The Care Priorities of Haemodialysis Patients

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Abstract

Background: Patients receiving haemodialysis have a reduced quality of life when compared to the general population and report deficiencies in satisfaction with care. As such it is important that we are able to evaluate dialysis care from the patients' perspective. Despite this, there is currently a paucity of evidence to suggest which aspects of care are important to patients themselves.

Aims: To describe what is important to patients about their haemodialysis care and whether their degree of involvement in treatment provision affects their experiences and priorities for care.

Methods: A qualitative survey of all in-centre and home haemodialysis patients at two renal centres and their satellite units was conducted. 7 focus groups were then held at 2 renal centres (total of 29 patients and 3 carers). Patients were divided into focus groups by their mode of haemodialysis provision.

Findings: Three final themes represent the aspects of dialysis that are important to patients. The first theme, 'Finding personal control' describes the emotional work and coping strategies utilised by patients as they tried to regain a sense of personal control. The second theme 'Maintaining social viability' illustrates how dialysis affects patients' social roles and responsibilities. The final theme, 'Integrating dialysis into life', describes the physical and emotional challenges patients' experience when trying to live their lives alongside dialysis.

Conclusions: The interactions patients have with staff and the way that care is provided had significant effects on all three of the final themes. The data highlight many ways in which communication; relationships with staff and the way care is organised can both positively and negatively affect patients' experiences of care. Understanding the care priorities of patients is fundamental to making real improvements to dialysis care which are of relevance to patients themselves.

Contents

List of Tables

List of Figures

List of Tables

List of Appendices

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Author's Declaration

I confirm that this work is original and that if any passage(s) or diagram(s) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference(s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct, and state that this piece of work is my own and does not contain any unacknowledged work from any other sources'. If applicable, the declaration should also include; 'I confirm that any patient information obtained to produce this piece of work has been appropriately anonymised.

Chapter 1 Introduction

1.1 Introduction

This chapter introduces the subject area of haemodialysis and provides a description of the context in which this study is situated. I then explain my personal interest in this area and how the research question was developed. Finally I finish with an outline of the chapters in this thesis.

1.2 Study background

1.2.1 Kidney failure

There are numerous causes for kidney disease; for most people chronic kidney disease causes a slow decline in kidney function over time but some people develop kidney failure more rapidly. When an individual's kidney function becomes so low that they develop symptoms from the build up of toxins, or they develop water retention that is no longer amenable to other treatments, they are classified as having end stage kidney failure (ESKF). Kidney failure can affect people of any age, but is more common in older people; the median age of those starting dialysis in the UK is 65 years[1] and the most common cause is diabetes[1]. Once someone has ESKF, the only way to prolong life is by providing renal replacement therapy (RRT), either by dialysis or kidney transplantation. The median age of patients receiving RRT in the UK has also increased, from a median of 55 years in 2005 to 58.7 years in 2014[2]. Currently 59,000 adults in the UK receive treatment for ESKF for kidney failure and this number continues to increase each year[2]

Once a person is identified as having low levels of kidney function, such that they are likely to progress to ESKF, they receive pre-dialysis education to inform them of their future treatment options. An individual can choose to have RRT or supportive care without dialysis. The latter is focused on treating the symptoms of renal failure rather than extending life, whereas RRT aims to replace some of the kidneys' functions. RRT will prolong life in many, but not all, people. Options for renal replacement therapy include peritoneal dialysis, haemodialysis and renal transplantation. Those without a live donor, who are suitable for and wish to have a renal transplant, have to wait on the national kidney transplant list and often require treatment with dialysis while they are waiting. All types of RRT remove some toxins that build up in the body, as well as excess water and salt. A kidney transplant will usually offer a better quality of life and patient survival than dialysis treatment, but not every patient is suitable for a kidney transplant. Even those that are suitable may have to remain on dialysis for many years until a donor kidney becomes available. Dialysis is able to remove enough toxins to keep people well, but only replaces a small fraction of normal kidney function.

There are two types of dialysis: peritoneal dialysis and haemodialysis. Peritoneal dialysis requires a plastic tube (catheter) to be surgically placed into the abdomen. This catheter is used to infuse and remove peritoneal dialysis fluid together with toxins, and excess salt and water from the body. Patients need to have peritoneal dialysis everyday, but this is done at home, by the patient and independent of frequent healthcare supervision.

Haemodialysis involves using a machine to circulate the patient's blood through an artificial kidney, where it is filtered to remove toxins and excess fluid. This machine is connected to the patient's blood stream through either a line (a plastic tube which takes and returns blood to the circulation usually through a large vein in the patient's neck) or a fistula or graft (connections made surgically between a vein and an artery, usually on the patients' arm, in which needles are placed when the patient attends for dialysis). Most people have haemodialysis for 3 to 5 hours three times a week and attend a dialysis unit where their treatment is provided by nursing staff.

1.2.2 Haemodialysis in the UK

In the UK the majority of those who start RRT are initially treated with haemodialysis[1]. Of those established on treatment, 41% are currently treated with haemodialysis, 6% with peritoneal dialysis and 53% have a functioning kidney transplant[2]. Approximately 25,000 people in the UK are currently treated with haemodialysis and this number is increasing[2]. The incidence of kidney failure is relatively low (65 people per million population) when compared with other chronic health conditions and treatment is complex and expensive[1]. Consequently most care is delivered by specialist centres. In the 1990s, as haemodialysis populations in the UK increased, most of these specialist centres developed satellite haemodialysis units closer to patients' homes. Dialysis units in the specialist centres are often referred to as hospital units to distinguish them from satellite units (although many satellite units are based at smaller hospitals). The majority of care within all dialysis units is provided by nursing staff and at satellite units there is no day-to-day medical cover. Historically satellite units tended to be reserved for patients whose condition was more stable.

While dialysis can prevent immediate death from renal failure, the mortality and morbidity of patients receiving dialysis is high, with a 2 year survival of 72% in the UK [3]. The main causes of death are cardio-vascular disease and infections, with dialysis patients at much higher risk of these than those in the general population[3]. In addition, many dialysis patients also have other health problems such as heart failure and diabetes. While there has been some reported improvement in the survival of haemodialysis patients in recent years[3, 4], many interventions that healthcare providers had hoped would improve survival have not done so. In view of the combination of reduced life expectancy, multi-morbidity, and increasing ages of those on dialysis, there has been a recent change in focus from solely aiming to improve life expectancy to also considering their quality life.

1.2.3 Home haemodialysis and shared care

When haemodialysis was first introduced in the 1960s-70s most patients dialysed themselves at home. Most of these patients were young and with a rapid increase in patient numbers and service expansion, the introduction of satellite units, and an increase in transplantation, the numbers having home haemodialysis declined. In 2002 the National Institute for Health and Care Excellence (NICE) published guidance advising that home haemodialysis should be available to all patients, suggesting centres should aim to treat 10-15% of haemodialysis patients with home haemodialysis. Underlying this guidance was a review that suggested some advantages to home over in-centre dialysis. These included lower costs, and limited evidence of increased clinical effectiveness, especially if home dialysis was used to increase the frequency of treatment. However there are many barriers to the uptake of home haemodialysis including fear, not wanting to dialyse without supervision, social isolation and a lack of space at home[5]. Home haemodialysis numbers have increased from 1-2% of all haemodialysis patients in 2002 to 4.3% in 2014[2]. While there is variation in the proportion of haemodialysis patients on home dialysis between units, the vast majority have not approached 15%[2].

1.2.4 Self-management

Concurrent with the interest in increasing the numbers of people dialysing at home, there has been growing interest in improving self-management of long-term conditions in the wider healthcare community [6]. In a review of self-management approaches for people living with chronic conditions Barlow et al. define self-management as, "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition"[7]. The term self-management has therefore been used to describe strategies that people use to live with a chronic illness, whereas the term self-care has been used more widely to describe the actions that we are all involved in to maintain good health[8], however these terms are often used interchangeably in the literature.

As the population ages, and the number living with chronic diseases increases, there is a need to find strategies to cope with a growing burden of care. The NHS has increasingly focused on strategies to promote self-management as a way of addressing this demand[9]. The provision of patient centred care has also become a priority for the NHS and this has necessitated a re-evaluation of patient-professional relationships and a move towards partnerships, rather than paternalistic approachs[10]. As such, the professional role has changed from decision maker to information and skill provider, with the aim of enabling patients to manage their own condition, with support, by providing the skills and knowledge required. Patient centred care is seen to have benefits for the individual and also promotes the concept of self-care with anticipated benefits for society. Consequently there has been increasing interest in integrating the concepts of patient centred care and self-management into all areas of health and social care[11]. Measuring the effectiveness of interventions that aim to increase self-care is challenging, but there is some evidence that supporting strategies that improve self-management can result in improved outcomes for patients[6].

The World Health Organisation defines health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”[12]. Addressing health literacy is seen as a key component for encouraging self-management[13]. Although there may be underlying confounders, studies in haemodialysis patients have found associations between low health literacy and higher mortality rates, higher numbers of missed treatments and higher numbers of hospital admissions[14, 15]. These studies, together with evidence from other health-care settings that improving self-care may improve outcomes for patients, has led to supporting self-care becoming a key ambition for the those involved in directing the delivery of services to patients with kidney failure in the UK[16].

1.2.5 Shared care programmes

An intervention called ‘shared haemodialysis care’ was developed in Yorkshire and the Humber to address the need to increase self-management in patients with kidney disease and increase the number of patients dialysing at home. Shared care aims to improve self-management by giving in-centre patients the opportunity to learn to undertake parts of their treatment for themselves. The whole haemodialysis treatment was divided into 14 tasks (Figure 1) and patients may learn any number of tasks with the support of the nursing staff. This requires practical procedural skills, but also aims to provide the opportunity for patients to develop a greater understanding of the dialysis process and become engaged in their care. Some patients may only wish to do one task, while others may proceed through all 14 tasks at their own pace, and consequently be able to dialyse themselves independently.

Figure 1: The 14 Tasks of Shared Care

1. Takes weight
2. Takes blood pressure and pulse
3. Takes temperature
4. Washes hands and arm
5. Lines machine
6. Primes machine
7. Prepares dressing pack ready for access
8. Programmes machine using prescription
9. Inserts one or both needles into AV Fistula/Graft or prepares tunnelled line for dialysis
10. Hooks up, bleeds out & commences dialysis
11. Problem solving on dialysis
12. Discontinues dialysis by hooking up & washing back
13. Presses needle sites after removal
14. Administers any injections via dialysis machine or subcutaneously

The programme is flexible enough to allow participation from most patients. To achieve this, the programme seeks to train all dialysis staff to support shared care through courses which explain the aims, objectives and evidence to support self-care, and provide staff with teaching skills and knowledge of adult learning methods. The programme has been running since 2010, with support from the Health Foundation. While originally established in 4 units in Yorkshire and the Humber, the programme has since been launched in other units throughout the UK, with further support from the Health Foundation.

1.3 My personal interest in this area

I am a renal specialist trainee in the Yorkshire and Humber region. Before embarking on my specialist training I worked at a renal unit in New Zealand, where all patients dialysed at home (either on home haemodialysis or peritoneal dialysis). As a result I was interested in the different attitudes and perceptions that patients in the UK and New Zealand had to home dialysis and self-care. While working at York Hospital I was introduced to the shared care programme. Work had been done to establish shared care in York alongside other units in the region and there was a desire to evaluate the programme. As the programme aims to provide patient centred care, it was important that the programme was evaluated from the patients' perspective. This led to a wider consideration of how we measure the aspects of care that are important to haemodialysis patients.

1.4 Evaluating care from the patient's perspective

National registries, such as the UK Renal Registry, report annually on haemodialysis outcome measures, including mortality, biochemical parameters and anaemia. This allows comparisons to be made between all renal units in the UK. Clinicians have chosen these measures, as they are regarded as having value in assessing the quality of care provided by dialysis units. Studies involving patients with chronic kidney disease have highlighted that patient treatment choices are more likely to be influenced by lifestyle factors, such as impacts on family and employment, rather than clinical measurements[17]. Additionally, differences in survival rates between treatment options may not affect patients' choices[18]. Consequently there is increasing awareness that patients and professionals may not share the same priorities for care.

For many chronic diseases there has already been a move towards measuring the patient's perspective on the quality and effectiveness of health care. This information is seen as important for improving standards and ensuring effective resource allocation within the NHS. As such, patient reported outcome measures (PROMs) have been used routinely in the NHS since 2009[19]. A review of the literature on adults with chronic kidney disease looked for existing measures that could be used as PROMs in routine kidney care[20]. While evidence was found supporting the use of various tools, such as the Kidney Disease Quality of Life (KDQOL) instrument, none of the recommended tools were initially designed or intended for use as PROMs[20] and there is little evidence for their use as measures of the quality of care. Additionally it is not clear whether these PROMs are measuring something that is important to patients, and whether the data they generate can be utilised to improve care in a way that is meaningful to patients.

Patient reported experience measures (PREMS) aim to measure patients' experience of care rather than its outcome. Patient experience is another important and measurable component of health care provision and improving patient experience is one of the key goals for the NHS[21]. Consequently interest in developing PREMs has increased. The more detailed data obtained through measuring patient experience allows the identification of areas where care processes can be improved[22] (Coulter, 2006). However PREMs have also been criticised for concentrating on managers or clinicians agendas rather than measuring what matters to patients[23]. A recent expert consensus meeting for the European Renal Association examined the evidence for current patient experience measures in RRT and concluded that more work needed to be done before a specific PREM could be recommended for use[24].

1.5 Developing the research question

Before being able to successfully evaluate care from the patient's perspective, there first needs to be an understanding of the components of care that matter to patients. Despite this, there is currently a paucity of evidence to suggest which aspects of care are important to haemodialysis patients. Additionally, the introduction of new ways of delivering care, such as home dialysis and in-centre self-care, has diversified the provision and experience of haemodialysis. What is important to someone on home dialysis may be different to someone who has dialysis provided by nursing staff in-centre. An understanding of what is important to patients about their care could inform care provision and suggest how care can be improved in a way that is valued by all patients. The research question that this thesis aims to answer is, "What is important to patients about their haemodialysis care?" I also seek to develop an understanding of patients' diverse experiences of care and whether their degree of involvement in treatment provision affects their experiences and priorities for care.

1.6 Outline of chapters

This chapter has introduced the background and issues central to this study. The research question and aims of the study have also been described. In the first of two literature review chapters, Chapter 2 reviews the existing tools that are used to evaluate care from the patients' perspective. In the second literature review chapter, Chapter 3, I present a review of the previous literature exploring patients' experiences of haemodialysis care. This review adds further context to this study, and a thematic synthesis of the data provides a framework describing the current research on experiences of people living with haemodialysis. My methodology is explained in chapter 4, including a discussion of the epistemological and theoretical backgrounds that underpin the study, and the methods chosen to gather and analyse the data. Chapter 5 presents the results of a survey of patients at the two renal centres involved in the study, and describes how this data was used to inform the development of a topic guide for the main study. Chapter 6 introduces the main results chapters and provides information about the study participants. Chapters 7, 8 and 9 present the main research findings and the over-arching themes which emerged from the data. The final chapter, Chapter 10, summarises and evaluates the key findings of the study and discusses these in relation to how they inform practice and service development. This is followed by a consideration of the strengths and limitations of the study and recommendations for further research.

Chapter 2 A review of existing tools used to evaluate care from the patients' perspective

2.1 Introduction

This chapter is the first of two literature review chapters. In this chapter I present a review of the existing tools used to evaluate care from the patients' perspective in haemodialysis populations. These tools are divided into two main groups: patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) or measures of patient satisfaction. The two groups are introduced following a short review of relevant tools. The chapter ends by considering the relationships between demographic characteristics of populations and patient experience or satisfaction measures.

2.2 Patient reported outcome measures

There has been a recent drive in the UK to ask what the NHS is producing in terms of health for society, not just what it is providing in terms of health care[19]. This has led to an increase in the use of patient reported outcome measures (PROMs) by the NHS and other healthcare organisations around the world. PROMs have been defined as measures of patients' functional status, symptoms and health related quality of life[25]. They do not measure a patient's experience of, or satisfaction with, the care they received but purely aim to measure a patient's perception of their health[19]. Consequently PROMs are measures of the outcome of health care activity that do not rely on clinical parameters. The National PROMS programme in England has been collecting data from organisations that provide inguinal hernia repairs, hip and knee replacements and varicose vein surgery, to measure the success of the surgery from the patients' perspective since 2009[26]. This information is then used to compare outcomes from the surgery across all hospitals in England.

The growth in the interest in PROMs has led to the development of an increased number of PROMs[27]. Despite this there is little evidence regarding the ability of PROMs to improve the quality of care. A systematic review of the impact of PROMs feedback to health care professionals concluded that there was only weak evidence to support the theory that feedback of PROMs data resulted in improved patient outcomes, and little evidence to support the use of PROMs as a performance measure[28]. Despite this uncertainty regarding the utility of PROMs they continue to be used to try and capture the patient's perspective on the outcome of care.

A recent structured review of PROMs for adults with chronic kidney disease recommend the SF-36 and EQ-5D (both of which aim to measure health related quality of life) as the generic measures with the most supporting evidence regarding their use in this disease group[20]. Of the disease specific PROMs assessed, the authors recommended the use of the KDQOL (Kidney Disease Quality of Life measure – a tool based on the SF-36 but including questions specific to renal disease). The authors found little evidence to support the belief that any of the three PROMs identified could be used to reliably measure the quality or outcomes of care, or that they would be responsive to changes in care over time. The EQ-5D is used by NHS England in other PROMs programmes[26] and has consequently been chosen by the UK Renal Registry as the generic measure to be used in a pilot of PROM data collection. As the EQ-5D, SF-36 and KDQOL measures were recommended as the PROMs with the most supporting evidence in the review by Gibbons and Fitzpatrick, 2010[20] I have examined the information provided by these tools in some more detail below.

2.2.1 EQ-5D

The EQ-5D was developed by a multi-disciplinary group of professionals from various countries in Europe. The group examined the literature regarding the measurement of health related quality of life with the aim of developing a single measure which could be used to compare different health states for economic and evaluative study[29]. The EQ-5D comprises 5 questions to assess 5 domains: mobility, self-care (specifically being able to wash and dress yourself), ability to do usual activities, pain/discomfort and anxiety/depression. Each question is answered using a three or five point scale. An additional visual analogue scale asks respondents to mark their health status from worst imaginable to best imaginable (EQ-5D VAS). The EQ-5D is a utility measure and hence a value can be applied to a particular health state using a scoring algorithm. This algorithm was created as a result of research into the general public's valuations of different health states[30].

The EQ-5D benefits from being quick and simple to complete and the scores are comparable between disease states.

A previous study (Kind et al., 1998) used the EQ-5D to survey a representative sample of the UK population and found significant differences in scores between groups defined by age, social class, education, housing tenure, economic position and smoking behaviour[31]. Consequently, if the EQ-5D is used to compare the outcome of treatment in dialysis units it will be important that these potential confounders are addressed.

The EQ-5D has been used less often than the SF-36 in studies with haemodialysis patients[20]. Two studies have used the EQ-5D. Manns et al., 2008[32] compared quality of life in patients treated with nocturnal and conventional haemodialysis and found no significant difference. Roderick et al., 2005[33], compared quality of life in patients dialysing in central and satellite units in the UK and also showed no difference, but as was shown in Kind et al.'s, 1998 study[31], there were significant correlations between scores and other socio-demographic factors including functional status, car ownership and educational level. The lack of difference in scores between the patient groups in these studies is perhaps not surprising as changing the way in which haemodialysis care is provided to a patient is unlikely to have a significant impact on any of the 5 domains measured in the EQ-5D.

Roderick et al.'s study did find a significant difference in the scores of the additional visual analogue scale component of the EQ-5D when patients were on and off dialysis[33]. A similar finding was reported using U index scores (the percentage of time a person spent in an undesirable state), with patients reporting significantly worse scores on dialysis days than non-dialysis days[34]. This deterioration in health state when receiving treatment illustrates one of the challenges of using PROMs in dialysis care. While most treatments in health care are designed to improve health status, dialysis is designed to prevent death from kidney failure. Unfortunately many patients experience symptoms during each treatment each time they attend[35-37] and many experience a slow decline in their health as they continue on dialysis over many years[38]. Dialysis is therefore distinct from interventions such as knee and hip replacements where the use of PROMs originated. While the EQ-5D VAS may be able to measure the difference in patients' perceived health status between dialysis and non-dialysis days the utility of this information to improve services is not clear as no matter how dialysis is provided, patients will still have to spend time undergoing treatment.

The EQ-5D is a simple tool that is easy to complete and can show that patients feel their health is poorer on a dialysis day. However, as a global measure of health related quality of life it is likely that it is not sensitive enough to be helpful in assessing the care provided to haemodialysis patients. Additionally results may be significantly affected by factors other than dialysis care, such as socio-economic status, making comparisons between patient groups, modalities or treatment centres challenging. As a health related quality of life tool the data it provides does not help identify ways in which dialysis care providers can effect meaningful change.

2.2.2 SF-36 and KDQOL

The SF-36, like the EQ-5D, is a generic measure of health related quality of life. Unlike the EQ-5D it is not a utility measure; hence a particular value cannot be given to a reported health state. Instead health related quality of life is reported as a score. The results of the SF-36 are given either as a separate score for each of the 8 domains assessed, or two composite scores, one for the physical component (PCS) and one for the mental health component (MCS) on a 0 to 100 scale[20]. It is widely used in many aspects of health care internationally and is the most evaluated generic measure of health[27]. The SF-36 was developed in the US from existing instruments that were adapted following a literature review[39]. It comprises 36 questions measuring health across 8 domains (pain, physical functioning, role limitations due to physical health problems, social functioning, vitality, mental health, role limitations due to emotional health problems and general health perceptions). Previous studies have shown lower scores in haemodialysis patients than the general population[40, 41]. While physical health scores tend to be significantly lower than population norms, mental health scores have been found to be closer to population norms[33, 40, 41]. Lower scores in the physical and mental health domains of the SF-36 have been found to be associated with greater morbidity and mortality in haemodialysis patients[42, 43]. In these studies increasing age and co-morbidities were also associated with lower scores, however when Roderick et al. 2005 compared scores in patients dialysing in central and in satellite dialysis units no difference was found[33]. Similar scores were also found when comparing patients receiving haemodialysis and peritoneal dialysis[44]. This data suggests that how dialysis is provided is likely to have less impact on SF-36 scores in dialysis patients than socio-demographic factors.

The Kidney Disease Quality of Life instrument (KDQOL) combines a generic measure with a disease specific measure, and was developed in the US for use in patients on both peritoneal and haemodialysis. It uses the SF-12 (a shorter version of the SF-36) as a generic core alongside a set of 35 dialysis specific questions. The disease specific questions were developed following 3 patient focus groups (with a total of 13 haemodialysis patients), a focus group with dialysis staff, and a review of 6 papers on quality of life in kidney disease patients[45]. The 35 dialysis specific questions (or 12 in the short form) ask patients to rate how bothersome specific symptoms have been to them on a 5 point scale. It also has questions about the perceived burden of their kidney disease and the effect of their kidney disease on their life[46].

A large review of 9,526 haemodialysis patients from 7 countries who completed the KDQOL (short form) showed that unemployment and psychiatric disease were associated with lower scores in all the generic domains and some of the kidney specific domains[47]. All the co-morbidities recorded in this study were also associated with lower PCS. In the UK, Roderick et al.'s comparison of in-centre and satellite dialysis services also used the KDQOL and found there was no significant difference in overall scores between the two patient groups but scores in the patient satisfaction, and staff encouragement of patients domains did differ; with higher scores found in the satellite dialysis unit patients[33].

While the above studies suggest that health related quality of life (HRQOL) is linked to hard outcomes such as mortality, they also suggest that HRQOL is related to many socio-economic factors. These other factors, such as educational level, unemployment, income and co-morbidities, are difficult to address through changes to dialysis provision. In addition, if HRQOL measures are used to compare dialysis units in the UK, the relationships between socio-economic factors and HRQOL must be accounted for. The UK review of PROMs for use in kidney disease also cautioned that there was a lack of longitudinal data and evidence of responsiveness for the PROMs they recommended[20]. If HRQOL measures are to be used to assess the quality of care provided by units, scores should respond to changes in the care provided. The non-specific nature of many of the items measured in these HRQOL measures, combined with the important confounders present in the relationships between scores and socio-economic factors, suggest that it may not be possible to show responsiveness in HRQOL tools.

Many trials of interventions in dialysis patients fail to meet hard clinical endpoints such as reductions in mortality[48]. Additionally there is increased recognition of the importance of including endpoints in these trials that are of importance to patients, rather than solely concentrating on clinical measurements[49-51]. Consequently some studies are now including HRQOL as an endpoint[52-54]. Despite this few have shown changes in HRQOL. Large trials of interventions that could be hypothesised to improve HRQOL such as aiming for higher haemoglobin levels (treating anaemia)[53] and using high flux dialysis (thought to possibly reduce joint pain and itch) have failed to have any impact on HRQOL[54]. A study of dialysis frequency did find a statistically significant (3 point) increase in the PCS component of the SF-36 for patients having frequent in-centre haemodialysis[55]. There was no difference in objective measures of physical functioning, suggesting patients felt physically better although this was not clinically measurable, but is a three point increase in the PCS sub-scale a meaningful change in physical health? A study of physicians in three other chronic disease settings (asthma, chronic obstructive pulmonary disease and chronic heart failure) attempted to set clinically important difference thresholds using the SF-36[56]. Although thresholds were similar between the asthma and COPD groups, the magnitude of difference set by the chronic heart failure group was greater, and all three groups' thresholds were greater than those set by a previous study of patients with rheumatoid arthritis[57]. This demonstrates a lack of consensus regarding what constitutes a clinically important difference and a suggestion that these may vary between chronic diseases. There is very little data on what patients would consider a meaningful difference. An evaluation of PROMs for use in the NHS concluded that it was difficult to assess what a meaningful difference was and concluded statistical significance testing would need to be used to make comparisons between health care providers[58].

Health related quality of life is complex. It is significantly associated with multiple confounders and socio-economic factors that are not directly related to dialysis care provision. There is little evidence to suggest these tools are responsive to changes in care, or to suggest what constitutes a meaningful difference in their scores. Consequently, while improving HRQOL appears to be a desirable aim, it may not be an appropriate measure of patients' perspectives of dialysis care provision. I have therefore explored patient experience measures as another group of tools that may be better suited to this role.

2.3 Patient experience and satisfaction measures

The difference between patient experience and patient satisfaction is not always clear in the literature. Patient satisfaction has been used as measure of service provision for many years. It has been used as both an outcome measure and a process measure, but the results have often been unhelpful in determining how care can be improved[23]; knowing a patient is either satisfied or unsatisfied does not identify what needs to be changed to improve satisfaction. As with PROMs, there are associations between patient satisfaction and socio-demographic factors[59] and this has led to criticism of their use in comparing health care providers[60]. These concerns have resulted in a move to develop patient experience rather than satisfaction measures.

PREMs measure details of a patient's experience of aspects of care rather than a global satisfaction[61]. Measuring patient experience asks patients to report on what actually occurred in their care experience rather than their overall judgement of the care received. Results are more factual and hence potentially more reliable[22, 60]. Measuring patient experience rather than satisfaction may therefore reduce the variation in results produced by the differences between patients rather than care provision[60]. The more detailed data obtained through measuring patient experience also allows the identification of areas where care processes can be improved[22].

A study using data from the World Health Organisation's World Health Study examined the association between peoples' satisfaction with their health care system and patient experience[62]. They concluded that patient experience was an important contributor to overall satisfaction but that it only represented about 10% of the variance in reported satisfaction. Some of the variance was attributable to aspects unrelated to patient experience such as personality, expectations and self-reported health status. All of the variables assessed in the study only contributed to 17.5% of the variance seen. They concluded that most of the variation in satisfaction reported was not related to patient experience but to factors that are not yet understood. Consequently the authors suggested that satisfaction with care was unlikely to be an appropriate measure of care quality as it is influenced by unknown variables outside the experience of care.

Studies have sought to investigate the reliability of patient experience in assessing care quality. A systematic review showed that across a range of diseases there was a positive relationship between patient experience and clinical effectiveness, reported by both patients and clinicians[63]. Additionally they showed links with adherence to treatment regimens, resource use, use of screening and clinical safety.

In the US, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey was developed to measure patients' perspectives on hospital care. Analysis of data produced by the survey has shown patients' experiences of a hospital demonstrate strong inter-patient correlation[64]. As well as asking patients to assess their hospital care experience in a variety of specific domains, such as communication with doctors, the HCAHPS tool also includes two global measures (overall satisfaction with the hospital and whether they would recommend it to a friend). Therefore the HCAHPS, while termed a patient experience measure, does also include global measures of satisfaction. In a study of patients' perceptions of hospital care in the US that used the HCAHPS, the first global measure was found to be associated with the quality of care provided by a hospital (measured through compliance with evidence based treatment guidelines for acute medical conditions)[64]. Nevertheless the authors warned that patient experience should not be used as a surrogate for clinical quality as this fails to acknowledge the importance of patient experience in its own right.

2.3.1 When to measure patient experience

The question of when to measure patient experience, or what time frame patients should consider when completing a measure, is especially relevant in the context of ongoing care for a chronic illness, rather than an acute episode of ill health. It has been suggested that results tend to be more valid if patients are asked about their experience of a recent health care episode, rather than their overall experience of care over time. Asking about a longer time course invites patients to choose the encounters on which to base their evaluation and hence they may report on memorable encounter that was unusually good or bad and not representative of usual care[65]. However as yet there is little evidence to support decisions regarding the timing of measurements[66].

2.3.2 What to measure

While many of the studies discussed above aim to respond to concerns regarding the validity of patient experience as an assessment of the quality of care, questions remain as to what information should be collected. A report for the Department of Health[67] advised against using PREMs to collect data that could be collected from other sources, such as patient records. Patient experience measures should focus on asking patients questions that can only be answered by patients themselves. This data can then be used alongside other clinical and process outcomes of care. Patient experience measures have previously been criticised for concentrating on managers' or clinicians' agendas and care should be taken to ensure that they instead focus on patients' agendas[23]. Consequently the identification of components of care that matter to patients is critical to the process of assessing patient experience. Despite this a disparity between what is currently measured and what matters to patients has been highlighted by previous authors[23, 66, 67]. The development of PREMs must first involve an analysis of what matters to patients if they are to result in evaluations of patient experience that are relevant, and useful for improving care in a way that is meaningful to patients.

2.3.3 Measuring patient experience in other health care settings

Two studies in the UK have surveyed patients to ask them to rank the importance of various aspects of care. The results were similar, although the second survey[68] was developed using data that included results from the first survey[69]. The aspects of care that were most important included cleanliness; being treated quickly in an emergency; clear explanations and information sharing; getting the best treatment; the knowledge of health care staff and their knowledge of your history; and being treated with dignity and respect[68, 69]. In a report on measuring patient experience in the NHS[67], Robert et al., 2011 carried out 50 narrative based interviews with patients about what was important when receiving care. In common with the above surveys, the main themes reflected the importance of relational aspects of care (these are the interpersonal aspects of care such as being treated with dignity). Although functional aspects of care were also important (such as efficient processes and cleanliness) relational aspects were more commonly cited. Data on functional aspects of care can be collected in other ways, but the patient is uniquely able to report on relational aspects of care.

Data from the HCAHPS survey in the US has shown that patients' ratings of their communication with nursing staff is the item most highly correlated with overall satisfaction with care[65]. Of the eight aspects of care most correlated with overall satisfaction, four were related to communication. Communication therefore appears important to patients when assessing their care, but other relational aspects of care have also been found to be important. Patients have highlighted the importance of health care staff having a positive attitude towards them, feeling like they are being treated as individual and not being labelled[67]. A critical interpretive synthesis of the experiences of health care that matter to service users concluded that health care delivery should promote an individual's ability to be who they value being and do what they value doing[70]. They argue this requires more than just effective communication; it also requires attention to positioning within relationships and the attitudes of health care staff. The attitudes of staff, and the balance of power within relationships was also seen to impact patients' experiences in a study of the sources of dissatisfaction with care[71]. Through in-depth interviews with patients they found dissatisfaction was related to threats to personal identity. Acts that were perceived as dehumanising, disempowering and devaluing were seen to endanger personal identities and cause dissatisfaction with care. Consequently relational aspects of care cannot be fully assessed through focusing on communication alone.

As discussed above patient experience requires a consideration of the functional aspects of care that are important to patients in addition to the relational aspects[67-69]. Patient experience should be viewed as a person's global interaction with health care services, and as such should include both the 'content of care' and well as the 'nature of care'[72]. While functional aspects of care also form an important element of patient experience this does not mean that patients must evaluate these aspects of care and consideration should be given to the best methods for collecting such data.

2.3.4 Measuring patient satisfaction and experience in haemodialysis patients

Although there are generic tools measuring patient experience these have often focused on in-patient acute care[67]. A report by the Kings Fund highlighted a gap in the information available about patient experience in individual clinical specialties[73]. Yet we can only assess this experience if we know what matters to patients receiving that specialist care.

In the case of haemodialysis care we might expect that patients share many of the priorities of patients receiving in-hospital acute care, such as cleanliness and information sharing. However haemodialysis is different from many other aspects of health care. Patients are treated for a chronic disease, often for many years, but usually require facility based treatment for half a day three times a week. The nature of this care is therefore different from the acute in-patient care from which data on patient care priorities have previously been derived. As patients spend a significant amount of their time undergoing haemodialysis, their experience of receiving care is also likely to have a significant impact on living with their chronic illness[74]. The need to develop kidney disease specific measures has been previously recognised, and my review found 4 main tools that have been developed and published in the academic literature. They are: CHOICE, CAHPS for dialysis, the Consumer Quality Index for In-centre Haemodialysis and the Renal Treatment Satisfaction Questionnaire and they are discussed in turn below.

2.3.4.1 CHOICE

The CHOICE (Choices for Healthy Outcomes in Caring for ESRD) patient satisfaction tool was developed in the 1990s in Baltimore, USA[75]. The group developed a taxonomy of aspects of care that were important to dialysis patients (both peritoneal and haemodialysis) following a focus group with 5 haemodialysis and 3 peritoneal dialysis patients. This initial taxonomy was then reviewed and edited by a group of nephrologists to develop a 98 item questionnaire. The questionnaire was subsequently used to survey 64 haemodialysis and 22 peritoneal dialysis patients in Baltimore, USA.

The ten items prioritised by *haemodialysis* patients were (in ranked order):

- How quick staff react in an emergency
- Number of staff available in an emergency
- How well the machines are maintained
- How helpful the social worker is
- The amount of information given to patients at the start of dialysis
- Care and concern from nephrologist
- Nephrologist making sure dialysis care is just right
- Nephrologist's decision about the how much dialysis is required
- Concerns about decisions regarding intra-venous fluid use
- How helpful nursing staff are

As the aim was to develop a tool suitable to be used by patients undergoing both types of dialysis not all of these priorities were included in the final CHOICE questionnaire. The peritoneal dialysis patients, while sharing some care priorities such as communication with nephrologists and patient education, also differed in other priorities. The shared tool has allowed comparisons of satisfaction with care between modalities[76], however the differences in the priorities of haemodialysis and peritoneal dialysis patients in this study suggests that separate tools may be better at measuring patient experience in these two groups. There are also concerns about the validity of the items in the CHOICE questionnaire as they were derived from a relatively small population in one US city and then modified by clinicians. The structure of the relationship between patients and their healthcare team may differ between the US and UK/Europe, with a greater emphasis on the nephrologist in the US. Consequently the items prioritised by US patients may differ from those prioritised by UK patients.

The authors went on to use their questionnaire in the CHOICE study; a multi-centre cohort study in the US assessing the treatment choices and outcomes of those starting dialysis[76]. The main focus was a comparison of ratings of excellent between those on haemodialysis and peritoneal dialysis. The items that haemodialysis patients ranked most often as excellent were caring of nurses; caring of staff; response to pain; and attention to cleanliness of access site. Just over half of haemodialysis patients rated their overall care as excellent (56%). The items with the lowest ratings were co-ordination with other physicians; frequency of seeing a nephrologist; accuracy of information provided by nephrologist; amount of information on choosing haemodialysis or peritoneal dialysis; and amount of fluid removed.

Peritoneal dialysis patients reported higher overall ratings of care. The three items with the greatest differences in rating between the dialysis modalities (after adjustments for baseline characteristics) were all related to information provision (amount of information on choosing haemodialysis or peritoneal dialysis, the amount of dialysis information from staff, and the accuracy of information from nephrologist). This is an interesting finding as it suggests that information provision may play an important role in satisfaction with care for dialysis patients. It also suggests that the way in which care is provided may change patients' perceptions of whether or not information needs have been met. However this was a cohort study and patients self-selected peritoneal dialysis or haemodialysis; it is therefore possible that the personality characteristics of those selecting a home based therapy also influenced perceptions of satisfaction with care, and their information needs. Satisfaction with care was also measured only a few weeks after starting dialysis, hence the results may not be applicable to patients who have been dialysing for longer periods.

In a further paper, the same group of authors also investigated the relationship between overall patient satisfaction and the frequency of seeing a nephrologist using the CHOICE study data[77]. They found no relationship. As described above, patient satisfaction is complex, hence it is perhaps unsurprising that a single variable could have a significant impact of patient satisfaction. Additionally, as patients spend more time with nursing staff it could be hypothesised that patients' experience of care from the nursing staff is more likely to be related to satisfaction with care than care from their nephrologist. This hypothesis is supported by the finding in Van der Veer et al.'s 2012 paper[78] (see 2.3.4.3 The Consumer Quality Index for In-Centre Haemodialysis Care) that the largest percentage of variance of ratings between dialysis centres could be explained by patients experiences of nurses' (not nephrologists') care. However, Van der Veer et al.'s study was carried out in the Netherlands and as discussed above there may be differences in the structure of patients' relationships with their health care providers between Europe and the US.

A recent paper reported the results of a survey of 1,846 patients in Poland, Hungary, Italy, Portugal and Argentina using the CHOICE tool[74]. Their primary outcome measure was the number of patients rating their overall care as excellent. Results were adjusted for numerous confounders. Less than half of respondents rated their overall care as excellent (46.5%) and there was significant variation between countries, with 13.7% of respondents in Poland rating overall care as excellent compared with 83.8% in Portugal. The three items that patients most often rated as excellent were 'attention of staff to cleanliness of access site', 'caring and helpfulness of nurses', and 'response of staff to your pain or discomfort'. Again there was considerable variation between countries, with 83.8% of patients in Portugal rating cleanliness of access as excellent and only 18.1% of patients in Poland. The top four ranked items were the same as in Rubin et al.'s 2004 study[76], despite being carried out in a different population of dialysis patients, in different continents, over 10 years after the original study was carried out. This stability of these areas of satisfaction suggests there may be utility in focusing on areas of lower satisfaction as potential areas for quality improvement.

Four of the five items that were least often ranked as excellent by the study population related to information exchange (amount of information from staff when choosing PD or HD, amount of dialysis information from staff, accuracy of information from nephrologist, and accuracy of instructions from nephrologist). The other item in the bottom five was 'ease of seeing a social worker', although this was only included in the questionnaire in Hungary. The authors observed that caring and concern of staff, especially nursing staff, tended to be ranked highly, while items related to delivery of information were ranked lower. This is in contrast with Rubin et al.'s 2004 study[76]. While both studies ranked accuracy of information from nephrologists and information when choosing PD or HD in the bottom five, the other low-ranking items in the Rubin et al.'s 2004 study[76] focused on processes of care (frequency of seeing a nephrologist, co-ordination with other physicians and amount of fluid removed). This could represent differences in health care organisation between the US and Europe/South America, or an improvement in dialysis care in the decade between the two studies. However we do not know if changes in care over time can result in changes in scores when using the CHOICE patient satisfaction tool as no studies have investigated this.

Palmer et al., 2014[74] found a positive relationship between a composite score of clinical outcomes in different countries and ratings of overall care as excellent, but they did not find any relationship between specific clinical outcomes and excellent ratings. Consequently there is no evidence to suggest that focused attempts to improve particular clinical outcomes would result in improved satisfaction with care.

From this study, it is not clear why there was variation in responses between countries. There may have been an influence of the quality of clinical care as shown in the relationship with the composite of clinical outcomes, but this is unlikely to explain all the difference. As the authors acknowledge, they did not assess the influence of different healthcare systems. Additionally patients in different countries may have different expectations or cultural responses to care[62]. As such it would have been interesting to know whether there was significant variation between dialysis units in the same countries, but unfortunately this data was not presented.

In conclusion both studies using the CHOICE questionnaire[74, 76] have shown that patients are less satisfied with items involving information delivery. While these studies therefore provide some insight into where patients feel more and less satisfied with care there are variations in ratings between countries[74], and variations between studies in the items with lowest satisfaction ratings. Additionally there are concerns with the validity and reliability of the tool and no longitudinal or UK based data. It is therefore not clear whether the CHOICE tool could be used within the NHS to produce data that could be used to improve care from the patients' perspective.

2.3.4.2 Consumer Assessment of Healthcare Providers and Systems for dialysis (CAHPS-ICH)

This tool was developed in the US to measure in-centre haemodialysis patients' experiences of care (although it also contains 3 global ratings questions)[79]. It is therefore distinct from the CHOICE tool which aims to measure satisfaction with care. It was developed by the Agency for Healthcare Research and Quality (AHRQ) with the help of a technical expert panel. When designing the tool they also reviewed 11 submitted tools and 2 renal-specific tools identified in a literature review (which tools are not detailed). An initial feasibility study involved focus groups with patients, care givers and clinicians although no data was published regarding this[79]. I contacted the AHRQ for further details but did not receive any response.

The tool consists of 58 items covering 6 areas:

- Nephrologist's communication and caring
- Quality of dialysis centre care and operations
- Providing information to patients
- Rating of kidney doctors
- Rating of dialysis centre staff
- Rating of dialysis centre

A study of 404 patients who had been on dialysis longer than 3 months and were asked to complete the CAHPS-ICH found that centres with a higher ratio of patients to nurses scored significantly lower on the patient information questions[80]. Similarly centres with a higher ratio of patients to nephrologists had significantly poorer scores on providing information to patients, as well as lower ratings for the dialysis centre, and dialysis centre staff. They also noted that longer waiting times were associated with worse scores on nephrologist's communication and caring, and quality of the dialysis centre care. The authors concluded that in appropriately staffed units patients had a more positive experience.

As this is a relatively new scale, there are no published longitudinal studies and it is not known whether or not this tool is sensitive enough to detect changes in response to changes in care. It has been designed for use within the US health care setting and it may not be readily applicable to the UK and this would require further study. It does benefit from the advantage of being primarily a patient experience rather than satisfaction measure (although a lot of the analysis used in the above study used the global ratings scores which are not experience but rather satisfaction scores[80]). As it has been designed for widespread use in the US, hopefully longitudinal data will become available but the challenge of responsiveness to changes in health care provision remains.

2.3.4.3 The Consumer Quality Index for In-Centre Haemodialysis Care

This tool is based on the generic Consumer Quality Index tool developed in the Netherlands[78]. The index tool is designed to measure patient experience, but additionally when the tool was piloted, respondents were asked to give a priority rating to each item. The authors argue this allows care providers to focus on areas with the biggest scope for improvement first. Van der Veer et al., 2012[78] used the CQI method as a basis for developing two measures; one for in-centre haemodialysis; and one for peritoneal and home haemodialysis. The items in the in-centre tool were derived from a previous patient survey used in the Netherlands as part of their dialysis centre certification process. They also held focus groups with 11 in-centre haemodialysis patients and 8 staff members. Various feedback rounds of the initial tool followed with interested parties.

Following piloting the tool consisted of 10 domains containing a total of 42 experience items. The authors state they based their survey method on the CAHPS and therefore acknowledge similarities.

The domains covered are:

- Nephrologists' care and communication
- Nurses' care and communication
- Social workers' care and communication
- Dieticians' care and communication
- Communication and co-operation between care providers
- Organisation of care delivery
- Medical tests
- Information in general
- Information on patient federation
- Environment during dialysis sessions

There was a high percentage of optimal care scores in many of the items. The three items given the highest priority rating by patients were; being taken seriously by nephrologist; having to wait <15 minutes for a taxi; and information on a centre's fire procedures. When they derived a quality improvement score (priority score multiplied by experience score) the top three items were; information on centre's fire procedures; waiting for a taxi <15 minutes; and nephrologist providing information for shared decision making. Of the ten items with the highest quality improvement scores, the other 7 were all features of communication and relationships with nephrologists and nurses. They found that the score for experience of nurses' care was the variable explaining the greatest variance in a centre's global ratings. Although they argue that this is why it is necessary to assess dietician and social workers' care separately (in contrast to the CAHPS), no features of dietician or social workers care were found in the top ten items prioritised by patients in the study.

Half of the items included in the pilot questionnaire were removed, either because insufficient numbers of respondents had experienced the item or because >90% of patients reported an optimal experience. The authors acknowledge that the final tool is specific to the Dutch health care setting, as patients in other countries may have different experiences of the items, and the items included in the final tool would be different. A limitation of the study was that the response rate was low (47%), and there was no comparison of characteristics of respondents and non-respondents. The priorities and ratings of items that informed inclusion in the final tool may therefore not be representative of the whole dialysis population. However the prioritisation process ensures that the survey is attempting to examine aspects of care that are important to patients and the specificity of questions highlights areas which can then be targeted to improve care. Again, longitudinal data are awaited.

2.3.4.4 The Renal Treatment Satisfaction Questionnaire (RTSQ)

This tool was designed to measure patient satisfaction with renal care for patients on haemodialysis, peritoneal dialysis and those with a kidney transplant[81]. The tool was developed using qualitative data from 40 interviews with patients at 2 renal units in the UK conducted for another study. The draft version used 6 items from the Diabetes Treatment Satisfaction Questionnaire in addition to a further 6 renal specific items. The final RTSQ was used to survey 179 patients in one UK centre, 25.4% of whom were receiving treatment with haemodialysis. One item was removed following piloting of the survey resulting in an 11 item scale.

The final 11 items were:

- Satisfaction with current treatment

- Satisfaction with control over renal condition
- Convenience of treatment
- Flexibility of treatment
- Satisfaction with freedom afforded by treatment
- Satisfaction with understanding of condition
- Satisfaction with time taken by treatment
- Discomfort or pain involved with treatment
- How well treatment fits in with lifestyle
- Would you recommend this treatment to others?
- Satisfaction to continue with present treatment

The survey showed that patients who had a kidney transplant were significantly more satisfied than those on peritoneal and haemodialysis. The authors concluded that as the RTSQ was sensitive to differences in scores between transplant and dialysis treatment groups it is effective in assessing differences in satisfaction between modalities.

In contrast to other tools, and despite the focus on communication seen in other studies of patient satisfaction, none of the items in the RTSQ directly assess satisfaction with communication. While satisfaction with understanding of condition may be considered an outcome of communication, studies have found that patients also value other outcomes and aspects of communication with staff[70, 71, 78].

As this tool is not specific to either dialysis care in general or haemodialysis it is not able to assess satisfaction with the more specific areas of treatment relevant to this patient group, hence its function as a tool for quality improvement is limited. As a more general measure it is able to compare all forms of renal replacement therapy, however this may have less utility and this is perhaps reflected in the lack of published literature that has used the RTSQ.

