The Impermanence of Reality: A Grounded Theory Study of the Experience of Transition to Palliative Care for People with End Stage Kidney Disease (ESKD)

By

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Thesis

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PART ONE

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ABSTRACT

There has been an increasing recognition over the last ten years of the importance of integrating palliative care alongside other aspects of care for people with life-limiting illness including kidney disease. Over the same time period, policy initiatives have aimed to address and improve the end of life care for all adults with kidney disease. However, little is known about the transitions experienced by people with end-stage kidney disease (ESKD) as they approach the end of life.

This qualitative study explored the transitions experienced by people with ESKD as they approached the end of their lives. A constructivist grounded theory methodology was used, and unstructured interviews were conducted with twelve people living with ESKD who were deemed to be approaching the end of their lives. The interview data were analysed and interpreted using the constant comparative method.

The core category of 'restructuring reality' emerged from the data analysis alongside three dynamic, interrelated conceptual categories and the subcategories within these. These conceptual categories were: ‘striving to maintain autonomy and control in decision making’, ‘managing uncertainty: knowing without clarity or confirmation’, and ‘the importance of personal virtues in transitioning through the illness’. The substantive theory which emerged from the data analysis and which conceptualised the process and experience of transition for people with ESKD in this study was defined as ‘the restructuring of reality during transition for people with ESKD approaching the end of life’.

The study findings provided valuable insight into the experience of people with ESKD as they approach the end of their lives. The tentative theory presented in this study added to the knowledge of the transitions experienced by people with ESKD.
as they approached the end of their life. The theory captured how participants made sense of and adjusted to the changes they experienced as their health deteriorated; it emphasised that being able to continue to contribute and be involved in decision-making about care was an important aspect of the transition process as people approached the end of their lives. The study findings also highlighted the importance of healthcare professionals undertaking end of life discussions with patients throughout their illness trajectory to ensure people with ESKD are afforded the opportunity to be involved in timely decision making and provided with good quality end of life care.
STATEMENT OF ORIGINALITY

The thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished), are fully identified as such within the work and attributed to their originator in the reference/bibliography or in footnotes. This thesis has not been submitted in whole or in part for any other academic degree or professional qualification.

Name: Kara Blackwell

Signature:

Date:
ACKNOWLEDGEMENT

I would like to thank the patients who participated in this study and who generously shared their stories with me during the interviews; they gave their precious time and energy to do this. Listening to their accounts was a humbling experience for me and reminded me of the strength, courage and optimism people often demonstrate despite the challenges they face as they approach the end of life.

I would also like to thank my academic supervisors Professor Sara Faithfull and Professor Ann Gallagher for their expertise, immense patience, support, and wisdom during my research journey.
OVERVIEW OF THE CHAPTERS

Chapter 1: The introductory chapter provides an outline of the researcher’s role and interest in the research area. This is followed by a summary of the background to the study. The rationale for the study, the study aims, and the research questions are presented.

Chapter 2: The literature review provides an overview of the current knowledge and empirical studies relating to renal palliative care. Consideration is also given to the wider literature concerning the transitions experienced by people with cancer and other life-limiting illness as they approach the end of life and draw inferences to end-stage kidney disease (ESKD).

Chapter 3: The chapter provides an outline of transition as the theoretical framework for this study. It includes a definition of transition and explores the concept in relation to the transitions associated with health and illness, ESKD, and palliative care.

Chapter 4: This chapter provides an overview of constructivist grounded theory and the rationale for its choice as a methodology for the study. The research methods are outlined and the ethical considerations are discussed.

Chapter 5: The chapter presents an analysis of the findings. The core category of ‘restructuring reality’ and the three interrelated categories of ‘striving to maintain autonomy and control in decision making’, ‘managing uncertainty: knowing without clarity or confirmation’, and ‘the importance of personal virtues in transitioning through the illness,’ are discussed. The substantive theory which emerged from the integration of the categories is presented.
**Chapter 6**: This chapter presents the discussion, the study’s implications, study limitations and conclusion. It situates the emergent theory and the findings of the study within the context of the current transition theory, ESKD, and palliative care. Recommendations for clinical practice, education and consideration of areas for future research are outlined.
CHAPTER 1
INTRODUCTION

1.1 Introduction

This introductory chapter outlines the background and rationale for this study. An explanation of the researcher’s interest in the research area is presented. This is followed by a summary of the background to the study, which situates the experience of transition within the context of palliative care. The incidence and prevalence of end-stage kidney disease (ESKD), the policy context pertaining to renal palliative care and the trajectories to the end of life for ESKD are discussed with reference to the concept of transition. This is followed by the aims of the study and presentation of the research questions.

1.2. Professional background of the researcher

I am a registered nurse with 26 years’ post registration experience, having spent a majority of my career working clinically within the specialities of haematology, oncology and palliative care. I have held a number of clinical and managerial roles; within these roles, I have had professional and management responsibility for specialist palliative care services and have continued to practice clinically within palliative care. While working in these roles I developed and maintained a particular interest in palliative care for non-malignant, life-limiting illnesses including kidney disease and have contributed to the development of palliative care services for these patient groups.

