD. This phenomenon has posed a challenge to clinicians, service providers and policymakers as scientific evidence in recent times has proposed a strong argument for greater adoption of this modality to improve patient outcomes on dialysis. The optimal uptake of HHD modality with current technology remains unknown. The case for HHD is made from the evidence of its benefits on clinical outcomes (better cardiovascular health, haemoglobin, blood pressure control, medication burden, sleep, nutritional status, fewer hospitalisations and better quality of life) compared to facility-based haemodialysis. Furthermore, published data have demonstrated extremely high technique survival rates (hence sustainability) in HHD[4]. Implementing home based therapies aligns closely with the government initiative of providing care ‘closer to home’[5]. The Department of Health in the UK carried out an extensive review of self-care support, encompassing large numbers of systematic reviews, observations and surveys in a wide variety of clinical conditions and found clear evidence of beneficial health outcomes for patients and better use of health and social care resources[6]. Studies support cost-effectiveness of HHD when compared to ICHD. In one systematic review of 27 studies undertaken between 1978 and 2001, eighteen of these considered cost effectiveness and showed lower costs associated with HHD[7]. Even switching from hospital-based to home-based haemodialysis would optimise cost effectiveness[8]. More appropriate economic

analysis will require other considerations, such as costs associated with home conversions, travel reduction, return to work and contribution thereby to the economy. The broader societal economic benefits of home haemodialysis include better full time employment of home and nocturnal dialysis patients[9]. Many dialysis units operate contracts with different funding sources and there are several cost variables which need to be considered.

Adoption barriers to home haemodialysis

Variation in the uptake and prevalence of HHD is a worldwide phenomenon. Different health care systems, variable practice and reimbursement models have been implicated. Demographics, service provision landscape and social attitudes have evolved over time. Comorbidities, such as diabetes, have been on the rise (32.7% diabetics starting RRT in 2010). Within the last decade, there has been a resurgence of interest in HHD. This may account for the small increase in the proportion of patients receiving haemodialysis in their own homes since 2006 (up to 3.4% in 2010). This however, falls far short of the NICE guidance. Interestingly, despite national policy, NICE guidance, several initiatives and interventions within a single health care system (NHS), UK registry data suggest an atlas of variation in the proportion of dialysis patients receiving home HD (0% in 13 centres, to >5% in 8 centres)[10]. In the last decade, very few studies have been done to understand this phenomenon nationally and internationally. Studies from several countries have contributed to the understanding of some reasons for why the rate of adoption of home therapies in general (PD & HHD), may be slow. Earlier studies failed to show any association between centre and patient demographics to modality prevalence[11]. An association study between social deprivation and survival on RRT in England and Wales between 1997 and 2004, found inequitable access to RRT of individuals from deprived areas, using the Townsend index[12]. An unpublished abstract by Ebah et al (Manchester, 136 patients over 7 years), presented at the Renal Association, UK (2010), found that socio demographic deprivation did not impact upon successful completion of training and commencement of self-care haemodialysis. Patients who presented within 3 months of requiring dialysis were less likely to receive a home dialysis treatment in a survey by Lamiere et al[13]. The impact of therapy specific patient education on choice is highlighted in several studies and does impact on home-based dialysis therapies— although these studies have mainly focussed on PD[14]. The quality and duration of pre-dialysis education and the level of support, in the form of a team of specialist nurses, may have an influence on the number of patients choosing a home modality[15, 16]. A systematic study of the barriers to uptake of home dialysis, in the USA[17] highlighted ‘current under-usage of home dialysis and identified problem areas including, limited and unmandated home dialysis training of nephrology fellows, lack of synchronised education of ESRD care providers, Medicaid services’ poor reimbursement policies which dis-incentivises home based therapy’. In an Australian survey, the most commonly reported impediments to expanding home dialysis

services were operational and infrastructural factors such financial disadvantage for home HD patients, and lack of physical infrastructure for training, support and education[18]. Areas of concern for expanding home dialysis programmes included psychiatry support, access to respite care and home visits, and lack of support from medical administration and the government. Clinician's bias to one or the other modality and poor exposure to PD during training or recent completion of training were found be associated with bias against home dialysis therapies in general[19-22]. A different survey investigated reasons behind prevalent in-centre haemodialysis patients, choosing not to perform self-care dialysis. The outcomes suggest that 'human factors such as, fear of change in general, fear of social isolation, not being prepared to stay awake on dialysis, time constraints preventing self-care, needle phobia and fear of reduced interaction were associated with a negative attitude towards self-care dialysis'[23]. Many surveys generally indicate the widespread belief of physicians and care providers of the benefit of HHD which is in sharp contrast to the practice of this modality in their units. A survey by the Renal Registry demonstrated a broad range of opinions about dialysis modality related survival and quality of life reasons held by UK nephrologists. In a large opinion based survey[24], over 7000 nephrology health-care professionals were given questionnaires at five major international dialysis conferences in 2006. This survey identified patient motivation as one of the strongest drivers of self-care dialysis at home. The need for dedicated resources for staff to devote time to developing such motivation is given as one of the major reasons for the slow adoption. Under ideal conditions, it is felt that one-third of all patients starting dialysis can be trained to perform self-care dialysis.

Limitations of published work

Most published analyses on adoption barriers to home haemodialysis from the UK, have been limited by examining factors in isolation, or from studies based on opinions, questionnaires and surveys which lack consensus. Many such surveys and studies are limited by gathering views of home haemodialysis enthusiasts. Registry data collection is limited to the clinical dataset and does not incorporate delivery aspects, patient-reported outcomes and factors that define treatment preference and pathways of this modality. Investigating centres with variable practice and uptake (high, low or absent) simultaneously can potentially eliminate bias and provide more complementary and valid datasets for comprehensive analysis and interpretation. There is published literature of interview-based studies involving small numbers of home and hospital based HD patients. Whilst they highlight the perceived problems with home HD procedure, they have not been solution seeking and the choice of patients for such qualitative studies, has not been systematic. Besides, studies have not captured the journey of the predialysis patient in the months preceding the start of dialysis, when the crucial decision making process is initiated. It is also apparent that very few studies have a focus on the views of predialysis patients in preparation for commencement of renal

replacement therapy, and in those where they have been included, HHD may not have been one of the modality choices on offer. Given the complexity of the decision-making process, further work with sufficient patient numbers is needed, to fully understand the nuances specific to home haemodialysis. In addition to patient clinical factors influencing their psychosocial state and choice of modality, a greater understanding of the complex interplay of patient and organisational factors and their impact on the adoption of home haemodialysis therapy is not available at the present time.

Study Objectives

The primary objective of the BASIC-HHD study, is to conduct a comprehensive and systematic study of the barriers to and enablers of successful uptake and maintenance of HHD across multiple centres with low, medium and high prevalence rates of home HD. Care pathways of predialysis, incident and prevalent dialysis patients will also be investigated under clinical, psychosocial and organisational domains.

Additionally, the secondary objectives are, to

- a) Investigate biomarkers and their links to cognitive attributes utilised in decision making in ESRD.
- b) Analyse scenarios of the uptake of different dialysis modalities over time and assess the impact on service design (based on system dynamics modeling)
- c) Assess impact of centre infrastructure, policy and regulations on implementation dynamics of HHD
- d) Conduct an economic evaluation to examine efficiency savings and value
- e) Evaluate carer perspectives and burden in the treatment journey of the patient

We believe that such study of HHD uptake, examining barriers and drivers at various levels, using a multi-layered approach that examines patient and organisational factors in parallel using mixed methods (parallel and convergent design) is an ideal methodology to address the research question. A comprehensive study, would aid development of a model of adoption of HHD, which would incorporate variables from both qualitative and quantitative studies. This is the overall aim of the proposed BASIC-HHD study.

MATERIALS AND METHODS

Study Design

This is a multicentre, prospective, observational cohort study using mixed research methods (combined qualitative and quantitative). Predialysis (CKD-5), incident and prevalent hospital and HHD patients will be studied. The predialysis (CKD-5) cohort will be followed prospectively. A convergent, parallel mixed methods design will be employed to study the cohorts. This means that quantitative and qualitative data will be collected, independent of

each other in a single phase, i.e., concurrently. Both quantitative and qualitative datasets will be analysed separately and comparing or combining the results of the quantitative and qualitative analyses will occur at the stage of interpretation.

Setting

The study is currently underway in the United Kingdom across five centres, in different geographic regions. By design, the centres recruited into the study, have variable prevalence of HHD and categorised to low (<3%), medium (5-8%) and high (>8%) prevalence centres. This heterogeneity provides an important backdrop to the study setting allowing the study of both centre and patient characteristics which might influence the local adoption of this modality. The centres in the study have been chosen on the basis of UKRR information on the HHD prevalence as of June 2010. Several centres also approached the host centre and the final centre participant list for the study was drawn, primarily based on resource availability at the local centres and the size of their home HD/RRT programme.

Ethical approval

This study has been reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES). Reference number: 12/NW/0170. The study is on the NIHR (CLRN) portfolio, bearing ID number 12346.

Study organisation

The BASIC-HHD organisation structure operates from the host centre (MRI). Host centre study team will handle overall management of the study at all centres, through recruitment of research nurses under the supervision of a principal investigator at each one of the participating centres. The individual centres will manage participant recruitment, data collection and data transfer. The host institution will address protocol education of nurses and colleagues in the participating centres and also help obtain site specific R&D approval prior to commencement of the study.

QUANTITATIVE study arm

Inclusion/Exclusion criteria-

Participant inclusion criteria

Participants are eligible for INCLUSION in the study if the following criteria are met-

1. Pre-dialysis patients who are under specialist renal team for management of advanced CKD will be considered for inclusion in the study, from either of these groups-
 - The CKD patient at recruitment, will have eGFR < 10mls/min (OR)
 - If eGFR between 10-20mls/min; anticipated dialysis start within 12 months
2. Prevalent conventional HD (in-centre) patients of variable dialysis vintage (minimum time on modality-8 weeks)
3. Prevalent HHD patients of variable dialysis vintage (minimum time on modality-8 weeks)

Participant exclusion criteria

Patients will be EXCLUDED from the study if, in the opinion or knowledge of the responsible clinician, any one of the following criteria is present:

1. Dialysis start in a patient not known to the specialist renal team for at least 3 months
2. Life expectancy < 6 months
3. Plans for renal transplantation (Live Donor Transplant) within 6 months of entry into study
4. Inability to complete questionnaires or face-to-face interviews
5. Concomitant major illness limiting assessments and follow-up
6. Factors limiting the offer of home haemodialysis such as uncontrolled psychosis/anxiety, severe learning disability, on-going drug/alcohol abuse, uncontrolled seizure disorder, dementia/poor short term memory.

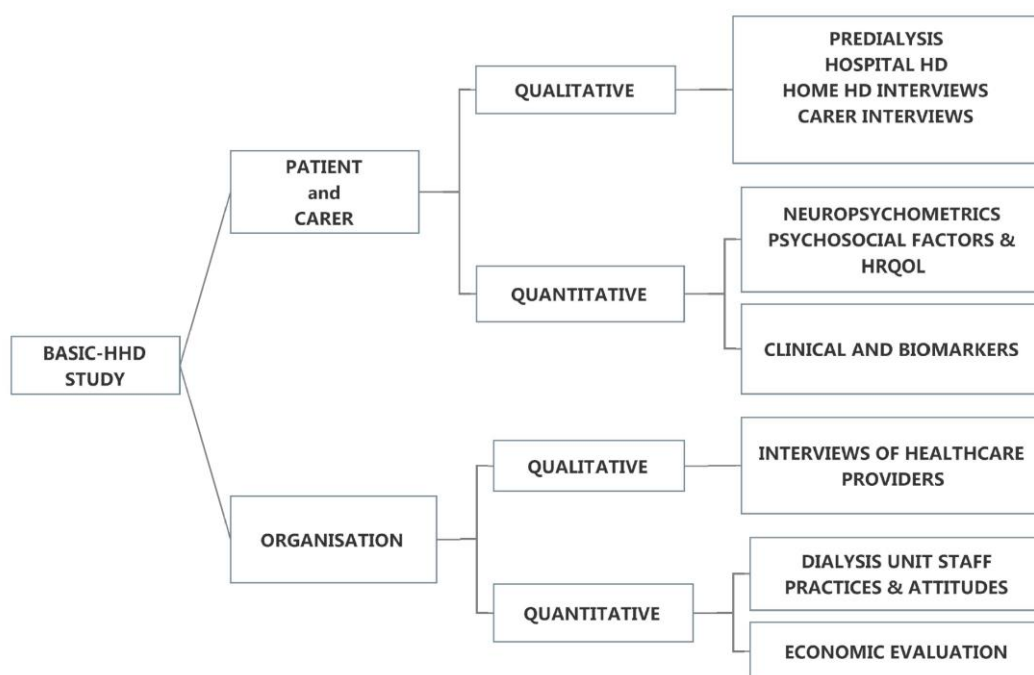


Figure 1- Schematic representation of the scope of the BASIC-HHD study

Patient participants

Written consent will be obtained from all patients prior to recruitment into the study. Prevalent and incident haemodialysis patients and predialysis patients will be approached for the study.

a. Patients in preparation for RRT, naive to dialysis (COHORT A)

We aim to recruit about 50 pre-dialysis patients from each centre. The anticipated total number of predialysis patients in the study is about 200. Patients will be identified from the prevalent pool (those known to specialist renal team for at least 3 months) and others may need to be recruited prospectively, as they are referred to the advanced chronic kidney disease clinics. To

generate a comparator cohort with the reference group (HHD group), some patients recruited will be age (within 5 yrs.) and gender matched with the HHD group (same number as the number of home patients recruited at each centre). The rest of the patient recruitment into this cohort will take into account the diversity in demographics of the presenting ‘pre-dialysis’ population.

b. Patients established in centre HD (COHORT B)

From the prevalent and incident conventional in-centre haemodialysis (CHD- in centre) pool, about 50 patients will be recruited from each centre. The anticipated total numbers of CHD patients in the study will be 200. Patients will be recruited from all three haemodialysis ‘shifts’, and from both (Mon/Wed/Fri) and (Tue/Thurs/Sat) groups, once they have been deemed eligible for inclusion into the study. Some patients in this group (same number as the centre HHD recruitment figure) will be age (within 5 years) and gender matched to the reference group-the HHD cohort, to reduce the potential confounds when the two samples are compared. The rest of the patient recruitment into this cohort will take into account the diversity in demographics of the hospital haemodialysis population. If total numbers of patients are fewer than 100, it would be appropriate to compare all of cohort B with cohort C (using a statistical adjustment for the confounding effects of age and gender).

c. Patients established on HHD (COHORT C)

From the prevalent and incident HHD pool, variable numbers of patients will be selected from each centre. All HHD patients from the 5 centres will be screened for eligibility. Based on the prevalence rates across all centres, it is expected that about 100 home haemodialysis patients would be able to participate in the study, subject to eligibility.

d. Patient transiting from predialysis to an established dialysis modality COHORT D

This group is derived from cohort A and will comprise of patients who have started a modality of renal replacement therapy during the 12 months from recruitment. It is anticipated that a third of the patients would have commenced dialysis.

Duration of subject participation

Individual participants will participate, up to a total of 12 months from recruitment into the study, unless

- a. Patient chooses to withdraw from the study
- b. Patient develops a major illness within 3 months of study entry that will preclude any assessments or follow-up, necessitating withdrawal from the study
- c. Terminal Illness
- d. Patient death

Some pre dialysis patients, who may have had to start renal replacement therapy relatively early in the course of the study, will be able to complete participation in the study early.

Recruitment size and population

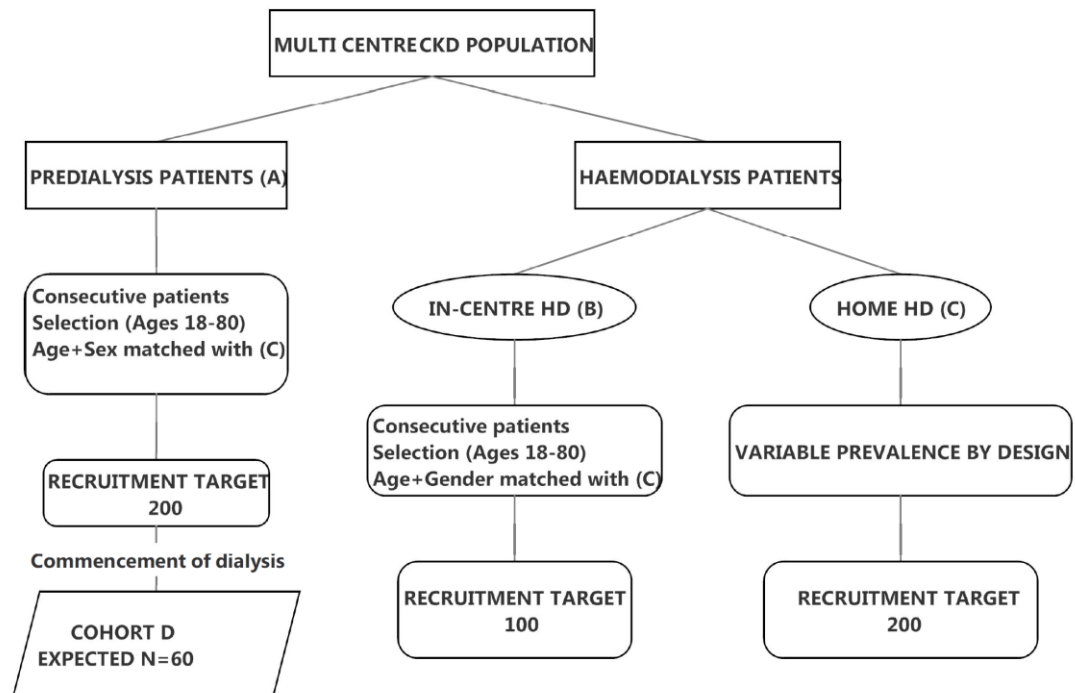


Figure 2-Schema of recruitment size and population

Follow-up visit

All predialysis participants(A) who have given consent to join the study; will be seen after consent, typically when they attend pre-dialysis clinic as per their usual clinic schedule or on a separate day if they so wish. Predialysis patients will also be reviewed >4 months after start of dialysis. During each one of these visits, patients will have blood sampling and neuropsychometric tests. Questionnaires measuring potential psychological predictors of modality choice and adherence will be given on the day and reminders to return the questionnaire will be sent on 2 occasions, one month after handing them out.

All hospital HD (In-centre) patients(B) who have given consent to join the study will have baseline information and laboratory samples collected at the time of their regular dialysis schedules. To standardise the research activity in this cohort, all patients will be seen just before commencement of haemodialysis and all neuropsychometric tests will be carried out mid-week (Wednesday for Mon/Wed/Fri schedule and on a Thursday for a Tue/Thurs/Sat schedule). Blood sampling will be obtained before commencement of dialysis. To ensure a consistent return rate, patients will be requested to complete the questionnaires in hospital, whilst on dialysis and in the first hour of treatment. No further visits will be required.

All home HD patients(C) who have consented to participate in the study will have their baseline information collected in a dedicated clinic for the study, which will be mid-week

(Wednesday for Mon/Wed/Fri schedule and on a Thursday for a Tue/Thurs/Sat schedule) and preceding their dialysis schedule by no more than 4 hours. At this time, blood sampling and neuropsychometric tests will be carried out and patients will be requested to complete the questionnaires at home. Time from/to the dialysis session will be documented by the patients. No further visits will be required. Patients from all cohorts will participate in answering the questionnaires. Non English speaking patients will have the opportunity to answer these queries with the help of an interpreter, using a standard script, as literal translations may not be available in all languages. These questionnaires will be given in a booklet to patients. Dialysis patients will be advised to answer these questions within the first hour of dialysis, so as to avoid the effects of haemodynamic changes on the output. Two attempts will be made to survey the patient cohorts in a 3-month period. These questionnaires will be repeated >3months after commencement of dialysis in the prospectively observed pre-dialysis cohort. All questionnaires will be reviewed for completeness and be manually scored and crosschecked by a second member of the team.

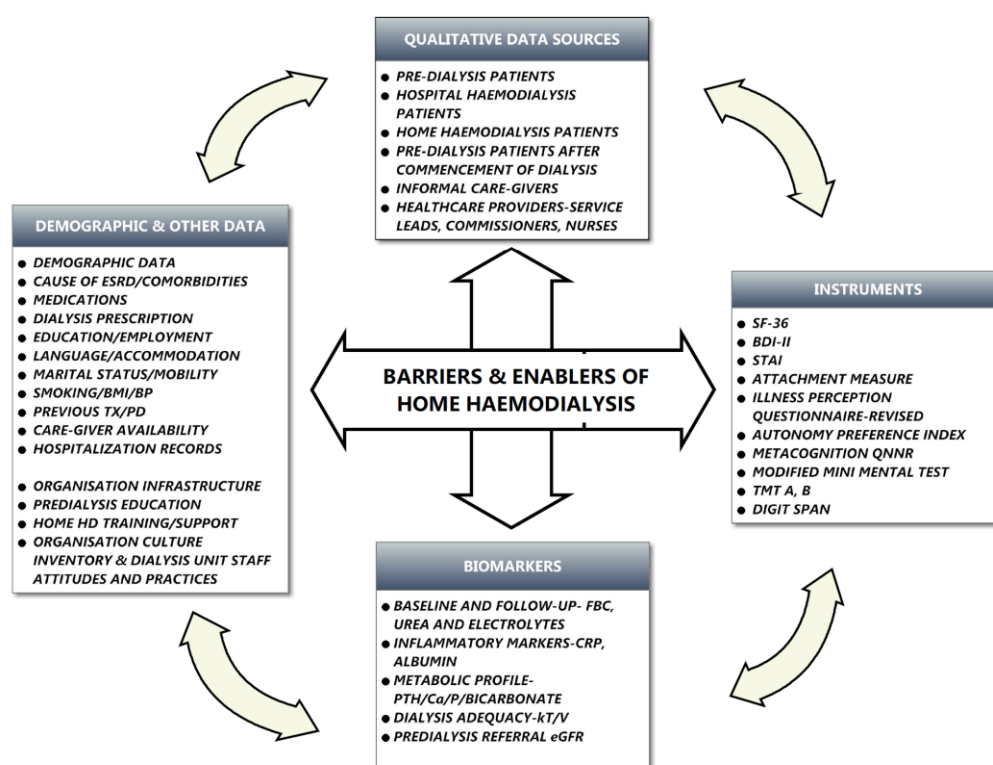


Figure 3-Synopsis of data to be obtained in the BASIC-HHD Study

Collection of biological samples

Samples will be sent to the Renal Research Labs for processing and storage. DNA, plasma, cells and a clinical/demographic data set will be held in the laboratories for research, with patient consent. The samples will be obtained from patients at the host centre and frozen in the biobank storage at -80°C, within two hours of collection. This is with a view to study

uraemic 'neuro'toxin assays in these patient cohorts. This remains the subject of a further study relating neurochemistry and behavioural biology. Many of the biochemical parameters being evaluated would be obtained routinely during the course of their medical management and would help in quantifying treatment and disease burden and illness related complications. These samples will be analysed at the South Manchester University Hospital laboratory.

Instruments employed in the study and rationale

All participants from the three study cohorts will complete questionnaires based on measures of psychosocial factors which are thought to be predictive of uptake and maintenance of HHD, providing us with a quantitative measure of psychosocial state. The questionnaires have been chosen to obtain information on predictors of outcomes rather than the outcomes only. These combined with interviews will add robustness to the data. The instruments which are being employed assess various aspects of human behaviour, illness perception, state of mind and quality of life.

Healthcare necessarily involves interpersonal contact. This is particularly relevant in end stage renal disease. Clinicians wishing to observe their patients' interpersonal styles will find descriptive prototypes of adult attachment quite useful. 'An understanding of interpersonal styles may allow clinicians to adapt medical care to the strengths and vulnerabilities that follow from particular patterns of adult attachment' [25]. The outcome of this 'attachment style' questionnaire will be the first one of its kind in the context of ESRD and the correlation of the questionnaire output with the demands of interpersonal interaction across the modes of dialytic therapies will be made amply clear. Autonomy preference index scale of Ende et al has been used in this study[26]. It was designed to measure preferences for autonomy in decision making in a general sense, as well as the extent to which people prefer doctors or themselves to make specific management decisions in three clearly defined clinical vignettes. These hypothetical situations have been used as in the original document, without any modification, as it best represents the stable situation, a moderately severe clinical state and a severe episode requiring hospitalisation, which are not specific to ESRD patients, but are unlikely to be unknown to them. The desire to be informed and participate in decision making, will be a desirable attribute in the context of ESRD, and its measurement reflects actual patient preferences. Whether decision making equates to autonomy is a different question and could well be the limitation of this tool.

The SF-36 is a modified version of the Medical Outcomes Study questionnaire. It is a generic instrument with 36 questions, without questions specific to ESRD. It is a reliable and valid tool which has been used in various patient populations, including ESRD[27, 28] There are eight scales describing domains of physical function, social, physical and emotional role function, mental health, bodily pain, vitality and general perception of the state of health.

Depression is particularly unlikely to be recognized in patients with end-stage renal disease (ESRD) because symptoms of depression may overlap with those of uraemia. Consequently, prevalence estimates of depression vary widely from 6% to 34%, depending on the diagnostic instrument and cut off point used [29, 30]. The Beck Depression Inventory (BDI), which has a sensitivity of 92% and a specificity of 80% using a cut off of 15[31], is being used to screen patients for depression, whilst also assessing their cognitive state. The BDI is a self-report inventory that has been extensively validated and used for measuring depression in various population groups, particularly in dialysis patients[32,33]. Although depression in haemodialysis population is well studied, anxiety is also recognised to be a very important problem in dialysis patients. Anxiety may be present independent of other problems or somatised as part of another mental ailment. In this study we have employed a widely used tool for measuring anxiety- Spielberger's State-trait anxiety Inventory[34]. It clearly differentiates between "state anxiety" and "trait anxiety". The inventory's simplicity makes it ideal for evaluating individuals with lower educational backgrounds too.

The Illness Perception Questionnaire-revised (IPQ-R) assesses the following illness perceptions- identity, chronic timeline, cyclical timeline, treatment control, personal control, coherence, causes and emotion reaction. Across several illnesses, the reliability and validity of the IPQ-R has been demonstrated[35]. There is now evidence towards the validity and reliability of the IPQ-R as suitable measure of illness perceptions in the context of ESRD [36, 37]. Illness perceptions drive coping and self-management behaviours and hence are an important measure in this study. Home modalities of renal replacement therapy, are very demanding of memory. Beliefs about one's potential to use memory efficiently will influence self-selection of such therapy [38, 39]. Also, individual differences in self-rated memory, do not correlate well with objective memory tests- this may imply that people's beliefs about their memory are inaccurate[40]. This is at least true of the general population. The metacognition questionnaire has two components - the meta-memory and meta-concentration. Additionally, this questionnaire has items worded that are consistently 'positive' and avoid a deficit connotation[41]. This has been used in elderly patients, but the questions have no specific age-focus and are applicable to the ESRD population, for the purpose of this study.

To allow for a comprehensive understanding of cognitive function, multiple measures must be included in the neuropsychological test battery. The tests would consider different domains of brain function- psychomotor efficiency and processing speed, learning efficiency and attention. Greater understanding of patient's cognitive state can be attained through combining subjective cognitive function, for self-reported everyday functioning, in addition to the cognitive psychometric tests. The neuropsychometric tools to be employed are: 3MS/Trail making tests and Digit span test. All neuropsychometric tests and the meta-cognition questionnaire will be conducted in the mid-week, pre-dialysis phase for dialysis patients. This

helps standardise the data collection across all centres. All sighted and literate patients will be invited to participate in these tests.

Notwithstanding the outcomes of questionnaire based psychosocial outcomes, any potential association with readily measurable biomarkers could inform day to day clinical management of patients presenting in advanced CKD clinics.

Patient study arm- QUALITATIVE

For an in-depth exploration of individual perceptions of problems and solutions, semi-structured interviews will be carried out and this process will help define the beliefs, behaviours, attitudes and sensitivities of patients in the different study cohorts. For the qualitative strand, a purposive sampling technique will be employed. The strategy best used in our study is one of maximal variation sampling, such that diverse individuals are chosen who are expected to hold diverse perspectives on the central theme, and their views will reflect a rich and complex picture of the reality. The qualitative idea is not to generalize from the sample but to obtain an in depth understanding of the issues in a few people who have been sampled, unlike the quantitative study arm.

The study sample will comprise pre-dialysis patients (Cohorts A+D), home haemodialysis patients (Cohort C) and hospital haemodialysis patients (cohort B). All adult patients aged 18 and over, with end stage renal diseases, who meet the inclusion criteria and no exclusion criteria, will be considered eligible for the study. The aim is to conduct about 20 interviews in each cohort or until thematic saturation is attained.

A recruitment grid is designed taking into consideration three factors- age, gender and ethnicity. Although it is not a requirement for recruitment, every effort will be taken to include patients with varying comorbidity profile. English, Hindi and Urdu speaking patients would be considered, representing the local population demographics.

Participants will be approached at their regular clinic consults by researchers with the study information leaflet and consent form. Where the patient expresses a willingness to consider participation, telephone contact will be made after a minimum of 24 hours of providing information. At this time, any questions will be answered and if the participant remained willing, an appointment for the interview will be scheduled. In a majority of instances this would be in the patient's own home or at the patient's request, the venue would include the hospital. Suitably qualified individuals will carry out the interviews. All interviews will be one-to-one. They will be audio-taped and then transcribed verbatim.

For purposes of the study, an interview schedule or topic guide has been developed with a view to cover the following areas-

- a. Barriers and enablers of home haemodialysis as patients perceive them
- b. The potential solutions as seen by patients

- c. Impact of self-cannulation on decision-making
- d. Views on assisted home haemodialysis

Carer study – QUALITATIVE

Participant eligibility (carers)

All adult carers (aged 18 and over) of patients undertaking home haemodialysis or carers of patients who are in the decision-making process, who meet the inclusion criteria and none of the exclusion criteria will be considered eligible for this study.

Carer Inclusion criteria

Participants are eligible for INCLUSION in the study if the following criteria are met-

- The patient needs to consider the individual to be their carer.
- The individual self-defines themselves as the patient's carer.

For the purposes of this research, a broad definition of the carer's role is employed. A carer in the context of home haemodialysis is understood to range from providing emotional support to the patient, to taking a degree of responsibility for the patient's dialysis procedure[42].

Carer Exclusion criteria

Participants will be EXCLUDED from the study if, in the opinion or knowledge of the interviewer, either of these criteria is present:

- An established primary care diagnosis of psychiatric illness
- A life-threatening physical illness

The participant information sheet will be provided to the participant, to make an informed decision concerning in the study. A copy of the signed informed consent and information sheet will be given to the carer. Carers will undertake semi-structured interviews, at a place of their choosing- their homes or at the hospital. About 20 carers will be interviewed or until thematic saturation is attained. All interviews will be audio-taped and transcribed verbatim. Adequate steps will be undertaken to ensure that distress, if any, caused to them when they verbalize their fears will be dealt with appropriately and professionally.

Provider study arm – QUALITATIVE

Alongside patient assessments, investigators will obtain information pertaining to the centres offering home haemodialysis. More specifically, this study seeks to help policymakers and renal care providers to understand and overcome barriers to delivering complex, patient-led medical procedures in the home by addressing the organizational, financial and policy influences on the uptake of HHD. This research project investigates how regulation, reimbursement rules and health policy impacts the provision of care for patients with chronic kidney disease.

Specific questions which will be posed include-

1. What factors impact on the adoption of technological innovations in renal care, especially home haemodialysis?
2. How do factors such as cost and financial arrangements (e.g. payment, incentives or penalties), implementation (e.g. training), intra-organisational issues (e.g. clinical leadership, resistance of incumbents to innovation), or environmental context (e.g. space at home, distance between home and clinic) limit the use of home haemodialysis to a level far below of what is generally considered desirable?
3. What impact do financial regulatory changes (e.g. PbR and the ‘best tariff practice’ in the UK, bundling of services and changes to reimbursement rules for home haemodialysis in the US) have on the behaviour of healthcare professionals and on care provision?
4. What impact will different policy choices and payment regulations likely have on the use of different dialysis modalities in the future?

Research Approach

This study will combine qualitative research through interviews with modeling. The interviews will address research questions 1, 2 and 3 and modeling will address question 4.

Design

This is a comparative multi-centre study. It will employ qualitative methodology in the form of 45 to 60 minutes in-depth semi-structured interviews. Data from the qualitative case studies and background interviews will be used to inform simulation modeling exercises to investigate the implications of implementing HHD under differing policy and financing options, and with differing care provision models.

Respondents

The background interviews will involve selected participants from leading (i) dialysis service organizations, (ii) dialysis machine design and manufacturing firms, (iii) national renal policy-making bodies.

The case studies interviews will involve (i) healthcare professionals, (ii) managers of selected renal care centers. The aim is to interview all personnel involved in the modality decision making process as well as the care of renal patients in each centre. These include:

- ☐ Physicians
- ☐ Nurses
- ☐ Medical/Clinical directors
- ☐ Commissioners

Economic Evaluation

Although the study is not powered to evaluate a definitive economic benefit of HHD, we will estimate costs related to hospitalizations, medications and cost-utility from the provider’s perspective based on data from at least 2 case-study sites. The study will analyse the

incremental costs of providing HHD, including direct costs (disposables, equipment, personnel, training, monitoring and technical services) and in-centre costs (HD unit overhead). We will also explore the potential impact of policy choices and financial conditions on HHD implementation under a variety of scenarios. We will use simulation modeling to analyse such impacts on patient flows through the system, the choice of dialysis modality and costs.

Provider study arm- QUANTITATIVE

From the different centres participating in the study, centre specific information will be obtained. The broad areas where detailed information will be sought include-

- a. Infrastructure
- b. Predialysis education and preparation
- c. Training for HHD
- d. Post-Discharge support structure

Dialysis unit staff-attitudes and practices (Organizational Culture Inventory™)

Understanding the collective thought processes informing a certain type of practice or behaviour is fundamental to effecting the desired change. The use of a quantitative instrument together with ethnographic approach followed by triangulation of results is likely to give a more complete picture of the practice in a unit. Such an approach in an area like dialysis methods has not been undertaken before and would add value to the information available. ‘The main appeal of such a method, lies in seeking to engage organizations and their problems on the level of meaning’[43]. One may not assume that everyone has a similar understanding of the issues and may have opinions and judgments that vary from the perceived norm. This Inventory by Cooke and Lafferty, 1987, is a quantitative measure of the culture in the unit/organization[44]. It evaluates the shared norms and expectations that guide thinking and behaviour of group members. It has previously been employed in the healthcare sector. It has 120 pre-defined questions and will have 20 additional questions introduced specific to the study context. The responses are made in a 5 point Likert scale. It is likely to take up to 20-25 minutes for completion. The tool has good face validity, and strong psychometric underpinning. Results can be graphically illustrated. The problems may be encountered with the length of the tool, but sufficient time will be given to staff to engage with this tool, as we investigate its application in a novel context.

Data protection

Each patient enrolled into the study, is assigned a unique identification number. All personal identification data are stored in hospital computers only and separated from medical and research data. Biological samples are identifiable only with their unique sample identifier and no patient identifiers are available within the Biobank. All information pertaining to OCI®

from specific centres are only known to the lead researcher and not available to the organisation that holds the licence to conduct the survey.

Quality Assurance

In order to ensure consistent performance across all centres, single researcher (AJ) has conducted induction days across all centres. The database will be continually cleaned and examined to ensure data entry is accurate and missing data is minimised. The database is backed up regularly to ensure no loss of data. Biological samples obtained are collected, processed and stored in appropriate conditions and by certified personnel. All qualitative aspects of the study will be reviewed by at least two qualified researchers. All costs related information will be procured after checking relevant documents from appropriate authorities.

Enrolment to-date

Enrolment as of the end of April 2013 comprises a total number of 350 patients across five centres. It is anticipated that the recruitment period will end in late 2013. Recruitment for the qualitative aspects of the study is about 75% complete.

Data analyses and statistical considerations

Quantitative data analysis

The sample size of the BASIC-HHD study of 500 patients was chosen as a realistically attainable cohort size based on feasibility considerations. This sample size ensures adequate statistical power to differentiate cohorts showing different behaviours with respect to the primary and secondary objectives. The power analysis is also based on the effects expected in the clinical measures.

Demographic data will be reported using means and standard deviations (for normally distributed data) or median and interquartile/full ranges (for skewed data) where appropriate. Simple comparisons between baseline data from the three study cohorts will be made using two-sided tests; analyses of variance for normally distributed data, Kruskal-Wallis for non-normal continuous data and ordinal data, and chi-square tests for categorical data, with the conventional 5% significance level. Individual cognitive test scores will be reported as mean and standard deviations. Scores will be reported both as normalized scores. In normalized scores, data are fit to a normalized scale allowing direct comparisons across scores. Factors which influence uptake and maintenance will be identified using multiple logistic regression analysis of the pre-dialysis cohort. Comparisons between the HHD (C) and Hospital HD (B) cohorts will use t-tests, Mann-Whitney U-tests and chi-square tests as appropriate, followed by multiple logistic regression analysis to identify significant independent discriminatory factors. The study will have 80% power to detect differences in the percentage of patients having particular factor attributes of 19% or more between the age-sex matched cohorts of 100 patients (i.e. 20% vs. 39%, equivalent to an odds ratio of approximately 2.5). For the pre-dialysis patients, of whom 10% are estimated to take up home haemodialysis, the study will

have 80% power to detect prognostic factors with an odds ratio of 4 or more for the whole cohort of 200 patients.

Qualitative data analysis

The interviews will be analysed using thematic analysis, a methodologically and epistemologically flexible approach; it is partly guided by the aims and the research questions stated at the beginning of the project and partly guided by the researcher's active identification of themes based on the accounts of participants' own views and experience. At least two researchers will analyse the interviews independently ensuring the reliability of the analyses. The initial coding of each interview will be compiled by both researchers independently, and the coding frames and themes will be refined and elaborated collectively in a dynamic way as more data gets collected. As sequential analysis progresses, significant data will be compressed so as to adhere around several analytic schema. In order to ensure the reliability of the qualitative analysis, the application of the coding frame by independent researchers will be periodically cross checked to establish a degree of uniformity.

Several techniques will be used to ensure the validity of the qualitative analysis including:

- Respondent validation
- Triangulation: (by looking for commonalities and anomalies at a sample level)
- Fair Dealing: our theoretical sampling approach explicitly aims to incorporate a wide range of different perspectives

Simulation modeling analysis

Using national and international renal patient registry data in addition to our findings from interviews and our analysis of the literature, we will also apply scenario ("what ... if") analysis using system dynamics modeling to investigate the impact of different policy choices and financial models on dialysis technology adoption, care pathways and costs. This will allow us to explore the factors influencing the choice of dialysis modalities and develop a number of scenarios of the likely development under a range of policy options (including changes in reimbursement/funding rules). The modeling explore the role of the factors identified as barrier and drivers in the case studies and also draw on the literature review, the data collected in the background interviews with industrialists, policy makers and healthcare professionals, historical registry data and policy documents.

Integration of Qualitative and Quantitative data and study outcomes

Combined qualitative and quantitative research methods are finding increased acceptance in clinical and biomedical arenas. The choice of a research methodology is typically informed by a research strategy. The study of adoption barriers to uptake of home haemodialysis would ideally involve research in clinical and biological factors interacting with psychosocial influences on health of the individuals concerned and health services delivery research simultaneously. It is also important to understand these together as there is little point in

developing services or measuring patients' outcome of health care, without an understanding of how people's beliefs and expectations about health, illness and treatment regimens on offer may interact with those of health professionals, and thereby influence uptake of services and adherence to therapy.

The choice of methodology to evaluate our research question is one of mixed methods. This choice evolves from a 'pragmatist' world-view which embraces paradigms that influence and underlie the conduct of qualitative and quantitative research methods, through a social science theoretical lens. The BASIC-HHD study will adopt a dynamic, synergistic approach[45] to the design process. This implies that, the sum of quantitative and qualitative research is greater than either approach alone.

Rationale for mixing methods

Bryman in 2006, in his work, offered 16 different reasons for why one may choose to mix methods in research. In our study, multiple reasons may be cited and new reasons may emerge as the study is underway. The following tabulation of typology of reasons (adapted from [46]) helps understand the purpose of the methodology.

Table 1-Typology of reasons for mixing methods

Typology of reasons for mixing methods	
Terminology	Explanation
Triangulation	Qualitative and Quantitative methods might be combined so as to mutually corroborate the findings
Offset	The methods have their own strengths and weaknesses, so combining the two would allow to offset the weaknesses and draw on strengths of both
Completeness	A more comprehensive account of the research question is possible
Different research questions	The two methods can answer different research questions
Explanation	The findings of one method may be used to explain the findings of the other
Credibility	Employing both approaches enhances the integrity of the findings

The four key decisions in the choice of design

These decisions address the different ways in which the quantitative and qualitative strands relate to each other. The strand refers to the component of the study that encompasses the

basic process of conducting qualitative or quantitative research: the question, data collection, data analysis and interpretation of results[47].

a. The level of interaction between the qualitative and quantitative strands: In our study, the implementation of the two strands will be independent of each other, i.e., the data collection and analysis will be separate, and the two will be mixed when drawing overall conclusions at the end of the study.

b. The priority of the quantitative and qualitative strands: The two strands will have equal emphasis i.e., both will have an equally important role in addressing the research question.

c. The timing of the quantitative and qualitative strands: The timing of the two strands will be concurrent, i.e., both methods will be employed in a single phase.

d. Mixing the strands: Mixing also referred to as, combining and integrating, is the explicit interrelating of the two strands, and this point of interface during our study, will be at the stage of interpretation of the results of data analysis. Primary mixing strategy is- merger after separate data analysis.

Prototypical characteristics of the convergent parallel design are -

- Parallel databases
- Data transformation
- Data validation

The abovementioned design variants may be employed based on the information ascertained. Crystallisation of findings from both components will be reported when discussing the results of the study. There is scope for comparison of raw datasets of one individual from both methods, as an example, the interview transcript and questionnaire reports can be compared and patterns looked for across cases. The notation system for this mixed methods design is QUAN+QUAL, i.e., both methods occur concurrently[48].

Study outcomes

The quantitative and qualitative studies which are being undertaken to understand patient clinical and psychosocial parameters, in the context of healthcare infrastructure and provider views from geographically distinct sites, will give the breadth and depth of problem perception and solutions. We seek to identify systemic issues that may deter the uptake of HHD and understand factors which may define the atlas of variation, to develop a tool to implement a practice changing model of care. Additionally, the study will highlight the beliefs and concerns of the major stakeholders- patients, care givers and healthcare providers on HHD. We will be able to ascertain the range of interventions and assistance that may be necessary for successful adoption. The association (if any) between patient-psychosocial factors and biochemical parameters, including specific toxin assays in the context of ESRD will also be analysed. The study findings will be disseminated to clinicians, organisations and health care strategists as guidance to inform future policy. Lessons from the implementation of the study design would

also pave way for more holistic research of chronic diseases in health care systems using this methodology.

DISCUSSION

Over the last five decades, the growth in demand for dialysis has increased exponentially. There is a growing need to develop methods for improving treatment outcomes whilst paying attention to costs. It is in this context, that there is renewed interest in home haemodialysis. The proposed benefits in HHD offering extended dialysis schedules are supported by randomised controlled trials and several observational studies. Despite the rhetorical remarks on the benefits of HHD, its practical uptake has been somewhat slow over the last decade and steps are being taken to increase its adoption, in the UK and globally. In the study of adoption of a well understood, complex intervention, such as home haemodialysis, a robust study methodology is important to delineate the issues facing the patients, caregivers and healthcare providers. Partnerships will be required between all stakeholders to adopt changes in attitudes, with the necessary regulatory alterations to implement clinically superior, patient-focused dialysis treatment programs, where informed patient choice is paramount.

Methodology is the rationale and philosophical assumption underlying a particular study and not merely, a collection of methods, although, methodology leads to and informs methods. Mixed methods papers in the field of nephrology are very few[49]. Historically, studies have been done to understand some aspects of this rather large question on ‘barriers and enablers of home haemodialysis’. Reports on different aspects of this issue, come from study designs which do not automatically lend themselves to accuracy or detail. These include close-ended questionnaire based surveys, completed probably, by individuals who are driven enthusiasts propagating home haemodialysis, thereby introducing bias. In some instances, home dialysis incorporating peritoneal dialysis and home haemodialysis, have been studied and although, this would capture the notion of ‘self-care’, nuances, specific to home haemodialysis may not be elucidated in detail. Identifying the barriers and enablers of home HD is only meaningful when probable solutions to the issues projected from studies, are also provided. In addition, within the financial constraints of the current health service provision, cost models and understanding optimal service delivery designs are fundamental to effecting the desirable change. The BASIC-HHD study has been designed to understand the patient, the care-giver and the healthcare provider in a rapidly changing health care climate, where emphasis on patient-centred choice and ‘care closer to home’ remains at the core of NHS ethos. The strength of this study lies in its methodology wherein a complex intervention of a life sustaining self-care technology is systematically studied in a holistic sense incorporating qualitative and quantitative research components studied simultaneously with equal emphasis in centres with varying prevalence and uptake of HHD. Incorporating multiple research

methods will help acquire a three dimensional view of the research findings, more likely to yield lasting solutions to the research questions.

Health systems reforms, have in the last 20 years evolved from provision of structured to managed care as, structural changes, on their own may not be able to deliver anticipated improvements in quality and performance in health care[50]. This has not been studied in a smaller context such as dialysis provision centres. Organisational culture denotes much more than just the way things are done and is a unique aspect of this study arm. The study will analyse attitudes and practices in the varying dialysis units. This may help distinguish frontline service delivery (functional behaviour) from organizational (structural) influences. Changing the way things are done on the level of functional redesign, is separate to attempting to understand why things are done in certain distinctive ways[43].

The BASIC HHD is a pragmatic study, suitably equipped with requisite expertise to carry out the work. We have invested the effort and time to form a team of researchers who are keen to study several facets of the research question in parallel, from across UK. Prospective recruitment of the pre-dialysis cohort will help understand the patient journey better and we anticipate recruiting patients from across the spectrum of illness severity. This will improve the generalizability of our findings. Bias and random error in handling data will be minimised by validation checks by the researcher on data entry by research nurses. Periodic visits to the participating units will ensure uninterrupted and uniform data gathering, and an opportunity to troubleshoot problems as they arise. Conceptually, the BASIC-HHD study is intended to be both confirmatory and exploratory in design and provide a scaffold for ancillary studies addressing specific psychosocial characteristics and biomarkers in the different study cohorts. Planned studies include an in-depth characterization of uraemic ‘neuro’toxins, namely the guanidine compounds and their impact on cognitive outcomes and decision making processes in ESRD. Exploratory work in search of a candidate biomarker in biological samples (Blood spots and saliva) for cognitive dysfunction in the context of ESRD is underway. It is also likely that progression of the ‘uraemic state’ impacts on physical factors such as, global DNA methylation, gene expression and metabolic pathways, which may influence mental health and quality of life. Its associations with psychological outcomes can now be combined to generate valuable information, for patient care.

In conclusion, the BASIC-HHD is a unique study in dialysis medicine, which will assemble pivotal information on dialysis modality choice and uptake, investigating users, caregivers and care delivery processes and study their variation in a multi-layered analytical approach within a single health care system. The study results would define modality specific service and patient pathway redesign with the potential of a paradigm shift in practice and providing future directions in dialysis care.

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Competing interests

The author(s) declare that they have no competing interests.

Author's contributions

All authors have contributed to the overall design of this study. SM is the chief investigator with overall responsibility for the BASIC-HHD study. AJ, as the study lead, participated in the study design and coordination, prepared the protocol, obtained ethical approval and participated in the liaising with all participating units. AW is responsible for overseeing the qualitative components of the patient study arm and the ICBS team (JB and SB) developed the organisation qualitative study arm and the health economics analysis plan. JM is the study statistician. PB is director of the renal research laboratory at Manchester Royal Infirmary and is part of the study steering group. All authors have read and approved the final manuscript.

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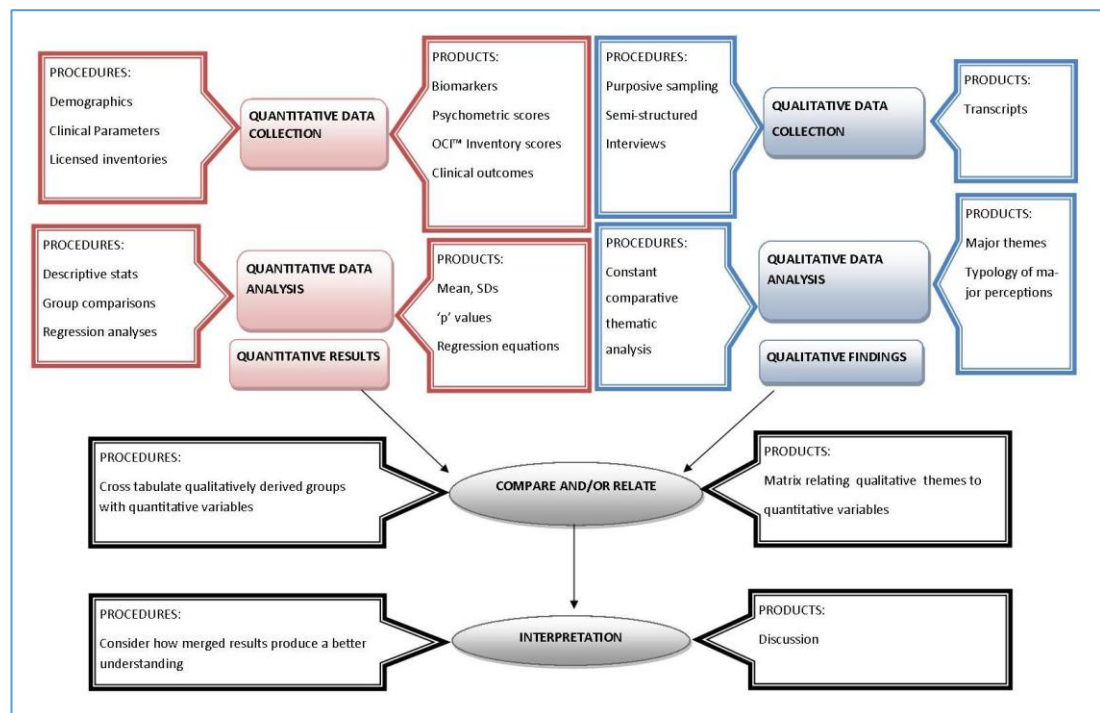
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Schematic representation of the CONVERGENT PARALLEL design of the BASIC-HHD study



Data analysis and interpretation for the study presented in this thesis

The data and analysis presented in this thesis includes-

- A retrospective observational analysis of 8-year data on home haemodialysis technique survival
- Global survey of attitudes, beliefs and practices of home haemodialysis
- BASIC-HHD study data as outlined in the protocol paper.

Omitted from this thesis

- Informal care-giver – qualitative arm of the study.
- Economic Analysis and System Dynamics Modeling
- The outcomes of the Organisation Culture Inventory™
- Evaluation of the ‘attachment questionnaire’ amongst study participants
- Study of uraemic neurotoxins and cognitive function

SECTION THREE

Results

*Home Haemodialysis-
Technique Survival
(Chapter 3.1)*

*Modality Relevance
(Chapters 3.2-3.3)*

*Patient factors associated with
home haemodialysis*

*Quantitative Studies
(Chapters 3.4-3.9)*

Qualitative Study (Chapter 3.10)

*Organizational Factors associated
with home haemodialysis*

Quantitative study (Chapter 3.11)

Qualitative study (Chapter 3.12)

CHAPTER 3.1

Technique Survival in home haemodialysis: a composite success rate and its risk predictors in a prospective longitudinal cohort from a tertiary renal network programme

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ABSTRACT

Background Resurgence of interest in home haemodialysis (HHD) is, in part, due to emerging evidence of the benefits of extended HD regimens, which are most feasibly provided in the home setting. Although specific HHD therapy established at home such as nocturnal HD (NHD) has been reported from individual programmes, little is known about overall HHD success.

Methods The study included 166 patients who were accepted in the Manchester (UK) HHD training programme through liberal selection criteria. All patients were followed up prospectively until a switch to alternative modality, to include 4528 patient-months of follow-up and about 81 508 HHD sessions during an 8-year period (January 2004–December 2011). Twenty-four patients switched to an alternative modality during the period. Combined technique survival (HHD_c) as a composite of training (HHD_{tr}) and at home (HHD_{home}) was analysed and clinical predictors of HHD modality failure since the commencement of the programme were calculated using Cox regression analysis. Technology-related interruptions to dialysis over a 12-month period and patient-reported reasons for quitting the programme were analysed.

Results Technique survival at 1, 2 and 5 years was 90.2, 87.4, 81.5% (HHD_c) and 98.4, 95.4 and 88.9% (HHD_{home}) when censored for training phase exits, death and transplantation. The combined HHD_c modality switch rate is 1 in 192 patient-months of dialysis follow-up. Age >60 years, diabetes, cardiac failure, unit decrease in Hb and increasing score of age-adjusted Charlson-comorbidity index were significantly associated with technique failure. Significant clinical predictors of HHD technique failure in a multivariate model were diabetes ($P = 0.002$) and cardiac failure ($P = 0.05$). The majority (61%) switched to an alternative modality for non-medical reasons. The composite of operator error and mechanical breakdown resulting in temporary HHD technique failure was 0.7% per year.

Conclusions HHD training and technique failure rate are low. Technical errors are infrequent too. Diabetes and cardiac failure are associated with significant risk of technique failure. Although absolute rates are low, training failure is proportionally quite significant, highlighting the importance of reporting the composite technique failure rate (to include early HHD training phase) in HHD programmes.

INTRODUCTION

Home haemodialysis (HHD) was at its peak of practice in the 1980s. It suffered high rates of attrition subsequently, in most countries, with the exception of Australia and New Zealand [1]. There is increasing body of evidence documenting the clinical and quality-of-life benefits of this modality compared with conventional thrice-weekly hospital HD [2–5]. This, combined with many other factors, has led to a resurgence of interest in HHD modality in the last decade, among all stakeholders. The National Institute of Health and Clinical Excellence (UK) recommendation of increasing prevalent home HD population to 10–15% of the total dialysis cohort [6] has been achieved in only a minority of dialysis programmes. The provision of HHD, its uptake and prevalence depend on several clinical, organizational, cultural and patient factors. Understanding the patient characteristics that predict HHD success or failure is critical to developing selection criteria, protocols, pathways and support systems that will help recruit those who are appropriate for HHD and provide them with the support that may be necessary to sustain the chosen modality. Technique survival or success of a specific dialysis modality treatment is typically reported when the patient is established on that particular therapy, in case of HD when established at home (HHD_{home}). The training phase for the chosen modality, however, can form an important limiting step in the patient's pathway, and may be crucial to its success. Its study may provide valuable insights into the modality uptake, more so in HHD than PD, as the former training phase (HHD_{tr}) can be significantly more prolonged than in the latter. Limited data are available on the outcomes of home HD training or HHD modality technique survival/failure and its predisposing factors [7, 8]. Most reports in the literature on technique failure refer to a specific subset of HHD, e.g. nocturnal HD (NHD), and tend to exclude training failure. Reports on treatment success in studies where HD regimen at home is the intended therapy (extended either in frequency, duration or both) can be invaluable, when analysing factors that influence uptake and sustenance of HHD.

We therefore sought to (i) examine the technical success rate from acceptance to exit from the HHD programme, (HHD_c) that was not due to death or transplantation and then (ii) define the clinical and patient-reported risk factors of failure on the modality, in one of the largest HHD programme networks in the UK.

Understanding HHD composite technique failure (HHD_c)

Technique failure is defined and understood in the context of peritoneal dialysis (PD), as the inability to continue the modality due to ultrafiltration failure or membrane incompatibility with good clearance, recurring or refractory peritonitis, necessitating a modality switch to HD [9]. No such consensus definition for technique failure exists in the HHD literature.

The HHD modality pathway would commence when the patient is accepted to be included in the home training programme through the successful practice of self-care at home. We believe that technique failure in HHD should encompass the failure of components of home HD procedure. This would consequently result in either temporary or permanent failure of the modality. The former includes instances such as vascular access problems, technological glitches or respite care. The latter is usually a consequence of the patient's inability to carry out the procedure due to medical comorbidities or due to psychosocial factors precluding continuation of training or the sustained practice of the modality. For the purposes of our study, the latter has been defined as permanent exit of patients from the training or the home programme due to physical or psychological incapacity, including displacement of modality from their own homes. Technique failure (HHD_c) is defined and understood in the context of HHD here, as the inability to continue the modality at any point from the commencement of training, necessitating a permanent modality switch. All patients are considered to be active on the HHD modality on commencement of training (HHD_{tr}) through to the period when the modality is undertaken at home (HHD_{home}). HHD_c represents the treatment modality inclusive of both these phases.

SUBJECTS AND METHODS

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The study cohorts include all incident and prevalent patients on HHD from the Greater Manchester East Sector Renal Network over an 8-year period (January 2004 and December 2011 both inclusive).

Study cohort and data acquisition

During the analysis, two study cohorts were defined, i.e. those who continued HHD (CHHD group) and those who switched to an alternative modality (SWD group), with the data censored for death or transplantation. Demographic and clinical data were obtained from the institutional electronic records and a prospectively maintained database for all subjects. These data include gender, ethnicity, carer availability, primary renal disease, comorbidities, dialysis vintage before initiating HHD, programme entry and exit dates, vascular access at the start of training, reasons for switching modality and previous transplant history. Biochemical variables such as albumin, CRP and Hb were also recorded at the start of HHD_{tr}. Information pertaining to technological failure was procured from the renal technical services' computerized log and examined for a 12-month period. All patients switching to an alternative modality and surviving at the end of the study period were approached to participate in a brief questionnaire which helped identify their perception of HHD and impact of information and education they received prior to acceptance of HHD. The reasons for modality switch were also ascertained.

Statistical analyses

Patient demographic data for both the groups are tabulated and their characteristics are summarized using descriptive statistics. Kaplan–Meier survival estimates were used to assess the unadjusted technique success at 1, 2 and 5 years for HHD_c and HHD_{home}. A survival analysis was performed to estimate the technique survival (analysis censored for all programme exits due to death or transplants with and without training failure). Cox proportional hazards models were used to identify patient characteristics or comorbidities that potentially predicted technique failure. *A priori*, some variables were considered to be risk factors for technique failure. These include, age at HHD start, gender, diabetes status, cardiovascular co-morbidities, vascular access type [arteriovenous fistula or graft versus catheter (CVC) at start of HHD] and biomarkers—haemoglobin and albumin at the commencement of HHD. Statistical analyses were done using SPSS v 19 and Graphpad Prism v5.

Service design and patient pathway

During the study period, the reporting network (serving a catchment population of ~1.6 million) saw a steady rise in home HD prevalence from 4 to 15% of all HD. In our programme, a recent estimate suggests that 25% of pre-dialysis patients choose PD and 15% of pre-dialysis patients choose HHD. All patients enter the programme through open selection criteria, principally led by patient choice and supported by a structured pre-dialysis and in-centre education programme and home dialysis assessment phase. Seventy-three percent of patients needing dialysis have been through the pre-dialysis education and preparation phase. Carer-facilitated and solo dialysis (10%) is offered, if appropriate. There are no rigid exclusion criteria, but frail patients and those with unstable mental illness would not be offered the choice of HHD. Currently, the programme does not offer HHD to those unable/unwilling to self-cannulate or require full assistance on HD. The assessment is performed by a team of pre-dialysis care nurses who utilize the Roper–Logan–Tierney model of nursing and the individual's relative and potential for independence in activities of living. The decision is ratified by a multidisciplinary team.

Patients undertake HHD training at a dedicated centre, removed from the main tertiary renal centre, with an average training time of 10 weeks. Most patients undertake extended high-flux dialysis using F4008 machines beyond 4 h three times a week. The prevalent HHD types include 15% short daily HD, 30% NHD (Nocturnal HD), 30% on alternate day schedules and 25% on conventional dialysis schedules.

RESULTS

Demographics

The study cohort consists of a total of 166 patients, from a single tertiary centre, Manchester Royal Infirmary, including the Greater Manchester East Sector Renal Network. Twenty-four of the 166 patients exited the programme while training or from home (SWD cohort), during the study period. The study demonstrates exit from the programme due to transplantation in 33% of patients, from the CHHD group. Thirty-three patients (CHHD) also had a previous history of transplantation.

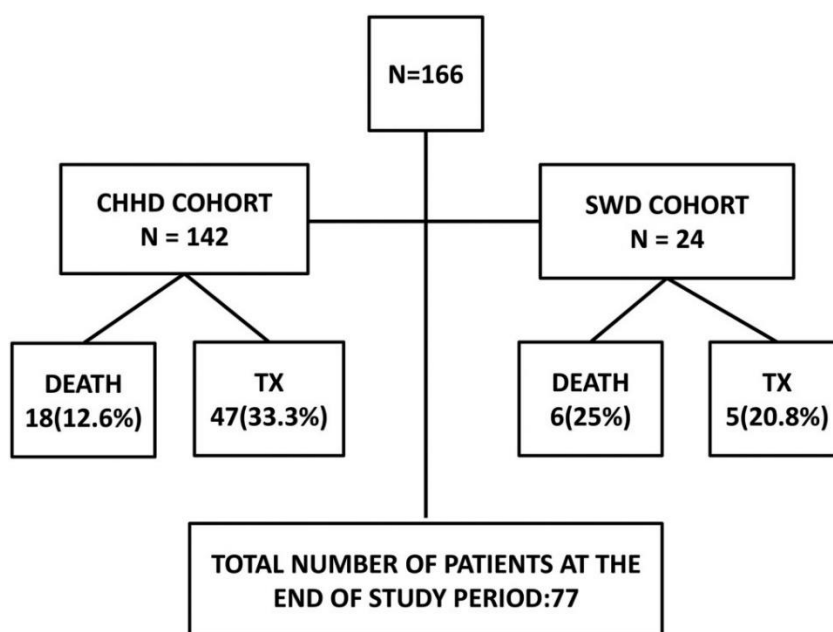


FIGURE 1: Patient disposition during the study period.

The baseline demographics of these patients are tabulated below (Table 1)

The mean age of CHHD and SWD cohorts is 48.3 and 51.6 years, respectively. The proportion of males in the former group are 65.5 and 62.5% in the latter. The distribution of ethnic minority patients between the groups shows 14% non-Caucasian patients in the CHHD cohort and 17% of patients in the SWD cohort. The availability of an informal care provider (defined as an individual who needs to provide physical help for the patient with the procedure) seems proportionally higher in the CHHD cohort at 48.6 versus 33% in the SWD cohort, but the difference was not statistically significant between the two groups.

A review of the cause for end-stage renal disease in the two groups identified the presence of diabetes as significantly higher in the SWD cohort ($P = 0.012$), but no differences with respect to other aetiology or the type of vascular access used at commencement of training (tunnelled catheter versus arteriovenous fistulae, $P = 0.17$).

Table 1: Demographics and comorbidities in the CHHD and SWD cohorts			
Patient Characteristic	CHHD Cohort (Continued HHD)	SWD Cohort (Switched modality)	P value
Number			
166	142	24	
Age			
Mean	48.3	51.6	ns
Range	20-77	26-71	
Gender			
Male	65.5%	62.5%	ns
Female	34.5%	37.5%	
Ethnicity			
Caucasian	86%	84%	ns
Non Caucasian	14%	17%	
Carer			
Available	48.6%	33%	ns
Not Available	51.4%	67%	
Comorbidity (% prevalence)			
Hypertension	45	58	0.27
Diabetes	9.1	29.1	0.012*
Coronary Artery Disease	16.9	29.1	0.16
Cardiac failure	4.2	1.2	0.12
Malignancy	4.8	1.2	1.00
*indicates significant difference between cohorts			

Charlson-comorbidity index

We employed age-adjusted Charlson-comorbidity Index [10] as a comorbidity instrument, a risk score calculated based on different weights for separate age classes and comorbid conditions. The median scores in the CHHD cohort and SWD cohort were 3 and 4, respectively (significantly higher in SWD, Figure 2). The 25th and 75th centiles for the scores were 2 and 4 for the CHHD group and 3 and 5.75 for the SWD group.

Patient exit from the programme

Figure 3 demonstrates the low incidence of annual technique failure rate despite a high HHD incident rate, year on year. Figure 4 depicts the time to exit from the programme during 4528 patient-months of follow-up for both SWD and CHHD cohorts. It is important to note that the exit from the programme appears to be the highest in the initial training period (54%). The composite training and home exit rate is 1 in 192 patient-months. The home exit rate censored for training exits (TEs) is 1 in 416 patient-months and TEs censored for home exits is 1 in 357 patient-months.

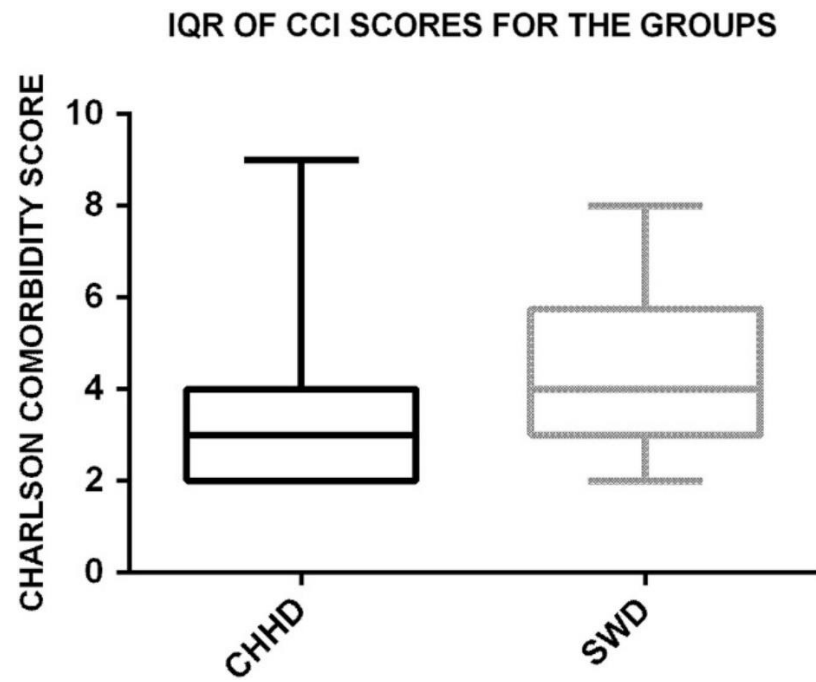


Figure 2: Interquartile ranges of age-adjusted CCI scores for the groups show a significantly higher CCI score in the SWD cohort.

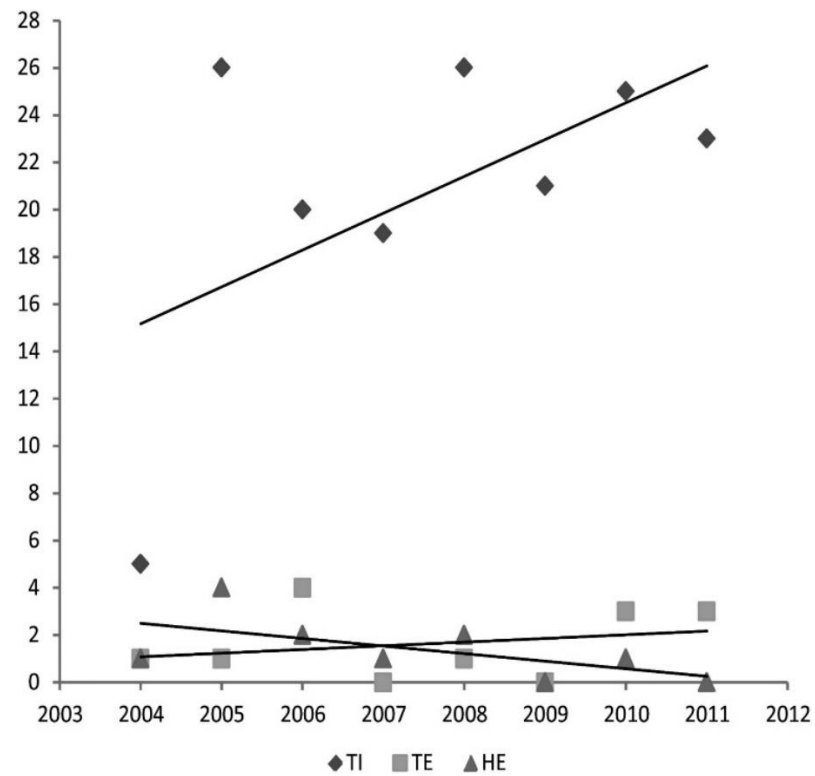


Figure 3: The graph demonstrates modality exit rates on a yearly basis. TE in a square plot represents the TEs and established home therapy exits are shown in the triangle plots (HE). The true incident numbers for home therapy on a year-by-year basis is shown in the diamond plot (TI).

Biomarkers

The biomarkers analysed were Hb, albumin and CRP at the start of dialysis. There were no significant differences in the median haemoglobin and albumin levels between the two cohorts.

Vascular access

There was no significant difference between the SWD and CHHD cohorts (Figure 5) as regards the type of vascular access at the start of HD ($P = 0.17$). In the reasons cited for exiting the training or home programme, vascular access complications did not figure significantly in the SWD cohort.

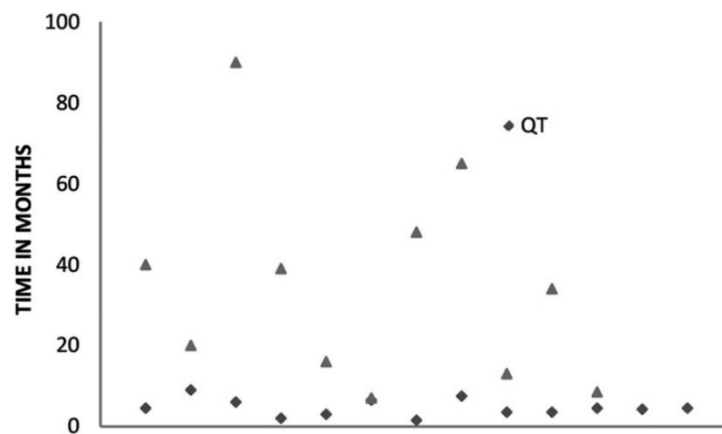


FIGURE 4: The graph demonstrates the time taken for modality switch. There are distinct points on the graph for time (months) taken to exit training (Quit Training-square points) and those who exited home HD (Quit home HD- triangle points). It may be noted that the majority of modality switches occur in the initial training phase.

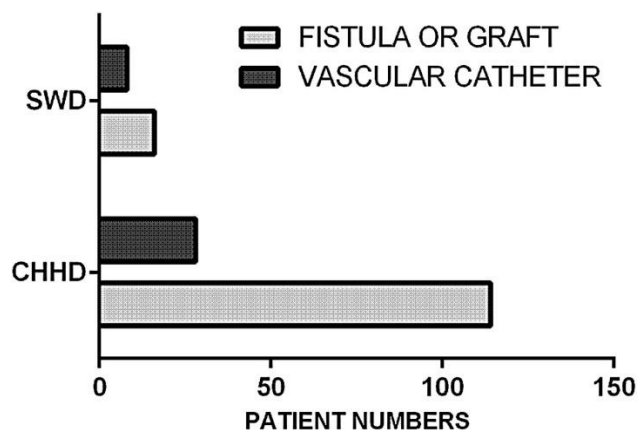


FIGURE 5: Patients in the two cohorts with either a native AV fistula or a catheter at the start of HD.

Technique survival estimates

Unadjusted Kaplan-Meier survival estimates in (Figure 6) show the overall HHD_{home} programme retention over time censored for programme exits due to death, transplantation and technique failure due to TEs. 98.4, 95.4 and 88.9% patients were retained in the HHD_{home} cohort at 1, 2 and 5 years. For HHD_c (TE included in the analysis), the 1-, 2- and 5-year technique survival rates were 90.2, 87.4 and 81.5%, respectively (Figure 7).

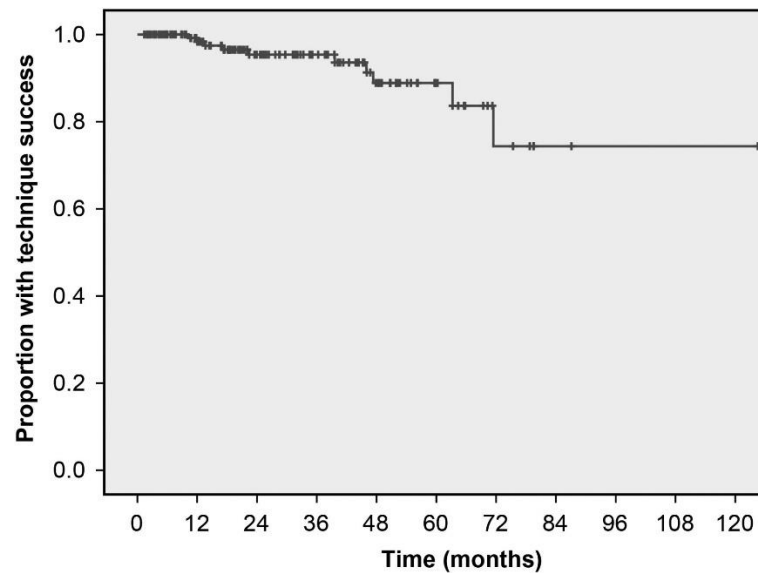


FIGURE 6: Proportion with technique success-based on all-cause programme exits HHD_{home} (censored for death, transplantation and TEs) 98.4, 95.4 and 88.9% at 1, 2 and 5 years.

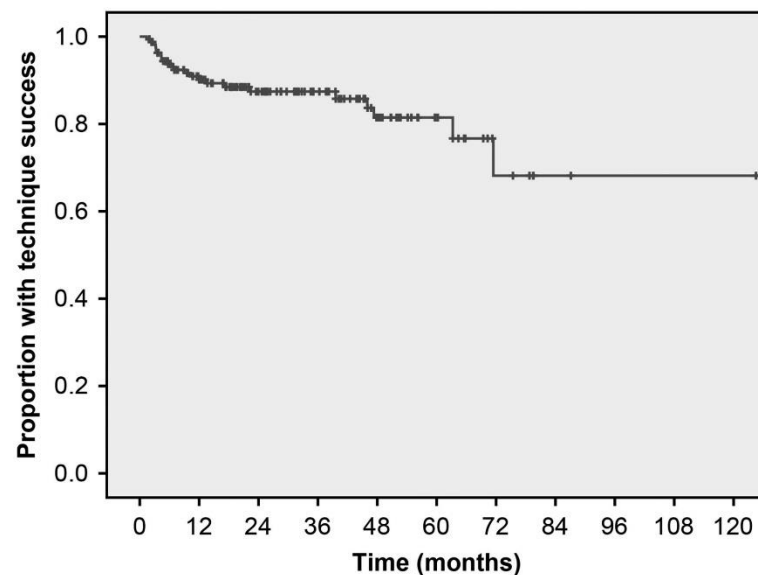


FIGURE 7: Proportion with technique success based on all-cause programme exits: HHD_c (censored death, transplantation) 1-, 2- and 5-year technique success 90.2, 87.4, 81.5%, respectively.

Univariate analysis of predictors of technique failure (HHD_c), using Cox's proportional hazards regression, identified age >60 years (HR 2.07, CI 0.67–6.37), diabetes (HR 4.08, CI 1.71–9.74), cardiac failure (HR3.67, CI 1.07–12.6), per unit increase in the age-adjusted Charlson-comorbidity index score (HR1.32, CI 1.07–1.63), as significant predictors of a negative outcome and per unit increase in haemoglobin (HR 0.83, CI 0.65–1.06) as a significant predictor of positive outcome (Table 2). In the multivariate model, diabetes and cardiac failure predominate (Table 3).

Table 2: Univariate analysis of predictors of HHD_c technique failure			
Factor	Hazard Ratio	95% CI	P¹
Age (years)			
18-39 (ref ²)	1	-	0.035 *
40-49	0.24	(0.06, 1.03)	
50-59	0.88	(0.28, 2.77)	
60+	2.07	(0.67, 6.37)	
Gender			
Male (ref)	1	-	0.75
Female	1.14	(0.50, 2.62)	
Ethnicity			
Caucasian (ref)	1	-	0.75
Non-Caucasian	1.18	(0.43, 3.21)	
Diabetes			
No (ref)	1	-	0.002 *
Yes	4.08	(1.71, 9.74)	
Cardiac failure			
No (ref)	1	-	0.038 *
Yes	3.67	(1.07, 12.6)	
Coronary Artery Disease			
No (ref)	1	-	0.15
Yes	1.93	(0.79, 4.74)	
Malignancy			
No (ref)	1	-	0.84
Yes	0.88	(0.26, 2.97)	
Charlson Comorbidity index			
(per unit increase)	1.32	(1.07, 1.63)	0.011 *
Haemoglobin			
(per unit increase)	0.83	(0.65, 1.06)	0.032 *
Albumin			
(per unit increase)	0.96	(0.90, 1.04)	0.33
*indicates significant difference between cohorts			

Table 3: Multivariate analysis of predictors of HHD_c technique failure			
Factor	Hazard Ratio	95% CI	P¹
Diabetes			
No (ref)	1	-	0.002 *
Yes	3.96	(1.66, 9.48)	
Cardiac failure			
No (ref)	1	-	0.05 *
Yes	3.38	(0.98, 11.6)	
*indicates significant difference between cohorts			

TECHNOLOGY FAILURE

We investigated temporary technique interruption, consequent to technological issues that may have arisen. For a single calendar year, 11 500 recorded HHD sessions resulted in 49 (0.4%) operator errors and 39 (0.3%) instances of mechanical breakdown leading to interruption of at least one dialysis session.

REASONS FOR MODALITY SWITCH

Eighteen patients in the SWD cohort who were alive at the end of the study period were asked to fill in a brief questionnaire seeking reasons for modality switch. Eleven of the 18 patients had responded (61% response rate), 1 had received a transplant, 1 dialysed at facility and 9 patients were receiving hospital HD. Several factors, often multiple and of non-medical nature, were identified for modality switch. Figure 8 shows a doughnut diagram depicting the reasons for modality switch for all-cause exits (HHD_c). The factors which determined technique failure due to home exit were of a medical nature in the majority of cases and this is elucidated in the tabulation below (Tables 4 and 5).

