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Opting not to Dialyse: A Practitioner Research Study to Explore Patient Experience

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**A thesis submitted to City University in accordance with the
requirements for the Degree of Doctor of Philosophy**

School of Community & Health Sciences

City University London

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DECLARATION

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ABSTRACT

As the number of patients reaching stage 5 chronic kidney disease (CKD) increases worldwide, a similar trend can be seen in the UK. A disproportionate figure are older, frailer and more dependent with an increased prevalence of comorbidities. Subsequently, there is greater awareness among nursing and medical staff that dialysis may not improve survival rates and may impact considerably on the quality of life of these patients. Renal Services are being developed in order to support those deciding not to dialyse, although little is known about their experiences or concerns. Over recent years a number of directives have encouraged the principles of palliative care within non-specialist settings for people who do not have cancer, but it cannot be assumed that all people with a terminal illness have the same end of life needs.

This Practitioner Research study explored the experiences of patients with stage 5 CKD who had opted not to undergo dialysis to treat their renal failure. Patients were managed within a Renal Supportive Care Service at a London Hospital Trust. Data were generated longitudinally via 30 case studies of patients over an 18-month period or until the patient's death, with additional data collected from 19 carers. Naturally occurring clinical consultations made up the 82 interviews and took place in the clinic setting or in the patient's home. Findings were fed back to the renal multidisciplinary team, with nurses working in the service and with a 'validation' group of UK nurses working with a similar population to check for relevance and resonance of the study findings. Field notes were maintained throughout the study and incorporated observations of patient trajectories once referred to the service. Data analysis was conducted following an approach advocated by de Wet and Erasmus (2005) which offers guidance on rigorous qualitative analysis.

Generally, patients entering the service were frail, in poor health and at an advanced age. Some patients appeared unclear about the decision-making process and what had been agreed in terms of how their kidney failure would be treated. Common presenting symptoms included breathlessness, oedema, pruritus, nausea and vomiting, lethargy and insomnia, pain, immobility, depression and bowel and bladder problems. Some symptoms were treated successfully while others, such as difficult-to-treat oedema, indicated that the end of life was approaching. In addition, patients had to manage an uncertain prognosis, with some preparing for death that didn't always arrive as expected and others living with the worry that deterioration could occur at any time. Seventeen patients died during the study, the average length of life from first referral into the service until death being 15 months (range: 1-35 months). Three trajectories to death were identified: a typical uraemic death; death caused by another illness other than renal disease; and death where the cause was unclear.

Previous research has studied trajectories to death in cancer, chronic disease and old age with little known about the trajectory in those with stage 5 CKD. This study demonstrates the uniqueness of the renal trajectory to death in those managed without dialysis and highlights how services might improve to better meet the needs of this population. Findings from this study are likely to be of international interest and have implications for policy, education and research.

ABBREVIATIONS

AVF	Arteriovenous fistula
CAPD	Continuous ambulatory peritoneal dialysis
CKD	Chronic kidney disease
CNS	Clinical Nurse Specialist
COPD	Chronic obstructive pulmonary disease
eGFR	Estimated glomerular filtration rate
ESRD	End-stage renal disease
NHS	National Health Service
NSF	National Service Framework
PMP	Per million population
PPC	Preferred Place of Care
PR	Practitioner Research
RRT	Renal replacement therapy
RTF	Rich text format
RSCS	Renal Supportive Care Service
SCG	Stroke comorbidity grade
UK	United Kingdom

CHAPTER 1

INTRODUCTION

The overall aim of this study was to explore the experiences of patients with stage 5 chronic kidney disease (CKD) who had opted not to undergo dialysis to treat their renal failure.

Specific aims were to:

- describe the characteristics of a cohort of renal patients with stage 5 CKD in a London renal unit who had decided not to embark on dialysis
- identify the healthcare needs of this group of patients
- describe the trajectory towards death (or not) of this population
- highlight issues for consideration when establishing a Renal Supportive Care Service (RSCS) for patients managed without dialysis

This chapter describes the background to the study and offers the reader an understanding of renal disease and its treatment. It highlights how many more patients with end-stage renal disease (ESRD) (known more recently as stage 5 CKD) are now deciding to refrain from dialysis and why this is important in terms of policy and practice. More detail is given of the relevance of this to research and education in Chapter 10. It also provides a prologue to the journey I took as a nurse working with patients and their carers within a RSCS and sets the study in context. It highlights how, as a practitioner carrying out research with a population for whom I had nursing responsibility, I was able to draw on my clinical skills and abilities to tease out, explore and appreciate the particular experiences that patients and carers reported to me.

It offers the reader an understanding of the present-day situation related to renal end-of-life care where the voice of the patient is generally silent and where the care that these patients require remains largely unknown. This study is important because it makes a unique contribution to a small body of knowledge urgently requiring input and offers evidence upon which future research, and importantly clinical care, can be focused. It has also generated a number of publications and presentations at national and international conferences and interest worldwide. Alongside this it has led to three awards. The influence this study has had is discussed further in section 10.1.4.

1.1 Background to the study

1.1.1 Growth in the number of patients with stage 5 CKD

Chronic kidney disease is not as common as other conditions, such as heart disease and cancer, but worldwide over 1.5 million individuals receive renal replacement therapy (RRT) (Cameron 2002). This number is projected to surpass 2 million by 2010, at an international cost of around a trillion dollars (Kossi El et al. 2007). Numbers are growing at an annual global average of 7% each year (Moeller et al. 2002). This is in contrast with only 5000 dialysis patients worldwide in 1970, mostly aged between 20 and 40 years. In the United States and Japan more than one in every 1,000 individuals is receiving dialysis treatment for

stage 5 CKD. In Italy it is one in 1,100 and in all industrialised countries it is more than one in 1,500 (Cameron 2002).

In the UK it has been well established that the number of patients receiving dialysis is increasing by approximately 6-7% per annum (Ansell et al. 2008). The provision of RRT is predicted to consume approximately 2% of the National Health Service cost in the next decade (Kossi El et al. 2007). There were 43,091 adult patients (Ansell et al. 2008) receiving RRT in the UK at the end of 2006, equating to a prevalence of 725 patients per million population (pmp) (Ansell et al. 2007). These figures include a disproportionate number of those who are older, frailer and more dependant. Older people with stage 5 CKD have increasing prevalence of comorbidities (Ashby et al. 2005); for example, the prevalence of ischaemic heart disease doubles between the ages of 45 and 80 in those with renal failure and body mass index falls by 20% along with a decreased serum albumin (Levy et al. 2004). In addition, there is also evidence of a rising involvement of palliative care teams with patients with stage 5 CKD in recognition of unmet needs (Rich et al. 2001).

1.1.2 Management of stage 5 CKD

Dialysis, an artificial replacement for lost kidney function, is used to treat stage 5 CKD and is normally initiated when there is evidence of uraemia, a toxic condition resulting from the presence of urinary constituents in the blood. Uraemia equates to CKD stage 5 or an estimated glomerular filtration rate (eGFR) <15 ml/minute (CKD Work Group 2002) (see Table 1.1). There are four renal replacement treatment options, which are discussed in *The National Service Framework for Renal Services. Part One: Dialysis and Transplantation* (DH 2004). These are haemodialysis, peritoneal dialysis, transplantation and conservative management also known as supportive care (Levy et al. 2004).

Table 1.1 Stages of Chronic Kidney Disease

Stage	Description	eGFR* ml/min/1.73 m ²
1	Slight kidney damage with normal or increased filtration	More than 90
2	Mild decrease in kidney function	60–89
3	Moderate decrease in kidney function	30–59
4	Severe decrease in kidney function	15–29
5	Kidney failure requiring dialysis or transplantation	Less than 15

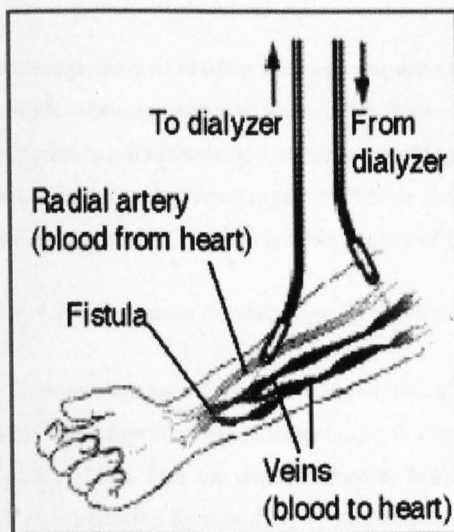
* Estimated glomerular filtration rate

When patients are diagnosed with CKD they need to be managed effectively, according to the stage they have reached. Patients between stages 1 and 3 should be managed within their primary care settings and referred to a nephrology service when they reach stage 4 to enable them to receive timely preparation for RRT. This can minimise complications and progression of the renal disease. It also ensures that there is time for patients to make choices that are clinically appropriate for them (DH 2004).

1.1.3 Initiating dialysis

Making the decision on which form of dialysis to choose is complex because it involves major changes in one's lifestyle and dependence on a treatment without which life would cease (Muringai et al. 2008). Access for dialysis depends on the treatment option chosen by the patient. There are two types of dialysis treatment: haemodialysis and peritoneal dialysis. In order to start timely haemodialysis patients should have vascular access surgery created many months before the need for RRT (Thomas 2002). The creation of a native arteriovenous fistula (AVF) is required and is a surgically created link between an artery and a vein (see Figure 1.1). Dialysis usually takes place in a haemodialysis unit three times a week, for four hours on each occasion. It involves a patient's blood being pumped from the fistula through tubing to a haemodialysis machine. The machine acts like a kidney, filtering waste products from the blood before returning it to the patient (see Figure 1.1).

Figure 1.1 Arteriovenous fistula

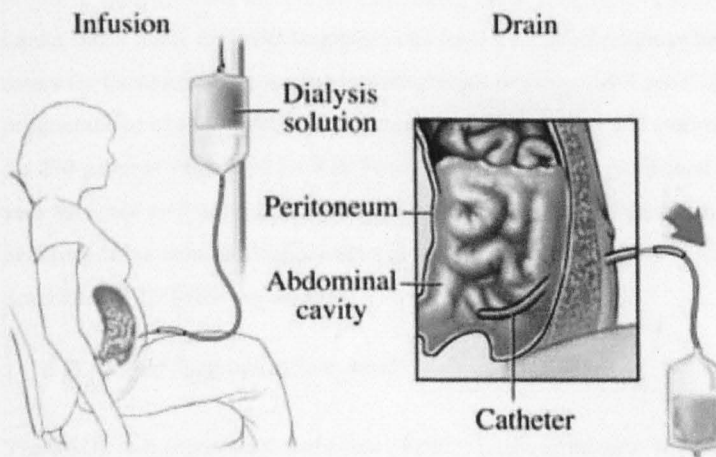


Arteriovenous Fistula

Other patients are managed on peritoneal dialysis, where a catheter is placed in the peritoneum and dialysis fluid is entered into the patient's peritoneal cavity (the inner 'belly'), which is covered by a thin membrane, containing many small blood vessels. Toxins from the blood diffuse into the peritoneal cavity across the peritoneal membrane. The advantage of peritoneal dialysis is that the patient can remain active

while the dialysis is proceeding. This is known as continuous ambulatory peritoneal dialysis (CAPD) and must be carried out four times a day (Thomas 2002) (see Figure 1.2).

Figure 1.2 The CAPD procedure



Although dialysis is often seen as a requirement to prolong life, without which people will die, it is an arduous therapy known to shorten life (United States Renal Data System 2005). Patients on dialysis often experience a multitude of symptoms resulting from their renal disease and its treatment. It also necessitates extensive changes in lifestyle that impact on many aspect of life and challenge the faculty of patients to maintain an acceptable quality of life (Jablonski 2007a).

1.1.4 The increased number of people being managed without dialysis

As the average age of those on dialysis increases there is an increased awareness, among renal healthcare staff that dialysing these patients may not improve their survival rate and may impact considerably on quality of life. This was demonstrated by Smith et al (2003), who studied the factors influencing the recommendation for non-dialytic treatment in patients approaching stage 5 CKD and the subsequent outcomes in patients opting not to dialyse. They concluded that in renal patients who were frail and highly dependent, the decision to dialyse or not had little impact on survival and that dialysis in such patients risked the unnecessary medicalisation of death via the use of dialysis treatments that could hasten death.

It has been approximated that 20% of the renal population in the UK are currently managed without dialysis (Smith et al. 2003) and although national figures are not yet available, it is suggested that approximately 1,500 patients annually may be commencing on a pathway that is supportive or palliative rather than curative (Ansell et al. 2005). A national meeting arranged by the Department of Health held recently in London, brought together professionals with an interest in how to best manage those patients opting not to

embark on dialysis. It is well recognised that we know little about this population and their needs and experiences remain largely unidentified (Murtagh et al. 2006; Noble 2006).

1.1.5 The hospital

The study took place within a renal unit at an acute NHS Trust in London. The Trust serves one of the most diverse populations in the UK in respect of language, culture, religion and ethnicity. Patients originate from a variety of countries including India, Bangladesh, Greece, the UK, the Caribbean and Sri Lanka speak many different languages and have a range of religious beliefs (2001 Census). The renal unit caters for those requiring specialist management of progressive renal disease. It offers a haemodialysis programme to over 600 patients and continuous ambulatory and automated peritoneal dialysis programme for 230 patients with stage 5 CKD. Renal transplantation is performed on approximately 80 patients a year for those well enough to undergo this procedure. Alongside these therapies, end-of-life care for those deciding not to commence dialysis or to withdraw from treatment is also offered through the RSCS described in the following section.

1.1.6 The Renal Supportive Care Service

The RSCS was established at the end of 2005. Goals of the new service included enabling patients to live life as fully as possible until death, with a specific remit to offer an enhanced, holistic approach to the assessment and control of symptoms as well as supportive management which would include high-quality palliative care for the patient and their family.

The service was developed with members of the multidisciplinary team (a renal consultant, a dietician, a pharmacist, a social worker, a pre-dialysis sister, an anaemia sister, a renal counsellor and a mental health liaison nurse) and a treatment pathway for patients who do not want to undergo dialysis but who require supportive and palliative care has been established. This pathway enables patients' access to healthcare professionals through their trajectory to death at an appropriate time. Although rare, some similar services were being developed nationally (Murtagh et al. 2006) and the *National Service Framework [NSF] for Renal Services: Part 2* includes a specific section on end-of-life care. It advocates the development of a combination of palliative care and renal skills to provide and extend services (DH 2005). It also considers the requirement for palliative care interventions when patients decide to abate (either refrain or withdraw from) dialysis, which will lead to death. Importantly it has been known for some time that renal patients have shortened life expectancy and carry a high symptom burden (Cohen et al. 2006), and it is becoming clear that many patients might not benefit from, or wish to endure, arduous sessions of dialysis.

In the past, patients who had decided not to embark on dialysis were followed up by a renal consultant, with little input from the multidisciplinary team, or discharged to the care of the General Practitioner. Now the RSCS has been established, patients who have made the decision not to undergo dialysis are referred by their consultant by letter into the service. Telephone contact is then made with patients or carers and appointments made for them to be seen within three months, or earlier if clinically unwell. Patients are reviewed three-monthly and referred to other disciplines as appropriate. They are encouraged to use the service as a coordinating centre where their condition is managed by one member of the renal

team, focusing on their overall, care rather than several groups, each managing a specific disease. The community team including the GP has access to the RSCS and can call for advice as needed. When a patient deteriorates and it is felt appropriate, they are referred to the community palliative care team for management and the RSCS remains available for advice and if requested, joint home visits. At this point the renal team hand over care to the community team. The development of this service during this study is discussed further in section 10.2.

1.1.7 Role of the researcher

This research arose from my work as a practitioner responsible, with the multidisciplinary team, for developing a new service for patients who had decided to withdraw from or refrain from dialysis. Having set up the service, it became clear that we knew very little about the needs and experiences of the patients we were managing, their progression and ultimate demise. The opportunity to undertake a PhD arose in 2005 and for the duration of the study I worked an average two days a weeks as a Clinical Nurse Specialist (CNS) as I undertook the study. This allowed me to practise and research simultaneously and allowed me access to a group of patients for whom I had management responsibility.

1.2 The history of renal disease

In order to illustrate the importance of this thesis to present-day renal medicine a short history of renal disease is now presented, giving an overview of developments in this area over the last century. It illuminates a move from dialysis as the gold standard treatment for stage 5 CKD to the present day and an understanding that dialysis will not benefit all. It introduces relevant policy which has had an impact on the care of those dying with renal failure.

1.2.1 Early dialysis and selection of patients

The kidney was the first human organ to be replaced by a machine, when the 'artificial kidney' entered the medical arena with the first human dialysis in 1924 (Royal Infirmary of Edinburgh 2006). A practical artificial kidney, or dialyser, was developed as a result of advances in science, followed by the acquisition of new synthetic materials, which made the application of these ideas possible. The apparent high cost and limited availability of this form of treatment immediately led to ethical questions which had never been raised before, centring around equity of access to treatment, when and if treatment could be denied, and the difficult decision of when, once established, it should be stopped (Cameron 2002).

Spiralling costs as the true number of people with kidney failure became evident raised major political and financial questions. These were addressed in different countries in different ways, and reflected, but also helped change, patterns of how medical care is provided. In developed countries, the problem could be solved by allocating a disproportionate amount of money to the treatment of relatively few kidney patients, but in the developing world the cost of treatment still limits its availability, as it does all forms of modern healthcare (Cameron 2002).

Ultimately, dialysis was not a definitive solution, as the kidneys were not restored to function, only substituted for. Several times a week patients had to attend the hospital for dialysis therapy which replaced only in part the function of their failed kidneys. Thus it was a prototype of a 'halfway' technology (Thomas 1971). As patients went on to live for years and some for decades, the terrible consequences of living with kidney failure for longer than could have happened naturally without dialysis became apparent. Dialysis was a palliative treatment as stage 5 CKD could not be cured. Patients suffered, and still do today, a myriad of problems, including coronary artery disease, peripheral vascular disease, pain, pruritus, lethargy, fatigue, cramps, depression and diabetes, with its associated problems (Abed Sekkarie and Swartz 2004).

In contrast to the continued similarity of dialysis procedures over many years, the social and financial context within which dialysis takes place has changed radically since the 1960s. Early acute dialysis took place within the hospital setting and in the late 1970s and early 1980s, peritoneal dialysis, a home-based treatment, was introduced. Never before was there a life-saving treatment which was so successful but also so repetitive and cumulatively expensive. Society struggled to afford to treat all who could benefit. In the 1960s an attempt was made to deal with the ethical problem of rationing by evaluating the social needs and worth of potential candidates for dialysis using a panel of people selected from various societal backgrounds (Alexander 1962). The issues were complex, raising not only matters of righteousness, equality and fairness, but also a novel debate concerning a new measure of outcome, 'quality of life', which until that time had not been addressed in any depth in any area of medicine (McGee and Bradley 1994). As this debate continued, the idea that a patient might decide to reject dialysis therapy was considered unthinkable but as I will now discuss the withholding and withdrawal of dialysis was something that was indeed occurring.

1.2.2 The social and economic context of dialysis abatement

Early thinking pertaining to dialysis withdrawal was concerned with viewing dialysis abatement as akin to suicide (Viederman and Burke 1974; Moon and Graber 1985). There is no mention in the literature at this time of patients making decisions not to commence dialysis, although withdrawal of dialysis was a common phenomenon in many renal units (Neu and Kjellstrand 1986).

Whether or not a patient should be allowed to discontinue life-supporting treatment had been a matter of intense debate for some time (Neu and Kjellstrand 1986), although most major religions were in agreement that if treatment was burdensome, a patient might withdraw from it and that such withdrawal was not suicide (Sacred congregation for the doctrine of the faith 1980). We have a situation today where it is more acceptable to make a decision not to embark on dialysis but some staff believe that most, if not all patients requiring dialysis should receive it (Mailloux 2004). Alongside this, the economic argument for rationing dialysis cannot be ignored. Authors such as Rombola (2002) make the serious point that in Italy every year 1,250 million Euros (approximately £1,000 million British pounds), 2% of the total health expenditure, are spent for approximately 41,000 patients on chronic dialysis. The author states that in terms of balanced health policy no ethical principles can justify the utilisation of such a huge quantity of resources by such a small number of patients. Health economists and government officials must surely have an interest in limiting very expensive, repetitive treatment to a population who might not benefit

from it (Cameron 2002). *'In no country, however rich, is the public purse bottomless ... thus there is an essential and necessary tension which cannot be resolved without a debate'* (Cameron 2002: 335). However *'A major problem in this area is that the tools so far available for economic comparisons of quantitative (and especially qualitative) treatment outcomes are clumsy and inaccurate'* (Cameron 2002: 335).

Today, as we wrestle with the problem of an aging, sicker population presenting for dialysis, this thesis is urgently required to illuminate the experiences of those patients who refrain from dialysis and to inform future service developments locally, nationally and internationally. With new knowledge concerning the trajectory of these patients, health professionals will be in a better position to support future patients in their treatment decisions.

1.2.4 Palliative care for those with non-malignant disease

From few patients receiving dialysis therapy we have today a debate regarding the selection of patients for dialysis, with papers from the United States (Friedman 1992), Canada (Kjellstrand and Moody 1994) and the UK (Chandra et al. 1999). As the UK moves away from the concept of patients as demanding consumers to one of informed participants, being able to choose treatment options and secure equitable access to services across the country is high on the NHS agenda (DH 2003). This includes supportive and palliative care through the trajectory of a terminal illness and care at the end of life.

Discrepancies have been highlighted in the care offered to those with non-malignant disease compared to cancer (Department of Health (thereafter DH) 2000) and it has been recommended that all NHS patients and their carers should receive palliative care appropriate to their needs. The Department of Health have established the End-of-life care Programme to manage this situation and aims to develop the skills of a variety of staff, including district nurses, GPs, hospital and care home staff in end-of-life care. There has also been a commitment to ensuring that all people at the end of life, regardless of their diagnosis, are offered choice around where they want to die and how they wish to be treated. Recently, the Department of Health has released the *End-of-life care Strategy* (DH 2008), backed with £286 million to provide high-quality care for all adults approaching the end of their lives. This gives a clear message that palliative care is to be made available to all those with a life-limiting condition rather than just malignant disease.

Those making decisions not to embark on dialysis are older, and it is well documented that many older people and their carers experience disadvantage and discrimination at the end of their lives (Help the Aged 2005). The need to secure dignity in dying has been of critical importance for older people and their carers, with many older people not having their wishes respected. There is a need to ensure that the voice of the older person is articulated and their concerns addressed.

1.2.4 Renal palliative care policy development

As the number of patients with renal disease increases, there has been national recognition of their palliative and end of life needs with the publication of the *National Service Framework for Renal Services: Part 2*. It states that people with stage 5 CKD should receive timely assessment of their

prognosis, information about choices available to them, and for those near the end of life a jointly agreed palliative care plan, created around individual needs and preferences. It sets out six markers of good practice:

1. Access to communication skills and knowledge of symptom control.
2. A prognostic assessment if required.
3. Judicious information and palliative care plan.
4. Ongoing medical care for patients who decide not to dialyse.
5. Death with dignity.
6. Culturally appropriate bereavement support.

In addition a renal version of the Liverpool Care Pathway (Marie Curie 2008) has been developed nationally (Douglas et al. 2007). This pathway has been developed in order to transfer the hospice model of care into other settings, and is utilised once a patient has been diagnosed as dying. Also, clinical guidelines on opioid use in stage 5 CKD managed without dialysis have been published (Murtagh et al. 2007c).

Although guidelines such as these are very welcome and begin to promote the requirements of a population managed without dialysis, their healthcare needs and experiences remain largely unknown. Much previous work has been based on expert opinion and small-scale research studies. Publication of the first textbook on renal supportive care (see Chambers et al. 2004) saw a focus on those being managed on dialysis rather than those managed without this treatment. Until more research is initiated with those opting not to embark on dialysis, it is difficult to establish services and offer optimum care.

1.3 Justification for the research

The notion that many renal patients have supportive and palliative care needs is relatively new. Over recent years a number of directives have encouraged the principles of palliative care within non-specialist settings for people who do not have cancer. But, as made clear by Froggatt and Houlst (2002), it cannot be assumed that all people with a terminal illness have the same end of life needs. Their work, focusing on developing palliative care practice in care homes, identified that the philosophy of palliative care needs to be integrated with gerontology and that practitioners from both disciplines need to work together to formulate palliative care specific to the needs of older people. As renal patients have not been asked what their needs are during the dying trajectory, it cannot be assumed that their healthcare requirements will be the same as those dying with other terminal illness, such as cancer.

This thesis has allowed the previously unheard voices of dying renal patients to be articulated. As other renal units in the United Kingdom begin to identify the need for high-quality palliative care for those dying with renal failure (see Murtagh et al 2006 and Noble and Chesser 2009), the learning from this study will be useful to others and inform service development locally, nationally and internationally. The study informs a gap in the body of knowledge related to renal patients who have opted not to have dialysis. As I cared for

patients and worked with staff struggling to understand the trajectory that unfolds following the decision not to dialyse, it was timely that research of this kind was initiated. Noble and Kelly (2006) note that a robust evidence base is required to support professionals, patients and carers. They also state that more renal patients need to experience a 'good death'. Although the term 'good death' is still not clearly defined and what is important for one patient may be very different for another, this thesis has explored the experiences of patients and carers as death closes in. The findings have allowed for the identification of priorities for care and, ultimately, improvements in this area can be made for this patient population.

As a practitioner working in this service I was ideally placed to carry out this study. I was known to the patients and had a responsibility to develop services based on the needs of patients and their carers. These needs were identified by talking to those I was caring for as a nurse and the interviews or clinical consultations with patients and their carers allowed for individualised care planning from which patients could only benefit.

1.4 Thesis overview

Following this first chapter, Chapter 2 describes a concept analysis of renal supportive care. This was an important first step in the development of the thesis as the idea of offering supportive and palliative care to those with renal disease was so new. The concept analysis identifies how the renal world had begun to acknowledge the supportive and palliative care needs of their population and pinpoints the terminology being used to describe services caring for dying renal patients. This was important as a natural expansion of the RSCS occurred, and patient and carer needs were identified. The team needed to articulate clear goals using terminology that would be understood. The concept analysis offered an opportunity to consider and make recommendations for appropriate language in a newly developing area and presented an occasion for giving meaning to the concept as found in the literature.

Chapter 3 locates the thesis theoretically in a presentation of theories or models related to death and dying. As this thesis uncovers trajectories to death in those with renal disease and explores healthcare needs and experiences along the way, major theoretical approaches considered useful in the study of dying are presented as a backdrop to the study. Selected literature on the end of life and how people cope with this is presented in order to allow the reader some understanding of the present knowledge base generally and highlights a lack of knowledge in the renal area in particular.

Chapter 4 comprises the literature review for the study. The chapter illustrates that, prior to this study, very little was known about those who decided not to embark on dialysis. Particular gaps are highlighted concerning how and why patients decide not to commence dialysis, their experiences and needs once they make this decision and their trajectory to death.

Chapter 5 outlines the qualitative approach taken and the methods used for data collection and analysis. Practitioner Research (PR) is described and its particular strengths in this study highlighted.

Chapters 6-9 illustrate a group of patients with unmet and difficult to identify supportive and palliative healthcare needs. They uncover the patients managed within a RSCS and offer an understanding of the experiences and healthcare needs of the patients and carers encountered. The chapters illustrate the wide range of concerns and difficulties that this population face. The decision that patients had made prior to being referred to the RSCS regarding the non-initiation of dialysis appears complex and patients presented differently in terms of how much they understood this decision. A central finding, therefore, is concerned with information provision in the context of stage 5 CKD. Patients encountered many symptoms and an attempt is made to determine the cause of these symptoms, as not all symptoms related to the renal disease itself. Questions around how successfully symptoms were treated are explored. It is argued that not all symptoms could be successfully managed by the RSCS and other professionals had to be called upon to ensure that physical and psychosocial concerns were also addressed. The findings around symptom management are therefore considered important in themselves and emphasise how important it is to treat symptoms wherever possible to improve quality of life. Furthermore, patients (and carers) experienced difficulties as they lived their lives knowing that death would come at some point soon, and this is explored. It is argued that some patients managed this situation by not talking about or dwelling on the inevitable death. This therefore conflicts with the present-day discourse which encourages openness around the end of life in order to prepare for a 'good death'.

Within the findings, the trajectory to death of those who died during the study is explored. Three types of death were uncovered. The various deaths identified are presented as narratives to illustrate the characteristics of each type of death. Through these trajectories, difficulties often arose in supporting and managing these terminally ill patients, who were complex in terms of health professionals being able to predict death. Description of inappropriate care received by some patients during the study as the end of life approached is offered. A key finding here is the need for appropriate intervention in the final stages of life.

In Chapter 10 the findings are assimilated and conclusions are made based on a discussion of the literature. I make recommendations that are specific to the case of patients managed within the RSCS where I worked. I suggest that within the limitations of this in-depth, qualitative study there are some principles that can be applied to similar settings, particularly within a renal environment but also in hospices or the community where specialists will be working with and caring for patients who have decided not to embark on dialysis to treat stage 5 CKD. This chapter also highlights the implications of the findings for policy, practice, education and research. Recommendations are made for consideration by the reader.

CHAPTER 2

A CONCEPT ANALYSIS OF RENAL SUPPORTIVE CARE

2.1 Introduction

This chapter provides a report of a concept analysis of renal supportive care which has since been published (Noble et al. 2007). It begins by reiterating how the renal world has begun to acknowledge the supportive and palliative care needs of their population and discusses why it was felt that a concept analysis of supportive care would be useful in informing this study. Following discussion of associated vocabulary with similar meaning to supportive care, the literature informing the concept analysis is presented. The attributes and antecedents are examined. Finally implications for the future of renal supportive care are highlighted.

2.2 Background

As previously discussed, there have been dramatic changes in the demography and long-term management of patients with stage 5 CKD (Smith et al. 2003), with numbers growing worldwide (Grassman et al. 2005). It is known that patients with stage 5 CKD are at higher risk of dying than the general population, with a median risk between one-third and one-sixth as long as non-dialysis patients of the same age and gender (Cohen et al. 2006). Being told that one has terminal renal failure and requires dialysis is therefore as much a prototype of communicating bad news as a diagnosis of cancer (Arnold and Solomon 2006), but this has only recently been acknowledged. It is becoming more evident and critical that a seamless structure of care is in place as renal patients embark on their journey from diagnosis to death. These patients have many physical and psychological symptoms comparable to cancer patients and advanced renal disease is a perfect example of a disease requiring input from those with palliative care expertise (Holley et al. 2003).

Having been involved in helping to establish a new RSCS for renal patients who had declined or decided to withdraw from dialysis treatment, and as similar services were being developed nationally, I felt it would be useful as part of this PhD to trace the evolution of the concept 'renal supportive care' to inform this doctorate and a wider debate in the literature. Although there was some uncertainty about how the role of the RSCS would evolve, it was deemed appropriate that terminology used to describe such a service be probed and clarified so that as natural expansion occurred, and patient and carer needs identified, the team could articulate clear goals and descriptions of what the service would provide. It is also presented to allow the reader a greater understanding of the RSCS itself, its early development and the contextual background within which it was situated.

The field of nephrology was shifting from an exclusive focus on increasing life expectancy to one providing greater attention to quality of life. This concept analysis not only offered an opportunity to consider and make recommendations for appropriate language in a newly developing area, but presented an occasion for giving meaning to the concept, as found in the literature, prior to undertaking the study that would identify the experiences of patients and carers themselves.

2.3 The concept analysis

2.3.1 Identification of the concept

Renal supportive care was examined using the Rodger's evolutionary method (Rodgers 2000) of analysis for concept development. This is a useful framework as it offers an inductive approach based on the idea that concepts are constantly evolving and changing. As knowledge and understanding is socially constructed, and evolves as people engage with and learn from each other, the way we think about concepts in the past, present and the future is likely to change over time. It is therefore important to capture how a concept is currently being articulated in relation to other phenomena associated with it. Identifying differences and similarities between similar concepts is useful as it can enhance understanding in relation to the concept, ensuring that related practice is more explicit and ideas regarding delivery clearer.

The concept analysis used subheadings suggested by Rodgers (1989; 2000):

- Identify concept and associated vocabulary, including surrogate terms.
- Identify and select appropriate setting and sample for data collection.
- Collect data to identify the attributes of the concept and the contextual basis of the concept, including antecedents.
- Analyse data in reference to the characteristics of the concept mentioned above.
- Identify inferences, theories and implications for future development of the concept.

Consideration was given as to whether or not the term renal supportive care was being used appropriately.

2.3.2 Associated vocabulary, including surrogate terms

As previously mentioned, conceptual confusion has arisen and a number of terms are being used interchangeably in the literature. These include supportive care, palliative care, end-of-life care, terminal care and, more specifically to nephrology, conservative management. Historically in the UK, palliative care services have focused almost exclusively on the terminal care of patients dying with cancer and palliative care is often referred to as 'terminal care'. As palliative care has developed, a widening of terms has followed and there has been a shift from using the phrase 'terminal care' to 'palliative care'. The terms 'palliative medicine' and 'specialist palliative care' are also used intermittently alongside 'end-of-life care', leading to confusion in the usage and application of terms (Clark and Seymour 1999). In 1995 The National Council for Palliative Care (formerly The National Council for Hospice and Specialist Palliative Care Services) (NCPC 1995) defined 'terminal care' as an important part of palliative care and something that should be offered to patients when no curative treatment was available and death could be expected within 12 months. There are problems with this as it is often difficult to predict the moment of

transition from palliative to terminal care, especially as changing patterns in the management of chronic disease evolve (Skilbeck 2005). Criticism of the term 'terminal care' has been made by Doyle (1993) who points out that the word 'terminal' suggests negativism and nothing more can be done.

A concept analysis of palliative care (Meghani 2004) aimed to trace the evolution of palliative care in the United States and draw comparisons with related concepts, such as hospice care and terminal care. The author states that there has been important evolution in the understanding of palliative care which has resulted in the emergence of new models of palliative care and concludes that palliative care has evolved to include populations who are not necessarily dying, '*but for whom alleviation of suffering and improvement of quality of life may be relevant goals*' (Meghani 2004: 153). She identifies four attributes of palliative care including, total active and individualised patient care, support for the family, interdisciplinary teamwork and effective communication, which appear as central tenets of what might be considered basic nursing care. Meghani makes the suggestion that it will '*depend upon the commitment of health professionals to recognise and integrate the changing concept of palliative care into everyday practice*' (2004: 153) but the question that must then arise is why the need for another concept such as palliative care when basic, quality care will do? Seymour (2004) identifies a number of concepts that have been used to define palliative care nursing, including teamwork, dignity, comfort, empathy, hope, suffering and quality of life, and goes on to discuss in more depth the concept of caring, which she says '*is perhaps the fundamental element of palliative care nursing*' (Seymour 2004), but why should this be different from what all nurses offer? It would appear that the view of palliative care being different from other types of care has its early historical background rooted in the idea that palliative care was specifically for those who were dying, predominantly from cancer, and that special skills were required to care for these dying patients that differed from other groups of patients.

Although the early hospice movement in the UK was only concerned with caring for those dying largely with cancer, subsequent developments have sought to extend services to those without cancer (Payne et al. 2004). Current policies in the UK have sought to introduce the concept of palliative care earlier in the illness trajectory (National Institute for Clinical Excellence 2003). As this change in direction has taken place, the term 'supportive care' has emerged. This was originally an accepted phrase within the context of care provided in addition to curative treatments for cancer patients (Department of Health (thereafter DH) 2000). More recently it has been expressed as care that:

... helps the patient and their family to cope with the illness and treatment of it – from prediagnosis, through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment. (NCPC 2005).

The key elements of supportive care in cancer services have been derived from evidence about what it is that people with cancer want, which includes clear information and to be treated with dignity and respect

(Seymour et al. 2005c). This work has not been carried out in the renal arena and the views of patients with renal failure at the end of life are still to be uncovered.

End-of-life care is a broad term that seems to identify more than the phase immediately before death and has been referred to as the last year of life although this can only be determined retrospectively (Seymour et al. 2001). In the UK the term has been used by the Department of Health in the National Service Framework for Older People (DH 2001) but as stated by Seymour et al (2005c) a clear definition of what this is, is missing. As we have difficulty determining the exact time of death and as we will all ultimately die at some point in time, this term, which has negative undertones, is probably only useful when a definitive diagnosis of death can be made as it may be a term that the public reject.

The term 'conservative management' has been utilised in the renal field to denote care offered to patients who have decided not to have dialysis (Burns 2006) but has also been referred to as supportive therapy (Burns 2006). Most of these patients are older, with comorbidities, and it has been observed that some may benefit in terms of survival, by not commencing dialysis (Smith et al. 2003). However evidence to prove this is scarce. Conservative management involves optimising care for those who have made the decision not to embark on dialysis and has also been termed 'maximum conservative management' by at least one author (Burns 2006). Although it is accepted that many patients on a conservative management pathway will ultimately die, some patients actually survive for considerable lengths of time and cannot be said to be dying at the time of referral. Few data are available at present to support this, again highlighting the new area of practice with which we are dealing with. This has led to difficulty in determining when a patient requires palliative care input and where they should be referred, as often conservative care is all that is on offer.

As a result of this terminological quagmire it was considered timely to question the nature of renal supportive care, both conceptually and pragmatically. According to Rodgers (1989), when the definition of a concept such as this is ambiguous or misunderstood the '*ability of the concept to assist in fundamental tasks is greatly impaired*' (1989: 330). Attempting to clarify terminology in the renal field and comparing this to similar terminology in other disciplines may help us define what it is that we are offering our renal population at a time when their needs from diagnosis to death are being recognised as more problematic than originally acknowledged (Cohen et al. 2006; Arnold and Solomon 2006).

2.3.3 Setting and sample for data collection

Published papers concerning renal supportive care between 1806 and September 2006 were collated from a review of databases, including CINAHL, Medline, PsycINFO, British Nursing Index, International Bibliography of the Social Sciences and ASSIA, using 'renal supportive care' as a key phrase. As this revealed no articles, 'renal and supportive care' were entered as key words. All articles in the English language were considered. This search yielded 275 records. All titles and abstracts were read. The majority of the papers referred to active treatment measures for patients with renal failure, often acute renal failure, where supportive measures were employed in the short term while the patient made a recovery. Only papers that added to the conceptual understanding of the term 'renal supportive care' were

ultimately selected. This yielded only eight records (Table 2.1). It was decided to add the term ‘palliative care’ to the search to identify if the terms ‘palliative care’ and ‘supportive care’ in relation to renal patients were being used in tandem and this yielded only three records, two of which were duplicates: the papers by Noble et al. (2005) and Shah et al. (2006). The third record was not relevant (Gridelli 2004). It was decided not to utilise the search terms ‘renal’ and ‘palliative care’, although it was assumed that many of the principles found in palliative care for the renal patient would be similar to those found in supportive care. It was felt that this would have added to the confusion previously identified and the aim was clearly to uncover the evolution of the term ‘supportive care’ for the renal patient only and make some recommendations for its use.

Table 2.1 Records retrieved relating to renal and supportive care

Fainsinger, R.L., Davison, S.N., and Brenneis, C. (2003) A supportive care model for dialysis patients. *Palliative Medicine*, 17 (1): 81-82. (Fainsinger et al. 2003)

Feudtner, C., Christakis, D., Zimmerman, F., Muldoon, J., Neff, J., and Koepsell, T.D. (2002) Characteristics of deaths occurring in children's hospitals: implications for supportive care services. *Pediatrics*, 109 (5): 887-893. (Feudtner et al. 2002)

Feudtner, C., Hays, R., Haynes, G., Geyer, J., Neff, J., and Koepsell, T.D. (2001) Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics*, 107 (6): E99. (Feudtner et al. 2001)

Germain, M.J. and Cohen, L. (2001) Supportive care for patients with renal disease: time for action. *American Journal of Kidney Diseases*. 38 (4): 884-886. (Germain and Cohen 2001)

Levy, J.B., Chambers, E.J., and Brown, E.A. (2004) Supportive care for the renal patient. *Nephrology Dialysis Transplantation*, 19 (6): 1357-1360. (Levy et al. 2004)

Noble, H., Chesser, A., and Kelly, D. (2005) The cessation of dialysis in patients with end-stage renal disease: developing an appropriate evidence base for practice. *EDTNA/ERCA Journal*, 31 (4): 208-211. (Noble et al. 2005)

Ragnarson-Tennvall, G. and Wilking, N. (1999) Treatment of locally advanced pancreatic carcinoma in Sweden. A health economic comparison of palliative treatment with best supportive care versus palliative treatment with gemcitabine in combination with best supportive care. *Pharmacoeconomics*, 15 (4): 377-384. (Ragnarson-Tennvall and Wilking 1999)

Shah, S., Blanchard, M., Tookman, A., Jones, L., Blizzard R., and King, M. (2006) Estimating needs in life threatening illness: a feasibility study to assess the views of patients and doctors. *Palliative Medicine*, 20 (3): 205-210. (Shah et al. 2006)

Additional sources, such as publications by the World Health Organisation (World Health Organisation 2004), the National Council for Palliative Care (NCPC 2004) and The Department of Health (DH 2001;2005) were also included to gain further perspective on the concept.

The World Wide Web (www) was also searched in English, utilising the key phrase ‘renal supportive care’, which yielded a massive 1,360,000 ‘hits’. A rapid on-screen review of initial sources was undertaken to exclude those that did not correlate directly with the nature, practice or development of

renal supportive care. Unfortunately, many of the hits referred to the same thing. For example, a book by Chambers et al. (2004), *Supportive Care of the Renal Patient* was referred to in 11 out of the first 30 hits. Several chapters of this book inform this concept analysis. Other duplicate sources were identified and disregarded. By the seventh page (70th hit) there were no new sources to be found (Table 2.2). The amount of data finally selected was small but it was felt appropriate to continue with the concept analysis. The concept 'renal supportive care' was being utilised in the renal world alongside 'renal palliative care' and it was deemed helpful to try to explicate the different meanings, if indeed there were any, in relation to the use of the concepts when caring for renal patients. The data obtained from the internet sites (n=9) and the articles obtained from the databases (n=8) were read and the content of each source and article was reviewed using key headings: definition or attributes, antecedents, consequences, related concepts and surrogate terms (Rodgers 2000). Each source was read and notes written under each of the above headings before data analysis and the final summary.

Table 2.2 References from the World Wide Web

Chambers, J., Germain, M, and Brown, E. (2004) *Supportive Care for the Renal Patient*. Oxford: Oxford University Press.
<http://www.oup.com/uk/catalogue/?ci=9780198516163>

Modernisation Initiative. Kidney Disease.
http://mykidney.org/what_we_do/supportive_care

Royal Society of Medicine. Journal of the Royal Society of Medicine. *Supportive Care for the Renal Patient*. Woolfson 2005; 98: 132
<http://www.jrsm.org/cgi/content/full/98/3/132>

Levy, J.B., Chambers, E.J., and Brown, E.A. (2004) Supportive care for the renal patient. *Nephrology Dialysis Transplantation*, 19 (6): 1357-1360.
<http://www.jrsm.org/cgi/content/full/98/3/132>

Jacobs, C. (2005) Supportive Care for the Renal Patient. Volume 1. *Nephrology Dialysis Transplantation*, 20 (6): 1280.
<http://ndt.oxfordjournals.org/cgi/content/full/20/6/1280>

End Stage Renal Disease Workgroup in End-of-life care
<http://www.promotingexcellence.org/i4a/pages/Index.cfm?pageID=3689>

internurse.com. Contents - International Journal of Palliative Nursing, Volume 12 Issue 8 (25 August 2006)
http://www.internurse.com/cgi-bin/go.pl/library/contents.html?uid=1591;journal_uid=14

Germain MJ and Cohen L (2001) Supportive care for patients with renal disease: time for action. *Oct*;38(4):884-6
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11576896&dopt=Abstract

NKF. Discontinuing treatment: key issues and ethical dilemmas. Chambers J.
<http://www.kidney.org.uk/Medical-Info/other/discontinuing-treatment.html>

2.3.4 Identification of attributes and antecedents

Analysis of the literature was inductive and themes were identified similar to content analysis, a research tool used to determine the presence of certain words or concepts within texts or sets of texts (Weber 1990). All data recorded under the heading definitions were gathered together to identify the attributes of the concept 'renal supportive care'. The same procedure was followed for the other categories listed above. Sources were grouped into key illuminative themes, which are described below.

2.4 Attributes of renal supportive care

2.4.1 Available from diagnosis to death with an emphasis on honesty regarding prognosis and impact of disease

The literature discusses the need for supportive care to be available to patients with stage 5 CKD from diagnosis to death, stating that this is integral to a 'good death' (Holley 2006). This is similar to supportive care in the cancer arena, the difference being that some patients with cancer will make a recovery whereas those with renal failure will live and die with their disease. Unlike the cancer specialty, renal specialists have tended to avoid this fact, focusing more on the scientific aspects of renal disease and its technical treatments. This is evident in the dearth of literature related to the care and experience of dying renal patients. Also, changes in demographics and clinical profiles of renal patients are occurring in conjunction with medical and ethical problems associated with long-term dialysis patients without definitive cure. Patients are treated via very demanding and expensive interventions which has led to the need for new approaches to caring for these patients (Jacobs 2005). It is imperative that open communication is encouraged in dialysis units so that patients are not dialysed inappropriately and are explicitly encouraged and assisted to be involved in decision-making. '*The option of not having dialysis must be an explicit part of this discussion*' (Levy et al. 2004). Patients need to understand that their prognosis is limited and in some cases dialysis may not be beneficial in terms of quality and length of life. It has become clear that dialysis and transplantation are associated with significant morbidity. Beyond extending the length of life, the idea of optimising the quality of a patient's life through 'supportive care', closely integrated with 'technical care', is now emerging as a priority in the management of patients with stage 5 CKD (Cohen and Germain 2004; Levy et al. 2004).

2.4.2 Interdisciplinary care

An integrated model of supportive care emphasises an interdisciplinary team approach (Reiter and Chambers 2004; Gokal 2004; Noble et al. 2005). There are differences in the way nephrology teams versus hospice or palliative care teams work. The nephrology team will usually address medical, psychosocial and existential problems that are associated with the renal disease and the dialysis treatment. Within the supportive care model, nephrology staff educated in palliative care can call on a number of other staff, such as psychologists and palliative care multidisciplinary teams to complement their management of these patients (Reiter and Chambers 2004). This calls for a change in the culture of the renal unit, which in the past has often been self-contained and self-managing. Although all the literature found mentions the important role of the renal multidisciplinary team, interdisciplinary team working is

something that appears to be evolving as renal supportive care services are established. This may be due to renal supportive care emerging from the renal pre-dialysis arena, where decisions are made about renal treatment modes. In the past, supportive and palliative care has not been offered as a treatment option. As staff are now focusing on the needs of those opting not to dialyse, their expertise is growing in tandem with increased communication with colleagues across other disciplines, for example palliative care, mental health and cardiology.

2.4.3 Restorative care

A broader construction of renal supportive care is evolving that embraces both restorative and curative care. '*Restorative care is disease-specific therapy that seeks to reverse, halt or minimise the underlying pathophysiological processes of disease*' (Reiter and Chambers 2004: 16) and alongside palliative care can maximise disease control and quality of life (Reiter and Chambers 2004; Noble et al. 2005; Holley 2006). This brings together the unique challenges in renal supportive care to apply dialysis technology appropriately and address the goals of the individual and their carers. This model of supportive care envisages a continuous overlap of restorative care and palliative care, and seeks to minimise the toxicity of treatment, the symptoms associated with renal disease and its comorbidities. Fewer restorative options may be available as the renal disease progresses, requiring greater reliance on palliative care interventions (Cohen and Germain 2004; Reiter and Chambers 2004; Lamping 2004) towards the end of life, especially as it becomes clearer that the patient is not benefiting from dialysis therapy and their general health is deteriorating.

2.4.4 Support for the family

Support for the family is essential in renal supportive care situations (Reiter and Chambers 2004; Levy 2004). Families caring for patients with a chronic, terminal illness face huge problems, such as fear of the unknown, of losing a loved one and fear of the level of care that is required (such as medication regimens) as well as anxiety and loss of status related to a loss of employment and related income. There is also the knowledge that without dialysis treatment the patient will die (Reiter and Chambers 2004), almost certainly within weeks. This means that patients will often continue with treatment while suffering debilitating side-effects such as fluid overload, fatigue and depression (Saini et al. 2006). Families live through this trauma with their loved ones and require psychological and spiritual support. Unfortunately, due to financial pressures in many hospitals, this will often be lacking and will tend to focus on the patient who attends the unit three times a week. Often families don't attend dialysis sessions as again due to financial pressures patients have to justify why they require transport and relatives are regularly barred from attending with patients. As renal supportive care services evolve, the support required for carers of those with stage 5 CKD continues to be highlighted and seen as a priority (DH 2005; NHS Modernisation Initiative 2006; Arnold and Solomon 2006). How this can be more effectively managed at this time of great financial difficulty for the National Health Service in the UK is something to be debated.

2.4.5 Effective, lucid communication to ensure informed choice and clear lines of decision-making

Achieving the goal of supportive care is not considered possible without effective, clear channels of communication. Importantly, supportive care in advanced renal disease contexts requires patients and the multidisciplinary team, along with families, to have open therapeutic dialogue regarding treatment options, advance planning, prognosis and preferred place of death (Cohen et al. 2001; Fainsinger et al. 2003) with the promotion of shared decision-making (Levy et al. 2004; Reiter and Chambers 2004; Levy 2004). When offering and discussing treatment, there is a balance to be achieved between the potential of the treatment offered and the associated side-effects. '*Extending life is not enough*' (Chambers et al. 2004). In stage 5 CKD, treatment has the potential to extend life at a cost in terms of morbidity that may initially be uncertain but in the long term is often severe. This is also costly in terms of finance and is something to be considered. In the UK, the National Institute for Clinical Effectiveness (NICE) (National Institute for Clinical Excellence 2006b) is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. As it becomes clearer that dialysis is not always of benefit for certain patient populations, it is possible that guidelines regarding the use of such treatment will come into force, as has happened already in the management of Alzheimer's Disease (National Institute for Clinical Excellence 2006a), causing some distress to patients and practitioners alike. The nephrology community would be wise to consider these guidelines against best evidence so that agreement is mutual and regulations are not imposed.

2.5 Antecedents and consequences of renal supportive care

Antecedents are phenomena which precede a concept (Rodgers 2000), and the antecedent to renal supportive care is a diagnosis of life-threatening renal failure, causing physical or psychological distress to the patient.

The consequences are the phenomena that are expected to follow a concept (Rodgers 1989). The literature demonstrates that renal supportive care encourages shared decision-making from a diagnosis of renal failure until death (Reiter and Chambers 2004; Holley 2006). It has implications for patients and their families and includes high-quality palliative care. It also encourages remedy of the denial of death that is often found in patients with stage 5 CKD, their carers and the staff who care for them (Cohen et al. 2001; Cohen and Germain 2004).

2.6 Analysis of data in reference to the characteristics of the concept

The integration of the principles and values of palliative care has been taking place in nephrology for over a decade, led by physicians in the United States who have established guidelines to help clinicians involved in decisions about withholding and withdrawing life-supporting dialysis treatment (Poppel et al. 2003). Less widespread detailed guidelines are available in the UK, although the Renal Association recommended in 2003 that guidelines for palliative care of those patients who choose not to dialyse be developed (Renal Association 2003) and the *National Service Framework for Renal Services: Part 2*

includes a specific section on end-of-life care as previously discussed (DH 2005). Unfortunately, the framework gives very little detail related to what specifically should be offered at the end of life for renal patients and there is no government money attached to taking the framework forward.

In the healthcare literature as a whole, supportive care may be considered a general term that, to date, has been most closely associated with cancer patient populations (World Health Organisation 2004; Skilbeck 2005; Seymour et al. 2005c). The literature search for this concept analysis failed to identify any reference to renal supportive care prior to 2003 (Fainsinger et al. 2003), but 2004 brought the publication of the first textbook devoted to supportive care of the renal patient (Chambers et al. 2004). With this has come a new examination of the supportive care needs of those with renal failure. It would appear that renal supportive care is now emerging from the goal of integrating the ethos of palliative care into the care of renal patients on dialysis as a stand-alone concept. Clarity is required if this concept is to be utilised appropriately and has been attempted by Levy et al. (2004). They state that a variety of symptoms might be present in patients with stage 5 CKD that are generally not well managed. As a result they argue that a 'supportive care' approach to care should be adopted. This is not concerned solely with the end-of-life phase, but should be considered an adjunct to the management of renal disease patients at all stages of their illness. In this emerging context, therefore, renal supportive care is not being presented as an alternative to dialysis but rather as a philosophical underpinning to the nature of the interventions employed – with the focus always on the individual patient. To this extent renal supportive care has similarities with the goals of the palliative care movement but, within the technological focus of dialysis contexts, it may not equate to the withdrawal of all treatment. This approach to renal supportive care as a philosophical agreement, focusing on decision-making and the promotion of quality of life, between those involved is also discussed by Levy et al. (2004), who emphasise the features necessary to achieve its aims (see Table 2.3). It is interesting to note that the terms 'palliative care' and 'conservative management' are listed within Table 2.3 giving the impression of supportive care as the overarching concept. This becomes more interesting when probed further, and many points listed seem concerned with issues related to the end of life, such as discussions with hospices, debriefing for staff following the death of a patient, bereaved family support and an open culture towards discussing death. Perhaps dressing up the terminology will enable renal practitioners to engage more readily with the problem that many renal patients face - that of a premature death.

Table 2.3 Examples of good practice in ‘renal supportive care’ (Levy et al. 2004)

• Regular (weekly) multidisciplinary meetings including counsellors, psychologists, palliative care doctors
• Joint renal–palliative care clinics
• Joint education programmes with the palliative care team
• Preparative discussions and meetings with community services (e.g. hospices, district nurses) prior to need
• Integration of nursing and psychological assessment notes into medical notes, or wide access database or electronic records
• Identification of named key worker for each patient (either on dialysis or being managed conservatively)
• Critical event debriefing of whole renal care team after a death
• Easy availability of interpreters, and use of a small cohort who become skilled in the necessary discussions
• Encouragement of advanced directives
• Open-door policy for support for bereaved families
• Development of an open culture discussing death, palliative care, supportive care during pre-dialysis meetings with patients (singly or in groups)

Levy et al.’s work (2004) is useful, as it has been developed by practitioners in practice. Unfortunately, the voices of patients and their carers are missing from this work, which means that we cannot be sure that what it is that practitioners think patients and carers require from renal supportive care services is accurately depicted.

2.7 Identification of inferences, theories and implications for future development of the concept

Although it is established that the evolutionary process adds rigour to the process of concept analysis (Rodgers 1989), there were some limitations to this work. The sampling method may have excluded papers that had something important to add to the concept. Only work completed in English was considered and this might have excluded important work published in another language.

This aside, this literature-based concept analysis demonstrates the key features of renal supportive care. In common with much palliative care literature, renal supportive care emphasises improved quality of life for both patients and their families, but this is what all practitioners should be striving for irrespective of the patient's diagnosis. Central to renal supportive care is the idea of helping the patient to make informed decisions when expensive dialysis treatments will not necessarily improve life expectancy and quality of life. There is an emphasis on openness about the chronicity of renal disease and the importance of recognising and accepting the devastating impact this illness has on patients and their families.

More research related to renal supportive care, and what it means to patients, families and professionals, will be essential to ensure that as the concept continues to evolve it is appropriate for those to whom it has most relevance. For instance, the overarching goal of integrating supportive care into the practice of renal dialysis and transplantation services from diagnosis onwards may have great benefit to patients. However, it will be important to clarify what patients and carers understand by renal supportive care to take such projects forward. By utilising focus groups involving patients and their carers, the concept can be made clearer by ascertaining the views of those affected by renal failure and can be utilised to inform future concept analyses. There are important links to be made with the cancer arena, and it may be that there is scope for more renal nurses to develop expertise in renal supportive care. This might help champion renal supportive care within a range of health settings as well as contributing to workforce development and education, patient experience and national policy in all areas delivering renal care.

At present it is unclear whether or not the name Renal Supportive Care Service is appropriate, as little is known about those deciding to forgo dialysis. It may be more appropriately named Renal Palliative Care Service to enable other disciplines a clearer understanding of the work involved especially as many patients do die. This aside, a small number of patients have outlived their prognosis and it may be hasty to change the name at present as patient trajectories to death have not been identified. There may be a need for supportive *and* palliative care, but if more patients are referred earlier and then live for longer it may not be appropriate to add 'palliative' to the name of the service due to the negative undertones still associated with this term.

2.8 Summary

The meanings associated with 'palliative' and/or 'end-of-life care' may have added to the expectation that supportive care is relevant only towards the end of life diminishing its perceived relevance at the time of diagnosis. Evidence exists that a combination of palliative *and* supportive care is most appropriate over the course of progressive, life-limiting diseases such as renal failure. Importantly, elements of both can be initiated at any point in the disease trajectory (Fainsinger et al. 2003). Historically, as 'palliative care' has been identified as offered towards the end of life, it may be appropriate to consider use of the term 'renal supportive care' in the hope that patients and their families do not confuse the care they are receiving with care only available to those who are going to die. While palliative care professionals may be keen to

challenge negative connotations themselves, this situation exemplifies the importance of being aware of the meanings that words attract.

The meaning of palliative care has evolved over the past three decades and enjoys a level of cultural understanding as yet absent from renal supportive care. Renal supportive care is a dynamic and emerging concept that is relevant to, but not limited to, the end of life phase of care (Levy et al 2004). Renal supportive care in its broadest sense suggests a central philosophy underpinning renal service developments that allow patients, families and the multidisciplinary team time to work together and with others across disciplines, to realise complex goals. In the future, renal supportive care will need to expand to encompass advance directives in line with ethical and legal prerogatives. In this context, renal supportive care is a core skill and the vehicle for the promotion of holistic renal care in any setting where renal patients are found, such as nursing homes and intensive care units. This will require the concept of renal supportive care to be translated into a comprehensible and transparent reality, which can be easily explained to patients and their loved ones.

Undoubtedly, renal supportive care will change (as palliative care already has) over time as better understanding of disease processes takes place and continued evaluation establishes how the quality of people's lives may be improved further. Important aims at present include questioning and then communicating the essential nature of renal supportive care to practitioners, patients and their families. This inquiry revealed a lack of literature related to the concept 'renal supportive care'. Theory development is required in this area and this concept analysis is therefore a first critical step in providing a conceptual foundation essential for this further development. This thesis is aimed at exploring the healthcare needs and trajectories to death of renal patients receiving supportive care and therefore informs development in this area.

CHAPTER 3

THEORETICAL PERSPECTIVES: EXPLORING THEORIES OF DEATH AND DYING

The previous chapter looked theoretically at the concept of renal supportive care in order to offer an understanding of a term recently introduced into the renal arena. It highlighted the key attributes of the concept and argued the appropriateness of using the term 'supportive care' when choosing the name for a new service caring for people managed without dialysis, particularly as some patients didn't die as expected. Nevertheless, many did go on to die and therefore major theoretical approaches deemed useful in the study of death and dying are introduced in this chapter. Also, in order to appreciate the wider relevance of this study to current thinking concerned with death and dying, theories or models that have informed developments in this area and influenced the way care is shaped and delivered towards the end of life are presented. Theories of death and dying are of particular importance as the concept of 'a good death' and how this can be achieved, is promoted in government policy in the UK (Ellershaw et al. 2003; DH 2008). The findings later in Chapter 8 concerning the trajectory to death or not in those with stage 5 CKD will link back to this chapter.

In an attempt to understand contributions that have previously been made to this debate, two central aspects are discussed in this chapter. The first part focuses on dying trajectories and explores these in patients with cancer, heart failure, chronic obstructive pulmonary disease (COPD) and old age. The second part goes on to discuss how people have been observed to cope with dying and deal with this knowledge, uncovering conceptual development in terms of awareness of dying; coping with dying in stages; intervals or using a task-based approach; hope when coping with dying and readiness to die theory. The final part of this chapter explains how little is known about those with stage 5 CKD, their trajectories to death and how they cope with the knowledge that they are dying.

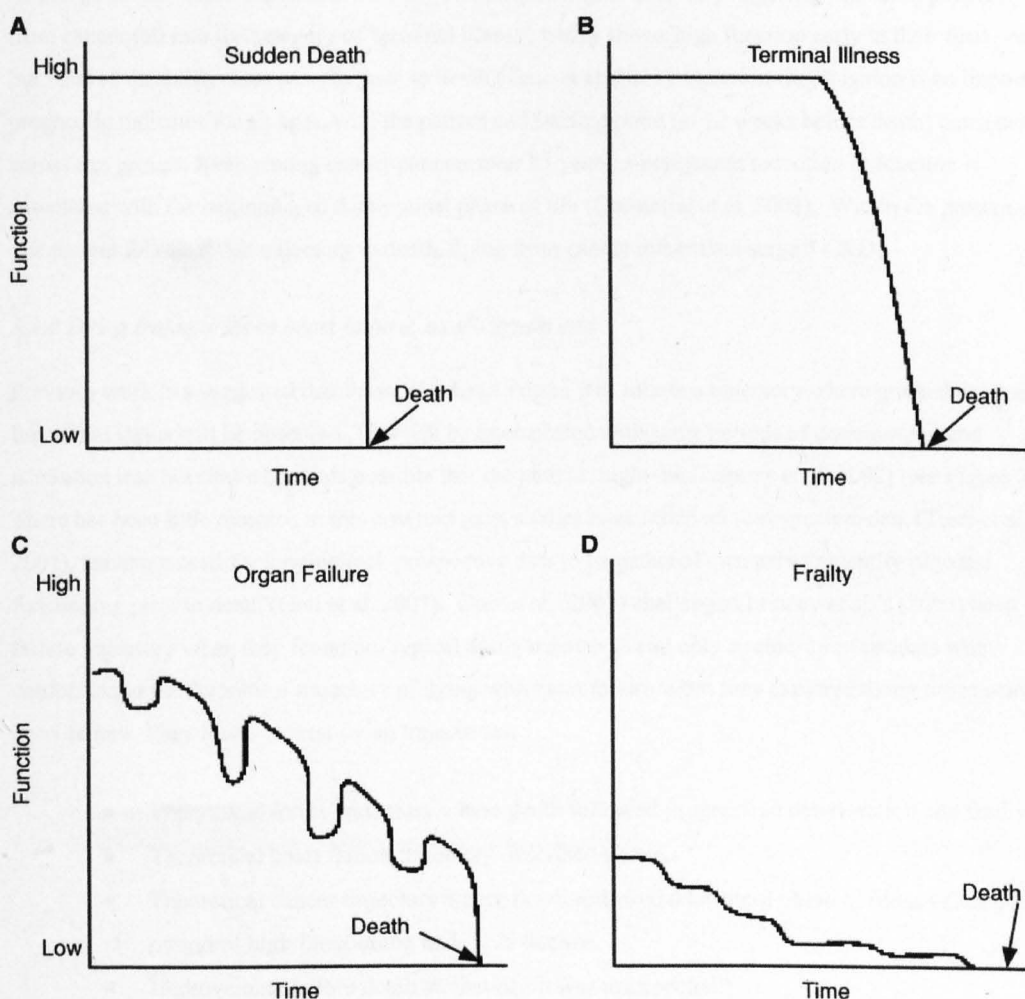
3.1 Dying trajectories

An important area of conceptual development in the literature has focused on the timing of illness and dying. 'Dying trajectories' are defined by the time involved between the onset of dying and arrival of death (Glaser and Strauss 1967). Glaser and Strauss (1967) discuss the 'shape' or characteristic course of the dying process with diseases where the trajectory is short, leading to a quick death, and diseases with extended dying trajectories involving a consistent or variable decline (Corr et al. 1999).

Dying concerns the length and time to death and symptoms that occur along the way. In the past the focus has been on those dying with cancer, but it is becoming clear that there is an urgent need to create a more inclusive paradigm of end-of-life care to manage people dying from chronic illness as well as cancer with a focus on needs rather than diagnosis (Murtagh et al. 2004). Dying trajectories are important for planning palliative care services, and theoretical models of specific illnesses and the decline to death are useful. Several theoretical models have been put forward to describe physical trajectories to death (Lunney et al. 2003) including:

- a) Sudden death with little prior warning.
- b) Death following a terminal phase of illness which takes place after a period of high functioning, then rapid decline as often seen in some patients with cancer.
- c) Death from organ failure where a gradual decline in functional status occurs but where acute deterioration along the way could cause death.
- d) Death following progressive deterioration, which often accompanies frailty, stroke or dementia (see Figure 3.1).

Figure 3.1 The typical disease trajectories identified in patients with different diseases. From Lunney et al. (2003)



The dying trajectory in stage 5 CKD has not been described. In theory patients should fit into (c) of Lunney et al.'s model above. The present thesis contests that this is not always the case, with many patients dying where the cause of death is unclear.

Physical dying trajectories that have been described include:

- dying trajectories in cancer
- dying trajectories in heart failure
- dying trajectories in COPD
- dying trajectories in old age

3.1.1 Dying trajectories in cancer: a sudden decline

Studies of the functional status of patients at the end of life suffering with cancer have found that they are often in relatively good health until one to two months prior to death (Teno et al. 2001; Lunney et al. 2003). At this point they often experience a steady decline (see Figure 3.1). It is suggested that most people dying from cancer fall into the category of 'terminal illness', which shows high function early in their final year, but marked disability three months prior to death (Teno et al. 2001). Deteriorating function is an important prognostic indicator for all ages, with the pattern and starting point (at 12 weeks before death) consistent across age groups. Even among cancer patients over 85 years, a permanent reduction in function is associated with the beginning of the terminal phase of life (Costantini et al. 2008). Within the present study one patient followed this trajectory to death, dying from cancer rather than stage 5 CKD.

3.1.2 Dying trajectories in heart failure: an uncertain end

Previous work has suggested that those with heart failure will follow a trajectory where gradual decline in functional status will be observed. This will be interspersed with acute periods of deterioration and admission into hospital where it is possible that the patient might die (Lunney et al. 2002) (see Figure 3.1). There has been little research in this area and most studies have relied on retrospective data (Teno et al. 2001), leaving a need for longitudinal, prospective data to be gathered quarterly to identify physical functioning prior to death (Gott et al. 2007). Gott et al. (2007) challenged Lunney et al.'s (2003) heart failure trajectory when they found no 'typical dying trajectory' and only a minority of patients who conformed to the theoretical trajectory of dying with heart failure when they explored dying trajectories in heart failure. They found several dying trajectories:

- Theoretical frailty trajectory where death followed progressive deterioration and frailty
- Theoretical heart failure trajectory described above.
- Theoretical cancer trajectory where death followed a terminal phase of illness after a long period of high functioning and rapid decline.
- Improvement before death so that death was unexpected.
- Fluctuating but not a downward trend where again death was unexpected.

The findings challenge the theoretical heart failure dying trajectory upon which current service developments are planned. Not all patients with heart failure will die predictably, and there is a need to reconsider current efforts to plan and deliver services to those with heart failure on the basis of the trajectory which is put forward in the literature (Gott et al, 2007). Within the present study one patient followed this trajectory to death dying from heart failure rather than stage 5 CKD. Two others, who hadn't died at the end

of the study, had followed this trajectory, presenting with heart failure as the prominent comorbidity and suffering gradual deterioration, particularly following admission to hospital.

3.1.3 Dying trajectories in COPD: an unpredictable death, usually in hospital

In attempting to determine the unique trajectory to death of those with COPD, Goodridge (2006) reviewed the literature relating to COPD at the end of life. Little empirical work has been carried out to uncover the physical trajectory to death. Goodridge (2006) concluded that people with COPD tend to live in a continuous state of poor health punctuated by intermittent exacerbations (Canadian Thoracic Society 2004) similar to some patients with heart failure (see Figure 3.1). In spite of the protracted course of COPD, death very often results from sudden complications, such as infection or cardiovascular events (Lynne et al. 2000), meaning that mortality data often underestimates COPD as cause of death with it more likely cited as a contributory factor (Pauwels et al. 2001). The unpredictability of death in this population makes prognostication difficult and patients are often admitted to the intensive care unit for mechanical ventilation where death can occur (Connors et al. 1996). Goodridge (2006) concluded that the unpredictability of death in those with chronic disease makes prognostication difficult and maybe even impossible using current models of care and impacts on the access of patients with COPD to palliative care. She highlights how this difficulty in prognosis poses different challenges in end of life decision-making to those faced with terminal cancer. One patient in the present study suffered from advanced COPD and was still alive at the end of the study.

3.1.4 Dying trajectories in old age: prolonged dwindling

The dying trajectory in old age, also known as ‘prolonged dwindling’ (Murray et al. 2005), applies to those people who escape cancer or organ failure and die at an older age of either brain failure, as in those with dementia, or generalised frailty of multiple body systems (Lynn and Adamson 2003). This trajectory is one of disability that worsens over time from an already low baseline of cognitive and/or physical functioning but is also viewed as ‘natural’. This trajectory, where frailty and dementia often prevail, means the provision of supported long-term care services either in the home or an institution will be required, but this trajectory and those who follow it have received very little attention from policy-makers (Abbey et al. 2005). This group, referred to as the ‘disadvantaged dying’ (Seymour et al. 2005b), often have a prolonged uncertain trajectory of dying, leading to difficulties identifying a phase that requires terminal care, especially when older people present with numerous comorbidities (Payne and Froggatt 2006). As palliative care services are configured to manage those dying with cancer (Hockley 2006), practitioners working in this field may have little experience of caring for people with long-term cognitive deficits (Payne and Froggatt 2006), leading to a deficit in the care required. Several patients in the present study were of an advanced age and frail. Some patients with stage 5 CKD may potentially follow a ‘prolonged dwindling’ phase and die from advanced age rather than renal disease, although this may be difficult to determine.

3.2 How people cope with dying

Another area of conceptual development has involved awareness of, and coping with, dying. If people are aware they are dying, there will be an attempt to cope with this knowledge. This is discussed as:

- awareness of dying
- coping with dying in intervals, stages or using a task-based approach
- hope when coping with dying
- readiness to die theory.

3.2.1 Awareness of dying

Four types of 'awareness contexts' or patterns of interactions between dying patients, their carers and staff have been described (Glaser and Strauss 1965):

- Closed awareness: A context in which a person who is dying does not realise the fact and carers and staff are unwilling to share this knowledge with the patient.
- Suspected awareness: Here the patient may suspect that diagnostic and/or prognostic information is not being shared. Patients may begin to deduce that all is not well but carers and staff continue to withhold this information.
- Open awareness: In this context there is willingness on the part of all involved to share information and there is open discussion about the poor prognosis and death that will ensue.
- Mutual pretence: In this context the patient, carers and staff all know that the patient will die but all act as if this is not the case. All parties behave as if things are not as they know them to be.

The central point emerging from Glaser and Strauss's work (1965) is that dying in society is typically an experience which is lived out in social contexts with more than one person involved in the process. Each of these awareness contexts is organised around the dying person and their desire to know or not know the truth about their diagnosis and prognosis and the willingness or unwillingness of carers and staff to share the information in question. This work has illuminated the ways in which patients, staff and carers may collude to resist sharing bad news. In particular, 'mutual pretence', where critical information is not shared, requires unremitting vigilance to maintain a strategy where knowledge is denied.

Weisman and Kastenbaum (1968) found that older people often communicated symbolically about impending death but staff seldom picked up on this and tended to underestimate the patient's awareness of their situation. They observed a pre-terminal period of life in which cognitive, interpersonal and medical changes occur but these changes were under-recognised. A key finding was fear of death but this was seldom expressed. Here the dying appeared to be more aware of their impending demise than staff and preparation for death often didn't occur.

Weisman (1972) offered another approach to understanding awareness and believed that the question was not what a person knew or did not know about impending death but rather when and with whom that person shares this knowledge. He proposed that denial could take many forms and he proposed the concept of 'middle knowledge', where people live with 'uncertain certainty' and acceptance of impending death or rejection of this certainty. He described how people might accept the facts of their illness and their impending death but resist this situation. He saw middle knowledge as marked by shifts in what could be seen and what was inferred. This could explain how some people seem to know and understand that they are dying, but talk as if they do not know or do not wish to be reminded about what has been told to them.

It is assumed that patients who decide not to have dialysis are aware that their life expectancy is shortened and many may live with 'uncertain certainty'. How they manage that concept in their daily lives is unknown.

3.2.2 Coping with dying in stages, intervals, or using a task-based approach

Kübler-Ross (1969) in her book, *On Death and Dying*, postulated a sequence of five 'stages' in response to awareness of impending death. These included: denial, anger, bargaining, depression and acceptance. These stages were described in various ways by Kübler-Ross as 'reactions' or 'responses', as 'defense' mechanisms and as 'coping' strategies. Although all stage theories are naturally sequential, and Kübler-Ross explains that dying people and others coping with dying could move from one stage to another and that various stages could sometimes exist side by side. This weakens the fundamental linearity expected with a concept of stages.

The value of this theoretical framework, and its most helpful feature, is the emphasis placed on the dying individual's responses to what is happening. Based on this, Corr (1993) proposed three points to be drawn from the work of Kübler-Ross:

1. Dying persons are not yet dead but alive and may have things they need or want to do.
2. Potential helpers cannot expect to provide effectual care for dying persons and others who are coping with dying unless they actively listen and determine priorities together.
3. There is much that everyone can learn from those who are dying and others who are coping with dying about common mortality and ways of responding to impending death.

The stage-based theory proposed by Kübler-Ross (1969) has been rejected by many well-known writers (Weisman 1972; Pattison 1977; Weisman 1977). Weisman (1977) insists that graphic stages can only be '*at best approximations, and at worst, obstacles to individualization*', identifying again the uniqueness of each person's personal trajectory to death. Weisman (1984) also distinguishes between '*defense mechanisms*', which attempt to avoid or ward off problems, and '*coping processes*', which he saw as involving more than an automatic response or a defensive reaction. He describes coping as an active

process - a doing with a positive orientation seeking to solve problems or adjust to challenges in living (Corr et al. 1999).

Pattison (1977) sought to frame understandings of dying with what he called the 'living-dying interval', defined as the period between the knowledge that death is coming and the time that it arrives. He states that we all project ahead a trajectory of our lives and that this trajectory is changed when a crisis occurs, such as the knowledge of death. A 'living-dying interval' is described as a personal trajectory through three phases: the acute phase where the diagnosis and prognosis is made clear; the chronic phase where individuals may cope with encounters in a variety of ways, often in an unpredictable manner, and the terminal phase where death comes closer and ultimately arrives (Pattison 1977).

After Pattison's (1977) work little was progressed in this area until Corr (1992) argued a need to critically examine previous models and draw on knowledge from other disciplines, such as bereavement studies. This was in order to look at how models might guide understanding of how people cope with dying. Corr (1992) identified four areas of 'task work' to be thought about in coping with dying:

1. Physical – centres on satisfying bodily needs and minimising physical distress.
2. Psychological – includes emphasising security, autonomy and richness of living.
3. Social – includes supporting and enhancing interpersonal attachments to individuals and social groups.
4. Spiritual – centres on the need to recognise, extend and reaffirm sources of spiritual energy and in doing so foster hope.

The idea of 'task' implies a degree of influence over how people can manage what is happening to them and is consistent with task-based models in mourning when someone dies (Worden 1991). Task work also allows for variation in the way that people might manage the many issues that may arise and how they address them. Tasks that may be important to one person may not be important to another. Listening carefully to what the person says is important to them will help to identify key tasks and how they are being addressed.

An important aspect of Corr's (1992) work centres on the idea that dying is not confined to the person who is dying and can affect all those who come into contact with that individual. Because of the impact on carers, any model must contribute to improved understanding, empowerment and participation for carers to cope with the dying process, and Corr argues that the task-based model fulfils these criteria.

3.2.3 Hope when coping with dying

The understanding of coping led Weisman (1972) to confirm the importance of hope in experiences of dying and to progress the concept of an 'appropriate death'. He used this term rather than a 'good death' due to the danger of identifying a 'good death' with the notion of a well-managed, well-behaved death but not the type of death desired by all. Weisman (1972) observes that hope and acceptance of death are basic

concepts because they assert that mortality is a dimension of living, not merely an end-point that cancels out all that has gone before. He believes that an appropriate death has four aims:

1. Reducing but not necessarily eliminating conflict.
2. Making dying people's dying compatible with their own views of themselves and their achievements.
3. Preserving or restoring relationships as much as possible.
4. Fulfilling some of the dying person's expressed aims.

