Self-management, psychological correlates, and clinical outcomes in people on dialysis for End Stage Renal Disease

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Index

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Abstract

The thesis that this dissertation aims to defend is:

> *Certain self-management behaviours in End Stage Renal Disease are predicted by self-efficacy, patient activation, and psychological distress, and in turn predict clinical status. However, self-management is often oversimplified and poorly operationalised, in both the literature and in clinical practice, to adherence and 'good/bad' distinctions that may impede future investigations and interventions.*

End Stage Renal Disease (ESRD) is a chronic condition associated with significant morbidity and increased risk of death. It is commonly treated with haemodialysis, a life sustaining treatment that last approximately four hours, repeated in a healthcare centre or at home, at least three times a week. ESRD also necessitates adherence to a complex set of dietary and fluid intake guidelines, in addition to a complex medication regimen, if the person is to avoid a further increase in the risk of severe symptoms and death.

Chronic illness self-management is more than just adherence to prescribed medical treatments however, and requires an individual to preserve their emotional wellbeing, maintain social support networks, and continue to function in a variety of social roles and situations. While this has long been recognised in the theoretical literature about self-management, these concepts are often not well translated into clinical practice or empirical investigations of self-management behaviour in ESRD. When operationalising self-management, some investigations treat the 'behaviour' element of self-management as being limited to dialysis, medication, and fluid adherence, or are ignored in favour of psychological correlates such as self-efficacy. A frequent criticism of the self-management literature is that self-efficacy is often treated as an outcome, rather than a psychological component of changes in behaviour, wellbeing, or clinical outcomes.

The investigations presented in this dissertation seek to investigate self-management in terms of specific behaviours that go beyond adherence. In doing so, they explore two different types of self-management behaviour, here termed ‘cooperative’ and ‘defensive’ self-management. These behaviours can then be examined in relation to adherence and self-efficacy, as well as other theoretically related factors including patient activation, psychological distress, and illness perceptions.

The first three chapters set out the background to the empirical investigations reported in this dissertation. Chapter one covers the background on ESRD and its treatment. Chapter two describes the current state of the conceptual and empirical literature concerning self-management. Chapter three combines a narrative review of empirical investigations into self-management in ESRD, and a review of publically available resources concerning self-management in ESRD. Chapter four describes the methods used in the following empirical chapters. Chapters five, six, seven and eight report original empirical investigations on self-management in ESRD. Chapter nine is a discussion of the combined findings, and their implications in the wider clinical and academic context.

Chapter 5 presents the results of a series of focus groups conducted with people on in-centre haemodialysis for ESRD, and the healthcare professionals involved in their care. These explored what each group understood by ‘self-management’, the behaviours and tasks that were important, and the practical, social, and emotional facilitators and barriers. A series of interviews conducted with patients eighteen months later revisited these concepts, focusing on motivations for engaging in self-management behaviours. The combined findings revealed that patient and HCP concepts around self-management overlap, but have a different focus, with HCPs seeing self-management as being about adherence, and patients seeing it as a complex balancing act to maintain their health, emotional wellbeing, and social roles. HCPs identified some patients as ‘good’ and others as ‘bad’.

Chapter 6 presents the results of a cross-sectional investigation of self-management behaviour and theoretically related psychological factors, including self-efficacy and psychological distress. Self-management was operationalised using an available scale that covered a variety of the behaviours patients and HCPs identified as important in chapter 5, which included both ‘cooperative’ and ‘defensive’ subscales. Self-efficacy, patient activation, and psychological distress were related to ‘defensive’ behaviours, with higher levels of psychological distress being related to the performance of more defensive behaviours. Higher self-efficacy was related to less frequent performance of defensive behaviours. A novel finding was that psychological distress mediated the relationship between self-efficacy and self-management behaviours. The implication that some proactive self-management behaviours may be associated with poorer emotional wellbeing is discussed.

Chapter 7 presents the results of an 18 month longitudinal study of self-management behaviour and clinical markers of adherence. It also reports a survival analysis in the same cohort followed up to 30 months. Higher frequency of cooperative self-management behaviours were associated with lower levels of adherence as indicated by clinical markers. This may be due to the dialysis units in which the study took place, and may in fact reflect how self-management support was conducted in the units at the time of the study. Higher self-efficacy was found to be associated with lower mortality over 30 months after controlling for factors such as age and residual kidney function, an original and potentially important finding.

The findings in chapters 6 and 7 raised additional questions about how self-management behaviours are measured and what those measurements indicate. To further investigate, and lay the groundwork for a new scale and general guidelines on the operationalisation of self-management in ESRD, a series of cognitive interviews were conducted. These are reported in chapter 8. They were conducted with people on home haemodialysis, a population whose engagement in a whole range of self-management behaviours is likely to be high. The role of social and emotional factors in the scale and behaviours discussed was also explored. The chapter concludes with a series of suggestions for measuring self-management behaviour in ESRD.

This dissertation will explore the concept of self-management for people on haemodialysis, the behaviours involved, and their relationship with psychosocial and clinical status.

List of tables

List of figures

List of abbreviations

BHDS: Behaviours in Haemodialysis Scale

CI: Confidence Interval

CHD: Coronary Heart Disease

CKD: Chronic Kidney Disease

COPD: Chronic Obstructive Pulmonary Disorder

CSM: Common Sense Model of Illness Representations

ESRD: End Stage Renal Disease

GAD-7: General Anxiety Disorder 7-item scale

GFR: Glomerular Filtration Rate

HCP: Healthcare Professional

HD: Haemodialysis

HRQoL: Health Related Quality of Life

ICC: Intraclass Correlation

IDWG: Interdialytic Weight Gain

IPQ: Illness Perceptions Questionnaire

KRU: Residual Renal Function

LL: Log Likelihood

MAR: Missing At Random

MCAR: Missing Completely At Random

MI: Multiple Imputation

MLM: Multilevel Model

MNAR: Missing Not At Random

PAM: Patient Activation Measure

PD: Peritoneal Dialysis

PHQ-9: Patient Health Questionnaire 9-item scale

QoL: Quality of Life

RA: Renal Association

REC: Research Ethics Committee

SCT: Social Cognitive Theory

Table of contents

List of appendices

A. Behaviour in Haemodialysis Scale (BHDS)

B. Self-efficacy in chronic disease 6-item scale

C. PHQ-9

D. GAD-7

E. Brief Dialysis Symptoms Inventory

F. National Research Ethics Service (NRES) approvals

G. Focus group schedules

H. Interview schedules

I. References to study outputs

Chapter 1: Kidney disease and its treatment

1.1 Introduction

This introductory chapter provides the clinical background to self-management in Chronic Kidney Disease (CKD). Some background on the physiology of the kidneys, kidney disease and its progression, and how the disease is treated, will lay the foundation for understanding the roles of the health service and the patient in living with advanced CKD, or End Stage Renal Disease (ESRD). Understanding the factors that contribute to the development of ESRD, its prevalence, and common comorbidities will help demonstrate the scope of the problem. The chapter will go on to set out the practical self-management tasks faced by patients with ESRD, as well as the typical picture of routinely undergoing dialysis in a hospital haemodialysis setting. Combined, this information will set out the clinical context that will make clear the self-management challenges faced by people with ESRD on haemodialysis.

1.2 The healthy kidney

The kidneys are situated behind the peritoneum (lining of the abdominal cavity), on either side of the spinal column. They extend roughly from the twelfth thoracic vertebra to the third lumbar vertebra. Each kidney is typically about 12cm long and weighs about 150g (Lote, 2012).

Blood is usually supplied to each kidney by a single renal artery arising from the abdominal aorta. The kidney is made up of a dark outer area called the *cortex,* and a lighter inner area called the *medulla*. The kidneys are connected to the bladder by *ureters*, muscular tubes approximately 30cm in length.

The basic functional unit of the kidney is called the *nephron.* A nephron is a tube that starts in a *Bowman's Capsule*, around a knot of capillaries called the glomerulus. From Bowman's Capsule the nephron extends into a complex tubular system extending from the proximal tubule, through the loop of Henle and into the distal tubule and collecting duct which connects to the ureter.

The purpose of the glomerulus is to produce an ultrafiltrate of plasma. 'Ultrafiltrate' refers to the fact that the filtering processes take place on a molecular level. Glomerular filtration is a key process of the kidneys. An almost protein-free ultrafiltrate passes into the Bowman's capsule from the glomerular capillaries. Molecular weight is the main determinant of whether a substance will be filtered, or will remain in the capillaries. In the average human male, the glomerular filtration rate (GFR) is approximately 180 L/day, or 125mL/min. As the filtrate is derived from plasma, and the average person has approximately 3L of plasma, the same plasma is filtered many times a day. The ultrafiltrate passes from the glomerulus into Bowman's Capsule and into the renal tubular system described above. Here it is further modified by selective reabsorption and secretory processes before eventual excretion as urine. During this process, 180L/day of filtrate is converted to around 2 L of daily urine output. The kidneys have a high blood flow. Between them they receive over 20% of cardiac output. This is required since many tubular processes are highly energy dependent.

The primary functions of the kidneys include excretion of waste products – many of which are toxic . Without kidneys, waste products would accumulate and kill the average person within a week or so. Kidneys also have a major role in maintaining fluid, electrolyte and acid-base balance. Additionally, the kidneys are responsible for the production of some hormones including renin, erythropoietin, and calcitriol. Renin has a role in the control of blood pressure. Erythropoietin controls erythropoiesis (red blood cell production). As a result, anaemia is common in people with advanced kidney disease, and erythropoietin and iron supplementation is often required to correct this. Calcitriol has a major role in calcium balance and in maintaining bone health, and is also commonly substituted in people with advanced kidney disease.

1.2.1 What is Chronic Kidney Disease?

Chronic Kidney Disease (CKD) is a long term, often progressive, condition. It involves damage or abnormality in both kidneys. There are a number of accepted terms, including Chronic Kidney Disease, Chronic Renal Failure, Chronic Kidney Failure and Chronic Renal Insufficiency.

CKD is usually diagnosed by finding evidence of retained waste products (urea and creatinine) in blood tests, often accompanied by the finding of excess protein in the urine (a sign of glomerular damage) and abnormal kidney imaging usually by ultrasound. In its early stages, CKD is usually asymptomatic. Additionally, many people will have early stage CKD by the end of their lives, but will die of other causes before it becomes problematic in terms of symptoms or other health consequences (Department of Health, 2005). In its later stages symptoms are often non-specific e.g.

tiredness, poor appetite, nausea and shortness of breath. However, when kidney failure is severe, it is fatal if not treated by a kidney transplant or regular sessions of dialysis.

1.3 Classification and progression

In the past two decades, renal services in many countries have adopted a common classification system for CKD. Primarily developed by the US National Kidney Federation in their Kidney Disease Outcomes Quality Initiative (K/DOQI), a five stage system based on estimated GFR is now used in UK's National Health Service (NHS). The five stages are shown in figure 1.1.

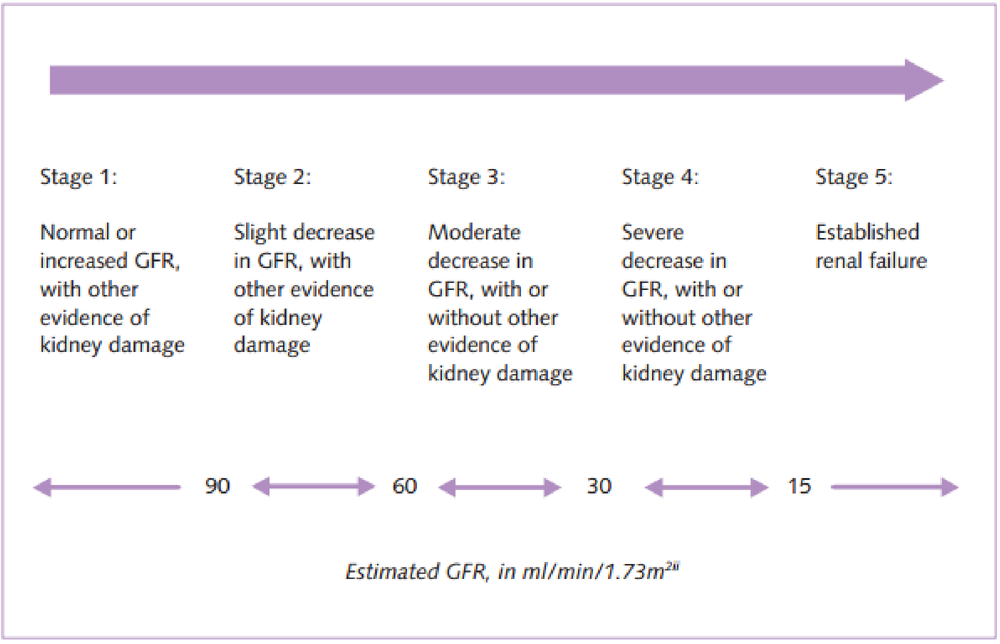

Figure 1.1: Stages of kidney disease by Glomerular Filtration Rate (GFR). Reproduced from the UK Department of Health's Renal Services Framework Part 2: Chronic Kidney Disease and Acute Renal Failure (2005)

Stages of kidney disease are measured as estimated glomerular filtration rate (eGFR). This is derived from equations based on a measurement of serum creatinine, age, sex and ethnicity. There are a number of such equations , the most commonly used being the MDRD-4 and CKD-EPI (Levey et al., 2007; Rule, 2010). Certain circumstances may require a 24 hour urine test, (e.g. for people with exceptional diets). For most purposes, eGFR can be thought of as a proxy measure for overall kidney function. An eGFR of between 90 and 60 ml/min/1.73m^2 does not necessarily mean that an individual has progressive CKD; only a minority of people who fall into stages 1 and 2 of the above categories will go on to stages 4 and 5. The formal definition of CKD proposed by the K/DQOI group takes this into account. They define CKD as occurring when one of the following two criteria is met:

1. Kidney damage is present for ≥ 3 months, as defined by structural or functional abnormalities of the kidney, with or without decreased GFR, manifest by either
    a. Pathological abnormalities, or
    b. Markers of kidney damage, including abnormalities in the composition of the blood or urine, or abnormalities in imaging tests
2. An eGFR < 60mL/min/1.73m^2 for ≥ 3 months, with or without kidney damage.

Stage 5 may be referred to as Established Renal Failure (ERF). ERF is currently defined by a GFR of less than 15 mL/min/1.73m^2. Creatinine is a waste product generated by muscle activity. As kidney function declines, serum creatinine levels rise, and elevated serum creatinine is another indicator of the progression of kidney disease. End Stage Kidney Disease (ESKD), or End Stage Renal Disease (ESRD) are when Renal Replacement Therapy (RRT) is indicated by way of symptoms (described below); ESRD is the term that shall be used throughout this dissertation. People with ESRD require either a transplant or dialysis to stay alive. This dissertation describes work conducted with people with ESRD on either in-centre or home haemodialysis.

1.3.1 Prevalence, symptoms, and risk factors

Due to the lack of symptoms in earlier stages of CKD, accurately assessing the number of people affected can be difficult. In 2000/2001, the prevalence of diagnosed moderate to severe CKD in the South East of England was 5,554 patients per million population (pmp) (John, Webb, Young, & Stevens, 2004). In this case, moderate to severe CKD was defined as a serum creatinine of ≥ 180 µmol/L in men and ≥ 135 µmol/L in women. More recently, the UK Renal Registry estimated that the incidence rate for starting Renal Replacement Therapy in 2011 was 108 pmp. This was an increase from 95 pmp in 2001 (Renal Association, 2012). This meant a total of 6,835 people started some form of RRT in 2011 in the UK. The prevalence (total number of people receiving RRT) in 2011 was 53,207, or 842 pmp. In 2000, the prevalence was 523 pmp. The number of people receiving RRT in the UK is increasing, as it is in many countries worldwide, including the US (Collins et al., 2013).

CKD does not typically exhibit symptoms until GFR starts to reach approximately 30mL/min/1.73m^2, or CKD stage 4. By the time stage 5 is reached and GFR is below 15mL/min/1.73m^2, the physiological consequences include the inability to excrete certain waste products, excess water and salts, and control the body's acidity. Haemoglobin production, blood pressure regulation, and bone formation also become dysregulated.

By stage 5, symptoms can include tiredness, nausea, and loss of appetite. Clinically, fluid retention (oedema), particularly around the ankles, is common, as is breathlessness, discolouration of the skin and raised blood pressure.

Risk factors for CKD and subsequent ESRD are most evident in demographic and clinical status, rather than direct results of lifestyle. The most pronounced risk factors are diabetes, age, hypertension, and South Asian, African or African Caribbean ethnicity. Male sex, being a smoker, and heavy alcohol use are also predictors of CKD.

Age is highly predictive of decreased kidney function. In 2001 in the UK, nearly half of all patients starting RRT were over the age of 65, despite this age group making up a quarter of the total population (Department of Health, 2005). In the NHANES III study conducted in the USA, 0.2% of individuals aged 20 to 39 had moderately or severely decreased kidney function (stage 3 CKD or greater). In individuals aged 70 and over, the rate was around 25% (Coresh, Astor, Greene, Eknoyan, & Levey, 2003)

Diabetes is the most common cause of ESRD. Estimated in 2006 from USRDS data, diabetes accounted for approximately 44% of all new cases of treated ESRD in the USA (Burrows, Li, & Geiss, 2010). As with many risk factors, this figure varies substantially between countries. In the DOPPS study, the percentage of patients with ESRD caused by diabetes varied from 10.4% in France, to 40.9% in the USA (Young et al., 2000). For the UK, the most recent Renal Registry report states that diabetic renal disease was the primary cause in 26% of people starting renal replacement therapy (Renal Association, 2013). Hypertension is the second most common cause of ESRD, estimated to be responsible for approximately 27% of all cases in the USA. This figure rises to 33.4% for African Americans (Lea & Nicholas, 2002). Male sex is associated with a greater risk of ESRD, and more rapid progression of the disease (Neugarten, Acharya, & Silbiger, 2000).

1.3.2 Comorbidity

Later stage CKD is frequently accompanied by other health conditions. This is particularly true of ESRD. After the initiation of dialysis, median survival is approximately 4-5 years, and the majority of patient deaths will be attributable to one of these comorbid conditions (Prichard, 2000). Cardiovascular conditions, abnormal blood pressure, diabetes, and related vascular conditions are common in people with ESRD, and some of these can be causes of ESRD, consequences, or both. Due to ESRD being more common with increasing age, cancer is also present in some patients. HIV/AIDS creates additional treatment challenges where present. Comorbidities increase mortality, and produce additional treatment and self-management challenges for individuals living with those conditions.

The most common cardiovascular comorbidities include ischemic heart disease and left ventricular hypertrophy, which are common in pre-dialysis populations (people who are approaching the threshold for, but not yet on, dialysis). Congestive heart failure is common after dialysis commences. Diabetes has a strong negative impact on survival and is associated with the presence of vascular disease (Morioka et al., 2001). Poor nutrition, which can be indicated by low serum albumin or subjective global assessment, is a strong predictor of mortality. The course of conditions such as diabetes is to some extent modifiable, which makes effective management an important element of care.

Hypertension is predictive of mortality in the general population, and is associated with CKD. Seemingly paradoxically, hypotension predicts mortality in people with ESRD (Hemmelgarn, Manns, Quan, & Ghali, 2003). This may be due to cardiovascular complications of advanced kidney disease, and the additional strain that dialysis causes. Between dialysis sessions, blood pressure rises as anywhere up to several litres of fluid is retained. The removal of this fluid over a 3-4 hour period can cause a rapid drop in blood pressure, producing strain on the cardiovascular system.

One of the most common tools for measuring the presence of comorbidities across different primary conditions is the Charlson Comorbidity Index (CCI). Developed in a sample of hospital inpatients, this list of 19 conditions provides weighted values that are prognostic of survival, and has been tested in populations with breast cancer, rheumatoid arthritis and congestive heart failure. It also takes age into account. This means that the CCI is more useful in clinical situations, but can complicate statistical analysis where age is already accounted for as a covariate. Due to the complex nature of ESRD, an adapted version with modified weights was developed (Hemmelgarn et al., 2003). In this study, the most common comorbidities for people dialysing for ESRD were (from most to least prevalent):

- Diabetes with complications: 43.5%
- Myocardial infarction: 27.9%
- Chronic lung disease: 27.4%
- Congestive heart failure: 26.2%
- Peripheral vascular disease: 18.6%
- Cerebral vascular disease: 13.9%

The conditions that were found to require higher weighting in ESRD (indicating an increase relative impact on survival) were: Myocardial infarction, congestive heart failure, cerebral vascular disease, diabetes without complications, metastatic disease, and lymphoma.

Age has been discussed as a risk factor for CKD/ESRD and poor outcomes above. Diabetes, cardiovascular disease, malnutrition and inflammation (these latter two factors are associated with hypoalbuminuria) are the conditions most closely associated with poor outcomes.

Comorbidities do more than complicate the clinical picture in terms of mortality. They also represent additional challenges to the person living with those conditions. The self-management challenges faced by people with ESRD (medications, fluid allowances, dietary modification, dialysis) rarely exist in isolation. This means that people will often have to attend additional clinics, make further dietary modifications and take additional medications on top of this already huge ESRD treatment burden. Additionally, for some there can be conflicts between dietary advice for the general population, CKD, and conditions such as diabetes.

1.4 Treatment of End Stage Renal Disease: Dialysis, transplantation and conservative management

As an individual with CKD approaches stage 5, or ESRD, options regarding Renal Replacement Therapy (RRT) should be considered. There are a range of options, and the decision is based on a combination of clinical considerations and patient preference. Most broadly, for most patients the options are dialysis, or kidney transplantation. A small number of people with, or approaching, ESRD opt not to have RRT in favour of a supportive approach – this is called conservative management. These are often older, frailer patients with other comorbidities, for whom the benefits of dialysis may be outweighed by the burdens (Jassal & Watson, 2009). In general, transplantation is the most effective form of RRT but is usually not suitable treatment for patients with a high comorbidity burden. Dialysis can take the form of either centre-based haemodialysis or home treatment by haemodialysis or peritoneal dialysis. Centre-based treatment is the dominant modality in Europe and the USA. Even when patients are being treated by dialysis, other interventions are necessary to keep patients as well as possible; these include dietary modification, limiting fluid intake and taking a number of medications.

Dialysis is a treatment that involves using a membrane to filter toxins from a person's bloodstream (a synthetic membrane in the case of haemodialysis, and the patient's own peritoneal membrane for peritoneal dialysis). The process also involves removing excess fluid, which is normally retained due to the inability to excrete urine.

Haemodialysis (HD) is where this process takes place in a machine external to the person's body. Blood is carried away from the person by tubes connected to an access site. This access site may be either a central venous catheter, or a fistula. If using a central venous catheter, this is usually located in the jugular vein in the neck. A fistula is a surgically joined artery and vein, usually located in the forearm. Blood is then passed through the dialyser, against a membrane with dialysis fluid on the other side. Through diffusion (down a concentration gradient across the selectively permeable membrane), and convection (down a trans-membrane hydrostatic pressure gradient), small and middle-sized molecules (molecular weight up to around 15Kd) move across the membrane into the dialysis fluid. Thus the blood is cleaned and then returned to the person's body via the access site. During each session, blood will make many 'passes' through the dialyser, each time removing more toxins. Fluid balance is maintained by ultrafiltration – convective removal of fluid by applying a negative pressure across the membrane. During a dialysis session, excess fluid is gradually removed in a controlled fashion, allowing the correction of fluid based weight gain since the last dialysis session.

There are a number of variations on the basic principle of HD. It can be carried out either in-centre or at home. In-centre, it may be carried out at a hospital, but it is common for each hospital providing dialysis treatment to have a number of 'satellite' units. This cuts down travel time for many patients, but may not be not suitable for anyone likely to require urgent inpatient care. Home HD uses similar technology, installed in the person's home. Dialysis can take the form of a standard 3-4 hour session, or overnight; termed 'nocturnal HD'. Home HD means that the individual and their partner or carer will set up, conduct, and clean up after each dialysis session. This requires training in the technical aspects, but can carry a huge benefit in terms of eliminating the time taken travelling to and from dialysis, arranging transport, and allowing the individual to dialyse at a time convenient for them.

Access, whether via a fistula or a catheter, is an important element of HD treatment. The preferred route of access is via a fistula, where an artery and a vein are surgically joined together and allowed to mature. This site can then be accessed via a needle inserted either by a healthcare professional, carer, or the patient themselves. The use of a fistula is associated with lower complication rates and increased survival compared to a catheter (Rose, Sonaike, & Hughes, 2013). A fistula can last many years, but it requires ongoing self-care. Some fail early, and some fail to ever mature. Developing a better understanding of how to create and preserve fistulae is considered a key challenge in ensuring good quality HD (Riella & Roy-Chaudhury, 2013).

Peritoneal dialysis (PD) utilises the person's own peritoneal membrane. Dialysate is fed into the abdominal cavity via a 'Tenckhoff Catheter'. The peritoneal membrane forms the filter between the small blood vessels running within the membrane and dialysis fluid. Through diffusion and osmosis, waste products are filtered from the blood into the fluid. As with haemodialysis, the dialysis fluid needs to be frequently changed in order to ensure that an optimal concentration gradient is maintained. PD can take the form of Continuous Ambulatory Peritoneal Dialysis (CAPD), where exchanges take place manually 3 – 4 times per day. In Automated Peritoneal Dialysis (APD) the exchanges are performed by a machine overnight. PD is usually conducted at home, and is often a preferable option for people who wish to continue to work. The greatest risk in PD is infection, which commonly necessitates a change to HD. PD may be contraindicated by the presence of abdominal scarring, hernias, morbid obesity, colostomy or polycystic kidney disease. However, it may be that surmountable barriers such as impaired vision or hearing, or psychological anxiety, are responsible for the comparatively low uptake of PD (Oliver & Quinn, 2008). Physician attitudes may also present barriers.

Kidney transplants are considered to be the most preferable option for people with ESRD. They have a good chance of success relative to other types of transplant, and if successful, mean that dialysis will not be required. The main risk is infection and rejection. Even if the transplant is successful, the individual will need to keep taking immunosuppressant drugs for the rest of their life. Immunosuppressant drugs also have side effects, such as an increased susceptibility to infection and increased risk of diabetes. It is a major procedure so not everyone is suitable. Additionally, a sufficient number of living or cadaver donors are required. People who have received a transplant usually have more energy, feel better, and are more able to lead a 'normal' life.

RRT may not be for everyone. ‘Conservative management’ is when a person with ESRD and their care team attempt to manage the symptoms of the disease and its complications without initiating RRT. There are many reasons why someone may choose conservative management, but it is most commonly preferred by people who are older with many comorbidities, where the survival advantage of dialysis is smallest. While dialysis probably offers a survival advantage to this population, this benefit almost completely disappears when only considering hospital-free days (Da Silva-Gane et al., 2012; Carson, Juszczak, Davenport, & Burns, 2009). In the latter study, survival for older patients with comorbidities was 37.8 months for those opting for RRT, and 13.9 months for those choosing ‘maximum conservative management’ though much of the difference in time was spent in dialysing in the dialysis centre or as a hospital inpatient.

Deciding which treatment is right for the individual is important, and this will frequently depend on more than just clinical considerations. Many consider a transplant to be the ideal treatment, but transplants are often not available immediately, or many be clinically contraindicated. PD and home HD offer more freedom to the individual, but require training and confidence to carry out the dialysis procedure. In-centre treatment means that trained staff will be on hand should anything go wrong, but requires travel time, arranging or waiting for transport, and potentially waiting for a machine to become available when delays occur. ‘Shared decision making’, between the person, their carers or those close to them, and the clinician should take into account all these factors (Durand et al., 2014).

In the UK, the NHS offers all of the above treatments to those clinically suitable for them. Figures 2 and 3 show the proportion of patients receiving each type of treatment (other than conservative management), split by incident and prevalent cases UK Renal Registry 2013). These figures did not include the proportion of people choosing conservative management.

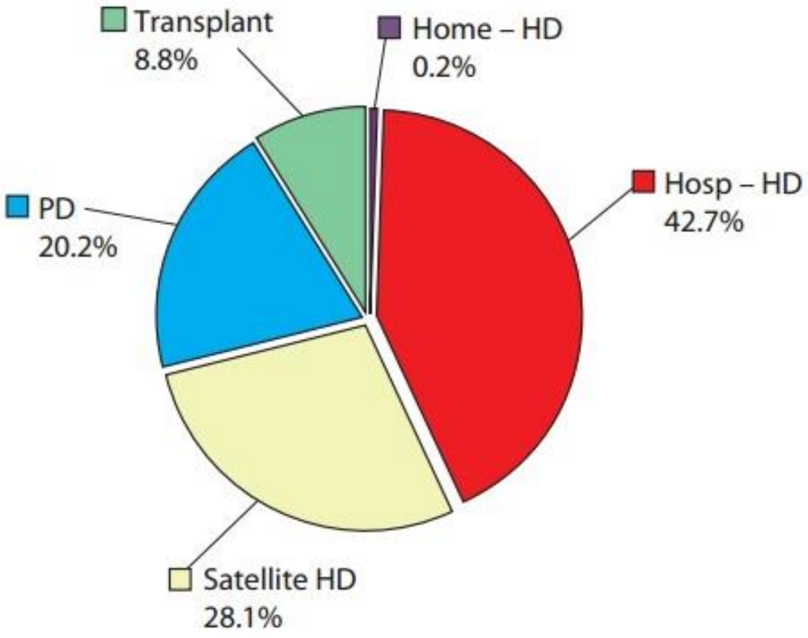

Figure 1.2: RRT modality at 90 days (incident cohort 01/10/2011 to 30/09/2012). Reproduced from the UK Renal Registry report 2013.

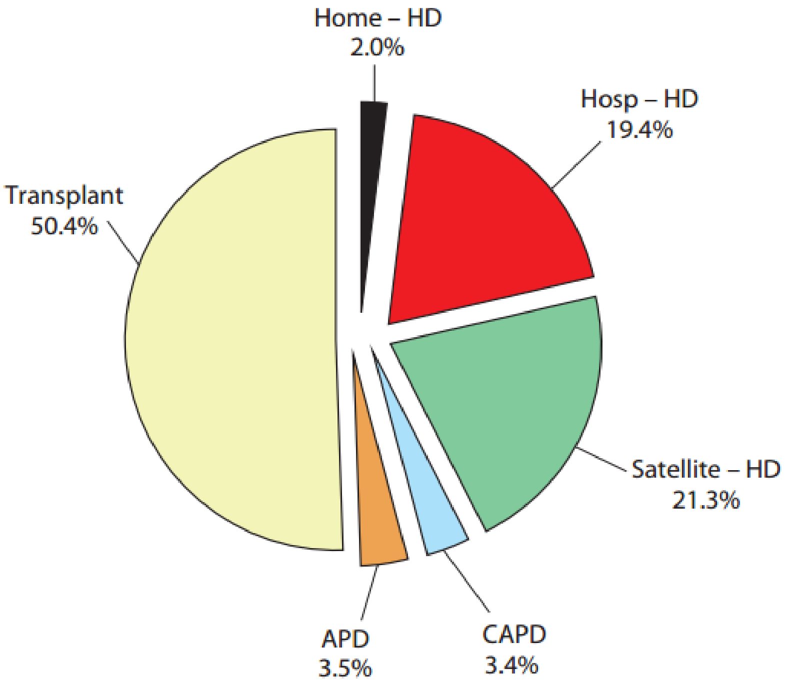

Figure 1.3: Treatment modality in prevalent RRT patients on 31/12/2012. Reproduced from the UK Renal Registry report 2013.

Figures 1.2 and 1.3 show that most patients do not receive a transplant until they have spent some time on dialysis. The average waiting time for a transplant for eligible individuals is approximately 2 years. Haemodialysis is the most common RRT in incident patients (71%), and the most common form of dialysis in prevalent patients (42.7% of all RRT patients). Only a very small number of patients use haemodialysis at home (0.2% incident, 2.0% prevalent), although home HD appears to be on the increase (Mitra, Brady, & O'Donoghue, 2011). Despite this, most prior work on self-management has focused on those undertaking home therapies, which constitute a minority of patients. While highly important, the majority undergoing in-centre HD should not be neglected.

1.5 The organisation of a typical in-centre haemodialysis service

In-centre haemodialysis tends to occur in either a hospital or a satellite setting. Typically, a given area of service provision will see nephrology services centred at a hospital site, where patients who are more ill will be treated. Satellite services will be mostly run by nursing staff and Clinical Support Workers (CSWs). Often, the choice of dialysis location for a patient in a given service is based on the distance of the unit from home. There is a move towards introducing more 'minimal care' units, where patients can perform most of their own dialysis. This may benefit people who wish to have more agency in their dialysis, but may be unable to dialyse at home (for example, available space or being worried about dialysing alone). These are rare in the NHS at present.

In-centre HD units normally comprises a number of 'bays', each with a bed or chair, and a HD machine. There may be as many as 20 bays in a single large room, with isolated 'side rooms' with a single bay each for patients with infectious diseases. In the main unit, patients are close enough to be able to talk, but often not very conveniently. As a typical session lasts 4 hours, entertainment is often provided in the form of radio, TV, or Wi-Fi, but these vary by unit.

The unit will have a number of ‘shifts’ throughout the day as machines are reused for different patients. For example, there may be a morning shift and an afternoon shift. The Renal Association recommends that a bay should be booked for no more than two shifts per day to allow patient choice of dialysis times, but this is often not practical due to the patient/machine ratio in a given service (Mactier, Hoenich, & Breen, 2011). Thus there may be two to three shifts throughout the day, and a ‘twilight’ evening shift, often used by people who continue to work during the day.

Getting to and from the unit can often be a challenge. Patients may choose to drive themselves to their session. However, they are encouraged not to drive home after, at least for the first few weeks after initiation of dialysis, as the dialysis process can leave people feeling tired, lightheaded, dizzy or faint – although many do still drive (Mactier et al., 2011). Friends, family or carers may drive the patient, or they may take public transport. If these are not options, the local NHS Trust will provide transport. Renal Association guidelines suggest that a person should be picked up no more than 30 minutes prior to their treatment, and no more than 30 minutes after their treatment ends, with a travelling time of less than 30 minutes in one direction. In practice, approximately 68% of patients have a travelling time under 30 minutes, and 66% of patients using hospital transport wait 30 minutes or less to be picked up for the return journey (National Kidney Care, 2010).

Clinic appointments with a nephrologist occur separately to dialysis sessions, but efforts are usually made to co-ordinate so that the two occur on the same day, if convenient for the patient.

1.6 Beyond dialysis: The daily self-management challenges of a person living with ESRD

The self-management challenges associated with ESRD will be split into medical, social, and emotional challenges, based on conceptual models of self-management described in chapter 2. It should be noted that there is a debate in the person-centred care literature about whether 'patient' is an appropriate term for someone living with a long term condition, as they are much more than that, and that it connotes an imbalance of power in favour of healthcare providers (Neuberger & Tallis, 1999). Alternatives such as 'service user', 'client', or 'consumer' have been suggested. However, previous work directly asking 1,037 people with various health conditions (including cancer, fracture, and HIV) for their preference has found that the term 'patient' to be preferable to the more market-focused alternatives presented above (Deber, Kraetschmer, Urowitz, & Sharpe, 2005). This preference has also been found in the psychiatric literature (Simmons, Hawley, Gale, & Sivakumaran, 2010). For this reason, the term 'patient' will continue to be used, with the caveat that all people living with long term conditions are more than that, regardless of the current parlance of the self-management literature.

1.6.1 Medical

Completing 4 hours of dialysis, three times a week, is only part of the treatment burden of ESRD. Treatment includes limiting fluid intake, dietary modification, taking medications, and managing comorbid conditions.

Once a person's renal function reaches end-stage, the amount of urine they produce falls. Urine output can eventually reach zero. As only a small quantity of imbibed fluid is lost through remaining renal function, sweat, and in stools, much of it is retained. Dialysis can remove this additional fluid through ultrafiltration. Weight gained from fluid in between dialysis sessions is called interdialytic weight gain (IDWG). High IDWG can increase the risk of oedema (swelling), hypertension, left ventricular hypertrophy and cardiac failure. Higher IDWG is also associated with cramps, dizziness and low blood pressure during dialysis due to the requirement to remove large amounts of fluid over relatively short periods. Patients are therefore advised to limit the amount of fluid they intake on a daily basis. For people with minimal residual renal function, this can be as little as 500ml per day. Fluid is also contained in many foods, which makes calculating fluid intake more complicated than counting glasses of water.

A key consideration when attempting to limit fluid intake is also limiting dietary sodium (most commonly sodium chloride, or salt). Sodium increases thirst, and causes extracelluar fluid retention. Optimal clinical management of ESRD requires sodium intake be significantly limited. This means that many processed foods are advised against. The relationship between sodium and fluid is such that it may not be worth advising a person with ESRD to limit their fluid intake if they are not also advised on a low-sodium diet (Tomson, 2001). Whilst urine output is maintained diuretics may be prescribed for fluid retention.

Whilst salt and fluid restriction, diuretics and ultrafiltration during dialysis form the basis of managing blood pressure, most patients on modern dialysis programmes are also prescribed anti-hypertensive medications. Many take a number of these agents.

Phosphorus is difficult to filter out during dialysis, meaning that preventing too much from entering the bloodstream in the first place is a priority. Dietary modification to avoid foods high in phosphorus is recommended. Additionally, tablets called phosphate binders are prescribed to be taken with every meal. Phosphate binders will bind dietary phosphorus in the digestive system before it enters the bloodstream, which is why they need to be taken in close proximity to meals. Phosphate retention is associated with bone disease and calcification of blood vessels, so control is important.

Potassium can be filtered by dialysis, but can build up quickly between sessions. Too much can result in muscle weakness and cardiac dysrhythmias which can be fatal. Many fruits, vegetables and dairy products are high in potassium, meaning many foods recommended as 'healthy' to the general population are recommended against for people with ESRD.

Polypharmacy, or being prescribed a number of medications, is common in ESRD. These medications are primarily to manage the physiological consequences of the disease. In addition to diuretics, antihypertensive drugs and phosphate binders, patients may also require to take many other medications. Anaemia is a common consequence of ESRD and may be treated using supplements of the hormone erythropoietin, iron, or both. Additionally, Calcium and vitamin D supplements may also be prescribed for people with ESRD. Many patients take statins to reduce cardiovascular risk. Pain medication is also required by many. Drug treatment for comorbidities adds to the pill burden. In a cross sectional study of 233 maintenance dialysis patients in the United States, the median daily number of prescribed pills per person was 19. For one quarter of patients, this exceeded 25 pills per day.

The presence of comorbidities increases the burden still further. Managing diabetes, the single biggest cause of ESRD, includes its own dietary requirements, blood glucose monitoring, and insulin administration, on top of the medical self-management tasks listed here.

Self-management behaviours relating to physical health go beyond adherence. For example, they may include the way the person communicates with their healthcare professionals, seeking information about kidney disease and its treatment, and making decisions about symptom reporting. Some of these behaviours may involve a person working cooperatively with their healthcare team. Others, such as not speaking up about symptoms and trying to handle them alone, may be more proactive or 'defensive'. See chapters 2 and 3 for more detail.

1.6.2 Social

The disruption to normal functioning that people on dialysis for ESRD face is not limited to the burden of clinical tasks. The disease, its consequences, and treatment demands also create barriers to continuing to function socially, and to continue in employment. This is also sometimes referred to as ‘role management’ (Lorig & Holman, 2003).

Dialysis is a time consuming process, and as such affects almost all domains of life. For those undergoing in-centre dialysis, 4 hours of treatment 3 times a week, plus travel and recovery time, means that those days may be ‘written off’ as dedicated only to dialysis. This makes fitting in a job, family life, friends, and other interests difficult.

Cognitive impairment may be common in ESRD, with estimates varying from 16% (Tamura et al., 2010), up to 70% of maintenance dialysis patients over 55 experiencing moderate to severe impairment (Murray, 2008). There are a number of potential causes; including “uraemia” itself and cerebrovascular disease (stroke risk is greatly elevated in people with CKD and ESRD). HD itself may also be associated with cognitive impairment (Pereira, Weiner, Scott, & Sarnak, 2005). Cognitive impairment can create difficulties in every day social functioning. In more mild cases it may make continuing to work in a complex and mentally demanding job more difficult. In more severe cases it may make even basic self-care and daily functions such as going to the shops or keeping social engagements difficult, even where physical impairment is absent.

The combination of time consuming treatment and cognitive impairment make continued employment difficult. In the US Comprehensive Dialysis Study (CDS), out of 585 people starting long term dialysis (including HD and PD) who were in paid employment the previous year, only 191 (32.6%) remained in employment 4 months after dialysis initiation. Depression also appeared to play a role in this relationship. Patients were screened for depression using the PHQ-2.

Of those still working, 12.1% were screened as depressed, compared to 32.8% of those no longer working. Whether this is a cause, effect, or reciprocal relationship is unclear.

The ‘renal diet’, with its myriad restrictions, makes cooking, being cooked for, and going out for a meal difficult. The ‘to avoid’ list for ESRD is complex and strict adherence requires knowledge of the exact ingredients of a meal. There is no simple ‘rule of thumb’ for foods to avoid, and many foods that are normally considered healthy are advised against, such as fruits, salads, pasta and wholemeal bread. This makes eating out a complex and difficult process, especially if some degree of cognitive impairment is present.

Reduced fluid allowances mean that social drinking is advised against for many people with ESRD. While people with ESRD can go to a bar with their friends or a wedding reception (for example), drinking alcohol is an important ‘social lubricant’ for many people (Park, 2004). The physiological costs of drinking alcohol typically include high interdialytic weight gains with all the attendant risks described earlier.

1.6.3 Emotional

Emotional adjustment to chronic disease can be a difficult process. Depression, anxiety, and a disrupted sense of self are common (Bury, 1982). More detail on depression and anxiety as they relate to ESRD and self-management can be found in chapter 3. The following is a brief consideration of the basic characteristics of the issues presented to a person living with ESRD.

Adjustment to ESRD means adapting to the burden of the disease, symptoms, treatment, loss of primary roles, loss of function, and an uncertain future. One way of measuring the impact ESRD has on emotional health is too look at the presence of depression and anxiety.

According the Diagnostic and Statistical Manual (DSM) of mental health conditions IV-TR, depression is the loss of pleasure or depressed mood, for 2 or more weeks, accompanied by other symptoms such as sleep or appetite disturbance, guilt and suicidal thoughts (American Psychological Association, 1994). Depression is likely the most common psychopathology in ESRD, with prevalence estimates typically ranging between 20-30% (Chilcot, Wellsted, & Farrington, 2009). It appears to be more common among people on HD compared to those on PD. It is associated with lower residual renal function, and higher depression appears to be associated with higher levels of inflammation.

Perceptions of loss appear to be important in the development of depression among those with ESRD (Kimmel, 2002). In a study of 191 people on HD, perceptions of loss were the strongest predictors of depression, which in turn predicted quality of life (Chan, Brooks, Erlich, Chow, & Suranyi, 2009). ‘Loss’ refers to loss of function, and to loss of primary roles such as family, social and work roles.

Treatment options for patients with depression are typically similar to those for the general population. Cognitive Behavioural Therapy and antidepressants are favoured by the UK’s National Institute for health and Clinical Excellence (NICE). There are additional barriers to treatment in this population however, including a desire to avoid additional appointments on top of dialysis and clinics in the case of CBT, and the potential for drug-drug interactions in the case of antidepressants.

Anxiety disorders include generalised anxiety disorder (GAD), obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PTSD). Depending on severity and nature, they can range from unpleasant to completely impairing a person’s ability to function. Estimates of prevalence in ESRD vary substantially, between 0 and 45.7% when using formal diagnostic interviews. One study estimated the most common forms of anxiety disorder in HD patients were specific phobias (26.6%) and panic disorder (21.0%) (Cukor et al., 2007).

Depression and anxiety are unpleasant conditions associated with lower perceived quality of life, and also related to mortality (Chilcot et al., 2009) (Chan et al., 2009). Furthermore, they can also impact social functioning, and may negatively impact medical self-care behaviours such as adherence to medication (DiMatteo, Lepper, & Croghan, 2000).

1.7 Summary

Chronic kidney disease has many causes, and can occur suddenly, but usually progresses slowly in later life. The disease is classified into five stages, with the disease being considered ‘established’ in stages 3 and 4. Stage 5 is also known as End Stage Renal Disease (ESRD), and is when renal replacement therapies such as haemodialysis are required to maintain life. ESRD is usually accompanied by comorbidities, with diabetes and vascular diseases being the most common. Without a kidney transplant, renal replacement therapy and lifestyle modification are time and energy consuming. Most people with ESRD will not receive a transplant, and instead rely on dialysis. Forgoing renal replacement therapy, referred to as conservative management, is also an option for a small proportion of older, frailer people. People with ESRD face a number of clinical, social and emotional self-management challenges. Depression and anxiety are present in at least 20-30% of prevalent ESRD patients, and may complicate an individual’s ability to effectively manage other areas of their treatment and life.

Chapter 2: Review of Self-Management in chronic disease

Gregory Bateson once said, "one cannot not communicate". The same is true for health behaviour and disease management. One cannot not manage. If one decides not to engage in a healthful behaviour or not to be active in managing a disease, this decision reflects a management style. (Lorig & Holman, 2003)

2.1 Introduction

Self-management is a term used to describe the actions people with any illness take in order to manage their condition and its treatment. The self-management literature has emerged in light of a changing landscape of health threats, which over the last 200 years has shifted from primarily acute, physician managed conditions, to chronic, long term conditions that require substantial management by the person living with the condition. There are many related terms, some used synonymously, some with subtle distinctions. This chapter aims to introduce the reader to the evolution of self-management as a sociological and psychological concept in a range of chronic diseases, where there is a rich literature to draw upon (for example, in diabetes). Chapter 3 will then consider the comparatively sparse literature on self-management in ESRD and the issues research in this area faces. As such, the present chapter will not consider self-management in ESRD in more than passing.

2.2 Shifting burden of disease and need for self-management

Two hundred years ago, life expectancy was largely determined by communicable, acute diseases such as tuberculosis or malaria. With the advent of effective vaccinations and antibiotics, many of these diseases have ceased to be significant threats to the populations in developed countries such as the United Kingdom (Horton, 2012).

As many life-threatening communicable diseases have been eradicated or cured, along with our greater understanding of how to prevent the spread of communicable disease, people are living longer. With an aging population has emerged an increase in the prevalence of so called, ‘diseases of old age’ such as Coronary Heart Disease (CHD) and End Stage Renal Disease (ESRD). In addition, other chronic conditions are increasing in prevalence due to population wide changes in lifestyle, such as diabetes (Cooper et al., 2013). Diabetes is, in turn, one of the major causes of organ failure, and is the main cause of ESRD (USRDS, 2012).

Here we define a chronic disease as one that cannot currently be cured, and that will therefore affect the individual for the rest of their life. The World Health Organisation’s list of non-communicable diseases (which with the exception of HIV, are largely synonymous with chronic diseases) includes such conditions as CHD, ESRD, diabetes, gastrointestinal conditions such as Crohn’s Disease and ulcerative colitis, respiratory diseases such as Chronic Obstructive Pulmonary

Disease (COPD) and asthma, and anaemia (WHO, 2010). While many mental health conditions such as depression and schizophrenia are lifelong, this review will focus only on chronic physical conditions, as the self-management issues in mental health conditions have their own set of complicating factors.

Chronic physical conditions tend to share a common factor compared to many acute illnesses; they cannot be treated by a physician alone. They require a substantial investment of time and effort from the individual to undertake the management of their own condition. For example, an individual with diabetes is advised to regulate their sugar intake, and self-administer insulin, throughout the day. Unless the person is being looked after as an in-patient, these kinds of tasks must be carried out by the individual.

2.3 Evolution of 'self-management' as a concept

Self-management as it is conceptualised today can be understood as arising from the biomedical tradition, and the tradition of cognitive psychology (Greenhalgh, 2009). This can be mapped onto the rise of the biopsychosocial model of understanding health and illness (Smith, 2002). As a concept, it competes and overlaps with ideas such as empowerment, self-care, whole systems approaches and critical public health. Modern conceptions of self-management can be seen in highly visible campaigns and initiatives such as the UK's Expert Patient Programme (Plews, 2005) and the Health Foundation's Co-Creating Health (The Health Foundation, 2011).

