

**Barriers to the elective start of  
renal replacement therapy:  
what are they, why do they occur and  
how can we overcome them?**

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**by**

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For my mum Patricia Buck  
with love and thanks  
for a lifetime of unwavering support

# DECLARATION

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The work described in this thesis was carried out under the supervision of Professor Richard Baker and Dr. Margaret Stone at the University of Leicester, Department of Health Sciences and of Dr. Graham Warwick at Leicester General Hospital, University Hospitals of Leicester NHS Trust. The work was completed between September 2004 and September 2008. This dissertation is my own work and contains nothing that is the outcome of work done in collaboration with others, except as specified in the text and acknowledgements. This thesis has not been submitted in whole or in part to any other University.

Jackie Buck  
September 2008



# ABSTRACT

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Jackie Buck

**Barriers to the elective start of renal replacement therapy: what are they, why do they occur and how can we overcome them?**

Patients known to the kidney care services before needing dialysis should not start dialysis urgently through a temporary vascular access catheter, as this is likely to lead to increased morbidity and mortality. The aim of this study was to understand why patients within the East Midlands Renal Network start dialysis urgently when they have been known to the kidney care services for four months or more, and to make some recommendations on how to prevent this.

An observational case-note survey found that patients who had an urgent dialysis start were more ill than those who had undergone elective dialysis initiation. Almost all had been known to the service for at least a year. They were less likely to have been seen in a predialysis clinic or to have attended a predialysis education session and older age was a significant barrier to an elective start. A qualitative study of patients who had recently started on dialysis showed that many had not been adequately supported psychologically, nor had their educational needs relating to self care and dialysis addressed throughout the disease process. A qualitative study of healthcare professionals suggested that they perceive distinct roles for themselves and for patients, with those who don't conform being judged unfavourably. Both studies revealed that are difficulties with of the timing of referrals within the kidney care service. Case studies highlighted the difference in perceptions of care between patients and healthcare professionals, the highly individual nature of involvement in illness management, and some difficulties with intercultural perceptions. Decision making preference varied but overall there was a lack of shared decision making.

This thesis shows the need for a shift in the relationship between healthcare professionals and patients towards a more patient-centred, personalised approach, with efforts made to tailor education and decision making styles to each patient.

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# CHAPTER 1

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## Introduction to thesis

### 1.1 Introduction

'... it is devastating no matter how much notice you have about kidney failure whether ... you're gonna be on dialysis the next day or you've had three years it's still devastating'

Patient 19, 2007

Starting dialysis is a major event for people with chronic kidney disease (CKD), their families and supporters. It signifies the death of their kidneys and for many a complete change to life as they know it, as they become reliant on external, artificial means of life support. The goal of renal services around the world is to ensure that the transition from independence to dependence on dialysis is as smooth a process as possible (Kidney Health Australia 2006; Vascular Access Working Group 2006). Indeed, the National Service Framework for Renal Services in the United Kingdom states that 'all adults...approaching established renal failure are to receive timely preparation for renal replacement therapy' (Department of Health Renal Team 2004). This is because patients who start dialysis in an emergency situation are at far greater risk of infections and other health related problems, and sadly, death within a year of starting dialysis (Lorenzo, Martin et al. 2004; Ishani, Collins et al. 2005). The purpose of this research is simple: to explain why some patients have a smooth transition onto dialysis and others do not, when they have been in the kidney care system for some time beforehand. In other words, what are the barriers to the elective start of renal replacement therapy?

This chapter is divided into three distinct sections, the first explaining chronic kidney disease and service provision, the second outlining barriers to care as experienced by patients with CKD and other health conditions. The third section

discusses the approach taken during this research study to investigate the barriers to elective dialysis initiation. The purpose of section one is to introduce the reader to chronic kidney disease and renal replacement therapy options, and to shed light on the many variables that potentially play a part in determining the outcome of predialysis care in terms of adequate preparation for dialysis and urgent dialysis start. This part of the chapter is structured so that each section builds on the previous section in order to lead to an understanding of the whole process.

I have started with the basics of the kidney and kidney functions as it is necessary to have an understanding of these in order to comprehend the role that the kidneys play in the body. This is followed by a description of the renal replacement therapy options in order to explain the implications of each in terms of planning for and accepting each type of therapy. I then go on to discuss the timing of renal replacement, as this is an issue for the nephrologist, before going into some detail regarding the optimum care of a patient in the period before they require renal replacement therapy. This is followed by a description of the renal services in the East Midlands.

Section two commences with a brief discussion of equity before detailing barriers to care that have been found in patients with CKD and other health conditions. This leads to an understanding of some of the barriers that *could* have an influence on hindering elective dialysis initiation and as such provides a starting point for considering the barriers to the elective start of renal replacement therapy.

Section three highlights some of the theoretical underpinnings of the research approaches used in this study. Finally, the research processes carried out to determine the barriers to the elective start of renal replacement therapy will be outlined.

### **1.2.1 Anatomy & physiology of the kidney**

The kidneys are paired organs located on the posterior wall behind the peritoneum on either side of the vertebral column. Together the kidneys receive 20% of the



cardiac output (Lote 2000). Blood flow to and from each kidney is served by a renal artery and vein, while urine containing waste products from each kidney is expelled through ureters into the bladder. The kidneys serve a complex range of excretory and endocrine functions which are briefly outlined in Box 1.1 below:

**Box 1.1 Functions of the kidneys**

1. Regulation of body fluid volume, necessary for normal function of the cardiovascular system.
2. Regulation of body fluid osmolality, important for the maintenance of normal cell volume in almost all tissues in the body.
3. Regulation of the balance of electrolytes such as sodium, potassium, chloride, bicarbonate, hydrogen, calcium and phosphate. The kidneys are often the sole route for excretion of these ions from the body.
4. Regulation of acid base balance (which must be maintained within very narrow limits to sustain normal metabolic functioning) is achieved in the kidneys by conserving base bicarbonate and eliminating hydrogen ions.
5. Excretion of metabolic waste products such as creatinine, urea and uric acid, end products of haemoglobin metabolism and metabolites of hormones.
6. Excretion of foreign substances including drugs and chemicals ingested in foods.
7. Production and secretion of hormones, including rennin which is an important factor in regulation of blood pressure and sodium and potassium balance. The kidneys also produce calcitrol which is necessary for the re-absorption of calcium, essential for healthy bone formation. Approximately 89 – 95% of erythropoietin, which stimulates the production of red blood cell formation in the bone marrow, is produced and secreted by the kidneys.

(Adapted from Koeppen & Stanton, 2001)

Each kidney contains approximately 1.2 million nephrons, which are the functional unit of the kidney. Nephrons consist of a glomerulus, where blood is filtered, and a tubular component where electrolytes, water and other substances necessary to maintain the constancy of the internal environment are reabsorbed into the bloodstream or are secreted for elimination (Porth 2002).

Normally functioning kidneys display a remarkable ability to perform the actions described above depending on the needs of the body in a wide range of conditions.

The average amount of urine excreted by an adult daily is 1.5 L, though steady state balance, where intake is equal to excretion, can be achieved with as little as 0.5 L and as much as 18 L. In other words, the regulation of volume, osmolality, electrolyte balance and other functions of the kidney can be maintained with very small or very large amounts of dietary fluid input. Diseases affecting the kidneys often result in the destruction of nephrons, which in turn leads to worsening symptoms as the functions of the kidneys are not met. However, the kidneys can adapt to the loss of nephrons at a slow rate, so that a person can have only 15% of nephrons remaining, yet can still feel as though they are functioning at near normal levels with some dietary modification. One reason for this may be that the remaining nephrons hypertrophy, thus the workload of each remaining nephron is increased. Other adaptations occur within the nephron to allow maintenance of some functions.

### **1.2.2 Aetiology of chronic kidney disease**

Many diseases can affect the kidneys. Some diseases are hereditary, such as polycystic kidney disease and Alport's Syndrome. Some diseases originate in the kidney, for example IgA nephropathy, whereas other kidney problems are a secondary result of a primary disease elsewhere, such as diabetes mellitus, systemic lupus erythematosus, and infections including hepatitis B (Datta 2003). It is estimated that approximately 30% of people with diabetes have diabetic nephropathy, making it the single most common cause of kidney disease (Obrador, Arora et al. 1999). Whatever the cause of kidney problems, most diseases follow a progressive course to chronic kidney disease (CKD), which eventually results in established renal failure (ERF). CKD results in progressive deterioration of glomerular filtration, tubular re-absorptive capacity, and endocrine functions of the kidney (Porth 2002).

### **1.2.3 Diagnosis/assessment**

Levels of renal functioning are measured according to blood and urine tests. Although many markers are tested, the most common diagnostic and monitoring tool is serum creatinine. This is because creatinine, which is produced by the



breakdown of creatinine phosphate in muscles, is excreted almost solely by the kidneys and rises steadily with progression of renal impairment. Normal serum creatinine concentrations range between 70 – 120  $\mu\text{mol/L}^{-1}$ , however creatinine concentrations in renal impairment can reach upwards of 1500  $\mu\text{mol/L}^{-1}$ .

Although serum creatinine concentrations are an important indicator of renal function, the sensitivity of the test, particularly during the earlier stages of the illness, is poor (Roderick and Feest 2005). In recent years there has been a shift towards reporting and taking clinical decisions based on glomerular filtration rate (GFR) as this is a more reliable indicator of kidney impairment. GFR can be measured most accurately by a test called 51 chromium EDTA which involves the administration of a small amount of radioactive substance followed by four hourly blood tests. This test is infrequently used as it is expensive and necessitates time spent in hospital. Instead, clinicians rely mainly on tests designed to provide an estimated GFR (eGFR). There are two ways this can be done; firstly, by obtaining a 24 hour urine sample and blood sample and calculating the creatinine clearance which equated to GFR. Secondly, and increasingly widely used, the eGFR can be calculated from the serum creatinine using formula that were validated during a large study in the United States (Levey, Bosch et al. 1999). These take into account variables such as age, sex and ethnic background, and other biochemical tests. There are several versions of the formula.

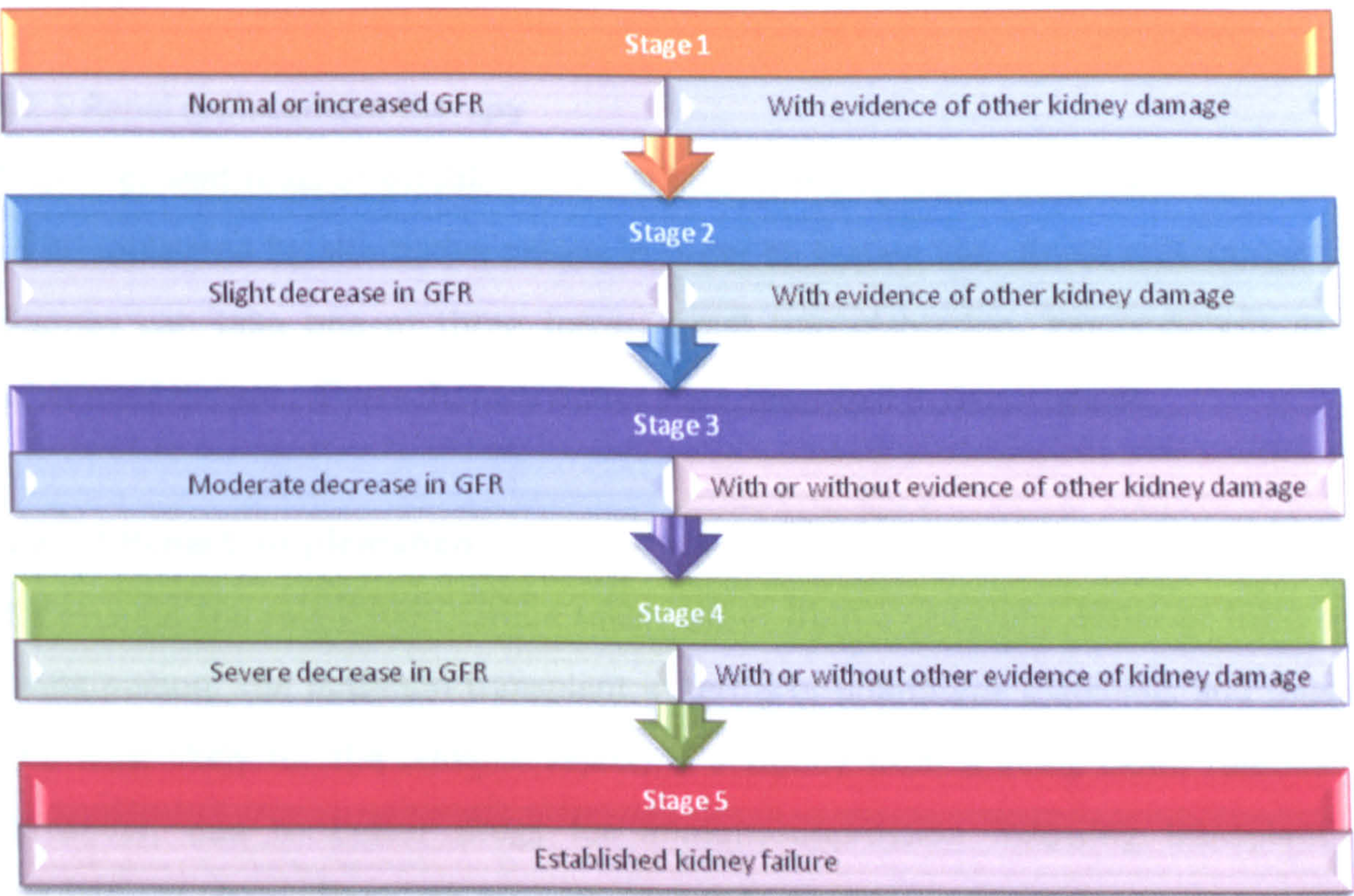
GFR forms the basis of classification of severity of CKD. A healthy adult has a GFR of 125 ml/min. CKD is defined as:

‘Kidney damage of not less than three months as defined by structural or functional abnormalities of the kidney, with or without decreased GFR, manifest by either pathological abnormalities or markers of kidney damage in blood or urine or imaging; or decreased function GFR of less than 60/ml/min/1.73  $\text{m}^2$  for not less than three months with or without evidence of kidney damage’ (National Kidney Foundation 2002)



Figure 1.1 below shows the stages of kidney disease, from stage 1, in which GFR is normal, to stage 5, where the GFR falls below 15ml/min, at which point patients enter established renal failure. The clinical care of patients in stages 1 – 3 is focused on delaying the progression of renal failure by measures such as correcting for anaemia and hypertension and treating cardiovascular risk factors. However, as patients enter stage 4, the focus shifts towards preparing patients for stage 5, established renal failure. This will be explained in more detail below. It should be noted that not all patients with CKD will go on to stage 5 with many dying, often from cardiovascular complications, before that point (Sarnak 2003). Indeed a study carried out in the United States reported that only 3% of patients with CKD stages 2-4 progressed to having renal replacement therapy, while 25% died within the five year follow up period (Keith, Nichols et al, 2004).

**Figure 1.1 Stages and classification of CKD**



**1.2.4 Global and UK perspective on CKD**

Chronic kidney disease and established renal failure are growing global public health concerns as the numbers of patients with CKD is increasing across the world (Bello, Nwankwo et al. 2005; Schieppati and Remuzzi 2005). It is estimated that



approximately 11% of Americans have CKD stages 1 to 5, many of whom are undiagnosed and undetected (Coresh, Astor et al. 2003). The number of people receiving renal replacement therapy for established renal disease in the United States is expected to almost double between 1999 and 2010 to 651,000. In the United Kingdom approximately 140,000 people are under the care of renal services for the pre-established renal disease stages, stages 1 – 5, of chronic kidney disease (Ahmad, Roderick et al. 2006). Additionally it is estimated that by the end of 2006 there were 43,901 adults in the UK on renal replacement therapy, an increase of 6.9% from the previous year (Ansell, Feehally et al. 2007). With government initiatives in place in the United States, the UK and other countries to increase detection of chronic kidney disease earlier (Department of Health and Human Services 2000; Department of Health Renal NSF Team 2005), and calls for similar measures around the world (Dirks, de Zeeuw et al. 2005), renal services are facing a rapid expansion in order to keep up with need.

#### **1.2.5 Renal replacement therapy**

Once a patient reaches established renal failure, the functions of the kidney need to be replicated by alternative means in order to sustain life. Renal replacement therapy can take one of three forms: renal transplantation, haemodialysis or peritoneal dialysis. These therapy options are described in detail below.

##### **1.2.5.1 Renal transplantation**

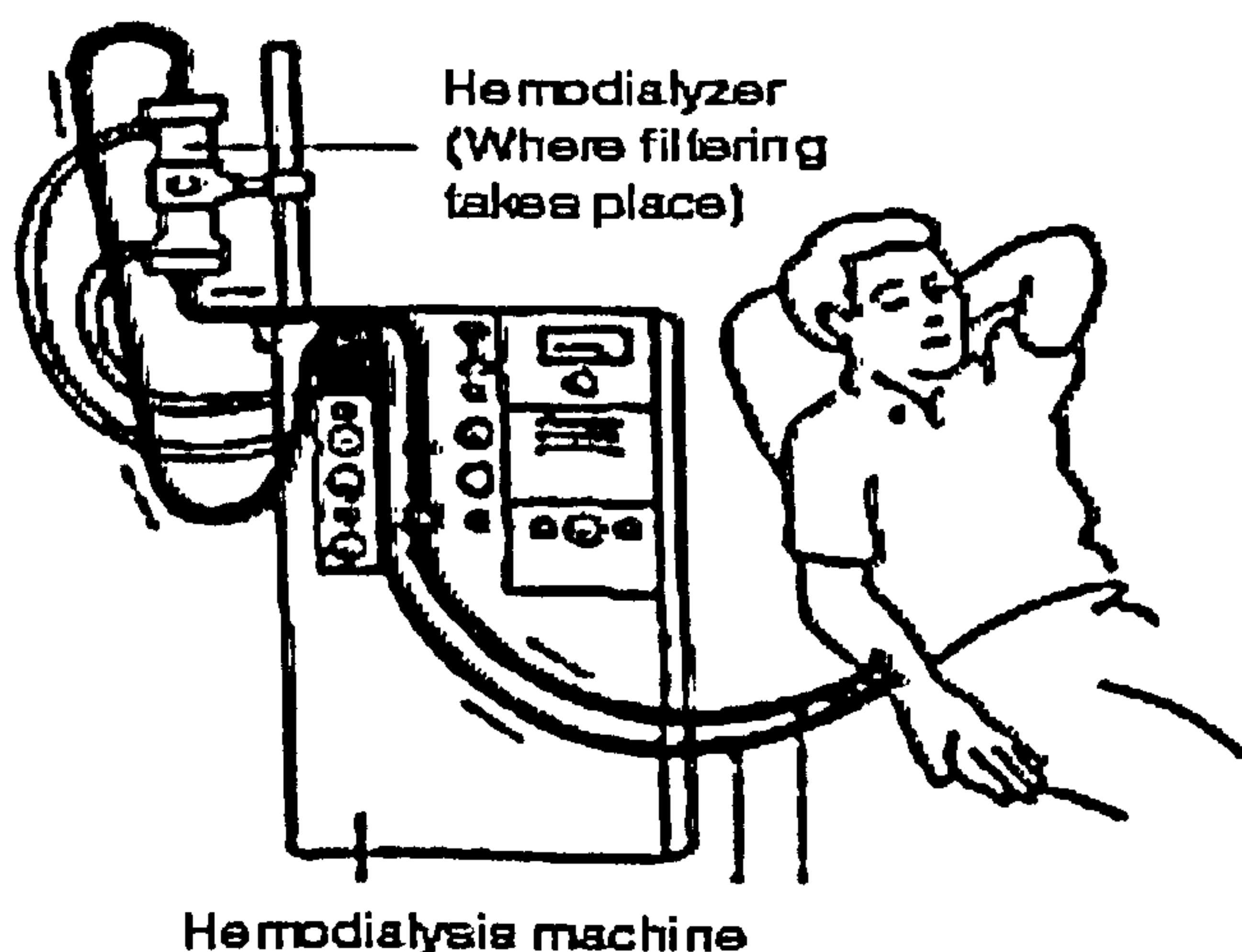
Kidneys for transplantation can be taken either from a cadaveric donor or from a living person. The optimum transplant in terms of phenotype matching, and thus the least likely for the body to reject, is a kidney from a living blood relative. However, due to better drugs for immunosuppression following transplant, transplants from living emotionally related relatives are increasing and are preferable in terms of survival over cadaveric transplants. Although cadaveric transplants are often successful, there are approximately 6480 people on the waiting list for a cadaveric kidney in the United Kingdom, so patients frequently start dialysis while waiting for a kidney to become available (NHS Blood and Transplant 2007).

Transplants are increasingly taking place pre-emptively, (i.e. before patients start on dialysis), however the majority are carried out on patients who are already on dialysis. In 2006 45% of patients on renal replacement therapy in the UK had a functioning kidney transplant (Ansell, Feehally et al. 2007).

#### 1.2.5.2 Haemodialysis

Haemodialysis is a therapy that involves removing the patients' blood and passing it through an artificial kidney machine to extract the toxic waste products, regulate electrolytes and fluid balance and correct for acidosis. In the artificial kidney, or dialyser, there are two chambers separated by a semi-permeable membrane. The patient's blood passes through one chamber, while dialysate fluid flows in the opposite direction through the other. Dialysate is formulated so as to allow diffusion of the molecules from the blood into the dialysate until a state of equilibrium is reached; this is the 'cleansing' part of haemodialysis. The water removal takes place at the same time through a process of ultrafiltration, which is regulated by the pressure across the dialyser membrane and the permeability of the membrane, as this affects the pressure inside the chamber. Blood is continually circulated from the body to the machine and back again until it is clean; this usually takes from three to five hours. Figure 1.2 shows a patient on haemodialysis.

**Figure 1.2 Example of patient undergoing haemodialysis**



Standard practice is for patients to undergo dialysis three times a week, though this may vary based on clinical and organisational need. Historically haemodialysis



took place within a hospital setting, however there are now many haemodialysis units situated in the community, allowing patients to undergo dialysis closer to their homes. It is also possible for patients to have haemodialysis equipment installed in their homes although very few patients choose this option. In 2005, 43% of patients on renal replacement therapy were undergoing haemodialysis in a dialysis centre, and only 1% at home (Ansell, Feehally et al. 2007).

#### **1.2.5.2.1 Vascular access**

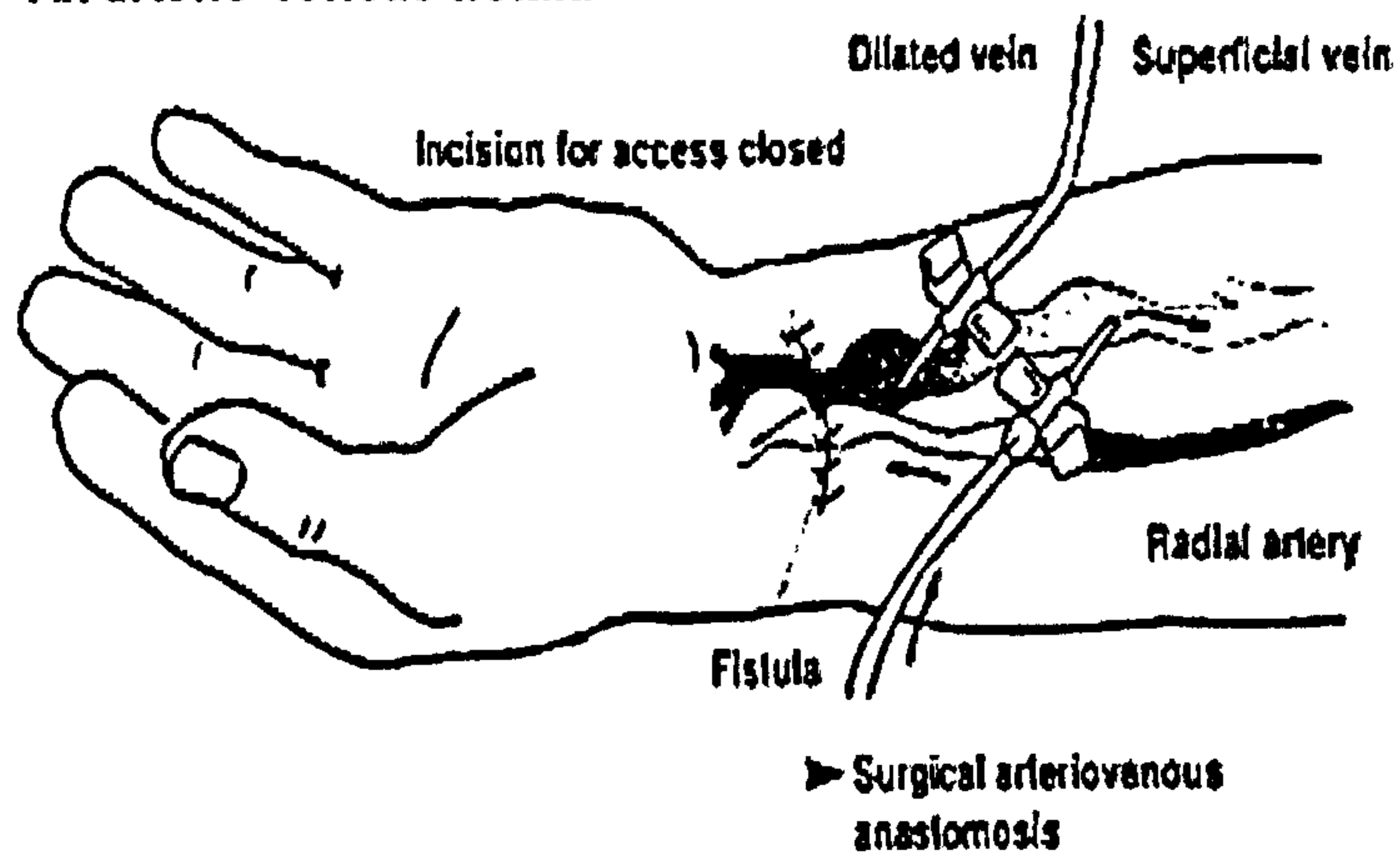
In order to undergo haemodialysis a patient must have vascular access, in other words an exit point for the blood for it to get into the machine, and an entry point for returning the blood to the body after it has been passed through the machine. This can be achieved through the creation of an arterio-venous fistula (AVF) or graft, or through percutaneous access achieved with a temporary or permanent catheter.

An AVF is created via a surgical procedure during which an artery, usually the radial, is joined to a vein, usually the cephalic, as shown in Figure 1.3. Following surgery the AVF must be allowed to develop, during which time the vein enlarges so that it is capable of sustaining the flow and pressure required for haemodialysis. The correct timing of AVF creation is important, however there are no strict guidelines as to how far in advance of haemodialysis the AVF should be created. According to Ota the AVF should be formed a minimum of four weeks prior to haemodialysis to allow time for it to develop, but in patients with diabetic nephropathy and older patients there should be a longer duration due to poor vasculature (Ota 2005). Most renal units aim to have an AVF formed well in advance of dialysis with many aiming for 3-4 months as recommended by the National Kidney Foundation (National Kidney Foundation 2001). AVF formation usually takes place under local anaesthetic. Prior to the operation patients are often seen by surgeons who assess the quality of the veins in order to determine the correct placement of the AVF. Once the AVF is matured, in other words big enough to use, haemodialysis can take place. This involves inserting needles into

the now enlarged vein to allow for blood exit and entry. Sometimes only one needle connected to a Y shaped connector is used.

**Figure 1.3 An arteriovenous fistula**

**An arterio-venous fistula**



Although haemodialysis initiation through an AVF is recommended many patients start dialysis via a venous catheter (National Kidney Foundation 2001; Department of Health Renal Team 2004). Catheters are used to carry out haemodialysis when venous access is required as a matter of urgency, either because an AVF is malfunctioning or is immature, or because the patient does not have an AVF. The catheter is inserted using aseptic technique into the internal jugular, femoral or subclavian vein. Dialysis through a catheter can be problematic as the catheter can frequently occlude due to problems relating to the position of the catheter, clotting, and thrombosis formation, any of which may necessitate reinsertion of the catheter. Dialysis through a catheter is associated with increased infections and mortality and should be avoided whenever possible (Lorenzo, Martin et al. 2004; Ishani, Collins et al. 2005).

**1.2.5.3 Peritoneal dialysis**

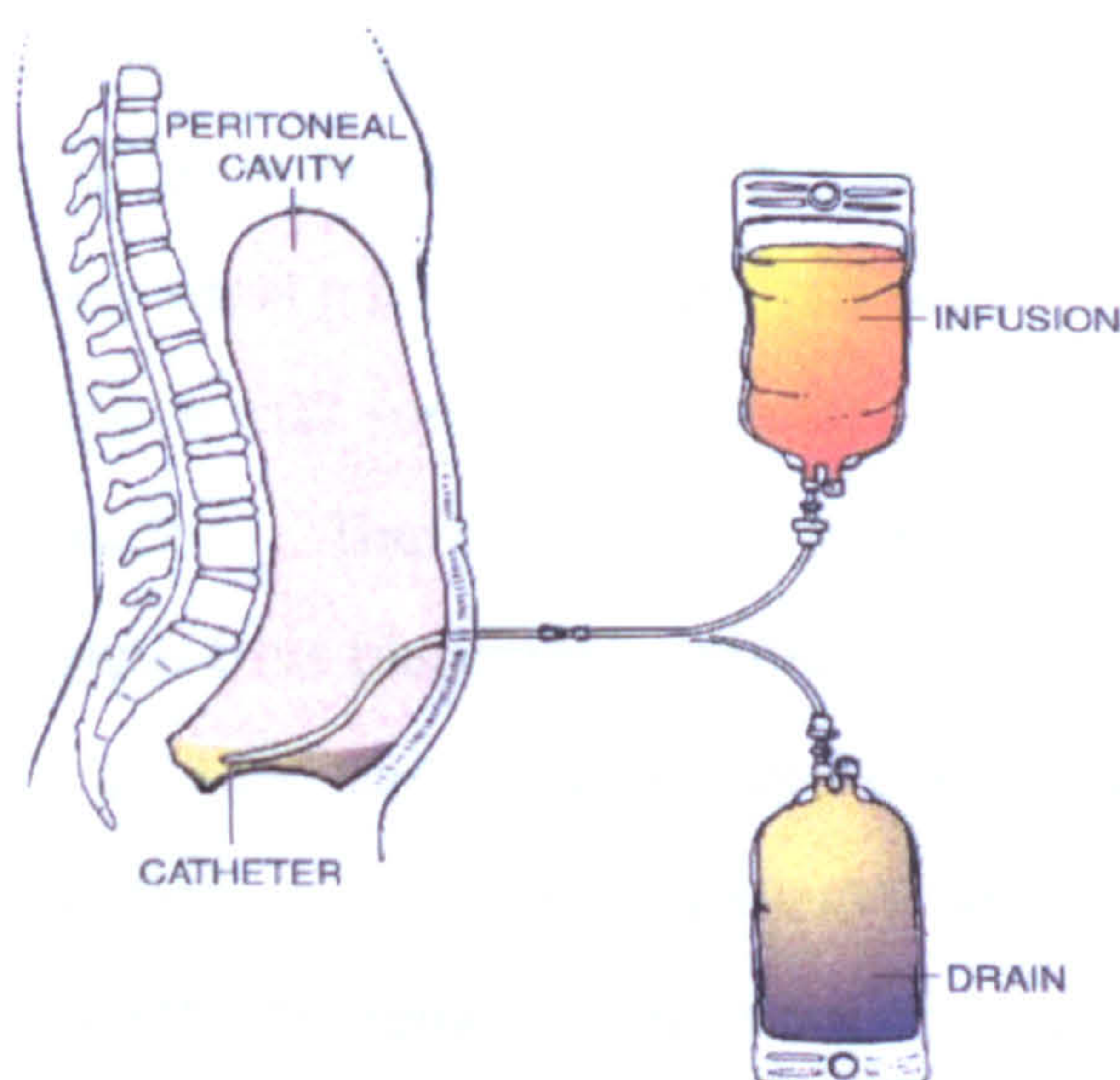
Peritoneal dialysis therapy aims to achieve similar results as haemodialysis in respect of removing wastes and excess fluid and balancing electrolytes. However, the processes by which this is achieved are different. Whereas in haemodialysis blood is taken out of the body and into a dialyser, in peritoneal dialysis the dialysis



fluid is inserted into the body where diffusion, osmosis and convection occur across the peritoneal membrane.

The peritoneal membrane is a semi-permeable membrane that surrounds the abdominal cavity. Usually the space between the membrane and the abdominal organs is filled with about 100mL of fluid which acts as lubrication; in peritoneal dialysis, fluid is inserted into this cavity. Solute and fluid exchange takes place between the peritoneal capillary blood and the dialysis solution inside the cavity. The fluid remains inside the abdominal cavity until equilibrium is reached, which typically takes four – six hours although this depends on the permeability of the membrane, something that varies between individuals. Figure 1.4 depicts peritoneal dialysis.

**Figure 1.4 Peritoneal dialysis**



Peritoneal dialysis can either be a manual procedure, in which gravity is used to drain dialysis fluid into and out of the abdomen, or an automated procedure, whereby the fluid is inserted and drained by a machine. Almost all patients who undergo peritoneal dialysis start with the manual method, known as continuous ambulatory peritoneal dialysis (CAPD), regardless of whether they stay on this type of dialysis or switch to automated. This involves manually filling and draining the abdomen approximately four times a day. Each cycle of fluid insertion and draining is known as an exchange and the time that the fluid remains in the



peritoneum is the dwell time. Automated dialysis can take several forms, but the most common is continuous cycling peritoneal dialysis (CCPD) which takes place during the night while the patient is asleep. The dialysis exchanges are carried out by a machine and the dwell times for this type of dialysis are shorter. Having CCPD often means that the patient does not have to carry out any exchanges during the day. Peritoneal dialysis is a home based treatment with patients only entering hospital for the initial teaching sessions on how to carry out peritoneal dialysis and for routine tests and follow-up appointments.

For all types of peritoneal dialysis, permanent and safe access to the peritoneal cavity is essential. This is achieved through the use of a peritoneal dialysis catheter, surgically inserted into the abdomen prior to dialysis initiation. The peritoneal dialysis catheter consists of three functioning segments; an outer part that lies above the skin and is connected to the solution transfer set, an intramural part which has one or more cuffs that lie subcutaneously and help to anchor the catheter as fibrous tissue grows around it, and the intra-peritoneal part which has many small holes for the dialysis solution to flow through (Wild 2002). Use of the catheter too soon after insertion can cause fluid leakage and lead to increased infections. There is no firm evidence to suggest the optimal time of peritoneal dialysis tube placement, although better results are found if there are at least 10 – 14 days between insertion and dialysis (Wild 2002; Gokal 2005), though a longer duration is required in patients with diabetic nephropathy. In 2006, 11% of patients on renal replacement therapy in the UK were undergoing peritoneal dialysis (Ansell, Feehally et al. 2007).

### **1.2.6 Choosing between therapies**

With no evidence to suggest that there are benefits from either type of dialysis over the other, wherever possible patients choose the type of dialysis that they would like to have at the beginning of RRT. Clinical and social contraindications to either haemodialysis or peritoneal dialysis were found to occur in approximately one third of patients in a large sample in the Netherlands, meaning that full patient choice was available for the remaining patients in the study (Jager, Korevaar et al.

2004). There are many factors to consider when choosing the dialysis modality, and these can broadly be divided into four areas; clinical, psychosocial, logistical and organisational. The decision is usually taken following a period of education, reflection and discussion with the patient, family/carers and multidisciplinary team. Table 1.1 shows some of the factors that have been found to play a role in decision making. Although organisational issues are not usually explicit factors in the decision, nevertheless they may be considered by the renal team and patient in some circumstances and they are included in this table.

**Table 1.1 Some of the factors that *may* influence modality of RRT choice (-negative, + positive, /neutral)**

	Clinical	Psychosocial	Logistic	Organisational
Haemodialysis	<ul style="list-style-type: none"> <li>- Poor vasculature</li> </ul>	<ul style="list-style-type: none"> <li>+ Preference to be cared for by others</li> <li>- Body image relating to AVF</li> </ul>	<ul style="list-style-type: none"> <li>/ Time taken up by dialysis (3 – 4 hours thrice weekly)</li> <li>/ Convenience of renal unit/travel time</li> <li>- Time slots for dialysis are not guaranteed to fit in with patients lifestyle</li> <li>- Leisure/business travel difficult if on haemodialysis</li> </ul>	<ul style="list-style-type: none"> <li>- Waiting time for AVF formation can be considerable</li> <li>- Dialysis slots are not always available at the time the patient needs to start dialysis</li> </ul>
Peritoneal dialysis	<ul style="list-style-type: none"> <li>- Previous abdominal surgery</li> <li>- Gross obesity</li> <li>- Poor eyesight</li> <li>- Chronic back pain</li> </ul>	<ul style="list-style-type: none"> <li>+ Preference for self care</li> <li>- Body image relating to PD catheter</li> <li>- Sub-standard levels of personal and environmental hygiene</li> </ul>	<ul style="list-style-type: none"> <li>+ Flexibility of schedule</li> <li>+ Travel easier on PD</li> <li>- Accommodation – inadequate storage space</li> </ul>	<ul style="list-style-type: none"> <li>/ PD training takes several consecutive days. Necessary before embarking on PD</li> </ul>

(Wuerth, Finkelstein et al. 2002; Jager, Korevaar et al. 2004; Cambi, David et al. 2005)



**1.2.7 Timing of renal replacement therapy initiation**

Although accurately predicting when someone is likely to need dialysis through regular predialysis monitoring is one of the main aims of predialysis care, according to Cassidy & Ter Wee, it is one of the most difficult to achieve (Cassidy and Ter Wee 2005). This is because there are no absolute guidelines as to when dialysis should be started for optimal outcomes, as the circumstances vary from person to person as well as varying between renal units and countries (Obrador, Arora et al. 1999). Jacobs suggests that there are three reasons why dialysis should be initiated in a timely manner. These are 1) to avoid the debilitating and sometimes life-threatening complications of advanced uraemia, 2) to maintain reasonable health and quality of life and 3) to prevent morbidity-mortality late in the course of RRT (Jacobs 2005). Table 1.2 below shows a list of symptoms of uraemia as experienced by patients, and the absolute indications for initiating dialysis stated by Cambi and colleagues.

**Table 1.2 Symptoms of uraemia and indications for initiating dialysis**

Some symptoms of uraemia	Absolute indicators for initiating dialysis (Cambi, David et al. 2005)
<ul style="list-style-type: none"><li>• Overwhelming fatigue</li><li>• Weakness</li><li>• Pruritis (itching)</li><li>• Nausea</li><li>• Vomiting</li><li>• Anorexia</li><li>• Weight loss</li><li>• High blood pressure</li><li>• Shortness of breath</li><li>• Swollen ankles</li><li>• Low mood / depression</li></ul>	<ul style="list-style-type: none"><li>• Hyperkalaemia not related to drug intake</li><li>• Bleeding</li><li>• Fluid overload / pulmonary oedema</li><li>• Hypertension resistant to drug therapy</li><li>• Pericarditis</li><li>• Nausea</li><li>• Vomiting</li><li>• Anorexia</li><li>• Uraemic encephalopathy</li></ul>

Cambi and colleagues concur with Jacob by stating that RRT should commence before symptoms of uraemia are present, (Cambi, David et al. 2005); however the difficulty of this may lie in the fact that, due to the long term progressive nature of CKD, many patients adapt to the changes that CKD brings both physically and

mentally. Therefore it is often difficult to determine the precise time when the benefits of dialysis outweigh the risks and inconveniences of the treatment.

### **1.2.8 Preparation for dialysis**

Preparation is vital in ensuring that patients have the best possible outcomes on RRT. The components required to ensure that someone is adequately prepared are varied and complex. Some elements that have an influence are timing of referral to renal services (Schmidt, Domico et al. 1998; Jungers, Massy et al. 2001; Kessler, Frimat et al. 2003; Khan, Xue et al. 2005), predialysis education (Levin, Lewis et al. 1997) and predialysis clinic attendance. Timing of referral is often thought to underpin the whole process, as patients referred to the renal services earlier have greater opportunities to access education programs, take part in clinical decisions regarding dialysis and transplantation, and ultimately start the RRT that they choose via an established vascular or peritoneal access route or by pre-emptive transplant. Exactly how far in advance patients should be referred in order to ensure the best outcomes has never been well established. Many studies have used three or four months to examine the effects of late referral though whether this is adequate remains inconclusive (Roderick, Jones et al. 2002; Stack 2003), with one study suggesting patients should be referred at least 24 months prior to RRT initiation (Holland and Lam 2000) and another suggesting greatest benefit if patients are referred 36 months in advance (Jungers, Massy et al. 2001).

As mentioned above, inadequate preparation is associated with starting dialysis using a temporary or semi-permanent vascular catheter, which in itself is associated with increased morbidity and mortality (Lorenzo, Martin et al. 2004; Ishani, Collins et al. 2005). Several studies have reported that a proportion of patients, who have been known to the renal services for some time before starting dialysis, still have urgent dialysis initiation through temporary vascular access (Chesser and Baker 1999; Stack 2003; Ansell, Feest et al. 2005); indeed data from a recent renal registry report show that in the United Kingdom as a whole, 42% of patients who have been known to renal services at least 12 months start haemodialysis with a catheter (Fluck, Ramon et al. 2006). However, very few



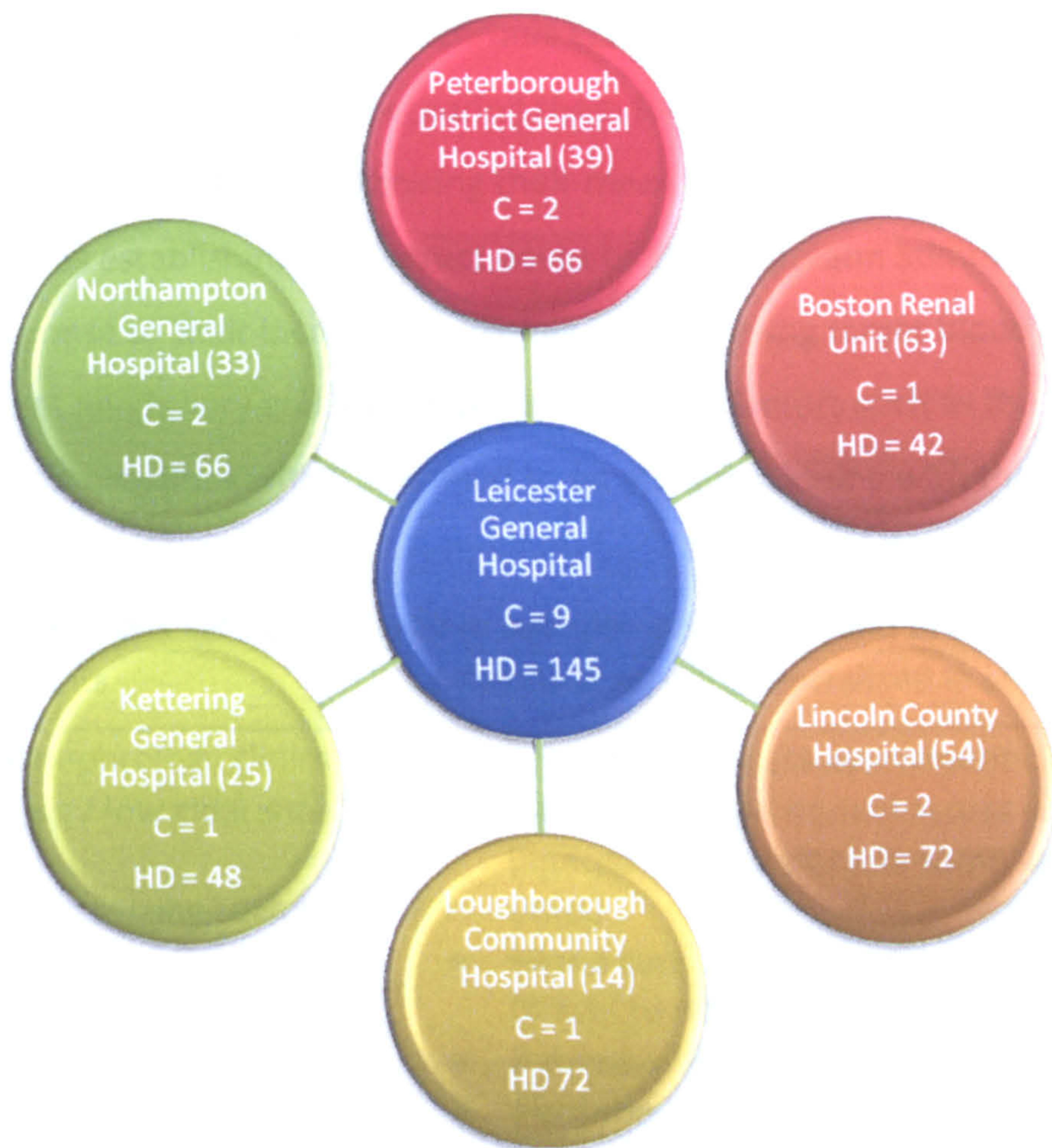
studies have examined in detail the possible reasons for unplanned urgent dialysis initiation. Chesser & Baker found that the delays within the renal service accounted for the majority of temporary catheters inserted in patients already known to the renal services, although they could not really elicit where and why such delays had occurred (Chesser and Baker 1999).

### **1.2.9 Description of the East Midlands Renal Network (EMRN) / Services within EMRN**

The EMRN is a network of renal care providers based on a hub and spoke model with Leicester General Hospital at the hub and satellite renal units as spokes. The network covers Leicestershire, Lincolnshire, Northamptonshire and north Cambridgeshire. At the time of the first phase of this study the network was estimated to serve a population of approximately 1.8 – 2 million people. In 2003 there were four satellite units in the network: Lincoln, Peterborough, Loughborough and Kettering. The network has now (2008) expanded to include a new satellite unit in Boston and a unit in Northampton which was previously under the care of the large renal unit in Oxford. Additionally a new renal unit in Leicester has been opened, but as this unit is still combined with the main Leicester renal unit I have not displayed it as a separate entity. Figure 1.5 shows a diagram of the EMRN with numbers of patients on haemodialysis in each unit, along with the number of attendant consultant nephrologists, and the miles from the main unit in Leicester.



Figure 1.5 The East Midlands Renal Network



(N) = miles from main unit in Leicester, C = consultants, HD = number of patients receiving haemodialysis

The clinical care of all patients in the network falls under the auspices of the University Hospitals of Leicester NHS Trust. Where possible patients are seen by nephrologists in the renal units closest to where they live, but some aspects of the renal service remain centralised in Leicester. Table 1.3 shows the elements of predialysis renal care and how they are organised. The main hospital and the satellite units share a common renal specific computer database, Proton.

Patients are usually seen in general nephrology clinics before being transferred to dedicated predialysis clinics. The predialysis clinics are intended to provide patients with longer consultations (approximately 20 minutes duration) with the physicians, with occasional input from dieticians, and to shift the focus of care towards preparing the patient for RRT. There are no set guidelines regarding the timing of transfer to predialysis clinics, timing of predialysis follow up



appointments and other aspects of care which are all at the discretion of each nephrologist. Managing patients with chronic kidney disease, particularly at an advanced stage, involves not only preparing them for the possibility, and ultimately the reality, of dialysis, but also optimising their medication to alleviate associated problems such as establishing the correct doses of Erythropoietin Stimulating Agents in response to their increasing anaemia and achieving target blood pressure results. Patient needs vary and are influenced by other factors such as the presence of comorbidities which also need to be managed in-line with the kidney disease.

**Table 1.3 Predialysis services offered in satellite units and main unit in Leicester**

All or some units	Additional services centralised in Leicester
<ul style="list-style-type: none"> <li>• General nephrology clinics</li> <li>• Predialysis / low clearance clinics</li> <li>• Diagnostic testing such as renal biopsy</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-surgery access assessment clinic</li> <li>• Vascular and peritoneal access surgery (limited amount done in some satellite units)</li> <li>• Home care team of nurse specialists (travel to whole network)*</li> <li>• Patient information day</li> <li>• Peritoneal dialysis training</li> </ul>

\*since the writing of this section the home care team has been decentralised and are now based within the satellite units

Dedicated patient education in the network takes two forms; a patient information day and home visits by a member of the team of renal nurse specialists from the home care team. At the time this research was carried out, the home care team were based in Leicester and travelled to cover the whole network. The patient information day is held in Leicester. Patients are given free choice of RRT unless there are clear medical or social contraindications to a particular form of RRT. The focus of the patient education offered by the network is on informing patients about the various RRT options. Leicester city and the surrounding urban area has a population of approximately 440,000 and has a diverse ethnic mix with approximately 40% of its population being of non-White British origin, though this level of diversity is not seen across the whole network ([www.leicester.gov.uk](http://www.leicester.gov.uk)). The patient information day is offered in English and Gujarati. A sample of the patient information day program is shown in Box 1.2.

**Box 1.2 Sample program from a patient information day**

<b>Renal Patient Information Day</b>	
<b>TIMETABLE</b>	
<b><u>Monday 2<sup>nd</sup> July</u></b>	
10.00am	Welcome
10.30am	Kidney Failure – ‘The facts and introduction of treatment options’
11.00am	Coping and adjustment
11.30am	Kidney patients association
12.00pm	Workshop (CAPD/HD)
12.45pm	Lunch – including Dietician Display
13.45pm	Workshop (CAPD/HD)
14.30pm	Pharmacy
14.45pm	Kidney transplant
15.00pm	Patient question & answer session

**1.3.1 Equity**

The National Health Service in the UK has at its core, a moral imperative; that is to provide care free at the point of use for all members of society, with the primary objective of equal access for equal need (Donaldson and Gerard 1993).

There are four main types of barriers to achieving equity: geographical, personal, organisational and financial, which will be discussed in further depth below.

Underpinning the whole discussion around barriers in this context is the notion of equity. Not to be confused with equality, equity relates to the concepts of social justice and fairness, and, broadly speaking, requires that funding and access to health care is fairly and justly distributed. Equity is a two dimensional concept, involving horizontal and vertical equity. Simply put, horizontal equity requires that equals are treated equally, in other words that there is equal treatment for equal need whereas the aim of vertical equity is to ensure that those with differing ability to pay contribute in proportion to their differing income or wealth (Donaldson and Gerard 1993).



Achieving vertical equity is an overt objective of the NHS, funded by one of the most progressive methods in the world, with those in the lowest income bracket contributing the least percentage of their income and those in highest income bracket contributing the most. Since its inception in 1946, demand for health services has outstripped supply (Harrison and Dixon 2000). This has led to the introduction of a number of measures to ration the provision of health care, though this has been done with varying degrees of translucency (New 1997). In order to achieve equity and reduce rationing in the NHS, many people have called for increased investment in the health services. Recently the government in the UK has embarked on a programme of spending that will place the British health care system among the best funded in Europe, with an estimated 9.4% of its gross domestic product (GDP) going into health care by the years 2007-2008 (Stevens 2004). However, others caution that no amount of spending will meet the demands of the health service or ensure an equitable system, a point illustrated by the USA which spends 13.9% of its GDP on health care yet has one of the least equitable health care system in the developed world (Davis, Schoen et al. 2007).