An important point is that some deaths can be appropriate for those who experience them (Weisman 1972).

3.2.4 Readiness to die theory

More recently, Copp (1999) claims to have attempted to address deficiencies in the work discussed above. She highlights a lack of empirical studies on the experiences of patients who face imminent death and the need to extend Glaser and Strauss's works (1965; Glaser and Strauss 1967) in relation to the trajectory concerned with certain death at an unknown time. In interviews with patients whose death was imminent, Copp found that reference was often made to the 'body' as separate from the 'self'. The nurses' constructions of a body-person split were made by reference to the body as a separate entity from the personal self, in attempts to determine the patient's 'readiness to die'. 'Readiness to die' appeared to be characterised by four modes:

1. Person ready, body not ready.
2. Person ready, body ready.
3. Person not ready, body ready.
4. Person not ready, body not ready.

A patient was found to exist in one mode at a time, but could change between modes depending on the physical condition of the person's body, but also their acceptance of their death. The body-person split and 'readiness to die' interpretations provide an additional facet to current theoretical conceptualisations concerning the dying process. Although theories on death and dying have focused on elements such as individuals' reactions to the notion that they will die, their awareness that death is imminent and the time and duration of dying, Copp (1999) highlights the notion of separating body and self as a theory for understanding readiness to die.

Copp's study was carried out in a hospice where all participants were dying of cancer and aware of their prognosis. It remains unclear whether or not her findings can be transferred to people dying from other conditions, where determining when the end of life might arrive may be more difficult. People with illnesses such as renal disease or heart failure may not be aware that such conditions will lead to death, unlike cancer where diagnosis can lead to people believing they will die. Cancer is more widely known as

a disease that can kill and it may be that people with cancer are more aware of their prognosis because of this.

3.3 Dying trajectories and coping with dying in stage 5 CKD: the unknown

The trajectory to death, if it occurs and how patients with renal disease manage that trajectory has not been studied, hence the need for the present study. There are features of renal disease, in particular the availability of dialysis, which differentiate it from other end-stage diseases, such as advanced heart failure and COPD. It is likely that the functional trajectories of patients with stage 5 CKD will vary depending on whether or not dialysis is undertaken and according to the presence of comorbid conditions (Murtagh et al. 2008).

Many patients making decisions not to embark on dialysis are older (Murtagh et al. 2006) and it is important that the needs of the older person are taken into account as the end of life approaches. Some renal patients may follow a 'prolonged dwindling trajectory' (Lunney et al. 2003), being frail and perhaps housebound, making access to health services difficult. There may be a need for input from specialist teams such as geriatricians to identify and treat problems usually specific to old age, such as dementia. Other patients may follow a chronic disease trajectory (Lunney et al. 2003) with dips in functional ability and regular admission into hospital. Others may die unexpectedly. In fact, they may or may not follow previous trajectories described by Lunney et al. (2003).

Murtagh et al. (2004) suggest, based on clinical experience, that the trajectory in stage 5 CKD may be that of a steady decline, with the rate of this decline varying according to the underlying renal pathology and other patient factors, although what these factors are is not made clear. It has also been suggested that high levels of comorbidity with renal disease, especially cardiovascular and cerebrovascular disease, make this trajectory particularly difficult to predict (Murtagh et al. 2004). In a similar way to those with other life-limiting conditions, patients with stage 5 CKD may receive acute intervention at the end of life, which may contribute to the ultimate death of the patient, with some patients being dialysed to death (Noble and Rees 2006).

3.4 Summary

This chapter has explored theories of death and dying postulated in the literature. It has discussed theoretical frameworks which have been proposed in the literature concerned with patients dying from cancer (Teno et al. 2001; Costantini et al. 2008), heart failure (Lunney et al. 2003), chronic obstructive airways disease (COPD) (Goodridge 2006) and old age (Lunney et al. 2003). Much work in this area has focused on the patient with cancer and little is known about how those dying with stage 5 CKD manage and cope with this situation and the trajectory they follow to death. It cannot be assumed that they will have similar experiences as those with other chronic diseases as those dying with heart failure and COPD have been shown to die unpredictably (Goodridge 2006; Gott et al. 2007).

The chapter has also discussed conceptual development around how people cope with dying. This included work concerned with awareness contexts when dying; how people cope with dying in stages, intervals or by using a task-based approach; and how hope is essential as people cope with dying. The chapter concluded with a discussion of dying and readiness to die theory. There remains an urgent need to understand the experience of death and dying in those managed without dialysis and the literature review in the next Chapter confirms this point.

Findings from this thesis, which begin to trace the trajectory of death for renal patients managed without dialysis, challenge the literature on death and dying by suggesting that these patients do not follow the predicted chronic disease trajectory discussed in this chapter. Their death is often complicated by the fact that its approach is difficult to predict and little is known about the population and how they progress to death. This is discussed in more detail in Chapter 8.

CHAPTER 4

LITERATURE REVIEW

4.1 Introduction

The previous chapter explored theories of death and dying, Chapter 4 locates this inquiry in the context of a body of knowledge and uses the results of a systematic search to examine the empirical evidence concerned with end-of-life care for those with renal disease and other life-limiting conditions. It highlights several gaps in the body of knowledge that form the foundation for this study. Findings from this literature review have been published elsewhere (Noble et al. 2008a; Noble et al. 2008b). It examines the literature concerned with the experiences of renal patients who make the decision not to embark on dialysis and the ensuing disease trajectory. This chapter also explores the literature pertaining to those opting to withdraw from dialysis. This is important as it helps situate the review, which was hindered by a dearth of literature related to those choosing not to commence dialysis. It is aided by reflecting historically on how decision-making in the renal field, related to treatment options that often lead to death, has evolved over time. Alongside this, decisions made to forgo treatment in other life-limiting diseases are also explored, but again, due to a paucity of studies, is brief in nature. In order to illuminate and draw comparisons with those suffering from other life-limiting illness, the empirical literature related to the experiences of these patients towards the end of life is also included.

The chapter begins by addressing the aims of the review, followed by the search methods used, the inclusion and exclusion criteria and the procedure which took place in terms of determining the value of each retrieved study. Key themes are discussed regarding: making decisions to forgo or withdraw from treatment – the renal perspective; making decisions to forgo or withdraw from treatment – other life-limiting diseases; length of survival without dialysis; prevalence of symptoms in stage 5 CKD; the utilisation of advance directives; the impact on families; and existential specific themes. It concludes with a summary which stresses the need for further research in order to understand the experiences of those opting not to dialyse.

4.2 Aim

The literature review was complex due to the lack of empirical studies found during the early stages of the review and is set out in detail below. Ultimately, the literature review aimed to answer the following questions:

1. What are the experiences of those opting not to have dialysis to treat stage 5 CKD?
2. What is the difference in experience for those withdrawing from dialysis compared with those choosing not to embark on dialysis to treat renal failure?
3. What are the experiences of those opting not to undergo treatment for life-limiting conditions other than terminal renal failure?

4. How do the experiences of patients with other life-limiting diseases compare with those who have opted not to dialyse towards the end of life?

4.3 Search methods

A review of the literature was carried out in December 2006 and updated until November 2008 as new literature was published. Citation alerts were established where an email message is received when new articles matching specified criteria become available in order to keep the search up to date. It was ultimately undertaken in four parts as the need to broaden the search became evident. The initial search was aimed at uncovering work relating to the care of patients who had opted not to have dialysis. Electronic databases searched included: CINAHL (1982-2006), Medline (1950-2006), PsycINFO (1806-2006), British Nursing Index (1985-2006), International Bibliography of the Social Sciences (1951-2006), ASSIA (1987-2006) and Cancerlit (1963-2006). The range of electronic databases was chosen to include items related to end-of-life care, palliative care, terminal care, supportive care, conservative management, gerontology, psychiatry, sociology, and health.

The following search terms were used to represent the inclusion criteria. They were checked against thesaurus synonyms in an attempt to include all words that might select papers specific to the search:

- 1. Terms related to stage 5 CKD:**

Renal failure or renal disease or chronic kidney disease or dialysis

- 2. Terms related to choosing not to have a treatment:**

Opt\$ out or treatment cessation or choosing not to or withdraw\$ or withhold\$ or abatement or stop\$ or refus\$

- 3. Terms related to decision-making:**

Decision\$ or decision-making or treatment option\$

The search was further refined by combining these three categories together. Articles with an English abstract were considered, which meant that some articles were found written in a variety of languages, including Japanese and Hebrew. Following retrieval of the original papers, bibliographies were scanned for references that related to the literature review questions. In addition, researchers with a known interest in the field were consulted regarding existing publications and work in progress.

4.4 Inclusion and exclusion criteria

Studies were included if they had been peer-reviewed and included adult populations with a principal diagnosis of stage 5 CKD. Studies describing patients undergoing the treatment modalities of haemodialysis, peritoneal dialysis or supportive care management or studies of patients discontinuing

dialysis were included. Studies of patients with a renal transplant were excluded as these patients will have received a functioning kidney. Studies which reported on any setting including the hospital, community, day care, out-patient, or nursing home were included. Empirical studies of any design were included but case series or case reports were excluded.

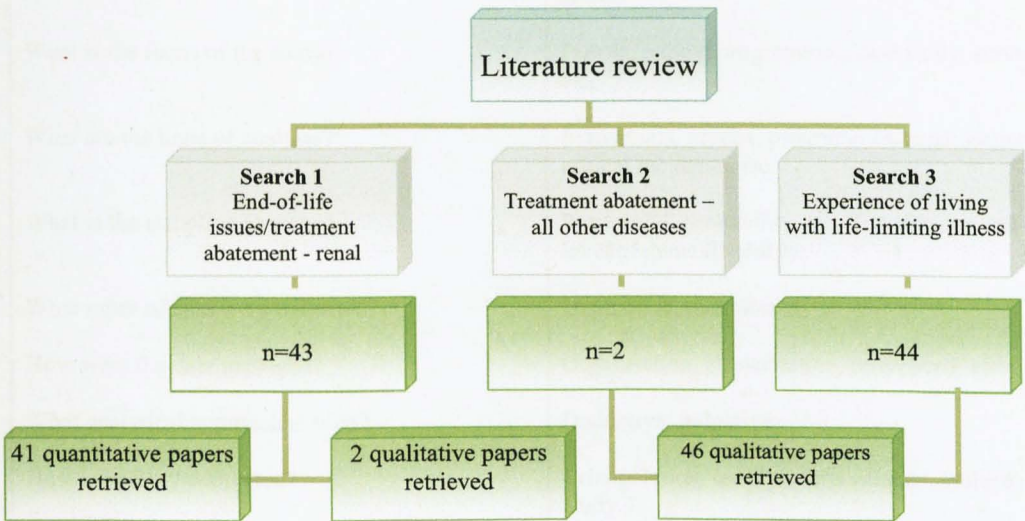
After the removal of duplicates, 35 abstracts were also rejected as not relevant to the review. For example, several papers discussed care in the intensive care unit and were associated with physician decision-making regarding appropriate treatment regimes (Morris 1996; Swartz et al. 2004). Others discussed a variety of matters including the concerns of nurses who challenge lawful (or unlawful) practices of healthcare employers (Hess 1993), transplantation (Gordon 2001) and cardiac surgical patients (Gersbach et al. 2006) demonstrating how difficult it is to ensure that the search terms used distinguish appropriate literature only. At this point 43 studies were retained (see Figure 4.1).

As this first search provided few empirical studies specifically related to those opting not to dialyse, a second search was carried out using the same search strategy detailed above but with the terms related to stage 5 CKD changed to terms related to life-limiting illnesses, including cancer, lung disease, heart disease, HIV, AIDS, diabetes, Parkinson's disease, motor neurone disease or chronic disease. It was deemed useful to attempt to draw comparisons between those opting not to dialyse and those suffering with other life-limiting diseases who had decided to forgo treatment. Two hundred and eighty-eight studies were uncovered after the removal of duplicates but it was quickly obvious that many papers were not relevant to the search as the majority of papers were not empirical studies. It was decided to add the terms 'qualitative' and 'quantitative' to the search but this revealed only five studies (Favre et al. 1993; Parkash and Burge 1997; Kuuppelomaki and Lauri 1998; Harris et al. 2003; Kendall 2006) none of which was related to the literature review questions. Eventually two papers were selected (Huijter and van Leewen 2000; Kacen et al. 2005). One was found by scanning the references of the first paper (Kacen et al. 2005) (see Figure 4.1). These two papers related to patients deciding not to pursue treatment viewed as potentially life-saving. Clearly, the whole question of the experience of withdrawing from treatment when suffering with a life-limiting illness requires urgent attention.

It was decided to broaden the search to target the qualitative cancer and chronic disease literature in an attempt to understand how the experience of living with a life-limiting illness had been tackled, what was revealed, and to scrutinise the methodology used to elicit new knowledge in this area, in order to hypothesise comparisons with those suffering renal disease. The search strategy remained the same but key terms searched were grouped into words that pertained to a life-limiting illness, as in the second search (cancer, lung disease, heart disease, HIV, AIDS, diabetes, Parkinson's disease, motor neurone disease or chronic disease) (n=810,317) and end-of-life care (n=405,9520). Once these articles were retrieved, they were reduced by using the keyword 'qualitative' (to specifically identify qualitative studies where possible (n=680)) and 'experience' (to avoid those studies that did not focus on the experience of the patient or carer (n=142) following removal of duplicates). The title and abstract of the selected 142 papers were scanned and papers were removed if they did not relate to the topic in hand. These included papers on the management of diabetes in palliative care (Quinn et al. 2006), the experiences of nurses (Rodrigues and Chaves 2005), studies related to giving information (Williams-Brown et al. 2002) and

even a rogue quantitative study (Lopez et al. 2005). The number of studies retained equalled 44 (see Figure 4.1).

Figure 4.1 Overview of the search strategy used for the literature review



4.5 Procedure

Following training in systematic reviews of the literature at the Institute of Education, University of London, and using guidance specified by Hart (2003), the literature was reviewed. Hart (2003) offers direction which includes:

- identifying key sources of information
- systematically analysing key variables and arguments
- critically evaluating literature in relation to justification and methodology

Hart also suggests that it is possible to understand design features and methodological choices of a piece of research by using questions originally produced by Pattern (1990) (Table 4.1)

Table 4.1 Questions posed by Pattern (Pattern 1990) to determine the value of empirical research studies

Issues	Options
What is the purpose of the study?	Basic research, applied research, action research
What is the scope of the study?	What is included, excluded, why and to what effect?
What is the focus of the study?	People, policy, programmes, case study, survey, etc.
What are the units of analysis?	Individuals, groups, programmes, organisations, critical incidents, etc.
What is the sampling strategy?	Purposeful, probability, etc. Significance and level of generalisability
What types of data were collected?	Qualitative, quantitative
How were the data managed?	Organisation, classification, referenced, etc.
What analytical approach is used?	Deductive, inductive
How is validity addressed?	Triangulation, multiple data sources, multiple study
When did the study occur?	Currency of findings, long-term investigation
How is the study justified?	Literature review and analysis, problem definition, practical outcomes
How are the ethical issues handled?	Informed consent, confidentiality, data protection, etc.
How are logistics handled?	Access to data, fieldwork, record-keeping

Source: adapted from Pattern (1990) in Hart (2003)

Each paper was briefly read for abstract and main points before assigning it with key words. The guidance described above was used to direct the evaluation. Each paper was examined for the purpose of describing and summarising the body of literature available in the area. Following this initial review, papers in each category were read in more detail and themed. The reading was supplemented by discussions with supervisors and colleagues regarding the findings of the review and the emerging themes.

4.6 Findings

In total 89 papers inform the literature review: 41 quantitative papers and two qualitative papers are used to inform the renal-specific part of the review. Most papers originated from the USA (n=20) and the UK (12), reflecting the majority of research that has been carried out in these two countries related to withholding and withdrawal of dialysis. Others came from France (4), Canada (2), Finland (1), Switzerland (1), Australia (1), Japan (1) and Hong Kong (1) (see Table 4.2).

Forty-seven qualitative papers centre on the experiences of those with life-limiting illness. This includes the two papers related to forgoing treatment for terminal cancer. The papers emanate from 15 different countries, including USA (n=16), Canada (6), the UK (6), Sweden (4), Australia (3), Finland (2) Ireland (1), China (1), Iceland (1), Latvia (1), Denmark (1), Hong Kong (1), Singapore (1), Norway (1), the Netherlands (1), and a joint paper from Israel and Australia (1) (see Table 4.3). This reflected an interest and concern with end-of-life issues across diverse cultures.

Table 4.2 Country of origin of papers informing the renal part of the literature review (n=43)

USA (n=20)	UK (n=12)	France (n=4)	Canada (n=2)	Finland (n=1)	Switzerland (n=1)	Australia (n=1)	Japan (n=1)
Abed Sekkarie and Swartz 2004 Badzek et al. 2000 Bordenave et al. 1998 Calvin 2004 Hines et al. 2001 Holley et al. 1989 Holley et al. 1991 Holley et al. 1999 Holley 2002 Kurella et al 2007 Mailloux et al. 1993 McDade-Montez et al. 2006 McKenzie et al. 1998 Munoz Silva and Kjellstrand 1988 Neu and Kjellstrand 1986 Phillips et al. 2005 Roberts et al 1988 Rutecki et al. 1994 Sehgal et al. 1992 Sehgal et al. 1996	Catalano et al. 1996 Chandra et al. 1999 Gunda et al. 2004 Lambie et al. 2006 Lamping et al. 2000 Murtagh et al. 2007 Murtagh et al. 2007d Naish et al. 2003 Rich et al. 2001 Saini et al. 2006 Smith et al. 2003 Wong et al. 2007	Birmele et al. 2004 Clement et al. 2005 Joly et al. 2003 Pollini and Teissier 1990	Bajwa et al. 1996 Singer 1992	Ikaheimo et al. 2005	Bosshard et al. 2006	Ashby et al. 2005	Fujimaki et al. 2005

Table 4.3 Country of origin of papers related to the experiences of those with life-limiting diseases (n=47)

USA (n=16)	Canada (n=6)	UK (n=6)	Sweden (n=4)	Australia (n=3)	Finland (n=2)	Ireland (n=1)	China (n=1)
Collett 1998	Bailey and Tilley 2002	Cochrane 2003	Benzein et al. 2001	Lethborg et al. 2006	Arman et al. 2002	O'Donnell 2005	Simpson 2005
Coyle 2004	Davies et al. 1990	Hopkinson et al. 2006	Friedrichsen and	McGrath 2004	Lindvall 1995		
Engle et al. 1998	Daneault et al. 2004	Murray et al. 2003	Erichsen 2004	Yates and Stetz 1999			
Hull 1989	Fletcher 2002	Murray et al. 2004	Lindqvist et al. 2004				
Kayser-Jones 2002	Koop and Strang 2003	Potter 2004	Thome et al. 2004				
Lin 2003	Wilson and Sinding	Souter 2005					
Mackey and Sparling	2003						
2000							
McCarthy 2005							
Minear 1998							
Nieto 2005							
Pope 1999							
Ryan 2003							
Ryan 2005							
Stetz and Brown 1997							
Vig and Pearlman							
2003							
Waite 2003							
Iceland (n=1)	Latvia (n=1)	Denmark (n=1)	Hong Kong (n=1)	Singapore (n=1)	Norway (n=1)	The Netherlands (n=1)	Israel/Australia (n=1)
Bergs 2002	Kalnins 2006	Rydahl-Hansen 2005	Lam and Fielding	Mak 2001	Landmark et al. 2001	Huijter and van Leewen	Kacene 2000
			2003			2000	

4.7 Key themes from empirical evidence

4.7.1 *Making decisions to forgo or withdraw from treatment – the renal perspective*

Discontinuation of dialysis is a common cause of death in stage 5 CKD patients in the UK and the USA (Ikaheimo et al. 2005). Stopping dialysis is thought to be less common in other countries, although studies from France (Birmele et al. 2004), and Finland (Ikaheimo et al. 2005) have indicated otherwise. Also, as Birmele et al. (2004) note, the differences in the studies can be attributed to differences in dialysis strategies and attitudes of physicians and patients in different countries, but can also be induced by the way dialysis withdrawal is reported. Mailloux et al. (1993) state that dialysis termination is not always stated as the cause of death and is a subjective outcome if the patient had high comorbidity. This can lead to different interpretations in the cause of death, and withdrawal from dialysis is not always recognised as the main reason for death. Until more international guidelines are formulated in this area the picture of events may always appear unclear.

This aside, these studies are helpful in allowing us to understand the practice that occurs in renal units, but they are all based on retrospective case note analyses. The need for prospective studies is evident so that, as data are collected, they can be checked for clarity to ensure that interpretation is accurate.

Several studies have attempted to understand how patients are selected for dialysis, their prognosis on dialysis and ultimately withdrawal practices (Pollini and Teissier 1990; McKenzie et al. 1998; Sekkarie and Moss 1998; Chandra et al. 1999; Smith et al. 2003; Joly et al. 2003; Clement et al. 2005; Bosshard et al. 2006; Lambie et al. 2006). These studies are primarily quantitative in nature and use questionnaires (Pollini and Teissier 1990; Sekkarie and Moss 1998; Clement et al. 2005; Bosshard et al. 2006), retrospective data analysis (Chandra et al. 1999; Lambie et al. 2006), and surveys (McKenzie et al. 1998). They all focus on the practice of clinical staff and add to the body of knowledge relating to the decision-making of staff, especially nephrologists. The patient voice is silent, raising questions about why this should be. A relatively recent study by Calvin (2004) sheds some light on this. She highlights the fact that although there is a general lack of knowledge about the end of life treatment preferences of patients undergoing haemodialysis, patients when prompted to think about this, chose to focus on living rather than dying. Grounded theory was used to explore decisions among haemodialysis patients and their end of life treatment decisions and a substantive theory of 'personal preservation' was developed (Calvin 2004). This consisted of three phases: (1) knowing the odds for survival, (2) beating the odds and being responsible and (3) taking chances. It offers an explanation for why so little literature is found regarding renal patients and care towards the end of life. Some patients may not want to focus on this difficult aspect of life and professionals therefore have a difficult task trying to approach this topic, perhaps finding it easier to ignore it.

Going back to the practice of nephrologists, Lambie et al. (2006) attempted to study the associations between nephrologists' opinions, availability of haemodialysis, patient characteristics and comorbidities, and facilities withdrawal rates in six countries including France, Germany, Italy, Spain, the UK and the USA. They found wide variations in the prevalence of waiting lists for new dialysis patients, in agreement

with starting dialysis for patients with advanced age, dementia and other comorbidities, and in agreement with withdrawal of dialysis. Differences within and across countries probably reflect differences in access to dialysis and the practice of withdrawal of dialysis in their units. Variations in practice seem to be a common problem. Some nephrologists accept all patients for dialysis, believing that refusal equates to passive euthanasia (Pollini and Teissier 1990) and others report very little instruction in medical ethics and life-sustaining treatments (Holley et al. 1991), highlighting an obvious need for education in this area.

As can clearly be seen, most of these papers focus on how physicians make dialysis decisions and little mention is made of patient choice or how patients make these difficult decisions. There is a huge gap in the body of knowledge in this area and renal patients appear to be a marginalised group who have not had their concerns heard during the difficult ethical debate that is apparent in the literature. Withdrawal from dialysis results in death in days, so it is a decision that has the most serious consequences (Birmele et al. 2004). It has been claimed that 'withholding or withdrawing life-supporting treatment is one of the most ethical issues for medicine in the late twentieth century (Neu and Kjellstrand 1986) and there is a lack of knowledge about the end of life treatment preferences of patients undergoing haemodialysis (Calvin 2004). Also palliative care for patients with stage 5 CKD is a neglected aspect of nephrology (Gunda et al. 2004) making it clear that these patients are likely to be receiving suboptimal care towards the end of life. As demonstrated by the literature, the patient's viewpoint is on the whole ignored. There is a paternalistic feel to what is uncovered, with clinician decision-making being at the forefront of the discussion.

It was not until 2005 that some attempt was made to comprehend the patients' story for refusing dialysis. There are only three studies (Ashby et al. 2005; Fujimaki et al. 2005; Chan et al. 2007) to be found worldwide; one of a qualitative and two of a quantitative nature. Ashby et al. (2005), in an Australian study, examined the experiences of patients opting not to have dialysis, or withdrawing from dialysis treatment, taking into account the social and personal impact of this decision. Patients were recruited from the renal units of two large Australian Tertiary hospitals in Melbourne. This referral-based study utilised a qualitative methodology consisting of semi-structured interviews which aimed to understand from the patients' perspective '*the reasons for, and issues surrounding, their decision*' (Ashby et al. 2005: 390). The authors state that this understanding required an approach that would be free from the personal assumptions healthcare workers might have regarding this phenomenon. For this reason, they decided that grounded theory (Glaser and Strauss 1967) was a qualitative research method that '*provided an alternative way of understanding the participants' beliefs and actions from those offered in the clinical setting*' (Glaser and Strauss 1967: 390). Unfortunately, they were unable to theoretically sample the population, as recommended by grounded theorists (Glaser and Strauss 1967), due to the fragile nature of the group. They had originally estimated that they would recruit 52 participants, but due to impaired cognition and medical deterioration only 11 patients were able to participate. They also recruited five relatives but do not explain why this number was also small. Participants were divided into three groups: those who had discontinued dialysis (n=4), those who had decided not to commence dialysis (n=7), and spouses of these patients (n=5).

The authors go on to state that '*the omission of theoretical sampling emphasises the phenomenological aspects in the methodologies of grounded theory*' (Ashby et al. 2005: 390) the meaning of which is not explored and no further reference is made to phenomenology. This suggests a confusion with the methodology utilised. It may well be that this unexplored area, that of dialysis abatement, requires a broader qualitative methodology to allow for the unfolding and analysing of data not previously collected. We cannot be sure what patients and carers will report so choosing a methodology is problematic and it may be that several different methodologies could be appropriate, depending on the story told.

The interviews took as long as the participants required and '*open-ended questions were introduced in a manner suited to the particular interview*' (Ashby et al. 2005: 390) but no more detail is offered regarding these questions so the study is difficult to replicate. The interviews were transcribed, coded, categorised, compared and analysed until '*theoretical explanations of the participants' experience was developed*' (Ashby et al. 2005: 390). One would have expected key concepts and relationships to have emerged and appear clearly articulated in the report, but only three main themes are conveyed.

- Poor quality of life, pain and suffering
- Desire not to be a burden
- Doctor-patient issues: prognostic uncertainty and a sense of abandonment

4.7.1.1 Poor quality of life, pain and suffering

For those withdrawing from dialysis, it is apparent that profound suffering has influenced their decision made in the context of the personal experience of declining health. The decision to withdraw from dialysis was one that had taken some time for the patient to actually intimate, and was often something they decided alone. They never discussed the decision with family or health professionals until they were clear that this was what they wanted. Reasons for this included fear that the decision would upset their family or that withdrawal would be viewed as akin to suicide or the result of religious beliefs. This hindered a decision to withdraw, leading to moral and ethical burdens for the patients involved. This was in contrast to those opting not to commence dialysis who made the decision with their families and were clear that they didn't wish to embark on such a demanding therapy, which would disrupt their lives and maybe extend them inappropriately.

4.7.1.2 Desire not to be a burden

Both groups articulated the wish not to be a burden on others. In the group withdrawing from dialysis, three out of four patients lived alone and relied heavily on children to shop and care for them. The desire not to be a burden was a clear reason for patients choosing not to commence dialysis. Patients expressed concern regarding the disruption that dialysis would cause to their family life. Many patients saw dying as a natural course that they would rather take than burden their children with issues related to dialysis. Patients also felt that undergoing dialysis would be a waste of resources and would adversely affect their quality of life.

4.7.1.3 Doctor-patient issues: prognostic uncertainty and a sense of abandonment

There were problems for those who decided not to commence dialysis. They felt abandoned by the healthcare team with little follow-up care. Added to this were prognostic uncertainties, which meant that patients felt angry if they outlived their prognosis, having made plans for their death and been left to arrange what remained of their lives. This prognostic unpredictability also affected those receiving palliative care at the hospital. When told by their doctor that their prognosis was uncertain, patients expressed a desire for death to come quickly and to be free of pain. They also feared a lingering death. Spouses also found the prognostic uncertainty difficult and felt abandoned as they attempted to manage difficult medication regimes and dietary modifications. The spouses, all wives, felt that if they made any change to medication or diet they might cause harm to the patient and their misdemeanour would be identified in routine blood tests used to assess renal function and therefore deterioration in health.

The authors conclude that it would be of considerable benefit to ensure that a proactive and open approach is taken towards end-of-life issues. They suggest that the clinical and health-promoting principles of palliative care be integrated into renal dialysis practice. They also advise that there is a need for clinical guidelines related to end-of-life care, advance directives, peer mentoring and clinical and health-promoting palliative care initiatives.

This study which focused on the needs of this marginalised renal group, points to the lack of research and evidence in this area of care. The authors state that they undertook a qualitative study based on the principles of grounded theory (Glaser and Strauss 1967). It is unclear, ultimately, what methodology was used to analyse the data and the paper ends up being rather descriptive and lacking a theoretical basis. This aside, the content is absorbing and novel. Never before have renal patients who have decided not to commence dialysis, been asked why they have made this decision. And this paper, although it needs to be treated with caution due to the small sample size and the queries related to methodology, has raised some interesting issues that would be worthy of further exploration. The paper offers new knowledge based on a limited sample size so the strength of the findings is not as great as if the authors had demonstrated a saturation of categories (Miles and Huberman 1994). What is lacking is a more in-depth review of how patients make these difficult decisions and what support they require from the renal healthcare team until death.

Fujimaki et al. (2005) and Chan et al.'s (2007) retrospective studies report motivation for refusal to embark on dialysis to include: not wishing to attend the hospital three times a week; feeling too old to have dialysis; that it would be more natural to die without dialysis, mainly due to age; and for family reasons, although it is not clear what these are. Chan et al. (2007) found that decisions related to initiation or withdrawal of dialysis were often related to personal beliefs and sentiments.

The study by Fujimaki et al. (2005) was written in Japanese and translated by a colleague's mother. Retrospectively it inspects dealings with patients who have 'refused' the offer of dialysis. They discuss '*how to grasp the meaning of this phenomenon*' (Fujimaki et al. 2005: 417). From the outset the paper takes a different stance from the previous study by Ashby et al. (2005) and intimates that the issue of deciding not to dialyse is peculiar and not fully understood. It strikes a similarity to early anecdotal papers

in the 1970s and 1980s when refusal of a therapy regarded as life-saving was viewed with surprise and unease (Viederman and Burke 1974; Moon and Graber 1985; Wise et al. 1985). The study, which ran over seven years, included seven patients who had refused dialysis, although five of these patients later embarked on emergency dialysis. The male/female ratio was 5:2 and the average age of the patients studied was 78 years. Data on clinical characteristics and household members were collected retrospectively from the case notes of patients.

As mentioned above results demonstrate that patients had several reasons for refusing dialysis, but as this was a retrospective case note review, there is little detail of the reasons given. Motivation for refusal included advanced age and not wishing to travel to hospital on a regular basis. These explanations support some of the data presented in the Ashby et al. (2005) paper, the difference being that in over half of the cases in the Japanese study (5/7), emergency dialysis was eventually initiated whereas this event did not occur at all in the study from Australia (Ashby et al. 2005). The Japanese study also concludes that '*We must make an effort to obtain consent to initiating dialysis if patients are assessed as suitable for dialysis*' (Fujimaki et al. 2005: 422) and the reader is left with the feeling that rarely would the authors consider dialysis an inappropriate treatment, veering towards offering it to all. This is in contrast to other countries, such as the USA (Friedman 1992), the UK (Smith et al. 2003; Gunda et al. 2004) and Australia (Ashby et al. 2005), although we cannot be sure that all healthcare professionals hold similar viewpoints (Loewy 2004). The studies by Ashby et al. (2005) and Fujimaki et al. (2005) highlight some of the cultural differences that are apparent in healthcare today, where the idea of refusing a treatment considered to be life-saving is not acceptable in some countries of the world.

Fujimaki et al.'s paper (2005) is again of interest as it attempts to elucidate the phenomenon of forgoing dialysis, but once more the small number of patients studied means it is limited in its intention and the urgent need for further study is accentuated. Data were only gathered from case notes. The study could have been strengthened by engaging with patients and carers when decisions had been made regarding treatment. In this way verbatim data could have been collected to support written reports. Of course this is less easy to do if patients and clinicians have conflicting views on treatment options, and as stated earlier, the sensitive area of palliative care may leave some feeling that it is inappropriate to ask dying patients for their stories as part of a research study.

4.7.2 Making decisions to forgo or withdraw from treatment – other life-limiting diseases

Moving away from renal disease, there is very little in the literature related to patients with other life-limiting diseases making decisions to withdraw from or refuse treatment for their condition. Only two studies were found worldwide (Huijer and van Leewen 2000; Kacen et al. 2005). In Amsterdam, Huijer and van Leewen (2000) attempted to explore the reasons that patients have for refusing chemotherapy and the way that oncologists then responded to them. The main purpose of this pilot study was to develop an understanding of the ethical aspects involved in treatment refusal and to generate questions for future research in this area. Unfortunately little detail of the methods used is given, but those that can be ascertained are described below.

Eight oncologists were asked to report how many of their living patients had refused treatment throughout 1995. Twelve patients were identified. Of these, three agreed to participate, with nine too unwell to participate or close to death. All three patients were female, diagnosed with breast cancer, metastasised breast cancer and metastasised ovarian cancer respectively. All had previous experience of chemotherapy. The time range between the consultation where treatment refusal had taken place and the semi-structured interview (of which we know very little) varied from several months to a year. Although the number of patients was low, the authors decided to continue with the study. They do not offer any justification for this action but it can be assumed that they decided the women would have valid and interesting stories to tell. A semi-structured interview took place with three of the oncologists to discuss the last patient, with whom they had had a conversation regarding treatment refusal.

The authors state that grounded theory methods (Glaser and Strauss 1967) were used to analyse the interviews and that the steps included: (a) examining the reasons for treatment refusal, evaluation of the refusal and communication about the refusal; (b) studying the interviews for themes; (c) developing categories to describe common themes in the interviews; and (d) refining the categories by relating them to literature on treatment refusal. Although the description of the process is vague, the authors present several interesting categories which are discussed from the patients' and oncologists' viewpoints.

4.7.2.1 Weighing the pros and cons of chemotherapy

From the interviews it became evident that deciding for or against chemotherapy was not just a matter of weighing the pros and cons. To understand treatment refusal, the authors suggest that contextual aspects related to the decision also need to be understood. Patients mentioned personal circumstances, such as a financial need to work, a need to study or the care of a dog as important factors in decision-making. On a broader scale, it became clear that contextual circumstances were also relevant to attitudes to life, suffering and death. Two patients had planned to reach old age and were not prepared to die soon. A more resigned attitude was expressed by the third patient who was not scared of dying, although she did not know what would come after death. All patients in the pilot study agreed that the advantages of treatment did not outweigh the disadvantages. The disadvantages of chemotherapy included negative experiences with previous courses, expected side-effects, perceived effects on others, uncertainty of the resulting effect on health, and the idea that an adjuvant treatment made no sense as long as they were feeling well.

The oncologists were concerned about the side effects and complications of the chemotherapy. Two explicitly mentioned the medical uncertainty regarding the course of the disease, the actual prognosis, and the results of chemotherapy in the individual patient. None of the oncologists talked about the context or the personal values of the patients. The refusals were evaluated from a medical or rather narrow psychological perspective (personality of the patient, anxieties, coping style). The patients' values were rarely mentioned.

4.7.2.2 Good reasons for treatment refusal

From the patients' perspective, 'good reasons' were complex issues regarding the process they had been through. The final decision required extensive deliberation, during which pros and cons of chemotherapy, personal circumstances, attitudes to living, suffering and dying, and the opinions of friends and relatives

were considered. During this deliberation, feelings played an important role. In all cases, the feeling that it was the right thing to do was decisive.

From the oncologists' perspective, 'good reasons' resulted from a rational balancing of the pros and cons of treatment. In their opinion, a patient could not have 'good reasons' to refuse treatment if there was a reasonable chance of recovery. One oncologist confirmed that refusing chemotherapy was tantamount to a death wish, and he would not hesitate in persuading the patient to accept treatment. Patients who refused for reasons other than on medical grounds tended to evoke disapproval.

4.7.2.3 Communicating about refusals

Only one of the patients felt that her physician respected her decision. The other patients' interviews demonstrated that communication became difficult because the oncologists felt their refusals were irrational. The patients did not get a chance to talk about their values and emotions and the reasons for their refusals. The difference of opinion about the final decision made these patients end the communication.

In the cases related by the oncologists, they all said that although they did not agree with a patient's refusal, they still respected the patient's choice. In these cases, the difference of opinion between the physician and the patient opened a specific discussion about rational decision-making. The physicians wanted to dissuade the patients by questioning the rationality of their decision, and the patients wanted to persuade the physicians of their right to refuse.

Although the sample in this pilot study is small, demonstrating some of the difficulties recruiting from this fragile population, and the methodology is unclear, it offers an interesting insight into the relationship between patients and their doctors when a patient's decision does not concur with medical advice and will lead to their death. Based on the conclusions of the pilot study, the authors recommend prospective research and that the study be extended to cancer care provided by general practitioners, nursing homes and hospitals. I would suggest that research in this area also be applied to those with other life-limiting diseases, specifically stage 5 CKD, where research of this nature is lacking. There may be similarities in experience although the decision to be taken in the renal speciality may not be so complicated. Some patients may fare better without dialysis (although we cannot be sure) and death can be caused by dialysis in some cases. Decision-making processes may therefore be different but are so far unexposed.

The second study by Kacen et al. (2005) relates to patients forgoing or stopping active treatment for cancer. The aims of this study, which was ongoing in 2005, were to explore how and why cancer sufferers make decisions regarding treatment, how family and healthcare professionals respond and the extent to which cultural values and beliefs may influence the views, understanding and actions of patients and others in this situation.

The authors state that the study was a qualitative field study using a phenomenological approach to data collection and analysis, and involved small research teams in Australia and Israel. Again, there is very little information regarding methodology and methods, and the only other information we are given is that a one-off focus group discussion and individual interviews were used to collect data from oncologists,

social workers, nurses and allied health professionals working in the oncology speciality. It may be that journal articles which limit the number of words that can be used to present a paper prevent authors from describing in more depth the methodology guiding the study and the methods used. The authors were aiming to interview 8-12 patients, 8-12 family members and 12-16 healthcare professionals. At the time the study was published, 24 staff had been interviewed, 11 patients and 10 family members. The rest of the paper reports on preliminary findings '*identified as strong themes within the data*' (Kacen et al. 2005: 109) but we are left to make our own decision regarding the trustworthiness of the findings so far as the methods of data analysis are not described. Themes included:

- The essential nature of the decision
- Reasons that patients give for deciding as they do

4.7.2.4 The essential nature of the decision

People with cancer are aware that they are making a critical decision when they forgo or stop treatment and are aware of the seriousness of the decision and its consequences. They see it as a rational and affirming choice, which reflects the person that they have become. The decision is not a single cognitive event and is often something that has been lived in the past, for example when a friend suffered cancer and its treatment, and the person vowed not to undergo such an experience. The decision is often made under pressure of time and a threat to life, and cancer is seen as a menacing invader creating a sense of urgency in those around the patient. If patients choose to refuse treatment, they must find the strength to resist pressure from others who may wish to change their mind. As in the previous study (Huijjer and van Leewen 2000) patients were encouraged to change their mind and staff were extremely persistent, calling patients at home to persuade them to alter their decision. These patients also made the decision alone, but generally for oneself, in what the patients regarded as in their own self-interest.

4.7.2.5 Reasons that patients give for deciding as they do

In a significant number of patients, perceptions of cancer as a fatal disease persist. People who forgo treatment may do so because of long held views of the futility of treatment that may postpone death but not cure the disease. Living longer is not always desirable if it is at a cost of bodily integrity or dependence on others. When treatment is seen to be interfering with a person's capacity to live what is perceived see as an ordinary life, then saving that life at whatever cost is not always an acceptable goal.

Some patients refused treatment due to fear. Some feared the treatment, some the stress it might bring and some the fear of losing control over one's body and life, and ultimately becoming dependant on, and a burden, to others. This may be because much media attention has been given to cancer and its negative aspects, and it may not correspond to those with stage 5 CKD who may know little about their illness and its effects.

Interestingly, it is common for patients to be told that the treatment advised is the only thing that will eradicate the cancer and prolong their life. This may be different from the renal speciality where some people may have to make a decision even when the doctor is unsure whether or not treatment will extend life. When a patient is sick with other diseases alongside the renal disease, it may be difficult to predict

how they will fare on dialysis, so the decision is complicated by this unknown entity and there is nothing in the literature which investigates or describes this phenomenon.

This study (Kacen et al. 2005) greatly lacks detail regarding methodology and methods but does manage to convincingly narrate some of the experiences of those with cancer who opt not to continue with or commence what is perceived as potential life-saving therapies. The difficulties encountered by patients when they go against the advice of their clinical staff are described, but the strength of character of the patients is also clear. Although we do not know what questions were asked of patients during the semi-structured interview, the findings give some insight into what the authors were trying to uncover and the findings could influence future interviews carried out with renal patients who are making similar decisions largely unacknowledged in the literature. It is essential that we know more concerning the renal trajectory so that we can inform future developments and educational initiatives.

Withholding, withdrawing and forgoing treatment for terminal disease other than renal failure is almost absent in the literature. Only two empirical studies inform this review (Huijer and van Leewen 2000; Kacen et al. 2005). There is much more literature to be found regarding experiences at the end of life when patients are aware they are dying, as discussed later, but the actual deed of treatment abatement is poorly acknowledged. As stated by Huijer and van Leewen (2000), one of the principles of modern-day cancer care is that it should be responsive to the wishes of patients and in keeping with their values. It is hoped that this ethic is integral to the work of renal practitioners, but there is a need to ask patients for their views on this. As previously stated, renal care has not always received the attention that the cancer speciality has managed to attract and sustain, and as a result there is a substantial lack of knowledge related to the renal patient.

4.7.3 Length of survival without dialysis

Possible length of survival is an important indicator when discussions regarding treatment options are taking place. As stage 5 CKD is predominantly a disease of the elderly and there is an increasing population age in developed countries, the number of patients developing renal disease is rising. Although it is generally accepted that older patients with significant co-morbidity do less well on dialysis (Smith et al. 2003; Joly et al. 2003; Murtagh et al. 2007d), little is known about their survival in comparison to patients who choose not to have dialysis.

In a recent paper, Kurella et al. (2007) address an expanding and very elderly population with stage 5 CKD and the need to understand more fully the role of dialysis for this population. The data they present is powerful, in that 10-15 months after starting dialysis, half of the patients over 80 years old are dead. Median survival for a 90 year-old commencing dialysis is approximately eight months, compared to 57 months for 90-94 year olds in the general population (Germain et al. 2007). Although the evidence that they present is crucial for informing healthcare policy, clinical practice and future prospective research, they do not discuss the consequences of not starting dialysis in this very elderly population and this remains an under-researched area.

Some researchers have attempted to address this problem. Chandra et al. (1999) highlighted the very poor prognosis of a small group of very high risk patients and, using this information, went on to assess another group of patients in a later study (Smith et al. 2003) to determine whether dialysis or palliative

therapy was the most appropriate treatment. This cohort study of 328 patients was carried out in a district general hospital in the UK. Once patients had made a treatment decision, they were either dialysed (n=258) or embarked on a palliative care pathway (n=63). Ten patients who were recommended for palliative care decided to commence dialysis.

Results from this study demonstrate that patients who opted for palliative care rather than dialysis were more functionally impaired, older and more likely to have diabetes. The ten patients who were recommended for palliative care but who opted to have dialysis had a median survival of 8.3 months, which was not significantly longer than survival beyond the putative date of dialysis initiation in the patients treated palliatively who lived an average of 6.3 months. More patients who dialysed died in hospital (65%) compared to those treated palliatively (27%), although the paper doesn't state where those treated palliatively ultimately died.

Although the sample size of the population studied is again relatively small, an extremely significant and important conclusion to this study is that in high-risk, highly dependent patients with renal failure the decision to dialyse or not has little impact on survival and that offering dialysis to such patients risks the unnecessary medicalisation of death (Smith et al. 2003). It goes some way to improving our knowledge regarding treatment options and related length of life. Unfortunately, it does not take into account quality of life and again the patient voice is silent. It may well be that the improvement in quality of life that might entail if there is not a need to attend hospital three times a week for a very rigorous treatment, such as dialysis, outweighs the benefit of a relatively small increase in the length of life (6.3 months vs. 8.3 months), but we cannot be sure, and until we ask the patient, can only speculate.

In a related study, Murtagh et al. (2007d) attempted to compare the survival of elderly patients with stage 5 CKD on dialysis against those who chose not to have dialysis. They carried out a prospective case note analysis of patients (n=129) over 75 years of age from four renal units and found that survival data in the dialysis group was better than in the non-dialysis group especially if the patient was younger, had a lower comorbidity score and ischaemic heart disease was absent. They suggest that older patients with renal failure and significant comorbidity, particularly ischaemic heart disease do not benefit from dialysis. Although the numbers in this study are again small and it has a retrospective design which imposes some limitations on its generalisability, it adds to the knowledge that is slowly evolving around treatment options for older patients with stage 5 CKD. More recently, Wong et al (2007) have analysed their experiences of managing patients treated without dialysis over a three-year period. They found a statistically significant trend for shorter survival in those with larger numbers of comorbidities, as determined by the Stroke comorbidity grade (SCG), a validated scoring system for the survival of patients on renal replacement therapy. Age did not predict survival. The authors report the importance of the SCG and how it might provide a potentially useful indication of expected prognosis in those deciding not to embark on dialysis.

Together, these quantitative studies offer a tentative examination of outcomes in a renal population of which we know very little. They are a starting point for further study, which must take into account the patients' experience, which is missing from much of the work carried out thus far. There is also a need to

understand the patients' trajectory on deciding not to have dialysis so that nursing and medical practice can be tailored to meet specific healthcare needs of these patients.

Clearly, prospective research, with larger numbers, is urgently needed to inform the nephrology community and their increasingly elderly population what it is that they may expect if they choose dialysis rather than a palliative care pathway. More evidence is needed to help us advise our patients and to enable a more informed choice when stage 5 CKD is reached and treatment options are discussed. As stated by Germain et al. (Germain et al. 2007) a question that requires answering is: '*Do our patients suffer more with dialysis (in particular considering access surgery, hospitalisations, and dialysis-related morbidity), with little gain in survival!?*' (Germain et al. 2007a: 199).

Based on the studies discussed above there is a strong economic argument for investigating survival and quality of life further in patients who embark on dialysis compared to those who don't. If evidence is produced which demonstrates that there is a cohort of patients for whom survival and quality of life is not improved by dialysis therapy, the money that could be saved by withholding dialysis in these circumstances could be channelled into palliative care. It is therefore crucial that we look at what the palliative care needs are for patients with stage 5 CKD.

4.7.4 Prevalence of symptoms in stage 5 CKD

In 2001 Rich et al. (2001) opened up a discussion concerning the palliative care needs of renal patients and increased referral to a palliative care team. They studied referrals to their team over a one-year period. Of those referred, 7% were not receiving dialysis but, unfortunately, they are discussed no further in this paper. Instead a focus was placed on the patients withdrawing from dialysis, their symptoms and their management.

Although there is much evidence related to symptoms for those with cancer (Coyle 2004; Friedrichsen and Erichsen 2004; Lindqvist et al. 2004; Potter 2004; Souter 2005; Hopkinson et al. 2006), evidence concerning the prevalence of specific symptoms for patients opting not to have dialysis is limited to two studies (Saini et al. 2006; Murtagh et al. 2007a). Saini et al. (2006) explored the similarities, and aimed to highlight any differences in symptom burden between those with stage 5 CKD not having dialysis and patients with advanced cancer. They carried out a quantitative prospective cross-sectional, pilot study to compare symptoms and quality of life across these two groups. Eleven patients with renal disease were recruited from the renal clinic and 11 cancer patients were recruited from the palliative care clinic. There was no difference between the two groups in terms of baseline demographics, comorbidity or performance scores.

Symptoms were self-assessed using the Memorial Symptom Assessment Scale Short Form (MSAS-SF) questionnaire (Chang et al. 2000), a well-validated method for assessing the presence, severity and frequency of symptoms in patients who have cancer, although it is less widely used in the renal population.

The symptoms in the MSAS-SF questionnaire are subdivided into physical and psychological symptoms, and the presence or absence of each of the symptoms is scored. Quality of life was assessed using the Euroqol EQ-5Q questionnaire (Brazier et al. 1993), a generic standardised instrument for describing health-related quality of life, again not previously tested in those not having dialysis so its value is uncertain.

The most commonly experienced symptoms in both groups were lack of energy (ranked number one symptom), shortness of breath (ranked second), pain (fourth most frequent symptom in the renal group, third most common in the cancer group), cough, dry mouth, numbness/tingling in feet/hands, taste change, feeling bloated, sadness, worrying and irritability. Renal patients also commonly experienced difficulty sleeping (ranked second most frequent symptom), oedema (ranked third most frequent symptom in the renal group), changes in skin, itching and lack of appetite. There was no significant difference between the two groups in the symptom profile overall, for any of the individual symptoms or the MSAS-SF subscales reported. Most symptoms were reported by both groups as causing 'a little bit of distress' (39% renal group, 36% cancer group). Some 16% of the symptoms experienced by the renal group, and 15% of the symptoms experienced by the cancer group, were reported as causing no distress ('not at all'). A total of 9% of symptoms in both groups caused 'very much' distress and pain and lack of energy were the most frequent distressing symptoms. The levels of psychological distress caused by these symptoms were similar for both groups. There was no difference in the reporting of the 'additional renal' symptoms between the two groups, or any difference in the resulting distress levels. Quality-of-life scores were similar for the two groups.

More recently, Murtagh et al. (2007a) have reported symptoms in advanced renal disease in patients managed without dialysis. This cross-sectional survey of patients with stage 5 CKD managed without dialysis took place in three renal units in the UK. Symptoms were assessed using the MSAS-SF (Chang et al. 2000) with additional renal symptoms. The study found that patients suffered a mean of 11.58 symptoms requiring symptom control similar to those with advanced cancer. Seventy-five percent of patients reported lack of energy or fatigue and pruritus. More than 50% reported dyspnoea, leg oedema, drowsiness, pain, dry mouth and muscle cramps. Other symptoms described included difficulty concentrating, insomnia, constipation, skin changes, dizziness, nausea and muscle pain.

Given the paucity of literature in this area, these two studies are important and indicate that the palliative needs of those with stage 5 CKD managed without dialysis may be at least, as great as for patients with cancer. Symptom prevalence and quality of life in renal patients managed without dialysis needs to be explored urgently as this study indicates a huge unmet need in terms of symptom management. Although it is helpful to undertake quantitative studies of this nature it is evident that answers gained by survey such as 'a little bit of distress', 'not at all' and 'very much' would be greatly enhanced if patients were allowed, through interview, to supplement these rather rigid statements with rich qualitative data. Patients need to be asked to describe the symptoms they encounter, the intensity of the symptoms and the impact they have on their everyday living.

The findings of both studies (Saini et al. 2006; Murtagh et al. 2007a) are consistent with other studies which have investigated the symptoms of patients with CKD who had not yet embarked on dialysis (Naish et al. 2003) and patients already on dialysis (Weisbord et al. 2003). Again this is interesting and perhaps relevant in that similar symptoms may be suffered, but there remains a pressing need for research related to patients who have rejected dialysis so that their palliative care requirements can be met effectively.

McDade-Montez et al (2006) investigated the role of depression symptoms in patients withdrawing from dialysis, highlighting this important symptom as a persistent problem in this population. They examined the prospective association between patient-reported symptoms of depression by using the Beck Depression Inventory (BDI) (Beck et al. 1961) and future risk of withdrawal from dialysis prior to death over an average 48-month period.

Available demographic and clinical characteristics included age, sex, marital status, education level, diabetic status, and time between first dialysis and date of depression assessment. Biochemical variables including serum creatinine, blood urea nitrogen, serum phosphate, serum potassium and interdialytic weight gains were collected. The BDI (Beck et al., 1961), a well-validated measure, consists of 21 items, each representing a category of depressive symptoms. It consists of two factors, one composed of cognitive and emotional symptoms of depression, the other composed of somatic complaints often associated with depression. The somatic factor is composed of items reflecting fatigue, appetite loss and insomnia, as well as other items that can reflect the physical symptoms or vegetative signs of stage 5 CKD and uraemia rather than depression.

The present study was the first to prospectively examine the relationship between patient level of depression symptoms and the decision to withdraw from haemodialysis, and is enormously significant. Patient depression significantly predicted the subsequent decision to terminate life-sustaining dialysis. One other study has examined the relationship between depression and dialysis withdrawal (Cohen et al. 2002). In Cohen et al.'s (2002) investigation of dialysis withdrawal and depression, the investigators' assessed depression after the decision to withdraw had already been made and reported to medical staff. The present investigation avoided some of the interpretative and methodological difficulties inherent in that approach by assessing depression in advance of the decision to withdraw from dialysis and following patients prospectively from the time of the depression assessment.

An additional significant finding from the present study was the association of age with the decision to withdraw, with older patients more likely to withdraw from dialysis. This corresponds with the few studies that have produced demographic findings of those who have opted not to embark on dialysis (Murtagh et al. 2006; Chan et al. 2007; Noble and Chesser 2009). But even though we can draw this comparison, we still need to ask patients about symptoms related to depression. Tools such as the BDI are helpful, but how can we ever be sure they are providing us with a true account of the participant if the participant does not substantiate the findings with their own words and descriptors.

The authors go on to suggest that illness severity or the physiologic condition of the patient plays a role in influencing withdrawal decisions to some degree but that this role did not obscure the significant effect of

depressive symptoms. They state that a more deteriorated physical state is in turn related to risk of withdrawal from dialysis and future research should include more direct measures of physical functioning to more clearly delineate the extent to which the depression effect they observed is a function of greater illness-related physical impairment among some patients. I would argue that patients also need to be asked about their experiences of life with renal failure to substantiate any claims that are made. Every patient will have a very individual experience and, at best, quantitative tools used to measure depression, physical function and decisions regarding dialysis can offer insight and a chance to hypothesise but surely have to be put into context of the patient's life world. The authors go on to theorise that several factors *may* predict a higher likelihood of dialysis withdrawal, including the idea that feelings of hopelessness may lead depressed patients to feel that 'enough is enough' and that remaining on dialysis represents a hopeless situation that will not improve. I would suggest that the authors could be a little more certain in their claims if they were to offer the patients a qualitative interview to tease out what the patient's view is on these conjectures.

This study contributes to the growing body of research suggesting that depression is an important factor to consider among those on dialysis, which may lead to patients withdrawing from dialysis. Whether or not patients are suffering from depression when they make the decision not to have dialysis and whether or not that depression contributes to a belief that life is not worth living, and for this reason dialysis will not be considered, remains largely unknown.

4.7.5 The utilisation of advance directives

From the literature review, five quantitative studies (Sehgal et al. 1992; Rutecki et al. 1994; Sehgal et al. 1996; Holley et al. 1999; Hines et al. 2001) related to advance directives in the renal population were found. All originate in the USA indicating less development in this area in other countries of the world. They focus on the role of advance directives in decisions to withdraw dialysis but there is no mention of patients who have opted not to have dialysis, although it is likely that they have a need for advance directives to simplify issues such as cardiopulmonary resuscitation and their ultimate place of death.

In Sehgal et al.'s (1996) study, American, German and Japanese nephrologists were asked, via a mailed questionnaire, for their views on advance directives. The total number of dialysis patients, cases of withdrawal from dialysis, patients with advance directives and the use of such directives per nephrologist were identified. They were then asked to state whether or not they would continue or stop dialysis in eight hypothetical cases, four including a patient with advanced Alzheimer's disease and four with a terminal brain tumour. There was a high prevalence of advance directives among American dialysis patients and American nephrologists were more likely to withdraw dialysis in incompetent patients if the family requested withdrawal and no advance directive was available. A family preference to stop dialysis increased the willingness of all three groups of nephrologists to stop dialysis, although American nephrologists were still much more likely to do so than German and Japanese nephrologists. The presence of an advance directive requesting that dialysis be stopped as well as a family preference to stop dialysis led to almost all nephrologists saying that they would stop dialysis, although a significant minority of the German and Japanese nephrologists would still continue dialysis, causing speculation as to why this should be. It is not clear if this decision is based on a personal view that patients should never refuse or be

refused dialysis. Finally, a disagreement between the family and the patient's advance directive led to a decreased willingness to stop dialysis by all three groups of nephrologists.

Here we have a focus on the views of the nephrologists caring for dialysis patients and a differing of practice across countries in relation to advance directives. The study offers only a descriptor of current practices across three countries and future work needs to focus on a clearer understanding of patient attitudes towards advance directives. The renal population opting not to embark on dialysis do not seem to have been offered advance directives. We need to know if advance directives may be of help to this group as death approaches and this needs to be part of a research agenda in this area of medicine. As services evolve that are specifically aimed at caring for patients with renal failure who are not going to commence dialysis, the use of advance directives needs to be considered and discussed with patients.

Within the UK we tend to emphasise personal autonomy, which may possibly extend to using advance directives in medical decision-making, but we cannot assume that all patients wish to engage with advance directives and we need to understand the public's view of this initiative, especially within the context of a life-limiting illness such as stage 5 CKD.

4.7.6 The impact on families

There was only one paper which alluded to the impact on families or carers when a patient did not commence dialysis (Ashby et al. 2005) and little is known about the long-term psychological impact of stopping life-supportive treatments on surviving loved ones.

Phillips et al. (2005) sought to determine if there was an increase in pathologic grief in family members after deaths that followed dialysis discontinuation. Twenty-six family members were interviewed approximately 55 months after patients had died and a low overall level of distress was found. Only one respondent remembered the death as having been 'bad', although 62% of patients were recalled as having suffered distressing symptoms in the last days of life. Respondents characterised good deaths as involving mental alertness, occurring at home, taking place while asleep, being peaceful, happening in the company of loved ones, and being largely pain-free.

The authors conclude that five years after dialysis discontinuation, families report low levels of distress and the findings suggest that families successfully adapt to the impact of dialysis withdrawal, although the results are only gained from a tool which has again not been validated in the dialysis population. Supported by qualitative interview data, the results could be viewed as more reliable, but it leaves unanswered the question of how families and carers respond and manage when patients decide not to commence dialysis. Little is known of the impact this has on their lives while living with that patient and after that patient's death. Prospective, qualitative studies to examine this phenomenon are urgently required.

Several studies (Hull 1989; Davies et al. 1990; Yates and Stetz 1999; Bergs 2002; Arman et al. 2002; Sinding 2003; Koop and Strang 2003; Simpson 2004; McCarthy 2005; Kalnins 2006; Hopkinson et al. 2006) attempt to understand the impact that terminal illness has on carers and significant others before

and after death. Koop and Strang (2003) carried out a qualitative interpretative study to explore the experience of bereavement following home-based family care for patients with advanced cancer. Eleven women and four men were recruited to the study and the length of time in the primary caregiving role ranged from one to 11 months.

The authors state: *'Given the lack of understanding about the perceived effect of home-based family caregiving on bereavement outcomes, an exploratory, interpretive, descriptive research orientation was used'* (Koop and Strang 2003: 131) in this study. They explain that within this qualitative approach, *'interpretative descriptions of increasing complexity and interrelatedness grounded in the conversations with the research participants form the foundational analytic process'* (p 131) but the method remains vague. Their search for categories and themes within the data focused on 'thick description' (Geertz 1973), a term not expanded on.

The authors report positive and negative experiences with positive outcomes predominating.

4.7.6.1 Positive bereavement experiences

Caregivers offered an overall sense of having accomplished something difficult but valuable, and spoke repeatedly of having done all they could and of having provided the best possible care. This sense of having done everything possible relieved the caregivers of guilt during their bereavement, with the reporting of enhancement of other relationships. In particular, the relationship between the caregiver and the dying family member was strengthened in the course of caregiving.

4.7.6.2 Negative bereavement experiences

One caregiver talked negatively of the house where the patient had died as a death scene or chamber and of a desperate need to escape because of the horrific events that had transpired there and the images they evoked. Caregivers also talked about experiencing an aversion to spaces in the house where particularly terrifying memories were evoked. Male caregivers reported a sense of remorse at having failed to reduce the suffering of their family member and spoke of having lost the battle on behalf of their loved one. This left them with feelings of guilt. None of the women in the study reported these particular negative responses.

The authors' state that the caregivers in their study appear to have met the challenges faced in caring for a loved one with cancer. This contrasts with a study by Stetz and Brown (1997), who investigated the experiences of carers caring for a family member with AIDS or cancer. In their grounded theory (Glaser and Strauss 1967) study, they found the emotional work of caring for a dying person was tremendously demanding, with many spouses awake for much of the night alleviating emotional suffering. They also discuss the impact of witnessing a death rather than just watching where a caregiver is heavily involved in care and sympathy, and empathy are aroused along with resentment and compassion. Often the patient's pain was indirectly felt with carers feeling afraid not only for the patient but also for themselves.

Clearly carers will have a very individual response to caring at the end of life, and their role is central to ensuring that patients are well cared for when terminally ill. Historically, there has been a focus on the needs of carers, especially those caring for a family member with cancer. Services have been put in place to support carers and patients but these structures are almost non-existent for the patient dying with renal failure. There is a pressing need to understand the experiences of carers when the person involved has stage 5 CKD. There may be similarities across diseases but making assumptions would be foolhardy when, as demonstrated, different studies produce different experiences. Studies need to demonstrate clear methodology so that replication is possible to support findings. If this does not happen, the validity of results and conclusions reached may be questioned. It is appropriate for practitioners working with these carers to attempt to understand their story and ensure that their experiences are shared across disciplines, especially in primary care where much of the caregiving role takes place. This can only enhance experience.

4.7.7 Existential specific themes

A large number of papers related to those with chronic illness facing the end of life exclude those dying with renal disease. They are concerned with existential issues, including the meaning of life (Pope 1999; Lin 2003), facing mortality (Nieto 2005), illness and facing the death experience (Wilson and Fletcher 2002; Ryan 2003; Vig and Pearlman 2003; Cochrane 2003; Lam and Fielding 2003; Thome et al. 2004; McGrath 2004; Ryan 2005; Lethborg et al. 2006), hope (Lindvall 1995; Minear 1998; Benzein et al. 2001), suffering (Murray et al. 2003; Daneault et al. 2004; Rydahl-Hansen 2005) and spiritual needs (Waite 2003; Murray et al. 2004). Interestingly, all papers have a focus on patients with cancer, except the paper by Vig and Pearlman (2003) which explores the experience of cancer and heart failure sufferers and the paper by Cochrane (Cochrane 2003) which focuses on those with HIV/AIDS. Existential issues in renal patients not receiving dialysis are ignored and not known. There may be much hidden suffering taking place, which is hugely unacceptable, and points at great inequality for this population.

A study by Murray et al. (2004) describes the experiences of illness and needs and use of services in two groups of patients with incurable cancer, one in a developed country, namely Scotland and the other in a developing country, Kenya. Patients and their carers in Scotland were predominantly concerned about the prospect of death and struggled to maintain a normal life while moving through hope and despair in the same day. They tried to remain positive, but frustration and anger were evident. Patients often felt unable to share their distress with family, friends or professionals. During radiotherapy and chemotherapy, regular hospital visits dominated the lives of both patients and carers, giving support and hope. However, patients had to deal with treatment side-effects. Patients worried about how carers would cope and carers worried about upsetting the patient and about how they would know what to do when death did occur.

In Kenya, pain dominated the experience of living with cancer, which was constant and unbearable for many. Many patients could not afford analgesia or basic essentials for care. Degrading medical problems were often evident and some patients tried to hide their illness from their families while all worried about finding the money to pay for treatment. Patients were accepting of their prognosis and the inevitability of death, and were rarely angry at the illness. Religious beliefs often provided comfort and peace. A

diagnosis of cancer brought an end to searching for a cure and signalled a time of preparation and waiting rather than intensive treatment. Although the cultural norm among this ethnic group is for the extended family to care for their ill, patients often thought they were becoming a physical and financial burden to their family. Carers described being burdened by the difficulty of caring, their lack of medical knowledge, the lack of drugs in the home, and their fear of not knowing what to do when the patient deteriorated. If the patient died, they were anxious about handling the body and either preserving it until the time of the funeral or arranging and paying for transport to a mortuary.

The findings of this study may not be generalisable as every ethnic group has geographic, social and cultural issues around death and dying specific to its remit. This aside, the study offers an interesting account of living with cancer in two different parts of the world, but raises the slightly worrying fact that while we know something about cancer sufferers and how they die in Africa, we know virtually nothing about renal patients not receiving dialysis and their experience of life and death, worldwide!

4.8 Summary

This literature review has clearly demonstrated that the fate of the patient who opts not to dialyse is poorly understood and has been little studied. Some studies, all quantitative in nature, focus on withdrawal from dialysis and many inspect the role that the physician has in this decision. Although these studies are of interest and provide insights into decision-making processes related to embarking on a therapy to treat underlying renal failure or to discontinue a therapy that may well lead to death, they marginalise the group who do not undergo dialysis. There is an urgent need for more research with a focus on renal patients opting not to have dialysis. As comparative studies continue it is paramount that the experience of these patients is not avoided. At present most of the published papers related to selection of dialysis suffer an important selection bias in that they concentrate on stage 5 CKD patients who were treated by dialysis, whereas little is known about the prevalence and outcome of those for whom dialysis is withheld or declined. Many questions are left unanswered and we know little about what happens to patients physically and psychologically.

In contrast, the literature review uncovered a wealth of studies which have explored the experience of living with a disease which will shorten life. Existential issues are described which relate to suffering and spiritual needs when facing death. The impact of the illness on carers is also explored. These specific issues in renal patients not receiving dialysis are ignored and not known, drawing attention to a population which has not had individual needs and experiences addressed.

CHAPTER 5

METHODS

This PR study explored the experiences of a group of patients opting not to dialyse. The chapter begins with an explanation of PR and follows with a brief return to the aims and objectives of the study. Details of the participants are offered, along with the methods used for data collection and analysis. An assessment of the quality of the research is included and details of the criteria by which research decisions were made and methods for data collection chosen are offered. This incorporates a discussion about how findings from the study were fed back to staff caring for similar patients on a regular basis to check for relevance and resonance and to gain new understandings of what was being uncovered. This greatly enhanced the trustworthiness of the findings. Following this generalisability, the findings are discussed and ethical considerations are explored.

5.1 Practitioner Research

The general aim of PR is to generate new knowledge from practice (Meyer et al. 2006) and involves a formal and systematic attempt by practitioners to develop new understanding in practice (McCormack 2007). PR originally evolved in education where it has been described as the '*questioning and testing of ideas by classroom research procedures*', and, '*systematic inquiry made public*' (Stenhouse 1975: 144). It also includes:

- teachers' work and teachers themselves as a basis for research;
- critical reflection and systematic study of practice;
- practitioner control and ownership of research

These principles presented in work by Stenhouse (1975), Elliott (1991) and Ziechner and Noffke (2001) can easily be transferred to health and social care research. PR is closely related to, and draws on, the methodologies of action research described by Kemmis and McTaggart (2005). It also draws on methods from a wider field than action research and allows the undertaking of small-scale research in case studies, ethnographic studies and for the eclectic use of methods (Campbell et al. 2004).

Practitioner research has been used to encompass a number of research-based activities undertaken in the fields of practice in health and social care and education. It implies that practitioners will learn from their research into practice, which is not always the case in other forms of research. PR is also concerned with improving rather than proving as an approach to research (Campbell 2007). It is argued by Groundwater-Smith and Mockler (2006) that in the field of practice-based research, those who carry out practitioner inquiry will ultimately engage with knowledge that is both 'theoretical' and 'practical' moving seamlessly between the two.

Defining PR is not easy. Simply put, it can be described as research carried out by professionals in disciplines such as education, nursing and social work where the research is conducted on or with individuals who are receiving care or teaching from the investigator in his/her capacity as a service provider

or educator (University of Manitoba 2004; Fox et al. 2008). This aside, Rolfe (2003) makes the salient point that a major difficulty in attempting to understand PR is that many writers cannot seem to concur on what it is or, more importantly, '*what it is for*' (Rolfe 2003: 132).

PR means different things to different people and the literature offers a confusing array of terms. In nursing, we have some practitioners doing research, attached to medical teams, assisting with large randomised controlled trials and other forms of research. Their nursing skills are often used to conduct the research; for instance, recruiting patients and helping to gather test data or interview patients. Here they use their skills as nurses to do research and are Practitioner Researcher's (Meyer 2007). Other health and social care practitioners are engaged in research, using their knowledge and expertise to enhance our understanding of issues to do with health and service delivery, usually as contract researchers on funded projects or as students studying for higher qualifications. These Practitioner Researchers use a wide variety of methods, often qualitative in nature, and draw heavily on theoretical discourses in other disciplines, such as psychology, sociology, social policy and health economics. Their knowledge of health and social care informs their analyses (Meyer 2007).

More recently, practitioners in health and social care have started to research their own practice known as 1st Person Inquiry and the practice of others, or 2nd Person Inquiry (Reason and Bradbury 2001b), in a more reflexive and participative way. Many do this as part of work-based learning or practice development initiatives. However, others do the same type of work but in a more systematic way, monitoring the process and outcomes of change and setting their learning within the context of a wider body of knowledge. Change here can take place in personal learning as well as in practice. Findings can then be used for theoretical generalisation and/or large-scale change as in 3rd Person Inquiry (Reason and Bradbury 2001b). These Practitioner Researchers are actively engaged in action research (Meyer et al. 2006).

Research is often conceptualised as a straightforward and linear process with a rational and logical plot, but practice-based disciplines such as nursing are complex, context-dependant and not suited to cleanly cut research procedures where everything goes to plan. This study therefore has the following characteristics:

- It is research carried out by a practitioner in response to a problem.
- It aims to bring about a direct improvement in the issue being researched.
- It aims to contribute to personal knowledge and theory (Rolfe 2001).

To achieve these aims the research was managed in a systematic manner ensuring that data were gathered methodically and were organised in such a way as to enable analysis. As it took place, questions that arose during data collection and at analysis were discussed and informed the findings. These questions often arose from the practice setting as care was planned for patients and often could not be anticipated. Practice therefore often drove the research. Alongside this, observation of the patient and the context within which they were cared for took place and also informed the analysis.

5.1.1 The advantages and disadvantages of Practitioner Research

Practitioner research enforces the ethos that research is not something exclusively confined to academia where the role of the practitioner is to implement the findings of the academic researcher (Rolfe 1998). The philosophy is one of practitioner *and* research rather than practitioner *or* research and it assists in developing a discipline and solving wider problems (Reid 2008). It centres on improvement, both personally and locally in the workplace, and aims to redress the balance between practical, professional knowledge and academic research, which has traditionally been viewed as more valuable. It is also argued that practitioners may have more knowledge of practice than external researchers, leading to more insightful or valuable research (Jarvis 1999). The potential benefits of PR include improving practice through encouraging critical reflection; informing but also challenging policy; allowing a dialogue between practice and research; and creating new knowledge through the work of practitioners (National Research and Development Centre 2008).

Disadvantages to PR have been highlighted. Because the Practitioner Researcher plays a dual role, there is the potential for certain ethical principles to be compromised. Questions concerned with voluntariness of participation, the vulnerability of participants, the potential for a conflict of interest on the part of the researcher, and whether consent is fully informed need to be taken into account (University of Manitoba 2004). There may also be inherent difficulties as insider researchers manage multiple roles, such as researcher, clinician, manager and student (Kilbride 2007). This can lead to feelings of frustration and a conflict of interest in managing workload.

5.1.2 Ontological and epistemological groundings

A paradigm as a worldview offers a general perspective on the complexities of reality (Polit and Beck 2006). Inquiry in the field of nursing is conducted mainly within two broad paradigms: the positivist/postpositivism paradigm with an emphasis on the rational and scientific (Guba and Lincoln 1994) and the naturalistic/constructivist paradigm. Here reality is not viewed as a fixed given but rather as a construction of the individuals participating in the research, with reality existing within a context (Denzin and Lincoln 2003).

As it has been recognised that there is a close relationship between knowledge and social structures and processes, traditional methods for the production of scientific knowledge have come under scrutiny. No longer are the researcher and the methods employed to carry out the research seen as objective and independent of the world that is being researched (Gibbons et al. 1994). Prior to the mid-1980s most nursing research was based within the positivist paradigm and quantitative and qualitative methodologies were often seen as opposed to each other (Webb 1989). Over time, the philosophy of science has produced useful principles related to epistemology (the grounds for knowledge) and ontology (the nature of the world) which include some basic assumptions that constitute the philosophical underpinnings of knowledge or theory (Coghlan and Brannick 2005). These two terms can be assessed along a continuum moving from an objectivist or realist to a subjectivist or relativist perspective. An objectivist view of the grounds for knowledge accepts the possibility that the external world can be accessed objectively (Coghlan and Brannick 2005) and assumes that *social and natural reality have an independent existence prior to human*

cognition (Coghlan and Brannick 2005: 5). A subjectivist view assumes that what is viewed as reality is restricted to the conscious self and its sensory state.

All research, whether quantitative or qualitative, is based on some underlying assumptions about what constitutes 'valid' research and which research methods are appropriate. In order to conduct and/or evaluate qualitative research, it is therefore important to know what these assumptions are (Myers 2007). The most pertinent philosophical assumptions are those which relate to the underlying epistemology which guides the research. Orlikowski and Baroudi (1991) suggest three categories, based on the underlying research epistemology: positivist, interpretative and critical. While these three research epistemologies are philosophically distinct, in the practice of social research these distinctions are not always so clear-cut (Lee 1999). There is considerable disagreement as to whether these research paradigms or underlying epistemologies are necessarily opposed or can be accommodated within the one study (Myers 2007).

Quantitative approaches which are based on positivism are often thought inappropriate as human beings cannot be treated like test tubes in a laboratory (Meyer 2003). Qualitative approaches, based on interpretivism, have been criticised due to a lack of concern about the complexity of practice, with a reliance on the researcher instead of the practitioner (Freshwater and Rolfe 2001). In contrast, practitioner-centred research, situated within a critical paradigm, with a focus on the generation of knowledge within expert practice using a reflexive approach, can be seen to bridge the gap.

I believe that research involves subjective perception, that different methods produce varying perspectives and that there is an underlying reality that can be studied (Lincoln and Guba 1985). The research-practitioner paradigm is based on an epistemology that recognises that there is a real world 'out there' but also acknowledges that any attempt to describe, measure or change this reality is interceded through a range of factors including language and cultural expression (Reason and Bradbury 2001a). This viewpoint is known as subtle realism and accepts that it is not possible to remove oneself from the social world in order to study it. It also argues that the goal of inquiry is to represent rather than reproduce reality (Miles and Huberman 1994; Mays and Pope 2000). Subtle realism makes the claim that observable facts, experiences and events are independent of the researcher's claims about them and accepts the possibility that there may be many valid descriptions and explanations of the same phenomenon (Mays and Pope 2000). The use of subtle realism, similar to any high standard qualitative study, requires reflexivity in inquiry so that all features of the process of inquiry, including the role and actions of the researcher are equally scrutinised. From this position, it is possible to assess the varying perspectives offered by different research processes and look for validity and relevance (Mays and Pope 2000). It is an approach that suits this study.

5.1.3 Reflexivity

In the literature, reflexivity is used in different ways which typically draw attention to the complex relationship between the production of knowledge and the range of contexts of such processes as well as the involvement of the knowledge producer (Alvesson and Sköldberg 2000). Reflexivity involves paying attention to how one thinks about thinking (Maranhão 1991). Alvesson and Sköldberg (2000) suggest that serious attention be paid to the weaving of specific linguistic, social, political and theoretical elements in

the process of knowledge development, during which time empirical material is constructed, interpreted and described. Reflexivity is linked with the researcher's self-awareness and how it impacts and transforms the research they undertake. A way of ensuring a sustained 'critical gaze' throughout the research process is by maintaining reflexive field notes or a diary journal. This aids the construction, collection and interpretation of data. For this purpose, reflexive field notes (Kingdon 2005) were kept and analysed and are discussed within the findings of this thesis.

