University of Derby

An investigation into the role of acceptance of illness and related factors in quality of life among renal haemodialysis patients.

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Abbreviations

ACT – Acceptance and Commitment therapy

AIS – Acceptance of illness scale

AKI – Acute Kidney injury

APD- Automated peritoneal dialysis

CAPD- Continuous ambulatory peritoneal dialysis

DASS – Depression Anxiety and Stress Scale

CBT- Cognitive behavioural therapy

CCPD - Continuous cycling peritoneal dialysis

CKD – Chronic Kidney disease

eGFR – estimated glomerular filtration rate

ESRD – End Stage Renal disease

HD – Haemodialysis

HHD- Home Haemodialysis

HRQoL- Health related QoL

ICQ- Illness Cognitions questionnaire

MCS – Mental Component summary score

MQoL-Mental Quality of life

NHS – National Health Service

PCS – Physical component summary score

PD – Peritoneal Dialysis

Pmp – per million of population

PQoL – Physical Quality of Life

PRD – Primary renal diagnosis

RRT – Penal replacement therapy

QoL- Quality of Life

Preface

The research and writing contained within this thesis has been solely authored by the doctoral candidate, with guidance and thesis direction advice only given by those stated within the supervisory package. Before beginning the studies, all research was considered and approved by the NHS North East (Tyne and Wear South) Research Ethics Committee.

Abstract

For patients with end stage renal disease, renal replacement therapy (RRT) is essential to a patient's survival. Haemodialysis is one RRT, and a growing body of evidence has suggested that how patients relate to this treatment is associated with both clinical and psychological outcomes. Adjusting to illness is a complex process (Dennison, Moss-Morris, & Chalder, 2009; Moss-Morris, 2013; Walker, Jackson, & Littlejohn, 2004) and one factor identified as important in other chronic conditions is acceptance. Evidence supports that acceptance can be important in helping patients manage conditions that cannot be improved through medication or therapies (McCracken, 1998; Veehof, Oskam, Schreurs, & Bohlmeijer, 2011). Findings from studies across a range of chronic conditions (Brassington et al., 2016; Poppe, Crombez, Hanoulle, Vogelaers, & Petrovic, 2013; Van Damme, De Waegeneer, & Debruyne, 2016) suggest that more positive acceptance of illness facilitates improvements in patients overall quality of life (QoL). However, there is limited research addressing the role of acceptance of illness and the impact on dialysis patients. This thesis has evaluated the role of acceptance and associated psychological variables in haemodialysis patients to develop an understanding of the influence of acceptance and to enable the development of targeted acceptance-based interventions.

This thesis aims to; gain an understanding of what acceptance means for dialysis patients; compare the influence of acceptance and associated psychological factors on patient outcomes, and examine the longitudinal relationships between acceptance and quality of life for dialysis patients. A mixed-methods approach was utilised and four methodologies were adopted; a systematic review evaluated the impact of acceptance on outcomes for patients with end-stage renal disease and how patients viewed acceptance in relation to these outcomes; cross-sectional studies compared the influence of acceptance, psychological and clinical variables on quality of life outcomes; a qualitative study explored patients experiences of accepting dialysis treatment, and a longitudinal study tested the impact of acceptance and psychological variables at 6 and 12 months post baseline. All participants were dialysis patients recruited from a single hospital site; a total of 102 participants were recruited. 98 were retained for analyses at baseline and 50 retained at 12 months. Ethical approval was obtained prior to the commencement of recruitment.

The research generated several important findings. Firstly, it highlighted that acceptance in dialysis was complex, with qualitative findings indicating that acceptance of illness in dialysis patients related to themes of ‘accepting the necessity’, ‘accepting the functional aspects’, ‘acceptance from experience’ and ‘acceptance from support’. This resulted in the proposal of a conceptual model utilising acceptance mindset to address how patients reach acceptance and how they interpret their illness and treatment.

Secondly, relationships between acceptance, psychological variables and QoL were identified; acceptance is a significant predictor of kidney disease QoL and physical QoL, with depression found to be a significant predictor for kidney disease QoL and mental QoL and was a significant mediator between acceptance and QoL. These findings demonstrate that acceptance is an important component of QoL in dialysis patients but also highlights the associations to other psychological variables. These associations in the cross-sectional study were confirmed longitudinally.

Thirdly, tests of longitudinal associations demonstrated that although there were no significant changes in overall acceptance levels over time, group changes masked individual differences. The individual changes in acceptance were associated with changes in mental QoL and kidney disease QoL. Changes in acceptance rather than depression were predictive of mental QoL and kidney disease QoL at 6 months. At 12 months changes in acceptance and depression were important predictors of mental QoL and kidney disease QoL.

The overall findings identified that acceptance of illness is an important aspect related to QoL for dialysis patients. Acceptance is a complex construct and relates to psychological factors, particularly depression. The qualitative analyses highlighted important areas related to acceptance and these were supported in the more complex analyses of QoL, these are areas that need considering in any future intervention developments. Although group acceptance did not change over time evidence at the individual level suggests that there may be benefit in targeting of interventions. Developing specific acceptance interventions targeted at dialysis patients may improve patients QoL and reduce the overall burden.

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Chapter 1 – Introduction to the research area

This chapter provides a detailed overview of the theoretical background and current evidence in end stage renal disease with focus on the impact of dialysis. It outlines the medical background before proceeding to review the psychological evidence associated with adjustment to dialysis. The theoretical underpinning of adjustment is explored with relation to acceptance. The concept of acceptance is then examined in relation to dialysis. The chapter concludes with the overall rationale for the research, including aims and objectives.

1.1 Medical Background

1.1.1 Kidney Function and Kidney Failure

The kidneys are vital organs which serve many important functions. Through understanding the structure and function of these organs the physical implications associated with their failure are given context. These physical implications are important because they are associated with patients psychological adjustment to end stage renal disease and are therefore a vital element to consider throughout this thesis.

Structure of Kidneys

Kidneys are organs which form part of the excretory (urinary) system (Marieb & Hoehn, 2013). They are bean shaped organs which are located below and posterior to the liver in the retroperitoneum (Koeppen & Stanton, 2013; Pasley, 2003). They are situated in the peritoneal cavity. Kidneys have three regions; the outer cortex, a medulla and hilum. The hilum is the entry and exit site for the kidney and from here the ureter exits. Within the kidney nephrons are the functional units. The renal corpuscle of the nephron comprises two elements, the glomerulus and the Bowman's capsule (Koeppen & Stanton, 2013). The glomerulus is a network of capillaries that filters the blood and resulting filtrate is captured by Bowman's capsule; a cup shape chamber. Exiting the renal corpuscle of a neuron is the renal tubule, a long structure comprising the proximal convoluted tubule, the loop of Henle and the distal convoluted tubule. This final part of the nephron connects to collecting ducts in the medullary pyramids which are contained within the kidneys (O'Callaghan, 2017).

Function of Kidneys

Nephrons function to cleanse the blood of toxins and expel waste as urine. The renal corpuscle initially filters the blood in the glomerulus through the effects of hydrostatic pressure (Koeppen & Stanton, 2013). At this point, almost all solutes, with the exception of protein, are filtered into the glomerulus through this glomerular filtration. The filtrate is collected in Bowman's capsule before entering the renal tubule. The renal tubule is where tubular reabsorption occurs and results in nutrients being reabsorbed however, excess solute cannot be reabsorbed (O'Callaghan, 2017). Through the filtration of blood, waste products are secreted into the kidney tubules and the filtrate eventually connects to the ureters where is excreted as urine. This process ensures the balance of electrolytes and water content is maintained. In addition, the kidneys secrete numerous hormones which are vital for the functioning of the human body, particularly Vitamin D, Erythropoietin and Renin (Koeppen & Stanton, 2013). Vitamin D only interacts with the body after it is activated by the kidneys, and consequently has a vital role in allowing the body to absorb calcium. Erythropoietin increases red blood cells through interaction with bone marrow and renin is important in blood pressure control. Most people have two kidneys yet some people are able to have an active and healthy life with just one kidney functioning. However, for numerous reasons kidneys can begin to fail and their functions become inhibited which results in patients exhibiting symptoms of increased blood pressure, anaemia, muscle weakness and softening of the bones (Goldsmith, Jayawardene, & Ackland, 2013).

Kidney failure

Kidney failure is defined as being a point where the kidneys no longer function sufficiently (Evans & Taal, 2015), this is also referred to as End Stage Renal Disease (ESRD) or stage 5. ESRD is usually a result of Chronic Kidney Disease (CKD) (Perico & Remuzzi, 2012), a long term condition where a person's kidneys do not function sufficiently. CKD usually involves the gradual deterioration of kidney functioning however it can also be a result of Acute Kidney injury (AKI) (Goldsmith et al., 2013).

AKI usually has a rapid onset and is a result of reduced blood flow to the kidneys (Bellomo, Kellum, & Ronco, 2012). Usually, this occurs when a person is unwell with other health conditions. The reduction in blood flow can be associated with low blood volume, reduced heart function, vasculitis, medications or blockages in the kidneys. Treating the underlying cause of AKI will usually improve kidney functioning however for some patients this can develop into CKD (Chawla, Eggers, Star, & Kimmel, 2014; Horne, Packington, Monaghan, Reilly, & Selby, 2017). Aside from being a result of AKI, CKD is usually a result of health conditions or heredity conditions which put a strain on the kidneys, these include diabetes, high blood pressure, high cholesterol, kidney infections, glomerulonephritis, polycystic kidney disease, blockages or long term medication usage (Edvardsson et al., 2013; Evans & Taal, 2015).

Kidney disease is measured in five stages and is based upon estimated glomerular filtration rate (eGFR) (Webster, Nagler, Morton, & Masson, 2017). This measure provides an indication of how effectively the kidneys are filtering waste from the blood. A normal eGFR is greater than 90 mL/min which indicates that the kidneys are functioning at 90% or over, this is defined as stage 1. Stage 2 relates to eGFR of 60-89 and is still not classified as chronic kidney disease. It is only once eGFR drops below 60 that CKD is diagnosed.

There are three stages in CKD, stage 3a mild to moderate loss of function (45-59), stage 3b is moderate-severe loss of function (30-44) and stage 4 severe loss of function (15-29). In the early stages of kidney disease, lifestyle and medications can slow down the progress of CKD however once eGFR drops below 15 patients are described as being in kidney failure, which is stage 5 – end-stage renal disease. Understanding the process underlying patients progression to ESRD is important in placing patients experiences in context and emphasises that the journey to dialysis can be a result of steady decline in kidney functioning or a result of sudden change.

1.1.2 End Stage renal disease (ESRD)

ESRD is the final stage of CKD, and is diagnosed when kidneys are no longer functioning sufficiently for a patient to survive without dialysis or kidney transplantation (Evans & Taal, 2015). Prior to beginning dialysis, patients who are nearing ESRD have usually been experiencing symptoms indicative of kidney failure. These may include; itching, muscle cramps, nausea and vomiting, oedema, changes in urination, difficulty breathing, and tiredness (Murtagh et al., 2007). Once diagnosed with ESRD patients will usually begin either Haemodialysis (HD) or Peritoneal dialysis (PD) or receive a kidney transplant. These renal replacement options take over the function of the kidneys and can result in the physical symptoms associated with ESRD improving.

1.1.3 Incidence and prevalence

1.1.3.1 National level.

It was estimated that globally the prevalence of CKD in 2015 was between 11 to 13 % (Hill et al., 2016) and 2.2% of deaths worldwide in 2015 were due to CKD, representing an increase of 1.8 % from figures estimated in 2005 (Wang et al., 2016). These proportions differ slightly from the figures in the UK, where it was estimated that between 1.8 million (4.3%) (Kerr, Bray, Medcalf, O'Donoghue, & Matthews, 2012) and 2.6 million (Public Health England, 2014) people had CKD. However, these differences were partially attributable to the UK figures representing patients with stage 3-5 CKD compared to all stages assessed in the global study. CKD was cited as a direct underlying cause of death in 2706 death registrations in 2017 (Deaths Register England and Wales, 2017). However the actual number of deaths associated with CKD was estimated to be higher, with CKD thought to be a contributing factor in an estimated 40-45000 premature deaths in the UK (Kerr et al., 2012).

Within the UK there is detailed annual reporting on renal replacement therapy (RRT) from all renal centres which is compiled as a component of UK renal registry annual report (Evans et al., 2018). This UK renal registry annual reports the details from the national monitoring system and has for 20 years provided data about prevalent and incident dialysis patients from a national to centre specific level. It benefits from having 100% coverage of the UK, with all units required to report (Evans et al., 2018). The report has been used as the key source of prevalence data relating to UK RRT and is referenced by government, clinical and research bodies (Damery et al., 2019; Kerr et al., 2012; National Institute For Health And Care Excellence (NICE), 2017; NHS, 2012). The relevant findings from the latest report indicated that in 2017, 8001 adult patients started on renal replacement therapy which equated to an incidence rate of 121 per million of the population (pmp) and was an increase of 2.6% from the 7759 patients who started in 2016. The median age for initiation of RRT was 63.7 years however this varied over the RRT modalities and the highest mean age was reported in patients initiating HD (66 years). Ethnicity also contributed to the age of RRT initiation with 65.3 years being the median age of initiation for white patients, 61.1 years for Asian patients and 56.5 years for black patients, indicating earlier progression to ESRD in

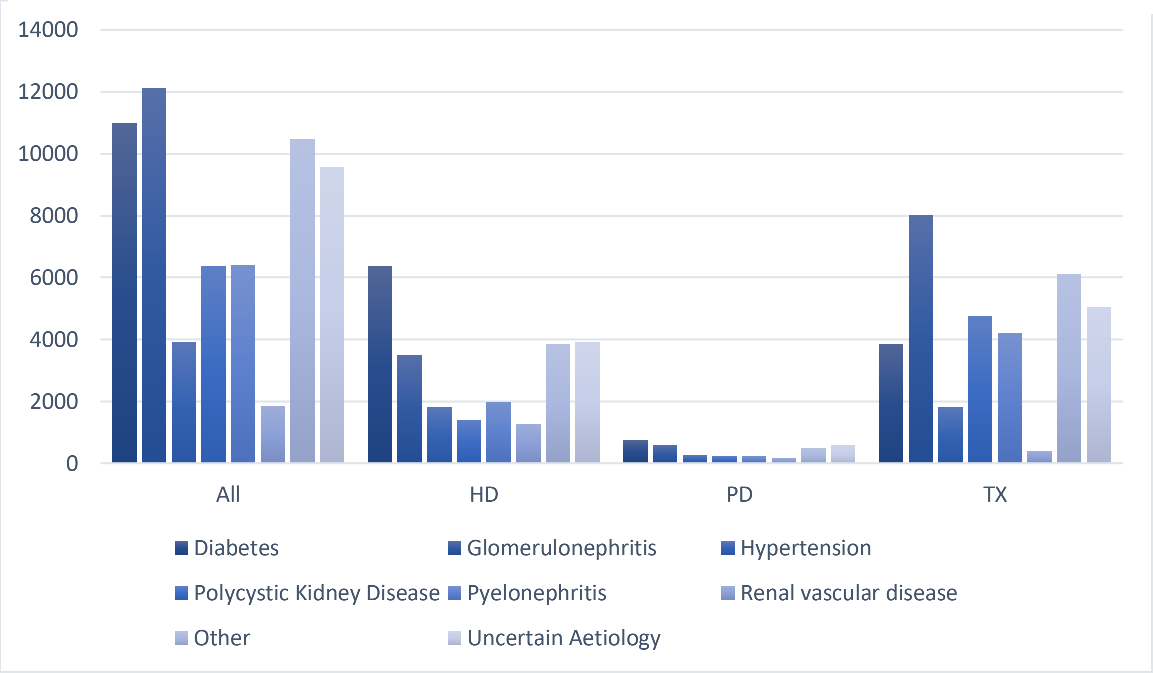
Asian and Black patients. There were also gender differences present in the number of new RRT presentations with the overall breakdown being 64.1% males and 35.9% females. Late presentations with ESRD are classed as those who commence treatment within 90 days of first contact with the renal service. In 2017 18.1% of RRT incident patients were classed as late presentations. Late presentation is important to consider when understanding patients experiences of dialysis because late presentation is indicative of lack of psychological preparation for RRT (Levin, 2000; Yokoyama et al., 2009).

In 2016, 64887 patients were receiving RRT in the UK (Peters, Westphal, Kramer, & Westerman, 2018) which was an increase of 3% from the previous year, this represents a prevalence of 983 pmp. This has increased significantly from the reported prevalence in 2000 which stood at 523 pmp. Out of the total number receiving RRT, 54.8% were transplant patients, 37.6% were receiving HD, 2.1% home HD and 5.5% PD. The cause of the increase in prevalence over recent years is unclear, there is an association between age and increases in renal replacement therapy though this is largely attributed to confounding variables (Herder et al., 2011). Moreover, increases in the prevalence of diabetes could be contributing to higher incidence of those receiving RRT, and advances in renal replacement technologies and treatments (Marshall et al., 2019; Yeo & Zhang, 2018) are likely to be accountable for the observed increases in improved mortality rates. The median age for patients on RRT was 59.2 years compared to 54.8 years in 2000 (The UK Renal Registry: Fourth Annual report, 2001). Patients age also varied significantly based upon dialysis modality - HD 66.8 years, PD 64.4 years and transplanted patients 54.8 years. This is potentially attributed to criteria which patients needed to meet to be eligible for the modality. The detailed reporting of prevalence in the UK provided valuable insight and allowed predictions and comparisons to be drawn between the sample characteristics and the reported data (section 4.4.1).

1.1.4 Causal factors

There are numerous causal factors contributing to patients developing ESRD. The primary renal diagnosis (PRD) for patients on dialysis in 2017 was Glomerulonephritis closely followed by Diabetes but this varies across modalities (**Figure 1.1**).

Figure 1.1 - Number of renal replacement patients by primary renal diagnosis.



Data adapted obtained from UK renal registry report (2018)

For dialysis patients the primary renal diagnosis is more likely to be diabetes, then uncertain or other aetiology whereas for transplant patients it is more likely to be glomerulonephritis, 'other or uncertain aetiology' then Polycystic kidney disease. This differentiation in PRD across RRT modality reflects the factors associated with underlying causes. Diabetes is a factor in renal disease because high blood glucose can damage the blood vessels in the kidneys, poor blood glucose control can contribute to kidney damage. However, this damage usually occurs gradually and is therefore more likely to be present with age. Glomerulonephritis is the term for a group of diseases that cause autoimmune damage to the glomeruli – the part of the kidney that filters the blood (Vinen & Oliveira, 2003). Glomerulonephritis is a cause of AKI and acute glomerulonephritis can occur suddenly, usually as a result of infections such as strep throat or illnesses such as Goodpasture's syndrome. Presentation can occur at any age, but it is one of the leading PRDs for patients under the age of 55 (UK Renal Registry, 2017). Therefore, partially explaining why this PRD is highest in the transplant modality, as younger patients are more likely to be assessed as suitable for transplantation due to fewer comorbidities and better overall health. Polycystic Kidney diseases is a genetic disorder that is characterised by fluid-filled cysts growing in the kidneys. These cysts can change the shape of the kidneys and reduce renal function. As this is a genetic disorder most cases occur where a child has a parent with the condition, although occasionally the mutation can occur on its own (Bergmann et al., 2018).

It is important to note and understand the cause of primary renal diagnosis which resulted in the need for RRT due to the potential differences in adjustment to treatment. Patients with Polycystic kidney disease have usually had prolonged contact with renal services. In 2017, 97.3% of patients who initiated RRT with a diagnosis of Polycystic kidney disease had been known to the renal services at least 90 days prior (MacNeill & Ford, 2017). For patients with a PRD of diabetes, this percentage drops to 92.4% but still accounts for most of the patients. For patients with a primary diagnosis of uncertain aetiology or 'other', the figures reduced to 84.1% and 64.9% respectively. This indicates that a greater proportion of patients with these diagnoses come to RRT with less than three months of preparation. This later referral has been associated with increased morbidity and mortality as well as significantly impacting patients QoL (Levin, 2000).

1.1.5 Treatment options

Patients with ESRD usually only have three treatment options they either require dialysis or kidney transplantation to survive, alternatively they can choose maximal conservative management. Understanding these options is important in perceiving patients experiences and potential future treatment options. Although this thesis focuses primarily on haemodialysis patients, some study participants will have experienced alternative RRT options and others may have been hoping for transplants or have been considering withdrawal from treatment.

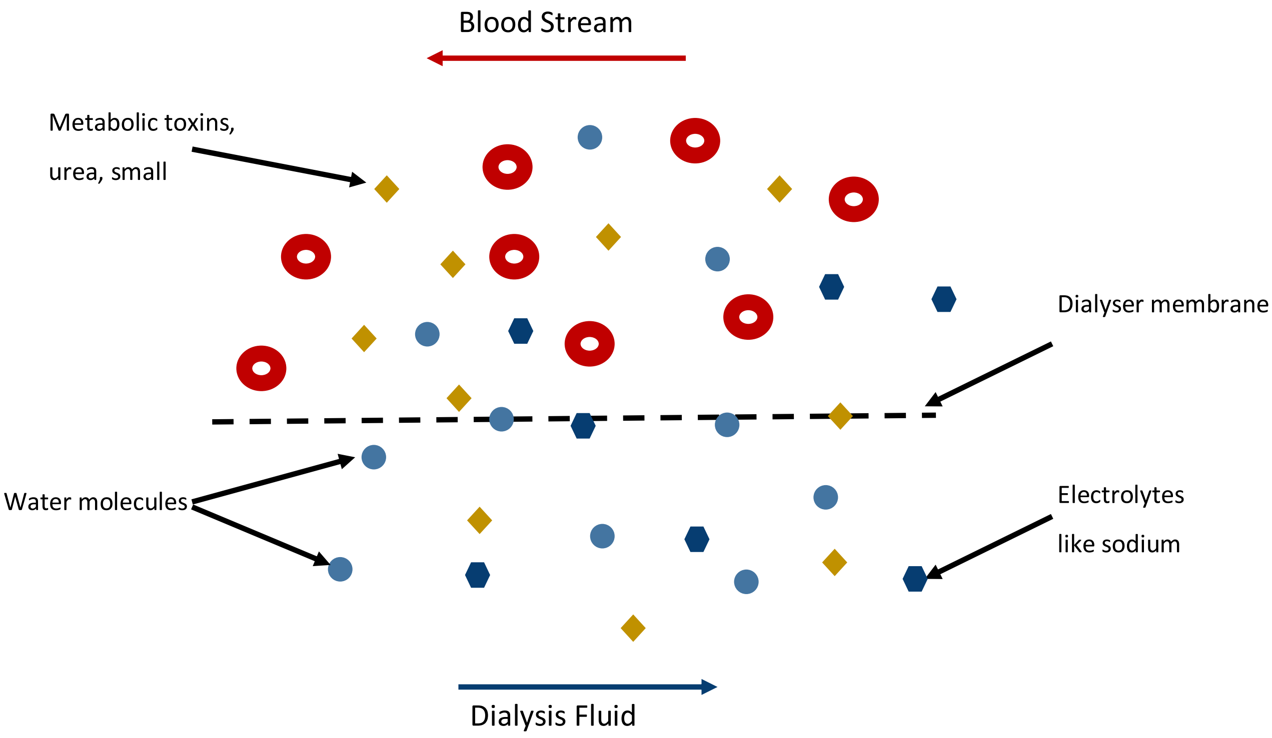
1.1.5.1 Dialysis

Dialysis involves the removal of waste products, salt and extra water to reduce the build-up in the body. It aims to keep levels of chemicals (potassium, sodium and bicarbonate) maintained at a safe level. There are two distinct types of dialysis, Haemodialysis (HD) and Peritoneal Dialysis (PD).

Haemodialysis

HD involves patients being connected to a Dialysis machine and the extracorporeal cleaning of the blood. Patients are connected to the machine through a fistula created in their arm, this allows access for patients to be connected to a machine with two small tubes. One tube takes blood away from the arm and into the machine whilst the other returns the cleaned blood. The Dialyser works by using an artificial filter containing fine fibres. These fibres are hollow with microscopic pores and filter the blood with the aid of dialysis fluid. The patient's blood flows through the inside of the filter in one direction whilst dialysis fluid runs through the filter in the opposite direction. Because of the semi-permeable membrane, the waste products which have built up in the blood can filter out of the blood and are drawn into the dialysis fluid through a natural process of diffusion (Figure 1.2).

Figure 1.2 - The process of diffusion in dialysis



Adapted from: (“Understanding Dialysis,” 2019.)

In addition to removing the build-up of waste products in the blood, haemodialysis uses a process of ultrafiltration to remove the water build-up which many patients suffer from as a result of difficulties passing urine. The ultrafiltration occurs as a result of the difference in pressure between the outside of the hollow fibre and that inside. If the pressure is lower outside, then the water will be removed. The whole process usually takes approximately 4hrs during which time the patient's blood will have circulated through the machine several times and will have been sufficiently cleaned.

Whilst dialysis carries out most functions of the kidneys it is not a complete replacement, therefore, patients need to take regular medications to help maintain blood pressure, lower phosphate levels and to prevent anaemia.

HD is a significant medical advance in the treatment of ESRD. The first successful dialysis treatment took place in 1945 and was carried out by Willem Kolff, but it was not until 1960 when the first patient started dialysis treatment for ESRD in America (Blagg, 2007). In the UK maintenance dialysis began shortly after, in 1961 at Royal Free Hospital and followed by other units including Edinburgh (1962) Newcastle (1963) and London (1964) (Hopewell, 2016) and in the mid, to late 1960s many units had opened. Originally HD took place primarily in hospitals but changed when home haemodialysis (HHD) was introduced towards the late 1960s (Crowther, Reynolds, & Tansey, 2009). There have been significant developments in dialysis technologies since their introduction with improvements in the machines, filters and techniques constantly developing currently established standards. In the UK for patients on HD, the recommended frequency and duration is 3 times a week for 4hrs, either at Hospital units or satellite clinics. Whereas for HHD, patients are able to dialyse to fit around their schedule e.g. 4 times for 4hrs, 5 times for 3hrs or overnight (Wilkie et al., 2019).

According to recent data the majority of UK patients dialyse in either satellite clinics (37.9%), hospital units (37.9%) or at home on HHD (4.4%). Over the past 15 years, there has been a clear reduction in hospital-based dialysis which has been mirrored by an increase in satellite delivered HD. During this time HHD has gradually increased but still accounts for a small proportion of patients on dialysis (Evans et al., 2018)

Peritoneal Dialysis

Peritoneal dialysis (PD) is carried out at home and uses the peritoneal cavity to act as a filter (McIntyre & Burton, 2009) patients circulate a dialysate into the cavity and this fluid absorbs waste products from the blood vessels in the peritoneum through diffusion. PD uses the peritoneum as the filter membrane which functions in a similar way to the HD. Dialysis fluid enters the cavity through a catheter in the abdomen. The fluid is held in the cavity for several hours to allow the waste products to diffuse into the fluid from the blood vessels in the peritoneum. Unlike HD water removal is achieved through the process of osmosis, facilitated by sugar contained within the dialysis fluid. After several hours the dialysis fluid which contains the waste products is removed and replaced with fresh fluid. This allows the blood to be constantly cleaned. There are two methods for PD; continuous ambulatory peritoneal dialysis (CAPD) and continuous cycling peritoneal dialysis (CCPD), also known as assisted peritoneal dialysis (APD). CAPD involves using gravity to move fluid through the catheter and involves fluid exchanges 3-5 times a day. CCPD uses a machine to perform multiple exchanges during the night whilst a patient sleeps. Latest guidelines state that peritoneal dialysis patients should be offered a choice of CAPD or APD where medically appropriate (NICE, 2018) however, in practice this modality is more often adopted by younger patients with fewer comorbidities (Evans et al., 2018) potentially due to the self-care required (Brown et al., 2010). Yet recent evidence questions this assumption with the finding that presumed clinical barriers were not evident in older patients (Lai et al., 2018).

1.1.5.2 Transplantation

Due to the improved quality of life (QoL) and life expectancy (Laupacis et al., 1996), kidney transplantation is often the preferred renal replacement option for patients with ESRD. Compared to dialysis patients there is a 95% 5-year survival rate post-transplant (from a living kidney donor) compared to 74.5% when looking at all RRT patients. However, the criteria for transplantation may contribute to the difference in figures. For a patient to be eligible for transplantation they need to be well enough to withstand surgery, be likely to accept the transplant and be willing to comply with medication and appointment requirements after transplantation (Wilkie et al., 2019). Patients may also be excluded from transplantation if they have significant health concerns, for example, severe heart disease, cancer with poor prognosis or AID’s. Therefore, out of 28876 patients receiving dialysis only 17.43% are active on the transplant list. Some patients receive kidneys from living donors, usually family or friends, for those for whom this is not an option they will be placed on the transplant list for a donated organ. In the year 2017-2018, there were 5,033 patients active on the kidney transplant list and there were 2573 transplants (1480 from deceased kidney donors), there were also 2908 added to the active transplant list during this time (*Organ*

Donation and Transplantation, 2018). For patients on the transplant list, there is usually a wait of several years before they are offered a transplant, this is partially due to the prioritisation of patients by the length of time on the list. After one year only 26% of patients active on the list are transplanted whereas by 5 years 72% have received a transplant. In 2017-18 the median wait for a kidney only transplant was 782 days, but this differs significantly by blood type, for example, the median wait time for patients with blood type AB is 231 days. During their time on the waiting list patients are advised to maintain a healthy lifestyle and to remain contactable and within reach of the transplant centre in case a donor organ becomes available. Whilst transplantation offers an improved quality of life and the potential for patients to remove the need for dialysis it is not a viable option for everyone. For those for whom it is an option the wait can be lengthy, and it is also not a guaranteed or complete solution; transplanted kidneys rarely survive more than 30 years. Some fail early with at least a 10% chance of failure in the first year, and that increases to a 20-30% chance by 5 years. When a transplant fails then patients' kidney function will again decrease, and they will need to consider other renal replacement options.

1.1.5.3 Discontinuation of treatment

The final option available to patients who reach ESRD is discontinuation of treatment. For patients who feel that dialysis is not improving or maintaining quality of life they have the right to stop treatment, usually dialysis. This decision is made by the patient with the patient's medical team and loved one's involvement. When a patient stops dialysis then the waste products begin to build up in their body and associated symptoms gradually appear. Once a patient ceases dialysis they usually survive for a couple of days to a couple of weeks. Out of 3418 deaths recorded for patients on RRT, 565 (16.53%) were due to treatment withdrawal (K. Evans et al., 2018). Treatment withdrawal was more prevalent in those over 65 with 18% of deaths in this age category being recorded as treatment withdrawal compared to 11% in those under 65. It is important to consider discontinuation of treatment as an option for patients as they are aware that this is a route they could take.

1.1.6 Impact of treatment

1.1.6.1 Physical consequences

The process of dialysis can have a significant impact on patients physically. Both during and after dialysis associated symptoms can impact patients. Fatigue has long been identified as a symptom patients experience after dialysis (Cardenas & Kutner, 1982) and is a complex area which has been under recognised in the dialysis population but can contribute significantly to a patients wellbeing (Jhamb, Weisbord, Steel, & Unruh, 2008). There are other acute symptoms HD patients frequently report including low blood pressure which presents with symptoms of nausea or dizziness, muscle cramps caused through fluid taken off during dialysis, and itchiness caused by mineral build up in the body between dialysis sessions. PD patients' regular symptoms may be less pronounced however they are at risk of peritonitis, a bacterial infection of the peritoneum. PD patients may be more likely to develop a hernia because the process places a strain on the abdomen, they may also put on weight due to the sugar contained in the dialysis solution.

Dialysis has long term physical implications for patients. CKD and ESRD are part of a complex relationship of cardio-pulmonary- renal interaction (Husain-Syed et al., 2015). Haemodialysis is associated with significant changes in blood pressure and systemic haemodynamics with intradialytic hypotension being a complication of treatment (Sulowicz & Radziszewski, 2006). Anaemia is another complication of dialysis and can be a contributory factor to cardiac events (Walker et al., 2006).

Furthermore, patients are subjected to a significant increase in overall and cardiovascular mortality (Levy, Viscoli, & Horwitz, 1996). For patients on RRT the leading cause of death is cardiac disease (22.7%) followed by infection (20 %) and treatment withdrawal (18%) however this is affected by age. For those under 65 the leading cause remains cardiac complications (28.9%) but in those 65 or over, the main causes are infection (20.9%), treatment withdrawal (20.9%) and cardiac disease (20.3%) (K. Evans et al., 2018)

Medical research has focused on approaches to treatment which may improve the outcomes for patients on Dialysis (Murali et al., 2019). Studies have highlighted that more frequent dialysis can infer clinical benefits for certain patients (Chertow et al., 2016; Fotheringham, Fogarty, El Nahas, Campbell, & Farrington, 2015) but also has the potential to improve health-related QoL (Garg et al., 2017). There has been a focus on advancing the understanding of intradialytic hypotension; through medications (Palmer & Henrich, 2008), technologies aimed at improving the dialysis regime (Selby et al., 2016) and exercise (Mcguire et al., 2018).

In addition to the physical consequences that dialysis triggers, there needs to be consideration into how the physical aspects have been implicated in QoL. One such study has identified that blood levels (HB) are associated with various domains of QoL, in that lower HB levels inferred lower QoL scores. (Bragg-Gresham et al., 2017). Further consideration needs to be given to the relationship between the clinical and psychological outcomes for patients on dialysis.

1.1.6.2 Cost to NHS

With over 28,000 people with ESRD receiving dialysis in the UK, and the vast majority (>25,000) receiving haemodialysis and a minority (approximately 3,600) receive peritoneal dialysis (MacNeill & Ford, 2017) the costs to the NHS are significant. Hospital-based haemodialysis costs over £27,000 per patient per year and consumes 1.3% of all NHS spending (Kerr et al., 2012). However, this cost is primarily related to the physical dialysis treatment and associated care, it fails to take account of the wider physical, psychological and social cost associated with dialysis. Therefore, it is important to maximise the benefits obtained by dialysis and improve patients' experiences of treatment.

1.1.6.3 Psychological consequences

Alongside the physical complications associated with dialysis, initiation and maintenance on dialysis has been associated with impact across an array of psychosocial factors. Some of the key associations are illness perceptions (Chilcot, 2012), depression (Chilcot, Wellsted, Da Silva-Gane, & Farrington, 2008), illness cognitions (Griva, Jayasena, Davenport, Harrison, & Newman, 2009), social support (Gurklis & Menke, 1995) and adherence (Alikari et al., 2018). However, these factors have often been overlooked in clinical research. It is therefore important to understand the psychological impact of dialysis, the associations with quality of life and the relationship with the clinical variables.

Depression has been reported to be four times higher in dialysis patients than the general population, with a review identifying reported prevalence in dialysis patients of between 5% and 71.4% (Chilcot et al., 2008), although it was noted some of this variance may be attributed to methodological issues with screening. Depression in dialysis patients has not only been linked to reduced QoL (Teles, Amorim de Albuquerque, Freitas Guedes Lins, Carvalho Medrado, & Falcão Pedrosa Costa, 2018) but also fluid adherence (Washington, Hain, Zimmerman, & Carlton-LaNey, 2018) and fatigue (Chilcot et al., 2016). Chilcot et al.

(2018) identified younger age, lower urine output and history of depression as consistent correlates of depression in HD patients. Poor adjustment to treatment is important because, in turn, it can relate to withdrawal from dialysis treatment, poor medication, poor dietary compliance and overall poor adherence (Taylor, Taylor, Baharani, Nicholas, & Combes, 2016). In addition to poor adherence, depression symptoms have been identified as predictive of all-cause mortality in HD patients (Chilcot et al., 2017).

However despite depression being identified as higher in the dialysis population potential barriers to accessing treatment have been identified by patients (Farrokhi, Beanlands, Logan, Kurdyak, & Jassal, 2017). When asked about barriers to participating in screening for depression programs, most patients identified at least one barrier to participation and those at greatest risk of depression described the highest number of barriers. Therefore, those most likely to benefit from the screening are the least likely to participate. Whilst it is perhaps understandable that patients may perceive the physical health problems they contend with as their priority, psychological barriers, denial and mistrust of mental health services are barriers that affect patient's participation in screening. This highlights that interventions specifically targeting depression alone may encounter difficulties in engaging patients in the process.

1.2 Psychological Background

1.2.1 Adjusting to Dialysis

1.2.1.1 QoL – Definition and concept

Quality of life has become a frequently used term in relation to health conditions and is often used as an outcome measure to assess the impact of interventions. The term quality of life began appearing in published research in the 1960's, but only in the past 20 years has it developed into a key outcome in the field of health psychology research. In the past 10 years alone there have been over 84,000 articles published in the field of health with over 2000 of these being in the area of renal disease (Table 1.2.1). With such a range of research claiming to be measuring QoL, it is important to understand what the concept is and how it is measured.

Table 1.2.1 - Search results for quality of life, health and renal disease over the past 60 years

	QoL	QoL and Health	QoL and renal disease
1960-1969	23	1	0
1970-1979	984	149	5
1980-1989	4032	538	10
1990-1999	35,692	8971	198
2000-2009	146,973	41,757	1,012
2010-2019	308,178	84,102	2,010

Search conducted 30/01/2019 – Quality of life mentioned in title, academic journals

Quality of life has been defined as;

"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (World Health Organization, 2019)

This definition clearly covers most areas of an individual's life but in health research the focus is often on health-related QoL (HRQoL) which evaluates the impact of health status on quality of life. Well-being, life satisfaction and comfort are terms which are also used to reflect an individual's state. Some research has used the terms interchangeably however whilst sharing common attributes differences have been identified between them. Well-being is found to be related to psycho-spiritual dimensions whilst comfort is a more holistic concept and QoL relates to an individuals' perception on their general life satisfaction (Pinto, Fumincelli, Mazzo, Caldeira, & Martins, 2017). The differences between these concepts is evident when examining how they are measured. HRQoL and wellbeing are primarily measured with standardised and established scales, some of which are general measures (Bowling, 2004) and others are disease (Bowling, 2001) specific.

1.2.1.2 HRQoL in Dialysis

HRQoL has been widely studied in dialysis patients, and from a variety of perspectives, with conflicting views emerging (Lopes et al., 2007; Vázquez et al., 2005). HRQoL is identified as both an outcome resulting from a combination of psychological and physical attributes but also as an influencing factor in patients clinical outcomes (Eneanya et al., 2019). This section explores these relationships and helps to clarify the importance of HRQoL in this population and identifies gaps in the research which informed the development of studies contained within this thesis.

1.2.1.3 QoL across dialysis modalities

QoL has been explored in relation to dialysis modality with inconclusive results (Boateng & East, 2011). Some evidence suggests that PD patients generally have better QoL than those on HD, although this was only identified in certain dimensions of QoL; kidney disease burden, patient satisfaction and support from staff (De Abreu, Walker, Sesso, & Ferraz, 2011). This finding is partially supported by a systematic review of studies exploring QoL across modalities (Ho & Li, 2016). 34 studies were included in the review and although overall no differences were found in HRQoL when looking at components of HRQoL (physiological, psychological, social and disease symptoms) a higher percentage of patients receiving PD had greater QoL scores across the components. This lack of clear conclusion is supported by a smaller review (Zazzeroni, Pasquinelli, Nanni, Cremonini, & Rubbi, 2017) which again found no significant difference overall but did identify that the burden of kidney disease was lower in patients on PD rather than HD. Further research has supported the finding that kidney disease burden is lower in PD patients however the research on the physical and mental component contradicted earlier suggestions with HD patients reporting significantly higher scores across both domains (Kang, Do, Lee, & Kim, 2017).

Recent research focusing on the longitudinal patterns in HRQoL by dialysis modality identified that in-centre dialysis patients had lower mean KDQoL scores in several domains when compared to those on home dialysis. In particular, the in-centre patients scored lower on the physical component scores than home dialysis patients however in the home category the PD patients had higher physical component scores, symptom problem scores, burden of kidney disease scores and effects of kidney disease scores compared to home haemodialysis patients. Interestingly it was also found that switching from home to in-centre dialysis was associated with a decrease in physical functioning (Eneanya et al., 2019). Although further clarification is needed to ensure that this is not attributed to a decline in physical state determining the modality change.

What may be a consideration with the lack of consensus across the results is that the studies were carried out in different countries and some of the differences may be down to local practices or cultural differences.

1.2.1.4 Characteristics affecting QoL

Physical and demographic attributes have been identified as important in QoL of dialysis patients, for example, obesity, age, gender, employment, income (P. D. Evans & Taal, 2015). Age has been identified as an independent factor in QoL for dialysis patients with increasing age being linked to improved QoL (Abdel-Kader et al., 2009). However, the influence of age must be considered in relation to the QoL domains being measured, for example; emotional QoL was identified as higher in older patients conversely physical functioning was lower (van Loon, Bots, et al., 2017). Similarly, self-rated health as measured by the EQ-VAS was identified as reduced in the more elderly but no significant difference was found for the EQ-5D-3 L components (Lowney et al., 2015). Even when measured through other scales such as the SF-36 there is support for the finding that age is associated with reduced physical QoL but not mental QoL (Ibrahim, Teo, Din, Gafor, & Ismail, 2015). These findings may be expected due to the natural physical deterioration that comes with age (World Health Organization, 2015).

Gender has been associated with differences in HRQoL across a range of conditions. Female cardiac patients were found to have reduced QoL compared to males (Emery et al., 2004; Gijsberts et al., 2015) and similar results have been evident in diabetic patients (Misra & Lager, 2009). However, the role of gender cannot be considered in isolation. For example, the impact of gender on QoL may be affected by age. In a chronically ill population younger men have been shown to have better physical health than older men, but for women older females were found to have better mental health than younger women (Jayasinghe, Harris, Taggart, Christl, & Black, 2013). This echoes earlier work which suggested that in HRQoL males have the advantage before the age of 45 but females have the advantage over 45 (Kaplan, Anderson, & Wingard, 1991).

In a similar manner to age and gender, employment and income have been associated with various QoL domains. In diabetes lower income is associated with reduced QoL (Glasgow, Ruggiero, Eakin, Dryfoos, & Chobanian, 1997; Wexler et al., 2006) and in ESRD unemployed patients scored lower across the QoL domains; physical function, role physical, bodily pain, general health, vitality and role emotional (Blake, Codd, Cassidy, & O'Meara, 2000). However, these studies did not evaluate the variables in isolation and therefore it is important that research into QoL take account of the impact of demographic factors.

Clinical biomarkers affecting QoL

Clinical measures are routinely taken to monitor dialysis patients, consequently research has explored the relationships between these biomarkers and QoL. These are important to consider when conducting studies of QoL in this population as they may be confounding factors to consider. However, the research in this area is inconclusive.

A review by Spiegel et al (2008) identified that dialysis adequacy (Kt/V) was a poor correlate for QoL and mineral metabolism (calcium phosphorous, PTH) and inflammatory markers (C-reactive protein, TNF) only showed small effect sizes and correlations. However, there were stronger relationships between nutritional biomarkers (albumin, creatinine and BMI) and mental and physical QoL (Spiegel, Melmed, Robbins, & Esrailian, 2008).

A later study has supported some of these findings with serum albumin and creatinine being positively correlated with physical component summary (PCS) scores and weaker correlates for (mental component summary) MCS scores being age, albumin and sodium (Broers et al., 2015). Other biomarkers of interest include vitamin d deficiency which has been associated with lower scores on the MCS but not the PCS (Anand et al., 2011). When exploring acceptance and personality in dialysis Poppe et al, identified that despite the inclusion of clinical measures they were not significant contributors to the overall regression model (Poppe et al., 2013). In PD patients creatinine, haemoglobin, serum pre-albumin, C reactive protein and haemoglobin were not found to be independently associated with QoL but Kt/V was significantly associated with the QoL domains of role-physical and sleep (Bakewell, Higgins, & Edmunds, 2002). However, not all clinical measures have associations with QoL, eGFR has been associated with depression but not physical or mental QoL (Campbell et al., 2013).

As with demographic characteristics, it is important that the clinical variables are considered in relation to the outcomes of interest. For example, in exploring the correlates of depression, it was identified that whilst urine output was significant to depression factors the measures of comorbidities, haemoglobin, serum albumin, CRP> mg/l, dialysis vintage, number of transplants and dialysis adequacy (Kt/V) were not (Chilcot et al., 2018).

Clinical variables have been associated with psychological factors which in turn relate to QoL, with Albumin and Haemoglobin levels being identified as independent risk factors for depression (Teles, Amorim de Albuquerque, Freitas Guedes Lins, Carvalho Medrado, & Falcão Pedrosa Costa, 2018).

1.2.1.5 Impact of HRQoL on clinical outcomes

HRQoL is important, not only because it relates to how patients feel in their daily lives but also because it has been linked to morbidity and mortality. Hall et al., identified that for dialysis patients the PCS of the SF-12 was most strongly linked to future hospitalisations and mortality (Hall, Luciano, Pieper, & Colón-Emeric, 2018). Similarly, a recent study has found that the MCS is not associated with mortality but lower PCS was (Pei et al., 2019). Physical function and walking behaviour have been associated with survival in CKD (Clarke et al., 2018). Serum Albumin and HRQoL have been identified as having predictive power for adverse events including mortality (Mapes et al., 2003) and therefore interventions to improve HRQoL should be viewed as a valued health care goal (Mapes et al., 2004). These findings have been supported by recent research which has related QoL in haemodialysis patients to serum albumin and in turn to clinical outcomes (Soleymanian, Nejati, Kabiri Esfahani, & Argani, 2017). Therefore, with QoL shown to be related to clinical outcomes in dialysis patients, it is important to consider the modifiable aspects related to QoL, particularly the impact of psychological components. In addition, further work is needed to understand how the physical aspects of QoL are implicated in the outcomes and why these have shown the strongest associations.

1.2.1.6 Psychological aspects of QoL

A cross-sectional study (Lowney et al., 2015) explored the influencing factors of HRQoL in Haemodialysis patients. This article suggested that it is difficult to differentiate between living with renal disease and the experience of deteriorating health due to renal disease. Therefore, it was proposed that QoL and symptom burden can inform when treatment needs to take a palliative turn. This study implied that dialysis can be a palliative treatment, which is supported by the suggestion that a palliative approach to dialysis can be beneficial (Grubbs et al., 2014). A palliative approach to treatment prioritises comfort and aligns with patient goals to reduce symptoms and improve QoL which contrasts with a disease-oriented focus in which dialysis is a rehabilitative treatment (Sawatsky et al. 2016). The distinction in treatment focus needs consideration in relation to QoL goal and interpretation (Kane, Vinen and Murtag, 2013).

To understand how best to manage the care of patients undergoing haemodialysis it is important to consider the symptom profile, to help facilitate identification of independent associations with HRQoL. Lowney et al's, (Lowney et al., 2015) cross-sectional study of UK haemodialysis patients measured symptoms through the Palliative Care Symptom Outcome Scale (PCSO) and HRQoL was measured using the EQ-5D-3. The results showed that the majority of haemodialysis patients experienced some symptom burden with more than 69% reporting at least 6 or more symptoms. Weakness, poor mobility and pain were the most frequently reported physical symptoms. In addition to the physical symptoms 44% reported depression and 40% reported anxiety. The key finding was that potentially modifiable symptoms related to QoL in dialysis were frequently reported and the symptom burden in renal disease was comparable to QoL reported in patients with advanced cancer and considerably lower than the age-matched population norms. However, it must be noted that there were differences in the way the components of QoL were associated with symptoms. For example, depression and transplant listing status were linked to poor quality of life as measured by the EQ-5D score whereas when using the EQ-VAS component breathlessness and itch were the key associations. Whilst the findings align to reports of lower depression and better HRQoL for dialysis patients accepted onto the transplant list (Osthus et al., 2012) discrepancy between measures raises questions about the utility of these measures in dialysis patients. Traditionally the EQ-VAS was the prelude to the EQ-5D yet now it is seen as a valuable tool to understand patients perspectives on their QoL however, the observed differences between the two may reflect the VAS measuring a broader construct of health, aligned to patients perspectives (Feng, Parkin, & Devlin, 2014). These findings highlight the need to consider the domains and constructs which are actually recorded in the selected QoL measure. With discrepancies related to societal valuation suggesting that the EQ-5D may underestimate the impact of dialysis on QoL (Voskamp et al., 2018) and comparisons favouring the SF-6D (Kularatna, Senanayake, Gunawardena, & Graves, 2019), questions are raised as to whether the EQ-5D is the most appropriate measure to capture QoL in haemodialysis patients. In addition, because symptoms have been associated with QoL, it is important to consider potential interventions that may be applicable and have the potential to alleviate some of the physical and mental symptom burdens.

In a comprehensive review of the psychosocial correlates of QoL, moderate associations between psychosocial variables and QoL in patients with ESRD were shown to be consistent across QoL domains (Chan et al., 2012). The study identified the level of association between psychosocial variables demonstrated a medium effect size (0.38) with affect and stress/stressor being the two categories which had the strongest correlations with QoL. Stemming from these findings it was suggested that QoL was largely influenced by psychological states rather than physical functioning. However, since no independent measures of physical functioning were included in the review this suggestion was still questionable. Additional factors of note in relation to the current thesis were that age and dialysis type were moderators between affect and QoL, although the mechanisms behind these associations were unclear. Study location, for example, country also impacted upon the strength of the associations. This suggested that generalisability of results between countries was questionable and differences might be influenced by clinical and cultural practices.

In pre-dialysis care, HQoL trajectories were examined in relation to the associated illness perceptions (Meuleman, Chilcot, Dekker, Halbesma, & van Dijk, 2017). Results showed that older age and cardiovascular disease were associated with poor physical QoL trajectories but in addition illness perceptions were linked to both physical and mental trajectories. Interestingly the study also concluded that despite there being different measures of QoL there were significant inter-correlations between them. The study concluded that psychosocial factors and in particular patients affect and cognitions were areas interventions may target to improve patients QoL and in turn potentially improve clinical outcomes. Whilst this study focused on pre-dialysis care the underlying mechanisms are potentially evident in haemodialysis patients and will be explored in this thesis.

1.2.1.7 Comparisons across chronic conditions

HRQoL is invariably linked to the type of health condition or conditions, which a person must manage. Across a sample of five conditions patients with Arthritis reported reduced QoL compared to those with Diabetes or Chronic Kidney disease (Ware, Gandek, Guyer, & Deng, 2016) however, this was closely linked to reported severity. For patients who self-reported their illness as being severe QoL was more impaired when compared to those who reported their illness severity as mild. This is an important consideration and suggests that when studying QoL a measure of disease severity should be included. However, diseases cannot be looked at in isolation as with ageing multi-comorbidities often become a factor. Evidence indicates that the more conditions an individual has to manage the higher the risk of disability and impaired QoL (McDaid et al., 2013). Kidney disease is often secondary to conditions such as diabetes and therefore comorbidities should be considered when conducting research with patients who have ESRD.

In patients on dialysis QoL has been identified as being affected by modality, with patients on HD having impaired QoL compared to those on PD (Dąbrowska-Bender, Dykowska, Żuk, Milewska, & Staniszewska, 2018). It is identified that this may be due to patients on HD being affected most by the ability to continue work and the change to life plans. However, this suggestion is in contrast to evidence which found intensive haemodialysis (short daily sessions) to be beneficial to QoL (Kraus et al., 2016).

QoL has been shown to be important in overall mortality for patients in the pre-dialysis population with QoL score being an independent predictor of all-cause mortality (Jesky et al., 2016). Which suggests that improving QoL may in turn relate to a survival advantage. However, this is in contrast to evidence suggesting that QoL was not associated with mortality (Grove, Schougaard, Hjollund, & Ivarsen, 2018). Interestingly these differences in findings may in part be explained by differences in measuring QoL. When utilising a different measure of QoL (KDQoL-36), the physical component scores were found to be associated with mortality and hospitalisation risk whereas other components did not show the same association (R. K. Hall et al., 2018; Lacson et al., 2010; Østhus et al., 2012). This suggests that specific aspects of QoL can be related to physical outcomes. Potentially this could be related to a characteristic of the sample population, in younger patients the mental component score has been found to be independently associated with death whilst the physical component score was only associated with risk of hospitalisation (Porter et al., 2016).

However, QoL cannot be examined in isolation as it does not have a homogeneous impact. For example, depression when comorbid with physical diseases incrementally affected HRQoL (Park, Rim, Kim, & Park, 2019). More specifically in dialysis patients depression has been linked to the emotional component of QoL (Rubio, 2017).

1.2.2 Psychological interventions

The evidence reviewed thus far indicates that HRQoL can be related to clinical outcomes for patients but although promising the evidence is not conclusive and lacks clarity about the importance of specific domains of HRQoL. HRQoL has been associated with clinical and psychological correlates both in patients with ESRD but also within wider clinical populations. These results suggest that not only is an improvement in HRQoL a potential benefit to patients, but the improvements may infer clinical gain. It is therefore important to understand the evidence and theory behind current psychological interventions and how they have been related to HRQoL

1.2.2.1 In Dialysis

In a review of self-management programs for dialysis patients associations were identified with improvements to depression and mental QoL but not eGFR and physical QoL (Lee, Wu, Hsieh, & Tsai, 2016) which suggests there are promising applications for self-management techniques but they do not address all aspects. It therefore suggests other approaches may be needed to tackle the physical component. One of the most established psychological therapies is cognitive behavioural therapy (CBT).

Cognitive behavioural therapy is a psychotherapy treatment which focuses on relationships between a person’s thoughts, feelings and behaviours and helps patients identify and change behaviours or beliefs. Brief cognitive behavioural (CBT) interventions for depression and anxiety have been found to improve QoL in dialysis patients in association with reductions in depression and anxiety (Lerma et al., 2017). Various approaches can be taken with CBT and there have been promising results for CBT interventions which incorporate mindfulness (Sohn et al., 2018). Group CBT has also been shown to improve depression and aspects of QoL in haemodialysis patients, interestingly it has been shown to be effective for the mental component of QoL but not the physical component (Duarte, Miyazaki, Blay, & Sesso, 2009). CBT has been adapted to help dialysis patients adapt to a specific symptom of dialysis, fatigue (Picariello, Moss-Morris, et al., 2018)

However, there are barriers to the delivery of psychological interventions, particularly with dialysis patients as the interventions usually involve patients committing a significant amount of their time. There have been other alternatives to the traditional face to face option which have been explored. Promising improvements to QoL and reductions in depression and anxiety have been shown through internet delivered CBT, however, this has only been demonstrated on a small scale (Chan, Dear, Titov, Chow, & Suranyi, 2016). In addition whilst online delivery may be feasible computer literacy may be a barrier preventing many patients taking up this option (Hudson et al., 2017).

Interestingly the interventions developed, specifically seem to address the mental component of QoL and associated psychological constructs (depression, anxiety) however the physical component of QoL shows little if any change through these interventions. Similar findings are present in diabetes patients with online CBT interventions showing changes in MCS and not PCS (Newby et al., 2017). This suggests that there is scope to explore or develop interventions which might address physical as well as mental QoL.

1.2.2.2 Across Chronic conditions

Across other chronic conditions alternatives to the traditional CBT approaches have been associated with promising improvements across QoL domains. Interventions have shown benefits across a range of conditions, for example, self-compassion has been proposed as a protective factor in HRQoL (Kim & Ko, 2018), a low-intensity acceptance intervention has been associated with significant changes in PCS and MCS in chronic pain (Baranoff, Hanrahan, Burke, & Connor, 2016) and group based acceptance and commitment therapy (ACT) interventions have been related to QoL improvements in both physical and emotional wellbeing (Han, Liu, Su, & Qiu, 2019). In Haemophilia related joint pain acceptance rather than coping has been suggested as a useful behaviour change target (Elander, Morris, & Robinson, 2013). ACT has shown to be a promising intervention for patients with chronic pain but there are potential challenges in implementation in real-world clinical practice (Feliu-Soler, Montesinos, et al., 2018). The promising support for ACT based interventions in conditions like chronic pain which cannot be improved indicates that this might be an applicable approach for interventions with dialysis patients.

1.3 Acceptance approaches

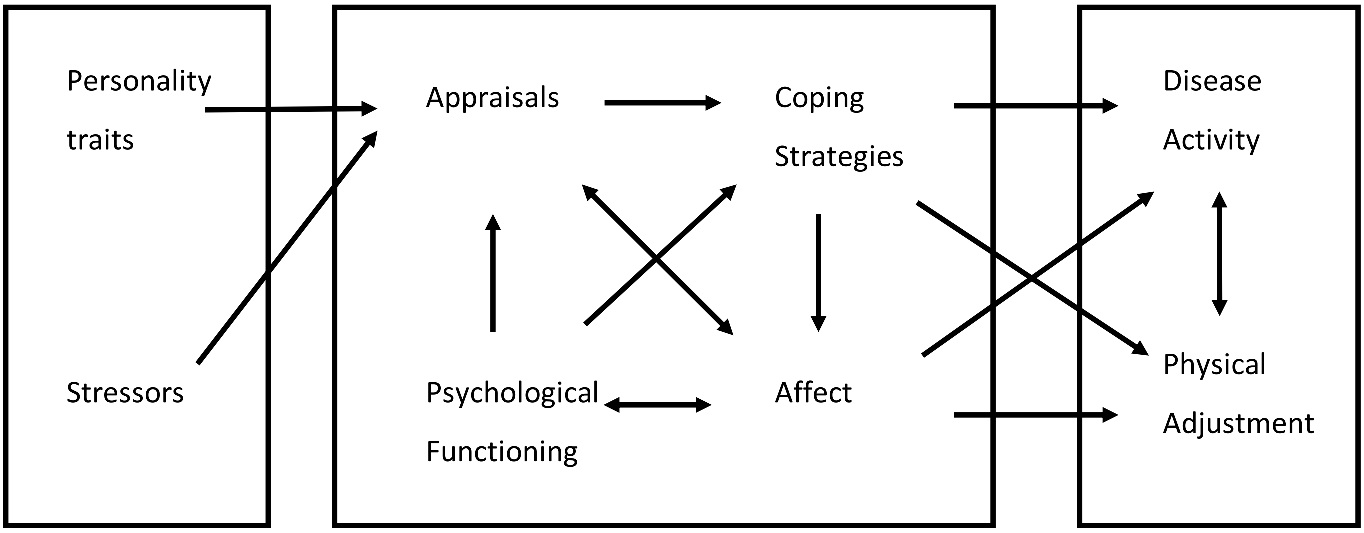
In similarity to other chronic conditions patients with ESRD have to make significant adjustments to their daily lives in order to manage the dialysis regime and associated symptoms. From initial diagnosis through to long-term maintenance on dialysis, patients have to manage their illness. Typically, in lay terms this is talked about in relation to patients **accepting**, **adjusting** to or **coping** with their illness. However, scientifically it is important to be clear what this relates to and how these terms relate to different aspects of illness.

1.3.1 Adjusting to illness

In an editorial piece Moss-Morris (Moss-Morris, 2013) discussed approaches to adjustment in chronic illness and argued for an overarching theory to specify the process of adaptation; proposing a new working model of adapting to chronic illness. Moss-Morris argued that despite the term adjustment being frequently used there is no consistent definition to the construct, in light of this view the same could be said for the term acceptance. From a mental health perspective adjustment has been related to the presence of psychopathologies however adjustment is linked to measurable symptomologies and fails to account for processes beyond the influence of affect. From the perspective of health psychology adjustment is typically defined as preserving functional status and managing affect in the face of illness (Stanton, Revenson, & Tennen, 2007) however this might not be applicable or entirely realistic across differing conditions. Adaption can be seen as an ongoing process, which may alter in relation to disease trajectory and the desired outcomes may also change accordingly. It is argued that adjustment should be multi-dimensional and relate to psychological, social and physical adjustment. From a health psychology perspective coping is often applied to help understand differences in adjustment – particularly the stress and coping model (Lazarus and Folkman, 1984). The crisis theory (Moos & Schaefer, 1984) has also suggested seven categories of adaptive tasks that are core to adjustment. This approach distinguishes between appraisal-focused coping, problem-focused coping and emotion-focused coping. It could be argued that acceptance may be a form of appraisal-focused coping, involving accepting the reality of a situation and redefining it as positively acceptable. However, learning to tolerate or accept difficulties and coming to terms with inevitable outcomes is also part of emotion-focused coping, which may be more important than problem-focused coping from the point of view of maintaining psychological wellbeing (Walker et al., 2004).

Hammond and Hirst-Winthrop (Hammond & Hirst-Winthrop, 2016) sought to understand the process of adjustment in those patients with type 2 diabetes. They suggested that adjustment "has been conceptualised as both a state and a process". With state being an optimal level of functioning within the constraints of the condition. However, before the state is achieved there is a period of adaptation and change. This is considered a process of adaptation. The process of adaptation is complex with a range of theories, including the World Health organisation international classification of functioning, disability and health (ICF) and stage models. Walker et al (2004) suggested a model of adjustment to chronic illness (Figure 1.3) and there are stage models based on the role of illness beliefs that have been suggested. Hammond and Hirst-Winthrop suggest that in type 2 diabetes, patients are on a continuum of adjustment.

Figure 1.3 - Model of adjustment to chronic illness (*adapted from Walker et al (2004)*)



Moss-Morris's (Moss-Morris, 2013) proposed a working model of adjustment, incorporates personal background, illness characteristics, social and environmental factors that are then link to critical life events and ongoing illness stressors. These lead to disruption to emotional equilibrium and quality of life which then leads to the employment of various strategies to achieve; either successful adjustment or adjustment difficulties and in turn good or poor psychological, physical and social adjustment. The factors associated with adjustment are highlighted in Table 1.3.1.

The factors identified in Table 1.3.1 are those which appear consistently across illness groups however it is argued that there is a need for evidence from specific illness groups. It is proposed that the role of each factor might be more influential at specific stages of illness. The example given by Moss-Morris suggests that acceptance and self-compassion might be more important as a disease progresses as opposed to problem coping strategies.

Table 1.3.1 - Comparison of factors associated with successful adjustment and adjustment difficulties

Successful Adjustment	***Adjustment difficulties***
Cognitive	*Cognitive factors*
Self-efficacy	*High Perceived stress*
Positive reinterpretation	*Coping with wishful thinking*
Acceptance of illness	*Negative illness/symptom representations*
Higher perceived social support	*Dysfunctional cognitions/cognitive errors*
	e.g. Catastrophizing
	Helplessness
	Suppression of negative affect
Behavioural	***Behavioural***
Coping – problem-focused and/or seeking social support	*Coping through avoidance*
Engagement in good health behaviours	*Unhelpful responses to symptoms*
Adherence to medical and self-management	*Venting or denying emotions*
Regimes	
Maintaining activity levels in the face of illness	
Appropriate expression of emotion	

Adapted from Moss-Morris, 2013

The working-model proposed by Moss-Morris attempted to standardise the thinking in this area and helped conceptualise the approaches. What is clear is that here adjustment, whilst still viewed as an ongoing process, is based on illness trajectories and has clear outcomes relating to the success of the adjustment. As with Walkers model (2004) of adjustment numerous factors are implicated. Internal factors; coping appraisal and affect, and external factors; personality and illness specific aspects are key in both approaches, but the working model included social and environmental factors. Of note, one factor implicated in adjustment is acceptance, suggesting that acceptance and adjustment are two different but linked processes.

Acceptance was also identified in the THRIVE framework as important to values and beliefs (White, Issac, Kamoun, Leygues, & Cohn, 2018). The THRIVE framework arose from a review of coping mechanisms for chronic conditions. The six groupings identified in coping were: therapeutic interventions, habit and routine, relational -social, individual differences, values and beliefs and emotional factors. This framework provided an overview of the multidimensional nature of chronic conditions and emphasised the necessity of the biopsychosocial approach. This framework distinguished between external and internal factors, highlighting that these are not mutually exclusive. However, this framework arose through a review across chronic conditions therefore the extent to which it applies in ESRD is still to be tested.

A review (Dennison et al., 2009) into patients adjustment to Multiple Sclerosis (MS) explored variables important to this process. They focused on psychological factors as predictors of individual differences in adjustment which is important because psychological factors have the potential to be more modifiable than illness factors. Psychological factors were defined as “potentially modifiable factors relating to individuals’ attitudes, thoughts, feelings and behaviours”. Acceptance was identified as one of five factors in the sub-category of positive psychology but was only measured in two studies out of 72, compared to thirty that looked at coping. Indicators of adjustment were looked at as depression, distress, anxiety, QoL, relationship satisfaction and social adjustment. Since the publication of this review numerous studies have explored the impact of interventions to improve psychological aspects of MS. These interventions have shown promise in areas including mindfulness (Simpson, Mair, & Mercer, 2017; Spitzer & Pakenham, 2018), positive psychology (Anderson, Turner, & Clyne, 2017; Leclaire et al., 2018), and prognosis communication (Dennison, Brown, Kirby, & Galea, 2018). However, there has still been limited study of acceptance in this population and although acceptance has demonstrated potential importance in MS patients QoL, further investigation was suggested (Van Damme et al., 2016). Therefore, whilst acceptance is theoretically an area of importance in relation to patient’s adjustment to MS there is limited evidence to support or refute the claims.

1.3.1.1 Coping with illness

The alternative view is that acceptance can be part of coping, which itself is often included in models of adjustment (Sharpe & Curran, 2006). One analysis of acceptance as coping distinguished between what can be termed “active acceptance”; an adaptive response to unchangeable circumstances, and “resigned acceptance”; maladaptive coping associated with negative psychological outcomes (Nakamura & Orth, 2005).

Despite coping being identified as a separate factor to acceptance in the adjustment models mentioned previously, acceptance has been linked to coping. In fact, acceptance has been presented as a strategy for coping with problems e.g. optimists might use acceptance as a coping strategy. One key indicator demonstrating that acceptance is frequently seen as a component of coping is that it is one of the measures of the COPE (Carver, 1997).
In the Dennison review emotion-focused strategies were consistently related to negative adjustment, wishful thinking and escape avoidance were strong correlates and predictors of poor adjustment (Dennison et al., 2009). Whereas problem focused and adaptive emotion focused coping strategies (positive reappraisal) were linked to better adjustment. However, the amount of variance accounted for by the coping strategies had considerable variability.

1.3.1.2 Acceptance

In the Dennison review it is noted that despite the widespread belief that acceptance is beneficial to adjustment only two studies (out of 72 identified) looked at acceptance. Both looked at the impact of acceptance on marital relationships, and even then, the findings were inconclusive. Overall, the review concluded that limited evidence about the role of acceptance prevented firm conclusions from being drawn.

In a subsequent cross-sectional study (Dennison, Moss-Morris, Silber, Galea, & Chalder, 2010), Multiple sclerosis acceptance was linked to general health questionnaire scores, suggesting that acceptance was related to less distress. However, the regression analysis did not identify acceptance as a significant predictor of distress when examined alongside unhelpful beliefs about the self.

Acceptance, on the other hand, can be a stage that is reached, as in Kubler Ross's model. Here acceptance is viewed as a state of peace and resignation to the inevitable and that acceptance is a positive outcome in the adjustment process. Suggesting that, rather than being a factor leading to adjustment, it is the successful result of achieving adjustment.

There has been the suggestion that "the terms acceptance and denial of illness … have little or no meaning for those with chronic illness" (Telford, Kralik, & Koch, 2006), argued against the stage approach. The paper concluded by suggesting labels of acceptance and denial are not necessarily useful for health professionals as this can result in inattention to the full stories of chronic illness presented by patients. Whilst this may hold true in relation to the consultation process, it does not mean that the concepts themselves do not exist.

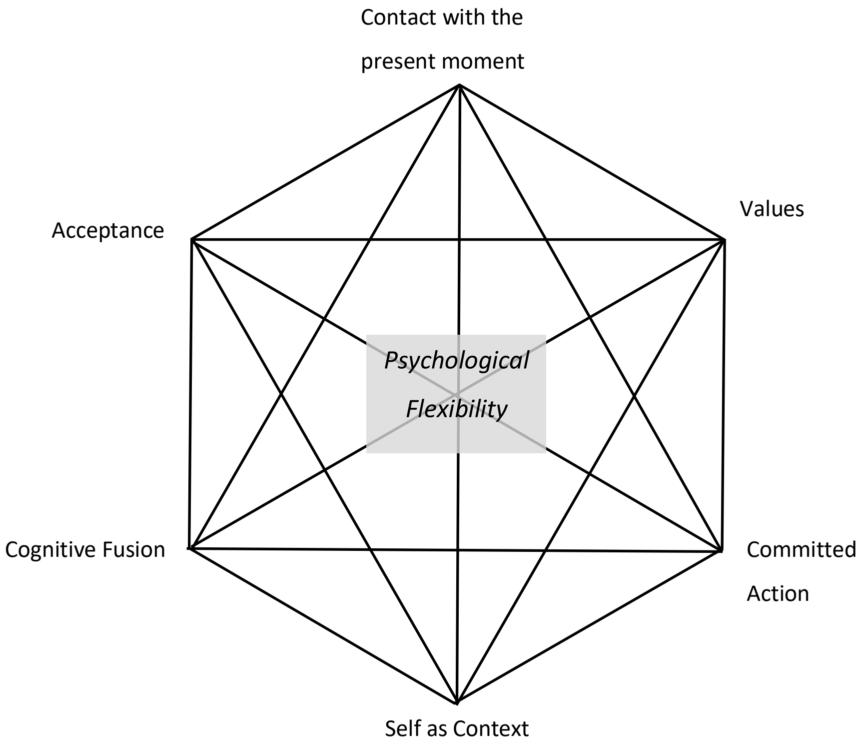
1.3.2 ACT -Definition and Background

The Acceptance and commitment approach (ACT) (McCracken & Vowles, 2014) is based upon relational frame theory (Hayes, Luoma, Bond, Masuda, & Lillis, 2006) which has its core in functional contextualism. ACT is behavioural but yet based upon "comprehensive empirical analysis of human cognitions" (Hayes p640). In ACT acceptance is "the active non-judgmental embracing experience of the here and now". Acceptance means actively accepting events as they are, not just accepting the perception of events. Values are important in ACT and are a key differentiating factor between ACT and other approaches. Once values are established then achievable value-based goals can be developed and actions and barriers to achieving the goals can be established. ACT is as interested in change strategy as it is in acceptance.