The goal of the NHS remains to create an equitable health care system. Mooney has suggested that the way to do this is by ensuring that groups with different needs receive appropriately differentiated treatment, as a way of ensuring health equality (Mooney, Jan et al. 2002). Some of the barriers that prevent this from happening are discussed below. Much of the literature on barriers to care focuses on the barriers to accessing primary and emergency care, but many of the issues that exist in accessing care may be applicable to patients in this study as they progress through a secondary care system.

### **1.3.2 Geographical barriers to access**

In terms of geographical access, accessibility is described as the ease or difficulty of reaching services in another place. According to Haynes the two components of accessibility are location of services relative to the population and the personal mobility of those who need to access services (Haynes 2003). In terms of equity, accessibility should reflect need, with the people with the greatest need for a

service able to reach it more easily than those with lesser needs. Clearly this isn't always possible due to the variation in the population distribution in urban, rural and remote areas.

Health status has a distinctive pattern in the UK that reflects the distribution of wealth and poverty, with the highest morbidity and mortality rates in large cities, and lower rates in rural areas. However, there are pockets of rural deprivation with very poor levels of health, and studies that have found that people in the most remote areas suffer the worst health overall, suggesting a link between poor health and access to services.

In a paper assessing whether the area a person lives in has an impact on long term illness and premature mortality, Congdon argues that measuring morbidity or health status variations over areas is important in terms of policy planning as it provides a good indication of health care needs (Congdon 1995). In his analysis of mortality and health in London and East Anglia, he suggests that health service provision does little to ameliorate the association between ill-health and deprivation regardless of location. This is in part due to the difficulty in determining the causes of ill health which may be influenced by factors such as environmental pollution and social class which is thought to have an effect on health related behaviours such as smoking and exercise (Congdon 1995).

### **1.3.3 Personal barriers to care**

There are many barriers to care, such as health beliefs, ethnicity, age and gender, which fall under the umbrella term of personal barriers to care. Health beliefs are fundamental at all points along the health care spectrum because they largely determine health related behaviours; from the factors influencing whether a person makes the decision to access health care services through to the decisions surrounding taking medications and actions to alleviate or prevent illness such as smoking, dietary intake and recreational exercise (DiMatteo, Haskard et al. 2007). Health beliefs, and consequent actions, are complex and can be mediated by a



number of factors, some of which are shown in Figure 1.6 below. Many of these factors in and of themselves can be regarded as barriers to care.

**Figure 1.6 Some of the factors influencing health beliefs**



Belonging to an ethnic minority group has been associated with poorer health care in both the United Kingdom and in the United States. Reasons for this are thought to be that patients from ethnic minority backgrounds are often more socially disadvantaged due to poverty, which has the knock on effect of influencing educational achievement, housing and employment prospects (Calman 1997; Shaw, Dorling et al. 2003). In a study carried out in the United States, Lenz and colleagues found that African American patients were disadvantaged compared to White Caucasian patients, in relation to meeting national standards for kidney care (Lenz, Mekala et al. 2005). Also in the United States, race and socioeconomic factors were found to have an impact on whether patients were placed on the kidney transplant list prior to starting on dialysis, with patients from ethnic minority backgrounds being less likely to be listed (Kasiske, London et al. 1998).



Within the United Kingdom, a study of Bangladeshi male smokers revealed a feeling of isolation from health services in general, and in particular, marginalisation from tobacco control initiatives (Croucher and Rahman Choudhury 2007). More widely, within England and Wales, Pakistani and Bangladeshi men and women had the highest rates of disability of all ethnic groups according to national census data (<http://www.statistics.gov.uk/focuson/ethnicity&identity>). Other findings from the census survey above highlight the effect of some of the other barriers mentioned in this section. For example women, although having a greater life expectancy, have more years in poor health than men, yet women were found to display fewer health damaging behaviours such as excessive alcohol consumption, and were less likely to be overweight than men.

In the United Kingdom older age has been recognised as a barrier to health care, due to largely implicit age discrimination (Grimley Evans 1997; Young 2006). The consequences of this are that older peoples' needs are sometimes inadequately met and health care outcomes can be poorer (Bowling 1999; Marshall 2000; Burt and Raine 2006). Discrimination based on age has its supporters who claim that within a system where there are limited resources, age can legitimately and morally be used as a basis for rationing. The major tenets of this argument are that older age affects peoples' capacity to benefit from interventions due to shortened expected life span, and that older people are more likely to have had a 'fair innings', in which case priority should be given to younger people to allow them to achieve the same (Williams 1997).

Within the sphere of kidney disease, it is only relatively recently that patients above the age of 65 were considered ineligible for renal replacement therapy in some areas though due to improvements in the success of these therapies this is now no longer the case (Dean 1994). In the UK, the median age of starting renal replacement therapy has risen from 63.8 years in 1998 to 65.0 years in 2006. In England the age category with the highest acceptance is between 75 and 79 years (Ansell, Feehally et al. 2007). Barriers to optimal care to remain based on age. In particular, older people are referred later to specialist renal services both in the UK



and abroad (Letourneau, Ouimet et al. 2003; Ansell, Feest et al. 2006).

Furthermore, age is a significant predictor of survival on dialysis with older patients being more disadvantaged (Stoves, Bartlett et al. 2001).

#### **1.3.4 Organisational barriers to care**

Organisational barriers to care usually refer to barriers that exist largely because of the way in which services are structured. In a research study examining the barriers to detecting and treating hypercholesterolaemia in patients with ischaemic heart disease, organisational barriers were found to be the most important barriers identified by primary care physicians (Hickling et al. 2005). In particular difficulties with the primary and secondary care interface, such as systems of referral and difficulties of communication between primary care and secondary care specialists were identified. Further barriers such as the processes for obtaining blood results were also highlighted. Organisational barriers are not solely limited to service structure at such a practical level however, as pointed out by Davies and Cleary in a research study seeking to understand the use of patient survey data in quality improvement in health care (Davies & Cleary, 2005). They suggest that organisational barriers can be slightly more abstract and found in the form of organisational approaches to patient care, or their underlying ethos. Some of the organisational barriers they found were a perception that there were competing priorities, a lack of quality improvement infrastructure, and a traditional hierarchical management approach which did not support change.

#### **1.4. Theoretical underpinnings of the research approach used**

An abiding mantra of the current government has been to place patients at the centre of the NHS. In 2000, the publication of the NHS Plan revealed a ten point proposal for NHS investment and reform designed to have an NHS constructed around the patient (Department of Health 2000). At the heart of this was the belief that patients were disempowered, that the relationship between the NHS and patients in the NHS of the 1990s was too hierarchical and paternalistic, (page 30 of NHS Plan) and that 'the patient's voice does not sufficiently influence the provision of services' (page 30 of NHS Plan).

The onus of the responsibility to engage with the public was firmly placed on health care providers with the implementation of the Health and Social Care Act in 2001, section 11 of which places a legal duty on NHS organisations to involve and consult patients and the public on the planning of service provision, the development of proposals for change, and discussions about how services operate. Together with the NHS Plan, this signified a change of direction for many service providers in the health service who frequently made decisions without consulting users of services. It is with this ideology of including patients in order to ensure that their opinions are included in the future service developments that I approached this research study.

Another major departure in the NHS reforms of the current government was the emphasis on raising standards of quality via, among other things, the introduction of national standards of care and organisational accountability. This relates back to the discussion of equity and inequalities earlier, as the purpose of the reforms was to ensure a high quality of care for patients regardless of where they live. One of the main routes taken to achieve this has been through the publication of National Service Frameworks (NSFs). NSFs are documents produced by the Department of Health in which long term strategies for improving specific areas of care are set out. Time frames for improvements are indicated along with measurable outcomes and performance indicators. In 2004 the first of two National Service Frameworks for Renal Services was produced, entitled Part One: Dialysis and Transplantation (Department of Health Renal Team 2004). As the name suggests, this focussed very much on patients who already have kidney disease and the standards of care they can expect as they approach renal replacement therapy and while they are on it.

The second NSF for Renal Services, entitled Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care was published in 2005 (Department of Health Renal NSF Team 2005). The emphasis of this NSF was on preventing and detecting CKD in patients at increased risk of developing the disease, prevention of



the complications of CKD in patients who already have the disease, and improving the end of life care for patients with end stage renal failure (ERF). Additional quality requirements were set for the treatment of acute renal failure. The most salient standards and quality requirements from both NSF's for this research are in summarised in Box 1.3.

### Box 1.3 Selected and annotated standards, markers of good practice and quality requirements from Parts 1 & 2 of the National Services Frameworks for Renal Services

**Standard 1:** All adults with chronic kidney disease are to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life

**Markers of good practice**

- Provision of high quality, culturally appropriate and comprehensive information and education programmes
- Education programmes tailored to the needs of the individual
- Individual care plans, regularly audited, evaluated and reviewed
- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills

**Standard 2:** All adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised

**Markers of good practice**

- Referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation. This principle should also be followed for people with a failing transplant
- Accelerated process with intensive input from the renal team for those who present late to renal units or as acute uraemic emergencies
- People with ERF given information about all forms of treatment so that an informed choice can be made
- Patients put on the national transplant list within six months of their anticipated dialysis start date if appropriate
- Anaemic treated to maintain an adequate haemoglobin level
- Management of cardiovascular risk factors and diabetes according to the NSF for Coronary Heart Disease and for Diabetes

**Standard 3:** All adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity

**Markers of good practice**

- Early referral for assessment and investigation for the best means of access, and timely surgery (current best practice being six months before haemodialysis, four weeks before peritoneal dialysis) which enables patients to begin dialysis with their vascular or peritoneal dialysis access established and functioning
- Monitoring and early intervention to minimise complications of the access
- Recording and regular auditing of the type of access in use at the start of dialysis time, time from referral to surgery, and complication rates for each procedure. Temporary access replaced by permanent access as early as possible.
- Proper training for patients, carers and members of the renal team in the care of the access

**Quality requirement four:** People with established renal failure receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed care plan, built around their individual needs and preferences

**Markers of good practice**

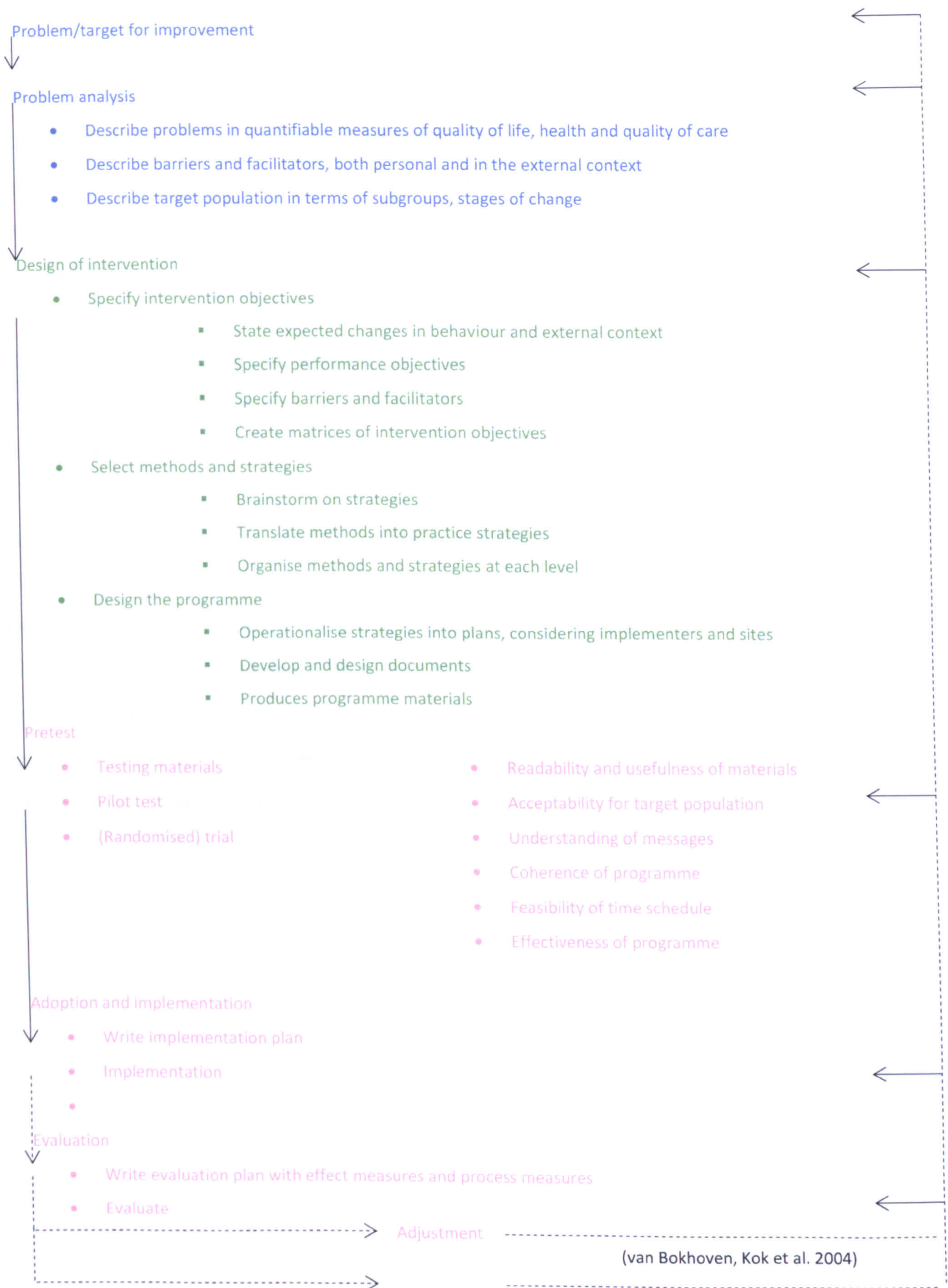
- The renal multi-skilled team has access to expertise in the discussion of end of life issues including those of culturally diverse groups and varied age groups, the principles of shared decision making, and training in symptom relief relevant to advanced non-dialysed ERF
- Prognostic assessment based on available data offered to all patients with stage 4 CKD as part of the preparation for RRT described in standard two of the NSF
- People receive timely information about the choices available to them, such as ending RRT and commencing non-dialytic therapy, and have a jointly agreed care plan built around individual needs and preferences in line with palliative care principles
- People who are treated without dialysis receive continuing medical care including all appropriate non-dialytic aspects of CKD, and wherever possible are involved in decisions about medication options
- Individuals are supported to die with dignity, and their wishes met wherever practicable regarding where they die, their religious and cultural beliefs and presence of the people closest to them
- The care plan includes culturally appropriate bereavement support for family, partners, carers and staff



Quality improvement in health services is a cyclical process of research, implementation of interventions and audit or further research as required. Figure 1.7, by van Bokhoven et al shows a diagram of the pathway of quality improvement research and implementation (van Bokhoven, Kok et al. 2004). The blue text signifies the steps taken in the first 2 phases of this research study. The green and pink text highlights next stages of this research study which are beyond the remit of this PhD thesis.



Figure 1.7. Design process for quality of care improvement interventions





## **1.5 Conclusion**

This chapter has provided background information on the functions of the kidneys, the causes of kidney disease, the prevalence of CKD and ERF, and the therapy options available when the kidneys fail. Vascular access has been discussed in the context of AVF formation, and the pitfalls of temporary catheter use have been highlighted. An overview of the East Midlands Renal Network has been provided in order that the reader can appreciate the elements of the service in our region as local services differ from those in other areas. Equity was briefly discussed in order to establish the reasons why we should be interested in understanding the barriers to care within our kidney care system. Some examples of barriers that are known to exist within kidney disease and other areas were given. An insight into the ethos of establishing patient centred services was given.

Patients who start dialysis urgently are at the increased risks discussed above in relation to temporary catheter use, namely increased risk of infections and early death. The purpose of this study was to identify barriers to patients starting dialysis in a the planned manner advocated by clinicians, patients groups and government initiatives, specifically when they have been known to the renal services for some time and should have had access to all of the services described above to ensure they have as smooth an entry onto dialysis as possible.

# CHAPTER 2

## Literature review

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### 2.1 Introduction

This chapter provides a review of the literature in relation to the research question, why do patients start on dialysis urgently when they have been known to renal services for some time? A brief background to the review is followed by a description of the methods used, then a review of the findings. The chapter concludes with a summary of the findings from this review. As this literature review was conducted at the beginning of this project in order to inform the design of the research study, only articles published before mid 2005 are included. Any further relevant research that appeared following this time is discussed in subsequent chapters.

### 2.2 Background

Most renal diseases cause renal failure over 10-20 years, providing opportunities for interventions to delay progression of renal failure, modify cardiovascular risk and complications of renal failure, and educate and prepare for renal replacement therapy (RRT). There is observational evidence that late referral to nephrology services is associated with a poorer outcome on dialysis (Innes, Rowe et al. 1992) and increased personal and health care costs (Eadington 1996). Timely initiation of dialysis has a number of benefits for patients with advanced CDK including fewer hospital admissions, decreased need for temporary vascular access, wider choice of renal replacement therapy, easier access to transplantation (Kessler, Frimat et al. 2003) and improved survival (Lorenzo, Martin et al. 2004). Despite the development of disease, age and sex registries in primary care, and evidence that optimal control of diabetes mellitus and hypertension may delay dialysis, many patients with renal disease are not referred in a timely manner. Although late referral is an important



barrier, a proportion of patients who are seen sufficiently early, defined for purposes of this study as four months before start of dialysis, still commence dialysis as emergencies. This reflects failure of the pre-dialysis care pathway.

### **2.2.1 Objectives of the literature review**

- 1) To identify reasons for the failure of the predialysis care pathway.
- 2) To identify interventions that reduce the incidence of failures of the predialysis care pathway.

## **2.3 Methods**

Methods for the literature review were based on the guidelines suggested by the Cochrane Renal Group for preparing a systematic review protocol (<http://www.cochrane-renal.org/forreviewers.php#protocol>). However, as I was interested in gathering literature from all research disciplines using a variety of experimental and observational methods, the inclusion criteria were extended to include all designs of studies. Therefore the studies included in this review were:

- 1) Descriptive quantitative studies such as surveys, case control and cohort studies, and qualitative studies such as patient interview studies.
- 2) Controlled studies such as randomised controlled trials of interventions to reduce the incidence of failures in the predialysis care pathway.

The following list of search terms and synonyms were drawn up and agreed by two members of the research team:

- Predialysis, pre-dialysis, pre-end stage renal disease
- Temporary access, temporary vascular access
- Barriers
- Elective
- Education

These were searched as keywords and combined using Boolean operators where necessary. For an example of the search strategy see Box 2.1. Following retrieval of the relevant articles, the reference lists were searched and further articles obtained if they appeared relevant. Articles that had cited key articles were also obtained and included if appropriate. This snowballing technique is described by Glasziou (Glasziou, Irwig et al. 2001). Both Medline and Embase were searched from 1966 until July 2005 when the review was carried out.

Two reviewers (me and Richard Baker, academic co-supervisor) independently screened abstracts for relevance, for evidence of investigation of the predialysis care pathway and for interventions designed to reduce the number of failures of the predialysis care pathway. We excluded articles that did not look specifically at the predialysis phase of patient care. Therefore, studies of patients with established renal failure already on dialysis were excluded. We also excluded papers that looked solely at the consequences of late referral as we were only interested in reviewing care that pertains to patients who have been known to the renal services for at least three months prior to the start of dialysis. Articles were limited to those in the English language as the cost of interpretation of articles could not be covered.

Box 2.1 shows the search strategy used and demonstrates that 11 studies were found that appeared to meet all of the criteria following abstract review. Ultimately only five studies met the criteria when all papers were obtained and these are reviewed below.



<b>BOX 2.1: Search history from literature review</b>		<b>Articles found</b>
1	predialysis.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	1476
2	predialysis.tw.	1476
3	pre-dialysis.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	659
4	pre-dialysis.tw.	659
5	1 or 3	2076
6	temporary access.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	45
7	5 and 6	2
8	temporary vascular access.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	60
9	cause.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	339735
10	8 and 9	8
11	from 8 keep 11, 17, 20, 34	4
12	from 8 keep 51-60	10
13	from 8 keep 11, 17, 20	3
14	education.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	232437
15	limit 14 to english language	206999
16	5 and 14	68
17	from 16 keep 1, 5, 12, 15, 19, 27...	11
18	from 16 keep 1, 4-5, 15, 19, 21-23, 27...	14
19	8 and 16	0
20	barriers.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	26236
21	5 and 20	7
22	elective.mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, nm]	30733
23	5 and 22	11

### **2.4.1 Main findings for Objective 1 – To identify reasons for the failure of the predialysis care pathway**

A paper by Chesser & Baker (Chesser and Baker 1999) examined in detail the reasons for failure of the predialysis care pathway as defined by the initiation of dialysis using a temporary catheter. The authors described the reasons why patients presenting to a large teaching hospital in London started on RRT using a temporary catheter. In this 16 month retrospective survey, notes from 178 patients were examined, and the reasons for temporary access were classified into one of four categories:

- 1) a failure of management within the renal team
- 2) late referral by another doctor to the renal team
- 3) late presentation to the medical profession
- 4) the patient decided late on the modality of treatment

Failure of management within the renal team was assigned if the patients had been known to the renal team for more than twelve weeks prior to the start of RRT.

Of the 178 cases examined, only 29% of patients had a permanent access at the time of commencing on RRT. Of those patients who started dialysis with a temporary access, 28% had been known to the renal services for 12 weeks or more. 37% were referred late by another doctor, 29% presented late to the medical services, and only 6% were patients who decided late on modality, despite having what the authors consider to be adequate counselling. The paper did not include a description of the counselling services offered to patients, only stating that for purposes of their analysis, patients were allowed six weeks from the time of their first nephrological consultation to decide on treatment modality. In their discussion, the authors offer little explanation as to why 28% of patients were failed by the renal services other than to speculate that it could be because of pressure on inpatient beds and operating theatre time. They also blamed inertia though failed to expand on that in any way. For the 6% of cases where patients failed to make a decision on time, patients inability to accept the severity of the problem and to consent to access procedures were thought to be a problem. Technical difficulties were also cited.



Without an understanding of the measures in place in the hospital to educate and support patients in the predialysis phase, and indeed an explanation of the system for referrals to the multidisciplinary team, it is difficult to interpret the findings of this paper and to consider how it might relate to other units. However, the paper does highlight the possible magnitude of urgent dialysis initiation in a UK renal unit.

More recently Marron et al presented findings of their analysis of the patient flow into dialysis and the choice of dialysis modality (Marron, Martinez Ocana et al. 2005). As part of this, they assessed the role of predialysis education in predicting whether or not patients known to the renal services for at least three months start dialysis as planned or unplanned. Patients were considered to have a planned start if dialysis took place as an outpatient via a permanent access line. Dialysis initiation was considered to be unplanned if it took place urgently because the patient had uraemia, regardless of whether or not the patient had a permanent access line. This retrospective survey combined data from 24 Spanish nephrology units on 608 patients starting dialysis in 2002. Some units had a dedicated multidisciplinary end stage renal disease clinic which provided predialysis care and education whereas others had standard nephrology care alone.

The results of the survey showed that approximately half of all patients started dialysis in a non-planned way, in fact of the 76% (N=474) who had been known to the renal services for at least three months, 33% (N=157) had non-planned dialysis initiation. Only 37% (N=231) of patients had received education on dialysis modalities, however this was shown to be statistically significant in determining whether those patients who had received education had a planned or unplanned initiation onto dialysis. Furthermore, dialysis education was shown to be associated with planned dialysis start with 73.4% of patients who had been educated starting as planned vs. 26.6% of patients who had not been educated. This result is confusing as dialysis education is undefined and it is not clear from the report how this differs from patients who received education on dialysis modalities. The numbers of patients in each group does not add up and it is unclear how these results were achieved.

This was a relatively large sample survey and as such it had the potential to provide rich data on factors that could influence planned dialysis initiation. However, because data were collected from 24 centres and care was not standardised, it would be difficult to predict which factors were effective. Educational interventions in the centres were inadequately described and terminology throughout the paper was inconsistent. The poor quality of reporting makes this study difficult to interpret as there were inconsistencies in the numerical data, which in turn did not correlate with the written text.

#### **2.4.2 Main findings for Objective 2 – To identify interventions that reduce the incidence of failures of the predialysis care pathway (summarised in Table 2.1, featured at the end of this chapter).**

Levin et al carried out an analysis of two Canadian studies, both of which examined the effect of a predialysis care package intervention compared to standard nephrological care (Levin, Lewis et al. 1997). The main objectives of the studies were to examine the effect of augmented predialysis care on the urgency of dialysis initiation. Secondary outcomes examined included hospitalisation within the first month of dialysis and the number of patients training for dialysis as outpatients.

The first of these two studies was carried out in Vancouver, and was a prospective cohort study that reported on 76 patients who had been known to the renal services for at least four months prior to the initiation of dialysis. Of those, 37 underwent a structured multi-disciplinary clinic-based education and follow-up predialysis programme. The outcomes of these patients were compared to 39 patients who received the usual standard of individualised physician care. There was no explanation in the paper as to how patients were entered into each group. Patients with failed transplants or unresolved acute renal failure were excluded.

The standardised predialysis clinic based programme consisted of two main elements - a comprehensive step-wise education programme that took place over several visits, and a predetermined schedule of visit frequency and laboratory tests based on level of renal functioning. The initial clinic visit lasted for three hours with



subsequent visits lasting approximately 90 minutes. At these visits patients spent equal amounts of time with the nutritionist, social worker, physician and nurse educator. Patients who received the usual individualised physician care were not seen in a comprehensive clinic, instead being followed-up in physicians' offices either by a nephrologist or general practitioner.

Patients in both groups were referred to a formal orientation-to-dialysis session of two-three hours duration presented by the nurse educator and social worker. The session used mixed media to demonstrate and discuss haemodialysis, peritoneal dialysis and palliative care. No information is given on how many patients in each group attended these sessions.

Analysis of this study data was solely descriptive with probability values only reported if they were found to be statistically significant at  $<0.05$ . The results appear to show a clear difference in the number of patients presenting to start on dialysis electively between the two groups. The authors state that urgent dialysis initiation was required in 35% of patients who received unstructured predialysis care compared to 13% of patients who were in the structured predialysis care programme. However, the numbers given alongside the percentages do not accurately tally to these percentages, as they report 4 out of 37 patients (10.8%) required urgent dialysis start in the structured care group, and 13 out of 39 (33.3%) in the unstructured care group. No explanation could be found in the text to explain this discrepancy.

The authors also found that those patients who went through the structured programme had a far higher proportion of patients who trained for dialysis as outpatients, 76% compared to 43% in the unstructured care group. No numbers were presented with these figures. No information was given about the patient characteristics prior to the start of the programme, however, more patients in the structured care group started dialysis with improved blood pressure, haemoglobin and calcium control than the unstructured care group.

Despite the poor level of reporting, the study does suggest that a structured predialysis programme consisting of comprehensive step-wise education and predetermined visit frequency and laboratory tests, is beneficial to patients in allowing more to start dialysis in a planned manner. However, the results of this study would have been far more credible had the reasons behind the treatment allocation been described, and far more robust had patients been randomised to the two treatment arms.

The second study reported in the same paper, by Levin et al, is a before and after study (also known as a pre and post intervention study), in which the results of an audit of patients starting dialysis before the implementation of a predialysis care package were compared with data from patients who were exposed to the care package. The study took place in Toronto. The predialysis care package consisted of two evening sessions for patients and families in which the options for living with end stage renal disease (ESRD) were discussed along with nutritional and pharmacological therapies for patients approaching ESRD. Following these two sessions, patients attended a predialysis clinic where they met individually for half an hour with a dialysis physician and a renal nurse co-ordinator. They then spent an hour with a social worker before having a group session with a renal dietician for half an hour. The focus of the predialysis clinic was on modality selection and access planning. The patients only attended one predialysis clinic before resuming follow-up by the primary nephrologist. It is not stated in the paper what the predialysis care situation was before the implementation of the package, however it is likely that it consisted simply of appointments with the nephrologists.

The comparison group used for the pre-intervention sample were taken from the 60 patients starting on dialysis in the three months prior to the implementation of the new programme in December 1991. Of the 60 patients starting on dialysis in this time, only 36 (60%) had been known to the renal services prior to commencing on dialysis. Of them, 26 (72%) had elective starts compared to 10 (28%) who had urgent dialysis starts. In contrast to the other studies cited in this review, the authors did



not state how long patients had been known to the service prior to dialysis initiation before they could be included in the study.

141 patients were seen in the predialysis clinic in the study time period, which was November 1991 and December 1993, though only 94 of them had attended the formal renal education programme. 96 of the 141 started dialysis during the time period studied and are therefore included in the analysis. Interestingly this is only 26% of the total number of patients who started dialysis during this time. While some patients would have been referred late, it also suggests that not all patients were entered into the predialysis clinic programme. This is not explained in the paper. There is no information on patient characteristics prior to the start of the education programme or dialysis.

The authors state that at 86%, more patients had a permanent access at the start of dialysis in the intervention group, although figures are not given of how many patients had a permanent access in the pre-intervention group. An unexpected increase in the number of patients having urgent dialysis initiation was found in the intervention group, something that the authors ascribed to the lack of resources for haemodialysis in Toronto at the time.

There are many aspects of this study that were not adequately explained in order for the reader to draw conclusions about the benefits of the intervention. The small number of patients in the pre-intervention group (36) was not a large enough sample to provide robust comparison, and the fact that it was drawn over a three month period means that seasonal variations would not have been captured. A pre and post intervention study with larger numbers of patients would have been better; though better still would have been a prospective study during the same time frame, ideally with patients randomised to receive either standard care or traditional care.

Research by Ravani and colleagues (Ravani, Marinangeli et al. 2003) from Italy seems to support the findings of the Vancouver study presented by Levin et al discussed above. In this pre and post intervention study carried out in two sites, data were

collected about one group of patients who received traditional nephrological care prior to the implementation of a structured predialysis programme in October 2000 (the pre-intervention group), and another group of patients who were involved in the programme (post-intervention group).

The programme was available for all patients with a Cockcroft and Gault creatinine clearance of less than 30ml/minute and consisted of physicians and nurses who dedicated approximately one third of their time to ensuring several elements of patient care were implemented. These were:

- 1) Organisation of pre-ordered laboratory testing
- 2) Application of recommended diagnostic and interventional strategies
- 3) Information and education concerning ESRD, which consisted of at least three two hour long formal individualised education sessions over three months
- 4) Progressively intense follow-up protocol according to kidney function level
- 5) Involvement of the familial environment (this is not fully defined)

Patients in the pre-intervention group were treated in an out-patient clinic setting according to traditional practice with no structured approach to progressive renal disease management.

The objectives of the study were to find out if the programme impacted on the urgency of dialysis initiation (emergency vs. planned start), the chance for selection and use of the first choice dialysis modality, and the use of health care resources. Dialysis starts were classified as emergency starts if dialysis was started via a temporary venous catheter. The criteria for emergency dialysis initiation were pulmonary oedema and or symptomatic uraemia.

Two hundred and twenty-nine patients took part in the study. Of those, 84 (36%) were referred to the renal services less than three months before dialysis initiation, so therefore were not eligible for inclusion in the programme. Of the remaining 145



patients, 52 had traditional unstructured care while 93 were enrolled in the structured care programme. The mean follow-up of these early referred patients was 40.2 months with no difference between the two groups. There were very few differences between the two treatment groups in terms of demographic characteristics and causes of renal disease. Those patients in the structured care programme started dialysis with a slightly, though statistically significant, higher haemoglobin level, and also with a higher GFR.

The most relevant finding in relation to this literature review is that of those patients who had been known to the renal services for at least three months, patients in the structured programme were far more likely to have a planned dialysis start, with only 8.6% having an emergency dialysis initiation. This contrasts starkly with 61.5% of the patients who had a traditional follow up who started as emergencies. This result was supported by a multivariable logistic regression model which was adjusted for age, sex and co-morbidities. This analysis showed that the odds of having an emergency start were 0.5 (95% CI: 0.25 to 1.12) for patients having traditional care compared to those referred late, which reduced to only 0.013 (95% CI: 0.013 to 0.075) for those who had been in the programme compared to those presenting late.

Other interesting findings of this study were that the possibility of participating in the dialysis choice process and the choice of dialysis modality were the same whether the patient had experienced a traditional follow-up or had participated in the programme, and was no different whether the patient had been referred early or late. The authors concluded that three months is insufficient time to allow patient participation in the process of dialysis modality choice. Patients in the structured programme had significantly shorter hospitalisations in the predialysis phase and were less likely to be hospitalised in the first three months on dialysis.

This study shows the benefits of a structured predialysis care programme in reducing the number of patients presenting for emergency dialysis initiation and also in reduction of pre and post dialysis hospitalisations. However, one element of it

remains confusing. In their introduction the authors state that the ideal management of CKD includes among other things, the patient making an informed choice of the most appropriate dialysis method, yet within their centres they comment that peritoneal dialysis was the proposed first choice dialysis treatment as it can be performed independent of the hospital and requires fewer nurses. This appears to be contradictory to what they state as the ideal and raises questions about the impartiality of the staff providing the predialysis education. In addition to this, the paper provides insufficient explanation of the intervention to fully understand the programme and assess how it could be replicated elsewhere.

This study appears to show clear benefit in some areas of predialysis management when patients are subject to a structured predialysis management system.

However, because the sample was accrued over different points in time and from two different centres, effects of the inevitable change in clinical practice over time and local variations cannot be elicited. Perhaps implementation of the programme at one site while maintaining traditional practice at another would have provided slightly more robust data. Clearly an experimental study involving randomisation would have been the optimum study design.

In a similarly designed study to that of Ravani and colleagues, Law et al report on the effects of a predialysis counselling programme implemented in a single centre hospital in Hong Kong (Law, Szeto et al. 2001). The pre and post intervention study compared patients exposed to the counselling programme (post-intervention group) with a pre-intervention group who had received standard care alone in the 12 months prior to implementation of the programme. All patients had been known to the renal services for at least three months prior to dialysis initiation. The programme consisted of a single multidisciplinary small group seminar session which included presentations on a variety of topics followed by a group discussion. Unfortunately, standard care was not defined. All patients attending the hospital between October 1995 and December 1997 were included in the predialysis counselling programme unless they had a life expectancy of less than six months or were due to have a living related transplant within six months of referral.



The two outcomes reported were urgent starts on dialysis and rate and duration of hospitalisation in the six months following dialysis initiation. Urgent starts were defined as dialysis that required a temporary catheter or dialysis initiated without prior planning by patients and the dialysis unit. Late referral was defined as patients who had been referred to the renal service less than three months before initiation on dialysis.

The results show that among patients who had been known to the service for at least three months, there was no difference in baseline clinical and biochemical characteristics such as body weight, blood pressure, and creatinine clearance rate on dialysis initiation between those that had received standard care and those that attended the predialysis counselling session. Furthermore, there was no difference in the rates of patients presenting for dialysis urgently between the two groups with 50.7% (N=34) in the predialysis counselling programme group and 60.8% (N=31) in the standard care group presenting in this way. The causes of urgent dialysis in both groups were very similar. Hospitalisation rates in the six months following dialysis initiation were likewise almost identical. The authors conclude that there is little benefit to patients receiving predialysis counselling, however acknowledge that outcomes such as quality of life and patient satisfaction might have varied but were not captured in this study.

No mention was made of patients who did not attend the counselling session, indicating that all patients attended, however this may not be the case. Additionally, it seems as though haemodialysis was not offered to patients in this centre making it largely ungeneralisable to centres in the UK where haemodialysis is the dominant treatment option (Ansell, Feest et al. 2004) and patients are given free choice of treatment modality whenever possible.

## **2.5 Summary & conclusion**

This review has revealed a small body of research into the reasons why patients start on RRT urgently when they have been known to the renal services for a time considered to be long enough to prevent such an occurrence. The suggestion by

Chesser & Baker (1999) that patients are in some way failed by the renal services is disturbing, not least because the reasons for this remain unexplored and are potentially preventable. The studies that have attempted to improve the situation have all done so by implementing new educational interventions in the predialysis phase, yet this is where the similarities between the studies end, making it difficult to draw conclusions from them collectively.

The educational interventions tested ranged from a single predialysis visit (Law, Szeto et al. 2001) which did not lead to an improvement in urgent dialysis starts, to a stepwise educational package over multiple visits, part of a package which did show an improvement in overall elective dialysis starts. This suggests that an element of time during which patients can go away and absorb the information to which they have been exposed before coming back with any questions could be an important aspect of this improvement. This is certainly in line with research in other clinical areas which has shown that small group teaching sessions over time lead to greater understanding and ultimately greater optimal patient response by empowering patients with knowledge of their condition (DAFNE Study Group 2002).

The two studies that showed a reduction in the amount of urgent starts were similar in that they were the only studies to have a structured predetermined algorithm for laboratory testing and clinic visits based on the individual patients' renal function. This may be a key element in improving the rate of elective dialysis starts but as this was only one aspect of the programmes it is difficult to know how much of an impact this had.

All studies used members of a multidisciplinary team to deliver the interventions reflecting the consensus in the wider literature that a multidisciplinary approach to patient care is optimum (Khan and MacLeod 1997; Goldstein, Yassa et al. 2004).

With the exception of the study carried out in Italy (Ravani, Marinangeli et al. 2003) where only nurses and doctors delivered the intervention, all of the studies involved physicians, nurses, social workers and dieticians. This may well be the optimum skill mix in renal centres, however in the UK, 36% of renal units do not have renal social



workers (Ansell, Feest et al. 2004). The relative contribution of each member of the team could be an important factor in delivery of the highest quality of care in the predialysis phase, and could account for some of the beneficial results, but due to the non-experimental nature of the studies in this review, it is not possible to determine which elements of the interventions were more or less effective.

All studies of interventions included in this review showed some level of inadequate reporting, with missing figures and misleading percentages as well as missing data being common. This reflects the general low quality of all of the studies, most of which did not describe standard practice in a meaningful way or give adequate information on the interventions. In general any studies that aim to test the effectiveness of an intervention through the use of a before and after, or pre and post intervention study, are weak as they only reflect the overall state of affairs before and after an intervention has been implemented and cannot account for factors other than the intervention that may explain any effects that are seen and interaction between the various elements of an intervention cannot be measured. Therefore, before and after studies have a low level of internal validity and are not suitable for determining best practice (Bryman 2004).

Ethnicity and socio-economic status are known barriers to accessing health services (Gulliford 2003), yet neither of these were mentioned in any of the studies in this review. Little is known about the heterogeneity of the populations in the studies in this review, however, this may be particularly relevant in other areas of the world such as Leicester, where the population of renal patients from non British White ethnic groups is currently 36% and rising (Ansell, Feest et al. 2004). Additionally, services in the wider East Midlands Renal Network cover a variety of urban and rural communities which may pose different challenges for renal services (Martin, Roderick et al. 1998).

Perhaps the most striking aspect of these studies as a whole, is that the patient account is completely absent from them all. The studies seeking to understand the reasons for urgent dialysis initiation used only secondary data from computerised

records making no attempt to understand the reasons from the point of view of the patients who had been through the process under scrutiny. None of the interventional studies appear to have been designed with input from patients, and patient opinions on their effectiveness do not appear to have been sought. Furthermore, patient help-seeking behaviour has not been taken into account, yet patients' beliefs about their health and health interventions is paramount to how they will respond to interventions and interactions involving health professionals (Morgan 2003). Therefore, understanding the process from the point of view of patients is vital.

This review has highlighted the need for high quality UK based research into the reasons why patients continue to present for urgent dialysis start when they have been known to the renal services for some time. The service in Leicester currently includes a dedicated predialysis clinic, a team of specialist nurses who visit patients in their own homes to provide predialysis care and information, as well as a structured multidisciplinary day long education session offered in both English and Gujarati. Despite this, approximately half of patients who start dialysis in the East Midlands Renal Network who have been known to the renal services for at least four months, do so urgently, often with temporary access catheters. The reasons for this need to be fully ascertained before improvements can be made to the service. This involves a thorough examination of the service from the perspective of all of those involved, especially the patients whose health is potentially compromised by the current system.



Table 2.1 Studies of interventions to improve predialysis care pathway (Objective 2)						
Author	Country	Study design	Mean age & modalities included	Intervention	Effect on urgent dialysis start	Quality issues
Levin et al, 1997, study 1	Canada, (Vancouver)	Prospective multi-sample cohort	Ages not given PD & HD	Standardised MD clinic programme. Stepwise education programme, predetermined schedule of clinic visits	Fewer urgent starts in intervention group	Not randomised. No information on patient allocation
Levin et al, 1997, study 2	Canada, (Toronto)	Before and after / pre and post intervention	Ages not given PD & HD	Predialysis care package of two evening sessions and one predialysis clinic visit	Increase in urgent starts in intervention group	Non-concurrent Small sample Standard care not explained Not randomised
Law et al, 2001	Hong Kong	Before and after / pre and post intervention	54.3 yrs (12.6) PD only	Single small group seminar by MD team	No difference in urgent starts between two groups	Non-concurrent Small sample Standard care not explained Not randomised
Ravani et al, 2003	Italy	Before and after / pre and post intervention	64.4 yrs (15.1) PD & HD	Standardised MD predialysis care package. of at least three education sessions and predetermined schedule of blood tests and clinic visits	Fewer urgent starts in intervention group	Non-concurrent Small sample Not randomised

# CHAPTER 3

## Phase 1 Methods and Methodology

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### 3.1 Introduction

Why do patients present for urgent dialysis initiation when they have been known to the renal services for some time? The following three chapters detail a cross sectional survey conducted in order to try to understand this phenomenon. This chapter will focus primarily on explaining how the researcher went about answering this question by detailing the practical aspects of the first phase of this research study, from study planning, through to data collection and data analysis. The methodological issues surrounding this phase of the research study are then discussed. Results and the discussion of results are in the following two chapters.

As little is known about this research area, the following objectives were formed to guide the research design, planning and analysis:

- To determine the percentage of patients presenting as ‘known acute’ (defined as requiring acute hospital admission or need for ‘non-permanent’ vascular access) in the East Midlands Renal Network over one year, broken down by age, sex, ethnicity, presence/absence of diabetes mellitus or other co-morbidities as recorded by UK Renal Registry coding
- To determine the calculated glomerular filtration rate at start of dialysis and rate of change over previous follow-up
- To determine the influence of choice of mode of RRT on entry to the programme and comparison of planned v. resulting mode of RRT
- The identification, where possible, of reasons for urgent entry to RRT programme



Because of the exploratory nature of the research question, a retrospective cross-sectional study design was employed as this allows the collection of a large quantity of data from a predetermined point in time. The sample consisted of patients who had started RRT in 2003 in the East Midlands Renal Network.

### **3.2 Ethics and research governance issues**

An application to conduct this research was made to the Leicestershire Research Ethics Committee in September 2004. Ethical approval was granted in January 2005 concurrently with research governance approval for the study to take place in Leicester from the University Hospitals of Leicester NHS Trust. Separate approval from each trust was also required and was granted by Kettering and Peterborough trusts in May 2005. Approval from the United Hospitals of Lincoln Trust was granted in August 2005. The time between submitting the ethics application and gaining permission from the ethics committee to carry out the study was used to set up this phase of the research. This involved defining the study population, determining the research questions, developing data capture and collection techniques and formulating an analysis plan. The steps involved in this process are discussed below.

### **3.3 Defining the study population**

The study population consisted of patients who started RRT in 2003 in the East Midlands Renal Network and who had been known to the renal services for at least four months prior to the initiation of RRT. This included patients who had a pre-emptive transplant as well as those who started on peritoneal and haemodialysis. The calendar year of 2003 was chosen as the electronic data were mostly complete for the whole year at the start of the study. A 12 month time frame was selected to ensure that any variations in seasonal uptake of RRT were captured.

The four month cut off was used as it this would allow sufficient time from referral for adequate preparation to start RRT in a planned manner. This figure is somewhat arbitrary, however, as the literature review showed that other studies had used periods of between one month to one year, and there is still no definitive

time frame in which patients can be adequately prepared for RRT. Table 3.1 below shows the variety of cut-off times used in the studies included in the literature review as well as the definitions of urgent dialysis found in these studies. Further timescales of studies in renal disease not included in the literature review can be found in Table 5.1.

**Table 3.1 Late referral cut-off and urgent dialysis initiation definitions of studies in literature review**

Author & date	Times	Urgent dialysis definition
Chesser & Baker, 1999	12 weeks	Initiation of dialysis via a temporary access catheter
Marron et al, 2005	3 months	Dialysis that took place urgently because the patient had uraemia regardless of whether they had temporary or permanent access
Levin et al, 1997 Vancouver study	4 months	Dialysis that required temporary access catheter or dialysis initiated without prior planning by the patients and dialysis unit
Ravani et al, 2003	3 months	Initiation of dialysis using a temporary central venous catheter
Law et al, 2001	3 months	Dialysis that required temporary access catheter or dialysis initiated without prior planning by the patients and dialysis unit

A couple of definitions were created for use in this study. Where possible, similar definitions to those found in the literature were used to facilitate accurate comparison; however this was not always considered appropriate. We defined urgent RRT initiation as requiring a temporary access for dialysis initiation or starting as an emergency case in a way unplanned by the patient and the consulting physician. This definition was also used by Levin et al (Levin, Lewis et al. 1997) and Law et al (Law, Szeto et al. 2001). Elective RRT initiation was defined as starting dialysis in a planned and timely manner using the type of dialysis access agreed by both patient and the clinical team, or having a pre-emptive transplant. Thus the samples were classified into one of these categories.



### **3.4 The research questions**

This section describes the development of and rationale underlying the research question. A preliminary literature review of barriers to an elective start to renal replacement therapy was carried out (prior to undertaking the full review reported in Chapter 2) and contact was made with some stakeholders in the renal services in order to develop an understanding of the predialysis care pathway. This included gathering information from meetings with dietitians, clinicians, a clinical psychologist and nursing staff, as well as observing predialysis clinics and accompanying the home care team on visits to patients' homes. Through these interactions with the team and the literature review, it was discovered that there were five main areas where data collection ought to focus on. These areas were: health status, socio-economic factors, risk factor management, service delivery and patient related factors. These are discussed in detail below along with the specific research questions that arose from these areas preceding the discussion.

#### **3.4.1 Question 1: How many patients start dialysis urgently in the East Midlands Renal Network?**

Initially it was important to establish the scale of the problem. Research from other areas suggests that from 10 – 35% of patients who have been known to renal services for some time start dialysis urgently, so understanding the scale of the problem in the East Midlands Renal Network was necessary in order to set the results in context (Ansell, Feest et al. 2005).

#### **3.4.2 Question 2: Were there any demographic or socioeconomic differences between the groups?**

There are several socio-economic factors that could potentially affect acute or planned dialysis initiation as discussed in section three of the introduction to this thesis. To assess for geographical barriers, outcomes of predialysis treatment at a peripheral unit was compared with outcomes of predialysis treatment at the main unit in Leicester to see if there were any differences. Barriers to accessing care are sometimes evident in patients from ethnic minority backgrounds, therefore this was explored. The effects of age and gender were also analysed.

Socioeconomic status was determined using the Index of Multiple Deprivation, 2004. The Index of Multiple Deprivation (IMD2004) is a measure of multiple deprivation at the small level area. The index is comprised of distinct domains that contribute to deprivation and are listed below (Box 3.1). Each small area, known as a super output area is indexed, or ranked, from between 1 (most deprived) to 32,482 (least deprived). Patients' postcodes were used to search for the rank of the area they live in. This information is compiled by the Office of the Deputy Prime Minister.

**Box 3.1 Domains contained within the Index of Multiple Deprivation**

- Income deprivation
- Employment deprivation
- Health deprivation and disability
- Education, skills and training deprivation
- Barriers to housing and services
- Living environment deprivation
- Crime

**3.4.3 Question 3: Were there any differences in the underlying causes of kidney disease or the presence of co-morbidities between the groups?**

Many patients with CKD have other health conditions which may affect the rate of renal deterioration and the ability of the body to cope with the effects of kidney disease, which may or may not be related to the underlying cause of kidney disease. Therefore the researcher was interested in finding out about the cause of CKD and also other comorbidities, as previous authors have suggested that the presence of other diseases, particularly chronic conditions, could be beneficial in ensuring that patients have elective dialysis initiation. This could be because these patients are under increased medical surveillance and likely to receive additional input from a wide variety of clinicians (Kazmi, Gilbertson et al. 2005).

To collect information on co-morbidities the clinical conditions as described in the UK Renal Registry were used so as to allow for meaningful comparisons of the results. These co-morbid conditions, listed in Box 3.2 below, are conditions that



are known to influence the decline of renal function or be associated with renal disease. Although not a co-morbidity, smoking is included here as well as it is considered to be a marker for vascular risk (Ansell, Feest et al. 2005). These data were obtained from the hospital renal computer system Proton, where it had previously been entered from the medical notes. The reliability of this information was checked while reviewing the medical notes. In addition to the Renal Registry co-morbidities, evidence was also sought of abdominal aortic aneurysm repair and pulmonary embolus as both have been associated with a sudden rapid decline in renal function that could be linked to urgent dialysis initiation.

The underlying diagnosis for kidney disease was readily available. These were grouped under seven broad headings: unknown aetiology, diabetic nephropathy, polycystic kidney disease, renovascular disease, glomerulonephritis, pyelonephritis/interstitial nephritis, other.

#### **Box 3.2 List of co-morbidities collected**

- Angina
- Previous myocardial infarction (MI) within last 3 months
- Previous MI > 3 months ago
- Previous coronary artery bypass graft (CABG) or coronary angioplasty
- Claudication
- Ischaemic/neuropathic ulcers
- Angioplasty (non-coronary)
- Amputation for peripheral vascular disease
- Cerebrovascular disease
- Diabetes
- Chronic obstructive pulmonary disease
- Liver disease
- Malignancy
- Smoker
- Abdominal aneurysm repair

#### **3.4.4 Question 4: Were there any differences in the renal function of the two groups at the start of RRT?**

Although renal failure follows a standard trajectory of decline, the rate of decline varies significantly between patients. There are many reasons for this, for example the presence of co-morbidities as mentioned above, intercurrent illnesses such as infections, and adherence to medical regimens. An unexpectedly rapid decline could constitute a reason for urgent RRT initiation. The researcher had hoped to record the rate of decline in renal function over time by recording eGFR, serum creatinine and weight at several time points during the predialysis period. In the event this was not possible as these data for patients whose predialysis care was outside of Leicester were not available. Instead, data were collected on the health status of the patient immediately prior to the first RRT as this was available. This information provides an insight into the level of renal functioning at a single time point, but unfortunately does not measure the rate of decline over time which would have been ideal. The measures used to assess this were eGFR, serum creatinine, albumin, phosphate, potassium and urea levels.