My reflexive field notes impacted on the research as I cared for the patients in the study. An example of this is concerned with how I first managed the clinical consultation. To begin with, as I tape recorded and then listened to these interviews, I quickly recognised with the help of my supervisor that my interactions with patients appeared to be based on a medical model. The interviews focused on symptoms and dealt less with the emotional impact of the renal disease. For example, when a patient mentioned a symptom I tended to talk about how we could treat that symptom with a tablet rather than explore how that symptom was impacting on the patient. An extract from my early field notes describes this:

I talked with Julianne my supervisor after she had read one of my transcripts. She pointed out how interesting it was that I was focusing on symptoms and how I would manage them. How the symptom affected the patient was not explored. I hadn't noticed this myself. I read the transcript again and was concerned to find she was right. I realised the clinical consultations were probably based on a medical model utilised and refined by me over the years I had worked as a renal nurse with medical colleagues. My aim now was to change the way the consultation was managed so that I could gain a more measured view of how the renal disease was affecting my patients not just physically but also emotionally (FN 241006).

Supervision for the study, which aimed to identify the new knowledge gained from within a service where little local or national guidance existed to inform practice, was received from experts in cancer and palliative care, action research, older adult nursing and primary care. Regular discussions were used to rigorously examine my progress through the research process and to acknowledge the possible impact that my personal experiences might have on the direction of the research.

5.2 Research aims and questions

The aim of this study was to explore the experiences of patients with stage 5 CKD who had opted not to undergo dialysis to treat their renal failure.

Specific aims were to:

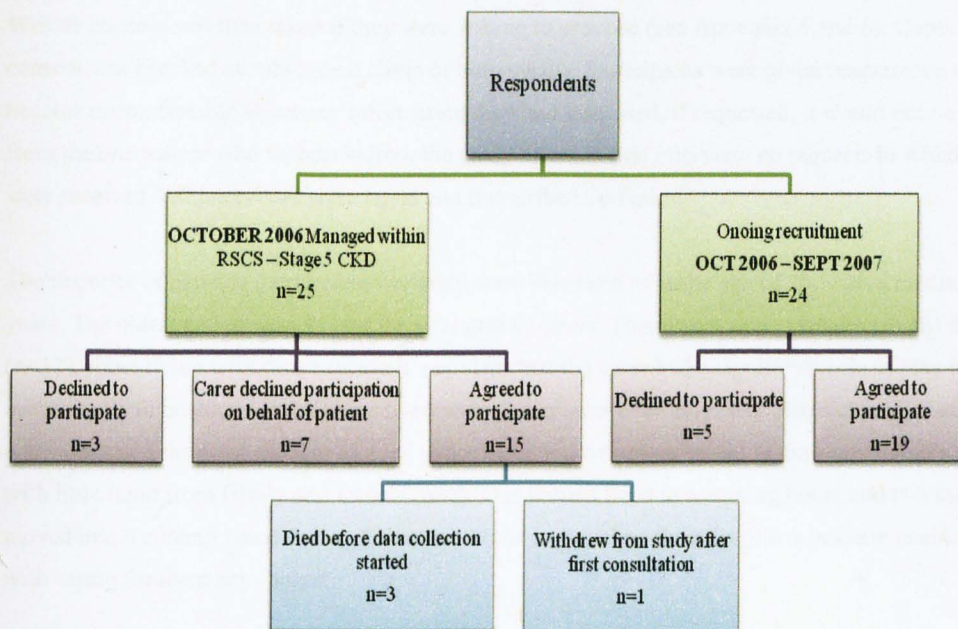
- describe the characteristics of a cohort of renal patients with stage 5 CKD in a London renal unit who had decided not to embark on dialysis
- identify the healthcare needs of this group of patients
- describe the trajectory towards death (or not) of this population
- highlight issues for consideration when establishing a RSCS for patients managed without dialysis.

5.3 Participants

5.3.1 Patients and carers

Specifically, it was those making decisions not to embark on dialysis, managed within the RSCS that were the focus of this study. Ethical approval for the study was sought and attained in September 2006. Following this, I spoke with each patient being cared for in the service at that time or their carer ($n=25$), either in clinic, on the phone or in their home, and 15 agreed to partake in the study. Three patients declined and carers of seven other patients said that the patient did not wish to participate. Of the first 15 patients recruited, three died before they were able to take part and one patient withdrew from the study after the first consultation (see Figure 5.1). Six carers agreed to participate at this time.

Figure 5.1 Patient recruitment to the study



From this time recruitment was ongoing until June 2007, with all new patients accepted into the service invited to take part in the study ($n=24$) (see Figure 5.1). In total, 30 patients¹ and 19 carers were recruited to the study. The invitation to participate was first made by telephone when contact was made with the patient or carer to organise a first appointment for their Supportive Care consultation. It was explained that a research study was being undertaken and if the patient or carer agreed, information about the study was sent to their home. Information included an 'Invitation to take part in a research project' covering letter (see

¹ See Appendix 1 for details of individual patient participants.

Appendix 2) and information sheets. One information sheet was specific to patients (see Appendix 3) and one to carers (see Appendix 4). This was to allow possible participants time to read the information at their own pace and then ask questions before making a decision about participating. No participants were excluded from the study. All patients who had been referred into the RSCS were given the opportunity to take part. Data collection took place from October 2006 to April 2008.

An exact sample size in qualitative research is difficult to estimate and can only be judged when it is felt that theoretical saturation has been reached and new data will not add to emerging theory. The figure of 20-30 participants has been identified as a typical number needed to ensure saturation and might include several interviews per person (Creswell 1998). No new themes emerged in the analysis of the later interviews so the sample was not extended beyond 30.

At first clinic or home visit a verbal explanation of the study was given to patients and carers and clarification of any questions offered. The longitudinal nature of the study was explained to participants to ensure they understood that there was an expectation that they would continue in the study over time. Written consent was then taken if they were willing to proceed (see Appendix 5 and 6). Continuing consent was checked at subsequent clinic or home visits. Participants were given reassurance that if they became uncomfortable about any information they had disclosed, if requested, it would not be used. Apart from the one patient who withdrew from the study after his first interview no requests to withdraw data were received. All interviews were taped and transcribed verbatim.

The majority of patients recruited to the study were older and over the age of 70, with a median age of 78 years. The oldest patient was 91 and the youngest 65 years. There were more females (n=18) than males (n=12), some living with carers where it was clear that the carer had a significant role to play in managing the patient's ill health (n=20). Others lived with a carer where the carer was also sick and it was unclear who warranted the most care (n=4). One patient's wife died before he did in the study. Others lived alone with little input from family and friends (n=5). One patient lived in a nursing home and two mothers were moved into a nursing home during the course of the study when their daughters became unable to cope with caring for them any longer.

Only one patient entered the RSCS with only renal disease and no other comorbidity. All other individuals had one or more comorbidities (discussed further in section 6.1.4). Seventeen patients died during the study, the average length of life from first referral into the service until death being 15 months (range 1-35 months). Sometimes those recruited at an earlier stage outlived those recruited at a later stage. For example, Trudy died after one month, but Cliff, the second person recruited to the study, was still alive when the study came to an end. Patient demographics are discussed further in section 6.1.

Patients with stage 5 CKD are seen by a nephrology consultant in a nephrology clinic and if they decide not to commence dialysis they are referred by letter to the RSCS for input, as described in section 1.2.6. It was assumed that patients were aware that they had deteriorating renal function and, by implication, that they would die. Chronic kidney disease may go undetected for a long period, so patients may or may not have been aware of their kidney problems for some time.

5.3.2 Staff

The two Clinical Nurse Specialists (CNS) who worked alongside me in the RSCS were also interviewed at regular intervals in order to share experiences and discuss patients referred into the service. Written consent was obtained from them (see Appendix 6). Some of these meetings were tape recorded (n=4). Other meetings were less formal and happened on an *ad hoc* basis when we had time together to discuss patients. Experiences relating to how patients presented and how they progressed until death were shared and insights were collated in my researcher's diary. Although there is a possibility that these staff may have been reluctant to honestly discuss with me their experiences or to concur with me rather than disagree, it is suggested that their rich and honest feedback appeared sincere. For example, when discussing findings with one CNS about the individuality of the patients, she agreed that each patient presented with complexities in terms of comorbidity and gave a description of a multifaceted patient she was managing:

Like a patient who is breathless with oedema and they don't have COPD or whatever, we manage that patient differently to the one with COPD ... But with COPD you have to consider the respiratory side of things and if they have heart failure as well, you have to consider the heart as well, because that can cause big problems too. All the diseases have to be considered (G - 2).

On another occasion the same CNS discussed how frustrated she was at hearing that a patient had been encouraged to commence dialysis when admitted to hospital, something I had come across during the study. I captured her feelings in my diary:

G said 'Yes Abdul, he was admitted and Dr P tells me the medical consultant said he had persuaded him to have dialysis. Cannot believe it ... When I saw Abdul he was so confused and I think so glad to see me. He was lost on that big ward with all the machines around him. Quite quickly I talked to him and he stuck to his decision. He didn't want dialysis'. She is seeing the same thing happen as me (G, 31/03/07, FN).

Descriptions offered were detailed and descriptive and I had no reason to disbelieve what these nurses recounted to me, particularly as their experiences also concurred with other nurses nationally, as discussed later in Chapters 6-9.

Practitioner Research offered the opportunity to vary data collection methods as deemed necessary, and other staff was included in the study as it evolved. Following the death of a patient, a staff nurse from the local hospice was interviewed in order to establish the details of this patient's death because it was felt that this knowledge would be of benefit to the study.

As a Practitioner Researcher I was in a position to feed back findings to the local multidisciplinary team to check for relevance and resonance. Notes were taken at multidisciplinary team meetings (n=4) held to discuss the progress of the RSCS and were captured in my diary. In relation to findings fed back concerning the decision not to embark on dialysis, some interesting points were made. One person questioned what happened if a patient insisted that they wanted dialysis even if it wasn't viewed to be in their best interests:

But if the patient insists or the family insists they want dialysis, don't the doctors then have to go with that or not? If they say they really want dialysis and I can remember someone recently

even though it wasn't thought to be in their best interests, they wanted dialysis, or their family. So isn't that the case that doctors ...? (T 28/06/07)

Another staff member wondered if ethnicity had any part to play in decision-making:

Of the ones that feel the decision's made for them, are they from an ethnic group? Maybe they aren't vocalising or just let the doctors make the decision for them when really they might want to say something, but they just don't feel able to? I don't know (T 26/08/07).

Insights, discussion and questions from the multidisciplinary team enabled me to think critically and deeply about my findings and often helped me in my decision-making during analysis. For example, several patients reported that they had not been fully involved in decisions about dialysis. Initially I felt uncomfortable with this, but after discussion with the wider team, the reasons why patients may have believed this emerged. It is possible that some patients allowed doctors to make decisions for them and took a passive role in decision-making, or they may have misunderstood the information given to them. Whatever the reason, the discussions informed my thinking. It is also likely that these discussions impacted on the practice of staff involved with patients making decisions to abate dialysis encouraging them to reflect on conversations with patients at times of decision-making around dialysis. Thus the research had an impact on practice as it was carried out.

As well as feeding back findings to the multidisciplinary team they were shared with five staff from three hospitals in the UK working with patients who had made the decision not to embark on dialysis. These five staff were utilised as a 'validation group' (McNiff 2002) made up of four expert renal CNSs and a doctor and offered a further opportunity for critical feedback and critical scrutiny of my work. Several meetings (n=4) were held with this group to invite comments on my findings. The meetings were tape recorded and transcribed.

Consent was obtained from all staff involved if data related to them was used within the findings. In some cases consent was retrospectively obtained.

5.4 Data collection

5.4.1 Interviews with patients and carers

The naturally occurring clinical consultation served as the interview with patients and carers. The only difference at the consultation was that it was tape-recorded with the consent of those present. Sometimes carers were in attendance or where a patient was unable to or did not wish to participate in the interview the interview took place with a carer. Many patients or their carers were interviewed on more than one occasion (see Table 5.1). The total number of interviews completed equalled 73. The clinical consultation was the primary means of data collection to explore in-depth with patients (and carers) their experiences and needs once managed within the RSCS. It was based on an interview schedule developed for use in the service (see Appendix 7), adapted from an interview schedule used by the Trust's local Palliative Care Team. Although the schedule highlighted a number of questions to be asked, such as how the patient was feeling about their illness and what their main worry had been since the last consultation, in reality the interview was open and driven by the patients' (or carers') needs and preferences. This enabled a more

person-centred approach to be taken and allowed for the identification of key problems and experiences as articulated by the participants. This was important as we were unaware what issues required attention and had to inductively work this out as we cared for patients and listened to their concerns. A key feature of these consultations as a research method was their ability to provide an in-depth personalised perspective of the experience for study participants. They also allowed for an opportunity to clarify and further understand the research issues being studied (Ritchie 2003).

Often the success of any interview will depend on the personal and professional qualities of the interviewer (Legard et al. 2003). A number of the key qualities attributed to a successful interviewer have been identified and include well-developed listening skills, the ability to think quickly, respect for and an interest in people and the ability to establish a good rapport (Thompson 2000). Although I had little formal training in qualitative interviewing skills, I had well developed interpersonal skills and had undertaken a certificate in Counselling at the Royal College of Nursing in London in 1996. Interpersonal skills had been developed through this course and throughout my nursing career, both as a manager and a clinician. Taking this taken into account, I was well placed to carry out the consultations. Once I had identified my tendency to focus on symptoms and their management, as discussed above (see section 5.1.3), the consultations became more patient centred and more emotional content emerged although as highlighted in section 7.3.2, an emotional component was absent from many of the interviews.

Table 5.1 Number of patient and carer interviews undertaken

	Name	Number of interviews with patient alone	Number of interviews with patient and carer	Number of interviews with carer alone	Total number of interviews
1	John ²	6	1	0	7
2	Cliff	3	0	0	3
3	Veronica	2	3	0	5
4	Mary	3	1	0	4
5	Arnold	1	0	1	2
6	Raymond	2	0	0	2
7	Sara	1	0	0	1
8	Abdul	0	0	2	2
9	Alfred	3	0	0	3
10	Sana	0	0	0	0 ³
11	Antoinette	0	0	3	3
12	Michael	2	0	0	2
13	Ada	2	0	1	3
14	Donald	0	0	1	1
15	Teresa	0	0	3	3
16	Sarah	2	0	0	2
17	Samuel	4	1	0	5
18	Marjorie	0	3	0	3
19	Paul	0	0	3	3
20	Trudy	1	0	0	1
21	Juber	1	0	0	1
22	Meena	0	0	3	3
23	Carmel	0	0	1	1
24	Akbar	1	0	0	1
25	Gillian	1	0	0	1
26	Marcia	0	2	0	2
27	Josie	0	2	0	2
28	Sandra	0	1	0	1
29	Diane	0	1	2	3
30	Daisy	2	1	0	3
	Total	37	16	20	73

² All names of patients changed to ensure anonymity.

³ Sana was cared for by a CNS who worked with me and it is data captured in an interview with her concerning Sana's case that inform findings relating to Sana's life and death.

The consultations were recorded using a small, inconspicuous, digital recorder in order not to inhibit the naturally occurring conversations. The data collected was stored electronically but was anonymised. Once tape recordings were transcribed, they were destroyed and any hard copies of collected data were kept in a locked cupboard. Participants were made aware that data would be confidentially maintained and that their names would not be used when reports of the study were published. As papers related to the study have been written, care has been taken to protect the identity of patients and no personal details have been released.

Field notes were also recorded in a diary at the time of each interview and are discussed below.

5.4.2 The diary

Alongside the interviews I maintained my research diary, containing personal reflective field notes of the clinical consultations and in which I recorded my thoughts and my observations. These field notes helped me to reflect on what occurred over the three years of the study and assisted in structuring my data. The diary was used to inform my thinking and analysis of the interview data rather than being used as a source of evidence. It contained data obtained by observation and via conversations in the renal field with staff. Within this diary I also maintained reflexive notes on my role as a researcher and a nurse. I also recorded notes on the research process documenting the decisions I made along the way. This was undertaken in an attempt to understand and resolve problems as they arose with the aim of systematically improving practice (Rolfe 1998), as well as to collect research data. This ensured that the consultation was not just an interview but also a way in which the care required by the patient or needs of the carers were taken into account and managed. My role as their nurse was of paramount importance throughout the study and the clinical care of the patient my prime concern.

Keeping this diary ensured that my data collection was not artificially separated from reflection and analysis (Altrichter et al. 2008). Analysis accompanying data collection was actively used for further development of the research. As preliminary results from analysis became clear, other data that were still required to fill the gaps in theoretical frameworks were illuminated (Glaser and Strauss 1967). For example, as I observed a particular trajectory to death, where patients appeared to move slowly towards death as their kidneys deteriorated, I started to look for this particular occurrence in other patients in order to verify this as a finding.

Entries in my diary were accompanied by the date of the event and contextual information such as the time, location, participants and anything which might be important to the research, such as memos (Bogdan and Biklen 1982). Memos are produced when attempting to recall and write about experiences that occurred at a specific period of time, for example after a visit to a patient's house. Within the memos, descriptive sequences containing accounts of specific activities, descriptions of events and portraits of individuals and their environment were maintained. Memos also contain interpretative sequences (Altrichter et al. 2008), which include interpretations, feelings, speculations, hunches and explanations of events. The substantive field notes were the descriptive record of observed events and conversations.

An early diary entry following a home visit to see Teresa and her daughter Noreen offers an example of a detailed field note:

Today I went to see Teresa and Noreen for the first time. Teresa was sitting in a chair dribbling and looked at me vacantly although she did smile when I said 'hello'. She was large with huge oedematous legs and could just about fit in her armchair. She smelled of urine and her daughter Noreen said she was unable to walk unaided. Teresa started to talk but her words were unintelligible. Noreen appeared distressed and said she was finding it very difficult to cope; her mother was often confused and had dementia. Although her mother had carers attending to her four times a day, she still felt the pressure to care for her mother as a daughter would. She was finding it very hard and was receiving counselling from the renal counsellor. She discussed her mother's last appointment at the hospital when she was told her mother couldn't have dialysis. She was so angry and her voice grew louder as she asked me why her mother couldn't have dialysis? I can see that her mother would find it very difficult coming to hospital three times a week and I am not sure that it would be possible to move her out of her house. I can see why the consultant may have painted a bleak picture but I can also see that Noreen has not fully understood the situation. She sees it as dialysis or death. There is much work to be done here (FN 110107).

This field note offers insight into the personal situation of the patient. It highlights some of the complexity of the situation, including the myriad of problems suffered by the patient which the carer also had to contend with. It draws attention to my thought processes as I managed this mother and daughter as a nurse thinking about the clinical and emotional support required in this situation.

Regular reflection on my own assumptions and prejudices were noted in my field notes. Theoretical development was encouraged as I attempted to reflect on the research being carried out in conjunction with interpretation at several levels:

- Contact with the empirical material: Using well-reasoned logic in interacting with the empirical data and rigorous techniques for processing the data.
- Awareness of the interpretative act: Recognition that all research work includes and is driven by an interpreter who often studies other interpreters (the participants). Assumptions and pre-understanding determine representation.
- Clarification of political-ideological contexts: Social science is embedded in a political and ethical context. Thus interpretations and theoretical assumptions upon which these are based are part of political and ideological conditions.
- The handling of the question of representation and authority.

(Alvesson and Sköldberg 2000).

A running list of contents was maintained on the first page of each diary. As well as a factual account of events, information that helped me develop a more profound understanding of a situation, which was often reconstructed later, was included in the diary. This incorporated what I observed, how I felt and how I reacted in certain situations. It also included personal interpretations, reflections, ideas and explanations for events as they unfolded (Kemmis and McTaggart 1982). The diary contained a number of vivid, thick descriptions (Geertz 1973) of several situations (Altrichter et al. 2008) which offered examples often discussed in-depth at supervision or with colleagues and encouraged reflection on practice situations.

By virtue of my role, I had privileged access to other contextual data which helped to describe what was occurring in the service. These took the form of a renal database where information regarding patients was maintained, and included medical letters and blood test results. When looking at symptoms suffered by patients, for example, I was able to search the database for any written record or letter that mentioned a symptom and these data were captured in my diary.

5.5 Data Analysis

This section describes the approach taken to analyse data collected during the study. For the purposes of clarity I have separated the data collection and data analysis activities in the thesis but in reality there was no clear division, as supported by Hammersley and Atkinson (1995). *The analysis of data is not a distinct stage of the research. In many ways it begins in the pre-fieldwork phase ... and continues through the process of writing reports ... the analysis of data feeds into the research design and data collection* (p. 205).

Within the study, analysis of data collected early on informed subsequent data collection and analysis of data continued whilst the thesis was being written up. *'Writing is also a way of "knowing" – a method of discovery and analysis'* (Richardson 200: 499). For example as several patients talked about the pain they were suffering this became an area which was explored with subsequent patients in order to determine whether or not pain was a symptom common to the patients in the study. As I wrote about the pain experienced by patients, I then went on to explore how this pain was managed and what it meant to the patients.

Each stage of the analysis is now described independently.

5.5.1 Interviews with patients and carers

Analysis of the data, an iterative process (Silverman 2000), was guided by an approach described by de Wet and Erasmus (2005), which offers guidance on rigorous qualitative analysis. These authors contribute to best practice in qualitative analysis and ensure that analytical procedures are transparent. Their approach draws on grounded theory techniques (Glaser and Strauss 1967) and some guidance is drawn from Miles and Huberman's (1994) method of qualitative analysis. Like most qualitative analysis, it precedes in a non-linear, iterative way (de Wet and Erasmus 2005). The contribution of the qualitative software package NVivo to systematic and rigorous practice is also emphasised (de Wet and Erasmus 2005).

5.5.1.1 Step 1: Listening to and reading the data closely

The first analytical step before coding involved listening to each interview via the tape recording in order to check for clarity and to take in the sense of the whole interview, some of which I found was lost at the initial consultation. This step is drawn from grounded theory techniques. This first stage of listening to the

transcription in its entirety helped to provide clarity of meaning and continuity of the conversation as a whole and in context. Listening several times offered a way of becoming familiarised with the data and served to develop insight and sensitivity into understanding what was going on (Miles and Huberman 1994).

The tape-recorded interviews were then sent to a transcriber for transcribing in full and verbatim. Every transcript page was labelled with the code of the interviewee and page numbers so that pages were easily identifiable (Miles and Huberman 1994) (see Appendix 8 for an example of a transcript). Once returned, they were read and checked for errors. The intention was to become immersed in the data as reading and rereading of the transcripts occurred (Silverman 2000). Reading the transcripts gave me an opportunity to interact, in a relatively informal way with the data. It helped me to understand fragments of data in context and to remain alert to unexpected responses (de Wet and Erasmus 2005). This practice can guard against a mechanistic application of procedures and counters the accusation that qualitative researchers only respond to the 'bangs that are loudest or lights that are brightest' (Lincoln and Guba 1985). It is argued that investigators need to be responsive to the words of the participant and use sensitivity and insight to determine what is important in the data. A lack of responsiveness might be found when overly adhering to instructions rather than listening to data (Lincoln and Guba 1985; Morse et al. 2002)

5.5.1.2 Step 2: First-level coding

The initial coding of transcripts involved assigning unique labels to text passages which refer to particular categories of information (Miles and Huberman 1994:56) A total of 1,056 codes were initially identified although some codes were amalgamated relatively easily such as 'admission to hospital' and 'admission to local trust'. Other codes were related to text found in different interviews. For example, the code 'angry' had five pieces of data attached to it to be reread and analysed.

The process of selecting a piece of data and assigning it to a category involves data fragmentation (Dey 1993) and contributes to data reduction (Miles and Huberman 1994). Codes bring together selected data and help in the identification of emerging themes. An example of an emerging theme, '*The decision not to dialyse*' can be seen in a Node Coding Report in Appendix 9. Coding is not simply mechanical. Rather, the identification of codes is partly analytical as they link various parts of the text to a particular concept (Coffey and Atkinson 1986). First-level coding is the process of naming and classifying data and results in a working set of codes (Miles and Huberman 1994). At this level codes are descriptive (de Wet and Erasmus 2005) but Miles and Huberman (1994) suggest that they can also be interpretative. The codes (also known as nodes in the NVivo software) were developed inductively from my research questions and the data, but it is also likely that my own personal views, which had emerged from my in-depth knowledge of the study setting, influenced the emergence of the coding framework (see Appendix 10 for list of codes). One transcript with attached nodes can be viewed at Appendix 11.

The coding was assisted with the use of Nvivo version 2.0, (QSRpty, Queensland Australia, 2004), qualitative software as I was handling vast amounts of data and needed to keep the study manageable. This qualitative software was used following recommendations from colleagues. Advantages of the

system include the ability to organise, store and retrieve data. Electronic versions of the transcripts were saved as rich text format (RTF), as required by NVivo, and imported into the software programme to enable computer-assisted coding (de Wet and Erasmus 2005).

NVivo facilitated the systematic organisation and analysis of data during the study. The program allowed transcripts to be grouped into document sets. Interviews for individual patients and carers were grouped into separate sets and each set saved numerically. Another set consisted of staff interviews. Initially, this practice helped me organise and classify data. Later in the analysis, the organisation of data facilitated text searches for the process of verification. For example, I used the software to search for codes within document sets in order to verify when patients or carers were saying similar things. Some carers and patients reported that death was very difficult to talk about. Using the first-level code 'Not talking about death', (a code that emerged from the data), I was able to conduct an electronic search to see how many respondents within and across data sets reported this particular experience. The process of using NVivo involved highlighting selected words or paragraphs for coding. Occasionally, multiple codes were developed for single segments of text. A constant search for emerging patterns took place as coding was carried out and memos were documented along the way in my research diary.

As the analysis was conducted, discrete incidents/events/ideas were noted in my diary. During this stage I began to compare themes with similar phenomena being labelled with the same code as a 'constant comparative method of analysis' took place (Glaser and Strauss 1967). This process was undertaken to develop 'categories', also known as 'conceptual labels', which were initially provisional but with the aim of moving from coding to interpretation, as discussed by Coffey and Atkinson (1986:69): *The move from coding to interpretation is a crucial one...Interpretation involves the transcendence of 'factual' data and cautious analysis of what is to be made of them*.

Lists of codes were maintained utilising sociological constructs, attributed by the researcher, and 'in vivo' codes which were taken from the language of the interviewees (Strauss 1987), also termed 'etic' or 'emic' respectively (Miles and Huberman 1994). Fine codes, which are extracted from within broad codes, were then identified (Wengraf 2001). These fine codes were again descriptive and interpretative. For example fine codes that arose from the code 'The decision not to dialyse' included 'The autonomous decision' and 'dialysis as death'. Again the diary was used to bring these codes together and this was found to be a useful way of organising the data further. It also assisted me in the analysis rather than keeping everything within the software.

5.5.1.3 Step 3: Second-level coding

Second-level or pattern-coding is a metacoding process (Miles and Huberman 1994) where explanatory or inferential codes identify an emerging theme or explanation. Second-level coding involved two steps. First, clusters of information, such as symptoms mentioned by patients, were identified. This was followed with a deeper level of analysis during which patterns and relationships in the data were observed (de Wet and Erasmus 2005). This second stage helped in producing the findings. The NVivo software was helpful at this stage in allowing me to organise data speedily and systematically. I had easy access to

the list of broad first-level codes and began to identify from these initial clusters of information reflecting common themes that I had captured in my diary. A field note written during this second-level coding stage offers an example of how this took place:

After initial coding of several interviews I have a code named 'Not talking about death'. As I have gone on with my analysis I am thinking about this code to which several fine codes have been added. They include: 'Cannot talk about dying' and 'worrying about dying'. I am wondering how this links with what I am now finding, the idea that few patients appear to want to talk about death and dying. First-level coding has moved on to second-level coding. There seems to be a desire not to engage in discussions about the poor prognosis. Participants seem to want to remain optimistic but also have fears that need to be resolved. This seems in conflict with present-day policy, where there is a push for openness when it comes to discuss dying. Many patients just don't seem to want to go there (FN 190308).

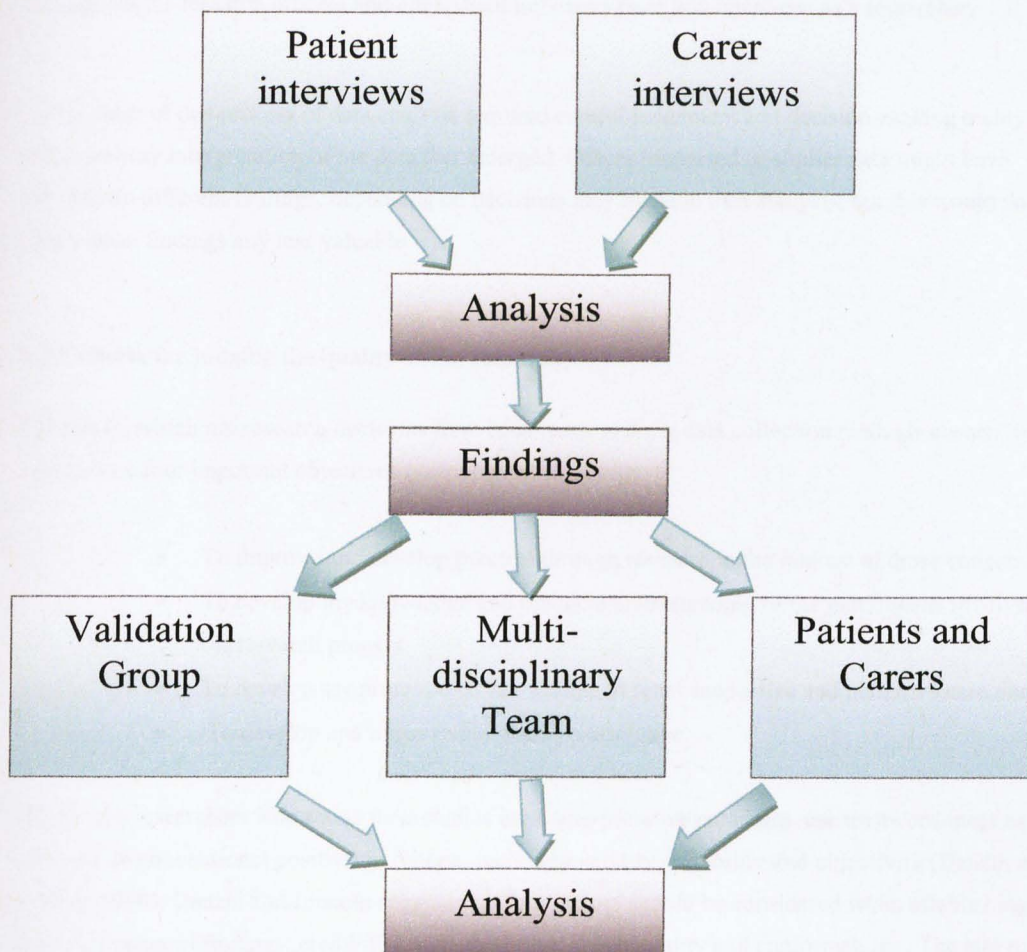
As the analysis took place I recorded in my diary the steps in my analysis and thoughts about the relationships and patterns in the data. These patterns were also influenced by what I had observed through field notes.

5.5.2 Interviews/meetings with staff

As analysis of the patient and carer interviews took place the findings were fed back to others on a regular basis and their responses noted. As discussed in section 5.3.2, a number of staff were interviewed during the study and notes of other meetings with staff were incorporated in my diary. The multidisciplinary team included a renal counsellor, a pre-dialysis sister, a CNS with expertise in anaemia management, nurses from the haemodialysis and peritoneal dialysis unit, a Chaplain and a consultant nephrologist.

Several interviews/meetings were tape recorded and transcribed, and followed the process described in Step 1 in section 5.5.1.1. These data were analysed in order to demonstrate how my findings were resonating with others working with a similar patient group and led to further insights on my part as I explored their experiences. Similarities and differences in practice were highlighted and incorporated into the final version of this thesis (see Figure 5.2). Particular segments of text that supported or challenged my findings were identified and used to illuminate the validity of the findings. Other data incorporated into my diary enabled reflection on events and what was being found in the data analysis, and helped me as I structured my data.

Figure 5.2 Using the patient and carer interviews to inform further analysis



5.5.3 Immersion/crystallisation

Immersion and crystallisation (Crabtree and Miller 1999; Richardson 2000) is a style of data reduction that was well suited to this exploratory research, where knowledge in the area was limited. It involves the systematic review of accumulated data and text in an iterative process, where I first immersed myself in the data sets I had available and then attempted to make sense of what I was finding in detail. Crystallisation, the process of temporarily suspending the process of examining or reading the data (immersion) in order to reflect on the analysis experience and attempt to identify and articulate patterns or themes noticed during the immersion process, followed.

Following much reflection, 'constant comparison' of data and discussions with my supervisors, intuitive crystallisations (Miller and Crabtree 1994) emerged in the form of my findings. Crystallisation provided me with a '*deepened, complex, thoroughly partial understanding of the topic*' (Richardson 2000: 934).

Crystallisation does not deny the real world but recognises that any attempt to describe and measure that world is influenced by a range of social and cultural factors. My account in this thesis can only ever be a partial understanding of the topic under study and, because of this, I have endeavoured to be reflexive throughout the research process and open about my own values and intentions as a researcher.

Every stage of this process of data analysis required careful judgement and decision-making on my part but it was my interpretation of the data that emerged. Others immersed in similar data might have decided on different findings, depending on decisions they made in data analysis, but this would not make those findings any less valuable.

5.6 Criteria for judging the quality of the research

Criteria by which my research decisions have been made and my data collection methods chosen have arisen from four important objectives (Altrichter et al. 2008):

- To improve and develop practice through research in the interest of those concerned.
- To develop my knowledge and practical understanding of the participants involved in the research process.
- To develop my professional knowledge of renal supportive and palliative care nursing.
- To develop and improve nursing as a discipline.

Qualitative researchers who frame their studies in an interpretative paradigm use trustworthiness as opposed to conventional positivistic criteria, including validity, reliability and objectivity (Denzin and Lincoln 1994). Denzin and Lincoln suggest that four factors should be considered when establishing the trustworthiness of findings: credibility, transferability, dependability and conformability. The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are '*worth paying attention to*' (Lincoln and Guba 1985: 290)

5.6.1 Trustworthiness

In order to enhance the trustworthiness of the study, a number of practices were adhered to. Detailed description has been given in this methods chapter describing the sample, the findings, data collection and analysis and the impact I may have had on the research (Miles and Huberman 1994). Section 5.6.4.2 in this chapter identifies how participants have been fairly managed within an ethical framework to ensure that they were not endangered in any way.

Alternative perspectives were available to enhance the trustworthiness of the study. Other nurses working in a similar position to me acted as a 'validation group' (McNiff 2002), as discussed in section 5.3.2 above, and offered an opportunity for critical feedback and critical scrutiny of my work. Specific issues discussed included any difficult patient scenarios encountered, what had gone well/not so well and trajectories of illness. Meeting with this group highlighted how the findings from my study were

resonating with their work. They gave several examples of similarities in practice and corroborated my findings.

My understanding of my research situation was also confronted with the views of other members of the multidisciplinary team, including the CNSs who worked directly with me, and this has helped me to come to a greater understanding of my research. This is demonstrated by another example from my field notes:

Today I presented the Renal Supportive Care audit to the renal multidisciplinary team. I felt a little anxious as renal consultants were attending who had referred patients into the service. Some patients had reported that they were not involved in decision-making and that the consultant had told them that they could not have dialysis. Whether or not this is true is uncertain but is what I am being told by patients. In discussing preliminary findings from my research I needed to convey the voice of the patients. When the presentation was over one of the consultants remarked 'isn't it interesting how so many patients are unresigned to their decision'. Another consultant responded 'there is only so much we can do'. This made me see things from another perspective. Perhaps the patients were misunderstanding or refused to acknowledge their own decision-making. Whatever the truth it has an impact on my practice. I am meeting with some patients who have feelings of anger and resentment related to opting not to dialyse. Sometimes they are hostile when they meet me. As their practitioner I need to manage these feelings and enable patients to make sense of what's happening (FN 2 190607).

Cross-checking my work with others having input into the care of patients in the study helped me to identify ways forward in terms of practice and the study, and added richness to my data sets. Their views and experiences were taken into account and form part of the final analysis.

Member checks (Guba and Lincoln 1981) have been discussed as a useful way in qualitative research to minimise errors, although they are not an objective check of validity. Findings were shared with participants at each consultation throughout the course of the study. The intention here was to confirm that a true understanding of what was related was gathered. The aim of this was to enhance understanding of individual perspectives on the issues, reduce misunderstanding and to gather further data where there was any confusion over what was relayed. This was a helpful way in checking that I had understood what the patient or carer had told me. Sandelowski (1993) contends that the use of member checks is a threat to validity. She advises caution in adopting validation strategies which promise to illuminate the practice of qualitative researchers. She argues that the views of the participants will depend upon the nature of the relationship with the researcher and conflicts of interest and need. She questions the research process itself and whether a lack of convergence necessarily invalidates interpretation. In this thesis, it was found useful to validate findings with patients as a way of checking for understanding of what they had reported and to ensure that they were receiving appropriate care and support.

In this thesis attempts have been made to be systematic and rigorous, and the data are presented as evidence in the hope that the 'spirit' of the data (Sandelowski 1993) has been maintained. Endeavours have been made to present the study's methods clearly and to be specific about the data analysis, in line with approaches advocated by de Wet and Erasmus (2005).

Triangulation is seen as a means of cross-checking the significance and relevance of issues arising from research studies (Silverman 2006). Triangulation is less concerned with the confirmation of findings and

a 'truth' but rather how different perspectives come to be constructed and meaning attached to them (Simons 2009). As discussed in section 5.5.3 immersion and crystallisation (Crabtree and Miller 1999; Richardson 2000) were well suited to this exploratory research, where knowledge in the area was limited and involved the systematic review of data. But as with a crystal, findings can be looked at in different ways and directions, allowing for alternative meanings to emerge depending on how data is viewed and analysed (Simons 2009). This allows for different ways of seeing and enables the development of further interpretations and deepening understanding.

These approaches offer the reader an opportunity to judge the trustworthiness of the data but also recognise that reality is assumed to be multiple and constructed. Given that it is usual for there to be more than one version of the same story, other researchers were not approached to check the reliability of the emergent themes. Data are presented in detail and in context to allow the reader to judge the relevance of the findings to them in their own practice settings.

5.6.2 Generalisability

Practitioner research is often written up as the study of a single case. Sharp (1998) suggests that there are three ways to generalise from the study of a single case. The first involves 'empirical generalisation' using sampling methods. Here a claim is made that due to the representativeness or typicality of the sample to the population, the findings from the sample are typical of the wider population (Sharp 1998). This was not the intention in the present study, as it was only the study of a single case of practitioner research and not the study of a sample of several cases representing a wider population. However, a rich description of how the study was conducted has been offered in this present Chapter in order that others might repeat the work in other contexts, with the possibility of empirical generalisation in the future.

The second type of generalisation, 'making the case', relies on persuading the reader that it is reasonable to generalise from the findings (Sharp, 1998), usually by providing a 'thick description' of the study setting (Meyer et al. 1999; Lincoln and Guba 2000). The term 'thick description' was introduced in the philosophical writings of Gilbert Ryle (1971), and developed by Clifford Geertz (1973) in the field of anthropology. Reflecting on the difference between a 'twitch' (involuntary eye movement, with no projected meaning to others) and a 'wink' (voluntary eye movement, with projected meaning to others), Ryle highlights the importance of context in interpreting meaning. In this study rich contextual detail is given (See section 1.1) in order that the reader can interpret whether the findings have wider relevance to themselves in their own practice situation. Through this description, the context of the inquiry is opened up and the descriptive detail offers the reader a chance to draw their own conclusions and judge the similarity or 'fittingness' between the study context and their own practice setting (Lincoln and Guba 2000). Within this study contextual detail and in-depth findings are described. The reader is therefore invited to decide on the applicability and usefulness of the findings in their own practice setting.

The third type of generalisation is 'theoretical generalisation' (Sharp, 1998); otherwise known as 'theoretical inference' or 'analytic generalisation' (Murphy et al. 1998). This relies on techniques such as analytic induction, a systematic examination of similarities between various social phenomena in order to develop concepts or ideas, and deviant case analysis where data appear to contradict patterns or

explanations that are emerging from data analysis. These techniques establish in a systematic way the potential for, and limitations to, the generalisability of theoretical claims that emerge from and within particular situations (Simons 2009). It is suggested by Geertz (1973) that in rich accounts of qualitative research, we are reduced to insinuating theories rather than having the power to state them. He argues that theory needs to stay rather closer to the ground than tends to be the case in the sciences, which are more able to give themselves over to imaginative abstraction. Theory is 'unseverable from the immediacies thick description presents' (Geertz: P25) Generality thus 'grows out of the delicacy of its distinctions, not the sweep of its abstractions' (P25). By analysing the rich descriptions of the experience of patients who had opted not to dialyse, this study adds to theory by postulating three trajectories to death (See Chapter 8). Clearly this theory is limited by the fact that it has only been derived from 30 cases. However, the fact that these cases were recognised by others working in the field (See section 10.1.2), it is suggested that the reader can have more confidence in the findings' wider relevance. Further, the rich descriptive narratives in Chapter 8 used to illustrate the three trajectories to death, offer further contextual detail to assist the reader in judging the trustworthiness and relevance of the findings.

The relevance of a study can also be viewed in terms of how important it is to practitioners and what it contributes to the accumulation of knowledge in a field (Altrichter et al. 2008). Fourteen articles from this study (See Appendix 12) have been published in national and international peer-reviewed journals and the work has won three awards (See section 10.1.4) and led to invited keynote presentations (See Appendix 12). This would suggest that the findings are viewed as being important by others and is contributing to the accumulation of knowledge in the field.

5.6.3 Ethical considerations

The local Research Ethics Committee granted ethical approval for the study prior to its commencement (see Appendix 13). However, the process of the study raised a number of issues that required consideration:

- Ethical considerations in relation to PR
- Ethical considerations in relation to dying patients
- Ethical considerations in relation to keeping a diary

5.6.3.1 Ethical considerations in relation to Practitioner Research

As I worked and researched as an 'insider researcher' (Robson 2002), I played a dual role: I was conducting research with individuals who were receiving care from me in my capacity as a nurse. This can pose specific problems for the design and conduct of a study. In particular, it was important to consider how my influence might impact on the ensuing results and how they were interpreted (Hewitt-Taylor 2002). There was also the potential problem of bias. Full use of supervisors was ensured so that this discussion took place regularly and bias was taken into consideration and managed appropriately.

As discussed, I had access to a 'validation group'. Members of this group were used to consider my data and to determine whether or not my findings resonated with their experiences and practice. Coercion was also a potential problem in this study as I was in a position of power where my status as a nurse could have been used to intimidate participants into agreeing to participate in the study (Oakes 2002). Coercion is associated with the exercise of power to cause someone to do something they might not do if they felt able to enact their own agency (Milne 2008). One way of attempting to shift some of the power differentials was to explain honestly to patients and carers that their care would not be compromised if they did not agree to be involved in the study and that it was entirely their decision to make. As in all research, it was very important for me to be honest and open about the research, the goals that I had and the benefits that I hoped might come from the research. Although I met patients and carers in a position of power they also held the power to influence whether or not the research would progress (Milne 2008). Without their participation it would not have been possible to carry out the study, and I was grateful for their consent and was always concerned that they were clear about what they had consented to be involved in.

Findings were fed back to patients and/or carers at each consultation by recapping on previous interviews and checking that the data collected were a true representation of what they had reported. Findings were also fed back to staff for comment via team meetings, academic days and local education programmes. This helped to keep the research process open and assisted me in opening up data as participants gave their interpretations of specific events.

I was aware that I could possibly bring my own personal beliefs and values to the study, having worked in the area for some time. I attempted to identify and record these beliefs and values and the perceptions of my position and relationships in the area being studied and with those involved. As I evaluated the possible effects on the data gathered, I regularly discussed my thoughts with my supervisors and colleagues in an attempt to ensure that bias was identified and dealt with appropriately.

An alternative view of insider research is that it can offer a depth and richness of data that might not otherwise be accessible (Ashworth 1995). Those who work outside an organisation may not be granted access to information that might be available to 'insiders'. The practicalities of spending appropriate time with participants may be difficult due to time constraints. I felt that by conducting the research as an 'insider', I was able to gain an understanding of the many sensitive issues involved in a RSCS. The patients and staff involved were familiar with my presence, which may have increased the possibility of a natural environment being observed (Hewitt-Taylor 2002). Alongside this, patients and carers were not being asked to do anything other than have their consultations tape recorded.

To ensure that my PR was of high quality, the research design and methods were compatible with the time constraints on me as a Practitioner Researcher. While working as a nurse and 'insider', I was observing what was taking place, systematically recording my experiences and reflections, making changes as necessary and developing the RSCS. The methods were also compatible with the professional culture of Clinical Nurse Specialists, Consultant Nurses and Community Matrons, where there is a drive to build upon the experienced professionals' ability to make many, often difficult decisions (DH 2007)

whilst utilising 'practical reflection' (Altrichter et al. 2008). I also used research methods that were integral to my work as a nurse. For example, an interview with a patient was a professional consultation but also a means to collect data on the patient's experience.

5.6.3.2 Ethical considerations in relation to dying patients

Dying people are perceived by society as vulnerable groups, leading some to believe that it is morally unjustifiable to involve dying people in research (De Raeve 1974). In considering this it should be taken into account that patients' dying trajectories are often from weeks to months and some even stretch to years. Although many patients may be perceived to be dying in as much as they face a certain death at an uncertain time (Copp 1999), many still have a lot of living to do.

One view of dying people is that they are in need of protection and should not be approached to be involved in research. An alternative view is that everyone, whether dying or not should make the choice for themselves (Mount et al. 1995). Throughout the study I ensured that patients were fully informed regarding the research process so that they could make appropriate decisions and retain the right to withdraw at any time without care being compromised. At all times I attempted to guard against the abuse of my professional power and constantly evaluated the patient's condition and whether he or she wished to continue to participate (Copp 1999). Each time I met with a patient or carer I recapped on the purpose of the study and checked that they were still happy to take part. As mentioned, one patient withdrew from the study. This patient was reassured that withdrawal from the study was completely acceptable and that his care and treatment would continue at a high standard regardless of this decision.

Renzetti and Lee (1993) suggest that anyone involved in sensitive research should have ongoing supervision to deal with difficulties that may arise in relation to the interview process and the impact on the researcher. Coaching and clinical supervision were organised locally to support me through potentially difficult times, although few of these arose throughout the study.

5.6.3.3 Ethical considerations in relation to keeping a diary

As with all data, a diary constitutes a record. My diary was private and contained intimate accounts and reflections and couldn't be made public without consent from the participants about whom I wrote. An ethical rule by which I worked was to never let my research become covert (Altrichter et al. 2008). I made efforts to ensure that the study was known about within the renal department. Posters were placed in the clinical areas (see Appendix 14). The research was presented at team and multidisciplinary team meetings and at the academic half-day which runs weekly and is attended by clinical staff within the renal department. As this study concerns one RSCS within the UK, and as there are few similar services available in the country, it may have been possible to identify some participants. As a result individuals were asked permission before relevant data were published.

5.7 Summary

This chapter discusses the strengths and weaknesses of PR in qualitative inquiry and makes the case for such an approach in a study where little is known about patients managed without dialysis. Potential benefits of PR include improving practice through encouraging critical reflection. It is also used to inform and challenge policy and encourages a dialogue between practice and research and to create new knowledge through the work of practitioners (National Research and Development Centre 2008).

The aims of this study were revisited, along with details of methods used for data collection and analysis. Trustworthiness and generalisability of the study have been addressed and ethical considerations explored and discussed. Rich description was offered of the context within which the research was managed, and of the research process itself, to allow readers to familiarise themselves with the setting before the findings are introduced. Detail has been given of the process of analysis.

This chapter on methods is provided as a forerunner to the following four findings chapters and allows the reader to judge the quality of the data that follows. The next chapter introduces the findings and highlights how many patients endured a complex and uncertain trajectory to death, which health professionals often found challenging. It establishes the direction of the overall thesis as it introduces the structure of each of the four chapters.

CHAPTER 6

INTRODUCTION TO THE FINDINGS

This study set out to explore the healthcare needs and trajectories to death (or not) of patients managed within a Renal Supportive Care Service (RSCS). Issues highlighted will be of interest to those setting up similar services in the future. The findings were generated from 30 patients who were managed in the service over a period of 18 months or until death. They are based on my repeated interviews/consultations with participants who I got to know over time as their practitioner responsible for managing their care. Seventeen carers also contributed to the study when they presented with the patient at consultation. As a practitioner working within a multidisciplinary team, I had the ability to feed back findings locally, and to other staff caring for patients managed without dialysis nationally. Many of the findings resonated with what they were uncovering in practice and their experiences are drawn on. Similarities in what they experienced are demonstrated and differences in experience critically examined.

In the findings chapters it is argued that those living life, having made a decision not to embark on dialysis, have multifaceted needs. This is heightened by the fact that the fate of these patients is generally unknown and their experience is absent from the literature. The findings illustrate a range of concerns and difficulties that patients faced and highlight their trajectory to death, if indeed it did occur. In addition they draw out the intricacies encountered by health professionals caring for them.

Supportive and palliative care for the patient managed without dialysis is a relatively new concept and services are striving to understand the patient journey once patients are referred for management. Little research has been carried out on this population and most knowledge is limited to anecdotal evidence. Several nurses alluded to this in the study as they discussed their experience of managing such patients:

Why did you go in and see that patient and think and do as you do? It is still all completely up in the air, isn't it? We are all working out clinically through clinical experience, what our feeling is about the patient and what their needs are but it is not evidence-based and we don't know the best things to do (CNS⁴ M0907⁵, M⁶).

There's unanswered questions for me clinically now that nobody else can answer ... I can say to patients in my clinical experience this is what I've seen, but actually it would be wonderful if we had research to back it up. This is what we would like and this is what's related to this and this is why you're ... there are so many unanswered questions (CNS, G0907, M).

Clearly, this lack of knowledge has hindered service development. This thesis offers an understanding of those accessing a RSCS, uncovers a number of healthcare needs and describes three trajectories to death not described before. It raises issues to be taken into consideration by others setting up similar services.

⁴ Clinical Nurse Specialist

⁵ Indicates location of data. Each set of numbers/letters represents a different interview, meeting, field note, etc.

⁶ Meeting.

This first findings chapter addresses the first aim of the study which was to describe the characteristics of a cohort of renal patients with stage 5 CKD in a London renal unit who had decided not to embark on dialysis. It introduces those who accessed the RSCS, reflecting on their ethnicity, age, gender and comorbidities. It offers the reader an opportunity to judge any similarities between the participants in the study and those they are managing within their own practice setting. Alongside this, several issues worthy of further consideration are highlighted. The chapter draws attention to the fact that the Muslim community was under-represented in this study and the Afro Caribbean community over-represented. The reasons for this are unclear, but it is suggested that it may be due to cultural differences. Many of the Afro Caribbean patients were vocal concerning the place that religion played in their life and how this affected their decision-making. With regard to the Muslim patients, it is suggested that input from family members and their wish to promote life at all costs may have been behind the relatively small numbers managed within the RSCS, compared to the dialysis population in general. Whatever the reason, a central finding here is the need to question the profile of those receiving supportive care to manage stage 5 CKD. This will ensure that services are set up and managed appropriately and are focused on patients' needs in the context of individual social and cultural backgrounds.

The patients were older than those found in the population usually managed with dialysis, but they were also frailer, sicker and many suffered more than one comorbidity. It is argued that renal failure in this population appeared as a disease of older age. Also the numerous comorbidities that patients presented with led to difficulties in determining what illness was most troublesome and what was the cause of presenting symptoms.

Chapter 7 describes a number of healthcare needs brought to my attention by patients as they were seen at consultation. It offers a descriptive analysis of what it was patients talked about and highlights needs that naturally emerged over time. Identifying these needs offers others insight into priorities for care of this population. The chapter begins by offering a reflection on the perceived decision that patients had made prior to being referred to the service regarding the non-initiation of dialysis. This decision appears to have been complex and patients presented differently in terms of how much they understood about the decision that had been taken. This had an impact on further information needs once managed within the RSCS, with some patients believing they had made an informed decision and some not realising that a decision had been made. A central finding, therefore, is the need for appropriate information provision in the context of stage 5 CKD.

The chapter continues by discussing the considerable number of symptoms that patients presented with. An attempt is made to determine the cause of those symptoms, as several symptoms were unrelated to the renal disease itself. It is argued that although some symptoms could be successfully managed, others could not and other professionals with additional expertise had to be called upon to ensure that physical and psychosocial concerns were addressed. The findings around symptom management are therefore considered important in themselves and highlight the symptom burden of this population.

The next part of this chapter raises the difficulties that patients (and carers) experienced as they lived their lives knowing that death would come at some point soon. The uncertainty of the prognosis meant that

some patients made plans for death too early and didn't then go on to die, leaving them to re-evaluate their lives and attempt to look to the future again. Along the way there were worries that deterioration had occurred and the impact of this on patients and their carers is discussed. Although this emotional component is discussed, it was absent from many consultations. The wish not to talk about or dwell on the inevitable death is explored and three reasons for this are presented:

- too difficult a subject to discuss
- the severing of hope if death was discussed
- not wanting to dwell on the inevitable.

Patients appeared to choose not to embark on detailed conversations about death and dying, not only with professionals but also with their families. Only one patient cried at consultation. Practical tasks such as ensuring that a will was in order were carried out but there appeared to be a need to contain the inevitable - that is death - and to focus on the life that was still left to live. These patients lived with the knowledge that they were going to die, but they were also elderly and sick and had often suffered previous ill health. They appeared to accept their prognosis with little emotion or were perhaps able to hide it from professionals and carers alike. Other nurses in similar positions reported similarities, but also differences, with some patients being very open about their circumstances and others reluctant to discuss their situation. Reasons for this are offered in this thesis but this area warrants further research. Emotional support is therefore an issue requiring further examination in this population.

Chapter 8 reflects on the different trajectories to death that emerged in those who died during the study, and how these differ from what has previously been described in the literature. It offers an interpretative analysis of my observations as I worked with patients, often until their death. The three types of death uncovered included:

- a typical uraemic death
- death from another cause other than renal disease
- death where the cause was unclear.

The three types of death identified are presented as illustrative narratives to exemplify the characteristics of each.

Chapter 9 presents the difficulties that often arose in supporting and managing these terminally ill patients. Difficulties included problems in identifying a terminal phase, with some patients not dying as expected and others outliving their prognosis. This led to some patients receiving inappropriate care as the end of life approached. This care was offered by health professionals in the form of:

- surgery and resuscitation
- encouraging the initiation of dialysis
- reducing professional input as death approached

- attempting to admit to hospital inappropriately.

A key finding here is the need for appropriate intervention in the final stages of life.

The patients who entered the RSCS are now discussed in order elucidate the characteristics of the population managed. A number of issues worthy of further consideration are highlighted.

6.1 The range of patients encountered

As stated above, this part of the thesis addresses the first aim of the study which was to describe the characteristics of a cohort of renal patients with stage 5 chronic kidney disease (CKD) in a London renal unit who had decided not to embark on dialysis. During this study I was able to follow up 30 patients with whom I had repeated contact as a specialist nurse over time. As I followed up these patients I kept records of those accessing the service. Although 30 patients were recruited to the study, and many findings resonated with other staff, the number in the study is relatively small. The findings related to the range of patients recruited to the study and need to be approached with caution. Nevertheless, I am presenting my findings in rich contextual detail so that the reader can judge if they are relevant and resonate with them and their practice. This is in addition to the detail of the service offered in section 1.2.6. A summary of each patient can be found in Appendix 1. I also highlight issues that arose during the study worthy of further consideration.

This section uncovers some interesting differences in those people who came through the service compared with the general renal population in terms of ethnicity, gender, age and number of comorbidities. It remains unknown whether the patients who arrived in the service were referred by health professionals on the basis of such criteria although other explanations have naturally emerged from the study discussed in this chapter. Details related to the how patients were managed when making decisions regarding treatment options are limited to what patients and carers reported. I was not privy to the decision-making process, which warrants further study to detect whether or not any biases on the part of those helping patients to make decisions are evident.

The patients in the study were being managed within a specialised service focusing on their renal disease and perceived end-of-life needs. They did not represent the renal dialysis population found in the Trust where the study took place, and therefore the anticipated care that they might require could not be compared to the care required by those on dialysis. For instance, the renal disease was sometimes the least of their problems, unlike those receiving dialysis, where much medical focus is on the dialysis treatment itself and management of the patient related to this (Germain et al. 2007).

The issues raised in this section are worthy of further study and include:

- ethnicity and religion
- gender

- age
- comorbidities

Each is discussed in turn below.

6.1.1 Ethnicity and religion

In this section I discuss who entered the RSCS and reflect on some disparities in terms of ethnicity. Ethnicity of the patients (see Table 6.1) was grouped using the ethnicity grouping utilised within the hospital where the study took place. This included: white, Afro Caribbean, Black African, Black/other/non-mixed origin, Indian, Pakistani, Bangladeshi, Chinese and other. Of the 30 patients in the study, 12 were white (including 2 patients from Greece), 12 Afro Caribbean, four were Bangladeshi, one was Indian and one was Pakistani. There was under-representation of the Muslim community and high representation of the Afro Caribbean community when compared with the renal population at the Trust where the study took place, and these findings are now discussed.

6.1.1.1 Under-representation of the Muslim community

Although the dialysis population at the hospital where the study took place consisted of a high percentage of renal patients who were Muslim, with 28% from India, Pakistan or Bangladesh, the number in the study opting not to commence dialysis was less at 20% (see Table 6.1). Although this is not a large number from which to generalise it is an interesting issue that may warrant further research. Bangladeshis constitute 33% of the local population of the hospital where the study took place, made up of approximately 196,106 people (2001 census)⁷. It is important to understand their health and the choices they make related to how they live if we are to improve care to this group, which has the highest mortality rate and is the most disadvantaged Asian group (Eame and Ben-Shlomo 1993).

Muslim patients, which include those from Bangladesh, are likely to define themselves and their individual merit as relative to, rather than independent of, the rest of their family. This differs from people from the United States and the UK, who often act on the belief that rules governing patient confidentiality are based on the concept of individual rights. For Muslims, major decisions usually involve all members of the extended family (Hammoud et al. 2005) and autonomous decision-making and informed consent are not seen as so important in the Muslim faith (Gostin 1995). The issue of opting for rather than against dialysis may be a cultural matter, with Muslim patients keen to embark on dialysis in an attempt to prolong life. Other staff in the renal unit where the study took place had some experience of working with patients making decisions about dialysis. In particular, one member of staff had experience caring for Muslim families and had noticed reluctance from family members, often a son or a daughter to allow the patient to receive bad news relating to their prognosis without dialysis and a wish for their parent to receive treatment at any cost. Sometimes the patient themselves pushed for dialysis at any costs. This was discussed at a team meeting by the renal counsellor:

⁷ To protect the identity of the research participants the reference for this information is withheld

Table 6.1 Demographics of patients recruited to the study

	Name	M/F	Age	Ethnicity	Diabetes	Heart disease	Rheumatoid/osteoarthritis	Cancer	Cerebro-vascular accident (CVA)	Chronic obstructive pulmonary disease (COPD).	Dementia	No. of Comorbidities
1	John	M	75	White		X		X				2
2	Cliff	M	82	White	X							1
3	Veronica	F	71	Afro Caribbean		X					X	2
4	Mary	F	91	White								0
5	Arnold	M	78	White		X						1
6	Raymond	M	70	White			X					1
7	Sara	F	77	Indian	X							1
8	Abdul	M	74	Bangladeshi	X	X				X		3
9	Alfred	M	86	White		X		X		X		3
10	Sana	F	70	Bangladeshi	X				X			2
11	Antoinette	F	77	Afro Caribbean	X		X					2
12	Michael	M	76	Afro Caribbean	X							1
13	Ada	F	84	Afro Caribbean	X	X			X			3
14	Donald	M	69	Afro Caribbean	X	X					X	3
15	Teresa	F	78	Greek	X	X	X		X		X	5
16	Sarah	F	80	Afro Caribbean	X							1
17	Samuel	M	85	Afro Caribbean	X	X						2
18	Marjorie	F	87	Afro Caribbean	X	X	X					3
19	Paul	M	91	White						X		1

20	Trudy	F	70	Afro Caribbean	X	X	X		X			4
21	Juber	M	74	Bangladeshi	X	X	X			X		4
22	Meena	F	69	Bangladeshi	X		X					2
23	Carmel	F	85	Afro Caribbean	X	X						2
24	Akbar	M	84	Pakistani	X	X		X				3
25	Gillian	F	80	Afro Caribbean	X	X						2
26	Marcia	F	77	Greek			X	X				2
27	Josie	F	68	White	X		X					2
28	Sandra	F	65	Afro Caribbean	X							1
29	Diane	F	77	White	X			X	X			3
30	Daisy	F	82	White	X							1
					N= 22 (70%)	N=15 (50%)	N= 9 (30%)	N= 5 (17%)	N= 5 (17%)	N= 4 (13%)	N= 3 (10%)	
		M= 12 (36 %)	Mean Age = 78	White=10, Greek=2 BC=12, Ben=4, In=1, Pak=1								

Counsellor: *But sometimes the patient insists or the family insists they want dialysis, and often they are the Muslim patients ... If they say they really want dialysis and I can remember someone recently ... that even though it wasn't thought to be in their best interests, they wanted dialysis, or their family wanted it (Couns⁸, N0607, M).*

A renal Clinical Nurse Specialist (CNS) working with patients making decisions not to have dialysis in another London Trust believed that Muslim patients couldn't make decisions about living or dying. Although she had worked with few Muslim patients she said that she had been told that they viewed dialysis as a choice about living and dying and that these patients would therefore usually want to accept treatment rather than face death:

But you know Muslims ... I spoke to that Muslim chap. Their religion doesn't allow them to make a decision about living or dying and they view dialysis as living or dying, deciding whether or not is living or dying basically. And what he said is that you can never ask them to decide, they'll always say you've got to keep going whatever you offer, unless there's a general consensus amongst several trusted doctors that say this is of no benefit to you. Even then there seems to be resistance (CNS, M1108, M).

Another renal nurse from the hospital where the study took place, based on her own experiences, felt that those patients from the Muslim community would opt for dialysis:

The Muslim population that we do have most of them actually opt for dialysis don't they? (RN⁹, G1108, M)

An alternative explanation for the under-representation of the Muslim community in the study was that other Muslim patients, not included in the study, had been persuaded by family members to embark on dialysis even though their prognosis on dialysis may have been poor. This may have been due to the close relationship between elders and their children, who wished to lengthen the life of their parent at any cost. All the Muslim patients in the study either lived with children or were very involved with children who lived close by. A second alternative explanation is that Muslim patients themselves wished to accept treatment at any cost to their health.

For those Muslim patients in the study who had not embarked on dialysis, their children sometimes felt that their parent should have been accepted for dialysis. This was the only ethnic group where family members took issue with the decision that had been made. Meena's¹⁰ son, Amut, asked why his mother wasn't able to have dialysis even though he had explained earlier in the consultation that the doctors had told him that his mother would die if she embarked on dialysis:

She (Meena) wanted to do dialysis but the hospital doctor told her, it's not safe for her to do dialysis, I don't know why, but they told her and, because she was scared for dialysis because they told her she's going to die with the dialysis and like, she cannot. She doesn't want to die like that because nobody wants to die. They told her that she's borderline. If she do dialysis, chance is she will die. So she didn't have dialysis, otherwise she would do dialysis (NB-1¹¹, int¹²).

⁸ Counsellor

⁹ Renal nurse.

¹⁰ Patient and carer names have been changed to protect anonymity.

¹¹ Number of consultation.

Amut went on to explain that his mother was to be treated with medication, that she might live for many months and that the family understood the position, but Amut's frustration at the decisions that had to be made regarding dialysis became clear later in the interview when he said:

One of the ladies I know, she's weaker than my mum and she's quite older than my mum and she's done a dialysis. I don't see anything happens to her. Why'd the doctor told us we cannot do dialysis? They didn't say that we cannot do dialysis, what I'm trying to say they told us she is borderline (NB-1, int).

Amut desperately wanted his mother to continue to live and had grave reservations about his mother refraining from dialysis. He made it clear that it was a family decision to be made by the use of the words 'us' and 'we'. On further discussion Amut explained that his mother was 'scared of operations' and that dialysis would be difficult for her, although Amut did not appear convinced that it should have been excluded.

The small number of patients from the Muslim community accessing the RSCS warrants further investigation. The dialysis population at the hospital where the study took place consisted of a high percentage of renal patients who were Muslim but the number in this study refraining from dialysis did not reflect this. It is clearly important that we attempt to understand why and how different cultural groups make decisions and to determine if there are similarities within groups that might indicate how someone of the same culture will respond in future. This can help in planning services to meet the needs of groups of patients from similar ethnic backgrounds.

6.1.1.2 Over-representation of the Afro Caribbean community.

Another notable feature in the study was the presence of patients from a Caribbean background: 14% of renal patients in the unit where the study took place are black yet 40% of patients included in the study were of Afro Caribbean heritage. Again these numbers are small but may be of importance so are worthy of discussion. Of those Afro Caribbeans who did come through the service almost half (at 42%) were older (over 80 years of age) and most had decided that dialysis was not something that they wished to endure at an advanced age and with multiple health needs. Like many patients in the study, they were frail, had problems mobilising and didn't wish to be burdened with attending hospital three times a week. Sarah, one of the fitter patients in the study, explained how well she was and questioned why she would want to have dialysis:

No, Helen, be truthful, at this stage what would I want with dialysis? At this stage of my life, what I want with dialysis? I'm eating, I'm drinking, I'm doing all my housework, yeah, no complaints, I am passing water very well, the only thing is the iron tablets get me constipated at times. But other than that I am feeling all right ... So see the picture of what I'm saying, and judge by yourself, if you were in my position would you have had dialysis? ... No, I'm not going to have it. Yeah. I'm going home (to Trinidad) and God spare my life (TC-1, int).

¹² Interview data.

Similar to Sarah above, many Afro Caribbean patients took solace in their Christian religion and the belief that God would support and guide them. Religion appeared to play a less important part in the lives of the 12 white or European patients. Interestingly, according to the renal counsellor, the Afro Caribbean group tends to under utilise the renal counselling service at the Trust where the study took place, but had a high attendance at the Renal Memorial Service, held in 2006 and 2007. It appeared to offer psychological support that was more relevant to many black patients, and supports the theory that black patients are more likely to describe their religious and spiritual beliefs as very important (Weisbord et al. 2007). The majority of black patients in the study alluded to their Christian faith and its importance in their lives especially now that they were coming towards the end of life. Religion and their belief in God was central to how they lived their lives and reference was made to God by many:

Samuel: *I mostly just pray to God and keep myself correct ... Well, God ... he tell me that, not going to hospital ... that it is a little too much for me, to go and come all the while for treatment ... so I'll just try and take the medicine, but I know I have to die some day, so no problem (TJ-1, int).*

Michael: *Yeah ... most time I really talk to God because in everything he helps me. I don't really understand people who don't believe in God because he's such a wonderful being that I could not live without him (SJ-1, int).*

These patients believed that God had helped them make the right decision and that he would care for and watch over them as they lived out the rest of their life.

Other nurses discussed similar experiences where Afro Caribbean patients had mentioned religion as central to their lives and the decision they had made regards treatment:

We always talk about the decision not to have dialysis and then you'll see them again and then they'll say, yeah because I'm not having it because ... and then they'll just drop in very quick, because of course God won't let them get to that stage of dying. God will help me to live. I'm like, what did you say? ... and that's definitely with Afro Caribbean, yeah (CNS, M1108, M).

The black Caribbean patients talk about religion a lot. Some mention it time and time again, how they go to church, how important praying is and how God has helped them decide what to do (CNS, G0507, int)

This over-representation of the Afro Caribbean population is an interesting finding in the present study and also warrants further research. As stated before, understanding how different cultural groups manage decisions regarding dialysis is important information for developing services. If religion plays a large part for some, then it will be important to take this into account and allow beliefs to be acknowledged and supported.

6.1.2 Gender

Another interesting finding in the study was the difference in the gender of patients accessing the service. Of the 30 patients recruited, 18 were women and 12 men. Although this difference is not hugely significant, it is of more interest when compared to the local dialysis population at the Trust where the study took place. Here the ratio is 63% male and 37% female. This trend is also seen nationally, where

patients presenting with stage 5 CKD are more likely to be male than female. In 2006 2,411 per million of the population (pmp) were male and 1,221 pmp were female (Ansell et al. 2007). Why more female than male patients were referred to the RSCS is not easily understood and analysis of data did not uncover any specific reason for this. It is not known if more women than men were persuaded by health professionals not to embark on dialysis as this study did not explore what happened prior to referral to the service. What is known, though, is that some men do make unhealthy choices with more men smoking and drinking alcohol than women (Help the Aged 2008). These choices may also reflect a way of life where risky behaviour, which may include accepting an arduous treatment such as dialysis, is practised. The women in the study may have made the decision not to dialyse based on quality-of-life factors and how these might be affected by dialysis. It is a possibility that men reaching stage 5 CKD do not take these factors into account and are more likely to opt for active treatment at any cost. It is also acknowledged that women live longer than men (Help the Aged 2008) so it may be that as the patients presenting to the RSCS were older, we should expect to see more women than men.

This is something that may be of interest to other professionals setting up similar renal services, as they may need to focus more of their care on women rather than men. As little is known about people making decisions to forgo active treatment across any of the diseases, this interesting finding warrants further research.

6.1.3 Age

Another interesting finding from the study relates to the age of the patients referred to the RSCS. The patients in the study were older than those commencing renal replacement treatment nationally and locally at the Trust where the study took place, with a median age of 77 years (see Table 6.1) versus 65 (Ansell et al. 2006) and 54 years respectively. The oldest patient was 91 and the youngest 65 years. Other nurses reported a similar finding in their population.

All our patients our older. We might have one or two in their late 60s but most are older (CNS, W1108, M).

Of all the patients I've seen, most are over 70, only a few are 60. I did see one in his 40s but that's really unusual (CNS, G0507, int.)

It could be suggested that patients were referred to the service on the basis of age, but the findings uncover other reasons, such as feeling too old to have dialysis and believing that the regular journey to hospital would be too burdensome. Many patients were frail, as is often seen in those with chronic disease and advanced age (Carpenter et al. 2000), and did not wish to undergo such a rigorous treatment as dialysis when in poor health and having lived a long life already.

Although the population was older, it did not appear that age was of central importance. Rather it was the health status of the patients that was significant, and this was generally poor due to other diseases whether it be renal disease or something else, such as chronic obstructive pulmonary disease or advanced diabetes. Many patients made it clear that they could not see any benefits in receiving a treatment such as dialysis

considering their present health status. Renal disease in this context appeared to be an illness of old age, something that evolved alongside other medical problems and it is this topic that is now discussed.

6.1.3.1 Renal failure as a disease of old age

The patients in the study had succumbed to renal disease later in life and this group did appear different from the general renal population managed on dialysis. They were older than the average patient found on dialysis, had multiple disorders and were generally sick and frail with previous ill health reported. An example of such a patient was John, who had already suffered from skin and prostate cancer and had advanced heart disease. He and his wife Mel talked about the significant effect dialysis would have had on his life and how they decided that this was not something that would be of benefit to him, particularly taking into account his age:

John: *Overall, there was the transport issue, three times a week and you have be on the thing (dialysis machine) for three or four hours ...and I think that it would wear your bloody life out ... I took the best of what there was on offer. Christ, I would have been going up and down that hospital, lying there with the stuff being pumped in me every day, and it is not pleasant, not, if you like, a pleasant way of life.*

Mel: *But somehow at the back of it, because of all the other things that he has had, the major operations that he has had through his life, and everything else, because I said, 'Could he have it at home?' and he said, 'No, because you have to have it in your tummy.' And they cannot do his, because he is scarred with all the operations... I began to get the feeling that it would be too much for him at this time of life (DB -2, int).*

John had been through much illness in his life and had developed renal failure in his 70s. The idea of an arduous treatment three times a week was not something that he felt worth contemplating.

Another patient, Alfred, described how he felt 'past his sell-by date' due to his advanced age and other illnesses including chronic obstructive pulmonary disease which impacted on his mobility and quality of life. He felt that dialysis at his age, taking into account his ill-health, would not be of benefit to him:

Well I'm 86 now going on 87, I'm past the sell-by date a long while and I cannot expect by having dialysis it would extend what life I'm going to have anyway. I don't think it will, but having listened to the fors and the against of it, I think there's more against at my age. The problems I have (other illnesses) make it against rather than for. Would that make sense? (FP-1, int)

He felt that his age and other illnesses made dialysis a poor option.

Other patients had a history of relatively good health that was suddenly interrupted by the detection of renal disease late in life. This is what happened to Marjorie:

Then what the doctor say to me, ... when I got sick, never had no sickness at all, I was quite healthy. I go to the doctor and I was, say 80 and the doctor couldn't believe it, he said I don't believe it. The doctor said I don't believe it, he said I don't believe that, he said I cannot believe it, your age. Suddenly I was quite jerky, and all of a sudden I just gone dead. He said I don't know how it (renal disease) does come on sudden, and I told him, you know I'm scared to even go to the street (TD-1, int).

Up until her diagnosis of renal disease Marjorie had been able to shop, cook and clean independently. Now she was unable to dress without assistance and she felt the suddenness of ill health hit her in older age. Although she suffered osteoarthritis that had deteriorated over the years she suspected that renal failure was causing the majority of her problems and preventing her from doing the things she was used to doing independently. Like many in the study, she felt she had lived a long life. Kidney disease had not become a problem until her eighth decade.

The patients recruited to the study were older than those commencing renal replacement treatment nationally and locally. Many patients had chronic disease associated with advanced age, and were frail. Many of these patients felt they couldn't or wouldn't tolerate dialysis at an advanced age appearing to understand the impact it might have on their quality of life.

6.1.4 Comorbidities

The number of comorbidities that patients in the study presented with was high. Only one patient, 91 year-old Mary, entered the RSCS with only renal disease and no other comorbidity although as her health deteriorated she developed other problems. All other individuals had one or more comorbidity. Other patients had one, two, three, four and five comorbidities respectively (see Table 6.1). Fifty per cent of patients had two or more comorbidities, often of longstanding, alongside their renal disease highlighting chronic health issues for many patients. The patients in the present study were characterised by the individuality of each one involved, renal disease being the one thing they had in common. It was often difficult to know what disease might be of gravest concern. Associated comorbidity meant that appropriate medical treatment of the patient was difficult to determine as symptoms could be caused by several comorbidities. I will now discuss this issue.

6.1.4.1 Comorbidity and the difficulties in deciding what to prioritise

Many patients presented having suffered a myriad of illnesses through their later lives and their present health needs were complicated by the fact that renal disease was often not the main problem causing concern. For example, John had been repeatedly diagnosed with skin cancer but when he first presented to the renal service it was his significant heart failure that was the principal worry. Alfred had poor respiratory function, which meant his breathing was laboured and he had difficulty walking any distance. He had also been diagnosed with cancer of his prostate and rectum previously and had been told that he had heart disease. Teresa had mental health problems, which affected her speech, diabetes, heart disease and severe osteoarthritis, which left her almost immobile, and Marcia had cancer of the bladder, osteoarthritis, colitis and latterly gallstone problems, which had led to several admissions to hospital.

Marcia's daughter reported deterioration in her mother's condition following a trip to Cyprus. She said her mother had *'got worse and really gone downhill. She cannot manage and is really weak'*. This led to an appointment with a renal consultant in the belief that her renal function was deteriorating. At consultation it became clear that this was not the case and it was her gallstones that were causing her to feel unwell. Increased analgesia was prescribed.