1.3.2.1 Theoretical basis for ACT

ACT is based upon the psychological flexibility model and the goal of ACT is to increase psychological flexibility. There are six core processes to ACT which are represented in the hexoflex diagram (Figure 1.4). Here acceptance is just one of the six processes and is thought to work through mindfulness and acceptance processes to increase values-based action. It has been proposed that the fusion of the common-sense model of self-reflection (CSM) and ACT may be a way forward in improving patients adaption to chronic health conditions and in enhancing their well-being and health. (Karekla, Karademas, & Gloster, 2018)

Figure 1.4 - Hexoflex of the acceptance and commitment process



Adapted from (Prevedini et al., 2011)

Psychological flexibility refers to an individual’s ability to consciously connect to the present moment and change their behaviour in line with their values (Hayes et al., 2006). Increasing psychological flexibility allows people to disengage from cycles of experiential avoidance and cognitive fusion. In the psychological flexibility model, acceptance is viewed more as a system of change rather than an end process, (Baer, 2010). As McCracken states “acceptance is not solely a pattern of overt action nor certainly a process solely based on cognition and belief. It is a process with interactions between action and experiences” (McCracken, 2010, p 1).

The psychological flexibility model has six processes (as discussed in section 1.3.2.1, p30) and these have been identified as a focus for process change in treatment (Levin, 2012). The model suggests that instead of focusing on attempting to change the intensity of the distressing experience the focus should be on how patients relate to the distressing internal experiences and from there they can develop value-based actions. Across the 6 core processes it has been suggested that there are core attributes of the process with which patients engage (Table 1.3.2)

Table 1.3.2 The identified components and intervention examples indicative of each process within ACT

Process	**Identified action**
Acceptance	Participants sit with, lean into, or relate to difficult thoughts in an accepting way
	Discussing how to practice acceptance
	Discussing or helping participants to notice the negative effects of suppression and avoidance
	Specifically targeting letting go of unhelpful experiential avoidance strategies
Defusion	Helping participants react in a literal way
	Guiding participants to let go of judgements and evaluations
	Instructing participants to engage in actions independent of their thought
Self as context	Contacting a sense of self
	Adopting a distinct observer perspective
	Using perspective taking to evoke support for flexibility
Committed-action	Making value led commitment
Values	Discussing the central feature of values
	Clarifying values
	Relating personal values
Mindfulness	Instructed mindfulness techniques or exercises

A meta-analysis into the efficacy of ACT interventions identified that acceptance or acceptance mindfulness interventions were frequently used approaches, whereas no interventions focusing of on self-as-context or committed action alone were identified (Levin, et al., 2012) . A key finding from this study was that acceptance was found to have an impact on primary theoretical outcomes in the psychological flexibility model. Therefore it was suggested that greater focus on components in isolation would be beneficial.

Considering the potential benefits of acceptance to psychological flexibility it is also important to note that acceptance is contained in other models of intervention, for example cognitive behavioural therapy (CBT) (Hayes et al., 2011). Therefore the utility and understanding of the process and outcome of acceptance across conditions is beneficial for informing how a range of interventions can be developed and refined. This is particularly important given that recent research has identified that acceptance has; utility as a potential mediator of quality of life in Irritable Bowel Syndrome patients (Bowers, Gillanders, and Ferreira, 2020), a mediating effect on psychological adjustment in cancer patients (Chen et al., 2020), and a mediating effect on change in physical functioning in patients with chronic pain (Cederberg, 2016).

Acceptance is a component of the psychological flexibility and coping models had is a potentially trainable construct and a core target of ACT and CBT based interventions therefore it seems reasonable that understanding this process and the potential impact of acceptance within the haemodialysis population warrants further focused study and therefore became the foci for this thesis. Particularly since illness acceptance has been identified as being core to quality of life improvements in other conditions (Bowers, Gillanders, and Ferreira, 2020).

1.3.2.2 ACT in practice

ACT interventions have been adapted with some success with the aim of improving quality of life, lifestyle and self-management for people with chronic conditions including cancer, cardiac disease, type 2 diabetes, epilepsy, multiple sclerosis, cerebral palsy, paediatric brain injury and other life-threatening illnesses (Graham et al., 2016), however the quality of studies reviewed was generally low.

An ACT group intervention for patients with a variety of long term conditions has shown promising findings (Brassington et al., 2016). The intervention was based upon ACT protocols for health conditions and has demonstrated that post-intervention reductions in depression and anxiety can be maintained. However, despite there being no overall improvements in QoL there were improvements in certain domains; physical limitations, emotional limitations and in the emotion domains. Suggesting that the intervention reduced the extent patients were limited by their condition and there was a trend suggesting that social QoL may also be improved.

ACT has become a more established intervention and an alternative to CBT for chronic pain patients, with studies supporting its effectiveness as a treatment. (McCracken & Vowles, 2014). A review of the evidence stated that ACT has the potential to be a cost-effective treatment avenue (Feliu-Soler, Cebolla, et al., 2018; Feliu-Soler, Montesinos, et al., 2018) however there needs to be consideration of how benefit may be maximised and whether interventions should be targeted. There is evidence suggesting that ACT may not be as beneficial to patients with low levels of mental resilience (Trompetter, Bohlmeijer, Lamers, & Schreurs, 2016). It may also be the case that certain aspects of ACT, such as psychological flexibility are important in mediating the effects of interventions (Lin, Klatt, McCracken, & Baumeister, 2018)

Chan (2013) suggested that acceptance in ACT has two components; one involving acknowledgement of experiences of illness without engaging in dysfunctional coping, the other involving active integration of the illness into life and pursuing important goals or values.

1.3.2.3 Acceptance Summary

In summary, despite the lack of consensus as to the definition of adjustment, it seems that several models view acceptance and coping as two processes/factors which contribute to a person’s adjustment to chronic illness. These are just two factors amongst many which are identified in the adjustment process. The extent to which these exert influence in the adjustment process can be affected by external factors, for example, critical life events and illness stressors, and individual characteristics. The role that coping adopts within the adjustment framework has been more widely researched in both general terms and in specific illnesses, but the role of acceptance is less clearly understood. Acceptance is currently a commonly used term and often seen to be important in illness management and behaviour change, but the underlying processes involved and the influence of acceptance needs to be examined. This will facilitate the development of both theoretical constructs and associated interventions in this area.

1.3.3 Evaluating the role of acceptance in Dialysis

Acceptance has shown promise in other chronic conditions and therefore is a potential area to inform the development of interventions for dialysis patients. Research in ESRD has begun to feature in qualitative and quantitative research into acceptance (Stalker et al., 2018) however there is no consensus about how acceptance relates to ESRD patients, or how acceptance links other factors. The systematic review (chapter 2) summarises the limited evidence for the role of acceptance in ESRD whilst informing the development of the empirical studies.

1.4 Rationale and aims of the research

1.4.1 Knowledge gaps and research objectives

1.4.1.1 Objective 1 To review the empirical evidence relating to the role of acceptance in ESRD/Dialysis

The introductory review of the literature highlighted that acceptance is a construct which fits into an overall model of adjustment. Whilst there is strong evidence that acceptance can be associated with adjustment to illness across other conditions there is no systematic review of acceptance in dialysis patients. With variation in methods, terms and approaches to studying acceptance it is important to understand the evidence base and factors deemed relevant to acceptance in the dialysis population. This knowledge gap informs the first research objective which is met through a systematic review and synthesis of qualitative and quantitative evidence of acceptance in ESRD (Chapter 2).

1.4.1.2 Objective 2 To qualitatively explore what acceptance means for Dialysis patients.

The current literature on acceptance in ESRD is limited and far from conclusive. Acceptance has been proposed in various forms, coping, accepting illness and through illness perceptions. It has been proposed that acceptance can be either positive or negative however there is a lack of understanding about how patients themselves view acceptance. To address this knowledge gap a qualitative study (Chapter 5) aimed to understand patients experiences of accepting their illness.

1.4.1.3 Objective 3 Compare the influence of psychological factors derived from contrasting theoretical models of adjustment (models of coping versus acceptance), on patient outcomes.

The current literature suggests that a range of clinical, demographic and psychological factors are associated with QoL outcomes however it is yet to be established how acceptance is related. Therefore, the cross-sectional study evaluated acceptance in comparison to other measures to identify the potential relationships between clinical, demographic and psychological factors (Chapter 4).

1.4.1.4 Objective 4 Measure and model acceptance and QoL measures longitudinally alongside the physical/clinical measures

In reviewing the literature there was a lack of longitudinal studies on acceptance and psychological variables in dialysis patients. To understand the processes involved and the causal factors associated with acceptance and QoL the final study took a longitudinal approach to firstly address how acceptance changed over time and secondly to address the clinical and psychological factors (including acceptance) associated with changes in QoL (Chapter 5).

1.4.1.5 Objective 5 To understand how the qualitative and quantitative perceptions of acceptance are related.

The studies adopt a mixed method approach therefore the final objective is to compare the findings of both approached to establish how the quantitative and qualitative findings are related and how they can inform theoretical perspectives and future research developments (Chapter 7).

1.4.2 Conclusions and implications for this thesis

This chapter has described the medical background to ESRD and dialysis treatment. Based upon the evidence presented, QoL in dialysis patients has shown to be impacted by clinical, biological and social factors yet to date there has been limited focus on psychological approaches to improve QoL. Current research has predominantly focused on affect, and whilst this is of clear importance and is considered in this thesis the literature review identified that acceptance was a potential alternative approach. This introduction has highlighted how acceptance has been identified as important for QoL in conditions such as chronic pain which cannot be improved medically and therefore has suggested that similar acceptance processes might be of relevance to dialysis patients. The systematic review in the next chapter summarises and evaluates the limited evidence for the role of acceptance in ESRD and informs the development of the later research studies into acceptance in haemodialysis patients.

Chapter 2 – Acceptance of illness in patients with end stage renal disease: A systematic review

The literature reviewed in chapter one identified that acceptance is not a clearly defined concept across the evidence base and that measurement of acceptance is varied. To date, acceptance has not been a sole focus of research into patients' experiences of ESRD but it has been included as a component of a number of studies (Chan, Brooks, et al., 2011; Karademas et al., 2009). This creates a question about what the current evidence is for the role of acceptance in patients' experience of ESRD. This chapter presents a systematic review and synthesis of the quantitative and qualitative evidence for the role of acceptance in ESRD.

2.1 Introduction

Chapter one highlighted that acceptance could be associated with the term's acceptance, adjustment or coping with illness. Chan's review (Chan, 2013) emphasised the importance of acceptance and provided an overview of acceptance in ESRD, and raised questions about whether there were different types of acceptance. The initial literature review presented in chapter one was the basis of a narrative review of acceptance in dialysis patients (Stalker et al., 2018) however the present chapter expands these findings by reporting the results of a systematic review exploring the impacts of acceptance on outcomes for patients with end-stage renal disease and how patients view acceptance.

2.1.1 Systematic review background

Reviews can take on a variety of forms, for example, less rigorous approaches are narrative, critical, scoping, or conceptual (Grant & Booth, 2009), however the overarching similarity with these approaches is that they are usually informed by a personal selection of the material reviewed. As a result, whilst these approaches can produce insights and facilitate development of thinking there is the potential for bias in the approach. In an attempt to reduce bias a systematic review is "a review with a clear stated purpose, a question, a defined search approach, stated inclusion and exclusion criteria, producing a qualitative appraisal of articles" (Jesson, Matheson, & Lacey, 2011, p12). The clear structure and stages of a systematic review reduce bias through utilisation of robust methodology, therefore resulting in such reviews being widely regarded and valued. Systematic reviews, syntheses of qualitative evidence and meta-analyses have become expected in health research and allow comparisons to be drawn across several studies. The introduction of specific journals devoted to review articles for example Health psychology review (Forshaw, Tod, & Eubank, 2018) emphasises the importance placed upon good quality review studies. Clear guidance has been developed for conducting and reporting of systematic reviews in the form of the Cochrane handbook for systematic reviews (Higgins, Alderson & Clarke, 2011). Originally the focus of the Cochrane reviews was on quantitative reviews of interventions but in more recent years the scope has widened to include qualitative evidence. The York Centre for reviews and dissemination has produced guidelines for conducting a systematic review (Centre for Reviews and Dissemination, 2009) and the Joanna Briggs Institute has produced guidance on array of systematic review approaches ("Joanna Briggs Institute," 2019). The later includes guidance for both quantitative, qualitative and mixed methods reviews.

The decision about review methodology is usually informed by the question of interest and purpose. In this thesis, a narrative review of acceptance literature has already been presented (section 1.3) however this raised key questions about the nature of acceptance in ESRD and the current status of the evidence. The aim of the thesis is to develop an understanding of acceptance from both a measurable and more holistic perspective, therefore a mixed-methods approach to the systematic review was selected.

2.1.2 Aims of the review

The association between acceptance and illness has been identified in specific chronic health conditions (Dennison et al., 2009) yet the role acceptance plays in renal disease has yet to be established. The term acceptance has been extensively used in relation to patients with end-stage renal disease (ESRD) but there is limited evidence clarifying what this means. The review aimed to answer the thesis objective; **what is the current evidence for the role of acceptance in outcomes for patients with end-stage renal disease.** It was expected that the findings would add to the current knowledge about the role of acceptance and be important in informing models of acceptance in ESRD. The findings from this review were also factored into the development of the quantitative and qualitative methodologies and were used to inform the interpretation of the results.

2.2 Methods

2.2.1 Design

The study was a mixed-methods systematic review (Pearson et al., 2015). A mixed-methods approach was taken as this allowed full coverage of qualitative and quantitative literature relating to acceptance in the ESRD population.

A mixed-method systematic review offers a more comprehensive synthesis of evidence than a single method and is particularly important in health research. The mixed-method approach can address the experience (qualitative) and effectiveness (quantitative) of approaches to inform wider decisions (Lizarondo , Stern , Carrier , Godfrey , Rieger , Salmond , Apostolo , Kirkpatrick , 2017). A mixed-methods review or mixed research synthesis can be more complex than a traditional systematic review or qualitative synthesis but this can confer benefits in the increased understanding of the concept in the area. However the practicalities of combining two established approaches has not achieved a consensus of opinion and the methodological approach is still largely theoretical (Hong, Pluye, Bujold, & Wassef, 2017).

Table 2.2.1 - Characteristics of different approaches to mixed-methods systematic reviews

	Integrated	**Segregated**	**Contingent**
	Convergent		**Sequential**
Question	Broad review question which can be addressed by both qualitative and quantitative studies	Overall review question with sub-questions which may only be addressed by one or other method	Broad question
Data	Requires data transformation	No data transformation	Synthesis of data conducted sequentially with one used to inform the other
Integration	Transformed data is integrated for synthesis	Separate and simultaneous synthesis with integration of the evidence	Sequential analysis of the studies with one conducted
Methods	Content analysis Vote counting Thematic synthesis	Realist synthesis Narrative summary Thematic synthesis Framework synthesis	Integration of evidence may not occur

Central to the mixed methods approach to systematic reviews is the integration of qualitative and quantitative data. Founded in mixed-methods literature there are three key designs to consider, integrated, segregated and contingent (Table 2.2.1). These have more recently been categorised into convergent or sequential designs. The convergent approach is the most utilised and can take two forms; data is synthesised together or synthesised separately and then integrated (Hong et al., 2017).

Where data is synthesised, there is a necessity to transform data to enable integration of findings, following a convergent approach the underpinning can be either quantitative or qualitative. A quantitative approach applies when qualitative data is transformed into quantitative. In this approach content analysis or vote counting of the qualitative data are most likely used to summarise the key findings. Following a qualitative approach, a thematic synthesis of results is conducted and extracted data coded and then attributed to themes. Where synthesis occurs separately for qualitative and quantitative studies the integration of a variety of approaches can be utilised, often underpinned by the overall question, and this can be either theory-driven or based upon the findings.

The current review question is "what is the current evidence for the role of acceptance in outcomes for patients with end-stage renal disease". However, this can be separated into two more specific questions.

1- What is the impact of acceptance on outcomes for patients with end-stage renal disease? (quantitative)
2- How do patients view acceptance in relation to adjustment/outcomes to end-stage renal disease? (qualitative)

With each approach addressing specific questions this fits into a convergent segregated mixed methods approach. As such following the Joanna Briggs institute guidance was appropriate (Lizarondo et al., 2017). Therefore, the current review followed the suggested stages: develop the review question, define the review criteria, literature searching, data retrieval, critical appraisal and data extraction. Adhering to this process a quantitative review and qualitative synthesis were conducted and then the results and findings were compared to establish how they complemented each other. The process was then concluded with a discussion of the findings, drawing of conclusions and considerations for practice and research.

Following the convergent approach, the opportunity to carry out meta-analysis was retained. Meta-analyses adopt a systematic approach but go beyond summarising studies through standardisation and weighting of studies through the utilisation of effect sizes (Borenstein, Hedges, Higgins, & Rothstein, 2011). However, meta-analyses are only suitable if there is sufficient commonality in the selected studies. After initial data extraction, it became apparent that different measures of acceptance were used across the studies and therefore the diversity of findings prevented meta-analytic approaches from being applied.

2.2.2 Search strategy and data sources

The systematic review was registered with PROSPERO (Stalker, Campagna-Sparkes, Elander, & Mitchell, 2017, Appendix 2). A systematic review into the role of acceptance in ESRD was initially carried out in May 2017 and rerun in July 2019 to identify any recent additions. The studies were identified by including the following databases: MEDLINE, CINAHL Plus, PsycINFo, PsycARTICLES and AMED. Manual searches were carried out on reference sections of all selected articles.

The search terms were:

- Acceptance terms: acceptance N3 (illness or disability) or "psychological adjustment" "psychosocial adjustment" or "illness perceptions" or illness N3 (burden or perception) or "treatment acceptance" or "acceptance of treatment" or “patients experiences”
- Renal terms: "renal failure" or esrd or ESKD or "renal disease" or "kidney disease" or dialysis or "renal replacement therapy" or “Hemodialysis” or "Haemodialysis" or "kidney failure"
- NOT transplant
- NOT child* or adolescent* or youth or “young person” or “child” or teen* were employed.

The same search strategy applied to the qualitative and quantitative approaches. Searches were carried out for terms related to illness acceptance and terms related to ESRD and then combined, duplicates were removed.

2.2.3 Inclusion and exclusion criteria

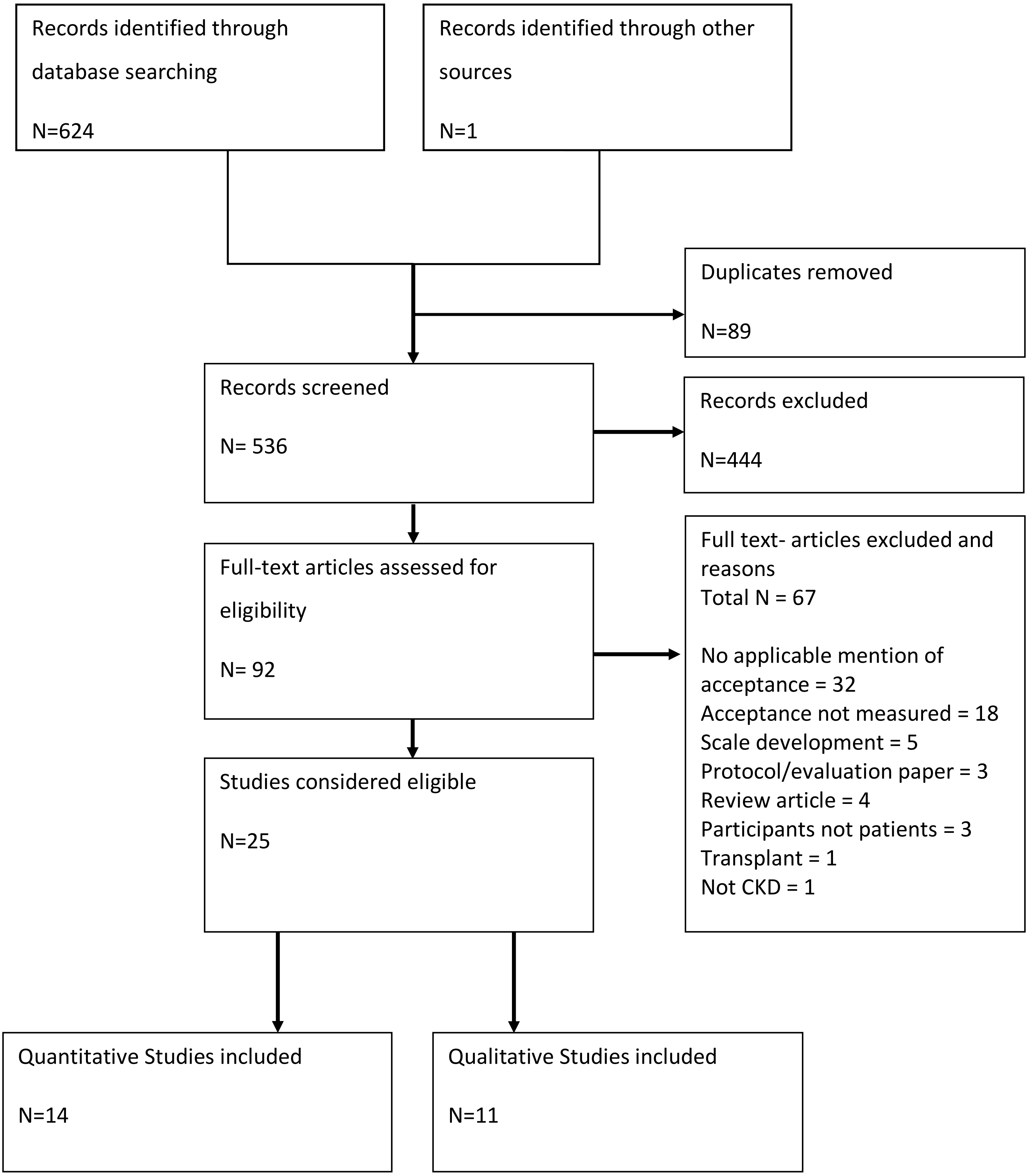
Inclusion criteria: English language studies were included if they involved adult patients (<18 years) with ESRD. All studies were from peer-reviewed journals. To conform to the mixed methods approach the inclusion criteria differed dependent upon the approach adopted by the study. There needed to be either; a quantitative measure of acceptance included or in the case of qualitative studies they needed to be relevant to the research question; exploring patients experiences related to acceptance. In relation to the identified literature, which has classed acceptance as both a process and an outcome, the acceptance definition was kept broad with inclusion of studies with acceptance or illness adjustment as a variable associated with an outcome measure including but not restricted to, psychological, clinical and behavioural outcomes OR any study with acceptance of illness or adjustment as an outcome associated with other variables including, but not restricted to, psychological, clinical and behavioural variables.

Exclusion criteria: Studies were excluded if they focused on transplantation. The reason to exclude transplant patients was the potential for differences relating to the acceptance processes between transplant patients and patients on or progressing to dialysis (Kostro et al., 2016). In addition, when piloting the strategy searching for terms related to “acceptance” in transplant patients, a significant number of studies were identified that did not relate to psychological acceptance, instead relating to medical issues for example factors affecting acceptance onto transplantation list (Bia et al., 1995) acceptance/rejection of organs (Bahri et al., 2009).

Search results

The results of the searches were extracted; the titles, then abstracts were screened by two reviewers. All potentially relevant articles identified by either reviewer were selected and full texts obtained. These full text articles were assessed against inclusion and exclusion criteria by each reviewer. The results of the full-text screening from each reviewer were compared and consensus reached on inclusion or exclusion, if consensus could not be reached a third reviewer aided the decision. Finally, the references for all the identified full-text articles were searched for any potentially relevant articles. This process identified 625 articles the outcome of the search process is presented in Figure 2.1 .

Figure 2.1 - Flow diagram outlining literature search and selection



2.2.4 Critical appraisal and data extraction

All retained full text articles were subject to assessment of quality. Quality assessment is a key aspect of systematic reviews and assesses the methodological and reporting quality of the selected studies. It is important to understand the methodological characteristics of the studies to ensure they are sufficient and appropriate to the research questions and aims. All quantitative full texts underwent the same review process using the quality assessment tool for observational and cross-sectional studies (National Heart Lung and Blood Institute, 2017). For qualitative studies the Critical Appraisal Skills Programme (CASP) UK for qualitative studies was used (CASP, n.d.) . Quantitative studies needed to specify methods of data collection, controls and appropriate analyses whereas qualitative studies should have described the method of data collection and methods of interpretation. Assessments of quality should include a risk of bias assessment that can be distinguished from assessments of methodological quality and addresses the question of the extent to which included studies should be believed. Risk of bias relates to the extent to which studies overestimate or underestimate the true effect of an intervention. Tools have been developed to specifically assess risk of bias however these have limitations and there is no consensus about which is most appropriate (Page, McKenzie, & Higgins, 2018). These tools are most applicable in clinical trials, but some risks of bias considerations are appropriate to both cross-sectional and qualitative studies. Whilst this review did not exclude studies based on quality or bias it did allow evaluation of the studies which informed the discussion of the findings.

The studies were all from peer-reviewed journals and to avoid translation bias only those articles written in English were selected. The quality assessment was undertaken by both reviewers and a consensus reached for each (Table 2.2.2 and Table 2.2.3). There were some variations in the quality of the studies, as evident in the quality assessments. The quality of the quantitative studies was similar across many questions; however several questions were not applicable due to the cross-sectional nature of the designs. Participation rates were usually reported but sample size justifications were rarely given. The question which achieved the largest variation in answers was whether confounding variables were controlled for, which was only clearly reported in seven out of the fifteen studies.

Table 2.2.2 - Quality assessment tool for observational and cross-sectional studies

	Brown & Fitzpatrick., (1988)	Chan et al., (2011)	Chiang et al., (2015)	Gillanders et al., (2008)	Jankowska-Polanska et al., (2016)	Jankowska-Polanska et al., (2019)	Karademas et al., (2009)	Kokoszka et al., (2016)	Lin et al., (2012)	Liu et al., (2017)	Oka & Chaboyer., (2001)	Poll & Kaplan de-Nour., (1980)	Poppe et al., (2013)	Rich et al., (1999)
Research Question	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Population	Y	Y	Y	Y	Y	Y	Y	Y	Y	y	Y	Y	Y	Y
Participation Rate	CD	Y	CD	Y	CD	CD	Y	Y	Y	Y	Y	Y	Y	Y
Same populations and uniformed eligibility criteria	CD	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Sample size justification	N	Y	N	Y	N	N	N	N	N	N	N	N	N	Y
Exposure of interest	N	N	Y	N	N	N	N	N	N	N	N	N	N	N
Sufficient Timeframe	N	N	Y	N	N	N	N	N	N	N	N	N	N	Y
Different levels of exposure?	NA	NA	N	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	N
Exposure measure - IV define, valid, reliable	Y	Y	Y	Y	Y	Y	Y	Y	CD	Y	CD	CD	Y	Y
Exposure assessed more than once	NA	NA	Y	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	Y
DV defined, valid, reliable	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Blinded	CD	CD	CD	CD	CD	CD	CD	CD	CD	CD	CD	CD	CD	CD
Follow-up rate	NA	NA	NA	N	NA	NA	NA	NA	NA	NA	NA	NA	NA	Y
Confounding variables measured	Y	Y	CD	N	Y	N	Y	N	Y	Y	N	N	Y	N

Y= Yes N= No CD = could not determine NA = Not applicable

Table 2.2.3 - Qualitative study CASP review

	Chatrung et al., (2015)	Gregory et al., (1998)	Gurklis & Menke., (1995)	Guzman et al., (2009)	Hain et al., (2011)	Sinclair & Parker., (2009)	Tong et al., (2009)	Walker et al., (2017)	Wright & Kirby., (1999)	Wright Nunes et al., (2016)	Wu et al., (2016)
Clear statement of aims	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate qualitative methodology	Y	Y	Y	Y	Y	NC	N	Y	Y	Y	NC
Is the research design appropriate to aims	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y
Recruitment strategy appropriate to aims	Y	Y	Y	N	Y	Y	Y	Y	Y	NC	Y
Data collected in a way that addressed the research issue	Y	Y	Y	NC	Y	Y	Y	Y	Y	Y	Y
Relationship between researcher and participant adequately considered	N	N	N	N	NC	N	N	NC	N	N	N
Ethical issues considered	Y	Y	Y	NC	Y	Y	Y	NC	NC	Y	Y
Data analysis sufficiently rigorous	Y	Y	Y	NC	Y	NC	N	Y	Y	Y	Y
Clear statement of findings	Y	Y	Y	Y	Y	Y	NC	Y	Y	N	Y
How valuable is the research	Y	NC	Y	N	Y	Y	Y	Y	Y	Y	Y

Y= Yes N= No NC = Not clear

The qualitative studies were rated to be of similar quality through the CASP checklist, with few studies taking into consideration the relationship between the researcher and participants but all clearly stated the aims. Some items were scored NC (not clear) where there was no evidence either way, which may reflect inadequate reporting rather than the item not being addressed.

Data from each article were extracted to answer several predetermined questions. These questions covered the objectives of the study, the characteristics of the sample, methodological approaches, analyses, results and interpretations. Each reviewer extracted the data independently and then the two extractions were compared. Any differences were discussed by the reviewers and text reviewed again to see if a consensus could be reached. This resolved most queries, with the majority being where one reviewer had indicated not reported but on second inspection evidence was identified in the article. If a consensus was not reached a third reviewer had the final decision.

2.3 Findings/Results

2.3.1 Quantitative Synthesis

The search strategy identified 92 studies, of which 14 met the inclusion criteria for quantitative studies. The number of participants included in studies ranged from 40 to 325. Key details from the studies can be found in Table 2.3.1. Twelve of the 14 identified studies were cross-sectional and two were longitudinal (Chiang, Livneh, Guo, Yen, & Tsai, 2015; Rich, Smith, & Christensen, 1999). There was variability across the studies in relation to the inclusion and exclusion criteria applied and as a result, the participants were at different stages of ESRD, ranging from pre-dialysis to being established on PD or HD. Seven studies focused on Haemodialysis, four compared between haemodialysis and peritoneal dialysis, two studied chronic kidney disease generally and one study focused on peritoneal dialysis.

Table 2.3.1 - Summary findings of quantitative studies included in the review

Study	Study design	Participants (n)	Dialysis (%)	Time on Dialysis Months (range)	Measures of acceptance	Findings
Brown & Fitzpatrick., (1988)	C	41	HD – 48.8 HHD – 24.4 CAPD – 26.8	81.6 (6-240)	Acceptance of Dialysis scale	Acceptance *r* clinical dietary abuse scores Acceptance *r* high internal locus of control score
Chan et al., (2011)	C	201	HD – 61.7 HHD – 13.9 CAPD – 24.4	70.1	Adjustment Scale of Reactions to Impairment and Disability Inventory - adapted for dialysis	NS path from illness acceptance to depression (retained in model due to theoretical consideration)
(Chiang et al., 2015)	L	262	No -CKD	NA	Acceptance of Disability scale (AOD-R)	Acceptance associated with sleep, education, exercise, comorbidities and low haemoglobin. AoD level associated with significant risk of progression to dialysis.
Gillanders et al., (2008)	C	106 patient 94 relatives/friends	HD- 100	50 (1-444)	Acceptance as part of COPE	Cognitive reappraisal of stress r acceptance Acceptance r positive reframing, planning ahead, using humour and behavioural disengagement
Jankowska-Polanska et al., (2017)	C	100	HD-100	HD >2years	Acceptance of Illness Scale	Higher acceptance of illness in young and more professionally active Males had more high and moderate acceptance of illness, higher acceptance associated with higher financial standing, less hospitalisation due to complications, less fatigue and improved QoL. AI independent determinant of high QoL in dialysis patients.
Jankowska-Polańska et al., (2019)	C	103	HD- 100	5.2 years (2.6)	Acceptance of illness Scale	Higher acceptance of illness results in higher quality of life in both PCS and MCS, AIS correlated with both PCS and MCS. Higher acceptance correlated with lower levels of depression and lower levels of anxiety. AIS and depression were independent determinant of MCS and PCS, anxiety was an independent determinant of lower quality of life in MCS.

Karademas et al., (2009)	C	128 chronic illnesses	CKD - 29.9	NS	Acceptance of Illness Scale	Illness acceptance –*r* psychological symptoms, *r* self-rated health and –*r* hospitalisation stress. Illness acceptance sig. predictor of psychological symptoms and self-rated health.
Kokoszka et al., (2016)	C	107 HD	HD- 100	NS	Acceptance of illness scale	Depression intensity *r* acceptance of illness
Lin et al., (2013)	C	191 PD	PD- 100	15 median (3-139)	Medical coping modes questionnaire	Depressed patients had higher score on “acceptance resignation” High acceptance resignation one of independent factors that predict depression
Liu et al., (2017)	C	227 HD	HD- 100	40 (1-103)	Medical coping modes questionnaire	Low mood associated with “acceptance-resignation” coping style.
Oka & Chaboyer., (2001)	C	325 HD	HD- 100	88.8 NS (>1 month)	Dialysis Acceptance Scale (based on Acceptance of Disability scale)	Dialysis acceptance R Dietary self-management self-efficacy but not dietary behaviour score
Poll & De-Nour, (1980)	C	40 HD patients	HD- 100	NS (>6 months)	Acceptance of Disability	Acceptance of Disability r education And AoD *r* Locus of control Patient acceptance does not change significantly number of years on dialysis.
Poppe et al., (2013)	C	99 CKD	HD-34	NS	Illness cognitions questionnaire (accommodative coping - subscale acceptance)	Acceptance +*r* MQoL and PHQoL Neuroticism –*r* with acceptance and MQoL Acceptance accounted for 18% variance in PQoL Acceptance and Neuroticism contribute to MQoL Acceptance and Neuroticism significant predictors of MHQoL
Rich et al., (1999)	L	67 D	HD – 62 HHD – 8 CAPD- 30	70.8 (1-285)	Illness attributions inventory (acceptance of responsibility)	Acceptance of responsibility may protect from development of negative mood

2.3.1.1 Acceptance definition

As part of the inclusion criteria for the review, all studies mentioned the term ‘acceptance’ in relation to patients with ESRD. Four studies failed to define what they meant by the term ‘acceptance’ but in the ten studies which did define acceptance, there was commonality in the definitions. Most frequently, definitions referred to the integration of illness into everyday life, whilst also relating acceptance to the emotional impact. The emotional component associated with acceptance of illness was described to be taking a positive meaning from illness rather than experiencing negative feelings. In addition, several studies also mentioned re-evaluation of life values and goals in relation to acceptance of illness.

Whilst some of the studies related acceptance to coping through terms of accommodation, an alternative description of acceptance was mentioned by two studies (Lin, Chen, Hsieh, & Chang, 2013; Liu et al., 2017). They both mentioned the “acceptance-resignation coping style” but only one study defined what this meant. They defined acceptance-resignation as patients regarding their illness as non-solving and suggested that this style of coping was associated with lack of hope and consequently associated with low mood. It is important to note that according to the acceptance of illness definitions, acceptance of illness is deemed a positive construct however the acceptance-resignation coping style is negative therefore comparisons between studies needs to consider the type of acceptance measured. The other coping definitions of acceptance provided by authors included acceptance as accommodative coping (Poppe et al., 2013). This definition is described in a similar way to illness acceptance and had a focus on adjusting goals in line with restrictions and limitations.

For the four studies which did not provide a clear definition of acceptance, some understanding of the interpretation of acceptance might be derived from the measures utilised. Two used coping-based acceptance measures whilst the remainder involved variants of scales which originated from Linkowskis (1971) Acceptance of disability scale. The differences between the definitions of acceptance and acceptance measures used needed to be considered when comparing the findings across the studies, because whilst all refer to acceptance, the underlying concept being measured may not be comparable. Therefore, results are structured by acceptance measure used rather than the definition of acceptance given by authors.

2.3.1.2 Acceptance measures

The majority of the measures of acceptance used were either derived from Linkowski's original acceptance of disability scale or were identified as a component of coping scales. The most widely utilised measure across the studies was the acceptance of illness scale (4 studies). Other acceptance measures focused on acceptance of disability through a number of scales (4 studies), acceptance of dialysis (1 study), acceptance as a subscale of coping (4 studies) and illness attributions (1 study). All the measures used in studies are reported in Table 2.3.1.

The acceptance of illness measure (Felton, Revenson, & Hinrichsen, 1984) comprises eight items and is based upon items from the acceptance of disability scale (Linkowski, 1971). Seven studies identified either the acceptance of illness scale or acceptance of disability scale as their measure of acceptance. Of these, four studies specifically used the AIS and four others were closely based on the Acceptance of Disability scale (AoD). One used the AoD-R, a revised 32 item measure; one used 29 items from the original AoD scale, and another developed an acceptance of dialysis scale based on the AoD scale. Whilst the scales used in the majority of the studies are all based upon the components of the AoD scale there are differences in scoring, for example, the AIS gives a five-point response scale from strongly agree to strongly disagree, the AoD is a four-point response scale. However, across all these variations the scoring retains the core aspect of higher acceptance being related to higher scoring across the items.

For the remaining six studies there were different scales utilised to measure acceptance. One study (Brown & Fitzpatrick, 1988) developed an Acceptance of Dialysis scale. This is a 10-item measure with a five-point response scale however unlike the AIS the higher score in this questionnaire reflects lower acceptance. Another study (Chan, Brooks, et al., 2011) adapted the adjustment scale of the reactions to impairment and disability inventory to be relevant to the dialysis population. Five studies adapted subscales of established measures as an indication of acceptance. Four of these studies used subscales of coping measures (COPE, the medical coping models questionnaire, of the illness cognitions questionnaire) whilst one focused on illness attributions with the acceptance subscale of the illness attributions inventory.

The differences in scales used to measure acceptance impacts how the correlates of acceptance can be compared. Particularly as most take the acceptance of disability/illness definition whilst the remainder discuss acceptance in relation to adjustment and coping. There are differences in the way the scales are utilised in the analysis, with some studies categorising levels of illness acceptance. Several studies used the AIS to categorise patients as high or low accepters. Three studies used the same categorisation (Jankowska-Polańska et al., 2017; Jankowska-Polańska et al., 2019; Kokoszka et al., 2016), categorising patients into low (AIS 8-18), moderate (AIS 19-29) and high accepters (30-40). The AoD scores were used to classify participants into high and low accepters using the median range of AoD scores as a cut-off (Chiang et al., 2015); below 86 was classed as low acceptance (out or a range of 32 to 128). With the variation in measures used for acceptance of illness, there are limited comparisons which can be drawn across the studies. Three studies provided summary scores for the AIS, the results were means of 22.26, 23.63 and 24.96 out of a possible range of 8-40.

2.3.1.1 Evidence for (and against) the role of acceptance

Evidence for the role of acceptance and associated variables are reported in Table 2.3.2. The table presents the significant and non-significant relationships reported in the studies to allow comparisons and conclusions to be drawn. The main areas considered were the role of acceptance related to demographics, clinical and psychological variables.

2.3.1.2 Demographic and individual characteristics

A number of studies compared both demographic and individual characteristics with acceptance. The two characteristics most frequently compared with acceptance were age, education and employment status. Chiang et al (2015) identified that patients with low acceptance of disease were more likely to have low education levels. Whereas Jankowska et al., (2017) failed to identify a difference in education levels across three levels of acceptance however they did demonstrate a difference in employment status, with those recorded as professionally active showing higher acceptance of illness. Poll and Kaplan de-Nour (1980) found a relationship between acceptance and number of years in education. Acceptance of

Table 2.3.2 - Reported findings between measure of acceptance and psychological, demographic and clinical variables.

	Demographic						Clinical							Psychological							
	Education	Age	Gender	Employment	Exercise	Social support	Adherence	Health	Diet	Sleep	Haemoglobin	Dialysis outcome	Fatigue	Depression	Stress/anxiety	Locus of control	Coping	QoL	Psychological symptoms	Self-efficacy	Personality
Acceptance of Illness /disability																					
Brown & Fitzpatrick (1988)							O		X							X					
Chan et al (2011)						X								O*						X	
Chiang et al (2015)	X	O	O	O	X	O				X	X	X									
Jankowska-Polanska et al (2017)	O	X	X	X		O						X	X					X			
Jankowska-Polanska et al (2019)														X	X			X			
Karademas et al (2009)								X							X				X		
Kokoszka et al (2016)														X							
Oka & Chaboyer (2001)									O											X	
Poll & Kaplan de-Nour (1980)	X	O														X					
Acceptance as Coping																					
Gillanders et al (2008)															X						
Lin et al (2012)														X							
Liu et al (2017)														X			X				
Poppe et al (2013)																		X	X		X
Other scales (illness attributions)																					
Rich et al (1999)														X							

X = significant finding O = no significant finding reported *retained in model reported despite no significant findings disease was higher in those with more years of education. Interestingly the relationships with education were apparent with acceptance measured by acceptance of disability scales as opposed to acceptance of illness scales.

Age was identified as an important factor in acceptance in one study (Jankowska-Polańska et al., 2017), with younger patients more likely to have higher acceptance of illness. Whilst Poll and Kaplan de-Nour (1980) identified a relationship between age and acceptance (-.19), however, it was not found to be significant.

Other characteristics linked to acceptance included gender, exercise and social support but the evidence across the identified studies was sparse and far from conclusive. For example, Chiang et al (2015), identified no difference in gender for AoD scores whereas Jankowska identified a significant difference between gender in AIS scores for haemodialysis patients with females reporting lower AIS scores.

2.3.1.3 Clinical variables

Across the selected studies several clinical variables have been linked to acceptance. Health, measured by self-rating was positively associated with acceptance of illness and acceptance of illness was found to be a significant predictor of self-rated health (Karademas et al., 2009). As evident in Table 2.3.1, variables associated with acceptance included sleep, haemoglobin, fatigue and diet. However, the evidence for these is only identified in single studies within the review and therefore no detailed comparisons could be drawn.

2.3.1.4 Psychological variables

Depression

The most widely measured variable alongside acceptance was depression. Six studies identified relationships between acceptance and depression. The measures used to identify depression included the Depression, Anxiety and Stress scale (DASS21) for one study, the Beck depression inventory (BDI) for four studies and for one study the Center for Epidemiologic studies depression (CES-D) scale. There is little direct comparability between the studies due to the variations in both depression measures and acceptance measures. In one study (Chan, Brooks, et al., 2011) the path between illness acceptance and depression was retained in the model despite the non-significant t value (-0.37) due to theoretical considerations. Another study (Kokoszka et al., 2016) employed both the mini-international neuropsychiatric interview (M.I.N.I) and the BDI. Using the M.I.N.I 78.5% of dialysis patients were diagnosed with depressive disorders however comparing this to the BDI scores indicated that the diagnostic criteria varied from the typical BDI classification for depressed symptomology.

In this study, the mean BDI score for patients with dysthymia was 13.75 which according to the BDI categorisation reflected mild depression. The category of major depressive episode had a mean score of 18.08 also reflecting mild depression according to the BDI classification. This study did identify different acceptance scores between the depressive disorders with the mean AIS score being 31.11 for patients without diagnostic levels of depression according to the M.I.N.I.. Lin et al (2012) used the BDI-II and defined depression as a score of >14 and compared this to acceptance resignation coping styles, they found a significant difference between the non-depression and depression group. Liu et al (2017) also looked at depression in relation to acceptance resignation coping but with depression measured using the CES-D. A significant difference was found between the acceptance resignation scores in those with low mood compared to high mood, in addition, acceptance –resignation coping style was independently associated with low mood (OR=1.228, p=0.022). A recent study added further evidence to support the association between acceptance and depression (Jankowska-Polańska et al., 2019). They found high acceptance to be correlated with lower levels of depression and depression to be an independent predictor of MQoL and PQoL alongside acceptance. Of note, some of the studies associating depression with acceptance included patients across dialysis modalities. Overall the fact that different measures were used to capture depression and illness acceptance makes the comparisons difficult, but both coping and illness acceptance were associated with depression and there was a consistent pattern of association between acceptance and depression.

Stress

Stress is another component that has been associated with acceptance. Gillanders et al., (2008) identified a relationship between cognitive reappraisal of stress and acceptance with greater use of reappraisal associated with both lower anxiety and higher acceptance. Karademas et al., (2009) also identified a negative relationship between illness acceptance and hospitalisation stress, which the authors suggested may mediate the effect of hospitalisation stress on subjective health measures. Jankowska-Polańska et al., (2019) supported these associations when they reported that acceptance was negatively correlated with stress.

Locus of control

Other psychological components related to acceptance were locus of control and coping. Locus of control relates to the extent to which a person believes they have control over events in their lives. Internal locus of control means that an individual believes that their own actions affect the consequences whereas an external locus of control means that they attribute events to external occurrences or forces, for example, fate. Early work by Brown and Fitzpatrick (1988) identified that acceptance of dialysis was more frequently reported by those with higher internal locus of control scores (r=-0.32; P<0.05). Poll and Kaplan (1980) also identified a difference in acceptance between patients with internal and external locus of control, however, the sample size in this study was low (n=40). Mean acceptance of disability scores were significantly higher in patients with internal locus of control (84.7) compared to those with external locus of control (66.4) (t=1.8, p<0.05).

Quality of life

Quality of life has been linked to acceptance. Significant differences in acceptance of illness scores were identified across the physical, psychological and environmental domains of the World Health Organisation QoL-BREF (Jankowska-Polańska et al., 2017). Acceptance of illness was a significant independent QoL determinant across the three identified domains. This was confirmed in the more recent study (Jankowska-Polańska et al., 2019) where acceptance was shown to be an independent predictor of PQoL and MQoL, independently of anxiety and depression. The findings demonstrated that depression was an independent predictor of both PQoL and MQol and anxiety was only found to be an independent predictor of PQoL. Similarly, QoL has been identified as important in relation to acceptance and personality (Poppe, Crombez, Hanoulle, Vogelaers, & Petrovic, 2013). When measured by the short-form health survey Poppe et al., (2013) found that acceptance was positively correlated with both physical health (PH) and MQoL, and acceptance was a predictor in both PHQL and MHQL.

2.3.1.5 Strength of the evidence

Most studies identified in this review were cross-sectional in design and identified a range of relationships between acceptance and associated variables. These relationships or differences identified were in many cases not predictive. However, some studies did treat acceptance as a predictor. Poppe et al., (2013) identified acceptance as a predictor of both physical and mental health-related quality of life. Jankowska et al., (2017) supported this with the identification that acceptance of illness was an independent predictor of physical, psychological and environmental domains in the WHO-QL. It was also identified that acceptance was not a predictor of the social relationship domain. This was further supported by Jankowska et al, (2019) who identified acceptance as a predictor of QoL whilst taking account of both depression and anxiety. Whilst these studies treated acceptance as a predictor of QoL the data was from cross-sectional studies and therefore the direction of influence was not conclusive.

Dietary behaviour was identified as being associated with dialysis acceptance however here the effect is apparent through dietary self-efficacy, which in turn affects dietary behaviour. Lin et al., (2012) and Lui et al., (2017) identified that the acceptance-resignation coping style was an independent predictor of lower mood. Acceptance of illness was also identified as a significant predictor of self-rated health and psychological symptoms (Karademas et al., 2009).

The longitudinal studies examined the influences on outcomes over time. Chiang et al., (2015) compared acceptance of disability (AoD) to rates of progression to dialysis and rates of death. Patients with low AoD were more likely to progress to dialysis and an elevated but non-significant risk of death was reported. Rich et al., (1999) found that patients who accepted responsibility for their problem without blaming themselves showed smaller increases in depression and anger over the duration of the study. Interestingly, when comparing the studies, acceptance measured by the acceptance of illness scale was associated with both demographic, clinical and psychological variables whereas acceptance as measured through coping or illness attributions was only associated with psychological components. However, the strength of the findings in mixed and there could be issues with reporting or study design with these studies failing to account for or report the demographic and clinical characteristics.

2.3.2 Qualitative synthesis

The overall search strategy identified 92 studies, of which 11 met the inclusion criteria for the qualitative synthesis. Participant numbers in included studies ranged from 7 to 129. Key details from the studies are presented in Table 2.3.3. 11 of the identified studies were interview studies and one was a focus group study (Tong et al., 2009). Participants all had CKD, with five studies including only HD patients, one only CAPD patients, one PD and HD patients and four studies focused on patients in pre-dialysis. Analysis approaches varied from simple content analysis (Gurklis & Menke, 1995) through to story theory (Hain, Wands, & Liehr, 2011). Articles were published between 1998 and 2017. The majority of the studies were conducted in the USA and the focus of several studies was on specific groups within the population; Thai individuals, older adults, Maoris, Filipinos and Taiwanese.

As with the quantitative articles were initially selected if the title and abstract indicated potential relevance to the review aims. Full texts were obtained, and all potentially relevant articles were assessed by two reviewers. Data extraction included selection of all relevant study information, themes and any relevant example quotes. Comparisons of data extractions between the reviewers allowed consensus to be reached. In the case of the example quotes where there were differences all quotes were retained in the review process and the clearest examples reported below. The extracted themes and quotes were reviewed, and consensus reached about the overarching themes related to acceptance across the studies.

Table 2.3.3 - Characteristics for qualitative studies included in the review

	Study	Participants (n)	Dialysis (%)	Time on dialysis Months (range)	Methodology	Phenomenon of interest
A	Chatrung et al (2015)	8	HD – 25 PD- 25	NS	Interviews Ethnographic	Wellness and religious coping among Thai individuals in Southern California (USA)
B	Gregory et al (1998)	36	HD - 100	> 3 months	Interviews Grounded theory	Patients perceptions of their experiences with ESRD and HD (USA)
C	Gurklis and Menke (1995)	129	HD - 100	39.2 months	Interviews Content analysis	Patients perceptions of stress, coping and social support (USA)
D	Guzman et al (2009)	13	HD- 100	1 month – 5 years	Interviews Phenomenological	Filipinos experiences of coping with haemodialysis (Philippines)
E	Hain et al (2011)	64	HD- 100	45 months	Interviews Story theory	Older adults experiences of undergoing haemodialysis (USA)
F	Sinclair et al (2009)	7	HD- 100	30 months (10-72)	Interviews Thematic analysis	Patients perspective on intradialytic weight gain (Australia)
G	Tong et al (2009)	9	CKD - 29.9	NS	Focus groups Thematic analysis	Patient's experiences and perspectives of living with CKD (Australia)
H	Walker et al (2017)	13	CKD – pre dialysis	NS	Interviews Grounded theory and thematic analysis	Maori patients experiences and perspectives of chronic kidney disease (New Zealand)
I	Wright and Kirby (1999)	10	CAPD - 100	5 x 12 months 5 x 6-8 weeks	Interviews Grounded theory	Adjustment to chronic illness (UK)
J	Wright Nunes et al (2016)	49	ESRD – pre-dialysis	NA	Interviews Grounded theory	Acceptance of diagnosis (USA)
K	Wu et al (2016)	15	ESRD – pre dialysis	40 (1-103)	Interviews Content analysis	Taiwanese experiences of ESRD (Taiwan)

2.3.2.1 Themes identified in the review

Four overarching themes (Table 2.3.4) were identified through the analysis of the themes identified by the studies authors (second order) and through the direct quotes provided (first order). The most salient theme across all the studies was "accepting a new life", which related to participants realisation that they had kidney disease and their acknowledgement of the effect on their lives. There were three subthemes identified which related to how people accepted a new life, these were 'moving forward', 'that's that' and 'grieving for an old life'. The next theme 'journey to acceptance' related to the process of acceptance and contained the sub-themes of 'gradual path' and 'destination reached'. 'Realistic expectations' was another theme prominent in most studies and was related to acceptance of the inevitability of the situation and participants confronting the life and death nature of the situation. Support was identified as important and study participants were described as using support to aid their acceptance of illness. The sources of support highlighted were from religion, the dialysis unit and family and friends. The following sections describe the identified themes with illustrations of associated sub-themes.

Table 2.3.4 - Themes identified across the studies in the review

	Accepting a new life	**Journey to acceptance**	**Realistic expectations**	**Support**
A Chatrung et al (2015)	X	X	X	X
B Gregory et al (1998)	X	X	X	X
C Gurklis and Menke (1995)	X	X	X	X
D Guzman et al (2009)	X	X	X	
E Hain et al (2011)	X	X	X	X
F Sinclair et al (2009)	X	X	X	X
G Tong et al (2009)	X		X	
H Walker et al (2017)	X		X	X
I Wright and Kirby (1999)	X	X	X	X
J Wright Nunes et al (2016)	X		X	
K Wu et al (2016)	X			X

2.3.2.2 Theme 1: A new life

The most prominent theme was that of ‘a new life’ with acceptance of ESRD meaning that patients felt that they had to adapt to a new life. The key themes and illustrated quotes extracted from the studies are presented in Table 2.3.5. The sub-themes related to how across the studies participants were shown to have accepted and adapted to a new life. Whilst there was an overarching theme of a ‘new life’ some themes were more positive and were about embracing a new life whilst others were focused on what participants had lost from their previous lives.

Subtheme 1: Moving forward

The sub-theme of moving forward related to the realisation that despite ESRD dialysis patients could still live their lives, as one study participant stated: “Once you accept it, you can go on with it. Now it’s part of living”. Within this theme there was the acknowledgement that a patient’s life had “changed from what it was” but there is a common thread in that when patients adjusted, they “try to get back to what’s normal as far as you can”. With the realisation that they could not do everything they did before, participants described that they learned to ‘live life as much as possible within your limits’ but that it shouldn’t ‘become the centre, otherwise you find the rest of life passes you by and you don’t get back to it.” This can be categorised as positive acceptance with some patients out to live life ‘to defy their illness’

Subtheme 2: That’s That

The theme ‘that’s that’, related to the neutral acceptance that was described by some study participants. This was portrayed as a practical and unemotional acceptance of illness, some study participants likened dialysis to a job, implying that it was not a big deal. Others stated that they “just get on with it now”. This no-fussed descriptions suggested that for some patients the acceptance of illness was very matter of fact and not necessarily linked to positive or negative feelings about their illness. In the case of dialysis, it is implied that it can be compartmentalised into the actual action of attending the centre and forgotten about when not at a session.

Table 2.3.5 - A New life : Themes and illustrative quotes

Subthemes	Themes from study	Illustrative quotes
Moving forward	Wellness (A) Redefinition of self (B) Maintaining a positive outlook (C) Balancing independence/ dependence (E) Personal meaning of CKD*(G) Adopting a new approach to being and living (I) Getting back to life* (G) Integrating illness/treatment into identity (I) Coping with the disease (K) Active acceptors (I)	‘‘I can do nearly all of the normal activities I usually do in life’’ (A) “And I guess to an extent I still feel great. But I am not able to do the things that I used to do. I’ll tire out quicker now …. But I mean, if I pace myself, I can go all day” (B) “The word is “acceptance” of reality if what my life is now. It’s changed from what it was and I say in the journey situation, I’m walking a different road but I still have some of these things from my other life there, too, to help me” (F) “Well it does not bother me as much now . . . It is more restricted now but I have decided that this is the way that life is going to be so you have to accept it” (I)
That’s That	Acceptance of being on haemodialysis (C) Redefinition of self (I) Adopting a new approach to being and living (I) Getting back to life (I) Lifestyle consequences (G) Living a restriction driven existence (E)	“I don’t dwell on my illness because dwelling on your illness can take you over” (C) “I come to dialysis and then leave: I don’t think about it between times” (C) ? “Well, it’s like having a second job. I just know that I’ve got to be here three times a week for three hours at each sitting.” (E) “I had to put it to the back of my head, not think about it” (H)
Grieving for an old life	Restrictions of living with chronic illness (C) Living a restriction driven existence (E) Existing not living (E) Magnitude of loss (F) Constant struggle (F) Lifestyle consequences (G) Redefinition of self (B) Processing Losses*(I) Impact of illness (A) Realising the long-term irreversible nature of the disease (K) Resigned acceptors (I)	“I didn’t have that drive I’ve always had all my life and I wasn’t able to carry out those things that made me what I am” (B) “I wish I could do something, wish I could go to school or work or do, you know, something. I can’t even take care of myself. I really don’t have much hope of being nothing but a patient.” (E) “I like freedom. I like to do what I like, what I want. I like to sleep in the morning, and I like to get up and do whatever I want. I don’t want to come here, but I have to. That’s why I come” (E) “I don’t know what it’s like to be normal anymore, to feel normal.” (G)

Note: letters in brackets indicate studies as named in table 2.3.4

Subtheme 3: Grieving for an old life

This theme was categorised by dwelling on the negative impact of their illness. For example, focusing on how illness has restricted their lives or fundamentally changed who they are. In some examples they referred to the loss of normal life, ‘I feel cross where I am at because I can’t live my normal life like I used to’. For others it was described that this loss of their old life referred to a change of role, for example, one quote related to the person seeing themselves as ‘nothing but a patient’ and another referred to being unable ‘ to do all the things that made me what I am’. Patients who appeared to be grieving for their old life were struggling to define themselves by this new role, for one patient this was made worse by cultural expectations where the contrast of roles was clearly described; ‘ the identity of working and being a working man, and the stigma of being sick and on dialysis and not being the tough guy’.

2.3.2.3 Theme 2: Journey to acceptance

This theme comprises of two subthemes: gradual path and destination reached. Table 2.3.6 presents the sub-themes and illustrative quotations.

Table 2.3.6 - Journey to acceptance: Themes and illustrative quotes

Subthemes	Themes from study	Illustrative quotes
Gradual path	Coping - acceptance takes time (C), Adopting a new approach to being and living (I) Transition to acceptance (F)	“It’s now part of living. It takes time to accept”(C) “It’s a process of getting used to it” (I) Gradually you get to do it automatically—like driving a car and it’s just part of what you do Well it does not bother me as much now (I)
Destination reached	Coping as Sailing: or the power to let go(D) Getting back to life* (I)	“and I came to an acceptance” (F) “I have to accept everything, I already accept it anyway” (D) “Once you accept it, you can go on with it” (C)

Subtheme 1: Gradual path

A common theme identified across the studies was that of acceptance taking time, it was described as a process of adjustment. The discussion in this theme related to coming to acceptance which involved 'learning to accept the reality of life and learning to let go'. The word 'learning' was frequently used by study participants, implying that it does take time to get to acceptance. Others drew contrasts between how things were at the start, with dialysis being described as 'very difficult at the start' but then compared that to current thinking by stating that gradually it becomes 'part of what you do'.

Subtheme 2: Destination reached

This sub-theme relates to acceptance being a state that is reached. With study participants describing acceptance in state like terms; 'I came to an acceptance', 'it's part of what you do. You have accepted it'. However, this destination may not be the end of the line as in some instances acceptance was described as being necessary to move forwards with life for example; 'once you have accepted it, you can go on with it', ' you move from acceptance - which is about accepting that there will be limitations and that some adapting of life will need to be done'. However, it is suggested that for some patients it as destination never reached with one illustrative quote stating 'I don't think you do adjust to it {haemodialysis} really'.

2.3.2.4 Theme 3: Accepting reality

The third theme related to the acceptance of the reality of the situation. Across most of the studies there was recognition that kidney disease is a serious illness and that dialysis was a life saving treatment. Many participants in the studies referred to this recognition of mortality but whilst some seemed to utilise this to help them 'value life' others clearly stated that in reality, if they wanted to live they had 'no choice' (Table 2.3.7).

Table 2.3.7 – Accepting reality : Themes and illustrative quotes

Subthemes	Themes from study	Illustrative quotes
Positive outlook /valuing life Value life	Adopting a new approach to being and living (I) Transition to acceptance Acceptance of illness(F) Redefinition of self (B)	"I am alive and I thought that I should live in a way that will bring the greatest profit to my life." (A) "Life is just like a song; it has a beginning and an end. There will come a time when everything will come to an end. Most people die at the age of 50. For me, I appreciate life because I was able to reach this far. In fact I was given a bonus" (D) "Well I appreciate life more—it concentrates the mind when you are told this, you have to rethink what you are going to do." (I) "I think that has been where my strength has come from because I have come to terms with dying" (I)
Resignation/ no choice	Realising the long-term irreversible nature of the disease (K) Coping with the disease (K) Facing the consequence of unavoidable deterioration (K) Resigned acceptors (I) Meaning of illness and treatment(B)	"I have to accept everything" (D) "There is nothing you can do… I know it's going to help me…keep me alive. I might as well take the treatment (B) "I don't see any other way out" (B) "It's either this or the boneyard, one of the two" (B) "You have an alternative: You can be here (at dialysis) or be dead" (C) I don't want to come here, but I have to. That's why I come" (E)

Subtheme 1: Value life

For some participants, the seriousness of their condition and the irreversible nature of it brought an appreciation of life. One quote suggested that once participants realised that if they wanted to live, they needed to be ‘willing to do anything it takes… you’ll start feeling better about it. You know and understand it’. Others talked about the realisation as being important for assessing priorities in life and resulted in them having to ‘rethink what you are going to do’. Studies described that patients ‘realized that this is saving my life’ and this realisation was described as important in facilitating a positive acceptance. For some patients, they felt that through coming ‘to terms with dying’ they had gained control and strength to manage their illness.

Subtheme 2: No choice

Whilst participants in the studies often acknowledged dialysis as lifesaving, an alternative to embracing it was described. This was patients feeling that they had no choice and therefore if they wanted to live, they felt resigned to the illness and treatment. Patients described how they ‘have to accept everything’ and a feeling of enforcement: ‘I don’t want to come here {dialysis}, but I have to. That’s why I come’. Patients acknowledged that there is an alternative, but this is not a favourable outcome, as one patient described it, ‘It’s either this or the boneyard’. However, whilst patients accepted there was no choice if they wanted to live, some patients felt forced into this acceptance, for example, one described how ‘you have no option – you have got to do it’.

2.3.2.5 Theme 4: Acceptance facilitated by support

Acceptance was not only due to individuals’ feelings about their illness, there were three key sources of support which the studies identified as important. Religious support was identified by several studies; however, it is noted that this may be a more prominent theme in specific cultures than others. Support from staff and patients was described as facilitating acceptance but for some study participants it was seen as a hindrance to their own acceptance. Finally, family and friends were identified as a source of support but also a motivation for acceptance. Table 2.3.8 presents the themes and subthemes identified

Table 2.3.8 - Acceptance facilitated by support: Themes and Illustrative quotes

Subthemes	Themes from study	Illustrative quotes
Religious support	Types of support (C) Quality of Supports (B) Religious Coping (A) Maintaining cultural identity (H)	“the need to learn to accept the reality of life and learn to let go instead of trying to control events and issues beyond their control. This concept is central to the teaching of Buddhism.” (A) “Religion helps me live with my clinical conditions” (A) “ My hope in Christ keeps me going…things will get better. I believe God has control overall” (C) “I believe my life is proceeding in accordance with God’s will. Religion gives me power, enhances my confidence, and provides me hope for getting better.” (K)
Support on the unit	Quality of Supports (B) Support Persons (C) Types of support (C) Feelings about social support (C) Informal Support Structures (G) Struggling with those providing care (E)	“We’re all in the same boat… I suppose we’re one, big, happy, family to a point” (B) “And when it’s somebody very negative, I try not to listen to them. I try to avoid those conversations. If somebody, if another patient, start with “I hate this” and “I don’t want to come here,” I just say, “Well, you have the alternative.” (E)
Family/Friends facilitate acceptance	Support Persons(C) Types of support (C) Feelings about social support (C) Family impact (C) Informal Support Structures (G)	“… I want to be there a bit longer for my girls, my grandkids, my great-grandkids…”(F) “It made me realise what my family means to me and thinks of me. I will say that they have been very supportive, all of them. I mean if I am going to go anywhere, my daughter will bring the kiddies and take me without argument. We are really close now” (I) “All my friends have accepted it. I always show them my tube—I SHOW IT OFF! Then they know what I am talking about. We all have a laugh about it—THAT REALLY HELPS” (I)

Subtheme 1: Religious support

Across several the studies, religion was identified as an important factor which facilitated acceptance. This was potentially due to the attribution of control or responsibility for their illness to a God-like entity or force. The idea that ‘everything happens due to my own actions’ allowed study participants to accept their illness and relinquish the control of their lives to God. Participants felt despite their reluctance they had to accept dialysis. In an illness with little hope of improvement (with the exception of transplantation), religion also offered additional benefits in that it provided a source of hope. Patients referred to how ‘things will get better’ and ‘religion gives me power, enhances my confidence, and provides me hope with getting better’.

Subtheme 2: Support of the unit

References to the relationships with patients on the dialysis unit described this relationship as being like ‘one big happy family’. Therefore, conveying the perception of a group that supports and cares for each other, but this statement is ended with ‘to a point’ which suggests whilst there are some similarities with family it is not quite the same. Whilst the support can be beneficial there are cases described which indicate the unit may not always be a source of support. One factor identified is that the death of other patients can bring home the realisation of their own situation, as one quote stated in reference to the passing of a patient; “my life flashed in front of me, and it’s still on my mind”. It may also be the case that for patients who have accepted their illness others yet to reach this stage might be a source of frustration, for example, it was stated: “if somebody’s very negative. I try not to listen to them”.

Subtheme 3: Family and friends

The studies show the importance of family and friends in patients’ acceptance of ESRD. Firstly, when friends and relatives were shown to accept a patient’s illness it was described how ‘THAT REALLY HELPS!’. These relationships have been shown to be important in helping patients adjust. However, it is not just through their actions, but friends and family were cited as reasons for patients to accept their illness and treatment. It was described in one quote how this participant ‘want(s) to be there a bit longer for my girls, my grandkids, my great-grandkids’. So family and friends were portrayed as having a dual role, they were described as helping patients come to an acceptance of their illness but also served as a reason for this acceptance.

2.3.2.6 Strength of the evidence

The qualitative studies were all of acceptable quality with clearly reported methodologies. Whilst the focus of the studies was varied, the overall similarities have resulted in clear themes which encompassed the findings of all the selected studies. It is acknowledged that these themes have been extracted from secondary data and therefore some elements might have been misunderstood when out of the original context, however, these themes were cross-checked between the two researchers and reviewed by a third.

The results might be more culturally sensitive. A number of studies were focused on specific cultures and therefore although the themes may be relevant in the sample population the extent to which these can be applied in other areas might be limited. A key example is religion facilitating acceptance, which might be more evident in religious cultures and the importance that an individual placed upon religion might be a factor in how they accept their illness.

Finally, the focus in these studies were on a range of patients from those who were pre-dialysis to those who were established on dialysis. Whilst this has allowed understanding of how patients accept illness; some themes might be salient to patients at different stages rather than to those only on dialysis.

2.3.3 Synthesis of qualitative and quantitative findings

The quantitative and qualitative syntheses yielded very different findings which is in line with the slightly different focuses of the research questions. The quantitative synthesis highlighted a wide array of relationships that have been identified with acceptance. The relationships with psychological variables were strongest but certain clinical and demographic variables were important. However, it was evident that many of the relationships were studied in isolation. In addition, there were two approaches which emerged as the focus of the quantitative studies; some measured acceptance as acceptance of illness whereas others explored acceptance as a method of coping. The qualitative synthesis identified four themes which emerged from the studies analysed and highlights the complex nature of acceptance.

Through the synthesis of both reviews the only demographic factors significant in both were employment and social support. The quantitative synthesis presented some evidence for employment relating to acceptance, this is supported by the qualitative findings that employment may be linked to both grieving for an old life but also moving forward. If patients identified employment as important to them then having to give up their employment because of their illness may be related to dwelling on their old lives. However, if patients were able to maintain their employment, this was described as a way of maintaining their normality, even if it took some adjustments to ensure it was possible. Social support had limited quantitative support however it came across as a strong factor influencing acceptance of illness in the qualitative review. This difference could be due to the way social support was categorised and compared with acceptance. The qualitative synthesis indicated that acceptance could be a result of social support factors but also a motivation, and that this support could come from, family, friends, other patients or religion.

Although the evidence related to acceptance and associated measures was varied there were some similarities, illness acceptance was related to demographic, clinical and psychological measures whereas coping acceptance was only related to psychological measures. The qualitative studies indicated that acceptance is a complex process where patients had to adapt to a new life. The subtheme ‘moving forward’ maps onto a positive acceptance of illness whereas the subthemes ‘grieving for an old life’ and ‘resignation’ map onto the acceptance-resignation coping style identified in the quantitative studies. In exploring patients’ experiences of illness, acceptance was presented as a multifaceted concept. Acceptance of a new life was associated with acceptance of physical and lifestyle restrictions, with how well patients felt being associated with a more positive moving forward. The loss of identity and role, alongside how a patient felt physically, was associated with grieving for an old life.

2.4 Discussion

Psychological aspects

The quantitative evidence is strongest in relation to the role that acceptance plays in depression. Several studies indicated a relationship between measures of acceptance and depression. These findings are similar to evidence in other conditions where acceptance has been associated with levels of depression in patients with chronic pain (Dindo, Recober, Marchman, O'Hara, & Turvey, 2015; Pinto-Gouveia, Costa, & Marôco, 2015), Parkinson's disease (Rosińczuk & Kołtuniuk, 2017) and stroke (Crowley & Andrews, 2018). However, it is considered that the reported relationships may be focusing on different aspects of acceptance, for example, studies identifying a more negative "acceptance-resignation" coping style were linked to greater signs of depression, whereas a positive acceptance of illness consistent with the ACT approach has been linked to reductions in depression. Stress and anxiety related to ESRD were shown to be associated with acceptance which is consistent with previous research in other conditions (Karademas et al., 2009).

