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**OLDER PEOPLES' VIEWS OF CHOICE AND DECISION-
MAKING IN CHRONIC KIDNEY DISEASE: A GROUNDED
THEORY STUDY OF ACCESS TO THE SOCIAL WORLD
OF RENAL CARE**

By:

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ABSTRACT

Chronic kidney disease (CKD) is increasing in prevalence worldwide, with the largest increase occurring in individuals over the age of 65 years. Providing renal replacement therapy (RRT) to this older population will challenge health care systems, in terms of resources needed, as well as healthcare staff caring for this highly dependent group, who frequently have multiple co-morbidities. This study aimed to develop a theory that adequately accounts for the social processes involved when older people, with CKD stages 4 and 5 access treatment. The study sought to explore the concerns they had with CKD when making treatment decisions and identified how their concerns were resolved.

This study employed grounded theory using the full complement of coding, categorisation, and theoretical development. Data was collected from interviews and observations of clinic consultations between patients and healthcare practitioners, from 21 older people who were at the point of making treatment decisions. The main concerns for older people in this study focused upon achieving safe care. This led to the development of the theory '*Negotiating a Safe Existence*', which explains the processes older people encountered during their treatment decision-making journey. The basic social process of negotiation enabled them to use strategies and tactics to secure a place of safe care. This process involved transitioning through three stages represented by the sub-categories '*Confronting a Deteriorating Self*', '*Sourcing Information*', and '*Traversing Disruption*'.

This grounded theory identified the importance of information to older people with differing awareness levels concerning the seriousness of their CKD. Varying degrees of negotiation were evident reflecting the differences in information awareness, their role in treatment decision-making, and their perceptions of risk and harm from dialysis. The theory represented an insight into the status passage of these individuals as they entered a critical phase of their CKD. The structural processes of the renal clinic, doctors, existing patients, and families all influenced older people's status passage. The findings highlighted older people's perception of self-care dialysis, with the majority of patients in this study employing risk-aversion strategies to ensure they received care in a place of perceived safety, which was mainly hospital based dialysis.

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LIST OF COMMONLY USED ABBREVIATIONS & DEFINITIONS

aAPD	Assisted Automated Peritoneal Dialysis
CKD	Chronic Kidney Disease
DoH	Department of Health
eGFR	Estimated Glomerular Filtration Rate
ERF	Established Renal Failure
ESKD	End Stage Kidney Disease (often referred to as established renal failure (ERF) – stage 5 CKD)
HD	Haemodialysis
Identity	“The traits and characteristics, social relations, roles and social group membership that define who one is. Identity can be conceptualised as a way of making sense of some aspect or part of self-concept” (Oyserman, Elmore & Smith, 2012; p 69).
KDOQI	Kidney Disease Outcomes Quality Initiative
NSF	National Service Framework
PD	Peritoneal Dialysis
Social World of Renal Care	Social world is a term applied to ‘universes of discourse’ through which common symbols, organizations, and activities emerge (Scott, 2015). Social world of renal care encapsulates the characteristic features of a clinical speciality with its own illness discourse, technological dominance and a world of chronic illness shaped by individual and group experiences.

RRT	Renal Replacement Therapy
SDM	Shared decision-making
Status Passage	The formal theory of status passage as originally conceived by Glaser and Strauss (1971) suggests individuals move from one situation or period of their life to a series of different locations or phases, and this is a continuous and ever changing feature of the life course (Kingston, 2000).

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CHAPTER 1

BACKGROUND AND INTRODUCTION

1.1 Introduction

This chapter introduces the context and background to the study and situates it in the context of the researcher's professional background in nursing.

1.2 Personal biography and its influence on study

This study was borne out of my professional experience, of over 25 years within the field of renal nursing. Whilst a staff nurse during the late 1980's, and when I first entered renal nursing, I remember the large numbers of older people accepted for dialysis on the unit where I worked. Here, I saw first-hand some of the difficulties older people experienced as they faced dialysis, which centred not only upon making treatment decisions for themselves but also for those close to them e.g. family and friends. As a mental health nurse, my interest in coping with chronic illness led to research at Kings College, London University, and at the University of York. I vividly remember two older patients who confided in me that they had only started dialysis to appease their family. They said that they had succumbed to their family's wishes to have dialysis treatment, as 'dialysis would make them much better'. However, the reality for these patients was very different. They stated that, had they known more about dialysis and its possible effects, they might never have made the decision to start dialysis. Thus, it appeared that their treatment preferences had been subsumed to those of their family.

During the early days of my renal nursing career, I was involved in a number of clinical practice projects relating to patient education. I knew the importance of education for patients facing treatment decisions. These projects were presented at national and international conferences, including the annual conference of the European Dialysis Transplant Nurses Association/ European Renal Care Association (EDTNA/ERCA), where I have been an active volunteer for over twenty years. My interest in decision-making, as a possible PhD topic, was influenced by research undertaken by Dr Anna Winterbottom, a Clinical

Psychologist from the University of Leeds, relating to decision support for patients approaching dialysis treatment. It is hoped that this current study will enhance the understanding of experiences of older people as they encounter treatment decision-making, helping inform clinical practice and ongoing improvements in care.

1.3 Rationale for study

A substantial body of literature exists, exploring decision-making in chronic illness (Serrano et al. 2016; Karasouli et al. 2016). However, studies of decision-making in older people with chronic kidney disease (CKD) are limited (Pugh et al. 2016; Berger, Jaikaransingh & Hedayati 2016; Tong et al. 2014). Most studies are quantitative (Tamura, Tan, & O'Hare 2012; Phillips, Street & Haesler 2016; Weernink et al. 2014) and fail to illuminate the underlying social processes which may be integral to decision-making (Thorne, Paterson & Russell, 2003; Allen, et al. 2015). Strengthening patient involvement in decision-making is an important focus in healthcare policy (Foote, et al. 2014; DoH 2010, 2012, 2013). Much of the existing literature focuses on decision-making, occurring at a single point in time between two individuals, namely, patient and doctor (Hussain, et al. 2015; Griva, et al. 2013). This individualistic approach to decision-making reflects health care policy agendas that emphasise individual choice and patient control in decision-making (Richards & Coulter 2007; DoH 2014).

Interest has been directed to the development of decision aids (Van Weert, et al. 2016; Munro, et al. 2016; Agoritsas, et al. 2015) to individualise decision-making and strengthen patient involvement within their care (O'Connor, et al. 2007; Stacey, et al. 2014; Bekker, et al. 2013). This has led to the development of decision aids to improve accessibility of information concerning treatments to patients (Chabrera, et al. 2015; Stacey, et al. 2014). The development of decision aids, as an adjunct to decision-making, whilst important, tends to characterise decision-making as occurring solely between the patient and doctor and minimises the wider social context in which decision-making occurs (Winterbottom, et al. 2016; Crotty, et al. 2015; Riva, et al. 2015; Graven & Grant 2014). A broader perspective of decision-making has the potential to complement existing clinical practices that are focused on ensuring older people choose treatments reflecting individual choice, preferences, and values (Mulley, Trimble & Elwyn 2012; Dyrstad, Laugaland, & Storm 2015; Dixon, et al.

2015). Older people are a high-risk group due to their higher morbidity and mortality (Prince, et al. 2015). It is important therefore, to develop an understanding of the challenges faced by older people as they choose treatments (Moustakas, et al. 2012; Van Weert, et al. 2016).

CKD is a life limiting illness and, unless a kidney transplant is undertaken, treatment is focused upon dialysis or renal supportive care (non-dialysis support) (Dring & Hipkiss 2015). Kaufman, Shim and Russ (2006) have argued that, with the increased focus upon promoting consumerism in healthcare, and the ever increasing availability of life extending therapies, this ‘...promotes the notion that ageing and death are not inevitable’ (p. 175). This raises questions as to how older people with CKD choose between the various modalities available and what influences their decision-making. Whilst some older people are informed of non-dialytic treatment (Morton, et al. 2012; Murtagh, et al. 2009; Muthalagappan, et al. 2013), inconsistencies are evident within the literature as to whether this is a common experience for older people (Schell & Cohen 2014). There is evidence that not all patients are aware of non-dialytic care (Finkelstein, et al. 2008; Morton, et al. 2010a; Harwood & Clark 2014), which raises the question as to whether older people are choosing treatments whilst being fully informed of all available options to them.

Treatments for CKD affect an individuals’ quality of life (Pagels, et al. 2012; Tyrrell, et al. 2005), therefore, treatments chosen should reflect an individuals’ values and personal preferences (Brown 2012; Caskey, et al. 2003; Noble, et al. 2015). A body of literature has emerged, focusing upon the optimum renal treatment modality for older people (Brown, Gardner & Bonner 2014; Foote, et al. 2014; Muthalagappan, et al. 2013; Brown, et al. 2010). Assisted automated PD (aAPD) is advocated as a modality for older people due to its beneficial impact upon a patient’s life style and its ability to maintain patients in their own homes (Brown 2012; Brown & Johansson 2011).

There is conflicting evidence within the general literature on the level of involvement patients prefer in treatment decision-making (Bastiaens, et al. 2007; Elkin, et al. 2007; Arora, Ayanian & Guadagnoli 2005). There is evidence from some quantitative studies that patients do engage with their doctors during the decision-making process (Say, Murtagh & Thomson 2006; Fraenkel & McGraw 2007). This poses the question as to how much involvement older people want and what their preferred role in treatment decision-making is. Furthermore, the nature of the consultation process itself and the environment created during the consultation

influences decision-making (Charles, Gafni & Whelan 1997, 1999; Joseph-Williams, Elwyn & Edwards 2014).

Studies of older people with cancer offer an insight into factors that may contribute to treatment decision-making (Elkin, et al. 2007; Balneaves 1999). A recent Canadian systematic review (Puts et al. 2015) identified that treatment choice based upon treatment convenience and its anticipated success rate. Additional factors include accepting the need for the treatment, having trust in the physician, and following the physician's recommendations. Factors responsible for patients declining treatment include: treatment discomfort, concerns over side effects, and transportation difficulties. The impact of health professionals, most notably the nephrologist, has been identified as an important factor in older people's decision-making (Morton, et al. 2010b; Davison 2010; Schell et al. 2012), although the extent of this is rarely reported.

Patient information and education are important in ensuring that treatment decisions made are based upon best available evidence (Davison & Breckon 2012; Winterbottom, et al. 2012). However, little is known about how older people access and utilise information as part of their decision-making. Pre-dialysis education has been identified as playing an important part in decision-making, concerning treatment modalities (Chanouzas, et al. 2012; Harwood & Clark 2013; Winterbottom, Bekker & Conner 2014), although what is less known is understanding the patient's perspectives of the education process and how this influences the final decisions that are taken (Song, et al. 2013; Robinski, et al 2014).

Without information, patients cannot engage in meaningful treatment decision-making (Stacey, et al. 2012). Information facilitates a patient's understanding of potential risks, benefits, and harm of treatment (Elwyn, et al. 2012; Matthias, Salyers & Frankel 2013). A number of theoretical models of decision-making exist of patient centred decision-making (Elwyn, et al. 2012; Moreau et al. 2012; Charles, Gafni & Whelan 1999) founded on partnership, information sharing, and exploration of values and preferences

With the increasing number of older people entering renal replacement programs (Prince, et al. 2015; Roderick, et al. 2008), research is needed that offers an explanation of decision-making processes within this patient group (Murray, et al. 2013; Lelie 2000; Badzek et al. 2000). No studies exist that consider the influence of a broader range of social processes that

may influence decision-making within this patient population. This, therefore, requires further study, paying particular attention to what older people's main concerns are when they encounter treatment decision-making and how these concerns are resolved.

1.4 Prevalence and incidence of chronic kidney disease in older people

Globally, the world is facing an epidemic of ageing, with the World Health Organisation (WHO) estimating that, by 2050, the older population will increase from the current 11% to 22%. From the years 2000 to 2050, it is estimated that those aged 60 years and above will increase from 605 million to 2 billion (WHO 2017). The United Nations study on ageing (UN 2015) indicates that the fastest growth will be in the group aged 80 years and over. By the year 2050, those aged 80 years and over will have tripled to 434 million. Older people will outnumber children aged 0-9 years by 2030. There will be more people aged 60 years, than adolescence and youths aged 10-24 years (UN 2015).

This rapidly growing ageing population is associated with an epidemic of chronic disease, including, obesity, diabetes, cardiovascular disease, as well as chronic kidney disease (Stevens, Lamb & Levin 2015; Eckardt, et al. 2013). The impacts of an ageing population and the rise in chronic disease upon healthcare costs are significant, promoting an urgent need to reassess healthcare resource utilisation (Stevens, Lamb & Levin 2015).

Globally, CKD is rising, especially amongst older people (Couser, et al. 2011; Jha, et al. 2013; Béchade, et al. 2015; Singh, et al. 2014) and is a challenge to healthcare systems (Couser, et al. 2011; Ene-Iordache, et al. 2016; Remuzzi, et al. 2013). Roderick et al. (2008) identified that over half of older people (>65yrs) had an estimated glomerular filtration (eGFR) rate of <60 ml/min /minute/1.73m², corresponding to stage 3 – 5 CKD, supporting the increasing concern regarding the high prevalence of CKD in older people (Taal 2015; Ronsberg et al. 2005). In the UK, older people represent the largest group commencing RRT, with the median age of all incident patients in 2014 being 64.8 years (Caskey, et al. 2016). Within the UK, large regional variations exist in the incidence rates of CKD for those > 75 years. This ranges from 89 per million age related population (PMARP), in the borders of Scotland, to 1,036 PRAMRP in the borough of Brent, in London. Variations in pre-disposing renal disease and comorbidities, as well as uncertainty regarding the suitability of dialysis for older patients has been suggested to account for the variations (Caskey, et al. 2016). A review

of international incidence rates of CKD, in Northern European countries, Australia, New Zealand, and the United States, indicates similar incidence rates (Gilga, Caskeyabc, & Fogarty, 2016).

One reason for the global increase in CKD is the increasing incidence and prevalence of diabetes mellitus, which is higher within the older population. A recent study by Guariguata, et al. (2014) analysed the incidence and prevalence of diabetes across 130 countries, identifying in 2013 a total population of 381.9 million individuals with diabetes. This number will rise to 591.9 million in 2035. By 2025, the number of adults with diabetes will increase by 55%. The highest prevalence will be in people aged 60-79 years (18.6%). Diabetes leads to micro-vascular damage within the kidney, affecting glomerular filtration rate (GFR). A major effect of diabetes mellitus is hypertensive kidney disease, resulting in further deterioration in kidney function (Thomas 2014). Approximately 40% of patients with diabetes will develop CKD (Bakris & Ritz 2009).

As CKD continues to increase in the UK, its economic impact upon the National Health Service (NHS) budget will be significant. The cost of CKD to the NHS from 2009 – 2010 was £1.44 - £1.45 billion, which equates to approximately 1.3% of all spending in the NHS. Spending on renal replacement therapy (RRT) consumed half of the NHS spending (Kerr, et al. 2012). An ongoing concern is that RRT may not always be the best treatment option for older people and may cause more harm than benefit (Corsonello, et al. 2016; Pacilo, et al. 2016), particularly to those with co-morbidities and impaired functional abilities (Badzek, et al. 2000; Beben & Rifkin 2015; Brown 2012; Foote, et al. 2014; Harwood & Clark 2014). It is known that symptom burden is particularly difficult for patients with stage 4 and 5 CKD (Murtagh, et al. 2007; Brown, et al. 2015). A recent Saudi Arabian study tested the CKD Symptom Burden Index (CKD-SBI) and identified that CKD patients, on average, reported 13 symptoms, with fatigue and pain being the most common. Older female patients on haemodialysis experienced higher symptom burden (Almutary, Bonner & Douglas 2016). As a result, there has been a continued rise and interest in conservative care as an alternative to dialysis for older people (Beben & Rifkin 2015; Low, et al. 2014; Morton, et al. 2012; Murtagh 2015). Conservative care focuses primarily upon slowing the decline in kidney function, symptom management, and the management of complications (Murtagh, Cohen & Germain 2011).

1.5 Physiological impact of chronic kidney disease

CKD is a progressive condition, which may result in end-stage kidney disease (ESKD). ESKD, sometimes referred to as established renal failure (ERF), requires dialysis, transplantation, or conservative care (Thomas 2014). When the kidneys fail, they are unable to excrete water and waste products such as urea, creatinine, and potassium or control the body's acid base balance, which eventually leads to death (Thomas 2014; Chalmers 2014). The kidneys stimulate erythrocyte production via erythropoietin and therefore play a major role in haemoglobin production, blood pressure control, and bone formation (Chalmers 2014). CKD leads to anaemia, hypertension, and renal bone disease due to altered calcium and vitamin D metabolism (Chalmers 2014).

CKD is classified into five distinct stages, to enable assessment of the impact of CKD on kidney function (KDIGO 2013). Each stage being assessed according to the impact of CKD on glomerular filtration rate (GFR), the presence of systemic uraemic effects and co-morbidities such as cardio-vascular disease, anaemia, and renal bone disease. The most advanced stage of CKD is stage 5, which is present when kidney glomerular filtration rate is less than 15mL/minute/1.73m². Estimated glomerular filtration (eGFR) rates corresponding to each stage of CKD are shown in Table 1.

Table 1 The KDOQI (2013) Stages of Kidney Disease. (re-printed with permission from KDOQI)

GFR Category	GFR ml/min/1.73m ²	Terms
G1	≥ 90	Normal or high
G2	60-89	Mildly decreased*
G3a	45-59	Moderate to mildly decreased
G3b	30-44	Moderate to severely decreased
G4	15-29	Severely decreased
G5	<15	Kidney failure

Abbreviations: CKD, chronic kidney disease, GFR, glomerular filtration rate * relative to young adult level

Staging of CKD assists in early identification and management of patients by primary care physicians; patients with late stage CKD are referred to specialist secondary care in resource rich countries like the UK. In the UK, early identification and management of CKD by

primary care physicians is a component of the general medical services contract and quality outcomes framework (QoF) (DoH 2014). This framework establishes rigorous audit measures and the achievement of the required set QoF target attracts a financial incentive for primary care physicians. Management of the earlier stages of CKD 1 – 4 focuses on delaying CKD progression, by managing the cause of the CKD and treating and minimising complications that may arise, such as anaemia and renal bone disease. When stage 5 CKD is reached, it is irreversible and necessitates regular dialysis treatment, kidney transplantation or conservative (renal supportive) care.

1.6 Aim of study

The purpose of this study is to develop a theory that accounts for the social processes involved when older people with CKD stages 4 and 5 consider treatment.

1.7 Research question

How do older people come to make the choices they do in relation to the treatment for their CKD and what factors are important in this process?

1.8 Study objectives

The main objectives of this current study are:

1. Explore the concerns of older people with CKD when making treatment decisions.
2. Identify how older people resolve their concerns relating to treatment decision-making.

1.9 Organisation of thesis

This thesis comprises five chapters:

Chapter 1 provides the rationale for the study and discusses the classification of CKD, through its various stages, and the progressive nature of CKD as an individual's disease progresses towards established renal failure (ESRD).

Chapter 2 outlines the physiological impact of CKD upon individuals, highlighting how a change in renal function affects all bodily systems. The impact of an increasing number of older people with CKD needing specialised nephrology care is explored. UK government policy, concerning the care of older people with CKD, is examined. This current study focuses upon older people with stage 4 and 5 CKD, therefore, literature related to patient choice and decision-making is introduced.

Chapter 3 discusses the choice of an appropriate research methodology, namely grounded theory, for this current study. The chapter outlines contemporary debates concerning the use of literature within grounded theory and the rationale for undertaking a brief review of literature. A critical discussion of the ontological, epistemological, and methodological basis of this current study is offered. A detailed account of the grounded theory study design, data collection methods, data analysis, and the development of the emergent theory arising from the study is then discussed.

Chapter 4 presents the findings of this study, drawing upon participant accounts.

Chapter 5 offers a theoretical discussion on the study findings, integrating extant literature to the emergent theory developed within this current study. The contribution that this study makes to clinical practice, education, research, and policy is outlined. The study is evaluated using specific criteria for evaluation of grounded theory.

CHAPTER 2

RESEARCH CONTEXT

2.1 Introduction

As outlined in chapter one, the purpose of this study is to develop a theory that accounts for the social processes involved when older people, with stage 4 and 5 CKD, consider treatment. This chapter begins with an overview of the physiological impact of CKD and treatments available. The importance of pre-dialysis education in supporting patients to make decisions, regarding their treatment and management, is addressed. The benefits of pre-dialysis education on treatment outcomes and patient decision-making are then discussed. This then leads onto a discussion of shared decision-making in health care, and the impact of UK government policy in strengthening commitment to shared decision-making. The influence of U.K. National Service Frameworks (NSF's), in supporting choice and shared decision-making within renal care, is addressed. The chapter concludes with suggestions related to facilitating decision-making with older people.

2.2 Overview of treatments and management of chronic kidney disease

CKD is characterised by a diverse range of symptoms, reflecting the progressive nature of the disease process and altered physiological functioning. This occurs due to the inability of the kidneys to excrete metabolic waste products and a disturbance of fluid homeostasis (Webster, et al. 2017). Treatment for CKD depends on the stage of CKD, the condition of the patient, and presence of any co-morbidity. Early stage CKD is usually managed in primary care by general practitioners; pharmacological management of co-morbid conditions ensures that renal function is preserved as much as possible (Galbraith, et al. 2017). As kidney function declines, decisions are made concerning available treatments in the form of dialysis, either haemodialysis (HD) or peritoneal dialysis (PD) (Thomas 2014). Depending on the patient's physical status, patients may be placed on the renal transplant list. Additionally, patients are also offered the option to be conservatively managed. Within the

UK, the Renal Association have established a range of standards to ensure patients are identified early in their renal disease and, when appropriate, receive the necessary specialist support from a nephrologist and renal service to help with planning, initiating and, if needed, withdrawing from RRT. Ideally, patients should receive dedicated specialised renal support when the estimated glomerular filtration rate (eGFR) is $<30\text{ml/min/1.73m}^2$ (Warwick, et al. 2014). This ensures that adequate time is available to enable patients and family members to participate in education and preparation to support decision-making and choice, concerning preferred treatment. The UK Renal Association (Warwick, et al. 2014) guidelines strengthen the importance of patients being offered education and preparation to make choices. These guidelines provide an important framework for directing future renal services and provide important benchmarks for determining the quality of renal services provided.

2.3 CKD and its effects on older people and quality of life

The negative impact of RRT on quality of life (QoL), functional ability and rehabilitation has been discussed in the literature (Wyld et al. 2012; Schell, et al. 2012; Ronsberg, et al. 2005). Measuring QoL in older people undergoing RRT is an area of concern, since QoL measurement tools generally reflect younger patient populations and attributes associated with younger populations (Brown, et al. 2015; Griva et al. 2014). McKee, et al. (2005) examined the reliability of instruments measuring QoL in older people with ERF, identifying QoL domains seen as important to older people. However, many domains reported as being important to older people were not reflected in many QoL measuring instruments. Additionally, bias exists in instruments, since QoL scores are influenced by physical health statuses, which are age confounded; this reduces comparison between different age groups (McKee, et al. 2005). McKee's findings conflict with the assumption that older people receiving dialysis have a poorer QoL than younger patients. Literature focusing on patient survival rarely considers parameters of QoL (Foote et al. 2012). This is a weakness in quantitative studies that ignore QoL. The effects of RRT on QoL life is an important area when discussing treatment and modality choice (Da Silva-Gane, et al. 2012). Conservative care (non-dialytic support) is a viable treatment choice where uraemic symptoms are controlled and supportive care offered (Raghavan, & Holley 2016; Hussain, Mooney & Russon 2013; Lewis 2013). Conservative care is less invasive and less intrusive into the daily lives of patients and their families.

2.4 Pre-dialysis education

A number of studies (Singhal, et al. 2014; Chen, et al 2013; Strand & Parker 2012) have focused on the benefits of pre-dialysis care of patients with early renal failure and its association with patient mortality. Metcalfe et al.'s (2000) study identified factors thought to affect early dialysis mortality. This one-year Scottish prospective cohort study identified patients who had received inadequate pre-dialysis care and referred late to nephrology services. These patients had mortality rates of between 6 and 8.9 times higher than patients who had timely referral to nephrology. This study identified an association between low serum albumin and early death in these patients. Whilst the study focused on the effects of non-elective presentation for dialysis, co-morbid illnesses, and low serum albumin, it was apparent that specialist nephrology care improved patient outcomes. The pre-dialysis phase ensures timely placement of vascular access, plus improved management of existing co-morbid illness and strengthening patient survival.

This study further adds to the growing evidence base supporting the positive impact of patient education and management during the pre-dialysis period (García-Llana, 2014; Walker & Marshall 2014). An important outcome in Metcalfe et al.'s (2000) study was the positive effects of education on reducing cardiovascular risk factors, which are known to be the highest cause of death in renal patients. Variability in pre-dialysis education is evident in published literature (Winterbottom, et al. 2012; Ormandy 2008; Jia, et al. 2012; García-Llana, et al. 2014). Guidelines from the National Kidney Foundation (NKF) and the Kidney Disease Outcomes Quality Initiative (KDIGO 2013) provide guidance, in terms of best practices for initiating pre-dialysis care. Delivery of pre-dialysis education is a matter of local choice and usually delivered within a multi-disciplinary model of care. This involves medical, nursing, nutritionist, social worker, and expert renal patients, all supporting the education of patients approaching renal replacement therapy. Strategies for delivering education vary between individual and group education sessions, with patients and families, through to the use of multi-media resources to facilitate information (Lecouf, et al. 2013; Diamantidis, et al. 2012).

Whether pre-dialysis education influences patients assuming self-care is debatable, since much of the existing literature on it suffers from methodological weaknesses, making outcomes of studies unreliable. Whilst, pre-dialysis education programs focus on providing

disease specific and treatment focused information it also supports patients to develop self-care if possible. Bonner, et al. (2014) reviewed the evidence of self-management programmes for patients at stages 1-4 CKD, concluding that the effectiveness of pre-dialysis education on self-care is less promising than anticipated. The review identified that, out of 2,051 papers on self-management programs, only five were suitable for review. The review identified variable consistency in the delivery, intensity, and duration of programs. Self-management programs improved knowledge and health-related quality of life, with some small effects upon adherence and progression of CKD. As the effectiveness of such programs is debatable, Bonner et al. (2014) argue that further research is required.

2.4.1 Pre-dialysis education and patient survival

Few studies have considered whether patients receiving pre-dialysis education survive longer when dialysis commences. One Italian study examined the impact of multi-disciplinary kidney disease management and its impact on survival rates. Ravani, et al. (2003) employed Cox's regression analysis to estimate the association between the types of pre-dialysis follow up and mortality in adult dialysis patients who were commencing treatment over a thirty month period and followed up for one year. This longitudinal cohort study of 229 patients consistently identified the benefits of a multi-disciplinary approach to pre-dialysis care. Whilst most of the patients in this study were male (62%) and elderly (median age of 70 years), the results point to the impact of controlling of hypertension, improving metabolic control, as well as attending to patients' nutritional status prior to dialysis as being critical factors. Patients receiving regular unstructured care had a similar risk of death to those patients referred late for dialysis. Patients undergoing the pre-dialysis education programme had longer survival rates (hazard ratio 0.48 95% CI 0.27, 0.87). This study supports the increasing body of evidence, which suggests that pre-dialysis education positively influences patient survival (Ravani et al. 2003). Whilst this study focused primarily on clinical outcomes, it would have been worth examining how features of the education programme itself influenced survival rates. Factors such as how disease specific knowledge is used when making treatment decisions, as well as the format of education provided, could have been considered.

Further work in North America by Yeoh, et al. (2003) confirms the benefit of pre-dialysis education on clinical outcomes. This study identified a cohort of patients over a three-year

period, actively encouraged to attend educational classes. Sixty-eight patients participated in the educational classes, with thirty-five patients deciding not to engage in the programme. A specific kidney education class was designed depending on the stage of CKD; one class for patients having mild to moderate renal impairment (creatinine 1.3-3.0 mg/dL), which focused on general kidney information, causes of renal failure, controlling diabetes and hypertension. The second class focused on 'choices' (options for dialysis) for those patients classified as having moderate to severe renal impairment (creatinine > 3.0 mg/dL). Following attendance at classes, patients were followed up for one hundred days following commencement of dialysis.

Yeoh, et al's. (2003) study demonstrated differences between patients attending the educational programme and those who did not. Those patients not attending the programme had a lower incidence of arteriovenous fistulae placement when starting dialysis with a temporary vascular catheter. The frequency of hospital admissions between both groups of patients was an important outcome. Patients in the education class had fewer visits (0.57 vs. 1.11, $p=0.035$) to the emergency room for a variety of reasons such as pulmonary oedema, vascular access problems, and gastrointestinal bleeding. The impact on length of hospital stay between both groups revealed marked differences. Patients not receiving pre-dialysis education had greater than seven times longer hospital stays than patients who received pre-dialysis education (9.9 vs. 1.4 days per patient, $p<0.001$). This study demonstrated the value of providing education, according to the severity of renal impairment, with more specific information provided, according to the urgency of dialysis start. This is important since few reported studies have specifically developed pre-dialysis education programmes in this targeted manner. How individual factors, such as motivation to learn, as well as how patients applied their disease specific knowledge in the management of their illness would have been valuable to understand. Within Yeoh et al.'s (2003) study, no information is provided as to why thirty-five patients refused to join the pre-dialysis education programme or whether their non-inclusion led to a degree of selection bias occurring. The researchers argue that larger prospective randomized controlled trials are needed, to determine the impact of pre-dialysis education on clinical outcomes.

Pre-dialysis education has been shown to be an important factor in supporting patient transition to treatment. When choosing treatment modality, Goovaerts, Jadoul & Goffin

(2005) demonstrated that, where patients are supported with a structured pre-dialysis education programme, most choose a self-care modality such as home dialysis or PD as their preferred therapy. In this study, which focused on the Pre-Dialysis Education Programme (PDEP), education included individual information provided by nursing staff to both patient and family. Information included specially prepared in-house video tapes used to educate on treatment modalities available and help to reduce fear and anxiety whilst promoting self-care modality choice. Whilst Goovaerts, Jadoul & Goffin (2005) identified that younger patients chose self-care modalities, up to 40% of patients in their sixties did not choose in-centre HD. The likelihood of self-care modalities being selected was associated with patients feeling well and referred early for education and support.

Patients need to understand all therapeutic options if effective choices are to be made during the pre-dialysis stage (Finkelstein, et al. 2008). Knowing precisely what information patients require to enable treatment decision-making is important. Finkelstein, et al. (2008) undertook a prospective observational study of 676 pre-dialysis patients (CKD stages 3-5, median age 66 years) to explore patients' perceived knowledge and education of treatment options for ESRD. This study identified that, despite 65% of patients being seen by a nephrologist for more than 1 year, knowledge of CKD amongst patients varied, ranging from 23% reporting extensive knowledge to 35% reporting limited or no knowledge. A significant number of patients reported no familiarity with transplantation, HD, CAPD, or APD. Patients who attended four or more nephrology visits yearly reported better knowledge of treatment modalities. The findings of this study suggest that the patients' lack of knowledge was related to the education skills of nephrologists and not due to a lack of referral for nephrology care. Whilst early pre-dialysis support improves patient knowledge, this was not the case in this study. Patients reported high levels of uncertainty and anxiety related to their condition and a lack of, or no, familiarity with treatment options available for CKD. The limitations of education provided by nephrologists were identified, which concurs with similar findings cited by Mehrota, et al. (2005).

Groome, Hutchinson, & Tousignant (1994) sought to identify which treatment aspects patients should know. A mixed methods strategy, including interview data and surveys of patients already receiving RRT and renal health professions, generated 1,269 items, based on five possible treatment options. This study questioned the benefit of consulting with patients

in identifying their information needs as there were no benefits identified from the contributions made by patients. Whilst there are a number of studies that have addressed the development of decision analysis tools for education of patients with ESRD (Couchoud, et al. 2015; Dusseux, et al. 2015), very few have specifically focused upon the needs of older people (Thamer, et al. 2015).

Klang, Bjorvell and Clyne, (1999), highlight the positive impact of pre-dialysis education programmes. Patients in the 'experimental group' (28 uraemic patients) receiving the intervention of four, two hour group teaching sessions felt they had gained knowledge to enable choice of dialysis modality. This differed from patients in the control group who received information via the doctor on an outpatient basis. When post evaluations were performed, patients in the experimental group were substantially more informed when measured against their pre-intervention knowledge scores. Of interest in this study was that, once dialysis treatment had started both experimental and control group patients scores showed no differences, suggesting that patients in the control group were able to access other sources of information. Whilst the pre-dialysis education programme enabled patients to choose their dialysis modality, the specific needs of elderly patients were highlighted. This study recommended the importance of individualised tailored programmes of education for older patients. Goovaerts, Jadoul and Goffin (2005) reported a similar observation in a Belgian study.

Tweed and Ceaser (2005) further support the need for tailoring information to older pre-dialysis patients. The importance patients attached to the 'renal patient information day' in helping patients' decision-making was confirmed. Limited knowledge was expressed by patients in Tweed and Ceaser's (2005) study relating to the risks and disadvantages of various forms of treatments. The family were cited as an important factor in providing a sounding board for patients during the decision-making process. This study identified that the main factors shaping decision-making concerns facing patients focused upon maintaining personal integrity, feeling forced into adapting, using information, and gaining support whilst experiencing the illness.

2.4.2 Social and psychological impact of CKD

The social and psychological impact of CKD has been well documented in previous studies (Davison, & Jhangri 2013; Zalai, Szeifert & Novak 2012). Depression is common in patients with CKD (Palmer, et al. 2013; Hedayati, Yalamanchili, & Finkelstein 2012) and it is important to minimize (where possible) the impact of CKD on psychological functioning. CKD affects both patient and significant others, thus the preparation of family during the pre-dialysis period is vital (Thirsk, Moore, & Keyko 2014; Morton, et al. 2012). The practical considerations required during the pre-dialysis period influence all aspects of both the patients' life and significant others. Baillie and Lankshear (2015) have identified the importance of pre-dialysis support to both patients and their families' in managing PD within the home setting. This ethnographic study, the first of its kind, illuminates the culture of the home setting as patient and family managed to deliver safe PD care. Themes arising from this study included the medicalisation of the home setting due to PD, the rigidity of treatment schedules, as well as the uncertainty in dealing with adverse events in the home environment. Despite these challenges, families' in Baillie and Lankshear's study (2015) sought a level of freedom by being creative in how they managed the home PD. CKD requires adjustment to a new way of living, which is stressful for all those involved with the patient. Decisions regarding treatment can be confusing for patients who may have limited time to make critical decisions (Harel, et al. 2016; Keating, et al. 2014). It is important, therefore, to examine how best to deliver pre-dialysis education to patients if they are to benefit from therapy.

Providing information is central to facilitating patients to make the right choices (Van Biesen, et al. 2014; Chanouzas, et al. 2012; Coulter et al. 2006). CKD is a major stressor for individuals (Harwood, et al. 2012a) who have to make lifestyle adjustments whilst coming to terms with their treatment and management (Ekelund & Andersson 2007; Hagren, et al. 2005; Logan, Pelletier-Hibbert & Hodgins 2006). Decisions involve whether to have HD, PD, or whether to be managed conservatively (Burns & Carson 2007). Decisions taken by patients and their families' need to be based on all available information including both risks and benefits of treatments available (Owen, et al. 2006; Noble & Lewis 2008). Commencing RRT is a decision taken by the nephrologists in consultation with both the patient and family (Mehrotra, et al. 2005). Patients are monitored initially on an outpatient basis, where GFR and creatinine clearance (CrCl) are measured; these are the key clinical markers of renal function (Abaterusso, et al. 2008). This 'monitoring period' is a one of high anxiety for

patients and family (Pelletier-Hibbert & Sohi 2001), since optimum clinical management is dependent on the patient's ability to follow specific prescribed treatment advice (Groome, Hutchinson & Tousignant 1994; McLaughlin, et al. 2008). CKD depresses cognitive functioning (Schira 1992), influences learning, and memory. Older patients must understand pre-dialysis information provided; this is a concern where some may have sensory impairment and concentration weaknesses (Lamar, Resnick & Zonderman 2003; Davison & Holley 2008). During the pre-dialysis phase, patients need to learn medication regimens and their importance in controlling blood pressure and renal bone disease. When patients cannot remember this information, this may result in fatal consequences (Alibhai, Han & Naglie 1999).

2.4.3 Effectiveness of pre-dialysis education

Renal health care professionals face a significant number of patients referred late for dialysis treatment. Many patients are referred to nephrologists with severe cardiovascular disease, hypoalbuminemia and nutritional disorders, secondary hyperparathyroidism, and dyslipidaemia. Slowik (2001) reported the positive effects of a multi-disciplinary programme, focusing on education and appropriate clinical interventions for patients with CKD.

The positive effects of pre-dialysis education on patient outcomes continue to be of interest to researchers with studies focusing on the impact of early interventions on outcomes that influence morbidity and mortality. Clinical outcomes include anaemia management, management of pre-dialysis hypertension, and the effects of CKD on cardiovascular function (Levin & Foley 2000).

In Canada, Goldstein et al.'s (2004) retrospective study examined new patients who had received at least three months of specialist pre-dialysis care. Patients were categorized whether they had attended a multi-disciplinary progressive renal disease clinic (PRDC) or not. To minimise the effects of confounding, patients, having previous failed renal transplant, acute renal failure or a history of dialysis therapy, were excluded. Patient demographics and residual renal function in all patients were similar at the start of dialysis. A positive impact of the PRDC was confirmed in that patients exposed to PRDC were more likely to commence dialysis with a functioning vascular access and had improved control of anaemia and

improved nutritional status. Furthermore, patients who accessed the PRDC had fewer hospitalizations at 1 year (7.0 versus 69.7 days/patient/year $p < 0.01$) and fewer deaths at 1 year (2% versus 23% $p < 0.01$). Whilst the presence of cardiovascular disease, old age, and non-PRDC care independently predicated death on dialysis, Goldstein et al. (2004) failed to consider the actual delivery of dialysis therapy i.e. quantification and efficiency of dialysis as being an important confounding factor. The study further argued the need to understand how the individual components of pre-dialysis education (content, mode of delivery, resources used) impact upon patient success with dialysis. Within the context of Goldstein's work, understanding how information retention influenced patient choice and decision-making concerning risks was not addressed. Goldstein et al. (2004) argued that rigorous comparisons of different approaches to pre-dialysis education and their effect on patient outcomes remained in their infancy and remained important for future research.

2.5 Psycho-educational interventions in CKD

Studies have reported the psychological impact of CKD during the pre-dialysis period. The specific benefits of psycho-educational interventions (PPI) during the pre-dialysis stage is worthy of further study. Multi-disciplinary pre-dialysis education involves both renal social workers and, frequently, a clinical psychologist. How to incorporate psycho-educational pre-dialysis support, to improve patient decision-making requires further inquiry. Devins et al's. (2003) randomized controlled trial involving fifteen dialysis centres across Canada examined the specific intervention of an individual slide educational session, a booklet regarding treatment and living with dialysis, as well three weekly follow up supported telephone calls. A comparison group of patients received the standard pre-dialysis education within their own dialysis centres. A total of 297 patients commencing dialysis within 6 to 18 months were recruited. The results indicated that time to dialysis in the PPI group were longer than the control group (17 months versus 14 months, $p < 0.001$). Patients using avoidance to minimize the threat of dialysis, commenced dialysis sooner. This study adds to the growing body of knowledge, suggesting the importance of providing patients with disease specific knowledge, as well as how illness-related knowledge used by patients, may be important in decision-making. This is consistent with earlier work (Klang, Bjorvell & Clyne 1998, 1999), suggesting that providing disease specific knowledge, and supporting its use during the adjustment and management of CKD, is important during the pre-dialysis stage.