Regarding the term 'self-care', it should be noted that the term 'self-care haemodialysis' and 'shared haemodialysis care' appear at certain points in this dissertation. In this case, these are used as specific terms to denote patient engagement in the process of haemodialysis itself (Dainton & Wilkie, 2013). Examples of tasks involved in self-care haemodialysis include inserting the needle into the fistula (self-cannulation), setting up the dialysis machine itself, and cleaning the machine after use.

The Health Foundation conceptualises self-management in a tripartite model based on biological, social and emotional challenges (see figure 1.1). This model can be traced back to sociological work by Corbin & Strauss (1985). The ‘three lines of work’ referred to in this seminal paper are illness work (biological), everyday life work (social), and biographical work (emotional). Illness work includes tasks such as adhering to prescribed medical regimen, such as taking medication. Everyday life work includes a broad range of tasks, such as cooking, cleaning, employment, and fulfilling roles such as being a parent. Biographical work includes working through the emotions and the changes in self-concept that may arise in response to illness.

Corbin & Strauss (1985) conceptualise these tasks as part of an ‘illness trajectory’, which includes illness work; tasks to be undertaken in response to changing situations (‘structure in process’), which in turn reciprocally interact with changing biographical factors. In essence, an individual’s illness trajectory is in part determined by their broader life circumstances. Further, ideas about what one is capable of, and one’s very sense of self, will change in response to changes in illness and changes in life circumstances.

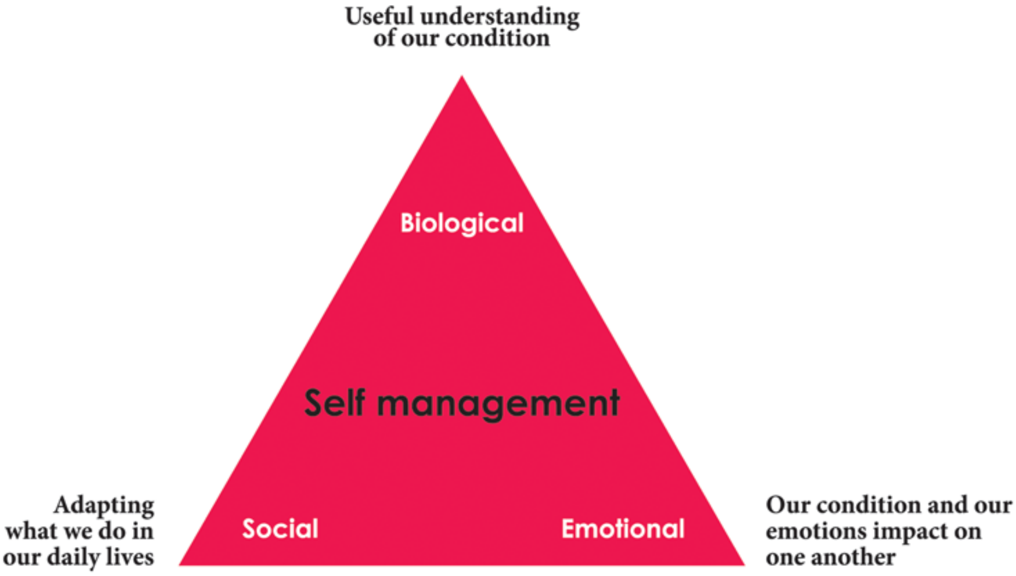

Figure 2.1: The self-management triangle from the Health Foundation

Importantly, this enduring sociological take on managing chronic illness looks at a picture beyond tasks directly related to the biological management of illness. It acknowledges that chronic illness is normally accompanied by changes in one's self-concept, appraisal of capabilities, ability to work, to maintain social roles and relationships and so on. While tasks such as taking insulin or modifying one's diet may be vital to maintaining health, successfully managing the illness may require that an individual adjust to going from a position of high earnings and fulfilling work, to taking a more backseat role, if they can even continue to work at all. Similarly, it may mean being unable to fulfil their normal role in a spousal relationship, moving from a position of equilibrium to one of dependency upon their significant other.

This model of self-management has famously been built upon by Kate Lorig and colleagues at Stanford in the Chronic Disease Self-Management Programme (CDSMP). These programmes can be either generic or tailored to a specific disease group, can be delivered either by Health Care Professionals (HCPs) or lay people, and can be delivered to a group or individuals. These programmes hinge upon the premise that the key to effective self-management is self-efficacy. Self-efficacy is a core component of Albert Bandura's Social Cognitive Theory (SCT). In essence, self-efficacy is one's confidence in one's ability to bring about a given outcome by successfully performing a given behaviour (Bandura, 1977). Self-efficacy and operationally similar constructs are still considered highly important in the initiation, continuation of and outcomes achieved through self-management, and so will be focused on later in this chapter.

The CDSMP has been adapted to the UK's needs as part of the Expert Patient Programme (EPP, Choices, 2013). There has been some controversy about how well the EPP has been implemented, and indeed whether it truly represents the patients it seeks to empower (Wilson, Kendall, & Brooks, 2007). Furthermore, there is debate over the extent to which the CDSMP itself has been proven efficacious (Greenhalgh, 2009). This debate hinges on what one considers the outcome of interest to be; CDSMP interventions frequently succeed in improving self-rated self-efficacy, but often fail to demonstrate improvements in clinical outcomes (Sobel, Lorig, & Hobbs, 2002). It may be that changes in clinical outcomes are not required for a self-management programme to be considered 'effective'. For example, it may succeed in producing changes in quality of life, due to changing how the actions people living with chronic illness take to cope emotionally, maintain social roles, or finding ways to fit their treatment into their everyday life in a way that is less intrusive. The debate about 'what to measure' is ultimately a question of perspective, one that will be addressed empirically in chapters 5 and 8 through focus groups and interviews.

2.4 Working definition of self-management

Part of the thesis that this dissertation seeks to defend is that self-management is often poorly operationalized, particularly in ESRD, and therefore the empirical chapters will seek to address this. However, it is necessary to set out with a working definition to build upon. Drawing on the work of Corbin & Strauss, and Lorig & Holman, this definition shall be formulated thus:

Self-management is the term given to the tasks undertaken by an individual living with a chronic disease and its treatment. Self-management tasks incorporate not only adherence to medically prescribed treatment, but also tasks relating to continued social functioning, and tasks of adapting emotionally to living with the condition and its treatments.

This definition clearly does not refer to one single dimension, but would logically appear to fit a three factor structure. One thing this definition makes clear is that when studying self-management, it is important to measure what people do to look after themselves.

Previous work on self-management would suggest that these three factors do not necessarily correlate, and that while they can be mutually reinforcing, they instead often require balancing by the individual living with the condition (Kralik, Koch, Price, & Howard, 2004). Kralik and colleagues used in depth interviews with nine people living with arthritis, and pointed to the possibility that people living with arthritis may see self-management as something very different to the healthcare professionals who care for them. In this dissertation, the terms, ‘medical’, ‘social’ and ‘emotional’ will be used to refer to the three domains. Medical is synonymous with illness work and biological self-management, as described above. ‘Social’ is broadly analogous to ‘everyday life work’, and ‘emotional’ to ‘biographical work’.

2.5 Self-management and self-efficacy

If self-management is a term for what people do, then self-efficacy could be considered a closely related psychological variable that is often regarded as moderating one’s capability to perform those actions. Self-efficacy as a concept was widely popularised by Albert Bandura and his work on Social Cognitive Theory (SCT). Broadly, it is one’s confidence in one’s ability to successfully perform a behaviour in a given situation (Bandura, 1994).

An important distinction should be made between *personal efficacy* or *efficacy expectations*, and *response-outcome expectancies* or *outcome expectations*. Personal efficacy is the extent to which one is confident that one can perform a given behaviour in a given set of circumstances. Outcome expectations describe what a person expects to happen should that behaviour be successfully performed. In other words, a person with diabetes may have a great deal of confidence in their ability to remember their morning dose of insulin, but they may not believe that consistently delivering this dose will control their blood glucose, or stave off organ failure or death. Conversely, they may have a great deal of confidence in the effectiveness of their medication, but lack confidence in their ability to remember to take their dose as prescribed.

A sense of personal efficacy can be derived from a number of sources. The focus of much empirical work has been on *performance accomplishments*, *vicarious experiences*, *verbal persuasion*, and *emotional arousal*. These are, in theory, modifiable factors that influence behaviour, making self-efficacy a natural target for self-management interventions (Clark & Dodge, 1999). Much of the existing literature on self-management hinges on the notion that improving personal efficacy will increase the extent to which individuals undertake self-management oriented actions, such as taking medications, attending clinics, and actively trying to continue their social routines and maintain a sense of self in light of their illness (Marks, 2005).

2.6 Self-management and Patient Activation

“Activation” is a term that has been used for decades to describe the extent to which patients are active and involved in their care (Snell, 2011). The idea that there are stages of activation is best exemplified theoretically by the transtheoretical stages of health behaviour change model (Prochaska & Velicer, 1997). This model posits that there are five stages of change, described in table 2.1 – pre-contemplation, contemplation, preparation, action, and maintenance. According to

Prochaska & Velicer, people not only have different levels of ‘activation’, but that people are constantly moving from one stage to another. Thus according to the model it is possible for individuals to move from contemplation, to preparation, and to begin to take action. Similarly, it is possible that individuals may move ‘backwards’ or relapse, and after a period of maintaining a health behaviour such as dietary modification, may end up back in the contemplation stage, or even back in pre-contemplation where they no longer recognise the need for the health behaviour.

Table 2.1: Stages of change and approximately equivalent Patient Activation Measure equivalents

Stage of change	Description	PAM equivalent
Pre-contemplation	Individual not planning to take action within the next 6 months	Believing patient role is important
Contemplation	Individual intending to take action in next 6 months. Aware of pros of behaviour change, but also acutely aware of cons	
Preparation	Individual is intending to take action within the next month. Some actions have been undertaken, or plans made	Having the confidence and knowledge to take necessary action
Action	Individual has made specific overt modifications to their lifestyle in the last 6 months. Must be a sufficient level of action to realistically achieve goals (e.g. weight loss)	Taking action to improve one’s health
Maintenance	Individual is working to prevent relapse, but not applying change processes as frequently as individuals in the action stage	Staying the course even under stress
Relapse	Individual has reverted to previous behaviour	

Testing this model was made difficult by a lack of well developed instruments. The Patient Activation Measure (PAM) was developed by Hibbard and colleagues to address what they viewed as a promising model, but with some flaws (Hibbard, Stockard, Mahoney, & Tusler, 2004). The PAM is a 22-item scale that measures ‘activation’ by asking individuals about their beliefs around their role in their care, assessing confidence, actions, and ability to cope under stress. A 13 item short form version was developed for clinical use, and use in research alongside other instruments (Hibbard, Mahoney, Stockard, & Tusler, 2005).

The PAM ultimately yields an ‘activation score’, which can be coded into a ‘stage’ of activation. In contrast to the six stages of the transtheoretical model, the PAM has four stages: ‘Believes active role is important’, ‘Confidence and knowledge to take action’, ‘Taking action’ and, ‘Staying the course under stress’. Thus the PAM measures some elements of general disease related self-efficacy, but also actions, coping and attitudes. Thus, despite its purported unidimensional structure, it contains many elements that are useful for examining psychological theories of behaviour change.

2.7 Measuring self-management

As above, self-efficacy is sometimes used as a psychological proxy for self-management. In these instances, self-efficacy can be measured by a number of scales, some of which are very general, and some of which are specific to the disease and the challenges presented by that disease. General self-efficacy in chronic disease is often measured by the Self-Efficacy for Managing Chronic Disease scale from Lorig and colleagues, which takes the form of a 33 item scale that assesses 10 dimensions including exercise and diet self-efficacy, or a brief 6 item version (Lorig et al., 1996). There are various disease-specific versions available for diabetes, arthritis and other chronic conditions. A 2009 systematic review identified 25 instruments designed specifically for evaluating self-efficacy in a given chronic disease: 13 for diabetes, 5 for asthma, 4 for arthritis, 3 for COPD and none for CHD (Frei, Svarin, Steurer-Stey, & Puhan, 2009). They found many of these to be poorly described in the papers detailing their development, notably failing to state the purpose they were being developed for and lacking a description of how they were validated. Nonetheless, there is a debate about whether it is adequate to measure self-efficacy as a general construct, or whether it is important to measure self-efficacy with regards to behaviours specific to the disease in question, for example self-monitoring of HbA1c in people with diabetes.

The conflation of self-management behaviours and self-efficacy can be problematic however, especially if we hold that the purpose of improving self-rated self-efficacy is to moderate a change in self-management behaviour. If we take this view, then self-management should be measured in terms of behaviour. Many studies have taken the approach where self-management is synonymous with adherence to healthcare professional (HCP) prescribed behaviours such as dietary modifications, taking prescribed medications and exercise. These adherence behaviours certainly form at least part of the category of ‘medical management’, although it is important that these are based on goals mutually agreed between the patient and HCPs (Allen, Wainwright, & Hutchinson, 2011). When measuring adherence, there are a number of approaches possible; the appropriate methods will vary by disease and setting.

One method of measuring adherence is the use of routinely collected biomarkers. In diabetes, HbA1C (glycated haemoglobin) is commonly used as a combined measure of dietary control and appropriate insulin usage (Glasgow, Boles, McKay, Feil, & Barrera Jr., 2003). This can be measured during clinic visits, and is regarded as a reliable reflection of an individual’s health behaviours. One drawback of this method is that in other diseases, arthritis for example, the relationship between medication adherence and disease activity can be so tenuous or unpredictable as to render the biomarker a poor reflection of adherence. This means that the measures used need to be carefully selected with expert clinical input, to ensure the validity of concluding that a biomarker really does measure adherence and not other unrelated factors.

For medications, another method of measuring adherence is pill counting. This is where leftover medication is recorded each time a new prescription is given. This method is less reliant on memory than self-report (Lee et al., 2007). However, this method still requires study participants to be honest about the amount of leftover medication, which may be influenced by demand characteristics; for example, the idea that it is bad to have leftover medication (Grymonpre, Didur, Montgomery, & Sitar, 1998).

Another commonly employed method is self-report. Compared to measuring bio-markers and medication counting, this method can be used to assess a much wider range of behaviours, such as exercise, diet, medication adherence, and other lifestyle factors including drinking and smoking. This allows researchers to capture a much broader range of medically related self-management behaviours. The drawbacks here are the same as found in self-report measures elsewhere; they require the participants to correctly interpret the question, which requires a certain level of language skill and comprehension in the language used. They are also subject to various memory biases, and may also be subject to demand characteristics (Prince et al., 2007). Some of these problems can be overcome to varying extents through good questionnaire design informed by cognitive interviewing, appropriate piloting, and validation against other methods mentioned above such as medication counts and biomarkers (Beatty & Willis, 2007).

Two commonly used examples of self-report questionnaires in diabetes are the Diabetes Self-Management Questionnaire (DSMQ, Schmitt et al., 2013) and the Summary of Diabetes Self-Care Activities (SDSCA, Toobert, Hampson, & Glasgow, 2000). The SDSCA contains 25 items, although a revised 11 item version has been suggested due to moderate to poor internal consistency ($\alpha = 0.47$) and test-retest reliability (mean *r* across subscales = 0.40). The revised scale measures 6 dimensions: diet, exercise, blood sugar testing, foot care, smoking, and activities recommended by the individual’s health care team. The SDSCA is intended for both clinical and research use, and measures only the ‘medical management’ component of the self-management triangle.

The DSMQ was developed specifically in response to what has been seen as a weakness of the SDSCA; the scores on the latter scale do not correlate with observed glycaemic control. The argument is that if structural relationships between self-care behaviours, psychological factors such as depression and anxiety, and outcomes such as death are to be explored, the measurement of self-care behaviours must be able to explain variance in factors that drive the clinical outcome of interest; in this case HbA1c. The DMSQ has a total of 16 items, which break down into four areas of self-management (termed self-care in this paper): glucose management, dietary control, physical activity, and health-care use. There are further self-management scales in diabetes, but these two are representative in that they are focused on medical management, but. They also demonstrate that it is important that medical aspects of self-management can be seen to explain some of the variance in clinical variables of interest. However, even within the medical domain, they do not cover broader behaviours such as information seeking and communication with healthcare professionals.

According to theory, self-management is broader than just medical behaviours. However, social and emotion related *behaviours* often remain undefined and unmeasured in studies of self-management. The literature on coping provides some potentially useful groundwork for defining how people with chronic illnesses attempt to manage their emotions, and is described below. Socially proactive behaviours tend to be considered far less frequently, and where social support is assessed, it is usually via measuring an individual’s perceived social support. Additionally, some interventions have been aimed at modifying social support, for example by implementing elements offering opportunities to reduce social isolation. These elements are rare, or rarely explicitly stated to be components of self-management interventions. In COPD, Kaptein and colleagues identified only two studies focusing on social support from the last 50 years (Kaptein, Fischer, & Scharloo, 2014). Both used social support as integrated elements of a wider intervention (Chavannes et al., 2009; Moullec & Ninot, 2010). In both cases, the aim was to improve quality of life.

2.8 Self-management and associated psychological variables

Self-efficacy is often held to be an important variable in predicting self-management behaviours. Theoretically, one would expect other variables such as depression and anxiety, to be related to self-management. Depression is a more common focus of research, but both depression and anxiety are overlapping constructs of what might be termed ‘psychological distress’ (Norton, Cosco, Doyle, Done, & Sacker, 2013). Studies into self-management among many chronic disease populations reveals that self-management is often adversely affected by the presence of depression and anxiety. For example, in CHD depression and anxiety are two of the most reliable predictors of poor self-management (Riegel, Lee, & Dickson, 2011).

Depression and anxiety appear to be the most commonly measured indicators of emotional management in self-management studies (Kaptein et al., 2014). For example, in COPD, a recent meta-analysis found 29 studies looking at psychological and lifestyle interventions to reduce anxiety and depression (Coventry & Gellatly, 2008). In these studies, the emotional component is treated as an emotional state, rather than actions taken to manage one’s emotions.

In CHD, one study addressed the relationship between self-management skills, and wellbeing and depression, in 296 older adults (>65 years old) in the Netherlands (Cramm et al., 2012). Self-management was assessed using the Self-Management Ability Scale, which includes six dimensions: taking initiative, investing in resources for long term benefits, taking care of a variety of resources, taking care of resource multifunctionality, being self-efficacious, and having a positive frame of mind. Note that this scale contains elements of both practical management skills, an emotional component, and includes social components in its assessment of ‘resources’. Wellbeing was measured using the Social Production Function instrument and Cantril's ladder. Depression was assessed using the Geriatric Depression Scale. Regression analyses showed that initiative taking, investment behaviour and a positive frame of mind were all predictive of lower depression scores. As predicted, the higher self-efficacy, the lower depression scores.

These putative relationships between self-management behaviours and depression are particularly important in people suffering with a chronic disease with a high self-management burden like diabetes, ESRD, or CHD. It is important to establish the extent to which life-sustaining self-management behaviours such as adherence to insulin regimes or statins, dietary changes, and exercise are impacted. Depression predicts survival in many diseases, including ESRD (Chilcot, 2012). There are theorised biological mechanisms specific to different diseases that may be responsible, e.g. cytokine function in cancer (Sephton, Sapolsky, Kraemer, & Spiegel, 2000). However, it is likely that self-management behaviours play an important role in survival. For example, in a type 2 diabetes population in the US, negative correlational relationships between self-management (as measured by the SCDSA, above), and depression as measured by the PHQ-9 (Lin et al., 2004) were observed. Major depression was associated with less physical activity, an unhealthy diet, and lower adherence to oral hypoglyemic, antihypertensive and lipid-lowering medications. However, performance of a variety of proactive preventative care activities was similar for those with, and those without, depression.

Measures of distress and self-care in these studies are predominantly cross-sectional, and cannot be used to infer causality. It is not clear whether depression drives self-management behaviour, or whether poor general self-care results in conditions that cause depression. It is likely that there is a reciprocal relationship, but this needs to be empirically established longitudinally. Whichever direction the relationship turns out to run in, or if it is reciprocal, an important question is whether modifying the driving factor can in turn ameliorate the dependent factor. For example, if certain patterns of self-management results in depression, it will be important to establish whether altering self-management activities through education, training, and goal-oriented enhancement of self-efficacy can ameliorate depressive symptoms.

2.9 Self-management behaviour and relationship with clinical variables and outcomes

The ultimate aim of self-managing chronic illness may depend on who is asked. Clinicians may have very different goals to patients (DeJesus, Vickers, Stroebel, & Cha, 2010). Trying to improve clinical outcomes will usually be on the agenda of HCPs, patients, and managers and health services as a whole, although the focus may vary. The clinical outcomes of interest will vary depending on the disease. For example, in diabetes HbA1c may be the chief outcome measured; in a large CHD study it may be the occurrence of a future cardiovascular event. Alternatively, health related quality of life (HRQoL) may be the outcome of interest (Zwerink et al., 2014).

It is important to note the difference between an actual outcome of interest and surrogate outcomes. Returning to CHD, controlling lipid levels is known to be important in preventing the risk of a heart attack. However, a person generally would not care about their lipid levels if they did not translate from a biomarker of cardiovascular risk into an actual cardiovascular event. The real outcome of interest is the cardiovascular event. Lipid levels are a surrogate outcome. This works well when the outcome of interest is known to be highly reliably related to the surrogate outcome. HbA1c and risk of retinopathy is a good example. One must be careful about claiming an outcome is important to the person with the condition when the link is less clear.

Some of the work examining the relationship between self-management and clinical outcomes has taken the form of interventional research. The evidence for the efficacy of self-management programmes has been explored in hundreds of trials of various kinds, with greatly mixed levels of methodological rigour (Warsi, Wang, LaValley, Avorn, & Solomon, 2004). In some conditions, there is a sufficient number of randomised trials, using similar enough outcome measures to conduct a meta-analysis. For example, in rheumatoid arthritis it has been found in multiple meta-analyses that self-management interventions produce a statistically robust, but clinically small improvement in pain and disability (Chodosh et al., 2005; Warsi, LaValley, Wang, Avorn, & Solomon, 2003). Other reviews have found that arthritis outcomes do not even reach statistical significant thresholds (Warsi et al., 2004). This may in part be due to the duration of the average study, which may not have been able to capture changes in outcomes such as functional disability, or may have been measuring the wrong outcomes.

In diabetes, meta-analyses have generally produced statistically and clinically significant reductions in HbA1c, representing greater glycaemic control (Norris, Engelgau, & Venkat Narayan, 2001). Importantly, it appears that this effect is apparent when measurements are taken in the short term (<6 months), and that longer term benefits tend to only persist if follow up procedures are employed. No improvement was found for mortality between self-management and control groups in two studies, one over 5 years, the other over 13 months (Malone et al., 1989; Hanefeld et al., 1991).

Hypertension typically uses blood pressure as the main clinical outcome, and self-management interventions have been found to result in a statistically and clinically significant reduction in both systolic and diastolic blood pressure (Chodosh et al., 2005).

In Chronic Obstructive Pulmonary Disease (COPD), attempts at meta-analysis have been hampered by heterogeneous outcomes variables, which would render statistically compiling outcomes theoretically problematic. However, a Cochrane review on the subject, looking at 14 trials, found that it is likely that self-management education programmes reduce hospital admissions (Effing et al., 1996), although no clear recommendations are made due to heterogeneity in interventions, study populations, follow-up times and outcome measures.

There are several common messages in each of these reviews. One of the main criticisms each makes is that the nature of the self-management intervention being employed is poorly described in the majority of articles considered for inclusion. Even the quality of the description of the intervention in those included in the reviews is often not especially high. This is problematic for obvious reasons; if substantially different interventions are being employed, they should not be entered into a single meta-analysis together, as meta-analysis relies upon an assumption of homogeneity of subject matter. Further, if we wish to conduct either exact or conceptual replications of successful interventions, being able to replicate the intervention itself is obviously a key component. Lastly, it is impossible to translate a trial-intervention formulated in a research setting into clinical practice if the contents of the intervention are unknown. The message here is clear; self-management interventions need to be better described in published literature or related protocols.

When considering the success or otherwise of self-management interventions, it is important to be clear about what the training aims to help people to self-manage (Newman, 2008). If the main aim is to improve psychological wellbeing or quality of life, then success should be measured by clinical diagnosis of depression or screening tools that allow some assessment of wellbeing. If the goal is to improve clinical control of blood pressure or HbA1c, this is what should be measured. The meta-analyses above are hampered by the fact that not only are the interventions poorly described, but they also may not have all been setting out with the same goals in mind. In light of this, overly broad phrases such as, ‘improving self-management’ or ‘increasing self-management’ seem next to meaningless.

Methodological issues above notwithstanding, there does appear to be promising evidence from accumulated randomised controlled trials that self-management interventions aimed at providing more than just education may be able to produce reliable and clinically significant improvements in key clinical outcomes for diseases such as diabetes and hypertension.

2.10 Self-management in models of health psychology

Many theoretical models in health psychology seek to explain some, if not all, aspects of self-management, resulting in overlap between models. Most commonly, models address the 'medical' aspect of the condition, and say less about predicting social or emotional outcomes – although both have a place in the predictive pathways of some models. Most commonly, health psychology models attempt to describe adherence, part of the medical aspect of self-management, as well as care-seeking behaviours. Other theoretical models not specific to health psychology have to date, for the most part, been used to describe adherence and care seeking behaviours. The following is a brief overview of salient models, and comparisons between them; for a more general review of the models in question, see Armitage & Connors (2000).

The active element of self-management is a set of behaviours that are more easily embedded into other existing theories – most commonly social cognitive theory (SCT), and the stages of change model (more commonly operationalised today as patient activation). Therefore, when examining the properties and utility of measuring medical, social and emotional variables associated with self-management, SCT and patient activation are often used as the theories guiding hypotheses.

As previously discussed, much of the self-management literature has been built upon Social Cognitive Theory, and self-efficacy in particular. Perceived self-efficacy, "… is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994). Part of the reason for this focus is that empirical work looking at SCT's descriptive, and predictive power as a model of behaviour change does not improve beyond what can be explained by self-efficacy (Armitage & Conner, 2000). Indeed, Armitage and Connor conclude that due to its central role in many theories, and the lack of empirical support for other elements of SCT, self-efficacy is therefore likely more important than SCT *per se*.

Patient activation largely emerged from the transtheoretical model of stages of health behaviour change (Prochaska & Velicer, 1997). Initially, the Patient Activation Measure was developed as tool to measure how important an individual believed their role in their care to be, their perceived knowledge about their treatment and condition, and their confidence to take action and stay the course under stress. This final component maps onto self-efficacy, while perceived knowledge and role are more distinct. Empirical work has been undertaken more recently in an attempt to develop patient activation from a single measure into a more comprehensive theory useful for generating hypotheses. For example, Hibbard and Mahoney (2010) attempted to incorporate the role of emotions and self-concept into patient activation theory. In a sample of 843 participants, 93.6% of which had one or more chronic conditions, higher patient activation level was found to be correlated with higher positive affect measured by a shortened version of the Positive Affect Negative Affect Scale (PANAS). They concluded that the PAM may be tapping into not just attitudes towards behaviour, but also affect and self-worth.

Despite this, patient activation remains largely underdeveloped as a theory, and remains largely untested in the ESRD population – which will be explored further in chapter 3. Despite their overlaps, SCT and patient activation are to some extent distinct, with patient activation being marketed as a clinically useful tool. Patient activation has recently received a lot of attention among healthcare policymakers in the UK (NHS England, 2013), and is being increasingly used as a routine clinical measure. Therefore, there are both theoretical and practical reasons to measure both self-efficacy and patient activation, and comparing their utility in predicting self-management behaviours and illness outcomes.

A third theory often guiding the self-management literature is the Common Sense Model (CSM) of Illness Representations (Leventhal, Leventhal, & Contrada, 1998). Leventhal's Common Sense Model of Illness Representations (CSM) posits that the coping behaviours undertaken by an individual in response to illness are driven by a dual-pathway system of illness representations.

These cognitive representations govern cognitive coping strategies, and emotional coping strategies, the results of which feed back into the illness representations. A strength of this model is that it attempts to explain more than adherence to a single health behaviour; it also seeks to predict whether people will seek social support, their psychological outcomes (depression, anxiety, general psychological distress), and whether they will engage in problem focused or emotionally focused coping. The core dimensions of illness representations are: timeline, control/cure, illness identity, cause, and consequences. Timeline is further subdivided into perceptions of whether the illness is acute or chronic, and whether the symptoms are continuous or cyclical. Control/cure can to a certain extent be thought of as analogous to Bandura's notion of self-efficacy; it is subdivided into treatment control (can the treatment help the illness – similar to outcome expectancies) and personal control (can the person maintain behaviours that will ameliorate symptoms – similar to perceived self-efficacy).

These illness representations are operationalised in the various forms of the Illness Perception Questionnaire (IPQ). The original IPQ did not include a cyclical/continuous dimension, nor did it differentiate between treatment and personal control (Weinman, Petrie, Moss-morris, & Horne, 1996). These additions were included in the revised illness perception questionnaire (IPQ-R, Moss-Morris et al., 2002). Finally, due to the expansive nature of these questionnaires (the IPQ-R contains 38 main items, plus a checklist of symptoms, possible causes, and open ended questions on causes, resulting in over 70 items), a brief version was devised (Broadbent, Petrie, Main, & Weinman, 2006). The brief version contains eight likert style items, plus a question asking the respondent to rank the three most important causes of their illness.

There has been a great deal of empirical investigation into the CSM (Hagger & Orbell, 2003). Illness representations of control and illness identity have been found to be a greater predictor of illness-related functioning and emotional outcomes than coping style, for example in chronic fatigue syndrome, even though illness perceptions still drive coping styles (Moss-Morris, Petrie, & Weinman, 1996). Theoretically, illness perceptions should be a good predictor of the steps that people take to self-manage, medically (adherence, presentation to healthcare services), socially (socially-oriented coping) and emotionally (emotion-focused coping, emotional outcomes).

Illness perceptions are useful to measure alongside self-efficacy, particularly the control/cure, timeline, and consequences dimensions, as this can give a good approximation of an individual's outcome expectancies, allowing investigation of cognitive representations that may interact with self-efficacy to better predict self-management behaviour.

2.11 Summary

Self-management is described in the psychological and sociological literature as having three dimensions; medical, social, and emotional. Self-management is a term for behaviours aimed at promoting health, often in light of serious illness. It is commonly incorporated into social cognitive theory, patient activation theory, and the common sense model of illness representations, all of which overlap to some degree. Self-management as a set of behaviours is often conflated with self-efficacy and patient activation, which are also held to be variables that predict or moderate self-management behaviours. Chapter 3 will examine how theories surrounding self-management have been applied to people with Chronic Kidney Disease (CKD), how these theories can be better tested, and why self-management behaviour needs to be better operationalised in this condition.

Chapter 3: Self-management in End Stage Renal Disease

3.1 Introduction

The previous chapter explored the concept of self-management from a general standpoint, across all chronic conditions. The social and emotional challenges faced by people living with ESRD are unique, as are the tasks required for optimal clinical outcomes. Therefore the following chapter concerns self-management specifically in ESRD. An overview of the daily self-management challenges faced by those with ESRD is provided in chapter 1. Briefly, people on dialysis for ESRD are faced with polypharmacy, performance of dialysis at least three times a week, narrow dietary and fluid restrictions, fatigue, mild cognitive impairment, and often reduced physical capabilities. The present chapter initially focuses on reviewing the literature concerning self-management and the role of psychosocial variables.

The second half of the chapter presents the results of a scoping review of materials that are available to the public via the internet, whether aimed at patients or healthcare professionals. This provides context for the work presented in chapter 5, which examines patient and healthcare professionals' perceptions of self-management. The aim is to explore what publically available materials say about self-management, and compare this with the views that patients and healthcare professionals actually hold.

3.2 Thematic review of previous work on self-management in ESRD

This literature review is guided by several key questions, to allow further exploration in the empirical chapters that follow.

Question 1: What aspects of self-management have previous studies looked at?

Question 2: What has been found on psychological factors associated with self-management?

Question 3: What tools exist for measuring concepts related to self-management in ESRD?

3.2.1 Search strategy

To obtain literature classified as focusing on self-management, a systematic search was conducted on PubMed and PsychNET. Further citations were then obtained from the reference sections of papers deemed relevant to the present review based on the following inclusion/exclusion criteria.

The initial search was conducted using the following criteria:

PubMed: (self management OR self care) AND (esrd OR dialysis)

PsychNET: self management AND dialysis

Abstracts were reviewed for inclusion using the following criteria:

Inclusion:

- Topic of the paper is self-management in ESRD, or late stage CKD focusing on preparing for dialysis
- Original research or review paper (including questionnaire development)
- Is about 'self-management', or self-management related topics, specifically adherence, decision making, or social/emotional adjustment
- Is focused on adults
- Originally in or officially translated into English

Exclusion:

- On children only
- Individual case study or opinion piece
- Not in English
- Focus is solely on comparing dialysis modalities, e.g. outcomes in home haemodialysis versus in-centre haemodialysis, or other aspects of medical management such as drug comparison studies

Paediatric renal papers were excluded as there are different issues, such as transitional care, that are beyond the scope of this dissertation. Case studies and opinion pieces were not included.

Late stage CKD was included as certain issues, such as dietary management and blood pressure control, or decision making regarding dialysis modality, are relevant to subsequent treatment as the disease progresses to ESRD. Studies in languages other than English were excluded due to translation being logistically beyond the scope of this dissertation.

3.3 Results

3.3.1 Prior reviews – interventions

A recent review presents one of the most comprehensive overviews of self-management for a renal audience (Novak, Costantini, Schneider, & Beanlands, 2013). However, much of the article is focused on presenting the concept of self-management, and only briefly touches on previous studies in ESRD. The review argues for 'whole-person' care, and that self-management support can be useful in helping people with ESRD, while not defining what should be measured when defining the success of such interventions.

A number of reviews attempt to summarize the literature on more focused questions, such as how self-management support interventions can improve adherence. For example, Welch & Thomas-Hawkins (2005) reviewed prior studies of psychoeducational interventions to promote adherence to fluid restrictions. They found nine studies of educational or Cognitive Behavioural Therapy (CBT) based interventions, which had mixed outcomes. The studies described included a theoretical component, although the application of theory to the intervention was often lacklustre. Theories used included the transtheoretical model of stages of change (Prochaska & Velicer, 1997), self-regulation theory (Leventhal et al., 1998), the health belief model (Rosenstock, 1974), and social cognitive theory (Bandura, 1985). The two studies that used social cognitive theory (Tsay, 2003; Tucker, 1989) proved effective at reducing Interdialytic Weight Gain (IDWG) with a self-efficacy training programme used by Tsay proving particularly effective. Self-monitoring was found to be one of the most promising components, producing significant effects in the five studies in which it was used. However, the performance of a theory driven intervention does not necessarily reflect the veracity of the theory it is based on. For this, hypothesis driven attempts to falsify individual mechanisms described by a theory are required.

A recent review of studies in the teaching of self-care behaviours for arteriovenous fistulae (AVF) documented practices of nurses as reported in the literature (Sousa, Apóstolo, Figueiredo, Martins, & Dias, 2014). No summary of evidence of efficacy was presented. Instead it was documented that most nurse led education on fistula care is delivered post-construction of the AVF, and is often a one off session, rather than ongoing or routinely supported. This is a common finding with self-management education in ESRD, despite the fact that all self-care behaviours associated with the disease, including AVF care, will likely be important for the rest of the individual’s life (Blomqvist, Theander, Mowide, & Larsson, 2010).

Burke et al. (2005) reported on two pilot studies for self-monitoring dietary intake in HD patients, one using pencil and paper, and one use electronic Personal Data Assistants (PDAs). Due to the pilot nature of the studies, no conclusions could be drawn about efficacy. However, the report does illustrate the potential role that technology can play in helping people to manage their diet.

Self-management interventions in a broad range of chronic conditions typically use either adherence or self-efficacy as outcome measures (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007). This appears to be largely true for interventions in the renal context as well. As noted in chapter 2, it is often a psychological outcome (such as self-efficacy) that is successfully modified, not adherence (Greenhalgh, 2009). It is therefore interesting that many of the renal self-management interventions described above appear to have success with both psychological outcomes and clinical markers of adherence such as IDWG. It may be that this is the result of publication bias, or possibly something specific about self-management in ESRD that is responsible for this.

Table 3.1: Self-management interventions in CKD

Study	Theoretical model	Aim	Intervention	Methods	Results	Conclusions
(Afrasiabifar, Karimi, & Hassani, 2013)	Roy's adaptation model (RAM)	Improve adjustment	Eight one hour education sessions over eight weeks	Single blind RCT, 59 patients (31 active, 28 control). Two month follow-up.	Physiological and self-concept, and role function scores improved in active v control	Education based on RAM could be effective
(Aliasgharpour, Shomali, Moghaddam, & Faghihzadeh, 2012)	Social cognitive theory/self-efficacy	Reduce IDWG	Six session self-efficacy training programme	Single blind RCT, 63 patients. Two month follow-up.	SE increased, IDWG decreased in active group compared to control group	SE training effective at reducing IDWG for people on HD
(Christensen, Moran, Wiebe, Ehlers, & Lawton, 2002)	Self-regulation (Kanfer & Gaelick-Buys, 1991)	Reduce IDWG		Single blind RCT, 40 patients (20 active, 20 control). Eight week follow-up.	Adherence improved in active group, worsened in control group. Significant difference at follow-up.	Self-regulation based intervention appeared effective at reducing IDWG

(Karamanidou, Weinman, & Horne, 2008)	Self-regulatory theory (Leventhal et al., 1998)	Change illness and medication perceptions		Single blind RCT intervention (N =19) v control (N = 20). Four month follow-up.	Illness understanding improved over time, even after cessation of intervention	
(Lin, Tsai, Lin, Hwang, & Chen, 2013)	Self-regulation (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002)	Improve self-management, self-efficacy, and slow CKD progression	Five week self-management based education programme	Single group pre-post design. Twelve month follow-up	Self-efficacy improved but self-management did not. Serum creatinine decreased.	Self-management education may slow CKD progression, despite not improving self-management behaviour
(Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012)	Self-efficacy, empowerment	Self-efficacy, QoL, clinical markers	Four individual and two group empowerment counselling sessions	Single blind RCT, intervention (N = 25) v control (N = 25). Twelve week follow-up.	Self-efficacy, QoL, BP, IDWG significantly improved in intervention v control	Empowerment counselling effective
(Moonaghi, Hasanzadeh, Shamsoddini,	Orem’s self-care model	Attitudes to dietary and fluid adherence	Face to face or video based education, over	Randomised trial, no control group. 75 participants,	‘Improvement’ in attitudes towards restrictions in both	Both face to face and video based

Emamimoghadam, & Ebrahimzadeh, 2012)			two sessions in one week	four week follow-up	groups pre-post. No difference between groups	education can change attitudes
(Nozaki, Oka, & Chaboyer, 2005)	Self-efficacy, CBT	Reduce IDWG	CBT versus standard patient education	Randomised, intervention (N = 11) v control (N =11). Follow-up at 12 weeks.	Both programmes significantly reduced IDWG. Effect lasted for 8 weeks in standard education, v 12 weeks in CBT	CBT based on self-efficacy theory may prolong the effects of self-management education on IDWG
(Royani, Rayyani, Behnampour, Arab, & Goleij, 2013)	Self-efficacy	Improve empowerment and self-care self-efficacy	Empowerment education, two sessions a week, for one month	Randomised trial, intervention (N = 40) v control (N = 40).	Improvement in self-efficacy and empowerment v control group	Self-efficacy and empowerment are modifiable in this population
(Sharp et al., 2005)	Health beliefs	Reduce IDWG	Four week CBT with some focus on health beliefs	Intervention (N = 29) v wait list control (N = 27), over four weeks, plus 18 week follow-up	Reduced pre-post IDWG when both groups were combined for longitudinal analysis	Intervention may be effective, but methods questionable
(Su, Lu, Chen, & Wang, 2009)	Social cognitive theory/self-efficacy	Improve clinical status and QoL	Self-management promotion based	Pre-post design, 30 patients on PD,	Volume status, QoL and rehabilitation	Multidisciplinary self-management

			on self-efficacy theory. In PD patients.	followed up for 6 months	status improved. Kt/V and KRU did not change.	promotion can be effective
(Tsay & Hung, 2004)	Self-efficacy	Empowerment, Strategies Used to Promote Health, depression	Self-efficacy based self-management counselling, three times a week for four weeks	RCT, intervention (N = 25) v control (N = 25), measures taken baseline and 6 weeks post intervention	Significantly greater improvement in empowerment, self-care self-efficacy and depression in intervention group	Self-efficacy based training can be effective
(Welch et al., 2013)	Social cognitive theory	Feasibility of intervention	Six week use of mobile app to aid self-monitoring	Intervention (N =24) v controls (N = 20)	App was found to be feasible and acceptable	Further studies required regarding efficacy

3.3.2 Prior reviews – observational

Observational research on self-management more frequently examines the psychological factors involved in self-management, although often as predictors of adherence to treatment. This relationship is potentially extremely important from a clinical perspective. Reviewing this relationship in depth, Clark, Farrington & Chilcot (2014) found that a number of psychosocial factors can predict non-adherence in ESRD, including mood, self-efficacy, social support, and illness and treatment perceptions. This work will be considered in more depth below, along with any relevant interventional studies.

3.4 Question 1 – What aspects of self-management have previous studies looked at?

Self-management is theorised to comprise of three domains: medical, social, and emotional management. This model has not been consistently applied to studies of self-management in ESRD, however. Questions of whether a division between these three domains are useful remains, as they are likely interlinked and overlapping. Further, while these three domains are frequently discussed, there is no accepted model for how they interact in self-management. Indeed, self-management itself is not so much a theory as a combination of other theories.

However, when using these three domains, unsurprisingly the majority of studies focus on medical management. Of these, most focus on adherence to prescribed treatment, be it fluid (Welch & Thomas-Hawkins, 2005), medication (Browne & Merighi, 2010), dietary adherence (Burke et al., 2005) or dialysis attendance (Kim, Evangelista, Phillips, Pavlish, & Kopple, 2010).

Where emotional and/or cognitive variables are studied, they are usually studied as predictors of adherence rather than as outcomes, moderators, or mediators. For example, depression has been found to be a predictor of adherence in a number of studies, and this is theorised to be linked to increased mortality in people with depression on dialysis (Taskapan et al., 2005). The impact of depression on quality of life has also been studied, with the predictable outcome that higher depression results in lower self-reported quality of life (Drayer et al., 2006). The impact of medical management on quality of life has also been assessed, including the impact of various biomarkers on QoL outcomes. While factors such as Kt/V were found to have a small effect on QoL, nutritional status and haematocrit demonstrated a moderate to large impact on QoL as measured by the SF36 (Spiegel, Melmed, Robbins, & Esrailian, 2008). The relationship between psychological variables and medical and social factors is likely to be complex, and future analyses should take this into account by including these factors as moderators or mediators.

Intervention studies included in this review were coded for whether they included medical, emotional, and/or social aspects of self-management. Out of 43 studies, 40 (93%) included a focus on medical management, either as a predictor or an outcome. Twenty-one (49%) included a significant focus on psychological factors, either as predictors or outcomes. Only two studies (5%) included social factors, such as perceived social support, or role functioning, as substantial elements of interest.

3.5 Question 2 – What has been found on psychological factors associated with self-management?

This section will focus on what has been found in ESRD self-management intervention studies that have a theoretical basis. However, it is important to restate that the success of an intervention based on a theory only provides support for that intervention, not necessarily the theory itself (though it may be suggestive of its veracity).

3.5.1 Social Cognitive Theory

As described in chapter 2, self-management is most often discussed in light of Bandura's Social Cognitive Theory (SCT). Other models include the Transtheoretical Model of Behaviour change, and Leventhal's self-regulation theory/common sense model of illness representation. While many studies into psychological factors and self-management are not theoretically driven (Welch & Thomas-Hawkins, 2005), these models have all been applied to ESRD with varying degrees of fidelity. These studies will now be considered.

As anticipated from SCT and previous self-management work in other chronic illness, self-efficacy and self-care ability appear to be correlated in ESRD (Bağ & Mollaoğlu, 2010). This study looked at a cross sectional sample of 125 people receiving haemodialysis in Turkey, and found that people in the highest self-care ability category scored significantly higher on the general self-efficacy scale (GES; Rimm & Jerusalem, 1999). Similar correlations have been found for clinical markers of adherence in a number of other studies in different countries. For example, in a Portuguese study of 113 people on haemodialysis, patients with an IDWG of less than 3.5% of total bodyweight had scored significantly higher on self-efficacy (Lindberg, Fernandes, Lindberg, & Fernandes, 2010).

Self-efficacy has also been used to predict quality of life in dialysis patients. In Taiwan, a study found that self-efficacy predicted a huge portion of the variance in quality of life scores ($r^2 = 0.475$, $p < 0.001$), while adding depression to the model increased the explained variance by a further 5.5%. The relationship between self-efficacy and QoL may be partially due to these constructs being partially overlapping. However, these studies only look at self-efficacy which is only part of SCT. In the USA, Patterson et al. (2014) tested self-efficacy, in addition to outcome expectancies and self-regulation (self-monitoring, goal setting, feedback), as predictors of physical activity among people on dialysis. While each component of SCT was related to physical activity individually, outcome expectancies were found not to contribute to final model, and was removed as a factor.

3.5.2 Common sense model of illness representations

The Common Sense Model (CSM) posits that health related behaviours are related to the cognitive and emotional representations people hold of their illness (schema). In ESRD, illness representations have been shown to be related both to depression (Chilcot, 2012b) and fluid non-adherence (Chilcot, Wellsted, & Farrington, 2010). While some argue that illness perceptions can be combined into a summary score, each dimension of illness perceptions relates to a distinct aspect of cognitive or emotional illness representations. In the previous example for fluid, perceptions of a shorter disease timeline are related to non-adherence. Another study again found that perceptions of a shorter illness timeline predicted phosphate binder non-adherence, as did greater emotional representations of ESRD (O'Connor, Jardine, & Millar, 2008). However, they did not find these relationships when it came to fluid adherence. Illness perceptions are a promising area to explore in future intervention studies. Illness perceptions have proven to be modifiable, and can result in changes to knowledge and understanding of ESRD (Karamanidou, Weinman, et al., 2008). Further studies are required to identify whether these changes translate into adherence, clinical outcomes, and quality of life (Kaptein et al., 2010; Clark et al., 2014).

3.5.3 Transtheoretical model of stages of change

The transtheoretical model purports that the success or failure of attempts to modify behaviour will depend, at least in part, on a person's "readiness to change". While many studies have examined the role of stages of change in dietary modification, few have examined the TTM in the context of self-management and ESRD. Molaison & Yadrick (2003) staged an intervention in 316 people on HD (216 intervention, 100 controls). The 12-week intervention was designed to move people from pre-contemplation to readiness to change, using techniques similar to motivational interviewing (Miller & Rollnick, 1992). Readiness to change was assessed using a 6-item questionnaire and placing them into one of five readiness categories. While the intervention succeeded in changing participants' 'readiness to change', as well as improved treatment related knowledge scores, fluid adherence did not improve over the course of the intervention. In fact, fluid adherence worsened between the beginning and the end of the study.

Other models

The health belief model (Rosenstock, 1974) has been used to explore dietary sodium intake in people on HD. In a study of 79 people, adherence to dietary sodium restrictions were associated with greater perceived benefits, and fewer perceived barriers to adherence to those restrictions (Walsh & Lehane, 2011). Perceived benefits are roughly analogous to treatment beliefs, often studied in concert with illness perceptions (Horne, Weinman, & Hankins, 1999).

3.6 Question 3 – What tools exist for measuring concepts related to self-management in ESRD?

General issues relating to measuring self-management are discussed in chapter 2. In most conditions, the purported tripartite structure of self-management has not been translated into specific scales for measuring self-management as a whole concept, but rather as individual components.