2.3.5 Demographic relationships with patient satisfaction and experience scores

If patient experience or satisfaction measures are to be used to compare populations such as dialysis units or countries it is important to understand the influence of demographics on the scores of such tools. Unless these potential confounders are considered, comparisons that are made cannot be assumed to result from differences in care provision alone. This is of particular significance when payments may be linked to outcomes from such tools (as has been suggested in the USA).

2.3.5.1 Age

Older age has been associated with higher satisfaction with care in many studies, both of dialysis patients[74, 82] and in other populations[83, 84]. A study of the satisfaction of patients with end stage kidney disease as compared with other Medicare beneficiaries in the US also found no correlation between patient satisfaction and age in their large ESRD population[85]. Similarly Rubin et al. 2004[76] found no relationship with age although the mean age in their study population was 10 years lower than in other studies[74, 82].

2.3.5.2 Ethnicity

Studies in the US have found that white/caucasian patients rate their care higher than non-white populations[76, 80]. In the Netherlands Van der Veer et al., 2012[82] found that those of non-European ethnicity rated their care higher than Dutch patients. While I could find no studies reporting on ethnicity and patient satisfaction or experience in UK dialysis patients, a large survey of cancer patients in the UK found that non-white patients reported lower levels of satisfaction with care[83]. Similar findings were reported in a study of patients using primary care in London[84].

2.3.5.3 Depression

Studies in dialysis patients have found associations between depression and decreased satisfaction with care[74, 76]. This has also been reported in other populations such as cancer patients[83].

2.3.5.4 Education

The results appear to be variable. In the Netherlands, those with post-secondary school education rated their care lower than those with lower than high school education[82]. Palmer et al., 2014[74] however, in their study of European and South American patients, found no relationship with educational status and similarly, in the US, Rubin et al., 2004[76] found no relationship between satisfaction with care and educational status. Yet in a larger US population, those with lower levels of education had significantly lower patient satisfaction[85].

2.3.5.5 Co-morbidities and health status

Some studies have found a negative correlation between the number of co-morbidities and satisfaction with care[76, 82]. However this is not a consistent finding[74]. Similarly poorer self-reported health status has also been associated with lower satisfaction scores[82, 85]. However again this is not a consistent finding across studies[76].

Findings of associations between demographic factors and satisfaction with care are thus variable between studies. This may be a result of differences in societal construct, expectations and systems between countries[62]. The tool or method used, and response rates are also likely to affect results. Many of the present studies examining such relationships also involve small populations and may not have the power to examine these relationships fully. There is a lack of consistent evidence, and no evidence pertaining to UK dialysis patients. However as there is no consistent measurement of patient satisfaction/experience in UK dialysis patients, this is not unexpected. It is important to acknowledge that the above factors are potential confounders that may affect the results of patient experience measures and which will need further exploration. If these tools come into mainstream use (as is planned for the CAHPS-ICH in the US) consequent data should allow assessment of these factors in more detail.

2.4 Conclusion

Measured quality of life is associated with many socio-economic, demographic and comorbidity factors. While certain aspects of haemodialysis care are likely to have an impact on quality of life, some aspects of quality of life are unlikely to be changed by an individual's experience of haemodialysis. Tools designed to measure quality of life, therefore do not necessarily measure something that is important to patients, and it is not clear whether the data they generate can be utilised to improve care in a way that is meaningful to patients.

More recently patient experience measures have been developed for haemodialysis in the Netherlands[78] and the USA[79], but we do not know if patients in the UK share the same priorities for care as those being cared for in different countries and within different health care systems. A recent expert consensus meeting for the European Renal Association examined the evidence for current patient experience measures in renal replacement therapy and concluded that more work needed to be done before a specific PREM could be recommended for use[24].

To be able to successfully evaluate care from the patient's perspective we require an understanding of the aspects of care that matter to patients. As a result in the second part of my literature review I present the results of a thematic synthesis of the experiences of adults living with haemodialysis and this is presented in the next chapter.

Chapter 3 A thematic synthesis of the experiences of adults living with haemodialysis

3.1 Introduction

My review of the current tools used to assess the patients' perspective on care quality highlighted the importance of ensuring that such tools are measuring the aspects of care that are important to patients, rather than the care priorities of clinicians or managers. Consequently I felt it was necessary to examine the literature relating to what haemodialysis patients feel is important about their care. No previous studies have addressed this specific question, however qualitative studies have explored patients' experiences of life on dialysis. I therefore decided synthesising this qualitative research would enable me not only to review what was already known, but additionally to develop concepts that could inform and be explored through my research.

3.2 Synthesising Qualitative Research

The synthesis of qualitative research aims to combine individual primary qualitative studies, of a subject of interest, to develop a new or enhanced understanding [86]. Qualitative research does not aim to produce findings that are generalisable to other situations, but instead to offer a rich description of particular groups within a specific context and offer generalisations at the level of concepts and themes [87]. Within the area of health care this can make it difficult to use qualitative research to inform practice or health care policy [88, 89]. The synthesis of qualitative research offers one way of responding to this problem. However, qualitative research is an umbrella term for many different research methodologies developed from different epistemological stand points [87]. Some have therefore criticised the amalgamation of qualitative studies as fundamentally flawed [90]. Additionally, the aggregation of data within individual studies has been considered as damaging to the integrity of the results of the individual studies, consequently bringing into question the validity of the conclusion of any such synthesis [88, 91]. Others have argued that bringing together the data from a group of qualitative studies allows a greater understanding of the topic of interest; the ability to derive new theory; results in conclusions that are more generalisable; or can suggest areas for further research [86, 90]. Additionally when considered within the context of health care, synthesising data can make qualitative research more accessible and therefore improve its utility to health care practitioners and policy makers [92]. The focus of my research question is to address what is important to patients about their care, so as to understand how we measure the quality of care from the patient's perspective. Synthesising the findings of the wide range of qualitative papers exploring the experiences of living with haemodialysis would allow me to develop concepts about the experiences of living with haemodialysis which could then be further explored in my research. While I therefore acknowledge the potential weaknesses that are debated regarding the synthesis of qualitative data, I felt the potential of this strategy to draw meaningful conclusions outweighed these concerns.

3.3 Method

3.3.1 Selection criteria

Primary qualitative studies exploring the experiences of adults aged 18 years or older receiving haemodialysis were eligible for inclusion in the thematic synthesis. As the aim of the synthesis was to understand the experiences of patients being treated with haemodialysis, studies that included patients receiving other forms of renal replacement, home haemodialysis exclusively, or the views of health professionals were excluded. As the views of patients with kidney disease and their carers may differ [93] studies in which the views of carers were sought were also excluded. Dialysis care is a relatively new area of health care and has changed considerably since it was first available [94]. To ensure relevance to current care the search was limited to papers published in the past 20 years. Due to resource limitations, articles not written in English or for which the full text was not available were also excluded.

3.3.2 Literature Search

With the assistance of a librarian I developed a search strategy to try and identify all relevant papers. Medical subject heading (MeSH) terms and text words for haemodialysis and chronic kidney disease were combined with terms found to be effective in identifying qualitative studies [95]. The initial search findings were combined with further terms to identify relevant studies (Appendix 1). Searches were performed in Embase, MEDLINE, CINAHL and PsychINFO in January 2015. Google Scholar and reference lists of relevant papers and reviews were also searched. I conducted an initial screen of titles and abstracts, full texts of potentially relevant studies were then obtained and assessed against the inclusion and exclusion criteria by myself and a colleague.

3.3.3 Assessment of the quality of included studies

The need for criteria for appraising the quality of qualitative research is not universally agreed [96, 97]. When conducting systematic reviews and meta-analyses of quantitative data, the quality assessment of included trials is crucial to minimise bias [98]. Most authors of synthesises of qualitative data have similarly attempted an assessment of quality. In systematic reviews of quantitative research, trials that are assessed to be poorly designed or conducted are excluded. However, it is less clear what should be the done with the results of a quality appraisal in qualitative synthesis [99]. While recognising the debate regarding the appraisal of qualitative studies, I decided to appraise the included papers to ensure they were answering the question that my thematic synthesis was aiming to address, and that there was no fundamental flaw in the research that questioned the validity of the findings before I proceeded to synthesise the data.

The use of critical appraisal tools or checklists are again controversial [99], however I decided that use of a tool would provide a clear record of my decisions regarding the appraisal process, and also allow for confirmation by others. There is little consensus on the most appropriate strategies for appraising qualitative research [96]. I therefore reviewed and piloted various tools and chose to use the Critical Appraisal Skills Programme (CASP) qualitative research checklist [100]. The CASP checklist is a recognised tool and has been used previously in systematic reviews of qualitative research [96, 101]. It utilises two screening questions followed by a further 8 detailed questions. The questions require a yes; no; or unsure response, which I felt was less subjective than other checklists which utilise a grading system for each question. The prompts that accompany the checklist also allow for constant referencing of the exact query of each question on the checklist.

One of my supervisors and I independently appraised the included studies using the CASP checklist and disagreements were resolved through discussion. All studies satisfied the initial two screening questions of the CASP checklist and were considered relevant to the review (there was a clear statement of relevant aims and a qualitative methodology was appropriate). As there are currently no accepted methods for the exclusion of studies based on their appraisal score I decided to include all the studies in the synthesis if they passed the first two screening questions [92, 96].

3.3.4 Synthesis of Findings

Many methods for the synthesis of qualitative research have been developed and the evaluation of these methods is still evolving [102]. The question that the synthesis aims to answer, and the data identified for the synthesis are therefore important considerations when choosing a methodology[98].

This synthesis was approached from a critical realist perspective, which accepts the existence of an independent social world that can only be understood through the interpretations of both research participants and researchers [103]. Thematic synthesis is not restricted in its use to a particular methodology and is an established method which aims to preserve a transparent link between primary studies and conclusions. I therefore considered it as an appropriate method of synthesising qualitative research for this review [92, 104]. Thematic synthesis is also a well structured method which I felt suited my needs as a novice synthesist [86].

The studies identified for the review involved descriptions of patients' experiences of life on dialysis across a heterogeneous group of papers, with different aims and conducted in different patient populations. Thematic analysis allows the identification of common themes across such a group of studies and therefore appeared a suitable method to apply [102]. Thematic synthesis, in common with other synthesis methods such as meta-ethnography, aims to use the primary data from incorporated studies to develop new interpretations [104]. While the studies in this paper did not directly answer my primary research question, utilising thematic synthesis could be used to develop an understanding of their experiences of life on dialysis that are relevant to their care.

Following the methodology for thematic synthesis described by the authors [92], I extracted all the results or findings from the included papers and coded the text line-by-line. The coding was then reviewed by one of my supervisors. Line-by-line coding allowed the translation of findings from one study to another [92]. Codes were developed to represent new concepts until all the data from the included studies had been coded. The final codes were then examined for similarities and grouped into 14 descriptive themes (Table 1) [92]. These were analysed to consider the effects of dialysis dependence on peoples' lives, and how this was relevant to care provision, to form analytical themes. This led to the construction of 4 analytical themes. The draft descriptive and analytical themes were presented to my supervisors, and through discussion, the descriptive and analytical themes were developed and finalised. The analysis was managed using NVivo version 10.

Table 1. Codes contributing to descriptive and analytical themes

Analytical theme	Descriptive themes	Contributing codes
A new dialysis dependent self	Changing identity	Altered body image Dependence and vulnerability Loss of identity
	Effect on family roles and relationships	Effects on family Guilt
	Changing social world	Impact on involvement in social world Lack of understanding from social world New social networks
	Changing future	Loss of future plans and ambitions Uncertainty Facing the threat of death
A restricted life	Constraints on time and diet	Desire for quality of life Restrictions imposed
	The effect of symptoms	Emotional impact

		Fear of things going wrong
	Loss of choice and freedoms	Incarceration Work of maintaining the dialysis regimen Time lost
Regaining control	Gaining own expertise	Testing boundaries Using test results to make decisions Shared decision making Critical events as motivators Developing own knowledge and abilities
	Accepting dialysis dependence	Gift of life Future hope Finding satisfaction in life Striving for normality Utilising time on dialysis Living on borrowed time Peer comparison
	Adjusting and accommodating dialysis	Gaining control Improvement in health at initiation of dialysis

		Seeing the dialysis unit as a place of safety and security
		Time as an agent to normalisation
		Release from burden of PD
		Being realistic
Relationships with health professionals	Information sharing	Knowledge requirements
		Uncertainty about the future
		Information sharing
	Building relationships with professionals	Continuity of care
		Being seen as a whole person
	Balance of power within relationships	Asymmetry of power
		Passivity
	Seeking expertise	Health care professionals’ knowledge and skills
		Access to health care professionals

3.4 Results

3.4.1 Literature Search

My search yielded 1369 articles from which 17 studies [35, 36, 105-119] involving 576 patients were included in the synthesis (Figure 2). The characteristics of included studies are shown in Table 2. The studies were published between 1998 and 2015 and included patients aged between 19 and 93 years. Studies were conducted from Europe (n=9), North America (n=5), Australasia (n=2) and Asia (n=1).

Figure 2. Results of search strategy and identification of included studies

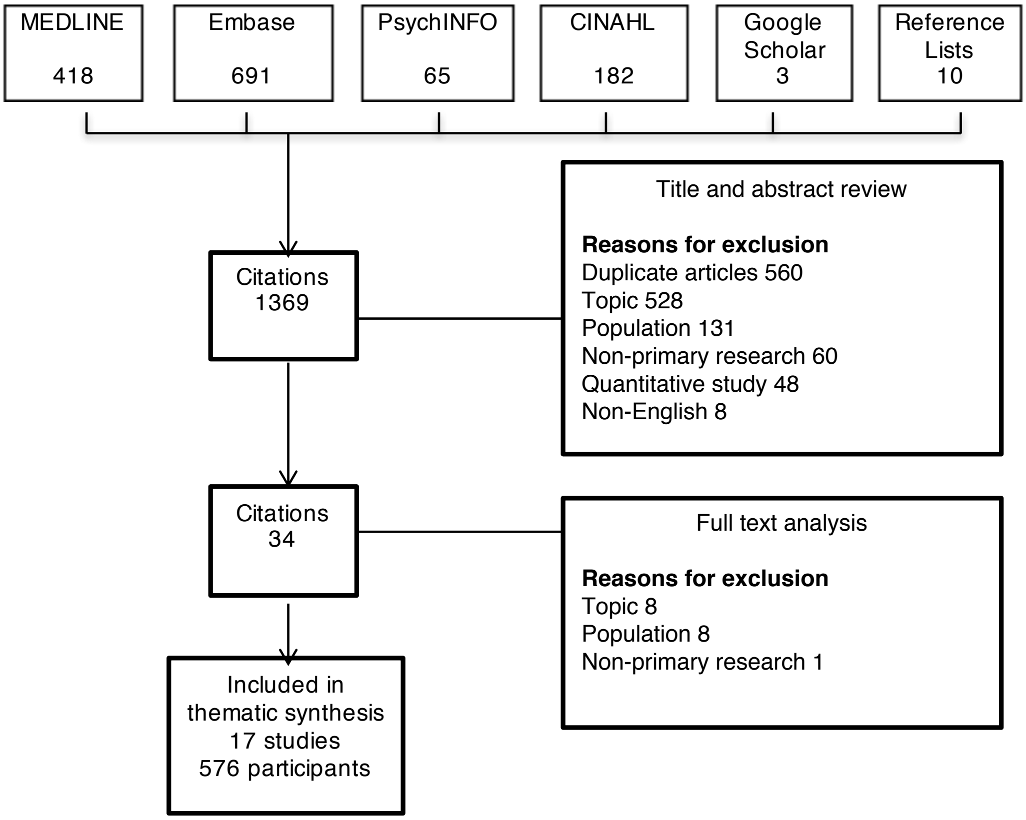


Table 2. Included studies

Study	Country	Year	Number of patients	Age of patients	Gender of patients	Duration of dialysis	Population	Data Collection	Method
Aasen et al.	Norway	2012	11	>70	4 F 7 M	4 1 year or less; 3 1-2 years; 4 4-6 years	5 hospital units	Interviews with open ended questions	Critical discourse analysis
Al-Arabi	USA	2005	80	>18	Not reported	Not reported	Community based out-patient dialysis centre	Semi-structured interviews	Naturalistic inquiry methods
Allen et al.	Canada	2011	7	38-63	3F 4M	Not reported	2 hospital units	Field observation, interviews and focus groups	Participatory action research
Anderson et al. *	Australia	2012	241	> 20	116 F 125M	Not reported	9 hospital renal wards and 17	Semi-structured	Thematic analysis

Axelsson et al.	Sweden	2012	8	66-87	3 F 5 M	15 months to 7 years	2 university hospital dialysis clinics and 2 smaller satellite centres	Serial qualitative interviews	Phenomenological hermeneutical method
Calvey and Mee	Ireland	2011	7	29 - 60	Not reported	1 month to 5 years	Not reported	Interviews using open-ended questions	Colaizzi's phenomenological method
Curtin et al.	USA	2002	18	38 to 63	8 F 10 M	16 to 31 years	Recruitment not clear	Semi-structured interviews	Content analysis
Gregory et al.	USA	1998	36	19-87	18 F 18 M	Mean of 2.66 years	1 university teaching hospital unit	Semi-structured interviews	Grounded theory
Hagren et al.1	Sweden	2001	15	50-86	8 F 7 M	6 <1 year 4 1-3 years 5 >3 years	1 dialysis unit	Semi-structured interviews	Content analysis

Hagren et al. 2	Sweden	2005	41	29 to 86	15 F 26 M	Not reported	3 hospitals	Semi-structured interviews	Content analysis
Herlin and Wann-Hansson	Sweden	2010	9	30-44	4 F 5 M	Not reported	1 public hospital and 2 private clinics	Interviews	Giorgi's phenomenological method
Kaba et al.	Greece	2015	23	Mean age 62	8 F 15 M	Average 5.7 years	2 hospital dialysis centres	Interviews	Grounded theory
Karamanidou et al.	UK	2014	7	32-68	4 F 3 M	2 to 7 years	1 renal satellite unit	Semi-structured interviews	Interpretive phenomenological analysis
Lai et al.	Singapore	2012	13	39-63	7 F 6 M	2-5 months	1 dialysis centre	Semi-structured interviews	Interpretive phenomenological analysis
Mitchell et al.	UK	2009	10	2 20-30; 1 30-50; 5 70-80; 2 >80	5 F 5M	2<1 month; 6 1-3 months; 2 4-6 months	1 medium sized renal unit	Semi-structured interviews	Content analysis

Russ et al.	USA	2005	43	70-93	26 F 17 M	Not reported	2 dialysis units (1 inner-city and 1 private)	Interviews	Phenomenological analysis
Shih and Honey	NZ	2011	7	46 -77	Not reported	4 to 10 years	1 satellite dialysis unit	Semi-structured interview	Heideggerian hermeneutical analysis

*Demographic information relates to a larger study from which descriptions of those on haemodialysis are reported in this paper.

3.4.2 Quality Appraisal

All 17 papers passed the initial screening questions and were included in the synthesis. Two papers satisfied all 10 items on the CASP checklist [100] (Table 3). Most studies reported a sufficiently clear and rigorous approach to data analysis. However in 4 studies insufficient information was reported. The need for transparency and full reporting is important for readers to understand the context within which the results are presented, as well as making an assessment of the credibility of the findings. However I felt that, despite a lack of information regarding the methodologies of some papers, the information that was provided was sufficient to ensure the methods were not fundamentally flawed.

One paper (Russ et al., 2005) satisfied only 5 items on the checklist. One of the recognised difficulties in assessing the worth of a qualitative paper lies within balancing the need for a transparent and well documented research process, against the relevance and value of its insights to the question posed [120]. Using the information provided in the paper the overall quality of this study is uncertain. However it presented highly relevant results that were well illustrated through patient narratives.

Table 3. Results of CASP checklist appraisal

	Clear statement of aims	Appropriate methodology	Appropriate design	Appropriate recruitment strategy	Appropriate data collection strategy	Relationship between researcher and participants adequately considered	Ethical issues been considered	Rigorous data analysis	Clear statement of findings	Value of research
Aasen et al.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes
Al-Arabi	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Allen et al.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes
Anderson et al.	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Unsure	Yes	Yes
Axelsson et al.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Calvey and Mee	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes
Curtin et al.	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Gregory et al.	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes

Hagren et al. 2	Yes	Yes	Yes	Yes	Yes	Unsure	Unsure	Yes	Yes	Yes
Herlin and Wann-Hansson	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kaba et al.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Karamanidou et al.	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes
Lai et al.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Mitchell et al.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Russ et al.	Yes	Yes	Yes	Unsure	Unsure	No	No	Unsure	Yes	Yes
Shih and Honey	Yes	Yes	Yes	Unsure	Yes	No	Yes	Yes	Yes	Yes

3.4.3 Synthesis

Analysis resulted in 14 descriptive themes, which contributed to 4 analytical themes. Namely: a new dialysis dependent self, a restricted life, regaining control and relationships with health professionals. The descriptive themes identified in each study are shown in Table 4. Selections of quotes to illustrate each theme are given in Table 5.

3.4.3.1 A new dialysis dependent self

Participants described how dialysis dependence had caused changes in many aspects of life, which consequently led to changes in their perception of self.

3.4.3.1.1 Changing identity

When commencing haemodialysis some participants struggled with feelings of vulnerability and their dependency on both dialysis treatment and caregivers [35, 36, 105, 107, 109-112, 115-119]. The "assembly line" [107] nature of dialysis and lack of interest shown by dialysis unit staff could also result in a loss of identity [105, 107, 109, 115]. Interference with earlier roles in society and social networks could also affect their personal identity. Those required to give up employment reported this affected their sense of self as reliable and able to provide for their families [110, 115, 119]. Additionally dialysis was seen to affect the physical self through the creation of vascular access (fistulae and dialysis lines) and other changes in appearance [35, 110, 116, 118, 121].

3.4.3.1.2 Effect on family roles and relationships

Participants valued family support but some reported that their role or relationships within the family had changed as a consequence of their dialysis dependence. Participants expressed frustration as dialysis resulted in a lack of time, energy or required relocation which resulted in them being unable to care for family members or carry out family duties [108-110, 115]. Some participants were now dependent on family for care or assistance and worried that they had become a burden to them [36, 109, 110, 116, 117]. Participants who thought their dialysis dependence had restricted their families' activities, such as holidays, also reported guilt [36, 110, 115].

3.4.3.1.3 Changing social world

Dietary and fluid restrictions, time spent on dialysis, and symptoms such as fatigue affected participants' abilities to engage in previously enjoyed social activities [35, 109, 110, 112, 113, 115, 118, 119]. Some participants were reluctant to discuss dialysis dependence with others or perceived they lacked understanding and compassion [108, 111, 112, 121]. Consequently this resulted in difficulties maintaining social connections and friendships. However, the dialysis unit could also provide a new social framework through the development of friendships with staff and patients [36, 107, 109, 110, 114, 115, 117].

3.4.3.1.4 Changing future

Participants explained that with dialysis commencement they had lost ambitions for the future such as enjoying retirement and travelling [109, 110, 116, 118]. With a diagnosis of end stage kidney disease, and consequent dependence on dialysis, patients are confronted with their own mortality [36, 109-112, 115, 116, 118]. This may be reinforced by the deaths of other patients on the dialysis unit [36, 111, 118]. The future became uncertain, as they feared complications or death [36, 109-111, 114, 115, 118]. Those waiting for a transplant also had to cope with the uncertainty of when or whether they would receive a kidney [111, 112, 114]. Many participants described feeling unable to plan for the future and consequently chose to "live in the moment" [35, 36, 109, 111, 112].

3.4.3.2 A restricted life

Dependence on dialysis presented new physical and emotional challenges to living life as they would choose.

3.4.3.2.1 Constraints on time and diet

The scheduling and time required for dialysis treatment restricts opportunities for employment, holidays and social activities. Additionally patients have fluid and dietary restrictions to which they are expected to adhere. These restrictions were often cited as sources of distress and adversely affected quality of life [35, 105, 109, 110, 112, 114, 115, 118, 121]. Participants described weighing up adherence to these restrictions against effects on their quality of life [35, 36, 109, 115, 116, 118].

3.4.3.2.2 The effect of symptoms

Some participants reported physical symptoms such as fatigue and pain [35, 36, 105, 108-110, 112-116, 118, 119, 121], or emotional symptoms including depression, anger, and isolation [35, 36, 105, 108-110, 112-119]. Physical symptoms such as fatigue were seen to further restrict the opportunities and time available to participate in desired activities [36, 105, 110, 113] and were reported to have deleterious effects on mental well being [105, 110, 113]. Many symptoms were seen to result from or be exacerbated by dialysis, and some expressed anxiety about the deterioration in health they experienced despite on-going dialysis treatment [36, 111, 115, 118].

3.4.3.2.3 Loss of choice and freedom

Some participants associated the need for dialysis with feelings of incarceration and powerlessness [35, 105, 109, 110, 112, 114, 115, 118, 121]. They reported a loss of freedom to live life as they desired. Maintaining the dialysis regimen became a job that they had no choice but to do [35, 109, 111, 113, 114, 118, 119]. Participants described losing time, not only to having treatment, but also travelling to, waiting for and recovering from their treatment [36, 109-116, 118, 119].

3.4.3.3 Regaining control

Some participants described how with time they had regained a sense of optimism and influence over the future.

3.4.3.3.1 Gaining own expertise

With time, participants developed their own knowledge and skills and this was seen as important for regaining control [35, 36, 107, 109-111, 114]. For some this knowledge came through testing boundaries set by health care professionals [105, 107, 108], while others reported health care professionals facilitated their personal abilities or knowledge acquisition [36, 113]. Participants stressed the importance of their expertise being acknowledged by professionals to allow shared decision making [105, 107-109, 112, 114, 117-119]. Making their own treatment decisions [107, 109, 112] or developing confidence in staff so decisions could be entrusted to them were seen as important ways in which control could be gained [109].

3.4.3.3.2 Accepting dialysis dependence

A process of acceptance of dialysis dependence was a common theme across studies. Participants reported differing routes to acceptance. For some it was resignation that there was no other option to stay alive [35, 36, 108, 109, 117, 118], whereas some chose to see the positives and viewed dialysis as a "gift" [121], providing life [36, 110, 111, 115, 117, 119, 121]. The support of family, friends and professionals was seen as important in coming to this acceptance [36, 116, 119]. Some patients were able to find optimism and hope for the future and this was seen to facilitate acceptance [109, 111, 115]. For many this hope was related to the possibility of future transplantation [35, 36, 110, 112, 114-116].

3.4.3.3.3 Adjusting and accommodating dialysis

Some participants found they were able to adjust to life on dialysis. They reported the importance of adapting other activities around dialysis and making the most of the time when not at the dialysis unit[35, 105, 111, 112, 114, 117, 118]. Others felt it was important to utilise the time spent on dialysis for activities such as study [114, 118]. The process of adjustment required participants to change their personal expectations [36, 111, 115, 117, 118] and was seen as an on-going process as new problems and changes in health were encountered [36, 111].

3.4.3.4 Relationships with health professionals

This final theme describes the importance of relationships with health professionals.

3.4.3.4.1 Information sharing

Some participants wanted more information from their healthcare providers [35, 36, 105, 107, 108, 110, 113]. They felt that information was not given freely, or was witheld from them [107, 108, 117]. This contributed to their feelings of uncertainty and conflicted with their attempts to obtain control [35, 105, 107-109, 118]. Some participants felt reluctant to ask questions or worried that this would be seen as complaining [105, 108, 109, 119]. As experts in their unique life circumstances, participants wanted to be listened to and involved in decisions about their care [36, 105, 107, 109].

3.4.3.4.2 Building relationships with professionals

Due to the frequency of contact with professionals on the dialysis unit, participants built relationships with staff, gaining a source of support [36, 109, 117]. Patients expressed that it was important to be seen as a whole person, not just a patient [36, 105, 107, 109, 115], and valued being cared for by staff they knew well [36, 112, 114]. Developing personal relationships also promoted confidence in care, reducing anxiety when attending dialysis [109, 114, 115].

3.4.3.4.3 The balance of power within relationships

Some participants described an asymmetry of power between professionals and patients when decisions regarding care were made [36, 105, 107-109, 118]. Some felt like passive recipients of care due to a lack of dialogue with professionals, deficiencies in understanding or confidence, or a sense of powerlessness [36, 105, 108, 109, 119].

3.4.3.4.4 Seeking expertise

Health professionals were valued for their expertise and skills, both technical and interpersonal [35, 36, 112-115]. Consequently participants felt anxious when new or inexperienced staff were encountered [36, 112, 114]. Ready access to the expertise of specific professionals, such as doctors, was also important [36, 113].

Table 4. Themes identified in each study (Number refers to the number of extracts coded at each theme in the included papers)

Themes	Aasen et al.	Al-Arabi	Allen et al.	Anderson et al.	Axelsson et al.	Calvey and Mee	Curtin et al.	Gregory et al.	Hagren et al.1	Hagren et al. 2	Herlin and Wann-Hansson	Kaba et al.	Karamanidou et al.	Lai et al.	Mitchell et al.	Russ et al.	Shih and Honey	**Total number of extracts**	**Number of studies**
Changing identity	3	6	2	0	6	5	13	7	5	2	2	4	2	5	1	3	4	70	16
Effect on family roles and relationships	0	7	0	4	3	4	0	8	5	1	0	1	3	3	3	1	1	44	13
Changing social world	0	4	3	10	4	5	3	6	1	3	5	3	1	3	5	1	4	61	16
Changing future	0	0	0	1	3	6	11	5	3	0	8	4	1	6	0	12	0	60	11

Accepting dialysis dependence	1	11	0	3	4	9	12	22	1	1	3	9	15	5	10	15	7	128	16
Adjusting and accommodating dialysis	0	18	1	1	9	2	39	20	5	2	3	6	16	1	5	19	5	152	16
Information sharing	10	1	8	9	6	1	2	13	2	2	0	1	6	2	5	17	5	90	16
Building relationships with professionals	7	0	9	1	10	1	0	12	9	3	6	5	2	0	1	0	1	67	13
Balance of power within relationships	18	0	12	2	4	1	2	16	6	1	2	0	5	0	1	1	4	75	8
Seeking expertise	1	0	0	0	0	0	0	9	3	2	3	1	2	0	0	0	0	21	7

Table 5. Illustrative quotations

A New Dialysis Dependent Self

Theme	Illustrative Quotation
Changing identity	*"I think dialysis is a detriment to maturity. I think you are placed over and over again in a dependent situation where you re-enact childlike relationships. From the machine to the staff, to the medical system, to the system that makes it all run, you know."* [111] *"There are a lot of things that we (dialysis patients) need to sacrifice. You can not work, you can not offer anything to your family."*[115] *"Looking at their (established patients') scars, I feel so scared. How do you expect me to go out in the public? I hide myself."* [116]
Effect on family role and relationships	*"My wife would have preferred it in another way. To go out, to go to a tavern, to be able to go on holidays. It's not only that you suffer but you also make others suffer."*[115] *"I don't want to start leaning on [daughter]… I don't find it easy, to be honest…I don't want to make*

	her life a misery" [117] *"I think that I am going to give a lot of trouble to my siblings, giving a lot of problems to your loved ones. They have to take time off (work) to do this and that for me… so I became a burden."* [116]
Changing social world	*"A lot of times your friends, your so-called friends, they don't really have time for you, you know, "cuz they go on with their own lives and, you know you're sitting around feeling tired. So that's not a good feeling. Lots of times friends drop you when you can't do anything."*[106] *"I can not meet my friend John any more. Because I cannot eat, I cannot drink, and I think to myself if I go out with John who drinks and eats, I will be tempted and eventually drink. And I did this once, I drank three ouzos. And the result was I had to go home and collapse. So I can not socialize with him."*[115] *"I got used to coming here and it is necessary for me to come, to meet with these fellows and the staff."*[115]
Changing future	*"Now there is a lack of purpose . . . I have nothing to look forward to at the moment."*[116]

	“How long will I live? It was the only thing I thought of - how long could one live with dialysis.” [112] *“It has a hold on my life since I can’t plan ahead and say, ‘this is for sure.”*[111]

A restricted life

Theme	**Illustrative Quotation**
Constraints on time and diet	*“Time is the worst part of it, because it takes too much time. From you, that is. You can’t do anything spontaneous, you become very tied down.”*[113] *“If you are supposed to really follow that regime, I would rather cut a couple of years off my lifespan. ... There is almost nothing you could eat. ... I certainly don’t become worse/more ill because of that. ... With moderation of course, you see, it can’t be like you can’t take even a slice of bread with cheese or two during the day. ... That much I don’t think it means. ... I don’t say that I just don’t care, you see, but they observe those test reports then... phosphate and... calcium, perhaps, but then I get scolded a bit.... They say that now you have to pull yourself together; this doesn’t go well. Now you destroy your years ... but this is my choice. ... My wife was really confused in the beginning and just tried to*

	take care and follow those lists. 'We don't do it,' I said. ... I am not able to do this." [105]
The effect of symptoms	"Itching is...the way it's been for the last couple of years makes me so depressed, you couldn't understand. I almost jumped the other night – from the balcony. If it hadn't been for my wife I would have jumped. That's how tired I am of it." [113] "This disease is very difficult, and no matter how hard you try, no matter how much strength you have, you will be weighed down with anxieties and get depressed. You are losing your self-control. I personally very often feel depressed because I asked "why me?"'[115]
Loss of choice and freedoms	*"It is mostly a mental strain. After all, I have no pain then, but one feels like being put a little bit into prison, if one could use an ugly word like that"*[105] *''Having to be here three days a week is what I call a 'command performance', no sooner do I start feeling better then I'm anticipating coming back again the next day. But there's no choice, no*

	modifying the experience."[118]

Regaining Control

Theme	Illustrative Quotation
Gaining own expertise	*"Now when I understand the machine, what the machine really does, I can go in and change the parameter...that makes me feel like I am contributing to my treatment"* [114] *"You're the doctor. I'm the patient, and let's see how we can work this together. I want to be an influence on that decision. I want to help make the decisions because I think I have a lot of [to] input on my situation"*[107]
Accepting dialysis dependence	*"It's a very different life, but I am willing to live it. I am willing to face whatever this different life brings about. I'm very aware of the drastic change in lifestyle . . . I can- not go back to the way it used to be. . . . It's like I have—I've lived two lives. One life when I was healthy and then this life with this illness."*[111] *"So I'm just really, really, lucky, or I could be pushing up the daisies."*[117]

	“When I got sick, and started with hemodialysis, I felt that I had to use the time. I started to study and therefore I have a life outside the dialysis. Now the dialysis is just a little part of my whole life and the other is with my studies, that is the real me... The dialysis is just something that I do in between” [114]
Adjusting and accommodating dialysis	*“It’s hard at first but you get used to it ... if people are socializing and you can’t maybe have as much as them or ... you can’t do what they are doing ... but you have got to be grown up about it and realize well it’s one of those things where you have just got to put up with so ... it’s hard but it’s ... you just have to get on with it ... Cause I’ve been doing it for so long now ... it’s more natural now than if I was, you know, not ill ...”*[35] *“I think you’ve got to be realistic...I’ve just got to readjust my life and do what I can”* [117]

Relationships with health professionals

Theme	**Illustrative Quotation**
Information sharing	*“[Doctors] think you don’t know what you are talking about. You’re not supposed to question.”* [36]

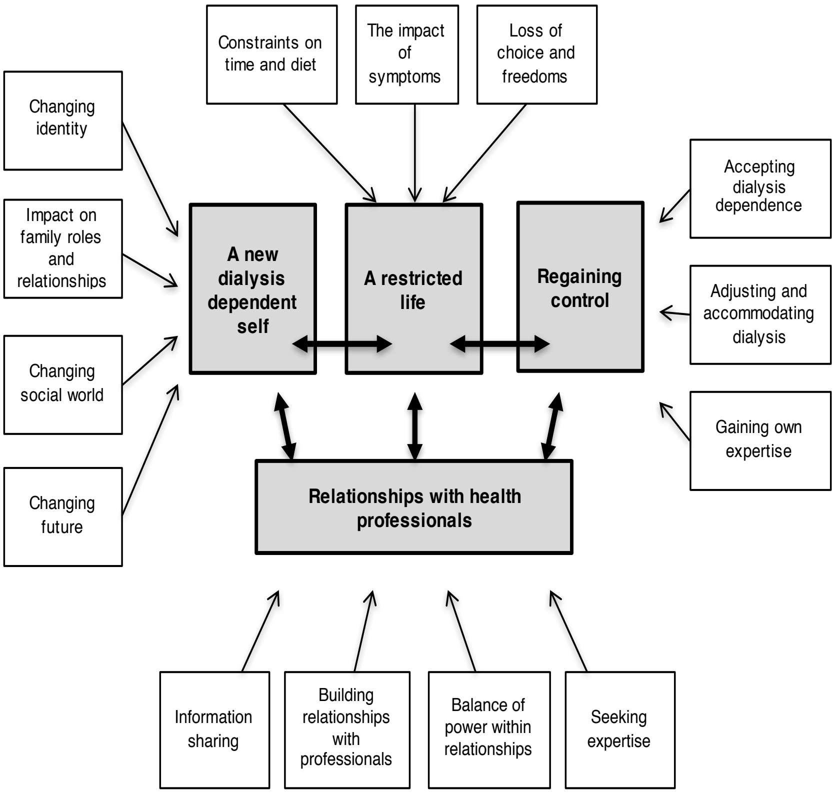
	"I want more information. ... Nurses do not tell me anything, other than the blood percentage. ... They could talk more about the illness and how it develops". [105] *"I can't fathom it. I can't look at my kidney, put it in my hand, and examine it myself. Why do I have to be on dialysis? What is kidney disease? How much of it [i.e., the disease] do I have to have before I need to be on dialysis? I ask these questions, but their only answer is to tell me to be here, to take water out of me. But that's not an answer! I'm left dangling."*[118]
Building relationships with professionals	"*When I first started the dialysis I was crying a lot. It was the head nurse who helped me to go through it and she was there for me listening to my problems. Without her I couldn't continue."*[115] *"The personal chemistry must work for me...otherwise they are not allowed to canalise my fistula....[laughs] ...I must have faith in that person, faith is very important..."* [114] *"They make one round, we only have it on Tuesdays, but then we also go through everything once a month with the nurse and the doctor, that's fantastic. That creates more of a personal relationship, there's a little chatting about all sorts of things as well, at least when I'm sitting there."* [112]
Balance of power within	*"You're [doctor] not listening to the whole situation. You took a piece of it, made your analysis, made*

relationships	*your decision, and you've moved on. But I'm still here living with whatever you left me with."*[107] *"If you come in and need a lot of drainage (ultrafiltration), they say 'why do you need so much' and start nagging me. Well I know that I've been bad, but it's impossible to stop yourself when you're thirsty. I've told them 'would you last on five dl a day?', then they'll tell me 'but we're healthy!' As if I didn't know."* [113]
Seeking expertise	*"I get so nervous when there are new nurses that are supposed to learn...they really don't know how to do it, so they talk to themselves to remember, and then you get nervous yourself. Then I start to think: do they really put the tubing right? So then I get a little bit worried."* [114] *"But the fact of the matter is that if someone can't get my needle in place – which actually does happen. Some people can't do it at all. But then there are those who get it right every time."* [113] *"In my experience, you don't see many doctors…Most of them, I must say, they all know their work, they're all good…if you can get them to come in to you."* [36]

3.4.3.5 Summation of these themes

The first three analytical themes can be seen to describe a journey of change through patients' initial realisation of their new and altered self, encountering the challenges to lifestyle that dialysis presents, followed by a potential acceptance and adaptation to regain a sense of control. This process of adjustment evolves over time in response to new health challenges and changes in life circumstances. Consequently an individual's transition along this pathway is likely to be subject to fluctuation over time. The fourth theme of 'relationships with health care professionals' can be seen to influence (either positively or negatively) the other three themes and therefore the potential for change. The influence of these relationships is therefore significant when we consider how health professionals can make meaningful changes to care, or cause harm through a lack of attention to their influences on these other areas. These key themes therefore provide a new framework that can be used to consider the aspects of care that may be important to patients (Figure 3).

Figure 3. Framework of the experiences of adults living with haemodialysis



3.5 Discussion

As this framework was developed from research exploring patients' experiences of dialysis dependence, it provides an opportunity to consider the aspects that are likely to be of importance to patients. While dialysis-requiring kidney disease is recognised to be associated with increased mortality and changes in other clinical parameters, relatively less attention has been paid to the psychosocial impacts of starting dialysis [122-124]. The need for further research into the psychosocial impacts of chronic kidney disease was also highlighted in a study of patients' priorities for health research [51].

Maintenance of roles in society and family have been reported as critical for maintaining hope among patients with kidney failure and patients have deemed the provision of information on how to maintain these roles as a more important focus for care than its clinical effectiveness [125]. Greater levels of social support have also been associated with improved quality of life, satisfaction with care and rates of hospitalisation [126].

The restrictions placed on patients as a result of their dialysis dependence have significant impacts on their lives and patients may be willing to accept a reduced life expectancy in exchange for fewer restrictions [127]. Interventions that minimise the impact of these restrictions are likely to be an important aspect of care for patients. The symptoms that patients experience are also seen to restrict their lives. These symptoms may be under recognised by health care professionals [128] and have been shown in other studies to be associated with reduced quality of life and increased mortality [129, 130]. Improved recognition of these symptoms may consequently lead to improved quality of life, however, there is limited evidence regarding effective strategies for managing such symptoms [131].

This synthesis also highlighted the importance that patients place on their relationships with health professionals. This requires professionals to be aware of the need for many patients to foster relationships that enable on-going information provision, communication and support. As discussed in the previous chapter a perceived lack of information sharing has also been linked with reduced satisfaction with care [74, 78, 80]. In common with other studies, this synthesis highlighted problems with information sharing between health professionals and patients with kidney disease [74, 78, 82, 132].

Gaining knowledge is facilitated by effective communication with health professionals and was seen by some as fundamental to maintaining a sense of control. For several participants, developing self-care abilities was also an important aspect of adjustment and resulted in a sense of control over their dialysis dependence. In other health care settings obtaining a sense of control has been linked to improved outcomes, the adoption of self-care and health promoting activities [133-135]. While adequate information provision and promotion of self-care may be important to encourage control for some patients, it is not clear whether other interventions could also promote control, especially for those who choose not to self-care.

The themes reported in this synthesis were well represented across the studies. There were no clear differences between included age ranges, geographical area or time of publication. The results of this synthesis share similarities with two previous studies reporting the experience of patients living with chronic kidney disease and peritoneal dialysis [17, 136]. Both studies also emphasised the importance of realisation, acceptance and adaptation to gaining control [17, 136]. However building relationships with health professionals did not appear to be of such importance in these studies. Patients living with pre-dialysis kidney disease or other forms of renal replacement therapy are likely to spend less time with, and have reduced dependence on health professionals. The nature and influence of these relationships may consequently be different and be of more significance for those on haemodialysis.

3.5.1 Consideration of results in relation to the wider sociological literature regarding chronic illness

The experience of living with chronic illness is an important area of research within medical sociology [137]. One of the key concepts within this work is Bury's theory of biographical disruption, in which he describes chronic illness as “a major kind of disruptive experience” [138] p.169. Although Bury's original work was based on the experiences of people living with rheumatoid arthritis, comparisons can be made with the conclusions of my thematic synthesis describing the experiences of people living with haemodialysis. I have therefore explored my conclusions further using the concept of biographical disruption.

Bury described biographical disruption in three stages. First he describes a "disruption of taken for granted assumptions and behaviours" [138] p.169. At this stage people become aware of symptoms or aspects of their bodies that had previously received little attention. Following the recognition that something is different, decisions must be made about who to confide in or seek help from. The second stage involves a recognition of the uncertainty that chronic illness brings "such that a fundamental re-thinking of the person's biography and self-concept is involved" p.169. The third stage then comprises a response to the disruption that the chronic illness has caused through a "mobilisation of resources" p.170.

Bury's first recognition stage considers how people come to be given a diagnosis of a chronic disease. Unlike rheumatoid arthritis, the early stages of kidney failure have few symptoms and it is usually picked up on routine blood tests. Most patients then have a period of follow up prior to requiring dialysis. While the process of symptom recognition and diagnosis are not featured in patients' accounts of living with dialysis, patients did describe a process of recognition in relation to the new symptoms caused by their dialysis treatment. They also start to understand the impact that their treatment has on their freedom and the restrictions it imposes. In describing people living with psoriasis, Jobling [139] described how dealing with treatment regimens could become part of the problem of living with chronic illness. In the context of those who require dialysis, the dialysis itself becomes the experienced manifestation of the problem. The symptoms and restrictions with which patients live are linked to the treatment, not the disease it is treating. As dependence on dialysis then becomes the disease, the first stage of this biographical disruption can be seen as the recognition of new symptoms and restrictions caused by the treatment. Analogous to the decisions that must be made of whom to confide in and seek help from, dialysis patients need to decide whom they can talk to regarding these new experiences. The new network of health care providers with which they are surrounded then become a potential source of not diagnosis, but information about their dialysis dependent situation.

The second stage of Bury's biographical disruption has parallels with my construct of 'a new dialysis dependent self'[138]. Many of the accounts of those living with dialysis describe how almost every aspect of their previous lives are impacted by the need for dialysis, leading to changing roles and social lives. People may view these changes, and the effects of their dialysis dependence, as changing their identities; which could consequently lead to a changing perception of self-worth [140]. Bury explains that this biographical disruption requires an individual to re-write their biography in an attempt to explain and give meaning to their illness [141]. He describes meaning as being divided into practical consequences for the individual as well as its personal significance. Both of these meanings can be seen in this theme of a 'new dialysis dependent self'. While consequences on family, social lives and employment are well described, so too are the significances to their identities and the way in which they feel they are perceived by others.

A further of my constructs, 'regaining control over life', describes the aspects of patients' accounts that reflected an acceptance and adjustment to life on dialysis. Bury's third stage of biographical disruption involves the mobilisation of resources available to people living with chronic illness [138]. This requires a consideration of the context within which the person is experiencing their illness. Bury, in his original discussion, considered more practical issues such as employment and social support. While these are also of importance to dialysis patients, patients' accounts tended to emphasise the importance of personal attitudes to life; deciding to live and attempting to see the positive in their situations. Mobilisation of resources often translated to a mobilisation of emotional resources for the dialysis patient. This could be considered a result of the overwhelming impact of dialysis, making it impossible for some to continue employment, or a consequence of the guilt experienced as a result of their increasing dependence on others. Another explanation may result from the recognition of a new type of narrative, which Frank has termed the "Quest" narrative [142]. In this modern phenomenon, those with chronic illness describe utilising the experience of ill health to see if something can be learned, and then passed on to others. For dialysis patients who describe living with a constant threat of death, the quest may entail learning how to develop the necessary emotional responses to cope with this. The quest narrative may have therefore been chosen by some to describe how they discovered personal meaning and value to dialysis dependent life. As such these emotional resources emerged as an important feature of the studies included in my thematic synthesis.

The focus of much of the work on biographical disruption and illness narratives has been to give a voice to the person who is suffering chronic illness [143]. Underlying this has been a criticism of medical dominance and a desire to separate the biomedical concept of disease from the sociological concept of illness [142]. My final theme of ‘valuable relationships with professionals’ may be seen as conflicting with this focus on the patients’ voice as I turn to focus on the health care providers. However, in the papers included in my synthesis, aspects of relationships with professionals were frequently discussed. This focus may be a result of many of the included papers being written by health professionals, and targeted at a health professional readership. Similarly, as a health professional myself, I may also have focused my attention on this particular area of interest. Nevertheless, patients did describe their relationships with professionals as being very important [110, 114, 144]. In the context of haemodialysis care these relationships have also been recognised as “unique due to their frequent and on-going nature” [145] p302. As Thorne conceded, there is often tension within these relationships, and many of the codes contributing to this theme reflected frustrations within these relationships.

