

Perspectives on peritoneal dialysis at home: an ethnographic study

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Study Summary

Background

Peritoneal dialysis is a daily, life-saving treatment for end-stage renal disease, performed at home by patients and their relatives. Increasing numbers of patients are requiring treatment for this disease and therefore clinicians are calling for more patients to use peritoneal dialysis. However, the literature revealed only a small number of qualitative studies that considered patients' experiences of their treatment, while a dearth of studies that explored relatives' perspectives was noted.

Aim and research questions

The study aimed to explore the experiences of patients and their families living with peritoneal dialysis. The specific research questions were:

- What influences patients' decisions to choose peritoneal dialysis?
- How does peritoneal dialysis impact on life and the home environment?
- How is peritoneal dialysis managed at home and integrated into everyday life?
- How do families perceive having a relative with peritoneal dialysis at home and what contribution do they make to the process?

Methodology and methods

The study employed ethnographic methodology and the methods included in-depth interviews and ethnographic observations with sixteen patients using peritoneal dialysis at home in Wales, and their relatives. Additionally seven specialist nephrology healthcare professionals were interviewed, who provided contextualising information about the care they give to patients and their families. The data were analysed thematically using Wolcott's (1994) approach of description, analysis and interpretation.

Findings

The sociological theory of illness trajectories was adopted as a conceptual framework, which guided the analysis and presentation of study findings. Participants reflected on the difficult process of choosing peritoneal dialysis, which was influenced by a preference for home, aversion to hospital and hope for control. The challenges of living with the treatment were described and observed, including medicalisation of the home, while participants tried to minimise their disrupted lives through creativity and flexibility. The future was associated with fear and uncertainty about deterioration, although participants maintained hope that they might receive a kidney transplant.

Conclusions

Through the use of ethnography, this study revealed the challenges of living with peritoneal dialysis, but also the ability of families to integrate the treatment into everyday life. The study also demonstrated the usefulness of ethnographic methodology to explore how patients and their families live with home medical treatments.

DECLARATION

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.



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Chapter One: Introduction and Thesis Overview

1.1 Introduction

End-stage renal disease is a life-limiting condition that is fatal if not treated with a renal replacement therapy. Its prevalence is rising throughout the world and subsequently increasing numbers of patients are requiring life-sustaining treatment. Peritoneal dialysis, which is performed daily in the home by patients or their relatives, is one such treatment. This thesis will, from a nursing position, consider the perspectives and experiences of both patients and relatives using peritoneal dialysis. This first chapter will begin by considering my personal motivations for undertaking this research, before outlining the aim and objectives of this thesis and highlighting the original contribution to knowledge that this thesis makes. An overview of the thesis is then provided.

1.2 Motivation for the study

The genesis of this study came from my personal and clinical experience in nephrology. I became interested in renal nursing after caring for my grandfather who died of end-stage renal disease (treated conservatively) when I was a student nurse. I later requested the nephrology and transplant unit for my final three month placement and found the speciality fascinating and enjoyable, but also extremely challenging. The stories of patients undertaking the various renal replacement therapies were both moving and courageous, balancing their lives and families with a dependence on technology to sustain their lives. I felt particularly drawn to peritoneal dialysis, and quickly learned the technique required for performing the treatment. When I qualified as a staff nurse I worked on the nephrology (dialysis) unit, in the high care unit and finally the transplant unit, and spent some time with the peritoneal dialysis specialist nurses visiting patients at home. During this period, my interest in the experiences of patients using peritoneal dialysis and their families increased, and I began to formulate an idea for a qualitative piece of research involving these families, to better understand how they lived with this treatment.

1.3 Aim and research questions

The aim of this research was to explore the experience of home peritoneal dialysis from the perspectives of patients, their families and healthcare professionals in the UK. The specific research questions were:

- What influences patients' decisions to choose peritoneal dialysis?
- How does peritoneal dialysis impact on life and the home environment?
- How is peritoneal dialysis managed at home?
- How is peritoneal dialysis integrated into everyday life?
- How do families perceive having a relative at home and what contribution do they make to the process?

1.4 Original contribution to knowledge: the culture of patients and families using peritoneal dialysis at home

To meet the aim and research objectives, an ethnographic approach was employed to explore the shared culture of individuals and their families living with peritoneal dialysis in their homes. Culture is defined by Lederach (1995) as “the shared knowledge and schemes created and used by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them” (p.9) and previous healthcare research has considered the culture of a specific clinical area, for example a medical assessment unit (Griffiths 2010). Although the participants in this study did not know each other and demonstrated that they adopted varying approaches to managing peritoneal dialysis in their homes, there was an identifiable shared culture between these families. Managing peritoneal dialysis involved the introduction and accommodation of vast amounts of medical equipment within the home, the acquisition and development of complex clinical skills, the establishment of routines and teamwork, and the ability to identify and manage crises (described in chapter six). Living with end-stage renal disease and this treatment also meant that individuals were aware of the (limited) options for their future: haemodialysis, transplantation or deterioration and death; which represented uncertainty and a lack of control (explored in chapter seven).

Exploring the shared culture of these individuals led to the identification of overarching themes, representing an original contribution to knowledge:

- Making the “right” decision: this thesis draws on the chronic illness literature and considers the theory of biographical disruption (Bury 1982) resulting from the diagnosis of a long-term disease, it is important to recognise that for many individuals in this study their lives had already been affected by other long-term diseases. Once patients had chosen peritoneal dialysis, they were fearful about starting treatment and failed to understand the treatment until they actually started using it. This is explored in chapter five.

- Liberation or constraint: patients hoped that peritoneal dialysis would offer them a flexible treatment that they could control, but the treatment impacted on their lives in a variety of ways, which is discussed in chapter six. This thesis explored the medicalisation of the home, due to the dominance and prominence of peritoneal dialysis equipment, and the complexity of managing peritoneal dialysis often in addition to other morbidities, which was exhausting for both patients and relatives.
- Cruel uncertainty: peritonitis (infection of the peritoneum) was a source of fear and uncertainty for patients and relatives, who strove constantly to prevent it. Episodes of peritonitis were associated with pain, confusion and guilt, but importantly the study highlighted that participants were often unfamiliar with the signs of infection that they should be observing, which is highlighted in chapter six. Additionally, the future was a source of great uncertainty, as presented in chapter seven.
- Freedom from peritoneal dialysis: to integrate the treatment into everyday life relatives were supportive of patients altering the timings or location of the treatment, and being creative with equipment to make the treatment less onerous. Participants' inventions made their lives much easier and they were proud of their creativity and integration. However, people who did not integrate the treatment generally found it more restrictive. This is also described in chapter six.

1.5 Thesis overview

This thesis will be organised into a further eight chapters. Chapter two firstly provides an overview of end-stage renal disease from an international, UK and Welsh perspective. The treatments, peritoneal dialysis, haemodialysis and renal transplantation, are introduced from both an historical and current practice perspective. Finally, the chapter presents an important contextualising debate concerning peritoneal dialysis: the international emphasis on promoting the use of peritoneal dialysis (which has been dwindling in recent years) in order to cope with the increasing numbers of patients requiring treatment for end-stage renal disease.

The next chapter (three) presents the literature searching strategy and then the literature is examined: the qualitative studies that explore how patients and their families experience dialysis, followed by the quantitative studies that consider quality of life and depression. The wider chronic illness sociological literature that provides

further context for this study is then discussed and the conceptual framework (chronic illness trajectories) is introduced.

Chapter four then presents the ethnographic methodology chosen for this study and the methods – interviews, observations and thematic data analysis - utilised to meet the study objectives. The participants who took part will also be introduced. Finally, the ethical issues will be discussed, including informed consent, confidentiality and public involvement in research.

Chapter five then presents the first of three findings chapters, considering participants' experiences of the pre-dialysis phase, in which they were diagnosed with end-stage renal disease, chose peritoneal dialysis and were then trained to use the technology in their homes.

The next findings chapter (six) considers the transformed lives of patients and their families living with peritoneal dialysis, including the medicalisation of the home, challenges of living with the treatment and the ways in which participants integrated the treatment into everyday life.

The final findings chapter (seven) describes participants' hopes and expectations for the future, which encompassed fear, uncertainty and loss of control, hope and comparison to others.

The discussion in chapter eight then places the findings from this thesis in context by considering the wider renal literature, home medical technologies literature, sociological theory, clinical guidelines and government health policies. Finally, the study itself and conceptual framework are critiqued. Chapter nine then concludes this thesis and presents the recommendations for clinical practice and future research.

To make the thesis easier to follow, the following levels of headings will be used throughout:

Chapter Heading

1.1 Section Heading

1.1.1 Sub-heading

Lower heading

With text underneath

Lowest heading With text by the side

1.6 Chapter conclusions

This introductory chapter has provided a broad overview of the genesis of this thesis and has specified the aim and objectives. This chapter has referred to end-stage renal disease and peritoneal dialysis and the next chapter will therefore explore and explain these clinical concepts.

Chapter Two: End-Stage Renal Disease and Peritoneal Dialysis

2.1 Introduction

This chapter will provide the context for this research project by presenting an overview of end-stage renal disease and the various treatments available. The first section will consider the role of the kidneys, what causes renal disease, the number of patients with the condition and the impact on the individual. The second section will then offer an historical overview and current practice perspective of each of the treatments for renal disease: peritoneal dialysis, haemodialysis and kidney transplantation. The final section will consider the utilisation of peritoneal dialysis internationally and the growing focus on this treatment by clinicians and researchers.

2.2 Overview of end-stage renal disease

This first section will discuss the functions of the kidneys and the definition, aetiology, prevalence, epidemiology and impact of end-stage renal disease. This is important contextualising information for this thesis to enable understanding of the devastating and broad impact of end-stage renal disease on the individual.

2.2.1 Role of the kidneys and definition of end-stage renal disease

The kidneys have multiple vital functions that contribute to the body maintaining equilibrium. These roles include water balance (preserving the environment within the cells, the volume of fluid outside of the cells and blood pressure), solute balance (preserving the concentrations of solutes within and outside of the cells) and excretion of metabolic end-products (removing toxins and therefore maintaining the internal environment within the body) (Fanning 2003). Furthermore, the kidneys are responsible for producing erythropoietin (to maintain the red blood cell count and therefore prevent anaemia), maintaining acid-base balance (excreting acids that cannot be removed by the lungs) and also balancing calcium and phosphate in the skeleton and extracellular environment (Fanning 2003). Loss of normal renal function results in the inability to maintain fluid, electrolyte and acid-base homeostasis – all of which affect the individual's physical and thus psychological health, affecting everyday function.

Kidney disease has been recognised for thousands of years, with treatments in Roman times including hot baths, enemas and sweating therapies (Fresenius Medical Care 2004). Despite this long history, and the introduction of effective renal replacement therapies in the mid-twentieth century, it was not until 2000 that the National Kidney Foundation in the United States of America (USA) sought to identify a generic definition of the disease (National Kidney Foundation 2002). Chronic kidney disease is classified from stage 1 to stage 5 and is defined as:

1. Kidney damage for ≥ 3 months, as defined by structural or functional abnormalities of the kidney, with or without decreased GFR*, manifest by *either*:
 - Pathological abnormalities; or
 - Markers of kidney damage, including abnormalities in the composition of the blood or urine, or abnormalities in imaging tests
 2. GFR $< 60 \text{ mL/min/1.73m}^2$ for ≥ 3 months, with or without kidney damage
- *Glomerular filtration rate*

(National Kidney Foundation 2002, p.3)

Glomerular filtration rate refers to the volume of filtrate (urine being formed by the kidneys) that is formed each minute, which in a healthy adult would be around 125ml (Porth 2004b), but reduces in patients with kidney disease. The estimated GFR (eGFR) is calculated by the patient's serum creatinine, age and gender, and the result is adjusted if the individual is African-Caribbean (Hurst and Thomas 2008). The patient is then defined as being in one of five stages of chronic kidney disease:

- stage 1: eGFR greater than 90 ml/min
- stage 2: 60 – 89 ml/min
- stage 3: 30 – 59 ml/min
- stage 4: 15 – 29 ml/min
- stage 5: eGFR less than 15 ml/min (National Kidney Foundation 2002)

Recognising the different stages of kidney failure is important in terms of preparing patients for the initiation of renal replacement therapy. If the individual is diagnosed as being in the fourth stage of chronic kidney disease, they can then be referred to nephrology services and planning for established renal care and renal replacement therapy can begin (Hurst and Thomas 2008), including either having a fistula formed (for haemodialysis), or insertion of a Tenckhoff catheter (for peritoneal dialysis), and/or activation on the renal transplant register. When an individual's renal function declines to stage five (end-stage renal disease), renal replacement therapy (haemodialysis, peritoneal dialysis and renal transplantation, discussed later in the chapter), or palliative care is initiated.

Within the renal literature there are multiple terms used to describe kidney disease. For the purposes of this thesis, 'chronic kidney disease' is used when the person has

not commenced renal replacement therapy and has a GFR of >15ml/min. 'End-stage renal disease' is used when the person has a GFR of <15ml/min and/or has started a renal replacement therapy.

2.2.2 Aetiology of end-stage renal disease

End-stage renal disease can be caused by any condition that disrupts the normal structure and function of the kidneys. The United Kingdom (UK) Renal Registry systematically collects data from the 71 adult renal centres in the UK and reports to the European Dialysis and Transplant Association (EDTA). The UK Renal Registry collates information about the causes of end-stage renal disease for patients established on renal replacement therapies and for patients new to treatment. This is significant as the data demonstrates that over time the main causes of end-stage renal disease are changing.

Patients established on renal replacement therapies

The most recent UK Renal Registry report presents data about patients using renal replacement therapies in 2011 (Shaw et al. 2012). The report does not provide information about the causes of end-stage renal disease for patients established on treatment by home nation, but instead distinguishes between patients over and under 65 years old. Overall, glomerulonephritis (an autoimmune disorder where the glomeruli, which filter waste in the kidney, are damaged) was the most common cause of end-stage renal disease across all ages. For individuals over under 65 years old, glomerulonephritis was the most common cause of end-stage renal disease, while uncertain aetiology was most common in people over 65 years. The Renal Registry cite concern at the number of patients without a certain diagnosis, querying whether computer software defaults to unknown aetiology, or whether a number of these patients could be identified with a more objective diagnosis including renal vascular disease and glomerulonephritis (Shaw et al. 2012). However, it is interesting to note that diabetes, hypertension and renal vascular disease (all long-term diseases) are more common causes of end-stage renal disease in patients over 65 years old. End-stage renal disease for patients under 65 is more likely to be caused by autoimmune or genetic disorders such as glomerulonephritis (biopsy proven), polycystic kidney disease and pyelonephritis (urinary tract infection that reaches the kidney). The table below depicts these causes of end-stage renal disease for patients established on renal replacement therapies in the UK.

Primary Aetiology	<65	>65	All patients
Uncertain aetiology	15.2	22.3	17.7
Diabetes	14.3	17.0	15.2
Glomerulonephritis*	21.8	14.0	19.0
Hypertension	5.0	7.2	5.8
Other	17.2	12.2	15.5
Polycystic kidney disease	10.0	8.9	9.7
Pyelonephritis	13.3	8.0	11.5
Renal vascular disease	1.1	7.6	3.4
Not sent	2.5	2.5	2.5

*Including glomerulonephritis not biopsy proven

Table 1: Aetiology of end-stage renal disease in the UK, by percentage (Shaw et al. 2012)

However, the aetiology of end-stage renal disease differs for patients newly started on renal replacement therapies.

Patients newly started on renal replacement therapies

Around one quarter of patients in all four countries in the UK starting treatment for end-stage renal disease have their illnesses attributed to diabetes mellitus: the leading cause of end-stage renal disease (Gilg et al. 2012). Wales and Northern Ireland have the highest percentage of patients whose kidney disease stemmed from this cause. This highlights the serious implications of diabetes, particularly when the incidence is expected to continue increasing (Diabetes UK 2010). The table below depicts the primary aetiologies of patients newly started on renal replacement therapies by home nation in the UK.

Primary Aetiology	UK	England	N. Ireland	Scotland	Wales
Uncertain aetiology	17.3	17.6	13.8	14.4	19.3
Diabetes	24.8	24.7	23.2	24.5	28.2
Glomerulonephritis*	13.3	12.7	12.8	17.4	16.9
Hypertension	7.0	7.6	4.4	5.3	3.3
Other	16.3	17.3	16.3	10.1	11.9
Polycystic kidney disease	7.2	7.2	7.4	9.1	4.5
Pyelonephritis	7.1	7.0	10.8	7.7	5.6
Renal vascular disease	6.9	6.0	11.3	11.4	10.4

Table 2: Aetiology of end-stage renal disease in the UK by country, percentages (Gilg et al. 2012)

This discussion of the causes of kidney disease has highlighted the long-term diseases, such as diabetes and hypertension, which lead patients towards renal replacement therapies. This is also pertinent when considering the numbers of patients with chronic and end-stage renal disease.

2.2.3 Challenges in quantifying the prevalence of renal disease

It is important to recognise the number of patients with the condition, but there is a lack of consensus about the prevalence of both chronic kidney disease and end-stage renal disease.

Prevalence of chronic kidney disease

Atkins (2005) warns that chronic kidney disease will continue to increase due to the epidemic of diabetes and hypertension, in both developed and developing countries. Chronic kidney disease has further been recognised as a significant international public health problem (Zhang and Rothenbacher 2008), yet it can be difficult to estimate the number of patients with the disease as patients do not often become symptomatic until they are in fourth stage with drastically reduced kidney function (Department of Health 2005). It is then difficult to prevent the disease progressing further (Zhang and Rothenbacher 2008). Zhang and Rothenbacher (2008) undertook a systematic review to establish the prevalence of chronic kidney disease; however the 26 studies that met the inclusion criteria were conducted in the USA, Mexico, Canada, Europe, Australia, China, Japan, Thailand and Singapore. Therefore, much of the developing world, such as sub-Saharan Africa and large parts of Asia, were excluded. The authors found that the prevalence of chronic kidney disease varied considerably according to how chronic kidney disease was measured and to other epidemiological factors, such as age, ethnicity and gender.

Within the UK, a longitudinal study of chronic kidney disease (John et al. 2004) concluded that the prevalence was 5,554 per million population. However, this study is now dated, included only women, and used only one method (serum creatinine) to identify chronic kidney disease. The Welsh Assembly Government (2007) estimated that 10,000 people in Wales had chronic kidney disease, and this number is continuing to rise with a 4.4% increase in prevalence between 2007-2008 (Tomson 2009).

Although estimating the numbers of patients with chronic kidney disease can be problematic, researchers and clinicians agree that the prevalence of the disease is

likely to increase with an aging population and epidemics of other long-term diseases.

Prevalence of end-stage renal disease

The Department of Health (2004) suggest that establishing the number of individuals with end-stage renal disease can also be difficult as not all adults in need of renal replacement therapy are identified. Additionally, Schieppati and Remuzzi (2005) criticise the variation in the quality of the data collected by the different national renal registries about patients using renal replacement therapies.

However, one of the dialysis medical companies, Fresenius Medical Care, monitors the total number of patients treated with dialysis worldwide. Fresenius Medical Care (2011) reported that in 2010 2.776 million patients used renal replacement therapies; an average prevalence of 400 per million population in 2010. Taiwan had the highest prevalence of end stage renal disease at 2,850 per million population, while for Japan this was 2,520 per million population, USA 1,950 per million population and 1,050 per million population in Europe (Fresenius Medical Care 2011). The prevalence of patients in the UK receiving treatment for end-stage renal disease was 842 per million population in 2011 (Cullen and Fogarty 2012), representing a 3% increase from the year before. Much of the variation in treatment numbers is attributable to the cost of renal replacement therapies (Atkins 2005), hence the relatively low average prevalence reported by Fresenius. Scheippati and Remuzzi (2005) reported that in developing countries a “sizeable proportion” (p.S9) of patients receive no treatment and die of uraemia.

There are thus substantial numbers of individuals affected by this progressive, limiting disease. The next section will thus present the epidemiology of end-stage renal disease in the UK, which is pertinent to this thesis.

Epidemiology of end-stage renal disease in the UK

This section will consider which groups of people are most affected by end-stage renal disease and renal replacement therapies in the UK, in terms of age, gender and ethnicity.

Age: The median age of an individual with end-stage renal disease in the UK is 58 years, with variations between renal replacement therapies: in patients undertaking peritoneal dialysis the median age is 63 years, patients undertaking haemodialysis 67 years and renal transplant patients a median of 52 years (Shaw et al. 2012).

Interestingly, Wales (17.2%) and Northern Ireland (16.9%) have a significantly higher percentage of patients over 75 years (Shaw et al. 2012) compared to England (15.6%) and Scotland (13.6%), which potentially has implications for the health of the patients in these countries, due to the likelihood of accompanying co-morbidities. Overall in the UK, patients under 65 were more likely to have a renal transplant (62.7%), with patients over 65 much more likely to undertake dialysis (75%) (Shaw et al. 2012). The median age of an incident adult patient (new to renal replacement therapy) in the UK was 64.9 (Gilg et al. 2012).

Gender: In the UK during 2010, 6,678 new adult patients were started on renal replacement therapies, of whom 63% were men and 37% were women (Gilg et al. 2012). Of individuals established on treatment, there are consistently more men than women undertaking renal replacement therapies in all age groups (Shaw et al. 2012).

Ethnicity: The statistics on ethnicity reported to the Renal Registry were incomplete in 2011, with only 71.8% of centres providing data. In the UK as a whole, 20.6% of patients undertaking renal replacement therapy were from a minority ethnic background, which is a high figure considering the ethnic minority population accounts for 12% of total UK population (Shaw et al. 2012). The actual percentage varied across the UK, being 22.6% in England and less in the other three countries (Shaw et al. 2012). This high percentage of individuals from minority ethnic groups with end-stage renal disease is significant for healthcare professionals, particularly in terms of health promotion and education.

Significant numbers of patients therefore suffer with end-stage renal disease throughout the world, as well as in the UK and Wales. The next section will consider the physiological impact of end-stage renal disease on these individuals.

2.2.4 Physiological impact of end-stage renal disease

End-stage renal disease affects many systems within the body and the subsequent symptoms are thus diverse, affecting an individual's ability to function in everyday life, as well as affecting their wider families. Individuals with end-stage renal disease

often have multiple morbidities due to the broad impact of the condition, which means that they may experience multiple symptoms and need to manage several diseases.

The clinical effects on different systems within the body and the subsequent effects on the patient are described in the table below.

Cardiovascular effects	<ul style="list-style-type: none"> • The most important determinant of survival on dialysis – due to effects of end-stage renal disease and dialysis treatment; • Chronic fluid overload in end-stage renal disease causes hypertension, left ventricular hypertrophy and left ventricular dilation (compounded by anaemia); • Disordered metabolism of carbohydrates and lipids contributes to atherosclerosis; • Haemodialysis can worsen myocardial blood flow, especially if the patient is anaemic.
Respiratory effects	<ul style="list-style-type: none"> • Pulmonary oedema following fluid overload, leading to breathlessness; • Respiratory compensation for metabolic acidosis (due to poor acid base balance).
Renal anaemia	<ul style="list-style-type: none"> • Less erythropoietin is produced, causing anaemia (leading to tiredness and breathlessness).
Immune system alterations	<ul style="list-style-type: none"> • Functional abnormality and delayed hypersensitivity in white blood cells; • Immunosuppressive drug therapy for patients with a kidney transplant; • Malnutrition; • Leading to increased risk of infection and difficulty fighting infection.
Nutritional effects	<ul style="list-style-type: none"> • Nausea and anorexia, caused by uraemia; • Alterations in gastric motility and gastric bleeding can occur; • Haemodialysis removes amino acids; • Peritoneal dialysis leads to albumin loss with each exchange.
Reproductive effects	<ul style="list-style-type: none"> • Men: altered sperm production and motility, erectile dysfunction; • Women: altered menstruation, including amenorrhoea, difficulty in conceiving and carrying a pregnancy to term. Immunosuppression can lead to complications during pregnancy for women with a renal transplant.

Electrolyte, acid-base and fluid imbalance	<ul style="list-style-type: none"> • Altered calcium and phosphate – leading to osteodystrophy; • Hyperkalaemia – urgent medical attention needed due to risk of cardiac arrest; • Metabolic acidosis.
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Table 3: Clinical impact of end-stage renal disease (adapted from Fanning, 2003)

The clinical effects of end-stage renal disease and renal replacement therapies are thus severe, contributing towards morbidity and mortality. The individual's psychological health is also affected, with an increased incidence of depression in this population (Levenson and Glocheski 1991) and altered body image due to oedema, anorexia and reproductive dysfunction. The literature review in chapter three considers the psychological implications of end-stage renal disease in additional detail, in terms of quality of life, depression, body image and coping.

This section has therefore provided a concise overview of how chronic kidney disease and end-stage renal disease are defined, the causes of it, how many people are affected and the impact of the disease. Without treatment for end-stage renal disease the illness is fatal and therefore starting a renal replacement therapy – a treatment, not a cure - is the only way to preserve life. This section has previously mentioned the three renal replacement therapies and these are discussed in more detail next.

2.3 Treatment options for end-stage renal disease

When an individual develops end-stage renal disease there are two options: conservative management with palliative care, or renal replacement therapy in the form of peritoneal dialysis (PD), haemodialysis (HD) or renal transplantation. Each of these three therapies has benefits and disadvantages, and the patient's preference is highly individual. It is also important to consider that patients are usually required to use dialysis while waiting for a kidney transplant. In 2010, only 6.6% of patients in the UK had a pre-emptive kidney transplant and therefore were not required to use dialysis (Gilg et al. 2012), while adult patients wait for a median time of 1,168 days (over three years) for a kidney transplant (NHS Blood and Transplant 2012b). Therefore, while government policy, healthcare professionals and researchers refer to the three renal replacement therapies, patients are not automatically able to have an instantaneous kidney transplant operation and often face a long wait while using

peritoneal or haemodialysis. Substantial consideration is given to renal replacement therapies and their impact on the individual in the literature review (chapter three).

This section will firstly outline the number of patients using each treatment, before describing how each treatment developed and works. Appendix One features pictures of each of the renal replacement therapies for information.

2.3.1 Utilisation of renal replacement therapies

Internationally in 2011, 1.921 million patients received haemodialysis and 237,000 used peritoneal dialysis, while 618,000 lived with a functioning renal transplant (Fresenius Medical Care 2011). Renal registries, mainly in developed countries, monitor the number of patients using different renal replacement therapies. The United States Renal Data System (2012) reported that in 2010, a total of 579,756 patients received renal replacement therapies: 376,352 used haemodialysis, 29,267 used peritoneal dialysis (5%) and 174,136 had a functioning kidney transplant. In Australia in 2009, 10,341 patients received dialysis (21% peritoneal dialysis) and 7,902 patients had a functioning kidney transplant (Australia and New Zealand Dialysis and Transplant Registry 2010). Schieppati and Remuzzi (2005) reported that 80% of patients receiving dialysis lived in Japan, Europe or North America, which the authors partly attributed to the varying numbers of patients developing end-stage renal disease, but also to the economic ability of countries to fund dialysis programmes. White et al. (2008) highlight substantial international inequality in the number of patients receiving kidney transplants, with transplants fewer in low and middle income countries due to lack of infrastructure and inability to afford post-operative, long-term immunosuppressant medications.

In 2011, 6,835 adults started treatment for end-stage renal disease: 363 in Wales, 5,774 in England, 495 in Scotland and 203 in Northern Ireland (Gilg et al. 2012). In total in the UK, 53,207 patients used renal replacement therapies in 2011 (Shaw et al. 2012), with significantly fewer patients using peritoneal dialysis than other treatments. The number of patients in the UK using renal replacement therapies is displayed in the table below, with 43.4% of patients undertaking haemodialysis, 7.2% using peritoneal dialysis, and 49.4% with functioning renal transplants. Therefore, in the UK almost half of those with end-stage renal disease have a kidney transplant, compared with the international percentage of 22.3% (Fresenius Medical Care 2011).

While the number of patients using peritoneal dialysis in Wales is small (n=221), this represents 8.2% of the population of patients with end-stage renal disease, compared to 5.2% in Northern Ireland, 7.4% in England and 5.8% in Scotland. Therefore, proportionally, Wales has a larger population of patients using peritoneal dialysis although it remains the lesser used renal replacement therapy, mirroring international figures.

	Peritoneal dialysis	Haemodialysis	Transplant	Total renal replacement therapy
UK	3,831	23,079	26,297	53,207
England	3,283	19,371	22,011	44,665
N. Ireland	78	725	707	1,510
Scotland	249	1,878	2,197	4,324
Wales	221	1,105	1,382	2,708

Table 4: Number of patients undertaking each renal replacement therapy in the UK (Shaw et al. 2012)

A brief history and physiological description of each of the renal replacement therapies is outlined below.

2.3.2 Peritoneal dialysis

Peritoneal dialysis involves cleansing the blood of toxins inside the body, using the body's natural membrane – the peritoneum. A catheter (Tenckhoff) is permanently inserted through the abdominal wall into the peritoneal cavity, where fluid is introduced to remove toxins. However, peritoneal dialysis is contraindicated in patients with abdominal scars, hernia, morbid obesity, inflammatory bowel disease, ileo/colostomy, diverticulitis, ascites, aneurysms or large polycystic kidneys (Oliver and Quinn 2008).

History of peritoneal dialysis

The concept behind peritoneal dialysis was identified by researchers in the late nineteenth and early twentieth century (Palmer 1982). Georg Ganter, a physician working in Germany, first used the peritoneum to treat a woman who was suffering from uraemia (toxins that accumulate in the blood when the kidneys are not functioning as normal), infusing a salt solution into her peritoneal cavity (Fresenius Medical Care 2005). While the procedure improved the patient's symptoms for a

short time, she later died (Fresenius Medical Care 2005). Peritoneal dialysis was then used on a small number of patients in the early and mid-20th century, but was hindered by lack of peritoneal access. Each dialysis session required a new puncture into the peritoneal membrane, making long-term treatment untenable (Fresenius Medical Care 2005). The permanent Tenckhoff catheter (Tenckhoff and Schechter 1968), pioneered by a physician, made the treatment viable, and limited numbers of patients were treated with peritoneal dialysis during the 1960s and 1970s (Thomas 2008).

In 1979 the first Continuous Ambulatory Peritoneal Dialysis (CAPD) system became available, with sterile PVC bags and varying strengths of dialysis solution, and overnight Automated Peritoneal Dialysis (APD) was established in the 1980s, allowing patients freedom from dialysis during the day (Thomas 2008). Geiser et al. (1983/4) evaluated the success of their first peritoneal dialysis programme and declared it the “optimal mode of treatment” (p.302), but acknowledged some limitations including the negative impact on body image. Modern equivalents of the two systems are available today, with individual CAPD exchanges carried out four to six times per day, taking up to 45 minutes per bag, and APD taking place for around nine hours per night with the patient connected to a machine next to the bedside.

How peritoneal dialysis works

The peritoneal membrane is a thin permeable layer of tissue with several blood vessels, and consists of two layers: the parietal layer which lines the inner surface of the abdominal wall, and the visceral layer which covers the abdominal organs (Kelley 2004). The space in between these two layers is the peritoneal cavity, and while it does not usually contain fluid it can accommodate up to five litres (Redmond and Doherty 2005), although between 1.5 and three litres of dialysis solution (dialysate) is infused in peritoneal dialysis.

The peritoneum permits waste to filter from the blood through the membrane into the dialysis solution in the peritoneal cavity, thus cleansing the blood of toxins (Kelley 2004). The cycle of peritoneal dialysis involves the infusion of the warm dialysate solution into the peritoneal cavity via the Tenckhoff catheter, allowing the solution to dwell in the cavity while the dialysis process occurs, and finally draining the dialysate solution (containing the waste products and excess water from the blood) out through the Tenckhoff catheter into a waste bag.

Three processes within the peritoneal cavity remove excess fluid and waste from the blood supply: osmosis, diffusion and convection. Osmosis involves the movement of water through a semi-permeable membrane from a solution of low concentration to a solution with a higher concentration (Porth 2004a). Dialysate contains glucose, an osmotic agent, and the higher the glucose concentration the stronger the osmotic effect (Wild 2008). Different strength dialysis solutions are thus available depending on how much ultrafiltration (water removal) is required for each patient. Diffusion is the natural movement of particles along a concentration gradient, from an area of high concentration to an area of low concentration (Porth 2004a). Thus the solutes usually removed by the kidneys (urea, creatinine, potassium, sodium) flow from the bloodstream into the dialysate solution, until equilibrium is attained (Wild 2008). Finally the process of convection occurs, whereby water and solutes are pulled across the peritoneal membrane at a faster rate than diffusion alone, allowing for the vast amount of ultrafiltration required for peritoneal dialysis (Wild 2008).

2.3.3 Haemodialysis

Haemodialysis occurs by cleansing the blood of toxins outside the body (Will and Johnson 1994), where solutes and water are removed from the blood using a semi-permeable membrane - the dialyser or “kidney” (Challinor 2008). Venous access is required in the form of a catheter in the neck (either in the jugular or subclavian veins) or groin (femoral vein), or a fistula (where an artery and vein are joined together, usually in the forearm, increasing the blood flow and pressure, thus causing the vessel to thicken and enlarge).

History of haemodialysis

Haemodialysis is a technique that developed in the early 20th century in Europe and the USA. The first published description of the treatment was in 1913 when two researchers removed the blood from animals and cleansed it on an external membrane, and the procedure was later tested on humans in 1924 in Germany without success (Fresenius Medical Care 2004). Finally, it was used successfully by Willem Kolff in the Netherlands in 1945 to treat a patient suffering from acute kidney failure (Fresenius Medical Care 2004). While the treatment became more widely used in the 1940s, particularly for patients with acute renal failure requiring short-term dialysis (Thomas 2008), it was not until the 1950s that haemodialysis machines became commercially available and use of the treatment grew. Like peritoneal dialysis, it was hindered by lack of permanent vascular access, until a shunt was invented in 1960 and later a fistula in 1966 (Fresenius Medical Care 2004). Initially

home haemodialysis was widely accepted in the USA and UK, to relieve pressure on hospital services, but became less popular with the introduction of peritoneal dialysis in the late 1970s. Long-term dialysis using this method was problematic due to vascular access, but became possible with the development of the radial artery-to-cephalic vein fistula in 1966 (Thomas 2008). Haemodialysis today takes place on average three times a week for four hours, through a fistula or permanent jugular (or occasionally femoral) catheter, with some areas offering short, daily treatments.

The majority of patients dialyse in hospital or satellite centres, although a smaller percentage of individuals use home haemodialysis. In the UK as a whole in 2010, 2.9% of patients undertaking dialysis received home haemodialysis, while in Wales this percentage was 5.2% (Castledine et al. 2011) .

How haemodialysis works

Four principles are employed in haemodialysis: diffusion, convection, hydrostatic pressure and ultrafiltration (Challinor 2008). Diffusion is employed by passing dialysis solution (containing similar solutes to the blood but in normal concentrations) on the opposite side of the semi-permeable membrane to the blood (Challinor 2008), which will result in waste products in the blood (urea, creatinine) passing from the area of high concentration (blood) to an area of low concentration (dialysate). Convection is dependent on fluid moving across a dialyser, and it “drags” (Challinor 2008, p.183) solutes across the membrane, increasing the transfer of solutes in haemodialysis. When blood is forced through the dialyser it exerts positive pressure on the membrane, as the pressure on the opposite side of the membrane (filled with dialysate) is lower, and therefore solutes and water are forced from the area of high concentration to an area of low concentration. When fluid moves across the semi-permeable membrane, due to hydrostatic pressure, ultrafiltration occurs (Challinor 2008), thus enabling the excess fluid associated with end-stage renal disease to be removed.

2.3.4 Kidney transplantation

Renal transplantation involves implanting the kidney and ureter (tube connecting the kidney to the bladder), into the abdomen of the recipient (leaving the recipient's original kidneys in place). The transplanted kidney comes from either living donor, who is usually a relative (Trevitt 2008) or a deceased person. A smaller number of patients with type one diabetes with end-stage renal disease are also able to have a renal-pancreas transplant (again leaving the original organs intact).

Patients are required to take daily immunosuppression medications to prevent the body rejecting the transplanted organ. The average life of a grafted kidney in the UK varies according to the type of donor, although this has improved over time. NHS Blood and Transplant, who monitor transplant activity in the UK, distinguish between deceased donors that died in the Intensive Therapy Unit (heart-beating donors) and those who died in the Emergency Unit (non-heart beating donors). The table below demonstrates that average one year graft survival for patients who received a kidney from a living donor was the highest at 96%, while it was similar for heart beating and non-heart beating donors at 93% and 94% respectively (NHS Blood and Transplant 2012a). Ten year graft survival was similarly highest for patients who had received a living donor transplant at 80%, followed by heart beating donor (71%) and finally non-heart beating donor (60%) (NHS Blood and Transplant 2012a). The table below reports one, five and ten year graft survival for the three types of kidney transplant. After transplant failure patients would either register for another transplant and/or commence dialysis, or palliative care would be initiated.

	1 year survival	5 year survival	10 year survival
Heart beating donor	93% (transplanted 2004-2006)	85% (transplanted 2004-2006)	71% (transplanted 1998-2000)
Non-heart beating donor	94% (transplanted 2004-2006)	87% (transplanted 2004-2006)	60% (transplanted 1998-2000)
Living donor	96% (transplanted 2004-2006)	92% (transplanted 2004-2006)	80% (transplanted 1998-2000)

Table 5: Graft survival rates after kidney transplantation in the UK (NHS Blood and Transplant 2012a)

History of kidney transplantation

Renal hetero-transplantation was attempted in Europe in the early 20th century, using goat, sheep and primate kidneys, with no immunosuppression medications and little success (Thomas 2008). Immunosuppression was developed in the 1940s, where researchers realised that by weakening the immune system, rejection of the transplanted organ was reduced – and the first successful kidney transplant took place in 1954 (NHS Blood and Transplant 2009a). With the advancement of surgical

techniques and medical management the number of successful renal transplants has increased dramatically since its introduction, rising 50% since 2000 (NHS Blood and Transplant 2009b). The field of kidney transplantation continues to expand with the introduction of antibody incompatible kidney transplantations, enabling larger numbers of patients to receive living donor kidneys from individuals who are not compatible and would therefore not usually be a suitable donor (Beimler and Zeier 2007).

2.3.5 Cost of renal replacement therapies to the NHS

The total cost of health services for renal disease has been reported at 1.2% of the overall NHS budget in England (Kerr et al. 2012), with the number of patients requiring treatment for chronic and end-stage renal disease continuing to increase. However, the estimated cost of renal replacement therapy per patient per year varies between studies, possibly due to what authors include in the calculations.

A multi-centre study provided a detailed analysis of the cost of different types of dialysis in the UK, which reported that the average total cost per patient per annum was:

- CAPD: £15,570
- APD: £21,655
- hospital-based haemodialysis (a nurse-run unit with medical support as required): £35,023
- satellite-based haemodialysis (at an individual nurse-run unit separate from the hospital): £32,669
- home haemodialysis: £20,764 (Baboolal et al. 2008)

The figures show that CAPD was 56% cheaper than hospital-based haemodialysis, and APD was 38% cheaper (Baboolal et al. 2008), which is a significant difference. Hospital-based haemodialysis is the most expensive alternative, possibly due to additional staffing costs compared to satellite haemodialysis units.

However, a more recent estimate of the cost of dialysis treatments to the NHS in England per patient per year (Kerr et al. 2012) reported that haemodialysis costs £26,835 (including transport to dialysis), while peritoneal dialysis costs £20,078. The authors do not, however, report on any differences between CAPD and APD, nor home, hospital or satellite-unit haemodialysis. This is possibly why the two papers disagree on the overall cost of renal replacement therapies. In terms of kidney transplantation, over the first five years kidney transplantation costs £14,618 per year (Kerr et al. 2012), making it the cheapest renal replacement therapy.

At present within the UK the decision as to which renal replacement therapy to have is not cost driven; but is made on the basis of quality of life, patient choice and medical history. However, with the predicted continued increase in the numbers of patients using dialysis evident (Department of Health 2004, Welsh Assembly Government 2009), the comparative costs may become more important.

This chapter has thus far presented contextual information about end-stage renal disease and peritoneal dialysis to frame this thesis. However, a key debate exists about the disproportionate number of patients using haemodialysis compared to peritoneal dialysis. This is discussed next.

2.4 Underutilisation of peritoneal dialysis

An important consideration for this thesis is the international increase in the number of patients requiring treatment for end-stage renal disease and the parallel decrease in the number of patients using peritoneal dialysis. These trends have led researchers and clinicians to consider ways of increasing the utilisation of peritoneal dialysis. This section will thus discuss the international utilisation of peritoneal dialysis, the argument that the treatment should be used more widely and possible reasons why patients do not choose it.

2.4.1 Effectiveness of peritoneal dialysis

The clinical effectiveness of peritoneal dialysis has been long established, with dialysis adequacy and patient survival being equal to haemodialysis (Rodrigues 2009). Furthermore, some clinicians assert that peritoneal dialysis should be the first line renal replacement therapy, particularly in individuals with residual renal function (Wankowicz 2009). Wankowicz (2009) also highlights the use of peritoneal dialysis in other groups, including older patients (enabling dialysis at home), obese patients (due to increasing numbers of obese patients with end-stage renal disease) and patients with congestive heart failure (improved fluid control). Li et al. (2007) further assert the benefits of peritoneal dialysis as a first-line treatment compared to haemodialysis, due to better cardiovascular control, avoidance of using vascular sites, better physiologic balance, avoidance of large machines (used for haemodialysis) and preservation of residual renal function. Residual renal function is correlated with improved quality of life and reduced necessity for fluid and dietary restrictions (Lameire et al. 2000), thus maintaining this function is arguably important.

Baboolal et al.'s (2008) study also demonstrated the financial benefits of home dialysis, in particular CAPD, which was considerably cheaper than all other forms of dialysis. The impact of dialysis on the patient is also central, but is not discussed here as the literature review (chapter three) focuses in depth on this.

2.4.2 Comparative use of peritoneal and haemodialysis

Internationally, increasing numbers of patients are developing end-stage renal disease, with the incidence rising by 8% each year (Schieppati and Remuzzi 2005). In parts of Asia peritoneal dialysis is the most widely used renal replacement therapy (Mok et al. 2004, Luk 2002), and the treatment is being promoted there as the solution to meeting the increase in the number of patients requiring renal replacement therapy (Li et al. 2007). However, the utilisation of peritoneal dialysis has decreased in the UK (Shaw et al. 2012) and the USA (Rodrigues 2009). A Canadian study (Oliver et al. 2010) with patients starting dialysis found that 64% of the cohort was eligible for peritoneal dialysis, considerably higher than the percentage of patients who actually started the treatment.

2.4.3 Reasons for underutilisation

Lameire and Van Biesen (2010) suggest that the reasons for this decrease in peritoneal dialysis utilisation are medical and economic, as well as “dogmatic” (p.76) factors and Tesar (2010) concurs. The authors do not detail these “dogmatic” factors, but the implication is that individual physicians view the treatment less favourably and therefore do not promote its utilisation. However, Oliver and Quinn (2008) suggest that the decline in the use of the treatment could be due to patients with end-stage renal disease being older with increased co-morbidities, inadequate training of healthcare professionals and a ‘breakdown in the process of care’ (p.452). Oliver and Quinn (2008) argue that to increase the utilisation of peritoneal dialysis and to support patients to make informed choices regarding renal replacement therapy, a six step process is required:

1. identifying patients with chronic kidney disease who will require pre-dialysis care and referring them to a nephrologist;
2. adequate education for patients regarding dialysis modalities;
3. adequate education regarding peritoneal dialysis if chronic dialysis is started as a result of acute illness;
4. appropriate multidisciplinary assessment of patients beginning dialysis to identify barriers to peritoneal dialysis, for example medical, cognitive, psychological or social;
5. provide assistance to support patients using peritoneal dialysis, for example support from family;

6. “accurate and balanced information” (Oliver and Quinn 2008, p.454) to ensure patients choose the right modality for them.

The National Service Framework for renal disease in Wales (Welsh Assembly Government 2007) emphasises much of this six-stage process, asserting that patients and their relatives should be referred to the nephrology multidisciplinary team before they reach end-stage renal disease, receive support and education to enable them to make an informed decision about which therapy to start, and have access to both types of dialysis. Despite clinical guidelines and international research, it is evident that the majority of patients continue to use haemodialysis rather than peritoneal dialysis.

There is thus much international focus on the declining use of peritoneal dialysis, despite the increasing number of patients requiring renal replacement therapies. Lameire and Van Biesen (2010) argue that peritoneal dialysis should be more widely utilised, with training for researchers and increased education for patients and healthcare providers:

more attention should be paid to research and education on peritoneal dialysis by the academic and non-academic training centres (Lameire and Van Biesen 2010, p.81) (p.81)

Additionally, researchers have stressed the importance of peritoneal dialysis and the need for integrating it with other techniques (Ronco et al. 2009, Lameire et al. 2000). Peritoneal dialysis is on the international agenda and there is growing attention from researchers and clinicians on ways to promote the treatment being used more widely, as it is in some countries in the Asia. It is therefore important to consider how patients and their families live with and use the technology.

2.5 Chapter conclusions

End-stage renal disease is a progressive, life-limiting disease that is increasing internationally and in the UK. This chapter reported the common causes of the disease (glomerulonephritis and diabetes) and the number of patients using the three different renal replacement therapies. An overview of each renal replacement therapy considered how the treatments evolved and how they are used today. An important debate in the international literature was also addressed: the increase in the number of patients requiring treatment for end-stage renal disease and the parallel decrease in how many people use peritoneal dialysis. This chapter briefly considered the impact of the different renal replacement therapies on patients and the next chapter will consider this in more detail.

Chapter Three: Patients' and Families' Experiences of Peritoneal Dialysis - Exploration of the Literature

3.1 Introduction

This exploration of the literature considers the impact of peritoneal dialysis, from the perspectives of patients and members of their families. Initially, the searching strategy will be briefly presented, demonstrating that a systematic approach to searching was undertaken. Searching, sifting and reading the vast body of international literature related to this topic revealed a disparate field: large numbers of quantitative studies examining quality of life and depression and a small number of qualitative studies exploring patients' and families' experiences in depth. While the focus of this review is exploring how patients and their relatives live with peritoneal dialysis, the paucity of research specifically focussing on peritoneal dialysis leads this review to consider more broadly the impact of end-stage renal disease and renal replacement therapy. The final section, however, will consider the wider sociological literature focussing on chronic illness and the chronic illness trajectory that was explored more organically during the course of this study.

3.2 Literature searching strategy

A systematic approach to searching the literature was undertaken, as advised by a librarian, covering five databases that may include relevant literature (CINAHL, SCOPUS, MEDLINE, ASSIA and PsychINFO) and the reference lists of papers were hand searched. In order to include research articles consistently, inclusion criteria were employed for the selection process, these include:

- English-language articles;
- primary research;
- peer-reviewed journal;
- research involving adult patients;
- articles relating to patient/family experience, perception of treatment and quality of life.

To remain abreast of the current literature, British Library alerts were established with key search terms. The diagram below demonstrates the searching strategy, key words and Boolean operators. The full searching strategy is outlined in Appendix Two, reporting the databases searched, terms used, limitations applied and the number of hits generated.

However, as the study developed, early reading of the chronic illness sociological literature was supplemented with further searching and exploration. The search strategy for this literature is explained in more depth in section 3.6.

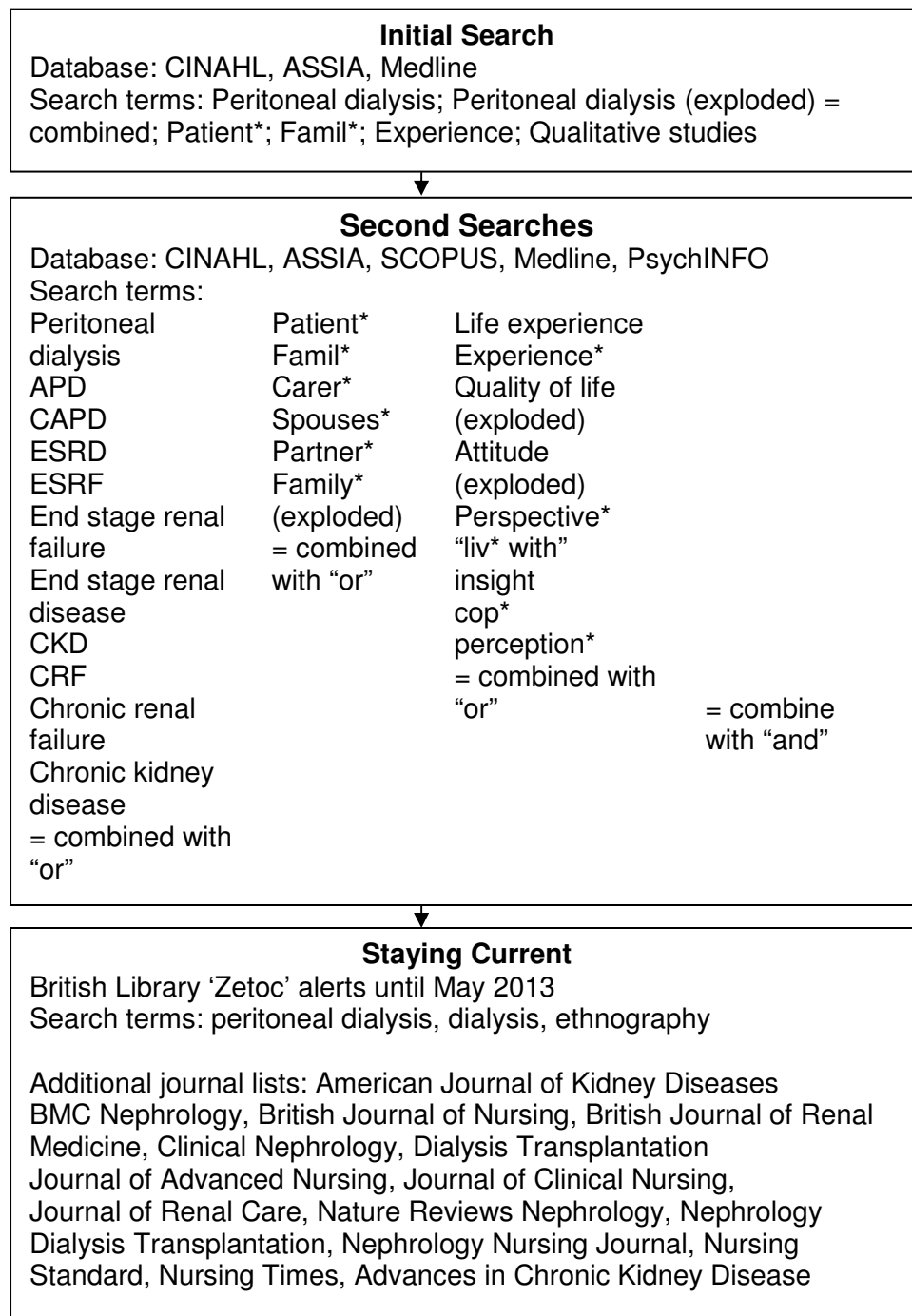


Figure 1: Literature searching strategy

This literature review will be presented in three sections, representing the varied literature: exploring the qualitative studies, quality of life and depression.

3.3 Qualitative studies exploring perspectives of peritoneal dialysis

This section will consider the small number of studies focussing on peritoneal dialysis, while looking to the wider renal literature to provide additional context to the review. The experiences of patients will initially be discussed, before the perspectives of the wider family are presented.

3.3.1 Patients

Only three qualitative studies focussed solely on participants using peritoneal dialysis, exploring adjustment (Wright and Kirby 1999), tiredness (Yngman-Uhlin et al. 2010) and self-management (Curtin et al. 2004). However, there are multiple qualitative studies that include a sample of patients with end-stage renal disease (including people using peritoneal dialysis) and consider the impact of end-stage renal disease on their lives. Before the findings of this qualitative synthesis are discussed, the studies are outlined below. The data extraction table in Appendix Three details the studies included in the synthesis, including aim, methodology, sample size and strategy, data generation and analysis methods, the main findings and any recommendations.

Introducing the studies

Only a small number of international institutions have undertaken and published qualitative research with patients using renal replacement therapies. The in-depth qualitative literature originated from four continents and seven different countries: the UK (Beer 1995, Hardiker et al. 1986, Wright and Kirby 1999), Sweden (Heiwe et al. 2003, Lindqvist et al. 2000, Yngman-Uhlin et al. 2010), Australia (Martin-McDonald 2003, Morton et al. 2010), USA (Clarkson and Robinson 2010, Curtin et al. 2004), Hong Kong (Mok et al. 2004) and New Zealand (Polaschek 2006, Polaschek 2007). Additionally, there is not a consistent country or institution undertaking qualitative research with patients using peritoneal dialysis: of the literature focussing solely on this treatment, one study was conducted in the UK (Wright and Kirby 1999), another in Sweden (Yngman-Uhlin et al. 2010) and the third in the USA (Curtin et al. 2004).

Of the 12 different studies included in this synthesis, six different qualitative approaches were employed: phenomenology (Polaschek 2006, Polaschek 2007, Yngman-Uhlin et al. 2010), exploratory-descriptive (Curtin et al. 2004, Lindqvist et al. 2000), phenomenography (Heiwe et al. 2003), narrative (Martin-McDonald 2003), naturalistic enquiry (Mok et al. 2004) and grounded theory (Hardiker et al. 1986, Wright and Kirby 1999). However, three of the studies (Beer 1995, Clarkson and

Robinson 2010, Morton et al. 2010) simply named their study design as “qualitative”, thus giving no detail of a specific methodology they employed. All the studies used semi or unstructured interviews, which, while an excellent source of data, excludes other qualitative data generation methods that could have offered further insight into patients’ experiences of the treatment.

A limitation of these qualitative studies is the numbers of participants using peritoneal dialysis, which are small in several studies. The number of participants using peritoneal dialysis varies dramatically, from four patients in Beer’s (1995) and Clarkson and Robinson’s (2010) studies, to 26 patients in Lindqvist et al.’s (2000) work. Morton et al. (2010) included a moderate sample of 13 patients using peritoneal dialysis, but included 60 patients undertaking haemodialysis, which is a substantial difference. Other studies did not identify how many participants undertook which dialysis modality (Hardiker et al. 1986, Mok et al. 2004), making it challenging to know whether a reasonable number of patients using peritoneal dialysis were included and their perspectives thus represented.

The literature was synthesised and three broad themes were identified: impact on life, coping and acceptance.

Impact on life

Both the symptoms of end-stage renal disease and the invasive treatment of dialysis have the potential to impact significantly on an individual’s life. The literature identified that body image was impaired by dialysis, patients felt fatigued and their reduced freedom led to feelings of anger and bitterness.

Body image Curtin et al. (2004) highlighted the negative impact of peritoneal dialysis on body image, due to the Tenckhoff abdominal catheter (access for the treatment). This exploratory-descriptive study, conducted in the USA, was one of three studies that only included participants using peritoneal dialysis (n=18), making it one of the core studies in this review (Curtin et al. 2004). An earlier study (Beer 1995) in the UK focussed on body image, with patients undertaking peritoneal dialysis (n=4), haemodialysis (n=4) or with a renal transplant (n=4), identifying similar themes. Patients using peritoneal dialysis were distressed by their enlarged abdomens (as a result of dialysis solution in the peritoneal cavity) and the Tenckhoff catheter being visible (Beer 1995).

Other studies reported similar findings to those of Beer (1995) and Curtin et al. (2004). Lindqvist et al. (2000) explained how participants using peritoneal dialysis emotively commented on their distended abdomens. Lindqvist et al.'s (2000) large qualitative study included participants using peritoneal dialysis (n=26), haemodialysis (n=30) and with a kidney transplant (n=30), but the authors enable distinction between the different therapies through the inclusion of data vignettes from the different groups of participants in their paper. Furthermore, Morton et al.'s (2010) recent qualitative study that explored patients' feelings towards renal replacement therapies, also identified that access for dialysis, including the Tenckhoff catheter, was not an acceptable change in body image. The impact of dialysis and associated dialysis access on patients' body image was thus upsetting for patients, but Beer (1995) identified that participants in her study came to accept this. Similarly, Wright and Kirby (1999) described patients processing their losses, including bodily function and body image. Wright and Kirby (1999), who also included patients only using peritoneal dialysis (n=10) in the UK in their grounded theory study, questioned whether loss is an ongoing characteristic of end-stage renal disease, and it did appear to feature in different studies.

Lifestyle restrictions and emotional impact Curtin et al. (2004) highlighted that chronic illness has the potential to restrict patients' flexibility in their lives, but identified in their study that all their participants (who had undertaken peritoneal dialysis for at least four years) reported freedom as a result of their treatment as it enabled them to take holidays and decide when to dialyse. This differs to participants using peritoneal dialysis in Lindqvist et al.'s (2000) study, who felt controlled by their treatment. Furthermore, two other studies identified that participants experienced lifestyle restrictions as a result of dialysis. While Morton et al. (2010) interviewed patients using haemodialysis (n=60), home haemodialysis (n=4), peritoneal dialysis (n=13) and with a transplant (n=18) in Australia, Clarkson and Robinson's (2010) study was much smaller with four participants using peritoneal dialysis and six haemodialysis. However, both studies found that participants reported limited holidays, strict dialysis regimes, diet and fluid restrictions, limited incomes and expensive medical costs.

While Curtin et al.'s (2004) seminal study found participants felt a sense of freedom when using peritoneal dialysis, other studies reported different experiences. Morton et al. (2010) highlighted that while some participants using peritoneal dialysis commented on feeling restricted by the treatment, others reported feeling freedom because of it. Furthermore, Clarkson and Robinson (2010) found that only patients

undertaking peritoneal dialysis in their study were able to continue working. Possibly this difference is due to the varying lengths of time undertaking peritoneal dialysis, as the participants in Curtin et al.'s (2004) study had all been on the treatment for at least four years, while in studies by Lindqvist et al. (2000), Morton et al. (2010) and Clarkson and Robinson (2010), participants could have been using the treatment for as little as three months, and therefore could have required additional adjustment time. Otherwise, this difference could be due to the varying preferences and perceptions of patients.

The emotional impact of the changes to daily life was discussed by Mok et al. (2004), who used a naturalistic approach with patients undertaking dialysis (n=11) in Hong Kong. Mok et al. (2004) identified that patients felt helpless, powerless, sad, angry, fearful, guilty and indebted to relatives, thus indicating a range of negative emotions resulting from their treatment. For example, one of Mok et al.'s (2004) participants commented that she felt guilty for being unable to play with her daughter, highlighting the impact of dialysis on this woman's life and her usual roles.

Tiredness and fatigue Yngman-Uhlin and Edell-Gustafsson (2006) identified that disturbed sleep and fatigue were a distinct problem for patients undertaking peritoneal dialysis in Sweden, with 62% of their sample (n=55) reporting too little sleep, and 87.7% reporting fatigue. A later phenomenological study by the same authors (Yngman-Uhlin et al. 2010) explored peritoneal dialysis patients' (n=14) perspectives of tiredness, highlighting the impact of it on their lives. Participants reported both mental and physical tiredness, with mental tiredness being the most severe. This affected their activities and social life, in turn causing loneliness. Yngman-Uhlin et al. (2010) concluded that tiredness affected patients physically, mentally, socially and existentially, and that healthcare professionals have a role in helping patients to overcome the problem through accurate assessment and intervention. An earlier Swedish study led by physiotherapists (Heiwe et al. 2003) also considered fatigue with a group of patients with chronic and end-stage renal disease, including pre-dialysis individuals (n=5), patients undertaking peritoneal dialysis (n=6) and haemodialysis (n=5). Through the use of phenomenography, whereby data analysis and description is directed by experiential description (Marton 1981), a participant in Heiwe et al.'s (2003) study identified mental fatigue as a heavy feeling, with reduced motivation to take part in activities. This appears to concur with Yngman-Uhlin et al.'s (2010) findings. Furthermore, Heiwe et al. (2003) explored physical fatigue, which participants described as feeling as though they had

someone sitting on their shoulders. Heiwe et al. (2003) recommended early referral for physical exercise training, which they argued could improve patients' activities and social lives.

Therefore, the literature demonstrates the impact of end-stage renal disease, and more specifically peritoneal dialysis, on patients' body image, daily lives and physical and mental tiredness. The next section discusses how patients cope with renal disease and dialysis.

Coping with dialysis

Within the theme of coping, four subthemes were identified, including the skills patients developed to cope with illness, the role of hope and family, and also the importance of attempting to remain in control.

Coping skills Wright and Kirby (1999), both clinical psychologists, asserted that coping skills are activities and thoughts which help a person to come to terms with their illness and continue with their life. Some participants in Wright and Kirby's (1999) study achieved this by staying positive, for example comparing themselves to others who they perceived to be worse off, which Lindqvist et al. (2000) and Mok et al. (2004) also identified. Interestingly, both Wright and Kirby (1999) and Lindqvist et al. (2000) also revealed that patients used upwards social comparison, whereby they identified other patients who were living well with either dialysis or a transplant. Therefore, it seems that patients compared themselves to others, either to make them appreciate their life or hope for something more. Both Wright and Kirby (1999) and Mok et al. (2004) also discussed that their participants used distraction, such as watching television or reading a book, to make themselves feel better.

Hope Several studies identified that patients used hope as a method of coping, including the hope of a renal transplant (Hardiker et al. 1986, Lindqvist et al. 2000, Martin-McDonald 2003, Wright and Kirby 1999), an overnight APD machine (Martin-McDonald 2003) or for their condition to stabilise (Martin-McDonald 2003, Wright and Kirby 1999). Interestingly, a multicentre cross-sectional study undertaken in the UK (Billington et al. 2008), highlighted the importance of hope as a buffer against anxiety and depression. Internationally, therefore, hope appears to be an important coping strategy for patients with end-stage renal disease.

Family Furthermore, Wright and Kirby (1999) identified that some participants considered that illness had helped them appreciate life more and brought their family together. Other studies highlighted the important role that families played in supporting patients undertaking dialysis and Mok et al. (2004), Polaschek (2007) and Clarkson and Robinson (2010) emphasised that families were participants' motivation for coping. Participants in Hardiker et al.'s (1986) grounded theory study additionally spoke of being grateful to their families for their support, which assisted them in coping with the disease. Hardiker et al.'s (1986) work is the first UK study identified in this review to explore patients' perspectives of dialysis, including participants using home haemodialysis and peritoneal dialysis (n=20). While the study is now dated and did not distinguish between patients using the two types of dialysis in the paper, the findings appear to resonate with later work. Overall, families thus played a vital role in helping patients to cope with end-stage renal disease, and the impact of dialysis on them will be discussed later.

Control Curtin et al. (2004) wrote at length about how their long-term peritoneal dialysis participants achieved self-management self-efficacy. One of the reasons Curtin et al.'s (2004) participants chose peritoneal dialysis was due to the perception that the treatment would offer autonomy and control over treatment. To maintain this control, participants in Curtin et al.'s (2004) study felt three areas were important: being a partner with healthcare professionals to manage their care, actively self-caring for their treatment, and feeling capable of caring for themselves. This has been similarly discussed in a later hermeneutic phenomenological study with patients undertaking home haemodialysis (n=15) and peritoneal dialysis (n=5) in New Zealand (Polaschek 2006, Polaschek 2007). Polaschek's (2006) participants also discussed feeling confident in their self-care abilities, whereby they adjusted their treatment depending on how they felt or to make it fit into their lives – participants were positive about having control.

Furthermore, Lindqvist et al. (2000) discussed the importance of their participants having as much control as possible over their lives, with Martin-McDonald (2003) highlighting that dialysis patients' ability to take control over their lives varied depending on their physical health and treatment. Martin-McDonald (2003) undertook a narrative study in Australia with a small sample of patients using peritoneal dialysis (n=5) and haemodialysis (n=5), and highlighted that patients needed support from healthcare professionals to have better experiences of treatment. Additionally, Yngman-Uhlin et al. (2010) discussed control in relation to

the tiredness experienced by their participants, and the ways in which participants tried to improve their health by taking control. For example, participants tried to think positively, plan the day around activities, go walking, be flexible and avoid caffeine and alcohol.

The literature has therefore explored how patients undertaking dialysis cope with their treatment, including comparison to others, remaining hopeful, the importance of family and maintaining control. The next section will consider the literature with regard to whether patients undertaking dialysis accept the treatment.

Acceptance

Despite the impact of dialysis on patients and their everyday lives, the literature highlighted that individuals reported that they had reached a point of acceptance. This was particularly discussed by Wright and Kirby (1999), who classified different types and styles of acceptance.

Types of acceptance Wright and Kirby (1999) discussed the different ways in which patients accepted their illness, by which they acknowledged it and its permanence. They categorised this as entailing emotional acceptance (positive affect rather than depression), behavioural acceptance (performing self-care behaviour) and cognitive acceptance (not worrying about the treatment). Cognitive acceptance in particular could potentially be difficult for patients, as dialysis is a life-sustaining treatment and thus it could be argued that it is natural for patients to worry. Indeed, Wright and Kirby (1999) acknowledged that patients may not reach acceptance in all three categories. Other studies have discussed patients building a new life around dialysis, for example Hardiker et al. (1986) highlighted that patients completed tasks at a slower pace, and Yngman-Uhlin et al. (2010) explained that patients structured their lives differently to deal with tiredness resulting from peritoneal dialysis. Mok et al. (2004) found that when participants in their study realised they could not change the situation, they accepted it.

Styles of acceptance Wright and Kirby (1999) also categorised patients as active acceptors who integrated peritoneal dialysis into their daily routine, and resigned acceptors who let go of past activities and roles. Similarly, several participants in Hardiker et al.'s (1986) study resigned themselves to dialysis and abandoned past activities. Interestingly, Wright and Kirby (1999) identified that patients with worse physical health were more likely to be resigned acceptors, and it is therefore possible

that acceptance is not due to emotional or cognitive factors, but due to physically not being able to undertake the activities of their past. Acceptance has therefore been discussed in different terms by different researchers, and it appears that it is affected by other factors, such as a patient's physical health.

Families were clearly key to patients' ability to cope with peritoneal dialysis and the wider families' perceptions of peritoneal dialysis are thus discussed next.

3.3.2 Family

Peritoneal dialysis is performed daily at home and therefore it can potentially have a substantial impact on families. Additionally, the review of the qualitative literature highlighted the importance of family to patients using dialysis. However, no qualitative studies were identified that only included family members of patients using peritoneal dialysis. Several qualitative studies have, however, included the families of patients undertaking peritoneal dialysis or haemodialysis. These studies, including study aim, methodology, sample, data generation method, data analysis, main findings and recommendations, are summarised in Appendix Four.

Introducing the studies

The five countries where the six studies were undertaken are, like the patient studies, all developed: Canada (Beanlands et al. 2005, Pelletier-Hibbert and Sohi 2001), Australia (White and Grenyer 1999), USA (Flaherty and O'Brien 1992), Hong Kong (Luk 2002) and Sweden (Ekelund and Andersson 2010). Interestingly, two family studies were conducted in Canada. The majority of papers described themselves as "qualitative" (Ekelund and Andersson 2010, Flaherty and O'Brien 1992, Pelletier-Hibbert and Sohi 2001), like the patient studies, or used phenomenological methodology (Luk 2002, White and Grenyer 1999), with one study adopting a grounded theory approach (Beanlands et al. 2005). Again, the papers describing their methodology as "qualitative" make it very difficult for the reader to understand which perspective the researcher comes from and whether the methods used are congruent with the methodology. Additionally, with the exception of Pelletier-Hibbert and Sohi's (2001) study utilising focus groups, all the studies used semi-structured interviews only. There are thus similarities between the patient and relative studies, in terms of the methodologies and methods employed.

All of the studies included appropriate numbers of participants; for example Flaherty and O'Brien (1992) included 15 relatives of patients using peritoneal dialysis and

White and Grenyer (1999) 16 relatives. However, as with the patient literature, two studies (Luk 2002, Pelletier-Hibbert and Sohi 2001) included a sample of participants with relatives undertaking peritoneal dialysis or haemodialysis, not distinguishing between the two dialysis modalities. This is disappointing and makes distinguishing dialysis modality specific factors challenging. The studies collectively provided insight into how dialysis affects the wider family. Luk (2002) included mostly partners (n=17) and also wider family members (n=13); Ekelund and Andersson (2010) and White and Grenyer (1999) included only partners; Beanlands et al. (2005) do not give detail; while Flaherty and O'Brien (1992) and Pelletier-Hibbert and Sohi (2001) included partners and wider family members including parents, children, siblings and nieces.

Three themes were identified from synthesising the literature: the different types of caring tasks, the impact of dialysis on lifestyle, fatigue, finances, health/death and emotionally, and finally coping styles and strategies.

Caring tasks performed by relatives

The patient section of this literature review demonstrated the impact that dialysis has on the individual and their family. However, before the impact of dialysis on relatives' lives is examined in detail, it is important to first appreciate the range of caring tasks and roles that were undertaken by relatives.