Table 4: Staff perceived reasons for home exits from the HD programme		
Reasons (home exits)	Patient Numbers (N=11)	%
Medical Issues	4	36.3
Loss of motivation	3	27
Lost job/Housing	2	18.1
Unable to cope-old age	2	18.1

Counselling, more intensive pre-dialysis education and preparation, and early engagement of carers and members of family in understanding what benefits there may be for the patients are believed to be possible influential factors on the modifiable reasons.

Table 5: Staff perceived reasons for training exits from the home HD programme		
Reason	Numbers	%
Lack of motivation	3	23
Stressful/unable to cope	2	15.3
Compliance	1	7.6
Lack of confidence	4	30.7
Lack of space at home	1	7.6
Medical issues	1	7.6

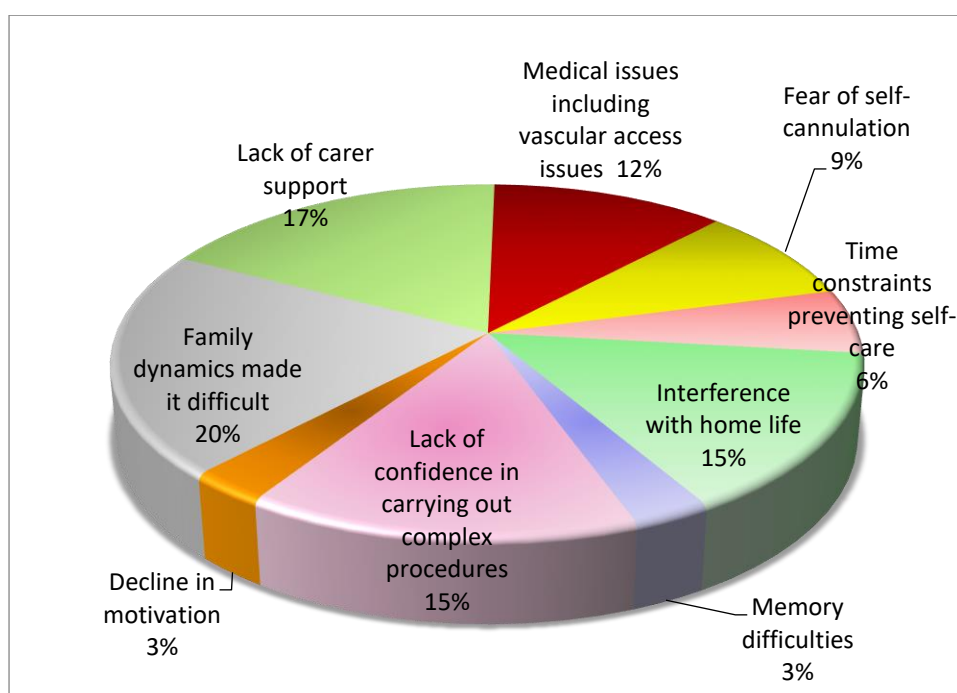


FIGURE 8: Patient reported reasons for modality switch from an HHD composite

DISCUSSION

The study demonstrates high HHD composite technique survival rates of 90.2% at 1 year and 81.5% at 5 years (HHD_c), and further improvement to 98.4 and 88.9%, respectively, when patients are established at home following completion of training (HHD_{home}). The high eligibility for transplantation in the cohort highlights the general well-being of the CHHD cohort, which is also exemplified by the median age-matched Charlson-comorbidity index scores of 3 (IQR 2–4). The low technique failure rate is comparable with historical reports on the outcomes from early days. The selection criteria for patients undergoing HD in the early years have been strict. The very early reports in 1966 showed the cumulative experience derived from 9 patient-years and 1000 overnight HD sessions [11]. Our programme differs

from historical HHD cohorts in many ways, including a greater emphasis on patient choice and education with liberal acceptance criteria. We believe that this enhances the validity of the reported findings.

More contemporary reports on HHD modality failure suggest unadjusted 1- and 5-year technique survival at 97.9 and 95.2%, respectively, for nocturnal HD (NHD). Technique failure, as defined by a physical or cognitive inability to perform NHD at home either alone or with assistance, was uncommon in this study (3% at 1 year and 5% at 5 years). In this study, age and diabetes remained significant with multivariate analysis (hazard ratios 1.07 and 2.64, respectively) for the composite of death and technique failure [12]. These studies remain limited to a specific type of home-based HD therapy and exclude training success or failure rates.

Technique failure is defined in our study as programme attrition consequent upon inability, physical or psychosocial, to continue HHD training or treatment at home. The study suggests that HHD composite technique success (HHD_c) is an improved measure of technique success and a crucial index for evaluating the HHD programme, offering more insight into the practice of the modality through the entire patient pathway. This minimizes selection bias for a specific modality and its success, allows an assessment of HHD in a more generic context. HHD technique assessment as an enabler for extended dialysis irrespective of the regimen, and less influenced by alterations of regimens interchangeably at home, often practiced by some patients, could offer more insight into the technology, practice and service delivery. Technique success at home alone (HHD_{home}) may increase bias by masking poor selection or training pathway. Training may take place in different locations and sometimes at home; however, poor training outcomes can significantly affect technique survival. Training success we believe is therefore integral to the sustenance of the HHD therapy. It is justifiable to seek a consensus definition for technique failure in HHD, alongside publications on the technique's utility. This will ensure uniformity in reported outcomes from several different sources, thereby rendering this information transferable. It is useful to note that the high rates of technique success in this study may be compared with those noted in transplant recipients who show graft survival of 92 and 94% at 1 year in donation after cardiac death and donation after brain death, respectively [13]. PD literature shows 1-, 2- and 3-year PD technique survival to be 87, 76, and 66%, respectively, in one study [14]. The study population in each one of these groups is not, however, directly comparable, due to differences in baseline characteristics. Although HHD demands complex technological set up, the extremely low technological failure rate is impressive and bodes well for the therapy itself.

There are some limitations to this study. The offer of HHD to diabetics deserves further investigation with an in-depth understanding of the barriers. Diabetes and cardiac failure were found to have significant associations with the risk of technique failure on multivariate

analysis. Systematic evaluation of the reasons for why diabetics have a high risk of technique failure in a retrospective analysis may be difficult. Perhaps, the psychological burden of multiple chronic ailments needs to be explored further. Medical interventions and vascular access issues are likely to be more common in diabetics. Additional strategies in preparation of patients for this therapy prior to commencement of training may therefore be quite important with due consideration to psychological counselling early in the training process. However, it is useful to note that despite higher prevalence of diabetics in those who chose to quit home therapies, the overall proportion of patients with medical reasons and vascular access problems were extremely small.

Further analysis of our data based on the frequency or duration of dialysis is difficult to interpret in this study, where the modality switch rate is extremely low. A majority of the exits occurred in the training phase, when patients are still not well established on extended hours regimen. At home, patients adopt the more intensive regimen, variably and sometimes interchangeably over the whole duration of the modality experience. Therefore, the association of different prescriptions with technique failure over a period of time is difficult to ascertain, unless this is being studied in a population receiving a homogenous dialysis prescription.

Study of the role of informal care-givers needs a more thorough evaluation. One of the key factors to be evaluated is ‘carer burden’. The data on early exits from the programme mainly in the training phase may be more related to carer issues than patient burn-out. Qualitative studies involving carers, while addressing the socio-cultural, family and material context in which the HHD technology is introduced, should focus on identifying issues to inform improvements or adaptations in the systems, organizational routines, training materials and programmes, and support provision. Patient recall bias may impact the outcome of questionnaires as some patients have had to retrospectively recall their experience. Analysis of patient hospitalizations and in-centre runs has not been undertaken and may add valuable insights.

It is important to note that we are reporting a single network experience. Larger studies are best conducted, once these definitions are clarified, to produce some uniformity of reports in the literature. International Quotidian Dialysis Registry and even national registries could address some of the limitations that have been highlighted above.

Combined research methods need to be employed to explore the drivers and barriers to HHD adoption and better define the ‘at-risk’ population. Prospective multicentre study combining quantitative and qualitative methods with control cohorts suitably matched in the predialysis

and in-centre dialysis subjects may provide more insights into mechanisms limiting the therapy.

CONCLUSIONS

This study is the first report of a composite rate of technique and training success on HHD therapy. This new index, we believe is a better quality indicator of HHD programme and its evaluation. Over four decades, technology, safeguards and our knowledge in the area have advanced significantly, but clinical practice needs to respond to these factors. Revisiting the issue of good technique success rates should provide us with the knowledge and confidence to redesign our practice in the future. The high retention rate in a large and diverse HHD programme provides optimism with regard to future growth of this modality and the benefit offered to the health of patients' lives on RRT.

CONFLICT OF INTEREST STATEMENT

None declared.

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CHAPTER 3.2

Home haemodialysis: beliefs, attitudes, and practice patterns

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ABSTRACT

There is increasing interest of the worldwide kidney community in home hemodialysis (HHD). This is due to emerging evidence of its superiority over conventional hemodialysis (HD), largely attributed to improved outcomes on intensive schedule HD, best deployed in patient's own homes. Despite published work in this area, universal uptake remains limited and reasons are poorly understood. All those who provide HD care were invited to participate in a survey on HHD, initiated to understand the beliefs, attitudes, and practice patterns of providers offering this therapy. The survey was developed and posted on the Nephrology Dialysis Transplantation-Educational (NDT-E) website. Two hundred and seventy-two responses were deemed suitable for complete analysis. It is apparent from the survey that there is great variability in the prevalence of HHD. Physicians have a great deal of interest in this modality, with majority viewing home as being the ideal location for the offer of intensive HD schedules (55%). A significant number (21%) feel intensive HD may be offered even outside the home setting. Those who offer this therapy do not see a financial disadvantage in it. Many units identify lack of appropriately trained personnel (35%) and funding for home adaptation (50.4%) as key barriers to widespread adoption of this therapy. Despite the interest and belief in this therapy among practitioners, HHD therapy is still not within reach of a majority of patients. Modifiable organizational, physician, and patient factors exist, which could potentially redefine the landscape of HHD provision. Well-designed systematic research of national and local barriers is needed to design interventions to help centres facilitate change.

INTRODUCTION

There has been resurgence in the interest of the worldwide kidney community in home hemodialysis (HHD) over the last decade. This interest is largely attributed to escalating research investment into the study of frequent and extended schedule hemodialysis (HD), which is best deployed in patient's own homes. Management of end-stage renal disease (ESRD) with HD began in the 1960s. The evolution of dialysis therapies has resulted in a gradual diminution of home-based therapies to be largely replaced by in-center HD. This phenomenon has posed a challenge to clinicians, service providers, and policy-makers as scientific evidence and health care systems have proposed a strong argument for greater adoption of this modality to improve patient outcomes on dialysis. The optimal uptake of HHD modality with current technology remains unknown. The case for HHD, is made from the evidence of benefits of intensive HD on clinical outcomes compared with facility-based HD, offering conventional HD practices [1, 2] Furthermore, published data have demonstrated extremely high HHD technique survival rates [3, 4]. Despite published work in this area, universal uptake is limited and poorly understood, but likely influenced by several complex individual and organizational factors. An open invitation to all who provide standard HD care to participate in a survey on HHD (specifically designed to link belief and attitudes to practice patterns) may highlight key gaps in service design and its provision and provide more appropriate solution-focused research questions for the future.

METHODS

The survey was developed by the authors and posted on the Nephrology Dialysis Transplantation-Educational (NDT-E) website (<http://www.ndt-educational.org/>). The survey was open to all health care practitioners for voluntary participation. Therefore, ethical approval and formal consenting process were not considered. The response period was between March 8, 2012 and May 8, 2012. The survey comprised of two sections: (1) 6 site-specific questions about the setup/provision for HHD therapy (practice patterns) and (2) 12 opinion-based responses relating to beliefs and attitudes for various aspects of the therapy. Once the response period ended, the data were compiled and analyzed for accuracy and reliability. The results are analyzed and presented using descriptive statistics.

RESULTS

A total of 439 health care professionals started the survey, but the total number of responses available for complete analysis is 272. Of those who completed the survey, 61.4% were from Europe, 9.6% from the Middle East, 8.8% from Asia, and 7.7% were from North America. Smaller proportion of respondents was from other regions—South and Central America (5.9%), Oceania (3.7%), and Africa (2.9%). The majority (35.7%) of respondents was between the ages of 45–54 years, 29% between the ages of 55–64 years, and 22.4% between the ages of 35–44 years. The vast majority of respondents were practicing nephrologists (93.4%) in a general nephrology setting (48.5%) or in a dialysis setting (43.8%). About 54% of the respondents worked in a hospital, 28.3% in an academic department, and 14.1% in a “free-standing” dialysis unit. All results have been presented in Tables 1-5.

1. Information on the size of the overall dialysis program is important. This has been provided in Figure 1. The data were missing from four respondents (Figure 1).
2. In Figure 2, the tabulation presents the responses to questions based on respondents' local centre set-up for modality education and training.
3. Figures 3 and 4 represent the response tabulation for questions based on respondent's beliefs and practices of HHD, including their views on local organizational culture and support and financial implications of HHD uptake.

Table 1: Discussion of dialysis options					
	Myself	Dedicated education team	Other staff	All options	None
No HHD	64 (43%)	24 (16%)	11 (7%)	44 (30%)	6 (4%)
1 – 5 HHD	15 (27%)	19 (34%)	8 (14%)	13 (23%)	1 (2%)
6+ HHD	6 (10%)	25 (40%)	1 (2%)	31 (49%)	0 (0%)

Those with greater number of HHD patients were significantly likely to have a dedicated education team ($p<0.001$)

HHD: Home haemodialysis

Table 2: Patients' choice of modality above all else			
	Always	Sometimes	Never
No HHD	71 (48%)	69 (46%)	9 (6%)
1 – 5 HHD	35 (62%)	20 (36%)	1 (2%)
6+ HHD	45 (71%)	17 (27%)	1 (2%)

Those with greater number of HHD patients were significantly likely to always place patients' choice of modality above all else ($p=0.001$)

HHD: Home hemodialysis

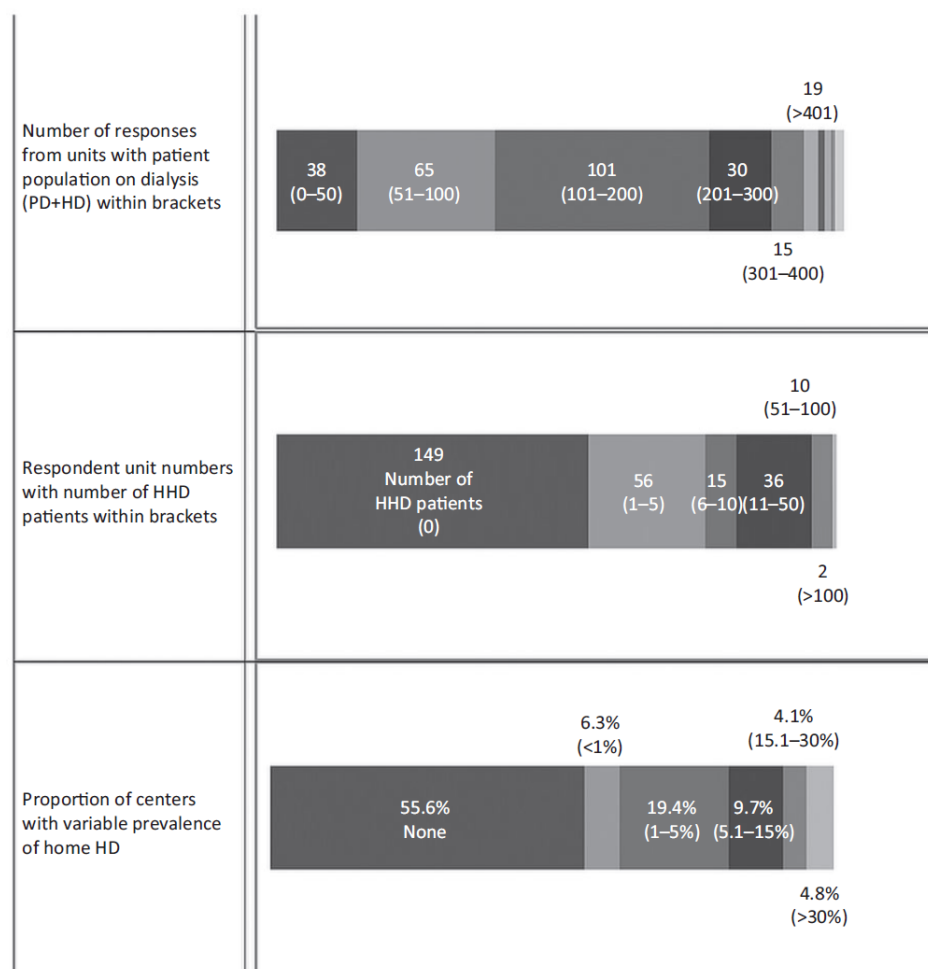


FIGURE 1: Sizes of overall dialysis programs and proportion of home haemodialysis (HHD) patients HD=Hemodialysis; PD=Peritoneal Dialysis

As noted from the tabulation above, 56% of respondents had no HHD patients. Respondents who did have patients on HHD had between 1 and 150 patients, with a median number of 6. Age of the respondent (as a surrogate for experience) had no significant relationship on the number of patients provided HHD (P = 0.86).

Given the high number of respondents with no HHD patients and the fact that the number of respondents with between one and five HHD patients were also high (n = 56), the relationship between numbers on HHD and HHD-related factors was assessed using simple chi-square statistics or tests of linear trend as appropriate, with numbers on HHD categorized as “none,” “1 to 5,” and “6+” (Tables 1-5).

Table 3: Timing of choice of HHD					
	Routinely in CKD 4 and 5 clinics	Routinely in ESRD patients in hospital	On patient requests only	In all places	Choices not offered or not available
No HHD	16 (11%)	4 (3%)	4 (3%)	4 (3%)	121 (81%)
1 – 5 HHD	19 (34%)	6 (11%)	17 (30%)	10 (18%)	4 (7%)
6+ HHD	24 (38%)	5 (8%)	5 (8%)	25 (40%)	4 (6%)

On multivariate ordinal regression analysis, the significant independent predictors of the number of HHD patients (using the outcome none, 1–5, and 6+ HHD patients) found that respondent's perception of “no financial disadvantage,” $P < 0.001$ with uptake of HHD, had a significant independent relationship with the number of HHD patients. Using a simple logistic regression analysis (using the outcome “none” vs. “at least 1 HHD patient”), the significant independent predictors of HHD were “discussion of dialysis option” (a greater percentage of those with a dedicated education team had HHD patients; $P = 0.001$), “belief in current evidence in favor of extended HHD” ($P = 0.045$), and “no perceived financial disadvantage” ($P < 0.001$).

Table 4: Evidence in favour of extended HHD			
	Yes	Not sure	No
No HHD	92 (62%)	35 (24%)	22 (15%)
1 – 5 HHD	40 (71%)	9 (16%)	7 (12%)
6+ HHD	53 (84%)	5 (8%)	5 (8%)

Those with a greater number of HHD patients were significantly likely to have belief in evidence around long dialysis ($p=0.006$)

Table 5: The following results show a comparison of responses to questions on participants' beliefs and practices in those who had or did not have home HD patients	
Those with HHD patients were significantly more likely to see no financial disadvantage	$P < 0.001$
Those with HHD patients were significantly more likely to have belief in current evidence for extended HHD	0.015
There was no significant difference between respondents with HHD patients and respondents with no HHD patients in the choice of therapy that offers the best outcomes	0.21
There was no significant difference between respondents with HHD patients and respondents with no HHD patients in the choice of best location for patients management	0.20
There was no significant difference between respondents with HHD patients and respondents with no HHD patients in perceived benefits of HHD	0.10
There was no significant difference between respondents with HHD patients and respondents with no HHD patients in perceived cost-effective therapy	0.16
Respondents with HHD patients had a significantly higher expectation of proportion of patients who could do HHD	< 0.001

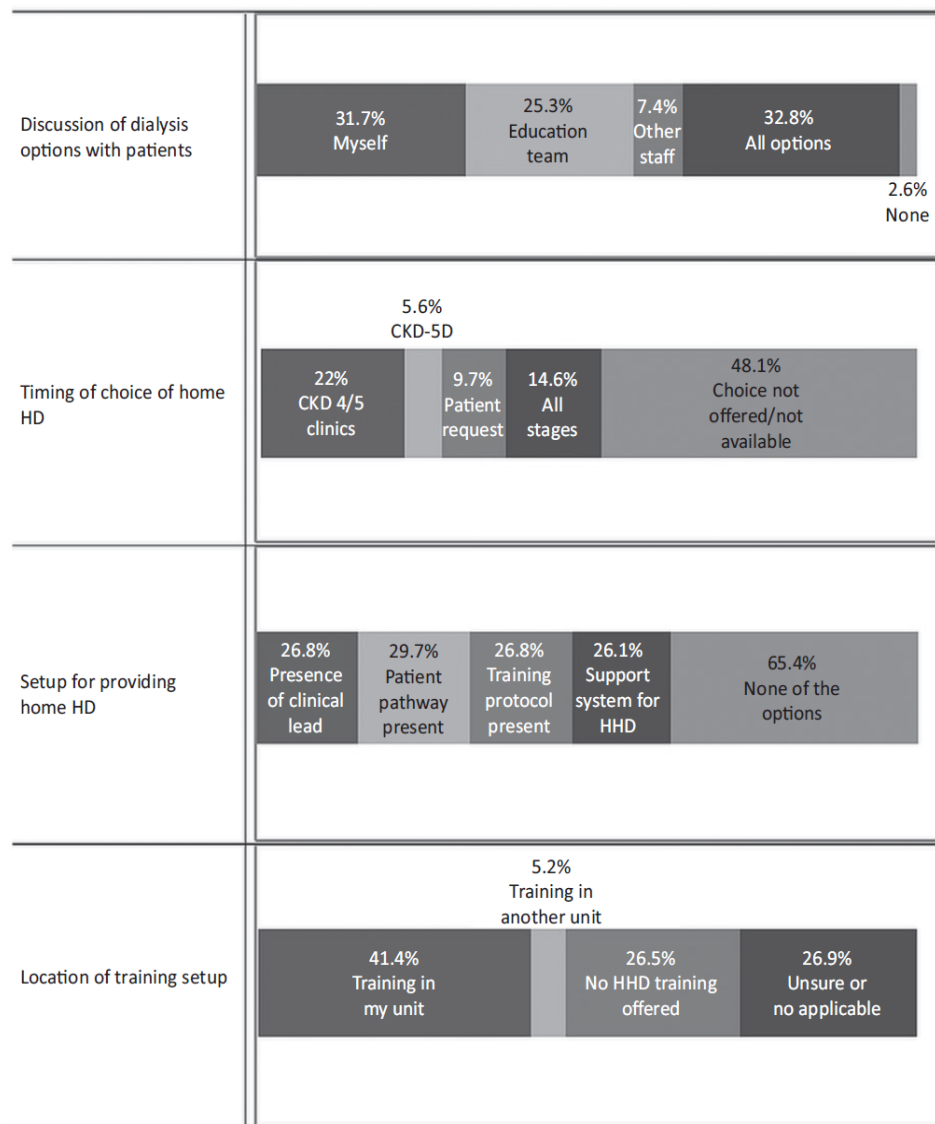


FIGURE 2: Features of respondents' local center provisions

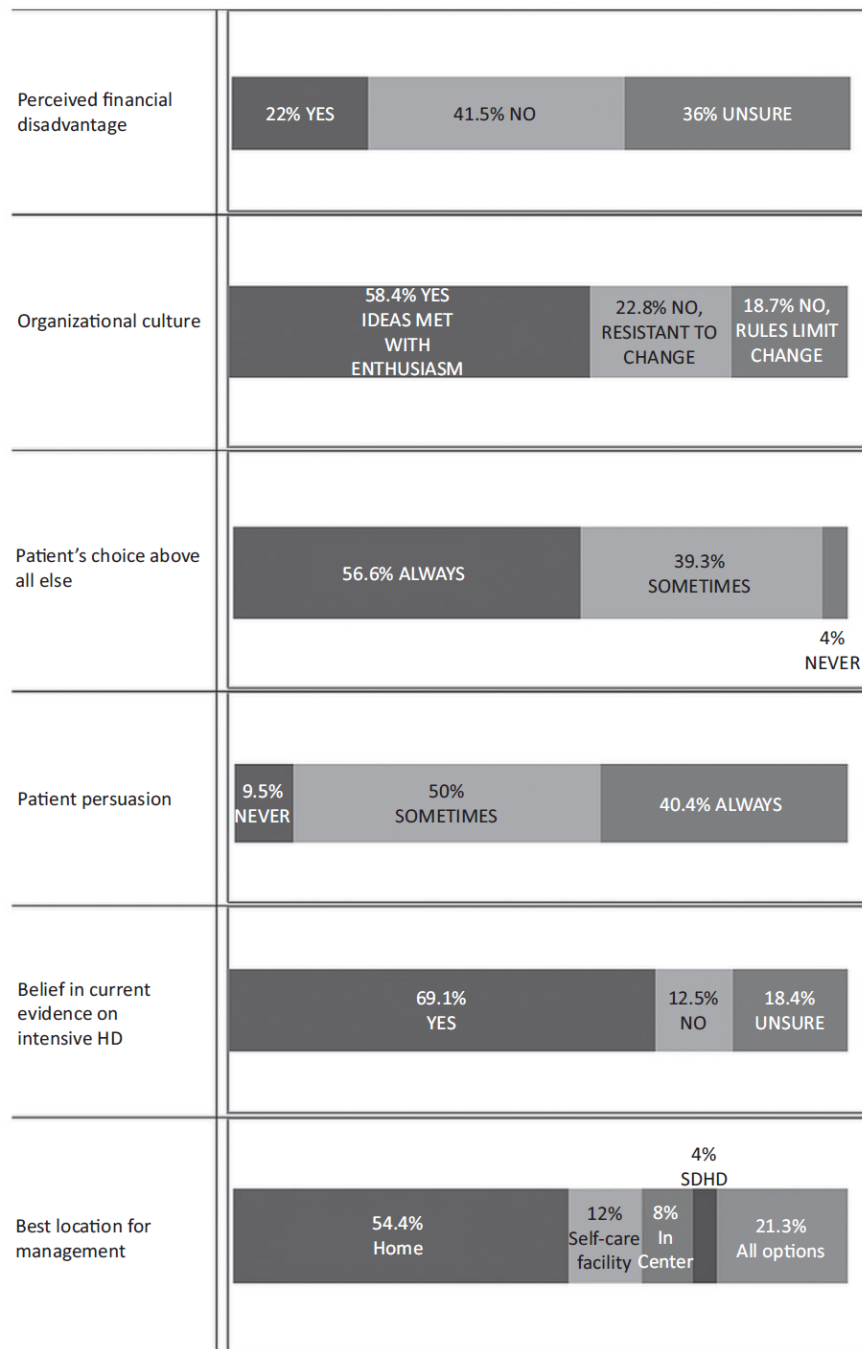


FIGURE 3: Responses based on beliefs, opinions and practices of respondents

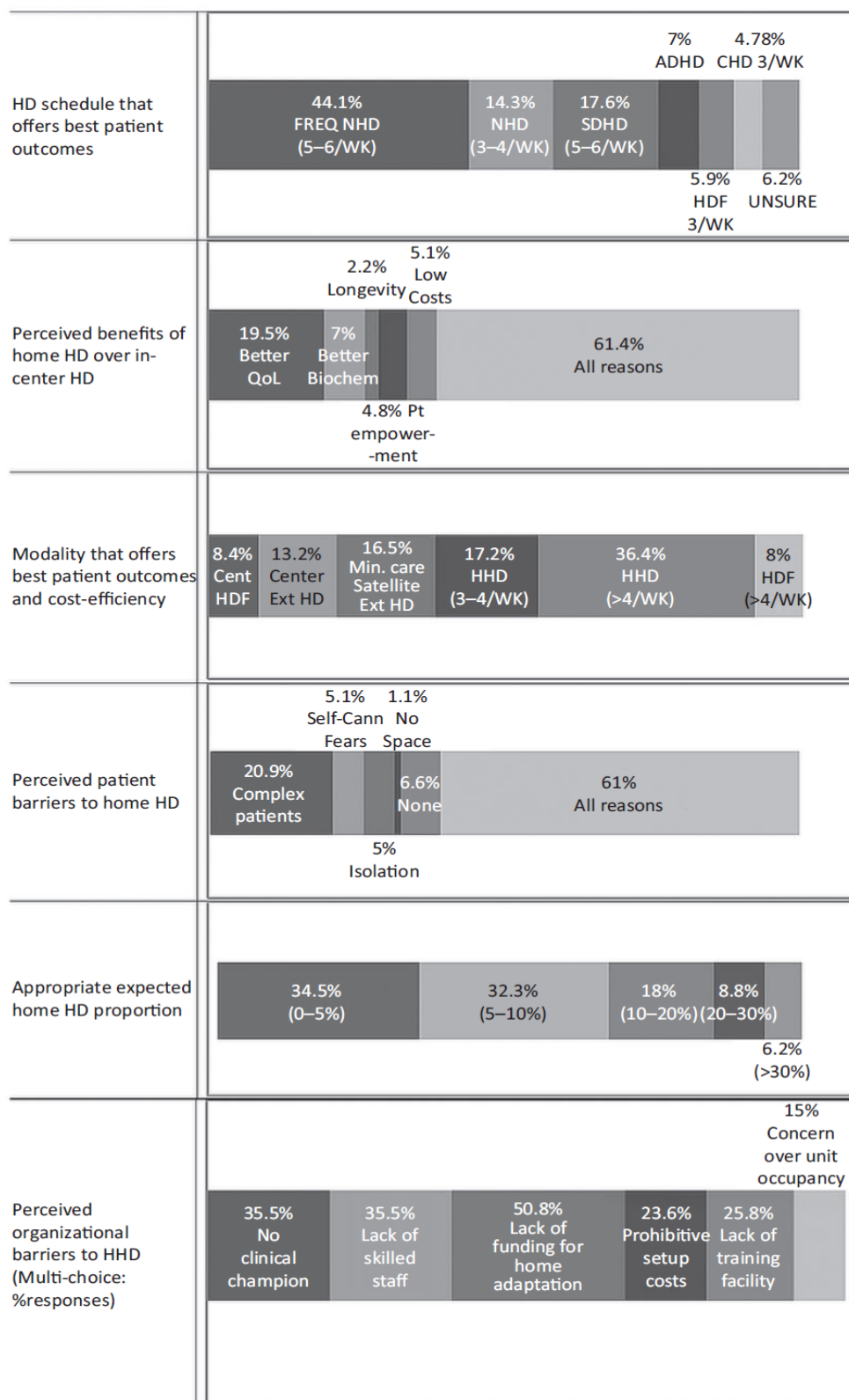


FIGURE 4: Responses based on beliefs, opinions, and practices of respondents (2).

ADHD = alternate day hemodialysis; CHD = conventional hemodialysis;

HD = hemodialysis; HDF = haemodialfiltration; HHD = home hemodialysis;

NHD = nocturnal hemodialysis; QoL = quality of life; SDHD = short daily hemodialysis

DISCUSSION

The primary goal of this survey was to understand the clinical setup and practices of providers engaged in the offer of renal replacement therapy to patients with ESRD. We also sought to understand the beliefs and attitudes of individuals with regard to adopting alternative HD schedules and home-based HD. Overall, the results indicate that there is great variability in the prevalence of HHD. Physicians have a great deal of interest in this modality, with some unanimity of view on home being the ideal location for the offer of extended or frequent HD schedules. This interest is evident from the fact that opinions on several aspects of HHD therapy have been expressed by 56% of respondents who do not have HHD patients in their units. This key finding may indicate systematic barriers despite belief and interest in the modality.

Differences in national health care provision at least in the developed world have often been implicated in this variability, but remain quite difficult to explain. This evaluation has participation from several countries, with 73% of responses from practitioners based in developed countries. The global scenario detailed in a recent review [5] shows an upward trend toward adoption of HHD. Australia and New Zealand lead the way, with 10% to 12% of all dialysis patients receiving HHD [5]. Finland and Canada have reported successful nocturnal HHD programs [6-8]. United States, which has historically considered HHD as an option for the select few, has shown an increase in the national uptake of HHD to 1.3%, [9] mainly short daily HD. The United Kingdom has long held the view that 10% to 15% of the dialysis cohort could be offered HHD [10]. However, this is yet to translate into clinical reality, and the UK renal registry has shown promising trends after a hiatus in the growth of this therapy for over three decades [11]. There is emerging interest in Asia, where HHD was practically non-existent, such as the nocturnal HHD program in Hong Kong [12].

It is of interest to note that respondents whose practice had greater number of HHD patients were significantly more likely to have a dedicated education team and offer the choice of HHD to patients in advanced chronic kidney disease clinics and to those receiving hospital HD. The quality and quantity of pre-dialysis education and the level of support, in the form of a team of specialist nurses, do tend to influence the number of patients choosing a home modality. [13, 14] Attending an options class pre-dialysis has been associated with more frequent selection of home dialysis, fewer tunneled HD catheters, and lower mortality risk during the first 90 days of dialysis therapy. [15] The impact of in-hospital pre-dialysis education program has also been positive on unplanned dialysis starts resulting in increased uptake of home dialysis therapies. [16] Adoption of action models such as the “PRECEDE-PROCEED” will offer a

framework for identifying intervention strategies for designing health education and health promotion programs. It guides planners through a process that starts with desired outcomes and works backward to identify a mix of strategies for achieving objectives.[17]

This evaluation sought to explore the HHD setup, which units have established to deliver this service. Sixty-five percent report the lack of a well-defined patient pathway, a clinical lead, a training protocol, and a support system for patients on HHD. A small proportion of physicians have used a different facility to train their own patients to practice HHD. To some extent, this relies on the availability of such services in accessible locations, and to a large extent, on physician's and patient's belief in the clinical and quality of life benefits of HHD. It is apparent that respondents with greater numbers of patients on HHD also believed in evidence that is currently available on extended/frequent HD schedules. In these instances, translation of this belief into practice needs investment of effort, enterprise, and money into building sustainable programs. The implementation of complex medical technology into routine practice requires support of the organization to which the physician is affiliated. Over 40% encounter either a systematic resistance to change in their organizations or find themselves limited by rules and procedures in the path to consideration of new possibilities. The role of a unit's organizational micro culture may not be underestimated in these instances.

Substantial literature is available on behavioural topics in ESRD such as “coping and adaptation,” “depression,” “exercise,” “counselling and education,” and “compliance.” However, “self-management” and “carer support” seem to be areas that are under-researched and remain to be explored.[18] Recent studies have also demonstrated that patients lack knowledge[19, 20] and are unclear about their role in the decision-making process.[21] There is therefore a need for collaborative work between physicians, nurses, social workers, and psychologists, among others, to understand the social and behavioral consequences of ESRD for a given individual, and treatment decisions may well need to be values based. Kidney disease is chronic and decision-making is ideally staged and incremental. Involvement of a team and engagement of the patient and carer early on are likely to be of most benefit to the patient.

Individuals providing this modality of care have a view on the financial implications of investing in HHD. Compared with respondents who did not have HHD patients, those who did were significantly less likely to perceive this modality as being financially disadvantageous to their units. Several studies pertaining to cost-effectiveness of therapy have been published from several health care organizations in different countries, and most of them

suggest that HHD is more cost-effective than hospital HD[22-25] Even switching from hospital based to HHD would optimize cost-effectiveness.[26]

Many dialysis units operate contracts with different funding sources, which might explain some of the variability in perception of the issue of cost-effectiveness. Publicly funded health care programs in several countries have incentivized optimal health care delivery through “pay for performance” programs.[27, 28] One recent review highlights the key issues with such programs and concludes that evidence on “payment for performance” effectiveness remains inconclusive.[29] Empirical research investigating the influence of these programs should be tailored to the specific setting of implementation of interventions such as HHD. One recommendation from this review is that “pay for performance should be a permanent component of provider compensation and is ideally ‘decoupled’ from base payments.”[27, 29] In the United Kingdom, Commissioning for Quality and Innovation was introduced in 2009 as a way to support a cultural shift to make quality and innovation central to all commissioner-provider discussion.[30] On the back of this framework, there has been considerable engagement in home-based therapies, but the direct and sustained contribution of this conditional income source to improvement in provision of HHD is yet to be demonstrated.

What then are the perceived patient and organizational barriers to adoption of HHD? The majority of participants attribute factors such as patient complexity and comorbidity, the fear of self-cannulation, the fear of isolation, lack of support, and lack of space within patients' homes as barriers to HHD. Many of these factors have been overcome in larger programs with longer experience and greater expertise. In resource-constrained health care systems, identifying reversible factors and addressing these very early may well result in greater self-management among patients and care closer to home. Lack of funding for home adaptation and lack of appropriate personnel were the perceived predominant organizational barriers to HHD. Surprisingly, about 15% of respondents in the survey were worried about a drop in “in-center” occupancy if HHD was promoted. As to what consequences units or individuals may suffer due to a drop in “in-center” numbers is not entirely clear, but reimbursement structures may be biased toward center-based dialysis. Among the perceived barriers, it is apparent that there are a few modifiable ones, which involve a change in attitude and perception, both on behalf of the patient and the provider. Respondents with HHD patients had a view that a significantly higher proportion of patients could be taking on HHD among those in need of renal replacement therapy compared with the ones who did not have HHD patients. It is plausible that the experience of providing HHD begets the modality uptake numbers, and more may need to be done to facilitate contact and sharing best practices between successful units and the motivated ones who do not currently have a program.

The survey has its limitations. One hundred sixty-seven participants chose not to answer the questions pertaining to the actual survey beyond the demographic details. Analysis of this cohort reveals that the majority of “nonresponders” were physicians, practicing clinical nephrology or dialysis medicine and based in Europe. Preferential participation may have introduced bias to the observed findings. Questions based on peritoneal dialysis provision and the experience of physicians in home dialysis therapies were not posed. This is an important area that may expose the lack of knowledge among practicing physicians or a mandated need in the trainee curriculum for this modality education.[31, 32] This was also highlighted in an Australian survey of health care professionals on their views on home dialysis.[32] In addition, majority of respondents were active in Europe, and answers may not reflect widely the prevalent knowledge and the beliefs from other parts of the world, where health care policies are also quite different.

SUMMARY AND CONCLUSION

This report confirms the great deal of interest in home-based HD and widespread belief in extended or frequent HD schedules. However, the survey demonstrates a significant disconnect between belief and practice. Despite the resurgence in interest, the therapy is still not within easy reach of a vast majority of practicing physicians and thereby to the patients they serve. Suboptimal patient preparation pathways, infrastructure limitations, and reimbursement strategies in different health care systems and professional willingness are major factors limiting the therapy. There is an unmet need for research in uptake of dialysis self-management and support systems, sustainable care models, and determinants of intention—behavior model in patients, professionals, and providers to better identify modifiable and nonmodifiable influencers in ESRD. Multi-method studies on these issues are likely to offer such rich, practical knowledge to identify barriers and facilitators to change that will lead to improved patient outcomes on dialysis. Importantly, a generation of nephrologists may lose out to the training opportunities in this field, if knowledge of home-based dialysis is not made an integral part of the training curriculum.

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CHAPTER 3.3

Time to recovery from haemodialysis - location, intensity and beyond

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ABSTRACT

Introduction: Prolonged recovery time (RT) affects patient's quality-of-life adversely. Shorter dialysis RT in home haemodialysis (HHD) noted in observational studies has been attributed to intensive dialysis regimens. Home patients adopt different HD schedules. There is insufficient literature on RT in HHD patients receiving different HD schedules.

Methods: Data was prospectively collected for BASIC-HHD study, a multicentre study of home and hospital HD across 5 tertiary centres in the UK. 288 patients answered the question, 'how long does it take for you to recover from a haemodialysis session?' 91 patients (31.8%) of study population performed home haemodialysis. Participants completed neuropsychometric tests and depression and anxiety screening inventories.

Results: RT is longest amongst 'in-centre' HD recipients (Mean 193 min; SD 295.37) and significantly higher than the mean RT of home HD recipients (Mean 67.3 min; SD 86.8). Within the home setting, RT was not significantly different between the intensive HD and conventional HD (67.8 vs. 66.5 min; $p>0.05$) groups but higher residual urine volumes in the standard home group had significantly shorter RT. Location of HD, not intensity, remained significant ($p=0.001$) in the unadjusted and adjusted multivariable analysis. Longer RT was associated with female gender, unemployed or retired 'work' status, and 'non-white' ethnicity, lower predialysis systolic BP and greater depression screening score.

Conclusions: Home-based HD and higher residual urine volumes are significantly associated with shorter RT. This home advantage for RT may be sustained by preserving residual renal function (in early stages) and increasing HD intensity (in later stages) of dialysis therapy.

INTRODUCTION

Time to recovery from a haemodialysis session for the patient, is the time it takes for the ill-defined feeling of malaise or profound fatigue after a haemodialysis session, which places significant limitations on the physical abilities of the individual, to disappear and for the individual to resume normal activities. The question of ‘recovery time’ has been validated in a Canadian study of 46 patients, with stable reported outcome over time and good test-retest correlation[1]. Recovery time, has been reported in observational research settings but is yet to be used widely in clinical practice.

Post dialysis fatigue or washout, places considerable patient burden on top of treatment regimen, and thus remains an important area of clinical priority and study. The pathophysiology of post dialysis fatigue recovery remains ill-understood, and may not be confined to physiological outcomes of dialysis prescription parameters. The impact of the surroundings in which patients dialyse may also have a bearing on this outcome. Understanding the role of location in ‘home’ vs ‘facility-based’ haemodialysis (HD) is difficult to dissociate from the effects of intensive haemodialysis therapies which are more feasibly deployed in patient’s own homes. The benefits of intensive haemodialysis regimens, are manifold[2]–[5]. The recovery time benefit at home is typically attributed to dose of HD. In a prospective study, increasing the frequency of haemodialysis sessions to 5-7 times per week (and a switch from facility to home-based HD) has been shown to reduce reported recovery time, improve quality of life, and reduce depression[6]. Recent cross-sectional and prospective observational studies on the subject have found associations between recovery time (RT) and health related quality-of-life (HRQOL)[1], [7], depression scores[7], [8], time to first hospitalisation and mortality[8]. In one of the largest cohort studies (DOPPS), RT was suggested as an audit measure for quality of HD therapy; but, was found to be longer in patients receiving longer dialysis (per 30 min) and shorter with extremes of ultrafiltration rates (<5mls/min and >15 mls/min)[8]. Nonetheless, survival benefits with longer dialysis have also been reported in DOPPS[9]. How do we reconcile patient survival with treatment-related patient fatigue?

Recovery time projects the combined physiological and psychological outcome for the patient and therefore deserves a multifaceted approach to its management. This encompasses the impact of treatment (HD) on physical and mental well-being and equally importantly, the role of patient’s affect and altered physiology on the reported outcome. The therapeutic role of improving the psychosocial dimension to changing this outcome measure is an understudied area. This is particularly relevant as recovery time is associated with psychosocial dispositions and understanding these parameters will help deliver targeted treatments.

The study aims to examine RT in home HD recipients and its association with variables beyond dialysis dose intensity. Demographics, clinical parameters, psychometric test outcomes, and dialysis intensity are explored in a large multicentre cohort of home HD patients with variable dialysis schedules and compared against a conventional HD population. We have studied the recovery time question in a representative sample of ‘home’ haemodialysis and ‘facility-based’ HD patients from across five tertiary centres in the UK to report RT in hospital and home HD patients receiving different HD schedules and examine factors which impact RT in home HD favourably.

METHODS

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Study design and setting

The data for the study of ‘time to recovery from HD’ is part of an ongoing programme of research (BASIC-HHD) designed to investigate prospectively, the facilitators and barriers to home haemodialysis (Barriers to successful implementation of care in home haemodialysis)[10] within multicentre renal networks in UK covering a dialysis catchment population of 6.33 million (UKRR, 2014). The study involves 5 UK centres, with variable prevalence rates of home HD. An integrated mixed methodology (convergent, parallel design) has been adopted for this study in a combined cross-sectional and prospective study design. The methodological details and scope of data collected in the BASIC-HHD study has been presented in the protocol paper[10]. Broadly, these include clinical variables, neuropsychometric evaluation of participants and a compilation of questionnaires to include the assessment of affect, autonomy preference and health-related quality of life. Knowledge of English language and visual intactness were required to undertake neuropsychometric tests.

Recovery time study population

The recovery time data are derived from the cross-sectional segment, in which 313 patients were enrolled. Prevalent ‘in-centre’ HD patients were approached if they fulfilled eligibility criteria and were willing to undertake neuropsychometric assessments and complete study specific questionnaires. All home haemodialysis patients from each participating centre were approached and self-care patients, in-centre were excluded from this analysis. In all, 288 patients responded to the recovery time question. Demographic, clinical and laboratory information was ascertained from patients and electronic medical records. Data were also collected on use of medications, including antidepressants and anxiolytics/hypnotics and total pill burden. The question on recovery time was posed at the same time as neuropsychometric evaluation of participants, by a member of the research team. All other questionnaires were completed by hospital dialysis patients whilst on HD, and by home HD patients in their own

homes. Patients were given these to complete, at the end of their cognition tests. The vast majority handed in their completed questionnaires on the same day (hospital HD patients) or handed them to the visiting community renal nurse. The patients were entrusted to complete this if they could do it independently. Where this was not feasible, a member of the research team read the questions to patients and marked patient specified responses.

Patient and HD treatment variables

The vast majority of 'in-centre' HD patients, received three sessions of HD/week (12 hours/week). Home HD patients had variable dialysis prescriptions relating to frequency and duration based on clinical needs and preferences. 30.8% of home HD patients received conventional HD, three times a week. All centres in the study had uniform practice of using dialysate sodium concentrations less than 140mmol/L (136-138mmol/L). Typical ultrafiltration rates were not recorded, but patients had to be stable on HD for inclusion in the study (for cognition assessments). 54% of hospital HD patients received haemodialfiltration, and all other HD patients received high flux haemodialysis. Predialysis blood pressures were obtained from the dialysis records. Standard Kt/V was derived using the Barth model[11]. Residual renal function was obtained from self-reported estimates or based on routine clinical measurements for non-study reasons.

Recovery Time Question

Post-dialysis recovery time was assessed by administering the following question: "How long does it take you typically, to recover from a haemodialysis session?" Responses were documented as suggested by the patient in minutes or hours. Final analysis was considered with RT in minutes.

Study Registration

This study was reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346).

Study instruments

All study participants completed a compilation of questionnaires based on measures of psychosocial factors providing us with a quantitative measure of their psychosocial state. These include measure of depression through the Beck Depression Inventory II[12] and the presence and extent of anxiety through the State and Trait Anxiety Inventory[13]. Tools for objective cognitive assessment include global cognition assessment through the use of the modified mini-mental state examination (3MS)[14], and executive cognitive ability through

the trail making test B (TMTB) scores[15]. These instruments were considered because patient's affect and executive cognitive ability may hypothetically be affected by treatment factors which increase recovery time and patients with different psychological dispositions may report RT differently.

The BDI is a self-report inventory that has been extensively validated and used for measuring depression in various population groups, including ESRD[12]. Although depression in haemodialysis population is well studied, anxiety is also recognised to be a very important problem which may be present independent of other problems or somatised as part of another mental ailment. BDI (0-10, 11-15, 16-20, 21-25, 26-30, 31+), STAI (20-29, 30-39, 40-49, 50+) and 3MS (94-100:1, 86-93:2, 81-85:3, 76-80:4, ≤ 75 :5) scores have been considered in ordered categories for analyses. 3MS categorisation is in the reverse order as mentioned above. It should be noted that a BDI score >15 previously has been shown to be highly predictive of a diagnosis of clinical depression, although the optimal cut-off has remained a debated issue. Questionnaires return rate: Overall completion rate for the recovery time question was 94.2%. The compiled validated questionnaires return rate ranged from 70%-100% for the inventories, across all participating units. The collective valid and complete responses averaged 82%.

Statistical Analyses

All analyses were carried out using SPSS 22. Baseline characteristics between groups were assessed using t-tests, chi-square tests and Mann-Whitney U tests. The conventional two-sided 5% significance level was used. Recovery time is non-normally distributed so a linear transformation was used to normalise it, enabling linear regression models to be used. To identify variables that are associated with time to recovery, each variable of interest was assessed in a single variable analysis. Variables with p-value of 0.10 or less in the single variable analysis were considered for selection in the multivariable analysis. Any variable with greater than 25% missing data was removed at this stage. A multivariable linear regression with a backwards step-wise selection method was used to identify the variables that are associated with recovery time. Multivariable analysis was adjusted for age, dialysis vintage, dialysis intensity and diabetes.

RESULTS

Patient Characteristics

Tables 1 and 2 present patient characteristics of the two study cohorts. Of the 288 patients who responded to the RT question, 91 patients (31.6%) did home HD. The home cohort was significantly younger with a mean age of 52.05 years. These patients were in employment in significantly greater numbers and had a significantly lower Charlson Comorbidity Index (CCI)

score and diabetes. The home patients had a significantly longer dialysis vintage and received significantly longer median dialysis duration per week. Compared to ‘in-centre’ cohort, home patients had significantly higher serum albumin and serum bicarbonate levels and a significantly higher proportion of patients achieved dialysis adequacy of standard Kt/V_{urea}>2.5 (55.4% vs 18.1%).

Table 1: Cohorts Characteristics (Demographics, comorbidities and dialysis parameters)					
		Overall	In-centre	Self-care	p-value
Cohort		288	197 (68.4%)	91 (31.6%)	~
DEMOGRAPHICS					
Age- Mean (std. dev.)		55.00 (13.80)	56.36 (14.44)	52.05 (11.82)	0.008 ¹
Gender	Female	91 (31.6%)	69 (35.0%)	22 (24.2%)	0.066 ²
	Male	197 (68.4%)	128 (65.0%)	69 (75.8%)	
Employment	Retired	121/287 (42.2%)	88/196 (44.9%)	33 (36.3%)	0.004 ²
	Unemployed	89/287 (31.0%)	67/196 (34.2%)	22 (24.2%)	
	Salaried or self-employed	77/287 (26.8%)	41/196 (20.9%)	36 (39.6%)	
Ethnicity	White	252/287 (87.8%)	170/196 (86.7%)	82 (90.1%)	0.42 ²
	Non-white	35/287 (12.2%)	26/196 (13.3%)	9 (9.9%)	
BMI	<25	109/287 (38.0%)	80/196 (40.8%)	29 (31.9%)	0.57 ³
	25-30	90/287 (31.4%)	54/196 (27.6%)	36 (39.6%)	
	≥30	88/287 (30.7%)	62/194 (31.6%)	26 (28.6%)	
CO-MORBIDITIES					
CCI Mean (std. dev.)		4.42 (1.97)	4.63 (2.03)	3.97 (1.76)	0.006 ¹
Diabetes	No	214/286 (74.8%)	135/195 (69.2%)	79 (86.8%)	0.001 ²
	Yes	72/286 (25.2%)	60/195 (30.8%)	12 (13.2%)	
Heart failure	No	274 (95.1%)	186 (94.4%)	88 (96.7%)	0.56 ⁴
	Yes	14 (4.9%)	11 (5.6%)	3 (3.3%)	
Ischaemic Heart Disease	No	215 (74.7%)	144 (73.1%)	71 (78.0%)	0.37 ²
	Yes	73 (25.3%)	53 (26.9%)	20 (22.0%)	
Dialysis Vintage in years Median (IQR)		2.81 (1.26, 5.43)	2.68 (1.05, 5.12)	3.47 (1.39, 6.82)	0.057 ⁵
HD Vintage: Median (IQR)		2.35 (0.97, 4.78)	2.18 (0.70, 4.60)	2.91 (1.36, 5.26)	0.017 ⁵
Dialysis per week – (hours/week) Median (IQR)		12.00 (12.00, 13.50)	12.00 (12.00, 12.00)	15.00 (12.00, 19.25)	<0.001 ⁵
Dialysis intensity	≤3 per week	223 (77.4%)	195 (99.0%)	28 (30.8%)	<0.001 ²
	>3 per week	65 (22.6%)	2 (1.0%)	63 (69.2%)	
SBP	≤115	46/283 (16.3%)	39/192 (20.3%)	7 (7.7%)	0.007 ²
	>115	237/283 (83.7%)	153/192 (79.7%)	84 (92.3%)	
DBP	≤85	212/283 (74.9%)	141/192 (73.4%)	71 (78.0%)	0.41 ²
	>85	71/283 (25.1%)	51/192 (26.6%)	20 (22.0%)	
HD Type	HD	182 (63.2%)	91 (46.2%)	91 (100%)	<0.001 ²
	HDF	106 (36.8%)	106 (53.8%)	0 (0%)	
Residual urine volume (per 100ml/day) Median (IQR)		0.80 (0, 5.00)	1.00 (0, 5.00)	0 (0, 5.00)	0.17 ⁵

¹independent samples t-test with unequal variances

²Pearson chi-square test

³Chi-square linear trend test

⁴Fisher’s exact test

⁵Mann-Whitney U test

BMI: Body mass index; CCI: Charlson Comorbidity Index; SBP: Systolic Blood Pressure; DBP: Diastolic Blood Pressure; HD: Haemodialysis; HDF: Haemodiafiltration

		Overall	In-centre	Self-care	p-value
Cohort		288	197 (68.4%)	91 (31.6%)	~
LAB PARAMETERS					
Hb	<9	16 (5.6%)	12 (6.1%)	4 (4.4%)	0.56 ²
	≥9	272 (94.4%)	185 (93.9%)	87 (95.6%)	
Alb	<30	28/287 (9.8%)	25 (12.7%)	3/90 (3.3%)	0.013 ²
	≥30	259/287 (90.2%)	172 (87.3%)	87/90 (96.7%)	
Bic	<22	78/283 (27.6%)	66 (33.5%)	12/86 (14.0%)	<0.001 ³
	22-28	180/283 (63.6%)	124 (62.9%)	56/86 (65.1%)	
	>28	25/283 (8.8%)	7 (3.6%)	18/86 (20.9%)	
PTH - Median (IQR)		35.75 (17.75, 61.43)	35.53 (15.80, 60.70)	37.35 (18.59, 70.35)	0.52 ⁵
Std Kt/V	≤2	41/274 (15.0%)	34/191 (17.8%)	7/83 (8.4%)	<0.001 ³
	(2, 2.5]	152/274 (55.5%)	122/191 (63.9%)	30/83 (36.1%)	
	(2.5, 3]	50/274 (18.2%)	35/191 (18.3%)	15/83 (18.1%)	
	>3	31/274 (11.3%)	0/191 (0%)	31/83 (37.3%)	
URR	≤65	58/278 (20.9%)	30/193 (15.5%)	28/85 (32.9%)	<0.001 ³
	(65, 75]	108/278 (38.8%)	74/193 (38.3%)	34/85 (40.0%)	
	>75	112/278 (40.3%)	89/193 (46.1%)	23/85 (27.1%)	
Phosphate	<1.1	43 (14.9%)	29 (14.7%)	14 (15.4%)	0.57 ³
	1.1-1.7	132 (45.8%)	88 (44.7%)	44 (48.4%)	
	>1.7	113 (39.2%)	80 (40.6%)	33 (36.3%)	
Serum Sodium	≤135	58 (20.1%)	42 (21.3%)	16 (17.6%)	0.016 ³
	136-140	153 (53.1%)	113 (57.4%)	40 (44.0%)	
	>140	77 (26.7%)	42 (21.3%)	35 (38.5%)	
PSYCHOLOGICAL PARAMETERS					
Antidepressant use (Yes)		46/287 (16.0%)	33/196 (16.8%)	13 (14.3%)	0.58 ²
BDI	0-10	131/265 (49.4%)	87/181 (48.1%)	44/84 (52.4%)	0.67 ³
	11-15	47/265 (17.7%)	31/181 (17.1%)	16/84 (19.0%)	
	16-20	25/265 (9.4%)	19/181 (10.5%)	6/84 (7.1%)	
	21-25	27/265 (10.2%)	21/181 (11.6%)	6/84 (7.1%)	
	26-30	18/265 (6.8%)	13/181 (7.2%)	5/84 (6.0%)	
	≥31	17/265 (6.4%)	10/181 (5.5%)	7/84 (8.3%)	
STAI State	20-29	91/249 (36.5%)	58/169 (34.3%)	33/80 (41.3%)	0.63 ³
	30-39	71/249 (28.5%)	52/169 (30.8%)	19/80 (23.8%)	
	40-49	56/249 (22.5%)	38/169 (22.5%)	18/80 (22.5%)	
	≥50	31/249 (12.4%)	21/169 (12.4%)	10/80 (12.5%)	
STAI Trait	20-29	69/246 (28.0%)	44/166 (26.5%)	25/80 (31.3%)	0.94 ³
	30-39	79/246 (32.1%)	56/166 (33.7%)	23/80 (28.7%)	
	40-49	52/246 (21.1%)	37/166 (22.3%)	15/80 (18.8%)	
	≥50	46/246 (18.7%)	29/166 (17.5%)	17/80 (21.3%)	
PCS		n=201 33.84 (10.46)	n=132 32.83 (10.54)	n=69 35.77 (10.09)	0.059 ⁶
MCS		46.57 (11.80)	46.48 (11.81)	46.74 (11.85)	0.88 ⁶
3MS	≤75	11/261 (4.2%)	10/184 (5.4%)	1/77 (1.3%)	0.004 ³
	76-80	10/261 (3.8%)	7/184 (3.8%)	3/77 (3.9%)	
	81-85	26/261 (10.0%)	22/184 (12.0%)	4/77 (5.2%)	
	86-93	103/261 (39.5%)	78/184 (42.4%)	25/77 (32.5%)	
	94-100	111/261 (42.5%)	67/184 (36.4%)	44/77 (57.1%)	
TMT B Median (IQR)		n=217 90.0 (69.5, 130.0)	n=137 109.0 (71.5, 146.0)	n=80 74.0 (61.0, 94.8)	<0.001 ⁵
TMT A Median (IQR)		n=266 43.0 (32.0, 60.0)	n=182 48.0 (35.0, 70.0)	n=84 36.0 (30.0, 47.5)	<0.001 ⁵

PTH: Parathyroid Hormone; URR: Urea Reduction ratio; BDI: Beck Depression Inventory; STAI: State and Trait Anxiety Inventory; PCS: Physical Component Score; MCS: Mental Component Score; 3MS: Modified Mini Mental State; TMT: Trail Making Test

Recovery time

Figure 1 presents the median and mean RTs for the two study groups (In-centre vs. Home) and also in groups based on dialysis intensity (standard vs. intensive HD recipients). It is greatest for the in-centre HD recipients (Mean 193 min; SD 295.37). Home HD recipients reported mean RT of 67.3 minutes (SD 86.8). Recipients of intensive HD (>3 sessions/week), reported shorter RT (Mean 72.1min; SD 94.7) compared to conventional HD recipients (Mean 177.1min; SD 281.9). But this difference was not evident within the home cohort (67.8-intensive HD vs. 66.5-conventional HD). Figure 2 shows the actual patient numbers on different home HD schedules presented by frequency and duration.

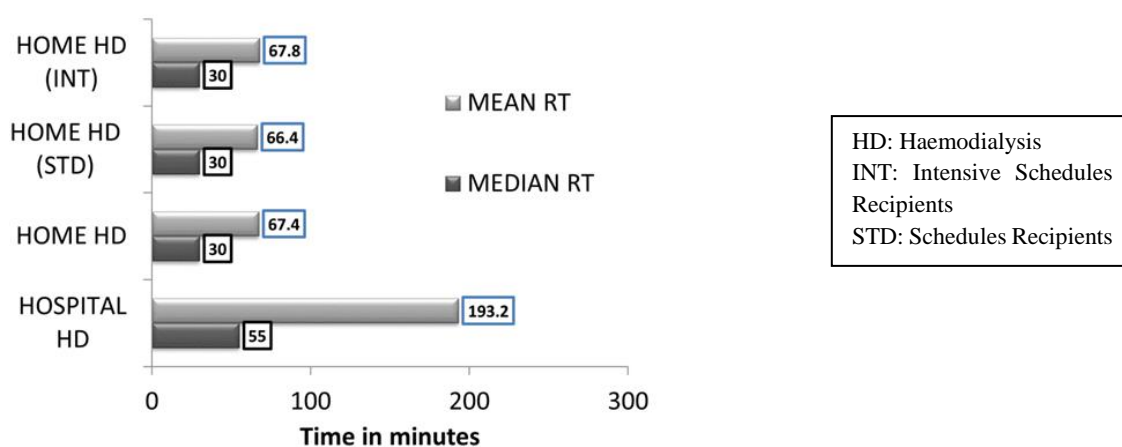


FIGURE 1: Median and Mean recovery times in the study groups

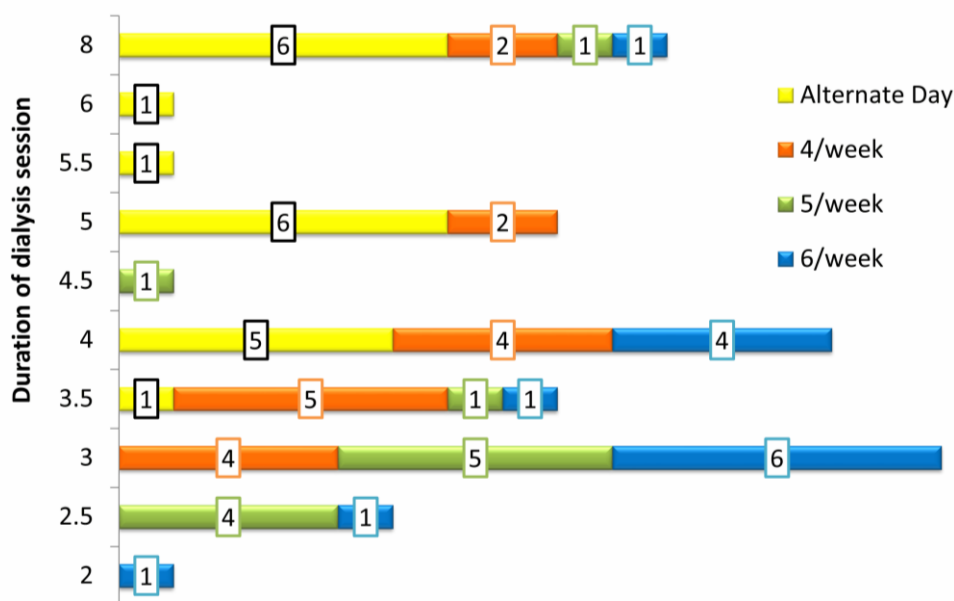


FIGURE 2: Number of patients in receipt of the different home haemodialysis schedules

Table 3: Single Variable Analysis (Combined group)			
		Estimated Marginal Mean (95% CI)	p-value
Age (per ten years) *		1.132 (0.994, 1.289)	0.062
Diabetes	No	50.09 (40.66, 61.71)	0.083
	Yes	72.32 (50.47, 103.61)	
Dialysis vintage in years (per year)*		1.015 (0.978, 1.052)	0.43
Dialysis intensity	≤3	63.03 (51.50, 77.14)	0.006
	>3	34.51 (23.73, 50.17)	
Cohort	In-centre	70.35 (56.92, 86.96)	<0.001
	Home	32.31 (23.65, 44.12)	
Gender	Male	44.61 (36.03, 55.23)	0.001
	Female	86.62 (63.27, 118.59)	
Employment	Retired	72.03 (54.74, 94.78)	0.011
	Unemployed	54.66 (39.69, 75.28)	
	Salaried/self-emp.	36.67 (25.99, 51.73)	
CCI (per score increase)*		1.096 (0.998, 1.203)	0.056
Heart failure	No	52.71 (43.88, 63.32)	0.038
	Yes	127.25 (56.54, 286.40)	
Residual urine volume (per 100ml/day)		0.955 (0.922, 0.989)	0.010
Alb	<30	106.58 (60.21, 188.65)	0.018
	≥30	51.70 (42.85, 62.37)	
Std Kt/V	≤2	57.40 (35.76, 92.14)	0.047
	(2, 2.5)	66.74 (52.19, 85.33)	
	(2.5, 3)	58.53 (38.13, 89.85)	
	>3	28.18 (16.35, 48.57)	
URR	≤65	42.53 (28.52, 63.43)	0.069
	(65, 75)	50.29 (37.52, 67.41)	
	>75	72.28 (54.21, 96.36)	
SBP	≤115	100.99 (64.74, 157.54)	0.003
	>115	48.39 (39.78, 58.87)	
BDI (categorical, included as a linear variable) *		1.134 (1.009, 1.274)	0.036
PCS (per unit)*		0.968 (0.948, 0.988)	0.002
HD type	HD	46.43 (37.10, 58.10)	0.015
	HDF	73.64 (54.88, 98.80)	
Antidepressants	No	50.46 (41.49, 61.37)	0.032
	Yes	86.22 (55.08, 134.96)	
Pill burden (per drug) *		1.066 (1.004, 1.132)	0.037

*The parameter estimate is the impact of the variable on (Recovery time + 5) and is multiplicative i.e. >1 relates to an increase in (Recovery time+5) and <1 relates to a decrease in (Recovery time+5)

CCI: Charlson Comorbidity Index; SBP: Systolic Blood Pressure; HD: haemodialysis; HDF: Haemodiafiltration; URR: Urea Reduction Ratio; BDI: Beck Depression Inventory; PCS: Physical Component Summary

Single variable analysis

Table 3 depicts the outcome of the single variable analysis in the combined cohorts. To make the recovery time variable approximately normally distributed, a transformation was required. The new variable is the natural logarithm of the time in minutes plus five. In the unadjusted univariate analysis of the combined group analysis, higher age, presence of diabetes and heart failure, greater CCI score, conventional dialysis intensity, and female gender were associated with significantly longer post-haemodialysis recovery times at the 10% level. Every 100ml increase in residual urine volume, pre-dialysis systolic blood pressures >115mmHg and HD as against HDF modality were significantly associated with shorter reported recovery times.

Weekly standard Kt/V_{urea} between 2 and 2.5 was associated with longer reported recovery times. Higher BDI category, current intake of antidepressant medications and greater pill burden were also associated with longer reported RTs.

Multivariable Analysis

Table 4 depicts the significant variables on multivariable analysis. Variables with significance of up to $p=0.10$ in the univariate analysis were included in the model. Group to which the patient belonged, remained significant after inclusion of other variables in the model. Demographic characteristics such as female gender, unemployed or retired ‘work’ status, and ‘non-white’ ethnicity were associated with longer recovery time. Lower predialysis systolic blood pressure and greater depression screening score category also related to longer reported recovery times. Higher residual urine volume was associated with shorter RT. Variables which emerged significant in the multivariable analysis were explored further within the subgroups. The modifiable variables include residual urine volume, predialysis systolic blood pressure, and self-reported depression screening category.

Table 4: Multivariable Analysis (Combined group)		
MODEL-1(UNADJUSTED)	Exponentiated parameter estimate (95% CI) *	p-value
Group (In-centre HD compared to Home HD)	1.993 (1.329, 2.989)	0.001
Gender (Male compared to female)	0.613 (0.409, 0.918)	0.018
Employment (Retired compared to salaried/self-emp.) (Unemp. compared to salaried/self-emp.)	1.704 (1.064, 2.729) 1.070 (0.641, 1.787)	0.036
Ethnicity (White compared to non-white)	0.519 (0.286, 0.940)	0.031
Systolic blood pressure (≤ 115 compared to >115)	1.701 (1.029, 2.810)	0.038
Residual urine volume (per 100ml/day)	0.956 (0.923, 0.991)	0.014
Ordinal BDI (per category increase)	1.129 (1.007, 1.265)	0.038
MODEL-2 (ADJUSTED**)	Exponentiated parameter estimate (95% CI) *	p-value
Diabetes (No diabetes compared to diabetes)	0.761 (0.490, 1.182)	0.22
Dialysis intensity (≤ 3 sessions compared to >3 sessions)	0.975 (0.511, 1.860)	0.94
Group (In-centre HD compared to Home HD)	1.915 (1.056, 3.474)	0.033
Gender (Male compared to female)	0.586 (0.398, 0.863)	0.007
Predialysis systolic blood pressure (≤ 115 compared to >115)	2.036 (1.227, 3.377)	0.006
Age (per ten years)	1.089 (0.949, 1.249)	0.22
Dialysis vintage (per year)	1.027 (0.989, 1.066)	0.17
Ordinal BDI (per category increase)	1.136 (1.015, 1.270)	0.026

*The parameter estimate is the impact of the variable on (Recovery time + 5) and is multiplicative i.e. >1 relates to an increase in (Recovery time+5) and <1 relates to a decrease in (Recovery time+5)

** Adjustment for age, dialysis vintage, dialysis intensity and diabetes
Ordinal BDI (Beck Depression Inventory) categories: 0-10, 11-15, 16-20, 21-25, 26-30, ≥ 31

Residual Urine Volume

Residual urine volume is a significant predictor of reported recovery time in the multivariable analyses and in the ‘in-centre’ subgroup analysis (Figure 3). It is not however significant in the ‘home’ cohort analysis. Dialysis intensity is a plausible mediator of this outcome. Therefore ‘standard HD group’ vs ‘intensive HD group’ analysis was carried out and residual urine volume emerged as a significant predictor of shorter RT in recipients of conventional HD ($p=0.003$). Within the home cohort too, this effect was maintained ($p=0.04$). No relationship was found in the intensive HD group, between residual urine volume and recovery time ($p=0.89$).

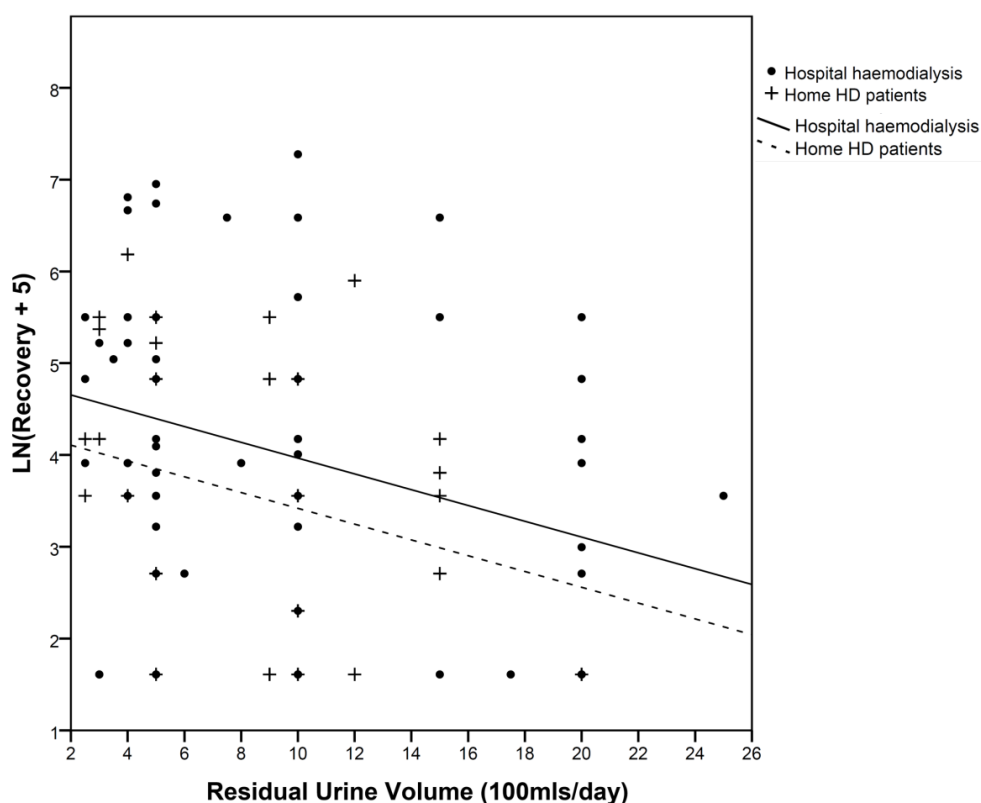


FIGURE 3: Scatter plot of residual urine volume and its association with RT in hospital ($n=65$) and home haemodialysis ($n=33$) recipients in patients with residual urine volume >200 mls/day.

Predialysis systolic blood pressure (SBP)

SBP was included as a dichotomous variable with the cut-off at 115. With SBP in this format, 79.7% of ‘in-centre’ patients had higher SBP (>115) and 92.3% of ‘home’ HD patients had higher SBP ($p=0.007$). We investigated if the association of the predialysis systolic blood pressure with RT is mediated by the Charlson Comorbidity Index (to include diabetes and heart failure). In the multivariable model, SBP remained significant at the 5% level ($p=0.02$).

after additionally adjusting for age ($p=0.21$) and CCI ($p=0.16$). In a model where CCI replaced SBP, CCI was not a significant variable in the model, suggesting the lack of any significant relationship with SBP ($p=0.57$). Additionally, both SBP ($p=0.002$) and CCI ($p=0.03$) were significant in a model with just these variables, suggesting an independent association with RT. In the home cohort, there doesn't appear to be a relationship between dialysis intensity and SBP, but with extremely small numbers of patients with low SBP, meaningful statistical analyses are difficult. There does not appear to be a relationship between SBP and residual urine volume in the combined group ($p=0.41$) or in the 'in-centre' group ($p=0.69$).

Beck Depression Inventory category

There is no significant difference between groups with respect to BDI scoring and antidepressant drug use. BDI is consistently associated with reported recovery time in the total study cohort and in the home sub group analysis. However, in the in-centre group, antidepressant use has a significant association with RT outcome. Statistically, there is an association between BDI category and anti-depressant drug use. The two variables are related and only one can be included in the model dependent on the group and the relationship with recovery time and other covariates in the respective final models. Using a cut-off method, with a score greater than 15 indicating depression, 34.8% of the in centre group and 28.6% of the home group have a high BDI score. Even after employing a cut-off method of categorising BDI scores, the relationship between BDI scores and anti-depressant use remains. More patients with diabetes are on drugs with anti-depressant properties, though the primary indication for their prescription is not related to depression. In our study, a higher percentage of those with diabetes took anti-depressants (22.2%) compared to those without diabetes (14.1%) in both the combined group and the 'in-centre' group (23.3% vs 14.2%) although the difference was not statistically significant ($p=0.10$ and $p=0.12$ respectively). The association of the antidepressants variable with RT remained significant at the 5% level after adjusting for diabetes ($p=0.04$). In the home subgroup, there is no statistically significant relationship between dialysis intensity and BDI ($p=0.44$). BDI remains significantly associated with RT in the conventional HD subgroup ($p=0.05$) and not so within the intensive HD subgroup ($p=0.09$).

Recovery time and cognitive outcomes

We examined the impact of recovery time on cognitive outcomes of individuals. The supposed pathophysiological mechanism of intradialytic haemodynamic instability underlying longer recovery time is also shared by cognitive dysfunction in haemodialysis recipients. In the dataset examined (using actual and imputed cognitive test scores), no significant association was found between recovery time and tests of global cognitive function (3MS; $p=0.27$) and

executive brain function (TMT B; $p=0.85$). This lack of association was maintained even in the subgroup analyses.

DISCUSSION

Recovery time as an outcome measure is of primary importance to patients and caregivers[1], [8]. Its association with hard outcomes is likely to be a function of the composite of physical and mental health status of individuals. Its utility as a surrogate outcome measure may come in course of time when we understand interventions which may impact change in this reported outcome measure. In previously conducted prospective studies of switch from hospital (conventional) to home (intensive) therapies, the lack of a comparator arm, makes observation of the effect of ‘location’ on reported RT, difficult to appreciate[6]. Whilst it is acknowledged that a cross-sectional study design does not lend itself to causal inferences, the possibility of exploring other variables of interest and investigating the findings in larger, well-designed studies remains. The study sample from five UK centres is representative of the general haemodialysis population, both ‘in-centre’ and at ‘home’. We have examined BDI scores in 5 categories and then as a linear variable, so as to not lose information that can be ascertained from scores further removed from the cut-off point. Given the perceived shared pathophysiology of prolonged recovery time and cognitive deficits in haemodialysis patients, we have also examined the impact of RT on cognitive outcomes of individuals. We have purposefully elicited an open response without prompts to the question on RT, and not considered them in categories so as to understand the patient-perceived significance of so-called ‘shorter’ or ‘longer’ recovery time in home haemodialysis.

Home v Hospital HD

In the unadjusted and adjusted multivariable analysis of the cohort of 288 patients, the location of the patient receiving HD is a significant outcome, when considered with other co-variables in the model, as it is acknowledged that the home cohort is likely a relatively healthier population. Typically, there are the often unmeasured aspects of hospital dialysis provision, including ‘waiting’ for transport, inconsistency of timings for pick-up and drop-off and including the physical and emotional experience of travel to and from the unit, three times a week[16]. Do patients factor these in when reporting RT? Does this effectively exacerbate the fatigue induced by the treatment itself? Whilst it may not be systematically captured in the RT question, it may not be ignored. It is logical to assume that physical health benefits of longer or frequent HD therapies may reduce postdialysis fatigue, but this is not borne out in our observation of the home conventional and home intensive HD recipients. The perceived ‘quality time’ in the interdialytic period, is a complex patient-specific parameter. Both

subgroups within the home cohort report similar post-dialysis RT, suggesting that location over and above dialysis intensity and other variables may have some role to play. Qualitative studies capture the ‘freedom’ and ‘flexibility’ afforded by home haemodialysis[17], [18]. In this context the intensity schedule of hemodialysis at home that best affords interdialytic ‘quality time’ and enhanced physical well-being remains to be understood. Dialysis schedules at home are often determined by patients themselves. It is possible that the home location lends itself to flexibility that allows patients to naturally opt for dialysis schedules that optimise recovery times.