The importance of the link between psychological variables and acceptance was supported by the qualitative findings, with the importance of a positive mindset being described as key to allowing patients to move forward with their lives. This outlook was described as a factor affecting patients' perspectives on life. This is consistent with literature and models of illness perceptions and emotion regulation (Gillanders, Wild, Deighan, & Gillanders, 2008; Griva et al., 2009). Across the qualitative studies patients described similar situations but their perceptions of the illness and the impact on their lives were shown to influence patient's acceptance. These findings suggest that psychological aspects of illness are related to how well patients accept their illness. Psychological factors may mediate but are not causal for this process, with both demographic and clinical factors also implicated.

Demographic

Quantitatively measured demographic characteristics were shown to be related to acceptance of illness but not coping acceptance. This suggests that acceptance might comprise two constructs; acceptance of illness, coping acceptance, however further research is needed to establish the extent of the observed differences.

The qualitative studies associated acceptance with demographic factors through patients describing acceptance in relation to their gender, age, cultural background, social support, employment and role. Social support was identified as facilitating acceptance and the impact of illness was associated with the extent to which the illness affected a patients' life. This is corroborated with data which that has shown illness identity to be associated with acceptance (Oris et al., 2016). For example, if patients are still able to take on the role they identify for themselves e.g. mother, grandparent, employee then this is associated with more positive experiences of illness. However, if patients feel that they are unable to fulfil a previous role, or they are resigned to a new role as a patient then this it is probable that this may associate with more negative interpretations of illness. This perception of illness is closely associated with an ACT approach to illness (Hayes et al., 2006; Prevedini et al., 2011) and might partially explain why illness acceptance rather than coping acceptance is associated with demographic variables.

The quantitative evidence behind social support and acceptance was limited however the qualitative evidence indicated that this is an important aspect in facilitating acceptance. This supports research suggesting that social support can both inhibit as well as encourage acceptance (Kostova, Caiata-Zufferey, & Schulz, 2014). The review findings add support to the suggestion that acceptance may moderate the effect between social support and depression, with acceptance having a buffering effect; in that for patients with low illness acceptance it is more likely that deficits in social support significantly impact upon depression (Costa & Gouveia, 2013).

Clinical

Links between clinical measures and acceptance were evident in some of the quantitative studies with the most interesting findings being the links between illness acceptance and dialysis outcomes (progression to dialysis and mortality). These findings suggest that acceptance is an important area to target with a potential that it may confer clinical benefits. This finding is not specific to ESRD, acceptance has also been associated with improved physical functioning in cardiac patients (Karademas & Hondronikola, 2010). Acceptance of illness may be associated with the demographic feature of age but if patients attribute clinical problems to ageing, acceptance of ageing may be linked to mortality.

Studies have suggested that 'old age' attributions were associated with perceived health symptoms and greater mortality (Stewart, Chipperfield, Perry, & Weiner, 2012).

Whilst individual clinical elements might be related to acceptance, the qualitative studies provided insight into how acceptance might be related to clinical outcomes. In the qualitative studies clinical factors were discussed in several ways. Firstly, acceptance was related to an acceptance of the severity of the condition and the potential outcome; death. This acknowledgement and understanding underpinned patients' thinking about their illness, with some using the knowledge to value life whilst others were resigned to this life. In turn, this thinking potentially impacted upon how patients accepted their illness. Secondly, acceptance was intertwined with the physical effects of ESRD or dialysis. Where patients described being held back by physical limitations this was associated with more negative views of acceptance but where patients focused on the positive effects, for example, dialysis made them feel better physically, then this was associated with more positive descriptions of acceptance.

2.4.1 Limitations of the review

The review included studies of patients at different stages of ESRD, from pre-dialysis to dialysis. Whilst this captured a range of views it is acknowledged that the most salient issues might differ across modalities and stages of dialysis. For example, the qualitative studies of pre-dialysis patients were more focused on accepting the diagnosis whereas dialysis patients were more focused on accepting the treatment and impact upon their lives. Therefore, the views of this latter group would have encompassed some of their past experiences however those yet to start dialysis might have voiced concerns based upon anticipation rather than experience. Although strong themes and robust findings were presented, caution is needed to ensure the interpretation is not overextended, in particular to the wider renal population. The quantitative and qualitative studies were conducted with specific samples and therefore findings might not be transferable. For example, themes on religion or cultural identity might be more applicable to some patients than others. The review process was strengthened by the employment of two independent reviewers for all aspects of the review process however due to constraints only English language studies were included and the selection of the search databases was influenced by availability. The influence of the researchers' subjectivity had the potential to affect the extraction of the data, although the inclusion of a second reviewer helped reduce this limitation. However, particularly for the qualitative synthesis, it is acknowledged that the primary researcher's previous experiences with patients might have affected the interpretation and construction of themes.

2.4.2 Conclusion and implications for Thesis

The findings of this review add support to the biopsychosocial approach adopted in this thesis. Biological, psychological and social factors were all identified as important in illness acceptance and the reviewed studies have provided an insight into how these factors might be related to acceptance in patients with ESRD. Understanding the role of acceptance is important in allowing the development of applicable interventions which can work on acceptance to improve QoL for patients.

This review addresses the first objective of the thesis: to review the empirical evidence relating to the role of acceptance in ESRD/Dialysis. In reviewing the evidence, the process has highlighted that there is only a small body of research into acceptance in ESRD and even fewer studies of patients on Dialysis. Whilst the cross-sectional studies reviewed have considered several variables, less than half the studies accounted for confounding variables and for those which have considered them, their inclusion was selective. As a result, the findings of the review informed the measure selection and inclusion for the cross-sectional component of this thesis, with the aim being to; compare the influence of psychological factors derived from contrasting theoretical models of adjustment (models of coping versus acceptance), on patient outcomes.

The review demonstrated the lack of longitudinal studies into acceptance in dialysis patients and supported the justification for a longitudinal component to the thesis and the aim to measure and model acceptance and QoL measures over12 months. Finally, the qualitative synthesis identified several key themes around acceptance however the focus of the studies was on patients' general experiences and not acceptance, highlighting the need to gain an in-depth understanding of acceptance in a representative UK sample of dialysis patients. The qualitative study (Chapter 5) enabled the specific exploration of what acceptance meant for dialysis patients and subsequently allowed comparisons to be drawn between the quantitative measure of acceptance in this sample (questionnaires) and the qualitative interpretation (interviews), addressing both objectives two and five of this thesis.

Chapter 3 – Methodology

This chapter outlines the methodology associated with the program of research in this thesis. The theoretical framework and epistemological position are discussed; these encapsulate the mixed methods approach adopted in the study design. Ethical considerations of conducting research with the dialysis patient population are discussed. Individual design elements for each study are outlined in this chapter and summarised in each study chapter.

3.1 Epistemological position/Paradigms

The ‘underlining philosophical assumptions that provide a foundation for using mixed methods’ needed to be considered as ‘acknowledging the worldview that is providing a foundation for the study is important’ (Creswell & Plano Clark, 2017, p34). Entwined in this is understanding the worldview or the beliefs, assumptions and knowledge that form the basis for the current studies. This consideration is of particular importance when adopting a mixed methods stance because the differing approaches can stem from contrasting epistemological positions. In designing the studies in this thesis, the incorporation of the approaches needed to be given careful attention.

The research paradigm is defined as *“universally recognized scientific achievements that, for a time, provide model problems and solutions for a community of practitioners”* (Kuhn 1962 p8) which essentially relates to a set of common beliefs and agreements about how scientific problems should be addressed and understood. It is argued that paradigms are not fixed and through a potentially cyclic process the normal science begins to shift, with anomalies failing to be accounted for by models. When the drift from the norm becomes excessive then this is the start of a model revolution where new radically different models emerge. When these new models become widely accepted then this essentially becomes the new paradigm and paradigm change is achieved. It is therefore important to understand related paradigms in the research being undertaken and ensure that research is not only confirming what is expected but also potentially challenging the established methodology where appropriate, to ensure that paradigm paralysis does not factor.

Paradigms consist of several key components; ontology, epistemology, axiology, methodology, and rhetoric. These components are the underpinning of research, therefore understanding the assumptions and relationships between them is important to the interpretation of the methodology and results. Understanding how the components relate is of particular importance when undertaking mixed-methods research because there is often conflict between the underpinnings of quantitative and qualitative methodologies.

The main considerations in social psychological research are

Ontology – What is reality?

Epistemology – How do you know something?

Axiology – What is the role of values?

Methodology – How do you find out something?

Rhetoric – What is the language of research?

The assumptions associated with these paradigms are usually grounded in theoretical perspective, for example, what is the best approach to use and influence the methods and sources through which data is collected.

Creswell and Plano Clark (2017) summarise four worldviews as postpositivist, constructivist, transformative and pragmatist, which are commonly agreed (R. Hall, 2013). Post-positivism (belief in a single reality, something which is measured and known) is most closely linked to quantitative methods, where clear measurements of a concept can be taken. Constructivism (no single reality or truth, reality needs to be interpreted) is most closely linked to qualitative methods as these attempt to identify the proposed multiple realities constructed by participants, to gain understanding or meaning of phenomenon's. Transformative approaches focus on 'the need for social justice and pursuit of human rights' (Creswell & Plano Clark, 2017, p37). Pragmatism (reality is constantly developed and interpreted) is most closely identified with mixed methods research. Pragmatic approaches adopt the best method to solve a specific problem, it is a 'what works' approach orientated towards real work practice. However it is acknowledged that there is difficulty in defining what works and a realist paradigm has also been suggested as an alternate single paradigm approach (R. Hall, 2013).

Pragmatism is the most appropriate approach to underpin the current study, with both singular and multiple realities being considered through what is practical and employment of qualitative and quantitative methodologies. The focus in the current studies is on selecting the most appropriate methodology for meeting the research questions, with both deductive and inductive approaches being valid. The researcher’s views, which might influence interpretation of the findings, are considered in this approach alongside the participants’ views, which may influence their understanding of their beliefs or how they shape their reality.

3.2 Theoretical framework for the mixed methods approach and rationale

The mixed methods approaches combine at least one qualitative and one quantitative component in a single research project (Bergman, 2008). There has been constant debate about what constitutes the appropriate structure of mixed methods research but in recent years it has become an established and valued approach in health psychology (Bishop, 2015)

From a psychological perspective, mixed methods research is typically a study taking elements of qualitative and quantitative research (Bishop, 2015). The aim of such approaches is to offer a broader perspective and come to a better understanding of the phenomenon of interest. The approach is usually based on pragmatism and is an attempt to bridge the gap between constructionist and post-positive paradigms. Because there was limited quantitative and qualitative research into acceptance in dialysis patients identified (chapter 2) it was important to understand both how psychological variables are associated with depression but also about how this related to patients experiences. Therefore, a mixed-methods approach allowed both aspects to be addressed.

The mixed-method approach can take on various formats in a study. Each can differ in the status of the approach and the order of delivery. The key to successful mixed-method approaches is integration. Typically this can be looked at as either concurrent (triangulation - both qualitative and quantitative data collected, analysed separately and then compared), embedded (quantitative data collected and then qualitative collected to explore the process) or sequential (as in a two-phased project with the findings from the initial phase informing the second phase). (O’Cathain, Murphy, & Nicholl, 2010).

The weighting applied to the methodology can be equal or one can have more dominance. For example:

1- Quantitative data may be collected first and then a subset of participants interviewed about their survey responses. This approach enhances the original quantitative findings by providing a more detailed understanding of the results.
2- Quantitative data may also be collected first and then a subset interviewed based on their responses. For example, if wanting to find out only about depressed patients' experience of illness.
3- Quantitative data might be collected to give objective markers of an intervention's effectiveness, but qualitative interviews may also come later to assess patients' perspective of the impact of a treatment or intervention.
4- Qualitative interviews might be carried out to inform the development/selection of quantitative measures or intervention development.

Table 3.2.1 demonstrates how status and design of mixed methods research can be weighted. More recently, the different approaches have been described as convergent design, explanatory sequential design or exploratory sequential design (Creswell & Plano Clark, 2017). Whilst there is variation on the approaches to categorisation the underlying message is that in mixed methods research it is important to consider how the qualitative and quantitative approaches are to be related.

Table 3.2.1 - Status and categorisation of mixed-methods approaches, adapted from (Burke-Johnson & Onwuegbuzie, 2004)

Status	Concurrent	Sequential
Equal Status	QUAL + QUAN	QUAL → QUAN QUAN → QUAL
Dominant Status	QUAL + quan	QUAL→quan qual → QUAN
	QUAN + qual	QUAN → qual quan → QUAL

Ultimately the approaches taken depend on the aims of the research. Despite weaknesses with the approaches the underpinning strength is; the hope that by adopting a mixed-method approach, one stance adds to the other and therefore provides a better understanding of the phenomenon of interest. The use of the two approaches to understanding a phenomenon in a study can also provide additional support for the findings. They can achieve a fusion of different perspectives, for example, subjectivity vs objectivity; exploratory vs confirmatory, wide vs narrow focus.

Why the mixed methods approach here?

The mixed-methods approach has benefits in the proposed study because the overall research question was exploring both experience and measurable effects. The overall objective was to examine the psychological factors associated with acceptance and the influence on patient outcomes. To understand the relationship and influence of psychological factors on outcomes a quantitative approach involving survey methodology was required. However, to explore the role acceptance had within this population and importantly what aspects were deemed to be important a qualitative approach was needed. In particular, understanding the role of technology acceptance is exploratory with limited existing evidence in support. Therefore, a convergent mixed methods approach was appropriate. The aim was to bring together the qualitative and quantitative findings to obtain a more complete understanding of acceptance in dialysis patients and identify where the results converge and diverge. This approach has been established in health psychology research (Moseholm, Rydahl-Hansen, Lindhardt, & Fetters, 2017; Westland et al., 2019) and renal research (Taylor et al., 2016) and is an intuitive approach to mixed methods research. It was applicable to the current program of research because the data from both the qualitative and quantitative studies were first analysed independently and conclusions drawn, then the findings from both approaches compared. It is acknowledged that there are a number of variants related to convergent designs and the current interpretations included strands of parallel-database variant (results synthesized and compared) and data-transformation variant (adding themes to the quantitative database) as appropriate to the research questions.

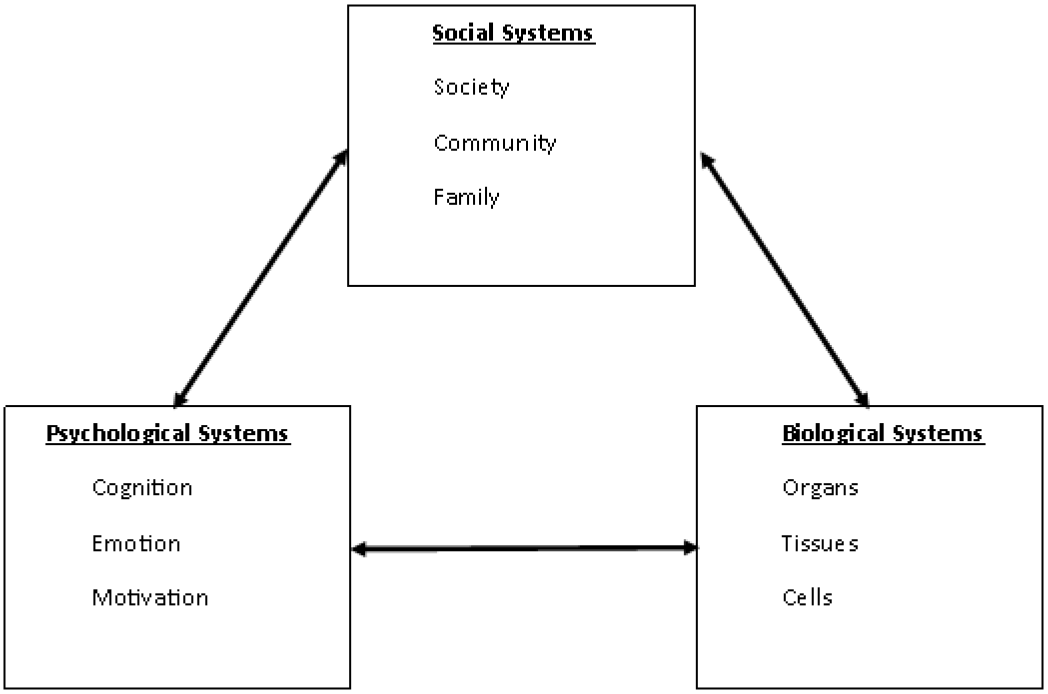
3.3 Relevant Theoretical models

Understanding the theoretical framework is important when comparing the framework adapted to the established models in the area. As outlined in the literature review chapter several key models are of potential relevance and needed to be considered. These are the working model of adjustment (Moss-Morris, 2013), the influential biopsychosocial model (Engel 1977 (as cited in Engel, 1981)), relational frame theory (Hayes, 2004), and Illness perceptions (Knowles, Swan, Salzberg, Castle, & Langham, 2014) as part of Leventhal's self-regulation model (Leventhal, Leventhal, & Contrada, 1998).

The biopsychosocial model underpins the current study approaches. Engel (1977) proposed the biopsychosocial model as a contrasting approach to the biomedical model which dominated at the time. The biomedical model failed to take account of the person who has the illness, their experiences towards illness, their views on illness and care in relation to the illness. Therefore, the biopsychosocial model addressed this by suggesting a bi-directional relationship between all three components (Figure 3.1). Since its inception the biopsychosocial model has 'become the orthodox overarching model for health, disease and healthcare' (Bolton & Gillett, 2019, p5). However, the model is not without criticism, particularly due to the vagueness from clinical, scientific and philosophical perspectives (Nassir Ghaemi, 2009). Yet, it can be argued that the vagueness of the model can be justified due to the complexities in the relationships. If the model is viewed as an overall approach, specifics can be addressed through more targeted models aimed at specific conditions under the umbrella of the biopsychosocial framework.

In the case of dialysis patients, the biopsychosocial model is appropriate because although the treatment is highly medicalised it is related to how patients feel and their QoL, and in turn can be related to the wider social systems such as the dialysis community and support from friends and family. The biopsychosocial approach has become established in renal research with recent research into the correlates of fatigue in haemodialysis (HD) patients supporting the use of the biopsychosocial model in renal patients (Chilcot et al., 2016) and the biopsychosocial framework guiding the analysis of patients coping with end-stage renal disease (ESRD) (Han et al., 2019).

Figure 3.1 - The interplay of systems in the biopsychosocial model



Under the general biopsychosocial approach more specific models have emerged. One example is the proximal-distal model, this model with the addition of psychosocial factors has been proposed as a biopsychosocial model in ESRD (Chan, Brooks, et al., 2011), and acceptance is one component of this model.

The development of specific models has included the suggestion of a working model of adjustment to chronic illness (Moss-Morris, 2013). Here acceptance is viewed as one of several cognitive and behavioural factors which can be helpful in achieving a successful adjustment to events or stressors which disrupt emotional equilibrium and QoL. This model positions acceptance alongside self-efficacy, social support, coping, engagement in health behaviours and maintaining physical activity as being beneficial in adjustment. The working model is appropriate in ESRD because initiation to dialysis is an event that requires adjustment however it is unclear which of the factors are most salient in this process.

The other models that have informed methodological decisions have been the relational frame theory which underpins the acceptance and commitment approach (discussed in chapter 1, section 1.3) and illness perceptions as part of the self-regulation models which have demonstrated an impact of ESRD on QoL (Timmers et al., 2008). These models have been influential in informing the decisions about which measures should be included in the current studies to ensure that comparisons and testing of these models could be conducted.

3.4 Research with Dialysis patients

The treatment options for end-stage renal disease is detailed in chapter 1 (section 1.1.5). In the development of the current studies consideration was given to the sample to be included. The treatment options are comparable in the sense that they treat ESRD but there are significant differences in QoL that have been identified between the modalities. One study identified that whilst home and in centre dialysis patients had similar demographic and clinical characteristics, in-centre patients had lower QoL across certain domains (Eneanya et al., 2019). They also identified a trend towards different patterns of HRQoL in patients who changed modality. Yet there is evidence that dialysis modality does not factor in QoL, with a systematic review suggesting that there is no difference in HRQoL domains between haemodialysis and peritoneal dialysis patients. However they note, PD patients generally reported higher percentage scores for QoL (Ho & Li, 2016). It is highlighted that these differences may be due to PD being more manageable in terms of patients' schedules or that this may be influenced by differences in clinical markers. Yet QoL scores have been shown to be higher in HD compared to PD patients and differences were shown across QoL domains (Kang et al., 2017). These findings suggest that whilst there may not be overall differences in reported QoL between modalities there may be differences across domains or aspects of QoL. This might be expected as the demands placed on patients across the modalities differ. Whilst this is one aspect that could be explored in relation to the current research questions the inclusion of a range of dialysis modalities may confuse relationships between acceptance and QoL. Based upon these considerations the decision was made to focus upon HD patients because these make up a substantial proportion of the patients on renal replacement therapy (RRT) (section 1.1.3). By focusing on the HD population in one centre, where most patients receive a similar dialysis regime, the relationships between acceptance and QoL could be explored in more depth. The benefits of working with HD patients were that all patients attended the same centre and therefore had similar treatment experiences. The population was also easily accessible for the researcher as patients were attending at least three times a week for their dialysis sessions, this aided in engagement and completion of the questionnaires.

However, despite the benefits of focusing on a single site, there are issues related to working with this population. Firstly, whilst using a single site controls for variability in the treatment environment, it means that results cannot be generalised to the wider dialysis population. The single site also had a limited number of patients who were eligible to be approached for the study which placed limits on sample sizes. With this limited potential sample, the majority of patients had also been approached to take part in other research studies. Whilst this had benefits in helping patients understand the extent of their involvement with the research it potentially hindered participation with some patients feeling overburdened by research.

Finally, there are other physical and psychological considerations to be taken when working with dialysis patients. A dialysis unit can be very different from other hospital wards and departments. Dialysis patients usually attend hospital three times a week for at least 4hrs. As a result, patients are generally more familiar with the staff and other patients than in other clinical areas. This can be beneficial in that staff are able to identify patients who are suitable for the study however their involvement could unintentionally exert pressure on patients to agree to take part in the research studies. With patients feeling they know the staff well there is the potential for this to affect how patients answer the questionnaires or interview questions as there could be concerns about confidentiality even when assurances are given. Consideration also needs to be given to the nature of the illness. These patients are all unwell, they have kidney failure and rely on dialysis for survival. As a result, many of the patients had co-morbidities which needed to be considered. Patients' with kidney disease due to diabetic neuropathy might have associated complications with sight or neuropathy in their hands. In addition, dialysis patients may have unrecognised cognitive impairments (Foster et al., 2016), which needed to be considered when consenting participants and collecting the data.

Sensitivity is needed with this population as 'confronting mortality' can be a component of being an ESRD patient (Morton, Tong, Howard, Snelling, & Webster, 2010). Due to the higher mortality rate, long term dialysis patients are likely to have known other dialysis patients who have passed away. 'Coming to terms with death' (Curtin, Mapes, Petillo, & Oberley, 2002) and 'being aware that death may be near' (Axelsson, Randers, Lundh Hagelin, Jacobson, & Klang, 2012) are factors patients encounter and the psychological impact needed to be considered, with sensitivity applied during data collection. For example, asking patients to complete a questionnaire about QoL when they have just discovered a fellow patient has passed away would not only be insensitive to the patient but also may affect the self-reported QoL. The month window for 6 month and 12-month questionnaire completion allowed flexibility in timing. A month allowed questionnaire timing to be at patients' convenience however because the QoL measures reflected patients' feelings over the previous month completion was not required on the exact follow up date. In addition, the affect measures could allow for the emotional state of the patient to be measured.

3.5 Methodological approaches to answer the research questions

This section provides an overview of methodological approaches adopted to address each objective of the study. Objective 1 has been covered in the literature review (Chapter 2).

3.5.1 Objective 2

The second objective in this program of work was to explore what acceptance means for dialysis patients. The focus was to get a more in-depth understanding of what acceptance means for dialysis patients. Therefore, a qualitative investigation was conducted through interviews with patients about their overall experiences of dialysis and aspects related to acceptance (chapter 5).

3.5.2 Objective 3

The third objective was to compare the influence of psychological factors derived from contrasting theoretical models of adjustment (models of coping versus acceptance), on patient outcomes. To address these objectives a mixed-methods approach was utilised. Firstly, quantitative scales captured key measures of acceptance and QoL in dialysis patients. These acceptance measures were compared, and the utility of these measures for use in this population analysed (Chapter 4 - Study 2a). Secondly, the key acceptance measures and psychological measures were analysed to understand the relationships between acceptance and QoL when clinical and psychological variables were accounted for (Chapter 4 - Study 2b). Finally, these were compared with the qualitative findings to evaluate the application of models of adjustment (Chapter 5).

3.5.3 Objective 4

To address the fourth objective, to measure and model acceptance and QoL measures longitudinally alongside the physical/clinical measures, a quantitative methodology was most applicable. Demographic, clinical and psychological measures collected at baseline were also collected at 6 months and 12 months following initial collection. Therefore, allowing analyses to identify predictive relationships between acceptance variables and outcomes (Chapter 6).

3.5.4 Objective 5

The final objective related to how the qualitative and quantitative perceptions of acceptance were related. This study involved comparing the findings of the empirical studies with the findings from the review studies to inform the overall understanding of the role of acceptance in dialysis patients and identify patterns or areas of focus. Mortality and clinical outcome measures were compared with both the quantitative and qualitative results.

3.6 Associated research

This project was associated with a medical engineering project to develop intelligent technologies for renal dialysis and diagnosis (the iTrend project (Selby et al., 2016)). The current studies have gone beyond the technological and engineering remit of the iTrend study and have identified acceptance as a novel area of study in the dialysis population. The connecting factor was the potential that both acceptance of technologies and acceptance of illness may contribute to patient quality of life (QoL) and wellbeing outcomes. The iTrend study focused on developing technologies to continuously monitor patients' blood pressure whilst they were on dialysis, with the aim being to develop a system whereby machine parameters can be adjusted to optimise dialysis for each patient. The current studies focus on the psychological aspects associated with acceptance of illness which by its nature covers how patients accept the treatment regimes, so the findings of this study will complement the current technological developments and may inform how such developments may be made more acceptable to patients in relation their QoL.

3.7 Ethical considerations

3.7.1 Ethical approval

Ethical approval for the study was granted by the NHS North East (Tyne and Wear South) Research Ethics Committee in May 2018 (Appendix 1). The qualitative and quantitative elements of the study were included in a single application that went through proportional review and approval was granted after minor amendments.

3.7.2 Ethical considerations with data collection methods/NHS research

The following sections outline how the standard ethical issues were addressed in these studies and any methodological implications which were associated with addressing the ethical concerns.

3.7.2.1 Recruitment

Potential participants were initially identified by the clinical team based on stated inclusion/exclusion criteria. Potential participants were first approached during their routine dialysis sessions and asked if they would like to find out more about the study. The researcher verbally informed them about the study and provided patient information sheets (Appendix 3) and consent forms to review. This initial introduction of the study allowed clarification about patients' initial understanding of the study to be obtained. Patients were given at least 24hr to consider their participation. In practical terms, patients were approached for consent at their next dialysis session – 48-62 hrs later. Only basic data to allow contact to be made with potential participants were collected at the initial discussion of the study.

3.7.2.2 Consent

Consent was obtained prior to the questionnaire data collection and prior to interviews being conducted. Prior to consent being taken participants had already been given written information about the study and they had the opportunity to discuss the study with a researcher and ask any questions. Once they had at least 24hrs to consider, participants were free to choose to consent to either the qualitative, quantitative study, both or to decline participation. The consent form outlined what was to be involved in the research, that it was voluntary and that they could withdraw from the study at any time. It was made clear that this would not affect their treatment in any way (Appendix 4).

In addition, efforts were made to check capacity to consent at baseline and additional time points. Part of the exclusion criteria related to capacity to consent. This was initially assessed by the clinical team who identified potential participants. It was also assessed by the researcher when initially discussing the study and again considered at each time-point. If participants did not appear to have a clear understanding of the research and their level of involvement, then the process of obtaining consent was concluded. If questions about capacity were raised/identified, then opinions about capacity were sought from the medical team.

3.7.2.3 Risks, burdens and benefits

Potential risks to patients from the questionnaire study were minimal. The questionnaires were designed to take 30 - 60mins to complete which was a lengthy time burden. To lessen this, participants were given options on how they would like to complete the questionnaires; online, paper, whilst on dialysis in hospital, at home. It was suggested that they could take breaks if needed. Participants had the option to complete the questionnaires individually or with the assistance of the researcher. This option was necessary to allow the inclusion of participants who had vision or dexterity problems, both common in this population.

It was not expected that the questionnaire would cause harm however there was the potential that the content of the questionnaire, which asked about patients' illness and how they cope, could be emotive for some patients. To reduce the risk only well established and validated measures were used in this study (section 3.12). Participants were reminded that they did not have to complete the questionnaires if they chose not to.

The interview study, whilst not designed to be intrusive or emotive, was based on discussion about patients' experience of their illness and dialysis. This, therefore, had the potential to be emotive and whilst some participants may have felt benefit from telling their story for others, they may have felt affected by the interview. During the interview, the interviewer could stop the interview, or reiterate to the participant that they did not have to continue. The debrief included signposting to support from the clinical and supervisory teams. At no point during or after the interview was clinical advice given to participants but signposting to clinical teams could be suggested.

3.7.2.4 Confidentiality

The research followed the Caldicott principles (Caldicott Committee, 1997) and complied with BPS guidelines regarding confidentiality. The data collected in the questionnaires and clinical information was based upon evidence suggesting links to acceptance. The interview data acted as confirmation of the quantitative findings and opened up avenues for future research. Therefore, all the data being collected in both the quantitative and qualitative studies directly linked to the research question.

Person-identifiable information was only collected where necessary and was destroyed when no longer required. Main databases were anonymised and participant numbers utilised instead of identifiable information. Any personally identifiable information collected was stored securely and only research team staff had access to the information. Personal information was not stored with data collected from questionnaires or interviews. During the development of the study the general data protection regulations (GDPR) came into force. The study complied with the GDPR principles which are underpinned by the Data Protection Act (1998) and included an additional GDPR statement which was given to all participants in addition to the recruitment information (appendix 8).

Confidentiality was considered in relation to the dissemination of the findings. For the qualitative study, only non-identifiable quotes are included in this thesis. This included anonymising any identifiable information in quotes but also giving careful consideration to whether information divulged could also lead to the identification of participants by those known to them, including the clinical team.

During the course of interviews or correspondence with patients, there was the possibility that information could be disclosed that suggested participants were at risk of harming themselves or there was a risk of harm to others, details on how this was managed follow in section 3.7.3.

3.7.2.5 Conflict of interest

The researcher was not part of the clinical care team and the researchers' role in contact with the participants was to collect data and not offer clinical advice. If there were cases where concern for participant's welfare was to be noted, then it was suggested to the patient they discuss with the clinical team and agreed that the researcher could also mention to the clinical team. Whilst these measures were in place to ensure that there was no conflict of interest, the patients' understanding of the researcher's role needed to be considered. From the researcher perspective, they are not considered to be part of the clinical care team; however, this differentiation may have not always been apparent to patients. This had the potential to influence the results and implications are considered in discussion of the findings.

3.7.2.6 Debriefing

After the completion of the questionnaire, patients received a short debriefing (appendix 5). The debrief mentioned what the next steps with the research were and reminded participants they could withdraw and gave them opportunities to ask questions. After completion of the interviews, patients received a verbal debriefing and a paper copy to take away. A short debrief was given after each session and a final debrief was given to participants at the end of the study. The final debrief covered the same information as the shorter debrief and also summarised the study as a whole as well as providing an overview of the next steps for the study.

3.7.3 Ethical considerations relating to psychological distress

During the course of interviews or correspondence with patients, there was the possibility that information could be disclosed which suggests participants are at risk of harming themselves or there is a risk of harm to others. This possibility was covered in the participant information sheet; it mentioned that there may be times when confidentiality needed to be breached. The procedure was that if a disclosure of concern were to be made to the researcher, then this was first mentioned to the participant and explained. Then ideally an agreement to discuss the disclosure with the medical team was sought from the participant. If such agreement were not forthcoming and if a serious risk was present, then confidentiality would be broken to inform the clinical team and ensure participants safety. This procedure only had to be enacted in one case and this was with the agreement of the participant obtained. Agreement was made with the patient that the medical team could be informed, the medical team were then immediately involved, and information related to the disclosure included in the medical notes. The participant in this one case was then, with their agreement, withdrawn from completing the later stages of the study to avoid causing further distress.

To avoid distress patients were informed through the participant information sheet and the consent process about the nature of the questionnaires/interviews which allowed them to opt-out if they deemed it to potentially be distressing. The debriefing document also signposted patients to sources of support should they have felt they experienced psychological distress.

3.8 Study Design

The aim of this research was to gain an understanding as to the role of acceptance in patients undergoing dialysis for ESRD. Overall the study adopted a mixed-methods approach, combining descriptive, qualitative and correlational designs and each study aimed to address specific objectives. The quantitative studies consisted of a cross-sectional study design utilizing baseline data and a longitudinal study utilising 6 month and 12-month data. The Qualitative study consisted of interviews at one-time point and had included the option of interviews at 12 months, but this was not utilised. The final discussion included triangulation of the data from the qualitative and quantitative studies in relation to the theoretical framework outlined (in chapter 1).

3.9 Empirical research

The research program utilised the same sample pool for both the qualitative and quantitative studies. The following sections outline the sampling framework and procedure involved in recruiting participants for the study.

3.9.1 Sampling

3.9.1.1 Participants

Participants were all dialysis patients of a single hospital dialysis unit. All patients were recruited in person at the hospital unit. Potential participants were first identified and screened by the clinical care team to assess initial suitability. Potential participants were compared to the inclusion/exclusion criteria and if deemed potentially eligible then they were approached in person by the researcher.

The inclusion criteria were age >18, receiving haemodialysis > 90 days, ability to complete questionnaires in English (Quantitative) and able to converse in English (Qualitative). The rationale for excluding patients under 18 was that their experiences were likely to have been different, as at 18 years this usually signals the point where children transfer from paediatric to adult services, a period of change and challenge (Bell, 2007). The rationale for including patients who had initiated dialysis for at least 90 days is that they were more established on dialysis, and it was more likely that they are more settled into the routine, this also aligned with the protocol for the iTrend study. This was important for the current work as the focus was on established dialysis patients, once the role of acceptance is understood in this population there is potential that acceptance could be looked at within the early initiation and pre-dialysis populations. Exclusion criteria for the study were metastatic disease or prognosis thought to be <12months in opinion of investigator and inability or unwillingness to provide informed consent. The rationale for the exclusion based on prognosis was that these could be confounding variables with acceptance during this time being more focused on acceptance of mortality rather than acceptance of illness (Wong & Tomer, 2011). Inability or unwillingness to provide informed consent was initially established by clinical review but also through early discussion introducing the research to participants.

3.9.1.2 Sample size calculations

For the qualitative thematic analysis, advice is that interviews should be conducted until data saturation (Saunders et al., 2017) is achieved. Data saturation is where no new themes are evident in the interviews. It was anticipated that the proposed sample size of 20-30 would provide sufficient numbers to achieve this and allow for sufficient comparison between potentially different types of acceptance. This was dependant on the quality of the interviews and reviewed throughout data collection.

For the quantitative study one rule of thumb for multiple regression is that n should be at least 50 plus the number of predictor variables (Tabachnick & Fidell, 1996). Power calculations were computed using G-Power (Faul, Erdfelder, Lang, & Buchner, 2007) for the main statistical tests. Sample sizes sufficient to detect a small to medium effect (Cohens d 0.3) at a level of at least 0.95 power ranged from 36-122 participants required. For example – for linear multiple regressions with 4 predictors, G-Power indicated that 60 participants would be required to identify an effect size of 0.3 and have a power of 0.952.

3.9.1.3 Anticipated population sample

In relation to the sample size calculations, the potential sample pool and generalisability to the national population was considered. The UK renal registry report (2018) provided annual national and centre-specific data which helped inform the understanding of the potential population and assess the practicality of the proposed sample size. The figures presented below were all obtained from the 2018 report which relates to data for 2017.

In 2017, 556 patients were recorded to be receiving RRT in the single hospital site used for recruitment, this equated to 34.4% on in-centre dialysis patients, 9.4 % on home dialysis, 14.2% on PD and 42.1% transplant. The majority of patients were white (83 %,) with the other major groups being South Asian (11.2%) and black (2.7). The majority of the patients were male with the breakdown being 61.9% male and 38.1% female. When compared to the national picture the hospital trust had a slightly lower percentage of patients on in-centre dialysis (-2.9%) but this difference may be partially due to the higher than average number on home haemodialysis (+ 7.4%). The centre had a higher proportion of PD (+ 8.8%) patients but a lower percentage who received a transplant (-13.1%).

At the end of 2017 at the renal unit, there were 243 patients on haemodialysis, with 191 dialysing in the hospital. For these patients the mean age was 65 years, the majority were male 60.7%, most were white (70.4%). These are similar to the UK figures of 67.5 years, 61.9% male and 71% white. Figures for the one-year survival were 82% for incident dialysis patients and 87 % prevalent patients. In 2017, 3.5% were in receipt of a transplant within the year however this may have reflected the fact that the centre was not a transplant centre and therefore only minimal inferences can be drawn from the figures. Nationally 4.7% moved from HD to transplant.

From these figures it could be estimated approximately 200 patients would be dialysing during the recruitment period. During this time, it would be expected that between 164-174 would survive 12 months and of these approximately 10 were likely to have moved from HD to transplant. Accounting for other changes in modality it might have been expected that 73% (146) of the population on HD would be on HD 12 months later. However, not all participants were to be eligible for the study at the outset. Therefore, the target sample size of 100 fulfils the sample size calculations for most analyses and should retain sufficient participants for 12 months analyses.

3.10 Qualitative (chapter 5)

3.10.1 Theory

The qualitative approach was based on semi-structured interviews and thematic analysis (Braun & Clarke, 2006) of the interviews. When interviewing the traditional approaches adopted are structured or unstructured interviews, with structured being more suited to quantitative analysis and unstructured, qualitative analysis (Howitt, 2016). In line with the philosophical underpinning, the used of semi-structured interviews allows exploration about participants' perspectives of their experiences on dialysis but also allows for comparisons between participants to assess the common realities whilst still retaining the individual perspective.

A qualitative analysis should be based upon the epistemological position of the research. Epistemology is the assumptions we make about the kind or nature of knowledge. The key epistemological positions are positivism, empiricism, hypothetico-deductivism, social constructionism, realism, relativism which fall under the overarching paradigms (discussed in section 3.1). Qualitative analysis approaches have different merits and the selection should be based on the research question, current knowledge in the area, epistemological positions and planned analysis, for example when taking a pragmatic approach, a realist or social constructionist analysis of interviews may be most appropriate depending on the question asked. The number of approaches to qualitative analysis are continually developing and being expanded. In health psychology the established methods currently include grounded theory (Strauss & Corbin, 1994) a deductive approach, IPA (Smith, 2004) an inductive approach, and thematic analysis (Braun, Clarke, Hayfield, & Terry, 2018). Thematic analysis has been described as a useful tool in health research (Braun & Clarke, 2014). There are three broad categorisations of thematic analysis; coding reliability, codebook and reflexive. Coding reliability is a partial qualitative approach where data are collected using the established techniques to report themes however the process is underpinned by quantitative post-positive thinking. Coding reliability thematic analysis follows a scientific approach where agreement on codes is reached by multiple coders. In contrast reflexive thematic analysis can be considered a fully qualitative approach which acknowledges the researcher as having an active role in the knowledge production process. Codebook thematic analysis is describes as 'a third school of TA' (Braun et al., 2018, p 7) which keeps the structured approach of coding reliability but shares the philosophy of reflexive thematic analysis. In analysing the interviews in the current studies an inductive (reflexive) thematic research approach was deemed to be appropriate, so rather than being driven by theory or patterns of meaning these were developed and evolved as the study progresses. This allowed the development of understanding of the concepts of interest.

3.10.2 Data collection method

Patients were provided information about the qualitative study along with information about the quantitative studies. Following the consent procedure (3.7.2.2) participants were interviewed whilst on dialysis during one of their usual sessions. All participants had the option to be interviewed whilst on dialysis, in their own homes, at the university or in another setting at the hospital. However, all opted to be interviewed on dialysis. This had advantages in facilitating recruitment to the study, but it came with drawbacks. The issues identified included various interruptions during the interviews; tea/coffee, clinical interruptions from staff or machine alarms and interruptions from other patients. These interruptions added to the distractions and noise during the interviews which could distract both the patients and interviewer during the interview process and potentially impacted on the depth or richness achieved in the data. In addition, the interviews on dialysis might have affected how patients described their experiences; if clinical staff or other patients were present then patients might have felt unable to fully disclose information about their experiences. However, for all patients they had been on dialysis for at least 3 months, so the unit environment was one they were familiar with, they were also used to answering questions and discussing their experiences with clinical staff (dieticians, physiotherapists, doctors) during dialysis. At the end of the study participants were debriefed (section 3.7.2.6) and provided with information about how to withdraw their data from the study if they changed their mind after the interview. No participants chose to withdraw their data from the interview study.

Semi-structured interview schedules were used to direct the interviews. This approach was deemed to be most suited to the research question. This was because there were no clear constraints or theories to be tested; instead the aim was to understand more about acceptance in dialysis patients. This explorative nature required participants to have the scope to discuss what was important to them rather than having the researchers' ideas imposed. When conducting an interview it has been suggested that there are nine stages which are covered before the interview is carried out (Howitt, 2016). These begin with conceptualisation, then preparation of the interview schedule, assessing suitability of the sample for in depth interviewing, interview trialling, inter-interview comparison, communication between interviewers, sample recruitment and selection, participant management and preparation/selection of the interview location. These were considered and issues addressed during the preparation for interviews (Table 3.10.1).

Interviews were all conducted by the same researcher to help maintain consistency. Interviews were digitally recorded and transcribed verbatim. Verbatim transcription was deemed appropriate as opposed to Jefferson notation (Jefferson, 2004) because the analysis was focused on the themes in participants’ talk rather than how the talk structure conveyed their meaning. Whilst verbatim transcription is sufficient for thematic analysis it does miss some key aspects of communication, e.g. proxemic communication (the use of physical space in conversation) kinesics communication (the use of body movements) paralinguistic communication (the use of volume and pitch) and chronemic communication (the use of speech pace and silence). Transcription was carried out by the researcher and a student assistant. Each interview was transcribed by one party and then checked by the other. This ensured the accuracy of the transcription was maintained across all interviews.

3.10.3 Data analysis

Detail relating to the qualitative analyses is presented in chapter 5 (section 5.3), here a summary of the approaches used are covered. The analysis adopted a thematic approach as detailed by Braun and Clarke, (2006, 2012, 2014). The thematic approach adopted an inductive stance where themes were derived from the data rather than being constrained by theoretical assumptions. This approach was appropriate due to the limited evidence on the role of acceptance in this population, and theoretical constraints may have overlooked previously unidentified constructs. The thematic analysis followed the six stages recommended for a thematic analysis; familiarisation, generating codes, constructing themes, revising themes, devising themes and producing the report (Braun & Clarke, 2006; Braun et al., 2018; Willig & Rogers, 2017).

Table 3.10.1 - Considerations addressed at each stage of interview preparation

Stage of interview preparation	Considerations
Research conceptualisation and development	The research focus was in line with the mixed methods approach and designed to address the targeted objective (section 1.4.1.2)
Preparation of the interview schedule	The interview schedule was designed as a guide to address the aims of the study but to be adjusted as necessary through the interview, for example, a topic might have already been covered in detail so it would be unnecessary to revisit. The schedule was designed to be open with more general questions about how patients came to be on dialysis, this was to help establish rapport with patients. The schedule them moved towards potentially emotive topic areas before letting participants conclude with anything further they wished to discuss. The schedule was discussed with other researchers to assess suitability.
Suitability of sample for qualitative interviews	The consent process was designed to exclude any patients who were unsuitable for interviewing. Issues with research in dialysis patients has already been discussed (section 3.4). In addition, the suitability for interview was assessed on a case by case basis.
Interview trialling (piloting)	It is acknowledged that during early interviews processes may need refining and issues may need to be addressed. There were two options, to carry out practice interviews or to begin main data collection but to be aware of these potential problems. To ensure that valuable data was not ignored the decision was made to take the later approach. The primary changes made after the initial interviews were to add additional prompts to ensure further depth to response.
Inter-interview comparisons	A series of interviews by the same researcher can bring influence to other interviews. Through the process of completing interviews issues or topics may emerge that then influence the researchers directing of future interviews. This may mean that topics emerge during the course of later interviews which may not have emerged if conducted earlier. This is one of the justifications for the semi-structured approach and will also be discussed in analysis.
Communication between interviewers	Communication between interviewers was not an issue in the study due to one interviewer conducting all the interviews.
Sample recruitment and selection	Participants were approached to participate in the study and were given the option to take part in the quantitative component, the qualitative component or both. No participants opted for only the qualitative study. The questionnaire study was completed first and on completion of this participants were reminded about the qualitative component and asked if they would potentially be interested in taking part. Those that indicated they might be were approached at a later stage to discuss participation in the qualitative study.
Participant management	Participants who had indicated an interest in the study were approached and information they had received about the interview process was discussed with the researcher. If patients were interested in taking part, then consent was obtained following the consent procedure. Participants were given prior warning about the interviews and timing of the interview was arranged based upon the needs of the patients.
Location of the interview	Despite other options being available all participants chose to be interviewed on dialysis. Consideration was given to limitations and benefits of this (section 3.10.2).

Familiarisation with the data was the first step and this was achieved through the initial transcription and subsequent checking of transcriptions against the original interviews. During the familiarisation initial analytic ideas were noted which informed the next stage, coding. Coding involved noting all aspects of interest in the text and assigning meaningful labels. Coding was initially wide and became more refined and developed as the process continued. Coding began manually but after manual coding of 13 participants coding was restarted in NViVo (Version 12, 2018) using the initial coding as a framework to develop further coding in NViVo, initial coding was checked by a second researcher. The next stage of the process involved theme development. Themes apparent in the coding were explored and discussed between the researchers, this led to the next stages of reviewing and defining the themes these were eventually developed into a theme map. These themes and associations are reported in Chapter 5.

3.11 Quantitative

3.11.1 Theory

Quantitative methodological approaches in this study employed both cross-sectional and longitudinal approaches. The cross-sectional approach allowed for differences in acceptance and relationships between acceptance and QoL to be explored. The longitudinal aspect allowed confirmations of these relationships to be tested and predictive relationships explored. By using both approaches the nature and potential changes in acceptance in dialysis patients could be tested.

3.11.2 Phase 1 – Cross-sectional procedure (chapter 4)

The questionnaire-based survey aimed to capture demographic, clinical and psychological measures at baseline and identify the relationships between them. To facilitate participation and to reduce the burden on participants the survey was designed to allow participation to be achieved through completion of online (Qualtrics) or paper questionnaire. At inception, it was anticipated that most participants would complete the surveys online whilst on dialysis, but in reality most opted to complete the paper questionnaires. Patients who completed the questionnaires could do so independently whilst on dialysis however this was often impractical with common issues being; fistula positioned in writing arm, poor eyesight, poor dexterity in their hands. As these are complications associated with dialysis it was important to ensure participation from these patients where practical. Therefore, 32.65% of patients completed the baseline questionnaires with the researcher and 67.35% independently. It is acknowledged that this difference is a potential limitation of the study. Evidence of differences in researcher aided completion responses were explored in analyses (section 4.4.1.1).

The questionnaire length was on average 45 minutes but varied greatly across the patients. It is acknowledged that this burden could lead to fatigue in participants and affect completion of the questionnaires. To minimise this, participants who completed the questionnaires independently were provided with the questionnaires at the start of the dialysis session and were advised to take breaks as they felt necessary, this aimed to reduce any pressure. Participants were also told they could complete the questionnaire at home and return it in their next session. For participants who completed the questionnaire with the aid of the researcher, the researcher would instigate breaks where necessary and appropriate within the questionnaire. Due to the nature of the end stage renal disease some participants were less physically capable of completing the questionnaire than others (on oxygen, recent hypertensive episodes, fatigued), therefore this required that questionnaires were completed over 2-3 dialysis sessions. If this were the case it was split by – session 1 – demographic factors, session 2- Kidney disease QoL questionnaire, 3 – psychological measures. Whilst it was not ideal to split the sessions, the split was designed to minimise the impact on the overall results and protect participants from being overburdened. The KDQoL questionnaire primarily asked the status of patients' wellbeing over the past month, rather than at a specific moment in time, whereas some of the psychological measures were time-specific.

Once participants had completed the questionnaires the date of completion was used to facilitate collection of clinical data from patient records through the use of case report forms. Questionnaire and clinical data collected were held anonymously under a unique patient identifier.

3.11.3 Phase 2 – Longitudinal (chapter 6)

The longitudinal study collected identical psychological questionnaire and clinical data at, 6 months and 12 months following completion of the first questionnaire. The only omissions at 6 and 12 months were certain demographic measures (education level) which were unlikely to have changed. The methods applied were identical to the cross-sectional study (section 3.11.2). Prior to being approached at these time points, clinical opinion about the suitability of continuation was checked. Patients were again directly approached by the researcher to ensure they understood what was required and verbally consented to continue. A number of participants were withdrawn at this point either due to inability to provide informed consent or physical/clinical condition at the time.

The 6 month and 12-month questionnaires were scheduled to be completed at exactly 6 months and 12 months from initial completion. However, it was impractical to ensure that this was achieved, primarily due to fluctuations in patients' physical wellbeing. On some occasions, it would take 3-4 visits to a patient before they "felt up'' to completing the questionnaire. To try to ensure timely completion participants were usually first approached 1 week prior to the anticipated date of completion and then there was up to one month for participants to complete the questionnaires. This allowed patients who were unwell or on holiday to complete the questionnaires within one month of their due date. Patients were given questionnaires and asked, where possible, to complete them using the same method as previously. For example, if completed with researcher assistance previously then this was the preferred method for 6 months and 12 months. This consistency was to avoid changes in questionnaire score due to method of completion.

Clinical data was collected through routinely collected information and extracted into case report forms (CRFs), mirroring baseline data collection. Data from baseline and subsequent time points were merged, by participant ID, to provide an anonymised dataset for analysis.

3.11.4 Quantitative measures

The main data collection sources for the cross-sectional and longitudinal studies were questionnaires and clinical records. The following section outlines the considerations relating to each measure including covering; the rationale for measuring the concept, suitability of the chosen measure in relation to the concept and in relation to the clinical population. Questionnaires were identified as the most appropriate tool for data collection. Using established questionnaires which have demonstrated reliability and validity in the dialysis populations helped provide comparability within the study and with published findings. Using self-report questionnaires can collect a lot of information over a short period of time however it is acknowledged that there are a number of factors that can affect responses. The motivation of participants may have affected how they answered the questions, particularly if they had a specific agenda or motivation for taking part in the research. Participants may have misunderstood the questions and self-report is therefore their report on their interpretation of the question. The length of the questionnaires can lead to fatigue and in turn can affect the responses. Care was taken to ensure that established questionnaires were included and they were assessed for applicability to the dialysis population.

3.11.5 Questionnaires

3.11.5.1 Demographic questions

This questionnaire was researcher-designed and collected basic information about the participants. This questionnaire was longer at baseline to collect additional data. Information included age, gender, ethnicity, marital status, dialysis type, length of time on dialysis, education level, employment, religious belief, comorbidities. Only marital status, employment and comorbidities were collected again at 6 and 12 months. Some of this demographic information was collected as part of the KDQoL-SF. Comorbidity data was obtained through questionnaires and cross-checked against patients

3.11.5.2 Acceptance measures

Objective 3 (3.5.2) was to understand more about acceptance in relation to current theoretical frameworks. In particular, attention was given to how and what acceptance means in the dialysis population. Because there are different approaches to acceptance the decision was made to include several measures which each captured a different aspect of acceptance. There were a number of measures identified which capture acceptance of illness, these included the acceptance of illness scale (Felton & Revenson, 1984), the adjustment scale of the reactions to impairment and disability scale (Chan, Brooks, et al., 2011), the acceptance of disability scale (Groomes & Linkowski, 2007; Linkowski, 1971), the illness cognitions questionnaire (Evers et al., 2001) and the brief COPE (Carver, 1997). The decision on the final measures to include were informed by the results from the systematic review (chapter 2) and the theoretical underpinning of this study (Stalker et al., 2017). The acceptance of illness scale (AIS) (Felton & Revenson, 1984), the illness cognitions questionnaire (ICQ) (Evers et al., 2001) and the COPE (Carver, 1997) were included because they were deemed to be measuring different concepts of acceptance.

The AiS comprises 8 items rated on a five-point Likert scale from strongly agree to strongly disagree, with a higher overall score conveying higher acceptance (Johnston, Wright, & Weinman, 1995). The AiS has been widely used across illnesses (Karademas et al., 2009; Kurpas et al., 2013; Obiegło, Siennicka, Jankowska, & Danel, 2016; Uchmanowicz, Jankowska-Polanska, Chabowski, Uchmanicz, & Fal, 2016) including in ESRD (Jankowska-Polańska et al., 2019, 2017; Keogh & Feehally, 1999) and has a high internal consistency (Cronbach's alpha = 0.81 to 0.83). In the Polish version (Bień, Rzońca, Kańczugowska, & Iwanowicz-Palus, 2015) the double negative of "my health does not make me feel inadequate" was replaced with "my health makes me feel inadequate", this was replicated in current studies. Permission to use the scale was obtained directly from the author through email communication.

The ICQ questionnaire measures cognitive acceptance and comprises 18 items. Participants rate how much they agree with statements on a 1 to 4 Likert scale, with 4 being they "completely agree". The item scores are totalled to obtain three sub-scores (Helplessness, Acceptance and Perceived benefits). A higher total score in the subscale indicated higher use of acceptance. The scale has demonstrated good internal consistency (Cronbach's alpha = 0.81-0.91) and good factor structure (Lauwerier et al., 2010). The scale has been used with stroke patients, MS patients, chronic pain patients (Crowley & Andrews, 2018; van den Akker et al., 2018; Viane et al., 2003) and those with chronic kidney disease (De Vries et al., 2019; Poppe et al., 2013). This questionnaire was freely available to use through the authors' website (Evers, 2017).

Finally coping acceptance, where patients use acceptance as a coping strategy, was measured using the brief COPE; 28 items to assess how patients cope, the instructions were amended to relate to dialysis. Patients had a 4-point response scale on which they indicate whether they have not been doing the action to whether they have been doing it a lot. There are 14 subscales each comprised of two items which relate to different ways of coping. A higher score on the subscale indicates higher use of that coping strategy. The scale is widely used (Nipp et al., 2016) and has been used with renal patients (Gillanders, Wild, Deighan, & Gillanders, 2008; Knowles et al., 2016; Knowles et al., 2014) and has good internal consistency across items (Cronbachs alpha = 0.5 – 0.9, acceptance = 0.57). The COPE is widely available and was obtained from the authors' webpage (Carver, n.d.).

3.11.5.3 Quality of life

Numerous scales measure health-related quality of life and there has been debate about whether disease-specific or generic QoL measures should be used. Many scales measure disease-related QoL (Bowling, 2001) and in kidney disease, one specific measure is frequently used, the KDQoL questionnaire (Hays, Kallich, Mapes, Coons, & Carter, 1994).

Quality of life in the current study was measured using the kidney disease QoL – SF (KDQoL-SF) (Hays, Kallich, Mapes, & Coons, 1995) this measure includes all the items of the core SF-36 (Hays & Morales, 2001) plus the burden of kidney disease symptoms/problems and the effects of kidney disease. The Short form health survey (SF-36) is a 36-item self-report instrument designed to measure Quality of Life across eight domains. These eight domains are physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional wellbeing, social functioning, pain and general health. The additional kidney disease targeted scales are symptom problems, effects of kidney disease, work status, cognitive function, quality of social interaction, sexual function, sleep, social support, dialysis staff encouragement and patient satisfaction. The rationale for including such a wide range of subscales in the current study is that in addressing the role of acceptance it can be established across which domains acceptance is of relevance.

Alongside the subscales of the KDQoL questionnaire, there are three scores which can be calculated. The physical composite score (PCS) and the mental composite score (MCS) are calculated from the SF-36 items (Taft, Karlsson, & Sullivan, 2001) however there has been some debate about how useful these are so it is advised that these scores are not used in isolation and they should be compared to the profile before conclusions are drawn (Ware & Kosinski, 2001). The kidney disease component summary (KDCS) (Saban, Bryant, Reda, Stroupe, & Hynes, 2010) aims to measure QoL issues specific to patients with kidney disease. In addition, the idea of a total quality of life score has been suggested and increasingly reported in literature (Lins & Carvalho, 2016) however this is in contrast to the original advice that there are two distinct concepts (physical and mental) and they cannot be combined. In response the current studies focus on the PCS, MCS and KDCS and does not utilise a combined score of QoL. The KDQoL questionnaire is freely available (Hays, Kallich, Mapes, Coons, & Carter, 1997)

3.11.5.4 Additional Psychological measures

The key objectives of these studies focused on acceptance and QoL however based upon the evidence and biopsychosocial viewpoint additional psychological measures were included. Depression has been associated with reduced QoL and outcomes within the dialysis population (Chilcot, Davenport, Wellsted, Firth, & Farrington, 2011; Chilcot et al., 2013). It was, therefore, important to capture this alongside measures of acceptance and QoL. In addition, anxiety has been identified as a key psychological factor for dialysis patients (Goh & Griva, 2018; Picariello, Moss-morris, Macdougall, & Chilcot, 2016). Stress needed to be considered, particularly when taking a biopsychosocial approach. Patients may have a variety of stressors to contend with on dialysis and these may affect perceived stress in HD patients which in turn had potential to relate to other psychological and clinical variables, alongside QoL. The decision was made that all three aspects (depression, anxiety and stress) should be captured. Options for measurement included utilizing separate measures for each or combined measures. The advantage for individual measures was that there would be increased comparability across other studies, for example, the Beck Depression Inventory (BDI) is an established depression measure. However, use of a separate measure for depression requires an additional measure for anxiety and stress, these could be the Hospital Anxiety and Depression scale (HADS), the Depression Anxiety and Stress scale (DASS-21) or the Hamilton anxiety rating scale, however the later requires clinician delivery. In Chan's (2011) study testing the proximal distal model these measures were captured using the DASS-21.

The DASS-21 and HADs scores are comparable across depression but may measure slightly different constructs in anxiety, which needs to be considered when comparisons are drawn. There also needs to be consideration given to the cut off points used in DASS (Tasmoc, Hogas, & Covic, 2013), because findings suggest that the depression scores in the HADs are higher than on other scales (BDI-II and DASS) (Lambert et al., 2015). However, despite these cautionary notes across many areas the DASS and HADs are found to perform consistently (Bener, Alsulaiman, Doodson, & Ayoubi, 2016; Sukantarat, Williamson, & Brett, 2007) and

DASS-21 has been shown to be a useful tool in measuring depression in the dialysis population (Liu et al., 2018).

Therefore the shortened DASS-21 (Henry & Crawford, 2005) was the chosen measure. The DASS-21 is a 21-item self-report instrument designed to measure the three related negative emotional states of (i) depression, (ii) anxiety and (iii) tension/stress. Participants' rate how much an item applies to them from 0 to 3. A higher score indicates higher levels of the emotional state. Internal consistency is very good (Cronbachs alpha = 0.82 – 0.93, acceptance = 0.57) and has been used in previous studies examining psychosocial adaptation to end-stage renal disease (Chan, Brooks, et al., 2011).

Self-efficacy reflects an individual's belief that they have the ability to succeed in specific situations or to accomplish certain tasks. Self-efficacy has been associated with coping and it is hypothesised that it may also play a role in acceptance of illness. A measure of self-efficacy was included to capture this. The established general self-efficacy scale (GSE) was included (Schwarzer & Jerusalem, 1995). The scale comprises 10 items rated on a 4-point Likert scale and participants' indicate the extent to which a statement is true of them. Scores range between 10-40 with a higher score indicating more self-efficacy. The scale has strong internal reliability (Cronbach's alpha = 0.76 – 0.90).

3.11.6 Clinical measures

The clinical measures to be extracted were determined through a review of the literature to identify clinical variables of potential interest. These were discussed with the clinical teams and variables added or removed according to advice received.

At each time point; baseline, 6 months and 12 months independent clinical data were extracted from the electronic renal patient database. These records contained all information about each dialysis session alongside information about phlebotomy results. Medical information collected in the questionnaire could be compared to clinical records for instances of comorbid conditions and medication type and dosage. Laboratory measures and dialysis measures were obtained for each participant.

Dialysis measures (dialysis prescription, access type and site, dialysis adequacy measures, complications related to dialysis, hospital admissions, dialysis recovery time) were usually extracted for the dialysis session associated with the date of questionnaire completion. The rationale for including these dialysis measures was to account for the influence of clinical/physical factors, which are particularly important when taking on a biopsychosocial viewpoint.

Comorbidity data was obtained through questionnaires and cross-checked against patients clinical records in the renal patient information system. All reported conditions were counted to provide a simple co-morbidity score. This score could then be utilised in subsequent mediation and regression analyses. During the longitudinal data collection participants were asked about changes in medical conditions and those data cross-checked with clinical records. Comorbidity scores were included in the regression analyses both cross-sectionally and longitudinally.

Laboratory measures had a variability of +- 14 days due to phlebotomy results being obtained monthly as part of clinical care. The rationale for the variability in timescale is that the majority of the questionnaire was not time specific. For example, the KDQoL questionnaire asks patients about their physical and emotional status over the preceding 4 weeks. In addition, whilst some clinical measures can fluctuate day to day the majority of the tests indicates trends and using monthly test result was deemed to be sufficient. The rationale for inclusion of the individual clinical measures is fully outlined in the following sections.

Serum Albumin

Albumin is a protein in human plasma and usually little is lost from the body due to excretion. The function of albumin is to maintain osmotic pressure which facilitates a range of molecules around the body. Patients may have high levels of albumin due to dehydration or the use of prescription drugs. Albumin is included due to the relationship with QoL. QoL, as measured by the SF-36, has been related to albumin levels in PD patients (Zhou et al., 2018), patients with albuminuria have demonstrated lower PCS (K. C. Wong et al., 1995) and similarly, those with higher albumin levels (>37 g/l) have reported higher PCS (Yang et al., 2015).

Haemoglobin

Haemoglobin is the protein molecule in red blood cells and is important in the transfer of oxygen and carbon dioxide. It is important as it helps maintain the shape of the blood cells and allows them to function correctly. When patients have low haemoglobin this is called anaemia and can be implicated in fatigue and has been associated with QoL (Eriksson, Goldsmith, Teitsson, Jackson, & Van Nooten, 2016). Higher levels of haemoglobin have been associated with better PCS (Yang et al., 2015). Haemoglobin levels have also been associated with QoL but not psychological variables in patients with end-stage renal disease (Chan et al., 2014). However, this has not consistently been found, with other studies finding no relationship (Saad et al., 2015). Based upon the potential relationship it is important to measure haemoglobin to account for any influence.

Phosphorus

Serum phosphate tests measure the levels of inorganic phosphate in the blood serum. Phosphate is important for energy production and nerve and muscle function. It is also important in bone growth, with most of the calcium in the body being combined with phosphates to help bones and teeth. Phosphate primarily comes from dietary sources and levels are usually managed through absorption and excretion through intestines and the kidneys. However, in patients with kidney failure this level needs to be monitored carefully to ensure that levels are maintained. Abnormal levels of phosphate do usually exhibit symptoms however because of the relationship with calcium there may be symptoms associated with abnormal levels, for example, fatigue, muscle weakness, loss of appetite, and cramps (Hruska, Mathew, Lund, Qiu, & Pratt, 2008).

Ferritin

Ferritin levels are tested to see how much iron a person’s body has stored for the future and is used as an indicator of iron deficiency because ferritin levels drops before serum iron falls. The relationship between ferritin and QoL has not been clearly established. Whilst there is some evidence that iron deficiency (as measured by ferritin levels), as opposed to anaemia, is linked to QoL in heart failure patients (Comín-Colet et al., 2013), there is limited evidence in kidney disease patients. As a result, ferritin has been included but the primary role will be to measure change between time points to ensure any changes in QoL and acceptance are not influenced by Ferritin.

Creatinine and eGRF

Creatinine is an indicator of kidney function and elevated levels suggest impaired kidney function or kidney disease. This is because when the kidneys are impaired are unable to clear creatinine sufficiently. Creatinine levels are associated with estimated glomerular filtration rate (eGRF) which estimates the rate of filtration by the kidneys. EGFR rate can be measured in two ways, through serum creatinine levels and through urine and blood tests. The eGRF rate at the study site is measured using eGFR however in August 2019 the hospital switched to epiGRF. Whilst the results are usually comparable and in clinical records the eGRF rate is reported alongside the new measure, additional checks were needed to avoid implications to the analysis. The reporting of eGRF in this study is based on the original method of calculation as opposed to epiGRF. eGFR rates are used to establish the level of kidney failure a patient has with a level less than 15 indicative of kidney failure.

Sodium

Sodium is an electrolyte in bodily fluids which helps regulate the levels of water in the blood, in turn helping blood pressure regulation. Low sodium (hyponatremia) is associated with excessive sodium loss, however symptoms are only apparent with rapid drops in sodium level as slow drops in levels may have no symptoms. Hyponatremia has been associated with mortality (Rhee, Ayus, & Kalantar-Zadeh, 2019) but not clearly associated with QoL (Md Yusop et al., 2013). Due to the links to mortality sodium has been included and is of particular interest in the longitudinal analyses.

Calcium

Calcium is a mineral important for healthy bones and muscle function, symptoms of too much calcium (hypercalcaemia) can include tiredness, weakness and loss of appetite, which are also symptoms associated with dialysis. However, calcium needs to be considered in relation to albumin because this binds calcium to the blood. There is little evidence to suggest calcium is directly linked to Qol and but there is limited evidence of its relationships with other variables and their subsequent effects on HRQoL (Spiegel et al., 2008)

Potassium

Potassium is another of the typical measures included as part of the renal functions test, alongside sodium and creatinine. Abnormal levels of potassium can affect the function of the nerves and muscles, which can include the muscles of the heart. With the leading causes of mortality being cardiac related (United States Renal Data System, 2018), including potassium is important when exploring relationships in longitudinal survival data.

Survival

Participants were followed up for survival and hospital admissions for the duration of the study. Number of nights admitted to hospital was collected from patient recollection but in addition data on admissions were obtained from clinical records. Basic mortality data collected for deceased patients were date of death and cause (text and code).

3.11.7 Quantitative analysis

Data were analysed cross-sectionally (Chapter 4) and longitudinally (Chapter 6).

Cross-sectional analyses

The baseline data were analysed cross-sectionally to compare the baseline characteristics. Differences in scores split by acceptance levels were explored with t-tests and ANOVAs. T-tests and AVOVA's aimed to test differences in means between groups (Field, 2018) with T-test's being used on two groups (e.g. male/female) and ANOVA used with more than two groups (e.g. acceptance level grouping). Data were screened for parametric assumptions and where these were not met non-parametric alternatives were used. Non-parametric tests reduce the impact of outliers and skewed distributions through ranking the data but as a result is less powerful than the parametric counterpart (Field, 2018). It is acknowledged that there are alternatives to non-parametric tests, such as robust methods, however the non-parametric tests were primarily used to ascertain the differences in acceptance across the sample and therefore were deemed to be sufficient.

Correlations and regressions were run to test the relationships between acceptance and the other baseline variables including QoL. Correlations were used to test the relationships between acceptance, psychological and clinical variables whilst regression analyses explored the extent to which independent variables (acceptance, clinical and psychological measures) predicted QoL. Correlational analyses were run first to identify associated variables and regressions identified if independent variables could predict the relationships with the outcome variable (Tabachnick & Fidell, 2013).

The comparisons between measures of acceptance among the study sample and those of previously published studies was conducted and the associations between measures of acceptance and other study measures were assessed using correlation and regressions.

Longitudinal analyses

Changes in acceptance over time, and the relationships between those changes and changes in other study measures, was assessed using regression analysis at 6 months and 12 months with change in the independent measures as predictors of QoL (Salkind, 2010). The alternative approach of using residualised change scores was explored (Castro-Schilo & Grimm, 2018) but and compared to the change score results and was not found to change results therefore the established change score approach was used. For 12-month data changes between baseline and 6 months were used to predict changes between 6 months and 12 months. Analysis and additional co-variables were selected based upon differences identified at baseline. Patterns of change over time were analysed through regression rather than structural equation modelling (Kline, 2011) was not applicable due to insufficient numbers being retained (Barrett, 2007). Latent change analysis was considered (Preacher, 2008), it is based on structural equation modelling and is particularly suited to the investigation of life courses and developmental processes but the resultant sample size at 12 months prevented adoption of this approach.

Model adjustments

Standard clinical variables were recorded to enable clear reporting of the sample characteristics and to allow comparisons between empirical studies and the wider dialysis population to be drawn. Within the regression models the clinical details entered into the models were, length of time on dialysis, serum albumin and comorbidity score. These variables were included in the regression analyses due to the strength of their links to dialysis quality of life outcomes. Length of time on dialysis (Merkus et al., 1999; Sayin, Mutluay and Sindel 2007) and comorbidities (Khan 1998, Maruschka et al., 1997) have been particularly linked to physical quality of life and serum albumin had the strongest quality of life associations across all the clinical measure recorded (section 3.11.6, p). Regression analyses all followed the same standard approach with age, employment, length of time on dialysis and comorbidity score always being entered into block one, then serum albumin always entered into block two. The variables entered into the remaining blocks were determined based upon the variables of interest and are detailed in the relevant chapters

Mediation analyses

Mediation analyses help to answer the “how” questions rather than the “when” or “for whom” (Hayes, 2018 p78). Mediation analysis helps to provide an understanding of the mechanisms which are at work in the process. In this thesis the focus is on how quality of life is related to acceptance and associated psychological constructs. Research has suggested that potentially acceptance has a mediating role in quality of life and psychological outcomes in other chronic conditions (Bowers, Gillanders, & Ferreira, 2020; Chen et al., 2020; Cederberg., 2016). which gave rise to the justification for including mediation analyses in the current studies. Mediation analyses were conducted where the regression analyses indicated the presence of the theoretical mediating effect of acceptance, through altered significance of predictor variables when additional variables were added to the model.