Types of tasks To explore caregivers' roles and activities, Beanlands et al. (2005) included relatives caring for patients undertaking peritoneal dialysis (n=12), haemodialysis (n=21) and home haemodialysis (n=4) in Canada. Beanlands et al. (2005) identified that relatives downplayed their caring roles, but in fact undertook complex tasks, including managing the dialysis itself and coping with co-morbidities. Additionally, an earlier phenomenological (discipline not specified) study by Luk (2002) examined relatives (n=30) of dialysis patients in Hong Kong and described common caregiving tasks including domestic work such as shopping and cleaning, assisting with dialysis care and moving around the home, and providing transport outside the house. These caring tasks interfered with relatives' lives outside of their caring role, for example studying or raising children. It thus appears that relatives take on dialysis care as well as the majority of household work when their relative is using dialysis. Furthermore, while carer fatigue was evident in Luk's (2002) research, participants in Beanlands et al.'s (2005) research struggled most with the emotional impact of caring, which will be discussed later.

Caring activities Five caring activities were identified by Beanlands et al. (2005), including: appraising, which included problem-solving and surveillance, whereby they continuously monitored their relative. The second activity of advocacy involved relatives speaking or acting in favour of the patient, which could be difficult for relatives as they also tried to maintain a good relationship with healthcare professionals. Another theme identified by Luk (2002) highlighted the importance of communication between the multidisciplinary team. Therefore, relatives seemed to feel a duty to support their relative when interacting with healthcare services, but found these interactions challenging. A third caring role identified by Beanlands et al. (2005) was juggling, which was highlighted above due to the multiple caring tasks undertaking by relatives. Further caring roles include routinising, whereby a routine was established to cope with the demands of dialysis, and coaching, which involved motivating the patient to undertake self-care activities (Beanlands et al. 2005). This contrasts with a finding in Luk's (2002) study where relatives protected patients from helping with tasks, such as housework. Beanlands et al.'s (2005) caring activities provided a useful insight into the complex roles that relatives adopted when caring for a person with end-stage renal disease. While the vignettes quoted by Beanlands et al. (2005) demonstrated the caring activities, additional data generation methods such as participant observation could have strengthened their findings and provided deeper insight into relatives' experiences of caring (Spradley 1980).

Relatives thus undertake multiple caring roles with regard to dialysis and additional domestic tasks. The specific impact of dialysis on relatives' lives, as reported in the literature, will now be discussed.

Daily impact of dialysis

Examination of the literature revealed that dialysis impacted on the daily lives of families, which led to reduced social life and ability to work, increased fatigue, deterioration of relatives' health and awareness of the patient dying. This gave rise to a complex mix of emotions towards the patient and life, including anxiety, anger, pride and love.

Lifestyle and financial implications The impact of dialysis on families' lifestyles has been described in the literature, in terms of limited social life outside of dialysis (Ekelund and Andersson 2010), other responsibilities in life affected (Luk 2002) and daily activities and holidays restricted (White and Grenyer 1999). Luk (2002) found

that relatives gave an average of three hours each day to their caring activities, which could be particularly difficult if relatives are also employed. Indeed, Luk (2002) further described the negative impact on the family of relatives ending employment to care for the patient undertaking dialysis. Additionally, Ekelund and Andersson's (2010) qualitative approach with patients undertaking dialysis and their relatives (n=21) highlighted the negative consequence of dialysis on families' financial situation, which was also found by White and Grenyer (1999).

Fatigue The three hours of caring tasks described by Luk (2002) were also found to contribute towards fatigue, with participants hoping for respite through the patient being admitted to hospital. However, White and Grenyer's (1999) Husserlian phenomenological study with both patients undertaking dialysis and partners (n=22), found that performing peritoneal dialysis required around 35 hours per week, also iterating that relatives felt fatigued by dialysis and their caring role. The previous section showed that fatigue impacted physically and emotionally on the patient, which was also found here with the wider family.

Relative health and patient death Notions of carer health and patient death emerged as a theme in this body of literature. Seventy percent (n=21) of carers in Luk's (2002) study reported their physical health worsening, while White and Grenyer (1999) found that relatives worried about becoming unwell and how they would then cope with the challenges of dialysis. This raises the issue of ensuring that relatives are supported and given respite time to enable them to continue caring for the patient and prevent their health deteriorating. Relatives were aware of the mortality risk associated with end-stage renal disease and Pelletier-Hibbert and Sohi's (2001) qualitative study with relatives of dialysis patients (n=41) highlighted that such was the awareness of the terminal nature of end-stage renal disease that some participants thought about death each day, demonstrating the uncertainty with which relatives of dialysis patients live daily. Caregiving was perceived to be most difficult when the patient deteriorated (Beanlands et al. 2005), which highlights that the support that relatives need to cope with dialysis is likely to be dynamic over time, as the patient's health changes.

Emotional impact The literature demonstrated that dialysis and the caring role invoked multiple emotions from relatives, including negative (anxiety, irritation, bitterness, fear, frustration) and positive (love, pride, respect) responses (Beanlands et al. 2005). Luk (2002) also described the negative emotions expressed by carers,

while some participants in White and Grenyer's (1999) study considered their dialysis-dependent relative to be "selfish, inward looking, not wanting to take responsibility and impatient" (p.1318). Dialysis thus clearly places stress on familial relationships. Despite this stress, White and Grenyer (1999) asserted that in fact dialysis had strengthened the family relationship, which was similarly found by Luk (2002) and some participants in Flaherty and O'Brien's (1992) study. Flaherty and O'Brien (1992) undertook a qualitative longitudinal study over two years with relatives of patients undertaking dialysis (n=50), and identified that 17% of families exhibited what they term "enfolded family style", whereby the family were closer as a result of dialysis. This enfolded family style was identified in 15% of peritoneal dialysis (n=15) families, thus representing a small number of participants (n=2).

Coping

The literature thus revealed the different caring tasks that families undertook to support their relative receiving dialysis, and the subsequent impact of dialysis on the family. The ways in which families cope with the impact of dialysis has been minimally explored by qualitative researchers.

Coping styles Flaherty and O'Brien (1992) explored the different coping styles among families of patients undertaking dialysis. The authors identified five different family coping styles, including remote family style (end-stage renal disease not affecting their family), enfolded family style (end-stage renal disease strengthened the family), altered family style (end-stage renal disease caused major changes), distressed family style (negative emotions about end-stage renal disease) and receptive family style (adjustment to end-stage renal disease). These family styles reveal the range of coping styles exhibited by families of patients undertaking dialysis. However, due to the number of peritoneal dialysis families (n=15, compared to 30 haemodialysis families) in this study (Flaherty and O'Brien 1992), the number of relatives who exhibited each individual coping style was small. It would be useful to identify further research that investigates these coping styles in other samples.

Coping strategies Coping strategies have been discussed in more detail by Pelletier-Hibbert and Sohi (2001) with their sample of relatives of patients undertaking peritoneal dialysis (n=17) and haemodialysis (n=25). They identified that families were flexible to cope with the unpredictable nature of end-stage renal disease, endeavoured to stay positive and looked to their faith for support. Staying positive and flexibility were similarly reported as coping strategies against tiredness by

peritoneal dialysis participants in Yngman-Uhlin et al.'s (2010) study. Furthermore, Pelletier-Hibbert and Sohi (2001) reported that hope of a renal transplant, with life returning to the pre-dialysis norm, was used by relatives as a coping strategy. Hope for a transplant was similarly used as a coping strategy in patient studies (Hardiker et al. 1986, Lindqvist et al. 2000, Martin-McDonald 2003, Wright and Kirby 1999), highlighting the emphasis that both patients and families placed on renal transplantation. While Pelletier-Hibbert and Sohi's (2001) findings have been identified elsewhere in the renal literature, the authors do not distinguish between coping strategies employed by peritoneal dialysis and haemodialysis families. Due to the different natures of peritoneal dialysis and haemodialysis, it is feasible that families' coping strategies could vary, but Pelletier-Hibbert and Sohi (2001) do not discuss these.

Families therefore adopt different coping styles and different coping strategies to mediate the impact that end-stage renal disease has on their lives, however few studies were identified that discussed these.

3.2.3 Summary of studies

The qualitative literature demonstrated that dialysis has a negative impact on multiple areas of an individual's life. In order to cope with this impact, it was identified that maintaining control, hope and support from family were important coping strategies. Furthermore, the literature with families of patients undertaking dialysis emphasised the impact of dialysis on their lives, including fatigue, lifestyle implications and a range of negative emotional responses. Despite this, studies have concluded that dialysis brings families closer together (White and Grenyer 1999, Luk et al. 2002), which demonstrates the resilience of families. Relatives also coped with the demands of dialysis by hoping for a renal transplant, emphasising the importance placed on renal transplantation by both relatives and patients.

These two syntheses have attempted to present important themes that emerged from the small number of qualitative studies considering patients' and their families' perspectives of end-stage renal disease and peritoneal dialysis. A considerable body of international literature was identified that quantified quality of life in these populations, which are discussed next.

3.4 Quality of life

Examining and quantifying quality of life emerged as a significant theme in the end-stage renal disease literature, where an abundance of studies from across the world explored the phenomenon from the 1980s onwards. A significant number of published studies compared quality of life amongst patients with end-stage renal disease undertaking renal replacement therapies. A smaller number of studies also considered the quality of life of patients' families. This review is not an exhaustive discussion of all of these studies but rather seeks to provide an overview of major themes in the literature and also to discuss some of the limitations in attempts to quantify quality of life.

The quantitative studies lack a consistent definition of quality of life, and what measures can be used to determine it. The World Health Organisation (1997) defines quality of life as:

individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (p.1)

The World Health Organisation emphasises the impact of physical and psychological health, independence and social relationships on quality of life, which are all affected in the presence of a long-term disease such as end-stage renal disease. Another definition is offered by Welch (1994), who asserted that quality of life includes four areas that describe the individual's experience:

physical health and symptoms, functional status and activities of daily living, mental well-being (including existential and spiritual aspects of living) and social health including social role functioning and social support (p.56)

This definition thus highlights the holistic nature of quality of life. The complex nature of the concept is also stressed by Merkus et al. (1997):

patients' level of quality of life is a result of a complex interaction of disease outcome, personal traits, coping behaviour, social support, and quality of care received (p.590)

Quality of life is thus highly individual and subjective, and Merkus et al.'s (1997) emphasis on the quality of care received is also interesting as it highlights the direct impact of others (including healthcare professionals) on individuals' quality of life. Differing ideas are thus posed by authors and researchers and therefore different assessment tools exist that attempt to measure this complex, individual phenomenon, which makes comparison between these studies more difficult.

This review will firstly explore the studies that considered patients' quality of life, before turning to the smaller body of literature that considers that of their families.

3.4.1 Patients' quality of life

In total, 34 relevant studies were identified that considered patients' quality of life. To enable easier discussion, this section of the literature review will be presented in two parts:

- the studies that compare patients using different renal replacement therapies quality of life (n=28). These studies will be presented according to the geographical area where the research was undertaken (North America and Australia; United Kingdom; Europe excluding the UK; and Eastern Asia) which correlates with when the studies were published, from 1985 – present;
- the studies that consider quality of life in patients using peritoneal dialysis only (n=6), from 1996 – present.

Quality of life in patients using all renal replacement therapies

A significant number of studies were identified that compared quality of life between patients using peritoneal dialysis and haemodialysis. While the focus of this literature review is not to compare renal replacement therapies, this is the dominant body of literature and it does provide useful information about the quality of life of people using peritoneal dialysis.

These studies use a variety of assessment tools, which generally focus on measuring physical or mental quality of life. These studies, which initially emerged from the USA, Canada and Australia in the mid-1980s and continued until recently, show minimal agreement. Researchers in the UK then followed and over twelve years published several studies considering this phenomenon, all of which reported that quality of life is comparable, if diminished compared to the general population norm, between the two treatments. Studies then began to emerge from Western Europe and, later, Eastern Europe, and like those originating in North America and Australia they have failed to establish whether peritoneal or haemodialysis is associated with better quality of life. The most recent studies were undertaken in Eastern Asia, where the prevalence of end-stage renal disease is increasing rapidly (Li et al. 2007), and they too dispute that either type of dialysis has better quality of life outcomes. The diagram below attempts to depict the publication trend by region and date. The sections below then describe, critique, compare and contrast the literature, taking

each geographical area in turn. A data extraction table detailing the studies can be found in Appendix Five.

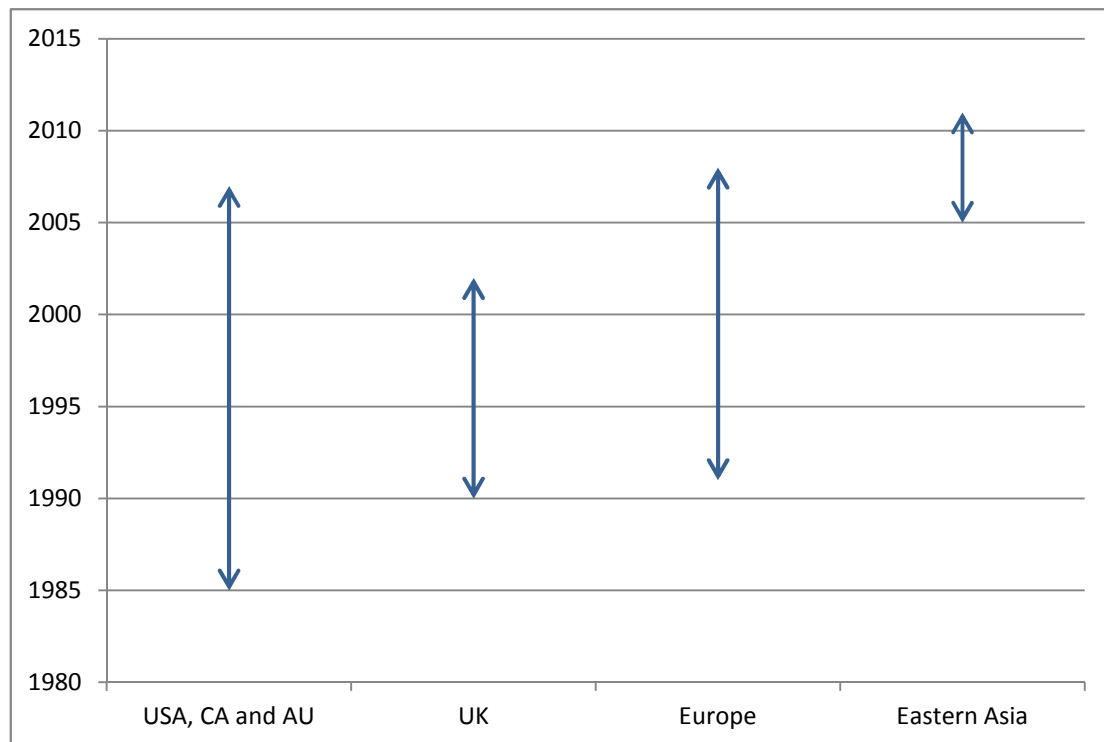


Figure 2: Quality of life literature comparing renal replacement therapies - time and geography

North America and Australia The earliest studies that considered quality of life originated from the USA, Canada and Australia. The earlier of these studies typically utilised multiple assessment tools, while the later studies applied one or two well-recognised and validated tools such as the Medical Outcome Survey short-form with 36 questions (MOS SF-36). Overall, while the studies agreed that kidney transplantation improved quality of life when compared with dialysis, patients using both types of dialysis reported this to be diminished.

Evans et al.'s (1985) seminal study adopted a cross-sectional approach with a random sample of patients using dialysis or with a renal transplant. Participants completed indices of Psychological Affect, Overall Life Satisfaction and Well-being, which revealed that patients using haemodialysis had poorer quality of life than patients using peritoneal dialysis (n=81), while a kidney transplant was associated with significantly better overall quality of life. A further cross-sectional study (Wolcott et al. 1988) also found that patients using peritoneal dialysis (n=33) reported better quality of life than patients using haemodialysis. Wolcott et al. (1988) included a

matched pair sample and administered 13 assessment tools covering physical, psychological and social dimensions, and also identified that participants using peritoneal dialysis reported less treatment stress and psychological disturbance, and were more likely to work. Simmons and Abress (1990) included patients using renal replacement therapies in their cross-sectional study that utilised 10 tools covering physical, emotional and psychological quality of life domains. They also identified that patients with a renal transplant had the best quality of life, followed by patients using peritoneal dialysis (n=510). Therefore, several of the early, cross-sectional studies identified that patients using peritoneal dialysis reported better quality of life than patients using haemodialysis, although it remained diminished compared to the general population.

By contrast, other early studies disputed that peritoneal dialysis was associated with better quality of life compared to haemodialysis. An early study also identified that patients with a kidney transplant reported significantly better quality of life than patients using peritoneal (n=24), haemodialysis or home haemodialysis, after administering the Time Trade-Off approach (Churchill et al. 1987). Quality of life scores between the three dialysis groups were, however, similar. Two further studies found that patients using home haemodialysis reported better quality of life compared to patients using other types of dialysis. Bremer et al. (1989) used affect scales and a dependence scale, finding that patients with a transplant exceeded normal quality of life for the general population, while patients using home or self-administered haemodialysis had average quality of life. Patients using peritoneal (n=79), hospital haemodialysis or with a failed kidney transplant reported significantly diminished, but similar, quality of life. Therefore, differences in quality of life can occur between patients using the same treatment, administered in different ways. Devins et al. (1990) measured quality of life domains, illness intrusiveness and hopelessness, with a small number of patients using peritoneal dialysis (n=11), home and hospital haemodialysis, and with a transplant. Their findings reiterated those of Bremer et al. (1989), identifying that patients using peritoneal dialysis and haemodialysis reported greater impact of treatment than people using home haemodialysis or with a kidney transplant. Therefore, other early studies from North America reinforce the finding that a working kidney transplant is associated with better quality of life outcomes, but that haemodialysis and peritoneal dialysis are similar but diminished. Home haemodialysis was, however, found to be associated with better quality of life than other types of dialysis. These early studies are now dated and the medical management and technologies used for dialysis have changed in the last twenty

years, possibly leading to altered quality of life results. Examining the recent literature is thus important.

Two more recent studies in the USA both explored quality of life with a cross-sectional sample of patients using dialysis. Diaz-Buxo et al. (2000) undertook a large national study in USA in conjunction with Fresenius Medical Care (a dialysis company), including 16,775 patients using haemodialysis but a considerably smaller number of patients using peritoneal dialysis (n=1260). Through the use of the MOS SF-36, they found that physically both groups of patients reported similar but diminished quality of life compared to the general population. However, on the mental health questions, patients using peritoneal dialysis reported better outcomes. Fong et al. (2007) undertook a smaller study using the Kidney Disease QOL tool with patients using nocturnal home haemodialysis and peritoneal dialysis (n=57), and identified that quality of life was similar between the two groups. Diaz-Buxo et al. (2000) and Fong et al. (2007) therefore reinforced several of the earlier studies and highlighted that quality of life was similar between different groups of patients using dialysis. Interestingly, patients using home haemodialysis had been found in the 1980s and early 1990s to report better quality of life than patients using peritoneal dialysis (Devins et al. 1990, Bremer et al. 1989), but the more recent study by Fong et al. (2007) did not report this. The use of different samples and assessment tools could be the reason for this difference, or perhaps improvement in peritoneal dialysis as a treatment in the years between the studies.

There was thus a lack of consensus among the cross-sectional studies about which type of dialysis correlated with better quality of life. Four longitudinal studies, measuring quality of life over time, were identified within Australian, American and Canadian populations. The earliest longitudinal study followed patients using peritoneal dialysis (n=51, follow-up 22) and haemodialysis (n=51, follow-up 47) over an 18 month period (Oldenburg et al. 1988). The small number of participants using peritoneal dialysis at follow-up is notable; several patients died and the majority received a kidney transplant. Oldenburg et al. (1988) identified that patients receiving haemodialysis reported higher psychological stress and social dysfunction at baseline, with distress at baseline predicting later distress. Additionally, adjustment was worse for patients using peritoneal dialysis. This study therefore highlighted that patients using different types of dialysis may experience reduced quality of life in different domains. Three later longitudinal studies all used the MOS SF-36 to assess quality of life in patients using dialysis. Mittal et al. (2001) found that

patients using peritoneal dialysis (n=43) reported lower physical quality of life than those using haemodialysis, which was stable over two years. Manns et al. (2003) included a similar sample of patients using peritoneal (n=41) and haemodialysis (n=151) in Canada, additionally administering the Kidney Disease QOL and European quality of life (Euro-QOL) tools. They also identified that quality of life was stable over the 12 month period, but that the scores for haemodialysis and peritoneal dialysis were similar. Finally, a large American study used the Health Experience Questionnaire with 230 people using peritoneal dialysis and 698 using haemodialysis over 12 months (Wu et al. 2004). Wu et al. (2004) found that participants' quality of life was diminished at baseline, although this varied between patients using different types of dialysis, while by 12 months there was significant improvement, although again these varied between participants using peritoneal or haemodialysis. Therefore, this study reinforced Oldenburg et al.'s (1988) finding that specific quality of life outcomes varies between patients using different types of dialysis, but also challenged Manns et al. (2003) and Mittal et al.'s (2001) findings that quality of life was stable over time.

It is thus notable that over 22 years, this wide range of studies from North America, and one from Australia, have failed to agree on whether patients using haemodialysis or peritoneal dialysis reported better quality of life. Crucially, the studies revealed that patients using peritoneal dialysis demonstrated diminished quality of life, particularly physically, reported that the treatment impacted significantly on life and felt they had adjusted poorly. However, the studies do not agree on whether quality of life was stable or dynamic over time for these patients.

United Kingdom Following the studies from North America and Australia, the next emerging body of literature came from the UK, although a relatively small number of studies were identified. These four studies are heterogeneous in nature through their use of different study designs and assessment tools, but overall reported similar findings that both types of dialysis are associated with diminished but comparable quality of life. One limitation of all four quality of life studies is the relatively small number of participants included, with none including more than 93 people using peritoneal dialysis, making it difficult to generalise the results to other patients using the treatment.

The earliest UK study by Auer et al. (1990) used a cross-sectional approach with an early cohort of patients using peritoneal (n=81) and haemodialysis. The authors

administered six tools covering life satisfaction and happiness and identified that life satisfaction was moderate and similar for both groups. A later survey study by Gudex (1995) included patients using peritoneal (n=93), home and hospital haemodialysis and with a kidney transplant (n=367). Using the Health Measurement Questionnaire, Gudex (1995) found that patients with a kidney transplant had better quality of life than participants using dialysis, who reported similar but diminished quality of life. Interestingly, Gudex (1995) reported that patients using haemodialysis felt dependent on a machine, while peritoneal dialysis was associated with confinement. Therefore, it is important to recognise that while quality of life may be similar, issues important to patients may differ between treatments. This finding was reinforced by a later cross-sectional UK study (Carmichael et al. 2000), which used the Kidney Disease QOL tool with patients using peritoneal (n=93) and haemodialysis. With the exception of significantly improved social functioning in patients using peritoneal dialysis, quality of life was otherwise similar between patients, but reduced compared to the general population (Carmichael et al. 2000). However, Carmichael et al. (2000) reported that participants rated different benefits of the two types of dialysis. While patients using peritoneal dialysis reported fewer dialysis-related symptoms, less adverse effects of kidney disease on life, better cognitive function, sleep and satisfaction with treatment; participants using haemodialysis reported less burden of kidney disease on lifestyle, better social interaction and social support (Carmichael et al. 2000). Therefore, two studies from the literature highlighted that while overall quality of life scores were similar and reduced between patients using peritoneal dialysis and haemodialysis, the two groups rated their experience of their treatment differently. Oldenburg et al.'s (1988) earlier longitudinal study also identified this.

Finally, the most recent UK study (Harris et al. 2002) used the MOS SF-36 and the Kidney Disease QOL tool and adopted a longitudinal approach with two cohorts of patients over the age of 70: new to peritoneal (n=36) and haemodialysis and established on peritoneal (n=42) and haemodialysis. Overall, Harris et al. (2002) identified that quality of life was similar and diminished for patients using both types of dialysis at baseline, 6 and 12 months. However, the Kidney Disease QOL tool identified that patients using peritoneal dialysis had better symptom scores at baseline compared to patients using haemodialysis, although this diminished by 6 and 12 months.

Importantly, the UK studies confirmed Oldenburg et al.'s (1988) earlier finding that while quality of life can be similar between groups, participants using the two types of dialysis may report different stresses. In particular, patients using peritoneal dialysis reported that they felt confined and burdened by the treatment, but conversely demonstrated improved social and cognitive function, satisfaction with treatment and better sleep quality. While symptom burden was found to be better for patients using peritoneal dialysis initially, over time symptoms worsened.

Europe The literature from the rest of Europe began to emerge shortly after the first study from the UK, with researchers in Western Europe and more recently Eastern Europe measuring quality of life. Again, the earlier studies used a variety of assessment techniques while the later studies use standardised tools, and overall the studies also reported varying results.

The earliest study came from newly reunified Germany in 1991 (Muthny and Koch 1991), where a large survey was undertaken with patients using peritoneal dialysis (n=68), haemodialysis and with a kidney transplant. An author-administered quality of life and life satisfaction assessment tool was completed by participants, indicating that patients with a transplant had higher quality of life than patients using dialysis. Interestingly, Muthny and Koch (1991) identified that life satisfaction was better for patients using peritoneal dialysis than haemodialysis, although again patients with a transplant were most satisfied. Merkus et al. (1997) later found that patients using peritoneal dialysis (n=106) rated quality of life better than patients using haemodialysis in the Netherlands, after the authors administered the MOS SF-36. However, this finding was challenged by a multicentre cross-sectional Spanish study (Moreno et al. 1996) that used the Sickness Impact scale and included large numbers of patients using haemodialysis (n=961), but smaller numbers of people using peritoneal dialysis (n=40) and home haemodialysis (n=7). Unlike earlier studies from North America that reported patients using home haemodialysis had better quality of life (Bremer et al. 1989, Devins et al. 1990), Moreno et al. (1996) found that quality of life was similar but diminished between patients using dialysis. However, the small number of patients using home haemodialysis (n=7) in this study could call this finding into question. Thus, there is again uncertainty about which type of dialysis was associated with improved quality of life. However, De Vecchi et al. (1994) included participants who had used both peritoneal dialysis (n=39) and haemodialysis for at least six months in Italy, which enabled participants to rate which type of dialysis allowed them improved quality of life on an author-designed

tool. The study identified that that peritoneal dialysis was better for work and family, while haemodialysis was better for appetite and general wellbeing. Crucially, patients rated their current treatment as superior, due to the trauma of moving between treatments (De Vecchi et al. 1994). This study highlighted one weakness of studies that compared quality of life between patients using types of dialysis: patients may always favour the treatment that they use due to the stress of changing treatments.

More recent studies from Europe continued to disagree about quality of life and dialysis modality, although disappointingly they included small numbers of patients using peritoneal dialysis. Wasserfallen et al. (2004) undertook a large cross-sectional study in Switzerland, using the EuroQOL-5D tool with patients using peritoneal dialysis (n=50) and haemodialysis (n=455). They identified similar and significantly diminished quality of life between participants. Sayin et al. (2007) used the MOS SF-36 and also found similar and diminished quality of life for patients using peritoneal (n=41) and haemodialysis in Turkey. However, they also found that their small number of participants with a kidney transplant reported similar quality of life to patients using dialysis. This contradicted all identified earlier studies comparing renal replacement therapies, including large-scale and longitudinal research, calling into question Sayin et al.'s (2007) finding.

A more recent cross-sectional study (Timmers et al. 2008) used the MOS SF-36 in Netherlands, however, reported that participants using peritoneal dialysis (n=42) had superior quality of life and two others agreed. Lausevic et al. (2007) included patients who were new (n=32) or established (n=67) on peritoneal dialysis, and a sample of patients established on haemodialysis. Although the Serbian study used a cross-sectional design, the inclusion of two cohorts of patients using peritoneal dialysis enabled Lausevic et al. (2007) to identify that quality of life improved after 12 months for these patients, as rated by the MOS SF-36. A similar study in Greece (Ginieri-Coccossis et al. 2008) included participants who had used peritoneal (n=41) and haemodialysis for less than four years, and more than four years (PD n=17). They reported similar findings to Lausevic et al. (2007) that quality of life was worse for patients using haemodialysis. However, Ginieri-Coccossis et al. (2008) found that quality of life was similar between both cohorts of patients, compared to Lausevic et al. who found improved quality of life over time. Participants in Lausevic et al.'s (2007) study were newer to dialysis than participants in Ginieri-Coccossis et al.'s (2008) study, possibly accounting for this difference.

Therefore, nine studies from across Europe considering quality of life provide conflicting evidence and fail to reach consensus when attempting to establish which type of dialysis is associated with better quality of life and whether this improves or is stable longitudinally. However, interestingly the studies revealed that patients using peritoneal dialysis reported increased satisfaction with treatment compared to patients using haemodialysis, particularly in terms of the impact of treatment on work and family. Crucially, while the quality of life studies focus on comparing peritoneal and haemodialysis, De Vecchi et al. (1994) suggested that patients who have used both types of dialysis favour the second one. Although this study is now dated, it highlights the importance of exploring individuals' experiences when using a treatment, rather than focussing on comparing patients using different dialysis modalities.

Eastern Asia A small number of recent studies have also been identified in Eastern Asia, where a growing number of patients are requiring treatment for end-stage renal disease. Indeed, Taiwan now has the highest prevalence of end-stage renal disease worldwide (Fresenius Medical Care 2011). These recent studies are homogenous in terms of study design (cross-sectional) and quality of life tools used.

Niu and Li (2005) used the World Health Organisation QOL measure with a convenience sample of patients using the three renal replacement therapies in Taiwan. Although the sampling technique is not robust for identifying a representative sample, the size was determined through a power calculation, resulting in a suitable sample size of each group of participants (n=80 per group). Niu and Li (2005) also reported better quality of life in patients with a renal transplant, and similar quality of life between patients using peritoneal and haemodialysis, which was reduced compared to the general population. Another Taiwanese study (Peng et al. 2011) used the MOS SF-36 and included large numbers of patients using peritoneal (n=301) and haemodialysis, echoing Niu and Li's (2005) finding that quality of life is similar between patients using dialysis. However, a Chinese study (Zhang et al. 2007) conversely found that patients using peritoneal dialysis had better quality of life compared to participants using haemodialysis. Zhang et al. (2007) also used the MOS SF-36 with large numbers of participants using peritoneal (n=412) and haemodialysis, finding that patients using peritoneal dialysis reported better quality of life in terms of: bodily pain, general health, emotional role, social functioning, vitality and mental health. Therefore, despite substantial sample sizes and the use of the MOS SF-36, Zhang et al. and Peng et al. identify different findings. Zhang et al.

(2007) recommended longitudinal research examining quality of life in patients using dialysis, which could help to clarify differences between the two types of dialysis.

Therefore, like much of the other international literature, studies from Eastern Asia agree that patients using dialysis have reduced quality of life overall, but fail to agree on whether peritoneal or haemodialysis is associated with better quality of life outcomes for patients. Interestingly, Peng et al. (2011) reported that patients using peritoneal dialysis reported better quality of life in a variety of both physical and mental domains.

Summary This large group of studies therefore present both a cross-sectional and longitudinal perspective of quality of life over 26 years. However, the studies contradict each other and overall it is difficult to establish which type of dialysis associates with better quality of life. The literature was almost unanimous in agreeing that kidney transplantation lead to better quality of life, with only one recent study (Sayin et al. 2007) identifying that participants with a kidney transplant reported similar reduced quality of life to patients using dialysis. The longitudinal studies also disputed each other as to whether quality of life was stable or improved over time. The studies have, however, also provided deeper insight about the impact of peritoneal dialysis on the individual, in terms of individuals' reporting that they had not adapted well to treatment and felt confined and burdened by it. However, participants also reported satisfaction with peritoneal dialysis in terms of their social function, better sleep, fewer symptoms and less stress.

Several studies included participants using peritoneal dialysis only, and these studies are useful as they often indicated which variables (such as social support or depression) correlated with quality of life. These studies are discussed next.

Quality of life in patients using peritoneal dialysis

A far smaller number of studies considered quality of life in patients using peritoneal dialysis only. However, like the above studies, the peritoneal dialysis quality of life studies originate from the USA (Steele et al. 1996), France (Pucheu et al. 2004), the Netherlands (de Wit et al. 2001) and the UK (Bakewell et al. 2002, Balasubramanian et al. 2011), with one study from Thailand additionally being identified (Sakthong and Kasemsup 2011). The data extraction table in Appendix Six outlines these studies.

Quality of life assessment The majority of the studies were cross-sectional and generally used similar tools to assess quality of life. The earliest of the studies, Steele et al. (1996), used the Patient Assessed Quality of Life tool with 49 patients using peritoneal dialysis in the USA, identifying that family life, overall health, religion and friendship were important determinants for quality of life. The other five studies all used similar quality of life assessment tools. Quality of life was reported to be significantly lower for patients using peritoneal dialysis (n=49) than the general population in Pucheu et al.'s (2004) French study, where the MOS SF-36 was used. de Wit et al. (2001) used the MOS SF-36 and the EuroQOL-5D to compare quality of life between patients using CAPD (n=56) and APD (n=37) in the Netherlands, and found that quality of life was comparable between the two groups of participants. A recent study from Thailand (Sakthong and Kasemsup 2011) used the World Health Organisation (WHO-QOL) and Kidney Disease QOL symptoms tool with 102 patients using peritoneal dialysis, identifying reduced quality of life in terms of dependence on medication, concentration, sex and finances. Quality of life was thus identified as reduced compared to the general population, with similar scores between patients using CAPD and APD. However, these cross-sectional studies do not provide an idea of quality of life over time.

Two longitudinal studies were undertaken in the UK that identified poorer quality of life in patients using peritoneal dialysis. However, the studies contradicted each other in terms of the stability of reported quality of life. Bakewell et al. (2002) undertook a two year longitudinal study, with 88 patients at baseline and only 20 patients at the close of the study. The study used the Kidney Disease QOL assessment tool and found that quality of life gradually declined between baseline, 6 months, 12 months and 24 months. In contrast, Balasubramanian et al.'s (2011) recent study found that quality of life was similar at one-year follow-up. Participants (CAPD n=178; APD n=194) completed the MOS SF-36 and reported quality of life significantly lower than the general population. Possible reasons for this disparity include the use of different assessment tools and the varying follow-up times. Both studies however highlight that quality of life was reduced in patients using peritoneal dialysis, compared to the norm for the general population.

Quality of life and other variables The majority of studies considered quality of life in relation to other variables, such as depression, social support and symptoms. However, the five studies all measured a variety of different variables and therefore little insight is gained from attempting to compare them. Instead, the additional

measures provide further information about the study population. For example, Steele et al. (1996) also administered the Beck Depression Inventory, finding that indeed depression was associated with poorer quality of life. Furthermore, Pucheu et al. (2004) used the Health Locus of Control tool and found that physical quality of life was associated with perceived internal locus of control. Bakewell et al. (2002) additionally correlated quality of life with hospital admissions, identifying that participants with perceived better physical and mental health quality of life had fewer hospital admissions. These additional tools are not consistent across the literature and therefore they provide additional contextualising information about factors affecting quality of life.

Therefore, only a small number of studies focussed specifically on quality of life and identified reduced quality of life in patients using both CAPD and APD. The stability of quality of life over time could not be established, due to the two longitudinal papers contradicting each other. Quality of life correlated with depression, locus of control and number of hospital admissions, but as only one study assessed each variable it is difficult to extrapolate these findings further.

The reduced quality of life for patients could conceivably affect members of their families, which is discussed next.

3.4.2 Relatives' quality of life

The Welsh Assembly Government (2007) highlighted the impact of dialysis patients' relatives, but considerably fewer studies have examined this. Six studies are included in this review and were conducted in: the USA (Dunn et al. 1994, Wicks et al. 1997), Japan (Shimoyama et al. 2003), Spain (Alvarez-Ude et al. 2004), France (Morelon et al. 2005) and the UK (Fan et al. 2008). Three of the studies involved family members/carers only (Morelon et al. 2005, Wicks et al. 1997, Dunn et al. 1994) and the other three included samples of patients and relatives. Due to the substantial number of papers that considered patients' quality of life, these studies were therefore grouped with the wider family papers. The data extraction table in Appendix Seven outlines each study.

Assessing families' quality of life

The studies included a variety of samples of participants and assessment tools, subsequently yielding different results. The earliest of the family studies included a small convenience sample of carers (n=38) of patients using peritoneal dialysis in

America, using the QOL Index and identified that overall participants reported their quality of life as “moderate” (Dunn et al. 1994). However, the meaning of this is ambiguous and a later study that included the relatives of patients using peritoneal dialysis in Japan (Shimoyama et al. 2003) contradicted this and reported that quality of life was below the general population average for all domains. Shimoyama et al. used the MOS SF-36 and Kidney Disease QOL short-form with another small sample (n=26). These studies used varying assessment tools in several countries, were conducted at different times and measured quality of life at a single time point, perhaps accounting for the variation. A longitudinal study (Fan et al. 2008) with relatives of patients using peritoneal dialysis in the UK assessed quality of life within three months of commencing dialysis (n=112) and again 12 months later (n=36). The vastly reduced sample at 12 months is of note, which the authors explained was due to refusal to take part, transplantation, switching to haemodialysis or death. Using the MOS SF-36, Fan et al. (2008) identified that relatives’ quality of life was reduced below the norm for all domains except bodily pain, and 12 months later quality of life was stable, excluding social functioning which improved. Fan et al.’s (2008) findings therefore supported those of Shimoyama et al. (2003) and highlighted that quality of life was reduced for the relatives of patients using peritoneal dialysis. However, the small samples in both studies are notable and larger studies are thus needed to confirm or challenge findings from these studies.

In terms of the studies considering relatives’ quality of life when the patient is using renal replacement therapies, Wicks et al. (1997) included a convenience sample of 92 relatives of patients using dialysis (peritoneal dialysis n=15) in their exploratory study in the USA and utilised the General Quality of Life Measure. Only 2% of their sample reported quality of life as “poor”, while the majority rated it as “good” or “excellent”, which appeared to reiterate Dunn et al.’s (1994) earlier findings. However, these findings are again disputed by a later cross-sectional study (Alvarez-Ude et al. 2004) with a random sample of relatives of haemodialysis (n=152) and peritoneal dialysis (n=69) in Spain. Through the use of the MOS SF-36, Alvarez-Ude et al. (2004) identified that carers reported worse quality of life than the general population. One limitation of these studies is the small number of participants that took part, making it difficult to generalise the results to wider populations. A large survey used an author-designed quality of life tool (Morelon et al. 2005) in France with a large number of carers of patients using dialysis (n=988) and or with a transplant (n=827). The authors stated that the majority of patients used haemodialysis, again highlighting the under-representation of families of patients

using peritoneal dialysis in the literature. Morelon et al. (2005) identified that carers of patients with a kidney transplant reported significantly higher quality of life than carers of dialysis patients – mirroring the studies that reported patients with transplants had better quality of life than those using dialysis. Carers of dialysis patients reported quality of life as good (28%), acceptable (44%), mediocre (20%) or poor (8%), thus similar findings to Wicks et al. (1997) and Dunn et al (1994).

The studies therefore contradict each other, with some reporting that for most relatives quality of life was moderate or good, and others that quality of life was reduced compared to the general population. It is therefore difficult to establish carers' quality of life and additional studies are thus required.

Correlating quality of life with other variables

Three of the studies considering family members focus on correlating quality of life with perceived burden of caring, reporting an inverse relationship between the two variables following the use of the Zarit Burden Scale (Alvarez-Ude et al. 2004, Shimoyama et al. 2003) or a Caregiver Burden Interview (Wicks et al. 1997). Depression was also identified as a concern for carers of patients using dialysis - 14% of participants in Morelon et al.'s (2005) study reported depression and Alvarez-Ude et al. (2004) warned that 28.3% of their sample were at risk of clinical depression. These studies therefore highlight the importance of ensuring that relatives feel adequately supported to adopt caring roles and cope with their relative's diagnosis.

Reviewing the quantitative studies considering families' quality of life highlighted disparities in research designs, data collection tools, findings and recommendations between studies. The few studies which examined familial quality of life highlighted a significant inverse relationship between quality of life and burden, which suggests that further support for families is needed.

3.4.3 Summary of quality of life studies

Therefore, the substantial body of literature indicated that patients with end-stage renal disease had reduced quality of life. There was disagreement between studies as to whether haemodialysis or peritoneal dialysis was associated with better quality of life, which is possibly due to the variety of assessment tools used to measure the phenomenon and the variety of populations included. However, it is questionable whether these assessment tools provide sufficient detail regarding patients'

experiences of undertaking renal replacement therapies, as they do not allow patients to provide additional information about matters important to them. The use of these studies is also uncertain, as patients' preference for one treatment over the other is highly subjective, and for some patients they have little choice between treatments, for example a patient with poor venous access has little choice but peritoneal dialysis, and a patient with peritonitis may require haemodialysis. De Vecchi et al. (1994) also highlighted that patients prefer the type of dialysis that they are using rather than a treatment they used before. Therefore, it may be more important to help patients choose the right treatment for them and to avoid unnecessary changes between peritoneal and haemodialysis, rather than attempting to decide which type of dialysis leads to "better" quality of life.

End-stage renal disease and renal replacement therapies were thus associated with reduced quality of life both for patients using the treatment and their wider families. A significant number of studies quantified patients' quality of life, while fewer considered their families'. A significant body of literature has also sought to quantify and explore depression in patients using renal replacement therapies, and this is discussed next.

3.5 Depression

Depression can have a profound impact on an individual's life and responsibilities (World Health Organisation 2010), and is defined as:

a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration (World Health Organisation 2010)

However, depression can be potentially difficult to both assess and diagnose in patients with end-stage renal disease, due to the symptoms of depression – disturbed sleep, anorexia, fatigue and reduced concentration – being associated with symptoms of end-stage and chronic kidney disease (Kimmel 2002). Furthermore, depression has been found to be under-diagnosed and undertreated in vulnerable patients using dialysis (Einwohner et al. 2004). Depression is intrinsically associated with quality of life, and multiple quality of life studies outlined earlier in the Quality of Life section and summary table allude to depression.

Eight studies were identified that considered depression in patients using renal replacement therapies, four of which included patients undertaking peritoneal dialysis

only and it is the latter that will be considered first. The data extraction table in Appendix Eight details each of the studies discussed below.

3.5.1 Depression in patients using peritoneal dialysis

These studies are recent and originate from four countries: the USA (Hong et al. 2006), Turkey (Bilgic et al. 2008), Hong Kong (Chan et al. 2011) and Singapore (Yu et al. 2012).

Prevalence of depression

All four studies quantified the prevalence of depression within their samples: 34.4% (Hong et al. 2006), 37% (Chan et al. 2011), 40% (Yu et al. 2012) and 53.3% (Bilgic et al. 2008) indicating a significant problem. The numbers of participants varied between studies: 64 (Hong et al. 2006), 141 (Chan et al. 2011), 20 (Yu et al. 2012) and 60 (Bilgic et al. 2008). Only Chan et al. (2011) adopted a rigorous approach to sampling, using a random sample and confidence intervals to decide its size (n=141). The other studies either used a convenience sample of eligible participants (Hong et al. 2006, Yu et al. 2012) or did not specify. A more appropriate sampling strategy for these quantitative studies would be probability samples (Thompson 1999), to allow for a more representative sample of the population. Possibly the small number of eligible patients at the researched dialysis centres made this technique unrealistic.

The studies used a varied selection of assessment tools: the Beck Depression Inventory (BDI) (Bilgic et al. 2008), Hospital Anxiety and Depression Scale (HADS) (Yu et al. 2012), a structured clinical interview for Diagnostic and Statistics Manual for Mental Disorders (DSM-IV) (Chan et al. 2011) and two questions about quality of life (Hong et al. 2006). While the BDI, HADS and DSM-IV are all validated tools for assessing depression, Hong et al. (2006) however asked their peritoneal dialysis participants two questions relating to depression, but they offered no insight into whether these questions had been validated for sensitivity and specificity. This therefore brings the validity of Hong et al.'s (2006) study into question. However, Hong et al. (2006) identified depression in 34.4% of their sample (34.4%); reporting similar prevalence to Chan et al. (2011) (37%).

Prevalence of depression over time

Three of the studies were cross-sectional and thus provided information about depression in their sample at a single time point. However, Hong et al. (2006) undertook a longitudinal study over two years with their sample of peritoneal dialysis

patients (n=64) in the USA, but they gave remarkably little detail about whether depression changed over time. Chan et al. (2011) identified that 21% of their sample (n=141) had past major depression, indicating that depression was a problem over time. They also identified that only 20% of participants with depression in their study were receiving treatment for the condition. This reiterates Einwohner et al.'s (2004) argument that depression was poorly identified in patients with end-stage renal disease, possibly due to the symptoms of depression being mistaken for symptoms of renal disease (Kimmel 2002).

Correlating depression with other factors

All of the studies used further assessment tools to identify whether depression was associated with other factors, such as quality of life or sleep. Hong et al. (2006) assessed participants' uraemic symptoms and used a likert scale to quantify quality of life. They identified that there was a significant association between depression, uraemic physical symptoms and quality of life. Bilgic et al. (2008), who included 60 participants using peritoneal dialysis, also used the MOS SF-36 to assess quality of life and also the Pittsburgh Sleep Quality Index, identifying that patients had suboptimal quality of life. Depression and poor sleep (present in 31.7% of participants) were associated with decreased quality of life. Furthermore, Chan et al. (2011) used the Cumulative Illness Rating Score and Multidimensional Scale of Perceived Support, and identified that depression was associated with perceived poorer social support, as were muscle cramps, chronic back pain and joint stiffness. Finally, Yu et al.'s (2012) small study with 20 patients using peritoneal dialysis also administered the Beliefs about Medicines Questionnaire, three items to assess adherence to medication, diet and dialysis regime, the Kidney Disease QOL tool, the MOS SF-12 and six kidney disease subscales (symptoms, effect, burden, social support, satisfaction and staff encouragement). They found that depression was not associated with adherence and that the symptoms of the disease had a negative impact on quality of life, while patients relied heavily on family members.

The studies therefore provided important, if heterogeneous, additional information to contextualise depression in their participants. Overall, the studies identified that depression was associated with reduced quality of life, perceived worse social support, distressing symptoms of uraemia and other conditions such as chronic back pain. While these studies thus used useful additional tools to provide insight into depression and other factors, the variety of assessment tools makes it difficult to draw comparisons between studies.

3.5.2 Depression in patients using all renal replacement therapies

The four studies comparing patients using renal replacement therapies were more homogenous, using similar samples and assessment tools. Interestingly, three of the studies were conducted from 2003 in the UK (Billington et al. 2008, Griva et al. 2010, Martin et al. 2003), while an early study considering depression took place in the USA (Sacks et al. 1990). All the studies assessed depression at a single time-point through the adoption of cross-sectional designs only.

Prevalence of depression

The studies used either the Beck Depression Inventory (Griva et al. 2010, Sacks et al. 1990) or the Hospital Anxiety and Depression Scale (Billington et al. 2008, Martin et al. 2003), but despite this the studies reported different rates of depression. Sacks et al. (1990) included patients using CAPD (n=14), haemodialysis (n=43) and with chronic kidney disease (n=16), and found that all participants were mildly depressed, with similar rates of depression between patients using peritoneal and haemodialysis. A later study by Billington et al. (2008) included patients using peritoneal (n=25), and home and hospital haemodialysis, and found that 39% of the sample were depressed, while 38% reported anxiety. One limitation of the studies by Billington et al. (2008) and Sacks et al. (1990) is the small number of participants using peritoneal dialysis, making it difficult to extrapolate these figures to wider populations. Additionally, Billington et al. (2008) unfortunately do not specify whether rates of depression varied between participants using different types of dialysis. This is significant as Griva et al. (2010) and Martin et al. (2003) identified that depression varied considerably between patients using different renal replacement therapies. Griva et al. (2010) included patients using peritoneal dialysis (CAPD=45, APD=23), hospital and home haemodialysis. They reported the overall prevalence of depression to be 38.6% (thus comparable to Billington et al. 2008), but in terms of treatment: home haemodialysis 8%, APD 26.1%, haemodialysis 42.4% and CAPD 48.9%. Patients using CAPD or haemodialysis therefore had much higher rates of depression compared to patients using APD or home haemodialysis. It is thus important to consider rates of depression between samples of participants using different renal replacement therapies, as the mean depression score may mask significant differences between groups of participants. Furthermore, Martin et al. (2003) included patients using peritoneal dialysis (n=72), haemodialysis (n=28) and with a kidney transplant (heart-beating cadaveric n=18; non-heart-beating cadaveric

n=21; live-related transplant n=21¹). While Martin et al. (2003) do not specify the prevalence of depression in each group, they do report that patients using haemodialysis or with a live-related transplant had the highest rates of depression and anxiety. This therefore contradicts Griva et al.'s finding above. Nonetheless, it is important to recognise that depression may vary between patients using different types of renal replacement therapies.

Depression is therefore a significant problem for many patients using renal replacement therapies, despite disagreement between studies of the prevalence of depression. The use of similar tools should make studies more comparable, yet there are disparities. However, the overall prevalence of depression appears to have decreased since 1990 when Sacks et al. reported that all patients had mild depression.

Correlating depression with other factors

Interestingly, these studies focussed on considering depression in relation to perceptions of illness and hope, rather than the peritoneal dialysis-only studies, which concentrated on the relationship with quality of life. With the exception of Martin et al. (2003), the other studies considered depression in relation to several variables. Billington et al. (2008) used the Trait Hope Scale, Significant Others Scale, Health Locus of Control and the Kidney Disease QOL scale, and identified that patients reported high burden from end-stage renal disease. Crucially, hope was inversely related to anxiety and depression and Billington et al. (2008) reported that hope can act as a buffer against affective disorders. Sacks et al. (1990) utilised the Perception of Illness and Role Disruption Questionnaire, finding that perception of illness correlated with depression and role disruption. Griva et al. (2010) also found that depression correlated with higher illness and treatment disruption and symptoms. They used the End-Stage Renal Disease Severity Index, Illness Perceptions Questionnaire, Perception of Illness and Treatment Effects Questionnaire. Sacks et al. (1990) recommended the assessment and modification of patients' illness perceptions, and Billington et al. (2008) advocated that healthcare professionals promote hope in patients with end-stage renal disease through therapeutic activities. The potential for healthcare professionals to change patients' illness perceptions and promote hope is questionable.

¹ Heart-beating cadaveric transplant from ITU; non-heart-beating cadaveric from A&E; live-related transplant from a relative

Summary of studies

Depression has a profound negative impact on the individual, and healthcare professionals thus have a responsibility to identify and treat depression in patients. These studies have indicated that depression was a problem for patients with end-stage renal disease, despite differences in prevalence between studies and populations of patients. One recommendation arising from several studies was routine assessment of depression and additional support from healthcare professionals. Some of the drawbacks of these studies have also been considered, with additional longitudinal research possibly being useful to illuminate the incidence of depression over time.

3.6 The chronic illness trajectory: a sociological approach

The focussed literature review thus highlighted the dominant themes in the renal literature, demonstrating the varied picture between the small number of relevant qualitative studies and the large number of quality of life studies that compared patients using different renal replacement therapies, with additional studies that quantified depression in this population. However, as the study progressed, it became apparent that these bodies of literature were insufficient to fully explore the challenges that a chronic illness such as end-stage renal disease generates. Therefore, further literature was searched that explored chronic illness, but due to the nature of the sociological chronic illness literature this search evolved organically, with initial texts identified through the reference lists of the qualitative renal literature. Chronic illness, defined as “conditions from which there is no possibility of a complete return to the pre-morbid state” (Taylor and Field 2003, p.117), has been researched extensively by sociologists and therefore for the purposes of this thesis, the seminal research was identified and discussed. The term “chronic illness” has been superseded by “long-term conditions” in research, clinical practice and government policy in recent years, however the literature here will be presented with the title “chronic illness” in keeping with the classic literature.

Unlike the renal literature, which is mostly published in a structured article format, the sociological literature is presented in extended articles and monographs, often with little explanation of methods and sampling. The literature focuses on a variety of conditions, using either one chronic illness to explicate issues relevant at a broader level (Bury 1982) or including individuals with different chronic illnesses and their relatives (Charmaz 1991, Corbin and Strauss 1988), using qualitative interviews to

gather data. Furthermore, other influential texts provide a useful overview of other researchers' primary work (Kelly and Field 1996, Nettleton 1995).

Rolland (1987) suggested that considering chronic illness as a trajectory could help healthcare professionals to understand it longitudinally, and acknowledge the changing nature of the condition. Corbin and Strauss (1988) argued that the volatile nature of disease and families' responses to it cannot be predicted. Understanding the required care only comes from the daily management of the disease at home (Corbin and Strauss 1988), which changes in response to alterations in the course of the illness. Rolland (1987) asserted that chronic illness has three stages:

- Crisis: pre-diagnosis of the chronic disease, where the patient is symptomatic of the disease, and the initial adjustment period where the patient and family acknowledge the condition and begin to adjust to it;
- Chronic: after the diagnosis and acknowledgement of the condition and before the terminal phase of the illness;
- Terminal: pre-terminal where the individual and family begin to understand the inevitability of death, and finally the mourning stage following death where the family reformulate their normality.

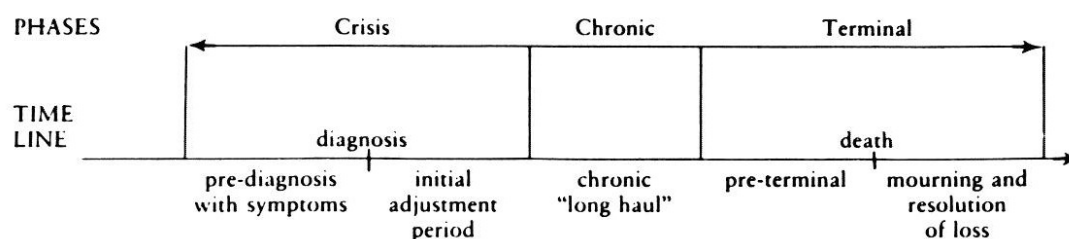


Figure 3: Time line and phases of illness (Rolland 1987, p.4)

These three phases can help facilitate an understanding of the changing and longitudinal nature of chronic disease, and the impact at each stage on the patient. It has also been more recently suggested that considering the illness trajectory for chronic disease can help healthcare professionals to plan and provide appropriate care for patients and their families (Murray et al. 2005).

Corbin and Strauss (1988) introduced the idea of "biography" (p.50), referring to an individual's life course of their experiences and identity, which will influence and be influenced by the management of the chronic illness. Biography includes three elements (Corbin and Strauss 1988):

- Biographical time: this refers to the individuals' perception of time, including their past, present and future, also encompassing the idea that our reaction to past events will influence our future reactions; as earlier suggested by Mead (1934);
- Conceptions of self: the unique experiences of life help individuals to interpret and react to events, changing their self-concept and thus their reaction to the situation;
- Body: as the body is responsible for managing an individual's idea of their self, it evolves according to the individual's ability to perform the tasks necessary to maintain their idea of self.

Corbin and Strauss (1988) highlight that illness trajectories are shaped not only by the nature of the chronic disease and individuals' responses to it, but by the input from healthcare professionals and family members. The idea of "biography" thus helps understanding of the impact of chronic illness on an individual's life course, and how they may respond to the stages proposed by Rolland (1987) in the illness trajectory of chronic illness. The three phases of the chronic illness trajectory and how they have been discussed by sociologists are discussed below.

3.6.1 Crisis phase

The diagnosis of a chronic illness marks the beginning of the trajectory and a new phase in the individual's and their wider families' lives. This is termed "biographical disruption" (p.169) by Bury (1982) as chronic illness devastates both everyday life and the individual's sense of self. Kelly and Field (1996) highlighted that the social human is derived from the ability of the individual to control their physical body, with chronic illness altering this. Furthermore, Nettleton (1995) explained that the body is taken for granted until chronic illness and therefore this change to the body affects the individuals' sense of self. Other sociologists, including Corbin (2003), concur. Taylor and Field (2003) suggested that the onset of physical disease impacts on the individual's identity and ability to cope with the condition, proposing three patterns: from birth/infancy, suddenly or over time. Each pattern of onset is associated with different challenges, such as mastering "normal" development skills (from birth), reconstructing everyday life (sudden) and increasing dependence on others (over time) (Taylor and Field 2003). Diagnosis of chronic illness is thus the beginning of a new identity for the individual (Kelly and Field 1996) and marks the beginning of substantial changes to everyday life.

3.6.2 Chronic phase

The major focus of the sociological literature is how individuals, and their spouses, manage chronic illness at home: termed “work”. However, this “work” often relates to managing the symptoms of chronic illness. Charmaz (1991) argued that the experience of symptoms teaches people what it is to have a chronic illness, negatively influencing daily activities. Therefore to minimise the impact of chronic illness and the subsequent symptoms, allowing them to fade into the background of everyday life, people use medical technologies, such as medications (Charmaz 1991). Corbin and Strauss (1985) suggested that advances in science led to treatments for chronic disease being complex and specialised, and it is conceivable that this would be even truer now in the light of ongoing medical research.

Charmaz (1991) explained that managing a chronic illness requires time and effort, but that over time the associated struggles become the norm for the individual and their family. The expertise and knowledge required to manage a chronic illness are learned over time (Nettleton 1995, Bury 1991), which results in the individual perceiving that they have a degree of control over their illness (Charmaz 1991). While individuals with a chronic illness may attempt to keep the condition at the edge of their lives, for some people their lives are restructured around and dominated by the illness (Charmaz 1991). Rolland (1987) described the chronic phase of the illness trajectory as the “long haul” (p.207) and sociologists have recognised the suffering that chronic illness brings to the individual, where their lives are “invaded” by the disease (Bury 1982, p.173). Suffering in chronic illness is caused by reduced physical capability (Kelly and Field 1996) and the emotional pain of changes to the self that changes in response to the physical impact of disease (Corbin 2003).

The sociological literature also recognises the role that relatives play in helping the individual to manage chronic illness and the burden this places on the wider family (Corbin and Strauss 1988, Charmaz 1991, Nettleton 1995). While Corbin and Strauss (1988) suggest that the work of managing chronic illness is shared between the individual, their family and friends, and healthcare professionals, they also highlight that unless the individual lives alone their partner will assume the majority of responsibility (Corbin and Strauss 1985). Corbin (2003) later suggested however that medical technology leads to the division of labour being unequal, with one partner carrying the burden, but not necessarily the patient. The supportive roles within a family are disrupted when chronic illness is present, leading to unequal work

distribution and children taking on unusual roles where they contribute to the work of managing the illness (Bury 1982).

3.6.3 Terminal phase

While some chronic illnesses, such as end-stage renal disease, are considered palliative (non-curative), not all chronic illnesses will in themselves lead to death. There is much written about death and dying in the sociological (and health) literatures and a literature review exploring this in more detail is beyond the scope of this thesis. The focus of this thesis is on living with end-stage renal disease, although the disease is ultimately terminal. Therefore it is recognised that while patients are in the chronic phase of illness, the possibility of death is associated with uncertainty (Bury 1982) and a lack of control over the body (Charmaz 1991), and thus the possibility of death becomes part of their present. Corbin and Strauss (1988) describe the possibility of death “looming” (p.286) over individuals with life-threatening illnesses, but also highlight the differences in illness trajectories for patients with different diagnoses.

While not assuming a sociological approach, palliative care services have adopted the illness trajectory approach to highlight the differences between the trajectories of dying. An analysis of data from 7,258 patients covered by Medicare (social health insurance) in the USA who died between 1993 and 1998 (Lunney et al. 2002), classified four trajectories of death (sudden, terminal, organ failure and frailty). The classifications of the proposed trajectories of dying (below) exemplify the differences between illness trajectories in individuals:

Proposed Trajectories of Dying

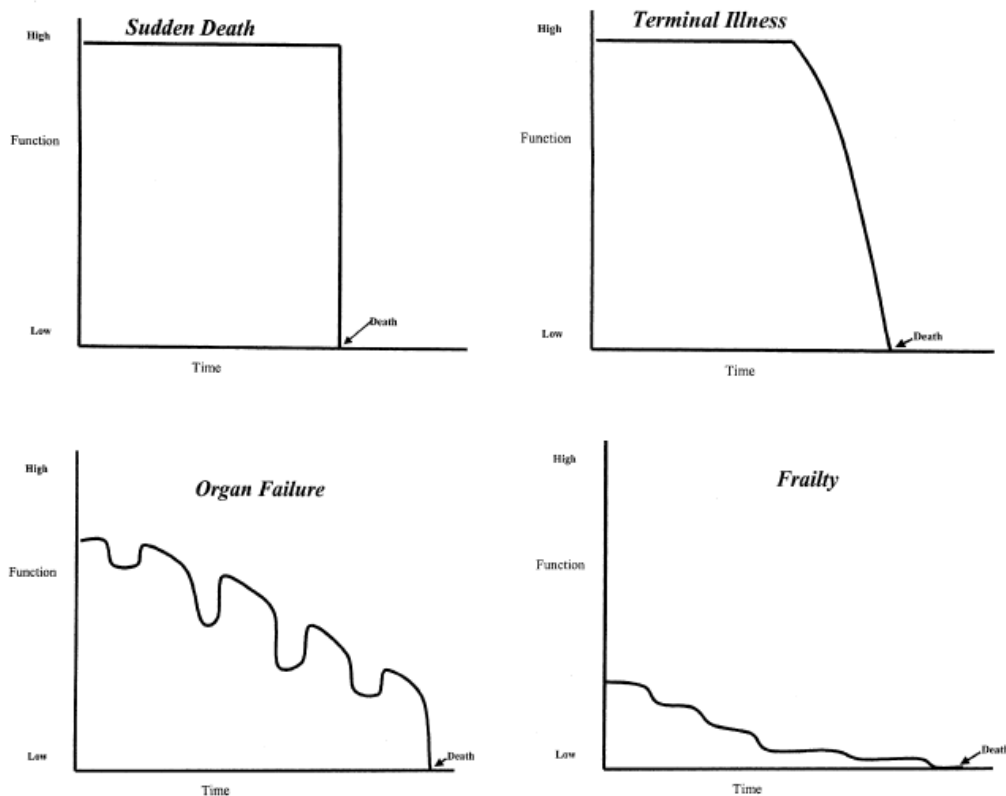


Figure 4: Proposed Trajectories of Dying (Lunney et al. 2002, p.1109)

However, Lunney et al. (2002) specifically excluded patients with end-stage renal disease, although they do not explain why. Palliative care healthcare professionals assert that the trajectory of dying for patients with end-stage renal disease is difficult to predict due to the underlying renal pathology, as well as other co-morbidities in this population, but suggest it may be a steady decline (Murtagh et al. 2004). In recent years the chronic illness trajectory has been adapted for end-stage renal disease and a closer examination of this trajectory is thus pertinent.

3.6.4 End-stage renal disease trajectory

Jablonski (2004) considered the illness trajectory for patients with end-stage renal disease using dialysis (primarily haemodialysis), with several additions to Rolland's (1987) original model. End-stage renal disease impacts on all areas of an individual's life, Jablonski (2004) argued, and thus the dimensions of life must be considered at all times during the crisis, chronic and terminal phases of the illness.

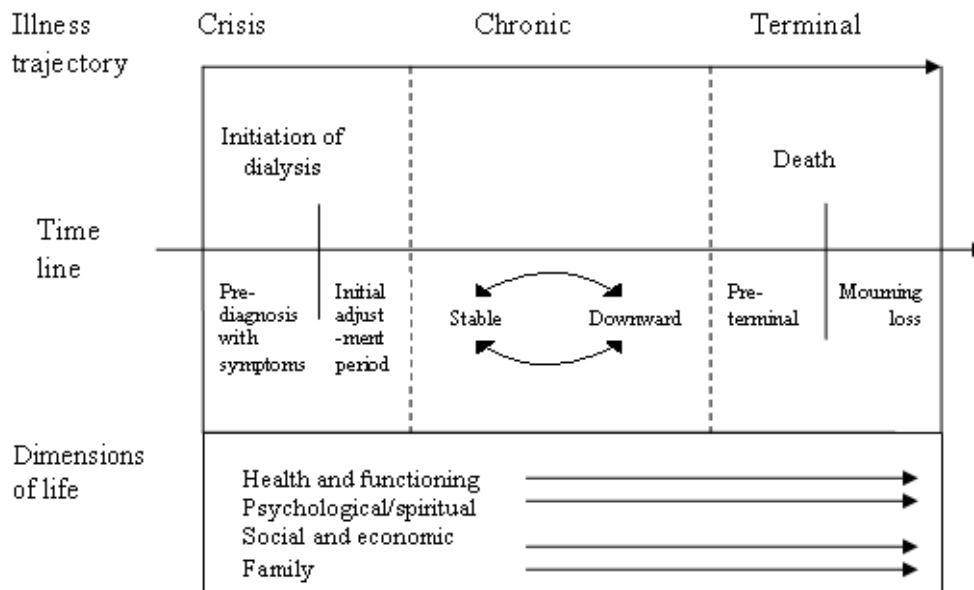


Figure 5: The ESRD illness trajectory and life dimensions (Jablonski 2004, p.54)

The importance of individualised care is emphasised by Jablonski (2004) in her work with patients undertaking dialysis, whereby she added the dimensions of life to Rolland's (1987) model: health and functioning, psychological/spiritual, social and economic, and family. These remind healthcare professionals of the holistic nature of end-stage renal disease, which impacts on all areas of an individual's life. Jablonski (2004) further added "stable" and "downward" phases to the chronic stage of the model, which reflects the clinical reality of living with end-stage renal disease: periods of stability, followed by deterioration (for example fluid overload or infection), then periods of stability and further deterioration.

Murtagh et al. (2008) argue that it is essential for healthcare professionals responsible for patients with end-stage renal disease to appreciate the illness trajectory of the disease, particularly as this patient population is aging and patients typically have multiple co-morbidities. They also suggest that the trajectory may help patients to understand the course of their illness (Murtagh et al. 2008). The illness trajectory of end-stage renal disease is highly individualised for patients, due to the different treatment options in the chronic phase: renal replacement therapies versus conservative management. The terminal phase also differs between patients, due to the sudden nature of death associated with cardiovascular complications in some patients with end-stage renal disease, with other patients having a more gradual decline (Murtagh et al. 2008).

The sociological theory of illness trajectories will thus act as a conceptual framework and will guide this thesis when considering how end-stage renal disease impacts on the individual and their family. While the research topic, questions and overall research design predated the discovery of this framework and arose from my clinical and research experience, I found it useful to use this framework when considering the detailed questions and later in the organisation of the research themes derived from the data.

3.7 Chapter conclusions

This literature review has sought to explore how peritoneal dialysis affects individuals and their families. Despite a considerable body of literature exploring patients' experiences of end-stage renal disease or dialysis, fewer studies were found that specifically explore patients' experiences of undertaking peritoneal dialysis. Therefore, the literature review included studies exploring patients' and families' perceptions regarding end-stage renal disease and dialysis, focussing on peritoneal dialysis where possible.

The small body of qualitative literature considering patients' perspectives of end-stage renal failure and peritoneal dialysis was analysed and synthesised into three themes, demonstrating the impact of both on everyday life, how patients coped with these impacts through hope, family, staying positive and control, and whether acceptance was reached. The smaller number of studies with patients' families revealed the variety of caring tasks undertaken, the negative impact of this on the family and how families coped, including hope and flexibility. The patient literature demonstrated that end-stage renal disease and dialysis are associated with increased rates of depression and worsened quality of life. The literature was inconclusive regarding which dialysis modality is associated with better quality of life, possibly due to the different populations included and the different questionnaires administered. A smaller number of studies also demonstrated that relatives' quality of life can be worsened by dialysis. However, these studies also revealed further insight about how peritoneal dialysis affects the individual, in terms of increased confinement and burden, while maintaining social functioning.

The broader sociological literature considering chronic illness was then explored in relation to the theory of illness trajectories. The seminal chronic illness texts were presented in relation to three stages of chronic illness, while this theory was then

explored in relation to end-stage renal disease. This conceptual framework will be referenced throughout the thesis due to the role that it played in planning and undertaking this research: discussed in chapter four.

3.7.1 Gap in the literature

There are few qualitative studies that have specifically focused on the experiences of patients undertaking peritoneal dialysis and their families, with only one UK study identified (Wright and Kirby 1999). No ethnographic studies with patients undertaking peritoneal dialysis or their families were identified, yet ethnography provides the opportunity to “understand another way of life from the native point of view” (Spradley 1980, p.3) and learn from the participants – thus collecting rich, holistic data. Therefore, the next chapter will present a study qualitatively exploring the impact of peritoneal dialysis on patients and their families in the UK, using ethnographic methodology.

Chapter Four: Methodology and Methods

4.1 Introduction

Crotty (1998) suggested that there are four elements to the research process, with the elements guiding each other: Epistemology; Theoretical Perspective; Methodology and Methods. Ensuring that each element is considered when planning a research study permits the researcher to maintain that the study is thorough and its outcomes credible (Crotty 1998). However, Crotty also highlighted that in reality this is not a linear process. While all four concepts are considered and encompassed within this thesis, this chapter will focus on the methodology (ethnography) chosen and methods (interviews and observations) employed. The epistemological perspective of the researcher (social constructionism) and the impact of this on the data generation process will also be recognised, while the previous chapter introduced the conceptual framework – chronic illness trajectories – guiding this study.