Klang, Bjorvell and Clyne's (1999) work in Sweden also supports the positive impact of structured pre-dialysis education programmes upon patient choice and decision-making. This study involved an experimental group, receiving a specifically designed pre-dialysis education programme (four two hour group teaching sessions on specific topics), and a control group already on dialysis, who received information and general care from their general practitioners. Questionnaire data from both groups focusing on disease specific knowledge, perceived amount of information, and sense of coherence, which focused on perceived manageability of life stressors, was collected. Patients receiving the specific pre-dialysis education programme received a disease specific knowledge test prior to commencing the programme, which was repeated between three to nine months following dialysis commencement. The results indicated that age was negatively correlated, with scores for information related to diet restrictions ($r = -0.42, p < 0.05$) and progression of renal failure ($r = -0.43, p < 0.05$). In the context of the study, the results suggest that the older the patient, the less they perceived they had received information concerning these issues. Men in the experimental group had higher scores for the overall amount of information perceived than women ($p < 0.001$). Significant differences in test scores existed once dialysis had commenced, with men having higher scores for information on kidney disease ($p < 0.001$), medication ($p < 0.001$), and diet restrictions ($p < 0.05$). Scores of disease specific knowledge e.g. knowledge of blood pressure, laboratory tests, and medication once dialysis had commenced were positively correlated with scores for perceived overall amount of information received ($r = 0.61, P < 0.001$). This further emphasises the importance of patients' perceptions of information received and, importantly, the association this has with disease specific information.

2.6 Role of shared decision-making – UK policy context

Whilst there has been a continuing attempt by successive UK governments to address the care of older people with the publication of various policy documents, namely National Service Frameworks (NSF) for Older People (DoH 2001), and a strengthening of the choice agenda, concerns remain regarding the care of older people in hospital. Older people, as a group, are frequently vulnerable and experience both physical and psychological declining health states. These vulnerabilities mean that older people as a group are at risk due to problems related to their altered physical and psychological states (Flatley & Bridges 2008).

Health service reforms within the UK seek to strengthen patient choice and their involvement in treatment decision-making (DoH 2012, 2015, 2016). The UK NHS commitment to supporting increased choice permeates many of the publications from the UK Department of Health (DoH). Since the publication of the document ‘*Liberating the NHS: No decision about me, without me*’ (DoH 2012), there has been a concerted approach to further raise the importance of choice and fostering shared decision-making in ongoing policy development. The publication ‘*No Decision about me without me*’ (DoH 2012) sends a clear message that patient involvement is not piecemeal but is throughout all aspects of care and treatment:

Greater involvement of patients in decisions about their care and treatment should encompass all instances where patients make decisions about any aspect of their care and treatment. This could be achieved through better personal care planning, self-management, as well as through shared decision-making (DoH 2012, p. 8)

The NHS Constitution (DoH 2015), launched in 2015, highlights the commitment enshrined in the NHS constitution in ensuring patient and family involvement in care decisions:

Patients, with their families’ and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment (Principle 5: NHS Constitution, DoH 2015)

An ongoing commitment to strengthening and legitimising the role patients and families’ within their care is evidenced in the NHS Choice Framework (DoH 2016). Both NSF’s for Renal Services (DoH 2004, 2005) argue that patients must have opportunities to engage in treatment decision-making. Both renal NSF’s form the foundation of the more recent publication *Achieving Excellence in Kidney Care: Delivering the National Service Framework for Renal Services* (DoH 2009). This publication reinforces the central components of the NSF frameworks, namely: a patient centered service, which ensures information, access, choice, and the provision of care as near to home as possible.

Providing a patient-centred service, ensures patients and their families’ have information to support informed decision-making. Supporting older people, to be involved in their care and shared decision-making, is an important goal within the NSF for Older People (DoH 2001). An ongoing focus in NHS policy relating to improving renal services for patients and families’ is that of timely pre-dialysis preparation as individuals approach possible treatment

for CKD. *Achieving Excellence in Kidney Care* (DoH 2009) identifies the central importance of information to enable patients make informed choices:

In order for patients to make informed choices, it remains critical that they have access to easy-to-understand, treatment-specific, comparable information on safety, experiences and patient satisfaction. The challenge is to ensure that suitable information is available for all audiences (DoH 2009, p.3)

The NHS Outcomes Framework 2015/2016 (DoH 2014) identifies specific indicators and areas for improving and enhancing quality of life for those with long-term conditions. A number of indicators and interventions are of relevance to the care of older people with renal disease, namely:

Domain 2: Enhancing quality of life for people with long term conditions

2.1 Ensuring people feel supported to manage their condition

2.7 Improving quality of life for people with multiple long term conditions. (DoH 2016)

2.6.1 Importance of shared decision-making

What constitutes shared decision-making (SDM) in healthcare has received increasing scrutiny (Stiggelbout, Pieterse, & De Haes 2015; Légaré, & Thompson-Leduc 2014; Tambuyzer & Audenhove 2015). Shared decision-making challenges the many assumptions on which care practices are delivered (Elwyn, Lloyd & Joseph-Williams 2013; Edwards 2009). In terms of models of decision-making, health care has moved away from the traditional paternalistic model, where the doctor assumes total responsibility of decision-making, to one where there is sharing of responsibility during the consultation process (Lelie 2000). The traditional relationship between doctor and patient is of interest within the Medical Sociology, with the doctor assuming the position of the expert provider and transmitter of knowledge whilst the patient assumes a passive role during the consultation, exercising low levels of control (Morgan 2003).

Turner (1995) that argues the power used by medical professionals during consultations is seen as the legitimate use of professional power and the social monopoly of knowledge. The move towards a consumerist society means that it is increasingly acceptable for patients to challenge expert knowledge. The lay knowledge of patients, coupled with the expert knowledge of the medical professional, are important components of the consultation. This

reflexive consumer (Giddens 1991), with their lay knowledge, often conflicts with the professional knowledge of the medical professional, where lay perspectives are not seen as acceptable in their eyes (Giddens 1991). Thus, an increased focus towards partnership within the consultation between medical professional and patient has emerged, leading to the sharing of power. Patient expectations during consultations have also moved towards the sharing of decisions and choice. Consequently, the medical consultation is often viewed as a process of co-construction.

It is generally accepted that patients should be actively involved in making decisions concerning their treatment and management (Stacey, et al. 2014; Joseph-Williams, Elwyn, & Edwards 2014). The benefits of SDM have been documented in various studies, including enhancing patient outcomes (Shay, & Lafata 2015), strengthening patient concordance with prescribed treatment regimen (Polinski, et al. 2014), as well as its role in patient satisfaction with the quality of doctor/patient consultation (Tambuyzer & Audenhove 2015). SDM has developed as an approach where both patient and medical professional jointly participate in the decision-making processes in partnership and, through negotiation, choose the most appropriate treatment (Cavanaugh 2015; Richards & Coulter 2007). In reality, the application of SDM has been identified as being inconsistent, primarily due to the varying levels of patient preferences for involvement in decision-making, coupled with medical professionals' failure to implement SDM (Elwyn, & Edwards 2014; Elwyn & Charles 2001).

The key components of SDM include the three phases of information exchange, deliberation, and treatment decision (Charles, Gafni, & Whelan 1997). For an accurate diagnosis and establishing a plan of treatment, understanding the information exchange process during the consultation is essential. Information helps minimise patient uncertainty, and power imbalances between patient and medical professional (Elwyn et al. 2013; Moreau, et al. 2012). Providing treatment choices to patients ensures that patients participate as information providers, rather than as a passive recipient of medical information (Chewning, et al. 2012; Davison & Breckon 2012). Medical encounters are often viewed as being independent of wider social influences. Studies of SDM are often conceptualised as occurring only within the confines of the dyadic relationship within the consultation room (Matthias, Salyers, & Frankel 2013; Rapley 2008). The beliefs of doctors and patients concerning their expectations for information influence communication during consultations (Bugge,

Entwistle & Watt 2006; Street, et al. 2003). Beyond the consultation, decisions are shaped over time by both knowledge and information, obtained through alternative sources. The growth in internet usage (Dedding, et al. 2011), as well as knowledge obtained through informal networks, plays a role in shaping decision-making.

Patient involvement in health care decision-making is accepted as an important factor in quality health care (DoH 2016). The General Medical Council (GMC 2008) advises doctors that:

The exchange of information between doctor and patient is central to good decision-making. How much information you share with patients will vary, depending on their individual circumstances. You should tailor your approach to discussions with patients according to: their needs, wishes and priorities, their level of knowledge and understanding of their condition, prognosis and the treatment options (GMC 2008, p.11).

Whilst there is general agreement for the involvement of patients in decision-making, there is no agreement as to what involvement actually means from the patients' perspective (Chewning, et al. 2012; Moreau, et al. 2012; Joseph-Williams, Elwyn & Edwards 2014). Although concepts associated with patient involvement have been developed, they adopt a narrow view of what the key features are for patient involvement in decision-making. This narrowed focus has the potential of failing to recognise the link between other variables that play a part in decision-making such as the relationships between patient involvement and health outcomes (Entwistle, Cribb & Watt 2012; Entwistle & Watt 2006).

One of the most influential SDM models developed is that which focuses on the micro-social issues involved in patient decision-making. The SDM, developed by Charles, Gafni and Whelan (1997), focuses on the nature of the communication process between doctor and patient and the selection of a range of options potentially available for management of the patient's condition. This model combines both the doctor's knowledge, as well as integrating patient preferences, regarding options presented. The key areas of focus within the SDM model include information transfer, deliberation, and decision implementation.

2.7 Referral of older people to renal services:

Referral of patients to renal services is important to patient survival since it provides time for optimum treatment preparation (Goovaerts, Jadoul & Goffin 2005; Ellis et al. 1998). Early referral (i.e. one year prior to commencement of RRT) enables physicians to effectively treat and manage co-morbidities such as renal anaemia, renal bone disease, and cardiovascular disease (Hemmelgarn et al. 2007; Goldstein et al. 2004). Older people, defined as >65 years (WHO 2017) are known to be referred late to specialist renal services, with up to 30% of them being referred less than 90 days before dialysis initiation (Ansell et al. 2007). Patients referred late (< 3 months prior to initiation of RRT) have missed opportunities for timely pre-dialysis education (Ellis et al. 1998; Eadington 1996; Goransson & Bergrem 2001). The consequences of late referral negatively affect patient survival and well-being (Khan & Amedia 2008; Loos et al. 2003). These patients have less time to participate in treatment decision-making, which reflects their individual preferences and circumstances (Schwenger et al. 2006). Late referred patients are more likely to commence on HD as their initial treatment modality (Létourneau et al. 2003; Farrington et al. 2007), rather than PD, which is as equally an effective dialysis therapy for older patients (Teitelbaum 2006; Dimkovic & Oreopoulos 2008). Appropriate treatment modality for older people plays an important part in how older people view their quality of life (Caskey, et al. 2003). For some older patients, dialysis may be inappropriate, since it further worsens their quality of life (Badzek et al. 2000). Providing dialysis to older patients (over 65 years) is now common, with 50% of all new dialysis patients being over 65 years of age (Caskey, et al. 2016). This presents a challenge in ensuring that patients, some of whom may have impaired memory and concentration weaknesses (Lamar, Resnick & Zonderman 2003; Sims, Cassidy & Masud 2003), understand pre-dialysis information.

2.8 Older people, altered cognition and decision-making

Literature suggests that, as a group, older patients are ‘high risk’ due to their co-morbidities and their increased mortality and morbidity (Davison & Holley 2008; Grun et al. 2003). Initial access to specialised nephrology services is of major importance to older people who continue to be referred late, which has serious consequences for them. Literature highlights possible influences on treatment modalities offered to older people and the increasing

concern of variations in how much choice is offered. Older people with CKD have needs that are very different from younger patients (Abaterusso et al. 2008), including sensory impairment, hearing impairment, multiple co-morbidities, and deterioration in cognitive function (Kurella et al. 2005). The precise underlying factors leading to cognitive impairment relate to a various factors and disease processes. Cognitive impairment has been suggested to occur years prior to patients reaching end stage renal failure; the link between eGFR and cognitive function is suggested (Murray et al. 2009). What is less clear, is how cognitive impairment relates to dialysis process e.g. dialysis cerebral ischaemia, volume and fluid loss, low intra-cerebral blood pressure, blood velocity, and cerebral perfusion (Murray et al. 2009). The impact of uraemia and metabolic processes associated with renal failure or the presence of underlying neurodegenerative disease may also play an important part (Murray et al. 2009). Older people adjusting to renal therapy are required to understand treatment information, and engage in some degree of self-care if possible. In the presence of cognitive impairment, decision-making may be compromised.

The link between cognitive functioning and factors associated with CKD pathology and RRT remains unclear. Murray et al.'s (2009) study measured cognitive functioning in 374 HD patients classified as having no, mild, moderate, or severe cognitive impairment. Moderate to severe cognitive impairment is common within the prevalent HD population. In Murray et al.'s (2009) study, 37% of HD patients were classified as severely cognitively impaired. This figure is thought to be more than three times the 5-10% estimated prevalence of dementia in the United States, in non-ESRD patients older than 65 years. This affects a patient's ability to follow treatment regimens, as well as engage in informed decision-making concerning their modality of choice. Health professionals caring for older individuals must ensure that all available treatment options have been explained if they are to make effective choices (DoH 2004, 2005). To facilitate this, older people need time to understand the implications of treatment modalities. The challenge for health professionals is determining the best strategy to deliver information, which enables choices to be made. This requires consideration that a significant proportion of older patients with CKD have some degree of mild to moderate cognitive impairment, which will influence the teaching and learning process.

Nulsen et al.'s (2008) two-year study included 132 new patients with CKD stages 4 and 5 referred to pre-dialysis care. Cognitive function was assessed using the Mini-Mental State Examination (MMSE), testing five areas of cognitive functioning: orientation, registration, attention and calculation, recall, and language. This study identified that increasing age was the major predictor of low cognitive scores ($p=0.005$). Patients with good cognitive function appeared (although not statistically significant) to stay longer as pre-dialysis patients and adopt more home-based therapies such as PD. Patients with cognitive impairment had higher hospitalisation rates and were more often on hospital-based HD and had higher mortality rates. Nulsen et al. (2008) argue that decision-making may be compromised due to impaired cognition.

Hain (2008) investigated further the impact of cognitive impairment in 64 older HD patients (mean age 72.71 years) and a possible association between cognitive impairment and adherence to treatment regimen. Hain (2008) argues that a strong link exists between cognition directly linked to patient decision-making, especially understanding the importance of dietary and medication adherence. Patient stories of health challenges whilst making lifestyle change were analysed using linguistic analysis. This study identified 39.7% of patients having evidence of cognitive impairment, with 58.2% of these patients showing evidence of non-adherence. These results provide directions for future research, since the renal healthcare team spend a significant amount of time educating patients in the management of their illness. This necessitates patients being able to understand and recall essential information.

Tyrell et al. (2005) focused on whether patients reluctant to adhere to treatment exhibited psychological factors that are not routinely assessed. Unlike Nulsen et al.'s (2008) research, this study considered depressed mood, self-reported QoL and cognitive impairment in fifty-one patients aged > 70 years, receiving outpatient dialysis. Sixty percent of patients were depressed, with between 30-47% of patients exhibiting cognitive impairment. Almost half of patients who exhibited a depressed mood were also cognitively impaired. These findings further highlight the impact of dialysis and the burden of treatment on older people. The researchers suggest further studies are required to consider regular assessments of older people who may exhibit an inability to follow treatment advice.

2.9 Shared decision-making: choosing dialysis modality and survival

The differences in survival benefits between treatment modalities were reported to inform treatment decision-making. Létourneau et al. (2003) report that younger patients (50-60 years) continue to be referred earlier to nephrology services, and benefit from specialist support to improve outcomes. In this study, 42% of younger patients aged 50 – 60 years were referred earlier to a nephrologist, in comparison to 27% for older patients (>75years). Of concern was the high proportion (81%) of older patients (>75years) who commenced HD as their initial therapy, rather than PD, which was offered to only 19% of older patients. This raises questions regarding access to early education and information provision for both patients and their families' to support treatment decision-making.

Clear differences were reported in survival rates between patients aged >75 years and those in the younger 50 – 60 year group. Survival rates at 1 and 3 years for the 50 – 60 year group were 93% and 45% for those aged >75 ($p=0.0002$). Within 2 years of starting dialysis, more than 50% of patients >75 years had died; median survival rate for this group was 22 months (95% CI 5.8-39.2) (mean survival 31 months, 95% CI 24.9-37.3). In stark contrast, those patients between 50-60 years who started dialysis survived, on average, 44 months (95% CI 39.2 – 50.4, $P=0.0024$). Couchoud et al.'s (2007) study of 3,512 patients explored case-mix factors associated with choice of dialysis modality and two-year survival in patients aged 75 years or older. The findings of this study concur with Létourneau et al.'s (2003) study reporting similar high mortality rates being linked with late referral and unplanned HD treatment. Unplanned HD was associated with a mortality rate of 50% higher than those patients who commenced HD in a planned and timely manner. Little et al. (2001) report that when 'free choice' of dialysis was offered to 254 patients, 55% chose HD (HD) and 45% chose continuous ambulatory peritoneal dialysis (CAPD). Being married and having received pre-dialysis counselling were independent predictors for choosing CAPD rather than HD. The role of social support in modality selection needs further consideration, since a high proportion of older people are either cared for by extended family members or nursed within residential care homes.

Patients' willingness to switch existing treatment to one, which offered better survival due to a higher dialysis dose, was the focus of a study by Bass et al. (2004). Across all modalities, e.g. HD, CAPD and continuous cycling peritoneal dialysis (CCPD) patient's preferences for

different modalities were similar. If a treatment could extend survival by 20%, a willingness to switch treatments was expressed by 75% of patients. Not all patients valued extending survival time; 30% of patients felt they would not change modality, even where there may be a 100% increase in survival. This study suggests that, for a proportion of patients, there is an acceptance of a shorter survival on dialysis. The presence of depression appeared to be a factor in the preferences expressed by patients. Discussions should be held with patients concerning their modality and dialysis dose they prefer, since patient preferences cannot be predicted by patient characteristics.

Vachharajani and Atray (2007) reported the five-year cumulative survival of older people over the age of 70 years at one year, 60% survival, three year 37% survival, and five year 20% survival. This study reported on two groups of patients; those undergoing dialysis and those not treated or where dialysis was withdrawn. Of those patients (twenty in total) who opted not for dialysis, eighteen died within three days of the need for dialysis, with two patients being alive at four and six months. This study further supports the importance of having honest discussions with patients and families' regarding the benefits of dialysis, particularly in the presence of multiple co-morbidities.

As stated earlier, older patients have co-morbidities such as ischaemic heart disease and diabetes mellitus. The adverse effects of co-morbidities on patient survival is reported in a number of studies (Murtagh et al. 2007; Kurella et al. 2005; Winkelmayer et al. 2002; Létourneau et al. 2003). Murtagh et al. (2007) reported that one and two year survival rates for patients managed via dialysis were 84% and 76%, in contrast to 68% and 47% for conservatively managed patients. Ischaemic heart disease is the single major consideration when advising older patients about dialysis. Moreover, in a study reported by Winkelmayer et al. (2002), PD patients had a higher death rate during their first 90 days of therapy, compared to HD patients; a higher mortality rate being reported in patients with diabetes mellitus. These findings conflict with the generally held belief that older patients' survival is better with PD, which is advocated as the modality of choice for the elderly particularly assisted PD (Brown & Johansson 2011; Dimkovic & Oreppulos 2008).

Few studies have considered the relationship between age, QoL and cost of providing treatment when determining the overall benefits of offering RRT to older patients. Lamping et al.'s (2000) study was one of the few studies, which sought to challenge healthcare

rationing in dialysis as it related to older people with CKD. The view that older people fare worse and experience substantially reduced quality of life with dialysis was challenged. Lamping, et al. (2000) recruited 221 patients aged over 70 years attending four dialysis units within London, UK. Whilst the 1-year survival rate was 71%, patients aged 70–74 years had a survival rate of 80%; this declined significantly in patients older than 80 years, whose one-year survival was only 54%.

This prospective cohort study clearly demonstrated that increased mortality was associated with advancing age, particularly in the group aged 80 years and above. An interesting finding from this study suggested that whilst peripheral vascular disease is a powerful predictor of increasing mortality, there was no association between diabetes, cerebro-vascular disease, and ischemic heart disease in predicting survival. Mental health quality of life scores were similar to older people in the general population. Whilst the average annual cost of treatment per patient was £20,802, the study demonstrated that age alone should not be used as a barrier when referring for treatment. The suggestion that older people have a level of resilience that enables them to cope and adjust to dialysis was cited within this study. These findings are consistent with other studies undertaken, although further research is needed which focuses upon older people on dialysis over time, with a specific focus on quality of life measurements. This study challenged the view that dialysis treatment should be directed by the patient's age alone. The results suggest that providing dialysis to older people must focus upon the benefits that dialysis brings.

2.10 Pre-dialysis education and treatment choice

Few studies have been undertaken concerning the effect of pre-dialysis education on choice of treatment modality and the impact of disease specific knowledge in the adjustment to dialysis. The benefits of pre-dialysis education in facilitating choice of dialysis and its positive impact on patient functioning and well-being has been demonstrated in the study by Klang, Bjorvell and Clyne (1999). This study in Sweden identified those patients receiving disease specific information (expressed through follow up) identified that the educational programme helped them in choosing their preferred mode of dialysis therapy. All patients in the experimental group were satisfied that they had sufficient information to choose dialysis, in comparison to less than 80% in the control group. At commencement of dialysis, no

significant differences were apparent in sense of coherence between both groups, although at commencement of dialysis, both groups had similar levels of knowledge. Whilst three specific groups of patients were identified e.g. younger adults, middle age, and elderly, no indication is offered concerning the cut-off age for those in the elderly group. Patients expressed concerns, when choosing dialysis, of conflict between being dependant on technology whilst also having some freedom on non-dialysis days; a finding that is consistent with other studies (Reid, Seymour, & Jones 2016; Axelsson, et al. 2015). An interesting finding was that concerns over safety and confidence in managing dialysis within the home setting, were cited as reasons for choosing centre dialysis. This is not uncommon and concurs with other studies, where risk and uncertainty regarding dialysis technology in the home setting, was seen as a strong motivating reason to locate care to the hospital dialysis unit (Walker, et al. 2015, 2016; Ziolkowski & Liebman 2016).

A weakness of the study was that researchers failed to consider other sources of knowledge that the control group may have accessed. This study highlighted that pre-dialysis education positively effects patient's ability to engage in an informed way, concerning choice of dialysis modality. Patients in this study emphasised the value of involving existing dialysis patients as an important source of knowledge, as well as the need to work closely with family members; this concurs with previous findings (Brunier et al. 2002; Chanouzas, et al. 2012; Winterbottom, et al. 2012; Harvey, et al. 2016; Kelly, et al. 2016). The researchers suggested that informal support mechanisms be considered in pre-dialysis education, as well as the specific educational needs of elderly patients. Patients who have knowledge to help them understand their treatment appear to experience enhanced decision-making (Green & Boulware 2016; Thorsteinsdottir, Swetz, & Albright 2015; Curtin, Johnson & Schatell 2004), promoting a greater understanding of alternatives and anticipated consequences of following particular actions.

Work by Sarrias, Bardón and Vila (2008) suggests that CKD patients, having undergone specific pre-dialysis education, express more independence in their decisions concerning treatment. As highlighted previously, CKD presents a high degree of uncertainty for patients. Patients having insight and understanding of their illness and its management are able to maintain control and manage the uncertainty encountered (Pelletier-Hibbert & Sohi 2001; Chiou, & Chung 2012). Transition to dialysis can be significantly influenced by the quality

and type of pre-dialysis education provided to patients (Green & Boulware 2016). Pre-dialysis education has been identified by some authors as important in facilitating patient empowerment and enabling patients becoming active members within their care, supporting positive adherence to treatment regimens (Tsay & Hung 2004; Keeney & McKenna 2014).

The positive benefit of pre-dialysis education on quality of life (QoL) was the focus of Levin et al.'s (1997) study. This study identified that patients exposed to a multi-disciplinary pre-dialysis team had superior outcomes during the first month of dialysis, compared to those patients not receiving formal pre-CKD education. Furthermore, this study highlighted that the pre-dialysis education group had fewer urgent dialysis starts, and well as fewer hospitalizations for symptomatic uraemia. Physiological benefits were noted, including improved blood pressure, calcium and phosphate control, and improved management of anaemia. Pre-dialysis education has been suggested to help individuals maintain continuous employment (Ribitsch et al 2013; Hope 2013; Walker & Marshall 2014; Davis & Zuber 2013). Pre-dialysis education appears to play an important role in modality selection, with 35% of patients in Klang, Bjorvell and Clyne's (1999) study choosing CAPD to ensure continuation of employment. Those patients receiving pre-dialysis education were more than twice as likely to continue employment after starting dialysis, than patients who did not receive educational intervention.

Choice of dialysis modality is an important factor influencing a patient's mental health quality of life (Mollaoglu 2004; Tsay & Healstead 2002; Szabo et al. 1997). In Szabo et al.'s study (1997), two groups of patients were compared, those who freely chose CAPD therapy and those who started on CAPD without choice. Mental health scores were significantly lower in the no choice CAPD population, compared to the CAPD choice population. Patients who were well informed, understood their treatment options, with 92% of patients starting dialysis on their preferred modality; 86% of patients expressed satisfaction with their chosen therapy. CAPD patients who were not offered a choice of therapy demonstrated lower of QoL scores. Improved levels of social and psychological well-being were reported in patients who freely chose to start CAPD as their first treatment modality, compared to patients who felt they had no choice regarding CAPD. Results for mental health differed between both groups, with 33% of the 'choice patients' ranking themselves in the upper third on the mental health scale, in comparison to only 18% in the 'no choice' group. These results further

confirm the importance of pre-dialysis education, in facilitating patients to make an informed choice regarding treatment.

2.11 Information strategies to enhance decision-making to patients: systematic reviews

A number of systematic reviews have been undertaken, which are of relevance to this current study. Pre-dialysis patients are required to make decisions regarding their treatment, based on a wide range of education materials and information provided during the medical consultation (Harwood & Clark 2014). O'Connor et al.'s (2009) systematic review of 221 decision aids covered seventy different topics; although none specifically related to decision aids with dialysis patients. This review suggests that decision aids, when compared to reported usual care, were better at improving an individual's knowledge (weighted mean difference (WMD) 19 out of 100, 95% CI: 13 to 24) concerning available options, as well as promoting a more realistic expectation (RR 1.4, 95% CI: 1.1 to 1.9) on the possible outcomes of care. Importantly, decision aids also play an important role in minimizing decisional conflict (WMD -9.1 of 100, 95% CI: -12 to -6), as well as encouraging more active participation (RR 0.43, 95% CI: 0.3 to 0.7) in decision-making. The most significant benefit of decision aids identified was the absolute improvement in knowledge of options and outcomes (O'Connor, Stacey & Entwistle 2003). Individuals were more likely to demonstrate a realistic expectation of the benefits and harms of the options presented. Within the context of pre-dialysis care, patients are required to make choices concerning the most suitable renal replacement therapy; therefore, examining further the use of decision aids with the dialysis patient population is important. As O'Connor, Stacey and Entwistle (2003) suggest, ongoing research is required to explore the specific impact of decision aids in clinical practice.

Teaching and learning approaches need to reflect the individual needs of patients. Decision-aids, which can support consultations with patients, may help deal with some of the difficulties associated with impaired cognition, memory, and concentration. O'Connor et al. (2009, p.2) suggest that 'decision aids are interventions designed to help people make specific and deliberate choices amongst options by providing information about the options and outcomes that are relevant to a person's health status'.

Pre-dialysis education may be offered individually or on a group basis. Few recent studies have reported the benefits of educating pre-dialysis patients, either individually or within a group setting. It is therefore valuable to consider two systematic reviews of individual and group patient education in diabetes, since this potentially may highlight issues relevant to renal patients. Both diabetes and CKD require adhering to prescribed treatment regimens, administration of medication, as well as assuming some degree of self-control. Deakin et al. (2005) reviewed group-based training for self-management in type 2 diabetes. Group based education lead to reductions in glycated haemoglobin, fasting glucose levels, systolic blood pressure and improved knowledge of diabetes. Deakin et al (2005) reported measurable benefits in fostering improved patient empowerment and psychosocial self-efficacy. Deakin et al (2005) recommends identifying patients' views of group based education and involving peer educators within education sessions. These questions are relevant to renal patients, since involving existing patients already receiving dialysis within the education process is often a component of pre-dialysis education programmes.

Pre-dialysis patients need to learn large amounts of complex information. As discussed earlier in this review, information related to CKD and its treatment is important in the transition of patients to dialysis. In renal care, no rigorous studies exist focusing on improving educational medium to enhance patient understanding of information. Studies with other patient groups, most notably cancer patients, have evaluated the effectiveness of providing summaries or recordings of consultations with medical staff. Pitkethly, MacGillivray and Ryan's (2008) systematic review of randomized and non-randomized controlled trials of audiotapes or written summaries of consultations provide some interesting results. The positive effect of providing summaries of consultations was apparent, in that 60%-100% of patients over the twelve studies cited listening to, or read the summary of their consultation at least once. Interestingly, between 41-95% of family members or friends found the summaries useful. Consultation summaries helped patients to recall information; however, there was no positive effect on reducing patient anxiety.

The beneficial effect of providing cancer patients with a written summary or a recording of their consultations has been demonstrated; this could be implemented in pre-dialysis education programmes. Conducting more qualitative studies on perceived patient benefits of taped consultations and in how patients use such interventions requires further investigation.

Since pre-dialysis education, programmes focus on information to facilitate patients' decision-making, transition and adaptation to dialysis, understanding patient preferences for different educational mediums needs examination. Patients' ability to understand pre-dialysis information is dependant, largely, on the quality of information provided, as well as its relevance to the individual within the context of their illness.

2.12. Audio-taping of education encounters with pre-dialysis patients

There may be some value in the effectiveness of taped clinical consultations for patients who encounter numerous health care professionals during their pre-dialysis experience. Pitkethly, MacGillivray and Ryan's (2008) systematic review may provide an insight into the needs of patients with CKD, who often fail to remember information given to them following consultations. This has important consequences, where patients need to understand medication regimens and adhere to dietary schedules.

Research focusing on the prevention of hypoglycaemia in type 1 diabetes, by Nordfeldt et al. (2003) may be applicable to CKD patients. This randomised controlled trial considered the effectiveness of an information brochure and videotape, as opposed to traditional means of providing information i.e. verbal. Patients in this study who received the information brochure and video demonstrated higher levels of learning. The production of a high quality video, was suggested to contribute to a reduction in hypoglycaemic episodes. These findings offer something of value to nephrology, where patients are required to prevent a catalogue of medical crises arising. These may result from the ingestion of dietary potassium or consuming excess fluids, resulting in pulmonary complications, leading to possible death.

Spousal support during the pre-dialysis phase has been identified as an important factor in an individual's adjustment to dialysis and decision-making. The effect of interventions from spouses, their level of distress, and its impact upon patient recovery was the focus of Mahler and Kulik's study (2002). Spouses were randomised to receive either a video demonstrating an 'optimistic approach' when dealing with recovery from surgery, in comparison to spouses who did not view the video. Patients whose spouses viewed the optimistic video coped better than the comparison group. Information to CKD patients is also shared with spouses and this impacts on their coping ability and decision-making, and ultimately upon patients. Ayril et al.'s (2002) study highlights that patients receiving the video had a 50% reduction in anxiety

levels than patients who did not view the video. This confirms the potential usefulness in providing information via video to CKD patients who experience high levels of anxiety prior to commencing dialysis. Video information could help in minimising or contributing to a reduction in the levels of anxiety experienced by patients.

2.13 Promoting self-care through information provision

Research undertaken by Lev and Owen (1998) examined the association between self-care efficacy and a number of measurements of adjustment, including health status, mood distress, symptom distress, dialysis stress and perceived adherence to fluid restriction. Patient levels of self-care efficacy were higher at four months than at eight months whilst enrolled on dialysis. This study identified that, as the disease progresses, various factors negatively affect patient perceived self-care efficacy. Strong correlations were evident between symptom management and quality of life, and the impact of self-care efficacy on mood states. One weaknesses of the study was that a number of the data collection tools used lacked internal reliability, potentially weakening the results. The small sample size (68 patients), and the effect of time on the changing illness state of patients whilst receiving dialysis potentially influences the findings of the study.

This longitudinal study demonstrated positive correlations between self-care, self-efficacy, and mood states than other measures of adjustment used in this study. Whilst the longitudinal design of the study enabled researchers to assess the impact of key variables over time, the researchers failed to take account of biochemical markers known to influence overall successful adjustment of patients to dialysis. Biochemical markers include haematocrit, potassium levels, serum phosphorus, as well as pre-treatment weight parameters. The results are in agreement with previous findings, that those strategies which improve patient disease specific knowledge, particularly those that enhance patient choice and control over treatment decision-making, positively impacts on self-efficacy. Despite these limitations, Lev and Owen (1998) argue that nurses are influential when working with patients and families' in providing information and knowledge and are key to patient adjustment. Educational strategies, which foster self-efficacy, have positive health benefits for patients due to fostering perceptions of control and adjustment. Further development of specific strategies, which increase self-care strategies and adaptation are required.

Studies focusing on adjustment to renal replacement suggest the impact of varied factors is important (Welch & Austin 2001). The role of psychological variables is important in patient adjustment to chronic illness generally, and specific studies within the dialysis population confirm this (Curtin et al. 2002). Patient expectations of dialysis therapy and their adjustment to treatment are known to influence patient outcomes. Managing illness-induced stress has been the focus of a number of studies (Powers, Baldree & Murphy. 1982; Eichel 1986). Managing stress has a positive benefit on patient well-being (Harwood et al. 2005). Preparing for dialysis is a stressful event and studies have identified the likely stressors endured by patients and their families' during the pre-dialysis stage.

Adjusting to chronic illness remains an important area of research within nephrology. The impact of adjustment to dialysis on patient's adherence to treatment regimens continues to be a focus for studies. Non-adherence remains a significant hurdle for patients undergoing dialysis treatment and the impact on patient morbidity and mortality has been documented. Therefore, it would seem that understanding preferences for pre-dialysis education considers the impact education has on patients' disease specific knowledge, in helping them manage their illness and participate in ongoing decisions, regarding their care and management. Increasingly, early management of patients within a multi-disciplinary philosophy of care is advocated in an attempt to delay the onset of dialysis (KDIGO 2013). A concern facing patients and their families' is the uncertainty associated with treatment, as well as the potential impact of dialysis on individuals and their significant others (Mok et al. 2004).

Studies focusing on the impact of dialysis on individuals have generally been quantitative in nature and whilst they identify factors that influence transition to dialysis, they rarely capture the subjective nature of the illness experience. Harwood et al.'s (2005) qualitative study identifies the stressors experienced by patients as they approach dialysis therapy. Unlike previous studies, which ask patients to quantify their stress related to their illness using rating scales, patients in Harwood et al.'s (2005) study were encouraged to recall how they prepared themselves for dialysis to enable them to cope. This study enrolled eleven patients having dialysis for more than six months. A number of methodological weaknesses were apparent in the study, particularly relating to sample selection. Random selection of patients was adopted, although it was unclear whether the patients' were a true reflection of the overall sample group. The themes, which emerged, are consistent with previous studies on this topic.

The physical stressors (fatigue, pain, decreased mobility, feeling sick) associated with altered physiological functioning were cited as particular stressors during the pre-dialysis phase. Additional themes that emerged included psychosocial stressors (burden to the family, depression), as well as logistical stressors (diet restrictions, long clinic waiting times, inability to have dialysis treatment of choice, uncertainty and not knowing). Of particular interest was the importance expressed by patients on having family members and spouses directly involved in pre-dialysis education and decision-making.

Consistent with previous studies, patients in Harwood et al.'s (2005) study valued the opportunity to visit the dialysis unit to view the facilities, which helped reduce uncertainty. An overriding theme emerging from this study was that of seeking the views of patients regarding their pre-dialysis care. Harwood et al.'s (2005) findings are consistent with earlier work by Devin et al. (2003), who explored the specific coping mechanisms of CKD patients identifying avoidance of reality being used frequently. One weakness of Harwood et al.'s (2005) study concerns recall bias, since the majority of respondents were asked to recall their experiences as they approached dialysis; the effects of changes due to time may have influenced the overall quality of the results. This study suggests the importance of providing written educational materials for patients to take home, as well as the need for formal educational classes for patients and families'. Notable in Harwood et al.'s (2005) study was that patients valued staff 'being up front' (p.301), when providing information on treatment regimens and waiting times. Harwood et al.'s (2005) study further reinforces the value of using patient experiences of preparing for dialysis in helping to design pre-dialysis programmes.

Previous research has examined how patient self-management behaviour and knowledge about their condition and treatment may influence their functioning and well-being. In North America, Curtin et al.'s (2004) multi-centre study, across fifty-two dialysis centres, examined the role of knowledge in facilitating self-care behaviours. Whilst a relatively large sample was included (372 patients), no information is provided on whether the sample size was adequate to test the power of the study. Using well-validated disease specific measuring tools, the researchers developed a self-management instrument based on their earlier work. They identified sixty self-management items, which were tested with a convenience sample of patients not involved in the main study. No internal reliability of the items is discussed

although amendments were made to the measuring tools following patient feedback. This study suggests that those patients most likely to engage in cooperative and participatory self-care strategies were associated with positive physical functioning. The results suggest that enabling patients to maintain optimum physical functioning through improved self-care knowledge potentially has a positive effect on patient overall success with self-care.

Dialysis presents challenges to patients in understanding complex treatment regimens and life within the confines of prescribed medical advice. Adherence to dietary and fluid restrictions and taking prescribed medications alleviates bone disease, anaemia, and hypertension (Mok 2001). Providing treatment specific knowledge and helping patients develop skills to promote independence is important. The majority of studies focusing on pre-dialysis education concern transition to established renal failure. Pre-dialysis education programmes frequently include information on the impact of CKD on the patient and significant others as well as available treatment options (Klang et al. 1998; Klang et al. 1999). Establishing the impact of pre-dialysis education on patient morbidity and mortality has gained increasing interest (Goldstein et al. 2004).

2.14 Dialysis for older people - in whose best interest

Nephrology nurses are in a unique position, in that they spend most contact time with renal patients in their day-to-day practice (Bennett 2011) and through this relationship come to understand the individual challenges faced by patients' dependent upon dialysis technology. Badzek et al. (2000) report that, in their study, 15% of nephrology nurses believed dialysis should not be offered to elderly patients. When questioned further, 80% of nurses expressed concerns that dialysis had been started in some elderly patients. Concerns in this American study (Badzek et al. 2000) related to patients' quality of life (QoL), inadequate patient and family knowledge, and lack of influence of patients on the decision-making process. The major recurring theme of the negative impact of dialysis on the patient's quality of life was reported. This study suggests that those health professionals having the greatest involvement with patients, i.e. nurses, had opposing views of the merits of offering RRT to older patients. Where patients are offered free choice of modality, accompanied by educational counselling, there is a higher likelihood that they choose a self-care modality. The influence of physician preferences in directing patient's modality choice is cited in a study by Little et al. (2001).