Simple mediation

Simple mediation analyses test the effect of variable X (antecedent variable) on variable Y (consequent variable) through the intervening variable M. The effects of Y can be through means of direct effects, the direct path from X to Y, or indirectly, for example with the effect of X on Y through M. This identifies how X influences M which in turn influences Y. Mediation analyses are only undertaken when there is a clear relationship between X and Y, when relationships are causal, and when there is a clear theoretical grounding (Hayes, 2018).

When computing mediation analyses the regression constants, errors in estimation of variables and the regression coefficients are used to estimate the consequents. In the analyses presented in this thesis those parameters were estimated using the PROCESS 4 macro which is run through SPSS.

Multiple mediations

Multiple mediation analyses are used where more than one mediator is involved in the effect. Multiple mediation models can involve either more than one mediator in the model being included simultaneously or in parallel, or more than one mediator in serial - where the mediators create a chain. Multiple mediation models have advantage over simple mediation models as they allow the module to test for multiple mechanisms and processes that are potentially at work. Process Model 4 run through SPSS was used to conduct multiple mediation analyses where appropriate, based upon regression outputs.

Triangulation

Triangulation of qualitative and quantitative data was utilised to strengthen the overall findings by comparing the data from the qualitative and quantitative studies. Following the convergent mixed methods approach the findings of the qualitative and quantitative studies were compared to enhance the understanding of acceptance in dialysis patients. The acceptance of illness scores were utilised to map onto the acceptance themes (section 5.5) and the core relationships identified in quantitative data were also compare to these themes (Chapter 7).

3.12 Conclusions

This chapter has detailed the methodological approached and the theoretical justifications upon which the empirical work was based. The limited research in the area of acceptance and dialysis informed the mixed-methods approach. Consideration was given to the sample and the most appropriate methods for use in this population. Questionnaires were used for the main quantitative data collection because these were standardised measures which could allow comparison of measures both cross-sectionally and longitudinally. Interviews allowed exploration of patients experiences of acceptance of dialysis. The decision was made to take a thematic approach to the analysis of the interviews because this aligned well to the quantitative studies and allowed a wide range of varied experiences to be explored.

The subsequent chapters outline the empirical studies, chapter 4 outlines the cross-sectional study of acceptance and associated variables, chapter 5 presents the analysis of participants experiences of acceptance in dialysis and chapter 6 presents the longitudinal study of acceptance in dialysis.

Chapter 4 –Evaluation of acceptance and associated psychological and clinical variables in haemodialysis patients.

4.1 Introduction

This chapter reports the results of studies testing the fundamental relationships between acceptance and clinical and psychological variables. The chapter summarises the key methodology used in the study (chapter 3 – provides detail) and describes the analytic approaches to the data. There are two main studies presented in this chapter; study 1 and study 2. Study 1 compared the influence on QoL through three measures of acceptance; 'Illness acceptance' as measured by the Acceptance of illness scale (AiS), 'coping acceptance' by the COPE and 'cognitive acceptance' by the Illness cognition questionnaire (ICQ). Study 2 sought to understand the relationship between illness acceptance and associated demographic and clinical variables and how these predicted QoL in dialysis patients. The results from both studies are discussed before implications for theory and the thesis are presented.

4.2 Methodology

4.2.1 Design Summary

This is a cross-sectional questionnaire study designed to allow collection of demographic, clinical and psychological data from haemodialysis patients at a single site. The cross-sectional design allowed assumptions to be tested and provided a snapshot of multiple variables at a single time-point. Data were analysed through cross-sectional regressions and categorical comparisons.

4.2.2 Participants and recruitment

Participants were all Haemodialysis patients at a single hospital site. Data were collected through questionnaires distributed to participants whilst they were undergoing dialysis. Recruitment to the study took place over a period of 6 months which began in July 2018. The rolling recruitment had advantages as during this time additional patients became eligible for the study; however, a limitation of this approach was its impact upon the profile of dialysis patients, in particular, affecting the length on dialysis variable.

4.2.3 Inclusion and exclusion criteria

During the recruitment period, a total of (208) participants were screened. This represented most of the haemodialysis population of the hospital unit (note, the number of patients at the unit was 202, August 2018). Data were collated and mapped against a range of parameters as outlined in Table 4.2.1. Eligibility screening (detailed in section 3.9.1.1) resulted in a total of (163) patients being approached. Of those approached 63% were interested in taking part and after one late exclusion, due to concerns about capacity to consent, 102 participants consented to the study and 99 completed the questionnaire.

Table 4.2.1 - Outcome of recruitment screening of haemodialysis patients

Outcome	N
Approached and interested and consented	102
Died before approach	2
Excluded due to cognitive impairment	8
Excluded due to physical health	7
Excluded due to language	16
Not approached	12
Not interested	55
Emailed – did not complete	6
TOTAL	208

Approximately 50% of the unit's haemodialysis patients were recruited to the study. With exclusions due to language, it meant that the sample was less representative of ethnicity. Whilst the majority of patients were approached, full inclusion of all patients was not possible, some patients were transient in nature (brief dialysis patients before transplant or PD). Recruitment ended 6-months after initial recruitment began.

4.2.4 Overview of measures and procedures

Participants who consented were asked to complete the baseline questionnaire (detailed 3.11.5 and appendix 7). Three scales measuring acceptance were employed; the acceptance of illness scale, the illness cognitions questionnaire and the COPE. Additional psychological measures captured QoL through the KDQoL questionnaire, depression, anxiety and stress through the DASS-21, and self-efficacy with the generalised self-efficacy questionnaire.

Participants were able to complete the questionnaire in a variety of ways, this choice was designed to reduce the burden for participants, the method are summarised in Table 4.2.2. Clinical data related to the dialysis session and blood test for the associated session were obtained from clinical records (detailed in section 3.11.6).

Table 4.2.2 - Summary of questionnaire completion method

Questionnaire completion method	N
Completed with researcher on dialysis	33
Completed independently on dialysis	38
Completed independently at home	25
Completed online	3

4.2.5 Scale Scoring

All scales were scored according to the published guidelines. Scoring was conducted in SPSS using appropriate syntax.

The acceptance of illness scale involved using a five-point scale from 1 to 5. The total of the 8 items converted to a score with 8 representing extremely low acceptance to 40 representing extremely high. No published missing procedure was provided for the scale therefore the standard procedure applied; if 2 or fewer items (less than 25%) were missing then these were replaced with the mean of the scale, therefore not affecting the mean. Only 2 participants had omissions and these were all individual items so the missing item was replaced with the mean.

The Illness cognitions questionnaire comprises 18 items on a four-point scale. It computes the total scores of 6 items for each subscale; Helplessness, Acceptance and Perceived benefits. Acceptance is the sum of items 2, 3, 10, 13, 14, 17, Helplessness is the sum of items 1, 5, 7, 9, 12, 15 and perceived benefits the sum of items 4, 6, 8, 11, 16, 18. There was no reported procedure for missing data so if less than 25% of the items in a subscale were missing then the missing value was replaced with the mean, this only occurred in one instance.

The brief COPE comprises 14 subscales each containing 2 items, the total for the subscale is the aggregate score for the two items. A missing item constitutes half the subscale and therefore missing data could not be imputed and therefore the subscale was classed as missing. There was one participant who missed an acceptance item which resulted in no coping acceptance score being obtained.

The KDQOL-SF^{TM} 1.3 has a complex scoring procedure (R. D. Hays et al., 1997). The published guidelines were followed, the key steps were; transformation of data from raw pre-coded values to the numeric value of the items, some items needed multiplying to ensure they were on the correct scoring range, items from the same scale were averaged to create the scale scores. The creation of the SF-36 component sub-scores followed the guidance for the SF-36; the PCS and MCS were computed through the combination of the SF-36 subscales (Ware Jr & Sherbourne, 1992). For PCS the subscales physical functioning, role physical, bodily pain and general health were combined to obtain the total and for MCS energy-fatigue, social functioning, role limitations and emotional wellbeing. Transformation and computation of scores was carried out through scoring syntax created in SPSS however to provide assurance the outcome scores were checked against the values obtained when entered into the EXCEL template provided by the rand corporation ("RAND KDQoL," 2017). Higher scores on all domains and component scores indicated better QoL in that area. The Short form health survey (SF-36) is a 36-item self-report instrument designed to measure quality of life across eight domains. These eight domains are physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional wellbeing, social functioning, pain and general health. According to the scoring manual, missing items are not taken into account when calculating the scale scores, this procedure was enacted however there were seven participants who had significant omissions in subscales (>25%) and therefore these were classed as missing.

The shortened Depression Anxiety and Stress scale (DASS) (Henry & Crawford, 2005; Lovibond & Lovibond, 1995) is a 21-item self-report instrument designed to measure the three related negative emotional states of (i) depression, (ii) anxiety and (iii) tension/stress. The subscales each comprise seven items, the aggregate total of the subscale items was multiplied by two to calculate the final score. If one item of a subscale was missing then this could be replaced with the mean of the subscale but if more items were missing then the subscale is classed as missing. There were six instances where one item was missing from a subscale these were all individual items which were therefore replaced by the mean.

The General self-efficacy scale (Schwarzer & Jerusalem, 1995) comprises ten items rated on a four-point Likert scale. Scores were obtained by calculating the sum of all items. If less than two items were omitted then these were replaced by the mean of the scale, only 4 participants had missing items, and these were all replaced by the mean.

4.3 Preparation for analysis

4.3.1 Missing Data and outliers

Data were analysed using SPSS (version 26, SPSS Inc, Chicago). The data analysis followed standardised procedures. Initially, data were cleaned which included screening for missing data and then checking for outliers (Clark-Carter, 2019; Field, 2018; Tabachnick & Fidell, 1996). Missing data were initially identified, then checked against clinical records or original questionnaires, if the data were missing then the procedure used depended upon the measure. For consistency, the latest clinical data was employed and for all other measures the published missing data protocol applied. Moreover, if an identified scale had no published procedure the following was adopted; less than 25% of a subscale missing then the missing values were utilised with the mean value of the subscale, more than 25% missing, then values were recorded as missing.

Outliers were checked using SPSS, box plots were visually checked and *z*-scores checked against the reference values of $z = 2.58$ and $z = 3.29$ (Field, 2018). Outliers were first checked for data entry error against the original data. Consideration was given to three methods of managing outliers; winsorising neutralises the effect of the possible outlier on the mean (Field, 2018), transformations improve the normality of distributions but also pull in outliers and reduces the impact (Tabachnick & Fidell, 2013), Square root or log transformations are effective in reducing the impact of high numbers but may not work for multivariate outliers. Outliers may be retained in analysis if the impact was negligible, in cases were outliers were marginal analyses were run both with and without the outlier corrections to the outlier to determine the impact. If the outlier did not change the result but changed the underlying assumptions, then it was appropriate to remove the outlier however if the outlier affected both then it was retained and acknowledged.

For one participant, there were numerous outliers identified. This participant had completed the questionnaire and at the same time made a disclosure of intention to self-harm (section 3.7.3). As a result, and with the potential impact of the data being skewed these responses were excluded from analyses.

The individual scores were checked for outliers by examining box blots and through conversion to *z*-scores and applying the -3.29/3.29 criterion (Field, 2018; Tabachnick & Fidell, 2013). There were several outliers (KDQoL_9b , KDQoL_13f, KDQoL_14b, KDQoL_14k, COPE 4, COPE 8, COPE 9, COPE 11, COPE 22, COPE 23, COPE 27, DASS 17) all were checked and found to be true values. The influence of these values was compared to the *z* scores of the subscale. For the kidney disease QoL scores and DASS scores item outliers were not reflected upon computation of the component scores nor their subscales. For the COPE scales individual item outliers in question 4 and 11 were related to the outliers in the substance abuse subscale, items 8 were strongly linked to the denial subscale and items 22 and 27 were closely linked to the outliers in the religion subscale. These outliers reflected the responses of the participants with a minority using substances or religion as a coping strategy.

Some cases where outliers in clinical records were identified as extreme by z scores (Field, 2018; Tabachnick & Fidell, 2013) but checking against the clinical record confirmed these figures matched those recorded. It is however acknowledged that there can be human error at point of entry in the clinical records. These cases were explored individually, several were found to be extremes and consistent with the patients' profile whilst others were identified by clinical staff as implausible results or they differed significantly from a patients' usual profile. In these cases, the data were treated as missing and therefore LOCF was implemented.

4.3.2 Data analysis conventions

Across all analyses, the same underlying principles and procedures applied, and all data were checked for outliers and screened for normality. Data analysis comprised of independent measures tests to compare differences across acceptance groups and correlations and regressions to understand the relationships between acceptance and associated variables. Checking of parametric assumptions was important to determine samples could be compared with the specific tests to obtain meaningful results. Parametric tests were the selected as they are more powerful in detecting an effect however this only holds true when a parametric test meets the assumptions needed (Clark-Carter, 2019). The conventions for parametric tests applied in this study were linearity, normal distribution, homoscedasticity/homogeneity of variance and independence. Independence in between-group comparisons was ensured with each participant only contributing a score to one group.

Normality is important in multivariate analysis because for estimates of the parameters which define models to be optimal the errors or residuals need to be normally distributed (Field, 2018). Although normality is not always required for analysis the solution is better when all variables are normally distributed (Tabachnick & Fidell, 2013). Normality is assessed by reviewing the distribution of the variables for skewness and kurtosis, if the data are normally distributed then errors in the model and sampling usually reflect this. These were reviewed through visual inspections of the graphical representation of the distribution and through calculation of z-scores of skewness and kurtosis. These scores are of importance with smaller samples, for samples above 100 statistically significant skewness does not deviate significantly from the norm to affect the overall analysis (Tabachnick & Fidell, 2013). The current study sample size indicated that whilst normality needs to be considered minor statistical variations may be acceptable, therefore each case needed to be considered individually.

Homogeneity of variance relates to whether the variance of the population scores between the samples is the same (Howitt & Cramer, 2007). Variation is expected to a certain extent however if the extent of the larger variance of the two samples is no more than four times larger than that of the smaller variance then a parametric test may still be appropriate but requires equal sample sizes (Clark-Carter, 2019). The significance of Levenes test is a method for assessing homogeneity and if significant Welch's test is the appropriate alternative to be reported (Field, 2018).

Robustness of parametric tests has been used as justification for carrying out parametric tests in violation of assumptions (Field, 2018). Parametric test are considered robust to some violations of normality and other approaches, for example, central limit theorem can be deployed (Field, 2018). Shapiro-Wilk and Kolmogorov-Smirnov are two tests used to assess normality however care is needed when interpreting them because they are underpinned by usual statistical conventions, they can be misleading. For example, in a small sample size a large violation may not be shown as significant and conversely for a large sample, a small unimportant violation may be shown as significant (Clark-Carter, 2019). Where sample size is large enough assumptions of normality are less important. In this study the sample size is 98 which is close to acceptable. There are alternative robust measures which can be used to combat data which violate assumptions, parameter estimates based upon trimmed means and bootstrapping however as yet the range of these available in IBM SPSS Statistics is limited (Field 2018). Transforming data is another way to address problems of normality and linearity however in this study due to the number of variables and given that different transformations were appropriate for the measures, it did not always correct the issue (Osborne, 2003). There were benefits in retaining original scoring, for example with the DASS-21 scores in a normal population a skew towards normal depression levels would be expected. Therefore, transformation was not used when aiming to understand the overall acceptance profile of the sample and regressions, which can be more robust, were used for more in-depth analysis of relationships.

For correlational analysis data were checked for linearity through scatter plots and all data were measured on a continuous scale. Bivariate normality was not checked in simple correlation however in multivariate regression residual plots were checked. Instead, for correlations distribution was checked in line with the procedure for parametric tests. For regression analysis assumptions of linearity were checked by the Durbin-Watson test, where the criterion of less than 1 or greater than 3 were indicative cause for concern (Clark-Carter, 2019). Multicollinearity was considered in regression models, variance inflation factor (VIF) indicates whether one predictor has a strong linear relationship with another predictor. If correlations between predictors had an $r > .8$ and/or a VIF greater than 10 then this indicated a cause for concern (Howitt & Cramer, 2017). Heteroscedasticity was checked by examining plots of standardised predicted values against standardised residuals. Finally, regression models were compared with robust estimates to confirm that they did not significantly deviate from the original (Field, 2018).

Effect sizes were calculated through SPSS or through G-Power (Faul et al., 2007). Cohens d (as cited in Clark-Carter, 2019; Field, 2018) is widely used and .2 indicates a small effect size, .5 a medium effect size and .8 a larger effect size. Omega squared (w^2) (Field, 2018) is used for ANOVA's with .01 representing small effects, .06 medium and .14 large effects. For Correlations the effect sizes where deemed to be small when $r = .1$, $r = .3$ is medium and $r =$

.5 is large (Clark-Carter, 2019; Field, 2018), alternatively, r^2 x 100 can be used to calculate effect size. To follow convention effect sizes reported are be r, except where specific comparisons on variance are drawn. For regression, f^2 is presented and can be interpreted as 0.35 being high, 0.15 being medium and 0.02 as small.

4.3.3 Subscale reliability

In measuring QoL it is important to understand the underlying domains which make up the component scores. Cronbach's coefficient alpha was used to assess the internal consistency of the KDQoL domain scores, these were compared to published results. A Cronbach's alpha above .70 is generally the considered minimum acceptable value for good reliability (Santos, 1999). Across the kidney disease scores all alpha values exceeded .7 except; work status, social interaction and sleep (Table 4.3.1).

Table 4.3.1 - Reliability of baseline kidney disease targeted scales compared to published results

KD_scales	No. of items	α	mean	SD	Published α[1]	mean	SD
KDQoL_Symptom_score	12	.843	73.43	19.28	.84	71.21	16.77
KDQoL_effects_KD	8	.837	62.99	24.66	.82	57.30	24.53
KDQoL_burden_KD	4	.812	39.49	27.55	.83	49.62	30.27
KDQoL_WorkStatus	2	.404	38.24	37.77	.83	25.26	37.82
KDQoL_Cog_function	3	.848	76.96	83.33	.68	79.11	19.75
KDQoL_Social_inter_qual	3	.642	74.21	21.01	.61	76.65	18.71
KDQoL_Sexual_function	2	.937	59.42	41.53	.89	69.30	36.17
KDQoL_Sleep	4	.645	52.46	21.55	.90	60.68	28.61
KDQoL_Social_support	2	.749	62.74	30.50	.89	64.61	27.73
KDQoL_Dialysis_encor	2	.843	83.09	19.04	.90	69.90	23.13
KDQoL_Patient_satisfaction	1	NA	76.23	18.06	NA	71.38	22.04

[1] (R. D. Hays et al., 1994)

The alpha value for social interaction exceeded the published value and was therefore not identified as a cause for concern. Sleep was lower than expected but still deemed acceptable. Work status alpha was far lower than the published results and the means higher. This might reflect a change in the question between the published values and the current version of the KDQoL. The question now reads “does your health keep you from a paying job” whereas originally this read “are you now able to work part-time”.   The two items which comprise work status were addressing questions with independent foci e.g. do you work and then whether health kept them away from a job. When patients are retired it was noted that there was some confusion about how to answer the second question. Whilst these items are retained the questions are raised about the utility of this domain.

The data showed that in the SF-36 domains all alphas exceeded .70 with the exception of general health (Table 4.3.2) however the published values only reached .70 and .69, therefore, the value of .652 is not vastly different and importantly the overall profile mirrored the published results, with general health being the lowest values in the two sets of results reported.

Table 4.3.2 - Reliability of baseline SF-36 scales compared to published results

4.4 Results

SF-36	No. of items	α	mean	SD	Published					
					α[1]	α[2]	Mean[3]	SD[3]	Mean[4]	SD[4]
Physical function	10	.927	38.06	28.22	.94	.90	51.83	29.73	37.52	28.76
role_physical	4	.828	31.19	37.33	.88	.93	32.46	39.68	39.56	35.10
Pain	2	.857	54.52	30.35	.89	.88	60.40	30.11	51.75	20.40
general_health	5	.652	36.56	19.07	.70	.69	42.88	24.32	37.77	9.59
Emotional_wellbeing	5	.818	69.44	21.31	.86	.81	69.54	20.36	64.19	14.91
role_emotional	3	.858	61.05	43.12	.84	.93	57.76	43.90	63.14	33.63
social_functioning	2	.774	58.55	29.85	.85	.76	63.57	29.77	57.28	57.28
energy_fatigue	4	.785	37.86	21.95	.88	.82	45.89	24.06	50.63	14.91

Published: [1] (Mingardi et al., 1999) [2](Finkelstein, van Nooten, Wiklund, Trundell, & Cella, 2018) [3] (R. D. Hays et al., 1994) [4] (Jankowska-Polańska et al., 2019)

The results sections address three core objectives of the study: demographics, profiles, acceptance measures

To address the objectives there are three sections to the results in this chapter. The objective covered by this study is to "compare the influence of psychological factors derived from contrasting theoretical models of adjustment (models of coping versus acceptance), on patient outcomes". To achieve this firstly the demographic profile related to acceptance across the population is reported. Understanding the profile informed the second analysis which explored these differences across measures to understand how these were related to QoL. Finally, the appropriate acceptance measures were used to predict how acceptance influences three domains of QoL.

4.4.1 Description of sample

4.4.1.1 Demographic Profile

The demographic profile of the sample is presented in Table 4.4.1. Participants had a median age of 62.50 (IQR 20) with the range being 21 – 90 years. Age was slightly negatively skewed (skew 2.26) which is above the 1.96 criterion (Field, 2018) however this was expected because ESRD is more prevalent with age. The median age of the sample population was slightly below the unit (median 65) and national profile (median 66.8) (K. Evans et al., 2018).

The study sample contained slightly more males than females which reflected the split on the unit (61.9% male). The majority of the sample were white (85%) which is higher than the proportion on the unit (7.4%) however this potentially reflects the language exclusion criteria applied during recruitment with the majority of the 16 excluded due to language being Asian nationality. The majority of participants were living alone although a large proportion were married (41.8%). More than half the sample was retired (56.1%) which reflected the age profile of the participants. Primary renal diagnosis had been recorded via both old and new EDTA codes. Old codes were transformed to new based upon the EDTA guidelines (European Renal Association European Dialysis and Transplant Association, 2019).

4.4.1.1 Psychological profile

The DASS-21 scores can be converted into categories of normal, mild, moderate, severe and extremely severe (Lovibond & Lovibond, 1995). The mean scores (Table 4.4.1) represent an overall profile of mild depression, moderate anxiety and normal stress within this sample. Due to the nature of the scale the results of all three DASS-21 scores were positively skewed towards the normal category.

Physical QoL scores were slightly skewed (1.996) but normally distributed across the population (Shapiro-Wilk $p = .62$) with no outliers. Mental QoL scores were slightly kurtoised (1.976) and deviated from normality Shapiro-Wilk ($< .001$) but no outliers were identified.

Table 4.4.1 - Characteristics of Haemodialysis patients participating in the study

Parameter	Total N=98
Gender (male), n (%)	64 (65. 3)
Age (years) mean (SD)	62.24 (13.97)
Ethnicity (white), n (%)	85 (86.7)
Marital status, n (%)	
Married or living with partner	47 (48)
Single, divorced or widowed	51 (52)
Education level, n (%)	
Secondary education or less	60 (61.2)
Further education beyond GCSE	37 (37.8)
Employment status, n (%)	
Employed full/part-time	22 (22.4)
Retired/not seeking employment	70 (71.4)
Other	5 (5.1)
Cause of Kidney disease	
Diabetes Mellitus	24 (24.49)
Glomerular disease	22 (22.45)
Tubulointerstitial disease	19 (19.39)
Miscellaneous renal disorders	11 (11.22)
Hypertension / Renal vascular disease	10 (1.20)
Other systemic diseases affecting the kidney	6 (6.12)
Familial/hereditary nephropathies	6 (6.12)
Comorbidities	
Diabetes	42 (42.85)
Heart disease	37 (37.7
Cancer	10 (1.20)
Lung disease	21 (21.43)
Stroke	12 (12.24)
Hypertension	41 (41.84)
Depression	4 (4.08)
Peripheral vascular disease	10 (1.20)
Mean time on RRT (months), mean (SD)	37.5 (46.55)
Psychological, mean (SD)	
Depression	11.98 (11.84)
Anxiety	10.55 (9.90)
Stress	11.53 (1.70)
PQol	32.77 (1.121)
MQol	46.25 (11.88)
KDCS	64.48 (15.35)
Self-efficacy	29.86 (6.74)
Acceptance, mean (SD)	
Ais	23.78 (8.90)
COPE – Acceptance	6.25 (1.92)
ICQ - Acceptance	15.11 (4.90)

The KDCS was found to be normally distributed Shapiro- Wilk (*p* = .138) with no outliers. Self-efficacy was identified as negatively skewed (-3.09) with 3 outliers. The data analysis procedure for outliers was followed however for self-efficacy, windsoring these values did not correct the outliers nor distribution; therefore, the original values were retained for analysis. The mean values for the KDQoL-SF questionnaire were compared to identify how the sample relates to the wider population Table 4.3.2).

The domains which differed by a score of +/- 10 were kidney disease burden, work status and dialysis encouragement. The sample had higher mean scores across all three domains which suggest that the sample have less burden, better work status and receive more encouragement to help them cope with dialysis in comparison to the wider population. When comparing the SF-36 domains this sample the only area which had greater than a 10-point difference was physical functioning, which was lower in the current sample than in the published values. This difference may occur due to the reference values not differentiating between peritoneal and haemodialysis patients.

The AiS scores were neither skewed nor kurtoised however questions about normality were raised with the Shapiro-Wilk test (*p* = .004) however the Kolmogorov-smirnov test was not significant (*p* = .052). No outliers were identified. Similar findings were present for the ICQ acceptance scores, data were neither skewed or kurtoised however the Shapiro-Wilk test was significant (*p* = .028) but the Kolmogorov-smirnov test was not significant (*p* = .200). Cope acceptance was significantly negatively skewed (*p* = 3.478), with the majority of participants scoring above 5 and the mean being 6.25.

4.4.1.2 Clinical profile

The mean biochemical profile of the sample is presented in Table 4.4.2. The clinical values were checked for outliers and mean results calculated and compared to published values in other studies. One (Picariello, Moss-Morris, Macdougall, & Chilcot, 2018) presented results from a range of patients on RRT and the other (Bieber et al., 2014) with dialysis patients.

Table 4.4.2 - Overview of clinical values of sample and comparisons with local and national values

Clinical details	Mean	SD	Derby Renal registry data 2017	UK Picariello, Moss-Morris, et al., 2018	Bieber et al., 2014	Expected Oxford Kidney Unit, 2018
Serum Albumin (g/L)	31.97	4.25	NS	38.44 (2.57)	39.1(.28)	More than 30*
Hemoglobin (g/L)	118.78	14.41	Median 116 (57)	114.56 (17.57)	109.3(.81)	100-120
Calcium (mmol/L)	2.28	.15		2.29 (.15)	9-9.2	2.1-2.5
Phosphate (mmol/L)	1.58	.53	1.5(.4)	1.44 (.51)	NS	1.1-1.7
Creatinine (mmol/L)	647.03	20.19	Median.08 to 1.4	521.08 (276.29)	NS	Dependant on muscle mass
eGFR (mL/min)	7.69	2.69		17.64 (17.27)	NS	NS
Sodium (mmol/L)	139.03	.32		142 (12.07)	NS	NS
PTH (pg.mL)	277.19	2.37		293.28 (263.71)	167-386	14-62
Potassium (mmol/L)	4.81	.72		5.00 (.66)	NS	4.00-6.00
Ktv (ml/min)	1.25	.027		NS	1.38-1.59	Above 1.3

* dependant on unit – Fresenius more than 30g/L, NS= not stated

The current study values were comparable and were in line with expected values with the exception of Kt/V, which was slightly below. Differences in Albumin levels could be attributed to the differences between the units with Fresenius units expecting values to be above 30. The influence of clinical variables on psychological aspects has been unclear and inconsistent in the literature. Therefore, it was decided to compare all the clinical variables with the psychological measures of interest. Data were checked for normality and outliers, and appropriate correlations run (Table 4.4.3).

Table 4.4.3 - Significant correlations (rs) between clinical and psychological variables

Clinical details	AiS	Depression	Anxiety	Stress	Self-efficacy	PQoL	MQoL	KDCS
Serum Albumin (g/L)						.308**		
Hemoglobin (g/L)								
Calcium (mmol/L)	.216*	-.218*	-.278**	-.223**				
Phosphate (mmol/L)								
Creatinine (mmol/L)								
eGFR (mL/min)								
Sodium (mmol/L)		-.244*	-.218*	-.260**				.279**
PTH (pg.mL)		.234*	.226*					
Potassium (mmol/L)					.282**			
Ktv								

*P < .05 ** p < .01

The only correlation with PQoL was with Serum Albumin. For MQoL there were no direct correlations however DASS variables were associated to calcium. Sodium was also associated with DASS variables and KDCS.

4.4.1.3 Categorisation of acceptance

Acceptance has been categorised differently in previous papers. Two studies used the same categorisation (Jankowska-Polańska et al., 2017; Kokoszka et al., 2016), both categorising patients into low (AIS 8-18), moderate (AIS 19-29) and high accepters (30-40). The other option was to categorise participants using a median split, into high and low accepters. The implications for analysis were explored. Firstly, dichotomising data loses some of the subtleties in the relationships and furthermore a median split is produced as a product of the data in that sample (Clark-Carter, 2019 p 307). In this study, a median split would categorise participants with a score about 22 as being high accepters yet in another population the median may be different and therefore not comparable. In addition, it was generally more appropriate to use continuous variables in multiple regression rather attempting to split the variable. A multiple regression is from the same family as ANOVA so unless there is good justification the former is the preferred method in the following analyses.

Table 4.4.4 - The mean (sd) QoL scores by 3-way and 2-way acceptance of illness splits using established cut-offs

	3-way split			**2-way split**	
	Low	**Mod**	**High**	**Low**	**High**
PQoL	28.57 (7.12)	31.71 (7.44)	38.98 (12.88)	29.62 (7.38)	36.34 (11.38)
MQoL	38.70 (11.13)	45.24 (11.39)	54.90 (6.95)	4.04 (1.99)	52.46 (9.262)
KCS	52.20 (11.94)	64.85 (13.62)	76.66 (1.09)	55.79 (13.55)	73.52 (11.45)

However, categorisation may be beneficial when looking at clinical utility of the measures and when comparing results from studies employing this approach. Table 4.4.4 highlights the mean differences in QoL scores when both the 3 way and median splits are used. There was a significant effect of three groups in PQoL (*f* (2,87) = 8.814, *p* < .001 *w* = .317), MQoL (*f*= (2, 87), 17.079, p < .001, *w* = .516), and KDCS (*f* (2, 95) =29.914, p < .001 *w* = .572) however, by exploring comparisons using Garbiel post hoc tests the main difference in physical QoL could be attributed to the higher accepters having better quality of life than both low (p < .001) and moderate accepters (*p* = .008) because the difference between low and moderate was not significant (*p* = .468). In MQoL and KDCS there were significant differences between all three groups.

Through conducting the same analyses with the two way split, significant differences were found between high and low accepters across PQoL (*f* (1,88) =11.040, *p* = .001, *d* = -.700), MQoL (*f* (1,88) =33.633, *p* < .001, *d*=1.222) and KDCS (*f* (1,96) =48.752, *p* < .001, *d* =1.41) scores.

4.4.1.4 Summary of the sample profile

Overall the sample was similar to the unit and national profile with some notable exceptions, the current sample were slightly younger, and ethnicity was under-represented. The sample means indicated mild depression, moderate anxiety and normal stress. The sample could be classed as moderate accepters of illness if using a 3 –way grouping or high if using the median split. Cognitive acceptance was classed as high using median split and coping acceptance was classed as high. However, the utility of median splits was questionable, as a result where the need requires the 3 levels of acceptance will be used to categorise participants into low, moderate and high accepters.

4.4.2 Study 1 – Comparison of Acceptance measures

The following analyses compare the acceptance measures in relation to demographic factors to inform understanding of the acceptance profile in the population and establish whether there are different types of acceptance present. The measures of acceptance are then compared to identify which exerts the most influence on QoL in dialysis patients.

4.4.2.1 Acceptance across demographic profile (*correlations and t-tests)*

Early analysis of the scores indicated that the AiS scores and ICQ scores were normally distributed however the distribution of the COPE acceptance was not normal (section Data analysis conventions 4.3.2).As a result, parametric tests were run to identify demographic influences on AiS acceptance and non-parametric on the COPE acceptance. There were no significant differences between the genders and illness acceptance (*t*= .246 (df=96) *p* = .806), cognitive acceptance (*t*= .226 (df 96) *p* = .822) nor coping acceptance *(U* = 958.00 , z= -.778, *p* = .437). Similarly there was no difference based on marital status on illness acceptance (*f*(=1.782, df 96 *p* = .185), cognitive acceptance (*f*= .387, df= 96 *p* = .535) nor coping acceptance *(U*= 1155.500, *p* = .883, N =97).

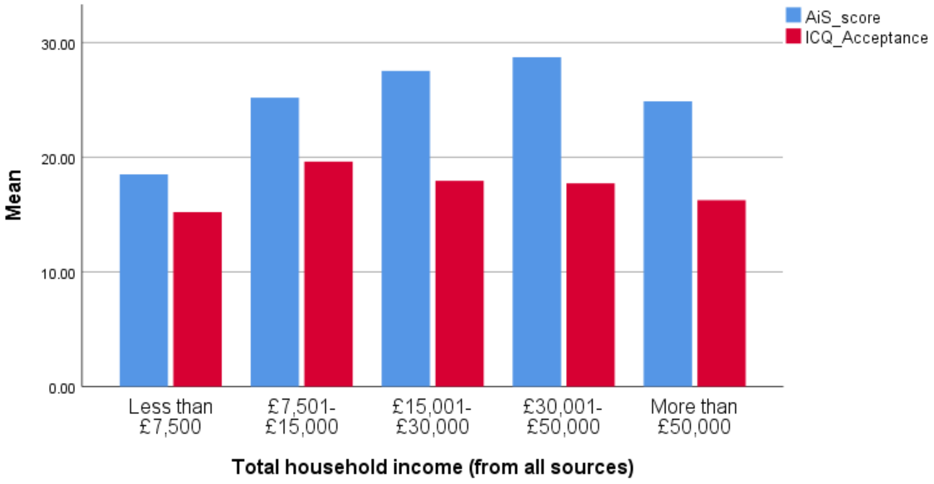
Employment status

Initial analysis of the six employment groups suggested there were significant differences in acceptance of illness scores (*f* (5,91) =2.866, *p* = .19, *w* = .296) and cognitive acceptance scores (*f* (5,91) = 4.218, *p* = .002, *w* = .377). Post hoc comparisons show that the cognitive acceptance differences were most apparent between those unemployed and seeking work and all other groupings except retired participants whereas illness acceptance differences were due to a range of differences across the groups. Those in full-time employment had significantly higher illness acceptance than part-time (*p* = .047), unemployed and not seeking work (*p* = .009) and other participants (*p* = .008). Retired participants had significantly higher acceptance than both those unemployed and not seeking work (*p* = .029) and those classed as other (.029).

Income

In relation to income only 68.36 percent response rate was achieved. No differences were identified in coping acceptance across income groups however significant differences were identified in both illness acceptance (*f* (4,63) =3.218, *p* = .18, *w*= .340) and cognitive acceptance (*f* (4,63) =2.614, *p* = .043, *w*= .294). Acceptance scores varied across the income groups with the lowest income reporting the lowest acceptance scores however for illness acceptance, acceptance was highest in the £30,001-£50,000 category however for cognitive acceptance it was highest with £7,501-£15,000 and then decreased across the income bands (Figure 4.1).

Figure 4.1 - Bar chart illustrating mean acceptance of illness score and mean cognitive acceptance by household income



Religion

Religion was identified in two questions: whether participants identified with a religious belief and, the extent to which religion or belief featured in their lives. 73.5 percept identified with a religion however only 16.3 percent of the participants classed "religion or belief [as} very important in my life". Across all three acceptance measures there were no significant differences in acceptance score between participants who identified with a religion and those who did not. The mean acceptance scores (Table 4.4.5) indicated that acceptance was greatest in participants for whom religion or belief was very important however these differences were not statistically significant (COPE *f*(*2*) = 4.846, *p* = .089, ICQ, *f* (2,83) =1.287, p = .282, AIS *f*(2,83) = .668, *p* = .515).

Table 4.4.5 - Mean scores (SD) for three measures of acceptance across religious importance

	3-way split		
	Religion or belief is very important	**Religion or belief in the background**	**Religion or belief does not feature**
Coping acceptance	7.214	6.083	6.106
	(1.423)	(2.125)	(1.809)
Cognitive acceptance	16.642	18.625	17.458
	(3.650)	(3.954)	(3.954)
Illness acceptance	26.857	23.792	24.042
	(8.037)	(9.041)	(8.582)

Clinical factors

Comparisons of acceptance measures showed that the number of overnight stays in hospital in the past 6 months were not significantly correlated however the number of prescription medications reported was correlated with illness acceptance (r = -.248, p = .019) but not with cognitive or coping acceptance.

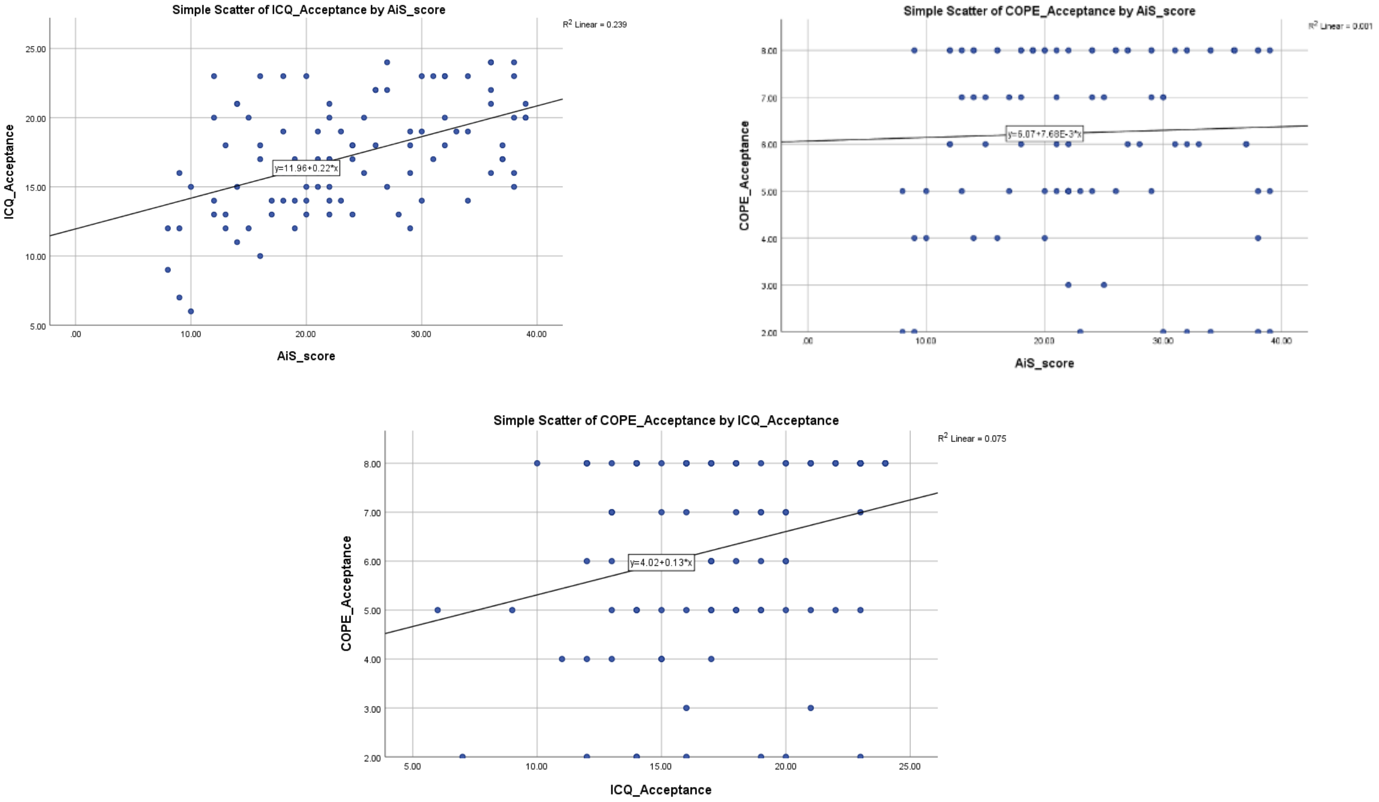
Interestingly, there was some variation between the self-report and clinical records reported number of medications. Mean number of medications by self-report was 7.67 (sd 4.344) and for clinical records 1.25 (sd 3.955), which was a significant difference (t(62) =7.194, p < .001, d = .621). However, the association (r = .763, p < .001) was strong enough to convey the same pattern with clinical record levels showing a similar correlation with illness acceptance (r = -.266, p < .017). Therefore, going forward self-report medication was the chosen unit of measurement because this was more likely to reflect what patients were actually taking rather than what was prescribed.

Age was correlated with illness acceptance (r = .217, p = .032) and cognitive acceptance (r = .250, p = .013) however it was not significantly correlated with coping acceptance (r_s= -.830, p = .418).

4.4.2.2 AiS, Coping acceptance and cognitive acceptance (correlations)

If all three acceptance measures were measuring the same underlying construct it would be expected that they were all correlated. Pearsons correlations were calculated for illness and cognitive acceptance however due to violations in the assumptions of normality for the coping acceptance scores Spearman's rho was also utilised. Figure 4.2 presents the relationships identified. The strongest relationship was between illness acceptance and cognitive acceptance (r = .489, p < .001), and can be described as a medium to large correlation (Cohen 1988). Cognitive acceptance and coping acceptance demonstrated a small correlation (r_s= .277, p = .006) however illness acceptance and coping acceptance were not correlated (r_s = .054, p = .598). This indicated that whilst there was some overlap between the measures there were key differences. To explore this further exploratory factor analysis was employed to test the loading of the variables.

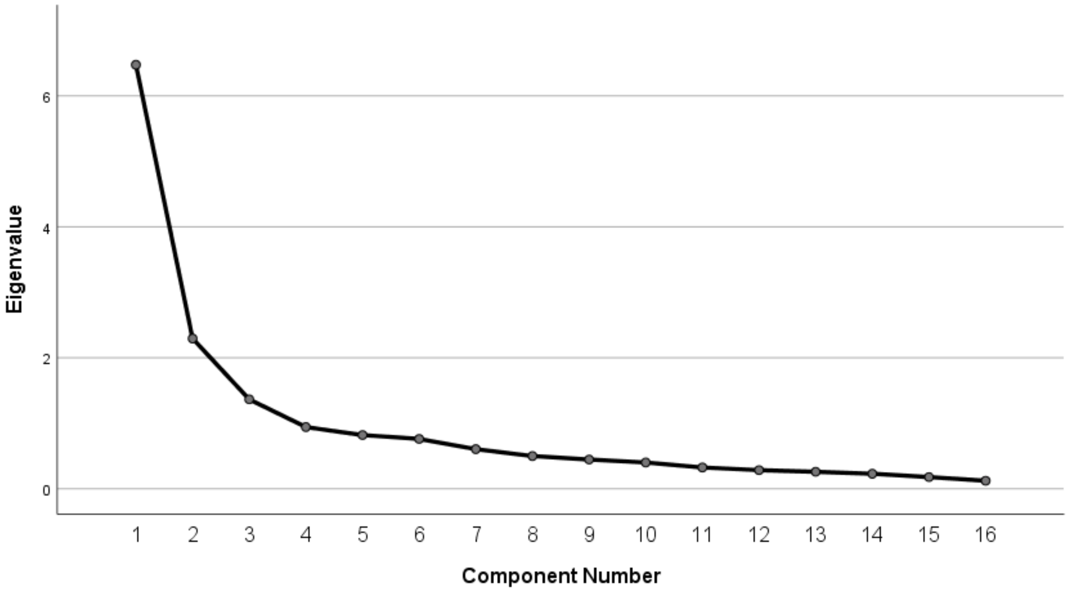
Figure 4.2 - Correlations between acceptance measures; acceptance of illness, coping acceptance and cognitive acceptance



Exploratory factor analysis is typically used to identify underlying constructs during scale development however it has been used to confirm variables.

The scree plot (Figure 4.3) indicated that there were three or four components to be extracted with three variables having eigenvalues >1. The rotated component matrix is presented in Table 4.4.6.

Figure 4.3 - Scree plot of components identified in exploratory factor analysis



The percentage of variance explained by the three factors was 63.333 and component 1 accounted for 31.055 percent. The results map onto the three different scales used in the study. In addition, there were no correlations with the individual items between the scales above *r*> .5. However, there were correlations within the scales.

To confirm the reliability of the scales Cronbach's alpha was calculated. The illness acceptance $\alpha = .908$ and mean values ranged from 2.22 to 3.71 with the lowest scoring item being "because of my health, I miss the things I like to do most" and highest " I think people are often uncomfortable being around me because of my illness". Inter-item correlations all exceeded .3 with the exception of *r* = .205 between "because of my health, I miss the things I like to do most" and highest " I think people are often uncomfortable being around me because of my illness" and *r* = .280 between " I think people are often uncomfortable being around me because of my illness" and " health problems make me more dependent on others than I want to be. Removing the former would result in $\alpha = .915$.

Table 4.4.6 - Eigenvalues from principal component analysis.

	1	2	3
COPE - I've been accepting the reality of the fact it has happened	.063	.164	**.787**
COPE- I've been learning to live with it	-.113	.121	**.820**
ICQ- I can handle the problems related to my illness.	.347	**.551**	.278
ICQ- I have learned to live with my illness.	.307	**.690**	.325
ICQ- I have learned to accept the limitations imposed by my illness.	-.056	**.702**	.106
ICQ- I can accept my illness well.	.250	**.812**	.031
ICQ- I think I can handle the problems related to my illness, even if the illness gets worse.	.192	**.754**	.025
ICQ- I can cope effectively with my illness.	.252	**.753**	.002
AiS- I have a hard time adjusting to the limitations of my illness	**.766**	.282	.032
AiS- Because of my health, I miss the things I like to do most	**.478**	.322	-.201
AiS- My illness makes me feel useless at times	**.834**	.238	-.178
AiS- Health problems make me more dependent on others than I want to be	**.771**	.115	.019
AiS- My illness makes me a burden on my family and friends	**.834**	.202	.017
AiS- My health makes me feel inadequate	**.863**	.235	.023
AiS- I will never be self-sufficient enough to make me happy	**.804**	.225	-.008
AiS- I think people are often uncomfortable being around me because of my illness	**.614**	-.081	.296

Rotation Method: Varimax with Kaiser Normalization. a Rotation converged in 5 iterations.

Illness cognitions $\alpha = .849$ with a mean range from 2.77 to 3.15 with the lowest being "I think I can handle problems related to my illness even if the illness gets worse" and the highest being "I have learned to live with my illness". Inter item correlations were all above .3 with the exception of the correlation between " I have learned to accept the limitations imposed by my illness" and " I can handle problems related to my illness". Removing the later would result in $\alpha = .853$.Coping acceptance $\alpha = .628$ with a means being 2.99 (1.212) and 3.26 (1.023). The items demonstrate a medium to strong correlation ($r = .464$).

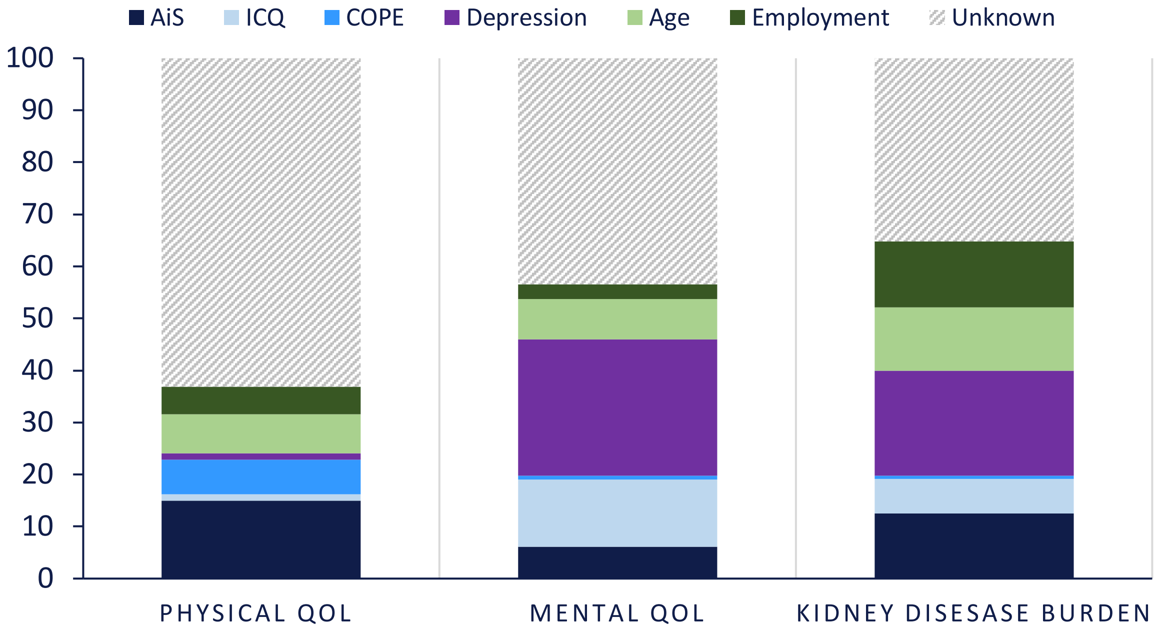
4.4.2.3 Types of acceptance and QoL

The impact of the three measures of acceptance on quality of life were evaluated using linear regression models. Three regression analyses were conducted; each focusing on different QoL scores as the outcome (PCS, MCS, KDCS). Variables were entered into the model in three blocks. Block 1 adjusted for demographic characteristics (age and employment) with income status omitted due to insufficient completion for this item. Block 2 contained the three acceptance measures and in block 3 depression was added, due to the theoretical links and correlations with illness physical QoL ($r = -.318$, $p = .002$), mental QoL ($r = -.689$, $p < .001$) and KDCS ($r = -.779$, $p < .001$) . All three blocks used the enter method: model improvement was evaluated using an f-statistic whilst improvement in variance was measured using R^2 change. Statistical significance level was assumed at $p < .05$. Durbin Watson values and ViF values all fell within acceptable ranges.

Overall acceptance, measured by the three scales, was found to be a significant predictor of physical QoL ($F(6,82) = 7.828$, $p < .001$) with an r^2 *of .364*, mental QoL ($F(6,82)$ 17.774, $p < .001$) an r^2 *of .534,* and burden of kidney disease ($F(6,90) = 27.604$, $p < .001$) with an r^2 *of .648*.

Figure 4.4 was constructed by calculating the percentage value each standardised beta represented. This proportion was then computed as a percentage of the r^2 value. By adding in the unknown component, a graphical representation of the data could be presented to illustrate the proportion of variance accounted for by each value. Figure 4.4 illustrates that across the three components; Illness acceptance was the strongest independent predictor of physical QoL ($\beta = .48$ $p < .001$) and an independent predictor of kidney disease burden ($\beta = .280$, $p = .005$) however for mental QoL cognitive acceptance was the strongest acceptance predictor ($\beta = .240$, $p = .009$).

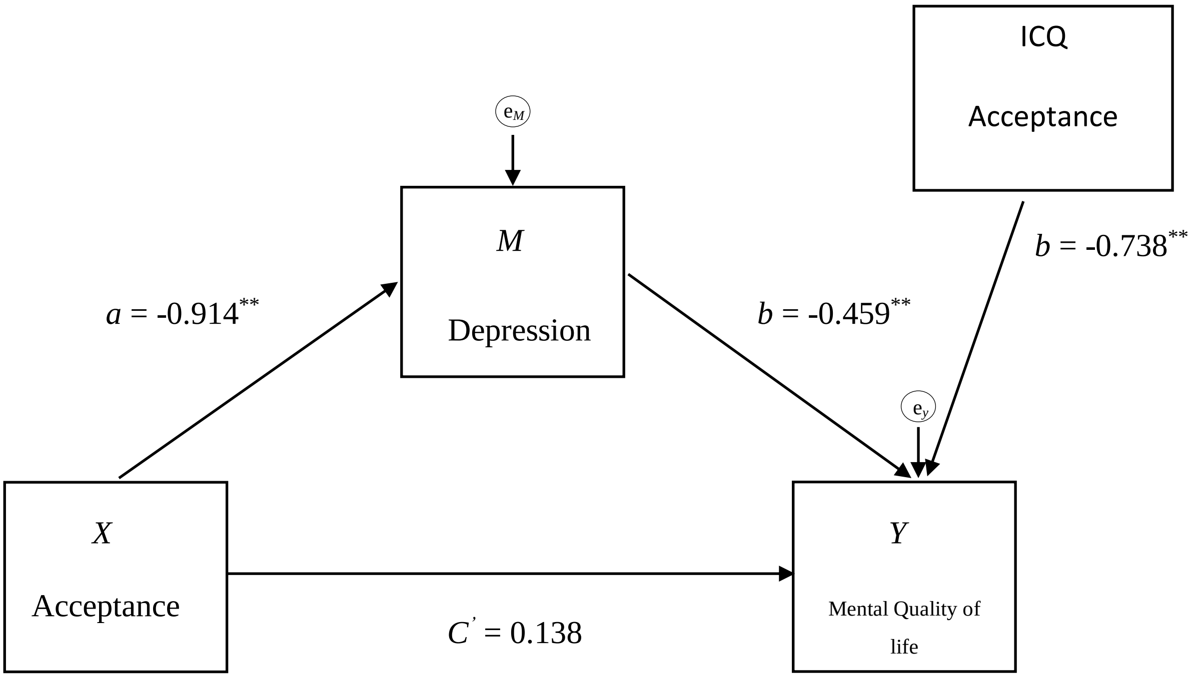
Figure 4.4 - Proportional representation of Standardised Beta values predictor variables



Coping acceptance was only a significant independent predictor of physical QoL (β = -.205, *p* = .030). Despite the strong significant contribution of acceptance, overall the physical QoL regression model accounted for the smallest proportion of the variance. Depression was a significant independent predictor of both mental QoL (β = -.419, *p* < .001) and kidney disease QoL (β = -.444, p <001).

When depression was introduced in block 3 illness acceptance switched from significant (β = .366, *p* < .001) to non (β = .100, *p* = .339) indicating the potential presence of a mediation effect. Simple mediation analyses were conducted following the recommended guidance (A. F. Hayes, 2018) using model 4 of the PROCESS macro (Figure 4.5). This process provides bootstrap confidence intervals for the mediated effects. A mediating effect was established if the 95% bias-corrected bootstrap CI did not contain 0 when run on 5000 bootstrap samples. In mental QoL acceptance was mediated by depression (Sobel= .559, 95% CIs .3525 to .7952, *p* < .001).

Figure 4.5 - Simple mediation model demonstrating the indirect effect of acceptance on MQoL



N=89, Indirect effect—*ab* = -0.914 (-0.459) = 0.5592 CI's .3525 to .7952

** significant at <0.001

4.4.2.4 Summary of acceptance measure results

Factor analysis indicated that three measures of acceptance; illness acceptance, cognitive acceptance and coping acceptance are measuring different constructs. The results of this study confirmed the reliability of the scales and therefore that these are appropriate measures in future analyses. The findings show that age, employment and income were associated with both illness acceptance and cognitive acceptance and then number of reported medications was correlated to illness acceptance. The decision on the most appropriate acceptance measure needs to be based upon the question being asked. With the outcome of interest being QoL the most appropriate measures are acceptance of illness for PQoL and KDCS and cognitive acceptance for MQoL however the mediating effect of depression on illness acceptance suggested it should be considered in further analyses.

4.4.3 Study 2 – Acceptance and QoL

The following analyses aimed to further explore the relationship with acceptance and QoL. Based upon the previous literature and the findings of the systematic review where acceptance of illness was the only measure to relate to both psychological, demographic and clinical factors, the decision was taken to focus on one measure of acceptance; acceptance of illness.

4.4.3.1 Acceptance of illness and QoL across component scores

Data were compared and appropriate correlations run between psychological and quality of life measures (Table 4.4.7). Spearman's correlations were used as opposed to Pearson's where data were not normally distributed. Correlations between DASS variables were all strong, with the strongest between stress and depression. The measures of depression, anxiety and stress demonstrated a negative association which indicated that as acceptance increased, depression, anxiety, and stress decreased. The psychological variables were correlated with QoL measures with the strongest associations identified as being with KDCS (r = -.373 to r = .670) and the MCS (r = -.540 to r = -.726). There were significant associations with the PCS (r = -.287 to r = -.446) but these were weaker. AiS was identified as a strong correlate with all three QoL domains; KDCS (r = .693, p < .001) MCS (r = .571, p < .001), PCS (r = .433, p < .001).

Table 4.4.7 - Correlations between psychological variables and acceptance of illness

	DASS-Depression	DASS - Stress	DASS-Anxiety	SF_36 Physical	SF_36 Mental	KDQoL KD component	Self-efficacy
AiS	-.720**	-.734**	-.589**	.433**	.571**	.693**	.605**
DASS- Depression		.766**	.657**	-.287**	-.670**	-.726**	-.640**
DASS - Stress			.669**	-.338**	-.601**	-.677**	-.559**
DASS- Anxiety				-.446**	-.373*	-.540**	-.356**
SF_36 Physical					-.103**	.447**	.297**
SF_36 Mental						.732**	.597**
KDQoL KD component							.644**

* p < .05, **p < .01 AiS: Acceptance of illness scale, DASS: Depression, Anxiety and Stress Scale, KDQol: Kidney disease QoL

Table 4.4.8 - Median values and interquartile range for KDQoL domains across three acceptance levels

	Low accepters		Moderate accepters		High accepters		Result	df	Non Para sig.	r_s
Kidney disease domains										
Symptom score	58.33	29.17	76.04	14.44	9.83	19.60	32.40	2	**.000****	**.602****
Effects of kidney disease	4.63	31.25	59.38	28.13	87.50	2.31	37.28	2	**.000****	**.657****
Burden of kidney disease	25.00	18.75	37.50	23.44	62.50	45.31	34.43	2	**.000****	**.647****
Work Status	.00	5.00	5.00	5.00	5.00	62.50	7.38	2	**.025***	**.369****
Cognitive function	6.00	46.67	8.00	3.00	93.33	13.33	3.06	2	**.000****	**.558****
Social interaction quality	6.00	2.00	73.33	23.33	86.67	2.00	31.84	2	**.000****	**.597****
Sexual function	5.00	10.00	37.50	84.38	93.75	31.25	3.40	2	.183	.224
Sleep	37.50	27.50	56.25	25.00	66.25	36.88	11.14	2	**.004***	**.401****
Social support	66.66	5.00	66.66	45.84	83.33	66.67	3.62	2	.164	.222*
Dialysis encouragement	75.00	25.00	87.50	25.00	10.00	25.00	4.97	2	.084	.157
Patient satisfaction	83.33	16.67	75.00	41.67	83.33	33.33	5.40	2	.067	.238*
SF36-Domains										
Physical function	25.00	25.00	32.50	48.75	36.94	62.50	8.72	2	**.013***	**.296***
Role physical	.00	25.00	25.00	43.75	75.00	75.00	29.10	2	**.000****	**.557****
Pain	32.50	45.00	45.00	42.50	8.00	55.00	23.67	2	**.000****	**.546****
General health	25.00	25.00	3.00	16.88	45.00	28.75	25.93	2	**.000****	**.614****
Emotional wellbeing	52.00	4.00	68.00	2.00	9.00	28.00	31.10	2	**.000****	**.621****
Role emotional	.00	66.67	5.00	91.67	10.00	8.33	2.28	2	**.000****	**.494****
Social functioning	25.00	25.00	62.50	25.00	62.50	25.00	33.71	2	**.000****	**.592****
Energy fatigue	2.00	35.00	37.50	15.00	5.00	3.00	24.16	2	**.000****	**.556****

* p < .05 **p < .001

4.4.3.2 Acceptance of illness across subscales

Illness acceptance was strongly related to all three QoL component scores however published advice suggests considering the subscale scores when interpreting the results. Differences between the QoL domains and published values have already been considered (section 4.4.1.1). Using the three categories of acceptance comparisons of Qol across the domains were drawn (Table 4.4.8). Significant differences were identified across all SF-36 domains of the KDQoL and across some of the kidney disease domains. The domains with no significant differences across the groups were sexual function, social support, dialysis encouragement and patient satisfaction.

To further understand the relationships between the sub scores and acceptance of illness, appropriate correlations were conducted (Table 4.4.8). These mirrored the differences identified and highlighted that the strongest relationships were between acceptance of illness and the extent to which participants reported the burden and effects of kidney disease. There were strong associations between acceptance of illness and emotional wellbeing and self-reported general health.

Illness acceptance was correlated with the COPE subscales, coping acceptance had already been shown to have no significant relationship with illness acceptance however eight subscales of the COPE were associated with illness acceptance. Self-distraction, denial, emotional support, instrumental support, behavioural disengagement, venting, planning and self-blame were all negatively associated with acceptance (r = -.214 to r = -.555), showing that as acceptance increased the use of these coping strategies all decreased.

Illness cognition subscales of helplessness and perceived benefits were compared to acceptance of illness. There was a significant negative correlation between acceptance of illness and helplessness (r_s = -.735, $p < .001$) but there was no relationship with perceived benefits.

4.4.3.3 Acceptance, Depression and QoL

The impact of illness acceptance on quality of life was further evaluated using linear regression models. The aim was to understand acceptance of illness and the relationships with clinical variables and associated psychological variables. Three regression analyses were conducted; each focusing on different QoL scores as the outcome (PCS, MCS, KDCS). Variables were entered into the model in three blocks. Block 1 adjusted for potential covariates (age, employment, length of time on dialysis and comorbidity score) as with earlier analyses (section 4.4.2.3), income status was omitted due to insufficient completion for this item. Block 2 contained serum albumin, which was included due to potential theoretic links. Acceptance of illness was included in block 3 and block 4 contained an additional psychological measures. These were depression, anxiety and self-efficacy and were included via the enter method. Statistical significance level was assumed at $p < .05$. Durbin Watson values and ViF values all fell within acceptable ranges.

Physical Quality of life

The regression analyses indicated that the selected covariates accounted for a small proportion of variance in physical quality of life (14.8%). When serum albumin was added this accounted for an additional 7.1% of the variance. The inclusion of acceptance of illness increased the model to 40.0% and the total model with the additional psychological variables accounted for 43.3% of the variance. The regression model summary scores are presented in Table 4.4.9.

Accounting for the demographic differences, the overall acceptance model for physical QoL was significant ($f\,(9,80) = 6.794$, $p < 0.001$) with large effect ($f^2 = .764$). Model values were in acceptable ranges (VIF 1.101 to 3.386), residuals were normally distributed and Durbin-Watson was 1.781. The model identified three significant independent predictors of physical QoL; serum albumin, acceptance and anxiety.

Table 4.4.9 –Baseline Regression model values for acceptance of illness and associated psychological variables on quality of life measures

Model		Unstandardised Beta	Standard Error	Standard Beta	t	p_value
Physical Component Score						
1	Age	.019	.096	.027	.203	.840
	Employment	-1.073	.690	-.214	-1.554	.124
	No. of conditions	-1.074	.562	-.201	-1.913	.059
	Time on Dialysis	-.033	.022	-.155	-1.502	.137
2	Age	.025	.093	.035	.271	.787
	Employment	-.740	.676	-.148	-1.095	.277
	No. of conditions	-.901	.545	-.169	-1.654	.102
	Time on Dialysis	-.038	.021	-.180	-1.798	.076
	Albumin	.666	.241	.280	2.766	**.007**
3	Age	-.089	.085	-.125	-1.050	.297
	Employment	-.466	.598	-.093	-.779	.438
	No. of conditions	-.761	.481	-.142	-1.582	.117
	Time on Dialysis	-.025	.019	-.115	-1.296	.199
	Albumin	.469	.216	.197	2.175	**.033**
	AIS	.530	.106	.455	5.012	**.000**
4	Age	-.108	.086	-.152	-1.255	.213
	Employment	-.306	.601	-.061	-.509	.612
	No. of conditions	-.627	.482	-.117	-1.299	.198
	Time on Dialysis	-.023	.019	-.106	-1.202	.233
	Albumin	.461	.217	.194	2.121	**.037**
	AIS	.445	.154	.382	2.879	**.005**
	Depression	.184	.133	.213	1.378	.172
	Anxiety	-.296	.139	-.290	-2.128	**.036**
	Self-efficacy	.118	.181	.075	.650	.518
Mental Component score						
1	Age	.393	.112	.470	3.505	**.001**
	Employment	-.862	.806	-.147	-1.069	.288
	No. of conditions	-.153	.656	-.024	-.233	.816
	Time on Dialysis	-.021	.026	-.084	-.817	.416
2	Age	.398	.111	.476	3.600	**.001**
	Employment	-.588	.807	-.100	-.729	.468
	No. of conditions	-.010	.651	-.002	-.015	.988
	Time on Dialysis	-.025	.026	-.101	-.995	.322
	Albumin	.548	.288	.196	1.905	.060
3	Age	.255	.100	.305	2.560	**.012**
	Employment	-.244	.703	-.042	-.347	.729
	No. of conditions	.166	.566	.026	.293	.770
	Time on Dialysis	-.008	.022	-.032	-.364	.717
	Albumin	.301	.254	.108	1.188	.238
	AIS	.665	.124	.486	5.347	**.000**
4	Age	.232	.084	.278	2.748	**.007**
	Employment	-.163	.588	-.028	-.277	.783
	No. of conditions	-.250	.472	-.040	-.529	.598
	Time on Dialysis	-.012	.018	-.050	-.678	.500
	Albumin	.236	.213	.085	1.111	.270
	AIS	.168	.151	.122	1.109	.271
	Depression	-.628	.130	-.622	-4.817	**.000**
	Anxiety	.380	.136	.317	2.796	**.006**
	Self-efficacy	.401	.177	.217	2.262	**.026**

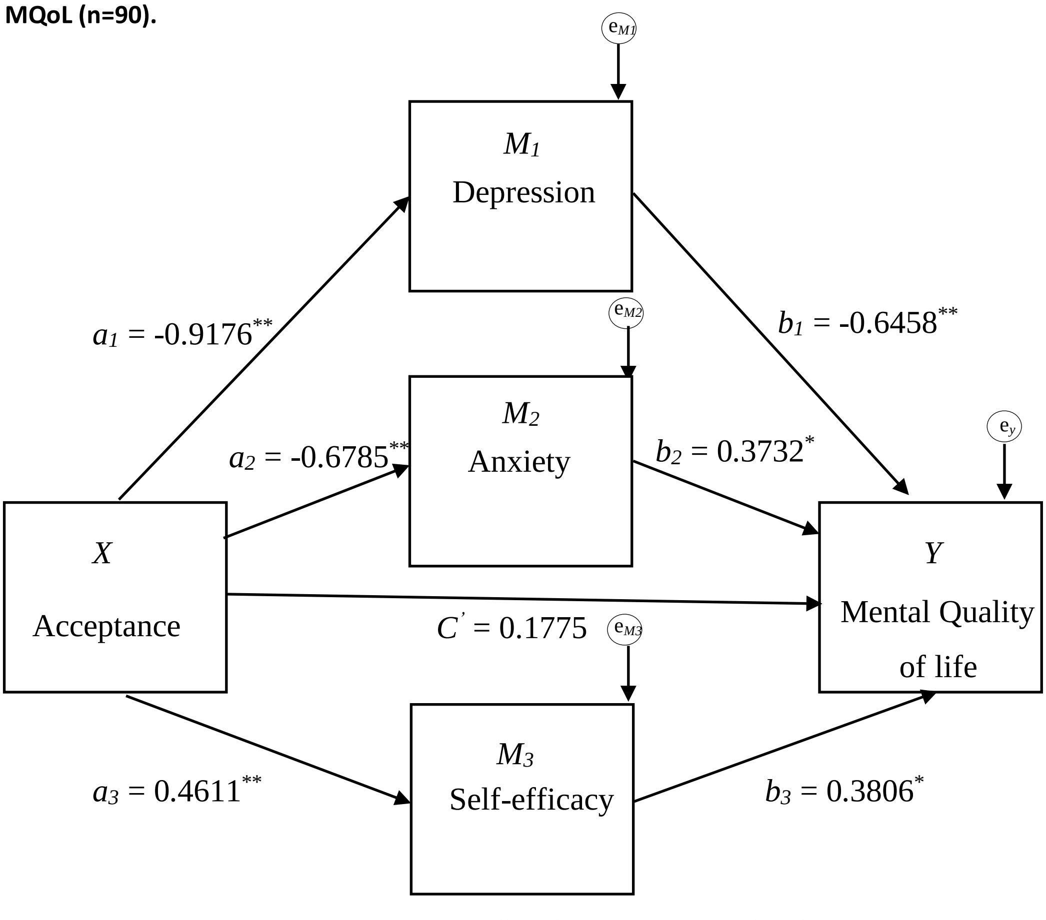
Kidney disease Component Score						
1	Age	.624	.133	.568	4.708	**.000**
	Employment	-2.854	.947	-.374	-3.014	**.003**
	No. of conditions	-1.130	.754	-.142	-1.499	.137
	Time on Dialysis	-.052	.031	-.160	-1.718	.089
2	Age	.633	.132	.576	4.776	**.000**
	Employment	-2.681	.956	-.351	-2.804	**.006**
	No. of conditions	-1.059	.755	-.133	-1.403	.164
	Time on Dialysis	-.055	.031	-.168	-1.809	.074
	Albumin	.399	.339	.110	1.175	.243
3	Age	.387	.108	.352	3.569	**.001**
	Employment	-2.064	.752	-.270	-2.745	**.007**
	No. of conditions	-.659	.592	-.083	-1.112	.269
	Time on Dialysis	-.022	.024	-.067	-.910	.365
	Albumin	-.042	.271	-.012	-.153	.879
	AIS	1.019	.132	.591	7.719	**.000**
4	Age	.310	.095	.283	3.273	**.002**
	Employment	-1.642	.647	-.215	-2.538	**.013**
	No. of conditions	-.931	.506	-.117	-1.838	.069
	Time on Dialysis	-.025	.021	-.076	-1.208	.230
	Albumin	-.092	.233	-.025	-.395	.694
	AIS	.394	.160	.228	2.469	**.016**
	Depression	-.625	.144	-.482	-4.355	**.000**
	Anxiety	.218	.143	.138	1.523	.131
	Self-efficacy	.424	.188	.186	2.257	**.026**

Mental Quality of Life

The regression analyses indicated that identified covariate differences accounted for a small proportion of MCS scores (15.5%). With the addition of serum albumin the model variance accounted for increased by 3.5%.. Acceptance of illness accounted for an additional 2.8% of the variance whilst the addition of the psychological variables increased the variance accounted for by another 39.9%. Three additional psychological variables were retained in addition to acceptance; depression, anxiety and self-efficacy. The overall model with demographic factors, psychological variables and depression accounted for 6.7% of the variance in MCS scores. The regression model was significant (*f* (9,80) = 13.711, p < .001) with large effect (f^2 = 1.545). Model values were in acceptable ranges (VIF 1.101 to 3.386), residuals were normally distributed, and Durbin-Watson was 2.106. The model identified that age, depression, anxiety and self-efficacy were significant independent predictors of MCS however acceptance was not a significant independent predictor (Table 4.4.9). Similar to earlier analyses, acceptance was an independent predictor of MCS until other psychological variables were added into the regression. Multiple mediation analysis identified that acceptance demonstrated an indirect effect on the mental component of

QoL, with the effect being mediated by depression (Effect= .5926, 95% CIs .3277 to .9392, anxiety (Sobel = -.2532 95% CIs -.5175 to -.0449) and self-efficacy (Sobel = .1755 95% CIs .0183 to .3394) with the total effect of acceptance on the mental component evident (*t* (90) = 5.644, *p* < .001, CI's .4484 to .9363) (Figure 4.6).