4.2 Aim, research questions and study design

4.2.1 Research aim and questions

The aim of this research was to explore the experience of home peritoneal dialysis from the perspectives of patients, their families and healthcare professionals in the UK. The specific research questions are:

- What influences patients' decisions to choose peritoneal dialysis?
- How does peritoneal dialysis impact on life and the home environment?
- How is peritoneal dialysis managed at home?
- How is peritoneal dialysis integrated into everyday life?
- How do families perceive having a relative at home and what contribution do they make to the process?

4.2.2 Study design

A qualitative study design was employed, more specifically utilising ethnographic methodology. Ethnography was considered the most appropriate methodology to meet the aim and objectives of the study, while in-depth interviews and observations were undertaken with a volunteer and then purposively sampled group of patients using peritoneal dialysis (n=16). Nine relatives were also recruited through

convenience sampling, most of whom were interviewed with the patient participants. A convenience, snowball sample of healthcare professionals (n=7) was also interviewed, to provide a broader perspective on how patients and families experience peritoneal dialysis and how they are supported by healthcare professionals.

The only two previously identified ethnographic studies with dialysis patients included Burnette and Kickett's (2009) work with Australian Aboriginal individuals using dialysis, but only two patients undertaking peritoneal dialysis were included. Furthermore, Burnette and Kickett (2009) did not include the observation of participants that characterises ethnographic work (Hammersley and Atkinson 1995). Blogg and Hyde's (2008) ethnographic work included a three-hour observation with the carers (n=5) of patients undertaking home haemodialysis in Australia, during which a semi-structured interview was conducted. However, their publication fails to include any fieldnote extracts and specifically focuses on haemodialysis. No previous ethnographic studies were identified in the UK with patients undertaking peritoneal dialysis and their relatives.

4.3 Ethnographic methodology

Ethnography is concerned with producing descriptions and explanations of phenomena (Hammersley and Atkinson 1995), and the ultimate purpose is the production of knowledge (Atkinson and Hammersley 1994). Spradley (1980) stated that the aim of ethnography is to portray a culture and "to understand another way of life from the native point of view" (p.3) - the central focus, therefore, is not studying the participants, but learning from them. It is an holistic approach (Liehr and Marcus 2002), involving the researcher participating in the everyday lives of the people they are studying, watching, listening, asking questions - collecting whatever data is available to uncover the issues (Hammersley and Atkinson 1995). Cresswell (1998) discussed the process of ethnographic work as typically involving observing a group for an extended period, where the researcher is involved in the everyday activities of the group. Detailed data is thus collected about the participants' world, and in-depth understanding of their views is developed (Denscombe 1998).

4.3.1 Choosing ethnography

I was familiar with other qualitative methodologies and approaches, but relatively quickly ethnography appeared the most suitable. Multiple studies identified in the literature review used phenomenology (both Husserlian and Heideggerian), but as

phenomenological data is collected via interviews only (Lavery 2003), I felt this would not provide the detail required to understand the complex impact of peritoneal dialysis on life at home. Several studies in the literature review utilised a form of grounded theory (either that described by Glaser and Strauss, or Strauss and Corbin). However, Glaser and Strauss's inductive approach involved using literature and theory to support emerging findings, while Strauss and Corbin undertook a preliminary literature review before generating data and following an iterative analytic cycle (McCann and Clark 2003). I felt that because I had worked as a staff nurse with patients using peritoneal dialysis, their families and healthcare staff, and had also started reviewing the literature to answer questions I had formulated when working clinically, I was too close to the topic to use a grounded theory approach. Therefore, this methodology was not considered appropriate for the project. The flexibility of case study research was appealing, encouraging the use of multiple data generation methods (Yin 1994). However, I felt that case study methodology was not fitting for the project due to the approach of generating predetermined propositions/hypotheses prior to data collection, which are fundamental to case study research (Yin 1994). The aim of this study was to learn from participants about their lives using peritoneal dialysis, rather than comparing data to propositions.

Observing people actually using this home medical treatment appeared fundamental to meet the aim and research questions: to understand patients' and families' perspectives and identify how peritoneal dialysis impacts on their lives. Therefore, adopting ethnographic methodology seemed the most appropriate for this study. The methods section of this chapter and the discussion chapter will explore the choice of methodology in more depth. Understanding the history surrounding ethnography was important prior to commencing data collection, and an overview is provided next.

4.3.2 Historical overview of ethnography

Debate exists about the origin of ethnographic research, which Atkinson and Hammersley (1994) asserted began with a shift in anthropologists collecting data first hand. Atkinson and Hammersley (1994) further commented that two stages existed in the emergence of ethnography: the Founders of Modern Anthropology and the Chicago School of Ethnography. The Founders of Modern Anthropology included Boas, Malinowski and Radcliffe-Brown, who collected information firsthand and described social and cultural characteristics (Atkinson and Hammersley 1994). This enabled the collection of tangible evidence about people's lives (Davies 1999). Atkinson and Hammersley (1994) suggested the founders perceived that social

phenomena needed to be understood for their distinctive nature, which created a tension between humanities and science. The Chicago School of Ethnography held a similar orientation and was influenced by pragmatist philosophers such as George Mead, who attempted the synthesis of science and humanities (Atkinson and Hammersley 1994).

However, Deegan (2007) strongly asserted that ethnography emerged in the early 20th century at the University of Chicago, where Robert Park and Ernest Burgess mentored students undertaking seminal ethnographic studies (Deegan 2007), including Anderson's (1923) *"The Hobo: the Sociology of the Homeless Man"*, Thrasher's (1927) *"The Gang: a study of 1,313 gangs in Chicago"* and Wirth's (1928) *"The Ghetto"*. The basic principle of the emergent Chicago School of Ethnography, was not to apply strict criteria to the research process, but instead to embrace an open attitude to "people, data, places and theory" (Deegan 2007, p.11) – incorporating triangulation of data (both qualitative and quantitative). Park and Burgess interlaced their students' ethnographies together, creating a "theoretical tapestry" (p.13) of scholarship and a "systematic theory and method" (Deegan 2007, p.14). Deegan's (2007) assertion that Park and Burgess personally mentored students with their ethnographic work is appealing, but is not consistent with a comment made by Anderson, who wrote in the introduction to a later edition of his work *"The Hobo: The Sociology of the Homeless Man"* (originally published in 1923), that the majority of the guidance he received from Park and Burgess was "indirect" (p.xii), further commenting:

The only instruction I recall from Park was "Write down what you see, hear, and know, like a newspaper reporter" (Anderson 1967, p.xii)

The Chicago School of Ethnography created a "vibrant and flexible theory of everyday life" (Deegan 2007, p.19), encouraging researchers to use multiple data generation methods, including living in the setting, working for local organisations, and acquiring autobiographical data from residents. The field of ethnography has developed over the last ninety years, with other professions – including nursing – adopting the principles endorsed by Park and Burgess to gain a holistic understanding of participants' worlds.

George Mead (1934) declared the self a product of social experience, and this idea is implicit in ethnographic work:

the self is something which has a development; it...arises in the process of social experience and activity...develops in the given individual as a result of

his relations to that process as a whole and to other individuals within that process (Mead 1934, p.135)

Mead's idea is therefore central to ethnography and suggests that individuals cannot be studied outside of their social environment or separate from peers who influence their development of self. This highlights the ideas of Corbin and Strauss (1988) discussed in relation to illness trajectories in chapter three, who argue that it is vital to consider the biographies of individuals when understanding their reaction to chronic illness.

4.3.3 Continuum of ethnography

Ethnography is not a prescriptive methodology and can be applied in a variety of settings to explore different issues (Savage 2000). Classic ethnographies, such as those named above, involved the researcher living as part of the cultural group and taking part in their social actions. Later ethnographies, such as Heyl's (1979) "The Madam as Entrepreneur", involved the researcher interviewing and observing participants over a prolonged period, but without necessarily partaking in activities.

Ethnography has been used widely in health and nursing research, in particular to explore the culture of different clinical environments, such as a medical assessment unit (Griffiths 2010), fertility unit (Allan and Barber 2005) and rehabilitation unit (Sinclair et al. 2009). Additionally, ethnography has been used to examine how healthcare is delivered or used in the home environment, such as partners' experiences of administering home haemodialysis (Blogg and Hyde 2008) and the home hospice care provided by nurses (Wright 2001). In these studies, the use of method again varies, such as one three hour observation incorporating an interview (Blogg and Hyde 2008); observing a medical assessment unit over three years, working as part of the clinical team to provide care and interviewing healthcare professionals (Griffiths 2010); and observing a fertility unit for four weeks and undertaking semi-structured interviews with healthcare professionals (Allan and Barber 2005). Therefore, ethnography has been utilised in varying ways, according to the research questions of the study and how these can be answered ethically.

Undertaking research in the home setting with participants who have a long-term health condition is not congruent with the early forms of ethnography. However, the advantages of the methodology, such as combining methods, can still be applied in the home setting. The following section explores the use of methods within this study

and the chapter eight discusses how successfully ethnographic methodology and methods were applied in this thesis.

4.4 Methods and the reality of data generation

This section will consider the final element of Crotty's (1998) research process: the methods employed to undertake the study. Firstly, negotiating access to the patient population will be discussed, before the recruitment and sampling techniques employed are described. The methods used to generate and analyse data are then presented, before my epistemological perspective is acknowledged. Finally, credibility, dependability, transferability and confirmability and how they were promoted in this thesis are explored.

4.4.1 Negotiating access

Hammersley and Atkinson (1995) described the difficulty of gaining access for ethnographic research, and of maintaining it throughout the project. There are five renal units in Wales that offer peritoneal dialysis (The Renal Association 2010) and a large university teaching hospital covering a substantial rural and urban population was approached for access. This hospital was chosen as it has the largest cohort of patients undertaking peritoneal dialysis (The Renal Association 2010), it was convenient geographically and I had previously worked as a staff nurse on the Nephrology ward. The Consultant Nephrologist and Home Dialysis Manager agreed that their population of adult patients undertaking peritoneal dialysis could be approached, with the Nephrologist acting as a local collaborator and the Manager agreeing to assist with the recruitment of participants. I was careful to keep in regular contact with both healthcare professionals, seeking their input and explaining my progress, to maintain a good working relationship with them. During data generation the Home Dialysis Manager left the Health Board and I therefore subsequently linked with a clinical nurse specialist in the Nephrology department.

4.4.2 Recruiting and sampling participants

Three groups of participants; patients, relatives and healthcare professionals; were recruited to take part in the study. I recruited patients and relatives as I anticipated that using home medical technology would impact on the wider family. Furthermore, I hoped that including nephrology healthcare professionals, who are experienced at caring for patients with end-stage renal disease, may provide a broader perspective about how patients are trained to use the technology, live with the treatment and are

supported to do so by healthcare professionals. Three different recruitment and sampling strategies were thus used, which are discussed below.

Recruiting and sampling patients

Patients undertaking peritoneal dialysis were recruited from the participating Health Board. To promote inclusivity, patients over the age of 18 who had undertaken peritoneal dialysis for more than three months and were under the care of the Consultant Nephrologist for peritoneal dialysis at the participating Health Board were sent a letter from the Home Dialysis Manager, with a copy of the participant information sheet. In the renal literature it is commonplace to include patients in research after they have received treatment for three months (Alvarez-Ude et al. 2004, Harris et al. 2002, Lindqvist et al. 2000, Madar and Bar-Tal 2009, Moreno et al. 1996) to allow time for adjustment. The participant information sheet was written in accordance with guidance from the Royal College of Nursing (2005) and requested that interested patients return a form (stating their name, address, length of time and type of peritoneal dialysis, and who they live with) in an enclosed envelope stamped and addressed to the researcher. The Home Dialysis Manager did not send information sheets to two patients, as she felt that they potentially posed a risk to me visiting them at home, and therefore in total 78 patients received information packs.

I received responses from 24 patients, yielding a 30.8% response rate, which I felt was acceptable as the study required both interviews and observations with patients and their families. The respondents included seven women and 17 men, with 22 responses being from patients over 60. However, the respondents were from varying geographical areas and included a good distribution of patients undertaking CAPD or APD. The majority of respondents lived with a spouse or partner, while one respondent lived alone and two with their sons.

Coyne (1997) argued that the sampling strategy employed in qualitative research “has a profound effect on the ultimate quality of the research” (p.623), while Hammersley and Atkinson (1995) highlight the importance of adequate sampling. In order to select a sample from the respondents I used a maximum variation purposive sample (Patton 2002), which allowed for variety within the sample, such as age, gender and location. Patton (2002) argued that this sampling facilitates two types of findings, both important for qualitative research: detailed descriptions of each case and common patterns that arise from the cases. I therefore chose a sample of participants of different ages, from different geographical locations, using the two

different types of peritoneal dialysis (CAPD and APD) and undertaking the treatment for different amounts of time. The sample is outlined in the table below. All patients were assigned a pseudonym.

	Age range	Time using PD	Type of PD	Lives with	Location
<i>Aileen</i>	71-75	>6 years	CAPD	Alone	City
<i>Benjamin</i>	71-75	>6 years	APD	Wife	Town
<i>Carl</i>	66-70	3-4 years	Both	Wife	Town
<i>Daniel</i>	71-75	2-3 years	APD	Wife	Town
<i>Evelyn</i>	66-70	>6 years	CAPD	Husband	Village
<i>Frank</i>	71-75	6-12 months	CAPD	Wife	Town
<i>Geraint</i>	61-65	>6 years	CAPD	Wife	Town
<i>Harriet</i>	61-65	4-5 years	APD	Partner	Town
<i>James</i>	71-75	1-2 years	Both	Wife	Village
<i>Kris</i>	81-85	>6 years	APD	Wife	Village
<i>Leila</i>	61-65	2-3 years	CAPD	Husband/ sons	City
<i>Matthew</i>	61-65	1-2 years	CAPD	Wife	City
<i>Norman</i>	81-85	4-5 years	APD	Son	Town
<i>Oliver</i>	66-70	3-4 years	APD	Wife	Town
<i>Paul</i>	61-65	3-4 years	CAPD	Wife	Village
<i>Rhodri</i>	50-54	1-2 years	CAPD	Wife	Village
25% female	Median: 68 Mean: 68.8	Median: 2.9 yrs Mean: 3.5 yrs	CAPD: 50%	87.5% with spouse	50% Town

Table 6: Patient sample

The Renal Registry collects and collates information about patients undertaking renal replacement therapy in the UK, which provides a useful point of comparison for the sample in this study. The median age of participants in this study was 68 years old, while the average age of a patient undertaking peritoneal dialysis in Wales is 64.8 years (Steenkamp et al. 2010). Therefore the age of the patients in this study was on average higher than the population using peritoneal dialysis in Wales. The range of ages in this study was 54 – 85, thus encompassing an older population of participants, which will be taken into account when comparing my findings to other studies. There are younger people undertaking peritoneal dialysis at the participating Health Board, but they did not offer to take part in this study. Ethical approvals precluded direct approaches to patients, and possibly their reasons for not volunteering include busy lives with dialysis, families and employment. Only four women were included in the sample, as the other three female respondents were

unable to take part: one respondent died and two received kidney transplants. While there are more males than females undertaking dialysis in the UK, in particular in older patients (Steenkamp et al. 2010), the male-female sample in this study is not entirely representative of the population of patients on dialysis in the UK. This is recognised as a potential weakness of the study.

The median time for a patient undertaking peritoneal dialysis in the UK is two years (Steenkamp et al. 2010) and in this study the median was 2.9 years (35 months) – a difference of almost one year. However, the range of treatment time in this study was six months to seven years, thus including experienced and newer patients and hopefully leading to a variety of patient perspectives concerning peritoneal dialysis. In terms of type of treatment, this study had a split of CAPD (50%) and APD (37.5%), with two participants undertaking both modalities intermittently. In Wales, 85.6% of patients undertaking peritoneal dialysis use CAPD, while only 14.4% use APD (Steenkamp et al. 2010), which again makes this sample appear unrepresentative. However, when looking at the whole UK population of peritoneal dialysis, I found that 53.6% of peritoneal dialysis patients use CAPD and 46.4% use APD (Steenkamp et al. 2010), making my sample more representative. I felt that it was important to include a fair proportion of respondents using each type of peritoneal dialysis, in order to provide an insight into life on peritoneal dialysis, not simply CAPD. Additionally, in Scotland and Northern Ireland there are higher percentages of patients undertaking APD than CAPD (Steenkamp et al. 2010). Finally, I chose to include patients from a variety of geographical locations, where patients were nearer or further away from the hospital where they attend clinic. All but two participants lived with their partner or spouse (Leila lived with her husband and sons), with one participant living alone (with good family support) and the other participant living with his son.

There has been great variation in the renal literature of how many participants undertaking peritoneal dialysis are included in studies, for example Beer (1995) included four peritoneal dialysis patients, while Lindqvist et al. (2000) included 86 patients (PD n=26). I had anticipated that 20 patients should ensure an adequate sample, but I found that because I undertook interviews and observations, often visited participants more than once and included relatives (n=9), I felt that I had reached data saturation after 16 patients. Data saturation occurs when no new information is revealed (Guest et al. 2006), although it is a challenging concept to determine (O'Reilly and Parker 2012). I ceased data generation when I felt that

participants were not revealing vastly different information to each other, which was identifiable through prompt transcription of transcripts and expansion of fieldnotes, and on-going data coding and analysis (which are discussed in detail later in this chapter). Overall, five of the original respondents were not included in the study (excluding respondents who received a kidney transplant or died), and a letter was sent to these individuals thanking them for volunteering.

Recruiting relatives

The patient participant information highlighted that I was also interested in recruiting relatives or friends to take part. I therefore took a relative information sheet and a self-addressed stamped envelope along with me to the patient interviews, for the patient to give to a family member (over 18 years old) whom they wished to invite into the study. I had hoped that this recruitment strategy would ensure that the patient chose a relative they felt was involved in their dialysis and could enable access to a potentially difficult group to contact. Beanlands et al. (2005) add that this approach ensures that patients feel in control of relatives' inclusion and has been successfully used in earlier qualitative studies with patients and families on dialysis (Flaherty and O'Brien 1992). However, in practice the majority of the relative sample (n=7) were recruited as they were present when I explained that research to the patient and they wished to take part, in the form of a joint interview with both the patient and relative. One relative was present during a subsequent observation and expressed a wish to take part. The relative sample is summarised in the table below.

Patient	Relative	Relation	Recruited
<i>Aileen</i>	Abigail	Great-niece	Subsequent observation
<i>Benjamin</i>	Beatrice	Wife	Interview
<i>Carl</i>	Christine	Wife	Returned relative information form
<i>Daniel</i>	Diane	Wife	Interview
<i>Frank</i>	Fiona	Wife	Interview
<i>James</i>	Janice Julie	Wife Daughter	Interview
<i>Kris</i>	Kaye	Wife	Interview
<i>Leila</i>	Lisha	Daughter	Interview

Table 7: Relative sample

I left a relative information pack with participants Aileen, Carl, Harriet, Norman, Oliver and Paul, but only received a response from Carl and Paul's wives. I then went on to interview Carl's wife, but when I emailed Paul's wife (as she requested) I received no

reply. Therefore, this recruitment strategy was not entirely successful and for further research I will consider additional ways of recruiting relatives to take part. Geraint, Matthew and Rhodri declined to have a relative involved in the study.

Interestingly, all the relatives included in the study were female, which was possibly due to the majority of the patient sample being male. Of the four female participants included in the study, one participant (Evelyn) was independent with her dialysis, relying on her daughter for assistance with shopping. Evelyn also cared for her husband who had cancer. Another female participant (Harriet) was assisted by her partner to organise her dialysis supplies and reported that her daughter was involved in her dialysis care. Neither of these participants' relatives responded to the relative information pack. The other two female participants who included relatives in the study (Aileen and Leila) were cared for by female family members. Aileen lived alone but received support from her niece and great-niece, and Leila lived with her husband and two sons but received support from her married daughter who lived locally. It is thus interesting that the relative sample was all female and this will be considered when presenting the findings.

White and Grenyer's (1999) Australian qualitative study with patients using CAPD and haemodialysis (n=22) and their partners (n=22) included an equal number of male and female patients. Therefore their relative sample was 55% female and 45% male, a more representative distribution. However, these authors were able to approach patients directly to take part in the study, which may have increased their ability to recruit a more equal gender proportion. A more recent Canadian qualitative study (Beanlands et al. 2005) asked patients using dialysis to identify a relative who was involved in their dialysis care, resulting in 37 participants of whom 32% were men. Finally, Wright and Kirby (1999) approached 10 patients undertaking peritoneal dialysis and also included five relatives, of whom four were partners and one a daughter. However, they do not discuss the gender of the four partners. Therefore, other qualitative studies with patients on dialysis have included a mix of male and female relatives, but the patients in this study chose female relatives to take part.

Recruiting healthcare professionals

I felt that including a sample of healthcare professionals who work closely with patients undertaking peritoneal dialysis would add a third perspective to the study, offering a wealth of experience with this group of patients and facilitating comparison between issues perceived as important by patients and relatives with those of

healthcare professionals. In order to recruit healthcare professionals I presented the research at a governance meeting for the Nephrology Directorate at the participating Health Board, requesting volunteers. One clinical nurse specialist and one doctor offered to take part. After the interview with the clinical nurse specialist a further three clinical nurse specialists volunteered, three of whom were responsible for pre-dialysis education. Snowball sampling can be criticised for being weak (Streeton et al. 2004), but in this research it was a successful way to recruit a sample that was proving challenging. I received no further volunteers until I spoke to the nurses and renal dietician responsible for the care of patients using peritoneal dialysis, which includes training patients to perform the treatment and monitoring them at home. Although the Home Dialysis Manager had explained the research to the nurses, I requested permission to meet with them to explain the study further because patients were likely to tell them that they had taken part. Following this meeting the renal dietician and one peritoneal dialysis nurse specialist offered to take part, with the final sample consisting of: one senior doctor; four clinical nurse specialists, two of whom had previous expertise in peritoneal dialysis nursing; one peritoneal dialysis nurse and one renal dietician.

4.4.3 Data generation methods: in-depth interviews and ethnographic observation

Two methods were used to generate data for the study: audio-recorded in-depth interviews and ethnographic observations recorded as fieldnotes, where I spent time in the homes of participants undertaking peritoneal dialysis. The theory relating to these two methods is discussed first, before the reality of data generation is explored below.

Interviews

Davies (1999) commented that interviews are perhaps the most utilised method of collecting social data, which was reflected in the qualitative studies presented in the literature review. Using interviews in qualitative studies allows the researcher to gain insight into participants' perspectives (Patton 2002), enabling understanding of their stories. Ethnographic interviewing generates "rich, detailed data directly from participants" (Heyl 2007, p.369), and is therefore fundamental for ethnographic studies. Spradley (1979) describes an ethnographic interview as being similar to a "friendly conversation" (p.57), warning against the interaction becoming interrogative and subsequently diminishing rapport. However, he also suggests that interviews must have an explicit purpose and the participant must be informed by the

researcher about what they are going to talk about, without being authoritarian (Spradley 1979). Furthermore, Spradley (1979) discusses the elements of an interview: greeting and explaining the project/interview, asking descriptive, structural and contrast questions, asymmetry between the researcher and participant talking, expressing interest and cultural ignorance, repeating, restating and incorporating the participant's words when asking questions, creating hypothetical situations, asking friendly questions and knowing when to leave.

Despite interviews being essential for qualitative work, Patton (2002) warns that it is the interviewer who determines the quality of the interview, and appropriate preparation and training are thus arguably required. To prepare for conducting the interviews, I practised interviewing colleagues and family members, and also reflected on the skills used when "interviewing" patients in a clinical setting, for example when admitting a patient to a ward. I also accompanied my academic supervisor to a group interview, and it was invaluable to see a skilled interviewer at work. Furthermore, my academic supervisor listened to one of my completed patient interviews and was satisfied with my technique, noting in particular the use of silence to encourage the sharing of further information.

Observations

Ethnographic fieldwork, encompassing observation, has been described as the "hallmark of cultural anthropology" (Spradley 1980, p.3), which allows researchers to describe the culture they are exploring – the aim of ethnographic research. Davies (1999) highlighted that participant observation is not a single research method and is in fact a compilation of research methods, including participating in the participants' worlds, unstructured interviewing and taking biographies. Participant observations have a dual purpose, for the researcher to engage in the activities appropriate to the situation, and to observe the activities and people in the given situation (Spradley 1980).

In preparation for observing patients and writing fieldnotes, I wrote a set of fieldnotes detailing a nursing shift that I had undertaken, where I practised detailing the ordinary. I also attended fieldnote workshops for PhD students in the School of Social Sciences, led by experienced ethnographers. One of my academic supervisors also read through one set of fieldnotes from the study and gave useful guidance on how to expand them.

Reality of data generation with patients and families in this study: interviews, observations and the use of fieldnotes

The anticipated process of data collection is detailed in the Appendix Nine, but I discovered that the data generation process was not linear and varied between participants. I had expected to interview each participant once and then observe them on up to three separate occasions, but this technique evolved (Savage 2000) and I discovered that one interview and one observation generated rich data. Additionally, not all participants were willing for me to observe them undertaking the treatment itself, but some were happy for me to observe the room in which they undertook the dialysis in their home. For example, I did not observe participants using APD at night, but instead they showed me where they kept the equipment and talked me through the process involved with undertaking the treatment. Other participants were not willing to be observed using the treatment or where they stored equipment, which was their choice. I wrote contextualising fieldnotes after all interviews, which included detail of my initial impressions from outside the home and once inside. All participants chose to be interviewed at home.

The table below demonstrates the length of interviews with the patient participants, the extent of observation, and the involvement of relatives in the data generation process. The number of interviews and observations undertaken, and whether these occurred separately or not, were determined by the participants and their wishes.

Patient	Interview length	Number of observations	Time spent generating data	Relative involvement
Aileen	01:06:13	2 (separate visits)	330min	Abigail (niece) involved during observation
Benjamin	00:34:46	1 (interview fieldnotes)	60min	Beatrice (wife) participated in interview
Carl	01:08:23 00:31:04 (Christine)	1 (during interview)	70min 60min	Christine(wife) interviewed separately (31:04)
Daniel	01:14:28 00:05:00	1 (separate visit)	150min	Diane (wife) participated in interview
Evelyn	00:46:33	1 (after interview)	90min	-

Frank	01:26:09 00:17:03	1 (separate visit)	210min	Fiona (wife) participated in interview and observation
Geraint	00:42:18	1 (interview fieldnotes)	90min	-
Harriet	00:27:11	1 (after interview)	90min	-
James	01:09:48	1 (separate visit)	135min	Janice (wife) and Julie (daughter) participated in interview and observation
Kris	00:51:19	1 (separate visit)	225min	Kaye (wife) participated in interview and observation
Leila	00:35:27	1 (after interview)	105min	Lisha (daughter) participated in interview and observation
Matthew	00:20:18	1 (interview fieldnotes)	40min	-
Norman	00:31:50	1 (after interview)	180min	-
Oliver	00:34:18	1 (interview fieldnotes)	60min	-
Paul	00:53:46	1 (separate visit)	230min	-
Rhodri	00:55:26	1 (after interview)	165min	-
Total: 14:11:20 Mean interview length: 00:44:48 (00:48:47 excluding 2 nd interviews)			Total: 2,290minutes 38hours	

Table 8: Patient and relative data generation

Interviews To give participants flexibility and develop an understanding of their experience, loosely structured in-depth interviews were utilised (Hammersley and Atkinson 1995), which I hoped would ensure that the data reflected issues important to participants and were not limited by my predetermined questions (Davies 1999). I wrote a topic guide (see Appendix Ten) influenced by my previous clinical experience, the literature and also by the guiding conceptual framework, which evolved over time. The topic guide questions included how participants were prepared for dialysis (to learn the history about their diagnosis and feelings about

peritoneal dialysis prior to starting the treatment), how they live with peritoneal dialysis and what support they receive to live with this treatment. I had decided to ask each participant the latter question as the literature review highlighted that patients undertaking dialysis need additional support (Curtin et al. 2004, Yngman-Uhlin et al. 2010, Mok et al. 2004, Lindqvist et al. 2000, Martin-McDonald 2003). These areas of discussion complemented the conceptual framework (Jablonski 2004), which considered end-stage renal disease according to the “crisis phase” of diagnosis and the “chronic phase” of treatment. Discussion of the “terminal phase” was implicit in our discussions, with most participants looking to the future in terms of receiving a renal transplant, changing to another type of dialysis or death. However, the ultimate aim of ethnographic interviews is to facilitate conversation, which allows participants the freedom to discuss issues important to them (Hammersley and Atkinson 1995), and the interviews were thus loosely structured without rigidly adhering to the topic guide.

I had expected the interviews to last around one hour, and I found that the mean length of the interviews was 00:44:48 (00:48:47 when the shorter second interviews with participants Daniel and Frank were excluded). There was variation in the lengths of the interviews; determined by how much detail participants were willing to offer. Prior to the interview I would explain to participants that there were general topics that I would like to discuss, but that generally the interview would cover what they wished to discuss about their life with peritoneal dialysis. All the interviews therefore covered when participants were told their diagnosis and prepared for treatment, how they lived with the treatment and what support they received to manage it, and the flow of the interviews varied according to what participants wished to discuss. In general I found that with most participants I only needed to ask general questions such as “when did you start seeing a doctor about your kidneys?” and then encouraged participants to continue talking with words such as “right”, “OK” or “really”. Hammersley and Atkinson (1995) endorsed the use of active listening skills such as these to facilitate the interview. All interviews were audio-recorded and transcribed verbatim, with fieldnotes written immediately afterwards to contextualise them.

When planning the project I had expected to interview patients and relatives separately to allow each privacy, which had been previously undertaken in the renal literature, for example (Alvarez-Ude et al. 2004, Belasco et al. 2006, White and Grenyer 1999). However, in reality when I arrived at participants’ houses the majority

of families expected to be interviewed together. I found that participants would expand their answers or clarify points by bouncing information off each other, as the following interview extract displays:

JB: why was it that you'd seen the doctor?

Kris: uh tiredness tiredness and um

Kaye: diabetic

Kris: uh diabetic and er my JP [sic] sent me to a specialist

JB: OK

Kris: um because he had noticed that, you know, blood tests that er indicated renal failure well renal, so I said er he said a specialist and um he diagnosed, after a while, I'd met him a few times and he diagnosed renal failure and um, can you help me out here?

Kaye: yeah it got worse

JB: OK

Kaye: about two years I think we were under the renal specialist and you got worse the counting whatever and uh he asked Kris did he want to go on dialysis, it was time to go on dialysis and then you saw another specialist

Kris: that's right yes"

(Int. Kris and Kaye)

I therefore feel that it was beneficial to interview families together and that the majority of participants expected to be interviewed together. Often, participants would use collective pronouns such as "the year two thousand we started" (Beatrice), "we've only been on it now about three weeks on the machine" (Diane) and "we didn't know barely anything about it" (Lisha), and therefore clearly saw the treatment as something to manage together. Kendall et al. (2010) similarly reported advantages of interviewing patients with a palliative care diagnosis and their relatives together. It is my view that it is appropriate to follow the patient's wishes regarding relatives' involvement in interviews and one couple in this study chose to be and were interviewed separately.

Observation and fieldnotes The literature review revealed no other published studies where ethnographic observations had been used to observe the impact of peritoneal dialysis in the home. I was particularly interested in this aspect of data generation and the potential data that would be gathered. The observations varied according to the participants' wishes, from observing participants undertaking a peritoneal dialysis exchange, to observing the environment where peritoneal dialysis paraphernalia were stored and the treatment performed, and observing an APD machine being prepared for the night's treatment and maintenance being carried out. I observed the impact of PD equipment on the home in communal and private areas (including variety of equipment for both PD and other areas of self-management, e.g. BP monitor, BM monitor, sharps bin), individuals' CAPD/APD storage spaces, dialysis

boxes storage areas, individuals preparing APD treatments, individuals undertaking CAPD treatments, infection control procedures, inventory, weighing bags, teamwork, waste disposal and innovative equipment (stands, bags, tables). I undertook several observations on separate visits, others after the interview and one during the interview when Carl spontaneously began his CAPD exchange in the kitchen.

I had planned on using Spradley's (1980) checklist for writing detailed fieldnotes when undertaking observations, which includes space, object, act, activity, event, time, actor, goal and feeling. However, in reality I found that this checklist was not useful for these observations, and Hammersley and Atkinson (1995) commented that a checklist for observations is crude. Instead I used a notebook and documented notes and diagrams of the home environment, expanding the accounts after the observation. For each participant, I wrote fieldnotes of the interview, which included notes about the room where the interview was conducted and whether PD equipment was obvious. For example, I did not observe Oliver's APD equipment, but I did note that from the pavement a pile of tied "Baxter" boxes signalled I was at the correct house and that I could see no other obvious signs of dialysis in the communal areas of the home. I wrote down what participants told me, what I saw and heard, sketches of equipment and room layouts, interactions and teamwork during PD exchanges, my role during observations (for example helping Kaye to carry a dialysis solution bag and attempting to lift a box of solution at James's house) and where different people sat (for example. in Frank's house during CAPD exchange).

I found that drawing diagrams of the peritoneal dialysis in participants' homes demonstrated the impact of the treatment on the home environment well. Indeed when I presented findings papers, which included the diagrams, at four different conferences (including internal and external events) delegates commented that the diagrams clearly explained how peritoneal dialysis affects participants' homes and made the findings "hit home". The example below demonstrates how the home environment is changed by peritoneal dialysis equipment (highlighted in blue).

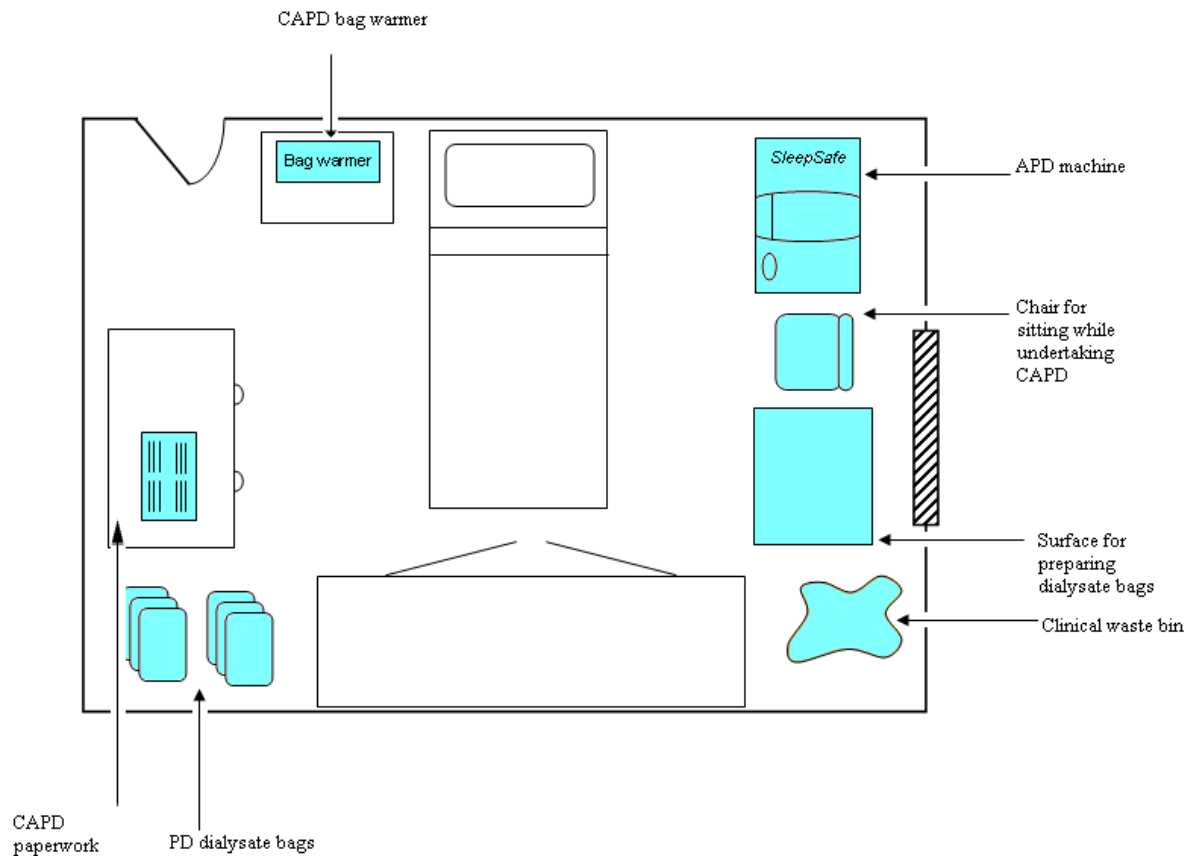


Figure 6: Frank's bedroom and peritoneal dialysis

I therefore found that these diagrams, in conjunction with fieldnote prose, helped me to document what I had observed and show the impact of peritoneal dialysis on the home environment, while making sure that they protected participants' anonymity (a photograph could jeopardise anonymity).

Emerson et al. (1995) warned that the way in which ethnographic fieldnotes are written can have a major impact on the field-relations, for example when they are written, how they are written and where they are written. Furthermore, it is reported that all ethnographic researchers feel ambivalence between writing notes at a noteworthy point of the observations and maintaining the genuineness of the moment and trust of the participants (Emerson et al. 1995). However, because the observations were overt and the participants were fully aware of their purpose (Emerson et al. 1995), I did not find that writing notes impacted negatively on the observation and participants were not fazed by them.

Reality of data generation: Healthcare professionals

I had planned to interview healthcare professionals once for around 30 minutes, due to time challenges within clinical settings. The mean interview length was shorter than the patient and relative interviews at 00:31:11 and thus on average the interviews therefore lasted as long as anticipated. The table below details the interviews with healthcare professionals:

Healthcare Professional	Interview Length
Doctor	00:21:17
CNS 1	00:39:44
CNS 2	00:18:11
CNS 3	00:27:37
CNS 4	00:46:43
PD nurse	00:40:56
Dietician	00:23:46
Mean interview length: 00:31:11	

Table 9: Healthcare professional data generation

Again semi-structured interviews were facilitated using a topic guide (Appendix Ten) and in general I structured the interviews around three general areas: information provided prior to patients commencing dialysis, the impact of peritoneal dialysis on the lives of patients and families, and whether patients and their families require further support from health or social care. In line with the reflexive nature of ethnographic work (Hammersley and Atkinson 1995), certain questions that I asked during the first interview with the Doctor, such as “what are the advantages of peritoneal dialysis?”, I did not ask in later interviews. I realised that ultimately patients do not undertake dialysis out of choice but out of necessity, and therefore the advantages of the treatment are in comparison to other renal replacement therapies. The aim of the research was to investigate life with peritoneal dialysis, not compare it to other renal replacement therapies, and I therefore did not ask this question again. During later interviews I asked questions about emerging themes and during my final interview with a peritoneal dialysis nurse I asked her questions that I had developed from earlier interviews, for example at what stage patients are introduced to the procedure of peritoneal dialysis.

These interviews provided useful information about the pathways leading to dialysis, the training patients received to use treatment and the support offered to patients

during their time using peritoneal dialysis. Most of the healthcare professionals had been working in a different capacity prior to their current role, such as a peritoneal dialysis specialist nurse or ward sister, and they therefore had a wealth of experience. However, much of the information they shared was useful contextual information, rather than offering rich insights into patients' lives.

Six of the healthcare professionals chose to be interviewed in their offices, rather than at the University, and one nurse asked to be interviewed after work in a cafe. All interviews were recorded digitally and transcribed verbatim immediately after the interview, with fieldnotes written to contextualise them. The interview undertaken in a café was a challenge to transcribe due to background noise and I therefore sent this interview to a transcription company. However, I then closely reviewed the transcript while listening to the audio recording and filled in missing text, which was primarily terminology that I was more familiar with than the transcriber. Three of the healthcare professionals also gave me copies of the information booklets they had produced for patients and families with information about peritoneal dialysis inside, and these were useful textual data to have.

4.4.4 Analysis: taming the data

A vast amount of qualitative data (300,000 words) was generated during my ten months in the field and therefore managing and rigorously analysing the data was a challenge. Qualitative analysis is the process of making sense of narrative data (Tesch 1990), which requires rigour, time and energy (Roper and Shapira 2000). Data analysis transforms unmanageable qualitative data into organised accounts, and the process of data analysis begins when the data is collected and the researcher begins to make sense of it. The following sections will thus consider different approaches to analysing qualitative data, data management and the reality of reflexive data analysis in this project.

Approaches to qualitative analysis

Qualitative researchers have proposed varying processes to analyse data, and Dey (1993) suggested that different approaches are used depending upon on the purpose and perspectives of the researcher. Several three-stage frameworks have been proposed by qualitative researchers, including Dey's (1993) cyclic process of Describing, Classifying and Connecting, and Huberman and Miles's (1994) process of Data Reduction, Data Display and Conclusion Drawing and Verification. Having examined the possible approaches to qualitative data analysis, I used Wolcott's

(1994) framework as a guide to data analysis, as it appeared to embrace the complexities of the analysis process.

Description, Analysis and Interpretation are the three stages proposed by Wolcott (1994) – encompassing the transformation of large amounts of disorderly data into an “authoritative written account” (Clifford 1986, cited in Wolcott 1994, p.9). Wolcott (1994) emphasised the importance of remaining close to the original data and treating descriptive data as fact – allowing the data to represent itself. Not losing sight of the original data is thus imperative. Furthermore, the framework appeared particularly useful for analysing ethnographic data, as Wolcott (1994) referred to analysing fieldnotes throughout the stages of analysis. Description considers what can be derived from the data and Wolcott (1994) argued that researchers choose accounts that are interesting or unusual and subjectivity is thus inherent in qualitative analysis. Wolcott (1994) proposed a method of sorting the descriptive accounts, which involves screening all descriptions according to the purpose of the enquiry – honesty is thus required to identify why descriptions are purposefully selected. Wolcott’s (1994) framework gives a different definition to the term “Analysis”. The general meaning of transforming the data is removed, and instead it precisely refers to “systematic procedures followed in order to identify essential features and relationships consonant with the descriptors” (Wolcott 1994, p.24). Interpretation involves the researchers exploring the analyses, considering the meaning and context. This phase can be over-interpreted or under-interpreted (Wolcott 1994) - there is a risk of over-speculating on the meaning or the data. Essentially, Wolcott (1994) argued, Interpretation is an ongoing reflective process that cannot be hurried.

The reality of data analysis in this study

The diagram below (figure 7) outlines the iterative nature of data generation and analysis in this study, which is explained in more detail beneath. However, data analysis is not a linear process as a diagram may suggest. The chart in Appendix Eleven therefore demonstrates how initial coding became the final themes in this thesis.

Process of Analysis	<i>Wolcott's (1994) process of transforming qualitative data</i>
Broad themes identified after data generation with six patients and their families ↓ Data generation ongoing. Data coded using NVivo ↓	<i>Description</i>
Themes identified, organised with according to illness trajectory framework ↓ Data generation ceased. All documents revisited and data extracted into theme tables ↓ Descriptive accounts written for all themes ↓	<i>Analysis</i>
Accounts collapsed and themes for thesis identified ↓ Themes compared to existing literature and policy	<i>Interpretation</i>

Figure 7: Process of data analysis

The data generated in this study were thus managed and analysed with consideration of Wolcott's (1994) approach of Description, Analysis and Interpretation. The majority of researchers recommend that data management and organisation is the starting point of data analysis (Coffey and Atkinson 1996) and is also the first stage of Wolcott's (1994) framework – sorting the data.

Data organisation began with identifying key themes and patterns, achieved through categorising, managing and recovering “the most meaningful” (Coffey and Atkinson 1996, p.26) elements of the data – creating analysable units from the whole data set. In order to manage the data I attended study days on NVivo 8, a computer assisted qualitative data analysis software package, which helped with the storage and

access of data, and codes were renamed as the categories changed (Hammersley and Atkinson 1995). I began to use this software after I had generated data with several participants, and I had already identified several broad themes. I found the process of coding the data into different topics useful to make the data more manageable, and it made me think through different topics that were arising, such as 'dialysis procedure', 'support', 'diagnosis', 'family involvement' and 'perceptions of different renal replacement therapies'. However, as this process evolved I generated a longer list of categories, with sub-categories. For example, 'dialysis procedure' became 'practicalities', which involved sub-categories such as 'alarms', 'boxes', 'infection control', 'location of exchange', 'procedure' and 'timing'. Themes began to emerge, which encompassed different categories. For example 'integration and creativity' was formed from the merger of the categories of 'confidence' and 'control', and recognising that confident participants were creative with peritoneal dialysis to increase their control over it. During my later interviews I began to ask participants about the emerging themes, and I thus adopted an iterative process of data generation and analysis.

The analysis thus fed other areas of data generation and the interviews became more focussed at times, as specific issues were identified (Hammersley and Atkinson 1995). I found that as themes began to arise during the data generation process, I would discuss these with other participants. For example, during the patient interviews and observations I had observed that patients are required to learn multiple new skills, including fluid balance, blood pressure monitoring, inventory skills as well as the peritoneal dialysis procedure, and I questioned this during an interview with a clinical nurse specialist. Additionally, during an observation with a later participant I discussed with him an emerging theme considering confidence, which we then discussed. However, I was also aware that my previous clinical experience, exploration of the literature and the guiding conceptual framework (Jablonski 2004) had influenced the topic guide, and would also influence the way in which I analysed the data. Therefore, I sought to be reflexive throughout data generation and analysis.

While Davies (1999) concurred with the ethnographic process of analysing data throughout the data generation period, she comments on the time when researchers withdraw from the field and distance themselves from the detail of the observations to allow the development of theory. It was indeed a challenge to feel confident that data saturation had occurred and I had sufficient data to analyse. I felt that I had reached

data saturation after generating data with 16 patients, nine relatives and seven healthcare professionals, and feeling confident to leave the field was supported by the coding and theme identification that I had undertaken. When I had identified different themes, I brought the data back together by creating a table of the themes and revisited each interview transcript and observation fieldnote, extracting the data which fitted into each theme, or multiple themes. If significant data did not fit into a theme or category, I created a new theme or category, but this was rare. I extracted data from all interviews and fieldnotes with all participants, treating fieldnotes and interview data equally. This process helped to bring the data together thematically and in detail, providing all the different examples of data which represented the theme and allowing contrasts to be made between them. During this period I also rewrote the literature review and this helped me to identify areas where my findings corroborated earlier research, contradicted it or had not been previously mentioned.

The volume of raw data, albeit organised thematically, remained intimidating and unruly. Thus in an attempt to “tame” the data, I wrote out each theme descriptively, highlighting the relationships between what participants were telling me: the “analysis” phase of Wolcott’s (1994) framework. This then enabled me to decide on key themes to include in this thesis and the deeper meanings in what participants had told me and what I had observed – the “interpretation” phase (Wolcott 1994).

However, while I decided to combine data from patients and relatives, as their stories were impossible to separate, I found that the healthcare professional data was useful as contextualising, background information. The healthcare professional participants provided extremely useful contextualising information about the ways patients present to the nephrology service, the information they provide about the different renal replacement therapies to patients and how they train patients to use peritoneal dialysis. Healthcare professionals also provided informative data about the support services they offered to patients. However, through interviewing and observing patients and relatives using peritoneal dialysis, I was able to gain a detailed insight into how these individuals live with the treatment. It is for this reason that data from healthcare professionals is limited to the beginning of the first findings chapter (section 5.2). This data could certainly be useful for further, secondary analysis and healthcare professionals’ time was not in vain as the contextualising information was vital to understanding patients’ experiences across the illness trajectory. Thus, the themes presented in the next three findings chapters feature minimal data from the

healthcare professional interviews, instead focussing primarily on patients' and families' experiences of the treatment.

The data generation and analysis process was thus an intense period, incorporating the use of different methods and the inclusion of different groups of participants.

4.4.5 Recognising the influence of social constructionism

Epistemology encompasses "how we know what we know" (Crotty 1998, p.8) and therefore a researcher's epistemological perspective will influence how they generate and analyse data. Social constructionism is particularly applicable to ethnographic research, which has highlighted that between cultures and societies an object may not change, but the way in which it is perceived does (Gergen 1985).

Social constructionism challenges the ways in which we understand the world and ourselves, encouraging us to question why we understand the world as we do (Burr 2003). The perspective holds that our understanding of the world is influenced by political and cultural factors, dependent upon current social norms of the time (Burr 2003). Gergen (1985) expanded this notion by explaining that over time our perceptions of constructions change, and therefore absolute truth cannot be asserted: we only believe in constructs from our current perspective. For example, in the Victorian era in the UK it was acceptable for adults to beat children, but over time this has changed and violence towards children is widely condemned in the UK today. Children have not changed, but adults' attitudes towards them have, possibly due to changing political and social norms. This suggests that one cannot have a static view of the world, instead it evolves according to wider social, moral, political and economic forces (Gergen 1985). Furthermore, Burr (2003) asserted that there is no such thing as an objective fact, all our knowledge is gained through observing the world from one perspective. Therefore, one person's perspectives are not superior to another's and we rely on our interactions with others to construct our ideas of "normal" (Burr 2003).

The data were thus generated in this study with an emphasis on exploring individuals' experiences of their illness and treatment, taking into account their lives prior to peritoneal dialysis. The aim of the analysis was therefore not to attempt to create a consistent narrative between participants, but instead recognise that they would have individual stories that may (and did) have similarities and also differences.

4.4.6 How to judge the findings: credibility, transferability, dependability and confirmability

It is important that the researcher can demonstrate credibility within the research process to enable others to trust the resulting findings and the possibility of applicability of the findings to other populations. Long and Johnson (2007) assert that rigour, reliability and validity are applicable and important in qualitative research, while LeCompte and Goetz (1982) state that ensuring the validity and reliability of research findings is essential in scientific enquiry, in order to demonstrate the credibility of the research. There is, however, much debate within the qualitative research field about whether these concepts are applicable or inappropriate (Rolfe 2006). Long and Johnson (2007) suggest that rigour is characterised by ensuring the reliability and validity of the research, while Tobin and Begley (2004) assert that “Rigour is the means by which we show integrity and competence: it is about ethics and politics, regardless of the paradigm” (p.390). To explain how the research presented in this thesis was undertaken in rigorous manner, Guba and Lincoln’s (1989) framework will be considered: credibility, transferability, dependability and confirmability.

Credibility

Sandelowski (1986) suggested that credibility (or “truth value” as she terms it) “resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects” (p.30). Credibility was promoted in this study by using both interviews and observations (Davies 1999, Denscombe 2010), as well as including multiple groups of participants (Denscombe 2010). Furthermore, Koch (1994) suggested that credibility can be achieved by the researcher considering their role within the research process and seeking participants’ thoughts on the findings generated through the study. Reflexivity and participant validation are discussed in more detail below.

Reflexivity: Reflexivity in qualitative research involves researchers turning “a critical gaze towards themselves” (Finlay 2003, p.3), and Wilkinson (1988) suggested that reflexivity is “disciplined self-reflection” (p. 493). Davies (1999) highlighted that all researchers are in some way connected to their research topic, and must be aware of the impact of their presence on the research process. Furthermore, Finlay (2003) asserted the importance of qualitative researchers acknowledging the central role

they play in their research, in terms of the relationships they build with participants and the processes by which they collect and analyse the data. Reflexivity is thus central to ethnographic research (Babcock 1980), as social research cannot be carried out in isolation from the biography of the researcher and influences from society (Hammersley and Atkinson 1995). This reflexive process, “the only cure for subjectivity” (Babcock 1980, p.11), is ongoing throughout the research project, including research design, data generation, data analysis and research recommendations. Overall, the aim of reflexivity is to avoid making suppositions about what is being said/done by participants (Heyl 2007), and to ensure the researcher considers the context in which data is being collected and their influence over the reporting of data. Wilkinson (1988) suggests three domains of reflexivity (personal, functional and disciplinary) and each are discussed below with detail of how I sought to be reflexive.

Personal reflexivity (Wilkinson 1988) involves the researcher considering the impact of their personal experience and values on the research, on the understanding that research ideas often arise from the researcher’s personal concerns or values. I was aware during data generation that I had pre-understandings of the research topic due to my previous clinical experience as a nurse. Therefore, I attempted not take anything for granted, for example how a peritoneal dialysis exchange was undertaken, and maintained thorough fieldnotes of all aspects of data generation. It is essential to highlight here how I presented myself to participants when generating data. It was important that patients and their families understood that I was a nurse, as recommended by the Research Ethics Committee, but also that I was in their homes for the purposes of undertaking research, not providing clinical care. The nursing methodology literature considers the roles of nurses when undertaking research, although this is often in a clinic or hospital setting (Bonner and Tolhurst 2002, Griffiths 2008). Gerrish (2003) undertook ethnographic work with district nurses, which involved her entering patient’s homes, but her research considered the nurses themselves rather than patients. Nurses undertaking ethnographic research may wear uniform when conducting research (Gerrish 2003, Griffiths 2008) but I chose to wear smart-casual clothes, to differentiate myself from a clinical nurse.

I explained to each participant prior to gaining consent that I was a qualified nurse and where I had previously worked, but that I was seeing them in a research capacity and no longer worked specifically on the nephrology ward. The majority of participants accepted this and saw me as a researcher. Overall, I felt that I

maintained my role as a researcher, rather than slipping into my role as a nurse, unless medical attention was required. I had responsibilities to participants under my professional code of conduct as a registered nurse (Nursing and Midwifery Council 2008) and thus during my ethical applications I had agreed that if I was concerned about the medical condition of a patient then I would report this back to my clinical contact, the Home Dialysis Manager (and later a clinical nurse specialist). I had not expected to do this, but in reality I reported several concerns back. These included a necrotic wound on a participant's finger, a lump around a participant's Tenckhoff catheter and additional information required about the APD machine, which participants had not reported to a healthcare professional. Finally, when I arrived to observe one participant I found her in pain and feeling nauseous, sitting on the sofa. While I thus immediately decided that observation was not appropriate and although the individual was not in need of urgent medical attention (e.g. paramedics), I was concerned about leaving her alone while she waited for the GP and we therefore agreed that I would wait with her. I did not collect any other data with this participant as she was later admitted to hospital and transferred onto haemodialysis. Overall, I was surprised that I needed to refer several patients back to the clinical team for further attention and I was grateful to have a good link with them. Furthermore, it was important that the healthcare professional participants saw me as a researcher, rather than a colleague. Therefore I again explained my role as a researcher, highlighting that I was not there as a nurse, which I felt was made easier as it had been over 12 months since my last shift on the nephrology ward.

Functional reflexivity encompasses the choices made by the researcher regarding research methods and data analysis and includes the researcher considering the relationship between themselves and the participants (Wilkinson 1988). Throughout data generation I ensured that I completed a research journal to track my thoughts and decisions and how these impacted on the research process, as recommended by qualitative researchers (Finlay 2003, Coffey and Atkinson 1996, Koch 1994). As highlighted above, I wrote fieldnotes after each interview and observation, which included my thoughts and reflections on these interactions with participants. Coffey and Atkinson (1996) argued that thorough documentation of these decisions is imperative as "part of the transformation of data from personal experience and intuition to public and accountable knowledge" (p.191), and I was thus careful in documenting the process of recruitment, data generation and analysis.

Finally, disciplinary reflexivity (Wilkinson 1988) involves the researcher considering their research with respect to the wider debates within their field, and reiterates Hammersley and Atkinson's (1995) assertion of the importance of considering the wider impact the research may have. Disciplinary reflexivity is demonstrated within the discussion chapter (eight) when the findings of this study are linked to the wider literature within the related fields and also in the conclusion chapter (nine) when the implications of the research for clinical practice and further research are presented.

Therefore, throughout the study I sought to be reflexive through self-awareness, completion of a research journal and fieldnotes detailing my decision-making during data generation and my perceptions of interactions with participants, and considering the findings in relation to other literature.

Participant validation Guba and Lincoln (1989) and Koch (1994) suggested that credibility within research can be promoted by validating the study findings with participants. I had intended to undertake participant validation of the results, whereby I would have sent a summary of the emerging findings to participants to discover whether they agreed with my interpretation of the data (Silverman 2005). While this had been undertaken in the renal literature (Landreneau and Ward-Smith 2007, Pelletier-Hibbert and Sohi 2001, Rittman et al. 1993), after data generation I was concerned about this process. Researchers have questioned the role of participant validation in qualitative research, citing concern for placing too much demand on participants' time or causing distress if the research topic is emotive (Barbour 1998, 2001). Additionally, it is important to recognise that a participant's individual experiences will be presented with the collective whole (Mays and Pope 2000) and it may not necessarily seem to participants to reflect their individual experience.

I felt that it could place too much strain on a vulnerable group of participants to read and comment on a summary of findings, and therefore I decided not to undertake participant validation. Sandelowski (1986) suggested that credibility in qualitative research is attained when people with experience of the phenomena relate to the findings presented by the researcher. The credibility of this study was endorsed when I presented the study findings at an international conference and I spoke to two fellow researchers (one specialised in nephrology, while the other had cared for her husband using peritoneal dialysis) and they concurred my findings. While working as a part-time staff nurse during my PhD, a patient who was soon to start peritoneal

dialysis told me his experience of the pre-dialysis period, which mirrored my analysis of this period. I also discussed my emerging findings with my clinical link - a clinical nurse specialist – who validated the themes that I had identified. After I had finished analysing the data, I also wrote a four page summary which I sent to participants. Although I did not hear from any of the patients or relatives who took part, to either concur or contest my analysis, two of the nurse participants informed me that the results resonated with their extensive clinical experience of peritoneal dialysis. Therefore, while I chose not to undertake participant validation on this project, I felt that I received validation of my analysis from other valuable sources.

Transferability

Koch (1994) suggested that the transferability of findings can only be decided by the reader if the setting and context is adequately described. The setting within this study was not one site, such as one ward in a hospital, but instead the homes of sixteen different families. Fieldnotes were maintained for each interaction with participants and before the findings from the study are presented in the next chapter, there is a short interlude introducing the participants in this study. The first findings chapter (five) describes participants' experiences before starting peritoneal dialysis, while chapter six then describes in detail how participants lived with peritoneal dialysis within their homes and how the treatment affected their daily routines and lives. This will encourage an understanding by readers of participants' social contexts and will highlight similarities and differences between how the treatment transformed their lives, enabling the reader to decide whether the findings can be transferred to other settings (Guba and Lincoln 1989). Sandelowski (1986) suggested that researchers must present the typical and atypical experiences of participants to encourage transferability or "applicability" (p.32) of findings to other settings, which are presented in the following findings chapters (five, six and seven). Finally, the discussion chapter (eight) presents the findings from this study in relation to the wider literature, suggesting transferability to other populations.

Dependability and confirmability

Guba and Lincoln (1989) suggested that dependability and confirmability can be ensured jointly. To ensure the dependability of research Koch (1994) recommended completing an audit trail of decisions made during the research. Sandelowski (1986) suggested that dependability is achieved when another researcher would reach similar findings from the data, following the researcher's audit trail. Furthermore, Guba and Lincoln (1989) argued that confirmability of the study findings is ensured

by demonstrating that the data and the researcher's interpretation of it are grounded in reality. As mentioned above, an audit trail was maintained throughout data generation to track the decisions made, thus encouraging both dependability and confirmability. However, Davies (1999) suggests that findings from ethnographic research cannot be replicated by other researchers due to the inimitable role that the researcher plays in the data generation process, particularly through the use of observation. Nonetheless, my academic supervisors reviewed a proportion of the data generated in the study and we compared themes that we had identified, which revealed overlap. Furthermore, the findings chapters include a vast amount of data extracts alongside the analysis, enabling the reader to see the raw data and my interpretation of it. Therefore, I suggest that dependability and confirmability were achieved in this study.

Therefore, throughout the research process I sought to promote rigour and conduct the study in a credible way. This section has highlighted ways that this was achieved, with reference to where else in the thesis credibility, transferability, dependability and confirmability are demonstrated. The discussion chapter (eight) will later debate the strengths and limitations of this research and my role as researcher.

This section has thus considered the data generation and analysis process in depth and the final section of this chapter will describe the ethical considerations inherent to this project.

4.5 Ethical considerations

The ethical implications for the research and of the research were considered at all stages of the research process. This section will therefore highlight how the principle and application of ensuring informed consent was approached, as well as maintaining confidentiality throughout the research process. The potential risks and benefits to participants taking part in this study are then explored, with final consideration of the potential risks to the researcher. Finally, the importance of involving the public in the research process was recognised and the way in which this was achieved in this study is discussed.

4.5.1 Seeking ethical approval

As a novice researcher the ethical applications required for this study presented a challenge to overcome, and were aided by support from my academic supervisor, a

research and development officer and a senior nurse in the collaborating Health Board. The process took almost nine months from beginning to complete the application forms via the Integrated Research Applications System (IRAS) to final approval from the Research Ethics Committee. In total four applications were submitted: academic school Research Review and Ethics Screening Committee, University sponsorship, Research Review by the collaborating Health Board and the Research Ethics Committee. This process is depicted in the flow chart below and the approval letters are in Appendix Twelve.

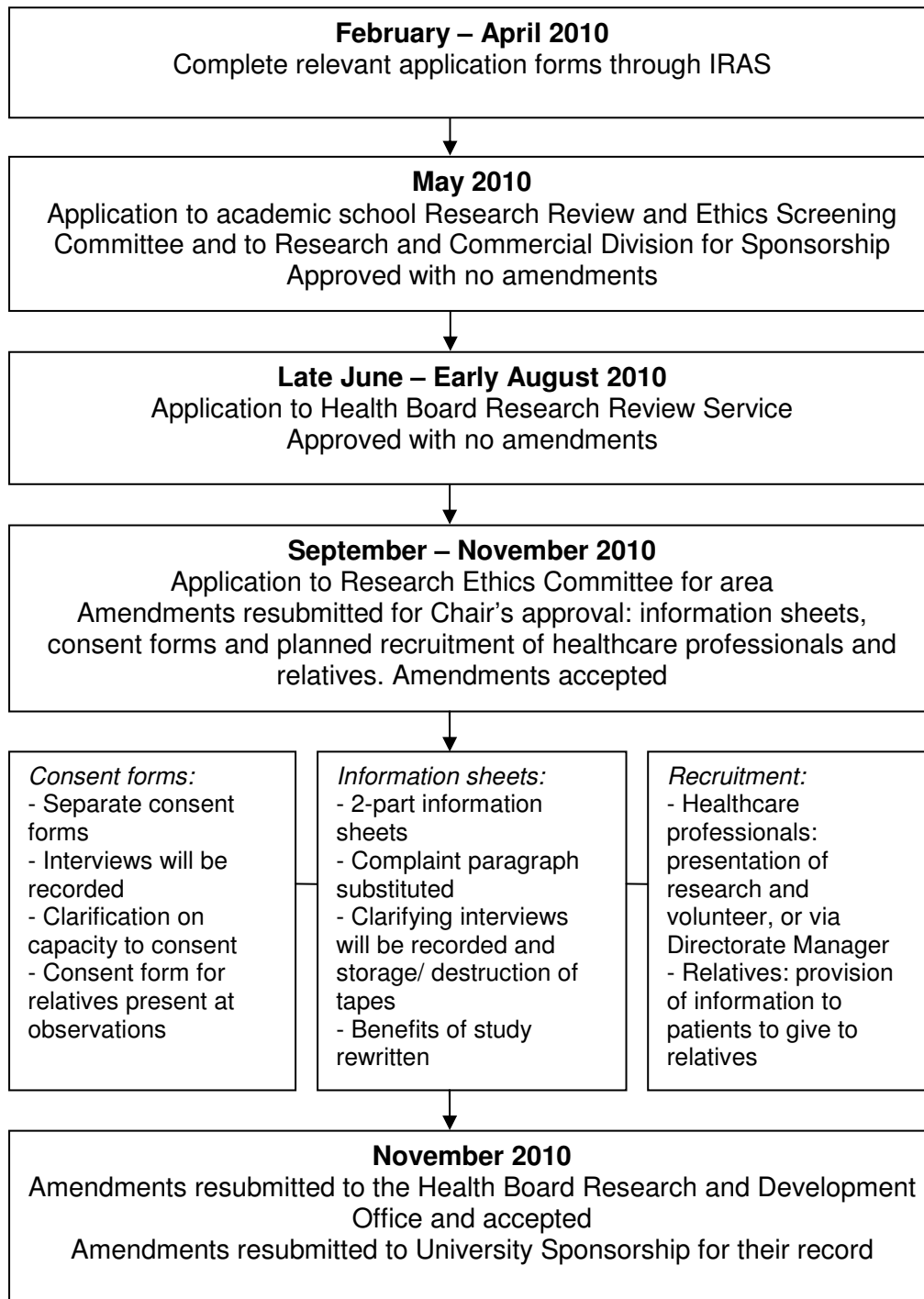


Figure 8: Flow chart of the ethics applications process

The university and Health Board committees did not require amendments to the study. However, the NHS Research Ethics Committee requested clarification on several points including how healthcare professionals would be recruited, and adding information to the consent form and information sheets. They also queried whether I would impact on the data collected during the ethnographic observations, and

whether observation is a valid data generation method. I acknowledged that I would have an impact on the data, but iterated that observation allows for detailed understanding of participants' worlds, and clarified what data I would be collecting (including where the treatment is performed, the impact on family relationships, whether peritoneal dialysis is seen as "normal" or whether it is disruptive). The panel also sought clarification as to how the results of the study would be used to influence a care pathway for patients using peritoneal dialysis. I explained that the current care pathway for patients undertaking peritoneal dialysis excludes support for their families and that the results from this study may be used with the clinical team to write this section of the care pathway. Furthermore, recommendations could potentially be made for additional support for patients to manage their treatment. The Research Ethics Committee were satisfied with my answers and the changes to information sheets and consent forms, granting approval for the study.

4.5.2 Informed consent

Informed consent is "at the heart of ethical research" (Welsh Assembly Government 2009, p.11) and is vital throughout the research process. The Royal College of Nursing (2005) defined informed consent in research as:

an ongoing agreement by a person to.. participate in research, after risks, benefits and alternatives have been explained to them (p. 5)

This definition highlights that informed consent is not a single occurrence but is instead an ongoing requisite. In order to achieve ongoing informed consent, the researcher must ensure the participant continues to understand the research information and any changes to this information, and continues to consent to take part in the study (Royal College of Nursing 2009). In order for an individual to give consent, three requirements need to be met:

the consent should be given by someone with the mental ability to do so;
sufficient information should be given to and understood by the participant; the
consent must be freely given (Royal College of Nursing 2005, p.6)

These standards ensure that individuals are not coerced into participating in research (Welsh Assembly Government 2002).

The participant information sheets and consent forms (see Appendices Thirteen, Fourteen and Fifteen) were written according to guidelines from the Royal College of Nursing (2009) and the National Patient Safety Agency (2009). However, the key ethical issues, including informed consent, right to withdraw, confidentiality and potential benefits/harms were reiterated and explained to participants when I met

them in person. The participant information letters were written with consideration of the diversity of individuals, in terms of the language used, and as recommended by the National Patient Safety Agency (2009), the “fog factor” was calculated for each participant information sheet, which denotes how understandable the information is. Example “fog factor” scores would be: 4 for a newspaper advertisement; 8 for a popular novel; 20 for a report on information technology (National Patient Safety Agency 2009). The calculation for this is explained in Appendix Sixteen. Two “fog factor” scores were calculated for each participant information sheet, one including the words “peritoneal” and “dialysis” in the long word calculation (long words with more than two syllables) and one excluding these terms, as they may be “long words” but they are familiar to all three groups of participants. The table below summarises the “fog factor” scores for each information sheet:

Information Sheet	“Fog Factor”
Patient (inc. peritoneal and dialysis)	10.7
Patient (exc. peritoneal and dialysis)	9.6
Relative (inc. peritoneal and dialysis)	11
Relative (exc. peritoneal and dialysis)	10.3
Healthcare professional (inc. peritoneal and dialysis)	10.6
Healthcare professional (exc. peritoneal and dialysis)	9.5

Table 10: Fog factor

These “fog factor” scores seemed acceptable, particularly as the information sheets were all separated into short paragraphs with clear headings, and recipients were encouraged to discuss the information with others and ask any necessary questions arising from the information.

While each participant completed the consent form only once, the purpose of the research was explained at subsequent observations with participants, to ensure that informed consent was ongoing. An online Informed Consent training package, available through the participating Health Board, was completed to assist me in taking informed consent. Additionally, ensuring that each participant has the capacity to consent and thus participate in research is fundamental for participants’ protection, and this was assured through the utilisation of the *Mental Capacity Act 2005 Code of Practice* (Department for Constitutional Affairs 2007). In order to assess a person’s ability to make a decision, the code (Department for Constitutional Affairs 2007) recommends four points to consider:

1. whether the person understands what the decision is and why they should make it;
2. whether the person understands the consequences of making or not making the decision;
3. whether the person is able to comprehend, retain, utilise and deliberate information relevant to the decision;
4. whether the person is able to communicate their decision verbally or non-verbally.

These issues were thus considered when assessing the capacity of an individual to consent to participate in the study. As a qualified nurse I am practised at considering the capacity of individuals to make a specific decision, and I applied these skills to assessing the capacity of research participants. It had been explained to participants that if they lost capacity to consent during the research process they would be excluded from the research, but this was not a concern during the research.

4.5.3 Confidentiality

Throughout the research process the confidentiality of all participants was maintained, according to guidelines issued by the Department of Health (2003) and the Welsh Assembly Government (2009). The Department of Health (2003) recommend a Confidentiality Model, which lists the four main duties of maintaining confidentiality:

1. protect patients' information;
2. inform patients how the information will be used;
3. provide choice - allow patients to choose whether their information is disclosed or used;
4. improve – ensure the above three duties by looking for ways to better protect, inform and provide choice.