The effect of healthcare staff influencing patients decisions is cited particularly where patients seek guidance on which mode of therapy is best for them. Little et al. (2001) suggest that the unconscious role of healthcare staff in directing patient choice may have been a factor in their study. This study suggests that where patients have contraindications for a particular therapy, then it is acceptable practice for physicians to direct treatment decisions. What is less known is how such decisions are communicated to patients and whether patients understand the rationale for why certain treatment modalities are not offered.

2.14.1 Family and significant others

The extent of patient involvement in the decision-making process and choice of dialysis modality was described through the views of nephrologists (Mendelssohn et al. 2001; Kaufman et al. 2006) and through the perspectives of nephrology nurses (Badzek et al. 2000). Understanding the views of relatives concerning modality choice was reported as important (Lee et al. 2008). Patient involvement in decision-making is central to effective delivery of optimum treatment and management. Lee et al. (2008) reported understanding why and how patients choose between various modalities in a Danish study. This study suggested flexibility, independence, and feelings of security as key factors in choosing treatment modality. Family members voiced the importance of being involved in the decision-making process. Relatives in this study expressed the need to meet with other family members and patients prior to making decisions. The total exclusion of patient involvement in the decision to commence HD was reported, with all HD patients not given any choice. Maintaining personal integrity was an important theme to patient decision-making, in Tweed and Ceaser's (2005) study exploring pre-dialysis decision-making.

The relationship patients and families' develop with the renal multi-disciplinary team is important in the patient's treatment journey. Within this relationship, discussions with patients and family concerning treatment preferences need supporting. Loos et al. (2003) and Tyrrell et al. (2005) suggest that, in some patients, active dialysis therapy is not appropriate due to their severe co-morbidities, thus, opportunities are needed to explore this with patients and families'. Older people's preferences for involvement in decision-making needs exploring as part of initial assessments and ongoing care.

2.14.2 Medical staff as key gate-keepers in treatment and management

Mendelssohn et al.'s (2001) study of 204 nephrologists' in America concerning their attitudes towards dialysis modality highlighted selection based on patient preference. Factors influencing modality decisions, in order of importance, were those of patient preference, quality of life, morbidity and mortality; least important were physician reimbursement. The impact of possible conscious or subconscious provider bias is cited as a weakness in the study, where physician decisions were made after considering medical and social factors, along with patient preferences. In principle, patient preferences and their own values were seen to be an important factor in shaping physician practices. Mendelssohn et al. (2001) suggests an element of caution, in that 'opinions expressed in a survey may not represent actual respondent practice' (p.26), an inherent limitation in survey research.

This study highlighted that the high number of older patients (> 60 years) receiving haemodialysis, was not age related but instead due to their increasing level of comorbidity. Physician reimbursement did not influence modalities offered to patients. This conflicts with Mehrotra et al.'s (2005) findings, that due to a lack of physician reimbursement when providing pre-dialysis care, this meant limited treatment options were presented to patients. The limited 'uptake' of home therapies, such as PD, was suggested to be the direct result of physicians failing to discuss all available treatment options with patients.

Kaufman et al.'s. (2006) ethnographic study identified how physicians, patients, and families' enter into and understand life extending medical procedures. Staff working in dialysis clinics framed the need to start dialysis in terms of '*when you need to start dialysis*' and not '*if*'. A process of 'normalisation' of the inevitable need to commence dialysis emerged, with minimal choice offered to patients. What choice was offered related to decisions regarding the position of dialysis access (arterio-venous fistulae). Physicians appealed to family members for their help in getting patients to accept the need for dialysis. Emerging from Kaufman et al.'s (2006) study was the importance of 'negotiation' and 'bargaining' with patients' to commence dialysis. Only two patients out of forty-three were involved in commencing dialysis as a proactive decision; most patients made no decision and stated that dialysis 'just happened'. Wuerth et al.'s (2002) study considered specific factors influencing modality choice; 83% of patients reported the doctor as being the most important factor in their treatment choice. These findings were also consistent with a large study of more than

two thousand patients with a variety of chronic illness, in which 69% of patients preferred leaving the decision to doctors (Arora 2000).

This initial review of literature considers the challenges in supporting treatment decision-making in older renal patients. Evidence indicates that health professionals, particularly medical staff, assume a dominant role in determining and mediating the process of decision-making related to treatment modalities offered to older people. From the limited evidence available, questions are posed, in terms of in who's 'best interests' are decisions concerning RRT being made. The influence of medical staff as 'gate keepers' to treatment along with issues of power and control during the decision-making process is alluded to in those studies addressed. Of interest, is how family members influence decision-making and the way in which medical staff use the family to encourage older patients to accept dialysis. The notion of 'time' appears to be an important mediating factor in the process of treatment decision-making. The timing of referral for pre-dialysis education from primary care physicians, along with the physical well-being of patients, appears to be an important factor in how older people access (or not) pre-dialysis education. Patients referred late are greatly disadvantaged due to the limited time they have to make effective treatment decisions. Educational approaches, which improve knowledge of available treatments, and the impact of altered cognition requires further inquiry when examining treatment decision-making.

This review has identified a paucity of studies, which focus on how older people with CKD make treatment decisions; little is known from an insider perspective from older people themselves. Evidence suggests that there are inconsistencies in the reported treatment decision-making experiences of older people. The amount of involvement older people want during treatment decision-making and how preferences and values for involvement during the doctor/patient encounter needs consideration (Arora, Ayanian & Guadagnoli 2005). Central to understanding this is considering the trajectory of CKD from its early stage management through to the final phase of planning for RRT. This trajectory requires older people to communicate with the health care team and make sense of the treatment and management processes, which govern their well-being. Understanding treatment decision-making of older people with CKD is important, since it identifies an area for research currently lacking within nephrology.

2.15 Conclusion

This chapter has discussed the contextual drivers underpinning this study, focusing upon an increasing numbers of older people with CKD. UK policy directives influencing patient involvement in treatment decision-making has been discussed. The physiological and psychological impact of CKD upon individuals has been outlined. The importance of early referral for pre-dialysis care is discussed, in the context of its positive impact on patient outcomes. As older people transition from primary care to secondary care, the value of decisional support strategies is outlined. This leads into the following chapter, which outlines the rationale for adopting grounded theory methodology, its origins, and debates surrounding grounded theory. The design of the study is outlined, focusing on theoretical sampling, data collection and analysis, and the development of the emergent theory in the study. The purpose of the study is to develop a theory that accounts for the social processes involved when older people, with CKD stages 4 and 5, consider treatment.

CHAPTER 3

METHODOLOGY

3.1 Introduction

The aim of this study is to develop a theory that accounts for the social processes involved when older people, with CKD stages 4 and 5, consider treatment. The first part of this chapter discusses the differences between the context of discovery and verification in the development of theory. The chapter then focuses upon the rationale for choosing a qualitative approach for the study, namely, grounded theory. Theoretical sensitivity is discussed in relation to researcher pre-conceptions and their influence upon the ontological, epistemological, and philosophical foundations of the study. The final part of this chapter outlines the development of grounded theory in the field of nephrology, focusing on how grounded theory was applied within this study. The specific components of this grounded theory study, relating to theoretical sampling, data collection (using interviews and non-participant observation), coding, and theory development, are then discussed.

3.2. Philosophical background

The philosophical background of the study reflects the differences between the contexts of discovery of theory against the context of justification of developed theory. The purpose of the study was the generation of a theory that would explain how older people with CKD resolved their concerns; therefore, discovery would ensure that:

...rather than forcing a few pet ideas on to their data, researchers should discover order and indeed develop their ideas from the data (Gibson & Hartman 2014, p. 11)

Since the purpose of the study was the discovery and generation of theory, as it relates to the concerns of older people whilst making treatment decisions, a research approach was needed that supports this. Much of the existing research on understanding decision-making has adopted a quantitative approach. However, since this study focused on understanding how older people resolved their main concerns, a quantitative approach would not meet this aim.

In comparison, qualitative research focuses on exploration and in-depth understanding of experiences and socially produced phenomena (Creswell 2014).

3.3 Choosing a suitable research methodology

Qualitative research is concerned with understanding experiences, opinions, and attitudes, as well as social interactions and the study of phenomena within study participants' natural settings (Denzin & Lincoln 2011). Qualitative inquiry enables multiple interpretations of data; there is engagement of the situation in the field by providing a holistic perspective of the context. Qualitative research offers a range of possible strategies of inquiry, although there is little consensus about how to classify these. Creswell (2014) suggests five main approaches including: narrative research, phenomenology, ethnography, case study, and grounded theory. Phenomenology was considered for this study and whilst it might provide an understanding of participants' experiences and illuminate the phenomenon (Holloway & Wheeler 2002) of decision-making, it would be less effective in explaining the behaviours older people engage in whilst resolving their main concerns, which was the aim of this study. For this reason, phenomenology was not deemed appropriate for this study. Ethnography focuses on 'cultural rules, norms and routines' (Holloway & Wheeler 2002, p.135). Ethnography produces an emic view of an individual's actions and behaviours within their cultural setting (Denzin & Lincoln 2011). Ethnographic research attempts to develop an understanding of the taken-for-granted meanings held by individuals within the culture researched (Hammersley & Atkinson 1983, p.8). Since the purpose of the study was not focused solely upon developing a cultural understanding, but a wider view of personal and social processes influencing treatment decision-making, ethnography was not pursued. Few studies have been undertaken that consider the social processes shaping decision-making in CKD (Kataoka-Yahiro, et al. 2011; Morton, et al. 2010b; Harwood & Clark 2012b). It was important that the research approach in this study ensured openness to the emergence of all possible factors influencing decision-making. Following a review of qualitative forms of inquiry, the decision was taken to employ a grounded theory methodology (Glaser & Strauss 1967).

As a research strategy, grounded theory is ideal for exploring the nature of emergent entities related to decision-making in chronic illness. Grounded theory facilitates researchers'

familiarity with the issues of investigation through extensive and iterative data collection and analysis. It enables the identification of patterns in data and their conceptualisation. Substantive theory is developed through the central grounded theory procedures of constant comparative analysis and theoretical sampling.

My interest in exploring behaviours and processes, which would account for how older people manage decision-making in CKD, led me to use grounded theory. I wanted to find out what really was going on within the organisational context of the hospital and how they influenced older adults' decision-making. During the early days of reading, *Discovery of Grounded Theory* (Glaser & Strauss 1967), I was struck by the creativity the methodology could provide, especially its ability to tap into the researcher's creativity, as well as the application of its systematic procedures.

3.4 The development of the grounded theory method (GTM) – an overview

Grounded theory originated in the mid-1960's with the work, in medical sociology, of Barney Glaser and Anselm Strauss, focusing upon the experiences of dying in USA hospitals (Glaser & Strauss 1965, 1971, 1974). This research led to the publication, *Awareness of Dying*, and the later publication, *The Discovery of Grounded Theory*. Glaser and Strauss (1967) highlight the motivation for the publication of *Discovery*:

We would all agree that in social research generating theory goes hand in hand with verifying it; but many sociologists have been diverted from this truism in their zeal to test either existing theories or a theory that they have barely started to generate (p.2)

Discovery is acknowledged as the founding work on grounded theory; Glaser (1998) indicates that he was developing the methodology as part of his doctoral work at Columbia University and that he wrote the initial draft of *Discovery*, further developing it with help from Strauss. Glaser (1998) reflects on the publication of *Discovery*, stating:

The licence to legitimately conceptualize as opposed to using either grand theory concepts or being obliged to find the concept in the literature beforehand was launched (p.32).

Grounded theory developed as a response to addressing the gap in sociology during the 1950s and 1960s (Gibson & Hartman 2014). It was during this time that grand theories were being

developed within sociology, as an attempt to explain everything happening in society from a theoretical perspective, with very little empirical testing (Gibson & Hartman 2014). In contrast to this, the originators of grounded theory, Glaser & Strauss (1967), defined grounded theory method as ‘discovery of theory from data- systematically obtained and analysed in social research’ (p.1).

Grounded theory revolutionised research practice, in that it directly challenged the dominant hypothetico-deductive approach to theory generation from qualitative data. Charmaz (2003, 2014) outlines the major impact Glaser and Strauss had on the advancement of qualitative research from an approach viewed as a precursor to quantitative studies. Glaser and Strauss challenged the gap between theory and research as well as challenging the view of the importance of data collection and analysis occurring separately. Whilst grounded theory originally emerged from the discipline of sociology, its use in current day research practice spans many disciplines, including social work, nursing, medicine, allied health, education, management, and business (Holton & Walsh 2017). GTM, in all its various forms, has a number of essential key features, as shown in Table 2.

Table 2. Key features of GTM

1. Aim is to discover or generate a theory.
2. Researchers are required to set aside pre-conceived theoretical ideas – as a result, substantive theory emerges.
3. Developing theory focuses upon the nature of interaction between individuals and phenomenon under study.
4. Theory establishes a credible relationship between concepts and sets of concepts.
5. Theory emerges from data obtained from interviews, observations, and documents.
6. As soon as data is available, analysis commences in a highly systematic way
7. Data analysis focuses on the development of categories and their inter-relationship and connections.
8. Ongoing sampling of data is driven by concepts emerging during analysis.
9. Constant comparison of data with additional data enables further development of concepts.
10. Data collection stops when there is no further development of conceptualisations.
11. Data analysis commences with open coding (focus on developing categories and their properties and dimensions) to selective coding (clustering of categories) and theoretical coding.
12. Developed theory can be reported in a narrative framework or as a set of propositions.

Adapted from Creswell (1998), Dey (1999), and Urquhart (2013a).

3.5 Philosophical roots of grounded theory - symbolic interactionism

In any discussion of grounded theory, the perspective of symbolic interactionism (SI) needs exploring. It is not unusual, for some writers to cite SI as the underpinning paradigm for grounded theory (Bryant 2009; Stern 2007). SI as an approach is rooted in the Chicago School of pragmatism, which contends that, through social interaction, an individual develops a view of self and context (Blumer 1969; Mead 1934). The founding father of pragmatism was George Herbert Mead (1863-1931), a philosophy professor at the University of Chicago. Pragmatism had a significant impact upon how grounded theory developed. Pragmatists believe that:

...we cannot know anything beyond our experience...experiences (is) ...a world of interrelated phenomena that we take for granted in everyday life (Hammersley 1989, p.45)

The above beliefs are evident in two key principles of pragmatism, namely views related to anti-foundationalism and fallibilism. Anti-foundationalism is a school of thought suggesting that objective knowledge cannot be fully known; fallibilism suggests that we can never truly understand the world due to our limited knowledge of it (Schwandt 2015). The role of symbolic language and social interaction in shaping how individuals view themselves was of major interest to Mead. This is reflected in his subsequent discussions of the differences between what he refers to as the “I”, “self”, and “me” (Benzies & Allen 2001). The “I” represent the inner voice of the individual, whilst “me” is constructed in how others respond to the individual. The “self” is developed because of the individual’s interaction with others (Benzies & Allen 2001). Symbolic interactionist research seeks to understand the processes through which an individual arrives at meanings within the context of their social lives (Bryant & Charmaz 2007). According to Stern (2007), SI provides a valuable foundation for grounded theory, but importantly it does not have to be the only basis. Within the context of this current study, how meanings are constructed by older people as they consider treatment decisions will emerge from the study data, reflecting the central tenets of symbolic interactionism.

3.6 Grounded theory method debates

Since its emergence in the 1960s, numerous researchers have aligned grounded theory with particular epistemological and ontological assumptions, resulting in a remodelling of the original methodology. The on-going development and remodelling of the methodology is viewed by some as a natural consequence of the application and evolving use of any methodology (Charmaz 2000). The natural evolution and development of methodologies is acceptable, although researchers should question the ongoing evolution of methodologies since the methodology may bear little resemblance to the original version. Bryant (2009) argues this concern:

...how far can one go with altering or revising GTM [grounded theory method] basic tenets before one ceases to be doing GTM' (para.18).

However, this view is not shared by Glaser (2003), who sees these changes as an erosion of the original methodology. Charmaz (2000) suggests that the original publication of *Discovery* (Glaser & Strauss 1967) was viewed as groundbreaking at the time, for a number of reasons, including how it questioned:

...(the) arbitrary division between theory and research, views of qualitative research as preliminary precursor to more 'rigorous' quantitative methods, claims that the quest for rigor made qualitative research illegitimate, beliefs that qualitative methods are impressionistic and unsystematic, separation of data collection and analysis and assumptions that qualitative research could produce only descriptive case studies rather than theory development (pp.510-511)

The tensions in the relationship between Glaser and Strauss corresponded with the publication of the *Basics of Qualitative Research* (Strauss & Corbin 1990). Glaser's response to this publication was an attack on the Strauss and Corbin text with his publication of *Basics of Grounded Theory: Emergence vs. Forcing* (Glaser 1992). Glaser sought to highlight major differences between the original version of grounded theory and the Strauss and Corbin text.

On-going publications from Glaser have sought to clarify the purpose, principles, and procedures that are the foundation of Glaserian grounded theory (Glaser 2001, 2003). One challenge researchers encounter when planning to use grounded theory is finding their way through numerous methodological debates and arrive at an informed decision as to which 'version' of grounded theory should be used. Birks and Mills (2011), recognise this challenge for those contemplating using grounded theory:

Trying to understand the general principles of grounded theory in context of the debate and discussion that is so much a part of this research tradition can be incredibly difficult. Where to start? What to read? Who to follow and why? (p.1)

Confusion over grounded theory is exacerbated by research textbooks that describe grounded theory only as a qualitative methodology. A closer examination of the Strauss and Corbin text demonstrates a privileged position of qualitative data; this is in contrast to the original grounded theory text by Glaser and Strauss (1967), which offered grounded theory as a general method that could use any kind of data, both qualitative and quantitative.

A key difference between Glaser and Strauss (and later between Glaser & Strauss & Corbin) relates to the interpretation of grounded theory (McCallin 2003). Strauss and Corbin offered explicit frameworks and procedures (Strauss & Corbin 1990, 1998,), whilst Glaser is less

explicit; advocating a creative approach and the importance of trusting in ‘emergence’. It is interesting to consider the nature of the disagreements between Glaser and Strauss in the context of their intellectual backgrounds. Glaser’s background in quantitative methods and theory generation from Columbia University (Glaser 1998) was in contrast to Strauss who trained in the Chicago school of qualitative methodology. The more practical and procedural nature of grounded theory, as advocated by Strauss, attracted more popularity initially, particularly within the fields of education and healthcare. Despite this earlier popularity of the Straussian approach, it has received increasing criticism due to the additional process of axial coding, which is viewed as formulaic and potentially forces the data (Bryant & Charmaz 2007).

Whilst there remain several points of debate between Glaser and Strauss, including sequencing of procedures and the role of verification, Kendall (1999) suggests that the crux of the debate relates to the issue of axial coding. Open coding for all possibilities in the data are similar in both the Glaser and Strauss approaches but this is where the similarity ends (Glaser 1992). In classic grounded theory, theory development follows a progressive process around the development of a core category, which has ‘emerged’ directly from the data. This is fundamentally different from the approach advocated by Strauss and Corbin, in which open coding is preceded by axial coding and the application of a coding paradigm that forces the researcher to identify conditions, context, action/interactional strategies, intervening conditions, and consequences (Strauss & Corbin 1998). Rather than favouring the inductive emergence of theoretical concepts, there is a testing of concepts and a fitting in of concepts to the paradigm, which counters the potential emergence of multiple possibilities. The key differences between Glaserian and Straussian versions of grounded theory are summarised below (see Table 3).

**Table 3 Additional differences between Glaser and Strauss
(Adapted from Jones & Alony, 2011)**

Glaserian	Straussian
<ul style="list-style-type: none"> Beginning with general wonderment (an empty mind) 	<ul style="list-style-type: none"> Having a general idea of where to begin
<ul style="list-style-type: none"> Emerging theory, with neutral questions 	<ul style="list-style-type: none"> Forcing the theory, with structured questions
<ul style="list-style-type: none"> Development of a conceptual theory 	<ul style="list-style-type: none"> Conceptual description (description of situations)
<ul style="list-style-type: none"> Theoretical sensitivity (the ability to perceive variables and relationships) comes from immersion in the data 	<ul style="list-style-type: none"> Theoretical sensitivity comes from methods and Tools
<ul style="list-style-type: none"> The theory is grounded in the data 	<ul style="list-style-type: none"> The theory is interpreted by an observer
<ul style="list-style-type: none"> The credibility of the theory, or verification, is derived from its grounding in the data 	<ul style="list-style-type: none"> The credibility of the theory comes from the rigour of the method
<ul style="list-style-type: none"> A basic social process should be identified 	<ul style="list-style-type: none"> Basic social processes need not be identified
<ul style="list-style-type: none"> The researcher is passive, exhibiting disciplined restraint 	<ul style="list-style-type: none"> The researcher is active
<ul style="list-style-type: none"> Data reveals the theory 	<ul style="list-style-type: none"> Data is structured to reveal the theory
<ul style="list-style-type: none"> Coding is less rigorous, a constant comparison of incident to incident, with neutral questions and categories and properties evolving. Take care not to 'over-conceptualise', identify key points 	<ul style="list-style-type: none"> Coding is more rigorous and defined by technique. The nature of making comparisons varies with the coding technique. Labels are carefully crafted at the time. Codes are derived from 'micro-analysis which consists of analysis data word-by-word'
<ul style="list-style-type: none"> Two coding phases or types, simple (fracture the data then conceptually group it) and substantive (open or selective, to produce categories and properties) 	<ul style="list-style-type: none"> Three types of coding, open (identifying, naming, categorising and describing phenomena), axial (the process of relating codes to each other), and selective (choosing a core category and relating other categories to that)
<ul style="list-style-type: none"> Regarded by some as the only 'true' GTM 	<ul style="list-style-type: none"> Regarded by some as a form of qualitative data analysis (QDA)

3.7 Constructivism

Since the work of Glaser and Strauss (1967), and Strauss and Corbin (1998), another application of grounded theory has emerged, most obviously in the work of Charmaz, with a social constructivist and experiential emphasis. Charmaz's (2000) key paper, titled *objectivist versus constructivist grounded theory* provides the foundation and thinking for her constructivist approach. The intension of constructivist approach according to Charmaz was to:

“..reclaim these tools from their positivist underpinnings to form a revised, more open ended practice of grounded theory that stresses its emergent, constructivist elements” (p.510)

Charmaz’s grounded theory is emergent and facilitates ongoing exploration within the substantive area. Constructivist grounded theory methods are offered as *a flexible set of principles and practices not....prescriptions or packages* (p.9). The procedures underpinning the constructivist approach are flexible and not prescriptive and help facilitate the emergence of data. Charmaz argues that it is possible to adopt the approach of Glaser and Strauss (1967) since the procedures offered are neutral. According to Charmaz (2006):

“We may think our codes capture the empirical reality. Yet it is our view: we choose the words that constitute our codes” (p.47).

An alternative view of reality is offered via constructivist grounded theory, based on the co-construction of reality. Charmaz (2003) discusses the co-construction of reality as an interactive process occurring between the viewer and those viewed. Constructivist research emphasizes the importance of participant stories and emphasizes understanding their lived experience (Charmaz 2003). Gibson and Hartman (2014) indicate that:

“working within an individualistic methodology, social phenomena can be reduced to intentional states of people. Such intentional states are meaningful in the sense that within them people attribute meanings to behaviour, organisations and so on” (p.45)

Bryant and Charmaz (2014) argue that emergence of grounded theory arises from the researcher and the questions asked and the means used to analyse the data. From a philosophical perspective, Charmaz argues the importance of the researcher’s perspective as being central when collecting data. The perspective of the researcher influences the developing theory, as well as the participant accounts shaping the emergence of the theory. Charmaz (2006) suggests that:

“neither data nor theories are discovered . Rather, we are part of the world we study and the data we collect. We construct our theories from our past and present involvements and interactions with people, perspectives and research practices” (p.10)

The assumption underpinning constructivist grounded theory is that there exist multiple social realities (Charmaz 2003; Charmaz 2006). Constructivist grounded theory is much

more diffuse and does not focus on a core category. This enables multiple realities and truths to be captured from informants rather than seeking out the participants' main concern. When viewed under the constructivist lens both the classical version of grounded theory promoted by Glaser and the versions put forth by Strauss, and Strauss and Corbin, can be criticized for retaining a positivist orientation towards qualitative research (Bryant 2009). As an alternative, the constructivist grounded theory:

"... celebrates first-hand knowledge of empirical worlds, takes a middle ground between postmodernism and positivism, and offers accessible methods for taking qualitative research into the 21st century. Constructivism assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward an interpretive understanding of subjects' meanings" (Charmaz 2003, p.250).

3.8 Choosing grounded theory methodology

Whilst different variations of grounded theory exist, each having their own assumptions and characteristics (see Table 3), Glaser's (1967) grounded theory was employed in the current study. Glaser's grounded theory's emphasis on emergence and discovery, with data directing the researcher, was something I found exciting. The process of discovery is foundational to the classic grounded theory developed by Glaser and Strauss (1967). The theory that was developed needed to reflect the perspectives of participants' in the field and explain how participants resolved their main concerns. Grounded theory developed during a time within sociology where verification of theory was favoured over theory generation; this led to the publication of the original version of grounded theory, as outlined in '*The Discovery of Grounded Theory*' (Glaser & Strauss 1967). Grounded theory developed during a time dominated by empiricism and positivistic research, which occupied a dominant position within the field of sociology. Since the original development of grounded theory, the methodology has evolved and undergone transformation in a number of directions, leading to what is referred to as 'second generation grounded theory'. Examples include Strauss and Corbin (1990), Charmaz (2000, 2006). Each approach has its own stance towards grounded theory; Strauss and Corbin (1990) focus on social phenomena; Charmaz (2000) focuses on the conceptualisation of meaning; whilst Glaser's emphasis is on core categories and social processes. Gibson and Hartman (2014) suggest that adaptations to the original grounded theory methodology have resulted in:

...threatening key aspects of the methodology ...and masked very different understandings about how to do grounded theory (p. 3).

Classic grounded theory is often perceived incorrectly as epistemologically and ontologically neutral. This assumption is supported by the fact that Glaser sees classical grounded theory as a general method in which any type of data can be used that is not aligned to any one particular perspective. However, this stance is not without its critics in social research, where researchers are required to be explicit concerning their philosophical orientations. The fact that grounded theory does not advocate any particular ontological or epistemological stance reflects grounded theory's flexibility to accommodate a wide range of theoretical perspectives. Published grounded theory studies adopt various approaches, thereby reflecting a different research focus and a diverse context of the research and the emerging data. The neutral stance advocated by Glaser concerning classic grounded theory's ontology and epistemology perpetuates a view that classic grounded theory is noncommittal and propagates an, 'epistemological fairy tale' (Bryant 2009, para.13). Holton (2007) outlines the stance advocated by Glaser:

this is not to say that classic grounded theory is free of any theoretical lens but rather that it should not be confined to any one lens; that as a general methodology, classic grounded theory can adopt any epistemological perspective appropriate to the data and the ontological stance of the researcher (p.269).

Gibson and Hartman (2014) undertook a re-discovery of grounded theory through examining the original grounded theory text in an attempt to delineate the core features of the methodology. With multiple variations of grounded theory, embracing methodological pluralism is important whilst protecting the essential core 'identity of the methodology' (Gibson & Hartman 2014, p.4).

Decisions as to which form of grounded theory to use, whether this be classical (Glaserian), Straussian, or Constructivist were driven by a number of factors. Firstly, as a researcher, it was important to explore my personal ontological, epistemological, and methodological assumptions I held. This was an important first step, although not without its difficulties, interrogating personal ontological and epistemological assumptions was, cognitively, a highly charged exercise. For example, I reflected on my stance towards knowledge creation and recognised that, on the one hand, I valued a realist ontology and positivist epistemology; empirical facts are indisputable and separate from experience. This was true of my beliefs

related to science, which had underpinned my clinical practice in renal nursing; however, at the same time, I value an interpretivist epistemology within a relativist ontological stance. How I positioned myself in relation to the study was a source of confusion. Questions were asked, such as could I align both at the same time? I realised this was my first problem, as I was attempting to confine my ontological and epistemological values into either a positivistic or interpretivist position.

My personal experiences have taught me the value of experience in the creation of new knowledge. Undertaking self-interrogation helped to make explicit what my (as a researcher) personal assumptions were, what theoretical perspectives I held and, importantly, how these shaped my thoughts and my approach to the substantive area of enquiry. In the early stages of the study, I undertook a period of reflective writing focused upon making explicit my personal assumptions related to a specific number of questions. Researchers must ask these questions when making explicit their personal philosophical positions, as identified by Birks and Mills (2011, 2015):

How do we define our self? What is the nature of reality? What can be the relationship between the researcher and participant and how do we know the world, or gain knowledge of it? (p.9)

My written reflective notes were set aside and later re-read and added to where needed. Exploring my assumptions enabled me to reflect upon my approach to the study and, importantly, my theoretical sensitivity to the substantive field. It was evident that my philosophical orientation had an influence on the methodological decisions taken. For example, in developing a theory, I decided that grounded theory had its own in-built checking mechanisms, through the constant comparative process. An accepted principle in some qualitative research designs is the need to go back to the participants and engage in member checking; I discounted this, believing that the constant comparative method would achieve this. Secondly, I had embraced what Gibson and Hartman (2014) refer to as methodological pluralism, which suggests that it is possible to adopt different philosophical stances in a grounded theory. This took time for me to realise initially, due to the conflicting grounded theory textbooks, suggesting that grounded theory must have a defined philosophical stance from the outset. For me, it was quite simple - I could adopt a more flexible stance to the study's underpinning philosophical basis. Gibson and Hartman (2014, p.17) address this

issue further in their discussion of the value of philosophy to grounded theory. There is a view that a heavy focus on philosophy may affect the researcher's ability to embark on the study, a type of philosophical digging (Gibson & Hartman, 2014), which,

...is a waste of time and effort. You should just get on with your research, and when you do it you will see that the most amazing theories will emerge. If bogged down in philosophical discussions, you will be less productive, less sensitive to what goes on in the social setting and no theory will emerge. Just do it is the mantra to which the researcher should adhere (Gibson & Hartman 2014, p.17)

3.9 Prior interests, preconceptions and reflexivity

This section outlines my personal interests and motivations brought to the study. Pre-existing concepts and ideas reflect the pre-conceptions I held as a researcher and the role they played in the study. Gibson and Hartman (2014) suggest that preconceptions are:

...especially problematic because they reflect a kind of selective blindness during the research process. What distinguishes preconceptions and prior interest is that we are often not aware of our preconceptions. Preconceptions can be much more difficult to detect and as a consequence, special care needs to be taken in order to handle them effectively (Gibson & Hartman 2014, p.111)

As a clinical nurse, I was aware that older people represented an increasing population within nephrology. I considered my previous work as a clinical nurse in pre-dialysis education and how older people just accepted treatments offered. I became aware of the political drivers within UK healthcare, focusing on the patient choice agenda and how it influenced debates within nephrology concerning the position of older people as recipients of renal care. The motivation to undertake the current study was driven by the need to understand how the process of decision-making could work in favour of older people. UK policy drivers, such as the National Service Frameworks for Older People (DoH 2001) and The National Frameworks for Renal Services (DoH 2004, 2005) emphasised the importance of choices for older people and their preparation for renal replacement therapy. These key drivers coincided with my interest in undertaking the current PhD study and legitimised the importance of the study within the field of renal nursing.

My personal motivations were driven also by the fact that my mother, as an older person with a life limiting illness, faced making treatment decisions regarding her care, albeit within a

different context e.g. Oncology. I became intrigued how older people established relationships with healthcare team members during their care journey. I noticed the approaches between numerous health professionals whom my mother encountered, and how much involvement (or not) in her care they offered her during clinical consultations as well as her views on this. Whilst attending her consultations with the Oncologist, it was her own perspective on her involvement in the decision-making process, which intrigued me.

At the beginning of the study, I had not considered my own pre-conceptions, which I held. It was during memo writing that I realised I had pre-conceived older people as being more passive recipients of their care than they actually were. I realised I had been immersed in how important patient empowerment was as a philosophy underpinning renal care. I held the view that *all* older people *should be empowered* since it was ethically and morally their right. This view was later challenged when it became evident that empowerment for some older people was difficult. It seemed that it was easier for older people to hand themselves over to health professionals who would make decisions for them, thereby removing the individual burden of decision-making. Striving to support patient empowerment, promoting choice and decision-making had been ingrained in me from my early days in renal care. As a mental health nurse, I valued therapeutic relationships, cultivating patient trust and person-centered care as all being integral to my practice as a renal nurse.

Older people entering healthcare, encounter complex health and social care systems as well as agents of their care (e.g. general practitioners, community nurses, nephrologist, dietician, and renal nurses) throughout their treatment journey. These ‘agents of care’ play an important role in an older person’s journey as they progress through their care pathway. The aim of the study was to build theory but, in doing so, it was necessary to align my own pre-conceptions within a philosophical position that was reflective of the theoretical sensitivity that I brought to the study.

3.10 Theoretical sensitivity

Theoretical sensitivity is central to grounded theory and necessitates openness on the part of researchers. Researchers’ demonstrating theoretical sensitivity develop insights and relationships within the data. A contradiction is evident in how researchers approach and deal

with theoretical sensitivity. Glaser (1978) gives mixed messages, where he advocates researchers not undertaking a literature review, yet at the same time suggesting researchers increase their theoretical sensitivity through reading widely, thereby increasing researcher sensitivity. Glaser (2003) is clear though, concerning the scope and focus of reading of literature arguing:

...the more a researcher searches all literature in any field for theoretical codes the more sensitive he becomes (p.43).

Glaser and Strauss (1967) originally recommended that grounded theory researchers omit the usual, traditional literature review in favour of investigating the concerning phenomenon and suspend or disregard knowledge held about the area researched. This was to ensure that the researcher's efforts to generate concepts from the data were not contaminated, stifled, or constrained by preconceived ideas, which could hinder the emerging theory being grounded in the data (Cutcliffe 2000; Glaser 1992). Glaser and Strauss's (1967) original stance on this issue has been slightly modified to account for the assumption that no researcher is capable of approaching a study with a complete lack of knowledge, experience, ideas or pre-suppositions (Glaser 1978; Strauss & Corbin 1998; Heath & Cowley 2004). It is impossible and unfeasible to expect researchers to enter a field of study completely devoid of influence of previous reading and experience (Heath & Cowley 2004). According to Glaser (1978, 1998), and Strauss and Corbin (1998), methodological reasons exist for undertaking a literature review. Firstly, reading related and unrelated technical and popular literature effectively expands the researcher's ideas concerning the phenomena being studied, thereby developing theoretical sensitivity (Glaser 1998; Strauss & Corbin 1998). Secondly, the researcher can clarify their existing conceptualisations, ideas, and understanding of the phenomenon researched by subjecting them to ongoing comparison with the data (Glaser 1998; Strauss & Corbin 1998). The important point to note is that reading literature has a place in contemporary grounded theory, since everything is data and contributes another perspective to the understanding of observed social processes (Glaser 1998; Backman & Kyngas 1999; McCallin 2003; Heath & Cowley 2004). Previous knowledge can be integrated into a study using constant comparative analysis to help refine emerging concepts and categories (Backman & Kyngas 1999; McCallin 2003; Heath & Cowley 2004). Glaser (1978, p.31) suggests that 'it is vital to read but in the substantive field different from the research' so as not to pre-empt the problems that might be identified by potential participants. This

early reading of the literature acts as a base of data for comparison with emerging concepts. As the study progresses, new data from a re-reading of literature will be integrated across the study, as appropriate.

3.10.1 Approaching the literature review – becoming theoretically sensitised

Within debates surrounding the use and place of literature within grounded theory studies, concerns arise where qualitative researchers need to be cautious and avoid confusion between an ‘open mind and an empty head’ (Dey 2007, p.176). Where researchers fail to consider literature, they may fall into the trap of presenting emerging theory as new or original (Bryant & Charmaz 2007). Whilst there is a commonly held perception that literature is ignored within grounded theory, this is not true; instead, literature has a different role to play within grounded theory and is addressed at a different phase within the research. In a more recent debate, concerning the role and place of literature within grounded theory, Gibson and Hartman (2014) argue that the issue has more to do with researcher sensitivity and pre-conceptions and how they are handled. Gibson and Hartman (2014) argue that researchers who ‘do use their prior preconceptions and interests to enhance their grounded theory’ have undertaken successful grounded theories (p.203).

One challenge when using grounded theory is to attain a balance in using and accessing literature to justify the research area, whilst being mindful of Glaser and Strauss’s (1992) concerns. Glaser and Strauss (1992) advocate pre-reading literature prior to initial data collection but researchers should be concerned:

not to contaminate, be constrained by, inhibit, stifle or otherwise impede the researchers effort to generate categories, their properties, and theoretical codes from the data that truly fit, are relevant and work with received or preconceived concepts that may really not fit, work or be relevant (Glaser 1992, p.31).

This point is addressed further by contemporary writers on grounded theory, who argue that ‘research questions derived from the literature may not be relevant to the field of research’ (Gibson & Hartman 2014).

Within grounded theory, literature is integrated later in the study once the substantive theory has emerged. Integrating the literature after the emergence of the grounded theory, situates the new emergent theory within the existing extant literature. Glaser and Strauss (1992)

contend that incorporating literature after the substantive theory has emerged provides an opportunity for the researcher to demonstrate how the emergent theory applies beyond the substantive area from where it emerged. Urquhart (2013a) suggests that, if researchers prioritise other theories, instead of focusing on their own data, *‘they lose ... the key delight and the key edge of the method: what Glaser (1992) calls “emergence”* (2013, p.17).

A number of practical concerns relating to not accessing literature exist, which can have serious implications for researchers. Dey (2007) believes this may lead a researcher to be unfamiliar with theories, which may apply to the area under study. This could lead to newly emergent theory being viewed as original and unique and may lack conceptual depth. Cutcliffe (2000) adopts a rather cynical stance, suggesting that it is somewhat naïve for a researcher to enter the substantive area of study devoid of knowledge. Urquhart (2013a) believes researchers new to grounded theory find it difficult not to impose their prior reading on data:

being faced with the task of looking for emergent concepts in the data without help from anything other than your own mind is a scary process (p.17).

The use of literature within grounded theory is contentious and often misunderstood (Birks & Mills 2011, 2015). An important aspect of accessing literature pertains to researcher reflexivity and their prior professional knowledge and its potential impact upon the research. Researchers entering a particular substantive field will have prior knowledge of the substantive area, as well as associated literature (McCallin 2003; McGee et al. 2007). As a researcher, my theoretical sensitivity is the result of my professional experience within renal care and prior study in the field. This provided professional domain specific knowledge, which was drawn upon during the later stages of the study: this is discussed in Chapter 4. My own reflexivity as a researcher, and how my professional knowledge influenced my thinking and the research process, is discussed later in this thesis.

Having reflected on Glaser’s (1978) and Dey’s (2007) views relating to literature use in grounded theory, it was apparent their views were similar. Glaser (1978) suggests that researcher derived professional knowledge and their awareness of the professional literature should not affect the inductive processes of the researcher. Instead, any preconceptions present must earn their place in the emergent theory, similar to all other data (Glaser 1978). In an attempt to address debates related to reading (or not) literature, Glaser (1978) believes

researchers should read broadly to help build up theoretical knowledge, yet remain open to the substantive field of study. The benefit of reading other theories, is that it enhances the researchers' theoretical sensitivity to possible theoretical codes (Glaser 1998). Broader reading of the literature strengthens the researcher's coding and theoretical writing skills. As the emergent theory surfaces from the data, it can be compared with extant literature, noting where it is similar or different (Glaser 1978).