Of the 30 patients in the study, 22 (73%) had diabetes, often the cause of their renal disease. Diabetes is the most common cause of stage 5 CKD (Lok et al. 2004) and is well known to cause other health problems (Watkins 2003). Other common conditions that the patients presented with included heart disease, rheumatoid or osteoarthritis, cancer, cerebro-vascular accident, chronic obstructive pulmonary disease (COPD) and dementia (Table 6.1). Other problems included hepatitis B, colitis, amputation, hernia, haemorrhoids, boils, eczema, leg ulcers and schizophrenia. The combination of several diagnoses meant patients in the study were in overall poor health and their management required intense input, especially at times of deterioration and particularly in the last phase of life as death approached. When Mary was unwell it was unclear if her widespread oedema had been caused by her renal disease or possible cardiac problems. At her last interview her carer, Agnes, also noted peripheral neuropathy as a problem and a possible urinary infection:

She'd been very peculiar... and I thought it was maybe another water infection. She could feel herself filling up with water ... and she had already got very little feeling in one foot. Something or other neuropathy. When we went to the geriatrician, she diagnosed peripheral neuropathy ... She was kicking the bad leg into bed with the good leg and arriving in a heap at the wall. I think then, there was quite a lot of fluid round here because what she'd had been in quite neat, small fitting skirts and she was now in loose baggy trousers which she discarded altogether in the end ... so I think the fluid was gradually coming up ... And by the weekend, she was quite chesty and breathless (SF-4, int)

These patients had more comorbidity than many of those receiving dialysis. Often dialysis patients, especially those who are younger, do not develop associated comorbidity till later in their dialysis treatment over many years (Reiter and Chambers 2004). Older patients accepted for dialysis are often perceived as 'fitter' than their elderly counterparts, with less disabling comorbidity (Feest 2004). It is usually as the renal disease progresses that problems arise (Reiter and Chambers 2004). This might indicate that those who made the decision not to have dialysis did so because they were finding it difficult to cope with their associated illnesses. This has implications for those managing similar patients and may point to a specific type of renal patient who may wish to utilise the RSCS rather than embark on dialysis. These patients may not feel well enough to undergo dialysis.

6.2 Summary

This chapter has presented the patients being managed within a RSCS and has highlighted some interesting findings in terms of ethnicity, gender, age and comorbidities, all of which are worthy of further consideration. There was under-representation of the Muslim community and over-representation of Afro Caribbean patients compared to the local population receiving dialysis locally and nationally. This may have been influenced by culture and religion. More females than males presented, again conflicting with data from the Trust locally and nationally, where more males present with and receive dialysis treatment. Generally, patients were frail, in poor health and at an advanced age. The number of comorbidities that patients in the study presented with was high and often it was difficult to know what disease was of the most concern. This chapter provides details of the make up of the patients entering the RSCS and the reader is invited to judge similarities and differences with those patients they are managing.

It is recognised that findings related to ethnicity and religion will vary depending on the composition of the local population being cared for; for example, some staff working outside the Trust where the study took place had little experience of managing patients from the Muslim community. This aside, it is interesting to note that findings discussed in the next three chapters were, in the main, corroborated by others working with patients opting not to have dialysis, and therefore the differences in composition and make up may be of less importance.

CHAPTER 7

IDENTIFYING THE HEALTHCARE NEEDS OF PATIENTS MANAGED WITHOUT DIALYSIS

This chapter addresses the second aim of the study which was to identify the healthcare needs of a group of patients managed without dialysis. The chapter highlights a number of healthcare needs identified by the patients in the study. It begins by exploring the decision made by participants in the study prior to entering the RSCS. It goes on to examine the healthcare needs brought to my attention in terms of the considerable number of symptoms that patients presented with. An attempt is made to determine the cause of these symptoms, as not all symptoms related to the renal disease itself. The experience of suffering associated with these symptoms is illustrated. Questions around how successfully symptoms were treated are raised and reasons for successful treatment are interpreted.

The chapter concludes by exploring how patients and carers dealt with the uncertain prognosis associated with stage 5 CKD. It raises the difficulties they had as they lived their lives knowing that death would come at some point soon. Worries concerned with when deterioration might occur are raised for both patients and carers. The wish not to talk about or dwell on the inevitable death is explored and reasons for this presented. The emotional component that might be expected from a population who are dying seemed to be missing during the clinical consultations and this is discussed.

7.1 The patients' decision

This section addresses the participants' perceptions of the decision-making process and raises some interesting issues that should inform the development of any RSCS. Although this study only focused on patients entering a service after the decision was made not to dialyse, many referred back to this decision-making process usually at first interview.

The RSCS had carried out a retrospective audit of patients notes in November 2008 to explore the decision-making process. All 194 patients who had been managed in the service from January 2005 to June 2008 were included. Using the renal database where letters and clinical notes were held it was established that a variety of decisions had taken place. Forty-one patients had withdrawn from dialysis; two chose not to receive dialysis after their transplant failed; two changed their minds after deciding not to have dialysis and subsequently underwent this treatment; 48 made an independent decision either alone or with family not to embark on dialysis; 39 patients had the decision made for them by a doctor; 46 patients and/or carers made the decision with the doctor. In 10 patients it was not clear from the notes who had made the decision. In six cases the patient was not told about the decision. One of these patients had severe autism and another was confused. In the other four cases, family members asked that the truth be kept from the patient in order to maintain hope.

This audit, although helpful, was based on retrospective data. It highlighted how decision preferences were varied and that more insight was needed to develop our knowledge in this area. The present study offered the opportunity to explore in more depth with patients and carers the decision that had been made.

Within the study there was considerable variation in how patients viewed this decision. This is explored as:

- the informed and autonomous decision
- the less informed decision.

Each will now be discussed in turn.

7.1.1 The informed and autonomous decision

Seventeen of the patients, or their carers on their behalf, felt they had made a lucid and informed decision not to embark on dialysis. Some patients made it very clear that they had received and digested much of the information offered to help them in their decision-making and felt they had made an informed choice. The reasons for deciding not to undergo dialysis were varied and included:

- the arduous nature of dialysis
- the difficulties in getting to hospital three times a week
- previous experience of dialysis
- age.

7.1.1.1 The arduous nature of dialysis

Patients made reference to receiving an onerous treatment that might take its toll due to the nature of dialysis, which would involve several trips to the hospital every week and the need to be attached to a machine regularly. Mary explained how she felt dialysis would *'really be a big bother all around'* entailing *'constant hospital care'*. Many patients seemed aware that dialysis, even if it were to lengthen life, would prove a high price to pay especially if mobility were a problem or other ill health was already impacting on their life. Some patients asked about home dialysis but this was not possible due to frailty and the likelihood that they would require nursing and medical intervention and support if they were to receive dialysis. This was only possible at the hospital where staff would be available to manage acute events.

John and his wife talked about *'making the right decision'* and how the *'wear and tear'* of getting to the hospital would have worn him out. They explained that it had taken them some time to make the decision and discussed how the consultant had helped them in their decision-making which they believed had led to a positive outcome:

John: *But, you know, I found it very good... He [consultant] didn't tell me what to do, but I think that he led me in the right direction ... What he was saying was the fact that if I had the medication, if I was going to ... deteriorate, the deterioration wouldn't be great, a more even course, and with the other one, with the stuff, I could get an initial boost ... Then have a vroom*

Mel: *Yes, we took a long time making this decision ... And we discussed it, and in the end I said to him, 'Well, it's three days out of a week but if you are going to get four good days, is it going to be worth it?' So we discussed with the consultant, and he said, 'Well, that is the best scenario; it could mean that the other four days are in bed' (DB-2, int).*

Clearly, John could see little benefit to undertaking dialysis, particularly when it would involve attending hospital regularly and perhaps feeling very unwell between dialysis sessions.

7.1.1.2 The difficulties in getting to hospital

John decided that dialysis would not be in his best interest and made this decision with his wife. Like others in the study he alluded to the need to travel to the hospital three times a week for dialysis and how this was something that had influenced his final decision. Raymond took a similar stance:

Raymond: *I don't think that I could stand coming here [the hospital] three, four times a week, whatever it takes; transport and all that (RT-2, int).*

For some the difficulty in getting to hospital was one of the main reasons for not embarking on dialysis. Some patients were very immobile and found it tremendously difficult to leave the house. Once being cared for by the RSCS it was possible for home visits to be carried out. Many patients were very grateful for this as they found travelling to the hospital traumatic and often near impossible.

Josie was a lady who had suffered ill health over many years due to diabetes and osteoarthritis and found mobilising around her small flat very difficult. Her brother Simon came to see her every day and bought her shopping. She had help with cleaning and personal care. She had huge, ulcerated, weeping legs, which she found painful and were difficult to move. Her main enjoyment was her many cigarettes she smoked every day. She explained how frightened she was that she might fall over:

Josie: *I have just started deteriorating and, you know, walking is a real problem ... I've got an ulcerated leg, and my legs give way and I am so frightened that I am going to fall. Simon [her brother] was taking me to the eye hospital and I didn't have a rail, because they have put a rail on since then, and Simon was with me, and I get to the door, and down I went! Ten stitches I had (MP-1, int).*

She went on to discuss the conversation she had with a doctor regarding dialysis and again emphasised how the need to travel to hospital on a regular basis had influenced her decision not to embark on dialysis:

Josie: *Anyway, I have never met this doctor, he was releasing me, you know? And he said to me, 'You will have to go on dialysis', so I said, 'If it is going to make me feel any better.' But when he said it would be two hours every other day I said, 'What? How am I going to get here?' I said, 'Apart from anything else I cannot' I said 'My brother is seventy! I cannot ask him to bring me up here every day and then come and get me. I wouldn't... It's not fair' (MP-1, int)*

Quite clearly Josie felt that dialysis was not a treatment that she would wish to endure if it entailed hours on a machine at the hospital three times a week. Not only did she find it extremely difficult to leave her flat, she was dependant on her brother for daily chores and didn't wish to impose further on him.

Josie lived very locally to the hospital but others didn't and dialysis would have entailed a long journey through London three times a week, usually via hospital transport, which was renowned by patients to be unreliable and uncomfortable. The journey to the hospital was often lengthened by the need to pick up other patients along the way. Realistically, this didn't appeal to those whose ability to mobilise independently was severely restricted, especially if they suffered a degree of pain or other troublesome symptoms.

7.1.1.3 Previous experience of dialysis

Some patients made the decision not to have dialysis because they had seen other friends or family undergo dialysis and several had died. They were not influenced by the medical team and chose to make a decision based on their personal experiences. Unlike John, who took a long time to reach his final decision, others made a rapid choice and never looked back. They feared dialysis as something that would shorten their life and needed little counselling around the decision. Sara, on attending for her first clinic appointment, was fearful that she would be coerced into having dialysis. Juber was clear that dialysis was not something that he would contemplate as he had seen other people suffering on dialysis.

Juber: *I not do dialysis. Doctor, he said do you want to do dialysis but I have seen dialysis people ... Yes on dialysis, very painful. Blood in hand ... and four hours in the hospital, and then come back to home senseless ... Then back again, back, next day, again ... Forty people in one room having dialysis, hospital full. I see the dialysis people, very weak. Me strong, me strong ... I no want a dialysis. I no want my life like that ... No, dead better (AR-1, int).*

Sarah was another patient who felt that dialysis was not something that was in her best interests as she had seen a friend die whilst receiving dialysis:

Sarah: *You see, I have friends that go through with dialysis and I, one girl I asked her once, why are you having dialysis? She said to me, they said I must have it. I said, well that's you and that's not me. I was supposed to spend a Saturday evening with her, but a friend was admitted to the ... hospital, so I said I'll go to the hospital and I'll come by you Sunday, put everything in the fridge. Sunday morning she phoned me about half past six and said, do not come for the day again, I feel like going to church ... Sunday night, eight o'clock, the phone rang. When I answered it was her fiancé, he said to me 'you were supposed to come by Julia today'. I said 'she phoned me and tell me not to come because she feels like going to church'. He said 'well I'm phoning now to tell you that she died in the church'. She took ill in the church, not feeling well and when they phoned the London they said they have no beds, they phoned Middlesex, they have no beds, and in the meantime she started to cough blood and she died (TC-1, int).*

Sarah could see no benefit to be had from commencing a treatment, which had, in her eyes, led to her friend's death. To her a life without dialysis was preferable to one that involved dialysis treatments, and she was prepared to adhere to all her medications and follow instructions from her medical team in order to live for as long as possible but without dialysis intervention. Sarah had also mentioned age as a reason not to commence dialysis and age is now discussed.

7.1.1.4 Age as a reason not to commence dialysis

Some patients felt they were too old to embark on dialysis and saw it as something to be avoided at their time of life. Age was of importance to some and dialysis was seen as something that would impact on quality of life and was often viewed as something not to be considered, especially when other illnesses prevailed and life would be hindered by hospital visits and dependence on a machine. Sarah could see little benefit to dialysis when she was able to regularly visit Barbados and lived alone independently, as she had done all her life. Sarah, after explaining her story above and referring to her 80 years, including the seven years that she had successfully managed without dialysis, said:

Sarah: *'No Helen be truthful, at this stage what I want with dialysis? ... See the picture of what I'm saying, and judge by yourself, if you were in my position would you have had dialysis?'* (TC-1, int)

Ada's son explained how he thought that dialysis would have been a difficult treatment for his mother to endure at an advanced age:

Jack: *Dialysis is hard on the body, and for someone her age, I mean, my mother was eighty-four when she died, so you are talking about someone of eighty-two, at that time [of the decision], you know, whose heart is enlarged, who is diabetic, who suffers from high blood pressure. She didn't need all that at her age* (ES-2, int).

Older patients in the study often appeared to have an easier decision to make. A treatment such as dialysis was not viewed as something that would extend their life particularly if they had lived a long life already.

7.1.2 The less informed decision

Many patients in the study appeared to have a good understanding of the decision they had made but others were less clear. Thirteen patients in the study appeared to have made a decision which was less informed. Reasons given by this group for deciding not to undergo dialysis were varied and are discussed as:

- dialysis as death
- dialysis or the injection
- no decision to be made.

7.1.2.1 Dialysis as death

For some patients the decision regarding dialysis was complicated by the fact that it was unclear whether or not dialysis would extend their life or bring about their death. This dilemma was apparent in those patients who felt that they had no option but to refuse dialysis, often believing that the health professionals also felt this way and that there would be no benefit to be had from this treatment. Some patients who felt this way were angry and believed that they were somehow giving up on life. They were unhappy with their decision but could see no alternative. Alfred talked of several encounters with his

physician. At the first he felt that dialysis was being put forward as an option but that at next consultation this had changed:

Alfred: *At first the doctor said if it goes, get too bad I was expected to go on dialysis, would I be happy with that? I said I'm not happy with dialysis after what I've read about it but I'm accepting if it's going to give me relief and help ... Second time I saw him he said to me I'm afraid we cannot do nothing at all to help you, I said regards to what? He said dialysis (FP-1, int).*

Alfred felt that he had no alternative but to say no to dialysis, as he believed this treatment would cause his death. But he also saw this as refusing a treatment that in other cases would save lives and felt angry at being caught in such a dilemma.

Raymond was another gentleman ill at ease with his decision. He had previously been seen in the RSCS and explained that he hadn't made a decision not to have dialysis. Based on this, he was referred back to his renal consultant for further consultation. On seeing his consultant he said he was told he had six months to live and was asked to take some time outside of the clinic room to make a decision regarding treatment. It was explained that dialysis would not be in his best interest:

Raymond: *Where should I start? Went to the clinic and the doctor there who saw me said, 'I've got some bad news'. I said, 'what's that?' He said, 'I give you six months to live and I don't think dialysis will help you'. This was twelve months ago now, I said ... well that upset me didn't it? And do you want dialysis or to go on pills? So I said ... I'll go on the pills' What else could I do? (RT-1, int)*

Raymond saw little option but to refuse dialysis but it was not a decision he was comfortable with.

Unlike Raymond and Alfred, some patients who felt that they had no option but to refuse dialysis appeared happy with the advice they had been given. This included Daisy, who, along with her daughter Geraldine, explained how the discussion regarding dialysis had progressed at a clinic visit with the consultant:

Daisy: *He said that normally and possibly they could put a stent in the blood vessels to open them up so that the kidneys had a better blood supply. I remember him saying, but in your case it will just finish the kidneys off, and so that wasn't an option at all... All I remember him saying was that you could have dialysis and that would be, you know ... He did say, 'if you were my Mum, I wouldn't recommend it.'*

Geraldine: *Although he did offer it to you, he did say that if you were his Mum, he wouldn't recommend it because it is a harsh treatment, it is not a cure, it is a treatment. So that is really sort of all we know, isn't it, about your kidneys? That somewhere along the line they have been failing you (EH-1, int).*

Daisy and her daughter seemed to have accepted that dialysis wasn't really an option in Daisy's case based on the personal advice offered by the doctor and took this advice without question.

7.1.2.2 Dialysis or 'the injection'

The idea that having an injection and oral medication to treat stage 5 CKD would result in a similar outcome as embarking on dialysis was misunderstood by two patients. Although it is difficult to know

who might fare worse on dialysis, there is little evidence to suggest equivocally that dialysis is unsuitable for some people (Smith et al. 2003). During the study it became clear that, although only a small number, some patients had opted for supportive care without fully understanding the decision they had made. Both of these patients had cognitive problems. Veronica and Michael talked about the treatment they were receiving for their renal disease. Their explanations were vague and lacked clarity concerning how and why the decision had been made. When asked about dialysis, Veronica referred to this as treatment using medication:

Veronica: *And he [the doctor] said, well, I'll get some of the treatment for my kidneys, so from that, I've been getting treatment for it right up to now ... The treatment is for the kidney. I told you I suffer with kidney trouble. How I know, I'm tired, very, very tired, and when I went to him, he told me I can survive with my kidney, and I've been getting tablets for it... My old husband can tell you more, I only take them ... Dialysis? That mean is it, the tablet, them I had to take twenty days? I think he said something about that (TA-1, int)*

It took Michael some time to remember why he had been referred to the RSCS. When he remembered he said: *'I am sick with my kidney'*. When asked about what he knew about his kidney disease and what the doctor had explained to him he remembered little. He also alluded to treatment in the form of medication:

Michael: *I don't remember what he did say ... I remember that he says the kidney getting smaller. I remember that. That's the only thing I remember. If he was to look after it, it, what did he say about that part? I don't quite remember what he did say. Yeah. It's like he was going to send somebody come to inject and give me tablets for it (SJ-1, int).*

What some patients did and didn't understand was often unclear but for these two patients dialysis was not something that they appeared to understand believing that any problems with their kidneys could be treated with medications.

7.2.1.3 No decision to be made

Several patients presented to the service stating that they had not made a decision regarding dialysis as there had been no decision to make. This included patients or carers who felt that the decision had been taken out of their hands as dialysis would have led to death. The reason for this was complex and often confounded by the fact that the patient was very unwell. Diane explained how she had first been diagnosed with lung cancer and then told that she also had problems with her kidneys and how dialysis would not be appropriate for her due to her extensive comorbidities:

Diane: *Well, they couldn't put me on dialysis, because of my other illnesses.. Diabetes, blood pressure, and me heart misses a beat I think... or something like that. And, what was the others? I have got so many blooming things (RR-1, int).*

Diane was also an epileptic and was taking morphine to help with breathing problems caused by her lung cancer. Like Josie above, Diane had huge, weeping legs, which were dressed on a regular basis by the district nurses. She also needed help with her personal care. Diane seemed to accept without question that dialysis was not an appropriate treatment for her and didn't encourage further discussion on the issue. Her daughter Annie was also present when I spoke to Diane. She appeared to agree with the decision that had been made, seeing such an aggressive treatment as something futile, unable to improve her mother's

quality of life and was much more concerned with practicalities. One such practicality was getting her mother to hospital every two weeks to have a blood test to check her warfarin level, necessary for those requiring anticoagulation therapy to treat heart problems, and whether or not this was necessary considering how traumatic the journey to the hospital was and how long Diane had to wait for transport. Like Josie, travelling to hospital was something to be avoided rather than embraced due to ill health, frailty and the frustration caused by the upheaval that ensued getting onto and off hospital transport.

Other patients or carers felt a decision was made that they were unhappy about and asked why dialysis couldn't be initiated. Some felt strongly that the option of dialysis should have been pursued and one patient did travel to Bangladesh for treatment. Another patient, Meena, was not able to have dialysis but her son Amur was unhappy with this.

***Amur:** Because what happened, she would like to do dialysis but what the doctor, hospital doctor told her, it's not safe for her to do dialysis, I don't know why, but they told her and, because she was scared for dialysis because they told her she's going to die with the dialysis and like, she cannot, she doesn't want to die like that because nobody wants to die. If she do dialysis, chance to be die. So she didn't have dialysis, otherwise she would do dialysis (NB-1, int).*

Others accepted that the doctor '*must know best*'. Asked about the decision Carmel's daughter Jane said:

***Jane:** Well we didn't make it, that's what he said, she couldn't have it. Basically, she could not be put on dialysis because of her heart. So I thought, you must know best (BO&D-1, int).*

Her mother was a very large woman who had advanced heart failure and found walking indoors difficult. There seemed no question that the doctor knew what would be best for Carmel and no mention was made of dialysis following the initial reference to it above. It just wasn't something to be contemplated, as advised by the doctor.

As can be seen, decision-making in this population was not straightforward and was often highlighted as a healthcare need requiring management and support. A second healthcare need identified was related to symptoms and how these could be managed. This is now discussed.

7.2 The symptoms

A high symptom prevalence was found in the patients in the study. This part of the chapter describes, in the words of the patients the symptoms experienced and the effects of these symptoms on the patients' and, in some instances, the carers', lives. Thirty different symptoms were reported at first consultation and included: altered taste, breathlessness, pruritus, lack of energy, dizziness, pins and needles in legs, nausea, vomiting, diarrhoea, constipation, poor appetite, poor balance, trembling, pain, immobility, insomnia, depression, poor memory, sore mouth/tongue, confusion, aching body, cramps, poor vision, weight loss, weakness, incontinence, phantom pain, difficulty swallowing, dry skin and headaches (see Table 7.1).

Table 7.1 Symptoms experienced by patients in the study

	Name	Breathlessness	Oedema	Pruritus	Nausea & vomiting	Tiredness, lethargy & insomnia	Pain	Immobility	Depression	Bowel and bladder problems	Other
1	John	X	X	X	X	X	X	X		X	Altered taste
2	Cliff	X	X	X	X	X	X	X	X	X	Dizziness, pins and needles, falls
3	Veronica		X	X		X					
4	Mary	X	X	X	X	X	X	X		X	Trembly, poor balance
5	Arnold	X	X	X	X	X	X	X	X	X	Poor memory
6	Raymond	X	X	X	X	X	X	X	X	X	
7	Sara	X	X	X	X	X	X	X			
8	Abdul	X	X	X	X	X	X	X	X	X	
9	Alfred	X	X	X	X	X	X		X		Dizziness
10	Sana		X				X	X	X	X	
11	Antoinette	X	X	X	X	X	X	X		X	Poor memory
12	Michael		X				X			X	
13	Ada	X	X	X	X	X	X	X			
14	Donald	X	X	X	X	X		X	X	X	
15	Teresa	X	X	X	X	X				X	
16	Sarah		X				X				
17	Samuel	X	X	X	X	X	X	X	X	X	
18	Marjorie	X	X		X	X	X	X			
19	Paul		X	X	X	X	X		X		Falls
20	Trudy						X	X	X		
21	Juber	X	X	X	X	X	X	X			

	Name	Breathlessness	Oedema	Pruritus	Nausea & vomiting	Tiredness, lethargy & insomnia	Pain	Immobility	Depression	Bowel and bladder problems	Other
22	Meena		X	X	X	X	X				Dizziness
23	Carmel	X	X		X	X	X	X	X	X	
24	Akbar				X	X	X	X		X	
25	Gillian	X	X	X	X	X	X	X	X		
26	Marcia	X	X		X	X	X			X	
27	Josie	X	X	X	X	X	X	X		X	
28	Sandra		X			X	X				
29	Diane	X	X	X	X	X	X	X		X	
30	Daisy	X	X	X	X	X	X	X			Falls

Other CNSs had noticed a high symptom burden in patients:

Depression, yeah. More than anything else, depression. I've seen hallucinations as well. Also I will be having a conversation and a patient will be so tired they fall asleep in the middle of it. I've seen breathlessness ... I've seen decreased appetite, sleep, most of them want to sleep all the time, very tired, nausea as well, unable to take their tablets many saying they get stuck (CNS, T0109, int).

For example, a lady with diabetes, has nausea and vomiting, gets very dehydrated. I see a lot of pain and there is depression. There are so many symptoms actually (CNS, W0907, M).

He had very severe nausea and vomiting and gastric stases related to his diabetes, then he had constipation and, I mean he had so many symptom issues. He slept poorly largely due to his pain, his sleep was particularly interrupted by a stabbing pain in his left foot. I'm just thinking of how many different symptoms he had. And then of course there's the psychological issues and the social issues (CNS, M0907, M).

I see so many symptoms. Pain, nausea, itching, sadness, not able to get about, difficulty sleeping. Some patients have lots and others have less but as they get sicker more symptoms do develop. Oh and tiredness and feeling very sleepy, that's a symptom and vagueness (CNS, G0507, int).

The more common symptoms that patients presented with will be discussed and the difficulties and successes in identifying and treating symptoms explored. Within the renal service, expertise could be offered in dealing with some of the symptoms that patients presented with, often the ones that were usually related to renal disease including breathlessness, pruritus, nausea and vomiting, lethargy and insomnia (Chambers et al. 2004). In order to treat other symptoms such as pain (including chest pain), and depression, liaison with other professionals, for example from the palliative and cardiac fields, was often required to ensure that all symptoms were identified and managed appropriately. Unfortunately, complexity arose when some illnesses caused similar symptoms, complicating diagnosis and treatment. For example heart disease and renal disease can both cause breathlessness and chest pain can be attributed to a cardiac event or anaemia caused by renal failure.

Symptoms often attributed to renal disease are discussed but, as will be seen, many of the symptoms of renal disease can be attributed to other comorbidity and illnesses.

7.2.1 Breathlessness

Breathlessness was a symptom suffered by 21 patients in the study at some point in their trajectory to death. Sometimes it was due to fluid overload caused by renal disease and/or associated anaemia, primarily due to a decrease in the production of erythropoietin by the kidney as the renal disease progressed. Occasionally, other diseases caused this problem.

Arnold suffered from COPD and had been breathless for some time. He explained how a favourite pastime - that of gardening - had been affected by his breathing and inability to carry out previous tasks:

Arnold: *Usually I say, 'Well, cut the grass and leave it at that.' The rest of the garden can go to wrack and ruin and I cannot do anything about that. I get out of breath so easily, and even walking thirty yards is too much for me. I can do it a bit with a stick! But, if I haven't got a stick (AS-1, int).*

His mobility had been affected and walking up stairs had become very difficult

'Oh yes... I can go up and down stairs that way, but it is just that up the stairs when you get to the top and you have got three stairs to go around the corner, that's when it knocks me out'
(AS-1, int).

John's quality of life was also affected by his breathlessness, although it was thought that this was due to his heart failure, as he wasn't showing deterioration in his renal function. He felt unable to take holidays, as he had to use oxygen at night and thought the equipment that he used too unwieldy and difficult to transport. He slept upright every night with four pillows and fell asleep listening to the radio. Field notes following a clinic consultation¹³ described this:

He [John] gets laboured breathing if he goes too far... He is still playing bowls but the people who he plays bowls with usually collect the bowls for him. John said he got tired and sleepy quite a bit and needed his oxygen. He usually goes to bed at 02.00 and he is lucky if he sleeps till 07.00. He tries to fall asleep with a radio on. He is frightened to stop the oxygen even though it is noisy and still takes the sleeping tablet at night (DB, 010706, FN¹⁴).

John's breathlessness improved for several months but following a chest infection deteriorated to the point where he was using continuous oxygen at home and was unable to leave the house. His-cardiac related breathlessness meant that he was referred to the community palliative care team for input. They were more experienced in dealing with this type of breathlessness in those with end-stage heart failure.

Several patients were frightened by their breathlessness and this caused them anxiety and led to problems sleeping. Some were given sleeping tablets with reported good effect, although Arnold did suffer drowsiness and had to stop his night sedation.

Five of the 17 patients who died became breathless towards the end of life. This was usually as a result of an inability to remove excess fluid as it accumulated due to the failed kidneys although, as mentioned, John's severe breathlessness was due to his heart failure. Once patients reached the point where a maximum dose of oral furosemide (a diuretic to remove fluid from tissues) was reached, the only option for further removal of fluid was admission to hospital for intravenous diuretics. At this juncture it became clear that the difficulty removing fluid meant that the kidneys had deteriorated to such a point that the end of life was now coming closer. This proved a marker for planning increased intervention in an attempt to allow patients to die in a place of their choice and step up symptom management. It included discharge from hospital as soon as possible if a patient wanted to die at home or in a hospice and referral to community palliative care if this had not happened already.

As presented, breathlessness was sometimes due to fluid retention. This led to oedema, another symptom now discussed.

¹³ This one patient interview was not tape recorded as I did not have the tape recorder available at that time. Instead, I wrote up notes immediately after the interview and these were analysed in the same way as the other patient and carer interviews.

¹⁴ Field note

7.2.2 Oedema

Oedema, or swelling due to the accumulation of excess lymph fluid was a problem for all except one patient in the study at some point in their illness trajectory. Oedema was an expected problem as the kidney is responsible for the removal of excess water. Many patients presented with foot or leg oedema, which was initially treated successfully with small doses of diuretics (usually 40mg furosemide), which could be increased if the oedema did not resolve or returned (up to a maximum dose of 250mg). Michael described how the diuretics he was prescribed initially helped with the swelling but how the swelling then returned and more tablets had to be taken:

Michael: *Sometimes I just feel like I'm all better, I feel better, I thought I was going to get better. That time my leg started swelling up again and that made me worried but I take the medicine and I feel better, honest to God, but then again, some days passed ... my ankle start to swell again. I now take another tablet (TJ –1, int).*

As mentioned above, once oedema became difficult to treat with oral diuretics the only option was admission to hospital for intravenous diuretics if this was felt appropriate. Associated breathlessness as the fluid accumulated was often also noted. Mary, prior to her last admission to hospital had considerable problems with fluid overload and oedema, which affected her ability to remain at home and be cared for. Agnes, her carer, described her last days:

Agnes: *And then she [Mary] had a fall in the bathroom and we picked her up and it was kind of downhill from there. And the main problem was the fluid on the legs, which made her more and more immobile ... so I think the fluid was gradually coming up ... And by the weekend [she died] she was quite chesty and breathless (SF – 5, int).*

Mary reached a point where her oedema was so advanced that she was admitted into hospital. Intravenous diuretics were commenced with little effect and she soon died. Fluid had built up gradually over a period of weeks following her recent discharge from hospital and her oral medication had done little to remove the excess fluid.

Oedema was problematic for many patients and added to their symptom burden. Sometimes it occurred early after referral into the RSCS but became more problematic as the renal disease progressed. It was difficult to manage if the end of life was approaching.

7.2.3 Pruritus

Another symptom that patients presented with was pruritus, or itching. This was usually caused by the kidney disease and was problematic for 21 patients at some point in their illness trajectory. A specific aetiology of uraemic pruritus has not been identified although elevated serum phosphate, raised parathyroid hormone levels and increased calcium phosphate deposition in the skin, dry skin and iron deficiency are all thought to contribute to it (Levy 2004). In the study, pruritus was often persistent and something that some patients lived with.

Mary: *Oh, the itch never leaves me really. I have this itchy skin that I have treatment for (SF–1, int).*

Sara's carer: *She is itching, very, very, all the time. Since she is itching and two days before we go the pharmacy I ask them any cream or any medicine, they give an aqueous cream – it doesn't work (DJ-1, int).*

Other patients suffered ill-effects from the pruritus:

Raymond: *But then I had an itch like you do, and scratched it just like that, without any notice, and I noticed that I had made it bleed. It then wasn't bleeding but a great big ulcer came up, a great big thing it was. It burst and it's in a right state now, I just hope that it doesn't get any worse (RT-1, int).*

Raymond ended up with an ulcer that required regular dressing by a district nurse and this became another nuisance that he had to contend with alongside other troublesome symptoms.

Pruritus was often difficult to treat and the community palliative care team was asked to intervene and prescribe a topical medication that had proved successful in other populations in treating itch. Occasionally some relief would be achieved but for others pruritus was a continual annoyance and medications made little difference. Raymond attended the Day Hospice where support was available for patients coming to terms with the physical and psychological challenges of terminal illness. He gained relief from the massage that he received there which seemed to alleviate his itching for a short period. Although not offered specifically to treat pruritus the massage of his skin seemed to offer a short-term reprieve, the massage perhaps distracting him from the itch.

Itch was observed by other nurses who found this a distressing symptom:

I see a lot of itch and it is awful for the patient. You try different things with the phosphate binders but it doesn't always work. It's really hard for the patient and they can be very distressed (CNS, G0507, int)

Itch was a predictable symptom as it is very common in renal disease. Managing it in the population in the study was difficult and other professionals were called upon to assist. A symptom which was more easily treated was nausea and vomiting and this is now discussed.

7.2.4 Nausea and vomiting

Nausea and vomiting, expected symptoms, were suffered by 27 patients at some point in their illness trajectory and were often caused by uraemia and the build up of toxins (Germain and McCarthy 2004). Whatever the initial cause, antiemetics were prescribed and seemed to help. Occasionally nausea and vomiting were short-lived and well managed with 'as required' medication.

Mary: *I still have the symptoms that I always have had with this [the kidney disease], but I have the cure for each of the ones, you know ... The thing for sickness and this that and the other. I don't get sick as much as I used to. I have got these tablets now, which just stop it straight away ... I only ever take one if I am feeling queasy and that would be not as often as once a week and so that is pretty good (SF-1, int).*

As with Mary, the nausea caused by uraemia could often be successfully treated but patients presented with nausea and vomiting related to other problems. At one consultation John clearly had a chest infection, causing him nausea and Raymond had constipation, which he attributed to his feelings of

nausea. Often it was difficult to decide if the nausea was attributed to the uraemia or another problem, although an antiemetic was usually offered in either case. In Alfred's case an antiemetic didn't work. He complained about sputum at the back of his throat that collected due to his respiratory problems:

Alfred: *It makes you feel so, so sick. You see you cannot clear it. I wash, wipe it and clear it and oh lovely, get it nice and smooth and within an hour or two it's back. I cannot bear it, it's horrid... if somebody's clever enough to get my saliva back working I'd appreciate that, because this dryness in my throat is terrible (FP-1, int).*

This symptom was particularly difficult to manage and several different treatments were prescribed in consultation with the community palliative care team, including mouth sprays and lozenges but with little effect.

Interestingly, alongside nausea and vomiting, patients didn't complain of loss of weight, as experienced by patients with advanced cancer (Poole and Froggatt 2002). They didn't suffer severe, sudden weight loss and cachexia. Some patients did report decreased intake of food but seemed to be able to consume enough calories for dramatic weight loss to be avoided. This finding added to the difficulty in identifying when a patient was approaching death as many patients looked acceptably well throughout their illness with little change in their outward appearance. This was clearly put by Daisy's daughter Geraldine and captured in field notes:

Geraldine: *Mum looks well. She has been well since she was told about the renal disease 18 months ago. I know her kidneys are getting worse but she is great at the moment. She has just had a great big dinner with us. She's OK (EH, 030208, FN)*

Patients seemed to only radically reduce their dietary intake at the end-stage of life when death was closing in and when their bodies had slowed to such a point that many remained in bed for most of the day.

7.2.5 Lethargy and insomnia

Feeling tired with concurrent lethargy was common, with 26 patients finding this debilitating and adding to the feeling that life was not as it previously had been, where daily chores, tasks or social needs had been attended to with ease. Fatigue could be due to a number of reasons, including the inability to sleep well at night, depression, anaemia, poor nutrition, medication and possibly uraemia. Determining its cause was difficult. Simple things like cooking and shopping, previously taken for granted were now unable to be managed and there was a reliance on others for help. Some patients had family members who helped with their care, others paid for private help and some received help from social services. Samuel complained of feeling '*Tired, tired, tired*'. Gillian attributed her tiredness to her heart failure:

Gillian: *The heart, the heart If I walk from here, I cannot do it, I am tired out. If I try to put my food in my mouth then I am tired. I cannot do anything anymore (JP-1, int).*

And Marjorie contributed it to her pain:

Marjorie: *You know when I go in the kitchen and cook I was in pain that time when I was sitting down, ... I go in the kitchen, if I got to start cooking and by halfway I got to sit down, because I tired. Like I tired. You know, like the back and thing hurt, but it goes and come. It don't seem so severe but some of the time it really hurts me and I am exhausted and I cannot do the cooking. The pain makes me so tired (TD-2, int).*

Conversely, some lethargic patients complained of insomnia and had great problems either getting off to sleep or remaining asleep through the night. The night was sometimes the time that most thinking took place causing anxiety and further distress. Samuel explained how he couldn't sleep at night:

Samuel: *I go to bed , hard night, I cannot sleep, hard night. I try to, I just cannot sleep, no sleep come to me, I just lie down there listen to the wireless or whatever but sleep never come (TJ-3, int).*

Arnold said:

Arnold: *Oh yes... The only trouble is that I go to bed at eleven o'clock at night, and I wake up at twenty past twelve (FP-2, int).*

Although there didn't always seem to be a reason for insomnia, often patients said they were worried about life and their illnesses and this added to them being unable to sleep well.

Other nurses working with similar patients found intense lethargy or fatigue towards the end of life one of the most distressing symptoms. They often felt there was little that could be done to help as patients complained about the intense exhaustion that they felt which made dying tortuous:

I can remember one lady dying and I went to see her at home, I went to see her quite a few times in that intensive period. She had taken to her chair, then her bed ... she had lots of lethargy and weakness. I remember going to see her in that last two weeks of dying and she said 'If I'd have known, if anyone had told me about this long drawn out death. I thought dying was going to be relatively easy'. And it was long and it was drawn out and I didn't know what to do or say. She was literally in her bed for I think three weeks taking that lethargy day by day (CNS, M0907, M).

I had a very similar lady with a GFR of around two. The key thing is this huge amount of lethargy, so much so, that it is crippling, and they will say to you... 'I am exhausted... I cannot...' They literally cannot move from their beds... I can think of a few patients who I can think of who said: 'Gosh, if I had known it was going to be like this, dying like this...' . It's so hard (CNS, M0208, M).

Lethargy, especially that associated with the approaching end of life, was distressing for patients and staff alike. Early in the illness, fatigue due to the renal disease itself was treated successfully with erythropoietin and this is now discussed.

7.2.5.1 Success in treating lethargy/fatigue caused by anaemia with erythropoietin

Often the initial exhaustion that was present in those with stage 5 CKD and associated low haemoglobin was resolved by introducing the drug erythropoietin, in injection form on a twice weekly or weekly basis. Erythropoietin, normally produced by the kidney and the hormone that regulates red blood cell

production, has been used successfully in renal patients undergoing dialysis and those with less severe renal disease who may warrant dialysis in the future (Germain and McCarthy 2004). The same effect of increasing the haemoglobin and feeling of well-being was seen in the patients in the study and the severe lethargy often described prior to erythropoietin administration lifted. Thelma explained how her mother Marcia rallied after her erythropoietin commenced:

Thelma: *Before, she looked really frail. Every time I went round she's really tired looking, didn't have any energy, couldn't be bothered to do anything. Then she started the injection and it changed ... She used to fall asleep a lot didn't you? During the day she'd have like some naps ... She didn't do any ironing, you know, hoovering looked like it could be done but after about a month or so, she perked right up. More like her old self (MOC-2, int).*

John: *The thing is that I don't know what it is. You do a great job ... and somewhere between you, with the EPO [erythropoietin] and the combination of the tablets that I am taking, they seem to be working ... I can now lay down for the first time in weeks (DB-1, int)*

Thelma explained that her mother had improved once she started her erythropoietin and although the tiredness didn't completely resolve as she still 'hoovered and did her ironing sitting down' it was now considered much less of a problem

7.2.6 Pain

Different types of pain were widely reported by 27 patients and included pain due to arthritis, a fractured hip, leg ulcers and cancer. No patient had pain due to renal disease specifically. Marjorie spoke about the severe arthritic pain she suffered at the base of her back:

Marjorie: *I just don't know what is happening to my body. Otherwise I'm all right, it's only just that pain, and I'm scared to go in the street or anything with just that pain in the back. Even now I'm sitting down it's started hurting me, normally I sit down it doesn't trouble me at all, but now when I sit down sometimes it's still right there in the middle of the backbone. Right there in the backbone towards my bottom there's pain, pain ... I've got a pain inside of the flesh, like inside of the bone, I don't know. The backbone. Like you put your hand on the back, put your hand on the back, its agony (TC-1, int)*

A multitude of conditions could cause pain. Sara had severe pain due to problematic mouth ulcers. Her carer explained how debilitating the pain was and how the treatment offered did little to ease the problem:

Sara's carer: *Last month, two months we see a tongue with pimples, pimples that have broken, bleeding coming. And now two or three days she cannot eat and there is a pain in here. She is complaining of bad pain in here. Last week I take her to her family doctor. He give me one tablet and one mouthwash liquor, but when she takes that tablet she is moaning, she is moaning with the pain of it and bleeding (DJ-1, int).*

Sara's mouth ulcers were complicated by the fact that not only were they painful, they were also very difficult to treat. Often health professionals, particularly the renal staff, were unsure how to treat very severe pain. They had little experience in pain management. The community palliative care team often led on managing severe pain, but in some instances treatments had limited results or unpleasant side-effects that meant they had to be discontinued. Alfred was given Oramorph, an opioid analgesic, by the community palliative care team and this successfully treated his severe shoulder pain but caused extreme drowsiness and had to be reduced to such an extent that his pain was poorly controlled. Morphine is

renally excreted and accumulates in patients with stage 5 CKD, which may explain the occurrence of such an adverse effect (Dean 2004). Another example included Carmel who took too much of the morphine prescribed for her arthritic pain and became 'sick, vomiting, vomiting, vomiting, vomit oh ages' according to her daughter and required a drug to reverse the accidental overdose which had occurred.

Other patients, such as Diane, had pain due to an unknown cause and had to undergo tests in order to determine a diagnosis that would explain the pain:

Diane: *I just went up for a test because at the time, I was getting awful bad pain, underneath my rib, just under here, and that's when they kept me in that night, because they wanted to find out what was causing it, and they went through all these different things, like x-rays and what have you and they took me down and give me a thing down the throat, a camera down the throat, and he told me it was lung cancer (RR-1, int)*

Once a cancer diagnosis was made, her pain relief was increased by the community palliative care team and her pain successfully controlled.

Pain was problematic for many patients in the study but as now discussed, several patients refused to take analgesia to treat pain, preferring instead to do without this medication.

7.2.6.1 Refusing to take analgesia to treat pain

Pain was often reported as severe, requiring regular analgesics, but interestingly several patients chose not to take all painkillers as prescribed as they felt they were taking too many tablets already and they might cause further harm to their already damaged kidneys. There appeared to be a lack of trust in the professionals prescribing the analgesics and a misunderstanding concerning the value of treating pain effectively especially as these patients were coming to the end of life. Meena's son, Amur, explained how his mother didn't trust her doctors so often refused her painkillers to treat her painful arthritis:

Amur: *Yes but she don't trust normal pain killers. She don't believe she needs them and she thinks the painkillers might have damaged the kidneys ... The GP explained that, but she don't believe him, she don't believe any people, even GP, she is saying, 'Because they lost my kidney' (NB-1, int).*

Meena had previously been prescribed an analgesic to treat her arthritic pain, which had caused some damage to her kidneys. Now she was prescribed an alternative medication but did not seem to understand, want to believe or perhaps trust the renal team or her GP that this medication would not cause further harm to her kidney.

Marjorie, although suffering 'pain inside of the flesh' and obviously having problems mobilising around her living area, also didn't like to take analgesia to achieve relief:

Marjorie: *I don't take painkillers, I don't take my painkiller. I've got it but I never take it. I'm taking seven tablets already so I never really take no painkiller. I have painkiller here but I don't never take it, it's too much (TD-1, int).*

Marjorie, like many patients in the study, was prescribed a large number of tablets to be taken on a regular basis that were necessary to treat her various diseases, discussed later in this chapter. Analgesia was a medication that was often prescribed on an 'as required' basis only and these extra tablets were viewed with caution. Patients were prudent in their ingestion of any pain relief, even paracetamol, which they were assured would not have any side-effects or cause further damage to their kidneys, preferring instead to endure their pain. These views were often firmly held and advice regarding analgesia offered by the RSCS and the GP was often ignored.

7.2.7 Immobility

Immobility and problems with walking, standing and the ability to be active and self-caring were problems for 20 patients in the study. Patients complained of '*feeling trembly*' in their legs, having a fear of falling (and many did suffer falls, as discussed below), painful knee and hip joints that made walking difficult and general dizziness and poor vision that could hamper the ability to be independently mobile. Often it was difficult to determine why patients were immobile and the cause put down to old age or other diseases that might limit the ability to mobilise freely. Some patients, such as Raymond, were confined to a wheelchair, making it difficult to live alone, encouraging loneliness and feelings of frustration. On talking to Raymond about visiting the local hospice in order for him to meet other people socially, Raymond wanted to go but the thought of attending in his wheelchair made the suggestion untenable:

Raymond: *It's just the thought. I cannot. Well, while I am in this wheelchair, I cannot push myself along. It's awkward; you have to get someone to keep pushing me about* (RT-1, int)

At Raymond's next consultation he was feeling low but explained how much he enjoyed attending the hospice. He discussed how it had been the right decision for him despite his immobility, which continued to cause him aggravation and frustration.

Often there was an expectation that patients might be prone to falling due to their general frailty and mobility problems followed by a search for how this situation could best be managed. A fall could lead to further deterioration in health and possible admission to hospital. When Josie fell she '*had to go to hospital for 10 stitches*' and now would not leave the house on her own. Paul fell four times before he accepted a call alarm, which he wore around his neck in case of further falls. Other patients, such as Juber, suffered several falls due to a specific illness, such as diabetes or low blood pressure, prior to being diagnosed with renal disease. Towards the end of life a fall often intimated that the patient was deteriorating.

Agnes: *And then she [Mary] had a fall in the bathroom and we picked her up and it was kind of downhill from there*' (SF-5, int).

Several weeks after her fall, Mary had died.

The immobility problems suffered by the patients in the study were not usually directly caused by their renal disease but attributed to old age and chronic disease. Some patients, such as Teresa, were so immobile that coming to hospital for a clinic appointment was something too difficult to anticipate and she required a home visit. Her confinement to a wheelchair, large body size, mental health problems and

very small living space meant that leaving the house to attend hospital was a feat too difficult to contemplate. For others, the long journey to hospital could not be tolerated and impacted severely on their already limited quality of life. Juber explained how weak he felt and how he found it very difficult to leave the house:

Juber: *Yes everything, now me very weak. No strong me eh? I cannot go to walk. I cannot walk. Slowly, slowly does it, this room and that room, then walk. And my wife help me every time you know. I am so weak and tired. I am slow to go and it's too hard. Leaving the house is terrible. Me weak and feel bad* (AR-1, int).

Immobility and an inability to carry out activities previously managed was problematic for many patients. It led to fear that a fall might occur if they attempted too much and prevented some patients from doing what they used this. This sometimes led to feelings of depression, and this topic and is now discussed.

7.2.8 Depression

Depression was reported by 11 patients in the study. Later in this chapter it is highlighted how patients rarely indicated any emotional needs at consultation, which was unusual in a population that is coming to the end of their lives. Although this could be attributed to a lack of experience on my behalf, at encouraging patients to discuss their emotional concerns, I was able to determine successfully that many were depressed. All patients were specifically asked 'Are you depressed?' Previous research (Chochinov et al. 1997) has shown that such a question can elicit a correct diagnosis. This negates the need for long questionnaires in a palliative care population that is often frail and unwell and where screening tools used should be brief (Lloyd-Williams et al. 2003).

Often the depression was attributed to an inability to do the things that patients had previously been able to do with ease, such as gardening, shopping and driving but others were depressed due to the decision not to have dialysis. Alfred initially felt 'right down' when he was told that he wouldn't be a suitable candidate for dialysis and Abdul, although he refused dialysis as he didn't want to attend hospital three times a week for treatment, became depressed after overhearing a doctor say 'the possibility is that he will die'. Arnold's wife didn't understand the severity of her husband's renal disease, but she noted a change in him the day he returned from a renal clinic appointment where it had been decided that he wouldn't have dialysis saying, 'Well he wasn't the same man'.

General ill health and immobility attributed to feelings of depression but usually patients refused antidepressants or counselling sessions from the renal counsellor. Raymond went to see the counsellor once but said he found it unhelpful although he did not elucidate why. Sometimes patients refused to see the counsellor, as it would mean further trips to the hospital when getting to the hospital took immense effort. They often felt that their problems could not be resolved and that health professionals could not help their situation, preferring to try to manage things themselves.

Samuel talked about being depressed due to time thinking about things that had happened in his life:

Samuel: *Yeah always depressed. Yeah, I married twice ... Had two ladies. The first one said well she wasn't satisfied with me so she went away ... Yeah and the next one now me live with*

her for 20 odd years and it was a council house and after she pay for the house then she turned me away (TJ-3, int).

Later in the interview Samuel's niece asked him about his depression and how she could help as the RSCS had done in the past, but he was clear that this was something he had to deal with alone, believing his situation could not be helped:

Sonia: *You haven't mentioned it to me, not that it's a problem but is it that you're worried about something?*

Samuel: *Well worried about a lot of things but because I don't talk, but I worried about a lot of things I never, I just keep to myself because you cannot help me. Yes, you cannot help me with this (TJ-3, int).*

Samuel, like others, felt that no one, including family or health professionals, could help with his low mood and feelings of helplessness, and declined any help offered. He also refused to attend a Day Centre or the Day Hospice, preferring not to mix with others he did not know.

Trudy cried for her loss of independence following a stroke and explained how she wished she had refused a necessary amputation of her leg so that her life would now be over. Even the thought of staying alive for her children couldn't help Trudy as she struggled to cope with the emotional impact of her illnesses:

Trudy: *Then I started on the strokes. ...I had another one, and so it went on. I had a trip booked to go to Barbados. I couldn't go, I had to cancel. I wanted to go but the kids were scared.*

[Trudy starts crying]

Trudy: *I cannot get my head around it. Being like this ... I mean I cannot even wash myself. I don't like being dependent on other people, I hate it. The stroke, it started in 2001. I thought I was getting better, next thing I had another one ... They even called the kids in to say goodbye ... and I had a diabetic ulcer and they had to amputate the leg, but I wish I had kept it, I would probably be resting in my grave by now. That would be better than being in here lying on a bed...Yeah, peace. I mean the illness people say you know the kids, at least I see the kids, but I don't like my children see me like this (VG-1, int).*

Not only did Trudy feel depressed about her poor health, she was also dependent on others for her hygiene needs and was unable to walk. Although her son visited regularly she didn't like her family to see her in such a dependant state and she felt her life had little value. Although she suffered little physical pain, her spiritual pain was evident and her helplessness and anguish clear as she spoke. Like others in the study, this was something that had to be endured and was now part of the life that was being lived.

Other nurses said they had seen depression displayed in many patients:

Depression, yeah. More than anything else, depression (CNS, G0108, int).

Yeah, it's low mood and depression. I think it's there in the background most of the time isn't it? ... I think it comes hand in hand with other symptoms. I think because of lethargy and weakness and feeling pains. And loss of former self (CNS, W0208, M).

Depression was a symptom often seen but one that was difficult to manage. Patients often refused medical intervention or psychological support often preferring to deal with this problem alone.

7.2.9 Bowel and bladder problems

Difficulties related to incontinence, altered bowel habits and urinary problems were alluded to by 16 patients in the study. Medications such as phosphate binders or opioids to treat pain could cause constipation. Other patients were incontinent of urine but the reason for this was not clear and was put down to advanced age, alongside other illnesses including renal failure. Faecal incontinence was blamed on 'an upset stomach' and often carers had to deal with episodes of incontinence. Janet, daughter of Donald said:

Janet: *Well he wasn't going to the toilet properly, he was wetting the bed a lot and everything and so. Then after that he did have an episode of diarrhoea and we would help him and then it would happen again (RT-1, int)*

Noreen described her mother Teresa's incontinence and the difficulties managing this at home in the community:

Noreen: *But when she's asleep the majority of the day, she's asleep apart from when she's got to get up to go to the toilet, by which time she's realised she wants to go to the toilet it's too late anyway, she's already wet herself. I buy them, because the lady at the hospital said, I buy her the TENA Ladies ... I'm sure, the district nurse said, I'm sure I've got something, I'll send to you that you can go and get them. But I never heard anything, I just buy them (MC-1, int)*

Noreen had problems obtaining the incontinence pads that might help her manage her mother's incontinence at home so continued to manage the situation as best she could using the Tena Lady pads suggested by a nurse at the hospital. For others, the situation would escalate and admission to a hospital or hospice took place. Abdul suffered profuse diarrhoea in the last weeks of life and his family felt no option but to have him admitted to the local hospice when he was later found wandering outside the front door. They felt that his distress at his incontinence contributed to him leaving the house:

Salma: *We sent him to the hospice in the end because he was having these episodes of diarrhoea and stuff and it got really bad at one point we were at home and it was 11.30, 12.30. Then it was 12.30 and we got a knock at the door and we wasn't expecting anyone like midnight, past midnight, and then my sister looked through the spy hole and it was Dad*

Fatima: *I think he did that because he was doing diarrhoea in his bed, on the floor, everywhere and he just didn't want to put all the pressure on us so he thought he'd go outside. And yeah it was a lot of stress on my mum as well but we only wanted him to stay in the hospice so that the diarrhoea could get settled and sorted out and then we wanted to bring him home. So the diarrhoea carried on for about a week there, because he ended up staying for two weeks, didn't he? (AM-2, int)*

Incontinence was a regular occurrence for many patients and difficult for carers to manage. Others, although not incontinent, suffered bowel and bladder problems brought on by the specific illnesses that they suffered. Marcia's colitis caused regular bouts of diarrhoea and Akbar required admission to hospital for constipation, one of the symptoms related to his growing abdominal cancer:

Akbar: *And when I felt like ill and I had got this thing, the doctor took an x ray. He said your food is stuck here; constipation and all that, and they got me an enema, in the belly that did relieve but didn't cure anything ... After that, when I went to hospital this time I fell over here, and they found this thing and they did what you call a... ultrasound ... Next week the results will be there; what is wrong with it? (RS-1, int).*

Akbar was told that he had inoperable liver cancer and he died soon after - the constipation a probable symptom of his terminal disease.

Bowel and bladder problems often related to incontinence were troublesome for many patients in the study and often difficult to manage due to difficulties in determining the cause of the symptom. Some symptoms were more successfully treated using a large number of medications and this is now discussed.

7.2.10 Treating symptoms successfully but with a large number of medications

Patients in the study had to take large numbers of medications but it became clear that some problems, once identified could be treated successfully especially if it was a symptom caused specifically by the renal disease. For example Samuel was treated with diuretics to treat his oedematous ankles, which appeared as his renal function decreased. He was pleased with the effect and explained how well the tablets had worked:

Samuel: *The swelling that come down much ... The tablets there, those white tablets ... I don't know what that is called but they make me feel better (TJ-5, int).*

John also reported an improvement in his condition since being prescribed a number of different medications:

John: *The thing is that I don't know what it is ... Somewhere between you, to me ... whether it is the EPO, or the actual combination of the tablets that I am taking, they seem to be working, and I can now lay down for the last three weeks, which I haven't done for a very long time (DB-2, int).*

Like John, Mary also reported an improvement in symptoms with the medication prescribed, and explained how symptoms were often alleviated and the need to take the tablet regularly reduced:

Mary: *It's very, very good, as fast as I've said I feel sick or I feel this I've got the antidote. Particularly I used to get a lot of sickness and then those tablets that you gave me, they are absolutely marvellous, they stop it invariably. And I don't need many of them, I never had needed many of them, but they've just, they've been very good, very good (SF-1, int).*

Although it was found that many symptoms could be treated successfully, as mentioned, patients often ended up having to take many medications to treat specific problems. The numbers of medications taken by patients in the study varied from eight to 22 varieties. Many patients had to take more than one of some of the medications prescribed, which led to some patients taking well over 30 tablets a day. One patient took 43 individual medications daily. One CNS, having had a similar experience, alluded to this as 'polypharmacy personified'. Some symptoms required more than one medication, such as uncontrolled hypertension, where one antihypertensive medication had not been sufficient to reduce blood pressure, or

extreme pain, where more than one analgesic was required to ensure adequate pain relief. Cliff explained how many tablets he took and how he arranged his morning around administering them:

Cliff: *Then I take the injection, then I write in the book, then I have one tablet. A bit later I ... take half of my tablets then, and then I come and make breakfast, then I take the other four tablets. I take twelve tablets every morning ... I take about 21 tablets a day (JG-1, int).*

Cliff was able to administer his many tablets himself but others had help. Some patients took their tablets begrudgingly, irritated by the number that were necessary to manage their symptoms. Jack said that his mother complained on a daily basis about the number of tablets she had to take:

Jack: *Well, no, no, I don't think she was interested in any tablets, I think that as far as she was concerned she was taking too many tablets. I think, for my mum, she felt that she was taking enough medication already. I think for her, I mean the amount of medication, that got on her nerves every day ... and there was always the subject every, almost every day, the amount of tablets that she was taking (ES-2, int).*

Interestingly, the number of tablets taken by the patients was noted by the transcriber of the interviews. She described how the tablets could be heard rattling during the interview as patients attempted to answer questions regarding the different types that they had been prescribed:

Transcriber: *Oh and you know, the rattling of the tablets Helen, and things like how many tablets are you taking? And just kind of the lists of tablets. It's so awful (DP-1, int).*

Clearly, medications and the number that had to be taken were problematic for many patients and carers alike, sometimes causing disharmony and frustration. Even though the medications often improved symptoms, there appeared to be a reluctance to take them and they perhaps reminded patients of their ill health and reliance on pills to manage their terminal renal disease.

The number of symptoms reported by patients in the study was high. Patients suffered a myriad of physical and often psychological issues requiring management. Frequently it was difficult to offer appropriate care, especially if a patient did not wish to accept what was on offer, for example analgesia to treat pain or antidepressants for depression. When dealing with some symptoms, such as pruritus, other professionals were called upon to help to offer additional expertise and knowledge.

Alongside these troublesome symptoms, patients lived knowing that they suffered 'kidney problems' and they had an uncertain prognosis. This had an impact on how they lived their lives and how their carers managed in supporting them. This is now discussed.

7.3 The uncertain prognosis

End-stage renal disease is a life-limiting disease that reduces a person's length of life. Although most of the patients in the study understood this, there was still a life to be lived and decisions to be made around how best to do this knowing the time to death was not clear. Several patients asked to travel back to their

native country, knowing that this might be their last trip home. Others planned with their families to go to the theatre or to spend more time with them as the disease progressed. For these patients, this meant that they could do the things they enjoyed while they were still well enough to do them. Patients and carers had to manage a situation where death was approaching but when this event would take place was unknown. Decisions had to be made about how to live with this situation and how best to manage what was left of a potentially shortened life. It included:

- preparing for uncertain death
- not talking about death.

Each is now discussed in turn.

7.3.1 Preparing for uncertain death

Patients in the study had to prepare for death knowing that renal disease would shorten their life. This uncertainty is highlighted as:

- wondering when death would come
- worrying about deterioration.

7.3.1.1 Wondering when death would come

On being told that they had renal disease, and having made the decision not to embark on dialysis, patients remained unclear about how long they had to live. Some patients made important decisions when they were given their diagnosis. Raymond had been told he had six months to live so went home and put his will in order and disposed of much of his furniture and clothes. Seventeen months later he had outlived his prognosis and had to think about buying new furniture. He had also made plans with his brother who was to come and help him with the garden when he retired:

Raymond: *What's the date then, 8th June, it'll be 18 months in July, and of course when I went home I had to arrange my will and everything, just sorted all that out ... I stopped buying things because I knew I won't be able to use them but I'm gradually getting back into buying things, the things I need ... I'm living in the front room downstairs and it's getting all cluttered up, so I bought about six drawer cabinets and put all the briefs in it ... Also the garden's going through a bit of a ruin and I've lost my gardener but my brother retires in six months and he said when he's got the time off he's going to come over a couple of days a week and sort the garden out (RT – 1, int).*

Not only did Raymond need to think about how best to manage his life now he had outlived his prognosis, he was looking forward to the future when his brother retired and would come to visit him more often and help with the gardening.

This difficulty in determining when a patient would die meant that life was precarious and uncertain, but there was a need to carry on living in some shape or form and with this came the need to decide how to live and what to do on a daily basis. This was often problematic for carers, who worried that a patient might die at any time. They found the uncertainty around prognosis difficult and worried that the patient might deteriorate at any time. This meant that regular checking on patients to ensure that they were still alive took place.

Rosalin: *I do look in the room sometimes and think, oh God is she breathing? Think oh God, what would I do? I suppose you just deal with it but I'm just thinking what would I do, what if she died and there she was when I looked in, all dead (AB-1, int).*

Harry: *I bring him a cup of tea every morning. That's my time to check he made it through the night. Some mornings my heart gives a lurch cos I think he is dead. He looks dead (DS-2, int)*

The uncertain prognosis led to difficulties for carers who were often managing sick and dependent patients at home. Carers asked how long a patient might live but it was difficult to predict. This uncertainty led to concern about whether or not they could manage the situation indefinitely and how their lives were on hold whilst the patient continued to live. For some carers, this situation became problematic and for one couple, the son and daughter-in-law of Paul, it caused problems in their relationship. They had little time together as Paul was dependent and wanted his son close to him. They were frightened to leave him alone and became increasingly desperate as he continued to live. His daughter in law Rosie described how the uncertain prognosis meant that there was an expectation that things wouldn't improve for some time, putting a strain on their own relationship:

Rosie: *It is not good. I am looking ahead here; I am looking well ahead, because this could go on for months and months and months. I don't really want to be in a position where we never get an evening in a month where we can talk to each other freely. It's not going to work that way, it is not going to help, or not happen smoothly. We will just ignore each other because that is what we do. Silence. We don't scream at each other at all, we just go quiet and I cannot bear the torment of it all (DS-3, int).*

Two other patients in the study were admitted to nursing homes when their daughters, having cared for them over many months, felt unable to manage any longer. This was heightened by the fact that it was unclear how long their parent had to live even though they had a terminal disease. This was usually a very difficult decision for family members to make, but was something that they often felt couldn't be avoided. It did not usually happen until the patient was heavily dependent. Carmel's daughter called the RSCS one day to say her mother was sitting on the commode and had been there for three hours. She felt helpless and wasn't sure what to do. This event precipitated a decision to transfer her mother to a nursing home where it was felt she would receive the care she now required until death.

In the main it was carers who expressed concern with regards to when a patient might die. Deterioration in the patient's health was also a worry and this is now discussed.

7.3.1.2 Worrying about deterioration

As previously discussed, many patients, once they had made the decision not to embark on dialysis, remained relatively stable. They were able to live as well as they had done prior to the diagnosis of stage 5 CKD and little changed. Some symptoms even improved as their renal failure was managed conservatively with medications. But for carers in particular there was always the worry that this would not last and things could change at any given time.

Noreen: *Before things like a cold or sniff would happen to Mum, I wouldn't take any notice of them, I'd think, oh just a little sniff. But since he, the Professor told me about it [the renal failure] it's like every little thing she gets now I'm in a sweat. So I don't know if he's made my life easier. I think he's made it harder in a way, because I'm always, the phone has to be switched on, has to be left on, just in case somebody finds her and she's dead. That's what goes through my mind. And I ring her about twice, three times a day (NC-2, int).*

Geraldine: *If she comes to our house and says she feels unwell, I immediately panic and think this is it. The renal disease is getting worse. I worry all the time (EH, 050608, FN).*

Some symptoms, such as itching, were expected symptoms of the renal disease for many patients, who had been told that it might occur at some point. This meant that itching for other reasons was occasionally attributed to deterioration in renal function. John developed an itchy head due to old cancer scars but thought that it meant that he had a renal symptom, which might indicate deterioration in renal function. His itch was resolved when he used olive oil to massage the dry, irritating area. This was similar to Teresa's daughter who thought that the severe itching that her mother complained of meant that her condition had worsened. This caused worry and concern:

Noreen: *Cos when she said to me the other day, I said how did you get that cut then? How did you cut yourself in that position? [Behind the knee] You know, cos it's such a place that. So she says, it was itching, all my legs are itching me, everywhere is itching, so that's one of the symptoms and I'm worried things are worse (NC-2, int).*

Teresa's itching was in fact due to extremely dry skin on her very oedematous legs.

Worry about deterioration was a concern for many in the study, especially for those who knew what symptoms might occur as a result of the renal disease. Although these worries were expressed, many patients chose not to talk about the impending end of life and this interesting finding is now examined.

7.3.2 Not talking about death

The majority of patients knew that not embarking on dialysis meant they could expect a shortened life but few openly discussed this, sometimes avoiding the topic or choosing not to ask any questions related directly to their illness and progress. Several possible reasons for this emerged and these are discussed as:

- death too difficult to discuss

- the severing of hope if death was discussed
- not wanting to dwell on the inevitable.

7.3.2.1 Death too difficult to discuss

The topic of death was often too difficult to discuss with others. Arnold, the only patient who cried during a consultation, chose not to discuss his prognosis with his wife and family as he did not want to upset them. He also mentioned that he found the subject 'morbid':

Arnold: *I think what it is, is that we don't talk about what's going to happen to me, or what is going to happen to her, or what might happen to her and might happen to me... Well, it is going to happen to me, I know it is, but we don't know when and we haven't got a clue and we never talk about it ...I don't know why. Is it because it might be a morbid subject? I was just thinking the first time the doctor told me that I had only got one kidney...and it is wearing out and I immediately jumped in my head... you are going to die! (AS-1, int).*

[Arnold starts crying]

In some circumstances carers described how hard they found it to discuss the end of life with the patient especially if they were a son or daughter. Paul's son Harry talked about 'burying his head in the sand' and 'pushing aside' any thoughts of a discussion on death even if it meant that more services could then be made available once his father accepted that he had a life-limiting illness and required palliative care. Similarly, Antoinette's daughter said: 'We never talk about dying, we never ever talk about it'. She found it difficult to explain why this was, feeling the topic was something that she could not raise:

Rosalin: *I just don't know how to bring up the subject with my Mum. You know you're dying, I know we're all dying but as I said to you I've never really brought it up, said 'oh you know you're going to die Mum'. I just cannot (AB-1, int).*

John rarely talked to his healthcare team or his family about the end of life. He had organised his will and explained to his wife how his estate should be shared, but little reference was made to his terminal disease. Even when his renal function started to deteriorate he refused to be drawn into conversations about death. When told 'things weren't too good' he responded with, 'Not too good. I don't like to hear those words, "not too good"', and continued to pronounce that he was generally well and coping when clearly he wasn't. His wife had explained that his breathing rendered him unable to leave the house as he struggled for breath on a regular basis but he refused to allow the community palliative care team to come to visit. Eventually, after several days of deterioration, he allowed his wife to call out the GP, although he was very reluctant for this to happen and warned her it would mean he would be brought into hospital. He was duly admitted to his local district general hospital. Whilst here a decision was made by John's wife and the medical team to document that he was not to be resuscitated. His wife explained how difficult she found it to have a conversation about death with her husband:

Mel: *The doctor talked about the resus thing so that won't happen. We didn't say anything to him, he's been asleep and they didn't say to say anything ... They have though been talking about hospice [CRIES]. I have to decide what to do with him. I think he will want to come home.*

I don't know, I don't know anything [CRIES]. I'm so sorry. I must stop. I cannot do this when I go in to see him.

Helen: *What will you say to him?*

Mel: *I don't know*

Helen: *Have you talked about dying?*

Mel: *No*

Helen: *Do you think John knows?*

Mel: *I don't know*

Helen: *Why do you find it so hard to talk to him about dying?*

Mel: *I don't know. It's so upsetting [CRIES] (DB, 040608, FN).*

Clearly, John and his wife found the topic of death one too difficult to discuss as John's health deteriorated. His wife was unable to explain why and even though it was known that John was dying and that he would benefit from palliative care input, his wife didn't seem sure whether he knew he was dying or not. This was a difficult situation for John and his wife and also for the healthcare team who had to manage a patient who appeared not to want to discuss the inevitable. For others, death was talked about but not in any great depth. Abdul's daughter described how her father made mention of a future without him:

Salma: *Yeah, a bit ... He wouldn't talk to us properly, he would talk about it a little but it was like he was talking to himself but he was not talking to himself he was talking to us so that we would listen. It's not like something where we would ask questions he was just talking generally. One thing I remember is he goes, 'Don't fight amongst you', because we're always screaming and shouting at each other and that's one thing he said, he goes, make sure you don't fight'. That was the day before he died. What he said once was, this person is standing in front of me ... He was talking about the angel of death but it was difficult to understand what he meant ... So he knew he wasn't going to be around for that long. But yeah he talked about that just at the end (AM-2, int).*

Other nurses had similar experiences and had noticed some patients and families refusing to accept help even when death was approaching.

Anyway, I rang the wife and I said, 'The GP has asked whether or not you would like your husband referred to the hospice, how do you feel about it? Are you managing at home? Is there anything more that you need? Is he well?' She said, 'Oh, he is quite well at the moment', and la, la, la, and we had this chat, and then two weeks later, he has died! You sort of think, I suppose that I should have just referred him anyway, but then they weren't ready for that at that point. She said we are getting to grips with the renal failure thing, and the other problems that he has got and we don't want intervention from the hospice yet (CNS, W0907, M).

It is very hard, because you have to allow people to be in denial as well, don't you, if that's their wish (CNS, G0607, int).

This patient was very unreceptive. It's as if they don't want to talk about it at all. They block it out or just don't go there (CNS, G0108, int)

Oh, well he just, he didn't like to talk about palliative care, it goes back to that stigma attached. He didn't view himself as dying, he viewed himself as choosing his treatment to live, like he knew it was going to be a reduced length of life, but a better quality of life. But ... you couldn't really

discuss, I mean he really linked palliative care with end-of-life care, and he didn't really want to face that, so hospice as well, stigma attached to hospice for him. I'm not dying, no I don't need that (CNS, M0108, M).

I talked about dying and where she would like to be. She was getting sicker. She said to me, 'oh, I don't really want to talk about it' and I said to her husband what about you? ... And he said to me 'well it's up to her what she wants'. So it's as if they had this invisible wall was put up as soon as I mentioned it (CNS, T0109, int)

They just don't want to go there ... one woman says it very well. She says, well, if I start to have to think about it I'd have to start to worry about it and I don't want to. So, you know she just doesn't want to unpack it really. And I think that's fair comment (Dr¹⁵, 0108, M)

Other patients were more receptive when it came to discussing the end of life. Often this was because they had been prepared to discuss what might happen early on in their illness or they appeared to have less problems engaging in these conversations:

Some people are more willing to discuss it, like the patient I saw today. I said to her you will need more help as time goes by because you'll become more unwell and I said to her have you made any decisions as to what you, where you'd like to be when you die? And she said to me well, I don't mind where I am as long as I'm comfortable, yeah. So she was more receptive towards it (CNS, T0109, int).

I call it a one-off doom and gloom discussion and they quite like that and I don't force them to have it, because if they said, oh no, no I don't want to hear, of course I wouldn't. But I actually say we're going to, talk about some difficult things and it's very well received, and later on you reap the benefits and they reap the benefits because you've had those discussions ... very frank discussions ... I always say to them 'Do you want to talk about things very frankly? How much do you want? Are you the sort of person that likes to know everything about your illness? Do you like to be active in choices or do you prefer other people to make the choices? ... Usually they say that they do and then sometimes they say, actually I don't want, yeah, I've had a couple that have said no I don't want to talk about dying (CNS, G08, M).

This one was very receptive and I've done the referral to the palliative care team in the community (CNS, T0109, int).

Clearly some patients were happy to engage in end of life discussions and appeared practical in discussing the future, whereas others were more reluctant. There may be many reasons for this and the topic warrants further exploration. For those health professionals caring for this group where prognosis is difficult to predict and the terminal nature of renal failure remains relatively unknown to the public, awareness of how patients manage this situation is essential. The wish to talk about and plan for death is very individual and may not always be what the patient desires.

For other patients in the study there was the issue of hope and how this could be severed if talk of death and dying was embraced.

7.3.2.2 The severing of hope if death was discussed

During the study, the children of Muslim patients talked openly of not wanting to discuss death and dying in an attempt to remain optimistic. Meena, a Muslim lady, although aware that she had stage 5 CKD, did not believe that she was soon to die and hoped to live 'maybe 10 or 20 years' according to her son Amur.

¹⁵ Doctor

Amur did not want her to be told anything different and made it clear that everyone had to die sometime and that discussions about death would not be helpful:

Amur: *I cannot talk to her about dying ... not me, I don't think so ... I would say that it is the worse thing that you can tell someone that you are going to die. I don't believe that thing. I believe that I am going to die, but I don't think we need to tell her, she needs to have hope about life (NB-1, int).*

Like Meena's family, Abdul's daughters didn't want their father to lose hope by discussing death and he rarely alluded to it. His daughter said he eventually talked in 'cryptic', about his impending death, but as a family they avoided the topic in order to sustain hope:

Salma: *Yeah, while he was in the hospice, he did talk about death but not everybody understood he was talking about death and religiously we believe that the angel of death does come and when the person is dying or when their soul's going to be taken they can actually see the angel of death because that's when it becomes visible to them. And my dad was speaking and he did say, 'there's this person he is waiting to take me, he's waiting there'. Because sometimes when he talks he, it's cryptic but you just have to clock on. But we didn't talk about death most of the time. We sort of pretended things were OK to give him some hope (AM-2, int).*

Some patients maintained hope by not asking any questions at consultation, including the results of blood tests. Blood tests were important markers for determining the progress of renal disease but before they were mentioned some patients would report 'I feel fine' even though they had some symptoms and were having problems at home. They appeared to believe that if they reported feeling 'fine', bad news might be held at bay. Sarah, a nurse, had a medical background and understood how important her blood test results were. When she reported symptoms of tiredness, weakness and itching, she put it down to 'flu' and a washing detergent she was allergic to. During the consultation she reported 'I feel fine' on five occasions but she was clearly not as well as previously.

Other patients, when asked how they were at consultation, elaborated little, saying they felt 'well'. Further probing might provide detail on specific troublesome symptoms but an emotional component to consultations was rare. Patients didn't appear to be in denial *per se* but seemed to be managing their lives without the need to discuss their feelings, knowing that the end of life would eventually come. Often humour was part of the consultation, as patients avoided talking about the possibility of deterioration and ultimately death. Veronica often joked about her husband and she denied any symptoms of her renal disease.

Helen: *And how have you been?*

Veronica: *Fine.*

Helen: *No pains?*

[Veronica laughs]

Helen: *What? Ah... you are going to say your husband, aren't you?*

[Laughter] (TA-2, int)

Veronica avoided a discussion about deterioration in her health preferring to focus on what was going well. At an early consultation she laughed as she said '*I hope to be here for Christmas*'. She had few symptoms and appeared calm and rational seeing little to be gained in trying to decipher how her kidney problems might impact on the rest of her life. At every interview Veronica avoided elaborating on her health choosing instead to answer questions briefly and to explain how she was adhering to the advice given to her about medications.

Hope appeared important for many patients and carers in the study and clearly health practitioners need to be aware of this. Although there is a balance to be drawn between optimism and reality, some patients didn't wish to dwell on the inevitable taking into account their age and ill health and seemed to accept pragmatically that life was coming to an end. This is now discussed.

7.3.2.3 Not wanting to dwell on the inevitable

For some patients there seemed an acceptance that life was coming to an end whether or not they had a diagnosis of renal disease due to their advanced age. For them there didn't appear to be a need to dwell on the renal diagnosis, but rather to live life as best they could in the time they had left. They talked little about impending death. In the study the renal disease often had little impact on patients' quality of life, especially when first diagnosed, and for those with less problematic comorbidities, there was little to remind them that they were living with a life-limiting condition. For some, luck was on their side in that they had reached old age before succumbing to serious ill health:

Daisy: *No, no, because 84? Gordon Bennett, I'm the lucky one, I'm very lucky at the moment I think ... I think, aren't I lucky? See I've had 84 good years, and they have been good years, and so that's why I'll say to my lot, I just think I'm very, very lucky. I have had pneumonia and pleurisy four times, got through it each time. I don't dwell on the kidney thing (EH-2, int).*

Ada's son Jack: *We didn't really talk, no. I think that it was something that she wanted to steer clear of. She knew the position, but I think that it was something that she put to the back of her mind all of the time. She just kept on saying, 'I am so sick, I am so sick.' But she just put it to the back of her mind. We knew the position, but really till the end I think that she wasn't going to ... Talk about it? No, she wasn't going to talk*

Helen: *And, towards the end, did you know that she was dying?*

Jack: *Oh yes, oh yes, oh yes (DJ-2, int).*

The fact that patients did not want to dwell on or talk about the fact that death was coming close was reflected in some of the experiences of their carers. Daisy's daughter didn't attend one of her consultations as she thought that her mother might talk more freely if she wasn't there and '*Maybe open up with any questions that she has*'. At her assessment Daisy talked about where she would like to die, as she had with her daughter, but did not bring up any new topics. Not only was she happy not discussing in detail death and dying with her nursing staff but she also avoided this with her family or perhaps did not see this as a useful way to manage her reduced life expectancy.