These principles were therefore maintained throughout the research process for all participants in the research. The participant information forms specified what data would be collected, the purpose of the research, that information collected would be disseminated and that participants' information would be kept confidential. The table below summarises the specific nature of how confidentiality was maintained throughout the research process.

<i>Use of personal addresses, postcodes, faxes, emails or telephone numbers</i>	Personal details about participants were not kept with research data. All personal information was stored in a locked filing cabinet in a locked office.
<i>Publication of direct quotations from respondents</i>	Participants were informed that anonymous quotations would be published in journal articles and conference papers.
<i>Storage of personal data on manual files</i>	Each participant was given a code and pseudonym, and this was used in the manual files, e.g. observation fieldnotes. All manual files were kept in a locked filing cabinet in a locked office.
<i>Storage on university computers</i>	Data were stored on my university computer. This includes written fieldnotes about observations, transcriptions of interviews and audio-files of interviews. This computer is password protected, and all audio files relating to the research were kept in encrypted files only accessible by the researcher.
<i>Storage on laptop computers</i>	No participant identifiable information was kept on a laptop computer.
<i>Access by others</i>	Monitors from the NHS Research and Development Office could require access to the study data to verify results. This was explained to participants in the participant information sheet, and confirmed by the participants by signing the consent form.
<i>Length of storage</i>	The Data Protection Act (United Kingdom 1998) stipulates that data must not be stored for longer than is necessary. However the Department of Health (2007) and the Welsh Assembly Government (2009) highlight the necessity of retaining information generated through research for longer to allow for further analysis of the data (with consent of the research participants). The data will therefore be stored for 15 years.
<i>Long term storage</i>	Data was stored in encrypted files on password protected computers, and in locked filing cabinets, for the period of time specified following the study. All patient identifiable information was stored securely, and

	all research data (for example transcribed interviews) will be anonymous. If and when data is destroyed, it will be done in accordance with consideration of security and confidentiality - as recommended by the UK Research Integrity Office (2009). Printed material will be shredded within the School of Nursing and Midwifery Studies and computers will be cleared of data before disposal or other use.
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Table 11: Maintaining confidentiality

4.5.4 Research risks and benefits

All research can be potentially harmful to participants and researchers (Long and Johnson 2007) and while it was not anticipated that this research would cause any physical or social harm to patients, it could have potentially caused emotional stress (Royal College of Nursing 2009). To minimise the risk of emotional distress, I was attentive and sensitive to participants during the interviews and observations. My clinical experience as a staff nurse helped this process, and in fact only one participant became tearful during an interview when he discussed how supported he felt by healthcare professionals. I ensured that I adequately prepared participants before the interviews, stating that the interview could be stopped at any time, and I ensured that after the interview I asked participants' to reflect on the interview. Financial burdens on the participants were reduced by data generation taking place at a time and place convenient for them, thereby reducing any need for taking time off work, hiring childcare or paying for transport. While research carries the risk of breaching confidentiality, all guidelines and government legislation, including the *Data Protection Act* (United Kingdom 1998), were closely followed to ensure this risk was minimised.

Participants in the study could have potentially benefited from partaking in the research. For patients and family members, they may have experienced reassurance in being able to share their experiences with an objective person. Lowes and Gill (2006) examined their participants' experiences of participating in qualitative interviews on an emotive topic (childhood diabetes and live-donor kidney transplantation). The majority of participants found the experience positive and supportive (Lowes and Gill 2006), but the authors conclude that the aim of qualitative interviews should not be to provide participants with therapy. Nonetheless, it is reassuring for researchers that qualitative interviews can be cathartic for participants.

Healthcare professionals may also have enjoyed sharing their experience and emphasising what they feel is important for their patients, as well as supporting the conduct of healthcare research (International Council of Nurses 2006). Participants may also have benefitted from the knowledge of potentially helping other patients undertaking peritoneal dialysis (Hallowell et al. 2010), as it was emphasised to participants that the aim of the research was to generate evidence relating to their experiences and potentially provide further support services to patients and families undertaking peritoneal dialysis. The majority of patient and relative participants commented that they were pleased that research was being undertaken about their experiences of peritoneal dialysis, for the following reasons: to make potential transplant donors aware of life using the treatment (Harriet), to make other people aware of their life with peritoneal dialysis (Leila and Lisha), or to potentially help other patients (Aileen, Benjamin, Carl, Daniel, Evelyn, Geraint, James and Paul).

I was aware that there was potentially a personal risk of undertaking the research with patients in their own homes. However, it was important that the research caused as little interference as possible and as patients using peritoneal dialysis have a strict treatment regime, conducting the interviews in patients' homes was more convenient for them. Additionally, because observations aimed to understand the impact of peritoneal dialysis on home-life it was imperative that these were undertaken in participants' homes. To minimise the risk of visiting participants at home alone, I followed various guidelines. I made sure that I researched the geographic area before visiting a participant, informed the Home Dialysis Manager before and after visiting each participant, drove to each appointment and dressed appropriately (Cardiff University 2009, Health and Safety Executive 2009). A risk assessment for personal and patient safety was conducted as recommended in the *Health and Safety in Fieldwork* policy (Cardiff University 2009), which indicated a low perceived risk to both the research participants and me.

4.5.5 Involving the public in research

The Welsh Office for Research and Development (now the National Institute for Social Care and Health Research - NISCHR) established the Clinical Research Collaboration Cymru (CRC-Cymru) in 2006 to "improve the quality, quantity and the processes of health and social care research in Wales" (Moore et al. 2007, p.2). *Involving People: Cynnwys Pobl* is part of the CRC-Cymru Co-ordinating Centre (Moore et al. 2007), which supports and promotes the inclusion of patients and carers in health and social care research. Patients and service users were involved

in the design of the research, as recommended by *Involving People* (Porteous and Rea 2009). The Kidney Wales Foundation were contacted to request if they would read the patient information and participation forms and ensure they were fit for purpose. The patient information and participation forms were then emailed to the Kidney Wales Foundation, where an individual using haemodialysis (who previously undertook peritoneal dialysis) reviewed the forms and felt they were appropriate. The patient reviewer also stated she felt that research into this area was important and should be undertaken. The UK National Kidney Federation was then approached, and the forms were then emailed to the organisation. The Chief Executive critiqued the documents and also felt the forms were appropriate for purpose. This ensured that the patient information forms are clear and relevant, and also enabled any feedback about the research design. The patient and staff information forms were also sent to the Home Dialysis Manager at the participating Health Board, who confirmed that they were suitable for purpose.

Therefore, ethical principles were considered and applied throughout the research process, from design through to data analysis.

4.6 Chapter conclusions

This chapter has thus considered, in-depth, the methodological approach adopted for this research and the methods employed. Ethnography was considered the most appropriate methodology to meet the aim and objectives of the study, while in-depth interviews and observations were undertaken with a volunteer and then purposively sampled group of patients using peritoneal dialysis (n=16). Nine relatives were also recruited through convenience sampling, who were mostly interviewed with the patient participants. A convenience, snowball sample of healthcare professionals (n=7), who proved challenging to recruit, were also interviewed. Ethical considerations were ensured at all stages of the research, with guidance from the research governance framework, professional organisations and UK government legislation.

The next chapter will present findings from the study according to the first stage of the illness trajectory: diagnosis and starting treatment.

Interlude: Introducing the Participants

Healthcare professionals

Seven healthcare professionals from multidisciplinary backgrounds took part in the study and a pseudonym was allocated to each participant. Stuart is a Nephrologist and Zoe is a Dietician. Trudy, Una, Veronica, Wendy and Yvonne are all specialist nurses. All the healthcare professionals are experienced at caring for patients with end-stage renal disease, and the specialist nurses had previously held different positions both on the nephrology ward and within other specialist renal teams. Little biographical information is provided here about the healthcare professionals to protect their right to confidentiality.

Patients and relatives

Sixteen patients and nine relatives took part in this study and their biographical details are summarised in the table below. Additionally, a short biography about each participant is described underneath.

Aileen and Abigail

Aileen is in her early seventies and retired. She is single with no children and lives alone in a bungalow. Her end-stage renal disease was caused by systemic sclerosis, an autoimmune disorder that affects connective tissue. Aileen has undertaken CAPD for six years and is independent with the treatment. Aileen sees her family regularly, particularly her niece and great-niece, Abigail. Abigail is in her early 20s, has a baby daughter and visits Aileen frequently.

Benjamin and Beatrice

Benjamin and Beatrice are also in their seventies, with four grown-up children. Benjamin is partially-retired, but continues to contribute to work-related projects. Beatrice assists Benjamin with dressing his Tenckhoff catheter – the access for peritoneal dialysis – but otherwise Benjamin is independent with APD. The cause of Benjamin's end-stage renal disease was Henoch-Schonlein Purpura, an immune disorder which led to glomerulonephritis. Benjamin has undertaken peritoneal dialysis – both CAPD and APD – for six years. The couple live in a large detached house.

Carl and Christine

Carl has diabetes mellitus, which caused end-stage renal disease and neuropathy, leading Carl to retire early. His wife Christine continues to work, as well as being responsible for the majority of Carl's dialysis care. Both are in their late sixties and live in a moderately sized detached house. Their daughter and grand-children live nearby, visiting regularly. Although Christine undertakes Carl's APD treatment, Carl occasionally uses CAPD independently. He has undertaken dialysis for 3 and a half years.

Daniel and Diane

Daniel and Diane are an energetic couple in their late sixties/early seventies, who are both retired. They live together in a small semi-detached cottage. For two and half years Daniel independently undertook CAPD and he transitioned to APD shortly before being interviewed. Daniel also has diabetes which led to chronic kidney disease, but he had a sudden decline towards end-stage renal disease following a bacterial infection. The couple have three children, two of whom live locally. Daniel eagerly awaits a kidney transplant.

Evelyn

Evelyn is in her late sixties and was diagnosed with poly-cystic kidney disease in the 1970s, before starting CAPD six years ago. She is retired and lives in a compact terraced house with her husband. Evelyn cares for her husband, who has a long-term malignancy, while their two daughters live nearby and visit regularly. Both daughters also have poly-cystic kidney disease, but are not receiving renal replacement therapies. Evelyn is independent with CAPD.

Frank and Fiona

Frank was the newest participant to CAPD, having undertaken the treatment for six months at the time of the interview. The couple are retired and live in a compact semi-detached house. Following an acute illness, Frank commenced haemodialysis while in hospital. Frank and his wife Fiona are both in their 70s, with both their daughters living nearby. Fiona is responsible for changing Frank's Tenckhoff catheter dressing and assists him with CAPD exchanges. During data collection Frank was preparing to start APD.

Geraint

Geraint is in his sixties, lives with his wife and is retired. His end-stage renal disease was due to diabetes mellitus and he has undertaken CAPD independently for six years. Geraint lives in a small bungalow and his daughter lives locally, visiting frequently.

Harriet

Harriet developed IgA nephropathy, an immune disorder where the glomeruli inside the kidney are damaged, in her late fifties when she had retired. She has undertaken peritoneal dialysis independently for four years, including both CAPD and APD. Harriet lives with her partner in a large detached house, while her daughter lives nearby and her son lives elsewhere in Wales. Harriet is also hoping for a kidney transplant.

James, Janice and Julie

James is in his seventies and lives with his wife Janice, in her late sixties. The couple are both retired and live in a terraced house. James started dialysis nearly two years ago and uses both CAPD and APD, which Janice and Julie (their daughter) share responsibility for. Julie is a mental health nurse who lives nearby with her family. James's end-stage renal disease was due to diabetes, but he also has emphysema.

Kris and Kaye

Kris is in his eighties and is cared for by his wife Kaye, who is in her seventies – both are retired. The couple lived in America when Kris commenced peritoneal dialysis seven years ago, but returned to their homeland two years later and they live in a small flat. Kris's end-stage renal disease was due to diabetes, but he has other medical conditions and is very restricted. Kaye is responsible for Kris's APD and their son is also able to perform the treatment. Both their sons live in America.

Leila and Lisha

Leila is in her sixties and lives with her husband and two sons in a large terraced house. Her daughter, Lisha, lives nearby with her husband and visits Leila regularly. Lisha supports her mum with CAPD and is also able to perform the treatment herself. Leila has diabetes mellitus, the cause of her end-stage renal disease, and has undertaken CAPD for nearly three years. She is also hoping for a kidney transplant.

Matthew

Matthew is in his early sixties, retired and has undertaken CAPD independently for one year. Matthew lives with his wife, who continues to work, in a moderate semi-detached house. Although Matthew visited the Nephrologist with chronic kidney disease, he commenced haemodialysis acutely in hospital following pneumonia. Matthew is unclear about the cause of his end-stage renal disease and is not eligible for a kidney transplant.

Norman

At 85, Norman is the oldest participant in the study, but he remains extremely active in his local community. Recently widowed, Norman lives with his son in a large detached house, and his daughter lives nearby with her family. Norman is unsure what caused his end-stage renal disease and he has undertaken peritoneal dialysis for four years, including both CAPD and APD. Norman's children assist him with his Tenckhoff dressing and moving the dialysis supplies, but Norman is otherwise independent with dialysis.

Oliver

Oliver is in his late sixties and lives with his wife in a large detached house. The couple have five children, some of whom live nearby. Shortly after his retirement, Oliver was diagnosed with renal cancer and had one kidney removed. Oliver started peritoneal dialysis nearly four years ago and has independently undertaken both CAPD and APD. Oliver is extremely active and particularly enjoys gardening. Once he has been cancer-free for five years, Oliver is hoping to register for a kidney transplant.

Paul

Paul recently retired and is in his early sixties. He lives in a large detached dormer bungalow with his wife, who continues to work, and their two children live nearby. Paul's end-stage renal disease was due to hypertension and he has undertaken CAPD independently for three years. Paul is also very active in his local community, enjoys walking and has created several inventions to make CAPD easier for him.

Rhodri

In his early fifties, Rhodri is the youngest patient in the study. Rhodri has diabetes and took early retirement after losing his sight. He has undertaken CAPD independently for nearly eighteen months. Rhodri lives in a terraced house with his

wife, who continues to work, and one of their two children. He is involved in a support group for blind people. Rhodri is also waiting for a kidney transplant.

Chapter Five: Reflecting Back - Journeys to Peritoneal Dialysis

5.1 Introduction

During data generation I routinely began interviews by asking participants to reflect back to the period before they started peritoneal dialysis, usually with a question such as *“at what point did you start seeing a doctor about your kidneys?”* This was to help me understand their diagnosis, subsequent choice of peritoneal dialysis (PD) and the training they received to learn how to perform the treatment. This first findings chapter therefore considers the period between patients’ diagnoses of end-stage renal disease and starting peritoneal dialysis – the “pre-dialysis” (Jablonski 2004) or “crisis” (Rolland 1987) phase of the illness trajectory. This phase was characterised by prolonged contact with different nephrology healthcare professionals, within the nephrology clinic, other spaces in the hospital and patients’ homes. During this time healthcare professionals began to enter patients’ homes to deliver care, marking the introduction of end-stage renal disease and associated treatments within the home space. Firstly, this chapter will provide an overview of patients’ trajectories from being told they would require dialysis to choosing peritoneal dialysis, told from the perspectives of healthcare professionals interviewed in this study. The next two sections will be presented from the perspectives of patients and their relatives and will firstly focus on decision-making and the reasons why they chose peritoneal dialysis. The final section will then describe the initial introduction of the treatment within the home space and the training that patient and relative participants received from healthcare professionals to perform peritoneal dialysis.

5.2 Diagnosis to dialysis: an overview

This section will provide an overview of the pre-dialysis period, from the perspectives of healthcare professionals interviewed in this study. Patients’ journeys leading to dialysis vary substantially, in terms of time, diagnosis and overall medical condition. Despite this, the healthcare professional participants explained that overall the majority of their patients follow a similar trajectory from being diagnosed with chronic kidney disease to starting dialysis. The healthcare professionals reported that most patients are referred to the nephrology clinic from their General Practitioners, where the Nephrologist diagnoses chronic kidney disease. Patients can spend many years

visiting the nephrology clinic, but when their chronic kidney disease is rated as stage four, whereby their kidney function (glomerular filtration rate) reduces to less than 30%, patients are referred by the Nephrologist to a team of clinical nurse specialists who focus on supporting them to make a decision about which renal replacement therapy to start. A minority of patients start haemodialysis in hospital in emergency circumstances and are later told of peritoneal dialysis (including patients Frank and Matthew in this study).

The pre-dialysis clinical nurse specialists deliver a “pre-dialysis education programme”, involving other members of the nephrology multidisciplinary team. The first stage of this programme involves the pre-dialysis clinical nurse specialists visiting patients at home to discuss the treatments for end-stage renal disease.

5.2.1 Entering the home

The home visit marks the introduction of the disease and associated treatment into the home environment, encompassing a pre-dialysis clinical nurse specialist visiting the patient and their relatives. The nurses in the study reported organising the home visit within two weeks of the patient being diagnosed with stage four chronic kidney disease and during the two-hour visit discuss the functions of the kidney, what kidney disease is and renal replacement therapies (peritoneal dialysis, haemodialysis and kidney transplantation). In addition to verbal information, the nurses also discussed the written and audio information they provide patients with at this visit, describing the treatments. In terms of explaining peritoneal dialysis to patients, which nurses explained can be a challenging treatment for patients to understand, the nurses discussed using various visual aides, including medical equipment, to simulate how the treatment works:

“we all take out a Tenckhoff [PD access] to show them what the tube looks like. We use a picture book, so they can see what the tube looks like when it’s in somebody. And we take the bags out, so they can see what the bags look like...and we demonstrate a very basic exchange, emphasising that we don’t just expect them to do it, that the PD team - when the time comes - will be there to support them”

(Int. Una - nurse)

Una also reported reassuring patients that this demonstration is not their only introduction to peritoneal dialysis - they will be supported to learn the dialysis procedure when they start treatment. This home visit therefore aims to introduce patients to the concepts surrounding chronic and end-stage renal disease and the possible treatments available to them, using different resources to explain. The

nurse participants then described inviting patients back to the clinic for additional information about their treatment options.

5.2.2 Back to the clinic

The healthcare professionals reported that patients are invited to an information morning in the nephrology clinic, where the treatment options are explained again, the dietician discusses the dietary restrictions associated with end-stage renal disease and people using different treatments describe their experience to the pre-dialysis patients. The pre-dialysis nurse specialists also described a five-week pre-dialysis patient group that they facilitate, which encompasses information sessions and again the opportunity for patients to hear other peoples' stories of peritoneal dialysis, haemodialysis and kidney transplantation:

“we have education from the pharmacist, from the psychologist, from ourselves the clinical nurse specialists...it's a five week programme, two hours a time...and we have one session where we have patients... will come in and give their story. So we'll have a patient who's on PD, a patient who's on haemo, a patient who's had a transplant and they will give their experience, cause what we're finding is patients really value other patients' experience”

(Int. Veronica – nurse)

Veronica recognised that they impart a considerable amount of information to patients during the home visit and information morning, and therefore she asserted that this group allows them to provide more in-depth insight into the treatments and living with end-stage renal disease. The nurses in this study – Trudy, Una and Veronica – all reported that patients evaluate this programme well, but that not all patients are offered the opportunity to take part due to the large numbers of patients that they visit. The nurses thus described offering three opportunities for patients and their families to receive information and support regarding their choice of renal replacement therapy. Patients' decision-making is discussed in depth later.

5.2.3 Approaching dialysis: Tenckhoff catheter insertion

After patients have made their decision about which type of dialysis to use and informed the Nephrologist, patients continue to return to the nephrology clinic until their kidney function reduces further. The doctor interviewed for the study described using “early symptoms as a trigger to start dialysis” (*Int. Stuart – doctor*), rather than simply using kidney function in isolation, but one of the specialist nurses, Wendy, reported that when kidney function is down to around 15% they begin to plan starting treatment. Once this stage occurs, patients are then referred to another team of healthcare professionals who ensure that dialysis access is secured. The

haemodialysis alternative to an abdominal catheter involves the joining of an artery and vein in the arm (fistula), causing it to swell and thus withstand needle insertion, or the introduction of a permanent catheter into the patient's neck.

Patients opting for peritoneal dialysis require an operation to have an abdominal catheter – called a Tenckhoff – inserted. This involves being referred to a surgeon and a subsequent operation under general anaesthetic (or local anaesthetic if general is contraindicated). Wendy explained that after the operation patients are either visited at home or return to the clinic to have their Tenckhoff catheter dressings changed by a nurse, highlighting a period of more intense involvement by the healthcare team. The nurse specialists reported that this can be a challenging period for patients as they recognise that this operation is a step towards starting dialysis: “it’s reality, the tube has gone in, dialysis is imminent” (*Int. Wendy - nurse*); “it’s becoming real” (*Int. Veronica - nurse*).

5.2.4 Time for dialysis: teaching patients the treatment

Starting dialysis involves the introduction of a new team of specialist nurses – the PD nurses – who teach patients to perform the treatment and then provide long-term care throughout their time using peritoneal dialysis. The participating Health Board trained the majority of patients to perform peritoneal dialysis in their own homes, taking up to five days – an intense and time-consuming process for patients and their relatives. Indeed one of the nurses recognised this as an “invasive thing” (*Int. Yvonne – nurse*). Yvonne thus reported visiting or telephoning patients the week prior to training them to use peritoneal dialysis to both introduce herself and instruct patients to ensure they have the correct equipment, including weighing scales, a hook on the wall and a table and chair to use during the procedure, as well as sufficient storage space for the dialysis solution. This stage thus marks the transition of medical equipment permanently into the home space.

In terms of the topics that the PD nurses teach patients, Yvonne explained that the teaching programme encompasses both practical skills and education covering a range of different areas including the actual procedure, monitoring for complications and changing the Tenckhoff dressing:

“we teach the bag exchanges, measuring fluid, assessing themselves, troubleshooting, looking for anything of signs of infection, charting adding the results, working the balance, um dressing, exercise, showering, erm, but also their medication, going through their medication giving... and also teaching them about phosphate balance”

(*Int. Yvonne - nurse*)

In terms of involving family members in this training process, both Yvonne and Wendy reported actively encouraging relatives to take part – particularly if the patient is physically unwell – but also encouraging patients to self-care if they are able to do so, to reduce the risk of infection (Wendy) or increase patient control (Yvonne). Healthcare professionals highlighted that this is an emotionally difficult period for patients, citing apprehension and “a lot of ups and downs” (*Int. Wendy – nurse*).

The diagram below depicts this journey described by healthcare professional participants from diagnosis to dialysis.

Healthcare professional involvement	Event	Space
Nephrologist	Diagnosis of chronic kidney disease ↓	Nephrology clinic
Nephrologist	Ongoing assessment ↓	Nephrology clinic
Nephrologist	*chronic kidney disease stage 4; kidney function 20-25mls/min* ↓	Nephrology clinic
Pre-dialysis specialist nurses Multidisciplinary team	Pre-dialysis education - home visit - information morning - support group ↓	Patients' homes Hospital Hospital/ social club
	Making the decision ↓	Patients' homes
Nephrologist	Making the decision ↓	Nephrology clinic
Nephrologist Pre-dialysis specialist nurses	*kidney function <15mls/min; clinical symptoms of uraemia* ↓	Nephrology clinic
Surgeon Specialist nurse PD nurses	Tenckhoff insertion and after-care ↓	Surgery Hospital/clinic Patients' homes
PD nurses	Being trained to perform peritoneal dialysis	Patients' homes

Figure 9: Diagnosis to dialysis

The pre-dialysis phase has thus been described by healthcare professionals. The next two sections consider two important stages of this pre-dialysis trajectory from the perspectives of patients and relatives interviewed in this study: making decisions about dialysis and actually starting treatment.

5.3 Decision making

Patients' choices about which treatment to start can be limited by their medical or surgical histories, and one of the renal replacement therapies may therefore not be appropriate. Whereas some participants reported that they chose peritoneal dialysis easily, others struggled to make a decision and were frustrated by healthcare professionals' refusal to make the decision for them. The decisions made by participants were personal and included a preference for home, perceived control and dislike of the haemodialysis procedure or access, with participants often citing a combination of reasons. While family members, including partners and children, were present for the pre-dialysis information sessions, it varied between participants whether they chose a treatment independently or sought input from relatives.

5.3.1 Making the decision: simple or a struggle?

Overall, the majority of patients in the study had clear reasons why they wanted peritoneal dialysis compared to haemodialysis, or felt they had little choice due to other medical conditions limiting their options. However, two participants struggled greatly with the choice and felt unsupported by healthcare professionals.

For a number of participants their decision about dialysis was simple, due to their choice being limited by confounding medical conditions or dismissal of one of the renal replacement therapies. Kris, who commenced dialysis in the USA, described that he was not able to undertake haemodialysis or receive a kidney transplant due to his cardiac history, and peritoneal dialysis was thus the only option:

“JB: did they tell you about the different types of dialysis?”

Kaye: oh yes

Kris: yes

Kaye: we knew about peritoneum or the haemo... but er Kris wasn't strong enough to have the haemo...

Kris: I've got other problems as well with my heart and stuff”

(Int. Kris and Kaye)

Kris was the only participant in the study who had no choice about which renal replacement therapy to start. Other participants had strong negative feelings about other renal replacement therapies, leaving peritoneal dialysis the only option. Christine described her husband Carl's loathing of hospitals and stated that he had also opted out from the choice of kidney transplantation as he felt organs should be for younger patients. Thus for Carl, peritoneal dialysis was the only option for him:

"I don't think there was any choice for Carl, um as soon as we went down to the the *[haemodialysis]* unit at the hospital he just said 'no, this is not for me', so there was no um, there was no thoughts of which way we were going to go, um the decision was straight away to do this *[PD]*. *[He]* doesn't like, he's always hated hospitals...he just didn't like the thought of going down there three times a week"

(Int. Christine)

Therefore some participants reported that they were left with little choice and subsequently the decision was made swiftly.

Furthermore, Evelyn's choice of renal replacement therapy was also limited by her concerns about receiving a kidney transplant. Evelyn explained her worry that a kidney transplant would be affected by polycystic kidney disease and despite reassurance from healthcare professionals that it should not, Evelyn was adamant about not considering a transplant:

"JB: did they talk to you about transplant?"

Evelyn: Uh yes, but at the time it thought well to me there was no point, because I thought 'well what's the point of me getting somebody else's kidney and that's going to turn out the same as the other ones', you know? But then they said 'no it shouldn't do' I said 'well it should or it shouldn't' I said, you know, 'to me it's it's not worth it' so I said 'no' I said 'forget it' you know, that's why I left it"

(Int. Evelyn)

Several participants were ineligible for kidney transplantation, including Oliver and Frank. Benjamin explained that because he had severe asthma, he was unable to tolerate the immunosuppressant medications that patients take for life following kidney transplantation:

"Benjamin: The um, what's it called? Reject um

Beatrice: Rejection

JB: Anti-rejection medication?

Benjamin: Would be um, you know, could be devastating as far as my asthma was concerned"

(Int. Benjamin and Beatrice)

Therefore, Benjamin and others were required to choose between haemodialysis and peritoneal dialysis. The majority of patients described choosing a treatment without too much difficulty following consideration of the benefits and drawbacks, but

Benjamin and Rhodri did not find it simple to make the decision and felt unsupported by healthcare professionals.

Feeling unsupported

Benjamin spoke with frustration about trying to decide which type of dialysis to undertake. He found the decision challenging and he reflected on that period – more than six years ago – with ongoing bitterness that the decision was not made for him by healthcare professionals. Benjamin described his confusion about not only which dialysis to choose, but why healthcare professionals would not advise him about which treatment would be the best:

“Ben: what they [nurses] didn’t do er which is, which I I can’t understand, um and neither did the consultants, is nobody tells you which one to do (pause) er I mean which is odd, it’s the one bit of advice you want is to be said ‘well this this is the best one for you’, but they they didn’t do that. In fact they went to great lengths to say ‘well it’s your decision’, which which struck me as very strange, still strikes me as strange um

Beatrice: Cause you are a bit confused at that time and you do need a bit of help

Ben: Well I mean how do you know, you know? I know it’s part of your lifestyle decision I suppose”

(Int. Benjamin and Beatrice)

Rhodri agreed that the decision was difficult and explained that he genuinely was not sure which treatment to choose. This seems to suggest that Rhodri is trying to justify the challenge that he faced in making a decision:

“to me it’s a big decision to make before you go onto dialysis to know which one, you know, you don’t know, you’re like a fish out of water, you don’t actually know which treatment would suit you better, you know, er I had to really think about it”

(Int. Rhodri)

Whereas Rhodri described eventually weighing up the benefits and drawbacks of the two types of dialysis, Benjamin continued to wish that a healthcare professional had made the decision for him. Benjamin commented that he found it confusing that healthcare professionals were reluctant to offer advice about which treatment would be best:

“Ben: I don’t really see what the sensitivity was, I mean it was the one thing you’d have thought you should you needed an expert to tell you, rather than making it an individual choice”

(Int. Benjamin and Beatrice)

Benjamin’s conviction that he should have been told which type of dialysis to choose is steadfast and implies his confidence in the healthcare professionals as the “experts” that would make the right decision for him.

Thus the majority of patients described making a choice without too much difficulty, particularly if their choice of treatments was limited. However, Rhodri and in particular Benjamin asserted that healthcare professionals should offer advice about which treatment is best for the patient, recalling the challenge they faced in making the decision and their confusion that they were not told which treatment to choose.

5.3.2 The case for peritoneal dialysis

Choosing a renal replacement therapy is a complex decision and participants reported different motivations and reservations. The participants in this study cited different and personal reasons for choosing peritoneal dialysis, including preference for home, dislike of hospital and haemodialysis, retaining control and fear of the fistula (haemodialysis access), with participants often citing a combination of reasons.

Home sweet home

Home was an important consideration and influence on why patients chose peritoneal dialysis. However, patients were often driven to this option by their dislike of spending prolonged time in hospital spaces.

For example, Lisha asserted that although her mother Leila favoured the 'comfort' of being at home; this was in the context of worry about her mother spending long periods of time in hospital for haemodialysis:

"Lisha: they said 'there's either peritoneal or haemo'...and we decided this [PD] would be better, because at least it's in her own comfort of her own home and the other one would be a lot more difficult because she'd be in the hospital for hours and stuff like that"

(Int. Leila and Lisha)

Furthermore, Matthew had started on haemodialysis suddenly following pneumonia and after several months of treatment at hospital he switched to peritoneal dialysis instead, due to concern that he was "wasting" his life in hospital. Matthew cited disliking haemodialysis because it meant that three days of his week were dedicated to the hospital:

"JB: what did you think when they first told you about peritoneal dialysis?
Matt: well at least it was daily, I could do it at home and I wasn't wasting three days of my life in hospital, you know, because that's at the end of the day, that's what it basically worked out, you know? I mean you couldn't go anywhere in the morning, because you had to leave here at 12 to get up for dialysis at one o'clock, you know, it's er and although it was sort of OK once you got there, it was three days of the week gone, you know? You couldn't

arrange anything sort of thing, so I found it was a lot easier then to do it at home”

(Int. Matthew)

Matthew’s concerns about haemodialysis dictating his week were also articulated by Daniel, who hoped that peritoneal dialysis would prevent him regularly attending hospital. Daniel also hoped that peritoneal dialysis would be flexible and enable him to undertake treatment at his caravan, which was extremely important to Daniel and his wife Diane:

“Dan: of course I was given the choice of what type of dialysis I wanted and I chose CAPD

JB: So why did you choose CAPD?

Dan: Cause I thought that was the most convenient for me. I didn’t want to go into hospital three days a week and at that particular time I had a caravan down in *[Seaside-Town]*, and we used to go down there very often down to the caravan, and I didn’t want to have say ‘well I can’t go down there because I’ve got to go to *[City]* or *[Local City]*’ or wherever three days a week, so I um decided to go onto the bags”

(Int. 1 Daniel and Diane)

Harriet concurred with Daniel and Matthew’s feelings towards spending time in hospital dialysing, additionally citing concern about travelling to hospital:

“it seemed the best option for me, because I didn’t fancy being in the hospital three days a week, trip to *[City]*”

(Int. Harriet)

Overall, participants were positive about remaining at home using peritoneal dialysis as it was perceived as a better option than haemodialysis, which involved travelling and spending significant amounts of time in hospital, causing disruption to their lives. Additionally, there was hope amongst participants that they would be able to live independently with peritoneal dialysis and retain an element of control over their lives.

The importance of retaining control

While home was thus an important consideration, other participants chose peritoneal dialysis because they perceived the treatment to be preferable to haemodialysis, in terms of giving them increased control over their lives. Rhodri described his realisation that although haemodialysis would release him from having responsibility for dialysis, he should have control over his own treatment and not be dependent on healthcare professionals:

“I thought ‘oh I’ll let, I’ll have the haemodialysis because it’s less hassle for me, somebody else can do it’ and then when I thought about it, it’s relying on somebody else to do, you know, for me to, you know, I have to rely on other

people to do it. I'm thinking 'well hang on, the other one is better for me like in the long run because I'm in control of it'"

(Int. Rhodri)

Control over treatment and subsequently daily life are important issues that were mentioned frequently throughout the interviews by participants in relation to peritoneal dialysis. Indeed the extracts above from interviews with Daniel and Harriet reinforce their hope that peritoneal dialysis would help them retain control over their daily activities, perceiving that conversely haemodialysis would determine their weeks. Oliver similarly discussed his hope of being able to organise peritoneal dialysis according to his routine - he felt strongly that haemodialysis could negatively affect his lifestyle. Interestingly Oliver qualifies his assertion of having control of his life when using peritoneal dialysis – “within reason” – recognising that treatments for end-stage renal disease will affect everyday life, but he hoped peritoneal dialysis would have a lesser impact:

“you’ve got to sort of waiting time before you get the dialysis etc, and by the time you’ve had it up it’s done. Er and being an active person that’s a bit abhorrent to me, so I said ‘right we’ll do the CAPD’, because I can organise my life in the way I want it, or within reason”

(Int. Oliver)

Oliver makes an important point about being an “active person”, which was also asserted by Paul. Paul described that he would not be able to cope with each lengthy haemodialysis treatment where he would be controlled by the treatment and confined to a bed:

“Paul: they spoke about haemodialysis and to be perfectly honest as far as I didn’t like the idea of it (laughs) to be honest

JB: And why was that? Why didn’t you like the idea of it?

Paul: Well to be fair, you know, I’m active sort of person, um to sit in the bed for at least four hours and allow recovery and this that and the other, I think oh couldn’t hack it”

(Int. Paul)

These participants thus chose peritoneal dialysis as they felt that it would allow them control over their lives and daily activities, whereas they considered attending the haemodialysis unit for four hours thrice weekly to be an unacceptable lifestyle change.

Fear of the fistula

Two participants cited another reason for disliking haemodialysis. Benjamin and Frank both cited fear about having a fistula formed for haemodialysis, which subsequently motivated them to choose peritoneal dialysis. The fistula is where an artery and vein are joined, leading to the conjoined blood vessel swelling and

enlarging, making repeated needle insertion sustainable over time. Similar to Rhodri above, Benjamin had also considered opting for haemodialysis, as he perceived peritoneal dialysis would negatively affect daily life. However, Benjamin cited concern about the fistula for changing his mind:

“Ben: initially I wanted I favoured haemo, because I worked it out that for I could go up there three times a week and be normal for the rest of the time, whereas the other one, especially the CAPD, was four times a day, which seemed a lot more disruptive, but (pause) but then I dunno, I didn’t fancy the idea of a fistula very much and um... all in all I thought it would be better to do it in the house and er and we settled for CAPD”

(Int. Benjamin and Beatrice)

Like Benjamin, Frank also disliked the idea of the fistula, but his feelings towards the dialysis access were stronger. Frank had started haemodialysis while in hospital and therefore did not follow the typical trajectory of the nephrology clinic. He had a central line inserted into his neck for haemodialysis and attended a dialysis clinic for several months, but he decided to switch to peritoneal dialysis when he was told he would require a fistula. Frank described his history of fistulas in the haemodialysis clinic and his upsetting experiences of them, including seeing other patients bleeding:

“Frank: I’d seen so much going on in the unit with fistulas uh

Fiona: Put you off a bit...

Frank: it’s like one of the nurses in *[names haemodialysis unit]* said, he said ‘you’ve probably been traumatised’ but um the swelling, you know, that takes place is um a little bit off-putting really... yes so that put me off and...then you get people coming off haemo and they’re there maybe for quarter of an hour twenty minutes to stem the bleeding, you know? Now in *[names haemodialysis unit]* it was a situation where uh on a few occasions people have come off haemo, they’ve been bandaged up and they’re walking down and all of a sudden there’s blood dripping off the ends of their fingers so (laughs), you know, I thought ‘oh do I want do I want this’... so, you know, I thought ‘well I’ll go for the Tenckhoff because it sounds a more’

Fiona: Gentle

Frank: A more yeah a gentler type of treatment more than anything and I thought well a night machine as well because there was they were on about a night machine I said ‘well a night machine that will give me my days off’”

(Int. 1 Frank and Fiona)

Frank was the only participant who described peritoneal dialysis as a gentler treatment, suggesting that he sees haemodialysis as aggressive, which substantiates the images of blood and swelling that he describes.

Participants thus described multiple reasons for their choice of peritoneal dialysis, which often centred on the desire for more control and the ability to continue with some aspects of their lives before dialysis. Their relatives’ involvement in this significant decision is discussed next.

5.3.3 Family involvement

A number of relatives, including partners and children, explained that they were present for the pre-dialysis education, both at the home visits and hospital information sessions. In terms of making the decision to undertake peritoneal dialysis, there were mixed reports from participants about whether their partners or children were involved in the decision, despite the eventual consequences of dialysis on the wider family.

Several wives and children in the study described that they had made the decision together with their relative using dialysis. For example, Leila and her daughter Lisha described that “they” had decided, suggesting that it was a joint choice. Benjamin and his wife Beatrice reported that they made the decision about dialysis together, as they did other decisions in their lives:

“Beatrice: we’ve been always made the decisions together really, you know, always been to all the clinics and all the meetings and (pause)
JB: OK and how about, you said you’ve got four children, were they involved? Did you involve them in the decision?
Ben: No
Beatrice: No not really, no no I mean we could’ve
Ben: I mean they knew about it”

(Int. Benjamin and Beatrice)

However, while Benjamin included his wife in the decision, they did not include their grown-up children. This was a common approach amongst participants, who often told their children that they needed treatment and what the choices were, but made the decision independently:

“JB: when you were told you’d have to go on dialysis, did you talk to your daughters about it? About what type of dialysis you should do?
Evelyn: No no no, we didn’t talk about that all, I told well they knew I was going on dialysis”

(Int. Evelyn)

“JB: what did they [children] think would be the best treatment for you? Or did they not have an opinion?
Harriet: I don’t think they had any real opinion, except obviously this is a more convenient option then being back and forth to the hospital”

(Int. Harriet)

“they’ve [children] all gone now, but er well I’ve never asked them about it, you know, they just seemed to accept that this is something I’m doing and that’s that”

(Int. Oliver)

Despite the limited input that patients described their children having in the dialysis decision, sons and daughters did attend the pre-dialysis information sessions with their parents, as described by Harriet and also by James's daughter Julie, and importantly were frequently involved in assisting their parents with aspects of their dialysis care.

Within other households, the patient independently made the decision about which dialysis to start. Fiona described that due to her husband's concerns about haemodialysis and being ineligible for a kidney transplant, he chose peritoneal dialysis without input from her:

"JB: you were together when you made the decision?"

Fiona: Well I didn't have much sort of say in it really, because you were more or less adamant you weren't going to have the fistula

Frank: Yeah

Fiona: And the alternative was just that - the PD - so it was more or less his decision"

(Int. Frank and Fiona)

Carl's wife Christine was adamant that her husband should make the decision independently. Christine firmly stated that the choice of which type of dialysis to undertake was the person who would have to use the treatment:

"JB: what did you think about it?"

Christine: The decision was his, um I just was prepared to go along with whatever, cause I'm not the one having the dialysis, I'm not the one that's feeling unwell, um so yeah I didn't question his decision"

(Int. Christine)

Although Christine reports that she did not feel the decision regarding dialysis choice was hers to make, in reality she was very involved in her husband's dialysis care and the decision about which treatment to undertake therefore affected both of them.

All patients in the study received help and support from their relatives to perform the treatment at home and additionally the treatment impacted significantly upon the home environment. Thus it is interesting that many patients reported making the decision independently, or with the input of their spouse only (with the exception of Leila's daughter Lisha, and James's daughter Julie), when in fact the decision to undertake peritoneal dialysis in the home had long-lasting implications for the wider family.

Having chosen to undertake peritoneal dialysis, patients then returned to the clinic and were reviewed until their kidney function reduced to the stage where they were reporting symptoms of kidney failure and needed to start dialysis.

5.4 Starting peritoneal dialysis: no way back

The peritoneal dialysis training programme marks the permanent introduction of medical equipment into the home environment and an intense period of involvement by specialist nurses.

The majority of patients in this study were taught peritoneal dialysis in a similar way – at home, for several days, by a peritoneal dialysis nurse – with only two of the sixteen participants reporting otherwise. Despite this, participants recalled similar key information from their training. This section will thus firstly consider participants' recollections of the training they received to learn peritoneal dialysis and discussion of familial involvement in this process, with final consideration of participants' initial feelings about using the treatment.

5.4.1 Being taught the treatment

Most participants were trained to use peritoneal dialysis by specialist peritoneal dialysis nurses in their homes, with only two of the sixteen participants (Kris and Matthew) reporting otherwise. Kris was taught peritoneal dialysis in a clinic while living in the USA and Matthew was taught on the nephrology ward. Despite this difference, patients recalled similar experiences and cited the importance of receiving praise from staff and using prompts, while preventing infection was a central message of the training. Relatives were also involved in this process to support patients.

Receiving praise

The length of the programme appeared to vary significantly between participants, but nonetheless they spoke with pride about the amount of time the training had taken and the subsequent praise they received from the nurses training them. While Geraint reported being pleased that it had taken him four, rather than ten, days to learn how to perform the treatment, Paul described learning in one morning. Both participants mentioned that the peritoneal dialysis nurse training them was positive and recalled how the nurses praised their achievement:

“*[names nurse]* she taught me like and um she she was fantastic, ‘you’re right Geraint’ she said ‘great, fantastic, you can do it on your own now’ after four

days 'a lot of people' uh she said 'take a couple of weeks'"

(Int. Geraint)

"[names nurse] came here on the morning Monday morning to do this and yes so I showed, she did it and then she come back lunchtime to do it and that was it, I'd trained meself, um she couldn't believe it, she said they'd never never known anybody train so quick um and so I just got on with it, you know"

(Int. Paul)

Other participants in the study reported two days of peritoneal dialysis training (Carl and Frank), with others reporting slightly longer (Benjamin). Participants reported learning the technique fairly quickly, with praise from the peritoneal dialysis nurses.

Prompts

In terms of learning the actual dialysis procedure, patients and relatives reported receiving practical support, particularly as they were anxious about remembering the procedure. Harriet described the training positively and she was comforted by the written instructions detailing the procedure that the nurses provided:

"the nurses were marvellous, they were really thorough and the instructions were very clear and they give you laminated sheets...it was very straight forward, I mean step-by-step and you can't go wrong"

(Int. Harriet)

Geraint similarly discussed being provided with written information about the procedure to remind him of the correct order:

"you had a chart in front of you say like um 'wash your hands' right 'take the cap off' right, all this list was in front of you for what you have to do, chuck it all on the floor [packaging from the exchange] and then obviously after you've finished you pick it up, put it in the yellow bag and that was it, but they were happy"

(Int. Geraint)

Other participants also had copies of the procedure in writing, including Aileen, James's wife Janice and Kris's wife Kaye (who was provided with it by the PD nurses when they moved to the UK), which they found reassuring and helped them to have confidence in using the treatment. Interestingly several participants continued to display the laminated instruction sheets, including James's wife Janice who had undertaken her husband's dialysis for two years.

Prevention of infection

The instruction regarding infection prevention appeared central and was recalled by multiple participants. Patients, including Oliver, reported that preventing infection involved hand washing skills, using alcohol hand-gel throughout the procedure and correctly disposing of the waste-products from a dialysis exchange:

“they put us through all the routines for hygiene washing your hands and all this, and er how to put er plaster on over the exit site, you know, all this sort”
(*Int. Oliver*)

Patients and relatives demonstrated a strict peritoneal dialysis procedure during later ethnographic observations, which included when to cleanse hands with alcohol gel to minimise the risk of infection. Evelyn stated that she kept forgetting to use the alcohol gel, leading the peritoneal dialysis nurse training her to intercept, which she took in good humour:

“she [*PD nurse*] just let me get on with it, you know, and if I done something wrong she’d go ahem (laughs) used to make me laugh, and I’d think to myself ‘oh what have I forgotten? Oh bloody hand rub’ you know, that’s all really, but the rest was fine, you know, every so often I’d forget the hand rub, but everything was alright”

(*Int. Evelyn*)

Kris was the only participant in the study to learn the procedure while living away from Wales. Kris and Kaye reported that their dialysis training took significantly longer (two full weeks) than the training undertaken by other participants in this study and also involved them being trained in a dialysis clinic. Again, the importance of preventing the spread of infection was reinforced by this couple, as they recount and demonstrate being taught to wash their hands:

“Kaye: the way they taught us was eight hours a day for two weeks it was wasn’t it about seven hours a day?...”

Kris: we was one day on hand washing I think, it on hands, and it was there was a routine as well, I can’t remember it ten times

Kaye: [*imitates washing hands*] wash your fingers, your wrists last - well you know all about it - and there’s you don’t shake your hands”

(*Int. Kris and Kaye*)

As the only couple in the study who learned peritoneal dialysis outside of Wales, Kris and Kaye provided unique insight into the potentially different infection prevention procedures that patients are taught. This was highlighted through their recollection of the strict infection control precautions they were instructed to follow and being screened to see whether they were suitable candidates for peritoneal dialysis:

“Kaye: now over there when they come to the house and check your house to see if it’s clean enough or whatever...if you’ve got suitable for dialysis at home, have you got a room, because they’re much more particular over there aren’t they?... we had to shut all windows

Kris: and you put a mask on every time

Kaye: a mask oh yes and gloves

Kris: well it was a tropical country...we were taught properly

Kaye: yes we were”

(*Int. Kris and Kaye*)

The couple discussed the different infection control procedures they were taught in the USA, while other aspects of infection control were the same as described by participants trained in Wales, for example shutting windows and washing hands for one minute. However, there are differences, leading one to question the evidence behind the procedures that patients are encouraged to follow. Despite these differences, all participants recalled being taught ways to prevent the spread of infection.

Emergency back-up

Patients described that it was not uncommon for their partners and children, who had accompanied them to pre-dialysis information sessions and had (in some households) helped them to choose a treatment, to also learn to perform peritoneal dialysis. This was either as a back-up in case the patient was unwell, or because relatives would in fact be responsible for the treatment. Within some families where the patient was not responsible for their treatment, several members of the families learned to perform peritoneal dialysis, to ensure they too had back-up if one of the relatives was unwell.

Oliver reported that his wife learned peritoneal dialysis to prepare for emergency circumstances:

“JB: was your wife trained to do the dialysis as well or is it just you?”

Oliver: no, [she] was involved, she hasn't done it since but she was involved in the training, so she knew so if I sort of broke my legs and couldn't move, she'd know what to do”

(Int. Oliver)

Matthew's wife learned peritoneal dialysis for the same reason, which was fortunate when Matthew was unwell with influenza and could not undertake CAPD exchange independently. Other participants' wives, including Rhodri and Frank, were also proficient at performing their husband's dialysis, although the patients continued to perform the treatment fairly independently. Carl's wife Christine and Kris's wife Kaye reported being taught peritoneal dialysis at the same time as their husbands, but over time assumed increased responsibility for the treatment.

Furthermore, Kris and Kaye explained that they taught their son in the USA to perform Kris's peritoneal dialysis, to enable Kaye to travel to the UK alone. Kaye reported that she was due to go into hospital for knee replacement surgery after our interview and therefore their son was flying to the UK to care for his father:

“Kris: our son learned as well he wanted to learn

JB: oh did he? OK

Kaye: well we taught him ourselves, but oh he's coming over now when I go in for my op

Kris: yeah because when you used to come home [UK] for a week he used to help me out

Kaye: yes yeah he's very good"

(Int. Kris and Kaye)

Other families similarly took a joint approach to learning the treatment, for example Norman's two children were also able to perform their father's dialysis. However, whereas some patients reported teaching their wives or children the procedure themselves, in other households children were actively involved in the training delivered by the PD nurses. James's daughter Julie and wife Janice shared responsibility for James's treatment, but Julie (a nurse) described helping her mother to learn the peritoneal dialysis procedure:

"James: they come and trained her

JB: OK and how did you find that?

Janice: well they trained Julie first, then me

Julie: they had three days to train us, so they did intense training on me and then I took my time with my mother, but they left us books and um information sheets and again telephone numbers"

(Int. James, Janice and Julie)

Lisha was similarly taught peritoneal dialysis by the PD nurses and helped her mother Leila learn the procedure.

5.4.2 Reality sets in

While some participants found peritoneal dialysis simple to learn, others struggled with the technique and the variety of tasks that they were taught. Patients explained that they felt fearful about starting peritoneal dialysis, which Kris and Kaye reported was due to their awareness of the significance of the procedure:

"Kaye: it's very frightening when you first start, isn't it Kris?

Kris: it is a bit, it's um, it's very scary

Kaye: because they make you very aware how serious it is... it was quite a big thing to learn how to do dialysis"

(Int. Kris and Kaye)

Additionally, Harriet reported anxiety due to concern that she would not be able to learn the procedure, while attempting to reassure herself:

"I was nervous, because you think 'oh will I be able to do it?' And then I thought 'well yes, lots of people do it, you can do it'"

(Int. Harriet)

Rhodri agreed with Harriet and was similarly concerned about his ability to use peritoneal dialysis. However, Rhodri described that he did not find the procedure difficult to learn and that patients starting the treatment should not be concerned:

“it’s a bit disconcerting when you first start it, because you do think um ‘how am I going to manage to do this? How am I going to remember to do all this?’ ...but I think they need to reassure people more at the outset and say ‘don’t worry about it, you know, you learn quite easy, it’ll come to you naturally and everybody’s the same’ and you know sort of reassure people and um the nurse like I said the nurse that trained me it was great”

(Int. Rhodri)

Like Rhodri, the majority of participants reported finding the procedure uncomplicated and easy to learn, including Benjamin and Carl’s wife Christine. Carl likened learning peritoneal dialysis to starting a new job, reasoning that he quickly felt comfortable using the treatment:

“Carl: Well I thought it’d be complicated, but it’s like everything else, you know, if you start a new job, it’s always complicated, but then you sort of get into it

JB: Yeah? So how long did it take for you to kind of get into it?

Carl: About two days... it didn’t take long, it’s just remembering the sequence to do things”

(Int. Carl)

There was generally consensus amongst participants that the procedure for peritoneal dialysis was simple to perform, despite anxiety that it would be a challenge.

However, not all participants found the treatment straightforward. Oliver, a retired engineer, explained that he found the procedure for peritoneal dialysis challenging to learn, which he attributed to his reducing kidney function and associated symptoms:

“one of things I found was that *[I]* must have been in pretty bad shape in a sense your memory goes a bit, you know, you start to sort of, I mean I know *[before]* dialysis I only had about 9 10% kidney function left for about five months and I was feeling er decidedly rough, but you find that um people give you instructions and you remember the last one, but you’ve forgotten what the first one is”

(Int. Oliver)

While other participants reported feeling unwell prior to dialysis, they did not report struggling to learn the procedure. This could reiterate the importance of relatives being present during the training, to offer support with remembering the procedure to some patients. Lisha was present during her mother Leila’s PD training, but the family reported finding the treatment overwhelming and technically difficult:

“Lisha: the whole thing at the time we just thought ‘we can’t do it, it just seems

so much' and it was very seemed quite difficult as well"

(Int. Leila and Lisha)

It is thus important to remember that patients and families can respond differently to dialysis and the new roles that they have to learn.

Furthermore, Kaye and Christine argued that until their husbands had commenced peritoneal dialysis, they did not understand what the treatment would actually entail:

"Kaye: and I don't think you understand what you're going in to, though they explain it

Kris: no

Kaye: you don't really understand"

(Int. Kris and Kaye)

"you don't actually understand it fully until you're actually hands on"

(Int. Christine)

While Christine reported finding her husband's treatment simple to perform, these extracts demonstrate that it can be challenging to prepare families for the reality of peritoneal dialysis and what it involves.

There was thus anxiety about being taught peritoneal dialysis and variation between participants about how easily they learned the procedure, with reports from two relatives that little could prepare them until their husbands actually started treatment.

5.5 Chapter conclusions

Patients and relatives described their reasons for opting for peritoneal dialysis, which included a preference for home or dislike of hospital, the perception that peritoneal dialysis would afford them more control than haemodialysis, or dislike of haemodialysis. This decision was a challenging one for patients to make, although for some their options were limited due to pre-existing medical conditions or ardent dislike for a certain treatment. However, a minority of patients described that they simply did not know which type of dialysis to choose and reported frustration that healthcare professionals would not make the decision for them, based on their clinical judgement. The final decision about dialysis type was made either by the patient independently or with input from relatives including partners and children, but while some relatives were willing to acquiesce to the patient's decision, choosing peritoneal dialysis affected the wider family as medical technology was subsequently introduced into the home.

When the time came for patients to start peritoneal dialysis, there were different experiences, with the majority of participants in this study being taught in the home by PD nurses. Interestingly, a couple who started peritoneal dialysis in the USA described being taught different infection control procedures to the participants who were trained in Wales, calling into question the evidence behind the rigid procedure taught to patients. Family members, including partners and children, were involved in the training process and patients were often keen for their participation as security in case circumstances arose where they required help with exchanges. Participants reported fear about the seriousness of learning the procedure and anxiety about their ability to actually perform the treatment, and while the majority found the treatment simple to perform, others found it challenging. Ultimately, two participants asserted that until their husbands were “hands-on” learning peritoneal dialysis, they did not understand what the treatment would involve. This raises important questions about the best ways to help families understand what peritoneal dialysis involves, before they face the treatment in their homes.

This chapter has thus detailed participants’ reflections on the pre-dialysis period and the next chapter will consider what happened next: the “chronic” (Rolland 1987) phase of the illness trajectory living with peritoneal dialysis.

Chapter Six: Transformed Lives - Living with Peritoneal Dialysis

6.1 Introduction

The previous chapter considered participants' reflections on the period between being diagnosed with end-stage renal disease and starting treatment – their journeys to peritoneal dialysis. This chapter now considers the next stage of the illness trajectory (Jablonski 2004, Rolland 1987): the transformed lives of families living with peritoneal dialysis, from the perspectives of patients and relatives, incorporating data from both interviews and ethnographic observations. The chapter begins by describing the alignment of peritoneal dialysis within the home, before considering the challenges of living with peritoneal dialysis, including dominance and living in fear, but also the importance of familial support. Finally the ways in which peritoneal dialysis is integrated into daily life will be explored, including flexibility and creativity.

6.2 Altered spaces: visibility and impact of peritoneal dialysis

During fieldwork the pronounced impact of peritoneal dialysis on the home environment was evident, from both outside participants' homes and once inside. Despite some participants' attempts to hide the equipment required for peritoneal dialysis by demarcating a treatment area away from the communal spaces in the home, the large amount of equipment required ensured that the home space was still significantly affected. Therefore, the signs of peritoneal dialysis were visible in all of the participants' homes, including the communal areas, separate dialysis rooms or converted rooms where participants both slept and dialysed. While there was variation between participants in how they managed their homes with medical technology, the spaces they used were all altered to accommodate dialysis and consequently their wider families were also affected by the treatment. This section will firstly consider the visibility of peritoneal dialysis prior to entering participants' homes, before exploring the impact inside.

6.2.1 Outside the home: first impressions

The impact of peritoneal dialysis on the home environment was evident from the first patient interview with Aileen. The following account is taken from fieldnotes (FN) and highlights that even before entering Aileen's home I observed the equipment associated with the treatment and the space it occupied:

“I parked opposite Aileen’s bungalow and crossed the quiet road to her front door, instantly noticing that a small bedroom next to the front door was piled high with chunky brown cardboard boxes, emblazoned with “*Baxter*” in bold blue italic lettering. I recognised the boxes from my days as a staff nurse on the dialysis ward – we had a cupboard piled high of boxed Baxter dialysis solution. This was confirmation that I was indeed at the correct house and my first sign of the impact that peritoneal dialysis can have on the home environment.”

(FN1 Aileen)

During later visits to participants’ houses, I often found that the signs of peritoneal dialysis indicated that I was at the correct house. It was at times a challenge to ensure I was at the correct house and therefore the signs of dialysis equipment such as alcohol gel (James) or dialysis solution boxes (Oliver) were often helpful indicators that I was at the right place:

“During our two telephone conversations, Oliver had been concerned that I would not be able to find his house. However, I found the lane in plenty of time. Mature trees hid the houses that led off from the lane, but a bundle of flattened brown dialysis boxes branded ‘*Baxter*’ and tied with string pointed me towards the correct drive and house.”

(FN Oliver)

Another sign that I was at the correct house was the yellow/orange clinical waste bags that were placed by the road-side, awaiting collection by the council. The labels adorning the bags, “clinical waste for incineration”, also highlight to neighbours and passers-by that medical activity is taking place within the home, potentially stigmatizing individuals undertaking home-based medical treatments and reducing their privacy.

The fieldnotes above describing Aileen’s house describe the dominance of peritoneal dialysis within her home, in terms of space and visibility of equipment. The next section will explore the impact of dialysis inside participants’ homes.

6.2.2 Inside the home: dominant dialysis

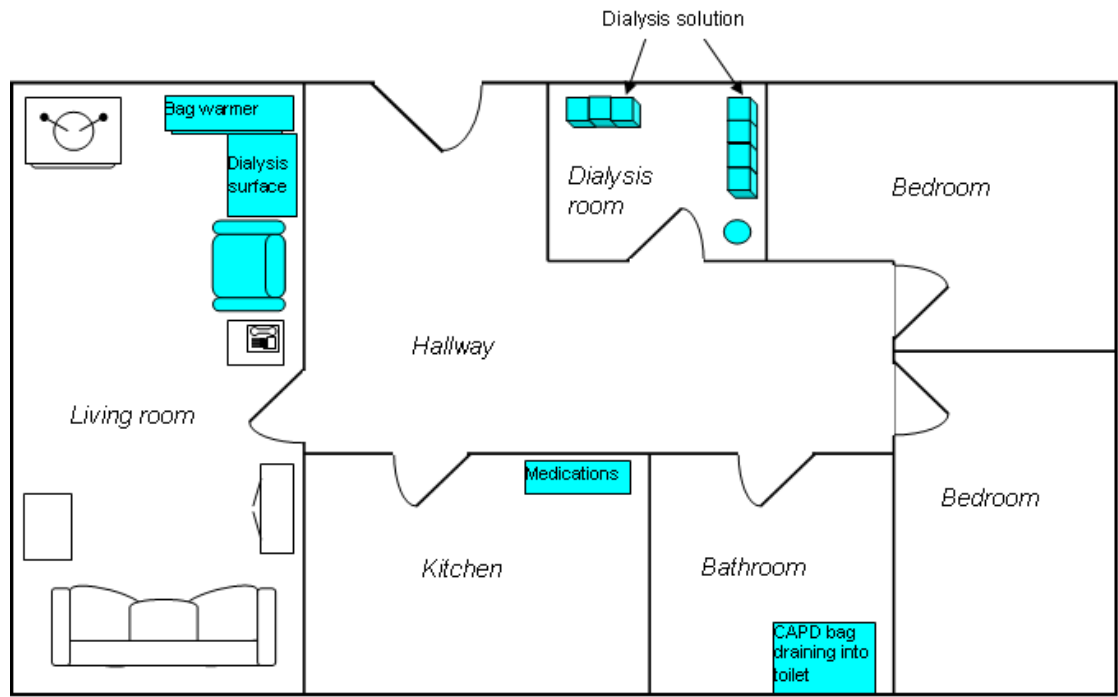
The volume of equipment required for peritoneal dialysis ultimately required participants to make changes to their homes, but the ways in which this was achieved varied substantially. Participants reported receiving around 40 boxes weighing 480kg (Oliver) of dialysis equipment each month, which filled spaces in and around their homes, including bedrooms, bathrooms, garden sheds and storage containers. While some participants tried to contain their dialysis exchanges and equipment within specific rooms, requiring conversion, others stored medical equipment throughout their homes.

Prominence across the home

For some participants in the study, peritoneal dialysis was spread across the home, with exchanges being undertaken in communal areas. Four of the sixteen participants – Leila, Aileen, James and Carl – particularly had visible medical equipment in their living rooms, with family life continuing around it. However, whereas Leila had minimal equipment in her living room and after each exchange disposed of the waste products in a yellow bag collected by the council, Aileen had an established “dialysis corner” in her living room. Participants therefore had different ways of storing and using the technology within their homes.

Aileen lived alone and while she stored dialysis supplies in a spare bedroom, she completed all her CAPD exchanges in her living room. The diagram below demonstrates the areas of the home influenced by peritoneal dialysis (highlighted in turquoise). Aileen’s living area was the most dialysis-dominated living room in the study, but Aileen did not appear perturbed by the dialysis equipment in the living room:

“After several knocks on the door and a wave through the living room window, Aileen opened the door and welcomed me inside the small hallway of the bungalow. Aileen led me into the modern living room, where on one side of the room a fireplace was adorned with framed photographs of smiling children and directly opposite was Aileen’s dialysis corner. This consisted of a leather armchair, flanked on one side with a small table holding a telephone, and above on the other side was an empty metal picture hook (which Aileen later explained is to hang the full dialysis solution bag to drain in during a CAPD exchange). Beneath the hook featured a low lying wooden coffee table, and on the floor next to this (in front of the window) was a “bag warmer”, an electrical surface upon which patients place the dialysis solution bag to warm, before it is infused into the peritoneum. On the floor in front of the coffee table was a yellow clinical waste bag, upon which sat a used dialysis solution bag and packaging from a recent exchange. The domesticity of the warm home, adorned with framed pictures, matching soft furnishings and children’s photographs, clashed with the medical equipment that stood so prominently alongside it.



(FN2 Aileen)

The “dialysis corner” contained the equipment required to complete each CAPD exchange, but Aileen also let the used dialysis equipment remain on the floor in the living room after exchanges. This was not observed in other participants’ homes – when a peritoneal dialysis exchange was completed, all used equipment was placed into the provided clinical waste bags. The diagram also demonstrates that Aileen used one of the work-surfaces in her kitchen to store her multiple medications, as well as permanently draining a used CAPD bag into the toilet. Furthermore, Aileen used one of her bedrooms to store her dialysis supplies, although this will be explored later. Although Aileen lived alone, she was visited regularly by her great-niece Abigail, who was present during my second observation with Aileen. Abigail made no mention of the dialysis corner and continued playing with her baby daughter on the living room carpet, with the dialysis equipment nearby. Dialysis was thus integrated and perceived as normal within this household:

“During my second visit to Aileen, her niece Abigail was visiting with her five-month old baby. I sat on the sofa with Aileen, who explained to me that she had been unwell with peritonitis. Abigail sat on the floor next to her daughter, who lay on the thick rug while Abigail played with her, several feet away from Aileen’s dialysis corner. While Aileen and Abigail discussed the challenges of peritoneal dialysis, neither made reference to the dialysis equipment within the room.”

(FN2 Aileen)

Although Leila showed me a separate room within her home for storing peritoneal dialysis supplies, which was complete with an armchair and surface for undertaking exchanges, she described completing the majority of her treatments in her sitting room. The fieldnotes demonstrate the subsequent equipment spread across the living space, contrasting with the comfort of the rest of the room:

“Leila lived in a large terraced house with her husband and two of her sons, but during my visit her daughter Lisha and several grandchildren were also visiting. While Leila’s husband remained in the front sitting room with some of their grandchildren, I interviewed Leila and Lisha within a light, smartly-decorated second sitting room, which led to the kitchen. Signs of Leila’s dialysis were throughout the space, including a metal drip-stand with a hanging weighing scales, a grey plastic ‘organiser’ (approximately 10cm x 10cm and stuck to the coffee table with rubber suckers) for the Fresenius dialysis system and a small box of caps to cover the end of the Tenckhoff catheter.”

(FN Leila and Lisha)

The drip-stand (used to hold the fresh dialysis solution bags during CAPD exchanges) was the most obvious piece of medical equipment, possibly because they are well-recognised with connotations of hospitals and medical treatment, thus contrasting to the domesticity of the home environment.

Peritoneal dialysis was thus evident in the communal areas of several participants’ homes, while family life continued around it. However, the visibility of equipment varied between participants. While most participants kept their communal areas dialysis-free, peritoneal dialysis requires a space where the treatment can be safely undertaken and thus multiple participants had a “dialysis room” that they had converted.

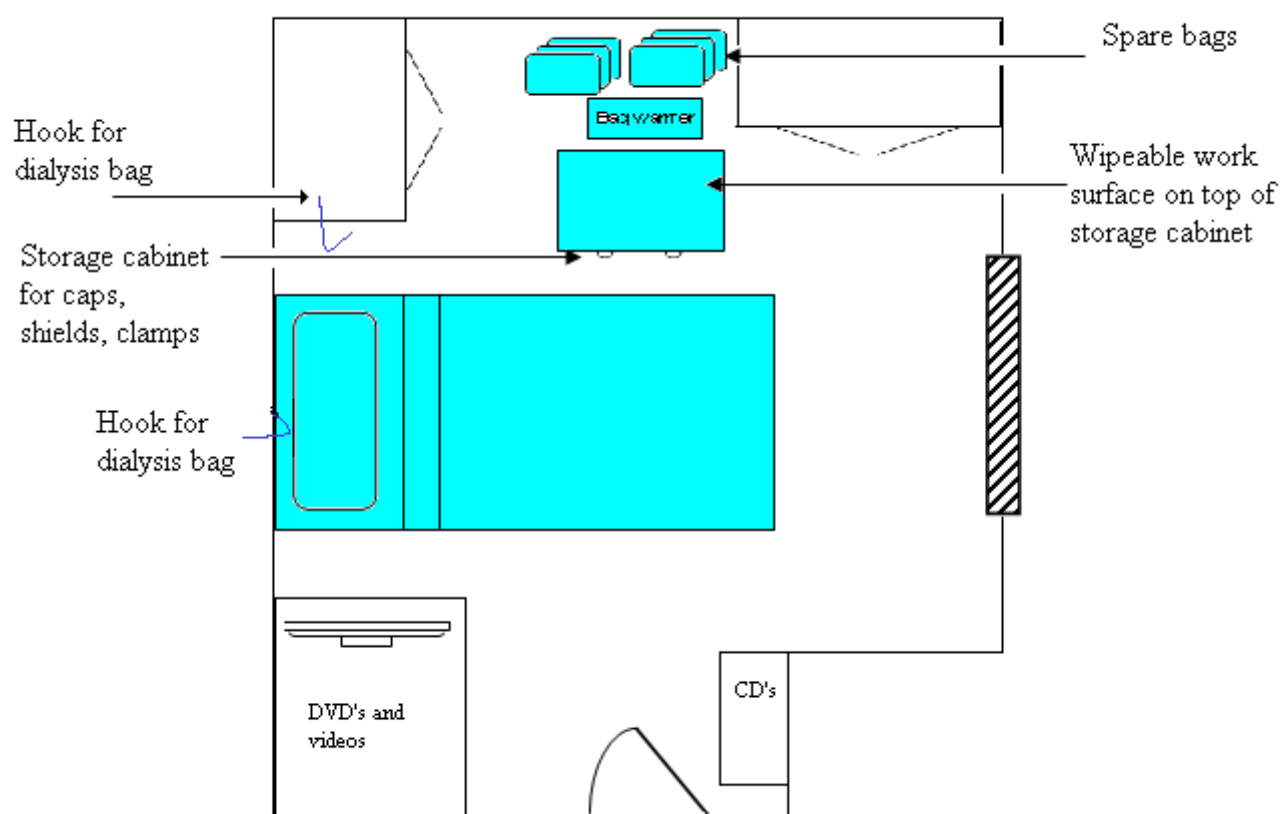
Separation and conversion

All participants’ houses were affected in some way by peritoneal dialysis, often resulting in participants dedicating one room within the house to the treatment. This was particularly true for CAPD, with multiple participants converting a spare bedroom into a dialysis space where they could undertake the four exchanges per day. Participants, including Daniel and Harriet (when they had undertaken CAPD), Evelyn, Geraint and Rhodri had dedicated and converted a room to peritoneal dialysis, for either completing the CAPD exchange, storing equipment, or a combination of both.