3.10.2 Approaching the literature within this study

At the outset of the current study and prior to choosing grounded theory, I engaged with literature about the challenges older people encountered when undergoing renal replacement therapy. This was driven by the request from the study funding body (British Geriatric Society), that a literature review be undertaken. This included exploring decision-making and the impact of cognitive impairment, frailty, multi-morbidity on quality of life and pre-dialysis care. As I read about grounded theory, I became aware of Glaser's stance against reading literature in the substantive area. This was a cause of concern to me as a novice researcher. However, as I read more concerning the place of the literature review within grounded theory research, I realised I did not fully agree with Glaser's position. The reason for this was simple, there was a need to situate my study and ensure that a gap existed in the literature supporting the purpose of my study. Once I had decided on a grounded theory approach, I approached the literature in a way that reflected the approach suggested by Urquhart and Fernandez (2013b). Their two-stage approach included an initial 'non-committal' stage and a later 'integrative' stage once data had been collected and the substantive theory emerged.

During the non-committal stage, I read material on UK health service policy about information provision to older people with CKD, older peoples' access to renal care and choice of modality of treatment. As I read literature during the non-committal phase, it was stored for possible later use during the integrative phase, and subjected to constant comparative analysis. As I read, I wrote memos or notes about the content in the form of a diary to record my developing insights and thoughts. It was evident from the process that my pre-conceptions focused upon the importance of choice, ensuring the inclusion of older people in the decision-making process and the related education process.

The non-committal stage of reading the literature was important when writing up theoretical memos later. I believe that this early reading of the literature honed my theoretical sensitivity during the subsequent coding and categorisation process: it increased my awareness to possible theoretical codes and enabled me to begin to identify the concepts that were the building blocks of the emergent substantive theory. However, I avoided further detailed reading of literature until the substantive theory had begun to emerge, as advocated by Birks and Mills (2015), to *'limit the impact that an unavoidable excursion into the literature can have on your research'* (p.23). The integrative review of the literature is presented within the discussion chapter of this thesis.

3.11 Developing a grounded theory in the field of nephrology

3.12 Research sites - main hospital site (regional renal centre)

Data collection was undertaken within a large UK hospital providing nephrology services to an additional two smaller satellite dialysis units, overseen by the main regional renal centre. The main hospital, as the regional referral centre, provides nephrology services to a population of approximately 1 million. Inpatient and outpatient nephrology services are included, with facilities for investigating, diagnosing and managing patients with renal disorders, immunological diseases, and those requiring renal services for poisoning. The main hospital renal unit houses a 24-bedded in-patient nephrology ward and a twenty-bedded haemodialysis (HD) unit. A specialist peritoneal dialysis (PD) centre is available for consultations on an ambulatory basis. The main centre includes a home HD programme, supported by a home dialysis nursing team. Seven nephrologists provide weekly nephrology clinics within the main centre, as well as dedicated renal clinics within outlying district general hospitals (DGH's). Since there are no nephrologists' present on-site within the DGH's, patients are referred to the main hospital for their ongoing nephrology care. The main centre has links with a national centre for kidney transplantation, approximately fifty miles away.

3.13 Recruitment and selection

Recruitment to the study required accessing a group of potential participants who meet the study inclusion criteria (see 3.13.1 & 3.13.2). Since I did not have direct access to the clinical notes of potential participants, the renal unit data administrator provided details of potential participants to me as the principal investigator; this was approved by the local research and ethics committee. The chief physician of nephrology services and the hospital Caldicott guardian (Roch-Berry 2003) authorised access to potential participants' information held on the renal unit patient database (CKD register). This level of authorisation was required by the UK Central Office for Research Ethics Committees (COREC). The CKD register identified potential participants attending the low renal clearance clinic.

I met with the renal unit clinical nurse specialist (CNS) to discuss potential participants who met the study inclusion criteria. The CNS gave potential participants the initial study information leaflet and principal investigator contact details. I contacted potential participants to discuss the study and provide further information (see Appendix 2 & 3). I arranged a follow up telephone call one week later to confirm their potential interest or not in joining the study. All potential participants requested that I meet with them in their homes. They were only consented and enrolled into the study once they had undergone cognitive screening using the Abbreviated Mental Test (AMT) and attained a score of 7 or more, which was in line with the study inclusion criteria.

Participants were initially selected via purposive sampling, and then subsequently, via theoretical sampling. They had been identified following referral by the nephrologist for renal education sessions to facilitate treatment decisions; they had reached a point in their illness where renal replacement therapy was being considered. Prior to referral for renal education, a nephrologist had met each participant to discuss treatment options although the specialist renal nurse provided further in-depth education regarding these. Participants had either stage 4 CKD (eGFR of 15-29 ml/min/1.73m²) or stage 5 (eGFR < 15 ml/min/1ml/min /1.73m²). Standard demographic information (age, gender, marital status), as well as co-morbidity data, was provided by the nephrologist. Participants were recruited to the study who met the following inclusion criteria:

3.13.1 Inclusion Criteria

1. Aged 65 years and above
2. Patients with stage 4 CKD (GFR of 15–29 ml/min/1.73m²) or stage 5 CKD (eGFR < 15 ml/min/1.73m²)
3. Attain a score of 7 or higher on the Abbreviated Mental Test (AMT) for cognitive function.
4. Able to provide informed written consent to participate in the study
5. Able to read and speak English
6. Mode of treatment and management of CKD not decided.

3.13.2 Exclusion Criteria:

1. Patients who were acutely unwell and were not deemed to be physical stable to undergo interview
2. Patients who were unsuitable due to altered cognitive state, as determined by the AMT

3.13.3 Assessment of potential participants' cognitive status

Prior to consenting potential participants into the study, an assessment of their cognitive status was undertaken using the Abbreviated Mental Test (AMT) (see Appendix 4). The AMT is a generic test of cognitive function and widely used in the care of older people as a screening tool for impaired cognition (Qureshi & Hodkinson 1974). A Professor of Gerontology advised on this aspect of the study design. The AMT test is easy to administer and involved asking potential participants a series of questions; a score of 1 being allocated to each correct answer. All potential participants were informed of how the screening questions would be used. I made it clear to potential participants that if they had difficulties answering the screening questions, I would inform them; they readily understood and joked about their memory abilities. It was necessary to inform potential participants that they needed to obtain a score of 7 or above for their consent to be taken and proceed to interview. Whilst the AMT is not a test of capacity, it highlights problems with cognition. AMT scores ranging between 0-3 suggests severe cognitive impairment, a score of 4-6 suggests moderate impairment, whilst scores above 7 indicate normal cognitive functioning (Qureshi &

Hodkinson 1974). Potential participants obtained AMT scores ranging between 7-10; the mean score was 8.5.

3.14 Theoretical sampling

Twenty-one participants were recruited to this study with data collection spanning the period July 2009 – September 2010. As can be seen from Table 4, a significant number of participants in this study had three or more co-morbidities with diabetes mellitus, hypertension and ischaemic heart disease being more prevalent. Participants were aged between 65 – 91 years (mean 74 years) and attending the ‘low clearance renal clinics’, where their renal function was monitored.

Table 4. Characteristics of study participants

Participant	M/F M=12 F=9	Age	Marital Status	CKD Stage	Comorbidity	Treatment proposed by Doctor	Final Treatment Modality
Ian	M	78	M	4	DM	HD/PD/	PD
Mick	M	80	M	5	PVD, TCC	HD/PD/CC	HD
Harold	M	78	Widower	5	DM/CVA/HPN	HD/PD/CC	HD
Dotty	F	65	M	5	PKD/ HypTH	HD/PD/Tx	HD
Arthur	M	84	S	5	DM/HPN	HD/PD/	HD
Alex	M	72	M	4	DM/HPN	HD/PD	PD
Kate	F	80	Widow	4	DM/IHD/Ca	HD/PD	HD
Tom	M	69	M	5	DM/HTN/	HD/PD/Tx	HD
Peter	M	73	S	5	Ca/HPN/IHD/RA	HD	HD
Kitty	F	74	W	4	Incomplete	HD/PD	HD
James	M	91	M	4	COPD/HPN/IHD	HD/PD	HD
Maurice	M	81	M	5	DM/HPN/	HD/PD	HD
Doris	F	67	M	4	DM/AF/Obesity	HD/PD	PD
Chris	M	66	M	4	DM/RTKN.Amp	HD/PD/Tx	HD
Peggy	F	65	M	5	DM/CVA	HD/PD	HD
Pauline	F	77	M	5	DM/HPN/IHD/ COPD	HD/PD	HD
Mary	F	70	W	4	RA/IHD	HD/PD	HD
Alan	M	67	M	4	Incomplete	HD/PD/Tx	HD
Bill	F	80	M	4	Incomplete	HD/PD	HD
Charles	M	83	Widower	4	Ca/HPN/IHD	HD/PD	HD
Betty	F	68	M	5	Incomplete	HD/	HD

Comorbidity Abbreviations: Diabetes mellitus (DM)/Peripheral Vascular Disease (PVD)/Cerebrovascular accident (CVS)/Hypertension (HPN)/Polycystic Kidney Disease (PKD)/Ischaemic Heart Disease (IHD)/Carcinoma(Ca)/Rheumatoid Arthritis(RA)/Chronic Obstructive Airways Disease(COPD)/Atrial Fibrillation(AF)/Right Knee amputation (RTKN)

Initially participants were selected via purposive sampling, with later participants selected according to theoretical sampling. Theoretical sampling ensures that the emerging categories and the researchers understanding of the developing theory direct sampling (Glaser 1978). Theoretical sampling is a crucial aspect of grounded theory and involves:

...the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges (Glaser & Strauss 1967, p.45).

The intention of theoretical sampling is not strengthening the representability of the emerging findings but developing the theoretical completeness of the findings. Theoretical sampling involves progressively focusing in on concepts in the development of the theory and ensures that the researcher progressively samples and develops an individual approach to data collection (Glaser & Strauss 1967).

In this study, I deliberately sought participants who had a particular experience or from whom particular concepts appeared significant from the data analysis. One example was that, having analysed the first two sets of interviews and reviewed codes and notes from the observation data, the role of the family in treatment decision-making emerged. Codes reflecting this category were initially conceptualised as *Family Influences*. In subsequent interviews, participants were theoretically sampled who were married and living with a spouse or the extended family. During interviews, participants were encouraged to tell their story of their CKD as well as treatment decisions that they were currently making. This added to the existing data set about particular concepts or categories, identified in the previous interviews. Sampling of new patients ceased once data saturation had occurred when no new concepts were emerging in the analysis.

Local operational issues at the research site, which I had no control over influenced accessing participants. The local research ethics committee requested that a sample size be identified which was a challenge. Despite my personal attendance to the ethics committee meeting to discuss sampling in grounded theory, a sample size was still requested. In response to this request, an initial sample size of forty participants was agreed; although I made the case that, the theoretical saturation would determine the final sample.

Sampling commenced within the main renal unit, where there was a degree of certainty there was sufficient scope to collect data. Glaser (1978, p.45) supports researchers choosing a site that will '*maximise the possibilities of obtaining data and leads for more data on their question*'. As data collection and analysis proceeded and the core category identified, sampling of patients from one of the two remaining outlying renal centres was undertaken.

These units were managed by the main renal centre, which ensured there was enough similarity between them to minimise differences (Glaser & Strauss 1967). Whilst theoretical sampling is critical when undertaking grounded theory, external factors e.g. changing clinical and operational needs and organisational politics, which researchers have little control over, impact upon maximising the full potential of research. The type, range, and amount of data sampled within a grounded theory study is determined by the developing theory. In the current study, this involved sampling patients in terms of their stage of CKD and the length of time prior to referral for renal education within the main renal centre.

3.15 Collecting initial data: semi-structured interviews

Qualitative interviews are the most frequently used data collection approach within grounded theory, although other types of data can be used (Nathaniel 2008; Bradbury-Jones et al 2017). Each participant was interviewed once, using semi-structured interviews; interviews became increasingly focused around data analysis and the emerging theory. This ensured that emerging questions and tentative hunches could be followed up through progressively focusing on areas directed by the data. (Bourgeault, Dingwall, & De Vries 2010). The early set of interviews resulted in a provisional set of codes and categories; these were followed up with further data collection through interviews and observations within the renal education clinic. Emerging from the data analysis was the category related to the complexity of self-care PD. I explored this further during ongoing interviews, which helped to develop the characteristics of the category. Ongoing interviews, whilst retaining a degree of flexibility, focused on open codes as they emerged within the new data collected. The emergence of the core category and the delimiting of the theory ensured interview topics became increasingly more focused. As interviews progressed, my focus was upon treatment safety, self-delivered or professional delivered care, as well as factors that enabled or restricted treatment decision-making, as these were consistently emerging within participant accounts.

The semi-structured interview approach can be challenging to those new to qualitative interviewing (Kallio et al. 2016; Hofisi, Hofisi & Mago 2014) and therefore, care is needed to ensure questions are broad and open yet avoid leading participants unduly. I drew upon the skills and experience I had gained from previous training in qualitative research. Interviews were informal and commenced with eliciting, from participants', their background

information concerning their CKD. It was evident that this approach inhibited the emergence of the core category, as participants' talked at length about previous medical histories, which had little bearing on the emerging theory. The focus during interviewing was to continue to generate and further saturate categories and their indicators (Glaser 2001). Initially, data collected was broad and varied, focusing upon participants' experience and understanding of CKD; this resulted in a number of paths being followed during data collection. Eventually, as the core category emerged and delimiting of the theory developed, data collection and analysis became more progressively focused until properties and categories were saturated; the stage of theoretical saturation emerged and a decision to stop sampling was taken. Interviews were complemented with periods of non-participant observation of participants and healthcare professionals (renal nurse, doctor) during the renal education classes as well as visits to the HD unit, along with observation of consultations between participants and their nephrologist. In total, 23.5 hours of data was collected through interviews and non-participant observation (see Table 5). Eight interviews were undertaken between July 2009 – November 2009, with the remaining thirteen interviews being conducted between March - September 2010. Interviews lasted, on average, 40 to 90 minutes.

3.15.1 Rationale for conducting semi-structured interviews

The use of interviews provided flexibility during data collection, enabling a process of mutual engagement between participants and myself. Participants were provided the time to share their perspectives and concerns relating to treatment decisions. Interviews facilitated the capturing of those hidden aspects of decision-making, which may not have been identified using non-participant observation alone (Creswell 2014; Parahoo 2006). When applying grounded theory, researchers strive to encourage 'spill', in an attempt to uncover the participants' main concern during interviews (Nathaniel 2008). As a researcher, I encouraged participants' to tell their stories, which assisted in discovering how they resolved their main concerns related to treatment decision-making. To achieve this, I created an environment, which enabled participants to feel their personal story was important to be shared with myself as the interested listener. Glaser (1998, p.124) encourages researchers to assume the role of 'big ear' to pour into incessantly'. Furthermore, Nathaniel (2008) stresses the importance of the researcher maintaining a sense of openness in listening to the stories they receive:

The researcher must be open to hearing the story from the informant's perspective. After all, the focus of the research in classic grounded theory revolves around the participant's own perception of a problem in their lives and their struggle to resolve the problem. Attentively listening to participants' stories and remaining open to their ideas and interpretation is the only way the researcher can arrive at the new knowledge (p.61).

Birks and Mills (2011, p.56) argue that irrespective of the particular stance taken by the researcher, interviews:

become the site for the construction of knowledge where clearly the researcher and informant produce this knowledge together. In the construction of such knowledge, information generated needs to reveal depth, feeling and reflexive thought (p.56).

As a research method, interviews are a feature of qualitative research. Rapley (2004) highlights the idea that we exist within an interviewing society, where the role and impact of interviewing:

...pervades and produces our contemporary cultural experiences and knowledge of authentic personal, private selves. Interviewing is the central resource through which contemporary social science engages with issues that concern it (p.15)

Generating the grounded theory required active participation of myself as a researcher in the generation of material which would support a key tenet of grounded theory, namely theoretical sampling. One of the strengths of qualitative interviewing is that it provides opportunities to collect narratives of the social world of renal care. The choice of interviews was that, as a data collection approach, interviews would provide rich dense data concerning participant understandings. Interviews were chosen, as the purpose of the current study was to uncover the concerns older people encounter when facing treatment decision-making. Interviews enabled the researcher to gather first-hand accounts of older people's concerns and facilitate the process of theory building through data collection. Silverman (2016) argues that one of the hallmarks of qualitative interviewing is their ability to:

produce accounts that offer researchers a means of examining intertwined sets of findings: evidence of the nature of the phenomenon under investigation, including the context and situations in which it emerges, as well as insights into the cultural frames people use to make sense of these experiences (p.63)

3.15.2 Conducting individual interviews

Individual interviews provided flexibility in the phrasing of questions but did not sacrifice the area of interest (Parahoo 2006). Participants were interviewed once in their own homes at their request. It was important participants' chose their preferred place for the interviews, where they would feel comfortable, and relaxed. Interviews were undertaken with participants after they had attended the renal education clinic session with the renal nurse specialist. Interviews were conducted within 2 weeks of participants attendance to the renal education clinic session. Not all education sessions with all participants could be attended due to issues beyond the researcher's control e.g. clinic meetings being re-scheduled at short notice by clinic staff; in total, ten renal education clinic meetings were attended.

An interview schedule was used (see Appendix 5) to facilitate interviews. As interviews progressed, the interview schedule was adapted to reflect emerging data and the need to pursue new lines of inquiry as well as theoretical sampling. As the core category began to emerge, this directed the progressive focusing of questions asked. During the first set of interviews, it was apparent that 'safety' was emerging as a consistent indicator in much of the data. Theoretical sampling directed where I needed to pursue new lines of enquiry. For example, in the early set of interviews, data indicated that participants' had knowledge deficits related to their CKD progression, its treatment as well as differing pre-dialysis education experiences. I therefore, sampled according to varying levels of pre-dialysis education as well as where they lived, geographically. Interviews highlighted the importance of a spouse and extended family in helping older people manage their main concerns related to treatment safety. I therefore theoretically sampled individuals who were married and living with spouses or their extended family.

Constant comparative analysis of interview data allowed me to compare emerging codes with codes, and categories with codes to help establish lines of inquiry within the interviews. The flexibility of the interviews enabled the interview process to pursue new lines of enquiry, although Rapley (2004) argues that researchers will always exerted control and that:

Interviewing is never just a conversation, it may be conversational, but you as the interviewer have some level of control (Rapley, 2004 p.26)

It was not possible at the outset of the study that I would know where data analysis would lead me. This was confusing and frustrating which is addressed by Glaser (1992) when he suggests that the grounded theory researcher must accept ambiguity, confusion, and setbacks

during data collection. Whilst the original plan had been to interview family members separately, later in the study this was abandoned, as earlier interviews with three participants suggested that including family members in the interviews was a better approach; this was undertaken with the agreement of participants'. Out of the twenty-one participants interviewed, eight significant others were present throughout the interviews; they did not always stay throughout the interviews and frequently wandered away to undertake other duties within the home. The three spouses that did stay occupied the role of informant when requested by participants', occasionally offering their perspective. I was careful to maintain my focus on participants but also mindful of the valuable contribution of family members.

There were two occasions whilst interviewing when the tape recording equipment failed; I abandoned tape recording and relied on field notes to capture the discussion. From a research design perspective, as my knowledge of grounded theory increased, I became more comfortable with capturing data through written summaries of encounters with participants with field notes written immediately following encounters with participants. As the research progressed, I increased my focus on "in the moment" data capturing and conceptualisation. Interviews were time consuming and transcription became burdensome, nonetheless, I could not fully abandon tape recording interviews or having the data transcribed. I was aware that capturing interview data in full through taping and transcribing could disrupt the production of a quality grounded theory. Participants may also be inhibited by the presence of a tape recorder, resulting in the "proper lining" of data (Glaser 1998, p.110). The excessive time and tediousness of taping and transcribing can divert the researcher towards a full description of the data, rather than its abstract conceptualisation and theory development (Glaser 1998, p.112). Whilst I appreciated the value of the concise nature of spontaneous data capture (Glaser 1998, p.108-109), as a novice grounded theorist there was a feeling of safety in having data recorded and transcribed. In summary, I transcribed nineteen interviews, with the data from two interviews captured through field notes written up immediately following interviews. Field notes were taken during non-participant observation sessions as well a detailed summary recorded immediately following each observation session. Transcribed notes from interviews were stored in a locked fireproof filing cabinet within the researchers office and only accessible by the researcher. Interview data was anonymized and coded from initial collection, to its use during data analysis and subsequent reporting of the study's

findings. Consent to use anonymized participant quotes from interviews was obtained during the initial consenting process.

Personally, transcribing interviews, whilst laborious, was important, since it enabled me to develop a closer understanding of the data. As I transcribed interview data, I could relate to the interviews and its context, as well as to the nuances of the interview, something that an external transcriber would not have been able to do. Whilst Glaser (1998) advocates not taping interviews, I could not relinquish this activity as a researcher. I wanted to have a record of my data that would provide an audit trail throughout the data collection process. The transcribed interviews and their digital recordings were stored using the qualitative data analysis software NVivo. This allowed me to revisit interviews and re-read transcripts whilst listening to the taped interviews. Glaser (1998) believes recording interview data is in direct conflict with the need to record only field notes during data collection. I do not agree with Glaser on this point and found that transcribed interviews and field notes enhanced the data capture and furthered my theoretical analysis. I believe that note taking during interviews, would have distracted me from tuning into what participants were saying and would have negatively affected the quality of the data obtained. The use of the tape recorder did not affect, in any way, the interaction between the participants and myself. Note taking during the interview, I believe, would have been highly distracting for the participants, which could have influenced the quality of the rapport I established with them. Birks and Mills (2011) are critical of researchers capturing interview data through field notes alone, suggesting such an approach results in:

...writing a one-sided account of the interview in this format effectively separates the researcher and participant as the constant comparison of abstract categories perceived by the researcher during the interview is pursued at the cost of participant voices... data in the form of recordings and transcripts exposes more about the nuances of language and meaning than field notes will ever be able to reveal (p.56)

Divergent views exist concerning transcribing interview data amongst grounded theorists. Researchers who position themselves epistemologically within the post-positivist paradigm argue strongly against transcribing interview data. Holton and Walsh (2017) suggest that researchers worry about not capturing all data or missing something important in the data. The suggestion that researchers look for patterns going on in the data all the time means that

there are '*endless opportunities to capture it...no one interview is precious*' (Holton & Walsh 2017, p.64). In contrast, post-modernist and constructivist researchers strongly believe that it is impossible to separate the researcher and researched during data generation (Birks & Mills 2011; Charmaz 2014). Whilst the intension of the current study was to stay faithful to the process of emergence within the data, I believe that transcribing the interviews and supplementing them with the written field notes greatly enhanced the data, which is supported by Birks & Mills (2015, p.74) who argue that:

....interview transcriptions do, however, when combined with your field notes, provide a rich data set (p.74).

3.16 Non-participant observation

Although the interviews were invaluable as a data collection approach, it was important that I sought other types of data to strengthen my theoretical sampling. I therefore used non-participant observation as an additional data collection approach, which yielded valuable data. Ten education sessions between the renal nurse specialist and participants were observed. Observed sessions lasted between 30-40 minutes, although sometimes sessions were shorter due to the limited attention span of the participants'. Observed sessions were undertaken within a dedicated teaching unit, integrated as part of the main renal unit. The renal nurse specialist, who informed me of the date and time that each patient would be attending, facilitated attendance to the sessions. Clinic staff were in control of this aspect of the data collection; it was important for me not to impose myself on the usual practice of clinic delivery. Whilst observing the education session, I recorded field notes (verbal data as it occurred and observations in a field journal) whilst the session was delivered. I summarised the content of sessions, as well as the interactions that occurred during the sessions and the behaviours of nurse and participant. To ensure that I was not too prominent in the room, I adopted a position that did not interfere or intrude into the interaction between the nurse and patient.

Following the education sessions, I accompanied participants and their family on six visits to the haemodialysis unit as part of the education session. Not all participants accepted the offer of a visit; for some participants, the reality of visiting the haemodialysis unit was too much to take in. Where this was the case, an agreement was reached that the participant

would inform the nurse specialist of a suitable time when they could visit the unit. During the unit visit, I observed participants' reactions to the clinical environment of the haemodialysis unit and the type of questions they asked of the nurse specialist. I was also able to observe how participants' interacted with existing patients who were receiving dialysis. I maintained an unobtrusive role during the visit and positioned myself in the background during the visit. I drew upon field notes written whilst observing clinic education sessions; these notes were analysed using constant comparison. Observations identified participants' concerns related to safety. In managing their concerns, older people employed strategies that enabled them to engage in a process of assuring a level of safety. For some, this included engaging in self-directed activities e.g. active information searching and mobilising family support, whilst others focused on their care being managed completely by the renal healthcare team.

I immediately wrote up my observations and reflections in field notes after observation sessions. In addition to the 13 hours of semi-structured interviews undertaken, 11.5 hours of non-participant observation were conducted (see Table 5). Grounded theory requires research in the field, in the participant's natural setting, if, as Glaser (1992, p.15) states, '*one wants to understand what is going on*'. Observation provided the opportunity to explore answers to contextual questions, which would not have been possible if only interviews had been used.

Table 5. Data collected across study sites

Study Site	Primary Purpose	Number of Patients Interviewed & Total Hours (TH) of interviews	Presence of Spouse / Family During Home Interviews	Participant Observation (Education sessions) Renal unit Visit TH= Total hours	Non-Participant Observation (sessions with Nephrologist)
A	Main regional Renal Referral centre	11 TH=7 hrs	5 (* Data included from 2)	10 (Includes all patients from sites A/B & C) TH=9.5 hrs Renal Unit Tour - (6) visits TH = 3 hrs	2 (Includes all patients from sites A/B & C)
B	Outlying District general Hospital	5 TH=3 hrs	2 (*1 Contribute to Interview)	No	No
C	Outlying District General Hospital	5 TH=3 hrs	1	No	No
Total		13 hours of interviews		9.5 Hours of Observation	2 hour of observation

3.16.1 Non-participant observation: nephrologist and patient consultation

Non-participant observation had not been identified as a data collection approach at the initial commencement of the study. Once data collection and analysis had commenced, there were indicators within the emerging theory, suggesting that I needed to understand the context of the consultation between participants and nephrologist. Whilst interviewing two participants they referred to the information sharing behaviour of the nephrologist. This required that I prepare a re-application to the research and ethics committee to undertake observation of the nephrologist and participant encounter. Access to the consultation meetings was not straightforward. I met with the nephrologists to obtain their permission to allow me to join their meeting with participants. Out of seven nephrologists, only one agreed to allow me to observe two of his sessions. The nephrologists were ‘key clinical gate keepers’ to the study, so I had to work within the boundaries they set. Attending the meeting of the one nephrologist provided a clearer understanding of the information sharing behaviours that patients had recounted within the interviews with me.

As a researcher, I felt from the conversations with some of the nephrologists, that I was treading a fine line. I had written in my research diary how different my relationship was with the nephrologists. I felt powerless to address this with them individually, as this may have been counterproductive. I reflected on an initial meeting I had attended at the beginning of the study, chaired by the chief of nephrology. I was invited to attend the renal unit meeting to present my proposed study to the members of the renal healthcare team. Medical colleagues attended this meeting, as well as other staff e.g. nurses, dieticians, social workers, and psychologist. On reflection, the chief of nephrology publically supported the study by inviting me to the meeting. This meeting was to legitimise my study to the wider renal healthcare team, so I was uncertain as to why there was a reluctance to involve me in the one-to-one consultations between participants and nephrologists. One factor I did consider was my role as a nurse researcher, evaluating nephrologists during their clinic consultation and this may have been why they were reluctant. Whilst the lack of access to participant and nephrologist consultations was a drawback, I could do nothing about this. The original intension was to focus on the information sharing behaviours of the nephrologist, as this was one of the early codes identified during the open coding but was abandoned.

3.17 Data analysis - selecting the unit of analysis

The unit of analysis within the study was the decision made by the older person. Constant comparative analysis is a fundamental technique within grounded theory. When using constant comparative analysis, data collection, coding and analysis occur simultaneously (Glaser & Strauss 1967). The method allowed me to move back and forth within the data, to change focus and pursue new leads revealed in the ongoing data analysis (Glaser & Strauss 1967). Constant comparative analysis continued for the duration of the study. Analysis began with the coding of incidents, which in turn led to the emergence of categories and their properties, finishing with their theoretical codes, which connected the categories with each other and to the core category. Glaser and Strauss (1967, p.105) identify four stages of the constant comparative method:

(1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory (Glaser and Strauss 1967, p.105)

Whilst analysis appears linear, the process was far more complex because I had to revisit each stage in any sequence throughout the course of the study. This meant that all the data collected over the course of the research had been compared and analysed and that the emergent theory reflected the data collected and the concerns of participants' (Glaser 1992, 1978).

3.18 Coding data: open coding

Substantive coding commenced with open coding; this first stage of constant comparative analysis involved me coding raw fieldwork data from observations and interviews, which I had transcribed verbatim. As I read transcripts, and coded each data segment, I examined them closely and compared each portion of the data for similarities and differences (Glaser 1992; Glaser & Strauss 1967). The focus for me at this stage was to look for emerging patterns, beginning with no preconceived conceptual thoughts or ideas. As I undertook my first attempt at open coding, many codes emerged (see Appendix 6), continuing until they were grouped together to form subcategories and categories (Glaser 1992). A category is a set of codes or concepts that are similar and are therefore, by definition, grouped together. During this stage of the analysis, an indication of a core category began to emerge. Participants' raised concerns about their fears of delivering self-care, hazards of treatment, and being cared for by healthcare staff. It was clear the core category was emerging, although further data was required to saturate the emerging category. A core category is the main category, which explains variations in the data and the behaviour of participants'. My first attempt at open coding was time consuming, as I was attaching conceptual codes within every sentence. Whilst Glaser (1978, 1992, 1998, 2001) suggests assigning codes only to incidents within the data that truly reflect conceptually the content, I found myself generating a long list of codes. This process involved line by line coding and was thorough enough to ensure full theoretical coverage (Glaser 1978); it allowed me to spend time going over the data to generate the various codes. This process is referred to by Glaser (1978, p.56) as 'running the data open'. For example, an incident was coded as 'avoiding involvement', as well as 'self-doubts'. The line-by-line coding approach that I initially adopted suggested I was attaching codes to every sentence, which was not that helpful. In some transcripts, hardly anything was said within a sentence yet more was said across a number of sentences. Sometimes, it seemed

a code was appropriate to one part of a sentence and another code related more to another section of the sentence.

Glaser (1978) suggests one way to deal with this is to maintain line by line coding but treat sections of data that could reflect a single incident. This approach helped me code numerous sentences together or even, in some cases, a whole paragraph. I did notice during my initial analysis that a single transcript would generate in excess of 60 codes, which were often unconnected. This worried me and I soon realized that what I had been attaching descriptive labels to incidents, instead of considering how conceptually they related to each other. As I read more about coding in grounded theory, it became apparent that researchers who are new to grounded theory frequently encountered the same challenge to the one I had experienced (Holton, 2010). As I continued with open coding (see table 6), I ensured three important questions posed by Glaser (1998) were always upper most in my mind:

What is this data a study of? What category does this incident indicate? What is actually happening in the data? (Glaser 1978, p.57)

These questions enabled me to make a stronger effort to ensure coding was conceptual. As shown in Table 6, open codes were identified in segments of data. The code *avoidance of making decision* comprises behaviours evident in the interview text included *thinking through, forgetting, avoidance, distancing, and denying*. These initial codes reflected the concerns of many of the participants' and led to a continuing focus of the code '*avoidance in making decision*'. During open coding, codes were attached to data segments, which were revisited at a conceptual level. Further integration of codes occurred until codes were delimited around the core category. I would revisit my earlier coding and refine codes (see Appendix 7), as patterns began to surface in the transcripts. This enhanced conceptual coding (albeit still at a novice level) and provided a more focused approach towards theoretical sampling. As can be seen in Table 7, my conceptual coding involved my theoretical insights and reflections on the emerging codes.

Table 6. Example of open coding (open codes in bold - bracketed)

<p>Code Name: acceptability of hospital dialysis<Internals\CJ13092010> -</p> <p><i>"It didn't strike me (acceptance, accommodating) with a panic of the other, what do they call the other? One's dialysis and one's."</i></p>
<p>Code Name: Acceptance and accommodating <Internals\NB902_23072009a & b</p> <p><i>"You're just somewhere where you don't want to be but you haven't, (clears throat) excuse me, you haven't got the wherewithal to get out of it. So you've got to, you've got to take it, you've got to put up with it and make the best of it you can."</i></p>
<p>Code Name: Avoidance of making decision<Internals\NB902_23072009a & b</p> <p><i>"Yes, because they had been saying to me, "Have you thought of, er, the dialysis?" (Directed decisions, treatment certainty) and I just said, "Yes, I've thought of it but I've forgotten it as well." (Thinking through, Forgetting, Avoidance) Because, just like I've said, I wanted to push it out of my mind.(Distancing thought, Avoiding) Maybe I was hoping there'd be a miracle cure(Cures, hope) that they'd come up with and I'd read about in the Daily Mail, "There's a pill available (Medical breakthrough, wishful thinking) for all kidney sufferers. Just take this pill and you're going to be alright (Recovery, Normality), , " that's what I would have liked"(Preferences, Wishes)</i></p> <p><i>So then I pushed that out of my mind,(Denying, Avoiding) see, the whole lot, but then that's when the ... it started to take effect (Changing Illness, Impact) and I was just getting weaker and weaker and (physical decline, progression)</i></p>
<p>Code Name: complexity of treatment <Internals\CJ13092010> -</p> <p><i>Well there was so much attached to it (Complex, Overload) and it was taking so much time (Time Demands, Intrusive, Dominance) up you know ...</i></p>

Table 7. Open coding with researcher reflection.

Example of open coding of transcript.(researcher comments noted) - Doris	OPEN CODING PROCESS
<p>RES: <i>she explained everything to me. And erm, I said about having it, I could have it at home or I could, and I prefer to go to the hospital. As I thought my husband has enough on his plate with me as it is and I thought, if I go there, it's giving him a break while I go down there and have it done. Er it was my decision, nobody else's [hm] and they thought I would, did the wisest thing.</i></p> <p>RES: <i>Oh yes they explained everything to me, I have no problems there [hm], but I, I felt better going to the hospital and having it done.</i></p> <p>INT: Tell me when, what it was like when you saw the PD, what did you think?</p> <p>RES: <i>Well to me, as far as I could see it, it was like a big blood transfusion type of thing. It didn't, it didn't, it didn't phase me at all [hm]. I thought well, it'll, well I've seen a lot of old people in that wing.</i></p> <p>RES: <i>No, it was more, how can I put it? Relaxed. To me they looked really relaxed, they weren't, no, they were not worried [yes]. You know that's the way I liked about it.</i></p> <p>RES: <i>Oh I got, I was talking to one of the old ladies [yes] that was in there. And they've, they didn't, wasn't worried about it, you know.</i></p> <p>INT: And how important was that chance to speak to another patient.</p> <p>RES: <i>Take a lot off my mind. You know, erm, it's alright people saying you're not, I'm not worried no, but there's still a little niggle at the back of your mind [yes] but now I felt a lot, lot better, going and seeing it. Erm, when they said to go down the dialysis and have a, you know, right it's coming quicker than what I thought, you know. But erm, when I got there, I was quite, it was quite interesting [yes], you know. It's all, how can I put it, how they do things, how, how the machine does it and, you know, and how it helps people and that. Things like that, you know.</i></p> <p>INT: Hm, hm. So you managed to speak to a lady [yes] who was having treatment [yes]. And what were you talking to her about?</p> <p>RES: <i>I was asking her what it was like. She said it was, actually she said it's just, you just sit near there and let it gone with the, it doesn't hurt you [right]. But I talked to my neighbour next door because he's on dial ... but his went wrong, his fistula, his got it in his neck. And it's knocking him a little bit I think, you know. He said don't let that frighten you, he said to me, I'm not eating [right] he said and I've been told off, I have to eat, you know.</i></p> <p>RES: <i>Well they all know [yes]. We've er sat down and we've told them all what's going on.</i></p>	<p>Benefit appraisal – taking care from the home removing responsibility – hospital therapy seems to provide a way of giving and providing relief from the suffering of dialysis treatments. Active treatment moves the individual into an increasing state of dependency. Respite for carers provided by hospital therapy. [<i>It seems that making a judgement may sometime forego what they would wish for themselves in an attempt to minimise impact and suffering on family members</i> [The enduring suffering brought about by RRT has to be balanced against resources available and the utilisation of these]</p> <p>Familiarisation – adopting hospital HD is seen in the context of a blood transfusion – this may minimise the reality that RRT is seen as a life sustaining therapy</p> <p>Communication / dialogue within those patients – impact of fellow patients – searching out, probing, questions, this is quite a powerful medium through which reinforces the relative benefit of hospital care. Relief, anguish is dispelled- it seems this visit locates the visitor (prospective newcomer) into the situation as a temporary visitor who hasn't quite arrived yet. At this stage decisions about hospital care are being tested out with what is on offer/</p> <p>There is a sense of urgency or time limiting nature of the visit – this signals the importance, reality and ignites stress/ uncertainty although the visit has a comforting value. The relationship between technology – seen as helping – this is viewed in a positive manner – Technology offers hope and assistance. Rationalising the merits of technology. Mixed stories concerning blood access and problems</p> <p>Availing self of stories/narratives from other patients on dialysis. Absorbing and building up pictures of what life maybe like</p> <p>Family sharing the impact of the treatment and what is happening</p>

3.19 Selective coding

Selective coding represented the second stage of constant comparative analysis and involved me focusing on a limited number of categories which best represented major aspects of the emerging data. Selective coding is similar to open coding, where data is constantly compared and I continued to look for similarities, categories, and properties of categories. Similar to open coding, analysis continued to develop the core category. Unlike open coding, which uses substantive codes, selective coding is more analytical and abstract, leading to conceptual names for categories (see table 6, table 7 & table 8). At each level of analysis, there is more integration and refining of abstract concepts covering the variations in behavioural patterns of the research participants (Glaser 1978).

Within the current study, the core category emerged quickly. I agree with Glaser's view (1998, p.138), when he states that the core category is 'run into'; this is precisely what happened as I analysed the data. Up until this stage in the analysis, separate concepts were emerging related to treatment safety and I began to see patterns emerging in the data relating to how participants approached their preferred treatment. For example, when participants went against the physicians preference for a home based therapy e.g. self-care PD. This behaviour was undertaken whilst they examined the impact of relieving treatment burden upon the family. Interestingly, a number of participants' talked about the vigilance of dialysis unit staff whilst they monitored patients during hospital dialysis. The hygienic dialysis unit environment minimized risks; safety was their prime concern.

It was evident that older people were not concerned about making the treatment decisions; they knew treatment was required, yet were concerned about being safe with future dialysis treatment. This core concern became apparent in a number of ways as properties began to emerge in the analysis. In some interviews, participants' talked about their increased level of risk if they were to have dialysis treatment at home. This allowed me then to focus ongoing interviews around questions related to home or hospital dialysis treatment. Additionally, other characteristics of the concept of safety emerged, including lack of confidence in abilities to perform self-care dialysis as well as issues relating to standards of hygiene within the home. I was able to see a patterning out in the data as the properties of safety emerged, along with their associated dimensions for each concept identified. I was able to go back to memos written earlier on evaluating self, which when written focused more on participants'

understanding of their skills and knowledge. Once the core category was discovered, it guided ongoing data collection and theoretical sampling. Glaser (1978, p.95) identifies the main criteria for the core category, stating that the core category must have the ability to explain behaviour for the duration for the research analysis. The core category must be the central theme and offer a continuous explanation of participants' behaviour from the beginning to completion of the research. The core category must easily account for variations occurring as relationships between the core category and other categories develop and expand. Therefore, a core category is open to easy modification, if required. On occasions, a core category may be classified as the basic social process (BSP).