In ESRD, most self-management studies have used clinical measures of adherence as a proxy measure for assessing medical self-management behaviours. These most commonly include interdialytic weight gain (IDWG) to assess adherence to fluid allowances, serum phosphate to measure adherence to dietary recommendations and phosphate binder medication, and sodium, again as a measure of dietary adherence. Self-report is sometimes used, although there is a wider debate about whether this method is ever sufficiently reliable when assessing adherence (Grymonpre et al., 1998). An instrument has recently been developed that assesses a wide range of adherence behaviours, from shortening/skipping dialysis, to medication and dietary adherence (Kim et al., 2010). It also assesses a variety of attitudes to treatment, and is potentially useful for exploring the relationship between the two. However, with 46 items it may be unfeasible for use alongside other instruments.

Assessment of emotional aspects of self-management has typically involved the use of tools developed to screen for mood disorders. These typically include depression and anxiety questionnaires, such as the Beck Depression Inventory II (Beck, 1996), the PHQ-9 (Kroenke, Spitzer, & Williams, 2001), and the HADS (Bjelland, Dahl, Haug, & Neckelmann, 2002). Mental health components of quality of life measures have also been used, most commonly the mental health component subscale of the SF-36 (Wight et al., 1998). These measures are screening tools, and are not to be used to conclusively diagnose psychopathology (Chilcot, Wellsted, Da Silva-Gane, & Farrington, 2008). Rather, they are used to assess mood. However, they may miss some psychological details important to adjustment in chronic illness. Furthermore, they often do not address what people do to protect or promote their emotionally wellbeing.

Most published studies on self-management included in this review did not address the issue of social functioning (95%). Perceived social support was assessed in one study, using the Social Support from Healthcare Providers scale (Neri et al., 2011). Other scales exist for assessing social support in chronically ill populations, such as the Duke Functional Social Support questionnaire (Broadhead, Gehlbach, de Gruy, & Kaplan, 1988). While it is useful to measure perceived social support, these scales alone do not capture behaviour, such as the seeking of social support, or participation in social activities.

Variables relating to self-management behaviour such as self-efficacy, illness perceptions, and readiness to change, have all been used in ESRD and appear to be valid and useful measures.

Self-efficacy can be measured using generic scales for self-efficacy in chronic disease (Lorig et al., 1996). It can also be assessed using ESRD specific scales, although these often relate to one specific adherence related behaviour, such as fluid adherence (Winters, Lindberg, & Sol, 2013). Illness perceptions can be assessed using tools developed in other chronic illnesses, but that have been validated for use in ESRD (Chilcot, Norton, Wellsted, & Farrington, 2012). “Readiness to change”, as per the transtheoretical model, can be assessed using the Patient Activation Measure (PAM), although this does not appear to have been extensively tested in ESRD populations.

Some tools have been developed or adapted for ESRD that may provide useful insight beyond the simple measures listed above. For example, Thomas-Hawkins developed a tool for use with people on HD, that examines role functioning (Thomas-Hawkins, 2005). Rather than look at physical functional status in terms of what people are able to do, it asks what they actually do. It breaks these role activities into three categories; personal care activities such as bathing and dressing; household activities, such as housework and shopping; and social and community activities, such as going out with family and friends or participating in social clubs. By measuring the extent to which people undertake these roles, they are providing a good measure of the ‘social’ side of self-management.

Two other questionnaires have tried to tackle the concept of self-management, one in early stage CKD, the other in people on HD. Curtin et al. (2004) developed a scale assessing self-management and knowledge with 372 patients on in-centre HD across 17 facilities. Based on prior self-management theories, and previous work by the authors, 60 items were developed and pre-tested in a small convenience sample of 25 people. After dropping 6 items for lack of clarity, these questionnaires were given to 372 people on HD. After item reduction and rotation using exploratory factor analysis, 8 domains, with a total of 37 items, remained. The domains were:

1. Suggestions to providers

   a. Example: Asked for a change in treatment based on information you learned on your own?
2. Self-care during haemodialysis
   a. Example: Cleaned/prepared your access site for needle placement?
3. Information seeking
   a. Example: Looked for additional kidney diet information?
4. Use of alternative therapies
   a. Example: Tried an alternative treatment (such as yoga, acupuncture, magnets or hypnosis?)
5. Selective symptom management
   a. Example: Kept problems or symptoms to yourself so as not to bother staff or your doctor?
6. Assertive self-advocacy
   a. Example: Spoke up to a caregiver because you thought they were doing something wrong?
7. Impression management
   a. Example: Tried to get staff or your doctor to think well of you, in order to get better care?
8. Shared responsibility in care
   a. Talked regarding a treatment or medicine you learned about, hoping the information might work for you?

The full questionnaire can be found in appendix A.

During development, the scale was concurrently administered with the physical component subscale 12 (PCS-12) and mental health subscale 12 (MCS-12) of the SF-12 quality of life questionnaire (Ware, Kosinski, & Keller, 1996). Cross sectional correlations revealed that self-care during haemodialysis and shared responsibility in care were both associated with better physical functioning. However, selective symptom management, assertive self-advocacy and impression management, were all associated with both poorer physical functioning and poorer mental wellbeing. Only knowledge was associated with greater mental wellbeing. It is not clear from available data which causes which, or whether it is a self-reinforcing reciprocal relationship.

The authors posit that the mixed negative/positive correlations result from different ‘styles’ of self-management. Shared responsibility in care, for example, is an example of ‘cooperative’ or ‘participatory’ self-management, where the patient works together with the care team. Selective symptom management, where a person withholds information from the care team and attempts to deal with the problem alone, is an example of ‘defensive’ or ‘protective/proactive’ self-management, which may be associated with poorer psychological and physical functioning. This question of self-management styles has not been extensively studied in ESRD, but raises important questions about the nuances inherent to self-management, and whether cooperative self-management or shared care may be more appropriate terms than self-management, which can imply the idea of health behaviours being undertaken in isolation.

The issue of cooperative and defensive self-management behaviours, covering a range of activities that go beyond adherence, warrants further investigation. For this reason, the scale was selected for use in the empirical chapters of this dissertation. As it did not have a specific title, the scale will be referred to as the Behaviours on Haemodialysis Scale (BHDS) for ease of reference.

One tool has been developed with the intention of reflecting the three domain background behind self-management in chronic illness. Lin and colleagues (2013) developed a 29-item multidimensional questionnaire for use with people with stage 2 and 3 CKD. As this tool focuses on pre-dialysis medical issues, it does not cover many of the medical challenges and life interruptions that are experienced in ESRD. For example, it does not cover the time, fatigue, and emotional issues associated with dialysis itself, or medication or fluid adherence and the social and emotional implications of these complex regimens.

However, the instrument is a potentially useful template for future instruments in ESRD. The final 29 items were obtained from a pool of 59 items, derived from an expert consensus panel and reduced using exploratory factor analysis and a sample of 252 Taiwanese respondents. The final scale has four factors; self-integration, problem solving, seeking social support, and adherence to recommended regimen.

This structure closely mirrors the three domain self-management model, and a similar scale in ESRD may allow for better assessment of 'self-management' as a behavioural predictor or outcome in studies that purport to examine this. Examples of items for each factor include:

1. Self-integration
    a. Managing food portions and choices in social activity
2. Problem solving
    a. Thinking over reasons about bad [sic] laboratory data
3. Seeking social support
    a. Asking family or friends for help when helpless or frustrated
4. Adherence to recommended regimen
    a. Don't follow care providers' suggestion to control weight

3.7 Scoping review of self-management materials available to the public

The previous section provided a review of the academic literature on self-management in ESRD. The following section describes a scoping review of web materials available on self-management, as well as educational materials on ESRD. This will allow for a comparison of academic and public-facing self-management materials, as well as providing additional context for the work in chapter 5 exploring self-management concepts among patients and healthcare professionals.

3.7.1 Search strategy

Online searches for publically available websites and materials were conducted using Google. These searches ranged from narrow to broad in scope, including as many synonyms as possible. Subsequent hits were recorded in a word file with the website's title and front page link, followed by a brief summary of materials found, and any that could be locally stored (.PDFs etc) were downloaded and filed.

As many websites that deal with education for chronic disease have their own links, a system was employed whereby all salient links from a website were followed up and listed in an indented fashion under the site from which they were found, before the results of the main search were returned to. This helped to identify the source of materials that were found for replicability and clarity.

The first search concerned self-management education relating to dialysis patients, and the primary search parameters used were:

("self management" OR "self-management" OR "self-efficacy" OR "self efficacy") AND (education OR resources) AND (haemodialysis OR hemodialysis OR dialysis)

Self-efficacy was included, as it is frequently associated with self-management interventions (Lorig & Holman, 2003). The two are often used more or less interchangeably However it should be noted that they refer to two distinct concepts; self-efficacy to one's sense of being able to achieve a desired outcome, self-management describing observable behaviour.

3.7.2 Findings

A list of the resources found during this search can be seen in table 3.2.

Table 3.2: Self-management resources available to for people with ESRD

Name	Focus	Description	URL
Self-management in renal resources, aimed at patients			
Kidney End-of-Life Coalition	End of life care planning	Has a section for patients that refers to some issues aligned with self-management, such as planning ahead and giving a sense of control	http://www.kidneyeol.org/Home.aspx
HealthLinkBC	Self-monitoring	A US site that has a programme with an emphasis on self-management	http://www.healthlinkbc.ca/
Kidney Health Australia	General self-management skills	Has downloadable factsheets such as, "You're in Charge – self-management health book" and, "Using the web to research kidney health information"	http://www.kidney.org.au/
DaVita	Diet, travelling, education	Includes a useful diet helper and guide to cooking recipes suitable for people on dialysis. Includes videos and recipies. Has a GFR and Kt/V calculator. Information on travelling very useful for people on dialysis.	http://www.davita.com/

Kidney Patient Guide	Emotional impact of renal disease, diet, finances, advice for carers, holidays	Covers a broad range of issues, many of which relate to self-management. Diet, holidays and finances included.	http://www.kidneypatientguide.org.uk/
National Kidney Foundation	Charity with broad remit	Includes a section on education on self-management behaviour (Guideline 5). Also includes diet guidelines via KidneyKitchen, including, recipes, links to dialysis patient cookbooks, and tips on low salt seasoning	http://www.kidney.org/
PatientsLikeMe	Peer to peer communication	Site designed to provide patients with the opportunity to share experiences	http://www.patientslikeme.com/
The Renal Gourmet	Diet	Kidney diet website written by a patient who has been on dialysis for 10 years	http://www.kidneycookbook.com/
American Association of Kidney Patients (AAKP)	Education	Non-profit US kidney charity. Extensive range of educational materials on diet, understanding clinical markers, treatment options, nutrition counting, and “Five way to be active in your care at the hospital”	http://www.aakp.org/
Kidney Research UK	Fact sheets	Includes fact sheets, information on financial help, and interactive health checks. Has free downloadable recipe book, as well as a DVD, “Living with kidney disease”	http://www.kidneyresearchuk.org/

British Kidney Patient Association	Factsheets	Includes fact sheets on psychological strategies for depression, renal diets, and “Renal patients take charge”	http://www.britishkidney-pa.co.uk/
Global Dialysis	Travel	Allows users to search for international dialysis centres for patients wishing to go on holiday. Includes phrase cards for travelling.	http://www.globaldialysis.com/
DPC: Dialysis Patient Citizens	Campaign for self-care education	Discusses issues such as patients often knowing their dry weight better than clinicians	http://www.dialysispatients.org/education-portal
Cleveland Clinic Foundation	Diet	Sells ‘Creative Cooking for Renal Diets’ and ‘Creative Cooking for Renal Diabetic Diets’	http://www.patientsupport.net/
Culinary Kidney Cooks	Diet	Includes a nutrition pyramid for people on dialysis	http://www.culinarykidneycooks.com/
Big D and Me	Shared experiences	A blog written by a long term dialysis patient. Includes a video of what it’s like to be on dialysis.	https://bigdandme.wordpress.com/

Self-management in renal resources, aimed at clinicians			
Kidney Care Matters Online	Promoting self-management	Emphasis on home dialysis modalities, aims to encourage self-management promotion and e.g. patient held kidney-care plans	http://www.kidneycarematters.nhs.uk/
Home dialysis central	Technical dialysis related self-management	Includes manual for staff to help teach patients to self-cannulate	http://www.homedialysis.org
PEAK: Kidney Care Partner’s Performance and Accountability in Kidney Care	Quality improvement	A voluntary quality improvement programme based in the US. Includes guidelines for best-practice, including sections on education and empowerment, and supporting self-management	http://www.kidneycarequality.com
Fistula First	Vascular access	Supports system wide changes to encourage fistula access over catheter usage. Contains a number of resources on self-management, focused both on fistulae and general tasks	http://www.fistulafirst.org/Default.aspx
Life Options	Self-management education, financial aspects of care	A website from the Medical Education Institute Inc. Produces a newsletter called the Renal Rehabilitation Report.	http://www.lifeoptions.org/

Ontario Local Health Integration Network (LHIN)		Includes a document, “Chronic Kidney Disease Initiative: Practitioner’s Manual”, including a section on patient self-management	http://www.centraleastlhin.on.ca/
Edinburgh Renal Unit	Both GP and patient information	Mostly fact-related information about kidney disease rather than self-management tips, but does include a Diet in Renal Disease section.	http://www.edren.org/

There were no online resources devoted solely to patient self-management, though many charities and organisations included at least some educational materials devoted to educating individuals about self-management. Some explicitly used the term ‘self-management’, while others discussed the kinds of tasks under different terms; sometimes self-care, sometimes simply, ‘living with kidney disease’.

The list provided is by no means exhaustive, and some results were excluded due to being of very low quality or relevance. For example, if the standard of English was insufficient, the website was nearly unreadable, or there was in fact no information about self-management.

One extremely strong theme that emerged was the frequent focus on diet. Renal cookbooks and dietary suggestions could be found in many places, including in one instance a cookbook for people with kidney disease and diabetes. As we have seen, these are common comorbidities, but finding complementary dietary advice for both can be difficult. As will be discussed in chapter 5, managing one’s diet is a substantial challenge for people with kidney disease, and the presence of these materials speaks to how much planning goes into self-management of diet in ESRD.

Several sites, such as DaVita, included calculators to allow patients to calculate their own GFR and Kt/V, as well as providing information to help people interpret their lab results, such as for phosphate. This encourages patient engagement, and also allows patients to modify their dietary behaviours based on informed reading of those results.

Some resources, such as the US National Kidney Federation, have information on travelling to other centres abroad for dialysis (http://www.kidney.org.uk/help-and-information/holidays/). This site includes feedback from patients who have been on holidays, and lists of centres that accept patients for treatment while on holiday. Global Dialysis is a site that specialises in helping people on dialysis find centres, with a search function allowing users to find dialysis units across the world.

Very few of the resources identified had much information on dealing with the social or emotional consequences of ESRD, instead focusing on practical issues such as diet, fistula care, information seeking, and decision making around dialysis modalities. The Kidney Patient Guide, a UK based, Wellcome Trust funded resource, is a notable exception, with information about adjustment, stress, anxiety, depression, anger, sexual problems, and how counselling may help.

There appears to be little or mention of a contrast between cooperative and defensive self-management, or analogous concepts. While information is provided about different dialysis modalities, there is little advice on how to go about shared decision making with healthcare professionals.

While there are many blogs on the subject of dialysis, Big D and Me was included as an example of a well written, long-running record of a patient’s experiences with dialysis and the self-management challenges they face. This could be seen as an example of one-to-many peer support, as many patients feel overwhelmed when they first start dialysis without context or peer support.

The search also resulted in finding resources aimed at renal services and clinicians, with the goal of encouraging the promotion of self-management. This draws attention to the issue that while many patients will simply self-manage, the culture of the dialysis unit may influence this. This issue is explored further in chapters 5 and 8 of this dissertation.

There are a variety of resources for people living with kidney disease. There appears to be more readily available information on diet, holidays, choosing a dialysis modality, and financial support, than there is on the emotional or social impact and what a patient struggling with these might do.

3.8 Summary

There is an increasing volume of self-management literature available for people with chronic illnesses. Much of this is not aimed at any one condition, although there has been a huge quantity made available for people with diabetes. Increasingly, there are materials for people with ESRD, although as with the academic literature, these materials tend to focus on medically related issues. It may be due to ESRD being a less common condition, but there are few readily available materials that talk about the emotional impact of ESRD in the same way as in, for example, cancer.

The Health Foundation bases its triangle of self-management (see chapter 2) closely on the work of Corbin & Strauss (Corbin & Strauss, 1985). It is interesting to note that the publically available resources promoting and supporting self-management in this case line up closely with some aspects of self-management research, but not others such as emotional and social aspects. Language barriers are an issue that is sometimes addressed in these materials, particularly for ESRD. As ESRD is overrepresented in people from South Asian populations, translation of both medical information, but also information on emotional and social issues, is of great importance.

There is a growing academic literature on self-management in ESRD, with an increasing frequency of publications in the last few years. Much of this work still focuses on medical self-management, with adherence to prescribed treatment being the most common outcome of interest. Tools exist for measuring some aspects of self-management in ESRD, as well as theorized drivers of behaviour such as self-efficacy and illness perceptions.

A scoping review of publically facing materials relating to self-management identified a number of useful tools for people with ESRD in terms of education regarding the illness and its treatment. However, as with the academic literature, there is a dearth of information on social and emotional issues. There has been almost no work on different types of self-management behaviour, and whether there is a distinction between defensive and cooperative style self-management behaviours.

The BHDS was selected as a haemodialysis specific self-management scale to use and investigate further in the following empirical chapters. Chapter 4 will give an overview of the methods that will be used to address the thesis:

> *Certain self-management behaviours in End Stage Renal Disease are predicted by self-efficacy, patient activation, and psychological distress, and in turn predict clinical status. However, self-management is often oversimplified and poorly operationalised, in both the literature and in clinical practice, to adherence and 'good/bad' distinctions that may impede future investigations and interventions.*

Chapter 4: Methods

4.1 Introduction

The present chapter will discuss the major methodological elements of the following empirical chapters. This will include the rationale for the methods used, and issues common to design, participants, settings, and analysis across chapters. Questionnaires will also be described in detail, along with methods for transforming raw scores into summary and subscale scores. Details of methods of qualitative and statistical analysis will also be covered. Some methodological issues specific to individual studies will be covered in the relevant chapters.

This thesis was developed in parallel with the SELFMADE study. This chapter shall begin with the background of each, and distinctions between the two will be set out. Ethical and governance considerations will be documented next. Then the research questions that the empirical chapters set out to answer will be presented, followed by the methods used to address each, divided into a qualitative section, and a quantitative section.

4.2 Background

Some of the work detailed in this chapter also contributed to the Self-Management and Dialysis Evaluation (SELFMADE) study, described below. This 3 year project was funded by the

National Institute for Health Research's (NIHR) Research for Patient Benefit (RfPB) programme. The author co-authored the grant application, was the day to day lead on the study, and was involved in all empirical work described in this dissertation. The aim of the SELFMADE study was to develop the role of a self-management facilitator and measure changes in a number of variables, such as adherence and self-efficacy, over time.

The methods described in this chapter were chosen to address the research questions described below in section 4.3. These questions follow directly on from the background literature and issues explored in the introductory chapters.

4.3 Research questions

The broad research questions being addressed in this dissertation are as follows:

1. How is self-management conceptualised by people on dialysis and the staff involved in their care? (chapter 5)
2. Are self-efficacy, activation, psychological distress, and illness perceptions related to self-management behaviours? (chapter 6)
3. Does self-management behaviour predict clinical markers of adherence? (chapter 7)
4. How can measurement of self-management behaviour in people with ESRD be improved? (chapter 8)

Some of these questions are addressed in multiple chapters.

4.4 The SELFMADE study

The SELFMADE study was a three year mixed methods project, funded by the NIHR and conducted in Hertfordshire, England. The purpose of the project was to develop a self-management 'facilitator' role. In order to inform this, a number of empirical steps were taken. Broadly, the project involved:

1. An academic review of the literature on self-management in ESRD
2. A scoping review of self-management and educational tools available to ESRD patients and the staff involved in their care
3. Focus groups held with both patients and staff, to assess their views on what constitutes, 'self-management', what is important, and what could be done to facilitate these behaviours
4. The implementation of a 'self-management facilitator' role using action research.
5. A collection of psychological and clinical measures to examine whether the facilitator role resulted in simple change over time
6. Interviews to assess changes in patient perceptions regarding self-management, and the efficacy of the facilitator's actions

Data from the study relating to patient and staff conceptualisations of self-management, as well as quantitative data on relationships between variables, will be used in this dissertation. The author of this dissertation was the day to day lead on the study, and was involved in drafting focus group/interview schedules, conducting focus groups and interviews and analysing results, selecting and administering questionnaires, and conducting the analyses.

Work that was part of the SELFMADE study that is not included by this dissertation includes the development and implementation of the self-management facilitator role using action research methods (Reason & Bradbury, 2000). This included the facilitator working directly with patients and setting up a number of services at the research sites. These services included peer support, introducing exercise bikes for use while on dialysis, a holiday information service, and setting up dialysis bays to allow interested patients to do more of their own dialysis in-centre. As is common in action research, the facilitator kept detailed notes of their experiences for later analysis. The SELFMADE study was primarily focused on this development process.

4.4.1 Distinctions between SELFMADE and this thesis

The author was the day to day lead of the SELFMADE study, and was involved in writing the grant application, wrote the study protocol, selected questionnaires to employ, obtained NHS ethics and R&D approval for the study, and was directly involved in all elements of data collection, analysis, and write up.

The SELFMADE project aimed to introduce a nurse facilitator role and assess its implementation using a variety of qualitative and quantitative methods. The focus of the project was on facilitators and barriers to self-management, and documenting the experiences of the process of introducing such a role. Quantitative data were collected in an attempt to establish whether there were changes in adherence or psychological variables over time.

The initial qualitative work on conceptualisation of self-management served a similar role for SELFMADE and this dissertation, however the analysis presented in chapter 5 is greatly expanded from the analysis the author conducted for the SELFMADE study. However, a broad range of data were collected by the author as part of this project in an attempt to investigate self-management in greater, more theoretically driven detail. This is the author's own work (chapters 6 and 7). Additionally, during the data collection process, difficulties participants faced in answering self-management related questions led to investigating the cognitive process used in responding to the self-management questionnaire. This is also unique to this dissertation and separate to the SELFMADE study entirely (chapter 8).

The application of theory, methods of analysis, and interpretation using the available data were all the author's own work. From this point on, all investigations will be presented in terms of their role in this dissertation, rather than the SELFMADE study. The only exception is chapter 5, which draws upon initial team coding for focus groups.

4.5 Ethics and governance approvals

The work described in chapters 5, 6 and 7 was approved by Cambridge South NHS Research Ethics Committee, REC reference 11/EE/0417. East & North Hertfordshire NHS trust acted as the study sponsor, and local Research & Development approval was obtained from Hertfordshire Hospitals R&D Consortium, reference RD2011-108.

The work described in chapter 8 was approved by NRES Committee North West – Greater Manchester East, REC reference 14/NW/0272. The work was sponsored by the University of Hertfordshire, reference LMS/PG/NHS/00154. Local Research & Development approval was obtained from Central Manchester University Hospitals NHS Trust, reference R03623. The author was the chief investigator, with Dr Sandip Mitra acting as the local collaborator for participant identification, recruitment and governance purposes. Consent was obtained from all participants in all studies.

4.6 Participants

Participants consisted of people on in-centre haemodialysis, home haemodialysis, and renal staff. Specific inclusion and exclusion criteria can be found in the relevant empirical chapters, but common factors are described here.

4.6.1 Chapters 5, 6, and 7

Staff participants were drawn from East & North Hertfordshire NHS Trust, as were patient participants for the SELFMADE study. This included three sites; Lister Hospital, Stevenage (site 1), Luton & Dunstable University Hospital (site 2), and St Albans City Hospital (site 3).

Specific inclusion/exclusion criteria will be described in each section. Common inclusion criteria for patient participants included:

- Presence of End Stage Renal Disease
- On haemodialysis for > 3 months
- Able to speak sufficient English to comprehend and respond to relevant questions in focus groups, interviews, or questionnaires

Exclusion:

- Under 18
- Unable to consent for any reason

4.6.2 Chapter 8

Patient participants described in chapter 8 were drawn from Central Manchester University Hospitals NHS Foundation Trust, including Manchester Royal Infirmary and its satellite units. Specific details of participant characteristics can be found in chapter 8.

4.7 Settings

4.7.1 In-centre dialysis

The work described in chapter 5, 6 and 7 took place in East & North Hertfordshire NHS Trust in the South East of England. The sites were, Lister Hospital in Stevenage, St Albans City Hospital, and Luton & Dunstable University Hospital. Of these, Lister Hospital is the primary centre where Trust nephrology services are based, including, for example, the consultant nephrologists.

The work described in chapter 8 was conducted in Central Manchester University Hospitals NHS Foundation Trust.

These centres share a number of characteristics. For example, all centres have a number of haemodialysis 'bays' located in a single room. Additionally, all have a number of 'side rooms' each containing a single haemodialysis bay, for patients with highly communicable blood borne diseases such as hepatitis B. Each unit has a mixture of chairs and beds, for use depending on preference and need. Most centres run three 'shifts' of patients, allowing each bay to be used three times per day. On some days, some centres run a fourth late shift (colloquially known as the 'twilight shift'). All centres operate Monday to Saturday.

Lister hospital is based in Stevenage, Hertfordshire. Nephrology services for E&N Hertfordshire NHS Trust are based there, including the consultant nephrologists for the area. In the unit itself, there are a total of 20 haemodialysis bays present in a single room, separable by curtains if necessary, with a further five side rooms, for a total of 25 bays.

St Albans City Hospital (SACH) has a total of 16 bays and two side rooms. Specific demographic characteristics will be explored by chapter, but the patient population tends to be older in this unit. Luton & Dunstable University Hospital (L&D) has a total of 20 bays in the main unit and three side rooms.

4.7.2 Home haemodialysis

Interviews with patients on home haemodialysis described in chapter 8 were conducted in participants' homes, one to one, in a quiet room. Different households will have different home haemodialysis setups. Current haemodialysis machines have sophisticated safety features that make it possible for people living alone to conduct their own dialysis.

What follows is a description of the methods used throughout this dissertation. Methods will be broken down into qualitative and quantitative methods, along with the research questions that they address.

4.8 Qualitative methods

A combination of focus groups, standard interviews, and cognitive interviews were used to address two of the above research questions:

1. How is self-management conceptualised by people on dialysis and the staff involved in their care?

4. How can measurement of self-management behaviour in people with ESRD be improved?

Question 1 is addressed in chapter 5 using focus groups and interviews. Question 4 is addressed in chapter 8 using cognitive interviews. A description of these methods follows here.

4.8.1 Focus groups

Focus groups were chosen as the most suitable method to investigate the concepts that people on dialysis and renal staff associate with self-management. Groups proceeded in accordance with a semi-structured format designed to elicit participants' views on what 'self-management' is, who it is for, how it can be achieved, and the facilitators and barriers to achieving it. This rich level of data, seeking a view of self-management driven by participants rather than pre-constructed ideas of the researchers, would not be possible using quantitative methods. Focus groups were chosen over individual interviews, as they are useful for reaching a consensus between participants (Hughes & DuMont, 1993). They come with their own set of drawbacks, such as the views of quieter participants not emerging next to more vocal participants, and consensus emerging due to perceived social pressure rather than genuine agreement (Kitzinger, 1995). These are important considerations that will be dealt with in the analysis in chapter 5.

Participants were recruited using purposive sampling (MacDougall & Fudge, 2001). Selection of staff participants was based on aiming for a range of roles and seniority, for example including doctors, nurses, and clinical support workers. Selection of patient participants was based on aiming for a range of number of years on dialysis (vintage), age, sex, and ethnicity.

All focus groups were conducted by two facilitators, including the author and one of two experienced qualitative researchers. All focus groups were conducted in a suitable on-site setting, such as a quiet meeting room. Audio recordings were made with all participants' informed consent, and sent to an external service for transcription. The author checked all transcriptions against the original audio for accuracy, especially regarding esoteric terms that may have been incorrectly transcribed (medication names, for example).

The analysis of focus groups was conducted by four members of the research team, made up of two senior qualitative health researchers, the author, and a nurse researcher. A thematic approach was employed (Fereday & Muir-Cochrane, 2008). Transcripts were entered into NVivo software (QSR International, 2006). A combination of *a priori* and emerging themes were used. Codes were generated independently by each of the four researchers using the first transcript. The team then met to discuss these independent codes and reach a consensus and develop a codebook. The team then independently coded the remaining transcripts, and met once again to reach a final consensus for each transcript. Codes were then organised into coherent themes. These results were then fed back to participants (both staff and patients) for validation. This final step was largely informal, with the intention of flagging up any findings that were objected to or considered inaccurate. As there were no significant disagreements, the validation process was not carried on any further.

4.8.2 Interviews

At 18 months follow-up, interviews with patients were employed to try to obtain a richer, qualitative picture to give context to the quantitative data that was being collected. Interviews were chosen over focus groups as there was an evaluative element to some of the questions. This made it important to try and gather individual experiences of the implementation of the self-management facilitator.

Interviews were conducted by either the author or another member of the SELFMADE team. As with focus groups, interviews were audio recorded, transcribed, and thematically analysed. Coding and analysis was conducted by the author.

4.8.3 Cognitive interviews

Cognitive interviewing is a technique that generally uses a questionnaire, or proposed items from a questionnaire, as a template for an interview (Willis, 2005). This type of cognitive interview is distinct from the term ‘cognitive interview’ used in forensic psychology to describe interviews with eyewitnesses, which are designed to minimise responder bias via the use of mnemonic procedures (Geiselman, 1984).

In cognitive interviews used to enhance questionnaire design, the interviewer may ask the respondent to either think-aloud as they complete the questions, or have the respondent fill in the questionnaire first, then ask a series of probe questions after. The aim is to obtain an understanding of the cognitive processes involved in arriving at an answer, rather than a simple score on a scale without context. Examples of previous use include developing the US National Cancer Institute’s Patient Reported Outcomes Common Terminology Criteria for Adverse events (Hay et al., 2013) and the PROMIS Pediatric Peer Relationships Scale (DeWalt et al., 2013).

It has been observed in previous research that the process of conducting and reporting cognitive interviews is highly heterogenous, difficult to replicate, and raises questions about the validity of their findings (Beatty & Willis 2007). In order to address these concerns, the interviews were conducted with the Cognitive Interviewing Research Framework (CIRF) proposed by Boeije & Willis (2013) in mind. This framework was developed by adapting four existing qualitative reporting frameworks (e.g. the British Medical Journal Qualitative research checklist) and confirming adequate coverage using eight further frameworks (e.g. Consolidated criteria for reporting qualitative research, COREQ).

In order to construct meaningful categories from the transcripts, coding followed an item-by-item approach to flag up the issues encountered per participant per question. A thematic approach was then taken, with participants responses to each question placed into coded categories. Categories were generated using *a priori* and emerging themes. *A priori* themes were generated from the existing literature on cognitive interviewing, as a number of common cognitive issues in questionnaire response are well documented (Knafl et al., 2007). Coding of themes wasundertaken by the author.

4.8.4 Inter-rater reliability

Coding of focus groups and interviews in chapter 5 involved the use of multiple researchers, each coding and organising those codes into themes before analysis by the author. After each coding a single transcript, coders came together and compared transcripts, resolving any disagreements by discussion for coding subsequent transcripts. After all transcripts had been coded, researchers came back together to compare and discuss specific codes for each transcript, and their organisation into themes, before interpretation and write-up by the author.

Cognitive interviews were conducted, coded, and analysed by the author alone. Triangulation between researchers to achieve inter-rater reliability tends to result in consistency of how themes are 'packaged', not in a change to their contents. An example of this was provided in the analysis of reports for independents coders of a series of focus groups on genetic screening for cystic fibrosis (Armstrong, Gosling, Weinman, & Marteau, 1997). As the 'packaging' of primary themes was already rooted in standard cognitive interviewing procedure, secondary coders were not used.

4.8.5 Questionnaire development

Research question 4 relates to improving an existing questionnaire, referred to in this dissertation as the Behaviours on Haemodialysis Scale or BHDS, which is described below in 4.9.3. Tools used for measuring behavioural elements of self-management in people with ESRD often either measure internal states (such as self-efficacy or patient activation), or focus only on medically related behaviours. It was considered desirable to develop a scale that measures what people *do*, beyond adherence.

4.9 Quantitative methods

Quantitative methods were used to address two research questions:

2. Are self-efficacy, activation, mood, and illness perceptions related to self-management behaviours?
3. Does self-management behaviour predict clinical markers of adherence?

4.9.1 Self-report and clinical data

In order to investigate the relationships between self-management behaviour, psychological states, and clinical elements of self-management such as adherence, data were collected at three time points over the course of 18 months. Previous work on self-management in ESRD has mostly looked at cross-sectional data, with a dearth of work looking at the predictive value of self-reported self-management behaviour and associated psychological variables over time (Novak et al., 2013). Research question 2 is concerned with examining how psychological factors predict self-management behaviour, and question 3 with how self-management behaviours may predict clinical status and survival over time.

Questionnaire data were obtained by the researchers on-site at the relevant dialysis units in E&N Hertfordshire NHS Trust. Potential participants were approached while dialysing, and given a 5 minute explanation of the study along with a Participant Information Sheet (PIS). Potential participants were given time to read the PIS, and were then asked if they would like to take part. Those agreeing were given a consent form and pack of questionnaires, which took most participants approximately 20 minutes to complete, after which packs were collected by the researcher. Data collection was conducted by the author and members of the SELFMADE team.

Questionnaires were disseminated at 0 months, 9 months, and 18 months. Routinely collected clinical data were also obtained for each participant at the same time point. The initial sample consisted of 104 participants.

A breakdown of the questionnaires and clinical measures used follows.

4.9.2 Questionnaires used (see appendices A to E)

A wide range of self-reported cognitions and behaviours were considered relevant to the work conducted here. Additionally, much of this work is exploratory in nature. For these reasons, brief versions of questionnaires were generally used to minimise burden on participants, but only when the brief versions were considered to have adequately comparable psychometric properties to the original versions.

Self-management behaviours were measured, as question 2 relates to predicting self-management behaviours, and question 3 relates to using self-management behaviours to predict clinical outcomes. Self-efficacy and patient activation were measured as they are theorized to be key predictors of self-management behaviour in both Social Cognitive Theory and emerging Patient Activation theory, and overlap while measuring slightly different concepts.

Depression and Anxiety were measured as proxies of emotional wellbeing, as part of the ‘emotional’ domain of the self-management triangle. Perceived Social Support was measured to represent the ‘social’ domain of the self-management triangle. Illness perceptions were measured as cognitions relating to illness may have an important interacting role to play with self-efficacy, patient activation, and self-management behaviour. For example, the control/cure subscale in illness perceptions provides a measure of outcome expectancies in Social Cognitive Theory.

Quality of Life was measured as a secondary outcome. Symptoms were measured as they may be an important covariate when considering relationships between other variables listed above.

Licenses for use were obtained where appropriate. Copies of each public domain questionnaire can be found in the appendices.

4.9.3 Behaviours on Haemodialysis Scale (BHDS)

As stated in the introductory chapters, self-management is theorised to comprise of three factors; emotional, social, and medical. Descriptions of the tools used to measure social support and emotional wellbeing are described below. The medical aspect of self-management is often measured through self-reported adherence, or various clinical proxy measures such as serum phosphate (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009; Karamanidou, Clatworthy, Weinman, & Horne, 2008). However, medical self-management can be conceptualised as a broader set of behavioural tools that go beyond adherence. For example, these behaviours can include decision making, information seeking and appropriate resource use.

In order to measure these behaviours, a self-report scale developed by Roberta Curtin and colleagues was employed (Curtin et al., 2004). A copy of the scale can be found in appendix A. This scale was developed with a population of people on in-centre haemodialysis for ESRD. Made up of eight subscales, it purports to measure the frequency of various medical self-management domains. Items are rated on a Likert scale from “Never” to “All the time”.

There is no abbreviated or distinct name for the scale provided in the paper describing its development, or in papers that have referenced it since. For ease of identification and to avoid confusion with other scales, it will be referred to throughout this dissertation as the Behaviours on Haemodialysis Scale (BHDS). It is important to note that this is for internal ease of reference, and is not a name provided by the original authors of the scale.

The scale initially consisted of 60 items split across 10 domains, with 6 items being eliminated by the original authors after debriefing interviews with a convenience sample of patients (n =25). Exploratory Factor Analysis (EFA) was used by the authors on data obtained from a sample of 372 people on in-centre haemodialysis in the United States. Three restrictions were used in the analysis; the number of iterations for convergence was constrained, and only items with a factor loading of > 0.5 and an Eigen value of > 1 were included. Questions were further reduced to 37 items across 8 domains.

The authors of the scale hypothesised that the construct measured by each subscale would fall into one of two 'styles' of self-management; co-operative/participatory, or defensive-proactive/protective. The eight subscales and associated internal reliability for each are listed in table 4.1 below, by self-management style:

Table 4.1: Self-management questionnaire subscales

Self-management style	Subscale	Internal reliability (α)	Example question
Co-operative	Suggestions to providers	0.80	Asked for a change in treatment based on information you learned on your own?
	Self-care during haemodialysis	0.77	Cleaned/prepared your access site for needle placement?
	Information seeking	0.78	Looked for additional kidney diet information?
	Use of alternative therapies	0.81	Experimented with treatments other than other prescribed by your doctor?
	Shared responsibility in care	0.77	Adjusted your phosphate binder dose to the size of your meal?
Defensive	Selective symptom management	0.79	Kept problems or symptoms to yourself so as not to bother staff or your doctor?
	Assertive self-advocacy	0.65	Confronted staff in order to get better care?
	Impression management	0.72	Tried to get staff or your doctor to think well of you, in order to get better care?

Participants also completed the SF-12 quality of life scale. From this, one can yield the Physical Component Summary-12 score (PCS-12) and the Mental Component Summary-12 score (MCS-12). Curtin and colleagues hypothesised that defensive self-management subscales would be negatively correlated with mental wellbeing measured on the MCS-12. This was borne out by the results. All three defensive subscales were negatively correlated with the MCS-12; selective symptom management ($r = -0.274$, $p < 0.001$), assertive self-advocacy ($r = - 0.166$, $p < 0.01$), and impression management ($r = -0.206$, $p < 0.001$). None of the cooperative subscales were associated with MCS-12 scores in either direction. All three defensive subscales were negatively correlated with the PCS-12; more defensive self-management behaviour resulted in poorer self-rated physical quality of life. Self-care during haemodialysis and shared responsibility in care were significantly positively correlated with the PCS-12. These findings lend weight to the idea that these different 'styles' are valid constructs, and that cooperative styles may be adaptive, while defensive styles may be maladaptive. This concept is explored further in chapter 6.

4.9.4 Patient activation

The transtheoretical model of health behaviour change (Prochaska & Velicer, 1997) is briefly introduced in chapter 2. Patient activation is essentially an operationalization of this model. The first Patient Activation Measure (PAM) developed by Hibbard and colleagues resulted in 22 items pertaining to four different dimensions relating to four stages of change (2004). The four dimensions are:

- Believes active role is important
- Confidence and knowledge to take action
- Taking action

- Staying the course under stress

Developed with robust sample sizes over three stages, the final 22 item PAM was tested in a separate national (USA) probability sample of people 45 years and older (N = 1,515). Infit reliability ranged from 0.71 to 1.44, while all but one outfit value ranged from 0.80 to 1.34. Construct validity was determined using comparisons with the SF 8, as according to patient activation theory, more activated patients should report significantly better health. This was indeed the case ($r = 0.38$, $p < 0.001$).

Using the data from same final sample of 1,515 people both with and without chronic illness, a shortened 13 item scale was developed (Hibbard et al., 2005). The psychometric properties of the PAM-13 were found to be comparable to the original PAM, with a slight loss of precision among some subgroups of respondents: those without chronic illness, 85 or older, with poor self-rated health, and those with low income. The 13 items are split across the same four dimensions as the original PAM.

4.9.5 Anxiety and depression (appendices C and D)

There are a number of tools available for measuring anxiety and depression, the two most common pathological aspects of negative affect (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2003). Examples include the Hospital Anxiety and Depression Scale (HADS) and the Beck Depression Inventory (BDI). These questionnaires provide a continuous numerical value related to self-reported symptoms, with higher scores representing greater presence of the relevant aspect of negative affect. While a cut-off score can be applied to categorise people displaying clinically significant levels of depressive symptoms, they should not be confused with a clinical diagnosis of psychopathology (Chilcot et al., 2009). Two scales are based directly on the DSM-IV-TR (American Psychological Association, 1994) criteria for the respective psychopathologies to which they pertain.

The Patient Health Questionnaire (PHQ-9) is a nine item questionnaire used to assess depression (Kroenke et al., 2001). Each DSM criterion for depression is rated as being present from 0 (not at all) to 3 (nearly every day). A copy of the questionnaire can be found in appendix C. The tool was developed by being tested in 6000 primary care and obstetrics-genecology clinics, assessed for construct validity using the Short-Form General Health Survey, and criterion validity was established by comparing the tool with assessments made by an independent structured mental health professional interview with 580 patients.

Due to being short and directly based on the clinical criteria for Major Depressive Disorder, the PHQ-9 is used in clinical practice as well as research. For example, the Veterans Health Association in the USA uses the PHQ-2 as an initial screening tool, and the PHQ-9 if an individual screens positive for depression (Smarr & Keefer, 2011). In the UK, the PHQ-9 is endorsed by the National Institute for Health and Clinical Excellence (NICE) for routine use in primary care, and secondary care mental health services, to measure changes in depression status from baseline to post-treatment. The fact that it is a clinical tool, as well as a research tool, means that understanding how scores relate to other variables such as self-management behaviour could be more directly applied to clinical practice.

The factor structure of the PHQ-9 has been investigated specifically in palliative populations. Chilcot and colleagues applied Confirmatory Factor analysis to data obtained from 300 participants receiving palliative care for a range of conditions (Chilcot et al., 2013). A two-factor structure emerged, comprising a cognitive-affective factor, and a somatic factor.

The GAD-7 was derived from the DSM criteria for Generalized Anxiety Disorder (Spitzer & Kroenke, 2006). It consists of seven main items, asking how often an individual has been bothered by each symptom over the last two weeks (e.g. “Feeling nervous, anxious or on edge”). As with the PHQ-9, responses range from 0 (not at all) to 3 (nearly every day). A final question asks that if any problems are checked, then “how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?” Four options range from, “Not difficult at all” to “Extremely difficult”. A copy can be found in appendix D.

The GAD-7 was initially tested on a sample of 2739 primary care patients in the USA. The first phase (n = 2149) was used in item selection and selecting cut-off scores. The second phase (n = 591) was undertaken to determine test-retest reliability. A telephone interview was conducted with 965 of the first phase participants to validate the selected cut-off scores for GAD (ICC = 0.83). A cut-point of 10 or greater showed both a sensitivity and specificity of greater than 0.80, but produced an inflated estimate of individuals with GAD in primary care of 23%. A cut-point of 15 produced a prevalence of 9%, more in line with epidemiological estimates, but sensitivity was low (48%). The authors recommend 10 as a screening cut-point, but that scores of 5, 10, and 15 may be taken as rough indicators of mild, moderate and severe levels of anxiety. Internal reliability for the scale was good (Cronbach α = 0.92), as was test-retest reliability (ICC = 0.83). Increases in GAD-7 scores from mild, to moderate, to severe, were found to be associated with a stepwise decline in SF-20 scores, in all 6 domains of functioning (mental, social, role, general, pain, and physical).

The PHQ-9 and GAD-7 are used in chapters 6 and 7.

4.9.6 Illness perceptions

Illness perceptions and their relationship to Leventhal’s Common Sense Model of Illness Representations (CSM) are described in chapter 2.

These illness representations are operationalised in the various forms of the Illness Perception Questionnaire (IPQ). The original IPQ did not include a cyclical/continuous dimension, nor did it differentiate between treatment and personal control (Weinman et al., 1996). These additions were included in the revised illness perception questionnaire (IPQ-R, Moss-Morris et al., 2002). Finally, due to the expansive nature of these questionnaires (the IPQ-R contains 38 main items, plus a checklist of symptoms, possible causes, and open ended questions on causes, resulting in over 70 items), a brief version was devised (Broadbent et al., 2006). The brief version contains 8 likert style items, plus a question asking the respondent to rank the three most important causes of their illness.

The B-IPQ was used in the present work due to practical considerations about participant burden. It has been found to be highly comparable to the IPQ-R. It has been used to investigate the effects of illness perceptions on physical functioning and medication adherence in multi-morbid adults (Schüz, Wolff, Warner, Ziegelmann, & Wurm, 2014).

4.9.7 Self-efficacy (appendix B)

Self-efficacy, and Social Cognitive Theory (from which self-efficacy derives), are discussed in chapter 2 (Bandura, 1977). Broadly speaking, self-efficacy is divided into specific and general elements. Specific self-efficacy relates to specific contexts and actions (Życińska, Kuciej, & Syska-Sumińska, 2012). General self-efficacy is a person's broader confidence across a whole domain of behaviours. Due to the broad range of self-management behaviours of interest in the work conducted here, general self-efficacy was measured. The brief version of the Stanford Self-Efficacy for Managing in Chronic Disease scale was used (Lorig et al., 1996). This scale has been translated into a number of languages, and validated in multiple studies (Ritter & Lorig, 2014). The brief scale involves six questions asking an individual to rate their confidence in managing their illness and related emotions and activities, from 1 (not at all confident) to 10 (totally confident). Scores for each question are then summed and divided by the total number of questions answered. In a study of 605 people with various chronic diseases, the scale displayed a range of values from 1 to 10, with a mean of 5.17, a standard deviation of 2.22, and an internal reliability of 0.91 (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

4.9.8 Health related quality of life

Two of the most common scales used to measure health related quality of life (HRQoL) are the EQ5D, and the SF-36 and its variants (Mukuria & Brazier, 2013).

The EQ5D has five dimensions; mobility, self-care, usual activities, pain, anxiety and depression, and a global ‘health thermometer’, which asks respondents to rate their health on a Visual Analogue Scale (VAS) from 0 to 100 (Rabin & de Charro, 2001). It was developed by multidisciplinary group of researchers from seven centres across five countries, and has been validated in a random sample of over 3000 adults in the UK (Dolan, Gudex, Kind, & Williams, 1996).

Another commonly used health-related quality of life scale is the SF-36. The SF36 is, in itself, a shortened version of a battery of 149 health status questions (Garratt, Ruta, Abdalla, Buckingham, & Russell, 1993). A shorter version still is available in the form of the SF-6D (Mukuria & Brazier, 2013). This version is most closely comparable with the EQ5D. While the two appear similar, there are some differences in their distributions, sensitivity to change, and ceiling effects. They also do not closely agree. However, there is no clear indication that one scale is, “right”, or which is clinically superior. The EQ5D is more commonly used, and allows for more direct comparison with other studies (Stel & Buskens, 2006).

There are several different versions of the EQ5D; studies described here use the EQ5D-5L, a version that uses a 5 point Likert scale in which items are rated from, “I have no problems…” to “I am unable to…”.

4.9.9 Social support

Social support was measured using the Duke-UNC functional social support scale (Broadhead et al., 1988). The scale is a brief eight-item inventory composed of two factors; confidant support, and affective support. The final items of this scale were derived by testing 14 initial items with 401 ambulatory participants from the Family Medical Center in Durham, North Carolina. As a self-report scale, it measures perceived social support, and not necessarily the actual availability of social support.

The “confidant support” includes questions about opportunities to talk about problems, availability of advice, and invitations to go out and do things with other people. Affective support is composed of questions about whether a person feels people care what happens to them, whether they experience love and affection, and whether help is available when they are sick in bed.

4.9.10 Data collection - questionnaire administration

Questionnaires were administered to participants while they dialysed in-centre. Potential participants meeting the inclusion criteria were identified using hospital records, and potential participants were approached by the author or another researcher while they dialysed. The purpose of the study was explained, and a Participant Information Sheet was handed out. An opportunity to ask questions was provided. Those agreeing to participate were given a consent form and pack of questionnaires. The researcher would then leave the participants as much time as they needed, before collecting the questionnaire, usually before the end of their dialysis session. All questionnaire data were stored in a locked research office at the research site. Data were transferred to an Excel database on a secure on-site computer in the research office. Data were pseudoanonymised using participant IDs whenever it was transferred off-site for analysis.