The distinctive nature of these relationships can be seen to influence all three stages of biographical disruption for patients. In the first stage they can provide access to information and assistance with new symptoms and a contact who has some understanding of the restrictions and challenges to living life on dialysis. In the second stage, the way in which care is organised can affect patients’ abilities to maintain life outside dialysis. Provision of emotional support and information may also address some of the uncertainty experienced. In the third stage professionals have the potential to act as a resource to help patients reach a degree of control through addressing individual’s information needs and their choices regarding dialysis provision and support. As a potentially modifiable aspect of care, a recognition and understanding of how these relationships may affect patients’ biographical disruption and narrative reconstruction could focus strategies for improvements in care.

The concept of biographical disruption has been subject to critique and modification. Of particular relevance to the context of dialysis are the concepts of 'biographical flow' [146] and 'biographical reinforcement' [147]. As Bury has acknowledged, the concept of biographical disruption must be considered within an individual personal context [148]. Pound et al., 1998 explored this further in their concept of 'normal crises', which relate to the understanding that many people have contended with previous significant disruptions to their lives, such as hardship, misfortune or other illnesses. While for some the need for dialysis may be life shattering, for others it may be just a further disruption in an already hard and disrupted life. The concept of 'normal crises' has consequently been linked to the socio-economic status and age of people when they develop chronic illness [149]. They go onto suggest that the life experiences that older age brings may provide people with the skills required to adapt and cope with disruptions. Alternatively, we may simply anticipate or accept the onset of chronic illness as we age [149].

Biographical disruption previously assumed that the individual had to do biographical work [150] to address the impact of chronic illness on personal identity. Bury refers to this as a process of legitimation [148]. Carricaburu and Pierret, 1995 considered the idea of biographical work in their study of HIV positive men. They demonstrated that the diagnosis of HIV could actually result in a reinforcement of their previous social or individual identities, rather than disruption. Dialysis patients vary greatly in age, health and backgrounds. Increasingly patients who come to be on dialysis bring with them significant co-morbidities. For these patients the concept of biographical reinforcement of their increasingly poor health and dependent status may be more appropriate, than the biographical disruption that dialysis may cause to others. This relationship between co-morbid factors and the perception of biographical disruption, or lack of, has previously been illustrated in people who have had a cerebro-vascular accident (stroke) [146].

Both of these concepts of 'normal crises' and 'biographical reinforcement' add to the argument that biographical disruption cannot be assumed, but rather each individual will experience the onset of chronic illness differently. How they experience it, is likely to depend on age, context and previously held expectations [151]. Consequently we come to focus on identity, and whether the need for dialysis treatment is perceived by the individual to require work to re-construct their identity or accepted as part of their existing perception of self. This concept may have particular consequences for the consideration of how we provide care within the dialysis unit. For example, we have recognised that while some choose to participate and subsequently carry out their own treatment, others have no interest in adopting self-care. Is this preference for the way in which their care is provided related to the impact they perceive dialysis has had on their identity? Those who have not perceived a significant impact on their identity, or who have in fact found dialysis has resulted in biographical reinforcement may be more accepting of the dependency of dialysis care, and seek a more passive role in their care. Those who perceive that dialysis has had a significant disruption to their identity, will start a process of re-construction, and as a consequence may seek a more active role in the provision of their care, with a need to develop their own skills and knowledge.

What is important to patients about their care and the way in which it is provided may therefore be linked to individual identities and the perception of disruption that dialysis care creates in their biographies as a whole.

3.5.2 Limitations

Most of the studies included in this synthesis did not report ethnicity, socio-economic groups or educational level. Additionally I excluded studies that were not published in English. As I excluded studies that included participants on other forms of renal replacement therapy, the views of some patients have been excluded from this review. Additionally due to the difficulties in searching for qualitative studies the search strategy may not have identified all relevant studies, however the themes identified were well represented across the studies included supporting the validity of the findings.

3.6 Conclusion

This synthesis has resulted in a framework that describes patients' experiences of living with haemodialysis and has facilitated a consideration of the aspects of care that may be of value to patients. The framework highlights the importance of the established relationships patients have with their health care professionals and how these relationships may influence patients' abilities to progress towards a sense of control. Comparison of the framework with Bury's theory of biographical disruption, and the literature surrounding how we experience chronic illness, suggests that the way care is provided may have important consequences for individuals' identities and biographical disruption. This synthesis has therefore resulted in a understanding of what aspects of care may be important to dialysis patients and these will be explored further in this thesis. Relating the results of the synthesis with the sociological literature has resulted in a theoretical understanding that will also inform my analysis.

My literature review therefore clarified the necessity and context within which I wish to understand patients' priorities for care. It has also resulted in the development of concepts to be further explored in the primary research which I will now describe. The following chapter discusses the study design and methodology used to address the research question.

Chapter 4 Methodology

4.1 Introduction

This chapter describes the design of the study and the methods I have employed to collect and analyse my data. Through providing explanation for my chosen methods and a description of every stage of the research process I aim to provide the reader with a clear understanding of how I arrived at my results. The chapter will cover a discussion of the standpoint underpinning the research question, the methodology and techniques used, the sampling strategy, a consideration of the role of the researcher in the research process and the approach used to analyse the data collected.

4.2 The role of qualitative research in health care

As modern medicine has been striving to provide effective patient centred care, health care providers have started to ask questions about how people experience care, and the meanings people give to aspects of health and disease [152]. While quantitative research studies the physical world, qualitative research studies how people perceive and experience their worlds [153]. Consequently, qualitative research aims to build a conceptual understanding of what people's beliefs are, and how and why they have developed [88]. Striving for care which is patient centred poses many questions which are best answered using qualitative methodologies [152] as this allows the researcher to understand the patient's world view. This recognition may have resulted in the increasing number of qualitative studies now published in medical journals [154].

In many areas of health care, quantitative surveys have been used to collect patients' views on particular issues. Surveys are a relatively cheap and quick way of obtaining data. They have the advantage of collecting data from large numbers of people in natural settings, consequently increasing generalisability. However they are unlikely to tell us why people think in the way that they do. The development of successful health policy(ies) requires an understanding of the views of those the policy will affect, but it is also important to understand why they hold these views [155]. As a quantitative method, surveys also require a pre-existing knowledge of a subject, such that a hypothesis can be tested using predefined questions. As such the nature of these questions depends on their source and does not necessarily explore the aspects of an issue that are important to those who are the subject of such research [49]. Qualitative research aims to observe how people experience a phenomenon, hence it can describe more fully the issues that are of importance to those studied [156]. When there is no or little knowledge of a subject, qualitative research can therefore be utilised to build a knowledge base and generate the questions that need to be asked.

Qualitative studies have been criticised for lacking in generalisability due to their focus on the in-depth views of a small number of participants [157]. However qualitative research does not strive to be immediately generalisable by using a representative sample in the way that quantitative research does. Instead it aims to develop from the data, new concepts and themes which challenge previous assumptions [87]. These overarching themes can then be applied to other studies and research areas at the level of conceptual or theoretical generalisations. If required, these concepts can then be further explored using quantitative approaches (such as surveys) to assess their applicability to larger populations [88].

The aim of this study is to explore what aspects of haemodialysis care are important to patients. I decided this would require a qualitative approach for two reasons. Firstly, there has been little research done in this area before. As such, a qualitative approach would allow me to address this question without posing answers that would be influenced by my assumptions as a HP. Secondly, by allowing patients to discuss their own views we gain an understanding of why particular aspects of care are important to patients and how these aspects of care are related to each other and patients' experiences.

4.3 Epistemology and Ontology

In this section I discuss the opposing epistemologies that explain the different approaches taken to developing knowledge in qualitative and quantitative research. I will then explain why, in response to my consideration of these opposing epistemologies, I chose to approach this research from a critical realist perspective.

In health care research the decision to use qualitative methods is likely to be pragmatic; a particular question may be best answered using a qualitative method. However, quantitative and qualitative research has been presented as developing from two distinct epistemologies, often referred to as positivism and interpretivism. The distinction between these epistemologies lies in their opposing ontologies; how we understand a phenomenon (epistemology) in dependent on what we believe exists (ontology)[158]. The positivist epistemology of quantitative research assumes a single reality [159]. Finding the truth of this reality requires strict control of experimental conditions to ensure results are representative of this truth and not affected by bias [160]. Criteria that minimise this bias must be met for research to be considered of high quality [98]. Many qualitative researchers do not share this belief in a single reality; rather the interpretivist epistemology underpinning qualitative research describes multiple subjective realities [87]. The researcher, rather than being considered impartial with no influence over the results, as is the case in quantitative research, is acknowledged as influencing the process [97]. In interpretivism, reality is constructed and knowledge is produced through a consensus of these constructs; additionally multiple knowledges may co-exist [87, 161].

This division of qualitative and quantitative methods on the basis of epistemology has been rejected by some authors who have argued that they are simply different tools used to address different types of research question [162]. However, this has been criticised for a failure to recognise the role the researcher plays in interpreting the data collected [163]. I agree that a pragmatic approach is needed when considering healthcare research; some questions are best answered either using a quantitative and others using a qualitative approach. However I also believe an understanding of the epistemology of qualitative methodologies is required to know how a particular method is best used and results interpreted.

This rigid epistemological dichotomy of paradigms has long been critiqued [164] and an approach which allows the use of both, is that of critical realism [103]. As a doctor I believe that bodies and diseases exist as part of a single reality and quantitative methods can be used in biological closed systems to predict outcomes. I also believe that social structures such as societies exist. However, as they are open systems, they cannot be identified independent of their effects and do not exist independent of their effects [165]. Critical realism accepts the existence of an independent reality, including a social world, but that these can only be understood through the interpretations of both research participants and researchers [103]. As such it is not ontologically restrictive and can be used to try and understand the complexities of reality and how we experience it [166]. Consequently, critical realism is seen as more suited to understanding the many interacting factors that contribute to the experience of disability, for example [166]. In view of this critical realism has also been used in the study of chronic illness. In a study of living with epilepsy the application of critical realism enabled an exploration of the interactions between biological, psychological and social mechanisms and their effects on peoples' quality of life [167]. In conclusion I believe that critical realism is a credible theory and has value for answering the research questions posed by this thesis.

4.4 Methodology

Qualitative research is an umbrella term for many different methodologies which have developed from distinct theoretical positions e.g. phenomenology, symbolic interaction etc. [168]. These theoretical backgrounds can be used to consider the different ways in which a research question can be posed and investigated. Many qualitative research methods are aligned with, and considered within a particular theoretical position, such as the use of participant observation in ethnographic studies. In contrast, critical realism recognises that the methodology chosen should depend on the subject of the research, and what one wants to know about it; it is therefore compatible with a range of methodologies [165]. As such my methods were chosen through a consideration of their effectiveness to answer the questions posed [103]. My justifications for the chosen methods are described below.

4.5 Methods

This study uses two data collection methods. The first stage of the study was a survey that collected free text written responses to the question, "what matters to you most about your dialysis care", from a large number of patients. The second stage was a series of focus groups, designed to allow patients to discuss what mattered to them in more detail. These two methods are described in turn below.

4.5.1 Survey

The first stage of this study was a survey that was distributed to all the patients undergoing haemodialysis in York and Sheffield, including in-centre, satellite and home dialysis patients. While surveys are often utilised as a quantitative method I used it primarily to collect qualitative data through one open ended question. The survey had 3 purposes. Firstly, as the literature review had revealed very little data on what was important to haemodialysis patients about their care, I considered that it would be challenging to develop a topic guide for the focus groups without relying on my own assumptions as a HP. Surveys with open ended questions have been utilised previously to gain insights into areas where there has been little prior research [169] . Consequently by conducting a survey I could collect data that could then inform the topic guide for the focus groups. Secondly gaining data from a large number of patients through a survey could act as triangulation for the focus group data [170] and aid consideration of the transferability of the findings [171]. Thirdly the survey could also be utilised as a recruitment tool for the focus groups and provide data that would aid sampling.

4.5.2 Focus groups

To answer the research question, I needed to collect the views and experiences of patients on haemodialysis. While interviews are suited to developing a depth of understanding, focus groups are considered better at providing a breadth of understanding [172]. The research question of this study is a very open question, and as suggested by my literature review patients' experiences of dialysis dependence are far reaching. Consequently I decided that my research question would be better answered by gaining a breadth of understanding from group discussions rather than the depth of an individual's experience. Additionally, to inform care provision and assessments of patient experience, I felt developing a shared understanding of care would have greater utility than individual narratives [172].

Rather than ask patients to describe their experiences of HP developed priorities, a key aim of this research was to develop an understanding of patients' care priorities. In interviews the dynamic is between the individual and the interviewer, whereas focus groups use group interaction to generate data [173]. This generation of data through interaction has advantages for this study, as it should result in less prompting being required from the researcher. Similarly the group interaction in focus groups can provide participants with ideas they have not previously considered [174]. As such participants do not only report on their views but can comment on other's opinions. Considering the views of others in the groups may also result in views changing [175]. However agreement may simply represent coercion, or participants agreeing just to get along [176]. As such focus groups can accentuate consensus and analysis should focus not only on agreement, but also consider individual opinions [174].

Understanding differences in opinions among participants is important and group interaction allows participants to explore areas of disagreement and explain their views [157]. As a result focus groups can generate knowledge of opinions on a topic and, through interaction between participants, provide insight into how these opinions have been formed. We can then start to understand the social, psychological or physical contexts in which these attitudes were constructed [176].

While group discussion may have advantages for data generation, it also poses the risk that dominant participants will lead and take over the discussion. This can stimulate debate if views are not shared, but good facilitation is necessary to ensure quieter participants are able to contribute [174].

As I was also interested in whether or not patients' views differed depending on their chosen modality of haemodialysis provision (whether they had nurse provided care, shared care, or self care at home or in the dialysis unit), I had to consider how I would compare these groups of patients. Focus groups allow people to share experiences, and therefore develop a collective identity [174]. In view of this I felt that organising the participants into focus groups with other patients who had chosen similar modes of care provision would provide further insight into preferences for care. A shared experience does not equate to shared perceptions or evaluations of care, but can act as a basis from which participants can discuss their perspectives and I thought this could provide a valuable insight into why patients have different preferences for care.

Being a participant in a group with shared experiences can also encourage patients to discuss their views more openly [157]. As I am a HP, participants may feel inhibited in criticising care in the context of an individual interview but may be more willing to share their criticisms within the context of a group. Providing participants with the opportunity to criticise care was important, as accounts of grievances can be useful in describing expectations of care [174].

One disadvantage of utilising focus groups in this study lay in recruitment, as haemodialysis patients spend large amounts of time having treatment, in different places, and at different times, whereas interviews could be carried out while patients were on dialysis. The risk of failing to recruit to focus groups was an important consideration. I did have the advantage of a large population from which to recruit and I felt that some of the difficulties in attending focus groups could be addressed by holding them at dialysis units so patients could attend before or after treatment. As focus groups appeared more suited to collecting the data that was required to answer my research question I concluded that the advantages of focus groups as a data collection methodology outweighed the logistical disadvantages and demands on the patients (which will be discussed later).

4.6 Ethical considerations

Ethical issues were carefully considered when designing the study and throughout the research process. Ethical approval was gained from Hull York Medical School ethics committee and from the National Research Ethics Service (reference 15/EM/0034). Individual approvals were also gained from each NHS site.

4.6.1 Consent

For the survey, consent was implied if participants completed and returned the survey. At the end of the survey participants were asked to give their consent to be contacted, if they were interested in attending a focus group, by signing their agreement and leaving contact details. When contacting participants who had expressed an interest in attending a focus group I provided them with a patient information sheet explaining what attending a focus groups would involve (see Appendix 2). They were also invited to ask any questions they had about the study. When participants attended for the focus group, a description of what was involved in the focus group was provided again and a further opportunity was given to ask any questions they had. I then obtained written informed consent from each participant prior to him or her taking part in the focus group Appendix 3.

It was also important that participants did not feel either coerced into participating, or that their care would be affected by declining to participate. The survey sheet explained that it was their choice whether to complete the survey or not and that their choice would not affect the care they received. This was also explained in the patient information leaflet provided to those considering attending a focus group. The dialysis unit staff distributed the surveys to patients and I only contacted them regarding attending a focus group if they expressed interest on the survey and left their contact details. Although I have previously worked at one of the units in the study I was not directly involved in the care of any of the patients at either unit during the study.

4.6.2 Confidentiality

Identifiable data was only sought to allow patients to be contacted if they expressed an interest in attending a focus group. This data was kept securely in accordance with the Data Protection Act 1998. Focus groups were recorded and then transcribed with names, places and any other identifiable data removed. The audio files were then destroyed. Prior to starting the focus group all participants were advised that their voices would be recorded. I also explained the importance of maintaining the confidentiality of others in the group, and sought verbal agreement from all participants, before commencing the focus group [174].

To maintain the confidentiality of the participants it was also important that we ensured they could not be identified from the quotations used in this thesis, or in publications. This was of particular relevance in this study as participants may be known to each other, and come from a fairly small group. Units are therefore not named in the results or analysis and quotations were only used if they did not identify the participant(s). In some cases names, places or other potentially identifiable details were changed to ensure anonymity. In addition patients are labelled with numbers rather than their names and limited demographic data are provided to protect their anonymity.

The importance of participants' privacy was also considered. Researchers must consider the information participants are willing to give, and not push for information they are not comfortable in providing [160]. One of the advantages of a focus group is that it allows participants to volunteer information or remain silent. When conducting the groups I was mindful to ensure participants did not feel coerced into revealing more information than they intended but were also given a space to speak. At the end of each focus group I also asked the participants if there were any comments they would like removing from the transcript [174].

4.6.3 Benefits and burdens for participants

The overall aim of this study is to benefit patients through developing an understanding of their care priorities, which can ultimately be used to modify care with the aim of improving services. Consequently participation in the research may be viewed as benefiting patients in general. Benefits to individual patients are harder to justify, but some focus group participants have reported finding the process cathartic [174].

There are many demands on haemodialysis patient's time and I was therefore mindful of the extra demands of travelling to and attending the focus group. I therefore tried to hold focus groups in geographically convenient places for participants and provided transport to attend the group.

When designing the study I also considered the possibility that issues discussed in the focus group may be considered stressful or difficult to answer by some participants. Patients were made aware that they did not have to answer any questions that they do not wish to. If a patient did become upset I offered to take a break and turn the audio-recorder off (this only occurred on one occasion). I only restarted the discussion if they were happy to do so. Expert facilitation can help manage situations, or discussion topics that may cause distress to participants. I was therefore helped in facilitating the groups by a researcher with expertise in focus group research.

4.6.4 Dissemination of results

It is increasingly recognised as ethically important to publish the results of research to ensure they are publically available [177]. We also have a responsibility to the participants who have volunteered their time and information to make these results available to those who are in a position to utilise them to effect change. I will therefore feedback to the units involved in the study and present the results at national meetings. I also aim to publish the results of this research in peer-reviewed journals and feed the results back to the participants, in an accessible format [160].

4.7 Subjectivity and Reflexivity

The epistemology underlying qualitative research acknowledges the influence of the researcher on every aspect of the research process from the question posed to the conclusions drawn [178]. Reflexivity requires the researcher to consider the influence they have on the research process and is a key element of qualitative research and contributes to the transparency and validity of the study [178, 179].

4.7.1 Researcher subjectivity

As discussed in the introduction I am a doctor that has worked in renal medicine for many years and have an interest in promoting self-care. These characteristics have led to my interest in this topic and affected the research question posed. However in designing the research I sought input from other specialists in the field of renal medicine as well as patients, and qualitative researchers. This collaboration was sought to ensure the research was justified and to strengthen the study design [179].

I have also considered my clinical role, experience and interest in the promotion of self-care in relation to the design of the study. To lessen the influence of my preconceptions on the aspects of care that were discussed in the focus groups, I used a survey with an open-ended question to derive data from patients to inform the topic guide. I also conducted the focus groups with another researcher who had no previous experience or knowledge of dialysis care. I believe this collaboration also helped address some of the impact my preconceptions may have had on facilitation of the focus groups. When analysing the data I considered how my preconceptions and background affected my analysis and discussed this regularly with my supervisors [159]. My academic supervisor, who again has no previous experience of dialysis care, separately coded two of the focus group transcripts and consideration of differences in coding, which were resolved through discussion, was a valuable part of the reflexive practice in this study. I have taken care to ensure that comparisons made between the patient groups are explicit, not implicit, and have tried to maintain a neutral reflexive focus when making interpretations [160].

4.7.2 My relationship with the study population

My clinical role is also likely to have affected my relationships with the participants in this study. I introduced myself as a doctor working in renal medicine to participants at the start of each focus group and a small number of the participants in York recognised me from when I had previously worked in the department. The effect of this relationship may have been different for individual participants; it may have caused some to be wary of criticising care whereas it may have encouraged others. My role as a health professional (HP) may also have prompted the participants to discuss the role of HPs in the provision of their care resulting in an overemphasis of the role of HPs and their positive influences. The presumption of my understanding of the context of the dialysis unit may also have provided data that would not have been collected without this shared understanding but could also have led to some lack of explicit discussion. Consequently my role is likely to have influenced the data generated in different ways and this must be acknowledged when considering the results of the study [103].

4.8 Research population

The study population was 2 renal units and their satellite units in the North of England (a total of 746 patients). These units were chosen as they had embedded the shared care programme over 5 years prior to this study starting and served geographically and demographically different populations. As these units are run and managed independently by distinct clinician groups, this adds a further aspect for comparison.

All patients receiving haemodialysis at either of the units (including satellite units and home dialysis patients) were invited to complete the survey. For the focus groups inclusion criteria were:

1. Patients receiving regular haemodialysis
2. Age 18 years or older
3. Able to provide written informed consent

4.9 Recruitment and sampling

4.9.1 Survey

I aimed to survey all the patients dialysing at Sheffield and York, associated satellite units and home dialysis patients between March and May 2015. I therefore met with a sister from each unit to explain the purpose of the study and to ask if they could distribute a survey to every patient and ask them to complete it while at the dialysis unit. I then phoned each unit after 2 weeks to check if they had been able to distribute and collect the surveys and returned to collect them 3 weeks later. For the home dialysis patients I asked the nurses at each unit to post the surveys (which included a stamped addressed envelope so they could be returned) to each patient.

The limitations of this method were that I had to rely on busy staff on the dialysis units to distribute and collect the surveys. Additionally those with problems with literacy or who did not speak English will have been excluded from my survey population. Unfortunately we did not have the resources to translate the survey and I asked staff not to assist patients in completing the survey as this may have biased the results.

4.9.2 Focus groups

As described above the surveys were also used to recruit patients for the focus groups. At the end of the survey, patients were asked to leave their name and contact details if they were interested in attending a focus group. From these respondents I was then able to identify a sample of participants to attend the focus groups. We aimed to recruit between 6 and 8 people for each focus group. This is viewed as the optimum number to allow analysis of interaction, while still being able to identify individual voices in transcription [174].

4.9.2.1 Group sampling

In contrast to quantitative research, the aim of sampling in qualitative research is to represent the diversity of a population [159] rather than achieving a representative sample. The populations of the two renal units in the study are geographically widespread; as such it would not be practical to ask patients from one region to come to a focus group in another region. We therefore chose to conduct separate focus groups in the two regions. Despite this geographical restriction in sampling, it was still possible for some theoretical sampling within regions.

As discussed earlier, when selecting people for a particular focus group, they should be selected for sharing a background characteristic [174]. This shared experience does not necessarily imply shared attitudes but can facilitate discussion between members of the group [174]. As one of the aims of this study was to explore whether patients' choice of haemodialysis provision (nurse-led, shared care, or haemodialysis) affected their care priorities, we grouped patients into different focus groups depending on their chosen modality of dialysis care. The groups were patients carrying out 0-1 tasks (nurse-led care), 2-4 tasks (small amount of shared care but tasks involved in setting up rather than doing the treatment), and 5-14 tasks (including home dialysis patients). Following the 5-14 and home dialysis focus group in York I felt that the home dialysis patients and 5-14 task patients had different experiences and therefore to explore this further two focus groups were organised in Sheffield; one with in-centre patients doing 5-14 tasks and a further group with home dialysis patients.

4.9.2.2 Within group sampling

The scope of this study did not allow for additional focus groups to evaluate the effect of socio-demographics on patients' care priorities. However, purposeful sampling can allow for the diversity of a population to be represented [174]. We aimed to use purposeful sampling of the volunteers to maximise the representation of the population and allow further intergroup comparison. The surveys collected patients' age, gender, length of time on dialysis, and ethnicity to allow purposeful sampling from those who volunteered to attend. While the aim was to sample patients to represent a wide range of characteristics, this was more challenging than I had expected in practice; the pool of volunteers was smaller in the 2-4 and 5-14 groups making purposeful sampling more difficult than for the 0-1 tasks groups. Due to the small numbers volunteering to participate some of the characteristics, such as gender, were more straightforward to purposefully sample than other characteristics such as non-white groups.

4.10 Data collection procedure

4.10.1 Survey

The survey collected some demographic data and then posed the free text question, "What matters most to you about your dialysis care?" Respondents were asked to list up to five things. The survey was designed by myself and then reviewed by peers and my supervisor. I then asked some patients if they would mind piloting the survey for me and tell me what they felt was not clear. This led to revision of the survey, which was then re-tested at a second unit, at which point no further changes were felt to be necessary. The surveys were then distributed as described. Once I had collected the completed surveys the data was then entered into a spreadsheet and imported into NVivo for analysis.

4.10.2 Focus groups

I conducted the focus groups with an experienced qualitative researcher with expertise in focus group research. As this was the first time I had been involved in a qualitative study this aided my learning regarding the facilitation of focus groups. Having such expertise also ensured that data generation opportunities were maximised and that any difficult situations that arose were managed appropriately. Having two facilitators for a focus group also aids smooth running of the group [174]. Previous studies utilising two facilitators have found that the differences in characteristics of the researchers can enrich data collection [180]. While I had an understanding and knowledge of dialysis care my co-facilitator did not; this likely affected our pre-conceptions as well as our personal relationships and interactions with the focus group participants and may consequently have enhanced data generation. As other authors have also reported, I found there was particular value in having a second facilitator when debriefing as we had often picked up on different features of the discussion or had different thoughts and perceptions regarding the conversations [180, 181]. These discussions aided both my analysis and reflexive practice.

The facilitator and I met several times before the focus groups to discuss the background to the study and what information we wanted to generate. I also presented the results of the survey and we discussed the topic guide. We also discussed our roles in facilitation and the organisation of the groups until we were happy with our preparation.

I had been in contact with all of the participants prior to the focus group. These contacts had either been in person at their dialysis unit, over the telephone or through email discussion depending on the choice of the participant. I also had some demographic details for each participant from their survey responses. Prior to each focus group, I discussed this information with the co-facilitator and this contextual information aided the development of rapport through informal discussions when patients first arrived at the focus groups.

We held the York focus groups in a meeting room next to the dialysis unit as this was familiar to all the participants and assisted many in attending before or after dialysis. I removed any materials that could act as prompts from the meeting room before starting the groups. In Sheffield we hired a meeting room, recommended by the research nurses, as it was central to the population with good transport links and car parking. We provided refreshments and these also aided informal discussions prior to the focus group starting. Having a second facilitator allowed me to concentrate on obtaining written consent and answering any questions while the other facilitator helped those with disabilities and made refreshments. The focus groups were recorded with two digital devices in case one of the devices failed to record.

We took the approach of jointly facilitating the focus groups. We also both took any notes that we felt were necessary during the discussion. We started each group by introducing ourselves, our roles in the study and our knowledge of dialysis. We then re-iterated the rationale and purpose for the focus groups and that any information shared would be anonymised. We confirmed that everyone understood that the discussion would be recorded and sought agreement from the group to respect each other's confidentiality. Following this we turned on the recording devices and asked each person in turn to introduce him or herself to assist with transcription.

For the discussion, I developed a topic guide utilising the survey results. However the topic guide was discussed at each debrief and modified if necessary. At the first group our introductory question, "Can you start by telling us what is important to you about your dialysis care" reflected the research aim. The participants did not appear to find this easy to answer and they seemed to want to start with narrative accounts to familiarise with each other. From the second group we therefore used the question, "Can you start by telling us a bit about your experiences of dialysis care" and this worked better. Although it did not directly ask the question we wished to answer, it did generate data that answered it. The participants enjoyed sharing their experiences and there was not much need for prompting as they often naturally discussed many of the themes from the survey data. However we used the following prompts if necessary to try and move the discussion on to cover other themes:

- What about staff? (During this discussion if not already covered we would ask about communication and how easy it was to see the HPs they were talking about)
- What about time?
- What about the dialysis unit environment? (When this was discussed we would ask about what they did on dialysis)
- What about your health?
- What about life outside dialysis?
- What about the success of treatment?
- Do you have any symptoms from your kidney disease or dialysis?
- What about the other patients?
- What about shared care/ self-care/ home dialysis? (Depending on the group)

Asking about staff was never required as a prompt but discussions mainly focused on the nurses and sometimes the doctors therefore in later groups we deliberately asked about other HPs. We also never needed the prompts about time and life outside dialysis. Only the 0-1 groups needed prompting to discuss shared care/ self-care, as this was a naturally discussed element of the dialysis experience in the other focus groups (perhaps because they knew they had been brought together because of their involvement in shared care/ home dialysis). If differences of opinion occurred we asked participants to theorise as to why they may hold different views [174]. We also found asking participants to theorise was useful when discussing choices regarding other patients' involvement (or non-involvement) in care.

We concluded each focus group by summarising the discussion, allowing participants to comment on, and check our understanding and interpretation. We also checked that no participants wished to have any comments removed from the transcript, and ensured they had contact details for myself should they wish to contact us.

Following the group, the facilitator and I shared our thoughts and observations and discussed any notes that we had made. I made notes of these discussions, which were useful to give context and record initial thoughts. These notes aided the analysis process however they did not form part of the formal analysis.

4.11 Approaches to data analysis

Analysis of focus group data differs from that of individual interviews. The unit of analysis is the group rather than the individual and analysis involves a consideration of not just what is said, but also the interactions between members of the group [172]. My analysis of the focus group data therefore includes a consideration of the interactions between participants and how these interactions contribute to understanding what aspects of dialysis care are constructed as important to the participants and why [182]. I chose to use thematic analysis to analyse the data from the free text question of the survey and the focus groups. Thematic analysis is a structured approach to qualitative data analysis that has been advocated for use by novices in qualitative data analysis and I felt it was therefore well suited to my situation [183]. It is a flexible method that can be used in studies with a variety of theoretical backgrounds and methods [184]. As a guide to my analysis I used Braun and Clarkes' six stage approach which is described below [183]. The analysis was managed in NVivo, version 10.

4.12 Thematic analysis

4.12.1 Focus groups

4.12.1.1 Step 1- Familiarising yourself with the data

The digital recordings of the focus groups were professionally transcribed. I listened to each recording alongside the transcription and my field notes to check for accuracy and familiarise myself with the data. I then read through the transcripts and started to make analytical notes.

4.12.1.2 Step 2 – Generating initial codes

I then started coding the data. Although my coding was sensitised by both my literature review and the survey data, I chose to carry out my coding of the transcript inductively. I felt inductive coding was more appropriate as this was an exploratory study and a key aspect of the study was generating an understanding of patients' priorities for care [184]. All the data in the transcripts that were relevant to the research question were coded.

4.12.1.3 Step 3 – Searching for themes

Once all the data was coded I then utilised a mind mapping application to organise my codes into sub-themes while considering the research question (see Appendix 6). These sub-themes, and the codes contributing to them, were rearranged by frequently referring back to the original data. Finally each sub-theme was given a title. For some groups of codes one particular code was used as a title for the sub-theme. The titles of other sub-themes are descriptions of groups of codes e.g. symptoms.

4.12.1.4 Step 4 – Reviewing themes

I then reviewed the sub-themes and their contributing codes and started to consider how each sub-theme was related to the overall research question. From this analysis I developed three over-arching themes. I found that writing about each of the sub-themes helped me with this analysis. At this stage some of the sub-themes were merged, renamed or broken up until I felt they encompassed all the original data.

4.12.1.5 Step 5 – Defining and naming themes

The original transcripts were then re-read in relation to the sub-themes and over-arching themes to check no relevant data had been missed and that the themes were an accurate representation of the data. The themes were also reviewed by one of my supervisors who had read the transcripts and coded a selection of them independently. The titles of all the themes were also re-considered to ensure they reflected the data they represent.

4.12.1.6 Step 6 – Producing the report

Finally I started to write about the over-arching themes and contributing sub-themes to produce my results chapters. This required some merging of coding groups into sections of the sub-themes, so the data could be described coherently. This writing also enhanced my consideration of the relationship between the data and the research question and clinical practice.

At this point the data contributing to each sub-theme and over-arching theme was reconsidered in relation to the level of self-care the participants were involved in. The data was divided into the different self-care groups and re-read looking for similarities and differences. These finding are discussed within each of the over-arching themes.

4.12.2 Surveys

When analysing the answers to the free text question in the survey I transcribed the data and followed a similar thematic analysis approach. The survey answers were short and offered little explanation, as this was not the purpose of collecting the survey data. Thematic analysis was therefore utilised to organise and describe the data rather than offer a detailed interpretation. The themes from this data were then used to inform the topic guide and as sensitising concepts to be explored further in the focus groups [185].

4.13 Issues of quality

During design of the study I also considered how I could ensure the quality of the research and hence its findings. While there are no agreed methods for ensuring the quality and credibility of qualitative research, there is some agreement on strategies that can be used and the information authors should provide, to allow the reader to assess the quality of the research [160, 171, 179, 186]. The strategies that I have used that are of relevance to this chapter are described below.

4.13.1 Research Design

- Consideration of the methods that would be most effective in answering the research question [103].
- Collecting data from using two methods (survey and focus groups) provided a degree of triangulation of patients' care priorities although the survey data was unable to contribute to the interpretation [170].

4.13.2 Data collection

- Surveys were designed with peer collaboration and tested with patients prior to use.
- The topic guide for the focus groups was derived from the survey data and modified following discussion with an expert facilitator prior to use. It was then further modified following use with patients to ensure it was effective in generating data that would answer the research question.

4.13.3 Data analysis

- Transcriptions were carefully checked against digital recordings before they were subjected to analysis.
- I utilised a recognised and structured approach to thematic analysis and have described this in detail [183].
- To assess my coding one of my supervisors also coded two of the focus group transcripts and differences in coding were then discussed. This resulted in some modifications to further coding [160].
- The development of coding and themes and my interpretation of the data has been reviewed by both my supervisors throughout the analysis process [160].

Reflexivity is also considered as an important aspect of the quality of a study and this was discussed earlier in the chapter and will be discussed further in subsequent chapters [178].

4.14 Summary

In this chapter I have endeavoured to provide a detailed description of the considerations and decisions that were made regarding study design, data collection and analysis to provide transparency and methodological context to the study. I have also addressed the issues of ethics, reflexivity and quality and how my consideration of these important issues has affected the methodology. In the following chapters I will present my results starting with the survey results.

Chapter 5 Survey results

5.1 Introduction

This chapter presents the results of the survey that was distributed to all the patients undergoing haemodialysis in York and Sheffield, including in-centre, satellite and home dialysis patients. The survey is provided in Appendix 4.

5.2 Response Rates to Survey

The response rates for the survey are shown in Table 6 below. These were calculated using data provided by the renal centres for the numbers of patients dialysing at each dialysis unit per quarter. The number of patients dialysing at each unit includes patients who would not have been able to complete the surveys due to physical or mental disabilities, acute illness and those admitted to hospital, as it was not possible to estimate this number.

Table 6 Response rates to the survey

Unit	No. of patients	Respondents	% Responding
Peter Moorhead	137	28	20.4
G Floor	148	43	29
Chesterfield	62	17	27.4
Barnsley	64	24	37.5
Sheffield Central	65	53	81.5
Rotherham	74	35	47.2
Sheffield Home Dialysis	46	16	34.8
York	61	39	63.9
Easingwold	34	23	67.6
Harrogate	45	28	62.2
York Home Dialysis	10	4	40
Total	746	310	42

Overall, the response rate was 42%. Previous surveys of UK dialysis patients have reported higher response rates; 62.3% for the Scottish Renal Experience Survey conducted in 2008 [187] and 61% for the Patient Transport Survey conducted in 2012 [188]. The Scottish Renal Experience Survey was a postal survey while the Patient Transport Survey, used a similar distribution method to this study.

The lower response rates in my survey may have been a result of survey fatigue on the part of the patients and staff. Many of the nursing staff I spoke to regarding the survey warned that the units had recently started their own regular surveys and expressed concern that the patients may not wish to complete additional surveys. Response rates from the three York units were similar to the other published surveys [187, 188]. Having previously worked in York, I am known to many of the staff;

as a result they may have been more willing to assist with the project and ensured that all the patients were given a survey. The response rates between the units vary greatly (between 20.4% for the Peter Moorhead unit and 81.5% for Sheffield central). This wide variation was also found in the 2012 Patient Transport Survey [188]. Some of this variation in response rates may be explained by the abilities of the patients to complete the survey. There may also have been differences in the numbers of English speaking patients and literacy levels between the units. Additionally the health of patients may be responsible for some of the variation as the two units with the lowest response rates are both central units which have patients who are not stable enough to dialyse at satellite units. The variation between satellite units (27.4% in Chesterfield and 81.5% in Sheffield central) also suggests that the staff distributing the surveys may also have influenced the response rate. There may have been differences in enthusiasm for the project, the number of staff available to distribute and collect surveys and in other time pressures for staff between the units [189]. The response rates may have been greater had I distributed and collected the survey myself however, as the survey was also a recruitment tool for the focus groups, I felt this strategy would not be ethically appropriate.

5.3 Comparison of respondents and non-respondents

The median age of both the survey respondents and the study population was 68 years. This is similar to the median age of the UK haemodialysis population of 66.9 years [190]. A comparison of the demographic information provided by the respondents to both the study population and the UK haemodialysis population [190] are presented in Table 7.

Table 7 - Comparison of demographics of the survey respondents to study population and UK haemodialysis population

	Respondents	All Sheffield and York Patients	UK Haemodialysis Population
Sex			
Female	40.1	38.1	38.9
Male	59.9	61.9	61.1
Ethnicity			
Non-white	8	11.6	21.1
White	92	88.4	78.9
Proportion of home dialysis (HHD) patients			
HHD	6.5	7.5	4.1
In-centre	93.5	92.5	95.9
Proportion of satellite unit patients			
Satellite	57.7	46.2	50.7
Central	35.8	46.3	44.5
Time on dialysis			
< 6 months	11.6	8.3	
6-12 months	9.7	10.7	
12-24 months	14.5	16.8	
2-5 years	31.3	25	
>5 years	31.9	36.7	
Socio-economic group (UK IMD quintile)			
1	22.1	14.5	
2	21	16.2	
3	16.9	17.6	
4	16.9	18.5	
5	23.2	33.2	

To allow a comparison of the socio-economic groups of respondents and the study population the survey asked patients to provide their postcodes which were used to find the Index of Multiple Deprivation (IMD) 2010 quintile for where they lived. The IMD is an overall measure of the deprivation experienced by people living in an area and is calculated based on 38 indicators of which income and employment are weighted the most [191]. From anonymised postcode data provided by the York and Sheffield units for all their patients, I was also able to calculate the IMD quintiles for the baseline population. While respondents were spread over all 5 quintiles, inspection shows over representation from those in higher (and therefore less deprived) quintiles. This finding corresponds with previous studies which have shown lower response rates in household surveys from those in lower socio-economic groups [192].

The proportion of respondents who dialysed in satellite units as opposed to central units was larger than the surveyed population and the UK population. As discussed above this may be a consequence of the better health of those who dialyse in satellite units and the other factors affecting response rates between units. The views expressed may therefore be more representative of satellite unit than central unit patients.

When the characteristics of the respondents are compared to the UK population there were was a lower proportion of respondents reporting a non-white ethnicity. This difference is likely to be a result of the ethnic make up of the geographical area in which this study was conducted, as compared with the UK dialysis population as a whole (ethnic minorities are over represented in the UK dialysis population [2]), and must be considered when interpreting the results of the survey. Similarly while the proportion of respondents on home dialysis was similar to the population surveyed in this study, this proportion was larger than is found in the UK population.

In conclusion the demographics of the respondents were similar to the population surveyed with the exception of an over representation of higher IMD quintiles. When considering the results' relevance to the UK population, the differences in proportion of non-white ethnicity and home dialysis patients must also be considered and the findings interpreted within that context.

5.4 Qualitative analysis of responses to free text question

The qualitative section of the survey asked, “What matters most to you about your dialysis care?” and invited respondents to list up to five things. Of the 310 responses to the survey 274 respondents (88.4%) wrote at least one comment. In total 798 comments were left which were each coded at least once. Some comments were coded multiple times as they were related to more than one topic [193]. Coding was inductive (as described in the methodology chapter 4 section 12.1.2) and was subject to revision as new data was coded. Codes were then grouped into 14 themes as demonstrated in Table 8. More detailed coding trees can be found in Appendix 5. The 14 themes are described in turn below.

Table 8 - Themes developed from coding of survey question

Theme	Number of respondents
Care	274
Relationships with staff	136
Time taken for dialysis	120
The dialysis unit environment	118
Maintaining health	74
Communication	55
Life outside dialysis	44
Access to MDT	39
Medical/technical aspects of dialysis	38
How time is spent on dialysis	21
Symptoms	20
Relationships with other patients	20
Social benefits of dialysis	15
Self management	14

5.4.1 Care

Care was the largest theme developed from the survey responses. Within these comments a need for confidence in the staff and the safety of care were most frequently reported. Respondents cited wanting to feel that they were "in good hands" P288 and that staff knew what to do in an emergency. Having confidence in care was often mentioned in association with the needling of fistulae. Building relationships with staff was also important for feeling both confident in care and safe.

> *"To feel comfortable with staff and feel safe with confident nurses" P43*
>
> *"Care by a group of nurses who know me and I them, so that I have confidence in them." P161*

Some respondents purely cited that they wanted good quality care without giving any further details and this was coded under 'good care'. This code included comments regarding good medical care from doctors, and good in-patient care.

Respondents frequently reported a desire for attentive care. They wanted to feel that "nothing was too much trouble" P144, and that staff were helpful and provided the attention they desired.

> *"Attentive and friendly staff" P20*
>
> *"All the care and attention given to me at every visit" P193*

Compassion and consideration from staff was also important to some respondents.

> *"Understanding and compassion from staff" P278*
>
> *"Thoroughly understanding nurses and HCAs" P62*

The idea of efficiency in relation to care was also mentioned and this may reflect the desire reported by many patients that dialysis treatment occupied as little time as was necessary (see 5.4.3 The time taken for dialysis).

The phrase, "being looked after" P59 was coded separately within this group as it suggested a more paternalistic idea of care that wasn't necessarily reflected within any of the other codes. The respondents to whom this code was applied were all in the 50-70 and >70 year age groups.

Respondents also described a desire for holistic care that addressed the "whole person" P256, by staff that cared for them both "medically and emotionally" P84. This was also reflected within the "relationships with staff" theme, with some patients specifically citing they looked for psychological support from nursing staff.

Other desirable aspects of care were that staff were polite, patient and provided individualised care.

> *"Personal care of my whole person and circumstances" P256*
>
> *"Personal attention the staff give you" P123*

5.4.2 Relationships with staff

This was the second most frequent theme. While it has similarities with theme of care, these comments directly mentioned the relationships with staff rather than the care provided by them. The respondents frequently cited a desire for nurses that were friendly and approachable. Respondents also wanted continuity of their relationships with staff, so they knew the staff and the staff knew them. This was cited as important for building rapport as well as developing confidence in staff as reported above.

> *"Treated by nurses I know" P50*
>
> *"Friendly, familiar faces, build up of rapport" P77*

Respondents also looked for support from their relationships with staff; some indicated a desire for emotional support.

> *"Support from staff" P283*
>
> *"Staff being there for you." P190*
>
> *"Staff relationship, good to have a chat to tell problems have a laugh etc." P88*

Some respondents specified a desire for staff to interact with them.

> *"Interaction between staff/patient" P70*
>
> *"How they treat you, the staff don't seem to want to talk when they putting you on dialysis" P192*

While respondents desired friendly relationships, some also cited that they wished staff to be professional and looked for respect from them. Two patients reported wanting friendly and professional staff, suggesting the two could co-exist.

> *"The staff are always professional and friendly" P146*
>
> *"Professionalism of staff, yet friendly and approachable." P301*

While the majority of the comments regarding staff relationships commented on their actions towards patients, respondents also praised nursing staff and reported on patients' concern for staff welfare.

> *"That there are adequate staff numbers I am really concerned that the staff there are stressed" P64*
>
> *"The lovely staff on the unit who help you at all times" P69*

5.4.3 The time taken for dialysis

Two of the most frequently coded items concerned transport between home and the dialysis unit and getting on and off dialysis quickly. Comments regarding transport related to waiting for it (either to or from dialysis) or journey times being prolonged by circuitous routes. Although less frequently cited, some patients felt that it was important that their dialysis unit was close to and convenient for where they lived. These aspects were all seen to impact the time taken to complete dialysis.

> *"Getting on and off dialysis as quickly as possible to keep my time at the unit to a minimum." P34*
>
> *"Transport to be on time for pick up and take home" P86*
>
> *"It's good to be close to where I live" P146*

5.4.4 The dialysis unit environment

Many patients commented on aspects of the dialysis unit environment. Most patients commented on physical aspects, however some patients mentioned the "atmosphere" of the unit. Cleanliness was the most frequently mentioned concern relating to the physical aspect of the unit. Comfort on dialysis was also important, with references to the quality and choice of furniture. The provision and quality of catering was also important to some patients, as was the temperature of the unit with most patients finding it too cold.

> *"Having a very clean environment to have my dialysis" P84*
>
> *"That I am comfortable. A choice of bed or chair would be nice." P100*
>
> *"Provision of drink and sandwiches" P248*
>
> *"Good environment – clean, warm, no noise" P21*
>
> *"I want it to be a happy atmosphere" P260*

5.4.5 Maintaining health

This theme represents two main codes: respondents' comments regarding dialysis keeping them alive and the importance of the stability of their health. Comments regarding things not going wrong on dialysis, not being admitted to hospital and vascular access not failing were included in the stability of health group.

> *"Giving me the chance to live a bit longer" P5*
>
> *"It's keeping me alive" P68*
>
> *"It keeps me as fit and well and able to live as active a life as possible" P161*

5.4.6 Communication

Although this may be considered part of care, and a consequence of patients' relationships with staff, this theme refers to comments regarding the significance of, and differing types of communication that were important to the respondents. Most of the comments regarded communication between patients and staff, however communication between staff was also cited.

> *"Co-operation between different departments" P59*
>
> *"Good link with York hospital" P2*

Respondents valued explanation and education regarding procedures, the dialysis process and other aspects of living with renal failure. They also wanted to be kept informed of changes to their care and to be listened to by staff and involved in decision-making. Some patients commented on the importance of a regular review of progress and prognosis within the setting of a clinic or with a doctor.