My interest in the experience of transitions for people approaching the end of life as a research topic initially developed in 2009 when I was a member of a research project advisory group undertaking a systematic review to understand the place of
death for non-malignant conditions. Contributing to this advisory group prompted me to consider what the psychosocial transitions were for people with a life-limiting illness as they progressed to the end of life and the need to understand these alongside the more tangible outcomes associated with the provision of palliative care. At that time, I was working clinically with palliative care and renal colleagues, this prompted me to pursue undertaking a study to explore the experience of these transitions for people living with ESKD who were approaching the end of life. I believed that gaining a greater understanding of the experience of transitions within the illness trajectory of ESKD was as important as understanding the type and context of these transitions in relation to the provision of palliative care for this patient population.

1.3. Transitions in palliative care

The term transition has been consistently used in the health and illness literature to describe a ‘person’s response during a passage from one life phase, condition or status to another’ (Meleis et al. 2000:10). As a concept, it embraces the elements of process, timespan and perception representing the psychosocial processes that people go through to incorporate change into their life (Bridges 2004; Chick & Meleis 1986; Kralik 2002; Kralik et al. 2006a; Schumacher & Meleis 1994). Transition has been proposed as a valuable framework for understanding the experiences of patients with chronic illness as they negotiate the illness trajectory (Davidson et al. 2007; Kralik 2002; Waterworth & Jorgenson 2010). However, less is known about the transitions associated with the trajectory to palliative and end of life care, particularly in patients with a non-cancer diagnosis in which the illness trajectory may be less clearly defined.
Palliative care for life-limiting illness has gained more prominence over the last decade, having been recognised as an approach that can benefit people with a variety of diagnoses as they approach the end of life (Cohen et al. 2006; Coventry et al. 2005; Douglas 2014; Fitzsimmons et al. 2007; Murtagh et al. 2006; Murtagh & Sheerin 2010).

Palliative care emphasises:

'an approach to care that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (World Health Organisation, WHO, 2002:3).

This definition implies a multitude of issues and transitions that are inherent in the trajectory of life-limiting illness. The transitions patients and their families may experience as they approach the end of life may be those associated with the shift in the focus of care from ‘cure to comfort care’, changes in symptoms, functional status, those relating to loss and those relating to changes in care setting (Davies et al. 1995; Larkin et al. 2007a; Marsella 2009; Ronaldson & Devery 2001). These transitions are often experienced concurrently and can be confusing and traumatic to patients and their families/carers. For people with ESKD the illness trajectory is more unpredictable, and the transitions associated with the shift to palliative and end of life care may be subtler than those seen in illness trajectories such as cancer in which emphasis has been placed on a shift from ‘curative’ to ‘comfort’ and the associated transitions experienced by patients during this phase of their illness (Marsella 2009; Schofield et al. 2006). Appreciating and gaining a better understanding of the subtleties in the transitions experienced by people with ESKD
as they approach the end of life may assist health care professionals to better deliver interventions, information and support to patients, not only in relation to physical changes but also the social, psychological and existential dimensions of their illness.

1.4. Classification, incidence and prevalence of Chronic Kidney Disease

Chronic kidney disease (CKD) describes abnormalities of kidney function or structure that have been present for more than three months and have implications for health (National Institute for Health and Care Excellence, NICE, 2014). The classification of CKD has previously been predominantly based on measured or estimated Glomerular Filtration Rate (eGFR) and described as CKD Stages 1-5. The updated NICE Guidance (2014) re-classified CKD according to a combination of Glomerular Filtrate Rate (GFR) and the albumin-creatinine ratio (ACR). The new GFR categories describe CKD in terms of G1-5 and have the same GFR thresholds as the previous CKD stage 1-5 recommendations. The ACR categories range from 1-3, with an increased ACR being associated with increased adverse outcomes. This NICE (2014) classification is outlined below:

Table 1: Classification of chronic kidney disease

<table>
<thead>
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<th>GFR and ACR categories and risk of adverse outcome</th>
<th>ACR categories</th>
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<tr>
<td>&gt;90 Normal and high mild increase</td>
<td>G1</td>
<td></td>
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<tr>
<td>60-89 Mild reduction</td>
<td>G2</td>
<td></td>
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<td></td>
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<tr>
<td>45-59 mild to moderate reduction</td>
<td>G3a</td>
<td></td>
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<tr>
<td>30-44 moderate to severe reduction</td>
<td>G3b</td>
<td></td>
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<td>15-29 Severe reduction</td>
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(Adapted from NICE 2014 Clinical Guidance CG182)
It is estimated that between 6.8-13% of the adult population in the United Kingdom have CKD stage 3-5, with a small but significant percentage of people progressing to stage 5 or G5 CKD, also referred to as end-stage kidney disease (NICE, 2014). ESKD is caused by a progressive and irreversible decline in kidney function which requires renal replacement therapy (RRT) for the person to survive. Renal replacement therapy (RRT) can take a number of forms including kidney transplantation, haemodialysis and peritoneal dialysis; dialysis can take place either in the hospital or at home. The choice of management of ESKD is complex, particularly for those people who are older, frail and who have co-morbidities in whom alternatives to RRT such as supportive non-dialytic conservative management may be more appropriate (Carson et al. 2009; Murtagh et al. 2007a).