#### **3.4.5 Question 5: Were there any differences in the management of risk factors and side effects of CKD between the two groups?**

There is a wealth of evidence that suggests that patients with CKD benefit from targeted management of cardiovascular risk factors during the predialysis phase as they are at increased risk of stroke and cardiac events. Hypertension is a particular problem for the majority of patients with CKD and current guidelines stipulate a target blood pressure of 130/80 in patients without proteinuria, and 125/75 in patients with proteinuria. Management of hypertension and other cardiovascular problems can take the form of lifestyle modification, for example stopping smoking, healthier eating and increasing exercise, and pharmaceutical interventions such as the prescription of statins for hypercholesterolaemia and ACE inhibitors for hypertension (Kshirsagar, Joy et al. 2000). Risk factor monitoring and management may be indicators of quality of care. It was speculated that patients who had received more intensive risk factor monitoring and management would have less chance of an urgent dialysis start. Therefore, it was planned to



collect data on the frequency of dietetic input in the 12 months prior to dialysis initiation as well as the drug profile at dialysis initiation.

#### **3.4.6 Question 6: Were there any differences in service delivery between the two groups?**

There are several factors that are related to availability and delivery of services that could affect urgency of RRT initiation such as patient education, predialysis attendance and frequency of appointments. These factors were explored to include: attendance at predialysis clinic (as opposed to nephrology clinic), amount of nephrology appointments in the 12 months prior to dialysis initiation, follow up by the home care team in the 12 months prior to dialysis initiation, attendance at a patient information day, length of time between referral for dialysis access and access creation, length of time between referral for dialysis access and dialysis initiation.

#### **3.4.7 Question 7: Were there any patient related factors that could explain differences between the two groups?**

Missed or cancelled appointments may have an impact on dialysis start in terms of the patient flow through the predialysis pathway. Therefore, it had been intended to collect information on how many appointments had been cancelled or missed in the twelve months prior to dialysis initiation. Although this information was available for some patients, during data collection it became apparent that data were incomplete for over half of patients. As a result of this it was not possible to carry out any meaningful analysis of appointments missed or cancelled by patients in relation to urgency of RRT initiation.

#### **3.4.8 Question 8: Were there any factors that were predictive of known acute RRT start?**

This is of course one of the main reasons for carrying out this study, as understanding what factors are predictive of the problem could lead to an understanding of how these factors could possibly be controlled by changes within

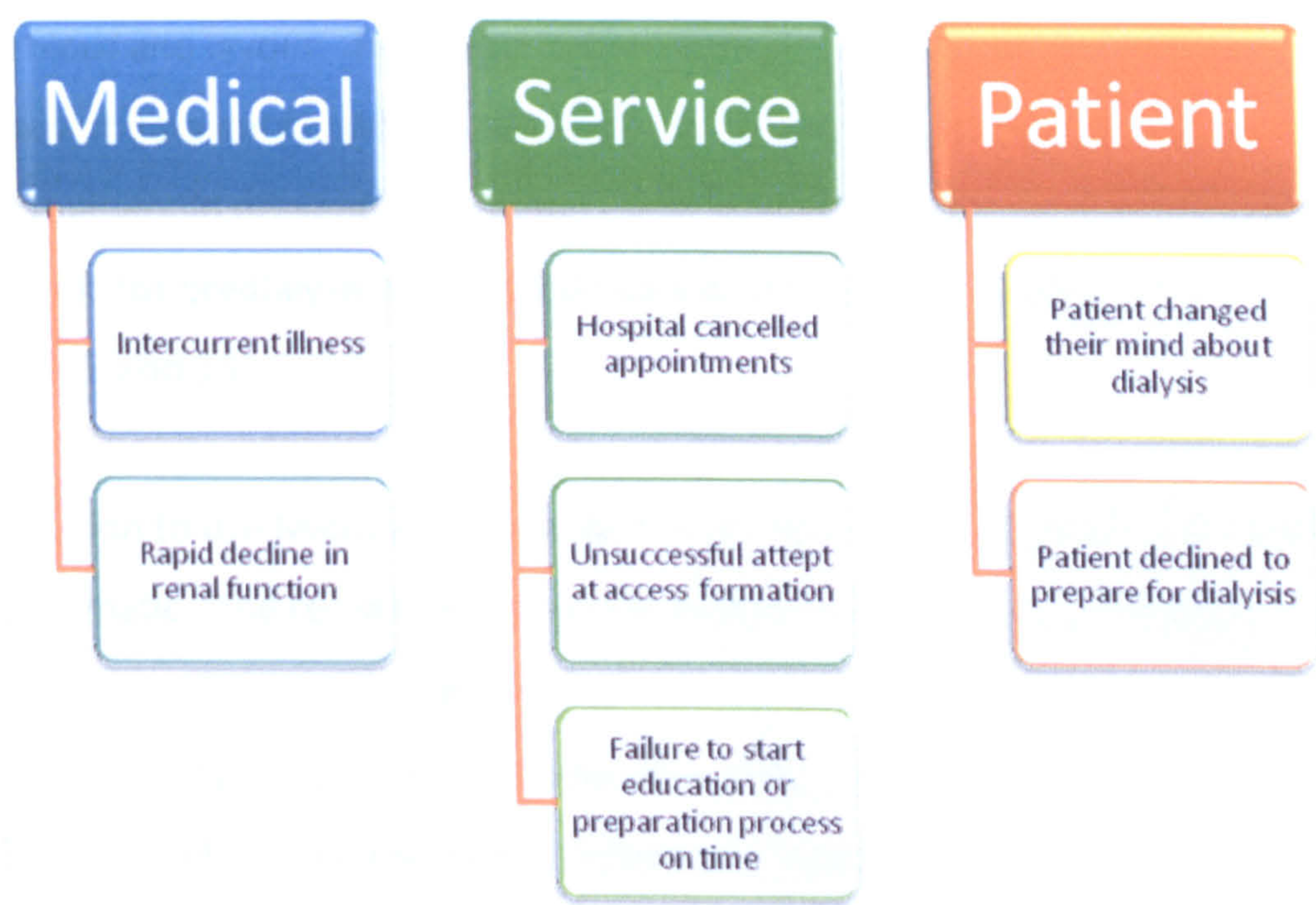


the system. A logistic regression analysis was used to determine which factors may be predictive.

**3.4.9 Question 9: What were the reasons for known acute presentation in those patients who had an urgent RRT start?**

The reasons for starting as known acute were derived from a larger list of reasons identified in the literature, these were grouped into medical related, service related and patient related as shown in Figure 3.1 below.

**Figure 3.1 Reasons for urgent dialysis start**



Following complete data collection, the reasons for known acute presentation were assigned by the researcher collecting the data. If there was any uncertainty as to the reason for known acute presentation, this was discussed with the consultant nephrologist in the team and a common decision was reached.

**3.5 Study tools**

A number of tools were used in this study that aided in the data collection, storage, handling and analysis. This section will describe these tools and their development and explain the rationale for choosing them.



As there were no standardised methods of collecting the data to answer the research questions, a case report form (CRF) was developed for use during this study (Appendix 1). The CRF was developed over a period of approximately three months and was designed to address the research questions discussed above. The CRF was five single sided pages, each colour coded to distinguish between different broad topics in the form.

Data were entered on the CRF into a Microsoft Access (2003) database that had been designed for this study. The database consisted of a number of forms designed to resemble the paper copy of the CRF as closely as possible in terms of both colour and layout. This was a deliberate measure taken to improve the accuracy of data entry. Where possible limiting parameters were created in the forms that would prevent entry of data that were clearly inaccurate. For example, in the field for predialysis haemoglobin levels, entry was restricted to values between 5 and 15.

The decision to use Microsoft Access as the primary electronic data storage facility was pragmatic. The researcher had prior experience of setting up databases for research in a previous occupation, and had been on several courses on database design and utility using Access. Access allows the researcher to run queries which can be very useful when identifying potentially inaccurate and incomplete data. Some numerical data, such as the laboratory variables, were entered into Microsoft Excel prior to transfer to Statistical Package for the Social Sciences (SPSS). Data analysis was principally carried out in SPSS version 12.1.

### **3.6 Procedures**

#### **3.6.1 Accessing the sample**

Preliminary data from *all* patients who started on RRT in 2003 in the East Midlands Renal Network were captured from the hospital renal computer system, Proton, by the renal unit data manager. This dataset included demographic details such as names and addresses, dialysis initiation status, and also blood results for the year prior to commencing dialysis.

In order to obtain the sample of patients who had started RRT in 2003 and who had been known to the renal services for at least four months previously, ineligible patients were identified and their data removed from the file. Firstly, details of all patients who had been transferred into the East Midlands Renal Network to start on dialysis and patients who had received a transplant from outside the EMRN were removed. Following this the details of all patients who had started RRT in 2003 in the EMRN who had received any predialysis care in the network were left, as well as those who started on RRT without any predialysis care. The data were sorted through and all data from patients who were labelled as 'unknown acute' were separated out into a separate Excel file leaving the data of all eligible patients. Finally the information for patients who had died was removed so that what was left was all of the eligible patients who could be contacted to ask for consent to use their data for this research study. Figure 3.2 shows in detail how the sample was ultimately achieved from a preliminary potential population of 186 to the final sample of 109.



Figure 3.2 - Sample progression chart

	Number	Subtotal
Patients starting RRT in the East Midlands Renal Network in 2003	186	186
Patients excluded because they were transplanted elsewhere or transferred from elsewhere	19	167
Patients who were known to the renal service for less than four months (unknown acute) and so were excluded from further analysis	36	131
Patients who were dead at the time of the study, therefore automatically included	33	33
Patients who were asked for consent to include their data in this study	98	
Patients who gave consent	81	114 (dead + consent)
Patients who were excluded following data collection because they were ineligible or the notes were missing (3 were actually unknown acute, 1 started RRT 2002, 1 set of notes missing)	5	
Patients included in the study	109	109
Final status of all <i>eligible</i> patients (not all gave consent)		
Unknown acute	Elective	Known acute
39	71	55

Based on preliminary data from Proton

Following data collection from medical records

Patients were asked for consent to include their data in this research study. Patients were contacted in one of two ways, either by post or in person. All patients who were on peritoneal dialysis or who were dialysing in the satellite units were sent a letter inviting them to take part in the study, plus an information sheet and consent form (shown in Appendix 2) and a prepaid, addressed reply envelope.

The invitation letters were created by mail merge in Microsoft Word so that the patient’s name and address were on the letter, as recommended by Bowling (Bowling 2002) and Edwards and colleagues (Edwards, Roberts et al. 2002), and were printed on the hospital trust headed paper as stipulated by the local research ethics committee. Signatures of all the consultant nephrologists in the EMRN at the time were on the letter. This was important for two reasons; firstly, as letters

were being sent to patients both in Leicester and from the rest of the EMRN, they would be able to recognise the name of their own consultant on the letter, rather than just the name of the researcher, thus lending to the credibility to the study by making it seem more personal. Secondly, by including the signatures of all the doctors, the patients may sense the importance of the study as it clearly had the backing of all the relevant senior clinicians.

Immediately prior to mailing the letters each name was checked on the hospital HISS and Proton computer systems to make sure that there was no record of the patient having died. This was an important step, as, during the course of gaining consent for this study, a number of patients did in fact die and the letter was therefore not sent. The documents were mailed in plain brown envelopes with pre-printed address labels.

Patients were asked to return the consent forms using the prepaid envelopes to me within three weeks of mailing. If patients did not respond within a month, a second letter was sent along with another information leaflet, consent form and prepaid envelope. This letter was much shorter and emphasised that patients could get in touch with the researcher to discuss the study. If a consent form was not received following these two attempts it was assumed that the patient did not wish to have their data included in the study and all of their data were removed from the study files.

In order to raise awareness among staff in the EMRN about this study, contact was made with all of the renal unit managers and all but one was met in person by the researcher to explain the study in detail. As patients were asked for their consent by letter, there was a chance that patients would mention the study to staff at the satellite units, so staff needed to know enough about it to explain the study a little if asked. The second reason for establishing contact was that when visiting the satellite units to collect the data, the staff would know the researcher and help if needed with the practical aspects such as finding an office to use. The researcher also met with all of the consultant nephrologists in the satellite units and in the



end it was their secretaries who requested the medical notes for me at the satellite units and arranged my visits at times when there would be a room for me to use. The exception to this was in Peterborough where the Clinical Audit Office required that all requests for medical notes be sent to them and that all data collection be carried out in the audit office.

3.6.2 Data collection

Data were obtained from several sources, both electronically and manually. Some data were collected electronically from Proton, some manually from Proton and the hospital information system HISS, but the bulk of the data came from paper based medical records. In addition, medical records were examined of patients whose predialysis care had been in one of the peripheral units. The source of data for each section of the CRF is shown in Table 3.2.

Table 3.2 – Sources of data items in CRF

CRF page	Section heading / data items	Source*
1	Background information	P & MR
1	Co-morbidities	P & MR
1	Drugs on admission	MR
2	Renal replacement therapy	MR
2	Dialysis access related information	MR
2	Patient information day	P & MR
2	Transplant related issues	MR
3	Care of patient by nephrologist/nephrology team	MR
3	Appointments with nephrologists in 12 months prior to RRT	H
3	Predialysis dietetic input	P & MR
3	Home care team input	P & MR
4	Missed/cancelled/delayed appointments	H
5	Laboratory values	P

\*P = Proton, MR = medical record, H = HISS



Before data collection began the data collection techniques were piloted on three sets of notes of patients from the previous year (2002). Next a procedure sheet was developed for data collection for use during this study (Appendix 3). This facilitated standardised and timely data collection and also ensured transparency in the research process so that it could be replicated if necessary. The title BERRT at the top of the procedures document refers to the acronym developed for the study. The full title was Barriers to the Elective Start of Renal Replacement Therapy.

A page numbered book was used to record information about patients which was used at the same time as completing the CRF. This was important as the data collection involved quite a lot of detective work. By noting down dates and events in a separate book it was often possible to establish the course of events prior to entering them onto the CRF. Very often a brief synopsis of the patients' predialysis course was recorded in the book, which was particularly useful when discussing queries within the team. The book also proved invaluable when completing data collection in the satellite units as it was possible to combine the data from Leicester with that in the satellite unit and make sense of it before committing it to the CRF. Each patient's unique identification number was entered into the appropriate section in the index and the page their information was on was recorded.

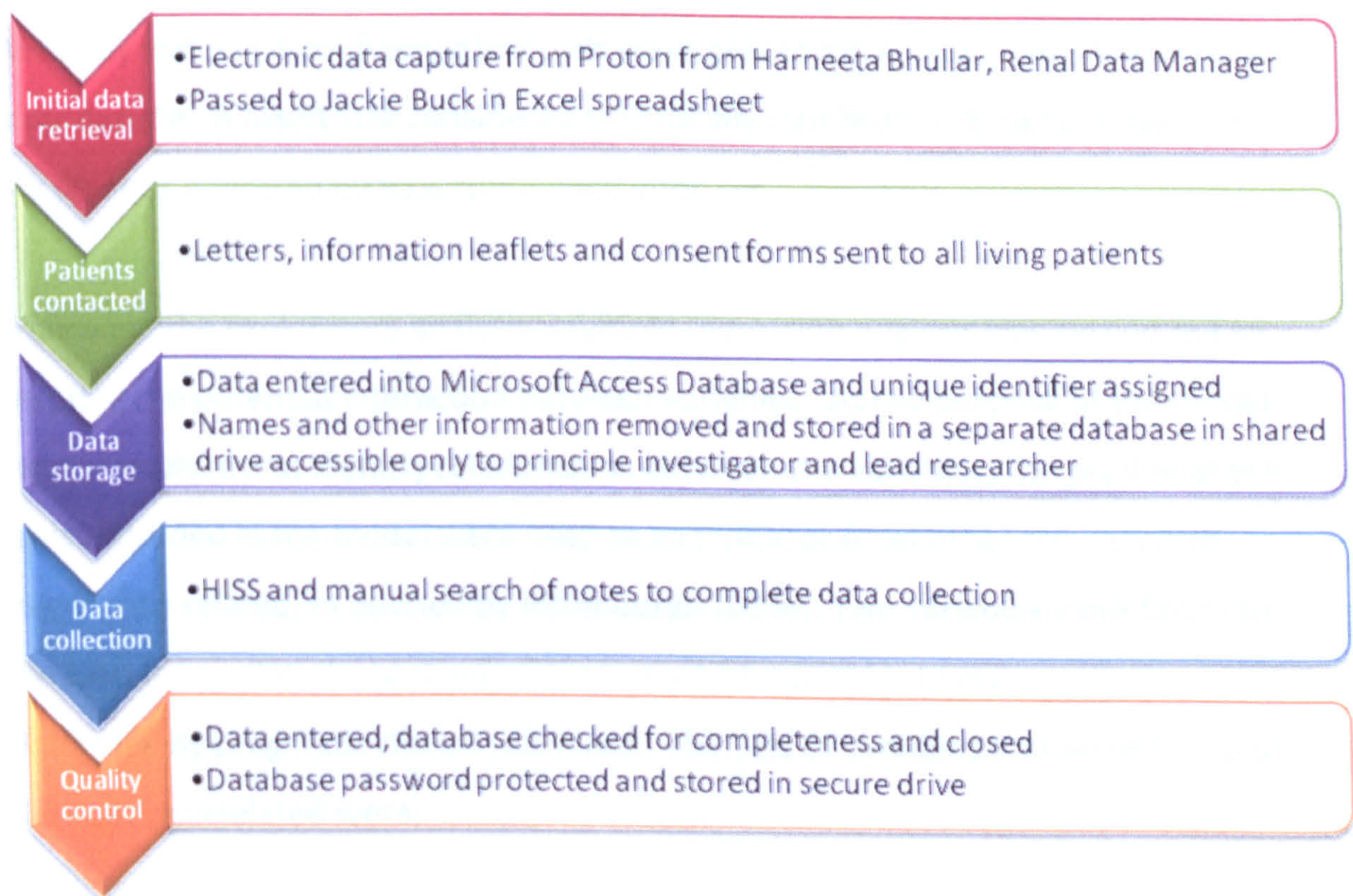
Furthermore discrepancies in the data as a whole were recorded. For example, while collecting the data it was noted that often the date for the beginning of RRT differed between the date provided in Proton and the actual start date. All of these instances were recorded in the book and were used to recommend that the system of entering the start date be changed to make it more accurate in the future. This was important because the knock-on effect of having an inaccurate date in Proton is that the laboratory values received at the beginning of the study were supposed to represent the laboratory values at the start of RRT as they were taken on the day of RRT commencement according to Proton. As so many were



discovered to be inaccurate much time was spent altering the electronic data to ensure the accuracy of results.

The main researcher (JB) carried out the vast majority of the data collection for this phase of the research. Graham Warwick, co-investigator, carried out the data collection from the medical records of twenty-five Leicester based patients in order to expedite the data collection. He was provided with the procedures for data collection (Appendix 3). The researcher then completed the data collection in parallel for two of these cases in order to test for consistency which resulted in two data items being changed. Additional data items were changed while collecting data from peripheral units as this was more accurate, and the correct data entered into the database. This largely pertained to accurate dates of referrals and appointments. A diagram of the flow of data through the study is given in Figure 3.3

**Figure 3.3: Phase 1 BERRT Study Data Flow Diagram**





### 3.7 Analysis

An analysis plan was created at the same time as the CRF, prior to the start of data collection. It was informed by the literature review and through observations of the renal team in the same way as the CRF had been developed. A number of research questions were created to guide the analysis (see section 3.4). These focused on health related issues such as increased co-morbidities, service delivery issues such as the type and frequency of clinic appointments, and socio-economic factors such as age and ethnicity.

Data were initially analysed descriptively using a series of histograms and scatter plots in order to visualise the distribution. Exploratory analysis was used to gain an understanding of the distribution of the variables in the two groups. Hypotheses were tested using chi-squared tests for dichotomous variables and results presented as odds ratios with 95% confidence intervals where possible.

Continuous data with a normal distribution were analysed using independent group t-tests, and non-normally distributed data were analysed using the Mann-Whitney test. 95% confidence intervals were presented as well as p-values where appropriate. A result was considered statistically significant if it had a p-value of  $<0.05$  or as indicated by 95% confidence intervals.

Following the exploratory analysis, multiple regression analysis was carried out to explore the potential interaction between variables. As the purpose of the model was to explore and identify relationships between the variables, the p-value of the tests included in the model were used as an indicator of whether the variables were truly related, as advised by Riffenburgh (2006). Two variables were found to be closely correlated and the decisions on which variables to remove were informed by pragmatic clinical relevance. The sets of variables that were found to be highly correlated were:

- Number of years known to the nephrology service and number of years since the first discussion about RRT



- The mode of RRT the patient planned to start on and the mode of RRT the patient actually started on

The mode of RRT that the patient planned to start on was of most interest, however because this relationship between the planned mode of RRT and the mode of RRT the patient started on was relevant, a new variable was formed and added to the model. This was whether the patient had the treatment (RRT) that had been planned, or whether they started on a different treatment to that planned, or there had been no predialysis plan.

Following the multiple regression analysis, multivariable logistic regression analysis was performed to identify variables predicting whether patients start dialysis urgently. The variables entered into the model were those identified from the univariable and multiple regression models to be of interest and not closely correlated. Logistic regression is typically used when the primary outcome under investigation is binary. It is used to investigate the relationship between causal variables and the output variables allowing for confounding variables that may be categorical or continuous (Campbell, 2001).

Backwards stepwise regression, whereby all variables of interest are entered into the model and then removed one by one based on the evidence of least contribution, was used in both the multivariable regression and the logistic regression analysis. According to Field backwards stepwise models are preferable to forward stepwise when performing exploratory analysis as they lead to fewer suppressor effects (Field 2005). Backwards stepwise regression leads to fewer type II errors.

### **3.8 Conclusion**

This chapter has described in detail the steps taken to address the aims of this, the first phase, of the research study. A thorough explanation was given of the development of the research questions, data collection methods and procedures,

the tools used in this study as well as the methods used to develop the analysis plan. The following chapter details the results.



# CHAPTER 4

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## Results of Phase 1

### 4.1 Introduction

The purpose of this chapter is to present the results of the cross-sectional survey of patients who started RRT in 2003 in the East Midlands Renal Network. The chapter is structured according to the research questions identified in Chapter 3. Where possible I have presented results from the whole sample as well as the breakdown by status group (elective/known acute). For completeness both non-significant and significant results are displayed. The results of the univariable and multivariable analyses are discussed together followed by the results of the logistic regression.

### 4.2 Results grouped according to research questions

#### 4.2.1 Question 1: How many patients start dialysis urgently in the East Midlands Renal Network?

Of the 165 patients who started RRT in the East Midlands Renal Network in 2003, 39 (24%) had been known to the renal services for less than four months (unknown acute) so were excluded from further analysis. Of the remaining patients, 71 (43%) had an elective RRT initiation and 55 (33%) had an acute dialysis start and therefore comprised the known acute group. Consent for their data to be used in this study was not received from 17 surviving patients, leaving a total study population of 109. Of these, 60 (55%) formed the elective group, and 49 (45%) comprised the known acute group.

#### 4.2.2 Question 2: Were there any demographic or socioeconomic differences between the groups?

The median age of the cohort was 63 years. Females accounted for just over a third of the sample, while patients of non-Caucasian origin comprised around a fifth. The median IMD2004 rank score was 17,358. The two groups were very similar in these respects; Mann-Whitney and Chi-square tests revealed no statistically significant differences (Table 4.1).

**Table 4.1: Demographic and socioeconomic factors**

	Elective (N=60)	Known acute (N=49)	P value
Age (yrs, med. & range)	59 (27 – 83)	66 (17 – 89)	0.132
Sex (% female)	35	43	0.434
None Caucasian (%)	18	27	0.357
Satellite unit (%)	47	43	0.704
≤ 1comorbidites (%)	60	57	0.846
IMD2004 (med. & range)	17,936 (1,862 – 31,930)	16,564 (1,072 – 31,336)	0.800

The breakdown of the location of predialysis care per unit, by initiation status is shown in Table 4.2. Because of the very small numbers in some of the categories a binary variable was created by combining data from the satellite units for comparison with the main unit in Leicester. The location was fairly evenly split with Leicester as the main provider of predialysis care for 55% (N=60) of patients and the satellite units providing the bulk of predialysis nephrological care for 45% (N=49). Of the patients who had been treated in a satellite unit, 57% (N=28) had elective and 43% (N=21) had known acute RRT initiation (p=0.846).

**Table 4.2: Location of predialysis care**

	Leicester (N=60) %	Lincoln (N=19) %	P'borough (N=19) %	Kettering (N=9) %	L'borough (N=2) %
Elective	53	47	74	56	0
Known acute	47	53	26	44	100



Although there was clearly local variation, when combined, receiving predialysis care from either the main renal unit or a satellite unit did not appear to affect the urgency of dialysis initiation.

#### **4.2.3 Question 3: Were there any differences in the underlying cause of kidney disease or the presence of co-morbidities between the groups?**

In the sample as a whole, diabetic nephropathy was the most common cause of CKD (24%, N= 26) followed by renovascular disease (17%, N=19).

Glomerulonephritis accounted for 16% (N=17), unknown aetiology 16% (N=16), polycystic kidney disease 11% (N=12) and pyelonephritis/interstitial nephritis in 9% (N=10). Causes other than those listed above were present in only 8% (N=9) and included traumatic or surgical loss of a kidney and analgesic toxicity.

Figure 4.1 shows a breakdown of the cause of CKD by initiation status. The greatest difference between the groups can be seen in patients with polycystic kidney disease, all of whom were in the elective group. Conversely, renovascular disease and diabetic nephropathy featured more strongly in the known acute group. Although there are some differences in the underlying causes of CKD between the groups, a chi-square test of the associations between cause of renal disease and initiation status was invalid due to the number of cells that contained values less than five. A binary outcome variable was created solely to examine whether presence of diabetes was associated with initiation status as this was the main cause of CKD. I included not only patients with diabetic nephropathy as a cause of CKD, but also patients who had diabetes that was not the cause of CKD in order to get a complete understanding of whether having diabetes in any way affected dialysis initiation status. In total, 30% (N=33) of patients had diabetes. There was no statistical difference in the number of patient with diabetes between patients who had an elective or urgent dialysis start ( $p=0.864$ ). Therefore, there does not appear to be an association between urgency of dialysis initiation and presence of diabetes.



Figure 4.1: Breakdown of cause of CKD by status

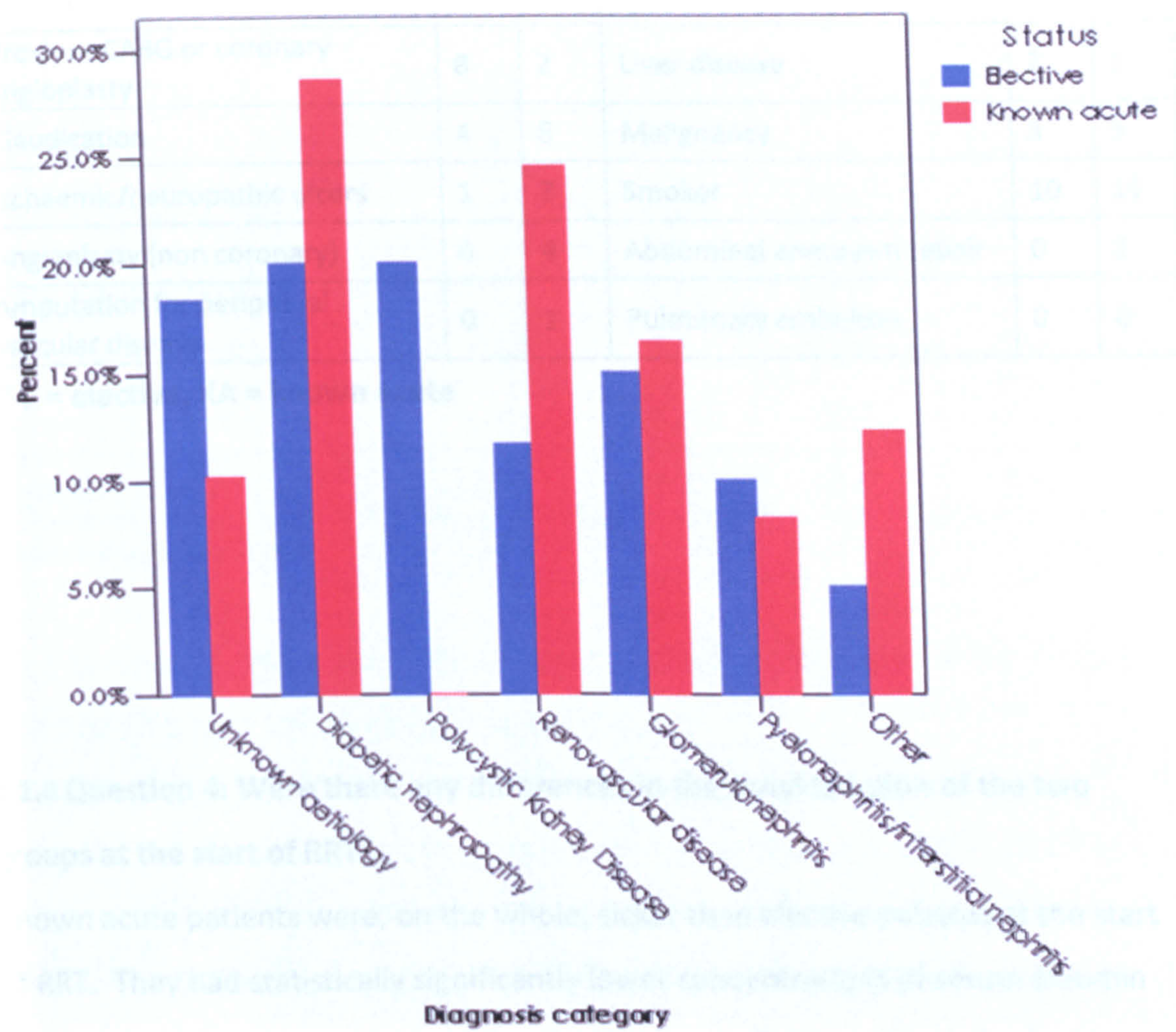


Table 4.3 shows the number of patients with each of the co-morbidities in the two groups. As there were so many variables and such small numbers in each, I created a binary variable to test for the effect of co-morbidities by dividing the sample based on whether the patient had zero or one or more co-morbidities. Sixty percent (N=36) of elective and 57% (N=28) of the known acute patients had more than one co-morbidity (p=0.846). Thus, these results show that the presence of the co-morbidities identified as being important in kidney disease do not appear to affect urgency of RRT start.



**Table 4.3: Co-morbidities present in each group as numbers per group.**

Co-morbidity	E*	KA	Co-morbidity	E	KA
Angina	15	13	Cerebrovascular disease	6	8
Previous MI within last 3 months	1	0	Diabetes	5	3
Previous MI > 3 months ago	6	6	COPD	3	4
Previous CABG or coronary angioplasty	8	2	Liver disease	2	1
Claudication	4	8	Malignancy	3	3
Ischaemic/neuropathic ulcers	1	3	Smoker	10	11
Angioplasty (non coronary)	0	4	Abdominal aneurysm repair	0	2
Amputation for peripheral vascular disease	0	1	Pulmonary embolism	0	0

**\* E = elective, KA = known acute**

**4.2.4 Question 4: Were there any differences in the renal function of the two groups at the start of RRT?**

Known acute patients were, on the whole, sicker than elective patients at the start of RRT. They had statistically significantly lower concentrations of serum albumin and haemoglobin than patients in the elective group (Table 4.4) and also had lower eGFRs and higher serum creatinine, urea and phosphate concentrations compared with the elective group. These results suggest that there is an association between urgency of RRT start and worse health in terms of renal function.

**Table 4.4: Laboratory variables at the start of RRT\***

	Elective (N=60)	Known acute (N=49)	<i>P</i> value	95% CI	
				Upper	Lower
Albumin (g L <sup>-1</sup> )	38.3	36.2	0.025	0.27	3.89
Bicarbonate (mmol L <sup>-1</sup> )	21.5	20.4	0.198	-0.63	2.99
Calcium (mmol L <sup>-1</sup> )	2.4	2.3	0.185	-0.26	0.13
Creatinine (umol L <sup>-1</sup> )	708.9	816.3	0.042	-203.27	-4.03
eGRF mls/min/1.73m <sup>2</sup>	7.5	6.2	0.002	0.48	2.16
Haemoglobin (g/dL)	10.5	9.7	0.005	0.23	1.42
Phosphate (mmol L <sup>-1</sup> )	1.9	2.2	0.008	-0.58	-0.09
Potassium (mmol L <sup>-1</sup> )	4.7	4.7	0.793	-0.29	0.38
Urea (mmol L <sup>-1</sup> )	32.9	38.4	0.003	-9.11	-1.94

\*independent samples t-tests

**4.2.5 Question 5: Were there any differences in the management of risk factors and side effects of CKD between the two groups?**

More known acute patients had high phosphate levels and had not been prescribed phosphate binders than patients in the elective group (35%, N=17 vs. 18%, N=11 respectively, p=0.047). Twenty-nine percent of the whole sample had not been prescribed an erythropoietic stimulating agent despite having anaemia defined as a haemoglobin <10g/dL, with 25% (N=15) and 30% (N=15) in the elective and known acute groups respectively (p=0.659). Only 14 patients in the sample had low bicarbonate levels ( $\leq 20$ ) and had not been prescribed bicarbonate, this accounted for 11% (N=6) of elective and 17% (N=8) of known acute patients, however there was no statistically significant difference between the two.



#### **4.2.6 Question 6: Were there any differences in service delivery between the two groups?**

In the whole sample, patients had been known for a median length of time of three years with no statistical difference in the length of time between elective and acute RRT initiation patients (Tables 4.5 and 4.6). All but four patients, two in each group, had been known to the renal services for at least one year. Just over half of the sample had attended a patient information day during the predialysis phase, though more patients who had an elective initiation had attended than patients who had an acute dialysis start. More patients who had an elective initiation had also been seen in a dedicated predialysis clinic (as opposed to routine follow-up in a general nephrology clinic). Additionally, discussions regarding RRT had occurred earlier in the elective group as had the first home care team visit to discuss RRT options. Patients who had elective RRT initiation had on the whole been referred earlier for vascular or peritoneal access creation where dialysis, as opposed to transplant, was the chosen mode of RRT. All of these differences are statistically significant. Although known acute patients had fewer consultations with renal clinicians in the year prior to RRT initiation this difference was not found to be statistically significant.

Information on cancelled appointments in the year prior to RRT start was only available from patients who had been followed up in Leicester (N=60). A binary variable was created (cancelled/not cancelled by the service) and patients who had been followed up in one of the satellite units from the analysis were excluded. Of the 32 elective patients who had been followed up in Leicester, 31% (N=10) had at least one appointment cancelled by the service in the year leading up to RRT. Only 21% (N=6) of the 28 known acute patients had cancellations. The difference between the groups was not statistically significant ( $p=0.559$ ). In this relatively small group of patients, these results suggest that there may not appear to be an association between having appointments cancelled and urgency of RRT start.

**Table 4.5: Service and treatment related factors – median & range**

	Sample (N=109)	Elective (N=60)	Known acute (N=49)	P value
Years known to the renal services	3 (0-24)	4 (0-24)	3 (0-16)	0.382
Years since first documented discussion of RRT (9*)	2 (0-24)	2 (0-24)	1 (0-7)	0.002
Months since first RRT counselling by HCT nurses	11 (0-86)	13 (2-83)	7 (0-86)	0.003
Months between access referral and RRT initiation*	-----	6 (1-27)	4 (0-38)	0.011
Number of nephrology appointments in year prior to RRT	8 (0-18)	8 (0-18)	6 (0-17)	0.053

Footnote:

\*16 patients in the known acute group had not been referred for access creation before starting on RRT, their data is excluded from this analysis as are data from the 9 patients who received pre-emptive transplant. This included both PD and HD access

**Table 4.6: Further service related factors – percentage per status**

	Sample (N=109)	Elective (N=60)	Known acute (N=49)	P value
Attendance at dedicated predialysis clinic	76% (69)	89% (41)	64% (28)	0.006
Attendance at predialysis patient information day	56% (61)	67% (40)	42% (20)	0.020

**4.2.7 Question 7: Did the mode of RRT the patient planned to start on affect RRT urgency?**

There was no documented evidence of any discussion of RRT options for four patients in the sample prior to them starting dialysis. Seven patients had discussed RRT options with either a nephrologist or a home care team nurse prior to starting dialysis but had remained undecided, and therefore by default commenced haemodialysis urgently. Of the 98 patients who had formulated a predialysis RRT



plan, 47 had chosen to commence on peritoneal dialysis. Of them, 30% (N=14) started dialysis urgently meaning that they started haemodialysis via a temporary catheter (known acute). Of the 41 patients who had planned to start haemodialysis, 56% (N=23) of them did so urgently. There was a plan for ten patients to receive a pre-emptive transplant. All but one of those took place without necessitating dialysis, meaning that there was only one of those patients who had an urgent dialysis start. These results show that there is probably an association between the planned RRT modality and urgency of dialysis start, particularly detrimental in patients who plan to start on haemodialysis, though this could not be tested.

**4.2.8 Question 8: Were there any factors that were predictive of known acute RRT start?**

In the logistic regression, three of the sixteen variables that were entered into the model (shown in Box 3.5) were shown to predict known acute dialysis initiation. These were age, phosphate level and attendance at predialysis clinic (Table 4.7). eGFR was found to be of borderline significance. Factors that were not predictive were sex, ethnicity, social deprivation rank, number of years patient had been known to the renal services, number of years since the first discussion of RRT, attendance at a patient information day, albumin, urea, creatinine, and haemoglobin.

**Table 4.7: Predictors of known acute presentation (N=90)\***

			95% CI	
	OR	Sig.	Lower	Upper
Age	1.039	0.024	1.01	1.07
eGFR	0.762	0.052	0.58	1.00
Phosphate	2.791	0.030	1.11	7.04
Predialysis clinic	0.111	0.001	0.03	0.43

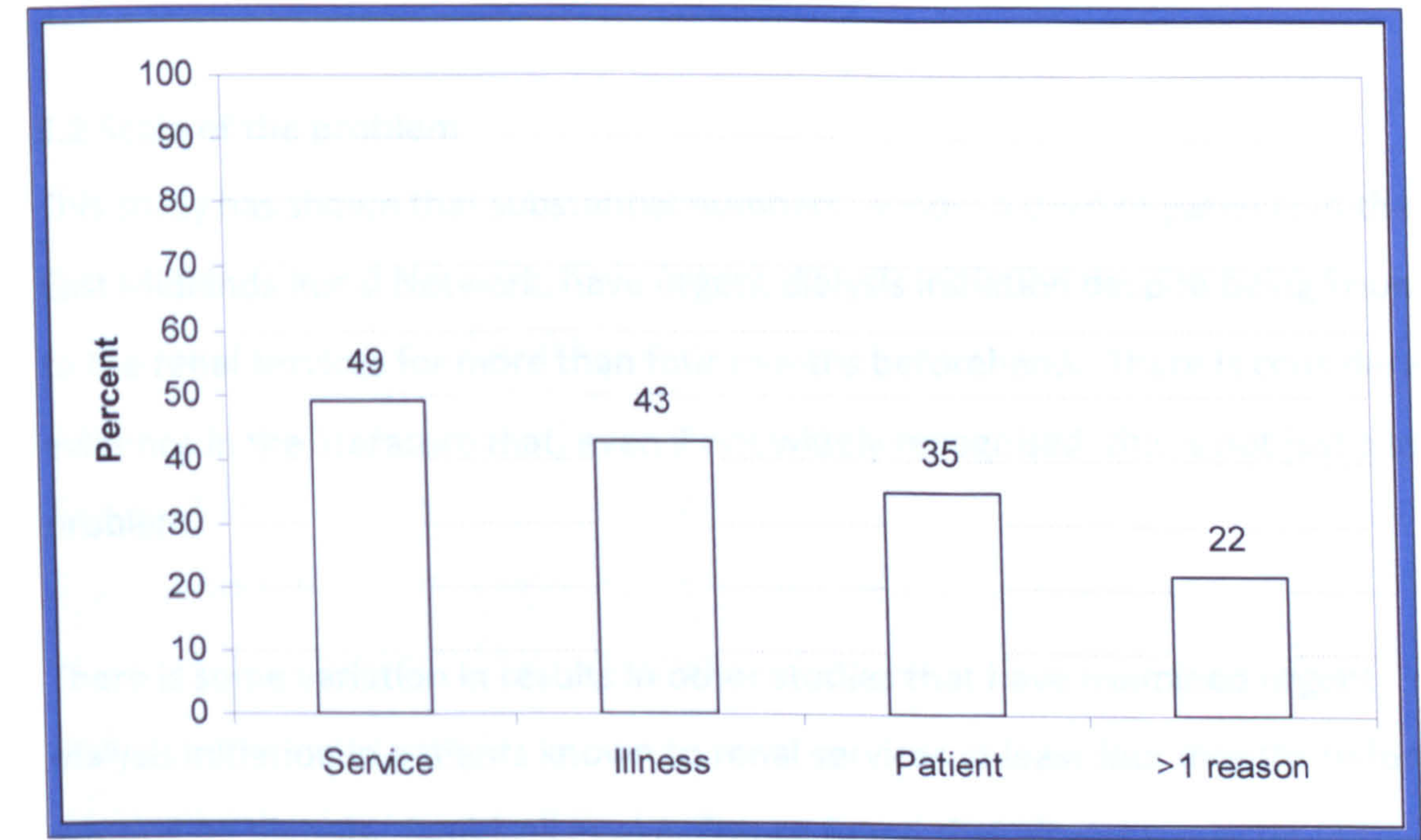
\*Footnote – data on predialysis clinic attendance unavailable for 19 patients from Peterborough, so their data was excluded from this analysis



**4.2.9 Question 9: What was reason for known acute presentation in those patients who had an urgent RRT start?**

Figure 4.2 shows the reasons assigned by the researcher for known acute dialysis initiation in the 49 known acute patients. Patient related reasons, present in about a third of patients, were generally that patients didn't attend clinic or other relevant appointments or cancelled access operations. There were medical (illness) related reasons in almost half of patients, and these tended to be where the kidney disease declined more rapidly than would reasonably have been expected or where inter-current illness precipitated the start of RRT. Service related factors, which were accountable for almost half of patients having urgent dialysis start, varied but were mostly related to late, or lack of, referral for access creation, and time spent waiting for access creation. There was a combination of factors in about a fifth of patients.

**Figure 4.2: Reasons for known acute RRT initiation**





# CHAPTER 5

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## Phase 1 Discussion

### 5.1 Introduction

This chapter highlights the findings of Phase 1 and places them in the context of the current literature. The scale of the problem is addressed before going on to reflect on the findings in terms of some of the more acknowledged barriers to care. The potential implications of urgent patients being sicker at the start of dialysis are then explored. The role of the predialysis clinic is discussed followed by a section on the common definition of late referral and its usefulness. I argue that this is an arbitrary, potentially misleading concept and that early referral is no guarantee of elective dialysis start.

### 5.2 Scale of the problem

This study has shown that substantial numbers, almost a third of patients in the East Midlands Renal Network, have urgent dialysis initiation despite being known to the renal services for more than four months beforehand. There is considerable evidence in the literature that, even if not widely recognised, this is not just a local problem.

There is some variation in results in other studies that have examined urgent dialysis initiation in patients known to renal services at least four months before starting on dialysis. Roubicek et al in France found that almost a quarter (23%) of patients required emergency dialysis (Roubicek, Brunet et al. 2000) while more recently Kessler et al, also studying French patients, found 31% of patients had an emergency dialysis start, and 33% started dialysis with a temporary catheter (Kessler, Frimat et al. 2003). With very similar results to mine, Roderick and colleagues in a small study from the UK showed that 36% of patients did not have a

permanent access at the start of dialysis (Roderick, Jones et al. 2002). Research in the United States indicated even worse results with only 41% of patients who had been known to renal services for at least four months before dialysis starting on dialysis through a permanent vascular access catheter. This means that a substantial majority (approximately 60% although exact figure was not given) started dialysis through a temporary catheter (Stack 2003). Set in this context we can see that the results of my study are not dissimilar and in fact show that the local renal service is probably about average in terms of numbers of known patients having urgent dialysis start.

### **5.3 Explaining urgent dialysis initiation**

For some patients urgent dialysis initiation was probably an unavoidable consequence of an unexpectedly rapid decline in renal function. Roubicek et al found that of patients who had been known to renal services at least four months before dialysis, those who had emergency dialysis were more likely to have diabetes or malignancy than those who had a planned dialysis initiation (Roubicek, Brunet et al. 2000). Although not quantified, Lorenzo and colleagues who examined data on patients starting dialysis with a temporary catheter and who were known to renal services at least three months before starting dialysis, concluded that intercurrent illness played a significant role in emergency dialysis start in known patients (Lorenzo, Martin et al. 2004). My results did not show any influence of having diabetes on urgency of dialysis start, nor did I find patients with more co-morbidities at greater risk, but I did find that illness in general, both renal and non-renal related, affected urgency of dialysis in 21 patients, mainly due to unexpectedly rapid decline.

In almost half of the patients in this current study (24/49) who had an urgent RRT initiation, the service was judged to be at least in some part responsible. Primarily this was related to timing of interventions, namely delayed initial discussions about RRT, later referral to specialist nurses for RRT counselling, and later referral for access creation. This finding builds on that of Chesser & Baker who found that delays within the renal service accounted for the majority of temporary catheters



inserted in patients already known to the renal services, although they could not adequately determine where and why such delays had occurred (Chesser and Baker 1999).

I did not find differences in some of the acknowledged barriers to service access and provision (Gulliford and Morgan 2003), such as sex, ethnic background, presence of co-morbidities or social status. These findings are consistent with findings of a study of equity of access to dialysis facilities in Wales where ethnic background and socio-economic status were not found to be factors in provision of services (White, James et al. 2006). The findings are at odds however with other studies which have highlighted the disadvantage of patients from ethnic minority backgrounds and lower socioeconomic states in terms of renal related outcomes (Kasiske, Snyder et al. 2002; Lenz, Mekala et al. 2005).

Though measured only as a binary variable of care provided in a satellite unit, versus care provided in the main unit, I did not find that geographical location had an effect on urgency of dialysis start. In a study examining the impact of early referral on urgent dialysis, Schmidt et al (Schmidt, Domico et al. 1998) found that there was no difference in terms of whether people had been referred early or late and whether or not they had an urgent dialysis start based on geographical location, measured as living more than an hour away from a dialysis centre.

One of the most important findings of this study is that older age was associated with urgent dialysis start, with the odds of a known acute start increasing by 4% per year of age in our sample (Table 4.6). Whether this is due to more intercurrent illness, or whether it is a consequence of age discrimination within our system, is beyond the scope of this study, however age as a barrier to care has been shown to exist in other areas, with older people in general being referred later to renal services (Letourneau, Ouimet et al. 2003; Ansell, Feest et al. 2006). Letourneau writes that older patients are referred later for two reasons. Firstly, because clinicians are undecided as to whether renal replacement therapy is a viable option for some older people they do not refer them to renal services, and secondly some

older people decide they want dialysis only when they become ureamic. My research suggests that even when patients are within the renal care system, the same situation could be occurring with patients perhaps not being referred for dialysis access on time. It is impossible to know from this study if this is the case, and if so, the underlying reasons for this. What does remain though is that older patients are being discriminated against based on age whether wittingly or not, contrary to the guidelines set out in the National Service Frameworks for Renal Services and the National Services Framework for Older People (Department of Health Renal Team 2004; Department of Health 2001). This finding highlights a need for further research, as with an increasingly ageing population greater efforts may be needed to tailor interventions to reduce the risk of acute dialysis start in older people.

I found that patients who started RRT urgently in our study population were 'sicker' than those who had an elective initiation as judged by anaemia, lower serum albumin and lower eGFR. In some cases this may be a consequence of intercurrent illness, although it is impossible to know for certain. What we do know is that this is not an unusual occurrence.

Lower serum albumin at the start of RRT has repeatedly been related to poorer survival on dialysis (Sesso and Belasco 1996; Stoves, Bartlett et al. 2001; Kessler, Frimat et al. 2003; Lorenzo, Martin et al. 2004). Of particular note is that Lorenzo et al showed an 8% increase in the probability of survival for every g/L rise in serum albumin at start of dialysis. Roubicek et al (Roubicek, Brunet et al. 2000) found that low serum albumin, alongside diabetes and malignancy were factors associated with emergency dialysis start in patients known to renal services, suggesting the relationship between poor overall health, nutritional status and albumin levels. The lower haemoglobin concentrations in the known acute group could be due to erythropoietin resistance but there is no data on iron status, prevalence of infection or severity of hyperparathyroidism to assess this.



Higher eGFR was associated with a 24% decrease in the odds of having an urgent start for every 1ml/min increase in eGFR at the start of RRT. Elevated phosphate levels were also found to be associated with acute dialysis start with a 280% increase in the odds of an urgent dialysis start for every 1mmol/L increase in phosphate. Known acute patients started dialysis with lower haemoglobin concentrations than elective patients, although equal proportions of patients in both groups had been prescribed erythropoietic stimulating agent. However, we do not have data on dosage or duration of erythropoietic stimulating agent treatment.

Although it is clear that patients who had an urgent start were sicker, the reasons for this cannot be fully understood from this study, and it is difficult to ascribe cause and effect. Is it that patients who were sicker had declined more rapidly, or is it that patients who should have ideally started dialysis earlier did not do so due to lack of access, adequate preparation or for other reasons? If the latter is the case then this research suggests that dialysis preparations should start sooner than it does for many patients, although trials such as the IDEAL Study are required to fully understand the optimum time for dialysis initiation (Cooper, Branley et al. 2004) .

The most striking risk factor that predicted known acute dialysis was attendance at a dedicated predialysis clinic, with patients who did not attend a predialysis clinic having a 90% increase in the odds of having an urgent, known acute, dialysis initiation. Other studies have demonstrated the potential of a multidisciplinary approach delivered via dedicated predialysis clinics in terms of better biochemical parameters at the start of dialysis, fewer hospitalisations to initiate RRT, and increased survival post RRT initiation (Levin, Lewis et al. 1997; White, Pilkey et al. 2002; Goldstein, Yassa et al. 2004; Curtis, Ravani et al. 2005). This study suggests that predialysis clinics may also offer a means to reduce the proportion of patients who have unplanned RRT initiation via a temporary catheter. In contrast to studies that have highlighted the benefits of multi-disciplinary team input in predialysis clinics versus standard nephrological care alone, (Levin, Lewis et al. 1997; White,

Pilkey et al. 2002; Goldstein, Yassa et al. 2004) the clinics in the EMRN are staffed by nephrologists and dieticians with nursing input in the community. Referral to a predialysis clinic in our service area tends to start a chain of events including referral to the home care team which in turn triggers an invitation to the patient information day.