Figure 4.6 - Multiple mediation model demonstrating the indirect effect of acceptance on MQoL (n=90).



Multiple mediation model demonstrating the indirect effect of acceptance on MQoL (n=90).
Total effect of X on Y .6923 p<0.001 LLCI .4484 UC .9363
Indirect effect .5148 LLCI .2544 ULCI .7985
Depression .5926 LLCI .3277 ULCI .9392
Anxiety -.2446 LLCI -.5175 ULCI -.0449
Self-efficacy .1755 LLCI .0183 ULCI .3394

** significant at <0.001 significant at * <0.05

Kidney Disease Score

The regression analyses indicated that identified covariates alone accounted for 24.5% of the variance. When serum albumin was added this only added .011 to the variance accounted for. The inclusion of acceptance of illness brought r^2 to .551 and the additional psychological variables increased r^2 to .688. Depression and self-efficacy were the two additional psychological variables that were retained in the model and both were independent predictors of KDCS along with acceptance of illness. The overall regression model was significant (*f* (9,88) = 21.574, p < .001) with large effect (f^2 = 2.205). Model values were in acceptable ranges (VIF 1.110 to 3.456) residuals were normally distributed and Durbin-Watson was 1.882. The model identified that acceptance was a significant independent predictor of KDCS alongside depression, self-efficacy, employment and age (Table 4.4.9).

4.4.3.4 Summary of acceptance and QoL

QoL in dialysis patients has been shown to differ across the levels of acceptance with higher accepters reporting better QoL. Acceptance of illness was shown to impact on all three aspects of QoL, either directly in the case of physical and kidney disease-specific component or indirectly in the case of mental QoL. These analyses have demonstrated the role of illness acceptance on QoL scores but they have also highlighted the multifaceted nature of QoL. Clinical variables demonstrated influence across all three aspects of QoL and additional psychological measures were identified as important in two (MQoL, KDCS).

4.5 Discussion

This exploratory study aimed to quantify the concept of acceptance in dialysis patients and identify the most appropriate tool to capture acceptance, concluding that acceptance of illness showed the most utility across the QoL domains. It then sought to measure the influence of acceptance on QoL in relation to key clinical and psychological variables. The results show that for dialysis patients across all three domains, QoL is related to acceptance, with higher acceptance being related to better QoL. However, the relationship is more complex, acceptance and mental Qol is mediated by depression.

The three measures of acceptance utilised in this study were shown to measure different underlying constructs. This provided a challenge in establishing which was the most appropriate in the dialysis population. The results indicated that cognitive acceptance and illness acceptance were the most sensitive to demographic differences whilst coping acceptance showed less definitive associations. Acceptance as measured by all three scales accounted for significant proportions of the overall variances in QoL scores but other variables were important, particularly depression. To further understand the influence of other variables on Qol acceptance of illness was the focus of further analyses in relation to the three aspects of QoL. Across the numerous domains of QoL, illness acceptance was shown to be related to all but four domains (sexual function, social support, dialysis encouragement and patient satisfaction). When considering a wide selection of clinical and psychological variables acceptance remained a strong predictor of QoL, either directly or indirectly. Of interest was the relationship between acceptance and MQoL which was shown to be mediated by not only depression but also anxiety and self-efficacy. These findings are discussed in the following sections, they are then evaluated, and the studies limitations discussed. Detailed discussion of the implications to theory, practice and future research are deferred until chapter 7 when comparisons are drawn with the longitudinal findings.

4.5.1 Measures of acceptance

The findings compared three types of acceptance, acceptance of illness (AiS), coping acceptance (COPE) and cognitive acceptance (ICQ). The results showed that whilst there was some similarity between them there were elements of difference.

Acceptance, as measured by the three measures was compared to demographic and clinical characteristics. From the results it can be inferred that the profile of a patient who is classed as a high accepter is likely to be older, on less medication, more likely to be in employment and is more likely not to have a low income. The differences between acceptance and religion were not significant, but this is potentially due to a limited number of participants reporting that religion or belief is very important in their lives. This is important to consider in relation to the extent to which the results can be generalised and particularly because in other conditions adjustment to illness has been associated to religion and spirituality (Ardelt, Ai, & Eichenberger, 2008; Baetz & Bowen, 2008). In the UK where the influence of religion or belief is falling (Office of National Statistics, 2013), the role of religion in acceptance may be less applicable however in cultures with strong religious influences acceptance and religion may be more important. This was noted in the systematic review where religion was shown as a source of support facilitating acceptance (section 2.3.2.5).

Coping acceptance has been studied in dialysis patients previously (Gillanders et al., 2008) and the present study mirrors the reported use of acceptance as a coping strategy in this population, with the majority of patients scoring high on coping acceptance. For both studies the use of acceptance was high with many patients reporting that they had accepted their illness. The sub-scale comprises of two items and both of which relate to what patients believe they have done; ‘I’ve been accepting the reality of the fact that it has happened’ and ‘I’ve been learning to live with it’. The results showed that most people agree with these statements, which were often seen a dichotomous by patients; either they had or had not accepted their illness. Whilst this finding has the potential in being useful in identifying those who believe they have or have not accepted their illness it added little to the understanding of what acceptance means for dialysis patients and how it relates to outcomes. This is supported by the lack of relationship between the acceptance of illness and COPE scales.

Cognitive acceptance as measured by the illness cognitions questionnaire has been utilised in previous QoL studies (Poppe et al., 2013). The reported means, SD and Cronbach alpha’s (16.84 (4.11), α =0.88) were marginally lower than the values in the current study but still comparable. The phrasing of the illness cognition questions primarily related to what a patient thought or believed about their illness, for example, “I can accept my illness well” or “I think I can handle the problems related to my illness even if the illness gets worse”.

Acceptance of illness scores were comparable to several previous studies, (Klim, Szkup, Starczewska, & Grochans, 2016 (23.25), Jankowska-Polańska et al., 2019 (23.96)). The scale items were phrased to be focused on the present, several opened with; ‘my illness makes me…’. Exploring core concepts underpinning the questions in the acceptance scales help to explain some of the differences between the scales. For coping acceptance, the majority of patients reported that they accepted their illness, cognitive acceptance reported wider variability however the majority agreed with the statements to a large extent. Whilst for illness acceptance there was further variability across most of the items. The only items with clear patterns of responses were, “I think people are often uncomfortable being around me because of my illness” to which most responded that they disagreed, and “because of my health, I miss the things I like to do most”. These questions suggest that for dialysis patients they do not feel that ESRD affects how people perceive them but it does affect daily life with many missing out on what they liked to do. This finding supports the key themes identified in the systematic review which highlighted that acceptance related to accepting a new life and accepting the reality.

With three measures of acceptance, it was important to clarify which was most important in HRQoL. Three measures were compared in relation to QoL. Acceptance of illness had the strongest relationship with PQoL however when considering the overall proportion of variance explained, there was still a large proportion of variance unaccounted for. The link between acceptance and physical QoL had been identified previously (Jankowska-Polańska, Blicharska, Uchmanowicz, & Morisky, 2016; Poppe et al., 2013) and the results complemented these findings. Acceptance of illness has been associated with PQoL across numerous conditions which share similar characteristics with dialysis, primarily in that patients have limited choice, to survive for many patient's dialysis is the only option. As demonstrated by the COPE scores most patients reported accepting that it had happened and that they had to learn to live with it. However, as demonstrated by the other acceptance scale scores, because a patient has accepted the inevitability of dialysis it does not necessarily reflect how they have accepted it in their lives. Acceptance of illness questions focused on how a patient currently felt about their illness and associated implications. The influence of acceptance on PQoL was apparent but the nature of the association could be two-fold. Firstly, the acceptance of illness scale captured how patients felt they were impacted by their illness and if a patient felt they had accepted their illness then although this may not have affected their physical functioning their perception may change. Secondly, the more patients accept illness the more likely they are to follow advice and adhere to medications (Witenberg et al., 1983).

In MQoL acceptance of illness was the strongest predictor until depression was added, which indicated that depression mediated the effect of acceptance of MQoL. This was confirmed with mediation analyses. Depression has been related to QoL in previous studies with dialysis patients (Belayev et al., 2015; Jankowska-Polańska et al., 2019) and whilst there is undoubtedly a strong relationship between the two the identification of the mediation effect offers another avenue which can be utilised to improve QoL. Working on acceptance to improve depression and QoL in dialysis patients is a promising future direction for research, and acceptance has been shown to be related to depression in other chronic conditions (Lewko et al., 2007; McCracken, 1998; Uchmanowicz, Jankowska-Polanska, Motowidlo, Uchmanowicz, & Chabowski, 2016). Interestingly in understanding the compilation of the MQoL regression model, cognitive acceptance also featured strongly but coping acceptance was barely evident. It shows that alongside how dialysis patients currently think and feel about their illness and also how they reflect upon it relates to patients overall MQoL.

The model relating to the KDCS accounted for the highest proportion of the variance out of all three models. This measure was most strongly related to illness acceptance but depression also featured significantly. However, there were some questionable factors relating to this measure. Firstly, employment featured as a significant independent predictor which is unsurprising as there is a work status component to the KDCS and work status has been associated with QoL (Blake et al., 2000). Secondly, dialysis encouragement was particularly high in this sample compared to reference values. This might reflect the culture on the unit where they encourage patients to be as independent as possible and is the aspects of the KDQoL most likely to vary between centers (Mazairac et al., 2012).

However, the relationships between QoL and acceptance need to be considered as part of wider biopsychosocial models. The influence of acceptance on QoL needs to take account of biological measures alongside psychological and social factors.

4.5.2 Acceptance and QoL

The findings showed that illness acceptance had a direct role in physical QoL and kidney disease-related QoL and that the role of acceptance in mental QoL was mediated by other psychological factors; depression, anxiety and self-efficacy. These results corroborate findings of the previously published research (Jankowska-Polańska et al., 2017; Jankowska-Polańska et al., 2019) whilst expanding knowledge in this areas by taking into account the association between acceptance and demographic, clinical and psychological variables. This study was the first to provide evidence that the influence of acceptance is present when these associations are factored into the model.

The result firstly highlighted that illness acceptance is strongly related to all three QoL domains. The correlation between physical QoL and AiS was almost identical to the results previously reported (Jankowska-Polańska et al., 2019) but the correlation with MQoL the current study was stronger than the previously reported results. This difference may be attributed to the demographic profile of the patients however there are indications that the psychological profile might vary between the two studies. The two studies utilised different measures for depression and anxiety and whilst the resulting correlations between PQoL and depression and anxiety were comparable the relationship with MQoL was only comparable for depression, the correlation between anxiety and MQoL was much higher in the published results (Jankowska-Polańska et al., 2019) this might partially explain the differences in the results.

In contrast to previous research the current study takes account of both demographic and clinical differences and with these additions' serum albumin was a significant independent predictor in the regression model for PQoL. This finding supports the evidence that serum albumin is important in PQoL (Teles et al., 2018). However not all previously identified associations are supported, population norms suggest that PQoL declines with age (Burholt & Nash, 2011; Jenkinson, Coulter, & Wright, 1993) and is further reduced for patients with ESRD (Aggarwal, Jain, Pawar, & Yadav, 2016; Timmers et al., 2008). However, this study found no relationship between age and physical QoL, moreover age was correlated with both MQoL and KDCS. This is not without precedent as no significant relationship between age and physical quality of life has been previously identified in coronary patients (Soto et al., 2005), with the suggested explanation being that this may be influenced by a relationship between life expectancy and perceived QoL. Whilst there may be cases where PQoL can be improved through increased physical functioning, many dialysis patients contend with a variety of physical comorbidities. It is therefore important to understand the mechanisms behind the association. For example, in chronic pain patients, acceptance does not directly reduce pain but instead, patients stop fighting the pain. Thus, allowing patients to focus on their responses to symptoms and orientate them in relation to their own goals. In doing so, the impact of the pain (and the actual pain) on their daily lives is reduced, this is achieved through increases in psychological flexibility (Feliu-Soler, Montesinos, et al., 2018). Conversely is it the case that acceptance is a mechanism which helps patients develop resilience to difficulties associated with dialysis and through associated actions patients are able to maintain a better physical QoL. In either case, acceptance may be a powerful tool that can improve QoL, and as a result, interventions may aim to improve physical QoL through improving acceptance. Further understanding of the function of acceptance allows the development of interventions to target the processes. This is of particular importance because PQoL has been associated with mortality (Knight, Ofsthun, Teng, Lazarus, & Curhan, 2003; Loosman et al., 2015; van Loon, Bots, et al., 2017) so improving PQoL through acceptance may also confer additional benefits.

For mental quality of life, the influence of acceptance was mediated by depression, anxiety and self-efficacy. A mediating variable “accounts for the relationship between the predictor and the criterion” (Baron & Kenny, 1986, p. 1176), and these findings suggest that acceptance of illness may directly influence depression, anxiety and self-efficacy and that those factors then influence mental quality of life. This is perhaps unsurprising as the effects of these variables on QoL have been well reported (Jha, Wang, & Wang, 2012; Vasilopoulou et al., 2015; Weisbord, 2016) but the role of acceptance in this relationship has until now not been the focus of analysis. Whilst there has been promising evidence (Hudson, Moss-Morris, Game, Carroll, & Chilcot, 2016; Lerma et al., 2017) to support the development of interventions to improve mental QoL by targeting depression, the current study’s findings suggest that patients may benefit from acceptance focused interventions. There is evidence that dialysis patients are reluctant to see themselves as psychologically distressed and this may foster resistance to engagement with interventions that directly target psychological distress (Farrokhi et al., 2017; Hudson et al., 2017) For patients resistant to depression targeted interventions, acceptance targeted interventions may appear more acceptable.

The role of psychological variables were shown to be important in how patients manage the kidney disease symptoms but here the relationships were all direct, without evidence of mediation. Age, employment, acceptance of illness, depression, anxiety and self-efficacy were all independent predictors of KCS in the regression model. This may be unsurprising due to the nature of the measure, it captures the extent to which patients are affected by kidney disease symptoms. KDCS increases with age, which suggests less impact of symptoms in older age.

Overall the study corroborates associations in recent research (Jankowska-Polańska et al., 2019). Physical QoL was lower than Mental QoL, and acceptance was correlated with both physical and mental QoL. However, the correlation between acceptance and mental QoL was stronger in the current study (r=0.569 vs rho = 0.36) yet the physical correlations were more comparable (r=0.482 vs rho =0.43). These differences may be due to differences in sample characteristics or methodological approaches and due to the categorisation of acceptance. The current study has extended the approach to include additional psychological and clinical variables which has confirmed the importance of depression and anxiety in mental QoL and indicated that these are mediators for acceptance.

4.5.3 Limitations of study

Firstly, despite offering a good representation of the population at the recruitment site the sample size was relatively small and the cross-sectional design prevented conclusions being drawn about causal inferences over time. This highlights another potential limitation, despite good representation from the recruiting site it was still only one site. Each unit may have unique characteristics which affect the generalisability of these results and whilst effort has been made to compare this sample with the national population and published samples there were some key differences. The sample was under-represented by ethnicity and reported higher dialysis encouragement but reported more impact of energy-fatigue. Including several sites would help neutralise the differences between units and allow greater generalisability of findings to the wider national and international patient populations. Future work should include a number of sites to ensure the sample is more representative of the UK dialysis population. In addition, the sample focused solely on hospital dialysis patients which means further work should identify if similar relationships are identified on satellite and home RRT's.

Whilst the study used validated questionnaires which have all been utilised ~~in~~ previously in renal research the differences in measures of depression, anxiety and QoL potentially limit the comparability with other studies. The utility of self-report measures has been widely discussed (Clark-Carter, 2019) and whilst there are benefits in that sufficient volumes of data were collected there was variability in how patients completed the questionnaires. Whilst the choice patients were given about how to complete measures was beneficial for patients the lack of researcher control undoubtedly affected the results. Patients who completed the questionnaires with the researcher had more complete data sets and any misunderstandings about the questions could be addressed.

4.5.4 Conclusions and implications for thesis

In conclusion, these studies show that acceptance of illness is an important factor in QoL for dialysis patients however further work is needed to identify how changes in acceptance may be associated with long-term clinical and psychological outcomes. The study first showed that both cognitive and illness acceptance are associated with different aspects of QoL but highlighted that the influence of depression needs to be considered when understanding MQoL. The study then identified that in PQoL serum albumin is an important predictor alongside illness acceptance. The factors implicated in MQoL were more complex with acceptance of illness being mediated by depression, anxiety and self-efficacy. In kidney disease aspects of QoL acceptance, depression and self-efficacy were all independent predictors.

The findings have implications for the development of research in this thesis. Firstly, by identifying illness acceptance as being important in all three components of QoL it supports the theoretical assumption that illness acceptance features and may be implicated in QoL for dialysis patients. It also highlights the complex nature of adjustment to dialysis and the importance of a biopsychosocial approach. The importance of depression and the relationship between acceptance and QoL needs further consideration. The findings have added some support to the themes identified in the review study (chapter 2) and these will be explored further in the interview study (chapter 5). The results conveyed in this chapter will be considered in the longitudinal study where the implications of acceptance and associated variables will be considered and compared to clinical and psychological outcomes for patients. This question is important because although the cross-sectional design is useful in offering insight into acceptance it does not allow causal differences to be drawn. By first establishing does acceptance change over time, and then factors associated with change over time there is the potential to develop interventions to target or address specific variables which in turn link to QoL.

Chapter 5 – A thematic analysis of the key components and approaches to acceptance of illness among haemodialysis patients

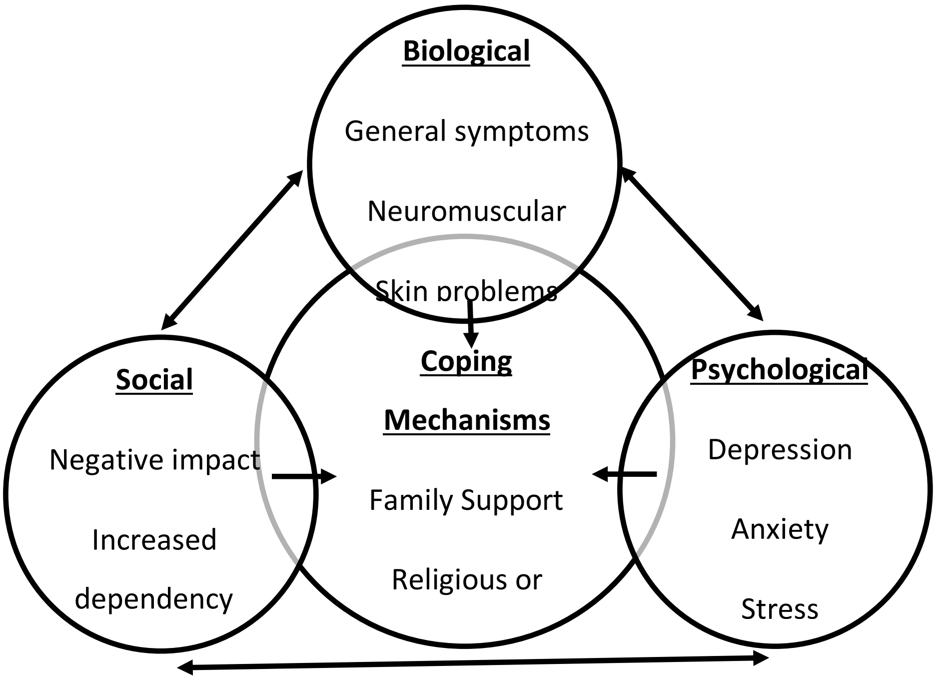
This chapter explores dialysis patients' experiences of accepting their illness through the thematic analysis of interviews with 27 haemodialysis patients. The background for the study is described and a brief overview of the methodology given (chapter 3 provides detail). A detailed profile of participants is presented before the themes are discussed. Four themes emerged: acceptance from experience, acceptance from support, accepting the functional aspects and accepting the necessity. These themes related to what patients had to accept and how they came to acceptance, and these are discussed in relation to the overarching theme of 'mindset'. These findings are discussed and evaluated at the end of the chapter.

5.1 Introduction

The systematic review (chapter 2) highlighted that despite acceptance being commonly referred to in the dialysis literature there is to our knowledge no study using qualitative methodology to specifically focus on understanding haemodialysis patients' acceptance of illness. The data to date identified that acceptance was an important component of how patients accepted "a new life" on dialysis, and that there was "a journey to acceptance" which involved "realistic expectations" and "support". These four themes particularly supported psychosocial aspects of the biopsychosocial approach however it was clear that the focus of the studies in the review was varied. As a result, there was a clear need identified for a more narrowly focused study of acceptance in a representative UK sample of dialysis patients. Previous studies have explored acceptance as one component in the complex process of adjustment or coping.

A recent study (Han et al., 2019) developed a conceptual framework (Figure 5.1) for the biopsychosocial impact of ESRD and coping mechanisms in elderly patients. In this framework acceptance is an important mechanism in allowing patients to cope with dialysis. They describe acceptance as functioning through positive thinking and problem solving which reduces the negative impact of treatment on QoL.

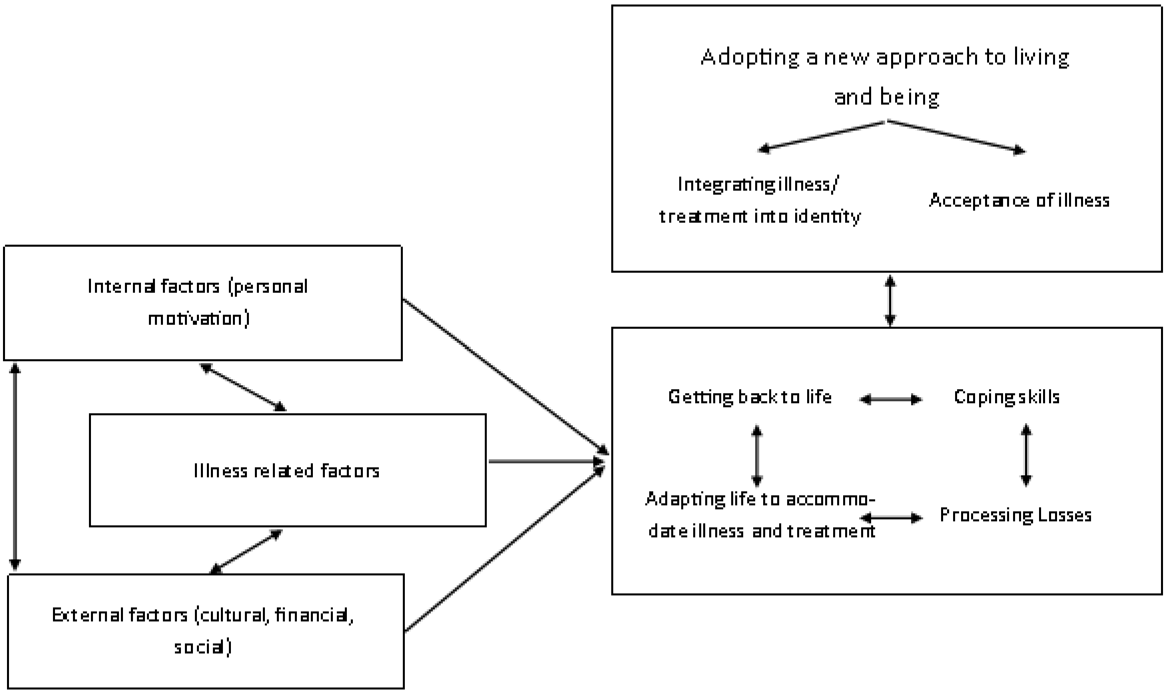
Figure 5.1 - Conceptual framework for the biopsychosocial impact of ESRD in elderly
(adapted from Han et al 2019)



Further qualitative studies identified acceptance of illness as the process which allowed CAPD patients to adopt a new approach "to being and living" (Wright & Kirby, 1999). This is part of a proposed integrative framework (Figure 5.2) where internal, external and illness factors feed into the adjustment process. Adopting a new approach "to living and being" was described as a dynamic relationship with these processes. Wright & Kirby, 1999 identified three elements of acceptance; emotional acceptance, cognitive acceptance and behavioural acceptance. Emotional acceptance was characterised by positive affect, cognitive acceptance was characterised by the absence of worrying thoughts about illness or treatment and behavioural acceptance related to engaging in self-care behaviours. The model supports a cognitive approach with beliefs about illness influencing affect and behaviour but it also highlighted the importance of 'desynchrony'. Wright and Kirby, described some patients as behaviourally accepting their illness however emotionally they did not demonstrate acceptance. This study also conveyed an important distinction between active acceptors and resigned acceptors.

Acceptance has been linked to patients perceptions of illness, a study into patients perceptions of living with ESRD identified themes of renal conflicts, forced adjustment and coping (Rees, Chilcot, Donnellan, & Soulsby, 2018). This study focused on illness perceptions and included patients on all RRT, but also drew subthemes from a sample of HD only patients, the relevant secondary subthemes were consequences, control, timeline and identity. In this study the role of acceptance was briefly explored in explaining how patients must become 'health literate' which 'involves confronting and accepting the nature of ESRD to achieve control' (p 8). The study also mentioned how transplantation offered hope but patients still accepted they would retain the identity of someone with renal disease. These themes suggested that acceptance is salient in a cross-modality sample of patients with ESRD however further evidence was needed in a haemodialysis sample.

Figure 5.2 - The process of adjustment (adapted from Wright and Kirby, 1999)



Social support has been identified as important in both the coping (Han et al., 2019) and adjustment models (Chan, Brooks, et al., 2011; Wright & Kirby, 1999) and was found to be key in the process of accepting illness in rheumatoid arthritis (Kostova et al., 2014). In another study of patients with chronic pain, acceptance has been associated with changing core aspects of the self; control, living day to day, adaptation of goals, acceptance of loss, futile resistance and spiritual strength in a study of how patients' can live with pain (Risdon, Eccleston, Crombez, & McCracken, 2003). However, the review data (chapter 3) only identified mixed evidence for the role of social support in acceptance in ESRD. Strongest data were evident from the qualitative studies, suggesting that qualitative approaches may be more appropriate in assessing social support in patients with ESRD.

Qualitative research in chronic illness has been key in developing the thinking around acceptance of illness, to take account of 'the wider social context of people's lives as well as the medical aspects' (Telford, Kralik, & Koch, 2006, p 458).

This study aimed to answer the question what does acceptance of illness mean to UK dialysis patients and how does acceptance of illness affect patients' experiences of dialysis?

5.2 Methods

5.2.1 Summary of the methodology

A detailed description of the methodology is provided in chapter 3 (section 3.10) and recruitment was integrated with the baseline study. Here a brief overview of the thematic analysis is outlined below.

All participants were dialysis patients at a single hospital site. Although not a criterion for inclusion all patients had previously opted to complete the baseline questionnaire and consented to data sharing between the two studies. The questionnaire captured demographic, clinical and psychological information about participants. Detail about the measures in the questionnaire are presented in chapter 3 (section 3.11.5). Ethical approval was obtained from the North East – Tyne and Wear South Research Ethics Committee (appendix 1) through the Integrated Research Authority System and subsequently approved by the University of Derby Human Sciences Research Ethics Committee. During the recruitment process participants received information about the study and written informed consent was obtained for all participants. Interviews were all carried out during a participant's usual dialysis session and interviews followed a schedule consisting of 10 open-ended questions (appendix 6). The interviews opened with general questions about patients' experiences and feelings about dialysis before focusing upon acceptance. Interviews were audio recorded and subsequently transcribed verbatim. The interviews ranged in duration from 12 mins 30 seconds to 43 mins and 51 seconds with mean length being 25.78 minutes. The interviews were all conducted by one researcher, the same researcher also collected the questionnaire data from participants.

5.2.2 Participants profile and procedure

27 dialysis patients were recruited to the qualitative study. All participants had previously taken part in the questionnaire study. They were interviewed about their experiences on dialysis following the semi-structured interview schedule (appendix 6). Participants were aged between 31 and 91 years old (mean = 63.81 (14.92), 18 were male and 9 were female. Twelve participants were married, 8 single, 5 divorced, and 3 widowed. The majority were retired (59.3%) with only 6 working (22.2%). Based upon the questionnaire responses the sample did not generally hold strong religious beliefs with only 4 participants indicating that religion or belief was important in their lives. Participants had been on dialysis for between 3 and 96 months with the median duration being 24 months. Detailed characteristics are presented in Table 5.2.1.

To act as a comparison the quantitative acceptance of illness and depression scores were calculated as part of the cross-sectional study (chapter 4.2.5) and informed the qualitative findings. Acceptance of illness scores ranged from 10 to 39, with 5 participants being classed as low accepters, 10 as moderate and 12 as high accepters using the established cut off scores (Jankowska-Polańska et al., 2017; Jankowska-Polańska et al., 2019; Kokoszka et al., 2016). Depression scores ranged from 0 to 36 which converted to 17 being categorised as normal and 8 categorised as moderate to extremely severe depression using the established cut off scores (Henry & Crawford, 2005; Lovibond & Lovibond, 1995). Names of participants were changed to protect participants identity. Pseudonyms were assigned based upon the most common birth names from the census closest to participants date of birth (Office of National Statistics). All participants were represented in the analyses and across the themes there was a good representation of participant experiences (Table 5.2.2).

Table 5.2.1 – Demographic and key characteristics of interview participants

Name	Age	Gender	Months on Dialysis	Primary renal diagnosis category	Transplant status	Acceptance of illness score	Acceptance category	Depression score	Depression category
Ron	91	Male	24.00	Hypertension / Renal vascular disease	Not fit	27.00	Moderate	2.00	Normal
Tony	50	Male	7.00	Glomerular disease	Temp suspended	32.00	High	8.00	Normal
Linda	68	Female	44.00	Glomerular disease	Temp suspended	19.00	Moderate	20.00	Moderate
Susan	69	Female	84.00	Diabetes Mellitus	Not fit	26.00	Moderate	2.00	Normal
Sarah	31	Female	26.00	Tubulointerstitial disease	Not fit	12.00	Low	36.00	Extremely Severe
Karen	47	Female	20.00	Miscellaneous renal disorders	Not fit	13.00	Low	24.00	Severe
Richard	70	Male	57.00	Glomerular disease	Not fit	34.00	High	0.00	Normal
Chris	42	Male	23.00	Familial / hereditary nephropathies	Active	38.00	High	2.00	Normal
Paul	67	Male	27.00	Glomerular disease	Not fit	39.00	High	2.00	Normal
Keith	70	Male	9.00	Glomerular disease	Not fit	29.00	Moderate	4.00	Normal
Ian	55	Male	5.00	Diabetes Mellitus	Active	21.00	Moderate	18.00	Moderate
Margaret	75	Female	72.00	Tubulointerstitial disease	Not fit	27.00	Moderate	0.00	Normal
Peter	51	Male	24.00	Glomerular disease	Active	39.00	High	0.00	Normal
George	81	Male	13.00	Diabetes Mellitus	Not fit	38.00	High	4.00	Normal

Name	**Age**	**Gender**	**Time on dialysis (months)**	**Primary renal diagnosis category**	**Transplant status**	**Acceptance of illness score**	**Acceptance category**	**Depression score**	**Depression category**
Stephen	58	Male	36.00	Diabetes Mellitus	Temp suspended	20.00	Moderate	12.00	Mild
John	69	Male	42.00	Tubulointerstitial disease	Not listed at patients request	36.00	High	2.00	Normal
Janet	67	Female	3.00	Miscellaneous renal disorders	Not fit	22.00	Moderate	12.00	Mild
Alan	72	Male	9.00	Miscellaneous renal disorders	Not fit	32.00	High	4.00	Normal
Brian	76	Male	36.00	Glomerular disease	Not fit	22.00	Moderate	6.00	Normal
Pat	74	Female	7.00	Tubulointerstitial disease	Not fit	38.00	High	0.00	Normal
Liz	63	Female	28.00	Diabetes Mellitus	Working up to fitness	30.00	High	20.00	Moderate
Bert	77	Male	11.00	Familial / hereditary nephropathies	Not fit	36.00	High	2.00	Normal
Ken	88	Male	76.00	Miscellaneous renal disorders	Not fit	12.00	Low	8.00	Normal
Julie	52	Female	3.00	Familial / hereditary nephropathies	Active	36.00	High	8.00	Normal
William	72	Male	10.00	Diabetes Mellitus	Not fit	21.00	Moderate	4.00	Normal
Mike	54	Male	96.00	Diabetes Mellitus	Not fit	10.00	Low	34.00	Extremely Severe
Matthew	35	Male	44.00	Other systemic diseases affecting the kidney	removed unfit	17.00	Low	18.00	Moderate

Table 5.2.2 Representation of participants and illustrative quotes across the identified themes

	Participants	Illustrative Quotes
Mindset	26	179
Theme 1 – Accepting necessity	25	143
Theme 2 – Accepting functional aspects	26	130
Theme 3 – Acceptance from experience	24	114
Theme 4 – Acceptance from support	26	108

5.3 Data analysis

5.3.1.1 Conducting thematic analysis

Thematic analysis is “a method for identifying, analysing and reporting patterns within the data” (Braun and Clarke, 2006, p. 79). The current thematic analysis takes a realist approach where it “reports experiences, meanings and the reality of participants” (Braun and Clarke 2006, p.81). The approach taken was a bottom up approach where the themes were identified in the data rather than applying pre-determined themes from theory (Chapman, Hadfield, & Chapman, 2015). This inductive approach was applicable because the limited research into acceptance within the dialysis population meant that whilst current models might have been applicable there was the risk that key components of acceptance specific to dialysis patients might have been overlooked.

The thematic analysis followed the six key stages which are widely accepted (Braun & Clarke, 2006, 2014, 2016; Braun et al., 2018). These were familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. For this familiarisation with the data was achieved through conducting the interviews, transcribing and checking the data and then repeated reading of the transcripts. Generating initial codes was conducted manually on an initial sample of 13 participants, this process was then repeated in NVIVO (NVIVO 12, 2018) with the initial codes set up and more codes added as the coding process continued. The NViVo analysis was carried out on all 27 interview transcripts. Once first coding was completed the initial themes were identified, through discussion and reviewing of the themes and data they were refined and final themes and sub-themes were identified.

5.3.1.2 Sample size and data saturation

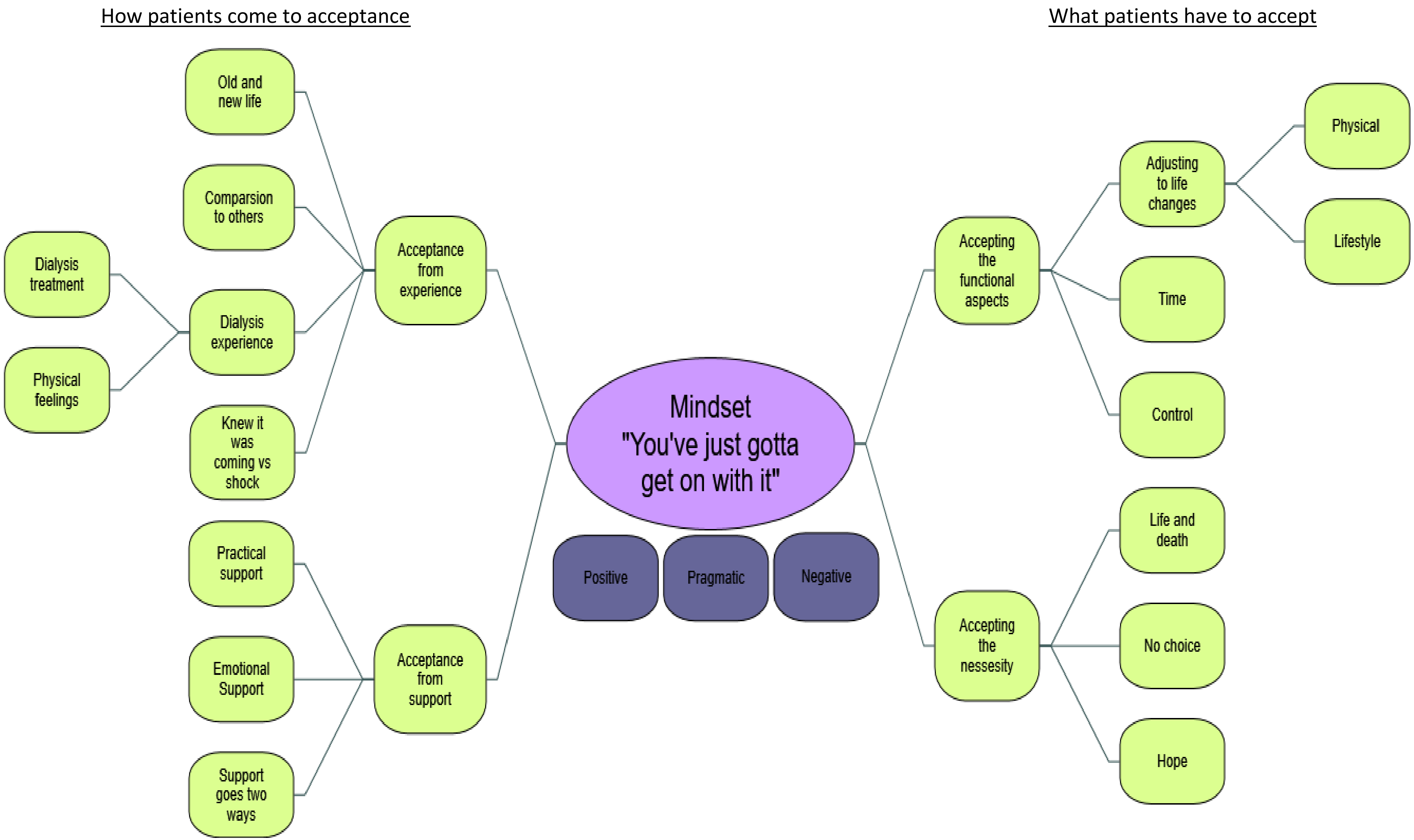
For thematic analyses, guidelines for sample size have ranged from 2 to over 400 (Fugard and Potts, 2015), and suggestions of between 12 and 101 were noted in a review study (Baker and Edwards, 2012) but usually reported without justification. Justifications usually focus on the type of data collection, size of the project and the depth of the analysis. Braun and Clarke (2013) suggested that for thematic analysis 6-10 participants were recommended for small projects. Another approach relies on data saturation being reached. Data saturation occurs when no new themes are identified, and has been reported to have been reached in studies with as few as 6 participants (Saunders et al., 2017). However, despite saturation being included in the quality checklists there is a debate on what it is and how or if it can be achieved. For the current study, the sample size of 27 for thematic analysis is sufficient to represent a range of patients and their perspectives and by 25 participants no new themes were emerging and therefore “data saturation” had been reached. Whilst it is acknowledged that this may not represent a true saturation of the data, the major themes were apparent early in the analysis and most new themes were sub-themes.

5.4 Findings

5.4.1 Overview

The initial analysis of the interviews identified four key themes about acceptance that can be interpreted through an overarching theme of “mindset”. The theme of mindset related to the perspective through which dialysis patients accepted the situation they were in. This mindset then permeated how patients’ accepted the functional aspects of dialysis. How they accepted the necessity of dialysis also related to the way patients achieved their acceptance of illness. The findings first discuss “mindset” and it’s implications, then explore each theme and associated subthemes to understand how participants accepted their illness and the impact of mindset on these perspectives. Figure 5.3 is a graphical representation of the themes and subthemes identified through the analyses.

Figure 5.3 - Acceptance theme and subthemes which were present in interviews with dialysis patients



5.4.2 Mindset

The overarching theme across all participants was the idea that "you just have to accept it" (appendix 9). Across all the participants there was the acknowledgement of the need for dialysis and the necessity to accept the practical aspects. However, there were differences in the ways in which participants' accepted the illness and treatment. It became evident that there were three key components of the acceptance mindset. Matthew who had been on dialysis for several years, summed up the perspective he saw on the unit:

> *"It all depends on the way the person's outlook is on life, and you can't sometimes sway that, you can try and help, give a little bit of light to people who see it from a negative or depressive nature and viewpoint but, because they're the ones that need lifting out, other people just take it in their stride "ahh I'm fine, sound, get on with it, not a problem", and you don't need to really try with them because they've already made their mindset right, but some people have just given up and that's when it's dangerous, and that's when you notice it and you try and sort of just say "it's okay, come on mate".* Matthew (AIS=L)

Matthew was clear that he perceived there to be distinctive "mindsets" which were apparent on the unit with some patients taking dialysis in their stride whilst others struggled with a more negative perspective. Through the analysis of the interviews there were three approaches which were evident: a positive, pragmatic and negative mindset which impacted on how participants accepted their illness. However, these perspectives were not mutually exclusive, with some participants adopting a combination of perspectives when reflecting on their experiences. This suggested that acceptance mindset is a continuum rather than discrete options.

5.4.2.1 Positive

The positive mindset was seen in participants who accepted their illness and the need for dialysis and embraced the experience. These participants frequently described making the most of the time that they were not in for dialysis.

> *"Just think positive, think, you need it to keep yourself alive you know, just try and organise your life for days when you're not here and you make the most of it then" Linda (AIS=M)*

Linda used the repetition of “you” and “you’re” to emphasise that it was her responsibility to make the most of it, which implied that to her, control was important. Participants also sought to identify the benefits of dialysis, for some this was simply that it allowed them to get out of the house. Karen was clear that the benefit to her was that she was able to socialise three times a week:

“Yeah I like the fact that I get, you know, I get company three times a week that I wouldn’t get because I live on my own. So that’s quite nice and, although we sit here alone, when we are getting on we are all chatting away, you know, and then when we getting off we are all telling each other what we are gonna do and, so that’s quite nice.” Karen (AIS=L)

However, despite the benefits identified there is an element of doubt created by the repetition of the phrases “quite nice”, almost suggesting that she is trying to convince herself. The focus on the positive aspect is evident in other ways for example, Chris saw the four hours on dialysis as a break from his busy life. Rather than grieving the loss of four hours of his day, he says he saw it as an opportunity; “it’s 4 hours of something extra to do”. He viewed most of the aspects of dialysis in a positive light:

> *“I’ve got a group of people around me that I come in to see and it’s quite a sociable thing you know, to have a natter, the staff are incredible, erm, and it’s, it’s a break from my day really, it’s something different to do and it’s, it’s quite nice.”* Chris (AIS=H)

Margaret drew comparisons with the way she approached dialysis, and whilst she was aware that this was her situation for the rest of her life it hadn’t stopped her from living:

> *“Oh no, I haven’t let it stop me from doing what I wanted to do, and I think that’s a big part of it as well, I think if you just sort of sit back and say, oh well this is it, you know, and this is it for the rest of my life, and I’m not going to be able to do anything, it’s giving up isn’t it really, you’ve really got to make up your mind that you’re going to live, but then again, I think it’s your frame of mind isn’t it, if you’re not going to let it affect you, it doesn’t affect you, if you think to yourself *gasps* this is the end of it and all the rest of it, it will be, you know, erm, I really don’t erm, think that people realise erm, how normal it can be” Margaret (AIS=M)*

Margaret’s view echoed participant’s views that mindset was important to how they let dialysis affect them. She compared her positive mindset to the alternative, a mindset of ‘giving up’.

5.4.2.2 Pragmatic

For some participants their outlook and reflection on dialysis were more pragmatic. They acknowledged that they needed dialysis and as a result, there was a more practical rather than emotive response to the situation. Linda described her perspective:

> *“I just sort of, err, like I said to the consultant, you know what I mean, well, there’s nothing I can do about it, it’s no good getting wound up and thinking I can’t do this, and I can’t do that, I mean, I still carry on the majority the things I used to do, you know”* Linda (AIS=M)

She was clear that there was nothing that she could do about needing dialysis but also acknowledged that she didn’t let it faze her. She did mention that it was the majority of things she could still do which implied there was some loss but that she wasn’t consumed by it. There was a sense that if participants had a pragmatic mindset in other areas of their lives then dialysis could be approached in the same way. Paul described how he faced dialysis as he would with any aspect of life:

> *“it’s the same with any other problem in life, it’s there, so, you know, you’ve either got to accept it or work round it or resolve it, erm, but err, no I just accept it and get on with what I do” Paul (AIS=H)*

By using the word ‘problem’ Paul acknowledged that dialysis is not something that is welcomed but when confronted with it the only option for him was to just accept it. Participants with this pragmatic approach saw little point in fighting against dialysis but were neither focused on the negative nor the positive aspects. For example, Janet described how trying to relax but also avoiding the difficulties with transport were the only aspects she could control over dialysis:

> *“Erm, try to take it in your stride because you need it, erm, you can’t avoid it, and it’s no good fighting against it and being upset or bothered by it, it’s just a procedure*

> *and just relax and that's all you can do, and if you can pay for your own taxis if you can afford it"* Janet (AIS=M)

However, with the use of "if you can" Janet acknowledged that taking control is not something everyone could do as other constraints affect this.

5.4.2.3 Negative

The negative mindset was one where patients were consumed with dialysis and the impact that it had on their daily lives. Tony was clear that even on non-dialysis days it was still on his mind, which is in contrast to the positive mindset where participants describe actively making the most of the non-dialysis days:

> *"You don't really get a rest day because you're thinking about here in the morning, so, although you're not here, it's always on your mind that you're here in the morning so you can't do owt can ya. You can't go out that night, you can go out in the day" Tony (AIS=H)*

Whilst most participants were clear that they would rather not have dialysis those with a more negative mindset were very vocal about how they "hate it" (Stephen). Sarah emphasised how much she hated it by stating that if there was not the protective factor of her son she would have chosen to stop dialysis, effectively implying that dialysis was worse than death:

> *"I hate it, I really do. I'm that depressed and down about having to come here, if I didn't have to come, if I didn't have my little boy then I would've stopped years ago. But yeah, I've got him, and he keeps me going"* Sarah (AIS=L).

As participants discussed the more negative thinking about dialysis, some suggested that they had not completely overcome the initial despair they felt. Brian initially discussed how he felt when starting on dialysis before proceeding to focus on how this negative thinking still permeated into his current thoughts:

> *"Oh, depressed, why me, you know, why me? Oooo, yeah that was a bit grim that actually because I live on my own now, I'm a widower apart from my cat who was very good company at the time *laughs* but you know, in the dark, dark hours of the night, you do sometimes think oh dear, yeah, this is not good"* Brian (AIS=M)

Matthew also attested to the idea that for some patients it was difficult to fully overcome these negative thoughts. He described his struggle to accept his illness, his journey on dialysis had been a roller-coaster of issues with compliance and maladaptive coping strategies:

> *"Yeah, in a way I think I've just thought sod it, and I've just let everything go to absolute crap because, yeah maybe it would be a lot easier for my friends, family, work colleagues, if I wasn't around because I put a lot of stress and strain on everybody else's life not just myself, I've got a lot of responsibilities and I'm letting a lot of people down and that breeds massive guilt and in turn has a knock-on effect all around, so I don't take taking medication seriously or coming to dialysis seriously and then it just, it spirals. And then it's like something slaps you around the face and you pull yourself back together again but for how long?"* Matthew (AIS=L)

Here Matthew alluded to the fact that the underlying negative thinking is still there and it would just a matter of time before he relapses into that role again.

5.4.3 Accepting the necessity

Accepting the necessity of dialysis came across strongly from all participants. This theme consists of three sub-themes which relate to what patients have to accept in relation to the necessity of dialysis. Acknowledging the life and death nature of treatment relates to how patients describe having to accept that dialysis is necessary for them to live, they also felt that they had little choice but to accept the treatment. Although for some patients the acceptance was only seen as temporary as they had the hope of transplant in the future.

5.4.3.1 Life and Death

In accepting the need for dialysis participants frequently mentioned the lifesaving nature of the treatment. However, the perspective which participants had on life and death differed. Some participants embraced the life-giving nature of the treatment:

> *"As I say, just embrace the fact that it's saving your life, or prolonging your life, erm, so that you can carry on leading as normal a life as possible."* Liz (AiS=H)

Others were very practically resigned about the situation:

> *"I say well, you know, thinking about it, I've just got to get on with it, there's nothing I can do about it… You know, you've got to come and have your dialysis, keep yourself going, so…"* Linda (AIS =M)

There were also some participants who were more negative and direct in their description of the situation. One participant described *"I've just got to stick it, I've just got to stick it out now till I die"* (John)**.** The repetition indicated an element of hesitance with the statement which implies difficulty in addressing the issue and the phrasing "just got to stick it out" is negative.

The awareness of the lifesaving nature is emphasised by the experience of life and death on the dialysis unit. For participants who had been established on dialysis for some time they reflected upon patients who had passed. Participants mentioned being confronted with the reality of their situation. The following extract demonstrates how participants were confronted and affected by fellow patients passing:

> *"Yeah, but I'm gonna go off, I'm going for home dialysis because, because it's like when I first fell ill in (Place), you know, there were about 10 people in my ward and 10 in the next ward and one person popped their clogs on that side and one on this side, so that depresses you a but, and even *name* in the yellow ward, he died a few months ago as well"* Peter (AIS=H)

In this illustrative case, the participant acknowledged how they had been affected by the passing of fellow patients and as a consequence, they were trying to remove themselves from the experiences by moving to home dialysis where they anticipated less of an impact. Another patient summed up the impact of patients passing, in particular noting that it made him consider and accept his own mortality:

> *"There's one or two died, that's upsetting when you know, you get one or two popping off…there's two people in here since I've been here that's died. Yeah, one had a heart attack, the other one got cancer in the bones, you know, I think sometimes you think of yourself, god, how long have I got?"* John (AIS=H)

These extracts illustrate that part of acceptance is realising that dialysis is lifesaving and requires acceptance of the treatment but in doing so participants were confronted by of their own mortality through the passing of fellow participants.

5.4.3.2 No Choice

For many participants acknowledgement of the lifesaving nature of dialysis was related to a feeling of having no choice. As one patient stated:

> *"I say I have accepted this, and I would rather not have to do it but there is no option is they"* Ron (AIS=M)

Many participants reported that they had accepted dialysis but that this was an enforced acceptance. One patient attested:

> *"I have accepted it, but I've got to, got to….I've got to, and not it's an everyday thing. I've accepted, accepted it for an everyday thing"* John (AIS=H)

They were adamant that they had "got to accept it" however by referencing this as an everyday thing it suggested that dialysis was now part of their life. In fact, John summed up his feelings later in the interview by stating "I didn't feel anything you know, it's a necessity so, that's it, I'm quite pragmatic".

These extracts highlight that participants felt they had to accept the necessity of dialysis, with participants feeling that they had no choice, however, this lack of choice was affected by hope.

5.4.3.3 Hope

For dialysis patients, hope was an important aspect related to acceptance. Some participants referenced the fact that they were hoping for a transplant. This, therefore, suggested that their acceptance was more temporal in nature, they've had to accept the situation is necessary at present but believed that this will change in the future and associated transplant as a gateway to a 'normal life'. Participants' stated:

> *"Yeah, you've got to accept that until you get a kidney, you ain't gonna be right" Ian (AIS=M)*

And

> *"I just want to be normal, and I want, I want a transplant" Sarah (AIS=L)*

Therefore, unlike patients for whom dialysis is the only option, patients on the transplant list had the hope of a different future and the option of a "normal life". One participant described how they accepted being on dialysis at present because there was the hope of a transplant in the future:

> *"Well, yeah, you do, you accept it, you know that one day you're gonna get a phone call saying get down to Nottingham, so, when that happens then the lifestyle will hopefully change again, you know" Peter (AIS=H)*

The use of "you're gonna get a phone call" suggested that it would happen for this participant and the use of "one day" suggested that it would just be a matter of time. However, the change in lifestyle is still only described as a hope, potentially indicating the acknowledgement of the risks and complications associated with transplant.

For other participants for whom transplant was not an option, hope was still important and many patients hoped for improvements in treatment or to be able to go onto home dialysis. As one participant who had previously experienced the transition from in-centre to home dialysis explained:

> *"Well, I think again because it was erm, because one was sort of part of a erm, group that was being trained for home dialysis you just sort of, you didn't. I didn't feel trapped or desperate or anything" Bert (AIS=H)*

However, the contrast is that for some participants they felt they had no hope of change:

> *"Oh yeah I've accepted what has happened to me, I've accepted that there can't be any change, I'm not going to have a transplant or anything. One day things are going to be the same" Ron (AIS= M)*

Here acceptance is fixed and described as accepting that the situation is not going to change significantly. However, some participants were less accepting of this lack of hope. Brian captured this in the following excerpt where he questioned why he was not eligible for transplant:

> *"Well, I'm accepting of it, that's it, you know, you can't do anything else but be like that, you fight against it and you think well, I've gotta get better and then you start enquiring about transplants and then you sort, oh, I'm very sorry but you've passed your sell-by date, that was a bit of a shock, to be told that I wouldn't even be considered, and I think that's wrong because, I mean they're doing hip replacements on people in their 90s you know, to, why not a kidney replacement for someone in their 70s?"* Brian (AIS=M)

Here Brian described having to fight to be considered for transplant and how he had looked for hope with it but when this possibility did not materialise he stated he accepted the situation but then conveyed a feeling of resentment towards the decision. For others they were very clear in stating that without hope of a transplant they felt they had nothing to look forward to:

> *"A bit fed up, still fed up, it wouldn't have been so bad, but I've never been on a transplant list so what have I got to look forward to?"* Mike (AIS=L)

Even for those participants who had the hope of a transplant it was not always described in a positive mindset. In the following extract Sarah described that a transplant would not be a cure which contrasted to the descriptions of transplant being the gateway to normality. Sarah still focused on the lifelong impact:

> *"I'm gonna have it for the rest of my life. Even with a transplant it's not a cure it's a treatment for it".* Sarah (AIS=L)

The sub-theme of hope was closely linked to what patients felt they had to accept. For participants who were hoping for transplant or home dialysis, they were hoping for a change in their situation which meant they described acceptance as a temporary state. They accepted they needed dialysis but saw it as a short term solution, whereas the other perspective conveyed was that a lack of hope related to a more resigned feeling of acceptance.

5.4.4 Accepting the functional aspects

Whilst acceptance is described as a mindset and participants described the necessity of acceptance it was evident that accepting the practical and functional aspects was important. Three key areas were discussed by the majority of the participants however similar adjustments were viewed differently by individuals.

5.4.4.1 Adjusting to life changes

> *"the process itself it's, It's not a problem, I mean, I don't, you don't have to do much really so it's just the change to your lifestyle"* Stephen (AIS=M)

Becoming a dialysis patient involves attending hospital three times a week for at least four hours and as a result it could be expected that acceptance would be related to these changes. The acceptance of these changes could be categorised into the discussion of lifestyle changes and then physical changes.

Lifestyle changes

Despite the obvious limitations imposed by dialysis some participants were very positive about dialysis and implied that they had accepted dialysis as part of their lives. Alan described that there were no drawbacks because he could still do the thing he viewed as important, getting out the pub for his pint. Therefore he did not see dialysis as an imposition on his lifestyle:

> *"Well, there's no drawbacks at all duck because you know with err, I says err, well I never plan nothing anyway, and I don't go anywhere not, you know, and I still go down on, still go out for the evening and have a drink like with the lads, no bother at all like"* Alan (AIS=H)

Another participant described adapting to lifestyle changes as a process of acceptance as opposed to fighting the changes. Chris described how important acceptance was in moving forward and as a result, it became a "normal" part of life:

> *"Erm, I'd just say you adapt very quickly, it, don't fight it, don't treat it like it's an enemy, just treat it as part, another part of your life and move with it and you'll adapt really quickly"* Chris (AIS=H)

Other participants even found positives about lifestyle changes. For example, Karen described how dialysis made no difference to her usual routine but that the treatment had the added benefit of enabling social contact.

> *"I'd only be sat watching telly at home probably so, makes no difference to me really. So I just watch tele in here instead of watching it at home. As I say you get people to talk to in here as well"* Karen (AIS=L)

Other participants acknowledged that there were difficulties but that it was important to find a way to manage and not let it get to them.

> *"Well, yeah, keep, just keep active, keep yourself occupied you know, erm, if you have to sit and rest just sit down for about an hour or so, but then you know, start saying right, I'm gonna do something, just go for a walk, I don't know, anything like that, and just carry on with your life, don't let it, don't let it get to you"* Peter (AIS=H)

Here Peter talks with fighting spirit about not letting it get to him and talked about practical ways that he managed. Participants described how they accepted there were limitations and the necessity for rest but described the need for a conscious decision to do something about it, to fight it. Participants commonly describe making conscious changes to help them accept their limitations. Travel and fluid restrictions were the two most common restrictions which participants discussed.

> *" I can't say that there's any, it does restrict you sometimes, you know erm, like if you got a wedding or something to go to you know, you have to sort of work out if it's, if it's err, over a weekend or something like that you know, or like, when we go on holiday I have to make sure that err, I can either have one done if they're doing Tuesday, Thursday, Saturday on holiday, I sometimes can't do Monday, Wednesday, Friday, I have to work out you know, that I need an extra one here and rearrange all that err, that's about it"* Linda (AIS=M)

Linda discussed the practical difficulties with holidays however these were discussed in relation to her role and how she could control it, the repetition of "I have to" suggests that these difficulties could be overcome but that it took effort and willing to control the situation. So whilst some participants accepted that there were restrictions, they identified ways to work with them to still live their lives, there were others who accepted that that part of their lives was behind them. Some participants discussed how dialysis meant they were unable to go on holiday or be as spontaneous as they might have been however they had accepted that they would no longer do these things.

Physical effects

For participants the physical impact of dialysis was a frequently discussed topic. Although there was variability in how participants felt they were affected. Across many participants a feeling of tiredness after dialysis was described:

> *"I'm knackered after that, I'm knackered. For the first couple of hours, I'm tired"* Susan (AIS=M)

> *"Very tired. Yeah, it drains you, yeah it does, I've always been a very active person, but some days I can get home and just do nothing basically. Yeah."* Stephen (AIS=M)

These participants described the feeling of tiredness, Susan implied that this lasts for a few hours whereas as Stephen suggested it's the whole day. For Stephen, comparing the extremes of 'very active' and doing 'nothing' highlighted the physical impact a patient has to contend with. Comparisons were also used by Karen who had accepted that the physical impact was not going to change. She suggested that realistic expectations were needed and they should be within what is achievable:

> *"Obviously things are still, things are still tough. I run out of me get up and go, still quite quickly but that's never gonna change. I'm never gonna be able to go run a marathon. I'm lucky if I can get up and down the stairs ten times a day let alone, you know."* Karen (AIS=L)

For others, accepting the physical impact meant taking practical steps to ensure they could partake in activities they valued. In the example below, by anticipating the feeling of tiredness after dialysis Chris described making adaptations to plans to ensure that the activities were manageable:

> *"Erm, I get tired quite easily so I get to sort of, like a work's night out on a Friday, I'm tired, erm, and like they're doing one, they're not gonna eat until 9 'o clock, and I'm*

> *tired, so, I'm not even gonna go and meet them 'til close to that, because otherwise I'll just be just totally wiped out by the end of the night"* Chris (AIS=H)

Some participants took a very practical view about dialysis and the physical feelings. Margaret explained how she saw dialysis as a process and that the effects were to be expected, she viewed patients expectations as being linked to acceptance. She described how she accepted how she was going to feel but also knew that she would feel better the next day, which rectifies the ill effects:

> *"Yes, yeah, but then you can't, *interruption*, you can't erm, take the blood out of your body can you, for four hours *interruption* erm, and you know, going through this process without it having an effect of you, can you? When you think about it, and I think that's something else that you have to accept, that you're not going to feel the same when you come off the dialysis, as what you do before, you know, and it does take you, sort of, well I find, if I go home and go to bed, when I get up, wake up the next morning, I feel so much better because, I've slept"* Margaret (AIS=M)

Unfortunately, the physical effects of dialysis are not all that patients have to contend with. For many patients there are other conditions which they need to manage. For some participants these problems were taken in their stride:

> *"I mean I've got more than kidney problems you know, I've got a few other problems, but I don't let anything bother me now…It's not worth it, I don't worry about it"* Susan (AIS=M)

For others there were other considerations which were more pressing. For Richard the diagnosis of cancer had become a more pressing issue and alongside the dialysis had led to less favourable coping strategies by referring to coping by having "more whiskey".

5.4.4.2 Time

> *"It does get better, it does get better, but you've still got it there all the time ain't ya, it's a pain in the arse"* Ron (AIS=M)

Time was a major aspect of acceptance, and acceptance was described by many as a process that takes time. Some participants, like Ron, acknowledged that their dialysis became better with time but that it was still an inconvenience. The length of time that it takes to adjust to dialysis and come to an acceptance of dialysis as part of their lives was variable, some felt that the process takes at least a year:

> *"Yeah, it takes most, I've been told it takes most people a year or even longer to get, yeah after about a year, I mean I wouldn't say it was exactly, but it was roughly yeah"* Susan (AIS=M)

Other participants described accepting dialysis as being a quick process, with Chris suggesting it took just three weeks until he felt settled with it:

> *"So, but, you kind of get used to it and it's amazing how quickly you adapt, it's just so amazing how quickly you adapt to stuff, you know, I think it took me about three weeks to get to the point where I was like, yeah, that's fine, I'm on with it now"* Chris (AIS=H)

However, it is not just the time it takes to accept dialysis. Participants also described how they had to accept the time restrictions placed upon them. The nature of dialysis means that it is a lengthy and time-consuming process and as a result many participants were very focused on 'time' and what it meant for them. For some *"four hours dialysis on a morning, basically wipes the day ou*t" (Paul), which suggested that the dialysis had wider implications than the four hours on the machines. Matthew emphasised the impact when trying to complete a working week;

> *"because it takes up sort of, three days of your week so now the working weeks I do Monday, Wednesday, Friday mornings, it used to be 7 'o clock in the morning, that's half your day gone and you're knackered after treatment, so that leaves me Tuesdays and Thursdays, really I should do Tuesdays, Thursdays and Saturdays but I kept the routine"* Matthew (AIS=L)

Interestingly Matthew acknowledged that switching to the other day pattern might be of benefit but he was reluctant to change the routine. Bert had previously experienced home dialysis and stated: "I think it was the fact that when you were on home-dialysis you could, it wasn't four wasted hours" (Bert) implying that now he is on hospital dialysis he is wasting time. However, other participants identified the importance of time but they suggested that it was most worrying prior to starting on dialysis and in fact time was not as difficult to adapt to, they just had to make the most of time on the other days:

> *"The easiest thing? Urm, I think the time factor. I thought that was going to be really difficult but as I say I packed everything into a weekend or Tuesday and Thursday. So I found that really the easy, the time, coping with the time"* Pat (AIS=H)

One of the biggest complaints from the dialysis participants was about the transport service provided by the hospital, and the main issue apparent across these complaints was the extra time that the transport added to a participants' day. This was apparent in interviews from those who directly experience the transport and from those who witness it in others. It appeared that the focus on time was magnified when participants felt it was being wasted.

> *"One of the biggest problems which everybody says, on dialysis is transport, 'cos I use hospital transport, it's getting here on time and then it's, sometimes you have to wait to go home afterwards which adds, could add an extra couple of hours on your day, and then when you do get home you haven't really got time to do anything"* Mike (AIS=L)

The waiting for transport both before and after dialysis was blamed for extending the day and increasing the impact of dialysis on a participant. Even for some of the more positive participants, the impact of transport was apparent:

> *"That's the main one, it's a really big one isn't it, when you, I mean you think 4 hours is a long time, then you find out you've got all the waiting with the ambulance and that makes it so much longer"* Janet (AIS=M)

Participants acknowledged that the delays were not due to the ambulance staff, instead putting blame on those that planned the routes. They were grateful for the service so some felt that they had to accept it:

> *"Yes, I have the transport, the hospital transport, erm, which is good and bad you know, I've, I mean, at the end of the day it keeps me alive so, you have to do what you have to do, yeah"* Margaret (AIS=M)

Others struggled with the perceived incompetence in the situation:

> *"You know, so, you can imagine waiting an hour and a half to travel 10 minutes it's absolutely ridiculous"* Brian (AIS=M)

This lack of understanding appeared to contribute to the difficulty participants had in accepting the waiting associated with transport. The illogical nature of the system in which some described being driven virtually past their house but then being driven miles to drop another patient before being dropped themselves seems to be the core of participants difficulties with the system, this was compounded by the impact that it had on time.

5.4.4.3 Control

Control and more specifically lack of control was an aspect that participants felt they had to accept. One participant who had previously experienced home dialysis was able, to sum up the impact of control and how it was easier to accept something you have some control over:

> *"Yes I think err, I think it's much easier to accept home-dialysis because you, you've got much more of your life under your, your own control basically, obviously more flexibility in terms of moving the times around a bit if necessary"* Bert (AIS=H)

Other participants also described how having control made them feel better about the situation. Karen dialysed in the shared care section of the unit, where patients are encouraged to take on more responsibility for their own care. She described the importance to them of feeling in control:

> *"Yeah I think so. I think that's the thing about shared care, I think you are in control more. I don't think I liked it as much when I was up there coz I wasn't in con, I'm a control freak."* Karen (AIS=L)

For other participants it was not about taking control of the treatment but taking control of the difficulties associated with it. For some this manifested itself in taking control of the transport to and from dialysis. Some patients chose to drive whilst others had alternative options. John described taking control by using the bus to avoid transport delays:

> *"And, getting home, I thought, I'm not having this. Then I started to feel a lot better, because when I first started, I wouldn't be able to, I wouldn't be able to get home on my own steam. I've got a bus pass anyway so, so I started to make my own way*

> *home and I've been making my own way home now for 2 and a half year" John (AIS=H)*

Some participants felt resigned to accept the treatment, which they had little control over, but described believing that they could take control of other aspects. In the following extract, Brian talks about taking control of other aspects by making his voice heard:

> *"you've gotta accept what's happening to you whilst you're in here but you don't have to accept anything outside those parameters, you know you can, you can object if you're not being treated right, if things aren't happening right or if you're unhappy and then you have to make your voice heard don't you? So, fortunately we at the moment, we're okay"* Brian (AIS=M)

Control was related to how patients felt they accepted a lack of control. Some felt they lacked control over the treatment whilst others strove to take control of as much as they could. Patients also looked to control other elements of their lives to reduce the negative impact of factors associated with dialysis.

5.4.5 Acceptance from experience

The theme acceptance from experience relates to how patients come to acceptance. There were three key subthemes relating to how patients come to their acceptance of dialysis. Participants used reflection between their old life before dialysis and their new life, and how they evaluated these differences was related to how they accepted dialysis. The experience of dialysis is associated with acceptance, with feelings and experiences of treatment and the dialysis environment being important. Participants also reflected on their own situation in comparison to the experiences of others, which helped them accept their own situation.

5.4.5.1 Knew it was coming vs shock

Acceptance of dialysis was frequently linked to the preparation that patients had received prior to dialysis. There were two distinct types of experience that were present in the data. Firstly there were a number of participants who described how they had known for many years that it was coming and they knew it would be needed. Participants described how they were prepared for dialysis and for those who had been aware of the prognosis for many years there was a sense of inevitability but also being grateful that they had avoided dialysis for this time:

> *"Yeah, I knew it was inevitable, yes. I'd appreciated that I'd had a good run for my money, you know"* Pat (AIS=H)
>
> *"Well, maybe because I knew about it for years that I would eventually have it, I erm, accepted it"* William (AiS-M)

The same person described that they knew it was coming and they had also been prepared physically with the fistula formation. This participant felt they had accepted dialysis as soon as they were told and looked for the positives:

> *"As soon as they said I've got to go on dialysis I accepted it because I knew that I'd had a good few years without, because I'd had the fistula in for 9 years before I came on dialysis. So I knew that was a positive part as well"* Pat (AIS=H).