Table 8. Substantive coding: increasing conceptualization during coding process.

Code	Text & Researcher reflections (RR)
Controllability/Integration/ Minimising disruptions	<p data-bbox="722 289 1464 472"><i>“Um, well my prime motivation was I’d be able to do it myself at home, which would mean I wouldn’t need obviously to, er, have these horrendous trips into hospital three times a week. Er, the fact that it could be done at night time was massively appealing because, um, that would have ... mean that there would be minimal disruption to my day-to-day life. Those were the major factors.”</i></p> <p data-bbox="722 472 1464 714">(RR) : Self-care has the property of controllability. Engaging in self-care places control over therapy in the hands of the patient - they can dictate how it will be integrated into their daily life. Home therapy alleviates the burden of travelling - again minimising disruptions to daily life is a big concern here. Disruptions are the main concern to AA who has a very active life - the need for treatment is one of a nuisance that must be managed in some way. Life is busy and packed so trying to find a slot that therapy at home can be relegated provides high levels of controllability.</p>
Strike a balance / Contemplating/ Advance planning / Strategizing	<p data-bbox="722 741 1464 892"><i>“Um, well there are three ... I think there are three periods in the day when you’ve got to do it. Um, it would just mean that there would be less flexibility really in terms of we would have to plan my life around those three, um, dialysis periods, rather than planning my life around the people that are important to me and things like that.”</i></p> <p data-bbox="722 892 1464 1014">(RR): Renal therapy dictates the scope and pace of life. Dialysis periods can dominate - it seems here AA is striving to strike a balance, contemplating possibilities, there is a sense of advance planning and strategizing what could be</p>
Re-engineering/integration/adoption /negotiation/ Active contemplation / Acceptance/ Adjustments /practical re-adjustments	<p data-bbox="722 1041 1464 1255"><i>“Um, well it was ... before we had that session we had no idea, we’d never seen it, we didn’t know how big it was, and um, at my side of the bed there just wouldn’t be room. I wouldn’t be able to get in and out of bed with that piece of equipment there because it’s quite a narrow, um, space between there and the, um, wardrobes. In fact, you wouldn’t even be able to get in your wardrobe where all your clothes are if it was there so there’s logistics to take into consideration.”</i></p> <p data-bbox="722 1255 1464 1558">(RR): Once a decision is made there is an almost re-engineering process occurring. Active processes of integration and adoption of technology into the home. Behaviours are seen to find a mutual place where technology and self can co-exist together in harmony. Giving up personal space is an active process of negotiation between husband and wife. There is this sense of adoption. Active contemplation, acceptance, and adjustments that would have to be made. There is a sense of the size of the technology which in some ways reinforces a sense of dominance within life. But in accepting this. There is a willingness to make practical re-adjustments to the home setting and personal space/ solution finding.</p>

Table 9. Selective coding, categories, properties and dimensions

SELECTIVE CODING			
CORE CATEGORY – NEGOTIATING A SAFE EXISTENCE			
SELECTIVE CODES	Sub-Category	Properties	Dimensions
Acceptance	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Awareness of information deficits 	<ul style="list-style-type: none"> • Recognising a changed self • Managing Uncertainty
Accommodating	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Normalising the dialysis unit environment 	<ul style="list-style-type: none"> • Connecting with treatment demands
Altered self-image	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Awareness of information deficits 	<ul style="list-style-type: none"> • Recognising a changed self • Managing Uncertainty
Appraising	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Normalising the dialysis unit environment 	<ul style="list-style-type: none"> • Connecting with treatment demands
Avoiding	Confronting a Deteriorating Self	<ul style="list-style-type: none"> • Receiving information on Progress 	<ul style="list-style-type: none"> • Recognising Dialysis is Needed
Awareness	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Information Deficits 	<ul style="list-style-type: none"> • Recognising a changed self • Managing Uncertainty
Being cared for	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Hospital Care is Safer Care
Burden	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Integrating PD into the Home • Hospital Care is Safer Care
Choices	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Exchanging information 	<ul style="list-style-type: none"> • Recognising Dialysis is Needed • Receiving information on Progress
Competency	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Working through Demands for Self-care 	<ul style="list-style-type: none"> • Realising Fears for Self-Care PD
Confronting	<ul style="list-style-type: none"> • Awareness of Information 	<ul style="list-style-type: none"> • Awareness of 	<ul style="list-style-type: none"> • Recognising a Changed Self

	Deficits	information deficits	Managing Uncertainty
Contemplating	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Exchanging Information 	<ul style="list-style-type: none"> • Receiving information on progress • Recognising Dialysis is Needed
Decision satisfaction			
Decision taken	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Exchanging Information 	<ul style="list-style-type: none"> • Recognising Dialysis is Needed
Decisional pressures			
Decisional responsibility			
Dependency	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strengthening Family Support 	<ul style="list-style-type: none"> • Sharing Decisions with Family • Negotiating Family Support
Deteriorating state	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Awareness of information deficits 	<ul style="list-style-type: none"> • Recognising a changed self • Managing Uncertainty
Family benefits	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Hospital Care is Safer Care • Integrating PD into the Home
Family Guidance	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strengthening Family Support 	<ul style="list-style-type: none"> • Sharing Decisions with Family • Negotiating Family Support
Feeling safe	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Hospital Care is Safer Care
Flexibility	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strengthening Family Support 	<ul style="list-style-type: none"> • Sharing Decisions with Family • Negotiating Family Support
Home therapy	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Integrating PD into the Home • Hospital Care is Safer Care
Hygiene	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Integrating PD into the Home • Hospital Care is Safer Care

Information provision	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Exchanging Information 	<ul style="list-style-type: none"> • Receiving information on progress • Recognising Dialysis is Needed
Informed decision	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Connecting with existing dialysis patients as experts 	<ul style="list-style-type: none"> • Sharing Knowledge with patients
Learning	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Working through Demands for Self-care 	<ul style="list-style-type: none"> • Realising Fears for Self-Care PD
locating self	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Working through Demands for Self-care 	<ul style="list-style-type: none"> • Realising Fears for Self-Care PD
Logistical Challenges	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Integrating PD into the Home
Managing restrictions	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strategizing for Disruption 	<ul style="list-style-type: none"> • Hospital Care is Safer Care
Positivity	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Normalising the dialysis unit environment 	<ul style="list-style-type: none"> • Connecting with treatment demands
Receptive to information	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Connecting with existing dialysis patients as experts 	<ul style="list-style-type: none"> • Sharing Knowledge with patients
Relationships	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Establishing relationships with experts 	<ul style="list-style-type: none"> • Recognising the nephrologist as expert
Risk to self	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Working through Demands for Self-care 	<ul style="list-style-type: none"> • Realising Fears for Self-Care PD
Self-Doubts	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Awareness of information deficits 	<ul style="list-style-type: none"> • Recognising a changed self • Managing Uncertainty
Sharing decisions	<ul style="list-style-type: none"> • Traversing Disruption 	<ul style="list-style-type: none"> • Strengthening Family Support 	<ul style="list-style-type: none"> • Sharing Decisions with Family • Negotiating Family Support
Transportation	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Connecting with existing dialysis patients as 	<ul style="list-style-type: none"> • Sharing Knowledge with patients

			experts	
Treatment benefits	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Connecting with existing dialysis patients as experts 		<ul style="list-style-type: none"> • Sharing Knowledge with patients
Treatment requests	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Exchanging Information 		<ul style="list-style-type: none"> • Receiving information on progress • Recognising Dialysis is Needed
Uncertainty	<ul style="list-style-type: none"> • Confronting a Deteriorating Self 	<ul style="list-style-type: none"> • Awareness of information deficits 		<ul style="list-style-type: none"> • Recognising a changed self • Managing Uncertainty
Wonderment	<ul style="list-style-type: none"> • Sourcing Information 	<ul style="list-style-type: none"> • Normalising the dialysis unit environment 		<ul style="list-style-type: none"> • Connecting with treatment demands

3.20 Theoretical coding

Following open coding, which identified the preliminary conceptual codes and categories, theoretical questions still required answering; this guided ongoing data collection. Whilst participants' concerns focused on treatment safety, it was less obvious how they wished to *managed themselves*, which was contrasted with how they strived to *protect themselves*. Uncertainties relating to this deficit were evident in the developing theory. There was the need for additional data to help further advance properties, connections, and the core category to the point of saturation. During theoretical coding, I uncovered various unanswered questions, which needed further exploration. To address this, I collected more data, to facilitate category saturation and enable the theory to develop via theoretical sampling (Glaser 1978).

Theoretical coding entailed coding for properties, connections, and links between the categories and the core category (Glaser & Strauss 1967). This was the stage where descriptive links between the categories were changed to more theoretical links e.g. (see table 9) (Glaser 1978). Theoretical links or connectors can be established and represented in a number of ways, including diagrams or models (see Chapter 4 Figure 1). Alternatively, researchers can use one or more of the theoretical codes, as described by Glaser (1978). Glaser (1978) identifies eighteen theoretical codes, referred to as coding families: the Six Cs, the Process Family, the Degree Family, the Dimension Family, Type Family, the Strategy Family, Interactive Family, Identity-Self Family, Cutting Point Family, Means-goal Family, Cultural Family, Consensus Family, Reading Family, and the Models Family. The theoretical codes known as the Six Cs is the family that Glaser (1978) recommends grounded theorists use because most studies fit into causes, consequences, contexts, contingencies, covariance's, and conditions for each data category. The Six Cs family, like the other coding families', is used to assist the researcher to identify the theoretical connectors between the various categories and the core category. This process required asking a number of questions when analysing the data. Glaser and Strauss (1967, p.74) provide questions to be asked of each category:

Is this category a condition of some other category? Is it a cause, context or a contingency of another category? Does this category co-vary with other categories? Is this category a strategy?

During theoretical coding, I used Glaser's (1967) coding families', but as there is very little explanation of how coding families' are applied, theoretical coding was possibly one

of the most demanding stages of the analytic process. I considered the 6Cs coding family (causes, context, contingencies, consequences, covariances, and conditions) and attempted to use them to integrate categories and determine relationships between them. My attempts at using the 6Cs was not very successful, as I found that not all aspects of the 6Cs family applied; more importantly, the data and codes suggested the theory *Negotiating a Safe Existence* was more of a process that participants went through. I therefore abandoned using the 6Cs and applied the process coding family (stages, phases, passages, and transitions). I could see the connections between each of the stages and how participants moved through transitions between their changing illness as they moved towards a new status as a dialysis dependant patient. The conceptualization of participants' concerns, and the manner in which they went about resolving them, were reflected in a variety of social processes, focusing upon relational aspects of their care. The process coding family enabled me to conceptualise the relationships between the substantive codes, as well as their relationship to each other. Glaser (1978) suggests that theoretical codes are:

...like substantive codes, are emergent; they weave the fractured story back together again. Without substantive codes they are empty abstractions" (Glaser 1978, p.72)

Following theoretical sorting of memos, I used diagramming to help visualise the connections between categories and the core category. The categories, which had emerged, reflected a new status of participants as they entered a critical juncture in their CKD. This necessitated participants developing an increasing awareness of a new illness trajectory and the transition, from being in a phase of monitoring, to one that was moving increasingly towards RRT. Early during the analytical process, concerns related to being safe in future renal treatment emerged. This concern was evident in numerous empirical indicators from the data collected from interviews and non-participant observation. Resolving this concern required participants to transition through three stages, including *Confronting a Deteriorating Self*, *Sourcing Information*, and *Traversing Disruption*. In applying the process coding family to the conceptualization of data, Glaser (1978) explains that:

The analyst cannot talk of process and not have at least two stages. Process is a way of grouping together sequencing parts to a phenomenon. Processing refers to getting something done which takes time or something happening over time (Glaser 1978, pp.74-75)

Category saturation occurred when theoretical sampling did not add any new information to the categories in the study.

3.21 Ethical considerations

Recruitment of participants to the study followed ethical approval through the University of Sheffield (see Appendix 1b), the UK National Research Ethics Service (NRES) and the local research ethics department where the research was conducted (see Appendix 1a). As a lecturer in renal nursing, I had an established professional relationship with renal nurses who had been previous students of mine. I had worked as an honorary staff nurse within the renal unit to help maintain my clinical skills as a renal lecturer. As part of the ethics approval process, a 'Research Passport' was required, which enabled me to collect data from the three sites. As a researcher, within a higher education institution, obtaining a research passport was important in obtaining a honorary clinical research contract, which enabled the research study to be undertaken within the NHS environment.

The chief of nephrology, who taught on the renal nursing programme, was a key gatekeeper to the renal service and was supportive of the study. Prior to gaining ethical approval, I attended two meetings of the local renal patient support group to discuss the proposed study. This was invaluable, since I heard first-hand accounts of treatment decision-making shared by patients during the meeting. I wrote memos following the meeting, which enhanced my theoretical sensitivity to the area under investigation.

I had secured an honorary clinical research contract within the hospital; this legitimized my role within the clinical setting. The primary contact in practice throughout the study was the renal clinical nurse specialist. I had to consider my researcher role, staff perceptions of me as well as the potential for power relationships developing. When planning my clinical time in the renal unit, I ensured clinical staff decided the times for my visits to the clinical setting. In this case, when a patient agreed to participate in the study, and I needed to undertake participant observation during the patient education sessions, this was scheduled by the renal nursing staff.

3.21.1 Consent and protection of subjects

Aging does not necessarily mean an older person is vulnerable, lonely, or indeed isolated. In fact, many older people lead productive active lives, with many older people being caregivers themselves. Despite this, natural physiological aging brings with it

physiological decline which can effect an older person's vision and hearing. This needs addressing when involving older people in research. In this study, I ensured that the size of font on information sheets was large and that included information was not overly complex. Also in terms of interviewing, I was mindful as a researcher that my interviewing style needed to give time for participants' to understand questions asked and allow additional time for questions repeated. The consent form and participant information sheets were piloted with a group of older people who were not directly involved in the study. These individuals were part of an older peoples group that contributed to nursing programmes. The feedback from these individuals was helpful, in that there was a need to use larger bold text and double-space the information sheets. I had to consider the physical status of older people in this study, which could have influenced their contribution to the study. Issues of fatigue, breathlessness, pain, and discomfort can contribute to differences in physical power between researcher and older people (Mody, et al. 2008).

In preparing older people to participate in the study, I had to consider how consent was to be managed. I adopted the process of both informed consent, as well as process consent. This required that, once I had secured consent from participants' (see Appendix 8) to participate in the study, I confirmed their consent during subsequent contact with each participant (Munhall 2012; Long & Johnson 2007). I had to consider that older people might have impaired capacity, dementia, or brain impairments (Johnston & Liddle 2007). As older people are a particularly vulnerable group, as a researcher I needed to consider any special measures required in gaining their informed consent. What constitutes informed consent is a debated issue, however (Wilson, Polloch & Aubeeluck 2010). According to Gillon (1986), informed consent is:

the voluntary uncoerced decision made by a sufficiently autonomous person, on the basis of adequate information, to accept or reject some proposed course of action that would affect him or her (p.113)

Within this study, informed consent was not viewed as an absolute, but instead as an ongoing process. Informed consent as a process is discussed by Wilson, Pollock and Aubeeluck (2010), who contend that this ongoing process of consent:

Continues after the consent form has been signed, creating a shared trust which goes beyond the mere explicit contractual arrangement. This form of consent hinges on the principle of non-exploitation and is based on the researchers integrity and awareness in each situation (p.143)

Only potential participants' who could read and understand spoken English were included in the study. When I discussed the study with potential participants, I ensured that they understood that they could withdraw from the study at any point, stressing their care and treatment would not be effected.

The exploratory nature of the study, meant considering possible negative effects of interviewing individuals who may become emotional and upset when discussing their experiences. Ashton (2014) who stresses the importance of nurse researchers giving advanced preparation for participants who may become distressed during interviews, particularly around sensitive topics. As a mental health nurse, I was comfortable in my capability to support individuals who express emotions, should the situation arise.

As a researcher, I needed to consider the importance of risk within the research. Risk, as it relates to older people, could lead to unpleasant memories and distress but also consider risks to myself as a researcher to ensure my own personal safety was addressed. This required that I adhere to the lone worker policy within the locality where the study was undertaken. Some older people may be lonely and therefore involvement in research and the opportunity to spend time with others offers some alleviation to their loneliness (Beauchamp & Childress 2001). Researchers need to consider that their role as researcher may offer more benefits more than risks. In the study, I was aware of this, as I had encountered three participants' who expressed to me how pleased they were to be involved in the study, as it broke up the monotony of their day. During a conversation with one participant, he became distressed and wept because he spent a large part of his day alone. When this occurred, I stopped the interview and offered him support and my concern was that my role had moved into that of a counsellor. I had discussed this situation with the unit Clinical Psychologist and, with the participant's approval, I was able to secure some support for him from the hospital.

3.22 Memoing

Memoing is fundamental to grounded theory. Theoretical memos are the building blocks of theory generation and as a reflective process, memos enable the researcher to analyse and make meaning from the data and the time spent with participants (Birks & Mills 2011, 2015; Gibson & Hartman 2014). Memos enabled the researcher to keep track of emerging theory and provided a mechanism to use when theorising about codes, categories, the core category and their relationships (Glaser 1978). Charmaz (2014) suggests memos:

...catch your thoughts, capture the comparisons and connections you make, and crystallise questions and directions for you to pursue. Memo-writing creates an interactive space for conversing with yourself about your data, codes, ideas and hunches (p. 162)

So crucial is theoretical memoing to grounded theory that, if researchers neglect to use memos or decide they are not important in their theory development, they are said to not be employing grounded theory (Glaser 1978). Memos are written during every phase of the research and are sorted and used in the analytical process to write the final substantive theory and subsequent report (Glaser 1978; Holton & Walsh 2017). Glaser (1978) emphasises the four main goals in memoing:

- To theoretically develop ideas
- To develop ideas freely
- To develop a memo fund
- To provide memos that are highly sortable.

Throughout the study, I kept a memo bank, which recorded my developing insights as my analysis progressed. Memos enhanced theoretical coding, as I was able to sort the memo bank and establish the interconnection and the relationships between the various categories as they related to the core category. The use of diagramming was helpful, as I could visualise the relationships between each stage of the developed theory and the numerous processes occurring during each stage of the substantive theory. At the outset, I found memoing quite cumbersome but then I realised that my memos were, as Birks and Mills (2015), indicate, snap shots of my experience during the study. Whilst I tried to set a specific time aside for memo writing, in reality, this did not always work. Memo writing, therefore, became an unscheduled activity, as I could not predict when I would be writing them. I did maintain a researcher field diary, which also documented aspects of data collection and queries that I noted down; fieldwork notes were helpful when I sat to write memos. Theoretical sensitivity was enhanced through memoing as I engaged with the data, questioned it, and tried to interpret it, in the context of my developing insights, as can be seen from the two memo examples below (see Tables 10 & 11).

Table 10. Memo – being kept alive

<p>Memo : Code - Being kept alive - Source - M10-S1-EDC-09/09</p> <p>Is the main concern of participants about being kept alive or is it safety in living with their CKD. I am more inclined to think it is about safety in the treatment from what I have seen. There does seem to be a preoccupation with best fit of what will work but how they assimilate/ integrate the demands of therapy. There is a forward processing of individuals - an almost welcoming to the club of the new arrival. It almost seems that the induction to the newbie into the club is a rather mechanistic process. I am conscious of the relationships, which emerge during interaction between patients, families' and professionals. The professionals occupy it seems a strong educational role advising, processing and ensuring that the transmission of information is unfolded. The chief concern during this initial stage is one of how to comprehend and accept, deny or challenge specific advice & information and knowledge to the affected individual. In the visit today, I was struck with the reaction of treatment plans and what seemed a distinct fear of PD (I remember Charles's thoughts!)...but an acknowledgement of being alive. It seems today there was lots of personal struggles surfacing.</p>

Table 11. Memo: Competence & Safe Care

<p>Memo: Competence & Safe Care - Source: M22-S1-ITNV - DC-09/09</p> <p>During initial interviews, I am conscious of the psychological impact that CKD brings to patients. The burden of having to adjust, accommodate a new way to survive is clear. Whilst the timing of the referral to the education clinic is important (e.g. stage of CKD, eGFR, general status) there is this initial confrontation that patients are now/ entering a time limiting trajectory. Time as a resource, is taken over by the illness and no matter how patients attempt to control of his, it is now out of their control. Quite early on in this study, the core concerns focused around competence, capabilities and the application of new knowledge. It is interesting to note how some patients adopt a positive approach - information gatherers, seekers and use this to almost dictate / control the process. It is like a tension between letting the illness take control or attempt to keep it at bay. Repeatedly coming through the data is feeling safe in the end. Both patient directed care as well as that provided by health care team. Safety manifests in the language used by patents.</p>
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3.23 Data management - use of computer-assisted qualitative data analysis software (CAQDAS)

From the outset of this study, I made a conscious decision to make appropriate use of a qualitative software package to help organise my study. To assist with the storage and retrieval of data (codes, memos, documents, digital recordings) relevant to this study,

QRS NVivo (www.qrsinternational.com) Version 8.0.335.0 was used throughout the study. I had made a decision to have a transparent system for storage of my work, although in hindsight I had not considered the significant amount of work that I needed to undertake to enable me to develop a level of working competence with the software. The additional costs incurred in purchasing the software, along with my attendance at an NVivo workshop in London, were a good investment once my familiarity with the software improved. The use of CAQDAS, whilst requiring considerable time to master in the early phases of the study was invaluable as a novice researcher.

The value of CAQDAS in grounded theory studies is contested, since it plays no real part in the conceptualisation of data (Holton & Walsh 2017). There are obvious benefits to using CAQDAS in research, particularly since they assist with the storage, retrieval, and organisation of data, as well as providing an audit trail of the research (Birks & Mills 2015; Gibson & Hartman 2014). Whilst these are invaluable in the conduct of qualitative data analysis, this is not so for a grounded theory study. Glaser (2003) argues that computer software has no role to play in the conceptualisation of data, advocating that researchers focus their time on developing their skills in conceptual memoing. A greater concern with the use of computer software is that they may drift the researcher towards description and away from the primary purpose in grounded theory, that of abstract conceptualisation. In doing so, this has the potential to prevent the theory from moving beyond detailed description to conceptualisation. During the study, NVivo was only used to store and sort data, as well as storing memos during the research.

3.24 Reflexivity

According to Parahoo (2006), reflexivity is strongly associated with qualitative research, which focuses upon in-depth exploration of topics, concepts, and beliefs (Engward & Davis 2015). Lincoln and Guba (1985) suggest that reflexivity is concerned with an explicit recognition of constructs, which may influence a study. Schwandt (2001), who defines reflexivity as, offers an alternative view of reflexivity:

The process of critical self-reflection on one's biases, theoretical predispositions, preferences. An acknowledgement that the enquirer is part of the setting, context and social phenomenon he or she seeks to understand and as a means for critically inspecting the entire research process (p.224)

Reflexivity is a vital thoughtful process, which strengthens a researcher's conscious awareness of their role throughout the research process (Finlay 2002). Engward and Davis (2015, p.1532) suggests reflexivity enables the explicit demonstration of transparency at multiple levels, including 'personal, methodological, theoretical, epistemological, ethical and political'. Gentles, et al. (2014) examined the origins of reflexivity in qualitative research, suggesting that one of the main reasons reflexivity has developed within qualitative research is because:

Specifically, researchers' roles and influence in shaping the representations of participant experiences are never completely accounted for or addressed (p.3)

Making explicit personal beliefs and my own orientation to the field of enquiry ensured that I was adopting a reflexive stance, through which the quality and rigor of qualitative research can be enhanced (Engward & Davis 2015). Engward and Davis (2015) suggest:

The adoption of a reflexive stance is therefore a possible means of enhancing the quality of qualitative research and establishing credibility both as a necessary element of quality and as a means of making the researcher's position transparent (p.1531)

In the context of this current study, I adopted a reflexive stance throughout the study, from the initial inception of the research, with the establishment of researcher positionality, and establishing transparency of personal assumptions and beliefs. A reflexive stance was established throughout the study and at key points within the research. The pre-conceptions and prior interests I brought to the study as a researcher were an important component in reflexivity. Engward and Davis (2015) point out the importance of:

researchers not seeing data as 'standing alone....and that the emergent analysis can take various forms which may or may not be dependent on what the researcher consider credible data (p.1531)

The above point further stresses the need for researchers to appreciate that data collection, and how data is understood, is influenced by their presuppositions, which direct both the type of data and the strategy for its collection (Engward & Davis 2015).

3.25 Conclusion

This chapter provided a detailed account of the rationale and choice of methodology for this study. The debates and tensions surrounding grounded theory have been discussed.

The procedural aspects of the study have been demonstrated, in terms of theoretical sampling, data collection, and analysis using constant comparative analysis. The importance of memoing as a critical feature of grounded theory was highlighted and deemed integral to the process of theoretical sorting. In the next chapter, the substantive theory *Negotiating a Safe Existence* is discussed, by drawing upon the voices of participants' in this study, to stay faithful to their perspectives. Concepts and sub-categories are presented, demonstrating their properties, dimensions, and their inter-relationship to the core category, in explaining how older people resolve their main concerns for safety in care.

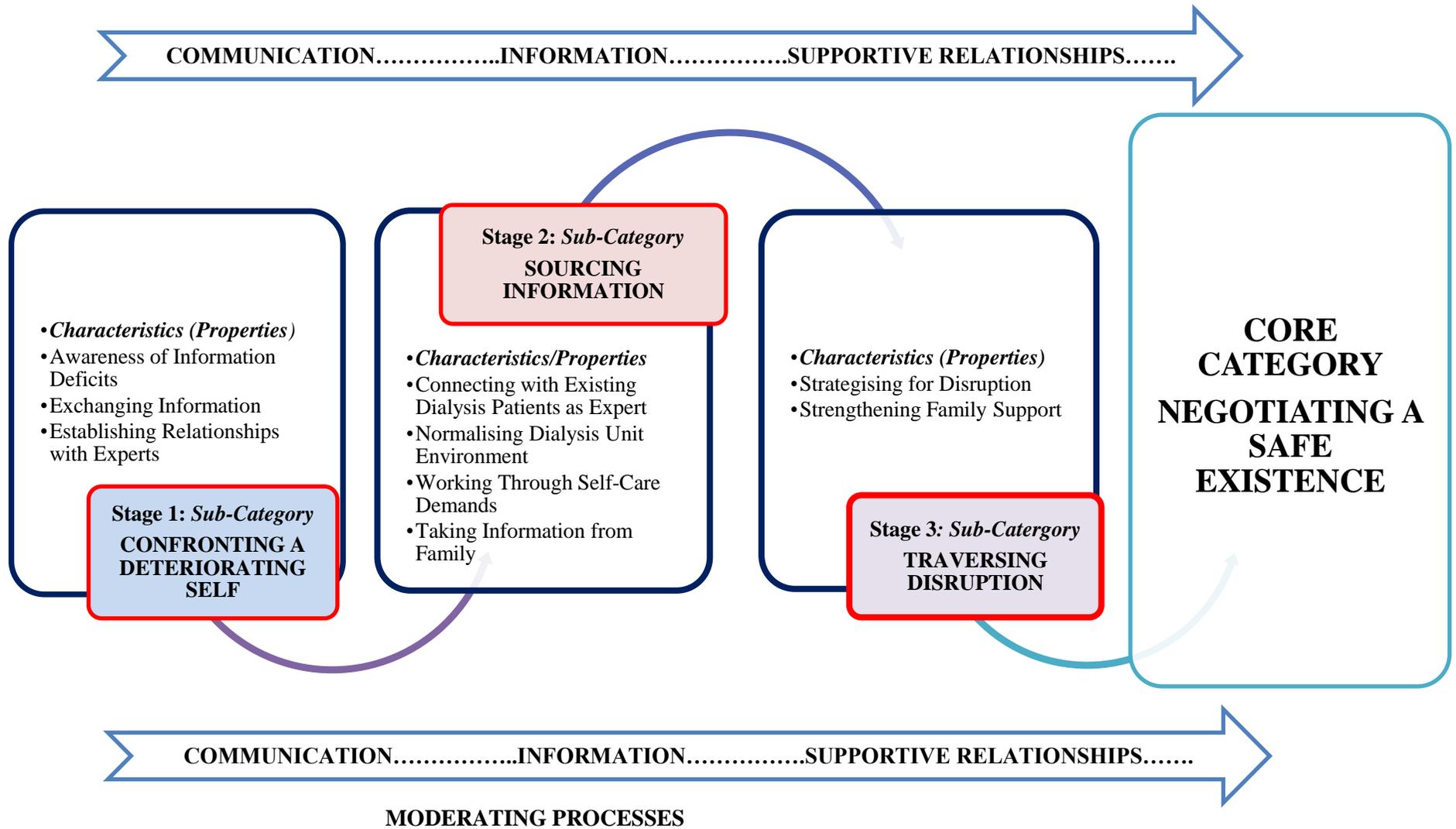
CHAPTER 4

FINDINGS

4.1 Introduction

The aim of this study was to develop a theory that accounts for the social processes involved when older people, with CKD stages 4 and 5, consider treatment. Therefore, the grounded theory presented here explains how the main concerns of older people were resolved. The substantive theory, *Negotiating a Safe Existence*, represents a three-staged process, comprising three sub-categories: *Confronting a Deteriorating Self*, *Sourcing Information*, and *Traversing Disruption* (see Figure 1). The theory describes the strategies older people use when treatment decision-making was encountered. The first part of this chapter discusses how the substantive theory emerged. The evolving nature of the developing theory is then discussed, as are how each of the three sub-categories are related and integrated. The presentation of the grounded theory draws upon primary data collected to demonstrate the grounding of the substantive theory.

Figure 1. Substantive Theory – Negotiating a Safe Existence



4.2 Negotiating a safe existence.

Negotiating a safe existence embodies the core concern of older people who used strategies to ensure safety in treatment. Participants' awareness varied regarding declining health status; those with knowledge appeared more engaged with possible treatment options, in contrast to those with limited knowledge, who engaged less with treatment decisions. The importance of education in enabling participants to make a treatment choice was clear.

Perceptions of threats to personal safety resulted in a series of tactics and negotiations, with the goal of either protecting self or managing self. Protecting self, reflected dialysis treatment being hospital based and managed directly by renal staff. This was contrasted with managed self, which represented taking personal responsibility, especially in managing home based PD. Negotiation represented the central category within the substantive theory, *Negotiating a Safe Existence*. Negotiation conceptually integrated the processes and strategies that older people engaged with during their treatment decision-making. Interpersonal processes linked to communication and supportive relationships moderated negotiation. Negotiation occurred during various levels of engagement, from the consultation period with the nephrologist, where treatment options are presented, through to locating information to inform decisions. Negotiation conceptualised relational components of decision-making within the professional communication with experts and through the nexus of family relationships.

Negotiating a Safe Existence was, therefore, a theory about how older people developed a series of tactics, strategies, and evaluations in order to access their preferred treatment modality. This involved *Confronting a Deteriorating Self*, *Sourcing Information*, and *Traversing Disruption*. As highlighted earlier in this thesis, there is a paucity of research within nephrology, regarding the experiences of treatment decision-making of older people. My intension is that, through privileging the voices of participants' in this study, a more meaningful account of the treatment decision-making concerns of older people could be conceptualised.

Older people were referred to nephrology services when their kidney function decline had reached a level where preparation for renal replacement therapy was needed. The first stage of the substantive theory, *Negotiating a Safe Existence*, commences during consultation with the nephrologist. The first sub-category, *Confronting a Deteriorating*

Self, comprises: *Awareness of Information Deficits*, *Exchanging Information*, and *Establishing Relationships with Experts*. *Awareness of information deficits* is characterised by two specific dimensions, including *recognising a changed self* and *managing uncertainty*. The characteristic *Awareness of Information Deficits* comprises the dimensions *Receiving Information on Progress* and *Recognising Dialysis is Needed*. Finally, the characteristic *Establishing Relationships with Experts* comprises the dimension of *Recognising the Nephrologist as Expert*. The first sub-category, *Confronting a Deteriorating Self* (see Figure 2) will now be discussed.

4.3 Stage 1: Confronting a deteriorating self

Confronting a Deteriorating Self represents stage one of the substantive theory, *Negotiating a Safe Existence*. Older people arrived at this stage, having followed a primary care pathway, which focused upon managing declining renal function. This stage was characterised by an awareness of information deficits, which compromised two dimensions namely: *recognising a changed self* and *managing uncertainty*. The strategies used by older people at this stage resulted from developing an understanding of the seriousness of CKD. Varying degrees of information deficits existed regarding declining kidney function. *Confronting a Deteriorating Self* is characterised by *awareness of information deficits, exchanging information, and establishing relationships with experts* (Figure 2).

The supportive relationships participants developed with healthcare staff enabled participants' to understand the importance of their changed health status. Kidney function tests enabled an understanding of changing kidney function and its physical impact. Knowledge of CKD, its treatment, and management varied, indicating differing awareness levels. The consultation with the nephrologist was an important critical illness juncture in which participants' realised they had little idea what was happening. A changed CKD status and increasing knowledge deficits ignited feelings of anger, denial, and uncertainty. The family provided physical and emotional support when physical deterioration was evident, as humorously recounted by Harold and his wife, Ada:

“Can I say that last night, he’s very weak ... very weak, because he’s lost such a lot of weight. But I got him out of the bath last night and (laughs) you know, /I just without looking ... I give him a good rubdown, you know with a [...and then we went out the bath, and I said, “Put your hand on my shoulder”, so Harold did... and what did we do, we went through into your bedroom, didn’t

we singing the song, “Oh, we ain’t got a barrel of money” (singing) and this is what we sing as we go” (Interview – Harold & Ada (wife)

4.3.1 Awareness of information deficits:

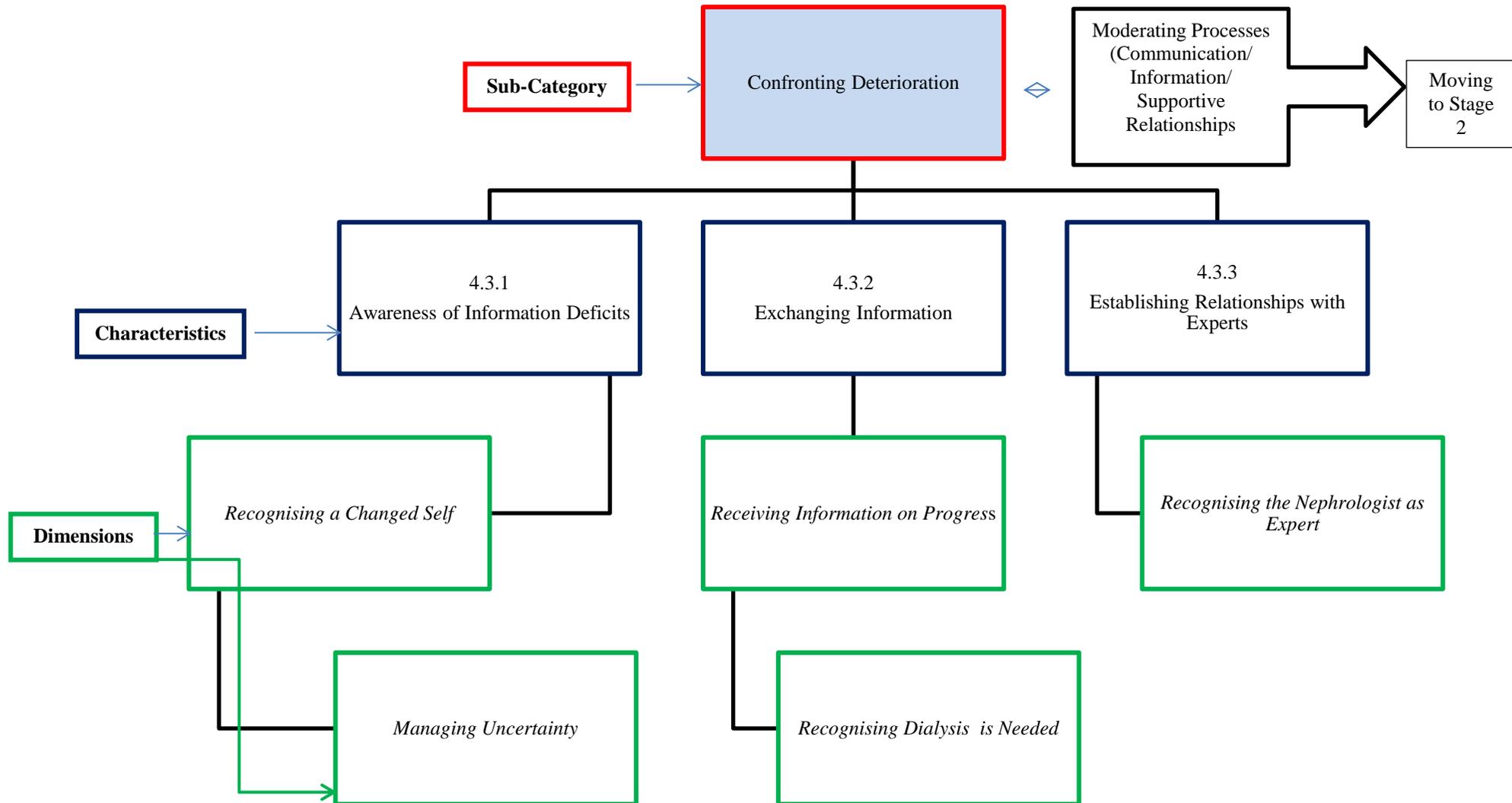
The majority of participants had limited awareness concerning declining physical status due to worsening CKD. Awareness levels varied between having no knowledge of deteriorating kidney function to a low level of awareness at the point when treatments were being considered. Mick relayed his complete surprise when he was referred by his doctor to the nephrologist:

“That’s as much as I know until I went, I had a slight stroke at the back end of November, when I came out of hospital, I had to go and see my GP, and he just said, “I’m referring you to the Renal Unit”, I hadn’t a clue what he was on about. Um, he never explained what was wrong, he just said, “I’m referring you to the Renal Unit” (Interview: Mick)

Peter described how he was informed by medical staff whilst in hospital with a chest infection that, as well as having heart failure, his kidneys had failed due to poor blood flow; chronic cardiac disease resulted in Peter developing renal failure:

“When I was, I was in hospital with pneumonia, that was 2008 and err, I didn’t know anything, the doctor came one day and we were both there, he said “oh you’ve got heart failure and kidney failure” (Interview: Peter)

Figure 2. Stage One: Confronting a Deteriorating Self



Tom, believed he had done everything possible to maintain his health, yet kidney failure arrived much sooner than he anticipated, as he explained:

“Well that was it erm, what can I say, it knocked me for six and I really thought I was on the upward hill, being stable and doing okay and then out of the blue this hits ya. I have been good and looked after myself but it’s decided to come at me now...it’s a shock really...it is” (Interview: Tom)

The above accounts from Peter, Mick and Tom echoed similar stories from other participants concerning the sudden arrival of kidney failure. Tom described how his deteriorating physical state was reinforced through information given by the nephrologist. The results of renal function test shared by the nephrologist during the consultation indicated that a new stage of kidney failure had arrived; this reinforced to Tom the reality of his condition. As can be seen, participants faced the reality of their changing condition, and, for many, it was completely unexpected. This led to a growing realisation that CKD was more serious and that their perspective of themselves had changed.