The finding that patients benefit from predialysis clinic attendance suggests that it is the regularity of predialysis monitoring, the longer consultations and the focus on dialysis preparation that appear to be effective in our service. Given the apparent benefits of predialysis clinic, further research is needed to understand the barriers to predialysis clinic referral and attendance.

Patients who had planned to have haemodialysis, as opposed to peritoneal dialysis or transplant, are particularly disadvantaged in the system in the EMRN with the majority of patients who planned to have haemodialysis starting dialysis urgently. This probably reflects deficiencies in the timing of referral for, and creation of, arteriovenous fistulae. Bearing in mind that almost all patients had been known to the system for at least a year before starting dialysis, this result is similar to that of Kessler et al who found that 40% of all patients starting haemodialysis had been known for a year before dialysis, yet started dialysis via a temporary catheter (Kessler et al, 2003).

#### **5.4 What is late referral?**

These results add to the debate surrounding the definition of late referral, which is variably described in the literature as anything from one to six months before dialysis initiation, although the most frequently used cut-off is three (Table 5.1). One explanation for the three month cut-off is that the general belief, supported by guidelines, is that arteriovenous fistulas should be created at least one, but ideally three to four months prior to first cannulation (National Kidney Foundation 2001). Therefore, if someone is referred within the time it theoretically takes to place and allow maturation of a fistula, they are considered to have been an early referral. However, as the creation of a fistula can only take place at the end of an



often complex decision making process about RRT modality, the usefulness of this definition is severely limited. It takes into account neither the education process behind the decision making aspect, nor the time taken to refer patients between clinicians and surgeons. Furthermore, with an estimated failure rate of primary fistula of 15%, (Rooijens, Tordoir et al. 2004) it does not allow for the creation of a second fistula if required.

Table 5. 1 Late referral cut-offs used in previous research	
Authors and Date	Late referral cut-off
Curtis, Ravani et al. 2005	3 months
Chesser and Baker 1999	12 weeks
Jungers, Massy et al. 2001	6 months
Kessler, Frimat et al. 2003	3 months
Levin, Lewis et al. 1997	4 months
Ratcliffe, Phillips et al. 1984	1 month
Roderick 2002	4 months
Roubicek, Brunet et al. 2000	16 weeks
Schmidt, Domico et al. 1998	1 month
Schwenger, Morath et al. 2006	8 weeks
Sesso and Belasco 1996	1 month
Stack 2003	4 months
Stoves, Bartlett et al. 2001	90 days

When questioned in a recent survey in Canada, the majority of practitioners thought four to twelve months were adequate in order to prepare someone to start on dialysis in a smooth manner, yet over a third said that for optimal preparation, at least 13 months were required (Mendelssohn, Toffelmire et al. 2006).

Universally, the call is for patients to be referred to renal services earlier (Jungers, Massy et al. 2001; Jungers 2002; Kessler, Frimat et al. 2003; Stack 2003). The

benefit this brings is that there is more opportunity to delay the progression of the illness through lifestyle and pharmaceutical management, and patients have greater opportunity to engage in the process of preparation for RRT. But, how early is early? One of the markers of good practice outlined in the UK Renal National Service Framework for patients with advanced kidney disease is that they are referred to a renal team within one year of the anticipated start of dialysis (Department of Health Renal Team 2004). Some evidence suggests this is a good cut-off point, for example Stehman-Breen et al found that patients who had been told about their renal disease at least a year before starting dialysis were more likely to start dialysis with a permanent access than those whose renal disease had been diagnosed less than a year before (Stehman-Breen, Sherrard et al. 2000). Yet, patients in my study had been known to the service for three years on average, and the length of time patients had been known to the renal services was not a significant factor explaining planned initiation of RRT. In France, almost a third (29%) of patients known for at least a year before dialysis had an emergency dialysis start (Kessler, Frimat et al. 2003). The UK Renal Registry for 2006 showed that definitive access was only present in 58% at dialysis initiation in patients known to the renal services for at least a year. Similar results have been reported in Canada, and to a lesser extent, the USA (Mendelssohn, Ethier et al. 2006).

My research shows that one year does not appear to be enough time to adequately prepare patients for a smooth transition onto RRT, particularly if haemodialysis is chosen. Given that predialysis care involves much more than preparation for dialysis, particularly delaying the progression of the illness and assisting patients to accept and adapt to having kidney disease, I suggest two things. One, that there should be a move away from a definition of late referral based purely on an arbitrary cut-off for a procedure which can only be performed at the end of an often long decision making process. Two, based on my results, I suggest extending the definition of late referral to at least 12 months, with the aim of getting patients who are likely to progress to stage 5 and require dialysis into the system far earlier whenever possible, though as our results suggest, being in the system in no way guarantees a satisfactory start on dialysis.



## 5.5 Limitations

Several qualifications about this phase of the study should be noted. At 109, the sample size was relatively small, data on 17 patients who withheld consent were not available and data collection was retrospective. Several steps were taken to ensure that the sample was adequate. This involved adopting several, though not all, of the recommendations contained in the systematic review by Edwards et al in which ways of increasing response rates to postal questionnaires were identified (Edwards, Roberts et al. 2002). The methods I used which were shown in the review to be effective were 1) personalising the letters, 2) sending stamped addressed return envelopes and 3) providing non-respondents with a second copy of the information sheet. Despite this, information was not obtained from 17 patients who were eligible and therefore I have no way of knowing if information from those patients could have altered the results in any way. The missing data may not have been missing at random. There may have been barriers to written English or other barriers to participating due to health status or other factors.

The data for this phase of the study were obtained from both paper based records and administrative computerised records, both of which have their limitations when used for research purposes. According to Hakim there are several disadvantages to using paper based records as a source of data in health services research (Hakim 2000). These are:

- the potential for error in copying the data
- the length of time taken to manually sift through the record to identify the relevant data and input it
- the cost that this can incur

In addition, there are the general problems associated with using data for a purpose for which it was not intended, mainly the incompleteness of some records and the variation between clinicians and between hospitals. For example, the information regarding predialysis clinic attendance is incomplete because of the difference in how this is recorded in the hospital in Peterborough. The lack of clarity in the notes meant that I was unable to trust the data for this variable which led to me assigning missing values. Similarly, the letters sent from the hospital

physicians to the general practitioners contains the information on the drug prescription in all hospitals except Lincoln, so the data from there were more difficult to collate.

## **5.6 Conclusion**

This chapter has provided a discussion of the results of the case note survey carried out to determine reasons for urgent dialysis initiation. Although the data reflect the practice, resources and patient population in one large regional nephrology service in the UK, other data from the UK, Europe and North America suggest this is not just a local problem (Ansell, Feest et al. 2005; Mendelssohn, Ethier et al. 2006). Therefore, we believe the findings have implications for services elsewhere.

Patients who start on dialysis urgently within the EMRN kidney care system are at a disadvantage. Not only do they have to undergo emergency dialysis through a temporary catheter, an often frightening and painful experience, they are more poorly when they start on dialysis and they have had later input from specialist predialysis services. Based on other research, it is possible to speculate that these patients have poorer survival than patients who have an elective entry onto RRT (Kessler, Frimat et al. 2003). Older people in particular are victims of deficiencies in care, though from this study it is not possible to understand why.

Despite these limitations, these results challenge the assumption that simply getting people into the system will enable the renal services to act to ensure that preparations are made for patients to have smooth dialysis entry. Further research is needed to understand the process by which people access RRT and the reasons why some present late for urgent dialysis initiation.

The next chapters explain the second phase of this research in which I carried out a qualitative study to delve deeper into the experience of having kidney disease and caring for people with kidney disease to see if I could understand better why some patients start dialysis urgently.



# CHAPTER 6

## Phase 2 Methods

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### 6.1 Introduction

This chapter and the five that follow describe a qualitative investigation of the experiences of patients with chronic kidney disease prior to starting on dialysis and the perspective of health care professionals who provide care for them during this time.

The broad aim of the qualitative study was to explore the barriers to patients starting on dialysis electively when they have been known to the renal services for at least four months, in order to develop theories explaining the reasons for urgent dialysis initiation and to recommend some interventions that could lead to a reduction in urgent dialysis initiation. Specific objectives and the method of addressing these objectives were:

1. To develop an understanding of the experience of being a patient with chronic kidney disease undergoing the transition to renal replacement therapy by interviewing patients who had recently started on dialysis
2. To develop an understanding of the experience of managing patients undergoing the transition to renal replacement therapy by interviewing consultant nephrologists and home care team nurses who had been involved in the care of the patients in the predialysis phase.

This chapter will describe in detail the methods used to achieve these objectives and the rationale behind their choice.

## **6.2 Research focus of interviews with patients**

Underpinning the patient interviews was the desire to understand and explore the experience of being a person with kidney disease. The study was guided by the following questions:

- What is it like to have kidney disease and how does this affect the patient's life?
- Which elements of the current system of care are effective, which are not and why?
- What improvements could be made to the system and why?
- Are there patient characteristics which play a role in:
  - How patients perceive and experience their illness and treatment?
  - How patients interact with health care professionals and the system.
  - Whether patients have an urgent or an elective dialysis start?

The patient interviews aimed to fulfil a dual role of describing, through understanding, the patient's experiences and also trying to generate theory that might help to explain the phenomenon of interest.

## **6.3 Research focus of interviews with health care professionals**

The health care professional interviews were undertaken to try to understand from the point of view of health care professionals why the system 'works' for some patients, in that they have an elective dialysis start, and does not 'work' for others, meaning that they have an urgent initiation onto dialysis. Additionally, I was interested to see whether their perceptions of events were based on impersonal factors such as timing of referrals, or if their perspective suggested also that interactions with the patients and patients' personal characteristics played a role



in how patients are perceived and treated in the system. I hoped to determine whether the latter may have had an influence on outcome in terms of urgency of dialysis start and also whether there was an awareness of this amongst health care professionals. The focus guiding the health care professional interviews was:

- What are physicians' views on why patients start on dialysis electively or urgently?
- Do patients' characteristics play a role in how they are treated?
- Which characteristics are valued by health care professionals in their interactions with patients?
- How do health care professionals' perceptions of the extent to which patients cooperate impact on the patient/professional relationship and subsequent dialysis initiation outcome?

#### **6.4 Sample and sampling**

In the original proposal for the study it was planned that only those patients who had started dialysis urgently would be interviewed and health care professionals would be asked to fill in questionnaires about each of these patients. I subsequently decided that interviewing patients for whom optimal dialysis initiation had taken place would also be important in helping to understand not only why the system does not work for some (known acute patients) but why it does work for others (electives). Furthermore, interviewing health care professionals would lead to richer, more complex data than using questionnaires. For this reason I submitted a protocol amendment to the ethics committee and interviewed both patients who start urgently and those who start electively and also the health care professionals who had looked after them in the predialysis phase.

Sampling in qualitative research differs from sampling in quantitative research. The aim of quantitative research strategies is to gather a sample as generalisable to the population under study as possible in order to ensure transferability of research results. In qualitative research the aim of the sampling strategy may differ depending on the theoretical framework underpinning the research.

The sample was driven by identification of patients first, followed by identification of the associated health care professionals, and was drawn using a flexible sampling approach. The sample was purposive and varied in order that the study could reflect the views of the renal population, which is diverse. Purposive sampling is a strategic approach whereby interview participants are selected based on certain criteria and can be used to ensure that people with certain characteristics are adequately represented.

In this study I was keen to ensure that males and females were fairly represented and that a number of Non-Caucasian patients were included to reflect the ethnic diversity found in Leicester. To this end a quota sample was created in order to avoid over-representation of any of these groups of patients. In practice it has been suggested that around 12 to 20 interviews should be enough to describe the phenomenon of interest when addressing a fairly specific research question (Holloway and Wheeler 2002; Green and Thorogood 2004). The table below shows the plan for the sampling strategy at the start of the study, and gives the values in order to ensure that patients of both sexes and of different ethnic backgrounds in line with the local renal population would be included based on a sample size of 20. It also shows the actual numbers of patients interviewed in each category. Initially a convenience sample was used as this provided an opportunity to assess people’s willingness to participate in the research, which in turn guided the sampling strategy.



Table 6.1 Phase 2 Patient sample – Target and actual sample			
	Male	Female	Non-Caucasian
Aim (N)	8 - 12	8 – 12	5 - 6
Actual (N)	13	7	6

As the study progressed I reviewed the sample regularly and targeted the sampling accordingly. A record of the sample was tracked using the sample tracking matrix. In the end, the sample comprised of 20 patients, 4 nurses and 5 physicians.

Often patients had seen more than one physician while in the renal care system. The physician sample was limited to the consultant nephrologist whose care the patient had been under most in the year before starting on dialysis. Generally patients had seen only one nurse in the predialysis phase, however, in the event that the patient had seen more than one nurse, the nurse who had most contact (identified from the Proton computer system) was interviewed.

### 6.5 Identification, access and consent

The sample consisted of patients who had recently started on dialysis whose predialysis care had been carried out in either Leicester or Loughborough. The decision to undertake this phase of the study solely in these areas was largely pragmatic, as travelling to interview patients and professionals throughout the network would have been beyond the scope of the time and the budget available. Patients were eligible for inclusion in this study if they had been known to the renal services for at least four months before they started on dialysis. The four month cut off was used for the reasons described in Chapter 3. New patients starting on dialysis were identified from a list generated at a weekly multidisciplinary meeting in which new dialysis patients are noted. The patients were contacted either by post or in person, depending on the type of dialysis the patient had started on and the location of haemodialysis. All patients were contacted within two months of starting on dialysis. As in phase 1, I checked on

the computer systems Proton and HISS that patients were still alive and were well enough to be approached before inviting them to take part.

#### **6.5.1 Postal invitation**

Patients who started CAPD or who were having dialysis in Loughborough (with predialysis care in Leicester or Loughborough) were sent an invitation letter, a patient information leaflet, a reply form and a stamped addressed envelope to return their response (see Appendix 4). The patient was asked to either respond using the reply form, or to contact me by telephone or e-mail. After I had received a positive response from the potential participant, I contacted them to discuss the study further and arrange a convenient time for the interview if appropriate.

#### **6.5.2 Personal invitation**

Patients who started on haemodialysis in Leicester attended for treatment three times a week. Therefore, these patients were approached in person while they were on haemodialysis. Either myself or another researcher working as part of the research team made the initial contact with the patient to discuss the study before arranging to see them again to discuss participation further. This meant that all patients were given at least 48 hours to consider whether they would like to take part, although in practice this was often longer. When I revisited the patient, any further questions were answered and if the patient wished to participate, an appointment was made for the interview.

Consent was taken on the day of the interview and patients were given the opportunity to ask any further questions before starting the interview. In the unlikely event that a patient had agreed to be interviewed but did not give consent for me to discuss their care with health care professionals (statement number four on the consent form), the contingency plan was that the interview would proceed and the case would be discussed with the wider research team to determine whether or not to include the interview in the study. However, all patients who agreed to be in the study gave full consent.



Health care professionals were contacted following the interviews with patients. All eligible health care professionals in the department had received an information leaflet about the study. If the health care professional agreed to be interviewed they were also given the opportunity to ask questions before signing a consent form. At this time the health care professionals were also shown copies of the patients' consent forms in which they gave permission for the interviews with health care professionals. For the health care professionals information leaflet and consent form see Appendix 5.

## **6.6 Data collection**

The data for this research study were generated through semi-structured interviews using interview topic guides. Interview topic guides are a flexible instrument used to provide varying degrees of structure to the interview and consist of a range of questions and prompts. I believe that this was important as I intended to sample a broad spectrum of patients and needed to ensure that the data were comparable to allow for meaningful analysis, something probably not possible using a completely unstructured approach. Similarly I was keen to ensure that the same areas were covered in the health care professional interviews, so a semi-structured approach was also taken in those interviews. At all times during the HCP interviews the hospital renal information system Proton was available for looking up information about patients. Medical records were available when obtainable.

### **6.6.1 Interview topic guide development**

*Patient interview topic guide* - The general guidelines for interview topic guide development were followed as outlined by Maykut & Morehouse and Bryman (Maykut and Morehouse 1994; Bryman 2004) in that the guide for use in patient interviews (Appendix 6) evolved following the literature review and broader reading around the experience of being a predialysis patient (Kelly-Powell 1997; Wilkinson 1998; Bass, Jenckes et al. 1999; Andrew 2001; Iles-Smith 2005). The areas of interest were narrowed down into topics, or categories, and questions were formulated that would help to explore the research focus within those

categories. The patient interview topic guide was developed around the five themes considered most likely to elicit useful information for understanding the patient experience of and view of the transition to dialysis. These were:

- 1) Background and understanding of kidney problems
- 2) Introduction to dialysis
- 3) Service related issues
- 4) Deeper understanding of the impact of kidney disease
- 5) Suggestions for service improvement.

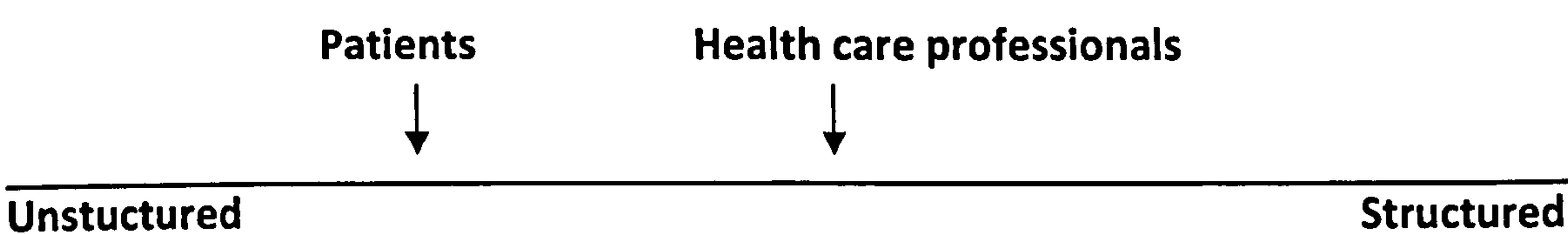
*Health care professional interview topic guide* – The guide (Appendix 7) used for the health care professionals' interviews was, by design, much shorter. This was deliberate as I was concerned that lengthy interviews would inhibit busy physicians and nurses from participating in the study. I focussed on eliciting opinions and reflections on practice. The categories for the physician interviews were:

- 1) Reaction to dialysis start as urgent/elective
- 2) Reflection on interactions with the patient
- 3) Reflection on own practice
- 4) Reflection on wider team role
- 5) Learning points

The questions were open ended to create a flow in the conversation, and as Polit, Beck & Hungler point out, to enable me to collect richer and fuller information (Polit, Beck et al. 2001). Although interview topic guides were used, they simply provided a framework for questioning. Because of the nature of the interviews, in reality the patient interviews were relatively unstructured whereas the health care professional interviews were more structured though not rigidly so. Figure 6.1 below suggests where each set of interviews would fit on a continuum between unstructured and structured.



**Figure 6.1 Relative structure of interviews**



**6.6.2 Interview location and procedure**

Green & Thorogood recommend interviewing patients at home whenever possible as they suggest this helps to offset the power imbalance between the interviewer and interviewee by placing the interviewer in an unfamiliar environment (Green and Thorogood 2004). However, I thought it important to give patients a choice of being interviewed at home or at the hospital, for three reasons: 1) I speculated that some people might prefer not to have a stranger visit them at home; 2) I wanted to ensure that patients felt at ease to speak, something which may not have been possible if others were in the house when the interview took place, and 3) I wanted to create the least amount of inconvenience to the patient so I was happy to be as accommodating as possible. In the end, all patients chose to have the interview at home.

Almost all of the interviews with physicians took place in their respective offices at Leicester General Hospital. By interviewing them in their offices, I wanted to expose them to the least amount of inconvenience, but I also wanted to pose the least amount of threat to them by seeing them in their own environment. The interviews with nurses were held in my office at Leicester General Hospital since the nursing team share two large offices, and privacy was assured only by the interview taking place outside of their usual environment.

I began each patient interview by explaining that I had deliberately not sought any information about the participant prior to the interview. I went on to say that this was because I was interested in trying to understand the circumstances and sequence of events from the point of view of the patient and did not want to create bias by having too much information about them beforehand. This led well

into the first question, which was to ask the interviewee about how long he/she had had kidney trouble. Asking patients about the background to their kidney illness in the first instance allowed the development of a narrative as the patient told the story in her or his own words. Through this I, the interviewer, and the interviewee pieced together the journey from pre-diagnosis to dialysis, which led well into the second topic, though of course there was flexibility within the interview to cover all topics as and when they arose.

I started the interviews with health care professionals by explaining that I had recently interviewed the patient and my understanding was that he/she had started electively/urgently and asked whether that was what they had expected and how they thought this situation had come about. This initial phase of the interview immediately focussed the interview on trying to understand what had happened on a broad level, before focussing on a more detailed discussion relating to the patient, their own practice and that of their colleagues.

### **6.6.3 Pilot interviews**

I carried out two pilot interviews to familiarise myself with the questions and the flow of the interview and to practise my interviewing technique. In the event, no real changes were made to the interview topic guides as a result of piloting, but these interviews provided a useful opportunity to develop the multiple skills involved in carrying out interviews for research purposes. Mason cites these as listening, remembering what people have said to you, achieving a good balance between talking and listening, observing, picking up verbal and non-verbal cues about the situation and the mood of the interviewee, and becoming accomplished in the practicalities of interviewing, such as making sure the equipment is still recording (Mason 1996).

### **6.6.4 Recording & transcription**

All interviews in this research study were recorded on an Olympus DM20 digital recorder and transcribed verbatim. The interviews were transcribed by an experienced professional transcriber external to the team. Following receipt of the



transcript I reviewed the transcript for accuracy. Basic demographic data such as study number, age and sex were included at the top of each transcript but all identifiable information relating to places or people was removed from the transcripts in order to provide participants with anonymity.

#### **6.6.5 Reflective practice**

Notes were not taken during the interview so that I could focus on the content of the interview and the interviewing technique. However, following each patient interview I made notes about the interview. The form of these notes was unstructured, but they generally covered areas such as how I felt during the interview, how the participant came across and initial thoughts about what they had said. The interview notes were used as data in the analysis.

#### **6.6.6 Identification**

Each patient who entered the study was assigned a study ID number. Associated health care professional interview transcripts were labelled according to the patient who was the focus of the interview, followed by the letter D for doctor or N for nurse. In reporting findings the identification strategy was changed so that each doctor or nurse was numbered sequentially.

### **6.7 Analysis**

Data analysis was carried out using the constant comparative approach originally described by Glaser who suggested that the 'constant comparative method is designed to aid analysts with...generating a theory which is integrated, consistent, plausible, close to the data...' (Glaser 1965). This includes concurrently analysing data and continuing data collection. As key themes, or core concepts, evolve within the data it is possible to go back and reanalyse data previously collected to see whether the concepts were present in previous interviews, and also to adjust questioning in subsequent interviews to explore certain points further. There are several discrete stages of data analysis, but the process is iterative, therefore there is considerable shifting backwards and forwards between each stage. These stages are listed here and described below:

- Familiarisation with the data
- Preliminary open coding/Development of the coding framework
- Coding of interviews
- Exploration of relationships and patterns between categories
- Generation of theory

#### **6.7.1. Familiarisation with the data**

Immersion in the data, also described as dwelling in the data by some qualitative researchers (Burns and Grove 2001), is an important aspect of qualitative research. The researcher has to become familiar with the data in order to understand and interpret their meanings and to appreciate connections between accounts. Bryman (Bryman 2004) suggests as the initial stage of analysis, to simply read through the interview without making any notes until the very end when only seminal thoughts relating to important aspects of the interview are jotted down. He suggests doing this as soon as possible following the interview.

As there was a time delay between carrying out the interviews and receiving the completed transcript, I listened to each interview, often more than once, usually within a week of carrying it out, and wrote down some key thoughts. I found this very useful, as when I came to code the interviews, sometimes a while later, I already felt familiar with the content and could very easily recollect the setting, the patient and the overall feel of the encounter. Immersion included re-reading of interview transcripts as suggested by Holloway & Wheeler (Holloway and Wheeler 2002).

The notes taken during this initial phase also formed part of the reflexive process and by listening to, rather than reading, a transcript I found myself later coding the interviews with the interviewee's voice very much in my head. This led me to feel that I was acting both as a researcher interested in understanding the problem so



that solutions could be found, but also as a nurse whose role involves acting as a patient advocate (Nursing & Midwifery 2004).

### **6.7.2 Preliminary open coding / development of the coding framework**

Coding is essentially a reductionist activity, the aim of which is to aggregate the data into categories that can then be explored and assimilated during the analysis. The initial stage involved the development of a framework which was created by reading through the first five interview transcripts and assigning open codes to text passages. Open codes are conceptual labels which are a means of describing the context or content of the text unit. This is achieved by reading the data and assigning a word or phrase that indicates the essence of the meaning of the unit under study, be it a word, sentence or paragraph (Maykut and Morehouse 1994).

Initial open coding of five interviews from each participant group was carried out manually using paper transcripts. One of my academic co-supervisors, Margaret Stone, undertook the same process independently with the same interview transcripts, and from our subsequent discussion I was able to organise our open codes in order to construct a basic initial categorisation framework. We defined both descriptive and conceptual categories and described their meanings and limits. This definition of the categories was essential in order to recognise later on whether a new text unit fitted into an existing open code or there was a need to create a new one. Descriptive codes were those that could be used to describe people, such as age, sex, or whether they had undergone dialysis preparation. Conceptual categories contained codes that emerged from the data to describe what patients were talking about, such as information gaps, experience of having CKD and family support. There was strong agreement between the two coders regarding the open codes and general themes emerging from the interviews. In addition to this, two members of the wider research team, Sarah Nicholson and Ann-Marie Cannaby, had both read three transcripts and agreed on the general categories.

### **6.7.3 Coding of interviews**

Interviews were then coded into the coding framework. This was achieved by examining each line of text to check whether it corresponded to, or fitted, one of the codes already created, or was referring to something we had not previously identified. Only five codes were added to the initial framework as I proceeded through the analysis and each instance was discussed with my primary qualitative supervisor, Margaret Stone, in order to ensure that my interpretation was appropriate.

Although initial open coding was carried out manually, the framework was constructed using QSR N6, and from that point forward all coding was carried out electronically. This facilitated systematic analysis while also maintaining an audit trail of the analysis, as promoted by Gahan & Hannibal (Gahan and Hannibal 1998).

### **6.7.4 Exploration of relationships and patterns between categories**

This step was achieved using different methods in the patient and health care professional interviews. For the patient interviews I analysed the association between categories by extracting and printing all data contained within the categories using the facility provided by QRS N6 and then manually exploring relationships. Patterns were sought between categories and per case. As an example of between category analysis, I examined the relationship between satisfaction with information and preparedness for dialysis across cases. An example of per case analysis was when I pieced together the overall description of the patient's experience of an illness trajectory by examining the categories relating to symptoms on a patient by patient basis

For the health care professional interviews I used the Framework approach originally described by Ritchie & Spencer (Ritchie and Spencer 1994). Framework analysis involves the same steps of data familiarisation and coding as described above, though the coding stage is referred to as indexing. The next step is called charting and involves creating a chart with the category headings across the top and the cases listed down each side. A précis of the data relating to each category



and case is entered into the corresponding box. This shows clearly where gaps and patterns and associations emerge from the data allowing further systematic exploration of relationships.

In reality I found that both methods were very similar and allowed for the same level of flexibility and depth of analysis. In the way that I used Framework it proved useful as an organisational tool that allowed for effective visual analysis of associations between and across cases.

#### **6.7.5 Generation of theory**

Strauss and Corbin state that within qualitative research, theory is 'a set of well developed categories...that are systematically related through statements that explains some relevant social or other phenomenon' (Strauss and Corbin 1998).

Theory generation is considered to be the highest level of interpretation and abstraction and is often not the aim of many qualitative research studies (Maykut and Morehouse 1994; Bryman 2004). This study set out to describe and interpret experiences and opinions in order to better understand the phenomenon of urgent dialysis initiation in patients known to renal services. In considering my findings I sought to go beyond generalisation of purely descriptive data by seeking to develop some theory relevant to the focus of my research.

#### **6.8 Conclusion**

This chapter has outlined in detail the methods used to undertake part two of this research study. From the objectives of the study, through to the development of the interview topic guides and the analysis, an attempt has been made to be as explicit as possible in order to satisfy the reader of the integrity of the research process undertaken. Please refer to Appendices 4-9 for further detail. The following chapter presents the findings of the interviews with patients.

# CHAPTER 7

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## Findings from patient interviews

### 7.1 Introduction

This chapter presents results from the patient interviews carried out during phase two of this research study. The full framework including the subcategories can be found in Appendix 8, although most of the findings presented in this chapter are derived from data contained within the conceptual categories, which were:

- Acceptance
- Information and education
- Knowledge and understanding
- Patient experience of care
- Attitudes and experiences of chronic kidney disease
- Making choices about RRT

The quantity and wealth of data emerging from the interviews was vast, I therefore guided my analysis by regularly revisiting the aim and objectives of the study and directing the analysis accordingly. In this chapter I will provide an overview of the themes most relevant to the study aims and to the patients who told me their stories.

Ultimately the findings were broadly grouped into three areas: patients' experience of renal service provision, patients' experiences of having chronic kidney disease, and understanding the patient experience. This chapter is



structured around these broad themes, preceded by a summary of the characteristics of the patients in the study.

Confidentiality was paramount in this research study; I have therefore limited the detail disclosed about patients, as I was concerned to avoid making them identifiable. In many cases patients are referred to only as numbers with no reference to age or sex. Although this information may have made the accounts more meaningful for the reader, I had to balance this with the assurance given to participants that anything they told me would be anonymous, which extends beyond omitting names (Nursing & Midwifery 2004).

## **7.2 Sample demographics**

The following categories were created in order to describe the sample: age, sex, employment status, dialysis initiation status (elective or known acute), ethnicity, years since diagnosis and presence of diabetes. During analysis of the interviews, it became apparent that the classification of elective and known acute was not adequately describing the sample. It was a categorisation that had clinical meaning, but did not pertain necessarily to the patient experience. Patients' stories had similarities irrespective of whether they had undergone urgent or elective dialysis, and some patients who had an urgent dialysis start had been well physically and prepared with either a fistula or peritoneal dialysis catheter in place, in the same way as elective patients. To capture this, a new category was created to indicate whether or not the patient had undergone preparation for dialysis in terms of having a fistula created or peritoneal dialysis catheter inserted. The patient characteristics are shown in Table 7.1.



Table 7.1: Characteristics of patients in phase 2 of the study

Patient number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	Total
Age group																					
≤40	X	X		X																X	4
41-60			X		X						X				X				X		5
61-69						X		X	X			X	X			X					7
≥70							X			X							X	X			4
Sex																					
Male	X	X	X	X	X	X	X	X	X	X	X		X		X						13
Female												X		X		X	X	X	X	X	7
Employment status																					
Employed					X						X								X		3
Not employed	X	X	X	X		X	X	X	X	X		X	X	X	X	X	X	X		X	17
Initiation status																					
Elective	X					X		X	X		X								X		6
Known acute		X	X	X	X		X			X		X	X	X	X	X	X	X		X	14
Ethnicity																					
White European		X			X	X	X	X	X	X	X	X	X	X	X	X			X		14
South Asian	X		X	X																X	4
Other																	X	X			2
Years since diagnosis																					
<1			X											X			X				
1															X						
2								X	X				X						X		
3						X															
4										X								X		X	
>5	X	X		X								X									
Diabetes																					
Yes			X			X				X			X		X			X	X		7
Preparation																					
Yes	X			X	X	X		X	X		X			X					X		9



## **7.3 Patients' experiences of renal service provision**

### **7.3.1 Clinic appointments**

When asked how they viewed their clinic appointments patients broadly discussed either their emotional reaction towards appointments, or described the appointments in detail and discussed the overall impact or both. The feedback on the experience of attending clinic appointments was often negative, though some patients did report positive experiences.

#### **7.3.1.1 Feelings towards clinic appointments**

Clinic appointments appeared to be an important event for many patients who were aware that it was during these encounters that they would be told both how their kidney function was progressing, and towards the end of the predialysis phase, the imminence of dialysis. Dread, apprehension, panic and fear were terms used by some to describe their emotions prior to their appointments. The quote below sums up the experience of some patients who were happy overall with the nature of the appointments but also conveys the emotional impact of going to the clinic and the possible after effects:

'... as far as the clinics were run I'd say they were very good, it was very efficient and no issue there but there was a feeling of dread on my behalf because of obviously my kidneys are deteriorating and erm ... it's you know waiting for blood results and obviously having more results and you know on the computer you can see like a steady decline and erm ... doctors are straight to the point you know they tell you what is going on which is good I think that's the best way to do it but it still makes you crumble a little bit and I hold it together when I'm in there and then when I get out it's like wowerr ... you know and I'd think (*whispers*) "Oh bloody hell you know I've gone down another per cent", and when you're getting below ten per cent er ... each per cent's very important ...' (patient 19)

The quote above also touches on another point made by some patients, that is, as dialysis was approaching, their attitude to clinic appointments changed. This can be seen in the quote below from a patient who described this very well:

‘for the first five or six years I only went once a year and er ... I never thought much about it really... It's only in the last sort of four or five years when things started to gradually go down erm ... that the erm ... visits became sort of more ... more important ... I realised that perhaps things were starting to change and erm ... you know they were becoming a bit more meaningful if you like... I knew that er ... by this time ... there was a slight deterioration and then perhaps they would say, "Well we'll see you in four months instead of six months", so I thought, "Well obviously a change is gonna come sooner or later". Although they still spoke in terms of years. Erm ... occasionally I would think, "Oh I wonder what they'll find today?" Perhaps you'd been a little apprehensive ... you do get a little more apprehensive as time goes by yes ... yeah.’ (patient 5)

Some patients expressed feelings of ambivalence about their appointments, describing them as necessary, just something that had to be done. There were several patients who had a strong negative view, describing their appointments as a waste of time. The reasons for this varied, but it seemed to be related to two aspects, the first of which was whether the patient was satisfied with the care they received during the consultation. This is illustrated in the quote below:

‘Well they're a waste o' time...because he never tells you about anything ... I've asked times an' times when he's saying "Oh your creatins up or this is ... or tha' your potassium's up or this is up", an' I say, "Well what can I do meself to bring it down?" an' it's just like ... "Well I dunno ... I dunno", ... you don't get no feedback at all from 'em ... they don' explain anything....It's just, "How do you feel? All right." The way you 'ave to take your urine, check your tablets ... an' within five minutes well you're back out the door again and well I just think it's such a waste o' time ...’ (patient 2)



The second reason why patients thought that the clinic appointments were not a good use of time was if the patient didn't believe that they really needed to be there, examples of which are shown in the two quotes below:

'... I thought, "You know they're telling me I'm poorly and I don't feel poorly, I shouldn't be here", 'cos there's some older people that do look ill that I used to sit thinking, "yeah you need to be here but I'm sort of twenty-five, twenty-six, feel great I shouldn't really be coming here"...' (patient 11)

'I thought it was just a waste of time that I am going, I don't think I'm ... I need ... I need this ...' (patient 20)

#### **7.3.1.2 Nature of clinic appointments**

The overall impression people gave of their clinic appointments, was that they were task driven and impersonal in nature. Patients often described the appointments in terms of the series of actions that comprised the routine of each appointment, as a typical quote from patient 5 shows:

'... they would take your blood pressure, ask you how you feel, they would look at the ... your details on the computer erm ... then I'd go and have er ... or provide a ... a water sample and er ... er ... then I'd go and have blood tests and for years we went without any problems' (patient 5)

Some portrayed an air of resignation and at times anger, suggesting dissatisfaction with the clinic encounters:

' we were waiting for two hours to see the doctor he ... all he done were just looked me tablets and wrote one or two things down in his book and said, "See you in two month time", and which is a load of crap really. So then he says, "All right now go up and get your blood test". So then I had to go up and sit in the waiting room then to get a blood test which was

probably another half hour ... which is probably another half hour wasted so...' (patient 10)

The impersonal nature of the clinic appointments are best summed up in the quotes from two patients below. Patient 12 was responding to a question about how she thought the clinic appointment experience could be better.

'I mean nice as he is he ... I mean basically what time has he got? I mean you ... you ... you go in the room, he says hello and you discuss your ... your blood things and he'll say a bit about the future and how do you feel and one thing and another and then it's a case of go out and you know get your blood taken ... go. (laughs) ... you're feeling this, that and the other you know th ... a ... a thousand and one things are going wrong with you, you want somebody to tell you about it but they don't do they? The answer is that they don't tell you what's wrong with you, why you're feeling like you do and they should do they ... shouldn't they? Should say' (patient 13)

'... making the person feel that they're erm ... comfortable enough to ask questions because you do get sort of (sighs) treated almost like a ... a sausage in a sausage factory you know you come in, you're give 'em your piece of paper they've sent you, "Oh right. Sit down over there", then they call your name, "Jump ... jump on the scales, then go and see the doctor". You're just ... shuffled around you know. Erm ... at no time are there any ... well I'll say interpersonal ... talking and that you know. Erm ... and for somebody who's perhaps a bit nervous you do need somebody to talk to. Erm ... I mean I was all right but you just get ... you ... you do feel you're a number or a statistic you know, "Come here, go and see that doctor", they tell you something devastating, you walk out, they shove two booklets in your hand and say, "The ambulance is waiting for you"' (patient 12)



As the quote from patient 19 in section 7.3.1.1 showed, not all patients were unhappy with the clinic appointments. The quote from patient 7 below highlights this, in that the patient talks about the advantage of having more time in the predialysis clinic, however, it also highlights another issue identified by a few patients – that of the lack of continuity as patients saw different doctors.

‘Well it was ... it was very good because er ... you had more time with Dr <name> erm ... or whoever er ... you saw instead of him. You didn’t see him all the time but again the lack of continuity in that way two or three other different doctors ... three or four ... in fact I don’t think I saw any one of them twice or perhaps I did. Erm ... yes I ... I was saying that I thought those sessions at the clinic were good. Erm ... one reason is they did at least have er ... I did at least have more time with them erm ... each appointment Dr <name> had a ... er ... a set of clinics on a particular day in which he spent more time with each patient. I think this is when they were coming up to dialysis er ... more to er ... and ... it's different from going to your GP where you had ten minutes and that's it you see ...’ (patient 7)

It is worth noting that although a number of patients commented that they had seen several different doctors over the course of their predialysis experience, there was no strong indication that this was viewed in a negative light, it was simply mentioned in passing.

### **7.3.2 The home care team**

When I originally created the coding framework I created a category for the home care team, followed by two subcategories, positive experiences and negative experiences. After coding all the interviews I discovered that the negative category was empty; there had been no negative views on the home care team and the service they provide.

The home care team were primarily spoken of as being providers of information, the main source of information and explanation about the different types of

dialysis options. The visit by the home care team nurse was often the first time that patients had discussed the different types of dialysis treatment with anyone in depth, therefore this aspect of their role appears to be vital, as illustrated by patient 13 below. Many patients mentioned that the home care team had time to spend with them, something very much appreciated. Some said that the nurse was with them for hours at a time.

‘Well you see the thing is they are ... they are coming to explain something and at ... at the moment is just in your mind as a ... as a worry if you like, as a niggling thing. They are there for you to ask them questions aren’t they? I mean they are there to explain what ... what ... what ... what er ... you know a thing in your tummy means. I mean that sounds horrific really to the average person to have something violating you ... you know er ... and then to live with it in ... in your tummy’ (patient 13)

However, the role of the home care team extended beyond information providers into something less tangible yet equally, possibly more, important to patients. That is, the home care team offered reassurance, encouragement, and served as a valuable point of contact. These themes are all present in the quote below from patient 7.

‘... forthcoming with information and he had time sitting here as you are sitting there you know. Er ... and the fact that you know when he went he did say, "Any problems you know ring our number", and you felt you were in touch with somebody and it had none of the restrictions of this, "See you in three months", thing of the clinics because you felt you could call on somebody straight away and whereas you can't do that with doctors erm ... so that is a very good arrangement’ (patient 7)

When questioned about what they thought of having someone come to their homes, all but one patient expressed a preference for home visits, as opposed to being seen in the hospital. The reasons for this varied. For a few patients it was a



question of convenience as portrayed by patient 17 below, but most felt that being seen at home was better because they were more relaxed and the whole encounter felt somehow less 'medicalised', as illustrated in the quotes below:

'I think it's a wonderful idea. I really do because in your own home you're more relaxed and you know you're in your own environment you know I think it's a brilliant idea. Yes. I think ...Oh yes definitely I think it's wonderful that they come to the home and you ... you don't have to traipse to the hospital you know just to be interviewed or whatever to give advice you know I think it's wonderful' (patient 17)

'... so it was, it was a very positive experience ... and it wasn't clinical ... it wasn't ... when she came it wasn't erm ... she didn't come round in a uniform or erm ... to the house erm ... you know it wasn't ... it wasn't all sort of about medical procedures as well and you know quite a ... well human's not the right word but you know it was erm ... I thought er ... it was adapted very well you know to my sort of circumstances...' (patient 19)

'I think it is more erm ... more personal really you know if s ... if somebody comes to your house they can have a drink of tea or they can ... you know erm ... things like that you know so it's more personal than erm ... if they had it in the hospital ...' (patient 18)

Two patients stood out when discussing the home care team, as the impact that home visits had on them was quite different from that described by the other patients. For them the home visits drove home the importance and severity of their condition. Interestingly, both patients were young, in their 20s, were of South Asian background and had had periods of non-attendance at clinics.

*Researcher:* 'what did you think of having somebody come to your house rather than you going to see somebody at the hospital?'

*Patient:* 'Yeah it was like erm ... there is some ... I think there is some major emergency or some problem or something that he ... he have came to my home'

*Researcher:* 'Really?'

*Patient:* 'Yeah I felt that there is something bad that he haven't called me or anything and he's straight away came to my home and ... so I was a bit shocked that why did he came he never told ... called me or anything and at about nine o' clock in the morning and he came er ... and then he asked me how are you keeping and a lot of things, I said I am feeling itchy ... itching and that, he goes I think that's the symptom of your kidney failure so and your blood tests are showing really high so I think you should come with me...' (patient 20)

It was following this visit that the patient was admitted to start on dialysis later that day. The other patient expressed similar thoughts:

' ... yeah ... like when <nurse> did come I thought, "This must be serious", sort of thing because no one's just gonna come to my house and say, "Why aren't you coming to hospital?" Normally they just give up on you like say, "If he's not coming hospital forget about him", and they just move on but I even appreciate that that they sent someone to my house to see what's happening and that or if they'd just left me alone I wouldn't be ... I might not even be alive today.' (patient 4)

### **7.3.3 Patient information day**

Eight of the people I interviewed had not attended a patient information day prior to starting on dialysis. For three patients, this was a conscious decision; two of them had been reluctant to take a day off work to attend and the other had not thought it necessary. The remaining five reported that they hadn't been informed about the day.



Of the patients who did attend there was a mixture of responses regarding the day. Overall, many patients found it beneficial and there were two over-riding reasons for this. Firstly, for some patients it was primarily a 'show and tell' session. They were able to see the different dialysis modes in action for the first time and this helped to clarify what they had previously been told by doctors and the home care team. For some patients the patient information day was an important factor in helping them to decide on the type of dialysis they would like to start on as illustrated by the quote below:

'No I went to the patients' information day. Er ... I saw the CAPD one, I saw the fistula one ... me an' my wife we both went, took the kids as well ... we saw everything ... how it would both happen ... the both dialysis, what the risks are ... y' know which one th ... this one I knew you you would get more infection the CAPD one...er ... I made my mind up straight away which one I was gonna go for. I wanna to go for the fistula, I wanna go the haemodialysis ...I was quite impressed you know. Erm ... they were explaining ... they explained nicely you know. You know how it works. How it's done. An' wha .. y' know an' what you 'ave to do. Y' know I ... I ... I ... it's quite interesting...Yeah well to me it was very important.' (patient 1)

The second benefit of the patient information day mentioned by many patients, was the sense of comfort and relief to meet other patients with chronic kidney disease. The following two quotes are typical when asked about what patients found good about the patient information day:

'Well I er ... (...) ... mixing with other people with the same problem and er ... you know you feel you're not the only one with it...Yeah. When you first ... when they first tell you you got summat wrong like that you ... you think you're the only one you know (laughs). Nobody else has got it only you and er ... you know you meet other people with it you know and it's different. Mmm it's a great help.' (patient 16)

‘yes it was er ... helpful and there were other people there in the same boat, you know, all new to it and er ...well initially you think, “Ooh well you know it’s just me”, ... it’s er ... it’s a very selfish way of looking at it but, “why me?”, and erm ... but when you see all these other people’ (patient 14)

Not all feedback on the patient information day was favourable, though only a few patients expressed criticism. One patient explained that for him there were too many people and that he would have preferred sessions to be smaller with the education spread out over several shorter sessions. His explanation for this was that firstly he was shy and felt unable to ask questions in front of such a large group and secondly he would have liked the opportunity to build a rapport with fellow patients which could have happened over a number of sessions. A couple of patients felt as though the patient information day sought only to present a positive review of the dialysis options, and that some insight into the potential problems and how to deal with them would have been beneficial, as seen in the quote below which arose when discussing the patient information day:

‘ but they didn’t explain that you could get infections or stuff like that ... your fistula doesn’t work you get a line put in. I didn’t even know what a line was until I had to put one in which was then a shock again. If I knew earlier sort of thing it would have been better for me. At least I'd know what I was going through...’ (patient 4)

A further drawback to the patient information day, which probably relates to the first criticism above, was the lack of interactivity, as highlighted in the quote below:

‘My ideal would be that that ... you had a person who was an expert on everything to talk ... to ask questions of. I mean that would be the ideal but that would probably not be possible because of the number of people. Er ... but certainly ... we found anyway we sat there and mostly it was a case of



listening, it wasn't a case of answering questions. You know what I mean?'  
(patient 13)

## **7.4 Patients' experiences of having chronic kidney disease**

### **7.4.1 Diagnosis**

The story of each patient's diagnosis was usually told close to the beginning of the interviews when patients were telling me about the background of their kidney disease. In many interviews I asked how being told that their kidneys were failing made them feel. Almost all responded with an emotional response, most often describing shock, devastation or disbelief as shown in the following three quotes.

'Erm ... yeah as I say it ... it was fifteen years ago erm ... yeah just a shock really because you're ... you know at that time I was er ... I was twenty-five and you're ... you're in your prime and erm ... yeah it were just a shock really you know' (patient 11)

'Erm ... devastated to begin with because I ... I remember coming out the consultant's room ... and just cried basically' (patient 19)

'Ahh it was er ... you know as if the ... the whole world you know fell on my face. I mean you ... you know it's ... it's ...it's something you know ... well like er ... you know as if you you know ... it's a ... it's a blow to you...Yeah...my reaction was ... I said, "Can't be", they said, "Yes it is". I said, "But I didn't feel anything"'(patient 3)

There was a strong awareness of mortality in the sample. Speaking in the context of receiving the diagnosis of kidney failure and facing the prospect of dialysis, some patients clearly saw an association between kidney failure and death as shown in the following quotes:

'...he said to me then erm ... "You're kidneys have failed totally", and I suppose when you hear somebody say that it's quite a shock and I

remember sitting there thinking, "I wonder how much longer I've got left to live?" And he ... he ... he told me and I thought, "But is he going to say, "But don't worry we can do something for you", or something like that and he didn't he just sat there and I thought, "Well ... ", I said, "How much longer have I got?" (patient 12)

'... I think if you don't know much about kidneys and you hear the word dialysis you think, "That's it, end of the road", kind of thing. Erm ... and basically I thought well there's no future you know I'm relatively young and you know I'm not going to have a future...' (patient 19)

'Terrible. Absolutely terrible. You know and I felt I were dying and I come out and ask him ... you know am I ... am I going to die?' (patient 16)

#### **7.4.2 Symptoms**

Descriptions of symptoms, or absence of symptoms, were present in all interviews. It emerged that this could be coded into four categories according to the time frame the patient was describing. These were pre-diagnosis, predialysis, dialysis imminent, and on dialysis. I analysed the description of symptoms as given by each patient individually and three typologies emerged based on patients' descriptions of symptoms during the course of their illness. These were:

- Trajectory perceivers: patients who described a clear illness trajectory, including those who described feeling very unwell immediately prior to dialysis
- Retrospective trajectory perceivers: patients who described an illness trajectory and feeling unwell only with the benefit of hindsight
- Non-perceivers: those who did not describe an illness trajectory or feeling particularly unwell prior to dialysis.

The description of symptoms and an illness trajectory often related to whether or not people described feeling benefits of dialysis.



The quotes below from patient 6 illustrate the descriptions of symptoms present at diagnosis three or four years earlier, the worsening over the year before dialysis, and then the time immediately predialysis when he was virtually housebound and unable to function independently. Here a clear illness trajectory is described with a subsequent positive benefit of dialysis:

*Patient:* '... sometimes I'd be caught very short for breath and I'd have to sit down literally and then within a minute I'd be okay again. That was one thing that started it going. I'd felt like a battery that had been drained. And then if I stopped and had a rest then I'd be okay again'

*Researcher:* 'And so that was three or four years ago?'

*Patient:* 'Yeah that's been building up over three or four years yeah...that intervening year (before dialysis) I was getting worse and well I was getting less energy, getting tired ... I think to sum it up basically if er ... my wife goes to work obviously I would literally just sit here all day in this chair and that was it and watch the tele I wouldn't want to go out, I couldn't be bothered to do anything really ... just felt bloody awful. Huh. It was painful ... hard to get out of the chair when I'd got no energy erm ... it's hard to stand up to do anything in the kitchen.' (patient 6)

The quotes from patient 11 show a rather different experience, where the patient describes feeling well and not really recognising that he was unwell until after he had started on dialysis.

*Patient:* 'Well I have all along er ... right up to the point where I had this food poisoning which as I say kick-started it erm ... I ... I've sort of felt fine all the way through haven't I? You know ... little bit tired towards the end'..

*Wife:* 'I think 'cos it was such a slow ... deterioration I think you probably didn't realise how poorly you were ...'

*Patient:* 'it's difficult for those ... for them to gauge erm ... so I mean we're we were quite lucky really mine's just gone up right until the end where it just flew up to fourteen hundred and something ... yeah very high. But even then I still felt okay...'

*Patient:* 'Just slowly but still erm ... within myself I was still capable of ... of getting up in the morning and going to work and ... and you know pottering around so ... whereas before I'd used to lie in bed on a Sunday because it's my only day off from work. I probably wouldn't get up 'til eleven o'clock er ... whereas now I mean last Sunday I was up at half past seven and we were out walking the dog on the common and you know making the best of the day ... it was so slow that you ... I just wasn't noticing that I was slowing down and ... and you know changing very, very slowly' (patient 11)

In the third category were patients who had not experienced a worsening of symptoms and who did not recognise that they were increasingly unwell, and consequently did not report a benefit of dialysis. This is summed up well by patient 2:

'within forty-eight hours of being in hospital then I were on dialysis so I were a bit cheased off about that 'cos I'd just carried on as normal I didn't think I were ... you know feeling any worse or ... I don't feel any different now than what I did before. In fact m ... er ... half the time I feel worse now now I'm on dialysis than what I was before' (patient 2)

### **7.4.3 Making decisions about RRT**

I didn't usually specifically ask about how patients chose between the options for dialysis and transplant, but this frequently arose during the interviews. Five patients were advised by health care professionals that they were suitable only for haemodialysis, so they did not engage in the decision making process in the same way, but many of the other patients described their reasons for choosing either



peritoneal dialysis or haemodialysis. Nine patients chose haemodialysis and four chose peritoneal dialysis. The reasons for choosing each appeared similar and fell into two main groups: body consciousness and intrusiveness.