4.9.11 Data collection - clinical variables

A range of clinical parameters were recorded. The two main variables were Interdialytic Weight Gain (IDWG) and phosphate. These were used as clinical markers of adherence, as both change in response to patient fluid and food intake.

Clinical parameters included Interdialytic Weight Gain (IDWG), serum phosphate, Residual Kidney Function (KRU), and serum albumin. Time since initiation of dialysis (in days) and date of either death or censoring for other reasons (receipt of a transplant, moving away from the area) were also recorded. By examining clinical variables, an estimation of levels of patient adherence could be made (Kimmel et al., 2000).

All clinical parameters were taken from routinely collected information held on the Trust clinical database, RenalPlus. IDWG is the difference between an individual's weight in KG as measured at the end of one dialysis session, and again at the start of the next. IDWG was recorded as both a latest score, and as a three month average. Serum albumin was measured as g/dL. KRU was recorded as ml/min primarily to be used as a controlling variable, as IDWG's value as an indicator of adherence is heavily dependent on KRU (Kimmel et al., 2000). In short, the greater the remaining amount of kidney function an individual has (indicated by KRU), the more fluid a person will be able to excrete as urine. This has implications for the advised fluid intake for each individual, and closely their IDWG matches their actual fluid intake (Vilar, Wellsted, Chandna, Greenwood, & Farrington, 2009).

4.10 Statistical analyses

All statistical analyses were conducted in Intercooled STATA 11.2, unless otherwise noted (StataCorp, 2009).

In chapter 6, statistical procedures were primarily cross-sectional in nature, to test for associations at baseline. Correlation matrices were used to investigate associations. Unless otherwise noted, significance in these matrices was calculated using Bonferroni correction for multiple comparisons. Multiple regression models were constructed based on both theoretically important variables, and relationships observed in correlational data, rather than via automatic selection process such as forward or backward stepwise regression (Harrell & Harrell, 2006). Variables known to be important confounds were included as controls in baseline models.

Chapter 7 aimed to assess whether self-management behaviour and associated psychological factors predict clinical status, and primarily utilised longitudinal analyses. Where clinical outcomes were binary, logistic regression was used, with baseline psychological and behavioural measures used as predictors. Cox Hazard regression was used to analyse the relationship between baseline psychological and clinical parameters and survival.

4.10.1 Hierarchical linear regression

The hierarchical regression methods used here involve entering predictors into a regression model in an order dictated by theory (Tabachnick & Fidell, 2006). In other words, rather than using automatic selection based on which variable adds the greatest predictive power (forward stepwise) or reduces R^2 by the greatest amount (backwards stepwise), predictors were specifically entered to test their contribution based on their theoretical importance. This can help reduce the problems with automatic selection processes overlooking important variables and identifying ‘noise’ variables as important (Derksen & Keselman, 1992; Huberty, 1989).

Hierarchical regression was conducted using the *hireg* command in STATA 11.2, with covariates entered in the first block, and other predictors added one by one in subsequent steps, selected on the basis of theory. R^2 change was noted at each step.

4.10.2 Mediation and bootstrapping

Mediation analysis is used in chapter 6. The method used is that described by Preacher and Hayes (2004), which involves significance testing the indirect effect between a predictor and outcome, a step absent from some methods of mediation (Baron & Kenny, 1986).

Simple mediation analysis allows the testing of the hypothesis that the relationship between two variables, X and Y, is mediated by a third variable, M. There are three basic requirements for establishing mediation. First, X should be significantly related to Y (the direct effect, *c*). Second, X should significantly predict M (path *a*). Third, M should significantly predict Y after controlling for X (path *b*). The indirect effect of X on Y can be expressed as the product of *a* and *b*. The indirect effect of X on Y via M, c', is therefore $c' = c - ab$. The Sobel method advocated by Preacher and Hayes (2004, 2008) then involves computing the ratio of *ab* to its estimated standard error, and a *p*-value for this ratio is computed in reference to the standard normal distribution.

One problem with this method of significance testing mediation effects is the assumption of normality. Additionally, the Sobel method alone tends to be inaccurate in all but large samples. Bootstrapping is a non-parametric method of resampling from an observed sample, allowing estimation that permits the use of tests that normally only work in larger samples, and does not depend upon an assumption of normality. As the indirect effect is estimated repeatedly over many resamples, confidence intervals can be estimated (Shrout & Bolger, 2002).

Sobel-Goodman mediation analysis was conducted in STATA 11.2 using the *sgmediation* command. Confidence intervals were estimated using the *bootstrap* command in combination with *sgmediation*, using 1000 resamples.

4.10.3 Survival analysis

Survival analysis in chapter 7 was conducted using Kaplan-Meier survival curves and Cox hazard ratios. Kaplan-Meier curves allow a comparison of two survival functions split across two groups. Thus it only allows for simple between group comparisons. Cox hazard ratios function more like multiple regression, and allow the use of multiple predictors and controlling covariates. Cox hazard functions allow the estimation of how much more likely an event is (e.g. injury or death) for each point of change in various predictor variables. Survival analysis was employed in chapter 7. A combination of Kaplan-Meier survival curves, log-rank tests, and Cox proportional hazards modelling were used.

Survival analysis is used to examine time to event data. In time to event data, the dependent variable is typically the number of days individuals remain in a study without experiencing the event of interest, for example death or the development of a certain disease. Due to such data rarely being normally distributed, and 'censored' data, specific statistical methods are required (Bewick, Cheek, & Ball, 2004). 'Censored' cases are where a follow-up time is known, but the event of interest has not yet occurred. For example, an individual is event free at the end of the study, or they drop out of the study early. In both cases the number of 'event free days' is known, and this period ended for reasons other than the occurrence of the event, i.e. the end of observation period or drop out.

Kaplan-Meier survival curves can be used to graphically illustrate the probability of being alive at time *t* (Kaplan & Meier, 1958). Stratification by group membership allows a visual comparison of the occurrence of events. The differences between these groups can be tested for statistically significant difference using a log-rank test. Log-rank tests involve calculating the expected events for the groups, then summing the ratio of the observed minus expected events to expected events for each group. The log rank value can then be compared against critical chi^2 values to assess statistical significance. Kaplan-Meier and log-rank tests are useful for simple group comparisons, but cannot take into account multiple, or continuous, explanatory variables.

To examine multiple continuous variables, Cox proportional hazard ratios were used (Cox & Oakes, 1984). Cox models are essentially multiple regression, where the dependent variable is the 'hazard', or probability of experiencing the event of interest given that patients have survived up to that point (Bewick et al., 2004). The model makes no assumptions about distribution, but does assume that the risk of an event in one group relative to the other does not change over time. In chapter 7, Cox proportional hazard models are used to estimate the hazard (risk of death), based on a number of continuous predictors.

4.10.4 Multilevel modelling (MLM)

Multilevel modelling is a form of regression analysis that takes into account the fact that, in the real world, variables are often related to each other based on some kind of grouping or 'clustering'. For example, a study looking at pupil performance on an exam in a school, we might expect performance of children in the same class to be more closely correlated with each other than with the performance of the whole school. This is called intraclass correlation (ICC). Ignoring this data structure can result in misattributions regarding the sources of observed variance.

Multilevel models (MLMs) address this by allowing for multiple 'levels' of data, where level 1 observations (e.g. exam score) are nested within level 2 variables (e.g. class), and further levels are possible (e.g. we could have multiple schools). This also allows for longitudinal analysis, as the individual can be treated as the level 2 variable, with different observations over time the level 1 variable. As observations are nested within the individual, this overcomes the problem of correlated residuals for repeated measures. This ability to handle longitudinal data is the primary function of multilevel models used in chapter 7, although 3 level models where patients are also nested within study sites are also employed.

MLMs have a number of advantages over other methods such as ANOVA, including the ability to handle different periods of time between observations for different participants, and the ability to handle missing data without listwise deletion of all cases where any data is missing (and the resulting loss of power this causes). For a more comprehensive discussion of the advantages of multilevel models for longitudinal data, see Kwok et al. (2008).

A key concept in multilevel modelling is that of fixed and random effects. A fixed effect is a parameter that is consistent across the entire sample, while a random parameter is one that is free to vary across groups defined by the level 2 variables. This applies to both the intercept and regression coefficients for each level 1 variable. In practice, when the intercept is fixed, we assume the mean score in the outcome variable does not vary across groups defined by the level 2 variable. When the intercept is random we can examine the variance of the group intercepts around the grand mean to see whether this is in fact the case. When the coefficient for a predictor variable is fixed we assume that the size and direction of the relationship between the predictor variable and the outcome variable is the same across level 2 groups. When this coefficient is random, one can look at the variance of the coefficients around the coefficient for all groups, for each level 2 group, to see if they significantly differ. For more detail on fixed and random effects see Hayes (2006).

Centring is an important concept for interpretation of certain parameters in MLMs. Centring involves modifying a variable so that, while relationships between variables remain the same (coefficients remain unchanged), the intercept will be more readily interpretable. Grand mean centring was used for most predictor variables, meaning that the intercept in the MLM can be interpreted as the mean value of the outcome variable when all predictor variables are at their respective means. This is intuitively more useful for interpretation than the intercept for untransformed variables, which would represent the mean outcome value when all predictors are 0. Grand mean centring simply means subtracting the mean for a given variable from each individual observation for that variable.

The main exception to grand mean centring is time. As time was measured in months from baseline, measuring from 0 makes intuitive sense. However, time should be centred based on the focus of the analysis (Biesanz, Deeb-Sossa, Papadakis, Bollen, & Curran, 2004). As such, time was re-centred for baseline, mid-point, and follow-up results in certain analyses. In combination with grand mean centring of other predictor variables, this means that the intercept in an MLM represents the mean of the outcome variable when the predictor variables are assumed to be at their respective means, apart from time, which is assumed to be at whatever value for time it was centred around. The specific centring for specific models will be discussed in chapter 7.

As MLMs were used primarily for their ability to handle longitudinal data in chapter 7, participants were typically the level 2 variable, with observations for variables such as self-management behaviour score and 3 month average IDWG treated as level 1 variables nested within the participant. Time was included as a covariate in months. The specifics of each model will be discussed in chapter 7.

4.10.5 Multiple imputation

Multiple imputation (MI) involves generating values where data are otherwise missing for individual responses (imputing), estimated based on observed data. This process is conducted over a pre-specified number of iterations (hence ‘multiple imputation’), and these imputed sets of data can then be used in parameter estimation in statistical analysis (Meng & Rubin, 1992).

MI is useful for handling missing data, when missing values would otherwise result in a loss of power. It should not be used as a method of ‘guessing’ missing values, but retaining as much of the observed data as possible. For example, many statistical packages will omit cases in a listwise fashion in multivariate models where a single observation for a single variable is missing. This would result in a loss of statistical power, as a large quantity of observed data would not be included in the analysis.

MI is only a valid tool when data are either Missing At Random (MAR) or Missing Completely At Random (MCAR) (Little, 1988). If data is MCAR, then there is no pattern to the ‘missingness’ of observations. That is, whether a given observation for a given variable is missing or not cannot be modelled based on the observed data. In this case, MI is useful for retention of observations and power. If data are MAR, then missingness can be modelled based on observed data; there is a pattern. In this case, MI can be used to take this into account. Finally, if data is Missing Not At Random (MNAR), then MI cannot be used. Data is MNAR if there is a real-world pattern to whether an observation is missing or not, but the variable(s) predicting missingness were not observed.

In chapter 7, MI was used to retain power in longitudinal MLM. Details are given in the chapter of how data were tested for MAR v MCAR.

4.11 Summary

This chapter summarised the general methodologies applied throughout this thesis. The next chapter sets out the results of qualitative work employing focus groups and interviews to explore how staff and patients conceptualise self-management.

Chapter 5: What does "self-management" mean to dialysis patients and staff that care for them?

5.1 Introduction

There is an extensive academic literature on self-management, that has been emerging over the past two decades, and dates back even further (Gibson, Britten, & Lynch, 2012). This literature is discussed in chapter 2. Furthermore, a number of practical initiatives have been launched by various healthcare organisations to promote better self-management. Despite this, there is often disagreement about what exactly 'self-management' entails, and how to promote it.

The medical challenges of ESRD are well documented, and general self-management tasks are considered to be well established in other conditions such as Heart Failure (HF) or diabetes (Glasgow et al., 2002). However, to date there has been little work exploring what people on dialysis for ESRD consider 'self-management', and what helps and hinders in an in-centre setting (Hutchison & Courthold, 2011).

Even rarer is examination of the beliefs renal staff hold about what patient self-management entails, and the role that they as healthcare professionals may play in enabling or hindering such behaviour. It is unclear whether staff and patients have congruent or incongruent ideas about what patient self-management entails.

5.1.1 Aims

The purpose of the work described here is to explore what patients and staff perceive 'self-management' to entail. The aim is also to establish facilitators and barriers to achieving these goals according to patients and staff. Comparing staff and patient views will also allow for the identification of any potential mismatch that could have implications for care.

Primary aims:

- Explore staff and patient perceptions of what effective self-management entails
- Establish facilitators and barriers to self-management in order to identify both systemic barriers, and those which could be overcome by individual behaviour or support
- Establish what motivates patients to engage in different types of self-management behaviour

Secondary aim:

- Compare staff and patient perceptions of facilitators and barriers to self-management

5.1.2 Self-management concepts among patients and staff

While there is an increasingly well developed academic literature on self-management, it is not always clear whether this concept transfers to those, 'on the ground'. This means people with long term conditions, their carers and families, and also healthcare professionals (HCPs) involved in their care. While a valid psychological or sociological phenomenon does not require understanding from the perspective of individuals in question to remain 'true', self-management is often presented as being about empowering patients, rather than achieving top-down goals set by institutions (Gibson et al., 2012). Understanding individuals' beliefs about self-management is an important part of documenting the concept, and reasons for different styles of management. Furthermore, should staff hold conflicting views to the patients they care for regarding the individual's role in managing their condition, this could have important implications for both cognitions and behaviours relating to self-management.

There has been work outside of the renal context into which perceptions about self-management in patients have been assessed (Novak et al., 2013), but less on the perceptions of staff. Self-management can be thought of as engaging in the behaviours necessary to problem solve the barriers to ‘looking after oneself’. Whether patients and staff view the desired outcomes of this set of behaviours to be purely clinical (e.g. living as long as possible), or whether this includes a good quality of life and continued social functioning is an important question.

It is possible that a reciprocal model, where social and psychological factors feed into medical management, medical and psychological factors feed into social management, and medical and social factors feed into psychological management would be relevant. Each side of the self-management triangle may be both a process and an outcome.

5.1.3 Beliefs about facilitators and barriers

Some of the most telling work analysing patients’ views on self-management has been qualitative work around facilitators and barriers. Such studies typically employ semi-structured interviews or focus groups to uncover what patients believe stops them from self-managing, and what helps. This discussion often involves identifying the kinds of behaviour they are trying to engage in. In many ways, engaging in behaviours that overcome these barriers can be thought of as the activities that comprise successful, active, self-management behaviour. This includes psychosocial factors that patients believe are relevant to their ability or otherwise to self-manage.

Jerant et al. (2005) conducted 10 focus groups with 54 individuals, 85% of whom were living with multiple chronic conditions. They were interested in what patients viewed as the barriers to ‘active’ self-management (see chapter 2), and barriers to self-management resources. They found that barriers to active self-management included: depression, problems controlling weight, difficulty exercising regularly, fatigue, poor communication with physicians, lack of support from family, pain, and financial problems. The study was conducted in the USA, and financial problems frequently related to health insurance. The questions posed to participants were open ended, such as, “What kinds of self-care problems do you encounter in living with your illness?". Depression and lack of social support were seen as barriers to "get[ing] on with life". Furthermore, the authors go on to posit that participants fell into one of four categories based on their "Perceived Level of Control" (PLoC) over their condition, and their self-efficacy for managing it. Those who were high in both appeared to be faring the best, while those who were low in both appeared to be faring the worst.

There have been similar findings in heart failure (Riegel & Carlson, 2002). Perceived barriers once again included physical limitations, emotional distress, and lack of social support. These barriers can be thought of as barriers to both adherence and good medical self-care. In another qualitative study on self-care in people with multiple comorbid conditions, a free listing exercise was used in 16 interviews to enumerate barriers to self-care (Bayliss, Steiner, Fernald, Crane, & Main, 2003). Once again, physical limitations, emotional impact of the disease, low self-efficacy, and unmet needs for social support were frequently raised as issues. In these studies, little information is given about how far emotional health and good social relationships are valued as self-care activities in themselves. It is clear, however, that individuals living with these chronic conditions in these studies believe that psychosocial factors play a large role in making medical self-management possible.

There has been comparatively little work on these perceptions in people on in-centre HD for ESRD (Curtin, Mapes, Petillo, & Oberley, 2002).

5.2 Methods

5.2.1 Overview

To address the study aims, a combination of focus groups and interviews were employed. Focus groups were conducted in 2012 early in the SELFMADE project. Interviews were conducted eighteen months later in 2013 after a period of activity of a ‘self-management facilitator’ as part of that project.

Focus groups were employed as a way of investigating the aims in a manner that promoted discussion among participants. Focus groups do not necessarily provide a description of participants’ individual viewpoints, but instead allow insight into discussion and ideas (Lehoux, Poland, & Daudelin, 2006). However, patient and staff focus groups were held separately, as, “… participants who are seen as possessing experience tend to dominate discussions and are deferred to by other group members who see them as the experts” (Smithson, 2000). Additionally, this allowed for a comparison of themes emerging from staff and patient focus groups. A copy of the focus group schedules can be found in appendix G.

Interviews were conducted 18 months after the focus groups. They provide a more confidential setting in which viewpoints that may be considered controversial can be aired, as well as allowing for the expression of individuals’ experiences (Kitzinger, 1995). Similar approaches regarding recruitment, procedure and analysis were followed for focus groups and interviews. As such, methods will be discussed together, with differences noted where relevant. In the intervening 18 month period, a programme of ‘action research’ activity took place as part of the SELFMADE study (see chapter 4 for details). A copy of the interview schedules can be found in appendix H.

5.2.2 Participants

Focus groups:

A purposive sampling technique was used to ensure a wide range of participants in the focus groups (Gobo, 2004). Factors taken into consideration when determining the range of patient participants included age, sex, number of years on haemodialysis (in other words, how ‘experienced’ they were as renal patients), and ethnicity. The primary consideration when sampling HCP participants was ensuring that a range of roles and levels of seniority were represented. A total of 15 participants took part in the patient focus groups (including a caregiver), and 15 participants took part in the HCP focus groups. Of the 15 patients, 5 participated at Site 1, all women, with a mean age of 51.6. Four patients participated from Site 2, 3 of who were women, with al mean age of 54.5. Six patients participated from Site 3, including 3 women, with a mean age of 65.7. Staff roles are detailed in Table 1. In addition, once coding was complete for the findings and derived themes, vicarious respondent validation (Creswell, 2012) was undertaken specifically through facilitated discussions with a further 8 patients and 30 staff, purposively sampled from people who could not attend focus groups. This ensured a full range of perspectives and confirmed the thematic coding.

See table 5.1 for an overview of patient and staff participants.

Table 5.1: Patient and staff focus group participants

Patients	HCPs
15 participants, 6 female	15 participants, 12 female
Mean age = 60.5 y/o (range = 40–83)	
Mean time on dialysis = 5.7 years (range = 1.3-11.5)	2 CSWs, 7 nurses (bands 5-8), 2 doctors (1 SPR, 1 consultant), 1 social worker, 1 pharmacist, 1 housekeeper and 1 manager

Interviews

A total of 15 interviews were conducted with patients. Of these, 10 were male. All participants had been on dialysis for at least 3 months, with five having more than 5 years of experience on dialysis. Five participants were on haemodialysis following the failure of a renal transplant.

A total of 10 interviews were conducted with staff involved in the care of people on in-centre haemodialysis. Of these, 7 were male, and 6 had more than 5 years of experience working in their respective dialysis unit. Participants were comprised of four nurses (one staff nurse, one charge nurse, one senior sister, and one matron), four Clinical Support Workers (CSWs), one physician's assistant, and one consultant nephrologist.

5.2.3 Setting

Focus groups and interviews were conducted in three dialysis units in East & North Hertfordshire NHS Trust. See chapter 4 for a more detailed discussion of each of the units. All focus groups and interviews were conducted in a quiet meeting room in the centre where participants dialysed or worked.

5.2.4 Personnel

The author facilitated focus groups and interviews, along with three other members of the SELFMADE team. In addition to the author, JR, interviews and coding were undertaken by PW, MO, and RB. The final analysis and interpretation were conducted and written up by the author and disseminated back to the rest of the team for confirmation.

5.2.5 Procedure

Upon arrival, participants were asked to confirm that they had read and understood participant information forms and to sign a consent form. All sessions were audio recorded. Recordings were sent to an external transcription service and later checked against the original recording by the author, who corrected minor errors in e.g. medical terminology.

5.2.6 Analysis

Analysis was undertaken using a thematic approach (Fereday & Muir-Cochrane, 2008). Thematic analysis is a methodology with a great deal of flexibility (Braun & Clarke, 2006). However, this flexibility means that underlying assumptions need to be made explicit. Thematic analysis used here can be considered to be a combination of inductive and deductive, as both *a priori* themes, and themes emerging from the data were considered. A constructionist perspective is employed, as it is the social construction of the idea of self-management, and the coherence or tensions of the concept between staff and patients that is of interest, rather than any one essential meaning within the individual (Holloway & Todres, 2003).

Focus groups:

Transcripts were entered into NVivo software (QSR International, 2006). The entire qualitative research team participated in coding. A combination of a priori and emerging themes were employed. A priori themes were derived from the discussion schedule, primarily “Challenges [to self-management]” and “What helps?” Each team member generated codes independently, coding the first transcript and then meeting to reach a consensus. Remaining transcripts were then independently coded, along with a recording of the first, and the team met once again to check for consensus and reach consensus by discussion where discrepancies remained. Next, the team organized the codes into coherent themes, wrote them up, reported them to the study steering group, and then fed them back to patients and staff members for validation.

Interviews:

Analysis was undertaken solely by the author. Thematic coding was undertaken for each transcript in sequence, coding using *a priori* themes and generating a list of emerging themes which were entered into a codebook. After reflecting on emerging codes generated for all transcripts, codes were condensed into themes, and transcripts were coded a second time to ensure all transcripts were coded against a complete set of themes.

Inter-rater reliability:

Inter-rater reliability was not considered to be necessary in these analyses, as it frequently does not add anything beyond the process of collaborative coding (Armstrong et al., 1997) (Pope, 2000).

5.3 Results 1: Focus groups

Five core themes were identified. “Challenges” and “What helps?” were the facilitators and barriers, and were defined as themes *a priori*. “Good patient/bad patient”, “Complex balancing acts” and “Unit as family” were all themes which emerged during the discussion. See table 5.2 for summaries and examples. All five themes were present in both staff and patient focus groups, but with some differences in frequency of occurrence and emphasis. These will be addressed throughout these results and the discussion.

The generation of codes and themes was undertaken as a group by the qualitative SELFMADE team. A separate analysis focusing on the “Unit as family” findings have been published elsewhere, jointly written by Professor Patricia Wilson and the author of this dissertation (Wilson et al., 2014). However, for this reason, an in-depth analysis of the “Unit as family” findings will not be included here.

Table 5.2: Themes emerging from focus groups

Theme	Definition	Example
1. Good patient/bad patient	Categorising patients as 'good' or 'bad' depending on their behaviour	Patients with low IDWG being referred to as, 'good patients'
2. Challenges	Barriers to performing self-management tasks	Embarrassment about taking phosphate binders in public
3. Complex balancing acts	The task of balancing competing medical, social and emotional demands	Choosing to have a drink at wedding to celebrate, knowing it may make the next dialysis session more demanding
4. What helps?	Things that make self-management tasks easier	Support from family or friends
5. Unit as family	The perception that the dialysis unit is like a found family	When a patient dies, they are missed like a member of the family

5.3.1 Good patient/Bad patient

Discussions with Health Care Professionals (HCPs) led to some clear outlines forming about what they perceived to be a 'good' patient, and what they perceived to be a 'bad' patient.

> "... *some patients turn up beautifully, religiously, never miss a session. Like they're anxious when their session shifts, it's because they're very, very fastidious and those ones would be perfect for encouraging self-care because they're conscientious and involved*..." (Female HCP, site 1)

Discussions around ‘good’ patients tend to include words like, “beautifully”, “religiously”, and “fastidious”. They are characterised by being timely in their dialysis and clinic attendance, taking their medications as prescribed, and adhering to fluid management goals – the practical elements of adherence for an HD patient. The use of ‘religiously’ to indicate ‘compliance’ came up at multiple sites:

> “*they* [young people with social problems] *take to not being compliant and they’re our sort of failures that never get their head round why they’ve got to come three times a week religiously, they pop in when they feel like it and they’re the ones that will never be able to self-manage because they can’t manage the basics in life*” (Female HCP, site 3)

Conversely, ‘bad’ patients did not adhere to their prescribed regimen. Non-adherent behaviours were described as “*naughty*”, and “*they don’t hear, no matter how many times we tell them*” (female HCP, site 1). The dichotomy between HCP perceptions of good/bad patients possibly reveals two things:

The first is that HCPs have an idea of what they would like active, engaged patients to be like. The second is that HCP expectations of patients’ reasons for non-adherence, and how to better encourage them, may need to be managed. This was at one point recognised:

> “*But their agenda and their way of life can be quite different, can’t it, and we need staff to recognise where they’re coming from and not have, perhaps, expectations that we think we would do something in a certain way and we’d be compliant. Well, you know, if you’re in a completely different situation in your life, you’ve got kidney problems maybe you’re not going to be like me, we’re quite different and we need to kind of educate ourselves around that and manage our own expectations, I think*.” (female HCP, site 1)

Patients sometimes defined themselves as good or bad, again in relation to fluid and medication adherence, rather than timekeeping or dialysis adherence:

> “*I’m dreadful taking tablets, I’m dreadful, I’ve got to take phosphate binders, my phosphate is very high and my potassium very high, I’m not an ideal patient to be honest...*” (female patient, site 3)

Both patients and staff frequently acknowledged that being good or bad did not exist in a vacuum, and that many factors contribute to the ability to manage their treatment, as well as challenges to living their life in a more general context.

Some HCPs acknowledged that patients sometimes made decisions about stopping dialysis early to spend more time with their family:

> “*And I think they think, well if I can shave off half an hour here, I’m going to get home half an hour I might just get in time to put them* [their children] *to bed…*” (Female HCP, site 3)

HCPs also acknowledged that some patients believed that changing their dialysis dose could compensate for fluid and dietary non-adherence. However, this was not generally positively regarded:

> “*They think, I can manage taking three and a half litres off, I feel fine afterwards, my blood pressure’s fine but they’re not looking at the bigger picture, that in five or ten years’ time they’re actually not going to be able to”* (Female HCP, site 3)

5.3.2 Challenges

Living with kidney disease presents a number of challenges, both in terms of self-managing treatment, and also managing one’s wider social, familial, and mental life. One theme that seems to permeate all of these domains is the desire for some kind of normality. Sometimes this can interfere both with adhering to treatment, and with a person’s everyday life:

> "*Well, we have in the past with business people, they don't want to be, you know, if they're doing their business lunch they don't want to be taking phosphate right in front of their clients so they quite often have a compliance issue which they know when to take the tablets but it's an image, you know, taking tablets in front of clients isn't the thing to do and controlling their diet when they're entertaining is quite difficult for them so I think from that point of view whatever job they're doing it's remembering to take their tablets with them*." (female HCP, site 1)

The use of the term 'compliance' is often considered outdated in the academic literature in favour of 'adherence', as the former is considered unnecessarily authoritarian (Aronson, 2007). However, it appears to still be in common use among HCPs, and may reveal something about how they view the HCP/patient relationship. In addition to wanting to try and preserve some normality in the face of loss presented by kidney disease, patients and HCPs identified that inconsistency within the dialysis unit, and in the care team, could present an issue, for a number of practical reasons. For example, patients may find it harder to communicate about their issues if they feel they are constantly restating themselves. Patients may not feel that they are supported or that they are understood if they are constantly dealing with new staff who are unfamiliar with them as individuals.

End Stage Renal Disease (ESRD) is often accompanied by serious comorbidities, including diabetes and hypertension. Patients and HCPs recognised that these present additional problems. Patients offered diet as a problem:

> "*... the only thing is you see being a diabetic, and being on dialysis, the two don't tally do they, they don't... you could eat something on dialysis, but you couldn't eat, you know, the two don't come together you see...*" (female patient, site 3)

HCPs across two sites raised the issue of time being precious to patients:

> “*I can understand, if you’re on dialysis three times a week, you don’t want to spend the other two days going to a podiatrist* [for diabetic patients] *and to get your eye test done and go to breast cancer screening, why would you want to, because it’s taking a day out of your precious days off*...” (female HCP, site 1)

Patients also recognised that time was precious for staff, and that there were practical limitations to the resources that could be provided in the unit for their care, although lack of access to a dietician and to consultants in the satellite units were issues raised on multiple occasions.

Both patients and HCPs recognised that the initiation of dialysis was often overwhelming. Currently, planned dialysis patients in Hertfordshire receive education about treatment prior to dialysis initiation, but little continued formal education after that. It was often felt that patients feel overwhelmed and forget much of what they have learned.

The challenges described above were noted by both patients and HCPs. Some challenges were raised by HCPs but not patients, and vice versa. Patients expressed some reservations about who is responsible for making decisions about their care – themselves, HCPs (and if so, who), or ‘the machine’. ‘The machine’ in a wider context came up as a source of fear and mistrust for patients at all three sites:

> “*They’re trying to sort out my blood pressure because I looked on my computer and thought I’ll try and sort it out. And the reading I got the other day was forty-eight over* [inaudible]*, on the computer it said “you’re dead”, which does, that scares me.* ” (male patient, site 2)

Other patients expressed an interest in knowing more about the dialysis machines, and what the buttons and lights did and meant. Some patients asked their care team questions and were satisfied, others were too intimidated to ask or felt that the HCPs were too rushed (their time was too precious) to bother them. Peer learning from more experienced patients, described below in “What helps?", was ventured as a possible solution. However, staff at one site (site 3), did express the idea that peer learning (at least informal peer learning) could be problematic and lead to the spread of misinformation.

5.3.3 Complex balancing acts and trade offs

Living with chronic diseases, and indeed as a member of the healthy population, involves making daily decisions about trade-offs regarding one's health. For example, drinking alcohol may be pleasurable, but too much too often will result in liver failure. Similarly, not everyone enjoys exercising, but engaging in regular cardiovascular exercise will lower the risk of coronary heart disease and a host of other health problems. Striking a balance between health and day to day happiness could be said to be a self-management task that everyone must undertake.

HCPs exhibited various positions on the subject of why HD patients might not adhere to prescribed treatment. HCPs also almost universally used the term 'comply' and 'compliance' – terms often regarded as outdated in the self-management literature as indicating an inappropriately authoritative relationship between HCPs and patients (Aronson, 2007). Some explanations of intentional non-adherence are given above (e.g. patients in their professional work role not taking their phosphate binders to appear 'normal' in front of clients). Some staff believed a lack of understanding to be the cause:

> "*And even the older ones, they don't hear, no matter how many times we tell them, that they have to count all their fluids, sometimes they don't really understand*." (female HCP, site 1)

While this is likely the case for some patients, for many the decision to not adhere was an intentional one, and often not taken lightly.

> "*I always ask anyway, now, uh, now that I've come to terms with it I always ask to see what my blood's doing, and over six years I know what I can eat and what I can't eat. And, you know, we call it cheating, say if I have a packet of crisps today I won't have nothing else, and then I'll have a bit of chocolate tomorrow, I won't have nothing else what I shouldn't have*" (male patient, site 2)

"Cheating" or "being naughty" when deciding to make trade-offs were frequent themes, as seen in the 'Good patient/Bad patient' discussion. At times this emerged as something that both patients and HCPs perceive as a "battle" or "taking sides", with patients on one side and HCPs on the other.

One particular exchange between patients and a carer (whose husband was on dialysis), during the focus group at site 2 illustrated this. Members of the discussion were informing a male patient that he had been eating things that HCPs advised against:

> Male patient: "*Whose side are you on? (all laugh)*"
>
> Female carer: "*I'm on my husband's side, I want to keep him alive as long as possible*."

In spite of this determination to keep her husband alive, she still went on to acknowledge that sometimes, for example, his loss of appetite meant that she would cook foods that were advised against:

> "*I've always thought, well it's going to kill him but now, you know, it's the only thing he's eating so it's like living on a cliff really isn't it, you don't know what you're doing*." (female carer, site 2)

In addition, many patients expressed that being happy in what they ate was important, and that failing to achieve this could lead to them becoming depressed. Complex balancing acts were also apparent for fluid management and social events. Some patients explained that they chose to indulge when they went out, or for big occasions. For example, one patient had indulged in a few drinks the weekend before the focus group for her son's wedding. Another patient described how he would go down the pub with his friends once a week, but would only have half a pint of lemonade.

Maintaining an achievable balance between healthful behaviours and staying positive and happy was definitely a complex area of challenges. Patients and HCPs also identified a number of things that may help with those challenges.

5.3.4 What helps?

The sections above have alluded to some of the things that may help patients to self-manage. Peer support came back time and again as something that either has helped, or that would be perceived to help in the future. This was recognised by patients and HCPs. Peer support was identified as helping patients keep their spirits up ("... *chivvy each other along...*", female HCP, site 1), and peer learning was generally considered to be helpful, and some patients were interested in the idea of having the opportunity to learn more about the treatment and particularly the dialysis machines. However, sometimes peer communication was regarded as a problem by HCPs:

"[describes a patient talking to another patient about eating and drinking without restriction due to their clinical status] … *the fact that somebody's talking to them about that they think they can do the same thing*. […] *So you tend to find sometimes too much information can be bad thing (laughs), especially amongst themselves. You have to kind of tell some of them like "no, don't sort of discuss that, you know, with each other" in that respect*" (Female HCP, site 2)

Discussions around the challenge of managing one's diet while on dialysis led to some suggestions from patients of what might help. The conflicting requirements of diabetic and dialysis diets led to the idea that supermarkets and food shops could be involved to include specialist sections for more rare conditions like ESRD. Even if this is unrealistic, it provides an idea of issues that HCPs may be able to provide some support with, or for which educational materials could be developed. On a related note, patients at another site noted that dialysis diet information sheets are almost always oriented around what a patient *cannot* eat, not what they *can*. There was recognition that this will vary based on comorbidities, and that a tailored approach would help:

> "... *it's* [dietary advice] *got to be hugely tailored, obviously as I say we've got different conditions, obviously some of us pass urine, some of us don't and that's going to have an effect on what's left in your blood and other things so there are going to be some conditions but I suspect they could probably break it into groups and say, you know, you're a Group A and you're a Group F*..." (male patient, site 1)

Tailoring of this kind was a central theme to discussions of education. As mentioned in 'Challenges', imminent new dialysis patients receive pre-dialysis education, but often feel overwhelmed and forget much of what they learn. Additionally, much of the information will be meaningless until they have a context in which to place it. This was recognised frequently, and the issues repeatedly identified were: that it needs to be tailored to the patient, that timing is important, and that to some degree it needs to be ongoing throughout the course of treatment:

> "*Yeah, they're overwhelmed when they first come on and it's too much and they take home the booklets and then the little bits they want to know, how am I going to get here, what kind of thing do I have to do, all the little rules that you know to follow. All that and the important stuff is forgotten because there's just too much to take in, so a little reminder, regularly*." (female HCP, site 1)

‘Little rules’, and tips and tricks seemed to be something that could be shared. For example, the type of phosphate binding medication (large swallowed tablet or flavoured chewable tablet) was important to patients across different sites, as well as how to remember to take them/have them to hand. Some medications have to be taken in the morning, and those were specifically stated to not be a problem. However, for phosphate binders, which need to be taken throughout the day with food, forgetting was raised as a frequent issue, in addition to intentional non-adherence as discussed earlier. One patient pulled out a large bottle of pills from a rucksack, which he kept with him so that he would have a plentiful supply at all times. Another shared a strategy where he would have some medications stored in his briefcase for work, some in the car, some at home, so that he would have both reminders and a supply of medications where they were needed.

A good portal of information and resources also came up as something that may help. Some patients frequently took ‘dialysis holidays’, where they take up free slots at other units (usually arranged online or over the phone) elsewhere in the country, or even abroad, allowing them to still have that freedom. However, a lack of readily available information about holidays seemed to be a barrier for some people, and this varied by site. While site 1 had a folder of useful resources patients could access, site 3 did not, and staff did not appear to have anywhere to direct one patient who particularly wanted to take a dialysis holiday to visit his daughter. Additionally, a number of helpful resources, such as the ‘Freedom Dialysis’ website and a magazine called, ‘Candis’, with information about travel insurance for the chronically ill emerged from these discussions.

One tool that has great potential use for patients wishing to self-monitor their clinical markers online is Renal Patient View (RPV). HCPs voiced support for RPV, but did not think that many of their patients used it. This was borne out in patient focus groups, where the vast majority were not even aware of it. Some patients did not own computers and had no interest in online tools. Some did not own a computer, but had relatives access useful websites on their behalf. Some patients seemed very interested in RPV, but were simply unaware of it. HCPs tended to agree that they did not do much to promote the service. Making patients more aware of tools like this may be something that could help those who wish to be more involved in self-monitoring.

Amidst all these challenges and facilitators, there was an interesting dynamic that emerged from both patient and HCP focus groups. For better or worse, there seemed to be a strong perception from many that the dialysis units were a kind of family.

5.3.5 Unit as family

Both HCPs and patients expressed that they felt the unit was, at times, like a family. This could often be seen as a metaphor in the subtext. For example, one HCP came across very much as a father figure trying to look after his naughty children:

> "*I mean particularly, you know, particularly a problem for the young or older children, you know, we have, I call them children because it's like we have a few patients sort of 18 to 22 don't we? We have a few patients and they are incredibly difficult to cope because, you know, they see their friends going out and about and running around and…*" (male HCP, site 3)

However, many patients and HCPs raised the idea of the unit as a family explicitly, and where they did, it was generally in a very positive light, as something that helps:

> "*... the people, yeah are great, it's like a little family I think, you know, you're all there for the same purpose and it helps you forget about your other problems as well I suppose and then because I was the first year when I come in, I learnt from other people how to cope with it*." (female patient, site 3)

HCPs across sites expressed a similar notion. At one site they went on to describe how they had been told by ex-dialysis patients (who had been successfully transplanted) or the carers of now deceased patients, that they missed the family once they were no longer attending the units:

> "*... if we've got patients who have carers say, we had one recently, an elderly lady whose daughter was the carer and she did everything with her and she said, I really feel like you're my family and her daughter died and she was so lost because she didn't even have us, she could come in and see us but that contact was lost and they do see us as family and we see them as family, when we lose a patient it really hits us and it's a big impact*." (female HCP, site 2)

Interestingly, sometimes the HCPs did not see themselves as the elders in the family dynamic:

> "*… because the older patients who have grandchildren, quite nice actually they treat us as their children*" (Female HCP, site 3)

Recognising this 'family' dynamic may be important to managing the relationships in the units, that are key to ensuring patients are supported in their efforts to manage their treatment and their lives.

5.4 Discussion 1 (focus groups):

The thematic analysis was conducted in accordance with the principle of homogeneity within themes/heterogeneity between themes (Braun & Clarke, 2006). It is therefore telling that despite adhering to this principle, the concept of time and time being precious appeared in numerous themes. Staff felt they did not have enough time to devote to patients. Patients felt that their treatment was a huge drain on their time that was preventing them from getting on with their lives.

There was a great deal of overlap between what staff and patients regarded as important medical self-management tasks. Adhering to fluid restrictions, taking medications, restricting the consumption of certain foods, and attending dialysis were all frequently identified by both groups. For HCPs, this appeared to be a black and white subject; patients who adhered were ‘good’, those who did not were, ‘naughty’. Some patients had clearly internalised this, and thought of themselves as ‘not ideal’ patients. Those that staff perceived as ‘good’, those who turned up to dialysis regularly and on time, and controlled their IDWG and dietary markers, were seen as good candidates for self-management support. However, one might argue that those who are doing these things are already self-managing effectively (from a clinical perspective, at least). This idea may speak volumes about what HCPs believe self-management is – ‘compliance’. It may be that the idea that only those who are self-managing well should be encouraged to self-manage would be worth challenging. It may be the case that clinical staff do not view it as their job to change the world-view or behaviour of those who do not look after themselves – but this would be at odds with the frequent instances of staff and service users discussing ‘telling off’ or ‘being told off’ for high IDWG during dialysis sessions. Giving patients a ‘telling off’ is not consistent with the ethos of self-management, where people make their own healthcare decisions. Furthermore, it may be counterproductive, as there is evidence that threatening health messages are more likely to be ignored when they are put across aggressively (Armitage, Harris, & Arden, 2011). Instead, inducing self-compassion (or self-affirmation) may be a more functional way to engender behaviour change (Wileman et al., 2014).

For many other patients however, there were frequent explicit or implicit references to complex balancing acts. Ultimately, these arise from tensions between medical needs, and social and emotional needs. They can involve cutting dialysis short to see family, or eating ‘forbidden’ foods because they were comforting, or going out and drinking with friends. The idea of living on a cliff edge raised by a carer was a powerful metaphor – balancing her husband's continued survival by adhering to guidelines, which she greatly valued, against maintaining his will to eat at all, and thus his will to live. It was clear from many discussions with patients that emotional and social outcomes were highly valued, and that treatment had to work for them, not necessarily the other way around.

By contrast, staff were highly focused on the idea of patients taking personal responsibility. This is highly concordant with the concept of patient activation, or an individual's readiness to take responsibility for aspects of their care. Any deviation from prescribed medical regimen was usually considered irresponsible. Only one social worker expressly voiced the idea that the patient's perspective may be substantially different to their own, and that their goals may be different to those that HCPs have in mind. The theme of taking personal responsibility for many patients came back to the idea of complex balancing acts; it was evident that they believed that their role in their care was to take good care of health, but not necessarily when doing so was perceived to conflict with their ability to look after their emotional health or their ability to work or otherwise socially function.

Social support was frequently cited as being valuable. HCPs tended to view the support of other patients as being important to the emotional wellbeing of other patients. People on dialysis expressed a similar notion, but with the added idea that a lot of learning of practical self-management skills could take place. HCPs thought this might be harmful, and promote the spread of misinformation.

From a psychological perspective, it is clear that HCPs believed that patient activation was an essential element of good patient self-management. Discussions frequently centred around self-management being for the 'right' kind of people, and that certain people had the right mindset, while others did not. Some were seen as hopeless cases ("They don't hear, no matter how many times we tell them"), who would never achieve that mindset, which conflicts with the aims of behaviour change interventions that attempt to move people along the 'stages of change' (Molaison

& Yadrick, 2003). The qualities of an activated patient were fastidiousness, conscientiousness, and a desire to stick to treatment in the face of difficult circumstances.

It is interesting that depression did not surface as a potential barrier to self-management from the staff perspective. While it was acknowledged that living with ESRD is difficult, emotional impact was usually discussed in terms of newer patients being ‘overwhelmed’ and taking time to adjust. Patients reported a similar feeling of being overwhelmed initially, but it was clear that striking a balance between physical and emotional health was a daily activity that did not end after a period of adjustment. It may be that HCPs do not recognise distress, or that they do not consider it to be relevant to self-management, a concept which tends to be categorised as compliance in this group. While patients discussed the balancing act of doing what makes them feel okay emotionally with medical needs, depression was not discussed. This may be more of a product of the focus group environment and the presence of others, or may reflect a tendency to avoid thinking about or discussing the problem, an approach to ESRD self-management that is discussed in further details in the interviews below.

It is also interesting that staff identified a lack of patient engagement as a barrier to medical self-management, and that several patients identified ‘not thinking about’ their illness and treatment as a coping strategy. While avoidant coping is often regarded as being maladaptive compared to, for example, approach based coping, empirical evidence shows a more complicated picture, where different coping styles are more or less effective in different situations (de Ridder & Schreurs, 2001; Roesch & Weiner, 2001).

Other emotions, such as guilt or shame, and a desire for normality, were all additional potential emotional barriers to optimal medical self-management. The idea of not feeling able to take one’s medication in front of business clients for fear of appearing weak was a powerful example of barriers that were not strictly practical in nature, and could be based on the psychological impact of living with the condition. ESRD and its treatment present many challenges to the previously held self-image of the individual, and fear of appearing abnormal or weak are common concerns. These challenges to self-image are often regarded as part of the biographical adjustment to a disease (Corbin & Strauss, 1985) sometimes included in the 'social' side of the self-management triangle (Lorig & Holman, 2003).

From these discussions, it appears that staff caring for people with ESRD view self-management as a predominantly medical task, characterised by adherence above all else. Patient activation was viewed as the most important trait for predicting who would make a 'good' self-manager, although other emotional and social factors were acknowledged as feeding in to the ability to medically self-manage.

By contrast, patients viewed self-management predominantly as a balancing act. Good medical outcomes were only one set of goals. According to these focus groups, factors that may contribute to medical self-management behaviours include:

- Patient activation – Readiness to take responsibility for care
- Social support from family and friends
- Participation in the unit as a 'found family'
- Emotional factors such as depression, guilt, shame

The relationship between social, emotional and medical self-management may be a tripartite reciprocal one. Patients identified their emotional wellbeing as being dependent on social support, as well as how their treatment was going. 'Good dialysis' days would leave them feeling better. In turn, the idea was expressed that they would feel more able to go out and socialise if they were feeling good, and if their treatment was going well.

Five themes were identified when discussing self-management with groups of staff and patients; "Good patient/bad patient", "Complex balancing acts", "What helps?", "Challenges", and "Unit as family". These focus groups were conducted at the same time that baseline quantitative measures used in chapters 6 and 7 were taken. Follow up interviews were then conducted 18 months later. During this time, a “self-management facilitator” had been introduced to the units. These interviews were partially evaluative of the project, as well as further exploring the perceptions of self-management. Themes surrounding these perceptions are described next.

5.5 Results 2: Interviews

A series of interviews were conducted with a separate sample to further explore behaviours that patients thought were important for self-management, and to assess whether their dialysis unit had done anything to aid self-management in the 18 months since the focus groups took place.

With a set of self-management topics established in the focus groups, interviews were oriented towards some of the topics that arose. The analysis was guided by three research questions:

1) What self-management tasks have patients been involved in over the previous 18 months?

2) What are the goals of those self-management tasks, from the patient’s perspective?

3) What is the role of the dialysis unit?

A key driver behind this analysis was the focus group finding that staff and patients have different perspectives on what self-management entails, with patients balancing medical advice against emotional coping and social functioning, while staff are understandably almost solely focused on clinical outcomes.

Quantitative data on self-management behaviours elsewhere in this dissertation (see chapters 6 and 7) was collected using the self-management scale developed by Curtin and colleagues (Curtin et al., 2004). In order to facilitate methodological triangulation, this scale was used to provide a set of *a priori* codes for the categorisation of self-management behaviours. These categories include *suggestions to (healthcare) providers* and *selective symptom management*, for example. See appendix A for a full list of subscales.

In order to address the questions, transcripts were coded by the author. Self-management behaviours were coded for which self-management category they fell into. They were also coded for the goal of the behaviour. Goal codes were condensed into themes, which will be reported here. See table 5.3 for a summary.

See table 5.3 for a summary of themes emerging from these interviews.