Rhodri had converted a spare bedroom within his home into a peritoneal dialysis space where he completed the actual exchanges. However, he kept minimal equipment for the exchanges in this space and stored the dialysis solution in an

outside shed. Instead, within Rhodri's dialysis room were multiple technological devices to entertain him during the procedure. To make the space work for him, Rhodri explained that he had installed two hooks (dark blue in the diagram) to hold the fresh dialysis solution bag, allowing Rhodri to sit or lie on the bed during the exchanges, as he preferred:

"Following the hour-long interview held in the living room, we went upstairs to undertake Rhodri's CAPD exchange. Rhodri's dialysis room was the back bedroom of the compact terraced house, which was a small but well-organised space. The room had a single bed adorned with a colourful geometric duvet cover in the middle of it, with a TV, DVD, VHS and CD player on the nearby bedside table. There were also storage units full of CDs, DVDs and videos. The far side of the bed housed a drawer unit with a wipe-able work surface on top, and hidden behind this were the bag warmer and a stock of fresh dialysis solution bags."



(FN Rhodri)

Daniel's wife Diane described the benefit of having a specific room for CAPD when Daniel used this type of treatment, because it prevented dialysis from being present throughout their home:

"Diane: it's bad enough being on dialysis, but I didn't really want the whole house taken over by everything, you know? I didn't want it in every room"
(Int. 1 Daniel and Diane)

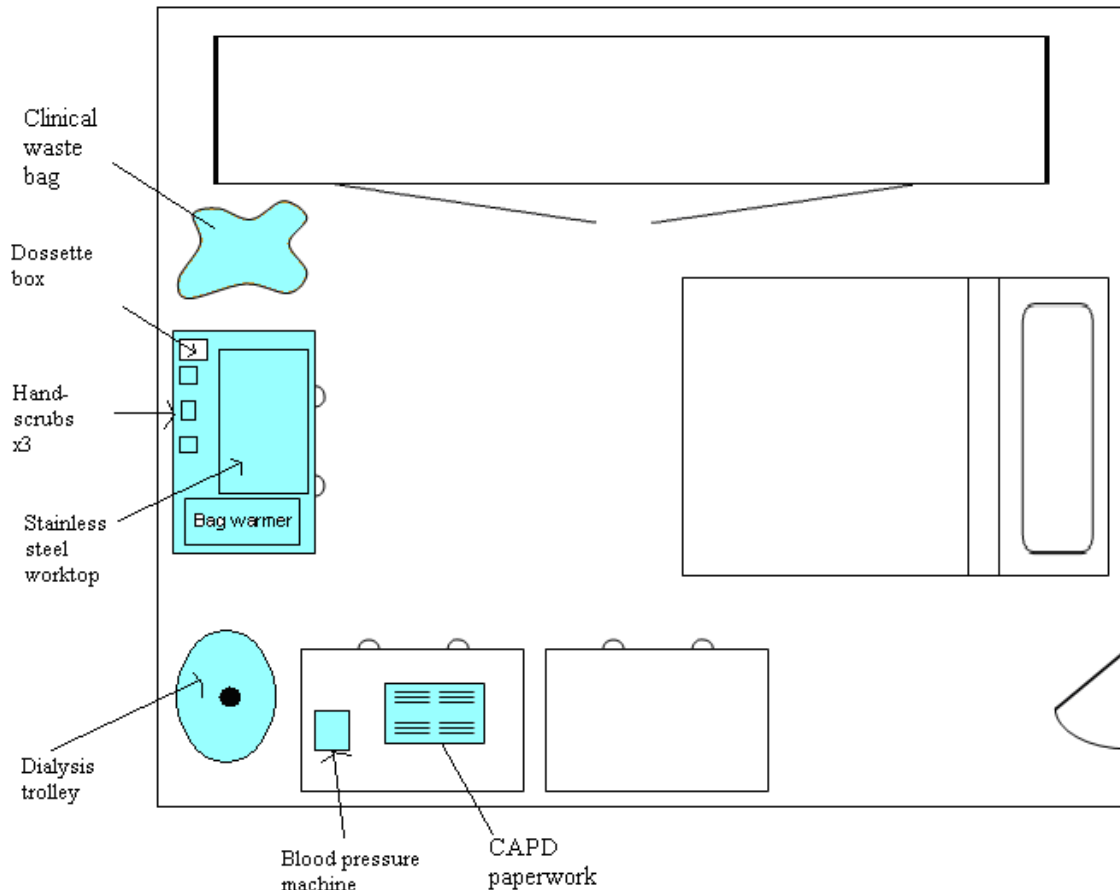
Harriet described similar reasons for dedicating one room to CAPD, stating that she did not want her bedroom to become a “treatment room” (*Int. Harriet*). For these participants it was therefore preferable to be able to separate dialysis from the rest of the home by dedicating a specific space to the treatment.

Conversion and compromise

Other participants did not dedicate a separate room to peritoneal dialysis, but instead incorporated it into their bedrooms. This was the case for all participants using automated peritoneal dialysis (APD) (Benjamin, Carl, Harriet, James, Kris and Norman), because the treatment is undertaken overnight while the person sleeps, but also for people using CAPD during the day (Frank and Paul). The domestic space was thus adapted to accommodate medical equipment, leading to a compromise between domestic and medical.

Paul’s home appeared free from peritoneal dialysis equipment, until I observed him undertaking a CAPD exchange. The fieldnotes reveal the alignment of copious amounts of equipment for CAPD within a bedroom environment, including CAPD paperwork, caps and shields, alcohol gel, metal bag warmer and clinical waste bag, using domestic furniture such as a chest-of-drawers to house this. Converting his bedroom into a dialysis space enabled Paul to segregate medical equipment from the rest of his home, but the fieldnotes highlight the disparity between the two spaces: the warmth of the home contrasting with the shabbiness of Paul’s separate room. Paul’s wife slept in a different bedroom and dialysis may have thus affected their relationship:

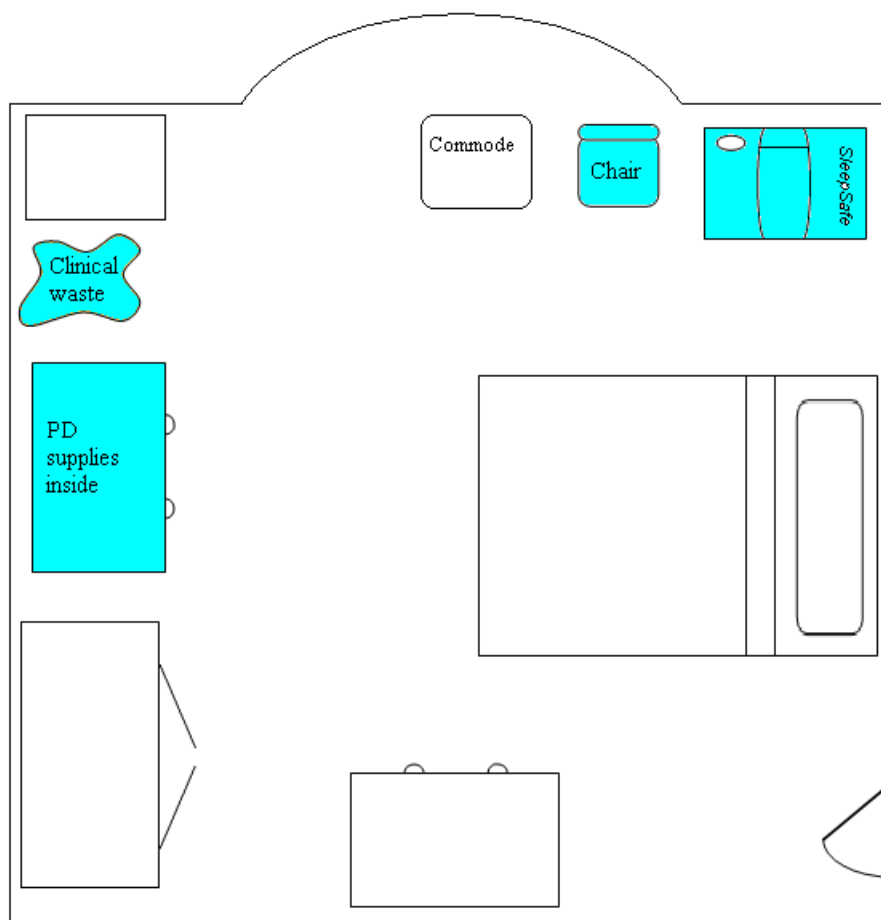
“Paul’s large house was beautifully decorated with matching solid oak furniture and soft fabrics, but his bedroom was a stark contrast. During my first visit Paul had mentioned that his wife has an upstairs bedroom, while he sleeps downstairs. Paul’s bedroom had bare walls in places with plain wallpaper in others. The carpet was shabby and the dated furniture was mismatched, with contrasting curtains that were not properly hung. While in the living room the soft furnishings matched and complemented each other, in Paul’s bedroom they did not. I felt that this was an interesting contrast and Paul later told me that his wife runs a painting and decorating business, which she was out doing during my observation. The room was dominated by dialysis paraphernalia, with one chest-of-drawers resting the dialysis record sheet and blood pressure machine and another housing the boxes of caps and shields, and assorted hand-scrubs. Paul explained that he had constructed a wipe-able surface out of stainless steel that slotted on top of the chest-of-drawers.”



(FN2 Paul)

This differed from other participants who took great care to ensure that the dialysis space was comfortable. However, the dialysis trolley seen in the fieldnotes was used by Paul to wander through his home while the CAPD treatment was exchanging, and thus he was not restricted to his bedroom during the treatment. Conversely, Norman undertook APD in his bedroom overnight, and I observed that the treatment fitted relatively discreetly into his bedroom, which was well decorated like the rest of his house. The fieldnotes highlight the chest-of-drawers where Norman kept his caps and the lines to connect him to the APD machine – hidden from view. Norman did not keep dialysis solution bags within his room; instead his son brought them upstairs each evening. Therefore, the room was not dominated by dialysis equipment; which instead it was more subtly present:

“Norman uses the Fresenius Sleep Safe machine, which was against the wall on a white computer desk by the bedside, with the organiser used for Fresenius exchanges on the keyboard draw below and the APD manual on top of the machine. In the night the drainage line runs from the machine out into the bathroom next door. Other than the machine and a yellow clinical waste bag, the room was free from dialysis paraphernalia. Norman showed me that he keeps the dialysis stock in the chest-of-drawers opposite the bed, and inside the drawers the line packs were neatly stacked up.”



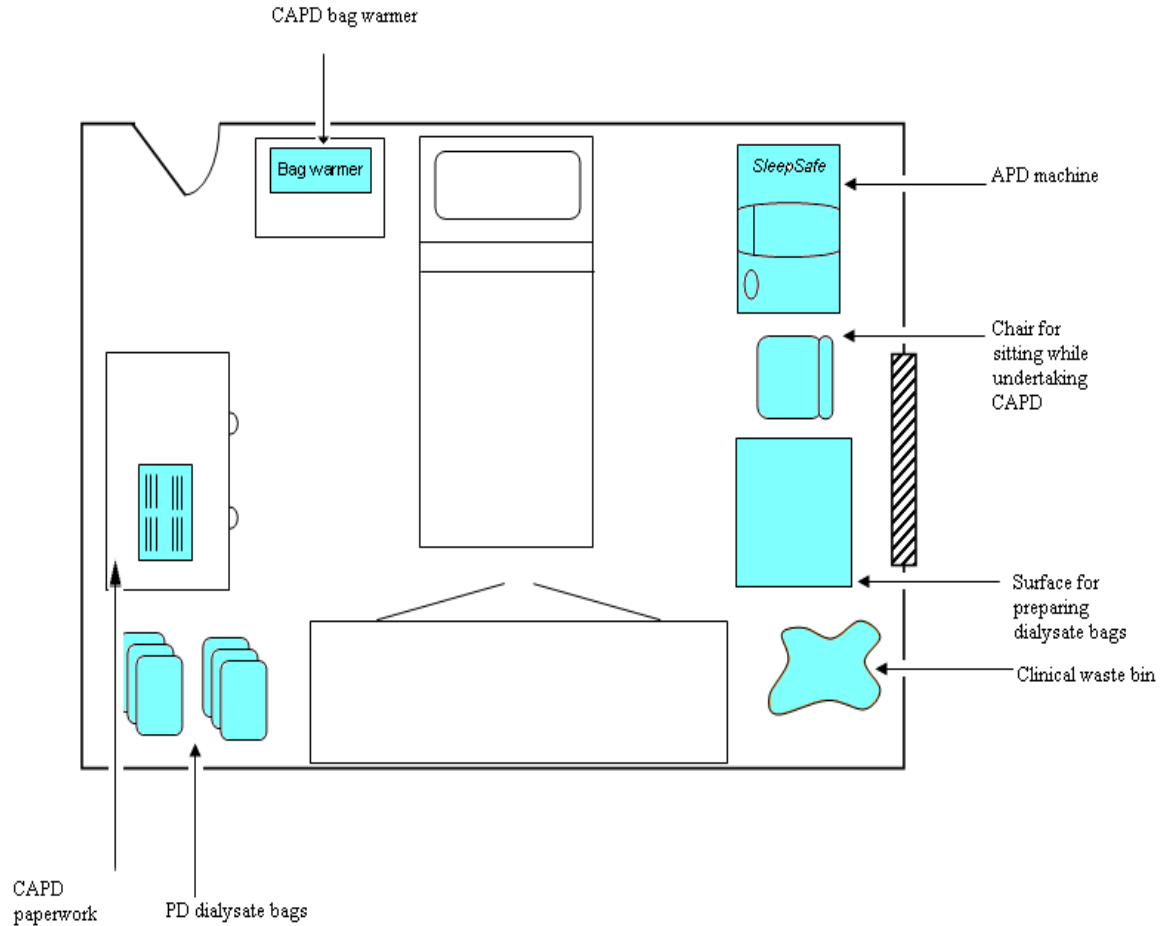
(FN Norman)

There was thus variation between participants in their efforts to discretely accommodate dialysis equipment within their homes, leading to various degrees of dialysis dominance.

However, several participants in the study undertook both CAPD and APD, leading to the need to store equipment for the two treatments. During my second visit to Frank and Fiona, when I observed Frank undertaking a CAPD exchange, the couple were about to begin APD. Frank's bedroom was subsequently dominated by multiple pieces of equipment for both CAPD and APD:

“Frank and Fiona showed me upstairs to Frank's bedroom, where he undertook CAPD and will be undertaking APD. The room contained a single bed – Fiona had slept in another bedroom for many years due to Frank's arthritis causing him restless sleep – and multiple pieces of equipment for peritoneal dialysis. While Frank washed his hands in the bathroom next door, Fiona explained the room layout to me. She said they had tried different layouts before settling on the current one. The dialysis equipment was spread across the room, occupying three sides of the space. Opposite the door was a supply of dialysis solutions bags (the majority were stored in the couple's garage), almost hidden by a chest-of-drawers upon which the CAPD paperwork was kept. On the bedside table sat the grey metal bag warmer

seen in many participants' homes, while the wall on the other side of the bed (in front of the window) was bordered completely by dialysis equipment. The Fresenius APD equipment, a large creamy-grey and blue digital machine, sat on a trolley in front of the window, with a chair bedside it. Along from the chair was a side-table (used as a clean surface for preparing the equipment for an exchange), and next to that in the corner an orange clinical waste bag."



(FN2 Frank and Fiona)

However, this amount of dialysis equipment for both CAPD and APD is potentially not uncommon, because individuals - including Carl and James - switch between the treatments, while Oliver undertook CAPD every few weeks to provide respite from APD alarms. Therefore, patients undertaking APD will also have equipment for CAPD within their homes, leading to increased amounts of equipment dominating the domestic space.

The impact of peritoneal dialysis upon the home environment was thus individual to different participants, with some people living amongst overt medical equipment and others storing it more discreetly. Participants were required to store a significant amount of peritoneal dialysis equipment in their homes, garages and gardens. This raises the issue about where individuals who live in more compact homes without

outside space would be able to store the equipment required for this treatment. Additionally, manufacturers should be aware that because medical equipment is stored in peoples' homes, it could be designed to be more aesthetically pleasing and thus align better with the home. Arguably the most dialysis-dominated environment belonged to Aileen who lived alone, but nonetheless other participants who lived with relatives also kept equipment throughout communal areas of the home or had converted one room within the home as a dialysis space. While demarcating one room to the treatment could influence the family's use of the home, it was often the preferred method to reduce the amount of medical equipment in other areas. Other participants were required to incorporate medical equipment into their bedrooms and the room thus became a compromise between domestic and medical. The visibility of equipment within these dual spaces varied between participants, with some attempting to discreetly hide equipment within the space. Ultimately, peritoneal dialysis affected the homes of all participants, altering and dictating the space. However, peritoneal dialysis impacted upon other areas of participants' lives and the next section therefore considers the challenges of living with the treatment.

6.3 Challenges of living with peritoneal dialysis

This section explores the challenges that peritoneal dialysis posed, moving on from the impact on the home environment and discussing the effects of the treatment on participants' lives. Firstly, two participants' daily routines are described to highlight the challenges of living with peritoneal dialysis. These challenges are then explored in more detail, including the dominance and disruption caused by peritoneal dialysis, as well as the perceived threats, fears and responsibility associated with the treatment.

6.3.1 Peritoneal dialysis and daily routine

The two case studies below demonstrate the daily routines of two participants Frank and Kris, both retired men who lived with their wives. These two case studies are included to exemplify many of the issues associated with the challenges of living with peritoneal dialysis, including their routines being dominated by the treatment, the responsibilities involved and the supportive roles of their wives.

The first extract describing Frank's daily routine highlights the repetitive nature of CAPD and how the four exchanges undertaken daily affect the remainder of the day. This extract also demonstrates the teamwork and shared responsibility that many

couples in the study adopted. The second extract explores the daily routine of a couple where the partner is responsible for dialysis care, highlighting the organisation required to manage the treatment and how the treatment and daily routine can synchronise.

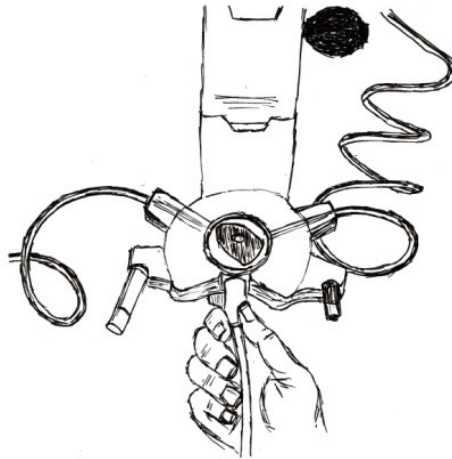
Frank and Fiona: Repetition and teamwork

Frank and Fiona are a married couple in their early seventies who live in a modern three bedroom semi-detached house, in a small town. Frank started haemodialysis suddenly in 2010, but had undertaken Fresenius² CAPD for six months at the time of data generation and was soon to start APD. Due to arthritis, Frank's walking and dexterity were affected, and Fiona was thus required to help with some elements of her husband's dialysis care. I interviewed Frank and Fiona twice and observed the couple performing a CAPD exchange, and the following extract is an amalgamation of this data, considering when and how CAPD is undertaken by this couple. The extract demonstrates that Frank and Fiona plan their day carefully around the four CAPD treatments, also revealing the different aspects associated with managing peritoneal dialysis. The actual CAPD process is also explicated, in terms of the skills required and time an exchange takes. Overall, the couple worked in partnership to manage Frank's treatment, taking shared responsibility.

"The couple described that Frank begins his first CAPD exchange by eight fifteen in the morning, with the assistance of Fiona. Pain from arthritis keeps Frank awake during the night and he thus often wakes early in the morning, while Fiona sleeps in the bedroom next door. Each CAPD exchange takes Frank around thirty minutes and he therefore finishes the first exchange by quarter to nine, weighing himself after this. The couple then eat breakfast downstairs, before Fiona washes in the bathroom, and then helps Frank to wash. The timing of the next CAPD exchange varies slightly depending on whether the couple are planning an outing in the afternoon. If they are, then they complete the second exchange at around 11.30 and then leave the house. Fiona reported that the couple particularly enjoy shopping and visiting garden centres, where they have tea and cake in the café. However, Frank now follows a daily fluid restriction of one litre, as advised by the hospital, and the couple therefore closely monitor how much Frank drinks. The day that I visited to observe Frank's second CAPD exchange of the day, the couple performed the treatment at around one o'clock in the afternoon. Having interviewed the couple in the sunny conservatory, looking out over the well-groomed garden, I went upstairs with Frank and Fiona to observe Frank's CAPD exchange in his bedroom.

² There are two different systems for CAPD and APD, which use slightly different equipment. The participants in this study undertook either CAPD or APD, supplied by either Baxter or Fresenius. The Fresenius systems are usually recommended for individuals with dexterity problems, for example Frank who had rheumatoid arthritis, and Matthew who was recovering from a stroke at the point of starting dialysis.

Frank's bedroom was dominated by dialysis equipment – the bag warmer on the bedside table, on the other side of the bed by the window was an APD machine, flanked by a chair and then a table with a worktop adorning it, holding the plastic Fresenius dialysis organiser. A clinical waste bag lay on the floor next to the table. Frank began the procedure by washing his hands in the bathroom next door, before returning to his bedroom and cleaning down the worktop with an alcohol-wipe. Frank took the CAPD bag off the bag warmer on his bedside table, and opened up the packaging. He struggled to pull apart the lines on the CAPD bag, which are made of thick, tough plastic. Frank then sat down in his chair next to his dialysis station and put the lines in the dialysis organiser (pictured below). He then put his Tenckhoff into the hole on the left of the organiser, and unscrewed his line from the old cap, placing the uncovered line into the central hole of the organiser. He then began the draining out process, which took around ten minutes. Throughout the exchange the couple and I talked freely and there did not appear to be any embarrassment about me being present during the exchange.



After ten minutes, Frank said that it had drained out for long enough and that it was time to start the draining in process. Fiona hung up the new bag on a hook hanging from the curtain rail and Frank began draining in. This was achieved by turning round the dial in the organiser. It took around ten minutes for the bag to drain in, and Frank then placed a new cap in the right hand hole and screwed his Tenckhoff catheter into the new line. He then placed his old cap over the completed dialysis exchange bags. Frank then put the Tenckhoff away and did up his trousers (having to lower his trousers slightly to do the exchange also makes it difficult for him to do the exchange outside of his home, Frank reported). Fiona weighed the bag at 2200ml, which Frank was very happy with. Frank took the finished bags into the bathroom, and Fiona followed with the orange clinical bag. Frank cut the dialysis bag and drained the contents into the toilet, and placed the drained bag into Fiona's waiting orange clinical bag. Fiona then replaced the orange bag in the bedroom and put out the cap and shield ready for the next exchange. Frank then completed the paperwork, documenting how much fluid he had drained out from his peritoneum, and Fiona opened the window, which she had shut during the exchange as advised by the PD nurses. Their routine was extremely synchronised, with each partner knowing their responsibility and working as a team to complete the exchange efficiently. Frank reported always performing his CAPD exchanges in his bedroom, never venturing from the home to undertake the treatment. Fiona explained that Frank ensures his treatment is undertaken regularly, leaving three to six hours between exchanges. The third CAPD exchange would then be started

between five and six o'clock in the evening, followed by the evening meal, with the final exchange before Frank goes to bed at half past ten at night."
(Written with interview and observation data with Frank and Fiona)

Kris and Kaye: Organisation and responsibility

Kris and Kaye are a married couple living in a compact two-bedroom modern flat within a residential complex, in a rural village. In their early eighties and late seventies respectively, Kris and Kaye have been married since their twenties, living first in the UK and later in the USA, before returning to the UK several years ago, leaving their children and grandchildren behind. Kris has undertaken peritoneal dialysis for seven years, first CAPD and later APD, and is now dependent on Kaye for his dialysis care. In addition to end-stage renal disease, Kris also has diabetes mellitus, heart disease and a degenerative disorder of the central nervous system, and is now restricted mainly to the home. The second bedroom within the flat was used to store non-dialysis medical equipment, including a wheelchair. I visited the couple on three occasions, conducting one interview and observing Kaye preparing her husband's APD machine. Through the couple's verbal descriptions of their daily routine, with additional ethnographic observation of some aspects, the following extract demonstrates the care involved with APD and how this may align with daily life. Kaye was responsible for her husband's treatment, taking control of the organisation and procedures involved. The extract shows that Kaye adheres to a strict routine by which she plans and undertakes Kris's APD care, while also being required to manage other aspects of his co-morbidities. Kaye was meticulous in her preparation of Kris's APD treatment, attempting to prevent the spread of infection.

"Kaye reported that Kris's APD treatment is finished by seven o'clock in the morning and Kaye thus rises and makes her way from the master bedroom, through the small hallway and through the living room into the kitchen, where she makes two cups of tea and takes one through to Kris. After tea, Kaye monitors Kris's blood sugar and then begins the process of disconnecting him from the APD machine, placing a fresh iodine cap over the end of his Tenckhoff catheter and documenting the figures from the machine that explain how much fluid Kris's treatment has removed. Kaye removes the dialysis lines from the APD machine and disposes of the empty dialysis solution bags and lines in a yellow clinical waste bag (the dialysis solution from Kris's peritoneum is drained straight into the toilet). Two carers visit the couple each morning between eight and eighty thirty, assisting Kris in the adapted shower room to wash, shave and dress. While the carers visit, Kaye cooks their breakfast in the small tidy kitchen. Kaye prepares a dosette box with a two-day supply of Kris's medications, keeping the day-time medications packed neatly away in a case in the living-room, with the night-time medications stored similarly in the bedroom. The day is now free for the couple to spend as they please, but Kris is restricted and therefore a trip to the local supermarket (where Kris would stay in the café in his wheelchair) is the furthest the couple would venture, except for the Nephrology clinic thirty

miles away when they are collected by an ambulance. Kris is also visited by other healthcare professionals, including the podiatrist and district nurses, to care for his diabetic foot ulcers.

I observed Kaye preparing Kris's dialysis treatment, which she begins every evening at five o'clock. While Kris stayed in his armchair by the window in the small living room, watching television, I followed Kaye into the master bedroom. Inside the bedroom on the left was the Baxter APD machine on a metal collapsible table. The machine was on top of the table, with a shelf underneath for storing the iodine shields and caps, and a shelf lower down for the dialysis solution bags. Kaye laid a towel down on the bed, and went to the bathroom to collect the fluid for dialysis. The bathroom was a considerable size, but much of the space was being used to store APD supplies. The area to the left of the door was filled with several layers of dialysis boxes, organised according to 5000ml or 2000ml bags, with shelves above holding boxes of APD cassettes (rows of lines that attach to the APD machine, carry dialysis solution from the bags and connect to the Tenckhoff catheter). Kaye gave me a 5000ml bag to carry through and place on the towel on the bed, while she carried the other, and I then carried the 2000ml extraneal bag (a stronger solution that drains in last and stays in Kris's peritoneum all day) while Kaye brought through the plastic APD cassette and two drainage lines. The drainage lines are 12ft each and Kaye uses both to ensure that the line is long enough to reach down the hall, into the bathroom and drain into the toilet.

Kaye demonstrated how she attempts to prevent the spread of infection when preparing the APD machine. She washed her hands in the bathroom for 60 seconds, using the method taught to her in the USA. Back in the bedroom, she shut the window and cleaned the APD machine with an alcohol wipe. Using a second alcohol wipe she then cleaned the bottom shelf of the APD table, and switched on the APD machine. Kaye explained that because of arthritis she cannot open the packaging of the dialysis solution bags easily and she therefore uses a blue clamp to score along the bags, making them easier to pull apart. She then rubbed alcohol gel into her hands. Kaye then took the 5000ml dialysate bag out of the packaging, explaining the importance of minimal contact with the bag to reduce the potential of contamination. She checked the strength of the fluid, the use-by date and that the fluid was clear, before placing it on the heating pad of the APD machine. She then repeated this with the second 5000ml bag, placing it on the bottom of the APD table. Finally she did the same with the 2000ml extraneal bag, placing it next to the 5000ml bag on the bottom of the APD table. In between each bag she used alcohol gel to cleanse her hands. Kaye then took the cassette out of the packaging and opened the drawer on the right hand side of the machine, before securing it inside and making sure that it was on properly. She then shut the drawer and secured it, before attaching the tubes on the outside of the drawer. Kaye then clamped all the tubes shut, which she commented can be difficult because of arthritis, before turning off the machine. After setting up the machine, Kaye gathered all the packaging and placed it in the yellow clinical waste bag in the bathroom (collected once a week by the council). Kaye was very quick at setting up the machine, taking 15 minutes from start to finish, while explaining to me what she was doing.

The couple reported that between half past five in the evening and half past eight, Kaye would cook their evening meal and afterwards Kaye would record

Kris's blood sugar, administer his insulin injection and provide Kris with the multiple tea-time medications he is prescribed. Kaye would then wash the dishes from the evening meal and make a cup of tea, before changing into her pyjamas at half past eight. After, Kaye would then switch the APD machine on and allow it to prime while she helped Kris get ready for bed and give him his night-time medications. By nine o'clock both Kris and Kaye would be ready for bed and Kaye would then connect Kris to the APD machine, before watching television in bed until around ten o'clock."

(Written from interview and observation data with Kris and Kaye)

The case studies highlight key challenges of living with peritoneal dialysis, including the dominance of the treatment on participants' daily lives, the fear of complications (in particular infection) and the steps taken to prevent them, and also the central role that many relatives play in supporting patients to use this treatment at home. These three key themes – dominance and disruption; threats, fear and responsibility; and keeping it in the family – are discussed in turn below.

6.3.2 Dominance and disruption

Peritoneal dialysis thus dominates daily life, altering and governing participants' routines. The extracts highlighted the range of skills and tasks undertaken by participants to manage peritoneal dialysis on a daily basis, requiring discipline and commitment. However, while participants were adept and expert at managing their treatments, ultimately peritoneal dialysis was exhausting.

Discipline and restrictions

Participants reported and demonstrated the complexity of managing peritoneal dialysis, which required discipline and resulted in restrictions on their lives. The extracts highlight the variety of tasks or skills that the patient or relative must undertake to effectively manage peritoneal dialysis at home: the technique for setting up and connecting the APD machine, and/or undertaking a CAPD exchange, completing paperwork, infection control (disposing of used dialysis equipment, hand washing, washing equipment and shutting the window), weighing themselves and the drained dialysis bags, storing and monitoring dialysis stock, caring for the Tenckhoff catheter, and managing and administering medications. Throughout these tasks patients and/or relatives ensured that dialysis was performed as taught, that blood pressure, weight and oedema were observed and documented, and the effectiveness of peritoneal dialysis was monitored (through weighing the bags). The majority of participants were confident and relaxed about the tasks involved to manage peritoneal dialysis and the discipline required for this, minimising the time-consuming

nature of the treatment. Matthew discussed the ease with which he performs the tasks associated with peritoneal dialysis:

“it’s er odds and sods, but, you know, it only takes sort of ten minutes, you know, do your blood pressure at dinner time, take your blood at whenever and I mean jump on the scales is nothing at all”

(Int. Matthew)

Medications are an important part of the treatment regime for end-stage renal disease, and all participants described taking broadly similar tablet medications including anti-hypertensive and phosphate binders. Furthermore, the majority of participants were diagnosed with co-morbidities, such as diabetes mellitus, and subsequently also took medications for those conditions. Multiple participants in the study required a regular injection of erythropoietin stimulating agent (e.g. Eprex; treatment of anaemia) and again while some patients were independent with this skill (for example Frank and Norman), in other families a relative was responsible for this (for example Kris’s wife Kaye). Participants were also required to learn the appropriate storage of these medications (in the fridge) and safe disposal of sharps (sharps boxes were collected by the local councils), demonstrating that the skill involves more than the injection technique alone. In addition to the routine medications, patients were also required at times to take additional medicines, for example injecting antibiotics when suffering from peritonitis (infection of the peritoneum). This skill involves the individual reconstituting, drawing-up and injecting antibiotics into an entry port on the dialysis solution bag. Often this skill was undertaken by relatives, including James’s daughter Julie and Leila’s daughter Lisha, as Lisha explained:

“Lisha: she was very unwell and I think in the beginning um we had to like inject her bags as well

JB: did you?

Lisha: with solution, I can’t remember what”

(Int. Leila and Lisha)

However, this advanced skill was again presented in a matter-of-fact way by participants, despite the added time it consumed and responsibility it required. This highlights how complex skills became mundane to participants, who were adept at performing them.

Participants particularly discussed the documentation that they kept for CAPD, which keeps a daily record of the patient’s blood pressure, oedema, how much ultrafiltration occurred from each CAPD exchange and the overall fluid balance. This record is

used to monitor how effectively each exchange is working by how much fluid is being removed after each exchange. Daniel had been particularly meticulous about maintaining CAPD records every day since commencing the treatment two years and six months ago – exemplifying the discipline required to manage this treatment. However, Daniel altered the forms for his convenience, including substituting oedema for blood sugar and documenting additional information to the form, e.g. home visits from the PD nurse, taking the forms along to the Nephrology clinic with him:

CAPD PATIENT RECORDS

Name		1.36% Weak (W) Yellow 2.27% Medium (M) Green 3.86% Strong (S) Red Extraneal Pink Nutrineal Navy											
System		Volume											
Date		Target Weight											
Date	2.4.10		3.4.10		4.4.10		5.4.10		6.4.10		7.4.10		
Weight							94.1		92.5		92.5		
Blood pressure	137/69		143/70		137/72		141/72		150/74		144/72		
Oedema (nil, mod, large)	8.3		8.1		6.9		7.9		8.0		7.4		
Bags	1 st	In 2100	Out 2900	In 2100	Out 2700	In 2100	Out 2600	In 2100	Out 2800	In 2100	Out 3000	In 2100	Out 2700
	2 nd	“	2300	“	2200	“	2300	“	2300	“	2300	“	2400
	3 rd	“	2200	“	2300	“	2500	“	2200	“	2100	“	2200
	4 th	“	2300	“	2300	“	2100	“	2100	“	2200	“	2200
	5 th	8400	9700	8400	9500	8400	9500	8400	9400	8400	9600	8400	9500
Balance +gain – loss			+1300		+1100		+1100		+1000		+1200		+1100
Dressing													
Urine (pre-clinic volume)													
Nurse initials													
Dr's signature													

(FN1 Daniel and Diane)

Other participants did not complete these forms in such a disciplined way as Daniel, for example Aileen, while others continued to complete them but clearly placed less importance on them than Daniel, including Evelyn.

The earlier discussion of Frank's routine highlighted the challenge for him to limit how much fluid he consumed. Other participants similarly described their struggle of reducing their fluid intake, particularly in terms of being able to socialise with friends, including Daniel, Oliver and Paul. However, Frank and Carl reported feeling dehydrated and therefore struggling to be disciplined and restrict their fluid intake:

“the first thing he'd [doctor] say was ‘you're in water retention, you can't drink it’... I tried to keep to it if I could, you know, cause you do get thirsty, there's no two ways about it”

(Int. Carl)

Carl reports “trying” to adhere to doctor's recommendations and this was similarly reported by other participants. In addition to monitoring fluid intake, patients undertaking dialysis can be required to alter their dietary intake, in particular reducing their potassium intake. While Harriet had followed a low-potassium diet prior to

starting dialysis, which she described as “we had to double boil everything...that was vile” (*Int. Harriet*), none of the participants in the study were required to drastically change their diet (Paul reported reducing his potassium intake by avoiding certain fruits and vegetables). Rhodri explained that although he was told that managing his diet could be complicated when undertaking dialysis, he found that in reality he was simply required to increase his protein intake:

“the dietary requirements are slightly different with being on dialysis. Um they gave me a lot of information um, which is quite a lot to take in when you first started paper-wise, but you need to read it all with the dietary requirements. It’s no special diet, it’s just you’ve got to um increase your protein levels to what you normally do to cause the dialysis takes it away”

(*Int. Rhodri*)

Both Harriet and Benjamin considered that one advantage of peritoneal dialysis was not being required to restrict their diets. Overall, adhering to fluid restrictions was considered to be a challenging aspect of living with peritoneal dialysis and required discipline.

Participants had become experts at managing their treatment and this section has attempted to emphasise the discipline required to manage peritoneal dialysis due to the multiple tasks that encompass the treatment, while highlighting the subsequent restrictions. Peritoneal dialysis had, for the majority of participants, become part of their daily routines, exemplified by Kaye: “it’s a way of life, it’s not um it’s no different it’s like putting your clothes on for us” (*Int. Kris and Kaye*). However, there were clear restrictions of the treatment, in terms of time, routine and fluid intake. Julie, James’s daughter, explained that CAPD ultimately restricted her parents and they found the treatment exhausting:

“Julie: my mother was shattered doing the *[bags]* four times a day and was very very, well the pair of them, were very very tied to the house, because we are very religious following instructions”

(*Int. James, Janice and Julie*)

Thus for other participants the multitude of tasks that peritoneal dialysis involved were overwhelming. Feelings of exhaustion were expressed by multiple participants, which is discussed next.

Exhaustion

Multiple participants reported that they felt exhausted, which they attributed to their increasing age, end-stage renal disease or due to APD waking them during the night. Participants using both CAPD and APD reported feeling tired, and while Benjamin

rationalised this as being due to his age, Leila subsequently struggled in her daily activities:

“Ben: I’m more tired than I than I used to be, I mean I always had stacks of energy didn’t I?”

Beatrice: Mmm

Ben: But of course I’m older too”

(Int. Benjamin and Beatrice)

“Leila: I’m feeling OK, better, just I can’t do anything, I can’t do any hard work, pain all the time pain, bones hurting and very tired ... my back hurting all the time, I can’t just five ten minutes more than that stand up”

(Int. Leila and Lisha)

However, for multiple participants in the study, their exhaustion was caused by APD disrupting their sleep.

Nearly half the participants in this study undertook APD as their regular treatment, although they had all performed CAPD for a period beforehand. Participants using APD included Benjamin, Daniel, Harriet, Kris, Norman and Oliver, and in addition Carl and James continued to use both CAPD and APD intermittently. However, the biggest criticism participants in the study had of APD was the disturbed sleep they experienced as a result of night-time alarms, representing the intrusion of home medical technology. Harriet and Norman described that lying on the Tenckhoff catheter or lines connecting them to the APD machine caused alarms to ring, but minimised the impact of their sleep being disturbed:

“if you lie on the line the alarm goes off and I just turn over, I don’t even wake really now”

(Int. Harriet)

“I mean one does sometimes um interfere with the the tube, you know, that is connecting one, so of course there is an alarm bell then, so one has to free the tube so to speak yeah yeah yes, but alright otherwise”

(Int. Norman)

However, other participants reported struggling with the persistent alarms disturbing their sleep. Daniel and Oliver explained that they can be disturbed several times during one night due to “low drain alarms” (where the APD machine is failing to remove the old dialysis solution from the patient’s peritoneal cavity). In addition to the alarms waking them, the participants describe being required to move from the bed to encourage the fluid to drain, posing a significant challenge during the night:

“Dan: But I mean last night the alarm it went off four times on um low drain volume, that was every fill or every drain it went off ... the only way I can get those alarms off is to sit up on the side of the bed and then you can watch what’s being drained on the machine and just sit there until it gets above the

alarm millilitres and then try and get your head down again. But it's er quite exhausting that is"

(Int. 1 Daniel and Diane)

"you can suffer sometimes from a lack of sleep, because um as your bowels move around that sort tube inside gets sometimes gets caught, so you can't drain out. So you're fast asleep and then the low drain alarm goes and you wake up and you've got to move about and stop, there we are. And often if it happens once in the night, it's going to happen several times, so some nights you end up with sort of fragmented sleep two or three hours sleep, so the next day you're...wiped out sort of thing"

(Int. Oliver)

These alarms and subsequent movement thus result in disrupted sleep, with Oliver additionally describing the resultant effect of this the next day.

However, nocturnal alarms did not cause exhaustion for the patient alone. Those who shared bedrooms with partners also reported their sleep being disturbed. Harriet again minimised the effect of these alarms, but she admitted that the more persistent alarms were more disruptive:

"I disturb him then, yes, I mean that's it, once the lying on the line one doesn't bother us, I can just turn over now and not even wake, but when the alarm persists well you're up then with the lights on"

(Int. Harriet)

Other participants identified that the alarms caused disturbed sleep for relatives, including Daniel and James. Oliver recognised that his wife was not only affected by the alarms but found them distressing, although he was unsure how this could be resolved. Oliver had started using APD because he found CAPD restrictive, but he commented that the nocturnal alarms were a significant problem:

"JB: does it wake your wife up at all, the alarms?"

Oliver: yeah at times and er she gets a bit er upset about it

JB: does she?"

Oliver: yeah so er that's another one a drawback to it, but I don't know what the answer is to that"

(Int. Oliver)

Using APD enabled participants to have the daytime free from dialysis, but the nocturnal alarms impacted on daily life due to the resulting exhaustion. The APD alarms thus highlight the intrusion of medical technology on daily life and a significant challenge of living with the treatment.

Peritoneal dialysis thus encompassed multiple areas that required discipline to manage, with additional responsibility at times when additional medications were required. There were also clear restrictions of the treatment in terms of daily routine

and time, particularly if participants used CAPD. While APD enabled participants periods during the day without treatment, multiple participants reported feelings of exhaustion due to their sleep being disturbed by nocturnal alarms. This also disturbed relatives and highlights a significant challenge of living with a home medical treatment.

6.3.3 Constant threats, fear and responsibility

Participants lived with the awareness that peritoneal dialysis could go wrong and they were fearful of this, in particular of peritonitis (infection of the peritoneal cavity). It also emerged that participants were not always aware of the signs that there was a problem, but learned through experience after serious complications. While participants generally managed peritoneal dialysis independently within the family unit, they were at times aware that they required extra support from healthcare professionals, particularly when concerns were identified.

Constant threats

Peritonitis, which can lead to patients switching to haemodialysis, serious morbidity and death, was a major concern for participants. Benjamin had undertaken peritoneal dialysis for six years and never developed an infection, but he and his wife reported that they perceived it to be an ongoing threat:

“Beatrice: they [*healthcare professionals*] always said ‘you’ll get it within on average...every two and a half years, most people have peritonitis’, so of course we you you keep waiting thinking ‘two years is up, we should be having peritonitis’”

(Int. Benjamin and Beatrice)

Peritonitis is a common reason that patients can no longer perform peritoneal dialysis and thus prevention is vital. The earlier fieldnotes from Frank and Kaye’s peritoneal dialysis techniques highlight that to prevent infection both patients and relatives carefully washed and dried their hands and cleaned equipment. Throughout the observations with patients and relatives performing peritoneal dialysis, they washed their hands, dried them with paper towels, cleaned the surfaces where dialysis exchanges were undertaken and used alcohol hand gel throughout the procedure. While I did not observe Daniel undertaking a peritoneal dialysis exchange, when he showed me the space that the treatment occupied, he made several references to hygiene and how he tried to ensure this:

“While observing Daniel’s dialysis spaces and innovations, he and Diane reiterated the importance of cleanliness and how they are meticulous about it. Dan reported that he washes his hands in the kitchen, drying them with a

paper towel, and then uses a paper towel to cover his hands while he walks up the stairs. Once in his bedroom, where the APD machine is by his bed, he then opens up the dialysis solution bags, ensures the machine is ready, uses alcohol hand-gel and cleans the surface, before connecting himself up. Diane also stressed the importance of keeping the APD machine clean, covering it with a cotton cover between uses and also cleaning it every couple of days.”

(FN2 Daniel and Diane)

Additionally, Rhodri explained that the PD nurses suggested methods to reduce the risk of infection:

“[PD nurse] told me to buy um Milton to clean the shower head ‘do that’ she said ‘you only need to do it once a week you know depending on how often you use your shower’ she said ‘if it’s in constant use you can perhaps once a fortnight’... I haven’t had an infection”

(Int. Rhodri)

Thus the importance of trying to prevent infection was something that patients and relatives were aware of and strove to achieve. Again, maintaining hygiene principles repeatedly throughout the day takes discipline and highlights the perceived threat of infection and fear of the consequences of this.

In terms of monitoring for signs of infection, patients often explained this to me when they performed CAPD exchanges. During an interview when Carl (who was undertaking CAPD temporarily at the time of my visit) spontaneously undertook a CAPD exchange, he explained monitoring each bag of drained fluid to check whether it was cloudy – an indicator of peritonitis:

“JB: so what else are you looking for? [as Carl examines the drained bag]
Carl: Cloudy and that’s clear, so I’ve got no infections”

(Int. Carl)

This was a daily reality for patients and families who were required to check each peritoneal dialysis exchange for indicators of infection and thus constantly monitor for the threat of infection.

Learning through experience: guilt and confusion

However, patients and relatives were not always familiar with the signs that there was a problem. James’s family discussed their feelings of guilt that they had not identified that James had peritonitis, their confusion about what signs they should be looking for and the perceived criticism they received from hospital staff:

“Julie: he had peritonitis
James: once...
Janice: but also we didn’t realise that that’s what it was, did we?
Julie: not at that point
James: we never had it before...”

Janice: but they always told us if he had it we would know he had it, cause you did ask what were the signs, didn't you, and they said 'if he got it you'll know' well we didn't, cause his bags
 Julie: he didn't have no fibrin, no tell-tale signs again
 Janice: the only thing was that it [PD effluent] was a little bit darker
 Julie: a little bit cloudy
 Janice: bit cloudy, but that was all
 Julie: nothing glaring...
 Janice: but we didn't know...
 Julie: and it was words like that 'if we'd caught it earlier we could've' well you're thinking 'is it our fault, you know, why didn't we know, you know, what were we missing?'
 James: they didn't explain enough
 Julie: no it was again he didn't have no clinical symptoms that you could think 'oh there's something wrong by here'"

(Int. James, Janice and Julie)

This struggle to recognise signs of infection was reflected in the experience of another participant who also reported confusion following an episode of peritonitis. While Aileen reported that she had been warned about the signs of peritonitis, because she had not had any previous episodes of peritonitis she was not familiar with the reality of the infection:

"After visiting Aileen to interview her we agreed a second date when I would observe her performing a CAPD exchange. However, this turned out to be four weeks later because Aileen developed peritonitis for the first time. During my visit, Aileen seemed confused about the infection, querying "how do you tell?" I asked her whether she had ever been told how to know if she had peritonitis, and she said yes she thought so, stating that she had it written down somewhere. However, she now knows that she needs to check to see whether the drained dialysis bag is cloudy, and she said she has been checking them"

(FN2 Aileen)

However, Aileen reported being aware afterwards what she needed to look for, which was also reported by James's family. In terms of learning the signs of complications through experience, Carl's wife Christine also discussed this with regards to when her husband developed pulmonary oedema:

"I didn't recognise it at the time, I didn't recognise what was happening, but once it's happened once, you're looking for [it], you're aware then, so I'm aware now, whereas I wasn't before"

(Int. Christine)

This case also highlights the importance of the wider family monitoring the patient and being aware of what to observe, because an acute episode of illness could make the patient unable to identify problems themselves.

While participants thus assumed responsibility for their treatment and were experienced at managing it, they were also aware that at times they needed additional support.

Seeking support from healthcare professionals

The participants in this study described the support that patients and relatives receive to manage peritoneal dialysis at home from healthcare professionals and there were several opportunities for them to report issues. Carl's wife Christine recognised the importance of reporting concerns to healthcare professionals:

“obviously they're relying on us to flag them up if there's a problem there's not a lot they can do if we don't say 'look um I don't think this is right, I don't think that's right'”

(Int. Christine)

Patients and relatives discussed that they reported different problems to healthcare professionals, including suspected peritonitis, infections around the Tenckhoff catheter and fluid overload. Participants were thus willing to report concerns to healthcare professionals and felt they were encouraged to do so. In terms of support from the peritoneal dialysis nurses, participants reported that they were regularly visited at home by the nurses, although the frequency varied between participants and how much support they needed – from twice per week to three monthly. The purpose of these visits varied from planned care, such as having the end of the Tenckhoff catheter changed, to providing acute care, for example treating peritonitis. Patients who were physically unwell or not coping were visited more regularly, while others were visited less frequently:

“Julie: if everything's OK it's once a month...when he's poorly they come

Janice: every week

Julie: well twice

Janice: they come twice a week”

(Int. James, Janice and Julie)

“Ben: we get all the support we've ever

Beatrice: We've ever needed

Ben: If we ask for it, we've had it... but otherwise the visits are

Beatrice: Three monthly”

(Int. Benjamin and Beatrice)

Therefore, patients and relatives reported that the team of nurses visited families according to their individual needs and if the patient required additional nursing care. Complications and problems with treatment thus resulted in additional contact with healthcare professionals and the responsibility for treatment being shared.

In addition to home visits by peritoneal dialysis nurses, patients were also able to telephone the nurses' office or individual number to report concerns, which many participants found reassuring. However, if participants were unable to contact a nurse they could become anxious. Frank described his frustration at the time it took for the nursing staff to respond to his concerns, compounded by the knowledge that the specialist team were physically a long way from his home:

"Frank: the thing is I'm thirty miles from the hospital for a start, so all I can do is to ring up and a lot of the times it's an answering machine. Alright you leave a message and they do ring you back, I'm not doubting that at all ...you do get the information, but there is a time lag"

(Int.1 Frank and Fiona)

This highlights the responsibility and fear felt by participants, particularly if they identified a treatment concern. A further challenge of living with a home medical technology is thus raised here: the responsibility of managing a complex medical treatment and feeling at times unsupported by healthcare staff.

Another avenue for reporting concerns was the Nephrology clinic, where patients were assessed by the multidisciplinary team. Again, the frequency that patients visited the clinic varied, which several participants used as a marker of how well their treatment was working and their physical condition. Thus while patients were able to report concerns at the clinic, they could also be made aware of concerns. Daniel and his wife Diane described the frequency of visits, relating it to Dan's physical condition:

"JB: How often do you go to clinic to see the consultant?"

Dan: Um every three months roughly...

Diane: At the beginning it was a little bit earlier, but now I think they're quite satisfied and they think if they're worried about anything they'll call Dan a little bit earlier, but when everything's going fine they say 'no we don't want to see you until such and such'"

(Int.1 Daniel and Diane)

Other participants similarly reported that the nephrology clinics are where problems can be identified and therefore are associated with anxiety, including Aileen, Benjamin and Carl's wife Christine.

Therefore, participants reported that they sought and received help from healthcare professionals. Often this was at times of crisis when a potential complication had been identified and additional nursing or medical support was required. However, the nephrology clinic in particular was associated with anxiety as it represented a space where problems could be identified, thus posing a threat to participants.

This section has alluded to the role of the family unit in managing peritoneal dialysis and this is discussed in more detail next.

6.3.4 Keeping it in the family

This section will consider the work of caring, surveillance, participants' feelings of being unsupported by relatives, and the burden of caring on women. Finally, valued support from friends will be discussed.

The work of caring

Support offered by relatives included both practical and emotional dimensions and their involvement varied tremendously according to the needs of the individual. Spouses, partners and children were involved with these caring tasks, which involved practical and emotional dimensions of both dialysis and non-dialysis care.

Practical support from children was described by Norman, Carl, Evelyn, James and Leila, which including carrying dialysis solution supplies. These participants were physically frail and thus unable to cope with the physical burden of organising peritoneal dialysis. Norman, who was a widower, lived with his son while his daughter lived nearby and he described that although he independently connected his APD treatment, he relied on his children to carry equipment for him and change his Tenckhoff dressing:

“about every three or four, every four or five days this connection to the body [*indicating Tenckhoff*] has to be cleaned, now I would not be able to do that on my own...so that's one item either my son or my daughter does... every night before I go to bed you see they er one of them [*children*] will take the things up, that's another item, then of course so far in the morning I'm able to put everything away, I'm still able to do that, nonetheless there's a certain amount of er um equipment that has to be disposed of, so one of them will bring that down”

(*Int. Norman*)

Participants also described receiving practical, non-dialysis support from members of their families. Evelyn lived with her husband, who had cancer, and was supported by her two daughters with non-dialysis tasks, such as food shopping and running errands:

“me daughter takes me out and then me other daughter she takes me shopping at the moment... she takes me down to Asdas or Tesco's or wherever we need to go”

(*Int. Evelyn*)

Emotional support was also offered by relatives, which was often demonstrated through accompanying the patient to clinic appointments, as reported by Daniel.

“Dan: Diane always comes to clinic with me, so she was there when we asked them ‘I’ve looked at this on the internet about the Homechoice’ um and yes she was with me in clinic when I asked the doctor there if I could go onto the machine”

(Int. 1 Daniel and Diane)

The majority of participants were accompanied to clinic appointments, highlighting that they were emotionally supported by relatives and also that relatives shared responsibility for patients’ treatments.

Surveillance

Relatives also played a surveillance role to ensure that the patient coped using peritoneal dialysis. This was achieved either through direct observation, or asking other family members to report back to the primary caregiver. Often, families surveyed the patient for signs of complications, such as Christine monitoring Carl for pulmonary oedema and James’s family monitoring for signs of peritonitis. Fiona and Abigail additionally monitored the effectiveness of their relative’s treatments by observing their general conditions. Families thus appeared to play an important role in surveillance and monitoring of complications.

The wider family often reported back any concerns to the immediate caregiver. James’s daughter Julie was closely involved with monitoring her father’s treatment, but the wider family – who lived further away – also played a role in surveillance:

“Julie: my sister lives in North Wales, so in fairness to her she’s she phones them she phones them every day, because we had little issues with medication, somebody - my mam - would forget to either give her own or give dad’s, so that was her little role and she [sister] makes sure they’re alright and if she feels that there’s something a squwith she then phones me and I check in”

(Int. James, Janice and Julie)

Similarly, Carl’s wider family – including daughter and grandchildren – monitored Carl when his wife Christine was at work. Christine was responsible for the majority of Carl’s dialysis care, but their family lived nearby and Christine explained how they therefore ensured that Carl was safe when she was absent:

“my daughter’s across the road... if I do go away for a little break for two nights, I don’t worry because she’s across the road. And we’ve got three granddaughters as well who are um twenty-one, nineteen and seventeen, they’re always back and fore, so we’ve got people he’s got people coming in and out. I mean, even if the girls only pop in for five minutes it’s the popping in for five minutes, if we move somewhere else he’d be on his own all day”

(Int. Christine)

These two participants highlight the importance of wider family involvement, particularly if the person has multiple co-morbidities and is dependent upon their partner. However, not all participants felt adequately supported by their wider families.

Seeking additional support

Although the majority of participants reported feeling supported from families, this was not the case for all participants, due to relatives living abroad (Kris and Kaye's sons) or the individual perceiving them not to be interested (Aileen). Matthew, for example, lived with his wife who was able to perform his treatment if required, but the couple did not have close relatives who were able to offer support. While Matthew did not appear to regret this, he was independent with treatment and therefore required minimal practical support at the time of interview. Conversely, Kris was dependent on his wife Kaye for his dialysis care and the couple described wistfully to me about how life would be different if their sons lived nearby:

"Kaye: we'd get out more I think, the boys would take us out in the car

Kris: yeah

Kaye: and we'd be going there for meals or they'd be coming here for meals"

(Int. Kris and Kaye)

However, the couple – who had decided to move back to the UK and thus away from their sons – did not appear resentful of the limited support they received from their family. Aileen was single with no children, although her sister, nieces and great-niece lived nearby. Aileen particularly felt that her family showed little interest in her, despite living nearby:

"she [sister] was going to come yesterday and pick up my key, so she can have a key made for this place, so I I felt like saying 'what's the point you're never in'"

(Int. Aileen)

Aileen is thus doubtful about her family's interest in her condition. Despite this, Aileen regularly saw her niece, great-niece and great-nephew, where they went shopping, had meals together and went on holiday. Aileen's house was full of photographs of her extended family and she spoke animatedly about them. Abigail, Aileen's great-niece, was present during an observation and she spoke affectionately about her aunt, worrying about her coping with peritoneal dialysis and asserting that she wished Aileen would accept her offer of a living-donor transplant. Thus Aileen appeared disappointed by her sister's minimal contribution, but other members of the family did appear to be more involved.

Therefore, the minority of participants perceived that their wider families could be more involved in supporting them to live with peritoneal dialysis.

Women's work?

During the process of data generation it became apparent that the majority of support and care from relatives was offered by women. While this could have been due to the majority of participants being older married men, in homes where there were sons present women continued to bear the burden of care.

Leila lived with her husband and two of her sons, with other relatives – including daughter Lisha – living nearby. While Leila was able to independently perform her CAPD exchanges, Lisha clearly visited regularly and assisted her with the treatment. Since being made redundant, Lisha had decided to not return to work to enable her to support Leila, and she took her mother to hospital appointments with the ophthalmologist, Nephrologist and endocrinologist. Although Leila's husband assisted with her medications, he was otherwise uninvolved in her dialysis treatment, nor were her sons. Lisha appeared accepting of her father and brothers' lack of assistance with their mother's dialysis, citing gender factors for their indifference. Furthermore, Lisha makes light of the situation by laughing, before conceding that they may assist with carrying the dialysis solution boxes upstairs:

JB: [to Lisha] what do your brothers think of it? [To Leila] what do your sons think?

Lisha: they're oblivious as men are (laughs)

JB: they're oblivious?

Lisha: you know what men are like

JB: yeah, OK

Lisha: they're oblivious, I think the most that they do is when the stock comes they'll come and pick it up and take it upstairs"

(Int. Leila and Lisha)

Similarly, both Evelyn and Norman had sons, but as in Leila's family, it was their daughters who offered support. Norman lived with his son and his daughter lived nearby with her young family, however she assisted her father with moving his dialysis supplies and cooking for him and her brother:

"Norman: my daughter does most, she is not living very far away, she's inclined to prepare an evening meal for us

JB: oh lovely

Norman: yeah yeah yeah sometimes she'll even join us here for an evening meal if her husband, her husband has to travel a lot with his job, so if

the husband is away she's inclined to have share the evening meal here with us"

(Int. Norman)

Thus the practical support provided by relatives, and in these cases children, did not necessarily involve dialysis care alone, but instead transcended into other aspects of everyday living. Although the sample bias could account for the distribution of care falling to women, within families where there were also men it continued to be women who provided the majority of care.

Other networks of support

Several participants described how they were supported by friends and neighbours, although others preferred to manage their treatment privately. Harriet, Carl and Norman all received support from neighbours and friends, which they valued. Harriet explained that she had felt physically very unwell in the lead-up to dialysis and her friends had offered considerable help, which had continued once she started treatment. Indeed, while Harriet and I chatted prior to the recorded interview, Harriet's friend popped in to see whether she needed anything:

"that's why friends come now so frequently, because in those days they used to come to help me and they would bring lunch and they would come and make me a cup of tea"

(Int. Harriet)

Christine, Carl's wife, took comfort from their neighbour visiting Carl during the day and helping him if necessary, particularly because Christine worked:

"We've got a neighbour, I don't know whether you saw neighbour talking to Carl at number two? He pops in all the time if Carl wants something and everybody's out at work and neighbour's there he'll do it, you know, he'll any little job that he can see needs doing, he'll do it"

(Int. Christine)

However, some participants did not include their friends in this aspect of their lives, due to feeling their friends would not understand (Benjamin and Beatrice) or preferring not to socialise (Kris). Kris had returned from living in America five years previously and Kaye explained that she struggled to make a group of friends, but additionally they reported not being interested in receiving practical or emotional support from friends:

"Kris: I can't understand support from friends

Kaye: I think it makes it harder I think... Kris doesn't like people in here, he can't stand people talking

Kris: well no I I do get irritated

Kaye: I go downstairs for my company"

(Int. Kris and Kaye)

Therefore certain participants welcomed support from neighbours and friends, while others preferred to manage treatment independently or with support from their families only.

All participants managed their treatment with support from relatives, including practical and emotional, dialysis and non-dialysis, and surveillance. However, a minority of participants commented that they would appreciate more support, due to relatives living further afield or perceiving them to lack interest. In addition to the support from partners or spouses, children and grandchildren were commonly involved, in particular women in the family. Although this could be attributed to the sample bias, nonetheless where there were sons in the family, it continued to be daughters that offered support. Several participants valued the input of neighbours and friends, while others preferred to manage the treatment within the family unit.

This section has thus represented key challenges of living with peritoneal dialysis, including the disruption and restrictions placed on everyday life, the persistent threats that peritoneal dialysis poses to the individual and thus the ongoing measures taken to prevent and identify complications, and the inimitable role that relatives play to support patients using peritoneal dialysis at home. Peritoneal dialysis dominates and disrupts everyday life, as well as the home environment, but participants made attempts to integrate the treatment into their everyday lives and thus assert control over it. This is discussed next.

6.4 Integration, freedom and asserting control

Peritoneal dialysis is thus a challenging treatment that impacts significantly upon the lives of individuals and their wider families, altering the home and proving a challenge to live with. However, the interviews with patients and family members revealed that in an effort to minimise the challenges posed by peritoneal dialysis, many participants were adept at integrating the treatment into daily life. Participants spoke with conviction about minimising the impact that peritoneal dialysis had on their lives by attempting to assert control over the treatment:

“I’ve been determined um to have the least impact as possible, um because it can rule your life I think, and it does rule your life, but to what degree it rules your life is up to you really isn’t it? So er when needs must, you get on with it”
(*Int. Christine*)

“Diane: we used to go out and Dan used to do his dialysis in the car, we never let it [CAPD] stop us
Dan: No

Diane: It was just we worked, you know, we made sure
Dan: Worked round it"

(Int. 1 Daniel and Diane)

Participants appeared to achieve this control and integrate the treatment into their lives by being flexible with when and where they undertook peritoneal dialysis exchanges, while being creative and innovative to use equipment that made the treatment easier to use – both in and out of the home. However, it emerged that there was significant variation between participants in how confident they felt to be flexible and creative with the treatment, leading to varying degrees of integration.

6.4.1 Flexibility with time and place: freedom and restriction

Many participants were flexible with when and where they undertook their treatments. Often flexibility involved either the timing of exchanges or the location, because if participants stretched out the time between two CAPD exchanges, they performed both at home and went out or undertook other activities in between. Conversely, if participants preferred to adhere to regular times between exchanges, they could take their treatment away from home with them. Participants using APD were restricted to the home for the location of their treatment, due to the machine required; however some participants altered their start times according to their plans. Participants reported that this flexibility improved their lives with the treatment, while those who were less flexible reported the negative impact of the treatment on their lives more strongly.

Timing of exchanges

The majority of patients demonstrated a degree of flexibility with regard to the timing of undertaking peritoneal dialysis. Those who were creative with the timings of their exchanges reported that this allowed them to continue with other aspects of their lives, while those who were rigid reported that the treatment was restrictive.

Not all participants were flexible with the timings of peritoneal dialysis exchanges and subsequently they struggled with integrating the treatment into daily life. In terms of CAPD, James's daughter Julie discussed the negative impact of the treatment on her parents' social lives and routine, due to their rigidity, resulting in their lives being restricted by James's treatment:

"Julie: we are very religious following instructions... you had to do it [CAPD] breakfast dinner tea and supper, and even though they told us that we could do it a little bit earlier and a little bit later, you don't because we didn't want to mess so we follow the instructions. So it was very time consuming and it was

very um restricting of what they could do, because they couldn't go out and visit people because they'd have to rush back then, and even though they'd told her they didn't have to, that's the way that they've been brought up and that was it"

(Int. James, Janice and Julie)

Similarly, Oliver changed to APD partly because he struggled with the impact of CAPD on his daily routine. Oliver reported that he found CAPD dominated his life and he felt controlled by the treatment, completing the exchanges at specific times:

"especially with CAPD is that you have to, it's always the back of your mind, whatever you're doing you've got to sort of think 'well it's eleven o'clock now, twelve o'clock I've got to, well around then, I've got to do dialysis' um and you tend to be thinking about that more often than er thinking about what you're doing. You're looking quarter to twelve, you know, I'll carry on for another fifteen minutes on this. So it sort of governs your life in that sense, it's like working to the clock. Um I mean when I retired from work I thought 'wow', you know, 'time's me own'. It wasn't. It was the dialysis that governed it"

(Int. Oliver)

While CAPD was reported as more restrictive than APD by Julie and Oliver, Kaye found that her social life was influenced by APD. Kris and Kaye cited the importance of following a routine to manage Kris's treatment, and therefore Kaye reported that she preferred limiting her social activities to altering Kris's treatment regime:

"Kaye: I was invited to a party on Saturday, I went at seven half past seven, I had to be back by nine to put Kris on. It's that type of, he could go on later, but no we've got into a routine

Kris: oh we have yeah

Kaye: and we stick to it"

(Int. Kris and Kaye)

Therefore APD could also lead to perceived restrictions if participants felt unable to change the time that they started the treatment in the evening.

However, multiple participants reported that they were flexible with the timing of their exchanges to align it better with daily life. The earlier description of Frank's routine highlighted that the couple performed the second CAPD exchange earlier if they were going out for the afternoon. It was not uncommon for participants to do this, which Aileen, Harriet, Matthew and Rhodri described. While Harriet simply described this in terms of planning ahead, Rhodri explained the importance of altering the timing of exchanges to minimise the negative impact of treatment on his life and thus retain control:

"I would work it around, you know, work my times around what I was doing, so again it was getting a bit organised"

(Int. Harriet)

“I tend to be flexible with it to suit your lifestyle, not sort of be adamant of changing it every four to six hours um regimental, because it can ruin your life you know, [if] you let it, it sort of rules you then and you do tend to watch the clock and you’ve got to watch your timings, but it can be quite flexible I think the CAPD”

(Int. Rhodri)

Other participants in the study similarly adjusted their dialysis times according to their plans, with encouragement from healthcare professionals. Matthew explained that a Nephrologist had encouraged him to alter the timings of his CAPD exchanges to allow him time away from the home, highlighting the important role that healthcare professionals play in giving patients confidence to be flexible with their treatment regime. This flexibility made peritoneal dialysis a more positive treatment to Matthew, allowing it to integrate more effectively with other aspects of his life:

“Matt: the doctors up there said that, I said ‘well I’m wasting a day because I got to go back sort of one o’clock-ish’ they said ‘no, well if you do two bags in the morning um say one at eight o’clock and then another one half past ten it gives it a chance to work in the system and then you go off for a day and then leave it til teatime’ so, you know, that was a bonus as well

JB: so is that what you tend to do now?

Matt: yeah not often, not too often

JB: no, but just if you’re going out somewhere?

Matt: but I mean if I want to go to town I do two in the morning and then go to town for the day”

(Int. Matthew)

Thus multiple participants were confident to change the timings of their treatment according to their social plans, while ensuring that they undertook the prescribed treatment per day.

Confidence to alter treatment timings appeared to increase over time. Daniel – who had recently started APD at the time of the study - reflected back on altering his CAPD timings for a special day trip. The extract highlights that confidence to alter peritoneal dialysis timings can build over time with Daniel describing that the first year undertaking treatment he did not attempt to change his regime to allow him to go on a day trip, but the second year he felt confident to contest the usual routine. Again the importance of healthcare professionals encouraging patients to have confidence to alter their CAPD timings (if feasible and safe) is also emphasised:

“You know the Balmoral? The ship that sails around the Channel? Well I get a free trip on that every year, so the first year on dialysis we never went did we? I never went. But last year I phoned up the nurses and said ‘look, I’d like to go on...the ship and you get on there at nine in the morning and you don’t get off until nine at night and by the time you’ve got on a coach and come home, and this that and the other, it’s a full, absolute full, day’ so um there was a bit of umming and aahing and they said ‘well look, do two before

you go, so you have to get up really early and do two and then er a break and then another one and do two when you come back'. Well it was a real long day wasn't it? And I didn't get, there was a delay on the coaches and everything, and I didn't get back here until about midnight and er then I had to do two so it was the very early hours of the morning before I got to bed, but I felt wonderful the next day"

(Int.1 Daniel and Diane)

Rhodri similarly reported that his confidence to alter treatment times increased with time. While Rhodri describes closely monitoring the timings of exchanges initially, when circumstances outside of his control meant he was late for an exchange, he realised that leaving slightly longer between exchanges would not be detrimental:

"when you first start it you're regimental, you know, you're watching the clock and you're trying to work out 'I've got to do it then, I've got to do it then, I've got to do it then' and, you know, you think 'I've got to do that because otherwise I'm going to be ill', but then as you tend to go on with it and you realise that it's not, you haven't got to be so hard and fast with it. There is limits to it obviously, but it's nice to know that you know you can go six or seven hours, or eight hours even, between and not run into a problem, you know? Things happen, you go out sometimes if you're catching the bus, the bus is late or it doesn't turn up or, first couple of times it happens you panic like hell, but then when you do the exchange and find oh well that was OK, you tend not to worry again then, you know, and as time goes on then you're more flexible with it, you know? Obviously you've always got it at the back of your mind that you've got to do it, but it tends not to rule your life then, you can sort of forget about it"

(Int. Rhodri)

Thus with time individuals reported gaining more experience of the treatment, realising that altering times slightly does not impact negatively, and their confidence to be flexible with the treatment could then increase, with encouragement in some cases from healthcare professionals.

Multiple participants therefore altered the timings of CAPD exchanges to allow them an element of flexibility to undertake other activities. In terms of APD, the treatment must be undertaken for the prescribed amount of time, which is programmed onto the machine by the peritoneal dialysis nurses according to their clinical need. Therefore, the only potential flexibility of APD is starting the treatment at earlier or later times. Frank, who had limited experience of APD, reported the importance of considering the start-time of the procedure according to his plans for the following day:

"Frank: you really have to think what you're going to do the next day, because if you want to make ... a nine o'clock start somewhere, you want to make sure you're in bed and laced up the machine at half past ten at the latest, because it's usually a nine hour programme, and the night I had the alarms it was nine and a half hours...if you wanted to get up at a particular time, you'd need to think about the time you go to bed"

(Int.2 Frank and Fiona)

However, while some patients would be able to be flexible with their starting time for APD, this could be a challenge for other patients with varying responsibilities.