> *"I can ask questions about my dialysis and always get answers to help understand it." P146*
>
> *"Being kept informed of any changes to my care and medication" P140*
>
> *"Having a say and being involved about treatment." P120*
>
> *"Would like to see the consultant twice a year to discuss my prognosis" P54*
>
> *"To be seen by a doctor every month" P196*

5.4.7 Life outside dialysis

This theme reflected comments regarding the effects of dialysis dependence on aspects of life outside the dialysis unit. In common with the coding group "time taken for dialysis", some comments related to minimising the time spent having treatment. Comments also related to the effect of dialysis dependence on other aspects of their lives such as family, employment and diet. Being able to continue to take holidays was also important to some respondents.

> *"Living a normal life with out dialysis affecting it" P118*
>
> *"Brought me closer to family being at home" P307*
>
> *"How much fluid you can have" P189*

Respondents also commented on the timing of dialysis slots; while some respondents were looking for flexibility so they could arrange dialysis around other events in their lives, some respondents desired the slots to be regular and routine.

> *"The flexibility of that care which allows me to attend important things at home" P57*
>
> *"Regular time and place- i.e. NGH early morning – as with the same group of fellow patients" P161*

5.4.8 Access to the Multi-Disciplinary Team (MDT)

Although many of the comments regarding respondents' dialysis experiences related to the nursing staff, respondents also stated that access to, and availability of, other members of the MDT was important. Respondents most commonly cited the availability of doctors as important, followed by dieticians. Other members of the MDT that were also mentioned included physiotherapists, social workers, pharmacists and specialist nurses.

> *"Would be good to see a doctor which none of us do even if just to check if we have any problems just to see us on the ward" P192*
>
> *"Knowing that should any issues arise that I need answers to medical/diet, dialysis in general etc. It will be directed to the person who can answer those questions" P109*

Of the 20 respondents on home dialysis, 9 commented on the importance of being able to contact the home dialysis team.

> *"Being able to contact home dialysis team easily for dialysis or medical problems" P295*
>
> *"Regular contact with the renal community team" P310*

5.4.9 The medical and technical aspects of dialysis

Several respondents reported that blood results and aspects of their dialysis prescriptions were important. For some respondents, access to their own blood results was important while, for others, the concern was that dialysis was working effectively to control their bloods. Similarly other respondents felt it was important that they were getting enough dialysis.

> *"Being able to access my own results via patient view" P302*
>
> *"Keeping my blood results correct" P132*
>
> *"Making sure I get my full treatment" P40*

5.4.10 How time is spent on dialysis

For certain respondents, what they did while they were on dialysis was important. The most frequently mentioned activity was watching television. Others wanted to be able to use the internet, be involved in activities like arts and crafts, read, sleep and smoke. Some felt that it was important to get "the best out of their time on dialysis" P132, while others felt that the provision of entertainment was important to relieve boredom, without which "time passes very slowly" P42.

5.4.11 Symptoms

This coding group represents all the comments regarding symptoms. Feeling better after dialysis and concerns regarding pain from needling were most frequently reported. While some respondents mentioned the symptoms alone, others commented on the importance of symptoms being managed.

> *"Management of symptoms e.g. cramp" P12*
>
> *"Pain free insertion of my needles" P7*
>
> *"Feeling much better after it" P252*

5.4.12 Relationships with other patients

Some respondents felt that the relationships they built with other patients were an important aspect of their dialysis experience. Some described the importance of being able to "talk to others on dialysis" P43, while for others developing new friendships was important.

> *"Getting to know the other patients and having a good rapport with them as we have now" P127*
>
> *"Knowing people on the same days" P228*
>
> *Social benefits of dialysis*

As seen in the theme 'relationships with other patients', the social benefits of dialysis were important to some respondents. Both the nurses and other patients were cited within this theme. Meeting other people and enjoying their company were valued as well as the "sense of community" P180 in the dialysis unit.

> *"When living alone the comfort of new faces and chat" P69*
>
> *"Being with others and not on own" P283*

5.4.13 Social benefits of dialysis

As also seen in the above theme, 'relationships with other patients,' the social benefits of dialysis were important to some respondents. Social interaction with both staff and other patients was cited. Meeting other people and company were important as well as the "sense of community" pt.180 in the dialysis unit.

> *"When living alone the comfort of new faces and chat" pt. 69*

"Being with others and not on own" pt.283

5.4.14 Self-management

This theme encompassed aspects of respondents doing, and being responsible for, their own dialysis. Most of these comments were from the home dialysis respondents who valued independence and being able to do their dialysis at home. Two in-centre respondents commented on the importance of shared care.

"That I can do dialysis in my own home" P300

"Being responsible for myself" P93

"Being independent" P178

"The option to self care when I come in based on how I feel" P62

5.5 The coding framework

Through coding the free text responses inductively I have developed 14 themes that represent the aspects of dialysis care that mattered most to the respondents. While the comments and coding groups that make up these themes give us some insights into why these themes are important, the short responses characteristic of a survey do not allow for explication of the ideas and beliefs that underpin them. The aspects of care which concerned correspondents were very varied and, in some cases, respondents showed disagreement. As described in the methodology, these themes were used to construct the topic guide for the focus groups to allow a more in-depth exploration. The focus group data can therefore aim to examine the reasons underlying these views, as well as similarities and differences between individuals or groups. The themes also acted as sensitising topics for the analysis of the focus groups to see how this further data added context and explanation.

5.6 Conclusion

The survey collected opinions from 274 haemodialysis patients on what mattered most to them about their dialysis care. When considering the results we must acknowledge that the views of non-white and more deprived patients are under represented in the survey and consequently the results may differ in these groups or a wider population.

The themes that resulted from analysis of this data highlight the range of aspects of care that matter to patients and the variety of responses. The survey has also provided an idea of the frequency with which these aspects of care were reported as important by respondents. However it does not necessarily follow that the aspects of care reported most frequently are the most important and this would need evaluating in a further study. What this data does highlight is the limitations of the survey; what do respondents mean by good care, and do patients' views differ on what constitutes good care? Through further exploration of these themes in the focus groups, I hope to gain a greater understanding of what matters to patients about their care and, importantly, why.

Chapter 6 Introduction to focus group findings

6.1 Introduction

This chapter precedes the three chapters that present the findings from the focus groups. It provides further information about the focus groups and demographic information about the participants. The chapter concludes by introducing the three findings chapters.

6.2 The focus groups

6.2.1 York

We aimed to hold three focus groups in York; one with patients doing 0-1 shared care tasks, one with patients doing 2-4 shared care tasks and a final group with patients doing 5-14 tasks (including home dialysis). From the 3 York based dialysis units a total of 94 surveys were completed and returned. 47 (50%) of those who returned surveys said they would be interested in attending a focus group. From the volunteers I purposefully sampled people to attend each focus group. The survey asked patients when they dialysed so we could try and arrange the focus group at a time when most of the volunteers could attend. When we had arranged a date I then contacted the volunteers. Following discussion about what the focus group would involve, the majority were happy to attend; however there were many barriers to attendance such as work and family commitments, feeling unwell after dialysis, dialysis slots having changed or having moved units since completing the survey, illness, hospital admissions and appointments. Although seeking family/carer views was not an aim of this study the participants were welcome to bring someone with them if they wished. Only one of the 0-1 group participants brought her husband who also contributed to the discussion.

We had aimed to recruit 6-8 patients per focus group. However we successfully recruited 4 patients plus 1 carer to the 0-1 group, 4 to the 2-4 group and 6 to the 5-14 group. Some of the volunteers were unable to attend at short notice due to acute illness and some people who had said they were unable to come did in fact attend. While debriefing after the 5-14 group we felt the group dynamics had been strained and that the home dialysis patients and the in-centre patients in this group had differing views and experiences. As the Sheffield unit has a much larger haemodialysis population overall, and more home haemodialysis patients, we decided to split this group into patients doing 5-14 tasks in-centre and a separate group of home dialysis patients.

6.2.2 Sheffield

From the 216 survey responses from the Sheffield patients, 105 people expressed their interest in attending a focus group (47%). Again, while the majority of people I contacted were happy to attend a focus group, we had similar challenges in recruiting due to the barriers outlined above. An additional problem in Sheffield was the large geographical area that the units are spread over. While the focus groups were held in a central location, the distances involved often made it difficult for people to attend before or after dialysis.

The numbers attending the focus groups in Sheffield were 4 plus one carer for the 0-1 task group, 5 for the 2-4 task group and 5 for the home dialysis group. I had recruited 4 people to attend the 5-14 task group but only one person attended, accompanied by his partner (Patient 20 and Carer 2). We therefore had to adapt this to an interview with the patient and his partner, but utilised the topic guide to direct questions. We consequently did not gain the breadth of experience we aimed to achieve from this 5-14 group. However the more narrative style of the interview added a depth to the data that would not have been gained in a focus group.

Despite not recruiting the 6-8 participants we aimed for in most of the focus groups I do not think this adversely affected the quality of the data. There are no absolute criteria for focus group size. Additionally, all the participants were keen to share their experiences and the focus groups were longer than we had anticipated, with a mean length of 92 minutes. It was often difficult to draw them to a close. I therefore feel that we gained adequate information to answer the question posed.

6.3 The focus group participants

Demographic details of the patients are shown below in Table 9. The ages of the participants are presented in age ranges to protect their anonymity. There was representation from all the dialysis units in York and Sheffield but this place data is also not presented to protect participants' anonymity.

Table 9 Demographics of the focus group participants

Participant	Focus group	Age	Gender	Number of self care tasks	Time on dialysis
Patient 1	1	50-70	Male	1	2-5 years
Patient 2	1	31-49	Female	1	>5 years
Patient 3	1	>70	Male	1	6-11 months
Patient 4	1	50-70	Female	1	2-5 years
Patient 5	2	50-70	Female	3	2-5 years
Patient 6	2	>70	Female	3	6-11 months
Patient 7	2	50-70	Female	2	1-2 years
Patient 8	2	50-70	Male	3	1-2 years
Patient 9	3	50-70	Male	7	6-11 months
Patient 10	3	50-70	Female	8	<6 months
Patient 11	3	31-49	Female	HHD	> 5 years
Patient 12	3	50-70	Female	HHD	> 5 years
Patient 13	3	18-30	Male	11	2-5 years
Patient 14	3	50-70	Male	9	6-11 months
Patient 15	4	50-70	Male	3	>5 years
Patient 16	4	50-70	Female	3	>5 years
Patient 17	4	50-70	Female	3	>5 years
Patient 18	4	50-70	Female	3	>5 years
Patient 19	4	50-70	Male	2	2-5 years
Patient 20	5	50-70	Male	11	1-2 years

Patient 21	6	31-49	Male	1	6-11 months
Patient 22	6	>70	Male	1	>5 years
Patient 23	6	31-49	Female	1	6-11 months
Patient 24	6	50-70	Female	1	>5 years
Patient 25	7	50-70	Female	HHD	2-5 years
Patient 26	7	50-70	Male	HHD	6-11 months
Patient 27	7	31-49	Male	HHD	2-5 years
Patient 28	7	50-70	Male	HHD	>5 years
Patient 29	7	50-70	Male	HHD	>5 years
Carer 1	1		Male		
Carer 2	5		Female		
Carer 3	6		Male		

HHD= Home haemodialysis

Fifteen (52%) of the participants were male. The age range of participants was wide but the majority were in the 50-70 age range which corresponds with the UK haemodialysis population [2]. There was also a wide range in the time participants had been on dialysis; the largest group was those who had been on dialysis more than 5 years (38%). Unfortunately we were unable to recruit any patients from non-white ethnicities.

6.4 The final themes and findings chapters

Analysis of the data from the focus groups resulted in the development of three over-arching themes. These are: finding personal control; maintaining social viability; and integrating dialysis into life. These themes are described in turn in the three findings chapters.

‘Finding personal control’ describes the emotional work and coping strategies utilised by patients as they tried to gain a sense of personal control over their dialysis dependence. ‘Maintaining social viability’ encapsulates how dialysis affected patients’ previous social roles and responsibilities. Additionally dialysis required patients to negotiate new relationships with staff and other patients. ‘Integrating dialysis into life’, describes the physical challenges patients’ experienced when trying to live their lives alongside dialysis, and how care provision affected their ability to respond to these challenges. While the themes necessarily represent participants’ experiences of living with dialysis dependence, the data describe the many ways in which communication, relationships with staff and the way care is organised can both positively and negatively affect patients’ experiences of care, and their lives outside the dialysis unit.

Quotes are provided throughout the findings chapters to provide evidence for the analysis and creation of themes and offer the reader some insight into the personal experiences of the focus group participants.

Chapter 7 Finding personal control

7.1 Introduction

This chapter discusses the issue of personal control in dialysis, how this can be made manifest in a variety of ways and how it may differ with the degree of self-care a patient is involved with. The theme of 'finding personal control' developed from patients' discussions of their individual strategies to find a personal sense of emotional control over their lives. The concept of the emotional work involved when living with a chronic illness is not new; the effects of chronic illness on identity and personal biographies is an important focus for the sociology of living with chronic illness. As described in Chapter 3, Bury has described chronic illness as a biographically disruptive event[138], therefore those living with chronic illness must work on restructuring their biography to take account of this disruption[143]. In Charmaz's work on chronic illness she described how an altered body could result in a perceived separation of the body and self[194]. A person's sense of self and identity may then need to be altered to take account of the illness affecting the body. Consequently, adapting to chronic illness may require the acceptance of a lesser identity[194]. Participants in this study described many ways in which dialysis dependence affected their sense of self and perceptions of control suggesting that many of the participants were involved in a restructuring of self and identity.

I identified 7 sub-themes in my analysis that contributed to the development of this theme. The first two sub-themes (emotional coping and finding acceptance) describe the strategies that participants utilised to help them cope with dialysis dependence on an emotional level. These themes were predominant throughout the focus groups and for many participants finding ways of coping emotionally was an important part of dialysis dependence. Through these strategies many patients found that they had come to an emotional acceptance of their dialysis dependence and described the significance of this to the group and to those whom they felt had not yet reached acceptance.

As well as describing emotional coping strategies participants also described other actions that they employed or which affected their sense of control and these are represented by sub-themes 3 to 7: gaining information, choice and making care decisions, being seen as an individual, managing dependency and striving for autonomy. Participants related these 5 sub-themes to their sense of emotional control but they are also more closely related to care processes and interactions with health professionals (HPs). Each of the 7 sub-themes is discussed in-turn followed by a comparison of the discussions around finding personal control between the patients' differing levels of involvement in self-care.

7.2 Sub-themes

7.2.1 Emotional Coping

The strategies used to cope with the emotional impacts of dialysis dependence were seen as an important part of living with dialysis and participants discussed them in all the focus groups. While not all participants shared the same strategies, individuals were keen to share their strategies with others.

Many patients utilised a strategy of looking for the positives in their situation. Others saw it as important to fight the illness or utilised humour to help them cope.

> *P10 I feel quite lucky at having dialysis and people look at me quite stupid as if to say, you know, are you mad, but you could have something a lot worse, ...and people say "Well how worse could it be?" But you could have something where you're in absolute agony all day, you could be bedridden, do you know what I mean? You could be laid up where you can't speak or you can't communicate with people...*

Positive re-appraisal is a recognised emotional coping strategy. In psychology positive re-appraisal is classified as an "approach" emotional strategy. Such strategies involve people confronting their emotions and have been reported to result in better adjustment than strategies of avoidance coping such as distancing and disengagement[195]. Many participants utilised social comparison when using positive re-appraisal. When we consider Charmaz's theory that chronic illness requires downward adjustments in identity[194] comparison with others living with conditions perceived to be worse than ESKD may mitigate against the distress of this adjustment.

The concept of illness as something that should be fought or battled against, as described by some participants in this study, was highlighted by Kelly and Dickenson as a modern approach to thinking about illness that has been popularised within the media[196]. This strategy could also be considered as positive re-appraisal and therefore a strategy which may help adjustment, however Bury warns that strategies that promote activism in the face of illness may in turn become oppressive cultural expectations for those suffering from chronic illness[197]. While a number of participants in this study described battling or fighting their ESKD there were no suggestions that this strategy had become an oppressive expectation.

Like denial, utilising humour could be considered as distancing and therefore avoidance coping. However participants who described using humour suggested they accepted the seriousness of their condition but they made light of the situation in order to cope with it. In other chronic illnesses having a positive disposition has been shown to be a useful coping strategy that helps people feel better about themselves and can actually result in improved adaption[195, 198].

Some of the participants who dialysed themselves felt the physical act of doing their own dialysis had important effects on their ability to cope emotionally. Instead of a treatment inflicted on them, developing an ownership of the treatment helped them see dialysis in a different way and therefore cope with it better on an emotional level.

> *I've found the difference, mentally, between having it done to me and doing it myself massive. The way I felt about my condition and my treatment changed almost overnight. I used to go to the unit, I was miserable, I hated it, I felt like a victim, ….now, well it's as simple as that, instead of it being done to me I'm doing it, I own it, It's my thing that I do to stay alive rather than strangers (sighs) sticking needles into me; hurting me quite often, it's a lot less painful doing it yourself.*

A recent thematic synthesis of patients' perspectives of home haemodialysis highlighted that patients felt choosing HHD could help them feel in control, however the focus in this synthesis was on the physical constraints of dialysis dependence[199]. For some participants in this study self-care was very important to emotional coping, not just physical coping.

The support of others was also seen by many as instrumental in emotionally coping with their dialysis dependence. Participants most frequently discussed family, other patients and staff on the dialysis unit as sources of support. Some mentioned receiving support from psychologists but not all had found this helpful. Some participants felt that support from psychologists or other more formalised support mechanisms such as patient support groups, was especially important for those who did not have such support readily available in their existing social networks.

> *P23: Yeah, it's good if you've got a good family network you can speak to as well. I know a lot of people don't have that, do they, really, a lot of people, so it's nice to be able to go to [patient support group] where you can speak to people …It's just knowing that you're not on your own really.*

Participants' chosen coping mechanisms appeared to have required an emotional investment. Many participants described the staff on the renal units as an important source of emotional support. Consequently when staff did not appear to understand their chosen emotional coping strategies this could become a source of stress and frustration to participants.

> *P19: Rigid; everything's black and white with them, you're not allowed to do this, you're not allowed to do that. And I've turned round to my consultant that comes regular and to the dietician, and I said "Do you know what you all need to start to do?" "What's that, what's that?" "Stop being so negative and be more positive." "What do you mean by that?" I said "Well every time we see the consultant or we see the dietician; your level's not right, this is not right, that's not right, you're not allowed to do this." I said "What are the positives? Come in and say to us, oh look, yes, your phosphate level looked really good this time, or, but it's always on the negative."*

This quote demonstrates how some participants perceived that HPs could conflict with their chosen coping strategies. Understanding individual coping strategies has been highlighted as important for collaborative care[200]. This study suggests that this includes the consideration of emotional as well as more practical coping strategies.

A further coping strategy that was frequently discussed was the denial of illness. Here participants made a distinction between illness and dialysis dependence; consequently dialysis was seen as a necessity to sustain life but not necessarily something that resulted in a perception of illness. This concept of denial of illness was important to many in emotionally coping with dialysis. In contrast, accepting dialysis dependence was also important and these apparently paradoxical approaches seemed to coincide for many participants (see sub-theme 2 "Finding acceptance"). Trying to live a normal life outside dialysis was seen to assist with the denial of illness as a coping strategy. As a result being able to maintain employment and go on holiday were seen as important contributors to emotional coping for some.

> *P7: I think it's quite empowering when you know, and, psychologically when you know you can go on holiday…because that means sort of psychologically, well you're not all that ill because you can actually go on holiday, and it really is, and I'm not painting a picture here, this is the reality.*

For some of the participants who utilised denial of illness as a coping strategy, trying to keep dialysis and life separate was a key part of their emotional coping. Subsequently this became a barrier to considering home therapies.

> *P8: ... I don't believe I'm ill, because I'm working…*
>
> *P7: I like that. (laughs)*
>
> *P8: … there's nothing wrong with me, you know, there's absolutely nothing wrong with me…*
>
> *P5: I feel exactly the same. (laughs)*
>
> *P8: …and if I gave up work all of a sudden it's an acceptance that I'm ill, and it's like I won't do home dialysis because home is home, illness is hospital and I can split the two, and I can go home and I'm not gonna feel sorry for meself because I know in the back bedroom I've got a machine there that's, that's clicking away or doing whatever.*

The denial of illness has similarities with Bury's concept of normalisation[143]. Bury described two types of normalisation; people either separated illness from the rest of their lives, consequently minimising the impact of illness on their identity; or treated the illness or treatment as normal and hence integrated it into their identity[143]. Participants in this study described utilising both types of normalisation as coping strategies.

Emotional coping required time and many patients reported using more than one strategy. This work of emotional coping was clearly important to patients but was also fragile. HPs were expected to understand patients' emotional coping strategies and when the HPs attitudes conflicted with these strategies this could become a source of conflict. This data therefore suggests that it is important for HPs to understand the work of emotional coping patients are involved in. Understanding an individual's chosen strategies may help HPs comprehend patients' care decisions and facilitate communication that avoids conflict with these strategies. Consequently this may lead to both more effective communication and enhance relationships with patients.

Dialysis unit staff may be unaware of the role that they play in emotional support. This data suggests that patients may welcome more communication about the emotional consequences of their dialysis with all HPs and this does not always need to be provided by mental health professionals. Dialysis unit staff should also be particularly alert to patients who do not have close social networks as they may benefit from other sources of support such as patient support groups.

This data also suggest that communication with patients regarding their emotional coping strategies would facilitate discussions regarding their modality of haemodialysis provision. For some patients self-care may facilitate emotional coping. However home based dialysis is unlikely to be accepted by patients for whom separating dialysis from the rest of life is a key strategy as having dialysis in the home results in the clinical environment intruding on life at home. Through understanding the emotional coping strategies used by an individual, HPs are better placed to communicate effectively with patients, offer individualised care and improve patients' experience of care.

7.2.2 Finding acceptance

Many of the participants in the focus groups described coming to an acceptance of the need for dialysis. This was highlighted as an important process and, as shown above, it could co-exist with the decision that they were not unwell. Those who had accepted dialysis dependence were keen to explain the importance of acceptance to participants whom they felt had not reached this same acceptance. It did not seem clear to participants how they had come to this acceptance, however discussions of the importance of acceptance were often set within the context of discussions regarding emotional coping strategies. Rather than being passive acceptance, this acceptance appeared to be a product of emotional work and coping.

> *P8: But you can do it, you've just got to say, right, I'm not gonna let this beat me, I'm gonna get on with my life, and it's like we said earlier on, I don't think I've now got anything wrong with me, I've just got this pain and come in hospital.*

Some patients reported that they were able to accept dialysis as a temporary measure while awaiting a transplant, however others felt hoping for transplantation challenged acceptance. They cited HPs as often perpetuating this idea.

> *P20: ...it's for the rest of your life, it's not till you get a transplant; forget about transplants...when I first started, and I'd wake up in the morning, oh I might get a transplant, and then after a couple of months you think I'm not gonna get a transplant. But that's the way they talk to yer, you're gonna get a transplant, everybody out there's gonna get a transplant, it's a perfect world.*

Some participants thought that having experienced previous illness helped them to accept dialysis dependence.

> *P25: ...when I got kidney failure...it didn't seem to me as, you know, bad as getting cancer, sort of thing.*
>
> *P26: Yeah, well I am, I'm a bit like you where I've had like cancer like four times, so when I was told I had to have dialysis...*

> *P25: You think oh well.*
>
> *P26: ... it were just something else I had to do.*

In a study of people recovering from stroke, those who had previous experience of chronic illness were less likely to interpret their stroke as a biographically disruptive event[146]. However other studies have suggested that, in those who have adjusted to chronic illness, the uncertainty brought about by new health problems could result in intensified distress[194]. When considering the degree of biographical disruption that an illness causes Williams argues that timing and context, as well as norms and expectations, affect the degree to which we perceive an illness as causing disruption[151]. Consequently previous ill health may affect the context in which dialysis dependence is encountered; this may then affect the degree to which this is considered disruptive and the sense of acceptance[201].

While the majority of the participants said they had managed to accept their dependence on dialysis, some described struggling with accepting that their life could now only be lived alongside dialysis.

> *P21: I've only been doing it eighteen months so I suppose I'm a relative newbie into it, but I find it really disruptive, it's absolutely like devastated my life really. Everything else has had to be concertinaed around it so it's become, it's part of your life now; not for much longer, not for much longer.*
>
> *P22: Are you on ....a kidney transplant list?*
>
> *P21: No, not exactly, I'm planning on stopping. That's my direction of travel is that I've tried it for eighteen months, don't particularly like it and possibly in the next six months I'll stop and, and take me chance really.*

In response to P21's comments other participants suggested strategies they had found helpful in coming to an acceptance including many of the emotional coping strategies discussed above. They also suggested more practical ways P21 could cope with dialysis including switching to peritoneal dialysis, having a line instead of a fistula, or moving to another dialysis unit. This suggests that patients utilise both emotional and practical ways of coping to help come to an acceptance of dialysis dependence. It also suggests they believe they have choices regarding their care and that these choices affect their ability to cope and come to an acceptance.

A lack of symptoms or physical evidence for ESKD may make the acceptance of dialysis dependence more challenging. At the end of the quote above P21 suggests that he is not sure that he needs dialysis by saying he may stop and "take me chance". Later in the discussion he explained that he did not feel he had any symptoms from his ESKD and that he was uncertain of the original diagnosis he had been given.

> *P22: You find it difficult coming to terms with the fact that it's…*
>
> *P21: I just can't…*
>
> *P22: … that it's permanent, yeah.*
>
> *P21: …I just can't get my head around it, yeah, whereas I don't feel ill and stuff like that…cos before I started dialysis I mean they were like, but don't you feel tired or owt? Well no, (laughs) not really,…*
>
> *P21: ...but where I got the illness from, where it came from, because …they said well, you know, it's hereditary; and we've been back through both sides of my family chain, no-one has, has got it. People have been tested, living relatives and stuff, no-one's got this the same thing. So suddenly a hereditary disease just bursts mysteriously into life…*

This suggests that those patients who do not experience many symptoms from their ESKD before starting dialysis, or those for whom the cause for their ESKD is not clear or in doubt may then find it more difficult to come to an acceptance of their dialysis dependence. Believing an explanation for illness has been shown to facilitate adjustment in people with ESKD and other chronic illnesses[202]. Previous studies have also highlighted the difficulties some patients may find in accepting dialysis dependence as a treatment for an illness for which they had no symptoms[118]. When considered with the results of this study these findings suggest that accepting the reason for, and diagnosis of, ESKD may play a role in helping patients come to an acceptance of dialysis dependency. Consequently it is important that this has been communicated clearly by HPs.

The concept of acceptance of illness originates in Kubler-Ross's work with terminally ill patients from which she developed her model of the five stages of grieving[203]. The model describes patients moving from denial through anger, bargaining, depression and finally to acceptance. This model is well known and the concept of denial as an undesirable state has permeated Western culture[198]. The prominence in the discussions of the importance of acceptance may therefore be understood in the context of societal belief of acceptance as a preferred or healthier state and is demonstrated by one participant who, supported by the rest of the group, was keen to explain that she was not in denial.

> *P23: …"we think you might be in denial, we think you might need to see a psychologist." I'd say "What do I need to see a psychologist for?" "Because you're not upset, you didn't burst out crying when you got diagnosed, you didn't." I mean I'm hard as nails me, to be honest, but I know for a fact I'm not in denial, it's been like fifteen month now and…*
>
> *P22: You've accepted it?*
>
> *P23: Yeah.*

More recent work has suggested that denial is not always an unhealthy emotional state. Charmaz, in her work on the altered identities of those with chronic illness[194] found that when people are unable to accept a lesser illness identity they continue to aim to regain a past (pre-illness) identity[194]. In times of improvement in health (such as after transplantation) those who had not accepted a new illness identity then found it easier to re-enter the pre-illness world that they had left. Following a metasynthesis of the experiences of people with chronic illness, Paterson also highlighted that denial could be utilised as a useful coping strategy however, she felt that the terms acceptance and denial had little meaning for those with chronic illness[204]. She described the individual response to chronic illness as more fluid, as fluctuations between 'illness in the foreground' and 'wellness in the foreground'. A focus on illness in the foreground was seen to allow people to reflect and learn about their disease so they may be able to come to terms with it. While Paterson was critical of the term acceptance, the concept of coming to terms with chronic illness therefore seems to persist and be seen as a desirable outcome.

Additionally, despite Charmaz's recognition that in some circumstances denial could be helpful, she concluded that acceptance of a new illness identity was the desired conclusion of adapting to chronic illness. As highlighted above, participants in this study used both acceptance and denial, and suggested that, in the setting of dialysis dependence, while denial of illness could be a useful coping strategy, acceptance of dialysis dependence was an important part of coping.

While some patients felt that they were able to accept dialysis while awaiting a transplant, others highlighted that hoping for a transplant could prevent acceptance. A study of HD patients on a transplant waiting list found that initially patients felt they could cope with dialysis as it was seen as a short-term measure however, when waiting lasted longer than expected they expressed frustration and described their lives as on hold[205]. When we apply Paterson's model[204] of responses to chronic illness as fluctuating between 'illness in the foreground' and 'wellness in the foreground' being on the transplant waiting list may encourage the persistence of an 'illness in the foreground' view and prevent transition to 'wellness in the foreground' as wellness is only seen to be associated with transplantation and not dialysis dependence. This is an important consideration for HPs as they may be promoting the idea of wellness being solely associated with transplantation. Care should be taken to promote wellness on dialysis and not to focus on the dialysis as a temporary state of illness until transplantation.

The importance of acceptance highlighted in this study has to be considered within the context that denial may be have been perceived by participants as an undesirable emotional state.   Nevertheless other work considering those living with chronic illness also suggests that finding some form of acceptance is an important strategy when coping with chronic illness. However, health professionals must use care when utilising these labels and also understand and acknowledge that some individuals may be utilising denial constructively as part of their personal coping strategies. Taking time to understand the complexity of individual narratives and beliefs regarding care can also be seen to be important when assisting individuals to come to terms with dialysis dependence. In those who appear to be having difficulties accepting their dependence on dialysis, exploring their understanding of the cause for ESKD and the reasons surrounding the decision to start dialysis may be helpful to patients. This is expanded on in the next sub-theme.

7.2.3 Gaining information

Information provision was an important concept. Adequate information allowed patients to make sense of their situation, decide on their priorities and make decisions about their care. Information was consequently seen as contributing to a sense of control.

Information was gained from various sources including staff, other patients, and the internet. Other patients were considered important sources of information, especially when first starting dialysis, as they could provide more realistic information than HPs.

> *P17: I was aware that when we had a new patient coming to our session….I don't feel that she was given enough information about what was happening to her, and when they started talking to her about her blood results and some of them weren't right, she got in a bit of a knot about, you know, well what can I do, what do I need to do? ….so I brought the books in for her so she could have a read and since then she's seen a dietician and she feels more informed about things. I think that is an important part of being a dialysis patient, and again feeling in control so that, you know, you don't suddenly have doctors, you know, jumping on you saying, oh we're gonna have to give you some more Calcichew or whatever...*

Access to information required the right HP with time available for communication. Some patients felt they weren't able to ask the questions they wanted, as staff appeared too busy.

> *P17: …we've got a lovely doctor who's based at our unit but he's very busy, or seems to be very busy, and if you've just got a slight query that you want to ask him about you feel like you're bothering him if he's, you're aware that he's, you know, walking a bit fast and he's got folders in his arms and, and you think well is this really important compared to what he might be dealing with another patient…*

As well as the availability of doctors, patients also wanted access to dieticians and specialist nurses. Many patients complained that doctors did not visit the unit on their dialysis days and those who dialysed in the evening felt they were disadvantaged as they were not able to see specialist nurses and dieticians. Patients in satellite units felt confident in the care of the nurses who treated them, however they still wanted regular review by medical staff. Nursing staff were considered good at addressing any problems encountered (and accessed the help of other professionals when necessary) however, medical staff were seen as a source of information on overall progress and consequently regular review by a consultant was valued. When they did meet with HPs the lack of privacy within the dialysis unit was seen as a further barrier to effective communication.

> *P21:… I think what always gets me is cos I'm on a, quite a big bay and there's quite a lot of people, I think there's thirteen beds on the bay that I'm on, but when the doctor comes to see anyone it's the magic curtain.*
>
> *P23: We always say that, the curtain that you can't hear through.*
>
> *P21: The curtain that you can't hear through; and he puts the curtain round to like...*
>
> *P23: And everybody's listening.*

As well as gaining information, being kept updated and informed of changes was seen as important for maintaining control. Frustration was often expressed that staff did not communicate changes in care processes or medication with them.

> *P21: Basically they don't tell you what's going on, they keep changing their mind and do stuff and then you only get to know about it afterwards that, you know, well on the day that they're gonna do it which is not very helpful if you're wanting to try and keep a semblance of control really.*

Both in-centre and home patients mentioned the internet as a source of information, however this seemed to be more important to home patients and their families. While in-centre patients could communicate with each other in the dialysis unit, home patients utilised the social media as a forum for communication with each other.

> *P28: ...And you're talking to people, well you're listening to people who's on there, via Facebook or whatever, and the problems that they're having or things that they're going through, or does anybody know how to stop scratching or you know, all the questions that, you know, we've probably all been through, you know, all of the time.*

However participants also warned that you had to be careful with information available on the internet. People describing complications the participants had not encountered could cause distress and anxiety, although participants also recognised that the experiences of others may not be applicable to them.

Most patients had access to their blood results, however the benefit of this was not apparent to all. Those with a clear understanding of their blood results utilised these results, alongside perceptions of how well they felt, to decide on the effectiveness of their dialysis. Other patients felt access to blood results was important so they could prepare for being reprimanded by staff when results were not satisfactory.

> *I personally go on patient view for my blood results, I get them before the nurses get them, so I sort of know (laughs) if I'm gonna get told off when I go in before (laughter) cos I always manage to, if my phosphate's low my potassium's high, if my potassium's low my phosphate's high, I can't balance that.*

This information was not just utilised for self-management but also to manage consultations with staff. It could therefore be understood to not be purely contributing to personal control but also to the control of their relationships with staff.

It was important that when information was provided it was clear and easily understood. Patients felt that the significance of blood results were not always made clear, and became confused and frustrated when different members of the MDT gave them conflicting advice.

> *P26: So I went on ward and I says to this, ...she were a sister, I said " I'm thinking about eating more fish rather than red meat". She said, "You can't have fish, you're a dialysis patient". So I says "Well why can't you have fish?" She said, "Because it's high in phosphate"...so I thought well*

> *she must know what she's talking about cos she were in blue (laughter)… So when dietician come, and I says to her "I were thinking about having more fish but I've been told you can't, it's not good for you, too much fish". She says, "There are certain fishes… that, are very high in phosphate but cod or haddock or salmon isn't, that's perfectly good for yer". ….So, and these are not people, I'm not talking to other patients now and getting, I'm talking to people who work on that kidney ward and they were giving me my dialysis and they were trained in dialysis… but I did find that a problem, that everybody come to me with a different set of rules.*

Obtaining accurate information was therefore important for understanding dialysis and necessary for self-management. Patients however highlighted various barriers to obtaining and understanding the information they required. A study of effective communication in chronic illness found three common themes across differing chronic disease groups; courtesy, respect and engagement[145]. These themes can be seen within the results of this study. Participants expected staff to keep them updated with changes made to their care, and to have access to privacy when it was required. Participants considered their bloods results within the context of how they were feeling and looked for HPs to respect the patient's expertise in consultations[206]. Participants also expressed the importance of HPs presenting information in a way that they could understand, and that adequate time and opportunity was provided for communication.

The importance of providing adequate time for communication has been highlighted in previous studies of both those with ESRD and other chronic illnesses[108, 144, 145]. In this study participants explained they would often make an assessment of whether a HP would have time and be receptive to their questions before asking them. While the availability of staff is therefore necessary for information sharing, successful information exchange also required the patient to feel that the HP was able to fully engage in the consultation. The issue of lack of privacy on the dialysis unit may also result in patients not being able to ask the questions they wish in a consultation and alternative settings for conversations should be offered. In-centre patients found their access to HPs varied depending on when they dialysed, whereas home patients felt they had good access as they were able to telephone HPs and arrange meetings if required. Units could therefore also consider whether in-centre patients would benefit from other ways of providing access to HPs rather than direct consultation on the unit.

Ensuring that staff are able to give appropriate advice also requires appropriate training. This may be particularly relevant to the nursing staff on the unit who have the most frequent contact with patients.

In this study, information was not limited to that provided by HPs and other sources were also important to participants. Consequently the use of reliable internet sites could be suggested and the role of expert patients in information provision considered. For home patients, the support gained from other patients via the internet was particularly important and could be employed to support home patients who may feel isolated.

Providing opportunity and time for communication, engaging in discussion and ensuring patients are kept up to date with changes are all important for supporting patients to gain the information they need. Considering how HPs could better provide this information is likely to play an important role in helping patients to find a sense of personal control.

7.2.4 Choice and making care decisions

As patients gained an experience and understanding of dialysis, they sought to act on preferences for care. Choice and opportunities to make personal decisions about care were valued. This was reflected within many discussions including the seating for dialysis, refreshments provided and the duration of treatment.

> *P10: ... they'll say, "Well you can have an ordinary bed but you might have to wait half an hour for it". So they give you the choice; and I always wait for a bed because it's so much more comfortable for me anyway.*
>
> *P9: For me I won't have anything but a chair. (laughs)*
>
> *P10: Yeah. Well everybody has their own tastes don't they?*
>
> *P9: That's right, yeah which is good. At least we're fortunate that we have a choice here that we want to be thankful for.*

Having gained advice from HPs, some participants then described testing the advice by seeing how they felt when they did not adhere to it. Through this process they came to a decision about what was right for them.

> *P19: My fluid intake for somebody with no kidneys... have you any idea what this, what the recommended is? Half a litre of fluid a day. …And unfortunately I'm sort of pushing the boundaries all the times with them and everything because they're giving me all these figures and everything and I know that I'm going way above the thing but it's because I'm active…*

As we asked about shared care in the focus groups, one of the care decisions participants discussed was whether to become involved with shared care and how much care they were willing to take on. While some chose to keep the responsibility for care with staff, all the participants agreed that it was important to be given the choice. One participant felt that being provided with choice regarding care was especially significant when other choices had been taken away as a result of their dependence on dialysis.

> *P13: … dialysis is still a massive pain in the arse...*
>
> *P10: It is a pain but...*
>
> *P13: ...cos I had to leave my job and I've got next to no money coming in and stuff. So for me it's just; it's not, I don't like not being, I don't like it not being a choice, but, you know, shared care can be, is a choice so at least I've got that.*

In discussions around care provision participants frequently used the word responsibility and this has possibly developed from the medical concept of professional responsibilities. Patients may have been exposed to these concepts through discussions with HPs as care choices became formalised as personal responsibilities. In one circumstance, a patient described having to sign a disclaimer because she chose not to adhere to the regulations of the dialysis unit.

> *P23: …at [Dialysis unit] they don't like yer covering your arm up, you know, with your blanket so I've had to sign a disclaimer, which I've signed, just…*

> *P22: For what?*
>
> *P23: To cover my arm up with a blanket because it is so cold...*
>
> *C3: Cos, you're cold. (laughs)*
>
> *P23: ...they then told me that if the tubes or whatever come apart I'll bleed to death in two or three minutes and they'll not know cos there's a blanket over me….*
>
> *C3: But they can tell because…*
>
> *P22: The machine will go off….*
>
> *P23: ….Well they made a point of fetching out a disclaimer.*

While participants welcomed being provided with choice, they were also suspicious of the motivations behind invitations to become involved in their dialysis care. Some participants felt that the main motivation was the transfer of responsibility for care from staff to patients. Others described a tension between wanting to be involved in their care but being concerned that staff may blame them if something went wrong.

> *P19: I think it's having that control. We want to feel in control, the minute that you're on that machine you lose control and you're reliant on somebody else, so by being able to go onto that machine and to do as little or as much as you want to do you're in control…we've had an instance where a patient went on, the weight was entered wrong, …instead of taking too much off they didn't take enough off. So they came to take her off the machine they weighed her, ooh you haven't lost any weight, went back to look and they were 2 kilos out…Now straightaway the nurse blamed the patient because; why didn't you check your weight? So again it's this give and take; we want to have some input into it but then again it shouldn't be twisted round, there shouldn't be any blame game either way.*

Participants felt that decisions about dialysis took time and consideration; they did not want to be pressurised into decisions by staff.

> *P8: I mean I was asked quite early on if I would consider home dialysis and at that point you don't know what's involved and everything else…*

> *P5: You've no idea.*
>
> *P8: ...so, but I said, "Yeah, it's something that I wouldn't rule out." At which point every time you went to the next stage, whether it be setting your tray up or putting needles in or whatever, are you considering home, … you're going to do home aren't you, and I was like "No, I'm not." You know, I expressed an interest because I didn't know any different...*
>
> *P6: You didn't know any different, and this is what I, cos I thought…*
>
> *P8: ...and, and it's like a dog with a bone that they just don't let it go, they don't let it go.*
>
> *P6: The feeling was that ooh, it'd be great to do it at home instead of trailing into the hospital, but when you get to the nitty-gritty of it it's not the same.*

When provided with choices, participants also highlighted that when they made a decision it was important this decision was then respected by staff. This concern was often discussed in relation to self-care activities, with some participants feeling that HPs would often not accept their choice to decline shared care.

> *P22: Of course we should be given choices all the time, but, and then those choices should be respected afterwards.*

The participants in this study described making many care related decisions, however their descriptions were not always the collaborative decisions with HPs that have been described by Paterson as central to patient centered care in her work on empowerment in chronic illness[206]. Some patients tested the boundaries that they were instructed to keep to and felt this process brought them into conflict with professionals. Other participants felt they were pressurised by HPs into making decisions without the time and experience they needed. Not allowing adequate time for discussion has been highlighted as a major barrier to collaborative decision making between HPs and patients[206]. In this study participants reported that the importance of time was not just relevant to discussions with HPs but also to allow them to develop a personal experience of dialysis. The importance of HPs respecting and engaging with the patient's views and priorities has been reported as central to collaborative care and empowerment[206, 207]. In this study when participants perceived that HPs did not respect their decisions they described feelings of mistrust and consequently relationships could become fractious. This seemed to have particular significance when patients felt that care responsibilities were being transferred to them against their will.

Choices were therefore valued but decisions required time, consideration, and sometimes testing through personal experience. In Charmaz's work on adjusting identities to take account of chronic illness she found that once work had been done to adapt an identity people may then be very reluctant to relinquish these new identities[194]. When patients have made care decisions and considered these decisions while adapting to a new identity, HPs who then challenge these decisions may be seen as directly conflicting with patients' sense of control. HPs therefore need to ensure that they provide choices for patients regarding their care provision. However it is also important to understand that patients may need to time to experience dialysis before they feel able to come to an informed decision about their care. Once patients have come to a decision it is also important that HPs understand the work that may have gone into that decision, and explore this if it is felt that a choice should be reconsidered. As shared care uptake is encouraged, it is particularly important that HPs understand patients' concerns about transfer of responsibility. While acknowledging these concerns in discussions and providing reassurance may address some of these issues, other interactions with patients should also be considered in this context. Words of reassurance may be ineffective if other activities within the unit reinforce the idea of responsibility transfer rather than shared responsibility.

7.2.5 Being seen as an individual

Preserving identity was seen as an important factor in maintaining control. Participants wanted to be seen as individuals and not treated as a patient that requires attaching to a machine as part of a "dialysis factory line".

> *P17: ...it has that sort of sterile feel about it and you feel like you're in a bit of a, it's not a production line or a conveyor belt, but I think because the staff are so busy as well that they don't have that time like in a smaller unit to chat to you and get to know you, and then it makes it that your treatment feels that much more impersonal and that you do feel like a*

> *patient because you're being dealt with like a patient rather than a person.*

When discussing individualised care, participants were looking for staff who knew them as people and dialysis prescriptions that were individualised to their needs. They also wanted to be involved in care decisions and preferred staff to discuss each treatment with them. They acknowledged that staff had expertise in providing dialysis however they felt they had expertise with regards to how their bodies responded to treatment. Therefore they looked to staff to respect their expertise and come to shared decisions about treatment with them.

> *P17: I think being talked to when they're programming the machine; because I've been in a situation where sometimes they ask you what you want to take off and other times they don't, and although they're looking at a prescription and they know what you should be taking off; again this is another one of those things where everybody's different; and I've discovered over the eighteen months that I've been dialysing that if I take off more than 2.5, which includes wash back, I get a tight chest and I get cramp, any less than that and I'm fine.*

As identity incorporates how we wish to be perceived by others, when participants were adjusting their identities to take account of their dialysis dependence it was important to be seen as their individual selves. The importance of being seen as an individual by HPs has been a theme in many other papers presenting the experiences of people dependent on dialysis[105, 107, 112, 115]. In common with the findings of this thesis they have also highlighted the risk that care can become impersonal when perceived as factory line care[107]. This may be a particular problem in dialysis due to the dependence on technology and shift based nature of care[115, 208].

As a result of the ongoing nature of contact with staff on the unit, patients may also wish to be able to present their desired identity so that relationships can be established. Establishing these relationships then allows people to present their narratives, ideas and priorities for care. This desire for developing relationships with staff and continuity of care may explain the perception that you were more likely to feel like an individual in smaller units. Individualised care is therefore seen to require staff that know you, your individual needs and expectations, and can then collaborate with you in care decisions. Being able to maintain an identity on the dialysis unit and be involved in decisions about care can then be understood to aid the development of a personal sense of control.

7.2.6 Managing dependency

Some patients described feeling vulnerable as a consequence of their dependence on dialysis. The dependency that is described by dialysis patients has been highlighted in other studies and includes dependency on staff, technology, family and the scheduling of treatment[115, 144]. This dependency has also been highlighted as a source of distress for dialysis patients[111]. In this study, some participants reported that the emotional consequences of this dependency opposed their sense of control.

> *P19: …as soon as you're on the dialysis you lose your independence, and if you're not of a nature to speak out or to ask you become vulnerable…*

Participants therefore described strategies that they utilised to manage their dependency. Some participants described how self-care helped them to feel less dependent and vulnerable.

> *P26: I went back to unit last week for three sessions… I weren't in control and I wanted to be doing it meself. I did put my own needles in, cos they let me do that, and I programmed my own machine, but I didn't feel I had the same control. Somebody else were looking after me, I weren't responsible for me, someone else were responsible for me…and I did feel when I went back somebody else were in control again, somebody else were in control of me, I weren't in control of my dialysis.*

Others participants who did not physically do the dialysis were still able to manage their feelings of dependency through monitoring the staff and dialysis machines, as well as developing knowledge about their treatment.

> *P17: …you need to speak to the nurse and be sure that, you know, you're going on the right fluid reduction, the right pump speed, and even if you don't know much about the way the machine works there are simple things. Things like turning the face of the computer round so that you can see what's going on...but the other bit is sometimes if the machine bleeps*

> *and you know that you can press it three times and stop it bleeping to be aware of, you know, the lines going up and down on the grid for the venous and arterial pressure, it just makes you feel a bit more part of your treatment…*
>
> *P16: In control or something, yes.*
>
> *P17: …and in control.*

Feelings of vulnerability could also be managed through building trust and confidence in the care provided by staff. When confidence in care was established the participants then felt able to relinquish control to staff they trusted.