Table 5.3: Themes emerging from interviews

Theme	**Definition**	**Example**
1. Preventing or reducing unpleasant symptoms	Actions taken to prevent or reduce the occurrence of uncomfortable symptoms both on and off dialysis	Maintaining a low IDWG to prevent 'going hypo' during dialysis
2. Coping by forgetting	Behaving in a way that helps the patient forget about ESRD or dialysis	Not seeking information about dialysis on non-dialysis days, as it would be a reminder about dialysis
3. Relieving boredom and reducing waiting times	Behaviours that reduce the monotony of the dialysis process, or make the process quicker	Performing self-cannulation as a way of getting on dialysis faster
4. Getting on with life	The act of getting on with one's life despite ESRD, or self-management behaviours that enable this	Indulging in food or drink during social occasions such as Christmas

5.5.1 Preventing or reducing unpleasant symptoms

As a central concern for dialysis patients, diet and fluid management was discussed during the interviews. One of the most common reasons for attempting to adhere to guidelines on fluid and dietary intake was the avoidance of unpleasant symptoms. Those who claimed to take *shared responsibility in care* often stated that the reason they kept their fluid and phosphate under control was to avoid unpleasant symptoms that accompany dialysis when a large amount of fluid needs to be removed:

> Patient(P) 9 female: "*I only take off what I feel I want to take off and then ask for advice when I go back to the clinic on a regular basis, but I probably don't take off enough fluid, I've passed out a couple of times after having too much taken off and I think it's probably scared me a bit. It's a horrible sensation so, I'm a little cautious with my fluid*."

This avoidance of on-dialysis complications were also the motivation behind certain *suggestions to (healthcare) providers*. Where patients had previously had bad experiences with having too much fluid removed, they described negotiating their dry weight (their weight when excess fluid has been removed by dialysis) with staff to avoid this in future:

> P5, male "… *I went hypo the other week. But it's, the dialysis had finished and I'd just been taken off, you know, I couldn't believe it and next thing you know I got oxygen mask on. That's a bit, see it's a bit scary, it's not very nice but I don't know why that happened. But no, it's pretty well under control, you know, they've got, they are good. And I can see the sister, when I saw her last time I said "look, I still think because of that would you please increase my dry weight again?" and they have done*."

Similarly, exercise during dialysis was popular because of symptom reduction. In months prior to the interviews, intradialytic exercise bikes had been introduced to the dialysis units. Some of the participants interviewed had been piloting these bikes during their dialysis sessions. Several participants praised the fact that the bikes reduced cramp during dialysis, which they were very positive about:

> P6, female "*I love it* [the exercise bike]*, I really do, it's especially helpful for someone like me because sometimes in here my legs do ache*"

In a similar vein, self-needling as part of *self-care on haemodialysis* was practiced by one respondent as she had previously experienced pain when staff were responsible for her needling.

> P4, female "*One of the nurses couldn't do it and it took him like five attempts, and it hurt. And then not long after that it went wrong and they done a new site, and I just thought, "Right, I'm not having that again. I'll do it myself*.""

During discussions about managing diet and fluid, long term survival was not mentioned by any of the participants, only short term symptoms.

5.5.2 Coping by forgetting

A number of participants expressed the desire to forget about kidney disease and dialysis when they were not present, expressing a desire not to be involved in *self-care on haemodialysis* or *shared responsibility in care* due to wanting to forget about dialysis to emotionally cope.

> P10, male "*But I try to make them off days if you like and not think about my dialysis on the days I'm not here and at weekends. I like to do something totally different*.
>
> Interviewer: "*It's having a break from it, making sure*…"
>
> P10: "*A complete break, and I think you need that otherwise your mind becomes bogged down with all that's going on with you, so yes*."

In addition to wanting to get on with their lives and relieving monotony, fear was cited as a motivation for this avoidant approach, which extended to *active information seeking*:

> P9, female: "*At the beginning I kept going on the internet and looking it all up and I got so confused, and some of it's so frightening when you start reading it, but no I'm quite happy for someone else to do that* [monitoring diet and providing dietary information] *for me*."

To some extent this seemed to extend to a form of *impression management*, where patients tried to keep their illness away from their family members by not showing how it affected them.

> P6, female: "*Yeah. Yeah, I think that's best sort of. I mean sometimes, I mean I'm tired when I get off of here so sometimes they notice like on the Saturday, you know the kids are there so and I go to bed, I'm so tired, I go to bed but apart from that I do try and really, really keep it away from family*."

Coping by forgetting appeared to be associated with not being interested in participating in care in general, and with not wanting to participate in *self-care on haemodialysis*.

5.5.3 Relieving boredom and reducing waiting times

During discussions about *self-care behaviours during haemodialysis* itself, participants frequently brought up the topic of boredom. In addition to reducing symptoms, the most common source of praise for the intradialytic exercise bikes was the fact that they seemed to help alleviate on-dialysis boredom:

> P11, male: "*I'd say the benefit* [of the exercise bike] *is you do feel better and it does relieve the boredom for however long you're going to do it (laughs)*"

Several participants stated that they wished they could be doing things that were useful to alleviate the boredom. For some that was working, while others stated a preference for being given tasks to do while on dialysis:

> P9, female: "… *unless they can find us something to do while you're lying here, something that we could do to help, perhaps the staff. I don't know what, but something maybe. We used to roll bandages years ago but they don't do that anymore do they (laughs)? So I don't know, but it would be nice to feel we were doing something as well*."

The desire to reduce boredom was often closely associated with the idea of saving time, both for the patient and for staff. The idea of self-needling and setting up the dialysis machines particularly appealed to one participant for its potential to save time:

> P9, female: "*Yes, I think I might try doing my own needling, I'd like to give it a whirl, but I have to, it will be a little while, I need confidence*"
>
> Interviewer: "*What do you see as the motivations for doing that yourself?*"
>
> P9: "*Just speeding things up a bit and helping the nurses out a little bit, because if you can do it yourself it's much quicker isn't it? So, yes, that's what I'd like to do*."

The idea of increasing knowledge about the machines to be able to turn off alarms was also cited as a potential way to save time for the staff, freeing them up to help other patients:

> P6, female: "*Yeah, it would be interesting just to go over the machines and sort of know how, especially the modern ones, to know how they work because then you can, it just saves so much time, it really does. I mean if someone's putting someone on and, it does, it just saves so much time, it would be logical for people to just lean over* [and switch the alarm on their dialysis machine off]. *I mean it's just logic isn't it*?"

The idea of reducing boredom and saving time co-occurred during discussions about the waiting room and transport in the form of *suggestions to providers*:

> P3, female: "*A bit of music, something or other. Well, I mean, sometimes they have, they have had it now and again. It's not an automatic thing, you know, to put it on, but someone will put it on. Yeah. While we have a good chat and all that. (Laughs)*"

5.5.4 Getting on with life

Some participants expressed fitting dialysis into their everyday lives, including work, into *suggestions to providers*. Some expressed that they did not think the system was designed in such a way that it was responsive to such suggestions, for example when discussing availability of dialysis timeslots that fit in with work:

> P10, male: "*I think there should be some sort of capacity in the system for them to cope with people's requests on that sort of thing. And I don't think it's been done at the moment*."

The same was true of the balancing act of *shared responsibility in care*, with attempts to keep IDWG and phosphate down tempered by a desire to enjoy important occasions:

> P4, female: "*It was after Christmas, obviously. They* [blood results for dietary markers] *were all over the place but they just said it was down to Christmas… You've got to live*"

This balancing act led some to make certain concessions to their wants, but not others. As in the focus groups, social drinking occasions and venues became seen as no-go areas, often causing patients to feel isolated and like they had lost friends:

> P7, male: "*I mean I do allow myself one cup of tea a day, first thing in the morning*. *I like to have a cup of tea and then for the rest of the day it's like sucking ice cubes and things like*

that, you know, which, you know, you do learn to live with it but at the same time, you know, I mean I've lost a lot of mates through it really. I mean I don't see my friends anymore, you know, where normally you could go and have a couple of pints and you just can't do that no more. "

5.6 Discussion 2: Interviews

5.6.1 Motivations for self-management behaviours

This analysis aimed at establishing what the goals of various patient self-management behaviours were. A common theme among the people interviewed is that even those who appeared to have their diet and fluid, for example, well under control, were often not interested in participating in the dialysis process. The avoidance of unpleasant symptoms, unsurprisingly, came out as the most frequently cited theme when discussing self-management behaviours. The most salient motivation for self-management appears to be preventing on-dialysis complications. In both the focus groups and interviews, there appeared to be a very common, explicit, ever-present fear of 'going hypo' on dialysis and experiencing dizziness, blackouts, and other unpleasant symptoms. In the interviews, at least, this motivation to avoid unpleasant symptoms was far more frequently referenced than anything to do with length of survival. The avoidance of death was almost completely absent from participant responses, although there may be other reasons for this. For example, it may be that participants felt it was not appropriate in the context of these interviews, or wanted to avoid thinking about or discussing the subject.

Trying to forget about dialysis appeared to be a very common coping strategy, that almost every participant in the interviews talked about in some capacity. This could be regarded as an emotional self-management strategy, regardless of whether one may consider it adaptive or maladaptive. It bears similarities to avoidant style coping, which is often associated with many negative outcomes (de Ridder & Schreurs, 2001). There is some evidence that avoidant coping may be associated with mortality in people with ESRD. However, some participants talked about this strategy as being an almost ‘one day on/one day off’ approach, where on dialysis days they had no choice but to think about their condition and treatment, and so on their off days they would try to forget about it. This ties in closely with the finding that *time is precious* from the focus groups; dialysis days are regarded by many patients as being too demanding and time consuming to allow for other activities, and involve feeling tired or drained. Therefore maximising the non-treatment related use of non-dialysis days is an attempt to capitalise on what little precious time they have available, and to regulate the difficult emotions associated with the demands of ESRD and its treatment. It may be that acceptance and adjustment would be more adaptive ways of coping.

In some cases, such as avoiding seeking out information that caused concern, this strategy appeared to be motivated by avoidance of unpleasant emotional states, in much the same way that many self-management behaviours were motivated by the aim of avoiding unpleasant symptoms. It may be, however, that in reality these two goals often conflict, as avoiding thinking about medical self-management tasks may result in poorer dietary and fluid control, resulting in more unpleasant symptoms. For many it seemed that coping by forgetting was simply out of wanting to get on with their life, and boredom with thinking about ESRD and dialysis.

During discussions about self-needling and other shared haemodialysis care behaviours, many patients did not seem interested in participating, and some overtly stated wanting to be taken care of. This was sometimes related to coping by forgetting; wanting to have to think about their treatment as little as possible, even while receiving dialysis. For others this was about fear of needles, or fear of the dialysis machines and their competence. One patient stated that the ability to engage further in dialysis self-care was down to a question of confidence, or self-efficacy as it is referred to in psychological literature. Perhaps it is unsurprising that in-centre patients would not be particularly interested in participating in their own dialysis, as many people capable of doing so would already be engaged in home dialysis. However, as there are often practical constraints that prevent home haemodialysis (such as lack of space in the home), or peritoneal dialysis (infection, personal preference), in-centre self-care haemodialysis care should not be overlooked.

Indeed, some individuals were interested in self-care haemodialysis behaviours. The motivations behind participation appeared to involve the desire to save time, or relieve boredom. Boredom while waiting for, or on, dialysis, and a feeling that time in constrained while not on dialysis, appear to be two of the most universal experiences from all the patients participating in the work described in this chapter. It is perhaps therefore unsurprising that the prospect of engaging in more of their own dialysis would be of interest more to address these problems than because of any perceived medical benefit.

Getting on with life appears to be an overarching aim for many on dialysis. Coping by forgetting appears to be one way in which participants do this, while others saw engagement in their care to be a way of reducing complications and allowing them to continue their lives, although sometimes both sentiments were expressed within the same interview. As in the focus groups, this balancing act between engagement and getting on with life by not thinking about dialysis came out as possibly the perceived central task in self-management. Medical self-management tasks were frequently perceived as being sufficiently disruptive as to be almost diametrically opposed to getting on with life, and this may explain why avoiding thinking about treatment was a common approach.

5.6.2 Self-management behaviour categories

The self-management behaviour subscales proposed by Curtin and colleagues appeared to be a useful way of categorising the medical self-management behaviours of patients. Of note is that comparatively few instances of ‘defensive’ self-management behaviour (*selective symptom* *management, assertive self-advocacy*, and *impression management*) were raised as issues. Where assertive self-advocacy and impression management were discussed, it was in relation to those outside the health service (for example, complaining to a Member of Parliament about state benefits) or trying to keep the difficulties of dialysis away from the family. No examples of selective symptom management were raised, but this was not specifically probed for by the interviewer.

5.7 Combined summary

This chapter has examined the concept of self-management for ESRD, both by asking what it consists of, and what it is for. This was achieved first by exploring what self-management means to patients and staff, and secondly, by further exploring the motivations behind carrying out these behaviours.

A series of focus groups established five themes that emerge when discussing self-management with patients and staff; good patient/bad patient, challenges, complex balancing acts, what helps?, and unit as family. Within these themes, a number of specific self-management tasks, facilitators, and barriers were identified. These fed into a series of interviews conducted 18 months later, as well as the introduction of new self-management support initiatives such as intradialytic exercise bikes and peer support.

The focus groups revealed that while the five themes emerged for both patients and HCPs, each had a different focus to the other, with patients apparently having different goals to HCPs, raising the question of who self-management, and self-management support initiatives, are for. The interviews were thus analysed to further explore self-management tasks in light of the motivations behind patient actions. Four themes were identified: Preventing or reducing unpleasant symptoms, coping by forgetting, relieving boredom and reducing waiting times, and getting on with life. These goals reveal that the way in which patients approach a whole range of self-management tasks, from information seeking to performing dialysis related tasks like self-cannulation, are influenced primarily by the desire to minimise physical, emotional, social, and biographical disruption.

Any conceptualisation of self-management in ESRD should take into account the disparities in both definition and goals that occurs between patients and staff involved in their care, as well as the similarities.

5.8 Conclusion

HCPs and patients agreed on many aspects of what constitutes ‘good’ medical self-management, but patients have a wider range of social and emotional goals, which HCPs predominantly saw as the means to the end of good medical self-management. Both groups identified a range of social and emotional elements that, whether an outcome or process, may contribute to successful medical self-management for in-centre HD. Many of these factors concord with the self-management literature for other chronic diseases such as diabetes and heart failure. The idea of the dialysis unit as a found family was a powerful idea that exemplified the importance of social support and learning.

The following chapter will quantitatively investigate some of the self-management behaviours covered here, and their associations with psychological status.

Chapter 6: Psychosocial determinants of self-management behaviours in people on haemodialysis

6.1 Introduction

Chapter 5 explored how patients and healthcare professionals (HCPs) conceptualise self-management and the things they do to take care of themselves. Responses were mapped on the tripartite model of self-management that focuses on emotional, social and medical factors. The present chapter will use cross sectional data to explore the relationships between self-management behaviour and psychological status.

As stated in the introductory chapters, self-management can be thought of as what people do. There are a number of theoretical drivers of these health and quality of life promoting behaviours. Typically, the literature has focused on self-efficacy (Bandura, 1977). Self-efficacy forms one part of Bandura’s Social Cognitive Theory (SCT). Bandura defines perceived self-efficacy as, “people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives”. While other factors such as outcome expectancies (what they think will happen if they successfully perform that behaviour) are important, self-efficacy has most frequently been tested, and often comes out as a predictor of adherence (Bandura, 1994, p. 71). In a prior study using SCT variables to predict variations in physical activity among people with ESRD, self-efficacy, but not outcome expectancies, emerged as significant (Patterson, Umstattd Meyer, Beaujean, & Bowden, 2014). More recently, the concept of ‘patient activation’ has come into focus. Based on the Transtheoretical Model of behaviour change (Prochaska & Velicer, 1997), patient activation is the concept of how ready an individual is to change their behaviour. The concept includes, but is not limited to, self-efficacy, and how strongly one identifies with the idea of being central to one’s own care (Greene & Hibbard, 2012). There has been little work to date on how patient activation many influence self-management behaviours in ESRD.

Other drivers of self-management behaviours may include mood. There have been documented links in ESRD between depression and adherence in both chronic illness generally, and ESRD specifically (DiMatteo, Lepper, & Croghan, 2000), while there have been mixed findings on the relationship between depression and survival in the ESRD population (Gee, Howe, & Kimmel, 2005). Social support is also predictive of mortality in ESRD, and may play a role in the relationship between depression and mortality (Plantinga et al., 2010). It is known that depression and anxiety are highly correlated, and there is a case that the two factors are related to an underlying concept of ‘psychological distress’ (Norton et al., 2013).

While there have been prior studies in ESRD examining mood and adherence, and self-efficacy and adherence, no work has looked at a wide range of self-management behaviours in relation to those combined factors. The results presented here are baseline results from a longitudinal study into self-management in patients receiving in-centre haemodialysis for ESRD (the SELFMADE Study). A number of psychological factors described above were studied, in addition to the BHDS to measure self-management behaviours. In this chapter, the question of which psychological factors predict self-management behaviour will be explored.

6.2 Methods

6.2.1 Design and procedure

Data were obtained for 104 people on maintenance haemodialysis for ESRD across three sites in Hertfordshire, UK. Questionnaires were administered while participants were dialysing, a method that has been shown to produce comparable results for depression screening to off-dialysis assessment (Chilcot, Wellsted, & Farrington, 2008). Data for clinical parameters was extracted from the local hospital database. The study was approved by Cambridge South Research Ethics Committee. All participants gave informed consent for participation in the study.

6.2.2 Setting

Questionnaires were administered at sites 1, 2 and 3 in East & North Hertfordshire NHS Trust. For more information, see “Setting” in chapter 4.

6.2.3 Participants

Eligible patients were approached across three dialysis centres in Hertfordshire. The sample consisted of the first consecutive 104 patients to consent, although a roughly proportional number of participants were approached relative to the size of the unit. All participants were adults, as care and life responsibilities are more likely to be undertaken by the family in paediatric haemodialysis, and these skills will be learned as they transition to adult services (Watson & Warady, 2011). All participants were able to speak at least basic English, as some questionnaires were unavailable in translated forms, and translation was beyond the scope of this study. Participants had at least 3 months of experience of life on dialysis, so that they had some experience of the situations described in the self-management questionnaire. While comorbidity was not an excluding factor (as comorbidity is present in the majority of people with ESRD, and exclusion would result in an unrepresentative sample), people due to receive a transplant or with very poor prognosis were excluded, due to the longitudinal nature of the study. Comorbidity status was recorded to be included as a confounding variable.

The following data were collected for each patient: age, sex, dialysis vintage, residual native kidney function (as interdialytic urea clearance – KRU), Charlson Comorbidity Index (Charlson, Szatrowski, Peterson, and Jones 1994), dry weight , and interdialytic weight gain (IDWG) and pre-dialysis plasma phosphate level, as markers of patient adherence to aspects of their treatment.

6.2.4 Materials

All potential participants were provided with an information sheet and an explanation of the study by a member of the research team. Those electing to participate were asked to provide signed consent, and provided with a pack of questionnaires. Questionnaires used included:

- PHQ-9, a tool to screen for depression, based on DSM criteria for major depression (Kroenke et al., 2001).
- GAD-7, a tool to screen for anxiety, based on DSM criteria for general anxiety disorder (Spitzer & Kroenke, 2006).
- The Self-Efficacy in Chronic Disease 6 item scale (SECD-6), a tool developed by Kate Lorig and colleagues to assess general self-efficacy in chronic disease (Lorig et al., 1996).
- The Patient Activation Measure 13 item scale (PAM-13), a scale derived from the Transtheoretical model of behaviour change, assessing how important a patient views their role in their own treatment, and their confidence in this regard (Hibbard, Mahoney, Stockard, & Tusler, 2005).(Hibbard et al., 2005).
- The Brief Illness Perception Questionnaire (B-IPQ), a short version of the illness perceptions questionnaires developed by Weinman et al. (Broadbent, Petrie, Main, & Weinman, 2006). It assesses illness cognitions relating to Leventhal's self-regulatory model of illness beliefs (Leventhal, Leventhal, & Contrada, 1998). While each domain of illness perceptions can be included in analyses as separate parameters, a summary score was used here in accordance with advice in the paper by Broadbent et al. due to the number of other variables being assessed.
- The EQ5D, a short 5 item inventory assessing health related quality of life (Rabin & de Charro, 2001). An additional sixth question uses a visual analogue scale to assess overall perceived health.
- The Brief Dialysis Symptoms questionnaire was created for this study, based on clinical judgement regarding common symptoms experienced by people on HD. The questionnaire asks whether an individual experienced each of 16 of the most common symptoms for people undergoing HD for ESRD. They are then asked, if they did experience the symptom, how much it bothered them, on a likert scale from 1

"Not at all" to 5 "Very much". Results were coded by scoring a 0 if the symptom was not present, and 1-5 if it was present, based on how much it bothered the participant.

6.2.5 Statistical analysis

Means and standard deviations were used to describe the participants, including a breakdown by dialysis unit. Pearson correlation matrices were constructed to analyse the basic relationships between variables. Based on these matrices and prior theory, hierarchical linear regression models were constructed. Variables were entered in an *a priori* theoretically driven fashion to avoid the problems of inappropriate variable selection by automatic methods such as forward and backwards stepwise regression (Thompson, 1995). Regression models were checked for compliance with assumptions using visual methods including kernel density and QQ plots. Multicollinearity was checked using Variance Inflation Factor (VIF). All models were found to be within acceptable parameters, and all predictors had a VIF of < 2 (Belsley, Kuh, & Welsch, 2004). All statistical analyses were conducted in STATA 11 (StataCorp, 2009).

Relationships between variables included in these regression models were further investigated using mediation analysis. The Sobel-Goodman method was used to investigate the size and statistical significance of the indirect effect between variables (Sobel, 1982). This was followed by using the Preacher-Hayes method for estimating confidence intervals using bootstrap resampling (Preacher & Hayes, 2004).

See chapter 4 for more details on hierarchical regression, mediation and bootstrap resampling.

6.3 Results

6.3.1 Descriptive statistics

The demographic properties of the patients in the sample are shown in table 1. The mean age of the sample was 63.6 (SD = 15.3), which is roughly in line with the UK national average age of 66 for people on HD (Renal Association, 2013). The majority of the sample was male (66.3%), which is typical of UK haemodialysis populations. The majority of participants came from the two largest dialysis units (Centre 1= 51, Centre 2 = 35), with the fewest coming from the smallest unit (Centre 3 = 18). Clinical variables were all within expected boundaries.

Summary statistics for psychological variables are also displayed in table 6.1. Patient activation was used as a continuous scale for the purposes of subsequent analysis, but for reference, the values for each cut-off point were; 37 participants in the pre-contemplation phase, 20 in contemplation, 27 in action, and 19 in maintenance.

Table 6.1: Descriptive statistics for participants

Variable				
Age (years; mean, SD)	63.6 (15.3%)			
Male *n*(%)	69 (66.3%)			
Female *n*(%)	35 (32.7%)			
Centre 1 *n*(%)	51 (51%)			
Centre 2 n(%)	35 (31.7%)			
Centre 3 n(%)	18 (19.2%)			

Variable	Mean	Std. Dev.	Min	Max
Self-report scales				
Self-efficacy (SECD-6)	6.9	2.0	2.5	10
Patient Activation (PAM-13)	55.1	12.7	32.2	100
Illness Perception (B-IPQ)	49.3	10.4	15	70
Depression (PHQ-9)	7.3	5.8	0	27
Anxiety (GAD-7)	4.5	4.9	0	21
Self-management scale				
SM suggestions to providers	4.1	1.5	2	11
SM haemodialysis	15.9	5.4	7	41
SM Information seeking	5.0	2.0	2	12
SM alternative therapies	2.1	0.7	0	6
SM symptom management	7.9	3.0	0	17
SM assertive self-advocacy	4.0	1.7	0	12
SM suggesting improvements	3.5	1.3	0	9
Clinical variables				
Dry weight (kg)	73.3	14.8	50.3	113.8
Charlson Comorbidity Index	4.2	3.0	0	15
IDWG (kg)	1.4	0.8	0.4	3.83
Phosphate (mmol/l)	1.7	0.4	0.7	3.35

	Mean	SD	Median	IQR
KRU (ml/min/1.73^2)	0.90	1.32	0.01	0.01 – 1.47

Note: IDWG = interdialytic weight gain, KRU = residual renal urea clearance

6.3.2 Correlations between psychological variables

Correlations for psychological variables are presented in table 6.2. Significance for all correlations was determined after applying Bonferroni correction for multiple comparisons.

There was a significant association between self-management and depression ($r = 0.33$, $p < 0.05$), and self-management and anxiety ($r = 0.36$, $p < 0.01$). However, these associations are positive; that is, the higher the screening score for depression or anxiety, the higher the level of self-reported self-management behaviours. This was further examined in tables 6.3 and 6.4 (see later). Table 6.2 shows no basic correlations between self-efficacy and self-management ($r = -0.13$, $p > 0.05$), or patient activation and self-management ($r = 0.14$, $p > 0.05$).

Self-reported health status, as measured by the EQ5D, was significantly positively related to self-efficacy ($r = 0.54$, $p < 0.001$), and negatively related to depression ($r = -0.40$, $p < 0.001$) and anxiety ($r = -0.35$, $p < 0.01$). Self-efficacy was negatively correlated with depression ($r = -0.56$, $p < 0.001$) and anxiety ($r = -0.50$, $p < 0.001$) – the higher a person's self-efficacy, the less likely they were to be depressed or anxious. Self-efficacy was also negatively related to illness perceptions ($r = -0.32$, $p < 0.05$).

Symptoms were significantly positively related to depression ($r = 0.62$, $p < 0.001$) and anxiety ($r = 0.53$, $p < 0.001$). The more symptoms bothered the individual, the more likely they were to be depressed and anxious. Symptoms were also negatively correlated with self-efficacy ($r = -0.50$, $p < 0.001$), but positively correlated with self-management behaviours ($r = 0.40$, $p < 0.001$). The more bothersome symptoms were present, the less confident an individual felt in managing their condition, but the more they reported doing to manage it.

Table 6.2: Zero order correlations between psychological variables, self-management behaviours, and symptoms

Correlation	1	2	3	4	5	6	7
1 BHDS							
2 EQ5D	-0.18						
3 Self-efficacy	-0.13	0.54***					
4 IPQ-R	-0.32*	-0.28	-0.32*				
5 PAM-13	0.14	0.27	0.41***	0.02			
6 PHQ-9	0.33**	-0.40***	-0.56***	0.36**	-0.2		
7 GAD-7	0.36**	-0.35**	-0.50***	0.33*	-0.32*	0.73***	
8 Symptoms	0.4***	-0.24	-0.50***	0.2	-0.15	0.62***	0.53***

Breaking the relationships between depression and self-management subscales down, it appears that depression was significantly positively related to information seeking (*r* = 0.36, *p* < 0.01), assertive self-advocacy (*r* = 0.33, *p* < 0.05), and impression management (*r* = 0.41, *p* < 0.001). These subscales have been described in previous work ‘defensive’ subscales, which may represent unhealthy attempts to manage one’s illness alone, or possibly due to a lack of trust in healthcare professionals (Curtin et al., 2004).

Table 6.3: Zero order correlations between depression and self-management behaviour subscales

Correlation	1	2	3	4	5	6	7	8
1 PHQ-9								
2 SM suggestion	0.24							
3 SM HD	0.08	0.10						
4 SM Info	0.36**	0.22	0.21					
5 SM alt	0.06	0.26	0.09	0.08				
6 SM Select	0.28	0.28	0.20	0.29	0.36**			
7 SM Advocacy	0.33*	0.40*	0.28	0.37**	0.02	0.33*		
8 SM Imp	0.41***	0.40***	0.06	0.30*	0.15	0.27	0.33*	

Note: Items 2 to 8 are subscales of the self-management behaviour subscales. These are: 2 Suggestions to providers, 3 Haemodialysis related activities, 4 Information seeking, 5 Alternative therapies, 6 Selective symptom reporting, 7 Assertive self-advocacy, and 8 Impression management

Given the apparent distinction between different styles of self-management behaviours identified by Curtin et al. (2004), two composite subscales were created; defensive self-management and cooperative self-management. Defensive self-management was the mean of selective symptom reporting, assertive self-advocacy, and impression management (mean = 4.18, SD = 1.24). Cooperative self-management was the mean of suggestions to providers, haemodialysis behaviours, use of alternative medicine, and selective symptom management (mean = 7.50, SD = 1.84).

Table 6.4: Zero order correlations between psychological variables and defensive self-management

Correlation	1	2	3	4	5
1 Defensive self-management					
2 Self-efficacy	-0.30*				
3 B-IPQ	0.29*	-0.32*			
4 PAM-13	-0.19	0.41***	0.02		
5 PHQ-9	0.49***	-0.56***	0.36**	-0.20	
6 GAD-7	0.46***	-0.50***	0.33*	-0.32*	0.73***

Correlation matrices were re-run with these new subscales and psychosocial variables, shown in table 6.4. Cooperative self-management did not correlate with any of these variables, and so was not investigated further in this analysis. However, defensive self-management correlated with self-efficacy, illness perceptions, depression, and anxiety.

6.3.3 Regressing psychological variables on self-management behaviours

Hierarchical linear regression was used to model the relationship between self-management, psychological distress, patient activation, and self-efficacy. Age, sex, residual kidney function, dry weight, and comorbidity were included in the baseline model as control covariates. Several models were constructed. As the PHQ-9 and GAD-7 were significantly correlated with self-management, and we would theoretically expect them to be related to self-management, these were included in the model first. Despite finding no basic correlations, we would theoretically expect self-efficacy and patient activation to be related to self-management, and so these were included next to check for interactions with psychological distress. The steps in creating the final model are shown in table 6.5.

The baseline model explained 20.1% of the variance in self-reported self-management behaviours. This model was statistically significant. In the second step, depression measured by the PHQ-9 was added, explaining an additional 3.5% of the variance (*F change* = 4.47*, p* = 0.037). For the final step, patient activation was added, explaining an additional 3.3% of the variance (*F change* = 5.38*, p* = 0.022). The final model explained 27.9% of the variation in self-management behaviour scores.

Table 6.5: Regression model predicting variation in self-management behaviours

Model 1	R^2 = 0.201 F = 4.91(5,98) P < 0.001	
	β	**p**
Age	-0.007	0.005
Sex	-0.138	0.051
KRU	-0.42	0.088
Dry weight	-0.001	0.735
Comorbidity	0.005	0.673
Model 2 (+ PHQ-9)	β = 0.015 R^2 = 0.236 F = 4.99(6,97) p < 0.001 F change = 4.47(1,97) p = 0.037	
Model 3 (+ PAM-13)	β = 0.016 R^2 = 0.279 F = 5.20(,94) p < 0.001 F change = 5.38(1,94) p = 0.022	

Anxiety was included as a step after depression in an exploratory model, but did not explain any additional variance. This is not surprising, as depression and anxiety are highly correlated in the observed data (table 6.2), and as we would expect from the background literature (Norton et al., 2013). Self-efficacy did not make any significant contribution to the model over depression, and so was not included in the final model. As previously noted, depression and anxiety were highly correlated, and results that held true for depression also held true for anxiety. For the purpose of the following regression and mediation analysis, depression was used as a single marker of general psychological distress.

A hierarchical regression model including the same covariates in table 6.5 was constructed, this time predicting the variation in the defensive self-management composite subscale. Self-efficacy, depression, and illness perceptions were then added to the model in individual steps. The results are presented in table 6.6. Self-efficacy and depression both significantly improved the model, but illness perceptions did not. Changing the order in which predictors were added, beginning with illness perceptions, resulted in illness perceptions and depression significantly improving the model while self-efficacy did not, implying self-efficacy and illness perceptions account for a similar portion of the variance in defensive self-management scores.

Table 6.6: Hierarchical regression with self-efficacy and depression predicting defensive self-management

Model 1	R^2 = 0.082 F = 1.70(5,96) P = 0.141	
	β	**p**
Age	-0.171	0.055
Sex	-0.112	0.657
KRU	0.123	0.888
Dry weight	0.008	0.339
Comorbidity	-0.21	0.647
Model 2 (+ self-efficacy)	β = 0.167 R^2 = 0.163 F = 3.08(6,95) p = 0.009 F change = 9.23(1,95) p = 0.003	
Model 3 (+ PHQ-9)	β = 0.059 R^2 = 0.215 F = 3.69(7,94) p = 0.002 F change = 6.301(1,94) p = 0.014	

6.3.4 Mediation analysis

As self-efficacy explains a greater portion of the variance in defensive self-management scores, and is of particular theoretical interest in self-management, mediation analysis was conducted on the relationship between self-efficacy, depression, and defensive self-management scores.

The Sobel-Goodman method was used. Self-efficacy was entered as the predictor, defensive self-management behaviours entered as the dependent variable, and depression entered as the mediator. Significant relationships were found between self-efficacy and self-management, self-efficacy and depression, and depression and self-management. The indirect effect was found to be significant. This was confirmed using bootstrapping based on 1000 resamples.

Defensive self-management behaviours were regressed on self-efficacy (path c). This model was significant $F(1, 103) = 9.86$, $p < 0.01$. Next, depression was regressed on self-efficacy (path a). This model was significant $F(1, 103) = 46.9$, $p < 0.001$. Defensive self-management behaviour was regressed on depression and self-efficacy (paths b and c'). The model was significant $F(2, 102) = 15.12$, $p < 0.001$. Using the Sobel-Goodman test, the indirect effect was significant (coefficient = -0.15, $p < 0.001$). Bootstrapping using 1000 resamples was used to obtain confidence intervals for the indirect effect (coefficient = 0.15, standard error = 0.05, 95% confidence intervals -0.25 to -0.05).

In order to test for an inverse relationship between self-efficacy and depression, the same analysis was conducted post-hoc, with depression as the predictor and self-efficacy as the mediator. Here the indirect effect was not significant. From this cross section of data, it appears that depression mediates the relationship between self-efficacy and defensive self-management behaviour, but that the reverse is not true.

6.4 Discussion

The aim of the study was to explore which psychological factors predict self-management behaviours in people on in centre-haemodialysis for ESRD.

6.4.1 Depression, anxiety, and psychological distress

In the observed data from this study, depression and anxiety were highly correlated. Furthermore, in almost every case, depression and anxiety produced highly similar results in every analysis they were included in. For this reason, depression and anxiety will be referred to as 'psychological distress' unless a finding is relevant to one variable but not the other.

6.4.2 Relationships between psychological variables

Correlation of an array of psychological variables revealed some interesting relationships. Self-efficacy was highly positively related to health status as measured by the EQ5D; people who were more confident at managing their condition had better health status. Further, health status and psychological distress were inversely related; people with worse health status were more likely to be depressed and anxious.

6.4.3 Relationship between psychological variables and self-management

For univariate correlations, only psychological distress was related to self-reported self-management behaviour. This concurs with previous literature from other diseases. For example, in a review of self-reported self-management behaviours in Coronary Heart Disease, psychological distress was related to performance of fewer self-management behaviours (such as breathing techniques, use of and incentive spirometer, and physical exercises) at home following bypass graft surgery (Fredericks, Lapum, & Lo, 2012).

The findings regarding relationships between self-management behaviours and psychological variables were surprising for two reasons. First, neither self-efficacy nor patient activation were related to self-management behaviours in the basic analysis. A host of prior empirical work links these factors to self-management behaviours, and so they were added to the regression analysis after psychological variables.

The second surprising finding was that psychological distress was *positively* correlated with self-management behaviours. That is, the higher the score on distress screening tools, the higher the number of self-reported self-management behaviours. The summed total of the self-management scale is a representation of how much a person is 'doing for themselves', but certain subscales are known to relate to different 'styles' of self-management (Curtin et al., 2004). By breaking the scale down into its component subscale totals (table 6.3) and relating these back to depression, it emerges that only the subscales relating to defensive behaviours are significantly related to depression.

Depression and patient activation emerge as predictors when modelling self-management scores using hierarchical regression. This remains true after controlling for common confounders in this patient group in the first step of the model: age, sex, residual kidney function, dry weight, and comorbidity. Anxiety did not significantly add explanatory power to the model, but the exact same steps were repeated with anxiety instead of depression, yielding almost identical results. This is not surprising given how strongly correlated depression and anxiety are in the literature and in the observed data here (Burns & Eidelson, 1998).

When breaking self-management down into its two component subscales of cooperative and defensive behaviours, it appears that self-efficacy and depression predict defensive, but not cooperative self-management. These predict defensive self-management scores even after controlling for known confounding variables. A mediation analysis suggested that, furthermore, depression mediates the relationship between self-efficacy and self-management behaviours. Given that many interventions to alter self-management and patient involvement hinge on self-efficacy, this analysis suggests that the presence of depressive symptoms may play a key role in the success or failure of those interventions. Therefore, treating depression may be a key first, or concurrent, step in modifying self-management behaviours, in addition to fostering self-efficacy.

The fact that the greater the self-efficacy, the less severe the perceptions of the illness, warrants further exploration, as there is a debate as to whether it makes theoretical sense to sum the domains of illness perceptions into a single summary score, given how distinct the domains of the scale are (Broadbent et al., 2006). Often perceiving an illness as more severe may simply mean that the individual is aware of the reality regarding the severity of their condition, and may be considered adaptive rather than maladaptive (Hurt et al., 2014). However, an in depth analysis of illness perceptions goes beyond the scope of this dissertation. Given the relationship between illness perceptions and mortality, this could produce interesting avenues for development of future interventions.

6.4.4 Relationship between bothersome symptoms and self-management

Interesting zero order correlations for symptoms emerged. Symptoms were measured by asking how many symptoms individuals experienced, and how much they bothered them. This proved to be positively correlated with psychological distress. This relationship is unsurprising, as individuals who are distressed are more likely to hold negative perceptions (Detweiler-Bedell, Friedman, Leventhal, Miller, & Leventhal, 2008). Additionally, worse symptoms may also be the cause of psychological distress. This relationship has been demonstrated in a number of studies in which reduction in somatic symptoms was associated with reduced psychological distress, including when there was no change in physiologic measures of illness (Katon, Lin, & Kroenke, 2007).

The more numerous and bothersome the perceived symptoms, the lower an individual's self-efficacy, while self-reported self-management behaviours were more numerous and frequent. This means that individuals reporting worse symptoms reported that they *felt* less confident in dealing with their illness, while reporting that they *did* more to manage it. It may be that those who are experiencing bothersome symptoms, and are engaging in proactive self-management strategies without symptom reduction, feel that they have less control over their condition and those symptoms.

Awareness of the impact of these different domains of self-management, and how they may variably affect confidence and behaviour, may be of particular importance when deciding what to measure in future research, and when designing interventions.

6.4.5 Strengths and limitations

Although the mediation model is highly suggestive of causation, the use of a cross sectional design means that it is not possible to reliably infer causation from the observed data. It is therefore not clear whether psychological distress prompts defensive self-management behaviours, or whether defensive self-management behaviours increase the likelihood of distress. This study did not investigate the role of social support, but future work could investigate the relationship between defensive self-management behaviours, psychological distress, and social isolation, which may be another mediator in this relationship, alongside patient activation.

Strengths of the research include a robust sample size, a sample that is representative of the wider UK renal population in terms of screening scores for psychological distress, and the examination of a novel combination of psychological factors in relation to a broad range of self-management behaviours.

6.4.6 Conclusion

Psychological distress, self-efficacy, and patient activation are associated with self-management behaviours in people with End Stage Renal Disease. These results support and go beyond previous findings that there may be different 'styles' of self-management, and that defensive 'do it all by oneself' self-management behaviours may be associated with psychological distress, a trait not shared by people who engage in cooperative self-management behaviours. Furthermore, self-efficacy predicts defensive self-management, and depression may mediate this relationship. If so, this has important implications for how interventions to modify self-management behaviour are conducted.

This chapter has explored how psychological variables predict self-management behaviour in this sample. The next chapter will examine the impact of self-management behaviours on clinical outcomes. An investigation of the relationship between self-management behaviour and associated psychological variables on clinical status and survival over time is presented in the next chapter.

Chapter 7: Longitudinal study of self-management behaviour and clinical status over time

7.1 Introduction

Findings presented so far have demonstrated that the concept of what constitutes ‘good’ self-management varies between healthcare professionals (HCPs) and patients. They have also shown that defensive self-management behaviours such as selective reporting of symptoms and assertive self-advocacy are associated with higher levels of psychological distress, and lower self-efficacy. Evidence has also supported the hypothesis that there are two subtypes of self-management behaviour; cooperative and defensive, and that these may have different relationships with emotional status.

The present chapter presents a novel analysis of the relationships between self-management behaviours, psychosocial status, and adherence as indicated by IDWG and phosphate. An analysis of the relationship between self-management and survival among people on haemodialysis will also be undertaken. This will be investigated using data captured at three time points (baseline, 9 months, and 18 months follow-up) from people on in-centre haemodialysis in the UK. It is hypothesised that self-management behaviours will predict changes in clinical status over time, as well as predicting survival.

7.1.1 Background

Compared to cross-sectional work, theoretically driven longitudinal studies into self-management have been comparatively rare. There is often a paucity of data on which to base hypotheses about change over time, but this makes collecting this data especially important. Hypotheses used to guide the analysis presented here were developed based on findings presented in chapter 6, and the background literature, some of which is covered in overview in chapters 2 and 3. A summary of relevant prior work is presented below.

7.1.2 Changes in patient activation, self-efficacy, and self-management behaviour over time

Most analyses of patient activation have been cross sectional, despite being framed as a useful tool for affecting behaviour prospectively in clinical practice (NHS England, 2013). In the work that has been conducted among chronic disease populations, it has generally been found to be fairly stable when no intervention is present. For example, in a group of 287 people with diabetes in the USA, patient activation did not change over 6 months where no intervention was present, although activation was associated with self-management behaviours like foot checking, eye examinations, and exercise (Rask et al., 2009). In another study with participants without chronic illness, changes in activation were associated with a change in health behaviours like exercise and eating breakfast (Harvey, Fowles, Xi, & Terry, 2012). As discussed in previous chapters, given cross sectional associations between activation and self-management behaviour (e.g. Smith, Pandit, Rush, Wolf, & Simon, 2014; Alegría, Sribney, Perez, Laderman, & Keefe, 2009), we may expect in the present study that if activation changes over time, so too will self-management behaviour. We may expect activation to change over time in an ESRD population, as this is what has happened over the course of the limited longitudinal observational work on the PAM in this population (NHS Kidney Care, 2013).

As addressed in chapter 6, self-efficacy is associated with self-management behaviour in multivariate models. They have also been shown to be correlated in previous studies when measured concurrently among people with CKD (Curtin et al., 2008). Studies among people with ESRD that have looked at self-efficacy over time have mostly been small, self-efficacy based intervention studies looking at clinical markers of adherence. For example, in a 12 week self-efficacy intervention versus control group study, self-efficacy increased in the active group and was associated with reductions in IDWG (Tsay, 2003). In another study, self-efficacy increased over the course of the study, and was associated with a small decrease in serum creatinine levels while GFR remained relatively stable (Lin, Tsai, et al., 2013). Given the focus on enhancing self-efficacy used in these interventions, it may be that it is the change in self-efficacy that affects the change in self-management – although Social Cognitive Theory (SCT) would argue that this is a reciprocal relationship. An improvement in one domain will affect change in the other.

7.1.3 Relationship between self-management behaviour and clinical status or adherence

Self-management as a set of behaviours can be difficult to disentangle from adherence as a single concept, and the two ideas are often conflated (see chapters 2 and 3 for discussion of this topic). While adhering to prescribed treatment may well be considered self-management behaviour, it is a very narrow aspect of it. The self-management scale from Curtin et al. (2004) was specifically chosen for this study as it represents broader topics in self-management, such as information seeking and patient-provider communication, while not asking about adherence. This means that broader self-management could be teased apart from clinical markers of adherence, in this case IDWG and phosphate.

In a previously described study, self-management behaviour did not change over time, but serum creatinine did (Lin, Tsai, et al., 2013). It may be that the specific behaviours that were asked about did not adequately capture lifestyle changes that were produced as a result of modifying self-efficacy.

There is some suggestion for example, that health related information seeking is related to adherence – but the relationship is not always a positive correlation. In the USA, a large national study found that information seeking was associated with attending breast, cervical and colorectal screenings on schedule (Shneyderman et al., 2015). Similarly, information seeking in Inflammatory Bowel Disease (IBD) predicted medication adherence (Pittet et al., 2014). In a more nuanced look at the topic, Carter and colleagues (2013) looked at different types of medication information seeking in people using multiple medicines. They found that patients seeking information from autonomous sources (such as looking something up on the internet) were more likely to be non-adherent than those who did not. Whether or not patients sought information from healthcare professionals was unrelated to adherence.

Engagement in shared decision making can also be regarded as a self-management behaviour. In a study of shared decision making in type-2 diabetes, no relationship was found between shared decision making and health outcomes, although the authors attribute this to statistical power (Branda et al., 2013).

7.1.4 Self-management and survival

The relationship between self-management behaviours as a broad measure and survival has not been looked at in detail in ESRD. When considering adherence, it is often taken for granted that adhering to a prescribed treatment will alter clinical status and mortality risk. It is known, for example, that high IDWG, hyperphosphetamia and skipping dialysis sessions is associated with increased risk of mortality (Saran et al., 2003). However, while hyperphosphatemia is a known risk factor for cardiovascular events and all-cause mortality, successfully adhering to dietary changes and use of phosphate binders does not necessarily modify that risk (Covic & Rastogi, 2013).

Outside of CKD, there is some mixed evidence about whether or not self-efficacy can predict survival. Two recent studies asked whether self-efficacy can predict survival in older, not necessarily ill, adults. One found that the 12-item version of the General Self-efficacy Scale predicted decline in physical function in this population, but not mortality (Hoogendijk et al., 2014). Another found that ‘sense of control’ (a concept related to self-efficacy) did predict 5 year mortality (Chipperfield et al., 2012). However, self-efficacy for managing disease is not only a specific domain, but also involves specific tasks to mitigate specific disease risks, so extrapolating from a generally well population may not be so useful. A five year study in COPD found that self-efficacy predicted mortality.

However, when Forced Expiratory Volume (FEV, a measure of lung function) was included as a covariate, self-efficacy's contribution to the model became insignificant.

There is little data on whether patient activation is associated with mortality. In a meta-analysis of patient activation-based intervention studies for people with type-2 diabetes, Bolen et al. (2014) found low evidence for such interventions to have any impact on mortality.

As higher IDWG is known to be a risk factor for mortality, and that improving self-efficacy and self-management behaviour can reduce IDWG (Saran et al., 2003), it is therefore theoretically plausible that direct measurement of self-management behaviour may allow prospective modification of mortality risk. It is unclear whether self-efficacy and patient activation should predict survival. If they did, we might expect this to be a result of changes in self-management behaviour. It may be that, once again, there are different approaches to shared decision making, or that a match between patient preferences and the service provided is important. Among psychiatric patients, it was recently found that treatment adherence was greatest when patient preference for their level of involvement was congruent with the type of participation they actually achieved, regardless of whether this was a high or low level of involvement (De las Cuevas, Peñate, & de Rivera, 2014).

We might reasonably expect clinical status reflecting adherence to be associated with self-management scores. It is worth noting however, that often the picture is more nuanced, and there are often different types of self-management and patient engagement.

7.1.5 Hypotheses

Based on the literature discussed above, and findings from chapter 6, two hypotheses were generated to guide the following analysis:

1. Self-management behaviour, patient activation, self-efficacy, and depression symptoms will significantly contribute to models predicting clinical status over the whole 18 months, after time and other covariates have been controlled for
2. Self-management behaviour, patient activation, self-efficacy, and depression symptoms will predict survival over follow-up

7.2 Methods

7.2.1 Participants

Data were taken from following up participants described in chapter 6 over 18 months. This includes baseline data (some of which is described in chapter 6), 9 month follow-up, and 18 month follow-up.

Eligible patients were approached across three dialysis centres in Hertfordshire. The sample consisted of the first consecutive 104 patients to consent, although a roughly proportional number of participants were approached relative to the size of the unit. All participants were adults, as care and life responsibilities are more likely to be undertaken by the family in paediatric haemodialysis, and these skills will be learned as they transition to adult services (Watson & Warady, 2011). All participants were able to speak at least basic English, as some questionnaires were unavailable in translated forms, and translation was beyond the scope of this study. Participants had at least 3 months of experience of life on dialysis, so that they had some experience of the situations described in the self-management questionnaire. While comorbidity was not an excluding factor (as comorbidity is present in the majority of people with ESRD, and exclusion would result in an unrepresentative sample), people due to receive a transplant or with very poor prognosis were excluded, due to the longitudinal nature of the study. Comorbidity status was recorded to be included as a confounding variable.