Thus while a great number of participants in the study altered their treatment times to allow greater flexibility and the ability to continue with other aspects of daily life, not all participants felt able to do so. For some participants their confidence to be flexible with their treatment appeared to increase over time, but others remained steadfast in a specific routine. The effect of this was feeling governed by dialysis and finding it challenging to fully enjoy other aspects of life.

In addition to flexibility with the timing of exchanges, some participants were also flexible with the location of peritoneal dialysis exchanges.

Location location location

The previous sections have highlighted the multiple pieces of equipment required to perform peritoneal dialysis and the subsequent impact of the treatment on the home environment, leading to alteration in how the home space was used. However, while several participants performed their dialysis treatments only in the home space, others felt confident to undertake treatments while away from home, both on outings or on holiday.

Geraint, James and Norman were willing to go on holiday and take their peritoneal dialysis treatment with them, but they were unwilling to perform their day-to-day CAPD exchanges outside of their homes. Geraint was concerned about the risk of infection if he performed exchanges in different locations:

“Geraint: I do it at home

JB: It's always at home?

Geraint: Yeah

JB: So if you go to family's houses

Geraint: No I wouldn't do it no, I wouldn't do it in front of people no...you gotta do it to um in a room that um is sterile”

(Int. Geraint)

Julie similarly described her parents' concern about making a mistake and they therefore preferred to perform James's routine exchanges in their house only:

“Julie: we didn't want to mess so we follow the instructions. So it [CAPD] was very time consuming and it was very um restricting of what they could do, because they couldn't go out and visit people, because they'd have to rush back then and even though they'd [PD nurses] told her they didn't have to,

that's the way that they've been brought up and that was it"
(*Int. James, Janice and Julie*)

However, Geraint and James were happy to take holidays and perform exchanges while there, suggesting that they are confident to alter the location of their exchanges if required.

Frank and Fiona, who had undertaken CAPD for less time than other participants (six months), performed peritoneal dialysis only at home and were wistful about how other people coped with taking the treatment on holiday. Although this couple described altering the timing of Frank's CAPD exchanges to allow them a period away from the home, this was clearly not enough as they report using emotive language that their lives have been 'ruined' by the treatment. Additionally, Fiona reported blaming her and Frank for not being able to retain control over the treatment:

"Fiona: I don't know whether we are letting it ruin our lives or or whether everybody's like that, it has to do something four times a day you know in this way, but it does tend to seem to be you know 'oh we've got to get back for doing the bag' you know it's that sort of feel about it, you know, but um dunno, it's just maybe us, maybe we're not letting it, you know, relaxing with it perhaps, you know. Cause we've heard stories of other people going away and all this sort of thing you know and making arrangements for a the thing to be done, but um I think you're a little bit more you know sort of cautious on those lines aren't you?

Frank: Yeah

Fiona: You like to be around to do the bag when it's supposed to be done (laughs) but um still this is how you are really isn't it? You know some people can not let it sort of go too much or involve or you know rule their lives too much um, and then there's other times, other people like us"

(*Int.1 Frank and Fiona*)

However, participants who were willing to perform the exchanges away from home, including Aileen, Daniel, Leila, Paul and Rhodri, reported the treatment more positively and felt able to continue with other aspects of their lives.

Similarly, other participants were unwilling to go on holiday with peritoneal dialysis, citing differing reasons. When Kris commenced peritoneal dialysis the couple lived in the USA and they described travelling for holidays to different parts of North America, as well as visiting the UK. However, since Kris's health deteriorated, the couple reported that these holidays were less achievable, particularly due to the other equipment that the couple would need to take on holiday to manage peritoneal dialysis and Kris's co-morbidities. The couple were, however, philosophical about

this, citing their increasing age as a mitigating factor, although Kaye was pensive that she would like to take a holiday:

Kaye: it is a way of life and it's alright for us because we don't do much now anymore, but young people I think it could be quite a chore for them

Kris: but they also got the energy to

Kaye: deal with it

Kris: to deal with it yes, I suppose that is we haven't got the energy, I haven't got the energy anymore and the very thought of it carrying these boxes and getting them out, I mean, yeah I'd rather stay here

Kaye: I'd like to have a little cottage by the sea for a week though

Kris: yeah we can do that, we can go

Kaye: but as you said, we'll have to get a van to go take all this"

(Int. Kris and Kaye)

While Kris's condition affected their opportunity to go on holiday, for Evelyn it was her husband who was too unwell to go away. Harriet, however, reported different reasons for choosing to stay at home. Since commencing dialysis several years before, Harriet had anxiously waited for a kidney transplant and she was concerned about being away on holiday and thus being suspended temporarily from the transplant list:

"I won't go far now, because I don't want to be suspended [from the transplant register], I don't want to risk a kidney for the sake of a holiday"

(Int. Harriet)

Harriet was the only participant to explicitly cite transplantation as a reason for staying at home, with other participants on the transplant register continuing to go on holiday in the UK, including Daniel, Leila and Rhodri. While other participants were therefore keen to retain aspects of their lives prior to dialysis, including holidays, Harriet's quote suggests that she was waiting for the next treatment and the potential freedom she hoped it would bring, rather than embracing the benefits of peritoneal dialysis.

Conversely, multiple participants spoke of undertaking their CAPD exchanges while outside of the home, for example while out shopping or at relatives'/friends' houses, including Aileen, Daniel, Leila, Paul and Rhodri. Both Daniel and Rhodri described going out for the day and completing CAPD exchanges while in their cars, which Rhodri summarised "I'm not saying it's the ideal environment, but hey you know it's better than being stuck in a house all day" *(Int. Rhodri)*. However, other participants were also willing to undertake CAPD exchanges while further away from home, to allow for special days out. While Benjamin therefore took CAPD equipment with him on work trips to London, other participants took their CAPD equipment on family day trips. On our second meeting, Aileen reported that she had visited Legoland with her

family and undertook an exchange easily in the car, before discovering that some public attractions provide a medical space for customers:

“Aileen described going to Legoland Windsor with her niece, great-niece and great-nephew. Towards the end of the trip Aileen said she returned to the car to do the CAPD exchange as the park was shutting. Aileen said she used the coat hook above the door to hang the dialysis bag on, which worked well. However, towards the end of her exchange Aileen reported being told by a security guard that she could have used their medical room to perform the exchange in.”

(FN2 Aileen)

Paul enjoyed regularly going on day trips and was thus proficient at performing exchanges while away from home. Like Aileen, Paul reported that he usually found that attractions had medical rooms he could use, making exchanges simple:

“Paul: I go to British castles and all that sort of business, and ah, you know, you think ‘well what am I going to do?’ And I’ve been in ... [names city] Castle and went in the dungeons down in there that was quite fun and then I’ve been what’s the big theatre in [names city]?”

JB: Oh the um [names theatre]?

Paul: Yeah I’ve done that a few times um I just go and see, you know, say ‘I’ve got this problem ... I’ve got to do it’ and what have you and more often than not they’ll oblige and tell you what they’re going to do and, you know?

JB: So do they have like a medical room?

Paul: Yeah well it was, the last one was like a flipping tip in there (laughs)”

(Int. Paul)

Participants thus felt able to perform CAPD exchanges while visiting attractions, to enable them a day out with their family, and also highlights that locations may have medical rooms to allow for easier exchanges for patients using medical technologies.

The two companies that supply peritoneal dialysis equipment deliver supplies throughout the world and patients thus reported that they are able to order their dialysis stock to be delivered to another location (with several weeks notice), throughout the UK and abroad. Participants described having dialysis stock delivered to other parts of the UK (James and Rhodri) and Europe (Carl and Norman), while other participants carried their own stock in their cars to go on holiday in both the UK (Daniel, Geraint and Matthew) and Europe (Benjamin). Multiple participants utilised the service offered by the dialysis companies, including Aileen who had been to Egypt with her extended family. Although Aileen described having to be creative with the equipment that she used to perform a CAPD exchange in her hotel room and relying on relatives to help her, this enabled Aileen to have a holiday and she was delighted, mentioning the holiday throughout my visits to her:

“there was a table [in the hotel room] in between that was marble so I could wipe it down and put the bag on there, and I said ‘oh dear what am I gonna

hang it up with?' You know, so the two of them [niece and her husband] they were holding the bags up, and they said 'oh my arms aching, oh my arms aching' so we gotta find somewhere else, you know, so anyway they found a hook in the bathroom, hooked it on there, used to take the chair in there and hook it up in there, and it worked out great"

(Int. Aileen)

Carl also reported performing exchanges while on holiday, both at the hotel and while on day trips. Similar to Aileen, he described how he was innovative with the equipment that he used while away from home:

"Carl: we went for a cruise somewhere, can't remember where it was it was in Greece, and um it was like not an all-day thing but quite a long time, so I took a bag with me and done it in the ocean

JB: OK, and that was OK?

Carl: Aye I pinched a hook that was hanging up to hang the bag up"

(Int. Carl)

Participants were positive about being able to go on holiday while undertaking peritoneal dialysis, although some did find the organisation involved challenging, including Benjamin, James and Kris.

Therefore, there was variation between participants about whether they felt confident to be creative or flexible with the time and location of the dialysis procedure. While some participants took the treatment on day trips and holidays, and reported positively for being able to do so, others were not confident enough to take the treatment away from home, citing various personal and dialysis specific reasons. Participants who performed peritoneal dialysis while away from home were required to adapt equipment to ensure they could perform safe exchanges. This is discussed next.

6.4.2 Creativity: innovations to ease the impact of peritoneal dialysis

The interviews and particularly the ethnographic observations revealed the different types of equipment that participants used to make peritoneal dialysis exchanges easier, both at home and away. Peritoneal dialysis requires multiple pieces of equipment to perform a simple exchange, such as weighing scales, line clamps and Tenckhoff caps. In addition to the equipment provided by the participating Health Board, several participants were innovative at creating and using different equipment to integrate peritoneal dialysis into their lives, both at home and away.

Freedom within the home

Within the home environment, the earlier fieldnotes demonstrated that participants performed CAPD exchanges both in the communal and private areas of the home. However, participants Daniel and Paul were dissatisfied that CAPD left them anchored in one room and they thus used stands to allow them more freedom around their homes during an exchange. Daniel's wife Diane reported that he had felt isolated in his downstairs dialysis room undertaking CAPD exchanges and therefore she had acquired a drip stand from the hospital:

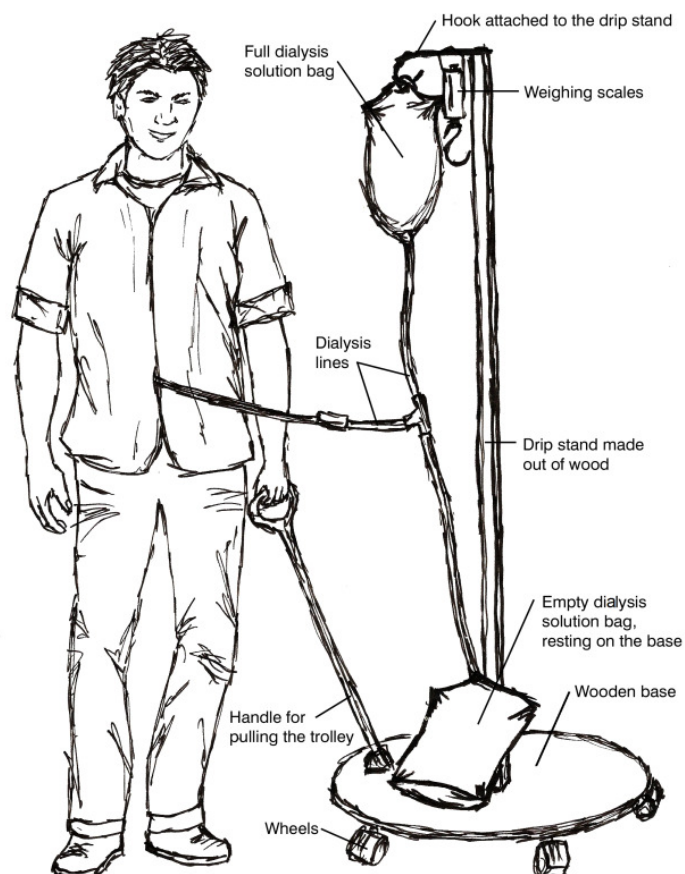
“Diane reported that Daniel used to feel quite isolated in the little sitting room performing CAPD, so she asked at the hospital if they had a spare drip-stand for them to use. The hospital were reluctant to give them one, but eventually agreed. The drip-stand, Diane reported, allowed Dan more mobility and freedom and he could watch television in the living room. Diane felt that this gave Dan a ‘psychological boost’.”

(FN2 Daniel and Diane)

Therefore Daniel used a more traditional piece of medical equipment to allow him to move around the house during CAPD exchanges. However, as a drip stand would not have a lower platform to place the CAPD drainage bag onto, he would have to carry this between rooms, stay in one position and then place it on the floor to safely perform the exchange.

After several months of CAPD treatment Paul designed and built a trolley which allowed him the freedom to move around the house while completing his CAPD exchange safely:

“Paul explained at the beginning of our first interview that he is different to other dialysis patients because he has a trolley that he uses to undertake his CAPD exchange all over the house. This trolley, constructed in Paul's shed, consisted of a wooden circular base, attached to four wheels, with a wooden stand attached. On the top of the stand was a hook, from which the dialysis solution bag hangs. Attached to the base was a handle that Paul used to pull the trolley, which he does carefully to ensure that he does not pull his abdominal catheter. Paul reported that this allowed him to watch television, empty the dishwasher and cook dinner, while undertaking a CAPD exchange. Additionally, he reported that his young grandchildren enjoy being pulled along on the trolley, standing on the base next to the drained dialysis bag.



“
(FN2 Paul)

Paul commented of his invention: “it’s lovely you know and it’s made life easy” (*Int. Paul*), highlighting the positive impact that this design has had on life. When I observed Paul performing a CAPD exchange we were able to wander between the rooms of his bungalow, while the fluid was either draining out of or into his peritoneum. After Paul’s CAPD exchange he also allowed me to pull the dialysis trolley and I was able to do so easily, noting how light in weight it was. Paul’s creativity thus allowed him to integrate his CAPD exchange with household chores or entertaining his grandchildren and prevented him being restricted to his bedroom where he kept his CAPD equipment.

Daniel and Paul were therefore very enthusiastic regarding their use of this equipment and these simple ideas allowed them more freedom within their homes during CAPD exchanges.

Freedom from the home

Participants were particularly innovative about the equipment they used to make peritoneal dialysis exchanges easier away from the home space. This ranged from

using standard household equipment to help with an exchange (Aileen), to sourcing specialist equipment on the Internet (Rhodri).

Aileen, who had undertaken CAPD for six years at the time of data generation, discussed undertaking a CAPD exchange at her niece's house, using household appliances to heat the dialysis solution bag before use. This enabled Aileen to easily complete her dialysis treatment while spending time with her family:

“Aileen also told me that she occasionally stays at her niece's modern flat in the countryside, taking with her a box of caps (to cover the end of her abdominal catheter) and iodine shields (to connect her abdominal catheter to the dialysis solution bag). Her niece warms the dialysis solution bag on the under-floor heating, on the cooker hood, or in front of the fire.”

(FN2 Aileen)

Furthermore, during the first interview with Daniel he had described difficulties he was having with APD, as the machine woke him repeatedly throughout the night due to 'low drain' alarms, leading him to be tired during the day. However, when I visited for a second interview and observation Daniel reported that he had solved the problem by sawing several inches off the APD table legs, thus lowering the machine allowing it to drain properly without disturbing the couple during the night. Daniel's brother was then creative and designed a table that was height adjustable and portable, ensuring that his brother was not disturbed by low drain alarms again while on holiday:

“Dan: on our last break my twin brother came to see us while we was down there on the South Coast and I was telling him about the height of the machine he said 'I'll make you a table' he's pretty handy with his hands and he's made me a uh small table that can adjust up or down you know six or eight inches...he measured up what I wanted and he said 'I'll see what I can do' and he came up with this table... and it folds up, all folds up, so I can put it in the back of the car and it as I say it moves up or down eight inches

JB: OK, so you'll be able to take it away with you?

Dan: Yeah

JB: To always get the right height?

Dan: Yeah

JB: That's brilliant

Dan: Yeah I was quite pleased with it”

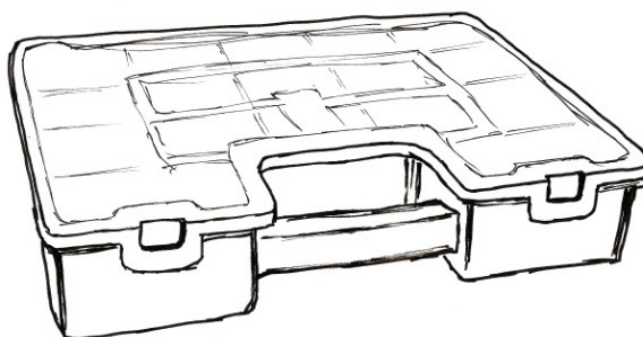
(Int.2 Daniel and Diane)

This also highlights the valuable role that family members play in encouraging and supporting creativity.

Several participants were innovative about how to transport dialysis supplies when out of their homes. Throughout Daniel's time using CAPD, before switching to APD, he continued to visit other towns for the day with his wife, and he had sought ways to

make this easier. Daniel achieved this through buying a tool-box from a hardware store, which acted both as a storage container for CAPD supplies, but also provided a wipe-able surface to connect the CAPD bag while away from home. This box was lightweight and ensured that Daniel had the supplies he needed to undertake a CAPD exchange while out of the house. Therefore, this simple idea meant that Daniel could undertake a CAPD while away from home, without worrying about not having the correct equipment:

“Daniel had a black and yellow plastic storage case (approximately 35x25cm) that he used to store supplies for CAPD, which he found extremely useful and had shown other patients undertaking CAPD. The case could fit one week’s supplies for CAPD, including alcohol wipes, caps and shields, particularly useful when Daniel and Diane went to stay in their caravan for several days.



(FN1 Daniel and Diane)

Similarly, Paul had bought a specific bag to store his CAPD equipment and dialysis solution bag while away from home, which he showed me during our interview. The picnic bag, combined with a hot water bottle, ensured that the dialysis solution bag remained warm for each CAPD exchange, while the other pieces of equipment could be safely stored. Paul described the impact that this cool bag had on his life, promoting his independence and also making CAPD exchanges away from home easier to complete:

“(Paul leaves the room and re-enters with a black picnic bag, approximately 40x40cm)

Paul: I’m sorry it’s all innovations in this place you see (laughs)...so what we do here is that this is a cool bag obviously but it’s done the opposite way, because I put an extra um insulation inside it and what I do is

JB: Ah hot water bottle

Paul: And then this is a wipe mat which I can wipe and ... I can keep that [dialysis solution bag] warm in there for about eight hours and sometimes what I do, if I’m going to do a double one or something, I’ll take a flask hot water flask and change it and then you know we’ve got all the clips and everything that’s all in there so you clip that off and you can use the gel and, you know, and so I’m independent shall we say (laughs)...you know saved me hell of a lot of time”

(Int. Paul)

These adapted carry devices thus made exchanges easier for participants to complete, enabling them to spend time away from home.

In addition to the CAPD boxes, participants also adapted their cars to enable them to undertake dialysis exchanges while away from home. Daniel and his wife Diane had adapted the rear seats in their car to enable Daniel to easily complete his exchange while away from home. To achieve this they used the CAPD case, along with a warming bag and a table in the rear of the car. This quote demonstrates the different equipment that Daniel and his wife took out with them to undertake a CAPD exchange – similar to Paul. By placing a table in the back of the car and taking the described equipment, this meant that Daniel could have a full day away from home and not alter his dialysis timings:

Dan: if I wanted to go out for the day I had to pack up bags and um get a cool bag and put a hot water bottle in it... and I'd go off to ... wherever we was going, and then find somewhere where I could do a bag change um in the town I was in, wherever I was

JB: OK, so where did you used to do a bag change?

Dan: In the back of the car

JB: Did you?

Dan: Yeah and that was alright and luckily the car that I bought a few years ago is fine because the back windows are dark so you can't see in, it's got a table in the back and what have you, so it was handy for doing that"

(Int. 1 Daniel and Diane)

Similarly, Rhodri was innovative about undertaking CAPD exchanges in the car while away from home. Rhodri also described the multiple pieces of equipment required for completing CAPD exchanges away from home, while maintaining hygiene principles:

"I've fitted up in the car that um I can take all my stuff in the car, I take a flask with warm water in for washing my hands, um I've got a box with all my stuff in that I need, I've got a baby changing mat to put the stuff on, I take the bag in my warming blanket and in a thermal bag and um I'll actually do the exchange in the car. I've fitted a hook up inside the car to hook the bag"

(Int. Rhodri)

Additionally, Rhodri discussed a device that he sought to make it easier to spend weekends away from home. Rhodri ordered an electric blanket, which can be charged in the car, and he described that it made going away for the weekend easier, without having to take his bag warmer (or use a hot water bottle like Paul and Daniel). Through the use of the internet and innovation, Rhodri found a simple way to keep CAPD bags warm away from home:

"To allow Rhodri to go away for a weekend or out for a day he decided to get find a piece of equipment to allow him to keep the bags warm. He therefore uses a 12V electric blanket (bought online for £12) that plugs into the

cigarette lighter in the car and keeps this inside a holdall, holding the dialysis solution bag. Rhodri described his warming box as allowing him to “lead a bit of life”, and feels that they should be provided by the Health Board for other patients.”

(FN Rhodri)

These three men thus used multiple pieces of different equipment not provided by the Health Board to enable them to safely perform dialysis exchanges while away from home, affording them freedom from their peritoneal dialysis treatments.

The use of creative equipment therefore helped patients to undertake peritoneal dialysis more easily when at home or away, thereby increasing their control over the treatment and aligning it better with everyday life. While participants were proud of their innovations and reported them positively, fewer participants were creative with equipment than flexible with time or place.

6.5 Chapter conclusions

This chapter has therefore explored the transformational effect that peritoneal dialysis has on the lives of patients using the treatment and their wider families. The first section considered the visibility of peritoneal dialysis from outside and inside the home. To accommodate the large amount of equipment required for peritoneal dialysis, participants converted a specific space inside their home and dedicated it to dialysis, or the treatment was spread throughout the house. Domestic spaces were then compromised with medical equipment, which was so for all participants using APD over night in their bedrooms.

The next section then considered the challenges of living with peritoneal dialysis and the disruption that this caused to participants' daily routines. Discipline and skill were required to manage the treatment each day, which for some participants led to exhaustion. Participants were fearful of contracting peritonitis – infection of the peritoneum – and therefore attempted to prevent or identify the infection at each dialysis exchange. During times of crisis, such as peritonitis, participants reported increased contact with healthcare professionals. The majority of participants were supported both practically and emotionally with both dialysis and non-dialysis tasks. Relatives played an important role in surveillance of the patient's medical condition and were often as skilled as patients at managing peritoneal dialysis. Despite the presence of male relatives, women took the burden of the work, although within

some households this could be attributed to the patient being male, older and married.

Despite these challenges, participants worked to minimise the impact of peritoneal dialysis by being flexible with time and place, and creative with the equipment they used when performing dialysis exchanges. This flexibility and creativity, which developed over time, enabled participants increased freedom from and control over peritoneal dialysis. Participants who felt unable to be neither creative nor flexible with their treatment reported increased restrictions on their lives.

The tensions of living with this treatment are thus highlighted here. Many participants chose peritoneal dialysis to allow them to remain at home, but the home environment subsequently changed and some felt restricted and controlled by the treatment. Others sought ways of integrating peritoneal dialysis into their lives, but this was accompanied by anxiety. Participants also lived in fear of a serious complication and thus spent their lives seeking to prevent such an event.

This chapter has thus explored and described the “chronic” phase of the illness trajectory (Rolland 1987), and the final findings chapter will consider the next stage.

Chapter Seven: Looking to the Future

7.1 Introduction

Ultimately, end-stage renal disease requires life-long treatment, and therefore participants faced limited options for the future: continue using peritoneal dialysis, change to haemodialysis, receive a kidney transplant or withdraw from treatment and prepare for death. This chapter will consider the next stage of the illness trajectory, labelled by (Rolland, 1987) as “terminal”, but will explore participants’ perceptions of their futures. Participants discussed their hopes or expectations for their futures with end-stage renal disease, which generally involved other treatments or at times alluding to the possibility of death. These decisions about the future were challenging and associated with fear of change, uncertainty and lack of control, hope and expectation, whilst participants compared themselves with others to offer reassurance.

7.2 Fear of change

Although peritoneal dialysis was a challenging treatment to live with, ultimately participants wanted to continue using the treatment, unless they were offered a kidney transplant. Several participants discussed the possibility that they may have to change to haemodialysis because peritoneal dialysis was becoming ineffective, which they described as a frightening prospect. Other reasons for needing to begin haemodialysis could include peritonitis, physical complications such as an abdominal hernia, or at the request of the individual. However, none of the patients in this study wished to transfer to haemodialysis out of choice.

Paul had undertaken CAPD for three years and felt he coped extremely well with the treatment, attending pre-dialysis talks to describe how he integrated the treatment into his everyday life. However, Paul described his disbelief at being told that he may require haemodialysis in the future, before telling me that he did not want to change treatment:

“I must admit it give me a little bit of a shock because when I spoke to Doctor [names doctor] and they was talking at one stage that because I’d done three years and they say that um peritoneal should only be three or four years or something”

(Int. Paul)

Furthermore, Aileen and Geraint had both undertaken peritoneal dialysis for six years and were now facing changing to haemodialysis – a prospect neither relished. Aileen and Geraint had earlier commented in their interviews that they disliked the possibility of haemodialysis because it would involve travel to and time in hospital, a view shared by multiple participants in this study. Geraint disliked the idea of transferring to haemodialysis due to the impact he perceived it would have on his life and freedom:

“JB: what do you think about starting haemodialysis now?”

Geraint: ...I don't really fancy it to be honest with you. Um you'll be limited to, you're limited now but like I can get around and do what I want, but I'm going to be more limited then, you know, I mean I like to go away for to have a few days break and one thing or another, but obviously I can't now if I have this haemodial', you know?"

(Int. Geraint)

During our discussion about choosing peritoneal dialysis initially, Aileen had spoken strongly of her dislike of haemodialysis and she maintained this view, hoping that changing treatments would not be necessary:

“Aileen: he [doctor] said ‘if it doesn't work out, the only other option is the haemodialysis’, so er I just hope and pray you that this will er work and I manage to pick up a bit, you know

JB: So how do you feel about the haemodialysis?

Aileen: Not very good (laughs)"

(Int. Aileen)

Aileen discussed the possibility of haemodialysis throughout our meetings, and eventually when I telephoned Aileen after a hospital admission, she reported that she had commenced haemodialysis and wished she could return to peritoneal dialysis. Multiple participants thus expressed anxiety about potentially changing to haemodialysis, due to fear of what this change would mean to their lives.

At the time of my separate interviews with Carl and Christine, Carl was facing the prospect of changing therapies to haemodialysis. Carl experienced multiple complications of type two diabetes, including retinopathy and amputations, leaving him extremely restricted. His wife Christine continued to work, but also assumed responsibility for Carl's APD. Christine appeared anxious about the prospect of Carl starting haemodialysis and described their hope that Carl could continue using peritoneal dialysis for as long as possible:

“Christine: we saw [the] doctor and he did mention the um, oh what's the name of the other one now?

JB: Haemodialysis?

Christine: Haemodialysis yeah, I think we're going towards that direction, but hopefully we can stave it off as long as possible, I don't know how long that

will be, but uh I'd like to perhaps see the year out maybe before we need to go down that road"

(Int. Christine)

However, the couple were realistic that haemodialysis was their future and while they were concerned about this change, they discussed how they could manage it. Both Carl and Christine separately described their preference for home, rather than hospital, haemodialysis. Home haemodialysis is arguably a more complicated procedure than peritoneal dialysis, often undertaken with the support of a relative, which involves additional medical equipment within the home. While the couple were matter-of-fact in their assertion for preferring home haemodialysis, this could be a daunting change and as stated would require additional training for Christine:

"if I can do it [haemodialysis] at home that's fair enough, you know, I don't mind that as long as I'm not stuck down there [*hospital*]"

(Int. Carl)

"he won't be happy going into hospital, he'll be a lot happier at home, so um I shall, er we shall, be on another learning curve"

(Int. Christine)

Thus while the couple were beginning to prepare themselves for a change of dialysis, they were keen to not change the location of dialysis and were adamant that they would continue to perform the treatment from home, enabling them to prevent Carl spending time in hospital.

Several participants were thus fearful of the future and the changes that this would bring to their dialysis treatment and therefore everyday life. This uncertainty about the future was echoed by other participants and is discussed next.

7.3 Uncertainty and lack of control

The future was perceived as uncertain by multiple participants and associated with a lack of control. Participants discussed uncertainty in terms of potentially deteriorating physically and also the possibility of receiving a kidney transplant, which was seen as a confusing process.

7.3.1 Living on the edge?

For some participants the notion of deteriorating physically was a realistic, near-future possibility. During data generation several participants expressed gratitude that they were alive, highlighting their recognition of the potential prognosis of end-stage renal disease. Certainly participants such as Harriet, who had known somebody who died of kidney disease 40 years ago, were aware that renal

replacement therapies are life-saving, and thus without treatment end-stage renal disease is fatal.

Participants did not necessarily discuss the possibility of death explicitly, but instead this was implied during other conversations. Daniel was physically active and considered himself to cope well with peritoneal dialysis, which he reported was working well – his blood results were “spot-on”, he revealed. However, during our first interview and when I revisited Daniel and Diane, there was an undercurrent of the possibility of deterioration. Although Daniel did not specifically discuss the possibility of deterioration or death in the future, he implied this when speaking about other aspects of life:

“Dan: I’ve got to go to the shed and get the other two, another twelve litres, and put it in this case and carry it all the way up the stairs, so it is a bit of a bind. Keeps you fit I suppose

Diane: Yeah well it does as long as your heart keeps going, you know

Dan: Well I suppose they’ll come a time when I won’t be able to get it up the stairs”

(Int. 1 Daniel and Diane)

“Daniel reported having too many savings to be able to have any financial assistance, but that using his savings to have a toilet fitted upstairs would use all his savings and he wants to ensure that his wife has savings if he dies.”

(FN2 Daniel and Diane)

While Carl did not discuss the possibility that his condition was deteriorating, his wife Christine made multiple references to this throughout our interview, and it was thus clearly a concerning issue for her. Christine poignantly described this as “the downward spiral”, suggesting that Carl’s condition is deteriorating outside of their control. Additionally, Christine discussed her uncertainty about the future once Carl commenced haemodialysis, highlighting the sense of unknown felt at beginning a new renal replacement therapy. Christine also looked further into the future and anticipated changes, for example holidays being untenable with haemodialysis, and thus further changes to their life together:

“we’re probably on the downward spiral now...I don’t know how well that will make him feel [haemodialysis] whether it will make him, because he has a lot of days now when he’s not feeling well at all, um so obviously it’s because um the things are not working like they were before...we’ve booked to go to Cyprus in um August, so uh I suppose selfishly we hoping that this [haemodialysis] won’t come up until after we’ve done that, because I think this is going to be the last time we’ll be able to do that”

(Int. Christine)

Carl and Christine’s case thus highlights the difficult and turbulent futures faced by some patients undertaking peritoneal dialysis when the patient is beginning to

deteriorate. The ways in which participants allude to their uncertain futures and death is also important; they do not explicitly mention it but rather imply it.

The potential for physical deterioration in the future was also recognised by other participants. Geraint spoke about this in positive terms, reflecting back over his life and the places that he visited. Interestingly Geraint discusses the number of years that he would like to live, rather than activities he would do or places he would like to visit:

“I’ve had a good life I’m sixty-five years of age ... I hope to see another five years. If I can see another five years, I’ll be happy”

(Int. Geraint)

James’s family discussed the period pre-dialysis when they were concerned about James’s physical health, and the family thus spent a busy year visiting places to make it a good year. However, Geraint did not talk about the possibility of deterioration in negative terms, instead focussing on what he had achieved in his life, for example the countries that he visited. Conversely, Frank and Fiona spoke emotionally about the prospect of Frank deteriorating. Both participants discussed the uncertainty of the future during my two visits and in both extracts the couple convey their perception of end-stage renal disease as a terminal condition, with a negative view of the future that involves Frank deteriorating further:

“Frank: It isn’t it isn’t a disease or disability whichever way you

Fiona: That you can see

Frank: That’s going to get better, you know, there’s more possibility of it getting worse rather than better”

(Int.1 Frank and Fiona)

“Fiona asserted that kidney disease is a difficult condition to live with, because there is no end to it. She commented that Frank will not have his good health again, and at this point Frank looked extremely pained.”

(FN2 Frank and Fiona)

This was a challenging and frightening way for the couple to live, which they clearly found difficult.

On the contrary, Benjamin argued that the way end-stage renal disease is presented to patients by healthcare professionals is too negative. Thus Benjamin perceived end-stage renal disease in different terms to Frank, perhaps because while Benjamin felt generally well undertaking peritoneal dialysis, Frank did not. This has implications for the way that end-stage renal disease is explained to patients, as Benjamin and Beatrice found it difficult to hear the likelihood of Ben dying:

“Benjamin argued that kidney disease is not terminal, it is chronic. Benjamin and Beatrice both said that this should be iterated to patients, rather than the statistics about the number of patients who die waiting for a transplant - they must be older people, Benjamin reasoned”

(FN Benjamin and Beatrice)

Interestingly, Benjamin explains these statistics to himself by considering that these must be other older people, rather than people like him, and in fact Benjamin was not registered for a kidney transplant.

Uncertainty surrounding deterioration and death was thus described by multiple participants, while there was variation in participants’ attitudes to end-stage renal disease and death. Participants also recognised that their futures were outside of their control, a frightening prospect for many.

7.3.2 Confusion about kidney transplantation

Half of the participants in the study were registered for a kidney transplant, but none had received an organ. It emerged that there was uncertainty amongst participants surrounding the issue of transplantation, both in terms of how the recipient of a kidney transplant is decided and how long they would have to wait.

It was not uncommon for participants to express confusion about which patients may receive a kidney transplant. Daniel had undertaken peritoneal dialysis for over two years and felt he coped well with the treatment, but he reported that he was also hoping for a kidney transplant. The uncertainty and fear associated with kidney transplantation is thus described here in relation to the process favouring younger patients:

“Dan: if a kidney came up I’d certainly take it, yeah I would. I just wonder whether age ever comes into it, you know? Cause if there’s, if a kidney comes up and you’ve got say five people who it’s suitable for and one is about thirty and has the full of his life in front of him and there’s an old bugger like me who’s seventy-two, who are they going to pick? Well they’re going to pick the young lad aren’t they, because his life is gonna be um affected a lot more than mine would be”

(Int.1 Daniel and Diane)

Daniel was self-deprecating about his right to a kidney transplant, when in fact he was hopeful that it would happen, which was reiterated during our second interview. In order to promote his chances of receiving a kidney transplant, Daniel reported that he ensured he attended the Nephrology clinic regularly. This extract highlights that a kidney transplant is never far from Daniel’s thoughts and he ensures that his chances of receiving an organ are optimised:

“Dan: he [doctor] said ‘your bloods are smack on’ he said ‘you don’t have to’ he said ‘this time you don’t have to have any bloods if you don’t want them’ but of course I have bloods because I’ve got to keep up to date in case there’s a transplant comes along”

(Int.2 Daniel and Diane)

The hope for a transplant is thus fraught with uncertainty and a perceived lack of control, while thoughts about receiving a kidney are ongoing.

Leila and Lisha were similarly concerned about the selection process for kidney transplantation and the likelihood of Leila being chosen. Leila had undertaken peritoneal dialysis for over two years and reported finding the treatment a challenge - she also hoped for a kidney transplant. Like Daniel, Lisha described being concerned about the likelihood of Leila receiving a kidney transplant, due to finding a suitable match as the family were Asian:

“Lisha: they’ve explained because um there’s less Asians, so it [kidney] would have to be tissue type and also they were saying that it would have to come from an Asian person as well

JB: really?

Lisha: yeah, so it’s the blood tissue type every quite a few factors within that, but they were saying like if it was Caucasian then they wouldn’t really, they’d consider it, but it would generally be from an Asian person, so it’s even more limited I guess

JB: OK, but is that what you’re hoping for?

Lisha: yeah I think she’s waiting for that

JB: you’re waiting for a transplant?

Lisha: yeah

Leila: I don’t know how many years it will take

Lisha: she has been waiting a while

JB: because it’s been two years nearly?

Lisha: um yeah”

(Int. Leila and Lisha)

Interestingly, Lisha comments that her mother is “waiting” rather than hoping for a kidney transplant, suggesting that life is on hold until the operation, but confidence that a kidney transplant will eventually come. Lisha stated that her mother struggled with the wait and used the control she has over her CAPD treatment to protest her lack of control over the transplantation process:

“Lisha reported that Leila sometimes becomes very upset in her long wait for a transplant and says that she does not want to continue with dialysis “what’s the point?” – sometimes refusing to perform her dialysis exchanges”

(FN Leila and Lisha)

Therefore, while Daniel used the possibility of a kidney transplant to make sure that he was regularly reviewed by the Nephrologist and ready for the transplant call, Leila conversely responded negatively to the uncertainty and the frustration this caused.

This uncertainty and lack of control was thus a challenge to live with, with little that participants could do to quicken the process.

7.3.3 False hope and dashed dreams

While none of the participants in the study had received a kidney transplant, both Daniel and Paul were called in for a kidney transplant operation, which was subsequently cancelled. This proved to be a traumatic experience, and highlighted to participants their lack of control about receiving a kidney transplant.

Daniel reflected on the day he was called in for a kidney transplant after showing me his detailed CAPD records, where he documented his blood pressure, weight and amount of fluid drained from the dialysis bags daily, as well as other significant clinical events. The couple described their jubilation that Daniel's chance of a kidney transplant had come, before this being abruptly ended by telephone. Their uncertainty around the kidney transplantation process was compounded by learning that other patients would have also been called for the same organ. Additionally, Dan and Diane reported being ready and prepared for a kidney transplant, in the same way that a pregnant couple might pack a hospital bag when awaiting the arrival of a new baby:

"Dan: On the eleventh, nearly had a kidney transplant that night 01:15 in the morning they phoned me up

JB: Really?

Dan: And said 'we've got a kidney for you' and we was er all jumping around and we were getting ready to go and they come back and said 'ah it's damaged, it's no good'

Diane: Well we went from high to low, but I tell you what I didn't know that Dan would not have been the only one who was called, so we were told afterwards by the Consultant that a few of you get called forward

Dan: If it matches yeah

Diane: If they match and then they choose the one that, so I mean it would have been even worse to have got down there to find out that you weren't the only one and you didn't get picked, so we're aware of that now, but we weren't before... right from the time that Dan went on dialysis I've always had a bag packed and every now and again I change it take it and you know make sure it's alright you know his wash-bag his pyjamas his everything everything that he'd need is in that bag, so we were just running round getting it all ready weren't we and I knew exactly where it was and we were, he was getting having a wash and a shave and rushing, and er then we had the phone call saying don't bother

Dan: Mmm yeah

Diane: At least we didn't get half way down to City

Dan: No no

Diane: That would have been worse

Dan: Yeah it would wouldn't it"

(Int.1 Daniel and Diane)

The extract clearly reveals the couples' disappointment and regret, while they try to remain positive by considering that the situation could have been worse. This was thus an emotional experience for Daniel and Diane, and increased their uncertainty about the transplantation process.

Another participant Paul described a similar disappointing experience after being called for a transplant operation that was then cancelled. Paul was ineligible for a kidney transplant at the time of our interview, having suffered several strokes since commencing peritoneal dialysis. However, when Paul first started dialysis he had been eligible for a kidney transplant and had been called in for the operation. Paul describes the events in tight detail, highlighting the significance of the experience. He reports similar emotions to Daniel: the excitement and anticipation that being called for a kidney transplant elicited, followed by disappointment that the operation was cancelled after having the necessary pre-operative preparation. The uncertainty surrounding the process appeared to make the experience more challenging for Paul, in terms of not being told by healthcare staff what was going on and then a rapid discharge in the middle of the night, without transport to get home:

“JB: so when were you called in for your transplant?”

Paul: Oh God I don't know, I can't remember now, it was sort of eighteen months in to the [treatment], I would have thought. I remember it very well. It was about four o'clock in the afternoon, nurse comes on [the phone] and ...she said 'I'll tell you that we've we want you to go as soon as possible to Hospital for transplant' (shock noise) 'oh shit here we go' (laughs) ...and then I rang round, told my missus she said 'right we're off' and so you do the normal things, you know, have a shower and all the rest of it you know and then er we drove down Pamela [wife] drove down and um went down the Hospital, went up [to the] ward and er went into the cubicle, you know, little thing. And they were testing everything and all the rest of it, heart stuff and er x-rays and all that sort of business, time was going on Pamela had gone back home or I thought she was I don't know where she was, she'd hopped it you know, there was nothing you could do because it takes, it's a long job, isn't it? So I was there and I had to go back down to emergency x-ray place ...so they had to have these extra x-rays and all the rest of it. Now when I went back up again I said to a nurse 'you know what was happening?' And all the rest of it, she said 'oh haven't you had a call?' I said 'no I've been off' um and they said er 'we've got a problem' and so that was the worst thing of all, but most positive worst thing was it was about twelve o'clock at night and they sort of dismissed me if you like (laughs) 'home boy', you know? You can't do it and that's it. Um so you walk, you go there and you've got to get your bag and you walk out of ward and you thought you're deflated aren't you totally, and then you walked out through concourse and it's empty, black, bloody not a cup of tea nothing and you think 'oh God' and so I got outside and I thought 'now what do I do?' Because I didn't know how to get hold of my wife...oh deflated, it's oh dreadful it was, you know, it was worse than having the

bloody job done to be honest, I felt awful afterwards, but there we are, that's life"

(Int. Paul)

Both Daniel and Paul therefore describe the painful experience of being summoned for a much anticipated kidney transplant, before the operation was cancelled. In Paul's case, he was then told that kidney transplantation was not an option for the future, which resulted in more deflation from his perspective.

The future was thus uncertain for multiple participants, who did not want to commence haemodialysis, but were aware of physical deterioration. The transplant process was challenging and was misunderstood by participants, despite the emphasis placed on the operation. For the two participants who were called for a kidney transplant, their feelings of joy soon turned to disappointment when the operations were cancelled, compounded by confusion of the process.

7.4 Hope and expectation

The future thus appeared frightening and uncertain for many participants in this study, but for others the future was also hopeful. Although kidney transplantation was the main source of hope, being able to continue using peritoneal dialysis also motivated a minority of participants.

Paul had undertaken CAPD for three years and was unsettled to hear from the consultant that he may not be able to undertake the treatment indefinitely. However, he spoke with conviction about continuing to use peritoneal dialysis for as long as possible, using stories of other patients performing the treatment for many years as a source of hope:

"Paul: Doctor was saying that some people are up to sort of fifteen years [using PD]. I'm going for that (laughs)

JB: You want to stay with what you're doing [PD]?

Paul: Yeah no way am I trying this (*mimicking cannulating a fistula*) it hurts (laughs)"

(Int. Paul)

Furthermore, Matthew was ineligible for kidney transplant and after a brief period using haemodialysis he was keen to remain undertaking peritoneal dialysis. At the time of our interview Matthew undertook CAPD, but reported mixed opinions about the treatment, and he therefore sought an alternative. Matthew had found that to allow him time away from home, he had to undertake two CAPD exchanges in quick succession before going out, and thus he perceived that APD could align better with his life:

“Matthew: I understand there’s one that you can do over night, so I’m going to start looking into that... I mean if you do it overnight your days are free then, you know

JB: ok, so that’s what you’re aiming for at the moment maybe

Matthew: yeah that’s what I’m looking to end up if you like (laughs)”

(Int. Matthew)

Therefore, while Paul hoped to maintain the status quo, Matthew looked to APD – remaining hopeful that they could continue undertaking peritoneal dialysis and avoid the need for haemodialysis.

Kidney transplantation was hoped for and anticipated by multiple participants. Harriet was in her early sixties and had undertaken peritoneal dialysis, both CAPD and APD, for over four years. Although retired, Harriet maintained her social life and looked after her grandchildren daily. Since commencing dialysis, Harriet had waited for a transplant and she described her frustration and feelings of inequality that she had not been called. Harriet’s life was affected by her long-term hope for a kidney transplant, for example she ensured that she was always within reasonable distance of the hospital if she received a telephone call offering her a kidney. However, Harriet felt that this sacrifice was justifiable, exemplifying the importance placed on kidney transplantation:

“I don’t want to risk a kidney for the sake of a holiday. I’ve had so many holidays anyway and I intend to have more so I can do without a holiday”

(Int. Harriet)

Due to their medical histories, Geraint and Oliver were ineligible for kidney transplantation at the time of the study; however they were hopeful that in the future this may change. Both participants described their hope for a kidney transplant but also their recognition of the shortage of available organs:

“JB: if you can go onto the [transplant] list after five years, is that what you’re hoping for?”

Oliver: er yes yeah

JB: would be a transplant?

Oliver: I mean it’s the luck of the draw isn’t it then?”

(Int. Oliver)

“I hope I can, you know, I can get a new kidney I mean, er but they’re few and far between”

(Int. Geraint)

During her interview, Harriet described that in the future, after kidney transplantation, she would go on holiday and Oliver also discussed what he would do after kidney transplantation: have a bath. This may appear mundane, but Oliver disliked showering due to his Tenckhoff catheter, and his future intention to bath suggests of

his conviction that he will eventually receive a kidney transplant. Participants thus remained hopeful that a kidney transplant would be in their future and began to consider how their lives may improve following the operation.

7.5 Comparison to others: warning and inspiration

Participants' expectations for the future, in terms of which renal replacement therapy to receive, were influenced by their experiences of seeing other patients using the treatments. While some participants used other patients' stories as warnings, others used them as inspiration.

7.5.1 Deterred by others' experiences

Several participants had observed other patients responding poorly to other treatments and used their experiences as a warning against these treatments. Paul's conviction to remain undertaking peritoneal dialysis for as long as possible was described above, compounded by his experience of haemodialysis. In terms of peritoneal dialysis, Paul felt that he had integrated the treatment well into his life and it did not confine him undertaking other activities, whereas he asserted that haemodialysis would restrict him, having observed this in other patients:

"Paul: I've seen haemodialysis on a number of occasions, because I've been on um up to the ward ... there was a poor guy he was only about 35 something like that and he was on um haemo and he said to the nurse he said 'for God's sake how much bloody longer is this going to be?' (laughs) I thought yes (laughs)

JB: Yeah, it hasn't changed your opinion of it?

Paul: No (laughs) no definitely not (laughs) stick as I am"

(Int. Paul)

Furthermore, not all participants were convinced that a kidney transplant would have a transformational effect on their lives, having witnessed other patients struggling following the operation. Rhodri, who was registered on the waiting list for a kidney transplant, raised multiple issues of his perception of kidney transplantation, which he strongly asserts is not a cure to kidney disease, but a treatment. This view was strengthened by meeting several other people with kidney transplants and realising that the operation does not free people from managing end-stage renal disease:

"some people's idea of a transplant is that, you know, they'll have a kidney transplant and your life will be completely changed and they'll be like brand new and I think unfortunately it doesn't, you're swapping one regime for another. Because different people I've seen have had a transplant, it does make a difference to their life, they're not tied to the dialysis... I spoke to someone who just had a transplant and they're thinking now it's not such a, it wasn't such a good idea, you know, whether it's not working well for them I don't know. It's all the other things that are associated with the transplant, uh

they thought they were going to have a transplant and that'd be the end of it, you know, but it's still you've still got to be looked at and you know your rejection and the drugs you've got to take to stop the rejection, it's a constant battle all the time to keep it in level then"

(Int. Rhodri)

Unlike Rhodri, Evelyn did not want a kidney transplant as she had polycystic kidney disease and was concerned that the condition would affect a transplanted kidney. However, Evelyn also looked at others to reinforce this decision and she reflected on other patients she had witnessed being unwell postoperatively:

"I went in to the ward and there's all the transplant patients there and there was quite a few, you know, quite bad and er they had to have blood changes and God knows what, you know, and I thought 'well was it all worth it?', you know? So that's why I'm glad I didn't actually bother"

(Int. Evelyn)

Therefore, some participants' expectations and fears for the future were in response to seeing other patients' bad experiences of different renal replacement therapies, and thus either hoping to remain using peritoneal dialysis or approach kidney transplantation with caution.

7.5.2 Inspiration

While Evelyn, Paul and Rhodri thus looked at the bad experiences of other patients' to justify their perspectives towards transplantation, other participants looked to others to reassure them about the future. Daniel, Diane and Harriet reported the positive experiences of others to give them hope about the future with a kidney transplant and to act as inspirational examples of what could happen to them. Daniel and Diane, who were frustrated at the wait for a kidney transplant, used the experience of a gentleman who was transplanted soon after starting dialysis to give them hope:

"Diane: we had a lift down in the car down to hospital or somewhere once with this chap, he was older than Dan

Dan: Yeah

Diane: He'd only been on dialysis five months and he got a kidney

JB: Really?

Dan: Mmm

Diane: Amazing that isn't it? Amazing cause some people are on for many many years"

(Int. 1 Daniel and Diane)

Furthermore, Harriet – a retired teacher – took hope from one of her former students who received a kidney transplant and went on to live an active, full life:

"Harriet: I know a few people who've been transplanted, someone I was in school with um she's had a living transplant and someone I taught has had two double transplants

JB: Really?

Harriet: Yes she had diabetes when she was in school so she's had pancreas, isn't it?

JB: Yeah

Harriet: And kidney twice and oh to think I taught her, she's so much younger than me and she's so fit now you wouldn't believe

JB: Really?

Harriet: Yes she goes salsa dancing and you name it she does it - amazing"
(*Int. Harriet*)

Considering the future was thus frustrating and uncertain for participants, where they lacked control, but comparing themselves to others – either positively or negatively - reassured participants about their future options.

7.6 Chapter conclusions

This chapter has thus considered the final stage of the illness trajectory, which would usually involve the patient dying, but here participants described their hopes and expectations of the future. The majority of participants hoped to either continue using peritoneal dialysis or receive a kidney transplant. Many participants were fearful of changing treatments, in particular if this meant starting haemodialysis. The future was uncertain and associated with a lack of control, in terms of deteriorating physically and when haemodialysis/death would come, but also in terms of the kidney transplantation process, which was poorly understood. Participants' near-miss experiences of kidney transplantation lead to increased confusion, due to poor communication and coordination in the hospital, or learning more about the transplant process. However, hope was ongoing that either peritoneal dialysis could be used long term or a transplant would become available. Participants compared themselves to others to reassure them of their decisions, either through seeing the positive or negative experiences of others.

This final findings chapter has presented the third stage of the illness trajectory. The next chapter will discuss the findings from this study in relation to the wider literature.

Chapter Eight: Discussion - Wider Considerations of the Research

8.1 Introduction

The previous three chapters have provided a detailed insight into how families live with peritoneal dialysis in their homes, using Rolland's (1987) illness trajectory framework to complement the research findings: journeys to peritoneal dialysis (past), living with peritoneal dialysis (present) and looking to the future. This chapter will now present these findings in the context of the wider literature and will be organised into three sections. The first section will explore the findings presented in this thesis in relation to the wider literature, theory and health policy. Section two will critique this piece of research, specifically exploring the perceived strengths and some limitations of the work. The final section will focus on the conceptual framework adopted for this study, in terms of adapting and utilising Rolland's (1987) chronic illness trajectory and Jablonski's (2004) illness trajectory for end-stage renal disease.

8.2 Exploring participants' perspectives

The study generated a substantial amount of data and findings that are relevant to patients and their families, healthcare professionals and researchers. However, to identify the usefulness of the study findings, it is important to consider them in relation to the wider literature at micro, meso and macro levels. The micro level compares the findings from this study to other research focusing on patients with end-stage renal disease, while the meso level draws on wider research from the home medical treatments/technologies literature, which includes medications, home dialysis, oxygen, parenteral nutrition and intravenous antibiotics (Corbin 2003). Finally, the macro level considers the findings from this study in relation to the broader sociological thinking on chronic illness. This discussion is organised into four themes: whether patients chose the "right" treatment, the tension between liberation and constraint resulting from peritoneal dialysis, the uncertainty of living with the treatment and what the future may hold, and the ways in which participants sought freedom from the treatment in the form of integration and hope of kidney transplantation. While the four themes are presented here separately, there is overlap between the sections, which will also be explored.

8.2.1 Making the “right” decision after diagnosis

The sociological literature considering chronic illness places substantial emphasis on diagnosis, arguing that it has a profound effect on the person’s sense of self as bodies are usually taken for granted (Nettleton 1995) and this phase thus marks the beginning of a new identity (Kelly and Field 1996). Bury (1982) termed the diagnosis of chronic illness and the impact on the self as “biographical disruption” (p.169) and Charmaz (1991) recognised that different chronic illnesses have different degrees of permanence, with long-term illnesses named as “intrusive” (p.42). End-stage renal disease is one such intrusive illness and diagnosis marks the start of a challenging period where important decisions about life-sustaining treatments must be made and patients become constrained by a health system that offers life-long renal replacement therapy or palliative care. While this diagnosis was understandably shocking for participants, for almost all participants in this study biographical disruption (Bury 1982) had already occurred with earlier diagnoses of long-term conditions, such as diabetes, which in some cases had led to end-stage renal disease.

Patients were then faced with making the “right” decision about which renal replacement therapy to use, which would impact on the rest of their lives. This section therefore explores these issues in relation to the literature. While this study focused on why patients chose peritoneal dialysis, it is also relevant to consider why patients did not choose peritoneal dialysis in light of the argument presented in chapter two (section 2.4) that greater numbers of patients should be using the treatment (Lameire and Van Biesen 2010, Wankowicz 2009).

Motivations

Patients with end-stage renal disease need to make a choice about treatment: peritoneal dialysis or haemodialysis, and the additional future possibility of receiving a kidney transplant (which, as discussed later in this chapter, was perceived as enabling freedom from dialysis). However, the current study identified that not all patients were able to choose from peritoneal, haemodialysis or kidney transplantation, as their co-morbidities contraindicated certain options, which was also identified by Breckenridge (1997a). Therefore, these participants chose life with peritoneal dialysis over no life-sustaining treatment. Participants with a choice of treatments in this study often cited multiple factors that led to choosing peritoneal dialysis, which have been identified elsewhere in the literature. Preference for home and concern about travelling to and being constrained to a hospital bed during

haemodialysis were motivating factors for patients choosing peritoneal dialysis in this and other studies (Lee et al. 2008, Morton et al. 2011, Wuerth et al. 2002). Furthermore, participants also hoped for increased autonomy and the ability to self-manage if they chose peritoneal dialysis (Morton et al. 2011, Wuerth et al. 2002, Whittaker and Albee 1996), enabling them freedom from healthcare professionals who would otherwise manage hospital-based haemodialysis. Interestingly, Tweed and Ceaser (2005) identified that pre-dialysis patients chose either peritoneal or haemodialysis in the hope that it would enable them autonomy and the ability to continue with usual activities in their lives. This emphasises that for a proportion of pre-patients peritoneal dialysis represents freedom and for others constraint. Harwood and Clark (2013) undertook a recent meta-synthesis of qualitative studies that considered pre-dialysis decision-making and iterated the need for separate qualitative studies to discover the nuances specific to home dialysis decision making.

However, it is also interesting to consider the reasons why patients may not choose peritoneal dialysis. Zhang et al. (2007) reported that lack of interest from patients, inadequate storage space and communication barriers meant that haemodialysis was their preferred choice. Additionally, physical barriers prohibited peritoneal dialysis being an option, including inability to lift bags, decreased dexterity or decreased vision, and common cognitive barriers including language, history of non-compliance, mental health conditions or dementia/memory difficulties (Oliver et al. 2010). Therefore, while peritoneal dialysis may be a suitable option for larger numbers of patients, for a certain proportion the barriers may be too substantial to overcome and haemodialysis is thus the option for them. Interestingly however, a number of patients in the current study chose peritoneal dialysis despite physical barriers to using the treatment, due to their intention that their families would learn the procedure. The role of families in the decision making process should thus be considered.

Support to make the decision

Participants generally reported making the decision about dialysis independently or with minimal input from relatives, despite the later implications of the treatment on the wider family. The involvement of relatives in decision-making appears to vary and both Lee et al. (2008) and Breckenridge (1997b) identified that relatives often played a significant role in choosing a renal replacement therapy, while Fex et al. (2011) reported that relatives were excluded from decisions about home medical technologies. While participants often made the choice independently, relatives

offered support in this process by attending pre-dialysis education and clinic appointments, relatives in Tweed and Creaser's (2005) study similarly supported patients but did not make the decision. However, patients in the current study chose the treatment knowing that they would be supported to manage the treatment at home. A study investigating why patients did not choose peritoneal dialysis (Zhang et al. 2007) reported that lack of interest from the family, lack of social support and inability to perform the treatment independently led to patients choosing haemodialysis. Furthermore, Oliver et al. (2010) found that family support was associated with eligibility for peritoneal dialysis, and also that patients with family support were more likely to choose the treatment. Oliver et al.'s (2010) study therefore highlights the fundamental role that families hold in supporting patients to use peritoneal dialysis and reinforces that it is thus extremely important to support families as well as patients to increase the utilisation of the treatment.

The National Service Frameworks for renal disease (Welsh Assembly Government 2007, Department of Health 2004) and clinical guidelines (National Institute for Health and Clinical Excellence 2011) stress the importance of patients making the decision about their own treatment. Participants in this study did not report a view that healthcare professionals were responsible for making the decision, which reiterates earlier work by Tweed and Ceaser (2005) where patients reported feeling supported but not coerced when choosing a type of dialysis. This contrasts with other studies that reported patients were heavily influenced by doctors (Fex et al. 2011, Breckenridge 1997b, Wuerth et al. 2002). A minority of participants in the current study were frustrated that they were left to make the decision as to which treatment to undertake when they felt it would have been more appropriate to be directed by healthcare professionals. This current study's findings were that patients did make the decision, however they did not always feel equipped to do so. It is therefore important that policy makers recognise that patients may need further support to cope with their increasing responsibility for decision making.

Living with the decision

Commencing peritoneal dialysis involved the introduction of medical equipment into the home, intensive training from healthcare professionals and the start of a new life with daily dialysis treatments. Bury (1982) described chronic illness as disrupting "the structures of everyday life and the forms of knowledge which underpin them" (p.169), and for patients using peritoneal dialysis the training period is the start of this disruption, and requires learning both skills and associated knowledge of the new

treatment. Therefore, patients quickly learned the reality of living with their decision. Participants in the current study reported that they received a structured education programme and relatives were commonly present to either help the patient use the treatment or to act as “back-up” if they were ever needed to perform peritoneal dialysis. Lee et al. (2008) explained that relatives in their study wanted to be present to feel confident in how treatment works, which is a similar finding to this study. Barone et al. (2011) asserted that “traineeship in the methodology to be used to treat oneself is a key part of success from the beginning and during long-term treatment” (p.97) and there is much early literature from individual centres pertaining to how patients are taught peritoneal dialysis, including international guidelines on what it should involve (Bernardini et al. 2006). However, this study did not focus on how patients are taught peritoneal dialysis by nurses, but instead how patients made sense of this stage of the illness trajectory and the fast approaching reality of dialysis. Even after considerable time using peritoneal dialysis, participants well remembered their feelings of fear, resignation and anticipation at starting life-sustaining treatment and the responsibility that accompanied it.

Corbin (2003) asserted that “Meaning of life is also derived from the body” (p.258) and in terms of learning to use peritoneal dialysis, patients are required to learn how to make their body function, which is a significant learning process. This study identified that patients reflected that they were nervous and worried about starting peritoneal dialysis, and that they failed to understand the procedure until they were “hands on”. No previous studies were identified that explored in depth this pivotal step in patients’ journeys with peritoneal dialysis from their perspectives. Most studies, including this one, do not include patients within three months of starting treatment to allow for adjustment, and have either investigated why people chose peritoneal dialysis or how they find the treatment once they are settled.

Therefore, this study reinforces findings from earlier studies that choosing peritoneal dialysis is a complex decision, influenced by multiple personal motivations. Patients in the current study were keen to report that they felt they had made the correct choice for them. While research has demonstrated that patients using peritoneal dialysis reported higher satisfaction with treatment than those using haemodialysis (Carmichael et al. 2000), in fact patients generally reported their quality of life as similar between the two treatments (see section 3.4.1 in the literature review). Furthermore, De Vecchi et al. (1994), who included patients who had used both types of dialysis, reported that patients favoured their current treatment, while Tweed

and Ceaser (2005) similarly reported that unsurprisingly patients defended their choice of renal replacement therapy and considered that they made the “right” choice.

8.2.2 Does peritoneal dialysis liberate or constrain?

Participants in this study attempted to maintain their usual lives while living with a debilitating disease and when diagnosed they thus sought a treatment that would promote this. Peritoneal dialysis appeared to offer this by enabling participants to remain at home and offered some degree of control over treatment, but was accompanied by dialysis training and equipment within the home, and the burden of responsibility and work shifting to the patient and their wider family. This section will now consider how patients managed their treatments, while considering whether peritoneal dialysis liberates or constrains patients.

Visibility within the home: institutionalisation and stigma

Corbin and Strauss (1988) referred to the home environment as the setting for the “work” of managing chronic illness. They highlighted that the home is organised to meet the domestic needs of the individual or family, but this changes when chronic illness is introduced. Participants in this study were keen to use dialysis within their homes, to liberate them from the confines of the hospital, yet their houses changed dramatically as a consequence and became more public spaces with regular visits from healthcare professionals.

While several primary research studies reference the negative effect of using peritoneal dialysis on the home environment, it is often mentioned briefly and with little explanation of how the treatment changes the home space or what this means to people using the technology. Clinical guidelines focussing on peritoneal dialysis report that patients should be aware that a “small room or shed will be needed to store deliveries of dialysis fluid” (National Institute for Health and Clinical Excellence 2011, p.5), but this appears to underestimate the impact. Morton et al. (2010) reported that patients were concerned about the modifications required to the home, particularly in terms of storing equipment. However, they provided little detail about how participants stored this equipment and what this meant to them, other than it being “negative”. A later study by Morton et al. (2011) similarly cited home modifications as a concern to participants but interestingly, while home modification was rated as a concern by patients, it was not by relatives. However, in contrast, the current study’s findings were that relatives were equally, or in some cases more,

concerned about the changes to the home environment. Similarly, in Fex et al.'s (2011) study relatives felt their homes had been "invaded" (p.340) by technology. Lee et al. (2008) further highlighted the negative impact of peritoneal dialysis on the home environment, labelling it unattractive and space-consuming. However, they did not describe how the equipment looked, where it was stored and how it aligned with daily life. One strength of the current study is the ethnographic observations that highlighted this information, described in the fieldnote prose and diagrams in chapter six, along with participants' feelings about this transformation of the home. These findings enable a better understanding of the realities of living with peritoneal dialysis and the impact of the treatment on the wider family.

Therefore, while peritoneal dialysis enabled freedom from the hospital, the result was the home taking on the appearance of a clinical space. One study from the home medical technology literature used both interviews and observations to explore participants' use of treatments (Lehoux 2004), using separate patient samples for each method. However, her observations concentrated on how patients were educated and supported with these treatments, and thus the focus differed from that of the current study. Despite the two sources of data, her study offered little insight about the impact on the home environment, other than a statement that participants' bedrooms looked like a hospital and dialysis waste fluid was emptied into the toilet (Lehoux 2004). This current study emphasised that there was variation between participants about where they stored dialysis equipment and whether they attempted to hide it. Furthermore, Fex et al. (2009) interviewed patients using home medical technologies, including three patients using peritoneal dialysis. Although the number of participants was small, Fex et al. (2009) highlighted that space was required for storing peritoneal dialysis equipment, the requirement for some to convert one room for storage and that for some participants their homes looked like hospitals. There were thus similarities to the findings of this current study. Charmaz (1991) commented on the economics of chronic illness and emphasised that some individuals may not be able to afford the cost of converting their home to accommodate management of the disease, nor the loss of space.

Fex et al. (2009) stated that the majority of participants tried to conceal equipment, but disappointingly they gave no detail about how this was achieved. The current study emphasised that some participants tried to limit the impact of peritoneal dialysis on the home by hiding equipment within domestic furniture or demarcating a non-public area of the home for treatment. They thus attempted to minimise the

institutionalisation of the home. Goffman (1963) suggested that the visibility of illness is associated with stigma, and individuals therefore attempt to minimise its visibility to present themselves as “normal”. Therefore, some participants in the current study may have attempted to reduce the stigma of living with peritoneal dialysis by attempting to hide it within their homes, although this was not so for all participants, some of whom lived comfortably with medical equipment mixed with domestic life.

Therefore, while several primary studies make reference to the negative effect on the home environment, they provide little insight into the realities of this and how the space becomes compromised by peritoneal dialysis. This study described through both text and diagrams the negotiation between either keeping the communal areas of the home dialysis-free with the risk that the patient becomes isolated, or maintaining social contact with the result that more rooms in the home are influenced by the treatment. Crucially, the significant amount of storage space required for peritoneal dialysis equipment has serious implications for whether patients can realistically consider the treatment and the perceived liberation and independence that it may afford.

The “work” of peritoneal dialysis

Corbin and Strauss (1988) categorised the management of a chronic condition as “work”, which they asserted affected all areas of the individual’s and their families’ lives. Different types of “work” are required to manage chronic illness: regime, crisis prevention and management, symptom management and diagnosing problems (Corbin and Strauss 1985). These different types of work were identified when considering how individuals using peritoneal dialysis in this study managed the treatment, highlighting the responsibility that they assumed in doing so. Charmaz (1991) described how individuals attempt to keep chronic illness from affecting everyday life, with an acute episode reminding the individual of the illness. However, this is not possible with peritoneal dialysis, which involves substantial, daily work to live with and manage. Participants chose peritoneal dialysis to afford them control over the treatment and the hope of independence, yet they were required to manage the treatment every day without fail.

The sociological literature has considered how individuals and their families manage chronic illness, the work and complexities of this, and the subsequent impact on the individual and wider family. This thesis has described the self-management involved with end-stage renal disease, such as titrating medications, diet and fluid, as well as

the more specific management of peritoneal dialysis, including the regime, aseptic technique and monitoring for peritonitis. Corbin and Strauss (1985) described that medical advances have led to complex and specialised management regimes, which remains particularly true for peritoneal dialysis. However, much of the literature considering self-management of chronic illness focused on the management of symptoms and Charmaz (1991) commented that they affected peoples' daily activities. For patients using peritoneal dialysis, it is not only the symptoms of end-stage renal disease that may affect their daily functioning and routine, but the management of a challenging and restrictive treatment. Intrusive illnesses can make people perceive that they lack control, and therefore good self-management can increase their control and enable the illness to fade into the background (Charmaz 1991). However, this was not identified with peritoneal dialysis. While people self-managed and thus were able to stay at home, the requirements of managing the treatment meant that it remained in the forefront of everyday life, dominating the home environment, with on-going anxiety about the potential for complications to develop. Charmaz (1991) did however recognise that for some people their lives have to be structured around their illnesses, which is a more accurate reflection of life with peritoneal dialysis.

This study highlighted the multiple aspects of peritoneal dialysis that patients, and/or relatives, are required to manage when using the treatment at home. Little attention is given in the literature to explicating the many tasks that constitute self-management for peritoneal dialysis, although the importance of self-management is discussed. Curtin et al. (2004) highlighted that participants were actively engaged with managing peritoneal dialysis, but the treatment heavily influenced their daily routine. Many participants in the current study felt restrictions of peritoneal dialysis on their daily activities and time, which has been found elsewhere in the literature. Lindqvist et al. (2000) reported that participants using dialysis experienced a lack of freedom and felt controlled by the treatments, while Clarkson and Robinson (2010) described restrictions on multiple areas of patients' lives. Participants reported restrictions of peritoneal dialysis on their everyday lives, in terms of time and activities. Charmaz (1991) suggested that the restrictions of chronic illness on the individual vary according to their age, with older people having less time pressures than younger people and therefore not suffering to the same extent. The participants in this study were older and only one patient worked, however, their responsibilities were on-going, such as caring for grandchildren or their partner. Additionally, several of the relatives who took part in the study continued to work and were responsible for

assisting the patient to manage peritoneal dialysis. Therefore age may not be an appropriate argument when considering the restrictions felt by families when managing this intense treatment.

McCarthy et al. (2010) further discussed the strict compliance of patients using peritoneal dialysis, where their participants routinely attended the nephrology clinic, followed dietary advice and made efforts to prevent infections. The current study reinforces previous research findings that patient or relatives actively assumed responsibility for peritoneal dialysis and the associated tasks. In terms of managing other chronic illnesses, Charmaz (1991) suggested that some people are able to manage their days around their illnesses, for example if they know they are unwell during the afternoon they would perform more demanding tasks in the morning. Patients using CAPD are not necessarily able to do this, as they are required to perform exchanges throughout the day, regardless of their symptoms. Participants reported choosing peritoneal dialysis to offer them independence, but this led to them managing a complex treatment and learning to live with the challenges this brought. Nettleton (1995) asserted that over time patients develop expertise, knowledge and experience to manage chronic illness and this was identified in this current study too. Managing the work of chronic illnesses has been recognised as being difficult and laborious (Nettleton 1995), particularly if, like the majority of participants in this study, people are managing more than one chronic illness (Corbin and Strauss 1985, Corbin and Strauss 1988).