Recognising a changed self

Information shared during consultations with the nephrologist, meant participants had to face up to a state of obvious physical deterioration, marked by increasing symptoms; for some, this meant being confronted with their mortality. Sudden changes in physical status occur in CKD and can bring unexpected life threatening consequences. For example, Harold experienced a life threatening bleed from his central vascular catheter:

“First got it put in the neck there now that, I did have trouble with that and I got a bit frightened with it because erm they’d been giving us tablets to thin my blood down. Now when they put this in my neck and it started bleeding I couldn’t stop it bleeding now that night, I bled all night and I kept putting patches on, and when I woke up the pillow was absolutely full of blood, I thought where’s all my blood gone, you know I can’t have any blood left in my body and me erm pyjamas there were covered.... soaked with blood like black pudding, me vest, and the doctor took it away and give us another one.” (Interview: Harold)

Bill, a retired factory worker, tearfully recalled the devastating impact of CKD on him when he realised the seriousness of his condition:

“Oh, God. Let me go, quick, up there.....heaven. And I sat there the other evening and I was crying my eyes out....Nobody wanted me and I thought, “Oh, well, that’s it, I’m on the way out, I might as well get measured for a box.” (Interview: Bill).

For Bill, feeling abandoned and anxious about his life, meant it was difficult for him to face up to a life that was potentially cut short. Accepting treatment withdrawal is an acceptance of death, in which there is no choice, a view shared by Arthur:

“It was sort of very brief and it was a sort of inevitable thing, you know you’ve got no options about this; you’ve got to go ahead with it.” (Interview: Arthur)

The vagueness in how CKD symptoms progressively worsened, and the nephrologists’ certainty that dialysis would definitely be commenced, exacerbated feelings of uncertainty. Ian shared his feelings of uncertainty about this:

“It became obvious, I kept going back to my doctor because I felt very sleepy, or else they would call me in ...I was told that, er, I would probably at some point in the future, not necessarily near future ... need dialysis, either the, the first one, and I can’t remember the terminology for, or the HD.” (Interview: Ian).

Bill described the lack of information he was given as his CKD changed:

“They’ve suspected it for some time, but obviously nobody had said anything, but then I knew for definitely that, er, my kidneys were starting to fail.....loss of appetite was the most noticeable one for the last month or 2 before, I was taken ill, I really didn’t want to eat very much at all..... and people were starting to notice, the family were noticing, what was wrong with me, why didn’t I want to eat my food? Oh well, you know, I don’t feel very hungry, not realising what was happening to me.....said yeah, I’ve made an appointment for you to see a doctor at the hospital, he’s going to have a word with you about it.....and it was a bit of a surprise and a little bit of a shock to realise that, and I didn’t realise exactly what was involved till I started looking into it a little bit, about dialysis and what is involved in it. (Interview: Bill)

Confronting a Deteriorating Self is a catalyst to developing increasing awareness (see Figure 2). Some participants were aware of their renal condition but the speed and suddenness of its arrival along with the need to decide on treatment came much sooner than anticipated. Doris explained when the nephrologist showed the kidney function graph of her declining renal function, she knew that she had to consider treatment; dialysis was fast approaching:

“I seem to remember that I thought ... it ... you know, that I would hit this dialysis line on this graph within about ... on average five years, well its coming up for three so I thought I had a little bit longer and then the nurse at the dialysis unit said that in ... in the referral letter the Dr had said I would be on dialysis in approximately a year, so that was a shock, because I thought ... I’ve always faced this thing positively, I’ve tried to ... not think oh God I’ve got, you know, I’ve got a terrible disease and, you know, woe is me, I’ve always thought right make the best of every day, do what I can ... and it was a bit of a shock that

I only had a year left to do what I want to do before my ... as I keep saying, my wings are clipped.....Well I ... I've been doing quite a bit of travelling you see so I'll have my wings clipped a bit” (Interview: Doris)

Managing uncertainty

Participants' concerns over their deteriorating condition were intensified by the levels of uncertainty they experienced. The reality of their changed situation, evidenced by worsening renal failure symptoms, was difficult to accept. Treatments, decided in advance by the nephrologist, were presented during consultations. An increasing level of symptom awareness e.g. breathlessness, anaemia, and itching ignites the importance of the management stage of CKD, which focused on the need for dialysis. Ongoing uncertainty resulted in participants' engaging in sense-making behaviours to access personal and professional information sources where possible. Information gathering behaviours included 'seeking out' and 'locating relevant information' to help manage uncertainty. These strategies provided a degree of control of the situation whilst participants' clarified what was happening to them.

4.3.2 Exchanging information

Participants' engaged in a process of *exchanging information*, characterised by a readiness to receive information to support treatment decision-making. Information exchange during the nephrology consultation resulted in participants' realising treatment was needed. *Exchanging information* was explained through two dimensions, including *receiving information on progress* and *recognising dialysis is needed*, which are discussed below.

Receiving information on progress

The diagnostic stage of CKD, and its severity, was characterised by *exchanging information* with renal healthcare staff. This stage was important in understanding the information sharing practices between nephrologists and participants. Information exchange was connected to monitoring of renal function, which heightened the importance of making decisions concerning dialysis. The time prior to commencing dialysis was a focus for participants, particularly when the nephrologist indicated a possible start date for dialysis. Iris realised dialysis was inevitable and that a decision was needed within a short time period:

“Well the Dr said , I think, I have ... she hasn’t really said an awful lot apart from that, er, we would need to think about dialysis er but I don’t think she thought that it would be for a few months” (Interview – Iris)

How the nephrologist shared information and how they involved participants in treatment decisions varied; this signifies the importance of the consultation as an information-sharing endeavour with participants. For example, Mick explained the options offered to him:

“date when it would be due and that was it, and then he went through all the options what there was you know, I could either have this bladder on which would take it away, or I could have the erm what they call it, the fistula in my arm which would give us a bit more leeway in doing jobs in the garden .” (Interview: Mick)

A number of participants highlighted the influence of the nephrologist in directing their treatment decisions. The sharing of renal blood results and eGFR status by the nephrologist signalled that, within a pre-determined time span, dialysis would be needed. Some participants recalled limited treatment options discussed with the nephrologist.

Recognising dialysis is needed

Recognising dialysis is needed is a dimension of *exchanging information*. The focus during nephrology consultations was the inevitability that dialysis would be commenced. Few participants’ recollected discussions concerning non-dialysis care as a treatment option. Harold recollected how the nephrologist presented the need for having dialysis, indicating that he might not have considered dialysis had he been informed of non-dialysis as an option; his decision for treatment was influenced by the information given:

“No. I think if they’d have put that thought in my mind, I’d have said, “I might agree with you to not have dialysis”, but having ... been briefed, um, about both (pause) I decided to go for the machine one, in, over there, even though, it, um ... the one I didn’t want at home, the home one I didn’t want, because it seemed too fiddly for me. I mean, having to clean anything and everything every day, three or four times a day.”(Interview: Harold)

Some participants’ delayed making a decision as a strategy to manage uncertainty related to treatment outcomes, as recounted by Maurice:

“Sometimes, I just say, Oh, well, we’ll wait and see. You know, and just put it that way” (Interview: Maurice).

James found acknowledging kidney failure difficult and his own assessment that his kidneys just needed to be “cleaned up” highlighted his limited awareness concerning the seriousness of his condition:

“I thought, well”, I put my hands together; I thought, well, I’m not like that, you’re a long way”. ... Er, mine (kidneys) just want cleaning up... You know, they’ve gotten so clustered in together” (Interview: James)

The emotional impact of dialysis was partly managed by rationalising the positive gains dialysis provided. This resulted in some participants’ working through treatment options, confirming that something positive was being done for their kidney failure. Dialysis maintains life and, whilst for some participants, life may be shortened, they became resigned to this. A gradual adjustment is linked to increasing awareness of the benefits of dialysis in maintaining life. Recognising dialysis was needed and having to make a treatment choice was not always viewed positively. Doris, a widow, led an active life and whilst being independent and in control, this was a different matter with her illness, as she explained:

“I would have preferred it if Dr or somebody, had said to me this is what you’re having, get your head round it ... and I would have accepted that, if you’d ... you know, ...and you said well we’ve looked at your case notes and ... and you’ve got ... because you’ve got this, this and this you have to have haemodialysis I’d have got my head round that and I would have accepted it ... Yeah I would have accepted that, on medical grounds, because you’d made a medical decision and that was best for me ...now what threw me was the fact that whatever, you know, whatever is wrong with me I’m suitable for either treatments, I can have either, now that was hard” (Interview: Doris)

It interesting that involvement in treatment decision-making is not always seen positively. Doris’s reaction to the need for treatment had come sooner than anticipated. Thus, her emotional readiness to engage in making a decision may explain her initial distain of being asked to choose a treatment modality by the nephrologist. This leads to the concern of negotiating a safe existence and participants’ encounters with experts.

4.3.3 Establishing relationships with experts

Relationships established with the healthcare team were important when facing treatment decisions. Participants’ valued the communication approach of healthcare team members and emphasised their skills in sharing information. Participants rarely questioned the wisdom of the nephrologist during treatment discussions. The relationship was critical in

understanding the importance of their expert care. Not knowing what was happening resulted in uncertainty. Dotty remembered how important her caring doctor and nurses were and their special skills in helping her:

“My Dr Oh he’s, oh he’s lovely It’s nearly first name terms now ...and the specialist nurse, she’s, oh she’s marvellous . I think she’s a hell of a nurse. She makes you feel a lot at ease when you go in and she, if you are a bit worried, she soon settles your mind you know.” (Interview: Dotty)

Forging relationships with renal staff was voiced throughout most of the interviews with participants during their stage of *Confronting a Deteriorating Self*. Relationships provided an important ‘anchor’ point during the early stage of treatment decision-making. All participants held the nephrologist in high regard as the expert and the prime information source adding a sense of safety.

Recognising the nephrologist as expert.

Information provided in a caring way, was highly valued by participants. Stanley shared his experience of meeting his doctor, who he praised:

“I mean my doctor is absolutely excellent, he answers every single question I’ve ever, you know ... ever asked sort of thing, he’s a wonderful source of information, and he’s really good at explaining things in a way that’s, you know, quite easy to take on board” (Interview: Stanley).

Peggy, a widow, lived with her family in a remote part of the countryside. She was highly dependent on her family and, whilst she vividly recalled how frightened she was regarding her CKD, she spoke with fondness regarding her caring doctor; the relationship developed with her doctor was very important:

“Well, I was worried. Really worried because I didn’t know how long it would be or... or what would happen. But he’s such a nice man that, you know, he’s really interested and I couldn’t have a nicer chap and he put me on these here injections” (Interview: Peggy)

Relationships, formed, were an important channel through which information was provided concerning CKD treatment. The consultation with the nephrologist is a time of uncertainty, although being receptive to the expert influence of the nephrologist, enabled the management of uncertainty. Ian’s treatment was decided by his doctor and whilst Ian lived alone and was self-caring, with no social support, he was swayed by what the nephrologist presented to him concerning PD being the best treatment option for him:

“he explained the machine treatment, also the bag treatment.... and he said that, because of the distance that I travel away I should do it at home. He said it would be much easier for me to be at home, and when you’re not being under dialysis then you could hopefully live your life all right round, whereas you’ll be trailing backwards and forwards to hospital, he says its very time consuming and everything else, yeah. Well, er, I was immediately attracted to the thought of doing it at home for the reason that, hopefully if, everything goes well and I am able to cope with it” (Interview: Ian)

The nephrologist’s consultation, centred upon the changing illness trajectory, which signified a new critical illness juncture; a juncture marked by increasing decline in physical well-being. The nephrologist’s communication emphasised the inevitability of dialysis. The nephrologist’s presentation of dialysis focused upon the benefits of haemodialysis, with little discussion concerning risks of treatment. Consequently, for some participants, there was no discussion concerning individual treatment preferences. The nephrologist, directed treatment decisions based upon their own personal preferences; this style of decision-making reduced participants responsibility in decision-making. Iris felt there was a definite bias towards PD therapy during the discussions she had with the nephrologist.

“... then I’d need to think seriously about at home and actually the impression I’ve had, it hadn’t actually been said, but I’ve had the impression that they’d prefer you to have it at home. Whether that’s right or wrong I don’t know but that’s well, kind of you get the feeling that they want you to go the other way towards doing it at home...the way it was really said to me.” (Interview: Iris)

Accepting, unquestionably, the nephrologist’s advice resulted in a treatment decision taken based upon limited information. For example, during Ian’s consultation, the focus was on what the nephrologist had already decided, which was that PD would be the best treatment for Ian, without any discussion of other alternatives:

“And he said yeah, this, in his opinion that would be probably the best way of doing it at the moment, he said....because if you travel back and forward to the hospital... But, he said, er, there’s a few factors to consider; you would have to go into hospital first of all to have the operation for the tube.....then, when that’s settled down, you go back in for some, a little while, where they monitor your, why, how you cope with the dialysis, can you.....do it on your own” (Interview: Ian)

The inevitability that dialysis would be started, along with the limited treatment options available, was recounted by Harold who came away from his short meeting with the nephrologist feeling he had no choice but to accept the nephrologist’s decision:

“The meeting with the doctor ... It was sort of very brief and it was a sort of inevitable thing, you know, you’ve got no options about this, you’ve got to go ahead with it”. (Interview: Harold)

In contrast, when the nephrologist presented the negative effects of hospital haemodialysis, this created the view that PD was the optimal treatment; directed decision-making was strengthened when participants have trust in the nephrologist. Accepting a self-care therapy, e.g. PD, required participants to negotiate support with the nephrologist as a component of the renal home care package. This involved re-visiting personal capabilities when deciding how treatment problems related to safety could be managed, should they arise. When Dotty discussed PD with the nephrologist, she had, no doubt that hospital based haemodialysis treatment was best, due to the amount of home adjustments PD required:

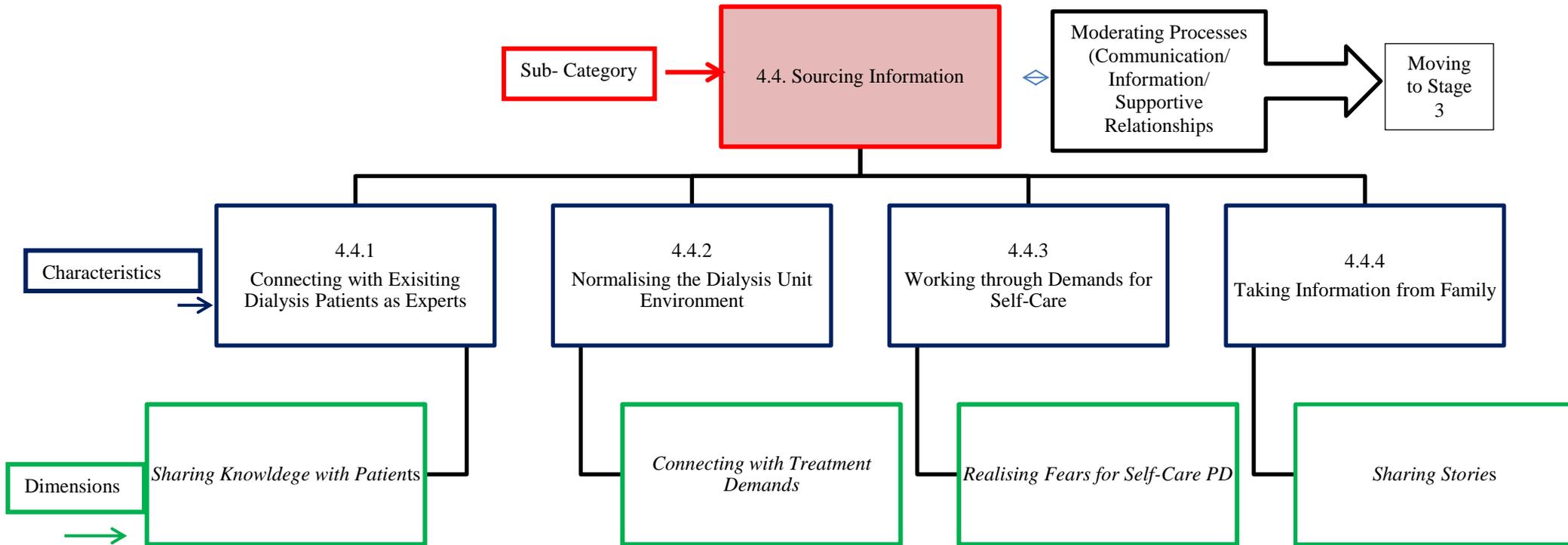
“Well the Dr said you have to have a special room for the storage ... Erm, yeah, you have to have it cleared so there’s plenty of room for storage. Yeah, loads of thingy. And thinking of our spare room, it’s full of junk anyway and I was thinking. ‘goodness me, I couldn’t clear that out’. Erm, and as my husband says, erm, with the hospital just being away, that seems the easy option to us.” (Interview – Dotty)

As participants moved through stage one of *Negotiating a Safe Existence*, a number of moderating processes were important, including interpersonal communications, information provision, and the supportive relationship of the caring healthcare team. Stage one focused upon *Confronting a Deteriorating self*, and the importance of gaining information and focusing upon the renal healthcare team’s expertise during decision-making. It is during this pre-contemplative phase of decision-making that participants become aware of the temporal nature of decision-making and that, within a specified time period, dialysis would be commenced; safety remained the main concern treatment. Understanding the changing context of CKD illness was a drive for participants in moving towards the second stage in *Negotiating a Safe Existence*, which focused upon *Sourcing Information*. Four properties conceptualise the sub-category, *Sourcing Information*, (see Figure 3) including *connecting with existing dialysis patients as experts*, *normalising the dialysis unit environment*, *working through the demands for self-care* and *taking information from family and friends*, which will now be discussed.

4.4 Stage two: Sourcing information

Sourcing information (Figure 3) represents the second sub-category of the emergent theory, signalling the focus of participants to obtain and understand information on which to base treatment decisions. *Sourcing Information* arises out of the consultation with the nephrologist and needing to understand more. Information gathering strategies are initiated, which serve to locate and identify information sources. Information is obtained through relationships with the healthcare team during learning encounters, which centred on treatment options, as well as connecting with existing dialysis patients as experts during the dialysis unit visit.

Figure 3. Stage Two: Sourcing Information



4.4.1 Connecting with existing dialysis patients as experts

Participants used questioning and listening behaviours focusing upon *connecting with existing dialysis patients as experts*, which enabled authentic stories of living with dialysis to be gathered. Receptivity to information enhances understanding of the impact of treatment upon self and family. Connecting with patients undergoing dialysis *through the sharing of knowledge*, a dimension of *connecting with existing patients as experts* was an important component of decision-making. Participants' engaged with existing dialysis patients, using prompts e.g. "how is dialysis", which then opened up conversations often of a humorous nature; some participants' remained silent and did not engage. The opportunity to access information directly from current dialysis patients was valued. Dotty remembered speaking to a patient during the dialysis unit visit and how this helped:

"Oh when I went on the visit, I was talking to one of the old ladies that was in there. And they've, they didn't, wasn't worried about it, you know. That takes a lot off my mind. You know, erm, it's alright people saying you're not, I'm not worried no, but there's still a little niggle at the back of your mind, but now I felt a lot, lot better, going and seeing it. The visit definitely helped.... when they said to go down the dialysis and have a look, you know, right it's coming quicker than what I thought, you know. But erm, when I got there, I was quite, it was quite interesting, you know. It's all, how can I put it, how they do things, how, how the machine does it and, you know, and how it helps peopleI was asking her what it was like. She said it was, actually she said it's just, you just sit near there and let it gone with..., it doesn't hurt you." (Interview: Dotty).

Kate valued the opportunity to speak to patients during the dialysis unit visit, which calmed her fears of the unknown and her concerns about where she would feel safe:

"Well I... I just said like what is it like, you know, he said oh yes, it's lovely in here. So I wasn't bothered if I had to go in, I wouldn't have been bothered but I was just a bit wary about doing it at home" (Interview: Kate)

The reality of living with dialysis, as told through the stories of existing dialysis patients, informed participants about the benefits and hazards of dialysis. This facilitated a process of 'unpicking', which involved uncovering the relevance of gathered information to self; information from current patients was seldom questioned. Treatment specific information (e.g. its purpose, action, side effects) shaped decision-making. Participants who took an active role in decision-making secured information concerning hazards associated with PD, e.g. infection (peritonitis); decisions are based upon the benefits and consequences of the therapy. Alex's account reflects similar experiences shared by participants in this current study, who sought to integrate information from various sources to enable an

informed decision. Alex was considering PD therapy and had attended an open day event for prospective patients, where he gathered treatment related literature, but he also used the opportunity to meet patients and healthcare professionals to gain further information:

“I’ve read, um ... I’ve read books that I’ve picked up at the open days in the hospital, one of which I borrowed. Um, it said that, um, there are infections risks if you’re not scrupulously clean, um, and that if, um, you repeatedly get infections then that could jeopardise the ability for you to continue with that particular system and you may have to, um, change to the hospitalised version of it. So talking to others about the risk of infections and where the tube goes in and of course the risk with the ones externally in hospital, erm, again of infections, you know, general infections while the process is being done, I know they keep everything sterile but there’s always the chance, you know.” (Alex)

Field notes from the observational session (see memo 12) with Alex highlighted the dynamic nature of the relationship between the renal nurse specialist and the family. I noted the positivity of Alex to absorb as much as he could, which was quite a contrast to many other participants, who negated any consideration of self-care. The powerful dyadic relationship between Alex and his wife was a supportive force as they strategized and used problem-solving strategies to embrace treatment. The transcribed field note of Alex, (see table 11), and his comment during the teaching sessions, highlights the complex nature of the education session but one in which participants such as Alex attempted to assume some degree of control.

Table 12. Field note memo- Alex

Alex (150810)– Education session (Field note Memo extract)

Assimilating information/ Strategizing/ Normalising/

I am struck with the **inquisitiveness** of Alex to learn more about his modality. It seems he is keen to have home PD. He is **searching** for information and demonstrating **active information seeking** strategies. This observation session was a very engaging session which demonstrated how participants' actively seek information. I am also struck with the **professional language** that is used by the nurses, it seems quite off putting as clearly Alex didn't quite understand. This was immediately picked up by the nurses who changed her strategy. What I was also struck with was the assumption by the nurse that Alex had definitely wanted dialysis.

Much of the session focused around **information transfer** of the complexity of PD and it was interesting to watch the professional artistry on display – the teaching skills of the nurse in conveying complex information. The role of the nurse was the provider of information whilst Alex as the receiver looked on. Alex's wife was present and the **joint focus on logistics** of bringing treatment into the home and how this could be managed was **worked out between them both**; clearly the decision to consider PD was a **joint affair**. The environment was supportive and relaxed and humorous despite the reality of the situation. Alex felt he needed to give the PD anatomical model a name...maybe it was his way of **normalizing** the whole thing.....the PD model from then onwards became known as 'Shelia'.

“I attended the open day and took copious notes and I know have loads of questions. The Dr has explained I need dialysis and the options that are available. Having night PD dialysis appeals to me...do I need to avoid constipation whilst having PD?...what is the difference between Peritoneal dialysis and haemodialysis?... also what happens to the clinical waste....do they take the cardboard away when supplies delivered.. the PD machine seems quite heavy...no good going on EasyJet with this.” (Alex – Education session Observation)

Choosing a treatment, which strengthened personal safety, was the main goal for all participants. Bill had concerns about how dialysis would affect his life and remembered being in hospital due to a lung infection. Bill used his time in hospital to speak to dialysis patients and remembered the negative feedback from them concerning dialysis:

“And they, er, had said it was, they found that it was very, very tiring, because they were coming in, er, saw the, the equipment and, er, and it sorts of puts you off, you think, er, because like will it happen to me? There was an old lady and a gentleman in the next bed to me, and he was telling me, you know, he'd travelled from probably about 20 miles, which he was doing regularly...and this lady, she'd been on dialysis for years and years she said. And she said, you know, she, in other words she was sick of it” (Bill)

Research suggests that narrative exchange between prospective dialysis patients and patients receiving dialysis provides authentic accounts of the reality of life on dialysis treatment (Winterbottom, et al. 2012). In the current study, exchanging narratives occurred through engaged patterns of communication behaviours e.g. direct questioning and probing. Problem solving with current patients provided important insights concerning hospital haemodialysis.

Sharing knowledge with patients

One dimension of *connecting with existing dialysis patients* was *sharing knowledge with patients*. The visit to the dialysis unit initiated a platform for narrative sharing, which provided an insight into the lived experience of ‘being on dialysis’. Participants assumed an advantageous position, in that they could freely observe dialysis care whilst still being free of dialysis. This strengthened personal awareness concerning the possible impact of dialysis on ‘self’ and ‘others’. Comparing self to others was a strategy participants used during the dialysis unit visit when sharing knowledge amongst patients. Accumulating information enabled participants to develop an advanced understanding of treatment; existing patients proved to be a powerful source of legitimate knowledge. Walter shared concerns relating to treatment impact during a visit to the dialysis unit.

“So I was talking to an old chap on there you know I said, you know I was concerned about side effects like and I said to him, I said erm do you get any side effects on this, he said no not really, the only thing is if they take too much out you feel a bit dizzy you know. He said all besides that, you know I’m alright.” (Interview: Walter)

The dialysis unit visit provided opportunities for participants’ to appraise the context of care delivered, leading to judgements concerning dialysis nursing staff capabilities whilst they provided care. The renal unit visit enabled participants to become aware of how dialysis functioned. The sub-category, *Sourcing Information* represents the middle stage of the emergent theory, focusing on strategies directed towards information acquisition, interpretation, and assimilation. Gathered information enables participants’ to consider features of the dialysis unit seen as acceptable to such an extent that they demonstrated behaviours, which normalised the dialysis unit environment.

4.4.2 Normalising the dialysis unit environment

During the early stage of decision-making, participants and their family visited the in-patient renal dialysis unit to observe the care setting. This visit enabled observation of the

hidden world of renal care. Of interest, was the manner in which participants' attempted to normalise the dialysis unit environment. Normalising reflected observations made by participants', when "focusing in" on features of the unit that they were not expecting. Doris was pleasantly surprised with what she observed and how relaxed patients were on dialysis:

"The unit was great, very interesting.. Erm my daughter came with me [hm] and er I, I don't know, I just, it was quite interesting. They didn't, as I say it didn't worry me. No, it was more, how can I put it?...relaxed. To me they looked really relaxed, they weren't, no, they were not worried. You know that's the way I liked about it" (Interview: Doris)

Participants, having no knowledge of the workings of the dialysis unit, made some interesting observations. Participants favoured dialysis within the hospital, rather than a self-care modality at home. Positive comments about the dialysis unit environment confirmed to participants that the dialysis unit was where care should be. The structural features of the unit, including the unit space, equipment and the overall caring milieu, were a point of focus. Participants connected with the units social support networks available. Networks included care givers e.g. nurses and doctors with their specialised knowledge and skills to deliver safe care. Normality was visible to participants through the communications occurring between patients and nurses and the experiences witnessed of those patients having dialysis. Betty visited the dialysis unit with her daughter and, having no idea what to expect, was pleasantly surprised at the behaviour of patients receiving dialysis. Betty's views echoed those of Arthur, who was surprised at the relaxed and normal atmosphere within the dialysis unit:

"Well I didn't know what to expect and they were just laid there these people, they didn't seem a bit concerned ...Yeah and this chap he was eating his sandwiches, you know." (Interview: Betty)

"They all had televisions and, er, you know, it was nice and airy. It was a new unit that's opened up I think. I thought it was superb, I was massively impressed. And the way ... they were on them weren't they and, err, and that's it. They looked so comfortable laid there... Well I was amazed really because you see it's just been all really done and they looked all so comfortable.....Well I... I just said like the, you know, he said oh yes, it's lovely in here. So I wasn't bothered if I had to go in, I wouldn't have been bothered but I was just a bit wary at home." (Interview: Arthur)

Within their visitor role, participants valued witnessing the caring and compassionate behaviours demonstrated by healthcare staff, which promoted a sense of safety, in

hospital dialysis care. Observing caring behaviours reaffirmed that hospital-based dialysis was the safest place for care. The nurses' responsiveness to dialysis patient needs and their prompt management of dialysis machine alarms were evaluated positively during the visit. Having confidence in staff providing dialysis care eased the burden of choosing treatment. For Kitty, hospital dialysis relieved the burden of treatment on her family; the unit visit re-confirmed that her dialysis care should be within the hospital. Hospital dialysis removed the direct impact upon her daughters, and this was a major benefit of having hospital dialysis treatment:

“but it was talked about the fact that you probably needed help with the PD machine and because I’m going ...I’ve looked at it quite a lot and decided that it’s the only possible thing to do is to go into hospital, it is not fair on two girls who both live away to expect them to come running after me and the rest of the family have disbursed here, there and everywhere it is not fair to expect neighbours to be there all the time, they have their own problems and you cannot rely on them, my best thing to do for me was to....., my biggest worry is ... you all don’t want to be dependent on er your children but I need them when I’m ill so the only thing to do.” (Interview: Kitty)

Uncertainty concerning dialysis treatment safety resulted in participants' appraising the dialysis unit environment, noting how clean and hygienic it appeared, due to fears of contracting infections. The high level of clinical sterility in the unit reaffirmed that the hospital was safe and where dialysis care should be. Chris lived alone and, whilst fiercely independent, relied on his family for some of his daily living activities. Despite home PD offering him greater independence and freedom, his fear of contracting infections, and the possible contamination from his pet dog, remained:

“Well, the thing is, I think it’s not hygienic at home. I mean, I keep my home tidy and that, like, but I think there’s germs all over, you know. And I’m always ... I mean, my bathroom, I keep it immaculate, you know, in case any germs get in it, but ... I’m petrified of getting an infection. You know, I keep my dog nice and clean as well, but ... there’s still germs, isn’t there, and ... I thought from a hygiene point of view that it was better in there.....I mean you can't do nothing while it’s going on, you're just sort of laid there for those hours. So whether it’s at home or in a hospital.” (Interview: Chris)

The interactions between staff and patients provided information, which shaped decision-making. Tom and Alan echoed the importance of the dialysis unit environment in their final decisions. The calm environment they observed made them feel safe; witnessing care in the dialysis unit reinforced their beliefs that the renal staff providing care were highly skilled:

“That's the main factor and, er, efficiency, you know, I mean if you've got the nurses and that seeing to it, It's much better than if you're doing it to yourself.... Well there's always a chance that personally you might make a mistake” (Interview: Tom)

“So someone's actually doing the treatment, providing the care, you feel happy about that...knowing that they've got the knowledge and skills” (Interview: Alan)

This was the first opportunity for James to see the dialysis unit activity; he remembered the positive impact of his first visit, and the valuable information he received:

“It was very clean ... the nurse explained how it all worked and everything. Absolutely, yeah, yeah ... It's amazing isn't it what they can do.” (James)

In contrast, Maurice's visit differed due to his previous hospital admissions for a chronic bowel disorder. Years of chronic ill health had necessitated frequent hospitalisations and surgery, leaving him questioning the level of risk he was prepared to take and possible outcomes of treatment:

“I get myself geared up to not pulling through it, erm, you get sort of a mind-set where you think, 'I'd better put my affairs in order in case I don't survive the, the general'It's almost as if, I suppose it's crazy thinking in some ways, I'm sure it is in fact, erm, the fact that you seem to think, or certainly I do, I don't know whether other people think like this, that the more times you go through, have a general anaesthetic, er, the nearer you come to, the higher the risk become” (Interview: Maurice)

As participants attempted to normalise the dialysis unit environment, this brought them face to face with the reality of treatment and accepting the demands it entailed. This reflection is documented in memo 13 below, of a visit to the dialysis unit with a participant and family member:

Table 13. Field note memo

050809 Visit to dialysis unit (Field Note - Memo) Shared bonds/Reality/ Information Processing/ Technological Dependency/ Being safe/ Being looked after/ Managing Disruption / Intrusiveness
<p>The visit to the dialysis unit is interesting. I noticed a connection between patients, it seemed as if there was a common bond between them, a sense of sharing their experience – they had been in the same situation. The Clinical nurse specialist who accompanied the family focused quite a lot on connecting with the patient and husband. It is obvious this nurse was very skilled in her use of therapeutic communication – I watched as she alleviated worry, fears, and initial sought to determine just how much was known about treatment options. Also there had been some thought to how information was best presented. The information about treatment being supported with pictures although the picture of the AVF was quite frightening to the patient.</p> <p>There was a connection between all as the reality of HD was unfolded. This is what it seemed...the unfolding of a new life which was full of the unknown. Nevertheless, the purpose of this meeting was to inform and guide and check out understanding.</p> <p>I am left wondering though about informational processing and the patient's ability to understand...this links to the studies that I have read on cognitive difficulties in older people with CKD. How much information is being retained? What link is there to learning styles? It seemed a one size fits all approach predominates. The visit was an immersion experience for both patient and family into this new world. The technological dependency a focus. There are concerns about being able to manage the demands of the HD treatment and the impact upon the wider family particularly relation to transportation. Yet the fact of being taken care of and being at the hands of competent staff came through during the visit here. It is obvious that anxieties about being safe with the final chosen treatment is paramount as is the need to live and minimize the disruption and intrusiveness to daily life (maybe the works of Gerard Devin's is worth following up as he talks about the strategies used to minimize intrusiveness)</p>

Connecting with treatment demands

As participants normalised the dialysis unit, they faced *connecting with treatment demands*, which characterised the dimension of *normalising the dialysis unit environment*. It was evident that participants realised they needed to submit to dialysis treatment schedules, and accepting dialysis was an all or nothing scenario. The degree of freedom a treatment modality offered was an important component of decision-making. Arthur remembered how surprised he was during the dialysis unit visit, seeing patients looking well on dialysis:

“Well I was amazed really because you see it's just been all really done and they looked all so comfortable. It's amazing isn't it what they can do.....fantastic, really impressed” (Interview: Arthur)

Hospital dialysis necessitates that few opportunities exist for participants to choose aspects of their treatment process, due to treatment scheduling. Deciding on hospital dialysis requires an acceptance of the physical attachment to a dialysis machine, a point echoed by Doris:

“Well (laughs) I thought, “Ah, well, I still don’t fancy being tied up to a machine”. ..No. I’ll take things as it comes.” (Interview: Doris)

Preferences for self-care PD were influenced by prior experiences of self-care management. Maurice reflected on his experience of managing his ileostomy, which brought negative thoughts on how demanding self-care actually is:

“So it’s looking at, I keep looking at it and thinking, ‘hell what’s round the next corner,’ you know?...But the idea of having a pipe hanging out of me would sort of take me back mentally to the, the the bag on job” (Maurice)

Appraising treatment consequences enabled judgements concerning the impact of dialysis. Assessing treatment impact occurred during a process of reflecting upon the needs of family and friends. The intrusiveness of dialysis into family life was a concern raised by Bill:

“I love being with my family and ...Yeah..... er, my wife and, but it’s just this, the invasiveness of the whole thing” (Bill).

The need for treatment required participants to estimate the possible consequences of treatment. For Maurice, information improved his awareness of the possible impact of dialysis upon himself and his wife, whom he sought to protect. Other participants echoed Maurice’s, views whose focus was to minimise the intrusiveness of dialysis treatment. Maurice shared his wife’s reaction to his need for dialysis treatment:

“Because I am probably a stubborn old sod as well and would decide for myself whether I wanted to put myself and my family through that because I noticed my wife was very distressed when she thought that was going to be an aspect of our life and that it was going to take up so much time.” (Interview: Maurice)

Concerns were voiced about the amount of control dialysis technology exerted. A sense of reduced personal control was managed by conferring positive attributes upon dialysis technology. At the same time, participants expressed gratitude for being alive due to dialysis intervention. Negotiating a treatment modality along with its place of delivery e.g. home or hospital, involved gathering information regarding the context of care and evaluating its consequence. Choosing hospital dialysis involved participants,

‘envisioning’ a future life with hospital dialysis. Charles, who had concerns about his safety, voiced the importance of the dialysis unit visit:

“You accept that you are in good hands you know. That’s what the National Health Service is all about. I thought it was anyway ...and it is by and large. They may make mistakes at times but er by and large you are in er the custody of experienced people ... and er both yourself and relatives er know there’s safety enough there like.” (Charles)

Participants evaluated personal capabilities to manage treatment by undertaking a risk benefit appraisal; trade-offs are considered whilst estimating the amount of inconvenience induced by dialysis treatment. Ted cared for his wife (Pauline), who had CKD and severe respiratory and cardiovascular disease, and preferred a treatment, which ensured safety and minimised any possible impact upon their grandchildren:

“Yeah, we do have grandchildren coming, you know, they come every morning and I take them to school and they stay so we thought probably it is best if we just go there and then it’s, you know. ... it sort of makes sense, but we thought about Pauline’s condition, it is best to do it in hospital where there are Nurses and Doctors available if something goes wrong, you know what I mean? If something goes wrong at say 1 o’clock in the morning, if she turns over and pulls something, you know, it’s, that is the only thing that sort of concerns us is that with Pauline’s mobility very poor and it would be probably a bit awkward to have it done at home.” (Interview: Ted - spouse)

Connecting with the demands of PD therapy requires appreciating that self-care PD required self-responsibility for care and accepting its impact upon the home environment.

4.4.3 Working through self-care demands

As participants became increasingly aware of treatment modalities, the demands of self-care dialysis were considered. Home haemodialysis was not an option for any participants, although some were suitable for home PD. As identified earlier, for some participants, treatment directed by the nephrologist were accepted. A large number of participants discounted PD as a treatment. One dimension of the sub-category, *Sourcing Information*, was characterised as *working through self-care demands*. In moving towards *Negotiating a Safe Existence*, self-care dialysis (PD) was associated with a number of fears.

Realising fears for self-care peritoneal dialysis

During renal education sessions, the complexity of PD and the amount of personal responsibility needed for safe PD treatment became evident; most participants dismissed PD as a suitable treatment. Participants displayed fears related to PD; fears represent an important dimension of *working through demands for self-care*. During PD education sessions, participants expressed horror and fear when seeing the anatomical PD torso used as a teaching aid. Stanley's encounter with PD had a profound impact, when confronted with the reality of PD. External PD tubing and PD catheter connections, needed for treatment, increased concerns regarding personal safety.

“Well I didn't like the idea of tubes hanging out of me on a night time having to do different things. Erm, the machine you're tied up during the night. ...With this thing here, the tubes, and it was about twice or three or four times a day at least.....Well the thing was I was thinking about infections you know. Well that's what put me off.....It put me off that, yeah, (laugh) you know” (Interview: Stanley)

Similarly, Kitty was offended and shocked by the degree of intrusiveness of the PD tubing; the level of personal responsibility needed to deliver safe PD worried her. Whilst Kitty thought the abdominal torso was humorous, she remained adamant that PD was not for her:

“Yeah that awful thing where they put the straw body (laughs) in front of you and I could not cope with that, I really couldn't....I couldn't cope ... because it offended my feelings is the fact that you were having tubes all, all over you and you were having to do it yourself” (Interview: Kitty)

The anatomical teaching model used to teach PD shocked participants to the extent that initial preferences for PD are dismissed. PD tubing reinforces vulnerability and a view that self-care PD was a threat. The safety of PD and the possibility of contracting infections were an ongoing concern. The amount of treatment time PD required and the manual dexterity skills needed to manipulate connection of PD fluid bags to the PD catheter were a concern. For many participants, it was pointless considering PD if arthritis was present due to limited manual dexterity. Some participants sought reassurances on their abilities to manage potential problems of PD treatment. An interest, in managing self, led to PD being considered as a treatment option. Learning PD required learning new information and engaging in self-reflective activities e.g. reviewing the principles of PD learnt during education teaching sessions.