7.2.2 Questionnaires

As described in chapter 4 (methods), questionnaire data were collected in the dialysis units, while participants were dialysing. Questionnaires included the self-management behaviours on dialysis questionnaire, PHQ-9, self-efficacy in chronic disease 6 item questionnaire, and the Patient Activation Measure 13 (PAM-13). The BHDS, PHQ-9, and, self-efficacy in chronic disease scale were administered at baseline, 9 months, and 18 months. Participant feedback during baseline data collection indicated that questionnaire packs were considered overly lengthy. In order to reduce participant burden during 9 month follow-up, the PHQ-9 and PAM-13 were omitted from questionnaire packs, reducing the total number of items to be completed. All questionnaires were administered at 18 month follow-up to allow pre-post comparisons over the whole 18 months.

7.2.3 Clinical status

Information on clinical status was collected from routine measures recorded on the RenalPlus database, accessed at Lister Hospital, Stevenage. In addition to residual kidney function (KRU) and Charlson comorbidity score, used as covariates in chapter 6, data were collected on latest interdialytic weight gain (IDWG) value in kilograms, latest serum phosphate in mmol/l, and three month averages for both. While latest scores give a more immediate picture of how a participant is doing clinically closest to the time they are filling in a questionnaire, IDWG can vary substantially from one dialysis session to the next. Including 3 month averages in addition to latest values allows analyses of how a patient is managing their fluid in general. IDWG was also converted to IDWG as a proportion of dry weight ([IDWG in kilograms ÷ dry weight] x 100), to account for higher expected IDWG for heavier participants.

7.2.4 Statistical methods

A brief overview of logistic regression, mixed modelling, and survival analysis is provided in chapter 4 (methods).

Basic exploration of data was conducted using Pearson's correlation, t-tests, and McNemar tests of proportions. Modelling was conducted using a combination of multilevel modelling, logistic regression, Kaplan-Meier and Cox proportional hazard analyses. A brief outline of these modelling methods follows; for more detail, see 4.10 Statistical analysis.

Multilevel models (MLMs) are regression models that take into account 'nested' structures in data, where observations (level 1 variables) are expected to be correlated based on common groupings (level 2 variables). In the following analysis, participant level observations at a given time point such as IDWG or self-management behaviour score are treated as level 1 variables. These are nested within participant, the level 2 variable. In practice this allows for correlation within participants (intraclass correlation or ICC) over repeated measures to be quantified and controlled for. As observations were collected from three different locations, research site was also tested as a third level variable and ICC assessed. All predictor variables were grand mean centered where appropriate, as discussed in each model. Time as a predictor was not grand mean centered, but instead left untransformed.

Logistic regression is a form of regression that is capable of handling a binary response variable, using either continuous or dummy coded categorical predictors. Here it was used to assess whether observations that were 'missing' or 'non-missing' for questionnaire items at 18 month follow up appeared to be due to systematic variation in observed demographic, clinical and psychological variables.

Survival analysis methods allow investigation of 'time to event' data. The event of interest in this analysis was mortality. Kaplan Meier survival curves were used to visualise cumulative survival over time for different groups, with participants stratified into one of two groups based on their baseline score for variables of interest. Log rank tests were used to test for differences between these basic groupings. While these analyses cannot handle covariates such as age or comorbidity, they were used to explore basic effects between potential predictors and survival. In order to further investigate observed group differences, Cox Hazard Proportion regression was used. Cox regression allows 'hazard' (chance of the event of interest occurring) to be regressed on multiple continuous and categorical predictors. This allows for controlling of covariates, and a more robust analysis of the contribution of predictors of interest after controlling for covariates.

7.3. Results

The results will begin with an overview of univariate change over time for IDWG, phosphate, self-management, self-efficacy, patient activation, and depressive scores. To address hypothesis 1 (predicting IDWG and phosphate over time), the relationships between these variables will be modelled. Hypothesis 2 (predicting survival) will then be addressed.

7.3.1 Univariate change over time

Change over time can be seen in table 7.1. IDWG, mean self-management, cooperative self-management, and defensive self-management remained mostly stable across the three time points over 18 months. Self-efficacy decreased from the start (*m* = 6.90, *SD* = 2.04) to the end of the study (*m* = 6.53, *SD* = 2.02), but this change was not significant (paired samples t-test, *t* = 0.91, *df* = 35, *p* = 0.37). Depression decreased from the start (*m* = 7.1, *SD* = 5.82) to the end of the study (*m* = 5.68, *SD* = 5.31), but this was also non-significant (paired samples t-test, *t* = 1.58, *df* = 33, *p* = 0.12). Patient activation increased from the start (*m* = 52.09, *SD* = 13.64) to the end of the study (*m* = 60.71, *SD* = 14.57), and this increase was significant (*t* = 3.02, *df* = 37, *p* < 0.01). Phosphate decreased from the start of the study (*m* = 1.71 m/mol, *SD* = 0.42) to the end of the study (*m* = 1.60 m/mol, *SD* = 0.40), and this result was significant (paired samples t-test, *t* =3.70, *df* = 157, *p* < 0.001).

Table 7.1 Descriptive statistics for clinical, behavioural and psychosocial variables over time

	Baseline		9 month follow-up		18 month follow-up	
	N	Mean(SD)	N	Mean(SD)	N	Mean(SD)
IDWG (KG)	103	1.44(0.80)	83	1.43(0.80)	78	1.45(0.77)
Phosphate (m/mol)	104	1.71(0.42)	83	1.71(0.44)	78	1.60(0.40)
Cooperative SM	104	7.50(1.84)	50	7.47(1.49)	38	7.65(1.84)
Defensive SM	104	4.18(1.24)	50	4.08(1.06)	38	4.08(0.85)
Self-efficacy	104	6.90(2.04)	50	6.63(2.02)	36	6.53(2.61)
PAM-13	104	53.54(13.64)	-	-	38	60.71(14.57)
PHQ-9	101	7.46(5.82)	-	-	35	5.6(5.31)

7.3.2 Attrition for self-management observations

At baseline, 104 participants gave consent and filled in all questionnaires. Between baseline and 9 month follow-up, 14 patients died, 8 received transplants, 2 switched from HD to PD, and 1 moved out of the area, totalling 25 patients (remaining n = 81). 50 participants were successfully followed up at 9 months (50 out of 81 = 61%) Between 9 month follow-up and 18 month follow-up, a further 8 patients died, and 6 received transplants, totalling 14 patients (remaining n = 65). Thirty eight participants were successfully followed up at 18 months (38 out of 65 = 58%). Unsuccessful follow-up of participants was most frequently due to changing dialysis shifts, participant holidays, and temporary hospitalisation. This overall attrition rate is similar to another recent study of the PAM (NHS Kidney Care, 2013).

In order to assess whether overall loss to follow-up was systematic, which would preclude further analysis of longitudinal self-management data, a combination of logistic regression and Little's test (Little, 1988) was used. The aim was to assess whether data were Missing Completely At Random (MCAR) or Missing At Random (MAR).

Whether or not data were missing at follow-up for each of the self-management variables was binary coded, 0 (present) or 1 (missing). A series of logistic regression models were conducted, where missing status for each self-management variable in turn was treated as the response variable, and other self-management variables and age, sex, comorbidity and KRU were entered as predictors. None of these six models returned a significant result for any of the predictors, indicating that whether data were missing or not was not systematically related to variables observed in the study.

Additionally, when all variables above, plus IDWG and phosphate, were entered into Little's Test, no relationship between predictors and whether follow-up values were missing or not emerged (Little's MCAR test, $chi^2 = 81.63$, $df = 82$, $p = 0.491$). Based on observed data, data were therefore assumed to be MCAR. This means that based on observed data, there did not appear to be a systematic reason for missing data. Methods of analysis could therefore remain unaffected by missing data, but results should still be interpreted with an awareness of the attrition rate. This rate of attrition is lower than in a study of the PAM in dialysis patients published by NHS Kidney Care (2013), in which of 296 participants at baseline, 72 (24%) completed the PAM at 12 month follow-up.

Table 7.2: Proportion of patients in each stage of patient activation at baseline and 18-month follow-up

Stage of activation	Baseline count (%)	Died	Transplant /transfer	Follow-up count (%)
Pre-contemplation	38 (36.54%)	4	3	4 (10.53%)
Contemplation	20 (19.23%)	2	3	10 (26.32%)
Action	27 (25.96%)	4	0	14 (36.84%)
Maintenance	19 (18.27%)	5	5	10 (26.32%)
Total n	104	15	11	38

It appears that the proportion of participants in each category has moved from the lower stages of activation to higher stages of activation (see table 7.2). For example, 36.84% of participants were in the pre-contemplation stage at baseline versus 12.82% in pre-contemplation at follow-up. By contrast 18.27% were in the advanced maintenance phase at baseline, compared to 25.64% at follow-up. Due to low power, stages 1 and 2 were combined into a 'low activation' group, and stages 3 and 4 combined into a 'high activation group'. Restricting analysis to only the 38 participants responding at both the start and the end of the study, at baseline n = 23 (60.53%) were in the low activation group, and n = 15 (39.47%) were in the high activation group. At 18 month follow-up, n = 10 (26.32%) participants were in the low activation group, and n = 28 (73.68%) were in the high activation group. A McNemar test showed a significant difference in observed versus expected events (McNemar's chi^2 = 8.05, *d.f.* = 1, p < 0.01), suggesting that a significant shift from low activation at the start of the study to high activation at the end of the study.

Hypothesis 1: Self-management behaviour, patient activation, self-efficacy, and depression symptoms will significantly contribute to models predicting clinical status over the whole 18 months, after time and other covariates have been controlled for

7.3.3 Multilevel models and the effect of research site

General background on MLMs is provided in chapter 4, and described briefly in the methods of this chapter.

Two separate MLMs were constructed; one modelling the variation in IDWG, and another modelling variation in phosphate. Both models constructed here included multiple observations (baseline, 9 month, and 18 month follow-up) for each participant, for the response variable (IDWG or phosphate) and predictors (e.g. self-management behaviour). These observations were ‘level 1’ variables. As we would expect observed values for each participant to be more related to each other than to the whole sample, participant ID was the ‘level 2’ variable. That is, data were ‘clustered’ within participant. It is also possible that observations at each research site may be clustered, and that research site may need to be included as a ‘level 3’ variable.

A simple regression analysis was used to test for differences between sites across outcome variables for each model. In each case, no significant differences between sites were found. Each initial model for IDWG and phosphate was run first with research site included as a level 3 variable to allow assessment of the Intraclass Correlation (ICC). These initial models (not shown) resulted in an ICC of <0.0001, and as such was negligible. By contrast, the ICC for participants (level 2) was 0.49. Therefore a 2 level model was used, and an equation setting out the components of the model will be provided in section 7.3.5.

7.3.4 Correlations between IDWG and self-management variables

Table 7.3 shows correlations between IDWG and self-management variables.

Table 7.3 Zero order correlations for clinical, behavioural, and psychosocial variables

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
1. IDWG (baseline)	1										
2. IDWG (9 months)	0.52***	1									
3. IDWG (18 months)	0.69***	0.36**	1								
4. Phosphate (baseline)	0.22***	0.14	0.17	1							
5. Phosphate (9 months)	0.20	0.09	0.19	0.76***	1						
6. Phosphate (18 months)	0.17	-0.01	0.28*	0.67***	0.63***	1					
7. Defensive SM	0.14	-0.10	0.06	0.16	0.24*	0.30**	1				
8. Cooperative SM	0.34***	0.17	0.20	0.24*	0.31**	0.29**	0.44***	1			
9. Self-efficacy	0.16	0.24*	0.10	0.01	-0.7	-0.11	-0.30**	-0.03	1		
10. PAM-13	0.08	0.25*	-0.10	-0.09	-0.07	-0.13	0.03	0.18	0.36***	1	
11. PHQ-9	-0.06	-0.12	0.01	0.13	0.26*	0.21	0.47***	0.23*	-0.56***	-0.21*	1

IDWG at baseline was correlated with mean self-management scores, but not at follow-up. This appears to be due to the cooperative subscale also being correlated with IDWG at baseline, but not follow-up. Defensive self-management was not correlated at any time point. Both self-efficacy and patient activation were correlated with IDWG at 9 months, but not baseline or 18 month follow-up. Baseline depression measured by the PHQ-9 was not correlated with IDWG at any time point.

7.3.5 The relationship between IDWG and self-management

In order to assess the relationship between self-management variables and IDWG over time, mixed models were built. A model with time as the only predictor was the starting point (model 1). Log likelihood change was then assessed in subsequent steps as demographic covariates were added (model 2), followed by self-management behaviours (model 3), then patient activation (model 4), then depression (model 5). Random slopes were added for cooperative and defensive self-management in model 6. In order to improve statistical power when estimating precision around parameter estimates, multiple imputation was used for self-management variables, based on 10 imputations. This only applies to parameter estimates, not log likelihood, as log likelihood cannot normally be calculated when using multiple imputation (Meng & Rubin, 1992). All predictors other than sex (a binary predictor) were grand mean centred to aid in the interpretation of the intercept. The models can be seen in table 7.4.

The equation for the final model (model 6) is as follows:

$$Y_{ij} = \gamma_{00} + [(\gamma_{10} + \mu_{1j})cooperativeSM_{ij}] + [(\gamma_{20} + \mu_{2j})protectiveSM_{ij}] + \gamma_{30}(time_{ij}) + \gamma_{40}(age_{ij}) + \gamma_{50}(sex_{ij}) + \gamma_{60}(comorbidity_{ij}) + \gamma_{70}(kru_{ij}) + \gamma_{80}(pam_{ij}) + \gamma_{90}(phq_{ij}) + \mu_{0j} + r_{ij}$$

Where Y_{ij} is IDWG for each participant for each observation ($_i$) nested within participant ($_j$). γ_{00} is the fixed intercept for the model; that is, the value of IDWG when all predictors are either zero, or at their grand mean (for those that were grand mean centred). γ_{10} is the fixed slope for cooperative self-management, and μ_{1j} is the variance of slopes for each participant around γ_{10}, in other words a measure of whether the relationship between cooperative self-management and IDWG is similar across participants or not. This fixed slope plus between slope variance component is repeated for defensive self-management ($\gamma_{20} + \mu_{2j}$). The following coefficients, $\gamma_{30}(time_{ij})$ to $\gamma_{90}(phq_{ij})$ are the fixed regression coefficients for the remaining variables. μ_{0j} is the random intercept, or variance of the intercept for each participant for all predictors around the overall intercept for all participants combined (γ_{00}). Finally, r_{ij} represents the residuals for each observation nested within participant.

Table 7.4 Steps for building an MLM predicting IDWG as a proportion of dry weight

Parameter	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
Intercept	2.00 (1.78, 2.20)*	2.01 (1.86, 2.29)*	2.06 (1.84, 2.27)*	2.06 (1.85, 2.28)*	1.96 (1.24, 2.70)*	1.94 (1.21, 2.67)*
Level 1						
Time	0.01 (-0.01, 0.01)	0.01 (-0.04, -0.01)	-0.01 (-0.01, 0.01)	-0.01 (-0.01, 0.01)	-0.01 (-0.01, 0.01)	-0.01 (-0.01, 0.01)
Age		-0.03 (-0.04, -0.02)***	-0.02 (-0.04, -0.01)***	-0.02 (-0.04, -0.01)***	-0.27 (-0.04, -0.01)***	-0.03 (-0.04, -0.01)***
Sex		-0.21 (-0.56, 0.12)	-0.17 (-0.50, 0.17)	-0.16 (-0.50, 0.17)	-0.17 (-0.51 , 0.18)	-0.17 (-0.51, 0.18)
Comorbidity		0.04 (-0.02, 0.10)	0.03 (-0.03, 0.09)	0.03 (-0.03, 0.09)	0.03 (-0.03, 0.09)	0.03 (-0.03, 0.09)
KRU		-0.20 (-0.32, -0.08)***	-0.17 (-0.29, -0.05)**	-0.17 (-0.29, -0.05)**	-0.16 (-0.28, -0.03)*	-0.16 (-0.28, -0.03)*
Cooperative SM			0.10 (0.01, 0.19)*	0.10 (0.01, 0.19)*	0.09 (0.01, 0.19)*	0.09 (0.01, 0.18)*
Defensive SM			-0.05 (-0.20, 0.10)	-0.50 (-0.20, 0.10)	-0.03 (-0.20, 0.13)	-0.03 (-0.19, 0.12)
PAM-13				0.01 (-0.01, 0.02)	-0.01 (-0.01, 0.01)	0.01 (-0.01, 0.02)
PHQ-9					-0.03 (-0.06, 0.01)	-0.03 (-0.06, 0.01)
Level 2						
Intercept (σ^2)	0.79 (0.65, 0.96)*	0.63 (0.50, 0.80)*	0.63 (0.50, 0.80)*	0.63 (0.50, 0.81)*	0.62 (0.48, 0.80)*	0.71 (0.53, 0.94)*
Cooperative SM						0.01 (0.01, 0.01)
Defensive SM						0.18 (0.03, 1.13)*
LL	371.05	363.23	278.31	278.87	274.18	274.00
-2* log likelihood		15.64*	169.84***	-1.12	9.38*	0.36

Notes: Values in brackets represent 95% confidence intervals

In Model 1, time is the only predictor included in the model, and the slope is non-significant as IDWG remained relatively stable at each time point. As time was uncentered, the intercept shows that mean IDWG for all participants at baseline was 2.00 (*95% CI* = 1.78, 2.20).

In model 2, age, sex, comorbidity and KRU were added to model 1. Slope for age (β = -0.3, *95% CI* = -0.04, -0.02) and KRU (β = - 0.20, *95% CI* = - 0.32, -0.08) emerged as significant predictors of IDWG. IDWG decreased as age and KRU each increased when all other variables, including time, were held constant. LL significantly improved from model 1 to model 2 (*2 x LL change* = 15.64, p < 0.01, df = 4).

In model 3, defensive and cooperative self-management were each added to model 2 simultaneously. The fixed slope for defensive self-management was non-significant, but for cooperative self-management was significant (β = 0.10, *95% CI* = 0.01, 0.19). As cooperative self-management increased, so did IDWG. The improvement in overall model fit from including self-management behaviour was large (*2 x LL change* = 169.83, p < 0.001, df =2).

In model 4, patient activation was added to model 3. The slope for patient activation was not significant (β = 0.01, *95% CI* = -0.01, 0.02), and its addition did not substantially change relationships observed in model 3. Log likelihood slightly increased, indicating worse model fit.

Model 5 added depression to model 4. As there was no mid-time point data for depression, only baseline values were included and it was treated as a time-invariant predictor. The slope for depression negatively related to IDWG, but this relationship was not significant (β = -0.03, *95% CI* = -0.06, 0.01). Model 5 showed significantly better fit than model 4 (*2 x LL change* = 9.38, p < 0.001, df = 1).

Model 6 tested the addition of random slopes for self-management behaviours, to test whether accounting for between-person variation in slope for IDWG regressed on self-management improved model fit, and whether slopes for IDWG on self-management for each individual were significantly different from the mean IDWG on self-management slope for all participants. The improvement in LL was negligible from model 5 to model 6 (*2 x LL change* = 0.36*, p* > 0.20*, df* = 2). The random slope estimates indicated that slopes for the relationship between defensive self-management and IDWG significantly varied from the mean slope for all participants combined (*β =* 0.18*, 95% CI =* 0.03, 1.13). In model 6, the fixed slopes for age, KRU, and cooperative self-management remained significant predictors of IDWG.

7.3.6 Correlations between phosphate and self-management variables

Table 7.3 shows correlations between phosphate at baseline and self-management variables. Self-management and phosphate were positively correlated with phosphate at baseline (*r* = 0.26, *p* <0.01), 9 month (*r* = 0.34, *p* < 0.01), and 18 month follow-up (*r* = 0.31, *p* < 0.01). This relationship was apparent for cooperative self-management, and for defensive self-management at both follow-up times, but not at baseline. Self-efficacy and patient activation were not correlated with phosphate. Depression was correlated with phosphate at 9-month follow-up only (*r* = 0.26, *p* < 0.05).

7.3.7 The relationship between phosphate and self-management

Mixed models for phosphate were built using the same method as for IDWG. Models were built by adding predictors in a theoretically determined fashion, all predictors besides sex were grand mean centred, log likelihood change was assessed using non-imputed data, while parameter estimates reported here were obtained using multiple imputation. The steps in building the model can be seen in table 7.5. The equation for the combination of predictors is the same as for IDWG, see 7.3.5 (predicting IDWG with self-management variables).

Model 1 treated each phosphate observation as the level 1 response variable. Participant ID was used as the level 2 variable. Time was entered as the only predictor, with a random intercept and fixed slope. Time was significantly related to phosphate ($\beta = -0.01$, *95% CI* = -0.01, -0.01). Between baseline and 18 month follow-up, phosphate decreased. Model log likelihood was -93.93.

In model 2, demographic covariates were added as predictors with random intercepts and fixed slopes. Age ($\beta = -0.01$, *95% CI* -0.01 to -0.01) and comorbidity ($\beta = -0.04$, *95%* -0.07 to -0.01) were significantly negatively associated with phosphate. Model 2 did not significantly improve fit over model 1 (*2 x LL change* = 3.06, $p < 0.20$, *df* = 4).

Model 3 added cooperative and defensive self-management to model 2. Neither cooperative self-management ($\beta = 0.01$, *95% CI* = -0.01, 0.03), nor defensive self-management ($\beta = -0.02$, *95% CI* = -0.07, 0.03), were related to phosphate. Model fit was significantly improved over models 1 and 2 (model 3 v model 2 *2 x LL change* = 24.40, $p < 0.001$, *df* = 2).

Model 4 added patient activation to model 3. Fixed slope for patient activation against phosphate was not significant, and significantly worsened model fit (*2 x LL change* = -4.58, $p < 0.05$, *df* = 1). In a separate model, self-efficacy was entered instead of patient activation for this step. Results were highly similar.

Model 5 added depression to model 4. Depression was not significantly related to phosphate in the model. Model fit was marginally worsened again compared to model 5 (*2 x LL change* = -0.15, $p > 0.20$, *df* = 1).

Model 6 added random slopes for cooperative and defensive self-management to model 5. The variance for the defensive self-management slope was significant ($\beta = 0.90$, *95% CI* = 0.03, 0.26), indicating that the relationship between defensive self-management and phosphate varied between participants compared to the mean relationship between the two for all participants. Fixed slopes for time and comorbidity remained significant, while age was reduced to non-significance. Model 6 did not significantly improve fit over model 5 ($\beta = 1.12$, $p < 0.20$, $df = 2$).

Table 7.5: Steps for building an MLM predicting phosphate

Parameter	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
Intercept	1.73 (1.65, 1.80)*	1.74 (1.66, 1.83)*	1.73 (1.65, 1.82)	1.75 (1.66,1.83)	1.74 (1.65, 1.83)	1.71 (1.59, 1.83)
Level 1						
Time	-0.01 (-0.01, -0.01)*	-0.01 (-0.01, 0.01)*	-0.01 (-0.01, -0.01)*	-0.01 (-0.01, -0.01)*	-0.01 (-0.01, -0.01)*	-0.01, (-0.01, -0.01)*
Age		-0.01 (-0.01, -0.01)*	-0.01 (-0.01, 0.01)	-0.01 (-0.01, 0.01)	-0.01 (-0.01, 0.01)	-0.01 (-0.01, 0.01)
Sex		-0.06 (-0.20, 0.08)	-0.06 (-0.20, 0.08)	-0.06 (-0.20, 0.09)	-0.05 (-0.20, 0.09)	-0.03 (-0.18, 0.12)
Comorbidity		-0.04 (-0.07, -0.01)**	-0.04 (-0.07, -0.02)***	-0.04 (-0.07, -0.02)***	-0.04 (-0.07, -0.02)***	-0.04 (-0.07, -0.02)***
KRU		-0.02 (-0.07, 0.03)	-0.02 (-0.07, 0.04)	-0.02 (-0.07, 0.03)	-0.02 (-0.07, 0.04)	-0.01 (-0.06, 0.04)
Cooperative SM			0.01 (-0.01, 0.03)	0.01 (-0.01, 0.03)	0.01 (-0.01, 0.03)	0.01 (-0.01, 0.04)
Defensive SM			-0.02 (-0.07, 0.03)	-0.02 (-0.06, 0.03)	-0.20 (-0.06, 0.02)	-0.03 (-0.08, 0.03)
Self-efficacy				0.01 (-0.01, 0.03)	0.01 (-0.01, 0.03)	0.01 (-0.01, 0.03)
PHQ-9					0.01 (-0.01, 0.02)	0.01 (-0.01, 0.02)
Level 2						
Intercept (σ^2)	0.35 (0.30, 0.41)	0.30 (0.25, 0.36)	0.30 (0.25, 0.36)	0.30 (0.25, 0.36)	0.30 (0.25, 0.36)	0.30 (0.24, 0.36)
Cooperative SM						0.01 (0.01, 0.01)
Defensive SM						0.09 (0.03, 0.26)*
LL	93.93	92.40	80.20	82.49	82.56	82.00
-2* log likelihood		3.06	24.40***	-4.58	-0.14	1.12

Notes: Values in brackets represent 95% confidence intervals

Hypothesis 2: Self-management behaviour, patient activation, self-efficacy, and depression symptoms will predict survival over follow-up

7.3.8 Survival analysis

To first explore whether self-management variables could predict survival in this population, basic Kaplan-Meier curves and tests of simple associations were employed. Each continuous predictor variable was split into a binary predictor along its mean to allow for a graphical exploration of basic survival differences between high and low scores for each variable.

Self-management behaviours (as well as cooperative and defensive subscales) and patient activation did not predict survival. However, self-efficacy did predict survival, with high self-efficacy predicting longer survival times (see figure 7.1).

To investigate whether this relationship would change in the presence of covariates, a Cox hazard regression was run, using self-efficacy (this time as a continuous predictor), and age, residual kidney function, sex, and comorbidity included as covariates (see table 7.6). Self-efficacy remained a significant predictor in the presence of these covariates.

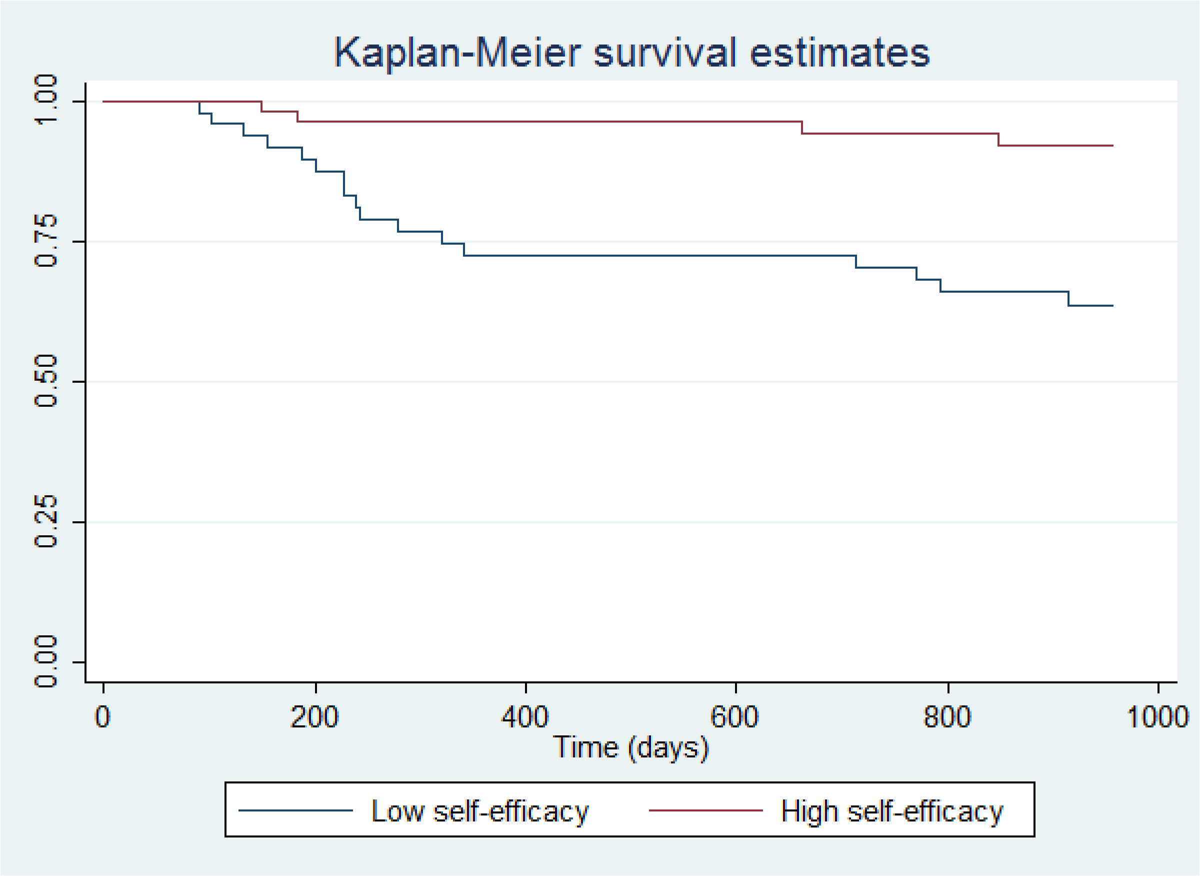

Figure 7.1: Kaplan-Meier survival curve stratified by self-efficacy

Table 7.6: Multivariate Cox Hazard regression predicting survival using self-efficacy and covariates

	Hazard ratio (SE)	**P**	**95% CIs**
Self-efficacy	0.70 (0.08)	< 0.01	0.55, 0.88
Age	1.00 (0.02)	0.99	0.97, 1.04
KRU	0.88 (0.15)	0.45	0.62, 1.23
Comorbidity	1.12 (0.09)	0.14	0.96, 1.31
Sex	1.52 (0.72)	0.38	0.60, 3.84
Model parameters	N = 103, -2xLL = 174.23, LR chi^2 = 12.78 (5 d.f.), $p < 0.05$		

7.4 Discussion

This chapter explored the relationships between self-management behaviours, psychological factors, and clinical status and outcomes cross-sectionally and over time. While self-management behaviours were associated with IDWG as hypothesised, the direction of the relationship was initially surprising; higher cooperative self-management scores were predictive of higher IDWG after controlling for time, age, sex, comorbidity, and residual renal function.

The three study sites displayed similar characteristics in terms of clinical and psychological parameters. This is not surprising as they are located in the same NHS Trust, but it is interesting that, for example, site 3 did not show any deviation in observed behavioural, psychological and clinical variables compared to sites 1 and 2, given the older population (see chapter 6 for breakdown of demographics by site). This may be due to the smaller sample size drawn from site 3.

Over time, IDWG remained stable, while phosphate levels decreased. The improvement in phosphate control may be due to programmes that were underway in the units to try and achieve this aim. Without programmes aimed at improving it, we may have expected phosphate control to remain relatively stable in established patients (Melamed et al., 2006). Particularly interesting is that over this period, patient activation increased. The fact that the units were attempting to emphasise the role of self-management for people on dialysis was associated with an increase in patient activation at the same time that phosphate was decreasing is interesting, but correlations and MLMs did not show an association between phosphate and patient activation.

Where appropriate, patient activation was treated as a continuous variable, as higher scores indicate greater levels of activation. However, Hibbard and colleagues recommend using cut-points to classify people into stages of activation: pre-contemplation, contemplation, action, or maintenance (Hibbard et al., 2004b). As one would expect with the rise in continuous activation scores, participants did appear to ‘shift up’ through the stages of activation, from pre-contemplation and contemplation towards action and maintenance, indicating that people's perceptions about their role in care had shifted. That activation should increase over time is consistent with findings elsewhere in UK dialysis populations (NHS Kidney Care, 2013). In chapter 5, staff identified high patient activation as being a key component for patient adherence, and for patients to be 'good' self-managers. The fact that patient activation increased was therefore a goal of initiatives within the Trust, and it was encouraging to see activation increase over the course of the study. The fact that activation was not associated with the decrease in phosphate warrants further investigation in future work.

In a cross section at baseline, IDWG and self-management were positively correlated; higher self-management was associated with higher IDWG. However, it is possible for particularly low IDWG to be unhealthy, as fluid intake is still required to maintain life. IDWG and self-management were positively correlated both when including IDWG as an absolute value, and when calculating it as a proportion of dry weight to account for baseline differences in body size. In chapter 6 it was found that the division into 'defensive' and 'cooperative' subscales that Curtin et al. (2004) proposed proved to be a useful distinction when examining the relationships between those behaviours and depression and anxiety (which were higher when defensive behaviours were high), and self-efficacy (which was low when defensive behaviours were high). Curtin et al. only used self-report measures of physical functioning, and no markers of clinical status, so there are no previous results to directly compare the findings here against.

Cooperative self-management was positively correlated with IDWG, a relationship which was not present for defensive self-management. This relationship persisted when using a mixed model taking account of within-participant covariance, factoring in time and background covariates. This seems counterintuitive, but it is important to remember that the behaviours assessed by the scale do not include self-reported adherence. Instead, it appears that in the observed data, those who were more likely to engage in behaviours like contributing to decisions about how much fluid to take off, or make suggestions to healthcare professionals about their care, had higher IDWG. Specifically, the ‘shared care in haemodialysis’ subscale appears to be most responsible for the relationship. It may be that those who engage in their own dialysis, and decisions about how much fluid to remove (for example), are more likely to select less stringent criteria than originally suggested by HCPs. Examples of patients negotiating higher dry weight values can be seen in chapters 5 and 8.

The finding that cooperative self-management and IDWG are positively associated is initially surprising. While a comparison of the BHDS and IDWG has not been made before, it may be expected from the self-management literature that those who show greater engagement with their care will have lower IDWG. It may be that in this sample, those who were identifying themselves as involved in their care were also choosing to drink more fluid between sessions, for example. At the time of the study, in-centre self-care haemodialysis was not standard practice in the dialysis units studied, with a relatively small number of patients doing more than weighing themselves. Furthermore, patients relying on increased dialysis dose to compensate for high IDWG due to poor fluid adherence was identified as an ongoing problem by HCPs in chapter 5 (Good/bad patient). Elements of self-care haemodialysis was, to an extent, actively discouraged at the time of the study. In this context, self-care haemodialysis may in fact have been less of a cooperative behaviour, and more of a defensive or even ‘antagonistic’ behaviour. Official policy was that patients should not change the settings on their own machines, for example. It may be that the participants who were trying to be more engaged in their own dialysis were those willing to be ‘told off’, something which occurred both with trying to change machine settings and coming into the dialysis unit with a high IDWG.

The units involved in the research have since initiated an official in-centre self-care haemodialysis programme, where patients can engage in more of their own dialysis, supported by HCPs only as necessary. This may change the dynamic between self-care haemodialysis behaviours and IDWG. Additionally, the influence of cooperative self-management on IDWG was small, and increased risk of mortality from higher IDWG tends to be observed only when IDWG is particularly high. However, this is an important finding to further investigate in future work. Randomized or cluster randomized controlled trials of self-care haemodialysis programmes may give a better picture of whether there is in fact a relationship here, and whether that relationship is casual in nature.

Defensive self-management was positively correlated with phosphate at 9 and 18 month follow-up, and cooperative self-management was positively correlated with phosphate at all three time points. These effects were not apparent in the fixed slope parameters when included in an MLM with covariates, but both cooperative and defensive self-management did significantly improve the model fit. This implies that self-management behaviour may be important in understanding phosphate levels, but not how they change over time.

Self-efficacy predicted survival. This effect has been observed elsewhere, such as in COPD, although studies on the topic are sparse (Kaplan, Ries, Prewitt, & Eakin, 1994). Self-management behaviour, both cooperative and defensive, did not predict survival. It may be expected that self-efficacy influences survival by affecting self-management behaviour, and that therefore self-management would act as a mediator between self-efficacy and survival. However, given the lack of any basic association between self-management and survival, no mediation analysis was warranted (Preacher & Hayes, 2004). Furthermore, given that self-management was associated with higher IDWG in multivariate models (and phosphate, in zero order correlations), it may be possible for self-management behaviour to be related to higher mortality due to being related to higher IDWG and phosphate, which are known risk factors for mortality in this population (Saran et al., 2003). This was not what was observed here however; survival was higher throughout the period of follow-up for those with higher self-management scores, both for defensive and cooperative self-management, but these differences were non-significant. There are many factors that contribute to mortality in this population, and how self-management may fit into this picture in larger samples is beyond the scope of this dissertation.

7.5 Concluding remarks

Cooperative self-management behaviours, such as shared haemodialysis care, were associated with higher IDWG over time, when controlling for a variety of demographic and psychological variables. This is contrary to the hypothesised relationship, that greater self-reported self-management behaviours would result in lower IDWG. However, examining these specific behaviours in relation to clinical markers of adherence is both novel and exploratory, and warrants further investigation. Similar relationships were observed in zero order correlations between cooperative self-management and phosphate, and defensive self-management and phosphate, but these relationships did not remain significant in multivariate models. Self-efficacy predicted survival in multivariate models controlling for demographic variables, but self-management behaviours did not.

In the next chapter, cognitive interviews based on the BHDS will be described. This will allow for an exploration of possible issues with the questionnaire, and an exploration of what participants are thinking when reaching their answers, and thus what is being measured. This will allow for both a more informed interpretation of the results described in chapters 6 and 7, and to lay the groundwork for improving the scale if necessary.

Chapter 8: Refinement of a self-management behaviour questionnaire for people on haemodialysis

8.1 Introduction

The aim of this chapter is to develop a series of suggestions for assessing self-management among people on haemodialysis. This will include an exploration of the Behaviours in Haemodialysis Scale (BHDS) using cognitive interviews, before summarizing lessons learned throughout this dissertation, and making a number of general suggestions for measuring self-management, as well as suggestions specific to the BHDS.

The empirical chapters so far have demonstrated that self-management is appraised as consisting of different aims and focus between patients and HCPs (chapter 5). They have also demonstrated that certain 'defensive' self-management behaviours are associated with higher levels of psychological distress when including patient activation and self-efficacy (chapter 6). While these findings are novel, they are not surprising in light of the background literature. What is potentially more surprising is the finding that certain cooperative self-management behaviours may be associated with higher IDWG and phosphate levels (chapter 7).

The BHDS developed by Curtin et al. (2004) is the focus of the present chapter. This questionnaire was adequately developed (see chapter 4, methods, for more detail), but during questionnaire administration for chapters 6 and 7, some participants expressed confusion at certain items, and others did not appear to be worded clearly. The surprising results in chapter 7 led to the decision to further explore the questionnaire items qualitatively, with the potential to revise the scale in the future.

As a starting point, patients on home haemodialysis were interviewed. People on home haemodialysis are generally considered to be more engaged in their own care, with those on in-centre haemodialysis frequently being considered those who are too old, frail or ill to dialyse at home (Woods, Port, Stannard, Blagg, & Held, 1996). This view was expressed frequently by HCPs in the focus groups and interviews in chapter 5. Additionally, participants interviewed in chapter 5 frequently had little or no experience in behaviours such as self-care (or shared care) haemodialysis, as self-care haemodialysis was not promoted in the dialysis units at the time of writing. This provided a useful perspective, but made it difficult to explore such behaviours in any detail. This information is desirable, as there is an increasing drive in the UK to promote in-centre self-care haemodialysis (Dainton & Wilkie, 2013).

Home haemodialysis patients were therefore considered a ‘gold standard’ starting point for exploring the BHDS where levels of engagement in care across a wide range of behaviours were likely to be high. Future work will extend this qualitative work into in-centre populations. Another advantage of starting with people on home haemodialysis is that it will allow the development of a home version of the BHDS to accompany the in-centre version.

The study was conducted with two specific aims:

1) To identify structural issues with items in the BHDS

2) To explore social and emotional issues arising in response to questions about cooperative behaviours, and in response to questions about defensive behaviours, in order to contextualise the results from chapters 5, 6 and 7.

The first aim relates to the difficulties participants appeared to have answering certain questions. Using a method known as ‘cognitive interviewing’, specifically using a think-aloud method, issues arising as participants describe their thought processes in answering the questions could be assessed.

This think aloud process, and the rich, in-depth answers it yields allowed more in-depth exploration of the questions that were only quantitatively addressed in chapters 6 and 7. This allows the second aim to be addressed. The authors of the BHDS proposed that the scale could be divided into eight subscales based on factor analysis. They then proposed that, based on the qualitative work that led to the selection of items, these subscales could be divided into 'defensive' and 'cooperative' subscales. Cooperative subscales represented behaviours that involved working with healthcare practitioners, while defensive subscales represented selectively keeping symptoms to oneself, or taking matters to higher authorities to get better care. 'Cooperative' implies a certain amount of social support. Further, the developmental work by the original authors, as well as the work described in chapter 6, demonstrates that 'defensive' behaviours appear to be associated with higher levels of psychological distress. This warranted further investigation.

Chapter 7 built upon this work by looking at how it related to change over time, and also how it related to clinical outcomes and survival. However, while administering the questionnaire, there were comments from participants about items being confusing, and individual items were being missed. When asked if there was a reason why an item was missing, participants sometimes identified this as a mistake, and others because they felt a question was not applicable or difficult to answer.

The BHDS was developed to allow better measurement of self-management behaviour specifically among people on dialysis for ESRD. It has been discussed in a number of papers since its development, although the scale itself has not been widely deployed (Griva et al., 2011; Appleby, 2013). Similar questionnaires exist, and appear to be more widely used in other chronic conditions, particularly diabetes (Toobert et al., 2000; Schmitt et al., 2013). A scale exists for assessing self-management behaviours in people on peritoneal dialysis, but the practical behaviours measured are sufficiently distinct to render it inappropriate for those on HD (Wang et al., 2014). Another scale, which included some emotional factors among people on dialysis was developed in Taiwan, but remained part of an unpublished Masters thesis (Li, Jiang, & Lin, 2014).

Another set of scale items closer to the BHDS used here were generated in collaboration with 13 nephrology nurses, and included sets of behaviours centred around themes such as advocacy and knowledge seeking (Costantini, Beanlands, & Horsburgh, 2011). However, a final version of this scale does not appear to have been published, and no relevant psychometric data appear to exist.

As the BHDS used here was developed for people on in-centre haemodialysis, adaptations may be needed if a version is also to be used for people dialysing at home. This is a secondary aim of these cognitive interviews. In addition, some items on the questionnaire appeared problematic during data collection reported in chapters 6 and 7. Missing items, or direct comments from participants during scale collection were more common for this questionnaire than for other scales.

Aim 2 of the interviews related to emotional and social aspects of self-management that may arise while answering questions. For example, interviews and focus groups reported in chapter 5 indicated that perceived social pressure to conform influenced the performance of adherence related behaviours for some individuals, and this may extend to other self-management behaviours. Perceived social support is also often seen as an important determinant in an individual's performance of self-management behaviour, particularly the support of a significant other where present. Emotional factors, including mood and anxiety, are often found to be important in the performance of self-management behaviours, and this association was found in chapters 6 and 7, where the presence of depressive and anxious symptoms were associated with the more frequent performance of 'defensive' self-management behaviours.

8.2 Methods

8.2.1 Overview

The overall aim was to generate suggestions for measuring self-management behaviour in future research. In addition to drawing on the work already described in previous chapters, cognitive interviews using the ‘think-aloud’ method were used to address structural and thematic issues in the BHDS. Guided by these aims, the questions addressed in the following cognitive interviews are:

1) What structural issues arise when patients respond to the BHDS, and how can they be improved?

2) Do social and emotional factors contribute to responses to the BHDS?

These two aims were addressed separately, by coding each interview twice – once for structural issues (aim 1), and once for social and emotional factors (aim 2). See chapter 4 (methods) for more detail on coding and analysis.

A copy of the BHDS can be found in appendix A.

8.2.2 Participants

A total of 8 participants were interviewed, four female and four male, with a mean age of 64 years. Participants were approached in clinic by their consultant nephrologist and given information about the study. Those agreeing to take part were then contacted by the author, and interviews were arranged. Consent was taken just prior to the interview. All participants were selected from Central Manchester University Hospitals NHS Foundation Trust.

8.2.3 Approval

Ethical approval for this work was provided by NRES Committee North West, REC reference 14/NW/0272 (see appendix F).

8.2.4 Procedure

Patients were first approached by a consultant nephrologist in clinic, who briefly explained the study and provided those interested with an information sheet explaining the study. Details of those interested were passed to the author, who gave participants at least two days to think about the study. The author then phoned participants to confirm their participation, and arranged for an interview to be conducted in the participant's home at a time convenient to them. Consent was obtained for all participants, and interviews lasted between 30 and 60 minutes. All information sheets included information on where to seek additional support if they were troubled by any of the discussion topics, as well as contact details for the investigator. In one case a participant became emotional during the interview, and in another a participant expressed symptoms of depression. In both cases, the author proceeded according to protocol, asking participants if they would like to stop, offering verbal support, and ensuring they were aware of counselling services available to them. Both participants opted to continue, and were already in contact with relevant support services.

8.2.5 Cognitive interviewing & analysis

Audio recordings of interviews were transcribed by the author and entered into NViVO 10 (QSR International, 2012). Responses were coded by question to allow side-by-side comparison of responses, as well as provide a structure for thematic hierarchies. Each question was assigned to one of two node classifications; cooperative or defensive, as defined by Curtin et al. scale (Curtin & Mapes, 2001; Curtin et al., 2004; Curtin et al., 2002).

Cognitive interviewing is a technique of conducting interviews, usually using a questionnaire or proposed questionnaire items as the template. By asking the participant to either think-aloud, or through the use of well thought-out probes, the aim is to ascertain the thought processes behind answering a given question, rather than just getting an answer. This allows for the identification of issues such as difficulty understanding terminology, ambiguity of meaning, strategies used for recalling information and difficulty accurately recalling information from events a long time in the past. For this reason, it is most frequently used in questionnaire design, before the final instrument is rolled out. It can, however, also be used to get more information about what goes through people's minds when faced with existing questionnaires. Examples of previous use include developing the US National Cancer Institute's Patient Reported Outcomes Common Terminology Criteria for Adverse events (PRO-CTCAE, Hay et al. 2013) and the PROMIS Pediatric Peer Relationships Scale (DeWalt et al. 2013).

Cognitive interviewing has been used in a number of conditions and scales. For example, the CollaboRATE study involved using in-depth cognitive probes to create a very brief scale that could effectively measure patient perceptions of shared decision making, using three highly refined questions (Elwyn et al., 2013).

See chapter 4 for more detail on cognitive interviewing.

Each transcript was then coded a second time for potential issues, using the following *a priori* categories frequently occurring in other cognitive interviewing studies (Knafl et al., 2007):

- Limited applicability: The question might not be answerable by everyone that the questionnaire is aimed at
- Unclear reference: It is unclear what a question is referring to

- Unclear perspective: Whose perspective is the participant meant to be answering from?
- Wording/tone: Participants may not understand a particular word. The wording tone may be considered inappropriate or offensive
- Descriptive quantitative data for the themes that emerge around problems encountered for each question will be used to provide a summary of the problems encountered.

Additional codes were generated for any other salient issues arising that may relate to the process of how a participant answers the question, generated as coding proceeded.

Each transcript was then coded a second and final time for examples of emotional and social issues arising during exploration of the interviews. These codes were then explored by question classification; defensive or cooperative.

A process of thematic coding was used for rounds two and three of the process (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2008). Previous studies in CKD have used this thematic process to explore self-management behaviours such as prescription altering and the use of complimentary medicines (Williams & Manias, 2014).

Questions are coded SM1 (Self-Management 1) to SM34.

8.3 Results of structural analysis

As there are 34 items in the BHDS, and some issues occur across multiple items, issues will first be considered by type, before specific problematic items are considered in more detail.