Other nurses noted similar experiences:

I think often they say I'm happy to let nature take its course. That's an older person sort of thing. Yes, I've had a good innings and I'd like nature to take its course. Thanks very much for talking but no thanks (CNS, W0708, M).

One patient said I'm too old for all this. I don't need to talk about all this ... I just live and hope and life goes on (CNS, T0109, int).

7.4 Summary

As this chapter has demonstrated, patients living life having made a decision not to embark on dialysis have multifaceted needs. It has drawn attention to the specific healthcare requirements of those managed within a renal service developed to meet these needs, as expressed by patients and carers. It has taken into account the experiences of other staff managing similar groups of patients as they reflected on findings from the study. Many of these findings have resonated with them and this adds strength to the validity of what was found.

The decision not to have dialysis is complex and, although many patients in this study appeared to have made an informed choice it has been argued that others appeared less clear about the decision-making process and what had been agreed in terms of how their kidney failure would be treated. Some reported little involvement in determining the usefulness of dialysis to treat their stage 5 CKD. Decision-making in this population has not been studied in any depth before apart from one paper that has arisen from the present study (Noble et al. 2009). As the incorporation of non-dialysis care into counselling for patients with terminal renal disease creates additional challenges for practitioners, there is a need to understand how and why decisions are made. These findings are therefore of great relevance and offer practitioners an insight into decision-making in this population.

Within this chapter the most common symptoms that patients in the study presented with have been described. It makes it clear that the cause of a specific symptom was not always easy to identify, especially when patients presented with several comorbidities. When it was apparent that a symptom was due to a renal-specific problem, management of that problem was often successful; but other symptoms not caused by the renal failure were better managed by other professionals, such as those expert in the care of patients living with cancer or heart disease. Some symptoms, such as oedema, when it became difficult to treat, indicated that the end of life was approaching. The experience of living with symptoms that arose in the population studied has been described, and how some patients had symptoms treated successfully with medication if they took it regularly. These are novel data - very little is known about symptoms in this patient group.

This chapter has presented original data concerning the patient and carer experience of managing life following a decision not to embark on dialysis. It has demonstrated how patients and carers had to prepare for a death that sometimes didn't arrive as expected and also live with the worry that deterioration could occur at any time. For some patients, their actual survival was considerably longer than the medical prognosis given. This prognostic uncertainty also had an impact on carers, who had to manage an

uncertain situation not knowing when the death of their loved one might come. This sometimes had repercussions for their own relationships.

While patients and carers lived with the knowledge that the end of life was approaching, there appeared a reluctance to discuss this in any detail. As presented, the participants found this subject difficult, sometimes fearing that hope would be lost if conversation was focused here. There appeared a desire not to dwell on something that was inevitable and therefore discussion was often avoided. For others a more open approach seemed to suit, and some patients felt able to discuss the end of life more openly. As a population where an emotional component might be expected, this was missing from those who participated in this study.

The next chapter is concerned with the trajectory to death taken by the patients in the study who subsequently died. It uncovers further complexity relating to how and why those patients who died study reached the end of their lives.

CHAPTER 8

IDENTIFYING THE TRAJECTORY TO DEATH IN PATIENTS MANAGED WITHOUT DIALYSIS

Having reflected on the healthcare needs of the patients in the study, this chapter moves on to offer an analysis of the trajectory to death in those patients who subsequently died. It addresses the third aim of the study, which was to describe the trajectory towards death (or not) of patients managed in the RSCS. While the study was taking place, 17 patients died. The average length of life from first referral into the service until death was 15 months (range 1-35 months). Each patient was referred with an eGFR below 15 or stage 5 CKD.

This chapter puts forward the possibility that there are three trajectories to death. Although the expectation was that death would occur from renal failure following a gradual decline in functional status, this was not always the case and patients did not follow a 'typical' dying trajectory. Three groups of patients were identified and are discussed: those who died a typical uraemic death, those who followed a more traditional organ failure death and those where death was caused by something else but the cause unclear. Although further research is required to explore these novel findings, an audit carried out prior to the study goes some way to corroborate what was found. The audit investigated the cause of death of patients managed within the RSCS during 2007. It concluded that of the 51 patients who had died after making a decision not to embark on dialysis, 20 had died a uraemic death, eight had succumbed to cancer, one to a cerebrovascular accident, one to a perforation of the colon, and 21 had died where the cause of death was unclear. Alongside this, the findings from the study were fed back to other staff managing patients without dialysis and they concurred with what was found having seen patients follow similar trajectories in their clinical practice. Their experiences are reflected upon in the chapter.

In order to present the various deaths encountered, 'rich descriptive' narratives are used to illustrate the characteristics of each type of death and the difficulties that often arose in supporting and managing these terminally ill patients. Interviews with patients, carers and staff, along with field notes captured in my diary inform the narratives. The value of these 'rich descriptive' narratives in developing theory cannot be under estimated (Geertz, 1973), as discussed in Section 5.6.2.

8.1 A predictable renal uraemic death

At the outset of the study it was expected that most patients would die a uraemic death caused by a build up of toxins in their bodies due to terminal renal failure. This was not the case for many, but some patients did follow a uraemic pattern, which has been described in the literature and is seen when dialysis treatment is withdrawn (Cohen et al. 1995; Cohen et al. 1996; Cohen et al. 2000a; Cohen et al. 2002; Chater et al. 2006). A typical uraemic death seen in those who withdraw from dialysis usually occurs within 10-14 days of stopping dialysis. Symptoms relating to the accumulation of toxins and fluid can be anticipated and managed and include nausea and vomiting, agitation, pruritus and oedema. Pharmacological treatment of uraemic symptoms, as well as the pain caused by other, non-renal comorbid disease can be accomplished with an awareness of the impact of renal failure on the excretion of various

drugs and their metabolites (Levy 2004; Johnson and Bonner 2004). During the study four patients died a typical uraemic death. Interestingly many had some improvement in health status after being reviewed in the Renal Supportive Care Clinic. In line with other trajectories (see section 3.1) this uraemic trajectory can be conceptualised in diagrammatic form as seen in Figure 8.1. The average length of life of this group was 20 months (range 9-33 months). A narrative of Raymond is now presented to illustrate this type of death.

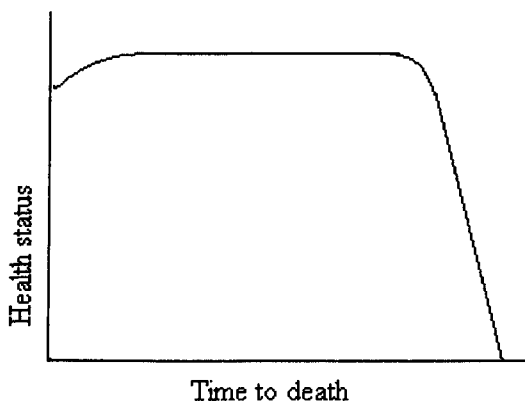


Figure 8.1 The uraemic trajectory to death (note improvement in health status after being seen in the Renal Supportive Care Clinic)

8.1.1 Narrative – Raymond

Raymond was 70 years old when he was referred to the renal team in 2003. He had severe and extensive rheumatoid arthritis and blood results confirmed him as having stable renal impairment with an eGFR of 28ml/min. It was presumed that Raymond's renal failure was caused by years of non-steroidal analgesic use to treat his painful and debilitating arthritis, for which he had undergone ten different operations over the years. In 2005 his renal function had deteriorated to the point where he required referral into the Renal Low Clearance Clinic (LCC), where decisions are made regarding renal replacement therapy. He decided not to embark on dialysis. His eGFR at this time was 11ml/min. In January 2006, Raymond was admitted to hospital, where he stayed for nine weeks. He presented having collapsed and was found to have an asymptomatic fracture of his right hip. Although his renal failure was progressive, with an eGFR at this time of 8 it wasn't causing uraemic symptoms.

On discharge from hospital, carers visited him several times a day to help him with washing, dressing and cooking. He was referred to the RSCS and seen three monthly. On first referral he had extremely itchy, red, dry patches on his skin causing him irritation and discomfort. He was referred to a dermatologist and with topical treatment the condition very quickly improved. Although Raymond's general health following this remained stable, it was noted that he appeared low in mood and he explained how he was feeling depressed after recently losing his mother and his dog. He agreed to be referred to the renal counsellor but only met her once because he didn't find it helpful and didn't wish to continue coming to

the hospital for appointments. In October 2006 Raymond agreed to a referral to the local hospice day unit after talking about feeling very isolated. His eGFR was 7ml/min.

Raymond attended the hospice once a week. The RSCS and the hospice staff talked regularly, especially as Raymond started to develop uraemic symptoms including pruritus and nausea, and had some degree of pain due to his arthritis. On 29 March 2007 a phone call was received from a Clinical Nurse Specialist at the hospice who said that Raymond was '*becoming muddled and frailer*' and asked if he could be admitted to the hospice. This seemed appropriate and Raymond was admitted there several days later. He died on 11 April 2007. A nurse who cared for him after his death described how Raymond came to the hospice for terminal care and, on admission, required '*full nursing care*' but was alert. In the last eleven days of his life after admission to the hospice things escalated and Raymond suffered more pain due to his chronic arthritis. He was soon unable to take his medication orally and became less aware of his surroundings as the toxic effects of terminal renal disease escalated. His death was typical of someone withdrawing from dialysis in that it was relatively quick, could be anticipated and symptoms could be identified and managed appropriately.

Nurse: Raymond was still conscious, he was still alert, responsive, he still could express his needs and everything, but physical things like washing, dressing and feeding needed really to be done by the nurses ... but most of his problem is really pain all over the body. It's mostly when he came here, he was mostly bed bound ... But he was still able to talk with us, he was still able to express his needs and everything ... The problem was he got loads of pain. Even in movement, and then he had problems swallowing tablets and medications. The doctor decided to put him on a machine so instead of him taking his medicine orally, they put everything in a machine to help him with his pain. And also one of his problems aside from the pain was the vomiting. He was on an anti sickness medication ... He was unresponsive, he wasn't alert anymore. You could see his changes in his breathing, more laboured and changes in his colour and everything ... Sometimes he complained of itchiness, probably because of the renal failure ... on the last, day when he was nearly on his last phase, he became very bubbly and chesty. So what we did is just keep on turning him and repositioning him in a position that made him more comfortable breathing with less chestiness ... As the days progressed, you could see that he was more sleepy, lethargic, and then less alert and responsive. Then eventually, on the day that he died, he became unconsciousness (HN¹⁶, 0507, int).

Clearly Raymond, although suffering a severe degree of renal failure for some years, was able to manage his life to the best of his ability, considering his other health problems until very near the end of life.

Raymond had been well at home for some time but gradually deteriorated prior to admission to the hospice. Even on arriving at the hospice, although he had become less mobile due to a pressure sore he was able to communicate his needs, but he was starting to become muddled probably due to progressive uraemia.

An interesting point to draw from this narrative is the fact that the palliative care nurses felt that they needed to speak to the RSCS before they admitted Raymond into the hospice. It is not clear if this was because they felt that the team should make that decision, having initially referred him to their service or if they were unsure whether it was the right thing to do. It may well be that they were unclear whether or not the admission would be appropriate because few renal patients had been admitted to the hospice. This lack of experience and knowledge regarding the dying trajectory of patients with renal disease highlights

¹⁶ Hospice nurse

again the importance of joint working between the renal and community palliative care teams and is discussed further in section 9.2.3.

The uraemic trajectory to death was encountered by other renal nurses and they revealed similar experiences where death came in the last few weeks of life following a period of stability and happened unpredictably:

We didn't see her for a wee while because she had moved out to where her daughter was quite a wee way away, but we used to ring her, and she remained quite well for quite a long time and then, she only became unwell in the last two or three weeks of life (CNS, W0708, M).

I think he was uraemic because he slowly went downhill at home ... He wasn't eating, lethargy, yeah. He was a typical uraemic (CNS, G0108, int).

The predictable uraemic trajectory to death was just one route to death highlighted in the study. Other patients died a predictable death but from another cause and this is now explored.

8.2 A predictable death from another cause other than renal disease

Three patients died from another illness and renal disease was clearly not the primary cause of death. These patients lived an average 9 months (range 2-17 months) after referral. The numbers are small, but as mentioned above, are supported by audit data arising from the service collected outside the present study. Also other staff corroborated these findings, having seen patients die not from their renal disease but clearly another cause.

We had a lady recently ... She came into clinic one day and I think that her eGFR was about seven, she did have heart failure as well. She came in a bit short of breath and lethargic, nothing much else ... yet again, two weeks later she was dead (CNS, W0708, M).

There was a patient with a brain tumour. The tumour caused his death. He didn't die from the renal failure (CNS, G0108, int).

In order to illuminate this type of death, where a patient died from another illness rather than the renal failure, two narratives are presented which describe the death of Akbar from cancer over a relatively short period of months and Ada from coronary heart disease from which she had suffered for many years.

8.2.1 Narrative – Akbar: Death by cancer

Akbar was 84 years old when he was referred to the RSCS. He had been seen by a consultant nephrologist for over five years and had a history of diabetes and cardiac disease. In clinic in March 2006, several problems were noted in a letter to his GP, including a recent admission to hospital for an angiogram, pain in the epigastrium and lower chest, often after meals, followed by occasional vomiting and shortness of breath. An endoscopy was arranged to investigate his symptoms.

Meanwhile Akbar's renal function remained stable and he was to be reviewed in two months' time. He underwent an endoscopy, which diagnosed gastritis and was prescribed two antibiotics. At a clinic visit in June 2007, following discharge from his local hospital, his consultant was told that he was admitted with abdominal discomfort and had undergone a liver biopsy. The results were awaited but his grandson believed the working diagnosis to be metastatic liver cancer. He was referred to the RSCS and visited at home on 27 June 2007. As he was neither breathless nor oedematous and his blood pressure was stable, his renal disease was not causing symptoms. Other symptoms included abdominal pain, for which he was taking paracetamol, a poor appetite due to difficulties swallowing and a feeling that food was sticking in his throat. He informed us that he had not fully decided yet regarding the treatment option for his renal failure. We advised him to wait until he had the biopsy results before making any decisions.

Akbar was using a Zimmer frame when mobilising but had had several episodes of falling over. He had a carer coming in twice a week to help him with his hygiene needs and had a home help visiting fortnightly. He attended a Day Centre whenever he was feeling well and was awaiting a wheelchair, which was being organised, by his surgery. He lived with his wife, who was in ill health, and his son and grandson.

Seven weeks later on 16 August 2007, Akbar was visited at home for the second and last time by the RSCS after '*requesting a home visit before he dies*'. Terminal cancer had been diagnosed and he appeared very weak with jaundiced skin and complained of abdominal pains and vomiting. His medications were changed to subcutaneous form. He died several days later relatively quickly with a short period of evident decline and following the typical cancer trajectory to death (see Figure 3.1).

8.2.2 Narrative – Ada: Death by coronary heart disease

Ada had a health history of diabetes mellitus and hypertension for more than 20 years, had suffered a previous cerebrovascular accident 11 years previously and had ischaemic heart disease with impaired left ventricular function. At her first consultation, her son Jack explained how Ada had been admitted to hospital on a regular basis following deterioration in her renal function and heart failure, five years previously, often due to an '*enlarged heart*'. When the first crisis took place Jack said:

Jack: *She had a really major crisis, where the kidneys failed completely and she had heart failure, she had an infection and wasn't expected to live at all... the doctor said to me, 'Listen, right, we are trying one last go and if things don't work, there is nothing else we can do'. I said, 'Alright.' And miraculously she started to pull around'* (ES-2, int).

After discharge Ada was admitted back into hospital on several occasions.

Jack: *I think she has been hospitalised, God knows how many times... maybe between seven and ten times, you know, for various reasons surrounding the heart and kidneys... she just kept on having crises' every now and again* (ES-2, int)

Jack went on to describe the admissions to hospital and how he knew that Ada was deteriorating:

Jack: *She would start with slight breathlessness, more difficulty getting from her chair to the bathroom, and I could tell, and this might go on for a couple of days and she [Ada] didn't want to go back into hospital and she didn't really want to accept, initially, at that initial stage, that*

maybe either fluid was building up in her lungs or some other thing was happening, but really I knew that in three or four or five days time, I would be taking her back to hospital because of her heart (ES-2, int).

In the beginning, Jack would take his mother to the GP first but as he became more experienced at identifying changes in her condition he said: *'I knew I could save a lot of messing around with x-rays and all that nonsense and so after that, I knew straight away that I would just have to take her to casualty and that was the usual procedure'.*

Jack felt supported by the hospital staff who managed his mother and usually let the RSCS know that an admission had taken place. Each admission was precluded by a build up of fluid caused by Ada's heart failure and intravenous diuretics were given prior to discharge. Jack described the events leading up to Ada's last admission to hospital:

Jack: *Yes, yes, she got a bit breathless, same thing... she had really been deteriorating over a period of two weeks, upstairs, and we actually moved her up to her bedroom, for the first time ever. The last two weeks before she died, that was it, she just went downhill very, very badly, and she could barely move from the chair to the commode. Barely, that is how bad it was, a space of just two yards... She could never sleep in her bed properly because she was always having four or five pillows, that was a problem in the end as well (ES-2, int)*

Jack described how he knew Ada was dying from the time the decision was taken to move her to her bedroom. He felt *'her body had weakened so much'*. She was admitted into hospital on a Thursday morning. Jack explained that his mother had been in *'considerable pain'*, which was causing her to *'scream out'*. Although Jack said that his mother had often had some form of arthritic pain, he felt unsure why she was in so much pain in the last days of life. A doctor telephoned him to ask if they could administer stronger painkillers and that there was *'nothing else that she could do'*. Ada died the following Monday morning following a typical heart failure trajectory, as seen in Figure 3.1.

In these two narratives it can be seen that deterioration in each patient's condition was relatively easy to identify, death could be planned for and appropriate management of symptoms initiated. Both patients died predictably and although they had symptoms towards the end of life, these seem to have been identified quickly and treated appropriately. Similar to those who died a uraemic death, the end of life was something anticipated and the aim was to make the patient comfortable. This was not so easy for those who died in a more complicated manner and this is now discussed.

8.3 An unpredictable death

For ten patients who died during the study the cause of death was not certain. The average length of life of these patients was 11 months (range 1-19 months). These were patients who were coming to the end of their lives and had a terminal illness, that of stage 5 CKD. Other staff had seen patients die where the cause of death was unclear:

I see many more sudden deaths where we don't really know what happened. We can guess but why someone died is not clear (CNS, G0108, int)

Why do many of them die? It's hard to say. There could be many reasons (Dr, 270607, FN).

Yeah, we've had quite a few recently that people have died or they've gone into hospital with a UTI and they've just not come out again (CNS, W0208, M).

As shall be shown, the prognostic difficulties surrounding those who opted not to have dialysis played a role in how these patients died. Abdul's narrative which follows, exemplifies a myriad of difficulties in predicting death, even though it was clear that he was dying. It provides a useful illumination of the features shared by many patients in the study where it was often difficult to predict how long someone would live, when they might be reaching the closing stages of life, and the final cause of death.

8.3.1 Narrative – Abdul

Abdul was a 77-year-old man originally from Bangladesh who was referred to the RSCS in September 2006. He had moved to the UK over 20 years previously with his wife and had seven children, six girls and a boy. It was suggested that he be seen at home due to his frailty and difficulties mobilising. He lived in a second floor flat with his wife and six other adults and had difficulty negotiating the stairs. When first visited in October 2006, Abdul's daughter Salma spoke on her father's behalf as he only spoke a little English and was sometimes confused. She was worried that his mobility was greatly limited, he tired easily and his ulcerated foot with protruding bone was causing him pain and misery. She was also concerned with his temper and said he often didn't talk to his wife. Salma thought her father was depressed but didn't think he would admit to this if asked. She thought that his depression had been brought on by a comment he had overheard at a recent hospital admission from a doctor who had said that he could die without dialysis. Salma was clear that her father didn't want dialysis because '*he didn't want to be going into hospital for the rest of his life*' but said hearing a doctor say that he might die because of this decision affected him mentally. When Abdul was asked by the RSCS about his decision, his daughter translated that he couldn't remember anything about the decision but was happy to be at home.

Subsequently, Abdul had several admissions into hospital for cardiac related chest pain through November 2006. On each occasion his family called an ambulance and he was taken to casualty and admitted for oxygen therapy only. No cardiac events were recorded. On a last admission, prior to discharge, and after a discussion with Salma, it was decided to try to keep Abdul at home when he had chest pain and treat the pain with oxygen and glyceryl trinitrate (GTN) spray to ease and prevent angina pains. The family seemed happy with this and Abdul was referred to the community palliative care team for symptom control and psychological support. The following week the family expressed their thanks for the services that were arranged prior to Abdul's discharge from hospital and seemed to be coping well at home. Abdul was frailer but was still able to take small amounts of food and talk with his family.

Two weeks later, in early December, the RSCS received a phone call from the community palliative care team who were worried that Abdul was hypertensive and unable to take tablets, and were asked if there was anything that could be prescribed in another form or if he could be admitted into hospital. It was

explained that little could be done about Abdul's swallowing problems and that a hospital admission would achieve very little. It was felt that Abdul was deteriorating and coming closer to the end of his life. The following week Abdul was eating a little bit more and taking his tablets but the palliative care Clinical Nurse Specialist called to say that Abdul's family were planning to bring him into hospital for intravenous fluids as they thought he was dehydrated. They had been told this by ambulance staff who had been called out to see Abdul. On speaking to the family, it was explained that fluid should not be given to Abdul as he was drinking and too much fluid would overload his kidneys. The family were happy with this and the community palliative care team decided to visit Abdul *'every other day instead of daily as he was pretty stable'*. On several occasions the family were called and it was explained that Abdul was dying. A full care package was put in place to help the family manage Abdul's hygiene needs as he could do little for himself.

Abdul again deteriorated at home and Salma said he became *'mute'*, not wishing to talk to the family and it was suggested by the community palliative care team that he be admitted to the hospice to offer respite to the family. However they refused as they wanted to keep him at home and they felt this was his wish. Abdul developed profuse diarrhoea and it was increasingly difficult managing his care at home. Eventually, a decision to admit Abdul to the hospice was made after he managed to leave his flat without any of the family knowing and was found standing in the doorway *'freezing cold'*. Abdul stayed for two weeks at the hospice. During this time a doctor from the hospice called the RSCS asking if she could transfer Abdul to the hospital as the family were asking for a transfer. He was having regular chest pain and the hospice didn't have access to an echocardiogram machine. It was explained that Abdul was coming to the end of his life and that the renal team would not carry out any further invasive procedures. Anti-anginal medication was increased and Abdul remained at the hospice. He was confused at times and his daughters said he became more depressed. Sometimes he spent the night itching, a possible side-effect of renal failure, and slept little. His family felt he was scared and decided to take him home again. Another daughter, Fatima, said: *'The first night he came home he slept so well the whole way through the night and into the morning'*. His family felt that he was happier at home, was sleeping better and it was where he wanted to be. He was eight days from death.

In these eight days Abdul became weaker and started to vomit more regularly. Salma told me how he was put on a medication that made him drowsy. She mentioned a morphine patch and how unhappy the family were that he was rarely awake. The district nurse said the patch was to treat itch but the family read that the patch was for pain relief. The family said he was *'drowsy, knocked out, and he didn't eat, he didn't drink, we couldn't wake him up'*. For two days he was like this and they eventually called out the emergency GP who told them their father was drowsy because of the patch and it should be left there. The family felt strongly that their father wasn't in pain so took the decision to remove the patch themselves. Fatima said that after the patch was removed, within two hours, he started *'becoming OK again and started talking to us. He opened his eyes for the first time in two days'*.

An hour before Abdul's death the district nurses arrived and decided that a urinary catheter was required as they thought he might be uncomfortable due to urinary retention. On reflection, Salma and Fatima thought that he had not passed urine because he'd had very little to drink over the previous three days. His

daughters said this attempt was unsuccessful and left their father in pain. They also talked of a palliative care nurse and doctor calling on the morning that their father died and disagreeing about the use of the patch, which made them feel angry and concerned that their father was not receiving the best care. They were told by the doctor that he had a strong pulse which meant they were shocked when he died later in the day. They thought the strong pulse indicated that he was *'really strong, really good, seemed healthy and was comfortable'*. When the family were alone later that day, their father who had been sleeping, suddenly awoke gasping for air, was sweating and his eyes were rolling. The family became frightened and called back the district nurses and spoke to the RSCS who tried to reassure them and said again that their father was coming to the end of his life. The district nurses told the family that Abdul was *'fine'* although he was complaining of chest pain intermittently.

Salma described Abdul's death soon after the district nurses left:

We kind of saw him take his last breath because he hadn't got strength to lift his own head up. We were talking and he was talking to us at that time, I was even asking do you want a cup of tea? And basically we were taking it in turns to be in the room with dad and he was asking for water. He was asking for water, which is a change because he never usually does and he did have it and then he said he wanted to go to sleep. And suddenly he felt really hot. He took off the covers and he was really hot and stuff and it was like he was trying to reach out. And then he was just making all these gasping noises and stuff and then suddenly I saw one side of his face just collapse. He just collapsed sort of thing and we were like, what's wrong and stuff? I got worried, I called everybody in and they all came and then he was taking, he took one breath and then I thought, no he's all right he's coming back and stuff, and then he took one last one and he was gone. And then at the same time we were on the phone to the ambulance and they were saying to do resuscitation' (AM-2, int).

Abdul's son commenced resuscitation. When the ambulance staff arrived they continued. They attempted to locate a vein to administer intravenous drugs but were unsuccessful. They placed Abdul on a stretcher to take him to hospital. No pulse could be found. His wife was crying and asking that he be left at home where he wanted to die but was told this was against regulations. He was resuscitated all the way to the hospital and pronounced dead on arrival.

8.4 Key messages from the narratives

As can be seen from the narratives above, patients died in a variety of ways and often death was complicated by the fact that the ultimate cause of death was uncertain. For those dying a typical uraemic death, it was easier to plan and manage the death, and even the hospice professionals, more used to dealing with those dying of cancer (Jablonski 2007b), seemed comfortable caring for patients like Raymond, who was clearly on a pathway to death caused by stage 5 CKD. This death was predictable and its conventional nature meant patients could be managed appropriately as they progressed towards death. For those who died of a cause other than renal disease and where it was easily determined what the cause of death was to be, care offered was also acceptable. Again the death was predictable once the illness that was actually to cause the death of the patient had been identified. Akbar died comfortably at home with terminal cancer, his renal disease unproblematic and of little importance towards the end of life. Also Ada died in hospital cared for by professionals who identified that she was dying of cardiac failure and that she needed to be made comfortable as she died. Unfortunately, some patients didn't experience the

expected uraemic death around which the RSCS had first been established. It was those patients who did not die in a predictable manner that caused most concern in the study.

Abdul's narrative highlights several issues that raise concern for all those who may be involved in caring for renal patients who have decided not to have dialysis. These include: difficulties of managing a population of whom little is known; the numbers of healthcare professionals who might be involved in a renal patient's care in the last phase of life and how this care is best coordinated; the numerous symptoms suffered by those with renal failure and how they can be appropriately treated; a lack of knowledge, which means carers may be inappropriately supported with adequate information and guidance on how and when death might take place; and the pressures brought to bear on families caring for their loved ones. Health professionals found themselves in difficult circumstances when faced with a patient who is certain to die but at an unknown time, as described by Copp (1999).

Abdul's narrative typifies the complexity of an eventful death where care seemed erratic and inappropriate. Professionals did not seem to be aware of the severity of the situation and the need for more participation to support a family. Abdul's family was unclear as to what to expect from their father's stage 5 CKD and his terminal diagnosis. This narrative has similarities with Gott et al.'s (2007) work with heart failure patients. They found no 'typical dying trajectory' and only a minority of patients who conformed to the theoretical trajectory of dying with heart failure. They highlight that those with heart failure may have several different trajectories to death, similar to those identified in this thesis. Their findings challenge the theoretical heart failure dying trajectory upon which current service developments are planned. Not all patients with heart failure or renal disease will die predictably. As Gott et al. (2007) suggest, there is a need to reconsider current efforts to plan and deliver services to those with chronic disease on the basis of trajectories put forward in the literature.

8.5 Summary

This chapter has identified three trajectories to death in patients diagnosed with stage 5 CKD who decided not to embark on dialysis. These include a trajectory where patients died a typical uraemic death, one where a more traditional, expected death occurred (such as heart failure or cancer) and a trajectory where the cause of death was unclear. This work represents the only prospective trajectory data captured qualitatively prior to death in this population. It was this third trajectory that caused most problems for health professionals attempting to manage patients who were dying but for whom the time of death remained unknown. Throughout the study, diagnosis of approaching death was often complicated by the fact that patients did not follow linear pathways, and how they died was not always entirely apparent due to the multitude of problems that they presented with and the difficulty determining the actual cause of death.

This uncovering of the trajectory to death in a population managed without dialysis has not been attempted previously and adds to the body of knowledge concerning trajectories to death in general. It is suggested that trajectories in this population are varied and often very individual. The trajectory that leads to death where the cause of death is not clear highlights a population who do not predictably die from

renal disease with other comorbidities impacting on their lives and often ultimately their demise. This will be of particular interest and relevance for those managing patients with renal disease, who clearly require palliative care as they live with a life-limiting disease.

The final findings chapter demonstrates in more depth the complexity of these patients and the challenges met by health professionals, particularly as the end of life approached.

CHAPTER 9

MANAGING THE DEATH (OR NOT) OF PATIENTS: THE DIFFICULTIES FOR HEALTH PROFESSIONALS

Having described the trajectories to death of those patients who died during the course of the study, this chapter considers a number of challenges encountered by professionals in identifying the end of life in this population. This chapter therefore goes some way to addressing the fourth aim of the study, which was to highlight issues for consideration when establishing a RSCS for patients managed without dialysis, although it is recognised that to some extent each of the findings chapters has addressed this aim. The issues discussed here are directly related to the attempt to identify the approach of the end of life in a population where this has not been explored before.

The chapter examines how the approach of the end of life was predicted in terms of increasing symptoms and sudden changes in condition. Conversely, it also notes how difficult it was at times to predict the end of life. This difficulty led to inappropriate treatments for many patients coming to the end of their lives - in the form of surgery and resuscitation. Teams sometimes withdrew as patients approached the end of life not believing that they were close to death. When they realised that patients were very unwell, an attempt was then made to admit them to hospital inappropriately. The fact that some professionals encouraged very ill and dying patients to change their minds regarding the decision not to embark on dialysis, leading to confusion for the patient, is also explored.

9.1 Attempting to identify the approach of death

As discussed in the previous chapter, those deaths caused by uraemia were less traumatic and occurred in a more peaceful and measured environment. Several patients died a 'uraemic death' where their kidney function continued to drop until life could no longer be maintained such as Raymond introduced above who died in the hospice. Sarah '*slipped away*' according to the ward sister who cared for her at the end of her life. These patients demonstrated a steady decline to death where it could be anticipated and planned for. Within the study, ways of identifying that death was approaching were explored and are discussed below as:

- tipping towards death
- identifying symptoms indicating that death was near.

Although death could sometimes be anticipated, it was complicated by two factors also discussed:

- dying unexpectedly
- living longer than expected.

9.1.1 Tipping towards death

'Tipping' was identified in several patients who died during the study and was something that was looked for in patients as specific events transpired. eGFR at first referral and at subsequent consultations was recorded for each patient and was a valuable marker for determining deterioration or 'tipping'. The average last recorded eGFR prior to death was 9.5. Many died with a lower eGFR and one patient's last recorded eGFR was 2. Sometimes patients presented looking and sounding as well as when previously seen, but their eGFR might show a decline, indicating that this could drop without the patient feeling an immediate impact. This aside, there was often something subtle that changed, which, on reflection, seemed to identify acceleration in the trajectory to death. This was discussed with colleagues and became known as 'tipping'. It required intense scrutiny of blood results, along with an in-depth knowledge of the individual patient and changes in circumstances.

Paul exemplified the nature of 'tipping'. He had remained stable for six months with little change in his blood tests following his decision not to have dialysis. His health seemed to have plateaued with little change on a day-to-day basis. At his last home visit his eGFR had dropped and he then had a fall. Although Paul was unhurt in the fall, his family explained how they had noticed a decline in Paul over the previous weeks and how he seemed more depressed making '*little eye contact*'. They also felt that he had '*lost a lot of weight and his eating had declined considerably*'. His situation had subtly changed and death was closing in. His appetite continued to deteriorate and his lethargy increased as he took to his bed. He appeared to have 'tipped' as his blood tests and he himself showed signs of deterioration.

'Tipping' was a concept which other CNSs identified with when speaking of patients who had deteriorated towards death. It was articulated at several meetings when discussing patients who had died, and appeared to be a term which had common meaning for those caring for patients managed without dialysis. It intimated hastened approaching death:

The bereaved carers that came ... they were saying about our service that it was great, the whole service was brilliant while we were well but actually when we tipped, they didn't actually say when we tipped but when we were dying ... that was when they needed help (CNS, T0109, M).

And then he did tip and he deteriorated very quickly. He'd tipped very quickly and was very symptomatic from the renal point of view, very fluid overloaded, nausea, vomiting ... a more rapid progression? (CNS, M0807, M)

But definitely tipping [in those managed without dialysis] is a really important concept. So I would concur with that entirely (Dr, M0108 M).

Although 'tipping' was something that was sometimes identified in patients who reported an event or symptoms that might indicate deterioration, blood tests didn't always reflect the same scenario. Sometimes the deterioration in blood results was minimal making the situation more complicated and the outcome less easy to predict. Sarah who had been told seven years prior to referral to the RSCS that she

would require dialysis to treat her renal failure was someone who 'tipped' physically but didn't show dramatic changes in her blood results. Sarah had been attending the service for over a year and had always arrived feeling and looking very well. She came by public transport to clinic and usually went home via her local market to buy fish for her tea. On her last visit she had just returned from Barbados. Outwardly she looked the same, but she explained how she had been unwell on holiday and how things were still not quite right. She discussed symptoms, which included a lack of appetite, lethargy and weakness, all which could be attributed to deteriorating renal function. Sarah was adamant her problems were caused by a flu virus caught on the aeroplane on the way to Barbados. She also explained how she had had a period of feeling very itchy, which can be a symptom of deteriorating renal function. It appeared that Sarah might be showing signs of 'tipping' in that symptoms had emerged indicating a possible decline in renal function. I recorded this in my field notes:

Sarah complained of emerging symptoms today. I think she may now start to deteriorate so requires closer observation (TC, 180407, FN).

Sarah had maintained her independence and interests and had few symptoms, managing well with very little renal function. Interestingly, at this point Sarah's blood results showed only minor deterioration and it was thought that she might be correct in her diagnosis of 'flu' and that a washing powder had caused the irritation. Again, I used my diary to record my thoughts:

It looks like Sarah is OK. She did just have flu. Her bloods haven't changed much (TC, 190407, FN).

Telephone contact was made with Sarah several times but, although she sounded well, she did deteriorate over the next few months and had died before her next appointment. No further blood test results were available and she died uneventfully at her local hospital slipping into a uraemic coma. She had 'tipped' and, on reflection, this was identified in her mentioned symptoms. It was not seen explicitly in her blood test results at that time, but perhaps it would have been seen if blood tests had been repeated several weeks later.

'Tipping' was a useful concept for articulating what was happening to patients who had a change in their condition after a relatively stable period. It usually indicated that the end of life was approaching. Often, when this point was reached an increase in symptoms occurred, indicating that the kidney function was deteriorating and that the end of life was approaching. This is now discussed.

9.1.2 Identifying symptoms indicating that death was near

Of the 17 patients who died during the study, many suffered symptoms that indicated kidney function had deteriorated to such a point that life could no longer be sustained. Symptoms included extreme tiredness and lethargy, where patients felt unable to get out of bed, and oedema that was difficult to manage with diuretics. Appetite was often reduced to such a point that little sustenance was ingested and was associated with nausea and vomiting in those following a uraemic trajectory to death. Although patients such as Abdul and Paul received acute medical intervention when close to death they had both shown signs that death was approaching as their kidney function decreased. Abdul's daughters talked about his last days of life and how

he reached the stage where he could not leave his bed. Weakness and lethargy were described, which eventually led to an inability to communicate:

Salma: *But still he would be talking to us normally, everything was fine, and then he got to a stage where he couldn't get out of bed and he got too weak then he was too tired even to come to the next room. Because I think when you last came he was walking around, he couldn't even do that ... And then slowly, slowly what happened he started not talking to us, he went a bit mute ... Like we would talk to him he wouldn't reply back and we just have to make his mind up for him and then after that he started deteriorating really fast, didn't he? (AM- 2, int).*

Other nurses witnessed 'crippling' lethargy as patients progressed to death:

Yes I had a very similar lady with a GFR of around 2, tiny lady, in the community ... the picture was, that she had so much lethargy, this huge amount of lethargy, so much so, that it is crippling ... They will say 'I cannot' They literally cannot move from their bed (CNS, M0907, M)

Often there was pruritus, sometimes incontinence and regularly oedema. Oedema had been noted as an end of life symptom by other nurses:

My learning from that is any sort of oedema that's very difficult to shift indicates that the person is coming towards end of life (CNS, G0607, int).

As discussed in the symptom chapter, when oedema became difficult to treat, the end of life could often be predicted.

For some reason not readily understood, pain often became a problem towards the end of life. Sometimes it was due to the underlying condition causing the original pain. For example, Raymond's arthritic pain greatly increased and Akbar's cancer pain required very strong analgesia. Others, such as Ada, had suffered pain much of her later life but this increased in her last days of life, as explained by her son, for reasons that were not quite clear:

Jack: *She was in considerable pain, I think, that is why when I spoke to that doctor that she [the doctor] actually phoned me to ask my permission to give her the painkiller. She explained you know, the fact that there was nothing else that she could do, and my mother was in so much pain, and she really felt that...She was always in some form of pain but I think that she was screaming out with it so the pain was considerable*

Helen: *Do you know what that pain was caused by?*

Jack: *I think, I may have been told, I am not absolutely certain I know. I am not absolutely certain (ES- 2, int).*

Other nurses had noted pain at the end of life. Often a cause could not be determined, although it was suggested that it was due to hypocalcaemia. Whatever the cause, it often allowed for the prescribing of diamorphine through the predictable 'pump':

We see all over aching body pain. In some patients we think it could be related to the hypocalcaemia but we're not sure (CNS, M0907, M).

Yeah, because there is often that just generalised pain that allows you to commence the diamorphine, the pump, whatever that pain is, so that could well be it (CNS, G0108, M).

In many cases patients deteriorated rapidly in the last few weeks of life, having been relatively stable for many months or even years. Many of the patients who died had a period of time where it could be identified that they had deteriorated. The end of life was approaching and death would ensue. Sometimes this was relatively well managed, especially if the patient suffered a uraemic death, as did Raymond who was cared for at the local hospice. Other patients had been in and out of hospital on several occasions over a period of years but there was ultimately a clear identifiable swift path to death, as in Ada and Sana's case. Sana's last weeks included several renal symptoms, including nausea, vomiting and oedema, that were well managed and described by a CNS:

The symptoms she got were nausea and vomiting and the pain, other than that she was fine. She only became oedematous recently, on her last week. She had enough support from the district nurses. We had Macmillan night time sitters ... The family was really happy she was comfortable and she coped (CNS, G0507, int).

The symptoms expected from those dying a renal death were very similar to those withdrawing from dialysis, so generally they could be planned for. However, in some cases patients who deteriorated did not die as expected. This unanticipated phenomenon meant that predicting that someone was dying was not always easy. This issue is now explored.

9.1.3 Not dying as expected

Attempting to identify the end of life in those with renal disease was complicated by the fact that some patients who were expected to die went on to live unexpectedly. These patients and their carers had usually been told that death was approaching and that plans for their death should be made. Discussions were sometimes held regarding where the patient would go to die, only for the patient to make a recovery and rally. Josie was one such patient who was admitted to hospital with a severe chest infection. She was monitored in the coronary care unit and although she made some recovery, her poor renal and cardiac function led the doctors to believe that she was soon to die. Josie agreed to discharge to the local hospice and it was believed she had only days or weeks to live. Her eGFR had deteriorated to 3 and she had very limited mobility. Josie was transferred to the hospice but didn't die. As she grew stronger over several weeks, plans were made for her transfer to a nursing home.

Like Josie, Diane was admitted to her local hospital following a stroke in October 2007. In the November her family were told that Diane was dying of renal disease. They were called to the hospital in preparation for her death. The medical team then decided to transfer Diane to another hospital where renal expertise was sought. Once there it was clear that she had a serious urinary infection, which was treated with antibiotics. Her daughter Annie described her catheter '*draining leak and potato soup*' and that once she had been '*given antibiotics her renal function improved and she wasn't dying anymore*'. There had also been problems deciding the extent to which Diane's lung cancer had deteriorated, with doctors offering a poor prognosis countered by a more optimistic one. Her daughter Annie's words were captured in field notes:

'We're constantly being told this is it, that Mum's going to die, and then finding out that it's OK and oh she's going to be OK; it's a very difficult situation to be in. Our emotions are all over the place (RR, 010107, FN).

Annie and her family found the situation very difficult. They had been told on several occasions to prepare for their mother's death only for her to rally and continue to live.

Other nurses had also experienced patients improving after it had been decided that they were close to death:

There was a lady down in P. and she was admitted for terminal care to one of the local hospitals. But ended up having to go to a nursing home because she didn't die quick enough (CNS, W0708, M).

Yes, I can't believe it, she was told that she only had a short time but she bounced back and is doing well (CNS, G0507, int)

In contrast to those patients who lived longer than expected, other patients in the study died unexpectedly and these are now discussed.

9.1.4 Dying unexpectedly

Some patients, although known to have life-limiting, terminal renal disease, died unexpectedly. This led to difficulties determining the cause of death. Trudy was only seen once by the RSCS and was soon after admitted to her local hospital where she died. The cause of death unclear. Juber had required symptom management at his local hospice and had a discharge date to return home but then died suddenly. It hadn't been thought by the hospice staff that he had quite reached the end of life. Again, the reason for his death was unclear and could have been attributed to his stage 5 CKD or his cardiac problems. Michael had been seen by the RSCS on several occasions over a period of a year and his renal function had changed little with his eGFR relatively stable at 15. He died suddenly after being admitted to his local hospital, having suffered a hypoglycaemic event. His death was put down to this. Other CNSs had similar experiences and one talked about patients being admitted to hospital with a minor complaint and dying there unexpectedly:

Yeah, we've had quite a few recently that people have died or they've gone in to hospital with a UTI [urinary tract infection] and they've just not come out again (CNS, W0708, M).

Although it became clear that death could occur at any point in this population, unexpected death was often a shock. This highlighted a need to ensure that patients and carers were aware that death could occur suddenly so that inappropriate interventions or admission to hospital were not initiated and to ensure that all involved were prepared for the worst.

Conversely, other patients in the study lived longer than expected following their original diagnosis of stage 5 CKD. This added to the difficulties in diagnosing approaching death and this is now discussed.

9.1.5 Living longer than expected

Some patients in the study lived with very reduced renal function. How life can be sustained with such poor function remains unknown. In addition, some patients were able to live relatively independent lives. Sarah's function was much reduced and it was unclear how life could be sustained under such circumstances. When her eGFR was just 4 she continued to manage well, with no help at home, and was coming by public transport for her hospital appointments. Veronica was also independent and came by bus for her consultation. Another patient, Sana, had such poor blood results it was felt death was imminent but she lived for several months with this very much reduced renal function. The renal nurse caring for her explained how surprised she was at Sana's extended survival:

Oh gosh yeah, in the February her eGFR was very low, about 3. I asked the district nurse to just recheck her bloods in January, to give us an insight on what's really happening with this patient ... I said to them most patients at this point have died ... but she [Sana] was often good and would help with cooking. And her family they just allow her to do that just to encourage her independence really. She was walking up and down the stairs, it was only in the last few days when she was unable to go down the stairs (CNS, G0507, int).

The ability of some patients to continue to live with such reduced renal function made it difficult to predict which patients would succumb to death first and who might continue to live for some time. What did become apparent, as clear in Sana's and Sara's cases was that once patients developed symptomatic uraemia where several symptoms emerged at once, death came within weeks. Prior to this it was difficult for health professionals to appropriately manage every patient due to the inability to predict how a patient might progress. In some cases this led to inappropriate medical interventions for people dying with renal disease. This is now discussed.

9.2 The utilisation of inappropriate care at the end of life

The difficulty in predicting that life was coming to an end caused problems for several patients in the study. As seen in Abdul's narrative, death, and when it would happen, remained an elusive factor. Abdul was admitted to hospital on several occasions prior to his death. This meant that his family and the health professionals were unclear when to accept that death was occurring, as opposed to suffering an acute event, which, following medical input, might result in Abdul's recovery. Even the district nurses who attempted catheterisation in the hour prior to Abdul's death did not seem aware that he was going to imminently die. During the study there were several ways in which the end of life was inappropriately managed for some patients. These included:

- offering surgery and resuscitation
- encouraging the initiation of dialysis
- reducing professional input as death approached
- attempting to admit to hospital inappropriately.

9.2.1 Offering surgery and resuscitation

Some patients in the study received what could be viewed as inappropriate acute treatment as the end of life was approaching in the form of surgery or resuscitation. Prior to the study, four other patients had been unsuccessfully resuscitated at the end of life. None of these patients who underwent acute intervention survived. For many patients their renal disease appeared hidden from professionals not experienced in caring for those with stage 5 CKD, even though many were very close to dying. One CNS described how the renal disease could not be seen unlike like some other ailments:

I think that's a real key thing that it isn't, you cannot often see it. You cannot see it, it's not a sore on someone that can be seen and acted upon (CNS, M0708, M).

As patients were often elderly and frail but didn't appear to be actively dying (although their blood results reported otherwise), there were problems for staff in appreciating how close to death many patients were. One such patient was Paul, who was offered surgery at the end phase of life. He had been registered on the *Gold Standards Framework* (GSF) (Thomas and DH 2005) at his GP's surgery for many months. The GSF is a register maintained in GP surgeries, which lists all patients with less than one year to live and requiring palliative care input. On his final home visit, bloods were taken and showed deterioration so he was referred to the community palliative care team. He was spending more time in bed sleeping for long periods and it was thought that death was close. One morning Paul awoke with acute abdominal pain and his GP was contacted. Following a home visit, she made arrangements for him to be admitted to his local hospital. In the casualty department he was reviewed by a surgeon and an obstructed bowel was diagnosed. Paul was given the option of urgent surgery and 'told that if he did not have the surgery he would die'. Paul consented to surgery and was taken to theatre. The RSCS was not contacted. On return from surgery he died later that day.

Paul's death highlights how difficult it can be for health professionals to either accept that death is near or that inappropriate treatment will be futile. It was known by Paul's family that he was dying and he was being seen by the community palliative care team. This aside, the doctors he met in the casualty department decided that if Paul didn't have an operation he would die and this seemed reason enough for him to be offered surgery even though he was terminally ill. Although Paul was dying a typical uraemic death in that his blood tests had shown deterioration, he had become frailer and was spending more time in bed. He himself, and those involved in his care at the time he presented in hospital, did not appear to understand that death was very close, or perhaps chose to ignore this.

Another patient, Arnold, was resuscitated twice before he died. Following his first resuscitation his family were told that he had 5-10 days to live. Several hours later he arrested again and another attempt was made at resuscitation although this time he did not survive. His wife said:

Now apparently they'd resuscitated him ... and they reckoned he would have another perhaps five to ten days, but... obviously he went again, and I think, I don't know whether you can give up, but I've got a feeling he just didn't want it anymore and he just went' (AS- 2, int).

The health professionals felt that it was appropriate to attempt resuscitation for a second time even though it was clear that Arnold was dying. This raises questions concerning the practice of the health professionals involved. It may not have been clear to Arnold's family that he was dying when he was first admitted to hospital, as he had not disclosed the severity of his renal disease to them. However, after the first attempt at resuscitation the family were told that he had only days to live and it was now apparent that Arnold was reaching the end of his life. Instead of allowing death to take its natural course, active intervention in the form of the second resuscitation took place. This may have been because there had been no discussion about what should be done if Arnold did suffer a second arrest, or it may be linked to the need of some health professionals to actively treat all patients, even those who are obviously dying. Whatever the reason, the course of events causes unease and raises ethical questions related to the inappropriate extension of life and the attempt to maintain life at whatever cost.

9.2.2 Encouraging the initiation of dialysis

Occasionally, some health professionals would encourage patients to commence dialysis even though they had made the decision not to have this treatment. On an admission to hospital to treat hypoglycaemia, Samuel was asked why he wasn't having dialysis. This led him to question his original decision:

Samuel: *The doctor at the hospital asked me why I not have the dialysis ... Maybe I should think about trying it so I see what happen. The doctor thought I should (TJ-4, int).*

Samuel was referred back to his consultant nephrologist for further input but after discussion decided that he would not embark on dialysis as he didn't feel it would be in his best interests.

Marjorie was admitted to her local District General Hospital for management of her diabetes and she was seen by the geriatricians. The consultant geriatrician informed the consultant nephrologist that he had 'been successful at getting Marjorie to change her mind and to accept dialysis' This led to further meetings with Marjorie and her consultant nephrologist in an attempt to understand what her decision now was. Marjorie had always made it clear that dialysis was not something that she wished to entertain, but she had now been influenced by a doctor who thought that undergoing dialysis would be in her best interests. Ultimately, Marjorie decided to adhere to her original decision and did not commence dialysis therapy.

On the day that Meena was admitted to hospital for the final time, her GP asked why she wasn't having dialysis even though it was clear that she was close to death. There was often a lack of understanding related to why a patient might decide not to have dialysis, often viewed as a life-saving therapy.

Other staff had similar experiences and had seen patients being encouraged to change their minds about treatment:

I think we've all seen this. He's received advice from a consultant friend in America suggesting two sessions of dialysis would be appropriate. He asked me 'do you feel it would be too late to commence dialysis at this stage?' (CNS, M0708, M)

I have just seen the geriatrician at ... and she told me she had spoken to Vera and got her to change her mind about dialysis [laughs]. She just thought that was the right thing to do (Dr, 0907, FN).

Interestingly, some professionals struggled to determine appropriate clinical treatment and, when the end of life was approaching, some decided to withdraw inappropriately, believing patients to be 'stable' and not in need of their services. This is now discussed.

9.2.3 Reducing professional input as death approached

Some patients in the study did not receive the specialist care that they required towards the end of life. This was often because the team caring for the patient in the community underestimated the input required. Although blood tests might show deterioration, staff did not always identify that a patient was close to death and chose to reduce contact. It was often felt that as symptoms were being well managed there was little else that they could do to help:

Because, oh initially yeah we were visiting her [RSCS], but then I said to them [community palliative care team], oh she just have a few weeks probably, so I'll stop seeing her and hand over to you. But you can always call me any time if you need advice or whatever. But ... the palliative care team stopped seeing her because her symptoms were well controlled. And there wasn't, they weren't doing anything they said (CNS, G0507, M).

Because this lady who died the other day, when I arranged for that emergency meeting with the doctors within two weeks she was dead. And when the hospice team went there for the first time they said 'oh, she's fine', you know, 'I don't think she's on, going to die soon' and I said really? (CNS, 0108, int)

As alluded to in section 7.2.4, many patients looked reasonably well up until death. They did not lose excessive amounts of weight, as many cancer patients do (Poole and Froggatt 2002), and the conclusion was often that they didn't require immediate palliative care input. This seemed to be dependent on whether or not there were specific symptoms that required treating. This could be problematic if the patient deteriorated quickly, as was often the case, as support and input were needed rapidly. In Abdul's case, the community palliative care team reduced their visits in his last weeks of life. His family clearly needed support, but the community staff appeared to believe that their input was not required on such a regular basis. Other nurses noted similar things causing frustration as they attempted to support patients whom they believed to be dying at home:

She very, very anaemic, obviously all of her bloods are going haywire, you know, not just her urea rising but her bi-carb being nine and her potassium being high, just everything. So, the whole renal picture going mad, plus, this huge amount of lethargy. That was it, symptom wise, but she was just feeling so awful. I got the specialist palliative care team, 'Please see her today because I think that this lady is dying. Within a week, I think that she will be dead. And they came to visit her, and no, they didn't think that she was suitable for specialist palliative care and if she deteriorated more they could come back. I was absolutely fuming! ...At the same time I wanted some urgent social care put in and they wouldn't accept her either. I was livid ... And so they didn't and she died, within the week (CNS, G0708, M).

The difficulty in identifying that these patients were coming to the end of their lives was problematic in the study. Conversely, if the community team were involved, they sometimes felt that admission to hospital was an appropriate action even though a patient was dying. This is now discussed.

9.2.4 Admitting to hospital inappropriately

Management of some patients in the study included suggestions from the community palliative care team and the GP that a patient be admitted to hospital for inappropriate interventions. This may have been due to the inexperience of community and hospice staff managing dying renal patients and the view that these patients needed to be managed acutely in hospital where renal specialists would be available. Sometimes there was a request to send a patient to hospital to have chest pain investigated or for fluid replacement if it was thought that a patient was dehydrated.

Sana's community team withdrew and when prompted to visit more often didn't note deterioration in her condition. Then, when things changed suddenly, there was a request to send her to hospital. Increased nausea and vomiting became difficult to treat and it was felt by the community palliative care team that admission to hospital for fluids might be advisable. This was not something that would be instigated by the renal team so close to the end of life as it would only lead to fluid overload. Previously such an admission had taken place only for Sana to be discharged back home again:

After two days she was still very nauseated, and then the family phoned, so she was seen again by the district nurse. We asked the community palliative care team to visit ... but they wanted me to come, I think support them because at that time they felt that they couldn't handle it anymore because, the nausea, which normally stops after two to three days was still going on. The community palliative care team they were thinking about bringing her to hospital. They said probably she's dehydrated maybe just for hydration purposes. I said no we don't normally give fluids to our end-stage renal failure patients. So if she comes to hospital we won't give her fluids anyway. And there was a time when she was admitted because they thought she was dehydrated but she wasn't, so we had to discharge her before (CNS, G0507, int).

Sana's community team did not recognise that she was coming to the end of life and the trajectory to death which is clearer for some cancer patients (Gott et al. 2007), did not appear to be easily recognised by health professionals unused to caring for renal patients. In this case the admission was averted, but lack of knowledge led to admission into hospital for some patients. Often the RSCS were not contacted for their opinion. Once admitted, active treatment was often initiated and hope offered particularly to carers, that the end of life could be averted.

The active management of dying patients gave their families hope that life could be prolonged. As Abdul died, resuscitation was attempted by paramedics called to his assistance by his son. He was pronounced dead when his body arrived at the hospital. His daughter, Salma, who accompanied him in the ambulance, had a suspicion that her father had already died as resuscitation was endeavoured, but the continued attempt gave the family false hope:

Because they kind of gave us a bit of hope because when they took him into the ambulance they were saying they needed to do more checks and stuff like that and then my big sister thought there was a bit of hope and that they can bring him back (AM-2, int).

Abdul's family knew that he was coming to the end of life. This had been explained on several occasions. They were under no illusions that death was imminent and all his family members were present in his house as his death arrived. Unfortunately, due to the uncertainty about exactly when and how death would occur - the hope that he might slip into a uraemic coma making the decision regarding time remaining until death easier to predict - and the unexpected rallying prior to death, the paramedics were called and a fruitless attempt at resuscitation was made.

Paul's family were offered hope in the form of a surgical operation and believed that this intervention was required in his best interests. His son said '*We hoped that he would be OK*' and had no reason to mistrust the opinion of the surgeons involved in this decision. John was admitted to hospital as he deteriorated to death and stopped eating and drinking. An intravenous infusion was commenced and a urinary catheter placed. A long discussion was had with a junior member of the medical team on the telephone regarding the futility of these treatments, and it was suggested that John be made comfortable. His wife decided that she would like him to be cared for in the local hospice. The following day his medical consultant took the decision that he was not yet close to death and that he should go to a nursing home if his wife could not cope at home. His wife now believed that her husband wasn't so close to death and there was time to discuss where he would like to be cared for. He died the following day before the conversation took place.

As families were offered hope in the form of active treatment they soon after had to come to terms with the fact that the treatment had not been successful. The fact that admission to hospital and medical intervention had not succeeded in saving the life of the patient was an added blow to those who hoped that death could be put on hold until a later time.

9.3 Summary

Little is known about the progression of those with renal disease not managed with dialysis. Identifying death in this population is difficult, but an attempt has been made in this thesis to elucidate the specific changes in a patient that occur as death approaches if they are following a uraemic trajectory. This included the identification of 'tipping', where a patient's condition changed after a period of relative stability, and the recognition that certain symptoms, including oedema, pruritus, nausea and extreme lethargy escalated that were difficult to treat. Pain often also increased but the reasons for this are unclear.

Identifying the approach of death was complicated by a number of factors. These included some patients not dying as expected and others dying suddenly. Other patients outlived their prognosis and many managed to live relatively well on much reduced renal function, confounding health professionals. In this study several dying patients were offered inappropriate care by health professionals. This took the form of resuscitation, surgery and acute interventions such as intravenous fluids. Some practitioners encouraged patients to embark on dialysis inappropriately, believing this to be the best course of action, or admitted the patient to hospital when care could have been managed at home. These actions offered hope to some carers that death could be allayed.

This chapter concludes the findings chapters and leads to the discussion. Here the findings are discussed in their wider theoretical and empirical context.

Chapter 10

Conclusions and recommendations

This thesis uncovers evidence of a complex group of patients managed without dialysis who present with multifaceted needs. The overarching aim of this study was to explore the experiences of patients with stage 5 CKD who had opted not to undergo dialysis to treat their renal disease. Specific aims were to:

- describe the characteristics of a cohort of renal patients with stage 5 CKD in a London renal unit who had decided not to embark on dialysis
- identify the healthcare needs of this group of patients
- describe the trajectory towards death (or not) of this population
- highlight issues for consideration when establishing a RSCS for patients managed without dialysis.

In this chapter, the study's findings in relation to these objectives are discussed further and their theoretical and empirical significance are explored. The findings are discussed with reference to Chapters 2, 3 and 4 in this thesis, which sequentially explored a concept analysis of renal supportive care, theories of death and dying and the empirical literature associated with this study.

This thesis provides a PR study of a RSCS, one of the first services of its kind worldwide. The literature review highlighted how little is known about those managed without dialysis, with the majority of papers focusing on withdrawal from dialysis and inspecting the role that the physician has in this decision. As this chapter will illustrate, this study serves to fill some of these important empirical gaps. The chapter begins by revisiting the key features of the study design, and illustrates how these lend weight to the claims made and conclusions drawn. I discuss the strengths and limitations of the study and the main points are summarised here as they relate to the overall conclusions. The remainder of the chapter comprises four main sections.

The first section describes how the service developed over the course of the study: from one where patients deciding not to embark on dialysis had very little input or support from the wider multidisciplinary team, to a service where the patient is centre stage in an attempt to offer quality, life-enhancing care focused on physical and psychosocial needs. This description offers a backdrop to the discussion and explains how the service adapted to patient need as the study progressed.

The second section argues that those managed within a RSCS have unmet needs that have not been uncovered in any depth before. It provides insight into the population which accessed the service and the illness experience, which is new knowledge. These patients suffer a high symptom burden similar to those with other malignant diseases such as cancer. It is argued that not all symptoms could be successfully managed by the RSCS and other professionals had to be called upon to ensure that physical and psychosocial concerns were also addressed. Symptoms identified include oedema, pain, debilitating fatigue, pruritus, nausea and vomiting, immobility, depression and bowel and bladder problems.

Prior to referral to the RSCS, patients had to make difficult decisions relating to a treatment option - dialysis – that is often viewed as life-prolonging. The thesis presents some of the first findings exploring the experiences of patients who make the decision not to embark on dialysis. The decision appears to have been complex and patients presented differently in terms of how much they understood what had been discussed. A central finding, therefore, is concerned with information provision in the context of stage 5 CKD. This section also raises the difficulties that patients (and carers) suffered as they lived their lives knowing that death would come some point soon. The wish not to talk about or dwell on the inevitable death is explored and reasons for this are presented. In conjunction with this, the emotional component that might be expected from a population who are dying seemed to be missing during the clinical consultations and this is discussed. It is argued that the dominant discourse in UK policy, which focuses on lifting the taboo around death and encouraging openness on this matter (DH 2008), conflicts with the preferences of some patients. Although many had accepted that death was coming in that they had put their affairs in order and written wills, they appeared to find further discussion of the topic unsettling and unhelpful. An alternative view of this finding is that as a Clinical Nurse Specialist (CNS) who has worked within a medical model for several years, I was focused on gathering biomedical data and offered patients little time to share their psychosocial circumstances. Interestingly, I did find this a problem in early interviews, and I was able to identify limitations in my present practice. I discuss this within this chapter. Emotional support is an issue requiring further examination in this renal population.

The third section argues that the fate of those dying with renal disease is often different from those dying from other causes, and their functional decline is difficult to predict. Patients who entered the RSCS did not always follow the typical chronic disease trajectory to death postulated in the literature, if indeed they did die. Of those who died, three novel trajectories to death were uncovered and these warrant further investigation. The study highlights how diagnosis of approaching death in patients managed without dialysis was often complicated by the fact that many did not follow linear pathways and how they died was not always entirely apparent due to the multitude of presenting problems. In addition, these inappropriate interventions often led to difficulties in determining what had actually caused the patient's death. The patients in the study could not be considered a collective group with a predictable trajectory and this caused problems for health professionals attempting to manage the final phase of life of this group of patients.

In the final section of this chapter I make recommendations for a way forward for renal supportive and palliative care services based on the findings presented in this thesis. I extrapolate principles that, within the limitations of this study, can be applied to other similar services managing those dying with renal disease. The study has yielded a large number of related publications (see Appendix 12) and within these many recommendations have been made. I have incorporated these recommendations into the conclusions of the present work.

This chapter aims to demonstrate how the data generated from this research contributes to new knowledge. Furthermore, it is suggested that increased understanding in relation to the trajectory and

impact of incurable and progressive renal disease not treated with dialysis will help to determine the specific supportive care needs of individuals through the illness trajectory.

At the outset of this study there was very little previous work in this area. Since then one doctoral study (Murtagh 2008), which corroborates some of the findings of this thesis, has been completed. This piece of work is discussed further in relation to the findings of the study.

10.1 Strengths and limitations of the study

Many of the strengths and weaknesses in the design of this thesis have been discussed in detail in Chapter 4. This section reviews the key strengths and weaknesses taking into account the findings that have emerged. It will allow the reader to assess the significance that can be attributed to the claims made in the remainder of this chapter.

This prospective study is unique in that it is the only one that has followed patients opting not to dialyse over 18 months or until death. It is the only study that has included in-depth interviews. As a Practitioner Researcher I was also able to access patients' clinical notes adding to the clinical detail presented. A great strength of this study has been the ability to approach a group of patients, as I worked as a practitioner and insider researcher managing patients around whom the research was built. This allowed me direct access to patients who shared with me their healthcare needs as they arose, rather than after the event enabling me to learn from patients as they expressed their concerns. In addition, I kept in-depth field notes concerning each patient's trajectory through the service. Another key strength was my ability to feed back to other staff as the study progressed, enabling staff to corroborate or not what was found and adding strength to the findings. Being an insider researcher is now discussed in terms of its strengths and weaknesses and is compared with the strengths and weaknesses of being an outsider researcher.

10.1.1 Insider versus outsider research

Practitioner research enabled an in-depth view of what happened to patients and their carers once they entered a RSCS. The study took place within the clinical setting and aimed to embed research within practice in ways that an outsider researcher would not be able to do (Fox et al. 2008). The approach allowed for unique access to a group of people as they experienced and lived out their trajectory through life with terminal renal failure. It is likely that other approaches, where the researcher was removed from providing clinical care, may have been rejected by the ethics committee as being too intrusive for those coming to the end of their lives. The committee was persuaded that PR would keep the best interests of patients at the forefront as patients and carers were not asked to do anything other than have naturally occurring clinical consultations tape recorded. Recording the learning from this process would not only help others in similar situations, but also enhance the care offered to the patients in the study as understanding of stage 5 CKD managed without dialysis was enhanced and priorities for their care identified through the consultation.

This aside, it could be argued that as the patients in the study knew me as their nurse, they may have withheld information from me which they thought might impact on their care and may have opened up more to an outsider researcher coming into the hospital or their home environment to interview them. The findings reflect a dominance of physical issues, with patients regularly reporting symptoms and the impact these had on daily living. Either this was a real concern to patients, and their psychological issues were less concerning or they may not have felt able to tell me about emotional aspects of their daily living and their life-limiting diagnosis. It may be that patients thought I expected to hear about their symptoms rather than anything else and chose to focus on this aspect. Alternatively, they may have wanted to specifically draw my attention to the problems that they found most troubling, i.e. their symptoms.

Conversely it may have been the very nature of the nurse-patient relationship and the trust between us that enabled patients to communicate more openly and honestly. As the responses they gave me at clinic consultations were to inform their clinical care, it is hoped that this was the case because the withholding of information may have had a detrimental effect on their treatment. Although this cannot ever be determined as a certainty, it is likely that patients were as open and honest as they would be whether they viewed me as their nurse or as a researcher, and therefore the study was likely to have been strengthened by my insider role (Coghlan and Brannick 2005).

The richness of the interview data has led me to believe that patients openly shared their experiences and were able to honestly report life events both positive and negative. For example, Trudy expressed many emotions during her only consultation before she died and appeared happy to talk about her anxieties and worries:

Trudy: No I didn't even know I had renal failure because I don't feel sick in any way, so when they said that I was quite surprised. ... Surely you would, would you feel pain? I was never in any pain. I mean I was working up to 1997 then they pensioned me off ... The first stroke was in 19, was in 2001. That was a TIA and I thought I was getting better. I had another one, and so it went on. I had a trip booked to go to Barbados, I couldn't go ... I wanted to go but the kids were scared.

[Trudy starts crying]

... I cannot get my head around it ... Being like this ... I don't like people, I mean I cannot even wash myself. I don't like being dependent on other people, I hate it ... The diabetes; I think that's the silent killer. I'm angry because my mum, I didn't know if she was diabetic. She never, West Indian parents don't talk about sickness; they talk all sorts of rubbish, but the important things they don't tell you. Apparently her parents were diabetic, so the whole family is diabetic. If I had known that, I used to drink like a fish, alcohol. I used to put away so much brandy and rum, all that time I didn't know I was diabetic. I saw her at home twice on the holiday, and she never said a word. I only discovered that when I went back for the funeral, my uncle told me. The doctor said I wouldn't, dialysis would, why is that, having dialysis, he said it wouldn't benefit me much. I have symptoms, how should I be feeling? (VG-1)

Trudy expressed surprise at her diagnosis, lucidity about her refusal to have an operation, grief with regards to her present condition, anger at her parents and regret about past activities. Her account offers a frank and candid explanation of her experiences, leading me to believe that Trudy felt comfortable talking to me and feeling no need to hide information.

Further research into patients managed without dialysis would benefit by using a PR approach to inquiry as it enabled the dovetailing of clinical practice with research and service development. Furthermore, my role as an insider rather than an outsider within this study meant I was in a suitable position to be accepted as a researcher as I worked as a practitioner alongside the multidisciplinary team. Being an insider allowed me access to knowledge and information that may not have been available through formal data collection methods or to an external researcher new to the organisation. This adds credibility to the study findings, although the issue of insider bias (Ruth 2002) and being too close to the data cannot be ignored. It has been suggested that an outsider may be less blind to the context of a research study and therefore find it easier to see issues more clearly, and an outsider anonymous to the group may be made privy to a differing rendition and provided with other perspectives (Smith 1999). Whatever stance is taken, the importance of reflexivity as an insider or an outsider is essential (Ruth 2002). In this study critical skills in self-awareness (particularly concerned with how I carried out early clinical consultations), sensitivity and reflexivity were of paramount importance (Coghlan and Brannick 2005). Such critical self-awareness helps to question biases from either viewpoint.

Titchen and Binnie (1993) suggest that the insider model is more successful due to the greater integration of authority within practice that a nurse undertaking research in their own organisation is able to achieve, although the stress of continuing a clinical role alongside that of leading a research study may be problematic. Difficulties in managing workload and the research study had the potential to lead to disillusionment and problems with workload in this study. This did not become problematic as my work at the Trust was limited and much of what I did at work was incorporated into the study. For example, a large number of the clinical consultations I carried out became interview data. I then had three full days a week to focus on writing and developing the thesis.

The potential for stress to arise was dealt with during supervision and personal coaching, and did not pose any particular problem. The study was undertaken to fulfil the requirements of a PhD, and reflexivity was strengthened through the university supervision process with experts in older adult nursing, cancer and palliative care and community nursing supervising the study.

A methodological strength of the study was the wide range of methods used during the research process, including interviews, recording of field notes and analysis of audit data which allowed the trajectory to death in those managed without dialysis to be examined from a number of different angles, thus giving richness to the account of the study. This was enabled by my practitioner, insider role with easy access to the service and patient data. I would suggest that PR can be usefully employed by practitioners in practice who wish to carry out research and develop services in their clinical area and can offer a depth and richness of data that might not otherwise be accessible.

10.1.2 Transferability of findings

This PR study enabled the patients of one RSCS to be studied in detail and in context. It has enabled a rich account of patient experience and an understanding of the trajectory to death, if it occurred, to emerge. Questions may arise in relation to issues of transferability from a study carried out in a specific

local context, such as this (Bowling 2002). Conversely, it is also suggested that the systematic nature of an in-depth PR study may generate contextual findings that resonate with others undertaking similar developments, and the potential for generalisation should therefore not be ignored (Lewis and Ritchie 2003). Within the study there were four ways in which the strength of the findings have been enhanced, allowing for saturation of categories and highlighting how findings from the study have been deemed relevant to others:

- At every clinical encounter findings from the previous consultation were fed back to patients and carers to check for understanding. Through this process any misunderstandings were identified and clarified.
- As learning was clustered from clinical encounters with patients and carers I fed back findings to two CNSs doing a similar job to me in the same RSCS, enabling the verification of similar experiences and discussion of confounding findings.
- Findings were fed back to the wider multidisciplinary team to encourage discussion and illuminate issues that were arising and to check for the relevance of what I was finding for the wider team.
- Findings were fed back to other specialist nurses and a doctor working in other Trusts, again to check how relevant the findings were to them in their practice.

Knowledge generated from this study resonated with other renal nurses setting up similar renal supportive and palliative care services throughout the country. This therefore adds credibility to the findings. Sharp (1998) argues that in-depth single case studies offer transferability through recognition. Findings have been presented at national and international conferences in London, Essex, Nottingham, Geneva and Dublin. On several occasions the practitioners who attended described some similar experiences to those experienced by me.

In this study, there has been a systematic approach to data collection and analysis within an appropriate theoretical framework, which has the potential for theoretical transferability (Sharp 1998). Theories have been constructed and tested through the processes of data collection and analysis, and are therefore more widely applicable beyond this particular setting. Techniques such as analytic induction and deviant case analysis have allowed for generalisability of the theoretical claims that have emerged within this study. The findings can be used to improve understanding about current practice in services offered to patients managed without dialysis, although related studies are needed to confirm or refute the explanatory theories developed to address the research aims in this thesis.

10.1.3 Reflections on methodological approach

This thesis has provided, through exploration, some of the first evidence of the experiences of patients with stage 5 CKD managed without dialysis. Some of the methodological challenges of researching end-of-life issues have also been highlighted, and a number of ways to address these are now discussed. This PR study explored a population about whom little is known. Practitioner research, although with

limitations as discussed in Chapter 4, enabled access to patients who might otherwise not have been happy to be part of the research. They were not asked to do anything other than have their consultations tape recorded and consent to having anonymised findings reported in the literature. They did not have to attend extra meetings or complete questionnaires or surveys, reducing the burden that may be attached to such methods. This was viewed as important when designing the study, acknowledging that those recruited would have limited life expectancy.

This thesis also enabled the observation of patients over time. There is a recognition of the need for longitudinal study in nephrology (Ring et al. 2000) and this thesis has addressed some of this need. Advanced illness such as renal disease is a relentless and often chronic reality. Much of its impact is seen over time (Murtagh 2008). In observing and caring for patients as they progressed through the disease pathway and approached the end of life, variations in illness progression and healthcare needs along the way have been extrapolated. Being a practitioner as well as a researcher may well have assisted in enabling this study to continue often up until death in many cases. Although it cannot be certain this personal contact is likely to have helped considerably in allowing access to patients and their carers at such an emotionally charged time. Often I was informed of a death by a family member or friend and several families donated money to the RSCS whilst I worked there as a way of thanking the team for the support they and their loved one received from the service. This approach is less resource-intensive and costly as the research became part of my part-time job. It also helped to overcome some of the problems associated with palliative care research, such as access to patients, gatekeepers who advocate on the behalf of patients and attrition from studies as patients deteriorate and are viewed as too unwell to take part in research (Seymour et al. 2005a).

In the role of practitioner researcher I was able to contribute to knowledge in feeding back findings from the study, and was also in a position to inform service development. The development of the service was of paramount importance as it led to a more patient-centred approach where the needs of the patient were priority.

10.1.4 The contribution of this study to renal supportive care nationally and internationally

As alluded to in the opening chapter, this thesis has contributed to a worldwide debate and general interest in the care of those who have opted not to dialyse. Throughout the process of the PhD I have been encouraged to share my work through publications. This has led to 12 articles and two 'letters to the editor' in peer reviewed journals; 12 presentations at scientific meetings around the world, including conferences in London, Essex and Nottingham in the UK and Geneva and Dublin. I have been invited as a guest speaker to the European Dialysis and Transplant Nurses Association conference in Hamburg this year, a research conference at The Royal Society of Medicine, London and to City University London to a research conference titled: 'How do we know about health in the "real world" to present the findings from this thesis. I have recently been commissioned by one national (*Journal of Renal Nursing*) and one international (*Journal of Renal Care*) journal to write up my findings further. At the same time I have received emails from around the world, including Israel, the USA, the UK, France, Italy, Uruguay and Japan, from practitioners interested in my work. Most recently, Lionel U. Mailloux, M.D., FACP and Clinical Professor of Medicine at the NYU School of Medicine in the United States, cited several times in this thesis, has contacted me to say '*I have enjoyed all your articles. I have had an interest in this field*

(withholding/withdrawing dialysis) for decades' (personal communication, 29 June 2009). He is writing a chapter for Michael Germain's book about death and dying and ethical issues in ESRD patients and has promised me a copy of his work.