Residual urine volume

Amongst the physiological parameters, residual urine volume appears to have a significant association with reported recovery time in recipients of conventional HD, both ‘in-centre’ and at ‘home’. The effect is greater in patients with larger residual urine volumes. It appears that the effect of loss of residual urine volume is perhaps mitigated by increasing dialysis intensity, suggested by similar reported recovery times in the two subgroups of the ‘home’ cohort, with greater mean residual urine volume in the conventional HD ‘home’ cohort. This also suggests that the effect of volume management during a typical 4-hour long HD session (ultrafiltration rate), plays an important role in the reported RT. The DOPPS study reported a reduction in RT with ultrafiltration rates (UFR) >15mls/kg/hr and a U-shaped association with UFR, even after adjustment for residual kidney function[8]. This paradoxical observation of shorter RT with rapid intradialytic weight loss deserves further investigation and has not been possible in our study due to lack of information on UFR.

Solute clearance and blood pressure parameters

The impact of time-averaged solute clearance may also be important in this context. This is seen in the single variable analysis where shorter RT was associated with larger standard Kt/V_{urea} and with relatively smaller sessional URRs (indicating short daily HD). We explored the relationship between predialysis systolic blood pressure and reported RT and investigated comorbidity index as a potential mediator. However, no consistent observations were found. This suggests that predialysis SBP <115mmHg was likely independently associated with longer reported RT. This is amenable to intervention in some instances in dialysis practice. As highlighted earlier (results), there is no relationship in this dataset between SBP and residual urine volume in the cohorts overall and within subgroups. In the DOPPS study Δ SBP was ascertained as the difference between pre and post dialysis BP and was not associated with recovery time (OR 1.00)[8].

Psychosocial states

Recovery time in our data had a significant association with BDI score category, in the multivariable analysis of study cohort and emerged as the only significant variable within the home subgroup. Within the home cohort, the adjusted (age, diabetes, dialysis intensity and dialysis vintage) and unadjusted single variable analysis shows a significant association of RT with both BDI and Anxiety Trait score. Anti-depressant use was a significant predictor of longer reported RT in the 'in-centre' cohort. In the exploratory analyses, antidepressant drug use was statistically related to BDI category. This finding was also noted in a Brazilian cohort study of hospital HD patients. Data indicated poorer HRQOL and higher depression probability for some patients despite shorter time needed to recover from haemodialysis[7]. Therefore, reported RT may not explain perceived quality-of-life or mental health disposition in entirety. The FREEDOM study (n=128 for the follow-up) reported a halving of the BDI score and a near 10-fold decrease in median postdialysis RT over a 12-month period in the subgroup of severely depressed hospital HD patients who switched to daily HD therapy at home. But the improvement in depression scores may not be attributed to improvement in RT. It must also be borne in mind that a higher BDI score was the only variable associated with a trend toward study discontinuation and thereby of failure to switch from 'in-centre' to 'home' HD therapy for daily HD[6]. This bidirectional association of depression screening scores with reported recovery time are difficult to disentangle from cross-sectional study designs. The impact of depression treatment on RT and of shortened RT on affect needs to be examined in specific interventional studies.

Demographics

In our data, age has no significant association with reported RT. Although surprising, this finding has been reported elsewhere too[7]. Male gender, full time employment and white ethnicity background in our study cohort are the significant demographic factors associated with shorter reported RT. The former two have been identified as significant associations in other observational studies too[7], [8].

There are methodological limitations to this study. As in any observational study, unmeasured confounding or other sources may bias the observed associations. Besides, lack of systematic ascertainment of information on ultrafiltration rate and intradialytic weight loss are significant limitations.

CONCLUSION

Recovery time from haemodialysis is often a quality-of-life limiting clinical problem for the patient. This study demonstrates that location (home) of HD and residual urine volumes have significant advantage on recovery times in haemodialysis recipients. The recovery time

benefit may be maximised in HHD by balancing dialysis intensity with preserving residual renal function. RT benefit can be a powerful patient and clinical driver for uptake of all forms of home HD as the first choice HD modality and should be encouraged. Dialysis prescription variables and proactive management of psychosocial issues which may positively impact recovery time need to be explored further in interventional studies.

Author's contributions

Research idea and Study design: AJ, SM, PB, AW; Data acquisition- from all centres under supervision of the PIs of the BASIC-HHD study group (Salford Royal NHS Trust - PI: Dr. Grahame Wood, Portsmouth Hospitals NHS Trust - PI: Dr. Juan Mason, University Hospital of North Staffordshire- PI: Dr. Sat Reddy, Ipswich Hospitals NHS Trust- PI: Dr. Praveen Ande); Data analysis/Interpretation: AJ, PF, SM. Each author has contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring all aspects of the work are accurately reported. SM takes responsibility that all study aspects are reported with honesty and transparency. All authors read and approved the final manuscript.

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CHAPTER 3.4

Social deprivation and socio-demographic influences on home haemodialysis prevalence in the UK

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ABSTRACT

Background: In the UK, socioeconomic disadvantage has been associated with lower use of home dialysis, mostly peritoneal dialysis. We explore the role of patient's socio-demographic, socio-economic differences and the centre's influence on home haemodialysis (HD) prevalence.

Methods: Data are derived from the cross-sectional arm of the UK multicentre study investigating barriers and enablers of home HD (BASIC-HHD study). Two centres each were allocated to low (<3%), and medium prevalence groups (5-8%) and one to high prevalence group (>8%). Sociodemographic information and index of multiple deprivation (IMD) ranks were ascertained from electronic records and Ordnance survey datasets, respectively. Patients were enrolled in hospital HD (n=213), home HD (n=93) and predialysis groups (n=222).

Results: 'Centre' to which the patient belonged was significantly associated with patient's modality in prevalent HD groups and modality-choice in the 'predialysis' group, in a confounder-adjusted multivariable analysis. Non-white ethnicity meant significantly lower odds of choosing a self-care dialysis modality in the predialysis stage (OR 0.21, CI 0.07, 0.62) and lower odds of home haemodialysis therapy in prevalent haemodialysis groups (OR 0.40, CI 0.14, 1.13). Other significant socio-demographic predictors of home HD group prevalence include, lower age (p=0.01), higher education (p=0.01), home ownership (p<0.01), childcare responsibility (p=0.02) and unrestricted mobility (p=0.03).

Conclusion: Centre effect accounts for much of the variation between centres in terms of home HD prevalence, even after accounting for sociodemographic factors, area-level socioeconomic indices and comorbidities. Unit practices and attitudes to home HD are likely to have a dominating impact on home HD prevalence rates and these need to be explored systematically at the organisational level.

INTRODUCTION

There is increasing burden of chronic kidney disease (CKD) worldwide[1]. For the management of end stage renal disease, home dialysis therapies provide advantages for both patients and service providers. Compared with ‘in-centre’ dialysis, both peritoneal dialysis (PD) and home haemodialysis (home HD) are more economical and offer better quality-of-life for patients[2-6]. PD is associated with comparable survival and home HD offers comparable or even better survival than ‘in-centre’ HD[7-11]. Home HD typically attracts a demographically homogenous cohort of patients, but this may be quite diverse in a PD context. The two home-based modalities are to be seen as complementing each other in the patient’s renal replacement therapy (RRT) journey. Over the years, home HD prevalence has been a small proportion of dialysis therapies undertaken by patients. Understanding barriers to uptake of home HD may enable changes that improve patient care and reduce service delivery costs.

Socioeconomic discrepancies in the uptake of home HD exist in different parts of the world. In the USA, full-time employment and Caucasian race were associated with greater home HD use[12]. However, in Australia with much greater prevalence of home haemodialysis population, socioeconomic status was not associated with its uptake[13]. In the United Kingdom, the prevalence of home HD is variable and ranges from 0% to 14% of the total unit’s dialysis population[14]. In a UK-wide ecological study, a third of the regional variation in renal replacement therapy incidence between areas could be explained by the demographic, health and access to health services factors[15]. Also, the proportion of incident dialysis patients on a home-based treatment within 1 year of starting dialysis was associated with the socio-economic status of individuals. Socio-economic disadvantage was associated with a lower use of home dialysis in this study independent of the effects of race and primary renal disease[16]. This knowledge is important but, combining PD with HHD, does not allow the teasing out of factors which may be implicated as barriers for one or the other form of dialysis. The physical demand for space and intellectual, cognitive and technical skill demands from patients for home HD performance are significantly greater than that for PD. The National Institute for Health and Clinical Excellence (NICE) recommended in 2002, that up to 15% of dialysis patients in a unit could receive home haemodialysis[17]. Nationally, more than a decade later, this objective is yet to be realised but the trend is promising.

The aims of the study are

- a. To examine the effect of ethnicity, area-level socioeconomic index (Index of Multiple Deprivation) and ‘centre influence’ on home haemodialysis uptake in the prevalent haemodialysis population.

- b. To examine the effect of ethnicity, area-level socioeconomic index (Index of Multiple Deprivation) and 'centre influence' on home dialysis modality choice amongst predialysis patients.

METHODS

Study design

The BASIC-HHD study is a mixed-methods, multicentre, combined cross-sectional and prospective observational study. The investigation of social deprivation and sociodemographic factors influencing the choice of location of haemodialysis is one aspect of a larger study designed to investigate the facilitators and barriers to home haemodialysis. An integrated mixed methodology (convergent, parallel design) has been adopted for this study. The methodological details and scope of data collected in the BASIC-HHD study has been presented in the protocol paper[18]. Broadly, these include clinical variables, neuropsychometric evaluation of participants and a compilation of questionnaires to include assessment of affect, autonomy preference, health-related quality-of-life and patient and carer interviews. Knowledge of English language and visual intactness were required to undertake neuropsychometric tests.

Study Registration

This study was reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) in 2012. Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346).

Study setting

The study involves five UK tertiary renal centres in different geographic regions, covering a dialysis catchment population of 6.33 million (UKRR, 2014). By design, the centres recruited into the study, have variable prevalence of HHD and categorised in low (<3%), medium (5-8%) and high (>8%) prevalence centres. This heterogeneity provides an important backdrop to the study setting allowing the study of patient characteristics within a range of centre practice patterns, which might influence the local adoption of this modality. The centres in the study have been chosen on the basis of UK Renal Registry information on the home HD prevalence as of June 2010 and include two 'low', two 'medium' and one 'high' prevalence centre. In this study, low prevalence centres include A and C; medium prevalence are D and E and high prevalence is centre B.

Study Participants

Participants were enrolled from 'predialysis' clinics, for the CKD-5 group. Eligible patients (determined by inclusion criteria) were approached consecutively, to achieve the recruitment target at each centre[18]. Prevalent 'in-centre' HD patients were approached if they fulfilled

eligibility criteria and were willing to undertake neuropsychometric assessments and complete study specific questionnaires. All self-care haemodialysis patients (93% at home) from each participating centre were approached. For the purpose of this study, patients doing self-care HD but based in-centre have been excluded, to keep the study population homogenous.

Variables and measurement

Independent variables considered include, demographic factors including age, gender, ethnicity, patient employment, marital status, childcare, first language, smoking status, mobility, BMI, informal care giver, accommodation, distance of home from training centre, previous PD and transplantation and visual intactness have been considered. Clinical variables include cause of primary renal disease, Charlson Comorbidity Index (CCI), comorbidities such as heart failure, diabetes and dialysis vintage.

Socioeconomic Deprivation Index

Deprivation data for individual postcodes were determined using Index of Multiple Deprivation, 2010. This deprivation dataset covers all of England and is reported at the Lower Super Output Area (LSOA) level, of which there were more than 32,000 with an average population of 1,614 at the time of the 2011 Census. In order to assign a deprivation rank to each observation, a spatial join was performed in QGIS 2.10 (open source GIS software) so that a new file was generated which contained individual observation details (such as home/hospital haemodialysis) and deprivation rank and quintile. The maps divide the Indices of Deprivation into quintiles, so that ranks from 1 to 6,496 are in the most deprived 20% of England, with equally-sized categories for the other quintiles. Index of multiple deprivation was chosen over Townsend Index as IMD covered 7 key areas which would map well with home treatment uptake (Income/employment/health deprivation/education skills/barriers to housing and services/crime and living environment).

Missing data

Missing information for the majority of datasets pertinent to this study was <5%. Partner employment data was available in <50% of cases and has not been considered for analysis. In the predialysis cohort, 206/222 (92.8%) provided a modality choice. 94.2% and 93.8% of patients provided childcare data in the predialysis and haemodialysis cohorts respectively.

Bias

The inclusion of patients who could participate in cognitive assessments lends itself to inclusion bias. Every patient who could understand English language in the clinic were approached for recruitment. This would imply that the healthier, literate patients may have been preferentially included in the study. This could be a potential limitation.

Statistical Analyses

For single variable, between centre comparisons, chi-squared tests were used for categorical data, while continuous variables were assessed using one-way ANOVAs when the data

distribution was normal and Kruskal-Wallis tests when the data distribution was not normal. Group comparisons – modality in the haemodialysis group and modality choice in the predialysis cohort – were assessed using chi-squared tests, Fisher's exact tests, t-tests and Mann-Whitney U tests, as appropriate.

Confounders of the centre-modality relationship were identified and included in a multivariable logistic regression analysis with haemodialysis modality as the dependent variable and centre as the independent variable. A variable was classed as a confounder if: associated with the dependent variable, associated with the independent variable of interest and not a direct effect of the independent variable of interest i.e. not on the causal pathway (reference - Confounding: What it is and how to deal with it, Jager et al., 2008). The ethnicity-modality relationship was assessed in the same way. A final model was examined that included both centre and ethnicity and any confounders of their relationships with haemodialysis modality. In the predialysis cohort, the same relationships were examined in the same way but modality choice was now the dependent variable.

Sensitivity analyses were performed that removed variables associated with IMD from the confounder model. Modality choice, the dependent variable in the predialysis cohort, was considered as home/PD vs hospital and as home vs hospital/PD. A subgroup analysis only including predialysis patients who chose home or hospital was performed.

The relationships and interactions between IMD, ethnicity and modality were explored to identify any relevant associations. This included examining the relationship between IMD and ethnicity in the different modalities in the haemodialysis and predialysis cohorts and also including an interaction term in the multivariable logistic regression models.

Analyses were performed using SPSS 22. A two-sided 5% significance level was used throughout the paper.

RESULTS

Haemodialysis groups

Distribution of patient characteristics by centre

This is presented in [Appendix S1](#). The five study centres had variable prevalence of home haemodialysis (by design: A/C-low prevalence; B: high prevalence; D/E: medium prevalence). Mean age of patients across the centres ranged from 50.4-57.8 yrs. Ethnic minority patient proportion was highest in centre B (high prevalence) at 23.9% (p=0.002). Patients who achieved post high-school level of education was significantly low in centre C (1.9%; p<0.001). There was a significant difference between groups with respect to salaried status of individuals and self-employment with highest levels in centre C compared to centres A/D and E. IMD rank distribution across the centre catchment areas was significantly different

between centres ($p<0.01$). Greatest proportion of home owners belonged in centre C (86%), with an average proportion elsewhere of 58%. The median training centre distance-calculated as the distance between the patient's residence and the main training unit- was significantly greater in centre C (15.1 miles; $p<0.001$). Comorbidity indices and diabetic nephropathy as causes of ESRD in patients, were not significantly different between study centres.

Patient characteristics within the home and in-centre haemodialysis groups

Table 1 presents the difference in characteristics between hospital and home haemodialysis patients across all study centres. Home HD patients were younger (51.7 vs 56.4 yrs.), more educated (43.3% vs 18.7%) and higher proportion of patients in self-employment or in salaried jobs (39% vs 19.9%). Significantly greater proportion owned their homes (77.4% vs 56.5%) in relatively less socioeconomically deprived areas ($p=0.03$), were married or in a relationship (74.2% vs 52.6%) and had young, dependent children (26.4% vs 11.7%). The median distance to the home HD training centre was significantly greater (13.1 vs 8.5 miles). Polycystic kidney disease as the primary cause of ESRD was higher in the home cohort (20.4% vs 10.8%) and diabetes (22.6% vs 9.7%) and renovascular disease proportion (0% vs 4.2%) was higher amongst 'in-centre' patients. There were lesser comorbidities in this cohort, but our study population had a greater proportion of patients with history of solid organ malignancies (19.4% vs 8%). 9.7% of home HD patients self-reported lack of complete independence with mobility and about 10.8% of patients self-reported poor visual acuity.

Table 1: Patient characteristics of the 'in-centre' and 'home-based' haemodialysis groups

Variable	In-centre (n=213)	Home (n=93)	p-value
Age – Mean (SD)	56.25 (14.63)	51.74 (12.10)	0.005 ^{1*}
Ethnicity – Non-white	26/212 (12.3%)	11 (11.8%)	0.91 ²
Gender – Female	75 (35.2%)	23 (24.7%)	0.071 ²
Education – Post-high school	38/203 (18.7%)	39/90 (43.3%)	<0.001 ²
Employment			
Retired	95 (45.0%)	33 (35.9%)	0.002 ²
Unemployed	74 (35.1%)	23 (25.0%)	
Salaried/self-employed	42 (19.9%)	36 (39.1%)	
IMD rank – Median (IQR)	11915 (4476-22122)	17611 (7382-25456)	0.022 ³
IMD – quintile			
1 (least deprived)	31 (14.6%)	22 (23.7%)	0.031 ⁴
2	37 (17.4%)	17 (18.3%)	
3	36 (16.9%)	18 (19.4%)	
4	45 (21.1%)	15 (16.1%)	
5 (most deprived)	64 (30.0%)	21 (22.6%)	
CCI Median (IQR)	4.0 (3.0-6.0)	4.0 (3.0-5.0)	0.008 ³ (IC>Home)
Training centre distance – Median (IQR)	8.5 (4.9-14.7)	13.1 (6.7-18.6)	0.006 ³
Partner employment	n=104	n=65	
Retired	59 (56.7%)	20 (30.8%)	0.004 ²
Unemployed	12 (11.5%)	11 (16.9%)	
Salaried/self-employed	33 (31.7%)	34 (52.3%)	

BMI - Median (IQR)	26.5 (23.0-31.6)	27.0 (23.7-30.8)	0.55 ³
Accommodation			
Home owner	118 (56.5%)	72 (77.4%)	0.002 ²
Living with parents	17 (8.1%)	6 (6.5%)	
Rental/friend/res. home	74 (35.4%)	15 (16.1%)	
Marital status			
Married or partner	112 (52.6%)	69 (74.2%)	0.001 ²
Single	63 (29.6%)	10 (10.8%)	
Divorced or separated	21 (9.9%)	11 (11.8%)	
Widowed	17 (8.0%)	3 (3.2%)	
Childcare			
>18 yrs; independent	97 (49.5%)	44 (48.4%)	0.003 ²
<18 yrs or >18yrs; dependent	23 (11.7%)	24 (26.4%)	
No children	76 (38.8%)	23 (25.3%)	
Smoking status			
Never smoked	119 (57.2%)	56 (60.9%)	0.29 ²
Ex-smoker	57 (27.4%)	28 (30.4%)	
Current	32 (15.4%)	8 (8.7%)	
Mobility			
Independent	155 (72.8%)	84 (90.3%)	0.003 ²
Walking Aid/Limited	41 (19.2%)	6 (6.5%)	
Wheelchair Bound	17 (8.0%)	3 (3.2%)	
Cause of ESRD			
Hypertensive Nephrosclerosis	14 (6.6%)	10 (10.8%)	0.016 ²
Diabetic Nephropathy	48 (22.6%)	9 (9.7%)	
Glomerulonephritis	33 (15.6%)	16 (17.2%)	
Polycystic Kidney Disease	23 (10.8%)	19 (20.4%)	
Renovascular Disease	9 (4.2%)	0 (0%)	
Chronic Pyelonephritis	16 (7.5%)	5 (5.4%)	
Others	39 (18.4%)	16 (17.2%)	
Unknown	30 (14.2%)	18 (19.4%)	
HD vintage (in years) – Median (IQR)	2.25 (0.73-4.78)	2.95 (1.37-5.31)	0.018 ³
Previous PD	60 (28.2%)	32 (34.4%)	0.27 ²
Previous Transplant	45/212 (21.2%)	39 (41.9%)	<0.001 ²
Vision – blind or poor vision	37/210 (17.6%)	10 (10.85)	0.13 ²
Diabetes	65/210 (31.0%)	12 (12.9%)	0.001 ²
Heart failure	11 (5.2%)	3 (3.2%)	0.56 ⁵
Solid organ malignancy	17 (8.0%)	18 (19.4%)	0.004 ²
Intra cranial event (stroke, TIA or bleed)	21 (9.9%)	7 (7.5%)	0.52 ²
Caregiver – alone	66/205 (32.2%)	14/90 (15.6%)	0.003 ²

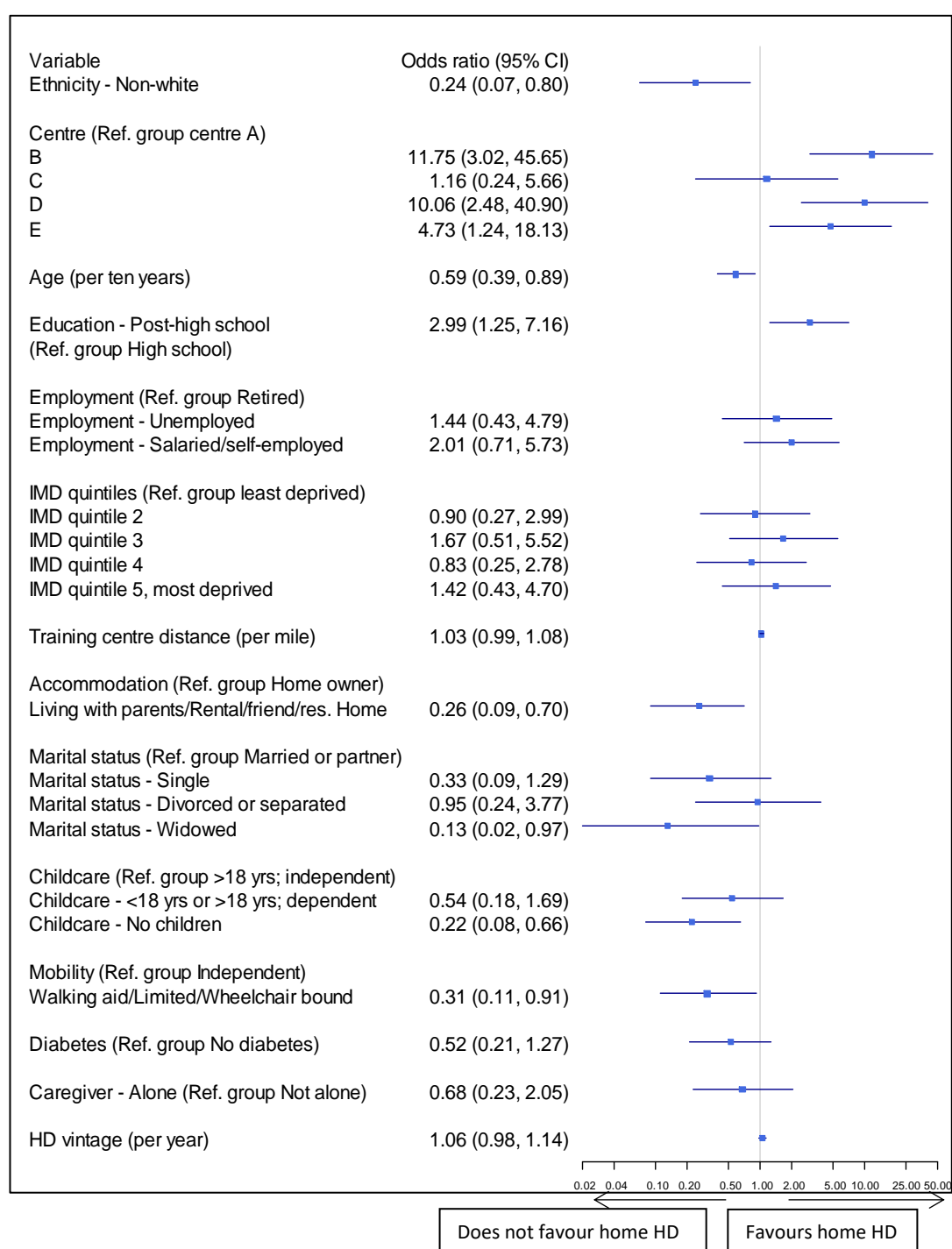
¹T-test ²Pearson chi-squared test ³Mann-Whitney U test ⁴Chi-squared test for linear trend ⁵Fisher's exact test *Unequal variances

Confounder-adjusted analyses of centre and sociodemographic variables in the HD groups

Confounder variables have associations with 'centre', 'ethnicity' and 'HD group-the dependent variable' (i.e. hospital or home HD). In the multivariable confounder-adjusted analyses, 'centre-effect' and 'white ethnicity' remain significant predictors of home HD location ($p<0.001$ and $p=0.02$ respectively), after adjustment for other variables in the model (**Fig 1**). Other significant socio-demographic predictors of home HD group prevalence include, lower age ($p=0.01$), higher education ($p=0.01$), home ownership ($p<0.01$), childcare responsibility ($p=0.02$) and unrestricted mobility ($p=0.03$). Excluding education, employment,

accommodation and training centre distance (due to the association between these variables and IMD), a second multivariable confounder-adjusted analysis ([Appendix S2: sensitivity analysis](#)), shows that, ‘centre’ to which the patient belongs remains significant ($p<0.01$) although ethnicity loses statistical significance, albeit marginally, in this model ($p=0.08$). Additionally, diabetes emerges as a deterrent to patients practising home HD treatment ($p=0.01$).

FIGURE 1: Confounder-adjusted multivariable logistic regression model of predictors of home haemodialysis uptake (n=260) in the prevalent haemodialysis cohorts; OR>1: Home HD group



Area level social deprivation indices (prevalent haemodialysis patient study groups)

Centres are different from each other with respect to distribution of patients in IMD quintiles amongst hospital HD group ([Appendix S3](#)). The distribution of patients from the hospital HD group in the five IMD quintiles of the medium and high prevalence centres show a greater proportion of patients in the bottom two quintiles (most deprived). The greatest distribution of patients in the low prevalence centres belonged in the top quintiles (least deprived). In the home HD cohort, the high prevalence centre had equal proportion of patients (28.6%) in the least and most deprived areas (IMD quintiles). The distribution of home and hospital patients from each study centre is depicted in the map that also captures areas of deprivation by IMD ranks (**Fig 2**).

There is a significant association of IMD quintile with ethnicity ($p < 0.01$), not limited only to the haemodialysis cohort, but also in the entire ESRD study group ($p < 0.01$). Specifically, it appears that non-white patients are more likely to be in the most deprived quintile; the largest difference is between the proportion of non-white patients and white patients in the fifth quintile (most deprived) (51.4% (19/37) vs 24.3% (65/268)). The data suggests that there is statistically significant association between IMD quintile and patient's HD location ($p = 0.03$). The analysis between HD group and IMD quintile in Caucasian patients appears to show a relationship ($p = 0.04$) that as the deprivation increases, the proportion of hospital patients increase. With such small numbers across the five quintiles, it is difficult to assess the association between IMD quintile and group, but there does not appear to be a significant association in the non-white patients ($p = 0.52$). It is interesting to note that in the non-white cohort, there is equal proportion of patients from the most deprived SES in the hospital and home HD groups (**Table 2**).

Table 2: Ethnicity, IMD and group in the study haemodialysis cohort

	Combined (n=305)		White (n=268)		Non-white (n=37)	
	In-centre (n=212)	Home (n=93)	In-centre (n=186)	Home (n=82)	In-centre (n=26)	Home (n=11)
Quintile 1 (least deprived)	31 (14.6%)	22 (23.7%)	29 (15.6%)	20 (24.4%)	2 (7.7%)	2 (18.2%)
Quintile 2	37 (17.5%)	17 (18.3%)	36 (19.4%)	16 (19.5%)	1 (3.8%)	1 (9.1%)
Quintile 3	36 (17.0%)	18 (19.4%)	34 (18.3%)	17 (20.7%)	2 (7.7%)	1 (9.1%)
Quintile 4	45 (21.2%)	15 (16.1%)	37 (19.9%)	14 (17.1%)	8 (30.8%)	1 (9.1%)
Quintile 5 (most deprived)	63 (29.7%)	21 (22.6%)	50 (26.9%)	15 (18.3%)	13 (50.0%)	6 (54.5%)
p-value*	0.035		0.048		0.52**	

*Chi-squared test for linear trend

** Chi-squared test for linear trend (exact test due to small expected frequencies)

Figure 2(a): Distribution of home and hospital haemodialysis patients across 5 study centres in 2011-2012 mapped to the postcode-based IMD rank (Low Prevalence Centres)

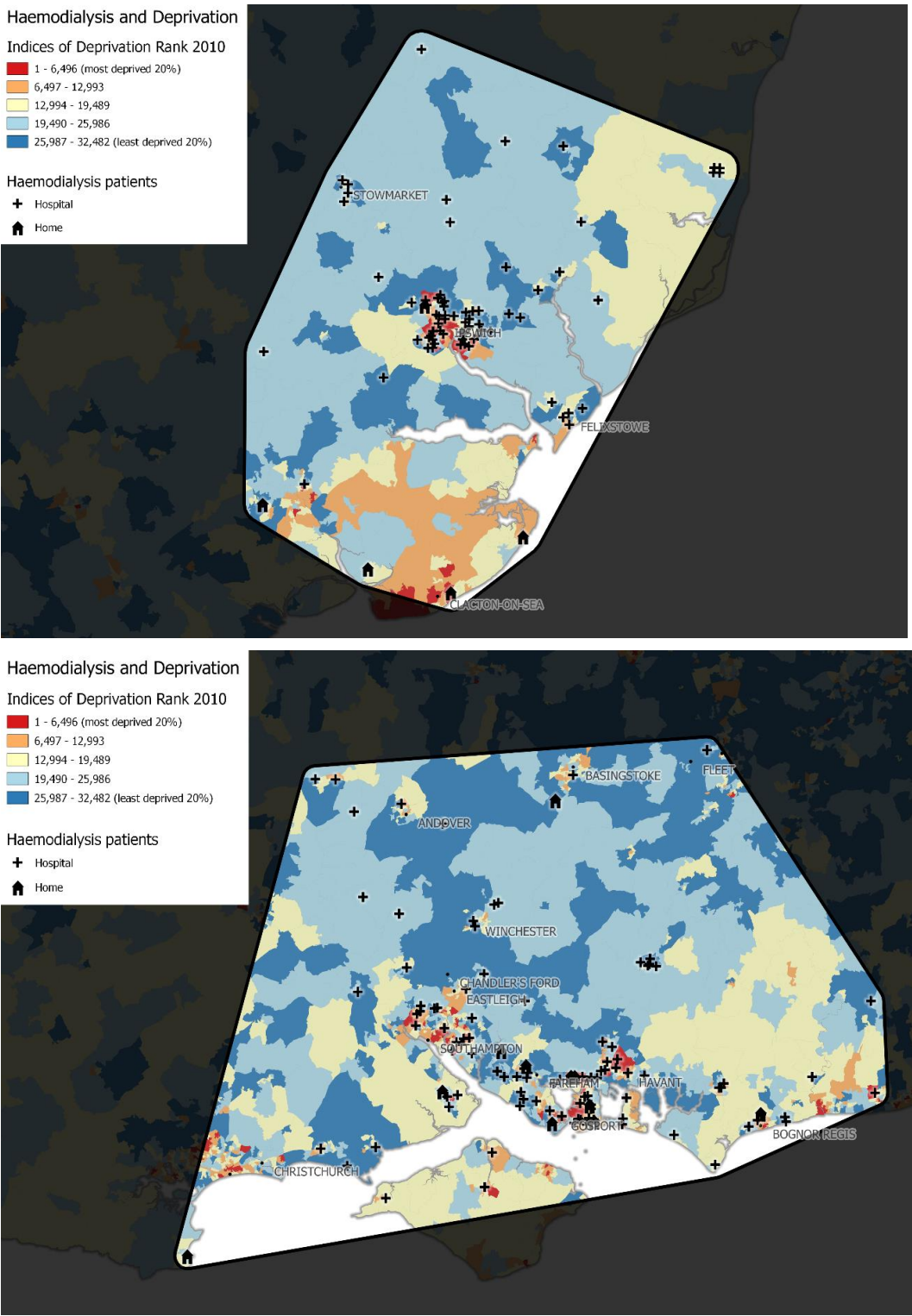


Figure 2(b): Distribution of home and hospital haemodialysis patients across 5 study centres in 2011-2012 mapped to the postcode-based IMD rank (Medium Prevalence Centres)

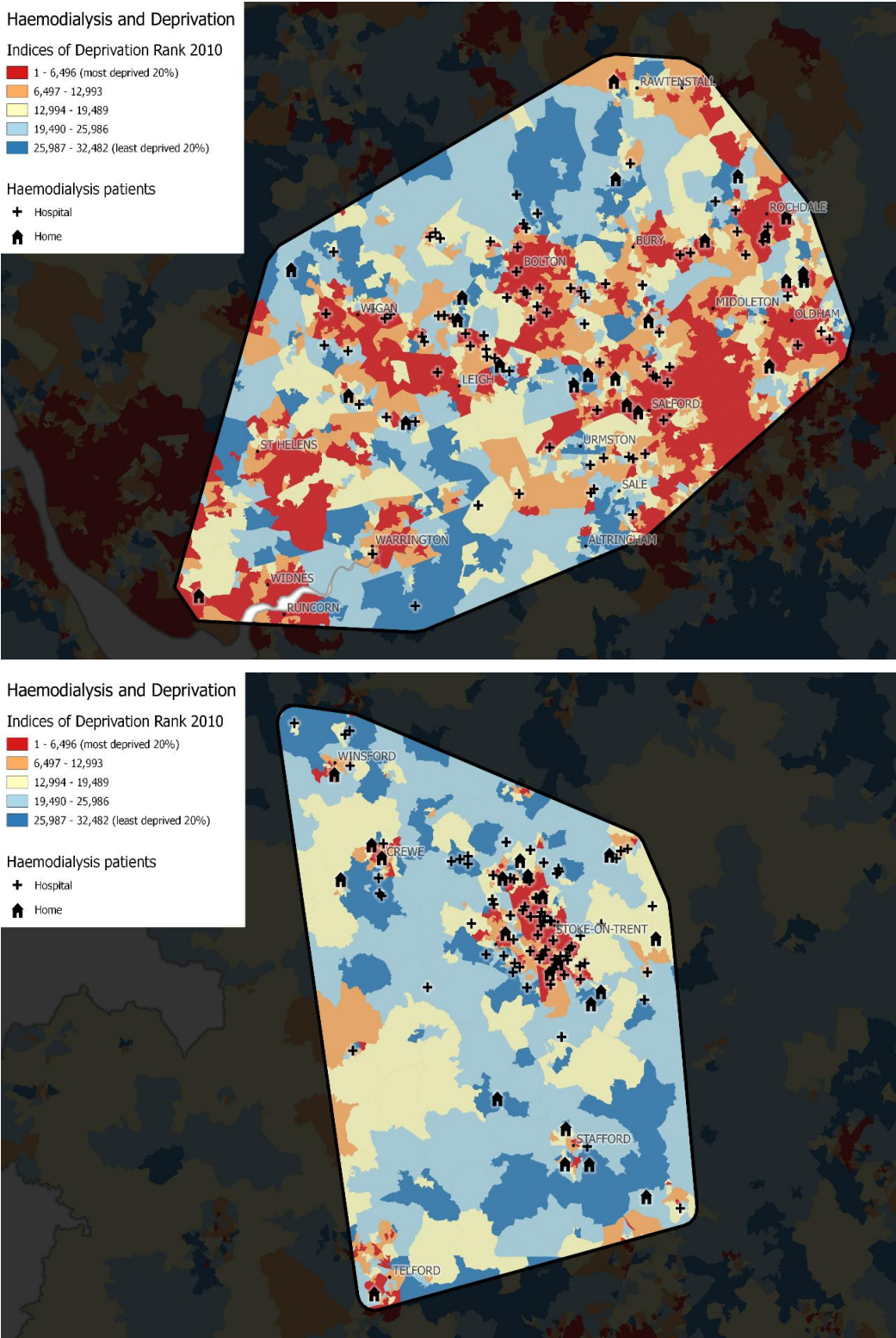
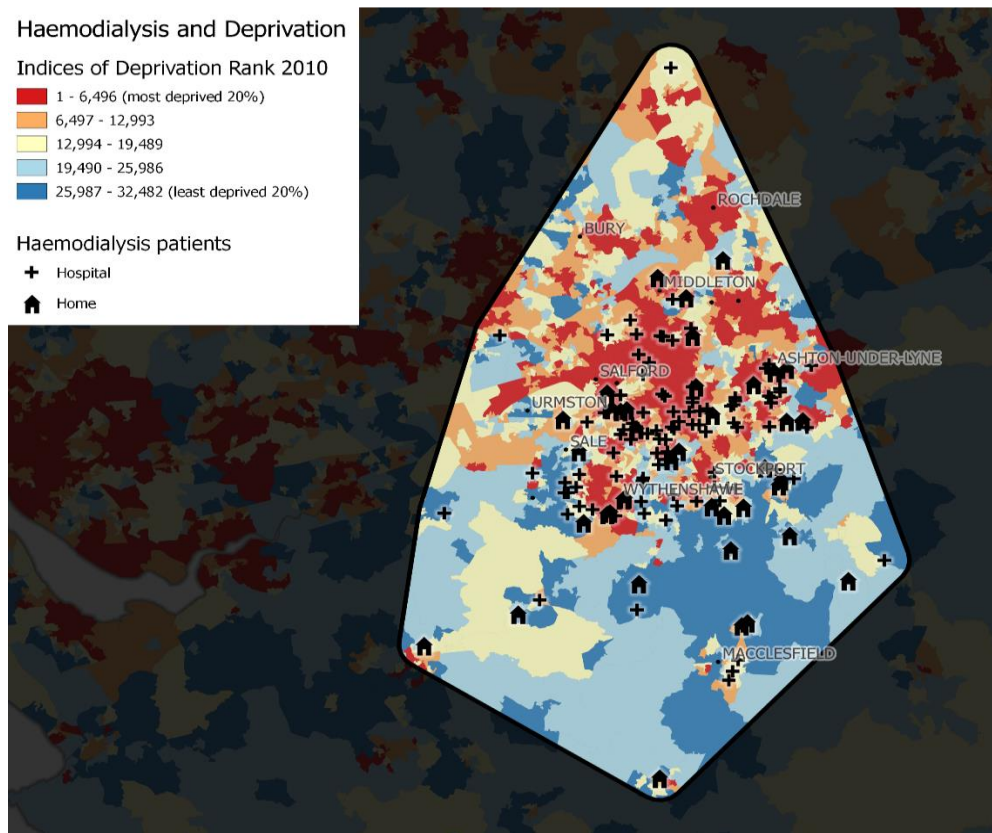


Figure 2(c): Distribution of home and hospital haemodialysis patients across 5 study centres in 2011-2012 mapped to the postcode-based IMD rank (High Prevalence Centre)



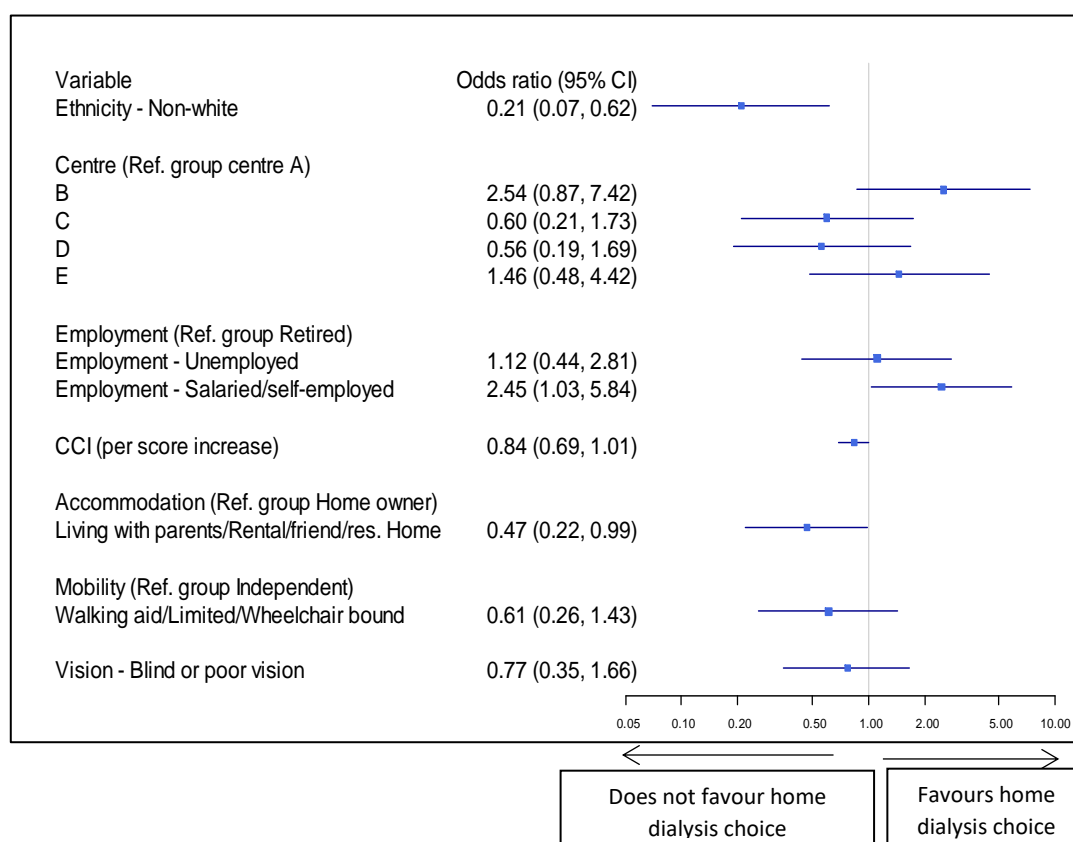
Predialysis cohort

The total number of patients who made their treatment choice in the predialysis cohort (n=206) were as follows- hospital HD (n=92), home HD (n=36), peritoneal dialysis(PD) (n=78). Due to the smaller numbers of patients in the home HD choice group, a home HD vs hospital HD choice analysis has not been presented.

Confounder-adjusted analyses of centre and sociodemographic variables in the predialysis group

In the confounder-adjusted multivariable analysis of the predialysis cohort (**Fig 3**), with modality choice as the outcome variable, ‘centre’ and ‘white-ethnicity’ remains a significant determinant of the patient’s choice of a home-based dialysis modality (p=0.01 and p<0.01 respectively). The other significant variable which favours home dialysis choice in the model is home ownership (p=0.04).

Figure 3: Confounder-adjusted multivariable logistic regression model of predictors of self-care dialysis modality choice (n=206) in the predialysis group; OR>1: Self-care modality choice



However, we believe that the socio-demographic factors which may allow for PD may be different compared with home HD. Therefore, the differences between the subgroups within the self-care dialysis cohort is also presented for clarity ([Appendix S4](#)). It is evident that centres are different with respect to home HD vs PD modality choice numbers in the predialysis stage. The centre with the highest prevalence of home HD also has the highest proportion of patients choosing this modality in the predialysis stage (Centre B). The centres where less home HD choice is represented had a proportionally higher PD choice. The average age of the PD population was about 5 years greater. The distribution of patients in the IMD quintiles was different between the groups. Approximately 55% of predialysis patients who made a home HD choice were ascribed to the lower IMD quintiles. This is likely to be due to a centre effect as the mean IMD rank of these centre catchment areas is in fact lower (Centres B and D) than the other centres in the study. Proportion of dependent children appears to be significantly greater in the home HD cohort. This is likely due to a relatively younger home HD population.

DISCUSSION

This study was designed to examine the importance of ‘centre’ in the context of patient’s sociodemographic dispositions and socio-economic status. This is particularly relevant given that financial reimbursement is uniform across all units under the National Health Service in the UK and increasingly pro-home therapies. Literature exists about RRT incidence, home dialysis uptake and transplantation options for people from economically deprived backgrounds at a national level[15, 19]. We have explored home haemodialysis in some detail as demographically, this group is relatively younger, abler and likely more informed in an increasingly digitally connected world. There are over 90 home haemodialysis patients in the study from five geographically distinct centres. We have also considered predialysis patients in these centres who make a choice of home-based dialysis over hospital HD. Irrespective of the centres’ catchment area, it is expected that the unit provide home HD to 10-15% of its dialysis population (NICE, 2002).

It is evident from the confounder-adjusted multivariable analysis of variables in the haemodialysis and predialysis cohorts, that ‘centre-effect’ has an important bearing on the uptake of home dialysis therapy. This is true even when IMD quintiles and ethnicity differences are factored into the equation. It has been established in previous studies that physician enthusiasm is an important driver of home therapies, independent of patient-level factors[16, 20]. Physician bias for peritoneal vs home HD may well impact home HD prevalence rates. The differential uptake of both types of treatment could stem from expertise, interest, training and support infrastructure, perceptions of cost-effectiveness of the two therapies and others such as target-driven modality offer. In our study, amongst PD and home-HD choice makers in the predialysis population, centres with high prevalence rates of HD had a proportionally high prevalence of patients making a home HD choice. In other centres, the lack of home HD numbers was made up by a greater proportion of PD choice. The differences between physician preference and actual practice has been established for quite a few years[21, 22]. The role of quality predialysis education in the choice of home therapies is well known[23]. In a study of attitudes of dialysis nurses to home HD, it was noted that dialysis nurses have views regarding modality selection that are strongly determined by their area of experience and expertise[24]. From a practice perspective, the current study has not delved into the different beliefs, practices and attitudes to home HD within each unit. But, in a qualitative study of financial incentives on home HD uptake within each of our study units involving senior practitioners, it was found that whilst tariff for home haemodialysis was not a clear incentive for its adoption due to uncertainty about operational costs, Commissioning for Quality and Innovation (CQUIN) targets were seen by the case study centres as a motivator

to change practices[25]. It appears that organisational factors have an overarching impact on home HD provision.

The role of socioeconomic status of individuals with respect to home HD use is important in this study. Across all regions viewed together, although home HD patients came from relatively less socially deprived areas, a higher proportion of patients on home HD from medium and high prevalence centres came from areas of relatively greater social deprivation. These centres also catered to a greater proportion of ethnic minority patients. This suggests that IMD ranks are an important association but do not fully explain the lack of a centre's engagement with home HD therapy. The greater the distance of the patient's residence from the main HD hub, greater were the chances of receiving home HD treatment. This is in keeping with the findings from other studies where uptake of home-based therapies was higher when located further from the main unit[26, 27]. The significance of home ownership in the uptake of home HD, both in the prevalent HD and predialysis groups requires a relook at the policies towards community re-housing of patients, extensions to patient's houses funded by local councils, stand-alone facilities within easy reach of patients for self-care haemodialysis and the cost implications of these measures compared to hospital-based dialysis.

There was no difference in the proportion of ethnic minority numbers between home and hospital HD groups in this study, but their distribution was quite varied across the centres, with the high prevalence centre also having the highest proportion of ethnic minority patients and contributing to the lack of statistically significant difference between the HD groups. The observation that non-white patients have equal presence in the home and hospital HD groups irrespective of their social deprivation index, at least in one of five centres, suggests to some extent that the choices available to them are equal and there may also be a possible role of family support systems in the uptake of this therapy. This is comparable to observations on choice made in a previous study in the UK[28]. However, cross-sectional studies from the USA show lower uptake of home therapies in ethnic minorities (Afro-Caribbean groups and Asians) compared with whites[29, 30]. It is useful to note that the odds of home dialysis choice are lower in the confounder-adjusted multivariable predialysis cohort analysis. The gap between choice and initiation of therapy was reported in one single-centre study pertaining to PD[31]. It is unclear as to when and how, information and pro-home decision bridge the gap between modality choice and initiation of therapy. It is quite likely that the younger, more informed, less co-morbid, non-white patient is more willing to undertake home therapies, and the relatively older patient in the ethnic minority group prefers to undertake hospital-based HD. This suggests that non-white ethnicity may have a generational divide in their approach to home dialysis therapy with different attitudes towards self-management at least in the ESRD context.

Our study has its limitations. Ethnicity in this study was reported as Caucasian vs others. This was due to the smaller numbers of patients in the ‘others’ category. The socio-cultural composition of this category and perceptions around home-based therapy could be different in separate groups. Area level socio-economic class as a proxy for individual-level SES data could potentially be a mismatch. Centre-level practice characteristics, including peritoneal dialysis and transplant rates, alongside patient-level information may help better understand the organisation’s impact more specifically, but that is outside the aim and scope of this paper. In conclusion, centre effect accounts for much of the variation between centres in terms of home HD prevalence, even after accounting for sociodemographic factors, area-level socioeconomic indices and comorbidities. Unit practices and attitudes to home HD are likely to have a dominating impact on home HD prevalence rates and these need to be explored systematically at the organisational level. Ethnic minorities may need socio-culturally sensitive education, more uniformly, in the predialysis phase to optimise their choice of self-care dialysis.

Disclosures

None

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AJ conceived the study idea and developed the methods, undertook the statistical analysis with PF and JM and wrote the manuscript. PB and SM contributed to the overall study design and were involved in the discussions of the analysis and writing of the manuscript. AJ is the guarantor for the study. We acknowledge the Baxter Extramural Grant for the BASIC-HHD study and the Manchester Academy of Health Sciences for supporting the conduct of the study.

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CHAPTER 3.5

Healthcare decision-making in end stage renal disease- patient preferences and clinical correlates

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ABSTRACT

Background

Medical decision-making is critical to patient survival and well-being. Patients with end stage renal disease (ESRD) are faced with incrementally complex decision-making throughout their treatment journey. The extent to which patients seek involvement in the decision-making process and factors which influence these in ESRD need to be understood.

Methods

535 ESRD patients were enrolled into the cross-sectional study arm and 30 patients who started dialysis were prospectively evaluated. Patients were enrolled into 3 groups- 'predialysis' (group A), 'in-centre' haemodialysis (HD) (group B) and self-care HD (93 % at home-group C) from across five tertiary UK renal centres. The Autonomy Preference Index (API) has been employed to study patient preferences for information-seeking (IS) and decision-making (DM). Demographic, psychosocial and neuropsychometric assessments are considered for analyses.

Results

458 complete responses were available. API items have high internal consistency in the study population (Cronbach's $\alpha > 0.70$). Overall and across individual study groups, the scores for information-seeking and decision-making are significantly different indicating that although patients had a strong preference to be well informed, they were more neutral in their preference to participate in DM ($p < 0.05$). In the age, education and study group adjusted multiple linear regression analysis, lower age, female gender, marital status; higher API IS scores and white ethnicity background were significant predictors of preference for decision-making. DM scores were subdivided into tertiles to identify variables associated with high ($DM > 70$: and low DM (≤ 30) scores. This shows association of higher DM scores with lower age, lower comorbidity index score, higher executive brain function, belonging in the self-caring cohort and being unemployed. In the prospectively studied cohort of predialysis patients, there was no change in decision-making preference scores after commencement of dialysis.

Conclusion

ESRD patients prefer to receive information, but this does not always imply active involvement in decision-making. By understanding modifiable and non-modifiable factors which affect patient preferences for involvement in healthcare decision-making, health professionals may acknowledge the need to accommodate individual patient preferences to the extent determined by the individual patient factors.

'Nothing is more difficult, and therefore more precious, than to be able to decide'
Napoleon Bonaparte

INTRODUCTION

Medical decision-making is critical to patient survival and well-being[1]. Over the last two decades, the convergence of influential ideas from the fields of bioethics, psychology, sociology and medicine has contributed to our understanding of the beneficial role of engaging patients in the medical decision-making process. The several potential benefits of involving patients in medical decision-making (DM) include reduced anxiety and depression, greater self-efficacy, improved concordance, and higher satisfaction with their physician [2–6]. Patient's expectations about exercising choice in medical decision-making have also been influenced by socio-cultural factors. These stem from increasing consumerist attitudes and litigious practices in the society, leading to the belief amongst healthcare professionals, that patients are best placed to evaluate the risks and benefits of alternative treatments [7], [8]. Of the models of healthcare decision-making that exist, an extreme and impractical version of the 'patient engagement model' of healthcare in practice would result in the providers supplying accurate information to patients without sharing their own views or experiences and then expecting patients to make tough medical decisions on their own. Research has demonstrated that patients' desire for information is typically underestimated by physicians [6]. What is less apparent is the extent to which they seek involvement in the actual decision-making process.

Healthcare decision-making is a highly complex process, the outcome of which is the interplay of several interrelated factors [7, 9, 10] and not limited only to uncertainty in scientific evidence. As decision-making is affected by several factors, it is prone to error[1]. It is not surprising therefore, as to why some patient decisions may be at odds with the healthcare provider recommendations, making even shared decisions difficult to implement in clinical practice.

In several clinical conditions, evidence shows that not all patients want to make their own decisions [6] and some would actively delegate the task to their healthcare professionals. This concept has not been well understood in chronic kidney disease (CKD). Patients with CKD are faced with incrementally complex decision-making throughout their treatment journey. Particularly in later stages, patients exercise choice and make decisions which impact on how they live from day to day. Some of these include decisions around dietary intake, medications, frequency of clinic visits, treatment options when they reach end stage renal disease (ESRD) and even the choice of not considering renal replacement therapy. Dialysis, a life-sustaining therapy, invites multiple levels of patient engagement with and without healthcare providers, making it an intellectually and emotionally demanding process. Accommodating individual

patient preferences for participation and true shared decision-making as the ‘ideal’ may be in potential conflict in some instances.

‘Autonomy’ in decision-making is one of several factors which may influence healthcare decisions throughout the ESRD journey. We chose to study this construct to understand its basis in undertaking self-care in the ESRD context. Decisions are taken based on the information patients acquire from healthcare providers and other sources. Also, the impact of ‘real’ vs ‘imaginary’ knowledge may influence patient attitudes to decision-making. Patients with ESRD are expected to assimilate a lot of new information in a particularly vulnerable phase of their illness, sometimes with limitations in cognitive and computational skills [11] and in relatively short time frames, leading to critical, life-changing decisions. Multiple inter-related skills are required to function optimally and produce the best outcomes for the individual circumstance. These include the ability to access and comprehend information, recall the same, weigh alternatives, infer and communicate decisions effectively and engage in a life-long process of learning [12, 13]. All of these activities are a product of complex processing of information in the brain of individuals. Executive brain function is a higher order cognitive ability that is a product of working memory, reasoning, task flexibility and visuo-motor speed. It is well known that chronic kidney disease is associated with considerable executive and episodic memory cognitive deficit, which is also progressively on the decline, after commencement of haemodialysis [11]. The reported prevalence of cognitive deficit in dialysis patients is of the order of 17-50 % [14]. Closely related to systematic, careful cognitive processing is the role of the patient’s ‘affect’ on decision-making. Understanding ESRD healthcare decision-making from a psychological perspective is paramount due to the high prevalence of depression or anxiety amongst these patients (up to 70 %) [15, 16].

Study objectives

Although ‘autonomy’ and ‘decision-making’ are not synonymous with each other, in contemporary medical literature, the two have been used interchangeably[24]. In the present study, ‘information-seeking’ and ‘decision-making’ preferences are evaluated in a large group of ESRD patients.

We sought to

- 1) Describe the properties of Autonomy Preference Index (API) instrument in ESRD population.
- 2) Examine clinical, psychological and neurocognitive correlates of ‘autonomous decision-makers’ vs ‘delegators’ in ESRD.
- 3) Study the impact of commencement of dialysis on decision-making, in a subset of predialysis patients.

METHODS

The API study data are derived from data ascertained for the BASIC-HHD study [18]. The BASIC-HHD study is a comprehensive and systematic study of barriers and enablers of the uptake and maintenance of home HD therapy. The study involves five UK centres, with variable prevalence rates of home HD. The centres reported similar structure of pre-dialysis education programmes with access to nurse specialists for information and dedicated ‘low-clearance’ clinics. An integrated mixed methodology (convergent, parallel design) has been adopted for the BASIC-HHD study in a combined cross-sectional and prospective study design. The methodological details and scope of data collected in the BASIC-HHD appear in a published protocol [18].

Study registration

This study has been reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346). Written, informed consent from participants was obtained for the study

Participants

Data presented here are derived from the cross-sectional and prospective segments of the BASIC-HHD study. 535 patients were enrolled in three groups. Predialysis patients for the CKD-5 group (group A), prevalent ‘in-centre’ HD patients (group B) were approached if they fulfilled eligibility criteria and were willing to undertake neuropsychometric assessments and complete study specific questionnaires. All self-care haemodialysis patients (93 % at home) from each participating centre were also approached (group C). Predialysis patients were approached consecutively from the predialysis clinics and hospital haemodialysis patients were approached in consecutive order across all shifts until the centre target for recruitment was reached. Most participants approached were willing to engage with the study and reasons for declining participation included a lack of interest in research participation, and ‘research’ fatigue.

Procedure

Psychological measures employed in this study were a part of compilation of questionnaires. Blood sampling and neuropsychometric assessments were carried out ahead of the dialysis sessions. HD patients returned the questionnaires on the same day or within a couple of dialysis sessions ‘in-centre’. Home HD patients returned it by post, as did the pre-dialysis patients. Visually impaired patients could respond to questions posed to them by the research team member.

Measures

The Autonomy Preference Index was used to study patient preferences for information-seeking and decision-making. This tool was developed and validated originally in a group of general medical patients [17]. This tool consists of two subscales: an eight-item information-seeking subscale and a six-item decision-making subscale. The format of the responses is on a 5-point Likert scale. Scores for both domains are linearized to range from 0–100 (percentage scores), with higher scores indicating stronger preferences for participation. In addition, in the original API there are eight items corresponding to three clinical vignettes representing increasing disease severity to assess if symptom severity plays a role in patient autonomy preferences. The API has been validated and utilized in numerous other patient populations. The tool was employed; unmodified, as the questions and clinical scenarios are both relevant and not unfamiliar to the ESRD population.

Additionally, all study participants completed a compilation of questionnaires [18]. In order to examine the potential impact of patient's affect and cognitive ability on their engagement with decision-making, additional instruments analysed in the present study are the Beck Depression Inventory II [19] and the State and Trait Anxiety Inventory [20]. Participants underwent cognitive assessment using the modified mini-mental state examination (3MS) [21], and trail making tests A and B (TMTA/TMTB) scores [22]. The scores from these instruments were considered in ordered categories for analyses: BDI (0–10, 11–15, 16–20, 21–25, 26–30, 31+), STAI (20–29, 30–39, 40–49, 50+) and 3MS (94–100, 86–93, 81–85, 76–80, ≤ 75).

Missing data

Overall the study had excellent data completion across all instruments used in the study (>82 %). The API subscales were complete in 85.6 % of the cases (Fig. 1). The only statistically significant difference between those who were missing both the API decision-making and API information-seeking scores ($n = 77$) and those who were not missing both is in ethnicity. Non-white patients were more likely not to complete both API scores than white patients. Ethnicity was associated with decision making in the final multivariable analysis for the decision making variable. Therefore, there is a chance that the point estimate may change slightly, depending on whether the non-white patients who responded had different scores to those who did not respond. However, with the relatively small amount of missing data and only 15 non-white patients not having either score, any change would be small. There was no relationship in the single variable analysis between ethnicity and information seeking so unless the missing non-white patients differed greatly to the non-white patients who responded, it is likely the lack of association would remain (see Additional file 1: supplementary information).

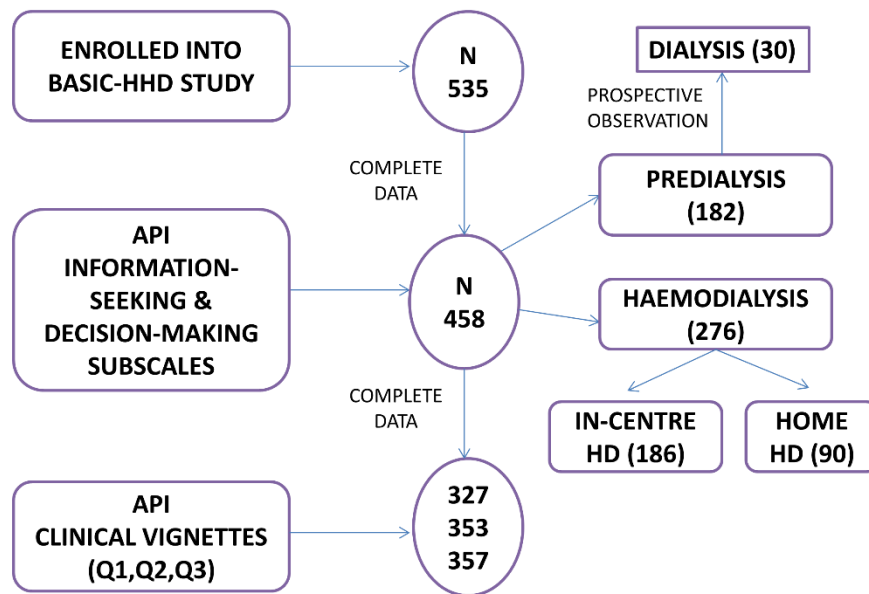


FIGURE1- Diagram depicting API data available for analysis (N)

Statistical analyses

All analyses were carried out using SPSS 20. Patient characteristics between groups were compared using ANOVAs, chi-square tests and Kruskal-Wallis tests using conventional two-sided 5 % significance level. Appropriate adjustments – Scheffé adjustments for pairwise differences in ANOVA, Bonferroni adjustments in z-tests of category proportions and Mann–Whitney U tests – were made to account for multiple testing when carrying out pairwise comparisons. Cronbach’s alpha was used to assess the internal consistency of the two API subscales in the ESRD group.

A confounder-adjusted analysis has been carried out for all variables considered in the study in accordance with the definition of a potential confounder [23]. Variables from this analysis were also used to inform the choice of variables in the multivariable regression model. The multivariable linear regression with a backwards step-wise selection method was used to identify the variables that are associated with the API decision-making preference of patients. The same selection method was used for API information seeking. Variables with p-value of less than 0.15 in the single variable analysis were considered for selection in the multivariable analysis. In the multivariable analysis, three variables were considered clinically important: age, education and group. The other variables were removed from the model until only those with a p-value less than 0.05 remained.

A linear mixed effects model with centre as the random effect has been used to account for a possible centre effect. The ICC (intraclass correlation coefficient) is the measure of the ratio of the between cluster variance to the total variance (between-cluster + within-cluster). ICC

close to 1 indicates the people in the cluster are very similar, whereas ICC close to 0 indicates the between-cluster variability is small compared to the within-cluster variability. Three patient subgroups, based on the API decision-making scores were also constructed, to understand factors associated with these scores in the highest and lowest tertile. The patient subgroup characteristics were examined using Mann–Whitney U tests, Fisher’s exact tests and linear-by-linear chi-square tests. Paired t-tests were used to examine change over time for the prospective data from 30 Group ‘A’ (CKD-5) patients.

RESULTS

Demographic and clinical characteristics of the ESRD population

A total of 458 responses were available. 39.7 % of the responses came from predialysis patients. Overall, patients receiving home HD were younger, more educated and in employment. They had the support of care-givers at home, predominantly, spouses. There were significantly greater numbers of patients with diabetes and greater comorbidity burden in the ‘predialysis’ and ‘in-centre’ dialysis groups. There was no significant difference between groups with respect to previously diagnosed affective disorders or in their screening for anxiety and depression using validated inventories. These group comparisons are important to adjust later analyses for potential confounders. The differences between the groups are illustrated in Table 1. Due to clinical importance and due to the fact there were differences between the groups, it was automatically included as a variable in both the API-DM and API-IS analyses. The group variable being included should therefore account for the differences in characteristics of the group.

API in ESRD population

We measured the internal consistency of the items in the API, in our study population using Cronbach’s alpha. This was acceptable for both information-seeking (Cronbach’s alpha = 0.774) and decision-making (Cronbach’s Alpha = 0.714) subscales of the API. The mean and standard deviations for all the items in both subscales are presented in the Additional file 2: supplementary material.

Table 1: Demographic, clinical and psychosocial characteristics of the ESRD study population						
Variable		Total (n=458)	Predialysis(A) (n=182)	In-centre HD(B) (n=186)	Home HD(C) (n=90)	p-value
Age Mean (std. dev.)			59.84 (13.28)	56.84 (14.78)	51.81 (11.67)	p<0.001¹ A>C p<0.001² B>C p=0.017²
Gender	Male	296 (64.6%)	110 (60.4%)	119 (64.0%)	67 (74.4%)	p=0.073 ³
Education	Post high school education	111 (25.1%)	43 (24.2%)	31 (17.5%)	37 (42.5%)	p<0.001³ A<C p<0.05⁴ B<C p<0.05⁴
Employment	Retired	213 (46.8%)	94 (51.6%)	87 (47.3%)	32 (36.0%)	p<0.001³ Retired A>C p<0.05⁴ Unemployed A<B p<0.05⁴ Salaried A>B p<0.05⁴ C>B p<0.05⁴
	Unemployed	115 (25.3%)	31 (17.0%)	64 (34.8%)	20 (22.5%)	
	Self-employed	35 (7.7%)	17 (9.3%)	10 (5.4%)	8 (9.0%)	
	Salaried	92 (20.2%)	40 (22.0%)	23 (12.5%)	29 (32.6%)	
Ethnicity	Non-white	46 (10.1%)	14 (7.7%)	20 (10.8%)	12 (13.3%)	p=0.32 ³
BMI (kg/m ²) Median (interquartile range)			28.38 (24.27, 32.45)	26.50 (23.08, 31.51)	26.53 (23.63, 30.83)	p=0.031⁵ A>B p=0.040⁶ A>C p=0.21⁶ C>B p=1.00⁶
Smoking status	Never smoked	257 (56.7%)	98 (54.1%)	103 (56.6%)	56 (62.2%)	p=0.57 ³
	Ex-smoker	133 (29.4%)	54 (29.8%)	53 (29.1%)	26 (28.9%)	
	Current	63 (13.9%)	29 (16.0%)	26 (14.3%)	8 (8.9%)	
Caregiver	Spouse/ partner	250 (56.2%)	111 (62.0%)	83 (46.6%)	56 (63.6%)	p=0.004³ Spouse/part A>B p<0.05⁴ C>B p<0.05⁴ F, R, S or C B>A p<0.05⁴ Alone B>C p<0.05⁴
	Child carer	24 (5.4%)	12 (6.7%)	6 (3.4%)	6 (6.8%)	
	Parent carer	34 (7.6%)	10 (5.6%)	16 (9.0%)	8 (9.1%)	
	Friend, relative, sibling or carer	19 (4.3%)	3 (1.7%)	13 (7.3%)	3 (3.4%)	
	Alone	118 (26.5%)	43 (24.0%)	60 (33.7%)	15 (17.0%)	
Marital status	Married	253 (55.2%)	106 (58.2%)	89 (47.8%)	58 (64.4%)	p=0.020³ Married B<C p<0.05⁴ Single B>C p<0.05⁴
	Partner	27 (5.9%)	11 (6.0%)	10 (5.4%)	6 (6.7%)	
	Single	103 (22.5%)	38 (20.9%)	54 (29.0%)	11 (12.2%)	
	Divorced or separated	40 (8.7%)	11 (6.0%)	17 (9.1%)	12 (13.3%)	
	Widowed	35 (7.6%)	16 (8.8%)	16 (8.6%)	3 (3.3%)	
Psych usage	Never offered	180 (40.8%)	70 (38.9%)	84 (48.8%)	26 (29.2%)	P<0.001³ Never offered B>C p<0.05⁴ Never used A>B p<0.05⁴ Used and found useful C>A p<0.05⁴ Used but not useful C>B p<0.05⁴
	Never used	209 (47.4%)	98 (54.4%)	69 (40.1%)	42 (47.2%)	
	Used and found useful	36 (8.2%)	6 (3.3%)	16 (9.3%)	14 (15.7%)	
	Used but not useful	16 (3.6%)	6 (3.3%)	3 (1.7%)	7 (7.9%)	
Primary cause of ESRD	Hypertensive Nephrosclerosis	55 (12.0%)	34 (18.7%)	12 (6.5%)	9 (10.0%)	p<0.001³ Hyp Neph A>B p<0.05⁴
	Diabetic Nephropathy	96 (21.0%)	45 (24.7%)	42 (22.6%)	9 (10.0%)	
	Glomerulonephritis	65	19	30	16	

		(14.2%)	(10.4%)	(16.1%)	(17.8%)	Diab Neph
	Polycystic Kidney Disease	55 (12.0%)	18 (9.9%)	18 (9.7%)	19 (21.1%)	A>C p<0.05 ⁴ B>C p<0.05 ⁴
	Renovascular Disease	12 (2.6%)	4 (2.2%)	8 (4.3%)	0 (0%)	Polycystic KD
	Chronic Pylonephritis/Reflux Nephropathy	29 (6.3%)	8 (4.4%)	15 (8.1%)	6 (6.7%)	C>A p<0.05 ⁴ C>B p<0.05 ⁴
	Others	83 (18.1%)	36 (19.8%)	32 (17.2%)	15 (16.7%)	
	Unknown	63 (13.8%)	18 (9.9%)	29 (15.6%)	16 (17.8%)	
	Yes	121/276 (43.8%)	~	83 (44.6%)	38 (42.2%)	
Hypertension	Yes	348 (76.0%)	152 (83.5%)	123 (66.1%)	73 (81.1%)	p<0.001 ³ A>B p<0.05 ⁴ C>B p<0.05 ⁴
Diabetes	Yes	123 (27.0%)	56 (30.8%)	56 (30.4%)	11 (12.4%)	p=0.002 ³ A>C p<0.05 ⁴ B>C p<0.05 ⁴
H/O Anxiety	Yes	14 (3.1%)	5 (2.7%)	5 (2.7%)	4 (4.4%)	p=0.69 ³
H/O Depression	Yes	48 (10.5%)	17 (9.3%)	18 (9.7%)	13 (14.4%)	p=0.39 ³
CCI Median (inter-quartile range)			5.00 (3.75, 6.00)	4.00 (3.00, 6.00)	3.50 (2.00, 5.00)	p<0.001 ⁵ A>B p=0.60 ⁶ A>C p<0.001 ⁶ B>C p=0.004 ⁶
BDI	0-10	239 (52.2%)	102 (56.0%)	91 (48.9%)	46 (51.1%)	p=0.78
	11-15	73 (15.9%)	27 (14.8%)	31 (16.7%)	15 (16.7%)	
	16-20	45 (9.8%)	18 (9.9%)	20 (10.8%)	7 (7.8%)	
	21-25	44 (9.6%)	17 (9.3%)	20 (10.8%)	7 (7.8%)	
	26-30	25 (5.5%)	6 (3.3%)	13 (7.0%)	6 (6.7%)	
	≥31	32 (7.0%)	12 (6.6%)	11 (5.9%)	9 (10.0%)	
STAI State	20-29	148 (33.4%)	54 (30.0%)	61 (34.5%)	33 (38.4%)	p=0.86
	30-39	131 (29.6%)	57 (31.7%)	53 (29.9%)	21 (24.4%)	
	40-49	100 (22.6%)	42 (23.3%)	38 (21.5%)	20 (23.3%)	
	≥50	64 (14.4%)	27 (15.0%)	25 (14.1%)	12 (14.0%)	
STAI Trait	20-29	121 (27.6%)	47 (26.3%)	49 (28.2%)	25 (29.1%)	p=0.43
	30-39	124 (28.2%)	46 (25.7%)	54 (31.0%)	24 (27.9%)	
	40-49	111 (25.3%)	55 (30.7%)	39 (22.4%)	17 (19.8%)	
	≥50	83 (18.9%)	31 (17.3%)	32 (18.4%)	20 (23.3%)	
TMT A Median (inter-quartile Range)			46.65 (32.25, 60.00)	47.00 (36.00, 69.00)	35.50 (30.00, 47.53)	p<0.001 ⁵ B>A p=0.39 ⁶ A>C p=0.001 ⁶ B>C p<0.001 ⁶
TMT B Median (inter-quartile range)			90.00 (68.50, 120.00)	113.00 (73.00, 145.00)	74.00 (61.00, 94.00)	p<0.001 B>A p=0.0236 A>C p=0.0076 B>C p<0.0016
3MS	≤75	11 (2.6%)	2 (1.2%)	8 (4.6%)	1 (1.3%)	p=0.05

76-80	14 (3.3%)	6 (3.5%)	6 (3.5%)	2 (2.6%)
81-85	35 (8.3%)	9 (5.3%)	21 (12.1%)	5 (6.5%)
86-93	157 (37.3%)	64 (37.4%)	69 (39.9%)	24 (31.2%)
94-100	204 (48.5%)	90 (52.6%)	69 (39.9%)	45 (58.4%)

¹ANOVA p-value for overall between groups mean differences

²Scheffe adjusted p-values for comparison of pair-wise group means

³Pearson Chi-Square p-value

⁴z-test comparing category proportions between groups, p-value with Bonferroni adjustment for multiple testing

⁵Kruskal-Wallis test p-value

⁶Mann-Whitney U test p-value with adjustment for multiple testing

Descriptive data analysis of the two subscales and clinical vignettes

The median score for the API information-seeking scale and the API decision-making scale in all three study cohorts is depicted in box plots (Fig. 2). For the API clinical vignettes, worsening symptom severity was associated with a change in treatment decision-making preference scores, and most patients in the collective ESRD group wanted shared decision-making with their healthcare provider if symptoms hypothetically worsened (Fig. 3).

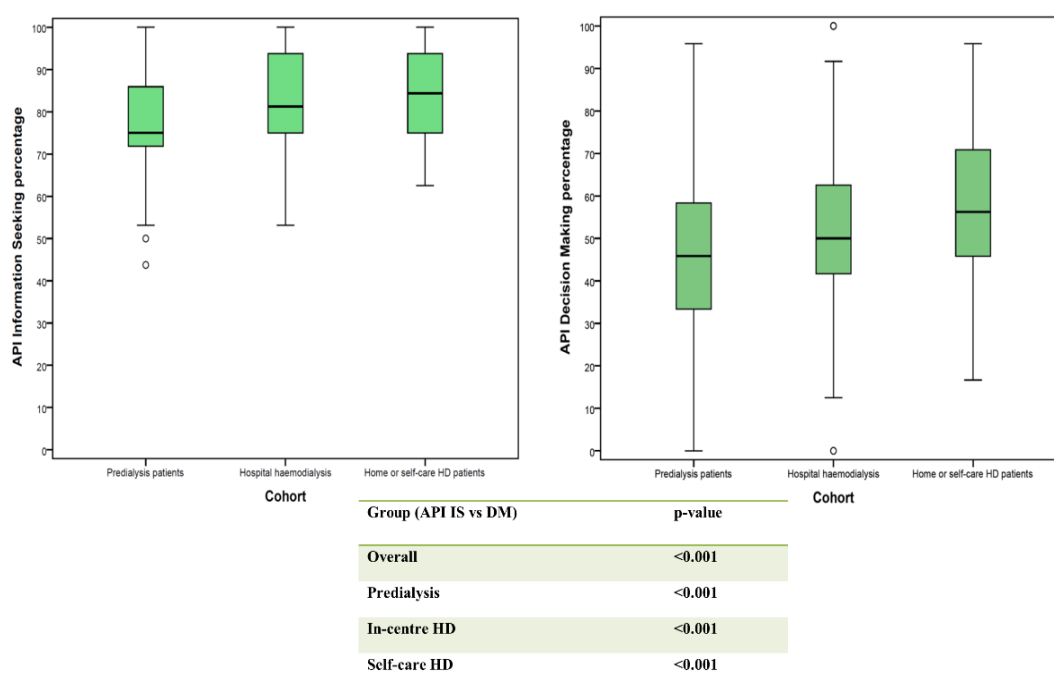


FIGURE 2 Box Plots showing the median scores on the API for Information-seeking and Decision-making subscales in all three study groups

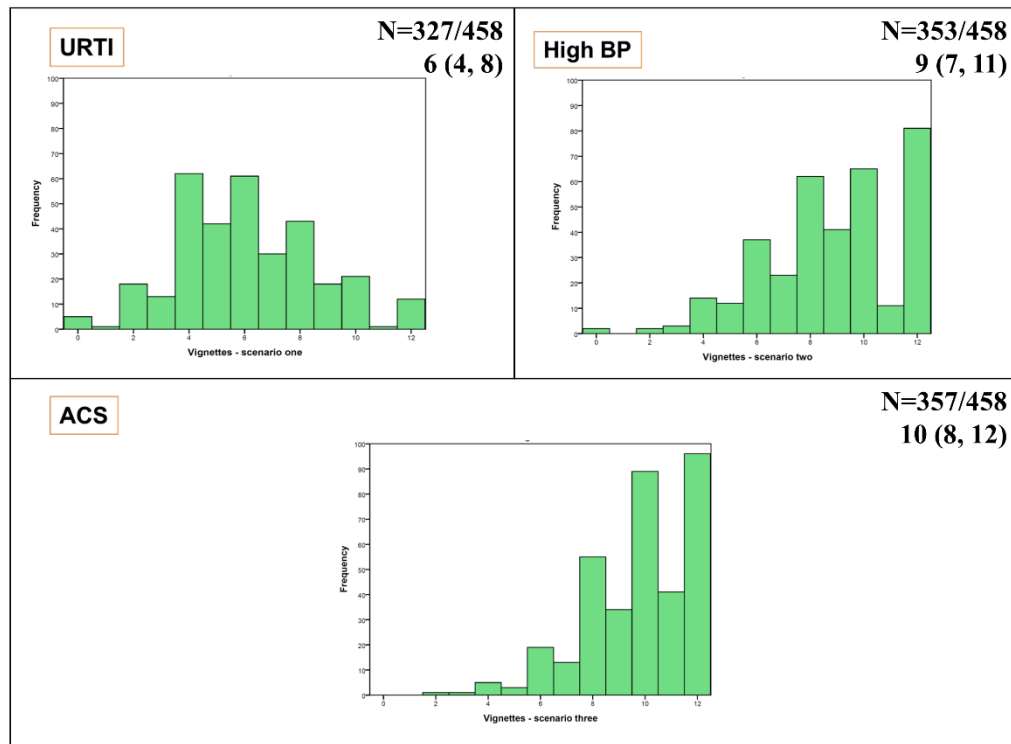


FIGURE 3: Responses to the three clinical vignettes from the API tool by the ESRD group. Actual scores are presented on the x-axis and frequency distribution of the scores is presented along the y-axis. The responses patients could choose from are provided in the API tool in the Additional file 3: supplementary material. Vignette 1: Patient preference for management of a simple upper respiratory tract infection (URTI). Median score 6 (Interquartile range 4, 8). Vignette 2: Patient preference for management of high blood pressure (BP). Median score 9 (Interquartile range 7, 11). Vignette 3: Patient preference for management of a heart attack or acute coronary syndrome (ACS). Median Score 10 (Interquartile range 8, 12)

Demographic, clinical and psychosocial factors predicting decision-making in ESRD

In the single variable analysis of the information-seeking subscale scores, the predictors at the 15 % significance level of high IS scores were (linear regression with just the variable of interest in the model): age, education, study group, gender, marital status, heart failure, BDI score, 3MS, IMD score (index of multiple deprivation), first choice of dialysis modality and perceived ability to consider self-cannulation for haemodialysis.