#### **7.4.3.1 Body consciousness**

Several patients chose haemodialysis because they found the idea of a permanent catheter in situ in their abdomen very off-putting. One patient said that she really couldn't cope with having a tube in her stomach, while another said that having the tube there permanently would cause her to worry in case something happened to it while she was going about her daily activities. The main objection to the tube seemed to be that it would be unsightly. Conversely, one patient mentioned that she chose to have peritoneal dialysis because she perceived having a fistula to be disfiguring:

‘there was a man with two huge lumps on his arm and I thought, "Oh that's revolting. I am not gonna have that", (laughs) and there ... there was a man in the next bed to me at the hospital had those ... oh and I used to ... turn me stomach over I couldn't look at his arm' (patient 12)

#### **7.4.3.2 Life intrusiveness**

Patients who chose to have haemodialysis frequently cited that they disliked the idea of peritoneal dialysis because it required them to carry out the procedure four times a day, something which they thought would impact on their lives, particularly if they were employed. Patients spoke positively about choosing haemodialysis because, apart from the time spent in hospital having the dialysis, the rest of the time they were 'free' to carry on a normal life. In that respect, haemodialysis was viewed by them as being less intrusive than peritoneal dialysis:

‘we talked about the options for dialysis whether it was gonna be erm ... peritoneal or haemodialysis and peritoneal for me I couldn't ... I don't think I could cope with a tube in my stomach and it wouldn't be practical for work part ... particularly. Erm ... my idea was if I can get sort of the

haemodialysis over and done with within the three days then I've still got four days of my week free basically' (patient 19)

On the other hand, the patients who chose peritoneal dialysis often did so for similar reasons, coupled with a strong desire to stay away from hospital. One of the other elements was the impact of the travel time and the transport issues associated with haemodialysis. These points are portrayed in the quotes from patients 20 and 15 below who both started haemodialysis urgently then chose to switch to peritoneal dialysis:

*Patient:* '... I was thinking of having a fistula but then I changed my mind I ... I thought that if I'm ... I need to go India or anywhere in the world if I wanna travel and I couldn't get onto my transplant within a time so I can still travel with the CAPD so I ... I ... I decided I would go with that'

*Researcher:* 'So that was why you decided ... so you could have your freedom to travel?'

*Patient:* 'Freedom to do everything because when I ... I came home and I was ... I ... I was going to the erm ... er ... <hospital> centre of dia ... er ... dialysis centre three times a week and I was really you know erm ... pushed out with the time that oh they're gonna come and collect and take me to there and I have to wait for them and I couldn't make any plans for the day because they usually come at three ... three o' clock or sometimes half two to come and pick me up and they drops me at eleven o' clock at night' (patient 20)

' I thought erm ... like er ... got a twenty mile trip every other day ... I didn't want an ambulance car erm ... because you never know when you're gonna get in and when you ... you're so restricted aren't you ... I didn't want an ambulance car and plus the fact I didn't want ... I mean it's all right on ...



probably on a day like today but when you got January and February and erm ... perhaps I've got something else wrong with me as well erm ... and the weather conditions are bad and perhaps ... perhaps they're delayed at that end because you know they ... they've had a back up of ... of things go wrong, I thought this one (peritoneal dialysis) would be less intrusive on my life if you like. At least it keeps me away from hospital a little bit more like you know ... so that was the main reason that we went for this one like you know' (patient 15)

#### **7.4.3.3 Involvement in RRT modality decision**

On the whole, patients did not express concerns about making the decision regarding dialysis or transplantation options. Many seemed to accept their part in the process and explained the rationale for their decisions. A few patients stood out, however, in that they mentioned that they would have liked more direction, particularly from medical staff, about which dialysis option would be best for them. The quote from patient 7 captures this; not only is he discussing how he would have liked more direction, but in general he emphasises the difficulty that he, and others, face when having to make such an important decision.

*Patient:* 'I still sort of at that stage I'd have been wondering about it and wanting to go back to er ... a person who's qualified to tell me whether ... which they thought best medically for example. Trouble is I don't think the ... Dr <name> would say that because he was all the time emphasising that it was in the end my choice you see. But it's all very well my choice all the time er ... without having some opinions to guide that choice. Er ... and I don't think I'd ever have found somebody to say, "Well for you such and such is better than such and such".'

*Researcher:* 'And that's ... would you have wanted that?

*Patient:* 'It might have been helpful to hear that but it would have been one of the things that would have swayed my direction. Erm ... again but really

it's a matter of hearing all the facts er ... the for's and against for each form of dialysis and I suppose having heard those you can't really balance them one against the other and decide one is better than the other ... probably because they all have their advantages and disadvantages and they are very different. It's like trying to choose between British Gas and Scottish Power (laughs)' (patient 7)

## **7.5 Understanding the patient experience**

### **7.5.1 Acceptance**

Acceptance emerged as a clear and strong theme during the first stage of open coding. Within the theme of acceptance, there were three initial categories that related to text referring to different aspects of patients' experiences. These were: 1) acceptance of having CKD, 2) acceptance of dialysis, and 3) acceptance of the timing of starting dialysis.

#### **7.5.1.1 CKD acceptance**

'...I think it only took about few weeks then we got used to it again then "Ooh fair enough ... I've got that problem, never mind, it's happened ... it's happened. Let's look ahead now, let's enjoy our life". That's it you know. I knew I'd got the problem I knew that's it now I know I've got it...' (patient 1)

#### **7.5.1.2 Acceptance of dialysis**

'I mean as I say uh ... up to a point I've accepted it 'cos I'm doing it but I still sit there thinking, "I don't feel any different. Why am I doing it?"' (patient 9)

#### **7.5.1.3 Acceptance of the timing of starting dialysis**

*Researcher:* 'And so you didn't go (to the patient information day) because you didn't think that you'd be starting on dialysis?'

*Patient:* 'No. Not that I wouldn't ... not so soon anyway. I weren't expecting it. I were expecting to have me fistula done an' ... you know the ... have that



for a couple o' month for it to settle down an' then I weren't expecting to go on the dialysis for ... 'til about I don't know ... end o' this year or summat.' (patient 2)

#### **7.5.1.4 The continuum of acceptance: barriers and facilitators**

As a means of exploring potential associations between acceptance and urgency of dialysis start, I had thought it might be possible to categorise patients as overall acceptors or non-acceptors. However, it became clear that this was too simplistic. Although most people *could* be categorised as acceptors or non-acceptors, these descriptors did not capture the complexity of the issue of acceptance, in particular the influence of time that was evident in some patients' course from non-acceptor to acceptor. By this, I mean that some patients who had been in the system a number of years described their early behaviour when they appeared to not accept their condition, timing, or need for dialysis; yet during the course of the illness, usually as they approached RRT, their attitude and behaviour changed to that of acceptance. On the other hand, there were patients who entered the renal system a relatively short period of time before they started on RRT and seemed to accept their condition and the implications of it much sooner. In addition, there were patients who had been known to the renal services for many years who accepted their condition early on in their illness, as well as those patients who never really reached acceptance.

While I was analysing the data coded under the three categories of acceptance, there were several themes that were emerging that could be associated with whether, how and when patients came to accept their condition and the implications of it, such as the need to prepare for and start on dialysis. I was able to classify these themes as barriers to, and facilitators of, acceptance during the predialysis phase. Because I was using constant comparative methods, I created two more categories within the categorisation framework and recoded the data into these new groups. It struck me that many patients described a process of acceptance that often took them from non-acceptance to acceptance. I came to view acceptance as a dynamic process, and not a static entity. Furthermore, it

became obvious that acceptance was something that could be viewed along a continuum. The barriers to and facilitators of acceptance were important in moving from one end of the line towards the other. Perhaps the biggest factor of all was time. A model showing the barriers and facilitators and their role in acceptance is shown in Fig. 7.1. To illustrate some of the context behind the barriers and facilitators, I will discuss the concept 'outlook' in greater depth.

The model shows that outlook was found to be both a barrier and a facilitator to acceptance. According to the Penguin Concise English Dictionary, outlook can be defined as 'an attitude or point of view' and it is this meaning that is referred to here. Instances where outlook appeared to be a barrier to acceptance were largely where patients spoke of having either a defiant attitude towards kidney disease, or where they spoke about blocking it out and choosing to deal with it later, all of which is encompassed in the quote below. Holding a negative view or expectation of dialysis was also a barrier.

'I sort of swept it under the carpet and thought, "Oh I feel fine...I'd sort o' still felt great, still doing everything I wanted to do .. I just sort o' thought, "Poohf ... you know I'll get on with my life and what'll be will be and I ... I live my life ...", well still live my life erm ... but at the time I was still er ... eating what I wanted having a few drinks when I wanted erm ... and going on holidays when I wanted you know I didn't sort o' say, "Oh dear I've got this problem I'm gonna stop living", ... we've still travelled all over the world and sort ... sort of said you know, "Sod 'em we'll do what we wanna do", and that's what we've done you know.' (patient 11)

On the other hand a positive outlook and expectation of dialysis appeared to aid acceptance as did a pragmatic approach to kidney disease and the need for dialysis. The next quote is from a patient who thought that dialysis would bring benefits but also shows his general outlook towards having kidney disease and dealing with it. This is fairly typical of the outlook of people who appeared to reach acceptance.



Researcher: 'And how did you feel when ... when you thought about the fact that you were gonna have to go onto dialysis?'

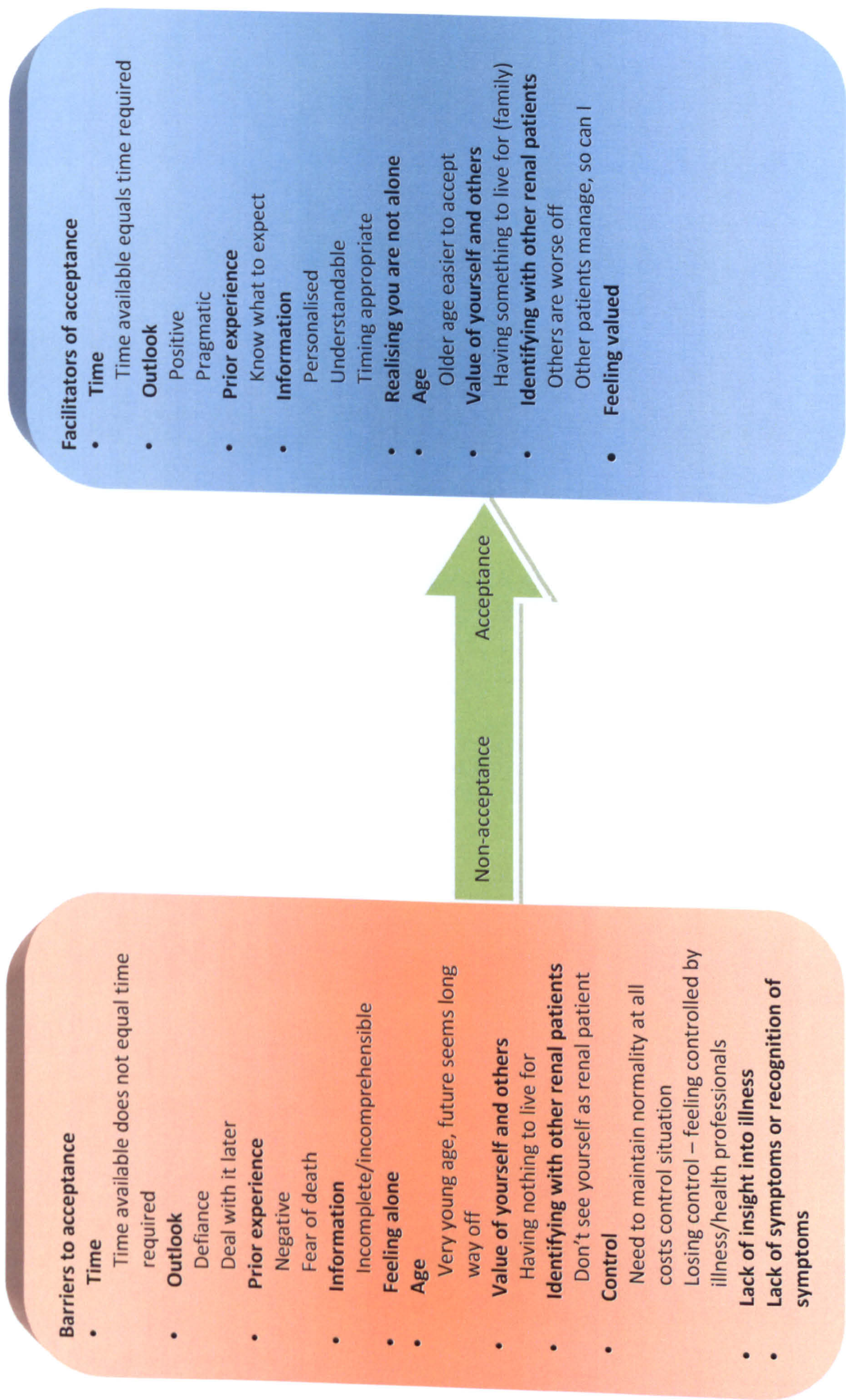
*Patient:* 'I was pleased I wanted to ... 'cos obviously I wanted some treatment ... form of treatment to sort ... try and sort me out but so far it's not ... don't seem to be very successful you know just have to hope it does get better.'

*Researcher:* 'So you were actually looking forward to it?'

*Patient:* 'Well I was really because as I say I was told I had low kidney function and dialysis would help me so I obviously I wanted it or some form of treatment to ... to help me ... accept it and not fight it you know. Why is this happening to me and all the rest of it ... just something's that's happened and there's nothing you can ... I don't think there's anything you can do to stop it and once you've got it accept the fact you've got it get on with it. So ... well that's my attitude anyway.' (patient 8)



Figure 7.1: A model of acceptance in patients with chronic kidney disease





## **7.5.2 Information**

The second major conceptual category related to information. Within this category there were separate codes labelled: sources, barriers, facilitators, perceived gaps, timing, and appropriateness. To some extent this was to be expected, as within the interviews I specifically asked patients what they had thought of the information they received prior to dialysis, and I also asked them to describe other information sources they had accessed other than the nurses and doctors in the renal care system.

### **7.5.2.1 Sources**

There were two main categories of information sources regarding information about kidney disease and RRT. By far the biggest source was hospital staff. Doctors fulfilled this by giving information during clinic appointments, and nurses during home visits. The patient information day was also a valuable source for many, though not all, patients. The second main information source was other patients. Very often these information exchanges occurred during casual impromptu encounters, and at other times they were prearranged. Some patients seemed to very much appreciate speaking to other people who were in a similar position to them, and valued their input highly. This can be seen in the quotes below:

‘... then they said, "Oh you're going to <town> now and I thought, "That's good", because I'd met people at the Day Patients' Unit that went to <town> you know you have ... how people ... patients talk and they all said "Oh they're much happier at <town> than at the <hospital>". (patient 6)

‘I think I found out more now in retrospect may be in some cases when it's too late er ... from talking to patients in waiting rooms...’ (patient 7)

Only one patient described her decision not to speak to another patient during the decision making process and her reasoning is given here:

'... yeah ... and then another one who had peritoneal dialysis ... she gave me the numbers, she says, "Oh ring them up", ... and this before I went onto dialysis ... "see what their experience was like". But I didn't and I really thought about it and I thought, "I don't wanna know if it's negative, at that point I just wanna make my own mind up", and erm ... I think it'd be really useful for people, I think it's a really useful tool but at that point er ... it wasn't for me ...'  
(patient 19)

#### **7.5.2.2 Timing of information delivery**

Timing of information delivery emerged as being important for two reasons. Firstly, some patients spoke about the gradual build up of information regarding dialysis and how this was beneficial in helping them to accept and cope with the idea of going onto dialysis.

*Researcher:* Can you think of anything that erm ... any improvements that ... that you think could be made to help other patients to understand their kidney problems and dialysis better in that run up to dialysis?

*Patient:* Mmm ... that's a hard question. Er ... it's ... I ... I suppose it starts when the patient is told, "Do you realise you've got ... you're going to have to have prob ... you're gonna have problems with your kidneys". And it's explained to them why they're gonna have problems with their kidneys and what possibly going to have to happen... you think about it and you know it's gonna happen and er ... you're ready for it sort of thing (patient 6)

'Erm ... well I didn't mind really. I mean you've got to face it and I was being introduced to it gradually so you found out things slowly you know it didn't... it wasn't all piled upon you a month before you were due to start it so it was nice to have the information erm ... of what options are open to you and it gave you time to think about it because you know you've got to have one of them anyway come what may...' (patient 5)



The second point related to timing of information was different, however, in that some patients gave the impression that information was often given often too late and in a reactive fashion. Patients highlighted that little is mentioned about emergency dialysis and what that entails, meaning that patients who go through this are often unaware of what is going on. What came across is that often information is given on a 'need to know' basis that does not suit all patients.

'I didn't even know what a line was until I had to put one in which was then a shock again. If I knew earlier sort of thing it would have been better for me. At least I'd know what I was going through ... going for' (patient 4).

'Er ... I remember on one occasion Dr <name> saying, "I'm not going to ask you to change your diet yet," you know or , "until dialysis", or something like that inferred. No that was the only indication I'd got that there was going to be any restriction on diet when I got there ...things that were given me. Erm ... months before somewhere I read about the necessary precautions of hygiene erm ... when you're on dialysis in order to prevent infection and this seemed pretty rigorous er ... when I read it in print (laughs) ... then I found I ... I didn't know anything about that erm ... when it actually happened I didn't know what to do. Erm ... I didn't know how to care for this area in ... in a course of showering and things like that. Erm ... and it was only when you know after a few days or a week I was able to come up with the right nurse to ask them and get some replies from them about it. Erm ... but again there was a ... a certain void there where nobody had actually talked that through before' (patient 7)

The third point regarding the timing of information is that it was clear that information was something that was required all along, from diagnosis onwards, yet, because the focus of the education in our system is on preparation for dialysis, it is something that is delayed until such time as dialysis is imminent.

*Patient:* 'I didn't know what dialysis ... I knew it was something to do with purifying your blood but he didn't really explain it to. I mean he's got a lot of people to see I don't suppose he can sit and explain to everybody what dialysis is erm ... so he ... he sort of said erm ... "You know we'll be keeping in contact with you", an' erm ... and that but I mean no nobody actually sat down and explained. I mean the first person to do that was <name> when he came to the house ... yeah'

*Researcher:* 'in your opinion when would that have been? The best time?'

*Patient:* 'Well I suppose erm ... when I'd just been told that m' kidneys had failed...I suppose (sighs) ... a few days after you've had that initial shock of being told, "Yeah your kidneys have failed", erm ... and you're wondering why you haven't keeled over dead on the spot you know erm ... and how (sighs) ... you ... you are sitting there thinking, "I wonder how much longer I've got? Will they tell me?" you know erm ... "Do I have to say something to get the doctor to tell me how long I've got?' (patient 12)

### **7.5.2.3 Gaps in information / education**

There were several instances where patients discussed the role of other patients in the context of making decisions about which RRT modality to choose. Sometimes the information that had been gained from other patients was incorrect, yet was used to form the basis of a decision, as can be seen in the quote from a patient who had chosen to go onto peritoneal dialysis before starting on haemodialysis urgently, partly because of the misinformation he had received from another patient

'Back at the er ... information meeting I didn't like the idea much from what I saw erm ... and from what I heard about the amount of time and somebody said, "Oh it takes about five hours". "Five hours?" It's not taken me five hours on this one and it doesn't take the other people five hours' (patient 7)



Wider ranging information such as what else could be done to delay progression would have been appreciated by some patients.

‘A little more emphasis on er ... what one could do then pre-dialysis to stop the rot erm (pause) I suppose so yes to as far as possible tell you everything rather than holding back on some of the possible problems erm ... or the more arduous parts of it ... of dialysis whichever form. Erm ... to give you in advance the information about erm ... fluid restrictions and diet and you know why this is being done and so on. I suppose it is off-putting but it's all ... it's still better than finding out afterwards or finding it out in little bits and pieces which worry you. You know a question comes up in your head and you can't ... you're worried about it because you can't find out until a week later or next month's clinic or whatever’. (patient 7)

#### **7.5.2.4 Behavioural aspects of information**

As the analysis progressed I came to realise that there were various ways in which people spoke about their satisfaction with the type of information, and that underlying this theme appeared to be two factors: 1) there were different patient typologies to explain information seeking behaviour, and 2) different people wanted different levels and types of information. What appears to tie these two factors together is that needs and behaviours related to information form aspects of patients' coping strategies.

Three patient typologies emerged from the data that described patient information-associated behaviour relating to the level of engagement patients had with health care providers and also information seeking outside the health care sphere. These were:

- Active internal – patients active in information seeking and engaged in information exchange but only within the health care environment
- Active external – patients active in information seeking and engaged in information exchange within and outside of the health care environment

- Passive – patients who appeared disinterested in information exchange or who chose not to engage in information exchange

#### **7.5.2.4.1 Active internal**

Patients who fell into the active internal category described gaining information and interacting with healthcare professionals and patients in order to understand their illness and how it could affect them. They also appeared to be engaged in the process of finding out about dialysis. However, while they were keen to know and understand about their illness and dialysis options, they relied heavily on health care professionals and opportunities provided by the hospital, such as the patient information day, for all of their information. They did not seek information from outside of the renal care system. This was a measured action by many patients who explained their reasons invariably as being either that they trusted hospital staff to tell them what they needed to know, or that they were inhibited from gaining information from elsewhere. An example of someone I classified as active internal was patient 14 who describes below why she did not go elsewhere for information:

‘No I didn’t. No. No I’m ... we’re not one of these people with a big medical dictionary and as soon as you get a pain you look up what it is ... no erm ... we’re more ... we accept what is there and er ... if we’ve got any questions you know we ask the erm ... the doctors and accept what they say’  
(patient 14)

Another patient then went on to further explain that he preferred face to face consultation due to the personalised nature of the discussion.

‘No. I haven’t got a computer so it’s not been easy you know so ... an’ other ... I can’t bother to ... asking people ‘cos I think it’s a ... think it’s a bit of a ... imposition kind of thing you know ... Oh yeah. I could follow the re ... reasoning so ... with it being face to face I could ask the question and if I wasn’t quite sure I could get clarified whereas if you’re going on a computer you can’t ask



the question you want to ask you can only get general information ... you can't get the answers you want I don't think' (patient 8).

He was not alone in this sentiment; in fact several patients spoke about the value of face to face consultation.

#### **7.5.2.4.2 Active external**

This category was comprised of the few patients who sought information outside of the renal care system. Three patients looked up information on the internet. Two reported that this was useful and beneficial, however in the quote below, one patient describes her experience of using the internet and her decision not to utilise it in the future to gather information about her kidney condition because she had a negative experience. The same patient also mentioned getting some information from the Kidney Research Foundation and she also made contact with the National Kidney Patient Alliance. She was also the only patient to bring up any of the charities or support groups working in this area.

'you know we got some information from the internet but I mean we read quite a bit of stuff on the internet about transplants and stuff and it was always people splitting up and I thought, "Ooh ..." you know and it's not worth reading about and I thought, "Ooh no", you know erm ... 'cos I thought oh you know that's the last thing I want anything to happen to my relationship you know and ... but no so I didn't bother with that' (patient 19)

The three patients who had used the internet were all younger, two in their twenties and one in her forties. Another patient sought information about kidney disease through personal contacts. His daughter knew someone who had kidney disease and he made a point of asking his daughter to find out more about their experience.

This group seemed different from the active internal group in that they were interested in finding out more information and had made efforts, with varying degrees

of success, to meet their information needs for themselves. They were not totally reliant on the health care services. However, only four patients fell into this group.

#### **7.5.2.4.3 Passive**

Patients who were passive, as far as information related behaviour was concerned, were again quite different. There were four patients in this category. Three patients' behaviour was very similar, in that they said that they really didn't want to know too much about what was going on and didn't seem particularly engaged in their clinic appointments or in the decision making process regarding renal replacement therapy options. Patient 17 describes this very well.

'...my daughter...she finds out a lot more sometimes than I do you know so er ... I have a tendency with something ... if they say, "Oh you've got to have an operation", ... "Oh whatever", ... I switch off, it goes in this ear, out the other and I ... I ... I don't take any notice, I don't ... I don't let it worry me, where my daugh ... daughter would listen and go into it more thoroughly and know what's going on so she sort of you know tell me and ... and funnily, strangely enough ... I don't know why it's silly but if somebody were to tell me that I just ... if it's something I don't want to know (laughs) I ... 'cos it ... it's awful I know ... you know I like the p ... I listen but I don't take it in if you see what I mean.'

(patient 17)

She then went on to explain that often she didn't like to know what was going to happen to her beforehand as knowing something could make her worry more, as seen in this example:

'I don't want to know. You know when they say, "Oh we're going to do this ... a needle ... this and that", and I say, "Right just do it, don't tell me what you're gonna do you know".'

(patient 17)



There was one other patient in this group who displayed similar tendencies, in that he didn't want a lot of information, yet for him it almost appeared to be a positive coping technique, something I came to think of as active denial. He spoke about avoiding the dietician during clinic appointments and not heeding dietetic advice because often it didn't fit in with his vegetarian diet.

'Yeah definitely yeah. I just sort o' thought, "Poohf ... you know I'll get on with my life and what'll be will be and I ... I live my life ...", well still live my life erm ... but at the time I was still er ... eating what I wanted having a few drinks when I wanted erm ... and going on holidays when I wanted you know I didn't sort o' say, "Oh dear I've got this problem I'm gonna stop living", erm ... I did everything which looking back like <name> just said was the best way to be...I ... I just sort of carried on living and ... and it was there in the back of my mind but I didn't er ... make an issue of it or talk to it about ... with ... with people or anything I just dealt with it and ... and got on with my life...as I say all the information was there and you know it was just me I sort of shoved it to the back of me mind and ... and didn't really pay too much attention to it to be honest...put me head in the sand if you like.' (laughs) (patient 11)

### **7.5.3 Satisfaction with information / education**

Not all information needs were met in these groups, which led to dissatisfaction. The primary cause of dissatisfaction was the frustration felt by several patients that the medical care they received focussed solely on treating the condition pharmaceutically, with little or no attempt to inform patients of actions that they could take to help themselves. This is expressed well below.

'I often wonder if during that time things weren't considered to be so inevitable you know the failure, the decrease in kidney function wasn't considered to be so in ... inevitable erm ... there seemed to be that er ... kind of attitude about it. Er ... they would tell you what's happening you know they would do all the tests er ... in other words they were watching your progress

but there was ... apart from changing medication there seemed to be very little erm ... that they might do or suggest that I did erm ... to try and arrest the failure to try and erm ... improve things. I would have thought you know there could be more going all out for that ... Erm ... I just wonder whether any ... anything else could have been done even recommendations for my way of life er ... what I could have done perhaps erm ... you know to remain healthier at that stage erm ... I got sometimes the feeling that the doctors were er ... sort of chemists er ... dealing with you from the point of view er ... increasing, changing or reducing the number of tablets taken erm ... according to the results of the previous blood test and so on.' (patient 7)

The third problem associated with information dissatisfaction was the feeling of some patients that health care professionals had not been completely open with them. This was touched upon in section 7.3.3 which highlighted one of the criticisms of the patient information day, in that it was seen as only providing a positive view of dialysis. It can also be seen in the quote from patient 2.

'when you ask them a question then you expect it t' be answered ... but they don't. The ... they don't give you any straight answers. They don't ... they don't tell ya how to improve yourself ... they don't tell you how t ... how you're gettin' on ... they don't explain all the different ... all the different things ... calcium, potassium an' ... all the other things that y ... er ... that go wrong wi' ya they ... they ... the just don't ... they don't tell ya anything. So ... outpatients is a complete and utter waste of time' (patient 2)

'Well that would be it. It ... it's being open and free even though you may think that people might go ... upset by it but in the end you're being kind to them. I ... I tell you now you're being kind to them because I would not have eye trouble er ... diabetes trouble or whatever er ... well diabetes is ... is ... trouble and it gets worse and worse I know that ... but a lot of the things that I was doing wrong in those days ... those early days I could have stopped doing. If



somebody had took me in a room somewhere and gave me the ... if you like er ... the bollocking of my life. Said now, “Look <name> you're in this position because of ... you're doing this, you're doing that, you shouldn't be doing this, you shouldn't be doing that, you're abusing your body, you're ... you're working seven days a week, you're working 'til ten o'clock at night, sometimes through the night, you are racking up your body ... your body is going to react, it's going to rebel”. And it did.’ (patient 13)

It emerged from some interviews that the language used by clinicians in consultations was perhaps too technical and that there was little explanation of some of the key terms that are discussed regularly. Certainly within the interviews very few patients used the correct words for common biochemical markers such as creatinine, potassium and haemoglobin and several patients didn't know the word fistula.

‘I say if ... if people could be told in detail a lot more what's happening as regards bloods er ... because I can't even remember the names of the different things they get from blood. All I can think of is haemoglobin ... is it ... is it haemoglobin?’ (patient 9)

**7.5.4 Information related barriers**

I have drawn together much of what has been discussed in this section into a table which highlights several barriers to information access and exchange which were identified in the interviews (Table 7.2). Generally barriers fell into three broad categories; practical barriers, interactional barriers and barriers internal to the patient. All categories contain barriers that prevent patients from seeking further information, such as the lack of computer access, or not wanting to impose on others by asking them to access information. Also across the practical and interactional categories there were barriers that were imposed by our current system, such as the reliance on information leaflets that are not suitable for all learning types, and the technical language used during consultations.

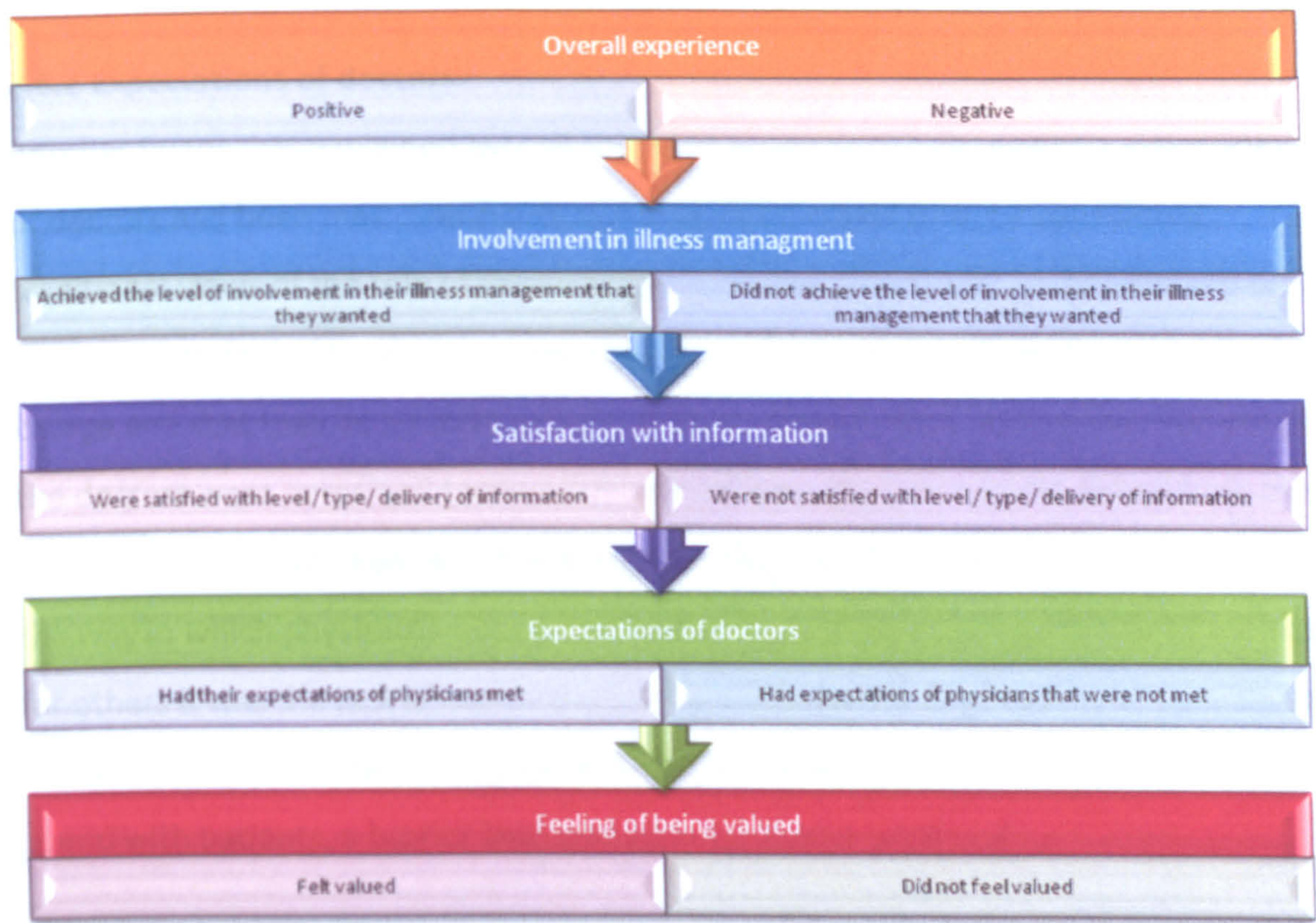
Table 7.2 Barriers to information access, exchange and action		
Practical barriers	Interactional barriers	Internal barriers
<ul style="list-style-type: none"> <li>• Lack of computer access</li> <li>• Lack of computer skills</li> <li>• Inability to access library independently</li> <li>• Lack of technical and medical knowledge needed to interpret texts</li> <li>• Written information not appropriate for all</li> <li>• Lack of time</li> </ul>	<ul style="list-style-type: none"> <li>• Generic / impersonal information</li> <li>• Unrealistic / unachievable advice</li> <li>• Communication style – heavy, unsympathetic</li> <li>• Lack of continuity of care</li> <li>• Technical language</li> <li>• Clinic stressful - too much to take in</li> <li>• Lack of follow-up and chance to ask questions</li> </ul>	<ul style="list-style-type: none"> <li>• Not wanting to impose on others to ask for help to access information</li> <li>• Too shy to speak up in front of a crowd to ask questions at patient information day</li> <li>• Not wanting to know</li> </ul>

**7.6 Overall satisfaction with predialysis experience (Figure 7.2)**

As the analysis progressed it emerged that patients could broadly be split into two groups. Approximately half of the patients were, on the whole satisfied with the level, type and delivery of information that they received, while almost half were not. The factors related to satisfaction with information have been discussed earlier and this was, in turn, related to whether people were satisfied overall with the level of support that they received during this time, including emotional support. Furthermore, it emerged that there were some common elements to patients’ experiences that seemed to determine their overall satisfaction with information and support, indeed their whole predialysis experience. The first major element was whether or not the patients achieved their desired level of involvement in their illness and illness management. The second was whether patients’ expectations of doctors were met. Satisfaction with information, level of involvement in illness management, and expectations of physicians all combined to produce a feeling of being valued overall by the system which was the final factor identified as being related to satisfaction with predialysis care.



Figure 7.2 Common elements that determined a positive or negative predialysis experience



7.6.1 Level of involvement with illness management

Patients within the sample varied in the level of involvement in their illness management that they wanted, and that they had achieved. Some patients, such as patient 20, emphasised the importance of feeling in control. She described a strong level of involvement with those decisions regarding her condition that she was happy with. Other patients were equally satisfied to have a much lower level of involvement with their illness management, following the instructions of the health care professionals and not necessarily wanting to participate in decisions to a great extent.

On the other hand, there were patients who have already been quoted who describe that they would have liked to have had more personal input into controlling their condition and those who would have liked more input from the health care professionals regarding their management, particularly when making decisions about dialysis options. Whatever the level of involvement that patients desired, it appeared



to be strongly related to their overall satisfaction, or dissatisfaction, with their predialysis care experience.

### **7.6.2 Expectations of doctors**

Another factor that explained overall satisfaction was whether patient's expectations of doctors had been met. Some patients expressed what could be considered traditional views of the role of doctors, that is doctors as experts, and bestowed on them a great deal of trust. For some, their expectation was that doctors were in charge and that they as patients would listen and follow the advice given. For others the doctors were perceived to have not shared their expertise to the extent that the patients would have liked, which led to dissatisfaction. For some this was manifest in the way in which physicians were perceived to have deliberately withheld information, for others it was the lack of explanations and the passivity displayed by the physicians. For yet others there was frustration that the physicians simply didn't have the time to spend with patients, a barrier that many patients were aware of.

### **7.6.3 Feeling valued**

The final element that was related to satisfaction is slightly more abstract. Patients who were largely satisfied had, on the whole, expressed sentiments that gave an impression that they felt valued by health care professionals, while the opposite was true of patients who were not satisfied with their predialysis experience. Examples that illustrate these feelings were found in sections 7.3.1.2 where patients gave the distinct impression that they did not feel valued when discussing the nature of clinic appointments. On the other hand examples of patients feeling valued are particularly apparent in section 7.3.2 when discussing the home care team.

## **7.7 Conclusion**

This chapter has presented the findings from the interview with patients carried out during phase two of this research study. Key areas of the current system were discussed in relation to the clinic appointments, home care team and the patient information day. In particular, the impersonal nature of clinic appointments emerged.



The home care team are largely held in high regard, and an important benefit of the patient information day appears to be the opportunity for peer support. The major themes to emerge from the interviews were the roles of acceptance and information. Barriers to and facilitators of acceptance were presented, highlighting the varying role that time plays, with some patients requiring more than others to reach a level of acceptance conducive to dialysis preparation. This analysis has shown the reliance of patients on health care professionals for information.

The timeliness of information delivery was important, and some patients felt that they had not been given full information. Three patient types were identified regarding information related behaviour; these were active internal, active external and passive. While some patients were satisfied with the level of information opportunities, many others were not. Overall level of satisfaction with information was one of the key factors associated with whether patients had an overall positive or negative predialysis experience. Other factors included whether they had achieved the level of input into their illness management that they would have liked, whether their expectations of physicians were met and whether on the whole they felt valued by the system. The following chapter will discuss and place these findings in relation to research in both kidney disease and other illnesses.

# CHAPTER 8

## Discussion of the findings from patient interviews

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### 8.1 Introduction

This chapter provides a summary of the main findings of the patient interviews carried out in phase two of this research study, and sets them in the context of what is already known in relation to chronic kidney disease and other areas by comparing the relevant literature. Areas where this study can add improve understanding of the predialysis experience and urgency of dialysis start will be highlighted.

### 8.2 Summary of principle findings

The analysis showed that the findings could broadly be grouped into three main clusters: experiences of renal service provision, experience of having chronic kidney disease, and understanding the patient experience. The first cluster of findings highlights the importance that clinic appointments hold for many patients as they described the emotional involvement they felt prior to, during, and after the event. Also evident was the ambivalence towards the appointments expressed by others. The appointments were described as largely task driven and often impersonal. The overriding impression many people gave was that they felt shunted between staff, and that there was a rush to get them in and out of the surgery. There was also a sense that the consultations were centred very much around the blood results and medication. Therefore, a more personal, perhaps holistic approach would have been welcomed.

The role of the home care team members was seen principally as provision of information. They were valued by patients due to the time the nurses were able to spend with the patients and family members, and for the reassurance and encouragement that they were able to provide. In essence they were seen to provide a more personal, intimate service than physicians. They were also seen as a point of



contact, a link between the patient and the hospital, which was important for some patients. In addition, the home visits and perseverance of one team member in particular served to drive home the importance and severity of their illness for some patients with a history of non-attendance.

The patient information day was a useful experience for many patients as they were able to learn about dialysis options. However, it also provided an opportunity for emotional support for patients, many of whom benefited from being among other patients with the same condition who were going through a similar process. Criticisms of the day were that it was too long, there were too many people, and that there was a lack of reiteration.

The second cluster of results highlights the experience of having kidney disease. The impact of receiving the diagnosis of CKD was felt strongly by all participants, with almost everyone mentioning the shock and impact the diagnosis had on them, and exposing the inadequate support offered by the health care service at this time. Many patients equated the diagnosis of CKD with death. Symptoms varied with some patients describing an ever worsening experience, displaying a strong illness trajectory. Others were aware of this illness trajectory only with the benefit of hindsight now they were on dialysis, whilst some did not recognise worsening symptoms of CKD at all during the predialysis phase. These experiences reflected whether patients experienced benefits from dialysis or not. Body consciousness and intrusiveness were the two main factors determining the choice of dialysis modality in patients who had a choice. Some patients found the experience of choosing between dialysis modalities very difficult and would have liked more professional input and guidance on the decision.

The third cluster of findings helps us to understand the main factors that may impact on a patient's experience of having kidney disease and being a patient within our kidney care system, and could, possibly, influence urgency of dialysis initiation.

Acceptance of having CKD, of needing dialysis, and of the timing of dialysis initiation emerged as a strong theme, with barriers and facilitators to acceptance identified.

The pivotal role of information on the whole experience was evident. The majority of patients relied heavily on health care professionals for their information needs, yet very often these needs were not being met. Barriers were identified to information access, acquisition and exchange. Patient typologies emerged to categorise information related behaviour. These were active internal, (patients who sought and engaged in information exchange within the health care environment), active external, (those patients who sought information elsewhere), and passive; (patients who did not seem to engage in the information exchange or appear interested in learning more about their condition and treatment).

### **8.3 Limitations and strengths**

The main limitation of this study is that, due to time constraints, the sample was limited to twenty patients. At first this had seemed adequate, however in-depth analysis of the final interviews revealed some new themes that could have been explored with other young south Asian patients. However, this was not possible.

My nursing background could present as both a strength and a limitation. The home care team (nurses) were highly regarded by the patients I spoke to and attracted no criticism whatsoever. I cannot rule out that patients were perhaps reluctant to criticise nurses in front of me, although I didn't get that impression whilst carrying out the interviews. On the other hand, having a nursing background certainly proved useful in establishing rapport with patients and health care professionals and being able to interpret patients' stories and symptoms.

Seven out of the twenty patients also had diabetes. Although there was no obvious effect discernable from the analysis, it must be acknowledged that there could have been factors relating to their inevitable increased prior interactions with the health care services that could have influenced their experiences.



## **8.4 What does this study add to previous research?**

### **8.4.1.1 Information - satisfaction and behaviours**

Some of the issues raised surrounding information and education needs have been raised elsewhere within the renal literature. In a small study reported in 1998 assessing effectiveness of information for predialysis patients, Wilkinson found that patients were satisfied with information given to them, yet that there was a lack of follow-up in terms of time for discussion (Wilkinson 1998). Five areas where patients would have liked improvements in information provision were identified and three of those mirror points from this study. These were that patients would like more social support and advice, the opportunity to meet other people on dialysis and the provision of more time to discuss problems. This ties in with the benefits that patients in the current study associated with meeting with and talking to other patients and the value they placed on having time to discuss problems. In a study specifically examining patients' predialysis experiences, one of the eight themes that emerged was information, with the finding that patients needed more information during the predialysis stage (Andrew 2001)

The information related behaviours identified showed that patients were either passive internal, active internal or active external with the majority of patients belonging in the first two categories. This study also showed that many patients did not have to make a decision about treatment choice and that of those who did, some would have liked more input in terms of guidance from health care professionals. Furthermore, satisfaction with the level of information and education received is one of the variables found to be important in overall satisfaction with predialysis care experience. The relationship between information related behaviour and decision making preferences is complex and will be touched on here, and in Chapters 11 and 12.

In a study examining women undergoing colposcopy, Barsevick & Johnson (Barsevick and Johnson 1990) sought to explain the association with information seeking

behaviour, involvement and emotional responses. They found that women who asked questions or requested written information about the forthcoming procedure did not always have a preference for involvement in health care, although women who requested information report greater confidence immediately following their clinic visits. Johnson et al reported a similar finding in their study involving patients newly diagnosed with breast cancer who had recently undergone surgery. The authors found that while 80% of women wanted a role in decision making regarding treatment options, 74% wanted their surgeon to make a recommendation with 94% following the recommendation when given. In contrast to the previous study, the authors found that younger people in particular were more likely to want the recommendation of their physician (Johnson, Roberts et al. 1996).

This suggests that even though many patients want to be informed of treatment options and forthcoming events, they do not necessarily want to make treatment decisions independently. According to Hashimoto and Fukuhara this may be explained by individuals' health locus of control. Their study revealed that in patients who depend less on others for their own health (ie have a high internal locus of control), active information seekers are likely to be active decision makers. However, for patients who depend on others, or external sources, for health control, the preference for information was not related to decision preferences (Hashimoto and Fukuhara 2004). Burker et al discovered that patients undergoing lung transplantation survived longer if they had a high to medium level of internal locus of control (Burker, Evon et al. 2005).

Patients' information seeking behaviours have been defined elsewhere, as coping strategies, with patients falling into two categories (Shiloh and Orgler-Shoob 2006). 'Monitors', who display cognitive confrontation are vigilant information seekers who focus on and magnify the threat that they face, whereas 'blunters' display cognitive avoidance and are more likely to avoid thinking about the problem in detail by distracting themselves. According to Shiloh and Orgler-Shoob, monitoring is motivated by the need to minimize uncertainty, gain control over the threat and use



the warning time to prepare responses that might reduce the impact of the threat. They also found that information-seeking preferences were predicted by the perceived function of information (Shiloh and Orgler-Shoob 2006). Monitoring, or high information seeking was found to be a counterproductive method of coping in some populations as stress levels increase without resolution of the problem (Miller, Rodolletz et al. 1996).

In a recent editorial Wissow points out that our understanding of the role of emotional states in the information seeking and assimilation process is increasing through recent developments in neuroscience. He suggests that the area of the brain that is responsible for weighing up the importance of incoming information appears to have regions that respond to various factors such as the degree of specificity or vagueness, the level of associated probability and the temporal nature, or the timing of the possible event under discussion. Therefore, he concludes,

‘we are wired to respond more strongly to things that will happen sooner, to information that is more specific, or that implies events of higher probability...information that is novel and that in addition has this type of content has the potential to overcome a current mood state and open up the possibility of a change in thinking’ (Wissow 2007).

The implications of this are relevant to this study, as it highlights the need for information and education to be relevant, or individualised, something that some patients highlighted as currently lacking.

#### **8.4.1.2 Information sources**

The vast majority of patients in this study sought information only within the context of the health care system. This finding is reflected in a large study involving 800 patients, in which James et al found that only 5% of patients with cancer sought information from the internet and that overwhelmingly patients wanted hospital doctors to act as the source of information regarding their health condition (James,

Daniels et al. 2007). The hospital doctor was the most commonly used source of information (96%) followed by leaflets (56%), family (49%), then nurses (49%). Similarly, Friis et al, who examined information seeking behaviour in patients with acute myeloid leukaemia, discovered that many patients want to receive information only from their specialist physician, and that this was more obvious in older patients (Friis, Elvedam et al. 2003). In the study by James above, internet use was more predominant in younger patients, although still only 25% of patients under the age of 30 used the internet to seek information about their cancer. Although the current study did not identify age as a factor in determining information related behaviour, the median age of patients interviewed was 62 years, reflecting the age of patients approaching RRT. Friis et al also highlighted that patients who did not want or seek additional information explained their actions as a coping strategy to maintain hope, something which could be applicable across other health states.

#### **8.4.1.3 Information and truth-telling**

Winterbottom et al evaluated the quality of patient leaflets about renal replacement therapy in UK renal units and found that most leaflets were difficult to understand. They also found that there was no mention of risk factors in most leaflets and that few contained any tools for aiding decision making (Winterbottom, Connor et al. 2007). Given the reliance of patients on information leaflets as their second most commonly used source, this has major implications. However, these findings also reflect the issues that a few patients raised in this study regarding truth-telling in relation to risks of therapies and side-effects (sections 7.3.3 and 7.5.3).

#### **8.4.1.4 Timing of information**

One of the findings of this study was that the timing of information is important. The benefits of the gradual build up of information emerged, alongside the frustration of patients who perceived that they did not receive the right information at the right time. In particular, there was an emphasis on receiving information from the time of diagnosis all the way through to starting on dialysis and beyond to reflect the changing nature of chronic kidney disease. In a recent report from the Picker Institute, Swain



et al state that 'the timing of information provision is almost as important as the information itself' (Swain, Ellins et al. 2007). The findings from their focus group study of patients with different health care needs marry well with the findings from my study as they report that patients' needs change over time. One participant with diabetes spoke about having received cursory information about the illness during a quick chat on the day s/he received the diagnosis, yet couldn't remember anything that was said due to the shock of being diagnosed. This highlights not only the necessity to support patients during what is undeniably an emotional time around diagnosis of chronic illness, but also the need to introduce information and education at the appropriate time.

#### **8.4.2 Acceptance**

Acceptance of having kidney disease and the need for dialysis was a major theme emerging from my interviews. Andrew also found that acceptance emerged as a strong theme in her study of predialysis patients, and as was shown in this study, she reported that it was something that only came with the passage of time (Andrew 2001). Acceptance in this study was a term used to identify the state that patients seemed to reach, or not, in terms of realising their condition, living with it, and preparing for dialysis. In this sense it mirrors the definition given by the Oxford English Dictionary which defines acceptance as: a willingness to accept (conditions, a circumstance etc). However, that definition suggests a passivity, which does not fully encompass the meaning, and complexity, of acceptance that I found in this study.

Acceptance first came to prominence in the late 1960s, early 1970s. In her work on death and dying, Kubler-Ross (Kubler-Ross 1973) identified five stages of adjustment to dying; denial, anger, bargaining, depression and acceptance. Acceptance was defined as the last stage, in which patients are no longer depressed, but feel a quiet calm and readiness for death. Although it is possible to speculate that patients with CKD perhaps go through similar stages as they adjust to their chronic condition and the life changes it may bring (Lappin 2007), the linear nature of adjustment was not always found in this study, nor was the notion that acceptance equates to calm and

readiness. While for some patients this may be the case, for others acceptance was an active process, a means of taking control, while for others acceptance centred more around acknowledging limitations and adjusting their lives and activities accordingly.

Within the health literature, acceptance has been most widely discussed in relation to pain and pain management. There the meaning of acceptance is viewed quite differently. According to McCracken et al, acceptance is 'willingness to experience pain without attempts to control it, and as persisting with healthy activities while pain is present, but doing so in a manner that is free from influences of pain itself' (McCracken, Vowles et al. 2007). In a study comparing patients who use control orientated responses to chronic pain, such as the use of analgesics and withdrawal from activity, acceptance based responses lead to continuing better quality activity and emotional functioning over time. In other words, attempts to change or eliminate pain or other experiences that come with it are less useful than acceptance responses in terms of adjustment to chronic pain. In some ways this appears counter-intuitive, as health care professionals have taught control responses for many years, but in the light of inevitable pain, trying to control it can lead to increased failure, frustration and hyper-vigilance, perpetuating feelings of lack of control and despair.