Consequences of peritoneal dialysis

Bury (1991) stated that “the ‘meaning’ of illness lies in its *consequences* for the individual” (p.453, author’s emphasis). The earlier literature review reported that peritoneal dialysis was associated with reduced quality of life, both physically and mentally, for the individual (see section 3.4.1) and their relatives (section 3.4.2). This section has highlighted the consequences of peritoneal dialysis in terms of the home and daily routine, and here two further impacts are discussed: exhaustion and dependence on relatives.

Exhaustion The phenomenon of tiredness/fatigue has been described in the renal literature for patients and, to a lesser extent, relatives. Yngman-Uhlin and Edell-Gustafsson (2006) identified that 88% of patients using peritoneal dialysis in their study were fatigued, and later described that both physical and mental tiredness were experienced by participants and progressed over time (Yngman-Uhlin et al.

2010), reducing their motivation to socialise and continue with everyday household tasks. This finding has also been reported by Heiwe et al. (2003) in their study of patients with chronic and end-stage renal disease. The finding of this study that fatigue constrained patients' abilities to function during the day thus supports the earlier literature. Participants chose APD to offer them increased freedom from the restraints of four CAPD exchanges per day, but it also trapped them to a bed for nine hours and led to exhaustion. However, while the majority of participants who experienced exhaustion in the current study used APD (due to the machine alarming), some participants using CAPD also felt tired. Bilgic et al. (2008) reported that 31.7% of patients using peritoneal dialysis in their study reported poor sleep, which negatively affected their quality of life. Problems with sleep, resulting in tiredness, have thus been reported in other groups of patients using peritoneal dialysis, but another study highlighted that patients using haemodialysis suffered with worse sleep (Carmichael et al. 2000). Therefore, disturbed sleep appears to be a problem in the wider renal population.

None of the studies described above recognise the exhaustion experienced by relatives, particularly if the APD machine is responsible for the patient's fatigue. Luk (2002) and White and Grenyer (1999) present relatives' experiences of caring for patients using dialysis and described their fatigue, which they attributed to caring responsibilities, rather than nocturnal alarms. However, this was a significant finding of the current study, with relatives reporting tiredness after being disturbed by APD alarms and patients expressing regret that the home medical technology negatively affected their relatives.

Dependence The sociological literature provides insight into the impact of chronic illness on the wider family. Bury (1991) highlighted that chronic illness disrupts family life and work distribution, with members of the family, including children, being required to take on additional roles and this phenomenon was identified in this study. Charmaz (1991) referred to this as a "spiralling effect" (p.56) of chronic illness, which ultimately affects relationships within the family.

Families were inextricably involved in supporting and caring for their relatives using peritoneal dialysis in this study, with partners in particular working in unison to manage the treatment. Interestingly, participants in this study reported choosing peritoneal dialysis to allow them freedom from the hospital and control over their treatment, yet the chosen treatment mode made them increasingly dependent on

relatives. Corbin and Strauss (1985) suggested that the partner takes responsibility for the treatment of chronic illness unless the patient lives alone, but this varied in the current study according to the patient's ability. Previous studies from the renal literature have similarly demonstrated that family members play a central role in helping to manage dialysis (Beanlands et al. 2005, Ekelund and Andersson 2007, Leung and Shiu 2007, Tong et al. 2009) and home medical treatments (Fex et al. 2009, Fex et al. 2011). Beanlands et al. (2005) documented that caregiving was complex, involving observation, decision making, knowledge and skill. Patients in this current study reported that their relatives offered practical (both dialysis and non-dialysis) and emotional support to the person using dialysis, which others have similarly identified in the home medical technologies and chronic illness literatures (Fex et al. 2009, Nettleton 1995). Overall, Fex et al. (2011) reported that family members were positive about home medical technology and accepted both it and the restrictions it had on life, as they were grateful that their relative was able to remain at home. However, a majority of patients in Fex et al.'s (2011) study were self-caring with their treatments, which was not always the case in this current study. Relatives in the current study were supportive of the patient and their choice for peritoneal dialysis at home, but they also reported a number of restrictions that the treatment placed on their lives.

While individuals using dialysis in White and Grenyer's (1999) study reported bitterly their increasing dependence on relatives, Hardiker et al. (1986) identified that patients using dialysis were grateful for the support from their families, which is similar to the current study's findings. In terms of patients' feelings about being supported by relatives to manage peritoneal dialysis, patients were incredibly grateful for the support they received from relatives and recognised that not all people using dialysis would have the same level of support available to them.

The renal, home medical treatments and chronic illness literatures have thus previously highlighted the "work" involved with managing illness. The importance of self-management has been explored at length in the chronic illness literature and this study therefore builds on this knowledge, with specific focus on peritoneal dialysis. The chronic illness literature discusses the work involved when managing crises and this study raised the significance of peritonitis to the individual and their family, particularly in terms of fear, guilt and confusion. Supporting the published literature, families in this study were also involved in the work of managing peritoneal dialysis, often assuming part or total responsibility for treatment.

8.2.3 Cruel uncertainty

Uncertainty is discussed at length in the literature in relation to chronic illness and end-stage renal disease. Corbin and Strauss (1985) and Bury (1982) highlighted the uncertainty surrounding the future for people with chronic diseases, which makes it difficult to plan ahead. Furthermore, Kelly and Field (1996) argued that the ability for individuals to plan for the future is compromised as the individual's control over their body and its abilities is diminished. Participants in this current study discussed their uncertainty at times of physical crisis and in terms of deterioration in the near future.

Crisis management

Corbin (2003) discussed the emotional suffering that accompanies chronic illness and the physical stresses on the body that result from the insult to the person's sense of self. This was particularly true for participants in this study at times of crisis. A crucial finding of this current study was the significance placed on contracting peritonitis and the threat associated with this. Participants who had contracted the infection explained the pain and uncertainty this caused and the guilt they felt for having allowed the infection to happen, that sometimes manifested itself in a justification why they were not to blame. No other studies were identified in the renal literature that qualitatively explored this phenomenon and what it means for individuals, despite it being extremely important to the participants in the current study. Episodes of peritonitis also revealed that individuals were unfamiliar with the symptoms of the complication. While participants in this study described the peritoneal dialysis procedure they were taught, which included observing signs of complications, in practice not all participants knew the signs they needed to report. Peritonitis is the major reason that patients require a transfer to haemodialysis and contributes to the death of 16% of patients using peritoneal dialysis (Li et al. 2010), and additional education about the signs and symptoms of peritonitis is thus vital, which Piraino et al. (2011) also recommended along with retraining of peritoneal dialysis technique periodically.

The sociological literature considering crises when managing chronic illness provides a helpful insight into the impact these have on patients and their families. Charmaz (1991) suggested that treatment allows chronic illness to be in the background of peoples' lives, but iatrogenic artefacts (those arising from treatment) brings the illness back to the forefront. While peritoneal dialysis is always prominent in people's lives, and they strive to prevent crises, when complications do occur this leads to

fear, uncertainty and concern. People with chronic illness have to achieve a delicate balance between illness and wellness that is destroyed when an acute episode of illness occurs (Charmaz 1991), leading to reduced self-worth, strength and control. The person's physical health deteriorates, but so does their "ill-self" (Charmaz 1991, p.45) that manages the illness. Participants in this study were therefore confused when episodes of acute illness occurred, as they tried hard to prevent such crises and they thus questioned their knowledge of their condition and treatment.

Times of crisis require additional resources to maintain control, leading to increased work for the person, their family and also healthcare professionals (Corbin and Strauss 1985, 1988). Participants in the current study felt well supported by the comprehensive care they received from the multidisciplinary team, in particular the nursing staff. In times of need patients and their relatives felt able to ask for additional support from the specialist nurses and were encouraged to do so by the nephrology team. This current study therefore supports Fex et al.'s (2011) finding that relatives learned when to involve the healthcare team in helping to manage medical technologies at home, and felt secure in the knowledge that they could telephone for additional support. In comparison to previous studies in the renal literature (Carmichael et al. 2000, Curtin et al. 2004, Griva et al. 2010, Niu and Li 2005, Yang et al. 2007), patients in this study did not feel that they required additional support from healthcare professionals.

This study and others have identified that patients using home medical treatments or living with chronic illness at home therefore attempt to prevent these crises by monitoring themselves. Fex et al. (2009) reported that participants using home medical technology (including peritoneal dialysis) followed measures to prevent infection or other complications, seen through following hygiene principles, and became aware of how to identify a problem. This current study described the ongoing daily measures undertaken by patients to both prevent and identify complications. Curtin and Mapes (2001) similarly highlighted that patients carefully monitored themselves for signs of a problem and were aware of when they required support from healthcare professionals. The sociological literature considering chronic illness also showed that patients with intrusive chronic illness become skilled at listening to their bodies and knowing when there is a complication (Charmaz 1991), enabling them to prevent the "downward spiral" (Corbin and Strauss 1985, p.239). Relatives can also be involved in appraising their relative's physical condition (Beanlands et al. 2005), which was earlier identified by Charmaz (1991) too. This

current study similarly found that relatives surveyed the patient to monitor for signs of a complication, which is particularly important as patients may be unable to identify complications themselves if they are acutely unwell.

Physical deterioration

Charmaz (1991) asserted that while people may accept chronic illness in the short-term, they may not accept it for the long term. Participants in this current study described their uncertainty about the future in terms of deterioration and death. This was identified in this study as a small number of patients were beginning to deteriorate and were not eligible for other renal replacement therapies, and their families found it extremely difficult to plan ahead.

The section above demonstrated that patients and their relatives fought hard during periods of crisis to maintain their physical function and protect their selves, monitoring for possible deterioration. It is these episodes that begin to prepare patients and their families for the end of the trajectory (Corbin and Strauss 1988), and participants in this study recognised this. Pelletier-Hibbert and Sohi (2001) identified that relatives of patients using dialysis found the uncertainty of end-stage renal disease extremely stressful, in particular the potential loss of their loved-one and the volatile nature of the disease. This was also found by Beanlands et al. (2005) who reported that relatives in their study found caregiving particularly challenging emotionally when the patient's health was deteriorating. The findings of this current study highlighted similar findings to Pelletier-Hibbert and Sohi (2001): relatives' uncertainty surrounding death and their lack of control and uncertainty about this.

Lindqvist et al. (2000) reported that participants with end-stage renal disease considered the future to be uncertain, while Martin-McDonald (2003/4) described patients' "overwhelming" (p.155) uncertainty. Conversely, Curtin et al. (2002) spoke of long-term dialysis patients' desire to continue living, seen through their commitment to the technology at each treatment. They also found that participants using long-term dialysis were aware of their uncertain futures (Curtin et al. 2002), but had come to terms with it and instead tried to stay positive. Overall, Curtin et al. (2002) highlighted that this uncertainty about the future was associated with a loss of control and therefore participants instead focus on the present, which perhaps came from their years of experience of the treatment. This finding was identified in the

current study too, with most participants discussing in detail their lives with peritoneal dialysis, with less focus on considering the uncertain future.

8.2.4 Freedom from peritoneal dialysis

Participants chose peritoneal dialysis in the hope that it would afford them the ability to stay at home and have control over their treatment. The reality of peritoneal dialysis was the home environment being dramatically changed, being required to manage a complex treatment and daily uncertainty about the risk of complications and future deterioration. Peritoneal dialysis thus liberated people from undertaking treatment in a hospital and crucially prolonged life, yet it also constrained and dominated each day. In response to this, participants sought freedom from the treatment. This was achieved through attempting to be creative to regain control over treatment and life, and through hope of escaping dialysis by having a kidney transplant.

Confidence to be creative and take control

Despite the impact of peritoneal dialysis on participants' everyday lives, the majority of people in this study were adept at integrating the treatment into their lives and retaining control by being flexible and creative. Many participants thus enacted "social logic" (Herzlich and Pierret 1987, p.212) where they integrated their treatment with other aspects of life, rather than "medical logic" which would involve rigidly adhering to a regime for the best physiological outcome. Participants were supported in this process by healthcare professionals who reassured them that they could take control of their treatment by either completing exchanges away from home (often using innovations to enable this) or slightly altering the time between CAPD exchanges. Fex et al. (2009) similarly reported that healthcare professionals supported patients to adjust home treatments within reason, while Polaschek (2007) conversely reported that participants hid modifications to their regimes.

Bury (1991) described that individuals may be initially uncertain about trying to manage chronic illness while minimising its effects, with participants in the current study reporting their initial hesitation about trying to manipulate their dialysis regimes to better align with everyday life. Keeping and English (2001) asserted that informal learning about peritoneal dialysis enabled patients to alter their treatment over time, while other researchers asserted that participants developed confidence to alter their treatment to reduce the restriction of dialysis on their lives, by making the treatment

fit with different activities or commitments (Curtin et al. 2004, Polaschek 2006, Polaschek 2007).

Charmaz (1991) suggested that feeling in control of the day can help people with chronic illnesses to feel that they are winning in their battle with the condition. Some participants in the current study achieved this by altering the times of their CAPD and APD exchanges according to their daily plans, which was similarly found by Fex et al. (2009) who interviewed patients using home medical technologies. Unfortunately the authors did not distinguish between the treatments (oxygen therapy, parenteral nutrition and dialysis), but they described in general how participants changed the timing of treatment to enable them to take part in other activities. Polaschek (2006) reported that participants using CAPD omitted an exchange to allow them to meet other commitments, which was not found in this study with any of the sixteen participants. In response to intrusive chronic illness people may also try to minimise the impact that it has on their lives through the use of “innovations” (Charmaz 1991, p.75), which was also identified in the current study. Researchers have reported that participants found ways to make the equipment associated with home medical treatments easier to carry or transport (Fex et al. 2009) and were able to perform peritoneal dialysis exchanges while away from home (Fex et al. 2011). Although Fex et al. (2011) provide no detail of how participants in their study achieved this, the findings of this thesis mirror those of Fex et al. in terms of the creative use of equipment to retain control. Like participants in Fex et al.’s (2009) study, the participants in this thesis used adjustments to increase their freedom from the technology, although all modifications required advance planning. Therefore, findings from the current study reinforce several of Fex et al.’s (2009) findings, however, this thesis again provides a more detailed insight into the changes patients make to the timing of exchanges and the variety of locations where participants were confident to undertake exchanges, including public spaces and even in the car. The ethnographic observations in this study supported the interview data and demonstrated how these adjustments and ingenuities were used in practice by participants.

The renal literature highlights that patients may feel confined by peritoneal dialysis and dependent upon it (Gudex 1995), negatively affecting their quality of life. This was identified with a minority of participants who did not attempt to regain control over their treatment, and subsequently they reported restrictions on their freedom from the treatment. Bury (1991) discussed the effort that is required from patients to

try and maintain normal activities and how it may not always seem worthwhile for patients. Several participants in this study had multiple co-morbidities, and therefore they reported that while it may have been possible to take a holiday while using peritoneal dialysis, taking other equipment (such as a wheelchair) seemed too much effort. Furthermore, patients may not have the resources to adapt the home or buy equipment (Bury 1991), and it is important to recognise that purchasing equipment such as carry cases to make life easier could be impossible for some patients.

The ability of participants to integrate the treatment into everyday life through flexibility and creativity was a significant finding of this study, which appears to resonate with the wider literature. Participants' confidence to alter their dialysis routine enabled them to continue with other activities in life and led to feelings of control over treatment. However, the ethnographic nature of this study has led to additional understanding of how patients and their families are flexible, or not, with their treatment and the impact of this on their lives. The fieldnotes reveal the equipment designed and used by participants, who described in detail how they were flexible with the treatment. These findings highlight the importance of patients feeling able to discuss adapting treatment with healthcare professionals and receiving encouraging, practical and safe advice in return.

Waiting for the Holy Grail

Charmaz (1991) highlighted that in response to chronic illness, people must discard their previous hopes and plans. However, in this study kidney transplantation offered participants the hope that life may return to "normal". The literature considering medical sociology is less helpful here, conceptualising transplantation as leading to uncertainty about the essence of the body and enabling it to become shared (Williams et al. 1998). This contrasts with the health literature that focuses on patients' experiences of transplantation and the meaning of it to them, which is supported by the findings of this study. Ultimately, patients hoped that a kidney transplant would lead to improved quality of life, which has been reported internationally in the renal literature (Bremer et al. 1989, Churchill et al. 1987, Evans et al. 1985, Gudex 1995, Muthny and Koch 1991, Niu and Li 2005, Simmons and Abress 1990). The emphasis placed on kidney transplantation by patients and relatives has been seen in the transplantation literature, and the wait is associated with both hope and trepidation.

Lindqvist et al. (2000) described their participants' hope for a kidney transplant as a way to have a "normal" life, despite some anxiety about the process. The majority of participants in the current study focussed on kidney transplantation as a positive outcome and considered what they would be able to do once they no longer used dialysis, with only one participant considering that the process may not be transformational to his life and would involve a strict medication regime. Wright and Kirby (1999) considered that their participants' hope for a kidney transplant was a form of coping, enabling them to remain optimistic for the future. Martin-McDonald (2003) discussed that a kidney transplant was seen by her participants as the "ultimate goal" (p.32), while Ekelund and Andersson (2010) also reported a kidney transplant as a "goal". Transplantation is reported in similar terms by patients waiting for a liver transplant (Wainright 2007, Watanabe and Inoue 2010, Forsberg et al. 2000).

This study identified that some participants were frustrated about when a kidney transplant would be available, after several years using dialysis and waiting. Previous research has considered the stress associated with the kidney transplantation process, particularly in terms of decision-making, concerns about the procedure and ongoing fear of transplant failure (Gill 2012). Furthermore, Pelletier-Hibbert and Sohi (2001) reported that the availability of a kidney transplant caused feelings of uncertainty for relatives of patients using dialysis, including whether one would be available, when and what the outcome would be. Again, the literature considering transplantation in other specialities highlights the uncertainty associated with the process, in terms of the liver transplantation process (Forsberg et al. 2000) and acquiescing control to healthcare professionals (Bjork and Naden 2008). It is important to recognise however that transplantation can be perceived in different terms according to the organ. Liver transplantation is seen as the only chance at life, but the operation also emphasises to patients that they are deteriorating (Wainright 2007, Forsberg et al. 2000). Similarly, patients approaching the final stages of heart failure pre-transplantation recognised the possibility of not surviving the operation (Sadala and Stolf 2008, Ivarsson et al. 2011). This was not identified in this study: commencing dialysis indicated physical deterioration, while transplantation was perceived as a way of improving everyday life.

Furthermore, patients have reported profound loss associated with kidney transplant failure (Gill and Lowes 2009). None of the patients in this study had received a kidney transplant. However one significant finding of the current study was the

experience of two participants who had received a telephone call informing them that a kidney transplant was available to them, before the operations were subsequently cancelled. This experience was associated with significant loss and uncertainty, making participants more confused about the transplantation process. This experience was made worse for one participant due to the lack of communication from healthcare professionals, he reported, along with being discharged in the night with little care from staff. This highlights the uncertainty surrounding the transplantation process, which is significant as patients and their families place considerable emphasis and importance on kidney transplantation. Sloan and Gittings (1999) interviewed patients using dialysis who had been called for a kidney transplant and were then told that the organ had gone to another patient in the USA. They identified that patients were not aware that other patients may be called for the same organ and were bitter and angry when they realised, but these feelings were mitigated by the knowledge that another person would have benefitted (Sloan and Gittings 1999). The patients in this study did not lose the opportunity of a transplant to another patient and were therefore not able to report similar feelings. No other studies were identified that describe patients' feelings of loss and uncertainty about having a transplant operation cancelled and the trauma that this causes the individual, and their family.

Therefore, participants sought ways to make their lives easier with peritoneal dialysis, through integrating the treatment into everyday life and sustaining hope for a kidney transplant. Unfortunately, the uncertainty associated with early management of peritoneal dialysis and around kidney transplantation meant that these too were at times associated with uncertainty.

Summary

This discussion has thus demonstrated where the findings presented in this thesis have resonated with the renal, home medical technologies and chronic illness literatures, suggesting the transferability of these findings to other populations. However, the original findings of this research have also been illuminated, some of which can be in part explained by the use of methodology employed. The research itself is therefore considered next.

8.3 Critique of the research

Wolcott's (1994) framework for the analysis of ethnographic data considers the importance of evaluating the research process, which is particularly pertinent as I

was a novice researcher. This section thus discusses the perceived strengths of the research, including the willingness of patients to participate, usefulness of ethnographic methodology and the nurse as researcher. The limitations of the research are then considered, including concerns about the sample, use of the data collected by healthcare professionals and for some participants that the data were generated during a single visit.

Patients were clearly keen to participate in the research, as seen by their immediate response to my recruitment letter. This patient group wanted their experiences known and shared. Unfortunately, I was unable to include all the patients who wanted to take part, due to time restrictions and reaching data saturation. Corbin and Strauss (1988) similarly discussed the “desire” (p.11) of patients to share experiences of chronic illness, citing it as the genesis of their later, seminal work.

8.3.1 The usefulness of ethnography

The literature search demonstrated that no previous studies with patients using peritoneal dialysis were identified that utilised ethnography, while the methods chapter explained my reasons for employing this methodology. I considered that including patients and their families, while interviewing and observing them using the technology at home, could provide an in-depth insight into how peritoneal dialysis is lived with in the home. The value of using interview and observation methods concurrently, the strengths of observing patients using peritoneal dialysis and the usefulness of ethnography to explore how patients and families live with home medical technology, will therefore be discussed.

Combining methods

Almost without exception the published research considering patients’ and families’ experiences of peritoneal dialysis elicited participants’ perspectives by using semi or loosely-structured interviews. However, section five of the methods chapter demonstrated that I decided to employ both loosely-structured interviews and observation of patients and families using and living with peritoneal dialysis in their homes. Overall, I found that interviews and observations worked well together, as asserted by Hammersley and Atkinson (1995), and I consider that both the participants and I would have felt less comfortable with the ethnographic observations had we not undertaken the interviews first, to build a rapport before observing a personal procedure.

The data generated by the ethnographic observations were invaluable and clarified points discussed in the interview. For example, while multiple participants had commented on the difficulty they have in manoeuvring the dialysis solution boxes during the interviews, it was not until an observation when I attempted (and failed) to lift a box weighing eight kilograms that I realised how difficult this really is for patients and their families. Again, this reinforces the powerful contribution that ethnographic observation makes to understanding issues described in interviews by participants.

Ethnographic observations

The literature considering peritoneal dialysis in the home has previously described that peritoneal dialysis takes up space (Lee et al. 2008), is aesthetically unpleasing (Fex et al. 2009) and the home environment becomes hospital-like (Lehoux 2004). However, these descriptions offer little clarity about the reality of peritoneal dialysis equipment within the home environment. While asking patients and relatives about the impact of peritoneal dialysis on the home generated useful description, triangulating this with observation data provided a valuable insight into how people actually live with home medical treatment. Observing the home environment and documenting it through annotated diagrams provided insight into how peritoneal dialysis impacted upon the home environment, how this varied significantly between individuals and how the treatment was incorporated into the home environment.

Furthermore, researchers have reported that patients become expert at self-managing their treatment (Curtin et al. 2004, Fex et al. 2009) and Lehoux (2004) reported that patients were proficient at managing different aspects of home medical treatments with other aspects of life. However, observing patients and relatives undertaking peritoneal dialysis in the current study indicated the extent of participants' knowledge, skills and competence. Furthermore, while participants in the study described their inventions for integrating peritoneal dialysis and this has been reported elsewhere (Fex et al. 2009), observing the equipment designed by participants and how they used this while undertaking peritoneal dialysis exchanges reinforced the interview descriptions. Additionally, drawing the equipment made it easier to understand how it is used and could facilitate understanding for individuals not familiar with peritoneal dialysis.

Therefore, ethnographic observations provided rich data, reiterating information gleaned from the interviews and demonstrating a wealth of data not observed elsewhere in this study or in the published renal literature. Thus overall, observation

was a powerful method that demonstrated the skills of patients and reflexively reinforced to me the multitude of tasks undertaken by patients and relatives.

Ethnography and home medical treatments

The literature review revealed no previous studies that used ethnographic methodology to explore the experiences of patients and families living with peritoneal dialysis. Although an Australian study by Burnette and Kickett (2009) reported their methodology as ethnographic, they undertook interviews only with Aboriginal patients using haemodialysis and peritoneal dialysis, and the lack of ethnographic observation is disappointing. While Lehoux (2004) adopted a symbolic interactionist approach incorporating interviews with three patients using peritoneal dialysis, she observed nurse visits to patients using home medical technology and reported few insights from their fieldnotes. Additionally, an Australian ethnographic study used observation with spouses of patients receiving home haemodialysis (Blogg and Hyde 2008), but they reported no data from their fieldnotes in the published article. There are thus limited previous studies that utilised ethnography with this population, including observation that typifies this methodology.

There is also limited evidence of the utilisation of ethnography for exploring the experiences of patients and families undertaking medical treatments in the home. Several studies have adopted ethnographic approaches to examine the use of home-based intravenous medications by nurses in Australia (Gardner et al. 2003), older peoples' use of assistive personal care devices in the home in Sweden (Lilja et al. 2003) and the use of a therapeutic activity kit for patients with Alzheimer's disease and their families in Florida (Hutchinson and Marshall 2000). However, there is little examination by these authors of the effectiveness of ethnographic methodology. This is also true for Burnette and Kickett's (2009) and Blogg and Hyde's (2008) studies, while Lehoux's (2004) study (while not labelled as ethnographic but appearing to use such methodology) also lacks discussion of the usefulness of the methodology.

This section has discussed the contribution that the observation data made to the overall findings of the study, particularly in terms of how peritoneal dialysis aligns with the home environment, how the treatment procedure is actually undertaken by patients and relatives, and how it is integrated into everyday life through creativity. There are thus important methodological implications of this study in terms of the

usefulness of ethnographic methodology to explore how patients and families live with home medical treatments. Allen (2012) highlights that the home setting is now the preferred place of care, with increasing responsibility being passed to relatives, and also to patients. The study has demonstrated that not only is the methodology and subsequent methods effective to meet the aims of the study, but they are also acceptable to patients and families living with home medical treatments, who were positive about demonstrating their treatment and creativity. This is an important consideration in light of Allen's (2012) assertion. However, one limitation of using ethnography in these settings is the inability to observe patients over the 24 hour period. Ethnographic studies in settings such as hospitals can include fieldwork during the night, but this was deemed inappropriate in this study to respect participants' privacy. Therefore, there needs to be negotiation between generating rich holistic data and being unobtrusive when collecting data in the home setting.

8.3.2 Nurse as researcher

Davies (1999) has previously highlighted that all researchers will impact on their data and I thus aimed to be reflexive throughout the study. I considered that while my prior knowledge of the field gave me ideas about peritoneal dialysis, I tried to ensure that participants provided their perspectives without me leading them. I endeavoured to do this through the use of open-ended questions, rather than leading questions. However, I was aware of my professional status as a nurse with regard to the use of terminology by participants and their expectations of me, especially when I was required to report concerns back to the clinical team.

Working within nephrology as a staff nurse, and conducting a detailed exploration of the literature, provided me with adequate prior knowledge about the research topic and I thus recognised that I had prior ideas about what participants might tell me. I found my prior knowledge extremely useful as participants would often talk using jargon and I did not need to ask participants to explain terminology to me, which allowed the interview to run more smoothly. I was also able to recognise if patients used terminology inappropriately, as they did at times. Terminology was used by participants throughout the interviews, as the objects or concepts they described had become regular, daily realities for them. Interestingly, one participant commented "they have put me on an extraneal, um I use all these technical terms because you understand them don't you". Therefore I consider my prior knowledge gained as a staff nurse was useful preparation for undertaking the research and allowed me to achieve an insider status with participants.

I therefore anticipated that being a nurse as well as undertaking research could impact upon the data, which I tried to minimise. However, I also found that my “insider status” as a previous nephrology nurse helped the interviews run smoothly, as participants felt comfortable to use terminology during our discussions. While participants generally recognised that I was a nurse undertaking research, there were incidences when I was required to report concerns back to the clinical team. There is thus an interesting dynamic between the dual roles of nurses undertaking research in a clinical field known to them.

8.3.3 Limitations of the study and thesis

Inevitably, there are limitations of this study and indeed this thesis. The methods chapter highlighted the disproportionate sample of patients recruited, with more male participants included than an analysis of the population would indicate as appropriate and the youngest person being in their early fifties, thus failing to represent the experience of people with jobs and young families. Ethical procedures in the UK made it impossible for me to approach patients and to minimise the workload of the nurses at the participating Health Board I opted for a single recruitment letter being sent to participants. On reflection, I could have recruited a more varied sample of participants by involving the team of nurses and targeting patients in clinics, but the individuals who participated were eager for their experiences to be heard and offered rich data. Another limitation of the study that was raised in the methods chapter is the challenge I faced in recruiting relatives, hence the smaller number of relatives included in the study. The relative sample was also relatively homogenous, including only women and mostly wives. However, like previous researchers (Beanlands et al. 2005, Flaherty and O'Brien 1992, Kendall et al. 2010) I agreed that patients should have control over whether relatives were included in the research.

When designing the study I chose to include healthcare professionals because I hoped that they would offer their perceptions of how patients experience peritoneal dialysis. The healthcare professional participants provided extremely useful contextualising information, but to understand how patients and their families experience illness and home technology I found the data from these individuals more revealing. An alternative approach is suggested by Kendall et al. (2010), who asked patients to nominate a healthcare professional to interview, and perhaps this would be a more useful way of triangulating data from patients, relatives and healthcare professionals about the individual patient. However, the idea of interviewing a healthcare professional about a specific patient is not without ethical implications. An

alternative approach could have been to ask them to think and talk about a specific patient (not naming them) who they perceived to be coping well and then discuss a patient who they thought was struggling. This approach has previously been undertaken successfully in education research when asking participants to discuss a specific student who they considered to be a “good student nurse” (Lankshear 1990, p.1989). This may have encouraged healthcare professionals to consider patients’ experiences of peritoneal dialysis. Ultimately, an important finding of this thesis is the importance of asking patients and their families directly about their experiences of illness and treatments.

Data were generated over time with some participants, while others were interviewed once only. A longitudinal design could have offered additional insight into life with peritoneal dialysis across the illness trajectory (Kendall et al. 2010). However, this study design may not have been appealing to all participants, possibly reducing the response rate, and it is important to recognise that individuals using peritoneal dialysis face a demanding treatment regime and a longitudinal study may therefore seem too onerous. There was also limited time to complete fieldwork within a three-year PhD studentship. A further longitudinal study could nonetheless help to capture patients’ and relatives’ experience of peritoneal dialysis over time, perhaps in terms of their ability to adapt the treatment or experiences of acute complications. Additionally, this study could have spoken to individuals at different stages of the chronic illness trajectory, for example people who are newly diagnosed with end-stage renal disease, people using the technology and people approaching the end of life. However, it would then have been necessary to present participants’ stories in separate chapters according to the stage of their illness. It is also likely that participants at different stages of the trajectory would have reflected back or looked to future stages of the disease trajectory, and such a study would thus also have collected data from groups of individuals who discussed all three stages of the illness trajectory. I found in this study that participants in the chronic stage of the illness trajectory looked to their past and future to establish their position in the present, as Corbin and Strauss’s (1988) theory around the individual’s biography would suggest. Therefore, I would suggest that it was valuable to speak to individuals in the chronic stage of the trajectory, with varying numbers of years’ experience of peritoneal dialysis, and to hear their experiences and expectations of the past, present and future.

This discussion has thus briefly outlined some of the strengths of the methodology and methods used, but also some of the limitations of the study, often in light of ethical challenges of recruitment and balancing rich data generation with not burdening participants. The final section of this discussion will consider the theory of illness trajectories and how this was both adopted and adapted for the study.

8.4 Conceptual framework considerations

The guiding conceptual framework for this project, illness trajectories, was introduced early in the thesis. This section will now critique how this theory was applied in this thesis and ultimately adapted to reflect the study findings.

8.4.1 Classic chronic illness and end-stage renal disease trajectories

Rolland (1987) asserted that considering the three phases of illness (crisis, chronic and terminal) can assist understanding of the longitudinal nature of long-term diseases.

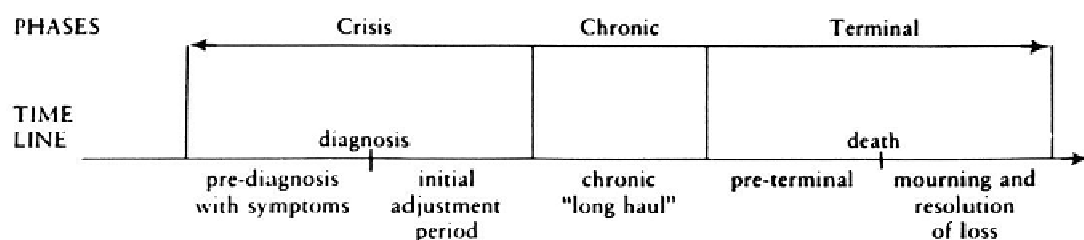


Figure 10: Time line and phases of illness (Rolland 1987, p.4)

The generic illness trajectory was adapted by Jablonski (2004) to be more specific to end-stage renal disease, adding dimensions of life (health and functioning/ psychological and spiritual/ social and economic/ family) as well as “stable” and “downward” to the chronic phase, reflecting the unstable nature of end-stage renal disease.

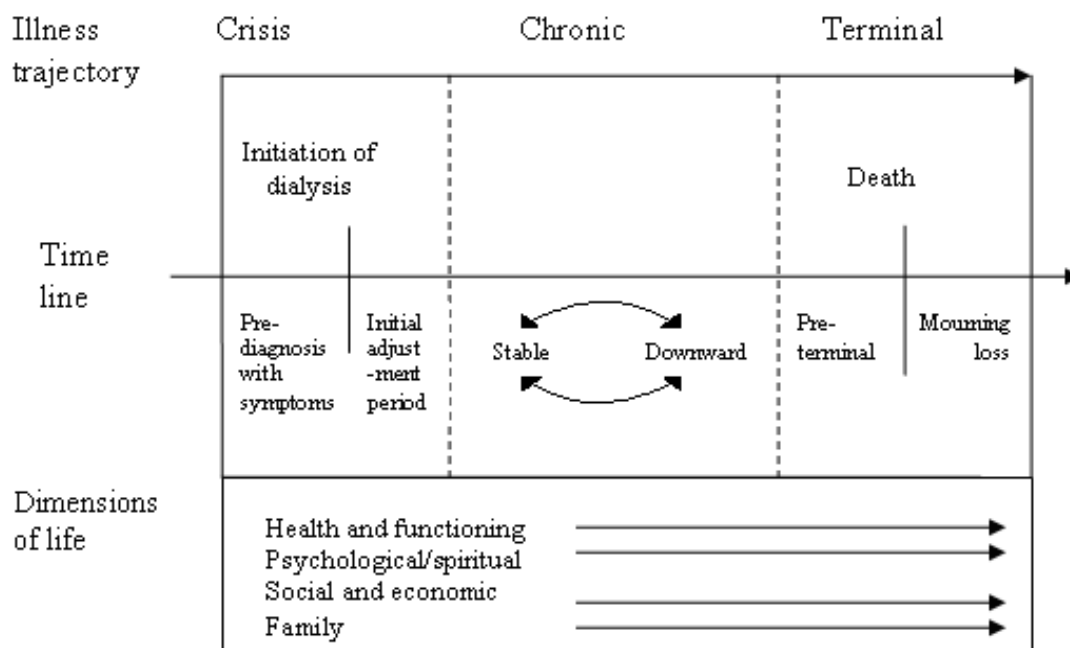


Figure 11: The ESRD illness trajectory and life dimensions (Jablonski 2004, p.54)

I asked participants in detail about the pre-dialysis phase and their lives with the treatment, while participants offered their hopes and fears about the future. Thus the conceptual framework influenced the study design and research questions, data generation and data analysis, while the findings chapters were organised according to these three phases. The following section will now consider the integration and proposed adaptation of the illness trajectory theory to this research.

8.4.2 Adapted illness trajectory for peritoneal dialysis

The illness trajectories of Rolland (1987) and Jablonski (2004) thus acted as a useful framework to provide context to the research, ensuring that as a researcher I considered the period prior to dialysis as well as participants' lives with the treatment, while allowing participants space to consider their futures. Jablonski's (2004) additions to Rolland's (1987) trajectory – stable and deterioration, and aspects of life – appear to resonate with the findings of the current project. However, to more adequately reflect the nature of living with peritoneal dialysis, several adaptations are proposed to the illness trajectory.

Journeys to dialysis

The crisis phase, where patients were diagnosed with end-stage renal disease and started on dialysis, was explored with participants in recognition of Corbin and

Strauss's (1988) argument that an individual's biography will shape their management of long-term illness. This was identified in the data when participants discussed how their reasons for choosing peritoneal dialysis and how they were taught the treatment affected their longer-term experience of the technology. This study highlighted that "journeys to dialysis" seems more appropriate than "crisis", as, although some do have to start suddenly, for many this period can take several years and incorporate an anticipated, planned start on peritoneal dialysis.

Living with peritoneal dialysis

Furthermore, patients and relatives did not see their lives with peritoneal dialysis as a "chronic" phase; it was their reality and everyday life, and this phase was thus renamed "living with peritoneal dialysis". The "stability and deterioration cycle", added by Jablonski (2004), remains as this was reflected in the data. Participants demonstrated this cycle in relation to episodes of peritonitis and fluid overload, while recovery from these complications was slow and the lasting fear they created was evident. This stable and downward cycle has been alluded to in other qualitative studies from the renal literature, for example in terms of patients feeling fatigued (Yngman-Uhlin et al. 2010) and families observing their relative using dialysis slowly deteriorating (Beanlands et al. 2005), and therefore appears appropriate to remain in the adapted model.

Looking to the future

However, the most pronounced change is the final phase: the future. The classic illness trajectories see the final phase of the illness trajectory as "terminal", but for people living with peritoneal dialysis the options for the future vary: haemodialysis, transplantation or death. Both haemodialysis and transplantation lead individuals to different stages of the illness trajectory (as depicted in the model below), not previously captured in Jablonski's (2004) nor Rolland's (1987) models, while death marks the end of the trajectory. Although people consider the future in terms of further treatment or possible deterioration, they endeavour to continue undertaking peritoneal dialysis.

The dimensions of life (health and functioning, psychological/spiritual, social/economic, family) added by Jablonski (2004) encouraged an holistic approach to data generation, while the findings suggest that the study revealed an in-depth insight into life with this treatment. Furthermore, the four dimensions of life

complemented the holistic ethnographic methodology employed, particularly in terms of the role that families play in supporting patients to live with peritoneal dialysis.

The adapted illness trajectory for peritoneal dialysis is displayed below.

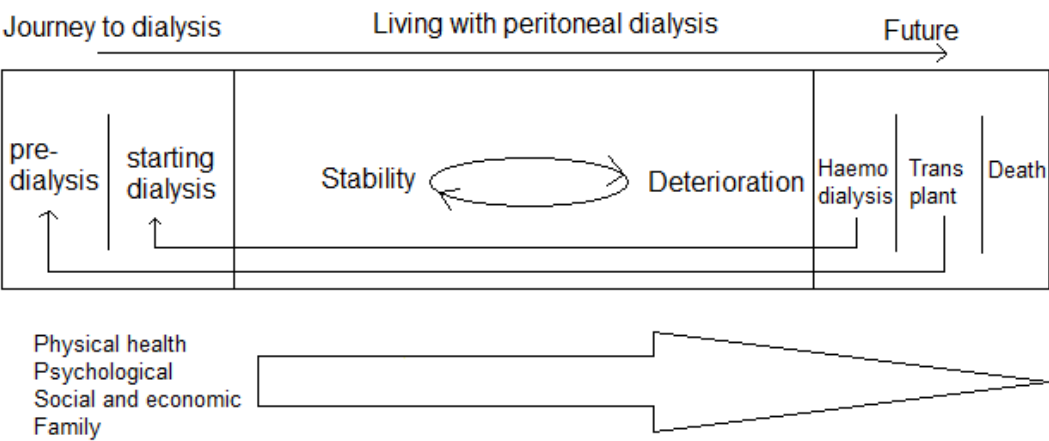


Figure 12: Adapted illness trajectory for peritoneal dialysis

While the proposed revised trajectory is specifically for peritoneal dialysis, it would be possible to easily adapt the model for haemodialysis and renal transplantation, highlighting that although the experiences of the three treatments are different, the model could reflect the reality of life with end-stage renal disease.

Therefore the illness trajectory theory for end-stage renal disease supported and influenced the project, particularly in terms of the crisis and chronic phases of the treatment. The framework has however been altered to accommodate the findings in this study, rather than fitting the findings strictly to a theory, and supported data generation and inductive analysis, without constricting them.

8.5 Chapter conclusions

This chapter has discussed the findings from the study in relation to the renal, home medical technologies and chronic illness literatures. The discussion identified areas where this study supported and disputed findings from the literature, additionally highlighting new knowledge gained from the study.

Identifying the limitations and strengths of the study is vital when considering research and honesty is required. The strengths of the study, including the use of

two methods and my biography as a researcher, were considered. Perceived limitations of the study were also presented.

Throughout this thesis the conceptual framework of illness trajectories has been presented, with this discussion chapter considering the usefulness of this. The discussion highlighted where the framework helped guide data generation and analysis, and a revised framework capturing patients' and families' trajectories with peritoneal dialysis was posed.

The final chapter will conclude the contribution to knowledge that this thesis has made and will make recommendations for clinical practice and future research.

Chapter Nine: Conclusions and Recommendations

9.1 Introduction

This final chapter will begin by providing an overview of this thesis, before summarising the main findings and how these answered the research aim and questions. The new knowledge generated from this thesis will then be explicated. Finally, recommendations for future research and clinical practice will be proposed.

9.2 Overview of the thesis

The background chapter provided an overview of end-stage renal disease and the treatments for this long-term disease, highlighting the global increase in the number of patients with the condition. The literature review then presented the varied picture of a vast number of quantitative studies that reported diminished quality of life in patients using peritoneal dialysis, while only a few studies adopted a qualitative approach. Fewer studies still were identified that considered families' perspectives of peritoneal dialysis. The sociological literature considering chronic illness in relation to the chronic illness trajectory was then overviewed, which provided the conceptual framework for this thesis.

The ethnographic study was then explained, including the reasons for choosing the methodology and the methods employed. In-depth interviews and ethnographic observations were undertaken with sixteen patients and nine of their relatives, with seven healthcare professionals additionally interviewed. The data were analysed thematically using Wolcott's (1994) three stage approach of Description, Analysis and Interpretation, which encompassed an iterative cycle between data generation and analysis.

The conceptual framework of illness trajectories (Jablonski 2004, Rolland 1987) influenced data generation and analysis, and assisted with presenting the findings. The three findings chapters considered patients' reasons for choosing peritoneal dialysis and their experiences of being trained to use the technology, the challenges of living with the treatment and finally their hopes and concerns about the future and the possibility of using other renal replacement therapies. The discussion chapter finally considered the findings presented in this thesis in relation to the micro (renal),

meso (home medical technologies) and macro (chronic illness) literatures. The importance of making the “right” decision when choosing peritoneal dialysis was discussed, and participants hoped that the treatment would enable them to remain at home and in control of treatment. The tension between peritoneal dialysis as a liberator and constrainer was revealed, as the treatment enabled people to remain at home and self-manage, yet restricted and dominated the home and daily routine. Managing physical crises and recognising deterioration in the future were sources of great uncertainty for patients and their families. Freedom was afforded through creativity with the treatment and maintaining hope for a kidney transplant, yet this at times caused increased uncertainty. The study was also critiqued in the discussion, highlighting the usefulness of ethnographic methodology when considering home medical technologies and my reflexivity as a nurse and researcher. Finally, the applicability of the illness trajectory framework was considered. Rolland (1987) and Jablonski’s (2004) illness trajectories were adapted to reflect the experiences of patients and their families when using peritoneal dialysis. This model encourages a holistic approach to acknowledge patients’ biographies prior to starting dialysis (affecting their later experiences), the impact of the treatment on areas of life, and the uncertainty associated with the future and the inevitable transfer to other renal replacement therapies or death.

9.3 Conclusions from the thesis

The aim of this research was to explore the experience of home peritoneal dialysis from the perspectives of patients, their families and healthcare professionals in the UK. The specific research questions, which this thesis has addressed, were:

9.3.1 What influences patients’ decisions to choose peritoneal dialysis?

- Patients chose peritoneal dialysis after receiving pre-dialysis education from a team of specialist nurses and nephrologist, either in partnership with their families or independently;
- Peritoneal dialysis was chosen as patients hoped it would offer them control over the treatment and enable them to remain at home, rather than travelling to a dialysis centre and spending four hours, three times per week attached to a haemodialysis machine;
- Patients reported that their prior experiences of dialysis influenced them, for example having a friend who coped well with peritoneal dialysis or observing other patients bleeding from a fistula for haemodialysis;

- A minority of patients struggled with the decision and would have preferred the nephrology healthcare professionals to make the decision for them.

9.3.2 How does peritoneal dialysis impact on life and the home environment?

- Peritoneal dialysis required time and skill, and subsequently managing the condition was disruptive to everyday life;
- Completing four CAPD exchanges or at least nine hours of APD required individuals to manage their time and other activities of life around treatment;
- Both patients and relatives reported exhaustion, particularly if they used APD and were disturbed by nocturnal alarms;
- The home environment was significantly affected by peritoneal dialysis, due to the volume and variety of medical equipment that was moved into the home;
- Participants either attempted to demarcate peritoneal dialysis by storing equipment and undertaking exchanges in one or two rooms, which required the home to be converted, or it was spread throughout the home in both communal and private areas;
- Others tried to hide equipment within the domestic space, for example within furniture.

9.3.3 How is peritoneal dialysis managed at home?

- Managing peritoneal dialysis required multiple skills and tasks: CAPD and/or APD exchange techniques, including aseptic procedure and hand-washing, blood pressure, fluid balance and inventory, titrating medications, weight, diet, aseptic dressing of Tenckhoff catheter and monitoring for signs of infection;
- Routine was generally seen as important to participants, enabling them to fit the requirements of peritoneal dialysis with other everyday routines, such as washing, dressing, eating and socialising;
- Patients were trained and then monitored by a specialist team of PD nurses who offered support as required by the individual, from visits several times per week at times of crisis to three monthly routine appointments. Additionally, patients attended the Nephrology multi-disciplinary clinic as required, up to three monthly;
- Patients and relatives stressed the importance of being able to identify a complication, principally peritonitis, and lived in fear of this. Yet at times participants demonstrated misunderstanding about what they should be

observing and learned from their experience when they or their relative experienced a complication. Preventing infection was seen as particularly important, along with reporting concerns to healthcare professionals, which they felt able to do.

9.3.4 How is peritoneal dialysis integrated into everyday life?

- Over time patients reported that their confidence with the treatment grew and they then felt able to assert control over the treatment, often with the support of PD nurses and Consultant Nephrologist;
- This was achieved by altering the timing, location and/or equipment used for peritoneal dialysis exchanges;
 - Timing: going to bed earlier and getting up earlier (APD), or leaving slightly longer between treatments (CAPD);
 - Location: performing exchanges while away from the home, for example on holiday (CAPD and APD), or while out for the day at relatives' houses, public spaces or the car (CAPD);
 - Equipment: the use of specialist carry cases making it easier to leave the home (CAPD and APD), a CAPD dialysis stand enabling movement around the house or a height-adjustable table for APD exchanges while away from home;
- Participants who felt unable to be creative with peritoneal dialysis and thus retain an element of life without treatment, reported greater restrictions.

9.3.5 How do families perceive having a relative at home and what contribution do they make to the process?

- Family involvement varied between participants, but everybody received support from relatives to a certain degree;
- Family members were supportive of patients choosing home dialysis and were keen to learn the procedure;
- Some relatives had assumed responsibility for managing the regime, particularly if the patient had multiple co-morbidities;
- Others acted in a supportive role during dialysis exchanges, for example helping to clear away packing;
- Others provided support with general domestic duties such as shopping, rather than dialysis-specific support.

9.4 Original contribution to knowledge

This study reiterated and reinforced a number of previous findings from the literature, which promotes the credibility of the current study and suggests that there is transferability of the findings to other populations of patients using peritoneal dialysis. However, crucially there were also a number of new findings, some of which can be attributed to the use of ethnographic methodology, not previously employed with this population.

Pre-dialysis

Participants were fearful about actually starting peritoneal dialysis, but were resigned to it. Despite good preparation, participants failed to understand the treatment until they were “hands on”.

Home environment

In terms of the home environment, this study provided substantial detail about how peritoneal dialysis affects this, for patients and relatives, which was evident from outside and inside the home. The use of fieldnotes and interview data highlighted the prominence and dominance of medical equipment within the home. Some participants demarcated peritoneal dialysis to other rooms, allowing other parts of the home to be dialysis-free, but causing isolation for some. There was variation between participants as to whether they tried to “hide” equipment, for example within domestic furniture. Others undertook peritoneal dialysis in communal areas to reduce isolation, leading to medical equipment scattered throughout the home. Overall, substantial storage space was required for peritoneal dialysis, ultimately affecting the home space.

Challenges

Relatives, as well as patients, reported exhaustion as a result of peritoneal dialysis and often APD. Peritonitis was a source of fear and uncertainty for patients and relatives, who strove constantly to prevent it. Episodes of peritonitis were associated with pain, confusion and guilt. Patients and relatives felt well supported by the healthcare services offered to them: home visits as required, telephone helpline, clinic visits and direct access to the ward.

Creativity and integration

To integrate the treatment into everyday life, relatives were supportive of patients to alter the timings or location of the treatment, and be creative with equipment to make the treatment less onerous. Participants' inventions made their lives much easier, e.g. dialysis carry bags and stands, and they were proud of their creativity and integration. However, people who did not integrate the treatment generally found it more restrictive.

Uncertain future

While studies have described the future as uncertain, this study highlighted the depth and significance of uncertainty felt by participants.

9.5 Recommendations

The new knowledge generated by this thesis has implications for future research and healthcare practice.

9.5.1 Research

- This study demonstrated that the training for peritoneal dialysis is a daunting experience for patients, while the training they receive may influence their later experiences and understanding of the treatment. Consideration of the dialysis training period is thus essential, possibly through observation of how the treatment is taught and patients' and carers' responses to it, to enable additional support if necessary.
- Peritonitis was found to be frightening and unsettling for patients and their relatives, yet there was also confusion about the signs and symptoms of the infection. It is therefore important to understand the extent to which patients and their families understand the symptoms of peritonitis, as well as their experiences of these crises.
- Only two participants in this study reported their negative experiences of being called for a kidney transplant that was later cancelled. It is pertinent to discover whether other patients have had similar experiences and what could have been done to improve the care they received during this unsettling time.

- One limitation of this study is that it did not collect data longitudinally. Patients' lives with peritoneal dialysis are not static, for example in response to acute illness their routines and understanding of illness change, and their confidence with the treatment appeared to increase over time. Therefore, a longitudinal study may be a useful way to identify participants' experience of peritoneal dialysis over time, to identify whether their support needs and perceptions of the treatment change.

9.5.2 Clinical practice

- Participants reported making modifications to their homes to accommodate peritoneal dialysis, which was a financial burden for some. Peritoneal dialysis is cheaper for the NHS than hospital haemodialysis and therefore local authorities could offer financial assistance for reasonable home modifications, such as building storage sheds for dialysis supplies, enabling people to stay at home if they and their clinical team prefer.
- The study highlighted that participants were not always familiar with the signs of peritonitis and therefore ongoing education from healthcare professionals about how to prevent and identify infections is vital.
- The transplantation process was associated with confusion and uncertainty for patients and their families. Additional education and information about the transplantation process, including how patients are selected and what to expect when they are called for a transplant, may reduce this uncertainty. Information about the transplantation process is provided pre-dialysis, which is a stressful time for patients and their families. Therefore, additional information at a later point may alleviate concerns.
- The stress of having a kidney transplant operation cancelled was also apparent and healthcare professionals need to recognise the trauma that this causes and handle how this news is communicated to patients. A counselling session after the operation is cancelled may be beneficial for patients.
- Participants reported that they valued each others' experiences, particularly in terms of how others integrated peritoneal dialysis into their lives. While one patient was invited to a small peer-support group organised by her PD nurse,

not all geographical areas offered such a service. Additional peer-support services for patients may therefore be beneficial, either through traditional support groups, a telephone service or virtual support through the internet.

9.6 Chapter conclusions

This final chapter has presented an overview of the thesis, identifying that the aims outlined in chapter one were achieved. The thesis demonstrated that ethnography is a beneficial and acceptable methodology to adopt when considering how patients and their families live with home medical treatments such as peritoneal dialysis. Furthermore, adapting the classic illness trajectory according to the perspectives of individuals using peritoneal dialysis offers greater insight into their experiences throughout their journeys with the treatment. The original contribution that this thesis makes to knowledge has been detailed, which in turn has implications for future research and changes to healthcare practice.

Post-Script

In the period between finishing data generation and sending participants a summary of the study findings, I was made aware that five of the patients who took part in the study had died. I hope that their stories can live on through this thesis and their families are coping with their loss. Two patients received kidney transplants and I sincerely hope that this has given them the lives they wished for. Three of the patients moved to haemodialysis and I hope they are finding it better than they feared. Finally, six patients are continuing to use peritoneal dialysis and I hope that in doing so they are living well.

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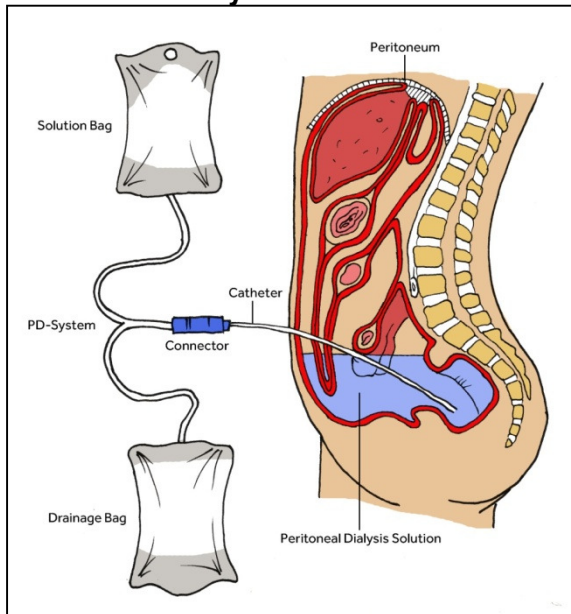
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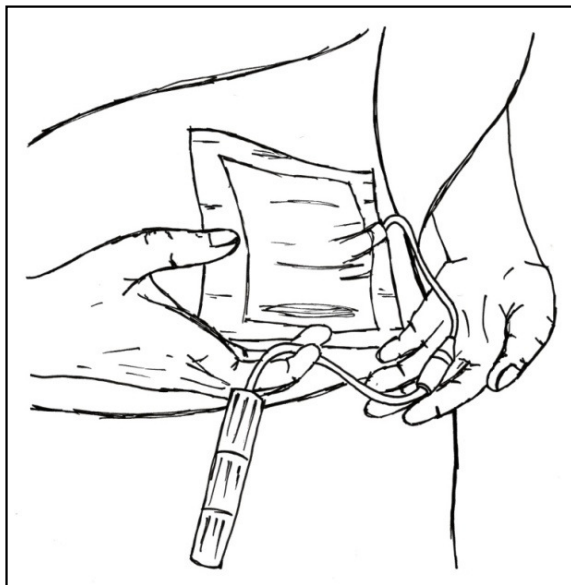
Appendices

Appendix One: Picture gallery of renal replacement therapies

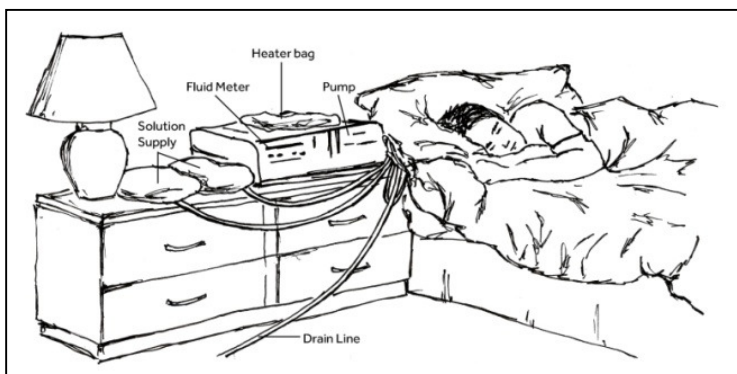
Peritoneal dialysis



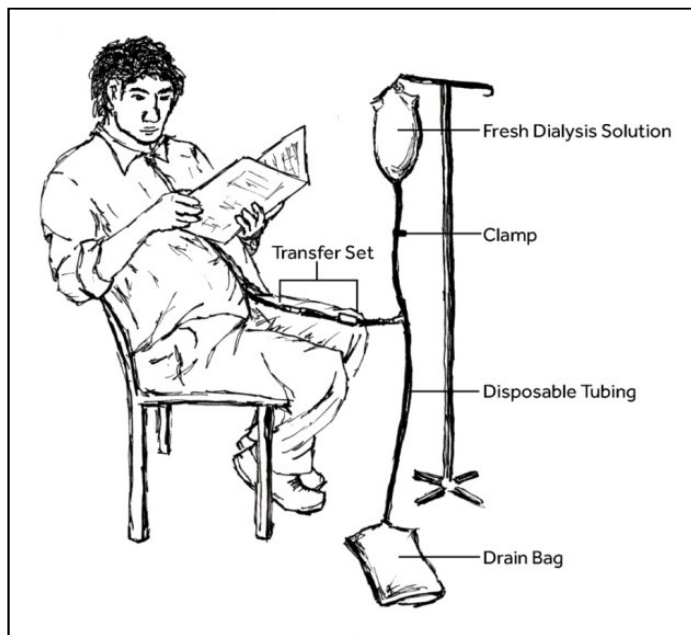
The principle of peritoneal dialysis



Peritoneal dialysis access: Tenckhoff catheter



Overnight Automated Peritoneal Dialysis (APD)



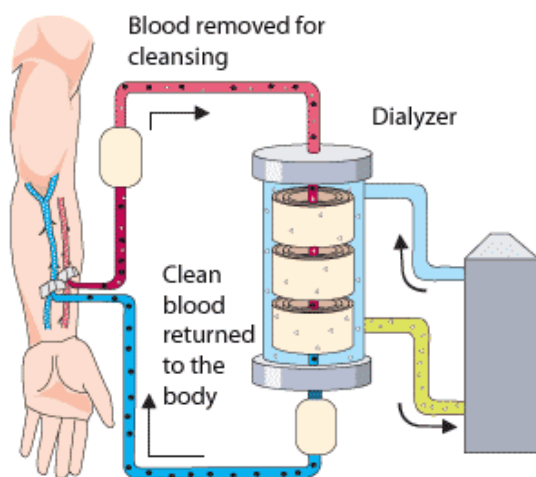
Continuous
Ambulatory Peritoneal
Dialysis (CAPD)

Haemodialysis



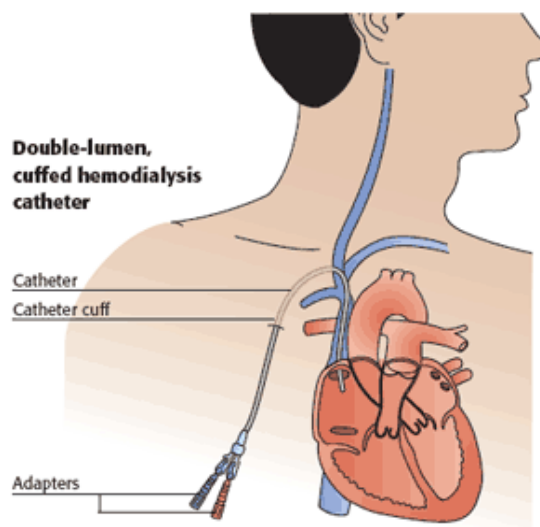
A haemodialysis machine by Baxter

(http://newsimg.bbc.co.uk/media/images/41274000/jpg/_41274484_dialysis_machine203.jpg)



Haemodialysis process via a fistula

(http://www.mediaresource.com/HealthNews/images/English/LP2_8.gif)



Haemodialysis access: "permcath"

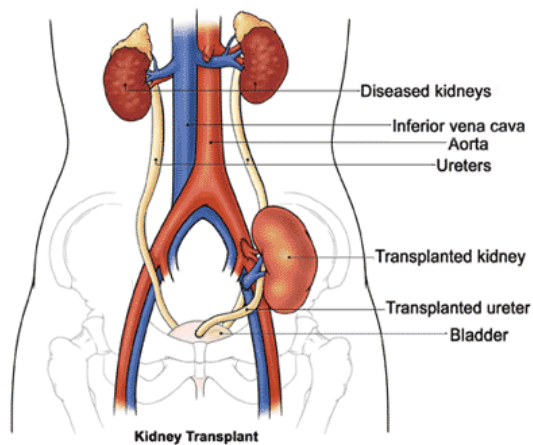
(http://2.bp.blogspot.com/_sgpBP3aUPS0/R9ipHX1aDjI/AAAAAAAAAacg/muGF8QLgS5Q/s400/catheter.gif)



Haemodialysis access:
arteriovenous fistula

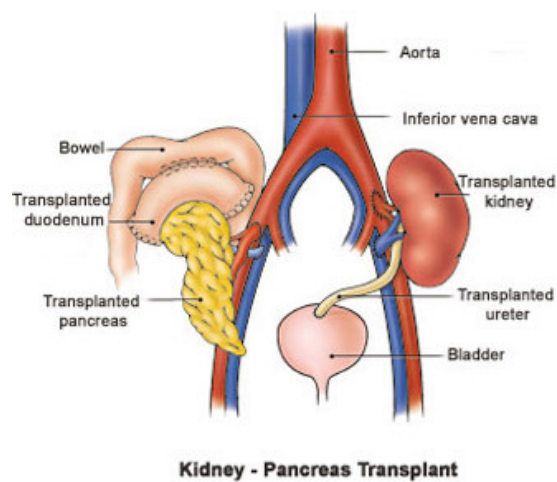
(<http://nephron.org/images/weintraub.jpg>)

Renal and Pancreas Transplantation



Transplanted kidney and ureter

(<http://www.cpmc.org/images/kidney/news/kidney-news1-single.gif>)



Transplanted kidney and pancreas

(<http://www.cpmc.org/images/kidney/topics/pancreas.jpg>)

Appendix Two: Literature searching strategy

A librarian in the Cardiff School of Nursing and Midwifery Studies assisted with undertaking the first and second CINAHL searches, and the search terms used in these searches were duplicated when searching other databases (Medline and SCOPUS). These initial searches with fewer search terms generated several useful articles, and the reference lists from these articles were used to undertake a more robust search with multiple search terms and several databases (CINAHL, Medline, SCOPUS, ASSIA, and PsychINFO). This robust search generated a substantial number of hits, of which over 100 were selected for further reading. Email alerts from the British Library ("Zetoc" alerts) were also set, including articles with "peritoneal dialysis" or "dialysis" in the titles, and the content lists for specific journals, including *Journal of Advanced Nursing*, *Journal of Clinical Nursing*, *Journal of Renal Care* and the *British Journal of Renal Medicine*. These alerts enabled new research considering peritoneal dialysis to be highlighted, which proved to be a useful technique for staying up-to-date with current literature. The final selection of research papers were chosen according to the following inclusion and exclusion criteria:

Inclusion criteria:	Exclusion criteria:
<ul style="list-style-type: none"> English-language articles Primary research, literature review or systematic review Peer-reviewed journal Robust methodology Research involving patients on peritoneal dialysis, or hospital dialysis patients if comparing peritoneal dialysis Research involving adult patients (over 18 years old) Research involving adult relatives/friends of patients on dialysis Articles relating to patient/family experience and perception of treatment. 	<ul style="list-style-type: none"> Studies focussing on bio-medical markers and measurements

Database	Search Terms	Limits	Number of hits	Selected
CINAHL 05/11/09	Peritoneal dialysis Peritoneal dialysis (exploded) = combined Patient* Famil* =combined Experience Qualitative studies = combined	English language	79	28

	=3 combined searches with "and"			
SCOPUS 08/02/10	Peritoneal dialysis + Patient Or Famil* + Experience + Qualitative		13	2
MEDLINE 08/02/10	Peritoneal dialysis (exploded) Patient Famil* =Combined Experience =3 combined with "and"	English language	23	3
CINAHL 24/03/10	Peritoneal dialysis CAPD APD Home dialysis Kidney failure, chronic "end stage renal failure" "end stage renal disease" ESRF ESRD = combined with "or" Patient* Famil* Carer* Spouses* Partner* Family* (exploded) = combined with "or" Life experience Experience* Quality of life (exploded) Attitude (exploded) Perspective* "liv* with" insight cop* perception*	English language	2100	50
SCOPUS 07/04/10	capd OR peritoneal dialysis OR apd OR crf OR esrd OR esrf OR home dialysis OR ckd OR chronic renal failure OR chronic kidney disease OR end stage renal failure OR end stage kidney disease OR end stage renal disease AND patient OR famil* OR family OR relative OR spouse OR care* OR partner AND experience OR quality of life OR qol OR perspective OR perception OR lived experience OR insight OR liv* with OR cop*		22	4

	OR attitude			
ASSIA 07/04/10	peritoneal dialysis or home dialysis or CKD or chronic kidney disease or APD or CAPD or end-stage renal failure or ESRF or end-stage renal disease or ESRD or chronic renal failure or CRF or end-stage kidney disease and patient or famil* or family or care* or spouse or partner or relative and experience or QOL or quality of life or perspective or perception or lived experience or insight or liv* with or cop* or attitude	English language	99	6
Psych-INFO 07/04/10	Peritoneal dialysis APD CAPD ESRD ESRF End stage renal failure End stage renal disease CKD CRF Chronic renal failure Chronic kidney disease = combined with "or" Patients (ex) Patient* Famil* Family (ex) Care* Relative Partner Spouse = combined with "or" "liv* with" Quality of life (ex) QOL Experience Perspective Perception cop* attitude insight = combined with "or" = combined with "and"		396	20
MEDLINE 07/04/10	Peritoneal dialysis (exploded) CAPD APD ESRD ESRF End stage renal failure End stage renal disease (no CKD as irrelevant results) = combined with "or" Patient Famil*		2018	58

	Family (exploded) Spouse Care* Partner Relative = combined with "or" Experience QOL quality of life (ex) Attitude Perspective "liv* with" Lived experience = combined with "or" = combined with "and"			
MEDLINE 27/05/2011	Peritoneal dialysis home dialysis CAPD APD Dialysis =combine with "or" Healthcare professional nurs* doctor/physician multidisciplinary team =combine with "or" Attitude experience perception =combine with "or" = combined with and		27	2

Appendix Three: Qualitative studies - patients with end-stage renal disease

Author and year	Country	Study aim	Methodology	Sample strategy and size	Data generation	Data analysis	Main findings	Recs.
(Hardiker et al. 1986)	UK	Exploration of illness roles in renal failure, identify coping	Grounded theory (Glaser and Strauss)	Random sample PD ³ and HHD (20)	Semi-structured interviews	Grounded theory coding and analysis (Glaser and Strauss) – little detail	Seeing illness as transitory, maintaining old lifestyle or construction of new lifestyle, gave up aspects of lifestyle, resignation to illness or resentment.	Appropriate interventions e.g. counselling
(Beer 1995)	UK	Perception of body image	Qualitative	Random sample CAPD (4) HD (4) TP (4)	Semi-structured interviews	Content analysis	Acceptance sought by self and society, dislike of access, loss of control. Transplant patients demonstrated increased acceptance	Further larger studies required
(Wright and Kirby 1999)	UK	Conceptualisations of adjustment to chronic illness	Grounded theory (Strauss and Corbin)	Home dialysis nurse selected sample. CAPD 6-8 (5) CAPD 1yr (5) relative (5) nurses (3) (age 45-70)	Semi-structured interviews	Open, axial and selective coding.	Adopting a new approach to living: integrating illness and acceptance	Scope for interventions to promote adjustment
(Lindqvist et al. 2000)	Sweden	Perceived consequences of end-stage renal disease	Explorative-descriptive qualitative	Multicentre (3) with eligible CAPD (26) HD (30) and TP	Unstructured interview	Content analysis	Wish for independence: normality, self-management,	Findings could benefit nursing assessment

³ PD – peritoneal dialysis. APD – automated peritoneal dialysis. CAPD – continuous ambulatory peritoneal dialysis. HD – haemodialysis HHD – home haemodialysis. TP - transplant

				(30)			deprivation and concerns.	
(Heiwe et al. 2003)	Sweden	Patients' experiences of physical/ functional capacity with chronic kidney disease	Phenomenography	Purposive sample of CKD/ESRD. Pre-dialysis (5) HD (5) PD (6)	Semi-structured interviews	Categories identified and relationships established	Physical and mental fatigue. HD varied fatigue, PD stable fatigue. Activities of daily living affected.	Early referral to physio
(Martin-McDonald 2003)	Australia	Experience of dialysis dependency	Narrative methodology	Purposive sample PD (5) and HD (5)	Three interviews over 3-6 months	Thematic analysis	5 continuums: "freedom-restrictions", "being normal-being visible", "control-acquiesce", "hope-despair" and "support-abandon"	Support patients to reach positive end of continuum, involve patients in care decisions
(Curtin et al. 2004)	USA	Examines self-management in long-term PD	Descriptive/ exploratory. Multicentre (15)	Eligible identified by PD nurses, willing PD (18)	Semi-structured interviews	Content analysis, data saturation, participant validation,	Self-management: autonomy/ control, normality (everyday life)	Interventions to support self-management
(Mok et al. 2004)	Hong Kong	Coping behaviours of patients with kidney failure	Naturalistic enquiry framework	Purposive sample of patients on dialysis (11)	Semi-structured interviews	Thematic analysis	Coping with fluctuating feelings, concerns, motivation for coping, relation focussed coping and coping strategies	Facilitating communication between patients and families
(Polaschek 2006)	New Zealand	Describe patients' perception of home dialysis	Critical interpretive methodology (hermeneutic)	Selected sample of dialysis patients HD (15) PD (5)	Semi-structured interviews	Thematic analysis	Confidence in self-care ability, modifying treatment, influence of life on dialysis, relationship with healthcare	Nurses need to negotiate dialysis with patients to work more effectively with

							professionals	them.
(Polaschek 2007)	New Zealand	Describe attitudes towards treatment regime	Critical interpretive methodology (hermeneutic)	Convenience sample of home dialysis patients (n=20)	Semi-structured interviews	Thematic analysis	Experimentation with treatment, normalise treatment, positive about control, life situation.	Nurses need to negotiate care with patients, to ensure efficacy of treatment.
(Clarkson and Robinson 2010)	USA	Lived experience of dialysis	Qualitative	Volunteers PD (4) HD (6)	Semi-structured interviews	Thematic analysis	Restricted life, limitations, body/mind/spirit, coping and areas lacking	Early holistic education for patients and families
(Morton et al. 2010)	Australia	Examination of patient views about treatments for end-stage renal disease	Qualitative	Purposive sample HD (60) HDD (4) CAPD (8) APD (5) TP (18) (age 18-65)	Semi-structured interviews	Categorised into positive or negative statements about treatment	Positive: freedom, convenience, self-care, simplicity, security. Negative: confinement, risk, pain, time commitment, dialysis access (body image), self-care, impermanence of treatment, change to home	Education should focus on relevant factors for patients.
(Yngman-Uhlin et al. 2010)	Sweden	Describe how patients on PD experience tiredness	Phenomenology	Purposive sample from three centres. CAPD (9) APD (5)	In-depth interviews	Phenomenological reduction.	Mental and physical tiredness. Need for sleep and rest, consequences in daily life, strategies for adjustment.	Regular assessment of sleeplessness, appropriate interventions.