In addition, the work from this thesis in combination with the development of the RSCS has led to three awards:

International Journal of Palliative Nursing (2007) Renal Supportive Care Service, Highly Commended. London, UK

Celebrating Success (2007) Renal Supportive Care Service, Runners up. Barts and The London NHS Trust, UK

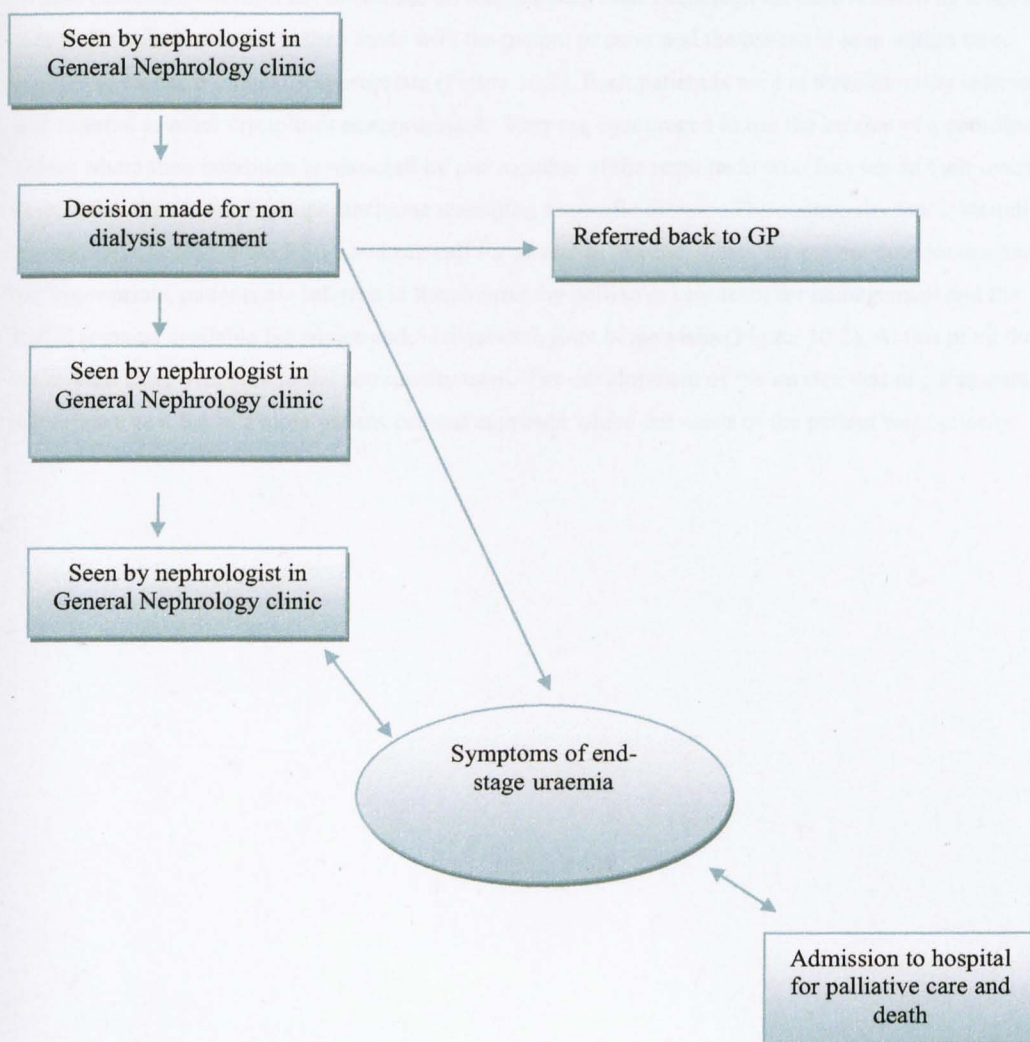
British Journal of Renal Medicine Awards (2008) A Patient-Centred Renal Supportive and Palliative Care Service (2nd Place). London, UK

Clearly, this study is viewed as important and has made an impact on renal supportive care worldwide. It continues to impact on the care of patients opting not to dialyse as practitioners engage with findings from the study and utilise these findings in their own workplace.

10.2 The development of the service during the course of the study

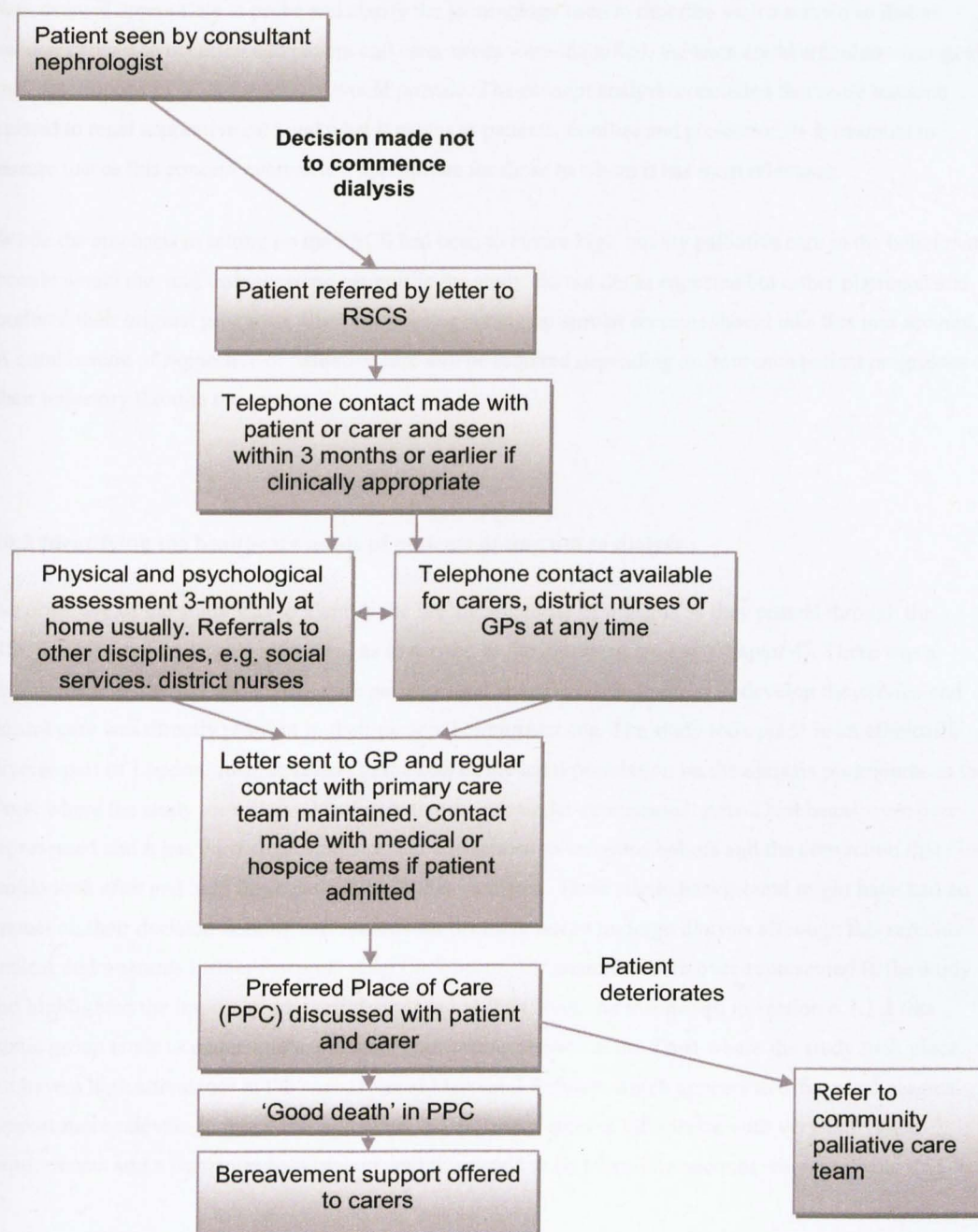
As the senior nurse responsible for setting up and managing the RSCS, I carried out this study working collaboratively with the multidisciplinary team, feeding back findings as the service developed. Over the course of the study the service changed considerably. When it was established in 2005 patients who had decided not to embark on dialysis were followed up by a renal consultant with little input from the multidisciplinary team, or discharged to the care of the General Practitioner. Little was known about their progression and ultimate demise (Figure 10.1). This qualitative PR study was undertaken to address this concern.

Figure 10.1 Typical pathway for patients who opted not to dialyse prior to establishing the RSCS



As the study progressed the service developed, and today we have a very different service from the one referred to in Figure 10.1 and a much clearer understanding of the patient pathway to death. Once a patient makes the decision not to embark on dialysis with their consultant they are referred by letter to the RSCS. Telephone contact is then made with the patient or carer and the patient is seen within three months or earlier if clinically appropriate (Figure 10.2). Each patient is seen at three-monthly intervals and referred to other disciplines as appropriate. They are encouraged to use the service as a coordinating centre where their condition is managed by one member of the renal team who focuses on their overall care, rather than several groups, each one managing a specific disease. The community team, including the GP, have access to the RSCS and can call for advice as needed. When the patient deteriorates and it is felt appropriate, patients are referred to the community palliative care team for management and the RSCS remains available for advice and, if requested, joint home visits (Figure 10.2). At this point the renal team hand over care to the community team. The development of the service was of paramount importance as it led to a more patient-centred approach where the needs of the patient were priority.

Figure 10.2 Care of patients for non-dialysis treatment - The patient pathway today.



10.2.1 The name of the service requires consideration

During early development of the RSCS there had been a debate about what the service should be named. The local Kidney Patient Association (KPA) had opted for RSCS as opposed to Renal Palliative Care Service due to the negative connotations of the term 'palliative', which implied that people would die. As highlighted in Chapter 2, it was decided to carry out a concept analysis to trace the evolution of the concept

'renal supportive care' - to inform this doctorate – to inform a wider debate in the literature and to inform service development. Although there was some uncertainty about how the role of the RSCS would evolve, it was deemed appropriate to probe and clarify the terminology used to describe such a service so that as natural expansion occurred and patient and carer needs were identified, the team could articulate clear goals and descriptions of what the service would provide. The concept analysis concluded that more research related to renal supportive care and what it means to patients, families and professionals is essential to ensure that as this concept evolves it is appropriate for those to whom it has most relevance.

While the emphasis in setting up the RSCS had been to ensure high-quality palliative care in the belief that people would die, interestingly some patients in the study did not die as expected but rather plateaued and outlived their original prognosis. Staff considering setting up similar services should take this into account. A combination of supportive or palliative care will be required depending on how each patient progresses on their trajectory through the service.

10.3 Identifying the healthcare needs of patients opting not to dialyse

An objective of the study was to identify the healthcare needs of patients as they passed through the RSCS. This remains largely unknown, as discussed in the literature review (Chapter 4). There was a requirement to identify and clarify with patients their specific needs in order to develop the service and ensure care was directly relevant to their personal circumstances. The study took place in an ethnically diverse part of London. In comparison to the size of the local population on the dialysis programme at the Trust where the study took place, Muslim patients were under-represented. Afro Caribbeans were over-represented and it has been suggested that this was related to religious beliefs and the conviction that God would look after and help these patients with their decision. Their ethnic background might have had an impact on their decision-making and reasons for deciding not to undergo dialysis although this remains unclear and warrants further research. Afro Caribbeans, for example, were over-represented in the study and highlighted the important part religion played in their lives. As mentioned in section 6.1.1.2 this ethnic group tends to under-utilise the renal counselling service at the Trust where the study took place, but have a high attendance at the annual Renal Memorial Service, which appears to offer psychological support more relevant to many black patients. Each patient entered the service with very individual requirements and a particular background, and this needs to be taken into account when planning RSCSs.

What is not clear is whether or not the service was able to access all those who needed it, whatever ethnicity, and this area warrants further research. It is known that certain groups fail to access palliative care services, such as hospice support (National Library for Health 2009), and that the majority of patients cared for there are white (Goodman 2007). This study has raised ethnicity as an issue.

More females than males accessed the service and the majority of patients were older - over the age of 70 years. Many had coexisting comorbidity, were frail and in poor health. Whether or not these findings are related to the local population only is not clear, but it is likely that others may come across some similarities, particularly in terms of age and coexisting comorbidity. Renal disease is known for its

chronicity and morbidity, including difficult and intractable symptoms which increase with age (Chambers et al. 2004).

10.3.1 The decision

As highlighted in the literature review, it was not until 2005 that we started to hear the patients' stories about forgoing dialysis, and since then there has been little empirical work to move this forward. There are only three studies (Ashby et al. 2005; Fujimaki et al. 2005; Chan et al. 2007) available worldwide and one paper that has arisen from this study (Noble et al. 2009). Findings from this study support some previous work but raise new issues regarding the complexity of the decision. Such findings are missing in previous studies due to small sample size or the prospective nature of the work, where reasons for dialysis abatement have been deciphered from patients' notes and not the patient themselves. Decision-making in this group is complex and decisions not to dialyse are fraught with uncertainty and often not sufficiently resolved.

As described in section 7.1, there was considerable variation in how patients viewed the decision not to embark on dialysis. These included:

- Those who felt that they had made an informed and autonomous decision, either on or against the advice of their doctor.
- Those who felt that they had no option but to refuse dialysis treatment as it would not have been of benefit and might ultimately cause their death.
- Those who stated that they had decided to opt for medication rather than dialysis three times a week and seemed to believe that either option would lead to the same outcome.
- Those who felt that there had been no decision to be made.

Some patients in the study were happy with the decision they had made. This is a similar finding to that of Kacen et al (2005), who explored how and why cancer sufferers made decisions to forgo or stop treatments such as chemotherapy or radiotherapy. Several patients in the present study knew they were making a critical decision to forgo dialysis. Similar to other studies (Ashby et al. 2005; Chan et al. 2007) age was important to some and dialysis was seen as something that would impact on quality of life. However, unlike Ashby's study (2005), patients did not mention dialysis as a waste of resources considering their age, seeing it more as something not to be considered, especially when other illnesses prevailed and life would be hindered by hospital visits and dependence on a machine. Some patients mentioned transport as a reason not to embark on dialysis, knowing transport services to be erratic. Transport issues are known to be problematic for the dialysis population in general (Feehally 2007).

Some patients did not appear to have made an informed decision. Bias free information allowing patients unfamiliar with kidney disease to make informed choice needs to be available (Feehally 2007). Physicians often misjudge the amount and type of participation patients want (Kindelan and Kent 1987). Some patients may not wish to make difficult decisions themselves and may wish for health practitioners to make decisions on their behalf. The elderly may be more likely to prefer having decisions made for them

(Woodward and Wallston 1987). This may change as a younger more informed population age although it cannot be assumed that this will be the case as it is difficult to predict how anyone will present when elderly, frail and struggling to survive. Information needs and decisional preferences have been studied in other contexts and some similarities to the present study can be found. Degner and Kristjanon (1997) explored this phenomenon in women with breast cancer. They found that 22% preferred to take the lead, 34% wanted the clinician to take the lead and 44% wanted to share the decision. Miller and Mangan (1983) referred to two groups of patients: 'monitors' who sought information and 'blunters' who put up barriers and avoided receiving information.

It cannot be presumed that decisions made by patients are fully understood and free from inappropriate professional or family influence, and the decision needs to be regularly revisited to check patient and carers' understanding and to allow them to change their minds if fitting. There is a need to understand how service providers can help ensure that such decisions are informed and supported by the best available supportive care thereafter.

10.3.2 Symptoms

This thesis adds to the body of knowledge concerned with the identification of symptoms in a population managed without dialysis and how they impact on everyday life. A number of symptoms were uncovered, as detailed in section 7.2. The study highlights a need for effective identification and management of symptoms as they arise. Only one study of symptom prevalence in patients managed without dialysis has been carried out (Murtagh 2008) and this took place after the outset of the present study. The majority of symptoms uncovered in the present study have been identified in Murtagh's (2008) thesis and therefore adds credibility to findings from the study. Symptoms uncovered in the present study not reported in Murtagh's work include: trembling, poor vision and phantom pain indicating that different methodologies may uncover varying symptoms (Murtagh used quantitative methods) but that the number of symptoms uncovered with each method was high. Some symptoms were reported due to specific problems, such as phantom pain in a lady who had undergone a limb amputation, demonstrating that the symptoms reported might vary depending on other comorbidity suffered by the patient.

Murtagh's (2008) doctoral study utilised a longitudinal quantitative survey of symptoms and concerns over time, with patient-completed questionnaires administered monthly until death or study end. Although her work illustrates a high symptom burden in this population (similar to the present study), there are differences as well as similarities (Table 10.1). Murtagh's (2008) study focused on data collected at baseline and a month before death, whereas the present thesis took note of symptoms at any point in the disease trajectory, when they were identified by patients as problematic, therefore reporting symptoms that could have been present at any point in the patient journey through the service.

There was a high prevalence of pain, nausea and vomiting, and oedema reported in 70% or more patients in the present study; dyspnoea, bowel or bladder problems, lethargy and immobility in over 60%; itch in 47% and depression in 37% (Table 7.1). Fatigue, itch, drowsiness and dyspnoea were highly prevalent in Murtagh's (2008) study, occurring in 70% or more of all participants at baseline (Table 10.1). Fatigue, itch, drowsiness and dyspnoea occurred in 80% or more of participants in the month before death.

Swelling of the legs, pain, anxiety and loss of appetite were reported by at least 70% of participants in the month before death. Some symptoms were more difficult to compare. For example, Murtagh (2008) reports nausea and vomiting as two separate symptoms whereas in the present study these two symptoms are reported together. Also Murtagh does not report immobility *per se*. Pain, dizziness, dyspnoea and lack of energy could all affect mobility levels.

Table 10.1 Comparison of symptoms between the present study and Murtagh's (2008) study

Present study – symptoms	Prevalence of symptoms	Murtagh's study at baseline (month before death)
Oedema	96%	Swelling of legs 64% (72%)
Nausea and vomiting	90%	Nausea 26% (59%) Vomiting 18% (37%)
Pain	90%	60% (73.5%)
Immobility	60%	Not recorded
Lethargy	53%	Fatigue 90% (86%)
Bowel or bladder problems	53%	Problems with urination 26% (24.5%) Constipation 42.5% (65%) Diarrhoea 7% (8%)
Breathlessness	50%	70% (80%)
Pruitus	47%	85% (84%)
Depression	37%	Not recorded - anxiety recorded at 65% (75.5%)

Murtagh's (2008) study involved the use of monthly questionnaires, which addressed symptoms and other concerns using the Memorial Symptom Assessment Scale – Short Form (MSAS-SF) (Chang et al. 2000), the Palliative Care Outcome Scale (POS) (Hearn and Higginson 1999), the Geriatric Depression Scale (GDS) (Yesavage et al. 1982), and a three-monthly questionnaire, which addressed quality of life using the Medical Outcomes Study Short Form-36 (SF-36) (Hays et al. 1994). This type of study has several drawbacks. First patients with limited life expectancy had to answer 51 yes/no questions, and 53 other questions generally asking them to score a symptom on a rating of 1-5. It has been argued that using quantitative tools in vulnerable populations such as those coming to the end of their lives is problematic, as self-completion measures may be inappropriate for patients who are too ill and frail to complete them (Ingleton and Davies 2004). Sometimes this may lead to the questionnaire being answered by a family member or carer with the potential for introducing bias (Hearn and Higginson 2001). Secondly, having reviewed the questions asked of patients, it could be argued that the suggestion that a patient might have a symptom is enough for them to believe that they have it, particularly when there is such a large range of symptoms to be considered. Thirdly, several symptoms listed had similarities. For example muscle cramps, muscle soreness and pain may have led some patients to report all three to denote pain in general. Another example included questions related to worrying, feeling sad, feeling irritable or feeling nervous. Clearly, these psychological issues may overlap and could lead to over-reporting.

Conversely, the present study allowed patients to use their own words to discuss the symptoms causing them concern, encouraging them to report what was of most importance to them. It is possible that this has led to a more accurate picture of the symptom burden in this population. Alternatively, some symptoms that patients were experiencing may not have been reported and explored, as the more serious issues took precedence at consultation. The qualitative approach also allowed illustration of the impact of symptoms on people's lives, which is less easy to gauge with quantitative tools. Clearly there are strengths and limitations to each methodological approach.

10.3.2.1 Comparing symptoms with dialysis and cancer populations

Symptom prevalence in patients discontinuing dialysis has been highlighted in only one study reported in three separate papers (Cohen et al. 2000a; Cohen et al. 2000b; Cohen et al. 2002) and combined for analysis by Murtagh et al. (2007b). In comparing symptoms with the present study, it can be seen that more symptoms were suffered by the patients managed without dialysis (9 symptoms vs. 7 symptoms), and where similar symptoms were reported, more patients reported them in the present study. For example, 90% of patients reported pain of some sort in the present study compared to 42% of the patients discontinuing dialysis; 53% reported lethargy compared to 25% (where fatigue and lethargy are viewed as similar symptoms); 50% reported breathlessness compared to 25% (where dyspnoea and breathlessness are viewed as similar symptoms), and 90% reported nausea compared to 13% in the group discontinuing dialysis (Table 10.2 and 10.3). As can be deduced, those opting not to commence dialysis appear to have a higher symptom burden than those withdrawing from dialysis to die, although more work is need to determine symptoms in both these populations.

Table 10.2 Reported prevalence of symptoms in patients discontinuing dialysis (n=79) in the last 24 hours of life (Murtagh et al. 2007b)

Symptom	Agitation	Diarrhoea	Dyspnoea	Fatigue	Myoclonus	Nausea	Pain
%	30	14	25	25	28	13	42

Table 10.3 Reported prevalence of symptoms in patients opting not to embark on dialysis (n=30) (the present study)

Symptom	Oedema	Pain	Nausea	Immobility	Bowel and bladder problems	Lethargy	Breathless/dyspnoea	Pruritus	Depression
%	96	90	90	60	53	53	50	47	37

Symptoms in those managed without dialysis can also be compared to those with cancer. Work by the Symptom Prevalence Group (Vainio and Auvinen 1996) identified common symptoms in 1,640 patients with cancer. Findings can be viewed in Table 10.4.

Table 10.4 Reported prevalence of symptoms in patients with cancer (n=1,640)

Symptom	Pain	Anorexia	Constipation	Nausea	Dyspnoea	Insomnia
%	57	30	23	21	19	9

Although there are some difficulties in comparing previous work with the present study, as not all symptoms can be compared like for like, it can be seen that renal patients managed without dialysis experience problems such as pain (90% vs. 57%), nausea (90% vs. 21%), dyspnoea or breathlessness (50% vs. 19%) and bowel problems (53% vs. 23%) more often than do cancer patients. They also suffer more symptoms than those reported in the cancer population (9 vs. 6 symptoms).

The findings of this present thesis are of immense importance as they point towards a population with a high symptom burden requiring symptom control. As services are being established to manage this group, this new knowledge is of great importance to ensure that symptoms are managed appropriately in an attempt to improve quality of life. Findings from the present study also indicate that as symptoms escalate and death approaches, symptoms such as fluid overload, pruritus and lethargy are difficult to treat and indicate that death is close. This new knowledge can help staff as they attempt to determine when the end of life is approaching.

10.3.3 Managing an uncertain prognosis

Although most of the patients in the study understood that they had a life-limiting disease that would reduce their length of life, many did not appear to want to talk about death and dying. This has been

found in other work (Seale 1998; Calvin 2004; Hammoud et al. 2005; McQuillan 2008). The majority were aware of the terminal nature of their illness and had made plans for their death, but many seemed to find it unhelpful to discuss end of life issues. Like those in Weisman and Kastenbaum's (1968) study, fear of death was seldom expressed but patients appeared to be aware of their shortened life expectancy. Unlike those older patients in Young and Cullen's study (1996) who were dying with cancer, death was not openly talked about and patients didn't talk about plans for their funerals or meeting dead relatives in another life. This conflicts with the openness which many patients with advanced cancer are said to display in discussing the end of life (Kutner et al. 1999) and with government policy in the UK (DH 2008), which promotes an openness in planning for death and an end to our death-denying culture.

The findings from this thesis challenge the current discourse in the literature and media promoting openness around death in order to enable people to die where they choose (DH 2008). Patients in the study chose not to embark on these discussions for a variety of reasons, including:

- death being a subject too difficult to discuss
- the severing of hope if death was discussed
- not wanting to dwell on the inevitable.

An alternative view of this finding is that, as a CNS who has worked within a medical model for several years, I was focused on gathering biomedical data and offered patients little time to share their psychosocial circumstances. Interestingly, I did find this a problem in early interviews and was able to identify limitations in my present practice. This led to me allowing more time for interviews and, where possible, I visited more patients in their own homes. The quality of my data was much improved through these processes and led me to discover new information that had been previously neglected. For example, although I had assumed that the patients entering the RSCS had made an informed decision not to dialyse and were aware that they would die as a consequence, in reality, I discovered some of them to be somewhat ambivalent about their decision and others seeming to lack an understanding of the decision that had been made. Many talked in some depth about what had been decided and I was able to encourage this discussion at consultation. Also, an emotional component was identified in many of the interviews revealing a number of patients who admitted to feeling depressed (see Section 7.2.8). The majority of patients chose to manage this symptom alone, refusing medical intervention or counselling services, indicating a need to accept and get on with their lives without dwelling on the emotional side of things. I would suggest that the patients in this study were happy to discuss more emotional, intimate concerns, but that for many death was a step too far and not something that they wished to dwell on with me as their nurse or often at home with their families and friends.

There is conflicting literature to be found when attempting to determine how keen people are to discuss end-of-life options and issues. It has been suggested that little is known about what people want when they are dying as this is a very difficult population to access ethically (Seymour et al. 2005a). Alternatively, it is postulated that many patients, particularly those with cancer, where most research has been carried out, prefer an open and honest environment where all possible information, whether good or bad news, is offered (Kutner et al. 1999; Jenkins et al. 2001). Interestingly, Jenkins and Fallowfield

showed that 87% of patients wanted all possible information, both good and bad news, but 13% of patients stated that in general they preferred to leave disclosure of details up to the doctor. These patients tended to be older - more than 70 years of age - as in the present study. It may be that those who are older have a different perspective from those who are younger and are less likely to engage in end-of-life discussions, perhaps because they are aware that their life is coming to an end and they find discussion unhelpful.

There is a small emerging discourse concerned with those who do not wish to discuss their impending death. Although there is evidence that some people do wish to have these discussions, and the cancer specialty has strived to confirm this, not all do. A personal communication with Professor Sheila Payne (6 April 2009) led to her comment *'Advance Care Planning is in my view based on an assumption that people are able and willing to contemplate their own death. It is a rational cognitive model which is deeply problematic'*. Clearly, some people are not able or do not wish to prepare openly for death and this needs to be taken into account. Professor Payne identified several people exploring end-of-life issues in patients with heart failure and COPD. They have found that many participants do not want to engage in advance care planning or discussions about death, but accept that they are dying and have planned their funerals and made arrangements for death.

Another perspective is that patients need to engage in discussions about the approaching end of life because they will ultimately witness their deteriorating body, a reduction in their ability to perform and increased fatigue (Fallowfield et al. 2002), so they will know that all is not well. In those with chronic illness suffered over many years it may be more difficult to determine when they actually weaken towards death, instead associating that weakness with advanced age and chronic disease.

Findings from the present study concur with those of Calvin (2004), who highlighted that although there is a general lack of knowledge about the end of life treatment preferences of patients undergoing haemodialysis, when prompted to think about this, patients chose to focus on living rather than dying. Patients in the present study did not adhere to the Kübler Ross's stage theory of dying (Kübler Ross 1969). They did not appear to move through stages that included denial, anger, bargaining, depression, and acceptance, where they openly discussed how they were coping and managing their terminal diagnosis, although it may be that they did display such emotion in the months that elapsed as they made their decision and were eventually referred and seen in the RSCS.

On the other hand, the findings are in contrast to those of Davison and Simpson (2006). They suggest that patients with stage 5 CKD are willing to discuss end of life issues openly and wish for more information earlier in their disease, including information on how certain interventions might help them maintain their roles and relationships. The reason for this may be that those with stage 5 CKD managed on dialysis have not been told that they are dying and until this news is given it may be easier to reflect on what you believe you may wish to happen at the end of life.

It cannot be assumed that all patients will want to engage in end-of-life discussions in such an open manner as that suggested by the UK government (DH 2008), and each patient needs to be assessed individually to determine how well informed they wish to be.

10.3.3.1 The place of hope

Weisman (1972) confirmed the importance of hope in experiences of dying in order to progress the concept of an 'appropriate death', as discussed in Chapter 3. Hope may be maintained by refusing to dwell on the inevitable death. There has been relatively little work done focusing on late illness and information needs (Innes and Payne 2009). What has been determined is that hope is a very personal concept created differently between individuals. Depending on what hope means for an individual, a paradox may exist if someone also wishes for realism. Patients may ascribe hope to something such as positive disease outcomes, which makes it unclear if hope and realism can be concurrently achieved in those with advanced disease (Innes and Payne 2009). Another paradox is found between the need for honesty and ambiguity. For example, Kutner et al. (1999) found that all patients wanted doctors to be honest, but 91% also wanted them to be optimistic. Although there is a push for openness and honesty, some studies suggest that patients wish for honesty but also want to maintain optimism. This paints a complex picture of patients who are clear in the knowledge that they will die but want to maintain hope and optimism until the end, or of apparently wanting to know but not wanting to know the absolute truth (Innes and Payne 2009). Opting for full clarity and openness may be detrimental to some patients and this needs to be taken into account. For some patients, hope may only be maintained by there being some ambiguity about the future rather than clear detail on what to expect and when it will happen (Innes and Payne 2009). Some patients and carers may wish to hold on to hope until death, even in the face of admission to a hospice and the approaching end of life (McQuillan 2008).

It has been acknowledged that Muslim patients may not want to be told or reminded of their terminal illness (Hammoud et al. 2005) in order to maintain hope. There may be cultural issues that need to be taken into account when discussing informational needs towards the end of life.

10.3.3.2 Older people accepting that the end of life is approaching

Those who are dying are not yet dead and may have things they need or want to do (Corr 1993). This may include not dwelling on the fact that death is pending. It may be that the patients in the study, the majority of whom were over the age of 70, had accepted their diagnosis and prognosis and were more focused on turning inwards and reflecting on life as a way of completing it, as found by Andersson et al. (2008). They found that older people receiving care in the last period of life often felt trapped by ill health and struggled to maintain dignity, but ultimately achieved peace in the presence of approaching death. This supports Tornstam's (2005) work in the area of gerotranscendence, with a redefinition of time, life and death and also the self in old age. A decrease in material goods is replaced by a greater need of solitary meditation. This indicates an acceptance of what is transpiring in old age rather than an outcry at the injustice of approaching death. Older cancer patients may be less troubled by their diagnosis than younger people and may be more accepting of death (Koffman and Camps 2004). These patients have been shown to be aware that death might come at any time and seem to accept this as part of their life course,

something that may not be encountered in a younger population with such a disease (Young and Cullen 1996).

Older people who are not dying have been found to believe that death is easier to face for those of advanced age (Catt et al. 2005) and are happy to talk about death and dying (Forbes 2001). Death has often been addressed as an inevitable completion of the life circle, something that had to be accepted since it cannot be avoided (Leichtentritt and Rettig 2000). This attitude is in conflict with the findings from the present thesis and it may be that there is a difference in outlook between older people who have been told they will die and those who are old and expect to die but have not been given a terminal diagnosis. This has implications for practitioners who need to be aware that not all older patients may want to dwell on the fact that death is approaching especially those who know this for a fact in light of a disease causing a poor prognosis. More recently, Gott et al. (2008) found that older people with heart failure did not want an open awareness of death and an acknowledgement of potential imminent death.

It may be that many of the patients in the study had accepted the severity of their disease but chose not to disclose very much in relation to how they felt about this, preferring to accept what had happened without great fear of death. This warrants further research although it is recognised that this would be ethically difficult to explore; a patient deciding not to discuss death and dying may not wish to discuss why this is so.

10.3.3.3 Comparison with the withdrawal from dialysis population

Those who make a decision to withdraw from dialysis will be aware that they will die within an average of 14 days. Although little is known about this population several studies have described how patients took some time to reach their decision (Cohen et al. 2000b; Ashby et al. 2005) which was often preceded by much anguish and physical distress (Jablonski 2007a). These patients may make a decision that ultimately brings them peace from the therapy that keeps them alive but physically unwell. They know their time to death will be short and, from personal experience, many are happy to talk about the end of life and make decisions about where they would like to die. They talk about the relief they feel having made the decision and often appear accepting of the decision they have made. This group of patients may be more willing to discuss the end of life because in many cases they have made the decision to end their lives and it is certain that they will die. This area warrants more research but it is acknowledged that ethically this is difficult as these patients are very vulnerable.

Patients opting not to dialyse may be different in terms of their conversation preferences because they do not face death so directly. Many will not suffer such physical distress and in the present study many suffered few symptoms for months and sometimes years. Many symptoms were managed successfully and life continued at a normal pace for some time, particularly when patients plateaued as seen in section 9.1.1.

Patients in the study did not seem to experience the same problems as those who decided to embark on dialysis. Here life has been described as '*permanently altered*' with '*reformulation of identity*' (Martin-McDonald 2004) and dialysis is described as a complex regime of restricted foods and fluids, arrays of

medications, technological management and aseptic techniques and skills. There is also the pressing reality of death without dialysis highlighting mortality. Martin-McDonald's study (2004) highlights themes of '*enduring*' and '*getting through*' an intolerable situation. '*Suffering*' is identified as a lost past is acknowledged and '*despair*' arises as suffering pervades the individual's ability to draw meaning from dialysis-dependency. This torment, despair and suffering did not appear in the present study perhaps indicating more acceptance in those maintained without dialysis and less suffering brought on by dependence on a machine in those receiving dialysis. It is recommended that future research focus on the emotional components of those managed without dialysis and how they manage and reconstruct their identities, if this is what happens, following a terminal diagnosis usually at an advanced age. There is also an urgent need for comparative studies to compare outcomes in those opting not to dialyse and a similar cohort deciding to commence treatment.

10.4 Exploring the trajectory to death (or not) of those opting not to dialyse

An objective of the research was to explore the trajectory to death (or not) in those making a decision not to embark on dialysis. This was important as the literature review (Chapter 4) highlighted a lack of knowledge in this area with this trajectory never being previously studied. This thesis has uncovered a renal trajectory or pathway that was often complex and difficult to predict.

As previously discussed in Chapter 8 there appeared to be three types of death;

- The **predictable uraemic death**, where patients plateaued on entering the RSCS, occasionally showing some initial improvement and eventually '*tipped*' relatively quickly over a period of weeks to death.
- The **non-uraemic death**, where death was caused directly by another illness other than renal disease, such as cancer or heart disease. Here death was predictable and once the end of life was in sight, death could be planned for and managed relatively well.
- The **unknown cause of death**, where it was unclear why death had occurred. Here patients either died relatively unexpectedly or received inappropriate treatment very close to death, making it difficult to assess the cause of death.

This study concludes that the fate of those dying with renal disease is often different from those dying from other causes. Although some patients in the study showed similarities to those following disease trajectories other than renal failure, others didn't and their functional decline was difficult to predict. The patients in the study could not be considered a collective group with a predictable trajectory. Trajectories to death are usually studied in a quantitative fashion and have been depicted in the literature as mean scores over time (Cheung et al. 2008). The present study is different in that the trajectories have been construed from the stories of patients, carers and staff over time, and from personal observations. This is a

novel way of collecting trajectory data. It shines a light on trajectories as observed longitudinally rather than measured using questionnaires.

Studies of the functional status of patients at the end of life suffering with cancer have found that they are often in relatively good health until one to two months prior to death (Teno et al. 2001). Some renal patients, particularly those following a uraemic pathway followed a similar pattern but others didn't. Previous work with heart failure patients has suggested a trajectory where gradual decline in functional status occurs, interspersed with acute periods of deterioration where the patient might die (Lunney et al. 2003). Again, several patients followed this pathway particularly if they suffered heart failure alongside their renal disease and the heart failure was the most concerning disease. These patients followed the organ failure trajectory (Lunney et al. 2003). Recently, the heart failure trajectory has been challenged by Gott et al. (2007), who depict individual trajectories of physical limitation scores over time for patients with heart failure, for the two years prior to death. As with the present study, they found considerable variation across individuals.

The heart failure or cancer trajectory was particular to those whose primary disease was to cause their death rather than the renal disease itself, but many patients did not conform to this pattern. Like people with chronic obstructive pulmonary disease (COPD), who tend to live in a continuous state of poor health punctuated by intermittent exacerbations of ill health (Canadian Thoracic Society 2004), some patients followed this trajectory. Others of more advanced age underwent what could be termed 'prolonged dwindling', as in those with dementia or generalised frailty of multiple body systems (Lunney et al. 2003). Paul, for example who was 91 years of age, lived for many months following his diagnoses of stage 5 CKD but he was frail, depressed and dependant on his family for care over a one-year period.

Other patients in the study followed a route where their renal disease appeared to plateau and deterioration was slow and difficult to predict over many months and even years. This trajectory has not been described before and adds to theoretical knowledge of dying trajectories. Murtagh's (2008) study demonstrates a marked increase in symptom distress and other concerns in the last two or three months before death. She reports that patients followed stable or steadily increasing patterns over time, with some following fluctuating patterns. She also adds that stage 5 CKD patients may follow a fourth pattern of functional decline towards the end of life, which differs from those previously described. Here functional status is largely maintained over much of the last year, followed by a very rapid decline in the final month of life. It has been suggested by one author that the duration of the final illness in patients managed without dialysis is short at 3-7 days (Williams et al. 2002), but this was not observed in this study during the final phase of life. Either patients died from a cause other than uraemia, received acute intervention at the end of life, (which prevented observation of the uraemic end phase), or died a uraemic death where the end phase could last from days to weeks. Plainly, determining what constitutes an end phase is not clear, making an attempt to describe how long it may last fraught with difficulty. Although the present study followed 30 patients in detail, it did not allow for close observation of every patient as death closed in, so clarity around the last weeks is difficult to determine. This last phase warrants more in-depth research to enable exploration of needs closer to the time of death and to further inform trajectories to death in patients managed without dialysis.

10.4.1 Difficulties for health professionals

This study has identified a group of patients with Stage 5 CKD managed without dialysis who experienced a number of different pathologies. They were often cared for by staff who did not recognise when they were coming closer to death. Many of these staff had little or no training in the care of patients with renal disease. Even though these patients can be described as having '*advanced, progressive, non-curable disease*' (Doyle et al. 1993) - a phrase that defines palliative medicine - they were not always treated in this way and palliative care was often not available until the very end stage of life, if at all. Some patients were encouraged to embark on dialysis when they became symptomatic of their renal disease even though the decision had been made with the patient that this was not in the patients' best interests. This may be due to the need by some health professionals to offer a treatment whatever the prognosis, described by Smith et al (2003) as '*the unnecessary medicalisation of death*'. Alternatively, a lack of understanding of the complexity of dialysis and its effect on those with multiple comorbidities, advanced age and general frailty (Germain et al. 2007) may have led to some professionals believing that dialysis would be of benefit to the patient. A lack of research carried out on the population in the study has led to a situation where it is unclear when dialysis will lengthen or shorten life. This lack of research has led to a position where patients are centre stage in a dilemma that is not easily resolved. Also, it is known that practitioners will hold their own personal views on the viability of dialysis treatment (Lambie et al. 2006)

Unfortunately, even when palliative care professionals were involved, patients were not always identified as dying. Some patients died unexpectedly and others who were expected to die, perhaps after discharge to a hospice for the last days of life, rallied round and continued to live. This often made any attempt to diagnose death difficult and could lead to patients receiving inappropriate care, such as surgery or resuscitation, with death usually following these acute events. McGrath and Henderson's (2008) study found that participants in all professional groups thought end of life issues were the major cause of ethical concern, creating tension between health professionals, patients and their families. Doctors indicated that a central anxiety centred on a duty to treat versus alleviating suffering when the patient was moving to the dying trajectory. It may be that health professionals in the present study were driven to do all they could for patients failing to recognise how close death was. Many doctors feel unprepared for end of life decision-making in their medical education and have to rely on experience from practice (Holley et al. 2003). If doctors are relying on experience, they may find treating the renal patient at the end of life difficult due to this lack of experience in this area; the numbers opting not to dialyse are relatively small in comparison to those with heart failure or COPD (Cameron 2002).

Many of the patients, although often frail towards the end of life, did not 'look' like they were dying, and the renal disease therefore remained hidden. They didn't suffer dramatic weight loss, as seen in those with cancer (Poole and Froggatt 2002) or suffer obvious distressing symptoms such as severe breathlessness, as in those dying with COPD or heart failure (Gott et al. 2007). This study demonstrates how difficult it is to identify imminent death in this renal population. It has implications in terms of timing and delivery for improving the quality of care for these patients and advocates a need for very individual care planning.

10.4.2 Tipping

In the study several patients were identified as 'tipping'. A 'tip' was acknowledged in those following a uraemic pathway to death, where an incident such as a fall or sudden development of troublesome symptoms occurred and the final phase of life ensued. Such developments gave warning of approaching death, although further research is warranted to ascertain the predictive value of such events. Murtagh's (2008) study describes an increase in symptoms in the last months before death as possible 'tipping points', thus using similar language to describe a time when transition occurs and death approaches.

Identifying and understanding when patients might 'tip' towards death can be identified best using longitudinal research, as utilised in this study and is an approach that is recommended. A 'tip' was the point at which identification of a terminal phase occurred following a period of relative stability. At this time healthcare professionals involved in the patients' care were made aware of a possible escalation to death. Identifying a 'tip' can aid in ensuring that symptom interventions are targeted to provide most benefit as the patient deteriorates and becomes more symptomatic. The PPC (Pemberton et al. 2003) should be clarified and achieved where possible.

'Tipping' has not been described in the literature. The word 'tip' means to 'push', 'knock over' or 'topple'. It also implies assuming a slanting or sloping position, an 'incline' or 'tilt' (Dictionary.com 2008). It is a word that implies a downward change in circumstances. It warrants further development as a word that can describe a change that occurs in renal patients managed without dialysis who have previously been well but go on to deteriorate. This change or 'tip' indicates that death is approaching more quickly and may be a marker for escalating care and support as the end of life approaches.

10.4.3 Patients and carers need to be supported through an uncertain prognosis and trajectory

The findings from this study have highlighted a group of patients and carers who had to live with and manage an uncertain prognosis. Many patients did not wish to talk about death and the end of life. Although the majority were aware of the terminal nature of their illness, because of the paucity of evidence, it was difficult to predict how much longer each patient would live. Patients often managed this situation by not dwelling on the fact that death was approaching and attempted to maintain hope by avoiding conversations with staff and carers which focused on the end of life.

Identifying when the end of life was coming closer was difficult, as the findings in this study reveal. This meant that some patients received acute interventions as death approached or some practitioners withdrew as death advanced. Some patients were admitted to hospital inappropriately. The findings suggest that many staff unused to caring for and managing those with stage 5 CKD did not have the expertise to offer appropriate care to a population with palliative care needs.

Carers faced a situation where they were often unsure what to expect in terms of how a patient might progress and some worried that they would suddenly die. Carers often had to manage difficult symptoms and worried about how they would cope as the patient deteriorated. Some carers made the decision to move the patient to a nursing home when they could no longer cope. If health practitioners remain

ignorant of the fate of those opting not to commence dialysis, it can be assumed that patients and carers will know less. They need to be made aware of the literature available in order to assist in the many decisions that might need to be taken along the trajectory to death, but research in this area must also be carried out in order for practice to be informed.

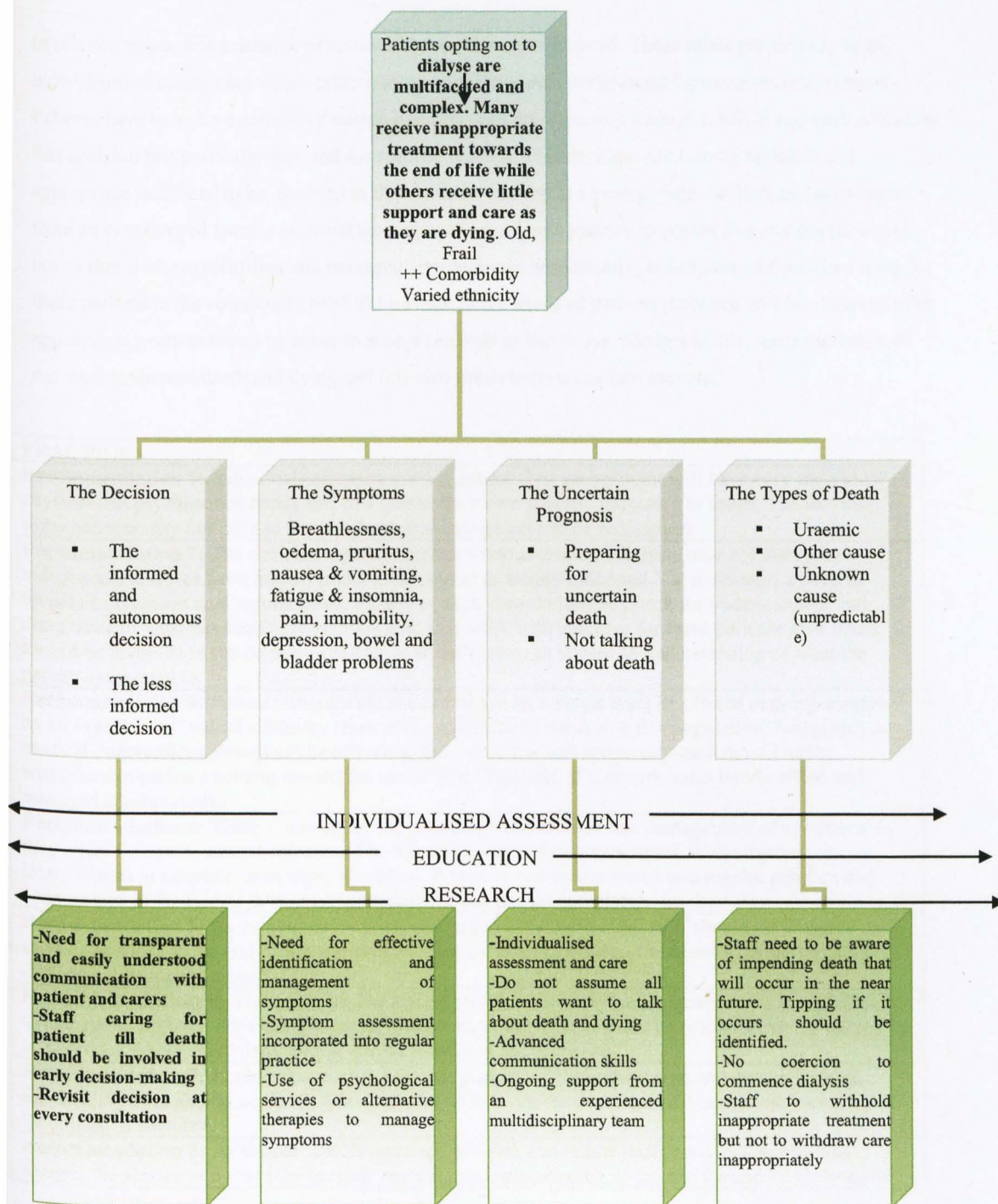
10.5 Recommendations for staff developing Renal Supportive Care Services

It's not like cancer where there's a final common trajectory ... actually you get quite a lot of diversity. So one size does not fit all, you've got to tailor it to the individual. And you've got to build in a degree of responsiveness to the unpredictability (Dr, M0108, M)

The findings from this study draw attention to a multifaceted population managed without dialysis with healthcare needs that require addressing, and a trajectory to death that is often unpredictable. This unpredictability leads to some patients receiving inappropriate care towards the end of life or others receiving very little as death approaches. The decision not to embark on dialysis, the high symptom burden and the need to manage an uncertain prognosis are healthcare requirements raised by the patients in this study and therefore require prioritisation. These findings emerge at a time when the needs of those who have opted not to dialyse remain relatively unknown although some other services are being developed to address this (Murtagh et al. 2006; Chan et al. 2007). Supportive and palliative care for patients who have reached stage 5 CKD is starting to emerge as a priority in the nephrology field. Recognition of need in this population is evident in the first ever textbook devoted to *Supportive Care for the Renal Patient* (Chambers et al. 2004), although its focus is on those managed on dialysis rather than those who have opted against this treatment. The *National Service Framework for Renal Services* (DH 2005) highlights the need for appropriate end-of-life care for renal patients and the Royal College of Physicians' report on the *Changing Face of Renal Medicine* (Royal College of Physicians 2007) in the UK recommends joint working between the renal multiprofessional team, primary care and other services such as palliative care promoting integrated care for patients with CKD. The recent *End-of-life care Strategy* (DH 2008), with a focus on death from any disease, has stressed the importance of education, training and continuing professional development for staff.

The findings from this study have made a number of important contributions to knowledge. Figure 10.3 provides a useful conceptual framework for others intending to set up similar services to the one presented in this study. It summarises the key contributions to knowledge in this thesis and how specific recommendations link to these key areas. Many of the recommendations from this study require improved professional skills set within a professional development framework which encourages best evidence-based practice and life-long learning. Although an understanding of those managed without dialysis is increasing, there is still much work to be done to truly understand the healthcare needs and trajectories to death in this population and ensure that they receive appropriate care, similar to those with cancer and other chronic diseases. This following part of this chapter therefore focuses on the recommendations for policy, practice, education and research.

Figure 10.3 Conceptual framework of key findings and recommendations



10.5.1 Recommendations for Practice

In relation to practice a number of recommendations are put forward. These relate particularly to an individualised assessment which takes into account individual preferences for treatment and support. Patients have to make a complex decision that precedes the trajectory through a RSCS and each will make this decision in a particular way and for specific reasons. This decision needs to be revisited and appropriate staff need to be involved in this decision-making at an early stage. Multidisciplinary input from an experienced team is essential throughout the patient's journey to ensure that any psychosocial issues that arise are identified and managed appropriately. Importantly, colleagues who will be caring for these patients in the community need to be aware of the needs of patients managed without dialysis, offer appropriate treatments and be ready to accept referrals as they arise. Alongside this, some patients will not want to discuss death and dying and this also needs to be taken into account.

PRACTICE
Recommendation 1: Individualised assessment is essential as each patient will have very individual physical and psychosocial needs and will follow their own specific trajectory to death. The fact that some patients may not want to discuss death and dying needs to be recognised.
Recommendation 2: The decision a patient makes not to embark on dialysis may not always be independent and free from inappropriate professional or family influence. There remains a need to revisit this decision on a regular basis, usually at each consultation, to check for understanding and acceptance of what has been agreed. Staff who will work with and care for these patients until death should be involved in the decision-making at an early stage to ensure an understanding of what the patient has agreed to.
Recommendation 3: Patients who decide not to embark on dialysis must be offered ongoing support by an experienced multidisciplinary team with experience of managing this population. Inappropriate medical interventions should not be offered at the end of life and conversely care should not be withdrawn in patients coming toward the end of life. 'Tipping', if it occurs, must be identified and managed appropriately.
Recommendation 4: There is a need for the effective identification and management of symptoms as they arise. Symptom assessment should be focused on identifying symptoms, with targeted interventions to alleviate them when identified. It needs to be incorporated into regular practice and become part of the role of those managing patients not receiving dialysis.
Recommendation 5: As symptoms intensify and prove difficult to treat, staff should be prepared to escalate services as the end of life approaches. This includes referral to community palliative care if this has not happened already.
Recommendation 6: The use of psychological services may help some patients who have difficulty to manage symptoms. For example, issues around immobility that cannot be resolved may be helped by an approach where small daily targets can be identified and achieved.
Recommendation 7: In order to care for and keep patients in the community, and reduce hospital admissions, there should be access to palliative care liaison and community and hospice services should be utilised as required.
Recommendation 8: As similar RSCSs develop, patients, carers and staff should be involved in naming the service as a first step towards ensuring an understanding of the service and its philosophy.

10.5.2 Recommendations for research

This study presents some of the very first research which explores the needs and trajectories to death in those managed without dialysis, but also highlights a number of future research needs in this area.

RESEARCH
Recommendation 9: Further study is recommended to generate knowledge on the benefits of supportive care for patients with stage 5 CKD versus dialysis therapy to inform decision-making in future. Research needs to be carried out which compares outcomes in these two groups so that identification of who might not benefit from dialysis and why becomes clearer.
Recommendation 10: Further study is required to explore decision-making in this population at the time that the decision is being made in clinic. This work will enhance the understanding of staff and the decision that patients have made.
Recommendation 11: Research into patients opting not to dialyse investigate and take into account the make up of patients accessing care so that needs based on ethnicity, gender, age and associated comorbidity are taken into account.
Recommendation 12: Ethnicity of patients opting not to dialyse in relation to the ability to access palliative care requires further study. It is unknown if ethnic minority groups with renal disease have problems accessing quality palliative care. Until this is explored, it must be assumed that they do as it is known that they do not access hospice services as regularly as their white counterparts.
Recommendation 13: A symptom assessment tool needs to be validated and used regularly in clinical care, as suggested by Murtagh (2008). Although this is a valid proposal, care needs to be taken not to develop tools that are burdensome or time consuming as the population using them is generally frail and has a limited life expectancy.
Recommendation 14: As recommended by Murtagh et al. (2006), there is a need to generate standards for the development of a RSCS and to conduct research on this topic.
Recommendation 15: Partnerships need to be developed between healthcare providers, international groups and academic centres to develop programmes of research which focus on those being managed without dialysis. Accurate information is required to ensure the provision of appropriate care to this population as services are developed.
Recommendation 16: More research is needed to generate knowledge of the benefits of supportive and palliative care for patients with stage 5 CKD, to ensure that the patients' and families' point of view is acknowledged in a qualitative manner.

10.5.3 Recommendations for education

The development of services for patients who have opted not to dialyse is now progressing. Staff need to be aware of the priorities of care for these patients and educational programmes which take into account the findings from this thesis need to be developed. How information is provided and communicated is also of paramount importance considering the enormity of the decision that these patients need to consider. As more patients with stage 5 CKD are counselled about treatment options staff are challenged to provide bias-free information allowing patients unfamiliar with kidney disease to make informed choices. There is much to learn about the provision of such information and how it is transmitted. The cross-fertilisation of ideas via disciplines, particularly renal medicine, and palliative care is required but other teams may need to be involved depending on the needs of each patient.

EDUCATION
Recommendation 17: Staff should partake in education concerned with those opting not to dialyse in a structured manner ensuring that the communication skills required are highly developed. A need for good communication is obvious, but understanding what needs to be communicated to best help patients is often under-recognised.
Recommendation 18: It is recommended that the specification of educational programmes that focus on how and why patients make the decision not to embark on dialysis are based on observations of practice that focus on the needs of the patients and individual staff members. Associated competencies should be developed and evaluated to ensure that more knowledge in this area is applied in the clinical setting.
Recommendation 19: Education focused on identifying and managing needs such as symptoms must be incorporated into educational programmes and have an evidence base.
Recommendation 20: It is recommended that joint working takes place between palliative care specialists and those with expertise in nephrology so that knowledge is shared in order to provide best

quality and expert care. Links with other teams, such as Older Adult and Heart Failure services, should be made where appropriate.

10.5.4 Recommendations for policy

The *National Service Framework (NSF) for Renal Services: Part 2* includes a specific section on end-of-life care. It advocates the development of a combination of palliative care and renal skills to provide and extend services (DH 2005). Although policy supports the idea of caring appropriately for those opting not to dialyse the problem remains that so little is known about them. This aside, policy that supports research in this area and also encourages access to supportive and palliative care services must continue to be developed.

POLICY
Recommendation 21: Palliative care services should continue to reconfigure their services to incorporate those dying with renal disease. Presently, these services are still geared towards caring for those with cancer (Hockley 2006), which means that practitioners working in this field may have little experience of caring for older people who happen to have renal disease, dying without cancer.
Recommendation 22: Increased awareness of the effects of stage 5 CKD needs to be communicated to the public. This is essential in providing a holistic approach to care which informed patients and carers can access.
Recommendation 23: In order to raise public awareness of the effects of stage 5 CKD it is recommended that screening, diagnosis, prognosis treatment options and care at the end of life is fully supported by government policy.
Recommendation 24: Consideration must be given when naming new services to ensure they reflect what is actually being offered. It is suggested that services established to support those opting not to embark on dialysis use the term 'supportive' rather than 'palliative' care or, alternatively, use both terms to reflect the nature of the work involved.

10.6 Closing comments

A number of important findings have emerged from this study, which was carried out while I worked as a practitioner. These relate to the complexity of patients living life having made a decision not to embark on dialysis. Such patients have multifaceted needs and a trajectory to death that is often unpredictable. This unpredictability leads to some patients receiving inappropriate care towards the end of life or others receiving very little care as death approaches. The findings from this study have thrown light on these phenomena and in this chapter recommendations for future practice, education, research and policy are made. This chapter closes with a summary of the contributions this study makes to the body of knowledge. The findings have filled some empirical gaps, provided empirical support for existing theory and added to existing theory.

10.6.1 Empirical contributions

Findings illustrate how the incorporation of non-dialysis care into counselling for patients with terminal renal disease creates additional challenges for practitioners. It is clear that decision-making in those managed without dialysis is complex and unique to each patient. Findings concerned with the decision not to embark on dialysis are therefore of great relevance and offer practitioners an insight into decision-making in this population, where intricate decisions have to be made as the stage 5 CKD population ages.

Novel data concerned with the most common symptoms that patients in the study presented with have been described. It is clear that the cause of a specific symptom was not always easy to identify, especially when patients presented with several comorbidities. Some symptoms not caused by the renal failure were better managed by other professionals, such as those expert in the care of patients living with cancer or heart disease. Other symptoms, such as oedema, when it became difficult to treat, indicated that the end of life was approaching. Findings concerned with symptoms are of importance for those who will be managing similar patients and their symptoms in the future.

This thesis has presented original data concerning the patient and carer experience of managing life following a decision not to embark on dialysis. Sometimes death did not arrive as expected but life had to be lived with the worry that deterioration could occur at any time. While patients and carers lived with the knowledge that the end of life was approaching, there appeared to be a reluctance to discuss this in any detail and the participants often found this subject difficult, sometimes fearing that hope would be lost if death and dying were discussed. Others were happy with a more open approach and were able to discuss the end of life more openly. Why this is so remains unclear and warrants more research.

10.6.2 Theoretical contributions

The findings provide empirical support for Lunney et al.'s (2003) theoretical models which were used to describe physical trajectories to death and support the fact that those with stage 5 CKD managed without dialysis often follow a specific trajectory to death. They also challenge Lunney et al.'s models as many patients with renal disease do not follow the predicted organ failure trajectory put forward by Lunney et al. Instead many follow a uraemic trajectory depicted diagrammatically in Figure 8.1 and others follow any one of the four trajectories postulated by Lunney et al (see Figure 3.1). This is a new contribution to the body of knowledge and highlights the importance of managing patients as individuals rather than trying to depict a specific trajectory that they may or may not follow. This work represents the only prospective trajectory data captured qualitatively prior to death in this population. Some patients died as expected from uraemia caused by their ESRD, others due to other illnesses, but a substantial number died where the cause of death remained unknown.

Secondly, the findings also support and add to the theory that some patients do not want to discuss death and the approaching end of life. They challenge the present day theoretical discourse apparent in the cancer literature that advocates openness and clarity of prognosis. They suggest that although people were aware that they were coming towards the end of life, having prepared their wills, they often did not wish to embark on further discussion of death. This impacted on carers who were unsure how to respond and highlights a need for compassion and understanding for patients and carers alike.

The final part of this thesis is a Postscript which identifies several important developments since this thesis was completed.

CHAPTER 11

POSTSCRIPT

As this thesis draws to a close several important events have taken place. First a Framework has been published entitled *End-of-life care in Advanced Kidney Disease: A Framework for Implementation* (NHS Kidney Care and the NHS National End of Life Care Programme. 2009). This document makes recommendations to ensure that people with advanced kidney disease receive the best care in the last years, and ultimately the days, of life and is a much welcomed development in the renal specialty. It focuses on those opting not to dialyse and those deteriorating on dialysis. This postscript draws out the key suggestions of this work as they relate to this first group. It reflects on the work in light of the findings from this thesis and offers a comparison with the NICE guidelines: *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer* (National Institute for Clinical Excellence 2004), which make recommendations for those living and dying with cancer. It explores the strengths and weaknesses of the Framework and identifies how progress is still to be made in many areas to ensure that renal patients opting not to dialyse are not disadvantaged as they approach the end of life. The postscript also discusses two other initiatives that are underway, including a proposal submitted to the local Primary Care Trust (PCT) for financial support of the RSCS and future research plans.

The first recommendation of the End-of-life care in *Advanced Kidney Disease: A Framework for Implementation* (NHS Kidney Care and the NHS National End of Life Care Programme. 2009) is the use of the term 'conservative kidney management' to indicate those patients making decisions not to embark on dialysis. It suggests that this pathway starts at a time when dialysis would have commenced. This thesis suggests that those opting not to dialyse live for approximately 15 months, a relatively short period of time. Patients usually require supportive and palliative care during this time as they manage their decision, numerous symptoms, an uncertain prognosis and an often unpredictable trajectory to death. It is less likely that they will receive this input if they are said to be receiving 'conservative management' of their renal disease for several reasons.

Having previously discussed terminology with renal patients from our local Kidney Patient Association it was clear that they did not like the term 'conservative management' and did not understand what it meant. In addition, many staff working outside the renal specialty do not fully understand this term. Confusion over what the term means has the potential for patients to not clearly understand what is on offer when they embark on a 'conservative management' pathway and to be omitted from potential supportive and palliative input in the community.

The Framework goes on to discuss trajectories to death and acknowledges the little that is known about end-of-life trajectories in those with stage 5 CKD. This thesis adds to this body of knowledge, uncovering several trajectories to death in those managed without dialysis. It also highlights how some patients may 'tip' towards death. This will be useful for those managing services for renal patients coming to the end of

life and will assist them in determining when and how the end of life may approach, enabling enhancement of care.

The Framework recommends the use of recognised end-of-life tools including the *Gold Standards Framework* (Thomas and DH 2005), *Preferred Priorities for Care* (National End of Life Care Programme 2009) and *The Liverpool Care of the Dying Pathway* (Marie Curie 2008) to facilitate assessment and review of renal patients during the end phase of life. This is to be commended, although there is still much work to be done to ensure that these tools are used nationally for patients with cancer who have been recognised as having supportive and palliative care needs. For other patients with non-malignant disease, such as those with ESRD, there may be lower uptake due to the under-recognition of supportive and palliative care needs in these patients as they approach the end of life.

Within the Framework there is a call for key-worker roles locally in the hospital setting and in the community palliative care team to coordinate care of individual patients across care sector boundaries. This was previously suggested in 2004 for those with cancer (National Institute for Clinical Excellence 2004). IT links and the development of a shared Summary Care Record is also promoted. These moves are congratulated and would be enhanced if other specialties were to be involved, such as older adult and heart failure teams. There is also a call for clinical leads within nursing and medicine but these roles would need to be taken on over and above present roles. Mention is also made of regular multidisciplinary team meetings to discuss individual patients, but it is not clear if this is a recommendation related to those managed off dialysis or just those who are deteriorating on dialysis. Alongside this, little emphasis is given to the idea of 24-hour support for those dying with renal disease compared to that being made available to those with cancer since the NICE guidelines (National Institute for Clinical Excellence 2004).

Education is seen as important in the Framework with core requirements for workforce development, including training in communication skills, the assessment of patients' needs and preferences, advance care planning and symptom management. Little is known about those opting not to dialyse so education can only be offered based on the small amount we know. The report goes on to detail research that is required in this area, highlighting a need for audit and studies in end-of-life care. The need for further qualitative study in this area to explore patient experience is omitted.

Several recommendations are missing from the renal Framework which can be found in the NICE guidelines. These include access to staff who are sensitive to the spiritual needs of patients; systematic psychological assessment at key points and access to appropriate psychological support; and access to complementary therapies. This thesis has demonstrated that patients have specific spiritual and religious needs so input in this area may be of benefit. Psychological assessments were not carried out but depression was reported by some patients and appeared problematic in the population studied. Input from psychological services could be of benefit. There was some evidence in this thesis of complimentary therapies helping in symptom management (See Section 7.2.3) and it is recommended that renal patients have access to these treatments (for example massage) and their effectiveness can be evaluated.

A second important development has taken place recently. In April 2009 a proposal was submitted to the local Primary Care Trust (PCT) to secure funding for the RSCS (see Appendix 15). Historically this service has received no financial input from commissioners. As findings were fed back to the multidisciplinary team at Board level and it became clear that there was a need for the RSCS, staff agreed that a priority was to secure funding for the service to continue its work. Findings from this thesis have also generated interest from staff working in the local community making decisions about how end-of-life care should be offered and managed, particularly for those with non-malignant disease. *The Marie Curie Delivering Choice Programme* (Marie Curie 2009) is available locally and aims to help local providers and commissioners of care to develop the best possible local services for patients requiring palliative care regardless of their diagnosis, so that they are cared for in the place of their choice.

Three clear objectives of the national *Delivering Choice Programme* (Marie Curie 2009) are aligned with those of the RSCS service:

- To develop patient-focused service models that serve local needs, ensuring the best possible care for patients at the end of their life
- To evaluate the economic impact to health services of more patients receiving end-of-life care at home as compared to hospital
- To disseminate findings to other health and social care providers to enable replication of solutions across the UK.

The proposal explains the role of the service, its objectives and achievements. It refers to this thesis and its findings, which have informed practice, and will lead to future research in this area (discussed further below). It also documents the growth of the service and calls for funding to ensure the service is maintained.

Unfortunately, the submission was not successful in this financial year and the renal team has been asked to wait for a decision from the PCT once a national tariff has been agreed to pay for those managed without dialysis. This underscores the disadvantage that renal patients managed without dialysis still face. Funding has not been made available to pay for their care nationally, which means that locally PCTs will not commit to offering financial support and renal units have to manage this decision within already stretched budgets. Since I have left the Trust, my CNS post has not been filled and the money has been used to pay for a second Matron to manage several renal areas. Renal Supportive Care, although seen as important, is low on the priority list where so many priorities compete. In addition, ignorance remains about what the service offers and the staff who are required to manage the workload. This is heightened by the fact that there is no financial reward attached to caring for these patients. Although this is disappointing, many staff remain optimistic that once a national tariff for patients managed without dialysis is agreed, the PCT will finance the RSCS.

A third development continues to take place. The CNS now leading the RSCS has completed a patient assessment module and is about to embark on a nurse-prescribing module with the local university. She has also completed an advanced communication training programme at a local hospice. Her advancement

in these areas can only promote more holistic care for the patients she will be managing as she becomes more competent at making independent clinical decisions. As her knowledge of patient assessment and medicines management increases, she will be able to share her learning with colleagues both locally and in the community, ensuring that patients have their physical and psychological needs met. Her well developed communication skills will assist patients as they manage difficult life events and transitions and enable her to converse competently with patients, carers and staff.

A fourth development has taken place, alluded to above and discussed in Recommendation 9 in the previous chapter. There has been a move to identify future research priorities in the area of renal supportive and palliative care locally. Having moved from the clinical environment to work in the local university I am collaborating with several staff members from the renal unit where the original thesis was undertaken and we are writing a research proposal for more much needed research. Areas being considered include a retrospective audit to compare length of life in over 200 patients previously managed in the RSCS and a similar cohort of patients who opted to dialyse. Results from this study will help to inform decision-making when patients present with ESRD and have to make treatment decisions where the treatment may outweigh any benefits. There is also a need to compare length and quality of life prospectively in these two patient groups and funding is to be sought from the British Renal Society later this year.

Lastly following a publication which arose from this study, *'Patient experience of dialysis refusal or withdrawal – A review of the literature'* (Noble et al. 2008b), I have been nominated by the International Research Promotion Council (IRPC) and Worlds Scientist Forum for the 'Eminent Scientist of the Year 2009 Award' in the field of Kidney and Nephrology Research. This award is conferred on those demonstrating professional achievement and research excellence in an area of research. The IRPC is an international organisation committed to promoting academic and research programmes in science and medicine in the developing and underdeveloped countries of the world.

Much work is still to be done. We are some way from reaching similar headlines to those seen in the press recently related to cancer such as *'Research highlights 15,000 premature cancer deaths per year'* (*Nursing Times*, 25 June 2009). Presently, we do not know how many patients nationally are embarking on a trajectory managed without dialysis so it is difficult to comment on how many of these patients are dying prematurely without appropriate care. This aside, this thesis has been the catalyst which has raised the profile of those managed without dialysis and identified a very real need for patients to be given equal access to services to support them physically and emotionally as the end of life approaches.

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APPENDIX 1: PATIENT PROFILES

John – 75 year-old British man living with his wife Mel, at home. His wife is in poor health but they manage without any help. Has moderate to severe left ventricular dysfunction. At early appointments, to which he came by hospital transport, he was very breathless at times but this improved. He has suffered cancer of the testes, kidney and skin in the past. Has two children, both who visit on a regular basis.

Cliff – 82 year-old white man living alone. He has diabetes for many years and manages his treatment independently. The district nurse attends on a regular basis to give his erythropoietin injection but he sees few other people and finds it difficult to leave the house due to general immobility. Has a carer attend once a day to help with his hygiene needs. His condition has changed little during the time he has been visited at home by the RSCS.

Veronica – 71 year-old Afro Caribbean lady living at home with her husband and son. She has a degree of dementia and attends a day centre three times a week. She attends clinic with her husband, who manages her tablets and generally cares for her although Veronica is relatively independent. She appears lucid at clinic and she and her husband arrive by public transport. She has had a myocardial infarction in the past but has made an excellent recovery.

Mary – 91 year-old English nun living in a community of nuns. She manages to attend clinic with her carer Agnes and is very well considering her renal function and advanced age. She helps out weekly at the Bring and Buy Sale, manages her hygiene needs and her medications. She has little relevant medical history apart from a fractured femur 9 years ago from which she recovered well.

Arnold – 78 year-old British man who lives with his wife who has heart problems. Has had cancer of the prostate in the past and spent time in ITU with appendicitis and peritonitis two years previously. He comes to clinic by bus. Has two children who live outside London. They pay their grand daughter to help with the gardening and cleaning.

Raymond – 70 year-old British single man who lives alone and is wheelchair dependant due to osteoarthritis. He attends clinic by hospital transport. He has one brother whom he sees occasionally. He has carers who help him with hygiene, preparing food, taking medications etc. four times a day and sometimes they take him out for a walk. He has started to use the internet, which he enjoys, but is frustrated that he can't go out alone.

Sara – 77 year-old widowed Sri Lankan lady who speaks Tamil and little English. She comes to clinic with a carer in a wheelchair but is able to mobilise. They come by hospital transport. She is occasionally incontinent of urine associated with dysuria and was treated for urinary tract infections the previous year. She has been diabetic for nine years. She has 8 children (2 in UK, 2 in Germany and 4 in Sri Lanka). Two children live locally. Her carer comes twice a day to help her with hygiene, preparing food, taking medications, etc.

Abdul – 74 year-old Bengali man who lives with his wife and two daughters Salma and Fatima. Several other family members live in the flat and others live close by. He has advanced peripheral vascular disease and a diabetic foot ulcer that won't heal. He has had a myocardial infarction but was considered unsuitable for coronary artery bypass surgery due to his poor health. He cannot leave the house alone and can only walk very short distances. He is seen at home by the RSCS.

Alfred – 86 year-old white man whose wife died during the course of the study while they were both in their local hospice. He has a son and daughter who visit him regularly at home and has deteriorated during the study. His main problem is COPD but also heart disease and cancer of the prostate.

Sana – 70 year-old Bengali lady who lives with her two sons and has a carer attend once a day. She has a daughter who is a dialysis patient and this played a part in her decision not to have dialysis. She does some cooking at home but goes out little. She has been diabetic for five years.

Antoinette – 77 year-old widowed Afro Caribbean lady who has recently moved in with her daughter Antionette and grand daughter aged 9. Her daughter works part-time and her other children live locally. She is seen at home by the RSCS as she finds it difficult to mobilise. Has pain due to osteoarthritis treated with a fentanyl patch. Daughter is caring but struggling as her mother becomes more dependant.

Michael – 76 year-old single, Afro Caribbean man who lives alone but visits a lady friend on a daily basis. He is independent and the lady friend cooks his meals. He has a degree of cognitive impairment and he is sometimes hard to follow. He has had type 2 diabetes for 13 years.

Ada – 84 year-old widowed Afro Caribbean lady who lives alone but whose son Jack visits nearly every day. She originally came to clinic but found this difficult so was seen at home by the RSCS. She had been a diabetic for more than 20 years. Her biggest problem is her significant heart failure and she has had several admissions into hospital to treat this.

Donald – 69 year-old Afro Caribbean man living at home with his wife and daughter and baby grandson living close by. He has a degree of dementia, heart disease and diabetes. He was found wandering the streets on a couple of occasions and was brought back by the police. He doesn't leave the house alone now.

Teresa – 78 year-old Greek lady who lives alone but has carers attending four times a day. Her only daughter also lives close by and visits on a daily basis. She has been diagnosed with dementia and although she looks alert and smiles and nods it is difficult to understand what she says. She has limited mobility due to oedematous legs and osteoarthritis in both knees. She doesn't leave the house unless it is to be admitted into hospital. She is visited at home by the RSCS. She has ischaemic heart disease and has multiple strokes but made full recovery.

Sarah TC – 80 year-old single Afro Caribbean lady who used to work as a nurse. She lives alone but is independent and travels across London on the bus. She attends clinic alones but has lots of friends and visits church regularly.

Samuel – 85 year-old separated, Afro Caribbean man who lives in warden-managed accommodation. He has a niece Sonia who lives nearby whom he sees occasionally. He is able to go out independently and comes to clinic by bus. He has been type 2 diabetic for many years but manages his medications independently.

Marjorie – 87 year-old Afro Caribbean lady living at home with her husband. She is housebound and is seen at home by the RSCS. She is visited by her step-children regularly. She has a carer attend to her twice a day. She has severe osteoarthritic pain in the base of her back and has had type 2 diabetes for several years.

Paul – 91 year-old widowed English man. He lives with his son Paul and daughter in law Rosie since he made the decision not to embark on dialysis. Very quiet man who says little about his illness. Likes to sit in the garden and smoke. He can mobilise and cares for himself although he could probably do with some help when washing and dressing but he refuses.

Trudy – 70 year-old Afro Caribbean single lady who lives in a nursing home. She has several children and one son visits regularly and takes her out to visit his home. She had a leg amputated three years ago and she has found it hard to adapt to being so dependant on others for her care. She has been diabetic for over 30 years.

Juber – 74 year-old Bengali man living with wife. His niece also lives very close by. He now finds it difficult to leave the house and is seen at home by the RSCS. He has several medical problems, including ischaemic heart disease, diabetes and chronic obstructive pulmonary disease. There is a query that he had a myocardial infarction 3 years ago but he is not sure.

Meena - 69 year-old Bengali lady whose husband lived in Bangladesh. She had lived in the UK over 20 years. She lived with her son and daughter-in-law. She had suffered diabetes and rheumatoid arthritis for many years and had undergone many admissions to hospital to treat these conditions. She spoke little English. She was able to mobilise well although she suffered regular pain.

Carmel BO - 85 year-old widowed Afro Caribbean lady living with her daughter, grand daughter, grandson and great-grandson. She has advanced heart failure and is visited regularly by the heart failure CNS. She is a very large lady and finds it difficult to leave the house. Her daughter finds her immobility a challenge and is not sure how she will continue to cope.

Akbar – 84 year-old Pakistani man living with his wife and his son and his family in a large house. He has some heart disease but his biggest problem is an abdominal obstruction causing pain. He has been investigated and awaits the results of tests.

Gillian – 80 year-old single Afro Caribbean who lives alone. Her niece helps her out regularly. She has heart failure and is visited regularly by the heart failure CNS. She is very breathless and this causes her distress. She finds it difficult to leave the house and doesn't enjoy her food anymore.

Marcia – 77 year-old widowed Greek lady who lives alone. Her daughter lives several miles away but brings her to her clinic appointments. She manages independently at home but things are getting harder. Has had several bouts of gall stones which cause pain and often require admission to hospital. Is able to go on holiday to Greece and although frail attends church by bus each week.

Josie – 68 year-old widowed lady from the East End of London who lives alone. Her brother lives nearby and visits daily. She has three sons, one of whom lives in Spain. The other two visit regularly. Her osteoarthritis has limited her mobility greatly and she rarely leaves the house.

Sandra – 65 year-old single Afro Caribbean lady, living with her daughter and several family members. She has few health problems and no renal symptoms. She has been diabetic and hypertensive for over 10 years. Sandra is reluctant to attend clinic appointments and keeps little contact with the RSCS.

Diane – 77 year-old widowed lady from the East End of London, living alone at home. Has carers attend twice a day and has a supportive family with a daughter who lives across the road. She is housebound and is seen at home by the RSCS. She made a good recovery from a stroke in 2003, has had diabetes type 2 since 1990 and had a right upper lobe bronchogenic carcinoma with local lymph node involvement diagnosed in 2007.

Daisy – 82 year-old widowed, English lady who lives alone but is visited regularly by her daughter Daisy who lives close by. She also goes to her house every Sunday for dinner. Has had diabetes for three years and has osteoarthritis but still able to get to the shops on a daily basis. Hairdresser visits once a week and she cooks for her teenage grandchildren regularly when they call on the way home from football matches. She is seen at home by the RSCS.

Version 2 – 17/08/2006

06/QO603/101

Dear

Invitation to Participate in a Research Project

OPTING NOT TO DIALYSE

I invite you to take part in a research study which I think is important. The attached information sheet tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely your choice. Please ask any questions you want to about the research and we will try our best to answer them.