Van Damme and colleagues examined the role of acceptance of chronic fatigue syndrome. In this paper they highlighted the complexity of acceptance, and defined it as 'halting the dominant search for a definitive solution of physical complaints and as a reorientation of attention towards positive every day activities and other aspects of life' (Van Damme, Crombez et al. 2006). They found that acceptance involves re-evaluation of personal goals, values and life priorities, and that acceptance was associated with an increase in physical and psychological health status.

Health locus of control appears again, this time in a paper examining acceptance of chronic illness in people with psoriasis vulgaris. The authors conclude that increasing



internal health locus of control and enhancing feelings of optimism lead to greater acceptance (Zalewska, Miniszewska et al. 2007).

Could the same be true of chronic kidney disease? Could it be that some of the patients who had achieved what I termed acceptance have learned their limitations and accepted their condition without resentment while continuing to pursue life as well as possible? This study does not answer these questions, but this may be an avenue worthy of further exploration.

### **8.5 What does this study add?**

The interviews with patients from phase 2 of this study have identified some key areas that increase our understanding of what it is like to have chronic kidney disease and how individual experiences could be enhanced. These findings highlight that information needs, and related behaviour, differ between patients. This suggests that a more personalised, individualistic approach to care may be necessary. The promotion of acceptance is worthy of further exploration as this seems to be crucial in terms of wellbeing and satisfaction prior to dialysis, and clearly could have an impact on patients' preparation for dialysis. Psychological approaches to acceptance warrant further investigation.

# CHAPTER 9

## Findings from health care professional interviews

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### 9.1 Introduction

This chapter presents findings of the interviews with health care professionals carried out during phase two of this research study. Initial open coding, as described previously, led to the creation of a coding frame with main and subcategories which can be found in Appendix 9. The main categories that emerged from the data were:

- Patient characteristics
- Medical
- Organisation and system
- Health care professional related factors
- External
- Decision making
- Information
- Roles and responsibilities

A framework was produced based on the coding frame with each of the categories represented by a separate framework chart. Interview data were then charted into the framework. An example of a chart can be found in Appendix 10. Progressive focussing revealed that the overarching theme to emerge from the interviews was allocation of responsibility for elective or urgent dialysis initiation. Three broad categories within this were: Physician/Nurse, Patient, and 'Other', the latter largely related to the role of the system as a whole in preparing patients for dialysis and to medical reasons, in other words factors outside the control of patients and health care professionals. This chapter describes the sample of interviewees before going on to discuss the findings within each of these broad categories. Barriers to fulfilment of

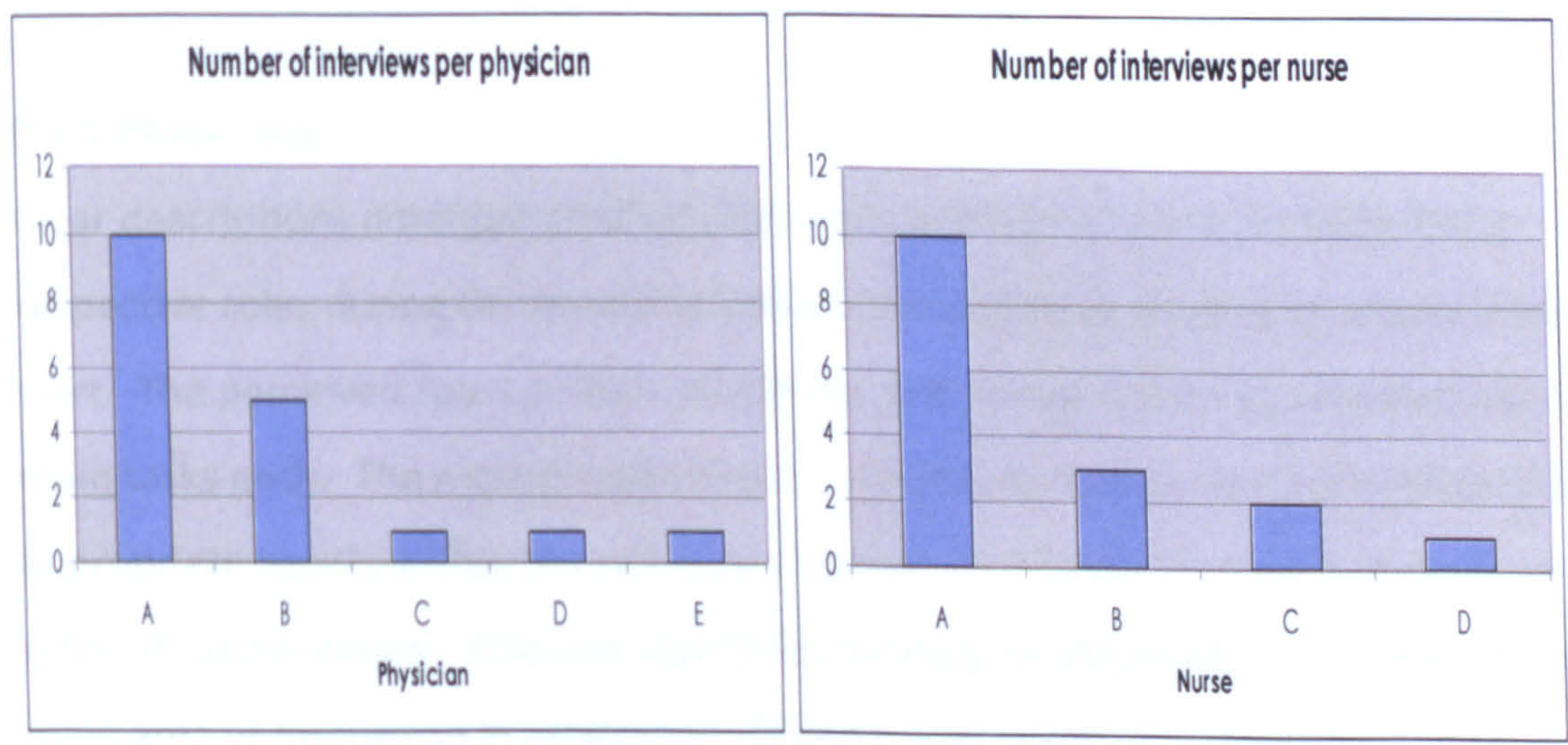


roles are also detailed. The chapter ends by showing how health care professionals view information and education. Where relevant, quotes are shown from both physician and nurses to display the similarity between the two groups of health care professionals. As with all interviewees for this study, confidentiality and anonymity are preserved at all times. To this end nurses and physicians are referred to as being female despite being from mixed sex teams.

## 9.2 Description of sample

There was a possibility, based on 20 patients having been interviewed, of obtaining 40 interviews; 20 nurses and 20 physicians. One physician and one nurse interview are missing due to unavailability and two nurse interviews are missing because the patient had not seen a nurse for predialysis care. In total 36 interviews took place with four nurses and five physicians participating in 17 and 19 interviews respectively. Two interviews were unusable due to a technical problem prior to transcription, one each with a physician and a nurse, leaving 34 available for analysis. Figure 9.1 shows the number of interviews included in the study undertaken with each health care professional.

**Figure 9.1 Number of interviews carried out with each health care professional**



The final interviews I carried out with health care professionals related to patient KA14. The coding and information from these two interviews was quite different in many ways to previous interviews. For this reason I have not included the analysis of



these interviews in these results as they will be discussed in greater depth as a case study in chapter 11.

### **9.3 Roles and responsibilities**

Urgent dialysis initiation is seen universally as a failure, with the purpose of this study being to understand why this happens. It is perhaps not surprising then that the main theme to emerge from the interviews was the allocation of responsibility for urgent or elective dialysis initiation. Responsibility in terms of physicians, nurses and patients is linked strongly to the roles that physicians and nurses perceive for each group.

Success, in terms of elective dialysis initiation, seems to depend largely on all parties involved fulfilling the expected role, as well as other factors, mainly relating to the components of 'the system' falling into place. Medical reasons for urgent dialysis start may sometimes override all others so that despite all parties carrying out their perceived roles adequately urgent start is sometimes seen as inevitable. An urgent start may not be preventable where there is rapid progression of kidney failure or intercurrent illness. Certain patient characteristics emerged that suggested that patients are seen broadly as good or bad patients. The following three sections will focus on the perceived roles of physicians, nurses and patients and how these affect perceptions of responsibility.

#### **9.3.1 Physicians**

Clear descriptions emerged of what physicians and nurses perceive to be their respective roles during the predialysis phase in relation to elective or urgent dialysis start. The perceived roles of both physicians and nurses can be generalised into two main tasks each. The main physician task is to ensure that patients are referred to the appropriate agents within the renal care system in a timely manner and to chase up referrals as necessary. This was identified strongly by physicians and nurses alike. The main area of discussion in relation to referrals was regarding timing of referral for dialysis access, be it vascular access for a fistula or access in terms of a peritoneal dialysis catheter. Secondary areas included referral to the home care team and referral for transplantation. Typical examples of how these roles were expressed can



be found in the quotes below in response to a question about whether the health care practitioner would have done anything differently for each patient:

‘if we had anticipated I suppose back in June that he was gonna be on dialysis in January then possibly we could have moved things more quickly with his ... his vascular access. Erm .. and indeed he's still n ... er ... waiting now for a ... for a fistula or he's on the waiting list’ (physician A)

‘We had that ... well I mean she came to us and from the day the first day I saw her she was referred for a transplant work up, referred for fistula ... referred for everything so we had her starting the first day I saw her’ (physician B)

‘No I mean he was active on the transplant list. He had a fistula...he started dialysis electively. We had his biochemistry and his haemoglobin controlled as well as we could ... so I don’t think there was anything really that we could have should have done differently’ (physician B)

The second physician task which was not described so clearly was to maintain some contact with patients who have missed appointments and to communicate results following clinic visits.

‘Erm ... well he had not attended at least three appointments as I can see from his notes and erm ... I'm not sure if I had written t' him in that time ... normally I would've ... I would've done so but erm ... and then eventually I get a call...from his GP asking for him t' be seen urgently. I did write to him in November two thousand and four encouraging him to keep appointments ... although I didn’t actually give him any further follow-up appointments at that time ... sort of passed it through to the General Practitioner’ (physician A)

During the course of the interviews, few physicians suggested that they would have acted differently with the benefit of hindsight. Of those that did, the focus was largely

on referring people earlier as can be seen above. One physician did reflect a little more on her practice and occasionally suggested other actions he could have taken as shown below, however this level of reflection was not typical.

‘Yes. I mean I'm ... don't get me wrong I'm not gonna flagellate myself too much about this but you know it's ... it's part of reflection in a way of what else could you have done and I suppose you know when his wife did say to me at one point on the phone, "Well why didn't you give him an earlier appointment instead of just sending him a three month appointment?" which at one point I think you know I did do because he'd missed five appointments, I thought, "Well I'm just you know ... fed up with this really you know". Erm ... but it probably is a ... it was a sign that I was just fed up with it which ... you know is probably not really an acceptable outcome really ... an acceptable position to ... to take really for someone like that.’ (physician A)

### 9.3.2 Nurses

The perceived nursing role in the predialysis phase appeared quite limited and was seen primarily to be to provide information on the various forms of dialysis in order to help patients to choose the type of dialysis that they would like to start on.

‘he'd made up his mind that haemodialysis was ... was for him as well. He'd already thought ... he looked at the information I gave him ... we gave him some written information, some er ... treatment option booklets er ... and he ... from an early stage he had a good idea of what he was gonna go for so ... that worked out quite well for him I think’ (nurse A)

‘... she'd been seen by the homecare team in er ... so a month after coming she'd been seen t ... in the homecare team and I'd seen her er ...she also insisted on having dialysis...but it was a matter of what type of dialysis and er ... her function was relatively stable and she was due to see the dialysis counselling team again and then...I don't know that she'd necessarily been



seen by the homecare team in between times for a definitive decision but we certainly hadn't referred her' (physician B)

The second perceived nursing role was to act as a point of contact for patients and their families as shown below

'I don't mind that for some patients I do say, "Look ring me, leave me a message I'll ring you back", if it's a ... a particular issue. They don't always ring ... not all patients ring. I'm quite happy to do that 'cos they don't always ring sometimes they're usually happy with the information but if it is a ... if it is something important and they do need to ring you then I think they need some point of contact really so ...(nurse A)

It emerged that not all patients are encouraged to contact the nurse. Nurse A describes how the nurse contact phone number is given only to some patients as opposed to others and attempts to rationalise why this was the case during discussion.

'you're the first point of contact... it's the control thing isn't it, 'cos there's a lot of people out there so it's trying to control that caseload and ... and think yeah er ... is this person really needy of me, will they need me ... if they're unsure what to do should they call me you know. So it ... it's er ...I try to judge it, whether I get that right is a different matter but it's ... to try and judge it, trying to give certain people a number, who I think may be are a little bit vulnerable and need that extra ... extra support. But some people will use it all the time you know...' (nurse A)

This illustrates the perceived limits of nurses' responsibilities towards patients; these involved making judgements about patients' needs and balancing that with nursing resources. There were several instances where nurses expressed that they would

have acted differently with the benefit of hindsight. In almost all cases this would have involved them spending more time with the patient.

### 9.3.3 Patients

Health care professionals consistently perceived that the patient's role in the predialysis experience can be broken down into three main tasks: to attend clinic, to 'take information on board' and to reach a decision about dialysis. These points are highlighted below.

'he did sort o' take the information erm ... and I think he did attend clinic reasonably well I think. I think he did come to clinic so erm ... although he was quiet I think he ... he was quiet and thought about the information he was given' (nurse A)

'I would say he was a very quiet erm ... he seemed to you know at all of the appointments he seemed to take in the information that he was given. He was er ... very erm ... amenable to suggestions and that and I would say was well-informed about you know the options and er ... I don't think that there were ever any problems or any concerns that he didn't understand what was happening and I think he was er ... if you like involved in the treatment decisions and made an initial decision probably partly based on our judgement about one form of treatment but you know was quite amenable to change when it became clear that that was gonna be a problem so' (physician A)...

'... if he'd actually come to clinic and we could have controlled his blood pressure but that didn't happen so he didn't have any dietetic input, he didn't have anything during those two years where he'd DNA'd ('did not attend'). Erm ... but if he'd carried on and had a early transfer to the pre-dialysis clinic we may well have been able to get him on the transplant list earlier, he could have had a fistula earlier, he could have had all his dietetic input, if we'd controlled



his blood pressure better he might not even be on dialysis today, we might have delayed his progression to dialysis. It's impossible to say' (physician B)

In addition to these tasks, it emerged that health care professionals perceived it to be the patient's responsibility to ask for additional support, and also that patients should fully disclose information that could be relevant to the outcome of the consultation:

*Researcher:* 'Anything anybody could have done differently for him?'

*Nurse:* 'He didn't ask for anything erm ... so I wasn't prompted to erm ... think about whether he needed you know a dietician involvement or ... not that we've got a social worker but erm ... anybody else might be able to help him. No I don't think so' (nurse B)

*Physician:* 'Well I think he was ... he is erm ... a sort of fairly stoical er ... relatively uncomplaining, possibly minimising you know his symptoms, you know not wanting to make a fuss. Fairly independent, fairly self-sufficient but ...'

*Researcher:* 'How did you find your appointments with him?'

*Physician:* 'Er ... erm ... again I ... I ... you know I would say he always ... they were always reasonably straight forward erm ... he never I think you know made a fuss or ... or complained overmuch er ... and in some ways I think perhaps if he had complained more you know that that would have probably driven us to ... to the issue of dialysis a bit earlier.' (physician B)

#### **9.3.3.1 Perceived patient characteristics**

Several patient characteristics emerged from the interviews that were associated positively and negatively by health care professionals with treatment and outcomes.

Following the analysis it became clear that patients could be loosely categorised as good or bad patients based on these characteristics. The main two characteristics that determined the perception of patients as good or bad to emerge were compliance and intelligence.

Good patients were those who were perceived to be compliant and intelligent as displayed below. Health care professionals clearly saw a connection between the two characteristics, with compliance and intelligence interlinked to suggest that intelligent patients are those that are compliant. In other words, patients were seen as being intelligent because of their perceived compliance. Compliance mainly related to attending clinic appointments and 'doing what s/he was told'. The patient's responsibility in the process was to be good.

'Self-sufficient, compliant ... he was someone who actually did what we asked of him. He'd accepted the need for dialysis and when we'd asked him to have fistulas and when we'd asked him to change his tablets he did it so, he was a very well-motivated patient I think' (physician B)

'... self-sufficient ... she was clearly a clever intelligent person... I think she understood this situation...understood what was required and she thought things through and did what she was told really...' (physician B)

'she was a very bright, intelligent lady, understood everything erm ... that was happening and a very sort of traditional elderly ... well you know elderly-ish lady who erm ... was very keen to comply and help and erm... just a very nice lady' (nurse B)

On the other hand, patients who were described negatively had the opposite characteristics. They were generally seen to be non-compliant, irresponsible and less intelligent as shown below.



'I would say he's a bit foolish and not very responsible...his pattern of behaviour over the years has not been what I would say entirely responsible or ... entirely conducive to good health for him' (physician A)

'He's not the brightest bunny so talking about tablets, you often didn't know whether he was actually taking it and you'd tell him about it once and then he'd forget that he was taking tablets or he'd get them wrong' (physician B)

This shows that the patients were largely expected to take care of their health, and to do as they are asked by health care professionals.

#### **9.3.3.2 Age**

Patient age was mentioned frequently by both doctors and nurses, particularly in relation to the decision to have RRT, and in particular the decision whether to discuss conservative treatment or not.

*Physician:* ' she wasn't a very active lady and we had discussed conservative management because she was very frail and she was eighty ... eighty-one at the time but she ... but she also insisted on having dialysis...

*Researcher:* And just out of interest what ... what tends to go into that thought process ...

*Physician:* 'Well, we would offer the fact that they don't necessarily have to have dialysis ...so for a twenty something year old we wouldn't say you don't have to have dialysis unless there was an obvious reason whereas for an eighty-one year old presenting with advanced renal impairment we would suggest that you know dialysis may not necessarily improve your quality of life' (physician B)

It also emerged that a patient's age may influence how the patient is viewed and treated by the system, with the failure to prepare a younger person somehow viewed as being worse than the failure to prepare an older person.

*Physician:* 'I think I should have made the effort whether that would have altered the outcome I'm ... I'm less certain. I think for a young man like him I think somewhere along that line in between September and the early part of this year I should have phoned him and spoken to him'

*Researcher:* 'Young man meaning that you would give him ... I mean would that have an impact?'

*Physician:* 'Well, I think it does actually. That's a good point, it shouldn't really should it but you know in erm ... you sort of think he's got more to lose in terms of his economic activity you know, the affect on his family erm ... maybe that's a prejudice on my part but erm ... I just sort of envisage that he's got ... as I say he's got more to lose if he ends up unwell er ... in terms of the knock-on effect. Not necessarily on himself but ... you know for forty-four or how old he is ... forty ... if a forty year old man dies of renal failure that's an absolute disaster, if a seventy-eight year old man dies of renal failure and his life expectancy's quite limited anyway you know so ... you know I think, I just do think that (sighs) for the younger patients whose life expectancy is ... you know when he's got no other co-morbid illness you know his life expectancy's actually very good even with dialysis' (physician A)

One health care professional stated that a patient's age may have affected her relationship with the patient because the patient and nurse were of similar age, something which the nurse saw as common ground which helped her to identify with the patient. Although only explicit in one interview, it is possibly implicit in other interviews, as can be seen in the quote above.



From the perspective of patient responsibility, in general all patients are encouraged and expected to participate in decision making. However, older people sometimes have the additional responsibility of addressing the option of conservative treatment.

## **9.4 Other factors perceived to influence urgent dialysis start**

### **9.4.1 Organisation of the system**

The most widely perceived overt barrier to elective dialysis start was delays and limitations within the health care system. Delays were largely in three areas: delays in referral to the renal care system from primary care or from other areas within the hospital, delays in referral within the renal care team, most often from general nephrology clinics to the predialysis clinics, and finally delays relating to access operations, be it delayed referral for access creation or long delays between referral for access creation and having the operation. Two of these factors, the timing of referral to the home care team and delays in the provision of access operations, are illustrated in the quote below:

*Researcher:* 'So what factors do you think played a part in him starting acutely?'

*Nurse:* 'Erm ... probably the timing of the referral ...to us (the home care team) ... well to a certain ... that's not really anybody's fault because he just pitched up... he probably got to a clinic visit and then everything was too late. Dr <name> asked us urgently to go and see him erm ... so everything is just way behind ... way behind schedule so just delays... in referrals to us really.'

*Researcher:* 'is there anything you would have done differently for him do you think?'

*Nurse:* Well, unless we got him earlier I mean I think because of his home circumstances that...getting him in earlier for a fistula would have been good. And may be if we could have got access erm ... you know within two weeks of

me visiting...he may have got three months may be of his fistula being able to mature and possibly may be start with a fistula, that may have been one good thing (Nurse A)

Control was mentioned explicitly less often, however a practical issue regarding control of referring patients for fistula formation was thought by one health care professional to have contributed to a patient having a known acute start as highlighted in the following quote:

*Researcher:* ... what would you have done differently if you could have, if there was anything ...

*Nurse:* 'at one time we were allowed to refer people for fistulas but then they stopped us doing it so I would have referred him there and then if I was able to erm ... but other than that probably nothing really ...' (nurse C)

#### **9.4.2 Medical factors**

There were only two patients whose urgent dialysis start was perceived to be caused by medical factors. Both had other medical conditions that necessitated an admission into hospital and that caused a rapid decline in renal function. One other patient was perceived to have undergone a more rapid decline in renal function than would have been expected, however this was seen as only one reason for his acute dialysis start in combination with other factors.

#### **9.5 Roles in education**

Education appeared to be viewed solely as the provision of information. Information was described almost as a good, or a commodity, something that was given and received. Health care professionals and patients were perceived as playing distinct roles in this process, which was described as a one-way exchange. The role of the health care professionals seemed to be to furnish the patient with information, patients in turn were expected to play a passive role and accept it.



‘he does listen to you and take information that you give him quite readily. Erm ... he ... he's nice, he's friendly erm ... and willing to take advice’ (nurse A)

‘the visits went quite well, they seem to accept what information I gave them, they understood what I was you know ... what our plans were for him and they had a ... a choice as to which kind of treatment he was going to have and ... no they seemed quite ... quite willing to have the information and accept what we said.’ (nurse D)

‘she’d already got quite a lot of information because she was interested, ‘cos I think that always plays a big part if they’re interested then they’ll erm ... they’ll take on the information a lot easier really’ (physician B)

#### **9.6 Barriers to elective dialysis start as perceived by health care professionals**

Barriers to elective dialysis start are suggested throughout this chapter, and have been drawn together in Table 9.1. The main three barriers perceived by health care professionals in relation to fulfilment of their own roles are late referrals to, and within, the renal care system, lack of time and lack of control over events.

*Researcher:* ‘What do you think we can learn from him then and what happened with him?’

*Physician:* ‘Well I ... I think er ... not to give up is what I think. Not to ... I mean there's a balance there, isn't there?, because you're ... at the end of the day you (sighs) ... you've only a certain amount of time and you're trying to distribute that time equally over a number of patients and sometimes you make judgements or choices about you're not going to pursue that any more or you're not gonna make the ... take the time to make the phone calls which are ... you know are more time-consuming than writing a letter ... you can dictate a letter in twenty seconds and that goes off, someone else does all the

work but if you phone someone up you know you can be ... it's quite time-consuming ... you can be fifteen, twenty minutes on the phone call quite easily' (physician A)

'that's part and parcel of establishing that relationship isn't it ... getting a good erm ... you know assessing them well just getting them to, you know, to talk to them on a friendly basis. Erm ... and that takes time really doesn't it? You know sometimes I think when they're in an' out o' clinic quickly you know the doctors don't have too much time ... it's sometimes nice just to give them that little bit of extra time so if they do have a question or explore some of the problems that they have you can just give them that hand so...' (nurse A)

**Table. 9.1 Summary of health professionals’ perceptions of expectations/roles played in predialysis care and barriers to fulfilment**

Components	Perceived expectation / role(s)	Perceived barriers
Physician	<ul style="list-style-type: none"> <li>• Ensure timely referral within the renal team and for dialysis access</li> <li>• Maintain contact with patients</li> </ul>	<ul style="list-style-type: none"> <li>• Late referral from within and outside renal care system</li> <li>• Lack of time</li> </ul>
Nurse	<ul style="list-style-type: none"> <li>• Provide information / educate patients on RRT options</li> <li>• Act as a point of contact for some patients</li> </ul>	<ul style="list-style-type: none"> <li>• Late referral from within and outside the renal care system</li> <li>• Lack of time</li> <li>• Patient unwilling/unable to take information</li> </ul>
Patient	<ul style="list-style-type: none"> <li>• Attend appointments</li> <li>• Compliance with instructions</li> <li>• Take on board information</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of intelligence</li> <li>• Being irresponsible</li> </ul>
The system	<ul style="list-style-type: none"> <li>• Respond quickly to referrals</li> <li>• Works together to ensure access is placed before required</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of flexibility</li> <li>• Slow to respond</li> </ul>
Medical/physical	<ul style="list-style-type: none"> <li>• Rate of decline in renal function as expected allowing adequate, and appropriate, time for preparation for RRT</li> </ul>	<ul style="list-style-type: none"> <li>• Rate of decline faster or slower than predicted</li> <li>• Intercurrent illness</li> <li>• Comorbidity</li> </ul>



## **9.7 Conclusion**

This chapter has presented the main findings from the interviews carried out with health care professionals. Roles and responsibilities of all participants have been identified, as have the barriers perceived to impact on carrying out those roles. The perception of education as simply the provision of information in a one way exchange has also been highlighted. The following chapter will provide a discussion of these findings.

# CHAPTER 10

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## Discussion of the findings from interviews with health care professionals

### 10.1 Introduction

This chapter provides a summary of the main results of the 34 interviews carried out with nine health care professionals during the second phase of this research study, followed by a discussion of the findings.

### 10.2 Summary of principle findings

In contrast to patients, who did not recognise the distinction between having an elective or known acute start, it was clear that health care professionals were very aware of the desirability of an elective start and viewed known acute dialysis initiation as a failure. In general, it emerged that health care professionals ascribed roles and responsibilities to themselves and patients. They viewed the failure of known acute dialysis initiation as a result of roles being unfulfilled, system failure, or an unavoidable medical problem.

The perceived role of the physician centred around ensuring that patients were referred to the appropriate agents within the renal care system in a timely manner, and maintaining some contact with patients following on from clinic appointments or when clinic visits were missed. The perception seemed to be that responsibilities were fulfilled if they ensured timely referrals, chased up those referrals if appropriate, and made some effort to follow up patients who did not attend. In addition, the perception was that they, the physicians, held expert knowledge which patients were expected to acknowledge through their health related actions.

The perceived role of the nurse was limited mainly to provision of information regarding RRT options. The health care professionals viewed this provision of



information as vital in assisting patients to make choices about RRT. However, their responsibility was regarded as being largely limited to providing the information and allowing patients to make the decision when there were no clear medical or social contraindications to either type of RRT. The other role identified was for nurses to act as a contact point for some patients, although this responsibility did not extend to all patients, with nurses rationing their resources according to their professional judgement of patient need.

Health care professionals largely expected patients to comply. This seemed to be measured by whether or not patients attended appointments and adhered to advice regarding medication. Patients were also expected to make the decision regarding RRT with the support available. Additionally patients were expected to ask for additional assistance and disclose information regarding their condition during consultations. Compliance featured heavily when discussing patients and it appeared that health care professionals thought that compliant patients were less likely to have an urgent start. It emerged that patients could largely be classified as good or bad patients with compliance being the definitive factor. Health care professionals broadly associated compliance with higher intelligence, and non-compliance with lesser intelligence.

The system as a whole was seen to be responsible for many patients starting on dialysis urgently, particularly if patients are referred late from outside the renal care system. Waiting times for fistula assessment and formation were often thought to be to blame, at least in part, for urgent dialysis. Health care professionals highlighted that medical reasons, related both to intercurrent illness or to comorbidities, may play a role in urgent dialysis start and that, when faced with these problems, there is little that can be done to prevent emergency dialysis.

### **10.3 Limitations and strengths**

There are two potential limitations to this part of the study. The first is the repeated interviewing of several of the health care professionals and the second is the influence that my professional background could have had on the interviewees.

#### **10.3.1 Repeated interviewing**

Interviewing the same person several times, albeit about different patients, means that the sample of health care professionals was very small at only nine, and that the majority of the interviews took place with one nurse and one physician (see Table 9.1). Therefore, these results are heavily influenced by the experiences and opinions of these two members of staff. There has been little research on repeat interviewing; however, my impression is that it produces two effects. First, the interviewees become familiar with the general format of the interview and anticipate the questions, something which could affect the spontaneity of the responses. On the other hand, as I and the interviewees became more familiar with each other there was often more off-topic interaction. In particular references to cases that had already been discussed increased as those previous cases were used to contrast the current case under discussion. Therefore, an ongoing relationship was established between myself and the interviewees. Specific examination of the effect of repeat interviewing in this type of study was not within the scope of this research, but was identified as a potential area for consideration and exploration in the future.

#### **10.3.2 Peer interviewing**

While it is widely reported that when health care professionals interview patients there is an imbalance of power, (Mason 1996; Holloway and Wheeler 2002) less is known about the influence of health care professionals interviewing each other. I was entering the interview situation with a dual background, that of a nurse and a researcher, and my status may have had an effect on the interview data generated.

Holloway and Wheeler (Holloway and Wheeler 2002) discuss the role of the nurse researcher in peer interviews and suggest that there are both advantages and



disadvantages. The main advantage is the shared language and background that can facilitate understanding of often complex concepts.

Chew-Graham studied the effect of general practitioner researchers interviewing fellow general practitioners and found that the researchers' professional identity had a strong influence on the data provided (Chew-Graham, May et al. 2002). For example, where general practitioners knew the interviewer it was easier to gain access to the sample. Furthermore, when interviewees recognise the similar professional background, the interviews provided richer and deeper data containing more personal accounts and data relating to attitudes and shared professional values (Chew-Graham, May et al. 2002). Coar and Sim found a similar influence associated with peer interviewing in their study of general practitioners who had been interviewed by fellow general practitioners. Additionally, many interviewees viewed the interview as a form of test and were keen to perform well under the perceived professional scrutiny (Coar and Sim 2006). However, in addition to potential disadvantages of peer interviewing of health professionals, these authors also suggest advantages such as the commonality of the shared technical language and professional status that gives rise to a greater depth of knowledge. They also point out, however, that other variables are at play, such as perceived seniority in the professional hierarchy which could influence the nature of the interviews.

I found myself in a relatively unusual position. While I have a nursing background, I had no prior experience of working in the field of renal medicine. Similarly I had not worked within Leicester before starting this research, so I had not met any of the interview participants in a professional capacity before entering the department as a researcher. Furthermore, I interviewed my own peer group, nurses, and the most senior clinical group, consultants. I think that the unfamiliarity with which I approached the subject was advantageous. As Murphy and Dingwall point out:

'by approaching a setting as an outsider, as someone who does not immediately understand why things are as they are, the qualitative researcher

is less likely to assume that its current arrangements are inevitable and is more likely to question why things are one way rather than another' (Murphy and Dingwall 2003)

On reflection I think that the points raised above were valid in this study. At all times there was a sense that I was interviewing fellow professionals, but I was aware that I strove to downplay my status as a PhD student and to present myself as a researcher simply interested in finding out how to make things better by understanding the current situation. I was also keen to ensure that I demonstrated a non-judgemental stance. I emphasised that I did not have a renal background and therefore did not have preconceived ideas about how the kidney care system could, or should, be arranged. My impression was that I was treated by both nurses and physicians as a fellow professional.

In both sets of interviews there was evidence that the interviewees were justifying their actions in light of the patient outcome. Many went through a virtual checklist of what they perceived to be their responsibilities. I did get the impression that some interviewees were defending their practice in light of the scrutiny that this study entailed. This observation, which has been described as impression management, comes as no surprise and is a common occurrence in interviews of all kinds (Murphy and Dingwall 2003).

#### **10.4 Compliance**

One of the dominant themes of these interviews was the emphasis on the importance of compliance as a desirable patient characteristic. Medical compliance is generally seen as the extent to which the patient's behaviour (in terms of taking medications, following diets, or executing other lifestyle changes) coincides with medical or health advice.

Compliance is defined in the New Shorter Oxford English dictionary as 1) complaisance, 2) agreement/accord, 3) the action of complying with a request,



command etc... The root of the word comes from complaisance, which itself is defined as politeness, deference, willingness to please others and acquiescence (Brown 1993). These definitions of compliance suggest a strong sense of passivity on behalf of patients that is very much at odds with the current guidelines on patient involvement in health care (Department of Health 2000; Department of Health Renal Team 2004). In order to understand the power inequality that such a dynamic entails, it is necessary to briefly examine the patient/doctor relationship in a historical context.

According to Kaba and Sooriakumaran, compliance as a feature of the patient/doctor relationship can trace its recent origins to the upsurge in socialised medicine, initiated in the 18<sup>th</sup> century (Kaba and Sooriakumaran 2007). Whereas health care had previously been the reserve of the wealthy, allowing physician and client equal status, physicians started to treat underprivileged patients who were seen to be more passive. At around this time the biomedical model of illness emerged in which experts used clinical and anatomical knowledge to diagnose and treat patients. Thus, patients became dependent on the physician's specialised knowledge, placing the physician in a position of power, and the patient in a position of passivity (Kaba and Sooriakumaran 2007). Within this context physicians tell patients how to act in order to restore or maintain health, and patients are expected to comply with instructions. This is highlighted very clearly in the American Medical Association's Code of Ethics from 1847 which states that:

'The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them.'

This type of relationship is described as paternalistic, with the physician adopting a parental role to the patient's child status (Hellin 2002). Characteristics of the paternal relationship in relation to decision making and information transfer are outlined in Table 10.1. Paternalism has its place, particularly in acute situations where full consideration of patients' wishes are impossible, however within the modern context

of chronic health care management, it is no longer considered to be an acceptable basis of a relationship between doctors and patients (Royal Pharmaceutical Society Working Party 1997). Indeed, the notion of compliance is outdated, and attempts have been made, particularly during the last decade, to place the relationship on a more equal footing with the promotion of the concept of shared decision making, described as concordance. Despite this shift in rhetoric, Coulter asserts that paternalism ‘is still the defining characteristic of medical care in the British NHS and in the health systems of other countries’ (Coulter 2002).

**Table 10.1 Models of decision making and patient physician communication**

Model	Professional choice	Professional as agent	Shared decision making	Consumer choice
Decision maker	Clinician decides	Clinician elicits patients views, makes decision	Information shared then both decide together	Clinician informs then patients makes decision
Information transfer	One-way: Doctor to patient	Two-way: Patient to doctor/doctor to patient	Two-way: Patient to doctor/doctor to patient	One-way: Doctor to patient
Paternalism			Consumerism	

Table adapted from (Charles, Gafni et al. 1997; Coulter, Entwistle et al. 1998; Kiger 2004)

The prominence of compliance as a theme in the health care professional interviews reflects a worldview in which health care professionals perhaps overestimate the role of medical management in the patient experience of health care, or underestimate the roles of other factors that exist for patients experiencing health problems. Trostel (Trostel 1988) refers to this worldview of medical compliance as an ideology, a system of shared beliefs of legitimate behavioural norms and values at the same time that they claim and appear to be based on empirical truths. Within the ideology of medical compliance, patients who are non-compliant are thought to be deviant; therefore the blame for non-compliance rests largely with the patients. Trostel goes on to say that



‘Those who use the label (non-compliant) mistakenly equate health care dominated by physicians – a specific outcome of a contemporary power distribution – with health management in general’ (Trostel, 1988)

What is missing from this notion of compliance is the recognition that health behaviours are the product not just of advice given by health care professionals, but a wealth of other factors as alluded to in Figure 1.6, section 1.2.2, showing some of the factors influencing health beliefs. Health and illness arise not just from personal behaviours, but also from genetic, environmental and social factors. So too do the responses and health beliefs that people exhibit when confronted with health related decisions (Donovan and Blake 1992). This is illustrated in a study examining patient’s attitudes to concordance in a sample with hypertension. The researchers found that

‘personal experiences and those of friends and family were major determinants in the formation of patients’ attitudes. These experiences appeared to reinforce attitudes and behaviour more strongly than did other sources of advice, such as doctors’ (Bane, Hughes et al. 2007).

The interviews with health care professionals revealed strong idealisation of the good patient. The main characteristics that determine whether someone is perceived as good or bad rest on their level of compliance, which is in turn associated with intelligence. The perceived relationship between compliance and intelligence has existed for decades (Donovan and Blake 1992). While evidence for this assumption is limited, there have been studies supporting this view, such as one examining asthma control and compliance in Israel which found that compliance was associated with higher education (Starobin, Bargutin et al. 2007). However, assumption of a link between compliance and intelligence may be mistaken; for example, it is possible that the efforts made to educate patients regarding their condition are delivered in such a way that only a subsection of the population may benefit. As Kiger points out, not only are there many teaching styles, but similarly there are many learning styles (Kiger 2004). This links to a further key theme to emerge from the healthcare professional

interviews, namely the perception of education and information and the roles that each participant plays in the process.

### **10.5 Information and education**

Trostel (Trostel, 1988) highlights that the literature on compliance suggests a medical worldview that problems with compliance reflect problems with the patient's behaviour, the solution of which lies, in part, in patient education.

It is striking that throughout the health care professional interviews and indeed the patient interviews, the overriding impression given is the perception that education of patients involves simply giving them information. It emerged that the role of the health care professional is to provide verbal and written information, and that the role of patients is to 'take on board' the information and then to either 'comply' with what they have been told, or to make a decision about dialysis options. Failure to do either reflected badly on the patient. This idea of education as provision of information is also evident in the papers cited in the literature review in Chapter 2 where education was offered (Inaguma, Tatematsu et al. 2006).

This understanding of patient education is limited in that it encompasses only a part of the role of education. Information provision is a tool of patient education, but does not reflect the whole process. According to a definition created in 1985, by a group of experts in the field, patient education is:

'A planned learning experience using a combination of methods such as teaching, counselling and behaviour modification techniques which influence patients' knowledge and health behaviour' (Bartlett 1985)

This definition highlights two important aspects of patient education. Firstly, that it is a planned learning experience, in other words, it has a strategic basis and occurs in a structured fashion. Secondly, that its purpose is multifaceted and extends not just to



increasing knowledge, but also to affecting people on a psychological level as well by addressing health behaviour.

Lorig defines patient education as ‘any set of planned education activities designed to improve patients’ health behaviours, health status, or both’ (Lorig 2001). In her view improving knowledge is patient teaching. She asserts that changes in knowledge may be necessary in order to change behaviours or health status, but that knowledge alone does not bring about changes in behaviour. She stresses that good health behaviours can be adopted without full knowledge underpinning these actions, citing the example of people cleaning their teeth without knowing how many teeth they have.

The common ground between the two definitions is that patient education is planned and has as an outcome the improvement of patients’ health status. This is something achieved through addressing health beliefs in order to influence health behaviours.

#### **10.5.1 Models of patient education**

To understand where the discrepancy arises between the view of information and education shown by the participants in this study and the definitions above, it is necessary to examine underlying assumptions of patient education. Kiger has identified several models of health education (Kiger, 2004). Findings from this study suggest that health care professionals within this sample adhere to the information giving model. This has been the dominant model for nurses and doctors for some time and is therefore also known as the medical model. Table 10.2, mainly taken from the book ‘Teaching for Health’ by Kiger, with some input from Ewles and Simnett (Ewles and Simnett 1999) shows some of the characteristics of the information giving model as well as the educational model which will be discussed later.

**Table 10.2 Models of patient education**

Model	Aim	Assumptions	Strategy	Tactics	Role of practitioner
Medical	Freedom from medically-defined disease and disability	The facts will persuade	Generate and promote clear and simple messages	Identify cost-effective methods of presenting information. Package the material attractively.	As expert informant, give talks, prepare booklets, exploit new media techniques to improve presentation
Educational	Individuals with knowledge and understanding enabling well-informed decisions to be made and acted upon	Education will elicit potential and achieve autonomy. Exploration of values and feelings will activate health action	Assess learning needs and readiness with reference to the group concerned and relevant research, then generate a systematic approach	Set clear objectives. Identify evaluation criteria. Ensure feedback.	As educator /enabler, lead the person to learning discoveries, set up opportunities to discuss feelings and challenge facts.

Kiger 2004, pg. 31, Ewles & Simnett, pg 43

Health care professionals who use the information giving model and its associated strategies assume that their role is to provide patients with information, facts and figures about the health issue in question, and it is then up to the patient to make decisions based on that information. The health care professionals view themselves as experts and patients as passive recipients of information, a view which also emerged from my data.

Critics of this approach point out that it is based on some fundamental flaws. Firstly, it is based on the assumption that information is understood in the same manner by everybody. Secondly, it assumes that people make conscious rational choices about health behaviours and that factual information alone will influence choices. It is this assumption of rationality that presents the greatest problem with this model as it does not take into account the complexity of the decision-making process that many people go through regarding health behaviours. If we based our health behaviours on rational decisions alone then health care professionals in full receipt of the facts would not smoke or be overweight, knowing as they do the risks engendered by both actions. It also assumes that the goals for health care professionals and patients are



the same, a view which can be problematic. For example, the lowering of blood pressure may be seen as paramount by a health care professional; however, if taking the medication has the effect of inhibiting people socially or making the patient feel unwell, the health benefits of taking the medication may be legitimately outweighed by other more personal and relevant factors. Kiger points out that there are significant limitations to the information giving model which are detailed in Box 10.1.

**Box 10.1 Criticisms of the information giving model\***

- What is rational to one person may not be rational to another
- The meaning and purpose of being healthy differs between people
- It assumes that everyone is anxious to achieve health
- It ignores the existence of other factors which affect people's beliefs, values and ultimately health behaviours
- Health care professionals assume that their health beliefs are right based on professional knowledge and expertise
- It ignores the question of motivating people to adopt particular health behaviours

\*Kiger, 2004

Furthermore, the medical model leads to a 'victim blaming' culture, shown in the findings in this study, as there is a disregard for the myriad of wider social, environmental and behavioural factors that influence health and health behaviours (Tones and Green 2004).

Given the drawbacks of the medical model, and in light of the current emphasis on involving and empowering patients, the educational approach to patient education offers a framework that is more closely aligned to the goals of patient choice and involvement in decision making. The educational model opposes the medical model in almost all aspects and represents a fundamentally different ideology, one in which the

goal is not to ensure that patients comply, but to ensure that they have the knowledge and skills to make informed decisions regarding health and health related behaviours. This may sit uncomfortably with health care professionals, as the result of this approach may be that patients choose health related behaviours that do not accord with medical opinion. The educational model is described as a Socratic, or a two-way approach to education because there is strong two way interaction at all stages of the process from design through to evaluation (Kiger, 2004).

The model does not assume dominance of professional opinion and expertise but seeks to promote the idea that medical opinion is just one of the influences on health behaviour. Health care professionals act as facilitators of patient education but encourage individual learning and learning from sources outside health professionals. Crucially, the educational model tackles the issue of motivation, a key factor in health behaviours.

The only criticism of the educational model comes from a public health perspective. The model does not seek to address the fundamental causes of poor health, such as poverty, and works with individuals or groups of individuals as opposed to communities. Critics point out that patients can only be empowered within the confines of their circumstances.

Other disease areas have benefitted from research into theory based education that places patients at the centre. In particular there have been a number of studies involving patients with diabetes which have attempted to refine techniques for optimum patient education. In 2002 a study was reported that had evaluated the role of education in teaching patients how to adjust their insulin doses to suit their diet, instead of the standard treatment which was to prescribe an insulin dose and ask patients to eat to within the confines of the insulin (DAFNE Study Group, 2002). The randomised controlled trial, known widely as dose adjustment for normal eating (DAFNE) took a relatively small sample size (169 adults with long term type 1 diabetes) and used trained educators to teach patients in the intervention group about how to



monitor their own glucose levels and adapt their diet and insulin therapy flexibly. The endpoints were set by the study team and it did not appear that patients were encouraged to set their own goals, however there were still some interesting findings. Patients who were shown how to manage their diabetes with a greater degree of autonomy reported a greater degree of dietary freedom and a lesser impact from diabetes on their quality of life. At six month follow up glycated haemoglobin levels were significantly reduced, though this finding was not found to exist at later evaluations. Essentially the original DAFNE study found that many of the benefits were in effect short lived, being significant at six months but less so at later stages, something that the authors attributed in part to patients' follow-up being carried out in their usual care setting with no further input from the study team and therefore possibly no reinforcement of the principles of self management and autonomy. Feedback from the study also suggested that this type of treatment was not suitable for everyone as some people were more comfortable with the tighter boundaries of their old insulin regimes.

What this study appears to highlight is that continual reinforcement and a change in the whole of ethos of care is probably necessary to establish long term changes in practice for both patients and clinicians. It also serves to emphasise that patients are individuals and that different approaches will suit different people better, as shown by the patients who wanted more guidance in their treatment. Of note also is that many of the patients in the study had been diagnosed with diabetes for a long time, with the mean duration of 16 years, which could have had an impact on how the programme was received and could lend support to the benefit of starting education and promoting self involvement earlier in the disease process.

Another well known study in the field of diabetes was reported more recently by Davies and colleagues, known as the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme aimed to do just that, but with patients who had Type 2 diabetes (Davies, Heller et al. 2008). The DESMOND study explicitly stated that a theoretical framework was used to structure the group

educational intervention delivered to approximately half of the 824 patients in the cluster randomised controlled trial. The DESMOND study differed from others in that participants were encouraged to set their own goals in relation to their diabetes management. The results showed that many of the objectives of the study, such as lower levels of glycaeted haemoglobin, were not achieved, however there were significant improvements in many of the more abstract endpoints. For example, there was a greater change in illness belief scores in the intervention group, as well as increased weight loss and improved perceptions of personal responsibility which were found to be positively associated. Participants in the intervention group were shown to have a better perception of their ability to influence the course of their disease and decreased levels of depression. These results were sustained up to twelve months, which was the duration of data collection.

The DESMOND study shows that it is possible to achieve an alteration in health beliefs by the use of a structured education programme. It shows fairly convincingly that these changes in health related beliefs can bring about some changes in behaviour, such as weight reduction or smoking cessation, but that it is probably the changes that patients are motivated to make for themselves that will prove successful for each individual. Evidence of decreased depression perhaps suggests that the feeling of autonomy that appeared to have been achieved could have led to an improved perception of patients role in controlling their illness, thus tackling the feelings of helplessness and frustration experienced by patients in my study into chronic kidney disease. At the very least the work carried out in diabetes shows that improvements can be effected which lead to overall improvements in patients quality of life.

## **10.6 Age**

Age emerged as a strong theme throughout the interviews. A patient's age appeared to have an effect on both how they were perceived by health care professionals, and how they were treated. The findings suggest that younger patients were regarded as having a higher priority status than older patients, simply because it was perceived that they had more to lose from having an urgent dialysis start in terms of the



economic impact and the possible effects on younger families. This is in line with the 'fair innings' argument of intergenerational justice set forth by Alan Williams, who firmly defends ageism as a moral philosophy in a system where there are finite resources (Williams 1997). His argument is based on the premise that older people have had a reasonable lifespan, and therefore it is their duty to waive their right to increased years in order that younger people should have the same right to a long life. As he points out, public opinion largely supports this approach as can be seen from the study carried out by Bowling (Bowling 1996) to elicit public views on priorities for health services. In Bowling's study, the public were presented with a number of scenarios and were asked to rank them in order of priority for health care spending. The highest priority was given to treatment of children with life threatening illness, the lowest to the treatment for people ages 75 and over with life threatening illness. In their views and practices, the health care professionals' attitudes found in my study are probably in line with those of many of their colleagues and peers (Shaw 1994; Carvel 2000).

Ageism is thought to be endemic in the National Health Service. In a report of a study of senior health and social care managers carried out by the Kings Fund, 3 out of 4 believed that age discrimination existed in their organisations (Roberts, Robinson et al. 2002). The basis of the National Service Framework for Older People was to eradicate ageist practices from the NHS (Department of Health 2004). Despite this, examples of ageism persist. In a recent study examining the timeliness of referral practice from primary care to renal specialists, older people with declining renal function were found to be at a disadvantage (Kee, Reaney et al. 2007).

Age seemed to be the determining factor in terms of whether or not the option of choosing not to have dialysis, but rather to pursue conservative management, was raised for discussion by the health care professional. This was couched in references to the patients' quality of life which was the determining factor. The interviews with health care professionals go some way towards helping to gain an understanding of

why this may be the case, with urgent dialysis start sometimes being seen as more of a failure when patients are younger.

## **10.7 Conclusion**

These interviews provide insight into how health care professionals perceive their roles and the roles of patients in the time before the latter start on dialysis. Evidence of the contradiction between the rhetoric currently espoused promoting shared decision making, and the reality of the value still placed on patients complying with wishes and instructions of health care providers is shown. The uneven balance of power perceived by health care professionals is highlighted, reflecting the fact that there are some features of the paternalistic model of care which appear to persist. This chapter has sought to provide the context for the current care and education models and has set forth an opposing education model which could address patients needs better. The ageism seen within this study has been discussed in light of the literature within other areas which indicates that ageism is deeply ingrained within the National Health Service.

The following chapter presents four case studies from the second phase of this research study.



# CHAPTER 11

## Case studies

### 11.1 Introduction

This chapter presents the findings from four patients' interviews along with corresponding findings from interviews with health care professionals about the same patients. Each case was chosen for inclusion in this chapter for different reasons. The first three case studies are relatively brief and are used to illustrate specific points regarding the relationships between patients and their physicians. The fourth case is different in that this is the divergent case mentioned in Chapter 9, section 9.2. This was the final group (patient, nurse, physician) of interviews carried out, in which some quite different findings emerged. Constant comparison of previous interviews confirmed a lack of similar findings in the other cases. This case study is presented in greater depth than the others in order to fully explore the areas of note within the interview.

### 11.2 Case study 1

#### Details of patient in case study 1

Sex: Male

Age: 39

Type of dialysis start: Known acute

Time known to renal services prior to dialysis: Approximately 6 years

The patient in the first case started dialysis urgently when he was admitted via accident and emergency with a nose bleed as a result of high blood pressure. He remained on haemodialysis following this initial admission. This case has been chosen to highlight the differences of perceptions that patients and clinicians may have of the



same interactions. The two quotes in Box 11.1 show the patient’s and clinician’s responses to questions about how they perceived predialysis clinic appointments. The patient had not been visited by a home care team nurse to discuss dialysis options so no nurse interview was carried out for this patient.