8.3.1 Frequency or duration

The timeframe for the behaviours reported in the questionnaire was 6 months. This sometimes presented some difficulties. For some, 6 months is a long period of time for remembering specific incidents, particularly if they do not refer to seemingly important or impactful behaviours or incidents. Additionally, certain behaviours are much more prevalent early in the process of adapting to dialysis. For example, SM11, “Looked for additional kidney diet information?” was sometimes difficult for participants to answer, as they may have diligently looked up large amounts of information on the subject when they first started dialysis, but not done so in the last 6 months. This does not, presumably, indicate a low information seeking self-management behaviour, but rather appropriate behaviour based on circumstances. For example:

> *Interviewer (I): Have you looked for additional kidney diet information?*
>
> *Patient 8 (SU8): No. Not really.*
>
> *I: Is that something that you would have done in the past?*
>
> *SU8: In the past, maybe, but now...*
>
> *I: But because you've been doing it so long...?*
>
> *SU8: Exactly. I know what's what.*

However, some did see this as an ongoing exercise:

> *I: Interesting. Err, looked for additional kidney diet information? Again [you've put] all the time*
>
> *SU6: I do it all the time, yes*
>
> *I: So is that an ongoing thing?*
>
> *SU6: It is an ongoing thing, because sometimes things change. The thing you wanting is good and another time they tell you is not good. So what I decided is now everything in*

> *moderation. Because what I find is... I've spoken to myself, you know self-talk, and I said to myself, "Eat everything you want... in moderation". I said, "That's the advice I have given you and that's it. Forget every other diet information out there. Do what I say." And that's what I do. So there's nothing I can tell you now I don't eat. There's nothing I tell you I don't drink. My motto is everything in moderation. And my blood results have been perfect [claps]*

Difficulty remembering due to the 6 month time period, combined with potential misunderstandings about whether a question was asking about whether a participant had ‘ever’ performed a behaviour, versus within the 6 month time window was evident in various items throughout the questionnaire, with different items proving difficult for different participants. For example:

SM3: “Asked staff or a doctor to do something differently because you thought there was a better way?”

> *I: Ok. Erm, have you asked staff or a doctor to do something differently because you thought there was a better way?*
>
> *SU1: Hmmmm [long pause, approximately 8 seconds], no*
>
> *I: Ok, you hesitated there, is there... what were you thinking might be something that you would have asked to do different, or is it just "no"?*
>
> *SU1: No, it's just the case you have to think things because it's been years since I've been on haemo. It's a long time to be at home dialysing.*

Some participants would simply include examples from long before the 6 month timeframe in arriving at their affirmative answer to questions.

SM1: “Asked for a change in treatment based on information you learned on your own?

SU7: Yes, sometimes I've done that, yes.

I: Have you got any examples perhaps?

SU7: Err, well, it, I've, this is now err, because I found out I have epo and this is like years back, and I went to my GP, and err, the first thing he said was he's not going to do it. And I can't remember totally because err, they said it's too expensive or something like that. And because I was much younger then I just started shouting and yelling and things like that in his office are you with me?

When asked for general comments about the questionnaire at the end of the interview, one participant volunteered the following:

SU1: No, no, your questions are ok to answer, but obviously some of them you need to think about... it's a time thing, when you've been on a long time, it's hard to recall certain incidents like, like you need an answer to, that's the only thing really

I: Yeah, so some of those questions here it's asking about things that you might have tried differently for example, so you find that quite difficult to think back

SU1: Yes, yes of course. To specific incidents... that's the only thing.

I: So when you're thinking about, when you're trying to give an answer to those questions and you can't think of anything specific, you just give a generally impression of what you think you might have done in the past, what sounds like something you might have done.

SU1: Yes.

8.3.2 Limited applicability

As the BHDS was developed for people on in-centre haemodialysis, there are a number of questions that were answered as ‘all the time’ in almost all cases. This may produce ceiling effects if the questionnaire were to be used quanitatively with people on home haemodialysis. These items may be considered to be of limited applicability from a quantitative perspective, particularly those relating to performance of dialysis itself such as self-cannulation. Items SM4 to SM10 pertain to self-management behaviours conducted during haemodialysis, and as such were almost always answered as, “All the time” by all participants. For example, item 4, “Cleaned or prepared your access site for needle placement?” was answered as “All the time” by all eight participants.

However, when talking through their answers, SU4 indicated that their partner had become involved in the process, perhaps indicating that a more useful question may be related to whether informal carers are involved in the process.

SU4: But erm, now he's doing it himself. Wash your hands…

I: That's interesting, now he's getting involved

SU4: Yeah, he does, "Ooo, you must wash your hands again", "Have you put Purell on?" So it's quite funny, you know, coming from being saying, "Ooo you must do that", yes I know! [both laugh]

SM5, “Weighed yourself?” and SM6 “Helped decide where the needles should be placed?” similarly elicited universally affirmative answers.

SM7, “Helped to decide the blood flow rate”, and SM8, “Helped decide how much fluid should be taken off?” again resulted in universally positive answers, but required more thought or explanation behind the answer. While both of these are prescribed by the patient’s nephrologist, participants sometimes alluded to making adjustments for themselves, based on discussions with their care team.

For example, when asked about deciding the blood flow rate:

> *SU2: Well it's basically prescribed, you do it over night, 8 hours overnight, three nights a week, err, then, you're err, you have the blood flow as low as you can get it really. So I dialyse on a rate of about 220 [cc/min, or cubic centimetres per minute], now this afternoon the dialysate flow was about 300, erm, now this afternoon because I was doing four hours because I'm having this biopsy tomorrow, erm, my dialysate flow is up to 500, only doing four hours, and I can increase the actual blood flow to about 250. Keep it at 250 because I use a 16 gauge needles, and you shouldn't really go above 250 for 16 gauge needles.*
>
> *I: Ok, erm, and is that sort of something you decided by yourself...*
>
> *SU2: In discussion*
>
> *I: Yeah. Ok, with your doctor?*
>
> *SU2: Yeah, mainly dialysis nurses*

How much fluid needs to be removed is a decision that is usually guided by a prescribed formula – whatever the participant weighs above their dry weight should be removed in any given dialysis session. While all participants answered that they decide how much fluid to remove, there were clear differences in how much thought and agency they put into this.

> *SU2: [My dry weight is] 64.5 [kg], and then, any weight above that is the amount of fluid I take off, so if I'm err, a kilo over weight, above 64.5, I take one litre of fluid off. So it's a sort of formula really.*

For others it was a process that involved more complex decision making

> *SU4: No, I decide erm, depending on what my weight is, and my blood pressure. And whether I've cheated [laughs] So that I've... if you've been out, you might have had more to drink, you think "ooo, better take a bit more off". I don't really like taking more than 2kg off.*

'Cheating' came up in interviews and focus groups reported in chapter 5. It is interesting that here the participant still describes it as such when they are the one responsible for making the adjustments to their dialysis dosage, and managing the consequences of their dietary and fluid choices.

One participant described how she modified her target weight from that prescribed by her care team, to one that she felt took into account her sickle cell disease:

> *SU6: The doctor say my target weight is 79.5[kg]. But I make my target weight 80 when I'm dialysing. The reason being that I need that shock absorber for myself. I need the 500ml in me, because of my sickle. You see with the sickle cell I'm supposed to drink loads of fluid, and with the kidney failure I'm supposed to be on fluid restriction. So when the doctors have finished their own, as regards to my kidney, I modify it as regards to me […] So you know, is err, is a juggling act with me. I know I'm complicated, and you know, I've always been all my life. My doctors say I'm special [interviewer laughs], what can you do with somebody who's special? [participant laughs], you know.*

The diversity of thought processes and practical activities involved in all eight participants arriving at the answer, "All the time" suggests that there may be subtleties not being captured by these questions when it comes to participants on home haemodialysis.

8.3.3 Unclear reference, wording, or misunderstanding

In some cases, participants reported not being clear on what a question meant. In others, it appeared that they were answering a different question to the one that had been asked. Sometimes this was as a result of ‘Conflicting clauses’, while in others it may be that it was not clear to what the question was referring.

SM26: “Acted more cheerful than you felt so that staff would give you better care?”

> *SU2: Err, no I don't think so. Don't think I have a lot of control over how I feel [both laugh] No. I mean, I felt a bit fed up this morning after I'd been down there, because some things were taking a long time to do*

As was common for this question, the participant talked about how much control they had over how they felt, or why they felt the way they felt, rather than whether they acted more cheerfully to affect the quality of their care.

> *I: Acted more cheerful than you felt so that staff would give you good care?*
>
> *SU3: I have done that, yes*
>
> *I: Is that something that you sort of do generally day to day, with everyone?*
>
> *SU3: I am, I am, yes. I am. They always call me smiley [interviewer laughs] Well, yeah, you see, that's what I mean by that, I always look on the good side of things, and be positive*

There were cases where there was confusion around whether non-renal behaviours were to be included in response to questions that were not specifically about aspects of renal care such as dialysis:

SM22: “Have you consulted a higher authority to officially complain regarding an issue or problem?”

> *SU4: [pause] No.*
>
> *I: Ok. What were you thinking when you were...*

> *SU4: I was just thinking about my leg accident... because, but, that wasn't really to do with renal much. I was in the hospital and I got on the bus, err, and I, I, I fell badly on the bus, because he took off really quickly, erm, and I went to the hospital transport. But that's nothing to do with renal things, is it?*

8.3.4 Difficulty producing an example

Sometimes participants would respond affirmatively to questions, but would not be able to provide an example when probed, indicating that they were going more by a general ‘feeling’ than by thinking back to specific instances. This was sometimes related to the “Frequency or duration” code

SM20, “Tried out different ways to handle problems or symptoms?”

> *SU1: Errrm, I would imagine so over the years, yes*
>
> *I: Can you maybe think of any specific examples, or?*
>
> *SU1: [Pause, 2 seconds] Not at the moment, not when you put me on the spot […] If I were dialysing a short time I'd probably be able to tell you but, as I say, a long time to come up with an answer for that*

8.3.5 Conflicting clauses

Sometimes participants would answer a question one way, while their think-aloud answer would reveal that this was because they were not taking into account a given clause in the question. For example:

SM17: “Handled problems or symptoms by yourself so you wouldn’t have to talk about them?”

SU5: Yes... I suppose I do really, I just get on with it really […]

I: So is it to not trouble other people, or is it because you don't feel comfortable talking about things?

SU5: No I don't think so, I'm that sort of person anyway. I've always been in the situation where I have to deal with things, so I do. I deal with things, mostly.

In this example, the participant was answering “A lot of the time” to the question, “Do you handle problems or symptoms by yourself?” without taking into account the second part of the question, which asked about whether this was to avoid talking about those problems or symptoms. It may be that two-part questions would be more appropriate here.

Questions SM9, “Watched the care you received to make sure everything was done right?” and SM10, “Stayed awake (when you would rather sleep) to make sure treatment was going ok?” resulted in the thought process in arriving at an answer appearing to be incongruent with the given survey answer. This appeared to be due to the conditional clauses in the questions. For example:

I: Do you watch the care that you receive to make sure that everything was done right?

SU4: I mean, yes yes, to a certain extent. I mean I thought that because I was in a specialist renal centre I was ok, but I was interested in what was happening, and how it was happening. Particularly since I was having to adjust the amount of Fragmin that I got, and the length of time that I was on

I: Yeah. So that was more a sort of interest thing than anything?

SU4: Oh yes, I was never in any queries about their quality of the care.

The participant answered in the affirmative to the question, but their think-aloud answer and follow-up probe revealed that this had nothing to do with “making sure everything was done right”. An active interest in what is going on may be considered a form of patient engagement, but their response was not necessarily an answer to the question that had been asked.

Similarly, for SM10 regarding staying awake:

> *SU5: Dialysis... well up 'til recently I've never been able to sleep on dialysis. But I have found in the last 2-3 weeks that I can do some sleeping, erm, although when I tried this morning my arm moved so the alarms went off, so that woke me up. I do... I can sleep some of the time on dialysis, but not always.*
>
> *I: Mhmm. Being able to sleep or not is not related to trying to see if treatment's going ok, it's something different?*
>
> *SU5: Yeah, really, yeah*

The fact that answers do not always align with what the question is really asking, by not factoring in important clauses, is not necessarily the fault of the question, as these clauses are clearly stated. However, it is important to note that the thought processes that lead to these affirmative answers do not always pertain to what the question is actually asking. In either case, when questions are frequently misinterpreted, responses should be interpreted with this in mind, or considered altogether unhelpful.

In cases of limited applicability, it would seem to be prudent to have a ‘Not applicable option’, a suggestion that participants agreed with when asked during the interviews.

8.3.6 Incongruous answers

In many of the cases discussed above, one answer was sometimes given as the question answer (e.g. “Never”, “All the time”), while the participant’s think-aloud answer implied that this was answer was ‘incorrect’ (using the information that they gave). In some of the quotes explored in the previous sections, this appeared to be attributable to elements of question design. However, in some cases, it appeared that the participant had simply misunderstood the question, or changed their mind part way through thinking about their answer.

SM32: “Asked questions or made decisions about your care with your staff or your doctor?”

> *SU6: I'll do that all the time, yeah. Sometimes now, I take the decision and then inform them later that this is what I'm doing, because you don't see them all the time. So when I see them I tell them, "This is what I'm doing now". You know. And when they have an appointment to come, then I leave a note for them for any new thing I'm doing so they will know about it, you know. So, yeah. I do that all the time.*
>
> *I: So would you say you take more decisions by yourself, or that it's more shared decision making.*
>
> *SU6: No, I take decisions by myself now, because like I said, once you're doing it at home, you see the doctor every 3 months or 6 months or whatever, if your blood results are good, and for me I see the nurse every 6 weeks. So it's not everything I will talk about the nurse and doctor before I do it, no no, there are things I need to do immediately and then tell them later. So, that's what I do.*

This question appears to be awkwardly worded, as it contains multiple behaviours which may result in different answers. Asking questions and making decisions are two distinct actions. Additionally, the initial sentence clause, “Asked questions or made decisions…” may be answered in the affirmative, while disregarding the second clause.

8.3.7 Wording or tone

In some cases, specific words caused some confusion. Most commonly, this related to the use of the word, “care” or “caregiver”

> *I: Mhmm. What do you understand by the term "caregiver", there?*
>
> *SU3: Well, somebody from hospital, you know. A nurse, a doctor, a home sister... anybody like that. Or even, even [participant’s husband], really. Erm. If it's [participant’s husband], and he's doing something wrong, then I'll say, "Oh no, we don't do it this way, have to do it that way." And erm, but he's...*

And

> *I: Have you spoken up to a caregiver because you thought they were doing something wrong?*
>
> *SU5: Have I spoken up...?*
>
> *I: To a caregiver*
>
> *SU5: Care... you mean the nurses?*

And

> *I: Taken responsibility for parts of your care or treatment?*
>
> *SU5: Erm. [pause] I don't really know... I mean... I usually talk it over with them anyway so... I'm not really sure about that one because… I can't really answer that one*

While not a question on the BHDS, when told the questionnaire would be about self-care behaviours, this term also caused some confusion

I: Just a few more questions asking you about how often you've done some of these self-care behaviours and things like that. The options are never, a few times, a lot of the time, or all of the time. And it's over the last 6 months.

SU7: What do you mean? Do you mean self...

The same participant also seemed to misunderstand what was being asked in the question, SM26, “Acted more cheerful than you felt so staff would give you good care?”

SU7: Yeah, when you know that you're going to get good care from somebody, you feel sort of like, happy? You know, that someone's looking after you

I: So you'd say it's the other way around?

SU7: Sorry what, how is that?

I: So, you feel more cheerful when you know you're going to see someone who gives you good care

SU7: Yeah

8.3.8 Specific items

Out of all questions, those which most commonly gave rise to issues detailed above were:

SM26, “Acted more cheerful than you felt so staff would give you good care”

These were mostly issues around wording (“care”), and conflicting clauses (“acting cheerful” “so staff would give you good care”).

SM31: “Adjusted your phosphate binder dose to the size of your meal”

This was a case of limited applicability; three of the eight participants were not taking phosphate binders at the time of the study due to long dialysis hours and well controlled phosphate.

8.3.9 General comments on acceptability

The questions asked were not seen as intrusive, and when asked, “Do you feel like there were any ‘right’ or ‘wrong’ answers?”, participants universally said they did not. Acceptability did not appear to be an issue with this questionnaire from the perspective of the participants.

8.4 Results from social and emotional analysis

8.4.1 Emotional

For the most part, responses to the questionnaire did not cover a substantial amount of social and emotional issues. This is because the questionnaire itself only touches on these issues in passing. However, where participants raised social and emotional issues, they frequently were discussed together.

SM26, “Acted more cheerful than you felt so staff would give you good care?” (Defensive)

SU2: I think probably I do Yeah occasionally. Yeah. Probably my wife's quite good at sussing out how I am, how I feel [both laugh]. She's got me taped.

I: Of course

> *SU2: And she cheers me up a lot, aight, you know, when I feel a bit down*

This participant said that they did act more cheerful than they felt, in response to this question from the 'defensive' subscale, but this led to them talking about the social support they received in a very positive light.

Answering the same question, another participant made it very clear that they would not attempt to hide how they felt, physically or emotionally, regardless of the social context they were in:

> *SU6: Nope. If I'm not well, if I'm having a [sickle cell anaemia] crisis here I would be screaming, I don't care if you're here, and I'm in a lot of pain I always scream out in pain. Until that pain goes then I will sleep or relax or whatever. There's really no point in hiding this.*

One question generated a particularly emotional response from the participant, SM16, "Kept problems or symptoms to yourself so as not to bother staff or your doctor?" (cooperative) P3 became tearful and upset as they thought through their response aloud. They explained that they felt extremely guilty about the amount of care that they had received on the NHS, and that they felt they were not giving enough back to society.

> *SU3: ... you know. I really have had so much, I feel so... [sniffs, starting to cry] upset about that. That I've had so much and other people are going without drugs... you know, when you see cancer patients and... hanging on to life. And I feel... I've had so much... I've been so fortunate...*
>
> *SU3: Just. Sometimes I just feel. As if I'm not giving anything back, when you know, I've had so much. [pause] And sometimes I sort of console myself by thinking, "Well, I nursed [participant's husband]'s mum with cancer." And she didn't... she stayed at home until the last few days. And then I had [participant's husband]'s dad living with*

> *us for ten years so he didn't have to go into, until he was 90-odd, so he didn't have to go into a home. And... my dad, I looked after him, because mum and dad were divorced, and he died, same year as [participant's husband]'s dad. And now my mum's 83, and she's needing more care. I just feel the last few years as if... I've taken a lot, and not put much back in, you know. Erm. And [participant's husband] says, "Well you do, you do do quite a bit..."*
>
> *SU3: Exactly, exactly. So that's it. Sometimes I do feel... very privileged, and, and, and embarrassed, or guilty, more than embarrassed. Thinking, "I daren't tell people I'm having something else done", because they must be thinking, "Well how ever much more is this woman going to have?" [laughs], you know.*

This reaction seems to have been more due to the illness and nature of the cognitive interviewing process, and the detail in which the participant was answering, rather than an inherent property of the question itself. Talking about serious illness can often produce strong emotional reactions, even when the topics are of a day to day technical nature. This illustrates the point that technical and medically focused self-management behaviours are only part of life on haemodialysis. Participants are also required to manage their mental health. Additionally, in the example above, the participant was coping with difficult perceived social stigma that may or may not have any basis in reality in this particular instance.

During general discussion during the interview, not in response to any specific question, one participant stated that:

> *SU7: [verbal hesitation] Well, since the last or so year I've been feeling really depressed you know, really down, it's just err... sometimes you feel like err, the example would be if a dog or animal would be in pain, put it down, you know. Sometimes I feel sort of like in that sort of like, sort of like... it might be better just to end it all rather than... in a way... You know, err,*

and then you don't... it's like err... there's nothing that you [verbal hesitation] to look forward to rather than getting up and dialysing, you know. When you've done the dialysing you sort of recover and then you're dialysing again

This same participant stated that:

SU7: I've got no friends at the moment, to say, you know, because over the time people just disconnected with me and err. Err, even while I was sort of well, you know, so called, "well" with the transplant because you know... it's... it's all like give and take really isn't it? Because I cannot offer anything to anybody, erm, so it's like erm, you need to offer people, even with friends there should... there's sort of like... it's difficult really, because you've got to be sort rich[?], err, you've got to have stuff [half laughs] to... and you've got to be able to entertain people as well, you know, so over the time just... they the few friends I had just sort of disconnected. The same with the relatives as well, over time. Err, disconnected and what's happened, I don't know if it's me being the thingy, it's just that the [verbal hesitation] the sort of err, you know. People say one thing in front of you, and one behind and so on and so forth are you with me, you know. You know, they're acting... there's an act people put on and err, you know I cannot sort of take that anymore. I cannot tolerate it anymore really. Over the time, over the last what, err, 15-20 years, I you know, I've sort of made a decision to dissociate myself with friends and relatives, and err, I find err, it's just they give you more problems than help to tell you the truth. They create problems within your household as well. Err, I just find people... I've not found anybody... any common thinking... so I'll, I disassociate with people now. I don't go out or anything.

This seems to exemplify the relationship between low social support and low mood among some people on dialysis. The interviewer followed up on this response and ensured that the participant was aware of the availability of psychological support. The participant was already aware of available services, and receiving support from a consultant clinical psychologist. The picture this presents is complicated. The individual seems to have chosen isolation, while simultaneously feeling lonely. The burden of haemodialysis was clearly a major cause of emotional distress, and they chose isolation over social support, which may perpetuate the emotional distress and make coping with the medical challenges life on dialysis presents harder still.

8.4.2 Social

One participant spoke about how she had the support of a friend, and how they involved both their partner, and their friend's partner in mutual support.

> SM12, "Asked family, friends, or dialysis patients for info regarding kidney disease and its treatment?" (cooperative)
>
> *SU3: One friend. I talk to. And... we sometimes talk about erm, different things with regards to not particularly dialy... well sometimes dialysis but it's normally about the knock on effects […] We might eat, ring each other, three times a year, four times a year? And just have a chat. And occasionally she comes round with her husband. And the two husbands'll have a chat as well, and we'll have a good talk. And erm, yeah. So it's, I think it's sometimes good as well, as I say. For the partners to be able to have a talk, and have a moan about things [laughs]*

Answering the same question, another participant talked about using a Facebook group for people on dialysis to seek information

> [Discussing a Facebook group for people on dialysis]
>
> *SU6: I'm on the list for transplant. And that's something I've never experienced, so I go to this site. So I listen to people who've been through it and what they went through, or what they're still going through and things like that*

The role of family members, particularly significant others, was vitally important.

SM11, "Looked for additional kidney diet information?" (cooperative)

SU7: Yeah, I do that while the, nowerdays my wife does it more than me and I get shouted at if I [both laugh] if I don't follow the diet, are you with me?

This question in particular seems to be explicitly about cooperative actions – seeking information from sources of social support.

8.5 Summary

The themes emerging during the structural analysis of the interviews are shown in table 8.1. Misunderstandings often arose because of wording, because participants answered one clause of a question without taking into account the whole question, and due to some self-management behaviours not neatly fitting into the 6 month timescale provided. Findings are discussed in detail, and potential improvements will be presented.

Table 8.1: Summary of themes emerging from cognitive interviews, and frequency of themes

Category	Definition	Example	Frequency of code	Arose in questions
Frequency or duration	Comments or examples of the participant having difficulty remembering how often an action was performed, or how long ago		8 instances	1, 3, 11, 20, 22, 25, 27
Limited applicability	Comments noting groups or situations for which the item would not be appropriate		21 instances	3, 4 (x4), 5, (x3), 6(x3), 7(x2), 8(x2), 9, 16, 29, 31(x3)
Unclear reference, wording, or misunderstanding	Comments about lack of clarity regarding what aspect of the family or condition, or situation the item is intended to address		15 instances	2, 4, 7, 8, 20, 22, 26, 28, 32, 34 (x2)
Difficulty producing an example	Participant finds it difficult to make a general answer concrete with an example		2 instances	20, 27

Conflicting clauses	When a participant answers ‘yes’ to one part of a question and ‘no’ to another	“Do you watch the care that you receive to make sure everything was done right?” “Yes I watched care but not to make sure it was done right”	8 instances	9, 10(x2), 16, 17, 26, 27, 30,
Incongruous answers	The answer does not make sense in light of the question asked		7 instances	11, 16, 24, 26 (x2), 30, 31
Wording or tone	A specific word is identified as being unclear or ambiguous, or the tone of the question is regarded as being inappropriate		6 instances	9, 21, 24, 26 (x2), 34
Emotional	Emotional factors identified in think-aloud response to the question		17 instances	2, 10, 11, 12, 13, 16, 22, 25, 26 (x6), 28, 30, 34
Social	Social factors identified in think-aloud response to the question		17 instances	2, 3, 4, 6, 8, 9, 11, 12 (x2), 20, 22, 25, 26 (x3), 33,

8.5.1 Structural

The structural analysis revealed that common problems included difficulties recalling the frequency of a behaviour, or remembering whether it was performed within the specified timeframe of 6 months. This was observed in eight different questions, and is likely to be more of a function of how the timescale is specified over the questionnaire as whole than for specific items.

Some questions were not applicable to the participant; most commonly questions relating to haemodialysis, including SM4, “Cleaned/prepared your access site for needle placement?”, SM5, “Weighed yourself?”, and SM6, “Helped decide where the needles should be placed?”. Similarly, the more general SM34, “Took responsibility for parts of your care of treatment?” was considered to be taken as a given for people on home haemodialysis on several occasions, and all participants answered affirmatively.

In some cases, it was unclear what the question was referring to, although this was spread out across different questions. Notably, SM34 again came up as being an unclear for five different participants, indicating the question may be too vague to be helpful.

Sometimes participants had difficulty producing an example – although this was the least common issue that occurred, being observed only twice, in response to SM20, “Tried out different ways to handle problems or symptoms?” and SM27, “Talked regarding a treatment or medicine you learned about, hoping the information might work for you?”.

Sometimes conflicting clauses were a problem, where a participant would answer affirmatively to the first part of a question, regardless of the conditional clause; this was most commonly observed for questions. This occurred for two participants in response to SM10, “Stayed awake (when you would rather sleep) to make sure treatment was going ok?”

A discussion of these findings is presented, followed by suggestions for modifying the scale based on these findings. For a summary of the categories, their definitions, and examples, see table 8.1.

8.5.2 Social and emotional

While the questionnaire is largely focused on the medical side of self-management, the characterisation of some subscales as being, “defensive” and others as being, “cooperative” does imply more and less socially focused behaviours.

Naturally, SM26, “Acted more cheerful than you felt in order to get good care?” tended to elicit responses with both emotional and social components. One participant noticed that he does act more cheerful than he feels, but his wife spots this and cheers him up anyway. Another participant noted that she does not act more cheerful for healthcare professionals, but does for social acquaintances as she gets tired of explaining herself. Another participant noted that she does not care what anybody thinks, and expresses herself freely whether they are healthcare professionals or social acquaintances. This question is considered to be part of the “Impression management” subscale, one of the defensive subscales. The first participant indicated that he believes that he does, and that he may conceal when he’s feeling down – but that his wife counteracts this by being able to interpret his non-communication and cheer him up. The second indicated that the question was context dependent for her, answering in the negative to the whole question (it specifies acting cheerful to get good care from staff), but indicating that she does conceal her feelings from social acquaintances out of tiredness with repetition. The final participant answered in the negative, indicating that she did not, and that she was happy with things being this way.

SM12, “Asked family, friend, or dialysis patients for more information about kidney disease and its treatment?” also induced responses about social status. Most participants said they did not, but those who did expressed the idea that they found this helpful, either from a friend face to face, or virtual support over the internet. Talking to a friend about kidney disease and its treatment was expressed as being more helpful as a form of emotional support for one participant, and a way of coping with fear of future complications and comorbidity.

8.6 Discussion of findings

8.6.1 Structural

A number of issues common to questionnaire design and wording were found for the BHDS, along with some less common. Problems with the timescale over which people were asked to remember, items with limited applicability, and unclear reference were found. Additionally, some items had multiple clauses, and participants would respond to the first part of the question without taking into consideration the modifying clause. These findings will be considered here, along with suggestions for improving the scale to take account of these issues. See table 8.1 for a summary of codes definitions and examples.

Some of the most common issues cropping up during the interviews related to assessing frequency of behaviours, or answering in accordance with the duration specified in the questionnaire. As the responses offered are, “Never”, “A few times, “A lot of the time”, or, “All the time”, it is important for the participant to be able to gauge the frequency of a behaviour. Most participants did not struggle to give one of these frequency based answers, although sometimes they would answer that they had performed a behaviour, while being unable to give any examples. In these cases it appeared that the participant was giving an answer based on the fact that it, “sounds like something they would do”, rather than because they could think of concrete examples where it happened. In these cases it may be that the accuracy of their estimate may be in question.

More problematic tended to be the specified time period of 6 months. For certain items, participants had difficulty remembering back over this time period. For others, the behaviours in question were most likely to have been performed before this time period began, especially if they were experienced dialysis patients. For example, finding out information about kidney diets was likely to have been performed at the initiation of dialysis. While two participants expressed that it was a matter of ongoing interest because evidence based information may change over time, it is unlikely that the core of renal dietary advice will change every 6 months. Therefore it may be unreasonable to classify constant checking on this front as a practical self-management behaviour. Staying current with such advice is an indicator of active interest, whereas constantly checking may be considered obsessive. The structure of questions and responses in the BHDS makes it difficult to assess the value of this item.

It may be that in some cases, a different time frame should be incorporated into the question itself, or alternatively, every question should come with its own time-period specification.

Another common problem that cropped up across the BHDS was that of limited applicability. For participants on home haemodialysis, questions regarding the practice of self-administering haemodialysis were of limited applicability and will experience ceiling effects, as they will always be performing these behaviours themselves. As such, different versions of a questionnaire would be required for people dialysing at home and those dialysing in-centre. In some cases, their informal carers helped with these behaviours, and this may be something useful to capture. Negotiations around dry weight and blood flow rate produced some interesting responses in this home haemodialysis sample, but may still experience ceiling effects should a home BHDS be developed, indicating questions would need to be reframed. Many definitions hold that the role of carers is very much part of the self-management picture, and that practical support is important in addition to social support, but this is not captured in the questionnaire. Additionally, asking about adjusting phosphate binder dose to the size of a meal does not make sense if the participant has not been prescribed phosphate binders in the first place.

The most logical solution to these kinds of problem is to include a ‘not applicable’ option in the questions. Items marked as ‘not applicable’ could then be missed off, and a pro-rata score formed of only items with a response included. While participants may be tempted to use this answer for questions where they do in fact have an applicable answer, this should reduce the problem of missing items. During data collection for chapter 6 and 7, non-completion of items in the self-management questionnaire were (where possible) followed up by asking participants to complete the missing items and why they might have missed them. While some participants simply accidentally missed the questions, some indicated that they had not provided an answer because the item was not-applicable, and they did not want to, “mess up” the results by providing an answer.

Some items resulted in participants identifying that it was unclear what the question was referring to. In some cases, this was due to individual wording. For two participants, the word, “care” was sometimes problematic, and in three cases the word, “caregiver” was unclear. It is clear that some participants saw the term, “caregiver” as referring to staff only, while others saw it as referring to their informal carers such as their partner or family. It may be helpful to clarify these questions by being more specific, or giving examples embedded in the question.

The final issue that frequently cropped up, that was particularly highlighted by the think aloud/elaborated answers given in these interviews, was that of questions with multiple clauses. This sometimes resulted in incongruous answers, whereby the ‘survey answer’ (e.g. “All the time”) did not align with the content of the elaborated answer. For example, asking a participant if they’ve, “handled problems or symptoms by yourself so they wouldn’t have to talk about them”, and the participant answering that this is something they have done all the time in the last 6 months, only to reveal that they were answering affirmatively to having handled problems or symptoms by themselves, but that this had nothing to do with having to talk about them.

Such questions may benefit from being split into multiple parts, i.e. “Handled problems or symptoms by yourself?” followed by, “If yes, was this so you wouldn’t have to talk about them?” (with a not applicable option in case the answer to the first part is no). Alternatively, two separate questions could be used.

While the focus of these interviews was on the structural issues inherent in the BHDS, the importance of social support was frequently visible. While the questions asked here focused on practical tasks, the importance of social support for psychological wellbeing was also identified.

8.6.2 Social and emotional factors

Despite only being addressed tangentially in the scale, social and emotional elements did feature in participants’ answers to questions posed during the cognitive interviewing process. They were sometimes raised at the end, during the general debriefing session in which the interviewer asked for their thoughts on the questionnaire. Where social issues were raised, such as support from family or friends, this was in response to ‘cooperative’ style questions as one would expect. Where emotional issues were raised, this was often in response to ‘defensive’ questions. This is not surprising, as data reported in chapters 6 and 7 revealed that depressive mood as measured by the PHQ-9 was related to the defensive subscale, but not the cooperative subscale.

The fact that social and emotional factors make an appearance, for example in the form of ‘acting more cheerful than you felt’, but that these dimensions are not more directly addressed, presents the question of whether ‘self-management’ scales do in fact measure the full range of self-management. In the next section, a series of suggestions for integrating these variables into future studies of self-management follows.

8.7 Suggestions for measuring self-management

This section will address how to take some of the lessons on conceptualising and measuring self-management in ESRD in future research, drawn from the findings of this chapter, and the broader dissertation. The discussion will progress from general points about measuring self-management in ESRD, to specific suggestions about the BHDS.

8.7.1 Lessons learned

A more comprehensive summary of the findings of the work presented in this dissertation can be found in chapter 9: Discussion. However, a brief summary of some key lessons learned about conceptualising and measuring self-management will be presented here.

In chapters 2 and 3, the literature reviews on self-management across chronic illnesses in general, and specifically in ESRD, revealed that self-management is usually conceptualised as comprising of medical, social, and emotional components (Lorig & Holman, 2003; Coleman & Newton, 2005). However, these reviews also revealed that in empirical quantitative work, both observational and interventional, self-management is operationalised as only including medical tasks, and more specifically adherence. In fact, “self-management” is often used as a synonym for adherence (Costantini, 2006). In many other cases, self-management is recognized as comprising a number of skills, such as decision making and taking action, but the focus remains on medical outcomes, and is rarely operationalised as including the balancing acts between medical tasks, social tasks, and emotional tasks that emerge time and time again from work with patients (see chapter 5, in addition to the present chapter). Further, many studies use self-efficacy as the outcome for an intervention to improve self-management, despite the fact that Lorig and colleagues in the Self-Management in Chronic Disease Programme (SMCDP) have argued that self-efficacy is a ‘weak outcome’ that is itself a predictor of self-management behaviour (Lorig & Laurent, 2007).

For patients at least, the concept of medical, social and emotional issues being important appears to hold true. In chapter 5, one of the most consistent themes to emerge was that of self-management as a, “balancing act” between what keeps one healthy, keeps one happy, and allows one to maintain a social role within the world. Staff understandably appeared to be more focused on medical aspects, specifically adherence, and this may explain why empirical papers on the topic tend to focus on this aspect.

Chapter 6 empirically supported the findings of the authors of the BHDS, that psychological distress appears to be associated with more defensive self-management behaviours. This may indicate that doing more by oneself, or keeping problems to oneself, may be the result of depression and anxiety. Chapter 7 found basic associations between these defensive behaviours and phosphate control, which would suggest that these behaviours may not only be associated with poorer emotional wellbeing, but may also result in poorer medical outcomes. However, this did not hold true in multivariate models, indicating that the variance was explained elsewhere.

The cognitive interviews exploring the scale in greater depth presented here would suggest that the terms ‘cooperative’ and ‘defensive’ may be misleading in some cases. The use of alternative therapies for example, may be seen as a ‘defensive’ act, rather than a cooperative one, particularly in the language it is couched in; ‘alternative’ therapy suggests one that is used in place of treatment recommend by a healthcare professional, whereas ‘complementary’ is more commonly used to denote an adjunct therapy, often those aimed at relaxation (UK National Health Service, 2015). A complementary therapy may indicate taking steps to maintain one’s emotional wellbeing while proceeding with recommended treatment, while an alternative therapy may involve a rejection of treatment recommended by doctors. The former may be seen as cooperative, while the latter as defensive.

All of this illustrates an important point when measuring any latent concept, but that seems to be particularly pertinent in self-management; one’s terms must be well defined and operationalised, and a consensus definition would aid comparison and interpretation between studies.

One thing that remains clear is that self-management is often a ‘messy’ concept without a neatly defined and universally accepted language. This is perhaps exemplified by a recent attempt to create a ‘taxonomy of self-management’ (Taylor et al., 2014). This was part of a metareview of the literature on self-management in chronic illnesses. The aim was to produce an accepted set of terms used in self-management to aid the review. This was based on previous work codifying active components of behaviour change techniques (Michie et al., 2013). However, the conclusions of Taylor et al. were that it simply wasn’t possible to do this for self-management, as the language used was too diverse across the literature. Taylor et al. ran into similar problems with identifying the appropriate self-management literature in the first place, as it is a broad and often poorly defined concept.

The following is a list of general suggestions for the measurement of self-management in ESRD based on these lessons.

8.7.2 General suggestions

1. Any empirical study of self-management should begin by reporting an operational definition of the concept.
2. Phrases such as, “increasing self-management” should be avoided unless adequate context and definition is provided. For example, “The goal of the study was to increase self-management” is too vague to be helpful. More specific language such as, “The goal of the study was to improve adherence to fluid restrictions” or “to increase the seeking of social support” would be preferable.
3. It is valid to study one aspect of self-management behaviour, but it is important to be clear about whether behaviour or psychological status are being measured. For example, high

levels of psychological distress, such as used in this dissertation, are an example of a psychological status. What a person does when confronted with low mood is a behaviour.

4. The concept of 'balance' between medical, social, and emotional needs should receive further study. The concept came up repeatedly in the qualitative work presented here, and elsewhere in the self-management literature, but is rarely investigated quantitatively. Further investigating how the decision making process works when weighing up choices could potentially prove to be highly informative.
5. Self-efficacy should not be conflated with self-management behaviour.

8.7.3 Alterations specific to the BHDS

Based on the findings in these cognitive interviews, there are some specific recommendations that may improve the quality of this scale:

Issue 1: Frequency or duration

The time period of six months resulted in some infrequent behaviours, such as searching for kidney diet information, to be recalled from the initiation of the dialysis process, which for most participants took place years prior to the interview

Suggestion: Separate items into several groups of questions, with varying time periods depending on the type of behaviour. Keeping the questionnaire simple would be paramount, so two or three different sections at most. These sections could include how often a participant has performed an action over time periods such as: "Ever", "The last 6 months" and "The last week". It may be helpful to distinguish between the two time periods. Alternatively, the question could ask for frequency for both "Ever" and "The last 6 months". This may also produce interesting data about behaviours that are performed more over the course of an individual’s life on dialysis, and which are performed less.

Issue 2: Limited applicability

Some questions were not applicable for all participants, leading to confusion about whether to leave a question blank, or provide an inappropriate answer.

Suggestion: Include a ‘Not applicable’ option. This could be for all questions, or limited to those that are conceivably not applicable to everyone. For example, it does not make sense to give a lower self-management score to a patient for not adjusting their phosphate binder dose to the size of their meal when they are not prescribed phosphate binders.

Suggestion: Have two different versions of the scale, one for people on in-centre haemodialysis, and another for people on home haemodialysis. Exclude the ‘Self-care haemodialysis’ subsection to avoid ceiling effects, and to protect future participants from unnecessary item burden.

Issue 3: Unclear reference, wording, or misunderstanding

Some specific items were unclear in their meaning or wording, resulting in participants being unsure of how to answer, or giving an answer to a different question than the one intended.

Suggestions:

- In SM21, the term, “caregiver” should be clarified. It is not clear whether it was intended to be restricted to professional caregivers in the original scale, but as self-management involves the patient’s informal caregivers, a definition including these should be used. For example, “Spoke up to a caregiver (for example, a nurse, or a family member who cares for you) because you thought they were doing something wrong?”

- SM24, “Tried to get staff or your doctor to think well of you in order to get better care?” could be split into two questions, “Have you tried to get staff or you doctor to think well of you?” “Have you tried to get better care?”
- SM26, “Acted more cheerful than you felt so staff would give you good care?” This item could be broken down into multiple parts, as for SM24. Alternatively, one question could be retained (as two questions) and the other dropped to avoid inflating the total item count.
- SM34, “Took responsibility for parts of your care or treatment?” could be rephrased to make the intended meaning of the question clearer. For example, “Taken responsibility for parts of your care or treatment that might otherwise be performed by staff or your doctor?”

Issue 4: Difficulty producing an example

Being unable to produce a specific example was anticipated as being a problem, but this was so rare as to not be problematic.

Issue 5: Conflicting clauses

Participants answered the first part of the question regardless of the whole question. A potential solution may be to use a two part question:

“17a: Do you handle problems or symptoms by yourself?”

“17b: If yes, do you do this to avoid having to talk about the problem or symptom?”

Conditional question can cause difficulty at the analysis stage, particularly if there is missing data. They can also be more confusing for participants. It therefore may be preferable to have two separate questions, each with a ‘Not applicable’ option (as above).

These conflicts usually resulted in misunderstandings, and as such have been covered under issue 3 (unclear reference, wording, or misunderstanding).

The questionnaire should be expanded to include social and emotional issues. The work in chapter 5 and the current chapter identified social and emotionally focused behaviours that may be important in self-management. Chapter 5 in particular that the question of 'who self-management is for' is important when considering what it entails. If we are interested in self-management from a healthcare professional perspective, only socially and emotionally focused behaviours that relate to clinical outcomes would be of interest. For example, an item might cover, "Turning down a drink when in a social situation, such as at the pub or coffee shop". If we consider self-management to be about the overall wellbeing of the individual, then we will be interested in behaviours that improve emotional and social wellbeing, undertaken while living with ESRD, regardless of whether they improve clinical outcomes. In this case, we might be more interested in the "balancing acts" that participants discussed in chapter 5. These might include items that look more like, "I sometimes eat something that makes me happy, even if I know it is recommended against". This is not just a question of content, but also of how questions are framed.

Indeed, perhaps a more concerted effort to measure both 'viewpoints' of self-management, to allow further investigation into how each approach relates to not just clinical, but also emotional and social outcomes (such as IDWG, psychological distress, and perceived social support) is desirable.

The next step in creating a revised scale will be to conduct another set of cognitive interviews based on the BHDS and generate a new specific set of items. In combination with the work presented in the present chapter, this will allow for the generation of both in-centre and home scales. It will also allow a qualitative comparison of the responses of home and in-centre patients to specific questions about self-management behaviour. The second set of interviews and creation of a specific set of items goes beyond this dissertation, but is a logical next step in improved measurement of self-management behaviour in people on haemodialysis.

8.8 Conclusion

This chapter looked at how the BHDS, a scale measuring behaviours for people on haemodialysis, could be improved. Cognitive interviews provided insight into participants' thought processes when responding to each question, and found that certain questions may provide inaccurate answers to due to problems with frequency or duration, limited applicability, unclear reference, and conflicting clauses. A number of suggestions were made as to how these problems could be overcome in a revised questionnaire.

Chapter 9: General discussion

9.1 Introduction

This dissertation has presented empirical investigations that support the thesis:

Certain self-management behaviours in End Stage Renal Disease are predicted by self-efficacy, patient activation, and psychological distress, and in turn predict clinical status. However, self-management is often oversimplified and poorly operationalised, in both the literature and in clinical practice, to adherence and 'good/bad' distinctions that may impede future investigations and interventions.

The core findings from these investigations include:

1. Educational materials on self-management exist, for both patients and staff involved in their care, but these rarely go beyond adherence

2. Renal staff tend to view self-management as being about adherence at all costs, while patients tend to view it as a series of complex balancing acts between their health, emotional wellbeing, and social functioning
3. The dialysis unit is viewed as a ‘family’, one that can either support self-management behaviour, or undermine it
4. ‘Defensive’ and ‘cooperative’ self-management styles have distinct relationships to patient activation, self-efficacy, and psychological distress
5. Self-management behaviours are positively associated with interdialytic weight gain (IDWG), and this relationship remains stable over time
6. Self-efficacy predicts survival among in-centre haemodialysis patients over 36 months
7. Existing tools for measuring self-management can be difficult to understand, and require reworking

9.2 Conceptualising self-management in ESRD

“… self-management is often oversimplified, in both the literature and in clinical practice, to adherence and ‘good/bad’ distinctions that may impede future investigations.”

The first set of investigations explored the views of patients and staff involved in their care on self-management, using focus groups, interviews, and thematic analysis. One of the core findings to come out of these was the fact that while there was much overlap between staff and patients in identifying important elements of self-management, they had a very different focus. Staff tended to focus on adherence, whereas patients identified complex medical, social and emotional balancing acts. Further, the staff focus on adherence to medical recommendations such as fluid restrictions, tended to be characterised by dividing patients into ‘good’ and ‘bad’, with a specific set of attributes that distinguished them. The distinction between good and bad patients has been observed elsewhere. In a study involving focus groups and interviews with patients and staff discussing the UK's Expert Patient Programme, staff appeared to have a very negative response to patients who displayed signs of distress during consultations (Wilson, Kendall, & Brooks, 2006).

This good/bad distinction seems salient to the psychological and health literature on self-management in two ways. Firstly, as noted, the self-management goals of clinicians and patients may be very different, with one group focusing on clinical issues such as survival, symptom control, and slowing disease progression, and the other balancing quality of life and role functioning with survival and low symptom burden. Indeed, what emerged in the course of the quantitative investigations in chapters 6 and 7, and was explored further in chapter 8, is that some self-management behaviours may be associated with poorer psychological health. These seem to be behaviours where the individual attempts to 'do it all themselves'.

This 'do it all yourself' is something that can be seen in the investigations in chapter 5. Junior staff in particular often believed that 'self-management' was a drive to get patients to do it all themselves, to reduce staffing and cut costs. Senior nursing staff were more concerned about the risk of litigation. This fear of litigation from self-managing patients who 'go off and make mistakes' has been observed elsewhere (Martin, 2004). However, this fear appears to be largely unfounded, and theoretically at least, it should be unlikely that any provider who provides good information should be liable for the actions of a self-managing patient (Wilson et al., 2006).

An interesting additional finding is that some among both staff and patients perceived the dialysis unit as being like a 'family', and that this was almost universally regarded as a positive thing. The properties ascribed to this family were social, supportive and cooperative, which in the context of the findings elsewhere in this thesis suggest that this is likely to be a positive quality worth nurturing. However, further exploration of this, and how such a dynamic could be captured to improve future self-management interventions, is required.

It is notable that emotional, social, and role functioning all came out as important factors to patients when discussing self-management. The importance of an individual adjusting to the challenges that life on dialysis presents is important, as it is in any chronic disease (Charmaz, 1983). However, perhaps because of the way the interviews and focus groups were structured, or because the focus was not on long term survivors, there was little discussion of transformational experiences. These have frequently been found in both dialysis populations (Curtin et al., 2002) and other chronic illnesses (Carpenter, Brockopp, & Andrykowski, 1999).

The fact that empirical studies often conflate self-management with adherence oversimplifies the matter, and misses the broad range of self-management behaviours that ESRD requires. Similarly, this same focus on adherence, along with the dichotomous good/bad distinction that staff hold raises the question of which aims ‘good’ self-management is trying to achieve, and who self-management is for.

9.3 Predicting performance of self-management behaviours

“*Self-management behaviours in End Stage Renal Disease are predicted by self-efficacy, patient activation, and psychological distress…”*

Self-efficacy and patient activation each predicted self-management behaviours cross-sectionally in different models. The association is what we would expect from evidence supporting Social Cognitive Theory and emerging Patient Activation Theory in other conditions (Bandura, 2004; Hibbard, Mahoney, Stock, & Tusler, 2007). What was more surprising was that total self-management behaviour score was associated with higher levels of psychological distress. That is, the more frequently self-management behaviours were performed, the more distressed an individual was. Investigating the self-management subscales revealed this to be due to the ‘defensive’ self-management behaviours, as opposed to the ‘cooperative’ behaviours. Defensive self-management behaviour was associated with higher levels of psychological distress, while cooperative behaviours were not. This may make intuitive sense when considered in terms of isolation; a tendency to pull away and manage situations alone when they could be managed cooperatively. This could be either an indicator or cause of social isolation and depressive symptoms.