In the single variable analysis of the decision-making subscale (Table 2), variables significant at the 5 % level (a linear regression with just the variable of interest in the model) and were considered for the multivariable analysis include: age, study group, employment, marital status, psychology service use, diabetes, heart failure, ischaemic heart disease history, CCI,

TMT A and API information-seeking subscale score. Additionally, variables up to 15 % significance were also included in the multivariable model. These include gender, ethnicity, informal caregiver availability and patient attendance of a treatment options education session. The confounder adjusted analysis has highlighted a number of significant variables in common with the unadjusted single variable analysis. The multiple linear regression selection process for the decision-making subscale (Table 3), which had age, education and study group adjusted for, selected lower age, female gender, marital status, API information-seeking scores and white ethnicity background at 5 % significance level, in favour of greater autonomy in decision-making. Education was not significant in the multivariable analysis. The multiple linear regression selection process for the information-seeking scores (Table 3), which had age, education and study group adjusted for, selected lower age, post high school education, marital status and per category increase in BDI score at the 5 % significance level as significantly associated with information-seeking. In the model where ‘centre-effect’ was evaluated, sensitivity analysis that suggests very little change for API-DM and for API-IS education and age are slightly less significant than in the model without the centre-effect included. The likelihood ratio test in both cases failed to reject the null hypothesis of there being no difference between the mixed effects model and the ordinary linear model.

Table 2: Single variable analysis and confounder adjusted analysis (Decision-making)					
Single Variable Analysis (API-DM)			Confounder Adjusted Analysis (API-DM)		
Variable of interest		EMM* (95% CI)	p-value	Confounders	Regression Coefficient (95% CI) p-value
Age (per year)**		71.60 -0.37 (-0.48, -0.26)	<0.001	Ethnicity, Caregiver, Marital status, Education session, Psych service use, API-IS, group	-0.33 (-0.48, -0.19) <0.001
Education	High school	49.88 (47.96, 51.80)	0.29	Age, ethnicity, psych service use, diabetes, education session	-2.31(-6.12, 1.50) 0.23
	Post high school	51.91 (48.64, 55.19)			
Gender	Male	49.49 (47.44, 51.53)	0.092	CCI	-2.03 (-5.47, 1.41) 0.25
	Female	52.45 (49.67, 55.24)			
Employment	Retired	46.05 (43.69, 48.42)	<0.001	Ethnicity, caregiver, marital status, psych service use, CCI, education session, TMT A	-2.61 (-7.65, 2.42) 7.97 (2.63, 13.30) 0.04 (-7.47, 7.55) 0.001
	Unemployed	57.13 (53.94, 60.32)			
	Self employed	50.00 (44.25, 55.75)			
	Salaried	56.63 (49.08, 56.18)			
	Employed	51.90 (48.79, 55.02)			
Ethnicity	White	50.90 (49.16, 52.64)	0.13	Age, employment	8.22 (2.86, 13.59) 0.003
	Non-white	46.65 (41.50, 51.80)			
BMI	<25	49.89 (47.08, 52.71)	0.74	Age, gender	-2.58 (-6.42, 1.26) -0.06 (-4.05, 3.93) 0.33
	25-29.99	50.12 (47.14, 53.09)			
	≥30	51.37 (48.52, 54.23)			
Smoking Status	Never smoked	51.19 (48.97, 53.40)	0.65	Age, gender, employment	1.98 (-2.81, 6.76) 2.50 (-2.78, 7.79) 0.64

	Ex-smoker	49.39 (46.30, 52.48)				
	Current	50.33 (45.90, 54.77)				
Caregiver	Spouse or partner	50.31 (48.07, 52.54)	0.12	Employment, psych service use, CCI, group	3.56 (-0.44, 7.55) -2.08 (-9.89, 5.72) 1.66 (-5.55, 8.88) 3.28 (-5.15, 11.71)	0.33
	Child	46.56 (39.26, 53.86)				
	Parent	57.35 (51.35, 63.36)				
	Friend, Relative Sibling, Carer	53.47 (45.22, 61.72)				
	Alone	49.05 (45.82, 52.27)				
Marital Status	Married or partner	51.22 (49.12, 53.31)	0.006	Age, employment, psych service use, TMT A, group	7.88 (1.51, 14.25) 3.95 (-3.40, 11.31) 4.29 (-3.95, 12.53)	0.041
	Single	51.86 (48.44, 55.28)				
	Divorced or separated	51.28 (45.73, 56.84)				
	Widowed	40.36 (34.49, 46.22)				
Psych service use	Not used	49.75 (47.96, 51.54)	0.088	Age, employment, caregiver, marital status, diabetes, TMT A, group	0.56 (-5.13, 6.24)	0.85
	Used	54.25 (49.40, 59.09)				
Diabetes	No	51.63 (49.70, 53.55)	0.021	Age, employment, psych service use	2.75 (-0.95, 6.46)	0.14
	Yes	47.21 (43.99, 50.43)				
Heart Failure	No	50.91 (49.23, 52.60)	0.042	Age	5.61 (-1.76, 12.99)	0.14
	Yes	42.99 (35.54, 50.44)				
IHD	No	51.51 (49.64, 53.39)	0.032	Age, gender, employment, diabetes, TMT A	-0.50 (-4.68, 3.68)	0.81
	Yes	47.24 (43.81, 50.66)				
Stroke	No	50.79 (49.07, 52.51)	0.28	Age, IHD, education session	-0.05 (-6.13, 6.04)	0.99
	Yes	47.38 (41.46, 53.31)				
Solid Organ Malignancy	No	50.26 (48.51, 52.01)	0.36	Age, employment, caregiver, psych service use, diabetes, group	-2.71 (-8.09, 2.67)	0.32
	Yes	52.78 (47.72, 57.84)				
CCI (per unit)**		60.67 -2.26 (-3.07, -1.44)	<0.001	Gender, ethnicity, caregiver, marital status, psych service use, education session	-1.87 (-2.79, -0.96)	<0.001
BDI in 6 categories (per category) – low score to high score**		49.20 0.60 (-0.43, 1.63)	0.25	Age, employment, diabetes, API IS	-0.28 (-1.33, 0.77)	0.61
Anxiety State in 4 categories (per category) – low score to high score**		49.56 0.47 (-1.14, 2.08)	0.56	Age, employment, ethnicity, marital status	-0.35 (-1.92, 1.22)	0.66
Anxiety Trait in 4 categories (per category) – low score to high score**		48.55 0.82 (-0.75, 2.38)	0.31	Employment, ethnicity, marital status, CCI, API IS	-0.60 (-2.18, 0.98)	0.46
3MS in 5 categories (per category) – high score to low score**		51.64 -0.63 (-2.49, 1.22)	0.50	Age, employment, diabetes, IHD, TMT A	0.98 (-1.03, 2.99)	0.31
Options education session	No	51.29 (49.40, 53.18)	0.11	Age, employment, group	0.11 (-3.73, 3.96)	0.95
	Yes	48.13 (44.77, 51.48)				
Predialysis education experience	Very poor/ Not useful/ Inadequate	52.53 (46.56, 58.49)	0.18	Employment, caregiver, marital status, psych service use, education session, group	1.95 (-4.91, 8.80) 1.58 (-2.30, 5.45)	0.69
	Good	50.72 (48.03, 53.40)				
	Excellent	47.62 (44.79, 50.45)				

TMT A (per unit)**		54.21 -0.07 (-0.13, -0.01)	0.018	Age, marital status, psych service use, diabetes, IHD	-0.01 (-0.07, 0.05)	0.78
TMT B (per unit) ^Δ		54.08 -0.02 (-0.06, 0.01)	0.22	Age, ethnicity, marital status, psych service use, diabetes, IHD, TMT A	---	---
API IS	Per percentage increase	26.56 0.30 (0.15, 0.44)	<0.001	Age, group	0.19 (0.04, 0.33)	0.010
Group	Predialysis Hospital Self-care	45.88(43.32, 48.44) 51.96 (49.43, 54.48) 56.81 (53.20, 60.41)	<0.001	Age, caregiver, marital status, psych service use, diabetes, education session, TMT A, API IS	-7.09 (-12.09, -2.09) -1.76 (-6.82, 3.29)	0.006

*Estimated Marginal Mean

**The results for these continuous variables are presented as the intercept, the parameter estimate and the 95% CI of the parameter estimate

^Δ Analysis not reported as >25 % missing values in the dataset

Table 3: MULTIVARIABLE LINEAR REGRESSION ANALYSIS: DECISION-MAKING SUBSCALE			
Variable		Parameter estimate (95% CI)	p-value
Education	High school	-1.23 (-4.83, 2.36)	0.50
	Post high school	~	
Group	Predialysis	-8.20 (-12.59, -3.81)	<0.001
	In-centre HD	-1.68 (-6.05, 2.68)	
	Home HD	~	
Gender	Male	-3.29 (-6.52, -0.07)	0.046
	Female	~	
Marital Status	Married or Partner	8.79 (2.92, 14.65)	0.015
	Single	5.43 (-1.35, 12.21)	
	Divorced/Separated	6.26 (-1.28, 13.80)	
	Widowed	~	
Age (per 10 years)		-3.27 (-4.54, -2.01)	<0.001
Ethnicity	White	10.62 (5.36, 15.89)	<0.001
	Non-white	~	
API (Information Seeking %)	Per percentage increase	0.15 (0.01, 0.30)	0.035
Between-centre variability		1.17 X 10 ⁻¹⁹ (1.05 X 10 ⁻³⁶ , 0.01)	-
Within-centre variability		253.25 (221.53, 289.52)	-
Intra Class Coefficient (ICC)***		4.61 X 10 ⁻²² (-)**	-
MULTIVARIABLE LINEAR REGRESSION ANALYSIS: INFORMATION-SEEKING SUBSCALE			
Variable		Parameter estimate (95% CI)	p-value
Education	High school	-2.06 (-4.41, 0.28)	0.085
	Post high school	~	
Cohort	Predialysis	-4.16 (-6.99, -1.33)	<0.001
	In-centre HD	-0.20 (-3.05, 2.64)	
	Home HD	~	
Marital status	Married or partner	1.84 (-1.96, 5.65)	0.002
	Single	-2.56 (-6.96, 1.83)	

	Divorced or separated	4.14 (-0.75, 9.04)	
	Widowed	~	
Age (per 10 years)		-0.79 (-1.60, 0.03)	0.058
BDI in 6 categories (per category increase)*		0.86 (0.24, 1.49)	0.007
Between-centre variability		1.14 (0.08, 16.36)	-
Within-centre variability		107.87 (94.40, 123.27)	-
Intra Class Coefficient (ICC)***		0.01 (7.28 X 10 ⁻⁴ , 0.13)	-

*BDI categories: 0-10, 11-15, 16-20, 21-25, 26-30, ≥31

**Standard error estimate of ICC very close to 0 so no confidence interval provided

***ICC is a measure of the correlation of observations in the same cluster. ICC close to 1 indicates the people in the cluster are very similar, whereas ICC close to 0 indicates the between cluster variability is small compared to the within cluster variability.

‘Autonomists’ vs ‘Delegators’

Decision-making subscale scores were subdivided into tertiles to identify variables associated with high (DM > 70: empirically designated as autonomists) and low DM (≤30: empirically designated as delegators) scores (Fig. 4). This shows association of higher decision-making scores with lower age, lower comorbidity index scoring, higher executive brain function, belonging in the self-caring cohort and being unemployed (although lack of employment may have been a conscious decision of the study participants) (Table 4). Some of these variables separate the two patient clusters (e.g. CCI, higher cognitive scores etc.), but these have not featured in the final multivariable model involving the total patient cohort, possibly due to differences being most extreme at very high and very low scores.

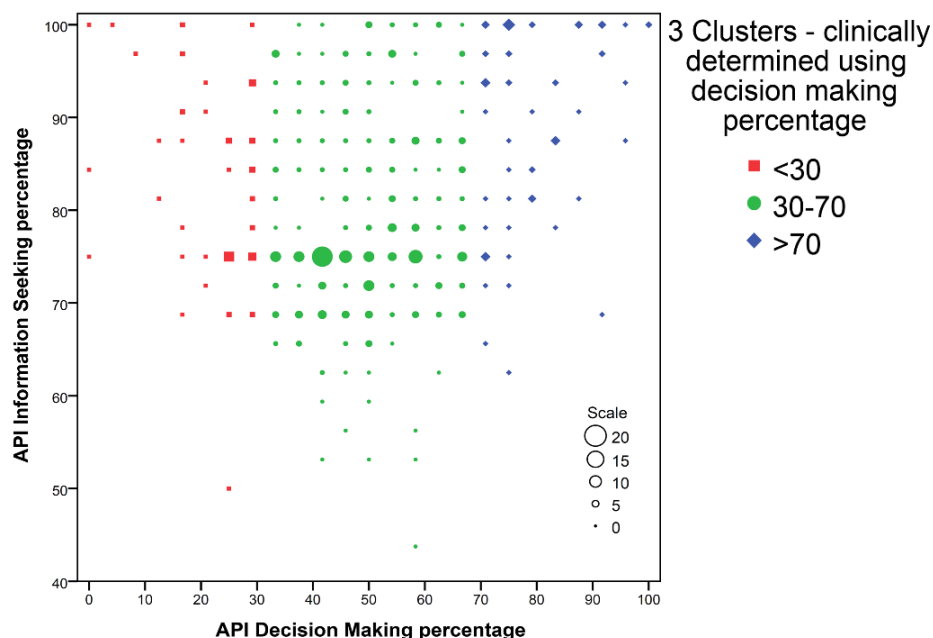


FIGURE 4 Distribution of patient clusters determined by high and low decision-making scores

TABLE 4: Cluster associations with demographic, clinical and psychosocial variables			
Variable	1(Delegators) (n=57)	3(Autonomists) (n=66)	p-value
Group			<0.001²
Predialysis	30 (52.6%)	15 (22.7%)	
Hospital	19 (33.3%)	27 (40.9%)	
Home	8 (14.0%)	24 (36.4%)	
Age- Median (IQR)	67.0 (56.0-71.5)	52.0 (42.8-63.0)	<0.001¹
Employment			<0.001²
Retired	39 (68.4%)	22 (33.3%)	
Unemployed	6 (10.5%)	24 (36.4%)	
Self-employed	4 (7.0%)	4 (6.1%)	
Salaried	8 (14.0%)	16 (24.2%)	
Marital Status			0.051²
Married or partner	34 (59.6%)	43 (65.2%)	
Single	9 (15.8%)	15 (22.7%)	
Divorced or separated	4 (7.0%)	6 (9.1%)	
Widowed	10 (17.5%)	2 (3.0%)	
CCI*	n=56	n=62	<0.001¹
Median (IQR)	5.0 (4.0-7.0)	3.0 (2.8-5.0)	
TMT A	n=56	n=64	0.008¹
Median (IQR)	49.0 (38.0-61.5)	37.5 (30.5-52.3)	
TMT B	n=43	n=54	0.007¹
Median (IQR)	105.0 (84.0-137.0)	72.0 (59.0-122.5)	
IS score	n=57	n=66	<0.001¹
Median (IQR)	84.38 (75.00-90.63)	93.75 (81.25-100)	

*CCI: Charlson Comorbidity Index

¹Mann-Whitney U test p-value

²Fisher's exact test p-value

Note: A sensitivity analysis was carried out with cut-off scores for the API-DM subscale for patient subgroups at 25/75 and at 35/65. The significant variable outcomes across all these analyses are comparable (supplementary material provided)

Decision-making in a prospective observation of the subset of dialysis starters

Complete API data on dialysis starters was available from 30 predialysis patients who commenced dialysis during the follow-up period up to 1 year from study entry. The data was completed at least 3 months after commencement of dialysis. The mean (SD) decision-making percentage score after commencement of dialysis was 37.79 (16.45), which was not significantly different from the predialysis mean (SD) of 40.52(11.73).

DISCUSSION

Clinical outcomes associated with RRT modalities are different. The challenge with interpreting reported outcomes on modality superiority are the sociodemographic, physiological and psychological differences which exist between patients in different

treatment groups, and the change over time in some of these factors. The systematic exclusion, through lack of information of patient's values, preferences and engagement, leading to the choice (or the lack of one) of modality may also have a bearing on the desired outcomes. In our study of patient preferences for autonomous decision-making in ESRD management, we have a large, representative sample population, including predialysis patients in the process of modality decision-making and patients established on 'in-centre' and 'self-care'(predominantly home-based) haemodialysis, from across five tertiary centres. To our knowledge, this is the first study which has examined the issue of patient preferences for information-seeking and decision-making in an ESRD population preparing to receive dialysis and that in receipt of haemodialysis therapy, simultaneously. We have also examined longitudinally, if DM preference in predialysis patients changes over time in a subset of patients, after commencement of dialysis therapy. The variables considered for analyses have been categorised in a manner meaningful for clinical interpretation. These apply especially to neuropsychometric tests and depression and anxiety screening tools where use of cut-off points may result in loss of information to be ascertained from scores further removed from the cut off mark. The coefficient of internal consistency of the two subscales of API is high, ensuring reliability of the test findings in our study population.

In a separate study by Flynn et al. [24], cluster analysis was used to understand the typology of patient preferences in a large group of older adults. The vast majority of them wanted information exchange, but differed in preferences for discussing and selecting treatment choices based on deliberation and decisional control. This study highlighted the need for strategies to improve information exchange and distinguish preferences for discussing and selecting treatment options. Our study has taken the understanding of the subject to individuals who are on a declining health course, those in receipt of different treatment types, respondents in varied sociodemographic groups and considered varied cognitive and psycho-affective factors which may also influence the actual response outcomes.

Demographic variables and patient preference for decision-making in ESRD

Age is an important factor in decision-making preference, with younger age group preferring a more active role in decision-making. Despite the fact that older patients wanted less participation in treatment decision-making, they nonetheless wanted a similar degree of information (high overall median scores on information-seeking subscale), demonstrating that wanting information and making decisions are separate constructs [25]. Even amongst the study cohort of high information-seekers overall, age still emerged as a significant factor for both information-seeking and decision-making, with high scores in favour of lower age. Higher confidence, greater overall perceived knowledge, greater overall retained information/knowledge and access to modern educational resources (internet), consulted by

the younger population may play a role, in this regard. Besides, the type of information required by the older age group and the manner in which information is provided to older patients may have to be tailored to individual preferences, such that, their engagement with the decision-making process is well facilitated and meaningful. Higher education, like age, was forced into our model for multivariate regression analysis and did emerge as a significant variable for information-seeking, but not for decision-making. This highlights the role of the individual's coping style and the complexity of ESRD decision-making process, making collaborative decision-making, a preferred route even amongst those who are well educated and actively seek involvement through information. Even in the cluster examination of 'autonomists' vs 'delegators', education, was not associated with either category. This is contrary to what has been noted in some other conditions where API was used to study decision-making preference [26–28] and also in other qualitative research in the area of medical decision-making [29]. Several studies have identified that gender is associated with DM preference, all finding that women are more likely than men to prefer a more active role[30]. This finding has been replicated in our ESRD study population too, although another observational study in ESRD patients, did not find significant gender differences, although a smaller study population may explain this [31].

The role of gender and the biology of decision-making remains an interesting area of research, but, the influence of gender on interpersonal relationship between the physician and the patient may influence participatory decision-making styles [32]. Employment is not a significant predictor on multivariate analysis, but remains a significant association in the cluster of low decision-making scorers. This is likely to be due to the fact that the employment variable is very closely linked to the 'cohort' variable, which was a significant predictor on the regression analysis. The cluster association showed that 'retired' individuals were more likely to assume a passive role in decision-making. Significantly higher proportion (37%) of unemployed participants were found in the 'autonomists' group, although the decision to stay unemployed may have been taken consciously by this group. Marital status also seems to influence decision-making preference, with married individuals more likely than unmarried, divorced or widowed participants to play an active role in decision-making. Ethnicity is associated with DM in our study, with white patients more likely to prefer to be involved in decision-making. Patient's role expectations, perceived role in the family context and emphasis on individuality may be a culturally determined phenomenon, influencing the passive role adopted by participants in the ethnic minority group [33]. The approach to imparting information and ascertaining patient's values and preferences should be culturally sensitive and account for the cultural diversity of different regions.

Cognitive function and decision-making preference in ESRD

We examined the association of scores from Trail making tests A and B and 3MS, a test of global cognition, with decision-making preference scores. The lowest tertile of decision-making scores was associated with poorer scores on the tests of executive brain function. Although this was not significant in the multivariate regression analysis, TMT A scores were significant on single variable analysis. This is likely due to a significant proportion of missing data on TMTs, largely due to patients' inability to complete tests or unwillingness to undertake the tests due to perceived complexity. There is evidence from literature linking age, cognition and other individual resources with health literacy in advanced age[12]. Results show that executive function and episodic memory explained literacy decline with age considerably. Executive function also had an indirect effect via risk aversion. The finding that impaired health literacy in old age is in part a function of cognitive decline even amongst persons without dementia, has clear implications for policy and intervention. Thus, it is high priority to reduce cognitive demands, particularly complex reasoning abilities and memory, inherent in the health literature materials and decision-making aids used by patients with even milder degrees of cognitive impairment. Learning styles specific information and reinforcement of consistent messages will ensure correct understanding. Impact of depression on DM was not significant in our study, but higher BDI scores were significantly associated with higher information-seeking. The ability to appreciate, understand the significance, express choice or engage in a logical process of analysing the information ascertained are known to be impaired in depressed patients in other studies [34].

Illness burden and decision-making preference in ESRD

None of the comorbidities emerged significant predictors of decision-making in the multivariate analysis. However, the Charlson comorbidity index score, a prognostic tool, was significant in the univariate analysis, and so were, diabetes, heart failure and ischaemic heart disease. In the cluster examination, the lowest tertile of decision-making scores was associated significantly with high comorbidity burden. The impact of illness on decision-making is difficult to dissociate from the role of medical care received for the illness on decision-making. Results from studies in published literature suggest that patient's preference may change in time as their experience of illness evolves [35] and that, experiences of interactions with healthcare providers may also affect patient's desire to involve themselves in current or future decision-making[26]. It is apparent from our study that in the small subset of predialysis patients, who were re-assessed at least three months after commencement of dialysis therapy, no significant change in their decision-making preferences, was observed. It is also apparent that the more complex or urgent the clinical condition, the more likely ESRD patients would consider adopting a more passive role.

Information preference and study group influence

Our study demonstrates that there is great appetite for information across all study groups. Even amongst the high information-seekers, API information-seeking score greater than 75, is associated significantly with greater preference for decision-making. The scores are significantly higher in the self-caring cohort and this may well be associated with an active coping style, the same group demonstrating higher preference for involvement in decision-making. The predialysis group was more likely to want shared involvement in the decision-making process compared to other groups in the multivariate analysis and cluster association of low decision-makers. The lack of concrete, personal experience of the treatment process may be the reason for their concern. Therefore, revisiting treatment options after commencement of dialysis may influence the choice of long-term dialysis treatment considerations including location and self vs shared vs institutional care.

Links with medical humanities and social sciences

The study findings are well in line with predictions drawn from established theories in social psychology. For instance, decision fatigue [36] is a psychological state, where the ability to process complex information and to make autonomous decisions is depleted due to e.g. emotional upheaval, resulting in impulsiveness, evasive behaviour or helplessness. The effects of illness burden on decision-making preference in ESRD can be seen correlating with both decision fatigue and emotional adjustment [37, 38]: a patient who has been only recently diagnosed with a severe illness is emotionally and cognitively handicapped due to mental fatigue, in comparison to a patient who has had time to process the emotional upheaval and adjust. Recent developments in the psychology of decision-making have revealed several factors influencing and distorting the ability to make autonomous, well-informed decisions, of which decision fatigue is only one. To facilitate patient autonomy in various stages of emotional adjustment and levels of fatigue, procedures including psychological support and appropriate information design become necessary to ensure the fulfilment of patient autonomy.

Practical implications of the knowledge of patient's decision-making preference

It is known from published literature that patients who are educated about all of their treatment options are significantly more likely to choose a home-based treatment option [39–41]. Information empowers patients to choose their RRT modality. The manner in which this information is presented therefore would influence the patients' choice of therapy. Many decisions of this complexity may well result in a shift in decision-making equipoise, making patient-led autonomous decisions, a function, limited by three key factors-patient characteristics, time constraints and clinical urgency. It is apparent from our study that subsets

of well-informed patients are still keen on involving the healthcare team in their decision-making process. There are patient characteristics which influence their wish to be involved in decision-making. These become apparent as the clinical encounter progresses over time. The reasons behind delegating the choice to another person need to be explored at a clinical and psychosociocultural level through collaborative decision-making, engaging patients, their family, and several members of the multi-disciplinary care team. This process typically operates in considerable time constraints, making a truly autonomous decision or shared decision-making by patient choice, an option for a limited few. The third point on clinical urgency is a situation where patients naturally lean towards their physician in making the right choices for them. Presenting all dialysis options as equal with the healthcare team remaining modality neutral (and therefore presumed unbiased), without clarifying the impact of each choice on the course of their illness, associated morbidity, mortality and quality-of-life, renders modality education practice unchanged and unresponsive to published scientific literature. Furthermore, patient's decision-making preferences ought to be juxtaposed to the systematic assessment of patients' affect and cognitive abilities and actual as against perceived knowledge. These remain integral to understanding the level and duration of healthcare provider engagement required to facilitate literacy and the decision process.

Study limitations

There are limitations to our study. Assessing healthcare provider's decision-making preferences would be important as decision-making happens during this bidirectional exchange of information. Assessment of actual knowledge as a predictor of decision-making preference would be useful. Although a number of clinical, psychological and socio-demographic variables have been considered, autonomy preference in a medical context is likely to be influenced by immeasurable factors and therefore our findings do not necessarily present an exhaustive list of predictors of autonomy preference in ESRD or explain the variance in autonomy preference. It is also not possible to ascertain from our study if preferred participation differs from actual participation levels when removed from hypothetical scenarios.

CONCLUSIONS

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The study explored decision-making preferences and its influencing factors in ESRD patients overall and according to their position with respect to dialysis commencement. ESRD patients prefer to receive information, but this does not always translate into active involvement in decision-making. This may not be acceptable or appropriate for everyone and the patient may choose to determine the extent to which they seek involvement. By identifying factors which might affect patient preference for involvement, health professionals may move away from a

normative, ‘one size fits all’ approach, be more sensitive to individual patient’s preferences and provide better patient-centred; individual-appropriate care.

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CHAPTER 3.6

Self-cannulation for haemodialysis: Patient attributes, clinical correlates and self-cannulation predilection models

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ABSTRACT

Background and objectives: With emerging evidence in support of home haemodialysis (HHD), patient factors which determine uptake of the modality need to be better understood. Self-cannulation (SC) is a major step towards enabling self-care ‘in-centre’ and at home and remains the foremost barrier to its uptake. Human factors governing this aspect of HD practice are poorly understood. The aim of this study is to better understand self-cannulation preferences and factors which define them in end stage renal disease (ESRD).

Design: In this multicentre study, 508 of 535 patients from predialysis (Group A: n=222), in-centre (Group B: n= 213), and home HD (Group C: n= 100) responded to a questionnaire with 3 self-cannulation questions. Simultaneously, data on clinical, cognitive and psychosocial variables were ascertained. The primary outcome measure was ‘perceived ability to self-cannulate AV access’. Predictive models were developed using logistic regression analysis.

Results: 36.6% of predialysis patients (A) and 29.1% of the ‘in-centre’ haemodialysis patients (B) felt able to consider SC for HD. Technical-skills related apprehension was highest in Group B (14.4%) patients. Response to routine venepuncture and the types of SC concerns were significant predictors of perceived ability to self-cannulate. There was no significant difference in concern for pain across the groups. In multivariable regression analysis, age, education level, 3MS score, hypoalbuminemia in Groups B & C and additionally, attitude to routine phlebotomy and the nature of specific concern for self-cannulation in Groups A, B and C, are significant predictors of SC preference. The unadjusted *c*-statistics of models 1 (derived from Group A and validated on A) and 2 (derived from B+C and validated on B), are 0.76 (95% CI 0.69, 0.83) and 0.80 (95% CI 0.74, 0.87) respectively.

Conclusions: There is high prevalence of perceived ability to self-cannulate. Modifiable SC concerns exist in ESRD. The use of predictive models to objectively define and target education and training strategies could potentially impact on HD self-management and future uptake of home HD.

INTRODUCTION

Haemodialysis (HD) for end stage renal disease (ESRD) remains the most widely prevalent dialysis treatment modality[1]. With mounting evidence in support of frequent and extended HD therapies, self-care HD (SCHD) and home-based HD (HHD) remain a viable and attractive option but with a low uptake, globally. Home-based treatment is associated with low technique failure[2], [3], better patient survival[3], [4], better health related quality-of-life[5][6], freedom, flexibility and employment potential[7]. HD requires access to the patient's vascular system. Commencement of HD through a native, purposeful, surgically created AVF compared to a vascular catheter is associated with the lowest risk of death, infections and cardiovascular events[8].

Self-cannulation of AV access is an integral, yet distinct, practical component of self-care HD. Self-cannulation (SC) is the technique by which patients insert needles into their own vascular access, an AV fistula or AV graft. A haemodialysis patient is exposed to well over 300 episodes of fistula cannulation every year. In the early days, ESRD patients had to be independent for all aspects of their care including self-cannulation. With increase in numbers of well-staffed units and patient co-morbidities, there is less emphasis on self-care. The practice of SC empowers patients and creates an opportunity for them to be active participants in their own care[9]. It ensures consistent needling technique, once expert skills are attained. It allows for greater understanding of the nature of one's vascular access including troubleshooting. With adequate education and support, best practice in vascular access care may be inculcated and practiced consistently.

Published literature in the area of self-cannulation of vascular access for HD is sparse and is largely limited to the discussion of cannulation techniques, i.e., button-hole vs. rope-ladder and associated complications such as pain[10], infections[11], [12] and vascular interventions[8], [13], [14]. Self-cannulation is the first concept; the pre-dialysis patient has to understand, for self-care HD and the first invasive step in practical application, upon commencement of home or self-care, facility-based HD training. The impact of self-cannulation concern or "fear" as a key human factor barrier to the uptake of home haemodialysis therapy has been identified in two studies[15], [16]. It poses a significant barrier to patient recruitment into these therapies both in clinical and research settings[15]. Factors which characterize the preferences for self-cannulation have not been studied in the context of ESRD.

Objectives

This study is designed to understand self-cannulation from the patient's perspective in a prospective multicentre study[17]. We aim to a) examine the prevalence of SC concerns in

ESRD b) understand the nature of SC apprehensions c) describe the clinical and psychological correlates of these concerns d) describe the typology of predialysis or ‘in-centre’ HD patients who show SC preference and e) propose predictive models for SC preference.

To the best of our knowledge, this is the first comprehensive study of self-cannulation in a large group of patients across the ESRD spectrum encompassing predialysis patients (cannulation naive), HD patients who receive institutional care (through staff-assisted cannulation) and (self-cannulating) HHD patients.

MATERIALS AND METHODS

BASIC-HHD study design

The study of ‘self-cannulation for HD’ is a patient factor study within a large multicenter, prospective, observational study designed to investigate the facilitators and barriers to home haemodialysis, the BASIC-HHD study (Barriers to successful implementation of care in home haemodialysis) [17]. The study involves 5 UK centres, with variable prevalence rates of home HD. An integrated mixed methodology (convergent, parallel design) has been adopted for this study in a combined cross-sectional and prospective study design. The methodological details and scope of data collected in the BASIC-HHD study has been presented in the protocol paper[17]. Broadly, these include clinical variables, neuropsychometric evaluation of participants and a compilation of questionnaires to include assessment of affect, autonomy preference and health-related quality of life. Knowledge of English language and visual intactness were required to undertake neuropsychometric tests.

Self-Cannulation substudy population

The self-cannulation substudy data are derived from the cross-sectional segment, in which 535 patients were enrolled. Patients were enrolled from ‘predialysis’ clinics, for the CKD-5 group (Group A). Eligible patients (determined by inclusion criteria) were approached consecutively, to achieve the recruitment target at each centre. Prevalent ‘in-centre’ HD patients (Group B) were approached if they fulfilled eligibility criteria and were willing to undertake neuropsychometric assessments and complete study specific questionnaires. All self-care haemodialysis patients (93% at home) from each participating centre were approached (Group C). In all, 508 patients responded to self-cannulation questions. Demographic and clinical information was ascertained from patients and electronic medical records. Responses to self-cannulation questions from patients registered blind and disabled, were excluded from SC study analyses (n=16). Responses to questions were recorded in an electronic database with deliberate choices. The questions on self-cannulation were posed at the same time as neuropsychometric evaluation of participants. All other questionnaires were

completed by hospital dialysis patients whilst on HD, by predialysis and home HD patients in their own homes. Patients were given these to complete, at the end of their cognitive tests. The vast majority brought the completed questionnaires back at their next predialysis clinic visit (within 4 weeks) or handed them in, to the visiting renal nurse from the hospital. Patients were reminded before their scheduled clinic appointments to bring in their completed questionnaires. The patients were entrusted to complete this if they could do it independently. Where this was not feasible, a member of the research team read the questions to patients and marked patient specified responses.

Study Registration

This study was reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346).

Self-Cannulation questions

Three simple study-specific questions were posed to all participants (Table 1). Participants had the choice of responding to more than one answer or even describe their concerns in the free text space and appropriate categorisations were used for analysis.

Table 1: Questions for the self-cannulation study		
SCQ1	How well do you tolerate needle insertion for blood tests?	Permitted responses: Do not mind/Fearful/I realize it is important for my well-being
SCQ2	Could you do the same (self-needle insertion), if required, for dialysis treatment?	Permitted responses: Yes/Yes, with some help/No/Unsure
SCQ3	What aspect of needling one's self for dialysis bothers you most?	Permitted responses: Pain/Watching the needle inserted/Fear of needle slipping out/Catastrophic bleeding/Infections/None of the above/All of the above

Study instruments

All study participants completed a compilation of questionnaires based on measures of psychosocial factors which are perceived to be predictive of uptake of self-care HD, providing us with a quantitative measure of psychosocial state. These include the presence and extent of depression through the Beck Depression Inventory II[18]; the presence and extent of anxiety through the State and Trait Anxiety Inventory[19] and preference for autonomy through the Autonomy Preference Index[20]. Tools for objective cognitive assessment include global cognition assessment through the use of the modified mini-mental state examination (3MS)[21], and executive cognitive ability through the trail making test B (TMTB) scores[22]. The metacognition questionnaire[23] was used for subjective cognition assessment. These instruments were considered because patient's affect and executive cognitive ability may hypothetically determine the perceived ability to undertake SC.

Some people are dispositionally more autonomous than others and may thus prefer self-care. Autonomy preference index scale used in this study was designed to measure preferences for autonomy in decision making in a general sense. The BDI is a self-report inventory that has been extensively validated and used for measuring depression in various population groups, including ESRD. Although depression in haemodialysis population is well studied, anxiety is also recognised to be a very important problem which may be present independent of other problems or somatised as part of another mental ailment. BDI (0-10, 11-15, 16-20, 21-25, 26-30, 31+), STAI (20-29, 30-39, 40-49, 50+) and 3MS (94-100:1, 86-93:2, 81-85:3, 76-80:4, $\leq 75:5$) scores have been considered in ordered categories for analyses. 3MS categorisation is in the reverse order as mentioned above.

Questionnaires return rate: Overall completion rate for the self-cannulation questions was 95%. The compiled validated questionnaires return rate ranged from 70%-100% for the inventories, across all participating units. The collective valid and complete responses averaged 82%.

Statistical Analyses

Analyses were carried out using SPSS 20 and R 3.1.0. Baseline characteristics between groups were assessed using ANOVAs, chi-square tests and Kruskal-Wallis tests. The conventional two-sided 5% significance level was used. Appropriate adjustments were made to account for multiple testing when carrying out pairwise comparisons. Variables included in the analysis comprised, demographic variables, clinical parameters and psychosocial factors which are clinically meaningful in the study context. Laboratory parameters of albumin and haemoglobin are included as surrogates of physical illness.

Models for predicting those patients who would consider self-cannulation were identified using multivariable logistic regression analysis using the backward step-wise selection method. The variables of interest are shown in Table 2. In the logistic regression model, the perceived self-cannulation ability answer (SCQ2) was the outcome and age was included as a fixed covariate. Responses to SCQ2 were dichotomised as 'Yes' and 'No'. The former includes- 'Yes', and 'May be' responses. Variables with p-value <0.10 , were considered for selection in the multivariable logistic regression model. Any variable with significant missing data ($>25\%$) was removed at this stage of the analysis.

The differences in characteristics between predialysis and dialysis patient groups, led to development of two models. MODEL 1 was built using group 'A' data (predialysis patients) and validated on the same group. MODEL 2 was derived from data on groups 'B' and 'C' (HD patients) and validated on group B data and on the separate 'A' data. The predictive strength of each model was assessed using the ROC (receiver operating characteristic) curve.

Discrimination was evaluated using the *c*-statistic, representing the area under the curve (AUC). Model calibration tests were also undertaken, to assess how closely the predicted probabilities reflect actual performance of the model. To adjust for overoptimism, Efron's enhanced bootstrapping procedure was employed which allowed for internal validation of our models[24].

RESULTS

Group demographic, clinical and psychosocial characteristics (Table 2)

The numbers of complete responses to the three self-cannulation questions were 491, 484 and 490 for SCQ1, SCQ2 and SCQ3 respectively.

Characteristic		Total (N=484)	Predialysis (Group A) N=202	In-centre HD (Group B) N= 189	Home HD (Group C) N= 93	Overall p-value	Within group p- values
Age (Mean, SD)			58.81(13.08)	56.60(14.38)	52.16(11.79)	p<0.001¹	A>B p=0.27 ²
							A>C p<0.001 ²
							B>C p=0.03 ²
Gender	Male	313(64.7%)	125(61.9%)	120(63.5%)	68(73.1%)	p=0.16 ³	
Education	Post high school	121(25.9%)	48(24.4%)	32(17.7%)	41(45.6%)	p<0.001³	A<C p<0.05 ⁴
							B<C p<0.05 ⁴
Employment	Retired	218(45.2%)	97(48.0%)	86(45.7%)	35(38.0%)	p<0.002³	
	Unemployed	120(24.9%)	39(19.3%)	62(33.0%)	19(20.7%)		A<B p<0.05 ⁴
	Self-employed	40(8.3%)	17(8.4%)	15(8.0%)	8(8.7%)		
	Salaried	104(21.6%)	49(24.3%)	25(13.3%)	30(32.6%)		A>B p<0.05 ⁴
							C>B p<0.05 ⁴
Ethnicity	Non-white	53(11.0%)	20(9.9%)	20(10.6%)	13(14.0%)	p=0.57 ³	
Informal Care-giver	Spouse/Partner	272(57.5%)	127(63.8%)	84(45.7%)	61(67.8%)	p<0.001³	A, C>B p<0.05 ⁴
	Child carer	27(5.7%)	12(6.0%)	9(4.9%)	6(6.7%)		
	Parent carer	34(7.2%)	11(5.5%)	16(8.7%)	7(7.8%)		
	Friend, Relative, Sibling or Carer	22(4.7%)	3(1.5%)	16(8.7%)	3(3.3%)		A<B p<0.05 ⁴
							B>C p<0.05 ⁴
Smoking	Never smoked	272(56.7%)	110(54.5%)	105(56.5%)	57(62.0%)	p=0.80 ³	
	Ex- smoker	142(29.6%)	62(30.7%)	55(29.6%)	25(27.2%)		
	Current	66(13.8%)	30(14.9%)	26(14.0%)	10(10.9%)		
Self-perceived vision	Poor/suboptimal	78(16.1%)	41(20.3%)	29(15.3%)	8(8.6%)	p=0.04³	A>C p<0.05 ⁴
Diabetes	No	352(73.2%)	139(68.8%)	132(70.6%)	81(88.0%)	p<0.005³	A,B<C p<0.05 ⁴
	Type 1	20(4.2%)	7(3.5%)	10(5.3%)	3(3.3%)		
	Type 2	109(22.7%)	56(27.7%)	45(24.1%)	8(8.7%)		A,B>C p<0.05 ⁴
Ischaemic Heart Disease	Yes	113(23.3%)	42(20.8%)	51(27.0%)	20(21.5%)	p=0.32 ³	
Heart Failure	Yes	24(5.0%)	10(5.0%)	11(5.8%)	3(3.2%)	p=0.64 ³	
Stroke	Yes	29(6.0%)	10(5.0%)	13(6.9%)	6(6.5%)	p=0.71 ³	
Solid Organ Malignancy	Yes	53(11.0%)	18(8.9%)	16(8.5%)	19(20.4%)	p<0.005³	A, B<C p<0.05 ⁴
Body Mass Index	(Median, Range)		28.37(6.62, 50.78)	26.25(13.42, 49.60)	27.01(18.40, 49.96)	p=0.009⁵	A>B p=0.02 ⁶
Dialysis Vintage	(Median, Range)	2.82(0, 32.98)		2.55(0, 26.98)	3.89(0.04, 32.98)	p=0.02¹	B<C p=0.02¹

Previous Peritoneal Dialysis	Yes	94(19.4%)	5(2.5%)	55(29.1%)	34(36.6%)	p<0.001³	A<B,C p<0.05 ⁴
Previous Transplant	Yes	91(18.8%)	8(4.0%)	44(23.4%)	39(41.9%)	p<0.001³	A<B, C p<0.05 ⁴
							B<C p<0.05 ⁴
Categorised BDI	0-10	224(51.5%)	96(54.9%)	84(48.3%)	44(51.2%)	p=0.75 ³	
	11-15	72(16.6%)	26(14.9%)	31(17.8%)	15(17.4%)		
	16-20	44(10.1%)	19(10.9%)	18(10.3%)	7(8.1%)		
	21-25	41(9.4%)	16(9.1%)	18(10.3%)	7(8.1%)		
	26-30	25(5.7%)	6(3.4%)	14(8.0%)	5(5.8%)		
	≥31	29(6.7%)	12(6.9%)	9(5.2%)	8(9.3%)		
Categorised STAI-S (Anxiety State)	20-29	141(33.9%)	49(28.7%)	59(36.4%)	33(39.8%)	p=0.52 ³	
	30-39	122(29.3%)	52(30.4%)	50(30.9%)	20(24.1%)		
	40-49	97(23.3%)	44(25.7%)	33(20.4%)	20(24.1%)		
	≥50	56(13.5%)	26(15.2%)	20(12.3%)	10(12.0%)		
Categorised STAI-T (Anxiety Trait)	20-29	111(27.1%)	42(25.1%)	44(27.7%)	25(30.1%)	p=0.26 ³	
	30-39	120(29.3%)	42(25.1%)	54(34.0%)	24(28.9%)		
	40-49	103(25.2%)	53(31.7%)	33(20.8%)	17(20.5%)		
	≥50	75(18.3%)	30(18.0%)	28(17.6%)	17(20.5%)		
Categorised 3MS	≤75	15(3.3%)	4(2.1%)	10(5.6%)	1(1.2%)	p=0.02³	
	76-80	18(4.0%)	9(4.8%)	7(3.9%)	2(2.5%)		
	81-85	36(8.0%)	11(5.8%)	20(11.2%)	5(6.2%)		
	86-93	167(37.3%)	69(36.5%)	74(41.6%)	24(29.6%)		
	94-100	212(47.3%)	96(50.8%)	67(37.6%)	49(60.5%)		A,C>B p<0.05 ⁴
TMT B	(Median, Range)		90.0(30, 270)	108.5(39, 349)	74.5(30, 267)	p<0.001⁵	A<B p<0.008 ⁶
							B>C p<0.001 ⁶
Metamemory Scale	(Mean, SD)		17.92(3.70)	17.77(4.35)	17.88(3.95)	p=0.93 ¹	
Metaconcentration Scale	(Mean, SD)		14.37(2.69)	14.85(3.29)	14.77(3.13)	p=0.27 ¹	
Autonomy Preference-DM	(Mean, SD)		45.94(16.88)	52.62(17.96)	56.52(17.83)	p<0.001¹	A<B p=0.003 ²
							A<C p<0.001 ²
Autonomy Preference-IS	(Mean, SD)		78.14(10.27)	82.15(11.37)	84.56(11.43)	p<0.001¹	A<B p<0.005 ²
							A<C p<0.001 ²
Opportunity to speak to HD patients	Yes	180(37.2%)	89(44.1%)	53(28.0%)	38(40.9%)	p<0.003³	A>B p<0.05 ⁴
Haemoglobin	Hb<9g/dL	24(5.0%)	7(3.5%)	13(6.9%)	4(4.3%)	p=0.30 ³	
Albumin	Alb<30g/L	35(7.3%)	8(4.0%)	24(12.7%)	3(3.3%)	p=0.001³	A, C<B p<0.05 ⁴

¹ANOVA p-value for overall between groups mean differences

²Scheffe adjusted p-values for comparison of pair-wise group means

³Pearson Chi-Square p-value

⁴z-test comparing category proportions between groups, p-value with Bonferroni adjustment for multiple testing

⁵Kruskal-Wallis test p-value

⁶Mann-Whitney U test p-value with adjustment for multiple testing

The home haemodialysis group was younger than the predialysis and ‘in-centre’ patients. Significantly higher proportion of patients in the home group had received post high-school education. A significantly higher proportion of group B patients lived on their own. About 27% of the total study population had diabetes with significantly less diabetes in the home HD group. Approximately one-third of patients in groups B and C had a previous history of peritoneal dialysis, a home-based therapy. Significantly higher proportion of patients in group C had a previous transplant. Predialysis patients scored significantly

lower than hospital and home patients on autonomy preference. In objective assessment of cognition of both memory domain and executive function, groups A and C performed better than B.

Response to routine phlebotomy-SCQ1 (Table 3)

The response to this question was ‘fear’ in a significantly higher proportion of group B patients who self-selected into in-centre HD with staff-assisted cannulation.

Table 3: Patient disposition towards routine phlebotomy for blood tests (SCQ1)				
Response to routine venous cannulation (SCQ1)	Predialysis group (n=203)	‘In-centre’ HD group (n=193)	Home HD group (n=95)	p-value (between groups)
Do not mind	148 (72.9%)	124 (64.2%)	81 (85.3%)	p<0.001¹
Fearful	16 (7.9%)	23 (11.9%)	2 (2.1%)	Do not mind B<C p<0.05 ²
Realise it is important for my well-being	39 (19.2%)	46 (23.8%)	12 (12.6%)	Fearful B>C p<0.05 ²

¹Pearson Chi-Square p-value

²z-test comparing category proportions between groups, p-value with Bonferroni adjustment for multiple testing

Perceived ability to self-cannulate for HD-SCQ2 (Fig. 1)

Overall 66% of responders felt they could self-cannulate their AVF. A positive response was received in 36.6% in Gr A and 29.1 % in Gr B. Patients who responded with a ‘No’ to SCQ2 in the self-care HD (Gr C), typically received assistance in cannulation from their informal care-givers.

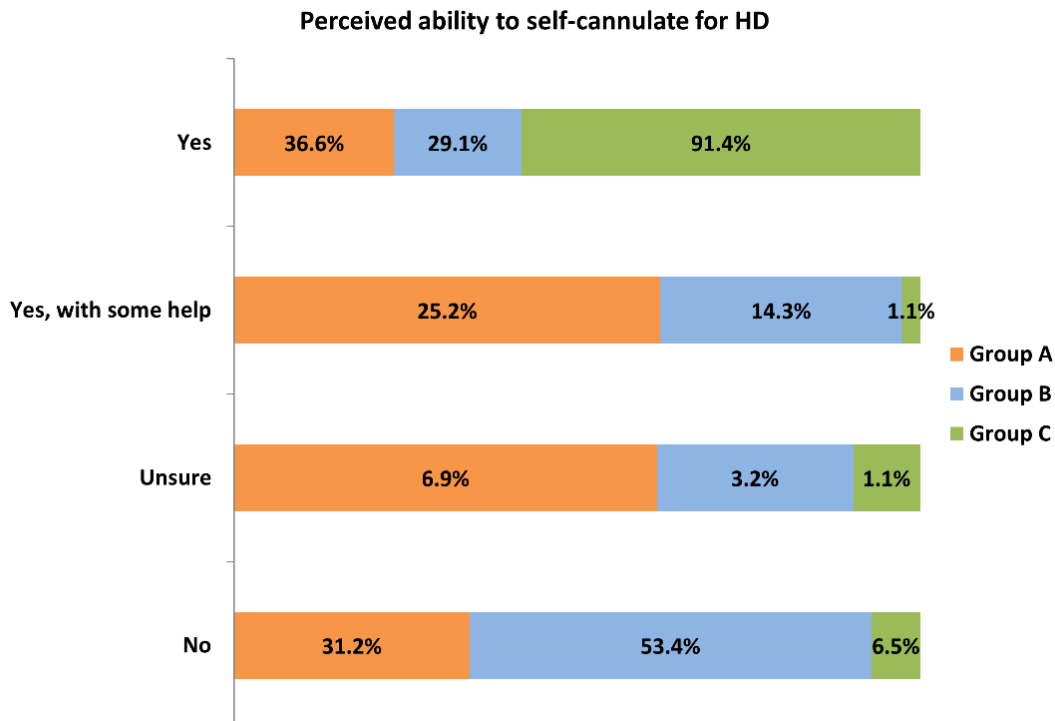


Figure 1: Bar chart shows the perceived ability of patients in the three study groups to self-cannulate. Group A: Predialysis cohort; B: Hospital haemodialysis cohort; C: Home haemodialysis cohort

Nature of concerns-SCQ3 (Fig. 2)

Concerns for self-cannulation were identified by patients in all study groups. Groups responded differently to this question. 30.3% of group B and 22% of group ‘A’ patients were fearful and concerned about all aspects of the procedure. Concerns over procedural complications were significantly higher in the self-care HD group ($P<0.05$). Pain as a cause for concern was felt equally in all study groups (approximately 10%). Technical-skills related apprehension was identified in 14.4% of in-centre patient responses as against 5% of predialysis and 1% of self-care HD groups’ responses ($p<0.05$). The ‘others’ category comprised of responses that did not fit into the other pre-defined categories and include reasons such as ‘watching the needle insertion’ and ‘lack of confidence’.

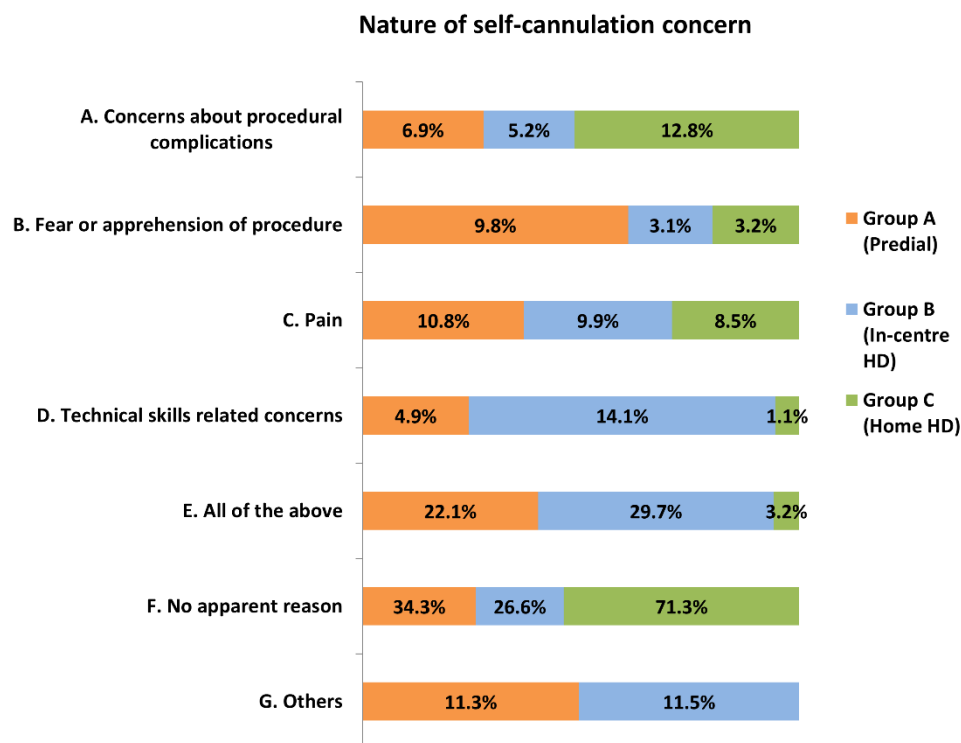


Figure 2: Bar chart depicting the nature of self-cannulation concern amongst patients in the three study groups.

Predialysis patients who felt able or unable to self-cannulate identified their reasons (Fig. 3). Significant differences in apprehensions between the negative and positive responders to SCQ2 were, pain ($p<0.05$) and fear of the procedure itself ($p<0.05$). About 25% of the ‘No’ responders and 20% of the ‘Yes’ responders felt however, that all aspects of SC were bothersome. 9.7% of the predialysis group with negative disposition to SC did not have any specific reason to dismiss self-cannulation for HD. 6.6% of those who would consider SC cited technical skills and ability as an important consideration as against 1.6% of the negative responders.

Model Building

The response to SCQ2 was dichotomised into ‘Yes (Yes, Yes, with some help) and ‘No (No and Unsure)’. Variables examined in the univariate analysis are shown in Table 4. Significant determinants of ‘yes’ to SC on univariate analysis in predialysis group (group A), were the types of response to SCQ1

and SCQ3 and lower trait anxiety scores. In addition to the responses to SCQ1 and SCQ3, other significant determinants in the HD group (groups B+C) were, age, education, employment, presence of an informal care-giver, history of malignancy, global cognition scores, TMTB scores and Albumin<30g/L (surrogate of physical illness).

Table 4: Univariate analysis					
Variable		Predialysis		In-centre and Home HD	
		Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value
Age (per year)		0.98 (0.95, 1.00)	0.03	0.97 (0.95, 0.99)	0.003
Age-controlled analyses below					
Gender	Male	1 (-)	0.57	1 (-)	0.22
	Female	0.84 (0.47, 1.52)		0.72 (0.43, 1.12)	
Vision	Normal	1 (-)	0.42	1 (-)	0.08
	Poor vision	0.75 (0.37, 1.52)		0.53 (0.26, 1.08)	
Education	High school	1 (-)	0.75	1 (-)	0.002
	Post high school	1.12 (0.55, 2.27)		2.67 (1.44, 4.95)	
Employment	Retired	1 (-)	0.62	1 (-)	<0.001
	Unemployed	1.41 (0.51, 3.94)		0.54 (0.25, 1.17)	
	Self employed	1.39 (0.43, 4.43)		1.22 (0.45, 3.30)	
Ethnicity	Salaried	1.96 (0.72, 5.33)		4.03 (1.55, 10.52)	
	White	1 (-)	0.75	1 (-)	0.45
	Non-white	0.85 (0.31, 2.35)		0.74 (0.35, 1.59)	
Smoking Status	Never smoked	1 (-)	0.54	1 (-)	0.88
	Ex-smoker	1.27 (0.66, 2.45)		1.01 (0.57, 1.77)	
	Current	0.76 (0.33, 1.76)		0.83 (0.39, 1.76)	
Informal Care-giver	Spouse or partner	1 (-)	0.98	1 (-)	0.001
	Child	1.32 (0.37, 4.68)		0.46 (0.15, 1.39)	
	Parent	0.97 (0.22, 4.26)		0.11 (0.03, 0.32)	
	Friend, relative, sibling or carer	1.16 (0.10, 13.39)		0.65 (0.24, 1.81)	
	Alone	0.88 (0.44, 1.77)		0.47 (0.25, 0.87)	
Diabetes	No	1 (-)	0.64	1 (-)	0.66
	Type 1	1.16 (0.21, 6.43)		1.76 (0.46, 6.73)	
	Type 2	1.37 (0.71, 2.67)		0.91 (0.48, 1.69)	
Ischaemic Heart Disease	No	1 (-)	0.21	1 (-)	0.45
	Yes	0.63 (0.31, 1.29)		0.81 (0.46, 1.41)	
Heart Failure	No	1 (-)	0.15	1 (-)	0.13
	Yes	0.38 (0.10, 1.41)		0.42 (0.13, 1.30)	
Stroke	No	1 (-)	0.15	1 (-)	0.22
	Yes	3.21 (0.65, 15.93)		0.55 (0.21, 1.44)	
Solid Organ Malignancy	No	1 (-)	0.96	1 (-)	0.03
	Yes	1.03 (0.37, 2.85)		2.44 (1.08, 5.48)	
Body Mass Index (per unit increase)		0.98 (0.94, 1.03)	0.48	1.03 (0.99, 1.07)	0.14
History of Peritoneal Dialysis	No	-	N/A*	1 (-)	0.97
	Yes			1.01 (0.60, 1.70)	
History of Renal Transplantation	No	1 (-)	0.63	1 (-)	0.09
	Yes	1.49 (0.29, 7.76)		1.65 (0.93, 2.96)	
Opportunity to speak to other HD patients	No	1 (-)	0.32	1 (-)	0.35
	Yes	0.75 (0.42, 1.33)		1.28 (0.76, 2.17)	
BDI in 6 categories (per category increase) – low score to high score		0.91 (0.74, 1.10)	0.32	1.04 (0.89, 1.22)	0.64
Anxiety State in 4 categories (per category increase) – low score to high score		0.88 (0.65, 1.19)	0.42	1.04 (0.81, 1.35)	0.75
Anxiety Trait in 4 categories (per category increase) – low score to high score		0.73 (0.54, 1.00)	0.05	1.05 (0.81, 1.36)	0.70
3MS in 5 categories (per category increase) – high score to low score		0.87 (0.62, 1.20)	0.39	0.51 (0.38, 0.69)	<0.001
Trail Making Test B (per unit increase)		1.00 (1.00, 1.01)	0.32	0.99 (0.98, 1.00)	<0.001
Meta Cognition Questionnaire 1 (metamemory)		1.01 (0.94, 1.09)	0.77	1.01 (0.95, 1.07)	0.74

(per unit increase)					
Meta Cognition Questionnaire 2 (metaconcentration) (per unit increase)		1.06 (0.95, 1.18)	0.34	0.98 (0.90, 1.05)	0.53
Autonomy Preference Index- Decision Making (per unit increase)		1.00 (0.98, 1.02)	0.79	1.01 (1.00, 1.03)	0.11
Autonomy Preference Index- Information Seeking (per unit increase)		1.00 (0.97, 1.03)	0.94	1.01 (0.99, 1.04)	0.26
Low Haemoglobin (Hb<9g/dl)	No	1 (-)	0.60	1 (-)	0.76
	Yes	1.57 (0.29, 8.42)		0.85 (0.31, 2.37)	
Low Albumin (Alb<30g/L)	No	1 (-)	0.23	1 (-)	0.009
	Yes	0.40 (0.09, 1.75)		0.32 (0.14, 0.75)	
SCQ1 (Routine phlebotomy question)	Do not mind	1 (-)	0.008	1 (-)	<0.001
	Fearful	0.32 (0.11, 0.93)		0.06 (0.02, 0.22)	
	Realise	0.38 (0.18, 0.79)		0.54 (0.29, 0.99)	
SCQ3 (Nature of concern question)	No apparent reason	1 (-)	<0.001	1 (-)	<0.001
	Concerns about procedural complications	0.13 (0.03, 0.45)		0.51 (0.19, 1.39)	
	Fear or apprehension of procedure	0.07 (0.02, 0.25)		0.08 (0.02, 0.44)	
	Pain	0.14 (0.05, 0.43)		0.15 (0.06, 0.40)	
	Technical skills related concerns	0.26 (0.06, 1.13)		0.18 (0.07, 0.45)	
	All of the above	0.23 (0.09, 0.58)		0.56 (0.28, 1.10)	
	Others	0.09 (0.03, 0.27)		0.11 (0.04, 0.34)	

N/A* Model does not converge due to small numbers of patients with previous PD history

Table 5: Multivariable logistic regression analysis				
Model Variables	Predialysis		Haemodialysis	
	Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Age (per year)	0.97 (0.95, 1.00)	0.05	0.96 (0.93, 0.99)	0.01
Education (post high school)	-	-	3.31 (1.40, 7.85)	0.006
SCQ1 (Routine phlebotomy question)		0.04		<0.001
Do not mind (Reference Category)	1	~	1	~
Fearful	0.42 (0.13, 1.34)	0.14	0.06 (0.01, 0.29)	<0.001
Realise	0.34 (0.13, 0.85)	0.02	0.52 (0.22, 1.23)	0.14
SCQ3 (Nature of concern question)		<0.001		<0.001
No apparent reason (Reference Category)	1	~	1	~
A Concerns about procedural complications	0.13 (0.04, 0.49)	0.003	0.49 (0.15, 1.61)	0.24
B Fear or apprehension of procedure	0.14 (0.04, 0.53)	0.004	0.02 (0.00, 0.21)	0.001
C Pain	0.16 (0.05, 0.50)	0.002	0.18 (0.05, 0.70)	0.01
D Technical skills related concerns	0.29 (0.07, 1.28)	0.10	0.21 (0.08, 0.60)	0.003
E All of the above	0.41 (0.14, 1.21)	0.11	1.05 (0.40, 2.76)	0.92
F Others	0.09 (0.03, 0.30)	<0.001	0.09 (0.02, 0.36)	<0.001
3MS category	-	-	0.59 (0.41, 0.85)	0.005
Low Albumin	-	-	0.23 (0.07, 0.73)	0.01
Informal Care Giver	-	-		0.06
Spouse or Partner (Reference Category)	-	-	1	~
Child	-	-	0.62 (0.14, 2.75)	0.53
Parent	-	-	0.18 (0.04, 0.71)	0.01
Friend, Relative, Sibling or Carer	-	-	1.18 (0.30, 4.54)	0.81
Alone	-	-	0.39 (0.17, 0.87)	0.02

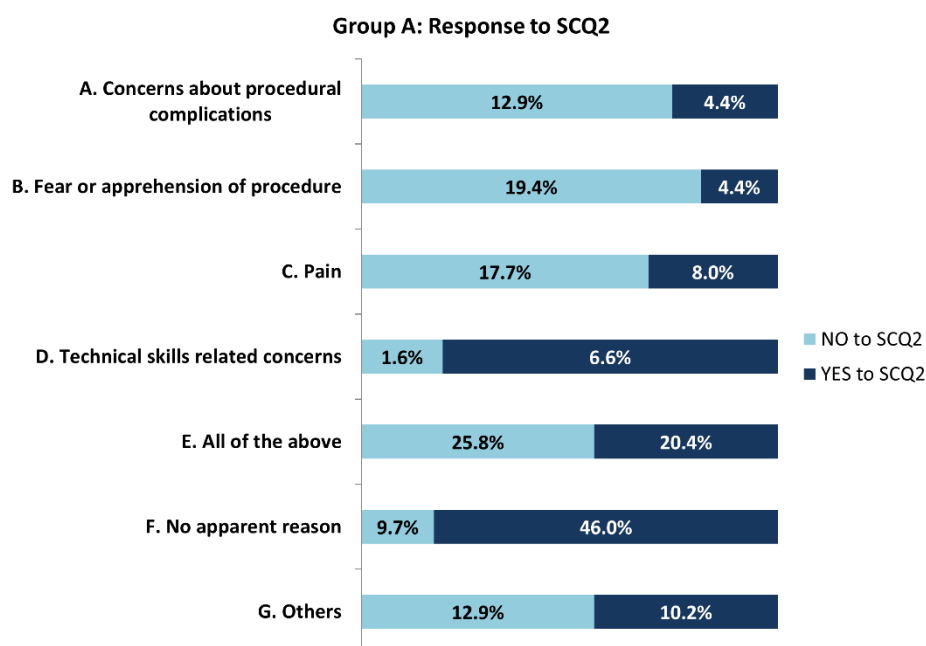


Figure 3: Bar chart depicting reasons for a negative response to 'perceived ability to self-cannulate' amongst predialysis (Group A) patients.

The final predictors of the outcome (yes to SC) in the predialysis group (Table 5) were lower age, readiness to undertake routine phlebotomy (SCQ1) & the type of SC concern projected (SCQ3). The latter means that compared to the response 'no apparent reason', all other category responses are associated with lower odds of responding positively to SC. Significant predictors in the haemodialysis group (Table 5) include lower age, higher education level, higher 3MS category (lower score), absence of low albumin, readiness to undertake phlebotomy and type of SCQ3 response. The latter, in the HD group means that compared to the response 'no apparent reason', all other category responses are associated with lower odds of responding positively to SC. Although TMTB was significant in the univariate analysis at 1% significance level, it was not included at multivariable stage, due to high numbers of incomplete datasets (25%). Using the information above, two predictive models were developed to estimate the probability of identifying predialysis and in-centre haemodialysis patients who may consider self-cannulation (Fig. 4).

Model 1 - Derived from group A data (pre-dialysis; n= 202) and validated on 'A' data, n= 195. The *c*-statistic from the ROC curve is 0.76 (95% CI 0.69, 0.83).

Model 2(a) - Derived from HD patient data (B+C; n= 246) validating on group B (n= 171). The *c*-statistic from the ROC curve is 0.80 (95% CI 0.74, 0.87).

Model 2(b) - Validating on independent group A (n= 178) data. The *c*-statistic from the ROC curve is 0.73 (95% CI 0.66, 0.81).

The Hosmer-Lemeshow, goodness-of-fit test for 'A' has $p=0.58$ and for 'B+C' on itself has $p=0.12$. These *p*-values come from testing the null hypothesis that the model is correctly specified. So $p>0.05$ suggests that we do not reject the null hypothesis for either model. Calibration-in-the-large and

calibration slope are 0.15 and 0.73 respectively (acceptable) for Model 1; 0.08 and 0.68 respectively (acceptable) for Model 2(a) and 0.26 and 0.64 respectively (suboptimal calibration) for Model 2 (b). Model 1 is of most interest and the sensitivity and specificity of the model using a probability cut-off score of 0.486 on the ROC co-ordinates, is 80.6% and 52.1% respectively.

The modeling equations are provided in the supplementary files 1(S1 File) and 2(S2 File).

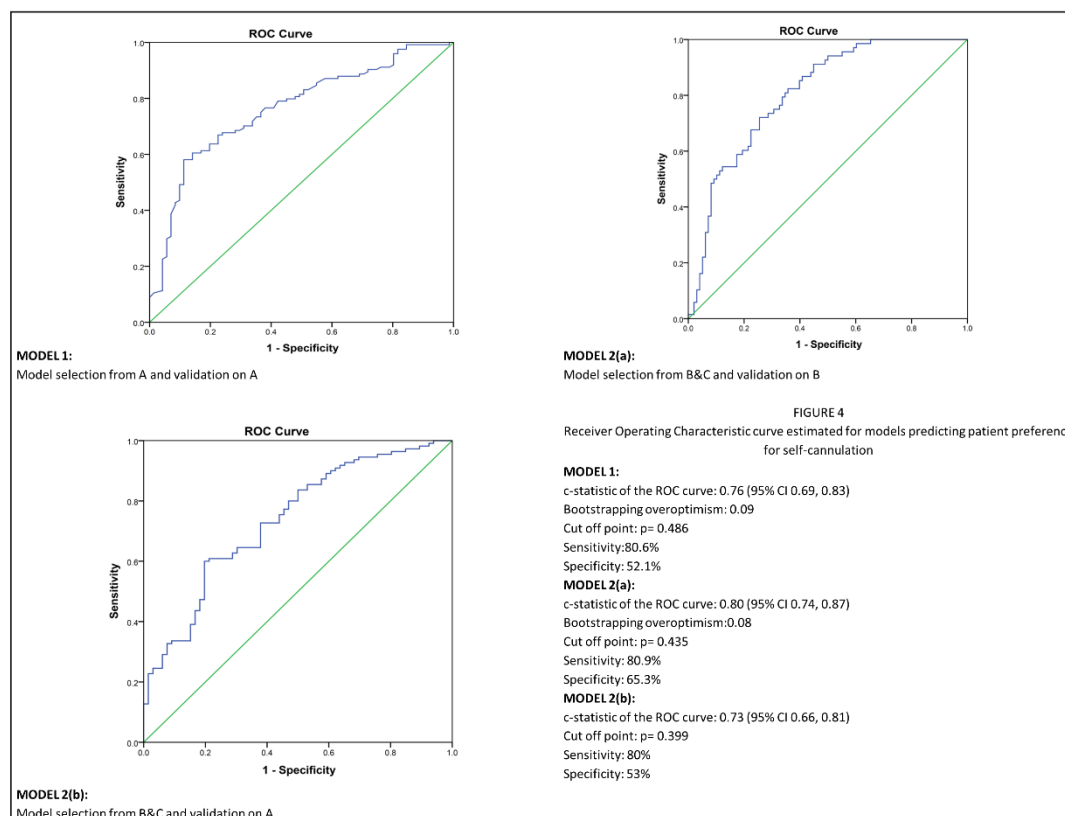


Figure 4: Graphs depicting the Receiver Operating Characteristic (ROC) curves for two models predicting patient preference for self-cannulation.

DISCUSSION

This UK multi-centre study provides an in-depth understanding of self-cannulation preferences in ESRD patients. To our knowledge this is the largest study of its kind to-date, exploring self-cannulation preferences in patients with ESRD. The study has had excellent response rates to the questions on self-cannulation (95%) and associated information from demographic, clinical and psychosocial patient factors (>80%). Furthermore, we have developed models to understand the ‘typology’ of patients who may prefer self-cannulation. A key strength of this study is the way in which some variables have been included for data analyses. Strictly dichotomising variables such as 3MS or BDI, results in loss of information to be ascertained from scores further removed from the cut-off point. Therefore, these variables are included in ordered categories. Not limiting the study to predialysis group that takes decisions on self-cannulation, is very important, so as to incorporate into our understanding, perceptions and characteristics of those who chose to be cannulated (in-centre

group) and those self-cannulating (home HD group) for HD. Another notable strength is that, data are generated from five centres which allow generalizability.

From our data, it is apparent that SC is an important barrier to uptake of home or self-care HD. Reassuringly, in many instances, this is a surmountable barrier. In a recent publication by Pipkin et al, a survey of the FHN trial investigators showed that the most commonly perceived barriers to intensive HD included lack of patient motivation, unwillingness to change from in-centre modality, and fear of self-cannulation[15]. Although ‘fear of SC’ is a broad terminology in use, more information needs to be ascertained from patients as to what the ‘fears’ are about. In another qualitative study of hospital HD and nocturnal home HD patients by Cafazzo et al, fear of SC as a deterrent to HHD, is a recurring theme[16]. Population of interest really, is the predialysis cohort, as once established on a therapy; it is rather difficult to electively change modality.

The predialysis cohort is of particular interest, as they engage with the concept of self-care HD, with no practical insight into the process. Understanding reasons for their negative disposition to SC is vital to providing case-specific intervention. The commonly perceived notion in practice, of pain being a significant deterrent for SC is questioned by the observation that the same proportion of individuals in a self-caring cohort, perceive pain, but, other persuasive belief constructs have determined their self-cannulation decision. Although 1 in 5 individuals are likely to find all aspects of SC overbearing, concerns over procedural complications, pain, and technical-skills which may dominate the decision to consider institutional care, are potentially modifiable. It is interesting that about 10% of predialysis patients who may not consider SC, have no specific reason for doing so, and these groups of individuals may be open to influence over their decision, provided other factors are favourable for self-care HD.

About 30% of patients being offered hospital HD feel able to self-cannulate. This suggests a ‘missed opportunity’ to promote self-care and shared-care in dialysis facilities impacting positively on the ever-constrained staff resource on HD units. This is of particular value in situations where, home adaptations are not feasible and all other patient characteristics allow self-care in hospital. This may also result in lesser waiting times before individuals commence HD, and greater patient independence. It is notable that diabetes is not a deterrent to the idea of perceived ability to self-cannulate. This may be due to the fact that patients are able to draw on their experience of subcutaneous insulin injections and may relate at a practical level with the concept of ‘self-needling’. Needless to say, the indirect impact of diabetes through blunting of cognitive abilities from microvascular disease would have adverse effect on the outcome of interest.

We introduce 2 models of ‘self-cannulation preference’. Model 1, from the predialysis group has shown good discrimination and calibration. Model 2, from the two HD groups has shown

good discrimination and calibration for the ‘in-centre’ group, but, suboptimal calibration for the predialysis validation group. The latter may be due to change in patient characteristics before and after commencement of HD. This often could be partially remedied through recalibration or structural model revisions (adding new variables). In this area, there is no precedent in the published literature. We have included several clinical and behavioural patient-specific parameters, categorised appropriately. Models have been derived from complete cases with minimal loss of cases to missing information. The predictive accuracies of both models are >70%. Validation and calibration procedures are required for these models to be useful in clinical practice and have been performed. Bootstrap re-sampling is a more effective technique for validating a prediction model than data-splitting. The utility of the models is highest in their respective groups (A on A and B+C on B). Nevertheless, validation of the HD model was also carried out on an independent data set in the ‘predialysis’ group, with a predictive accuracy of 71.3%.

The key challenge lies in the identification and management of the patient who is undecided about self-care for HD solely from SC concerns. The application of the SCQ1 as an initial screening tool to all patients appears to be a good discriminator to understand patient preferences in SC. Predictive modelling in this area of self-care HD is a complement to the clinician’s/nurse’s experience, expertise, and intuition and can fit seamlessly into the clinical process. By offering a systematised way to make clinical decisions and utilize resources, the care planning process can be streamlined. In the context of pre-dialysis care, tools to objectively determine SC preference will help focus resource on patients who need them most, and tailor the nature of intervention to the specific case in question. This data is transferable between members of the multi-disciplinary teams thereby allowing a more standardised predialysis service through better understanding, communication, and cooperation in interdisciplinary teams. The SC decision-aid (currently lacking in the portfolio of dialysis decision choices) may allow patient engagement with SC, even if for ‘trial’ of the procedure. Multifaceted approach to managing such patients is required. These may include behavioural counseling for those concerned for various aspects of the procedure. Innovation in SC training through adoption of virtual, 3-D simulation training may alleviate specific concerns for some. These may also have utility as educational tools in the pre-dialysis phase. The role of expert patients as teachers of SC technique remains to be explored. A further step in targeted SC education and training strategies to a specific subgroup willing to engage and likely to succeed may allow effective resource utilisation to drive better outcomes. The models provide scope for standardisation of care by mitigating subjective biases such as staff perceptions and preferences.

The study has a focus on patient perspective and lacks trainer/caregiver perspective on SC. This may be clinically relevant. A prospectively collected large dataset would be the ideal data

from which to derive predictive models. It is important to also externally validate our prediction models on other predialysis and hospital HD patients. That being said, these models (and future improvements to the models) cannot be used as a standalone. These tools are adjuncts to decision-making process by healthcare-providers in order to efficiently manage patients with ESRD and help promote self-care haemodialysis where feasible.

Conclusion

Self-cannulation in dialysis is a neglected area of research in HD and there is an urgent need to address ‘the elephant in the dialysis room’. There are substantial numbers of ESRD patients who may be able and willing to consider SC. This study provides an insight into the modifiable concerns around self-cannulation.

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Disclosures: None

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CHAPTER 3.7

Illness beliefs in end stage renal disease and associations with self-care modality choice

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ABSTRACT

Background: Interest in self-care haemodialysis (HD) has increased because it improves patients' clinical and quality-of-life outcomes. Patients who undertake self-management for haemodialysis, may hold illness beliefs differently to those choosing institutional care, at the time of making modality choice or moulded by their illness and dialysis treatment experience.

Study Design: The study data are derived from the BASIC-HHD study, a multicentre observational study on factors influencing home haemodialysis uptake. 535 patients were enrolled into three groups-Predialysis CKD-5 group, prevalent 'in-centre' HD and self-care HD groups (93% at home). We explore illness perceptions in the cross sectional analyses of the three study groups, using the revised Illness Perception Questionnaire (IPQ-R). Predialysis patients' illness beliefs were reassessed prospectively, typically between 4 and 12 months after dialysis commencement.

Results: Illness beliefs subscales are significantly different between in-centre and self-care HD groups. In a step-wise hierarchical regression analysis, after adjustment for age, education, marital status, diabetes, dialysis vintage, depression and anxiety scores, IPQ-R subscales, personal control ($p=0.01$) and illness coherence ($p=0.04$), are significantly higher in the self-care HD group. In the predialysis group, no significant associations were found between illness representations and modality choices. In prospectively observed predialysis group, scores for personal control, treatment control, timeline cyclical and emotional representations reduced significantly after commencing dialysis and increased significantly for illness coherence.

Conclusions: Illness beliefs differ between hospital and self-care haemodialysis patients. Patient's affect and neurocognitive ability may have an important role in determining illness beliefs. The impact of modality upon illness representations may also be significant and remains to be explored.

INTRODUCTION

End stage renal disease (ESRD) is a global health concern associated with increased morbidity and mortality[1]. With increasing impetus on self-care in ESRD, home haemodialysis (home HD) has seen resurgence in physician-level and patient-level interest and most recently, in practice[2] with the national uptake of home haemodialysis in the UK, rising to 4.7% in 2013[3]. This increase in uptake is also backed by research which has demonstrated benefits of intensive haemodialysis such as that carried out at home, not limited only to clinical and quality-of-life outcomes, but also to cost-effectiveness[4]–[13]. There is growing interest in ‘centre-based’ self-care haemodialysis (HD) where home is not an appropriate location from a patient or the care-provider perspective. Self-care HD affords the patient greater autonomy, but necessitates significant level of engagement not only at the outset, but throughout the course of illness management. Dialysis therapies impose major social, personal, psychological and physical impact on patients and their families. Patients, who undertake self-management using complex technology for haemodialysis either in their own homes or in hospitals, may have illness beliefs different to those choosing institutional care. Equally, as illness perceptions are not fixed but shaped by the knowledge and experience of both the illness and its treatment, those who experience self-care haemodialysis may develop a different set of illness beliefs from those who experience centre-based haemodialysis.