Some participants described that acceptance happened before they had even gone onto dialysis; this implies that the process of acceptance was viewed as a mental process rather than a physical process:

> *"I suppose I accepted it long before I was even on it. So I accepted the fact that it was gonna happen so, I knew it was coming yeah. "* Karen (AIS=L)

Despite knowing it was coming, participants described not letting it interfere with their lives as one participant described it, it was "just like a little cloud on the horizon sort of thing" (Chris) and another who had known about the diagnosis for 50 years stated:

> *"I think he actually did me a favour in saying that if I went on as I was doing, when I was young, I wouldn't be on dialysis until the year 2000 so you sort of shove that to the back of your mind don't you, and erm, get on with the rest of your life, it didn't frighten me, didn't scare me at all, you know"* Margaret (AIS=M)

However, another common scenario described by participants was that dialysis was a shock. Even when participants were aware that they had problems with their kidneys the actual going onto dialysis came as a shock. Stephen described how at one of the routine appointments his life changed:

> *"it was a life changer…I had to do it [check-ups] every year, obviously. Uhm, and I, I've been here ever since from 5 years ago. I came home to get checked over and they said if you leave you'll only have 2 or 3 weeks" Stephen (AIS = M)*

Another described having to accept the diagnosis with no prior indication of kidney problems, and they described a situation where they had to accept dialysis despite having no physical symptoms. They described the initial denial and disbelief when they were told:

> *"so I done a blood test and then three hours later they said you better get down to A&E, your kidneys have gone, I had no clue whatsoever, no pain nothing at all…Well, it was a bit of a shock, I thought erm, I seriously thought that when I went for a blood test another old boy went in there to do a blood, so I thought they'd mixed the results up*" Peter (AIS=H)

The sub-theme of knew it was coming vs shock illustrates the two ways participants felt they had come to become a dialysis patient. For participants who knew it was coming, the journey to acceptance was described as more controlled and some participants described the feeling of acceptance prior to starting dialysis. This appeared to make the transition smoother. Participants who knew it was coming also described making the most of their lives prior to initiating dialysis and therefore conveyed a feeling of gratitude rather than resentment.

5.4.5.2 Old and new life

Many participants related previous life experiences to how they have adjusted to dialysis. For some, this was in the form of how their previous experience enabled them to accept dialysis. One elderly participant reflected upon his experiences in the war and how this affected how he approached dialysis:

> *"I mean there are things that I am aware of, what happened to me. While I was in the army and I didn't know what I was going to turn out with me, when I was injured but everything turned out alright eventually. I've had a bit of practice if you understand, with that sort of thing"* Ron (AIS=M)

He discussed how being a solider previously meant that he could "stand anything going". Ron in reflecting on his life also felt that acceptance was part of ageing, he stated: "I mean, 91 years of age now so I think that is part of acceptance". Age was a frequently mentioned factor which participants referred to, which seemed to be a justification, the phrase "at my age" was frequently used. Participants referred to aspects of their old life and justified why it was not just dialysis but age that they were contending with. For example, one participant discussed how they would not be travelling anyway, regardless of dialysis and another how they cannot do what they used to because of their age, therefore facilitating acceptance of the lifestyle changes.

> *"Yeah, but that history as well, I mean remember I'm nearly 70 years old so I don't think I'd be going at that age anyway *laughs*"* Keith (AIS=M)

> *"I can't do the things I used to be able to do but erm, I mean, I'm 88 so erm, things are not all going right" Ken(AIS=L)*

Accepting restrictions related to dialysis were impacted by how participants viewed the situation. Acceptance may not just be about accepting dialysis but also about accepting ageing and that dialysis is only part of it. Some participants, like Margaret, who was able to attribute kidney problems to the ageing process and that seemed to facilitate acceptance.

> *"But erm, the way I'm feeling at the moment yes, I've got a problem with my back and my legs and all the rest of it, but I would probably have that anyway at my age… So, it's just part and parcel of the thing isn't it, you know, growing old"* Margaret (AIS=M)

Reflecting on their old lives was another factor which made dialysis more acceptable. Older participants were able to reflect on what they had achieved and their previous lives. Being thankful that he'd had a "good innings" affected how they Ken accepted dialysis.

> *"Erm, well I suppose it has really, erm, erm, you know, I've had a good life really erm, I played sport right up in to my 50s and erm, I played golf in to my 80's so you know I've accepted that erm, dialysis is keeping me alive, and I'm very grateful, very grateful for it, yeah" Ken (AIS=L)*

Being grateful and reflecting positively on their previous lives seemed to affect acceptance in a positive way. For example, one patient described that *"I was lucky I had an extremely fulfilling career before, before the err, before it struck and so did my wife really"* (Bert), through the interview it was evident this patient valued career and academic success and therefore having achieved a fulfilling career affected their perception of the current situation. Conversely, other participants, particularly the younger ones, felt like they were "*never gonna be able to go and do some stuff that I, you know, I used to do"* (Karen) and compared their current life to previous experienced. Sarah is a mum and has to manage her kidney disease alongside looking after her son:

> *"I can't do anything when I go out. I don't go out drinking anymore, I don't go out with my friends. I have no friends because of it."* Sarah (AIS=L)

Sarah's comparisons were related to what she felt she should be doing and how her current life compared. She blamed her illness for the lack of friends and loss of a relationship, she had a negative view on her experiences on the impact of dialysis which affected her overall interpretation of her situation. For other participants' the reflection between old life and new life was more practical. George described how his life had changed since starting dialysis:

> *"You know, I'm not, I'm not as, as energetic as, as I used to be, let's put it like that, erm, I used to walk about a fair bit but I just find I'm not anymore, and I used to go on holiday a lot and erm, and I haven't been on holiday apart from erm, a day or two here and there, since I've erm, you know, since I've been in hospital so, it's, it's hit that side of my life a bit, and, and to be honest erm, I'm not at all as lively and, and energetic as I used to be, and I don't think I'm as cheerful as I used to be you know, I used to be erm, you know, very positive about things and so on but I, I think it's, I feel as if I'm, I'm you know, it knocks me out, I come in to hospital and I know that it's going to be 24 hours before I can you know, feel energetic enough to get involved with anything again, and that's, erm, well it's disappointing really, it's disappointing because I had you know, I did quite a lot of stuff"* George (AIS=H)

He had previously had a busy and successful career and although retired believed "you've gotta do something, you can't just sit at home can you, I mean I'm supposed to be intelligent, you can't put up with that". Up until dialysis he had been involved in many voluntary roles in the community. He described the change between his old and new life as a loss with the use of "I used to…", "I don't…" "I'm not…" frequently in this extract. This loss is preoccupying and the focus of the majority of the interview rather than looking forwards. George was not alone in this view, with other participants focusing on how their new life compares to old:

> *"Well, it's, it's *huffs*, I mean I used to be out every night erm, but now you think ahhh I just can't be bothered, it's cold you can sit there with your feet up, watch the telly, read, carry on reading what you were trying to read during the day"* Brian (AIS=M)

Brian described how he used to go out but couldn't be bothered now, although in this extract it is not directly linked to dialysis. Instead, he mentions the cold and being comfortable at home, raising the question as to whether it is the effects of dialysis or his current mindset.

Participants' previous experiences were linked to their current interpretation and acceptance of the situations, however throughout the interviews it was unclear whether acceptance mindset influenced experiences or experiences facilitated mindset. It is likely that it is a bidirectional association. If patients feel more positive, the interpretation of their experiences may be more positive, however for some positive mindset may be dependent upon positive experiences.

5.4.5.3 Comparison to others

> *"But other days I think, well, there's always somebody else worse off than I mean, well, so just get on with it, carry on, count ya blessings, but, it does put strains"* Matthew (AIS=L)

Participants continually drew comparisons with others, which appeared to allow them to accept their own situations. Ron described how he believed that acceptance was important to doing well on dialysis:

> *"There's a lot more people worse off, and a lot of those are the people who have not accepted that what has happened to them or is happening to other people, they don't. I mean some of the patients that come here are so cantankerous and the way they talk to some of the nurses here. I'd of put my boot right up their backside, but that's not on."* Ron (AIS=M)

This comparison with other patients allowed participants to identify positive elements in their own lives. Comparison was also described as providing an incentive for patients to attend to the advice they had been given and to make the most of what they have. For example, Brian described the impact that seeing others had on him.

> *"Well, I don't know I mean everyone's different, depending on, obviously I mean there's some, there's some pretty poorly people, erm, I mean you see them, stretcher cases, wheelchair cases, all that kind of thing, well that's an incentive to not get like that and try and make sure that you don't carry on with all the bad habits that have got you here in the first place you know, I mean you see people with advanced diabetes and they start having their toe chopped off, then it's a foot, then it's a leg, you know, it actually terrifies me that does, you know, and once you, I mean, fortunately I'm still, obviously my, everything seems to work with me bar my kidneys"* Brian (AIS=M)

Brian described the fear of becoming one of "those patients" but used that to reflect on his own fortunes with his health. Although it's not just patients on the unit that comparisons were drawn with, other participants were grateful that they could be treated with dialysis whereas in other conditions this might not be possible, the following quote illustrates Georges perspective:

> *"Fine yeah, it's keeping me alive 'int it, so you know, people, other people have things that they can't hook there selves up to a machine three times a week so, I'm always a positive person anyway, things could be a lot worse so, yeah"* George (AIS=H)

Participants also drew comparisons to family members who had been through similar experiences, and this was particularly evident in those who had hereditary kidney disease. The instances described by these participants were all of positive role models. Julie described how her mum had been through the same and had a transplant and been on dialysis:

> *"No, but my mum was on, err, my mum went through the same, mum was on dialysis for 7 years erm, and she had a transplant erm, which lasted for 7 years so, I sort of knew what to expect so it wasn't, didn't phase me really 'cos it, I'd seen it with my mum and it was fine"* Julie (AIS=H)

She described how her mum wasn't held back by the kidney disease and therefore she had adopted the same mindset. Julie (AIS=H) stated that her mum "used to go to Australia every year for a month and, you know, so, didn't let it stop her and I think I'm the same, same mindset". Therefore a positive experience of others adapting facilitated her own acceptance.

Drawing comparisons with others was generally detailed by participants as a positive strategy which allowed them to feel that their own situation was manageable. However, in some instances, participants drew comparisons which emphasised how their lifestyle had been affected and how they could not do the things that other people could, for example, travel or socialising.

5.4.5.4 Dialysis experience

Obviously, a key aspect of dialysis is the treatment itself. Patients' experiences of dialysis, their thoughts about treatment and the dialysis environment were all associated with how they accepted dialysis.

5.4.5.4.1 Experience allows transition

Participants frequently reflected upon how their experience of the treatment allowed them to realise that it was not as bad as they had initially anticipated. Wrapped up in the experience was the development of knowledge and understanding about the treatment. Ron discussed how once he understood what was happening then it led to acceptance.

> *"Once I came on this thing it took a while before I got the picture in my mind of what actually was happening. And once that became obvious to me what was going off there it was again part of acceptance."* Ron (AIS=M)

A lot of the emphasis was on the patient understanding what they were doing, for example, Karen described how she needed to understand what she was doing when she stated *"once I knew what I was doing I was like, oh I can do this, this isn't going to be difficult" (*Karen). Chris neatly described the journey and emphasised how there was an invisible barrier to cross, suggesting a dichotomy between not accepting and accepting dialysis.

> *"Yeah, and it, it's like, like crossing a barrier, it's like going from, I'd have no idea what this is about to, I'm doing it all the time and actually, it's not that bad, and it's quite a strange transition, yeah"* Chris (AIS=H)

However, it was not just understanding the experience that was important, becoming more familiar with the whole experience including the staff allowed the participants to feel more at ease. Brian described how important this aspect was and how feeling relaxed with the experience helped acceptance of the situation. However, he noted that this took time, which aligned with other responses suggesting that this initial period could be difficult:

5.4.5.4.2 Thoughts about treatment

Dialysis involves patients being attached to a machine, so many participants naturally described their thoughts about the treatment process. They felt they had to accept being attached to the machine but whilst it was disconcerting at the start it soon became accepted.

> *"Oh, fine. Yes. It's my friend now. No when I first started I was terrified, coz I'm not very tech savvy and I just looked at it and thought; never gonna work that out, never in a million years- look at me now."* Karen (AIS=L)

Some participants even rationalised the treatment by likening it to the mechanics of a car:

> *"I'm just like a car, if the mechanic says I've changed the oil in your car, you're automatically gonna say the car, oh yeah, it's running a lot better, it's not running better, there was nothing wrong with the car in the first place…That's all it is, I got just an oil change but why should I be any different? You know, I know obviously it's cleaned the crap out, out of the system but erm, at the end of the day you're not, it doesn't affect me because I'm getting dialysis and regularly, if I wasn't then it'd be a problem"* Peter (AIS=H)

This approach demonstrates a practical approach to the treatment, by likening their body to a car they are saying there is nothing wrong with them it is just a process of maintenance. There were other perspectives to the treatment some participants like Pat just thought it was wonderful:

> *"I think it's wonderful. I think it is a fantastic modern day miracle I really do. I'm so grateful for it"* Pat (AIS=H)

Other participants acknowledged the benefits of improvements to dialysis treatment but were still not happy with the whole treatment, questioning why the limits were not being pushed:

> *"It could improve, I mean these new filters that they've put on are working good, you know so that's an improvement that the, I don't totally understand the mechanics of these things but the, the clearance at the end of the 4 hours has gone up, which is good yeah, so that's a positive, and I think it should be you know, rather than erm, things to be set at the minimum, I think they should be constantly pushing, I think we should be pushing and, you know pushing the settings up to get the clearances higher, well, that's me, that's my attitude towards things"* Brian (AIS=M)

There are reasons why dialysis settings are set to certain parameters, however this did not appear to be understood by all patients, potentially affecting their acceptance of the situation. Despite some questioning about treatment and suggestions that in the future they will be able to "grow your own kidneys" (Matthew), participants were generally very thankful for the dialysis service and the NHS.

> *"Well, erm, I'm very grateful for the free service, you know, I don't know how much it costs but it's in the thousands over the years, and I'm very grateful for it you know, the national health is brilliant, there's no doubt about it"* Ken (AIS=L)

5.4.5.4.3 Treatment environment

The physical environment on the unit was an aspect participants had difficulty adjusting to, and in turn, may have impacted upon how patients accepted the treatment aspect of their illness. In particular, one aspect participants struggled with was the "telly-wars" (Mike). This might be a specific issue to this unit however it stresses the importance of the environment in the dialysis experience. Tony summed up the issue nicely:

> *"If you get four people in one room and they're all watching a different channel on there, that's enough to drive anybody crazy…You've gotta sit here through four hours of that!... Yeah, you know, it's horrible, yeah, especially people that like Jeremy Kyle, I can't watch that, I can't even listen to it"* Tony (AIS=H)

Some participants felt that they could exert some control and managed to avoid being subjected to the noise by taking action, like Ron who found benefit in his impaired hearing:

> *"I'm fortunate in the fact that I've got hearing aids and I can just switch 'em off there when people come in next to me and start playing the Wizard of OZ or something like that, yeah."* Ron (AIS=M)

Other participants felt that they were forced to endure it. Mike described how the environmental discomfort added to what was already a negative and scary situation.

> *"Yeah, so you've got that, you're feeling awful, you feel worried, frightened, scared, and then somebody next to you, and I said, can we have that turned down and the nurse said no, it's their radio, it's their television, you've got to allow them their, I said their space is two foot from my space you know, so I have to listen to it just as much as they do, rah rah rah, anyways so, that was my main bone of contention"* Mike (AIS=L)

Although some participants did see the television as positive, alongside other attributes of the environment.

> *"they put me straight on here, and then for the first three months it's quite difficult to take on board and, it's adjusting but you get looked after really nicely here, I can't complain, I've got food, wonderful stuff, TV, a nice relaxing bed and good company so you can't complain" Matthew (AIS=L)*

5.4.5.4.4 Treatment makes you feel better

Patients' experiences of their physical health prior to starting dialysis were mentioned by participants as helpful in allowing them to accept the treatment. The most common story was that participants had suffered physical decline prior to starting on dialysis, however this was often not fully apparent to the participants until they started on dialysis. As Julie described;

> *"but since I've been on it I realise I've felt quite a lot worse than I thought I did, 'cos I feel so much better now that I'm on it so, yeah"* Julie (AIS=H)

For some participants the benefits were very immediate:

> *"Then they (needles) did get a little bit more painful, but I've felt so much better since I have been on dialysis. I feel it has given me my life back"* Pat (AIS=H)

As Pat describes the benefits were restorative, the treatment experience had been positive and she felt better than before which negated the pain of the needles. This experience was replicated by Alan who stated that due to dialysis *“I’ve got a bit of youth back in me … I am positive about it because it’s doing me good”.* This emphasised how the physical experiences of dialysis were important to patients emotional state.

Participants who had noticed the difference that dialysis had made in their overall physical health were able to accept how poorly they had been and that the current state was an improvement. Many also noted that after the two-day break they had each week they notice the difference and it emphasised the benefit of the treatment.

> *”Yeah, when you’ve got the 2 days off, yeah, and err, come in on the Monday and then you know that you’ve had it, you know, you do feel a lot better ”* Linda (AIS=M)

The improvements in physical health were seen as important in enabling some patients to make improvements in other areas of their lives, for example, Julie had noticed the improvement in her energy whilst on dialysis and therefore felt she had been able to have more of a social life. This reduced the overall impact that she felt dialysis had on her life:

> *“Keeping me alive, makes me feel better than I’ve felt in a long time erm, got a lot more energy, been doing a lot more things erm, so my social life has got better, so, yeah” Julie (AIS=H)*

However it was not all positive, and how a treatment session goes can have a wider impact. Some sessions can be straightforward but it was acknowledged that a negative dialysis experience could affect the patients physically which in turn could have wider impacts.

> *“You get good days and bad days, if you have a day where your clearance isn’t very good or your machine’s alarming or you’ve, your arteries are playing up or something like that, you haven’t eaten properly so you’re just, not feeling great, erm, they, they can impact everything else like, afterwards, so you’d just be too tired to do something”* Chris (AIS=H)

Chris talked about the good and bad days which he had experienced and was evident in other interviews. Whilst participants had good and bad sessions the interpretation and frequency of these affected how participants accepted treatment.

5.4.6 Acceptance from support

5.4.6.1 Practical support

The practical support given to patients was important in allowing them to accept their illness. For Chris, he was still working full time when he went onto dialysis and the fact that work allowed him to have flexible hours to accommodate dialysis made the adjustment easier:

> *"Erm, I think what made it easier was work, erm, being flexible enough to say, yeah okay, we'll let you do these hours, and you can do your dialysis at this time and we'll work around that"* Chris (AIS=H)

These practical adjustments can allow patients to reduce the impact of the treatment on their lifestyle, in Chris's case he was able to keep working which was important to him. Participants also valued the practical advice given to them by staff which allowed them to become more knowledgeable about their condition. For some participants this knowledge and understanding were important for the acceptance of dialysis:

> *"It did yeah, I mean it probably took a month or two but then as I say I then started asking the nurses, you know "what does this do, what does that do" erm, and it helped me considerably to understand more"* Liz (AIS=H)

Participants also valued the practical support with lifts or with care at home, which was discussed in a way that suggested the support helps reduce the burden of dialysis. For example, Karen avoided hospital transportation with the support of her mum but she was aware that this was not likely to continue indefinitely:

> *"Well mum brings me and picks me up most times, the thing is mum is now 70 and at some point she's gonna say that's it. I can't bring you anymore"* Karen (AIS=L)

However practical support was not always there when participants need it. Some participants found that support was not available and had to cope with the practical aspects themselves. Some participants like Richard felt abandoned by his family, and Mike felt that he had no support:

> *"I mean same as me cancer, I told family that I've got it, and I would say, as I say, it was err last May when I had it, about a month ago when I were told about it, err, and nobody's been round, I ain't bothered." Richard (AIS=H)*

> *"Well, you can't go anywhere, err, if I need, I went for about 3 years without even having a day out 'cos I needed people to take me and no one would take me and I couldn't get there, get anywhere myself" Mike (AIS=L)*

The practical support that participants received from those around them was viewed as valuable and important in accepting the illness. Margaret had extensive family support, and she could not imagine coping without it:

> *"Erm, well yes, they do because erm, I mean, at the end of the day, you know, the people that surround us are support aren't they, and yeah, as I say, my daughter's and my granddaughter, they readily took on the role of erm, the nursing part, erm, and, and, even my grandson's, you know, they're there all the time for me, it's always, if you need us nan, you've got my phone number haven't you? So, you've got that support and having that support is a, it plays a big part because you know those people are there for you, erm, I don't know what it would be like if you hadn't got that support really, I would think it would be a bit, you know, I don't know, I've never experienced it so I can't really say"* Margaret (AIS=M)

5.4.6.2 Emotional support

Alongside practical support, participants felt that emotional support was also important but like practical support it was not always received. Some participants felt they had *"Accepted what's happened, but you have got to have the right support"* (Ron). The emotional support was described as coming from family, friends, staff and other patients.

The emotional support from staff was generally discussed positively by all participants, even those who were more negative about the dialysis experience overall. Ron described how staff affected his experience of dialysis:

> *"And also, the staff in here I find are so, well when I say perfect, and I'm using that word because the way they treat patients is wonderful and that is one thing that has*

> *influenced me, and I thought well look at any of the nurses and I know that they are there for me. And that makes easy when you've got them there."* Ron (AIS=M)

He had high regard for the staff, describing them as 'perfect' and that his universal support applied to any of the nurses. However, some participants felt that although the staff tried they did not understand:

> *"I mean, the staff don't always tell them what they're going to go through. I think because they don't go through it themselves. I'm not blaming the staff, you know they don't know, they're not on here..."* Susan (AIS=M)

Sarah felt that her family also didn't understand:

> *"My family don't understand, I have nobody to speak to apart from a couple of staff here and people I speak to outside the hospital but apart from that I've got nobody, and it gets to me a lot sometimes, and I don't like talking about how I feel because I feel like people think I'm being a drama queen. And my family don't understand what I go through every day and it does get really hard." Sarah (AIS=L)*

Sarah described how despite having a few people she still had 'nobody' to talk to about her experiences because people didn't understand. This was echoed by other participants who felt that unless you have been through it you can't understand. Although this was typically seen when discussing how difficult dialysis could be, Peter also felt that other people could not understand how well he had accepted dialysis:

> *"Yeah, so you know, don't expect sympathy from anybody, you know, just get on with it, it's like, when I was in the shop people say, but you're so upbeat, you're not…, I say well what do you want me to do, cry?" Peter (AIS=H)*

Peter discussed how people questioned his positive attitude toward dialysis. He was not looking for sympathy but instead indicated that others struggled to accept his approach.

5.4.6.3 Support goes two ways

Participants discussed how practical and emotional support related to their acceptance of illness, but for many although they received support they also had to support others. For many of the ageing participants with partners, they felt that their partners supported them but they also reciprocated support. Ron talked about the support of his wife more than any other patient and was incredibly appreciative of how she had accepted the changes brought about by his dialysis but he was also very caring and supportive to her. Whilst on dialysis his main concern was whether she was alright at home:

> *"I'd got the support of my wife. And the fact that her life had changed because of things…And that is the main thing in my mind. I'll be thinking while I'm here about, wonder what she's doing right now. Is she doing what I told her she shouldn't do until I get home"* Ron (AIS=M)

Other participants felt unable to receive support because they had to care for others, either elderly parents or partners or their children. They felt that they often had to just get on with it and that dialysis was not always their main concern. Tony, had to care for his dad whilst Janet had a son with mental health difficulties and found that whilst her son accepted she needed dialysis, she still had to care for him and dialysis made it difficult for him; she stated *"I suppose my life revolves around him, and to some extent, his revolves around me"* (Janet).

> *"Well they can't, how can they help? My dad's really ill, he's got emphysema, he's on oxygen he is. I still see him every day, I go around to his house everyday… No, they don't help me, no, I don't really need any help, but, I manage, I manage on my own"* Tony (AIS=HL)

> *"Yeah, yeah, erm, my son, particularly doesn't like it, he accepts I've got to have it, but he doesn't do very well, I mean before I went on to dialysis he'd have ups and downs, whereas now, the days when I'm in here they wind him up and he seems to be ill all the time, he hasn't really had a good patch"* Janet (AIS=M)

Across the interviews, acceptance of illness was shown to not only affect the patient themselves but those around them and this was acknowledged by participants.

To summarise the findings they can be looked at in terms of what patients have to accept (Table 5.4.1) but also how they reach acceptance (Table 5.4.2). The tables highlight the positive and negative perspectives for each aspect as these were the extremes. The pragmatic stance was the middle ground between the two.

Table 5.4.1 - What patients have to accept

	Negative	Positive
Physical changes	*“It makes me so tired” Sarah AiS L*	*“I’ve got a bit of youth back in me Alan Ais H*
Lifestyle changes	*“It’s a life changer” Stephen AiS M*	*“it’s not interfering with my life anyway” Alan AiS H*
Impact on time	*“It drags, it always drags” Mike AiS L*	*“make use of the time” Bert Ais H*
Lack of control	*“My life’s being dictated enough for me already” Sarah Ais L*	*“I thought, I’m not having this.” John AiS H*
Dialysis is lifesaving	*“I mean, either I stick it out or I keel over” Karen AiS L*	*“I feel it has given me my life back.” Pat AiS H*
There is little choice	*“I’ve accepted it there’s no point not“ Matthew AiS L*	*“It’s just something you’ve got to accept isn’t it” John AiS H*
Hope or lack of hope	*“so what have I got to look forward to? “ Mike AiS L*	*“I expect once I get a transplant I’ll feel better again” Julie AiS H*

Table 5.4.2 - Coming to acceptance

Theme	Negative	Positive
Comparisons between old and new life	*“I’m never gonna be able to go and do some stuff that I, you know” Karen AiS L*	*“I still carry on the majority the things I used to do” Linda AiS M*
Comparisons to others	*“I’ve seen a lot of people come and go” Matthew AiS L*	*“there’s always people worse than yourself” John AiS H*
Experiences and understanding of treatment	*“Just turn up here, get needles stuck in you” William AiS M*	*“I think it’s wonderful. I think it is a fantastic modern-day miracle I really do” Pat AiS H*
Physical effects of dialysis	*“Very tired. Yeah, it drains you, yeah it does” Stephen AiS M*	*“It just transforms the way I feel so you know, I think it’s fantastic Pat Ais H*
Practical support	*“he’d do things if I’m desperate” Mike AiS L*	*“I think what made it easier was work, erm, being flexible” Chris AiS H*
Emotional support	*“I’ve got nobody, and it gets to me a lot sometimes” Sarah AiS L*	*“the people that surround us are support aren’t they…they’re there all the time for me” Margaret AiS M*
Supporting others	*“I suppose my life revolves around him, and to some extent, his revolves around me” Janet AiS M*	*“no, I don’t really need any help, but, I manage, I manage on my own” Tony AiS H*

5.5 Triangulation of findings

To understand how the findings related to the cross-sectional study, findings from the two studies were compared. The qualitative analyses were initially conducted without linking to the data so that the analysis was not influenced by acceptance scores or perceptions from the quantitative data. The data from the acceptance of illness scores generally mapped onto the positive and negative mindsets themes and is evident in Table 5.4.1 and Table 5.4.2 however there were some discrepancies where some patients’ descriptions were classed as positive but the acceptance of illness scores were pragmatic or negative. There were also cases where the descriptions of acceptance varied, so a person described some aspects positively and others in a more negative or pragmatic way, however this may be representative of the individual differences within the sample.

It was also useful to consider whether the themes mapped onto the constructs measured in the acceptance of illness questionnaire (Table 5.5.1) to establish whether acceptance measured was reflected in the patients' experiences of acceptance. The questions could be associated with the thematic category and there was some overlap with the sub-themes but the questions were more general so a number of sub-themes could be linked to the question and could be open to patient interpretation. Interestingly some of the questions linked to both what patients had to accept and how they came to acceptance, for example the question “because of my health I miss the things I like to do most” related to the experience (old life/new life) but also acceptance of the lifestyle changes. This suggests that how patients accept dialysis relates to what they have to accept.

Whilst the comparison with the acceptance of illness questionnaire is useful it highlights that acceptance in dialysis patients may be more complex than can be captured in the generic questionnaire and may explain some of the variation between acceptance of illness score and the perspective patients take when talking about acceptance of their illness.

Table 5.5.1 - Comparison of AiS questions and thematic categories

Acceptance of illness question	Thematic category	Sub-theme
I have a hard time adjusting to the limitations of my illness	Accepting the functional aspects	Lifestyle changes
Because of my health, I miss the things I like to do most	Accepting the functional aspects Acceptance from experience	Lifestyle changes/time Old life/new life
My illness makes me feel useless at times	Accepting the functional aspects Accepting the necessity Acceptance from experience	Control no choice
Health problems make me more dependent on others than I want to be	Acceptance from support	Practical support
My illness makes me a burden on my family and friends	Acceptance from support	Practical/emotional support
My health makes me feel inadequate	Accepting the functional aspects Acceptance from experience	Lifestyle changes Comparison to others Dialysis experiences
I will never be self-sufficient enough to make me happy	Accepting the necessity Acceptance from experience	Hope (lack of) Comparison to others
I think people are often uncomfortable being around me because of my illness	Acceptance from experience Acceptance from support	Dialysis experience

5.6 Discussion

This study aimed to understand what acceptance of illness meant to dialysis patients in the UK and how patients reached "acceptance". Taking an inductive approach four key themes were identified, two relating to what patients feel they have to accept and two relating to how patients reach acceptance. Embedded in these were 13 subthemes and the overall "mindset" of patients permeated through the themes. These findings suggest that patients felt that they had to accept dialysis treatment and the associated implications as there is little alternative, however the mindset of patients affected how patients accept these aspects. Similarly, there were key themes related to how patients come to acceptance, through experience and through support. Here how patients viewed the experiences and support were discussed in distinctly different ways, which could be categorised into the "mindset" adopted. When compared to the acceptance of illness measures there was some overlap however the acceptance of illness questions were general and overlapped both how and what patients had to accept. The themes supported some of the themes identified in the systematic review, but the thematic analysis also explored the concept of acceptance in more detail and identified additional aspects of interest.

5.6.1 What acceptance means to dialysis patients

Across all the participants it was evident that they felt that they had to accept dialysis and they were able to identify functional aspects. These key themes relate well to two of the themes identified in the systematic review; 'accepting a new life' and 'realistic expectations'. In the systematic review, accepting a new life was predominantly about coming to accept the impact that dialysis has on patients' lives, which is key in the current study but in addition, the current study highlighted the importance of the impact of time and lack of control.

Accepting the reality of the situation and the themes of valuing life and no choice echoed themes identified in the systematic review and have been extended in the current study, in the systematic review the reality of the situation was explored in terms of valuing life or a feeling of resignation. In the current study, the themes of life and death and no choice were present, but the analysis suggested that these can be viewed in positive, pragmatic or negative ways. In addition, the current study identified that hope was important in acceptance, a suggestion that has been identified in previous literature.

What patients had to accept aligned with the theme of forced adjustment identified in previous research (Rees et al., 2018) however the current study has clarified what patients felt forced to accept by identifying the functional changes that were necessary. The acceptance of the necessity of dialysis had similarities to themes previously identified namely “change in outlook” and “hope vs uncertainty”. However, the current study, whilst supporting the importance of the recognition of mortality, suggests that in acceptance outlook or mindset should not be overlooked in relation to these aspects.

5.6.2 How patients come to acceptance

The current study suggested that patients come to acceptance through experience and through support. Acceptance from experience partially supports the ‘journey to acceptance’ theme identified in the systematic review; however it extends this further by exploring how patients journey and reach acceptance. In Rees et al’s study this related to the change in outlook described.

Support was important both in the systematic review and the study of patients perceptions (Rees et al., 2018), and was also reiterated in this study. However, the support described in the current study is categorised by type of support rather than source of support. Practical support was described as important in acceptance because it was seen as beneficial, reducing the burden of the functional aspects of dialysis. Emotional support was important in helping patients accept these burdens and put the necessity of dialysis into perspective. One aspect of support that did not appear in the current study was religious support, which appeared strongly in the systematic review but was not identified in the current study nor in Rees et al’s study of illness perceptions. This finding is not surprising in the current study because the descriptive data suggested that the participants did not rate religion or belief has important in their lives. The importance of social support in acceptance has been identified in other conditions (Kostova et al., 2014; Risdon et al., 2003) as important in aiding the process of acceptance and this holds true in the findings with dialysis patients, although the cultural variations need to be considered when extending the findings.

5.6.3 Mindset or outlook or perspective

The concept of “mindset” was mentioned by patients and appeared to affect how patients interpreted experiences and how they viewed the impact of dialysis, however there is a lack of clarity about what this means. The terms mindset, outlook and perspective are used at various points to describe how patients interpret situations. In the study by Rees et al mindset related to patients' change in outlook, and often there had been little differentiation between terms. It could be argued that mindset is the thoughts or beliefs which affects a person's outlook and this can in turn affect thoughts, feeling and behaviours. It is suggested that three categories of mindset are evident in the current study; negative, pragmatic and positive, however the use of categories is more functional than exclusive. Throughout the interview patients would not necessarily exclusively represent views from one mindset however there was a tendency to fall somewhere along a continuum from negative to positive. The idea of positive and negative acceptance has previously been proposed (Chan, 2013) and has been supported in the findings from the cross-sectional study (chapter 4) and it could be that mindset as described here is an 'acceptance mindset'.

5.6.4 Appropriate models

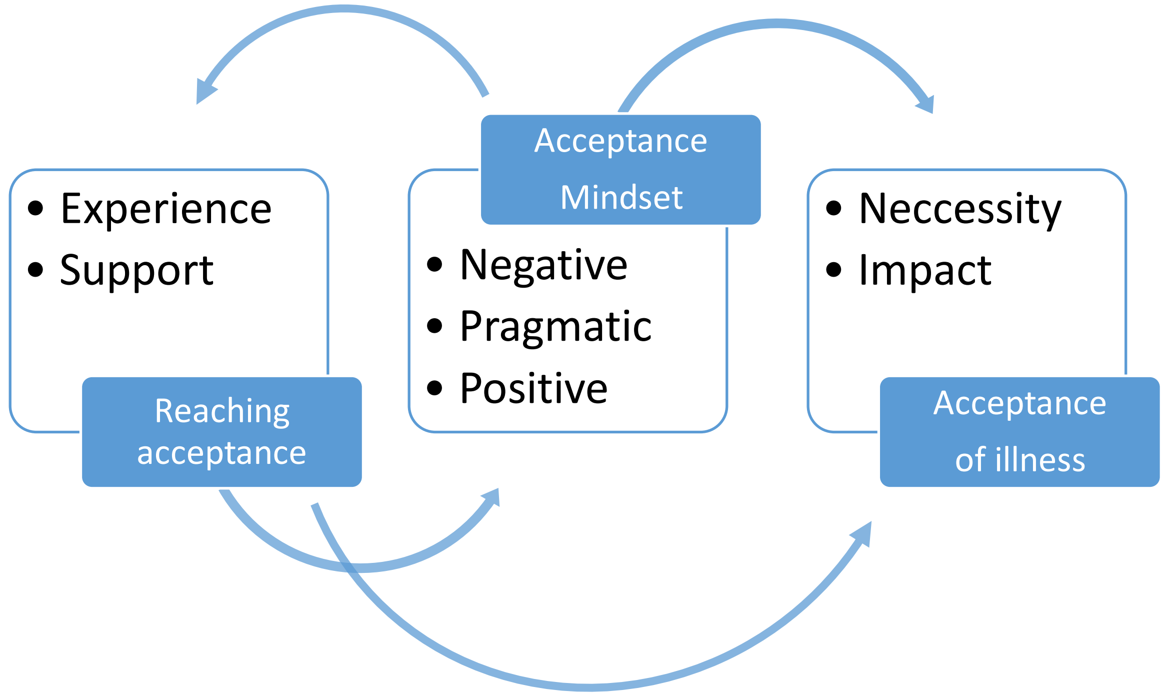
In regard to the current literature, there has been limited focus on acceptance in dialysis patients so the findings of the current study will be discussed in relation to the models previously identified as applicable.

Acceptance has been presented as part of the coping mechanisms (Han et al., 2019) and serves the function of allowing patients to cope with dialysis. The present findings add support to this biopsychosocial approach with acceptance allowing patients to adjust to the physical, social and emotional implications of dialysis and their illness. However, on that interpretation acceptance is part of a coping framework. Instead, Wright and Kirby proposed that an integrative framework provides more insight into the mechanisms related to adjustment in this model, with the idea of internal, external and illness factors featuring in adjustment (Wright & Kirby, 1999). Aspects of the model are apparent in the current findings: 'processing losses' relates to the acceptance of necessity, 'adapting and accommodating illness and treatment' and 'getting back to life' relates to accepting the functional aspects. Acceptance is defined as part of 'adopting a new approach to living and being' which is similar to the current study where acceptance involves having to accept dialysis and associated implications of the illness. The model suggests that adjustment involves internal, external and illness factors which are to some extent identified in the current findings although here patients' outlook or mindset are seen as a factor affecting adjustment whereas in the current findings mindset, is seen to relate to both how patients reach acceptance and how they interpret external and illness factors.

5.6.5 Conceptual model

From the thematic analysis, the concept of mindset was apparent and permeated through the ways that patients reached acceptance and what acceptance meant to them. The findings and themes were detailed in (Figure 5.3 p164)and the theoretical relationships based upon the findings are presented in Figure 5.4. In this interpretation, adopting this approach places mindset as a core concept which has a proposed bidirectional relationship between how dialysis patients reach acceptance and also impacts on how they accept their illness. Patients' current state of acceptance of their illness is shown in this model to be based upon their experiences in reaching acceptance and also their acceptance mindset.

Figure 5.4 - Conceptual model of acceptance



This model is a simplified diagram of the core components identified in the current study and is designed to clarify thinking about acceptance. It adopts a continual adjustment approach however if mindset, experience and support are constant then it would be supposed that acceptance of illness would remain stable.

5.6.6 Strengths and limitations of the study

The current study built upon the systematic review, which identified clear themes relating to acceptance and support, and further develops the findings of research into dialysis perceptions of illness. It benefited from a large sample size which allowed detailed explorations of the themes to be conducted. The mixed method approach of the thesis allowed the acceptance data from the cross-sectional study to be linked to participants to further understand the data. Interviews were transcribed and analysed by more than one researcher which adds validity to the findings.

The study was not without limitations. Firstly, the sample of patients was only obtained from one dialysis unit, which means the findings may not be generalisable. The retrospective categorisation of patients by acceptance of illness score meant that the number of patients classed as low accepters was small, so the sample was more likely to represent patients who felt that they had, at least to some extent, accepted their illness. So whilst the current sample provides insight into acceptance in a general sample of haemodialysis patients, it might have been interesting to have a more detailed understanding of patients' experiences when they were struggling to accept their illness. This might be partially due to the inclusion criteria requiring patients to have been on dialysis for at least 3 months. Following initiation onto dialysis, patients described how it took time to reach acceptance, implying that these early stages are key, so it could be useful to interview patients soon after this initiation.

It is acknowledged that interviewing patients in the dialysis unit whilst they were on dialysis was not ideal however this was participants preferred option and for questionnaires, this approach has previously shown no impact upon the results. Interviewing patients on dialysis meant the impact of social desirability bias could not be ignored. Social desirability bias (Howitt, 2016) could have affected how patients described their experiences, if there was an expectation that you 'just have to get on with it' then participants may have felt they could not describe the difficulties that they had encountered honestly. There was the possibility that medical staff or patients could have overheard patients' responses and as a result their responses may have been more guarded than if the interviews were conducted in another location.

The influence of the researcher in the interviews and analyses could have impacted on some participants' responses and the interpretations. The researcher had previously completed the questionnaires with the patients so therefore there was an element of familiarity which might have affected how patients answered the questions as prior knowledge may have been assumed. The researcher also acknowledges that prior and preceding knowledge of the patients potentially influenced the interview and affected interpretation in the analysis. To minimise this, interviews were transcribed by one researcher and checked by another who had not met the participants, and data coding and extraction was also cross-checked between researchers and supervisors.

5.6.7 Conclusions and implications for thesis

The qualitative study corroborated the findings of the systematic review and expanded upon them by focusing on what acceptance meant to dialysis patients. Through the analysis it became apparent that acceptance is related to process (how patients reached a state of acceptance) and state (what acceptance of illness meant to them).

The findings highlight key aspects in how patients reach acceptance which is of particular interest when the relationship between acceptance and QoL is considered. The conceptual model suggests that acceptance mindset and how patients reach acceptance are modifiable aspects which could be utilised to develop positive acceptance of illness and may confer benefits in QoL.

The results highlight the complexity of acceptance and support the importance of a biopsychosocial approach. They also support the idea of positive and negative acceptance, although these findings suggest that viewing acceptance as a continuum would be a more applicable stance to adopt.

Chapter 6 – Testing the longitudinal impact of acceptance of illness and associated psychological variables on quality of life

6.1 Introduction

This chapter explores the longitudinal impact of acceptance among dialysis patients. The chapter presents the key methodology used in the study (chapter 3 provides detail) before outlining the findings and discussing the results. The study builds upon the findings of the first studies (1 and 2) as reported in Chapter 4 and evaluates the role that acceptance plays in ESRD over time.

The systematic review (chapter 2) highlighted that the study of acceptance in patients with end stage renal disease (ESRD) has predominantly been conducted through cross-sectional approaches. Studies that have adopted a longitudinal approach identified that acceptance was related to progression to dialysis (Chiang et al., 2015) and was protective against negative mood (Rich et al., 1999). The predictive role of acceptance in quality of life among dialysis patients has yet to be fully explored. Acceptance has been demonstrated as a predictor of anxiety and depression at 6 months in a stroke population (Crowley & Andrews, 2018) and changes in acceptance of pain have been shown to predict better mental QoL (Elander et al., 2013), therefore it was conceivable that acceptance for this ESRD population might be linked to changes in QoL. Comprehending longitudinal relationships between acceptance and associated clinical and psychological variables may allow for a more sophisticated understanding of how acceptance might be a modifiable factor which could be targeted by an array of interventions.

The four questions being addressed in this longitudinal study (study 3) were;

- What are the characteristics of the participants at 6-months and 12-months?
- Is the mediation model identified in baseline data present in the 6- and 12-month data?
- Does acceptance change over time in haemodialysis patients?
- Do changes in acceptance of illness and associated psychological and clinical variables predict quality of life at 6 months post-baseline?

6.2 Methodology

6.2.1 Design Summary

This was a longitudinal study with questionnaire data collected at baseline, 6 months and 12 months. The principal analyses were conducted with baseline and 6-month data, supplementary analyses included 12-month data.

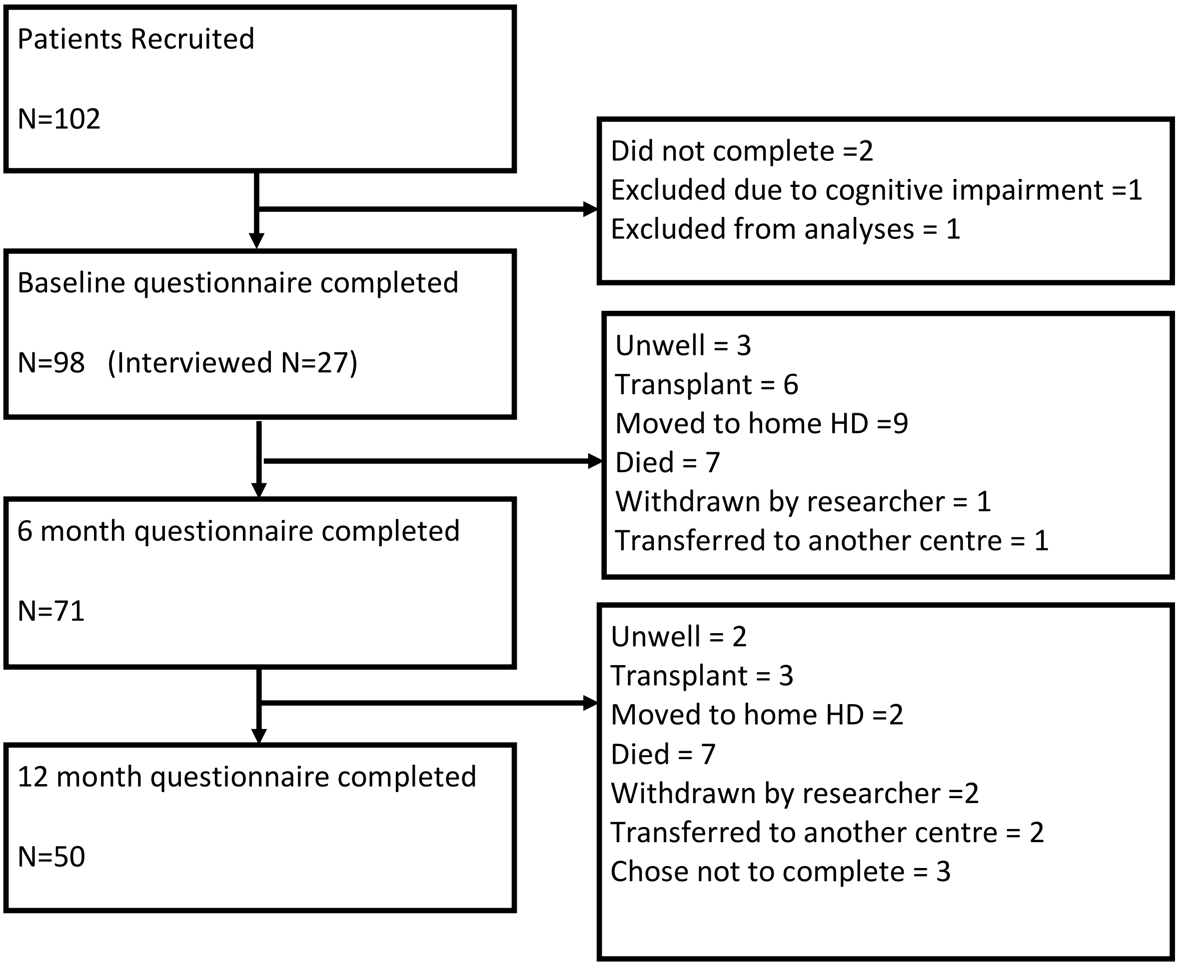
6.2.2 Participants

Questionnaires were distributed to participants whilst they were on dialysis. Participants who were recruited at baseline were approached 6 months after the initial completion of the questionnaire and again at 12 months. 6-month questionnaire data were collected between February 2019 and August 2019, and 12-month data between August 2019 and December 2019.

During follow-up, all eligible participants were approached if they were still patients on the dialysis unit. The decision was made that patients who had changed dialysis modality (HHD, PD or transplant) were not followed up. Whilst these patients might have provided interesting findings relating to acceptance, QoL and dialysis modality, it was anticipated that the numbers would not be sufficient for meaningful analyses (based upon UK renal registry data (Evans et al., 2018)). Inclusion of these participants into the main data set would have potentially influenced final results due to differences in QoL based on modality changes (Bakewell et al., 2002; Boateng & East, 2011; E. A. Brown et al., 2010; Ginieri-Coccossis, Theofilou, Synodinou, Tomaras, & Soldatos, 2008). Mortality data (date of death, cause of death) were collected for patients who died during the follow-up period. Patients who were seriously unwell during the 6 month or 12-month data collection windows were excluded based upon clinical opinion or significant hospital admissions; categorised by current inpatient stay of a duration of over two weeks. Timeline for completion of questionnaires was one week prior to the questionnaire due date and there was one month following for completion. This designated timeline allowed patients with minor illnesses, short admissions or holidays to be retained. Completions at 6 months ranged between 175 to 212 days with the mean time for completion being 187 days after baseline and 76% completing within a week of the 6-month due date. Completions at 12 months ranged between 358 and 392 days with the mean time for completion being 368 days and 72% completing within a week of their due date.

A total of 71 patients completed the 6-month questionnaire which was a retention rate of 72.45%. The main reasons for non-completion at this time point were transferring renal replacement modality (15.31%) and death (7.4%). All patients chose to continue although one was withdrawn by the researcher due to concerns about capacity to consent. For 12-month questionnaires the retention rate was 51% with the main reason for non-completion being death. By 12 months a total of 14.3% of the original participant group had died, 11.2% had moved to home dialysis and 9.2% of patients had received a transplant. From the remaining 64 participants eligible to complete the 12-month questionnaire, only three participants chose not to complete the 12-month questionnaire, although a number were excluded for other reasons including prolonged illness and transferring to another centre. Follow-up rates and reasons for non-completion are presented in Figure 6.1.

Figure 6.1 Recruitment flow chart



6.2.3 Overview of measures and procedures

Procedures followed those outlined in the cross-sectional study (section 4.2); these were repeated at 6 months and 12 months. Participants were reconsented into the study and requested to complete the questionnaire again. The only difference for this questionnaire was the removal of demographic measures which were unlikely to have changed during the prior 6 months, for example, ethnicity and education level. Acceptance and other psychological measures were retained: the acceptance of illness scale, the illness cognitions questionnaire, the COPE, the KDQoL questionnaire, the DASS-21, and the generalised self-efficacy questionnaire. Participants were encouraged to complete the questionnaire via the same method as at baseline however there were instances where participants opted for a different method. For example, reasons given for the change in collection method were predominantly practical with patients being unable to complete the questionnaires independently due to changes in eyesight or fistula location. Six additional patients completed the questionnaire with the researcher and three opted to complete the questionnaire at home rather than independently on dialysis. Collection of the clinical data related to the dialysis session closest to questionnaire completion date and blood tests for the associated session were obtained from clinical records.

6.2.4 Missing Data and outliers

Data were analysed using SPSS (version 26, SPSS Inc, Chicago). The data analysis followed standardised procedures for missing data and outliers outlined in the methodology (section 3.11.7.) and cross-sectional analyses (section 4.3.1.). For participants who did not complete, consideration was given to the use of last observation carried forward (LOCF) as this can maintain power. However, if distributions of observed values at 12 months are unequal then LOCF may be biased (Lachin, 2015) and extended models are more applicable to clinical trials (Mavridis et al., 2019), LOCF was only considered for comparison. Therefore, only participants who completed the questionnaires were included in 6 month and 12-month analyses to examine the longitudinal relationships between variables but consideration to the profile and destination of non-completers is explored in detail.

The missing data were further considered in the longitudinal analysis, and based upon the completion analysis the data was not missing at random, with the majority of missing data at 6 and 12 months being due to either patients changing RRT or patients death. The approach of complete case analysis was deemed to be most appropriate due to the study not being an intervention study nor randomised clinical trial. It is acknowledged that when data are missing not at random there is the risk that there may be an overestimation of benefit however in the current studies the same procedures were followed from baseline through to 12 months and the same core variables were identified as independent predictors across the quality of life variables, even with reduced sample sizes. The options for multiple imputation were considered but for 12 months this was a large proportion of the sample and in such cases it has been suggested that observed data is used but the missing data and limitations considered (Jakobsen, Gluud, Wettersley and Winkel, 2017). Therefore two comparative approaches were used to provide sensitivity analyses, these were last observation carried forward – implying no change over the timeframe - and mean imputation. They provided comparisons which indicated that the core independent predictor variables and mediation effects were evident in these analyses although at reduced significance. For example in the multiple regression to predict MCS at 12 months, acceptance of illness was approaching significant (mean imputation t=1.761, p=0.82, complete case t=1.695 p=0.98) but with the inclusion of depression acceptance reduced further in significance whilst depression was a significant independent predictor (mean imputation t=-2.377, p=0.20, complete case t=-2.636, p=0.012)f

Individual scores were checked for outliers through box blots and through conversion to z-scores and application of the -3.29/3.29 criterion (Field, 2018; Howitt & Cramer, 2017; Tabachnick & Fidell, 2013). Several outliers at 6 months (KDQoL_3, KDQoL_9b , KDQoL_14b, KDQoL_14k, COPE 4, COPE 8, COPE 9, COPE 11, COPE 16, COPE 22, COPE 23, COPE 27, DASS 8 and DASS 15) were checked and found to be true values. The influence of these values was compared to the Z-scores of the relevant subscale. The kidney disease QoL scores and DASS scores item outliers were not reflected in the component scores for their subscales. The COPE scales showed, individual item outliers reflecting the patterns identified in the cross-sectional study with outliers mapping onto the substance abuse subscale and the religion subscale. These results replicated the findings in the cross-sectional study (section 4.3.1) and therefore the management of outliers followed the same processes. Clinical data procedures were in line with those outlined in the cross-sectional studies.

6.2.5 Data analysis conventions

Data analysis conventions were discussed in detail in the cross-sectional study (section 4.3.2); these same conventions (linearity, normal distribution, homoscedasticity/homogeneity of variance and independence) were applied.

6.2.6 Scoring

Scoring for individual scales replicated that applied in the cross-sectional study (section 4.2.5). Change scores were computed by subtracting the baseline value from the 6-month value which results in a positive score indicating an increase over time (Castro-Schilo & Grimm, 2018). Computation of change scores allowed correlations between change scores to be run using either Pearson’s or Spearman's correlations to identify variables related to changes in acceptance. Mortality data on all participants were collected at 12 months and patients were either classed as alive or deceased.

6.2.7 Subscale reliability

Subscale reliability was computed at 6 months and compared with baseline reliability. (Table 6.2.1). The 6-month alphas for kidney disease QoL closely replicated the baseline alphas with the range of difference being between 0.003 (Symptom score) to 0.108 (social support). For the SF-36 subscale, the differences ranged between 0.003 (social functioning) and 0.178 (general health) when compared to the baseline scores. The differences between baseline and published alphas ranged between 0 and 0.079 for one study and between 0.002 and 0.053 for another (Table 6.2.2). The findings support the reliability of the scale and identified no causes for concern.

Table 6.2.1 - Reliability of 6- and 12-month kidney disease targeted scales compared to baseline results

		Baseline			6 months			12 Months		
Kidney disease QoL scales	items	α	mean	SD	α	mean	SD	α	mean	SD
Symptom score	12	.843	73.43	19.28	.840	75.24	18.42	.860	75.17	19.29
Effects of KD	8	.837	62.99	24.66	.817	67.84	22.95	.877	64.69	26.57
Burden of KD	4	.812	39.49	27.55	.909	36.97	31.78	.824	35.25	27.40
Work status	2	.404	38.24	37.77	.333	40.85	33.07	.297	35.00	32.34
Cognitive function	3	.848	76.96	83.33	.787	77.09	20.34	.808	74.53	23.32
Social interaction quality	3	.642	74.21	21.01	.710	71.83	21.22	.778	75.87	24.13
Sexual function	2	.937	59.42	41.53	.921	53.66	39.45	.975	43.00	40.68
Sleep	4	.645	52.46	21.55	.583	54.82	20.18	.660	53.45	22.13
Social support	2	.749	62.74	30.50	.641	70.19	24.55	.672	63.33	30.12
Dialysis encouragement	2	.843	83.09	19.04	.737	84.51	16.96	.828	81.25	20.40
Patient satisfaction	1	NA	76.23	18.06	NA	78.87	18.68	NA	73.00	21.53

Table 6.2.2 - Reliability of 6 and 12 months SF36-scales compared to baseline and published results

		Baseline			6 months			12 months			Published	
SF-36	Items	α	mean	SD	α	mean	SD	α	mean	SD	α[1]	α[2]
Physical function	10	.927	38.06	28.22	.919	39.01	28.66	.926	35.60	27.97	.94	.90
Role physical	4	.828	31.19	37.33	.877	31.34	39.35	.830	26.50	32.11	.88	.93
Pain	2	.857	54.52	30.35	.878	58.20	29.57	.856	53.25	28.72	.89	.88
General health	5	.652	36.56	19.07	.830	38.45	24.52	.661	36.60	22.14	.70	.69
Emotional wellbeing	5	.818	69.44	21.31	.860	68.90	21.61	.808	69.44	21.09	.86	.81
Role emotional	3	.858	61.05	43.12	.905	54.76	45.77	.864	48.67	44.77	.84	.93
Social functioning	2	.774	58.55	29.85	.771	53.70	29.76	.783	54.50	31.01	.85	.76
Energy fatigue	4	.785	37.86	21.95	.801	35.00	21.81	.772	37.20	21.53	.88	.82

Published: [1] (Mingardi et al., 1999) [2](Finkelstein, van Nooten, Wiklund, Trundell, & Cella, 2018)

6.2.8 Analytic approaches

The analyses using the 6- and 12-month data aimed to address four key questions, these are outlined below and evaluations about the associated analyses are provided.

What are the characteristics of the participants at 6-months and 12-months?

The sample size had reduced at both 6 and 12 months therefore the evaluation of the characteristics of the participants were presented and compared. Characteristics of completers were compared with the non-completers to understand whether there were any observed differences.

Is the mediation model identified in baseline data present in the 6- and 12-month data?

To confirm whether the mediation effect of depression on acceptance of illness was present at 6 months, the same mediation model (section 4.4.3.3) was re-run on the 6-month data. Whilst acknowledging that this is a subset of the original sample it would be expected that the mediating effect of depression should still be evident in the 6-month data although significance levels would be expected to be reduced due to sample size.

Does acceptance change over time in haemodialysis patients?

To test whether acceptance changed over time two methods were employed; examining differences between baseline and 6-month data and examining change scores. Differences between baseline and 6-month data were analysed using paired sample t-tests for parametric data and Friedman's test for non-parametric data. However, comparing the differences in group means/rank scores does not allow comparison of individual change therefore change scores were computed for all variables. Pearson's and Spearman's correlations were run to explore relationships between changes in psychological and clinical variables.

Do changes in acceptance of illness and associated psychological and clinical variables predict quality of life at 6 months post baseline?

To test whether acceptance predicted QoL at 6 months three regression models were run, one for each QoL outcome; mental QoL, physical QoL and kidney disease QoL. For these longitudinal regressions, consideration was given to the use of residualised change scores in the regression model as opposed to difference scores however there is debate about which approach is most appropriate. Upon reviewing the literature the most favourable approach would have been to use a latent change score framework (Castro-Schilo & Grimm, 2018) however the sample size was not sufficient to adopt this approach. The two potential alternative approaches to measure change over time involve using change scores (gain scores) to calculate the differences between the original scores or to calculate residualised change scores. Unless assumptions are met the residualised change score approach runs a greater risk of type 1 error (Farmus, Arpin-Cribbie, & Cribbie, 2019) and therefore change (gain scores) were used in the reported regression. However, the results were also compared with regressions run using residualised change scores to confirm whether the gain score findings were still apparent using the residual scores.

Do changes in acceptance of illness predict quality of life at 12 months?

The 6-month regression analysis was rerun with the 12 months data to test whether the longitudinal relationships identified at 6 months were still present after 12 months. The regression models were repeated as run at 6 months and the change score model results reported.

6.3 Results – Study 3

To address the objectives there are four sections to the longitudinal study. The thesis objective addressed by this study was to “compare the influence of psychological factors derived from contrasting theoretical models on patient outcomes”. To address these aims the longitudinal analysis has been split into four questions; What are the characteristics of participants at 6months and 12 months?, Is the mediation effect identified at baseline still present?, does acceptance change over time? and how do changes in acceptance of illness relate to quality of life at 6 months and 12 months?.

6.3.1 Characteristics of the participants at 6-months and 12-months.

6.3.1.1 Completers vs non-completers

The demographic profile of the sample was examined and completers of 6 month questionnaires compared to non-completers (Table 6.3.1). Data for non-completers were separated into 3 sub-groups due to the differences in the identified outcomes; transplant or home dialysis is deemed a favourable outcome whereas or ill health or clearly death is unfavourable. Completers of the 6-month questionnaire were older (median age 67, IQR 22) than the non-completers (median 58, IQR 14).

Table 6.3.1 Demographic characteristics of participants split by 6-month completer status (n=71)

Parameter	Completers	Transplant/ Home HD	Deceased	Other
Gender (male), n (%)	44 (62.0)	11 (73.3)	5 (71.4)	4 (80.0)
Age (years) mean (SD)	63.9 (14.4)	54.7 (13.6)	62.9 (6.6)	61 (10.6)
Ethnicity (white), n (%)	62 (87.3)	13 (86.7)	7 (100.0)	4 (80.0)
Marital status, n (%)				
Married or living with partner	43 (46.4)	9 (60.0)	4 (57.1)	1 (20.0)
Single, divorced or widowed	38 (53.5)	6 (40.0)	3 (42.9)	4 (80.0)
Education level, n (%)				
Secondary education or less	43 (61.4)	8 (53.3)	6 (85.7)	3 (60.0)
Further education beyond GCSE	27 (38.6)	7 (46.7)	1 (14.3)	2 (40.0)
Employment status, n (%)				
Employed full/part-time	13 (18.8)	9 (60.0)	0 (0.0)	0 (0.0)
Retired/not seeking employment	48 (69.6)	5 (33.3)	4 (57.1)	3 (60.0)
Unemployed	8 (11.6)	1 (6.7)	3 (42.9)	1 (20.0)
Cause of Kidney disease				
Diabetes Mellitus	19 (26.8)	1 (6.7)	1 (14.3)	3 (60.0)
Glomerular disease	15 (21.1)	5 (33.3)	1 (14.3)	1 (20.0)
Tubulointerstitial disease	12 (16.9)	3 (20.0)	1 (14.3)	1 (20.0)
Miscellaneous renal disorders	8 (11.3)	2 (13.3)	1 (14.3)	0 (0.0)
Hypertension / Renal vascular disease	7 (9.9)	2 (13.3)	1 (14.3)	0 (0.0)
Other systemic diseases affecting the kidney	6 (8.5)	0 (0.0)	0 (0.0)	0 (0.0)
Familial / hereditary nephropathies	4 (5.6)	2 (13.3)	0 (0.0)	0 (0.0)
Comorbidities				
Diabetes	31 (43.7)	5 (33.3)	2 (28.6)	4 (80.0)
Heart disease	30 (42.3)	4 (26.7)	2 (28.6)	1 (20.0)
Cancer	8 (11.3)	1 (6.7)	1 (14.3)	0 (0.0)
Lung disease	12 (16.9)	4 (26.7)	3 (42.9)	2 (40.0)
Stroke	10 (14.1)	1 (6.7)	1 (14.3)	0 (0.0)
Hypertension	26 (36.6)	8 (53.3)	4 (57.1)	3 (60.0)
Depression	3 (4.2)	1 (6.7)	0 (0.0)	0 (0.0)
Peripheral vascular disease	8 (11.3)	0 (0.0)	1 (14.3)	1 (20.0)
Mean time on RRT (months), mean (SD)	34.0 (32.6)	27.07 (62.6)	86 (104.1)	48.8 (33.4)

Further examination demonstrated that transplant patients and home patients had lower mean age, however the differences between the groups was not significant (Kruskal-Wallis H = 5.683 df= 3 p=0.128). The non-completers subgroup contained a higher proportion of males (74.1%) than the completers (62%) but this difference was not significant.

Appropriate statistical tests compared mean/median differences between the groups for psychological measures at 6 months (Table 6.3.2) and (Table 6.3.3) The only significant difference between the groups at 6 months were anxiety (Kruskal-Wallis H = 9.406 df= 3 p=0.024) and ICQ acceptance (Kruskal-Wallis H = 7.965 df= 3 p=0.047) and at 12 months ICQ acceptance (Kruskal-Wallis H = 13.01 df= 3 p=0.005).

Table 6.3.2 Psychological measures split by 6-month completer status (n=71)

Parameter	Completers	Transplant/ Home HD	Deceased	Other	K-Wallis /*f*	P
Psychological, mean (SD)						
Depression	12.06 (11.52)	8.80 (9.34)	15.14 (13.66)	16.00 (20.30)	.924	.820
Anxiety	10.28 (9.56)	6.53 (5.21)	20.00 (9.52)	13.20 (15.01)	9.406	.024
Stress	11.30 (10.71)	8.80 (7.88)	18.00 (10.39)	14.00 (6.73)	4.259	.235
PQol	32.77 (10.01)	37.87 (10.43)	26.33 (9.41)	32.23 (6.98)	6.309	.098
MQol	47.01 (11.87)	43.63 (11.98)	41.85 (13.04)	49.97 (10.72)	2.060	.560
KDCS	64.95 (15.37)	66.24 (15.89)	57.63 (14.33)	61.97 (16.85)	2.005	.571
Self-efficacy	29.77 (6.80)	31.40 (5.42)	30.00 (4.90)	26.20 (11.32)	.594	.898
Acceptance, mean (SD)						
Ais	24.14 (9.25)	24.15 (9.25)	18.29 (4.86)	19.40 (10.04)	4.836	.184
COPE – Acceptance	6.14 (1.99)	6.53 (1.96)	7.14 (1.21)	5.60 (1.34)	3.287	.349
ICQ - Acceptance	17.13 (3.70)	16.60 (4.11)	21.14 (2.27)	15.40 (7.64)	7.965	.047

Table 6.3.3 Psychological measures split by 12-month completer status (n=50)

Parameter	Completers	Transplant/ Home HD	Deceased	Other	K-Wallis /*f*	P
Psychological, mean (SD)						
Depression	12.78 (11.74)	7.80 (8.92)	10.29 (11.17)	17.08 (15.27)	4.311	.230
Anxiety	10.63 (10.03)	6.70 (4.69)	13.43 (10.57)	13.08 (12.17)	4.143	.246
Stress	11.37 (10.71)	8.10 (7.61)	12.14 (10.80)	16.77 (13.40)	4.051	.256
PQol	33.10 (10.69)	36.52 (10.43)	27.29 (8.76)	32.92 (6.33)	6.248	.100
MQol	48.02 (11.19)	43.88 (12.71)	48.43 (12.90)	40.52 (11.27)	6.162	.104
KDCS	63.69 (15.48)	67.71 (15.05)	67.42 (16.31)	59.17 (14.28)	3.809	.283
Self-efficacy	29.53 (7.31)	31.50 (5.56)	31.93 (4.46)	26.38 (7.15)	4.798	.187
Acceptance, mean (SD)						
Ais	24.25 (9.13)	26.75 (7.06)	22.50 (8.90)	18.69 (9.14)	6.585	.086
COPE – Acceptance	6.26(1.91)	6.65(1.81)	6.21 (2.15)	5.62 (1.85)	3.286	.350
ICQ - Acceptance	17.02 (3.64)	17.00 (4.07)	20.50 (3.01)	15.00 (4.80)	13.01	.005

ICQ acceptance was highest in patients who died in the 6 months prior to 6-month questionnaire completion and these patients were significantly more anxious than the other patients. At 6-month patients who died all rated as high cognitive accepters by median split using the ICQ acceptance score, however all but one were rated low accepters based on acceptance of illness scores.

At 12 months the only significant difference between the completion groups was ICQ acceptance and this was a result of the deceased patients scoring significantly higher than the remaining three groups. The descriptive data suggested that transplant and home patients the better psychological profiles however this was not reflected in the statistical tests.

6.3.1.2 Profile differences in 6-month and 12-month completers

The differences in acceptance score and changes in acceptance were examined based upon demographic characteristics. No significant differences in acceptance were identified based upon gender, marital status, or religious importance (Table 6.3.4). Differences in acceptance scores based on employment status were identified in relation to cognitive acceptance (f(6,64)= 3.15, p = .009) but unlike baseline, differences in illness acceptance scores based on employment were not apparent (f (6,64) = 1.88, p=.097).

Correlations were run to compare scale variables and acceptance measures. At 6 months the number of overnight stays in hospital in the prior 6 months was significantly correlated with acceptance of illness (r=-.255, p=.032) but neither with cognitive nor coping acceptance. The baseline data for, number of prescription medications correlated with illness acceptance (r_s = -.347, p = .004) but this was not observed for cognitive or coping acceptance. Age correlated with cognitive acceptance (r_s=.340, p=.004), at 6 months but no statistical correlation was observed for illness acceptance. At 12 months age, number of hospital stays and number of medications were not correlated with acceptance as measured by either the ICQ, AIS or COPE.

Table 6.3.4 Differences in acceptance of illness score split by individual differences at 6-months (n=71) and 12-months (n=50)

	Acceptance of illness score Mean (SD)				Effects at 6 months			Effects at 12 months		
	Baseline	6 months	12 months		Time	Between subjects	Interaction	Time	Between subjects	Interaction
Gender										
Male	23.938	24.500	24.143	*f=*	.083	.075	1.267	.664	1.303	.172
	(8.983)	(9.237)	(10.291)	*p=*	.774	.785	.264	.419	.193	.680
Female	23.471	23.926	21.905							
	(8.877)	(9.143)	(7.918)							
Marital status, n (%)										
Married or living with a partner	26.838	23.546	24.400	*f=*	.539	.597	**4.45**	.637	.432	.145
	(9.296)	(9.114)	(9.209)	*p=*	.465	.442	**0.39**	.429	.514	.705
Single, divorced or widowed	23.000	23.763	22.344							
	(8.875)	(9.319)	(9.835)							
Education level, n (%)										
Secondary education or less	24.250	23.605	24.000	*f=*	.464	.313	.308	1.703	.053	2.130
	(9.795)	(9.701)	(9.843)	*p=*	.498	.578	.583	.198	.818	.151
Further education beyond GCSE	26.280	24.259	21.647							
	(7.866)	(8.079)	(9.324)							
Employment status, n (%)										
Employed full/part-time	25.417	25.460	23.833	*f=*	.213	.1.764	.594	1.14	1.628	.133
	(11.397)	(10.021)	(10.496)	*p=*	.646	.179	.557	.291	.208	.876
Retired/not seeking employment	25.889	24.125	24.221							
	(8.531)	(8.629)	(8.601)							
Unemployed	20.280	18.250	10.212							
	(7.675)	(7.851)	(8.601)							
Religious importance										
Religion or belief very important	27.333	26.000	21.857	*f=*	.774	.526	.179	2.025	1.892	.880
	(8.370)	(8.301)	(6.201)	p=	.383	.594	.836	.163	.165	.423
Religion or belief in background	24.421	23.750	21.352							
	(9.429)	(10.756)	(9.246)							
Religion or belief does not feature	25.267	23.448	27.800							
	(8.902)	(8.236)	(8.954)							

6.3.1.3 Psychological profile

The DASS-21 scores were converted into categories of normal, mild, moderate, severe and extremely severe (John & Julie, 2003; Lovibond & Lovibond, 1995) with mean scores against categorisations evidenced in (Table 6.3.5). The results infer that patients who had a transplant or moved to HHD during the 6 months after baseline had the best psychological profile at baseline whilst higher levels of depression and anxiety and acceptance scores were evident for those who had died during the time-period. However, due to low numbers in the identified categories, the differences in the results were not significant except for anxiety where a significant difference between mean ranks was noted (Kruskal-Wallis H = 9.406, p =.024). Due to the properties of the scale, results of all three DASS-21 scores are positively skewed towards the normal category, comparable to and as expected from the cross-sectional data.