Treatment decision-making involved evaluating the level of personal capacity for self-care competence. Appraising treatment complexity was connected to the personal impact of PD and whether it could be self-managed. This resulted in participants' contemplating possible future care scenarios as a strategy to explore what could happen when becoming a dialysis patient. Concerns related to treatment failure and the responsibility for self-care. Treatment anxiety was partly managed through delayed decision-making, which provided time to gather information on what self-management involves. Preferences for assuming self-care resulted in a process of negotiation, which involved mobilising family networks for additional support. Confirming family support for self-care occurred within a communication process, where treatment roles and responsibilities are clarified. Communication confirmed family members' perceptions of participants' capability for self-care. Feedback from the family reassured participants and alleviated fears of being alone whilst managing treatment. Securing family support meant individuals could move towards increasing engagement with and preparation for PD.

Accepting the possibility of undertaking self-care initiated 'up-skilling' behaviours, involving learning manual PD skills, and assimilating complex treatment information. Reflecting on the mechanics of PD brought participants to a deeper understanding of how to manage PD safely. PD offered greater freedom and independence, yet required a higher level of self-care. Limited confidence in personal capability to manage PD is expressed frequently; dilemmas arose when participants understood the importance of self-care, yet had unresolved fears concerning personal safety. Not all participants have similar treatment choices available. Due to Bill's prior abdominal surgery, he could not have PD, which he wanted; a restricted choice meant Bill had no option but to accept hospital HD:

"Well what else do you do, you've got to do it haven't you, we've got to go, I'll have to go, what's the alternative." (Interview: Bill)

Physical limitations e.g. poor eyesight and arthritis meant PD is difficult; existing physical disability dictated which treatments options were possible. Frustrations arose when preferred treatments were not possible as voiced by Mike:

"That's what I wanted but I can't have, I thought it would be easier...because I've had operations on my tummy." (Interview: Mike)

Accepting either HD or PD required giving up personal time and restructuring daily life. This involved calculating the cumulative time taken up by dialysis from self and family. Acceptance leads to resignation and a readjustment of personal priorities, as discussed by Alex:

“Um, well there are three ... I think there are three periods in the day when you’ve got to do it. Um, it would just mean that there would be less flexibility really in terms of we would have to plan my life around those three, um, dialysis periods, rather than planning my life around the people that are important to me and things like that.” (Interview: Alex)

Alex understood the demands of PD and its dominance within his life; home based PD resulted in significant personal responsibility for his own care. Responsibility included delivering PD treatment during periods when his personal capacity to care for self may be reduced. Other participants expressed this similar concern:

“Oh you have to do it yourself its eight times a day or four times a day yourself. And you wake up some mornings and you’re feeling rotten and when you’re feeling rotten you force yourself and you can get and you can get out that’s it ” (Interview: Charles)

There was a continuing awareness of the potential burden of the treatment on family and friends irrespective of the modality chosen. Self-care required accepting responsibility for care but also the burden of shifting care to others. Chris was initially attracted to the amount of freedom PD offered but other factors shaped his decision:

“Well I thought it’s a good idea like, and then of course they went into details on it and that was when I went off it because it meant you were going to carry that water about with you all day long in that bladder, plus it meant I was going to do the treatment at home and you’d have to have a sterile room. The wife’s not capable of doing that and of course we’ve got the dog jumping about and things and I thought well that is out of it, it would be better to have it in my arm and go up the hospital and get it done. It’s more erm sterile than anything isn’t it so that was it.” (Interview: Chris)

Choosing self-care PD involved examining personal values, preferences, and the level of family support needed. Negotiating family support enhanced a feeling of personal safety and supported the decision to assume self-care PD. As with any chronic illness, managing the disruption to daily living was critically important. This was also the case with dialysis and was an important component of decision-making. Family member involvement in decision-making concerning home PD provided freedom from travelling to hospital for HD treatment; this secured a greater degree of control over treatment, as Ian reflected:

“...my daughter you’ve just met, she’s probably going to be the one who’s going to help me most, I would like to do it here, and that’s the decision I made. Um, well my prime motivation was I’d be able to do it myself at home, which would mean I wouldn’t need obviously to, er, have these horrendous trips into hospital three times a week. Er, the fact that it could be done at night time was massively appealing because, um, that would have ... mean that there would be minimal disruption to my day-to-day life. Those were the major factors.” (Interview: Ian)

Shifting responsibility for PD care from oneself to others was an important component of the decision-making process. Three participants, who choose PD, negotiated additional family support, which increased their confidence in their abilities. Mary, whose family provided the necessary reassurances, which shaped her decisions, shared this:

“It’d be awful. I can’t go down there three times a week ... It’s a long way to go..... Oh, no, I’m not leaving my family like that.... I like my family round me, if I can get them, sooner the better. They support me and are always there for me” (Interview: Mary)

4.4.4 Taking information from family

Taking information from the family connects to the sub-category, *sourcing information*. At this point in decision-making, participants’ engaged in active information gathering, which necessitated being receptive to information from family members. Information on treatment outcomes are discussed with the family. Treatment decisions have far-reaching consequences, for individuals and their families’. Participants consider information from the family and act upon it, whether in their best interest or not. Walter was under no illusion how the information he received from his family had shaped his decision. Walter’s daughter was adamant that he must have treatment, something Walter viewed positively. His daughter’s views justified the importance of having treatment, as he explained:

“Yeah, your daughter says, “You don’t need it, you’re getting it.” ...I am Happy. Sighs).Something was being ... something positive was being done. On her part, as well as on mine. She was doing (laughs) it for me. (Sighs. She was doing it on my behalf” (Interview: Walter)

It seemed that participants, who were fortunate to have a family, used them as an additional resource when checking out their treatment intentions, especially where uncertainty existed over a course of action. In Doris’s case, the information she received from her son further reinforced what she intended to do:

“Well the oldest son, he, he was the one that said about erm, well if it was up to me I think you would be better going to the hospital, I said well I think I should go myself. So that was decided straight away. That was my own decision that. But they confirmed what I’d wanted to do” (Interview: Doris)

Sharing stories

Decisions, concerning preferred treatment, requires an ability to ‘make sense’ of treatment related information which participants gathered. The way in which information was used during decision-making varies; information regarding HD e.g. vascular access, needle pain, fatigue and bleeding is used to justify decisions that HD is unsuitable and that PD is best. Dwelling upon negative stories from existing dialysis patients, and family members concerning HD, justifies the need to avoid it, irrespective of the truth of the story. Maurice dwelt upon the negative story from a family member who had undergone HD:

“Well, he said it was painless and all this carry on....and I says, “Oh, well, it, I don’t suppose it would be too bad”. I tried, but when my, um, cousin came round to tell me about her kidneys, but she was waiting for a ... er, she said it was really bad.” (Interview: Maurice)

Information gathered from personal contacts strongly facilitated treatment decision-making. Mary reflected on her cousins’ experience of HD and her decisions were influenced by the story, which justified why any form of treatment was unacceptable:

“... she was there for two hours a day and when she went off for three days or something, she said. And, er, when she comes back, she just had to go to bed, she was too tired. Oh, it looked horrible. I said, “How can you manage that?” “Oh”, she said, “Well, I get wired up when I go to hospital with it”. And you’re, er, you’re tied to a machine. But, she says, “believe me”, she says, “it’s painful for two hours”, and she says, “and when you come back”, she says, “you’re as sick as a pig and you’re stuck in bed”. I said, “Oh, I don’t want that”. Straightaway I said, “I don’t want that”. Now, I’m glad I didn’t go. And I’m not going. If I do have to die, I die, and that’s it. But I’m not having that treatment.” (Interview: Mary)

Confronting the possibility of death was a consequence of CKD and a reminder of the fragility of life. The death of a family member due to HD reinforced treatment hazards, which heightened further possible adverse treatment outcomes. Mary’s story echoed other participants’ who focused upon the negative effects of dialysis. Mary’s decisions were framed by her cousin’s personal story, which affected her profoundly. When making a treatment decision, negative stories of dialysis treatment have the potential to ‘tip the balance’ away from having treatment, as Mary states:

“Not after my cousin said it ... what it was like, I think ... You see, she died before...she bled to death. ... She went three times and both times, she came back sick and bad. So it wasn't doing her much good, was it and I am certain I do not want that?” (Interview: Mary)

As participants gathered, information to support treatment decision-making, negative accounts of self-care PD directed the decision that treatment must be hospital-based HD. Betty was unsure whether to accept any kind of treatment for her CKD at a time when she felt physically well:

“She had this big thing in her arm, “Well”, she says, “I’ll advise you not to go”, she said, “If you’re alright”, she said, “which you look better than I do”, she says, “as”, um, “I’d advise you not to have it. Because”, she says, “it’s very painful well, she said it would be a good thing if I tried it. It would help. Well, some people, it hasn’t helped” (Interview: Betty)

What was apparent within the participants’ accounts was the need to minimise disruption and the impact of treatment, which was achieved through *sourcing information* (see Figure 3) from existing patients. When considering treatment demands, irrespective of the treatment chosen, moving beyond disruption was important, if *Negotiating a Safe Existence* was to be achieved. *Traversing Disruption* reflects the final stage of the substantive theory.

4.5 Stage three - traversing disruption

Traversing Disruption (see Figure 4) is the final sub-category of the substantive theory *Negotiating a Safe Existence* as participants moved towards either hospital based dialysis or PD. Disruption manifests in various ways, including treatment impact on daily living e.g. treatment scheduling, amount of treatment time and disruption to family life. Two characteristics of traversing disruption demonstrated by participants included how they went about *strategizing for disruption* and their actions taken in *strengthening family support*.

4.5.1 Strategizing for disruption:

Various strategies assisted in *traversing disruption* as participants attempted to minimise treatment impact. Each treatment presented different types of disruptions to participants, including intrusiveness into daily life, adjustments needed to home environments to accommodate treatment supplies, as well as impacts upon recreational activities, as Dotty explained:

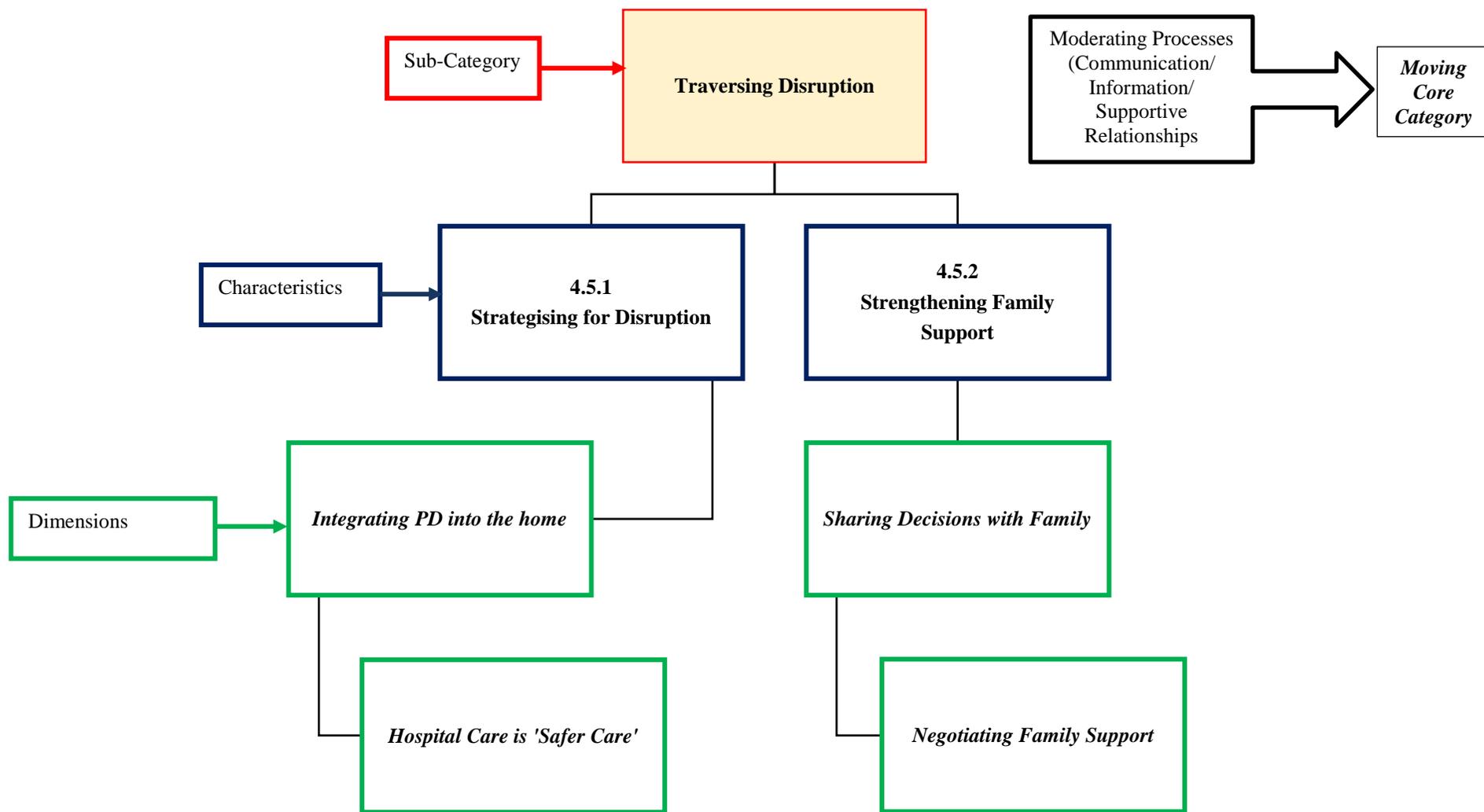
“The only one thing I have an issue is like going away. You know, having holiday. But as we, we’ve spoken about this…….We can still do it and even if we just go away for a long weekend [yes] you know, like that, have a break there. But, as I say, other than anything else, I’ve not really bothered, never thought about it [yes] you know” (Interview: Dotty)

Accepting disruptions was not always achievable, as can be seen from Mick’s account concerning PD. Home PD required attention to hygiene standards within the home and the absence of domestic pets to minimise infection. Mick’s initial interest in PD was dismissed when he was advised that he would not be able to keep his pet dog; something he found unacceptable (Interview –Mick)

“Well there were two problems; one was the dog because the Drs said we would have to get rid of the dog (Molly) ... and there was no way I was going to get rid of the dog...”(Interview: Mick)

Strategizing for disruption includes managing the challenges of travelling to hospital for dialysis as well as the disruption of integrating PD into the home environment.

Figure 4. Stage Three: Traversing Disruption



Integrating PD into the home

Participants strategized for disruption, as evidenced by the dimension *integrating PD into the home*. Practical adjustments are required to integrate PD into the home when undertaking PD. Alex valued minimising the amount of time spent away from home and he chose PD whilst working through a plan to re-organise his home environment to accommodate the dialysis equipment and supplies. *Integrating PD into the home* occurred as part of the problem solving process in preparing for PD, which Alex explained:

“Um, well it was ... before we had that session we had no idea, we’d never seen it; we didn’t know how big it was, and um, at my side of the bed there just wouldn’t be room. I wouldn’t be able to get in and out of bed with that piece of equipment there because it’s quite a narrow, um, space between there and the, um, wardrobes. In fact, you wouldn’t even be able to get in your wardrobe where all your clothes are if it was there so there’s logistics to take into consideration..... I mean there are decisions to be made about sleeping together and things like that. If you’re going to do it at night time you’ve got to be connected up all night, so um, if we wanted to continue to sleep in our, um, own bedroom we would have had to have changed sides in the bed” (Interview: Alex)

Exerting personal control over dialysis treatment was an important component in treatment decision-making. Taking control initiates engagement with dialysis, facilitating its integration into daily life. Negotiating to have PD provides a protective element, given that the amount of time relinquished to treatment is under greater direct personal self-control. Exerting control facilitated working through patterns of daily life to minimise disruptions whilst enhancing a sense of normality. PD activated partnership working within the family whilst helping to negotiate family support and involvement in treatment decisions. In comparison, hospital HD offered the benefit of a network of social connections with other dialysis patients, which minimised loneliness, a point echoed by Edith (Mick’s wife):

“...and when he gets there, he knows he’s safe, he’s only got to look out the bed sideways and somebody will say what’s the matter Michael. Now if he does that here I wouldn’t know if he was bad or not would I ...and not only that, its company isn’t it, it’s company, he can lay and talk like he’s talking to you..... But I mean its company isn’t it, and they can exchange, yes I get that pain, oh, oh it’s not so bad then, oh it’s not just me. So there is lot of aspects to it I think. So hospital is the better place” (Interview: Edith – spouse)

One strategy which helped to manage disrupted living was evaluating the trade-offs between hospital HD, and home PD; the setting where care is delivered was important.

The care setting was conceptualised by the dimension, *hospital care is safer care* reflecting judgements made when making final decisions.

Hospital care is safer care

Hospital dialysis was seen as restrictive due to the scheduling of dialysis treatment times, which must be followed. Choosing hospital dialysis necessitated surrendering to treatment, whilst accepting that hospital dialysis was the ‘safer option’. Anxiety diminished confidence in one’s personal abilities to perform a home based, self-care therapy, such as PD; choosing hospital dialysis eased anxiety. Charles accepted the views of family members that care is safer when delivered in hospital. For Charles, his sister’s concerns, regarding hazards of home PD were not easy for him to accept:

“Now by going to hospital she knows that I’m in the care of these people up there but if you are doing something on your own anything could go wrong and she felt like you know it would be awful. ... and er they do their best to help but they don’t want to be put any more pressure than they have to be.” (Interview: Charles)

Families reinforce the view that hospital was the optimal place for care, as Walter explained:

“you know where you go to dialysis, it’s there for you and you’ve got your doctors and everybody there you know and I didn’t fancy them machine, tied to a machine during the night you know. So I said to her I said well I think, well even me two sons said I think we’d better go and go the hospital and get dialysis...No, I just decided when I come home. Like I say me sons were here at the time and we you know all three of us decided....And not only that, they’re thinking about getting me out the house, meeting different people and out you know what I mean.” (Interview: Walter)

Fear of abandonment whilst managing the complexity of home PD adds to increasing uncertainty. Alan lived alone, and whilst fiercely independent, was concerned about maintaining his independence whilst contemplating the reality of taking responsibility for his own treatment:

“Yeah you see you know you’re on your own, you’ve got all this to do, I know somebody who will come in and you know all this business but it’s still on your own.” (Interview: Alan)

Negotiating to have home dialysis required accepting the increased level of responsibility for ones-self and the possible dependency on family and friends. In contrast, hospital dialysis offered potential gains for family members, since it relieved their burden as direct

care agents. Forgoing personal treatment preferences minimised the impact of treatment upon the family. Potential dependency upon family members and possibly being a burden was a dilemma. Dora's view typified a common experience encountered as CKD worsened. Worsening symptoms brought multiple physiological disruptions, which progressively incapacitated her. Her decision to have hospital dialysis was taken to relieve the burden of care from her husband whilst creating space for him to recuperate:

"I could have it at home or I could, and I prefer to go to the hospital. As I thought my husband has enough on his plate with me as it is and I thought, if I go there, it's giving him a break while I go down there and have it done. Er it was my decision, nobody else' and they thought I would, did the wisest thing." (Interview: Dora)

Similar to Dora, Tom's decision to negotiate to have hospital dialysis reflected his concern for his family, as well as his confidence in the skills of dialysis unit staff.

"... they felt about the same way. More so because they were thinking in terms of me being on my own er and thinking of their er what their involvement might be ... and they weren't very happy to think that I would have to be er messing about on my own. They would be wondering were things alright you know because it doesn't matter how far away you are... they erm accept that you are in good hands you know. That's what the National Health Service is all about. I thought it was anyway." (Interview: Tom)

The fears of hazards of dialysis treatment and adverse events occurring during dialysis treatment are very real for older people contemplating dialysis. Fear of dialysis machine malfunctioning was a focus when considering dialysis at home; hospital dialysis partly minimises this fear due to the vigilant monitoring of dialysis machines by nursing staff. Dialysis staff competency and their responsiveness when managing hazardous events was an important consideration during the decision-making process. Hospital dialysis provided reassurance that care was 'handed over' to skilled health professionals. Mick travelled twenty-five miles for hospital dialysis and accepted the disruption of travelling knowing he would be safe during dialysis:

"And I think if you're at home, it's a big responsibility for me ... Even when I go through there in a night ...It's, it's a chore going through but you know I get drove there so that's not so bad....but when I get there I feel safe, there's all them nurses there which I can ask if anything goes wrong....It's a big responsibility I think for the one who's trying to do it, and then if anything goes wrong, can you get to somebody to give you some help" (Interview: Mick)

Possible harm during home PD was a deciding factor for participants who chose hospital dialysis. In the absence of a family network for additional support during dialysis, personal safety remained a concern. Whilst the home environment was a place of familiarity, it represented an unsafe environment when delivering self-care PD dialysis. James echoed this sentiment in his interview:

... um, I didn't like this, um, I didn't like the look of it, and more like Dr Who, you know. Er, but I thought, "Well, at least it ... something's being done, at least they'd ... they know what they're doing, if anything went wrong in the house, we couldn't cope." If anything had gone wrong, with this tube carryon, I thought, "No, no way, I'm definitely making the right move, by going in there." You might not think so, you probably ... you, um, but that's all I can put it down to (Interview: James)

Pre-occupation with maintaining hygiene standards within the home influenced decisions to undergo hospital dialysis. Hospital was associated with safer care, where vigilant staff monitor care; monitoring during dialysis treatment strengthened the value in choosing hospital dialysis.

4.5.2 Strengthening family support

Family networks were an important additional support when self-care PD was decided; this characteristic was conceptualised as *strengthening family support*. Few participants in the study chose self-care PD, despite being a good candidate for PD by the nephrologist. The three participants who chose PD had extensive family networks to draw upon and ensured participants received their preferred treatment. *Strengthening family support* enabled participants to negotiate to have either hospital haemodialysis or self-care PD. The family were important in shaping and directing treatment decisions; Harold's account demonstrated the extent his family had upon his decisions taken:

"Oh I would say Nine out of ten, I think, the ... more, if it hadn't have been for them, I think I might have made the wrong one and said, "No, I won't bother with treatment, just leave it." Um, I wasn't frightened about treatment, I've not frightened of the treatment, but ... my daughter says, "You're having it, dad." My wife said, "You're having it." So why argue with ... You don't argue with two women. I mean, we make ... we have joint decision ... I mean, we've never, one's never said, "We'll do this, we'll do that, we'll do the other." We've always had a joint, er, as far as we're concerned, throughout ... our married life and I think it's worked well. Otherwise what's the point in getting married?" (Interview: Harold)

Sharing decisions with family

Mobilising family support raised concerns of dependency on family members. A collaborative style of family communication facilitated shared decision-making, and examining treatment options prior to mutual agreements reached. Negotiating adjustments within the home environment to accommodate PD dialysis occurred within a consultative process with family. Bill shared his family's preferences where dialysis must be provided:

"... and my sister and the brother-in-law's feelings oh you don't want to be messing around on your own. You'd be better up there Bill and we know you're safe up there." (Bill)

Accepting the treatment preferences of family members at the expense of individual preferences arose as more of an obligation to family; managing conflicting interests between self and family were not easily resolved. The family provided a sounding board and assisted in shaping decisions, particularly where uncertainty was high. Actively mobilising the family was a strategy used when deciding whether self-care therapy was feasible; backup strategies for additional support from family were established. Family involvement in problem solving helped activate the necessary logistics needed when adjusting the home when accommodating home dialysis supplies. Ian wanted home PD but found reviewing the adjustments needed to his home challenging:

"And, er, people will take away the clinical waste and things like that. And also, erm, I would really need to devote some space to it, and we've got 3 bedrooms, er, there is a smaller bedroom which..." (Ian)

The value of collaborative problem solving with the spouse is highlighted in James' account:

"We'd just go along with what's ... you know, we'd work it out between us, and whatever is best we'd do it. I mean we recognise that there's going to be a few little problems to sort out and a new way of life to a certain extent, but to keep that as normal as possible. We're very adaptable I think to actually ...I tend to be one to actually face up to problems when they arise rather than try to anticipate loads of possible problems that possibly won't arise... Yeah, yeah, and adapt." (James)

Home PD was easier to accept once an assessment of the impact of PD on the home was completed. Examining the consequences of home PD upon the family was an important part of decision-making. Securing family members as extra care agents helped to manage

self-doubts, enabling sharing and implementation of treatment decisions. An expectation of family member involvement in treatment delivery suggested an obligation to the sick family member. Ian's daughter agreed to take on a primary care-giver role; his dependency on her was highlighted in his account. Ian's reliance on informal care was essential to his final decision for home PD:

"...my daughter you've just met, she's probably going to be the one who's going to help me most, I would like to do it here, and that's the decision I made. Erm, simply I suppose for selfish reasons, I would be at home, wouldn't need to be travelling through to the city. Yes, my daughter was with me at the hospital, she's been going with me, you know, just to keep in the picture, because I think while she hasn't said so, I think she knows that when the time comes she's going to be heavily involved in helping me.....she's helping me a lot now. It makes me feel a lot better, yeah. I know she's, she's a very capable person...a very capable person. Yeah. She won't panic, I mean she's not, no, sort of, you know, I can't do this and I can't do that..."(Interview: Ian)

Collaborative family decision-making strengthened accepting changes to the family due to dialysis. Managing decisional uncertainty involved sharing decisions within the family, which enabled exploring all perspectives of the decision; this shared style of decision-making ensured *Negotiating a Safe Existence* on the final chosen modality. The family network provided an important arena where the family directed and reinforced views; family communication supported the need to have dialysis. Collaboration within the family occurred in a purposeful and engaged manner, and involved exploring the risks and benefits of treatment. Shared decision-making within the family reinforced the level of family commitment and support available.

Negotiating family support

Traversing Disruption signifies the final stage (Figure 4) of the emergent theory *Negotiating a safe existence*, and focused around the preferred place of care. Concerns relating to personal safety were resolved by using strategies to either protect self or manage self. Both strategies strengthened individual protection, whilst having dialysis care. Protecting self, ensured maximum safety and a re-alignment of care to the hospital dialysis unit under the direct responsibility of renal care experts. Vigilant monitoring, a feature of protecting self, instilled feelings of safe care due to the attentiveness and management of hazardous events by renal care staff. A consequence of protecting self is that of re-directing the burden of care from self and family to professional experts. Managing self, comprised strategies supporting individual self-care PD. Managing self

was enhanced and facilitated through collaborative negotiations with family, to optimise delivery of PD. Managing self, enabled empowerment and autonomy to be exercised, which enhanced personal control over treatment demands.

The theory *Negotiating a Safe Existence* represented a process of interaction, as older people move through stages as they negotiated preferred treatment and its place of delivery. The theory provided a conceptual insight into the changing identity of older people as they progressed forward to secure access to a treatment modality that, in turn, enhanced a personal sense of safety. The theory's sub-categories of *Confronting a Deteriorating Self*, *Sourcing Information*, and *Traversing Disruption* are connected through communication, information, and supportive relationships and the ongoing need to resolve uncertainty, which characterised the changing status of older people. Compromises are needed in terms of treatment scheduling, travelling to the hospital, relinquishing personal time in exchange for ensuring safe care, and re-distribution of burden of care from family to health professionals.

4.6 Conclusion

This chapter has discussed the three stages of the substantive theory *Negotiating a Safe Existence*, which reflects the core concern of older people with CKD whilst considering treatment options. The three stages, *Confronting a Deteriorating Self*, *Sourcing Information*, and *Traversing Disruption*, has been discussed, demonstrating the characteristics (properties) and associated dimensions of the theory. How each category connects to the core category and basic social process of negotiation has been examined. The importance of information to facilitate informed decisions is highlighted. Older people place importance on the relational components of their encounters with healthcare team members, particularly the nephrologist. Being treated with respect in a caring and compassionate manner is highlighted as a feature in the majority of consultations with nephrologists. The level and amount of information older people received or were able to gather was central to their main concerns regarding treatment safety. For some participants, *Negotiating a Safe Existence* is an on-going stressful experience as they make sense of their changing illness trajectory. In the presence of information deficits and limited resources, participants evaluated available alternatives, e.g. home based PD and hospital dialysis. The strategies used by participants included searching for information, through connecting with existing dialysis patients, as well as sharing stories

with family and friends. In the following chapter, a more in-depth theoretical discussion of the emergent theory and its integration with existing literature is offered, to demonstrate how the emergent theory adds to, and extends, existing knowledge.

CHAPTER 5

DISCUSSION, RECOMMENDATIONS & CONCLUSIONS

5.1 Introduction

The aim of this study was to develop a theory that accounts for the social processes involved when older people with CKD stages 4 and 5 consider treatment. The study identified the strategies used by older people in resolving their main concerns related to their treatment. The theory of *Negotiating a Safe Existence* presented here explains the combination of processes, tactics, and strategies that older people engaged with in order to negotiate safety in care. This study adds to our understanding about how knowledge of the social world of renal care influences older peoples' decision-making regarding safe treatment. The basic social process of negotiation conceptualises the behaviours and strategies employed to secure a sense of safety.

The study contributes to current patient care research within renal services in a number of ways. Firstly, the main concerns of older people revolved around being safe whilst receiving dialysis. Few studies exist within the speciality of renal care that have identified safety as the core concern of older people requiring dialysis. This current study therefore, highlights the importance of attending to feelings of vulnerability older people express. The current study identified strategies used by older people to secure a sense of safety. Secondly, the study demonstrates the value of employing a qualitative approach in identifying older peoples' experience of renal care; an area that has been largely ignored. Thirdly, enabling older people to articulate their perceptions of their main concerns allowed a close exploration of what safety meant to them.

The study has identified the determinants within the social world of renal care that act as enablers or barriers to feeling safe whilst receiving dialysis. This study demonstrated the differing perspectives of safe care, as perceived by older people, and has contributed to current strategies to ensure safer care in renal practice. The identification of safety as a core concern for older people entering renal care is novel; no studies exist that have identified safety during dialysis as the main concern of older people when making

treatment decisions. Finally, the focus on safety provided the context around which information became central to older people as they encounter CKD. An absence of information demonstrated how older people sought alternative routes to locate information sources on which to base their treatment decisions. The findings of this study demonstrated the difference between active and engaged information seekers, in contrast to those adopting more receptive and passive information acquiring behaviours.

The theoretical contribution of this study relates to insights about how study participants realigned their own social worlds through the processes of accommodation and assimilation. The substantive theory: *Negotiating a Safe Existence* extends our understanding of ‘awareness contexts’ as originally developed by Glaser and Strauss (1974). Within the stages *Confronting a Deteriorating Self* and *Sourcing Information* two additional categories of awareness are proposed, namely: ‘suspended awareness’ and ‘transient closed awareness’. The theory provides an insight into the information readiness of participants during their transition into secondary care. *Negotiating a Safe Existence* supports status passage theory (Glaser & Strauss 1971), in identifying how social processes within renal care shape the renal care journey, which is examined below.

5.2 Negotiating a safe existence – a status passage

Status passage represents the phases of transition or turning points that an individual passes through within their social roles and life course; chronic illness represents one such life status (Glaser & Strauss 1971). Glaser and Strauss (1971 p.2) suggest that:

‘Status passages may entail movement into a different part of a social structure; or a loss or gain of privilege, influence, or power, and a changed identity and sense of self, as well as changed behaviour.’

This may involve developing new attributes or a change in an individuals’ social position or role. Kingston (2000) suggests that:

Status passage suggests all individuals move from one situation or period of their life to a series of different locations or phases, and this is a continuous and ever changing feature of the life course (p.218)

As a formal theory, status passage is described as:

...theory developed for a formal or conceptual area of sociological inquiry-such as status passage, stigma, deviant behaviour, socialization, status congruency,

authority and power, reward systems, organisations or organisational careers
(Glaser & Strauss 1971, pp.177-178)

The theory of status passage has been applied in a number of differing research areas. This has included understanding tooth loss (Gibson et al. 2017), falls in older people (Kingston 2000), dementia awareness (Tolhurst & Kingston 2013), awareness contexts in dying (Timmermans 1994), and identity formation following resuscitation technologies (Timmermans 1996). However, the current study is the first of its kind to apply the theory of status passage to the experience of older people with CKD as they encounter treatment decision-making. Using the six dimensions of status passage : *reversibility, temporality, shape, desirability, circumstantiality, and multiplicity* (Glaser & Strauss 1971), the discussion below highlights the status passage of older people during their transition towards a new stage in their CKD.

5.3 Reversibility and status passage

Glaser and Strauss (1971) identified that status passages are constantly in motion and, in some contexts, are reversible. However, in this study, participants' chronic illness status was marked by continuing decline in their kidney function and reversal of their CKD was not possible (Tolhurst & Kingston, 2013). CKD is non-reversible due to the primary disease e.g. diabetes or hypertension leading to progressive loss of kidney function. Most participants believed their CKD was the consequence of natural ageing and diabetes. They were not afforded opportunities to engage in self-care activities, which may have delayed kidney function decline. These findings concur with those of Lopez-Vargas et al. (2014), which emphasise how pre-dialysis education enables patients and families to understand CKD. Lopez-Vargas et al (2014) suggests that an individual's capacity to slow down CKD progression, may relate to poor knowledge of their disease and its comorbidities. Lopez-Vargas et al. (2014) believes the progression of CKD may be delayed or symptoms reversed if patients are able to communicate actively with the health care team. This would improve patients' capacity to understand about adherence to treatment whilst motivating them to make lifestyle modifications. Previous studies similarly suggest that many older people with CKD have poor knowledge at the stage of decision-making (Tonkin-Crine et al. 2015; Muthalagappan et al. 2013).

The theory of *Negotiating a Safe Existence* highlights how participants' understanding of CKD and its changing status was limited, especially when referred by their doctor to

specialist renal services. This highlighted that participants were unaware of the relationship between their worsening CKD and their need for management by a nephrologist. The nephrologist is in a pivotal position of influence in participants' understandings of illness transitions.

5.4 Temporality and status passage

Temporality denotes the rate, pace and speed of status passage and whether the passage is scheduled or non-scheduled in nature (Glaser & Strauss 1971, p.33). *Negotiating a Safe Existence* demonstrates the temporality of the status passage, where the rate of CKD decline was beyond participants' control. Lack of control ignited uncertainties concerning the inevitable progression towards dialysis. The theory *Negotiating a Safe Existence* demonstrated that when the speed of kidney function decline was rapidly progressive, participants experienced stress as they became aware of their changing situation. Stress was partly managed through apportioning blame, thus easing threats to self and the family as reflected in other research (Ekelund & Andersson 2007; Logan, Pelletier-Hibbert & Hodgins 2006; Harwood et al. 2005). The rapid pace of CKD decline often resulted in a disruptive, crisis event occurring, further exacerbating uncertainty: Glaser and Strauss (1971, p.29), suggest that such unscheduled events '*generate an identity crisis for a pasagee who does not wish to move*'.

The experience of participants in this current study concurs with Kristiansen and Antoft's (2016) ethnographic study of how patient education programs enabled living with rheumatoid arthritis. Patient education regulates the unpredictable and de-regularised aspects of status passage into living with chronic illness. Status passage of living with rheumatoid arthritis occurred through a socialisation process between patients, lay experts and health professionals. *Negotiating a Safe Existence* highlights how tactics and strategies were used to manage disruption and regain control. This was particularly a feature of stage two, *Sourcing Information*, where the search for, and use of, information shaped the pace of the status passage. Here, the relational dimension of 'connecting' between those who had completed the status passage (existing dialysis patients) and those who were yet to receive dialysis was particularly significant. Where connection was successful, anxiety and uncertainty related to the status passage of illness transition was partly alleviated. Echoing other research, participants in this study used information to help make sense of the status passage they faced (Thomas-Hawkins et al. 2007) and

manage uncertainty (Goovaerts, Jadoul & Goffin 2012, 2015; Covic et al. 2010; Murray et al. 2009). Overall, this study demonstrates how ongoing uncertainty and anticipation were key properties of the temporal dimension of status passage for participants: these features of temporality have not been addressed in any status passage research to date.

5.5 Shaping and status passage

The shape of the status passage is a combination of its direction and temporality, as well as who controls and directs the passage (Glaser & Strauss 1971). *Negotiating a Safe Existence* sheds light on how multiple agents (doctor, nurse, spouse, sons and daughters) shaped the status passage of participants in this study. Primary care doctors initiated the status passage into the social world of renal care when making referrals into specialist renal care services. Other agents were also significant in *Negotiating a Safe Existence*, for example, families occupied an important part in shaping and directing the status passage, as seen from discussions participants had with their family members concerning treatment options and the way in which treatment preferences of family members were important in the final treatment decision-making process. *Negotiating a Safe Existence* illustrates that the movement of study participants through the stages of *Confronting a Deteriorating Self*, *Sourcing Information* and *Traversing Disruption* was a largely regularised process under the control of the nephrologist. The nephrologist assumed a directive role in final treatment decisions. Participants' trust and faith in a credible authority meant that they tended to accept the nephrologist as a legitimate expert and some took a passive role in decision-making accordingly. This perhaps reflected their preferred identity during their changing chronic illness status. Handing the authority for decisions to the nephrologist may have assisted in removing decisional burden for some participants and the management of uncertainty. Glaser and Strauss (1971) do not highlight the passive role individuals may legitimately choose during their status passage.

The findings of the current study are consistent with the other research. Some studies identify the importance of the first encounter with the nephrologist during decision-making in CKD (Harwood et al. 2012; Loiselle, O'Connor & Michaud 2011). The work of Kaufman, Shim and Ross (2006) and Wuerth et al (2002) shows how nephrologists direct and constrain treatment choices and illuminates how physicians, patients, and families enter into and understand life extending medical procedures. The findings also resonate with Morton et al.'s (2010c) qualitative review examining patient and family

perspectives of their decisions concerning CKD treatment. The latter highlights limited choices given to patients and the central role of the nephrologist's preferences in influencing treatment decisions made.

Status passage theory (Glaser & Strauss, 1971) highlights the importance of participants knowing the direction of their status passage as well as its outcome. In the current study, this represented an ongoing concern throughout the status passage because, as Glaser and Strauss (1971, p.35) emphasise:

'Individuals wish to know not only where they are going (direction) but approximately how soon they will arrive there'

As noted above, experienced dialysis patients helped in the shaping of the status passage, particularly during stage two, *Sourcing Information*. Participants considered the value of information from dialysis patients as part of their decision-making. This finding resonates with research by Keeney and McKenna (2014), where 68.3% of patients engaged in information sharing with others, with 58.8% of these patients making their final decisions based upon stories related to the type of dialysis as well as living with dialysis. This was influential in enabling participants to understand the time dimension of their status passage. This finding is also consistent with the work of Winterbottom et al. (2008, 2012) who identified the influential role of storytelling amongst patients during treatment decision-making.

Visiting the dialysis unit was a particular opportunity for connecting participants with the reality of dialysis and highlighted how they used informal information sources as part of decision-making. During the visit, participants who sought information adopted engaged, information-gathering behaviours. This finding is consistent with Bonner and Lloyd's (2011), findings that patients classified as engagers, actively seek out information from numerous sources, particularly other patients; this resonates with participants in the current study. Participants who were less involved with treatment decision-making adopted a more passive approach and were less inclined to seek information, preferring to rely on the information they received.