Box 11.1 Different perspectives	
Physician 1	Patient 2
‘You know you could have a ... a discussion with him, you could offer him advice and in... in those visits he would be quite erm... receptive and er... you know willing to take on your suggestions so I wouldn’t say there were... I wouldn’t have thought there were any difficulties...’	‘Because he never tells you about anything... I've asked times an' times when he's saying "Oh your creatins (sic) up or this is... or tha' your potassium's up or this is up," an' I say, "Well what can I do meself to bring it down?" an' it's just like..."Well I dunno... I dunno,"... he ... you don’t get no feedback at all from 'em... they don' explain anything’

There are clear differences of opinions here about how successful the clinic consultations were. The physician perceived that he and the patient had a reasonable relationship, that the patient was receptive and that there were no difficulties. The patient on the other hand expressed frustration at the lack of relevant and personalised information and guidance about actions he could take to help himself. It is very likely that both of these accounts are true representations of how each party perceived the situation, as it is possible that the patient did act in the way described while with the physician, but harboured his feelings of frustration when outside of the clinical environment. This example raises an important question: if the patient was so unhappy with the outcome of his consultations, why did he not address the problem with the physician? I believe that there are possibly two interrelated explanations for this.



As discussed in Chapter 10, section 10.4, the physician patient relationship is sometimes based on an imbalance of power where the patient is submissive in relation to the dominance of the physician. This status is possibly reinforced within our kidney care system where often the health care professionals appear to value patients who comply with instructions. The health care professional interviews also revealed a lack of understanding of the notion of shared decision making. As was shown in the findings in Chapter 7 and discussed in Chapter 8, many patients are happy for health care professionals to take the lead and respect the knowledge and experience of the health care professionals enough to place complete trust in them. Figure 7.2 shows that one of the elements found to lead to an overall positive predialysis experience was whether patients' expectations of physicians were met. In this case, the opposite was true. The patient had an overall negative experience and part of that was because his expectations of physicians were not met. This brings us again to the question of why he did not address the problem at the time.

According to Goffman, within all social interactions there is, what is termed, a ceremonial order (Goffman 1967). Within health care specifically, the ceremonial order was described extensively by Strong & Davis who analysed parent physician interactions in a paediatric environment in Scotland (Strong and Davis 1977). Their work showed that a bureaucratic format existed that dictated the behaviour of both patients and physicians in medical encounters. The patient role was deemed to be one of passive deference to the professional role of expert. The consultations were judged to have been led by the physician in terms of the timing and pace of the discussions. Patients were inhibited from expressing concerns and asking questions.

Despite being carried out over 30 years ago, it would seem that similar roles exist within our culture today for many physicians and members of the public, and that these roles could be stifling patients and leading to frustration and misunderstandings. Britten and colleagues examined misunderstandings in relation to prescribing decisions in general practice and found that fourteen categories of misunderstandings arose. All of the misunderstandings were associated with patients' lack of

participation during the consultations regarding their expectations or preferences of the consultation (Britten, Stevenson et al. 2000). The misunderstandings were also characterised by general practitioners' incorrect assessment of patients' expectations and their desire to fulfil their side of the relationship by meeting expectations.

### **11.2.1 Perceived reasons for urgent dialysis start**

Health care professionals generally expressed clear opinions on the reasons for urgent or elective dialysis start. In this case the physician placed the blame mostly on the patient though also noted that medical reasons may also have had a role to play. The quote below (also shown in section 9.3.3.1) highlights that the physician thought that the patient was largely to blame

'I would say he's a bit foolish and not very responsible...his pattern of behaviour over the years has not been what I would say entirely responsible or ... entirely conducive to good health for him' (physician A)

For the most part the physician was referring to the patient's lack of attendance at predialysis clinics in the years prior to starting on dialysis. When asked, the physician stated that he did not know why the patient had chosen not to attend appointments. The quote below, taken from the patient's account, shows why the patient stopped attending.

'I stopped going ... 'cos I thought it were just ... time it takes for me to get over there, sit down an' wait for an hour ... and then go in ... five minutes just for 'em t' check your tablets on a screen that they've already got an' you've gotta cart all your tablets down ... an' then t' say, "All right I'll see you in two month", ... an' I just think it's just a waste o' time unless they're ... unless they're gonna explain t' you then I think it's pointless going.'

Though speculative, it is feasible that if the patient had received care during the time that he was out of the system, he may possibly have had a better dialysis start. This



highlights the importance of investigating the reasons for patients none attendance at appointments and perhaps indicates an area where care systems could be altered to try to identify problems and implement solutions in a timely manner.

### 11.3 Introduction to case studies 2 and 3

The second and third case studies use data from two patients, along with the associated health care professional information, in order to illustrate points regarding choice and decision making. As has been discussed in Chapters 7 and 8, decision making is a key component of the patient experience during the predialysis phase. Specifically patients are encouraged to choose, where deemed appropriate by health care professionals, the type of RRT that they would like. In Chapter 8, section 8.4.4.1 I discussed the different roles that patients like to assume. In presenting and considering cases 2 and 3, the data from both sets of interviews are used to suggest a possible area where improvements could be made that could benefit patients.

#### 11.3.1 Case study 2

##### Details of patient in case study 2

Sex: Male

Age: 75

Type of dialysis start: Known acute

Time known to renal services prior to dialysis: Approximately 2 years

The seventh patient to be interviewed for this study started on dialysis urgently after becoming increasingly unwell at home and calling the home care team for advice. He was admitted into the day case unit because of weakness and fluid overload and was admitted from there to start on haemodialysis through a catheter. He did not have a fistula, a peritoneal dialysis catheter or any firm plan regarding which dialysis option he would prefer. During the year before dialysis he had indicated that he would prefer peritoneal dialysis but no further action had been taken to ensure he was prepared for this. He left hospital on haemodialysis and remained on haemodialysis at a satellite unit.



In their reflections on this patient and their management of him, the health care professionals both identified that there had been a plan for him to start on peritoneal dialysis, and that there was clear blame on their behalf for not having his peritoneal dialysis catheter placed before he needed dialysis.

However, the accounts of the health care professionals can be compared to the way in which the patient spoke about making the decision and how, once he had been started on haemodialysis, he chose to continue on haemodialysis. According to the health care professionals he had been fully involved in the decision making process, with the physician noting

‘I think he was set for dialysis. He ... he was otherwise en ... engaged in it, he'd made a choice, he'd been counselled he just needed the procedure doing to allow him to start.’ (physician C)

The patient himself, however, seemed less certain that a firm decision had been made and discussed how much he had struggled to make a choice, something which is highlighted in the quote below, already given in Chapter 7, section 7.4.4.3.

‘I (was) still sort of at that stage I'd have been wondering about it and wanting to go back to er ... a person who's qualified to tell me whether ... which they thought best medically for example. Trouble is I don't think the ... Dr <name> would say that because he was all the time emphasising that it was in the end my choice you see. But it's all very well my choice all the time er ... without having some opinions to guide that choice...’

He stated that he chose to stay on haemodialysis after seeing how convenient it was for him and on the recommendation of a fellow patient.



### 11.3.2 Case study 3

**Details of patient in case study 3**

Sex: Female

Age: 40

Type of dialysis start: Elective

Time known to renal services prior to dialysis: Approximately 2 years

By contrast the patient in case study three describes a very different experience of choice and decision making. The patient started haemodialysis electively through an arterio-venous fistula. She had planned when she would have the fistula created and when she would start dialysis. A physician unfamiliar with her had urged her to start dialysis sooner, but she had postponed this until her fistula had matured and she was no longer able to cope without dialysis. She ascribes her positive experience to the relationship she developed with her health care team, as can be seen below.

‘I was very lucky with ... Dr <name> ... because I was still in control so he was quite happy for me to carry on as long as I ... I think he knew you know ‘cos of the relationship I’d built up over erm ... that year he knew I was sensible enough that I would come in you know if I felt really ill ... if my life was threatened erm ... but he gave me that control and I was so grateful for that ... it wasn’t somebody who’d say “Well right we’re just gonna do this, you’re gonna have that”, ... you know take the control away and he didn’t...’

The health care professionals involved with her in the year before dialysis both praised her for intelligence and ability to make decisions and cope with her situation.

### 11.3.3 Discussion of case studies 2 and 3

These two cases present two very different images. The first is of a patient who hadn’t really made a strong decision and who was uncomfortable with making the decision about his dialysis, possibly because he felt poorly equipped to make this decision. The second is of a patient who placed high value on the role that she was



able to play in decision making processes. This reflects the differing roles that patients want to play regarding choices about treatments, as was discussed in Chapter 8, section 8.4.1.1.

What became clear through the analysis of patient and health care professional interviews together is that within our kidney care system, patients are generally treated the same when it comes to making decisions. Where there were clear social or medical reasons for patients to have a particular treatment the health care professionals make the decision on behalf of the patients. If not, patients were given information about both types of dialysis options and are then expected to come to a decision on their own. While this is entirely appropriate for some patients it may not be for others as previously discussed (Chapter 8, section 8.4.1.1).

In a comprehensive study of decision making preferences Deber and colleagues found that of the 2704 patients questioned, only 1% of patients wanted to make treatment related decisions autonomously. The vast majority, 78%, wanted a shared decision making role, while 20% of patients preferred a passive role in decision making (Deber, Kraetschmer et al. 2007). In their study of decision making and information needs in patients with end-stage renal disease on dialysis Orsino et al found very similar preferences with 80% of patients expressing a desire for a shared decision making role (Orsino, Cameron et al. 2003). The studies reported by Deber et al and Orsino et al both showed that in general older patients were more likely to want to take a passive role and allow health care professionals to make decisions on their behalf, although both reports were keen to point out that by no means did all older people wished to take a passive role. It appears that patients within our kidney care system are expected to either take on a passive role, when the decision is made for them, or to be autonomous and reach their own decisions as was shown in case study above. An approach involving effective shared decision making, which might have been of benefit in the case of patient seven in case study 2, does not seem to occur often. The value of gauging and adopting the best decision making model is clear from case study three.



Involving patients in treatment decisions is a relatively new concept in the field of health care. According to Grol, 'shared decision making and informed choice illustrate the emancipation of the patient' (Grol 2001). Accordingly, the skills required to allow shared decision making have possibly been absent from clinical education. Elwyn and colleagues carried out a study with general practitioners and developed a series of competencies required to enable shared decision making, shown in Box 11.2.

**Box 11.2 Competencies required to enable shared decision making**

1. Deciding how to involve the patient in the decision making process
2. Exploring their ideas about the problem
3. Describing the treatment options
4. Providing tailor made information
5. Checking that the patient understands the information and exploring their reactions
6. Finding out the patient's preferred role in the decision making process
7. Making or deferring decisions
8. Arranging follow-up

(Elwyn, Edwards et al. 2000)

I would suggest from the findings of my research that point number six, finding out the patient's preferred role in the decision making process, is possibly the most important, and is an area that requires further development within our kidney care system.

Recognising patients' preferences for involvement has been the subject of some research over the past few years with few conclusive results. In a recent study examining whether patients' preferences for involvement in decision-making regarding the use of medicines could be predicted, Garfield and colleagues discovered that it was very difficult to predict preferences based on a model developed from the current evidence. While they showed that younger people of higher social class were

more likely to prefer to be involved in decisions, they found that gender, ethnic group, health status, quality of life and time since diagnosis were not predictors (Garfield, Smith et al. 2007). They advocate individual assessment of preferences with each patient and conclude that preferences for involvement in decision making change over the course of patients' illness and vary according to the decisions to be made.

Another point worthy of mention here is that the focus of decision making in kidney disease is very much on which type of dialysis a patient will start on. This was certainly the case within this study and is echoed within the literature (Law, Szeto et al. 2001; Goldstein, Yassa et al. 2004; Goovaerts, Jadoul et al. 2005; Inaguma, Tatematsu et al. 2006). Decisions regarding other aspects of management such as those involving medications and tests seem to be made almost exclusively by health care professionals. Perhaps if a more patient-centred approach were adopted throughout the process, patients, such as patient seven, would be better prepared for involvement in dialysis treatment decisions.

On reflection the area of decision making would have been worthy of further exploration within the interviews with both patients and health care professionals. Certainly decision making, involvement in treatment decisions, and what influences preferences has emerged from this study as an area for future research.



## 11.4 Case study 4

### Details of patient in case study 4

Sex: Female

Age: 21

Type of dialysis start: Known acute

Time known to renal services prior to dialysis: Approximately 3 years

The fourth case is presented in five sections. The first provides a summary of the major findings from the interview with the patient, the second and third a summary of the major findings from the physician and nurse interviews respectively, the forth highlights areas of congruence between the accounts, while the final section explores differences in the accounts. The patient started on haemodialysis urgently through a catheter before going on to peritoneal dialysis. She is of Pakistani origin.

### 11.4.1 Summary of findings from patient interview

The two main themes to emerge from the interview with the patient were regarding knowledge and acceptance. The patient’s knowledge of chronic kidney disease was better than most of the people I interviewed. She spoke about symptoms and some of the biochemical parameters as well as the medications she was prescribed which she discussed in the context of often forgetting to take them. She also mentioned how she was shown graphically how her kidney function was progressing. In the first quote she is talking about when she went to her GP and insisted on further tests as she felt unwell.

‘she (the GP) said it’s nothing to worry but I insist her and then she did that and then it comes out that I’ve got a kidney problem er ... and my creatinine and potassium was er ...slightly high and GFR was ... low as well so she decided to put me to the hospital’



'he (the hospital physician) told me that I don't know why you've got ... why you're not getting any symptoms when your blood tests are really high and you haven't got any single erm ... symptom ... no itchiness, no swelling no sickness and nothing at all'

'...the diagrams which was ... computer was showing by the blood result of my whole history it was keep going down and at one stage er ... last year two thousand and six er ... in March it was stable, was going at a straight line and then it was suddenly going down ...'

*Researcher:* So were you taking medicines before you started on dialysis?

*Patient:* 'Yeah. Yeah it was for...my blood pressure and er ... for other things as well Adcal and (...) and these kind of ... ferrous sulphate all ... there was well five, six maybe seven I was ... I was taking'

*Researcher:* 'But it's not easy to remember to take them is it...'

*Patient:* 'No. Usually you know I ... I can with the morning one and the night one but when I have to take it during the day I always forget that because sometimes it has to be before you eat, before your meal and sometimes it er ... it is after your meal so I always forget the two ... two medicines two times so that was hard and sometime I have to tell my friends can you please remind me after lunch I have to take my medicines but they're the same as me.  
(laughs)'

Acceptance emerged as the major theme. She spoke about not accepting her illness and gave some reasons why. First of all, the quotes below highlight how strongly she



denied having kidney problems. The quote shows how not only did she not accept her diagnosis predialysis, but how she is still struggling to accept it even though she is now on dialysis and can see that her blood results are improving, something she has in common with some other patients.

*Researcher:* So how did it feel when you were so young being told that you had kidney problems?

*Patient:* I never believed him in the first place er ... in two thousand two, I never believed it and I was doing what he told me to not do ... and I was doing everything and I thought he must have been mistaken or something that my blood tests have shown something wrong or er ... some ... some way it have been changed with someone else blood test report and I was thinking about that because I never had no news from my family, relatives, that they had kidney failure so I never thought that I'm gonna have one'

*Researcher:* So you just didn't believe it.

*Patient:* Yeah I ... I never believed it. So suddenly when ... this time in erm ... February time when they took me in hospital and I started dialysis and all that ... and then I f ... I felt it might be but still I'm feeling that I haven't got a kidney failure, still (laughs) in the present time. (laughs) I'm still not accepting it I don't know why ... is that but still I'm on dialysis and everything and I feel that before coming onto dialysis I was fine and after coming on dialysis I feel a bit erm ... tired and that on ... but I don't know but my blood test are erm ...showing fine erm ... everything is normal, everything is fine er ... than before because it was going really high, my creatinine was nine hundred and eighty something and now it's er ... with dialysis it's four hundred and something so it's coming down a lot'.

There were several reasons that she gave for not accepting, or believing that she had kidney problems. Firstly, the main barrier to her acceptance appeared to be that she didn't have, or recognise that she had, any of the symptoms associated with kidney failure. This was reinforced when she spoke to other patients, all of whom described having symptoms predialysis. Secondly, as the quote above shows, there was no history of kidney disease in her family, and crucially for her, she believed that no cause was ever found for her kidney failure, which, coupled with her lack of symptoms, strengthened her conviction.

#### **11.4.2 Summary of main findings from the physician interview**

The findings from the physician interview are difficult to summarise because at times they appear to be quite contradictory as will be shown below. The contradictions arose largely as the interview progressed, so these findings are laid out somewhat sequentially. On the whole, the main theme pertained to blame. The physician blamed the patient for having an acute dialysis start and used strong language to indicate this, though as the second quote shows, there was some level of acceptance of health care professional responsibility as well, although this was limited.

'No erm ... er ... my perception of this was this that she brought all this on herself...absolutely and unequivocally'

'it could not have been worse and I really believe that <name> who was her Homecare (nurse) that ... and I ... the amount of time I spent with her and the fiancé and the other family members trying to get her to engage ... every clinic visit was fifteen or twenty minutes and er ... it never sank in partly because she was frightened, partly because she didn't want it to be true, partly because she was twenty-one but ... hopeless... from our perception it was a complete failure and we felt like we'd given it our best shot and we really, really believe the fault was with her ... or was with our inability to help her believe that we were telling the truth and it really was going to be like this and it wasn't just going to go away...' ...



As we can see, the physician recognised that there was a problem with acceptance. The main areas identified in the physician interview as barriers for acceptance were to do with her young age which the physician found challenging not only for her in terms of it affecting her acceptance, but also for him in terms of how he interacted with her.

‘I think the interviews (clinic appointments) were characterised to start with by her not really believing me you know she’s young, slim, pretty, fit ... the world was her oyster and I don’t think she believed a word I was saying to start with ...’

‘I was dealing with a difficult adolescent and I’m ... I was disappointed because I thought I ought to be able to find the way into this and I can’t ... can’t get through this one at all so I was a ... irritated with myself’

However, there was a perception that her cultural background was also hindering her acceptance, or hindering the physicians’ ability to, what he terms, engage with her. Furthermore, the physician mentions several times the perceived lack of family support. The following two quotes reveal these themes, as well as the continued theme of blame being placed on her.

‘When you have a family difficulty and Dad offers and then daughter says I don’t want Dad to give me a kidney and then ... and those sorts of difficulties happen you always think to yourself do we get inside the dynamic well enough ... my personal perception erm ... is that this was a not untypical problem of Muslim family and a young very westernised lass who was ... and I think that was creating a difficult family dynamic so she always wanted to come on her own and never wanted Mum and Dad to come to the clinic with her even though she was only twenty-one, said they all understood what was going on and then when it came to it and Dad said I want to give her a kidney she actually ... at one point called up...she said I don’t want you to do any more

about this so she brought that on herself ... so I don't think we could have done much differently about that'

'you ask yourself where her support structures were and when I met mum and dad ... when I met dad he was a very drab looking guy, and I thought well that's where your support structures aren't. I fear that what she did was go home and not even ... not tell them anything.'

The physician spoke at length about what could have been done differently for her, and suggests that one of the problems had been that the patient had been treated solely by, in the physician's words, white middle aged men. This was seen to be a barrier to full interaction with her. To counteract this the physician reflects that a young Asian female nurse would have been best suited to care for her, as the perception is that this would have been beneficial in breaking down the perceived cultural, as well as age, barriers.

The contradiction mentioned above relates to the timings spoken about in the account given by the physician. For the majority of the interview the physician speaks freely from memory about the patient. It is only towards the end of the interview that he looks up some data on the hospital computer system Proton and finds that much of what he had assumed in terms of timing was quite inaccurate. The following quotes are taken sequentially and highlight this well.

'she had been coming to my clinic for I would guess about a year erm ... we had a biopsy which proved she had IgA nephropathy and her kidney function was relentlessly...I spent, I would judge, three or four months engaging her in conversation, explaining to her that this was going to happen'

'my perception is that even when we were well over six months er ... ahead of a predicted start date we were telling her that this was really going to happen'



*Researcher:* And can I ask...I'm aware that she didn't go to the pre-dialysis clinic because you saw you ...

*Physician:* No she saw ... she saw me because she ... she just ended up in my clinic, erm ... that's a very good question, it was moving very quickly ... relatively speaking, I mean I always have in my mind that there's no point in ... well I'll re-phrase that ... I have in my mind the notion that to put somebody into the pre-dialysis clinic you probably need to be six months before dialysis to make it worth it ... I've always felt reluctant about sending people to pre-dialysis clinic saying in ... I think they're going to be on dialysis in a couple of months...'

The physician perception up until this point is that he had only been seeing her for about a year and that she had been in regular contact with the home care team who had also spent considerable time with her. He also justified his decision not to refer her to the predialysis clinic in terms of his perception that he had only known her for a few months before she needed to prepare for dialysis. The next series is taken from when the physician looks at Proton towards the end of the interview.

'Oooh heck ... (pause) Feb ... March two thousand and four ...First time I saw her. Creatinine three hun ... creatinine one sixty, creatinine doubled by March two thousand and five ... in a year yeah...

'Now let's look in some letters ... this'll be fun. (quietly) Oh God ... (pause) (sharp intake of breath) (sighs) (pause) February two thousand and six, <name female member Homecare Team>, January two thousand and seven <male member Homecare team name> ...'

'So creatinine four-forty, urea seventeen when she sees <female member Homecare team> ... now I can't believe she didn't see <name> 'til January-oh-

seven when her creatinine was seven hundred-and-twenty, that just does not figure ... it really doesn't ... when did she start dialysis? ... Third of February two thousand and seven ... which does surprise me er ... er ... it appears to show that <name> ... well <name> visited her at home for the first time in January two thousand and seven ...'

'it's very interesting this I mean my ... my time memory may be very misleading here. No it says January two thousand and seven ...'

As these quotes highlight, the physician's perspective both of the time that he had known the patient and the time that the patient had spent with the home care team were inaccurate based on the information available on the computer system. From memory he thought he had known the patient 'about a year' when in fact the computer system revealed it was three years. The computerised documentation showed that the home care team nurses had only visited 12 months before she started on dialysis then again only a month before dialysis.

#### **11.4.3 Summary of main findings from the nurse interview**

The main themes to emerge from the interview with the nurse about this patient were around her acceptance of her kidney problem and the need for dialysis. The perceived barriers to acceptance were her youth, and her lack of symptoms, or recognition of symptoms. These barriers were seen to be interrelated. The nurse described that he experienced difficulty interacting with her because of her young age and suggested that the patient would have been better served by someone with specialist experience in treating younger patients. Overall the nurse described the patient as intelligent, self-confident and determined.

'Yeah she was too f ... anxious ... sort of yeah ... and ... and may be very young and probably feeling ... always felt what's the problem 'cos I feel quite well all the time so I think er ... there was some ... I think there was some sort of



problems with “I feel okay, there’s not a problem here” and she always felt that way’

‘I think we can learn a lot really I think. Certainly her age and her youngness and her ... you know when people feel young and well and ... it ... may be a little bit of specialist help, I know sometimes when they're young and adolescent ... may be talking in a more you know er ... talking to them as an adult yes but you’ve just gotta find the right ways to ... to make them understand really you know and whe ... er ... I mean ... you know what it’s like you know when you're seventeen, eightèen, nineteen, you just wanna do the things that young girls do...’

The nurse perceived that there may have been cultural aspects involved in her care, but he spoke about cultural issues largely in the context of how this affected his interaction with her and her family, and not necessarily as a barrier.

‘I always felt that we could never reach her you know. Whether it was a cultural thing ... ‘cos er ... I feel there was always a cultural thing with <name> because being a Muslim and very close Muslim family er ... there’s that ... quite a lot work to do to ... to break into that family as a ... a white western boy who’s going into their ... that’s quite a challenge in itself and feeling comfortable in that environment erm ... although they were very welcoming and you know ... they're ... I think they're always a little bit anxious er ... you know during the first visits you know ... there’s quite a lot ... I always feel there’s quite a lot to earn their respect and ... before you can start getting to them ... and ... and may be that was one of the issues where we would wanna learn, maybe it’s a cultural thing I don’t know.’

He also spoke about the need for cultural awareness particularly when delivering personal care to a young Muslim woman, for example when he discussed his own discomfort at having to examine her peritoneal dialysis catheter site. Within this

context he spoke in general about his perceived personal vulnerability when visiting the homes of young women in particular.

Whereas the physician had believed that the patient received little in the way of family support, this is contrary to the nurses' account in which he described very supportive and worried parents, although he also mentioned that there were sometimes family arguments.

'... and she also had a fairly ... difficult relationship with her parents. Her parents were very concerned and did understand the situation so from my conversations with her there was always some very heated discussion between her and her parents which was in <language> which I didn't understand but from ... from the tone of the ... of the conversation, it was very loud and very ... you know lots of arguments really...and her father was always very worried about their daughter and erm ... would always try and impress upon me to try and make her see sense to take in some of this information to think about her future care.'

'But the family are very good, I've ... I've tried to include the family as much as possible you know, especially with the Mum and Dad being very concerned about their daughter, very worried about their daughter erm ... you know you need to involve them as much as possible ... '

Barriers that the nurse perceived to him giving optimal care were, as mentioned above, that he felt unable to fully interact with her due to her age and possibly their different cultural backgrounds, as well as not having enough time with her. In addition to the nurse suggesting that a specialist in caring for younger people would have been appropriate in this case, the nurse also thought that the patient would have benefited from attending the predialysis clinic instead of remaining in the general nephrology clinic.



**11.4.4 Similarities and differences in accounts**

Examining the same case from a variety of angles reveals some areas of overlap in the accounts, and some areas of discrepancy. All participants recognised that there were problems with the patient believing, and accepting, the presence of a kidney problem. The reasons for this differ however between the patient and, partly, between the two health care professionals. The table below summarises the perceived barriers to acceptance as described in each interview.

**Table 11.1 Barriers to acceptance identified in case study 4**

	Lack of diagnosis or family history	Lack of symptoms	Young age	Cultural background	Lack of family support
Patient	✓	✓			
Physician		✓	✓	✓	✓
Nurse		✓	✓		

This reveals that the health care professionals ascribed largely psychosocial reasons to the patients’ lack of acceptance, whereas from her account it appeared that it was probably rooted more in her disbelief that she had a problem when she felt well within herself, or did not recognise that she had symptoms of kidney disease. This is something that she had in common with other patients and has shown itself to be a major inhibitor to acceptance throughout this phase of the research study.

**11.4.5 Discussion of case study 4**

This case study presents a divergent case from the previous interviews. The findings from the patient interview were similar in many ways to those from other interviews, particularly the role of acceptance. Where she differed slightly from some patients was in her relatively good knowledge of chronic kidney disease and appropriate use of terms linked with it. The divergence was most notable within the health care professional interviews. Of note were three areas where the differences were most obvious. These were 1) in the characterisation of the patient as being non-compliant yet intelligent, 2) the emphasis on the role her cultural background may have played

in her care and 3) the difference in perceptions between the physician and nurse. This case study also highlights a strong example of recall bias which may have wider implications and flags up some issues around the accuracy of documentation.

Recall bias is an inherent limitation of many research studies where participants are asked for their accounts of proceedings retrospectively. In acknowledgement of this, all health care professionals had access to the hospitals computer system Proton throughout the interviews, and many also had access to the patients' paper medical records, yet these were used infrequently. Nurses relied solely on memory while Proton and the notes were consulted only six times during the interviews with physicians. In light of the results from this case study, I can only speculate that similar memory distortions could have occurred in other interviews although at the time I was struck by how well nurses and physicians seemed to remember the patients and had written as such in my field notes. Possible outcomes from this could be to recommend that medical records and Proton be consulted during each interview; however this would negate the point of this phase of the study, which was to elicit perceptions and opinions of health care professionals. Instead I would recommend that attempts could be made to marry the information given by patients and health care professionals with that obtained from the medical notes and Proton in order to ascertain the extent of the recall bias.

As discussed in the previous chapter, in other interviews compliance was largely linked with intelligence, with the perception being that patients who were intelligent were largely compliant, yet this case was different and seemed to challenge the health care professionals' notions of the characteristics they usually associate with compliance. The nurse in particular said several times that the patient was intelligent and she herself displayed a good level of knowledge of kidney disease and treatment options.

Both healthcare professionals spoke a number of times about the patients' cultural background associated with her being a Muslim. The physician couched this within the context of her having a difficult relationship with her parents because she came to



clinic appointments without them and asked that her father not be a donor. Yet, as a woman in her late teens and early twenties, is it unreasonable for her to attend clinic appointments on her own? At a time when many young people have left home already to go to university or to start employment, perhaps it is not unusual for people of this age to establish and maintain a level of independence regarding their interactions with health care providers.

Furthermore, she was not the only patient within this study who had refused a kidney from a living donor, and this in itself is not uncommon. One study showed that 80% of 115 patients refused to consider a living related kidney donation from a family member (Murray and Conrad 1999). As Sajjad and colleagues highlight in a comprehensive review of the dynamics of recipient-donor relationships, there are complex psychosocial issues in living kidney transplantation (Sajjad, Baines et al. 2007). Recipients often report feeling guilty and indebted to the donor with many feeling uncomfortable about accepting a kidney donation that a family member may ultimately need. Recipients are also concerned about the disappointment that a transplant failure can bring to the donor (Waterman, Stanley et al. 2006). Within the interview the patient showed insight into her own problems with forgetting to take medication suggesting that this could be one reason for her reluctance to proceed with the transplant, as she knew that ultimately forgetting to take immunosuppressant medication could lead to transplant failure.

Overall the review by Sajjad and colleagues highlights that relationships between donor and recipient within a family may change as a result of the transplantation and that it is not unusual for there to be a period of adjustment (Sajjad, Baines et al. 2007). This suggests a need for greater psychological support from the renal services, something that may have been missing for this patient. Seen within this context, her initial refusal to accept her fathers' kidney is perhaps not all that unusual and shows that greater efforts to understand her motives could have been beneficial in finding a way forward.

The emphasis on the patients' cultural background, and the unease with which the health care professionals spoke of it, suggests that there could be barriers to full interaction with Muslim patients, maybe based on stereotypical ideas of beliefs and practices, and difficulties encountered when trying to cross the perceived cultural divide. That there are cultural issues in health encounters is something that has been borne out in a study out in the Netherlands in which consultations between ethnic minority patients and native born physicians were compared with consultations between native born patients and physicians in general practices (van Wieringen, Harmsen et al. 2002).

One of the major findings was that ethnic-minority patients experienced more problems in their relationships with general practitioners and that they were less satisfied with the communicative behaviour of the general practitioner than the native born patients. Furthermore, while in 24% of consultations in the study there was no mutual understanding reached regarding the health problem, this was more prevalent in interactions with patients of ethnic minority backgrounds. Lack of mutual understanding itself was more likely to lead to non-compliance, defined as the intent of the patient to carry out the instructions issued from the general practitioner. Of note is that while there were differences in health beliefs and locus of control in the two groups of patients, this was not associated with differences in mutual understanding. These results reveal that it is difficult to isolate the factors that influence the interpersonal exchange between people of different cultural backgrounds and suggest that an interaction of many variables could be accountable for lack of satisfaction and ultimately mutual understanding.

A critical literature review of cultural differences in intercultural communication has led to the conclusion that there are five key predictors of culture-related communication problems, these are: 1) cultural differences in explanatory models of health and illness; 2) differences in cultural values; 3) cultural differences in patients' preferences for doctor-patient relationships; 4) racism/perceptual biases and 5) linguistic barriers (Schouten and Meeuwesen 2006).



The findings from my study presents an area for further research in which health care professionals' beliefs and actions towards patients from other cultures, particularly Muslim patients, should be explored in order to understand what, if any, influence this may have on how patients are treated within our system and how communication and relationships can be eased. Much of the previous research in this area has focussed on the patient perspective, therefore I suggest that it is particularly important to approach future studies with the aim to understand these issues from the health care professionals' perspective as well, as the communication process is two-way and must be informed by cultural beliefs held by both parties (Penn, Kar et al. 1995). Further research studies in this area should be informed by the five domains identified in the review above. A greater understanding of the role of cultural issues could lead to improvements in care through health care professional education on intercultural communication (Schouten, Meeuwesen et al. 2005).

### **11.5 Conclusion**

This chapter has presented four case studies, chosen to highlight particular areas within the interviews which mainly came to light when viewed on a case by case basis. Case study one highlights the different perspectives of the same situation that may be held by patients and health care professionals. It is possible to infer that there remains a strong ceremonial order to clinic appointments which some patients appreciate but which may stifle open dialogue, thus limiting the interaction and leading to frustration and lack of understanding on both sides.

Case studies two and three highlight the range of preferences that patients have for being involved in treatment decisions. Within the current kidney care system it would seem that shared decision making is scarce, yet evidence suggests that this is the preferred decision making model of patients with chronic kidney disease and across other disease states. This is an area where there is a clear need for development within our system, and within which improvements could lead to better patient outcomes.

Case study four reveals that there is a perception by the health care professionals that matching patients with health care providers based on age and ethnic background could bring about benefits by enhancing communication. This suggests an awareness of the culturally stereotypical views held by some of health care providers. This case study highlights the need for better intercultural understanding and examination of cultural perceptions and their origins. In an area such as Leicester where so many patients are of ethnic origins different to the predominantly white European origin of the kidney care providers, this is of particular importance.



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# CHAPTER 12

## Overall discussion: Summary, implications & future research

### 12.1 Introduction

In this thesis I have presented an investigation of the reasons why patients start on dialysis urgently when they have been known to the renal services for some time. Chapter 1, the introductory chapter, explained chronic kidney disease and highlighted the complexity of the process of dialysis initiation. The literature review in Chapter 2 provided a detailed account of the measures taken by researchers to overcome the problem. The first phase of this study, reported in Chapters 3 – 5, provided background data regarding the scale of the problem locally and highlighted some factors that may contribute to patients having an urgent dialysis start. The second phase, Chapters 6 – 11, comprised a detailed account of an in-depth qualitative study that has led to an increased understanding in three vital areas. These are: 1) the experience of living with the consequences of having chronic kidney disease, 2) perceptions of the current kidney care service and 3) the attitudes of health care professionals towards patients with chronic kidney disease.

In this, the final chapter of this thesis, I aim to concisely draw together and discuss the results and findings of both phases of the research. The chapter is structured to answer four questions which relate to the aims of this study in terms of confirming, quantifying, exploring, and considering methods of addressing, the topic under consideration. Table 12.1 below shows these questions and the origin of the data used to answer them. The chapter concludes with suggestions for future research areas that have arisen from this piece of research, including the outline of a specific proposal for a research programme which would build on the findings documented in this thesis. The strengths and limitations of the research phases have been discussed

in these earlier chapters, and although not repeated here have been acknowledged in preparing the discussion that follows.

**Table 12.1 The questions answered in Chapter 12 with data origins**

Data origin	Question
Introduction/Literature review in Chapter 2/ Phase 1	Is there a problem of patients starting dialysis urgently when they have been known to renal services within the East Midlands Renal Network?
Literature review in Chapter 2 Phase 1 & Phase 2	What are the barriers to patients starting on dialysis electively?
Phase 2	Why do these barriers exist?
Health literature & reflections on findings from this study	How can these barriers be overcome?

**12.2 Is there a problem of patients starting dialysis urgently when they have been known to renal services within the East Midlands Renal Network?**

Reports of patients starting on dialysis urgently when they have been known to renal services, be it for 3,4,6, to 12 months prior to dialysis, are widespread (Roderick 2002; Ansell, Feest et al. 2006). Data from this study have shown that within the East Midlands Renal Network approximately a third of patients known to renal services for at least 4months before needing dialysis start dialysis in an emergency situation via a temporary haemodialysis catheter, and that almost all of these patients had been known to renal services for at least a year, which is comparable to national data (Ansell, Feest et al. 2006).

**12.3 What are the barriers to patients starting on dialysis electively?**

The barriers identified in this study are personal, medical, and organisational. Geographical barriers were not found to exist. Data from phase one of this study reveal several possible barriers to elective dialysis presentation. As would be expected, patients who started on dialysis urgently were, on the whole, more ill than those who had an elective dialysis start. A further barrier is delayed discussion of dialysis and later consultation with the home care team regarding dialysis options. Additionally, non-attendance at a dedicated predialysis clinic was strongly associated



with an urgent dialysis start. Common to both phases one and two was the impact that age may have on a person's likelihood of starting dialysis urgently. Data from phase 1 showed that there was a strong association between older age and urgent dialysis start, with the odds of having an urgent dialysis start increasing by 4% each year. Age also emerged as a theme in the health care professional interviews with the suggestion that younger patients are treated and viewed differently from older patients within our kidney care system. Other findings from phase two suggest that acceptance plays a very important part in patients' readiness to prepare for dialysis, and that there are many barriers and facilitators to acceptance. The type, timing and mode of delivery of information and education proved to be a barrier for some patients. Findings from health care professional interviews suggest that sometimes their approach to, or relationships with, patients may prove to be a barrier in terms of their emphasis on compliance and 'good behaviour'. The health care professional interviews also highlighted the intricate nature of the timing of referrals within the kidney care system with late referrals and delayed action once referrals have been made being seen as major barriers.

#### **12.4 Why do these barriers occur?**

It would seem that many of the barriers identified are interrelated and may be indicative of a traditional approach to health care. As was noted in Chapter 10 section 10.6, ageism, with its emphasis on the greater benefit of treatment as a right of younger people, is endemic within the NHS and is certainly not isolated to the population I studied. The paternalistic approach to patients that is suggested within the health care professional interviews explains, in part, the emphasis on patient compliance and the medical model approach to information giving and education which proved to be a barrier for many patients. Similarly, the problems with acceptance that many patients face could be related to the limited level of psychosocial support available throughout the whole disease process.

It is beyond the scope of this study to fully explain the reasons for some of the organisational barriers that were shown in phase 1 to have contributed in almost half

of urgent dialysis cases and were further identified by health care professionals in phase 2; however, my overall impression is that some of these are related to the current structure of care. For example, this study shows that the current focus on ‘the golden year’ before dialysis may be slightly misleading as discussed in Chapter 5, section 5.4. As phase one showed, almost all patients who had an urgent dialysis start had been known to the renal services for longer than a year. This suggests that even a year in the system studied may not be long enough to prepare for a smooth transition to dialysis. From a practical point of view this may soon change however with the imminent introduction of the 18 week wait initiative in which it will be incumbent on the health service to ensure that patients awaiting elective procedures, such as the creation of vascular access, undergo the procedure within 18 weeks from referral ([www.18weeks.nhs.uk](http://www.18weeks.nhs.uk)). However, my reasons for suggesting that the golden year may not be the most appropriate approach is concerned with the shift in care that seems to take place when someone is approaching dialysis, and how this is not always in the patient’s best interest.

## **12.5 How can these barriers be overcome?**

Overcoming barriers to elective renal replacement therapy can be viewed as a process requiring two inter-related approaches. These are 1) organisational changes based on, and informed by, 2) changes in how patients are perceived and treated within the kidney care system.

### **12.5.1 Patient / health care professional relationships**

Based on my findings, I would argue that the most fundamental change that is required is a shift in the focus of the relationships between health care professionals and patients. A move towards a more holistic, patient centred approach, should underpin any organisational changes. As mentioned in Chapter 10, section 10.4, the balance of power has shifted over the recent decade towards a less paternalistic approach and towards a more equal relationship often described in terms of concordance. Concordance has been used to describe the ideal outcome of a physician/patient interaction in which both patient and physician reach an agreement



about the treatment plan. The term was first used in this context by the working party of the Royal Pharmaceutical Society of Great Britain who's remit it was to examine the concepts of compliance and adherence in relation to the taking of prescription medication. The working party state that:

‘Concordance is based on the notion that the work of prescriber and patient in the consultation is a negotiation between equals and that therefore the aim is a therapeutic alliance between them. This alliance may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient's agenda and the creation of openness in the relationship so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment’ (Royal Pharmaceutical Society Working Party 1997)

This definition is open to scrutiny. One of the criticisms of this definition, and indeed the concept of concordance, is the assertion that the consultation and therefore the whole relationship, is a negotiation between equals with critics claiming that this is simply untrue due to the imbalance of medical and health knowledge between the parties. Such a literal and narrow translation of the word ‘equals’ is unhelpful. Instead, the word in this context should be taken to mean people of equal standing and worth but with different backgrounds, knowledge and ideas. The thrust of concordance is to bring people together to create an environment where all views are taken into account and respected.

As this research has shown, some patients are very keen to take part in treatment decisions and others are happy to leave decisions to health care professionals. Moving towards a shared decision making approach should not adversely affect those who do not wish to be so involved in decisions about their care. Assessment of patients' preferences regarding involvement in treatment decisions and care is not always easy, and preferences can change over time. Therefore there is a clear need for the development of tools and approaches that can assist with identifying

preferences for involvement in decision making and which can be incorporated into regular care.

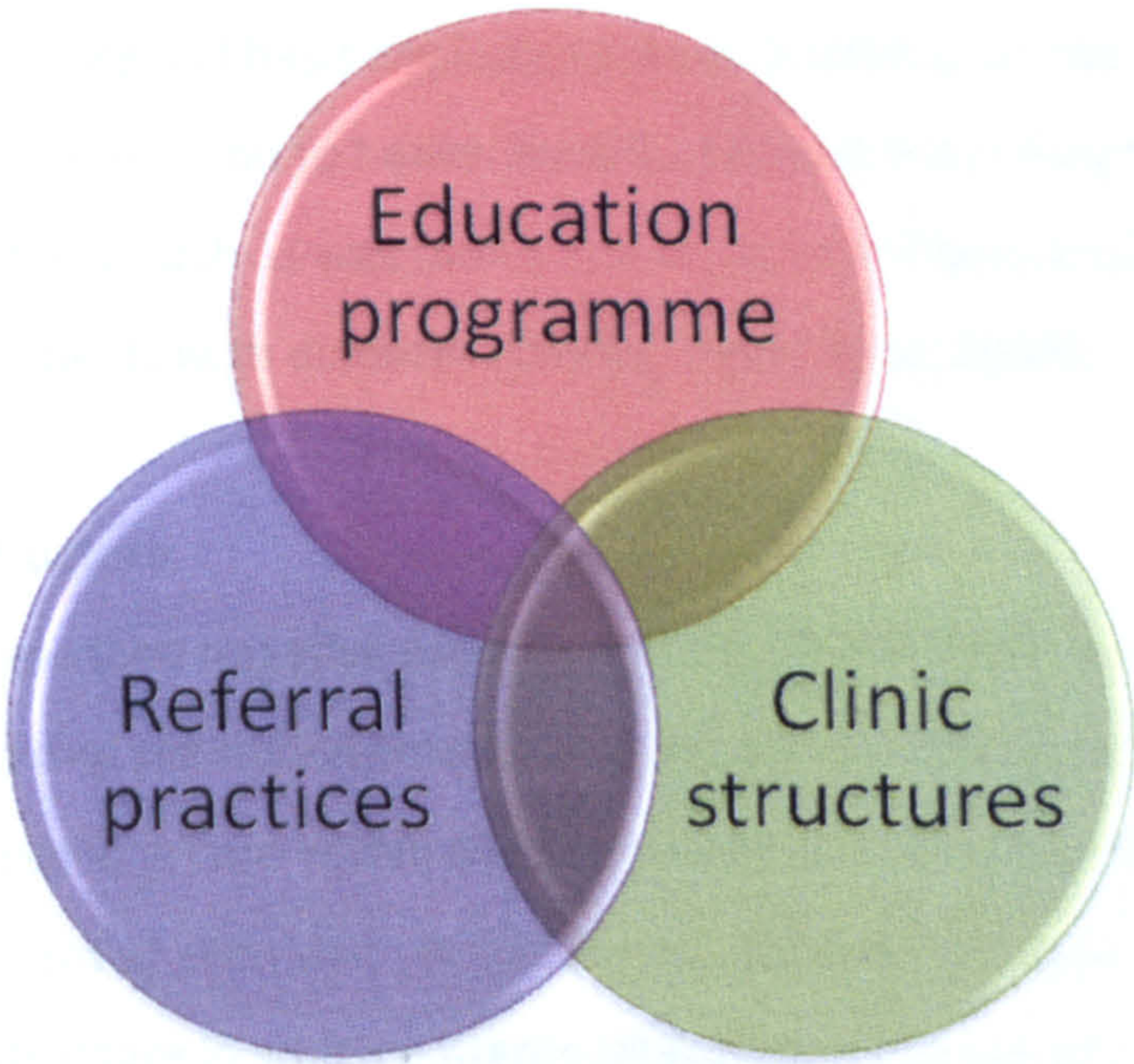
### **12.5.2 Organisational changes**

My findings suggest that preparation for dialysis should not be viewed as a separate aspect of care which marks a great junction, but instead should be one of the many factors incorporated into generalised education throughout the disease process. As discussed in Section 1.2.3, the majority of people with CKD will never require dialysis, and therefore it may be argued that it could be upsetting to discuss dialysis early in the course of the illness, however I believe that it would be possible for this topic to be addressed earlier on with the emphasis on a gradual introduction. This would allow patients the opportunity to learn about it over a longer period of time and would allow a build up of knowledge that some patients pointed out is lacking at the moment due to the single education session and the time pressure to make a decision. Also, it is possible that acceptance, which emerged as a barrier to elective dialysis start and is time related, may be achieved by a longer introduction to dialysis. Many patients expressed fear at the time of diagnosis as the perception many held was that chronic kidney disease is a fatal illness. Incorporating early support and education, including an introduction to the role of dialysis and transplantation, could serve to provide hope if handled sensitively.

Based on reflections on my findings, I would suggest that there are three areas where organisational changes could be effected to bring about better outcomes for patients, which could decrease the number of patients starting on dialysis urgently. These are shown in the diagram below which seeks to emphasize the way in which these proposed changes are inter-related.



**Figure 12.1 Organisational changes necessary to overcome barriers to elective dialysis initiation**



**12.5.2.1 Education programme**

The importance of information and education was clear throughout this study. Results from phase 1 showed that patients who had had an elective dialysis start were more likely to have been to the patient information day, and information emerged as a major theme from the interviews with patients and health care professionals in phase 2. The literature review in Chapter 2 of this thesis revealed that patient education interventions were often used to try to decrease the numbers of patients starting dialysis urgently, albeit with varying effect. The majority of these studies lack two elements crucial to patient education: a theoretical basis and input from patients in the development stage. According to Lorig, whose research has provided the foundation for the Expert Patient Programme currently being trialled in England ([http://www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH\\_5380856](http://www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH_5380856)), ‘it is irresponsible to plan a patient education programme that is not based on one or more theories’ (Prohaska and Lorig 2001). A recent systematic review of patient education for patients with kidney disease revealed that lack of a theoretical basis is not confined to the predialysis phase, and indeed it is a problem across the spectrum of chronic kidney disease and established renal failure (Mason, Khunti et al. 2008). Using psycho



sociological theories to underpin patient education programmes can provide an explanatory framework for planning, implementation and evaluation of these programmes. A theoretical basis can help to drive the focus on the entirety of the patient experience in relation to health beliefs and how these may translate into health related actions, such as was found in a study of a theory based educational programme for patients with diabetes (Davies, Heller et al. 2008).

#### **12.5.2.2 Clinic structure**

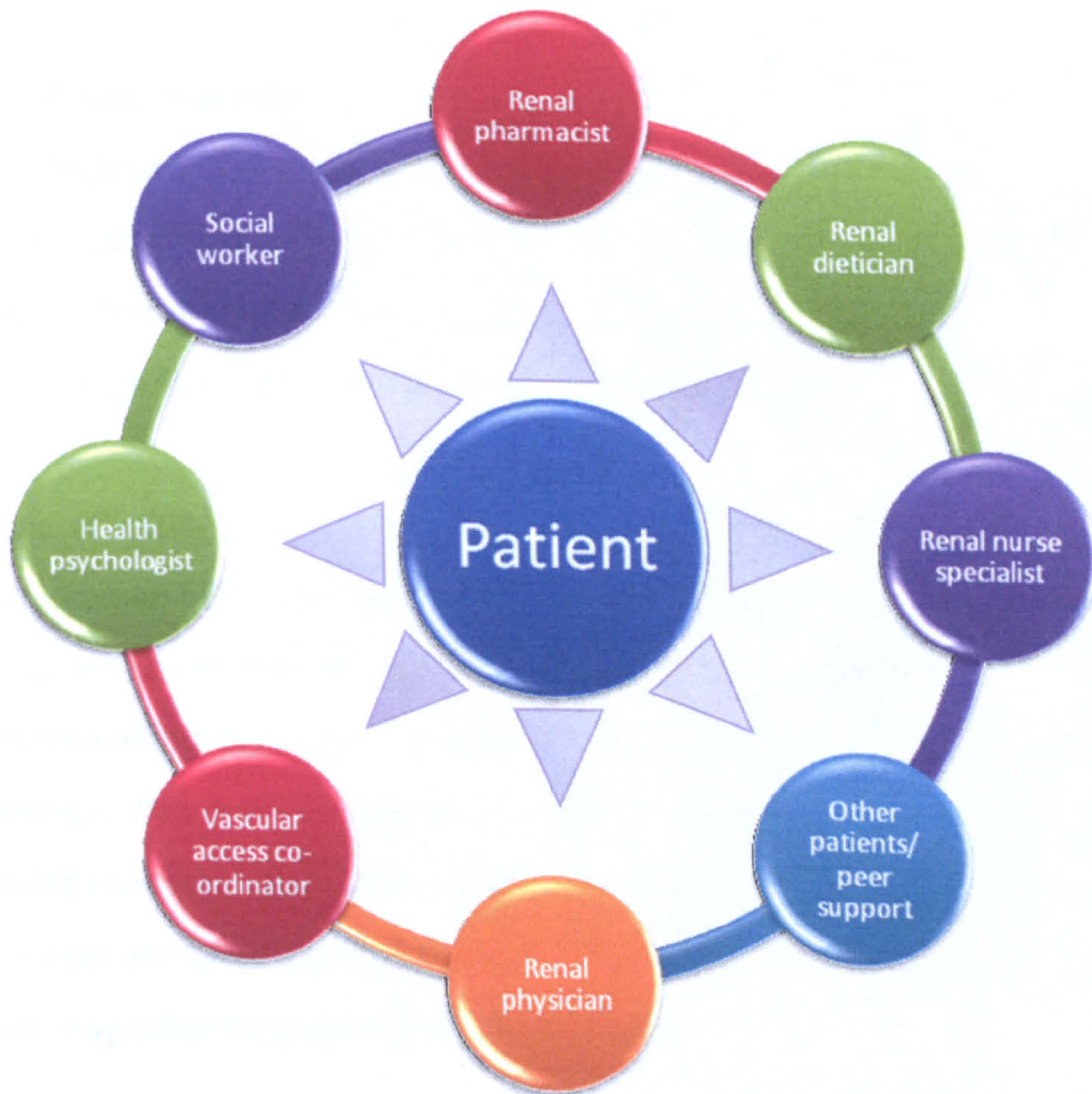
Many patients described negative aspects of their clinic experiences, with the perception being that the appointments are task driven with limited physician contact time. Patients receiving care within the predialysis clinics in Leicester usually see only a medical consultant at each visit. Reflection on my findings leads me to suggest that a revised clinic structure in which patients attend clinics to see one or more people from a range of professional groups could alleviate some of the barriers to elective dialysis start identified by my research.