Table 6.3.5 - Baseline psychological categories of completers and non-completers of the 6-month questionnaire

	Completers	Transplant/ Home HD	RIP	Other
Depression	Mild	Normal	Moderate	Moderate
Anxiety	Moderate	Normal	Extremely severe	Moderate
Stress	Normal	Normal	Mild	Mild
AiS	Moderate	Moderate	Low/Moderate	Moderate

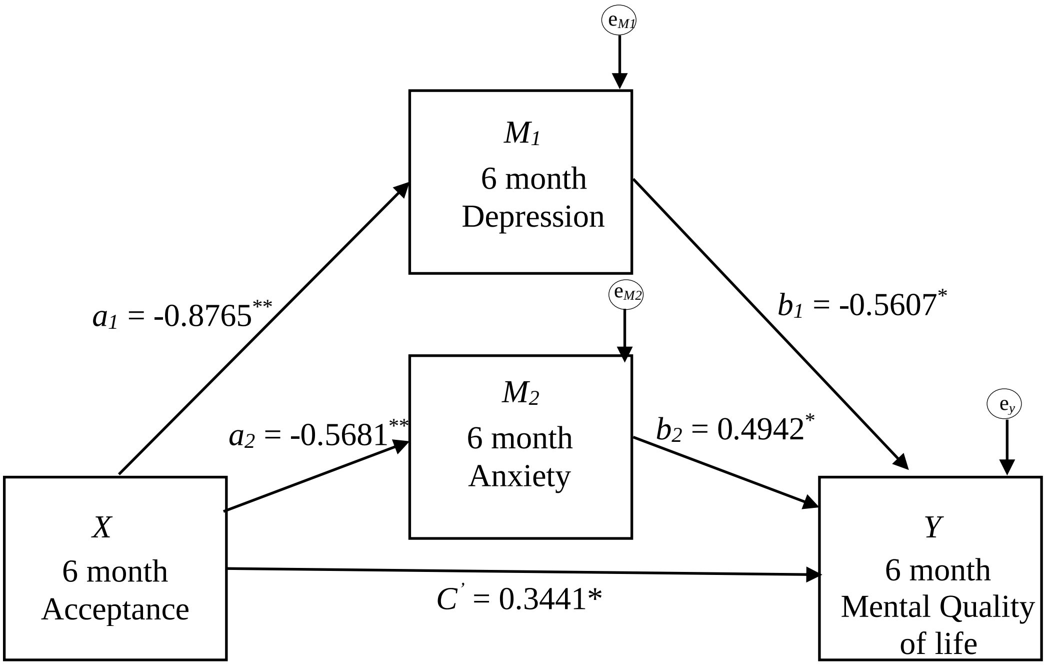
6.3.1.4 Summary of participant characteristics at 6 and 12 months

Most non-completions at 6- and 12-month time-points were due to participants changing modalities having the potential to bias the results. Overall sample characteristics at 6 months were comparable with baseline, with only one exception being initial anxiety; which was higher in patients who had died. However, whilst overall differences at 6-month and 12-month time-points were not significant, the findings seemed to suggest that extremes were potentially lost to follow up. These findings have implications for the overall results as both depression and anxiety have been linked to acceptance at baseline. Whereas at the 12-month time-point the sample is reduced and appears to account for individuals who had presented higher and lower on these measures, potentially impacting the 6- and 12-month findings but also representative of the turnover of patients in dialysis units.

6.3.2 The mediation in the 6- and 12-month data

The cross-sectional analyses were re-run with the 6-month data to confirm whether the relationships identified at baseline were still present. If the relationships were present it would support initial findings although it is acknowledged that any changes in relationship or significance could be a result of the smaller sample size. The regression models included demographic factors of age and employment in block one, clinical variables were entered in block two and acceptance of illness in block 3, additional psychological measures were entered in block 4. For PQoL the model remained significant (*f* (8,59) = 3.335, *p* = 0.003), acceptance remained a significant independent predictor (t = 2.119 p=0.038) however serum albumin and anxiety were no longer significant. For MQoL the model remained significant (*f* (8,59) = 11.062, *p* < 0.001), age (t=2.840, p=.006), depression (t=-3.176, p = .002) anxiety (2.296, p=0.025) and self-efficacy (t=2.299, p=0.025) remained significant independent predictors, acceptance of illness (t=2.208, p=.031) became a significant predictor whilst employment was close to significance. For KDCS the overall model remained significant (*f* (8,59) = 16.777, *p* < 0.001) with age (t=-3.347, p=.01), acceptance of illness (t=3.065, p=.003), depression (t=-2.142, p=.036) and self-efficacy (t=2.554, p=.018) all remaining significant independent predictors whilst employment was no longer significant.

Figure 6.2 **Multiple mediation model demonstrating the indirect effect of acceptance on MQoL at 6 months (n=68).**

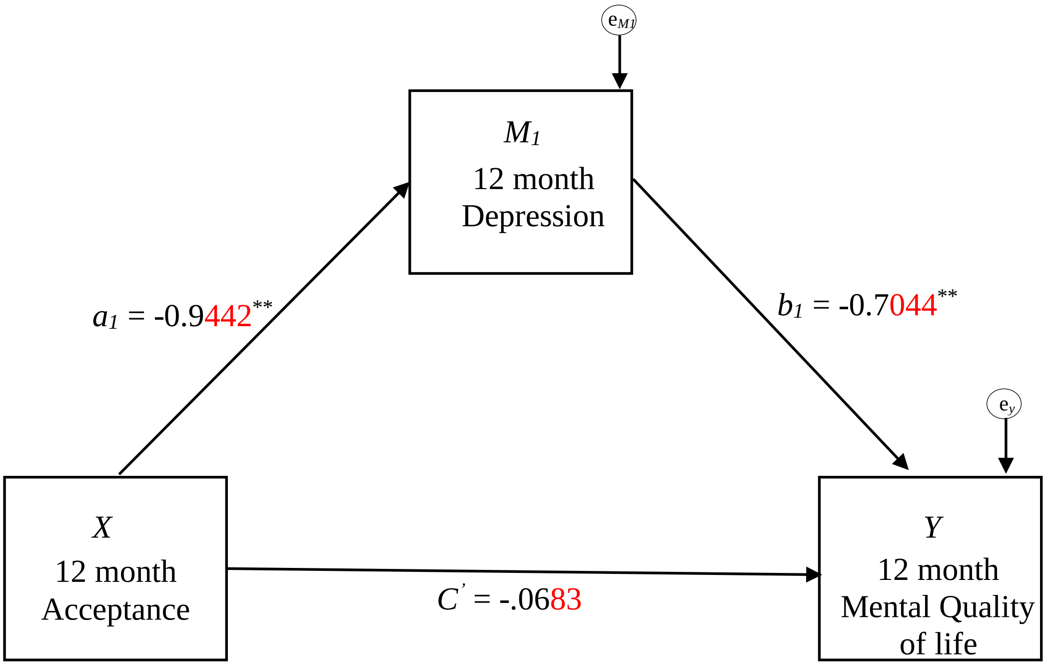


Total effect of X on Y .7228 p<0.001 LLCI .4762 UC .9695
Total Indirect effect .3788 LLCI .1105 ULCI .7177
f Indirect effect of depression .4914 LLCI .2436 ULCI .8099
Indirect effect of anxiety -.2881 LLCI -.5788 ULCI -.0352
** significant at <0.001 significant at * <0.05

For MQoL the sample no longer indicated full mediation between acceptance, depression and MQoL, instead partial mediation was evident but only for depression and anxiety (Figure 6.). The mediation effect of self-efficacy was no longer significant.

At 12 months the PQoL model remained significant (f (9,39) =6.750, p < 0.001), with acceptance (t=3.155, p =0.003) and employment (t=-3.776, p<0.001) significant independent predictors. For MQoL the model remained significant (f (9,39) = 7.861, p < 0.001), age was no longer significant (t=1.663, p=.104) and depression was retained (t=-4.833 p <.001). Acceptance was no longer an independent predictor (t=-.543, p< .591) however a strong mediation effect remained (Figure 6.). Anxiety and self-efficacy were no longer independent predictors of MQoL. For KDCS the overall model remained significant (f (9,39) = 14.227, p < 0.001) with age (t=-2.870, p=.007), acceptance of illness (t=2.303, p=.027), depression(t=-3.804, p<.001) retaining independent significance, self-efficacy was no longer an independent predictor (t=.725, p=.473).

Figure 6.3 - Mediation model demonstrating the indirect effect of acceptance on MQoL at 12 months (n=48)



Total effect of X on Y .5960 p=0.002 LLCI .3006 UC .8915
Total Indirect effect .6643 LLCI .2792 ULCI .9248
** significant at <0.001 significant at * <0.05

6.3.2.1 Summary of mediation model evidence at 6 and 12 months

The key finding was that the core of the mediation model identified at baseline was still present at 6 and 12 months despite reductions in sample size. Some of the variables from baseline had reduced significance; however these were marginally significant variables at baseline. Importantly, acceptance of illness remained a significant predictor of physical QoL and kidney disease QoL, and the effect of acceptance on MQoL was mediated by depression and anxiety at both 6 months and 12 months.

6.3.3 Changes in acceptance over time

To address the question of whether acceptance changed over time analyses were run examining the differences between scores at each time point and analyses were run comparing change scores.

6.3.3.1 Differences between baseline, 6- and 12-month scores

Differences between baseline, 6 months and 12-month scores were compared for the psychological measures. There were no significant differences in total scores in any of the psychological measures between baseline and 6 months and there was only one significant difference between baseline and 12 months; KDCS (Table 6.3.6). Across all acceptance measures there were no significant differences between baseline and 6 months; acceptance of illness (t (70) =.573, p=.568), cognitive acceptance (Z = -.028, p =.978) or coping acceptance (Z = -.020, p =.30). At 12 months there were no significant differences when testing differences between group scores (Table 6.3.6), indicating that group acceptance scores did not change over time.

6.3.3.2 Relationships

All the 6-month psychological measures were significantly correlated with the associated baseline measure (Table 6.3.6). All correlations were strong except for coping acceptance which with an r-value of .350 indicated a moderate correlation. This was replicated at 12 months with all correlations $r>.518$ except for coping acceptance which only demonstrated a moderate correlation with baseline values ($r=.322$, $p<0.05$).

Table 6.3.6 - Differences and correlations between psychological variables at baseline, 6 months (N=71) and 12 months (N=50) variables

	Baseline Mean (SD)	6 month Mean (SD)	12 month Mean (SD)	*f* value	*P*	6 month Correlation	*p*
Acceptance of illness	24.100 (9.157)	23.960 (9.085)	23.300 (9.265)	.347	.708	.689	**.000**
Cognitive acceptance	16.960 (3.653)	16.960 (4.199)	16.320 (3.814)	1.355	.263	.612	**.000**
Coping acceptance	6.225 (1.918)	6.449 (1.684)	6.286 (1.671)	.290	.749	.350	**.003**
Depression	13.040 (11.719)	13.320 (12.326)	13.720 (12.552)	.143	.867	.703	**.000**
Anxiety	10.800 (10.052)	9.760 (8.300)	10.320 (9.982)	.451	.638	.633	**.000**
Stress	11.520 (10.771)	10.720 (10.131)	11.150 (11.151)	.345	.709	.657	**.000**
PQoL	33.200 (10.663)	33.860 (11.173)	31.895 (8.992)	1.210	.303	.755	**.000**
MQoL	47.590 (11.229)	45.560 (12.284)	45.675 (11.363)	1.250	.292	.679	**.000**
KDCS	63.764 (15.608)	65.629 (14.583)	62.341 (15.013)	3.813	**0.025**	.813	**.000**

6.3.3.3 Change scores

Change scores (6 month – baseline) and (12 month – baseline) were calculated and compared for all psychological (Table 6.3.7), clinical (Table 6.3.8) and QoL subscales (Table 6.3.9).

For acceptance of illness, scores indicated that the mean change was -.493 at 6 months and -.800 at 12 months. This suggested minimal changes in acceptance of illness over the 6 months. On closer examination 46 (64.78%) of 71 participants had an acceptance change score of <+/-5 points indicating that for the majority of participants illness acceptance was a stable construct, conversely this suggests that for 35.22% of the sample acceptance did change. Change scores for cognitive acceptance were also normally distributed with a mean of -.0282 (SD 3.427). Similarly, changes in coping acceptance scores were normally distributed with a mean change of .2714 (2.160).

For the other psychological variables mean changes were minimal, with the greatest change being mean change reduction on Mental QoL at 6 months however this would not infer clinical significance (Evans, Margison, & Barkham, 1998).

Table 6.3.7 - Mean changes in psychological variables between baseline and 6 months and 12 months

		6-month changes			12-month changes	
Change in:	N	Mean change	St. deviation	N	Mean change	St. deviation
Acceptance of illness	71	-0.493	7.248	50	-0.800	8.271
Cognitive acceptance	71	-0.028	3.427	50	-0.640	3.141
COPE Acceptance	70	0.271	2.160	49	0.061	2.313
Depression	71	1.099	9.214	50	0.680	9.576
Anxiety	71	-0.113	7.855	50	-0.480	8.949
Stress	71	-0.676	8.665	50	0.000	8.466
Helplessness	71	0.873	3.810	50	0.820	4.202
Self efficacy	71	-0.662	6.031	50	-0.460	4.674
Physical QoL	66	1.088	7.397	47	-1.062	9.157
Mental Qol	66	-2.057	9.693	47	-1.900	10.433
Kidney disease QoL	71	0.338	9.089	50	-1.378	8.027

Table 6.3.8 - Mean changes in clinical variables between baseline and 6 months and 12 months

			6 months		12 months	
Change in:	N	Mean change	St. deviation	N	Mean change	St. deviation
KtV	69	0.001	0.241	49	0.038	0.234
Na	71	-1.056	3.545	50	-1.080	3.282
K	71	0.086	0.822	50	-0.058	0.699
Bic	71	0.366	2.904	50	1.080	3.089
Urea	71	0.329	6.283	50	-1.176	6.431
Create	71	16.380	181.340	50	-0.340	205.877
eGFR	71	-0.197	2.422	50	0.143	3.083
HBA1C	16	8.125	20.539	12	3.167	19.743
Ca	71	-0.013	0.192	50	-0.023	0.213
P04	71	-0.016	0.668	50	0.042	0.674
Alb	68	-0.647	3.928	50	-0.720	4.945
PTH	71	23.992	184.679	50	23.020	214.059
Ferritin	71	97.141	478.773	50	85.500	431.895
Hb	71	1.296	16.632	50	-1.560	20.048

For clinical variables the mean change scores reflected the differences in units of measurement with most variability in the higher scoring variables. For the clinical variables, following discussion with the clinical team, none of the observed variations were identified as being of concern.

With changes in QoL the mean change score values are comparable across the subscales due to the standardisation with scoring. As a result, subscales with the greatest changes could be identified. Interestingly work-status aspect of QoL showed the greatest increase whilst the role – emotional showed the greatest with the exception of sexual functioning, which showed a slightly higher decrease but these items were only answered by a smaller sample of participants.

Table 6.3.9 - Mean changes in QoL subscales between baseline and 6 months and baseline and 12 months

	6 months			12 months		
Change in:	N	Mean change	St. deviation		Mean change	St. deviation
Symptom score	70	1.591	13.900	49	2.125	15.068
Effects of kidney disease	71	1.510	15.977	50	0.252	16.370
Burden of kidney disease	71	-5.458	20.861	50	-6.000	23.588
Work status	71	7.747	26.251	50	5.000	29.014
Cognitive function	71	-0.282	14.184	50	-2.800	15.184
Social interaction quality	71	-2.911	18.161	50	1.867	17.407
Sexual function	36	-8.681	24.608	24	-15.625	29.775
Sleep	70	-0.274	15.997	50	0.367	16.688
Social support	71	5.164	25.911	50	-3.000	26.872
Dialysis encouragement	71	0.176	19.876	50	-2.750	23.185
Patient satisfaction	71	1.409	18.633	50	-3.667	25.263
Physical function	71	3.599	22.797	50	-1.944	28.209
Role physical	70	-0.714	35.091	49	-4.592	33.336
Pain	71	2.218	23.047	50	-2.550	26.344
General health	71	0.986	16.553	50	-1.800	16.926
Emotional wellbeing	71	-1.014	14.685	50	-0.240	14.238
Role emotional	68	-8.333	46.565	48	-15.972	48.128
Social functioning	71	-5.458	27.608	50	-7.250	27.559
Energy fatigue	71	-3.169	17.428	50	-1.800	16.468

6.3.3.4 Relationships between change scores at 6 months

The above analyses have indicated that through examining both differences and change scores, for a large proportion (64.78%) of dialysis patient's acceptance remained stable. However, it was important to understand the factors and processes associated with changes in acceptance because these may be targets for acceptance-based interventions. Changes in illness acceptance were correlated with age (r=-.319, p = 0.007), changes in acceptance were related to age with younger patients showing more increases in acceptance and older more decreases. Changes in acceptance were not associated with length of time on dialysis (r=-.061, p =.620). There were no significant demographic correlations with either change in cognitive or coping acceptance.

Relationships between changes in illness acceptance, cognitive and coping acceptance and clinical measures (Kt/V, sodium, potassium, Bic, Urea, creatinine, eGFR, HBA1C, Calcium, phosphate, Albumin, PTH, Ferritin and HB) were tested with appropriate correlations. Out of 42 potential correlations, only one significant relationship between acceptance measures and clinical measures was identified; changes in coping acceptance was correlated with changes in calcium (r=-.377, p = .001). Additional psychological measures (Depression, anxiety, stress, self-efficacy, PQoL, MQoL, and KDCS) were compared with clinical measures. Out of 98 potential relationships, there were four significant correlations identified, these were all correlations with changes in PQoL. Changes in PQoL were significantly correlated with changes in urea (r=.296, p=0.016), creatinine (r=.256, p=0.38), HBA1C (r=-.544, p=0.036) and P04 (r=.278, p=0.024).

Relationships between changes in illness acceptance and changes in psychological measures were examined through appropriate correlations (Table 6.3.10). Out of the three acceptance measures, changes in acceptance of illness reported the most significant correlations and relationships were identified with changes in depression, anxiety, stress, MQoL, KDCS and self-efficacy. Change in cognitive acceptance was only correlated with depression and stress and changes in coping acceptance showed no significant correlations with the psychological measures.

To further understand changes in components of MQoL and KDCS the subscale change scores were correlated with the acceptance change scores and depression (Table 6.3.11 and Table 6.3.12). Depression was included in these analyses due to the strength of the correlations and the associations identified in the cross-sectional analyses (sections 4.4.1.1 and 4.4.3.3). Changes in acceptance were significantly correlated with changes in the emotional wellbeing, social functioning and energy fatigue subscales of the MQoL, the same subscale changes were correlated with changes in depression. Changes in acceptance of illness were related to changes in physical functioning, pain and general health but there were no associations with depression. Although the findings showed no significant relationships between overall changes in PQoL and acceptance of illness between acceptance of illness and with components of PQOL were observed.

For kidney disease-specific QoL components the only overlap in correlations between acceptance and depression was with effects of kidney disease. Changes in depression and kidney disease effects were negatively correlated whilst changes in acceptance and kidney disease effects were positively correlated, indicating that increases in acceptance related to improved QoL related to the effects of kidney disease, however, increases in depression were related to a reduction in QoL in relation to kidney disease effects.

6.3.3.5 Summary of acceptance over time

The analyses of acceptance over time indicated that for the majority of haemodialysis patient's acceptance did not differ significantly between baseline, 6 months and 12 months, potentially supporting the suggestion that acceptance is a state reached. However, on closer examination of the change scores there were relationships identified between changes in acceptance and psychological but not clinical variables. The influences of these changes on QoL were explored further in the regression analyses.

Table 6.3.10 - Correlations of change scores between psychological measures at 6-months

	Cognitive acceptance	Coping acceptance	Depression	Anxiety	Stress	PQoL	MQoL	KDCS	Self-efficacy
Acceptance of illness	**.284***	0.12	**-.414****	**-.328****	**-.297***	-.047	**.300***	**.390****	**.302***
Cognitive acceptance		.132	**-.241***	-.218	**-.264***	.079	-.027	.207	.173
Coping acceptance			-.007	.056	.101	-.174	.039	.042	-.106
Depression				**.681****	**.754****	.083	**-.313***	**-.381****	-.075
Anxiety					**.630****	-.158	-.050	**-.246***	-.173
Stress						-.043	-.082	-.213	-.103
PQoL							**-.447****	-.025	.179
MQoL								**.428****	.158
KDCS									**.288***

* correlations significant at p<.05 ** correlations significant at p<.001

Table 6.3.11 - Correlations between changes in acceptance measures and kidney disease QoL sub-scales at 6-months

	Change in										
	Symptoms	Effects of KD	KD burden	Work status	Cognitive function	Social interaction quality	Sexual function	Sleep	Social support	Dialysis encouragement	Patient Satisfaction
Acceptance of illness	.205	**.255***	**.303***	**.261***	.170	.22	-.089	-.049	.196	.130	.044
Cognitive acceptance	.13	**.244***	.201	-.037	.102	.143	-.126	-.015	.063	.186	-.037
Coping acceptance	-.17	-.077	**-.263***	-.109	-.191	-.033	.157	.124	.015	-.139	-.002
Depression	**-.263***	**-.309***	-.206	-.048	**-.340****	-.225	-.038	-.036	-.144	-.083	-.048

* correlations significant at p<.05 ** correlations significant at p<.001

Table 6.3.12 - Correlations between changes in acceptance and changes in MQoL and PQoL sub-scales at 6-months

	Changes in							
	Physical function	Role physical	Pain	General health	Emotional wellbeing	Role emotional	Social functioning	Energy fatigue
Acceptance of illness	**.283***	.091	**.310****	**.273***	**.426****	.033	**.407****	**.369****
Cognitive acceptance	.170	.063	-.043	.153	.163	.003	.155	.071
Coping acceptance	-.028	-.026	-.158	-.233	.018	.061	.017	.091
Depression	-.214	-.078	-.110	-.144	**-.433****	-.154	**-.361****	**-.391****

* correlations significant at p<.05 ** correlations significant at p<.001

6.3.4 Changes in acceptance and 6-month QoL

The impact of illness acceptance on quality of life at 6 months was evaluated using linear regression models. The aim was to understand how changes in psychological and clinical variables predicted 6-month QoL scores. As with the baseline analyses, three regression analyses were conducted; each focusing on different 6-month QoL scores as the outcome (PCS, MCS, KDCS). Variables were entered into the model in four blocks. Block 1 adjusted for potential characteristics (age, employment, length of time on dialysis and simple comorbidity score) and the respective baseline QoL score. As with earlier analyses (section 4.4.3.3), income status was omitted due to insufficient completion for this item. Block 2 added the change scores for serum albumin, which was included due to potential theoretic links and correlations identified between variables supported their relevance (section 3.11.6). Acceptance of illness was included in block 3 via the enter method and block 4 contained the additional psychological measures. These were depression, anxiety, and self-efficacy and were included via the enter method. Statistical significance level was assumed at $p < .05$. Durbin Watson values and ViF values all fell within acceptable ranges.

6.3.4.1 Physical Quality of life

The regression analyses indicated that potential covariates accounted for a small proportion of variance in physical quality of life (PQoL) but with the inclusion of baseline PQoL 61.9% of the variance in the model was accounted for. When change in serum albumin was added to the model, the variance accounted for increased to 62.8%. Change in acceptance of illness was entered into the model through but only increased the variance to 64.2% and anxiety increased this further to 66.3%. The regression model summary scores are presented in Table 6.3.13.

With the demographic differences and baseline PQoL controlled for in the model, the overall acceptance model for physical QoL was significant ($f\,(8,54) = 13.261$, $p < 0.001$) with large effect ($f^2 = 1.967$). Model values were in acceptable ranges (VIF 1.076 to 1.882, residuals were normally distributed, and Durbin-Watson was 2.292. In addition to baseline PQoL the model identified no other significant predictors of PQoL although change in AiS (t=-1.786, p=.080) and change in anxiety (t=-1.840, p =.071) were approaching significance.

6.3.4.2 Mental QoL

The regression analyses indicated that identified covariates accounted for a small proportion of variance in mental quality of life (MQoL) but with the inclusion of baseline MQoL 48.5% of the variance in the model was accounted for. When change in serum albumin was added the variance accounted for only increased by 0.01%. Change in acceptance of illness score was entered into the model through the enter method and increased the variance to 55.0%,and the addition of depression took the model to 58.1%. The regression model summary scores are presented in Table 6.3.13.

Accounting for the demographic differences and baseline MQoL, the overall acceptance model for mental QoL was significant (f (8,54) = 9.342, $p < 0.001$) with large effect (f^2 = 1.387). Model values were in acceptable ranges (VIF 1.083 to 2.238), residuals were normally distributed, and Durbin-Watson was 1.643. The model identified two significant independent predictors of 6-month mental QoL; baseline MQoL and change in acceptance of illness.

6.3.4.3 Kidney disease QoL

The regression analyses indicated that demographic differences accounted for a small proportion of variance in the kidney disease component score (KDCS) but with the inclusion of baseline KDCS 67.5% of the variance in the model was accounted for. When change in serum albumin was added this increased the variance by 0.01%. Change of acceptance of illness score was entered into the model and increased the variance to 73.3% and the inclusion of depression meant the overall model accounted for 75.2% of the variance. The regression model summary scores are presented in Table 6.3.13.

Accounting for the demographic differences and baseline MQoL, the overall acceptance model for kidney disease QoL was significant (f (8, 54) = 22.418, $p < 0.001$) with large effect (f^2 = 3.032). Model values were in acceptable ranges (VIF 1.104 to 2.240), residuals were normally distributed and Durbin-Watson was 1.784. The model identified three significant independent predictors of 6-month kidney disease QoL; baseline KDCS, change in acceptance of illness and change in depression.

Table 6.3.13 - 6-month regression model summary score values for acceptance of illness and associated psychological variables on quality of life measures

Model		Unstandardised Beta	Standard Error	Standard Beta	t	p_value
Physical Component Score						
1	Age	.113	.083	.143	1.370	.176
	Employment	-1.305	.644	-.220	-2.027	**.047**
	No. of conditions	.483	.528	.078	.916	.363
	Time on Dialysis	-.038	.027	-.122	-1.416	.162
	PCS	.741	.093	.694	7.987	**.000**
2	Age	.103	.083	.131	1.251	.216
	Employment	-1.111	.662	-.187	-1.678	.099
	No. of conditions	.495	.526	.080	.942	.350
	Time on Dialysis	-.037	.027	-.118	-1.376	.174
	PCS	.758	.094	.710	8.099	**.000**
	Change Serum Albumin	.271	.231	.100	1.174	.245
3	Age	.092	.082	.116	1.114	.270
	Employment	-1.089	.656	-.183	-1.660	.103
	No. of conditions	.468	.521	.075	.897	.374
	Time on Dialysis	-.042	.027	-.134	-1.567	.123
	PCS	.761	.093	.713	8.209	**.000**
	Change Serum Albumin	.292	.229	.107	1.272	.209
	Change in AIS	-.221	.154	-.119	-1.436	.157
4	Age	.123	.082	.156	1.495	.141
	Employment	-1.181	.644	-.199	-1.833	.072
	No. of conditions	.472	.510	.076	.925	.359
	Time on Dialysis	-.045	.026	-.142	-1.687	.097
	PCS	.782	.091	.732	8.547	**.000**
	Change Serum Albumin	.327	.225	.120	1.450	.153
	Change in AIS	-.273	.153	-.147	-1.786	.080
	Change in Anxiety	-.241	.131	-.154	-1.840	.071
Mental Component score						
1	Age	.185	.129	.202	1.434	.157
	Employment	-.841	.868	-.122	-.969	.337
	No. of conditions	-.713	.710	-.099	-1.003	.320
	Time on Dialysis	-.010	.036	-.027	-.268	.790
	MCS	.627	.116	.601	5.406	**.000**
2	Age	.179	.131	.196	1.371	.176
	Employment	-.770	.900	-.112	-.856	.396
	No. of conditions	-.711	.716	-.098	-.993	.325
	Time on Dialysis	-.009	.037	-.026	-.256	.799
	MCS	.631	.118	.604	5.370	**.000**
	Change Serum Albumin	.105	.313	.033	.336	.738
3	Age	.202	.124	.221	1.636	.108
	Employment	-.785	.849	-.114	-.924	.359
	No. of conditions	-.638	.676	-.088	-.944	.349
	Time on Dialysis	.004	.035	.012	.120	.905
	MCS	.641	.111	.614	5.780	**.000**
	Change Serum Albumin	.059	.296	.019	.200	.842
	AIS	.561	.200	.261	2.812	**.007**
4	Age	.214	.121	.234	1.774	.082
	Employment	-.913	.830	-.132	-1.100	.276
	No. of conditions	-.493	.663	-.068	-.744	.460
	Time on Dialysis	.003	.034	.008	.088	.930
	MCS	.640	.108	.614	5.923	**.000**
	Change Serum Albumin	.152	.292	.048	.519	.606
	Change in AIS	.427	.206	.198	2.074	**.043**
	Change in Depression	-.286	.145	-.189	-1.973	.054

Kidney disease Component Score						
1	Age	.109	.113	.103	.966	.338
	Employment	.112	.803	.014	.140	.890
	No. of conditions	.203	.596	.026	.341	.734
	Time on Dialysis	-.019	.032	-.045	-.593	.555
	KDCS	.715	.081	.775	8.879	**.000**
2	Age	.102	.115	.096	.890	.377
	Employment	.216	.836	.027	.258	.797
	No. of conditions	.221	.600	.028	.369	.714
	Time on Dialysis	-.019	.032	-.045	-.584	.561
	KDCS	.721	.082	.781	8.801	**.000**
	Change Serum Albumin	.134	.278	.037	.482	.632
3	Age	.141	.105	.133	1.337	.186
	Employment	.156	.765	.019	.204	.839
	No. of conditions	.217	.549	.028	.395	.694
	Time on Dialysis	-.008	.029	-.019	-.275	.784
	KDCS	.772	.076	.837	10.125	**.000**
	Change Serum Albumin	.044	.256	.012	.171	.865
	Change in AIS	.521	.145	.253	3.592	**.001**
4	Age	.154	.103	.146	1.501	.139
	Employment	.057	.745	.007	.076	.939
	No. of conditions	.320	.536	.041	.597	.553
	Time on Dialysis	-.013	.029	-.031	-.457	.650
	KDCS	.769	.074	.834	10.379	**.000**
	Change Serum Albumin	.082	.249	.022	.328	.744
	Change in AIS	.373	.157	.182	2.382	**.020**
	Change in Depression	-.241	.113	-.157	-2.136	**.037**

6.3.5 Changes in acceptance and 12-month QoL

6.3.5.1 Physical QoL

The regression analyses indicated that the identified covariates accounted for a small proportion of variance in physical quality of life but with the inclusion of baseline PQoL 50.6% of the variance in the model was accounted for. When change in serum albumin was added this increased the variance accounted for to 54.8%. Change in acceptance of illness was entered into the model and change the variance accounted for to 56.4% and change in anxiety resulted in 58.2% of variance being accounted for by the model. The regression model summary scores are presented in Table 6.3.14**.**.

With the demographic differences and baseline PQoL controlled for in the model, the overall acceptance model for physical QoL was significant ($f\,(8,37) = 6.443$, $p < 0.001$) with large effect ($f^2 = 1.392$). Model values were in acceptable ranges (VIF 1.074 to 1.757), residuals were normally distributed, and Durbin-Watson was 1.925. In addition to baseline PQoL the model identified two significant independent predictors of 12-month physical QoL;

change in serum albumin and employment. Change in acceptance of illness was not significant but at p =0.554 it but did increase the variance accounted for by the model.

6.3.5.2 Mental QoL

The regression analyses indicated that the identified covariates accounted for a small proportion of variance in mental quality of life but with the inclusion of baseline MQoL 36.4% of the variance in the model was accounted for. serum albumin was added this increased the variance slightly to 37.6% . Change in acceptance of illness score was entered into the model and increased the variance to 41.9%. Change in depression increased the variance accounted for to 51.1%The regression model summary scores are presented in Table 6.3.14

With the demographic differences and baseline MQoL controlled for in the model, the overall acceptance model for physical QoL was significant ($f\,(8,37) = 4.838$, $p < 0.001$) with large effect ($f^2 = 1.045$). Model values were in acceptable ranges (VIF 1.094 to 2.177), residuals were normally distributed, and Durbin-Watson was 2.084. In addition to baseline MQoL the model identified one significant independent predictor of 12-month mental QoL; change in depression. Change in acceptance was approaching significance in block 3 at p=0.98 however the inclusion of depression in block 4 resulted this reducing to p=.492.

6.3.5.3 Kidney disease QoL

The regression analyses indicated that identified accounted for a small proportion of variance in KDCS but with the inclusion of baseline KDCS 75.8% of the variance in the model was accounted for. When serum albumin was added this increased the variance to 76.0%. Change of acceptance of illness score was entered into the model and increased the variance to 82.0% whilst the addition of change in depression increased the variance to 84.2%. The regression model summary scores are presented in Table 6.3.4.

Accounting for the demographic differences and baseline MQoL, the overall acceptance model for kidney disease QoL was significant ($f\,(8,40) = 26.681$, $p < 0.001$) with large effect ($f^2 = 5.329$). Model values were in acceptable ranges (VIF 1.038 to 2.283), residuals were normally distributed, and Durbin-Watson was 2.224. The model identified four significant independent predictors of 12-month kidney disease QoL; baseline KDCS and change in acceptance of illness, change in depression and age.

Table 6.3.14 - 12-month regression model summary score values for acceptance of illness and associated psychological variables on quality of life measures

Model		Unstandardised Beta	Standard Error	Standard Beta	t	p_value
Physical Component Score						
1	Age	-2.193	.748	-.413	-2.931	**.006**
	Employment	.427	.786	.062	.543	.590
	No. of conditions	.032	.033	.112	.971	.337
	Time on Dialysis	.493	.101	.561	4.890	**.000**
	PCS	-2.193	.748	-.413	-2.931	**.006**
2	Age	.099	.084	.156	1.179	.246
	Employment	-2.342	.729	-.441	-3.211	**.003**
	No. of conditions	.194	.772	.028	.251	.803
	Time on Dialysis	.035	.032	.122	1.087	.284
	PCS	.491	.098	.559	5.021	**.000**
	Change Serum Albumin	.390	.206	.209	1.893	**.066**
3	Age	.133	.088	.211	1.512	.139
	Employment	-2.502	.738	-.471	-3.393	**.002**
	No. of conditions	.030	.779	.004	.039	.969
	Time on Dialysis	.038	.032	.131	1.177	.246
	PCS	.488	.097	.556	5.026	**.000**
	Change Serum Albumin	.387	.205	.207	1.889	.067
	Change in AIS	.172	.144	.137	1.197	.239
4	Age	.153	.089	.243	1.722	.093
	Employment	-2.662	.743	-.501	-3.582	**.001**
	No. of conditions	.201	.786	.029	.255	.800
	Time on Dialysis	.039	.032	.134	1.206	.235
	PCS	.479	.097	.545	4.949	**.000**
	Change Serum Albumin	.428	.206	.229	2.076	**.045**
	Change in AIS	.093	.156	.074	.597	.554
	Change in Anxiety	-.161	.129	-.156	-1.252	.219
Mental Component score						
1	Age	.124	.133	.163	.933	.356
	Employment	.320	1.083	.050	.296	.769
	No. of conditions	-.629	1.083	-.075	-.581	.565
	Time on Dialysis	-.019	.046	-.055	-.420	.677
	MCS	.534	.145	.534	3.691	**.001**
2	Age	.114	.134	.149	.851	.400
	Employment	.295	1.087	.046	.272	.787
	No. of conditions	-.788	1.103	-.094	-.714	.479
	Time on Dialysis	-.019	.046	-.053	-.404	.689
	MCS	.559	.148	.558	3.770	**.001**
	Change Serum Albumin	.251	.300	.110	.836	.408
3	Age	.206	.142	.269	1.450	.155
	Employment	-.157	1.095	-.024	-.143	.887
	No. of conditions	-1.087	1.092	-.130	-.996	.326
	Time on Dialysis	-.011	.046	-.030	-.233	.817
	MCS	.507	.148	.507	3.428	**.001**
	Change Serum Albumin	.224	.293	.099	.763	.450
	AIS	.348	.206	.229	1.695	.098
4	Age	.242	.133	.317	1.828	.076
	Employment	-.549	1.029	-.085	-.533	.597
	No. of conditions	-.844	1.020	-.101	-.828	.413
	Time on Dialysis	.007	.043	.019	.157	.876
	MCS	.503	.138	.503	3.656	**.001**
	Change Serum Albumin	.212	.273	.094	.779	.441
	Change in AIS	.143	.206	.094	.695	.492
	Change in Depression	-.409	.155	-.344	-2.636	**.012**

Kidney disease Component Score						
1	Age	.033	.109	.032	.307	.761
	Employment	.175	.880	.020	.198	.844
	No. of conditions	-.098	.846	-.009	-.116	.909
	Time on Dialysis	.023	.035	.050	.657	.515
	KDCS	.835	.085	.860	9.834	**.000**
2	Age	.037	.110	.036	.336	.738
	Employment	.198	.888	.023	.223	.824
	No. of conditions	-.037	.858	-.003	-.044	.965
	Time on Dialysis	.023	.036	.050	.647	.521
	KDCS	.832	.086	.857	9.712	**.000**
	Change Serum Albumin	-.140	.236	-.046	-.593	.556
3	Age	.168	.103	.161	1.635	.110
	Employment	-.495	.801	-.056	-.618	.540
	No. of conditions	-.897	.788	-.082	-1.138	.262
	Time on Dialysis	.034	.031	.074	1.091	.281
	KDCS	.809	.075	.834	10.733	**.000**
	Change Serum Albumin	-.150	.207	-.049	-.724	.473
	Change in AIS	.505	.137	.272	3.686	**.001**
4	Age	.208	.099	.200	2.109	**.041**
	Employment	-.861	.774	-.098	-1.112	.273
	No. of conditions	-.815	.747	-.074	-1.091	.282
	Time on Dialysis	.047	.030	.101	1.543	.131
	KDCS	.793	.072	.818	11.066	**.000**
	Change Serum Albumin	-.140	.196	-.046	-.714	.480
	Change in AIS	.364	.142	.196	2.556	**.015**
	Change in Depression	-.278	.116	-.177	-2.390	**.022**

6.4 Discussion

The discussion evaluates the impact of the longitudinal data. It discusses the relationships identified in the results and how they relate to existing literature and findings from the cross-sectional and review studies.

6.4.1 Confirmation of baseline findings

The current study was an opportunity to re-test the models identified in the baseline analyses. In doing so the core components of the models replicated those evident in the initial analysis. For physical QoL, acceptance remained a significant independent predictor; serum albumin and anxiety lost significance. For mental QoL relationships closely mirrored those identified at baseline with depression, anxiety and self-efficacy being retained as significant predictors but in addition at 6 months acceptance was a significant predictor. For kidney disease QoL the model was very similar with only employment losing status as an independent predictor. These minor changes to the predictors were evident where levels of significance were marginal; therefore the reduction in sample size at 6 months may have been influential. This is particularly important when the characteristics of the 6 months non-completers are considered.

The 6-month non-completions were mainly attributable to the death of patients or the change of RRT (home or transplant) and descriptive data suggested that there may be differences in these samples, for example, the deceased patients had significantly higher anxiety at baseline. Whilst the non-completer data at 6 months was based upon small numbers and is therefore difficult to generalise it is conceivable that the sample retained at 6 months has lost patients that represented higher and lower scores in certain domains. This is of particular interest as the qualitative study and previous research highlighted the importance of hope in acceptance (Boone, Roessler, & Cooper, 1978; Zawadzka & Byrczek, 2012) and illness perceptions (Rees et al., 2018). The qualitative study found patients who had hope of transplant or changing modality may be more accepting of illness due to viewing the acceptance as a temporary state. Patients who have changed modality or received a transplant would have been aware of this potential at completion of the baseline questionnaire. The study also highlighted that physical feeling and low physical functioning were key aspects of acceptance. Decline in physical QoL in prevalent dialysis patients has been well reported (Findlay & Mark, 2017; van Loon, Bots, et al., 2017; van Loon, Hamaker, et al., 2017) therefore if participants who died before 6 months had been experiencing physical decline then this potentially impacted the baseline acceptance scores.

As with baseline results, these findings suggest that acceptance of illness is important to physical, mental and kidney disease quality of life but that acceptance of illness cannot be looked at in isolation as both depression and anxiety were important aspects to consider. These findings support the work of Jankowska-Polanska et al (2019) who identified that acceptance of illness affects QoL but that symptoms of depression and anxiety also affect quality of life, however there were minor differences. For example, that study identified depression as an independent predictor of physical QoL whereas the current study did not identify this relationship. The current study has tested the baseline mediation model with the 6-month data indicating the mediating role of depression and anxiety on acceptance and mental quality of life identified in baseline data and the 12-month data adding further support to the role of depression. However the cross-sectional nature of the confirmatory analysis cannot fully answer the question of whether acceptance affects QoL or whether

QoL affects acceptance, as it had been suggested that in chronic heart failure it is exacerbation of chronic heart failure symptoms which is related to deterioration in health-related QoL and therefore the ability to accept the illness (Obiegło, Siennicka, et al., 2016). However, the longitudinal study started to allow further insight into the effects.

6.4.2 Acceptance over time in dialysis patients

The systematic review highlighted that acceptance has predominantly been looked at from a cross-sectional or observational stance. By measuring acceptance over time, differences between time points could be studied to test these approaches. These differences suggested that overall there were no significant changes in acceptance between baseline and 6 months or between baseline and 12 months, as has been identified in cardiac patients (Karademas & Hondronikola, 2010). However, despite no significant differences the relationships between acceptance and 6-month and 12-month outcomes could still be explored as in the cardiac study illness acceptance was predictive of emotional well-being and physical functioning and seen as a protective factor for subjective health.

The change scores supported the initial analyses and indicated that for the majority of patients there were minimal changes in illness acceptance, cognitive acceptance or coping acceptance however there were some participants who showed changes in illness acceptance and these changes were correlated with changes in depression, anxiety, stress, mental QoL, kidney disease Qol and self-efficacy. Whilst the number of participants represented a minority of the sample it did suggest that for some patients' acceptance can increase and for others, it can reduce.

Acceptance has also been defined as both an ongoing process (Hammond & Hirst-Winthrop, 2016) but also a state that is reached (Kübler-Ross, 2009) and the results of this study cannot confer full support to either approach. Over 6 months the majority of patients showed little change in acceptance which supports the suggestion that acceptance is a state reached however a smaller number of patients reported fluctuations in acceptance. Although there was no association between changes in acceptance and length of time on dialysis, suggesting that these fluctuations were not attributable to patients being recently started on dialysis. In fact recent evidence suggests that there is no change in QoL after initiation of dialysis (Van Loon et al., 2019) and that HRQoL is generally stable (Eneanya et al., 2019). This was further supported in the current studies where length of time on dialysis was not identified as a significant predictor of any of the quality of life outcomes. These patients for whom acceptance varied are of interest, as they provided insight into how acceptance changes related to other psychological and clinical variables. Changes in acceptance of illness were related to changes in the kidney disease component, specifically, the effects of kidney disease, the burden of kidney disease and patients work status. This is of interest because all three relate to patients' perceptions of the effects of illness. Work status has been associated with HRQoL in haemodialysis patients (Dąbrowska-Bender et al., 2018) therefore it is conceivable that changes in employment were related to patients ability to accept their illness. Changes in acceptance of illness were related to the physical function, pain and general health domains of physical quality of life and to the emotional well-being, social functioning and energy fatigue domains of mental and physical QoL. This demonstrates that for some patients' acceptance can change over time and is associated with other aspects of change. To further understand the longitudinal relationships between acceptance and QoL additional analyses were run.

6.4.3 The relationship between acceptance and quality of life.

The systematic review highlighted that acceptance has predominantly been looked at from a cross-sectional or observational stance. By measuring acceptance over time, differences between time points could be studied to test these approaches. These differences suggested that overall there were no significant changes in acceptance between baseline and 6 months or between baseline and 12 months, as has been identified in cardiac patients (Karademas & Hondronikola, 2010). However, despite no significant differences the relationships between acceptance and 6-month and 12-month outcomes could still be explored as in the cardiac study illness acceptance was predictive of emotional well-being and physical functioning and seen as a protective factor for subjective health.

The change scores supported the initial analyses and indicated that for the majority of patients there were minimal changes in illness acceptance, cognitive acceptance or coping acceptance however there were some participants who showed changes in illness acceptance and these changes were correlated with changes in depression, anxiety, stress, mental QoL, kidney disease Qol and self-efficacy. Whilst the number of participants represented a minority of the sample it did suggest that for some patients' acceptance can increase and for others, it can reduce.

Acceptance has also been defined as both an ongoing process (Hammond & Hirst-Winthrop, 2016) but also a state that is reached (Kübler-Ross, 2009) and the results of this study cannot confer full support to either approach. Over 6 months the majority of patients showed little change in acceptance which supports the suggestion that acceptance is a state reached however a smaller number of patients reported fluctuations in acceptance. Although there was no association between changes in acceptance and length of time on dialysis, suggesting that these fluctuations were not attributable to patients being recently started on dialysis. In fact recent evidence suggests that there is no change in QoL after initiation of dialysis (Van Loon et al., 2019) and that HRQoL is generally stable (Eneanya et al., 2019). This was further supported in the current studies where length of time on dialysis was not identified as a significant predictor of any of the quality of life outcomes. These patients for whom acceptance varied are of interest, as they provided insight into how acceptance changes related to other psychological and clinical variables. Changes in acceptance of illness were related to changes in the kidney disease component, specifically, the effects of kidney disease, the burden of kidney disease and patients work status. This is of interest because all three relate to patients' perceptions of the effects of illness. Work status has been associated with HRQoL in haemodialysis patients (Dąbrowska-Bender et al., 2018) therefore it is conceivable that changes in employment were related to patients ability to accept their illness. Changes in acceptance of illness were related to the physical function, pain and general health domains of physical quality of life and to the emotional well-being, social functioning and energy fatigue domains of mental and physical QoL. This demonstrates that for some patients' acceptance can change over time and is associated with other aspects of change. To further understand the longitudinal relationships between acceptance and QoL additional analyses were run.

6.4.4 Limitations and strengths of the study

Firstly, this is a longitudinal study and can therefore allow directional causality between acceptance and QoL to be examined. This has extended previous research (Jankowska-Polańska et al., 2017; Jankowska-Polańska et al., 2019; Obiegło, Uchmanowicz, Wleklik, Jankowska-Polańska, & Kuśmierz, 2016) and allowed the relationship between acceptance and QoL to be explored in greater depth. The study also used well-established measures and standardised procedures to capture data for this study on a well-defined clinical sample.

It is acknowledged that levels of regression identified by the models were variable, they were strongest for kidney disease QoL and weakest for mental quality of life which suggest that other variables account for some of the variances in QoL. Whilst attempts were made to control for other factors, individual variations could have impacted upon the results. Changes in medical diagnoses, medications and certain demographic factors were not factored into the model. In addition, aspects were overlooked, given the importance of social support as highlighted in the qualitative study and established literature (Alexopoulou et al., 2016; Untas et al., 2011), more information could have been obtained regarding changes in social support, during the study. There were examples where marital status had not changed but the support had altered (wife going into a care home, partners receiving cancer diagnoses/hospital stays), and on reflection these were not adequately accounted for. Whilst these were individual cases, future work should attempt to account for significant changes in not only social support but physical state, change in transportation and changes in session timing. This is particularly important given the array of functional aspects related to acceptance that were identified in the qualitative analyses.

Another limitation of the study was that patients were already established on dialysis, the criteria for inclusion was that patients had been initiated on dialysis for at least 3 months. Whilst this is standard practice in many dialysis studies, the rationale for this is that it is a period of adjustment and therefore in the context of acceptance it is a time that might be of particular interest. Given that both the systematic review and qualitative study identified that acceptance takes time, capturing this early period on dialysis is important. Therefore, consideration should be given to exploring how acceptance changes from pre-dialysis through to being established on dialysis.

A general limitation for the quantitative approach was that this study relied on self-report questionnaires and whilst a useful method to collect large volumes of data the data was still based upon self-report and therefore had the potential to be biased. The longitudinal aspect of the study added validity because the same patients answered the same questionnaire and where possible extraneous variables were kept constant, for example participants completed questionnaires in the same way as initial completion and the same order. In addition, clinical data were extracted from routine blood test results and dialysis and diagnostic information were obtained from clinical records in the same way as baseline.

Another limitation to consider is that overemphasis might be being placed upon the results that indicate that changes in acceptance predict QoL, but there are questions about what a noticeable change in quality of life would be for patients. In rheumatoid arthritis changes of 7.1 in physical functioning, bodily pain and physical component summary score were estimated to be minimal clinically important levels of improvement (Ward, Guthrie, & Alba, 2014) and in chronic kidney disease a score change of 5.7 in the physical component summary score was deemed to be of minimal clinical importance (Erez, Selman, & Murtagh, 2016). Mean changes in the QoL summary scores were below this level however there were no interventions in this study and findings were simply an indication of spontaneous change over time and therefore clinical significance is arguably less applicable.

6.4.5 Conclusions and implications for the thesis

This study has confirmed the relationships between acceptance, depression, anxiety and quality of life in dialysis patients and further highlighted that acceptance cannot be considered in isolation. It then highlighted that when adopting a longitudinal approach acceptance does not change significantly over time for most patients, however when predicting QoL at 6 and 12 months, changes in acceptance are predictive QoL scores.

This study has addressed the gap in the knowledge identified in the systematic review; the lack of longitudinal studies. It has supported the findings of the qualitative study which suggest acceptance is a complex process and in addition, the findings from the qualitative study have helped inform the understanding of the current study. By understanding the longitudinal relationships between acceptance and the associated variables, the findings suggest that changes in acceptance relate to QoL and therefore it is conceivable that this is a modifiable factor which can be targeted by intervention developments, however this cannot be done in isolation as other factors, particularly depression are important.

The next chapter concludes the thesis with a general discussion of the findings from the systematic review, quantitative and qualitative studies, and details the contribution that this makes to theory. It concludes the thesis by exploring how this may relate to future research developments and in turn how this could be related to practice.

Chapter 7 – General Discussion and conclusions

This chapter summarises the findings from the studies detailed in this thesis and outlines the contribution to the current body of knowledge in this area. Implications for theory and practice are discussed before the strengths and limitations of the whole research approach are reviewed. The chapter concludes by exploring options for future directions in research and how these enable the development of acceptance-based interventions for dialysis patients.

7.1 Introduction

This thesis set out to investigate the role of acceptance and related factors in quality of life for renal haemodialysis patients. Through the course of the thesis five key objectives were addressed. The initial narrative review (chapter 1, (Stalker et al., 2017) and systematic review (chapter 2) examined the empirical evidence relating to acceptance in ESRD (objective 1). The review highlighted that acceptance in ESRD has received limited focus and therefore justified why understanding more about patients' experiences was needed. The findings of the systematic review underpinned the development and selection of measures and questions for the subsequent studies. Interviews with haemodialysis patients allowed the concept of acceptance to be explored (chapter 5 – Objective 2). To further understand the psychological components of acceptance and theoretical associations the cross-sectional study tested these relationships (chapter 4 – objective 3) findings were confirmed and extended by the longitudinal study (chapter 7 – objective 4) which tested whether acceptance changed over time in dialysis patients and examined factors associated with acceptance and as importantly, QoL. The findings from both the qualitative and quantitative studies were compared to address whether they complimented this approach and the discussion of the findings and is continued with the current chapter (objective 5).

The studies conducted in this mixed methods research have extended the current understanding about acceptance in haemodialysis patients and built upon and tested existing theoretical associations. The approach has explored both experiences and measurable constructs to understand and highlight the importance of acceptance. This chapter summarises the findings from the research and discusses the contribution to knowledge and theory before critiquing the studies and examining the future directions for research.

7.2 Summary of findings

The systematic review and synthesis of quantitative and qualitative literature highlighted that there was limited research focusing on acceptance in patients with ESRD. The quantitative research included in the review addressed different research questions and consequently, the measures included were varied and limited comparisons could be drawn. What was evident in the results was that acceptance was viewed from different perspectives, for example, acceptance as a method of coping or acceptance as patients' perspective on their illness. Acceptance of illness was reported to be associated with a range of demographic, clinical and social measures whereas coping acceptance was only reported to be associated with the psychological measures. This informed the methodological decision to include acceptance of illness as the main measure of acceptance whilst retaining coping and cognitive acceptance for comparisons. The qualitative synthesis highlighted that acceptance in ESRD was complex and involved four themes: accepting a new life, journey to acceptance, realistic expectations and support. These themes had links with some of the quantitative measures but in addition added depth to the understanding. For example, employment and social support were key components of the qualitative analysis but were not fully accounted for in most of the quantitative studies. These findings supported the biopsychosocial approach adopted and confirmed the importance of the adoption of a mixed-methods stance.

The cross-sectional analysis aimed to answer several key questions. Firstly, whether measures of acceptance differed and, secondly, how acceptance related to health-related quality of life (QoL) when clinical and psychological variables were considered. The results indicated that acceptance of illness, cognitive acceptance and coping acceptance measured different constructs, with illness and cognitive acceptance being the most closely associated with QoL, however the findings also highlighted that depression had a mediating effect on acceptance of illness. This was confirmed when additional psychological and clinical variables were accounted for in the regression models. With additional variables included, acceptance of illness was an independent predictor of physical quality of life and kidney disease quality of life, and the influence on mental quality of life was mediated by depression, anxiety and self-efficacy. However, the impact of clinical variables in QoL was found to be minimal. Length of time on dialysis and number of conditions reported were not identified as independent predictors in any of the models and serum albumin was only an independent predictor in PQoL models. These relationships were tested further in the longitudinal studies and acceptance scores related to the qualitative findings.

The qualitative study extended the findings of the qualitative review by identifying similar themes (importance of support, and the necessity of accepting a new life and accepting the functional aspects) but also highlighted the importance of “mindset”. The findings from the review presented mindset as an overarching theme which permeated into how patients came to an acceptance and how patients viewed what they felt they had to accept. From this a conceptual model was suggested (section 5.6.5) in which the acceptance mindset affected how patients reach acceptance but also their acceptance of illness state. However, this conceptual model was focused on only one small part of what is potentially a much wider process not all of which is within the remit of this thesis, but it is conceivable that additional psychological aspects including depression would feature in this process.

The longitudinal study allowed the mediation model to be tested further and the questions of whether acceptance changed over time and how this related to QoL to be examined. The mediation effect of depression on acceptance and mental QoL was evident at both 6 months and 12 months. This showed that despite the reduction in sample size the core effects were still evident, and that acceptance was important in physical Qol, kidney disease Qol and (through mediation by depression) on mental QoL. These associations might initially seem promising and suggest that improvements in QoL could infer changes in QoL however, across the sample during the 12 months there were no significant group differences in acceptance of illness (nor coping nor cognitive acceptance). Whilst this might be due to the observational nature of the study it raises questions about whether acceptance is indeed a state reached. On more detailed examination, there were individual changes across the sample with acceptance increasing for some patients and decreasing for others. This suggested that for some patients’ acceptance had the potential to change and interventions developed may be more beneficial to subgroups of the dialysis population. However, although the results show that changes in acceptance were significant predictors of 6-

month mental Qol and 6- and 12- month kidney disease quality of life the levels of change in the QoL variables were minimal and would not reflect clinically significant changes.

The mixed-methods approach allowed acceptance to be explored from various perspectives. The analysis of the interviews was supported with the inclusion of the acceptance of illness scores for participants which indicated that mindset might not be easily categorised by the acceptance of illness measures because acceptance is more complex than how it is represented in the measure. This suggests that there is scope to develop a more detailed measure of dialysis acceptance covering the core elements participants identified from their experiences. However, despite questions over the measurement of acceptance, the core components of the interview data and questionnaire analyses overlapped. Changes in acceptance of illness were associated with changes in the effects of kidney disease and work status which, related to themes of accepting the functional aspects of dialysis, and changes in physical functioning and wellbeing related to accepting the necessity. However, although changes in social functioning were associated with changes in acceptance of illness, social support, patient satisfaction and dialysis encouragement, this did not fully support the importance given to social support in the interviews. This difference between the qualitative and quantitative approaches was also evident in the qualitative synthesis which raises the questions about the disconnect between the two.

Across the studies, acceptance was identified as an important variable in QoL however it cannot be viewed in isolation. The concept of “mindset” was found to be important in the qualitative studies and from the questionnaires it seems conceivable that “acceptance mindset” is not a solitary concept and comprises acceptance, depression and anxiety. These psychological components are clearly linked through the studies however acceptance had the strongest links to physical and kidney disease QoL.

Table 7.2.1 is a replication of the findings from the systematic review with the addition of the findings from the quantitative studies in the thesis. It shows that whilst some areas were addressed and measured in the studies there were aspects which were overlooked notably adherence, personality and exercise. The following sections review the findings in relation to the current literature with reflection upon how these findings contribute to knowledge. They also consider contribution to theory and the implications for future research.

Table 7.2.1 - Relationships identified in the review study compared to acceptance of illness relationships identified in this thesis

	Demographic						Clinical							Psychological							
	Education	Age	Gender	Employment	Exercise	Social support	Adherence	Health	Diet	Sleep	Haemoglobin	Dialysis outcome	Fatigue	Depression	Stress/anxiety	Locus of control	Coping	QoL	Psychological symptoms	Self-efficacy	Personality
Acceptance of Illness /disability																					
Brown & Fitzpatrick (1988)							O		X							X					
Chan et al (2011)						X								O*						X	
Chiang et al (2015)	X	O	O	O	X	O				X	X	X									
Jankowska-Polanska et al (2017)	O	X	X	X		O						X	X					X			
Jankowska-Polanska et al (2019)														X	X			X			
Karademas et al (2009)								X							X				X		
Kokoszka et al (2016)														X							
Oka & Chaboyer (2001)									O											X	
Poll & Kaplan de-Nour (1980)	X	O														X					
Acceptance as Coping																					
Gillanders et al (2008)															X						
Lin et al (2012)														X							
Liu et al (2017)														X			X				
Poppe et al (2013)																		X	X		X
Other scales (illness attributions)																					
Rich et al (1999)														X							
<u>Current studies</u>																					
Cross sectional	X	X	O	X	-	O/X	-	X	O/X	O	O	-	-	X	X	-	O	X	X	X	-
Longitudinal	O	X	O	X	-	O	-	X	O	O	X	O	-	X	X	-	O	X	X	X	-

X = significant finding O = no significant finding reported - = not measured *retained in model reported despite no significant findings

7.2.1 Biological and demographic characteristics

ESRD is a clinical condition and by aligning to the biopsychosocial model it was expected that biological and demographic characteristics would be associated with acceptance processes either directly or indirectly.

In the current sample, acceptance was related to age, employment and income which have all been previously linked to QoL (Evans & Taal, 2015). The finding that acceptance was positively correlated with age indicated that acceptance increased with age. However, it has also been suggested that age is related to reduced QoL (Ibrahim et al., 2015) which would infer that with age comes a reduction in QoL. However, in these reported findings age was related to PQoL and not mental QoL. Conversely, in the current study age was related to MQoL and KDCS but not PCS, and this finding for KDCS was replicated at 12 months. Notably, the previous study contained a majority of patients at stage 3 ESRD, therefore not on dialysis (Ibrahim et al., 2015). Rather, the current study supports the findings suggesting that the relationship between age and QoL is related to the specific domains (Abdel-Kader et al., 2009; van Loon, Hamaker, et al., 2017), with mental QoL increasing with age. It is conceivable that increases in mental Qol and KDCS could be related to patients ageing and accepting the necessity of dialysis as part of the process. The same may hold true for the comparisons drawn with others, among younger patients the comparisons between their lives and their contemporaries might be more diverse than the older patients. This is supported in the current data where participants in the interview study described comparing themselves to those they perceived to be “worse off” than themselves, facilitating their acceptance of illness.

Employment and income have been associated with QoL in diabetes (Glasgow et al., 1997) and ESRD (Blake et al., 2000) and to some extent the current study supports these findings and confirms them in a sample of haemodialysis patients. Employment was identified as important in acceptance of illness with acceptance of illness highest in participants who were in full-time employment and lowest in the unemployed. Previous research has also identified acceptance as being higher in patients who were working, however limited comparisons can be drawn because this study did not differentiate between the unemployed and the retired (Jankowska-Polanska et al., 2017). The interview study provided some insight into why employment was important, participants described how being able to continue work and the practical support in accommodating treatment allowed them to minimise the lifestyle impact and to retain some identity from their “old life”. Therefore, for patients for whom work was still relevant being in employment facilitated a more positive acceptance of their illness. However, there is debate about whether acceptance is facilitated by employment or whether acceptance of illness is the first step which then allows patients to continue working (Vooijs, Leensen, Hoving, Wind, & Frings-Dresen, 2017).

In reviewing the literature, the evidence for clinical variables having a role in acceptance and QoL was varied. The systematic review highlighted that haemoglobin, dialysis outcome, fatigue, and sleep were related to acceptance (Chiang et al., 2015; Jankowska-Polańska et al., 2017) whilst nutritional biomarkers (Spiegel et al., 2008) and dialysis adequacy (Manns et al., 2002) were also identified as important factors. However, despite the inclusion of clinical measures into the current studies limited associations were identified, supporting the findings of Poppe et al., 2013. Acceptance of illness was only correlated with calcium and the only variable included in the regression models for QoL at baseline was serum Albumin and this was only a significant predictor of PQoL. One aspect to consider is that all participants were dialysis patients and therefore many of the clinical variables were under control or actively being managed through routine care. Dialysis units aim to ensure patients’ clinical measures adhere to the nutritional and dialysis adequacy guidelines (National Kidney Foundation, 2015). Therefore, if individual patients’ levels altered then treatment would be changed to achieve maximum benefit, and prolonged changes in measures would be indicative of physical decline (Young et al., 2000). This is of importance when considering the changes in clinical measures where at 12 months changes in serum albumin were only related to change in physical QoL, indicating a decline in physical measures is represented in physical QoL. However, despite the clinical measures at 6 months being of minimal relevance in all but physical QoL, the clinical profile was comparable to similar studies suggesting that the clinical profile of the sample was representative of other dialysis samples (Bieber et al., 2014; Picariello et al., 2016).

Dialysis outcomes including survival and mortality have previously been reported as related to acceptance (Chiang et al., 2015) however the current studies lacked the power to test the longitudinal effects of acceptance on mortality. The descriptive data suggested that there might be differences related to acceptance and dialysis outcomes however with the exception of differences in anxiety and cognitive acceptance the findings were limited.

7.2.2 Psychological factors

The strongest psychological evidence in the systematic review was that acceptance was associated with depression (Jankowska-Polańska et al., 2019; Kokoszka et al., 2016; Liu et al., 2017). The evidence associating depression with acceptance was apparent in the different scales for acceptance and depression. In the current studies, the association between depression and acceptance was one of the strongest of all the psychological relationships, but interestingly there was a mediation role of depression between acceptance and mental QoL. The mediation effect was present at all three-time points and was therefore a consistent effect within the sample of dialysis patients. This finding was consistent with research showing increasing acceptance can be effective in reducing depressive symptomatology (Bohlmeijer, Fledderus, Rokx, & Pieterse, 2011). However these findings were not in isolation as the association between acceptance and depression has been previously noted however there are questions about the direction of the relationship with recent evidence in cardiac patients demonstrating that illness perceptions and coping acceptance mediated the relationship between physical symptoms and depression (Chen, Fang, An, Wang, & Fan, 2019). However, in this study the focus was on acceptance-resignation coping as opposed to acceptance of illness. In addition, it must be considered that the relationship between acceptance and depression is complex as evidence has demonstrated acceptance being the mediator between pain catastrophizing and depression (Vowles, McCracken, & Eccleston, 2008). Therefore, the relationship between acceptance and depression on QoL needed considering in the wider scheme of psychological, clinical and social variables.

In the current research the additional psychological variables were considered, anxiety and self-efficacy were associated with stress and anxiety supporting the relationships identified in the systematic review (Gillanders et al., 2008; Jankowska-Polańska et al., 2019; Kokoszka et al., 2016) and self-efficacy were associated with acceptance as previously identified (Chan, Steel, et al., 2011; Oka & Chaboyer, 2001). However, these previously identified relationships had mainly been looked at in isolation, whereas the current thesis explored their relationship with acceptance and extended the findings by identifying strong relationships between these psychological variables and QoL. In addition, changes in the psychological variables were associated with changes in certain domains of QoL supporting the guidance suggesting that QoL cannot be examined without first examining the sub-components (Ware, 2000). However, these associations were most apparent in mental rather than physical QoL with changes in physical variables showing associations with physical QoL.

7.2.3 Social factors

There was limited evidence for social support identified in the quantitative review however it became apparent it was an important aspect in the qualitative review (section 2.3.2.5). This difference was echoed in the thesis with the quantitative data providing mixed evidence for the role of support and the qualitative analysis identifying support as a key theme (section 5.4.6). Some of the variations in the views of social support may stem from its measurement. In the current study markers for social support included marital status and the social support questions in the KDQoL, however these were restrictive. For example, the question “how satisfied are you with the amount of time you are able to spend with your family and friends?” might be difficult to untangle from the impact that dialysis has on their time. The qualitative study allowed patients to explore their experiences of dialysis and reflect upon them which potentially allowed the importance of support to be communicated. Interestingly support was split into sub-themes based upon the type of support rather than the source of support (Kostova et al., 2014), suggesting that it can be the support itself rather than just the givers of support that are of importance. The relationship between social support and acceptance was important because acceptance had been identified as a buffer between social support and depression (Costa & Gouveia, 2013). Social support had also been associated with HRQoL in patients’ with ESRD (Ibrahim et al., 2015).

7.3 Relevant psychological models

7.3.1 Acceptance: state vs cycle

The current findings could be interpreted to suggest that in haemodialysis patients acceptance is a state that is reached because when looking at the whole sample acceptance did not change over time which is in line with the staged approaches (Kübler-Ross, 2009). However, through examination of individual changes it was apparent that the group scores masked changes with individual score both increasing and decreasing across the sample. The qualitative finding supported the idea of an end goal with patients describing acceptance taking time, however the cross-sectional results found no relationship between acceptance and length of time on dialysis. With the current findings it is still conceivable that rather than a state, acceptance is a continuous cycle of adjustment (Hammond & Hirst-Winthrop, 2016). Although there were no significant changes in acceptance in the sample, some individuals showed large increases or decreases across the 12 months. Changes in acceptance were associated with self-reported changes in psychological outcomes and pain, social functioning and general health whereas changes in depression were associated with fewer variables. These relationships support the idea of emotional equilibrium disruption (Moss-Morris, 2013), in which the most salient changes are physical status changes associated with acceptance. In this thesis the proposed aspects of successful cognitive adjustment, self-efficacy, acceptance of illness and perceived social support were all positively correlated, consistent with Moss-Morris's model. However, in this model acceptance of illness is an ongoing state of adjustment, yet even if acceptance is a state there are questions about how this is defined and whether it is a positive or negative construct.

7.3.2 Acceptance: positive or negative

It has been proposed that acceptance can be either positive or negative (Chan, 2013; Stalker et al., 2017). The interviews supported the proposal of positive and negative acceptance but suggested that acceptance mindset is a continuum between positive and negative with pragmatic acceptance being the middle ground. The interview analysis suggested that dialysis patients felt that they had no choice but to accept the treatment, but it was how they accepted the treatment and illness that was important. The inevitability of dialysis treatment has been described in previous studies (Rees et al., 2018). This differentiation in acceptance may partially explain the differences in the reported acceptance levels between different scales. For example, the two items on the COPE scale could be interpreted in either a positive or negative way for example "I've been learning to live with it" could be interpreted as "I have no choice" or "I'm not going to let it hold me back". This relates to the findings in the qualitative study where participants felt they had "just gotta accept it" but on further analysis how they "got on with it" varied with some adopting a more positive stance and others a more negative. These findings support the suggestion that an “active acceptance it an adaptive reaction to unchangeable situations” (Nakamura & Orth, 2005).