According to the Common Sense Model of Self-Regulation (CSM) [14], when patients are confronted with a threat to their health, such as in permanent kidney failure starting dialysis as a life sustaining therapy, they draw on their personal models of that health threat to guide their behavioural and emotional responses to it. These models comprise a set of “cognitive representations” or beliefs about the threat, and a set of “emotional representations” or emotional responses to the threat. Together, cognitive and emotional representations are referred to as illness perceptions; the two sets of representations are held to drive different sets of responses, but to be interdependent, so that beliefs about the health threat impact on emotional responses to the threat, and vice versa [14]. Illness perceptions are personal and may be idiosyncratic, and are derived both from concrete perceptual experiences of illness (e.g. the experience of symptoms) and from abstract sources of knowledge (e.g. information from health care professionals such as predialysis education before start of dialysis, or in the media). According to the CSM, the effectiveness of behavioural responses to cope with the health threat, which may include seeking medical help and self-management behaviours, is continually appraised and the information gained from these appraisals may be used to modify and update illness perceptions[14]. Research using the framework of the CSM has led to the specification of the dimensions of cognitive representation of illness. These comprise representations of how the illness was caused (cause), how long it will last and what its course

will be (timeline), what the consequences of the illness are (consequences), the symptoms that are associated with the illness (identity) and how the condition is controlled or cured by one's own behaviour or treatment[15], [16].

The illness perceptions of patients with ESRD have received much attention in recent years. It is apparent from a number of studies examining the association between illness perception and outcomes in ESRD patients that personal illness beliefs have a predictive value. Illness perceptions have been shown to be associated with depression, health related quality-of-life, adherence with treatment (fluid and medications), and survival[17]–[22]. As noted above, illness perceptions are thought to be constantly updated as patients acquire new knowledge and experience of their illness[23]. In a longitudinal study of HD patients, over a 2-year follow-up period, patients had fewer negative emotional reactions to the illness, better understanding of the illness, and improved perception of treatment control[24]. Similarly, illness understanding in dialysis patients varies between patients as a function of the length of time on dialysis over a wide range of durations [25] and in the same patient within the first year on dialysis[26]. Understanding patients' illness perceptions is important if we are to understand the emotional impact of ESRD. In the published literature, the impact of home-based dialysis modalities on emotional well-being has been explored in small groups of patients[18]. Information on the extent to which illness perceptions influence adjustment in ESRD especially in relation to the different treatment modalities is largely limited to hospital HD vs home-based dialysis modalities, a significant component of the latter being peritoneal dialysis, another home-based renal replacement therapy. The technological complexity of home HD (particularly during the training phase when patients learn self-cannulation) and the intensive rigorous routine of daily schedules present challenges of a different magnitude to peritoneal dialysis. Therefore, cognitive and emotional representations of patients who undertake self-management in the home HD context is important to understand the disconnect between the clinical benefits and the uptake of the modality.

In the current study, we have explored illness perceptions amongst recipients of hospital and self-care haemodialysis and of those participants in CKD stage-5, predialysis, who have made a modality choice. We have examined whether there are differences in illness perceptions in patients receiving home vs hospital-based haemodialysis. On the basis of the common-sense model, we hypothesize that due to different illness and treatment experiences in the three groups, perceptions will vary as a function of treatment type. More specifically, we hypothesized that as a result of illness experience, self-care haemodialysis patients would have greater illness coherence, personal control and treatment control. Also, as patients acquire information, these beliefs would change significantly with commencement of dialysis, irrespective of modality type. Furthermore, we hypothesised that a higher score on 'positive'

beliefs about illness (defined as higher illness coherence, personal control and treatment control) was associated with choice of self-care therapy in the predialysis stage.

METHODS

The IPQ-R study data are derived from data ascertained for the BASIC-HHD study[27]. The BASIC-HHD study is a comprehensive and systematic study of barriers and enablers of the uptake and maintenance of home HD therapy. The study involves five UK centres, with variable prevalence rates of home HD. An integrated mixed methodology (convergent, parallel design) has been adopted for the BASIC-HHD study in a combined cross-sectional and prospective study design. The methodological details and scope of data collected in the BASIC-HHD appear in a published protocol[27].

Participants and Procedure

Data presented here are derived from the cross-sectional and prospective segments of the BASIC-HHD study. 535 patients were enrolled into three groups. Predialysis patients for the CKD-5 group, prevalent ‘in-centre’ HD patients were approached if they fulfilled eligibility criteria and complete study specific questionnaires. All self-care haemodialysis patients (93% at home) from each participating centre were also approached. Predialysis patients were approached consecutively from the predialysis clinics and hospital haemodialysis patients were approached in consecutive order across all shifts until the centre target for recruitment was reached. Most participants approached were willing to engage with the study and reasons for declining participation included a lack of interest in research participation, and ‘research’ fatigue. Psychological measures employed in this study were a part of compilation of questionnaires. HD patients returned the questionnaires on the same day or within a couple of dialysis sessions ‘in-centre’. Home HD patients returned it by post, as did the pre-dialysis, CKD-5 patients. Neuropsychometric assessments were carried out ahead of dialysis commencement. Visually impaired patients could respond to IPQ-R questions posed to them by the research team member. A small subset of predialysis patients(n=42) commenced dialysis and these patients completed the study questionnaires again between months 4 and 12 post dialysis commencement.

Measures

The Revised Illness Perception Questionnaire (IPQ-R) was used to measure illness representations. The psychometric properties of the IPQ-R have been previously tested on centre-based HD patients, and the structural validity, internal reliability, test-retest reliability, and discriminant validity are within acceptable limits. The IPQ-R assesses nine components of illness representation in three sections. It is a generic instrument, designed to be adapted for use with different health conditions. For the present study the term “my kidney disease”

was used to describe the patient's illness. The first section seeks to establish *Identity* where participants are asked 'yes/no' questions about 14 different symptoms and if they believe these symptoms are related to their kidney disease. This aspect has not been considered for analysis in the present study.

The second section contains 38 questions addressing 7 subscales. Subscales which theoretically represent positive beliefs about the controllability of the illness and a personal understanding of the condition include *personal control*, *treatment control*, and *illness coherence* dimensions. High scores on *identity*, *timeline*, *consequences*, and *timeline cyclical* scales demonstrate negative beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, consequences of the illness, and the cyclical nature of the condition, respectively. The third section focusses on 'causes' and includes 18 patient-perceived causes of underlying kidney disease (i.e., lifestyle, hereditary, stress, chance, drugs etc.). Sections 2 and 3 require participants to respond using a 5-point Likert scale (strongly disagree to strongly agree). Cronbach's alpha for all subscales was ascertained as a measure of internal consistency in the study group.

Additionally, all study participants completed a compilation of questionnaires. In order to examine the potential impact of patient's affect and cognitive ability on illness perceptions, additional instruments analysed in the present study include Beck Depression Inventory II (BDI), State and Trait Anxiety Inventory-Trait (STAI-T) and the modified mini-mental state examination (3MS). The scores from these instruments were considered in ordered categories for analyses: BDI (0-10, 11-15, 16-20, 21-25, 26-30, 31+), STAI-T (20-29, 30-39, 40-49, 50+). 3MS (94-100, 86-93, 81-85, 76-80, ≤ 75).

Missing data

Overall the study had excellent data completion across all instruments used in the study (>82%). The IPQ-R subscales were complete in >80% of the responses from all three study groups across all study subscales (Figure 1).

Statistical Analyses

Analyses were performed using SPSS 22 and STATA 14. Patient characteristics between groups were assessed using chi-squared tests and Kruskal-Wallis tests. The conventional two-sided 5% significance level was used. Separate analyses were undertaken for the combined haemodialysis group (self-care and hospital) and the predialysis group. Missing data (using the same predictor variables) were analysed using chi-square test, Fischer's exact test, T-test and Mann-Whitney U test.

For the combined haemodialysis group, a multivariable backwards stepwise regression was performed to ascertain the illness perception variables that have the most significant association with the HD modality. The dependent variable was the modality group. The predictor variables (clinical, demographic, psychological and cognitive tests) which were

significant at the 15% significance level in the single variable analysis were included in the multivariable models. Variables were removed, until only those statistically significant at the 5% level remained. Hierarchical regression was also used to assess the significance of differences in illness beliefs between study groups in an adjusted analysis that accounted for clinically important variables. In stage one: age, education level, marital status, dialysis vintage and diabetes status were added. In stage two BDI and STAI-State and Trait were included and at the final stage, the IPQ-R subscales were added. In the predialysis group, multiple regression including the seven subscales was considered with modality choice as the outcome. Any patients in this predialysis, CKD 5 group, who had previous experience of dialysis were removed from the analysis (n=12). Paired analysis of IPQ-R subscales using the Wilcoxon signed rank test and paired t-test was conducted for the prospective analysis of CKD5 patients who commenced dialysis.

Study Registration

This study has been reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346). Written, informed consent from participants was obtained for the study.

RESULTS

Recruitment into the study and data completeness (>80%) has been presented in the study flow chart (Figure 1).

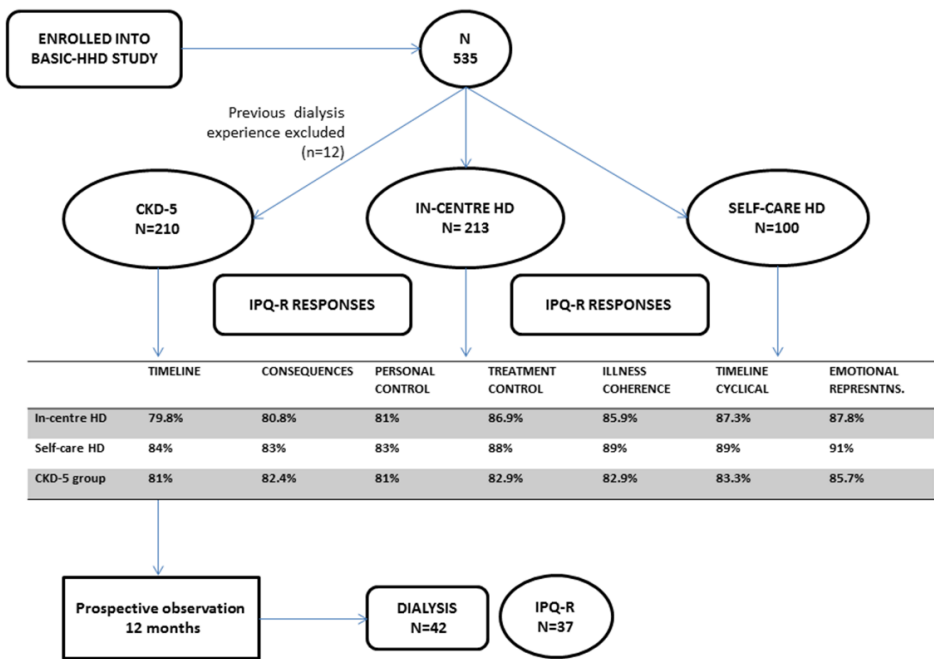


FIGURE 1 Study Flow Diagram

Responders vs non-responders

There are no statistically significant differences in characteristics between those with no missing data and those with some missing data in the HD groups. There is statistically significant difference in the proportion of non-white patients with missing data compared to those with no missing data in the predialysis group. This is likely related to lack of knowledge of English language, sufficient to respond to the questions.

Table 1: Characteristics of patients included in the study				
Variable	CKD-5 (N=210)	Hospital HD (N=213)	Self-care HD (N=100)	P-value
Age¹	62.00 (51.75-69.00)	59.00 (46.50-68.00)	53.00 (44.00-59.75)	<0.001
Education² – (post-high school)	50/205 (24.4%)	38/203 (18.7%)	42/97 (43.3%)	<0.001
Ethnicity² non-white	21/210 (10.0%)	26/212 (12.3%)	13/100 (13.0%)	0.67
Employment² Retired Unemployed Salaried/self-employed	104 (49.5%) 40 (19.0%) 66 (31.4%)	95 (45.0%) 74 (35.1%) 42 (19.9%)	35 (35.4%) 25 (25.3%) 39 (39.4%)	<0.001
Dialysis vintage³	-	2.72 (1.11-5.23)	3.68 (1.44-7.12)	0.039
Number of dialysis sessions per week³	-	3.0 (3.0-3.0)	3.5 (3.0-5.0)	<0.001
CCI¹	5.0 (3.8-6.0)	4.00 (3.0-6.0)	4.00 (3.0-5.0)	<0.001
Diabetes²	72/210 (34.3%)	65/210 (31.0%)	14/99 (14.1%)	0.001
Heart failure²	12 (5.7%)	11 (5.2%)	4 (4.0%)	0.82
BDI (score)¹	10.0 (5.0-18.0)	11.0 (5.0-20.0)	10.0 (4.0-20.0)	0.59
STAI-State (score)¹	36.0 (26.8-45.3)	34.0 (27.0-45.0)	35.0 (24.0-43.0)	0.45
STAI-Trait (score)¹	39.0 (29.0-47.0)	37.0 (29.0-47.0)	36.0 (28.0-48.0)	0.69
3MS (score)¹	N=196 94.0 (89.0-98.0)	N=198 91.0 (87.0-96.0)	N=86 96.0 (89.0-98.0)	0.001
Caregiver presence² /Alone	51/206 (24.8%)	66/205 (32.2%)	15/97 (15.5%)	0.007
CKD 5 education evening²	77 (36.7%)	31 (14.6%)	25 (25.0%)	<0.001
Peer patient education²	94 (44.8%)	59 (27.7%)	39 (39.0%)	0.001
Cause of ESRD² Hypertensive nephrosclerosis Diabetic Nephropathy Glomerulonephritis Polycystic Kidney Disease Renovascular Disease Chronic Pyelonephritis Others Unknown	41 (19.5%) 55 (26.2%) 18 (8.6%) 25 (11.9%) 5 (2.4%) 8 (3.8%) 37 (17.6%) 21 (10.0%)	14 (6.6%) 48 (22.6%) 33 (15.6%) 23 (10.8%) 9 (4.2%) 16 (7.5%) 39 (18.4%) 30 (14.2%)	10 (10.0%) 11 (11.0%) 16 (16.0%) 23 (23.0%) 0 (0%) 6 (6.0%) 16 (16.0%) 18 (18.0%)	<0.001

¹Median and interquartile range presented with p-value from a Kruskal-Wallis test

²Number and percentage with p-value from a Pearson chi-squared test

³Median and interquartile range presented with p-value from a Mann-Whitney U test
Pre-dialysis excludes those who previously had dialysis (n=12)

Patient characteristics in the different study groups

Characteristics of patients included in the study have been presented in Table 1. The three study groups are different from each other with respect to age, education level, dialysis vintage, Charlson comorbidity index, cause of ESRD, peer patient education, presence of

informal care-giver and in the overall numbers of patients from each study centre. Between patients in the dialysis groups, the self-care cohort was relatively younger, had higher levels of post-high school education, had lower prevalence of diabetes, often had an informal care-giver and had greater number of dialysis sessions per week compared to the 'in-centre' HD recipients. Between groups overall, there was no difference in anxiety and depression scores.

Cronbach's Alpha

The overall measure of internal consistency was good for the IPQ-R subscales although lower for treatment control, and the individual results are as follows: Timeline ($\alpha=0.80$); Consequences ($\alpha=0.73$); Personal control ($\alpha=0.76$); Treatment control ($\alpha=0.63$); Illness coherence ($\alpha=0.90$); Timeline cyclical ($\alpha=0.80$); Emotional representations ($\alpha=0.88$).

Illness beliefs amongst haemodialysis patients

There are differences in illness beliefs between hospital and home haemodialysis patients. The single variable analysis of illness beliefs in the entire HD study cohort suggests that all subscales of the IPQ-R are associated with BDI and STAI-T scores (Table 2). In the single variable analysis with 'group' as the outcome variable, several clinical and psycho-socio-demographic factors are associated with belonging in the 'in-centre' vs 'self-care' group. With respect to subscales of the IPQ-R, significant differences exist between the two HD groups. Self-care haemodialysis patients have greater perceived timeline scores ($p=0.004$) and illness consequences ($p=0.037$), higher personal control beliefs ($p=0.037$) and greater illness coherence ($p=0.001$) (Appendix S1). All variables that were significantly associated with modality group at the 15% level in the single variable analysis were included in multivariable models with 'group' as the outcome variable. In this analysis, younger age, post high-school education, non-diabetic status, having a spouse, and greater sense of personal control and of timeline were significantly associated with the self-caring haemodialysis group. Illness coherence was the last variable to be removed from the model (Table 3).

Table 3: Multivariable analysis depicting odds ratios for variables associated with self-care haemodialysis		
Variable	Odds ratio (95% CI)	p-value
Age (per ten years)	0.60 (0.46, 0.80)	<0.001
Education		0.003
High school (reference)	1 (-)	
Post high school	2.86 (1.43, 5.72)	
Diabetes		0.008
No diabetes (reference)	1	
Diabetes	0.30 (0.13, 0.73)	
Marital status		<0.001
Married or partner	1 (-)	
Single	0.12 (0.05, 0.33)	
Divorced or separated	0.71 (0.25, 2.00)	
Widowed	0.31 (0.06, 1.50)	
Timeline (per score increase)	1.08 (1.00, 1.17)	0.041
Personal control (per score increase)	1.08 (1.01, 1.15)	0.018
Illness coherence (per score increase)	1.07 (0.99, 1.15)	0.088

(Odds Ratios > 1 = Self-care haemodialysis group)

TABLE 2: Single-variable analysis of the subscales of illness beliefs with clinical and psychosocial variables															
	Age	Education	Dialysis Vintage	Diabetes	Heart Failure	Caregiver presence	Peer patient education	Marital status	BDI	STAI-T	Dialysis sessions/week	Ethnicity	Gender	Employment	Group
Timeline*	0.61	0.12	0.04	0.016	0.39	0.42	0.25	0.30	0.085	0.27	0.006	<0.001	0.89	0.71	0.012
Consequences*	0.06	0.61	0.52	0.32	0.53	0.84	0.15	0.092	<0.001	<0.001	0.21	0.71	0.86	0.32	0.051
Personal control	0.57	0.27	0.90	0.022	0.97	0.46	0.12	0.60	0.012	0.004	0.94	>0.99	0.046	0.003	0.037
Treatment control	0.39	0.10	0.12	0.039	0.45	0.41	0.72	0.85	0.014	0.003	0.001	0.06	0.58	0.004	0.20
Illness coherence	0.08	0.054	0.002	0.069	0.72	0.90	0.21	0.29	0.024	0.001	0.016	0.59	0.53	0.15	<0.001
Timeline cyclical	0.09	0.72	0.99	0.33	0.87	0.59	0.30	0.46	<0.001	<0.001	0.88	0.28	0.002	0.099	0.84
Emotional representations	0.01	0.26	0.33	0.39	0.97	0.89	0.064	0.44	<0.001	<0.001	0.72	0.33	0.004	0.018	0.71

*Transformation used: LN (35 - Variable)

We also carried out a step-wise hierarchical logistic regression analysis to find significant associations of HD group status (self-care vs in-centre) with demographic and medical variables, mood and illness perceptions (Figure 2). After adjustment for age, education, marital status, diabetes and dialysis vintage in step 1, BDI and STAI-S/STAI-T score in step 2, the inclusion of all seven illness perception subscales in step 3 shows that the most significant differences between the groups with respect to illness beliefs lie in personal control ($p=0.01$) and illness coherence ($p=0.04$), higher in the self-care HD group. BDI and STAI, although not significantly different between the two study groups, was found to be correlating with several dimensions of illness perception. Illness coherence is associated with higher 3MS scores in the HD study population.

Personal control or treatment control beliefs held by participants were explored for any significant association with their perceived ability to self-cannulate for haemodialysis. No significant association was determined in a logistic regression analysis at 5% significance level ($p=0.09$). However, higher sense of personal control was associated with greater perceived self-cannulation ability.

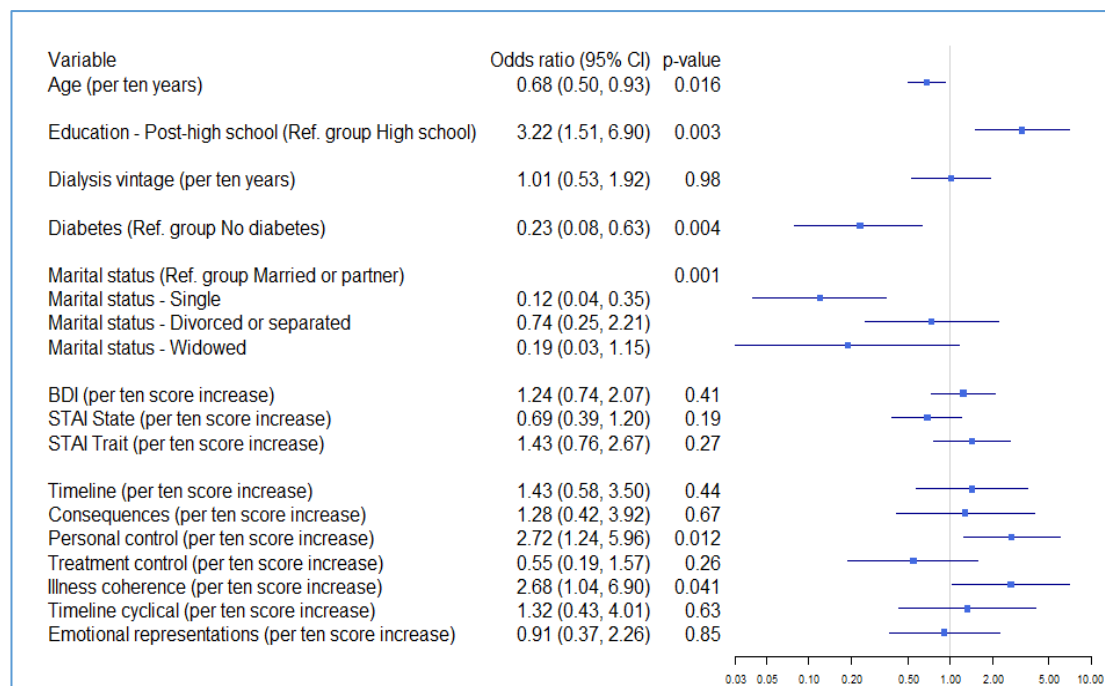


FIGURE 2: Hierarchical logistic regression depicting associations of self-care vs hospital care group status with clinical, sociodemographic and psychological factors (N=214)

OR>1 denotes self-care HD group

IPQ-R in the CKD-5 study group

CKD-5 participants in the cross-sectional cohort made modality choices. We examined the illness beliefs at this stage to see if there is a difference observed between those who choose ‘in-centre’ HD vs home HD and in-centre HD vs the combined home dialysis groups (peritoneal dialysis (PD) and home HD). The results are presented in Table 4. Essentially, no differences were found between the hospital and home HD groups, but, illness coherence was significantly different between choosers of ‘in-centre’ HD and the combined home dialysis group.

TABLE 4: CKD-5 Predialysis Group-Differences in illness perceptions between participants who choose hospital HD vs other modalities (logistic regression analysis)				
IPQ-R subscale (per score increase)	Hospital vs Home HD choice		Hospital vs PD+HD combined	
	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value
Timeline	0.92 (0.81, 1.05)	0.21	0.97 (0.88, 1.07)	0.58
Consequences	1.07 (0.91, 1.25)	0.43	0.97 (0.87, 1.07)	0.52
Personal control	1.09 (0.95, 1.25)	0.20	1.07 (0.98, 1.18)	0.14
Treatment control	0.93 (0.77, 1.12)	0.45	0.88 (0.77, 1.01)	0.071
Illness coherence	1.11 (0.98, 1.25)	0.11	1.15 (1.04, 1.26)	0.004
Timeline cyclical	0.98 (0.82, 1.16)	0.78	0.95 (0.84, 1.07)	0.40
Emotional representations	1.03 (0.92, 1.14)	0.66	1.03 (0.95, 1.12)	0.50

The 12 predialysis patients who had non-zero data for dialysis vintage were excluded from the analysis.

OR>1=Self-care HD choice

HD: Haemodialysis

PD: Peritoneal Dialysis

TABLE 5: Change in illness perception from predialysis to dialysis phase (n=37)				
Variable	Pre Mean (std. dev.)	Post Mean (std. dev.)	Change Mean (95% CI)	p-value (paired t-test)
Timeline*	27.0 (22.0-30.0)	29.0 (25.0-30.0)	0.0 (-1.0, 4.0)	0.11 ¹
Consequences	22.2 (3.5)	21.9 (4.0)	-0.3 (-1.5, 1.0)	0.67
Personal control	20.5 (4.1)	18.3 (5.8)	-2.2 (-4.1, -0.3)	0.027
Treatment control	17.0 (2.8)	15.0 (2.7)	-1.9 (-3.0, -0.9)	0.001
Illness coherence	17.0 (4.7)	19.9 (5.5)	2.8 (0.7, 5.0)	0.012
Timeline cyclical	11.2 (3.0)	8.6 (3.4)	-2.6 (-3.8, -1.3)	<0.001
Emotional representations	18.1 (5.1)	16.1 (5.5)	-2.0 (-3.7, -0.3)	0.021

*Median and interquartile range due to non-normality (median and IQR change in change column)

¹Wilcoxon signed-ranks test

IPQ-R and prospective data analysis

In the subset of participants who commenced dialysis (n=37) in the study period (12 months), their illness perceptions were typically assessed >4 months after commencement of therapy and compared with those obtained at baseline (hospital-based HD (n=24), home HD (n=0) and peritoneal dialysis (n=13) participants). Patients had lower personal control and treatment control 4 months after starting dialysis, perceived their kidney condition to be less cyclical and had less negative emotional representations of their illness. Additionally, participants had greater understanding of their kidney disease as evidenced by higher illness coherence scores after starting dialysis (Table 5).

Perceived causes of their illness

Participants in both groups identified the beliefs they held about the causes of their illness. No significant differences were identified between the groups as to several internal and external causes of their illness, with the exception of smoking (Figure 3). A significantly higher proportion in the self-care group disagreed that smoking was responsible for their kidney disease. Over 40% of participants in both groups attributed their illness to chance or bad luck. A higher proportion of patients in the self-care cohort agree to ‘self-punitive’ factors contributing in some way to the reasons for their illness. About 25% of patients in both groups also attributed ‘poor medical care’ as a cause of their illness.

DISCUSSION

Beliefs about illness course are potentially important predictors of self-managing behaviour in the chronic illness context, perhaps because they perceive their illness to be serious or severe. Disease duration (timeline) typically refers to whether the disease is believed to be short or long-lasting. In previously published research, patients who viewed their condition (coronary heart disease, asthma, hypertension, diabetes) as chronic were more likely to be adherent with treatment regimens[28]–[30]. From our data, it is apparent from the multivariable model that self-care haemodialysis patients show greater understanding of the disease chronicity. This perhaps allows individuals to undertake the behaviour that allows self-management – in this context it includes frequent dialysis, fluid and dietary control etc. It is also likely, that the abstract notion of longer illness duration belief (*My disease is chronic...*) is subdued by symptoms stability achieved through better dialysis, in turn promoting self-care haemodialysis. Another construct that is closely aligned with ‘illness course’ belief is the ‘illness consequences’ belief. In the unadjusted single variable analysis, self-care HD patients perceived greater impact of illness consequences upon their lives. This perceived seriousness of their condition possibly leads to taking control of their disease management into their own hands. Equally, it is difficult to discern the perceived effects of home-based HD, the treatment,

from disease effects on people's lives, in the prevalent haemodialysis patients. It is surprising to note that patients with a higher co-morbidity profile in the 'in-centre' haemodialysis setting perceive lower illness consequences than their home HD counterparts. This suggests that perception of illness consequences from extra-renal morbidity may temper the expectations from their illness secondary to kidney disease.

In our study, in both the multivariable analysis and hierarchical regression models, perceived 'personal control' separated 'in-centre' patients from 'self-care' haemodialysis patients. As hypothesised, the sense of personal control was significantly greater in the self-care group. It is important to understand if the sense of perceived personal control resulted in self-selection into the self-care HD group or if in fact, this may have been the result of the positive clinical outcomes associated with home HD. The causal direction is difficult to ascertain from a cross-sectional study design. However, we examined a large cohort of predialysis patients who made their modality choices and we examined illness beliefs between groups which made different choices and found no difference in 'personal control' beliefs in patients who chose hospital-based HD vs home-based dialysis therapies. In a study by Timmers et al., significant differences in perceptions of personal control and understanding were found between haemodialysis and peritoneal dialysis patients[31], but not so in another study[18]. The reasons for the inconclusive findings could well be the manner in which the different types of PD therapies were considered together for analysis in the studies and the lack of larger patient numbers in the different study groups. This emphasizes the need to look at modality specific clinical and psychological outcomes. The notion of increasing sense of personal control and thereby potentially better psychological adjustment to therapy is an attractive option for patient care[32]. The concepts of shared care and 'in-centre' self-care lend themselves to this sense of increased control. This may well facilitate a proportion of patients to consider home haemodialysis in the future, as their illness and treatment understanding improves over time. In fact in our study, perceived ability to self-cannulate was associated with a greater degree of perceived personal control.

Illness coherence was found to be significantly higher in the home HD cohort after adjustment for demographic, clinical and psychological variables. Patients in the predialysis setting are provided education on various modality options. The information they acquire is in the abstract and no difference was observed in our study cohorts between illness understanding in predialysis patients who chose haemodialysis in hospital vs at home. However, this difference is significant between prevalent HD patients in the different locations. In the longitudinal examination of predialysis patients, illness coherence increased significantly after dialysis, likely a result of the actual experience of dialysis. It is however useful to note that illness understanding is significantly different between the hospital HD vs home-based dialysis choosers (combined PD +HD). This is likely a result of a lack of patients choosing home HD

compared to PD and also the lack of adjustment for other variables in this subset analysis. This finding suggests that perhaps global cognitive function does play an important role in illness understanding as suggested also by the significant association of this aspect of illness belief with higher 3MS scores in the prevalent HD population in our study. This allows us to explore educational and psychological intervention options in the predialysis phase and beyond to influence the choice of self-care haemodialysis if appropriate.

Beliefs about causes of illness have been studied historically within an attribution theory framework in several clinical conditions. Attribution theory helps classify beliefs into internal and external causative factors. Having a causal theory about one's illness has been found to be related to better adjustment and coping in some situations. We explored the causal beliefs in HD patients based in hospital and those who self-care. As suggested by authors of the IPQ-R[15], principal components analysis was carried out, but, no satisfactory scales emerged, indicating that different causal beliefs do not cohere. The lack of difference between the two groups with respect to perceived causes of their illness is an important finding. The great majority of patients in both study cohorts, disagreed with the factors posed to them as their causes of illness, although the extent of disagreement was significantly greater in the self-care cohort. Amongst those who agreed, greater proportion of patients in the self-care cohort identified stress and other behavioural factors for their belief in illness causation. Whilst causal beliefs were not significantly different in the overall comparison between the two groups, the positive responses may in fact be a reflection of the day-to-day experience of living with the illness and coping with the treatment regimens at least in some instances (as the original cause of kidney disease may have been diagnosed several years earlier). Therefore, effects of causal attributions on modality choice or adjustment with therapy is best studied prospectively.

This is the first study to report a strong association of objective neurocognitive deficit (3MS) with perceived illness coherence in the context of ESRD. The association between neurocognitive ability, especially, executive functions on self-regulation is well established[33]. However, the systematic examination of the relation between neurobiological factors alongside social-cognitive, emotional, affective and physiological processes in ESRD remains to be explored. That, neurocognitive ability may moderate the association between attitude, intention and behaviour is key to understanding the individual differences in biologically ingrained self-regulatory abilities and the response to health and illness communication. This could be a subject of future research.

In our study, we have explored illness beliefs in large, representative cohorts of hospital and home haemodialysis recipients. The study provides an understanding of illness beliefs prevalent in the hospital vs the self-care haemodialysis groups, and in predialysis vs dialysis participants. It remains to be seen whether interventions may be effective in driving changes in negative illness perceptions amongst predialysis and hospital haemodialysis patients,

resulting in a positive impact on patient experience and outcomes in dialysis. We have considered sociodemographic factors and psychological dispositions and neurocognitive function of individual participants in the analyses. The study has had excellent response rates to all study-related questionnaires (82% overall). The internal consistency of IPQ-R in this study cohort is good overall. A key strength of this study is also the way in which some variables have been utilised for data analyses. Strictly dichotomising variables such as BDI or STAI-S/T/3MS, results in loss of information to be ascertained from scores further removed from the cut-off point and as such, the categories have been treated as linear variables.

The cross-sectional design makes causal inferences difficult. The directionality of the significant associations found between self-care HD and patients' perceptions of illness understanding and personal control cannot be established and reciprocal causation cannot be ruled out. Significant proportion of cognitive test scores were missing and could not therefore be considered for the regression models. The duration of prospective observation of predialysis patients did not allow us to capture a large number of dialysis starts.

Practice implications

Understanding illness beliefs of patients with end stage renal disease is paramount in effecting self-care behaviours. As illness understanding evolves, education and information may be perceived differently in the predialysis and dialysis phases. Designing such education programmes may require more in-depth understanding of patients' psychological factors. Opportunities to promote self-care should be sought in both these phases of treatment journey. That self-care may impart a greater degree of perceived sense of control and ability is an interesting outcome for patients in any setting- hospital or home-this may influence clinical benefits noted with this treatment modality, reinforcing the message around self-care haemodialysis. The nuances of modality specific illness beliefs are important to comprehend so that interventions may be tailored to individual needs. It would be interesting to further understand if different levels of patient engagement (shared care) in haemodialysis can alter illness beliefs in a positive way so as to influence important clinical and quality-of-life outcomes in hospital HD patients.

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Disclosures

None

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CHAPTER 3.8

The burden of cognitive impairment in patients with end stage renal disease and impact on dialysis modality choice

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ABSTRACT

Background: Kidney disease is associated with significant cognitive dysfunction. Executive brain dysfunction is most often affected in patients with renal impairment. Subjective reports of cognitive ability have not been studied extensively in chronic kidney disease. We investigate the association between objective and subjective cognitive function in predialysis patients and also investigate if cognitive function is significantly associated with self-care dialysis modality choice.

Methods: The study of cognition in predialysis phase of chronic kidney disease is part of the BASIC-HHD study, a multicentre, observational study of barriers and enablers of home haemodialysis. From the cross-sectional arm, 220 predialysis patients' data was used to ascertain the demographics, clinical, laboratory and neuropsychometric variables. The latter includes trail making tests A and B- for executive function; 3MS-for global cognitive function and metacognition questionnaire for subjective assessment of one's cognitive ability. The outcome variable was hospital and self-care modality choice. Deficit in cognition has been defined as 3MS score <80 and TMTA/B scores >1.5 SD above the mean.

Results: Within the study cohort, 90 patients chose hospital haemodialysis and 114 patients chose self-care dialysis. The median 3MS, TMTA and B scores were greater for the hospital vs self-care group. Metamemory was not significantly different between groups but metaconcentration score was significantly worse in the hospital-choice group. Univariate analysis showed variables significantly ($p < 0.05$) associated with self-care modality choice- these included lower TMT A and B scores and higher metaconcentration scores amongst others. Hierarchical regression showed highly significant association between perceived concentration and self-care modality choice ($p < 0.01$). Adjusted and unadjusted analyses showed a significant association between perceived concentration and TMTB scores ($p < 0.01$). With every 1.6-minute increase in TMTB, there was a one-unit reduction in metaconcentration score and this was associated with 20% lower odds of choosing self-care modality over hospital haemodialysis.

Conclusions: Patient's own perception of their cognitive ability has a significant association with self-care modality choice. Subjective report of 'metaconcentration' is strongly associated with poorer outcome on trails making test B, a test of executive brain function.

INTRODUCTION

Chronic Kidney Disease (CKD) is a worldwide public health issue[1, 2]. The shift in demographics to a more aging population has meant a rising proportion of individuals diagnosed with CKD. This also means that, a significant proportion will start dialysis at some point. Incident renal replacement therapy (RRT) numbers, in the UK, have increased from 50 per million population (pmp) in 1980 to over 150 pmp in 2013 for the age group 45-64[3]. Rising prevalence of type 2 diabetes and obesity around the world (8.6% worldwide)[4], is likely to create a surge in numbers of patients in CKD stages 4 and 5. Morbidities in this population cohort are largely related to cardiovascular and cerebrovascular health. Cognitive deficits are increasingly being recognised as a major problem with a three-fold increase in CKD compared to the general population[5]. This is a potential new area for research into its pathogenesis and management. The management of cognitive deficits is desirable very early in the course of CKD as more advanced stages of kidney disease are associated with greater impairment of cognitive function[6]. In one study, those with mild, moderate and severe renal impairment were compared, and the authors concluded that for every 10 ml/min decrease in estimated glomerular filtration rate (eGFR), the risk of cognitive dysfunction increased by 15%-25%[7]. This issue is more of a problem in older individuals and those established on dialysis, with prevalence of cognitive impairment in haemodialysis patients estimated to be about 30-70%[8]. The presence of cognitive impairment in this cohort is also associated with higher mortality[9, 10]. The pathogenesis of the accelerated cognitive decline in CKD is attributable to vascular injury from traditional risk factors, and from direct neuronal toxicity of uraemic retention solutes[11]. It is believed that microvascular disease of the brain is responsible for the pattern of cognitive deficits seen in kidney disease and is related to the patients' vascular risk profiles. This is typically manifest as impaired executive brain function. The focus on cognition in CKD is extremely important as the notion of self-care haemodialysis relies on cognitive intactness. There is greater impetus on self-management in long term conditions[12, 13], but the cognitive context in which such decisions are taken by patients' needs further research. This applies to both objective cognitive deficits and patient's assessment of his or her own cognitive ability. The latter is grossly underrepresented in kidney disease literature. Few studies have been published to date in patients with kidney disease, specifically seeking to examine the association between subjective and objective cognition assessments[14, 15]. The KDQOL-CF subscale with three questions was shown to be a limited instrument for accurately assessing cognitive function[15] and bore no relationship with executive function test, most implicated in CKD[16-18]. More recently, a study found modest

correlation between subjective and objective assessments but, the former was a predictor of the patient's self-reported measure of activities of daily living, although both subjective reports may well be influenced by negative affectivity[14, 19]. In other population groups, subjective assessment of impaired cognition has been associated with poorer health-related quality-of-life, reduced daily functioning[20] and increased risk of hospital attendance[21, 22] and is also predictive of future cognitive decline[23-25]. Besides, the identification of cognitive impairment is important to assist patients in making well-informed treatment decisions, in ensuring treatment compliance and in preventing functional decline[26]. The choice of self-care dialysis decisions is expected of patients after information on dialysis modalities is provided to them. Hence, the possibility of the influence of patient's assessment of how their memory works, and how they judge their own abilities and effectiveness may predict their choice of dialysis modality.

The aims of the present study are

- a) Describe the brief metacognition questionnaire in patients with CKD-5 as a measure of subjective cognitive impairment and explore the association between subjective and objective cognition tests.
- b) Examine associations of dialysis modality choice (hospital vs self-care) with measures of objective cognition assessment including global cognition and executive brain function and subjective cognition assessments, including memory and concentration.

METHODS

Participants and recruitment

Data for the present study are derived from that ascertained for the BASIC-HHD study[27]. The BASIC-HHD study is a comprehensive and systematic study of barriers and enablers of the uptake and maintenance of home HD therapy. The study involves five UK centres, with variable prevalence rates of home HD. An integrated mixed methodology (convergent, parallel design) has been adopted for the BASIC-HHD study in a combined cross-sectional and prospective study design. The methodological details and scope of data collected in the BASIC-HHD appear in a published protocol[27]. Data presented here are derived from the CKD-5; predialysis cohort of the BASIC-HHD study. 222 patients were enrolled in this group. Predialysis patients for the CKD-5 group were approached if they fulfilled eligibility criteria and were willing to undertake neuropsychometric assessments and complete study specific questionnaires.

Study Registration

This study has been reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346). Written, informed consent from participants was obtained for the study. Psychological measures employed in this study were a part of compilation of questionnaires. Blood sampling and neuropsychometric assessments were carried out at their routine hospital clinic visits. Visually impaired participants were excluded from this analysis (n=2).

Independent variables

These included objective tests of cognition, Trail making tests A/B[28], Modified Mini Mental State Examination (3MS)[29], subjective assessment of cognition scales- Metacognition questionnaire[30], demographics- age, gender, ethnicity, education, employment and marital status; clinical variables- Charlson Comorbidity Index (CCI)[31], cause of end stage renal disease (ESRD), diabetes, heart failure, intracranial vascular events, ischaemic heart disease, systolic and diastolic blood pressures; laboratory variables- urea, creatinine, phosphate, PTH, bicarbonate, albumin, haemoglobin and medications including Angiotensin Converting Enzyme (ACE) inhibitors, central nervous system influencing drugs, antidepressants, antiplatelets, cholesterol-lowering drugs, erythropoietin, folic acid and the number of anti-hypertensive drugs and total pill burden; psychological screening tools- Beck Depression Inventory(BDI)[32], State and Trait anxiety inventory (STAI)[33].

Cognitive Assessments

Objective tests:

Tests of cognitive function were assessed by study co-ordinators across all participating centres after completion of training in the application and procedure for using these tests. A guide was available to consult at the time of testing. Only participants conversant in English language were included in this aspect of the study. The 3MS is a test of global cognitive function that includes assessment of orientation, attention, calculation, language, and short-term memory. Trail Making tests are a measure of cognitive abilities such as speed and fluid intelligence and they have been hypothesized to reflect a wide variety of cognitive processes including attention, visual search and scanning, sequencing and set shifting, psychomotor speed, abstraction, flexibility, ability to execute and modify a plan of action. 3MS score < 80 is deemed deficient. The timed trail tests A and B are deemed insufficient if the duration exceeds 1SD from the mean of the present study cohort (>87 seconds in TMT A and >197 seconds in TMTB). All three variables were treated as continuous variables for the purpose of the univariate and multivariable analysis.

Subjective tests:

To enable understanding of the patients' beliefs about their own memory and concentration, the brief metacognition questionnaire was employed. This questionnaire has two subscales the *metamemory subscale* (5 questions) and the *metaconcentration subscale* (4 questions). This tool was developed in 2011 in a cohort of elderly women. Metacognition is highly relevant for sustained independence in older age. This tool has not been validated in the kidney disease population, but the parameters used to assess the outcome, namely independence, was deemed common to both population groups. The responses were given on a Likert scale (1- strongly disagree, 2- disagree, 3- neither agree nor disagree, 4 - agree and 5- strongly agree) and then summed for each subscale. The range of scores for metamemory subscale is 5-25 and that of the metaconcentration subscale is 4-20.

Data completeness:

Number of eligible participants	220
TMT A	208 (94.5%)
TMT B	169 (76.8%)
3MS	206 (93.6%)
Metamemory subscale	215 (97.7%)
Metaconcentration subscale	213 (96.8%)
Decision on modality choice (outcome variable)	204 (92.7%)

TMTB test data suffered from missing data that appears to be missing not at random and missing at random. Where patients gave – up part way through completion the data is considered missing not at random. Missing at random data included those where participants did not complete any data or where the administration was deemed incorrect. In 8 cases, the data was imputed to 300 seconds where the administrator explicitly mentioned that the patient ‘gave-up’ completing TMTB test after persisting for some time (missing not at random data). However, of these 8 imputed cases, only 6 were considered for the analysis, where information on modality choice as the outcome, was also available.

Statistical Analyses

Analyses were performed using SPSS 22 and STATA 13. A two-sided 5% significance level was used throughout the analysis. Baseline characteristics were assessed between the three modality choices in the predialysis cohort using chi-squared tests, Fisher's exact tests, ANOVAs and Kruskal-Wallis tests, as appropriate.

Single variable analyses using chi-squared tests, Fisher's exact tests, independent t-tests and Mann-Whitney U tests, as appropriate, with modality choice as the outcome, grouped as self-care (PD and home) and hospital, revealed which cognitive, medical and demographic

variables were significant. A hierarchical logistic regression analysis was then carried out for each one of the cognitive variables (5 models) with modality choice as the outcome. The differences within the self-care group were investigated to assess the suitability of grouping PD and home. The relationships between the subjective and objective cognition variables were investigated using correlations and linear regression.

Sensitivity analyses were carried out involving multiple imputation with chained equations to account for missing data in all the cognition variables based on variables including CCI, age, gender, ethnicity, education, employment, BDI, scores on other tests of objective cognition and the outcome variable – modality choice (Appendix S1).

RESULTS

Patient Characteristics

There were 220 participants in all. 90 patients chose hospital haemodialysis and 114 patients chose self-care dialysis (peritoneal dialysis-PD and home haemodialysis – HHD). Of these 114 patients who expressed their preference for self-care dialysis, 36 patients preferred home haemodialysis and 78 patients preferred peritoneal dialysis. The characteristics of these participants are presented in the Table 1. Between the three groups overall, significant differences were observed in age, CCI, BDI score, STAI-S, greatest in patients choosing hospital haemodialysis. Serum creatinine and metaconcentration scores were lowest in hospital HD choosing participants. PTH was significantly higher in the home HD choosing cohort. Within the self-care group, no significant differences were observed in any dependent variable category, including tests of cognition, between participants who chose PD vs HHD.

	Hospital (n=90)	PD (n=78)	Home (n=36)	p-value
TMT B – Median (IQR)	n=64 102.0 (78.5-132.3)	n=63 90.0 (63.0-118.0)	n=30 94.0 (64.5-122.5)	0.11 ⁴
TMT A – Median (IQR)	n=83 49.0 (32.0-62.0)	n=74 41.5 (30.0-60.0)	n=34 42.8 (31.2-55.9)	0.086 ⁴
3 MS – Median (IQR)	n=85 93.0 (88.5-97.0)	n=74 95.0 (91.0-98.0)	n=34 92.5 (88.0-96.5)	0.066 ⁴
MCQ1 (metamemory) – Mean (std. dev.)	n=89 17.7 (3.8)	n=76 18.2 (3.3)	n=35 17.4 (4.5)	0.53 ²
MCQ2 (metaconcentration) – Mean (std. dev.)	n=88 13.9 (2.4)	n=74 15.1 (2.8)	n=35 14.6 (2.9)	0.016 ²
Age – Mean (std. dev.)	62.6 (12.3)	58.3 (12.9)	53.6 (13.0)	0.001 ²
Gender – Female	36 (40.0%)	28 (35.9%)	15 (41.7%)	0.80 ¹
Education – Post high school	19/87 (21.8%)	20/76 (26.3%)	12/35 (34.3%)	0.36 ¹
Employment				
Retired	51 (56.7%)	36 (46.2%)	12 (33.3%)	0.053 ¹
Unemployed	19 (21.1%)	13 (16.7%)	7 (19.4%)	
Salaried/ self-employed	20 (22.2%)	29 (37.2%)	17 (47.2%)	
Ethnicity – Non-white	12 (13.3%)	3 (3.8%)	5 (13.9%)	0.079 ¹
Marital status				
Married or partner	56 (62.2%)	53 (67.9%)	23 (63.9%)	0.71 ³

Table 1: Characteristics of study participants				
	Hospital (n=90)	PD (n=78)	Home (n=36)	p-value
Single	20 (22.2%)	13 (16.7%)	7 (19.4%)	
Divorced or separated	6 (6.7%)	3 (3.8%)	4 (11.1%)	
Widowed	8 (8.9%)	9 (11.5%)	2 (5.6%)	
Cause of ESRD				0.081 ¹
Systemic	50 (55.6%)	29 (37.2%)	13 (36.1%)	
Renal	17 (18.9%)	24 (30.8%)	13 (36.1%)	
Other/Unknown	23 (25.6%)	25 (32.1%)	10 (27.8%)	
CCI – Median (IQR)	5.0 (4.0-7.0)	4.0 (3.0-6.0)	4.0 (3.0-5.0)	0.009 ⁴
Diabetes	32 (35.6%)	22 (28.2%)	10 (27.8%)	0.52 ¹
Heart failure	4 (4.4%)	4 (5.1%)	1 (2.8%)	>0.99 ³
Ischaemic Heart Disease	18 (20.0%)	18 (23.1%)	6 (16.7%)	0.72 ¹
IVE	9 (10.0%)	5 (6.4%)	2 (5.6%)	0.59 ¹
Urea – Median (IQR)	22.6 (18.6-28.2)	23.1 (18.6-29.4)	23.1 (19.7-26.0)	0.86 ⁴
Creatinine – Median (IQR)	377 (338-459)	428 (343-524)	429 (383-500)	0.046 ⁴
Hb – <9	3/89 (3.4%)	2/77 (2.6%)	2/35 (5.7%)	0.77 ³
Alb – <30	4/89 (4.5%)	2/77 (2.6%)	0/35 (0%)	0.65 ³
Bic				0.99 ³
<22	37 (44.0%)	32 (42.7%)	17 (48.6%)	
22-28	43 (51.2%)	39 (52.0%)	17 (48.6%)	
>28	4 (4.8%)	4 (5.3%)	1 (2.9%)	
PTH – Median (IQR)	23.6 (14.0-35.2)	22.2 (12.3-35.1)	32.3 (17.5-48.3)	0.051 ⁴
Phosphate				0.14 ¹
<1.1	11 (12.5%)	11 (14.5%)	2 (5.7%)	
1.1-1.7	61 (69.3%)	43 (56.5%)	28 (80.0%)	
>1.7	16 (18.2%)	22 (28.9%)	5 (14.3%)	
SBP – ≤115	4/89 (4.5%)	9/76 (11.8%)	1 (2.8%)	0.10 ¹
SBP – Mean (std. dev.)	143.7 (19.2)	137.5 (21.4)	140.1 (17.5)	0.14 ²
DBP – >85	16/89 (18.0%)	15/76 (19.7%)	6 (16.7%)	0.92 ¹
DBP – Mean (std. dev.)	76.3 (11.1)	77.1 (11.4)	73.4 (11.9)	0.26 ²
ACEI or ARB	41 (45.6%)	47 (60.3%)	21/34 (61.8%)	0.098 ¹
Folic acid	10 (11.1%)	11 (14.1%)	5/34 (14.7%)	0.80 ¹
Number of antihypertensive drugs – Median (IQR)	3.0 (2.0-4.0)	2.5 (2.0-4.0)	3.0 (2.0-4.0)	0.28 ⁴
EPO	31 (34.4%)	30 (38.5%)	8/35 (22.9%)	0.27 ¹
CNS	7 (7.8%)	7 (9.0%)	4/34 (11.8%)	0.79 ¹
Antidepressants	18 (20.0%)	10 (12.8%)	3/34 (8.8%)	0.22 ¹
Antiplatelets	39 (43.3%)	24 (30.8%)	13/34 (38.2%)	0.24 ¹
Statins/EZE	53 (58.9%)	41 (52.6%)	24/34 (70.6%)	0.20 ¹
Pill burden – Mean (std. dev.)	7.5 (2.6)	6.9 (2.5)	8.2 (3.4)	0.069 ²
BDI – Median (IQR)	12.0 (5.8-22.3)	7.0 (4.0-12.3)	9.0 (6.0-14.5)	0.009 ⁴
STAI State – Median (IQR)	39.5 (29.3-47.8)	32.0 (26.0-40.0)	33.0 (25.3-46.0)	0.026 ⁴
STAI Trait – Median (IQR)	41.0 (30.0-47.0)	34.0 (29.0-46.0)	35.0 (27.0-42.8)	0.093 ⁴

¹Pearson chi-squared test ²One-way ANOVA ³Fisher's exact test ⁴Kruskal-Wallis test

Cognitive deficit burden in ESRD

In the study cohort, based on the cut off for identification of objective cognitive deficit: 3MS<80, TMTA/B>1.5 SD from the mean for the study groups, the proportion of participants with cognitive deficits in the three groups are-

	Overall	Hospital	PD	Home
3MS (<80)	6/193 (3.1%)	3/85 (3.5%)	1/74 (1.4%)	2/34 (5.9%)

TMT A (>87)	15/193 (7.8%)	7/83 (8.4%)	6/74 (8.1%)	2/36 (5.6%)
TMT B (>197)	12/157 (7.6%)	6/64 (9.4%)	3/63 (4.8%)	3/30 (10.0%)

Univariate analysis

In the single variable analysis of the association of key variables of interest with modality choice (Table 2), variables significantly ($p<0.05$) associated with self-care modality choice include lower TMTB scores, lower TMT A scores, higher metaconcentration scores, lower age, being in employment, renal-limited cause of end stage renal disease, lower CCI, use of drugs such as angiotensin converting enzyme inhibitors, higher serum creatinine, lower BDI and STAI-S/T scores. Variables associated with self-care choice at $p\leq 0.10$ include higher 3MS score, lower systolic blood pressure and lesser anti-depressant drug use.

Table 2: Univariate analysis of study variables with modality choice as outcome			
	Hospital (n=90)	Self-care – Home HD or PD (n=114)	p-value
TMT B – Median (IQR)	n=64 102.0 (78.5-132.3)	n=93 90.0 (63.0-119.0)	0.043 ⁵
TMT A – Median (IQR)	n=83 49.0 (32.0-62.0)	n=110 42.0 (30.0-56.3)	0.029 ⁵
3 MS – Median (IQR)	n=85 93.0 (88.5-97.0)	n=108 94.5 (91.0-98.0)	0.063 ⁵
Metamemory – Mean (SD)	n=89 17.7 (3.8)	n=111 17.9 (3.7)	0.61 ³
Metaconcentration– Mean (SD)	n=88 13.9 (2.4)	n=110 14.9 (2.8)	0.006 ³
Age – Mean (SD)	62.6 (12.3)	56.8 (13.1)	0.001 ³
Gender – Female	36 (40.0%)	43 (37.7%)	0.74 ¹
Education – Post high school	19/87 (21.8%)	32/111 (28.8%)	0.26 ¹
Employment			
Retired	51 (56.7%)	48 (42.1%)	0.022 ¹
Unemployed	19 (21.1%)	20 (17.5%)	
Salaried/ self-employed	20 (22.2%)	46 (40.4%)	
Ethnicity – Non-white	12 (13.3%)	8 (7.0%)	0.13 ¹
Marital status			
Married or partner	56 (62.2%)	76 (66.7%)	0.86 ¹
Single	20 (22.2%)	20 (17.5%)	
Divorced or separated	6 (6.7%)	7 (6.1%)	
Widowed	8 (8.9%)	11 (9.6%)	
Cause of ESRD			
Systemic	50 (55.6%)	42 (36.8%)	0.020 ¹
Renal	17 (18.9%)	37 (32.5%)	
Other/Unknown	23 (25.6%)	35 (30.7%)	
CCI – Median (IQR)	5.0 (4.0-7.0)	4.0 (3.0-6.0)	0.003 ⁵
Diabetes	32 (35.6%)	32 (28.1%)	0.25 ¹
Heart failure	4 (4.4%)	5 (4.4%)	>0.99 ⁴
Ischaemic Heart Disease	18 (20.0%)	24 (21.1%)	0.85 ¹
IVE	9 (10.0%)	7 (6.1%)	0.31 ¹
Urea – Mean (std. dev.)	23.3 (7.7)	24.0 (6.6)	0.51 ³
Creatinine – Median (IQR)	377 (338-459)	428 (348-513)	0.013 ⁵
Hb – <9	3/89 (3.4%)	4/112 (3.6%)	>0.99 ⁴
Alb – <30	4/89 (4.5%)	2/112 (1.8%)	0.41 ⁴
Bic			
<22	37 (44.0%)	49 (44.5%)	0.93 ²
22-28	43 (51.2%)	56 (50.9%)	
>28	4 (4.8%)	5 (4.5%)	
PTH – Median (IQR)	23.6 (14.0-35.2)	25.2 (13.2-38.2)	0.45 ⁵
Phosphate			
<1.1	11 (12.5%)	13 (11.7%)	0.40 ²
	61 (69.3%)	71 (64.0%)	

Table 2: Univariate analysis of study variables with modality choice as outcome			
	Hospital (n=90)	Self-care – Home HD or PD (n=114)	p-value
1.1-1.7 >1.7	16 (18.2%)	27 (24.3%)	
SBP – ≤115	4/89 (4.5%)	10/112 (8.9%)	0.22 ¹
SBP – Mean (std. dev.)	143.7 (19.2)	138.4 (20.2)	0.059 ³
DBP – >85	16/89 (18.0%)	21/112 (18.8%)	0.89 ¹
DBP – Mean (std. dev.)	76.3 (11.1)	75.9 (11.6)	0.81 ³
ACEI or ARB	41 (45.6%)	68/112 (60.7%)	0.032 ¹
Folic acid	10 (11.1%)	16/112 (14.3%)	0.50 ¹
Number of antihypertensive drugs – Median (IQR)	3.0 (2.0-4.0)	n=112 3.0 (2.0-4.0)	>0.99 ⁵
EPO	31 (34.4%)	38/113 (33.6%)	0.90 ¹
CNS	7 (7.8%)	11/112 (9.8%)	0.61 ¹
Antidepressants	18 (20.0%)	13/112 (11.6%)	0.10 ¹
Antiplatelets	39 (43.3%)	37/112 (33.0%)	0.13 ¹
Statins/Ezetimibe	53 (58.9%)	65/112 (58.0%)	0.90 ¹
Pill burden – Mean (std. dev.)	7.5 (2.6)	7.3 (2.9)	0.65 ³
BDI – Median (IQR)	12.0 (5.8-22.3)	7.5 (4.0-13.0)	0.005 ⁵
STAI State – Median (IQR)	39.5 (29.3-47.8)	32.0 (26.0-42.3)	0.010 ⁵
STAI Trait – Median (IQR)	41.0 (30.0-47.0)	35.0 (29.0-45.0)	0.049 ⁵

¹Pearson chi-squared test ²Chi-squared linear trend test ³Independent samples t-test ⁴Fisher's exact test

⁵Mann-Whitney U test

Hierarchical regression analysis of associations of self-care modality choice

In the hierarchical regression analysis (Table 3), the significant associations of self-care modality choice across all models with cognition tests, included Caucasian ethnicity, lower BDI scores, and lower CCI, after adjustment for other variables in the model. TMT A, TMT B and 3MS were not significantly associated with modality choice after adjustment for CCI (age is factored into CCI), BDI, employment, ethnicity and gender, although the direction of effect suggests that better scores on tests of cognition are associated with choice of self-care dialysis modality. The test of subjective cognitive ability, metaconcentration subscale, but not the metamemory subscale was highly significantly associated with self-care modality choice ($p<0.01$).

Association between objective and subjective cognitive assessments

In the adjusted analysis (adjusted for CCI, BDI and education) (Table 4) of the association between TMTA/B, 3MS and the metamemory and metaconcentration subscales, significant association was noted between TMTB and the metaconcentration scale ($p<0.01$). Parameter estimate of -0.10, suggests a small (0.1 unit) change in metaconcentration score with a 10 second increase in TMT B. Therefore, with every 1.6-minute increase in TMTB, there is a one-unit reduction in metaconcentration score and this is associated with 20% lower odds of choosing self-care modality over hospital haemodialysis.

Table 4: Association of metacognition scales with objective tests of cognition			
Objective Cognition Test	n	Parameter estimate (95% CI)	p-value
Adjusted (for CCI, BDI and education) regressions with metamemory as the outcome			
TMT B (per ten second increase)	144	-0.09 (-0.19, 0.02)	0.097
TMT A (per ten second increase)	180	-0.15 (-0.39, 0.08)	0.19
3MS (per ten score increase)	179	0.33 (-0.66, 1.33)	0.51

Adjusted (for CCI, BDI and education) regressions with metaconcentration as the outcome			
TMT B (per ten second increase)	141	-0.10 (-0.17, -0.03)	0.004
TMT A (per ten second increase)	177	-0.10 (-0.26, 0.06)	0.21
3MS (per ten score increase)	176	0.43 (-0.26, 1.12)	0.22
Table 3: Hierarchical regression analysis of cognition variables with modality choice outcome			
Variable		Odds ratio (95% CI)	p-value
First Stage (Employment, CCI and BDI)			
Employment	Retired	1 (-)	0.41
	Unemployed	1.12 (0.44, 2.85)	
	Salaried/ self-employed	1.68 (0.77, 3.68)	
CCI (per unit increase)		0.85 (0.71, 1.01)	0.066
BDI (per ten-unit increase)		0.67 (0.49, 0.93)	0.018
Second Stage (Ethnicity and Gender)			
Employment	Retired	1 (-)	0.30
	Unemployed	1.35 (0.51, 3.56)	
	Salaried/ self-employed	1.88 (0.84, 4.20)	
CCI (per unit increase)		0.83 (0.70, 0.99)	0.038
BDI (per ten-unit increase)		0.69 (0.50, 0.96)	0.029
Ethnicity – Non-white		0.26 (0.08, 0.90)	0.033
Gender – Female		0.86 (0.45, 1.64)	0.65
Third stage (TMT B variable added) 137/220 (62.3%)			
Employment	Retired	1 (-)	0.10
	Unemployed	1.34 (0.42, 4.24)	
	Salaried/ self-employed	2.88 (1.08, 7.70)	
CCI (per unit increase)		0.87 (0.71, 1.08)	0.22
BDI (per ten-unit increase)		0.74 (0.50, 1.09)	0.13
Ethnicity – Non-white		0.13 (0.03, 0.62)	0.010
Gender – Female		0.90 (0.42, 1.93)	0.78
TMT B (per ten second increase)		0.96 (0.90, 1.02)	0.16
Third stage (TMT A variable added) 170/220 (77.3%)			
Employment	Retired	1 (-)	0.29
	Unemployed	1.69 (0.60, 4.76)	
	Salaried/ self-employed	1.91 (0.83, 4.37)	
CCI (per unit increase)		0.85 (0.70, 1.02)	0.084
BDI (per ten-unit increase)		0.66 (0.47, 0.94)	0.021
Ethnicity – Non-white		0.28 (0.08, 0.98)	0.046
Gender – Female		0.86 (0.44, 1.69)	0.67
TMT A (per ten second increase)		0.91 (0.79, 1.05)	0.21
Third stage (3MS variable added) 172/220 (78.2%)			
Employment	Retired	1 (-)	0.53
	Unemployed	1.44 (0.53, 3.93)	
	Salaried/ self-employed	1.61 (0.69, 3.73)	
CCI (per unit increase)		0.85 (0.71, 1.03)	0.097
BDI (per ten-unit increase)		0.66 (0.47, 0.94)	0.020
Ethnicity – Non-white		0.28 (0.08, 0.97)	0.044
Gender – Female		0.85 (0.44, 1.65)	0.63
3MS (per ten increase in score)		1.59 (0.86, 2.96)	0.14
Third stage (metamemory variable added) 178/220 (80.9%)			
Employment	Retired	1 (-)	0.24
	Unemployed	1.47 (0.55, 3.94)	
	Salaried/ self-employed	2.02 (0.90, 4.53)	
CCI (per unit increase)		0.83 (0.69, 0.99)	0.038
BDI (per ten-unit increase)		0.67 (0.48, 0.95)	0.023
Ethnicity – Non-white		0.26 (0.08, 0.91)	0.035
Gender – Female		0.86 (0.45, 1.64)	0.64
Metamemory (per unit increase in score)		1.01 (0.93, 1.10)	0.80
Third stage (metaconcentration variable added) 175/220 (79.5%)			
Employment	Retired	1 (-)	0.22
	Unemployed	1.49 (0.53, 4.20)	
	Salaried/ self-employed	2.09 (0.91, 4.79)	
CCI (per unit increase)		0.79 (0.66, 0.95)	0.013
BDI (per ten-unit increase)		0.75 (0.52, 1.08)	0.12
Ethnicity – Non-white		0.28 (0.08, 0.99)	0.048
Gender – Female		0.82 (0.42, 1.61)	0.56

Metaconcentration (per unit increase in score) (OR>1= Self-care modality choice)	1.20 (1.05, 1.37)	0.008
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DISCUSSION

The cognitive ability of predialysis CKD-5 patients, is a window into the patient's ability to ascertain, retain and process information and come to a rational well thought-through decision in a hypothetical context. In choice of self-care dialysis, multiple cognitive processes enable the individual to shift perceptions from chronic predialysis state to an alternative, imagined perspective of treatment-dialysis, through culmination of learning experiences from the past, planning, prediction of imagined events, insight, creativity and emotional responses. The complex neurobiology of cognition in the face of emotion and affective disorders which our patients experience, is under-researched in patients with kidney disease. However, impairments in cognitive flexibility and contextual abstraction have been found in other conditions such as Parkinson's disease and depression in the context of goal-directed behaviour and adaptive decision-making[34]. In a recent publication from our study group, we demonstrated that the lowest tertile of decision-making scores on a decision-making scale was in fact associated with poorer scores on tests of executive brain function[35].

Our study has attempted to explore the association between measured cognitive deficits and self-care modality choice. The influence of patient's assessment of how their memory works, and how they judge their own abilities and effectiveness may predict their choice of dialysis modality; therefore, a pragmatic brief tool to measure subjective cognitive capacity has also been incorporated into the study[30]. This is the first study of its kind in the dialysis choice context. The data completeness rate for all aspects of the study combined is excellent.

Our findings suggest that greater cognitive ability is associated significantly with greater self-care dialysis modality choice in the univariate analysis, although none of the three measures of objective cognition is statistically significant in the regression models. Patients' self-reported metaconcentration however, is highly significantly associated with self-care modality choice. The objective tests of cognition lack statistical power and the systematically missing data for reasons of inability to complete the test indicates that there could potentially have been a statistically significant association if patients persevered and completed the tests. However, it is to be noted that recruitment and retention of patients in studies of cognition is difficult[26, 36].

The metacognition questionnaire captures patients' belief about their metamemory and metaconcentration components of cognition process and it is important as not every functional area of the brain is affected equally in patients. In an otherwise healthy group of elderly

patients, one study reported that individuals lacking in self-concept, show less problem-solving, perhaps because they do not think it is worth trying[37]. If cognitive decline is consciously perceived by individuals, they may no longer practice their cognitive skills and rely on external assistance[38]. Our study does show statistically significant association of the metaconcentration scores with tests of executive function (TMT B), quite like another recent publication on the subject in the dialysis population[14]. This is not surprising, and it raises the possibility of the metaconcentration measurement as an effective proxy/complement to objective tests of executive brain function. This remains to be proven and so does the validation of the metacognition questionnaire in the population with renal disease. Other variables associated with hospital-based modality choice, after adjustment of cognitive status, include non-Caucasian ethnicity, higher BDI and CCI scores. The latter variables are known to be associated with and adversely affect both executive and global cognitive functions[39-42].

Cognitive impairment and/or depressive mood in patients with ESRD, can affect patient behaviours, attitudes and compliance[43, 44]. In a routine clinical consultation of the predialysis patient in the UK, patients spend considerable lengths of time being assessed physically in preparation for commencement of dialysis. Communication with the healthcare team is less than ideally placed to identify all but the most obviously cognitively impaired patients. In these instances, depression may co-exist or even overlap. Whilst some units provide their patients with access to psychotherapy, the vast numbers of practitioners may be oblivious to the insidious development of a psychopathological state in their patients. In one study involving physicians' estimation of dialysis patients' cognitive ability during clinical consults, it was found that doctors had a tendency to underestimate the deficiency when it was present, and only four cases out of the twenty-one impaired patients were classified by their doctor as being cognitively impaired[45]. In the same study, doctors could not identify 25.5% of patients who were depressed and 45% of those depressed were also found to be cognitively impaired. This knowledge is important for not just the decision-making phase, but thereafter on dialysis. Unidentified cognitive deficits may explain non adherence with diet, fluid management and also disruptive behaviours on the dialysis unit. Many CKD patients also report sleep disturbances and these can directly affect memory and concentration[46]. In one study of CKD-4/5 patients, sleep-disordered breathing was detected in 49.1% patients[47]. This group also fared poorly on tests of working and verbal memory, attention and psychomotor speed. Better understanding of the relationship between sleep and cognition is required, to plan further interventions.

There is also evidence from literature linking age, cognition and other individual resources with health literacy in advanced age[48]. The finding that impaired health literacy in older age is in part, a function of cognitive decline even amongst persons without dementia, necessitates

interventions to reduce cognitive demands, particularly complex reasoning abilities and memory from patients, inherent in the health literature materials and decision-making aids used by patients with even milder degrees of cognitive impairment. The question of cognition assessment is therefore important today from a research perspective to answer several questions on pathophysiology, potential pharmacological and non-pharmacological interventions, the timing of commencement of these interventions, the appropriate manner of monitoring, the ideal combination of tests etc., notwithstanding the implications of negative tests on patient behaviour and the healthcare team's practice.

Our study has limitations. The cross-sectional study design does not confirm the causal impact of cognition on the reported choice of modality. The limited data on TMTB demonstrated the difficulty of lack of 'effort' on the patients' and the administrator's part to 'try hard' at the neuropsychological tests, making the results in our study show a relatively smaller proportion of predialysis patients as having significant cognitive impairment. The use of a tool yet to be validated in the kidney disease community, makes it difficult to make any recommendations for its use in clinical practice. Despite the limitations, the study highlights some important practice points. There may be a role for subjective cognition assessment as a measure of patients' ability to undertake self-care tasks. These patients may well need extra support to cope with the burden of the disease. There is need for a comprehensive, yet practical neuropsychological battery of tests that can be employed routinely in clinical care and understand the role and implementation of these tests in clinical practice.

In conclusion, patient's own perception of their cognitive ability has an important association with self-care modality choice. Subjective report of 'metaconcentration' is significantly associated with poorer outcome on trails making test B, a test of executive brain function. Several areas of unmet need in understanding cognition in kidney disease, should underpin the basis for future research.

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[Disclosures](#)

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CHAPTER 3.9

Which predialysis patients may choose a self-care dialysis modality?

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ABSTRACT

Background: Self-care haemodialysis is associated with better patient outcomes and improved patient-reported quality-of-life. Despite this there appears to be a shrinking proportion of patients in receipt of self-care dialysis compared to fully-assisted, centre-based dialysis. The aim of this study is to ascertain the predictors of self-care dialysis choice (peritoneal dialysis and home haemodialysis) and explore the differences between predictors of peritoneal dialysis and home haemodialysis.

Methods: 199 patients with complete information, were included in a logistic regression model with self-care and full-assisted dialysis choice as outcome variables. Several independent variables including demographic, clinical, psycho-cognitive variables were considered for the analysis. A multinomial logistic regression analysis was done to determine the predictors for all three modality choices. AUROC was used to assess the discriminating ability of the logistic regression models.

Results: Perceived lower cognitive ability, higher comorbidities index (age is included in the index), lack of home ownership and non-white ethnicity were the statistically significant predictors of fully-assisted dialysis modality choice over self-care dialysis. The final model includes mobility and centre despite p-values of 0.07, because including both as a step in the variables selection procedure for the model is statistically significant. Perceived inability to self-cannulate was a significant predictor of peritoneal dialysis over home haemodialysis choice. The 6-variable prediction model had an AUROC of 0.75. There did exist a decision-initiation gap in the choices made by predialysis patients. 56% of predialysis patients chose self-care dialysis modalities, but 30% of these patients ended up commencing fully-assisted hospital-based dialysis. These patients were more likely to be male and retired from active employment.

Conclusion: Patients should be able to consider self-care therapies option in all but the most limiting physical and cognitive states. There is a greater need to understand the decision-initiation gap between the chosen and actual dialysis modalities.

INTRODUCTION

Self-care haemodialysis is associated with better patient outcomes and improved patient-reported quality-of-life[1, 2]. There are economic benefits to the provider too[3, 4]. There has been a gradual increase in home haemodialysis numbers across the United Kingdom over the last 4-5 years, but the disparities across centres is evident from the UK renal registry data[5]. Barriers and facilitators of home haemodialysis uptake has been investigated in quantitative and qualitative studies within the last decade[6, 7]. The increase in prevalence of home haemodialysis also follows a number of regional and national initiatives and incentivisation of home therapies in the UK. Perhaps the biggest change has come about in the mind set of practitioners who are now more willing to engage with the idea of home haemodialysis. The offer of this therapy demands the investment of time, expertise and robust patient monitoring for safe and effective outcomes. Creating a home haemodialysis programme engages a range of patient profiles, typically, the young, able and willing. There are others who are undecided and disengaged. The ability to capture the latter would be crucial to expanding a home haemodialysis programme and remains a challenge.

In a previous study of predictors of self-care dialysis, patients who perceived freedom and lifestyle advantages were more likely to choose self-care. Advantages of self-care dialysis as a predictor of self-care dialysis choice, had an area under the ROC curve of 0.81 [8]. This finding is consistent with previously published retrospective studies in which patients reported that greater autonomy, independence and flexibility influenced their selection[7, 9, 10]. Several such studies have identified these data from quantitative and qualitative analyses[7, 11-15]. In other studies, where clinical and demographic factors were considered, nephrologist follow-up before renal replacement therapy, was the single most important predictor of home dialysis modality choice and other independent predictors of peritoneal dialysis choice were the presence of a spouse, dialysis counselling experience and residence removed from the base unit[12, 16]. Nephrologist's view on modality selection from the NECOSAD study, shows that in the absence of obvious contraindications, patient preference dictates modality choice and this may be modified by predialysis counselling[17, 18]. In one large survey of 7000 nephrologists, physicians believe that under ideal conditions, one-third of all patients starting dialysis can be trained to perform self-care dialysis[11]. However, the study of several different bio-psycho-social variables simultaneously, which may influence this outcome has not been considered previously, especially for home haemodialysis. Also, the translation of selection to initiation on the modality of choice is just as important and in one study addressing this issue, of the 124 patients who chose PD, only 59 (48%) started with this modality and 52% started HD, the vast majority with central venous catheters [19]. Social and medical

factors may well explain this difference, but a staggering 52% of patients starting hospital haemodialysis although initially convinced of self-care dialysis, needs closer observation.

The aims of this study are

- a) To ascertain significant associations of self-care dialysis choice (peritoneal dialysis and home haemodialysis) and explore the differences between variables associated with choice of peritoneal dialysis and home haemodialysis.
- b) Examine the modality ‘decision-initiation’ gap in the prospective study cohort.

METHODS

Participants and recruitment

Data for the present study are derived from that ascertained for the BASIC-HHD study. The BASIC-HHD study is a comprehensive and systematic study of barriers and enablers of the uptake and maintenance of home HD therapy. The study involves five UK centres, with variable prevalence rates of home HD. An integrated mixed methodology (convergent, parallel design) has been adopted for the BASIC-HHD study in a combined cross-sectional and prospective study design. The methodological details and scope of data collected in the BASIC-HHD appear in a published protocol. Data presented here are derived from the CKD-5; predialysis cohort of the BASIC-HHD study. 222 patients were enrolled in this group. Predialysis patients for the CKD-5 group were approached if they fulfilled eligibility criteria and were willing to undertake neuropsychometric assessments and complete study specific questionnaires.

Study Registration

This study has been reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346). Written, informed consent from participants was obtained for the study. Psychological measures employed in this study were a part of compilation of questionnaires. Blood sampling and neuropsychometric assessments were carried out at their routine hospital clinic visits.

Independent variables

These included demographics- age, gender, ethnicity, education, employment and marital status; clinical variables- Charlson Comorbidity Index (CCI)[20], cause of end stage renal disease (ESRD), diabetes, heart failure, intracranial vascular events, ischaemic heart disease, systolic and diastolic blood pressures; laboratory variables- urea, creatinine, phosphate, PTH, bicarbonate, albumin, haemoglobin and medications including Angiotensin Converting

Enzyme (ACE) inhibitors, central nervous system influencing drugs, antidepressants, antiplatelets, cholesterol-lowering drugs, erythropoietin, folic acid and the number of anti-hypertensive drugs and total pill burden; psychological screening tools- Beck Depression Inventory(BDI), State and Trait anxiety inventory (STAI), Illness perception questionnaire-revised (IPQ-R), Autonomy Preference Index (API), and objective tests of cognition, Trail making tests A/B, Modified Mini Mental State Examination (3MS)[21], subjective assessment of cognition scales- the metacognition questionnaire.

Data completeness

CCI	222 (100%)	Metaconcentration	215 (96.8%)
Ethnicity	222 (100%)	Centre	222 (100%)
Mobility	222 (100%)	Index of Multiple Deprivation	222 (100%)
Accommodation	221 (99.5%)	TMT B	169 (76.1%)
BDI	194 (87.4%)	Perceived ability to self-cannulate	209 (94.1%)
Illness Coherence	184 (82.9%)	Modality choice	206 (92.8%)

Outcome variable

- a. Modality choice- Hospital haemodialysis vs self-care dialysis (peritoneal and home haemodialysis)
- b. Hospital haemodialysis vs peritoneal dialysis vs home haemodialysis choice

Statistical Analyses

Analyses were performed using SPSS 22 and STATA 13. A two-sided 5% significance level was used throughout the paper. Chi-squared tests, Fisher's exact tests, independent t-tests and Mann-Whitney U tests were used to assess the two group modality choice outcome for the variables of interest. Chi-squared tests, Fisher's exact tests, ANOVAs and Kruskal-Wallis tests were used when modality choice was assessed as a three category outcome. A clinically considered group of variables with p-values of less than 0.2 were included in the initial multivariable logistic regression with modality choice in two groups as the outcome. Variables were removed and the model re-run until only variables that were close to significant remained. The model with and without the close to significant variables were compared to assess if they should remain. A similar process was followed for the multinomial logistic regression with the three category modality choice as outcome.

A confounder adjusted analysis has been performed for the six main variables of interest. A confounder, is classed as a variable that is associated with the outcome, associated with the variable of interest; and has neither a direct effect of the variable of interest nor on the causal pathway between the variable of interest and the outcome. In this analysis, confounders that

are likely to be expressed via other variables or do not seem clinically plausible have been removed. A sensitivity analysis where all confounders are considered has also been performed.

As a sensitivity analysis to account for missing data, multiple imputations with chained equations were performed in STATA 13. AUROCs (area under the receiver operating characteristic curve) were used to assess the discriminating ability of the logistic regression models.