> *P17: I had [shared care] offered to me within a short while of arriving as a patient at the unit…and I'm the sort of person who likes to generally feel in control. But I just felt no this is just such an important part of my life that I want to feel safe, and I think I would, I'd feel, you know, safer with them looking after me.*

Participants who managed perceptions of vulnerability and dependency through establishing trust in staff could then feel let down when care did not meet their expectations. The control they felt they had gained could be lost. These responses were often related by the participants to inadequate numbers of staff on the dialysis unit.

> *P17: … sometimes you're left holding your, your [needle puncture] sites and you've an idea that they've probably stopped [bleeding] but, you know, you can't really do much to look to see if everything's OK, and you don't want to risk a blood bath, and just sometimes, you know, the nurse who's been dealing with you will go off and either start taking somebody else off, which again, as I say, is probably a staffing issue, but sometimes they're just cleaning machines and wiping beds; and I know that's something they've got to do and it's got to be there ready for the morning staff, but when you've been there for what could be…*
>
> *P16: Ever and a day basically. (laughs)*

Other studies have suggested the enforced dependency of dialysis may result in passivity and a reliance on others[94, 118]. While participants in this study acknowledged perceptions of dependency and vulnerability these acknowledgements were often found alongside discussion of the strategies employed to manage dependency. While some reported seeking information and involvement in self-care activities, for others building trust in those providing care was the preferred strategy. Previous work in the experience of chronic illness had suggested that when faced with vulnerability people's responses depend on their perception of self, social, economic and psychological resources[209]. In this study care provision, including options for self-care and the attentiveness of care, as well as the nature of patients' relationships with staff were also factors affecting patients' ability to manage dependency. It is therefore important that professionals understand the relationship between knowledge and control. For some patients this may mean simple strategies such as explanation of the dialysis process or ensuring the dialysis machine screen in turned towards them so they can see how much time is left. Other patients may only find a sense of control when they are able to dialyse themselves, independent of nursing staff. The level of involvement and an individual's information needs are likely to be related to the perceptions of self, social, economic and psychological resources highlighted in previous studies, however the care provided can directly affect how successful HPs are at meeting these needs. The recognition that control is not only gained from practical involvement in treatment but also through attentive nursing care, trusting relationships with staff, and the provision of information also has significance as units tend to focus on increasing physical involvement as the main way to improve patients' sense of control.

7.2.7 Striving for autonomy

As seen above participants described having to find ways to cope with dependence on dialysis but they also described striving to maintain a sense of autonomy despite this dependence. Those who dialysed at home found a sense of independence from the whole system, and those self-dialysing in-centre achieved independence from staff.

> *P20: Yeah, I like me independence. Now I come in, if there's a machine free I come in, get gowned up and get washed and gloves on, I set the machine up and I do what I want with my machine and that's it.*

Patients expressed frustration that other aspects of care precluded independence. Participants described not being able to access the dialysis unit without staff members letting them in, and they were not allowed to make their own drinks in the kitchen. Many patients found themselves dependent on hospital transport and were frustrated at not being able to contact transport control when it did not arrive (they had to contact the dialysis unit who would then contact them on their behalf) and some would have preferred to be given financial support to organise their own transport. Patient 21 expressed frustration that staff wouldn't let him walk home but insisted he waited for a taxi to take him.

> *P21: I had a problem with the taxis cos I live four hundred yards from the hospital, and I wanted to walk home and they won't let me; it's a nightmare. They let me walk in in a morning…but they won't let me walk back.*

Some decisions by staff were therefore seen to conflict with participants' desires for autonomy. This struggle for autonomy consequently became a source of frustration to many participants. Some had tried to change the system but reported being unable to access those who could effect change.

> *C3: There is a key pad to get in the [dialysis unit]; so you put a number in, but they don't tell the patients what the number is. So we have to stand outside and press a buzzer and wait…and we've spoken to the manager about this, they go, it's not my decision it was somebody higher up than me that told me we've got to do it.*

Previous explorations of living with chronic illness have described how dependence on others and loss of previous held control may result in a heightened desire for control over others aspects of life[210]. Perhaps as a result of having to cope with dependency on dialysis, striving for autonomy became an important focus for patients. However the provision of care could be seen to present multiple barriers to this drive towards independence. While those requiring dialysis must accept a degree of dependence and therefore relinquish some control, being asked to depend on others for things they considered unnecessary became disempowering and a source of frustration and conflict with staff. As people with chronic illness struggle with downward adjustments to identity, removing further control may be seen as asking them to make even greater adjustments to identity.

HPs may consider empowerment in relation to managing health care regimens, however they may not recognise that overcoming disrupted identities is a significant part of living with chronic illness that also has significance for empowerment[211]. While home dialysis and self-care may promote independence and empowerment for some, it is also important that HPs consider how other aspects of care may be changed to increase independence among all patients. These changes could be relatively straight forward (such as providing patients with door codes) and have a positive impact on all patients, not just a selected group. Additionally seeking to develop a culture of autonomy within the dialysis unit through small changes to care provision such as door access or kitchen facilities may consequently lessen patients' identity adjustments. Patients may then feel more able to take on self-care activities. Consequently to increase patient empowerment and self-care within the dialysis population, it is important to consider how care as a whole can be changed to foster independence and to not focus solely on the dialysis treatment process. Having presented all the sub-themes contributing to the theme of finding personal control, in the next section I have compared the data between participants' degree of involvement in self-care.

7.3 Personal control and differing self-care levels

Individuals employed differing strategies to find control however some similarities and differences were seen when the data from the focus groups was compared by participants' involvement in self-care.

The emotional coping strategies used by participants such as positivity, humour and denial of illness were common across all groups. In addition to these strategies, some of those on home dialysis and in the 5-12 task groups thought that taking on the responsibility for their care had helped them cope emotionally with dialysis dependence.

Home dialysis and self-caring patients often focused on the support they received from family members. The emotional support of staff was not discussed as frequently by these groups as compared with those that did less self-care. In-centre patients may therefore be more likely to seek emotional support from HPs.

In contrast to in-centre patients, home patients felt they could easily access MDT members despite seeing HPs infrequently. They thought ready assistance when required was more important than regular contact (although one patient who was new to home dialysis found this reassuring). In-centre patients' frustrations regarding access to HPs were centered around a desire to be seen when they were already at the unit (rather than having to make additional visits for appointments) and staff having the time to talk to them. In comparison home patients had to phone or visit to seek assistance, in which case they were more likely to have time and staff allocated to address their concern.

Home patients felt they had control over their treatment, whereas discussions among in-centre patients were dominated by struggles for control. While the 5-12 task patients reported feelings of independence from staff in the delivery of treatment, some still felt that dialysis controlled their lives due to the lack of flexibility provided by the dialysis unit and the need to travel. The home patients who reported a loss of independence when dialysing in-centre supported this concept.

Those who were less involved in self-care were more likely to highlight aspects of the organisation of care (such as the screens of the dialysis machines facing away from them) as barriers to control. It may therefore be that HPs do not recognise that those less involved in self-care also seek control. While for some patients being involved in the practical provision was central to finding a sense of personal control this data highlights that many other aspects of care can also effect patients' sense of control. These other aspects of care may be significant to all patients and should therefore be considered alongside programmes encouraging the uptake of self-care.

7.4 Conclusion

While all the participants were involved in a process of finding personal control their ways of coping were individual. This was clearly seen within the discussions regarding self-care; whereas some found that by being responsible for their own care they had greater personal control, others found control by imparting that responsibility to staff. Despite choosing to have nurses providing their dialysis they were not passive recipients of care. The choice to have professional led care was an important element of the ongoing process of finding control for these patients.

Although not highlighted by the patients themselves, there was a clear tension within the data between staff encouraging the uptake of involvement in self-care and the frustrations of patients who highlighted various ways in which the care they received prevented autonomy and self-management. Care providers are therefore seen to be giving conflicting messages. Patients' perspectives of care are influenced by all their experiences; they are less likely than care providers to consider aspects of care in isolation.

While recent discussions regarding patient empowerment have focused on managing regimens and communication with HPs they have lacked a focus on the important process of adjusting disrupted identities[211]. In this study responding to threatened identities and finding a sense of control was very important to patients, and the way HPs provide care and communicate with patients could be seen to affect this work both positively and negatively. Understanding this work and considering each patient's individual narrative is therefore likely to improve the care HPs are able to provide.

Chapter 8 Maintaining Social Viability

8.1 Introduction

This chapter addresses the theme of maintaining social viability, principally through the examination of patients' discussions around their roles and relationships with others. Five sub-themes have contributed to this theme. The first two sub-themes describe the impact of dialysis dependence on existing social frameworks – first, family relationships and secondly broader society. Sub-themes 3 and 4 describe the new relationships that patients build with staff and other patients. The final theme describes how power within relationships between patients and staff can be seen to affect the experience of care. Finally I discuss the differences in social viability in relation to patients' involvement with self-care.

8.2 Sub-themes

8.2.1 Family relationships and roles

Participants were keen to explain that dialysis did not just impact on them, but also on their family members and family life. Participants described how their treatment affected their own role within the family unit and the lives of their family members.

8.2.1.1 The time taken from family life

The time that dialysis took away from family life was a common frustration among both in-centre patients and family carers involved in the focus groups.

> *C2: When you're thinking he's living with them just about as much as what he lives at home.*
>
> *P20: Yeah.*
>
> *C2: ...the amount of time he's here now.*
>
> *P20: ...I spend four days at home with her and three days a week without so that's half me life.*

Consequently home dialysis patients reported that being able to spend more time with family was one of the advantages of home dialysis. However they also acknowledged that while home dialysis gave them time with their family, it also consumed the time of family members as they often helped with dialysis or had to stay in the house while dialysis was in progress.

> *P26: It is a little bit more pressure on yer partner when you do it at home, cos like I used to go to unit and my wife would go shopping, to the supermarket … but now she has to be there, there's no way she'd leave my house while I was on dialysis.*

Some of the older participants (both male and female) who dialysed in-centre wanted the reassurance and company of having family members with them while they were on dialysis (especially when they relied upon them for transport to and from the unit), however in some units this was not allowed. The participants reported that they had been told at some units there was not enough space to allow a family member to stay, however they suggested that some units that did have space would still not let family stay and the reasons behind this were not clear. One participant, who had recently started home dialysis, felt that because his wife had not been able to spend time on the dialysis unit she had not been able to gain the same understanding of dialysis that he had. He felt this subsequently made home dialysis training more challenging.

The time that dialysis took away from normal life was a recurrent theme in this study and affected many aspects of life. Participants (both patients and carers) remarked that this impacted on the time they were able to spend together as a family. While this has also been cited in other studies of patients requiring dialysis [113, 116, 121], this has not been a feature in studies of other chronic illnesses[212], possibly reflecting the significant time commitment that dialysis requires. In view of the time that must be given to dialysis treatment, participants were keen that they were still able to find time to be with family. For some this meant dialysing at home, while others wanted to be able to spend time with their family on the dialysis unit. For patients who find that the time taken away from family life is a particularly challenging aspect of dialysis, home dialysis may help address this. For others home dialysis may not be possible for other reasons. Consequently it is important HPs consider the reassurance and support some patients may gain from having a family member accompany them on the unit. Family members may also be more willing to provide transport if allowed to stay on the unit. While some units allowed family members to stay others did not; units may therefore wish to consider the advantages of allowing family to accompany patients while on dialysis.

8.2.1.2 Family learning about dialysis

Some participants felt preventing family from coming to the dialysis unit also affected communication between staff and family members.

> *P15: And another little point that I think we can generally agree on, there is a gross lack of knowledge of the total effects, and I mean total by all the family, of your condition, a total lack of it. And guess who doesn't have the time and trouble to talk to them? The doctors, right? …. It has some impact on the partners but no-one takes the time and trouble to talk to the partners; and it's no good saying, well the nurses will tell you because the nurses don't have time to tell you, partners aren't encouraged on the wards anymore; that again has come with shortage of time.*
>
> *P17: Yeah, cos they've got a big responsibility, haven't they.... from just simple transport to you know, taking you to hospital when you're not well and, just being there and just understanding, what on a day-to-day basis, let's say the fluid, the food that you're not supposed to eat or...*
>
> *P15: And I don't mean to be sexist but … how many women will be staggered at the salt in a ready meal, right? So to the woman she's got to change her cooking habits… But how well will that go down? And it'll go down better I think when someone in authority, like a doctor, cos they're up there...*

Several participants were concerned that family members had information needs that weren't being met. Some felt staff should communicate more with family members directly, especially regarding aspects of care that involved them. While both men and women reported that their partners would benefit from better communication with staff, men often highlighted their wives roles in food preparation as a particular concern. As suggested in the quote above patients may find asking those they rely on to change their cooking habits difficult. Other participants felt family were more likely to understand and accept advice if they received it directly from staff. It may be that not having to instruct family themselves also helped the participants manage their concerns about burdening family members (see below).

Three home dialysis patients described their wives using internet based support groups to seek information about dialysis. All three agreed that, as well as trying to fulfil their own information needs, their wives would also seek information on their behalf.

> *P26: My wife's always on the internet, I never go on it, I just let her go on it, I find that easier; she just tells me what I need to know then.*

While there were more male home dialysis patients than female in the focus groups none of the female patients reported that their husbands sought information on their behalves. In the quote below, P1 who is describing his daughter's visit to the dialysis unit, implies that he thinks wives may be particularly interested in visiting the unit. This highlights that male and female partners may have differing roles and needs regarding information provision[213].

Patients reported different experiences regarding contact between family members and staff. While some thought staff could make more of an effort to communicate with their families, others thought that the staff had involved family members. P1 appreciated the staff arranging for his secondary school aged daughter to visit the unit when he had first started dialysis.

> *P1: ...they brought her in, and [nurse specialist] took her round on a tour and she asked all the questions, looked at everything…she just answered all her questions ….but after that visit where she'd been brought there was nothing she was imagining, she knew what it was all like and that [fear] was all gone and that was fantastic and, you know, it can help not just wives but anyone.*

Several participants discussed the importance of children developing some understanding of dialysis and the difficulties of explaining dialysis to them. While P1 felt that visiting the unit had helped his daughter P27 felt dialysing at home had helped his children.

> *P27: On the other hand, my kids didn't really know what I was doing before I dialysed at home; it was difficult to really talk to 'em about it.*

> *They've got very used to it now, they can see exactly what it is, it's not a big deal; it's an everyday thing. Is that a good thing or a bad thing? I don't really know. It's a thing.*

The importance of access to information and its role in developing a sense of control was described in chapter 7. Participants were keen to explain that their family members also had information needs and that these may not be considered or addressed by staff. Considering patients within their family context is therefore important to patients and may require discussion of the roles different family members take in the care of an individual. Previous studies have shown that within families women often act as guardians for family health[214] and in this study the female partners of some male patients appeared to have important roles in information gathering and addressing dietary modifications. The gender of carers of haemodialysis patients and how it affects their roles and responsibilities requires further study. While studies have recently found low levels of health literacy among patients with chronic kidney disease[215], and have explored the information practices of patients[216], the role of family members in this process has not been addressed. Consequently ensuring we are communicating with family members, especially regarding aspects of care they may be involved in, has the potential to improve the experience of care, and possibly adherence to aspects of treatment.

8.2.1.3 Burdening family

Patients were concerned about the effects that their dialysis dependence had on their families and did not want to become a burden to them. Consequently, not wanting to place responsibilities for care on family members became an important barrier to home dialysis for some.

> *P19:…but if anything were to go wrong with that machine while you're on the dialysis you're dependent on your partner to sort out that issue, and that's what I wouldn't want to do.*

Two participants said they had moved from peritoneal to haemodialysis because of these concerns. The responsibility placed on family members also created anxiety for those currently on home dialysis.

> *P27: So there's that aspect of it, you are putting things on your family that otherwise they wouldn't have to deal with, you know, you'd be away at the unit and there'd be nurses there putting bloody saline into yer, and that is a cost, they do worry more.*

Home patients varied in how much they relied on family members for dialysis care. A few dialysed independently while others were totally dependent on family for their dialysis. Most had adopted a “team approach” with their partners and this back up was seen as particularly helpful when first starting to dialyse at home. The involvement of family members could consequently change over time. If patients developed further health problems they may need more help; one patient explained his wife had had to learn to needle his fistula as a cerebrovascular accident (stroke) had left him unable to do this himself. Even when home patients dialysed independently, they still felt that it was important for a family member to be at home in case something went wrong. This represented a further source of guilt as they felt this time commitment also burdened family members.

As well as the responsibility placed on family members when dialysing at home participants also worried about the emotional distress they could potentially cause family members if something went wrong during their treatment.

> *P20: ...if anything happens and I die on that machine that’s a horrible thing to find.*

The vast majority of participants who dialysed at home relied on their family members, even if this was only to be present in case of an emergency. Consequently the burden placed on family members was cited as an important barrier to the uptake of home dialysis for some. This has been highlighted in other studies of home dialysis patients and modality decision-making[199, 217]. As described earlier, in-centre patients also relied on family members for aspects of care including transport, assisting with dietary changes and the sourcing of information. However these requirements did not appear as significant to participants as the reliance for dialysis care. This discussion suggests that the responsibility placed on family and the emotional consequences of involvement in care were much more significant to patients and carers than practical burdens. As such this data suggest that the burden of care placed on family members should be considered as part of pre-dialysis education and home dialysis training. HPs should be particularly conscious of the emotional burdens that patients and carers may experience as a result of their involvement in care and discuss these with patients and their families.

8.2.1.4 Effects on family roles and responsibilities

As well as concerns regarding the burden placed on family members as a direct consequence of dialysis, dialysis dependence was also seen to affect family income, holidays, the time available for child-care, and the ability to visit extended family and attend events. Two patients explained that, due to dialysis, they were no longer able to work and bring money into the family.

> *P13: …dialysis is still a massive pain in the arse ...cos I had to leave my job...and I've got next to no money coming in and stuff.*

Another participant explained that due to the exhaustion she experienced after dialysis she struggled to do the housework.

> *P7: … I absolutely agree with you, it just wipes you out completely.*
>
> *P6: Now I thought it was just ladies that…. I thought well we have to go home …we have to think about housework, doing the washing, cooking meals, you see, and I thought well is it just us women….and you've said it, it just wipes you out.*

Their dialysis dependence therefore prevented them maintaining their roles and responsibilities within the family and this caused resentment towards dialysis. The negative effects that dialysis dependence can have on a person's ability to fulfil desired roles and responsibilities within the family has been reported in other studies of those on haemodialysis [35, 108, 110, 112, 115]. These range from the more physical aspects such as being able to work and provide, to emotional responsibilities such as being seen as reliable or a source of support. Much of our identity is formed by our responsibilities to others and how we perceive others see us[194]. The degree to which dialysis dependence disrupts these roles and responsibilities may therefore affect not just family members but also patients' identities and personal control (see chapter 7).

The disruption of roles and responsibilities is not isolated to dialysis dependence and has also been reported by family members in other chronic illness settings[212].

In dialysis however the constraints are often related to the treatment itself rather than the illness and have been shown to be an important consideration for patients when choosing between treatment options for ESKD[217]. How HPs can best support patients to maintain these roles and responsibilities should consequently be considered during pre-dialysis education. The modality of haemodialysis provision such as home or self-care may also affect whether an individual is able to continue with previous roles such as employment. For those dialysing in-centre, consideration could also be given to the scheduling of sessions and how this may affect patients' roles and responsibilities outside the dialysis unit.

In conclusion, patients consider the effects of their dialysis dependence within their family setting. As a result they look to HPs to consider the effects dialysis has on their family and for communication and care that supports both family involvement and their role within it.

8.2.2 Social networks and beyond - A need for understanding

While it was important to patients that their family developed an understanding of dialysis, it was also important that other people within their social networks, and society as a whole, understood what it meant to be dialysis dependent.

8.2.2.1 General Practitioners

Some patients felt their general practitioners had little knowledge of ESKD and would defer decisions to the renal unit. Consulting them was therefore seen as having little utility.

> *Well my GP in [home town], I don't see much of him now because when I do go he'll sit there and say, "Well that's a renal problem, I don't really know what to do with yer, bring it up at [renal unit].*

8.2.2.2 The NHS

They also felt that those who ran the NHS as a whole did not understand the unique dependence on the NHS that dialysis patients had.

> *P16: I think the thing is the NHS needs to look at renal because dialysis is not like being a normal patient, normal patients go into the ward, they're in there for a week or whatever, they have their treatment, then they're discharged and they go for a follow-up visit six weeks later and then*

> *providing everything's all right that's it they're off the list. But for us it's a lifetime experience really and there's, the only way off it is either death or a transplant; and it is our life. So consequently all these cutbacks that you're talking about they do impinge upon the life of the patient, but for us it, it's all we've got…. So really they ought to look at dialysis in a different light because of the fact that we are going in there week in, week out regardless of bank holiday, Christmas, holidays, whatever, you've still got to go to dialysis nearly every other day…*

8.2.2.3 Society

The frustrations of not being understood also extended to friends and lay understandings of the disease. Patients felt there was little understanding of the life threatening nature of ESKD; they felt the public perception was that ESKD was easily treated with dialysis and kidney transplants were curative. They were frustrated that society did not recognise that being dialysis dependent meant you were unwell, and having ESKD was not just a matter of having to attend dialysis. Several participants made comparisons with cancer care and felt those with cancer were better understood.

> *P5: Can I say that I think kidney failure is a forgotten disease? You mention cancer, you mention heart problems, there's the adverts on TV, there's everything, there's never anything about kidney failure… I've had cancer, I'm two and half years down the road now, I was a kidney patient before, I was on dialysis, all these same problems that I'm having now, I got breast cancer, it changed like that…because I was a cancer patient and believe you me, touch wood, I've had a good experience with it; give me cancer any day above kidney failure…*
>
> *P7: Yeah; and kidney failure is still life and death isn't it?*
>
> *P5: … it was nothing compared to kidney failure, when people, now when I say to them and I've had cancer, they go, "oh gosh", and I go, yeah but I've got kidney failure as well; oh yes, but they sort that out don't they?*
>
> *P7: Yeah, and…you don't look as if you're ill*
>
> *P5: And, and they say, oh yes, but that's sorted out easy, you know.*
>
> *P7: Because you look well, I mean you're not losing your hair…*

This quote also demonstrates that dialysis patients felt that to some extent their illness was not as visible to others (for example people with cancer are recognised due to hair loss) and this invisibility contributed to the lack of acknowledgment of illness by society[218].

Participants felt that it was important that those in their social worlds understood what it meant to be dialysis dependent, not just people involved in their health care. Additionally participants in this study felt that even if others knew they had ESKD, the disability that they experienced as a result was not clear to them. This could therefore have relevance to the empathy, understanding and legitimisation of sick roles they received. Within the context of the United Kingdom and the NHS, this lack of understanding and recognition was also seen by participants to affect the health care provided and their experiences of primary care.

While the negative consequences of recognition of illness have been examined in the extensive literature regarding stigma[219], there has been less discussion of the potential benefits associated with social recognition of illness[218]. While it may be clear that an understanding of illness would be beneficial for those involved in providing or organising our healthcare, the participants in this study suggest that benefits could also be gained from a wider social understanding. For HPs working in renal services it is also easy to forget the lack of understanding of ESKD in wider society. Many organisations and charities do work to raise awareness of kidney disease, however the focus is often to increase detection rates rather than on what it means to have ESKD. It is important that organisations and HPs working in renal services recognise the lack of understanding in the wider population and consider how they may raise awareness of the personal consequences of ESKD to other aspects of the health care community and the lay community.

8.2.3 Building relationships with staff

Participants' relationships with staff were one of the most frequently discussed themes within the focus groups. For in-centre patients these discussions focused on the nurses on the dialysis units. The staff were often seen as the most important element of a unit, consequently when participants discussed holiday dialysis the first question they asked usually related to what the staff on the unit were like. This theme explores why the participants in this study valued these relationships.

8.2.3.1 Personal relationships

Getting to know individual staff members was an important aspect of starting dialysis. As discussed in Chapter 7 participants felt it was important to be seen as a person by staff; staff were therefore valued if they expressed interest in patients' lives outside the unit.

> *P17: I think the best thing about the [dialysis unit] is that you feel like you're a person and not a patient. Being a small unit you've got a regular group of staff and obviously they're not always on your session but over a period of sessions you meet the same people, and they're interested in you without being nosey. If you want to tell them something about what's happening in your personal life they take a great interest in it; and I think that for me is the best bit.*

While developing personal relationships was valued, patients highlighted two factors that hindered this; firstly a lack of continuity of care and secondly the time staff had available to talk to them.

> *P17: It has that sort of sterile feel about it and you feel like you're in a bit of a… it's not a production line or a conveyor belt, but I think because the staff are so busy as well they don't have that time like they do in a smaller unit to chat to you and get to know you, and then it makes it that your treatment feels that much more impersonal and that you do feel like a patient because you're being dealt with like a patient rather than a person who's got another life outside the dialysis unit.*

As patients valued the relationships they developed with staff members, continuity of these relationships became important. They were frustrated by staff moving around and described a sense of abandonment when they did not get to see the professionals with whom they had built relationships. Some participants reported a sense of loss when they changed dialysis modality or when staff left.

> *P4: I did feel as though [Consultant] had abandoned me, … I do like to see my own consultant a lot more.*

> *P10: And I was so upset when my peritoneum stopped working and I had to come and have haemodialysis because I knew …it would now be new people; and it's silly to have that fear really because they're all as nice as each other, do you know what I mean? But I felt a real sense of loss that I wouldn't be having [peritoneal dialysis nurses] anymore…*

Continuity of care allowed trust in individual members of staff to develop. Developing trust and confidence in the abilities of nursing staff was an important aspect of care, especially in relation to the nurses' needling skills. Participants also reported they were more likely to accept the advice of doctors if they had built a relationship with them and respected them.

> *P26: I think after a time when you seen doctors, there is certain ones you listen to and take more notice to, you respect some of 'em more than you respect others…*

The participants described a need to develop personal relationships with staff. This allowed trust and individualisation of care to develop. Once these relationships had been established participants valued their continuity and were reluctant to let go of them. The patient-professional relationships between these patients and renal unit staff (especially nursing staff) are unusual in health care in that they are long-standing and interactions are frequent. These factors may contribute to the fact that many of the participants felt they had gone on to develop friendships with the staff in the unit or referred to them as 'family'. Previous studies of patients on haemodialysis have also described how patients desired friendships with staff [110, 114]. While the usual healthcare provider – patient relationship may be assumed to be a one-way provision of care; friendships involve mutual care and interest. Participants' descriptions of their reciprocal relationships with staff are therefore explored as part of this sub-theme.

8.2.3.2 Reciprocal relationships

Possibly because of the desire for friendships with staff, as well as valuing staff who were interested in their personal lives, participants also liked finding out about the lives of the staff.

> *P16: I appreciate the familiarity with the staff, they know about me, they know about my family and similarly they tell us things about their*

> *families as well and their children; so you don't feel like you're going actually to hospital. I regard it as the renal social club really where we get together and chat to the staff…*

P16 suggests in this quote that seeing the staff as her friends helped her cope with dialysis as she was able to see dialysis as a social club rather than a clinical treatment.

Participants also explained they would listen to staff conversations and consequently this provided an insight into their concerns. Patient's concerns for the welfare of the staff became a predominant theme within the discussions among in-centre patients. These concerns included the work conditions of staff, stress levels, their health and safety. They disliked seeing the dialysis unit staff criticised by seniors and were frustrated by perceptions that employers did not share their high regard for them.

> *P1: …we always see them at the end of the day when they're at the most, you know, they've had it and, you know, it, it gets to the point where…well we all really get to know 'em don't we?*
>
> *P2: Oh yeah.*
>
> *P4: Yes.*
>
> *P1: And instead of them worrying about us we're worrying about their health.*
>
> *P2: Definitely, we do.*

> *P1: ... it would be really, really nice if someone somewhere, not from a patient's side, could just show the nurses that they're appreciated, you know what I mean...*
>
> *P2: Yeah*
>
> *P4: Mm, I agree with you.*
>
> *P1: ...because the powers that be just don't seem to care a lot of the time…*

The participants also described how they were keen to assist the staff through agreeing to come in at different times, or attend other dialysis units if they were busy. One group discussed that they would cut short their dialysis times so that staff did not have to go home late.

> *P1: ...cos I mean you get on late and you see the nurse and they're so shattered, and none of 'em will say "Well cut your time down so I can finish". But a lot of us patients say "Well no, you know, I'll only do three and a half, or I'll only do three hours" and that's what happens.*

For many participants their relationships with staff were considered to be reciprocal and not one-way transactions of care. The data suggest that this investment in developing friendships with staff may have helped some cope emotionally with dialysis by seeing dialysis as a social event. Additionally developing friendships allowed participants to care for staff; this may consequently have helped participants cope with their feelings of dependency. As discussed in chapter 7 finding ways of managing this dependency was an important aspect of emotionally coping with dialysis for many participants.

The term 'intimacy' has been used in the literature to describe the close relationships that can develop between nurses and patients[220]. Timmerman identified conditions that needed to met for intimacy to occur; reciprocity, trust, emotional closeness and self-disclosure[221]. Participants in this study described all four conditions in relation to their relationships with staff suggesting that they may have been seeking intimacy in these relationships. Previous studies of nurse-patient relationships have also highlighted the desire of patients to find out information about staff to develop intimacy within the relationship, however these relationships were assessed as remaining skewed towards dealing with the patients problems[220, 221]. Participants in this study frequently discussed their concerns for the nursing staff suggesting that patients may not view these relationships as skewed to the same degree as HPs. As trust and reciprocal information sharing are considered to contribute towards the development of intimacy, the development of close relationships with staff may also have relevance for the promotion of adherence and self-management.

Studies have suggested that there needs to be a degree of continuity for intimacy to develop[222, 223]. The longevity of relationships between patients and renal unit staff is likely to encourage the development of intimacy within these relationships.

However continuity could also be considered by staff as a reason not to develop intimacy in relationships with patients[224]. Studies have also suggested that work pressures and the culture of nursing may discourage the development of such relationships[222, 224]. A study of dialysis nurses found the “blurring” of traditional patient-professional boundaries was a potential source of stress among dialysis nurses as they tried to maintain boundaries and their relationships with patients[225]. However others have argued that the development of intimate relationships with patients is central to caring, and can enhance personal and work satisfaction[224].

While patients may derive benefits from developing close relationships with the staff on the dialysis unit, these benefits have to be balanced against the disadvantages that may be considered by staff.

While professional bodies advise against ‘improper’ emotional relationships and recommend maintaining ‘professional’ relationships with patients there is little guidance on friendships or close relationships[226, 227]. To some extent individual HPs are left to negotiate their own level of closeness in their relationships with patients. Within a HP-patient relationship complete reciprocity is unlikely to be desirable (by HPs or patients) or therapeutically useful as the focus must remain on the patient. However some participants in this and other studies have suggested they gain from building friendships with staff[228] and as they try to establish friendships a degree of reciprocity may be seen as necessary by patients. A study of oncology nurses relationships with patients found that nursing staff were comfortable with some degree of self-disclosure and felt this was possible while maintaining professional boundaries[228]. The nurses in this study also utilised the term friendships but identified them as ‘professional friendships’ to reflect the need for maintaining professional boundaries within these friendships[228]. It is important to recognise that self-disclosure remains the choice of the HP and must be balanced against the risk of over-involvement. The risk of be coming over-involved is felt to be higher in HPs with less experience, however it has been argued that this may be guarded against by the social order and accepted practices within a healthcare environment[224]. The data in this thesis demonstrates diversity among haemodialysis patients and their approaches to relationships with others. We must also acknowledge that there is diversity amongst renal unit staff. Their approaches to relationships with patients may be influenced by experience and the culture of the unit, but will also be consequent on individual choice.

The longevity and frequency of the relationships dialysis unit staff have with patients is likely to increase the risk of over-involvement for both patients and staff and is a risk that must be managed by staff. Consequently dialysis units should consider training and the encouragement of reflection on their relationships with patients, especially for staff who are new or inexperienced. While both patients and staff may benefit from some level of reciprocity and self-disclosure there must also be a consideration of the risks including the stress this may place on some staff through trying to meet unrealistic or inappropriate care demands, the risk of favouritism towards certain patients and the distress involved in the event of their death[222]. The data from this study also illustrated how these relationships could affect the care that patients received and this is discussed in the next part of this sub-theme.

8.2.3.3 Relationships and effects on care

The previous 2 parts of this sub-theme have described the development and importance participants placed on the close relationships they felt they held with staff. Participants also described how these relationships affected their care both positively and negatively. For some patients it seemed important to develop a personal relationship so as not to be considered a task or work by the nursing staff.

> *P5: Even though they're not speaking to you, they're just walking past and saying, you all right there today [name], or something; and that's fine, that's all you need...*
>
> *P6: Yeah.*
>
> *P8: It's the acknowledgement you're not a number and part of a job.*

Personal relationships were also seen to increase the empathy staff had towards them.

> *P8: If you're an outsider going into a different unit in a hospital you're very much pushed in a corner and it's done out of duress, whereas when you're in your own local unit the empathy and camaraderie between the staff and you is just in a different league.*

In addition to the concept that caring for staff helped address patients' concerns regarding dependency, it may be that developing personal relationships helped address these concerns through changing patients' perceptions of themselves from objects of work for staff, to people for whom the staff cared and wanted to help.

8.2.3.4 Negative consequences of relationships with staff

Some participants found their relationships with certain staff members did not provide the care and understanding they sought. While continuity with staff with whom participants had built positive relationships was valued, when relationships did not meet their expectations participants could feel trapped; they could not choose different staff and were dependent on them indefinitely.

> *P19: I've seen it across from renal nurses down to auxiliaries, they must accept and understand how the patient feels… I have actually had a nurse turn round to me, and she turned round and said, "If you don't like it you know what you can do." "Excuse me, what can I do? ...What am I gonna do? I'm here for life."*

As they were dependent on the staff, indefinitely trying to maintain 'good' relationships with the nursing staff was important to many participants. Perhaps as a consequence of this some participants described being reluctant to do things they felt may upset the nurses.

> *P22:I have a good relationship with all of them the nurses, they're pretty good, they're good.*
>
> *P23: I think you don't want to upset them either do yer?*
>
> *P22: No, no, because they're the ones that have the needle in their hand.*

> *P23: So they will actually take more off if you really push the point, but then they really sorta have a go at yer when your blood pressure drops…*

This could affect participants' willingness to enter negotiations about their care as they were wary of challenging staff, and did not want to be criticised by them.

The familiarity of the relationships built with the nursing staff seemed to blur traditional boundaries. Accepted practice allows the sharing of information within the healthcare team[229], however one patient was dismayed that something personal she had shared with the doctor had then been shared with the dialysis unit nurses.

> *P23: … when you see the doctor I think everything you say with the doctor should be confidential…I said, "This should be confidential what I've said in that room with that doctor, this nurse shouldn't be coming out and chatting to all the other nurses about what I've spoken about"…and [dialysis unit nurse] just said "Oh well we need to know everything what's said in that room." So now I don't say anything to that doctor; so all that's happened is I've closed down my communication now, that's all that's happened, I won't say anything…*

She felt she was no longer able to confide in the doctor, as she didn't want the nursing staff to be informed about issues she considered confidential. This suggests she viewed her relationships with the nursing staff differently from usual patient-HP relationships; the nurses had become social contacts or friends and consequently she did not want personal information shared with them.

Participants also felt that because of the close relationships they had with nursing staff they were able to more readily detect when the latter were stressed or tired. These comments were often in the context of concern for the welfare of staff, however participants also highlighted that this awareness could cause anxiety about how tired or busy staff may not be providing safe care. As well as being able to detect these negative emotions in staff members they also felt that staff could transfer negative emotions to them.

> *P19: …what happens there is that you get nurses apologising for their behaviour because they're stressed, they're running around, they're overworked so they're passing that frustration and everything else and their own personal experience of work onto patients…*

Participants stressed that staff maintaining a positive and calm attitude played an important role in their efforts to emotionally cope with dialysis. Consequently this transfer of negative emotions may not only result in feelings of stress or anxiety but also affect the success of patients' efforts to cope with dialysis.

The close relationships the participants felt they had with staff were therefore thought to improve care through individualisation, improving empathy and helping with emotional coping and feelings of dependency. When good relationships had been established, their continuity was valued but the enduring nature of the relationships between patients and staff on the unit could also be a disadvantage when relationships were not successful. Maintaining good relationships was therefore a priority and the participants in this study appeared to feel HPs attitudes towards them could affect their care. Studies in other healthcare contexts have described how patients strive to be seen favourably by nursing staff to receive better care[220, 222, 230] and this may partly explain participants' willingness to help the staff when required. Participants also suggested that being thought of favourably by staff helped with feelings of being a burden. This corresponds with a previous study which found that feeling liked by nursing staff was important for patients to maintain self-esteem and autonomy[230].

While patients may be driven towards developing close relationships with staff, the importance of these relationships and a perceived need to promote and protect them could then adversely affect the care they receive and this was illustrated through patients choosing to reduce treatment times, choosing not to bother busy staff and being less willing to challenge or be involved in decision making. Consequently while we may assume that close relationships would encourage information exchange the desire of patients' to maintain good relationships could actually impair information exchange and change patients' perceptions of appropriate information exchange between staff. Participants suggested the friendships they had with staff could also result in the ready transfer of emotions from staff to them; it seems likely that this transfer will also work in reverse and may be one reason why a previous study highlighted the "blurring" of traditional patient-professional boundaries as a source of stress among dialysis nurses[225].

In conclusion participants' relationships with staff were a key aspect of care for them, and the significance of these relationships may be under-recognised by HPs[230]. The participants described many benefits from developing close relationships with staff but also highlighted tensions between maintaining good relationships and good care. It is important for HPs to consider the value placed on these relationships by patients but also recognise their complexity and inherent tensions. While it may be that the desire for close relationships with staff were over-represented in this study (as those who felt positively towards staff may be more likely to volunteer to attend a focus group) a desire for close relationships or friendships with nursing staff has been reported in previous studies of both dialysis patients and in other healthcare settings[110, 114, 228]. This study highlights many of the benefits patients reported from close relationships with staff, however the data also highlighted how these relationships could be seen to adversely affect care and have disadvantages for nursing staff.

Understanding how the need to maintain these relationships may adversely affect care may allow HPs to ensure that they still encourage information exchange and involvement in care decisions. It may also be helpful for HPs to consider their boundaries and that maintaining these boundaries may be necessary for the provision of good care and their emotional well being as well as that of their patients. Consequently understanding the concepts in this sub-theme gives some explanation for the significance placed on, and tensions within, dialysis patient-HP relationships that previous work has observed[145].

8.2.4 Relationships with other patients

When participants started dialysis the relationships they developed with staff added a new social dimension to their lives. In addition to these new relationships with staff most of the in-centre participants also described developing new relationships with other patients.

8.2.4.1 The value of relationships with other patients

Talking to other patients was difficult outside the dialysis unit due to time constraints or difficulties with transportation; consequently these relationships mainly developed in the unit. Talking to other patients was seen as easier in smaller units and could be facilitated by the arrangement of seating within the unit.

> *P20: It was better, like I say, because when you're all close knit; I mean me second time around we was in bays of four, four patients per bay, and the bay was half this room; so when you think you've got four patients in there you all had a good banter going…*

> *P23:..and that's the other thing, they push the machines forwards and you can't even see the person next to yer so they just block you.*

Talking to other patients had the advantage of helping pass the time but for some social contact at the renal unit was more significant. For P2 the social benefits of coming to dialysis unit were so important she had chosen not to go on the transplant waiting list.

> *P2: I just want to say that if I did get a transplant I would be on me own in my bungalow….I'd just be sat watching telly, I know it sounds awful but I'd rather be here…*
>
> *P3:…. My wife thinks I have a marvellous time (laughter) she's almost jealous, because when I tell her what happens and about the nurses and the, you know, meeting people like yerself, and drinks and toast and breakfast, you know, well...she'll tell people "He's on dialysis but, you know, he's, twelve hours, he's having a marvellous time".*

For some participants the dialysis unit was an important part of their social lives. Previous studies have found that dialysis patients are prone to social isolation as a result of low self-esteem, loss of employment, symptoms and dietary restrictions [108, 112, 114, 115, 144]. For some, fostering relationships with other patients may therefore compensate for the loss of social contact in other aspects of life[231]. Previous studies have highlighted that the loss of the social environment of the dialysis unit can be a barrier to the uptake of home therapies[5, 232] and, in this study, it was seen to affect choices regarding transplantation. The social value of the dialysis unit is therefore a key factor for patients when making modality decisions. Participants highlighted how the organisation of the dialysis unit may affect their ability to socialise and HPs could consider how the arrangement of seating and machines could assist communication between patients who wish to talk to each other.

As well as providing companionship, other patients were seen as useful sources of advice and information. Sometimes this information was seen as more 'believable', or more readily available than advice from professionals, however some participants acknowledged that the experiences of others were not always applicable to them. As information from other patients was often highly regarded, it could influence decisions about care especially if they felt positively towards the person giving the advice.

> *P20:… well all I can say is what a complete and utter arsehole he was, everything was doom and gloom with him. Now that was CAPD and that put me off CAPD; but I will admit if he'd have been as good as the haemo patient who wasn't doom and gloom maybe I'd have thought more about it, I don't know.*

As well as advice, participants felt that other patients offered a shared understanding or empathy which could not be provided by their alternative social contacts. Other patients therefore often became an important source of support, especially when starting dialysis.

> *P4: By talking to them, it's really the only thing that we're able to do, and to reassure them that we've gone through the starting off…talking is the most important thing, and communication, which is often lacking in staff.*

> *P1: Yeah, but thing is on dialysis, we're all in, basically, in the same boat...*
>
> *P2: Of course we are.*
>
> *P1: ...everybody's going through roughly the same things and everybody helps each other, don't they, when, they're having a bit of a rough time.*

Some participants particularly enjoyed offering such support, or felt they had a personal responsibility to do so.

> *P2: I put it on myself to, to embrace new people, cos I feel like I wanna protect 'em, you know what I mean?*

While most participants highlighted the advantages of meeting other patients on the dialysis unit this was not the case for all; P22 stated that he did not want to get 'involved with other patients'. Those on home dialysis also highlighted the advantages of gaining information from other patients, however they were less interested in developing social relationships.

> *P27: Some people are sociable; I mean I'm not a sociable person, to be honest (laughter) I'd far rather be sat in a room on my own with an iPad*

> *than surrounded by people. So for me, getting out of the unit; it sounds terrible doesn't it? But I'd rather not have to be going through the social aspect of it; that's not who I am. Some people love that, you know, you see them, they come in, have a laugh and a joke, it's clearly right for them, why would they wanna change that?*

A previous study of pre-dialysis patients with kidney disease explored the use of peer support and concluded that other patients could provide more practical information than that provided by health professionals[233]. One participant in this study acknowledged that professionals hold factual knowledge about dialysis, however he explained they have 'never been there or done it' and only other patients shared an experience of having dialysis. This was seen as particularly valuable information when making modality decisions. In addition to providing experiential information, participants also related the concept of shared experience to the support they gained from other patients. Other studies have also highlighted the value of peer support in offering a shared understanding [234, 235] and found the sharing of experiences of living with illness may improve enablement among patients[234]. In this study developing relationships with other patients provided friendship, information, and played a role in emotional support for many patients, especially when starting dialysis. However not all patients wanted or needed relationships with other patients. These preferences likely reflect individual choices, contexts and experiences as some participants had more negative experiences of these relationships than others.

8.2.4.2 Negative consequences of relationships with other patients

Participants also described negative consequences from developing relationships with other patients; they reported feelings of loss and sadness when patients they were friends with died, had a transplant, moved units or suffered complications. Participants who had experience of this found it made them wary of fostering close friendships in the future.

> *P23: Well I've only been there at [dialysis unit] for twelve months and, and I think there's already been two people or three people who have passed away, one who I knew quite well; in fact I was talking to him on the Wednesday and on the Friday our receptionist quite bluntly just says "Oh have you heard that so-and-so died last night in his sleep?" And it*

> *were just, I just says "Oh my God, that's such a shock."… he was only young; so it is sad…*

Some participants chose not to enquire when patients had, "gone off the unit" for fear of hearing they had died. Other participants wanted to know what had happened but found that staff could be insensitive when breaking news of deaths, or would be reluctant to inform them and they would consequently struggle to find out what had happened.

As participants developed friendships with other patients a sense of camaraderie developed. As a result participants reported feeling affronted if they perceived staff were not caring for others appropriately.

> *P23: I was on a ward … and I really, really bonded with them and they're all eighty years old; …she's eighty year old… but they speak to her like she has got no brains, and she has; and you can see she's hurt sometimes how they speak to her, even if it's just a little thing …and they wait every single time for her to say "Can you help me up please?" Just help her up… she's been in there for how many years, you know she needs helping up. It's awful, they shouldn't do that, shouldn't wait for her to ask, it's upsetting…*

While participants may have been happy with the care they personally received, their opinions of staff and relationships with them could be damaged by their perceptions of the care they offered others in the unit. Together with the reports from some patients that staff could be insensitive when breaking the news of other patients' deaths this suggests that HPs may not be alert to the strong emotional attachments patients can develop towards each other and how this may influence their relationships with HPs.

Seeing other patients die, or encounter emotional or physical difficulties could also lead to anxiety and distress as participants reflected on their own health and mortality.

> *P20: And then you come in one day, oh where's? Died. Then you think hang on a minute, that bugger was as healthy as me last time I see 'um, they're dead, oh hang on a minute that could be me. So then it comes home then, hang on a minute this isn't a joke anymore this is serious,*

> *they've already snuffed it, am I next? So yeah, there is two ways of looking at that of getting friendly with the patients on the ward.*

P20 concluded he no longer wished to develop close relationships with patients due to the difficulties he had experienced when previous friends from the dialysis unit had died; both because of the sadness of their deaths and because their deaths forced him to consider his own mortality. A study of people attending support groups for cancer patients described how the deaths of others in the group could be challenging for participants, however the study reported this was accepted by participants as part of the experience of attending the group[235]. In contrast some of the participants in this study described how they were surprised when they first started dialysis at the frequency of the deaths of other patients (P23). The high mortality rate of those on dialysis may not be apparent to those who start dialysis and they may also not have considered how building relationships with patients may result in having to cope with their loss. Patients who had experienced the loss of other patients had differing strategies to cope with this aspect of dialysis but many chose not to develop such close relationships in the future. While warning all patients of the high mortality associated with dialysis treatment when they start is unlikely to be helpful (and no patients suggested they would have liked to have been pre-warned) it is important that HPs are aware that some patients may find this a particularly distressing aspect of dialysis and are prepared to discuss patients feelings and responses to the deaths of other patients.

8.2.4.3 Criticism of other patients

In most of the discussions concerning other patients, participants referred to their peers positively, however a few discussions involved criticism of other patients. Some disapproved of the actions of others who were seen to cause disruption, or were uncooperative with staff. Some of the criticism of other patients related to their self-care choices. Several self-caring patients resented patients who chose not to be involved in their care, whereas some non-self caring patients resented the nursing time taken to teach those who did want to self-care.