Appendix Four: Qualitative studies - families of patients with end-stage renal disease

Author	Country	Study aim	Methodology	Sample strategy and size	Data generation	Data analysis	Main findings	Recs.
(Flaherty and O'Brien 1992)	USA	Describe psychosocial adaptation among families to ESRD	Longitudinal qualitative	Family of patients on HD (30) HHD (5) CAPD (14) APD (1), from previous study	Semi-structured interviews	Content analysis	Five coping styles: remote, enfolded, altered, distressed and receptive.	Additional support if remote or distressed coping styles exhibited
(White and Grenyer 1999)	Australia	Investigate bio-psycho-social impact of ESRD	Phenomenology (Husserl)	Patients on HD (n=9) and PD (n=16) and partners. ?sampling strategy	Semi-structured interviews	Bracketing, thematic analysis, respondent validation	Positive relationship between patient and partner. Overpowering impact of dialysis on their lives	Family-centred approach with advanced counselling skills needed to support families
(Pelletier-Hibbert and Sohi 2001)	Canada	Experience of family members of patients on dialysis	Qualitative	Relatives of patients on PD and HD (41), invited through patients	Focus groups	Thematic analysis	Living each day, flexibility, positivity, hope of a transplant and faith in God	Pre-dialysis and regular reassessment of coping and a specialist nurse for families
(Luk 2002)	Hong Kong	Caregivers' perceptions of home dialysis	Phenomenology (discipline not specified)	Convenience sample caregivers (30) HHD and PD	Semi-structured interviews	Thematic content	Economic status, work related fatigue, psychosocial aspect, informational support and co-operation within the team	Adjustment support, home visits, respite, counselling, education
(Beanlands et al. 2005)	Canada	Examination of care-giving activities and abilities	Longitudinal grounded theory (Glaser and Strauss)	Volunteer caregivers HD (19), HHD (4), HD	Semi-structured interviews	Iterative coding and categories, triangulation	Multiple emotions: angst, annoyance, bitterness, discouragement, fear,	Support for carers' existential knowledge.

				centre self-care (2) and PD (12). Second interviews (20)		n.	frustration, love, pride and respect	
(Ekelund and Andersson 2010)	Sweden	Identify psychosocial problems in patients on dialysis and partners	Longitudinal qualitative	Eligible patients HD (22) and PD (17), and partners (21). 12 months later: 29 patients and 15 partners.	Questionnaire-based semi-structured interview (considering appraisal and coping)	Biographical analysis (narrative – Wilkinson 2000)	Patients without a partner lonely and sought social support. Dialysis impacted on the families of patients with partners	Additional individualised support

Appendix Five: Studies comparing quality of life between renal replacement therapies

North America and Australia (n=12)							
Author and year	Location	Study design	Sample: size and technique	Data collection tool	Data analysis	Main findings	Recommendations
(Evans et al. 1985)	USA, multicentre (n=11)	Cross-sectional	Random probability sample: TP (n=144) HD (n= 347) HHD (n=287) Volunteer sample: PD (n=81)	Index of Psychological Affect, Index of Overall Life Satisfaction and Index of Well-Being	Bivariate correlation analysis	Dialysis patients poorer QOL than general population and TP. HD poorer quality of life than PD ⁴	No evidence of successful rehabilitation. Careful consideration who to treat with RRT
(Churchill et al. 1987)	Canada	Two-stage observational study	All eligible volunteers. 1st stage HD (n=42) HHD (n=42) PD (n=31) TP (n=79) 2nd stage HD (n=38) HHD (n=38) PD (=24) TP (n=73)	“Time trade-off approach” (TTO) 0 (low QOL) –1 high QOL) Rand Corporation Health Insurance Experiment. HCP/relative completed Spitzer QOL Index and QOL VAS	Little detail	TTO: ESRD is 0.63 HD= 0.43 HHD= 0.49 PD= 0.56 TP= 0.84. QOL significantly diminished. QOL overestimated by HCP	No recommendations

¹ QOL: quality of life. TP: transplant patient, HD: haemodialysis patient, PD: peritoneal dialysis patient, HHD: home haemodialysis patient, HDF: haemodiafiltration patient, RRT: renal replacement therapy, HCP: healthcare professional, RRF: residual renal function, Hb.: haemoglobin, ADL: Activities of daily living, SF-36™: Short Form Health Survey Questionnaire; VAS: Visual Analogue Scale

(Oldenburg et al. 1988)	Australia	Longitudinal, 18 months	Eligible volunteers HD=51 PD=51 (base) HD=47, PD=22 (follow-up)	Psychosocial Adjustment to Illness Scale, Psychological Symptoms Inventory and Locus of Control Behaviour scale. HCP rated patient adjustment	Cross-sectional analysis using principal components analysis. Multiple regression analysis.	Dialysis patients lower QOL than average, particularly vocational, psychological and sexual function. Distress and dysfunction predicted by initial reaction to dialysis and initial adjustment to dialysis.	Prompt treatment of psychological distress needed.
(Wolcott et al. 1988)	USA, multicentre (n=3)	Cross-sectional	Matched pair sampling method (age, sex, diabetes, time on dialysis), HD and PD (n=33)	13 tools covering: physical, psychological and social QOL. HCP rated patients' adjustment.	Correlational analysis	PD patients higher QOL and employment, less treatment stress and psychological disturbance than HD	Psychological profiling to ensure patients choose right dialysis modality for them, reducing switching between HD and PD
(Bremer et al. 1989)	USA, multicentre	Cross-sectional	Random sample first TP (n=166), second TP (n=21), failed TP/ on dialysis (n=30), HD (n=105), PD (n=79). Volunteer sample HD patient completing dialysis (n=41), HHD (n=47)	Positive and Negative Affect Scale, Affect Balance Scale, Helpless-Independent Scale and Satisfaction with Sexual Relations Scale Co-morbid Index	Multiple classification analysis P<0.01)	TP patients exceed average QOL, HHD and HD-Patient similar to norm. PD, HD and failed transplant patients were below the norm. Dialysis patients reduced health satisfaction.	No recommendations.
(Simmons and Abress)	USA	Cross-sectional	Sampling not specified. Current	10 tools covering:	Multivariate analysis of	TP best QOL, then PD, then HD. Lower	Rehabilitation concerning. Careful

1990)			TP (n=91), historical TP for >5 years (n=82), HD (n=83) and PD (n=510)	physical, emotional and social aspects of QOL	variance	employment dialysis groups	consideration who to assign to each modality
(Devins et al. 1990)	Canada	Cross-sectional	Stratified sample (by age, number of transplant failures, non-renal illness and gender) HD (n=39), HHD (n=15) PD (n=11) TP (n=34)	QOL domains , Illness-Intrusiveness Scale, Beck Depression Inventory, hopelessness and concern indicators, illness-related variables, uraemic symptoms, activities of daily living	ANOVA	Burden of treatment felt by all participants. TP less illness intrusion, PD needed most time for treatment, but greater satisfaction than HD. TP and HHD higher levels of positive effect.	No recommendations.
(Diaz-Buxo et al. 2000)	USA, national multicentre	Cross-sectional	All patients who completed SF-36 in 1996, sent by Fresenius Medical Care. HD (n=16,775), PD (n=1,260) (CAPD=728, APD=532)	Medical Outcome Survey SF-36 , demographics, laboratory data (FBC and U&E)	Analyses of variance and co-variance (1) no adjust. (2) case-mix adjust. (3) case mix and lab variable adjust.	Physically: dialysis patients lower than average; no differences PD vs. HD after adjustment. Mental health: better for APD patients, also better for CAPD patients after adjustment.	None
(Mittal et al. 2001)	USA	Longitudinal, every 3 months for 24 months	Volunteer sample, eligible PD (n=43) HD (n=134)	Medical Outcome Survey SF-36	ANOVA	PD lower physical QOL (despite fewer hospitalisations) – explained by lower albumin. Depression PD 26.1% HD 25.4%.	SF-36 useful tool for assessing QOL. QOL not predicted by Hb.

						Stable longitudinally.	
(Manns et al. 2003)	Canada	Longitudinal, baseline, 6 and 12 months	All eligible volunteers HD (n=151) PD (n=41) 18% did not complete follow up.	Kidney Disease QOL, Euro-QOL and MOS SF-36	Bivariate and multivariate analysis	Similar for PD and HD. QOL diminished in those needing assistance with ADL. QOL stable over time.	Early interventions would benefit patients long-term
(Wu et al. 2004)	USA, multistate (n=19), multicentre (n=81)	Longitudinal, baseline, 3months, 6months, 12months	2/3 eligible patients enrolled, oversampling PD for statistical comparison. Sample reflected USRDS on age, gender and race. HD (n=698) PD (n=230)	Health Experience Questionnaire, including MOS SF-36 and 14 dialysis domains. Socio-demographic, Index of Co-existent Disease, choice	T-tests to compare modality and longitudinal scores. Bivariate and multivariable analyses for QOL between modalities.	PD patients better scores on pain, travel, diet restrictions and dialysis access at base and 1yr. Less financial concerns at 1yr. HD better vitality and sexual function at 1yr. In general, HD better improvement than PD. 64.4% completed follow-up (n=585), those who completed had better QOL scores on MH, social function, symptoms, travel, recreation and access.	Cannot advocate PD or HD over each other. Drs need to be honest with patients about specific impact of dialysis modality.
(Fong et al. 2007)	Canada	Cross-sectional	All patients approached, Nocturnal HHD (n=36) and PD (n=57)	KDQOL , BDI, Illness Intrusiveness Scale, Charlston Co-morbidity Index	Multivariate analysis, ANOVA	QOL, BDI and illness intrusiveness similar. NHHD lower social support, but increased sexual function. PD patients less burden.	Further research

United Kingdom (n=4)							
Author and year	Location	Study design	Sample: size and technique	Data collection tool	Data analysis	Main findings	Recommendations
(Auer et al. 1990)	UK, multicentre (n=2)	Cross-sectional	All patients 1981-84 PD (n=81) and HD (n=78)	Six tools covering life satisfaction, life happiness, dialysis stress, sexual relations and semantic differential	Non-parametric, ANOVA	Life satisfaction similar. Patients over 60 more positive. Worse sex-life post-dialysis	None
(Gudex 1995)	UK, multicentre (n=24)	Survey design	Random sample (20%) taken from European Dialysis and Transplant Association Register. PD (n=93), HD (n=95), HHD (n=59) TP (n=367)	Health Measurement Questionnaire	SPSSx p<0.01	TP highest QOL, little difference between dialysis. TP lower distress than dialysis. HD dependent machine, PD felt confined, TP in pain	Consider effect of RRT on family
(Carmichael et al. 2000)	UK	Cross-sectional	Questionnaires to all patients on dialysis >1month. HD (n=49) PD (n=97).	Kidney Disease QOL-SF Demographics, clinical characteristics, co-morbid factors	Unpaired t-tests, one-way ANOVA. Multiple regression.	Regression showed HD reported less burden on lifestyle of kidney disease. Social functioning better for PD than HD. PD: less dialysis-related symptoms, less adverse effect of kidney disease on	Psychological counselling to help patients come to terms with disease and lifestyle changes.

						life, better cognitive function, sleep and satisfaction with treatment. HD: less burden of kidney disease on lifestyle, better social interaction and social support.	
(Harris et al. 2002)	UK, multicentre (n=4)	Longitudinal, cohort. Baseline, 6 and 12 months	Cohort one “new” patients PD=36 HD=42. Cohort two “stock” patients PD=42 HD=54 All eligible patients – 70% agreed. Patients over 70.	Medical Outcome Survey SF-36, Kidney Disease Quality of Life Questionnaire (KDQOL)	Multiple linear regression analysis, case-mix controlled	SF-36 – no QOL difference HD vs. PD. KDQOL symptoms showed PD better QOL at baseline, but not at 6 or 12 months.	Larger multicentre longitudinal studies. PD a good option for older people.
Europe ex. UK (n=9)							
Author and year	Location	Study design	Sample: size and technique	Data collection tool	Data analysis	Main findings	Recommend -ations
(Muthny and Koch 1991)	Germany, multicentre (n=11)	Survey	PD (n=68), HD (n=290) and TP (n=761) patients ?sampling technique	Author questionnaire: patient history, medical complications, life satisfaction, QOL and rehab and socio-demographics	ANOVA	TP superior QOL to dialysis. Not satisfied with life: 30% HD, 17% PD, 5% TP. Anxiety levels similar across groups.	Careful consideration of indication criteria for each group.

(De Vecchi et al. 1994)	Italy, multicentre (n=12)	Cross-sectional	Sampling strategy not specified. HD (n=74) PD (n=39) – dialysed on HD and PD for >6months	Author-created, rating PD vs. HD on 34 items	ANCOVA	PD better for work performance and family relationships, HD better for general wellbeing and appetite. Patients preferred current treatment due to stress of moving	HCP careful examination of suitable candidates for each treatment.
(Moreno et al. 1996)	Spain, multicentre (n=42)	Cross-sectional	Representative sample of hospitals, assigned corresponding fraction of sample group to each centre, random sample chosen HD= 891, PD=40, HHD=7, HDF=70	Karnofsky Performance Scale and Sickness Impact HCP completed Friedman Co-morbidity Index	ANCOVA with case-mix adjustment	Moderate QOL impairment, no differences between modality. Co-morbidities decrease QOL. Higher Hb. Linked with better QOL.	Appropriate management of anaemia
(Merkus et al. 1997)	The Netherlands, multicentre (n=13)	Cross-sectional	Consecutive sample HD=120, PD=106, compared to healthy sample (n=1063)	Medical Outcome Survey SF-36	ANOVA and multiple linear regression	ANOVA demonstrated advantage of PD. Multivariate analysis showed PD better mental health. Low Hb, low RRF and co-morbidities = poorer QOL	Regular formal assessment of QOL – emphasis on patients' perceptions of QOL

(Wasserfall et al. 2004)	Switzerland, multicentre (n=19)	Cross-sectional	All willing patients, HD (n=455) PD (n=50) Response rate 82% HD and 78% PD	EuroQOL-5D generic quality of life questionnaire	Two-way ANOVA	Similar QOL, both substantially diminished. PD greater restriction activities. Anxiety/depression and pain/discomfort highest impact on QOL	If depression targeted QOL could improve by 20%.
(Lausevic et al. 2007)	Serbia	Cross-sectional	Incident PD (n=32), prevalent PD (n=67) (one centre) HD patients (n=192) (second centre) ?sampling techniques	MOS SF-36 , doctor completed the Index of Coexistent Disease	ANOVA, correlation analysis	HD lower QOL than PD. Short and long-term PD similar QOL scores, improving after 12months	Further research on interventions to improve QOL in ESRD patients
(Sayin et al. 2007)	Turkey	Cross-sectional	All volunteers at single-centre HD (n=75) PD (n=41) TP (n=20)	MOS SF-36 , BDI, State-Trait Anxiety Inventory	Correlation coefficients	Increased vitality in TP patients. Similar and reduced quality of life for all groups. Depression and anxiety in dialysis patients= decreased QOL	Further research to assess underlying factors/mechanisms between psychosocial factors and QOL

(Ginieri-Coccossis et al. 2008)	Greece, multicentre study (n=3)	Cohort study	All completed questionnaires, <4 years dialysis HD (n=39) PD (n=41) >4 years dialysis HD (n=36) PD (n=17)	World Health Organisation QOL , General Health Questionnaire Multidimensional Health LOC	ANOVA	Long-term HD had worst QOL, short-term HD highest anxiety and insomnia scores. No difference long and short-term PD	Development of healthcare services and management strategies
(Timmers et al. 2008)	The Netherlands, multicentre	Cross-sectional	Random sample of a larger multicentre (n=38) study sample PD (n=42) and HD (n=91)	MOS SF-36 ; Illness Perception Questionnaire	Parametric tests, multiple regression analysis	PD better QOL than HD. PD better illness perception - personal control and illness coherence. Illness perceptions contribute to QOL	Further research to identify whether individual or group based initiatives can be used to benefit patients and improve perception of illness
Eastern Asia (n=3)							
Author and year	Location	Study design	Sample: size and technique	Data collection tool	Data analysis	Main findings	Recommendations

(Niu and Li 2005)	Taiwan, multicentre (n=2)	Cross-sectional descriptive correlation study	Power calculation: demonstrating at least 62 pts per group. Convenience sample, HD (n=80) PD (n=80) TP (n=80) Excluded if history of transplant rejection, peritonitis or venous access infection	World Health Organisation QOL questionnaire with two extra questions specific to Taiwanese culture	Descriptive and inferential statistics, including one-way ANOVA	QOL lower for dialysis than transplant patients. Dialysis patient QOL lower than general population. Lowest scores for all groups on mental health.	Psychological support services for patients, e.g. support groups and counselling
(Zhang et al. 2007)	China, multicentre (n=10)	Cross-sectional	PD (n=412) HD (n=661) Retrospective analysis of notes, completion of tool	Medical Outcomes Survey SF-36 Notes analysis: Charlson Co-morbidity Index	Parametric and non-parametric, co-variate analysis, p<0.05	PD higher QOL on 6/8 domains, except physical function and role. HD significantly higher hospitalisation.	None
(Peng et al. 2011)	Taiwan Multi-site (14)	Cross-sectional	? recruitment/sampling strategy. HD=866 PD=301 (CAPD=268 APD=33) (inclusion: >18, literate, >1month dialysis. Exclusion: cognitive impairment, psychiatric disease, infection, heart failure)	MOS SF-36 Biochemical and haematologic parameters within one month of SF-36.	Descriptive statistics, non-parametric tests, chi-square, regression analysis	Overall, quality of life similar between PD and HD patients.	Longitudinal research needed.

Appendix Six: Studies considering quality of life with patients using peritoneal dialysis

Quality of life studies with patients using peritoneal dialysis							
Author and year	Location	Study design	Sample: size and technique	Data collection tool	Data analysis	Main findings	Recommendations
(Steele et al. 1996)	USA	Observational	First 49 eligible PD patients	Patient Assessed Quality of Life tool , somatic symptom assessor (KDS-2). Beck Depression Inventory, Patient Rated Anxiety Scale, Furthermore, staff-assessed quality of life was completed by HCP	Multiple regression	Depression a signifier of QOL. Important for QOL: family life, overall health, religious involvement and extra-familial relationships. HCP underestimate issues important to patients. BDI was high end normal, with high levels of somatic symptoms –anxiety scores were mild.	Quality of life assessments for all patients. Consider patients' QOL rather than HCPs' assessments
(de Wit et al. 2001)	The Netherlands, multicentre (n=16)	Cross-sectional	All eligible patients at centres asked (>18, >3 months,	Self-report Medical Outcomes Survey	Student's t-tests for APD vs. CAPD differences.	APD significantly better social functioning. CAPD patients more depressed and anxious.	Longitudinal research needed.

			sight, Dutch speaking). CAPD (n=56) APD (n=37)	(MOS) SF-36 and EuroQol-5D. Administered Standard Gamble and Time Trade-Off	Multiple regression with case-mix for relationship between variables and QOL. $P < 0.05$	APD predicted better MH. QOL comparable between APD and CAPD, APD favourable in a few domains.	
(Bakewell et al. 2002)	UK	Longitudinal, 2 years	Patients on PD >3months enrolled on other studies included (n=88), 6M=68, 12M=39, 24M=20	Kidney Disease QOL , Co-morbidity index, Subjective Global Assessment and albumin, Townsend social deprivation scale, hospital admissions and infections	ANOVA, Pearson's correlation, multiple regression, $p < 0.05$	Gradual decline in QOL over 2 years, all domains significantly worse at 2years. Number of hospital admissions associated with mental and physical health, and kidney disease issues. Overall, gender, ethnicity and nutrition associated with QOL.	More social support for men and Asian patients. Interventions to target QOL areas that are poor.
(Pucheu et al. 2004)	France, multicentre (n=3)	Cross-sectional	PD patients (n=47) ?sampling strategy (inclusion: >18, French-speaking, illiterate) Excluded patients with diabetes or autoimmune disease	KDQOL, MOS SF-36 , Clinical data, socio-demographics, kidney disease specific tool, Multidimensional Health	Student's t-tests to compare results with gen. pop. PCS and MCS compared with Pearson correlation coefficients,	PD patients poorer QOL (except pain), than general population. QOL not associated with clinical data e.g. duration on PD, severity of disease. Physical QOL associated with internal HRLOC and medical	Regular evaluation of QOL. Further research, psychological interventions.

				Locus of Control, validated Ways of Coping Check-List	multiple regression for QOL scores	power HRLOC. QOL not associated with problem-focussed coping.	
(Balasubramanian et al. 2011)	UK	Longitudinal: baseline and 1 year	All new PD patients monitored CAPD (n=178) APD (n=194)	MOS SF-36 ; Co-morbidity data, modality change, independence, RRF, peritonitis. (baseline and one-year later)	Intention to treat analysis: effect of APD/CAPD choice on clinical outcomes. Descriptive statistics. Regression analysis, t-test.	Overall PD QOL significantly below expected for general population. CAPD poorer baseline QOL all domains. At follow-up QOL similar. Technique survival statistically better for APD. Karnofsky score and dependency on other to perform PD significant predictors of PD technique survival. PD modality not independent factor for PD technique survival. APD associated with fewer peritonitis episodes but not significant.	CAPD and APD are effective – choice should be the patient's.
Sakthong and Kasemsup (2011)	Thailand	Cross-sectional, multicentre (n=10)	Random sample of 12 patients from each centre using PD, 102 eligible	WHO-QOL brief version, KDQOL symptoms	Descriptive statistics, t-tests for differences in WHO-QOL between groups according to	Positive QOL in terms of social support, personal relationships and spirituality, but worse QOL in terms of dependence on medication, concentration, sex and	-

					socio-demographic variables. Multivariate regression analysis of WHO-QOL domains	financial resources. Symptoms of end-stage renal disease associated with worse QOL. Thai PD patients QOL comparable with other countries.	
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Appendix Seven: Studies considering families' quality of life

Author and year	Location	Study design	Sample: size and technique	Data collection tool	Data analysis	Main findings	Recommendations
(Dunn et al. 1994)	USA	Descriptive correlational	Convenience sample PD spouses (n=38)	QOL index , dyadic adjustment scale, Jalowiec Coping Scale	Descriptive statistics, correlation analysis and regression analysis	Overall QOL "moderate", 28% reported marital adjustment as "average". Problem-focussed coping strategies used, as well as prayer	Early marriage counselling, nurse spending time with the spouse alone, pre-dialysis education, referral to a social worker and spouse support group.
(Wicks et al. 1997)	USA	Exploratory descriptive observational study	Convenience sample of carers (n=92) of patients with ESRD awaiting TP HD (n=52) PD (n=15) HHD (n=2) Pre-dialysis (n=18)	General Quality of Life measure and Caregiver Burden Interview. Author-developed health rating tool	Descriptive statistics and ANOVA	2% rated QOL poor-very poor, 17% rated QOL adequate, 57% rated QOL as good and 23% rated QOL as excellent. 35% mild-moderate burden, 5% moderate-severe burden. Increased burden: decreased QOL. Decreased burden: improved carer health	Studies to promote interventions to enhance patient and family outcomes
(Shimoyama et al. 2003)	Japan, multicentre (n=2)	Cross-sectional	1/3 PD patients from hospitals (n=26), PD caregivers from support group (n=34) ?sampling strategy	Medical Outcomes Survey SF-36, Kidney Disease QOL Short-Form , Zarit Burden Interview (caregivers only)	One-way ANOVA, t-tests, Spearman Rank Correlation Analysis, p<0.01	Carer: below norm on all outcomes, increased burden=decreased QOL.	Patient burden of kidney disease: psychosocial support specific to renal care needed. Further research with larger numbers, then appropriate interventions.

				Demographics			
(Alvarez-Ude et al. 2004)	Spain	Cross-sectional	Random sample patients HD (n=152) and PD (n=69) and their primary caregiver	Medical Outcome Survey SF-36 , Zarit Burden Interview scale, Functional Social Support Questionnaire. HCP co-morbidity index and Barthel Index Dependency	Standard statistical tests and Pearson's correlation coefficient	Carer QOL slightly worse than general population. Mental health worse when social support low. Higher burden: lower QOL. 32.6% caregivers moderate burden; 28.3% of caregivers at risk of clinical depression.	Assessment of the family, psychosocial measurements, support groups, time away for families, and public support.
(Morelon et al. 2005)	France, multicentre (n=?)	Survey	5000 questionnaires sent out ?sampling strategy. 1815 returned; TP partners (n=827) Dialysis partners (n=988). ?DX modality.	Author-designed questionnaire with 16 relatives of ESRD patients. Covering patients' health, impact on partner, partner involvement and partners' needs	Fisher's exact test; p<0.01	TP significantly higher QOL. Dialysis partners reported QOL: 28% good, 44% acceptable, 20% mediocre and 8% poor. Practical restrictions TP 38%, DX 81%. 14% DX and 8% TP reported depression.	Better information availability about ESRD and RRT, financial aid, material support and easier access to psychological treatments.
(Fan et al. 2008)	UK	Longitudinal, over 1 year	112 pairs of PD patients and carers completed initially, 36 returned questionnaires after 12 months (not completed due to TP, HD, refusal, death)	Medical Outcome Survey SF-36	Correlation coefficients	QOL reduced in all domains for carers except bodily pain, but higher than patients'. At 12 months, better social functioning, but no other changes.	Continue to carefully select and support patients and carers. PD can be a good option for dependent patients

Appendix Eight: Studies considering depression in patients with end-stage renal disease

Patients using peritoneal dialysis							
Author and year	Location	Study design	Sample: size and technique	Data collection tools	Data analysis	Main findings	Recommendation
(Hong et al. 2006)	USA	Longitudinal	All PD patients at one centre, number completed questionnaires n=64	Collected monthly for 23 months: assessment of uraemic physical symptoms, Likert-scale for quality of life, two questions relating to depression	Descriptive statistics, univariate analysis, multivariate regression	34.4% patients reported depression in the two questions. Significant association between quality of life, physical symptoms and depression.	Clinicians should carefully assess patients for depression and treat as necessary.
(Bilgic et al. 2008)	Turkey	Cross-sectional	CAPD patients (n=60), receiving treatment for >6 months. ?sampling technique	Beck Depression Inventory (BDI) , Medical Outcome Study SF-36, Pittsburgh Sleep Quality Index	Descriptive statistics, correlation analysis, multi linear regression	Suboptimal QOL. Depression significant indicator of decreased QOL, present in 53.3% participants. Poor sleep in 31.7% of participants, also associated with decreased QOL.	Depression and sleep quality need to be regularly assessed and treatment instigated. Psychosocial support also needed.
(Chan et al. 2011)	Hong Kong	Cross-sectional	Decide by confidence interval: random sample then recruited who met inclusion criteria (>18, PD, Chinese, communicate in Cantonese and	Cumulative Illness Rating Score, Structured Clinical Interview for DSM-IV (Diagnostic and Statistical	Descriptive statistics, Chi-square test and Fischer's exact test. Bivariate analysis and	16% of patients had current major depression. 21% had past major depression. Lifetime prevalence= 37%. Depressed patients more likely to have distressing muscle	Multidisciplinary approach to meet mental health needs. Prospective research to examine cause between

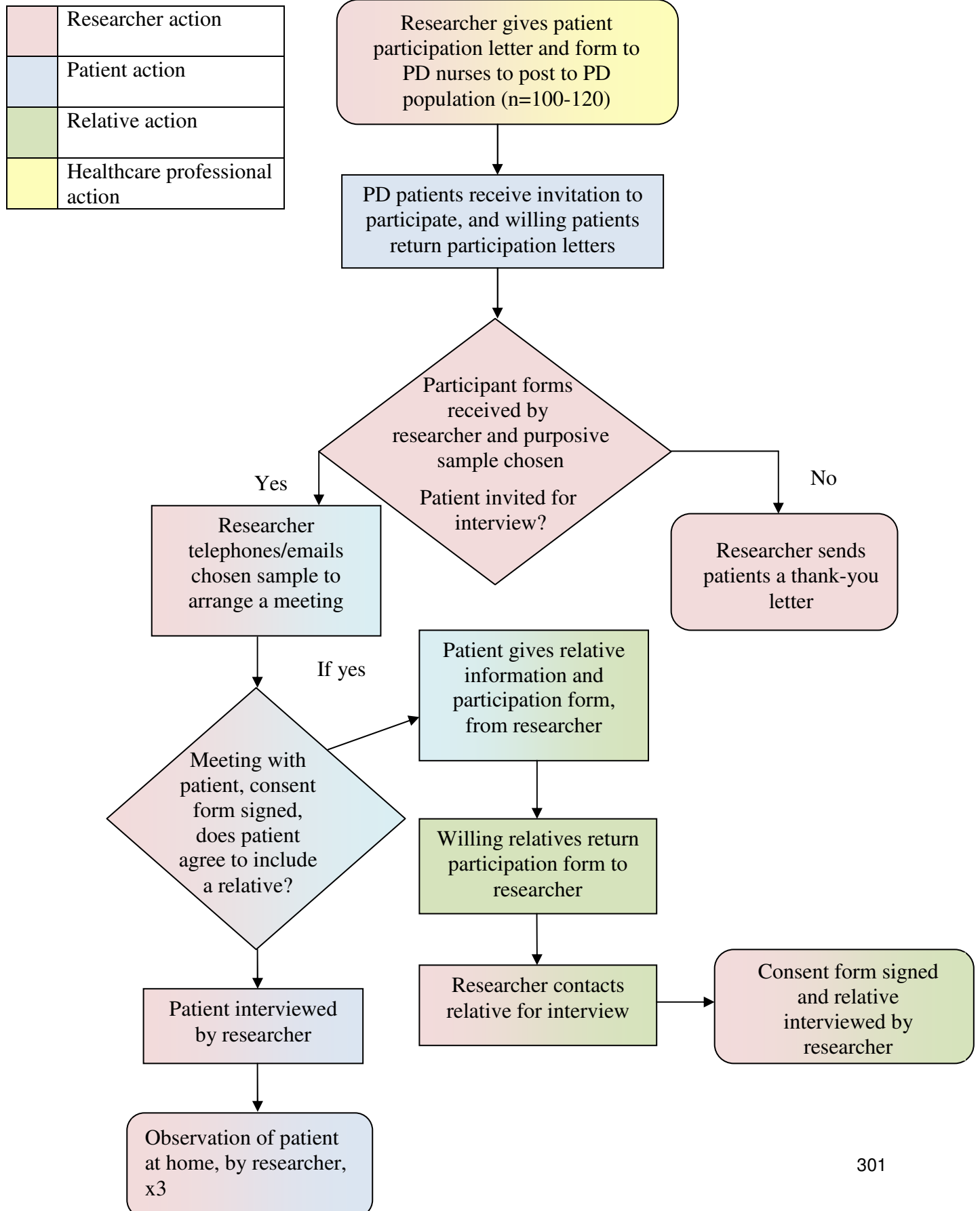
			physically well) n=141, 90% CAPD	Manual for Mental Disorders), Multidimensional Scale of Perceived Social Support	logistic regression analysis.	cramps or chronic back pain. Bivariate analysis: distressing muscle cramps, chronic back pain, joint stiffness, low perceived social support correlated with depression. Less than 20% of depressed people receiving treatment.	depression in PD patients and risks.
Yu et al (2012)	Singapore	Cross-sectional	Eligible patients selected by nurse in single-centre (n=29), 20 eligible and agreed (CAPD=5, APD=15)	Beliefs about Medicines Questionnaire (BMQ), three items developed to assess adherence to medication, diet and PD regimen, Hospital Anxiety and Depression Scale (HADS) , KDQOL, SF-12, six kidney disease subscales: symptom, effect, burden, social support, satisfaction, staff encouragement	T-test, correlation	Depression identified in 40%, but not associated with adherence. QOL showed concern for lifestyle burden, less so for symptoms. High reliance on family members. High self-efficacy in managing disease, good awareness of necessity of medications and low concern of disruption caused by medicines. Satisfactory levels of adherence for diet, medicine and dialysis regime. Adherence to PD higher in APD than CAPD. Medication adherence worse in patients who worked. Dietary adherence better in patients who lived with family, but	Regular monitoring and potential interventions to support patients to manage and adjust to PD.

						worse than medication or treatment.	
Patients using renal replacement therapies							
Author and year	Location	Study design	Sample: size and technique	Data collection tools	Data analysis	Main findings	Recommendation
(Sacks et al. 1990)	USA	Cross-sectional	CAPD=14, HD=43, chronic kidney disease=16. Sampling strategy unclear: volunteer/ convenience	Beck Depression Inventory (BDI), Cognitive Depression Index (CDI) , perception of illness (IEQ), role disruption questionnaire (SAS-SR)	Descriptive statistics and correlation	BDI and CDI – all participants mildly depressed. IEQ correlated with BDI, CDI and elements of SAS-SR. Similar scores between HD and PD patients for CDI and BDI. CAPD more accurate perception of illness severity.	Evaluation and modification of illness perceptions, particularly in HD and chronic kidney disease patients.
(Martin et al. 2003)	UK	Cross-sectional	PD=72, HD=28, live-related TP=21, heart-beating cadaveric TP=18, non-heart beating cadaveric TP=21. Sampling not clear ?volunteer	Hospital Anxiety and Depression Scale (HADS) for anxiety (HADS-A) and depression (HADS-D)	Descriptive statistics, parametric (ANOVA) and non-parametric tests (Kruskal-Wallis)	HD and live-related TP had highest anxiety and depression scores.	Routine screening of anxiety and depression in renal patients, particularly HD and live-related TP, to allow for interventions.
(Billington et al. 2008)	UK	Cross-sectional	Eligible patients approached, 42% returned questionnaires (23% unusable due to missing data) n=103 (PD=25, HD=71, HHD=7). Medium	Trait hope scale, Significant others scale, health locus of control scale, HADS , Kidney Disease QOL measure	Correlational analysis, multiple regression analysis	Depression=39%, anxiety=38%. High burden of kidney disease reported. Hope inversely related to anxiety and depression.	Hope should be encouraged through therapeutic activities

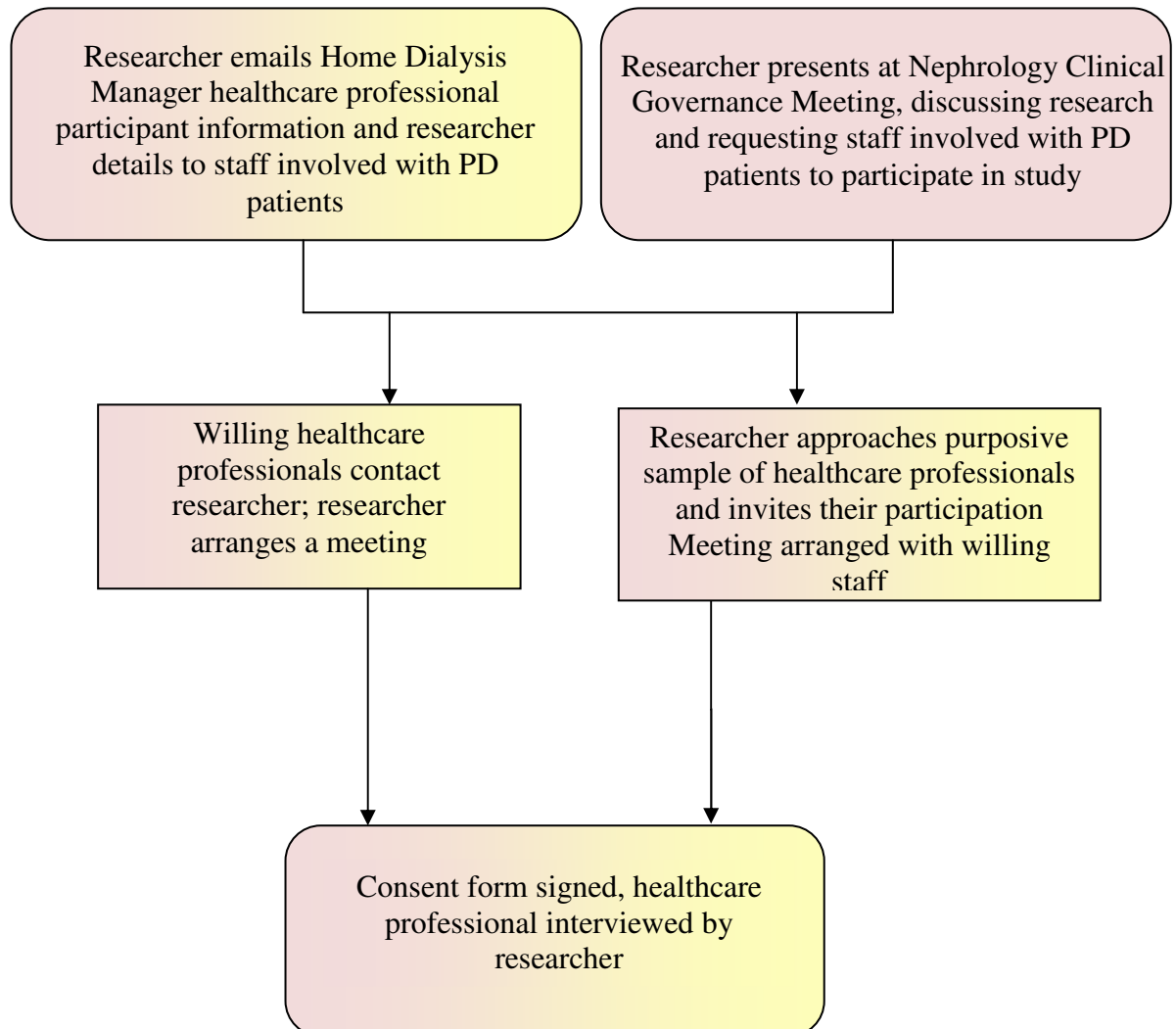
			effect size.				
(Griva et al. 2010)	UK	Cross-sectional	Eligible patients contacted, 88.4% dialysis (CAPD=45, APD=23, HD=25, HHD=52) consented.	End-Stage Renal Disease Severity Index, BDI , Illness Perceptions Questionnaire (IPQ), IEQ, Treatment Effects Questionnaire (TEQ)	Bivariate and multivariate analysis, multiple linear regression	Mean depression score= mild depression. 38.6% depressed. CAPD highest depression (48.9%), HHD lowest (8%); APD (26.1%), HD (42.3%). Depression correlated with low control beliefs, higher illness and treatment disruption, higher consequences, poor medical care attributions and more symptoms.	Additional research considering relationship between treatment modality and resilience/social circumstances

Appendix Nine: Research flow chart

Patient and Relative Sampling and Data Generation



Healthcare Professional Sampling and Data Generation



Appendix Ten: Topic guides for semi-structured interviews

Patient (and relative) Interview Topic Guide

1. You said in your form that you have been undertaking peritoneal dialysis for X years, but when did you start seeing a doctor about your kidneys?
Early symptoms
Reaction to diagnosis
Family's reaction to diagnosis
2. Why did you choose peritoneal dialysis?
How was the decision made?
Who was present?
Have you used any other forms of renal replacement therapy?
How did you feel about haemodialysis and transplantation?
3. Where were you trained to use peritoneal dialysis?
Who trained you? How long did it take? Who else was present?
How did you find the treatment at first?
4. What is your normal routine with peritoneal dialysis?
When do you perform your first, second, third and final treatments? Or, what time do you start and finish APD?
Who does the treatment? You and/or your relative?
How long does an exchange take? What else do you do while performing an exchange?
5. How do you feel peritoneal dialysis impacts on your life?
Physically
Psychologically
Socially
Economically (employed?)
Impact on the home environment – where do you perform the treatment?
Ability to go on holiday? How does this work with PD?
6. How have you adjusted to performing peritoneal dialysis?
Psychologically
Physically
Socially
As a family – what do they think about the treatment?
7. What support have you had whilst undertaking the treatment? At home/hospital?
Do you feel you need additional support?
Who from? Like what?

Nb. Questions about the future (transplant, haemodialysis, deterioration) were revealed when discussing patients' reasons for choosing peritoneal dialysis, how well they were coping physically with the treatment and through discussion of how they manage the technology (e.g. having bloods taken at clinic to remain up-to-date on the transplant register).

Healthcare Professional Interview Topic Guide

1. How do you prepare patients and families for commencing peritoneal dialysis?

What information do you provide patients with before commencing peritoneal dialysis?

How is the decision regarding treatment modality made? With whom? Over what time period? Who chooses?

2. How do you feel peritoneal dialysis impacts on the lives of their patients and families?

Physically, psychologically, socially, financially

3. What support is currently given to patients and families at home on PD?

What do you feel about this support?

What further support do you feel would benefit peritoneal dialysis patients and families, if any?

Appendix Eleven: Data analysis process - theme progression

Initial coding	Interim analysis	Final themes
Anger Attitude <ul style="list-style-type: none"> ESRD, HD, PD, Transplant, general Confidence Control Coping Creativity Diagnosis <ul style="list-style-type: none"> Aetiology, family, physical condition, reaction Future <ul style="list-style-type: none"> APD, condition, HD, mortality, transplant General recommendations Learning <ul style="list-style-type: none"> Peer, prior knowledge Life before ESRD Lifestyle implications <ul style="list-style-type: none"> Diet and fluids, feelings about changed lifestyle, holidays, home environment, impact on family, leisure, life outside dialysis, money, routine, self-care, sleep, work NHS Physical health Practicalities <ul style="list-style-type: none"> Activities during exchange, alarms, bowels, boxes, CAPD vs. APD, complications, family 	Crisis Diagnosis and reaction Choosing a renal replacement therapy What is peritoneal dialysis – difficulty in conceptualising Being trained and starting peritoneal dialysis – fear, anticipation and relief Chronic Living with peritoneal dialysis <ul style="list-style-type: none"> Home environment Stigma Routine and procedure Feelings towards treatment Physical impact Leisure and work Holidays Learning <ul style="list-style-type: none"> Complex world of PD Language X Self-monitoring Diet and fluid Support <ul style="list-style-type: none"> Family, healthcare professionals, peer, other Creativity, confidence and control <ul style="list-style-type: none"> Confidence over time, creativity, maintaining control The Silver Lining	Journeys to peritoneal dialysis Diagnosis to dialysis <ul style="list-style-type: none"> Entering the home, back to clinic, approaching dialysis, time for dialysis Decision making <ul style="list-style-type: none"> Simple of a struggle, the case for PD, family involvement Starting peritoneal dialysis <ul style="list-style-type: none"> Being taught, reality sets in Living with peritoneal dialysis Altered spaces <ul style="list-style-type: none"> First impressions, dominant dialysis Challenges of living with PD <ul style="list-style-type: none"> Daily routine Dominance and disruption Threats, fear and responsibility Keeping it in the family Integration, freedom and asserting control <ul style="list-style-type: none"> Flexibility with time and space; creativity and innovations.

<p>involvement, infection, infection control, location of exchange, medications, physical impact, procedure, recommendations, Tenckhoff, timing, waste</p> <p>Pre-dialysis</p> <ul style="list-style-type: none"> Choice, family involvement, information, recommendations <p>Rationalisation</p> <ul style="list-style-type: none"> Alive, comparison to others, luck, other, unlucky <p>Role</p> <p>Starting dialysis</p> <ul style="list-style-type: none"> Feeling better, reaction, training <p>Success</p> <p>Support</p> <ul style="list-style-type: none"> Family, friends, healthcare professional, others, peer, recommendations <p>Thinking of others on PD</p>	<ul style="list-style-type: none"> Feeling lucky, thinking of others, success X <p>Options for the future</p> <ul style="list-style-type: none"> Continue PD, transplant, haemodialysis, automated peritoneal dialysis <p>Terminal</p> <p>Awareness of deteriorating and dying</p>	<p>Looking to the future</p> <p>Fear of change</p> <p>Uncertainty and lack of control</p> <ul style="list-style-type: none"> Living on the edge, confusion about transplantation, false hopes. <p>Hope and expectation</p> <p>Comparison to others</p> <ul style="list-style-type: none"> Deterred, inspiration.
--	--	--

Appendix Twelve: Ethical approval letters



18 November 2010

Miss Jessica Baille
PhD student
School of Nursing and Midwifery Studies
Room 415 Eastgate House
Cardiff University
Newport Road
CF24 0AB

Dear Miss Baille,

**Project ID : 10/CMC/4887 : Perspectives On Peritoneal Dialysis At Home:
Implications For The Management Of A Chronic Condition**

REC Reference: 10/WSE04/49
Amendment: As requested by REC

Thank you for recent correspondence notifying the [REDACTED]
[REDACTED] of amendments to the above study.

The documents received were:-

Document	Version	Date
Covering letter summarising changes		3 November 2010
[REDACTED] Wales REC favourable opinion letter		1 November 2010
Letter of Invitation to Participant: Patient	1.1	20 October 2010
Participant Information Sheet: Patient	1.2	20 October 2010
Participant Information Sheet: Key Informant	1.1	08 October 2010
Participant Information Sheet: Relative/Friend	1.1	20 October 2010
Participant Consent Form: Patient	1.1	20 October 2010
Participant Consent Form: Relative/Friend	1.1	20 October 2010
Participant Consent Form: Key Informant	1.0	20 October 2010
Participant Consent Form: Relative/Friend for observations	1.0	20 October 2010

Version 1.0 09.06.10

Page 1 of 2



LN-HW129X

I can confirm that the amendment has been favourably reviewed and that you may continue with this study accordingly.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the R&D Office if any external or additional funding is awarded for this project in the future.
- Inform the R&D Office of any further amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start / end dates.
- Complete any documentation sent to you by the R&D Office or University Research & Commercial Division regarding this project.
- Adhere to the protocol as approved by the Research Ethics Committee.
- Ensure the research complies with the Data Protection Act 1998.

Yours sincerely,

[Redacted Signature]

[Redacted Name]
R&D Coordinator

CC R&D Lead [Redacted]
Chris Shaw, Research and Commercial Division, Cardiff University



GIG
CYMRU
NHS
WALES

Canolfan Gwasanaethau
Busnes
Business Services
Centre

Wales Research Ethics Committee

Telephone:

01 November 2010

Miss Jessica Baillie
PhD Student
Cardiff University
415, School of Nursing and Midwifery Studies
EastGate House,
Newport Road, Cardiff
CF24 0AP

Dear Miss Baillie

Study Title: Perspectives on peritoneal dialysis at home:
implications for the management of a chronic
condition

REC reference number: 10/WSE04/49

Protocol number: SPON839-10

Thank you for your letter of 25 October 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair,

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Canolfan Gwasanaethau Busnes
Ty Churchill
17 Ffordd Churchill
Caerdydd, CF10 2TW
Ffôn: 029 20 376820 WHTN: 1809
Ffacs: 029 20 376826



Business Services Centre
Churchill House
17 Churchill Way
Cardiff, CF10 2TW
Telephone: 029 20 376820 WHTN: 1809
Fax: 029 20 376826

rhan o Bwrdd Iechyd Lleol Addysgu Powys / part of Powys Teaching Local Health Board

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV	Dr AJ Lankshear	25 October 2010
Protocol	1.0	20 April 2010
Reviewer 1 Comments	No version, undated	
REC application		08 September 2010
Letter from Sponsor	Cardiff University	26 May 2010
Letter of invitation to participant	1.0	20 April 2010
Letter of invitation to participant	1.1 - Patient	20 October 2010
Participant Information Sheet: Patient	1.2	20 October 2010
Participant Consent Form: Relative/Friend for observations	1.0	20 October 2010

Response to Request for Further Information		25 October 2010
Participant Information Sheet: Key Informant	1.1	08 October 2010
Participant Information Sheet: Relative/Friend	1.1	20 October 2010
Participant Consent Form: Patient	1.1	20 October 2010
Participant Consent Form: Relative/Friend	1.1	20 October 2010
Participant Consent Form: Key Informant	1.0	20 October 2010
Questionnaire: Patient Interview Topic Guide	1.0	08 September 2010
Questionnaire: Relative/Friend/Significant Other Interview Topic Guide	1.0	08 September 2010
Questionnaire: Key Informant Topic Guide	1.0	08 September 2010
Reviewer 2 Comments	No version, undated	
Letter from C&V UHB		02 August 2010
Letter re funding: RCB Wales		21 September 2009
Curriculum Vitae	J Bailey	08 September 2010
Evidence of insurance or indemnity	Zurich Municipal	27 July 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/WSE04/49

Please quote this number on all correspondence

Yours sincerely



Chair

Email:



Enclosures: "After ethical review – guidance for researchers" SL- AR2

Copy to: R&D office for Cardiff University

Appendix Thirteen: Patient recruitment letter, participant information sheet and consent form

Dear

I am writing to invite you to take part in a research study entitled “Perspectives on peritoneal dialysis at home”. The study is being carried out by a research student (Jessica Baillie) at Cardiff University, in collaboration with *participating Health Board*. The study is exploring the experiences of patients and families regarding peritoneal dialysis treatment.

Information about the study is enclosed, and if you have any queries you can talk to me or Jessica. Our contact details are listed in the study information.

Yours Sincerely,

Home Dialysis Manager

Information about the Research

Study title: Perspectives on peritoneal dialysis at home

You are invited to take part in the above research study as you are undertaking peritoneal dialysis at the moment. Before you decide if you would like to take part in this research, please read the following information and feel free to discuss it with others. My name is Jessica Baillie, I am a qualified nurse, and I am investigating patients' and families' experiences of receiving peritoneal dialysis (PD) at home, and work.

Peritoneal dialysis is a treatment for chronic kidney disease, which as you know involves filling and draining the abdominal cavity with a glucose solution. The findings of the study could be used to help support patients on peritoneal dialysis and their families. The research is being carried out with the patients of Dr ----- and the PD Nurses based at the *participating Health Board*. My contact details are at the bottom of this information sheet, please do not hesitate to contact me with any questions you may have.

What is the research about?

The research is about developing an understanding of the experience of patients when peritoneal dialysis is undertaken at home, why the treatment was chosen and how it impacts on everyday life and the home environment. The experiences of family members/ close friends who are involved with a relative on peritoneal dialysis are also sought, to understand how peritoneal dialysis impacts on home life.

Why is the research being undertaken?

Little research has been conducted in the UK that focuses on the experiences of patients on peritoneal dialysis and their families. The findings and recommendations of this study would therefore aim to provide more evidence of how healthcare professionals (e.g. Consultant, GP, nurses) can support patients and families undertaking peritoneal dialysis at home.

How and where will the research be undertaken?

I would come to your home (although an office at Cardiff University is available if you prefer) to interview you for about an hour, where you could talk about your experiences of being on peritoneal dialysis. This interview would be recorded on a digital recorder, with your consent. If a relative/close friend would be interested in being interviewed about their experiences of the treatment, then their interview would be conducted too at a time and place handy for them. Finally, I would spend up to three mornings or afternoons with you (when convenient for you) while you carry out your normal day, to observe how peritoneal dialysis is undertaken. You would be provided with verbal information about the study at every stage of the research. At the end of the study you will receive a written report explaining what the study found.

Do I have to take part?

You do not have to take part in the study, and your care will not be affected by not taking part. If you decide to take part and then leave the study, your care will not be affected.

What are the potential benefits of the research?

This research may not benefit you personally. The information we get from this study may help healthcare staff to further support patients on peritoneal dialysis at home.

Is there any risk of harm from the research?

There is no predicted harm from the research, although it is possible that discussing some aspects of undertaking your treatment and its effect on your life and family may be distressing. If this happens the researcher will be able to contact the clinical team to provide you with support.

What do I do now?

If you are interested in taking part, please complete the attached form and return it in the pre-paid envelope by (four weeks from now). I will then contact you to organise a time convenient to meet with you. The form asks a few questions about your dialysis and social situation, to help me select a variety of individuals to include in the study. Not everybody who completes the attached form will necessarily be included in the research and you will receive a thank you letter if you have not been included.

Who to contact?

If you have any questions or queries, please feel free to contact me:

My contact details

Alternatively, you can speak to the Home Dialysis Manager, at the *Participating Health Board* on 0-----.

Additional Information about the Research

Study title: Perspectives on peritoneal dialysis at home

What about confidentiality?

All the information collected will be treated confidentially, with your name and address removed. All data will be safely stored. The tapes used to record the interview will be safely stored, and the tapes will be destroyed when the interview has been transcribed. The data collected will not be shared with anybody else in the study or external agencies, but may be reviewed by *the participating Health Board* to monitor the conduct of the research.

What will happen with the results of the research?

The findings of the study will be discussed with the healthcare team at the *participating Health Board*. The findings will also be submitted for publication in journals for healthcare professionals.

Who is funding the study?

I am a qualified nurse and PhD student at Cardiff University. I am being funded by the Research Capacity Building Collaboration in Wales, which is a Welsh Assembly Government scheme to boost research in Wales.

Who has approved the study?

The study has been approved by the Research Ethics Committee for South East Wales, and has undergone scientific review by the Joint Health Board and Cardiff University review service (Cardiff Research Review Service). Research and Development approval has been issued following this review by the *participating Health Board* Research and Development Office.

What if something goes wrong?

We do not expect any harm to come to you from taking part in this study. However, if you are not happy about any aspect of the study, please feel free to contact me on the details above. Alternatively, you can talk to the Home Dialysis Manager about any aspect of the research. If you wish to make a more formal complaint, the *Participating Health Board* has a complaints service, and they can be contacted on 0-
-----.

Other considerations

If you lost capacity to consent during the study you would be excluded and no new information would be collected from you. However, previous information collected during interviews/observations would still be used – the researcher will explain this in full if you decide to take part in the study.

Perspectives on peritoneal dialysis at home: implications for the management of a chronic condition

Please complete the following information and return it in the pre-paid envelope.

Name.....

Age.....

Address.....

.....

Are you currently on:

Continuous Ambulatory Peritoneal Dialysis (CAPD) during the day

or

Automated Peritoneal Dialysis (APD) during the night

How long have you been on Peritoneal Dialysis?

Who do you live with?

Spouse/partner

Friend

Lodger/Landlord

Alone

Parent/sibling

Children

Other.....

How would you prefer to be contacted? (Please provide email address/ phone number)

€Email.....

€Home phone number.....

€Mobile phone number.....

Thank you for taking the time to complete this form.

Consent Form

Study Title: Perspectives on peritoneal dialysis at home

Please initial
box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that my interview will be recorded on a digital recording device. I give permission for this.
4. I understand that data collected may be looked at by responsible representatives from involved organisations for the purposes of monitoring and auditing the conduct of the research. I give permission for this.
5. I understand that data collected will not be transferred to any commercial organisation.
6. I understand that if I lose the capacity to consent, that I will be withdrawn from the study. I understand that any information collected from interviews/observations before the loss of consent will still be included in the study.
7. I agree to take part in the above study.

☐☐☐☐☐☐☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for participant, 1 for researcher

Appendix Fourteen: Relative information sheet and consent forms

Information about the Research

Study title: Perspectives on peritoneal dialysis at home

You are invited to take part in the above research study as you have a relative/friend undertaking peritoneal dialysis at the moment. Before you decide if you would like to take part in this research, please read the following information and feel free to discuss it with others. My name is Jessica Baillie, I am a qualified nurse, and I am investigating patients' and families' experiences of receiving peritoneal dialysis (PD) at home.

Peritoneal dialysis is a treatment for chronic kidney disease, which as you know involves filling and draining the abdominal cavity with a glucose solution. The findings of the study could be used to help support patients on peritoneal dialysis and their families. The research is being carried out with the patients of Dr ---- and the PD Nurses based at *the participating Health Board*. My contact details are at the bottom of this information sheet, please do not hesitate to contact me with any questions you may have.

What is the research about?

The research is about developing an understanding of the experience of patients when peritoneal dialysis is undertaken at home, why the treatment was chosen and how it impacts on everyday life and the home environment. The experiences of family members/ close friends who are involved with a relative on peritoneal dialysis are also sought, to understand how peritoneal dialysis impacts on home life.

Why is the research being undertaken?

Little research has been conducted in the UK that focuses on the experiences of patients on peritoneal dialysis and their families. The findings and recommendations of this study would therefore aim to provide more evidence of how healthcare professionals (e.g. Consultant, GP, nurses) can support patients and families undertaking peritoneal dialysis at home.

How and where will the research be undertaken?

I would come to your home (although an office at Cardiff University is available if you prefer) at a time convenient for you, to interview you for about an hour. During the interview you could talk about your experiences of having a relative at home on peritoneal dialysis. This interview would be recorded on a digital recorder, with your consent. You would be provided with verbal information about the study at every stage of the research.

Do I have to take part?

You do not have to take part in the study; if you decide to take part you can leave the study at any point without giving a reason.

What are the potential benefits of the research?

This research may not benefit you personally. The information we get from this study may help healthcare staff to further support patients on peritoneal dialysis, and their families, at home.

Is there any risk of harm from the research?

There is no predicted harm from the research although it is possible that discussing some aspects of your relative's/ friend's treatment and its effect on your life and family may be distressing. If this happens the researcher will be able to contact the clinical team to provide you with support.

What do I do now?

If you are interested in taking part, please complete the attached form and return it in the pre-paid envelope by (four weeks from now). I will then contact you to organise a time convenient to meet with you. Not everybody who completes the attached form will necessarily be included in the research and you will receive a thank you letter if you have not been included.

Who to contact?

If you have any questions or queries, please feel free to contact me:

My contact details

Alternatively, you can speak to the Home Dialysis Manager at the *participating Health Board* on 0-----.

Additional Information about the Research

Study title: Perspectives on peritoneal dialysis at home

What about confidentiality?

All the information collected will be treated confidentially, with your name and address removed. All data will be safely stored. The tapes used to record the interview will be safely stored, and the tapes will be destroyed when the interview has been transcribed. The data collected will not be shared with any external agency, but may be reviewed by *participating Health Board* to monitor the conduct of the research.

What will happen with the results of the research?

The findings of the study will be discussed with the healthcare team at the *participating Health Board*. The findings will also be submitted for publication in journals for healthcare professionals.

Who is funding the study?

I am a qualified nurse and PhD student at Cardiff University. I am being funded by the Research Capacity Building Collaboration in Wales, which is a Welsh Assembly Government scheme to boost research in Wales.

Who has approved the study?

The study has been approved by the Research Ethics Committee for South East Wales, and has undergone scientific review by the Joint Health Board and Cardiff University review service (Cardiff Research Review Service). Research and Development approval has been issued following this review by the *participating Health Board* Research and Development Office.

What if something goes wrong?

We do not expect any harm to come to you from taking part in this study. However, if you are not happy about any aspect of the study, please feel free to contact me on the details above. Alternatively, you can talk to the Home Dialysis Manager about any aspect of the research. If you wish to make a more formal complaint, the *participating Health Board* has a complaints service, and they can be contacted on 0-
-----.

Other considerations

If you lost capacity to consent during the study you would be excluded and no new information would be collected from you. However, previous information collected during interviews would still be used – the researcher will explain this in full if you decide to take part in the study.

Perspectives on peritoneal dialysis at home: implications for the management of a chronic condition

Please complete the following information and return it in the pre-paid envelope.

Name.....

Address.....

.....

Email.....

Phone number.....

Name and relationship to individual on peritoneal dialysis

.....

How would you prefer to be contacted? (Please provide email address/ phone number)

€ Email.....

€ Home phone number.....

€ Mobile phone number.....

Thank you for taking the time to complete this form.

Consent Form

Study Title: Perspectives on peritoneal dialysis at home

Please initial
box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and without my legal rights being affected.
3. I understand that my interview will be recorded on a digital recording device. I give permission for this.
4. I understand that data collected may be looked at by responsible representatives from involved organisations for the purposes of monitoring and auditing the conduct of the research. I give permission for this.
5. I understand that data collected will not be transferred to any commercial organisation.
6. I understand that if I lose the capacity to consent, that I will be withdrawn from the study. I understand that any information collected from interviews/observations before the loss of consent will still be included in the study.
7. I agree to take part in the above study.

☐☐☐☐☐☐☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for participant, 1 for researcher

Consent Form

Study Title: Perspectives on peritoneal dialysis at home

Please initial
box

1. I confirm that the study has been explained to me, that I have had the opportunity to consider this information, ask questions and have had these questions answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
3. I understand that data collected may be looked at by responsible representatives from involved organisations for the purposes of monitoring and auditing the conduct of the research. I give permission for this.
4. I understand that data collected will not be transferred to any commercial organisation.
5. I agree to take part in the above study.

☐☐☐☐☐

Name of Participant

Date

Signature

Name of Person taking
consent

Date

Signature

When completed: 1 for participant, 1 for researcher

Appendix Fifteen: Healthcare professional information sheet and consent form

Information about the Research

Study title: Perspectives on peritoneal dialysis at home

As a healthcare professional involved in the care of patients on peritoneal dialysis (PD), you are invited to take part in the above research study. Before you decide if you would like to take part in this research, please read the following information and feel free to discuss it with others. My name is Jessica Baillie, I am a qualified nurse and I am investigating patients' and families' experiences of receiving peritoneal dialysis at home, and work. The perspectives of healthcare professionals are also sought. It is hoped that the findings of the study may be useful in helping to support patients on peritoneal dialysis and their families, and is being carried out with the patients of Dr -----. My contact details are at the bottom of this information sheet, please do not hesitate to contact me with any questions you may have.

What is the research about?

The research is primarily about understanding the experience of patients when peritoneal dialysis is undertaken at home, why the treatment was chosen and how it impacts on everyday life and the home environment. The experiences of family members/ close friends who are involved with a relative on peritoneal dialysis are also sought, to understand how peritoneal dialysis impacts on home life. The study is also interested in understanding how healthcare professionals involved with patients on peritoneal dialysis view the treatment, its impact on the individual and family, and how they prepare families for undertaking the treatment at home.

Why is the research being undertaken?

Little research has been conducted in the UK that focuses on the experiences of patients and their families on peritoneal dialysis. The findings and recommendations of this study would therefore aim to provide more evidence of how healthcare professionals (e.g. Consultant, GP, nurses) can support patients and families undertaking peritoneal dialysis at home.

How and where will the research be undertaken?

I would come to your place of work (although an office is available at Cardiff University if you would prefer) to interview you for about 30 minutes. The interview would cover the following topic areas: (1) what information you provide patients and families with before commencing PD, (2) how you feel PD impacts on the lives of your patients and families, (3) what further support you feel would benefit patients on PD and their families (if any). This interview would be recorded on a digital recorder, with your consent.

Do I have to take part?

You do not have to take part in the study, and if you decide to take part you can withdraw at any point without giving a reason.

What are the potential benefits of the research?

This research may not benefit you personally. The information we get from this study may help healthcare staff to further support patients on peritoneal dialysis at home.

Is there any risk of harm from the research?

There is no predicted harm from the research.

What do I do now?

If you are interested in taking part, please email or telephone me. I will then contact you to organise a time convenient to meet with you. Not everybody who volunteers will necessarily be included in the research and you will receive a thank you email if you have not been included.

Who to contact?

If you have any questions or queries, please feel free to contact me:

My contact details

Alternatively, you can speak to the Home Dialysis Manager on 0-----.

Additional Information about the Research

Study title: Perspectives on peritoneal dialysis at home

What about confidentiality?

All the information collected will be treated confidentially, with your name and address removed. All data will be safely stored. The tapes used to record the interview will be safely stored, and the tapes will be destroyed when the interview has been transcribed. The data collected will not be shared with the *participating Health Board* or anybody else in the study or external agencies, but may be reviewed by them to monitor the conduct of the research.

What will happen with the results of the research?

The findings of the study will be discussed with the healthcare team at the *participating Health Board*. The findings will also be submitted for publication in journals for healthcare professionals.

Who is funding the study?

I am a qualified nurse and PhD student at Cardiff University. I am being funded by the Research Capacity Building Collaboration in Wales, which is a Welsh Assembly Government scheme to enhance research in Wales.

Who has approved the study?

The study has been approved by the Research Ethics Committee for South East Wales, and has undergone scientific review by the Joint Health Board and Cardiff University review service (Cardiff Research Review Service). Research and Development approval has been issued following this review by the *participating Health Board* Research and Development Office.

What if something goes wrong?

We do not expect any harm to come to you from taking part in this study. However, if you are not happy about any aspect of the study, please feel free to contact me on the details above. Alternatively, you can talk to the Home Dialysis Manager about any aspect of the research. If you wish to make a more formal complaint, the *participating Health Board* has a complaints service, and they can be contacted on 0-
-----.

Consent Form

Study Title: Perspectives on peritoneal dialysis at home

Please initial
box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and without my legal rights being affected.
3. I understand that my interview will be recorded on a digital recording device. I give permission for this.
4. I understand that data collected may be looked at by responsible representatives from involved organisations for the purposes of monitoring and auditing the conduct of the research. I give permission for this.
5. I understand that data collected will not be transferred to any commercial organisation.
6. I agree to take part in the above study.

☐☐☐☐☐☐

Name of Participant

Date

Signature

Name of Person taking
consent

Date

Signature

When completed: 1 for participant, 1 for researcher

Appendix Sixteen: “Fog Factor”

The following formula is provided by the National Patient Safety Agency (2009) to calculate the “fog factor” of participant information sheets:

- Count the words and sentences then divide the words by the sentences
- Count the long words (more than two syllables)
- Divide the long words by total words, and multiply by 100
- Add the two scores together and multiply by 0.4 to give the fog index

Example “Fog Factor” Scores:

- A newspaper advertisement 4
- A popular novel 8
- A report on information technology 20

To calculate the fog factor scores, the names of people were excluded (for example, Jessica Baillie) but the names of places were included (for example Cardiff University).

Patient Information Sheet

Words: 1,122

Sentences: 92

Words / Sentences: 12.2

Long words: 164

Long words / Total words x 100: 14.6

Two scores x 0.4: 10.7

Long words (ex. peritoneal dialysis): 133

Long words/ Total words x 100: 11.9

Two scores x 0.4: 12.5

With “peritoneal dialysis”	10.7
Without “peritoneal dialysis”	9.6

Relative Information Sheet

Words: 1,019

Sentences: 89

Words / Sentences: 11.4

Long words: 164

Long words / Total words x 100: 16.1

Two scores x 0.4: 11

Long words (ex. peritoneal dialysis): 146

Long words/ Total words x 100: 14.3

Two scores x 0.4: 10.3

With “peritoneal dialysis”	11
Without “peritoneal dialysis”	10.3

Key Informant Information Sheet

Words: 935

Sentences: 81

Words / Sentences: 11.5
Long words: 141
Long words / Total words x 100: 15.1
Two scores x 0.4: 10.6

Long words (ex. peritoneal dialysis): 115
Long words/ Total words x 100: 12.3
Two scores x 0.4: 9.5

With "peritoneal dialysis"	10.6
Without "peritoneal dialysis"	9.5