RESULTS

Of the 222 predialysis patients, information on preferred dialysis modality was available for 206 patients (92.7%). 92 patients chose hospital haemodialysis (41.4%), 78 patients chose peritoneal dialysis (35.1%) and 36 patients chose home haemodialysis (16.2%) as their preferred dialysis modality option. The characteristics of study participants are presented in Table 1. This table also elucidates the findings of the single variable analysis as the outcome variable is in fact the different modality choices.

Table 1: Single variable analysis-modality choice in three groups					
		Hospital (n=92)	PD (n=78)	Home (n=36)	p-value
DEMOGRAPHIC VARIABLES	Age – Mean (SD)	62.3 (12.4)	58.3 (12.9)	53.6 (13.0)	0.002 ²
	Gender – Female	38 (41.3%)	28 (35.9%)	15 (41.7%)	0.73 ¹
	Education – Post high school	19/89 (21.3%)	20/76 (26.3%)	12/35 (34.3%)	0.32 ¹
	Employment				
	Retired	52 (56.5%)	36 (46.2%)	12 (33.3%)	0.043 ¹
	Unemployed	20 (21.7%)	13 (16.7%)	7 (19.4%)	
	Salaried/ self-employed	20 (21.7%)	29 (37.2%)	17 (47.2%)	
	Ethnicity – Non-white	12 (13.0%)	3 (3.8%)	5 (13.9%)	0.084 ¹
	Marital status				0.63 ³
	Married or partner	56 (60.9%)	53 (67.9%)	23 (63.9%)	
	Single	22 (23.9%)	13 (16.7%)	7 (19.4%)	
	Divorced or separated	6 (6.5%)	3 (3.8%)	4 (11.1%)	
	Widowed	8 (8.7%)	9 (11.5%)	2 (5.6%)	
	Accommodation – Not home owner	30 (32.6%)	17/77 (22.1%)	7 (19.4%)	0.18 ¹
COMORBIDITIES	IMD – Median (IQR)	13660 (4851-24194)	18213 (6582-27186)	11112 (6193-18527)	0.22 ⁴
	IMD quintile				0.27 ¹
	1 (least deprived)	18 (19.6%)	24 (30.8%)	4 (11.1%)	
	2	14 (15.2%)	13 (16.7%)	4 (11.1%)	
	3	15 (16.3%)	10 (12.8%)	7 (19.4%)	
	4	20 (21.7%)	12 (15.4%)	12 (33.0%)	
	5 (most deprived)	25 (27.2%)	19 (24.4%)	9 (25.0%)	
	Cause of ESRD				0.058 ¹
	Systemic Renal	52 (56.5%)	29 (37.2%)	13 (36.1%)	
	Other/Unknown	17 (18.5%)	24 (30.8%)	13 (36.1%)	
	CCI – Median (IQR)	5.0 (4.0-7.0)	4.0 (3.0-6.0)	4.0 (3.0-5.0)	0.009 ⁴
	Diabetes	34 (37.0%)	22 (28.2%)	10 (27.8%)	0.40 ¹
	Heart failure	4 (4.3%)	4 (5.1%)	1 (2.8%)	>0.99 ³
	Ischaemic Heart Disease	18 (19.6%)	18 (23.1%)	6 (16.7%)	0.71 ¹
	Stroke	9 (9.8%)	5 (6.4%)	2 (5.6%)	0.62 ¹
	Solid Organ Malignancy	14 (15.2%)	4 (5.1%)	2 (5.6%)	0.056 ¹
	Mobility – Not independent	28 (30.4%)	13 (16.7%)	3 (8.3%)	0.010 ¹
	Vision – Blind or poor vision	27 (29.3%)	16 (20.5%)	4 (11.1%)	0.072 ¹

Table 1: Single variable analysis-modality choice in three groups						
			Hospital (n=92)	PD (n=78)	Home (n=36)	p-value
	SBP – ≤115		4/91 (4.4%)	9/76 (11.8%)	1 (2.8%)	0.094 ¹
	SBP – Mean (SD)		144.0 (19.1)	137.5 (21.4)	140.1 (17.5)	0.11 ²
	DBP – >85		16/91 (17.6%)	15/76 (19.7%)	6 (16.7%)	0.90 ¹
	DBP – Mean (SD)		76.4 (11.0)	77.1 (11.4)	73.4 (11.9)	0.25 ²
LABORATORY VARIABLES	Urea – Median (IQR)		22.6 (18.8-27.9)	23.1 (18.6-29.4)	23.1 (19.7-26.0)	0.85 ⁴
	Creatinine – Median (IQR)		377 (338-460)	428 (343-524)	429 (383-500)	0.054 ⁴
	Hb – <9		4/91 (4.4%)	2/77 (2.6%)	2/35 (5.7%)	0.64 ³
	Alb – <30		5/91 (5.5%)	2/77 (2.6%)	0/35 (0%)	0.40 ³
	Bic	<22	38 (44.2%)	32 (42.7%)	17 (48.6%)	0.97 ³
		22-28	43 (50.0%)	39 (52.0%)	17 (48.6%)	
		>28	5 (5.8%)	4 (5.3%)	1 (2.9%)	
	PTH – Median (IQR)		23.7 (14.5-36.4)	22.2 (12.3-35.1)	32.3 (17.5-48.3)	0.060 ⁴
DRUGS	Phosphate	<1.1	11 (12.2%)	11 (14.5%)	2 (5.7%)	0.15 ¹
		1.1-1.7	62 (68.9%)	43 (56.5%)	28 (80.0%)	
		>1.7	17 (18.9%)	22 (28.9%)	5 (14.3%)	
	ACEI or ARB		42 (45.7%)	47 (60.3%)	21/34 (61.8%)	0.099 ¹
	Folic acid		10 (10.9%)	11 (14.1%)	5/34 (14.7%)	0.76 ¹
	Number of antihypertensive drugs – Median (IQR)		3.0 (2.0-4.0)	2.5 (2.0-4.0)	3.0 (2.0-4.0)	0.28 ⁴
	EPO		32 (34.8%)	30 (38.5%)	8/35 (22.9%)	0.27 ¹
AFFECT	CNS		8 (8.7%)	7 (9.0%)	4/34 (11.8%)	0.86 ¹
	Antidepressants		18 (19.6%)	10 (12.8%)	3/34 (8.8%)	0.25 ¹
	Antiplatelets		40 (43.5%)	24 (30.8%)	13/34 (38.2%)	0.23 ¹
	Statins/EZE		55 (59.8%)	41 (52.6%)	24/34 (70.6%)	0.20 ¹
	Pill burden – Mean (SD)		7.5 (2.6)	6.9 (2.5)	8.2 (3.4)	0.066 ²
	BDI – Median (IQR)		12.0 (6.0-23.0)	7.0 (4.0-12.3)	9.0 (6.0-14.5)	0.007 ⁴
	STAI State – Median (IQR)		40.0 (29.5-48.0)	32.0 (26.0-40.0)	33.0 (25.3-46.0)	0.019 ⁴
	STAI Trait – Median (IQR)		41.0 (30.0-47.8)	34.0 (29.0-46.0)	35.0 (27.0-42.8)	0.075 ⁴
COGNITION TESTS	Metamemory – Mean (SD)		17.7 (3.8)	18.2 (3.3)	17.4 (4.5)	0.55 ²
	Metaconcentration – Mean (SD)		13.9 (2.4)	15.1 (2.8)	14.6 (2.9)	0.019 ²
	TMT B – Median (IQR)		102.0 (78.5-132.3)	90.0 (63.0-118.0)	94.0 (64.5-122.5)	0.11 ⁴
	TMT A – Median (IQR)		49.0 (32.0-62.0)	41.5 (30.0-60.0)	42.8 (31.2-55.9)	0.086 ⁴
	3 MS – Median (IQR)		93.0 (88.8-97.0)	95.0 (91.0-98.0)	92.5 (88.0-96.5)	0.066 ⁴
SELF-NEEDLING	Response to phlebotomy- Do not mind		62 (69.7%)	53 (75.7%)	30 (83.3%)	0.24 ¹
	Fearful		5 (5.6%)	7 (10.0%)	2 (5.6%)	
API	Important for well-being		22 (24.7%)	10 (14.3%)	4 (11.1%)	0.001 ¹
	Perceived ability to self-cannulate-Yes		51/86 (59.3%)	36/71 (50.7%)	32 (88.9%)	
ILLNESS PERCEPTIONS	Autonomy Preference		44.8 (16.3)	47.4 (17.0)	47.0 (16.8)	0.63 ²
	Decision-making: Mean (SD)					
	Autonomy Preference					
	Information-seeking		75.0 (71.9-84.4)	75.0 (75.0-84.4)	75.0 (75.0-87.5)	0.69 ⁴
	Median (IQR)					
	Timeline – Median (IQR)		26.0 (24.0-29.0)	26.0 (24.0-29.0)	26.0 (21.0-29.0)	0.69 ⁴
	Consequences – Mean (SD)		21.7 (3.7)	20.4 (4.2)	22.0 (3.9)	0.079 ²
	Personal control – Median (IQR)		21.0 (16.0-23.0)	21.0 (18.0-23.0)	21.0 (18.0-24.0)	0.58 ⁴
	Treatment control – Median (IQR)		17.0 (15.0-19.0)	16.0 (14.0-18.0)	17.0 (15.3-20.0)	0.17 ⁴
	Illness coherence – Median (IQR)		18.0 (14.0-20.0)	20.0 (17.0-21.0)	20.0 (15.0-22.8)	0.002 ⁴
	Timeline cyclical – Median (IQR)		11.0 (8.0-14.0)	9.5 (8.0-12.0)	11.5 (8.3-12.0)	0.047 ⁴
	Emotional representations –		18.6 (5.1)	17.1 (4.9)	18.5 (5.3)	0.15 ²

Table 1: Single variable analysis-modality choice in three groups					
	Mean (SD)	Hospital (n=92)	PD (n=78)	Home (n=36)	p-value
CENTRE	Centre				
	A	14 (15.2%)	11 (14.1%)	3 (8.3%)	<0.001 ¹
	B	17 (18.5%)	15 (19.2%)	23 (63.9%)	
	C	23 (25.0%)	24 (30.8%)	1 (2.8%)	
	D	23 (25.0%)	8 (10.3%)	8 (22.2%)	
	E	15 (16.3%)	20 (25.6%)	1 (2.8%)	

¹Pearson chi-squared test

Centres A/C: Low Prevalence (<3%)

²One-way ANOVA

Centre B: High Prevalence (>8%)

³Fisher's exact test

Centres D/E: Medium Prevalence (5-8%)

⁴Kruskal-Wallis test

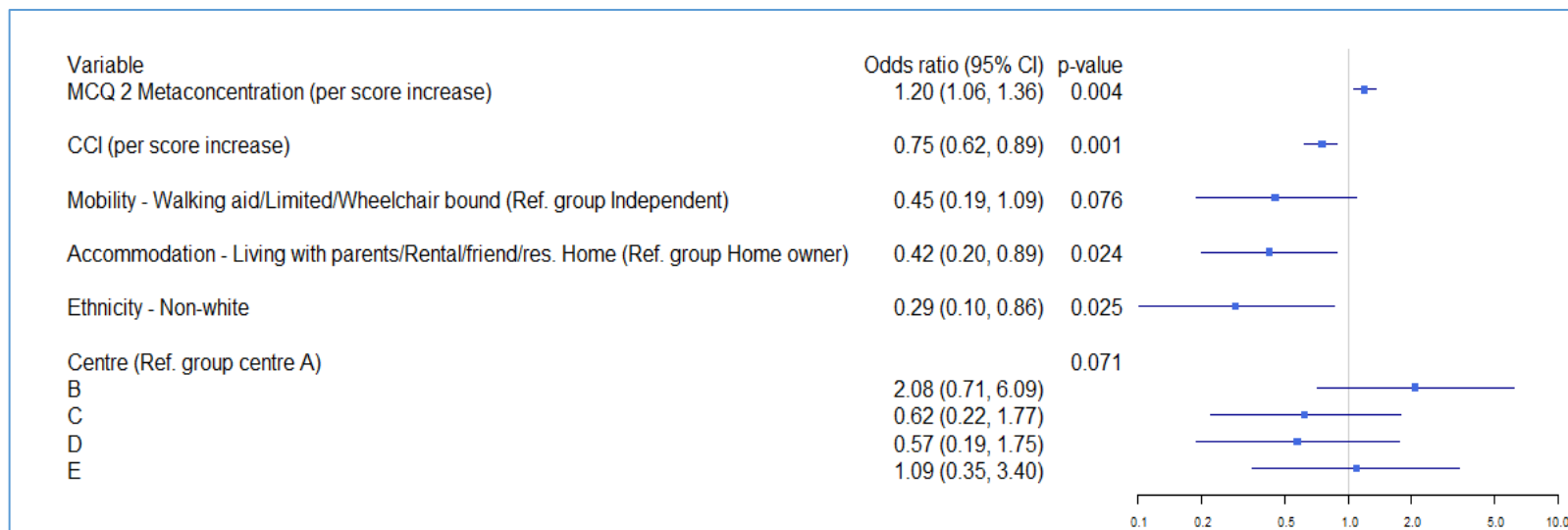
The univariate analysis shows the variables significantly associated with self-care modality choice. Patients who preferred to undertake hospital haemodialysis were generally older, retired from active employment, had higher CCI and systemic cause for ESRD, greater proportion were not independently mobile and had self-reported poor vision. No significant differences between the groups were noted with respect to diabetes, heart failure, ischaemic heart disease, stroke, pill burden or classes of drugs consumed. Anxiety and depression screening scores were higher in the hospital HD choice cohort and lower self-reported cognitive ability in the form of metaconcentration. Home HD choice cohort reported greater perceived ability to self-cannulate, much greater than patients who prefer peritoneal dialysis. Illness coherence was significantly lower in the hospital HD choice cohort compared to the self-care cohorts. The distribution of the modalities is also significantly different between the five study centres.

Multivariable analysis of predictors of modality choice

After consideration of the clinically important variables (from previous studies) and the single variable analysis, the following variables are considered for selection in the multivariable logistic regression model: CCI, ethnicity, mobility, accommodation, BDI, illness coherence (IPQ-R), metaconcentration and Centre. The final model includes mobility and centre despite neither being significant at the 5% level because including both as a step in the selection procedure is statistically significant (Figure 1). Metaconcentration, CCI, accommodation and ethnicity were statistically significant associations of dialysis modality choice.

Confounder-adjusted analyses

Confounder adjusted analysis (Table 2) shows that CCI (a composite variable) and accommodation (loss of significance) are sensitive to including confounders. MCQ2, mobility and centre appear to be more robust to the inclusion of their confounding variables. Ethnicity changes due to the relationships with other study variables. Age, employment, centre and ethnicity in our dataset appear to be interlinked and so inclusion of these variables alongside ethnicity results in changes in its odds ratio outcome.



OR>1: Self-care dialysis modality choice

FIGURE 1: Significant associations of self-care modality choice

Table 2: Confounder Adjusted Analysis (Significant Associations of Self-care Modality Choice)							
Variable of interest	OR (95% CI) – single variable	p-value	OR (95% CI) – multivariable¹	p-value	OR (95% CI) – confounder adjusted analysis	Confounders	p-value
MCQ2 Metaconcentration (per one increase in score)	N=200 1.16 (1.04, 1.29)	0.009	N=199 1.20 (1.06, 1.36)	0.004	N=120 1.19 (0.99, 1.43) N=152* 1.19 (1.02, 1.38)	TMT B, ethnicity, creatinine, BDI, STAI state, STAI trait, consequences (IPQ-R), illness coherence (IPQ-R), timeline cyclical (IPQ-R), emotional representations (IPQ-R)	0.066 0.024
CCI (per one increase in score)	N=206 0.81 (0.70, 0.93)	0.002	N=199 0.75 (0.62, 0.89)	0.001	N=150 0.89 (0.69, 1.14) N=186* 0.85 (0.69, 1.06)	TMT B, TMT A, 3MS, employment, ethnicity, cause of ESRD, centre, vision	0.35 0.14
Mobility – Walking aid /limited / wheelchair bound	N=206 0.37 (0.19, 0.74)	0.005	N=199 0.45 (0.19, 1.09)	0.076	N=150 0.39 (0.15, 1.00) N=186* 0.41 (0.18, 0.94)	TMT B, TMT A, 3MS, age, employment, ethnicity, CCI, diabetes	0.050 0.036
Accommodation – not home owner	N=205 0.56 (0.30, 1.04)	0.068	N=199 0.42 (0.20, 0.89)	0.024	N=170 0.61 (0.26, 1.44)	Age, employment, BDI, STAI trait, centre	0.26
Ethnicity – non-white	N=206 0.50 (0.20, 1.29)	0.15	N=199 0.29 (0.10, 0.86)	0.025	N=169 0.13 (0.03, 0.58)	Age, employment, CCI, BDI, STAI state, STAI trait, emotional representations (IPQ-R), centre, mobility	0.007
Centre A B C D E	N=206 1 (-) 2.24 (0.88, 5.70) 1.09 (0.43, 2.76) 0.70 (0.26, 1.85) 1.40 (0.52, 3.78)	0.096	N=199 1 (-) 2.08 (0.71, 6.09) 0.62 (0.22, 1.77) 0.57 (0.19, 1.75) 1.09 (0.35, 3.40)	0.071	N=161 1 (-) 2.84 (0.73, 11.05) 0.57 (0.16, 2.06) 0.76 (0.20, 2.91) 1.20 (0.33, 4.36)	Age, employment, ethnicity, CCI, STAI state, STAI trait, SCQ1, accommodation	0.14

There are 222 predialysis patients considered in the analysis, of which 206 made a modality choice (the outcome). The odds ratio here is in terms of the odds of choosing home HD or PD compared to the reference group – hospital HD.

¹The final multivariable model includes the six variables of interest: MCQ2, CCI, mobility, accommodation, ethnicity, and centre

*Excluding TMT B (due to this variable having >20% missing data)

Peritoneal dialysis vs home haemodialysis

A multinomial logistic regression model has also been done to look at the two home modalities separately. The same set of variables were considered as for the multivariable regression analysis. Additionally, ‘perceived ability to self-cannulate response’ was considered due to its significant association with the outcome of interest in the single variable analysis. Table 3 shows the outcomes of the multinomial logistic regression analysis. In this case, the 95% CI for the relative risk ratios are very wide and so would need to be treated cautiously, as also the numbers of home haemodialysis patients are quite small. In this analysis, subjective cognitive ability, comorbidity index and perceived inability to self-cannulate are the significant predictors of the three modality choices.

Table 3: Multinomial logistic regression analysis		
Variable	Relative risk ratio (95% CI)	p-value
Overall		
Metaconcentration	-	0.012
CCI	-	0.005
Perceived inability to self-cannulate	-	<0.001
PD vs hospital HD		
Metaconcentration (per one increase in score)	1.21 (1.06, 1.38)	0.004
CCI (per one increase in score)	0.77 (0.65, 0.92)	0.004
Perceived inability to self-cannulate	2.01 (1.00, 4.03)	0.051
Home HD vs hospital HD		
Metaconcentration (per one increase in score)	1.11 (0.95, 1.29)	0.19
CCI (per one increase in score)	0.79 (0.63, 0.99)	0.039
Perceived inability to self-cannulate	0.22 (0.07, 0.68)	0.009

It is useful to note from Table 4, associations between variables, especially variables which are significant in the multivariable analysis. The associations between metaconcentration and BDI, TMT B and Illness coherence are significant. CCI is significantly associated with ethnicity, mobility, illness coherence and TMT B. Metaconcentration and CCI are not significantly associated with each other and therefore remain independent predictors of modality choice.

Table 4: Associations between study variables									
	CCI	Ethnicity	Mobility	Accomm.	BDI	Illness coherence	Meta conc.	TMT B	Centre
CCI	-	-	-	-	-	-	-	-	-
Ethnicity	0.002	-	-	-	-	-	-	-	-
Mobility	<0.001	0.081	-	-	-	-	-	-	-
Accomm.	0.20	0.31	0.85	-	-	-	-	-	-
BDI	0.45	0.13	0.084	0.006	-	-	-	-	-
Illness Coherence	0.007	0.40	0.22	0.89	0.010	-	-	-	-
Metaconc.	0.49	0.29	0.49	0.49	<0.001	<0.001	-	-	-
TMT B	<0.001	0.75	0.018	0.55	0.84	0.051	0.035	-	-
Centre	0.003	0.033	0.001	0.048	0.23	0.54	0.78	0.27	-

The final model (n=199) and the imputed model (n=222) have an AUC of 0.75 (figure 2). This model is therefore good at discriminating choice of hospital haemodialysis and self-care dialysis choice made by predialysis patients.

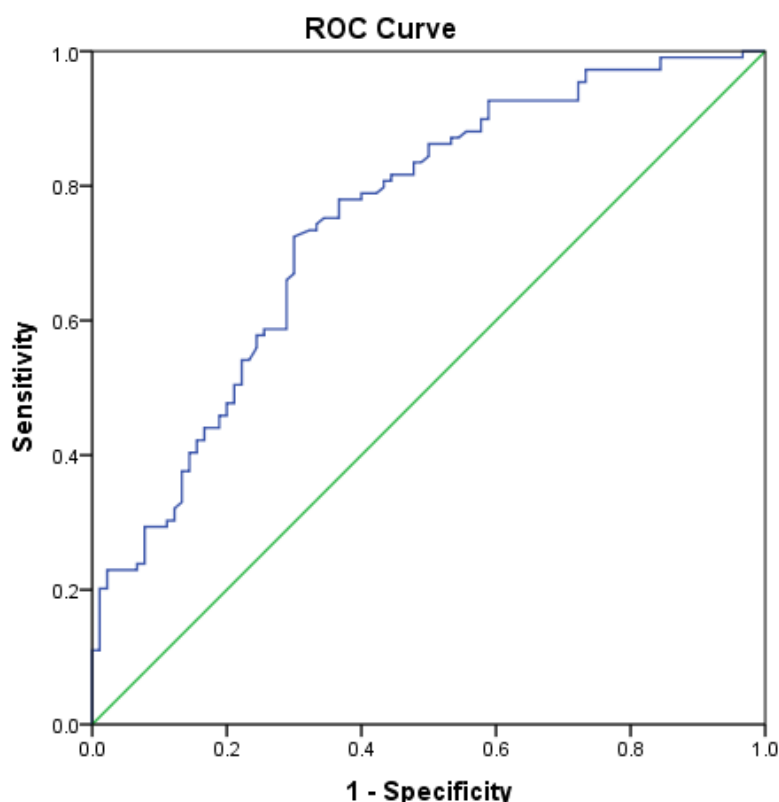


Figure 2: AUC for the final model (n=199 model with six variables)

Decision-Initiation gap in dialysis modality

In the prospective observation of our predialysis study cohort, one year on from when patients joined the study, 84 predialysis patients started one of three dialysis modalities; paired data on choice and initiation was available for 82 patients. Of the 82 patients, 44% of patients chose hospital HD, and 88.9% of patients started hospital treatment. The rest (11%) commenced self-care dialysis as shown below (Table 5). 56% of predialysis patients chose home-based dialysis modalities. 30% of these patients (n=14) ended up commencing hospital-based dialysis. The reasons for this have not been ascertained as part of this study, however, the characteristics of those who selected self-care dialysis and started self-care dialysis has been compared with those who selected self-care dialysis and started hospital-based dialysis in Table 6. Due to small patient numbers, only descriptive statistics has been used to present the results.

Table 5: Numbers of patients who chose home-based dialysis and started hospital HD

Initiation Decision	Hospital HD	Peritoneal dialysis	Home HD	
Hospital HD	32	3	1	36/82 (43.9%)
Peritoneal dialysis	7	25	0	32/82 (39.0%)
Home HD	7	0	7	14/82 (17.1%)
	46/82 (56.1%)	28/82 (34.1%)	8/82 (9.8%)	

The patients who chose self-care dialysis and ended up in hospital, had a higher mean age, were more likely to be retired males, greater proportion of patients were of non-white ethnicity, had a higher median CCI, were less likely to be mobile, had greater median BDI score, lower mean metaconcentration score and higher TMT B score. The greatest proportion of those who started hospital HD were also from the high prevalence centre as also was the proportion who continued self-care HD.

Table 6: Differences in characteristics of patients between dialysis decision-makers and initiators			
Variable	Selected self-care but started hospital HD (n=14)	Selected self-care and did self-care dialysis (n=32)	p-value
Age – Mean, std. dev. (range)	60.6, 9.4 (43-73)	55.5, 12.6 (29-75)	0.18 ²
Gender – Female	1 (7.1%)	15 (46.9%)	0.016 ³
Education – Post high school	4/13 (30.8%)	6/30 (20.0%)	0.46 ³
Employment			
Retired	10 (71.4%)	9 (28.1%)	0.012 ³
Unemployed	0 (0%)	7 (21.9%)	
Salaried/ self-employed	4 (28.6%)	16 (50.0%)	
Ethnicity – Non-white	2 (14.3%)	2 (6.3%)	0.57 ³
CCI – Median (range)	5 (2-7)	4 (2-9)	0.33 ¹
Mobility – Not independent	3 (21.4%)	2 (6.3%)	0.16 ³
Accommodation – Not home owner	3 (21.4%)	11/31 (35.5%)	0.49 ³
BDI – Median (range)	n=11 14 (0-36)	n=27 10 (0-29)	0.33 ¹
Illness Coherence – Median (range)	n=11 19 (6-25)	n=25 19 (11-25)	0.60 ²
Metaconcentration Mean (range)	n=13 14.5 (10-20)	n=29 15.0 (10-20)	0.60 ²
TMT B Median (range)	n=10 98.5 (63-230)	n=24 90.0 (34-300)	0.81 ¹
Centre			
A	2 (14.3%)	2 (6.3%)	0.094 ³
B	5 (35.7%)	10 (31.3%)	
C	0 (0%)	9 (28.1%)	
D	3 (21.4%)	2 (6.3%)	
E	4 (28.6%)	9 (28.1%)	

Centres A/C: Low Prevalence (<3%)

Centre B: High Prevalence (>8%)

Centres D/E: Medium Prevalence (5-8%)

DISCUSSION

This study is unique in its assessment of the significant predictors of self-care dialysis, in that, it has the largest number of robust patient co-variables to examine their association with the outcome of interest (self-care dialysis vs fully-assisted hospital HD). It also captures information pertaining to the gaps between decision and initiation of the chosen dialysis modalities, a feature that is often not found in similar publications. There are several studies of dialysis modality predictors based on surveys and qualitative studies [8, 9, 15, 22-25].

The significant predictors of dialysis modality choice from the multivariable analysis is important in many ways. The prediction model has an AUROC of 0.75, which shows a good discriminant ability amongst patients choosing home and hospital dialysis therapy. Whilst it is true that higher comorbidity may not be associated with the choice of self-care dialysis, it appears from the univariate analysis that, it is a combination of age, and multiple comorbidities which is likely to deter the choice of self-care modality. Diabetes or heart failure on its own, especially when well controlled, may not be a deterrent to self-management choice. This is an important consideration when selecting patients' suitability for home-based dialysis, as it allows us to expand the criteria for patient selection based on their physical status. However, it must be borne in mind that the home HD technique failure rate is highest in patients with diabetes and established cardiac failure[26, 27]. These patients may be more suitable for peritoneal dialysis, especially when they have marked cardiac dysfunction[28].

Self-perceived impaired cognitive ability, is independently associated with self-care modality choice after adjustment for co-morbidities (chapter 3.8). We have also ascertained that metaconcentration is associated with depression scores and illness coherence. These variables lose significance in the regression model alongside metaconcentration. Therefore, it is very likely that the latter does capture some of the effects of BDI and illness coherence. Addressing depression may help improve metaconcentration and illness coherence. That, illness understanding is associated with perceived ability to concentrate is important, as acquiring information that patients use in order to learn a complex technology, such as dialysis can be difficult without self-concept. In a previously reported study, metaconcentration in the kidney disease context was significantly associated with executive brain function (chapter 3.8).

From the data presented in this study, it is important to understand the implications of cognition on self-care dialysis choice, as it may be possible to validate these in a prospective study and is also far easier to deploy compared to objective tests of cognitive function. It may also help identify those who could benefit from intervention in the early stages. Perceived inability to self-cannulate for haemodialysis was another significant determinant of home

haemodialysis choice. It is evident that predialysis patients who chose peritoneal dialysis have a significantly greater fear of self-cannulation. This knowledge can ensure that this issue should be specifically sought in this group of patients and addressed over time, given the limits on the duration of peritoneal dialysis technique and the prospect of allowing the patient to continue home therapy through home haemodialysis provided there is no significant advance in comorbidity or cognitive decline. Also, as patients who made the hospital HD choice may not be particularly averse to the idea of self-cannulation, this may be actively encouraged in a select few[29].

Patients not owning homes (60% lower odds) and of non-white ethnicity (70% lower odds) are significantly less likely to consider self-care dialysis options, after adjustment for each other, comorbidities index, perceived cognitive ability and centre characteristics. This is an important observation, as a significant increase in the choice of self-care dialysis can only be achieved through tackling these potential barriers to self-care dialysis. Batched dialysis in community houses, and in free standing units may be an option for some. Self-care in-centre dialysis should be actively promoted in the subset of patients. Tailored education and information package for the patient and the family may help promote the choice amongst non-white patients. Language barrier may be an issue and if so, dialysis care partner who may be fluent in English may be engaged in the process.

Another interesting observation is the cohort of patients who chose self-care dialysis and started hospital-based dialysis modality. Female patients were significantly more likely to persevere with their chosen modality. This may be a result of a younger group of patients, with childcare responsibilities. The other significant difference between these groups was in the proportion of retired and employed patients, the former- greater in the hospital start group. These patients are likely older with a greater comorbidity profile. These observations raise an important question of monitoring patients who choose to undertake home dialysis. Equally, it is important to revisit this situation in a hospital setting so as to allow them to return to home dialysis therapies, once stable. This can only be achieved through a robust follow-up programme of identifying suitable hospital patients for home dialysis.

Our study has limitations. Prospective determination of predictors would be more appropriate, but follow-up of large numbers of patients can be logistically difficult given the array of measurements employed in our study. It may have been useful to systemically, ascertain reasons for alternative modality starts. This was not feasible in our study.

In conclusion, significant predictors of self-care dialysis choice are patients' perceived cognitive ability, perceived ability to self-cannulate and comorbidities index of which age is an important factor. Non-white ethnicity and lack of home ownership also result in

significantly lower odds of choosing self-care dialysis over fully-assisted form of dialysis therapy. The centre to which the patient belongs may also have a bearing on dialysis modality choice, although not statistically significant in the final model. Patients should be able to consider self-care therapies option in all but the most limiting physical and cognitive states. There is a greater need to understand the decision-initiation gap between the chosen and actual dialysis modalities.

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CHAPTER 3.10

Predialysis patients' views of dialysis information and decision-making process underpinning their choice of home and hospital-based haemodialysis modality: a qualitative study

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ABSTRACT

Background: Home dialysis therapies are advantageous for both patients and service providers from clinical, quality-of-life and economic considerations. The uptake in the UK nationally has increased nationally over the last few years, but it is still far short of the NICE technology appraisal guidance from 2002. Patient, care-giver and organisational barriers may be responsible for its uptake and prevalence. We aim to describe predialysis patients' dialysis education experience and their decision-making process underpinning their modality choices of home and hospital-based haemodialysis.

Methods: Semi-structured interviews with adult patients known to have CKD 5 were recruited from one large tertiary renal centre in the UK with relatively high prevalence of home haemodialysis (11.5%). These patients had made their choice of dialysis modality-home or hospital, after going through a structured educational programme offered by the institution.

Results: In total, 18 patients participated in the study (home haemodialysis choice: n=8; hospital haemodialysis choice: n=10). We identified five themes related to home dialysis choice: *a) Information* (dialysis information and choice) *b) Communication* (healthcare team messaging), *c) Confidence* (self-efficacy, safety and security in hospital), *d) Pursuing fulfilment* (work and ambitions, social engagements and responsibilities, *e) Impact on significant others* (Caregiver participation, haemodialysis machine at home).

Conclusion: There appears to be divergence of attitudes, experiences of dialysis education, and decision-making processes within subgroups of predialysis patients who choose home-based and hospital-based haemodialysis. There is room for improvement in the manner of communication of dialysis information, through incorporating behavioural management programmes and a more personalised training package. A 'self-care' first policy, as far as possible, irrespective of the location may allow patients to take better control of their disease management in the longer term. Physicians need to consciously seek psychological dispositions of their patients, and be more actively engaged in dialysis decision-making with them, and not limit their role to ratification of the choices made.

INTRODUCTION

Globally, the population with chronic kidney disease is increasing[1, 2]. In the United Kingdom, the incidence of renal replacement therapy amongst individuals aged 45 to 64 has increased from 50 per million population (pmp) to over 150 pmp in just over two decades since 1980[3]. This age category includes individuals who are likely to be in the most productive years of their life. Patients in this age group are relatively abler and may choose to undertake self-care dialysis over in-centre haemodialysis. The rationale for home dialysis over hospital haemodialysis (HD) from a clinical standpoint is increasingly clearer. Home dialysis therapies are advantageous for both patients and service providers. Compared with ‘in-centre’ HD, both peritoneal dialysis (PD) and home haemodialysis (HHD) are more economical and offer better quality-of-life for patients[4-7]. PD is associated with comparable survival and home HD offers comparable or even better survival than ‘in-centre’ HD[8-10]. In the UK, the Renal National Service Framework (NSF) in 2004[11], recommended the delivery of high quality, clinically appropriate forms of dialysis to be designed around individual patient needs and preferences. The NICE technology appraisal guidance in 2002, recommended an ambitious target of 10-15% of dialysis population for home haemodialysis uptake[12]. Globally, the prevalence is varied and influenced by several local factors. In the UK, even within the National Health Service, home HD prevalence is quite varied. Through several local, regional and national initiatives in the last decade, there has been growth in the prevalence of home haemodialysis and it is estimated to be 4.7% nationally in 2014[13]. Notwithstanding organisational barriers to home haemodialysis therapy prevalence, patient-specific barriers limit the possibility of realising benefits of home HD treatment.

In the last decade, several qualitative and mixed-methods studies have been published to understand the perspectives of patients and their caregivers on home haemodialysis, mostly from Australia and New Zealand where 12-18% of dialysis patients are on home haemodialysis[14-18]. The vast majority of studies have focused on the views of prevalent home and hospital haemodialysis patients. A recent systematic review on the subject, included a small total predialysis population (n=15) pooled from various studies[19]. Some other studies have focused on the more intensive forms of dialysis therapies, such as nocturnal haemodialysis[16, 20]. It is acknowledged that the actual experiences of patients on these therapies is important to understand patient perspectives of the treatment undertaken by them. However, predialysis patients make their choices in the abstract and these are often, a result of their understanding of information presented in a certain psychosocial context, which in turn is influenced by several innate and external illness and health service-related factors. The

disconnect between the lived and anticipated experience of haemodialysis was described recently by our study group[21].

Most studies have presented some patient perspectives that limit the uptake of home haemodialysis. These include, fear of self-cannulation, fears about dialysing alone- for medical and social reasons, dependence on the hospital team-both physically and emotionally and concerns about home haemodialysis on caregivers[19]. Whilst these are typically observed in practice, patients' information-seeking attitudes and perception of dialysis information ascertained from the dialysis counselling sessions, may better inform the reasons for choosing home over hospital haemodialysis and vice versa.

The aim of this study is to understand predialysis patients' views and experiences of dialysis education and the decision-making process underpinning their modality choice of home and hospital-based haemodialysis.

METHODS

Study Context

The present qualitative study, is part of a multi-centre, multi-method cross-sectional and prospective observational study to investigate the barriers and enablers of home haemodialysis (BASIC-HHD study)[22]. The qualitative studies were carried out in one tertiary centre with the highest prevalence of home haemodialysis amongst the five study centres.

Study Design

Theoretical Framework

The methodological orientation which has been considered for this thematic data analysis has been used within the 'grounded theory' framework using the constant-comparative method.

Participant Selection

Participants were eligible if they had chronic kidney disease stage 5, were aged 18 years or over, and were English speaking. Participants should have undertaken predialysis education offered at the study centre and made their dialysis modality choice of home or hospital-based haemodialysis. Purposive sampling was used to capture a range of patient demographics namely age, ethnicity, and gender. Participants were approached based on their eligibility through telephone contact as well as face-to-face, to obtain consent for their participation. Participants with severe mental health or learning difficulties, as established from their medical notes, were excluded, as they would not be safe pursuing home haemodialysis. All

participants (n=18) were recruited from one tertiary hospital, with a proportionally high prevalence of home haemodialysis at 11.5% (67 home HD patients) of the total unit dialysis population (589), with 30.9% 'in-centre', 43.6% in satellite units, and 14% peritoneal dialysis patients in 2012-13. All participating predialysis patients had received education from a dedicated predialysis education team comprising nephrologists and senior nurse specialists and would typically be offered information booklets, audio-visual information, one-on-one session demonstration with dummies, attendance at a multidisciplinary seminar, peer patient interaction, visits to home haemodialysis training unit and the main dialysis facility. During these interactions, patients were exposed to home HD, PD, satellite HD, transplantation and conservative care treatment options. All predialysis patients, would also have had the opportunity to revisit these education programmes and/or discuss treatment options with their nephrologist or with one of pre-dialysis coordinators.

Ethical approval for the study was obtained from the Greater Manchester West Health Research Authority/National Research Ethics Service (Reference 12/NW/0170). Eligible patients were contacted by a member of the research team (RM) and invited to participate. All patients were told of their right to refuse to participate or withdraw from the study without giving a reason, in the knowledge that their standard of care would in no way be affected.

Setting

Predialysis patient interviews were carried out in a place of patient's choosing- this was either in their own homes or in a quiet room in the hospital. The interviews were limited to the study participant and no family member contributed to the data ascertained.

Data collection

All interviews were conducted by two independent researchers (RM, CD). RM conducted face-to-face digitally audio-recorded semi-structured interviews with 12 patients, CD undertook the remaining 6. All participants were recruited and interviewed between December 2012 and April 2013. Interviews lasted from 30 to 60 minutes. Qualitative interviews were conducted until data saturation was achieved. Transcripts of interviews were not returned to participants for comment/correction.

Based on previous published information on haemodialysis patient perspectives, an interview topic guide was designed by all members of the research team on predialysis patients' experiences of their chosen modalities. The topic guide consisted of open questions, supplemented with probes to allow exploration of patients' meanings. This is provided in the appendix.

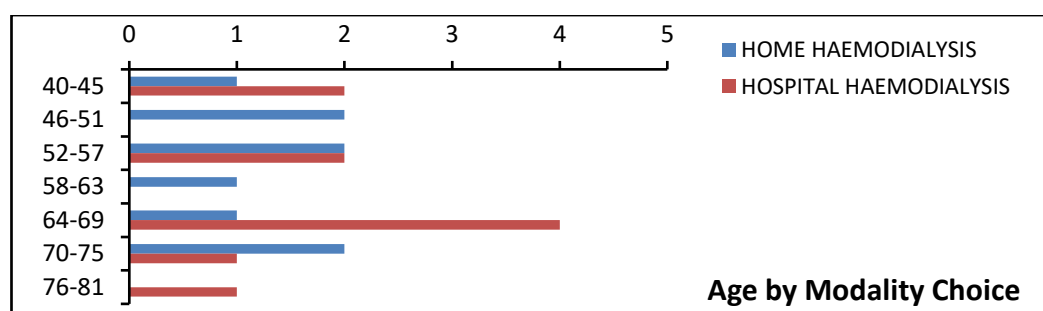
Patient demographics

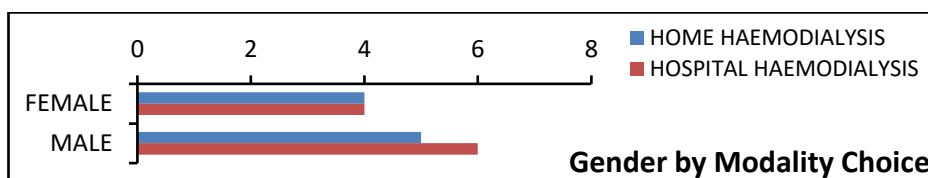
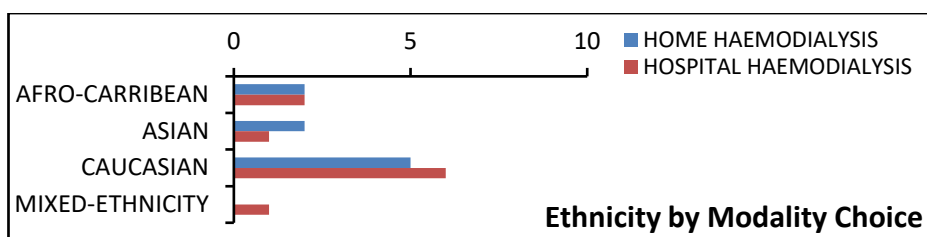
18 patients participated in this project. Select patient demographics are presented in Table 1.

Participant ID	Age	Gender	Ethnicity	Modality Choice
A	42	Male	Afro-Caribbean	Hospital HD
B	54	Male	White	Hospital HD
C	40	Male	White	Hospital HD
D	72	Male	White	Hospital HD
E	54	Male	Mixed-Ethnicity	Hospital HD
F	69	Male	White	Hospital HD
G	68	Female	Asian	Hospital HD
H	69	Female	White	Hospital HD
I	76	Female	Afro-Caribbean	Hospital HD
J	65	Female	White	Hospital HD
A1	56	Female	Asian	Home HD
B2	65	Female	White	Home HD
C3	75	Female	White	Home HD
D4	40	Female	Afro-Caribbean	Home HD
E5	46	Male	Afro-Caribbean	Home HD
F6	70	Male	White	Home HD
G7	58	Male	White	Home HD
H8	50	Male	White	Home HD

There is good representation of age range, gender and ethnicity within the two modality choices, as depicted in Figure 1. The mean age of patients choosing home haemodialysis was 57.5 years and those choosing hospital haemodialysis is 61yrs. Approximately 39% of the participants were non-white.

Figure 1: Demographics by modality choice





Research team and Reflexivity

Personal characteristics and relationship with participants

Both researchers conducting interviews were well aware of qualitative interview techniques through their educational background. The analysis of the data was conducted by the main researcher AJ, a practising nephrologist. It is quite likely that some interpretation of patient opinions may be shaped by routine clinical experience of similar situations[28]. The non-involvement of the first author in the interview process has perhaps helped the patients speak their minds about their interaction with members of the healthcare team without any reservations and the data analysis was also done by the first author, with anonymised datasets.

Data analysis

All audio recordings and transcripts were read by the first author (AJ) and reflexivity was maintained throughout the process to remain self-aware and examine potential biases throughout the project. Interview transcripts were uploaded into 'Dedoose.com', a cloud-based qualitative analysis software to facilitate storage, management and coding of the data. A thematic analysis approach was employed in accordance with the six steps proposed by Braun and Clarke[23]. AJ became conversant with the data by reading each transcript and by listening to the audio recordings to understand the tone of communication. Subsequently transcripts were coded line-by-line. The codes were generated inductively and thematically. AW reviewed codes from 20% of the interviews to test inter-rater reliability. Themes and sub-themes were compared with one another and with the original transcripts. Series of discussions within the study group to review and refine the coding scheme allowed us to capture a greater depth of topic specific concepts. We specifically explored the similarities and differences in themes around treatment decision-making between pre-dialysis patients who chose home and hospital-based haemodialysis.

FINDINGS

Thematic analysis

Five major themes emerged from the data analysis. These are labelled-

- a) Information
- b) Communication
- c) Confidence
- d) Pursuing fulfilment
- e) Impact on significant others

Information

Dialysis information and choice

Predialysis patients, who made their modality choices mentioned that access to information regarding dialysis was typically quite good, and that the healthcare team, comprising of both doctors and specialist nurses was approachable and friendly. Most patients found the 'education evening' sessions satisfactory. Some patients however voiced their concerns about these sessions being rushed, crowded, long, unclear, overwhelming, or inappropriately timed late in the evening. It is useful to note that predialysis patients who felt the educational sessions experience as being 'inadequate' in any respect, had chosen hospital haemodialysis. Patients generally liked the idea of dummies to explain the process and also felt that the group education evenings allowed them to obtain information even when the patient was a passive listener, simply by being exposed to a whole array of questions posed by others. Other specific aspects well appreciated include looking at the dialysis needles, as for some, the size of the needles was an important piece of information, and helped allay anxiety.

'When you first go and they let you know that you're moving on to another section, they had me in this room and this nurse was talking about it and she had a dummy and all that kind of thing. And she went through everything, but there's such a lot at one stage'. D, 72 Male, Hosp HD on volume of information

'That was when I first made the decision to go on home haemodialysis. And she showed me and I thought, "oh they're not too bad them." H8, 50, Male, Home HD on looking at needles for cannulation

Some patients highlighted their concerns about the lack of practical and procedural details in the manner in which information was presented to them. Participants expressed their satisfaction at the opportunity to interact with other patients. However, some patients disliked talking to other patients about their illness- such responses were usually seen from patients choosing to undertake hospital-based haemodialysis. Internet was deemed, a useful source of information by some and 'bogus' by others. Many patients reported being influenced by their family and friends into choosing one or the other modality. Predialysis patients with hospital

HD choice, often seemed to suggest the influence of friends in their choice of dialysis modality.

'And they've all got their own specialities and I found that they threw it at you a bit quick and, you know, you come out shaking your heads and saying what was that all about'. H, Female, Hosp HD on group dialysis education

'And you could hear things that you don't think about, other people are asking, you see'. G7, Male, on benefits of group education sessions; Home HD

'We'll take you to the unit and show you sort of people... well it's not like a day out at Blackpool is it, I don't want to go and see people'. J, Female, Hosp HD on peer-patient interaction

'Simple reason a lot of that on there's bogus'. B on internet use; Male, Hosp HD

'Yeah, that's how I know about dialysis because when she was on dialysis she didn't like it so I know I'm not going to like it'. E, Male, Hospital HD; influenced by a friend's choice

Participants perceived the lack of a real choice with dialysis options and felt that dialysis was merely a holding measure. The 'real' solution lay in getting a kidney transplant.

'You know; with dialysis you are only managing it'. E5, Male, Home HD

'But the best way is to have a new kidney' J, Female, Hosp HD

Participants reported some instances of information gaps and seemed to perceive the meaning of some aspects of dialysis care differently. In a few situations, these have led to a specific modality choice. These are exemplified by the quotes below-

I think it's cleaner and more efficient'. (HD>PD) and 'Well it's a clean environment at hospital'. D, Male, Hosp HD

'Because, and it wouldn't be enough for me because it's both of my kidneys because most people who are doing it it's just one kidney but for me it's both of my kidneys that have gone bad. So doing it at home it will be better'. D4, Female, Home HD

'And I tend to think if you're doing home dialysis, I think you fall down the list of getting a kidney. I think if you go to hospital you've got more chance'. J, Female, Hospital HD

Communication

Healthcare team messaging

Participants realised that dialysis prolonged life and expected improvement in their general state of health upon commencement of haemodialysis. Some had a deep understanding of the limitations of haemodialysis thrice weekly and felt persuaded by the information on the benefits of intensive haemodialysis which led them to choose home HD.

'Well I presume I'll feel better and I'll have more energy maybe, because I am tired a lot and cold a lot, that's the only thing there's any difference to when I was younger. But I think if you're taking the bad stuff out and replacing it with good stuff then I should feel better after it, so...' B2, Female, Home HD

'As much as possible. Cuz I've been told they like you to use it at least 3 times a week or maybe more. Cuz the more you do it, the more beneficial for the individual like you know'. G7, Male, Home HD

Some patients reported discomfort with the idea of sharing machines, in case infections were passed on. Some patients carried with them misperceptions about dialysis information, and the healthcare team expediting dialysis starts.

'But if I bring the machine home, I think it is much better for me. Then I won't have to share the machine then, it will be just me. Because that's the problem to me, a lot of people using the same machine'. E, Male, Hosp HD

'Well it was alright for, you know, informing me of the different types, you know. It's just when all they want to do is just put me on dialysis and stick me in a corner, you know. I ain't up for it'. A, Male, Hosp HD

Patients also voiced concerns over inconsistent messages from different members of the healthcare team regarding dialysis options and start of HD. Clinics being 'too busy to allow a chat' was the experience of one patient's trip to the hospital clinics. Lack of trust in healthcare services was a common complaint from a few predialysis participants. Incidentally, all of them belonged in the hospital-HD category of the predialysis cohort. Home HD choosers however, reported that clinician validation of their choice and communication of their confidence in the patient's ability helped dialysis decision-making.

'I can understand, I laugh about it but, like I said I get all my information on the... which you shouldn't do, they should be there for you but you see there's that many. You go there, there's that many they've only got time... they haven't got time to sit down and talk to you, you know, so where do you go? It's not their fault, it's the system, they haven't got the money have they, the National Health, so much'. H, Female, Hosp HD

'Well they always say I've got complications. Well I've only got complications because no one's got the balls to like actually do something about it. so obviously it's getting worse, which just drives me up the wall'. A, Male, Hosp HD

'I can't explain it...when you go to that hospital I find one doctor contradicts the other. This is my opinion and I've seen different doctors there'. H, Female, Hosp HD

'The people that I've met in connection with dialysis all seem very confident. They said...I think that's quite important for the people who are responsible for either setting-up your dialysis or advising you need to be confident not only in that they can do it but that you can do it, that they can teach you to do it. I think that's very important. So an attitude of mind would be important in that'. F6, Male, Home HD

Other aspects of communication that boosted confidence in the choice of self-care haemodialysis included, visit to the training unit, speaking to self-caring haemodialysis patients, the assurance of a sign-off of their competencies before allowing them to undertake haemodialysis independently and the back-up or respite care should that be required into the future.

'Knowing that I've got the back up there, great yeah. Obviously I'll have to go to hospital x for the learning - for teaching me how to do it properly, and then once I have the confidence to do it myself. Yeah, I think I'll be quite happy with it'. G7, Male, Home HD

Confidence

Confidence is a significant factor in dialysis decision-making especially when the choice is between institutional care and home-based dialysis. Confidence applies to the patient's belief

in self to cope with technology in home haemodialysis and also belief in the healthcare system to deliver the best outcomes for the patient.

Self-efficacy

Self-efficacy refers to an individual's belief in his or her capacity to execute behaviours necessary to cope with challenging tasks. Several predialysis patients expressed confidence in their ability to learn new skills. Patients who chose home-based HD expressed this more often. The range of inability projected by some predialysis participants ranged from 'feeling unqualified' and lack of confidence in technical ability to frank apathy for self-care.

'Yeah, the machine is nothing complicated to learn. It's just simple thing. I can't find a problem with that, so that make me feel easy anyway'. E, Male, Hosp HD

'Well otherwise it would be all here on my own trying to do it when I don't feel like doing it. That's the reality. If it was left to me or my own devices, I probably wouldn't do it'. B, Male, Hosp HD

Fear of self-cannulation was one of the reasons mentioned for choosing hospital over home haemodialysis. Whilst it was perceived as a necessary evil by some home haemodialysis choosers, others expressed their dislike for needles but also their perceived ability to overcome this fear in time. For some of these predialysis patients, other actions associated with handling sharps such as injections for erythropoietin, insulin use and even routine phlebotomy may have tempered their fears. One participant found the technical aspects most worrying. Participants who chose home haemodialysis felt 'being in control' was important to them. This would apply also to their own time, day and duration of haemodialysis therapy. Freedom from hospital visits and the flexibility to accommodate other interests was liberating for participants who chose self-care haemodialysis.

'I have a phobia with needles so sticking needles in me is not exactly good'. A, Male, Hosp HD

'Well having insulin for 12 years you have needles every day, it just doesn't bother me'. C, Male, Hosp HD

'So I thought well if that's the case I'd like to be in control myself and do it myself. It seemed like I was having... like I said about my injections, the nurses would come in. I said no I'll do it myself, you know'. C3, Female, Home HD

Safety and security in hospital

Some participants, especially those who chose hospital-based dialysis, expressed their satisfaction in receiving frequent medical attention and in that process, anticipated improvement in general well-being.

'Like I say, the only thing that worries me about doing it at home compared with the hospital, at least I've got the nurse or the assistant or whatever they are there in case anything goes wrong' F, Male, Hosp HD

'If I'm there in their face every week my health is going to be better looked after. can't look after my own health properly can I because I'm not an expert'. J, Female, Hosp HD

'No I've got a lot of faith in them'. J, Female, Hosp HD

Others felt safer in hospitals in case of emergencies whilst receiving haemodialysis. Participants also acknowledged the role of practitioners and placed their faith in optimum delivery of care.

Pursuing Fulfilment

Work and Ambitions

Kidney failure was the reason some patients found their ambitions curtailed. Participants who chose home therapy, were more inclined to re-establish their self-identity at work. To be able to continue working, some participants chose to undertake home HD when it may be required.

'So I said if I do it at home I'll do it nights so during the day I'll be free to work'. D4, Female, Home HD

'But I think I'm always thinking about one day I go on dialysis, it's like they tie me up here and I'm not free to do anything. So it's stop me to think some big things like do business or make more money or something like that, yes. Before I'm like businesswoman, I like to, you know, do some things for my family'. A1, Female, Home HD

Some patients reported difficulty in coping with multiple responsibilities and illness and therefore could not perceive continuing in their jobs. The unpredictable course of illness was a concern expressed by some and mentioned of the difficulty looking into their future without the actual experience and assessment of dialysis.

'It's not like it's going to end. It's going to keep going and going and, you know what I mean? Tablets, tablets, tablets man. It's not going to stop is it?'. E, Male, Hosp HD

'Actually because I haven't got that experience yet, so I don't...actually I don't know, I've no idea at all'. A1, Female, Home HD

Social engagements and responsibilities

Many patients valued their social life immensely and feared having lost some of it through the diagnosis of kidney failure. Others developed a more productive coping style by choosing to undertake activities such as 'dance' to help upkeep an active social life. Participants who were active socially looked at home haemodialysis as a socially-friendly treatment option. Others who feared social isolation or movement restricted by home HD, looked towards hospital HD to fill that void.

'Plus it would leave me free for the days. Because twice a week we go shopping, Mondays and Thursdays, some weeks, once or twice a month we've got a club meeting and that's an evening. I know it's what I call an evening', F, Male, Hosp HD

'And really that amount of time is taken out of your life. So you have to think about what's important, what do I want to continue doing, and what could possibly be ditched'. F6, Male, Home HD

'But a lot of them have said that because of this, rock'n'roll, helps them get through it. It's unbelievable'. G7, Male, Home HD

'Want to get away from it because I'm going to get totally isolated and I don't fancy that isolation'. J, Female, Hosp HD

Many participants reported that home haemodialysis would potentially allow relationships with family to thrive. This is particularly true for carers with responsibility towards young children. Some have acknowledged the need for family to recognise the therapy as ‘a part of life’.

‘Well I don’t think... I’ve got five kids, the youngest is only 7 and if I had to start on it now I wouldn’t want to scare her’. C, Male, Hosp HD

‘But I want him to see that this is just part of my life for now really, yes. And for him not to be scared, yes’. D4, Female, Home HD

Impact on significant others

Caregiver participation

Predialysis patients mentioned the availability of an informal care-giver as an important pre-requisite for home haemodialysis. The fear of dialysing alone pushes people into choosing hospital based HD. The participants also see the role of the care-giver beyond moral support – in fact, there is an expectation from some to part take in self-cannulation for HD if required.

‘Can’t do it here on my own because I’m on my own, you know, and I do understand that if I was home dialyse I’d need somebody with me in case anything went wrong’. B, Male, Hosp HD

‘I can do it, yes, yes. But if I don’t then I know she is here for me so... yes because I’m lucky enough she is here, yes’ H8, Male, Home HD

Participation of the family at the clinic consults and in understanding dialysis was perceived by some to be the basis for their decisions. Some participants also mention of a lack of real knowledge amongst family and the feeling that the participant may be at ‘death’s door’. Shared decisions with family often resulted in the choice of home-based dialysis modality.

‘The way people perceive me is slightly negative because they see me as being at death’s door which I clearly am not’. F6, Male, Home HD

‘No I did tell them but, well they are normal I mean none of them has gone through any dialysis. Well their reaction is. oh dear, you know. But they have not commented very much. Yes, I don’t think they are aware of what is happening you know’ G, Female, Hosp HD

Haemodialysis machine at home

Participants had concerns for family members, both young and old. Whilst most hospital HD choosers mentioned the emotional burden on the spouse, there was concern also around machine noise. Another hospital HD choosing participant felt unable to shoulder the responsibility of safeguarding the dialysis machine.

Others also found the treatment intrusive in the home setting. Participants who chose hospital-based HD had particular concerns about medicalising the home environment and the machine as a potential reminder of their illness. Some participants’ decisions were influenced by the proximity of their homes to satellite dialysis units and thereby avoiding ‘the medical stuff’ at

home. In some instances, the real limitation was the lack of physical space or compatibility with the home HD machine and its consumables, necessitating hospital HD, much to the annoyance of some patients.

'Well they said I could have one at home, but I wouldn't want Susan to go through that, you know what I mean'. C, Male, Hosp HD

'I didn't want her to be in that room with me wife and that machine because I didn't know if that machine what noise it makes and things like that. You know, thought it wouldn't be fair on her'. G7, Male, Hosp HD

'But as time's gone on and with X now just opening that new centre, I thought, I don't want all this stuff in my house'. J, Female, Hosp HD

'I have too many people coming and going and I've got like five grandchildren come and they're all under eight, and it's just too much of a responsibility to have a machine like that in the house, not to be able to guard it sort of thing, you know'. D, Male, Hosp HD

'I thought, no, I don't want to go in to my bedroom and see these machines'. J, Female, Hosp HD

'The only thing is I wanted it at home but I can't because... because they came a fortnight ago and they didn't pass it'. H, Female, Hosp HD

DISCUSSION

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In the predialysis phase of chronic kidney disease, as patients prepare themselves for a life-changing treatment option, our study has identified information, communication, confidence, personal fulfilment and impact on care-givers as key considerations in their choice of dialysis modality. In published literature, the reasons for dialysis decisions have been extrapolated from the lived experiences of home-based dialysis and hospital-based haemodialysis patients; although more recently, there have been attempts to ascertain perceptions of predialysis patients or at least, highlight the disconnect between views of haemodialysis patients of the modality they had not chosen from the modality they were pursuing[14, 15]. Our own experience of this shows that, not all predialysis patients perceive information on dialysis identically, even though the modality and pertaining information is uniform and is sourced from the same repository of information. Also, the experience of patient's knowledge acquisition process and the expectations from self and the treatment, appear to be different between patients who choose hospital and home based haemodialysis.

Our predialysis study group, articulated the lack of a real choice. Patients understood the purpose of the educational sessions and the role of several other hospital-authorized sources of information including expert patient support, information booklets, videos, dummies, visit to the training unit, access to predialysis care team, free access to home haemodialysis conferences for those who wish to part-take and regularly scheduled clinic visits for all. Patients variably accessed external resources such as the internet and their own observations of people who have had dialysis. Yet, the manner in which information is perceived and understood appears to be somewhat divergent within the predialysis group. The level of

engagement of patients with the process seems different. Home choosing group appears to more often express satisfaction at the content of the educational programme and their ability to picture their current lives accommodating home haemodialysis. They preferred to interact with other patients and fill information gaps by looking up at web-based resources. Generally, patients in the home group were more accepting of their diagnosis of kidney disease, more receptive to information as they looked to adapt positively to the situation at hand. On the contrary, participants in the hospital choosing sub-group, expressed reservations about the healthcare team's inability to help them and explicitly mentioned of the lack of trust in healthcare services. Ironically, they chose a hospital-based treatment modality for themselves. There seems to be an underlying feeling of anger and helplessness about their clinical condition. The expectation of rational decision-making in this state of mind therefore, is inappropriate. Perhaps then, all patients may not be well served by the same entry-point for access to dialysis education. Typically, in most centres, this is determined by eGFR (lab-test of kidney function) cut-off, variably between 15 and 25mls/min. The progress to dialysis from this stage is a function of the underlying disease process, co-morbidity and the need for intermittent hospitalizations. Somewhere along this trajectory, patients at varying stages of preparedness are required to come to a decision on dialysis modality or accept a clinically recommended option, which may be in conflict with their own preference. Therefore, a personalised management approach is recommended. This should incorporate individualized teaching methods – in time, style and content spanning predialysis into early dialysis phase. This should also encourage positive adaptation to illness through guided behavioural therapy by a clinical psychologist. However, the process has to start from the clinician's consulting room. Therefore, greater awareness of psychosocial health integrated with biosciences is important in the training process for all physicians.

It is also apparent that patients perceive incorrect reasons for their choice of dialysis modality. These may be a consequence of the manner in which information was given by the healthcare team or the patient's own interpretation influenced by their illness experience. Nevertheless, these should be revisited by the healthcare team and they should satisfy themselves about the knowledge the patient has acquired and the reasons for choosing a certain dialysis modality. The audio-visual aspect to learning has been important for many- this includes, seeing the machine, seeing the needles for cannulation, seeing a fistula so it is not perceived to be a foreign body. Perhaps, as some patients seek, the very practical details (pros and cons) are quite important to them in the course of decision-making. Incremental dialysis education will allow patients to cope with the volume of information.

Participants elucidated their reasons for choosing the modalities they had, and also mentioned of factors which boosted their confidence in the choices they made. Clinician validation of

their choice was important and as one participant mentioned, a ‘good practitioner should guide patient’s decision-making’. This is well supported from other studies on the subject too[19]. Other factors such as training unit visits, seeing the equipment etc., helps the process; leaving only technical uncertainty to be dealt with at a later date. Perhaps, technological advances may allow for building of simulations for patients to understand the technical details even before they commence therapy. Patients opting for self-managed dialysis are younger and generally technology-savvy. Another remarkable aspect of information content that seems to have helped some patients, is the possibility of intensive haemodialysis, only currently practical in home circumstances. These patients were cognitively engaged with information and perhaps others who may be ambivalent may be persuaded by such information. Others found that responsibilities such as work, family and social life which gave them a sense of fulfilment, can only co-exist with home haemodialysis. These patients had a great sense of self-efficacy and functioned from a ‘can-do’ attitude despite underlying fears and anxieties of the unknown. This ‘motivation’ to some extent may be collaboratively developed in patients. Motivational interviewing styles remove paternalistic approach in the patient experience and allow for progressive collaborative decisions[24-26].

In instances where the choice of hospital-based HD was made from the lack of physical space at home or concerns over medicalising home, there is a need to create ample opportunities for such patients to self-care in the hospital setting. Where safety and sense of security in a hospital setting is the limiting factor, there may be opportunity to allow for shared-care at the outset with graduation to self-care as patients gain confidence in the process. From a policy perspective, the cost-benefit of sponsored self-care HD in tailored accommodation in patient’s own gardens or free-standing units should be considered against hospital-based haemodialysis. Self-cannulation was highlighted as an important consideration by few individuals. The nature of the proposed ‘fear’ of self-needling is important to understand. For some, the experience of routine phlebotomy or erythropoietin injections may well allow some patients to consider the possibility of self-cannulation and this should be explored in the hospital setting where other reasons have disallowed home haemodialysis[27]. Perhaps training a family member for cannulation or an assisted-cannulation service may engage more patients to choose home haemodialysis.

Caregiver support is a vital aspect of patient’s decision-making. Their participation in the patient’s treatment journey may give an insight into the nature of support that a patient can expect. The education information should incorporate carer-specific information, so they understand what they may be required to do and the kind of support available, such as respite care that may help them make a pro-home choice. The burden placed by the treatment on

family members is immense and units should incorporate respite care provision into their planning.

Our study has some limitations. The study excluded peritoneal dialysis patients, the other modality choice available to them. All study participants were recruited from a single centre, with a relatively high prevalence of home haemodialysis, and this may be perceived as both an advantage and a limitation. The contrast between the home and hospital modality choosers is possible as a consequence. But, involvement of patients from multiple centres would have provided rich and potentially diverse information on education programmes local to the units. The first author did not conduct the interviews, so field notes on patient's behaviour and interaction with their spouses or other members of the family could not be ascertained. However, audio recordings, with its limitations gave good insight into the interview process. The researcher is a practising nephrologist and it is quite likely that some interpretation of patient opinions may be shaped by routine clinical experience of similar situations[28]. The practice of clinical nephrology has possibly motivated more practical considerations for patients and physicians, in the discussion of issues that have emerged inductively from the study.

In conclusion, the study highlights the views of dialysis education and information held by predialysis patients and the rationale for choosing a specific modality type. There appears to be divergence of attitudes, experiences of dialysis education, and decision-making processes within subgroups of predialysis patients who choose home-based and hospital-based haemodialysis. There appears to be an 'illness-centric' approach to life in patients making the choice of hospital haemodialysis and a 'life-centric' approach to illness management in patients making the choice of home haemodialysis. There is room for improvement in the manner of communication of dialysis information, through incorporating behavioural management programmes and a more personalised training package. A 'self-care' first policy, as far as possible, irrespective of the location may well allow patients to take better control of their disease management in the longer term. Physicians need to consciously seek psychological dispositions of their patients, so as to enable timely and expert help for those who need it. Physicians also need to be more actively engaged in dialysis decision-making and supporting patients through this process with them, and not limiting their role to ratification of the choices made.

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CHAPTER 3.11

Multidisciplinary staff attitudes to home haemodialysis therapy

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ABSTRACT

Background: There is significant improvement in the evidence base for home haemodialysis. In the UK, several local, regional and national initiatives have helped dissemination of the message. However, the uptake across different regions in the UK remains uneven, more than a decade after the National Institute for Health and Clinical Excellence, set an ambitious target of 15% uptake for home haemodialysis in individual dialysis units.

Methods: This survey is part of the BASIC-HHD study (Barriers to Successful Implementation of Care in Home Haemodialysis), an observational study of patient and organisational factors designed to investigate the barriers and enablers of home haemodialysis therapy, in the UK. The study centres had variable prevalence of home HD by design (low prevalence; LP <3% (2), medium; MP 5-8% (2) and high prevalence; HP >8% (1)). This survey was administered electronically, and had twenty questions pertaining to home HD beliefs and practices. A total of 104 members of staff across five study centres were approached to complete the online survey. Descriptive statistics have been used to present the findings.

Results: The survey had a 46% response rate overall. Majority of respondents had >10 years of experience in the field. Most believed in the benefits of home haemodialysis therapy. Significant proportion of respondents across all centres believed that preconceptions about patients' and carers' ability to cope with home haemodialysis influenced the offer of therapy (35% to a great or very great extent). Upto 45% of respondents across all centres believe that staff knowledge and bias influences offer of home HD therapy. 44% of respondents from LP centres believe that display and presentation of dialysis information lacked clarity and uniformity as against 18% from HP centre. Over a third of all practitioners surveyed also felt that hospital HD patients were not provided sufficient information to make a home transition. Respondents from low prevalence centres also felt they needed better set-up for training patients for self-care HD (33.3% vs 72.8%). A greater proportion of respondents from the HP centre expressed concerns over care-giver support and respite care for patients on home HD (63.7% vs 33.3%).

Conclusions: Survey results indicate that across all centres in the study, there is appetite for growing home haemodialysis. There are some differences in attitudes and areas of practice between low and high prevalence centres, articulated in their responses to the survey questions. There are other domains where all centres have expressed concern and addressing these will be influential in navigating change from current course

INTRODUCTION

The beginning of the 21st century has witnessed significant changes in the healthcare landscape within the National Health Service of the United Kingdom. In the context of renal replacement therapy, the emphasis has shifted from institutional care to self-managed dialysis, typically in patients own homes, and more recently, also in hospitals and free standing units. These changes are compatible with higher expectations from informed patients, of their healthcare providers. In 2002, NICE (National Institute for Health and Clinical Excellence) issued a technology appraisal guidance and provided practitioners with an ambitious target of 15% of the dialysis population for home haemodialysis (home HD) uptake in individual centres[1]. This was followed by the Renal National Service Framework (NSF) in 2004, recommending the delivery of high quality, clinically appropriate forms of dialysis to be designed around individual patient needs and preferences, keeping the target for maximising delivery by 2014[2]. Despite these initial measures, the renal registry recorded the national home haemodialysis figures at its lowest in 2006, with just 425 patients nationally (<1%) across the UK in receipt of home HD[3]. The salutary work of NHS Kidney care, founded in 2008 and the idea of ‘care closer to home’ from Lord Darzi’s report spanning the management of all long term conditions[4, 5], gave the impetus to change practices across the UK.

Since 2010, there has been a gradual increase in the prevalence of home haemodialysis through several local, regional and national initiatives and it currently stands at 4.7% nationally and varies from 0% to 14% across different centres[6]. Clearly, none of this rise is likely to have been achieved without the engagement of staff and the presence of clinical champions for home HD. In a qualitative study of financial incentives for promoting home-based haemodialysis, it was found that while the Department of Health tariff for home haemodialysis is not a clear incentive for its adoption due to uncertainty about operational costs, Commissioning for Quality and Innovation (CQUIN) targets were seen by the case study centres as a motivator to change practices[7]. The complex interplay of clinical, political, financial, expertise and interest driven care-provider attitudes to home HD therapy interleaved with ‘patient choice’ makes sustained improvement in services, tardy and varied.

In our survey of frontline healthcare providers, we seek to explore the beliefs and attitudes of the multidisciplinary team to home haemodialysis therapy, as we explore the larger question of barriers and enablers of home HD, in the UK.

METHODS

This survey is part of the BASIC-HHD study (Barriers to Successful Implementation of Care in Home Haemodialysis). This is a combined cross-sectional and prospective, mixed-methods

(convergent, parallel design) observational study of patient and organisational factors designed to investigate the facilitators and barriers of home haemodialysis therapy. The methodological details and scope of data collected in the BASIC-HHD study has been presented in the protocol paper[8]. The study centres had variable prevalence of home HD by design (low prevalence<3%, medium 5-8% and high prevalence >8%). The total dialysis catchment population of all five study centres is 6.3 million.

This survey was administered electronically, by a third party and it comprised twenty questions pertaining to home HD beliefs and practices (generated by the research team) alongside the use of an instrument called the Organisational Culture Inventory® (OCI), aimed at capturing cultural norms and expectations in an institutional setup. The findings of the OCI® are outside the scope of this paper. The outcomes of the dialysis practice questionnaire presented here include questions which were informed by the previously conducted international survey on beliefs, attitudes and practices of providers of home haemodialysis therapy by Jayanti et al. [9]. The survey demographics included primary role as care-provider, primary area of operation, seniority, years in service, gender, and the centre code (provided to anonymise responses for analysis). Potential respondents were identified by the principal investigators in each study centre. A total of 104 members of staff across five study centres were approached to complete the online survey. The response rate to the questionnaire was 46% (48 complete responses) after 8 weeks of response time (May 2013 to July 2013) and e-reminders every two weeks. The respondents also had the option of not identifying their centres and choose a ‘prefer not to respond category’ which was chosen by 44% of the respondents (n=21). Responses were made on a 5-point Likert scale (Not at all, to a slight extent, to a moderate extent, to a great extent, to a very great extent). Statistical analysis was carried out using SPSS 22. Due to the small numbers of responses to questions, data have been analysed largely, using descriptive statistics.

Study Registration

This BASIC-HHD study was reviewed and approved by the Greater Manchester West Health Research Authority National Research Ethics Service (NRES) Reference number: 12/NW/0170. The study is on the NIHR portfolio (ID 12346).

RESULTS

Survey demographics are presented in Table 1. The survey had a 46% response rate overall. The vast majority of respondents had >10 years of experience in the field and the majority belonged to the nursing fraternity, with equal proportions of ‘in-centre’ and ‘home therapies’ nursing staff. Medical staff responses primarily came from senior clinical staff. The centres to

which they belonged were identified only by 27 participants. 9 respondents identified themselves from low prevalence centres, 7 from medium prevalence and 11 from high prevalence centres.

Table 1: Survey Demographics		
Demographic		Respondent numbers
Years in service	1-2	0
	2-5	3
	5-10	2
	>10	45
	Prefer not to respond	1
Gender	Male	12
	Female	38
	Prefer not to respond	1
Primary Role	Nursing	43
	Medical	7
	Managerial	1
	Prefer not to respond	0
Seniority	Consultant physicians	5
	Registrar Grade Doctors	2
	Staff Nurses	17
	Specialist Senior Nurses	19
	Managers	4
	Prefer not to respond	4
Primary area of operation	Predialysis Service	10
	Hospital haemodialysis	18
	Satellite haemodialysis	5
	Home haemodialysis	4
	Combined peritoneal and home haemodialysis	8
	Prefer not to respond	5
Centre (complete data)s	Low	9
	Medium	7
	High	11
	Prefer not to respond	21

Description of responses to queries (Figure 1 and Table 2) The responses to the survey questions from 48 respondents has been depicted in a bar graph in Figure 1 and elaborated upon below.

Q1 Do you personally identify with the values and beliefs on home haemodialysis prevalent in your unit? 77% of the respondents did so to a great or very great extent and about 10% did so only to a slight extent. The response to this question from low (LP) and high prevalence (HP) centres was different (n=27). 44.4% of respondents from LP centres and 81.8% from HP centres, believed in their unit's home haemodialysis practice.

Q2 Do you feel information on dialysis modalities is clearly displayed and presented to patients, uniformly, by all members of staff? 10% of respondents did not believe that this was happening and less than half (42%) believed to a great extent that information was being presented clearly and uniformly by all staff members. The difference in responses was different based on centre prevalence. 44.4% of respondents from LP centres vs. 18.2% from HP centres did not believe that display of information was clear. Also 75% of medical

practitioners felt to a moderate extent that practices could improve as against 55% of nursing staff.

Q3 Do you feel adequately advised and supported to be able to take decisions pertaining to offer of renal replacement therapy, at all times? About two-thirds of respondents felt that were supported in their RRT decisions to a great extent. About 27% felt that way only to a moderate extent. There was no significant difference between low and high prevalence centres with respect to the response to this question.

Q4 Do you feel your pre-conceptions about ability of patient and carer to cope influences the offer of home haemodialysis? About 35% of respondents believed to a great or very great extent that their preconceptions about the patient's ability to cope influenced their offer of home HD to the patient. This proportion was significantly greater in the HP centre at 55.5% vs 18.2% in the LP centres. Also, nursing staff were more like to be influenced this way compared to medical staff (35% vs 75%).

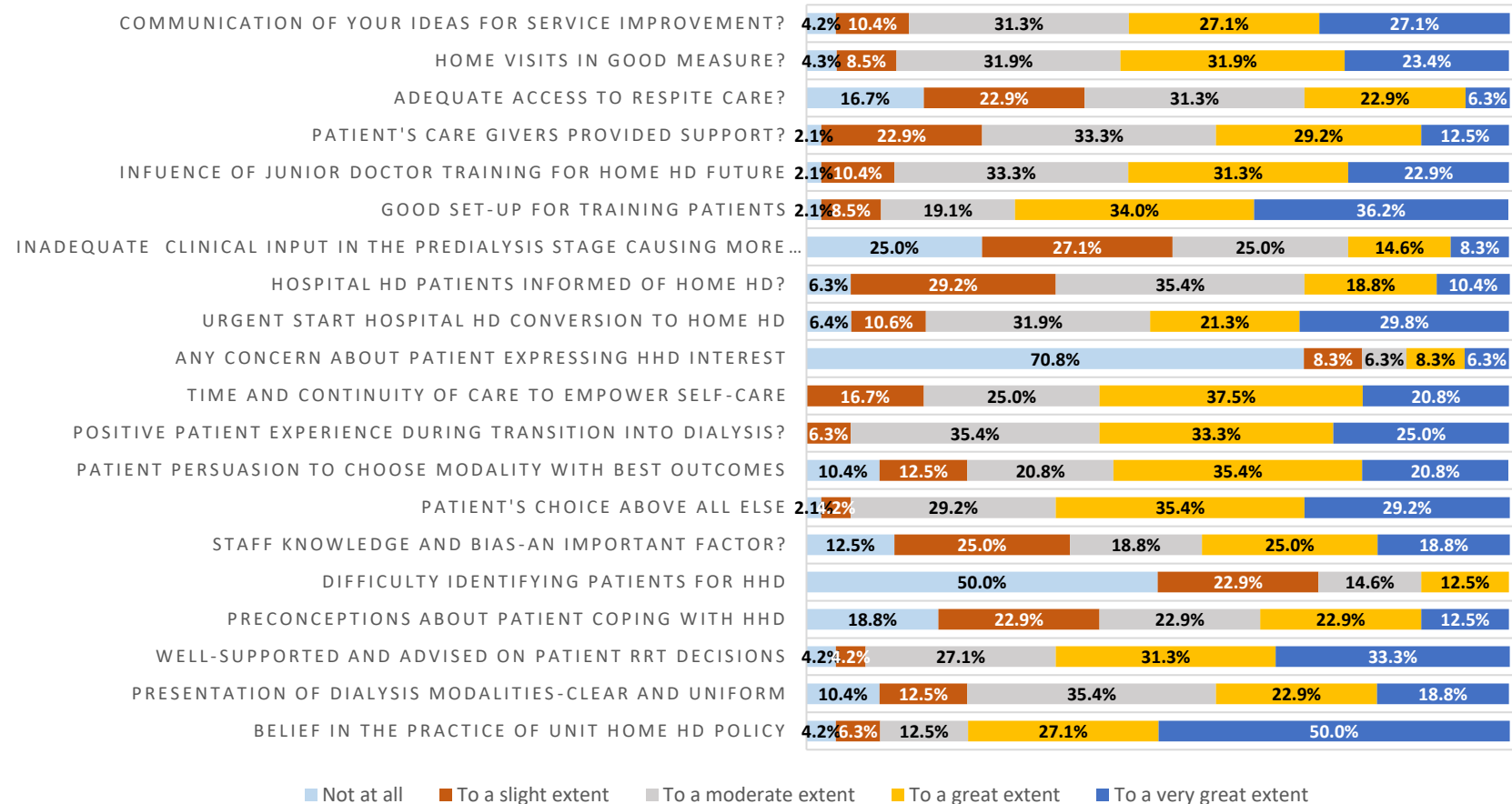
Q5 Do you feel you have difficulties identifying suitable patients for home HD? 50% of patients did not feel they would have any difficulty identifying a suitable patient for home HD. It is useful to note that 27% did however recognise this as a problem to a moderate or great extent. No differences in proportions were observed between centres with varying prevalence.