Yours sincerely

APPENDIX 3: PATIENT INFORMATION SHEET

OPTING NOT TO DIALYSE

Protocol reference number:

I invite you to take part in a research study, which I think is important. The information, which follows, tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely your choice. Please ask any questions you want to about the research and I will try my best to answer them.

Why have you been approached?

You have been invited to take part because you have currently decided not to have dialysis to treat your kidney failure. I hope to find out more about this experience and what it is that you might want from the Renal Supportive Care Service. I will be asking for your permission to audiotape the interviews. I will then analyse the data collected and share this with a wider audience. I would also like to talk with your carer/s and hope to approach them also. The study is being carried out as part of an MPhil/PhD study. The study supervisor is Karen----

What does the study involve?

If you agree to take part in the study I will tape record the interviews that take place in the normal course of caring for you. Each time I will speak to you for approximately one hour. This interview will be arranged at a time and place that is most convenient to you and will be carried out by me or my colleague . The interview will be very informal and will give you time to tell me about your experiences and needs. It will be a time for you to tell your own story about renal failure and tell me what your needs are.

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

If you withdraw from the study only the data collected up to your withdrawal will be used if you agree. You can withdraw from the study at any time.

What will happen to me if I take part?

If you decide you would like to participate, then I will ask you to sign a consent form to confirm this. Your clinic interviews or interviews at home or in hospital will be recorded. You may be included in the research for up to one year. This will not involve any extra visits to hospital.

I will tape record the interviews that take place in the normal course of caring for you in the hospital or at home. With your consent I may use quotes from your interviews when the results are published but I will not identify you by name. All the tape recordings will be stored safely and will be anonymised. Only I will have access to the tapes which will be destroyed once the data is transcribed. I will discuss the content of tapes with my study supervisors but will not name you.

All information which is collected about you during the course of the study will be kept strictly confidential. If you consent to take part in the research the people conducting the study will abide by the Data Protection Act 1988, and the rights you have under this Act.

Harm

I do not expect that you would be harmed in the course of this study but in the event that something does go wrong and you are harmed during the study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence you may have grounds for a legal action for compensation against ---but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

It is recognised that the audio equipment may be unsettling during your interview. You can request for the equipment to be turned off at any time.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get might help improve the treatment of people with renal failure who have decided not to have dialysis.

What happens when the research study stops?

When the study is finished the only thing that will change is the interview with your nurse will not be tape recorded.

What if there is a problem and Contact Details for further information:

If you have any worries or concerns you can contact me on;
If you have any complaints you can contact;

Patient Advice and Liaison Service (PALS)

Who is organising and funding the research and where was it reviewed?

The research is being organised by me, a full time MPhil/PhD university student who is also a Registered General Nurse, sponsored by ---. This study was

given a favourable ethical opinion for conduct in the NHS by the ---.

What will happen to the results of the study?

Following completion of the research study the results will be distributed to the Kidney Patient Association and NHS Trust personnel via written summaries, pamphlets, teaching materials, guidelines and care pathways. I would also hope to publish the results in academic journals and present results at renal and palliative care conferences. If you want to be kept informed of the results directly I can keep you up-to-date.



St Bartholomew School of Nursing and Midwifery

OPTING NOT TO DIALYSE

Protocol reference number:

I invite you to take part in a research study, which I think is important. The information, which follows, tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely your choice. Please ask any questions you want to about the research and I will try my best to answer them.

Why have you been approached?

You have been invited to take part because you have a relative/friend who has decided not to have dialysis to treat their kidney failure. I am hoping to find out more about this experience and what you think you and your relative/friend want from the Renal Supportive Care Service. As you may attend hospital appointments with your relative/friend or may be at home if they are visited at home I will be asking for your permission to audiotape the interviews that take place in the normal course of caring for your relative/friend. I will then analyse the data collected and share this with a wider audience. The study is being carried out as part of a PhD study. Karen

What does the study involve?

If you agree to take part in the study I will tape record the interviews that take place in the normal course of caring for your relative/friend in the hospital or at home. Each time I will speak to you and your relative/friend for approximately one hour. The interview will be very informal and will give you time to tell me about any concerns or worries that you have in relation to your relative/friend.

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You will be free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a

decision not to take part, will not affect the standard of care your relative/friend receives.

If you withdraw from the study only the data collected up to your withdrawal will be used if you agree.

How will this study help?

I hope to understand more fully what renal patients, and their carer/s, who decide not to dialyse expect from a Renal Supportive Care Service and also what their experiences are at this time. This will inform the future development of the Renal Supportive Care service and ensure that we have a greater understanding of the needs of the patients attending this service.

What will happen if you take part?

If you decide you would like to participate, then I will ask you to sign a consent form to confirm this. You may be included in the research for up to one year. This will not involve any extra visits to hospital.

I will tape record the interviews that take place in the normal course of caring for your relative/friend in the hospital or at home. With your consent I may use quotes from your interviews when the results are published but I will not identify you by name. All the tape recordings will be stored safely and will be anonymised. Only I will have access to the tapes which will be destroyed once the data is transcribed. I will discuss the content of tapes with my study supervisors but will not name you.

All information which is collected about you during the course of the study will be kept strictly confidential. If you consent to take part in the research the people conducting the study will abide by the Data Protection Act 1988, and the rights you have under this Act.

Harm

I do not expect that you would be harmed in the course of this study but in the event that something does go wrong and you are harmed during the study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence you may have grounds for a legal action for compensation against the University but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

It is recognised that the audio equipment may be unsettling during your interview. You can request for the equipment to be turned off at any time.

What are the possible benefits of taking part?

We cannot promise the study will help you or your relative/friend but the information we get might help improve the treatment of people with renal failure who have decided not to have dialysis.

What happens when the research study stops?

When the study is finished the only thing that will change is the interview with your relative/friend's nurse will not be tape recorded.

What if there is a problem and Contact Details for further information:

If you have any worries or concerns you can contact me on;
---If you have any complaints you can contact;

Patient Advice and Liaison Service (PALS)

Who is organising and funding the research and where was it reviewed?

The research is being organised by me, a full time MPhil/PhD university student who is also a Registered General Nurse, sponsored by ---. This study was given a favourable ethical opinion for conduct in the NHS by the ---

What will happen to the results of the study?

Following completion of the research study the results will be distributed to the Kidney Patient Association and NHS Trust personnel via written summaries, pamphlets, teaching materials, guidelines and care pathways. I would also hope to publish the results in academic journals and present results at renal and palliative care conferences. If you want to be kept informed of the results directly I can keep you up-to-date.

APPENDIX 5: PATIENT CONSENT FORM

Centre Number:
Number:

Study Number:

Patient Identification

Please initial
box to indicate agreement

1.	I confirm that I have read and understand the information sheet dated 17/08/2006 version 2, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3.	I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from --- where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4.	I agree to take part in the above study.	
5.	I understand that direct quotations may be used by the researcher when sharing results from the study possibly to associated researchers within/outside the European Economic Area. I understand that all results will be anonymised. I give permission for direct quotations to be used	

Name of Patient

Signature

Date

Name of Person taking consent
(if different from Investigator)

Date

Signature

Investigator

Signature

Date

APPENDIX 6: CARER/STAFF CONSENT FORM

Centre Number:
Number:

Study Number:

Participant Identification

Please initial
box to indicate agreement

1.	I confirm that I have read and understand the information sheet dated 17/08/2006, version 2 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or my legal rights being affected.	
3.	I understand that data collected during the study, may be looked at by responsible individuals from ---, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.	
4.	I agree to take part in the above study.	
5.	I understand that direct quotations may be used by the researcher when sharing results from the study possibly to associated researchers within/outside the European Economic Area. I understand that all results will be anonymised. I give permission for direct quotations to be used	

Name of Participant

Date Signature

Name of Person taking consent
(if different from Investigator)

Date

Signature

Investigator

Signature

Date

APPENDIX 7: INTERVIEW SCHEDULE

SUPPORTIVE CARE PATIENT RECORD

Hospital number:
Preferred language:
Marital status:
Religion:
Living arrangements- Lives alone? Yes No NK
Ethnicity:

Last name:	
First name:	
Title:	Sex:
DOB:	Age:
Patient's Address:	
Postcode:	
Tel:	
GP name:	
Address:	
GP Tel:	
Fax:	

Carer/Other relatives

Surname	Forename	Title	Relationship
Address		Tel Home: Tel work: Tel other:	

Other professionals (for CPCT/DN please enter name of team on front of form, details e.g. nurse name below)

Description (e.g. Breast Care Nurse)	Name/Team	Tel	Fax

Social history:

Family members:

Occupation:

Home Circumstances:

Interests:

Past medical history:

Name

Hospital No.

Interview guide

- Ask about any symptoms patient may have. Might include;

- **Fatigue/tiredness**
- **Pruritus**
- **Anorexia**
- **Pain**
- **Dyspnoea**
- **Nausea and vomiting**
- **Restless legs**

- Ask how feeling about illness or treatment

- Ask what main problems/ worries have been since last visit?

- Ask how family or friends feeling

- Ask about everyday life and what patient enjoys or finds difficult

- Ask what help patient feels they need at present

CONTINUATION NOTES

[illegible]

032 RR & D 1 06.09.07

Researcher

Interviewee

J: Nurse

D: Daughter

Ok...

Well, Rose, what I would ask you first then is can you just tell me, the history of your health, and tell me about all your illnesses and where the renal problems come in.

Well, I found out that I had this cancer, lung cancer, but I also found out that me kidneys wasn't working properly, but then when they discharged me before from the hospital, they said they wasn't doing too bad, but they seem to have...you know, said that it is all the same like now, still... it is still alright, as far as I know... They checked me all out with all of the others...other things... and they said that everything was alright...so... I just keep me appointments what I have to have, you know?

Ok.

But the diabetes... I don't see no-one now for the diabetes... I used to see Dr...C?

Right.

I was in his care and then they put me through to... Professor P

Ok.

But I am under Professor K at The ---for me cancer...

Right...

And... but that don't seem to have travelled any or... got any bigger or anything like that... so they was quite pleased with that. Which means that I don't go back now 'til the twenty-ninth of this month... and that is over three month's lapse, you know?

Good, good.

Good really...

So, it was recently was it? That the cancer was diagnosed?

February, wasn't it?

Ok. And recently that they told you that you had problems with your kidneys?

No, that was before, before they diagnosed it. The cancer. That was done before.

Ok. So, had there been some talk about the treatments for your renal failure?

Well, they couldn't put me on dialysis, because of my other illnesses.

What is your other illnesses?

Diabetes, blood pressure, and me heart misses a beat I think... or something like that.

Ok...

And... What was the others **02:15**? I have got so many blooming things...

D: You are not taking tablets...

These are all me tablets...

D: Mum, what I was going to say, you are not taking tablets for epilepsy now, are you?

No, no...I don't have to have them.

D: She had epilepsy.

Was that a long time ago?

Yes, but I had hardly had the shake...

D: She still gets the shake...

I still get it, occasionally... but nowhere near as bad as I used to.

D: I am not sure when that diagnosis was for the renal problems.

Don't worry. We can find that out anyway.

Ok. And your heart misses a beat?

Well, something like that... something to do with the heart beat... but he said it was nothing to worry about; the doctor. They did x-rays and everything. I had an MRI scan...

D: And you have problems with your breathing... That is what she has the morphine for...

The nurses advised me to take that.

D: From the hospice that is.

So, have you got the Macmillan Nurses from ---coming in?

Yes... yes...

D: And she also... I don't know if... Was this about trying to make all her care at home, was it? Or something? So she has to go to blood tests every other week at The L. Hospital.

Is it The --- Hospital, Mum?

Yes... yes...

Is that for her warfarin?

Last night, I fell asleep in the end and I forgot to take my warfarin last night.

Don't worry about that.

Jaryn, maybe I can get you to make a list of all the different...

J: Yes...

Oh, S... we know S.

She is a lovely girl, S.

S and her team come to see you at home?

D: It is mostly on the phone.

No. They phone me up all the time... to see if I am alright...

Oh, good...fine...

But, she said she is going to make an appointment to come around and see me again.

Ok...

She has been around to see me...

D: If anything deteriorates or something changes... anything... any problems... if Mum ain't well, we always ring her, to update her, but she don't need them to come around, she is alright at the moment.

Ok. So, what we would aim to do is work a little bit like S, so that we are there for the renal side of things, and so if there were any issues with the renal side of things we could co-ordinate it together.

D: Is there any way... like, do all the services work together at all?
You know, see like the blood test, she is out for the whole day, usually, on a Monday, she is normally gone for a whole day, just to go and get a blood test, because she has to have transport because we are all at work.

Mmmm... No, I think that is something that we need to look into, you know, how important...

How often do they change the warfarin?

I will show you my book.

Do they do a lot of chopping and changing?

D: It has changed a bit, hasn't it Mum?
Only because I didn't know...

That is what I am on now (GESTURES), this one.
But... it goes different right the way through.

Ok, right, I don't know enough about warfarin to be able to say, Oh no, you don't need these blood tests. But I think there is something about quality of life...and...

But they took the blood test for this one on Monday...

Yes... yes... But you don't really want to have to be going up there two times a month, do you?

D: You go every other week...

Every other week, normally, I go.

D: So, it is twice a month... I think to them it is important, because I think that I might still have a message from them and they did phone me and say... 'Make sure that you arrange transport, we can't do it, and as your Mum...' They did leave me quite a...

Pushy message?

D: So, it must be important, is what I am thinking.

That is the one I ring for the transport...

**Who do you ring...
That is transport...**

This is transport.

And who is the... this DN... That is the district nurse... that is your family doctor... (LOOKING)

I used to have a district nurse, but then they found that the warfarin was going all over the place, you know, and...

Sorry, R, we will just take down these numbers so that we can talk to them and see what they suggest...

Yes...

So we'll try and get it reduced. Because this is what it is about now, trying to maintain your care at home...

I think that it is this Monday that I have got to go.

D: It is Mum; she has left me a message saying make sure that you book transport...

J: But she has just had blood test...

D: She's had blood test this week...

The last Monday, yes...
I'm supposed to have gone... I'm supposed to have gone this Monday.

Oh right, so you didn't go this Monday...

D: She was in hospital.

I was in hospital.

Oh right... it is a very specific test, and I bet in casualty they didn't ask for that test.

D: No, I am sure...

But they took that... and they said... they had increased it to five milligrams every day.

Ok.

D: You know that blood test that she is having? Do you need a lot of blood to test it?

Probably not.

D: So, I mean, you know... it probably sounds silly... I am not medically minded at all... but you know when you do a urine sample, and you have them sticks...

Yes...

D: And she does that for the diabetes, is there not something that can check...

No...

D: What a shame, isn't it?

I know...

D: You would think that there would be something that you could invent... someone who is medically minded.

Yes... make yourself rich!

D: Yes...

There isn't! So, it must be a substantial amount...

D: Do it girls and make yourself some money!

Absolutely!

Right... R, going back to your problems... what is your biggest problem at the moment?

My biggest problem is me legs because I can't get shoes to fit me. I had to... took me out and bought me a couple of pairs of those yesterday but where I have the bandages, I have to have the bandages...

D: Her bandages are on constantly. They are always... Her legs are always bandaged up, which she obviously can't... She probably needs to get some air to them aswell, but they are very weepy her legs and...

They run all of the time...

D: They have deteriorated haven't they? You can see. Like she has got quite... Soon as they... They are really bad, her legs...

And how often is the district nurse coming into dress them.

Twice a week.

Twice a week.

She comes in Mondays and Thursdays.

Have you got a good GP?

D: Yes.

Nice doctor...

Is it very painful?

No, it is not painful at all. They just itch...

And how long has it been like this?

I've had these this for about two years...

And what did they say was the cause?

They just said it was a skin complaint. They was supposed to have made arrangements for me to see the repair service at M Hospital, but when I was in there last time, they came up and just said put some cream on them...

D: It is related to your diabetes Mum.

Yes...

It is very, very difficult treating... well, as you know, if you have had it for two years, trying to get on top of this and get it treated and getting these dressings on to try and keep it clean. But often the healing process is very much impaired. It is quite swollen, isn't it? Has it been swollen like that for a long time?

All the time... Well, not all of the time. They went down once. But it is all of the time, isn't it?

D: She has got... that is water, isn't it? She has always got that. So, Mum, when you stand up, sometimes... She has got the shape of the chair... She is really...

So, you have had those; high blood pressure for quite some time.

Yes, since I was... carrying my first child.

Really?

It says nineteen-ninety here! So, I presume that is wrong.

D: Yes...

How old is your oldest child?

Fifty-one, isn't she, Christine?

D: Fifty-three.

Fifty-three. Fifty-three?

How many children have you got?

D: No, she ain't!
She is ten years older than me!

Oh.

How many have you got?

Five.

All girls?

No three girls and two boys.
And fifteen grandchildren and one great grandson!

Do you have them all round here?

No.

D: She is the **10:42**.

Do you get out ok R?

Well, I have got a scooter now.... The Macmillan Nurses gave me money to buy a scooter...

D: You don't get out that much Mum, do you?
She goes downstairs...

Well, I...

D: You have got to tell them everything that you do.
She misses out on quite a few of the trips. If they have a trip here, she misses out on... They take on as many as they can, but there are some that she can't...

I can't climb the steps into the coach...

Of course...

D: Or her scooter can't get on.

You were on a trip the other day, weren't you? When we were coming to see you the other day, you went on a trip, did that go alright?

I can't remember.

D: Where did you go?
Witherspoons, did you?

Oh yes, we went to Witherspoons and had a lunch out.

That is great.

D: If she can get somebody to push her, then she can go...

Because sometimes they are not insured to carry the scooters on the buses.

But, it is an electric chair that you have got there, is it?

D: She has got a normal wheelchair, and she has got an electric one outside, yes.

Ok, alright...

This is the thing where they take all me blood pressure...

J: So, when you go to the hospital...She goes to the hospital for her **11:45**, and she needs to be on the wheelchair...the normal one...

D: This one? The normal?

J: Does this building have a lift?

D: Yes. She is waiting to move to a flat downstairs...

Downstairs on the ground floor...

D: There is a flat empty...downstairs, and she is going to go downstairs...

J: Ok.

That will be better.

D: We are waiting for that. It is not finished yet.

J: So, I think that if... I am not sure but **12:10** to the lab at once. Now, if it doesn't, maybe we can ask the district nurses to do it while they are doing the dressings, because...

If they will do a blood test...

If they do the blood test... they don't always do a blood test...

I think that we can co-ordinate it somewhere; we just need some time to look into it all.

Now, what else do you go to the hospital for?

Nothing really, not unless I have...

I have got to go and have my eyes done on the twentieth...

D: Eighteenth, Mum, ain't it?

Eighteenth...yes...

Now, eyes, you are probably...

Good job you are here...

Don't worry, don't worry...

Where do you go for your eyes?

I have got to go to M, but I have to go the diabetes clinic to have them done.

D: She went and got her eyes... Did the optician refer you Mum, didn't he?

Yes, they sent me...

D: They checked her eyes and suggested that she goes to the hospital.

Ok. Eyes, you probably will keep needing to go to the hospital for...

D: That was an air freshener going off...

That was clever!

Eyes. What else? Anything else that you go to the hospital for?

D: They do your feet downstairs now do they Mum?

No, no, I have got to go to the doctors to have them done. We used to have a chiropodist come in, but they have a got a new van now, and it is too big to get through our gates, so...

Oh, right...ok...

They have had to move it to outside Asda's, or go to our own doctors there.

This is for getting your feet done?

Yes.

So you get your feet done regularly?

Yes.

Because they are long aren't they?

D: I was going to say, because you don't look like you have had them done, Mum!

Well, when she came last time it was a rush job, because we was going out, wasn't we, and the coach was waiting for us.

D: So, you didn't have your toenails done?

This time, she didn't do, and she cut them, but this time she didn't do...

Ok. R, coming back to your kidneys, can you tell me anything more about your kidneys, or what else you understand, or what else was said?

No, I can't think...

All I know is that they just couldn't give me the... dialysis and that... because of what the illnesses that I have got like... But I can't remember anything else what she said at the moment... I just can't think...

Have you got any questions about the renal failure?

I know that I mustn't have... I mustn't have bananas... or that; because of the... what did I say that it was?

D: Potassium.

Potassium, doing me kidneys no good.

Mmm.

And I didn't know that.

Mmm.

D: Can you tell us more about that?

Mmmm. You have lost quite a lot of function in your kidneys, so a normal person would function in the late nineties... And you have got about thirteen percent of you function left. Ok? So, your kidneys are really not working very well, although you may not feel any different and you may continue to pass water etcetera, but normally what happens is there is a slow deterioration in your kidney function over time and we would expect to see that happening, and we normally detect it on the blood tests only, because often people do feel quite well. Sometimes there are other symptoms that can come as your kidneys deteriorate, and that includes things like fluid retention, but you have probably got some fluid retention for some other reasons aswell, and you have got other conditions that may cause you many more problems than the renal disease. So it is just kind of watching and waiting and seeing what happens?

D: So, what causes the renal failure then?

Often it is diabetes. So, if you have had diabetes, or hyper-tension, those sorts of things for a long time, they can cause damage to the little tubules in the kidneys and over time we just see that slow damage coming through. And often many of the patients that we see are diabetic. There are lots of other reasons aswell, but I think that is probably the reason in your Mums case.

D: So, how quick does that deteriorate then? If she is at thirteen percent?

Well, we see about sixty or seventy patients through the year. Some of those patients are, patients who have been on dialysis and have made a decision to come off dialysis, now those patients do die very quickly. But we have this other group of patients who make a decision not to have dialysis, and because our service is so new, we are still trying to observe what happens to everybody, and for example we have got a handful of patients who have got four percent of function are doing really well. So, some people do better than others, and we just can't quite be sure who is going to do better and who is going to do worse. So, we have to wait and see...
It is very hard to give a time limit or anything like that.

D: So, on her records, have you got where she was and where she is at, sort of thing, so that we know...

In terms of her care...yes.

So, for example, January, beginning of the year, there was eighteen percent... and April, sixteen percent, and so we are now down to thirteen. Now what we sometimes see is that people quite quickly drop down, but then kind of tail out... it all sounds a bit confusing, isn't it? This percent and whatnot, so that will seem like a quick dip, and then you might see that people are on seven percent for a year... six percent for a year... so it can really, really become quite slow, and it might be that other problems cause more problems...

D: And you check that by blood test, did you say?

Yes. Usually, we are hitting problems when people start to get symptoms. So, start to get breathless...

D: You haven't had...

Haven't had anything it all...I feel better actually...

D: Mum, hang on, breathless, you did get...

Oh, yes, I got breathless...

But that is probably to do with the cancer. And that is where we have to be very careful about working out what is causing what and why.

D: Yes.

So I think that at this stage where your function, although it is not great, it is not terrible, a breathlessness type episode is probably due to the cancer, and will be treated very well...by this... But then we also have to be careful with this...

D: She is not actually... you have been much better since you have had the **18:48**, haven't you?

Tell me about the cancer, R, what happened when you had the cancer?

I just went up for a test because at the time, I was getting bad pain, underneath my rib, just under here, and that is when they kept me in that night, because they wanted to find out what was causing it, and they went through all these different things, like x-rays and what have you and they took me down and give me a thing down the throat, a camera down the throat, and he told me it was lung cancer. But, as I say, years ago I used to smoke really heavy but then I packed it in and I ain't smoked for, what? Fifteen, twenty years...

D: About twenty years...

But they said that it wasn't through what I smoked, Professor P said, it is not what I smoked in them years, because that would have cleared out... it is passive smoking. So...

D: She worked in a factory, and everyone smoked, so it is more likely to be that than what she smoked herself.

Ok.

D: That was K, weren't it? That told you that?

No, P.

Ok, so then you had the tube down and they told you that you had lung cancer, and then what happened?

They just had to go and see Professor K, and he told me all about it, and I had a lymph node or something there, between...

So, you had some surgery...

No...

D: They have done no treatment...

They can't do nothing... No treatment...

D: It is untreatable and there is nothing that they can do.

Ok.

And have they explained to you how it might progress?

They said... well, they couldn't really... say how...it would progress...you know.

D: What happened was that in February; she had already been to hospital, October the year before, hadn't you? Because you weren't well? With the same sort of thing, and they had done an x-ray there, but they couldn't see it, but what they have done February when we went there, we said, "Well look, she was in in October with this same complaint, and nothing..." Basically they kept her in... and then let her home, nothing happened in October, did it Mum?

No...

D: And when in February they found that it was cancer, we asked them to look back...to see if they could find the... in the archives, somewhere, the x-ray from October, because they have obviously... they must have missed it...

But they couldn't find it...

D: I thought that they had said that they had found it, and it hadn't changed and it hadn't grown at all, since the October to the February when they found it. But, I mean, chances are they would say that anyway, because they would end up getting in trouble if something was there in October and they had missed it.

I have had so many things said to me... I can't remember anything...

D: We did ask them to look. I can't even remember who we spoke to. It wasn't one of the top doctors, was it? It wasn't...Whoever it was, said that it hadn't changed from the October to the February, because we asked them to go back and have a look. We knew something was wrong in October, because she hates going into hospital and when she agrees to go to hospital...

There's something wrong...

D: Pretty much like this weekend, she never ever goes and she has not been well since Thursday, but by Sunday morning, the pain in her neck had got that bad, that she said, "Oh, perhaps I should go then." So we knew that there was something was wrong in the October... But they kept you in, didn't they? It was just like she was sitting up in hospital and she may as well be at home, really...

Ok.

D: They can't give her no timescale... Sorry. They can't say, "You have got this long left," or anything like that, because they really don't know, because they can't treat it because of all her other medical problems, can they Mum?

No...

We went to Bath for that, didn't we?

D: Yes.

Alright. So, R, how are you feeling now?

I feel fine, yes.

You feel fine? Ok.

Do you worry about all of these conditions?

No...

You are not a worrying type person?

I know that I have got them and that is it!

Yes, ok...

Stay with it, haven't I?

Ok...

I have got used to the idea now... Not much that I can do about it...

Ok...

Well, you know that we are here, and we have got S...? At the Hospice, you have your district nurses coming in, ok? And we are going to try and sort out the warfarin.

Yes.

You had your blood tests done on the second, and we think that was ok at the moment, wasn't it, in terms of the tablets etcetera, in terms of your renal problems... we wouldn't change anything...

J: She said that she...23:50...

I mean, they mentioned a problem with her blood test, didn't they? While she was in, but they may have just meant that it showed that she had a renal problem, because sometimes they get a bit phased...

D: What happened was that all the computers was down and when we went to hospital, everything crashed... so when they done the blood test they had nothing that they could check it to... So, obviously it has come back that they... they agreed that it could be, and it could show any of her other little problems that she is actually being treated for now... that might be what it was, but until they can confirm that... Obviously they didn't want her to let her go, in case there was something else... and once they checked they was happy for her to go, so maybe it was...

You just had an extra day, or whatever...

And it what just a very painful neck, you had?

Yes.

And it is arthritis?

It was like a shock right round me shoulders here, and way up... across me head...

D: But she was in really bad pain... but then as soon as it was sort of over... she was alright...

I was rubbing...

D: They thought that it could be muscle spasm aswell... didn't they?

Yes, at first...

And now it has gone?

D: Well, she... has it gone now Mum? Completely?

No, it is not completely... it is still there...little aches...like, you know, but nowhere near as bad... as what it was...

Karen phoned up the emergency doctor up the road...

Ok.

He said, that "without seeing her, I would say that she is having muscle spasms..." and then I went to the hospital and they said that it was arthritis that I have got, and it was affecting the nerves in me neck and that was what was causing the pain... so they have put me on **25:27** and co...codeine or something...

Co-codomol?

D: Co-dydramol.

Co-dydramol...

J: R, can we take a look at all your tablets?

There is a new one there darling... these are all my warfarin tablets...

Codeine... and 25:51... And they are working?

Oh yes...yes...

Well, what I would say to you and your family, is that you have got S's number, but you have also got our number now aswell, ok? So, I think that jointly we would try to manage you... But probably to begin with from afar, because... somehow we will get a blood test done, on a regular occasion, but it will probably be linked in with your warfarin, so you maybe a patient who needs to have a blood test done a little bit more often, but we will try and get it done at home.

Yes, alright...

D: That would be better Mum, wouldn't it, than keep going to the hospital, because she goes... she has to leave here at half eight, and everything...

Sometimes... if they get here at half eight...

D: I know, but you have to be ready and downstairs, didn't you for half eight...

No, I don't have to be... I just wait up here now. 'Til they come and get me...

D: You was going downstairs, wasn't you?

But, she missed... because of that she misses out on having a shower on that day... All the things that are important, that she can't do herself, everything...

And there must be people who get to a point where they just can't leave their house, but they are warfarin and it must be managed in the community?

Because there are older and frailer people who these things happen to... and if you have a stroke or something... that couldn't get out... So there must be a way of managing it, it is not impossible.

I just push me wheelchair downstairs to the lift, and I wait down there for the ambulance driver to come and get me...

And do you have some carers coming in to help you?

Yes, yes...

And do they come in every day?

Yes.

How many times a day?

Once?

Once... and the night carer.

Someone comes in at night? Good. Is that enough?

She has to come in to make sure that I get me tablets right, and she helps me out with pyjamas, but I can't stand having my pyjamas on early like that, because we go downstairs and have a cup of tea of a night time... and we have a little chin wag down there and it takes the boredom of watching the telly all of the time...

Are they a nice lot here?

Oh yes, they are alright.

Who is that one sitting outside? With her can of beer?

That is S... she is a drunkard. She is our alcoholic.

D: Yes...

We have a lot of them.

She seemed really nice; she was shouting up to let us in!

She is lovely.... She is lovely.

So, there is lots of people that you can get on with and talk with?

Oh yes...

So, you are not isolated...

D: My sister lives right facing...

Really? Brilliant...

D: But she does work, that is the only thing.

No, that is fine, you have to get on, and there's lots of help now. And that is lovely having her there so that she can pop in and things like that.

Well, she was doing most of my caring, wasn't she?

D: Yes, she was doing everything.

But someone is getting a carer's allowance?

No... no-one...

Someone needs to apply for a carer's allowance. And have you got a disabled badge?

Yes... I have... it is downstairs.

But even though you are having carers come in etc, because one of your family members will be doing a substantial amount of...

D: It is Karen... She does everything... she picks up her shopping...

But we was told that she couldn't get carers allowance, because she earns too much money...

D: She don't earn too much money Mum... she works in a school...

No, I am saying they said.... That with her wages...

I don't think it is teamed... I don't think that it is tested against your wage... it is just something that is meant to come to you for paying... I think that it goes to the carer now...

But she does deserve...she does...

D: Karen does. Even though Mum has got carers... like yesterday...cooker needed cleaning, and the microwave...it is things like that. I mean, yesterday I was here, but Karen would normally do all of that.

So, has she had it rejected?

D: I have got no idea... I don't think that she has applied for it...

That is what they said...

D: I don't know if she might have spoken to somebody...

I think that I spoke to her the other day on the phone the other day and told her that she needed to get... wherever you get the form from...post office...

D: She should get... Karen should get the carers money, she should one hundred percent get it...she comes over and she brings over her dinner... she takes washing... Mum has an accident; you can't phone up and say, "I need a carer now!" Karen does it.

And do you get a disability allowance or anything like that?

I get DLA, yes...

The higher one.

No, the middle rate... I have applied...

I think that what you need is someone to help you fill the forms out because she can be a bit independent... When we was trying to get the carers... she says: "No, I can do that." Well, I thought, you can't actually do that, because when we come up, she say, "No don't worry, I will do that later." But she doesn't do it later; Karen comes up and does it. Rather than putting on the carers... that sounds horrible... but rather than getting the carers to do what they should actually be doing, she says, "Don't worry love." She is one of them, but then Karen ends up doing it! Like yesterday... I come up and the toilet did need cleaning Mum... like she don't like

to... But it needed cleaning... so I cleaned the toilet, but really, she has got somebody doing housework...

Is there somebody who comes to do the housework?

D: You get someone once a week...

They do it between them...JanJan and Carla...

D: I don't know what this system is, but Mum used to...

Because they...

D: Let me just say... because then Helen might know what it is, mightn't she?
What happens is that JanJan comes in, in the morning, to give me Mum a shower. When she moves downstairs she is going to have a shower that they can wheel her into. At the moment she has a bath, and a bath... It is so... We need somebody to hurry them up with the flat really, because it is all done, apart from a seat being fitted and a bit of....

The seat is in there.

The seat is in the bathroom. And all they are waiting to do is...

D: A bit of 31:38...And that has been a good six weeks.

Who is in charge of that?

D: R...

Is it done through the warden here?

D: No, it is done through---. But anyway, we have got off the subject, what I was going to say about...We should worry about the carers first. JanJan is the lady who does her in the mornings...
She has not been yet.

She'll be here in a minute.

D: Because somehow the rounds are being changed...

All chopped and changed around... where they are so short staffed...

D: So, now, Mum seems to have Jan, and Jan will put a wash in and then Patience takes it out, or something like that.

No, Patience put the washing in this morning and Jan takes it out later on.

D: So, somehow, they seem to be share-caring Mum.

Share care...

D: I don't know if that is right, or wrong, or whatever... but apparently their rounds have all been changed. But this is Mum's morning bath... What time do you get up?

About half past seven... Patience woke me up knocking on the door this morning.

D: So really, like her morning care is now turning into a bit lunchtime... Whether that is anyone's fault...

But they come from an agency local, don't they?

D: No, they are from the council, aren't they Mum?

No, no... no...

D: They are an agency?

They usually buy them from an agency.

D: Right, so that is something, I think, that needs to be reassessed, because Mum really gets on with...

I like me carers...

**The problem will be the risk of then them being changed, of course...
If you are saying that you want someone in earlier... blah...**

D: No, not something earlier... I am just curious about how the job from one carer now shared between two... They are friends, aren't they Mum? Jan and Patience?

Yes, they are all lovely, all of them.

D: It is now hard to pin down...

J: So, what does Patience do in the morning...

D: She just comes up and got your washing and put it in, didn't she Mum?

Yes, this morning... and give me... yes...

I mean, we can ring the agency... and try and assess it, but what we tend to find with all of these caring agencies, is that it is quite erratic. And you have to be on at them all of the time.

You can't... You see, they can't decide what they want to do, they get... I mean, Jan went home the other day and she had finished her work and they phoned her up to come back and get someone's shopping.

Have any of you ever rang them, at the agency?

D: Mum's happy with it. I did come up a little while ago, because the housework... Karen was doing everything... and then, like we would come down on a weekend... and have to go right through... so I said to Jan... what actually... what hours are you getting? And really, I thought that if we make a little schedule...

Yes.

J: They normally have a book where they sign...

I didn't want the book...

J: Oh.

D: Why didn't you want the book?

I didn't.

D: Oh... What I mean, is then we know who is doing what and that is why you should have a book.

No, I didn't want the book.

D: So, anyway, I thought that if we put like a little job sheet up and then we can see whether Karen has had to change the bed...

And what did that show?

D: When I spoke to Jan, Jan said no, she will do it now...
Jan said that she will do that.

Ok...

D: But now, it is all changed again, hasn't it, because Patience has had to do half of it with her...

Well, Patience does something... because she phoned me this morning, Jan, and said: "Did Patience put your washing in?" So I said, "Yes."

And will they do anything that you ask them to do?

Oh, if I want anything done, you know, they are good.

But, you don't ask very often, no?

If I wanted it done, they would do it for me.

D: This is what we are saying Mum, it is because you have to give them the jobs to do, that is why we are saying, if we have a little job sheet up there, these are jobs that could be done when she has got the hour.

You are not taking liberties, she has got to do it, otherwise when we come down, we have to do the work, whereas really, if we have got a couple of hours, on a Saturday, it would be better to take you to Lewisham, or take you for a walk over the park, rather than think... "Well, I have been there for a couple of hours, and I have had to do the toilet, or clean the microwave." Do you understand what I mean? That is there job to do. That is what they are getting paid for. So that is the job that they should be doing, which is why you have to have a book.

No, I don't want the book.

Well, maybe you can just have a little list now and again that says, just a couple of things that need doing.

But, you get on well with them?

Yes.

And they help you out?

Oh yes.

Ok...

The one that does the night caring, I have to sign her paper...

And so you have someone come in in the morning who helps you get washed and dressed and someone at night-time who puts you...

Makes sure I take me medication... and me pyjamas...

Makes sure you... ok...

Can't stand that, having my pyjamas downstairs...

No. So, do you put them on after then?

No, I can get them on...

You can? Ok...

D: A lot of the time, you don't put your pyjamas on, do you? You just keep the t-shirt on.

Just keep me t-shirt on and then go down stairs...

And if you had to change your t-shirt, you could put a new one on?

Oh yes...

D: They don't get her dressed in the morning. They give you a shower, don't they?

Unless I have... Unless I have any trouble, you know, getting things on.

Because the... when they put the bandages on... you can't see them, the...this type of thing, that is self adhesive, and when they put that on, I can't... I can't put me trousers on, because it drags on the trousers... So, I have a job... And then I get all out of breath then...

But, now, they have started putting the stocking over the top of that, so that is easier to get me trousers on.

Ok, and do any of the other residents come and see you here? Or the people who live here?

Oh, my friend round the corner did, she came in the other afternoon.

Yes.

D: And the warden comes up every day...

Everyday... to check that we are alright...

D: As soon as she gets here in the morning she comes up and just gives everybody knock to make sure that they alright... She is quite nice. She is onto things if...

If there's a problem.

And how does the system work? Do you have a buzzer, or... what if you fell? Have you got something in case you fell? Have you got that with you?

You have that around your neck?

At the moment... Well, yesterday and the day before... the signal went out of the system... it broke down, the system... and although we could call out on this... and it wasn't going through their system at the other end... and so...

When are you hoping to go downstairs? It is nearly ready?

What is?

Downstairs is nearly ready, your new flat down there...?

Yes... I just want them to hurry up because at the moment it is getting hard for Jan like...

We can ring the warden and get all of the details and then... ring the company...

D: I might actually... I'll just grab my bag... I am not sure if it is in there...

Because, R, you know, you have got the cancer, and you have the renal problems and I know that it sounds strange, but we can also try and use those to speed things up, because you know, people are sometimes sympathetic, more sympathetic, if they hear that you have certain conditions, and so it might mean that we just write a letter and we can speed things up.

D: Well, that is all I am waiting for, to get a form to sign. He has been quite good, R---, and he did say that he would give me a call back... to check through these details...

Well, sometimes a letter from the hospital is the quickest way of speeding things up aswell...

Ok, have you got any other questions for us R?

No...

Ok...

J: So, R, how much **40:23** are you taking?

Two... There you are...

We'll speak to S and decide what to do next, and how best to manage things. Is that alright R?

Yes...

Ok, and then we will...

PHONE RINGS

D: I can ring down to Jane from here, can't I Mum?

Just pull the cord.

D: What cord?

PHONE GOES OFF

D: What pull the red cord?

Yes. And ask for Joyce?

D: Can that go through somebody else?

No, no, it goes straight down to Joyce.

She won't think it is an emergency, will she?

No.

Right. I better turn that off.

END OF INTERVIEW

NVivo revision 2.0.163

Licensee: HELEN nOBLE

Project: PhD data User: Administrator Date: 17/04/2007 - 11:45:50

NODE CODING REPORT

Node: Decision

Created: 13/10/2006 - 13:19:06

Modified: 17/04/2007 - 11:22:07

Documents in Set: All Documents

Document 1 of 42 001 DB 05~10~06 2nd int

Passage 1 of 10 Section 0, Paras 413 to 419, 448 chars.

413: When I saw him, he drew a different graph, and said this is what happens...when you have treatment, and this is what happens when you don't have treatment... you know, and so basically what he was saying in one way, was at the end of the day, you are going to die... (CHUCKLES)

414:

415: Mmmm...

416:

417: P:But it is what route you take...

418: LAUGHS

419: But, you know, I found it very good... you know? I didn't tell me what to do, but I think that he led me in the right direction...

Passage 2 of 10 Section 0, Paras 422 to 433, 732 chars.

422:

423: P:What he was saying was the fact that... and this is like with you and medication, if I was going to... what do you call it....deteriorate, the deterioration would be great, a more even course, and with the other one, with the stuff, I could get an initial boost...

424:

425: On dialysis?

426:

427: P:Then have a voom...

428:

429: C: Yes, we took a long time making this decision...

430:

431: Did you?

432:

433: C: And we discussed it, and in the end I said to him, "Well, it is three days out of a week but if you are going to get four good days, is it going to be worth it?" So we discussed with the consultant, and he said, "Well, that is the best scenario; it could mean that the other four days are in bed...." Because he wasn't very well, and it might mean being kept in hospital...

Passage 3 of 10 Section 0, Para 435, 825 chars.

435: It is so 00:19 insistent when they are putting it in, but I think that overall, that... the hospital thinking that now... that is the transport and you have been on the thing for three or four hours and I think that the three days a week, it would wear your bloody life out, you know, so in actual fact, I know sometimes that you haven't got a choice, and you have only got a choice, you have got to take the best of what there is, ain't you?

But, having had the choice I think that I made the right choice, you know, as I go on, I am more convinced, because I think, Christ, I would have been going up and down that hospital, lying there with the stuff being pumped in me every day, and it is not pleasant, not, if you like, a pleasant way of life, but if you have got another life you are going to keep hold of it, aren't you?

Passage 4 of 10 Section 0, Paras 439 to 447, 289 chars.

439: Don't know... don't know...

440:

441: C: We don't know because we thought about it quite a bit...

442:

443: P: I actually really consigned myself to having the treatment at the beginning... I sort have had made up me mind that I was sort of going...

444:

445: Why? What happened?

446:

447: P: I don't know... I thought I had to have it...

Passage 5 of 10 Section 0, Para 449, 599 chars.

449: I think that one of the things was the way that the consultant spoke, he didn't say, "don't have it", he wouldn't would he? But somehow at the back of it, because of all the other things that he has had... the major operations that he has had, and everything else, because I said, "Could he have it at home?" and he said, "No, because you have to have it in your tummy." And they can't do his, because he is scarred with the operations... So I began to get the feeling that he thought... and he didn't say anything as such, and I began to get the feeling that he thought that it would be better for him...

Passage 6 of 10 Section 0, Para 451, 147 chars.

451: His first thing that sort of changed it was, "you don't have to". See, I was under the impression really at first, that I didn't have an option...

452:

Passage 7 of 10 Section 0, Paras 456 to 464, 377 chars.

456: And then he says...

457:

458: P: He didn't say, don't have it... but he said, "You don't have to", which made me realise that there was another way...

459:

460: C: There was a choice...

461:

462: P: I said, "What about that?"

463:

464: C: I asked him, didn't I, because he said he was talking to him about it and I said, "What happens if you change your mind?" You can still go and have dialysis and it is not a problem...

Passage 8 of 10 Section 0, Para 466, 634 chars.

466: I appreciate that it takes time to set up... Because you come in and like have an operation on your arm, to have the thing fitted and you have to wait and see if it rejects... you know and that was, if you like, in one way, the turning point, but you have to appreciate that at the time, also I was pretty low. I mean, I do manage to keep pretty bubbly and, what do you call it, 'up', I am not a pessimist... I am a bit optimistic in some ways and I do try to keep my spirits up, but, at that particular point in time, after I had... I don't know now...I forget...two or three weeks going in and out of hospital, breathless... I was pretty rough...

467:

Passage 9 of 10

Section 0, Paras 473 to 478, 392 chars.

473: And once you had made the decision, how did that feel?

474:

475: P: That felt a lot better straight away really...

476: I mean, it wasn't all right today and then gone tomorrow... and then your little doubt comes, you know, have I made the right decision? And then you say, "If the worse comes to the worse, I will have to go back to it..." you know?

477:

478: C: You go through all sorts of things really, don't you?

479:

Passage 10 of 10

Section 0, Para 482, 268 chars.

482: Because you think to yourself, if he does, what he has done, is it going to shorten his life at the end of the day? But, if he gets... I mean, he is seventy-six now... If he can get another few years... Whereas if it went the other way, would those few years be worth it...?

483:

Document 2 of 42

001 DB 1 July 06

Passage 1 of 3

Section 0, Para 9, 372 chars.

9: More and more DB feels confident that he has made the right decision. The wear and tear of coming up to hospital would have been difficult. He keeps his fingers crossed. He said some one had 'shined' on him and made him go in the right direction. He said that the consultant he had seen (RT) had never told him what to do but had guided him and the decision had been his.

Passage 2 of 3

Section 0, Para 11, 52 chars.

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001 DB 3RD JAN 07

Passage 1 of 2

Section 0, Paras 5 to 13, 3004 chars.

5: Well no, the frightening thing about it really is the fact that when they told me, they said, oh, you got one kidney working 60%, the other one working 40. Now fortunately, the one that was, the one with the cancer was the one with 40, and I'm saying to somebody, I said to the chap, one of your consultant chaps, I said, well, I've only got a 60% kidney. He said, no, you got a 100% kidney ... he's saying, that kidney's got to do

all the work, before when I was there, this was doing 60% and that was doing 40%. He said, no ... 100%, it's got to do 100% of the work now, *which is a nice thing though, you know.*

6:

7: **Yeah. So what made you come to the decision of not having dialysis?**

8:

9: I must say, I would say personally, not that he told me to do it, but I think it was the consultant, cos I thought originally I had no option. I didn't know that I had a choice, and I had to come to see him a couple of times, and we got to the stage where he told me they were going to stick this thing in my arm to

10:

11: **For dialysis.**

12:

13: Yeah, and then I had to wait about six or seven weeks or something before they do it, and he told me about that, and this particular time I went and he was talking, and my wife said to him about the option and so said to him, well, if he comes here three days and he gets four good days, so that's better than nothing, really, that's what she was saying, and he said, no, not necessarily. He said, that's the best you can get. He said, you could have three days' treatment and you could end up four days in hospital or in bed rather. He said, it's not necessary. So then he drew *an old* graph, and he said, well, if you have *the op*, this is what the graph is, and if you don't or if you have dialysis, this is the way to go and this is where you go, and he didn't say don't do it, but I think he led me in that direction, and in one way, I'm grateful cos I think I made the right decision, to be honest, but whether I did or not, I don't know, but I could imagine coming up here three times a week, no ... if you got no choice, you can't, you hang on to life, don't you? But if you've got no choice, then you've got no choice, you got to do that, but as I said, in this particular case, I think that would have been very weary and I don't think I would have felt the way I do today if I'd been having that *cleanage* two or three days and oh, bloody hospital going, no, no, I think anyway, so I think in that way, I got to be grateful to him, although he never said, not at any time did he say don't have it. The only one thing he did say to me, he said, if you get a letter to do the thing, he said, I think he said, ignore it at first. Don't immediately answer it. I think that's what he said ... I don't know, but I think he is very clever, myself, but that's what he's there for, isn't he? He's presumably the top man in that job, so that's it. So as I said, I still think I made the right decision, but I think that he was the one who helped me, guided me along the road, like, so

Passage 2 of 2

Section 0, Para 17, 390 chars.

17: *say it to behold you and ...* and in fact, basically from the time when I made that decision, I did sort of go out the platform, you know what I mean. I got better at a different level. I'm not saying I got brilliant, but whereas I was on this level ... take that off me, and I was on a different, I suddenly got better on a different level, in that way, I think, don't know, but that's it.

Document 4 of 42
Passage 1 of 6

003 TA 4 JAN 07
Section 0, Paras 37 to 39, 533 chars.

37: **So what did the doctor told you about your kidney problem?**

38:

39: He just said, one of my kidney is bad, and I think he had to give me this injection. I get an injection every day, every week, and I get so many tablets, I take about four tablets, I think I ... I can't, look, my old man can tell you the amount of tablets that I, he's the one who, the doctor tell him that he is supposed, give me the tablets, mine are

supposed to, you know what I mean ... do anything, and I get an injection every Monday, that's all I can tell you, my dear.

Passage 2 of 6

Section 0, Paras 41 to 51, 468 chars.

41: Yeah, I know your tablets and your injection, but then I was particularly looking at the information you get from the doctor regarding your kidney failure, like what treatment is in offer. Did he mention about dialysis?

42:

43: That mean is it the tablet them I had to take twenty days? Is it, hold on, I think he said something about that and my

44:

45: It was going through the machine.

46:

47: I think my old man tell him, no.

48:

49: OK, so your man, your husband told the doctors, no.

50:

51: No.

Passage 3 of 6

Section 0, Paras 53 to 59, 376 chars.

53: Why do you think did he not opt you to have dialysis?

54:

55: I wanted to carry on with the tablet. I've been taking the tablet them for years, so just carry on, I didn't

56:

57: So do you know what dialysis entails?

58:

59: What he explained to me and tell me, you take, is it something you, oh, in the long time ... he was telling me about that. Explain it to me and tell me what it is, please.

60:

Passage 4 of 6

Section 0, Paras 67 to 77, 433 chars.

67: Oh, yeah, yeah, he asked me to choose, I tell him

68:

69: Yeah, whether you want to have that dialysis or you don't want to have that.

70:

71: No. My old man tell him ... I remember that, my old man said, no, we'll manage, still carry on with the tablets and the injection.

72:

73: So did you say that the tablet and the injection will

74:

75: Yeah, they do me fine.

76:

77: So do you mean these tablets and the injection is a form of treatment for your renal failure?

78:

Passage 5 of 6

Section 0, Para 79, 125 chars.

79: Well, I've been taking the injection for a long while and the tablet, and touch wood,

you know what I mean, I feel all right.

Passage 6 of 6

Section 0, Paras 85 to 95, 628 chars.

85: Yeah? OK. So there was actually, yeah, I think that was in April, isn't it, when you saw Prof in clinic and then these things were discussed with you and then you decided not to have dialysis, and are you still happy with that decision?

86:

87: Yeah, I'm happy. I'm quite happy what I'm taking. Well, it make me feel, you know what I mean, so why come off it now, just carry on.

88:

89: So are there any, so you don't regret having that decision?

90:

91: No.

92:

93: And your husband's still happy with that?

94:

95: Well, I suppose so. If he would say to me, change over, whatever, you know what I mean, but I'm quite happy with what I'm taking.

Document 5 of 42
Passage 1 of 5

004 SF 2 211206

Section 0, Paras 117 to 131, 1328 chars.

117: I want to talk to you about the time that you found out that you had renal disease, and about making your decision not to have dialysis.

118:

119: Yes.

120:

121: Would you tell me about that and what happened at that time, and what it was like? If you can remember.

122:

123: Now let me think, I've known for a long, long time to have renal disease because, well this is very old history, but about 18 years ago, a long time ago, I had this illness and it was called polyarteritis, and Dr B said to me, when he'd got me through it, that my kidneys were affected and I would need attention for the rest of my life which they would give me. And carried on like that for years and lived quite an ordinary life, able to get out and do things and kept a strict diet, but apart from that I was pretty normal really. And then one day when I went to the clinic the doctors I saw said to me that they had done all they could and it was a question of would I like to have, what it's called now.

124:

125: Dialysis? Is that what you mean, the machine, the dialysis machine?

126:

127: That's it. Would I like to have that, and I thought about it. I'm living in a community and it would really be a big bother all around, it would honestly, and my age was then about 90 so I decided I didn't want the dialysis, I'd rather.

128:

129: What do you mean by big bother?

130:

131: I'd rather not bother.

132:

Passage 2 of 5

Section 0, Paras 133 to 153, 864 chars.

133: Is it a big bother?

134:

135: Well it is a big problem, it's very hard and they really haven't the time to play around. And I don't regret that decision at all because of my age, if I'd been 20 years younger I would have had it. So that was a decision I made and I don't regret it.

136:

137: Did it take you long to make that decision?

138:

139: No, it didn't really, no.

140:

141: What did they explain to you at the hospital about the dialysis? What did they say?

142:

143: Well they didn't really explain it, to be honest, but I sort of knew about it as it were.

144:

145: Can you remember what you knew?

146:

147: Well that it needed constant hospital care, that's all I can say really.

148:

149: So there was the option of dialysis, or what was the other option if you didn't have it?

150:

151: The other option was to have palliative care which is what I'm having.

152:

153: And how do you feel with all of that now? How does it all feel now?

Passage 3 of 5

Section 0, Para 155, 144 chars.

155: It feels fine, I don't regret any of that, I don't feel that I didn't understand or nobody took any trouble, I don't feel any of those things.

Passage 4 of 5

Section 0, Paras 211 to 225, 674 chars.

211: And since you made the decision not to have dialysis and are receiving palliative care, apart from the sickness or any of the symptoms that you might get from renal failure, do you think about anything else in relation to it?

212:

213: No. It was really and truly the bother to the community and the fact of my age, it didn't seem to justify it. As I said, if I'd been 60 instead of 90 I wouldn't have hesitated.

214:

215: And what if you didn't live in a community and you lived on your own?

216:

217: If I lived on my own I'd have, well I

218:

219: Who knows?

220:

221: I think I still should have said the same thing.

222:

223: And as you say, it's something you now are glad that you did?

224:

225: Yes, I don't regret that at all.

Passage 5 of 5

Section 0, Paras 227 to 229, 102 chars.

227: And you've done rather well actually, haven't you?

228:

229: I think I have actually. I really think I have.

Document 6 of 42

Passage 1 of 3

006 RT 2 180107 2nd int

Section 0, Para 13, 646 chars.

13: Where should I start? Went to the clinic and the doctor there who saw me said, I've got some bad news, I said, what's that? He said, I give you six months to live. This was twelve months ago now, I said ... well that upset, didn't it? And do you want dialysis or to go on pills? So I said, I don't want to keep coming up here every other day to have dialysis so I'll go on the pills, said all right, we'll try them out. Anyway, they seem to work OK, they stopped me going up there to have dialysis on the machines and whatever. And I've been on the pills ever since, and the ... the same. I mean that's all, I don't think I've missed

Passage 2 of 3

Section 0, Para 65, 185 chars.

65: Yeah, because he said come back in half an hour or whatever, and said, and you decide there and then which you want, so I told him and just popping them, taking the tablets ever since.

66:

Passage 3 of 3

Section 0, Para 69, 112 chars.

69: Yeah, because I knew what was happening on my way to the clinic every day, and I just couldn't cope with that.

Document 7 of 42

Passage 1 of 4

007 DJ 1 12~10~06 1st int

Section 0, Para 77, 254 chars.

77: She knows, but she don't like it, before one of her family friend, her age is forty-two or something, and she took the dialysis and after she died, so she looked after that lady in hospital at home, and she saw her life and she don't want the dialysis....

78:

Passage 2 of 4

Section 0, Para 83, 52 chars.

83: And she is worried that this age is gone, dialysis...

84:

Passage 3 of 4

Section 0, Paras 96 to 100, 205 chars.

96: She went to the doctors and everyone said that urine passing is the problem, that for the patient the dialysis was best but she said...

97:

98: P: SPEAKS TAMIL

99:

100: C: She don't feel anything and so she is not worried...

Passage 4 of 4

Section 0, Para 166, 228 chars.

166: She is fine... She was talking to me... that I don't want to come because she was worried because she might come for dialysis today. She said I have spoken to Dr and he told me that I won't go for dialysis and why am I here?!

167:

Document 8 of 42

008 AM 1 16~11~06

Passage 1 of 2

Section 0, Paras 207 to 217, 655 chars.

207: probably is if it is a decision that he has made... Do you feel that he has been well informed? About your other options?

208:

209: Yes...

210:

211: Yes? And do you feel that it was his decision?

212:

213: Yes, it was definitely his decision.

214:

215: **Did he discuss it with all of you, or did he...just decide himself?**

216:

217: He was basically... the doctor was there and I was translating and I was telling him all the options and then he was asking... he said, he said that if he could have a single operation... like because the dialysis was for the rest of his life... but if you have a single operation that would prolong it for another ten years or something, he would rather have that rather than... so...

Passage 2 of 2

Section 0, Paras 571 to 594, 467 chars.

571: **No dialysis?**

572:

573: P:I don't know...

574:

575: C: He doesn't remember...

576:

577: **He doesn't remember?**

578: **Does he not remember what happened at the hospital?**

579:

580: P:Now... I said no...my head...

581:

582: **Your head?**

583:

584: C: Yes, don't worry...

585:

586: P:Nobody ask me...

587:

588: **He doesn't remember?**

589:

590: C: He is saying that if something happened six months ago, if you come back again and ask him, he won't remember...

591:

592: Tell me, what is wrong with you? Tell me what is wrong with you? What is your biggest problem?

593:

594: P:Not any problem...

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009 FP 1 291106

Passage 1 of 13

Section 1.1.1.1, Para 31, 343 chars.

31: Just how I felt in general and he said to me once, not the last time I saw him, but the time before, regarding dialysis. At the first ... if it goes, get too bad I was expected to go on dialysis, would I be happy that? I said I'm not happy with dialysis after what I've read about it but I'm accepting if it's going to give me relief and help.

Passage 2 of 13

Section 1.1.1.1, Para 39, 919 chars.

39: Yeah it kept stable. Well the last time I saw ... it had gone up to 440, that was a jump of 95 in a couple of months and he said to me, he said it before, I like to get it correct, that he don't think dialysis would help me at all and he'd have to see how it goes and if it is a case I have to well I have to, second time I saw him he said to me about the ... level going up, of course he said I'm afraid we can't do nothing at all to help you, I said regards to what? He said dialysis. He said if it gets so bad the only way that it'll help you is if you come and take you into hospital and stay in there, you won't be able to leave and I was not very pleased with that so I asked around and got one other opinion and I got, I'm sorry I can't, he told me something that the blood is not good enough and I wouldn't stand it but I been told that the one thing that mattered in the blood count was OK and I could stand it.

Passage 3 of 13

Section 1.1.1.1, Para 59, 472 chars.

59: Well I'm thinking what a lot of people think, some people will say, it's the age factor and I believe that's what all the problem is and I can understand that to a certain degree. See I was very fit in my younger days, very fit, I played every sort of sport which you could name and they were amazed when I went into there for this operation, I have worked until I was 76 and I was as fit as a fiddle until I had that angioplasty and I've gone downhill with the kidneys,

Passage 4 of 13

Section 1.1.1.1, Paras 69 to 75, 513 chars.

69: Going back to when he was talking to you about dialysis, what did he explain to you Dr, what did he tell you about dialysis and why was he saying it wouldn't be appropriate for you?

70:

71: Because of the condition of my blood.

72:

73: The condition of your blood?

74:

75: Whatever that was, whatever that condition because the ... thing now is, well I wouldn't like to know what it is because I've had a bit of a hectic time lately and I wouldn't like to know. It was up 440 and that was September or late August or September.

76:

Passage 5 of 13 Section 1.1.1.1, Paras 301 to 311, 720 chars.

301: But at your last appointment with Dr he said that he wouldn't be giving you dialysis?

302:

303: Exactly.

304:

305: Would you say you agreed with that?

306:

307: I did in a way but not when you're talking to somebody and he says well if that happens you've got to go in hospital, it would be more hospitalised as the dialysis is done.

308:

309: Well you'd have to come up three times a week.

310:

311: No stay in, and I naturally said I don't want to stop in hospital all that time, whatever time I've got left I don't want that to remain in hospital that's what I hadn't said what I meant. I'm assuming that having said that he took it to say that I don't want the dialysis, but for me to say I'm opting out or I refused to have dialysis, I never have done.

Passage 6 of 13 Section 1.1.1.1, Para 315, 390 chars.

315: Exactly, yeah that is exactly, but I just want to tell you that as when he were discussing it with me and in discussion he said to me you've got to come in hospital just to have that taken off you and I said I don't want to come in hospital, I don't want to and he had to be taken it then to say you're refusing the treatment to take it off your leg, that to me is what's happened with Dr A

Passage 7 of 13 Section 1.1.1.1, Para 355, 300 chars.

355: I can understand that, but you're saying to me what nobody else has said, if I go on dialysis it could be worse for me. Only one person's said that and that's C he said you've got two chances, either you accept dialysis and it accepts you or else it'll make you bad and you're saying the same thing.

Passage 8 of 13 Section 1.1.1.1, Para 363, 185 chars.

363: I've thought of that many times, I've spoke to my wife about it, but as I've said to you she's so uptight with everything you can't really hold a sort of discussion like that with her.

364:

Passage 9 of 13 Section 1.1.1.1, Paras 367 to 375, 559 chars.

367: Oh yes, speak to my son and my daughter and they give a good answer.

368:

369: What do they answer?

370:

371: Dad it's for you to decide.

372:

373: It's a hard one isn't it?

374:

375: Oh really I said, I wouldn't like either of them to say well yes you go for dialysis and then something happened that puts them in a bad position, so if I do make the decision myself either way I've only got myself to thank, but I want to try if I can and make the right decision and from you I can see that I'm hoping to be help me to be able to make that decision, I don't know whether you will, but I'll try.

Passage 10 of 13 Section 1.1.1.1, Para 387, 198 chars.

387: Thank you, that's made that decision. So we're coming to it, we're getting there because I think my answer is nearly no to dialysis now because I can't think that's going to do me any good to have.

Passage 11 of 13 Section 1.1.1.1, Para 395, 111 chars.

395: Well I think I've already made my own mind up within myself regarding that. I'm not living a quality life now.

Passage 12 of 13 Section 1.1.1.1, Para 403, 112 chars.

403: Not really. From my own point of view I don't think dialysis is going to extend my age, my life with age wise.

404:

Passage 13 of 13 Section 1.1.1.1, Para 419, 114 chars.

419: Yes, but I don't think I'll, well it may do as I say, if after a while, but at this moment in time I would say no.

Document 10 of 42 011 1st AB 081206 carer
Passage 1 of 8 Section 0, Paras 43 to 63, 1383 chars.

43: We talked about the dialysis situation for. When she

44:

45: Kidney.

46:

47: The kidney. When we used to see Doctor, with the very long surname,

48:

49: P?

50:

51: That's the chap. And he explained to myself and my Mum about what was involved and in his expert opinion, sometimes it's good to have, sometimes it's not so good. If, for example, what kind of quality of life are you going to have by having dialysis. So when he tried to explain to her that three times a week down into the hospital and attached to this machine for five hours, is it, I think? Four or five hours, with also there was a risk of infection, she would have to have a small incision for a, or a small operation to have, and again, even just from having operation, he explained that there could be infection which could also be fatal, and she was, oh no, no, no, I'm not going through that, no, no, I'm not doing that. Three times a week in hospital, oh God no, no, no.

52:

53: She kind of said that to me.

54:

55: Yeah. No, no, I'm not doing that. And then again yourself sent me to the Whitechapel and I met a really nice lady there and she gave me a DVD, a video.

56:

57: Sarah?

58:

59: Yeah, a black lady.

60:

61: Yeah, Sarah, yeah.

62:

63: And I went there and she talked me all through it and she was saying, look sometimes again quality of life is what you're looking for, what does your Mum want to do? As a family you need to talk about it.

64:

Passage 2 of 8

Section 0, Para 67, 2666 chars.

67: No. I went and I got the video and she explained it all to me, I brought the video, she lent it to me, I brought it home and Mum refused to watch it. She refused to watch it. I said, how are you going to? No, no, I'm not doing that, no, no, no. OK I took it back and then my brother was saying, oh, well you're going to die if you don't have it, and my other brother was going, oh I'm going to give you my kidney. He's 40. And she started going, Owen's going to give me his kidney, and I was saying, look don't be ridiculous, why would you want to take Owen's kidney, Mum? The fact is I think Doctor C said that even if she did get a new kidney, cos the diabetes is so bad it is no guarantees it wouldn't just rot away the same. So there was no, then my brother frightened her, you're going to die if you don't have a go on this machine. And then she got, well I don't know what to do now, what shall I do? I said, I'm not going to make the decision for you. Oh what, I said, don't, it's all down to me, I don't want the decision to be made by me. And then it got to the stage where she just didn't talk about it. My aunt comes and sees her sister once a week and I said, can you speak to her about it? Oh, I don't know anything about this dialysis, I don't know anything about this dialysis. So she's kind of sweeping it underneath her wheelchair and pretending it's not really, or because she's OK at the moment it's fine but I said to her, what will happen is your body's just going to one day just break down and you're going to have to make that decision. And I said, and sometimes if the doc, because you've not made the decision yourself the decision might be taken out of your hands and I said, Mum I'm not going to make that decision for you, *I'll leave that*. But again she just gets a bit ignorant towards the whole, cos one time she used to say, no, there is no way I'm having another operation and having this three times a week going to this hospital, attached to a machine for five hours, I'm not doing it. Too old, I've been through enough, I'm not doing it. And then a little while ago, well I say it's months back, it was like, oh I don't know what shall I do? She was asking the Doctor, we were somewhere and he was trying to explain it to her again, I can't think where it. And she said, what do you think I should do? And he said, well it's really up to you Mrs Blow, you have to make the decision. But sometimes I've said to her, you do realise that it, maybe there isn't going to be a decision to be made because it could be so bad that it could just go into, I don't think it's a coma they go into or just.

Passage 3 of 8

Section 0, Paras 79 to 87, 1161 chars.

79: Yeah, I think she does. Because if you were speaking to her today and she, I think she probably sounds like she doesn't want it, and then. I think she's quite tired with the whole, I think obviously she wants to live but I think the thought of having been

attached to a machine and having all this stuff. And I said to her, look Mum, again you're going to have to keep that wound cos it's going to be there all the time, just covered by a plaster or something isn't it, I would have thought?

80:

81: Well it's *probably*, well up here *probably*.

82:

83: Oh is it in the arm? Up here is it?

84:

85: Yeah.

86:

87: And I said, you're going to have to be attached to it and she's like, oh. I said there's one you can have at home all night and she said, oh no, I don't want that, I think. So that's why when she said to me tonight, what are they going to come to talk about, I think that's when she got suspicious. Cos I said to her a few weeks ago, you know the doctors and nurses are coming to see you, you probably wouldn't ... oh I don't know about this dialysis, I'm not having it. Then it was, oh I don't know what to have. So I don't know how far, at the moment she's still going,

Passage 4 of 8

Section 0, Para 159, 137 chars.

159: No, don't think she's even, my Mum is really strange sometimes, she doesn't even. If she has thought about it she never talks about it.

Passage 5 of 8

Section 0, Para 175, 593 chars.

175: Yeah, this is what, this is the way I've understood it, not reading between the lines or around it but it just sounded like, that if she did there was no guarantees anyway that it was going to be a lot longer life or for what she's going to be going through three times a week, being attached to these machines, absolutely hating it, whinging the whole time about it. Is there going to be any, is she going to be any better to get up and walk around to the toilet or go into the garden? I don't know, I really don't know. So that's the way I read it and I think she read it that way as well

Passage 6 of 8

Section 0, Para 195, 309 chars.

195: How are they going to do it? How would they do it? Just the three times a week alone would just pee her off. Just getting that bus and wanting to go up to the L. three times a week and then she'll expect me to come and pick her up or drop her off or sit and I can't sit there for five hours obviously.

196:

Passage 7 of 8

Section 0, Paras 203 to 207, 438 chars.

203: And then she gets really peed off because she finishes at say 12 o'clock and they're not picking up the last person till 2 so she's got to sit there for 2 hours. She really gets, oh my God.

204:

205: Gets what? Angry?

206:

207: Yeah. She's, out all day, I finished 12 o'clock and I had to wait for 2 hours and he drives all the way around London, I'm the last person. Cos once she never got back till after 5, she left about 10 o'clock in the morning.

208:

Passage 8 of 8

Section 0, Para 211, 33 chars.

211: She ... she was really pissed off.

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Passage 1 of 4

014 TR 1 Dec 06 daughter
Section 0, Paras 389 to 391, 225 chars.

389: So let me ask you about, you know when you made the decision not to have dialysis, what did the doctor tell you when you were discussing this thing?

390:

391: M You see at my age you can't get ... because it'll bring a heart attack on.

392:

Passage 2 of 4

Section 0, Para 401, 155 chars.

401: Basically what they were saying was because my dad suffers from strokes and high blood pressure, and the actual process of dialysis is very, quite violent.

Passage 3 of 4

Section 0, Para 405, 729 chars.

405: F It's really harsh, yeah, a really harsh process, it could raise his blood pressure and cause a stroke, a major stroke which could cause him to be paralysed on one side, and they're saying they don't think it's a good idea because if that were to happen that would be a bad quality of life. But basically the impression I was getting was they were saying they don't think it's a good idea for him to take it, but he had to make the decision basically, because they made all the negative points. Because how I see it is if you're going to give someone a decision, you give the negative as well as the positive, you say the disadvantages, this is what's going to happen to you, this is what the possibilities that could happen.

406:

Passage 4 of 4

Section 0, Para 409, 1589 chars.

409: Yeah, you have to balance it out. This is what could happen to you, you could suffer a stroke, this could happen to you, you could have a poor quality of life, blah de blah. On the other hand, that might not happen, and if it doesn't happen the process happens like this, you'll get a better, you won't feel as ill, write it out so that you can think about it, the pros and cons. But they didn't, they just kept saying, you could have the stroke, because looking at this I can see that you've had this and that strokes already, the results of this says that, the results of that says this and what have you and blah de blah. So go away and think about it and come back, and obviously when we spoke to everyone we said, when he spoke to everyone, everyone said no. Because obviously if you're saying there's very high probability that you're going to have the stroke, then it's not worth it, is it, at the end of the day? Because he's better off, we thought it better off for him to have mobility in all his arms, legs, limbs, everything and go out that way, rather than going through dialysis, having a stroke, having part of his body not being able to work, and maybe through depression go out that way. And the dialysis won't help anyway because he'll be depressed because of the fact that that's happened. And that's how we made the decision, and he basically said he didn't want to have it done if that was the case, we all agreed with that

decision. So when we went back in a month's time we just told them no, and he said, I think that's the best decision. So there you go.

Document 12 of 42 016 2ND NC CARER OF MC 020307
Passage 1 of 1 Section 0, Para 119, 1542 chars.

119: Well that was last year, wasn't it? Yeah, last year, I was mortified because I think I told you before, there was, when she was under the diabetic at ME there was no-one ever telling me she was losing her kidney functions until Y mentioned it that day. Otherwise I'd never have known, if he hadn't have mentioned it I wouldn't have known anything about it. The fact that he mentioned it and said what he did say shocked me into thinking, Christ, if he's telling me she can't have renal dialysis because of only 20% function, why did they wait until there was only 20% function, why didn't someone tell me or tell her or advise us in some way? But no-one did, no-one did. So yeah, I was cross as well as mortified, because I thought there's no communication here, why didn't someone tell me that this is the situation now? Nobody ever told me so I was none too pleased. This is like you're dying and no-one tells you that you're dying until the last minute, oh, by the way, sorry, forgot to tell you, you're dying. And it's like, hey, why didn't you tell me a year or two ago I had this problem, that my kidney was failing? Why did you wait unless it was 20% before you thought to tell me? So yeah, I was quite angry, and I was quite shocked because I thought, well fancy telling me this time, halfway down the line, why didn't someone give me advance warning. I don't know, maybe I would have tried to look at ways to help her, like maybe die, I don't know, but they didn't give me a chance to do that because no-one told me.

Document 13 of 42 016 NC 1 110107 daughter
Passage 1 of 5 Section 0, Para 25, 482 chars.

25: He was a very nice, very nice doctor and he just told it the way it is cos I said to him, I don't want you to put frills on it, just tell it how it is. So that's what started it off cos I came out there and I was in hysterics. He said to me, she's only got 20% of her kidney functioning and it's a matter of six to a year. And I thought, why didn't anybody else like the diabetes clinics tell me she had renal problems? Cos at the time I didn't know much about renal diabetes.

Passage 2 of 5 Section 0, Para 61, 673 chars.

61: He said there was nothing more he could do for her. As I said to him, can't you give her dialysis? And he said, no cos it would kill her. I suppose it's too late in the day. I don't know. That's the reason he gave me, it would kill her. So I don't really know, but I thought well, why wait till it's only 20% functional before you tell me in the first place. So shouldn't he have told me when it was like, when she could have had dialysis. Shouldn't someone then have said to me, well look, she can have dialysis. Before it got to the stage where she suddenly got 20% of it functioning, couldn't someone have mentioned it earlier? You know what I'm trying to say?

Passage 3 of 5 Section 0, Para 69, 485 chars.

69: He's not going to take that decision, he says that it would kill her. I suppose that's because she's got other health problems. Probably her heart wouldn't be able to manage it. I don't know much about renal dialysis but I do know that some people find

it really traumatic, you know? And I suppose with her having a heart problem, professor probably was thinking on them terms as well, that there'd be too much stress for her heart. So maybe that's why he said it would kill her.

70:

Passage 4 of 5

Section 0, Para 73, 441 chars.

73: Cos he didn't really go into a lot of details about it, *cos you know*, you're not in there long enough. That's what he said and I thought, why wasn't it offered to her before that then? Why wait till it gets to the 20% mark? Why didn't someone pick up on it and say, well OK, she's got 80% of her kidney working, we can offer dialysis, but nobody ever did. Last year was the first time I found out she had renal problems so I was shocked.

Passage 5 of 5

Section 0, Paras 151 to 157, 726 chars.

151: So when she came to see Dr. Y, did she know what was being discussed? Did she understand at that time?

152:

153: No, she didn't have a clue. She didn't have a clue whatsoever. She saw me all crying and upset, I was trying not to, she didn't ask. She didn't ask me why I was crying. She didn't ask me what we were doing in there, she just knew we were seeing a doctor *and that's it*. I was the one coming out crying and she was sitting there wondering, what's she crying about?

154:

155: Because she didn't understand?

156:

157: I don't think she understood any of it really. I don't think so. That side of her, part of her brain's deteriorated a lot. Simplest things *task*. Simplest things now, she just can't remember and gets all confused.

Document 14 of 42
Passage 1 of 4

017 1 Mrs S wife of AS 120107
Section 0, Paras 21 to 25, 278 chars.

21: Yes, and course he went to the L first and he saw P ... and they said he couldn't have, what's the thing where you inject?

22:

23: Dialysis?

24:

25: Dialysis yes, it wasn't suitable for him to have dialysis, now why I don't know because I never went into that, why would that be?

Passage 2 of 4

Section 0, Para 41, 282 chars.

41: Well he just said that he couldn't have dialysis and that he'd got to take, I think he took some drugs, I don't know quite what he took so much, it seems ever so many tablets, but he, up until I suppose the last three years, I would think the last three years have been pretty grim.

Passage 3 of 4

Section 0, Paras 71 to 77, 719 chars.

71: So go back now to when he heard about his kidneys, how did he take that, did he feel OK about it?

72:

73: Yes I think he was just surprised and said well I've been all these years with one, I can't see it's going to make much difference, that was his words at the time, can't see that it makes much difference.

74:

75: And what if he had been offered dialysis, do you think he would have taken that option?

76:

77: I don't think he would, I don't think the thought of going in doing that three times a week would appeal to him at all, even, I think even if you said to him well it's going to make you better, I don't think he could be convinced that it would, no he was very funny like that and I would say that, that last week he gave up,

Passage 4 of 4

Section 0, Para 81, 429 chars.

81: Well he didn't seem to be particularly worried, he said I've lived all these years not knowing that I've got only one kidney and he'd never had waterworks problems, so he said, I can't see it's going to make any difference, if I've only got the one and of course he knew he was too old for them to even consider doing anything, operating, I don't know whether they can give you a new kidney even if one's not much good, can they?

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018 TC 1 180107

Passage 1 of 7

Section 0, Para 9, 323 chars.

9: I saw Mr Y on different visits and then he said, and he came up with dialysis, and I said I'd have to make my mind up. So two friends of mine were on dialysis at the London who died, so I said to myself I'm not having it. And every time I go to the clinic he's asking me, have you made your mind up? I say, no, not yet.

Passage 2 of 7

Section 0, Para 9, 417 chars.

9: he next time I attend the clinic I saw a Chinese doctor, he said, morning, he introduced himself, and the next thing he said to me is, you are refusing dialysis. I said, yes, I don't think I could have it. He said, I'm referring you to, we are opening a new palliative unit and I'm sending you there. I said, what about my treatment, he said, no, it won't be affected, you'll get it, I said, all right.

Passage 3 of 7

Section 0, Paras 33 to 37, 542 chars.

33: No, every time I visit he would ask, have you made up your mind? I'd say, no, not yet.

34:

35: Had you not made up your mind?

36:

37: Not yet. No, H, be truthful, at this stage what I want with dialysis? At this stage of my life, what I want with dialysis? I'm eating, I'm drinking, I'm doing all my housework, yeah, no complaints, I am passing water very well, the only thing is the iron tablets get me constipated at times. But other than that I am feeling all right, more than this morning, I've never had this experience yet and I had it today.