> *P14: It's not difficult to get your pack ready, is it; they should be encouraged to do that. I see a lot of people just come in and sit on their arse and do nothing…*

> *P9: … when we're short-staffed; and also if somebody hasn't done anything; like me, I can needle but I need somebody there at the moment. If somebody before me hasn't done anything and their machine hasn't been set up, you've got a long wait, haven't you, sometimes?*

> *P6: There's somebody that does his [own] machine…*
>
> *P5: That's a bed that's taken up, yeah.*
>
> *P6: …and sometimes he even gets it wrong…*
>
> *P5: Exactly.*
>
> *P6: …so a staff member has to go and fix it...*
>
> *P5: …so it takes longer.*
>
> *P6: ...and I once had to wait three quarters of an hour because I was the next in line, and he happened to be next to me…*
>
> *P5: Because he was trying to do it himself, yeah.*
>
> *P6: …because he'd got it wrong he had water all over, he tried to do it himself and all I felt like, it took me all my time to stop saying, for God's sake get…*
>
> *P5: Just do it for him.*

Recently there has been a focus on peer support as a strategy to improve or encourage self-management skills within healthcare[234]. Patients in this study described the influence that other patients could have when they were making care decisions, especially when these decisions related to modality choice or choosing whether to be involved in shared-care. Yet P20 (see section 8.2.4.1) explained how the opinions of other patients could be very influential despite not being a balanced representation of the advantages and disadvantages of a particular treatment. HPs must therefore be cautious when utilising peer support or patients in education programmes for other patients.

This data described how those who chose not to be involved in shared-care resented the time that was taken to train those who did want to self-care. As such the influence of peers within the dialysis unit environment may negatively as well as positively influence shared-care uptake. Additionally if an individual's choice to be (or not be) involved in their dialysis treatment is seen to adversely affect the care others receive (as was suggested in quote above) this may cause a divide and foster resentment between the patients in the unit.

In accordance with this study, previous studies have also highlighted the importance of the relationships dialysis patients develop with each other[110, 232], however these studies have not explored these relationships in such depth. Participants valued the companionship, support and information they gained from friendships with each other, however these friendships were subject to loss. Confronting the death or illness of others could lead to distress, fear and uncertainty; consequently some patients chose to protect themselves by keeping an emotional distance. It is important that HPs are aware of the significance these relationships may have to some patients. As such, news of a patient's death or illness should be dealt with sensitively and with consideration that some patients may wish to know more than others. Staff should also be alert to the questions that patients may have about their own health following such incidents and that some may find it helpful to discuss these concerns.

Relationships between patients are also seen in this data to have influence over modality decisions. While HPs may be able to utilise patient peers to support the uptake of self-care it is also important to recognise that peers can have a negative influence. Ensuring that those learning self-care activities do not feel they are adversely affecting the care of others is likely to be as valuable in promoting self-care uptake as peer support. Acknowledging the influence patients opinions can have on other patients also requires HPs to safeguard the provision of balanced and unbiased information to patients.

8.2.5 Power and social interaction on the dialysis unit

The social interaction with staff and patients within the unit was of such value to some patients that they suggested isolating patients from other patients or staff on the unit could be used by staff to discipline misbehaviour.

> *P21: I'm probably a bit of a nightmare for 'em. I'm also quite a lot younger than most of the people on my ward and, so they stick me in the corner out of the way (laughter) where I can't annoy anybody really. Cos*

> *we tried to get a petition up on the ward just to change things, and the nurses just didn't see the funny side of it all really.*

> *P3: I don't even like being in little rooms at the end.*
>
> *P2: No, I don't.*
>
> *P3: I mean I was put in there one night...*
>
> *C1: Put on the naughty step.*
>
> *P3: Yeah.*

These examples not only confirm the significance of social interaction for some participants but also highlight that participants considered that staff had the power to punish them. The concept of being subject to discipline by staff also supports the perception that it was important to ensure that staff like you as their opinions could influence the care you received and where you received it.

Staff holding power in their relationships with patients was also described through discussions of how the staff managed the patients in the renal unit. Although the participants often referred to staff as family or friends they suggested a need for staff to be able to exercise authority over patients. Participants felt it was important that individuals could not demand a particular member of staff to put them on dialysis, or that they sit next to a particular person. It was essential that everyone in the unit was treated equally and this was seen as the responsibility of staff to enforce.

> *P8: ...oh, yes, there has to be interaction between staff and patients, but at the end of the day the staff are the boss, it isn't the tail wagging the dog here, right, you've got to say, right, sorry Fred, but you're there today...*

Staff were therefore seen to hold power over patients and the participants appeared to see this imbalance of power as necessary for ensuring equality of care for all. This can be related to Foucault's theories of power and knowledge and how they are used within the discourse of institutions for social discipline and conformity[236].

Foucault considered power to be a positive force that is held by all individuals and actioned through relationships and the discourses of institutions[236]. In the dialysis unit staff appear to utilise a discourse of control in their relationships with patients to organise and discipline patients. The patients then accept this discipline and self-regulate[236], hence accepting the control of the staff as necessary for the successful functioning of the renal unit.

It has been argued that HPs require power to be able to act in their patients' best interests[237]. The literature has also highlighted how a conflict can arise when HPs are tasked with using their power to advocate for the individual, but in parallel, are also required to ensure the best outcomes for the community as a whole[237, 238]. This conflict is seen by some to potentially weaken relationships between individual patients and their HP[238]. In this study however, patients appear to suggest that they value the social authority of the nursing staff on the unit and expect them to utilise this authority to ensure equality of care for all. However participants were also worried that staff would use their authority on the unit to discipline them through enforcing social isolation. This data does only provide one side of the story; it may be that staff are not using social isolation for discipline or that they feel they need social authority on the dialysis unit to respond to misuses of power by patients. There is increasing recognition of the role of patients in the development of their relationships with staff and that patients use these relationships to build power[239]. While this increased power may result in better care experiences, it can also be misused. Consequently staff keeping some authority on the unit may be necessary for the well being of staff as well as ensuring equality of care for all. Nevertheless it may be useful for HPs to reflect on how their use of social authority may be interpreted by patients.

8.3 Social viability and self-care levels

There is a clear distinction between the social worlds' of home dialysis and in-centre patients. Patient 27 felt that home dialysis had brought him closer to his family, while several in-centre patients felt that dialysis took time away from family life. Most of the home dialysis participants in our study required input from family members to some extent. While home dialysis therefore permitted time to spend with family rather than on a dialysis unit, participants then had to evaluate the burden they were placing on family members for their care. None of the home dialysis patients who attended the focus groups brought a family member with them, however P20 who was currently dialysing in-centre wanted to return to having dialysis at home. We were therefore able to ask his wife (Carer 2) how she felt about him dialysing at home.

> *C2: I want him back to have it at home, yeah, because I know how happy he was about it, don't we? It's all he goes on about.*

While we have to consider that her answer may have been affected by P20's presence she suggests that she was willing to accept any negatives of having dialysis in exchange for the emotional benefits home dialysis provided for her husband. A thematic synthesis of the views of both patients and carers of those on home haemodialysis found that carers did express both a burden of responsibility and emotional stress, however there was less discussion of physical burdens[199]. This emphasis on the emotional rather than physical burdens was also a finding of this study.

As well as needing to accept a level of dependence on family members, in common with many in-centre patients, those dialysing at home also reported changes to their roles and responsibilities within the family. Many had given up work, retired or changed to part-time work as a result of their dialysis dependence. Home dialysis therefore did not always provide a way of continuing with previous roles and responsibilities.

While home patients valued the home dialysis team, they did not discuss forming strong bonds with them or reciprocal relationships. Patient 10, who was learning to self-care with her husband did feel she was developing an important relationship with the home dialysis nurse who was teaching her, however patients who had dialysed at home for longer felt that relationships with particular nursing staff became less important.

> *P14: Once you guys get independent then would you want [home dialysis nurse] all the time or would you want somebody else following, you know, taking over? Cos it sounds to me like [home dialysis nurse] is very important to begin with and then when you're established and know what you're doing she seems more required there than somebody looking after you guys; so could it be somebody different?*

> *P10: It could be for me, yeah. I mean I...*
>
> *P11: Yeah.*
>
> *P12: I wouldn't mind.*

Home dialysis patients felt that being able to trust the person who was teaching you was important but they did not discuss needing empathy or understanding from nursing staff. While the focus of discussions for in-centre patients was the nursing staff, home patients discussed their relationships with consultants more frequently; they described developed trusting and personal relationships with individual doctors and valued continuity in these relationships.

> *P25: I ask to see a certain doctor every time I go so there is that continuity of care*

Some participants considered the perceived isolation involved in dialysing at home, or in a self-care unit as a barrier to adopting self-care. Patient 14 had chosen to self-care within a staffed unit rather than a self-care unit because of his concerns regarding social isolation.

> *P14: Yeah the self-care one. We've got one guy in there at the moment and he don't want to be there, he wants to be in with the rest of us; cos I go there for the social side as well, you shout, you get to know people, you have a conversation…*

Patient 20 who self-cared in a staffed unit (but wanted to return to home dialysis) felt he also had less interaction with staff as a result of providing his own care, however he didn't feel this was a drawback.

> *P20: So nobody comes to see me, that's it, so there's nobody there to fill me book out, I just do everything me self.*
>
> *C2: The only person you see is your cuppa tea lady innit?*
>
> *P20: Yeah… Well no, I'm quite happy the way it is though.*

It is important for HPs to recognise that patients who self-care in staffed or non-staffed units may experience a degree of social isolation, however it must also be recognised that while some may see this as a barrier to the up-take of self-care others may view this as an advantage.

In contrast to many in-centre patients, home patients did not discuss developing friendships with other patients or utilising them as a source of support, however they did value the advice of other dialysis patients and accessed this advice through the internet. Whether in-centre patients looked for support from other patients more than home patients did, or whether friendships that developed were a consequence of the time spent together is not clear. Several home patients did say they were not interested in developing relationships with other patients. Consequently for those who utilise self-care units or dialyse at home, social contact and support from the unit may not be as important.

There appeared to be differences between the social worlds of home and in-centre patients. The value of the dialysis unit as a source of social support appears to influence the choices patients make with regards to care. While home patients do not seem to develop strong relationships with nursing staff they value personal relationships with doctors. All groups reported the effects of dialysis on their families. These discussions were more prominent among home patients who had to negotiate the changes to family life and relationships necessitated by having dialysis in the home. While in-centre haemodialysis could also impact family life, negotiating relationships with staff and other patients in the dialysis unit dominated their discussions and appeared to become an important part of their social worlds.

8.4 Conclusion

This analysis suggested that dialysis dependence required a reassessment of participants' social worlds. For some their family roles and responsibilities changed and they needed to assess the impact of their dialysis dependence on family life.   As their needs and abilities changed, how dialysis dependence was viewed and understood within their social world became important. In addition to examining the effects of dialysis dependence on their existing social world they simultaneously had to negotiate the new social world of the dialysis unit.   They formed relationships with other patients and staff and developed an understanding of both the advantages and disadvantages of these relationships. How dialysis care is provided and interactions with staff can be seen to influence how this social world is experienced. For in-centre patients the time patients spend on the unit, and the value placed on their unit based relationships, suggests that for many patients the dialysis unit plays an important role in maintaining their social viability. However these relationships are complex with poorly defined boundaries and inherent tensions that need to be understood and managed by both patients and HPs. The data also demonstrates diversity regarding how these relationships are experienced and considered by patients. Factors such as existing social networks, length of time on dialysis, age and attitudes to self-care may all affect an individual’s approach to their social viability and it is important that this diversity is recognised by HPs.

Chapter 9 Integrating Dialysis Into Life

9.1 Introduction

In chapters 7 and 8 I explored the challenges that patients face in coming to terms with their dialysis dependence, both personally and socially. This chapter explores the more physical challenges presented by dialysis dependence. Being dialysis dependent requires a considerable time commitment. The 'value' of time, and the factors that contribute to time being relinquished for treatment are explored in the first sub-theme. The second sub-theme discusses the practical and emotional adaptions that people made to integrate dialysis into their daily life. For many participants living with renal failure also resulted in symptoms and a heightened level of uncertainty. How these symptoms and heightened uncertainty influenced their lives and how dialysis care was seen to affect these two aspects of living with their renal failure are described in sub-themes 3 and 4. There were differences in these themes according to the level of participants' involvement in their care and this is discussed at the end of the chapter.

9.2 Sub-themes

9.2.1 Time taken for treatment

As dialysis is a very time consuming treatment, many participants considered the time taken for treatment as one of the most important features of their care.

> *Q1: ...how important is the time element?*
>
> *P13: It's top of the list ...cos I mean while I'm here I'm not with my wife and daughter; so obviously I'd always choose to be with them first but I have to come here. So it's, at the very least try and be here for as little as possible...*

Participants were keen to explain that the time taken for treatment was not just that spent on the dialysis machine but also included time spent waiting for transport, travelling to the unit and waiting to start treatment. Each of these aspects are therefore discussed in more detail below.

9.2.1.1 Time taken for dialysis

The time taken for treatment was an important consideration for participants when choosing between dialysis modalities or thinking about self-care options. P20 described how he felt that peritoneal dialysis would take up more of his time than doing haemodialysis.

> *P20: Because when I went through it all, everyone was pushing [peritoneal dialysis]; it's a lot cheaper, it's a lot easier for training up, any idiot can do it, but it takes over your life. Then it was… three times a day seven days a week, whereas haemo was once a day three days a week; so I took that option, that was the only reason why.*

It was important to participants that the time spent having dialysis was not lengthened more than was necessary. For some participants this could become a source of conflict with staff. Patients are sometimes advised to increase their treatment time to ensure dialysis is clearing toxins effectively or when patients are having problems with fluid accumulation. Such advice from staff was often resented or treated with suspicion. P19 explained that he did not believe staff were advising increased treatment times for clinical reasons; he thought it was to reduce the workload of the nurses.

> *P19: The next issue is the time on dialysis, there's a big push; and again it's down to, they won't admit it, but it's again down to increasing patients' times on dialysis. The longer the patient can spend on dialysis, it helps shift patterns… and it improves the workload of the nurses because they don't have to get as many patients on in a short time space. So it was interesting; I've been up to Scotland in the last month and when I went to dialyse there, ….she said "Oh how many hours are you doing?" I said "Well three and half." "Ooh, three and a half" she says, "that's not very long." I said "Well how long are you doing?" "Well it's a minimum of five hours."*
>
> *P16: Well it's a bit trade-off really between sitting by the machine and having a life.*
>
> *P19: Yeah, exactly.*
>
> *P16: You know, I'd rather a life.*
>
> *P19: I just said to them there's no way I'd do that.*

9.2.1.2 Getting on and off dialysis

Waiting to be put on dialysis was frustrating for patients as it added to the time taken for their treatment and was consequently a further source of tension with staff.

> *P2: I just get a bit cheesed off, … waiting to get on, but I understand that that's because there's a nurses' shortage…*

As well as causing frustration for patients, P1 felt that having patients waiting to get on dialysis was also a source of stress for the staff.

> *P1: I mean we have times where we more or less go straight in, the machine's ready; the nurses are not stressed because they've…every time they come out they're looking at all these faces thinking how long, how long, how long, which puts them under more pressure if you ask them about it.*

The participants felt that not having enough staff on the unit was the main cause of having to wait to get on dialysis. As this was perceived to be largely avoidable it was particularly resented. Some participants reported reducing their treatment time if they had to wait too long, a strategy that may result in inadequate treatment as well as increase tensions with staff.

> *P2: ... if you are waiting extremely late, we're talking two and a half/three, I might say to the nurse, look, I'm sorry but I'm gonna say to you now that I'm not prepared to do a full treatment cos I've already been sat out there for two and a half hours, I don't wanna have my full treatment; and they can't force yer to have the full treatment, they can say well, you know, that's not the best idea...*

As well as staff shortages some participants blamed other patients (who did not arrive on time for their dialysis) for contributing to the time they spent waiting for treatment. They also highlighted organisational and practical factors that contributed to the time spent waiting; these included slots not being staggered, not having enough beds or chairs, and having to wait in a waiting room rather than come into the unit and get things set up themselves. Some participants felt that being able to set up their bed or chair as they wished and make their own refreshments before they started would increase the time available for the nursing staff to put people on dialysis (and hence reduce waiting times).

> *P15: Now one of the rules they invented for the efficiency was you could only go in when the total bay was ready for you. Now many of us did our table anyway, many of us went and brought our own juices anyway, that saved the girls' time; but no, that's all gone, you have to sit outside and wait.*

Participants who chose to do a small amount of self-care often suggested this speeded up the process of getting on dialysis as they collected and set-up the equipment ready for the nursing staff. Speeding up the process of getting on dialysis was also given as one of the main motivations for choosing to be involved in shared care.

> *P19: …I try to do as much as I can and I think the reason being is to assist the nurses because we're short staffed, you know, I want to get onto that machine as quickly as possible, if I can help I will help.*

Participants who did more of their care in the unit (5-12 tasks) thought that by doing so they were releasing nursing time and consequently decreasing the time others had to wait. However some felt being able to put themselves on dialysis simply reduced the frustration of having to wait for nursing staff to do it.

> *P13: …that's one of the reasons why I wanted to get into shared care is because there can be four or five spaces available but whoever's next is waiting forever for the next available nurse that can needle, whereas if I'm next I don't have to wait for that nurse, I can just go straight in, get me needles in, get the machine done, sorted, I don't have to wait for any nurse at all.*

As described in chapter 8 those who were learning to self-care could be blamed for causing delays by those who did not self-care, and those who self-cared sometimes blamed those who didn't for using nursing time for things they could do for themselves. As minimising the time spent on dialysis was so important to many participants, some of those who were not involved in their care saw the extra time that would be needed to learn self-care skills as a significant barrier to up-take.

Despite not having to wait for staff to assist, those who dialysed at home or in unstaffed units felt that the process of dialysis could actually take them longer because they had to do everything, including clean up after dialysis. This was seen as an important disadvantage of self-care units and had resulted in P13 moving back to a staffed unit.

> *P13: I tried the self-care unit for only two weeks and; I do pretty much everything I can here, I needle, line the machine and finish up and everything, but then going to [self-care unit] it does take a hell of a lot longer, doing all those extra little bits it all adds up to a lot more time, and time's important to me. That's why I stopped going to [self-care unit].*

Some home patients also felt that the process took longer. However overall they thought they saved time by not having to travel to the unit, or wait to get on the machine when they got there.

> *P25: And there is always the thing about the unit, I mean I know it's the flexibility at home, but, you know, if there's a problem with the machine or they've had a bad experience with a patient and then you might have sat in the waiting room for half an hour...*
>
> *P28: Correct.*
>
> *P25: ...three-quarters of an hour before your time, so then, you know, you're there for about four or five hours when you should only be there for three and a half/four, do you know what I mean?*

When relying on others for transport and treatment, the overall time taken could be very unpredictable. Therefore, while it may take longer to self-care the time taken was predictable and this may have been a further advantage of self-care for some.

9.2.1.3 Travelling for dialysis

For some travelling to dialysis added significantly to the time taken for treatment. P3 had chosen to move house to be closer to the dialysis unit for this reason.

> *P3: ...So with dialysis in view we found a nice flat across the road...where I can walk here in …four minutes …it's just a little walk I go for, you know, three times a week.*

Some participants reported that they had been advised by staff that, for clinical reasons, they should increase the frequency of their dialysis, however they had declined because of the time it took to travel to the dialysis unit.

> *P5: Like doing it every day, that has been suggested but I mean I travel an hour each way…and that's in a car, not in the ambulance, [the ambulance] takes two hours you know.*

Despite concerns regarding journey times participants felt some degree of travelling was required to ensure expert staff were treating them.

> *P19: there's mentions of disbanding these satellite units and starting to dialyse in your local health sorta centre, so where you go for your GP surgery they're talking about having your machines there...how the hell's that gonna work; …do the NHS realise what a renal patient requires? I think they've just got it in their head that oh we'll put a few machines in there, we'll get all the patients to be able to go in there, hook themselves up and job sorted. So, and again it's this thing of do they really know how to put the needles in? You know, if you put a satellite into little centres like that you're not gonna get trained staff in there and that's what, you know, I don't really understand…*

9.2.1.4 Hospital Transport

Many participants relied on hospital transport to get to the dialysis unit. The two centres in the study (York and Sheffield) appeared to differ in the way this was delivered, with the majority of patients at one centre having their transport delivered by individual taxis whereas, at the other patients mainly relied on ambulances travelling with other (non-renal) patients. For those who relied on ambulances, transport was often a considerable source of frustration and a focus for discussions in the focus groups. Taxis were seen as better than ambulances (participants from the first unit said the transport had recently changed to a system of taxis and it was now, "much better"), but not as good as your own transport as you still had to rely on someone else. As discussed in chapter 7 this reliance on others for transport could notably affect their sense of control.

> *P20: Now I don't expect a car on me own…but to come down the motorway past here, go to [a different city], drop this patient off then come back here, well hang on a minute, what the hell am I going to [other city] for? So now I won't do it, I'd rather persevere and drive meself 'cos that way I decide what time I leave, what time I get home and if I'm having a rough; well I've done it once or twice, if I'm having a rough day I'll call in on the motorway and have a cup of tea or summat and; so yeah, I decide what I do. So the transport thing is my way of getting a bit of control back…*

Delays in getting to dialysis and getting home could considerably add to the time taken away from normal life. Transport delays also affected patients who did not rely on transport (if the person dialysing before them had arrived late they would have to wait for them to finish before they could get on a machine). Life was seen as difficult to organise around transport as they were never sure when they would be picked up or taken home.

> *P7….I actually came out of the taxi service, I had a taxi and I couldn't stand it, I'd be sitting from half past five, I was supposed to be on at six and they might come at half past six, … and I just thought this is my life, this is my life, I could be doing something. But, you know, I'm looking out the window cos I don't want to keep them waiting, so in the end I actually drive myself.*

Several patients suggested they could organise their own transport if they were financially supported to do so. They felt this would have cost savings for the NHS as well reducing travel times for them.

> *P6: This is one big thing; I personally feel that if they allowed whoever drives, such as me, an allowance instead of using the ambulance service, to me I'm sure it'll be a lot cheaper giving somebody just 30 pence or so in a mile, or whatever it is, I don't know what average mile allowance is nowadays, but to me I would think that it would be a lot easier for us to,*

> *for our husbands to drive us both there and back, with a bit of an allowance for petrol.*
>
> *P5: If, we've said if they pay for one journey…*
>
> *P6: One way.*
>
> *P5: …one way, just one journey, one way he would come up and down and up and down.*

Some participants also felt that the dialysis unit should be responsible for organising transport and were frustrated that they were unable to directly communicate with those who did (only the staff at the dialysis unit were permitted to contact the ambulance control centre). Transport issues were a significant part of the dialysis experience for many patients who felt waiting for transport could worsen mental and physical symptoms. Several participants also felt that the ambulance staff could be rude and unhelpful and contrasted their experiences of the transport staff with the staff on the renal unit.

> *P10: ...it's like you go in that ward and you enter one world and it's a fantastic world and then you come out and you're treated like dirt...*
>
> *P12: And reality hits.*

Transport was consequently seen to have a considerable affect on the overall experience of dialysis care.

9.2.1.5 Access to health professionals on dialysis

As a significant amount of time was spent on the dialysis unit having treatment, participants wanted to be able to see nurse specialists, doctors and other members of the MDT on dialysis rather than having to attend the hospital for additional appointments.

> *P14: [Consultants] come out to [satellite unit] they always come out on a Tuesday and a Thursday; well it's all right if you dialyse Tuesday, Thursday, Saturday, but if you dialyse Monday, Wednesday, Friday, it's an extra day there…*

Those who dialysed in the evening felt this was a particular problem as they attended the dialysis unit outside normal working hours. Consequently they would have to come in separately during the day to see anyone other than the dialysis nurses, requiring more time spent at the hospital.

In conclusion, the time that had to be relinquished for treatment was for many the most important feature of dialysis dependence. While HPs may only consider time as an important element in defining adequate treatment, participants viewed the time taken more holistically; from waiting for transport to the dialysis unit until they got home again.

Previous studies have also highlighted the time required for dialysis as one of the main concerns of dialysis patients due to the considerable impact it has on their lifestyles[36, 111, 118]. Some participants in this study resented the time they had to give up as is it made maintaining employment or socialising challenging, however many discussions focused purely on the loss of freedom experienced through having to relinquish time for treatment. A study comparing patients' activities and emotions on dialysis and non-dialysis days found that despite spending significantly longer in an undesirable emotional state on dialysis days, there was no difference in patients' activities[34]. They concluded that the difference in well-being seemed to be due to a sense of liberation from dialysis on non-dialysis days, rather than the utilisation of time. This suggests that patients for whom the loss of time does not have significant social impacts may still find the loss of time challenging as it affects their sense of freedom.

While some studies have shown that increasing the duration of dialysis may improve the quality of treatment and thus clinical outcomes[240, 241], some of the participants in this study did not appear to be aware of this and had formed their own theories as to why HPs were trying to increase their treatment time. A study investigating haemodialysis patients' beliefs about treatment found that patients often lacked an understanding of the need for suggested treatments and had consequently attributed this need to diverse factors such as bad luck, mismanagement by doctors, stress or that it was something they deserved because of past actions[202]. This suggests the importance of HPs exploring patients' beliefs about the need for treatment and ensuring that their reasoning is clearly explained. In such discussions it is also likely to be helpful for each party to explain how they are evaluating the success of treatment as patient's priorities (e.g. minimising the time spent away from home) may be very different from the HP's.

A previous study, which utilised the time trade off technique, did find that 80% of patients would accept 1 hour of extra dialysis for a 20% increase in survival[18]. This suggests that some patients would be prepared to increase the duration of their treatment for improvements in clinical outcomes. However, predicting individual clinical benefit is challenging and each patient must weigh this against their personal priorities. While an increase in 1 hour of treatment to HPs may be an increase from 3 to 4 hours of dialysis, to the patient this may mean an increase from 6 to 7 hours out of their day.

Previous studies of patients' experiences of dialysis have not highlighted the time spent waiting to get on to treatment. Whether this represents differences in care provision or reporting is not clear, however the participants in this study did experience different waiting times at different units. They had varying suggestions as to how this could be improved, but many were related to doing more for themselves rather than relying on the nursing staff. These did not necessarily involve the dialysis itself but included making their own refreshments, setting up their bed space, getting the required equipment and taking their own observations (blood pressure, pulse and weight). While the final two of these suggestions are included in shared-care, the other suggestions are not. Consequently patients may suggest aspects of the wider dialysis experience that they would be willing to do and which may not have not been considered by staff. Perhaps because of the context of the NHS, participants were keen to ensure that nursing time was used effectively and accepted that nursing staff numbers were limited. However they strongly felt that units should ensure there were adequate numbers of nursing staff to allow them to get on and off dialysis promptly. Additionally participants in this study demonstrated links between the time taken for treatment and their sense of control; the ability to live their lives outside dialysis; the amount of treatment they were willing to have; and the uptake of self-care. Consequently ensuring adequate staff numbers affects many other areas of care that are important to patients.

It has previously been recognised that transport to and from dialysis in the UK does not always meet the expectations of dialysis patients or staff[188]. In 2012, the NHS surveyed patients about their experiences of transport to and from dialysis and highlighted many of the issues that were discussed in this study, including delays, journeys with multiple drop offs, and the desire some patients have to be financially assisted to organise their own transport[188]. Issues with transport have consequently received recognition as having important impacts on the practicality of patients' lives, however participants in this study also expressed how transport could affect their sense of control and independence. Participants suggested they would gain more control from being able to communicate with those providing transport directly or being supported to provide their own transport. Ways of improving patients control over their transport should therefore be prioritised alongside strategies to improve control over dialysis (such as shared-care).

In-centre participants spent significant amounts of time on the dialysis unit or travelling to it. Participants highlighted many aspects of care that contributed to lengthening the time away from their normal lives. It is important for HPs to understand how dialysis is experienced from the patient's perspective and ensure that communication allows a mutual understanding of each other's beliefs and priorities for care.

9.2.2 Adapting to life on dialysis

As dialysis had such significant demands on their time, the participants described how their lives had to be adapted around treatment. This included physical as well as psychological adaptions and affected many aspects of the participants' lives. Many aspects of care were seen to affect how patients managed this process of adaption and these are described in turn below.

9.2.2.1 When dialysis happened

Being able to choose when they dialysed was very important to some patients who had strong, but differing views, on their preferred time slot. Participants felt that being able to dialyse at their preferred time helped them to adapt their lives around dialysis.

> *P19: …for me it is trying to fit it in with work commitments; so it's basically initially starting off; I had a morning slot which wasn't conducive to work and I was only part time but then when I…informed them that I wanted to go back to full time work, they managed to move my shift pattern to the evenings. It's not ideal but it's sort of the best thing that the unit could have done; so it enables me to fulfil full time work. But*

> *there again there's having the flexibility cos when I'm off on holidays I like to try and get the dialysis over and done with rather than hanging around waiting for it, so they've been really good in basically me giving them my holiday dates and then them saying, right, we can fit you in on an early slot; or if they can't they'll sometimes ring you up saying, oh we weren't able to organise it but we've now got a slot, do you want to come in? And it's sort of, you know, it's on that kinda relationship I have with them where they know they can give me a phone call and ask me whether I would like to go in early or not, so. That's the one thing that I do like about it, yeah.*

Other participants suggested dialysis units could do more to let them know when they could come in earlier or later (if things were running behind). While in-centre patients had fixed time slots for their treatment they wanted a degree of flexibility from the unit so they could attend important events. Some participants felt their unit did provide some flexibility, however several reported frustration at having to provide large notice periods.

> *P23….I wanted to go to the funeral but they couldn't change my dialysis and it clashed with the funeral, so that were a bit sad; I, I would have liked to have gone and paid…*
>
> *C3: They couldn't?*
>
> *P23: No, cos it was quite late notice, you know, at our place I think you have to put about a month's notice in to, or they'll ask somebody if they'll swap with yer.*

They appreciated staff who assisted with requests to change slots. As facilitating these requests was seen as goodwill, rather than standard care, this may further contribute to the need to maintain good relations with the nursing staff (see chapter 8). This flexibility allowed dialysis to happen around other priorities in their lives, however some participants reported that from time to time other things in life had to take priority over dialysis. On these occasions they wanted staff to respect their decisions regarding whether they could attend for dialysis, or needed to reduce their treatment time.

> *P14: I don't want to be there all day, I have a life away from that, that's not my be all and end all, I go there because I have to; you make the best of it but I want to be off. If I only want do three hours I'll do three hours and I'll go, and they get used to me doing that. If I don't want to turn up for one I won't turn up for one because that's it, you know, I have other things to do.*

The flexibility of choosing when to dialyse (and when not to) was viewed as one of the main benefits of home dialysis by both in-centre and home patients. Patient 20 had previously dialysed at home and because of a recent illness was now dialysing in-centre. He explained how having the flexibility to choose when he was going to dialyse helped him to live his life as he wished.

> *P20: Well once I got into the training programme and I started doing stuff meself, then it started dawning; hang on a minute, I can do this any day, any time I want, and I liked the idea of this, and the more I'd got doing for meself the more I realised I've got a life again. Cos at the minute I ain't got a life, three days a week I'm here; I leave at quarter past eleven don't I? I get home at seven o'clock at night; so three days a week my day's had it, where at home… I dialyse Monday, Wednesday, Friday, I dialyse every other day and sometimes I get two days off, …it don't matter when I do it. So I dialyse Monday, have Tuesday off, dialyse Wednesday; if summat comes up on Wednesday well no this week I'm going to have Wednesday as me two day, I'll have Wednesday off, I'll dialyse Thursday. I can't do that here I've got to come Wednesday, I've got to come Friday. In the early days I started doing a bit of work as well and I'd dialyse when I got home afterwards, or if summat was gonna go up, I'd dialyse, get up early morning, I had a life back.*

This flexibility was linked to control by several home patients; they felt in control of their dialysis rather than dialysis controlling their lives.

> *P25: The thing I prefer about home haemo to hospital haemo is that I have control over it rather than it having control over me. So I can choose to do the home dialysis whenever I feel and it fits around me.*

In-centre patients often cited the flexibility of home dialysis as its main advantage. They also agreed that a lack of flexibility was the main disadvantage of self-care units. They felt self-care units would only be advantageous if each patient had their own machine so they could dialyse at their convenience.

> *P8: I think from my point, if you're working like I am, to go in at four o'clock in a morning or go in at eight o'clock at night or at lunchtime or whatever, somewhere different and do it, yeah, I could see the benefits of that.*
>
> *P5: Providing no-one else is on that machine when you want to go…if there's only two machines and there's three of you, that do the self-care you've still got to come to an arrangement between…the three selves as to who's going to use it at which times; so it isn't as convenient as it's made out.*
>
> *P8: No, it's not a drop-in centre.*
>
> *P5: No, no, it's not as convenient as it, as they go, oh well it's so convenient, you know, it's…*
>
> *P8: Let's face it...*
>
> *P7: Well I don't think it is at all…*
>
> *P8: …everybody's going to want the same hours.*
>
> *P5: Exactly.*

Having some control over when dialysis happened was important to all the participants and could have a considerable impact on their lives, such as the ability to work. Flexibility appeared to be closely related to the degree of control participants felt they had over their lives. Home patients felt choosing when to dialyse provided them with control, whereas in-centre patients struggled with living life around dialysis and many felt dialysis had control. Most participants had found ways to adapt to the time burden of dialysis, however they felt the time slot they had could affect how successful this adaption was and sought some flexibility from the dialysis unit. A previous study of self-caring patients who were offered a choice of dialysis time slots found 50% either changed their times, or opted for variable time slots, suggesting that many patients would choose a more flexible or different schedule if it were available[242]. Flexibility was important to all participants, and viewed as the main advantage of home dialysis. The suggestion that this flexibility must be available for the success of self-care units clearly has relevance for the uptake of self-care and service development.

9.2.2.2 Altering expectations

Participants described many ways in which they made practical adaptions to accommodate dialysis; however some participants felt it was also important to adapt their expectations. Their previous activities and plans for the future had to be reconsidered.

> *P8: …you can't expect to do the things that you used to do when you're on dialysis and that's the main thing. You know, I was talking to [another patient] out there and he said "Things that used to take me a day to do work-wise now take me the thick end of three or four days" because you can only do so much. So, you know, if you were a young mum for example or somebody like that coming in for dialysis you need help at home, you ain't going to go home do the washing, the ironing, the cleaning, it isn't going to happen. So, you know, you've got to take it outside the dialysis sphere, if you like, it isn't just what happens in hospital, it's what happens outside…*
>
> *P6: It's the whole.*

Participants felt they had to change their previous expectations to what they could realistically achieve; this affected their roles, responsibilities and lives outside the dialysis unit. Some of their plans for the future, such as travelling in retirement, had to be re-evaluated. Participants felt that other aspects of life on dialysis, such as the extreme fatigue experienced many participants, were unexpected. As a result they felt that the possibility of having to alter their expectations could be better addressed in pre-dialysis education to allow time to prepare both mentally and physically for the adaptations they would need to make. HPs were therefore seen to play a role in creating expectations for life on dialysis as well as supporting patients to manage them.

9.2.2.3 Desire to be normal

Many participants expressed a strong desire to maintain as normal a life as possible. P4 felt he was able to have a normal life. However most participants thought achieving a sense of normality was difficult.

> *P19: The one thing that I try to do, and it's becoming more and more difficult, and that is to lead a normal life on dialysis, and I'm finding as we go along it's getting harder and harder.*

For some patients it was important to live life to the full by planning activities for non-dialysis days, for others it was simply important that they were free from being on dialysis. Being able to maintain employment, hobbies and interests was seen as important to maintaining a normal life.

> *P8: I, think it's important that, that you do adjust your lifestyle and you have other interests because it's very easy to go within your shell and that's it, and you've got to say, right, OK, I can't do this anymore...*
>
> *P7: What can I do?*
>
> *P8: What can I do, what's gonna get me out the house? And I mean I used to play a lot of football and I've found that difficult now because I haven't got the energy to run around a field for an hour, but now I do walking football, I'm doing that tonight; and there's always something that you can do. I mean I still play golf but I get a buggy, I know I can't walk eighteen holes but I can get a buggy and if I'm playing with somebody I might walk a hole and I'll get in the buggy for the next two or three and I'll walk out. But you can do it, you've just got to say, right, I'm not gonna let this beat me, I'm gonna get on with my life, and it's like we said earlier on, I don't think I've now got anything wrong with me, I've just got this pain and come in hospital.*

For some participants, in addition to the financial and social benefits, maintaining employment contributed to a sense of normality.

> *P16: I think it's to every renal unit's advantage really if they can accommodate people who are working because it keeps them in*

> *employment, it keeps them paying taxes, it keeps them, you know, away from the renal situation all the time; and my experience was like that.*
>
> *P8: ...and if I gave up work all of a sudden it's an acceptance that I'm ill.*

Those who managed to maintain employment felt this was very important to them. Some participants had been able to adjust their hours around treatment or work part-time, however many participants had left their jobs when they commenced dialysis. For those of working age this was often seen as a loss; some had enjoyed their jobs or felt that employment gave them a sense of purpose, whereas for others the loss was financial.

> *P11: ...[the meeting at the Job Centre] was one of those things you know that helps you into, or is supposed to help you back into work, cos I was really depressed... she turns round and went "Oh you're unemployable". I went "Oh thanks". And I was going because I was depressed and I said "I'm, just sitting around waiting for, what, what's the point?"...*
>
> *P10: Well I was a [occupation]...and it was a fantastic job but I'll never do that again, but I've just had to accept that I won't do it again, you know, it's too much of an active job, I just haven't got the energy.*

Working alongside dialysis was seen as challenging due to both the time commitment of dialysis treatment and the exhaustion many participants experienced. Despite the increased flexibility that was experienced by home patients they also found maintaining full-time employment challenging.

> *P28: I don't think working and running dialysis should ever run side by side, really, so.*
>
> *P25: I think it's hard.*
>
> *P28: It is definitely hard, cos it's mind over matter doing it, so, because (a) you need the money to be able to live, and you need the dialysis to live as well, so, but the two don't work hand in hand.*

While many participants shared a desire for a normal life, their definitions of normal and their objectives for life outside the dialysis unit were individual. In-centre patients focussed on adapting their lives around their dialysis, perhaps due to the fixed nature of their treatment.

> *P5: I know someone that's not on dialysis goes, oh it's only three days a week, I go, it's a massive part of your life, everything has to revolve…*
>
> *P7: Revolve round it.*
>
> *P5: …they said it shouldn't but everything has to revolve round…*
>
> *P8: It does.*

In contrast when we asked the home patients what qualities they thought they shared that may have resulted in them choosing home dialysis, P25 suggested that it might have been because they did not revolve their lives around dialysis.

> *P25: A feature I think from today is that we're all quite matter of fact about our condition, we're not terribly bound-up by it all, and I think that might be a factor that means we're happy to go away and be more independent. It's not the centre of our universe, that's the impression I get from all of us.*

As discussed in chapter 8, many of the home patients were not interested in building social connections with other patients suggesting their focus was on their lives outside dialysis. Whether they had brought this attitude to dialysis, or whether they were able to adopt it because of the more flexible nature of home dialysis, was less clear.

The desire to try and maintain as normal a life as possible was a strong theme in the discussions. Having some flexibility and control over when dialysis happened was important to the majority of participants in this study and connected with attempts to live a normal life. This finding is also reflected in a study exploring the experiences of people living with chronic illness, which found living normally required the flexibility to be spontaneous. However chronic illness often led to reduced flexibility and consequently lessened the ability of people to live normal lives[204].

Maintaining a degree of normality was seen as challenging by many participants in this study but also viewed as important to ensuring a sense of purpose. A previous study of long-term dialysis survivors also acknowledged the challenges of adjusting life around dialysis and suggested it was important that elements of patients' previous lives were combined with their dialysis dependent lives for them to maintain their identities[111]. Facilitating the adaption of life around dialysis is consequently not just of practical importance but also has significance for patients' perceptions of control and sense of self.

For dialysis providers it is therefore important to consider how dialysis provision can support people to continue to participate in the activities that they value. Participants are likely to utilise a sense of how normal their lives are when evaluating their treatment. Maintaining as much of patients' pre-dialysis life as possible should therefore also be a focus for HPs and patients should be supported to maintain activities such as employment alongside dialysis or consider alternatives. Participants felt that home haemodialysis had a significant impact on their sense of normality and control over life, it is therefore important that this is communicated in pre-dialysis education and could be considered as an alternative treatment option by those who are struggling with in-centre schedules.

9.2.2.4 Holiday dialysis

Other aspects of care such as being able to go on holiday were also important to maintaining a sense of normality. Holiday dialysis was highly valued by the participants and they were keen to hear about each other's experiences.

> *P12: You'll have to write about it in [the] newsletter …it's kind of useful for the rest of us to know; yeah, we're interested in your holiday but we're more interested in what was it like in the renal units rather than the rest. The holiday's your own but the renal side affects all of us; so anyone who ever writes anything about a holiday and how they coped and what the staff were like etc. I think is of interest to all of us.*

In one focus group a member found that speaking to others about their experiences had given her the confidence to speak to staff about arranging holiday dialysis so she could visit her daughter and grandchildren.

For some participants holiday dialysis was seen as having important psychological benefits.

> *P7: I think it's quite empowering when you know, and, psychologically when you know you can go on holiday…*

Other patients however did not want to go on holiday as they felt having to dialyse meant they would be unable to enjoy their holiday.

> *P13: I've never wanted to go away, in this country or abroad, cos the last thing I want to have to do is think about dialysis when I'm anywhere…*
>
> *P14: If you go abroad you'd be amazed at how much better it is...*
>
> *P13: Yeah, but I mean I've still got to go, that's the thing, I really don't want to have to think about it...it could be amazing but I don't want to go.*

Perceptions of how easy it was to arrange holidays varied. For some the work of arranging holiday dialysis was seen as too onerous and consequently not worth the effort, while others found it an easier process. They appreciated staff that helped them arrange holiday dialysis provision however some participants found the advance planning difficult and missed the ability to be spontaneous. There was dissatisfaction with the availability of dialysis units when planning holidays, and many found it was easier to arrange dialysis abroad than in the UK and this was another source of frustration.

> *P16: I also appreciate your problem regarding holidays; it is very difficult in some cases to get a holiday, and I have been told it's easier to get dialysis abroad…*
>
> *P15: It is.*
>
> *P16: …than it is to get dialysis in, somewhere else in Britain, particularly in an NHS hospital…And even if an NHS hospital says yes they will take you, they can't guarantee the place, ring back six weeks before you're due to go, which happened to me once when I was going to Wales; so obviously I needed to get some accommodation so I booked the accommodation near to where I thought I would be dialysing …and then six weeks before I was due to go they said, sorry, we can't take you now but we've got you a place in [another hospital], but my accommodation was already booked….So you're always a victim basically of the system and how they can fit you in, but basically you're just grateful to get anywhere that's a bit of a change.*

Home patients would have liked portable machines to take on holiday as other dialysis units often had different machines; as a result they were unable to dialyse themselves when they were on holiday. The different machines on holiday units resulted in home patients having to rely on staff, however they viewed staff as technicians, whom they wanted to be able to instruct to maintain their control. Having unfamiliar staff responsible for your care was seen as barrier to holiday dialysis by both in-centre and home patients. Language barriers when abroad could also prevent them from having control of their dialysis.

> *P27: Rome was quite nerve-wracking cos I don't speak any Italian.*
>
> *P25: That's what puts me off going abroad is the language barrier.*
>
> *P27: So I would have done well to learn "I'll do my own needles, thank you very much". That would have been very useful…and just knowing the basic numbers, so I could tell them how much to take off would have been good as well.*

Holiday dialysis was valued by the majority of patients and could be seen as empowering. Nevertheless not all patients wished to go on holiday as the restrictions of dialysis attendance contradicted with the freedom they saw as essential for enjoying a holiday. As highlighted above a lack of flexibility and spontaneity has been found to be a feature of living with chronic illness[204] and in this study. Patient 12 cited the lack of spontaneity afforded by dialysis as reducing her enjoyment of holidays.

Some patients found the challenge of organising holiday dialysis or disrupting their schedule too burdensome. This may be related to the emotional struggle many people experience when adjusting to chronic illness[194]; the risk of upsetting this new found balance by going on holiday may be too difficult to contemplate for some. As the information gained from 'successful' holiday patients was valuable, a forum for sharing experiences may increase confidence in the idea of dialysing at another unit.

Discussions regarding holiday dialysis also reflected participants' priorities for care. As such in-centre patients focussed on gaining information about the staff on the holiday unit to establish confidence in them, whereas home patients were focussed on how they could maintain control over their dialysis treatment. While home patients still valued holiday dialysis, they had to weigh up the freedom of dialysing away from home against this loss of control.

9.2.2.5 How time is spent on dialysis

Just as some participants felt it was important to make the most of the days when they were not on dialysis, for several it was important to be able to utilise the time they spent on dialysis. While some participants used the time to work, or enjoy their hobbies, others focused simply on finding a way to pass the time.

> *P7: I like it cos I sort of leave my jobs, anything like that on the Wi-Fi I leave 'til I'm on dialysis and then I'm busy. But I get tired doing that, after about an hour I'm…*
>
> *P8: Yes, I do.*
>
> *P7: …I'm real tired, and then I like, thank goodness for televisions.*

Many participants found that being on dialysis made them tired. Some things, such as watching television and spending time on the internet, were seen as easier to do than others, like reading. Socialising with other patients and staff was also seen as an important way of passing the time.

> *P8: Because one of the things that hits you, you're hooked up to a machine for four hours, boredom sets in and, if you're not feeling well, it's all well and good people saying, oh bring a book, do this; you read a couple of pages and you've had enough…*
>
> *P5: Yeah, you can't read.*
>
> *P8: …you just, you can't focus on it...*
>
> *P8: …so you've got to have the banter, you've got to have the interaction with people around. And, yes, we all know that nurses are, they're very much stretched and everything else, but the time they take to interact with you as a patient is absolutely invaluable.*

One unit provided art and physiotherapy and these were valued, however not all units had access to these services and some felt this was unfair. As well as these services offering an enjoyable way to pass the time, participants liked the social interaction with those providing the service. In the unit where art was provided some complained they had never been asked if they would like to participate.

Others felt that all patients should receive access to the same services and resented the fact that they were not available to them.

> *P4:…if they can have physio here we should be able to have it over there, if they get the art here; I know that the art is funded differently, but it's just another, something to do while you're on dialysis.*

Participants appreciated staff that assisted them in being able to spend time doing what they wanted on dialysis and complained that staff sometimes didn't consider this when providing care.

> *P17:…you know, you can't do anything much with this arm [pointing to arm with fistula], then you've got the cuff on this arm [pointing to other arm] and you're trying to have a drink of tea or, you know, just read or something.*

Some patients chose to sleep on dialysis, however for patients who wanted to utilise the time it was important that the nurses kept the lights on. Their choices could therefore be seen to conflict with each other.

> *P3...and the staff nurse I think, turned the lights out...*
>
> *P1: Yeah, patients want lights out, I've heard that quite a few times.*
>
> *P3: ...so I'm reading a book, you know, I've got a computer, I've got books, I've got a paper. I mean the only way I get through four hours is by having something to do...*

Home dialysis patients talked less about what they did on dialysis. Several commented on the benefits of being able to spend time with their families. One home patient was on nocturnal dialysis and therefore could dialyse while asleep at night.