Q6 Do you feel staff knowledge and bias is an important factor in patients taking up home HD? 44% of all respondents agree greatly or very greatly with this question. A larger proportion of respondents in the LP centre (55.5%) believe that staff knowledge and bias is an important factor in home HD uptake compared to 36% in HP centre. Medical staff believe this to be more of an issue (57.5%) than nursing staff (40%) although both disciplines agree that this is a significant issue.

Q7 In your own practice, do you place patient's choice of modality above everything else, in the context of kidney replacement therapy? 94% of respondents to a moderate extent or more would place patient's choice above all else. The responses across the three prevalence groups were 44.4% (LP), 71.4% (MP) and 54.6% (HP).

Q8 Do you try and persuade your patients to choose the dialysis modality that offers best outcomes, even if they are nervous about trying it? Although a large proportion of respondents would try and persuade patients to consider a specific modality, a significant 23% would offer little or no persuasion. 55.5% of LP centre respondents would pursue this upto a moderate extent only as against 36.4% of respondents from HP centre. Medical staff tend to persuade to a greater extent than the members of nursing fraternity (87.5% vs 50% respectively).

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Q9 Do you feel patients are provided a positive experience during the transition from the pre-dialysis phase through to commencing a dialysis modality? 58.5% of all respondents feel that patients are being provided a positive experience during their transition from predialysis to dialysis phase to a great or very great extent. Amongst those who identified their centre, although the vast majority believed they did the right things during patient transition, about 10-15% of respondents from the MP and HP centres believe that there is room for improvement.

Q10 Are you able to offer adequate time and continuity of care to empower patients to care for themselves? Approximately 42% of respondents felt from a slight to moderate extent that they could offer their time effectively to empower patients to care for themselves. 89% of LP centre respondents and 54.6% of HP centre respondents felt to a great or very great extent that they could afford the time the patients needed to promote self-care.

Q11 Do you feel concerned if a patient expresses interest in doing haemodialysis at home? Approximately 1 in 5 respondents would be concerned from a moderate to a very great extent if patients expressed an interest in doing home haemodialysis. 17.5% of nurse respondents as against 0% of physician respondents would be greatly concerned. Similar proportions of respondents across the high and low prevalence categories would express concerns to a small or large extent.

Q12 Do you feel that urgent starts on hospital HD could convert to home HD at every available opportunity? About half of all respondents (51%) believe to a great or very great extent that this should be considered at every available opportunity and there is no difference in the manner of response from centres with different home HD prevalence. However, 20.5% of nurses vs 0% of physicians believe that this may not be considered at all.

Q13 Do you believe that patients on hospital HD are currently adequately informed of the option of home HD? Over a third of respondents (36%) believe that the opportunity to move from hospital to home is not adequately available to patients. Only 29% of respondents felt that this information was available for hospital patients. Respondents from low (100%) and high prevalence (91%) centres felt only to a slight to moderate extent that this information is adequately available to hospital HD patients.

Q14 Do you feel inadequate clinical input in the pre-dialysis stage is the reason for high hospital dialysis starts? 50% of respondents to a moderate or greater extent feel that clinical input in the predialysis period could be optimised for home dialysis starts and this response is uniform across all centres.

Table 2: Responses to questions depicted by centre prevalence				
	Question	Response Category	Centre Prevalence	
			Low	High
Q1	Belief in home haemodialysis	Great extent + very great extent	44.4%	81.8%
Q2	Display and presentation of dialysis information	Not at all + to a slight extent	44.4%	18.2%
Q3	Advice and Support for RRT decisions	Great extent + very great extent	66.6%	63.7%
Q4	Preconceptions about patients' abilities	Not at all + to a slight extent	55.5%	18.2%
Q5	Difficulty identifying patients for home HD	Not at all + to a slight extent	66.6%	72.8%
Q6	Staff knowledge and bias	Great extent + very great extent	55.5%	36.4%
Q7	Own practice with patients	Great extent + very great extent	44.4%	54.6%
Q8	Persuade patients to try a modality even if patient is nervous	Not at all + to a slight extent + moderate extent	55.5%	36.4%
Q9	Positive experience at transition	Not at all + to a slight extent	66.7%	54.6%
Q10	Time and continuity of care for patient empowerment	Great extent + very great extent	88.9%	54.6%
Q11	Concerns if patient interested in HHD	Great extent + very great extent	22.2%	27.3%
Q12	Facilitate Hosp HD to Home HD for urgent starters	Great extent + very great extent	44.4%	53.8%
Q13	Home HD information for hosp patient	Not at all + to a slight extent + moderate extent	100%	91%
Q14	Inadequate clinical input predialysis	Moderate extent + great extent + very great extent	66.6%	54.6%
Q15	Set-up for training in home HD	Great extent + very great extent	33.3%	72.8%
Q16	Mandated Training for trainee physicians in home HD	Great extent + very great extent	55.5%	45.5%
Q17	Care giver support	Not at all + to a slight extent	22.2%	45.5%
Q18	Respite Care	Not at all + to a slight extent	33.3%	63.7%
Q19	Home patients well supported	Great extent + very great extent	44.4%	45.5%
Q20	Better service ideas	Not at all + to a slight extent	22.2%	18.2%

Q15 Do you feel you have a good set-up for training home patients? 70% of respondents feel to a great or very great extent that they have a good set-up for training for home HD. Only a third of the respondents from LP centre (33%) as against 73% of respondents from HP centre believe they have a good training set-up.

Q16 Do you feel mandated rotation of all junior medical staff through home HD training would influence the long term uptake of home HD? 87% of all respondents feel this to be the case, with no significant differences across the different centres.

Q17 In the current set up, do you feel 'patient's care-givers' are provided adequate support? 25% of all respondents feel that no support or slight support is provided currently to patient's care-givers. This response is different between centres, such that 45.5% of HP centre responses suggest minimal support as against 22% from LP centres and 14.3% from MP centres.

Q18 Do you feel there is adequate access of patients to respite care? 40% of all respondents feel patients have either no access or minimal access to respite care. This response is exaggerated from HP centre with 63.7% of respondents feeling that patients have less access to respite care compared with 33.3% of LP centres' and 28.6% of MP centres' respondents.

Q19 Do you feel home visits are being provided in good measure and patients at home feel well supported? 87.3% of respondents feel that home visits are being provided in good measure and across all centres respondents feel that patients at home are well supported.

Q20 Are you able to put your ideas across freely to better the service provision in your area of clinical practice? 87% of respondents feel they are able to contribute to ideas which better service provision to a moderate extent or greater. Across all centres about 20% of staff feel that they may not be able to contribute all that well. No difference in proportions was observed between medical and nursing staff. Those who preferred not to identify their centre did not respond differently.

Generally, for all questions we examined the differences in responses to queries from those who identified their centres vs those who did not. No significant differences were observed in the pattern of their responses.

DISCUSSION

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Several studies have been done over the years to understand healthcare practitioners' attitudes to home-based dialysis therapies[9-11]. Most practices globally have reported that the most commonly encountered impediments to expanding home-based haemodialysis services are, financial disadvantage for home HD patients, and lack of physical infrastructure for training, support and education. The majority of nephrologists would recommend home haemodialysis to more patients if these impediments could be overcome[11]. In the UK, the drive to increase numbers of patients on home HD has trickled down from a policy-level to practice-level, but the spread across the units remains uneven[6]. This survey attempts to capture the gap between intent and practice of home haemodialysis across five geographically distinct locations in the UK with variable prevalence of home HD. All these centres have been approached for the e-survey, 10 years after the NICE directive on ideal proportion of home HD patients from a unit's dialysis population. In this decade, several schemes to incentivise home-based dialysis have been promoted by the Department of Health. The uptake of peritoneal dialysis and home HD by patients can only be sustained by staff interest and expertise, although financial support can help resource these long-term projects. The information avenues available to patients for undertaking self-care HD, are at the predialysis stage and whilst on hospital HD. Patients

engage with several members of staff during their treatment journey who provide their perspective on home HD, irrespective of the unit's overarching policy on home therapies.

It is evident from our survey that not all healthcare professionals in an organisation feel the same way about home haemodialysis. Therefore, there is likely to be asymmetry of intent and/or practice between centres with high (HP) and low prevalence (LP) of home haemodialysis. The majority of care-providers do believe in the merits of home haemodialysis treatment. However, the chasm between nature of responses from low and high prevalence centres in support of home HD may come as a surprise. Belief in therapy is paramount to promoting its practice. This is not limited to physicians alone and in fact applies to all members of the team who care for patients with ESRD. Another aspect of practice which seemed obviously different between LP and HP centres was one of determining the patient's suitability for home HD. Whilst informed judgement of patients' and carers' ability to cope with home HD is welcome and essential, preconceptions about this may be misleading and deny the patient, possibility of home HD therapy. Specific issues to consider include patient's cognitive and technical ability, patient's resolve, family support systems etc., which may not be apparent at the outset. Our survey has shown that responses from practitioners in the HP centre have greater experience of larger numbers on home HD. More liberal criteria may allow for greater number of patients to consider this therapy, as greater experience is gathered. There may be greater risk of training failure in doing so, but, it allows for objective evaluation of the patient's ability to undertake self-care haemodialysis[12]. A recent study has established that an education initiative can modify the opinions of in-centre HD nurses towards home modalities and this should be incorporated into the many strategies for expanding a home HD programme[13].

Higher proportion of individuals in a LP centre feel that staff knowledge and bias influences offer of home HD therapy. Upto 45% of respondents across all centres believe this to be the case. There is evidence from other long term conditions such as diabetes, that structured self-management training programmes are vital initiatives to ensure uniform and consistent staff knowledge. Basing self-management practices upon knowledge and skills developed through practice and experience alone has been found to be insufficient preparation to deliver self-management in other chronic ailments and in fact may be ineffective and inappropriate[14-16]. With increasing trend in home haemodialysis, a nationally agreed structured educational initiative for all healthcare providers would be an appropriate next step in the ESRD self-care context. Trainees in nephrology need to be provided opportunities to train in home therapies. This may well include working alongside nurses, clinical psychologists and social workers including visiting patients in their own homes, so that clinical medicine is not practised in a vacuum but, in an appropriate, personalised, psycho-social context.

There appears to be other differences from a practice perspective too between LP and HP centres. 44% of respondents from LP centres believe that the display and presentation of dialysis information lacks uniformity or clarity as against 18% from HP centre. Over a third of all practitioners surveyed also felt that hospital HD patients were not provided sufficient information to make a home transition. This was higher from the LP centre compared to the HP centre. There are multiple information resources for patients during the predialysis and hospital HD stages, but there is compelling evidence to suggest that an effective educational programme bodes well for self-care dialysis choice by patients [17]. More recently, a consensus conference outcome on the quality standards for predialysis education, was published[18]. Most of these recommendations are based on qualitative and quantitative evidence available and these need to be embraced more widely for a more uniform uptake of home haemodialysis. Our survey shows that a greater proportion of respondents, particularly physicians would persuade their patients to try home therapy. This is quite important as it is well known that physician validation of patient's choice and confidence goes quite some way in helping patients choose home-based treatment[19]. The set-up for training patients to undertake self-care HD is vital to its success. Only a third of the LP centre respondents felt satisfied with the infrastructure to train patients for home HD. Exemplar units with successful programmes have been forthcoming with how they have built their programmes, on knowledge-sharing platforms such as conferences and also through teams visits to such units. Initiatives such as the 'Implementing hemodialysis in the home: A Practical Manual', a peer-reviewed, comprehensive, open-source, web-enabled, practical manual supported by the International Society for Hemodialysis, can help discern the nuances of starting or expanding a home haemodialysis programme (www.home-hemodialysis.com)[20].

The survey also shows that irrespective of the current prevalence of home HD in individual centres, there is room for improvement. A greater proportion of respondents from the HP centre expressed concerns over care-giver support and respite care for patients on home HD. Whilst it is true that such problems are more obvious in centres which have larger patient numbers on home haemodialysis, informal care-giver support and respite care are crucial for the long-term success of a home HD programme[21]. The home respite care model may come with its own additional expenditure and staffing issues and the 'in-centre' respite care model may be inflexible with frequency of schedules or duration of treatment in what are usually dialysis units running to full capacity. The need to incorporate this aspect of care when designing the home programme cannot be emphasized enough. Other aspects of service provision which have been highlighted in this survey include, the need to improve patient experience in transition from predialysis to the dialysis phase, as under 60% of respondents

perceive it to be optimal and 50% of respondents feel the need for greater clinical input in the predialysis stage to optimise self-care dialysis uptake.

The survey has its limitations in the 46% response rate and further limited by the option of anonymised centre responses. That having been said, there was no difference in the type of responses from either group. Typically, a survey can project only broad perspectives. Survey responses may be limited by the number of questions posed. Practices in individual units may be influenced by local agreements with clinical commissioning groups and may change over time to reflect the national recommendations. The process of recruiting respondents for the survey may be biased despite attempts to include all care providers in the patients' treatment journey, perhaps limiting responses only from enthusiastic professionals.

In conclusion, across all centres in the study, there is appetite for growing home haemodialysis. There are some differences in attitudes and areas of practice between low and high prevalence centres, articulated in the responses to the survey questions. There are other domains where all centres have expressed concern and addressing these will be influential in navigating change from current course.

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Disclosures

None

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CHAPTER 3.12

Perceptions and experiences of financial incentives: a qualitative study of dialysis care in England

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ABSTRACT

Objective: The objective of the study was to understand the extent to which financial incentives such as Payment by Results and other payment mechanisms motivate kidney centres in England to change their practices.

Design: The study followed a qualitative design. Data collection involved 32 in-depth semi structure interviews with healthcare professionals and managers, focusing on their subjective experience of payment structures.

Participants: Participants were kidney healthcare professionals, clinical directors, kidney centre managers and finance managers. Healthcare commissioners from different parts of England were also interviewed.

Setting: Participants worked at five kidney centres from across England. The selection was based on the prevalence of home haemodialysis, ranging from low (<3%), medium (5–8%) and high (>8%) prevalence, with at least one centre in each one of these categories at the time of selection.

Results: While the tariff for home haemodialysis is not a clear incentive for its adoption due to uncertainty about operational costs, Commissioning for Quality and Innovation (CQUIN) targets and the Best Practice Tariff for vascular access were seen by our case study centres as a motivator to change practices.

Conclusions: The impact of financial incentives designed at a policy level is influenced by the understanding of cost and benefits at the local operational level. In a situation where costs are unclear, incentives which are based on the improvement of profit margins have a smaller impact than incentives which provide an additional direct payment, even if this extra financial support is relatively small.

Strengths and Limitations of this study
<ul style="list-style-type: none">▪ Qualitative research provides unique insight into how financial incentives for quality improvement are perceived by kidney centres; this is important in helping understand better how financial incentives function in practice.▪ Interviews at five kidney centres purposely selected to represent variable prevalence of home haemodialysis; however, does not give a comprehensive overview of perceptions across all kidney centres in England.▪ Does not examine the actual costs and financial benefits of different dialysis modalities or the influences of patient preferences and wider organisational factors in decision-making around kidney care treatment modalities.

INTRODUCTION

It is a major challenge for policymakers worldwide to ensure that healthcare systems provide good quality care at affordable costs. Governments have been implementing payment structures which are intended as incentives for improving quality in healthcare provision. In this study we looked at financial incentives in kidney care. As of 2011, more than 53 000 people (0.08% of the population) are in receipt of kidney replacement therapy in the UK¹. This has been reported to take up 2% of the National Health Service (NHS) budget². New financial incentives have been aimed at kidney care in the past few years to improve quality of delivered care and to take care closer to people's homes. This is in line with the current general goals within the NHS³ and specifically in kidney care⁴. These developments make kidney care an interesting case for the study of the relationship between incentives and the uptake of different methods of providing expensive long-term care.

Evidence on incentives in healthcare

One of the ways health systems worldwide strive to improve quality in healthcare is by the use of 'pay for performance', linking quality targets to provider revenues. This can either involve a financial reward or a penalty. There has been considerable research into the effectiveness of using monetary incentives to improve quality in healthcare, largely in the US context^{5,6}. Reviews of published evaluations have concluded that the research shows either no, or only modest, positive impacts of pay for performance on quality⁷. A recent review of systematic reviews shows that there is inconclusive evidence on whether pay for performance has an effect on practice⁸. Study results range from very positive to negative, with most studies of insufficient quality from which to draw firm conclusions, and problems in comparability due to the diversity in the design of pay for performance programmes. Eijkenaar⁹ discusses the different design elements of pay for performance programmes, concluding that they should be broad but comprehensible, involve healthcare providers in the design, give incentives to groups rather than individuals, and should ideally be decoupled from the base payment for the service.

Pay for performance in England

Despite inconclusive evidence on their effectiveness, governments in many countries have in recent years employed financial incentives to improve quality. In England, the Department of Health has employed several forms of financial incentives. In the primary care sector, the Quality and Outcomes Framework (QOF) was introduced in 2004. This comprised an incentive system paying up to 20% of the income of a general practitioner's practice⁷, spanning both clinical and organisational aspects of care, as well as patient experience¹⁰. At the same time the Department of Health also started replacing the previous system of block contracts in the secondary care sector with Payment by Results, an activity based payment

system with tariffs based on national average costs, adjusted for case mix. On average about 60% of a hospital's activity is reimbursed via the tariff¹¹. The tariff rewards providers for increasing productivity, should encourage them to improve efficiency and hold tighter control of costs, and also gives the Department of Health the opportunity to incentivise high quality care by paying a higher tariff price: The Best Practice Tariff. There were 15 Best Practice Tariffs active in 2012, rewarding those practicing the best clinical care in, for example, acute stroke care or total hip and knee replacements¹¹. A number of concerns have been raised over the use of Payment by Results and Best Practice Tariffs, notably the cost information on which the tariff is based. A recent report¹² found that reported unit costs can differ substantially between providers without clarity on whether this is due to real differences in costs or differences in allocation of costs or data collection. In addition, substantial annual variations in the reported unit costs on which the tariff is based mean that providers are discouraged from making decisions based on the cost-income balance of individual services, offsetting a loss in one service by a profit in another. Both these features make the tariff less likely to achieve the intended improvements in efficiency of services. The Best Practice Tariff has been shown to have an impact on achieving improvements in the areas of cholecystectomies and hip fractures, but not in the case of stroke care, possibly because providers needed more time to implement the incentivised changes in practice¹³. The same evaluation found that clinicians tended to be receptive to the Best Practice Tariffs, but to increase the chance of success it is important that the rewards outweigh the increased collection burden. Another form of pay for performance is the Commissioning for Quality and Innovation (CQUIN) scheme, introduced in 2009 with the intention to 'support a cultural shift to make quality and innovation part of the commissioner-provider discussion everywhere'¹⁴. Clinical commissioners in local trusts—who purchase a majority of healthcare services in the NHS—play an active role in developing CQUIN goals for each provider. CQUIN makes a proportion of a provider's yearly income conditional on reaching quality targets agreed between the commissioner and provider. Most of these targets are agreed locally, based on what the provider and the commissioner both find important, but there are also a limited number of national and regional targets. CQUIN goals should include indicators on four domains: safety, effectiveness, patient experience and innovation¹⁵. The proportion of the provider's income that is conditional on achieving the CQUIN target has grown from 0.5% in 2009 to 2.5% in 2012¹⁵. A recent evaluation of CQUIN¹⁵ concluded that while it has helped commissioners and providers to identify and prioritise local needs for quality improvement, the impact on quality has been minimal. Several problems were identified, including clinician dissatisfaction over the way CQUIN goals were developed, and unclear and imprecise outcome measures, which emphasised processes rather than clinical outcomes. Freedom to use local indicators, though potentially useful for engaging clinicians, has also resulted in a lack of standardised outcome measures.

The short-term nature of the CQUIN goals was also found to limit the motivation for Trusts to make investment in measures to improve performance. A quantitative analysis shows that of the nine CQUIN goals analysed, only hip fracture returns show an improvement¹⁵.

Kidney care

While for some patients with advanced kidney failure conservative care is the preferred option, the majority will opt for dialysis, as it remains an effective life-saving and life-sustaining therapy. Although transplantation is considered the gold standard for kidney replacement therapy, available donor organs are a limited resource with an average waiting time of 3.2 years for a kidney transplant in the UK¹⁶. Dialysis can be administered by a healthcare professional (typically a skilled nurse) in a hospital, or self-administered in the patients' own homes, independently or with minimal assistance. It is administered using an artificial kidney with access to the patient's blood (haemodialysis) or to the patient's abdomen (peritoneal dialysis (PD)). The management of advanced kidney failure in a patient might involve either form of dialysis at home depending on their general health and personal preference. In Europe and North America, in-centre or hospital-based haemodialysis, 3 times/week for 4 h, is by far the most common therapy^{1, 17, 18}. Home haemodialysis (HHD) offers the flexibility of more frequent (5–6 times/week) and longer (7–8 h overnight) dialysis sessions, and is conveniently and comfortably performed in the patient's own home according to their preferred schedule. Current evidence suggests that more frequent or longer HHD is more physiological and likely to improve clinical outcomes¹⁹⁻²¹, and patients report an improved quality of life²². HHD may not, however, be the right option for all patients. Choice of dialysis modality is personal and contextual for each patient and may change over time. It is a lifestyle choice as well as a medical one, and decisions involve input from the patient, the informal caregiver and healthcare professionals. There is a potential to save costs with HHD. Most economic studies show that HHD is less costly than in-centre haemodialysis²³⁻²⁷, with all studies showing reduced nursing costs for home dialysis patients. A comprehensive economic analysis will require consideration not only of treatment costs, but also of costs associated with home adaptations (e.g., changes in the water supply) and of benefits such as reductions in travel and earlier return to work. Whether there are cost savings when performing frequent HHD is less clear, as more consumables (i.e., dialysers, needles, etc) may offset savings on resource and infrastructure²⁸. In 2002 the National Institute for Health and Care Excellence (NICE) produced guidelines on home compared with hospital haemodialysis for patients with endstage kidney disease²⁹. It is recommended that all patients who are suitable for HHD should be offered the choice of undertaking haemodialysis in the home or in a hospital kidney centre. It was estimated that up to 15% of dialysis patients may choose to undertake HHD. In 2004, the Department of Health published the National Service Framework (NSF) for renal services, which promotes patient-centred provision of kidney services, including choice over HHD³⁰.

In 2011, 1.7% of patients on kidney replacement therapy (3.3% of all dialysis patients) were on HHD¹. Another topic of interest in kidney care is the type of vascular access that is used for patients on haemodialysis. Access type for chronic haemodialysis can be permanent, such as a native arteriovenous (AV) fistula or an AV graft surgically created in the lower arm, or semi-permanent, in the form of a tunnelled venous catheter. Patients with an AV fistula or graft are generally believed to have better health outcomes than those with a catheter³¹, and suffer from fewer complications such as methicillin resistant *Staphylococcus aureus* (MRSA) infections³². In recent years there has been considerable emphasis on increasing the use of permanent access via fistula. The zero tolerance approach in the NHS towards MRSA and the fact that incidences of MRSA are one of the national measures to calculate financial bonuses (Quality Premiums) for NHS clinical commissioning groups, potentially influences the uptake of permanent vascular access³³. Clinical practice guidelines published in 2011 by the Renal Association and the Vascular Society of Great Britain and Ireland also promote the use of AV fistulas and grafts over catheters³⁴. Moreover, timely and appropriate surgery for permanent vascular access is one of five standards to be achieved in the NHS for 2014 as stated in the NSF for renal services³⁰. Additionally, a National Kidney Care Audit was undertaken in both 2009 and 2010 to determine the extent of fistula use in the UK^{35,36}.

Financial incentives in kidney care

As of 2011–2012, dialysis modalities (excluding acute dialysis and paediatric dialysis) have been paid for by a mandatory tariff under Payment by Results. Transport and some medication costs are not included in this tariff and covered by a different mechanism. PD, as a continuous technique, is paid on a per day basis; in-centre haemodialysis is paid per dialysis session³⁷. Trusts receive the Best Practice Tariff for patients who receive in-centre dialysis with an AV fistula or graft, as opposed to dialysis via a venous catheter, is to create an incentive in line with the current guidelines on vascular access. The Best Practice Tariff for vascular access is an incentive towards using fistulas/grafts for haemodialysis, as the tariff is higher and the costs are lower than for dialysis with a catheter. If the Trust reaches a predetermined proportion of patients undergoing in-centre haemodialysis on a fistula, then its income for haemodialysis is comparable to a situation in which there is no Best Practice Tariff and prices are set at the national average cost. The proportion of patients needed for equal income has gone up from 75% in 2011–2012 to 80% in 2012–2013³⁸. In April 2012 HHD was given its own mandatory tariff; previously a non-mandatory tariff was in place^{38,39}. This tariff is paid on a per week basis, and amounts to the same sum of money as the in-centre Best Practice Tariff (i.e., three in-centre dialysis sessions on an AV fistula or graft). This makes the income for HHD and in-centre dialysis on a fistula the same on a weekly basis. The HHD tariff is meant as an incentive for providers to expand their home programme, as the modality now provides a consistent income³⁹ which does not depend on negotiations between the kidney

centre and its commissioner; and the overall costs for HHD are presumed to be lower than for in-centre haemodialysis. The tariff for HHD is the same irrespective of the nature of vascular access and frequency of dialysis sessions performed at home—typically 4 sessions/week, but ranging from 3 to 7 sessions/week.

Since 2010 there have been several CQUIN targets relating to home therapies (HHD and PD), in which a locally negotiated proportion of patients have to be on home therapy for a Trust to gain the reward⁴⁰. There have also been other CQUIN targets in kidney care, for example, aiming to reduce the time between a patient starting on dialysis and being referred for a transplant. In 2010 eleven hospitals had explicit CQUIN targets for home therapies. We used Renal Registry data to compare the percentages of patients on HHD and PD in December 2009 and December 2010, for hospitals in England with and without a CQUIN target for home therapies. A Mann-Whitney U test shows a significantly higher increase in the percentage of patients on HHD in the hospitals with a home therapies CQUIN target. While this correlation does not prove a causal link, it suggests that the relationship between CQUIN targets and the uptake of HHD is worth investigating. For PD there is a decline in percentage for both groups, with the percentage declining at a lower rate in the kidney centres which have a home therapies CQUIN target, although this does not reach significance. Table 1 shows the changing percentage of prevalent patients on home therapy before and after the introduction of the CQUIN targets^{41, 42}. In summary, the tariff for HHD should function as an incentive, by design, because it generates the same income as the more expensive alternative (in-centre haemodialysis); the Best Practice Tariff should function as an incentive for AV fistula access for haemodialysis because it pays more and is cheaper than the alternative (dialysis via a catheter); and CQUIN is an incentive because it provides additional (albeit relatively small) payment when a certain percentage of patients remain on a home therapy.

[Aims of this study](#)

Through this study we wish to understand the extent to which the financial drivers, such as the tariff and the other payment mechanisms, motivate clinical kidney centres in England to change their practices in dialysis. We looked at all the payment structures in this single clinical area in the study sites, in order to gain an in-depth understanding of the relationship between these structures and clinical decision-making. We adopted a qualitative approach to investigate the subjective experience of health professionals and managers on payment structures that aim to improve quality of kidney care. The subjective experience is important as it correlates well with change behaviour, ultimately informing whether payment structures could act as incentives in the way policymakers have intended.

METHODS

We performed a qualitative study in the form of 45–60 min in-depth semi structured interviews with 27 healthcare professionals and managers in five kidney centres from across England, serving a total of roughly 5.3 million catchment population. We also conducted five background interviews with commissioners and industry experts.

The five kidney centres were selected based on their prevalence of HHD. This ranged between low (<3%), medium (5–8%) and high (>8%) prevalence, with at least one centre in each one of these categories at the time of selection. Of the two centres with a prevalence below 3%, one had a total dialysis population of over 600, the other less than 200. The larger centre had only set up their HHD programme in the past few years. Those centres with a prevalence of 5–8% had total dialysis populations of approximately 250 and 500. Each had historically had a small HHD programme but had recently started developing it further. The centre with a prevalence of HHD of over 8% had around 600 dialysis patients, and had been growing their programme for over 10 years. For each kidney centre we interviewed at least the following: one or more nurses, one or more consultant nephrologists involved in HHD, and one or more of the following: clinical director, financial manager and general manager. Interviews covered the organisation of the dialysis service (with a focus on HHD), the tariff and financial aspects of dialysis provision, as well as attitudes towards and opinions about the different dialysis modalities. The transcribed interviews were analysed by two researchers using thematic analysis, a methodologically and epistemologically flexible approach. The analysis was guided by the aims and the research questions of the project and by the researcher's active identification of themes, based on the accounts of the participants' own views and experience. This study was part of the BArriers to Successful Implementation of Care in Home Haemo Dialysis (BASIC-HHD) study⁴³ which includes an in-depth organisational study which informs and provides a context for this work.

RESULTS

Dialysis tariff

In order to understand the impact of the tariff on kidney care, it is important to first consider the way in which costs are perceived in various kidney centres and across NHS Trusts. Staff from the case study Trusts held a range of opinions on whether the different tariffs were sufficient to cover the costs of the dialysis modalities (see box 1). However, not all of the kidney centres had sufficient detail and clarity of the costs involved in different modalities; rather, they were only aware of the costs and income of the kidney centre as a whole and only had partial knowledge of the costs of the individual treatment modalities (even though Trusts

have to submit costs of each modality to the Department of Health as a basis for the tariff). This makes it difficult for these centres to compare tariffs against the true costs of these modalities. An assessment such as whether a specific modality is financially beneficial or loss-making is therefore a best estimate rather than a proven fact. Opinions on the cost/income balance of HHD ranged widely, from it generating a significant profit to it being financially detrimental to the kidney centre. Centres differed in how they accounted for the costs of training patients for HHD. Training for HHD typically takes place in-centre while the patient is dialysed. Extra costs are incurred when training patients at the time of in-centre dialysis, because of additional nursing input that may be required in teaching. Some centres do not consider the costs of training separately at all, viewing it as part of in-centre dialysis expenses. Others see training patients in self-care as additional expenditure, the costs of which have to be recovered when patients start dialysing at home. As most patients on HHD are also the patients who are most likely to receive a transplant, it can be seen as a loss of investment if they get a transplant relatively soon after starting on HHD. Interviewees' perceptions on how long it takes for HHD to bring in the same amount of money for the Trust as in-centre dialysis ranged from a few weeks to 2 years. These differences were partly due to differences in how long it takes to recoup the total upfront investment (training, home adaptations, and the costs of the dialysis machine for centres which make an outright purchase rather than lease). They were also the result of real or assumed differences in operational costs of HHD, and therefore the amount of money left for paying for the upfront costs under the current tariff (see box 1). Commissioners differed in opinion with regard to whether HHD is cost saving and were aware of the risk centres face if patients drop out of the programme early (see box 2). Another issue is the frequency of dialysis at home. In one centre cost considerations influenced the frequency of HHD sessions that were prescribed, but this was less the case in other centres. While the weekly tariff for HHD is fixed, the costs for some HHD patients will be higher than for others, depending on how often they dialyse and consequently how many consumables they use per week. In some of our case study Trusts the acceptable frequency of dialysis for HHD patients had been discussed, with some centres concluding that the HHD patients who dialyse 3 times/week balance out the costs of those choosing to dialyse 6 times/week in the programme as a whole. One centre was convinced that the Trust was losing money on frequent dialysis but refused to let cost influence the quality of patient care. In another centre patients were not allowed to dialyse more than 4 times/week because of cost constraints under the current tariff. Centres differed in their estimation of how much money is saved by reduced nursing time, and how many extra dialysis sessions this would cover in terms of consumables (see box 3). Other uncertainties and local differences in the cost of HHD arise from how in-centre respite care or patient retraining for HHD is accounted for, how overheads from the kidney centres for different modalities are calculated, and whether the dedicated dialysis machine that each

individual patient will need at home is purchased or leased. In summary, there appears to be no consistency among kidney centres in the way the costs of HHD are understood. It is therefore unclear whether the apparent cost differences in HHD were still applicable, if the cost calculations were uniform in each centre.

Box 1

“Because we haven’t devolved the costs down on each modality, I couldn’t tell you whether PD [peritoneal dialysis] or haemo[dialysis] or whatever was more profitable for us at the moment.”

(Centre 4, interviewee 1)

“If we don’t get beyond 2 years with a patient that’s gone home [onto home haemodialysis], as is often the case because they tend to be the healthier ones that are far more likely to get a transplant, ...we never get past that 2-year point to be able to start seeing some return on all the investment that we’ve made. So, if the turnover of patients is high, it actually is very detrimental, financially, to the service.” (Centre 2, interviewee 4)

“Our profitability starts when they’re at home and anything that prepares them for home is integrated into the main haemodialysis programme. Maybe it’s a matter of just how you view it.” (Centre 1, interviewee 6)

“We lose money...on those patients for the first 2 years because we invest so much time in their training, so much manpower and the home visits, etc., buying the machines, the technician support. And all those things added up, it’s not until you get past that 2-year stage that we actually start seeing a little bit of a comparison with in-centre patients.” (Centre 2, interviewee 4)

BOX 2

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BOX 3

“Although there’s been a lot of talk about home haemodialysis, when I came to starting to look at the evidence base for this, it isn’t really that strong as in the economics of it” (Commissioner 1)

“It’s cheaper. It is a lot cheaper to dialyse at home.” (Commissioner 2)

“So you set up somebody’s home, you put the machine in, and get them trained, you start them off and 3 months down the road they have a transplant. ...You lose quite a lot of money.” (Commissioner 1)

“So probably the first year the Trust won’t be making a profit on that tariff but after that they would be, so it’s a good tariff.” (Commissioner 2)

“There are a lot of people doing three times, three and a half times, four times a week. Even if you had 10% or 20% patients doing five or six times a week, you’ve made enough savings here to offset that.” (Centre 1, interviewee 6)

“If they dialyse more than three times a week, it’s not enough because the tariff...only ... gives you three times a week.” (Centre 2, interviewee 4)

“Patients can have a maximum four sessions of home haemodialysis a week. So if somebody needs a fifth session it’s not paid for, so they can’t have a fifth session.” (Centre 5, interviewee 2)

Table 1. CQUIN target (April 2010) and change in proportion of kidney patients on home therapy based on Renal Registry data

	CQUIN target for 2011 unless stated differently		Home haemodialysis (%)			Peritoneal dialysis (%)		
	Home haemodialysis	Peritoneal dialysis	Dec 2009	Dec 2010	Difference	Dec 2009	Dec 2010	Difference
Birmingham Heart of England	Total 35% by 2015*		2.8	3.6	0.8	7.1	9.2	2.1
Birmingham QEH	Total 35% by 2015*		2.0	2.9	0.9	15.6	15.1	-0.5
Dudley Group of Hospitals	Total 35% by 2015*		0.9	0.9	0	26.4	28.2	1.8
Liverpool Aintree University Hospitals	+1.7%	+5.0%	2.1	4.4	2.3	4.8	4.4	-0.4
Liverpool Royal Infirmary	+2.0%	20% total	2.6	3.8	1.2	17.9	14.5	-3.4
Royal Preston Hospital	+1.0%	+2.0%	4.7	4.8	0.1	13.8	11.2	-2.6
Salford Royal Infirmary	+1.3%	20% total	N/A	N/A	N/A	N/A	N/A	N/A
Shrewsbury & Telford Hospital	Total 35% by 2015*		1.3	2.7	1.4	13	9.9	-3.1
University Hospital of North Staffordshire	Total 35% by 2015*		1.6	4.4	2.8	19.3	19.9	0.6
Wirral University Teaching Hospital	+2.3%	+1.3%	1.4	1.8	0.4	15.8	16.6	0.8
Royal Wolverhampton Hospitals	Total 35% by 2015*		0.9	1.3	0.4	14.6	18.6	4
Average England hospitals with CQUIN			2.03	3.06	1.03	14.83	14.76	-0.07
Average England hospitals no CQUIN			2.08	2.29	0.21	16.28	15.67	-0.61
Difference in averages					0.82**			0.54***

Best Practice Tariff

The Best Practice Tariff for patients doing haemodialysis in-centre via fistula/graft had led the case study centres to put considerable emphasis on making sure patients get fistula surgery well before they start dialysis, as well as trying to aim for patients who dialyse using a vascular catheter to switch to a fistula (see box 4). The opinions of interviewees on the Best Practice Tariff were generally negative. The 80% target for patients on a fistula was seen as very high and there were concerns that it encourages centres to create AV fistulae in patients who might not benefit more from the surgery. There were also ethical concerns around patient choice—some patients may not want surgery for a fistula to avoid the need for cannulation. The interviewees emphasised that kidney centres should not direct patients to have vascular surgery for dialysis, conflicted by the higher Best Practice Tariff (see box 5).

Commissioning for Quality and Innovation schemes

The kidney centres we interviewed were all making efforts to reach their home therapy CQUIN targets, for instance by improving patient education in the predialysis phase. One commissioner stressed the positive impact CQUIN schemes have had on the uptake of home therapies: We put CQUINS in to help push the home therapy percentages,... working with the network on what percentages they should be. And it has made a big difference... You can see that Trusts are now more in tune with [this approach] (Commissioner 2). However, the clinical centres raised concerns about these targets. Since it is usually the younger, healthier patients who go onto home therapies, these are also the patients most likely to receive a kidney transplant. A centre with a high transplant rate might therefore find it more challenging to reach or sustain its home therapy CQUIN target. As one interviewee put it, Should I stop transplantation to meet the CQUINs? (Centre 5, interviewee 2). Just as with the Best Practice Tariff, another important factor is patient choice. Setting a CQUIN target on an issue that is based to a great extent on patient choice and their perceptions of the modality and its implications means that a Trust risks being penalised if insufficient patients wish to dialyse at home (see box 6). This may lead to encouragement of patients towards home therapy mainly for financial reasons, potentially with inadequate support structures and set up. One of the centres had discussed this issue with their commissioner, and they agreed on a more flexible target. They would receive the reward for reaching their home therapies target, or if a questionnaire showed that new patients were given the opportunity to make an educated choice. According to one commissioner, providing it was clear that the centre was making 'active positive changes', it would be awarded the CQUIN payment even if it was failing to meet the target. However, it was also clear that flexibility was possible under the CQUIN framework. One of the centres had agreed a 5-year CQUIN plan with their commissioner, with

the target proportion of patients who should be on home therapies increasing each year, clearly focusing on a longer term sustainable model, beyond the life of the CQUIN.

BOX 4

“The only tariff I’m sort of aware of at the minute is looking at their access because...they get more money, I think, for a fistula rather than a line, so there’s a massive push towards trying to get their access sorted so we do get that tariff in” (Centre 1, interviewee 8)

“The surgeons say, there’s no such thing as an emergency fistula. They’re now changing their minds and actually thinking, no, we need to actually bring somebody forward and do their operation sooner otherwise they’re going to end up with a line. So we’re much, much tighter about putting lines into people and putting tunnelled lines in when it’s going to be long term” (Centre 3, Interviewee 5)

“There is an industry of looking at why patients start dialysis on lines, why patients are on lines, what can we do for the patients that are on lines to get them a fistula, what can we do with patients with fistulas to prevent them needing a line whereas that maybe time that’s spent doing that, could be better spent doing something else.” (Centre 3, interviewee 1)

BOX 5

“The one that possibly is lunacy is the use of lines versus fistula in the Best Practice Tariff...It could be a slight perverse tariff that you’ve got elderly people who are actually going to go for an operation...one or 2 years before they’re end-stage when it’s difficult to predict and could start dialysis perfectly adequately and safely on a line, but the Best Practice Tariff suggests that we lose money if we try to do that. So there may be an issue around putting fistulas in people who probably aren’t going to benefit..., you may have multiple attempts of forming a fistula and then fail and setup on a line, when you could probably predict that that would happen and they should really just start on a line.” (Centre 3, interviewee 1)

“The tariff is working towards incentivising more patients to have a fistula, but at the end of the day you’ve still got that patient choice which you can’t force somebody...We shouldn’t be saying, well, you ought to have this done because it gives us more money. The idea is to provide a quality service that the patient is happy and this is the way we can treat the patient and that’s the way it should be.” (Centre 1, interviewee 7)

BOX 6

“The CQUIN targets drive our practice. They’re again, a bit of a double-edged sword. You can be under the microscope if you’re not achieving. And you can be sending patients home, but there can be things happening outside your control, like transplants and death, and things like this.” (Centre 2, interviewee 1)

“When we were asked before about CQUIN targets, I said, if we’ve been round and canvassed every single patient in our unit, and they are doing what they should be doing, and we haven’t hit targets because they are doing what they want to do...I don’t think we should be penalised for that.” (Centre 4, interviewee 2)

“If there is feasibility without affecting people and patient care... you should meet the CQUIN.” (Centre 5, interviewee 2)

“Concerns were expressed about the length of time required to make changes to centres to meet the target, compared with the size and duration of the resulting CQUIN rewards. Moreover, because CQUINs only give a monetary reward for 1 year, this was seen by some as insufficient incentive for the effort of changing local practices. According to one interviewee, “[we] soon realised that what [we] were signing up for was actually a very short-term deal ... Why do we want to worry about this amount of money? We might just be doing fine. Is it worth it?” (Centre 1, interviewee 6)

DISCUSSION

Our interviews have shown that not all kidney centres in England look at the costs of the different dialysis modalities in detail, focusing mainly on the total costs and income of the centre. This in itself is not surprising. Until April 2011 kidney care was covered by block contracts between the Trust and its commissioner. In this arrangement, the kidney centre

usually received a predetermined sum of money per patient, regardless of the modality⁴⁴. There are no reference costs for HHD, but a financial audit by the Kidney Dialysis Project Group in preparation for the reference costs exercise showed that Trusts report costs for HHD ranging from £28 to £133 per session⁴⁵. This may reflect an actual difference in costs or a difference in how providers disaggregate and record costs¹². The costing studies available in the literature do also not necessarily reflect the method by which kidney centres in our study sample calculate their costs. The HHD tariff was intended as an incentive for this modality³⁹ and the unexplained variation in estimated costs impacts on how a certain modality can be incentivised with a tariff. One of the centres did not see the tariff for HHD as an incentive because it is not until the second year of a HHD patient's treatment that the net income from in-centre and HHD is the same. There was also concern about the turnover of patients on HHD and its adverse impact on costs as upfront investment is lost.

Some kidney centres struggle to know whether the HHD tariff is an incentive or not: if they do not know the costs of a specific modality, they are unlikely to understand the additional value of the tariffs. This is similar to a finding in an early study of Payment by Results⁴⁶ where it was observed that there was 'evident uncertainty about the reliability of price signals given by the Payment by Results tariff' to incentivise providers to select services with a high price-cost margin. While the national tariff for HHD was not seen as an incentive by all participants in our study, CQUIN targets were seen as an encouragement to improve numbers of patients on HHD, even though the payment is relatively small compared to the total income a Trust earns for dialysis services. It gives centres an extra, very visible sum of money for the current year. Even the case study kidney centre that perceived HHD as financially detrimental has expanded its home programme in order to reach the CQUIN target and receive the additional income. It seems that the additional income outweighs any prevailing uncertainty around the costs of HHD. As CQUIN is an additional incentive decoupled from the base payment, this may contribute to the effectiveness of the model. The benefits of such incentives have been suggested in previous works⁸. The positive results of both our quantitative analysis (see table 1) and our qualitative findings on the CQUIN target and uptake of HHD are in contrast to a quantitative evaluation of CQUIN which shows a relative improvement in only one out of nine studied CQUIN goals¹⁵. The Best Practice Tariff for vascular access is also seen as a clear incentive because dialysis with an AV fistula or graft attracts the higher tariff and is regarded as the cheaper longer term option for vascular access. The Best Practice Tariff was implemented when improvements in vascular access were widely considered as a crucial issue in the care for dialysis patients and it was made the subject of an NSF standard³⁰ and a national audit^{35,36}. This might have given additional impetus to the uptake of AV fistulae. The evaluation of the introduction of Best Practice Tariffs for the Department of Health¹³ exposed criticism on the vascular access Best Practice Tariff that is similar to that encountered in our

study. The required percentage set in the Best Practice Tariff should in theory take into account issues around patient choice and the unsuitability of some patients for a particular treatment modality³¹. In practice, however, concerns were reported in our study over the tension between patient choice and the Best Practice Tariff, from fears that a centre may be financially ‘penalised’ if patients do not want an AV fistula or graft to concerns that the incentive to create AV fistula may be based on the financial incentive and not only on clinical suitability and selection process. We also found an ethical dilemma between CQUIN targets for home therapies and patient choice. As one participant said, if a CQUIN target for HHD has not been attained but patients have made educated choices then the centre does not deserve to be penalised. In this case, the centre and commissioner bypassed the potential pitfall by making educated patient choice an equally important indicator for reaching the CQUIN target. CQUIN targets are generally used to reach a specific target over 1 year. Some commissioners have, however, negotiated a multiyear home therapy CQUIN target, with the target percentage increasing each year. This overcomes the potential problem, raised in our interviews and in a recent evaluation of CQUIN¹⁵, that there might be less of an incentive to invest in a relatively small, short-term target. While decoupling incentives from the base payment appears to be promising (ie, via CQUIN type payment structures), changes to the tariff might also foster the uptake of HHD. To make the tariff for HHD a true incentive for kidney centres, they could be reimbursed per HHD session. This would be an approach somewhat similar to the Best Practice Tariff for vascular access in that the cost advantage becomes clearer. Because expenses for more frequent dialysis sessions would be covered, an equal payment for HHD and hospital haemodialysis sessions would be a clearer incentive. However, in a resource-constrained NHS this will increase the immediate expenditure by commissioning bodies. According to the 2008 Payment by Results Interim Report commissioners are likely to view paying per HHD session as undesirable because the costs are not linear due to the investment in a dedicated dialysis machine for each patient and variable depreciation⁴⁵. On the other hand it has been argued that the long-term health benefits of frequent haemodialysis, such as lower hospitalisation rates, may outweigh the initial costs. And even though some kidney centres are not convinced that HHD is financially beneficial for their Trust, others claim that their Trust is already making a significant profit on HHD under the current tariff. If anything, this strongly suggests that more research into actual costs breakdown by modality at a unit level is needed in order to provide suitable tariff. A specific feature of HHD is that a significant initial (and individual) investment in a specific patient has to be made upfront, but the income to cover this expense is only earned back over time as long as that patient receives HHD. A potential approach to reduce the risk for Trusts would therefore be to unbundle the initial investment costs such as home conversions and extra training, and pay separately for them.

Strengths and weaknesses of the study

Our qualitative study involved five kidney centres. We are unable to present a comprehensive evaluation of pay for performance in kidney care in general. We believe that variable prevalence of HHD in these geographically distinct study sites provide credible data and insight into the issues involved that need further research, on a wider scale. This paper does not examine the actual costs and financial benefits of different dialysis modalities or the influences of patient preferences and wider organisational factors in decision-making around kidney care treatment modalities. While these factors will shape the uptake of a treatment modality, we are confident that the highlighted issues are of importance and also of relevance beyond the case study centres, and point to concerns which should be taken into account in developing financial frameworks for kidney care.

Future research

In order for the tariff to be set in a way that it acts as an incentive, it will be important to better understand actual and perceived costs in kidney centres in England.

CONCLUSION

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The impact of financial incentives designed at a policy level is influenced by the understanding of cost and benefits at the operational level. In a situation where costs are unclear, incentives which are based on the improvement of profit margins have a smaller impact than incentives which provide an additional direct payment, even if this extra financial support is relatively small. When trying to provide an incentive by paying the same amount of money for a service that is assumed to be cheaper by policymakers, it is important that local decision-makers have a clear view of the costs and agree that this service is cheaper. Because kidney centres in England are not clear on the costs of HHD, being paid the same amount of money as in-centre haemodialysis is not seen as an incentive. Paying a higher tariff for a service that is clearly cheaper, or giving an additional sum of money when a specific target is reached, is seen as an incentive. This can be observed in the cases of the Best Practice Tariff for in-centre dialysis on a fistula or graft, and the CQUIN targets for home therapies.

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SECTION FOUR

Discussion

*Discussion- Home
haemodialysis technique and
its implementation barriers*

Top study statistics

Narrative synthesis of a multi-method investigation into barriers and enablers of home haemodialysis

Mapping BASIC-HHD study to dialysis research priorities

One of the most important decisions made by our patients in the course of their journey with chronic kidney disease, is to weigh their medical and psychosocial circumstances and choose a renal replacement method or opt for conservative management. The decision has significant implications on patients' lives and on funded healthcare systems. Transplantation is accepted worldwide as the ideal renal replacement method, but donor organ shortages implies the need to provide dialysis therapies to the vast majority of patients. Therefore, research into the various modalities of dialysis has gathered pace over the years. But, expanding research beyond the science of dialysis, into the realms of patient-oriented outcomes has become the focus in recent times. One however, cannot happen at the expense of the other. A Canadian study reported that globally, the overall gap between current research and patient priorities was large[1]. The NIHR initiative in the UK, a national advisory group, INVOLVE, was established in 1996 to promote formal involvement of patients in setting the research agenda[2]. Amongst the top ten dialysis research priorities identified by patients, their care-givers and clinicians from the James Lind Alliance initiative in Canada, 50% of the questions had a focus on information, lifestyle and quality-of-life[1]. This is also true in a study published from Australia[3]. The pertinent questions have been tabulated in Table 1.

Table 1: Five of the top ten research priority questions from dialysis patients

1.	What is the best way of informing patients with kidney failure about the advantages and disadvantages of different forms of dialysis; and how can we ensure that people get the right information, at the right time, and in the right way to ensure informed decision-making?; How can communication between patients with kidney failure and health care providers be improved, and does enhanced communication (including providing test results) increase patients' ability to participate in the management of their condition?
2.	How do the different dialysis modalities compare with one another in terms of their impact on quality of life and mortality, and are there specific patient factors that make one modality better for some patients with kidney failure than others? How can haemodialysis be tailored to a patient [in terms of: length, frequency, location and schedule (e.g. day/night-time)] to enhance effectiveness and quality of life?
3.	What is the psychological and social impact of kidney failure on patients, their family, and other caregivers, and can this be reduced?
4.	What are the causes and effective treatment(s) of depression in dialysis patients?
5.	What are the best ways to manage or prevent complications that occur during or shortly after the hemodialysis treatment itself (i.e. low blood pressure, cramping, nausea, headaches)?

The study on barriers and enablers of home haemodialysis, encompasses bio-psycho-social patient factors and may be mapped to 5 of the 10 research priority areas. The importance of these domains of research is exemplified in the study findings and they provide avenues for further exploration in future studies. Dialysis modality decision-making is a convoluted story

with several stakeholders involving, *the patient*-medical, psychosocial and cognitive domains, *the care-provider*- knowledge, attitudes, incentives; *the organisation*- renal replacement therapy education, dialysis programme, priorities, *the healthcare systems*- reimbursements, tariffs; and *the industry*- technological innovations, costs. It is therefore unsurprising that the varied rates of home therapies uptake worldwide, are influenced by the types of barriers that exist in the different countries.

Research paradigm for assessing barriers to uptake of home haemodialysis

There is a significant gap between the recommendations from the National Institute for Health and Clinical Excellence (NICE) on ideal home haemodialysis prevalence rates (10-15%)[4] and the actual clinical practice[5]. This practice gap undermines the benefits realised from research on home haemodialysis, and it is therefore vital to understand barriers to optimal home HD healthcare delivery. Interventions designed to change practice can only be implemented based upon accurate assessment of the causal factors which detract from achieving target outcomes. From a clinical practitioner standpoint, bridging the hiatus between global evidence and local realities can be a challenging and delimiting experience.

Methodology for the assessment of barriers to change practice typically has taken the form of survey-based data collection from healthcare practitioners and from patients[6]. Both healthcare practitioners and patients have also been involved in qualitative studies such as focus groups, and semi-structured interviews. The third type of methodology which is the mixed-methods model, can be a combination of interviews, surveys, site visits, participant observations and reviews. Survey-type instruments dominate the study design of research on barriers. Even more importantly, the focus can be confined to one or a few perceived, predetermined barriers to effecting change, and addressed by a volley of ‘closed’ questions. Therefore, a strong conceptual model is important to guide the study design and analysis; especially in a complex healthcare environment.

The current study, BASIC-HHD, evolved in its design over a few months. We have been informed from previous separate observations that there are a multitude of factors which influence dialysis modality choice. The overall study has factors grouped around four characteristics, important to adoption of change, akin to the model of diffusion of innovation[7]: characteristics of the healthcare provider, characteristics of the beneficiaries of change (patients), characteristics of the organisation (prevalence of home HD), characteristics of the modality (home haemodialysis-technology/technique). To my mind, it was also very important to address some factors in greater detail. For example, ‘fear of self-cannulation’ may be a valid reason for not choosing home haemodialysis, but, the all-encompassing nature of the response fails to discern the surmountable from the

insurmountable. I have resisted the temptation to list the barriers to adoption of home haemodialysis from a ‘barrier-focused’ survey/interview. The whole exercise has been open-ended serving a more exploratory function within a conceptual framework. Therefore, I have had the opportunity to study some of the ‘topics’ in greater detail, allowing for the observation of clinical, psycho-cognitive and social variables independently, before examining them in a prediction model. Extrapolating the dialysis choice concerns from a prevalent pool of dialysis patients, has some advantages and disadvantages. Whilst it does allow for creating a framework of questions, it does not capture the ‘abstractness’ or the ‘vacuum’ in which some decisions are made. Therefore, information for some aspects of the study are drawn from CKD-5 (pre-dialysis), home and hospital HD patients and for the others, from predialysis patients alone. The combined scope of patient parameters in the study (co-variates), the quantitative, deductive examination of these variables, the qualitative, inductive approach to examining barriers to home haemodialysis, and lessons from predialysis and prevalent haemodialysis patients are a significant strength of this study. The examination of these patient variables in the context of practitioner views (both quantitative and qualitative) from study centres with variable prevalence of home HD, lends itself to a systematic, multidimensional examination of this complex subject. Therefore, the research paradigm which embraces both quantitative and qualitative methods has helped illuminate the ‘how’, the ‘how much’ and the ‘why’ for the BASIC-HHD study.

Home haemodialysis: the implied and the sought

The burgeoning literature on home haemodialysis is a testament to the modality’s popularity amongst providers and patients alike. The reported growth of home haemodialysis prevalence in the UK shows a promising trend[8]. Evidence against the two-day gap in conventional dialysis schedules[9, 10] and benefits of intensive dialysis in some patient groups[11-13], the re-emergence of concepts such as recovery time[14, 15] and the Registry’s interest in other such patient-oriented outcome measures[16], drives home the point that reconciling length-of-life with quality-of-life will dominate the practice scenario in the coming years.

With this background, I have sought to fill the gaps in literature by studying the ‘technique survival’ of home haemodialysis therapy, from a longitudinal observation of the cohort of home HD patients over 8 years in a tertiary renal network programme[17]. Treatment journey from acceptance of the modality to a thriving modality practice at home is a useful measure of the success of the components that go into making the home therapy programme. The results of this study have been very insightful. Generally speaking, home HD technique survival is excellent at 1, 2 and 5 years from the time the modality is chosen (90.2%, 87.4% and 81.5%). More importantly, if training exits are also censored from the death and transplantation censored analysis, these figures are even better (98.4%, 95.4% and 88.9%).

The gap between the two survival curves, is explained by information on the reasons for training exits- lack of patient confidence and motivation are the main staff-perceived reasons. Medical issues do not seem to dominate the reasons at this stage, although co-existence of diabetes or cardiac failure are the main predictors of home HD technique _{composite} survival.

These reports offer permissibility to explore and understand patients' choice and the decision-initiation gap thereby making this therapy, a longer-term success for the patient. The question however is, do all patients have this choice? The registry reports in the UK with home HD prevalence rates varying between 0% and 14% [8], and the widely variable international prevalence figures [18], tell a different tale. My own observations of the 'choice to all' question, from the global survey of predominantly European practitioners is that, for 56% of respondents in this survey, home HD was aspirational, as they had no patients receiving this form of treatment [19]. The significant independent predictors of having at least one patient on home HD were, belief in the current evidence supporting extended HD regimens, presence of a dedicated team for discussion of dialysis options and no perceived financial disadvantage from home haemodialysis. The lack of appropriately trained personnel and funding for home adaptation (35% and 50% respectively) are widely perceived to be the key barriers to adoption of this therapy. All of these factors transcend geographical boundaries and could potentially apply to practice in the National Health Service.

Lost in translation: the information-perception gap

Dedicated team for delivering dialysis education is a pre-requisite to optimise home dialysis uptake, as identified by respondents from the aforementioned global survey. This is a crucial point in the patient journey, when they amass information in the hope of making informed decisions. There is evidence that patients who attend a dedicated options class are more inclined to choose home-based dialysis therapies [20, 21]. A lot depends on the interval between consulting the renal services and commencement of dialysis therapies. Clearly, unheralded dialysis starts tend to undertake the least favourable route of hospital-based haemodialysis via central venous catheters [22]. The attempts to minimise this in the UK through 'best practice tariffs' is met with criticism and acclaim in equal measure, in our study which reported on perceptions and experiences of financial incentives in a qualitative study of dialysis care providers [23].

In the words of one interviewee,

"The tariff is working towards incentivising more patients to have a fistula, but at the end of the day you've still got that patient choice which you can't force somebody... We shouldn't be saying, well, you ought to have this done because it gives us more money. The idea is to provide a quality service that the patient is happy and this is the way we can treat the patient and that's the way it should be." (Centre 1, interviewee 7)

‘Informed choice’ has become a euphemism for individual choices that take account of information given during a counselling course. The question is, what constitutes good dialysis counselling? Over the years, there is increased recognition of the importance of giving information that patients can easily understand, in a manner that appeals to patients and their care-givers and decision-aids have now come into existence through these processes. The material for information is one, very important aspect of dialysis counselling. These materials comprise, written information, audio-visual aids, and peer-patient interaction. Increasingly, peer-education is being recognised as an important method of improving uptake of home-based modality choice. A project (ACE project) is currently underway in West Midlands, UK, to evaluate the peer-educator model to support dialysis decision-making. It is evident from the qualitative study on predialysis patients who made home and hospital dialysis choices, that not all patients perceive information in the manner, providers expect them to. All of them have had access to the same resources. Many have made and communicated their choices. However, there appears to be an undercurrent of rational-emotive barriers, that we may not always recognise from a few, brief, pointed interactions. This brings into focus the issue around timing of delivery of information to patients. The evidence around this is limited and the practice is typically dictated by case-load. Patients gain entry into discussions pertaining to dialysis options based on eGFR and its rate of decline. It does make practical sense to be doing so. But, are patients being short-changed in the process? There is just enough time to do all it takes to obtain a decision and create a dialysis access- features of care linked to remuneration. There lies the problem. When clinical care, ill-defined/informed metrics and remuneration are bundled together, patient experience is likely compromised. Studies on the timing and frequency of delivery of information would be useful. The wrap-around behavioural counselling is likely to make these patient interactions, more meaningful.

In the report on healthcare decision-making in end stage renal disease (ESRD), we used the information-seeking and decision-making subscales of the autonomy preference index to ascertain the appetite for information amongst patients with ESRD and the expected consequence, which is decision-making. 52.6% of patients in the lowest tertile of decision-making scores- ‘the delegators’, belonged in the predialysis group[24]. Information-seeking did translate to higher decision-making, but limits were placed by illness severity, cognitive ability and having a social companion. Therefore, whilst information is sought, it does not always imply that informed decisions would be forthcoming. Juxtapose this with what our patients have to say.

‘But a good practitioner would guide the patient in the decision-making’ F6, Male, Home HD

‘Well it was alright for, you know, informing me of the different types, you know. It’s just when all they want to do is just put me on dialysis and stick me in a corner, you know. I ain’t up for it’. A, Male, Hosp HD

The gap between information and perception can only be filled by time, attention, guidance and validation of patients' abilities. This would require practitioners to spend a lot of time assessing patients beyond the limits of physical illness. Addressing patient concerns and 'affect' will have a significant bearing on the choices they make. The discourse on 'information' for dialysis therefore needs to include information in its literal sense and also processing of that information leading to the choices patients make. Not all choices seem to be made on accurate information. Modality choices, it appears, is also made from misconstrued information. This is exemplified in the following patient quotes-

'Because, and it wouldn't be enough for me because it's both of my kidneys because most people who are doing it it's just one kidney but for me it's both of my kidneys that have gone bad. So doing it at home it will be better'. D4, Female, Home HD

And I tend to think if you're doing home dialysis, I think you fall down the list of getting a kidney. I think if you go to hospital you've got more chance'. J, Female, Hosp HD

There is a need therefore to get the patients to recapitulate what they may have understood and even to revisit the information from time to time. These will have resource implications. Better ways of information update such as combining hospital visits with a refresher course periodically, may be an option. This may also give us opportunities to revisit home therapies, where appropriate, whilst addressing the psycho-affective health of patients. The survey of practitioners from the five UK study centres, highlighted the differences in response to the question on information dissemination to patients, between centres- 'Is information on dialysis modalities clearly displayed and presented to patients, uniformly, by all members of staff?' where 44.4% of respondents from low prevalence centres vs. 18.2% from high-prevalence centre, felt there was room for improvement in the manner education was imparted.

[The elephant in the room: the burden of cognitive impairment](#)

In all of the patient-oriented papers I have presented thus far, there is one inescapable observation. Higher cognitive function is associated with several dimensions of self-management. These include higher autonomy preference, greater illness coherence, perceived ability to self-cannulate and self-care dialysis modality choice in the predialysis phase. An important revelation in our study of cognitive deficit and implications on self-care dialysis modality choice, is the role of patients' perception of their own cognitive ability (metacognition) on their preferred dialysis modality (self-care dialysis vs hospital-based HD). The objective cognition tests were not significantly associated with modality choices in adjusted regression models. Importantly, the association of patients' perceived ability to concentrate with a key test of executive brain function (Trails Making Test B), is of considerable significance, in view of the ease of its administration and potential outcomes associations. The utility of this screening as a proxy/complementary test in the predialysis

assessments of patients remains to be explored in research. In the passage of time between making modality decisions and commencing dialysis, progressive cognitive impairment is inevitable. This may well contribute to the decision-initiation gap, so often seen in practice. So, questions such as, how do we best measure cognitive abilities of our patients? How and when in the treatment journey can we address these issues? What are the ideal outcome measures on the research of cognitive deficits in the CKD context? What can we do to advance our understanding from epidemiology to the neurobiology of cognitive impairment in CKD? etc., are pertinent questions due to the potential for interventions which may change the course of patient care. In a narrative review of the impact of cognitive deficits on self-care decision making in patients with chronic heart failure, there was a paucity of studies describing their relationship and the authors concluded that a knowledge gap existed regarding the relationship between the two[25].

The processes which will help allow the choice of self-care dialysis modality start very early even as the eGFR is about a 60ml/min mark; as it has been established that cognitive impairment begins quite early in the CKD process. Management of cardiovascular risk factors are central to stemming the decline in brain function, as is well known from published literature[26-29]. But, the significant associations of higher depression levels with metaconcentration, implies there is another angle to the management of patients to promote self-care dialysis and address cognitive impairment. This, is psycho-affective therapy, modified to suit individual needs. The lack of understanding as to the best tests and appropriate metrics in this area has meant that this aspect of the chronic kidney disease patient management has been in the relegation zone for decades. The impact of different self-care dialysis therapies on the state of cognitive dysfunction remains unanswered in a prospective research design and findings are often confounded by poorly matched controls[30]. The Frequent Haemodialysis Network trials, showed no evidence supporting frequent haemodialysis on improved cognitive function, but the study was unblinded, and small sample size with significant drop-out may limit the application of these findings in clinical practice[31]. Therefore, the bidirectional impact of cognitive function on self-care dialysis modality choice and that of home-based dialysis modalities on cognitive function is an evidence-limited area at the present time.

[Mind over matter: illness appraisal in treatment choices](#)

Patients who are confronted with a threat to their health, such as in permanent kidney failure requiring dialysis as life sustaining therapy draw on their personal models of that health threat to guide their behavioural and emotional responses to it[32]. In our cohort of predialysis patients, 'illness coherence' was the most significantly different aspect of illness perception between hospital and self-care modality choice groups. Illness coherence which relates to

illness understanding, is associated with perceived cognitive ability as highlighted in the preceding discussion on cognitive burden in predialysis patients. Additional attributes which patients may acquire as a result of undertaking self-managed dialysis includes a higher sense of personal control. However, a key finding of this study is the highly significant association between depression and anxiety screening scores and all of the subscales of the illness perception questionnaire. Given the high prevalence of affective disorders in patients with chronic kidney disease, addressing these may help alter illness perceptions. Asking patients about how they view their illness gives physicians the opportunity to identify and correct any inaccurate beliefs patients may have. Once a patient's illness perceptions are clearly laid out, a physician can try to influence and shift those beliefs in a direction that is more compatible with treatments associated with better health outcomes. Following are some exemplar quotes depicting patients' frames of mind- both emotion-focused and problem-focused coping, in the predialysis phase when dialysis decisions are made.

'Bloody despair sets in. I'm telling you, I haven't got the... I can't do half of what I want to do; I still want to do it and I can't. I haven't got the energy; I haven't got the bloody inclination these days. And everything is such an effort and I just think, why worry, why worry anymore, let it happen.' B, Male, Hosp HD

'But it's about the mind really, I feel more depressed than anything else'. E, Male, Hosp HD

'Emotionally I feel I'm not... you know, like before I'd like, you know, do business, I carry on business, but when I know I had kidney problem it made me, you know, think again.' A1, Female, Home HD

'You wouldn't say it's had an impact on life but psychologically when you think about it. Ya know, it's... there's nothing much you can do about it.' E5, Male, Home HD

'I shall rise to the occasion'. F6, Male, Home HD

'I'm mentally prepared for transplant or dialysis. And most of the time I don't think about it whether I'm going for dialysis or going for transplant. Like that's my motto, enjoy your life as much as you can. I go to badminton and go back and watch telly and enjoy it, so whatever happens, happens, you can't do anything'. H8, Male, Home HD

[The sobering truth: socioeconomic disparities and home haemodialysis uptake](#)

Socioeconomic discrepancies in the uptake of home haemodialysis exist in different parts of the world[33, 34]. In the UK, according to one study, a third of the regional variation in renal replacement therapy incidence between areas could be explained by the demographic, health and access to health services factors and socio-economic disadvantage was associated with a lower use of home dialysis, independent of the effects of race[35]. In our study reporting on predictors of home dialysis uptake (chapter 3.10), across all study centres, 'ethnicity' and 'home ownership' were independent predictors of self-care dialysis choice amongst predialysis patients. Patients of non-white ethnicity show a 70% lower odds of choosing self-care dialysis modality, after adjustment for home ownership, comorbidities index, perceived cognitive ability and centre characteristics. This finding is most astounding. In our report on

healthcare decision-making, ethnicity was significantly associated with decision-making and white patients were more likely to prefer involvement in decision-making. Patient's role expectations, perceived role in the family context and emphasis on individuality may be a culturally determined phenomenon, influencing the passive role adopted by participants in the ethnic minority group and the 'sick-role' behaviour may impact on the extent of self-management participation. The approach to imparting information and ascertaining patients' values and preferences should be culturally sensitive and account for the cultural diversity of different regions. However, there is an interesting observation to be made from the socio-economic catchment areas of the five study centres. In the confounder adjusted analysis of 'ethnicity and modality-choice' in the predialysis phase (presented in chapter 3.4), patients of non-white ethnicity from higher IMD quintiles (poorer socioeconomic status) receiving home haemodialysis were found in medium and high home HD prevalence centres. Therefore, there appears to be an overarching impact of centre's policies and practices on patient's dialysis modality uptake, irrespective of the ethnicity status, at least as far as home haemodialysis modality is concerned. Lack of accommodation compatible with home haemodialysis, is an important deterrent to its choice and is met with frustration by some patients (see quotes below).

'The only thing is I wanted it at home but I can't because... because they came a fortnight ago and they didn't pass it'. A bit annoyed actually. I'll be honest with you yes, a bit annoyed'. H, Female, Hosp HD

'The only thing is if I am going to dialyse from home this place is going to be too small isn't it. That's the only thing, you know storage space and that. It's dead small'. E, Male, Hosp HD

What are the alternatives for such patients? Systematically seeking out such patients for self-care dialysis in free-standing units, removed from hospitals may be an option. At the very least, such patients should be allowed to undertake self-care dialysis in a hospital dialysis unit, preferably with free access to the unit in his/her own time. At a larger policy level, cost-effectiveness of add-on porta cabins vs institutional dialysis over the medium to long term should be ascertained in future research.

[Self-cannulation: the necessary evil](#)

'Yeah, no, I'm not frightened of needles or anything like that. Uh, I'm like a tea bag, honestly. I've got more holes than a tea bag. But, uh, no, I haven't got any problems with that'. G7, Male, Home HD

'Well, I'd say that they're a necessity for the treatment option you chose so they're something that you need to do and something you'll have to do, so just get on with it'. H8, Male, Home HD

Responses such as the abovementioned quotes from patients in our study, may seem to suggest that self-cannulation may not be a potential obstacle in the decision to choose self-care haemodialysis. However, patients who face the daunting task of undertaking well over 300 episodes of self-cannulation on a yearly basis, seem to have other persuasive beliefs which

allows them to consider this part of the process. It is perhaps more important to become aware of the numbers of patients who may actually be willing to self-cannulate. About 1 in 3 individuals in the predialysis cohort and in the hospital haemodialysis cohort would be willing to consider self-cannulation. A further 25% of predialysis patients, feel able to consider this with some help. It is useful to note that patients who preferred peritoneal dialysis, were most averse to the idea of self-cannulation[36] (chapter 3.10). Exposure to routine phlebotomy or the experience of injecting themselves for insulin or erythropoietin, appears to have tempered the fear of self-cannulation for some. Showing patients needles may help allay anxiety. Allowing patients to handle needles and use them on dummies even whilst in the predialysis phase, may give some patients confidence from the more tactile experience.

'Well having insulin for 12 years you have needles every day, it just doesn't bother me'. C, Male, Hosp HD

'That was when I first made the decision to go on home haemodialysis. And she showed me and I thought, "oh they're not too bad them.' H8, Male, Home HD

'For the past ten years, I have got used to it. Because that's all they ever does, you know when I go every three months they just took blood every time. Just take blood blood blood, that's all they ever do. So I got used to the needles'. E, Male, Hosp HD

Routinely in clinics with patients, there is a need to expand and understand the stated 'fear' of self-cannulation as there may be a modifiable concern, thereby allowing self-care haemodialysis, at home or in hospital.

Multidimensional taxonomy of barriers and enablers of home haemodialysis uptake

Research on the subject of barriers to home haemodialysis is important to take the steps which may enable starting or expanding a home haemodialysis programme. National, multicentre studies are useful in generating large patient-level 'barrier' evidence, but, to bring about a strategic change in practice, local studies of barriers in a well-defined conceptual/analytical framework would be important. I do feel that within reason, a root cause analysis is justified for every potential case that is not considered for self-managed dialysis. This will allow a deeper understanding of patient and organisational barriers and inform appropriate calibration of policy, application for funds, institute appropriate educational interventions and build the team that is most likely to deliver the outcomes. National home haemodialysis guidelines will help provide guidance from a systematic synthesis of a large body of complex literature, largely observational. This may not be ideal, but it provides a beginning for some who would otherwise be left to assimilate all the information there exists and infer. Lack of robust evidence providing dialysis modalities comparative effectiveness may be limiting the adoption of home haemodialysis. Until such time, 'modality neutrality' and 'patient-choice' would be grey areas in the kidney literature. In Table 2, I have presented the many dimensions of the

approach to barriers and enablers of home and self-care haemodialysis drawn from practice, literature and findings of the BASIC-HHD study.

Table 2: Multidimensional taxonomy of barriers and enablers of home/self-care haemodialysis			
Criterion for categorisation	Category of barriers		Examples
Are barriers modifiable?	Surmountable	Patient	<ul style="list-style-type: none"> ➤ Rigid entry criteria at the stage of expanding home HD ➤ Temporary frailty following acute illness ➤ Well controlled epilepsy with care-giver assisted HD ➤ Mild cognitive impairment with care-giver assisted HD ➤ Psychological fears and maladaptive coping styles ➤ Home physical environment ➤ Social support systems
		Provider	<ul style="list-style-type: none"> ➤ 'Self-care first' policy ➤ Knowledge gaps ➤ Attitude and behaviour/ unit culture related ➤ Enhancing physician-patient dyad experience ➤ Multidisciplinary input readily accessible ➤ Physical-space for training ➤ Dialysis education program-comprehensive and inclusive ➤ Geography-Free standing units/self-care in-centre HD ➤ Assisted home HD service ➤ Optimisation of program size to retain interest and expertise ➤ Annual home HD program forecast to minimise resource burden and maximise resource planning ➤ Unit level understanding of costs and expenditure to leverage financial incentives
	Insurmountable	Patient	<ul style="list-style-type: none"> ➤ Uncontrolled seizure disorder ➤ Severe metabolic and electrolyte derangements ➤ No vascular access options ➤ Severe visual impairment ➤ Severely impaired dexterity ➤ Cognitive impairment ➤ Poor housing conditions

		Provider	<ul style="list-style-type: none"> ➤ Extremely small dialysis program with uncertain future prospects which precludes resource allocation to home HD program development
Sources of barriers	Patient-level	Medical	<ul style="list-style-type: none"> ➤ Unstable cardiovascular status (severe, symptomatic cardiac failure-may do better on PD) in the predialysis phase ➤ Difficult vascular access (although home-based central venous catheters (IJ) may be allowed on a patient-by-patient basis) ➤ Less than optimal vascular access flow rates (adjust other factors such as duration of dialysis to maintain adequate clearance) ➤ Contraindication to standard anticoagulation use ➤ Seizure disorder (well-controlled situations may permit care-giver assisted home HD) ➤ Visual impairment (mild-moderate may be surmountable/care-giver assisted home HD) ➤ Hearing Impairment (modified alarms-light/vibration permitting) ➤ Absolute indications for intensive dialysis (pregnancy/volume related hypertension/some metabolic derangements)
		Psychological	<ul style="list-style-type: none"> ➤ Severe, uncontrolled psychosis (home HD contraindicated) ➤ Severe depression with suicidal ideation ((home HD contraindicated) ➤ Maladaptive coping styles (CBT/Counselling) ➤ Technophobia (CBT/desensitization) ➤ 'Fear' of self-cannulation (most are amenable to intervention/assisted cannulation-caregiver/staff) ➤ Locus of control (internal vs external) ➤ Mild-moderate depression/anxiety ➤ Perceived poor cognitive ability (trial of training/dialysis care partner/shared-care HD)
		Knowledge	<ul style="list-style-type: none"> ➤ Misconstrued information on benefits or disbenefits of dialysis modalities leading to choices ➤ Dialysis counselling tailored to individual needs-style/time/content/language/consistent messaging/physician validation ➤ Visit to the training unit/benefits of intensive HD/ practising cannulation on dummies/ seeing needles used for HD

			➤ Information on average waiting times/ transport times/ sharing machines etc.
		Social	➤ Housing- Space/ Plumbing/ Electricity/Hygiene training/re-housing/free-standing units/porta cabins/ community houses for batched HD/ Premixed dialysate) ➤ Employment (nocturnal dialysis) ➤ Travel (portable device use/ self-care HD) ➤ Holiday/Leisure (portable device use) ➤ Assisted home HD service ➤ Self-care HD in-centre, where social interaction is the main reason for hospital-based HD
		Cognitive	➤ Cognitive impairment (mild cognitive impairment may permit care-giver assisted home HD)
	Practitioner-level	Knowledge	➤ Lack of experience of home HD ➤ Lack of knowledge of technical/patient factors connected to Home HD (Conference attendance/mentorship programmes/online tools/ practice guidelines) ➤ Lack of support staff with knowledge of home HD
		Attitudes	➤ Lack of motivation to change/learn ➤ Lack of belief in evidence around home HD ➤ Misperceptions and predetermined beliefs in who can and can't undertake self-care haemodialysis ➤ Lack of understanding of financial disposition of the unit and implications of a home HD programme to costs ➤ Delegation of modality discussion in entirety to the education team ➤ Complexities and fears associated with the unknown
	Organisation-level		➤ Lack of a program philosophy ➤ Lack of the full complement of team: nurse educator/psychologist/social worker/nephrologist ➤ Poor allocation of resources (staff and funds) to renal services ➤ Approach to renal replacement therapy with 'in-centre' dialysis as default modality attitude

		➤ Recruitment of medical and nursing staff with no special interest in promoting self-care dialysis therapies
	Healthcare system	<ul style="list-style-type: none"> ➤ Inadequate primary care input resulting in late referrals to nephrology services ➤ Unintegrated services (dialysis services in primary care setting) ➤ Higher tariffs for self-care dialysis in general ➤ Batched-community houses for HD-ease of process/financial incentives through local councils)
	Industry	<ul style="list-style-type: none"> ➤ Lack of a healthy market competition for HD machines designed for home use ➤ Reconciling portability and efficiency of the HD machine ➤ Simplified, user-friendly machine for use by patients who may be mildly challenged in their cognitive/computational abilities.
Durability of barriers	Long term	<ul style="list-style-type: none"> ➤ Healthcare system related factors (macro-policies) ➤ Industry-level factors (in some countries)
	Medium term	<ul style="list-style-type: none"> ➤ Industry-level factors ➤ Organisation-level factors ➤ Practitioner-level factors (until understanding is established) ➤ Patient-level factors (depending on resource allocation and multidisciplinary staff availability)
	Short term	➤ Practitioner-level factors
Types of barriers	Behavioural barriers	<ul style="list-style-type: none"> ➤ Patient and provider lack of knowledge/awareness/skill ➤ Peer-influence factors
	Rational-emotive barriers	<ul style="list-style-type: none"> ➤ Patient and provider lack of self-efficacy/confidence/self-assessment ➤ Patient's protracted emotional response to illness perception (emotion-focused coping towards problems)
	Evidence barriers	<ul style="list-style-type: none"> ➤ Generation of new evidence on comparative effectiveness of different dialytic therapies ➤ Home haemodialysis practice guidelines ➤ Locally generated information on finances and dialysis services involving all stakeholders ➤ Evidence on 'what works' in the predialysis stage

	Resource barriers	<ul style="list-style-type: none"> ➤ Funding barriers ➤ Time barriers ➤ Staff and expertise barriers (resource barriers are interlinked and negatively feedback into each other)
	Process barriers	<ul style="list-style-type: none"> ➤ Healthcare system factors ➤ Organisational factors ➤ Team-structure/composition and differences
Direction of influence	External	<ul style="list-style-type: none"> ➤ Evidence addressing key determinants of choice of dialysis modality ➤ Resource barriers (dedicated staff, funds, physical space, time) ➤ Healthcare system, and organisational factors ➤ Patient's clinical characteristics
	Internal	<ul style="list-style-type: none"> ➤ Knowledge, attitudes and behavioural factors (Patient and provider)
Level of barrier	Macro level	<ul style="list-style-type: none"> ➤ Industry-level factors ➤ Healthcare systems related factors ➤ National and International observations/evidence
	Meso level	<ul style="list-style-type: none"> ➤ Group and team factors ➤ Organisation-level influences ➤ Regional factors
	Micro level	<ul style="list-style-type: none"> ➤ Practitioner-level factors ➤ Patient-level factors (one-on-one)

Limitations

The BASIC-HHD study was an ambitious study at the outset. The study design which combined multiple-methods to address the overarching question was an appropriate one. However, within the independent ‘methods’ streams, there were limitations. The parallel, convergent study design of mixed methods is ultimately as good as the component study methods. Perhaps, nested qualitative studies within the larger study groups would have been appropriate. Mixed methodology with the same study subjects within both method domains is another potential approach, but not practical in the BASIC-HHD study. The vastness of the subject was evident as the study evolved and required research associates to help with the interview process in the qualitative study. This also meant the lack of continuity between the interviewer and the data analyst. It was not possible to return to participants the interview transcripts for checking, one of the hall marks of good qualitative analysis.