7.3.3 Psychosocial model of adjustment

The current studies most closely aligned to the biopsychosocial model for ESRD proposed by Chan et al., 2011, however the current study focused specifically on the illness acceptance component whilst also testing the longitudinal relationships. In Chan et al’s model the path between illness acceptance and depression was only retained due to theoretical considerations, however the current study has supported this inclusion by identifying a strong relationship between these components, in addition, it has identified a mediation effect. The complex relationships in the biopsychosocial model are a framework for understanding the processes. The studies focused on an overall outcome of quality of life with additional evaluation of individual QoL domains. This allowed the studies to demonstrate that acceptance relates to aspects of QoL in different ways with some components being more salient. For example, from the quantitative findings it might be proposed that the following variables should also be considered in the model; anxiety, stress. The proposed model suggests that positive affect mediates the relationship with Qol and that acceptance works on this through depression however it would be interesting to test the concept of positive and negative acceptance on positive affect and whether the measure of acceptance influences the relationship. In the THRIVE framework acceptance was associated with values and belief (White et al., 2018), in the current findings acceptance was associated with values and beliefs in the themes (accepting the functional aspects and acceptance from experience) identified in the qualitative study however other elements of the thrive coping framework were evident (Table 7.3.1) across the studies suggesting that acceptance cannot be studied in isolation, nor is it only associated with values and beliefs.

Table 7.3.1 - Comparison of THRIVE framework to Thesis findings

THRIVE component	Definition	Evidence in Qualitative studies	Evidence in Quantitative studies
Therapeutic interventions	Presence of therapeutic interventions	Not studied	Not studied
Habit and routine	Forming positive habits and engaging in relevant behaviours	Accepting the functional aspects	KDQOL - effects
Relational-social	Interaction with people around them	Acceptance from support	KDQOL – support
Individual differences	Enduring or dispositional factors		Demographic and clinical profile
Values and beliefs	Value attitudes and beliefs	Acceptance Mindset	Acceptance of illness Illness cognitions Religion Self-efficacy
Emotional factors	Emotional response	Accepting the necessity - Hope	Depression Anxiety Stress

7.3.4 Measuring acceptance

The findings indicate that acceptance measures are variable and studies in this thesis have measured coping acceptance (Carver, 1997) cognitive acceptance (Evers, 2001) and illness acceptance (Revenson & Felton, 1989). The cross-sectional analyses highlighted that there are differences in the results with some correlation between cognitive and illness acceptance but not coping acceptance, suggesting that these are measuring different constructs. This is important to consider when comparing findings because if they are different constructs they cannot be directly compared. The cross-sectional analysis highlighted that acceptance of illness accounted for the highest proportion of variance in QoL in comparison to the other measures of acceptance. Acceptance of illness has been utilised in studies comparable to those in the thesis (Jankowska-Polańska et al., 2019, 2017; Karademas et al., 2009). The content of the questions offers insight into the measures with the acceptance of illness measure focused on how patients feel the illness has impacted upon them whilst cognitive acceptance related to their thinking about illness and functional aspects. When comparing the AiS scores to the qualitative themes there were some discrepancies suggesting that the acceptance of illness measure captures the main themes but that elements of the subthemes are overlooked. This raises questions over whether other measures might be more applicable, acceptance measures relating to acceptance and commitment approaches include the acceptance and action questionnaire (AAQ) (Wolgast, 2014), the engaged living scale (Trompetter et al., 2013) and the valued living questionnaire (Wilson, Sandoz, Kitchens, & Roberts, 2010), and these are important to consider because current ACT-based intervention studies in this population have omitted such measures (Dehghani, 2016; Jafskesh Moghadam, Shahabizadeh, & Bahrainian, 2016; Karimi & Salimi, 2019) which makes it difficult to interpret the effects of the interventions. It would therefore be important to consider both acceptance of illness and ACT-based measures in any study of ACT-based interventions. In addition to the comparison for inclusion of acceptance-based measures, the comparison with the AiS scores suggests there may be scope for development of specific acceptance-of-dialysis measures based upon AiS.

7.4 Practical/clinical Implications for research

7.4.1 Informing interventions

The most promising aspect of the current research is the potential that acceptance can be a target of interventions which relate to depression and then QoL. It is also promising that acceptance is related to PQoL however the changes in PQoL were related to physical or clinical changes rather than changes in acceptance. These relationships still need further exploration. The findings of the current studies suggest that acceptance of illness is important in QoL and can change for some patients over time but whether interventions can facilitate these changes in dialysis patients needs further exploration.

In dialysis patients to date, there have been no specific interventions developed to target acceptance of illness, and acceptance and commitment interventions whilst showing promise lack robust evidence to support their use (Dehghani, 2016; Jafskesh Moghadam et al., 2016; Karimi & Salimi, 2019) ACT-based interventions may be the most applicable to dialysis patients because of the evidence for their utility in other conditions (Brassington et al., 2016; Graham, Gouick, Krahé, & Gillanders, 2016) however lessons from other RCTs need considering. Current evidence for ACT-based interventions, whilst promising, is often based on lower quality studies testing low intensity interventions (Graham et al., 2016). Whilst there is benefit in developing low intensity interventions as they are cost-effective, comparisons with higher intensity interventions are needed to draw firm conclusions (Feliu-Soler, Montesinos, et al., 2018). The present findings support the case for interventions to improve acceptance, however as identified across the studies, acceptance in dialysis is complex and therefore interventions should be tailored for dialysis. These considerations are taken into account when considering the future directions of this research (section 7.6).

7.4.2 Practical and clinical significance

The immediate impact of the findings of this thesis in relation to clinical practice are indicative rather than conclusive in the short term due to the requirement for robust intervention data to inform clinical practice. However, the study can help inform clinicians' understandings of acceptance in dialysis. Social support emerged as very important for facilitating patients' acceptance of their illness however support did not have to come from family and friends, the support from staff at the unit and from other patients could also facilitate acceptance. This feeds into more practical considerations about the dialysis environment. The interview respondents also indicated that there were key times related to acceptance, for example when reminded of their own mortality through the passing of other patients (section 5.4.3.1). In considering the impact of patient deaths on the unit these findings need considering in terms of the impact that patient deaths have on clinical and other staff, with evidence indicating that whilst some nurses accept deaths of patients, others avoid thinking about death (Tranter, Josland, & Turner, 2016). Conversely, transplant is identified as a source of hope for some patients but the impact of the change in transplant status should also be considered and may require additional support to facilitate acceptance of the change in status. The qualitative findings can inform how clinicians and other staff prepare patients in the pre-dialysis phase by highlighting salient factors which can facilitate a more positive acceptance of illness.

7.5 Strengths and limitations of research

This thesis has reported studies which focused on one key aspect of adjusting to illness, acceptance. It is one of the first to explore acceptance longitudinally in a dialysis population and has identified key relationships between psychological variables and acceptance. It took a representative sample of haemodialysis patients and measured clinical variables alongside psychological data to provide a comprehensive understanding of acceptance however it is not without limitations.

Firstly, acceptance is only one small part of a bigger process. This epitomises the nature of the biopsychosocial approach yet understanding the relationship acceptance has with associated variables suggests that acceptance might be a target for interventions to improve depression and QoL in haemodialysis patients. However, by focusing on acceptance there was the potential for other relationships to be overlooked. The analyses attempted to explore as many of the relationships identified in the systematic review however themes identified in the qualitative review demonstrate that other areas could have been further explored by quantitative analyses if appropriate measures had been included.

It is noted that there are limitations with the mediation design. In mediation designs strong inferences on direction of causation should be avoided and for genuine mediation effects to be confirmed, randomisation would be needed. This was a limitation of the current study design and also raises questions over the utility of the mediation design within the cross-sectional analyses. This was partially addressed with the longitudinal design but needs further consideration in studies resulting from this thesis. It is also acknowledged that mediation is a form of path analysis and it is sometimes current practice to present mediation analyses in these ways. It is also acknowledged that there are numerous considerations, for example, in the planning conduct and reporting of mediation analysis that need to be considered in taking these approaches forward, for example into ACT-based intervention randomised control trials (Vo, Superchi, Boutron and Vansteelandt, 2020). These considerations were partially addressed in the current studies by controlling for confounders but they need further consideration in resulting studies.

The sample size was relatively small in comparison to other studies (Chan, Brooks, et al., 2011) and therefore prevented the use of more complex modelling. The sample was also homogenous in that it was from one unit, so whilst this controlled for variations in practice across the units the generalisation to the wider haemodialysis population is limited. The characteristics of the sample were compared to statistics from the wider dialysis population (Evans et al., 2018). This suggested that the sample was comparable on most statistics however further research would benefit from obtaining a wider sample across dialysis units.

Inherently with research comes the risk of bias; sampling bias, selection bias, response bias (Coolican, 2017; Howitt, 2016). Some attempt was made to address these in the studies. For the quantitative study the majority of potentially eligible participants in the unit were approached and information on the outcome of the recruitment process is fully reported (section 4.2.2). It is noted that there was likely to be some response bias, with certain patients more likely to respond to the survey or study. This is particularly evident when looking at the acceptance scores of participants in the interview study, only a small proportion scored low on acceptance of illness, therefore the interview findings contained more responses from patients with higher acceptance. It is conceivable that those patients lower in acceptance may have been underrepresented in the thesis studies. In addition, the sample only recruited haemodialysis patients therefore the findings are only related to a subgroup of patients of RRT.

The questionnaire study relied on self-report measures which had benefits in collecting large volumes of data. The measures were all valid and reliable in the dialysis population however on reflection the utilisation of the DASS-21 for the depression measure could have been improved with the use of the BECK depression inventory (Beck, Steer, & Brown, 1996). This would have allowed greater comparisons with previous studies (Chilcot et al., 2013; Costello, 1999; Kokoszka et al., 2016).

Retention was a major obstacle in this study but not unexpected from calculations based on the renal registry data (section 3.9.1.3). This thesis has reported detailed outcomes for the dialysis participants recruited in the study which has highlighted that the majority of patients were lost to follow up through natural movement between modalities or because of patient deaths. These findings suggest that there is potential for future studies to examine the impact of changes in modality on patient’s acceptance but that consideration is needed to ensure sufficient retention for meaningful analysis at follow up.

7.6 Future directions

Currently, the evidence for acceptance of illness in dialysis patient shows promise but is an emerging field. Therefore, there are numerous future directions into which this positive research could develop. The development of an acceptance measure for dialysis patients could aim to encompass key aspects identified in the qualitative review but overlooked in the quantitative. However, this requires consideration in relation to the ACT model, a first step would be to compare acceptance of illness measures and ACT based measures to establish which elements are most appropriate and then establish how a comprehensive measure can capture acceptance in dialysis patients.

Another area to focus on is the differences across modalities, the current studies have focused on haemodialysis patients and therefore the findings need testing across modalities. The differences between modalities have been previously discussed but differences in acceptance have not been explored as a result the current findings cannot be generalised but can inform the development of future research to explore these differences. Study 3 suggested that there were potential differences between the modalities when studying the outcomes at 6 and 12 months but further work would be needed to establish if significant differences existed.

Study 3 lacked the power to fully test the long-term impact of QoL for dialysis patients and whilst the descriptive data offered initial insights a long term follow up of acceptance, mortality and quality of life is warranted. Based upon the retention rate in the studies in this thesis and previous studies (de Abreu, Walker, Sesso, & Ferraz, 2011) exploration of these variables would benefit from a multi-centre trial with several years follow up. Other longitudinal studies in dialysis patients have required over 300 patients to achieve sufficient numbers for more detailed analysis.

Acceptance in pre-dialysis is another area that has the potential to be of interest in the development of interventions. PREHAB (Willingham et al., 2019) interventions are currently being tested in pre-dialysis patients with the aim to prepare them for dialysis and improve the transition. This initial adjustment to dialysis treatment was described as important by interview participants, with the suggestion being that it takes weeks, months or possibly a year to adjust. Whilst the exact time is likely to be due to individual variations, understanding the process and the role of acceptance at these time points is crucial in identifying and targeting appropriate support. The suggestion from the qualitative analysis was that if patients had “known it was coming” for a considerable time before dialysis initiation acceptance was easier, patients felt they had had time to accept and focused on the years they had avoided dialysis. However, when dialysis initiation was unexpected the lack of preparation was associated with inhibited acceptance.

A final future development to be based upon the findings from this thesis would be the development and testing of acceptance-based interventions. This process of which is already underway and discussed in the next section.

7.7 Developing an acceptance-based intervention

Several aspects to consider in the development of interventions to target acceptance can be countered. The studies in this thesis have highlighted the relationships between acceptance and quality of life in dialysis patients. However, it was evident that the relationship was more complex with the mediation of depression. These findings have provided context and outlined causal assumptions which can be useful in guiding intervention development (Moore et al., 2014). Research has previously highlighted the associations between depression and QoL (Belayev et al., 2015; Jankowska-Polańska et al., 2019), but the current findings suggest that when targeting acceptance, depression should also be considered. Therefore, when developing interventions, outcomes should consider the process and do so by measuring acceptance, depression and QoL. Through this, the mediation model can be tested in an increased sample and will allow testing through structural equation modelling (Hayes, 2018).

Evidence from chronic pain literature suggests that support for ACT-based interventions has primarily arisen from light touch/low-intensity acceptance interventions (Veehof et al., 2011). It has been suggested that acceptance-based interventions can be beneficial in a range of patients (Brassington et al., 2016) however the utility of acceptance interventions across the whole dialysis population is questionable based upon the current findings. The current findings indicate that because acceptance is varied across the sample there is the potential that interventions may be most applicable to patients who are early in dialysis initiation or for whom circumstances have changed (removal from transplant, changes in social support). Therefore, any ACT-based intervention needs to consider how the target patients are identified and establish the cost-effectiveness.

Once the target sample is identified the next stage is developing the intervention. ACT has shown promise in other conditions but the evidence in dialysis is limited (Graham et al., 2016). However tailoring acceptance based interventions (Levin, Haeger, & Cruz, 2019) and developing interventions for chronic conditions (Vowles, McCracken, & O'Brien, 2011) has shown promise. Considering the complexity surrounding patients' experiences with dialysis, as identified in the patient interviews, developing ACT-based interventions for dialysis patients requires adaptation to address dialysis patients' acceptance needs. Developing from the current findings the ACT for dialysis study (IRAS 267104) has received funding from Kidney Care UK and the British Renal Society to consult patients over the adaptation of psycho-educational materials based upon ACT. This will build directly on the finding presented in this thesis. The first stage of the study will involve consulting patients about the content, techniques and delivery of the ACT materials to ensure they are suitable for dialysis patients. The materials being reviewed consist of fictitious case-based descriptions based upon ACT. These case studies are underpinned by the ACT principles in the hexoflex model (section 1.3.2.1) and introduce ACT-based techniques, including mindfulness, and thought diffusion. The consultations will use a qualitative adaptation of the Delphi method (Brady, 2015), that will build on the findings of the qualitative study in the thesis by treating dialysis patients as subject matter experts to consult them about potential content of ACT-based intervention materials that take account of themes identified from the present interview data. The results from the consultation exercise will inform the development of a model of ACT tailored for dialysis patients. This will then be tested in a proof-of-concept study to evaluate the acceptability and feasibility of the developed intervention, prior to the development of a full randomised trial. The feasibility trial will include acceptance measures to address acceptance of illness and ACT-related processes and measures of affect and QoL measures, these measures will be of particular importance in subsequent RCTs to test the acceptance processes.

The feasibility trial will inform the future directions of the research. If feasibility is demonstrated, then funding for a large scale RCT to test the adapted materials will be sought. This RCT would require a multi-centre approach to ensure sufficient retention and representation of dialysis patients and address some of the limitations identified in this thesis.

7.8 Conclusions

The research presented within this thesis furthers our understanding of the role of acceptance in patients' adjustment to dialysis. The findings have indicated that acceptance is important in influencing a patients' QoL but that other psychological variables are also implicated. The mediation effect of acceptance on mental QoL by depression is a novel association which suggests that acceptance can be targeted as opposed to depression to improve mental QoL. The research also highlights that although group acceptance scores did not change there were individual changes. This is of particular interest as there were no intervention effects tested within these studies so any changes over time occurred spontaneously, without intervention. It therefore seems conceivable that acceptance may be a modifiable variable which could be targeted by interventions.

Interventions in other chronic conditions have demonstrated that acceptance is potentially modifiable and has utility in conditions which do not improve with treatment, for example chronic pain. The findings presented in this thesis have provided the foundation for the development of an acceptance-based intervention for dialysis patients which is currently undergoing development and testing. In addition, the findings may have clinical and practical significance for medical professionals. Through this thesis complexities relating to acceptance have been explored; time, environment, social support, control, values. These are important considerations in facilitating acceptance for dialysis patients and could be factored into the pre-dialysis or initiation stages of treatment to facilitate patients' adjustment.

To conclude, acceptance is only one part of a much wider adjustment process and therefore cannot be considered in isolation. However, for dialysis patients who 'have just got to accept it' enabling a more positive acceptance of their illness may confer long-term psychological benefits.

Publications and Planned publications resulting from this thesis

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P (DRAFTED) The impact of acceptance of illness on quality of life outcomes for haemodialysis patients – a cross-sectional study.

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P (In preparation) Haemodialysis patients experiences of accepting illness: A thematic analysis

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P (planned) The longitudinal effects of acceptance of illness and associated psychological variables on QoL in Haemodialysis patients

Publications

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P. (2018). What is acceptance, and how could it affect health outcomes for people receiving renal dialysis?. Health Psychology Update.

Conference presentations

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P, What aspects of acceptance influence health related quality of life in Haemodialysis patients? Division of Health Psychology Conference, Manchester, 10th July 2019 – Poster Presentation

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P. The impact of acceptance of illness on quality of life outcomes for haemodialysis patients. UKKW conference 2019, Brighton, 4th June 2019 – Poster presentation

Stalker, C., Elander, J., Mitchell, K., Taal, M. W., Selby, N., & Stewart, P. The role of Acceptance in Dialysis, East midlands doctoral conference, September 2017- 3 minute Thesis presentation

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9 Appendices

Appendix 1 - Ethical Approvals

NHS
Health Research Authority
North East - Tyne & Wear South Research Ethics Committee
HRA Newcastle
Newcastle Blood Donor Centre
Barrack Road
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 02071048084

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

6 April 2018

Miss Carol Stalker
Dept of Psychology (CLANS)
University of Derby
Kedleston Road
Derby DE22 1GB

Dear Miss Stalker

Study title:	**An investigation into the role of illness acceptance and technology acceptance on outcomes for patients on dialysis - a mixed method study.**
REC reference:	**18/NE/0111**
Protocol number:	**N/A**
IRAS project ID:	**240228**

The Proportionate Review Sub-Committee of the North East - Tyne & Wear South Research Ethics Committee reviewed the above application in correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

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.

A Research Ethics Committee established by the Health Research Authority

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non-registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

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").

Summary of discussion at the meeting

The Sub-Committee reviewed the above application and raised the following issue to be addressed:

Social or scientific value; scientific design and conduct of the study

Provide the rationale for excluding patients with a malignancy of prognosis of less than 12 months from the study, as this is an important group.

You provided the following response – "There are a number of reasons why patients with a malignancy prognoses of less than 12 months are excluded. Firstly this study is running along the iTrend study and may include up to 50 patients from this study, therefore the criteria for inclusion and exclusion maps onto their inclusion and exclusion criteria. The rational for this is to avoid introducing different criteria which may create differences between the iTrend and non-iTrend participants.

The second reason is due to the main variable of interest - acceptance of illness. Theory relating to acceptance of illness may differ from acceptance of terminal diagnosis. Whilst both are valuable areas of study the psychological processes involved may be different; for example acceptance of illness may be seen as an ongoing cycle of adjustment (Hammond and Hirst-Winthrop 2016) which varies through illness. In end stage renal disease patients it suggests that at certain times acceptance may change, for example with changes in dialysis regime. However this process may be affected in patients with terminal diagnosis, and in this situation the traditional model (Kubler-Ross 1969) might be more influential. This is a staged approach with the final stage being acceptance. The proposed study is exploring the role of acceptance and psychological variables therefore including patients with a malignancy of prognosis of less than 12 months may capture a different process and be a confounding factor.

Finally, due to the longitudinal nature of the study, patients are being followed up for 12 months which may not be possible in this group.

To summarise, the main rationale is that there might be different processes of acceptance which are working on psychological variables and therefore there was seen to be no reason to deviate from the established inclusion and exclusion criteria for the iTrend study. Whilst we completely agree that the excluded patient group is an important subgroup the role of acceptance within this group may be better researched with a study specifically designed to capture the nature of acceptance within this group and something we may consider in future work".

The Sub-Committee was satisfied with the response provided.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UoD Indemnity evidence]		15 July 2017
Interview schedules or topic guides for participants [Interview schedule]	1	05 March 2018
IRAS Application Form [IRAS_Form_19032018]		19 March 2018
Other [Debrief]	1	06 March 2018
Other [Debrief]	1	06 March 2018

Participant consent form [Consents - all]	1	15 February 2018
Participant information sheet (PIS) [Home PIS]	1	05 March 2018
Participant information sheet (PIS) [Hospital PIS]	1	05 March 2018
Referee's report or other scientific critique report [University College approval]		02 June 2017
Research protocol or project proposal [Protocol]	2	05 March 2018
Summary CV for Chief Investigator (CI) [CI CV]		15 February 2018
Summary CV for student [CV- student/CI]		15 February 2018
Summary CV for supervisor (student research) [CV -supervisor]		21 February 2018
Summary CV for supervisor (student research) [CV - DoS]		12 March 2018
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Study flow chart]	1	05 March 2018
Validated questionnaire [Questionnaire pack]		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

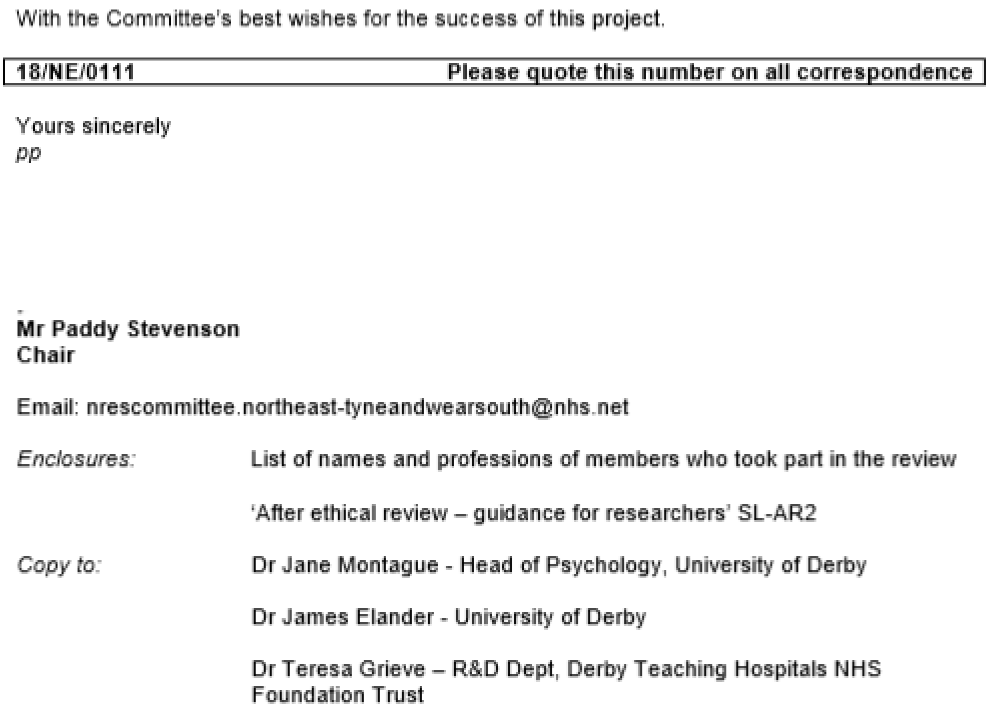
The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/



With the Committee's best wishes for the success of this project.

18/NE/0111 **Please quote this number on all correspondence**

Yours sincerely
pp

Mr Paddy Stevenson
Chair

Email: nrescommittee.northeast-tyneandwearsouth@nhs.net

Enclosures:	List of names and professions of members who took part in the review
	'After ethical review – guidance for researchers' SL-AR2
Copy to:	Dr Jane Montague - Head of Psychology, University of Derby
	Dr James Elander - University of Derby
	Dr Teresa Grieve – R&D Dept, Derby Teaching Hospitals NHS Foundation Trust

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Carol Stalker
University of Derby - Psychology - CLANS
Kedleston Road
Derby
DE22 1GB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

17 April 2018

Dear Miss Stalker

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**An investigation into the role of illness acceptance and technology acceptance on outcomes for patients on dialysis - a mixed method study.**
IRAS project ID:	**240228**
REC reference:	**18/NE/0111**
Sponsor	**University of Derby**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA/HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA/HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Prof James Elander
Tel: 01332 593048
Email: j.elander@derby.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **240228**. Please quote this on all correspondence.

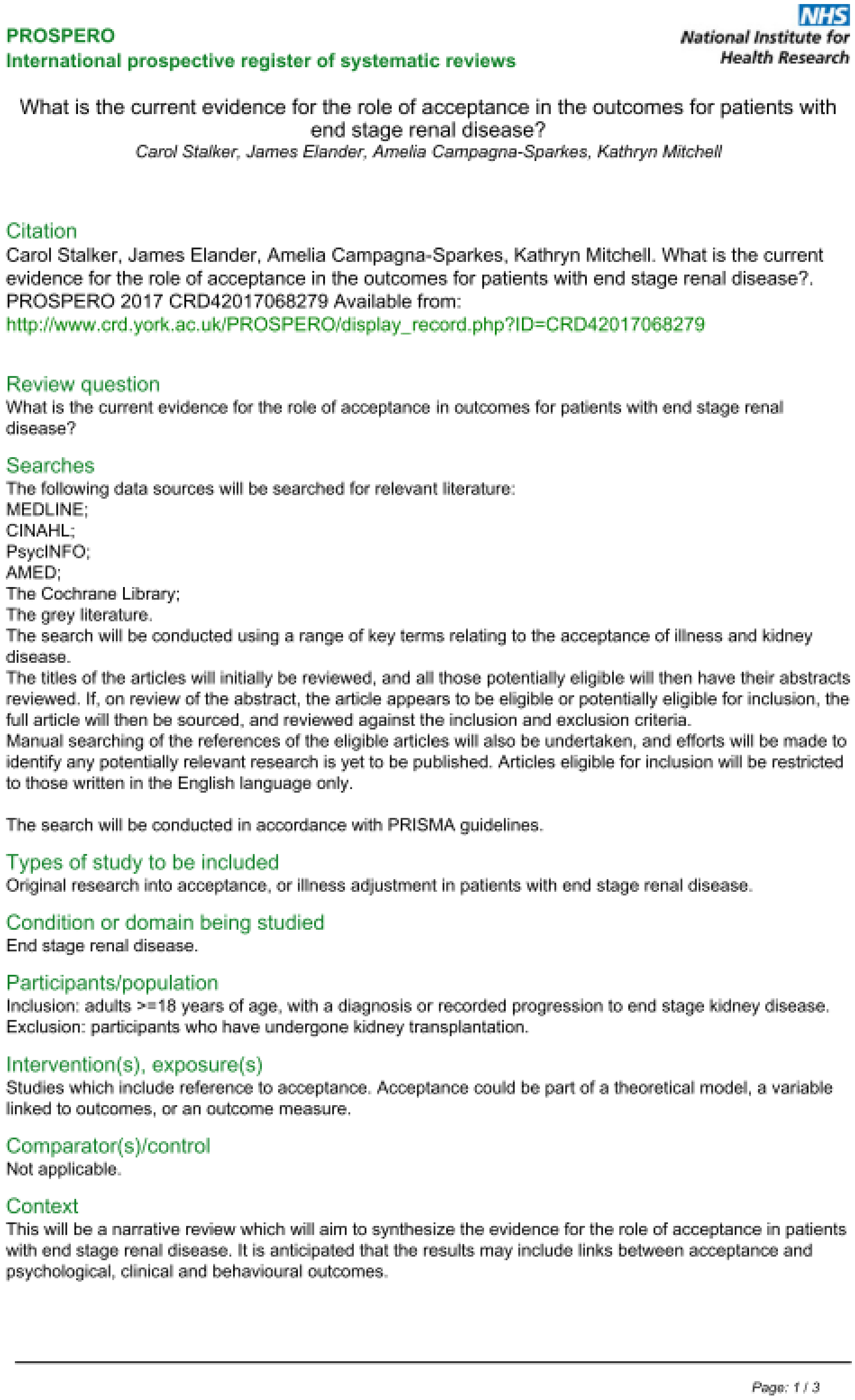
Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: Dr Teresa Grieve, R&D Contact, Derby Teaching Hospitals NHS Foundation Trust

Appendix 2 - Prospero Registration



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

What is the current evidence for the role of acceptance in the outcomes for patients with end stage renal disease?

Carol Stalker, James Elander, Amelia Campagna-Sparkes, Kathryn Mitchell

Citation

Carol Stalker, James Elander, Amelia Campagna-Sparkes, Kathryn Mitchell. What is the current evidence for the role of acceptance in the outcomes for patients with end stage renal disease?. PROSPERO 2017 CRD42017068279 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017068279

Review question

What is the current evidence for the role of acceptance in outcomes for patients with end stage renal disease?

Searches

The following data sources will be searched for relevant literature:
MEDLINE;
CINAHL;
PsycINFO;
AMED;
The Cochrane Library;
The grey literature.
The search will be conducted using a range of key terms relating to the acceptance of illness and kidney disease.
The titles of the articles will initially be reviewed, and all those potentially eligible will then have their abstracts reviewed. If, on review of the abstract, the article appears to be eligible or potentially eligible for inclusion, the full article will then be sourced, and reviewed against the inclusion and exclusion criteria.
Manual searching of the references of the eligible articles will also be undertaken, and efforts will be made to identify any potentially relevant research is yet to be published. Articles eligible for inclusion will be restricted to those written in the English language only.

The search will be conducted in accordance with PRISMA guidelines.

Types of study to be included

Original research into acceptance, or illness adjustment in patients with end stage renal disease.

Condition or domain being studied

End stage renal disease.

Participants/population

Inclusion: adults >=18 years of age, with a diagnosis or recorded progression to end stage kidney disease.
Exclusion: participants who have undergone kidney transplantation.

Intervention(s), exposure(s)

Studies which include reference to acceptance. Acceptance could be part of a theoretical model, a variable linked to outcomes, or an outcome measure.

Comparator(s)/control

Not applicable.

Context

This will be a narrative review which will aim to synthesize the evidence for the role of acceptance in patients with end stage renal disease. It is anticipated that the results may include links between acceptance and psychological, clinical and behavioural outcomes.

Page: 1 / 3

Main outcome(s)

Any study with acceptance or illness adjustment as a variable associated with an outcome measure including, but not restricted to, psychological, clinical and behavioural outcomes.
Or:
Any study with acceptance or illness adjustment as an outcome associated with other variables including, but not restricted to, psychological, clinical and behavioural variables.

Additional outcome(s)

None.

Data extraction (selection and coding)

The titles and/or abstracts of articles will be reviewed by two authors based on the questions, and the inclusion/exclusion criteria established for this review. All studies which may potentially meet the inclusion criteria will be retrieved as full texts, screened by two authors and assessed for eligibility. Any disagreements will be resolved with a third author, and corresponding authors will be contacted to request additional information if necessary. Data extracted from the studies will be used to populate a data extraction form, which will be piloted and amended as necessary prior to the implementation of the full extraction process.

Risk of bias (quality) assessment

Where applicable, the Cochrane Collaboration's tool for assessing risk of bias, or the ROBINS-I tool will be used to assess the risk of bias for all the research which is being considered for inclusion in the final review. These assessment tools will include consideration of the risk of bias due to confounding variables, participant selection, deviation from protocol, missing data and selection of reported results.

Strategy for data synthesis

The data is likely to comprise a broad mix of qualitative and quantitative findings. This indicates that a narrative synthesis will be the most suitable analytical procedure, and this will compare the acceptance of illness and the reported outcomes. Should sufficient data and consistency be found between variables, then a meta-analysis may also be carried out.

Analysis of subgroups or subsets

None planned.

Contact details for further information

Carol Stalker
c.stalker@derby.ac.uk

Organisational affiliation of the review

University of Derby
https://www.derby.ac.uk/

Review team members and their organisational affiliations

Miss Carol Stalker. University of Derby
Professor James Elander. University of Derby
Miss Amelia Campagna-Sparkes. University of Derby
Professor Kathryn Mitchell. University of Derby

Type and method of review

Systematic review

Anticipated or actual start date

31 May 2017

Anticipated completion date

31 August 2017

Funding sources/sponsors

University of Derby

Conflicts of interest

None known

Language

English

Country

England

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Attitude; Behavior; Disease Progression; Humans; Kidney Failure, Chronic; Renal Insufficiency, Chronic; Prognosis

Date of registration in PROSPERO

14 June 2017

Date of publication of this version

14 June 2017

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Versions

14 June 2017

Appendix 3 – Participant information sheets

Participant Information Sheet

(Version 2.0 a)

Title of Study: The role of acceptance for Dialysis patients

Name of Researchers: Miss Carol Stalker, Professor Kathryn Mitchell, Professor James Elander, Professor Paul Stewart, Dr N Selby, Professor M Taal,

REC Number : 240228

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve. Please take time to read the following information carefully. One of our team will go through the information sheet with you and answer any questions you have. Feel free to ask for more information or to clarify parts of the study that you do not understand. If you wish you can talk to other doctors, nurses, friends and family about the study.

What is the purpose of the study?

The aim of the research study is to look at psychological aspects that are linked to patients wellbeing and responses to treatment. The hope is that we can develop a greater understanding of how patients respond and react to illness and in particular the impact of being on dialysis. By understanding, these associations' steps can be taken to help patients adjust to dialysis and improve quality of life. The research study will use questionnaires and interviews to understand more about what you think and feel about dialysis. This data will then be linked to clinical data which is routinely collected during your dialysis sessions. We will then be able to compare your questionnaire responses with your clinical data and interview responses to identify which areas may be most influential in improving overall experiences on dialysis.

Why have I been invited?

You are being invited to take part because you are having regular haemodialysis for chronic kidney disease. We are inviting 150 participants like you to take part.

Do I have to take part?

No. It is completely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights. If you withdraw or decide not to take part it will not affect the standard of care you receive in any way.

What will happen to me if I take part?

If you are given information about the study and are considering taking part, one of our research team will contact you and arrange to meet you to discuss the study. This is likely to be during one of your regular dialysis sessions. You will have an opportunity during this initial meeting to discuss any questions you may have. We will also check with you at this point that it is possible and safe for you to take part. After this, you will be asked to sign a form to say you consent to be part of the study. Once you have agreed to take part in the study, we will make arrangements for you to start the study.

There are two parts to the study and you can choose to take part in both or if you would rather you can take part just one. There is the questionnaire study and the interview study.

The questionnaire study.

If you choose to take part in the questionnaire study then you will be provided with a questionnaire to complete at three time points. You can choose whether you would prefer to complete a paper questionnaire or an online version. Ideally, these will be completed on the dialysis unit during one of your routine sessions; alternatively you can complete these at home. The questionnaire will take approximately 30 minutes to complete and asks various questions about you, your dialysis regime, how you feel and what you think. We would like to compare the results from the questionnaire to your data which is routinely collected during your dialysis sessions (sodium, potassium, urea, creatinine, calcium, phosphate, parathyroid hormone and haemoglobin levels) and dialysis measures (dialysis prescription, dialysis adequacy). To enable us to do this when we ask you for consent we will specifically ask about this. If you do consent to this then the research team will be able to access the relevant information from your medical notes. We will ask you to complete the questionnaire at the start of the study, then again six months later and finally 12 months later. This will allow us to monitor changes over time. We will ask you to complete the questionnaire in the same format as originally completed (e.g. paper or online). Before being asked to complete the questionnaires at 6 months and 12 months you will be asked if you are still happy to continue and if there have been any new medical problems.

The interview study

If you choose to take part in the interview study then you will be asked to participate in two interviews. One at the start of the study and one approximately 12 months later. The interviews will take about 1 hour of your time and will ask you questions about your experiences and feelings about dialysis. Interviews will be arranged by the researcher and take place at a time and place that is convenient to you. This could be on the dialysis unit, at the University of Derby or in your own home. The interview will be digitally recorded to ensure we have an accurate account of your experience and notes will also be taken throughout the interview in order to aid the analysis process. The recordings will be held securely and transcribed shortly after the interview All information will remain anonymous as any identifiable information (e.g., names) will be removed or replaced with pseudonyms (a false name) during transcription. The interview at 12 months will take the same format but some of the questions may refer back to the things you said in the first interview. Recordings for the interviews will be stored securely until the completion of the research at which point the data will recordings will be destroyed.

Links to the iTrend study

There is another study underway in the Dialysis unit which involves collecting data about blood pressure and heart rate from patients whilst they are on dialysis. If you are part of the iTrend study and would like to take part in this study then there is no reason why you can’t. However if you choose to participate in both we will ask if we can link the data from the iTrend study to data collected in this study. By doing this it will allow us to develop a more detailed picture of how your experiences of dialysis link to your physical wellbeing.

Expenses and payments

Unfortunately, no payment can be offered to you for your participation in this study. Transport to and from dialysis will be as your usual arrangements.

What are the possible disadvantages and risks of taking part?

There are no risks to taking part in this study. The disadvantages of taking part are:

Time inconvenience: completing the questionnaires will take some time, approximately 30 minutes each time. Taking part in the interviews may also take up to 1.5 hrs of your time. To reduce the impact questionnaires are designed to be completed at a time and in a way most convenient to yourself. Interviews will also be scheduled at a time and place to fit with your needs.

What are the possible benefits of taking part?

The information we get from this study may not help you directly. In future, we are aiming to use this information to understand more about the role of patients thoughts and feelings in how it affects dialysis and quality of life. Understanding what is important in adjusting to the dialysis regime may allow for the development of interventions to help patients manage any difficulties they encounter.

What happens when the research study stops?

When the research study comes to an end we will analyse the data. The results will be published and may lead to further research studies or a change in the way we manage patients with chronic kidney disease. We can send you an information sheet letting you know the results and what they mean.

What if there is a problem?

We do not expect anything to go wrong. If you have any concerns or queries about any aspect of this study, you should ask to speak to Miss Carol Stalker (who will be undertaking the day to day running of the study), who will do her best to answer your questions. (Contact number 01332 591480). If you remain unhappy, we will arrange for you to speak with Professor Elander (who will be overseeing the study) or Dr Selby.

If you wish to complain about the conduct of the research you should contact Professor Kathryn Mitchell, University of Derby, Kedleston Road, DE22 1GB.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information collected about you during the course of the research will be handled with confidence. This includes only breaking confidentiality if you disclose something which may put yourself or others at harm. It is necessary to record in your hospital notes that you are participating in this study, for your benefit and protection.

Some parts of your medical records and data collected for the study will be looked at by authorised persons from the University of Derby who are organizing the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you.

You will be allocated a study number and which will be used with your data so it is not linked to your personal information. No one will access your records except study personnel and personnel from appropriate regulatory agencies. Your information will be kept in accordance with the Data Protection Act 1998 and European general data protection regulations.

Your personal data (address, telephone number) will be kept for 6 months after the end of the study. All other research data will be kept securely for 7 years.

All data collected for each patient will be transferred to a trial master file. It will be archived at secure archive facilities at the University of Derby. Computer held data including the study database will be held securely and password protected. All data will be stored on a secure dedicated web server. All collected data will be kept for 7 years as per UoD policy

All research data will be shared with the University of Derby and the University of Nottingham, and be analysed by Carol Stalker.

Your medical details will not be made available to anyone outside the research team and those who are normally involved in your treatment.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far will still be used in the project analysis unless you specifically wish that it is not.

Will any genetic tests be done?

No genetic tests will be performed as part of this study.

What will happen to the results of the research study?

The results of the study will be submitted to journals for publication and to scientific meetings for presentation. A report of the results will also be published. You will not be identified in any report/publication. Copies of these will be available on request where possible.

Our results are published in a regular patient information leaflet produced by the renal department at Royal Derby Hospital, you can also ask about the results of the study at your routine outpatient follow up appointment.

Who is organising and funding the research?

This research is being organised by Carol Stalker, under the supervision of Professor James Elander and Professor Kathryn Mitchell from the University of Derby. This work is part of a PhD project.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the North East (Tyne and Wear South) Research Ethics Committee.

Further information and contact details

For further information or to discuss this research study please contact any of the following:

University of Derby

Carol Stalker	Professor James Elander
Post Graduate Research Student	Professor of Psychology
(Chief Investigator)	

Main Contact

01332 591480	01332 593048
c.stalker@derby.ac.uk	J.Elander@derby.ac.uk

Department of Renal Medicine

Royal Derby Hospital

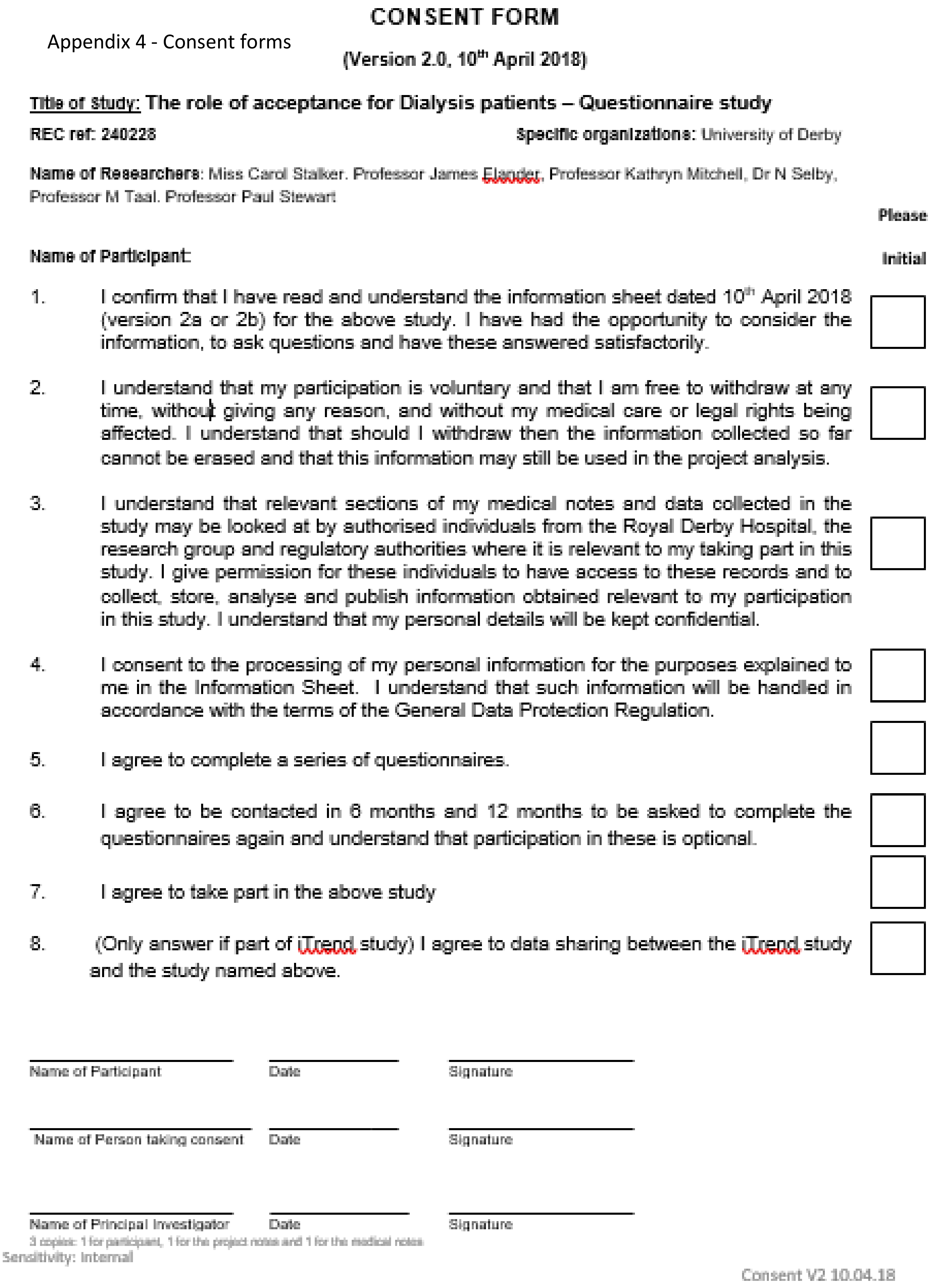
Miss Kelly White	Dr Nick Selby	Professor Maarten Taal
Renal Research Nurse	Associate Professor of Nephrology	Professor of Medicine

Contact:

Tel: 01332 789344 (direct line)

To find out more about the regulation of Research within the NHS visit: www.nres.nhs.uk

Appendix 4 - Consent forms



CONSENT FORM

(Version 2.0, 10th April 2018)

Title of Study: The role of acceptance for Dialysis patients – Questionnaire study

REC ref: 240228 **Specific organizations:** University of Derby

Name of Researchers: Miss Carol Stalker. Professor James Elander, Professor Kathryn Mitchell, Dr N Selby, Professor M Taal. Professor Paul Stewart

Please Initial

Name of Participant:

1. I confirm that I have read and understand the information sheet dated 10th April 2018 (version 2a or 2b) for the above study. I have had the opportunity to consider the information, to ask questions and have these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the Royal Derby Hospital, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained relevant to my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I consent to the processing of my personal information for the purposes explained to me in the Information Sheet. I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation. ☐
5. I agree to complete a series of questionnaires. ☐
6. I agree to be contacted in 6 months and 12 months to be asked to complete the questionnaires again and understand that participation in these is optional. ☐
7. I agree to take part in the above study ☐
8. (Only answer if part of iTrend study) I agree to data sharing between the iTrend study and the study named above. ☐

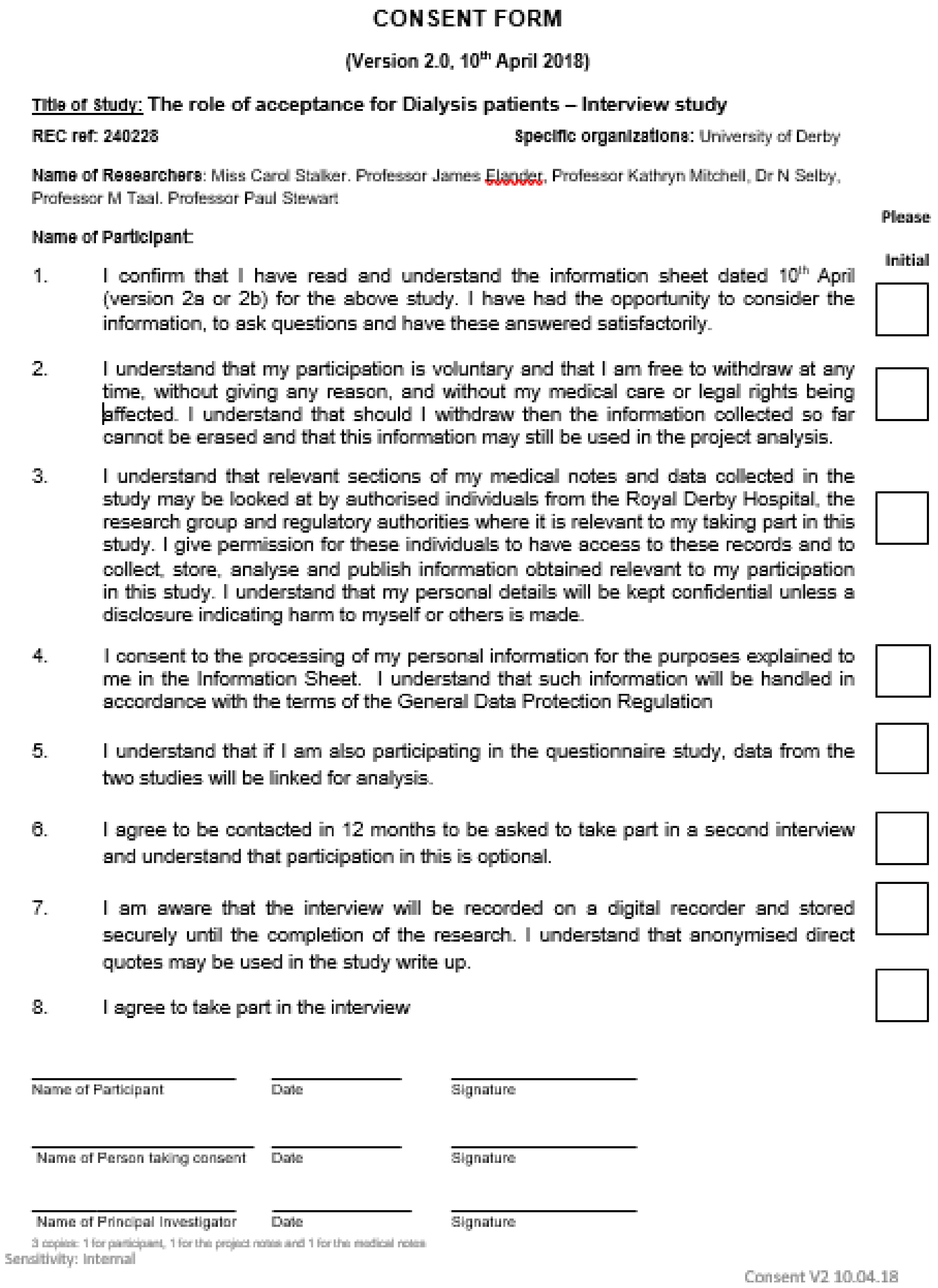
Name of Participant ______ Date ______ Signature ______

Name of Person taking consent ______ Date ______ Signature ______

Name of Principal Investigator ______ Date ______ Signature ______

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Sensitivity: Internal



CONSENT FORM

(Version 2.0, 10th April 2018)

Title of Study: **The role of acceptance for Dialysis patients – Interview study**

REC ref: 240228 **Specific organizations:** University of Derby

Name of Researchers: Miss Carol Stalker. Professor James Elander, Professor Kathryn Mitchell, Dr N Selby, Professor M Taal. Professor Paul Stewart

Please Initial

Name of Participant:

1. I confirm that I have read and understand the information sheet dated 10th April (version 2a or 2b) for the above study. I have had the opportunity to consider the information, to ask questions and have these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the Royal Derby Hospital, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained relevant to my participation in this study. I understand that my personal details will be kept confidential unless a disclosure indicating harm to myself or others is made. ☐

4. I consent to the processing of my personal information for the purposes explained to me in the Information Sheet. I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation ☐

5. I understand that if I am also participating in the questionnaire study, data from the two studies will be linked for analysis. ☐

6. I agree to be contacted in 12 months to be asked to take part in a second interview and understand that participation in this is optional. ☐

7. I am aware that the interview will be recorded on a digital recorder and stored securely until the completion of the research. I understand that anonymised direct quotes may be used in the study write up. ☐

8. I agree to take part in the interview ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature
Name of Principal Investigator	Date	Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

Sensitivity: Internal

Consent V2 10.04.18

Appendix 5 - Debriefing documents

Debrief – questionnaires (baseline and 6 months)

Thanks very much for helping us with our research by completing these questionnaires. We are hoping to find out more about patients experiences of dialysis, how this affects upon your day-to-day life and how they may be linked with your physical wellbeing. We will be in contact again in 6 months to ask you to complete the questionnaires again. You do not have to complete the questionnaire again if you decide you would not like to continue with the research please just let us know.

If you have any questions about or research please get in touch with us.

Thank you again for taking part! We really appreciate it.

If you would like further details of the study please contact Carol Stalker (c.stalker@derby.ac.uk) or on 01332 591480. If you need to contact anyone regarding Dialysis issues please contact the renal team in your usual way or through the renal main reception on 01332 88259.

Debrief - questionnaires (Final)

Thanks very much for helping us with our research by completing these questionnaires. We are hoping to find out more about patients experiences of dialysis, how this affects upon your day-to-day life and how they may be linked with your physical wellbeing. This is the final time we will ask you to complete the questionnaires. We will now be comparing the data you have provided throughout the study to help us understand the factors which are most important in affecting your quality of life and adjustment to dialysis. By identifying these relationships we can start to develop ways in which quality of life and adjustment to life on dialysis can be improved.

If you have any questions about or research please get in touch with us.

Thank you again for taking part! We really appreciate it. Keep an eye out for information about the findings of this research in department research newsletter.

If you would like further details of the study please contact Carol Stalker (c.stalker@derby.ac.uk) or on 01332 591480. If you need to contact anyone regarding Dialysis issues please contact the renal team in your usual way or through the renal main reception on 01332 88259.

Debrief – Interviews (Initial)

Thanks very much for helping us with our research by sharing your thoughts and experiences through this interview. We are hoping to find out more about patients experiences of dialysis, how this affects upon your day-to-day life and how they may be linked with your physical wellbeing. We may be in contact again in 12 months to ask you if you would like to take part in another interview. You do and if you decide you would not like to continue with the research please just let us know.

If you have any questions about or research please get in touch with us.

Thank you again for taking part! We really appreciate it.

If you would like further details of the study please contact Carol Stalker (c.stalker@derby.ac.uk) or on 01332 591480. If you need to contact anyone regarding Dialysis issues please contact the renal team in your usual way or through the renal main reception on 01332 88259.

Appendix 6 - Interview schedule

Interview Schedule

Opening questions

What type of dialysis are you on?
Can you tell me how long you have been on Dialysis?

Deeper questions

What happened in the lead up to you going onto dialysis?
Prompt -Can you tell me about your experience of …Diagnosis, preparation

Can you tell me about how you felt when you first started on dialysis?
Prompt - *What did you find difficult? What was easiest to adjust to?*

How do you feel about Dialysis now?
Prompt - *Can you tell me about your experience of … positives, negatives, dialysis machine*

What is a typical dialysis day like for you?
Prompt - *Good day, bad day*

What is a rest day like for you?

What would you advise someone who is new to dialysis?

How do you feel acceptance may have played a part in your experience on dialysis?
Acceptance of illness, acceptance of medical treatment, acceptance of restrictions

Dialysis Experiences Questionnaire

Version 2.0

University of Derby

Researcher - Carol Stalker

Please return completed questionnaire to researcher by hand or post in enclosed postage paid envelope to

Carol Stalker – GTA
University of Derby
CLANS – Psychology
Kedleston Road
Derby
DE22 1GB

What is the purpose of this study?

This study is being carried out in cooperation with physicians and their patients. The purpose is to assess the factors associated with quality of life of patients with kidney disease.

What will I be asked to do?

For this study you will be asked to complete the following questionnaire. I will take approximately 30 mins to complete. The questions will ask for information about you and how you manage on dialysis.

The sub-sections of the questionnaire are;

About you

About your Dialysis

About your quality of life

About how you cope with Dialysis

About what you think and feel about Dialysis

About how you manage on Dialysis

Confidentiality of information?

You don't have to give your name. Your answers will be combined with those of other participants when we make a report about the findings of the study. Any information that might make it possible to identify you will be regarded as strictly confidential. In addition, all information collected will be used only for the purposes of this study, and will not be disclosed or released for any other purpose without your prior consent.

Do I have to take part?

You don't have to fill out the survey, and you can refuse to answer any question. Your decision to participate will not affect your chance to receive care.

If you are still happy to take part please read the questions carefully and answer as accurately as possible.

Participant Number -

Date -

Demographic questionnaire

The following questions will ask some information about yourself.

1. **Please enter your date of birth (DD/MM/YYYY)** ____________________________

2. **How old are you?** ____________________________

3. **Are you?**
   - ☐ Male
   - ☐ Female

4. **Please enter the first part of your postcode? E.g. DE22** ____________________________

5. **Please select the highest level of education you have reached?**
   - ☐ Left at age 16 or less
   - ☐ GCSE's (General Certificate of Education)
   - ☐ A-levels (Advanced level)
   - ☐ Vocational school or some college
   - ☐ University Degree
   - ☐ Professional graduate degree
   - ☐ Other (Please specify) ______________________

6. **Please indicate your marital status**
   - ☐ Single
   - ☐ Married
   - ☐ Co-habiting
   - ☐ Divorced
   - ☐ Widowed
   - ☐ Separated
   - ☐ Other – please state ____________________________

7. **What is your current employment status?**
   - ☐ Full-time
   - ☐ Part-time
   - ☐ Unemployed and looking for work
   - ☐ Unemployed and not seeking work
   - ☐ Student
   - ☐ Retired
   - ☐ Homemaker
   - ☐ Carer
   - ☐ Other – please state ____________________________

8. **If employed please tell us your type of employment** ____

9. What was your total household income (from all sources) before taxes in the LAST CALENDAR YEAR, including yourself, your partner, and others you regard as family who live in your household? (Please remember your answers are confidential).

☐ Less than £3,000
☐ £3,001-£7,500
☐ £7,501-£15,000
☐ £15,001-£30,000
☐ £30,001-£50,000
☐ More than £50,000
☐ Don't know

10. Please state your ethnicity

White
☐ White British
☐ White Irish
☐ Any other white background

Mixed
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed background

Asian or Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Any other Asian Background

Black or Black British
☐ Caribbean
☐ African
☐ Any other Black Background

Other Ethnic Group
☐ Chinese
☐ Any other Ethnic Group

☐ Prefer not to say

11. Please indicate your religious belief

☐ Christian
☐ Muslim
☐ Hindu
☐ Sikh
☐ Jewish
☐ Buddhist
☐ Other religion (Please state)

☐ No Religion

☐ Prefer not to say

____

12. Which of the following most closely represents you?

☐ My religion or belief is very important in my life
☐ I have a religion or belief but it is generally in the background in my life
☐ Religion or belief does not feature very much in my life
☐ Prefer not to say

Dialysis Information

The following questions will ask you for some information about your Dialysis

13. What type of Dialysis are you currently on?

☐ Haemodialysis – Hospital
☐ Haemodialysis – Home
☐ Peritoneal Dialysis - CAPD
☐ Peritoneal Dialysis - APD

14. How long have you been on this type of Dialysis?

____________years __________months

15. How long have you been on any type of Dialysis?

____________years __________months

16. What caused your kidney disease?
Select all that apply

☐ Don't know
☐ Hypertension (High Blood Pressure)
☐ Diabetes
☐ Polycystic Kidney Disease
☐ Chronic Glomerulonephritis
☐ Chronic Pyelonephritis
☐ Other (please specify):

____

17. Do you have any other illnesses – Please state

____

____

18. Do you currently take prescription medications regularly (4 or more days a week) that are prescribed by your doctor for a medical condition? Please don't count over the counter medications like antacids or aspirin.

☐ No - please skip to question 17
☐ Yes

18 b. How many different prescription medications do you currently take?

Number of medications ________________

19. How many days total in the last 6 months did you stay in any hospital overnight or longer? *(If none, please write in 0)*

Number of Days _______________

20. How many days total in the last 6 months did you receive care at a hospital, but came home the same day? *(If none, please write in 0)*

Number of Days ________________

Quality of Life for Patients on Dialysis

Instructions
For Filling Out Survey

A. This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

B. This survey includes a wide variety of questions about your health and your life. We are interested in how you feel about each of these issues.

C. Please answer the questions by marking the appropriate box or by filling in the answer as requested.

Example:

During the past four weeks, how much back pain have you had?

(Mark one box)

None ☒ 1

Very mild ☐ 2

Mild ☐ 3

Moderate ☐ 4

Severe ☐ 5

D. Several items in the survey ask about the effect of kidney disease on your life. Some items will ask about limitations related to your kidney disease, and some items will ask about your well-being. Some questions may look like others, but each one is different. Please answer every question as honestly as possible. If you are unsure about how to answer a question, please give the best answer you can. This will allow us to have an accurate picture of the different experiences of individuals with kidney disease.

1. **In general, would you say your health is:**

Excellent	Very Good	Good	Fair	Poor
☐	☐	☐	☐	☐

2. **Compared to one year ago, how would you rate your health in general now?**

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐	☐	☐	☐	☐

3. **The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, Limited a lot	Yes, limited a little	No, Not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
Lifting or carrying groceries	☐	☐	☐
Climbing several flights of stairs	☐	☐	☐
Climbing one flight of stairs	☐	☐	☐
Bending, kneeling, or stooping	☐	☐	☐
Walking more than a mile	☐	☐	☐
Walking 500 metres	☐	☐	☐
Walking 100 metres	☐	☐	☐
Bathing or dressing yourself	☐	☐	☐

4. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	Yes	No
Cut down on the amount of time you spent on work or other activities?	☐	☐
Accomplished less than you would have liked?	☐	☐
Were limited in the kind of work or other activities?	☐	☐
Had difficulty performing the work or other activities (for example, it took extra effort)?	☐	☐

5. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	Yes	No
Cut down on the amount of time you spent on work or other activities?	☐	☐
Accomplished less than you would have liked?	☐	☐
Didn't do work or other activities as carefully as usual?	☐	☐

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or clubs?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

7. **How much bodily pain have you had during the past 4 weeks?**

None	Very mild	Mild	Moderate	Severe	Very severe
☐	☐	☐	☐	☐	☐

8. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

9. **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	☐	☐	☐	☐	☐	☐
Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
Have you felt downhearted and unhappy?	☐	☐	☐	☐	☐	☐
Did you feel worn out?	☐	☐	☐	☐	☐	☐
Have you been a happy person?	☐	☐	☐	☐	☐	☐
Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

11. Please choose the answer that best describes how true or false each of the following statements is for you.

	Definitely true	Mostly true	Don't Know	Mostly False	Definitely False
I seem to catch things a little more easily than other people	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐

Your Kidney Disease

12. How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't Know	Mostly False	Definitely False
My kidney disease interferes too much with my life	☐	☐	☐	☐	☐
Too much of my time is spent dealing with my kidney disease	☐	☐	☐	☐	☐
I feel frustrated dealing with my kidney disease	☐	☐	☐	☐	☐
I feel like a burden on my family	☐	☐	☐	☐	☐

13. These questions are about how you feel and how things have been going during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
Did you isolate yourself from people around you?	☐	☐	☐	☐	☐	☐
Did you react slowly to things that were said or done?	☐	☐	☐	☐	☐	☐
Did you act irritable toward those around you?	☐	☐	☐	☐	☐	☐

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
Did you have difficulty concentrating or thinking?	☐	☐	☐	☐	☐	☐
Did you get along well with other people?	☐	☐	☐	☐	☐	☐
Did you become confused?	☐	☐	☐	☐	☐	☐

14. During the past 4 weeks, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
Soreness in your muscles	☐	☐	☐	☐	☐
Chest pain?	☐	☐	☐	☐	☐
Cramps?	☐	☐	☐	☐	☐
Itchy skin?	☐	☐	☐	☐	☐
Dry skin?	☐	☐	☐	☐	☐
Shortness of breath?	☐	☐	☐	☐	☐
Faintness or dizziness?	☐	☐	☐	☐	☐
Lack of appetite?	☐	☐	☐	☐	☐
Washed out or drained?	☐	☐	☐	☐	☐
Numbness in hands or feet?	☐	☐	☐	☐	☐
Nausea or Vomiting?	☐	☐	☐	☐	☐
(Haemodialysis patient only) Problems with your access site?	☐	☐	☐	☐	☐
(Peritoneal dialysis patient only) Problems with your catheter site?	☐	☐	☐	☐	☐

15. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
Fluid restriction?	☐	☐	☐	☐	☐
Dietary restriction?	☐	☐	☐	☐	☐
Your ability to work around the house?	☐	☐	☐	☐	☐
Your ability to travel?	☐	☐	☐	☐	☐
Being dependent on doctors and other medical staff?	☐	☐	☐	☐	☐
Stress or worries caused by kidney disease?	☐	☐	☐	☐	☐
Your sex life?	☐	☐	☐	☐	☐
Your personal appearance?	☐	☐	☐	☐	☐

16. The next two questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people's lives.

How much of a problem was each of the following in the past 4 weeks?

	Not a problem	A little problem	Somewhat of a problem	Very much of a problem	Severe problem
Enjoying sex?	☐	☐	☐	☐	☐
Becoming sexually aroused?	☐	☐	☐	☐	☐

17. For the following question, please rate your sleep using a scale ranging from 0 representing "very bad" to 10 representing "very good".

If you think your sleep is half-way between "very bad" and "very good," please mark the box under the number 5. If you think your sleep is one level better than 5, mark the box under 6. If you think your sleep is one level worse than 5, mark the box under 4 (and so on).

On a scale from 0 to 10, how would you rate your sleep overall?

[Mark an ☒ in one box.]

Very bad									Very good
1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

18. How often during the past 4 weeks did you...

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
Awaken during the night and have trouble falling asleep again?	☐	☐	☐	☐	☐	☐
Get the amount of sleep you need?	☐	☐	☐	☐	☐	☐
Have trouble staying awake during the day?	☐	☐	☐	☐	☐	☐

19. Concerning your family and friends, how satisfied are you with...

	Very dissatisfied	Somewhat dissatisfied	Somewhat satisfied	Very satisfied
The amount of time you are able to spend with your family and friends?	☐	☐	☐	☐
The support you receive from your family and friends?	☐	☐	☐	☐

20. During the past 4 weeks, did you work at a paying job?

Yes	No
☐	☐

21. Does your health keep you from working at a paying job?

Yes	No
☐	☐

22. Overall, how would you rate your health?

Worst possible (as bad or worse than being dead) — Half way between worst and best — Best health possible

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Satisfaction with care

23. Think about the care you receive for kidney dialysis. In terms of your satisfaction, how would you rate the friendliness and interest shown in you as a person?

Very poor	Poor	Fair	Good	Very good	Excellent	The Best
☐	☐	☐	☐	☐	☐	☐

24. How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't Know	Mostly False	Definitely False
Dialysis staff encourage me to be as independent as possible	☐	☐	☐	☐	☐
Dialysis staff support me in coping with my kidney disease	☐	☐	☐	☐	☐

These questions deal with ways you've been coping with the stress in your life since being on Dialysis. There are many ways to try to deal with problems. These questions ask what you've been doing to cope with Dialysis. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true **FOR YOU** as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

	I haven't been doing this at all			I have been doing this a
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real".	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I’ve been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I’ve been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs	1	2	3	4
23. I’ve been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I’ve been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

Thoughts about illness questionnaire

Instructions

On the next page is a list of statements by people with a long-term illness.

Please indicate the extent to which you agree with them by circling one of the answers following the statement. An example is provided below.

Example If you agree with the statement below to **a large extent**, circle 3:

	Not at all	Somewhat	To a large extent	Completely
I have learned to live with my illness.	1	2	[✓ 3]	4

Work through the entire list of statements in this way. Do not spend too much time considering your answer. Your first impression is usually the best.

QUESTIONNAIRE

To what extent do you agree with the following statements?

	Not at all	Somewhat	To a large extent	Completely
1. Because of my illness I miss the things I like to do most.	1	2	3	4
2. I can handle the problems related to my illness.	1	2	3	4
3. I have learned to live with my illness.	1	2	3	4
4. Dealing with my illness has made me a stronger person.	1	2	3	4
5. My illness controls my life.	1	2	3	4
6. I have learned a great deal from my illness.	1	2	3	4
7. My illness makes me feel useless at times.	1	2	3	4
8. My illness had made life more precious to me.	1	2	3	4
9. My illness prevents me from doing what I would really like to do.	1	2	3	4
10. I have learned to accept the limitations imposed by my illness.	1	2	3	4
11. Looking back, I can see that my illness has also brought about some positive changes in my life.	1	2	3	4
12. My illness limits me in everything that is important to me.	1	2	3	4
13. I can accept my illness well.	1	2	3	4
14. I think I can handle the problems related to my illness, even if the illness gets worse.	1	2	3	4
15. My illness frequently makes me feel helpless.	1	2	3	4
16. My illness has helped me realize what’s important in life.	1	2	3	4
17. I can cope effectively with my illness.	1	2	3	4
18. My illness has taught me to enjoy the moment more	1	2	3	4

DASS21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

AiS Questionnaire

Please indicate the extent to which you agree with them by circling one of the answers following the statement.

	Strongly Agree				Strongly Disagree
I have a hard time adjusting to the limitations of my illness	1	2	3	4	5
Because of my health, I miss the things I like to do most	1	2	3	4	5
My illness makes me feel useless at times	1	2	3	4	5
Health problems make me more dependent on others than I want to be	1	2	3	4	5
My illness makes me a burden on my family and friends	1	2	3	4	5
My health makes me feel inadequate	1	2	3	4	5
I will never be self-sufficient enough to make me happy	1	2	3	4	5
I think people are often uncomfortable being around me because of my illness	1	2	3	4	5

SE- Questionnaire

		Not at all true	**Barely true**	**Moderately true**	**Exactly true**
1	I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2	If someone opposes me, I can find the means and ways to get what I want.	1	2	3	4
3	It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4	I am confident that I could deal efficiently with unexpected events.	1	2	3	4
5	Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
6	I can solve most problems if I invest the necessary effort.	1	2	3	4
7	I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8	When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
9	If I am in trouble, I can usually think of a solution.	1	2	3	4
10	I can usually handle whatever comes my way.	1	2	3	4

Appendix 8 - GDPR statement

GDPR statement for Research Study – The role of acceptance in dialysis patients

Researchers will be collecting data from your participation in this study as described in this information sheet and consent form. This is the legal basis on which we are collecting your data. **While this allows us to use your data, it also means we have obligations towards you to:**

- Not seek more information from you than what is essential and necessary for the study;
- Make sure that you are not identified by the data by anonymising it using ID codes;
- Use your anonymised data only for the purposes of this study and for any relevant publications that arise from it.
- Store data safely in password-protected databases to which only the named researchers have access
- Not keep your information for longer than is necessary (usually for seven years);
- Safely destroy your data by shredding or permanently deleting them

The University of Derby will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. Researchers on the project with access to the data are highly qualified and experienced and have been very careful to ensure the security of your data.

The study was approved for its ethical standards the North East (Tyne and Wear South) NHS Research Ethics Committee. However, in the unlikely event that you feel you need to make a complaint regarding the use of your information, you can contact the Data Protection Officer at the University of Derby: James Eaglesfield (01332) 591762 or the Information Commissioners Office 0303 123 1113.

Further information about the project can be obtained from the project team (main contact- Carol Stalker) either by phone (01332 591480) or email (c.stalker@derby.ac.uk) at the University of Derby, Kedleston Road, Derby DE22 1GB.

Appendix 9 - Word Tree