This suggestion is supported by several studies which have concluded that patients benefit from attending multidisciplinary clinics in nephrology (Goldstein, Yassa et al. 2004; Hemmelgarn, Manns et al. 2006; Komenda and Levin 2006). In these studies the emphasis has been on the benefit seen in physical parameters such as mineral metabolism, nutrition and blood pressure, with little mention of the psychological effects that could be gained. However the potential for benefits related to quality of life and patient satisfaction is something which could be usefully investigated. From these studies it is not possible to draw conclusions about the ideal model of a multidisciplinary clinic due to wide variation in the staff groups included. Given the complexity of chronic kidney disease the staff groups which could be involved are numerous, including dieticians, nurse specialists, physicians, vascular access co-ordinators, psychologists, social workers and transplant co-ordinators. A model which allows patients the flexibility to be involved in the decision about who they should see at each visit, and which also allows health care professionals to refer patients to each other, could serve to provide a customised service to patients based on their



individual needs. This is likely to involve longer appointments and could impact on other areas of the current service, something which will be discussed below in section 12.6 (areas for future research). Figure 12.2 shows the core concept of a revised clinic, the centrality of the patient and the inter-relationship of the health care professionals.

**Figure 12.2 Model of possible clinic structure**



**12.5.2.3. Referral practices**

Many barriers were associated with delays in referrals and follow-ups during the predialysis phase. It should be possible to build in the streamlining of referrals within a revised clinic structure. Two developments could assist in this. Firstly, the creation of clinical guidelines regarding the timings of referrals within the multidisciplinary team and, secondly, patient held records. Clinical guidelines, which should be developed with input from all stakeholders, can be useful in terms of promoting consistency and establishing standards which can be audited ([www.nice.org.uk](http://www.nice.org.uk)).



Although not widely used in kidney care, patient held records have been evaluated in other areas, with mixed results. In a pragmatic randomised controlled trial in cancer care by Williams and colleagues, patient held records were found to facilitate communication between patients and health care professionals (Williams, Cheung et al. 2001). Patient held records could serve as a tool for patients to help to monitor the progress of referrals shifting the onus of responsibility from solely the health care professionals to both parties.

## **12.6 Areas for future research**

This thesis has highlighted several areas where future research could prove beneficial in improving the experience of patients with chronic kidney disease both through increasing our understanding of the interaction between health care professionals and patients and through the testing of different models of service delivery.

### **12.6.1 Age and ethnicity**

As has been discussed extensively in Chapter 5, section 5.3, Chapter 10 section 10.6 and mentioned in this chapter in section 12.4 , age does appear to have an impact on how patients fare within our current kidney care system, with older age placing them at a disadvantage. This certainly warrants further exploration as the population ages and the age of patients on dialysis rises. Research should focus both on how health care professionals attitudes towards patients could influence their care, and how service needs may differ for patients of different ages.

Chapter 11, section 11.3.5 revealed how intercultural communication difficulties based on stereotypical images may have played a small part in how a Muslim patient was treated and cared for within our system. A greater understanding of how health care professionals regard patients from other cultures than their own and how this could have an impact on care and communication could be useful in highlighting areas of misconception.



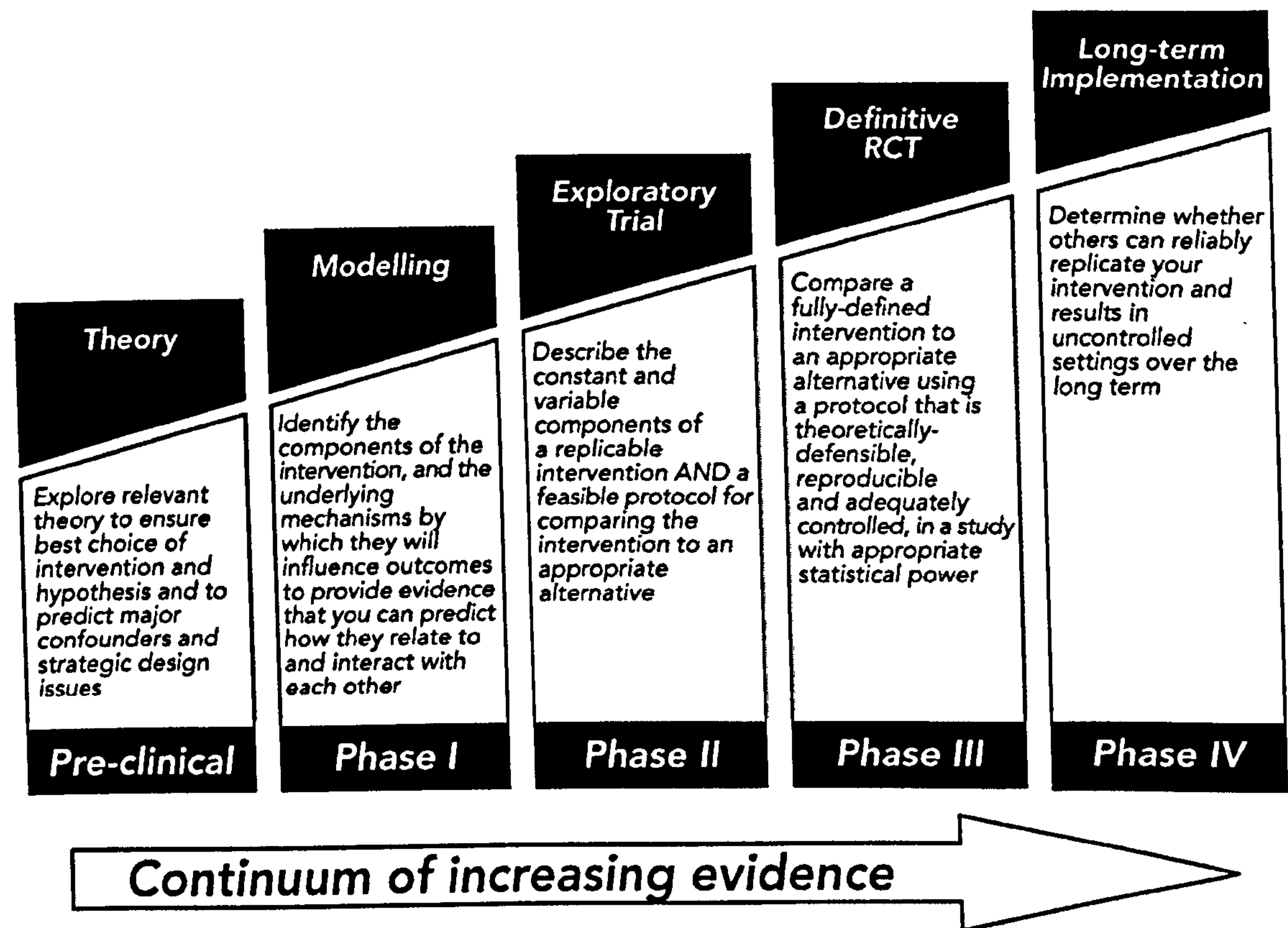
### **12.6.2 Service redesign involving patients and stakeholders: outline proposal**

In the following sections I will outline a proposed plan of investigation for building on the findings from the research presented in this thesis. The literature review in Chapter 2 revealed that while there have been studies carried out with the aim of reducing the number of patients starting dialysis urgently, the role of the patient in the planning, implementing and evaluation of these studies has been severely limited. This contrasts with the current ethos of embedding patients views within research and within service redesign and delivery as discussed in Chapter 1, section 1.4. With this in mind I propose there is a strong need to carry out a research study which encompasses many of the changes suggested in this chapter which involves actively seeking patients' views and eliciting their preferences for service delivery. This should extend beyond simply asking patients what they would like, as this could lead to a list of improbable services. It should rather entail patients making choices regarding aspects of service delivery which would require prioritising some options over others in order to allow for a realistic and pragmatic service. I believe this is something best achieved by the use of a technique such as a discrete choice experiment, which is discussed below in section 12.6.2.1.

A further limitation of the studies discussed in Chapter 2 is the non-experimental nature of the designs which leads to concerns regarding validity. The latter may be best addressed by using a randomised design. I believe that overall the research that is detailed within this thesis and that which should ensue, is consistent with the 'Framework for development and evaluation of RCTs for complex interventions to improve health' proposed by the Medical Research Council (MRC) (Medical Research Council 2000) and shown in Figure 12.3 below. Within the framework, five stages are outlined, three of which are carried out as preparation for the fourth stage which is a randomised controlled trial. The work within this thesis has provided evidence for phase one, the preclinical stage, in which theory is explored to explain the problem and choose the best interventions. I suggest carrying out the next phase by undertaking a discrete choice experiment which would identify the components to be studied in a pilot study, before being fully tested in a randomised controlled trial. The

results of stage one of the proposed research programme, the discrete choice experiment, would be used to inform the development of stage two by informing the detailed design of the intervention.

Figure 12.3 MRC Framework for trials of complex interventions



12.6.2.1 Stage 1 – Discrete choice experiment

This thesis has identified several areas where changes could be made and, within these, multiple ways of delivering change. These potential changes are principally related to the delivery of patient education and the structure of the predialysis clinic in terms of staffing. To choose which changes to make and to be certain that these changes are appropriate and in line with what patients would find acceptable, I suggest carrying out a discrete choice experiment to elicit patients’ preferences for the delivery of education and the staffing structure of pre-dialysis clinics.

Discrete choice experiments (DCEs) are based on economic theory and in particular the idea that an individual’s preference for goods (or services) is not based on the good *per se* but rather the attributes (or characteristics) of the good. DCEs have been



widely applied to health care settings where services can be described in terms of several dimensions (Ryan and Gerard 2003). Because DCEs are an economic method and based on the principle of trade-offs they are a useful tool for developing patient centred services where change is necessary but additional funding is not necessarily available. As with all preference elicitation methods, they ensure that patients’ views are embedded in the research process. In this case, using a DCE would ensure that the pilot study, and ultimately the RCT, are responsive to patients’ preferences.

A DCE is conducted in three stages: design, implementation and analysis. The design stage defines the attributes (and corresponding levels) that describe the service. The attributes for the proposed study would be identified from the patient and staff interviews about predialysis care as discussed in this thesis. In the design of a DCE, attributes and levels are combined to describe possible (hypothetical) service delivery packages (or scenarios). Considering all possible combinations (the full factorial) would be an overwhelming task for respondents, therefore a reduced number of combinations is selected using experimental design methods (Hensher, Rose et al. 2006). These combinations are arranged into choice sets, and patients are asked to complete a questionnaire where they pick their preferred scenario. An example of a typical choice set is shown below in Figure 12.4.

**Figure 12.4 Example of a possible DCE choice set**

<i>Attribute of possible service</i>	<i>Option A</i>	<i>Option B</i>
Frequency of appointments per year	6	8
Time spent in clinic per visit	2 hours	30 minutes
Education	In clinic	4 evening sessions
Professionals delivering main care	Dr & Nurse	Dr / Nurse alternating
Home visit	No	Yes
If I had to choose my preference is	Option A <input type="checkbox"/>	Option B <input type="checkbox"/>

In the implementation stage, a sample of patients would be asked to complete the DCE questionnaire. I would recommend including 150 patients approaching renal

replacement therapy (expected to start RRT within 18 months/patients with an estimated glomerular filtration rate of <25 ml/min/1.73m<sup>2</sup>) and 150 patients who have recently started on renal replacement therapy. The preferences of both groups of patients could be compared in order that we can understand whether changes desired by patients who have been through the predialysis year in our care system match those of patients approaching the predialysis phase. Analysis would best be carried out with input from a health econonmist and a statistician

**12.6.2.2 Stage 2 – Exploratory pilot study**

The aim of the pilot study would be to test the feasibility of the interventions and to make adjustments as necessary to the content and delivery of the interventions before proceeding to a randomised controlled trial. The DCE would provide the basis for the interventions to be tested in an exploratory pilot study. This could take the form of a 2x2 factorial design in which patients would be randomly assigned to one of four groups as shown below, with each group consisting of 10 patients who have approximately one year before starting on dialysis based on rate of decline of eGFR.

Group 1)	Standard care (clinic & education)
Group 2)	Standard clinic + revised education
Group 3)	Standard education + revised clinic
Group 4)	Revised clinic + revised education

I would recommend that the educational programme should be underpinned by the principles of social cognitive theory with the aim of empowering patients to make relevant behavioural changes and informed choices about their illness management. It should be developed according to the process outlined by Lorig (Lorig 2001) which involves five stages: 1) needs assessment 2) planning 3) implementation 4) evaluation 5) dissemination. The needs assessment in the form of patient questionnaires and/or focus groups could be carried out concurrently with the DCE. However, the planning stage could be implemented only following patient feedback on the structure of the programme which would be obtained from the DCE. As a result of my research as



presented in this thesis, I envisage that the clinic structure would change to include nurses and allied health care professionals carrying out patient consultations in parallel with medical staff. However, the frequency of contact with nurses, allied health care staff and doctors would again be determined by the DCE.

Modifications indicated by the findings from the exploratory (pilot) study would provide the final interventions and study design that would be tested in a full randomised controlled trial.

## **12.7 Conclusion**

This chapter has shown how this thesis has addressed the aims of the research study, which was to identify barriers to the elective start of renal replacement therapy. Several recommendations have been made where changes could be implemented to bring about a lowering of the number of patients starting dialysis urgently, as well as areas of future research which could ensure that the findings from this thesis are used to form a strong basis for evidence based quality improvement.

# Appendix 1

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Case report form from phase 1



# BERRT Study

## Phase 1 Case report form

Unique ID				Status	elective / known acute		
Consent received	____/____/____			Consent obtained by	SN / GW / JB / Letter		
Date of birth	____/____/____			Date started RRT	____/____/2003		
Age on admission		Sex	F / M	Ethnic group		Location	
Mode of RRT patient started on	Transplant		Home Haemo		Haemodialysis		Peritoneal D
1° renal diagnosis							
<b>Comorbidities from registry and notes (tick if positive)</b>							
Angina		Cerebrovascular disease					
Previous MI within last 3 months		Diabetes					
Previous MI > 3 months ago		COPD					
Previous CABG or coronary angioplasty		Liver disease					
Claudication		Malignancy					
Ischaemic/neuropathic ulcers		Smoker					
Angioplasty (non coronary)		Abdominal aneurysm repair					
Amputation for peripheral vascular disease		Pulmonary embolism					
<b>Drugs on admission (tick if positive)</b>							
Phosphate binder		Epoetin		Anticoagulant			
Lipid regulator		Iron		Bicarbonate			
ACE inhibitor/Angiotensin II RA		Diuretic		Alpha blocker			
Calcium channel blocker		Vitamin D		Beta blocker			

<b>Reason patient presented as known acute</b>					
Illness related		Service related		Patient related	



**Renal Replacement Therapy & Dialysis Access Information**

<b>Renal replacement therapy</b>					
Date of first documented discussion of RRT				____/____/____	
Venue of first documented discussion of RRT					
Had mode of RRT been decided at time of admission?				Y / N	
If so, what was decision?	Transplant	Home haemo	Haemo	PD	None
Approximately how long was the decision making process from first documented discussion to decision on mode of RRT?					
Had patient significantly* changed mind about mode of RRT?				Y / N	
<b>Dialysis access related information</b>					
Did patient have a PD catheter on admission?		Y / N	If yes, was it functioning?		Y / N
Did patient have a fistula on admission?		Y / N	If yes, was it functioning?		Y / N
If patient did not have dialysis access on admission, had s/he been referred to have access formed?					Y / N
<b>Access formation</b>	Date referred ____/____/____	Date seen by vasc. surg ____/____/____		Date access created ____/____/____	
Did patient start dialysis using a temporary catheter?					Y / N
<b>Patient information day</b>					
Did patient attend a patient information day before admission?					Y / N
Approximate date patient attended patient information day					
Length of time since patient attended patient information day					
<b>Transplant related issues</b>					
Was patient in the process of being assessed for transplant?					Y / N
Was patient actively waiting for cadaveric or living transplant?					Y / N

\* significant change: a change that led to a delay in creating access or commencing on RRT in planned way



Nephrology Service Input

Care of patient by nephrologist/nephrology services					
Date patient first referred to nephrology service			___/___/___		
Date patient first seen by a nephrologist			___/___/___		
Length of time patient waited to see a nephrologist					
Was patient seen in the predialysis clinic?			Y / N		
Date patient first seen in predialysis clinic			___/___/___		
Length of time patient was followed up in predialysis clinic					
Length of time patient has been known to nephrology service					
Nephrology appointments in 12 months before admission (date & grade – Reg/Con)					
___/___/___		___/___/___		___/___/___	
___/___/___		___/___/___		___/___/___	
___/___/___		___/___/___		___/___/___	
___/___/___		___/___/___		___/___/___	
___/___/___		___/___/___		___/___/___	
Predialysis dietetic input ( how long since patient saw dietician?)					
Number of times patient saw dietician in 12 months before admission			Date last input ___/___/___	Months:	
Home care team input					
Date patient first referred to home care team			___/___/___		
Date patient first seen by home care team			___/___/___		
Length of time between referral and home care team visit					
Home care contacts in 12 months before admission (visits and phone calls)					
___/___/___	___/___/___	___/___/___	___/___/___	___/___/___	___/___/___
___/___/___	___/___/___	___/___/___	___/___/___	___/___/___	___/___/___



Missed or cancelled appointments

Missed, cancelled and delayed appointments		
Appointments cancelled by hospital in 12 months before admission		
Appointment	Date	Reason
	___/___/___	
	___/___/___	
	___/___/___	
	___/___/___	
	___/___/___	
Appointments cancelled by patients in 12 months before admission		
Appointment	Date	Reason
	___/___/___	
	___/___/___	
	___/___/___	
	___/___/___	
	___/___/___	
Appointments patient DID NOT ATTEND in 12 months prior to admission		
Appointment	Date	Reason
	___/___/___	
	___/___/___	
	___/___/___	
	___/___/___	
	___/___/___	



# BP and blood results

Blood pressure and blood chemistry			
Mean values over 12 months prior to admission (from excel table)	Mean systolic pressure	mmHg	
	Mean diastolic pressure	mmHg	
	Mean weight	kg	
	Mean potassium	mmol L <sup>-1</sup>	
	Mean PTH	mmol L <sup>-1</sup>	
	Mean phosphate	mmol L <sup>-1</sup>	
	Mean calcium	mmol L <sup>-1</sup>	
	Mean bicarbonate	mmol L <sup>-1</sup>	
	Mean haemoglobin	g/dL <sup>-1</sup>	
	Mean albumin	g/L <sup>-1</sup>	
Creatinine at start of RRT		μmol L <sup>-1</sup>	
Difference in creatinine between 12 months before admission and admission		μmol L <sup>-1</sup>	
Difference in creatinine between last and current admission		μmol L <sup>-1</sup>	
Urea at start of RRT		mmol L <sup>-1</sup>	
Difference in urea between 12 months before admission and admission		mmol L <sup>-1</sup>	
Difference in urea between last and current admission		mmol L <sup>-1</sup>	
GRF at start of RRT			
Difference in GFR between 12 months before admission and admission			
Difference in GFR between last and current admission			
Difference in weight between last and current admission		kg	
Reason(s) given in patient records if patient starting as known acute			
Form filled in by		Signature	
Date completed	____/____/____		



# Appendix 2

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Information leaflet phase 1



## Information leaflet for patients

March 2005

Study title: Barriers to elective start of renal replacement therapy – what are they, why do they occur and how can we overcome them?

(in other words...why do some people end up coming in as emergency patients to start on dialysis when we have known them for a while?)

### Phase 1: Retrospective case note review

We are writing to ask you if we can use information contained in your patient case notes to help us in a research study. Before you decide, it is important for you to understand why we are doing this research study and what it will involve. Please take your time to read through this information carefully, speak to others about it and please get in touch with us if you would like any more information.

#### What is the purpose of the study?

This patient case note review forms the first part of a three-year study which we hope will lead to improvements in the care of patients with kidney problems in our region. Below is an explanation of the **whole** study, but please remember we are writing to you *only* about the first part (phase 1).

Why we are doing the study: When patients with kidney problems are approaching the stage when they will need dialysis, we try to ensure that everything is in place for patients to start on dialysis in a planned way. This means ensuring that:

- 1) we help patients to make a decision about the best type of dialysis option for them
- 2) this decision is made in enough time to ensure that a permanent dialysis access point (either a catheter for peritoneal dialysis or a fistula for haemodialysis) has been created

We try to ensure that this process goes smoothly for every single patient who we know is going to need dialysis, and for many patients the transition onto dialysis does go well. For other patients however, dialysis starts only when they are very unwell and there isn't enough time to create a permanent dialysis point. This is bad all round - for patients, their families and for the hospital. Patients who start dialysis in this way are often much more unwell, so extra pressure is put on them and the system. We think that there are probably **many** reasons why this happens. The aim of this research is to find out what those reasons are and to put some measures in place to try to



make sure that as few patients as possible have an unplanned start on dialysis. The study is divided into three parts:

Phase 1: Retrospective case note review (the part we are writing to you about now)

Phase 2: Prospective case by case analysis (interviews with patients)

Phase 3: Design and implementation of new measures

Phase 1 simply involves us looking at the case notes of all of those patients who either started dialysis or had a transplant last year who we had known for at least 4 months. We will be collecting data to see if there are any patterns and differences between those who started dialysis or had a transplant as planned, and those who started as emergency patients. This will help us to plan the second phase of the study.

Examples of the kind of information we will collect are:

- ◆ when was the patient last seen at clinic?
- ◆ had the patient been booked in for an operation to have dialysis access created which was then cancelled? If so, why?

We want it to be absolutely clear that we are not collecting and storing any information that is in any way linked to you. In other words, personal information such as your name, where you live, and your date of birth will not be collected. We will use your name simply for collecting the data from your notes, then your name will be removed and your data will be assigned a unique and random number. So, please be assured that everything that we are collecting will be completely anonymous.

You may be surprised that we are writing to you simply to ask if we can look at and use your notes for this reason, but it is a stipulation of the Data Protection Act (1998) that we seek permission from patients to use their information for research purposes.

### **Why have I been chosen?**

We are writing to you because you either started on dialysis or had a planned transplant in the period we are reviewing (2003) and therefore we would like to collect information from you notes.

### **Do I have to take part?**

No, you do not have to give us permission to look at your notes for this research study.

### **What will happen to me if I take part?**

Nothing will happen to you at all whether you allow us to look at your notes for this research study or not.

### **What do I have to do?**

Please complete the enclosed consent form and return it using the prepaid (free) envelope by the **XX of XXXXX**. Please call or e-mail us if you have any questions before you sign the form. Contact details for the researchers are on the last page of this leaflet.



### **What are the possible disadvantages and risks of taking part?**

There are absolutely no disadvantages to you allowing us to look at your data for this reason. If you choose not to let us gather the data from your case notes for this research it will not impact on your clinical treatment at all.

### **What are the possible benefits of taking part?**

If you allow us to use the information in your case notes for this study, it will be analysed together with all the data from the other patients who started dialysis in the East Midlands area last year and will give us a comprehensive picture of the predialysis process for patients under our care. Probably the only benefit to you of allowing us to use your information is the satisfaction of knowing that you are contributing to research which will eventually benefit other patients who are going through what you have been through.

### **What happens after my information has been gathered?**

We will use the information we gather to see if there are any differences between those patients who start dialysis as planned and those who start in an unplanned way. We will use the information to design the next part of the research project.

### **Will my taking part in the study be kept confidential?**

Yes. No one will know whether or not you allowed us to have access to your case notes for this research study other than the researcher carrying out the research. Again, we would like to stress that when we collect the data it is completely anonymous.

### **What will happen to the results of the research study?**

We hope that we will be able to learn some things from the information we collect. We would present any results to other members of our professions at conferences and through journal publications. We will also use the information from phase 1 to plan phase 2, and together with the information we gather in phase 2 use it to come up with some interventions/measures for phase 3, which should lead to improvements in our service.

### **Who is organising and funding the research?**

The research is being carried out by a nurse research fellow (Jackie Buck) based in the renal department at Leicester General Hospital. The research is being supervised by Dr. Graham Warwick who is a consultant nephrologist at the hospital, and is further being overseen by a steering group made up of doctors, nurses, patients and other members of the multidisciplinary kidney team and university researchers.

The research has been funded by a grant from the Edith Murphy Foundation, which is being administered by the National Kidney Research Fund.

### **Who has reviewed the study?**

The study was reviewed by a panel of 14 experts before the funding was granted by the National Kidney Research Fund. Ethical approval for the first two parts of the study has been granted by the Leicestershire Research Ethics Committee.

## **Summary**

Just to recap: We are writing to you to ask if we can gather information from your notes as part of a research study into the care of pre-dialysis patients. All data will be anonymous. If you agree to let us to use information in your case notes for this research study, please let us know by signing the consent form and either sending or handing it back.

## **Contact for further information**

If you would like more information on anything to do with this study, please get in touch with either:

Jackie Buck (Nurse Research Fellow)  
(Consultant)

John Walls Renal Unit  
Leicester General Hospital  
Gwendolen Road, LE5 4PW  
LE5 4PW

Tel: 0116 258 4110

E-mail: [jackie.buck@uhl-tr.nhs.uk](mailto:jackie.buck@uhl-tr.nhs.uk)

or

Dr. Graham Warwick

John Walls Renal Unit  
Leicester General Hospital  
Gwendolen Road,

Tel: 0116 258 8038



# Appendix 3

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## Procedures for data collection Phase 1

## Procedures for data collection – Phase 1 BERRT Study

- 1) Match patient name with the unique identifier using the master Unique Identifier list (hard copy kept in drawer labelled Phase 1 in tall filing cabinet, Jackie's office). Put unique ID at the bottom of all pages of the CRF.
- 2) Use 'returned consent forms' folder to fill in date consent received (on shelf in Jackie's office)
- 3) Open Excel. Go to the spreadsheet 'Background data from Proton' in G drive, Phase 1 folder. Use 'find' function to identify patient, and fill in fields relating to patient status, date of birth, ethnic group, sex, renal diagnosis. Fill in co morbidities and make a note of the date given for starting on RRT and also the date first seen by the nephrologist.
- 4) Open Proton. Using the patient's name, go to paramedical section and fill in information on page 2 about whether the patient attended the patient information day (this can be changed later if more info is found in the notes). Fill in the information on page three regarding when patient was seen in the last 12 months by the HCT and by the dieticians.
- 5) Open HISS. Using the patient G number, go to the appointment enquiry screen and document all nephrology appointments patient attending in the 12 months prior to start on RRT on page three of CRF. Also fill in page four with cancelled and missed appointments.
- 6) Use medical notes to complete the rest of the form. Use letters in the back of the patient's notes to find out who the patient saw at each visit (consultant / registrar) and also when patient was referred to HCT, predialysis clinic, vascular access etc... Write down statements in the letters that might be important in explaining why a patient might have started as known acute. Use the clinic / hospital notes to find out more information such as the drugs the patient was on before they started RRT and to find out when the first documented discussion was of RRT etc...
- 7) If the actual date of start of RRT found in the notes is different from the date in Proton, use the actual date as the start of RRT and make a note of it in the back of the CRF completion notes book. Use this date for working out the blood results for the 12 months prior to admission.
- 8) Open excel. Go to spreadsheet 'Elective BP and blood results' or 'Known acute BP and blood results' in G drive, phase 1 folder. Using 'find' function to find patients data in the first table. Highlight the fields you are interested in bearing in mind that many of the cases have results from dates that are after the patient started on dialysis. This is where it is important to use the actual date of start of RRT from the notes as it could make a big difference to the results if the date from Proton is used and it is incorrect. Make a note of the field labels as they will be the same in each sheet. Go to row 100 of each table and use the 'mean' function and the dates you are interested in to find out the mean values. Document on the CRF, page five. Document creatinine, urea and GFR on admission using actual date and figure out the difference in the values from 12 months prior and four months prior if possible.

### Notes:

- 1) Use the CRF notes book to write things down as you are going along. This helps to make sense of and unravel the story.
- 2) Use green highlighter in CRF notes book to highlight any language that might be useful or give insight.
- 3) Use red pen to write down any further action that need to be taken at bottom of page.
- 4) Remember to write down actual and Proton date of start of RRT in back of book.
- 5) If notes from other areas need to be accessed, write down the patient unique ID under the area section in the back of the CRF notes book



# Appendix 4

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Patient information leaflet phase 2



## **Barriers to the elective start of renal replacement therapy:** what are they, why do they occur and how can we overcome them?

*A research study to find out about your experiences before you started on dialysis*

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why we are doing this research study and what it will involve. Please take your time to read through this information carefully, speak to others about it and please talk to us if you would like any more information.

### **What is the purpose of the study?**

We aim to find out about people's experiences in the time leading up to starting dialysis.

### **Why have I been chosen?**

We are asking patients who have started on dialysis at Leicester General Hospital or Loughborough Hospital who we have known for at least four months to take part in this study.

### **What will happen to me if I take part?**

After you have read this information sheet you should take some time to make up your mind about whether or not you would like to take part. If you decide to take part then you will be asked to read and sign the consent form. We are asking you to agree to three things:

- 1) To be interviewed by Jackie Buck (the researcher)
- 2) To allow Jackie to talk to the doctors and nurses about your care
- 3) To allow Jackie to look at your medical notes to collect information about your care

Jackie will then make an appointment to meet you to carry out the interview.





Jackie Buck

Jackie - who is a registered nurse and the researcher who is leading this study - will come and interview you, either in your home or here in the hospital, whichever you prefer. The purpose of the interview is to find out about your experiences in the lead-up to going on to dialysis. The interview will probably last for about an hour, though it could be longer depending on how much you have to say. If you do not speak English then an interpreter will accompany Jackie to the interview.

The interview will be recorded using a digital recorder. This is so that we have an accurate record of the conversation that we can listen to and use to compare with other interviews. We will also talk to your doctor and the nurses in the home care team who have been involved in your care so that we can get a complete picture of your journey towards dialysis. Paper copies of what you say will be made. In accordance with the Data Protection Act, 1998, all recordings and paper copies will be securely stored for 10 years before being destroyed.

### **What happens after my information has been gathered?**

Members of the research team will compare what you have said with what other patients have told us in interviews, and try to find out if there are any similarities or important differences. We will use the information to design the next part of the research study.

### **What are the possible disadvantages and risks of taking part?**

We do not anticipate that there are any disadvantages or risks of taking part. The researcher (Jackie Buck) is a qualified nurse with experience in interviewing and talking to patients. If anything arises during the interview that she feels you need help with, she will try to make sure you have information on who to contact.

### **What are the possible benefits of taking part?**

There are no direct personal benefits to taking part in this research though by doing so, you will be making a contribution towards improving the services for patients with kidney problems before they start on dialysis.



### **Will my taking part in the study be kept confidential?**

Yes. All of the information collected from you or about you will have your name removed and you will only be referred to by a number or false name.

### **What will happen to the results of the research study?**

We will use the information to design some new measures which should lead to improvements in the service patients starting on dialysis will receive. We will present any results of this study to other members of our professions at conferences and through journal publications so that they can also learn from the study.

### **Who is organising and funding the research?**

The research has been funded by a grant from the Edith Murphy Foundation, which is being administered by the National Kidney Research Fund (NKRF). The Edith Murphy Foundation granted the money specifically to fund research for patients with kidney problems here in Leicester. Before the money was awarded, the study was reviewed by a panel of 14 experts from the NKRF.

The research is being carried out by a Nurse Research Fellow, Jackie Buck, based in the John Walls Renal Unit at Leicester General Hospital. The research is being supervised by a steering group made up of Dr. Graham Warwick, who is a consultant nephrologist at the hospital, as well as nurses, patients, other members of the multidisciplinary kidney team and university researchers. The study has been approved by the Leicestershire Research Ethics Committee (2).

### **Do I have to take part?**

No, you do not have to take part in this research study. If you don't want to be involved this will not affect your care in any way. Furthermore, if you do decide to be involved then change your mind, you are free to withdraw at any time without this affecting your care.



### Contact for further information

If you or your friends or family would like more information on anything to do with this study, please get in touch with Jackie Buck or Dr. Graham Warwick at the John Walls Renal Unit, Leicester General Hospital, Gwendolen Road, LE5 4PW

Jackie Buck (Nurse Research Fellow) or  
(Consultant)  
Tel: 0116 - 258 8040 or 258 4375  
E-mail: jackie.buck@uhl-tr.nhs.uk

Dr. Graham Warwick  
  
Tel: 0116 - 258 8038

### Summary

**Just to recap:** We are asking you to let us interview you about your experiences leading up to being on dialysis. We are also asking you to allow us to talk to members of the kidney team about your care and collect information from your medical notes. All data collected will be anonymous. We are doing this study to discover more about what happened during the time *before* you started on dialysis.

If you agree to take part in this research study, please let us know by signing the consent form and handing it back to Jackie Buck, Dr. Warwick or the nurse in charge. If you would like to talk to someone before signing the consent form, please get in touch with Jackie or Dr. Graham Warwick (numbers above) or ask one of the staff to call them for you.

**Thank you very much for taking the time to read this.**



If you would like a written or taped translation of this leaflet please contact the Service Equality Manager on 0116 258 4382.

আপনি যদি এই লিফলেটের অনুবাদ - লিখিত বা অডিও টেপ'এ চান, তাহলে অনুগ্রহ করে সার্ভিস ইকুয়ালিটি ম্যানেজার ডেভ বেকার'এর সাথে 0116 2584382 নাম্বারে যোগাযোগ করুন।

यदि आप को इस लीफ़लेट का लिखती या टेप पर अनुवाद चाहिए तो कृपया डेव बेकर, सर्विस ईक्वालिटी मैनेजर से 0116 2584382 पर सम्पर्क कीजिए।

જો તમને આ પત્રિકાનું લેખિત અથવા ટેપ ઉપર ભાષાંતર જોઈતું હોય તો મહેરબાની કરી ડેવ બેકર, સર્વિસ ઇક્વાલિટી મેનેજરનો 0116 2584382 ઉપર સંપર્ક કરો.

Haddaad rabto warqadan oo turjuman oo ku duuban cajalad ama qoraal ah fadlan la xiriir, Maamulaha Adeegga Sinaanta 0116 258 4382.

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਲੀਫ਼ਲਿਟ ਦਾ ਲਿਖਤੀ ਜਾਂ ਟੇਪ ਕੀਤਾ ਅਨੁਵਾਦ ਚਾਹੀਦਾ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਡੈਵ ਬੇਕਰ, ਸਰਵਿਸ ਇਕੁਅਲਿਟੀ ਮੈਨੇਜਰ ਨਾਲ 0116. 2584382 ਤੇ ਸੰਪਰਕ ਕਰੋ।

**Eğer bu broşürün (kitapçığın) yazılı veya kasetli açıklamasını isterseniz lütfen servis müdürüne 0116 258 4382 telefonundan ulaşabilirsiniz.**



# Appendix 5

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Information leaflet for health care professionals, phase 2



Barriers to the elective start of renal replacement therapy:  
what are they, why do they occur and how can we overcome them?

*A research study looking at the predialysis care pathway*

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why we are doing this research study and what it will involve. Please take your time to read through this information carefully and please talk to us if you would like any more information.

### **What is the purpose of the study?**

We aim to find out why some patients who have been known to the renal services present acutely unwell and start dialysis in an emergency manner or with a temporary catheter. We will use the information from this study to develop interventions to reduce the number of patients who start on dialysis as emergency cases.

### **Why have I been chosen?**

We are interviewing the lead consultant and home care team nurse who was involved in the care of patients who come in to start on dialysis who have been known to the renal services for at least four months. We are also interviewing the patients. The patient who we will be discussing is fully aware that we are talking to you about his or her care and has given written consent.

### **What will happen to me if I take part?**

After you have read this information sheet you should take some time to make up your mind about whether or not you would like to take part. If you decide to take part then you will be asked to read and sign the consent form. The researcher, Jackie Buck, will then make an appointment to meet you to carry out the interview at your convenience. The patient's notes will be available during the



interview. We expect that each interview will last between 15 and 30 minutes

The interview will be recorded using a digital recorder. Interviews will then be transcribed verbatim. In accordance with the Data Protection Act, 1998, all recordings and paper copies will be securely stored for 10 years before being destroyed.

### **What happens after my information has been gathered?**

Members of the research team will compare what you have said with information from other interviews to try to find out if there are any similarities or important differences. We will use the information to design the next part of the research study.

### **What are the possible disadvantages and risks of taking part?**

We do not anticipate that there are any disadvantages or risks of taking part.

### **What are the possible benefits of taking part?**

There are no direct personal benefits to taking part in this research though by doing so, you will be making a contribution towards improving the services for patients with kidney problems before they start on dialysis.

### **Will my taking part in the study be kept confidential?**

Yes. All of the information collected from you or about you will have your name removed and you will only be referred to by a number or false name.

### **What will happen to the results of the research study?**

We will use the information to design some new measures which should lead to improvements in the service patients starting on dialysis will receive. We will present any results of this study to other members of our professions at conferences and through journal publications so that they can also learn from the study. You will also be sent a report from the study.

### **Who is organising and funding the research?**

The research has been funded by a grant from the Edith Murphy Foundation, which is being administered by Kidney Research UK (KRUK). The Edith Murphy Foundation granted the money specifically to fund research for patients with kidney problems here in Leicester. Before the money was awarded, the study was reviewed by a panel of 14 experts from KRUK.

The research is being carried out by a Nurse Research Fellow, Jackie Buck, based in the John Walls Renal Unit at Leicester General Hospital. The research is being supervised by a steering group made up of Dr.



Graham Warwick, who is a consultant nephrologist at the hospital, as well as nurses, patients, other members of the multidisciplinary kidney team and university researchers. A favourable ethical opinion for this part of the study has been granted by the Leicestershire Research Ethics Committee (2).

### **Do I have to take part?**

No, it is completely your choice. Even if you do decide to be involved then change your mind, you are free to withdraw at any time.

### **Contact for further information**

If you would like more information on anything to do with this study, please get in touch with Jackie Buck or Dr. Warwick of the John Walls Renal Unit, Leicester General Hospital, Gwendolen Road, LE5 4PW

Jackie Buck (Nurse Research Fellow) or (Consultant)	Dr. Graham Warwick
Tel: 0116 258 8040 or 258 4375	Tel: 0116 258 8038
E-mail: <a href="mailto:jackie.buck@uhl-tr.nhs.uk">jackie.buck@uhl-tr.nhs.uk</a>	

### **Summary**

**Just to recap: We are asking you to let us interview you about individual patients whose care you have been involved with. The aim of this study is to find out about the events leading up to dialysis for patients in Leicester. If you agree to take part in this research study, please let us know by signing the consent form and handing it back to Jackie Buck.**

**Thank you very much for taking the time to read this.**



# Appendix 6

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Interview topic guide for patient interviews, phase 2

# BERRT Study

## **Background and understanding of kidney disease**

- How long have you had problems with your kidneys?
- How did you find out that there was a problem with your kidneys? Who told you about it? Can you remember what you were told?
- What was your reaction when you were told that your kidneys might fail?
- What did you expect to happen with your kidneys? Is this what happened?

## **Introduction to dialysis**

- How was dialysis first introduced to you?
- How did you feel when you were first told about dialysis?
- How have you been feeling in yourself in the last few months? Had you any unusual symptoms? What did you put them down to?
- Did you think that you would have started dialysis by now? Why?
- How do you feel now that you are on dialysis?

## **Service related issues**

- Thinking back to before you started dialysis, how did you view your visits to the kidney clinics?
- How did you find your hospital visits to the kidney clinics? What did you think of the advice you were given? Was it useful? Did you get on alright with the staff?
- Were your hospital appointments easy or hard to get to?
- What did you think of the nurses coming to your home to talk to you? Did you like having someone come into your home? Was it useful?
- Did you go to the patient information day? What did you think of it? What was useful about it?
- Did you try to find out more about kidney problems from other sources, such as the internet, books, your GP, friends, family?

## **Deeper understanding of impact of kidney problems & suggestions for improving service**



- How has having kidney problems affected your life?
- What has been the most difficult aspect of living with your kidney condition?
- Can you suggest any improvements that can be made that will help other patients to understand their kidney problems and dialysis better?
- If you could offer any advice to the nurses and doctors looking after patients in the run up to dialysis, what would it be?



# Appendix 7

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Interview topic guide for health care professional interviews,  
phase 2



**Barriers to the elective start of renal replacement therapy:  
what are they, why do they occur and how can we overcome  
them?**

**Reaction to dialysis start as urgent/elective**

- Were you surprised that \_\_\_\_\_ started dialysis as known acute / elective?
- What factors do you think played a part in \_\_\_\_\_ starting dialysis in the way that she/he did?

**Reflection on interactions with the patient**

- How would you describe \_\_\_\_\_ as a person?
- How did you find your clinic appointments with \_\_\_\_\_?

**Reflection on own practice**

- Looking back over the past year (or however long it is) is there anything you would have done differently for \_\_\_\_\_?

**Reflection on wider team role**

- What about the other members of the nephrology team, is there anything you would change about how they acted for \_\_\_\_\_?

**Learning points**

- What do you think we can learn from this case?



# Appendix 8

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Coding frame, patient interviews, phase 2



# **Coding frame from patient interviews**

## **Core theme 1 - Knowledge and expectations**

### **Sub themes**

1. Lack of knowledge
  - a. about kidneys/kidney function
  - b. about kidney disease and management (predialysis)
  - c. about dialysis processes
2. Expectations of kidney problems before dialysis
3. Expectations of dialysis (before starting)
  - a. Positive expectations of dialysis
    - i. Life saving
    - ii. Curative of other disease processes
    - iii. Time giving – living longer with dialysis
    - iv. Relieving – relief of symptoms
  - b. Negative expectations of dialysis
4. Expectations of doctors
5. Expectations of NHS

## **Core theme 2 – Information**

### **Information**

1. Adequacy
  - a. Didn't meet needs – lack of information
  - b. Met needs
2. Language – jargon used but not understood
3. Not individualised
4. Sources of information
  - a. Hospital as main source of information (including doctors, home care team, patient information day)
  - b. Friends/family
  - c. Other health care professionals (outside renal services)
  - d. Internet
  - e. Other patients
5. Time Time perceived to be a barrier to delivery of information



6. Timing of information
  - a. Gradual delivery perceived as a good thing
  - b. Gradual delivery perceived as a negative thing (information up front is a good thing)
  - c. Time interval between information given and next opportunity to ask questions
7. Divulgence
  - a. Information perceived to have been with-held (they don't tell you anything)
  - b. Information being held back to protect patient
8. Explanations not thorough enough

### **Core theme 3 – Patient experiences & attitudes**

#### **Sub-themes**

1. Diagnosis
  - a. Kidney specific problem prompted diagnosis
  - b. Inter-related disease causing CKD
  - c. Unexpected finding from something unrelated (actual or in patients perception)
  - d. Impact of diagnosis
  - e. Reaction to diagnosis
    - i. Shock
    - ii. Disbelief
    - iii. Why me?
    - iv. Death better than the future
2. Symptoms / quality of life
  - a. Description of illness trajectory – worsening of symptoms in run up to dialysis
  - b. Perceived to be asymptomatic – didn't feel bad or worse in run up to dialysis
  - c. Poor quality of life as normal, not perceived to be worsened by kidney problems
3. Impact of illness on life
  - a. Isolation – description of feeling alone/lonely with kidney disease
  - b. Impact on employment
  - c. Impact on social life
  - d. Impact on activities of daily living (cooking, walking etc)
  - e. Limited impact on life
4. Role in decision making process regarding RRT



- a. Treatment recommended by health care professional because of medical or social reasons
- b. Patients had choice of treatment
  - i. Statements about why they chose haemodialysis
  - ii. Statements about why they chose peritoneal dialysis
  - iii. Statements about difficulty making the decision
  - iv. Statements about would have liked more input into decision
- 5. Attitudes towards kidney problems
  - a. Fighting it – not letting it rule your life
  - b. Acceptance – statements about accepting illness and limitations
  - c. Adapting lifestyle to kidney disease
  - d. Denial
  - e. fatalistic
- 6. Disclosure
  - a. Statements about the process of telling other people about the illness and prognosis
  - b. Statements about not telling other people about the diagnosis/prognosis
- 7. Being normal – statements where people use the term 'normal'
- 8. Experience of dialysis

## **Core theme 4 – Experience of renal service delivery**

### **Sub-themes**

- 1. Clinic appointments
  - a. Feelings towards them
    - i. Apprehension
    - ii. Acceptance / resignation
    - iii. Apathy
    - iv. Negative views (such as waste of time)
  - b. Time
    - i. Statements about acceptable waiting time
    - ii. Statements about unacceptable waiting time
    - iii. Enough time with doctor
    - iv. Not much time with doctor
  - c. Consultation with doctor – statements describing consultation with doctor
  - d. Transport / Accessing clinic appointments
    - i. Transport no problem or problems overcome
    - ii. Transport problematic, problems not overcome



2. Home care team
  - a. Benefits of home visits
    - i. More relaxed at home
    - ii. Family can be involved
    - iii. More time than in clinics
  - b. Other benefits of home care team
    - i. Accessible outside of clinic appointments
  - c. Other statements about home care team
3. Patient information day
  - a. Positive statements about patient information day
    - i. Peer support – realising you are not alone
    - ii. Information
    - iii. Other benefits
  - b. Negative statements about patient information day
    - i. Too many people
    - ii. Information
    - iii. Not enough time for questions
    - iv. One-off
4. Relationships with members of health care team
  - a. Dr / patient relationship
    - i. Confidence in doctors fulfilled
    - ii. Confidence in doctors not fulfilled
    - iii. Honesty – statements where patients seem to value honesty/truth/being upfront
  - b. Nurse / patient relationship
    - i. Positive statements about nurses (in home care team)
    - ii. Negative statements about nurses

## **Core theme 5 – Areas / suggestions for improvement**

### **Sub-themes**

1. Educational needs
  - a. Knowledge about kidneys
  - b. Knowledge about disease process
  - c. Knowledge about dialysis process
  - d. Knowledge about technical aspects
  - e. Knowledge about medication
  - f. Knowledge about self management



- g. Knowledge about when things go wrong
- h. Knowledge about lived dialysis experience
- i. Practical aspects of delivery
  - i. Smaller groups?
  - ii. Several sessions?
  - iii. Much earlier education
- 2. Emotional support needs
- 3. Clinic appointments
  - a. More meaningful
  - b. Better use of time
- 4. Individualising information
  - a. Patient specific
- 5. Decision making process personalised to suit patient preference



# Appendix 9

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Coding frame, health care professional interviews, phase 2

## **Coding frame for health care professional interviews**

- 1) Patient characteristics
  - a. Concordance
  - b. Intelligence
  - c. Engagement
  - d. Acceptance
  - e. Age
  - f. General comments
- 2) Medical
  - a. Progression
  - b. Intercurrent illness / co-morbidity
  - c. Other
- 3) Organisation and system
  - a. Time available
  - b. Timing
  - c. Continuity
  - d. Other resource issues
  - e. Chance
- 4) Health care professional related factors
  - a. Relationship with patient
  - b. Acceptance of responsibility
  - c. Communication
  - d. General attitudes
- 5) External factors
  - a. Family
  - b. Work
  - c. Others
- 6) Decision making
  - a. About mode of RRT
  - b. Other
- 7) Information
- 8) Roles and responsibilities
  - a. Physician
  - b. Nurse
  - c. Patient
- 9) Cultural



# Appendix 10

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Snapshot example from Framework chart used in the analysis of health care professional interviews, phase 2

	Concordance	Intelligence	Engagement	Acceptance	Age	General comments	Overall
E1D	Mostly did as he was told, didn't always take phosphate binders but dr. OK with that because patient owned up					Patient has the choice to not take tablets, patient choice	cheerful, pleasant, honest, GOOD patient
E1N	Nice, friendly, willing to take our advice and get on with it			accepting	married, young family	sociable, positive attitude, nice patient to look after (QQ). listens, takes advice etc...	GOOD patient, nice, easy
E2D	Self-sufficient, compliant, did as he was told (QQ)	Intelligent	Involved in process	Accepting			GOOD patient, compliant, did as he was told
E2N			engaged	accepting		quiet, difficult to break down at first, worried, anxious, patient became more confident over time	
E3D	Attended clinic, took advice		Involved in decision making process			Quiet, restrained, flat affect, not outgoing, his quietness might have affected how much information he got	GOOD patient, attended well, involved in decisions, understood what was going on
E3N	went to his appointments		Engaged in the process	Accepted and just got on with it		Quiet, didn't have any insight when first visited, but made decision quickly, took information, compliant	GOOD patient



E4D	Took information, amenable to suggestions		involved in process, agreeable				Very quiet	
E5D	Missed many appointments, dr. gave up a bit in the end	Intelligent	Didn't engage much in process of preparing for dialysis	In denial, didn't accept severity	young man, more to lose - economic activity, impact on family, life expectancy (QQ)	Stoical, pleasant but reserved, wanted to get in and out as quickly as possible	Denial of symptoms to last minute related to non-acceptance	
E5N	Not very compliant with attending PID			Didn't accept kidney disease or need for dialysis well. Suggests a psychologist could have helped him to cope, accept and think about adaptations	General comment on age, allocation of resources and timing of visits	anxious, buried his head in the sand - was in denial	Denial perceived to be a good coping mechanism for him as he had many competing worries and was a long time off needing dialysis when first spoken to by HCT	
E6D	Compliant, did what she was told, always came to clinic (QQQ)	Intelligent	Engaged in process of decision making, and in care			Pleasant, compliant, self-sufficient, knew her own mind, understood situation, thought things through did what she was told		
E6N	Very determined personality, interested in staying well but didn't do anything she wasn't ready for		Very interested and engaged in her care and decision making	Didn't want to start dialysis when medical team thought she should, needed to feel it was the right time for herself	Young age... similar age as nurse, she thought it helped her to empathise with the patient, also was asked for speedy visit by Dr. because of her age	Very interested and determined person. Determination made it difficult sometimes because she stayed very much in control which doesn't always fit in with the NHS	Interested in her care and determined to stay well and have fistula/start on dialysis only when she was absolutely ready. Good patient.	

# Appendix 11

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Paper published from phase 1



The following published article from Appendix 11 is not available in the electronic version of this thesis due to copyright restrictions:

Buck, J.; Baker, R.; Cannaby, A. et al. 'Why do patients known to renal services still undergo urgent dialysis initiation? A cross-sectional survey' in *Nephrology Dialysis Transplantation*, 2007, 22 (11), pp. 3240-3245.  
doi: 10.1093/ndt/gfm387

The full version can be consulted at the University of Leicester Library.

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