Within the quantitative study component, particularly where generic questionnaires were employed, pre-survey pilot or a focus-group brainstorming sessions were not carried out, limiting the choice of questions to those generated from routine clinical experience. The study design which conceptually included both cross-sectional and prospective datasets in the quantitative and qualitative arms were limited in some respect to the quantitative arm alone and with a follow-up period that could not capture the dialysis starters in greater numbers. Some aspects of the study would lend themselves better to prospective examination of data, even if in a confirmatory sense. e.g., decision-initiation gap for dialysis modality, perceived ability and actual ability to self-cannulate, change in illness perception during the dialysis journey or the longitudinal qualitative study of predialysis patients after commencement of dialysis. Age-matching across all groups proved difficult at the time of recruitment and therefore, the mean ages of predialysis cohort is significantly greater than that of the home HD cohort, but not so compared to the hospital HD cohort. This may have little impact on dialysis modality decisions, the chief outcome variable for most aspects of the study. In quantitative study of the organisation, information on finances from each participating unit was not forthcoming, therefore economic analysis was not feasible. Recruitment for study of complex cognition tests was difficult as patients wished to discontinue the tests when it was proving difficult for them. This led to administrative errors in some instances through lack of documentation of time to complete. However, this has given some learning points as to an appropriate sample size/ complexity and bias that is to be considered ahead of another study of patient cognition in chronic kidney disease. In the overall assessment of the findings, it is important to note that no causal analysis is possible from the cross-sectional study design and findings are limited to significant associations with outcome of interest. Clearly, in this study

where several outcomes have been explored, the statistical power was examined post-hoc, and as such, several key chapters have adequate statistical power to address the key hypothesis.

Future research

There is interest in the home haemodialysis therapy expressed by multidisciplinary staff and driven ultimately by patient well-being in the dialysis setting (Recovery time proving to be a composite benefit of location of care, clinical benefits and other variables). This is reassuring and supportive of national initiatives in promotion of access to home HD treatment for many patients. The study reveals that in the predialysis stage there exist multiple, critical junctures where disease burden, cognitive load, and complex healthcare contacts intersect, leading to transient periods of potential instability, requiring support at physical and psycho-socio-cognitive levels. The factors which are potential destabilisers during patient and care-provider interactions, are modifiable to a considerable extent. Research undertaken to test complex and layered interventions to measure change is complicated by the lack of distinct causal pathways between all potential interventions and the outcome of interest. It is because of their multifaceted nature and dependence on physico-psycho-social contexts, that complex interventions pose methodological challenges. However, it may be possible to study a complex intervention model for a subject like this, through cluster randomised controlled trials which incorporates process, context and outcomes evaluation. Our data goes some way in clarifying the components of such an evaluation. There are several gaps in literature pertaining to dialysis modality choices. Here are only a few practice-related questions for potential research in this area. Others have been covered in the respective topic areas.

Domain	Topics
Dialysis modality	Comparative effectiveness research of alternative dialysis modalities. Is modality-neutrality an appropriate method of dialysis education?
	Modality switch outcomes data (PD to home HD and vice-versa)
	How should optimum modality mix be determined?
Dialysis Counselling	The best time/methods for dialysis education of CKD patients
	Physician interaction with patient and modality outcomes
Psychological interventions	Dialysis education and behavioural therapy impact on self-care modality choices-intervention studies
	Pharmacological and non-pharmacological management of depression and impact on dialysis modality choices
Cognition in CKD	How do we best measure cognitive abilities of our patients?
	What are the ideal outcome measures on the research of cognitive deficits in the CKD context?
	How and when in the treatment journey should these issues be addressed?
	Enhancing the understanding of the neurobiology of cognitive impairment in CKD?
	What interventions may limit the advance of cognitive impairment in CKD?
Self-cannulation	Fistula and patient outcomes with self-cannulation compared to healthcare professional cannulation of AV fistulae.
	Interventions in predialysis phase to promote self-cannulation for haemodialysis

Conclusion

The BASIC-HHD study has shown us that across the five centres with variable prevalence of haemodialysis, patient-level barriers and provider-level barriers are perceived to be present in varying proportions. Patient-level barriers at one centre (e.g., socioeconomic status; ethnicity) do not present an impediment at another. Likewise, perceived financial barrier in the way of providing home HD therapy in one centre is not a real barrier at another centre. The multidimensional taxonomy of barriers to home haemodialysis depicts a palette of perceived barriers, but the solution to these problems is not a shift in national policy alone (as is exemplified in the gap between NICE guidelines and practice). Every unit will need to invest in understanding local barriers, using a systematic framework as presented above, in ‘real-time’ and not as a one-off exercise.

Our study has shown that patient-level predictors of modality choice are potentially modifiable except in instances when the choice is dictated by a high degree of physical/cognitive limitation. It also appears that physician-level barriers are most readily overcome when systems are modified to alter the existing levels of knowledge and attitudes regarding home haemodialysis (clinical and economic). The approach to patient selection and modality education should be graded and an individualised package of counselling and knowledge assessment led by the physician in conjunction with robust support from allied healthcare professionals, is likely to yield the most benefit.

The renal registry should incorporate metrics to track modality decision-choices for selection of ‘in-center’ haemodialysis. This may allow some meso-level and macro-level problems to emerge and provide the basis for effective changes in national policy and practice. Any ‘in-house’ issues which emerge, can be tackled systematically through perpetual measurement of barriers. A registry driven action is most likely to bridge the gap between evidence generation and actual change in practice. The practice change applies to ‘self-care dialysis’ vs ‘fully-assisted dialysis’ care. The nuances of home haemodialysis intensity are still a subject of ongoing research and will need to be modified based on patient-specific circumstances.

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Key Study Statistics

90.2%, 87.4% & 81.5% are the 1, 2 and 5-year technique survival rates respectively, for haemodialysis_{composite (training+ home)}

10% reduction in reported recovery time from haemodialysis with every 200ml increase in residual urine volume

14% increase in reported recovery time from haemodialysis with every 5-unit increase in Beck depression inventory score

1 in 3 (approximately) predialysis patients (36.6%) and hospital haemodialysis (29%) feel able to consider self-cannulation for haemodialysis

10% of predialysis patients have no apparent reason for perceived inability to consider self-cannulation.

15% higher odds of choosing self-care dialysis for every unit increase in illness coherence

20% lower odds of choosing self-care dialysis over hospital HD for every unit reduction in metaconcentration score

1.6-min increase in TMT B score for every unit increase in metaconcentration score

70% lower odds of choosing self-care dialysis over hospital HD if the ethnicity is non-white in an adjusted regression analysis

45% of all respondents in a survey of healthcare practitioners feel that staff knowledge and bias influences the offer of home haemodialysis therapy

*Ethical Approval for BASIC-
HHD study*

*Letter of access for healthcare
provider interviews*

*Topic guide for predialysis
qualitative study*

*Topic guide for healthcare
provider study*

Posters

*List of publications/grant
applications connected to the
programme of work*

*Supplementary material from
published work*

Ethical Approval for the BASIC-HHD study



Health Research Authority

NRES Committee North West - Greater Manchester West

Barlow House
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4 Minshull Street
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M1 3DZ

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26 March 2012

Dr Sandip Mitra
Consultant Nephrologist
Central Manchester Foundation Trust
Department of Nephrology
Manchester Royal Infirmary
Oxford Road
M13 9WL

Dear Dr Mitra

Study title: "Bringing the benefits of home hemodialysis home : Investigating the patient pathways and adoption barriers" A Multicentre, Prospective, Observational study to investigate clinical, patient-related psychosocial and organisational factors that influence the uptake and sustainability of home haemodialysis [BASIC-HHD (Investigating BARriers to Successful Implementation of Care in Home Hemodialysis)]

REC reference: 12/NW/0170

Thank you for your letter of 20 March 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of

A Research Ethics Committee established by the Health Research Authority

the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		01 February 2012
Covering Letter		16 March 2012
GP/Consultant Information Sheets	1	15 February 2012
Interview Schedules/Topic Guides	Topic Guide (Pre Dialysis) - Version 1	15 February 2012
Interview Schedules/Topic Guides	Topic Guide (Dialysis Patients) - Version 1	15 February 2012
Interview Schedules/Topic Guides	Topic Guide Health Care Professionals - Version 1	15 February 2012
Investigator CV	Anuradha Jayanti	
Investigator CV	Sandip Mitra	
Letter from Statistician		03 February 2012
Letter of invitation to participant	Healthcare Provider - Version 1	09 March 2012
Letter of invitation to participant	Patient - Version 2	09 March 2012
Other: Letter from Funder - Baxter Clinical Evidence Council		
Participant Consent Form: Healthcare Provider	1	09 March 2012
Participant Consent Form: Patient	2	09 March 2012
Participant Information Sheet: Healthcare Provider	1	09 March 2012
Participant Information Sheet: Pre-Dialysis	2	09 March 2012
Participant Information Sheet: Home Haemodialysis	2	09 March 2012
Participant Information Sheet: Hospital Haemodialysis	2	09 March 2012
Protocol	1	15 February 2012
Questionnaire: The Modified Mini-Mental State (3MS)	Validated	

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Questionnaire: Attachment Measure Questionnaire Relationship Questionnaire	Validated	
Questionnaire: Autonomy Preference Index	Validated	
Questionnaire: Beck Depression Inventory (BDI-2)	Validated	
Questionnaire: Mood/Depression Assessment Questionnaire	Validated	
Questionnaire: Illness Perception Questionnaire (IPQ-R)	Validated	
Questionnaire: Your Health and Well-Being (SF-36 V2)	Validated	
Questionnaire: STAI-Y	Validated	
Questionnaire: Organizational Description Questionnaire	Validated	
Questionnaire: Questionnaire for Health Care Providers (Practice-Focus)	1	15 February 2012
REC application	3.4	16 February 2012
REC application	3.4	09 March 2012
Response to Request for Further Information		20 March 2012
Summary/Synopsis	1	15 February 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

With the Committee's best wishes for the success of this project

Yours sincerely

pp. A. Totenhofer

Dr Lorraine Lighton
Chair

Email: shehnaz.ishaq@northwest.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Lynne Webster - Manchester Royal Infirmary

Letter of access for healthcare provider interviews

Central Manchester University Hospitals 

NHS Foundation Trust

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Dr Steffan Bayer
Research Fellow
Imperial College Business School
South Kensington Campus
London, SW7 2AZ

Our ref: LOA/1926/LB

Dear Dr Bayer

PIN: R01383

RE: HONORARY RESEARCH CONTRACT NOT REQUIRED

Title of project: Bringing the benefits of home haemodialysis home: investigating the patients pathways and adoption barriers - a multicentre, prospective, observational study to investigate clinical, patient-related, psychosocial and organisational factors that influence the uptake and sustainability of home haemodialysis - BASIC-HHD

This letter confirms your right of access to conduct research through Central Manchester University Hospitals NHS Foundation Trust (CMFT) for the purpose and on the terms and conditions set out below. This right of access commences on 9th August 2012 and ends on 8th August 2013 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as defined above.

The information supplied about your role in this research project at CMFT has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to CMFT premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through CMFT, you will remain accountable to your employer Imperial College London but you are required to follow the reasonable instructions of **Dr Sandip Mitra** in this NHS organisation or those given on his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation

1

by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with CMFT policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with CMFT in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on CMFT premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

CMFT will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours faithfully



Lorraine Broadfoot
Research Operations Manager

Date: 15/10/2012

CC. Dr Sandip Mitra and Dr Anu Jayanti
N.Hussain – Senior HR Administrator

Topic Guides for Patient Interviews (Predialysis)

Research question:

‘What influences patient choice of home haemodialysis over hospital haemodialysis?’

CHOSE HOSPHD

1. Can you tell me about your current health?
2. Can you tell me about your medical history?

FOLLOW-UP: When did your kidney disease start? How old were you?

FOLLOW-UP: How does your condition impact on your life?

3. I understand you are currently in the process of choosing a renal replacement therapy.

FOLLOW-UP: Have you come to a decision of a treatment option? If so, what decision have you come to?

FOLLOW-UP: Can you talk me through the main factors that helped you to arrive at a decision?

PROMPT: Health professionals? Other patients? Family/friends? Internet? Other sources?

FOLLOW-UP: Was anyone else involved in your decision? If so, how were they involved?

4. What does it mean to you to have chosen hospital haemodialysis?

FOLLOW-UP: How do you feel about how hospital haemodialysis will work once you start it?

5. How have you been getting information about the different treatment options?

PROMPT: Health professionals? Other patients? Family/friends? Internet? Other sources?

FOLLOW-UP: What information were you given about the different treatment options?

FOLLOW-UP: How do you feel about the level of information you received?

PROMPT: Adequate/inadequate?

FOLLOW-UP: Is there any more (particular) information that you would like, that would make you feel more prepared?

FOLLOW-UP: If you wanted more information about your kidney condition or the treatment options, would you be able to get it?

6. You may have heard about home haemodialysis. If so, can you tell me what you know about it?

FOLLOW-UP: Has your doctor or nurse or anyone else discussed home haemodialysis with you? What have they told you?

7. What are the advantages of your choice to you as compared to home haemodialysis?

FOLLOW-UP: Do you have any particular concerns about starting hospital haemodialysis?

FOLLOW-UP: How will you go about addressing these concerns?

8. Are you hoping to go on the transplant list?

FOLLOW UP: How did you decide to not/go on it?

9. Is there anything that I haven't asked about that you would like to add?

Topic Guide for Healthcare Practitioner Interviews

- This is a long and inclusive schedule. While it covers the issues we will investigate in our interviews, individual questions will be selected and adapted to the needs of each interview depending on the professional position of the interviewee as well as the national context (this schedule is broadly created for the UK context). Below each category of questions it is indicated for which groups of people this category is relevant.
- Some questions or prompts appear or are repetitive as they may fit under different themes. During the course of an interview, they will not be asked more than once.
- Prompts will be used at a minimum and only when needed for the interview to flow.
- Following the exact sequence of the questions below, even if it makes sense, is not mandatory during interviewing. However, all relevant to the position of the interviewee questions will be a

A. Questions on professional background and personal job

Questions for: everyone.

1. Could you tell me about your specific role in relation to care for end-stage renal disease (ESRD) patients?

- a. How did you come about taking this role?
- b. What is your actual role? Responsibilities?
- c. Day-to-day work operation?
- d. How long have you been in this role?

B. Questions on departmental operation in relation to care of ESRD patients

Questions for: medical staff, administrators, medical directors, dialysis technicians

2. How is renal care organized in this hospital/service?

- a. Organizational structure and leadership/hierarchy?
- b. Internal rules?
- c. External guidelines?

3. What are the main aims and objectives of your department/service?

- a. General (departmental) policies and targets?
- b. Policies and targets relating to modalities of haemodialysis?

C. Questions on decision-making with regard to modality

Questions for: medical staff, medical directors

4. What is the process of decision-making with regard to the dialysis modality for each patient?

- a. What are the factors taken into account?
- b. Who contributes to the decision?
- c. Who is ultimately responsible?
- d. Are all modalities explained to the patient? (incl. home haemodialysis)
- e. Does the patient influence the decision?

D. Questions on home haemodialysis (HHD) in general

Questions for: medical staff, social workers, dieticians

5. Focusing on HD, what is your view on home versus in-centre HD?

Would you recommend one over the other and when/why?

- a. Benefits and drawback of each
- b. Suitability for different groups of patients

6. What are the benefits and drawbacks when comparing HHD versus in-centre HD?

- a. Psychological and physiological (dis)comfort of patient
- b. Environmental factors such as home space or distance to HD centre
- c. Technology and anticipated technological advances
- d. Training of patients and their families.
- e. Health professionals' engagement

- f. Management of any health related risks
- g. Medication
- h. Hospitalisations and re-admissions
- i. Reimbursement and financial burden or benefits to the National Health Service (NHS), your specific department and even the patient

7. Do you think patients' quality of life is better for those performing HD at home or in-centre?

Do you feel patients have a preference of one location over the other?

- a. Experience of patients' feedback?

E. Questions on frequent (including nocturnal) home haemodialysis

Questions for: medical staff, dieticians, social workers (this question will be preceded by a discussion of different types of frequent home hemodialysis)

8. Focusing on HHD, what are your views on conventional, alternate night, short daily and nocturnal HHD, especially in terms of clinical outcomes?

Could you compare them and would you recommend one over the other and when/why?

- a. Benefits and drawback of each

9. What are the benefits and drawbacks of doing frequent HHD?

- a. Time constraints
- b. Psychological and physiological (dis)comfort of patient
- c. Technology and anticipated technological advances
- d. Training of patients and their families.
- e. Management of health related risks
- f. Medication
- g. Hospitalisations and re-admissions
- h. Reimbursement and financial burden or benefits to the National Health Service (NHS), your specific department and even the patient

10. Do you feel patients prefer to do more or less frequent HHD?

- a. Experience of patients' feedback?

F. Questions on modalities of Renal Replacement Therapy (RRT) beyond transplantation

Questions for: medical staff, dieticians, social workers

11. What is your view on peritoneal dialysis (PD) versus home haemodialysis (HHD) in terms of clinical outcomes?

Would you recommend one over the other and when/why?

- a. Benefits and drawback of each modality
- b. Applications on different groups of patients

12. What are benefits and drawbacks when comparing PD with HHD?

- a. Psychological and physiological (dis)comfort of patient
- b. Technology and anticipated technological advances

- c. Training and staff engagement
- d. Medication
- e. Hospitalisations and re-admissions
- f. Reimbursement and financial burden or benefits to the National Health Service (NHS) and your specific department

13. Do you think patients' quality of life is better under either of these two modalities?

Do you feel patients have a preference of one modality over the other?

- a. Experience of patients' feedback?

G. Questions about technology

Questions for: dialysis technicians, nurses and physicians

14. What are the differences, if any, in machines used at home and in-centre?

15. How easy is it for a patient and their family to use the existing technology?

16. How does existing technology affect choice of modality?

17. How would you like technology to improve?

18. Do you anticipate significant technological innovations in the next 5 years or so?

What do you think these will be?

H. Questions on possible improvements in the department

Questions for: everyone

19. What do you think could be improved in the unit, if anything?

- a. Would you like to change the way your department chooses between different modalities?
- b. Some people think there should be more HHD. What is your opinion on this?
- c. Can patients choose the modality they want?

I. Questions on national health system operation

Questions for: everyone (we will adapt detail of question with regard to who we are talking to)

20. How does national policy affect the care of ESRD patients?

- a. National guidelines and regulations?
- b. Incentives and penalties relating to specific practices?

21. How do you think that the payment for the care of ESRD patients under Payment By Results influences these patients' care and your department's operation/performance?

- a. Incentives and penalties? (Best Practice Tariff)
- b. Advantages and disadvantages for the department?
- c. Advantages and disadvantages for the patients?
- d. Future move from PCTs (Primary Care Trusts) to GP (General Practitioner) Commissioning?

22. Does the move to PbR influence patient care and your services?

J. Questions on (response to) changes

Questions for: everyone

23. How have things changed since you started working in renal care?

24. Would you like to see any changes in national policy about ESRD care?

If yes, what are these changes?

- a. NICE guidelines
- b. More support from government

25. What do you envisage will change in renal care practice in the next 5 years?

- a. Due to technology
- b. Due to regulations and guidelines

26. In the health sector things are changing all the time (from policies to technology).

How do you think that your department responds to such change?

- a. Is there interest in change and innovation?
- b. Do you feel equipped to embrace changes?
- c. Do particular groups of professionals respond in a different way to others?
- d. Is there resistance to innovation?

27. How do you picture that your department will operate in 10 years?

K. General concluding questions

Questions for: everyone

28. Is there anything you would like to talk more about?

29. Is there anything we haven't mentioned that you would like to talk about?

Academic output connected to the research subject

<i>Peer reviewed publications</i>	
▪	'The anticipated and the lived experience of home haemodialysis: is there a disconnect?' R. Majeed, A. Jayanti , T. Schultz, P. Brenchley, A. Wearden, S. Mitra. Accepted for publication in British Journal of Health Psychology
▪	'Time to recovery from haemodialysis-location, intensity and beyond' Anuradha Jayanti ; Philip Foden; Julie Morris; Paul Brenchley; Sandip Mitra on behalf of the BASIC-HHD study group Nephrology (Carlton). 2015 Dec 4. doi: 10.1111/nep.12692.
▪	'Healthcare decision-making in end stage renal disease-patient preferences and clinical correlates' Anuradha Jayanti , Markus Neuvonen, Alison Wearden, Julie Morris, Philip Foden, Paul Brenchley, Sandip Mitra on behalf of the BASIC-HHD study group. BMC Nephrology (2015) 16:189 DOI 10.1186/s12882-015-0180-8
▪	'Self-cannulation for haemodialysis: patient attributes, clinical correlates and self-cannulation predilection models' Anuradha Jayanti , Alison Wearden, Julie Morris, Philip Foden, Paul Brenchley, Sandip Mitra PLOS-ONE 10(5):e0125606 doi:10.1371/journal.pone.0125606
▪	'Technique survival in home haemodialysis: a composite success rate and its risk predictors in a prospective longitudinal cohort from a tertiary renal network programme' Anuradha Jayanti , Milind Nikam, Leonard Ebah, Gill Dutton, Julie Morris and Sandip Mitra. Nephrol. Dial. Transplant. (2013) 28 (10): 2612-2620 doi:10.1093/ndt/gft294
▪	'Barriers to successful implementation of care in home haemodialysis (BASIC-HHD): 1. Study design, methods and rationale', Jayanti Anuradha , Wearden J Alison, Morris Julie, Brenchley Paul, Abma Inger, Bayer Steffen, Barlow James, Mitra Sandip. BMC Nephrology, 2013, 14:197. DOI: 10.1186/10.1186/1471-2369-14-197
▪	'Home haemodialysis: beliefs, attitudes and practices' Anuradha Jayanti , Peter Stenvinkel, Sandip Mitra. 11 MAY 2014 DOI: 10.1111/hdi.12176
▪	Inger Abma, Anuradha Jayanti , Steffen Bayer, Sandip Mitra, James Barlow. Perceptions and experiences of financial incentives: a qualitative study of dialysis care in England. <i>BMJ Open</i> 2014; 4 :e004249 doi:10.1136/bmjopen-2013-00424'
<i>Book chapter</i>	
▪	'Progress in home dialysis'(p 67-88) Sandip Mitra and Anuradha Jayanti Renal failure-causes, prevention and treatment, Nova Science Publishers, Publication Year: 2013, ISBN:978-1-62257-824-5
<i>Invited contributions</i>	
▪	Anuradha Jayanti , Sandip Mitra. Clinical Outcomes and quality of life for home haemodialysis patients. Journal of Renal Nursing, Vol 6, No.5, September 2014, 220-225

<ul style="list-style-type: none"> ▪ Anuradha Jayanti, Sandip Mitra. Technique survival in dialysis: incorporating the human dimension. Journal of Renal Nursing, Nov 2013, Vol. 5, Issue 6, 27, 288 – 290
<i>Under review/revision</i>
<ul style="list-style-type: none"> ▪ ‘Illness beliefs in end stage renal disease and associations with self-care modality choice’ Anuradha Jayanti, Philip Foden, Julie Morris, Sandip Mitra, Alison Wearden; PLoS-ONE, 2016 ▪ Social deprivation and socio-demographic influences on home haemodialysis prevalence in the UK. Anuradha Jayanti, Philip Foden, Alasdair Rae, Julie Morris, Paul Brenchley; Sandip Mitra on behalf of the BASIC-HHD study group; Nephron 2016 ▪ Multidisciplinary staff attitudes to home haemodialysis therapy Anuradha Jayanti, Philip Foden, Sandip Mitra. BMJ Open.
<i>Posters and Abstracts</i>
<ul style="list-style-type: none"> ▪ ‘Healthcare decision-making in end stage renal disease-patient preferences and clinical correlates’ Anuradha Jayanti; Markus Neuvonen; Alison Wearden; Julie Morris; Philip Foden, Paul Brenchley, Sandip Mitra on behalf of the BASIC-HHD study group. Poster presentation at the 52nd ERA-EDTA Congress, May 2015 (741-SP) ▪ ‘Time to recovery from haemodialysis-trial by drugs’ Anuradha Jayanti; Julie Morris; Philip Foden, Paul Brenchley, Sandip Mitra on behalf of the BASIC-HHD study group. Poster presentation at the 52nd ERA-EDTA Congress, May 2015 (742-SP) ▪ ‘Time to recovery from haemodialysis- does dialysis location matter?’ Poster presentation at the American Society of Nephrology annual meeting, November 2014: PO903 ▪ ‘Relationship between subjective and objective cognition deficits in patients receiving haemodialysis’. Poster presentation at the American Society of Nephrology annual meeting, November 2014: PO965 ▪ ‘Is self-cannulation the weakest link in the uptake of home haemodialysis?’ A.Jayanti, P.Foden, J.Morris, A.Wearden, S. Mitra, Institute of Cardiovascular Sciences, UoM, May 2014 ▪ Disconnect between the lived and the anticipated experience of home haemodialysis- addressing the perspective gap: Results from a qualitative study. Majeed-Ariss R, Jayanti A, Wearden A and Mitra S, Renal Association, 2014 ▪ Sustaining growth in Home Haemodialysis-role of clinical and human factors Jayanti A, Mitra. S March 2013; BMJ evidence live; University of Oxford ▪ Technique Failure in Home Haemodialysis- A single centre experience.(FP-607) Jayanti A, Nikam M, Ebah L, Morris J, Mitra S ERA-EDTA, Paris, 2012 ▪ Vascular Access in Home Haemodialysis: Trends and Outcomes (FP-575) Nikam M, Jayanti A, Ebah L, Mitra S ERA-EDTA, Paris, 2012

<ul style="list-style-type: none">▪ Breaking barriers in the uptake of HHD: Focus on socio-demographic factors Ebah L, Jayanti A, Nikam M, Summers A, Mitra S BRS Conference, Manchester, May 2012			
Oral Presentations			
<ul style="list-style-type: none">• ‘Patient factors in home haemodialysis uptake’ Manchester Home Dialysis Conference, Manchester, September, 2014			
<ul style="list-style-type: none">• 'Home haemodialysis in the elderly-creative solutions for the future' Euro-PD Conference Maastricht, Netherlands, October 2013			
<ul style="list-style-type: none">• 'Adoption of home haemodialysis: A case study in the interaction of health service design, delivery and patient factors' Primary Care and Health Services Research Group University of Manchester, Manchester, UK, November 2013			
<ul style="list-style-type: none">• 'Technique survival in home haemodialysis-experience from a large, tertiary network programme' British Renal Society Meet, 2012			
<ul style="list-style-type: none">• BASIC-HHD study: a contemporary research design': Pan Manchester Research Forum, Manchester December 2012			
Grant Applications			
Baxter Extramural Grant	196,000 USD	April 2011	Co-author/ Study lead
NIHR CLAHRC Grant Funding	53,000 GBP	June 2012	Author/ Study Lead
Baxter Extramural Grant	199,800 USD	November 2014	Lead Author/Co-I
Technology Innovation for Clinical Application			
Innovation Fund for the SBRI-Kidney Initiative (£103,000 for Phase 1), 2014	Awarded by DoH, to develop an innovative technology based solution that will enable self-cannulation for haemodialysis	<u>Outcome</u> The commercial organisation has faced extreme financial complications, necessitating discontinuation of the prototype development	
Global Forum for Home Hemodialysis			
Invited Faculty	Led a small team to develop an online practical manual for the setting up and running of a home haemodialysis program. May 2015.Chicago, USA. Project led by the International Society of Hemodialysis (http://home-hemodialysis.com) Completed-February 2016		

Appendix S1: Differences in study centres with respect to sociodemographic and clinical variables

Variable (Prevalence category)	A (n=43) (Low Prev.)	B (n=73) (High Prev.)	C (n=61) (Low Prev.)	D (n=65) (Med. Prev.)	E (n=64) (Med. Prev.)	p-value
Group						
In-centre	39 (90.7%)	38 (52.1%)	50 (82.0%)	43 (66.2%)	43 (67.2%)	<0.001 ¹
Home HD	4 (9.3%)	35 (47.9%)	11 (18.0%)	22 (33.8%)	21 (32.8%)	
Age – Mean (SD)	57.84 (15.71)	50.45 (13.32)	55.72 (12.63)	55.49 (13.68)	56.53 (14.59)	0.033 ²
Ethnicity – Non-white	3/42 (7.1%)	17 (23.3%)	3 (4.9%)	11 (16.9%)	3 (4.7%)	0.002 ²
Gender – Female	17 (39.5%)	24 (32.9%)	23 (37.7%)	16 (24.6%)	18 (28.1%)	0.39 ¹
Education						
Post-high school	12/42 (28.6%)	33/69 (47.8%)	1/54 (1.9%)	13/64 (20.3%)	18 (28.1%)	<0.001 ¹
Employment						
Retired	22 (51.2%)	26 (36.6%)	19 (31.1%)	26 (40.6%)	35 (54.7%)	<0.001 ¹
Unemployed	14 (32.6%)	25 (35.2%)	13 (21.3%)	28 (43.8%)	17 (26.6%)	
Salaried/self-employed	7 (16.3%)	20 (28.2%)	29 (47.5%)	10 (15.6%)	12 (18.8%)	
IMD rank						
Median (IQR)	18253 (7612-25548)	11062 (3233-23682)	19228 (9379-25517)	10630 (4161-18346)	11344 (5397-22670)	0.004 ³
IMD – quintile						
1 (least deprived)	9 (20.9%)	14 (19.2%)	13 (21.3%)	6 (9.2%)	11 (17.2%)	0.057 ¹
2	12 (27.9%)	9 (12.3%)	17 (27.9%)	7 (10.8%)	9 (14.1%)	
3	6 (14.0%)	10 (13.7%)	14 (23.0%)	14 (21.5%)	10 (15.6%)	
4	8 (18.6%)	14 (19.2%)	8 (13.1%)	16 (24.6%)	14 (21.9%)	
5 (most deprived)	8 (18.6%)	26 (35.6%)	9 (14.8%)	22 (33.8%)	20 (31.3%)	
CCI						
Median (IQR)	5.0 (3.0-6.0)	4.0 (3.0-5.0)	4.0 (2.0-5.3)	4.0 (3.0-6.0)	4.0 (3.0-6.0)	0.49 ³
Training centre dist. Median (IQR)	4.2 (3.6-13.4)	9.6 (6.4-13.1)	15.1 (7.5-26.0)	12.3 (7.6-15.6)	7.0 (4.9-15.1)	<0.001 ³
Partner employment						
Retired	12 (63.2%)	14 (29.8%)	15 (45.5%)	17 (51.5%)	21 (56.8%)	0.19 ¹
Unemployed	1 (5.3%)	10 (21.3%)	3 (9.1%)	4 (12.1%)	5 (13.5%)	
Salaried/self-employed	6 (31.6%)	23 (48.9%)	15 (45.5%)	12 (36.4%)	11 (29.7%)	
BMI						
Median (IQR)	24.9 (21.7-32.3)	26.1 (24.1-30.4)	26.8 (22.2-33.2)	26.6 (22.7-30.9)	27.0 (24.5-32.3)	0.72 ³
Accommodation						
Home owner		n=72	n=58			0.005 ¹
Living with parents	29 (67.4%)	42 (58.3%)	50 (86.2%)	36 (55.4%)	33 (51.6%)	
Rental/friend/Res. home	4 (9.3%) 10 (23.3%)	8 (11.1%) 22 (30.6%)	0 (0%) 8 (13.8%)	6 (9.2%) 23 (35.4%)	5 (7.8%) 26 (40.6%)	
Marital status						
Married or partner	22 (51.2%)	48 (65.8%)	40 (65.6%)	34 (52.3%)	37 (57.8%)	0.31 ^{1*}
Single	14 (32.6%)	17 (23.3%)	13 (21.3%)	17 (26.2%)	12 (18.8%)	
Divorced or separated	3 (7.0%)	4 (5.5%)	6 (9.8%)	9 (13.8%)	10 (15.6%)	
Widowed	4 (9.3%)	4 (5.5%)	2 (3.3%)	5 (7.7%)	5 (7.8%)	
Childcare						0.027 ¹

>18 yrs; independent <18 / >18yrs(dependent) No children	26 (61.9%) 4 (9.5%) 12 (28.6%)	28 (39.4%) 14 (19.7%) 29 (40.8%)	21 (38.2%) 6 (10.9%) 28 (50.9%)	30 (52.6%) 12 (21.1%) 15 (26.3%)	36 (58.1%) 11 (17.7%) 15 (24.2%)	
Smoking status Never smoked Ex-smoker Current	40 (93.0%) 1 (2.3%) 2 (4.7%)	43 (59.7%) 18 (25.0%) 11 (15.3%)	33 (57.9%) 19 (33.3%) 5 (8.8%)	28 (43.8%) 26 (40.6%) 10 (15.6%)	31 (48.4%) 21 (32.8%) 12 (18.8%)	<0.001 ¹
Mobility Independent Walking Aid/Limited Wheelchair Bound	34 (79.1%) 7 (16.3%) 2 (4.7%)	65 (89.0%) 5 (6.8%) 3 (4.1%)	51 (83.6%) 6 (9.8%) 4 (6.6%)	47 (72.3%) 13 (20.0%) 5 (7.7%)	42 (65.6%) 16 (25.0%) 6 (9.4%)	0.010 ^{1**}
Cause of ESRD Hypertension Diabetic Nephropathy Glomerulonephritis Polycystic Kidneys Renovascular Disease Chronic Pyelonephritis Others Unknown	7 (16.7%) 8 (19.0%) 4 (9.5%) 9 (21.4%) 1 (2.4%) 4 (9.5%) 2 (4.8%) 7 (16.7%)	6 (8.2%) 12 (16.4%) 12 (16.4%) 14 (19.2%) 0 (0%) 6 (8.2%) 19 (26.0%) 4 (5.5%)	5 (8.2%) 17 (27.9%) 17 (27.9%) 4 (6.6%) 1 (1.6%) 1 (1.6%) 9 (14.8%) 7 (11.5%)	6 (9.2%) 9 (13.8%) 4 (6.2%) 6 (9.2%) 2 (3.1%) 7 (10.8%) 13 (20.0%) 18 (27.7%)	0 (0%) 11 (17.2%) 12 (18.8%) 9 (14.1%) 5 (7.8%) 3 (4.7%) 12 (18.8%) 12 (18.8%)	<0.001 ¹
HD vintage (in years) Median (IQR)	2.28 (0.96-4.03)	2.35 (0.97-5.10)	1.62 (0.52-4.58)	1.62 (0.84-4.45)	3.43 (1.94-5.69)	0.025 ³
Previous PD	10 (23.3%)	24 (32.9%)	17 (27.9%)	15 (23.1%)	26 (40.6%)	0.18 ¹
Previous Transplant	9/42 (21.4%)	19 (26.0%)	23 (37.7%)	14 (21.5%)	19 (29.7%)	0.25 ¹
Vision Blind or poor vision	11/42 (26.2%)	6 (8.2%)	11 (18.0%)	10/64 (15.6%)	9/63 (14.3%)	0.14 ¹
Diabetes	11/42 (26.2%)	18 (24.7%)	16 (26.2%)	18/63 (28.6%)	14 (21.9%)	0.94 ¹
Heart failure	2 (4.7%)	5 (6.8%)	0 (0%)	3 (4.6%)	4 (6.3%)	N/A***
Solid organ malignancy	4 (9.3%)	10 (13.7%)	3 (4.9%)	11 (16.9%)	7 (10.9%)	0.28 ¹
Intra cranial events (stroke, TIA or bleed)	7 (16.3%)	6 (8.2%)	2 (3.3%)	10 (15.4%)	3 (4.7%)	0.044 ¹
Caregiver – alone	14/42 (33.3%)	16 (21.9%)	17/56 (30.4%)	10/60 (16.7%)	23 (35.9%)	0.093 ¹

¹Chi-squared test ²One-way ANOVA ³Kruskal-Wallis test

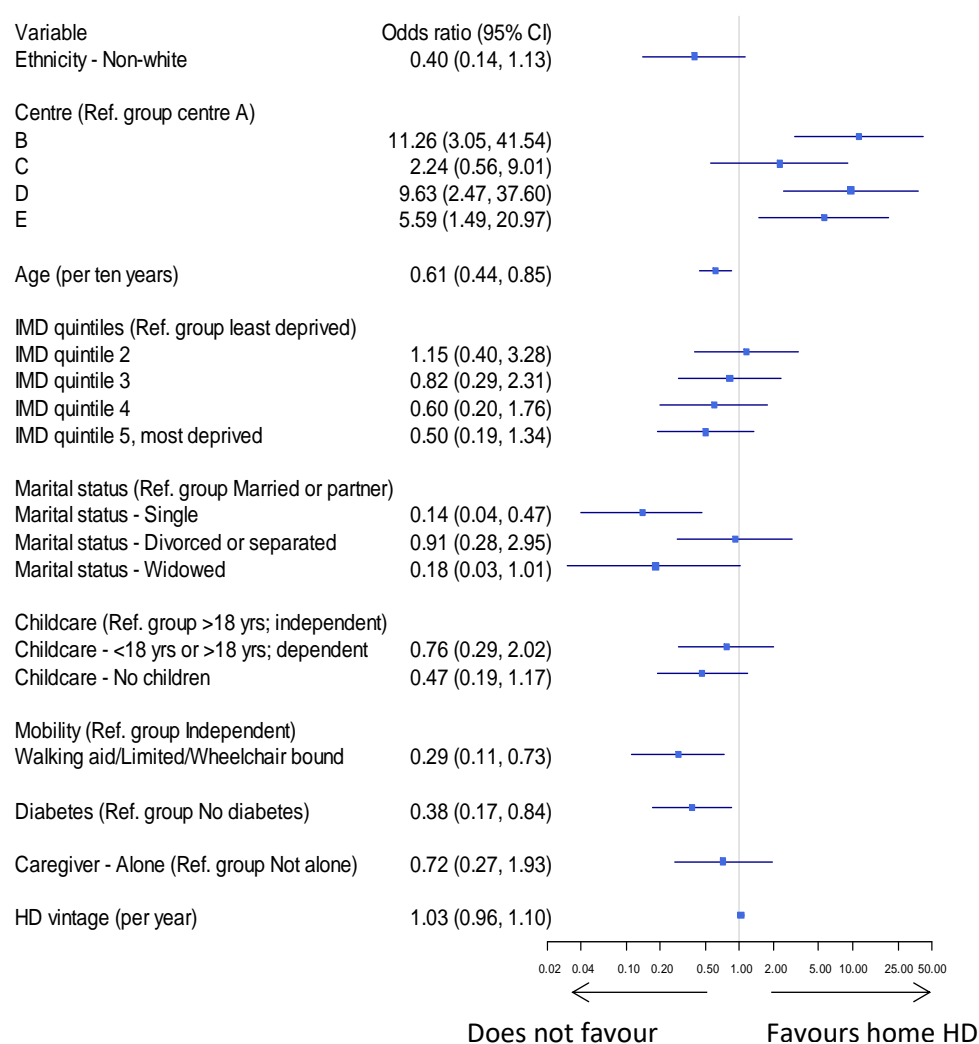
*As married or partner vs other three groups due to small expected frequencies

**As independent vs other two groups due to small expected frequencies

***Too few numbers to assess formally (p>0.05 from chi-squared test where assumptions about expected frequencies are broken)

Appendix S2: Confounder adjusted multivariable analysis: sensitivity analysis.

(Education/Employment/Accommodation/Training centre distance excluded as variables associated with IMD)



Appendix S3: Area social deprivation index distribution by centre and home locations of haemodialysis recipients

			Centre-based HD					Total (n=213)
			A (n=39)	B (n=38)	C (n=50)	D (n=43)	E (n=43)	
IMD Rank		Mean	17618	10970	17413	10035	12548	p<0.001
		Median	20195	8100	18918	9321	9204	
Quintile	Quintile 1 (least deprived)	Count	9	4	9	2	7	31
		% within Centre	23.1%	10.5%	18.0%	4.7%	16.3%	14.6%
	Quintile 2	Count	12	3	14	3	5	37
		% within Centre	30.8%	7.9%	28.0%	7.0%	11.6%	17.4%
	Quintile 3	Count	4	6	12	9	5	36
		% within Centre	10.3%	15.8%	24.0%	20.9%	11.6%	16.9%
	Quintile 4	Count	6	9	8	11	11	45
		% within Centre	15.4%	23.7%	16.0%	25.6%	25.6%	21.1%
	Quintile 5 (most deprived)	Count	8	16	7	18	15	64
		% within Centre	20.5%	42.1%	14.0%	41.9%	34.9%	30.0%
			Home-based HD					Total (n=93)
			A (n=4)	B (n=35)	C (n=11)	D (n=22)	E (n=21)	
IMD Rank		Mean	11433	16686	20565	16267	16188	p=0.61
		Median	10483	17628	20636	16120	15960	
Quintile	Quintile 1 (least deprived)	Count	0	10	4	4	4	22
		% within Centre	0.0%	28.6%	36.4%	18.2%	19.0%	23.7%
	Quintile 2	Count	0	6	3	4	4	17
		% within Centre	0.0%	17.1%	27.3%	18.2%	19.0%	18.3%
	Quintile 3	Count	2	4	2	5	5	18
		% within Centre	50.0%	11.4%	18.2%	22.7%	23.8%	19.4%
	Quintile 4	Count	2	5	0	5	3	15
		% within Centre	50.0%	14.3%	0.0%	22.7%	14.3%	16.1%
	Quintile 5 (most deprived)	Count	0	10	2	4	5	21
		% within Centre	0.0%	28.6%	18.2%	18.2%	23.8%	22.6%

Centres A & C: Low prevalence/Centre B: High Prevalence/Centres D & E: Medium Prevalence

Appendix S4: Differences in characteristics between PD and home HD choice makers in the predialysis cohort

Variable	PD (n=78)	Home (n=36)	P-value
Centre			
A	11 (14.1%)	3 (8.3%)	<0.001 ¹
B	15 (19.2%)	23 (63.9%)	
C	24 (30.8%)	1 (2.8%)	
D	8 (10.3%)	8 (22.2%)	
E	20 (25.6%)	1 (2.8%)	
Age – Mean (std. dev.)	58.35 (12.94)	53.56 (13.02)	0.069 ²
Education – Post-high school	20/76 (26.3%)	12/35 (34.3%)	0.39 ¹
Employment			
Retired	36 (46.2%)	12 (33.3%)	0.43 ¹
Unemployed	13 (16.7%)	7 (19.4%)	
Salaried/self-employed	29 (37.2%)	17 (47.2%)	
IMD – quintile			
1 (least deprived)	24 (30.8%)	4 (11.1%)	0.064 ¹
2	13 (16.7%)	4 (11.1%)	
3	10 (12.8%)	7 (19.4%)	
4	12 (15.4%)	12 (33.3%)	
5 (most deprived)	19 (24.4%)	9 (25.0%)	
Training centre distance – Median (IQR)	13.1 (4.9-19.2)	12.3 (8.9-15.4)	0.97 ³
Accommodation – Home owner	60/77 (77.9%)	29 (80.6%)	0.75 ¹
Childcare	n=75		
>18 yrs; independent	43 (57.3%)	15 (41.7%)	0.029 ¹
<18 yrs or >18yrs; dependent	12 (16.0%)	14 (38.9%)	
No children	20 (26.7%)	7 (19.4%)	
Mobility –			
Walking Aid/Limited/Wheelchair Bound	13 (16.7%)	3 (8.3%)	0.23 ¹
Caregiver – alone	21/76 (27.6%)	8 (22.2%)	0.54 ¹
CCI – Median (IQR)	4.0 (3.0-6.0)	4.0 (3.0-5.0)	0.38 ³
Ethnicity – non-white	3 (3.8%)	5 (13.9%)	0.11 ¹

¹Pearson's chi-squared test

²t-test

³Mann-Whitney U test

Autonomy Preference Index questionnaire

AUTONOMY PREFERENCE INDEX

Decision-making sub-scale

A. General Items for decision making preference:

1. The important medical decisions should be made by your doctor, not by you
2. You should go along with your doctor's advice even if you disagree with it
3. When hospitalized, you should not be making decisions about your own care
4. You should feel free to make decisions about everyday medical problems
5. If you were sick, as your illness became worse you would want your doctor to take greater control
6. You should decide how frequently you need a check-up

B. Vignettes: Patients respond to each item on a five-point scale. Response choices are: 'you alone', 'mostly you', 'the doctor and you', 'mostly the doctor' and 'the doctor alone'.

Upper Respiratory Tract Infection: Suppose you developed a sore throat, stuffy nose and cough that lasted for 3 days. You are about to call the doctor on the telephone. Who should make the following decisions?

7. Whether you should be seen by the doctor.
8. Whether a CXR should be taken
9. Whether you should try taking a cough syrup

High Blood Pressure: Suppose you went to your doctor for a routine physical evaluation and he or she found that everything was all right except for your blood pressure (170/100). Who should take the following decisions?

10. When the next visit to check your blood pressure should be.
11. Whether you should take some time off work and relax.
12. Whether you should be treated with medication or diet.

Myocardial Infarction (Heart attack): Suppose you had an attack of severe chest pain, lasted for almost an hour, frightening you, so that you went to the emergency room. In the emergency room, the doctors discover that you are having a heart attack. Your own doctor is called and you are taken to the intensive care unit. Who should be making the following decisions?

13. How often the nurses should wake you up for your temperature and blood pressure?
14. Whether you may have visitors from your immediate family.
15. Whether a cardiologist should be consulted.

Information-seeking sub-scale

7. As you become sicker you should be told more and more about your illness
8. You should understand completely what is happening inside your body as a result of your illness
9. Even if the news is bad, you should be well informed
10. Your doctor should explain the purpose of your laboratory tests
11. You should be given information only when you ask for it
12. It is important for you to know all the side effects of your medication
13. Information about your illness is as important to you as treatment
14. When there is more than one method to treat a problem, you should be told about each one.

SUPPLEMENTARY MATERIAL Missing data analysis

Variable	Not missing (n=458)	Missing (n=77)	p-value
Cohort			0.11 ²
Predialysis	182 (39.7%)	40 (51.9%)	
In-centre HD	186 (40.6%)	27 (35.1%)	
Home HD	90 (19.7%)	10 (13.0%)	
Age			0.075 ¹
Mean (std. dev.)	57.04 (13.90)	54.01 (12.97)	
Gender – male	296 (64.6%)	49 (63.6%)	0.87 ²
Education – post-high school	111/442 (25.1%)	22/74 (29.7%)	0.40 ²
Employment			0.11 ²
Retired	213/455 (46.8%)	25 (32.5%)	
Unemployed	115/455 (25.3%)	27 (35.1%)	
Self-employed	35/455 (7.7%)	6 (7.8%)	
Salaried	92/455 (20.2%)	19 (24.7%)	
Ethnicity – non-white	46/457 (10.1%)	15 (19.5%)	0.016 ²
BMI (kg/m ²)	n=455		0.51 ³
Median (IQR)	27.18 (23.85-31.97)	27.73 (24.33-32.64)	
Smoking status			0.55 ³
Never smoked	257/453 (56.7%)	44/75 (58.7%)	
Ex-smoker	133/453 (29.4%)	18/75 (24.0%)	
Current	63/453 (13.9%)	13/75 (17.3%)	
Marital status			0.74 ²
Married or partner	280 (61.1%)	43 (55.8%)	
Single	103 (22.5%)	21 (27.3%)	
Divorced/separated	40 (8.7%)	8 (10.4%)	
Widowed	35 (7.6%)	5 (6.5%)	
Diabetes – yes	123/455 (27.0%)	28/76 (36.8%)	0.079 ²
CCI	n=443	n=75	0.55 ³
Median (IQR)	4 (3-6)	4 (3-6)	
BDI		n=22	0.70 ³
Median (IQR)	10.0 (5.0-19.0)	12.0 (0.0-18.3)	
TMT A	n=427	n=68	0.11 ³
Median (IQR)	45.0 (33.0-60.0)	39.5 (29.0-57.0)	
TMT B	n=338	n=55	0.65 ³
Median (IQR)	90.0 (69.0-122.3)	87.0 (67.0-120.0)	

¹t-test

²Pearson chi-squared test

³Mann-Whitney U test

The only statistically significant difference between those who were missing both the API decision making and API information seeking scores and those who were not missing both is in ethnicity. Non-white patients were more likely not to complete both API scores than white patients. Ethnicity was associated with decision making in the final multivariable analysis for the decision making variable. Therefore, there is a chance that the point estimate may change slightly, depending on whether the non-white patients who responded had different scores to those who did not respond. However, with the relatively small amount of missing data and only 15 non-white patients not having either score, any change would be small. There was no relationship in the single variable analysis between ethnicity and information seeking so unless the missing non-white patients differed greatly to the non-white patients who responded, it is likely the lack of association would remain.

SUPPLEMENTARY MATERIAL

TABLE: Item statistics for both subscales

INFORMATION-SEEKING SUBSCALE (N=452)		
(CRONBACH'S ALPHA 0.774)		
	Mean	Std. Deviation
I7	3.04	.831
I8	3.21	.762
I9	3.41	.602
I10	3.34	.545
I11	2.86	1.001
I12	3.34	.638
I13	3.27	.692
I14	3.46	.529
DECISION-MAKING SUBSCALE (N=451)		
(CRONBACH'S ALPHA 0.714)		
	Mean	Std. Deviation
D1	1.98	1.264
D2	2.13	1.170
D3	2.32	1.189
D4	2.60	1.001
D5	1.27	.942
D6	1.82	1.074

SUPPLEMENTARY MATERIAL:

Sensitivity Analyses with different API-DM score cut-offs

Patient subgroups

Cluster	Cluster size (N=451)	Decision Making percentage Mean (standard deviation) Median (IQR and range)	Information Seeking percentage Mean (standard deviation) Median (IQR and range)
1 DM≤25	35 (7.8%)	18.21 (7.77) 20.83 (16.67-25.00, 0-25)	82.86 (11.65) 84.38 (75.00-90.63, 50.00-100)
2 25<DM<75	368 (81.6%)	49.41 (11.89) 50.00 (41.67-58.33, 29.17-70.83)	n=362 79.74 (10.67) 75.00 (71.88-87.50, 43.75-100)
3 DM≥75	48 (10.6%)	82.64 (7.75) 79.17 (75.00-87.50, 75.00-100)	90.76 (9.78) 93.75 (84.38-100, 62.50-100)

Patient subgroup characteristics

Variable	1 (n=35)	3 (n=48)	p-value
Cohort			0.001 ²
Predialysis	19 (54.3%)	9 (18.8%)	Predialysis 1>3 <0.05 ³
Hospital	14 (40.0%)	23 (47.9%)	
Home	2 (5.7%)	16 (33.3%)	Home 1<3 <0.05 ³
Age Median (IQR)	67.0 (56.0-72.0)	52.0 (40.0-63.0)	<0.001 ¹
Employment			0.001 ⁴
Retired	26 (74.3%)	16 (33.3%)	Retired 1>3 <0.05 ³
Unemployed	3 (8.6%)	19 (39.6%)	
Self-employed	1 (2.9%)	2 (4.2%)	
Salaried	5 (14.3%)	11 (22.9%)	Unemployed 1<3 <0.05 ³
Marital Status			0.16 ⁴
Married or partner	20 (57.1%)	30 (62.5%)	
Single	6 (17.1%)	12 (25.0%)	
Divorced or sep	2 (5.7%)	4 (8.3%)	
Widowed	7 (20.0%)	2 (4.2%)	
CCI Median (IQR)	n=34 5.0 (4.0-7.0)	n=45 4.0 (2.5-5.0)	0.001 ¹
TMT A	n=34	n=47	0.038 ¹

Variable	1 (n=35)	3 (n=48)	p-value
Median (IQR)	51.5 (35.3-64.8)	38.0 (32.0-50.0)	
TMT B	n=25	n=41	
Median (IQR)	120.0 (82.0-148.5)	74.0 (59.5-142.0)	0.11 ¹
API IS (percentage)			
Median (IQR)	84.38 (75.00-90.63)	93.75 (84.38-100)	0.001 ¹

¹Mann-Whitney U test ²Pearson chi-squared test

³z-test comparing category proportions between groups with Bonferroni adjustment for multiple testing

⁴Fisher's exact test

Patient subgroups

Cluster	Cluster size (N=451)	Decision Making percentage Mean (standard deviation) Median (IQR and range)	Information Seeking percentage Mean (standard deviation) Median (IQR and range)
1 DM≤35	92 (20.4%)	26.59 (8.28) 29.17 (25.00-33.33, 0-33.33)	n=91 82.04 (10.44) 81.25 (75.00-90.63, 50.00-100)
2 35<DM<65	258 (57.2%)	49.48 (7.67) 50.00 (41.67-54.17, 37.50-62.50)	n=254 78.70 (10.83) 75.00 (71.88-87.50, 43.75-100)
3 DM≥65	101 (22.4%)	75.00 (9.15) 70.83 (66.67-79.17, 66.67-100)	n=100 86.66 (10.72) 87.50 (78.13-96.88, 62.50-100)

Patient subgroup characteristics

Variable	1 (n=92)	3 (n=101)	p-value
<u>Cohort</u>			<0.001 ²
Predialysis	48 (52.2%)	25 (24.8%)	Predialysis
Hospital	32 (34.8%)	45 (44.6%)	1>3 <0.05 ³
Home	12 (13.0%)	31 (30.7%)	Home
			1<3 <0.05 ³
Age			
Median (IQR)	66.0 (56.0-71.8)	52.0 (44.0-59.5)	<0.001 ¹
<u>Employment</u>	n=91		<0.001 ²
Retired	61 (67.0%)	32 (31.7%)	Retired
Unemployed	9 (9.9%)	38 (37.6%)	1>3 <0.05 ³
Self-employed	7 (7.7%)	10 (9.9%)	Unemployed
Salaried	14 (15.4%)	21 (20.8%)	1<3 <0.05 ³
<u>Marital Status</u>			0.027 ²
Married or partner	53 (57.6%)	65 (64.4%)	Widowed

Variable	1 (n=92)	3 (n=101)	p-value
Single	17 (18.5%)	24 (23.8%)	1>3 <0.05 ³
Divorced or sep	8 (8.7%)	9 (8.9%)	
Widowed	14 (15.2%)	3 (3.0%)	
CCI	n=91	n=95	<0.001 ¹
Median (IQR)	5.0 (4.0-7.0)	4.0 (3.0-5.0)	
TMT A	n=86	n=95	0.005 ¹
Median (IQR)	49.5 (37.5-63.3)	39.0 (32.0-53.0)	
TMT B	n=66	n=80	0.018 ¹
Median (IQR)	103.0 (73.4-134.8)	78.5 (61.3-117.0)	
API IS (percentage)	n=91	n=100	0.003 ¹
Median (IQR)	81.25 (75.00-90.63)	87.50 (78.13-96.88)	

¹Mann-Whitney U test ²Pearson chi-squared test ³z-test comparing category proportions between groups with Bonferroni adjustment for multiple testing

Supplementary material (Chapter 3.6)

SUPPLEMENTARY FILE 1: Model Equation for predicting self-cannulation preference in predialysis patients

Group A Model: MODEL 1

$$\ln(p/(1-p)) = 3.60 - 0.03*Age - 0.87*Fearful - 1.09*Realise - 2.01*A - 1.96*B - 1.82*C - 1.24*D - 0.88*E - 2.36*F$$

where p is the probability of saying yes to the self-cannulation question.

The variables in the above model can be understood as follows:

Age is the patient's age

There are three categories for SCQ1 (routine phlebotomy question): do not mind, fearful and realise it is important.

Use Fearful = 1 if patient answers the needle insertion for blood test question with fearful, Fearful = 0 otherwise

Use Realise = 1 if patient answers the needle insertion for blood test question with they realise it is important for their well-being, Realise = 0 otherwise

The patient should have answered the needle insertion for blood test question - they do not mind if they are not in one of the other categories. In this case, Fearful = 0 and Realise = 0

SCQ3 (Aspect of Needling that Bothers you most question) has 7 categories:

0: No apparent reason

A: Concerns about procedural complications

B: Fear or apprehension of procedure

C: Pain

D: Technical skills related concerns

E: All of the above

F: Others

If the 0 category is the answer, A-F are all 0 in the model above.

If any of the A-F categories are chosen, substitute 1 for the letter of the patient's answer in the equation above and substitute 0 for all the other letters.

SUPPLEMENTARY FILE 2: Model Equation for predicting self-cannulation preference in haemodialysis patients

MODEL 2- Groups B+C

$$\ln(p/(1-p)) = 4.83 - 0.04*Age + 1.20*Education - 2.75*Fearful - 0.65*Realise - 0.71*A - 3.97*B - 1.69*C - 1.54*D + 0.05*E - 2.38*F - 0.53*3MS \text{ category} - 1.47*Low \text{ Albumin} - 0.47*Child - 1.73*Parent + 0.16*FRSC - 0.95*Alone$$

where p is the probability of saying yes to the self-cannulation question.

The variables in the above model can be understood as follows:

Age is the patient's age

Use Education = 1 if patient has done post high school education, Education = 0 otherwise

There are three categories for SCQ1 (Needle Question): do not mind, fearful and realise it is important.

Use Fearful = 1 if patient answers the needle insertion for blood test question with fearful, Fearful = 0 otherwise

Use Realise = 1 if patient answers the needle insertion for blood test question with they realise it is important for their well-being, Realise = 0 otherwise

The patient should have answered the needle insertion for blood test question with they do not mind if they are not in one of the other categories. In this case, Fearful = 0 and Realise = 0

SCQ3 (Aspect of Needling that Bothers you most question) has 7 categories:

0: No apparent reason

A: Concerns about procedural complications

B: Fear or apprehension of procedure

C: Pain

D: Technical skills related concerns

E: All of the above

F: Others

If the 0 category is the answer, A-F are all 0 in the model above.

If any of the A-F categories are chosen, substitute 1 for the letter of the patient's answer in the equation above and substitute 0 for all the other letters.

3MS category is a number between 1 and 5 that corresponds to the 3MS scores as follows:

1: 94-100

2: 86-93

3: 81-85

4: 76-80

5: ≤ 75

Use Albumin = 1 if the patient has an albumin level less than 30, Albumin = 0 otherwise

There are five categories for Informal Care Giver: spouse or partner, child, parent, alone and a combined category of friend, relative, sibling or carer.

Use Child = 1 if patient's informal care giver is their child, Child = 0 otherwise

Use Parent = 1 if patient's informal care giver is their parent, Parent = 0 otherwise

Use FRSC = 1 if patient's informal care giver is a friend, relative, sibling or carer, FRSC = 0 otherwise

Use Alone = 1 if patient does not have an informal care giver, Alone = 0 otherwise

The patient's informal care giver should be their spouse or partner if they are not in one of the other categories. In this case, Child = Parent = FRSC = Alone = 0

Supplementary Material (Chapter 3.7)
Illness Perception Questionnaire – Revised

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name.....

Date.....

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom since my illness			This symptom is related to my illness	
	Yes	No		Yes	No
Pain	Yes	No		Yes	No
Sore Throat	Yes	No		Yes	No
Nausea	Yes	No		Yes	No
Breathlessness	Yes	No		Yes	No
Weight Loss	Yes	No		Yes	No
Fatigue	Yes	No		Yes	No
Stiff Joints	Yes	No		Yes	No
Sore Eyes	Yes	No		Yes	No
Wheeziness	Yes	No		Yes	No
Headaches	Yes	No		Yes	No
Upset Stomach	Yes	No		Yes	No
Sleep Difficulties	Yes	No		Yes	No
Dizziness	Yes	No		Yes	No
Loss of Strength	Yes	No		Yes	No

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1					
My illness will last a short time					
IP2					
My illness is likely to be permanent rather than temporary					
IP3					
My illness will last for a long time					
IP4					
This illness will pass quickly					
IP5					
I expect to have this illness for the rest of my life					
IP6					
My illness is a serious condition					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no affect on the outcome of my illness					
IP18	My illness will improve in time					
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. _____
2. _____
3. _____

TOOLS USED TO ASSESS COGNITION

MODIFIED MINI-MENTAL STATE EXAMINATION

1. DATE AND PLACE OF BIRTH

DATE: YR.....MONTH.....DAY.....
PLACE: TOWN.....STATE.....

2. REGISTRATION No. of presentations_____

#NO.

#1: SHIRT.....BROWN.....HONESTY.....

#2: SHOES.....BLUE.....MODESTY.....

#3: SOCKS.....BLACK.....CHARITY.....

3. MENTAL REVERSAL

1 TO 5 (Can ___ Can't ___ do)

If he can, count backwards from 5 to 1

Accurate	2
1 or 2 errors/misses	1
More than 2 errors/misses	0

DLROW (Can ___ Can't ___ do forward (W-O-R-L-D))

0 1 2 3 4 5

4. FIRST RECALL OF THREE WORDS

Spontaneous recall	3
After "Something to wear"	2
After "SHOES, SHIRT, SOCKS"	1
Still incorrect	0
Spontaneous recall	3
After "A colour"	2
After "BLUE, BLACK, BROWN"	1
Still incorrect	0
Spontaneous recall	3
After "A good personal quality"	2
After "HONESTY, CHARITY, MODESTY"	1
Still incorrect	0

5. TEMPORAL ORIENTATION

YEAR	Accurate	8
	Missed by 1 year	4
	Missed by 2-5 years	2
	Missed by > 5 years	0
MONTH	Accurate or within 5 days	2
	Missed by 6 days to 1 month	1
	Missed by > 1 month	0
DATE	Accurate	3
	Missed 1-2 days	2
	Missed 3-5 days	1
	Missed > 5 days	0
DAY	Accurate	1
	Inaccurate	0
SEASON	Accurate or within 1 month	1
	Missed by > 1 month	0

6. SPATIAL ORIENTATION

STATE	0	2
COUNTY	0	1
CITY	0	1
STORE/HOSP/HOME	0	1

7. NAMING

Forehead ____ Chin ____ Shoulder ____
Elbow ____ Knuckle ____

8. FOUR-LEGGED ANIMALS

1 point for each animal. Discontinue after 30 seconds or after 10 correct responses, whichever occurs first

9. SIMILARITIES

ARM-LEG	Body part, Limb, Extremities	2
	Long, bend, muscles, bones, etc.	1
	Incorrect; DK; tells difference	0
LAUGHING-CRYING	Expressions of feelings/emotions	2
	Other correct answer	1
	Incorrect; DK; tells difference	0
EATING-SLEEPING	Necessary bodily functions	2
	Other correct answer	1
	Incorrect; DK; tells difference	0

10. REPETITION

'HE WOULD LIKE TO GO HOME'	2
One or 2 missed or wrong words	1
More than 2 missed or wrong words	0

11. THREE STAGE COMMAND

____ TAKE THIS PAPER WITH YOUR L (R) HAND,
____ FOLD IT IN HALF, AND
____ HAND IT BACK TO ME

One point for each part of the command

First part: Score 0 if the subject uses the preferred hand

Second part: Score 0 if the subject folds the paper more than once

Third part: Score 0 if the subject simply puts the paper down instead of handing it back to the examiner

Scoring for 'Read and Obey'

Closes the eyes without prompting	3
Closes the eyes after prompting	2
Reads aloud the command, either spontaneously or after prompting, but does not close the eyes	1
Neither reads correctly, nor closes the eyes	0

Scoring for the writing test

1 for each word except the first one, provided there is no spelling error.

0 for inappropriate use of upper case.

Can write all of it in uppercase.

12. WRITING

I would like you write 'HE WOULD LIKE TO GO HOME'



13.

READ AND OBEY

'CLOSE YOUR EYES'

14. COPYING INTERSECTING PENTAGONS



	EACH PENTAGON	
5 approx. equal sides	4	4
5 but un-equal (>2:1) sides	3	3
Other enclosed figure	2	2
2 or more lines	1	1
Less than 2 lines	0	0

	INTERSECTION
4-cornered enclosure	2
Not 4-cornered enclosure	1
No enclosure	0

15. SECOND RECALL OF THE THREE WORDS

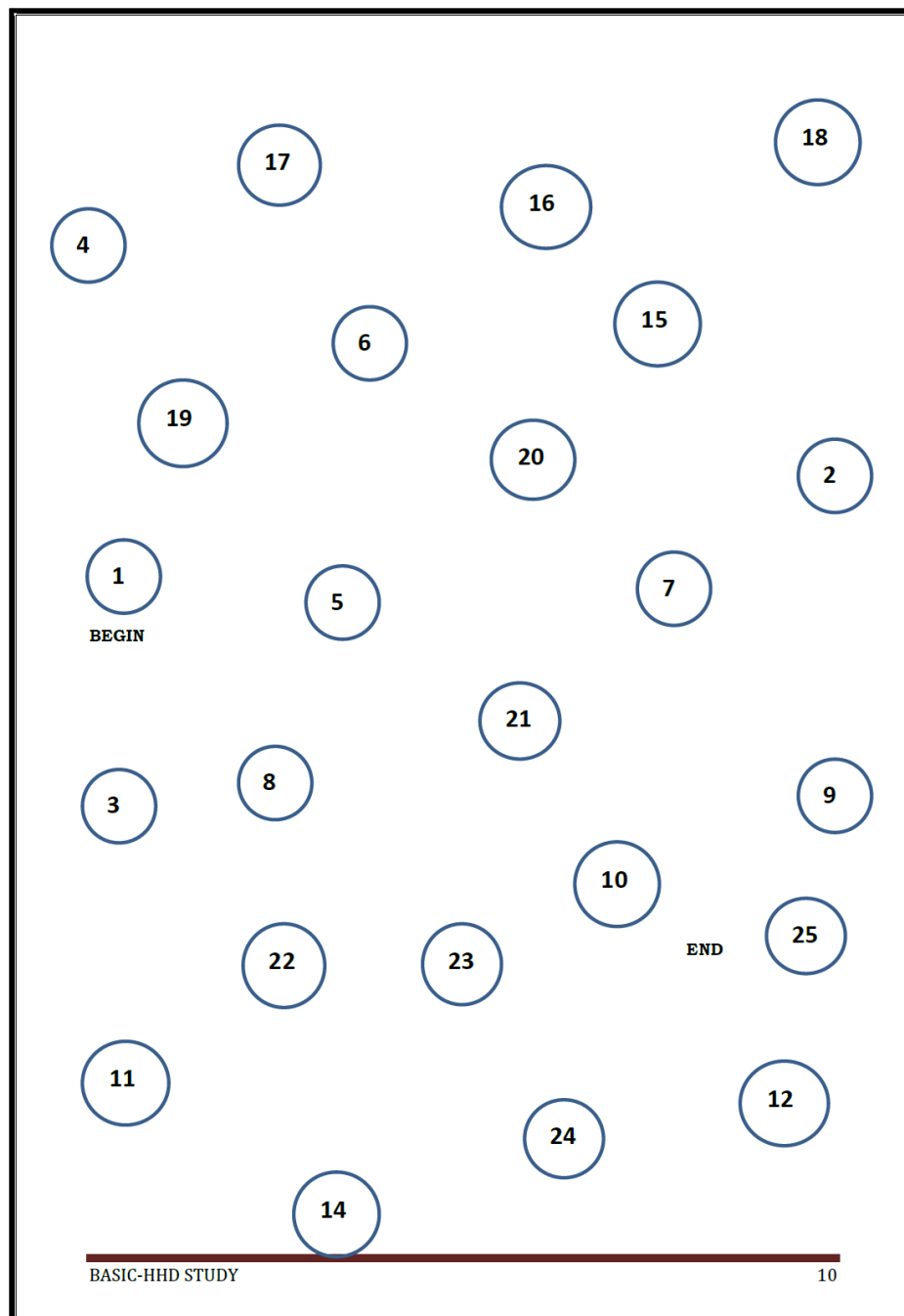
CLOTHING: (SHOES/SHIRT/SOCKS)	0	1	2	3
COLOUR: (BLUE/BLACK/BROWN)	0	1	2	3
VIRTUE: (HONESTY/CHARITY/MODESTY)	0	1	2	3

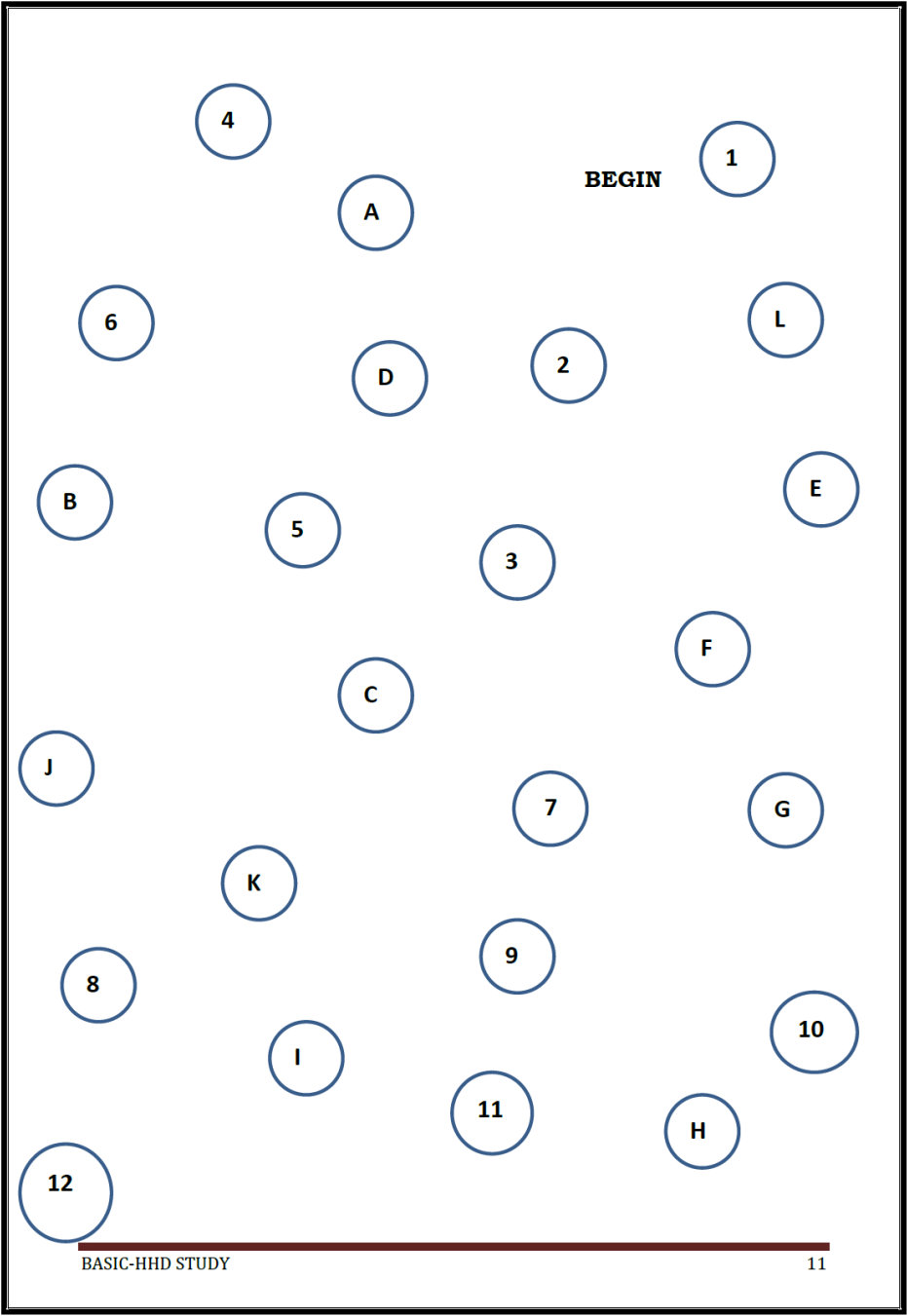
TOTAL SCORE:

TRAIL MAKING TESTS A & B

Patient Instructions:

"There are numbers in circles on this page. Please take the pencil and draw a line from one number to the next, in order. Start at 1 (point to the number), then go to two (point to the number), then go to three (point to the number) and so on. Please try not to lift the pencil as you move from one circle to the next. Work as quickly as you can."





META-COGNITION QUESTIONNAIRE

Please tell us how much you agree or disagree with each of the following questions by placing an X in ONE box alongside each question to indicate your answer.

1= strongly disagree; 2= disagree; 3=neither agree nor disagree; 4=agree; 5 strongly agree

	1 strongly disagree	2 disagree	3 neither agree nor disagree	4 agree	5 strongly agree
1. I have no trouble keeping track of my appointments					
2. I am good at remembering conversations I had					
3. I have no trouble remembering where I have put things					
4. I am good at remembering the content of news articles and broadcasts					
5. I am usually able to remember exactly where I read or heard a specific thing					
6. I am good at concentrating on television or radio broadcasts					
7. I am able to watch a whole film from the start to the end					
8. I have trouble concentrating during conversations					
9. I am good at concentrating when reading					

Multiple Imputation: Hierarchical regression (220 in each of the following analyses)

Variable		Odds ratio (95% CI)	p-value
First stage (employment, CCI, BDI)			
Employment	Retired	1 (-)	0.23
	Unemployed	0.90 (0.38, 2.10)	
	Salaried/ self-employed	1.73 (0.80, 3.72)	
CCI (per unit increase)		0.83 (0.70, 0.98)	0.031
BDI (per ten unit increase)		0.69 (0.51, 0.95)	0.023
Second stage (ethnicity and gender added)			
Employment	Retired	1 (-)	0.20
	Unemployed	1.01 (0.42, 2.42)	
	Salaried/ self-employed	1.91 (0.87, 4.17)	
CCI (per unit increase)		0.81 (0.68, 0.96)	0.017
BDI (per ten-unit increase)		0.70 (0.51, 0.97)	0.031
Ethnicity – Non-white		0.35 (0.12, 0.99)	0.048
Gender – Female		0.85 (0.47, 1.56)	0.60
Third stage – TMT B added			
Employment	Retired	1 (-)	0.25
	Unemployed	1.03 (0.42, 2.49)	
	Salaried/ self-employed	1.84 (0.83, 4.06)	
CCI (per unit increase)		0.83 (0.70, 0.99)	0.040
BDI (per ten-unit increase)		0.69 (0.50, 0.96)	0.028
Ethnicity – Non-white		0.36 (0.13, 1.05)	0.061
Gender – Female		0.84 (0.45, 1.54)	0.57
TMT B (per ten second increase)		0.96 (0.90, 1.02)	0.18
Third stage – TMT A added			
Employment	Retired	1 (-)	0.22
	Unemployed	1.04 (0.43, 2.52)	
	Salaried/ self-employed	1.90 (0.87, 4.16)	
CCI (per unit increase)		0.83 (0.69, 0.99)	0.044
BDI (per ten unit increase)		0.70 (0.50, 0.96)	0.028
Ethnicity – Non-white		0.36 (0.13, 1.03)	0.058
Gender – Female		0.85 (0.46, 1.56)	0.60
TMT A (per ten second increase)		0.94 (0.82, 1.07)	0.36
Third stage – 3MS added			
Employment	Retired	1 (-)	0.26
	Unemployed	1.00 (0.42, 2.40)	
	Salaried/ self-employed	1.82 (0.81, 4.08)	
CCI (per unit increase)		0.82 (0.69, 0.98)	0.028
BDI (per ten unit increase)		0.70 (0.50, 0.96)	0.029
Ethnicity – Non-white		0.37 (0.13, 1.05)	0.062
Gender – Female		0.87 (0.47, 1.60)	0.65
3MS (per ten increase in score)		1.15 (0.68, 1.95)	0.60
Third stage – Metamemory added			
Employment	Retired	1 (-)	0.19
	Unemployed	1.01 (0.42, 2.41)	
	Salaried/ self-employed	1.91 (0.87, 4.18)	
CCI (per unit increase)		0.81 (0.68, 0.96)	0.017
BDI (per ten-unit increase)		0.70 (0.50, 0.97)	0.030
Ethnicity – Non-white		0.35 (0.12, 0.99)	0.048
Gender – Female		0.85 (0.46, 1.55)	0.60
MCQ1 Metamemory (per one increase in score)		0.99 (0.91, 1.08)	0.84
Third stage – Metaconcentration added			
Employment	Retired	1 (-)	0.20
	Unemployed	0.95 (0.38, 2.32)	
	Salaried/ self-employed	1.87 (0.84, 4.14)	
CCI (per unit increase)		0.79 (0.66, 0.95)	0.011
BDI (per ten unit increase)		0.76 (0.55, 1.07)	0.12
Ethnicity – Non-white		0.36 (0.13, 1.05)	0.062
Gender – Female		0.85 (0.46, 1.57)	0.61
MCQ2 Metaconcentration (per one increase in score)		1.16 (1.02, 1.31)	0.020