In the context of the qualitative work presented here, some of these results are not surprising. During the cognitive interviews in chapter 8, there were examples of individuals displaying a high sense of self-efficacy and ‘do it all oneself’ attitude, accompanied by high levels of psychological distress. Conversely, individuals who appeared to be coping better emotionally identified cooperative relationships with their healthcare teams. The idea that depression may be the mediating variable between self-efficacy and defensive self-management is interesting. High levels of psychological distress may be responsible for the performance of more defensive self-management behaviours in those with low self-efficacy, as indicated by the findings of the mediation analysis.

One limitation of the work presented here is that perceived social support was not measured at the start of the study, when participant numbers were highest. This limits the ability to test the hypothesis that perceived isolation was the mediator of the relationship between high performance of defensive self-management behaviours and high levels of psychological distress.

Disease related knowledge was not measured in the studies presented here, but may be related to self-management, with self-efficacy as a mediating variable (Rimal, 2001). However, Bandura notes that many studies have demonstrated that increasing participant knowledge alone rarely changes behaviour, and maintains that self-efficacy is the critical variable (Bandura, 2004). He also contends that changing levels of perceived social support does not change behaviour unless it enhances self-efficacy (Bandura, 2002). If social support fosters dependence, then it may in fact reduce self-efficacy and thus self-management capacity.

In prior longitudinal studies in other chronic conditions, self-efficacy was found to predict unaided smoking cessation in heavy smokers (Carey, Kalra, Carey, Halperin, & Steven, 1993). The use of latent growth models identified those with high patient activation as being more likely to engage in more frequent self-management behaviours over a 6 month period (Hibbard et al., 2007).

The finding of a relationship between psychological distress and certain ‘defensive’ self-management behaviours is a replication of the findings obtained as part of the validation process for the BHDS (Curtin et al., 2004). The finding that self-efficacy is related to fewer ‘defensive’ self-management behaviours, measured by the BHDS, is novel. Furthermore, the finding that depression mediates the relationship between self-efficacy and defensive self-management is novel and potentially important. Defensive self-management behaviour was related to higher serum phosphate levels in chapter 7 at 9 and 18 month follow-up, although this did not hold true in multivariate analyses.

9.4 Self-management behaviours as predictors of clinical status

“… and in turn predict clinical status”

Self-management behaviours were associated with clinical status at baseline. The original work on the BHDS did not include measures of clinical status such as IDWG and phosphate, so the potential direction of a relationship was unknown. However, it was hypothesised that cooperative self-management would be associated with lower IDWG and phosphate. The results described in chapter 7 showed a very different story, with cooperative subscales being correlated with higher IDWG at baseline, and remaining associated with IDWG in a multivariate longitudinal model. As discussed in chapter 7, the longitudinal model may suffer from the attrition rate of respondents, but the fact that IDWG and cooperative self-management behaviours were positively correlated cross sectionally may indicate that this relationship warrants further investigation, as there is currently a drive for more patients to be responsible for more of their own dialysis (Dainton & Wilkie, 2013).

Patient activation increased from the start to the end of the 18 month study period. Over this period, the SELFMADE facilitator was introducing some new services aimed at providing peer support, encouraging exercise, helping participants to organise holidays, and providing some one-to-one goal setting. Additionally, there were other research studies going on at the same time in the units trialling a brief self-affirmation intervention (Wileman et al., 2014). It may be that these activities, partly focused on improving self-efficacy and patient activation, were responsible for this change, although it is unclear why patient activation increased while self-efficacy did not. An alternative explanation is that those with lower patient activation were lost to follow-up, although baseline patient activation was not associated with whether follow-up observations were missing or not.

The relationship between self-efficacy and survival has not previously been demonstrated among people on in-centre haemodialysis. In chapter 7, self-efficacy predicted survival, while self-management behaviour did not. One of the most theoretically likely causal mechanisms by which we may expect self-efficacy to predict survival would be via increased performance of self-management behaviours, and thus greater adherence to IDWG. However, IDWG and phosphate were not associated with mortality in this sample. However, this is not entirely surprising, as previous research has found that the relationship between IDWG and mortality is small, and only evident for very large weight gains (Hecking et al., 2013).

There is some evidence from studies in other chronic illnesses that self-efficacy is linked to survival, for example in chronic obstructive pulmonary disorder and coronary heart disease (Kaplan, Ries, Prewitt, & Eakin, 1994; Sarkar, Ali, & Whooley, 2009) This is the first time that self-efficacy has been shown to predict survival among people on dialysis for ESRD. Other previous studies have suggested that such a link should exist by logical extension of relationships between self-management behaviour and survival (Zrinyi et al., 2003), but none have demonstrated this.

9.5 Measuring self-management

"… poorly operationalised… that may impede future investigations"

Indications that the HDBS may contain some weaknesses became apparent during the quantitative empirical investigations described in chapter 6 and 7. The investigation described in chapter 8 was aimed at ensuring that the thought processes used when responding to questions matched up with how they would be interpreted in the analysis stage. A number of areas of potential weakness and areas for improvement were identified. Lessons on measuring self-management were collated from throughout this dissertation and presented as a series of suggestions for future measurement.

A secondary aim of exploring respondents' answers in greater depth was to obtain more information about the character of their responses when answering defensive questions, and when answering cooperative questions. This potential distinction has not received enough attention in the literature to date, and further understanding of these clusters of behaviours could be vital in encouraging self-management that is beneficial to patients.

This is the first study that has used and reported cognitive interviewing techniques to try and better understand the cognitive processes of people on haemodialysis when answering questions about their self-management behaviours. These interviews have produced some novel insights into both structural elements of the BHDS, as well as the broader issues around self-management behaviours. Understanding the cognitive processes of responding to questions about self-management behaviour can help improve the design of future scales to better capture subtleties that are currently being missed. With such a broad interest in the implementation of self-management interventions in the NHS, and indeed worldwide, understanding the validity of measures used, is vital. With an absence of 'gold standard' self-management measures, particularly in ESRD, using qualitative methods to explore both the validity and structural robustness of measures is vital. Evaluating self-management interventions in the future will require the creation and selection of appropriate outcome measures, along with an understanding of what they are measuring.

The development of a new scale goes beyond the scope of this dissertation. However, the next stage in the process of developing the BHDS into a more useful tool for measuring self-management behaviour would be to conduct further cognitive interviews with people on in-centre haemodialysis. Social and emotional elements of self-management behaviour could be more explicitly included. Appropriate items could be modified, new items selected, and piloting could begin.

9.6 General remarks

This dissertation has sought to investigate self-management behaviour, both as a concept, and in terms of how it relates to variables that it is frequently associated with in theory, academic literature, and increasingly, clinical practice.

One of the most important messages to have emerged throughout is "Who is self-management for?". This question should be asked whenever a new study, initiative, or intervention is being undertaken. Chapter 5 demonstrated that patients and healthcare professionals (HCPs) had overlapping ideas about what self-management entails, but a very different focus in their ideas about what was important – balance or adherence. Similarly, the motivations that patients reported for engaging in predominantly medically-focused self-management behaviours were generally driven by a desire to maintain their social and emotional wellbeing.

In the interviews conducted 18 months after the focus groups, there were a mix of views from participants on whether they'd like to be more involved in their own haemodialysis or not (shared haemodialysis care), usually only being interested if it would cut down on waiting time. Understanding motivations such as this are important as new initiatives emerge to promote self-care haemodialysis (Dainton & Wilkie, 2013; Glidewell et al., 2013). As survival results from chapter 7 suggest, self-efficacy may be an important factor to improve, but understanding why patients would or would not want to engage in their own care is key to securing that engagement. Furthermore, the intervention should be aimed at helping patients to work towards the goals that are important to them, and 'time' came up repeatedly in chapters 5 and 8 as one of the most precious things to people on dialysis.

When designing future self-management interventions, particularly those using online support, it is useful to note that there are resources available online, as documented in chapter 3. However, these materials frequently only touch on the emotional and social aspects of living with ESRD. Given the fact that psychological distress may mediate the relationship between self-efficacy and self-management behaviour, it may be important to include these elements in designing future online resources, and when deciding which resources to direct patients towards in clinical practice.

Results from chapter 7 suggesting that greater engagement in cooperative self-management behaviours may be associated with higher IDWG may call into question whether greater engagement will even necessarily produce improved clinical outcomes. Replication of the data obtained in that chapter would lend strength to those findings. However, to evaluate the impact that haemodialysis self-care behaviours have on clinical status, a prospective, randomised controlled trial would be required. Observational data presented in chapter 7 may be confounded by unmeasured variables not controlled for.

At the time of writing, there is a building drive in the United Kingdom to promote self-management, and to find ways to measure the success of interventions. Currently the method favoured by NHS England is by introducing the PAM-13 into routine clinical care (NHS England, 2013). Patient activation was related to self-management behaviour in chapter 6, but it will be important to distinguish ‘activation’ from self-management behaviour.

Additionally, ‘shared haemodialysis care’ is now a ‘CQUIN’. A CQUIN is a guideline set by the Commissioning for Quality and Innovation Scheme in the NHS. These guidelines state this goal as, “To offer the choice to in-centre haemodialysis patients to become involved in tasks relating to their dialysis. Patients are to be supported to do as little or as much of their treatment as they feel able or wish to do”. The focus of this goal is stated to be improving patient experience; however, it only concerns the practical delivery of dialysis, and not the wider social and emotional aspects of self-management. This may be an appropriate goal for increased participation in haemodialysis in light of the work in this dissertation. Interviews and focus groups identified services users who wanted to be more involved in their care, and those who wanted to be treated by others; in both cases, there were a variety of reasons. Chapter 7 indicates that this participation may not necessarily result in improved clinical status, albeit when shared haemodialysis care was not officially supported. However, if we ask, “Who is self-management for?”, it may be that participation enables patients to work towards their non-medical self-management goals, such as saving time through more flexible treatment times or seeing more of their family, or feeling more in control of their care. It remains important to integrate support for other elements of self-management into in-centre haemodialysis care.

9.7 Limitations

While the work set out here has produced novel findings, guided by theory and methodological rigour, there are nonetheless limitations to be addressed.

The focus groups carried out here were rigorously coded by a team of four researchers in such a way that agreement and accuracy were paramount. However, all members of the coding team were involved with the project, and therefore will have had some pre-conceived ideas about what they might find in the results. The integrity of the results could have been improved by adding an external coder completely blind to the aims and goals of the project.

The quantitative investigations reported here were conducted while patients dialysed. For depression and illness perceptions, intra versus inter dialytic questionnaire completion has shown to yield almost identical results (Chilcot, Wellsted, & Farrington, 2008). The on-versus-off dialysis properties of questionnaires such as that for self-management behaviours are unknown, and participants may therefore have produced different answers if completing the questionnaires while not on dialysis. However, given the similar performance in each condition of other instruments, this was deemed acceptable for the purposes of these studies. Investigating these properties may be an important part of further developing the self-management questionnaire.

The attrition rate for completion of questionnaires was high, if commensurate with similar studies conducted in the same population (NHS Kidney Care, 2013). This resulted in a loss of power for longitudinal analyses where repeated questionnaire results were used. This may have implications for the validity of the findings where analyses use questionnaire data as repeated measures, namely the multilevel models described in chapter 7 and the finding that patient activation increased over time. Despite attempts to statistically investigate patterns of missing data, and account for missingness using multiple imputation, mitigating statistical processes are not a perfect substitute for a more complete set of data.

The data reported throughout this dissertation, both qualitative and quantitative, was collected at sites that were running multiple research projects, and that were implementing multiple interventions oriented towards themes around self-management (peer support and self-affirmation, for example). This can complicate interpretation of longitudinal qualitative results, and may have influenced participants' responses in the 18-month interviews described in chapter 5. However, to an extent this represents 'business as usual' for both the sites studied, and sites in the wider NHS and other healthcare systems worldwide. Service developments, complex interventions, and research projects are constantly going on, and so observing participants in this setting may in fact be more representative of a 'real world' population than one in which no such activity is taking place.

The quantitative data reported here are all observational, and therefore caution is warranted when interpreting causal relationships, even where data were longitudinal. Additionally, observed relationships may be due to unobserved variables that were not, or could not, be included in multivariate models. Where possible, randomized controlled trials (RCTs) would offer the best evidence for causality. This may be possible in future investigations of self-care haemodialysis behaviours and IDWG, for example. This example is particularly salient due to the findings in chapter 7. Participants interested in undertaking more of their own dialysis in-centre may be randomized to receive training and use self-care bays, or to a control group that would continue receiving dialysis as normal. Self-reported self-management behaviours could be recorded, as well as direct observation or record keeping of which parts of dialysis patients are performing – and the two could be compared to validate the self-report measure. By following up IDWG over time, an assessment of the contribution of self-care haemodialysis to IDWG could be more reliably made.

9.8 Practical implications and directions for future research

From the investigations presented here, there appear to be salient, practical reasons for better conceptualising and communicating what self-management is.

Taking into account the gap between HCP and patient views on what self-management means will be vital for making interventions successful. A self-management intervention implemented by, for example, a specialist nurse or a health psychologist would stand a much lower chance of success if the clinical staff that surround the patient day-to-day were giving different messages about what self-management entails. Further, service level changes will increase the likelihood of the success of interventions

As a more sophisticated and specific language surrounding self-management evolves, there is a need for good quality research into interventions or service level improvements that may help foster it. The results presented here suggest that these interventions should be based on an awareness that beneficial self-management may not always refer to the patient doing more by themselves. It may be important to find ways to address the question of defensive self-management with patients, and discourage strongly defensive self-management behaviours. Perhaps the notion of ‘self-management’ itself would be better reconceptualised as ‘cooperative management’ (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

Further research should seek to investigate the reasons why certain defensive behaviours appear to be linked to higher levels of psychological distress. For example, what might it be about patients attempting to carefully managing the impressions they give staff, or about withholding symptom information, that may cause the association with psychological distress?

A more complete investigation of Social Cognitive Theory in people on dialysis could include a test of knowledge, as well as more specific tests of both self-efficacy and outcome expectancies. The work presented here was conducted with the aim of capturing a broad range of self-management behaviours, but it may be instructive to focus on predicting a very specific set of behaviours using Social Cognitive Theory.

‘Self-management’ needs to be broken down and operationalised by its component behaviours if it is be of empirical value in conceptually guiding research and clinical practice. Ultimately, behaviours aimed at maximising psychosocial wellbeing and optimal medical outcomes may not always be entirely mutually reinforcing – but it is for the individual living with the condition to set their priorities and decide where their balance lies, and how to spend the precious time that they have.

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List of appendices

A. Behaviour in Haemodialysis Scale (BHDS)

B. Self-efficacy in chronic disease 6-item scale

C. PHQ-9

D. GAD-7

E. Brief Dialysis Symptoms Inventory

F. National Research Ethics Service (NRES) approvals

G. Focus group schedules

H. Interview schedules

I. References to study outputs

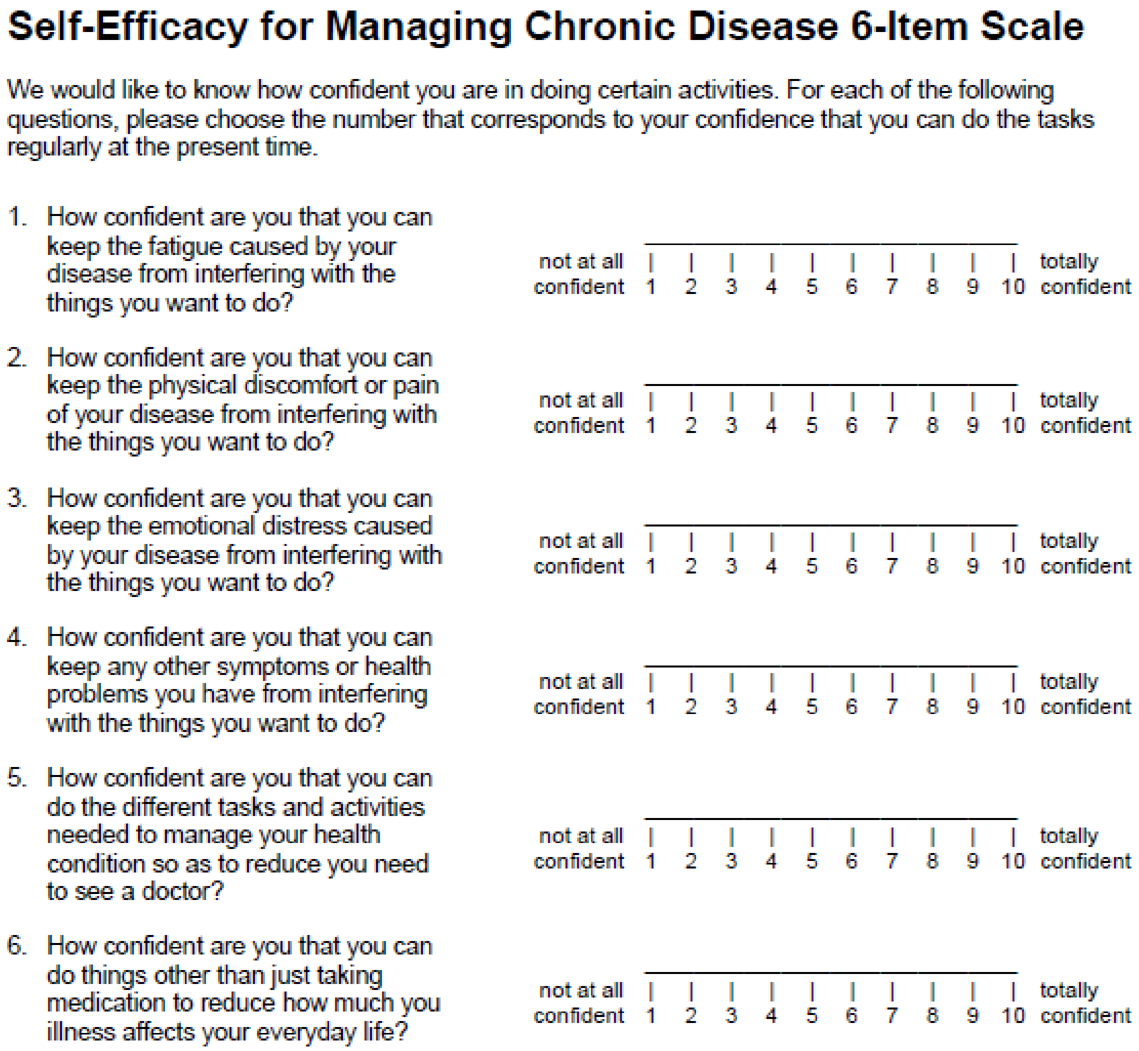
Appendix A: Behaviours in Haemodialysis Scale (BHDS)

Have you...?	How often have you ever done this?			
	Never	A few times	A lot of the time	All the time
1. Asked for change in treatment based on information you learned on your own?	1	2	3	4
2. Told staff or doctor you wanted something changed about your treatment or care?	1	2	3	4
3. Asked staff or doctor to do something differently—thought there was a better way?	1	2	3	4
4. Cleaned/prepared your access site for needle placement?	1	2	3	4
5. Weighed yourself?	1	2	3	4
6. Helped decide where the needles should be placed?	1	2	3	4
7. Helped decide the blood flow rate?	1	2	3	4
8. Helped decide how much fluid should be taken off?	1	2	3	4
9. Watched the care you received to make sure everything was done right?	1	2	3	4
10. Stayed awake (when you would rather sleep) to make sure treatment was going okay?	1	2	3	4
11. Looked for additional kidney diet information?	1	2	3	4
12. Asked family, friends, or dialysis patients for info re: kidney disease and its treatment?	1	2	3	4
13. Asked questions regarding something you read regarding kidney disease and its treatment?	1	2	3	4

Have you....?	How often have you ever done this? Never	A few times	A lot of the time	All the time
14. Tried an alternative treatment (such as yoga, acupuncture, magnets, or hypnosis)?	1	2	3	4
15. Experimented with treatments other than those prescribed by your doctor?	1	2	3	4
16. Kept problems or symptoms to yourself so as not to bother staff or your doctor?	1	2	3	4
17. Handled problems or symptoms yourself so that you wouldn't have to talk about them?	1	2	3	4
18. Put up with problem or symptom because you thought nothing could be done about it?	1	2	3	4
19. Decided which problems to report to doctor/nurse and which to handle on your own?	1	2	3	4
20. Tried out different ways to handle problems or symptoms?	1	2	3	4
21. Spoke up to caregiver because you thought they were doing something wrong?	1	2	3	4
22. Confronted staff in order to get better care?	1	2	3	4
23. Consulted a "higher" authority to officially complain regarding an issue or problem?	1	2	3	4
24. Tried to get staff or your doctor to think well of you. in order to get better care?	1	2	3	4
25. Hid true thoughts because you feared staff might be angry and take it out on you later?	1	2	3	4

26. Acted more cheerful than you felt so staff would give you good care?	1	2	3	4
Have you....?	How often have you ever done this? Never	A few times	A lot of the time	All the time
27. Talked regarding a treatment or medicine you learned about, hoping the information might work you?	1	2	3	4
28. Learned more about the dialysis machine, dialyzer reuse, or other technical topics?	1	2	3	4
29. Checked settings on the dialysis machine to make sure they were the same as usual?	1	2	3	4
30. Looked for information or talked with a pharmacist about your medications?	1	2	3	4
31. Adjusted your phosphate binder dose to the size of your meal?	1	2	3	4
32. Asked questions and made decisions about your care with staff or your doctor?	1	2	3	4
33. Pointed out to your doctor that some part of treatment was not working?	1	2	3	4
34. Took responsibility for parts of your care or treatment?	1	2	3	4

Appendix B: Self-efficacy in Chronic Disease 6-item scale

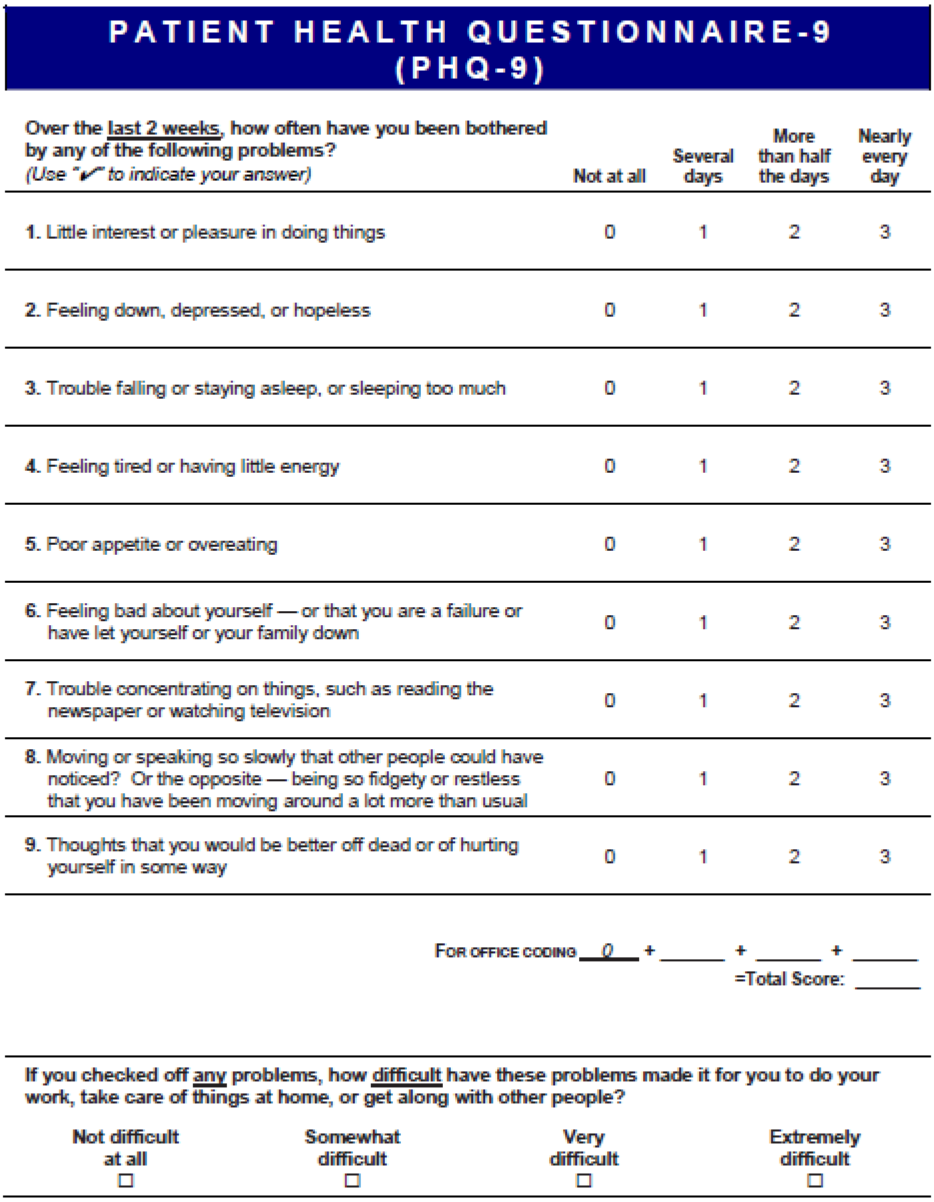


Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?	not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?	not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?	not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?	not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?	not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident
6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?	not at all confident	1	2	3	4	5	6	7	8	9	10	totally confident

Appendix C: PHQ-9



PATIENT HEALTH QUESTIONNAIRE-9
(PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

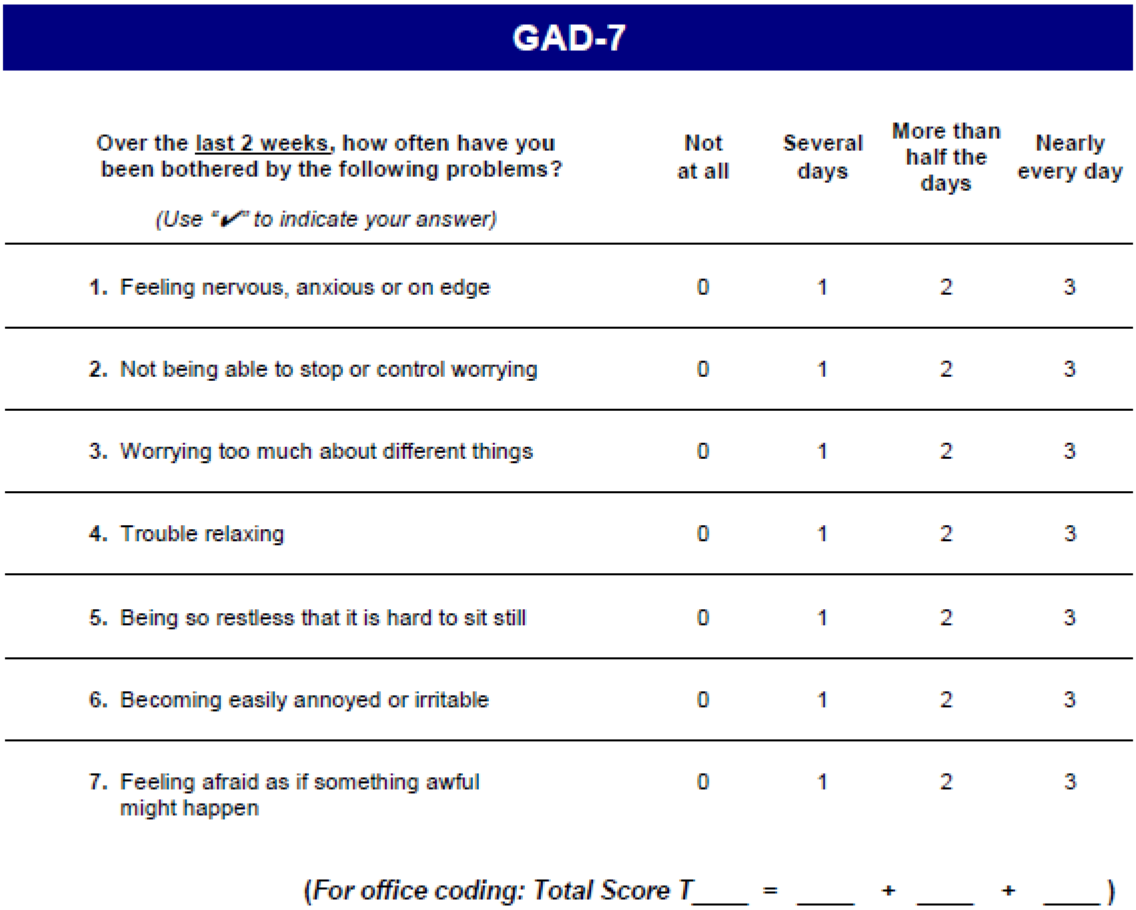
FOR OFFICE CODING __0__ + ______ + ______ + ______

=Total Score: ______

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ☐	**Somewhat difficult** ☐	**Very difficult** ☐	**Extremely difficult** ☐

Appendix D: GAD-7

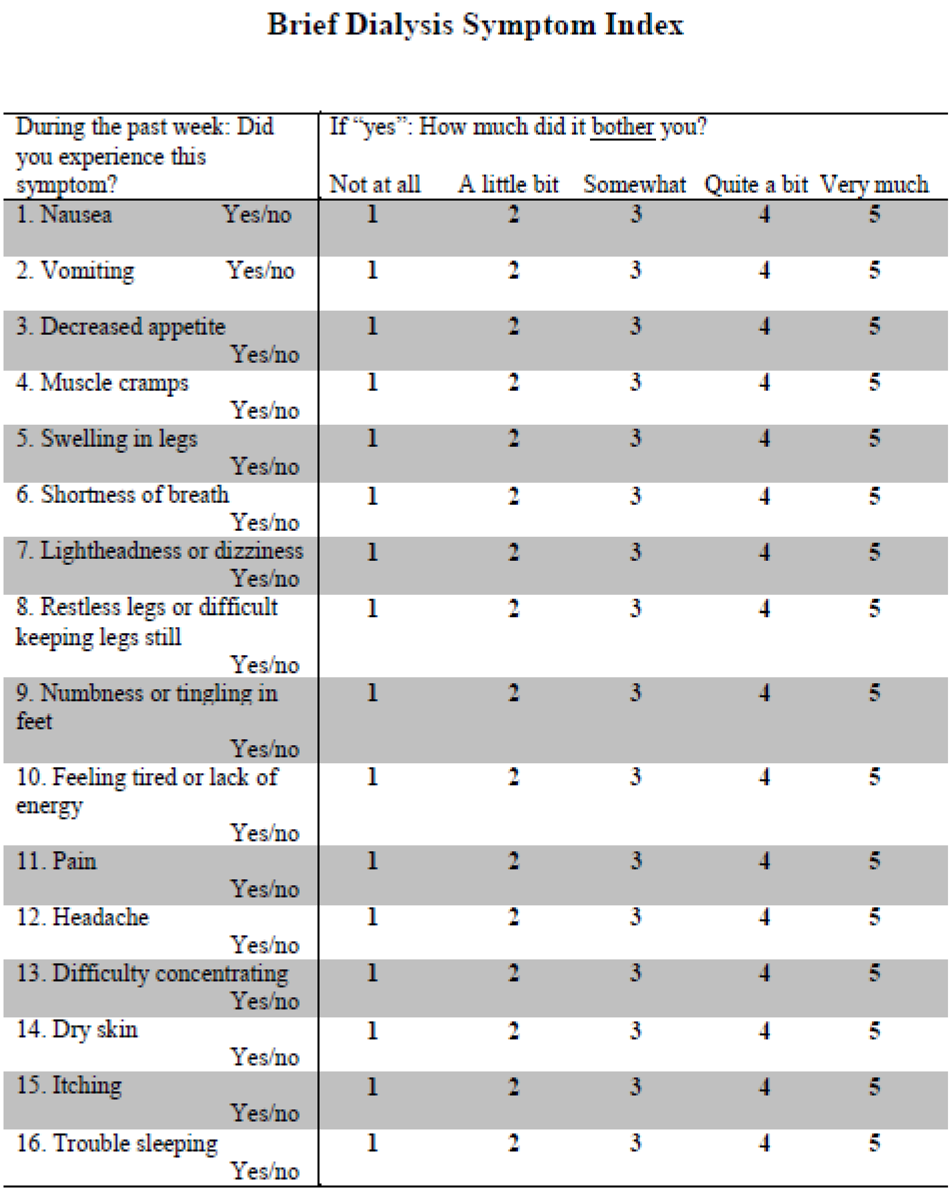


GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

(For office coding: Total Score T____ = ____ + ____ + ____)

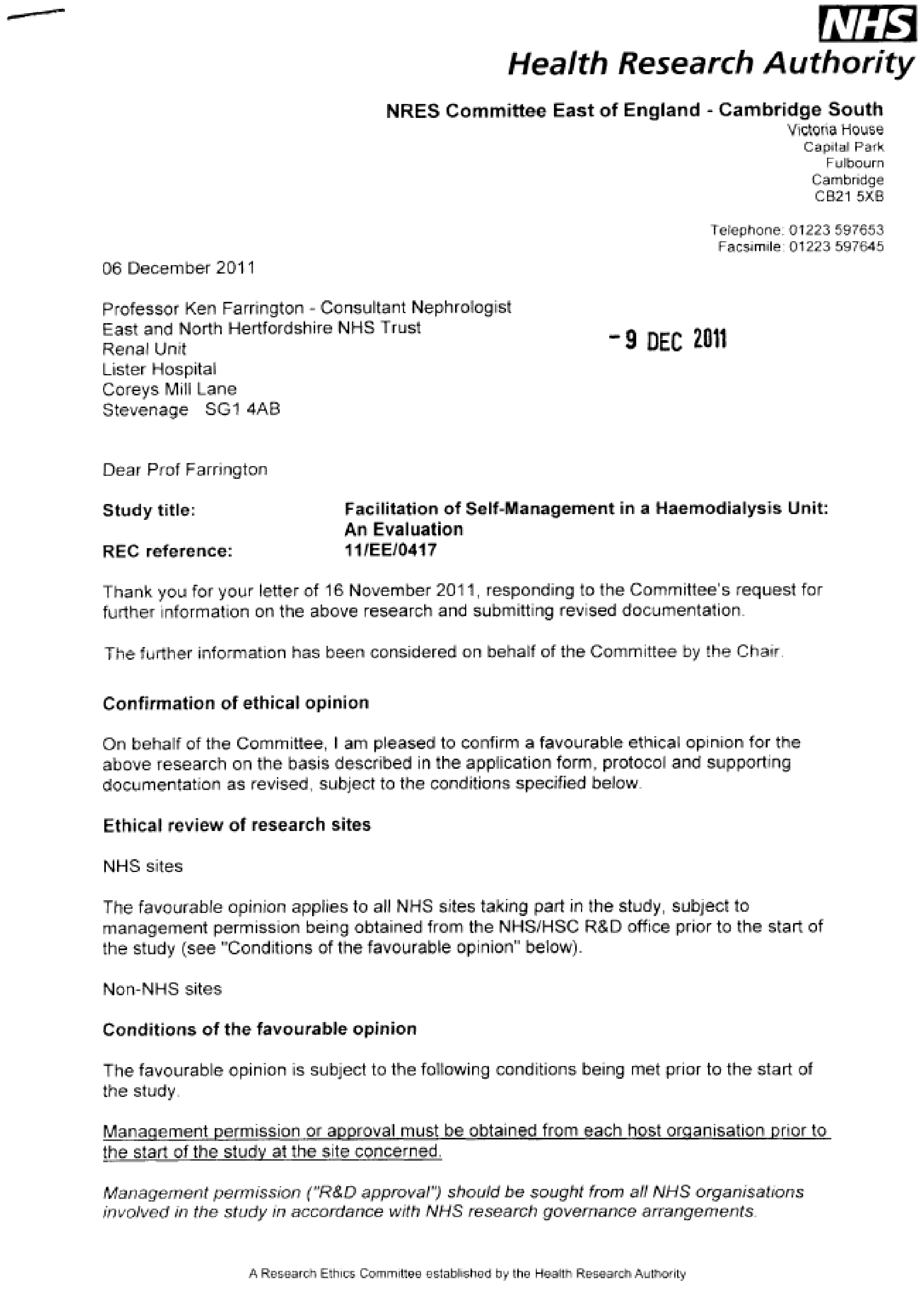
Appendix E: Brief Dialysis Symptoms Inventory



Brief Dialysis Symptom Index

During the past week: Did you experience this symptom?		If "yes": How much did it bother you?				
		Not at all	A little bit	Somewhat	Quite a bit	Very much
1. Nausea	Yes/no	1	2	3	4	5
2. Vomiting	Yes/no	1	2	3	4	5
3. Decreased appetite	Yes/no	1	2	3	4	5
4. Muscle cramps	Yes/no	1	2	3	4	5
5. Swelling in legs	Yes/no	1	2	3	4	5
6. Shortness of breath	Yes/no	1	2	3	4	5
7. Lightheadness or dizziness	Yes/no	1	2	3	4	5
8. Restless legs or difficult keeping legs still	Yes/no	1	2	3	4	5
9. Numbness or tingling in feet	Yes/no	1	2	3	4	5
10. Feeling tired or lack of energy	Yes/no	1	2	3	4	5
11. Pain	Yes/no	1	2	3	4	5
12. Headache	Yes/no	1	2	3	4	5
13. Difficulty concentrating	Yes/no	1	2	3	4	5
14. Dry skin	Yes/no	1	2	3	4	5
15. Itching	Yes/no	1	2	3	4	5
16. Trouble sleeping	Yes/no	1	2	3	4	5

Appendix F: Ethics approvals



NHS
Health Research Authority

NRES Committee East of England - Cambridge South
Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597653
Facsimile: 01223 597645

06 December 2011

Professor Ken Farrington - Consultant Nephrologist
East and North Hertfordshire NHS Trust
Renal Unit
Lister Hospital
Coreys Mill Lane
Stevenage SG1 4AB

-9 DEC 2011

Dear Prof Farrington

Study title: **Facilitation of Self-Management in a Haemodialysis Unit: An Evaluation**
REC reference: **11/EE/0417**

Thank you for your letter of 16 November 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

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.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

NHS
Health Research Authority
National Research Ethics Service

NRES Committee North West - Greater Manchester East
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7820

22 April 2014

Mr Jonathan Reston, Research Fellow
Centre for Lifespan and Chronic Illness Research
Health Research Building
University of Hertfordshire
AL10 9AB

Dear Mr Reston

Study title:	**Developing a self-management questionnaire for people on dialysis**
REC reference:	**14/NW/0272**
Protocol number:	**LMS/PG/NHS/00154**
IRAS project ID:	**141199**

The Proportionate Review Sub-Committee of the NRES Committee North West - Greater Manchester East reviewed the above application on 22 April 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Elaine Hutchings, on the email address below.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, 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).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Appendix G: Focus group schedules

FOCUS GROUP – CLINICIANS

ARRIVAL

- Greet everyone as they arrive, offer refreshments and encourage them to take a seat
- Explain that you will be the person who helps to keep the discussion going and that the other person will not be talking but will take notes and record the discussion to help you remember how the group went.
- Go through the Information Sheet and remind them they can still say withdraw at any time, remind them that although we will write about what was said in the group that their names will not be used.
- Take signed informed consent.
- Agree with the group the ground rules for the focus group: that anything said in the discussion will not be repeated elsewhere, there are no right or wrong answers, that people will speak one at a time, that every person's views are valuable and should be listened to.
- Assure the group that the discussion will last no longer than 45 minutes.

END OF FOCUS GROUP

- After 30 minutes begin to bring the focus group to a close. Summarise what you think people have said and the main issues that people talked about. Ask the group if that sounds right or if you have forgotten to mention anything. Ask if there is anything that people would like to add.
- Thank people for taking part in the focus group and answer any final questions about what happens next in the study.

DISCUSSION PROMPTS

Remind the group what they have been invited to talk about i.e what they think is important in helping people on haemodialysis to self-manage

Prioritising needs in haemodialysis self-management

- *In your experience what are the important things for self-management in patients on dialysis?*

- If not raised in discussion ask for their opinions on how important the following are:

    - *Fluid intake*
    - *Diet*
    - *Medications*
    - *Exercise*
    - *Mental well being*

- *If you had to rank all the things you have talked about, what would be the top 2 in terms of importance?*

What are the challenges in trying to look after themselves?

- *Thinking about some of the things you think are important in self-management, what are some of the difficulties patients face in keeping to these?*

- *If you had to rank the difficulties you have spoken of, what are the 2 most difficult?*

What helps to self-manage?

- *Currently what kind of things do you find patients do to help theselves self-manage?*

- *Do you think that there are any things you could be doing that you are not already to help your patients self-manage?*

- *Is there anything else that could help patients look after themselves better?*

Finally

- *Is there anything else you would like to say about self-management when on dialysis?*

FOCUS GROUP – PATIENTS

ARRIVAL

- Greet everyone as they arrive, offer refreshments and encourage them to take a seat
- When everyone has arrived or within 10 minutes of the stated start time, welcome everyone, introduce everyone and ask if people are happy to have a badge with their first name on it.
- Explain that you will be the person who helps to keep the discussion going and that the other person will not be talking but will take notes and record the discussion to help you remember how the group went.
- Go through the Information Sheet and remind them they can still say withdraw at any time, remind them that although we will write about what was said in the group that their names will not be used.
- Take signed informed consent.
- Agree with the group the ground rules for the focus group: that anything said in the discussion will not be repeated elsewhere, there are no right or wrong answers, that people will speak one at a time, that every person's views are valuable and should be listened to.
- Assure the group that the discussion will last no longer than 60 minutes.

END OF FOCUS GROUP

- After 45 minutes begin to bring the focus group to a close. Summarise what you think people have said and the main issues that people talked about. Ask the group if that sounds right or if you have forgotten to mention anything. Ask if there is anything that people would like to add.
- Thank people for taking part in the focus group and answer any final questions about what happens next in the study.

DISCUSSION PROMPTS

Remind the group what they have been invited to talk about i.e what they think is important in helping people on haemodialysis to take good care of themselves.

Prioritising needs in haemodialysis self-management

- *In your experience what are the important things to remember in looking after yourself when on dialysis?*

- If not raised in discussion ask for their opinions on how important the following are:

    - *Fluid intake*
    - *Diet*
    - *Medications*
    - *Exercise*
    - *Mental well being*

- *If you had to rank all the things you have talked about, what would be the top 2 in terms of importance?*

What are the challenges in trying to look after themselves?

- *Thinking about some of the things you think are important when looking after yourself, what are some of the difficulties you face day to day?*

- *If you had to rank the difficulties you have spoken of, what are the 2 most difficult?*

What helps to self-manage?

- *Currently what kind of things do you find help you to look after yourself?*

- *Do you think that there is anything your health staff could do to help you that they are not already doing?*

- *Is there anything else that could help you look after yourself better?*

Finally

- *Is there anything else you would like to say about taking care of yourself when on dialysis?*

Appendix H: Interview schedules

INTERVIEW SCHEDULE

CLINICIAN

BACKGROUND

- *Can you tell me a little about yourself*
    - *What is your role on the renal unit?*
    - *How long have you worked on the unit?*

SELF MANAGEMENT – GENERAL

- *In your opinion, what are the key things a patient has to do for themselves to maintain optimum health whilst on dialysis?*
- *What kind of difficulties do you find they experience in self-managing?*
- *What kind of things have you found helps a patient to self-care when on dialysis?*

EVALUATING THE SELF MANAGEMENT FACILITATOR ROLE

- *How closely have you worked with* INSERT FACILITATOR'S NAME *on the renal unit?*
- *How has she helped your patients? Can you describe this in more detail for me?*
- *Do you think the unit has changed at all since* INSERT FACILITATOR'S NAME *started working there? If so, how?*
- *What else do you think staff in the unit could do to promote self-management?*
- *Is there anything else you think* INSERT FACILITATOR'S NAME *could do to help*
    - *Patients self-manage more effectively*
    - *Staff promote self-management more effectively*

CONCLUSION

- *Is there anything else you would like to say about helping patients to look after themselves more effectively?*

INTERVIEW SCHEDULE

PATIENTS

BACKGROUND

- *Can you tell me a little about yourself*
    - *How long have you been on dialysis?*
    - *How often do you come to the Unit?*
    - *Apart from the problems with your kidneys, do you have any other health issues?*
    - *Do you live on your own or are there other people at home?*
    - *Do you work?*

SELF MANAGEMENT – GENERAL

- *What kinds of things do you have to do to look after yourself because you are on dialysis?*
- *On a day to day basis, how difficult is it to look after yourself?*
- *What kinds of things do you find helps in taking care of yourself?*

EVALUATING THE SELF MANAGEMENT FACILITATOR ROLE

- *Are you aware of or have you met* INSERT FACILITATOR'S NAME *on the renal unit?*
- *What do you think her job is on the unit?*
- *How has she helped you? Can you describe this in more detail for me?*
- *Do you think the unit has changed at all since* INSERT FACILITATOR'S NAME *started working there? If so, how?*
- *Has the way any of the other staff works with you changed since* INSERT FACILITATOR'S NAME *started? If so, how?*
- *What else could the unit do to help you look after yourself?*

CONCLUSION

- *Is there anything else you would like to say about how the unit helps you look after yourself?*

Appendix I: References to study outputs

Conference talks

Reston, JD., Wellsted, D., Bieraugel, R., Wilson, P., Da Silva-Gane, M., Offredy, M., Farrington, K. Psychological distress among haemodialysis patients: The relationship between self-care, anxiety and depression. Paper presented at: The joint conference of the Renal Association and the British Renal Society 2014, 29 April - 02 May, Glasgow, UK

Reston, JD, Bieraugel, R, Wilson, T, Offredy, M, Wellsted, D, Da Silva-Gane, M & Farrington, K. You can't choose your family... Knowledge spaces and self-management in the dialysis unit. Paper presented at: International Research Conference of the Royal College of Nursing 2013, 20-22 May, Belfast, UK – Slides available:
https://www.rcn.org.uk/__data/assets/pdf_file/0003/511806/2013_RCN_research_2.7.1.pdf

Davis, B., Reston, J., Bieraugel, R., Wilson, P., Wellsted, D., Da Silva-Gane, M., Sridharan, M., Vilar, E., Svarlino, R., Scarlino, A., Farrington, K. Facilitating Intradialytic exercise in haemodialysis patients: A single centre pilot study evaluating motivational interviewing. Paper presented at: The joint conference of the Renal Association and the British Renal Society 2014, 29 April – 02 May, Glasgow, UK.

Conference posters

Reston JD., Wilson, P., Bieraugel., R., Wellsted, D., Offredy, M., Da Silva-Gane, M., Farrington, K. The potential for increased self-management in patients on in-centre haemodialysis. Poster session presented at: The joint conference of the Renal Association and the British Renal Society 2014, April 29 - May 02, Glasgow, UK

Reston JD., Wilson, P., Bieraugel., R., Wellsted, D., Offredy, M., Da Silva-Gane, M., Farrington, K. Journey to cultural change: Experiences of facilitating self-management in an in-centre haemodialysis setting. Poster session presented at: The joint conference of the Renal Association and the British Renal Society 2014, April 29 - May 02, Glasgow, UK

Reston JD, Farrington K, Bieraugel R, Wilson T et al.Self-management: What helps, what hinders? Staff and service user perspectives on self-management in people on haemodialysis. Poster session presented at: British Renal Society conference 2013, May 14-16, Manchester, UK

Reston JD, Farrington K, Bieraugel R, Wilson T et al. Does self-management support in haemodialysis patients improve clinical and psychological outcomes? Poster session presented at: British Renal Society conference 2012, May 1-3, Manchester, UK

Bieraugel R, Reston JD, Wilson T, Offredy M et al. SELFMADE: Self-Management And Dialysis Evaluation. Poster session presented at: British Renal Society Conference 2012, May 1-3, Manchester, UK

Journal paper

Wilson, P. M., Reston, J. D., Bieraugel, R., Da Silva Gane, M., Wellsted, D., Offredy, M., & Farrington, K. (2014). You Cannot Choose Your Family: Sociological Ambivalence in the Hemodialysis Unit. Qualitative Health Research. doi:10.1177/1049732314549030