> *P11:I'm on nocturnal now, I do it overnight; far better…you just don't have to think about it during the day, come ten o'clock, well nine o'clock you start theoretically to get the machine ready, ten o'clock you're on, you sleep overnight, come off six o'clock in the morning.*

Other studies have also cited the importance some patients place on being able to use the time spent on dialysis so it was not lost[114, 118]. In this study P8 explained he worked on his laptop until he became too tired. As he used the time on dialysis to work, he felt this was a reason to choose in-centre care as he could leave the nurses to do the treatment while he focused on his work.

How patients pass the time may reflect their choice of coping strategy (see chapter 7). Those who choose avoidance coping may choose to sleep, while those adopting coping strategies that involve confronting their emotions and problems may try to use the time to achieve other goals. Whatever they chose to do it was important that staff supported them and considered this when carrying out care. However one of the challenges for staff appears to be supporting individuals chosen activities while ensuring these choices do not unfairly affect others and consideration could be given to how the organisation of the unit may better facilitate this.

The concept of equality of care for patients is seen in many themes in this data and may be of particular significance to participants in the context of the NHS as a publically funded health system. HPs should be alert to provisions of care that may seem unfair to patients and those providing services on the dialysis unit may also wish to ensure they invite everyone to participate.

9.2.2.6 Catering

Catering provision was variable between units. Participants felt that all patients should have access to good catering provision. They commented on the need for appropriate food and wanted catering to reflect what they would normally eat at home.

> *P21: Can I just mention the food situation? ...I'm in a morning... if you don't want whatever the warm option is, although it's generally cold, is they have a range of sandwiches. Now this is half past seven/eight o'clock in a morning, and they'll have like turkey, pork, or beef. And I mean I suggested, every now and again we get a little questionnaire we have to fill in, and, and I've suggested that maybe instead of wasting money on bacon and sausage and stuff like that, what people probably would prefer were toast, you know, just a slice of toast.*

Some participants felt that some of the food provided was inconsistent with their dietary restrictions, and others were frustrated that staff (appropriately in view of advised fluid restrictions) enforced reduced volumes of drinks.

In common with other aspects of care, equality of provision between units was seen as important. Participants wanted catering that reflected normal eating patterns and units might wish to consider how this could better be provided. Some participants also wanted the same control over what they consumed as they had outside the unit. While staff may accept that patients are responsible for their own decisions outside the unit, when in the dialysis unit they may not want to be seen to condone or be accountable for choices they view as inappropriate. At the same time patients may interpret staff who criticise them or do not allow them to exercise their own choice as being paternalistic or patronising. Some of the recent literature has suggested chronic illness management requires a new approach and suggests that HPs should relinquish control of the management of illness to patients and as a result accept that they cannot be responsible for patients' choices[243]. However the dialysis unit is unusual as it is a setting for the provision of chronic illness management, but by health care staff, in a health care facility. Relinquishing control may therefore be challenging for dialysis staff, especially as some patients' choices may be life threatening or incompatible with what they would consider as good care. It may be that both patients and staff would benefit from sharing their concerns with each other in attempts to facilitate a mutual understanding.

9.2.2.7 Managing dietary restrictions

Both dietary and fluid restrictions were seen as a difficult part of managing dialysis dependent life. They affected social situations and family life. P12 saw these restrictions as losses that could contribute to depression.

> *P12: Yeah, but it, we're talking with regards depression, there are things that sort of slowly hit you that you can't do that anymore or you can't eat this anymore or...*

Some participants felt that the restrictions suggested by professionals were unrealistic and prohibitive.

> *P19: The ones that really irritate me unfortunately are the dieticians …they're different ones each time and they're very judgemental, …you're not eating this, you're not eating that, you're not, and… again you're this dialysis patient who's trying to run his life as good as possible and you've got a dietician there saying to you, you can't do this, you can't do that. My fluid intake for somebody with no kidneys... have you any idea what the recommended is? Half a litre of fluid a day. And I just laughed at her; I said, "Have you tried to drink half a litre of fluid per day?"*

Others found dieticians to be positive and helpful, and felt they were more able to adapt to restrictions.

> *P17… I've always found that the dieticians who've come to see me have been quite positive, and I was joking with her the other day and saying I hadn't eaten a banana for about a year and a half, and she said "Well the thing is what you could do is …on a Wednesday or a Friday you could have a banana because it's gonna be dialysed out of you the following day." So she was trying to be positive in that way. But I know what you mean, it is difficult. I mean I've now got friends who I visit [and they] are used to the idea that if I say I'll have a small coffee…they will give me a small coffee…*

Those on home dialysis felt they did not have to restrict themselves significantly as they could dialyse more often and this was consequently seen as a further benefit of home dialysis.

> *One of the things that I really like about controlling the dialysis myself is I dialyse a lot more often than I did when I was going to a unit, so I don't worry nearly as much about my fluid restriction and my diet; and I love food. So I find I dialyse two days out of three; and that was really helpful, I hardly have to think about it. So that for me is a big benefit.*

The participants in this study held differing views of their relationships with dieticians, however in common with a previous study of patients' perspectives on dietary change[244], they did agree on a desire for individualised advice that was seen as empowering and realistic. Having access to the expert advice that dieticians can provide is therefore important to patients when attempting to adapt their dietary intake.

Adapting to dietary restrictions was seen as easier for some than others. The attitudes and assistance of staff were important factors in this process. P19 above found keeping to his fluid restriction very difficult and used the word 'judgemental' to describe the dieticians whereas P17 found the dietary restrictions more manageable and used the word 'positive' to describe dieticians. This suggests patients' perceptions of whether staff are judgemental, or informative and helpful, may affect whether they feel they are able to adapt and consequently adhere to advice. A review of 'patient-centeredness' in chronic illness concluded that there was evidence to support the concept that involving patients in their care through supporting and informing them to make their own decisions was related to improved adherence. However they did suggest this may be a result of developing treatment plans that are centred around the patient's priorities rather than adherence per se[245]. Studies have also found that patients who are seen by nursing staff as difficult are less likely to receive supportive and informative care[230]. Both patient and staff perceptions are likely to affect the nature of their relationships, and in-turn how these relationships are viewed are likely to affect whether patients feel able to achieve goals such as dietary modification. HPs should therefore aim to support and inform patients and work with them to develop patient centred treatment plans. They should also consider how the labelling of patients as 'difficult' or 'non-adherent' may negatively affect the care they receive while paradoxically these patients may actually be in need of greater support[246].

In conclusion, adapting to life on dialysis required work and involved many aspects of life. In his study of chronic illness Bury observed that the meaning of illness lies in its consequences for the individual and the disruption it causes to everyday life [141]. The degree of disability caused by an illness is not just related to its symptoms but is also consequent on an individual's social circumstances[247]. Consequently, the degree of adaption participants were involved in related not just to their renal failure (and any other medical problems) but also their roles, responsibilities, social and economic resources. The process of adaption is therefore unique to each patient. However this data does provide an understanding of the way in which dialysis affects life and the challenges this presents.

Bury differentiates coping (a cognitive process) from strategy (the actions people take to manage chronic illness)[148]. While much of this sub-theme constituted discussions regarding ‘strategy’, in many of the discussions participants’ strategies, or attempts to find strategies, can be linked to descriptions of cognitive coping. These links between strategy and coping may be particularly helpful in gaining an understanding of the approaches that patients choose to utilise in response to their dialysis dependence.

Many of the discussions contributing to the concept of adaption surrounded the way in which care was provided. For patients, it is often the treatment itself (dialysis), rather than the disease that made them dialysis dependent, that is seen as their disability. Consequently their dialysis care, and the staff that provide it, may be seen as the disability as well as the response to it; their perceptions of disability and the way care is provided are inextricably linked. This may pose a particular challenge to staff who wish to support patients in the face of their disability but may also be viewed by them as agents of the disability. This concept may also relate to finding that home patients appeared to find it easier to adapt to dialysis dependence; their focus was on managing *their* illness and *their* treatment (with were interlinked) rather than on an external provision of care.

9.2.3 Managing symptoms

Managing symptoms was another important part of managing life on dialysis. The participants mentioned a range of symptoms. The most frequently discussed were low mood, pain from needling, and feeling exhausted.

The treatments and interventions offered by staff were not always viewed as successful and discussions often focussed around finding ways of living with these symptoms rather than seeking a cure for them.

> *P27: But it seems to me dialysis, it just throws up things, they usually last for three to six months and then they go. So I had the problem with, you know, itchy legs and after about six months it just stopped; and I've had problems with low blood pressure, that lasted for about six months, I couldn't stand up half the time, and then that stopped, and then I had*

> *high blood pressure, same; and, you know, they give you medicines for these things and none of 'em work, you just have to wait for your body to get used to it. This is my experience anyway; you just have to wait for them to go away and eventually they seem to. I've not had anything actually that hasn't just ultimately gone away.*

9.2.3.1 Low mood

Participants often related ‘feeling down’ or low in mood to the losses encountered when starting dialysis, especially to perceptions of losing control.

> *P20: I’m not in control of it now no more, at the minute dialysis is controlling me and this is getting me down cos I know it shouldn’t.*

Many participants feared depression. Finding strategies to address these negative emotions was very important.

> *P10: So we had a few tears at the beginning and then after that [husband] and I decided that there weren't gonna be any depression, because I knew if I got depressed I don't think I'd have got back up; so it's never happened, we just don't allow it to come in.*

The passing of time and finding ways to live their life alongside dialysis were seen to help with feeling low in mood. Some participants had received treatment from a psychologist and the majority of these participants had found this helpful.

> *P7: But just sometimes that depression just comes over and I’ll just, I’m wanting to do so many things, I’ve found it very difficult giving up a very active life and looking forward to retirement and doing X, Y and Z in retirement and it’s just all gone...but having said that, I've played a few games of golf so I’m getting back to what I was before, but I’m not playing as much and I’m having to adapt to it. But just sometimes, when I first started I just thought I can’t live my life like this, I’m not doing what I want to do and I would really get quite low, but I had a bit of counselling and I’ve got to say that was excellent…*

Some participants felt self-care helped with their low mood through helping them gain a sense of control (see chapter 7). Unrealistic expectations for life on dialysis were also seen to contribute to ‘feeling down’ and therefore participants felt that it was important that pre-dialysis education prepared people for the realities of dialysis.

Previous studies have shown that depression is more common in those on dialysis[248] and is associated with adverse outcomes, including increased mortality and reduced quality of life[249, 250]. The literature on haemodialysis patients has documented the risk and adverse outcomes associated with depression, and some studies have assessed treatment strategies, yet comparatively little attention has been given to identifying the causes and investigating potential preventative strategies. In this study support from psychologists, pre-dialysis education and self-care were all seen by participants to have a role in the treatment and prevention of depressive symptoms. Participants also suggested a connection between perceptions of control, attitudes to illness and adjustment with depressive symptoms. Recent work exploring people's psychological adjustment to chronic illness has also highlighted the importance of adaption, finding control, self-management and positive attitudes[251]. This study suggests that participants were able to identify, and in some cases confront, factors that could be adversely affecting their mental health. The data also suggests ways that HPs may be able to prevent or support patients with depressive symptoms such as preparing people for the realities of dialysis in pre-dialysis education, and supporting patients in finding a sense of control over their situation.

9.2.3.2 Pain from needling

The needling skills of nursing staff were very important to participants, as repeated attempts at needling their dialysis access were painful.

> *P6: Well I mean to me it's just getting the needles in without, and getting it right first time round cos it can be quite painful.*

Participants from many units said they preferred being needled with the buttonhole method (a method of inserting needles into the fistula through tracks in the skin that allows the use of blunt rather than sharp needles), as it was less painful, although some participants acknowledged an increased risk of infection with this method. Others participants said they would have preferred to keep a dialysis line as this would have avoided the need for needles.

> *P23: …in hindsight I would have never had my line took out, I'd have just kept it up forever.*

Participants varied in their preferences for using anaesthetic at needling sites but it was important to be offered a choice. Those who needled themselves often reported that this was less painful or thought it was easier to tolerate self-inflicted pain. The feeling of being unable to needle yourself (most cited this as due to psychological reasons rather than physical) was also a frequently reported barrier to self-care.

A thematic analysis of patients' perspectives of haemodialysis vascular access[252] reported that the pain some patients experienced when having their access needled was the most commonly reported problem with having a fistula or graft. It is not clear whether this synthesis included any patients using the buttonhole technique but they did not report any relationship between needling techniques and pain. In common with our study they found that some patients preferred to keep their lines and they reported that patients found a lack of needles as the main benefit of lines. They also reported that having confidence in the skills of the needler was seen as an important way of coping with the fear associated with cannulation. In this study having confidence in the nurses' needling skills contributed to their desire for continuity of care from nursing staff they knew (see chapter 8).

Patients had different ways of managing the pain from cannulation. Again self-care was one of the strategies used by some patients to manage pain and anxiety related to needling, whereas self-needling was also an important barrier to self-care for others. In this study, participants related the degree of pain to the needling technique used and the type of access. While HPs may focus on other important clinical concerns such as infection when contemplating vascular access these data suggest discussions with patients should also include a consideration of the pain experienced in relation to needling.

9.2.3.3 Fatigue

Fatigue was the most common symptom discussed by participants. It affected their ability to maintain normal roles and responsibilities and took further time from their lives, as they needed to rest.

> *It's the tiredness that really gets to you...and because I've gone out at quarter to eight in the morning and I don't get home until about quarter past two because of the travelling; and most days I end up having a sleep in the afternoon, which I shouldn't be at my age.*

Participants often reported that they would choose a dialysis time slot based on how they managed the fatigue caused by treatment.

> *P7: I think for my life the twilight just suits me cos I can get straight to bed, but I'm desperate for my bed when I get home. But even on the day of dialysis I've got to pace myself very carefully knowing that I'll be going on; if I do too many things…that use energy then I can be quite ill on dialysis, so my day's got to be paced the day of dialysis, and then usually the day after I'm OK. But the times I have had to go on a day dialysis I absolutely agree with you, it just wipes you out completely.*

Those who dialysed in the morning often reported feeling tired for the rest of the day. Those dialysing in the afternoon or evening frequently reported that they benefitted from being able to go straight to bed when they got home. However they still found they had to pace themselves before going to dialysis. The exhaustion experienced after dialysis was seen as worse when they dialysed following a two-day break. Energy levels were better on non-dialysis days but as a result many found they could only live their lives on four days of the week.

> *P6: I go home, I have some lunch and sometimes I can't even stand and make a sandwich, [husband]'ll bring the things to make me sandwich to the dining table and I have to sit there and make it because I can't stand long enough to…*
>
> *P5: I agree.*
>
> *P6: …yeah, and, as I say, by ten o'clock I'm wiped out, but then as soon as I wake up, the next morning …*
>
> *P5: The day after you're OK, Yeah.*
>
> *P8: Yes, you're fine.*
>
> *P6: …I am fine.*
>
> *P7: Great and firing on all cylinders.*

> *P6: But it means two days in the week that you're having to fit everything else in and that's difficult.*
>
> *P5: Exactly.*

Fatigue was mostly experienced after dialysis treatment. Within the literature there has been increasing interest in what is referred to as an individual's recovery time following dialysis. Studies have found that longer recovery times have been associated with higher mortality and reduced quality of life[253]. While clinical considerations have focussed on ways of reducing recovery times, the participants' discussions were focussed on adapting life around the fatigue. For some participants this recovery significantly reduced the time available to participate in their life. Solutions again depended on individual preferences and social contexts and this was reflected in the discussions around how the timing of dialysis could help them manage fatigue. In one group participants discussed the idea that more frequent dialysis could reduce recovery times. However the time required for extra dialysis was felt to abrogate any benefit. Addressing ways in which fatigue could be reduced is therefore likely to be welcomed by patients but HPs should also consider how they may be able to support patients in managing their fatigue and dialysis scheduling may again play a role in addressing this.

In conclusion, managing symptoms was seen as an important part of living with dialysis. Participants reported various symptoms, however they were mostly seen as problems to cope with and adapt to rather than things that could be cured. HPs should therefore be aware that patients may not volunteer symptoms as they could consider them as untreatable. While some symptoms may have no cure, these data suggest that HPs can still play a role in helping patients cope with them.

9.2.4 Managing uncertainty

Participants discussed struggling with uncertainty in many areas of their lives. While this is not unique to dialysis patients, participants described how being dialysis dependent had created new uncertainties.

9.2.4.1 The uncertainty of treatment

Those who dialysed in-centre had to manage the uncertainty created by depending on the dialysis unit to provide their treatment. There was uncertainty regarding when transport would arrive, when they would get on the machine and consequently when they would get home. Some felt this made it difficult to plan any other events for the day. As discussed above the uncertainty of how long their treatment would take was a source of frustration to many and contributed to the perception that they were not in control of their lives.

The uncertainty of who would be needling their vascular access could also result in significant anxiety for some participants. The needling skills of the nursing staff were felt to vary and some participants reported fearing which nurse would be putting them on dialysis. This anxiety had led to some participants choosing to needle themselves.

> *P12: But I think that's also why it was important for me to learn how to needle myself, because I've had some really bad nurses and you don't want anyone, and because I wanted to sort of leave [unit] and venture off on holidays around Britain I needed to feel secure in who was gonna needle me, cos my veins aren't the brillest, and so by learning to do it myself it was like I'll do it, you don't need to come anywhere near me, thank you very much, I don't want your hands on me, I'll do it myself…*

Home patients did not share all the concerns of in-centre patients in relation to the uncertainty of treatment. However they reported encountering problems with the machines, their vascular access and their health. It was therefore important to them that they had access to help, and that this was provided quickly and efficiently.

> *P25: I think it's knowing, what's important for me is just, as I said, knowing the support is there when you need it...*
>
> *P29: It is, yeah.*
>
> *P25: Yeah, it's always there when you need it; and that's the most important thing for me now.*

Both home and in-centre patients therefore highlighted the importance of confidence in the staff in relation to coping with uncertainty. For home patients the focus was on their availability and support if something was wrong whereas for in-centre patients it was their technical skills. For those who felt unable to develop confidence in staff, or when this was not possible (when dialysing in a unit where the staff were not known) self-care was seen as alternative strategy to manage the uncertainty of treatment.

9.2.4.2 Uncertainty of health

Many participants considered themselves to be in good health. However they were aware through their own experience, or through talking to other patients, of the potential health complications that were associated with dialysis and were keen to avoid them. This was especially true for problems with dialysis access.

> *P1: I've lost a fistula and that was a lot to do with not very good access and people not taking notice of emails...*

As dialysis access problems were particularly feared, pro-active care and monitoring were valued, especially if this could prevent hospital admissions.

> *P24: But the positive thing this time was after I'd had the monthly blood taken they found that my clearance wasn't as good as it should be; so they said "We'd like you to go for a scan to see if your graft is narrowing". And that was done pretty quickly, over about three days I had the scan, they rang me to say it was narrowing, could I go in for the angioplasty; and they seem to be keeping a better eye on things now than waiting for it to clot up and having that period in hospital, they seem to be checking my flow and my clearance more readily and offering these scans more readily, which I found was a big, big, big help to me rather than having to spend time in hospital. So I'm glad about that.*

When problems were encountered it was important that they were addressed quickly. For those dialysing at satellite units, it was important to have confidence in the nursing staff to pick up problems and contact the parent unit if necessary.

> *P4: But we do have very good nurses and they are absolutely excellent, and they get on that phone straight away.*

Measures to prevent and efficiently manage problems were important to patients, especially if this could avoid hospital admission. Again establishing confidence and trust in the nursing staff played an important role in addressing this concern.

9.2.4.3 Life expectancy and the end of life

Participants in all the focus groups acknowledged that without dialysis they would die. They were familiar with the concept of stopping dialysis and choosing to have palliative care, however they did not wish to dwell on the subject of death and in some groups it was simply referred to as 'the alternative'. A few participants did share their worries about dying.

> *P2: ...that's what worries me about how long you've got.... Sometimes I have a think about it, then I think [own name] don't be so ridiculous, cos nobody knows how long they've got...*
>
> *P4: No, quite.*
>
> *P2: ...really do they?*
>
> *P4: They could walk out there and be knocked over by a bus.*
>
> *P3: Well I feel on borrowed time anyway.*

While patient 2 reasons that nobody knows when he or she will die, by making the statement she appears to understand that her life expectancy may be different to those who are not dialysis dependent. As described in chapter 8, participants highlighted how the deaths of other patients on the dialysis unit could result in a consideration of their own life expectancy. While many participants appeared to have considered their death, the majority were reluctant to discuss this further within the context of the focus group. These conversations often moved on to a discussion of the positives of having access to life sustaining treatment. Nevertheless, these discussions suggest that the participants viewed their lives as more fragile and less certain than others.

Dialysis patients are not unusual in considering death as a source of uncertainty, however many previous studies have also found that dialysis patients appear to be more closely aware of their mortality[37, 110, 118]. In this study participants appeared to use emotional coping strategies such as looking for positives or avoidance to cope with these issues. A study exploring advance care planning in patients with ESKD found that patients desired more information about end of life issues and that this could address some of their uncertainties regarding death[254]. While this was not explored in this study, patients did appear to be aware that they could choose to stop dialysis and have palliative care if they wished. HPs may wish to explore this further in certain patients and consider discussing advanced care planning as a way to address uncertainty around death.

9.2.4.4 Waiting for a transplant

In addition to the other uncertainties associated with dialysis dependence, some patients faced the uncertainty of if, and when, they might receive a kidney transplant. Patient 20, who had had two previous transplants, explained that when he received the transplants he then worried about the uncertainty of how long they would last.

> *P20: For the length of that transplant you're, the slightest little problem with it you're worrying is this me transplant packing up.*

If his transplant failed, he was faced with the prospect of returning to dialysis; he was consequently never without the uncertainty of renal replacement treatment.

A previous study of haemodialysis patients on transplant waiting lists found that participants experienced hope until they exceeded the average waiting time, at which point they started experiencing uncertainty[205]. There is little that HPs can do to address the uncertainty of the transplant waiting list, however it may be helpful to discuss this uncertainty with patients. As cited in chapter 7 supporting patients to find positive ways to live with dialysis may result in better adaption and emotional coping than focusing on dialysis as a temporary measure until transplantation, especially when this may be over many years.

In conclusion participants described many uncertainties in relation to living with haemodialysis. Other studies involving haemodialysis patients have found uncertainty can adversely impact patients' sense of control and therefore their abilities to cope and manage dialysis dependence[111]. The participants in this study also identified many aspects of care that helped them manage their uncertainty such as developing trusting relationships with staff, staff that were responsive to their problems, interventions to prevent complications, and for some self-care.

9.3 Integrating dialysis into life and self-care levels

Both home and in-centre patients considered flexibility as the biggest advantage of home dialysis. This flexibility allowed patients to dialyse around other events in their lives rather than living around dialysis. Patient 26, who was new to home dialysis, explained that he had found this new freedom challenging as he was used to the strict in-centre regimen.

> *P26: …I've just bought a caravan so I'd like to go away for some weekends but I don't know how many weekends I'm allowed, do you know what I mean?*
>
> *P28: As much as you like.*
>
> *P26: But this is what I can't...*
>
> *P28: It's your life.*
>
> *P26: …I talked to my own team, and they said, "Well do what you want, if you feel OK just do it"...But I find it very hard to like break the regimen I'm in.*

Home patients felt they would find it very difficult to return to the restrictions of in-centre dialysis. P20 felt that as a result of moving from home dialysis to in-centre dialysis he had lost control of his life as dialysis was now controlling it (see chapter 8). P20 was self-caring within the unit, but in common with the views of other participants, he still found having to attend for dialysis at fixed times prevented him feeling in control. Flexibility is therefore seen as the key advantage of home dialysis, consequently there was general agreement that self-care units would only be successful if they were able to offer this same degree of freedom; especially as they were seen to have important disadvantages over in-centre units such as the extra time that needed to spent setting up and cleaning after dialysis.

Home patients felt that the flexibility of dialysing at home, and the increased frequency with which many chose to dialyse, allowed greater freedom from dietary and fluid restrictions. Fatigue however was a dominant symptom for all patients and many agreed this symptom was worse following a two-day break. While some in-centre participants chose to dialyse 4 days a week, many participants did not think this was feasible for them as this would result in further time being lost to dialysis and not all units were able to offer extra sessions. Dialysing more frequently was viewed as easier at home and many home patients chose to dialyse on alternate days because of the symptoms associated with a two-day break.

For those who dialysed in-centre getting on to dialysis as soon as possible after arriving was a priority. This was one of the main reasons cited for involvement in self-care for all who participated. For some of those who were involved in small amounts of self-care it was the sole motivator. Being able to needle yourself had the advantages of not having to wait for the nursing staff, being less painful, and also removed the uncertainty and anxiety related to depending on nursing staff.

Some home patients thought that the loss of control they associated with in-centre dialysis was related to the uncertainty created by relying on others to provide treatment and transport. Self-caring at home freed them from this uncertainty. They did worry about experiencing problems at home and it was therefore very important to them that they felt confident staff would be available to offer assistance if required. While in-centre patients discussed the uncertainties created by observing complications in and deaths of other patients, this was not a focus of discussion within either of the groups containing home patients. This may be because home patients are not confronted with these problems as regularly and therefore do not consider the uncertainty of their health as frequently; a further factor that may facilitate home patients moving closer to the ideal of a 'normal' life.

9.4 Conclusion

When commencing dialysis participants described their struggles to maintain what they considered a normal life. Many aspects of life had to be changed as a result of dialysis dependence but the most challenging was the time that had to be relinquished for treatment. In-centre patients also had to adapt their lives around the inflexible regimen prescribed by the renal unit. The degree of disability their dialysis presented to them and the care they received were seen to be inextricably linked. Having found ways to adapt to this new regimen, when their expectations for treatment were not met this could then became an important source of frustration.

All participants saw home dialysis as having clear advantages in regards to integrating dialysis into life; flexibility, convenience, and the ability to dialyse more frequently, which was seen to improve symptoms and allow the relaxation of dietary restrictions. However, barriers such as fear, needling and not wanting the home medicalised still prevented uptake by the majority. While the main advantages of home dialysis were seen to lie within the theme of integrating dialysis into life, independent care within the unit could not provide these benefits unless patients had access to their own machine at a time of their choosing.

Adapting to dialysis affected many aspects of life and involved a considerable amount of consideration and work by all patients. Through exploring this work participants highlighted how the attitudes of staff and the way care is provided affected, both positively and negatively, the success of their attempts to integrate dialysis into their lives.

Chapter 10 Conclusions

In this chapter I start by discussing the relevance of the findings of this thesis to the wider approaches taken by health care providers to the provision of haemodialysis care. I then discuss the practical implications of the findings to haemodialysis care in general and then, more specifically, to the shared care programme. Following this I have compared my findings to the framework identified in the thematic synthesis of patients' experiences of living with haemodialysis presented in chapter 3 and then the existing patient experience/satisfaction measures described in chapter 2. Finally, I conclude by considering the strengths and limitations of this thesis and its implications for future research.

10.1 So what is important to patients about their care?

The three overarching themes presented in chapters 7, 8 and 9 of this thesis represent the work patients described being involved in when living with dialysis. These are finding a personal sense of control, maintaining their social viability and integrating dialysis into their lives. Through discussion of these overarching themes in the previous chapters, I have illustrated how the care patients received was seen to be related to their perceptions of success or failure in these areas of work. As the data contributing to the findings of this thesis were derived from patients they are presented from their perspective. The research question however was posed by and for health care providers, and the data is most useful when also considered in relation to how professionals organise and provide haemodialysis care. From this perspective I suggest that there are four areas of care that are important to patients and warrant further consideration by health professionals: care that supports people to find a sense of control, care that is individualised, care that is holistic and care that supports people to achieve their goals. These are described in turn below.

10.1.1 Care that supports people to find a sense of control

One of the three over-arching themes of this thesis describes the work that patients are involved in when trying to find a sense of control over their dialysis dependent lives. Many of the explanations patients provided for the importance of other aspects of care were also related to a desire for control. These aspects of care are both functional and relational. Functional aspects include the flexibility to dialyse around other commitments, being able to organise their own transport, or provide their own treatment. Building confidence and trust in the skills of individual members of staff, gaining information through relationships with staff and being involved in care decisions are also seen to facilitate control through relational aspects of care.

How care affects perceptions of control are individual to each patient, and different patients may utilise directly opposing approaches to care when seeking a sense of control. Some patients only feel in control of their care if they provide it themselves, whereas for others trusting a nurse to provide their care ensures a sense of control and security. Understanding how care strategies affect an individual's sense of control first requires an understanding of how dialysis dependence is seen to affect that individual's identity and priorities. Being able to maintain employment and roles as family providers for example may be of overwhelming importance to some patients and consequently impact on many of their decisions regarding care. Patient's perceptions of control are consequently linked with the concepts of biographical disruption and identity; those for whom dialysis dependence has a bigger disruptive impact are likely to feel less in control of their lives. In turn, the degree of disruption can be related to an individual's care priorities and therefore how they evaluate care. Consequently developing an understanding of the biographical disruption an individual is experiencing as a result of their dialysis dependence will assist HPs in supporting patients to regain a sense of control over their lives.

The strategies used by some patients to find a sense of control may conflict with the care priorities of HPs. For some patients, exercising control can have serious adverse consequences for their health such as not attending dialysis sessions, and this presents challenges for HPs. Exploring these strategies in relation to perceptions of control may facilitate the joint identification of alternative mechanisms that could be used to facilitate control without adversely affecting the patient's health or bringing them into conflict with staff.

In research and policy regarding chronic disease management the term patient empowerment is often cited as a desirable function of care that can result in improved outcomes for patients [255, 256]. Empowering patients involves HPs facilitating patients to be involved in decision making and management of their condition. Definitions often link empowerment with the concept of control.

> *"Empowerment is a process of helping people to assert control over the factors which affect their health"*[257]

HPs are viewed as being able to facilitate patient empowerment by ensuring patients understand their roles in managing their health and are provided with the information and skills required to do so[258]. The concept of patient empowerment is therefore focused on helping patients manage their chronic disease. The findings of this thesis suggest this concept should be broadened to supporting patients to find control over their illness. Care provision does not only have a role to play in helping patients manage their health but can also facilitate patients to develop a wider sense of control over living with their chronic illness. While this may be through the development of knowledge and skills, this thesis also demonstrates that control can also be sought through developing trust in others to provide care.

10.1.2 Care that is individualised

Throughout my findings were descriptions of diversity among patients. This diversity was seen in patients' backgrounds, care priorities and choices.

As described above, considering how we can best support patients to find a sense of control requires knowledge of individuals' backgrounds and priorities, as well as consideration of how dialysis may be affecting their pre-dialysis identity. For HPs to develop such knowledge requires time and continuity of care. As modern healthcare strives to become increasingly efficient, care can become fragmented; the time needed to build the relationships with staff that were valued by participants in this study may consequently be lost.

Relational aspects of care are recognised as important to patient satisfaction and NICE have produced guidance on improving patient experience which highlights the importance of individualised care[259]. This guidance advises HPs to consider care within many of the practical contexts of patients' lives such as physical disabilities, and family and social networks. The importance of considering care within these contexts was demonstrated in this thesis, however individualised care was also closely linked to preserving their identities. Patients did not just want care to address their individual contexts but also how they saw themselves and how they were seen by others. This may be facilitated through the nature of their relationships with staff but also through processes of care such as the timing of dialysis affecting the maintenance of employment. Providing individualised care is therefore not just a process of recognition for patients but also of action.

10.1.3 Care that is holistic

Individualised care requires a holistic approach. To know an individual patient is to understand their lives outside the care environment and how their lives affect how they live with their illness. Holistic care is described by the Health Foundation as care, *"that takes into account the whole person – not a narrow focus on their condition or symptoms but also their preferences, wellbeing and wider social and cultural background"*[260]. Again my findings would support this concept of holistic care which is closely related to care that is individualised and supports patients to find a sense of control, as described above. However, this thesis also describes another approach to holistic care; care that considers the experience of dialysis as a whole. For patients, their dialysis care starts from when they are waiting at home for their transport and lasts until they get back, consequently they want staff to consider their care from the same perspective. Transport, getting into the unit, and waiting for treatment should be considered as important as the experience of dialysis itself. As such, strategies used by units should not focus on the treatment alone but also consider all aspects of the dialysis experience. The way dialysis care is commissioned and managed may make this challenging, but if units wish to improve patients' experiences of care they must adopt a holistic approach to their consideration of dialysis care. This same concept may also be important in other chronic illness settings, especially when multiple agencies are involved or care is provided in a variety of settings.

10.1.4 Care that supports people to achieve their goals

The participants in this study described diverse goals for their lives, from spending time with family, maintaining employment, travelling or just staying alive, but they all describe having goals. Those who felt that dialysis was in control of their lives still described pursuing other objectives. Supporting patients to achieve their goals could be seen as an aspect of holistic care. However in the setting of dialysis care I think it warrants specific consideration in view of the unique burden dialysis has on peoples' time. Many patients no longer experience kidney failure as the illness. Dialysis becomes the manifestation of the illness and the cause of their symptoms and hardship. Dialysis is experienced as a disability with which they must learn to live. Considering dialysis as a disability reflects the finding that some patients in this study accepted dialysis dependence while denying illness. The UK Equality Act defines disability as *"a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities"*[261]. While dialysis dependence may not strictly meet this definition the World Health Organisation describes disability more broadly;

> *"Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Disability refers to the negative aspects of the interaction between individuals with a health condition and personal and environmental factors"*[262].

This broader definition, which includes activity and participation restrictions, would recognise dialysis dependence as a disability. Just as health care for people with physical disabilities often focuses on helping people to achieve their goals, this is therefore also an important aim for those providing care for people dependent on dialysis. Exploring an individual's goals may help identify how care could assist in achieving them, whether it is arranging holiday dialysis, changing slots to help with fatigue or supporting someone to dialyse at home.

Supporting people to achieve their goals could be considered as an aspect of holistic care. However it also requires an individualised approach and may contribute to finding a sense of control. These four aspects of care are therefore closely linked but I believe they provide health care providers with clear concepts within which to consider their role in care provision for dialysis patients. Reflecting on the existing definitions of patient empowerment, individualised care, holistic care and disability has also highlighted how this thesis contributes and expands these definitions in relation to the wider context of the management of chronic illness.

10.2 Implications for healthcare provision

Throughout the findings chapters of this thesis I have discussed the results in relation to healthcare provision, however in this section I will focus on how my findings can be used to inform care provision at a unit level. I start by discussing haemodialysis care in general and then discuss the findings in relation to the shared care programme.

10.2.1 Haemodialysis care in general

10.2.1.1 Organisation of care

How care delivery was organised within units could be seen to affect how patients experienced care in a variety of ways and this provides units with the opportunity to consider how the organisation of care within a unit could be modified to improve patients' experiences. Aspects such as dialysis machines arranged to enable patients to monitor their own treatment and providing access to kitchen facilities and the unit itself, may improve patients' perceptions of autonomy and self-management. Some patients also valued being able to socialise on the dialysis unit and the arrangement of the unit could be seen to facilitate or prevent this. While some patients wanted to sleep on dialysis, others wanted to read therefore larger units may want to consider whether different areas could be created within units to address these preferences.

10.2.1.2 Continuity of care

Developing trusting relationships with staff was very important to many patients and this was seen as easier in smaller satellite units. This could be addressed in larger units through caring for patients in smaller groups with corresponding staff. Continuity of care was also important for patients' relationships with doctors and units should examine where this could be improved, especially when moving from one area of renal services to another. This is particularly relevant in some areas where care provision has become increasingly fragmented[263]. Units should consider the importance of continuity of care to patients when making decisions regarding the organisation of care provision.

10.2.1.3 Investing in nursing staff

The importance of patients' relationships with the nursing staff was clear throughout the focus groups with in-centre patients. The nursing staff played an important role in providing emotional support to patients and this may not be clear to nursing staff or be something for which they feel appropriately trained. The significance and complexities of these relationships may be under-recognised by staff [230] and a consideration of how these relationships can both positively and negatively affect care may be helpful to both staff and patients. The reciprocity that was described by patients may be difficult for nursing staff to manage and could possibly represent one of the reasons that these relationships have been reported as a source of stress for staff elsewhere in the literature [145, 225]. Recognising the challenges these relationships pose to staff and encouraging discussion may help staff manage them and guard against any negative effects they could have on care. In view of their importance to patients and the potential effects on staff, the nature of these relationships warrants further research. However units should consider ways in which they can support and train nursing staff to manage their relationships with patients.

Patients also sought information on various aspects of managing their dialysis and kidney disease from the nursing staff. Units must therefore ensure that they invest in the education of nursing staff to support them in this role and so they know when to seek more expert help and advice for a patient. Investing in staff through education is also known to improve job satisfaction and retention[264]; this is not only advantageous for the individuals and the organisations they work for but, in this study, staff leaving was described as a source of distress for patients; consequently retaining staff may also increase patients' satisfaction with care.

10.2.1.4 Information provision

The patients in this study described how gaining information contributed to developing a sense of control and coping with their kidney disease. They also described challenges in obtaining information or engaging with it. While most patients had access to their bloods results, few of them engaged with these results. If we wish patients to understand and adhere to the outcomes of care that HPs value we need to engage patients with such outcomes. Thought should be given to strategies such as reports for patients on their monthly bloods that make this information accessible and encourage discussion with staff members while they are on the dialysis unit. Patients also recognised the importance of gaining expert information from specific members of the MDT and avenues to access this information should be considered that do not necessarily involve attending the hospital, such as telephone or email correspondence. This may also address some of the concerns regarding the privacy of consultations on the dialysis unit. Patients also highlighted the importance of being kept up to date with changes that were made to their care, in addition to more general changes in the management of the unit; as such units may also wish to consider whether they have successful strategies in place to do this. Patients also described listening into staff conversations and HPs should be alert to this when discussing information that they may not wish patients to hear.

10.2.1.5 "Attentive" care

Not all patients can or will want to be involved in self-care. However this study demonstrates that these patients still seek control over their care. For these patients developing trust in the nursing staff and having attentive care was seen as important for developing a sense of control. Patients linked the numbers of nursing staff to how attentive their care was. As discussed in chapter 2, the results of the CAHPS-ICH pilot also found that patients at units with higher ratios of nursing staff to patients had more positive experiences of care[80]. While challenging in the current NHS climate, ensuring adequate staffing of dialysis units is important for patients' experiences of care.

10.2.1.6 Transport

Transport was one of the most discussed topics in the focus groups and an important source of dissatisfaction with care in addition to affecting perceptions of control, treatment times, self-care and life outside dialysis. As described above, patients perceive transport as part of the dialysis experience. While the organisation and commissioning of transport may make it difficult for HPs to address, if units wish to improve dialysis care for patients, they must try and engage transport providers and commissioners to explain the significance of transport to dialysis patients and work with them and patients to develop solutions. Solutions that provide greater control to patients are likely to be particularly welcomed.

10.2.1.7 Pre-dialysis education

HPs may view renal care as divided into distinct services providing care for different groups of patients. These divisions did not seem as apparent to the patients in this study. When patients considered their dialysis care they also discussed pre-dialysis care and transplant services. Discussions regarding pre-dialysis care were particularly prevalent and, as the participants now had experience of dialysis, they were able to reflect back on their pre-dialysis care and had many suggestions as to how it could be improved. Pre-dialysis care involves educating patients about the different options for renal replacement therapy and supports them in choosing between these options. In the units involved in this study, the participants reported that their pre-dialysis education had not provided much information on living with haemodialysis and many felt units could improve how they provided this information. Many of the symptoms patients experienced, such as fatigue after dialysis, were unexpected and participants felt the information they were given pre-dialysis could result in unrealistic expectations. Units should therefore consider how they could improve the provision of such information to patients before starting haemodialysis. Some of the aspects of care patients would have liked to have more information on are listed below.

- How to manage life when on dialysis
- Possible complications
- Symptoms associated with dialysis
- Dietary advice
- What blood results mean
- What a fluid restriction is and how to manage it
- Why your weight is important on dialysis and how your correct weight is worked out
- Shared care
- How the dialysis machine works
- How to ask questions and to whom to speak
- How to emotionally cope with dialysis

These aspects of care are wide ranging and would be best provided through a multi-disciplinary approach utilising the expertise of all the HPs that provide care to dialysis patients. Introducing the different members of the team in pre-dialysis care would also inform patients of the support and expertise available to them and enable them to target questions to appropriate members of staff.

10.2.2 The shared care programme

10.2.2.1 Informing patients

The shared care programme had been running for 4 years prior to the start of this study. Despite this some of the patients in the 0-1 task focus groups had not heard of shared care. Those who had heard of shared care often did not have a clear understanding of what it was and many patients felt the motivation for the programme was to reduce staff numbers or transfer responsibilities for care to patients. Those who were involved in shared care also commented on a lack of understanding among those who were not involved. This suggests that more could be done to explain both the functions and motivations behind the programme to patients in addition to addressing some of the misconceptions that patients hold about shared care.

10.2.2.2 Considering the culture of the dialysis unit

The findings described a paradox between patients' wider experience of dialysis care and the aims of the shared care programme. While patients were being encouraged to be involved in what were perceived to be complex or high risk tasks such as needling their fistula, they were not allowed to do simple tasks such make their own hot drink or have access to the dialysis unit. When encouraging the uptake of shared care, units should ensure they do not consider the dialysis treatment in isolation but also consider how the culture of the dialysis unit more generally could encourage autonomy and provide patients with more control. Addressing the culture of the unit to develop a context of independence rather than dependence may then result in patients feeling more able to take on shared care activities.

10.2.2.3 The influence of peers

The opinions of other patients were seen to have considerable influence over patients; consequently peer support is likely to facilitate the uptake of self-care. However peers may discourage as well as encourage uptake and units should take care to ensure that those involved in shared care are not seen to be negatively affecting the care of those who are not. When considering the influence that peers can have on patients we should also recognise that an individual may need to hear the experiences of those involved and not involved in shared care to know which approach will provide the best outcomes for them.

10.2.2.4 Dedicated shared care areas

Both those involved and not involved in shared care suggested that dedicated areas within the dialysis unit for shared care patients may address some of the problems associated with uptake. There was some resentment between those involved and not involved in shared care about each other taking up nursing time and this may have contributed to the suggestions for separate areas and nursing staff. Patients also cited the importance of developing trusting relationships with the staff teaching them and cited deficiencies in continuity of care and nursing time as challenges to learning shared care skills. Having dedicated areas and nursing staff for those who wish to learn to do more tasks may therefore address these concerns as well as providing peer support.

10.2.2.5 Self-care units

Patients raised concerns about the new self-care units/areas where patients who were self-caring could come and dialyse themselves. As flexibility was seen as the main advantage of home dialysis, many patients could not see the advantage of self-care units unless they offer patients the flexibility to dialyse when they choose. Additionally patients were concerned about the extra time that dialysis would take if they had to set up before and clean up after dialysis. As the social interaction provided by the dialysis unit was also very important to some patients they were concerned about the social isolation of dialysing in a self-care unit. Units may therefore want to consider offering self-caring patients some degree of choice and flexibility of when they attend dialysis. Input to help with setting and clearing up may also be welcome. Ensuring staff continue to interact with those that are self-caring and that help can be accessed easily is also likely to encourage and maintain self-care.

10.2.2.6 Pressure to self-care

Some patients described feeling under pressure to take on shared care or home dialysis. This could become a source of tension in their relationships with staff and lead to resentment. All patients felt it was important to be given the choice to take up shared care however staff must ensure that they are not pressurising patients. When patients are involved in shared care, assumptions that they will progress to increasing numbers of tasks or home dialysis should also be avoided. Pressurising patients may have the reverse effect and result in patients feeling less inclined to take on more care.

In conclusion the findings of this study suggest a variety of strategies that may increase satisfaction with care and increase the uptake of shared care. While some of these strategies may be fairly straightforward to implement, others are more challenging. Through first understanding what is important to patients we are more likely to be able to improve care in a way that is meaningful to them.

10.3 Contrast between findings and thematic synthesis

My thematic synthesis of the experiences of adults living with haemodialysis resulted in 4 themes from which I developed a framework describing a journey of change. The first three themes describe a potential for change from patients' initial realisation of their new and altered self, to encountering the challenges to lifestyle that dialysis presents, followed by a potential acceptance and adaptation to regain a sense of control. The fourth theme 'relationships with health care professionals' could be seen to influence (either positively or negatively) the other three themes and therefore the potential for change.

The aim of my primary research was to find what was important to patients about their care. The focus was therefore on care provision. Nevertheless many of the findings of the focus group study can be viewed through the personal journey of change that the framework describes. My findings also add to the framework. Firstly they add description and detail to some of the themes. In the thematic synthesis accepting dialysis dependence, adjusting and accommodating dialysis and gaining personal expertise were seen to contribute to regaining control. When we consider this concept within the findings of the focus group study the concept of gaining control is understood to be more complex and many wider aspects of dialysis care contribute to this theme such as emotional coping strategies, developing trusting relationships with staff, being seen as an individual, transport provision, flexibility and managing uncertainty. This not only develops the understanding of the concept of control but also provides HPs with the detail necessary to both support patients in developing a sense of control and identify ways in which care can be improved in a way that is meaningful to patients.

One of the notable differences between the thematic synthesis and my primary research findings is that the representation of diversity among dialysis patients in my primary research is less apparent in the thematic synthesis. The strategies used by patients to transition along the pathway described in the thematic synthesis are seen in the focus group study to vary between people and across time. As described above, supporting patients to make this transition requires an individualised approach and an understanding of their priorities and goals for care. My study was conducted in units providing shared care and also involved home haemodialysis patients. The findings therefore also add insight into the differences between patients who have chosen different modalities of haemodialysis provision as well as illustrating how these care choices influenced progression towards a sense of control.

The importance of the fourth theme, patients' relationships with HPs, was also demonstrated in the focus group study. However my findings add to this theme by describing the complexities of these relationships. These relationships are not just mechanisms for functions of care, such as information provision, but also have roles in emotional support and social viability. The reciprocity demonstrated in these relationships offered some advantages to patients but could also adversely affect care and become a source of stress and tension for both patients and staff. Through focusing on dialysis care in the focus group study, the findings suggest this fourth theme could be expanded from focusing solely on patients relationships with HPs to their interactions with care provision more generally. The data showed that many other functions of care provision could affect patients progression towards a sense of control including timing of dialysis, flexibility, self-care, continuity of care and transport provision.

Finally my findings also represent care in the UK and within the context of the NHS. The NHS is very different to the healthcare systems in which many of the studies included in the thematic synthesis were conducted. As discussed in chapter 2, patients' experiences and priorities for care are likely to be influenced by healthcare systems and it is therefore important to note that the findings of the focus group study reflect the experiences of patients in the NHS. For example, patient transport and waiting times were an important feature of care for patients in the focus group study, but were not a key feature in the data in the thematic synthesis. Additionally discussions regarding equality of care and the efficient use of resources are likely to be influenced by the context of the NHS and were not present in the thematic synthesis data.

In conclusion, the findings of this thesis advance the framework developed from the thematic synthesis of the experiences of patients living with haemodialysis. The findings of my primary research provide explanation as well as the detail and context that is required to use the framework within the current care provision of the NHS.

10.4 Implications for the evaluation of haemodialysis care from the patients' perspective

The findings of this study demonstrate the diversity of haemodialysis patients and their priorities for care, this represents a significant challenge when considering how we measure quality of care from the patient's perspective. How we measure care also depends on what we want to do with the information. If we want to obtain information to improve care for the individual patient, we are likely to need to utilise different measures than if we want to gain information with which to compare populations. In chapter 2 I reviewed four existing measures of patient satisfaction/experience designed for use in haemodialysis populations. I now therefore compare my findings to the aspects of care assessed by these tools to evaluate their utility for measuring what was important to patients in this study.