The visit represented a valuable resource in the shaping of the status passage. During the visit participants displayed vigilant behaviours when considering the risks of treatment to themselves and families. Participants accepted the consequences resulting from the final treatment choices they made, including compromising on having to travel to hospital for

safe dialysis treatment, and relinquishing personal time to dialysis treatment away from home. As the theory demonstrates, the status passage for some participants was directed by families who facilitated the status passage to undertake home PD. As a feature of the status passage, participants had to reorder their personal priorities, as seen by the compromises they made. Negotiating care to the hospital minimised treatment intrusion upon the family. Participants' choosing PD, understood the risks and benefits of home PD. Exercising control gave an element of freedom that was a positive consequence of home PD.

The direction of participants through the status passage was helped by caring behaviours e.g. trust, respect and compassion demonstrated by renal healthcare staff. The quality of communication between the renal healthcare team and participants was very important to participants (Bastiaens et al. 2007). These relational behaviours enabled participants to manage anxiety and stress associated with their status passage. As the substantive theory demonstrated, information was influential throughout the status passage. Resources, including leaflets, expert patients and doctors influence status passage. This is consistent with previous studies by (Klang, Bjorvell & Clyne 1999; Murray et al. 2009; Ormandy 2008) on the importance of information in managing the anxiety related to decision-making. Attending to informational needs of patients during the early stages of CKD, helps resolve uncertainty and stress associated with CKD (Lopez-Vargas et al 2014). Lopez-Vargas et al (2014) examined patients' perspectives of their CKD. Six primary themes emerged, including, medical attentiveness, learning self-management, contextualizing comorbidities, prognostic uncertainty, motivation, coping mechanisms and knowledge gaps. The status passage of participants was shaped by pre-dialysis education received. A limited number of participants could highlight having received pre-dialysis education when referred to specialist nephrology care, demonstrating how prior knowledge at the point of entry to the status passage is important to treatment decision-making.

The current study does not concur with Morton et al.'s (2011), findings that pre-dialysis discussion of self-care results in patients choosing a self-care treatment. Unlike Morton et al's. (2011) findings that patients were satisfied with their pre-dialysis education, in the current study participants felt their education had been inadequate, despite receiving pre-dialysis education. This finding is important, since it suggests that merely providing information does not always lead to an improvement in knowledge. In contrast to Ribitsch

et al.'s (2013) study, few participants wished to assume a self-care treatment, despite their early referral to a nephrologist and receiving pre-dialysis education. Goovaerts et al.'s (2005) suggests that early exposure to self-care treatment modalities positively effects choice of a self-care therapy such as home PD. An individual's engagement in self-care depends on a number of factors including assessing the impact of self-care, evaluating self-care capacity, identifying possible stigma associated with self-care and determining support available (Audulv et al 2009).

Stage two of the theory highlights how information could slow the status passage until information was understood and then shared with others. The theory demonstrates how information gathering and processing strategies were important to the status passage. The findings from this study resonate with Audulv et al's. (2009) findings, that, when negotiating self-care, individuals encounter conflicts in managing competing preferences during decision-making. Participants in the current study similarly experienced conflicts related to engaging in self-care and their personal capability to deliver it. The status passage towards *Negotiating a Safe Existence* highlights the ways in which self-care conflicts are resolved. Audulv et al.'s (2009) findings suggest that negotiation occurs as an internal dialogue within individuals; this was not so in the current study. Rather, participants used negotiation to locate external resources and mobilise family support whilst they worked through treatment decisions as part of the status passage.

Information helps in understanding the risks and hazards of RRT to participants and significant others, e.g. families. Participants used information when assessing the potential treatment burden on families as well as assist in identifying ways to protect them. Throughout the status passage, participants focused on protecting others; only once this had been addressed could their status passage progress. Kingston (2000 p.226) suggests that an undesirable status passage has consequences:

...upon the other passages that individuals may be travelling through, for example, the ageing process, with its physical, psychological, social and spiritual consequences. These undesirable passages, while demoralizing the individual, may also have an impact upon partners, family and friends of the victims (Kingston 2000)

Participants evaluated information, and as a result, difficulties sometimes arose as to which decision to follow. When decisional conflicts occurred, this led to difficulties in making a high quality decision. This may explain why participants referred to the nephrologist or families to help direct treatment decisions. Stress associated with

decision-making is a feature of status passage in *Negotiating a Safe Existence*. In the current study, participants encountered ongoing stress throughout their entire status passage. Sharing decision-making with families is an important dimension of status passage, especially in the stage of *Traversing Disruption*. Sharing decisions, offered protection from making the decision, and focused upon collaborative decision-making rather than avoiding the decision.

5.6 Desirability and status passage

Glaser and Strauss (1971 p.89), suggests:

The desirability of a status passage provides the motivational basis for actions that shape the passage. Its shaping results in part from the degree of desirability felt by the agent and the passagee toward the specific dimensions of direction and timing as they unfold. Desirability pertains both to the passage as a whole and to the specific dimensions of it.

CKD is an undesirable status passage that challenges all aspects of everyday life (Bury, 1982; Charmaz, 1983) leading to a reconsideration of self-identity (Strauss, 2008). The degree of undesirability maybe experienced differently due to varying situational and social contexts of the status passage (Glaser & Strauss 1971). The three stages of *Negotiating a Safe Existence*, highlights participants' concerns related to the undesirable aspects of their changing CKD status and the potential outcome of the status passage related to eventual dialysis. As the theory demonstrates participants used normalising strategies to manage the undesirable aspects of the status passage. *Negotiating a Safe Existence* demonstrates that because of increasing awareness levels; participants confront the undesirable consequences of their status passage. The consequences of the status passage negatively influenced their self-identity, self-esteem and emotional well-being. As participants searched for safety, the possible undesirable effect of the status passage upon others becomes evident. The consequences of this meant that the status passage towards *Negotiating a Safe Existence* required negotiating with families to secure safe dialysis treatment. As was seen, the status passage in these contexts became a more diffuse experience involving significant others.

Negotiating a Safe Existence as an undesirable status passage demonstrates the use of risk avoidance behaviours by participants. Whilst RRT is inevitable, it was interesting how

participants minimised their illness in an attempt to relieve the burden of the illness upon their family. This concurs with status passage theory in that:

In some cases-particularly in illness passages- the people involved feel that the less said about the passage to all concerned the better, until it is over. These passages are kept secrets as much as possible (Glaser & Strauss 1971, p.113)

The undesirability of the passage meant participants minimised and concealed their CKD from family members until symptoms became more visible; increasingly open levels of awareness initiated sharing with families. This concurs with status passage theory (Glaser & Strauss 1971, p.113) which suggests that:

At the other extreme is the degradation ceremony, which emphasises the end to a very undesirable passage for all concerned. The awareness context is fully opened, the undesirable details announced for all to hear

Treatment decision-making required passagees to identify the level of personal responsibility acceptable. The burden of self-responsibility represents a particularly undesirable component of decision-making as participants searched for safety. As the theory demonstrated, participants attempted to establish personal control on some aspects of the status passage. Control was exerted through a co-alignment process with families, particularly those participants choosing home PD. In the search to secure safe care, the majority of participants had control taken away or they gave it away freely. The consequences of accepting self-responsibility meant engaging with wider social networks e.g. family to secure their support.

During stage one, *Confronting a Deteriorating Self*, participants faced the undesirable reality of their changed CKD status. This stage of the status passage, signalled disruption, which was unexpected. As the theory demonstrated, participants faced the potential undesirable intrusion of dialysis into family life. This component of status passage represented a powerful reason to negotiate an agreement for the provision of hospital-based dialysis for the majority of participants. As was evident in the theory, moving forward and accepting dialysis signalled the final closure of the status passage. Whilst the outcome of status passage e.g. dialysis was undesirable, participants focused on the high level of competence of doctors and nurses. This represented a positive outcome of hospital dialysis. The theory *Negotiating a Safe Existence* demonstrated that achieving safety was associated with being monitored by staff whilst receiving dialysis; vigilant staff re-confirmed that the hospital was safe.

5.7 Circumstantiality and status passage

Circumstantiality focuses on the social relationships within the status passage, and whether individuals undertake the status passage individually, or as part of a collective group. This component of status passage theory highlights the social foundations of the passage. In the current study, participants valued connecting with existing dialysis patients. Participants actively sought to connect with existing patients to determine the social basis of their status passage. The community spirit, which developed between participants and existing dialysis patients, highlighted that they were ‘all in it together’. This finding concurs with Kristiansen and Antof’s (2016) study of the status passage of individuals with rheumatoid arthritis, where a shared collective community spirit emerged. In the current study, the structure of the renal education clinic and dialysis unit visit served to connect those undergoing the status passage with those on dialysis. A consequence of the unit visit was the connection of participants in a social sense with each other. That the social arena of the dialysis unit was important to the status passage was evident in participants’ accounts of the development of new social networks. The use of humour and jokes (e.g. relating to the PD torso) by participants helped them cope with the ambivalence in life brought on by their changing CKD status. Jokes were an important normalising strategy within the status passage.

The second stage of the substantive theory, *Sourcing Information*, is reflective of Strauss’s social psychological theory concerning newcomers and experienced individuals within an organisational environment (Strauss 2008). Social psychological theory adopts a symbolic interactionist perspective and focuses upon understanding individual behaviour within its social context. It considers the meanings underlying social interactions and how they are created, maintained and understood.

5.8 Multiplicity and status passage

As the theory demonstrates, the status passage of some participants towards safe care was influenced by other competing passages occurring at the same time. Consequently, this meant that some participants had difficulties managing the demands they faced. For example, the presence of unstable diabetes or excessive pain had the effect of temporarily halting or stalling the status passage towards safe care until other passages had been managed. Such competing passages required additional time and energy and the re-ordering of personal priorities to manage them. The emergence of a crisis event e.g.

deterioration in physical well-being or exacerbation of symptoms, also influenced an individual's movement through the status passage. For example, a sudden admission to hospital meant that the status passage being temporarily halted or delayed. This finding concurs with status passage theory in which the passage can be affected by multiplicity. Studies of living with chronic illness identify this challenge, which further supports its importance as a feature of *Negotiating a Safe Existence* (Kristiansen & Antoft 2016; Beard & Fox 2008; Bury 1982; Charmaz 1983)

5.9 Status passage – summary

- The theory, *Negotiating a Safe Existence* concurs with status passage theory (Glaser & Strauss 1971) in that viewing the social world of renal care through a symbolic interactionist lens enables a closer understanding of how behaviours and interactions amongst key agents of renal care shapes treatment decision-making.
- *Negotiating a Safe Existence* represents the accounts of older people as they managed their status passage to achieve safe care and highlights the importance of information in supporting treatment decision-making and facilitating status passage.
- *Negotiating a Safe Existence* contributes to status passage theory in identifying that status passage is more fluid and less linear than initially described by Glaser and Strauss (1971).
- This study extends understanding of awareness contexts (Glaser & Strauss 1974) by identifying the existence of two additional awareness categories as part of status passage. Suspended awareness identifies how awareness is temporality put on hold. Transient closed awareness reflects attempts to cope with the unpleasant features of status passage.
- Status passage is influenced by the socialisation process occurring between participants and existing dialysis patients, particularly through the mutual sharing of stories of illness experience
- The substantive theory extends the theory of status passage by highlighting the significant control of the nephrologist in controlling and shaping the status passage
- Older people value dialysis, as a lifesaving technology, as an aspect of their social identity (Mueller 2005).

5.10 Evaluation of the study

In this section, the theory of *Negotiating a Safe Existence* is evaluated using the criteria of ‘work’, ‘relevance’, ‘fit’, and ‘modifiability’. Applying these criteria offers an opportunity to consider the study’s implications and its limitations. The theory of *Negotiating a Safe Existence* provides an insight into, and a conceptual understanding of, the experiences older people encounter as they transition into renal care.

5.11 The Grounded theory product

Literature exists which debates the hallmarks of ‘good’ research (Miles & Huberman 1994; Lincoln and Guba 1999). In addressing the goal of ensuring good research, Lincoln and Guba (2011) stress the importance of researchers focusing on the ‘trustworthiness’ of the study:

The basic issue in relation to trustworthiness is simple: How can an inquirer persuade his or her audiences (including self) that the findings of the inquiry are worth paying attention to, worth taking account of? (p.398)

According to Lincoln and Guba (1985), researchers should be rigorous in detail as they account for the conduct of their study. This includes the use of member checks, and ensuring that the data, categories, and interpretations actually apply to the individuals in the study. In addition, in opening up the study for review, through an ‘audit trail’, it makes transparent the precise processes and detailed accounting of the specific conduct of the study, as well as the actions taken. In doing this, Lincoln and Guba (1985) suggest that credibility, dependability, confirmability, and transferability establish the trustworthiness of the research. These measures are justified and commonly understood as key features in qualitative research.

5.12 Criteria for evaluating grounded theory research

The criteria used by Guba and Lincoln (2003), according to Glaser (2003), were an

...almost hysterical pursuit of trying to solve the worrisome accuracy problem by an external unrelenting accountability requirement imposed on honest, skill and ability (p.147).

Glaser is clear that grounded theory research is concerned with concept development, rather than description and, therefore, the theoretical products of the grounded theory are

what matters most (Glaser 2003). Glaser offers four guiding criteria to judge the grounded theory product:

*Does the theory **work**, to explain relevant behaviour in the substantive area of the research? Does it have **relevance** to the people in the substantive field? Does the theory **fit** the substantive area? Is it readily **modifiable** as new data emerge? (p.17)*

These four criteria were used when evaluating the theory *Negotiating a Safe Existence* in the context of older peoples' experiences of accessing the social world of renal care. Glaser (1978) suggests that grounded theory works when it explains or predicts what may be occurring within the substantive area of study. In the case of *Negotiating a Safe Existence*, the theory offered some interpretation of the varied contexts in which treatment decisions were made by older people with stage 4 and 5 CKD. A deeper understanding of relevant issues in the context of CKD was provided. This included how caring relationships were established and maintained, how they sourced information, the way uncertainty was managed, and how various tactics and strategies were used to ensure safety. The three sub-categories of *Confronting a Deteriorating Self*, *Sourcing Information*, and *Traversing Disruption* provided a clear account to those caring for older people during treatment decision-making.

The grounded theory must also be relevant. In terms of research, the researcher cannot know more than the individual can as they live through these varied experiences daily. Glaser (1978) argues that there exists all manner of people, living their lives:

...in the know' but "from the analysts point of view this "know", are indicators that have yet to be conceptualised. The analysts gives the knowledgeable person categories, which grab many indicators under one idea and denotes the underlying pattern....once ideas can be seen as conceptual elements that vary under diverse conditions , actions options are provided to the man in the know (Glaser 1978, p.13).

The theory, *Negotiating a Safe Existence* offered relevance for older people entering renal care and identified important concepts that provided an insight into the concerns of older people, which helped improve the information and support needed to respond to their concerns (Glaser 1978). The theory also offered a rich perspective that demonstrated the individual ways participants must go about when managing their concerns as they continued to learn to live and adjust to the demands of CKD. The emergent theory provided a sympathetic focus on the challenges participants face and how they managed their concerns as they contemplated a new identity within renal care.

The third criteria Glaser (1978) offers to judge the worth of the theory is that of ‘fit’, meaning the connection between the data and the emerging categories:

Data should not be forced or selected to fit pre-conceived or pre-existent categories or discard in favour of keeping an extant theory intact (p.4)

The use of grounded theory processes including, open coding, comparative analysis, memoing, theoretical sampling, and selective coding ensures fit but is dependent on the competent application of these processes. As someone new to grounded theory, I made great efforts to apply these processes during coding and category development and in writing memos. The memos acted as an audit trail and supported the writing up of the findings, which demonstrated a degree of fittingness. The theory developed, will be judged by those who read it to determine whether it has workability and relevance based upon their own experiences.

The final criteria to judge the value of the theory, *Negotiating a Safe Existence*, is that of modifiability. Glaser was at pains to stress that grounded theory did not generate findings or test concepts.

The research product constitutes a theoretical formulation or integrated set of conceptual hypotheses about the substantive area under study. That is all, the yield is just hypotheses (Glaser 1992, p.16)

Grounded theory, whilst producing theory, remains to be modified. The theory *Negotiating a Safe Existence* may have some generalisability to other individuals who live within the confines of a life limiting illness and who need to engage with life sustaining technology to prolong that life. There may be some significance to other older people with CKD, but this depends on its “enduring grab”, meaning that it has something to offer others and will be possibly adopted. There is definitely ‘grab’ in the theory *Negotiating a Safe Existence*, particularly relating to perspectives regarding shared decision-making when individuals face decisions concerning preferred place of care.

5.13 Recommendations for further research

The diverse range of issues arising from this study highlighted the potential for some very exciting and innovative research. Among the findings of this study, older people highlighted information deficits as they transitioned into secondary care services. It would be valuable to consider research that specifically focuses on the changing information

needs of older people across their renal care pathway, with a specific focus on individualising learning for older people. Few studies have reported how learning styles of older people are considered within renal care. Therefore, research focusing on the learning styles of older people and the results used to individualise educational packages offers an interesting path for future research. Future research could focus upon initial learning styles and how these are built into the pre-dialysis education programmes. Furthermore, considerations of health literacy within the older person, and how educational strategies reflect of the role health literacy in pre-dialysis education programmes needs further research. The culturally diverse patient population receiving renal care also provides a valuable opportunity to focus upon the role of culture within the patient pre-dialysis journey. There is also the potential for some interesting research, which focuses on the impact of gender and older people facing treatment decision-making in renal care, an area that has largely been unexplored to date.

The continued development of decisional support strategies, specifically focused on the needs of older people, offers a valuable area for future research. Such research would enable the specific needs of older people as learners to inform decisional support tools. Decisional support tools, which build upon diverse medium and technologies, would offer an opportunity to strengthen creative approaches in supporting patient decision-making.

One exciting area for further research is to extend the application of status passage theory to renal care and to focus on how macro and microstructures within the renal care environment influence decision-making.

5.14 Recommendations for clinical practice

There is a need to address information provision for older people earlier during their pre-dialysis management by strengthening integrated collaborative working between primary care and specialist nephrology teams; this ensures older people are prepared for future treatment decision-making. The standard application of decisional support tools should be considered to ensure older people and their families' are fully aware of the risks, benefits, and potential harm of treatment modalities. Involving expert renal patient groups in the development and testing of decisional aids should become standard practice. The importance of the dialysis unit visit to older people in this study demonstrates its value during the information gathering stage of decision-making. It is recommended visits to the dialysis unit, as a requirement of pre-dialysis education, should become standard.

The findings of this study highlighted how older people often struggled to obtain information to support treatment decision-making. To enable older people to communicate their needs and ensure their preferences are considered, the use of decision coaches could be made available. A decision coach assumes a supportive and advisory role, helping individuals develop the skills needed to understand information on which to base treatment decisions.

Ensuring patient assessments integrate older peoples' perspective of what safe care means to them and what attributes are seen as important to them would be of real value. This will highlight, to front line clinical staff, elements of clinical care and service delivery that are valued by patients and their families'. This could lead to the development of indicator tools of safe practice.

5.15 Recommendations for education

Strengthening pre-dialysis education programmes, with a focus upon education relating to the stage of CKD, is a key recommendation. Further considerations to incorporate audiotaped consultations with patients as standard practice, which can be used by patients and families, The training and education of renal healthcare professionals, in supporting patient decision-making, especially related to discussing conservative care (Moustakas et al. 2012), is essential.

5.16 Recommendations for policy

Providing timely support for decision-making needs to become policy throughout all parts of the renal care pathway. Local institutional guidelines and standards can be developed to ensure this is integrated into renal care. This must also be seen as policy for those responsible for commissioning renal services to ensure a stronger strategic focus is fostered. There needs to be policy which focuses upon an individual's readiness to engage in SDM when assessing their progression through their care pathway. Educational policies need developing which highlight the impact of education of older people within primary care and how it influences older peoples' transition to secondary care when referred for specialised renal care.

Further policy development related to integrating SDM within the renal care pathway should continue to be an important focus. This will ensure that, when older people

transition between primary and secondary care, there are clear policy guidelines concerning where older people can have stronger involvement (and voice) in decisions over their care, whether this is within primary care, prior to diagnosis, during secondary care referral, or once a diagnosis has been made.

5.17 Conclusion

The importance of continuing to focus on the challenges older people encounter as they encounter treatment decision-making has been identified within this thesis. The importance of information as a key determinant of decision-making has been identified and, in the context of this study, the findings indicated that ongoing work is needed to ensure older people have information available that enables them to make the right choices. During the earlier part of this thesis, the importance of shared decision-making in renal care was addressed, highlighting that, whilst the current UK policy drive is to ensure ‘*No Decision about me, without me*’, as advocated in recent health care policy (DoH 2012) is delivered, the reality was something very different. Findings from this study suggested that decisions concerning treatment for ESRD, for the majority of older people in this study, were directed by physician preferences. The findings suggested a picture of the powerlessness that older people experience during their transition from primary to secondary care. A kidney patient, Nicholas Palmer (Kidney Health Report 2013), who, as Head of Advocacy, of the National Kidney Federation, highlighted the importance of information to enable informed decisions to be taken:

Access to information helps us to take control, share in decision-making and allay our fears. We need knowledge to question, challenge, seek help and help ourselves - this is the power we must use to insist that standards are raised in order to realise our ambitions for the whole kidney pathway (p.4).

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APPENDICES

APPENDIX 1a	NHS Ethics Approval
APPENDIX 1b	Study Approval – University of Sheffield
APPENDIX 2	Participant Invitation Letter to Study
APPENDIX 3	Participant Information Sheet
APPENDIX 4	Abbreviated Mental Test (AMT)
APPENDIX 5	Interview Schedule
APPENDIX 6	Initial Open Coding
APPENDIX 7	Refinement of Codes
APPENDIX 8	Participant Consent Form

APPENDIX 1A

22 January 2009

Mr John M Sedgewick

Dear MrSedgewick

Full title of study: Older People's Views of Choice & Decision - Making in Established Renal Failure - A Grounded Theory Study
REC reference number: 08/H0905/104

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.

This Research Ethics Committee is an advisory committee to
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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>
Peer Review		15 October 2008
Letter for funding		30 June 2008
CV Key Worker		
CV Key Worker		
CV Key Worker		
Participant Information Sheet: Relative/Significant Other	V:2	01 October 2008
Letter of invitation to participant	V:1	01 October 2008
Interview Schedules/Topic Guides	V:1	23 October 2008
Compensation Arrangements		
Peer Review		16 October 2008
Letter from Sponsor		22 October 2008
Protocol	V:1	01 November 2008
Investigator CV		21 October 2008
Application	V1:1	17 November 2008
Response to Request for Further Information		
Participant Consent Form: Relative	V:2	01 January 2009
Participant Consent Form: Patient	V:2	01 January 2009
Participant Information Sheet	V:2	01 January 2009
Covering Letter		20 January 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review -guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of

changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email

108/H0905/104 Please **quote** this number on all **correspondence**

With the Committee's best wishes for the success of this project



The
University
Of
Sheffield.

School Of
Health
And
Related
Research.

APPENDIX 1B

University of Sheffield
School of Health and Related Research
Regent Court
30 Regent Street
Sheffield
S1 4DA

16 October 2008

To whom it may concern:

RE: **John Sedgewick**
Older People's Views of Choice and Decision Making in Established
Renal Failure – A Grounded Theory Study

The said proposal has been reviewed by three named supervisor and meets the requirements of the MPhil/PhD programme.

Supervisors:

Dr Lorraine Ellis
Dr Tony Blackett
Professor Stuart Parker

Yours sincerely

Lorraine Ellis PhD, MSc, RGN
Senior Lecturer



THE QUEEN'S
ANNIVERSARY PRIZES
1953-2002
2002-2008

APPENDIX 2

John Sedgewick

October 20th 2008

RE: Research Study – Older People's Views of Choice and Decision-Making in Renal Failure

Dear

Thank you for agreeing to participate in the above study. I am undertaking this study as part of my PhD at the University of Sheffield. This study is concerned with understanding how you came to make the types of choices and decisions that you made regarding your treatment and management for your renal failure.

During this study I will make arrangements to meet up with to discuss much more your own personal experiences, this will involve an interview and possibly a group discussion with other patients involved in this study. I will discuss with you shortly what your involvement in this study requires as well as discuss where you would like me to hold your interview. This can be in the hospital, the university where I work or if you prefer in your own home. All travel expenses will be reimbursed for your involvement in this study which I will discuss with you.

Once again can I thank you for agreeing to participate in this study and I will be in contact very shortly. Should you wish to speak to me in the meantime you can call me on the following number at the University of Teesside: XXXX.

Kind Regards

John Sedgewick

APPENDIX 3
Patient Information Sheet

Research Project Title:
Older People's views of Choice and Decision-Making in Established Renal Failure – A Grounded Theory Study.

Principal Investigator: John Sedgewick

1. Invitation to participate in study

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

2. Purpose of research project ?

This purpose of this study is to understand more fully how older people with Chronic Kidney Disease make decisions concerning the treatment and management they receive. The number of older people with Chronic Kidney failure is increasing. It has been suggested that older people are the largest group of individuals currently being treated for kidney failure.

Understanding how older people make decisions concerning their treatment and management is important since the results of the study will help staff caring for older people to provide more individualised care and support. Very little research has been undertaken on this topic so this study will also provide important information for a wide range of staff that care for older people with kidney failure. Finally an important purpose of this study is to enable a deeper understanding of the specific needs of older people who are required to make decisions about their treatment and care.

3. Why have I been chosen?

You have been chosen to participate in this study as you are currently attending the renal clinic and being cared for by a number of renal health staff. Whilst visiting the renal outpatient clinic your kidney function is being monitored closely whilst at the same time having discussions with the renal staff about treatment options and management. As well as your involvement in this research we may also wish to involve any close family relative / friend who you feel has been involved in your treatment decisions but this will be discussed with you if needed.

4. Do I have to take part?

Your involvement in this study is completely voluntary and should you decide to refuse to participate there will be no penalties. The care that you are currently receiving from the renal unit staff will not change. Should you decide to participate in this study you can freely withdraw at any stage without any penalties. To help you decide whether to take part you can keep this information sheet (and be asked to sign a consent form) and you can still withdraw (without giving a reason) at any time without it affecting your treatment & care you receive at the moment.

5. What will happen to me if I take part?

You will be interviewed by myself where we will discuss your thoughts and views. Interviews will be carried out in a place convenient for you, this can either be in the quiet room in the hospital, the university where the researcher works or if you prefer interviews can be carried out in your home. If you decide to travel to the hospital or the University for the Interview all travel expenses will be covered for you.

When you attend your first **renal education meeting** with the renal nurse the researcher in some cases will be present during the education session to observe the process of education only and will not take part in the session. The researcher will take notes following the observation session and will share these with you. You will be informed whether the researcher will be present during your education meeting.

During your second meeting with the Nephrologist (Kidney Doctor) you will discuss your views / preferences regarding your treatment. At this meeting the researcher may be present and will not take part in any of the meeting between you and your doctor but will observe your discussion related to your thoughts regarding your treatment choice/s.

6. What do I have to do?

The researcher will contact you to discuss your possible involvement in this study and make the necessary arrangements to meet up with you. During the interviews you will be asked to discuss your experiences of choices you have made and how you come to make decisions regarding your treatment and management.

The audio recordings of interviews made during this research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. Where information from the interviews is to be used in a publication this will be discussed with you and your consent obtained.

7. What are the possible disadvantages and risks of taking part?

There are no disadvantages of taking part in this study. Should you become upset during the interviews regarding your treatment and management decisions the interview will be stopped and opportunities will be made available for you to discuss how you feel with either the Pre-dialysis nurse specialist who you will have met during your care or the renal unit social worker who can provide additional support.

8. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will lead to the development of educational approaches to help older people make choices concerning their care. It is hoped that the results will also help further develop the services and care offered to older individuals who have chronic kidney disease.

10 What if something goes wrong?

If you have any concerns or complaints as a result of your involvement in this study you should contact the Principal Investigator. If at any point you feel that your concerns are not dealt with by the Principal Investigator to your satisfaction you can contact the University's 'Registrar and Secretary'.

11 Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential and securely stored. You will not be able to be identified in any reports or publications.

12 What will happen to the results of the research project?

The results of the research will be published in relevant professional journals as well as presented at local, national and international conferences related to the research topic. You will not be identified in any report or publication from this research project.

13 Who is organising and funding the research?

This research is being funded by the British Geriatrics Society / Dunhill Medical Trust

14 Who has ethically reviewed the project?

This project has been ethically approved via The School of Health and Related Research department's ethics review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University. This study has also been reviewed by the Ethics Committee and the Research & Development Committee at the hospital where the study will take place.

15 Contact for further information

If you require further information please contact:

John Sedgewick, Principal Investigator

Supervisor/s of Project

Dr Tony Blackett

If you do decide to participate in this research study you will be provided with a copy of the information sheet and a copy of the signed consent form.

Thank you for your participation in this research project

APPENDIX 4

ABBREVIATED MENTAL TEST SCORE

Respondent ID #

Question ^[1]	Score
What is your age? (1 point)	
What is the time to the nearest hour? (1 point)	
Give the patient an address, and ask him or her to repeat it at the end of the test. (1 point) e.g. 42 West Street	
What is the year? (1 point)	
What is the name of the hospital or number of the residence where the patient is situated? (1 point)	
Can the patient recognize two persons (the doctor, nurse, home help, etc.)? (1 point)	
What is your date of birth? (day and month sufficient) (1 point)	
In what year did World War 1 begin? (1 point) (other dates can be used, with a preference for dates some time in the past.)	
Name the present monarch/dictator/prime minister/president. (1 point) (Alternatively, the question "When did you come to [this country]?" has been suggested)	
Count backwards from 20 down to 1. (1 point)	

APPENDIX 5

Interview Schedule (Patient)

Q1. Tell me what you understand about your current illness
(Prompts describe in own words)

Q2. How has your illness affected you so far?
(Prompt physical effects of renal failure, psychological, social)

Q.3 What care have you been having so far for your renal failure?
(Prompts Primary care, Pre-Dialysis Clinic, other care (Diabetes, CVS)

Q.4 Can you tell me what has effected your decisions concerning your treatment so far?
(Prompts information given, preferences, support from family / friends/ others, own views about health & illness,)

Q.5 Was there any particular information given that you remember
(Prompts written information, audio- visual, individual one to one, legibility, comprehensiveness, understanding)

Q.6 What effect did the type of information given to you help you in making the decisions you made
(Prompts: benefits, harms, risks, promoted choice)

Q.7 How did you come to make the decisions you have made about what treatment you wanted
(Prompt – process, consultation with others, provision of treatment specific information)

Q. 8 How do you see your role in the decisions regarding your treatment & care?
(Prompts – active or passive role, views of health professionals as experts)

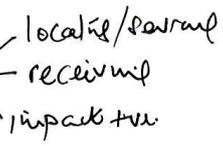
Q. 9 Are you satisfied with the decisions that you have made concerning your treatment
(Prompts benefits vs. treatment, involvement in decision making,

Q.10 In making the decisions that you have now made what were the most important things to you that mattered

Initial Open Coding (Free Nodes)

1. a lot of information to take in — Information load.
2. acceptability of hospital dialysis — acceptability of hospital dx.
3. acceptance
4. Acceptance and accommodating } accepting & accommodating
5. acceptance of restrictions
6. Accommodating family pressures for decisions to be made — Family pressure
7. Accommodating possibilities
8. active management of restrictions
9. adhering to treatment requirements
10. amazement
11. annoyed
12. Appraising reality of changed circumstances ✓
13. Appraising value of new social relationships ✓
14. Avoidance
15. Avoidance of making decision } Decision avoidance.
16. avoidance of reality
- ~~17.~~ Avoidance of restrictions imposed by machine
18. avoidance of travel
19. awareness future treatment plans & protocol
20. awareness of consequences of infection — Awareness of risk to infection
21. awareness of limitations
22. Awareness of negative effects after treatment — Awareness of -ve s/e to
23. awareness of treatment
24. being captured....
25. being cared for by others — Taken care of.
26. being comfortable with decision — Satisfied with decision
27. Being forced against wishes —
- ~~28.~~ being knocked down...being finished
29. being looked after } Being Cared for.
30. being monitored
- ✓31. Being open to information from others — Openness to external information
- ~~32.~~ being positive
33. being taken care of — Being Cared for.
34. being told
35. burden of existing illness
36. chances of living with dialysis
37. choices
38. Cleanliness' — cleanliness
39. collaborating } Relationships positive & met
40. communication with medical team excellent
41. comparing self to other patients
- ✓42. complexity of treatment —
- ✓43. concerns making mistakes — Fear of making mistakes
- ~~44.~~ confirming
- ~~45.~~ conflicting medical advice
- ~~46.~~ confronting
- ~~47.~~ contemplating death over negative aspects of treatment
- ~~48.~~ decisional influences

- 49. delays starting treatment — Tx delay.
- 50. demonstrating PD technique — Practical demonstration
- 51. developing new approaches to manage
- 52. diagnosis
- 53. dialysis inevitable — Inevitability of dx.
- 54. dialysis unit environment
- 55. disbelief
- 56. discussing
- 57. Dislike of altered body image } threat to body image.
- 58. Distancing of self — Distancing
- 59. Doctor decides — Medical decider
- 60. Evaluating self with others - severity assessment
- 61. explanations — Communication
- 62. extending life — life extension.
- 63. facing up to — Facing consequences
- 64. family benefits from decisions taken — Family benefits
- ✓ 65. family preferences
- ✓ 66. family support
- ✓ 67. fears of infection — Infection
- 68. feeling very ill dialysis would be needed
- 69. feeling well and not ill
- 70. fitting into lifestyle — Accommodating tx into ADL.
- 71. fluctuating blood results } Fluctuating physical state
- 72. fluctuating condition
- 73. following treatment
- ✓ 74. gathering advice from others — Information gathering
- 75. home based treatment
- 76. hope
- ✓ 77. horror at need for dialysis
- 78. humour
- 79. impaired vision — limitations.
- 80. impressed
- ✓ 81. inability to manage self —
- ✓ 82. inability to read information — Valuing self-care
- 83. Independence & self care valued
- 84. inevitability of dialysis
- 85. Infection risks — risks
- 86. information
- 87. Information gathering
- 88. information lacking
- 89. information provision
- 90. information sharing
- 91. information sources
- 92. information transmission
- 93. informational sources } information practices
- 94. Informed decisions
- 95. informing doctor needing dialysis
- 96. it first came to light
- 97. it has increased in stages rather than continuously.
- 98. knowing all information — information



- 99. knowing benefits & outcomes — Awareness of outcome/benefits
- ~~100.~~ knowing with certainty
- 101. left to self at home a worry — personal responsibility.
- 102. limitations imposed } restricted options
- 103. limited options } restricted options
- 104. living by self } loneliness
- 105. loneliness } loneliness
- 106. maintaining normality
- 107. Managing family pressure to make decision — family pressures.
- 108. Memory difficulties — poor memory.
- ~~109.~~ mental preparation
- 110. mentally making adjustments to accommodate — accommodation adjustment
- 111. messy doing treatment at home — honest Messy.
- ✓112. minimising disruption
- ~~113.~~ miscommunication
- 114. motivated to manage self — self management motivation
- ~~115.~~ need to have treatment
- 116. nice environment of dialysis unit — dialysis unit environment positive
- 117. No understanding
- 118. No understanding of dialysis } understanding poor.
- ~~119.~~ not wanting to be part of the club
- 120. nurse guiding choice of treatment — nurse directed DM.
- 121. nurses care — being stat.
- ~~122.~~ options available
- ~~123.~~ partnership
- 124. Patients looked peaceful — Peaceful patients
- 125. personal responsibility for decisions — Personal responsibility.
- ~~126.~~ physical limitations
- ✓127. positive care environment
- ✓128. preference for hospital treatment
- ✓129. preventing disruption
- ✓130. quality of medical consultation —
- ~~131.~~ Rather not know
- ✓132. rationalisation of benefits of hospital treatment rationalisation
- ~~133.~~ Realisation of similarities to other patients
- ✓134. receiving advice from family members — family member advice
- ~~135.~~ reduced flexibility
- 136. reflecting on care provided — reflection
- 137. Refusal to accept treatment needed — refusal of tx
- 138. reinforcement of decisions taken
- 139. relationships with other patients — patient relationships.
- 140. relieved that dialysis not need just yet
- ✓141. relieving burden on family members — relieving family burden
- ~~142.~~ Requesting dialysis
- ~~143.~~ resignation to diagnosis } Resigning self.
- 144. Resigning self to treatment } Resigning self.
- ~~145.~~ resistance to dependency on machine
- ~~146.~~ respecting decision
- ✓147. responsibility for decision taken } decision responsibility
- ✓148. responsible for decisions } decision responsibility

- ✓ 149. risk awareness
- 150. Running away from decision } Decision denial:
- 151. Running away from reality
- ✓ 152. safety in hospital — hospital safe
- ✓ 153. saving your life
- ✓ 154. self care motivator
- ✓ 155. self doubt
- ✓ 156. Self management therapy too complicated — self care is complex
- 157. sharing decisions
- 158. sharing diagnosis with family } Sharing is strength DM.
- 159. sharing experiences
- ✓ 160. shock
- ✓ 161. spouse involvement
- ✓ 162. stand and take it
- ✓ 163. sudden diagnosis
- ✓ 164. symptoms of illness — Connected to others
- 165. talking with others
- ✓ 166. technical mastery and skills — Mortality
- ✓ 167. thinking about death — Infection threat
- ✓ 168. threats of infection
- 169. time consuming nature of dialysis } Tx time consuming
- 170. time requirements of treatment
- 171. time to treatment
- 172. treatment confidence
- 173. Treatment demand a concern
- 174. treatment impact } Tx demands
- 175. treatment information exchanges
- 176. treatment intrusion
- 177. Treatment time
- 178. treatment demands on self
- 179. uncertainties } uncertainty
- 180. uncertainties
- 181. unsuitability of home environment a concern — home environment unfavorable.
- 182. value of being monitored — Being monitored.
- 183. valuing information
- 184. Valuing new relationships in renal unit — Forming new relationships
- 185. wait & see what happens
- 186. working together
- 187. worried treatment will fail — Fears of tx failure
- 188. worry about time constraints } time
- 189. worry about time demands for treatment

APPENDIX 7

Refinement of codes (delimiting process)

1. Acceptance
2. Accommodating
3. Altered self image
4. Appraising
5. avoidance
6. Avoiding
7. Awareness
8. Being cared for
9. Burden
10. choices
11. Competency
12. Confronting
13. Contemplating
14. Decision satisfaction
15. Decision taken
16. Decisional pressures
17. Decisional responsibility
18. Dependency
19. Deteriorating state
20. Family benefits
21. Family guidance
22. feeling safe
23. Flexibility
24. Home therapy
25. Hygiene
26. Information provision
27. Informed decision
28. Learning
29. locating self
30. Logistical Challenges
31. Managing restriction
32. Positivity
33. Receptive to information
34. Relationships
35. Risk to self
36. Self-Doubts – managing uncertainty
37. Sharing decisions
38. Transportation
39. Treatment benefits
40. Treatment requests
41. Uncertainty
42. Wonderment

APPENDIX 8

CONSENT FORM (PATIENT)

Title of Project: **Older People's views of choice & decision making in Established Renal Failure – a grounded theory study**

Name of Researcher:
John Sedgewick
Participant Identification Number:

Please initial box

1. I confirm that I have read and understand the information sheet/ letter (delete as applicable) dated [] for the above project and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. *Contact John Sedgewick on XXXXXX should you wish to discuss this project further*
3. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses.
4. I understand that all tape recordings of interviews undertaken during the study and data collected during observed renal education sessions will be kept in a locked cupboard and destroyed after 3 years of completion of the study.
5. I agree to take part in the above research project.

Name of Participant _____ Date _____
Signature (or legal representative)