38:

41: You see, I have friends that go through with dialysis and I, one girl I asked her once, why are you having dialysis? She said to me, said I must have it. I said, well that's you and that's not me. I was supposed to spend a Saturday evening with her, she prepared and everything for me, but a friend phoned and was admitted to Hospital, so I said, all right, I'll go to Hospital and I'll come by you Sunday, put everything in the fridge. Sunday morning she phoned me about half past six and said, do not come for the day again, I feel like going to church. I said, all right, I'll come tomorrow, Monday. Sunday night, eight o'clock, the phone rang, when I answered it was her fiancé, he said to me, is that ... I said, yes. He said, you were supposed to come by Una today, I said, she phoned me and tell me not to come because she feels like going to church. He said, what time was that, I said, it was around half past six this morning. I said, didn't she tell you? He said, no, well I'm phoning now to tell you that she died in the church. I said, I beg your pardon? She took ill in the church, not feeling well and when they phoned the L. they said they have no beds, they phoned, they have no beds, and in the meantime she started to cough blood and she died. So she used to come from Tottenham on a morning, have her bloods done, I'm not saying that she might have dialysis or she go home and then have it, go back two days again and have it. So I never, and I think it must be nearly, how much years now, Dr J mentioned dialysis and I'm doing all that I have to do.

45: So see the picture of what I'm saying, and judge by yourself, if you were in my position if you would have had dialysis? Yeah, and that's just it.

46:

49: No, I'm not going to have it, it's too late now to have it. Yeah. I'm going home and God spared my life.

50:

61: So at 81 what are you going to do with dialysis? I know people on dialysis already, yeah, when I was at Windsor they had ... anyone, they put it, the ... in and you put a bag on, you wash out every morning, I don't want it for myself.

37: Yeah, and I went to see the professor, and the girl turned around and said, would you want to sign a dialysis form? I said, yes, I would. And then because the professor was on the phone and then he got off the phone and he said, how old are you? I said 79, going on 80. He said, well, you look pretty lively. I said, I am. I said, I don't want to go on dialysis, and he turned around and said, yes, at your age, he said, I agree with you. Dialysis is for the short term and as I am coping without it and as I also got prostate cancer and as in some future years, six months, a year, two years, three

years, I'm going to pass on, what difference will it make? That's it.

38:

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Passage 1 of 5

021 TD & H 1st 280307
Section 0, Paras 1 to 11, 568 chars.

1: So I just wanted to ask you to tell me the story of your renal disease and anything about that that you think is important, and I'm not going to stop you, I just want you to tell me the story.

2:

3: F About what? No clue what you mean with the renal disease?

4:

5: Kidney failure.

6:

7: F Is that kidney failure?

8:

9: Yeah. Have you got something wrong with your kidneys?

10:

11: F Well that's what they said, but I don't know what happened. It is because even when I said I've got the pain, she said she don't think the kidney cause the pain, so what could cause the pain in the back?

12:

Passage 2 of 5

Section 0, Paras 159 to 173, 1084 chars.

159: When they told you about that did they talk about treatment for that?

160:

161: F They never find out, I've been going to the doctor for years and years and years and you don't know if they know what to do, what's the matter with me. And it's this lady, this last doctor here.

162:

163: Your GP?

164:

165: F No, the one in hospital. That lady, she found it was in the kidney, **166:**

167: Oh yes, B

168:

169: F That's right, yeah, she's the one that find it all.

170:

171: And tell me what she said to you, can you remember?

172:

173: F Well she said, she was telling me that the kidney just is not functioning properly. And she was asking me if I would like to take some *name, what?* Dialysis. I said to her I don't know that name, because I've never heard that name before and I don't know what it's all about. You go, *she said* you go on a machine and thing, but I don't know what about it, and somebody was telling me that if I can do it they will take me, they will take me because I have to go on the machine two or three times a week you know. So *I never tell her but I decided* again, and

Passage 3 of 5

Section 0, Paras 177 to 185, 697 chars.

177: Well, she wanted mostly to see my husband, she said I must tell him to come in, they were bent on getting to see her.

178:

179: Hang on, you're going too fast for me, I didn't hear that.

180:

181: F She tell me to bring my husband and come

182:

183: Your husband up to the hospital?

184:

185: F Yeah, ... internal, but he can't come ... in the ambulance, he must come by himself. And he never went. So I went back to her again and she take my blood pressure, she take everything and said it wasn't too bad, and she can't know the reason why my back was painning me. Why it's not through the kidney, she said it's not through the kidney why the back hurting me, so I don't know what it is. So the last, *I went there* last Monday and

Passage 4 of 5

Section 0, Paras 195 to 215, 892 chars.

195: And did she talk again about the dialysis?

196:

197: F No, she didn't say anything about it again. She be telling me that she getting someone to come and see me instead of I coming up there all the while, so they'll come here and see me. That's all she said to me.

198:

199: So you're not having the dialysis?

200:

201: F No, I don't think so. You think it's essential ...?

202:

203: M That's our question, that's a sensible question.

204:

205: F Because I haven't got a clue what about it. I just don't know what it is, so I don't know about, but she say she will get them to put you on the machine only to wash out some part of your blood or anything, I do not want it.

206:

207: Yes, and you would have to go to the hospital three times a week.

208:

209: F A week, that's right, I can't be bothered with that now.

210:

211: You don't want to bother with that.

212:

213: F No, so. No, I can't bother with that.

214:

215: And did she say what would happen if you didn't?

Passage 5 of 5

Section 0, Para 217, 124 chars.

217: No, no, she didn't say a word. ... But she ..., the doctor, she said she don't think it's the cause of the pain in the back.

218:

Document 18 of 42

1ST SJ 271206

Passage 1 of 3

Section 0, Paras 29 to 53, 649 chars.

29: Tell me when you first knew there was anything wrong with your kidneys then, tell me about that and what happened and what they said to you.

30:

31: I didn't know that anything wrong with my kidney until since the other day.
32:
33: **When you met with Dr Y?**
34:
35: Yeah.
36:
37: **And what happened? What did he say? Or how did you get referred to him?**
38:
39: Pardon me?
40:
41: **How did you get referred to see him? Who sent you there?**
42:
43: I couldn't say. Maybe I know but I don't recall it. That *just sounds just* a person did send me there, I don't know.
44:
45: **Do you think it was your GP maybe, your doctor?**
46:
47: I don't know who.
48:
49: **But anyway you got to see him.**
50:
51: Yes.
52:
53: **And what did he say to you?**

Passage 2 of 3

Section 0, Para 55, 167 chars.

55: I know the day when they put me on something like this, to lie on there, using whatever they use to rub across my back here, anything like that. It was a young woman.

Passage 3 of 3

Section 0, Paras 70 to 91, 647 chars.

70:
71: No, I don't. I don't remember what he did say.
72:
73: **Did he talk to you about dialysis?**
74:
75: About what?
76:
77: **Dialysis, going on a kidney machine?**
78:
79: I remember that he says the kidney getting smaller. I remember that. That's the only thing I remember. If he to look after it, what did he say about that part? I don't quite remember what he did say.
80:
81: **Don't worry.**
82:
83: I don't quite remember.
84:
85: **Did he tell you how we would treat your kidney problem?**
86:
87: But it's dangerous, if he is to look after it.
88:
89: **It would be dangerous?**

90:

91: Yeah. It's like he was going to send somebody come to inject and give me tablet for it but it's never that way. Nobody didn't come.

*This Node codes no other
documents in this set.*

APPENDIX 10: LIST OF NODES

NVivo revision 2.0.163

Licensee: hELEN nOBLE

Project: PhD data User: Administrator Date: 19/04/2009 - 16:45:41

NODE LISTING

Nodes in Set: All Free Nodes

Created: 09/10/2006 - 12:15:51

Modified: 19/04/2009 - 16:36:12

Number of Nodes: 1056

- 1 +++drugs
- 2 2nd admission that week
- 3 about Helen
- 4 About his father
- 5 about the death
- 6 About wife who is carer
- 7 accepting
- 8 accepts now cant prolong life
- 9 accomdation
- 10 act for visitors
- 11 admission for diabetes
- 12 Admission o hospital
- 13 admission to hospital
- 14 admitted to local trust
- 15 advance directive
- 16 affairs sorted
- 17 affecting wife
- 18 age
- 19 age 2
- 20 ageism
- 21 aggressive to carer
- 22 always forgetful
- 23 anaemai
- 24 anaemia
- 25 And I think the more you even mentio
- 26 And she'd never been a nuisance~
- 27 And their attitude was, well she's g
- 28 Aneurysm
- 29 anger
- 30 angioplasty
- 31 Angry
- 32 angry to get home
- 33 ankle oedema
- 34 annoying family
- 35 any questions
- 36 Appetite
- 37 appetite decreasing
- 38 appetite improved
- 39 appetite poor
- 40 appointments
- 41 Are you saying that he might suddenl
- 42 arguing
- 43 Arthritis
- 44 Asking for help

45 asking if kidenys working
46 Asking me understand her view
47 Avoidance of decision
48 awake at night
49 back aching
50 back pain
51 Bad journey to hospital
52 bathing
53 became argumentative
54 been sick but lived long
55 being a carer
56 Being careful
57 belly pain
58 benefit of RSCS
59 benefits of RSCS
60 Bereavement
61 Better than last time
62 Better than wife
63 Biggest problem
64 biggest problem appetite
65 biggest worry
66 blame
67 blaming cause of tiredness on virus
68 bloated
69 Blood pressure
70 Blood test
71 blurring eyes
72 boils
73 boils on bottom
74 Bonus
75 Borderline
76 BP
77 Breathing
78 breathless
79 breating
80 brewing symptoms
81 'buck up'
82 burst appendix and ITU
83 But it's, no, this is really hard~
84 But then it might not be, and then i
85 ca bladder
86 Calcichew
87 Calcium
88 called GP
89 calling on daughter
90 Calls in the night
91 calmer at home
92 can pts demand dialysis
93 can visit at home if we want
94 can wash himself
95 Cancør
96 cancer causing itching
97 cancer does not mean withdrawal
98 cancer on head
99 cancer recurrence but not worried
100 cant be bothered washing
101 cant be helped

102 cant communicate
103 Cant eat
104 Cant see
105 cant take tablets properly
106 cant talk about dying
107 cant walk
108 cardiologist
109 care
110 care at home
111 Care from wife
112 Carer
113 carer angst
114 carer coping poorly
115 carer diagnois of death
116 carer enjoyed challenge
117 Carer for each other
118 carer has renal disease
119 carer knew she was dying
120 carer knows when pt unwell
121 carer more relaxed
122 CARER POST DEATH
123 carer stressed
124 Carers
125 carers allowance
126 Carers needs
127 carers not turining up
128 carers relationship
129 carers trying to cope
130 caring for others
131 case managing
132 cause of renal failure
133 causing friction
134 central point of contact
135 Centralised records~
136 changed personality
137 changing mind
138 Check by Dr
139 chest trouble
140 chesty cough
141 children
142 Choice
143 choosing to live
144 clinic appointment
145 close relationship
146 close to death
147 cold virus
148 collitis
149 comes every day
150 Coming to appointments
151 communication problem
152 Community help
153 community team
154 Complained to council
155 compliant
156 concerns
157 conflict with GPs
158 Confused

159 confused about children
 160 confusion
 161 Confusion about drugs
 162 confusion with treatment
 163 Constipation
 164 Contact SC
 165 coped OK without wife
 166 coping
 167 coping after death
 168 coping with renal disease
 169 Could change mind
 170 Could start dx~
 171 couldn't cope with her dying at home
 172 couldn't do garden
 173 couldn't do gardening
 174 couldn't help others like he used to
 175 counselling offer
 176 counsellor
 177 Crying
 178 Crying about death
 179 Culture
 180 D~So what is the solution~
 181 daily diet
 182 Daily routine
 183 dangerous driving
 184 daughter bossy like father
 185 Day care
 186 Day centre
 187 dead leg
 188 death
 189 Death of friend
 190 Decision
 191 decision dx
 192 decision re where to live
 193 decisions
 194 degrading
 195 dementia group
 196 dementia screen
 197 dementia training course
 198 denail of death by doctors
 199 denial
 200 denial~
 201 Dependant
 202 Depressed
 203 Depression
 204 Deteriorating
 205 Deterioration
 206 diabetes
 207 Diabetic
 208 Diagnosis
 209 diagnosis of renal failure not a sur
 210 dialysis
 211 dialysis decision
 212 Diarrhoea
 213 Did see him when he died
 214 didn't commit suicide
 215 didn't know 'kidney's bad'

216 didn't like carers group
 217 didn't stop driving
 218 didn't want to go to hospital
 219 died on dx
 220 Diet
 221 dietician
 222 different carers roles
 223 difficult behaviour
 224 Difficult coping
 225 difficult to get advice
 226 difficult to manage
 227 difficult to switch off
 228 Difficult to travel to B
 229 difficulties getting to clinic
 230 difficulties getting to hospital
 231 difficulty walking but can get bus
 232 difficulty with decision
 233 diffcult to gauge what is an impoirt
 234 Dilaysis decision
 235 Disabled badge
 236 disagreement
 237 District nurse
 238 district nurses
 239 diuretics
 240 dizzy
 241 DL
 242 DN
 243 does everthing herself
 244 does own shopping
 245 doesn't know about kidney
 246 Doesn't know what wants from service
 247 doesn't like her job
 248 doesn't need anything else
 249 doesn't regret decision
 250 doesn't talk aobut kidney failure
 251 doesn't think about blood results
 252 Doesn't want change
 253 Doesn't want dialysis
 254 doesn't want family to ahve to care
 255 Doesn't want her to die at home
 256 doesn't want her to suffer
 257 doesn't want home helps
 258 Doing all that she ahs to
 259 doing her housework
 260 Doing the right thing
 261 doing too much
 262 done privately
 263 don't see children
 264 dont want to upset him
 265 don't want to upset him
 266 dossøtt box
 267 downhill after aneurysm
 268 Drinking
 269 Driving
 270 dross
 271 Drs not aware of symptoms
 272 Dx decision

273 Dying
 274 early treatment
 275 eating more
 276 eGFR
 277 end
 278 end of life
 279 end stage renal failure
 280 end will come quicker
 281 Epo
 282 Epo and BP
 283 EPO reduction a good sign
 284 euphoria post withdrawal of dx
 285 exacerbation planning,
 286 examination can predict results
 287 expected with RF
 288 expensive cab fare
 289 experimented with
 290 explaining dialysis
 291 Explaining that things not so good
 292 extreamly tired
 293 eye problem
 294 Faith
 295 fall
 296 fall and downhill
 297 fall lost confidence
 298 falling when getting up
 299 falls
 300 Family
 301 family coercion
 302 family dynamics make things difficul
 303 family help
 304 Family pleased with her decision
 305 family releuctant to use patch
 306 feel her fault if something happened
 307 feeling alright
 308 feeling better
 309 feeling cold
 310 Feeling down
 311 feeling fine
 312 Feeling low
 313 feeling OK
 314 feeling tired
 315 feeling unwell
 316 Feeling well
 317 feels giddy in morning
 318 feels he was different
 319 feels strong
 320 felt like she was dying
 321 fighter
 322 Finance
 323 Fine, I'm really
 324 fingers crossed re results
 325 First attended
 326 first heard of renal problems
 327 first stage of renal problems
 328 flu
 329 fluid

330 fluid overload at the end of life
331 fluid retention
332 focus of renal dr
333 follow up
334 forgetful
335 Forgets tablets
336 fragmented team
337 Free Node
338 friend paying for help
339 Friends
340 Frightened to change pattern
341 Frusemide
342 funeral
343 gallstones, hospital
344 garden
345 gave up
346 Gets bored
347 Gets cross
348 getting iller
349 getting older
350 Getting out
351 getting to the hospital
352 getting worse
353 GFR and weight
354 give and take
355 given up
356 giving up
357 God
358 going downhill
359 going home on holiday
360 Going on holiday
361 going to bed
362 going to other son's house
363 good death
364 good GP
365 good to know people in the service
366 Good treatment
367 got by each day
368 got worse after renal problem
369 GP
370 GP no help in crisis
371 GP sends to hospital
372 GP will send to renal team
373 Grandchildren
374 Grateful
375 grateful for help
376 guality about colostomy
377 had a cold
378 had enough
379 had operations
380 had to set things in order
381 Hands are swollen, and foot are swol
382 happier at B.
383 happy to be admitted
384 Happy to see us
385 hard for carers
386 hard to bleed

387 Has experience as a nurse
 388 Has to live downstairs
 389 have improved
 390 having crisis
 391 he could be quite awkward, at times~
 392 He doesn't talk to us!
 393 he helped with her mother
 394 He is very tottery now as well~
 395 He knows he's really ill~
 396 he was always right
 397 he's sort of closing down~
 398 headache
 399 health history
 400 health problems
 401 heart
 402 heart failure
 403 heart failure nurse
 404 help
 405 Help at home
 406 help for carer
 407 help from family
 408 Helps her to cope
 409 hep B~
 410 her mother
 411 herbs
 412 hernia
 413 HF nurse
 414 high calorie drinks
 415 his morning he was very ratty with m
 416 history of pt
 417 Home on the bus
 418 Home visit
 419 Homoholic
 420 Hope for the best
 421 hoping for the best
 422 Hospice
 423 Hospice day care
 424 hospital confusion
 425 how carer feeling after death
 426 how coping
 427 How feeling mentally
 428 how he looks
 429 HOw long will live
 430 how managed at home
 431 how RF presented
 432 How to make better
 433 How we are helping
 434 how we could improve things
 435 how will progress
 436 ht failure
 437 humpour
 438 Husband helps
 439 husbund cares for her
 440 husbund in charge
 441 hypertension
 442 hypo
 443 Hypoglycaemic

444 hyprocalcaemia causing pain
 445 I am trying to last out as long as I
 446 I don't know how to make him sunny,
 447 I don't know if I'll be able to cope
 448 I mean I don't want to rock the boat
 449 I think that's, the frustration is n
 450 I told you I suffer with kidney trou
 451 I would need attention for the rest
 452 I'm going to smack him when I see hi
 453 I'm just the daughter~ ...
 454 idn't know who to turn to, t
 455 if you're psychologically distressed
 456 ill health
 457 illness changed him
 458 I'm on full alert~
 459 immobility
 460 impact of diagnosis
 461 impact of renal failure
 462 Important
 463 Improtance of RSCS
 464 improvement
 465 improving
 466 in and out of hospital
 467 In emergency
 468 in hospital many times
 469 incompetence with angio
 470 incontinence improved
 471 incontinence pad fell out
 472 incontinent
 473 Independant
 474 infection
 475 Injection
 476 injection as treatment
 477 insomnia
 478 insomnia due to breathing
 479 interested in blood tests
 480 interpretuer
 481 is forgetful
 482 isolation
 483 Itch
 484 itch ~ due to eczema
 485 itching
 486 itchy
 487 Its getting harder and harder and ha
 488 its like having a baby
 489 It's like having a little baby~
 490 Job
 491 joint care needed
 492 Joking
 493 Journey
 494 keeping busy
 495 kidney
 496 kidney disease
 497 kidney problem
 498 kidneys becoming normal
 499 kidneys caused all problems
 500 kidneys no problem

501 kidneys not a problem
 502 kidneys not causing a problem
 503 Kidneys not working
 504 knee
 505 knew he wasn't going to get better
 506 knew she was dying
 507 knew when admission imminent
 508 Knowing about renal failure
 509 KNowing death will happen
 510 knowledge challenged
 511 knows he is sick
 512 knows she ahs renal failure as tired
 513 knows will die
 514 lack of food
 515 lack of knowledge
 516 Lack of knowledge re medication
 517 lack of power
 518 Lack of understanding re symptoms
 519 lacks confidence
 520 last week
 521 learning experience
 522 leave well alone
 523 leaving well alone
 524 lethargy
 525 letter re kidney problem
 526 life put on hold
 527 likely to bleed
 528 Likes attention
 529 likes living with son
 530 littel eye contact
 531 Little help from rest of family
 532 lived alone
 533 lives with family
 534 livid long with renal failure
 535 living alone
 536 Living arrangements
 537 living long
 538 living long with low eGFR
 539 living with partner
 540 lonely
 541 Long healthy life
 542 long trip for father
 543 looking well
 544 looks for honesty in people
 545 loosing weight
 546 Loss of independance
 547 lost belief in doctor
 548 lost weight
 549 lots of difficult pts
 550 Lots of medication
 551 lots of operations
 552 loved grandchildren
 553 lucky to have lived so long
 554 lump
 555 lump on head
 556 lump on shoulder
 557 M~And he gets grumpy about that beca

558 main problem
559 Makes pt do things
560 malaena
561 managing at home
562 Managing in the community
563 may ahve been OK if not told
564 Mc millan
565 Me back all is hurt~
566 meals
567 Meals on wheels
568 Medication
569 medication foir pruritus
570 mental illness
571 methadone
572 might have dementia
573 Might have to move house
574 Might need Dx
575 Mind over matter~
576 miserable
577 misses getting blood results
578 misunderstanding aobut urinary sympt
579 mixed feelings about being told
580 Mobility
581 mobility good
582 mobility problem
583 model of care
584 Money
585 more to learn
586 mother didn't understand
587 mother had mental health problems
588 moved in with son
589 Moving clinic
590 moving house
591 multiple losses
592 mum dying
593 Mum understands
594 name of service
595 Nausea
596 Nearly died
597 need a break away
598 need computer screen
599 need for specialist palliative care
600 needed specialsit PC
601 needle phobia
602 Needs dialysis
603 nephew dying
604 never had a life
605 Never know when you will go
606 never the same after his friends die
607 night time sitters,
608 no appetite
609 no complaints
610 no counselling
611 NO DNAs
612 no energy
613 No English
614 no help needed

615 No I'm not going back,
 616 no money to support wife
 617 no other worries
 618 no problems
 619 no puritus
 620 NO questions
 621 no regrets
 622 no sickness
 623 no sign of kidney problem
 624 no symptoms
 625 No time awareness
 626 no time on their own
 627 NO to counsellor
 628 No to day centre
 629 No, I've always been a loner
 630 No, the only sickness that I have is
 631 Non adherence
 632 non communion
 633 non compliance
 634 Non compliant
 635 non-communicative
 636 non-compliance
 637 normality
 638 Not a very good life, is it~
 639 Not able to do things
 640 not admitting to illness
 641 not allowed ground floor flat
 642 not anaemic
 643 Not approachable
 644 not caring for himself
 645 Not close to his children
 646 not coping
 647 not depressed
 648 Not eating
 649 not feeling usual self
 650 not feeling well
 651 Not going out
 652 not her problem
 653 not interested
 654 'not much to live for'
 655 not need ing much help
 656 Not planning end of life
 657 Not really getting worse
 658 not sure if ahs dementia
 659 not sure if can ahve PD
 660 not sure if he wants to be there
 661 not sure why at clinic
 662 Not taken seriously
 663 not taking pain killers
 664 not taking painkillers
 665 Not taking tablets
 666 Not talking
 667 Not telling wife
 668 Not tlaking about death
 669 not walking
 670 not well
 671 not worried about renal problems

672 Nothing had changed
 673 nuisance
 674 nursing homes
 675 occupation
 676 oce was confused
 677 oedema
 678 Oh he's, oh, yeah, we're on edge~
 679 Old to have dialysis
 680 olice iol to treat cancer itch causi
 681 On the end of life
 682 one way destination,
 683 only talking to certain people
 684 Only worries about how feeling
 685 operation
 686 optimistic
 687 Organise own cleaning
 688 other
 689 Other doctor
 690 other hard decisions
 691 other illness
 692 out of his misery
 693 outlived prognosis
 694 overdose
 695 overwhelmed
 696 own decision not to ahve dx
 697 Pain
 698 pain at death
 699 pain in kidney
 700 pain relief from palliative care
 701 painful back
 702 palliative care
 703 paranoid schizophrenia~
 704 parents relationship
 705 part time job
 706 Partnership
 707 passing less urine
 708 Passing time
 709 Passing urine
 710 passprt problem
 711 Past sell by date
 712 patch for pain
 713 permission to die
 714 Phosphates
 715 Physiotherapty
 716 place of death
 717 planning a trip
 718 Planning end of life
 719 planning time away
 720 planning to make a trip
 721 Plans for future
 722 played with the children
 723 police came
 724 polymyalgia
 725 Poor appetitie
 726 poor eyesight
 727 poor memory
 728 poor sleeping

729 Poor treatment
 730 positive attitude helps you live lon
 731 Possibly continuing to loose faith i
 732 Post death
 733 post death culture
 734 post mortem
 735 PPC
 736 Praise
 737 Prescription
 738 previous bugger
 739 previous ill health
 740 Previous loss
 741 private
 742 probably wouldn't have had dialysis
 743 problem with carer
 744 problem with catheter insertion
 745 Problem with DN
 746 Problem with GP
 747 problem with knees
 748 problems
 749 problems between son and wife
 750 problems getting things organised
 751 problems with carers
 752 problems with discharge
 753 problems with district nurse
 754 problems with district nurses
 755 problems with father
 756 problems with social services
 757 Problems with speaking English
 758 problems with transport
 759 professionals not taking responsibil
 760 Prognosis
 761 prognosis difficulties
 762 Prognosis made things difficult
 763 progression of renal disease
 764 prolapse
 765 prostate
 766 prostate cancer
 767 pruritus
 768 psychologicial issues
 769 Pt feels doing well
 770 pts individual
 771 public transport
 772 put brother in charge of will
 773 Quality of life
 774 query
 775 question
 776 reading about death by kideny diseas
 777 reason for blood test
 778 reat service for our patients c
 779 rellief when he died
 780 refused social care
 781 refused to discuss death
 782 refusing blood test
 783 refusing help
 784 regrests being told prognosis
 785 relationship with mother

786 relationship with team
787 relief
788 Religion
789 reluctant to talk
790 renal clinic
791 Renal counsellor
792 renal team superb
793 Renovation
794 request blood test
795 resentment from others
796 Resentment of pt and family
797 Resigned to things going wrong
798 Respite
799 respite for carers
800 responsibility
801 Restricted
802 resus
803 resusitating
804 ringing RSCS
805 Role of carer
806 Rough time
807 rough when younger
808 Routine
809 salt
810 Saying things are OK
811 scared
812 scratching
813 scratching caused by washing powder
814 second opinion
815 see why carer finding it difficult
816 seeing at home
817 selective hearing
818 send symptoms back to GP
819 senna
820 She says she is living long~
821 shock
822 shock at death
823 shock at diagnosis
824 shock at prognosis
825 shock at urea and eGFR
826 shutting down
827 sick but not sick
828 sickness
829 sinusitis
830 Sister knows he is bad
831 Sister sick
832 six month appointment
833 six months to live
834 skeptical of DR
835 Sleeping
836 sleeping habits
837 slept on holiday
838 smiling
839 smoking
840 snappy
841 So I think, I think she needed the t
842 So much fluid

843 so much stress that I even thought o
 844 so painful sometimes,
 845 So the non answering thing is just h
 846 So we have to talk to him about that
 847 Social
 848 social benefits
 849 social care at home
 850 social servcies
 851 social services
 852 social worker
 853 Soldier on
 854 some carers are nice
 855 some pts make clear decisions
 856 Something else to think about
 857 son died
 858 Son present
 859 son unable to talk about helaht and
 860 Sons view on Mums problem
 861 Sore mouth
 862 Sore tongue
 863 speaking to carers on their own
 864 spitting
 865 Split from husband
 866 stairlife
 867 stairlift
 868 stairs
 869 Stick with what you know
 870 still driving
 871 stopped going to church
 872 stopped medication
 873 stopped smoking
 874 stopped washing
 875 strating to feel better with capsule
 876 strenght of character
 877 strong character
 878 struggled on
 879 struggles
 880 struggles on
 881 Stubborn
 882 suicide
 883 suicide plan
 884 support
 885 support at home
 886 supportive care service
 887 suppot for palliative care team
 888 suspicious
 889 swelling in legs
 890 swollen legs
 891 Symptoms
 892 symptoms typical
 893 Tablets
 894 tablets instead of dialysis
 895 taking tablets
 896 Talking about death
 897 talking about dying
 898 talking aobut dying
 899 TC

900 terminal phase
901 terminal phase
902 Terrible emotion
903 that last week he gave up,
904 That's how much I've struggled
905 the general body not feel good
906 the renal team were superb~
907 the start of the problems
908 they feel unhappy
909 things getting worse
910 things go wrong with medication
911 Think positive
912 thinking about dying
913 thinking about the future and how de
914 thinks will live long
915 thirsty
916 thought could speak English
917 Thought he had to have
918 thoughts about dying
919 thoughts on his death
920 throbbing
921 Time at hospital
922 time in clinic
923 time it takes
924 Time living with daughter
925 tip them over,
926 tipping
927 Tired
928 tiredness
929 tiredness and pain
930 told bad news about kidney failure
931 told kidneys working OK by health pr
932 told to stay at home
933 took to bed
934 tottery
935 transport
936 treating itch
937 treatment
938 Treatment for kidney problem
939 treatment for renal failure
940 Trembly
941 trial of dialysis
942 trust in god
943 trying to admit at EoL
944 Ulcer
945 Unable to do all care
946 unable to do much
947 Uncertain of how things will progres
948 uncertainty
949 UNCERTAINTY re washing of hair
950 uncomfortable
951 Understanding why at clinic
952 unsure why in pain
953 upbeat
954 upset not angry at death
955 upset when couldn't help others
956 uraemic bleeds

957 urgency to get things done
958 urinary retention
959 Urine output
960 us visiting
961 used to humiliate her
962 used to wet bed
963 Uses stick
964 Using internet
965 using oxygen
966 UTI
967 vague
968 Veins collapsing
969 venting anger
970 Very glad when medication stops
971 very strong, strong individual
972 Views on her illness
973 Visit at home
974 walking
975 Walking hard
976 wanted family to help
977 wanted the operation
978 wanted to be independant
979 wanting prognosis
980 Wants from service
981 wants no information
982 Wants nothing more from service
983 wants to be cremated
984 wants to be with his son
985 wants to die with mothert
986 wants to keep mother at home
987 wants to make things better
988 wants to sleep all the time
989 Wants to stay at home
990 Wants us back
991 ward good
992 water tablets
993 water tablets caused problems
994 waterworks
995 We never spelt out death and dying a
996 weak
997 weak and vomiting near end of life
998 weak, SOB, like a baby
999 week he died
1000 weight
1001 Weight loss
1002 Well he wasn't the same man,
1003 Well that's one of the reason I take
1004 weren't told symptoms
1005 what happens with RF
1006 what he misses
1007 What is happening
1008 what Mum knows
1009 What Mum likes doing
1010 What pt like in the past
1011 what rels cant do
1012 What would life be like on Dx
1013 what's happening

1014 when he got lost
1015 why upset him if its not long
1016 why we are there
1017 wife does tablets
1018 Wife had heart attack
1019 wife sick
1020 Wife social
1021 wife unwell
1022 wife upset by decision
1023 wife with diabetes
1024 wifes problems
1025 will
1026 Will die anyway
1027 willpower
1028 Wills
1029 wishes at the end of life
1030 withdrawal
1031 withdrawal of palliative care team
1032 withdrew
1033 Wobbly on feet
1034 wonders why she has to do things
1035 wont change clothes
1036 working history
1037 worried about swelling
1038 worried that death will be painful
1039 worried that he will fall
1040 worries
1041 worries of carers
1042 worry to wife
1043 would die if had dialysis
1044 Would like to be able to walk more
1045 would rather be at home
1046 would rather die than have prolapse
1047 wouldn't discuss hospice
1048 wouldn't talk about illness
1049 wrong medication
1050 Yeah, cooking food~
1051 Yes, a bit breathless~
1052 Yes, I am sick with my kidney!
1053 Yes...I am not a cripple you know!
1054 You can never tell her... 00~43 she th
1055 You can never tell what will happen~
1056 zapped cancer on head

APPENDIX 11: TRANSCRIPT WITH CODES

NVivo revision 2.0.163

Licensee: hELEN nOBLE

Project: PhD data User: Administrator Date: 19/04/2009 - 17:03:41

DOCUMENT CODING REPORT

Document: 018 TC 2ND 180407

Created: 24/04/2007 - 20:42:16

Modified: 12/05/2008 - 12:06:54

Description:

I'll just leave it there. So tell me first of all about the tiredness, what does it feel like?

Nodes in Set: All Free Nodes

Node 1 of 1056 age 2

Passage 1 of 2 Section 0, Para 3, 3 chars.

age

Passage 2 of 2

Section 0, Para 101, 3 chars.

age

Node 2 of 1056

appetite poor

Passage 1 of 1

Section 0, Para 3, 276 chars.

That's all. But you know, it was the appetite because I've gone off of meat and I use potato or I boil some spaghetti and the fish I had in the freezer, I used it up. So it's just using an egg. This morning I had two sausages and two slices of bread, toast and that was it.

Node 3 of 1056

appointments

Passage 1 of 1

Section 0, Paras 259 to 279, 1101 chars.

When J phoned me yesterday, I would say, look, ... leave us here, I did my thing, so I will go. Because when I made the appointment last week, when doctor gave me the appointment, he told me, I think it was Monday, and I said to them, no I have an appointment out in London on Monday. So they make it today and when I Laughter! said the appointment for the L. is Wednesday 12 o'clock. And it's hard doing two things in one day? Yeah, and his is 4.30. No, when I go now, I will read before ... 3 o'clock. So I could just ... by the surgery. Do you want me to ring and see if there's an earlier appointment? For me? No, because I wouldn't, I can't do it. No?... it was, yours is Wednesday, his is Wednesday, that's a ... I say yeah, the appointment is 12 o'clock. So she said it will be too much to come and when I reach in and I see yours is Wednesday, then she changed it to Wednesday and I said, well look I'm not going to bother them in the surgery again soon. 12 o'clock, I'll have time to get to him for half past four. It's no trouble. If you're sure. And he's quite all right.

Node 4 of 1056 biggest problem appetite
Passage 1 of 1 Section 0, Para 47, 86 chars.

My appetite, that's all. ... no problem. And I take every day as they come, you know?

Node 5 of 1056 blaming cause of tiredness on virus
Passage 1 of 1 Section 0, Para 51, 142 chars.

eah. I'm all right, to the tiredness. Because I myself have been wondering why pick up this virus and I'm feeling so tired. So I don't know

Node 6 of 1056 blurring eyes
Passage 1 of 1 Section 0, Paras 225 to 229, 308 chars.

You see and when I get up in the morning sometime my eyes, kind of blur, I put the drops in but it didn't clear it up to now. What, today? I put them before I left home this morning. But I'm all right, I'm fine. Because if I wasn't all right I was going to phone and say I ain't keeping the appointment.

Node 7 of 1056 can visit at home if we want
Passage 1 of 2 Section 0, Para 121, 68 chars.

Well I'd like to get out of the home, but if you want you can come.

Passage 2 of 2 Section 0, Paras 123 to 145, 409 chars.

I don't mind. Yeah? You tell me. When it'll be? Two to three months? What would you rather? Yeah, you tell me and I'll make myself available. Laughter Is it easier if we come to you do you think? Or would you rather get out and come to the hospital? No. it's just that you'll have to climb some stairs and the exercise will do you good. Laughter We'll come to you then, that's a date is it? Yeah.

Node 8 of 1056 cold virus
Passage 1 of 1 Section 0, Para 15, 159 chars.

Well I didn't have to go anyway because when my friends round they realised I've picked up this cold virus, they will look at me. So I hadn't to go anywhere.

Node 9 of 1056 dietician
Passage 1 of 1 Section 0, Paras 233 to 251, 576 chars.

But then when I realise how I was in bed from since February say, I go to my appointment. Shall I get the dietician to ring you? She'd never phone? Do you want me to get the dietician to ring you? Yeah, she was supposed to phone the doctor to order these drinks. And she only write him and tell him. There are definitely some drinks that you can have and she can advise. Yes, I don't know. I'll sort that one out. But when they

check it in the formula, too much protein and too much sugar. Any problems that you have, Thelma, or any queries, do ring us, me or Jarin.

Node 10 of 1056 does everthing herself
Passage 1 of 1 Section 0, Paras 93 to 97, 205 chars.

Anything. When I does everything for myself. I know you do. We can't help you at all. Everything I does for myself. If I can do it, do it. When the time come that I can't do it, I will take the help.

Node 11 of 1056 doesn't think about blood results
Passage 1 of 1 Section 0, Paras 183 to 185, 292 chars.

Someone always gets it in the end don't they? What's it like waiting for the blood results every time? Well I don't usually remember it. Only if they phone me and say, well you know, we're going to put you on iron tablets, your haemoglobin low, anything like that ... but it never happened.

Node 12 of 1056 doing her housework
Passage 1 of 1 Section 0, Paras 33 to 39, 244 chars.

And what have you been doing since you got back? Nothing. I wash, if anybody want to come and iron for me ... Laughter... very much. I said to ... put all my nighties and do some hoovering and that's that. But I'm feeling all right otherwise.

Node 13 of 1056 dross
Passage 1 of 1 Section 0, Paras 169 to 175, 226 chars.

How is J?J? Well. You spoke to her on the phone. Yeah. She's very well. She'll probably come with me to see you. We'll come together. I can talk to you and she can do the bloods, she's expert at that, I'm not.

Node 14 of 1056 expensive cab fare
Passage 1 of 1 Section 0, Paras 161 to 169, 469 chars.

if I'd gone on the bus I was going to reach for 12 o'clock. Phoned for a minicab, when I go I phoned the cab people. And this Indian chap came and when I reached ... I asked him, how much do I owe you? He tell me £10. . So I said, if you just give me a receipt, so when I go up I'm going to phone Ps. Phone who? P's ... Yes, and check? That's a lot of money. No £10 he charged too much. Before fares went up, it used to be £6.

Node 15 of 1056 feeling alright
Passage 1 of 9 Section 0, Para 23, 34 chars.

So other than that, I'm all right.

Passage 2 of 9 Section 0, Para 27, 31 chars.

No. I'm perfectly all right.

Passage 3 of 9 Section 0, Para 31, 30 chars.

Yeah, I'm feeling all right.

Passage 4 of 9 Section 0, Para 39, 36 chars.

But I'm feeling all right otherwise.

Passage 5 of 9 Section 0, Para 75, 34 chars.

So, but other than that I am fine.

Passage 6 of 9 Section 0, Paras 77 to 79, 67 chars.

And no other questions for me?No, because I'm feeling all right.

Passage 7 of 9 Section 0, Paras 81 to 83, 95 chars.

ood.Yes, I'm feeling fine. ... having my porridge early in the morning and I'll be all right.

Passage 8 of 9 Section 0, Para 157, 33 chars.

Well I don't know, I'm all right.

Passage 9 of 9 Section 0, Para 161, 57 chars.

Yes, I feel all right. This morning I want to be in town

Node 16 of 1056 feeling tired
Passage 1 of 3 Section 0, Paras 1 to 3, 165 chars.

I'll just leave it there. So tell me first of all about the tiredness, what does it feel like?No, just a normal thing. You work all day and you just feel tired.

Passage 2 of 3 Section 0, Para 7, 80 chars.

No, the tiredness was general when I reach home and it doesn't seem to wear off.

Passage 3 of 3 Section 0, Para 27, 37 chars.

I slept all on the way coming back.

Node 17 of 1056 feeling unwell
Passage 1 of 1 Section 0, Para 27, 222 chars.

As I say, it's only when I went home and this thing, what ever it was was on the aircraft, in the air. I came back and the flight was good. I slept all on the way coming back. When I land in the morning it was freezing.

Node 18 of 1056 fingers crossed re results
Passage 1 of 1 Section 0, Para 153, 170 chars.

Yeah. Because I was saying, I won't have my bloods done until I come to this appointment. So just keep my fingers crossed that the result's all right, which I'll hope.

Node 19 of 1056 friend paying for help
Passage 1 of 2 Section 0, Para 101, 1427 chars.

I can do it. I have a friend, she's asthma and all kind of complicated. She went home to Tobago for, she went home since November and you name ... she put everything in her house. She has Stannah lifts, she has everything. She brought a woman from Tobago, she says that we have company, she knows somebody's sleeping there in the night. Well I had to tell her day before, she bring a problem. She pay this woman's passage to travel from Tobago first class together with her by Virgin Airlines. She pays the woman £70 a week. The woman isn't paying rent, she not paying boarding or lodging, nothing. Everything is free. And she introduced this lady to the neighbour next door. Well she said, some of the days you just hear the bell ring, she get up, she have a shower and the bell ring and the neighbour come and they go on out in this weather for today. No, well I have to laugh. She said if she was a cup and a plate and she put it down on the table and she says, oh could you move that cup please. She wouldn't use it, move the plate you know? I said to her, she's sitting ... she'll be another six months. I said, well you like her? Because if the government was paying her that as a home help, she had to work. And again, you said, you tell her, move the cup. You didn't say move the plate. She get mad. And then her friend was, yeah she complained and then the friend tell her, give her a little chance.

Passage 2 of 2 Section 0, Para 105, 303 chars.

Give her a little chance to tell the girl to sit down. And she every six months. And I said to her when she goes she could open business, £70 a week she getting all her needs free, boarding and lodging and so it's a good thing I said because I might have take the job and then I had to do everything.

Node 20 of 1056 hard to bleed
Passage 1 of 1 Section 0, Paras 177 to 181, 230 chars.

Not with these fine veins there.I know, they're had aren't they?For all these years the vein's still hard to get, I can't understand why. Not here alone, when I was in hospital the doctors couldn't get it. They gave up on ...

Node 21 of 1056	keeping busy
Passage 1 of 2	Section 0, Paras 187 to 209, 749 chars.

ure you're going to be all right going home?Yeah. I'm fine. When's the time now?Quarter to one.I'll be in time for doctor, I could go in the grocery on in the bank and I can't go in the bank, that means that I have to go home and then go back. ...Don't do too much while you're feeling a bit low.No, I don't do anything, you know?Good.LaughterYou just mentioned the bank and the grocery shop.Yeah. Well you see I can leave home, go out to the bank and then take a bus and go to the high street and then come around.Is there anything you can't do that you used to be able to do?I does everything. I even, if I go up to ... town, I'll take the bus and drive around the airport, city airport and then go home. Just sick of rail.

Passage 2 of 2	Section 0, Paras 213 to 217, 45 chars.
----------------	--

I don't like sitting indoors.No?... at all.

Node 22 of 1056	No I'm not going back,
Passage 1 of 1	Section 0, Para 113, 23 chars.

No I'm not going back,

Node 23 of 1056	normality
Passage 1 of 1	Section 0, Para 43, 176 chars.

You see that since I came back, I didn't do any big shopping because I want to get some porridge oats and all that. I think I'll go to the grocery and do my shopping tomorrow.

Node 24 of 1056	put brother in charge of will
Passage 1 of 2	Section 0, Para 113, 280 chars.

I've put my brother. I get my solicitor to give a letter to him to take to the court as a forward to me. So anything, he'll let me know. I ain't bothered about all them things now. I tell him they could do what they want with the house just don't vandalise it and break it up.

Passage 2 of 2	Section 0, Para 117, 1022 chars.
----------------	----------------------------------

My brother will, can he provide it better. I came up here and I work and I bought a plaque and I always show it what I work for. That was his and he choose to leave me over everything which was very good of him. I didn't know until he died. So me only, the wife was never nice to him, not because he's my brother and he divorced her. ...

put your name down when the will probating, the money in the bank is to share and give everybody something and the daughter have already sent me four solicitor letters. So I just phoned her solicitor one day and I tell them do not send me any more letters. Because what my brother did was legal and official and that's, that is in Trinidad, not in England. And he never send me anything again. So because everybody, nobody expected to add that way. Nobody. She has a house up here. Her brother up here, he has a house. Her brother back there, he has his own house and three girls and they have their own house. So none of them asked him for anything but this one up here.

Node 25 of 1056 scratching
Passage 1 of 1 Section 0, Para 55, 566 chars.

When I go to bed at night and I take a sheet and cover all from here, right down, I just scratching, scratching, scratching and scratching and when I scratching down here, scratch, ... feel itchy I'll scratch and then. My cousin asked me what washing powder I use and I told her they use a different kind over there and this is an allergy from the washing powder. When I get out of bed I'm all right, no scratching. I will sit up all day but as soon as I go to bed at night and I take the cover and cover my feet, that scratching will start. I came back, nothing.

Node 26 of 1056 scratching caused by washing powder
Passage 1 of 1 Section 0, Paras 57 to 71, 467 chars.

So the scratching's stopped now?Yeah. So I think it was the washing powder.We'll keep an eye on that.When I get out of bed on mornings there's no scratching until I go to bed in the night, not in the day, nothing, nothing.And is it still happening here now when you're back in London?No it's not happening.Because you know one of the side effects of the kidneys can be the itchiness?No it's the washing power, the soap powder they use to wash clothes.

Node 27 of 1056 slept on holiday
Passage 1 of 1 Section 0, Paras 9 to 15, 235 chars.

So what did you do on your holiday?Sleep.All the time?I went nowhere. Well I didn't have to go anyway because when my friends round they realised I've picked up this cold virus, they will look at me. So I hadn't to go anywhere.

Node 28 of 1056 strating to feel better with capsule
Passage 1 of 1 Section 0, Para 19, 272 chars.

It was, that's what's going on in the West Indies, it's over here too. So I don't know. Because the sneezing and the coughing, but it's clearing up now since I start with these capsules. I'm not, it's not so bad. I know I'm feeling well, fine ... off my body gradually.

No other nodes in this set
code this document.

APPENDIX 12: PUBLICATIONS AND OTHER OUTPUT

Publications in peer-reviewed journals

Noble H, Chesser A, Kelly D. (2005) The cessation of dialysis in patients with end stage renal disease: developing an appropriate evidence base for practice. *EDTNA/ERCA Journal* 31; (4): 208-211

Noble H, Kelly D. (2006) Supportive and palliative care for end stage renal failure: the need for further research. *International Journal of Palliative Nursing* 12; (8): 362-367

Noble H, Rees K. (2006) Caring for people who are dying on renal wards: A retrospective study. *EDTNA/ERCA Journal* 32 (2): 89-92

Chun-hung C, Noble H, Lo, SH, Kwan TH, Sze, WK (2007) Palliative care for patients with end-stage renal disease: experiences from Hong Kong. *International Journal of Palliative Nursing* 13 (7): 310-314

Noble H., Kelly D., Rawlings-Anderson K. & Meyer J (2007) A concept analysis of renal supportive care: the changing world of nephrology. *Journal of Advanced Nursing* 59 (6) 644-653

Noble H, Meyer J, Bridges J (2007) Decision-making for renal patients at the end of life. *European Journal of Palliative Care* 14:5 204-207

Noble H, Chesser A, Go J (2007) Developing a Renal Supportive Care Service for patients opting not to dialyse, *End of Life Care Journal* 1 (3): 51-55 .

Noble H, Meyer J, Bridges, J, Kelly D, Johnson B (2008) Patient experience of dialysis refusal or withdrawal – a review of the literature. *Journal of Renal Care*. 34 (2): 94-100

Noble H (2008) Supportive and palliative nursing care for the patient with end-stage renal disease. *British Journal of Nursing*: 17 (8) 498-504

Noble H, & Lewis R (2008) The Role of the nurse caring for dying renal patients. *Nursing Times* 104 (23) 26-27

Noble H, Meyer J, Bridges J (2008) Why end-stage renal patients choose not to have dialysis *End of Life Journal* 2 (3) 41-45

Noble H, Meyer J, Kelly D, Johnson B, Bridges J (2008) Reasons renal patients give for deciding not to dialyse: prospective qualitative interview study. *Dialysis & Transplantation* 38 (3): 82-82

Noble H & Chesser, A (2009) Moving forward: advancing renal supportive and end of life care. *British Journal of Renal Medicine* 14 (2) 18-21

Nulsen R & Noble H (2009) Gone but not forgotten: A service to remember renal patients who have died. *End of Life Care* 3 (2): 56-62

Letters in peer-reviewed journals

Noble H & Lewis, R (2008) Letter to the Editor: Acceptance and rejection of dialysis – the need for patient evaluation *Journal of Renal Care* 34 (1):45

Murtagh F, Noble H, Murphy, E (2008) Correspondence: Palliative and End of Life Needs in Dialysis Patients. *Seminars in Dialysis* 21: 2 p. 196

Research presentations at scientific meetings

Noble H, Rees K. (2005) Renal in-patient audit of palliative care related deaths'. Oral Presentation. EDTNA/ERCA Conference, Geneva, September 2005

Noble H. (2006) Supportive Care Services for dying renal patients. Oral Presentation. RCN Nephrology Forum Conference. London, October 2006

Noble H, Meyer J, Kelly D, Johnson B, Bridges J. (2006) Opting not to dialyse: Implications for Renal Supportive Care service development. Poster presentation, Doctoral Celebrations Conference. City University, London, October 2006.

Noble H, Meyer J, Kelly D, Johnson B, Bridges, J (2006) Opting not to dialyse: Implications for Renal Supportive Care service development. Poster presentation, EDTNA/ERCA UK Seminar, Nottingham. November 2006

Noble H (2006) Opting not to dialyse: a literature review. Oral presentation, EDTNA/ERCA UK Seminar, Nottingham. November 2006

Noble H, Meyer J, Kelly D, Johnson B, Bridges J (2007) Palliative care research in the field of nephrology. Oral Presentation. Cancer and palliative care: new research, new applications, Middlesex University, London. February 2007

Noble (2007) Dialysis or Death. Oral Presentation (invited speaker). St Francis Hospice Annual conference, Essex. November 2007

Noble H, Meyer J, Kelly D, Johnson B, Bridges J (2007) Renal Nurse, Renal Researcher: Practitioner Research in Action. City University. January 2007

Noble H (2007) Renal Supportive and Palliative Care - The 4th Treatment Option. Renal Celebration Event, Barts and The London NHS trust, London. October 2007

Noble (2008) Dialysis or Death, What little we know (invited speaker). St Josephs Hospice, London. April 2008

Noble H (2008) Uncovering the trajectory to death in those opting not to dialyse. Oral Presentation. The British Society of Gerontology Researchers in Aging, Brunel University, Uxbridge. May 2008

Noble H (2008) Death, Dying and Dialysis: A new Renal Supportive and Palliative Care Service. Oral Presentation. St Francis Hospice 7th Annual Kaleidoscope Conference. Dublin Castle, Dublin. June 2008

Noble H Meyer J, Kelly D, Johnson B, Bridges J (2009) Researching Health/Researching Illness. **Invited Speaker** Oral Presentation. City University London. July 2009

Noble H Meyer J, Kelly D, Johnson B, Bridges J (2009) Healthcare needs and trajectories to death in those opting not to dialyse. **Invited Speaker** Oral Presentation. EDTNA Conference. Hamburg, Germany. September 2009

Book chapters

Palliative Nursing: Enhancing the Spectrum of Nursing (2009) *In press*

Other contributions

Noble H (2006) Improving care for renal patients at the end of life. *Nephrology News*. The RCN Nephrology Nursing Forum. Autumn, 4-5

Noble H (2007) Decision-making and advance planning – an evidence guide for palliative professionals. *Specialist library on the National electronic Library for Health webpages?* See: <http://www.library.nhs.uk/palliative/ViewResource.aspx?resID=271069&tabID=289>

Noble, H (2007) Annual Report of The Renal Supportive Care Service, *The Silver Lining Appeal*. 34: 54-56

Awards

International Journal of Palliative Nursing (2007) Renal Supportive Care Service, Highly Commended. London, UK

Celebrating Success (2007) Renal Supportive Care Service, Runners up. Barts and The London NHS Trust, UK

British Journal of Renal Medicine Awards (2008) A Patient-Centred Renal Supportive and Palliative Care Service (2nd Place). London, UK

APPENDIX 13: ETHICS APPROVAL

Mrs Helen Noble
PhD student, Clinical Nurse Specialist

30 August 2006

Dear Mrs Noble

Full title of study: **Opting not to dialyse: Implications for Renal Supportive Care Service development**
REC reference number: **06/Q0603/101**

Thank you for your letter of 17 August 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research site

The favourable opinion applies to the research site listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	06 July 2006
Investigator CV	1	07 June 2006
Protocol	1	20 June 2006
Covering Letter	1	06 July 2006
Letter from Sponsor	1	16 June 2006
Peer Review	1	01 July 2006
Compensation Arrangements	1	16 June 2006
Interview Schedules/Topic Guides	1	07 June 2006
Sample Diary/Patient Card	1	07 June 2006
Letter of invitation to participant	1	21 April 2006
Letter of invitation to participant	2	17 August 2006
Participant Information Sheet	1	07 June 2006

Participant Information Sheet: Carer	1	07 June 2006
Participant Consent Form: Patients	1	07 June 2006
Participant Consent Form: Carer/staff	1	07 June 2006
Response to Request for Further Information		17 August 2006
Amended Part C	2	06 July 2006
BLT Provisional Indemnity Letter		17 August 2006
Consent Form - Carer/Staff	2	17 August 2006
Consent Form - Patient	2	17 August 2006
To who it may Concern letter	1	05 April 2006
To Whom it may Concern letter	1	05 June 2006
Timetable	1	07 June 2006
Winter and Munn-Giddings Guidance	1	07 June 2006
Staff Information Sheet	1	07 June 2006
Supervisor CV	1	18 June 2006
Checklist	1	06 July 2006
Guidance for assessing action research	5	07 June 2006
Advertisement	1	07 June 2006
To whom it may Concern letters	1	05 June 2006

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q0603/101

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

P.P. Senior Administrator
Chairman

Enclosures:

*Standard approval conditions
Site approval form*

Copy to:

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	06/Q0603/101	Issue number:	1	Date of issue:	30 August 2006
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Chief Investigator:	Mrs Helen Noble
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Full title of study:	Opting not to dialyse: Implications for Renal Supportive Care Service development
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This study was given a favourable ethical opinion by --- 1 on 24 August 2006. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

<i>Principal Investigator</i>	<i>Post</i>	<i>Research site</i>	<i>Site assessor</i>	<i>Date of favourable opinion for this site</i>	<i>Notes ⁽¹⁾</i>
Mrs Helen Noble	PhD student, Clinical Nurse Specialist	---	---	24/08/2006	

Approved by the Chair on behalf of the REC:

..... (Signature of Administrator)

..... (Name)

- (1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension or termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Opting not to dialyse: Implications for Renal Supportive Care Service

Development

A PhD study



The Renal Supportive Care Service (RSCS) cares for those patients who have decided not to have dialysis. Its specific remit is to offer an enhanced, holistic approach to the assessment and control of symptoms and high quality palliative care for the patient and their family.

Results from this study will inform RSCS development as the stories from patients, their carers and staff are used to advance development of the service and impact on its future direction.

This study is being carried out by Helen Noble,
Clinical Nurse Specialist, Renal Supportive Care.



If you have any questions about the study please call
Helen on --- or email ---

APPENDIX 15: PROPOSAL TO REQUEST FUNDING SUPPORT FOR THE PROVISION OF RENAL SUPPORTIVE AND PALLIATIVE CARE

Executive Summary

The DH published the "End of Life Care Strategy" on 17 July 2008 and committed to increase the funding to £198 million for end of life care in 2010/11. Its aim is to provide people approaching the end of life with more choice about where they would like to live and die. The award winning Renal Supportive and Palliative Care (RSPC) Service at --- was established to address the need for patients with end stage renal failure.

Part of the focus of Renal National Service Framework is on patients having access to information that aids their choice in the management of their condition, choices that seek to assist patients with achieving the best quality of life. It is equally important that this level of focus is maintained for patients with end stage renal failure who require palliative care.

As ---PCT and its partners are working together with the Marie Curie Delivering Choice Programme to improve the choices available to service users and their families in terms of treatment options and their right to choose preferred place of care at the end of their life, the RSPC service at --- follows the same principles.

Over the past 3 years, there has been a sharp rise in the number of referrals to the service leading to more patients dying in their Preferred Place of Care, a rise which is expected to continue as the population presenting with ESRF increases at 10% per annum. In a bid to manage the increasing patient numbers on the current staffing establishment, the service has had to cap the number of referrals to 50 resulting in patients being refused input on the basis of insufficient staffing.

The purpose of this proposal is thus to seek funding to maintain and support the --- RSPC Service to accommodate its continuing growth. Investment in the service will allow for better access for patients to RSPC services at --- whilst maintaining the high quality of patient care the service provides. The DH "End of Life Care Strategy" mentions that "it is difficult, if not impossible, to calculate the cost of end of life care in this country". Based on current staffing costs to provide RSPC service, we are proposing a local tariff of £4,200 per patient per annum from the Commissioners.

We currently have 50 patients and it is projected that with the tariff to fund the staffing costs at -- -, we will be able to meet the demand for RSPC services in ---.

--- seeks for approval of the proposed tariff from the Commissioners for our renal and supportive and palliative care from 1 August 2008.

Clinical Leads

General Manager

18 July 2008

Acronym

CNS	Clinical Nurse Specialist
ESRF	End stage renal failure
GSF	Gold Standards Framework
PPC	Preferred Place of Care
RSPC	Renal Supportive and Palliative Care Service

1. Purpose of this Document

This proposal serves to seek funding support from the Commissioner for the provision of Renal Supportive and Palliative Care at ---. It provides the context, an overview of the service provided to patients with end stage renal failure, and the achievements which the Trust has made towards patient choice and better patient experience in end of life care. It details the funding required in terms of staffing and non staffing costs to provide a sustainable and quality service.

2. What is Supportive and Palliative Care?

According to the World Health Organisation (WHO)'s definition, palliative care includes symptom management during both acute and chronic illness and end-of-life (terminal) care¹. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable in the course of the illness in conjunction with conventional care for the renal patient.

3. Context

The need for palliative care for patients with end stage renal failure (ESRF) is well recognised. In the UK it has been established that the number of patients receiving dialysis is increasing by approximately 10% per annum². This 10% includes disproportionate numbers of those who are older, frailer and more dependant. Older people with ESRF have increasing prevalence of co-morbidities³.

Increasing age together with co-morbidity of the dialysis population, has led to an increased awareness that dialysing these patients may not improve their survival rate and may impact considerably on quality of life. Some research has indicated that in renal patients who were high risk and highly dependant, the decision to dialyse or not had little impact on survival and that dialysis in such patients risked the unnecessary medicalisation of death⁴.

It has been approximated that 20% of the renal patient population in the UK are currently managed without dialysis⁵ and although national figures are not yet available it is suggested that approximately 1,500 patients annually may be commencing on a pathway that is supportive rather than curative⁶.

Currently a number of policy initiatives and national guidelines have pointed to the need for supportive and palliative care for all. Specific to renal services is The *National Service Framework for Renal Services*, stipulating that '*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 palliative care plan, built around their individual needs and preferences*'⁷; the Renal Association's renal palliative care initiative developed in collaboration with the American Society of Nephrologists⁸; the Royal College of Physicians' recommendations on renal palliative care⁹ and a renal version of the *Liverpool Care Pathway for the Dying*¹⁰ developed by the Marie Curie Palliative Care Institute. Other related policies include the *National Service Framework for Older People* which calls for the provision of palliative care for those with non-malignant conditions; the *NHS Cancer Plan*¹¹; and the *NHS Improvement Plan*¹².

We realise there is an ongoing and increasing demand for renal palliative care in the local areas we serve. There is a relatively high proportion of Africans, African-Caribbeans and South Asians living in the boroughs¹³ which are within the catchment areas of the Trust. Evidence on higher incidence of ESRF is well established in these ethnic minority groups^{14 15}. Risk of ESRF also increases dramatically with age in these population groups¹⁶. In view of this, the Renal Supportive and Palliative Care (RSPC) Service has been established since January 2005.

As --- and its partners are working together with the Marie Curie Delivering Choice Programme to improve the choices available to service users and their families in terms of treatment options and their right to choose preferred place of care at the end of their life, the RSPC service follows the same principles.

Three clear objectives of the national Delivering Choice Programme are aligned with those of the RSPC service:

- To develop patient-focused service models that serve local needs, ensuring the best possible care for patients at the end of their life;
- To evaluate the economic impact to health services of more patients receiving end of life care at home as compared to hospital; and
- To disseminate findings to other health and social care providers to enable replication of solutions across the UK.

4. Renal Supportive and Palliative Care Service Objectives and Scope

The RSPC service, based at ...¹⁷, offers an inpatient and community service to those patients who choose not to dialyse. It also manages those who have decided to withdraw from dialysis. The service is nurse-led and offers:

- Proactive and coordinated follow up of all patients in the RSPC Service
- Appropriate medication management and titration of doses accordingly
- Support of patients and their carers through the trajectory to death and after as post bereavement care, for example
 - Provision of appropriate equipment to support patients who wish to die at home e.g. electric beds/commodes
 - Support for patients where English is not their first language by community advocates as appropriate
- On-going medical care and access to specialist care, such as
 - Appropriate referrals to other agencies e.g. dietician, renal counsellor, pharmacist, anaemia nurse and liaising with primary, secondary, tertiary care as required
 - The assessment of anxiety and depression and where appropriate referral to a clinical psychologist/counsellor
 - Referral to Specialist Palliative Care at an appropriate time

The primary objectives of the service are to:

- Provide renal patients with ESRF choice over place of care during the end phase of life
- Provide a direct clinical role, assessing patients at home or in the clinic working in partnership with PCTs
- Provide indirect clinical support providing consultancy and symptom control advice to clinicians as patients die in their Preferred Place of Place (PPC).

Other objectives are to:

- Provide educational support, leading on renal supportive and palliative care training for clinicians within the PCTs
- Lead nationally in improving renal supportive and palliative care and assist in the development of national policy and guidelines (see section 5 below)

Renal supportive and palliative care planning is initiated by the nephrology team. Two groups of patients, under the care of the Renal Unit, are referred into the service:

- Group A – Those with a life expectancy of 1 year approximately who have made the decision not to have dialysis
- Group B - Those with a life expectancy of 10-12 days who have decided to/are considering withdrawal from dialysis

The patient pathway for these patients are provided in Appendix I. Patients in the RSPC service have access to a multidisciplinary care team consisting of renal palliative care nurses, consultant nephrologists, counsellors, dieticians, social workers, community advocates, anaemia nurses, chaplain etc. The service at the --- is currently led and managed by a Senior Clinical Nurse Specialist (CNS) who also has management responsibility for the pre-dialysis service, anaemia service and renal counselling service.

¹⁷ Anonymised for confidentiality

5. Achievements of BLT's Renal Supportive and Palliative Care Service

The RSPC Service is a win-win for both patients and service providers and commissioners. It provides a much improved patient experience. Patient satisfaction with the service is high. An evaluation in 2008 concluded that 90% of patients found the communication skills of staff good or excellent, 80% felt their illness was discussed with them in a way they could understand, and 90% felt well supported by the service. Examples of feedback from patients and carers are provided in Appendix IIa.

As part of BLT's continuous improvement efforts, an annual multi-faith Renal Memorial Service has been set up. The most recent of these was attended by over 200 relatives, friends and carers of renal patients from our unit who had died the previous year. Evaluation provided positive comments (Appendix II b). This initiative has also been attended by significant numbers of doctors and nurses, which in turn has helped raise awareness of the need for supportive and palliative care for the renal population as whole.

The service has won two awards - Barts and The London Celebrating Success Awards 2006: Highly commended in the Excellence in Teamwork Award; International Journal of Palliative Nursing Awards 2006: Runners up Non-cancer award; and it has been mentioned in the literature^{17, 18}.

Equally important, there has been an increase in the number of patients dying in their Preferred Place of Care and a reduction in the numbers of patients dying on the renal wards from an average of 60 per year (2003-2005) to 33 (2007), freeing up beds and resources for other patients. Consultant nephrologists find the service also of value to the clinical team, as time has been released in nephrology and low clearance clinics. This has resulted in more patients being managed in these clinics.

Collaboration with our primary care and palliative care colleagues has become closer and stronger. The RSPC team are regularly invited to teach on their educational programmes. The team have been asked to present papers related to the service locally, nationally and internationally. They have been heavily involved in the implementation of the national end of life tools. The recently launched *Renal Liverpool Care Pathway for the Dying* is now used with any dying patient on our renal wards following a successful pilot. The *Preferred Place of Care* tool has been introduced and audited, with a second audit due in September 2008 utilising the revised tool now known as *Preferred Priorities for Care*. There has been ongoing support of the *Gold Standards Framework* (GSF) across the PCTs. The RSPC team provides ongoing support to primary care teams through CNS support, practice based training sessions and advice on symptom management. They also support local care homes (nursing) implementing GSF as part of a national programme, supported by the Macmillan team.

Last but not least, the service has also contributed to research in renal palliative care which is still under developed. The frequency of symptoms in this population is virtually unknown. Only one study highlights a huge symptom burden¹⁸. In our service we are identifying symptoms that include: oedema (96%), pain (90%), nausea and vomiting (90%), immobility (60%), bowel and bladder problems (53%), lethargy (53%), breathlessness (50%) and depression (37%). A qualitative research study, which involves 30 patients and carers, is trying to identify for the first time emergent patient trajectories to death. Once we more fully understand how patients die we can then share this knowledge with our community colleagues and others setting up similar services. This kind of research work enhances our understanding for proactive patient management.

6. Funding sought for service provision

¹⁸ Since this proposal was written the service has won a third award from the British Journal of Renal Medicine for 'A Patient-Centred Renal Supportive and Palliative Care Service'.

6.1 Growth in the demand for the renal supportive and palliative care

The success of the service has seen an increase in the number of patients referred into the RSPC Service. Table 1 provides a comparison of patient activity in relation to renal palliative care in 2005 and 2007. Patient numbers have doubled. Clinic consultations have halved in number but home visits have increased by over 90%.

Table 1 Patient activity level in 2005 and 2007

Year	2005 (Jan-Dec)	2007 (Jan-Dec)
No. of patients referred	38	86
No. of clinic consults	59	32
No. of home visits	5	93
Preferred Place of Care achieved	3 (14% of the total number of patients referred)	54 (77% of the total number of patients referred)

As of 3 May 2008, 50 patients are presently being managed by the service but this number fluctuates on a regular basis with new deaths and new referrals. On average, the length of life of those patients referred to the RSCS has increased year on year – average length of life is 6.5 months in 2005; 7 months in 2006; 13 months in 2007. This reflects earlier referral to the service and related improved palliative care for a population where previously this was not available.

6.2 Tariff required

The number of patient referrals has more than doubled over the last three years. As the population presenting with ESRF increases at 10% per annum there will be an expected continued increase in the numbers referred to the RSPC service. We believe this service could bring in savings for the commissioners and free up hospital resource so that more renal patients can be treated. The savings would come from:

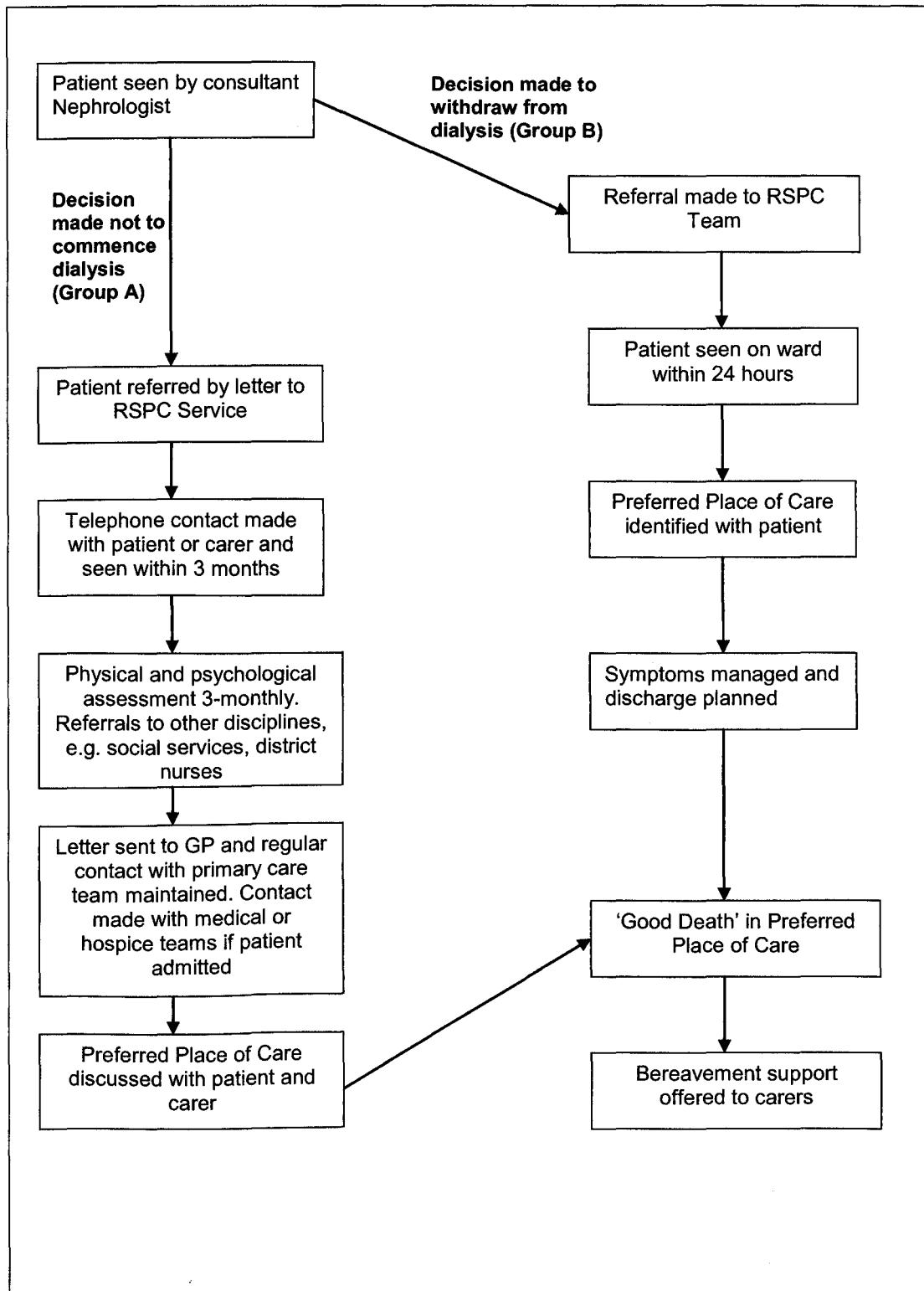
- Having some ESRF patients who might not have started dialysis
- Reduction in hospital admissions and length of hospital stay
- Reduction in Nephrology Outpatient visits

Currently there is NO national tariff for palliative care for patients with renal disease. We deliver the much needed service by competing with other services for the same pool of funding within the Trust. Funding from the Commissioner will help us deliver a sustainable and quality service. Based on staffing costs to fund the services, we are proposing to have a tariff of £4,200 per patient per annum from the Commissioners. We currently have 50 patients and it is projected that with the tariff to fund the staffing costs at ---, we will be able to meet the demand for RSPC services in ---.

7. Conclusions

This business case clearly identifies the need for renal supportive and palliative care at ---. Investment in this area will see more patients receiving quality care towards the end of life and contribute to improved patient experience. The RSPC service is also central to improving education and care in this area as quality research is undertaken and knowledge imparted to colleagues in the PCT.

Appendix I Patient Pathway



Appendix II

a) Example of patient feedback

'You have made a difference: its knowing that you're there. Before I didn't know who to turn to - no-one actually was there that I could turn around to and say, look, I just need some moral support, I can't do this on my own. There was no-one'.

'The palliative team have been great. I think without you I would be lost. I think it's a brilliant service ...if you ever need any petition signing I'll sign because, I tell you, it gives you that extra knowledge knowing that there is somebody there you can turn to'.

b) Positive comments received for the annual multi-faith Renal Memorial Service

'It was perfection'.

'A lovely service, just right. Thank you, much appreciated to help with the loss of a loved one'.

'To recall all the help that the renal department showed my father, for the extra years they gave us'.

'Just the opportunity to see some of the Nursing staff who cared for my father'.

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- ¹ World Health Organisation(WHO) (2004). Palliative Care: Symptom management and end of life care. http://whqlibdoc.who.int/hq/2004/WHO_CDS_IMAI_2004.4.pdf
- ² Ansell, D., Feest, T., Rao, R., Williams, A., and Winearls, C. (2006). UK Renal Registry Report 2005. Bristol, UK: UK Renal Registry.
- ³ Ashby, M., op't Hoog C., Kellehear, A., Kerr, P.G., Brooks, D., Nicholls, K., and Forrest, M. (2005). Renal dialysis abatement: lessons from a social study. *Palliative Medicine*, 19(5):389-396.
- ⁴ Smith, C., Silva-Gane, M., Chandra, S., Warwicker, P., Greenwood, R., and Farrington, K. (2003). Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clinical Practice*, 95(2):917-930.
- ⁵ Ibid.
- ⁶ Ansell D et al. (2006). op cit
- ⁷ DH (2005). National service framework for renal services: Part two. London: The Stationery Office. The National Service Framework for Renal Services, Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care. p.vii
- ⁸ Renal Physicians Association and American Society of Nephrology (2000). Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis Clinical Guideline Number 2. Rockville, MD
- ⁹ The Royal College of Physicians (2007). The changing face of renal medicine in the UK: the future of the speciality. Report of a Working Party 2007. London: RCP.
- ¹⁰ Marie Curie (2008) Liverpool Care Pathway for the Dying Patient (LCP). [http://www.mcpcil.org.uk/liverpool_care_pathway.\[19/3/2008\]](http://www.mcpcil.org.uk/liverpool_care_pathway.[19/3/2008])
- ¹¹ DH (2000). The NHS Cancer Plan: A Plan for Investment, A Plan for Reform. London: HMSO
- ¹² DH (2004). The NHS Improvement Plan: Putting people at the heart of public services. London: The Stationery Office
- ¹³ Greater London Authority (2008). Data Management and Analysis Group. Greater London Constituency Profile. <http://www.london.gov.uk/gla/publications/factsandfigures/dmag-briefing-2008-08.pdf>
- ¹⁴ Roger Beech, Martin Gulliford and Paul Roderick. Renal disease <http://hcna.radcliffe-oxford.com/renaldisease.htm>
- ¹⁵ Lightstone E (2001). Preventing kidney disease: The ethnic challenge. The National Kidney Research Fund. . http://www.hammersmithkpa.org.uk/pdfs/ABLE_positioning_paper.pdf
- ¹⁶ Blank L and Peters T et al (2005). Regional differences in the provision of adult renal dialysis services in the UK. *Q J Med* 2005; 98:183–190
- ¹⁷ Noble H, Chesser A, Go J (2007) Developing a Renal Supportive Care Service for patients opting not to dialyse, *End of Life Care Journal* 1 (3): 51-55

¹⁸ Murtagh, F., Addington-Hall, J., Edmonds PM, Donhue, P., Carey, I., Jenkins, K., and Higginson, I. (2007) Symptoms in advanced renal disease - a cross sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. Journal of Palliative Medicine, 10(6):1266-1276.

Renal Supportive and Palliative Care Proposal

(A) PAY COSTS				
Post/Staff Grade	Annual unit cost	Proposed FTE	Costs (incl. on costs)	Assumption
Clinical				
Consultant	121,000	2 hours per week	11,000	Assumes one session of 11 weekly sessions
Nursing				
Nurse Band 8a	54,000	0.7	54,000	
Nurse Band 7	48,019	1	48,019	
Nurse Band 6	41,954	0.5	20,977	
Other				
Secretarial support Band 4	29,000	0.6	17,400	
Dietician	44,000	1 hour per week	1,173	Assumes an internal recharge of time stated
Pharmacist	54,000	30 mins per week	720	Assumes an internal recharge of time stated
Renal Counsellor Band 7	48,000	1 hour per week	1,280	Assumes an internal recharge of time stated
Pay costs total			154,569	

(B) NON PAY COSTS				
	Unit cost	Frequency	Total (incl. VAT)	
IT & communications equipment				
- Networked Computer	1200	4	4,800	One computer for each FTE staff
- Printer	150	1	150	
- Fax	200	1	200	
- Telephone handset	20	4	80	
Travel	30	90	2,700	~ 7 visits per month. £20 eac for each visit plus £10 for car parking
Stationary & printing			3,000	Patient information packs/leaflets
Renal palliative care conferences	500	3	1,500	
Telephone charges	230	12	2,760	Mobile and land line bills
Community advocate	5,000	1	5,000	
Misc.			3,000	Minor office works
Non pay costs total			23,190	
Central overheads		20%	35,552	
TOTAL COST			213,311	
Number of patients managed by the team			50	
Cost per patient			4266.224	
		Per month per patient	355.51867	