10.4.1 CHOICE Questionnaire

Of the 20 items on the CHOICE tool the first 8 ask respondents to rate aspects of the care they receive from nephrologists. Only 1 question asks about the care that is provided by nursing staff. The care received from nursing staff, and patients' relationships with them, were frequently discussed in this study and contributed to the two most frequently coded themes from the questionnaire data presented in the thesis. With the exception of home dialysis patients, the care received from nursing staff was seen to have a more significant impact on patients than that received by nephrologists suggesting that this tool may not be focusing on what is important to dialysis patients in the UK. Additionally the CHOICE tool does not assess any aspects of the time relinquished for dialysis, emotional wellbeing, and involvement in decisions, individualisation of care or autonomy and self-care.

Consequently it does not assess many of the aspects of care that were found to be important to patients in this thesis.

10.4.2 The renal treatment satisfaction questionnaire

This questionnaire does not assess any aspects of the care provided by, or patients' relationships with health professionals. It does ask about satisfaction with time taken for treatment and has questions relating to the effect on lifestyle. As this measure has been developed to be used for all patients with chronic kidney disease, the items lack the specificity that would be required to provide information that could suggest where dialysis care could be improved.

10.4.3 The CAHPS for dialysis

The CAHPs does cover more aspects of care that were highlighted as important by participants in this study than the above two tools. As it has been constructed for use in the USA, some of the questions are consequently related to their particular health care system. This tool has similarities with the CHOICE questionnaire as many of the questions concerning communication relate to nephrologists rather than nursing staff. There are other questions relating to 'dialysis centre staff' but there are no questions that ask specifically about any members of the MDT other than nephrologists. While the other tools have not asked specifically about the effects of dialysis on life outside the dialysis unit, one question in this tool does ask if dialysis centre staff have asked how kidney disease affects other aspects of their life but there are no further questions relating to this. Additionally there are no questions about emotional support, autonomy or self-care. One question asks about waiting times but there are no questions relating to transport/travel. While this questionnaire does ask about some areas of care that were important to patients in this study such as attentive care, staff treating you as an individual, and pain on needling there are other areas of care that are not covered and the questionnaire would need modification before it would be applicable to dialysis provision in the NHS.

10.4.4 The consumer quality index for in-centre dialysis

In common with two of the tools above (CHOICE and CAHPS), this tool also starts with numerous questions relating to the care received by nephrologists, but there are 3 questions relating to nursing care. There are also 3 questions regarding social workers and 3 regarding dieticians. While the participants of this study did highlight the importance of support from dieticians, social workers were not discussed. In the development of this tool there was a question relating to waiting times for taxis and patients rated it as the second most important aspect of care, however it was removed from the final tool as the responses did not correlate well with the overall scale (low item-total correlation)[78]. This highlights the importance of ensuring that measuring what is important to patients is not lost in the development of such tools.

This questionnaire includes several items that were not highlighted as important by participants in this study, such as the provision of information about the patient federation, complaints procedures, and fire procedures. It does however ask about some aspects of care that were highlighted as important by patients in this study and are not measured in the other tools, such as suitable dialysis times, however there are also other important issues that are not addressed such as the impact of dialysis on life outside the dialysis unit.

The authors of the consumer quality index for in-centre haemodialysis do suggest that their tool may not be suitable for use in other health care systems as the items prioritised by Dutch patients may be different to those in other countries. Comparison of the items included in the tool and the findings of this thesis would support this view and suggest that while there may be some correlation between the important aspects of care for the Dutch patients studied by the authors and the population studied in this thesis there may also be important differences. Such tools are therefore likely to require substantial modification to ensure they are relevant for use in the UK. The differences in the items included in these tools demonstrate the importance of considering who designed a particular tool, and for what context/system, before they are uncritically applied.

10.5 Strengths of the study

The findings of this study provide an understanding of both what is important to patients in the UK about their care and why. Through reflecting on the relevance of these findings to clinical practice this thesis suggests strategies that could be utilised to improve care for haemodialysis patients.

The study also sought to explore the diversity of haemodialysis patients by involving patients with different preferences and approaches to care. The data therefore describe the diversity of the haemodialysis population and hence allows consideration of how we can better provide individualised care to patients. As the renal community, both in the UK and other countries worldwide, looks to increase home dialysis, self-care and patient engagement, understanding patients' views towards the different modalities of haemodialysis provision also provides important information for those developing such programmes.

A recent review of PROMs found that patients had only been involved in selecting which outcomes to measure in 10.9% of tools reviewed[265]. Through taking a qualitative approach to understanding what is important to patients about their care this thesis provides data that could be utilised, with further research, to develop measures of care that are of relevance to patients.

10.6 Limitations of the study

The findings of this thesis are limited to those who took part in the study, and like all qualitative research, are not intended to be representative of a larger population. This study took place in the north of England in two centres that were different from many other units in the UK in that they had been involved in the creation and adoption of the shared care programme. Those who volunteered to take part in the focus groups may also have different views to the population as a whole. Consequently the findings in this thesis may not be representative of all haemodialysis patients in the UK, but they do highlight which aspects of care were commonly important to patients and should therefore be taken into consideration when addressing how care can be measured or improved from the patients' perspective.

As discussed in chapter 4, my role as a health care professional may have affected the data that was gathered. This may have particularly impacted on the findings regarding patients' relationships with health professionals as the participants may have modified their views in response to my role as a health professional.

A further limitation is that the views of families and carers were not a focus of this study and the views of health professionals are not represented. While I chose to focus on the views of patients themselves, to generate findings that represented what mattered to patients about care, the participants highlighted the impact that care had on their families and this would benefit from further research. Similarly I chose to exclude the views of health professionals, however as decisions regarding the provision and evaluation of care are often made by health professionals it is important to understand any differences in the views of these two groups and again this could be investigated in further research.

Non-white groups were under represented in those who responded to the survey (and the population from which the focus group participants were selected). Consequently the findings of this thesis primarily reflect the views of white patients. This is an important consideration as over 20% of those requiring renal replacement therapy in the UK are non-white and this again should form a further focus for future research[2].

10.7 Future research

While a qualitative approach to the research question has provided a depth of understanding, a greater breadth of understanding could be gained through further research using a quantitative approach. By utilising a survey or ranking study, the differences in priorities between demographic groups, patients in different units, health care systems or countries could be better understood. Understanding the differences between groups would inform strategies for improving care for all groups. A ranking strategy would also be required to use these findings to develop a tool that could be used to evaluate care from the patients' perspective.

This thesis highlights the importance of patients' relationships with health professionals, but also their complexities. The findings illustrated how these relationships could have both positive and negative effects on care and acknowledge some of the challenges these relationships present for both patients and staff. As the views of health professionals were not collected in this study this limits the understanding of these relationships. Further research involving both patients and staff and focusing on the success and failures of these relationships is important for both improving care and supporting staff.

10.8 Conclusion

This thesis provides a depth of understanding of what is important to patients about their care. The findings provide valuable information for those providing and organising care for haemodialysis patients as well as adding to some of the concepts used when considering chronic disease management more widely. The findings suggest strategies that dialysis units can use to improve care for patients in a way that it meaningful to them, and inform further development of the shared care programme and the up take of self-care in the UK. As there is growing interest in using patient experience and outcome measures in renal services this data also provides a basis from which such measurements could be developed to ensure they are measuring what is important to patients about their care. Finally, the results of this thesis also have a wider applicability for those interested in genuinely accessing patients' views and discovering their experiences of living with chronic illness.

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Appendices

Appendix 1 Search string used in literature search for thematic synthesis

1. hemodialysis/ or hemodialysis patient/ or hemodialysis.mp.

2. h?emodialysis.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

3. exp chronic kidney disease/th [Therapy]

4. 1 or 2 or 3

5. interviews.mp. or interview/

6. finding.mp.

7. incidental finding/ or finding.mp. or case finding/*

8. qualitative.mp. or qualitative analysis/ or qualitative research/

9. 5 or 7 or 8

10. 4 and 9

11. quality of life.mp. or "quality of life"/

12. patient satisfaction.mp. or patient satisfaction/

13. society/ or patient/ or hospital/ or patient experience.mp. or therapy/

14. total quality management/ or health care quality/ or patient experience.mp. or patient care/

15. expectation/ or patient expectations.mp. or patient attitude/

16. 11 or 12 or 14 or 15

17. 10 and 16

Appendix 2 Patient information leaflet for focus group participants

A Qualitative Assessment of the Care Priorities of Patients Treated with Haemodialysis

Participant Information Sheet

You are being invited to take part in a research study about your dialysis treatment. The main question that the study wants to ask is what are the most important things about dialysis from a patient's point of view? Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Please feel free to discuss this with your friends and relatives. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

What is the purpose of the study?

We want to try and understand from patients what factors about their dialysis treatment affect their experience when they come for haemodialysis. We want to know what they think contributes to good quality treatment and what they think represent good results from treatment. As part of this study we want to see if patients who are taking part in a shared care treatment programme in Yorkshire have different views from patients that have their treatment completely managed by nursing staff. We want to use this information to improve the dialysis care we provide for patients and allow us to compare the quality of care provided at different units.

Why is the study being done?

Currently we decide how good dialysis treatment is based on measures that doctors think are important, including the results of blood tests, blood pressure results and how long patients live on dialysis. Every dialysis unit in the UK collects this data and it is used to compare the care that dialysis units are providing. We do not routinely collect data on how good patients feel their care is. We do not know what aspects of care are most important to patients. We do not know if different patients have different views on what is important. We therefore would like to speak to patients to collect this information so we can use it to improve the care we provide to all patients on haemodialysis. The study is an educational project in collaboration with Hull York Medical School. We have obtained ethical approval for the study from Leicester Research Ethics Committee.

Who can take part in the study?

Anybody who is having haemodialysis at one of the units involved in the study can take part. We will divide patients who volunteer to take part into groups depending on whether they are taking part in shared care or not.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A *decision to withdraw at any time, or a decision not to take part, will not affect the care you are receiving.*

What will happen if I take part?

If you agree to take part we will ask you to attend a meeting with around seven other patients who are also on haemodialysis. As a group you will be asked questions about what you feel is important for good dialysis. You will be free to discuss any aspects of your treatment that you like. You will be able to share your ideas and comment on what other people in the group say. There will be one researcher asking the questions and chairing the discussion and another researcher will be taking notes on what people say. The discussion will also be tape recorded, so that the information can be analysed later. The researchers will not be directly involved in looking after your dialysis treatment.

We expect the discussions will last approximately one hour. We will pay for any transport costs involved in attending the meeting and will provide light refreshments.

As part of the study we will also ask you to complete a tick box survey that has been designed to assess quality of life in patients having haemodialysis.

After the meeting, the tape recording of the discussion will be typed out so that the researchers can analyse the conversation for themes that seem to represent patients' views and what is important about quality of life, quality of treatment and outcomes from treatment. In the typed copy of the discussion each participant will be identified by a code, but not by name. From this point you will be anonymous and no one will be able to identify you during further analysis of the data.

Are there any disadvantages/risks in taking part in the study?

The main disadvantage to taking part in the focus group is that you will have to give up some of your time to attend the focus group. There is a small possibility that issues you may consider upsetting or difficult to answer will be discussed in the focus group. However, the researcher asking the questions and running the group is very experienced and knows how to deal with such situations appropriately. You also do not need to answer any question that you do not wish to.

Will my own GP know that I am taking part in the study?

With your consent we will inform your GP that you are taking part in the study and send them some information about the study. If you do not wish your GP to be informed we will not contact them.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Keith McCullough on 01904 725374 and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the HYMS Research Support Office directly (01904 321780 or research@hyms.ac.uk).

Will the information the researchers collect be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Data, transcripts and recordings will be kept in password protected computer storage spaces and only used for this project. Only the researchers will have access to the data. Written extracts may be used within publications relating to the study, but care will be taken to ensure that individuals cannot be identified from the details presented. All data will be treated in accordance with the Data Protection Act 1998.

What if I change my mind?
Participants are free to withdraw from the study and have all their information removed before the end of the focus group. If participants wish to withdraw during the focus group then all contributions made up to that point will be kept.

What will happen to the results of the study?
The results of the study will be published in a medical publication and also possibly on the internet. We will send a copy of the report and results to everyone who takes part in the study. No names or other indentifying information will be published in any reports.

Who can I talk to for more information or advice about the study?
The main researcher is Dr Keith McCullough. He can be contacted at York Hospital, Wigginton Road, York or on 01904 725374.

If you would like to speak to someone independent about taking part in research you can contact Dr Hoefield at York Hospital, Wigginton Road, York on 01904 725393. He is not involved with this study.

Appendix 3 Consent form for focus group participants

Consent Form

A Qualitative Assessment of the Care Priorities of Patients Treated with Haemodialysis

Please initial boxes

I have read the information sheet for this study ☐

I have had the opportunity to ask questions about the study ☐

I understand the purpose of the study and how I will be involved ☐

I understand that the focus groups will be audiotaped ☐

I understand that if I withdraw from the study during or after the focus group the information gathered during the focus group will be kept ☐

I understand that all information collected in the study will be anonymised and that if it is presented or published all my personal details will be removed ☐

I confirm that I am taking part in this study voluntarily, and I understand I may withdraw from the study at any time and for any reason, without my medical care or my legal rights being affected ☐

I agree to participate in this research project ☐

Name of patient	Signature	Date
Name of person taking consent	Signature	Date

Dialysis patient survey

We are always looking for ways to improve our service. We would be very grateful if you could take the time to complete this survey to help us understand what matters to you about the dialysis service and care you receive. This will help us understand what is important to you. It should take you 5-10 minutes to complete.

You are completely free to choose to take part or not, it will not affect your care in any way. Your answers will be kept confidential and will only be seen by the research team. Thank you.

First some questions about you:

1. How old are you? **........** years

2. Sex ☐ Male ☐ Female

3. Where do you have dialysis (which unit)? ....

4. Which days do you normally have dialysis?

☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday ☐ Saturday ☐ Sunday

5. What time do you normally have dialysis?

☐ Morning ☐Afternoon ☐ Twilight

6. Do you do any of these parts of your dialysis yourself?

☐ Weigh myself ☐ Do my blood pressure

☐ Set up the dialysis machine ☐ Prepare the 'putting on' pack

☐ Programming the dialysis machine ☐ Needle your fistula/graft or prepare your line

☐ Connect to the machine and start dialysis ☐ Discontinue my dialysis

☐ Strip and disinfect machine after dialysis ☐ Give my heparin

☐ Give my epo/neorecormon/aranesp ☐ Deal with alarms or problems

7. Do you want to do more of your dialysis yourself?

☐ Yes ☐ No ☐ Not sure

8. How long have you been on haemodialysis?

☐ less than 6 months ☐ 6 - 11 months ☐ 1 year – less than 2 years

☐ 2 - 5 years ☐ more than 5 years

9. Have you ever had a kidney transplant? ☐ Yes ☐ No

10. Have you ever been on peritoneal dialysis? ☐ Yes ☐ No

11. What is your post code? ……………………………………………………

12. What is your ethnic group?

White ☐ Asian/British Asian ☐

Black/African/Caribbean/Black British ☐ Mixed/Multiple ethnic groups ☐

Other (please describe) ………………………

Now we would like you to tell us about your experience of dialysis care

(please turn to the next page)

13. What is important to you about your dialysis care?

Please list up to 5 things

1...

....

2...

....

3...

....

4...

....

5...

....

14. How would you rate the quality of care you have received as a dialysis patient overall ?

☐ Poor ☐ Fair ☐ Good ☐ Very Good ☐ Excellent

15. In general how would you rate your overall health?

☐ Poor ☐ Fair ☐ Good ☐ Very Good ☐ Excellent

Thank you for completing this survey!

We would like to talk to some patients in a group with other haemodialysis patients about what matters most to them about their dialysis care.

If you would be happy for someone to get in touch with you about this, please sign below:

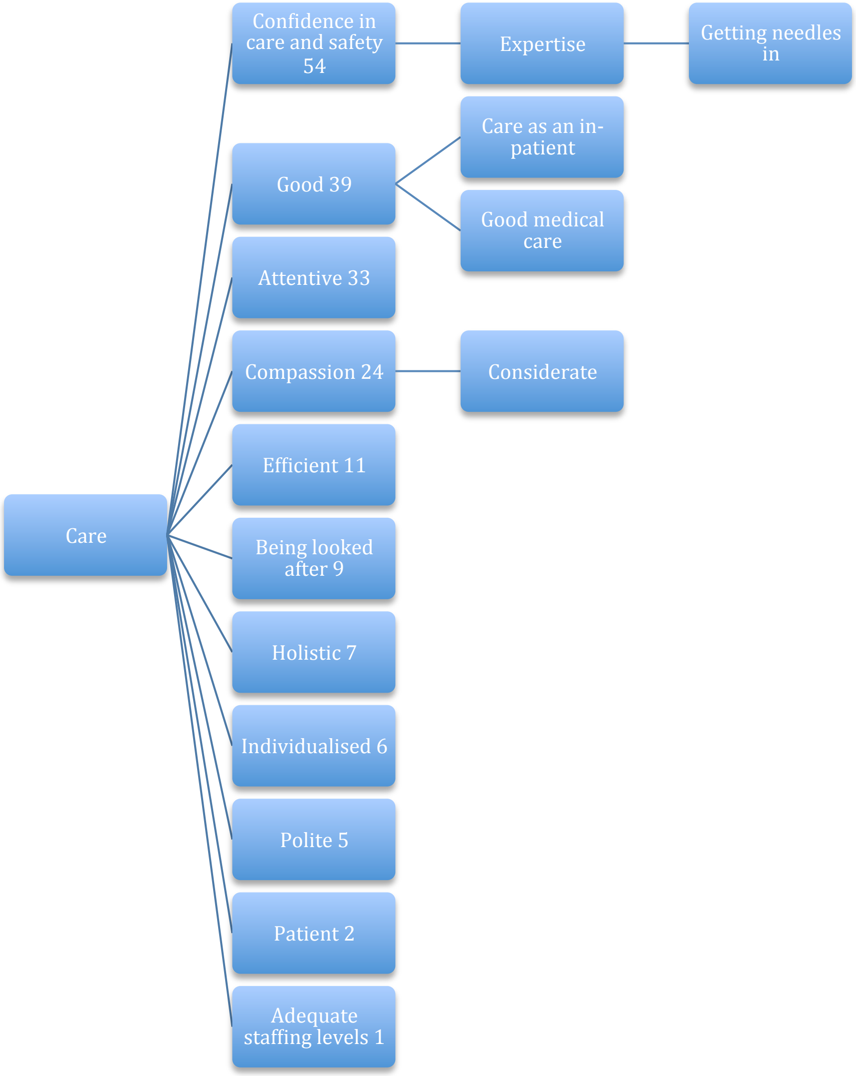
Signature ....

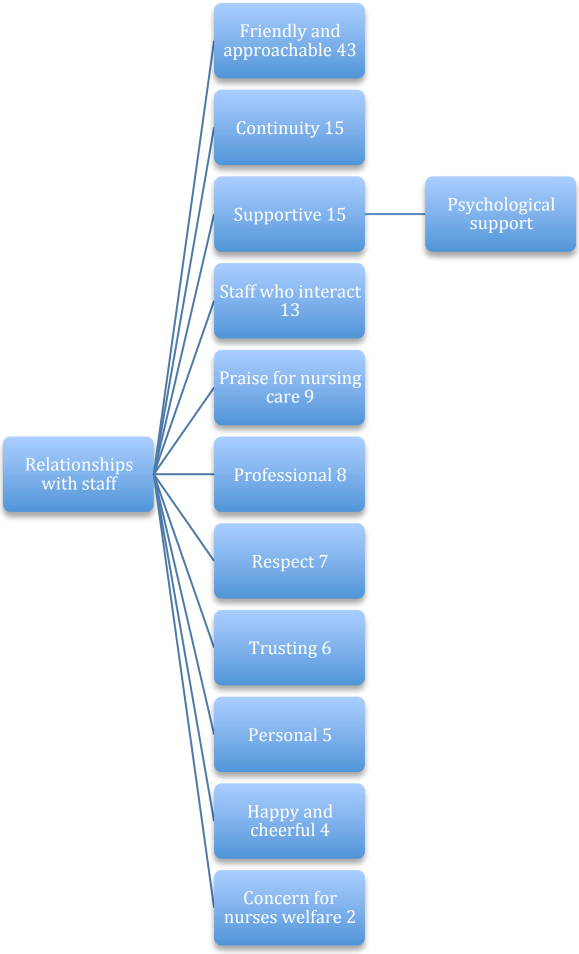
My name ....

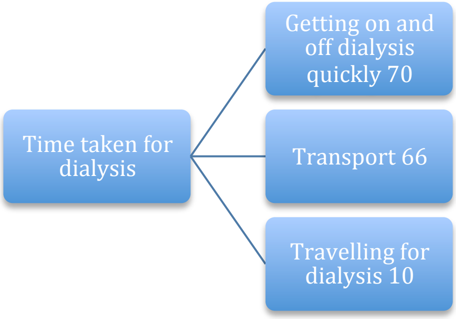
Telephone number ....

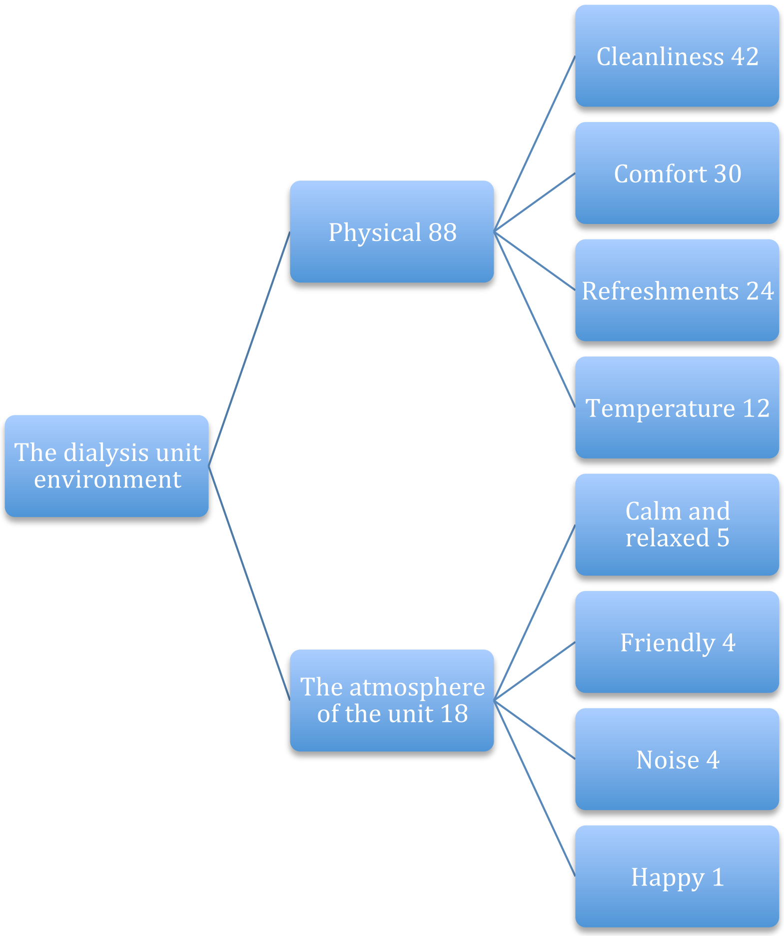
Appendix 5 Coding trees for survey data

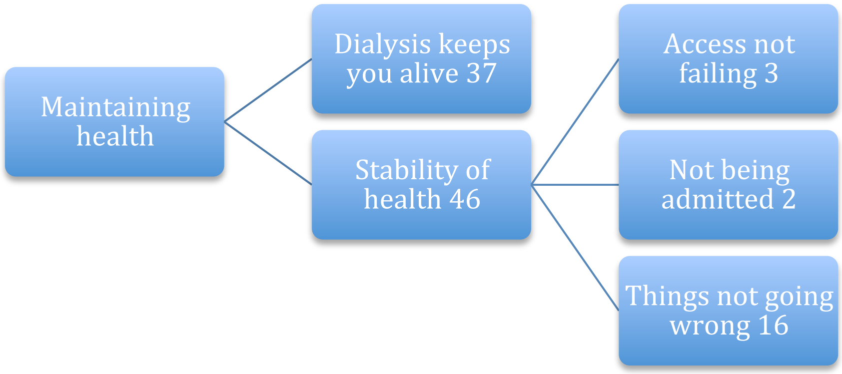
Coding trees for each of the 12 of the 14 themes developed from the survey data are shown. For two of the themes (relationships with other patients and the social benefits of dialysis) a single code was used as the theme therefore no coding tree is shown. The numbers in the coding labels represent the number of respondents to which the coding label was applied.

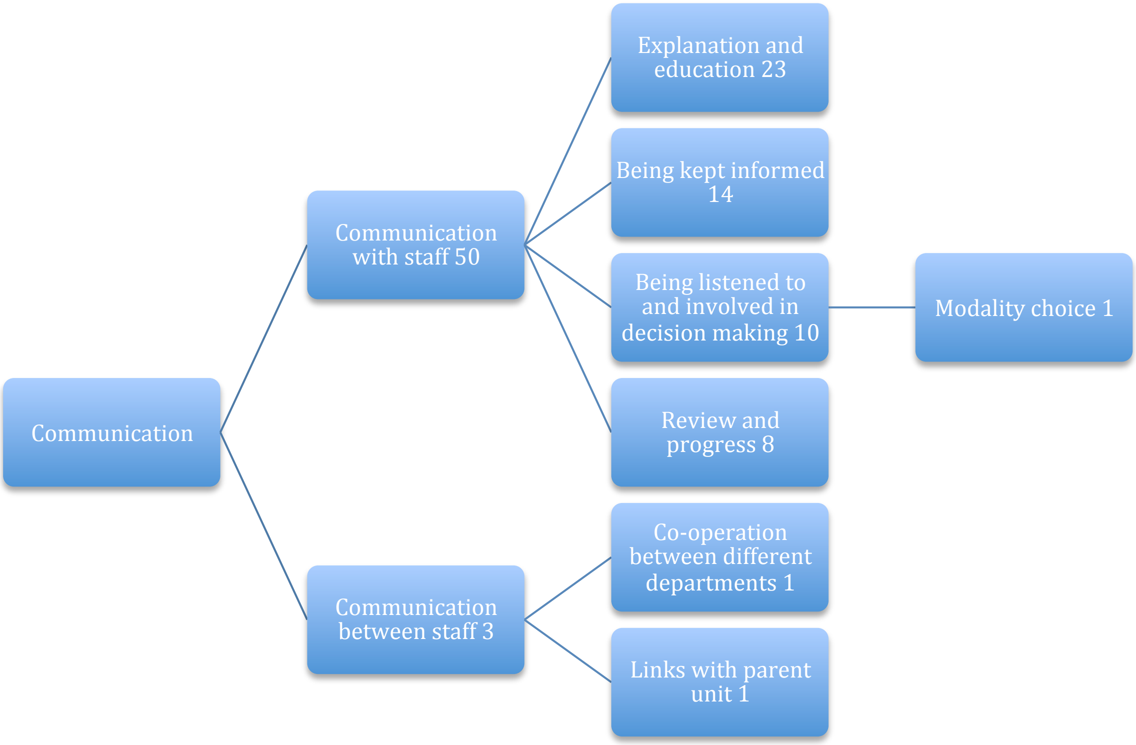


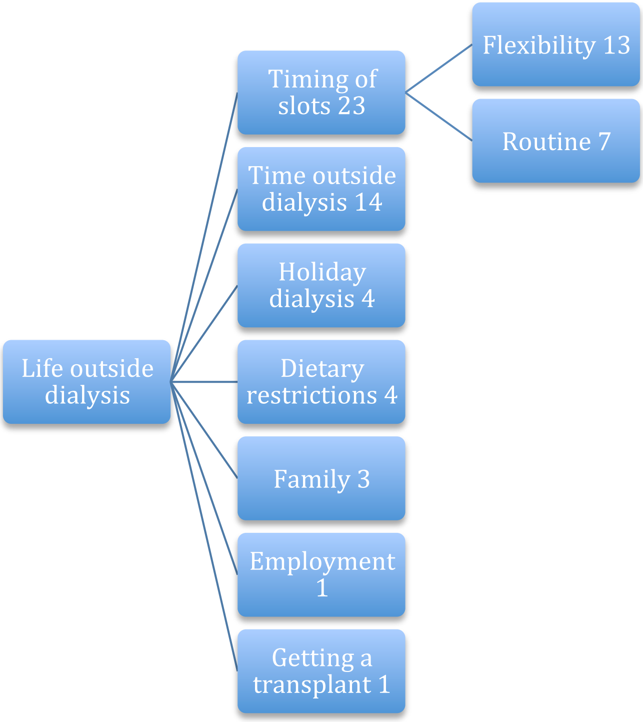

Relationships with staff
Friendly and approachable 43
Continuity 15
Supportive 15
Psychological support
Staff who interact 13
Praise for nursing care 9
Professional 8
Respect 7
Trusting 6
Personal 5
Happy and cheerful 4
Concern for nurses welfare 2

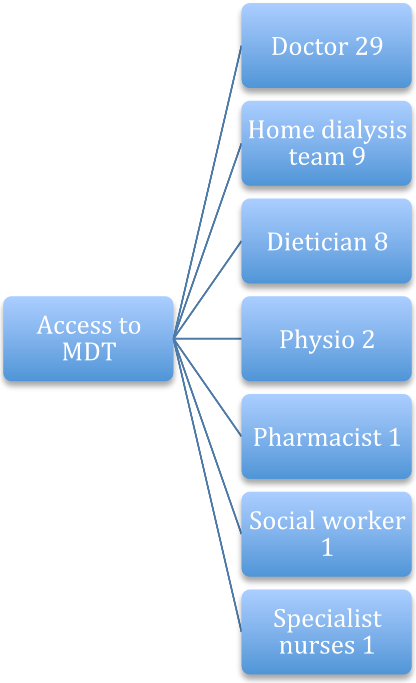

Time taken for dialysis
Getting on and off dialysis quickly 70
Transport 66
Travelling for dialysis 10

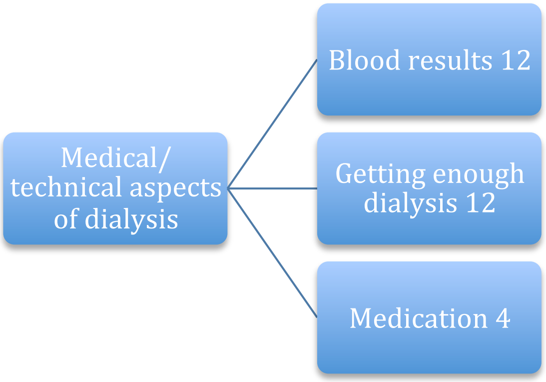

The dialysis unit environment
Physical 88
Cleanliness 42
Comfort 30
Refreshments 24
Temperature 12
The atmosphere of the unit 18
Calm and relaxed 5
Friendly 4
Noise 4
Happy 1

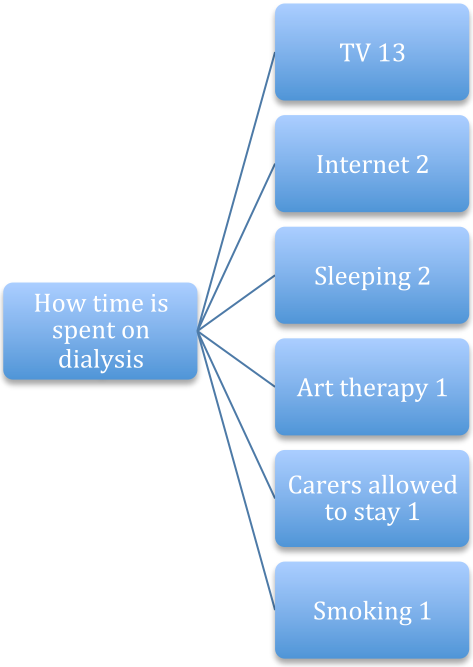

Maintaining health
Dialysis keeps you alive 37
Stability of health 46
Access not failing 3
Not being admitted 2
Things not going wrong 16

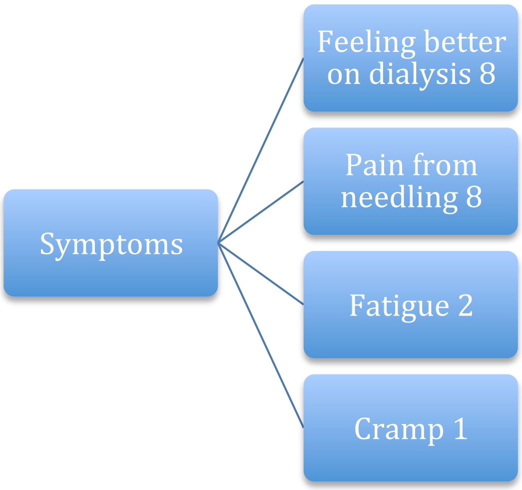

Communication
Communication with staff 50
Explanation and education 23
Being kept informed 14
Being listened to and involved in decision making 10
Modality choice 1
Review and progress 8
Communication between staff 3
Co-operation between different departments 1
Links with parent unit 1

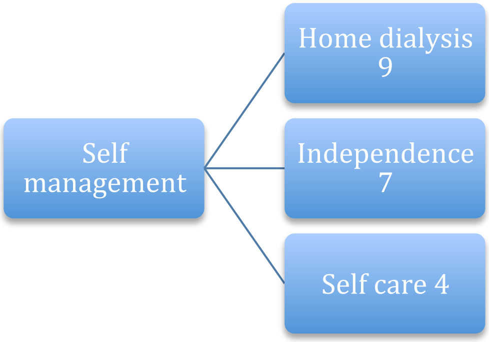

Life outside dialysis
Timing of slots 23
Flexibility 13
Routine 7
Time outside dialysis 14
Holiday dialysis 4
Dietary restrictions 4
Family 3
Employment 1
Getting a transplant 1


Access to MDT
Doctor 29
Home dialysis team 9
Dietician 8
Physio 2
Pharmacist 1
Social worker 1
Specialist nurses 1

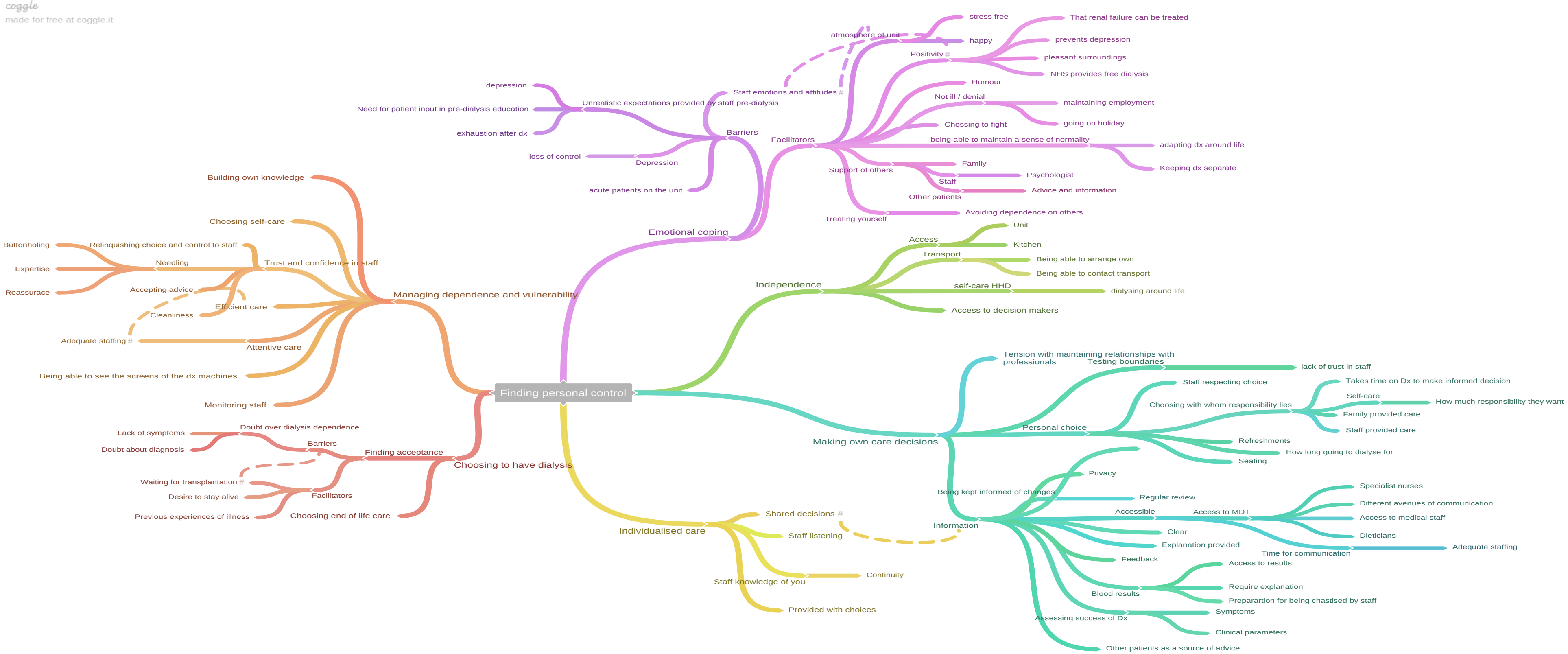

Medical/ technical aspects of dialysis
Blood results 12
Getting enough dialysis 12
Medication 4

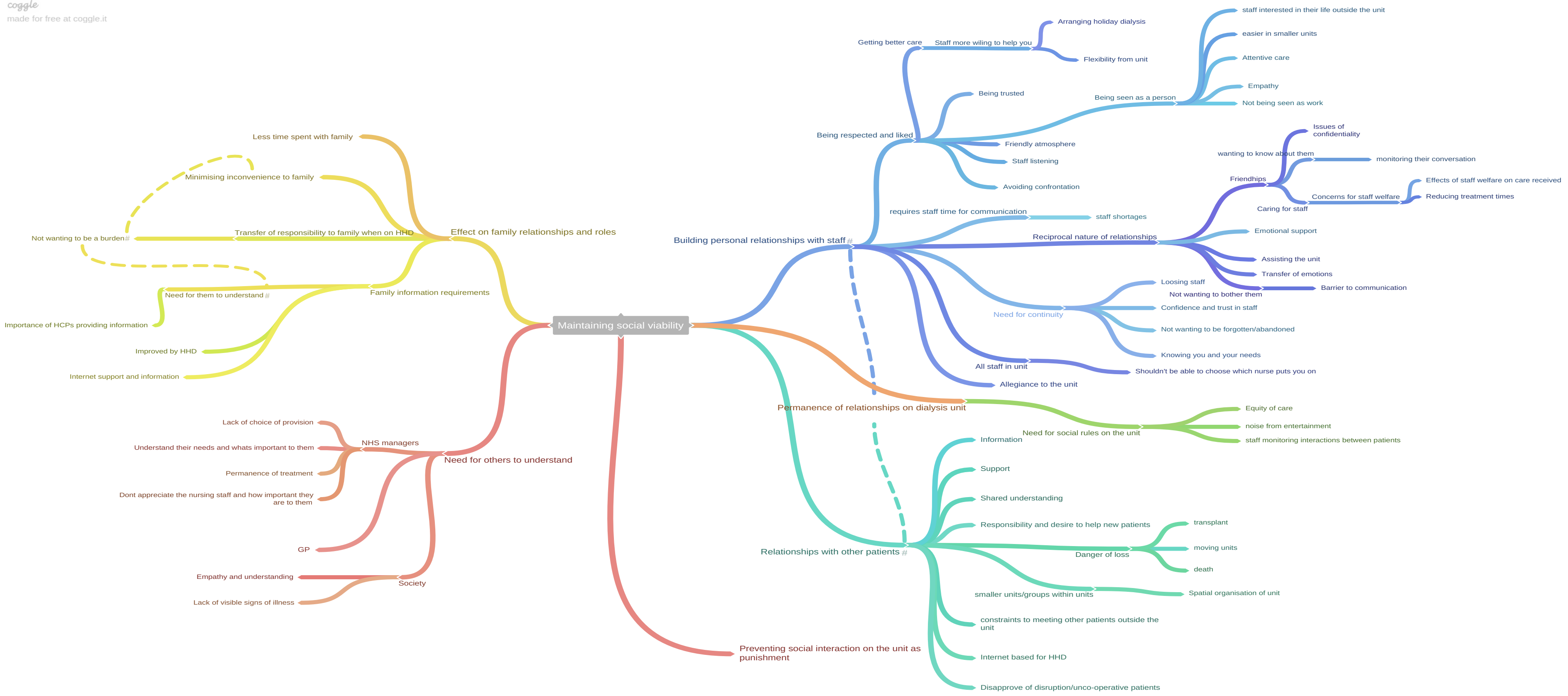

How time is spent on dialysis
TV 13
Internet 2
Sleeping 2
Art therapy 1
Carers allowed to stay 1
Smoking 1

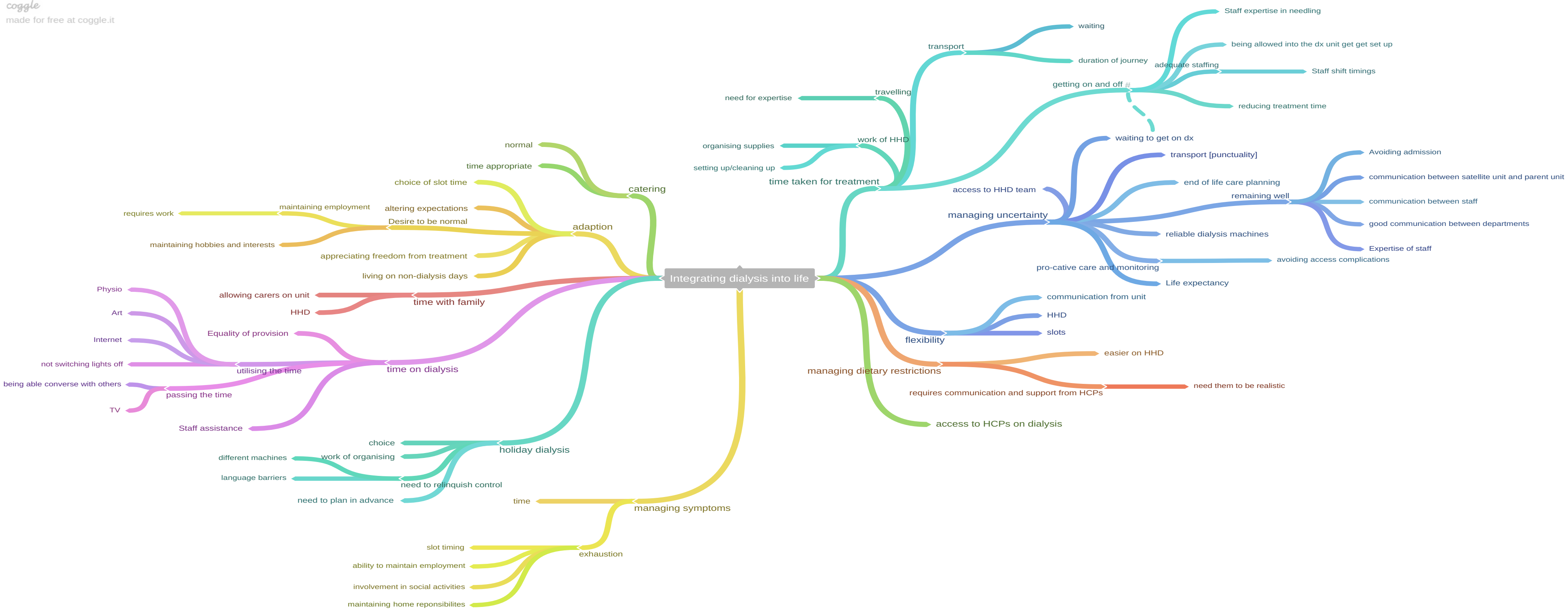

Symptoms
Feeling better on dialysis 8
Pain from needling 8
Fatigue 2
Cramp 1


Self management
Home dialysis 9
Independence 7
Self care 4

Appendix 6 Coding maps for focus group data




Maintaining social viability
Effect on family relationships and roles
Less time spent with family
Minimising inconvenience to family
Transfer of responsibility to family when on HHD
Not wanting to be a burden
Family information requirements
Need for them to understand
Importance of HCPs providing information
Improved by HHD
Internet support and information
Need for others to understand
NHS managers
Lack of choice of provision
Understand their needs and whats important to them
Permanence of treatment
Dont appreciate the nursing staff and how important they are to them
GP
Society
Empathy and understanding
Lack of visible signs of illness
Preventing social interaction on the unit as punishment
Building personal relationships with staff
Being respected and liked
Getting better care
Staff more wiling to help you
Arranging holiday dialysis
Flexibility from unit
Being trusted
Being seen as a person
staff interested in their life outside the unit
easier in smaller units
Attentive care
Empathy
Not being seen as work
Friendly atmosphere
Staff listening
Avoiding confrontation
requires staff time for communication
staff shortages
Reciprocal nature of relationships
Friendhips
Issues of confidentiality
wanting to know about them
monitoring their conversation
Caring for staff
Concerns for staff welfare
Effects of staff welfare on care received
Reducing treatment times
Emotional support
Assisting the unit
Transfer of emotions
Not wanting to bother them
Barrier to communication
Need for continuity
Loosing staff
Confidence and trust in staff
Not wanting to be forgotten/abandoned
Knowing you and your needs
All staff in unit
Shouldn't be able to choose which nurse puts you on
Allegiance to the unit
Permanence of relationships on dialysis unit
Need for social rules on the unit
Equity of care
noise from entertainment
staff monitoring interactions between patients
Relationships with other patients
Information
Support
Shared understanding
Responsibility and desire to help new patients
Danger of loss
transplant
moving units
death
smaller units/groups within units
Spatial organisation of unit
constraints to meeting other patients outside the unit
Internet based for HHD
Disapprove of disruption/unco-operative patients


Integrating dialysis into life
catering
normal
time appropriate
adaption
choice of slot time
altering expectations
Desire to be normal
maintaining employment
requires work
maintaining hobbies and interests
appreciating freedom from treatment
living on non-dialysis days
time with family
allowing carers on unit
HHD
time on dialysis
Equality of provision
utilising the time
Physio
Art
Internet
not switching lights off
passing the time
being able converse with others
TV
Staff assistance
holiday dialysis
choice
work of organising
different machines
language barriers
need to relinquish control
need to plan in advance
managing symptoms
time
exhaustion
slot timing
ability to maintain employment
involvement in social activities
maintaining home reponsibilites
time taken for treatment
travelling
need for expertise
transport
waiting
duration of journey
work of HHD
organising supplies
setting up/cleaning up
getting on and off
Staff expertise in needling
being allowed into the dx unit get get set up
adequate staffing
Staff shift timings
reducing treatment time
managing uncertainty
waiting to get on dx
transport [punctuality]
access to HHD team
end of life care planning
remaining well
Avoiding admission
communication between satellite unit and parent unit
communication between staff
good communication between departments
Expertise of staff
reliable dialysis machines
pro-cative care and monitoring
avoiding access complications
Life expectancy
flexibility
communication from unit
HHD
slots
managing dietary restrictions
easier on HHD
requires communication and support from HCPs
need them to be realistic
access to HCPs on dialysis