The number of people commencing dialysis for ESKD in the United Kingdom has remained stable over the last decade with approximately 7000 new patients commencing; in contrast, the number of people receiving dialysis at the end of 2013 was 56,940, an increase of 4% from the previous year (Gilg et al. 2014). Those people receiving dialysis were older; the percentage of people receiving dialysis aged over 70 increased by 6.8% between 2000-2013 with the highest prevalence rate being in those people over 85 years of age (Gilg et al. 2014). The annual mortality rates for patients on dialysis continue to exceed 20% (Davison et al. 2015). The stability seen in the incidence of people commencing dialysis over the last decade may, in part be due to the introduction of conservative management as a treatment option for patients with ESKD. Although definitive data was not available, it is estimated that between 14-20% of older people with ESKD in the United Kingdom, the United States and Australasia opt not to commence dialysis and are managed conservatively (Carson et al. 2009; Hussain et al. 2013; Morton et al. 2012; Murtagh 2009; Stevens et al. 2010). An increase in the number of people with
ESKD is projected to continue in parallel with the ageing of the general population and the growing prevalence of cardiovascular disease and diabetes mellitus (Brown 2012; Brown & Johansson 2011; NICE 2014). This will increase the necessity to integrate palliative alongside the other aspects of care for people with kidney disease.

1.5. The policy context - renal palliative care

The last decade has seen an increased recognition and focus within palliative care policy on the provision of palliative care for people with life-limiting illness other than cancer. The importance of improving end of life care for people with advanced renal disease was initially acknowledged in the Renal National Service Framework (NSF) Part 2 in 2005 (Department of Health, DOH, 2005a). The NSF for Renal Services (DOH, 2005a) highlighted the need for appropriate end of life care for renal patients, stating that people with stage 5 chronic kidney disease (end-stage kidney disease) should receive timely assessment of their prognosis, information about the choices available to them and, for those near the end of life a jointly agreed palliative care plan, created around individual needs and preferences. However, the document only endorsed palliative care for those on dialysis who were coming to the end of their life and failed to identify the supportive and palliative care needs of other people with kidney disease, such as those managed conservatively. Subsequent to this, the Royal College of Physician report ‘the Changing Face of Renal Medicine in the UK’ (Royal College of Physicians 2007), recommended joint working between renal multidisciplinary teams, primary care and other services such as palliative care, promoting integrated care for patients with chronic kidney disease.

The End of Life Care (EOLC) Strategy (Department of Health, DOH, 2008) represented the first national strategic plan aimed at promoting high-quality care for
all adults approaching the end of life regardless of underlying diagnosis. A key recommendation of the EOLC strategy was that death should become an explicit discussion when patients were likely to die in the next twelve months, acknowledging the need to better recognise patients who were likely to be in the last twelve months of life. The strategy outlined the key role for health and social care professionals in helping patients to come to terms with the transition from ‘curative care with a focus on cure or chronic disease management, to palliative and end of life care’ (DOH 2008:5). The strategy recognised that definitions of the beginning of palliative care varied according to the individual perspective of the patient and health professional, and that this had implications for the timing of the transition to palliative care.

The End of Life Care in Advanced Kidney Disease - A Framework for Implementation, (Department of Health 2009) built on the EOLC strategy (DOH 2008) and developed a specific end of life framework for patients with advanced kidney disease. It explored the kidney-specific issues of end of life care and focused on patients opting for conservative management and those ‘deteriorating despite dialysis’ in whom withdrawal of dialysis may become an option, with the aim of supporting renal services to offer high-quality end of life care in the last year, months or days of life. Key elements of the framework included the encouragement of timely recognition that the end of life phase was approaching, sensitive communication with these patients and carers/families, holistic assessment, joined up planning including recording patients on ‘a cause for concern’ register and effective multi-professional working across boundaries.

More recently the NHS Kidney Care publication ‘Getting it right: End of life care in advanced kidney disease’ (NHS Kidney Care 2012) reported the key findings of the project groups set up in three renal centres in the United Kingdom which had
implemented the end of life care in advanced kidney disease framework. The report evaluated the approaches used in these centres and provided recommendations based on this work which included a focus on achieving best practice and workforce considerations. The report concluded that a systematic approach to the identification of patients, sensitive discussions with patients and their carers, a structured approach to recording wishes, key link workers to coordinate care and improved training made a difference to the care provided to patients at the end of life.

1.6. Palliative care for people with end-stage kidney disease

The importance of integrating palliative care alongside other aspects of nephrology care as a means of improving the outcomes for people living with end-stage kidney disease (ESKD) is now considered an essential component of care (Davison et al. 2015; Douglas 2014; Fassett et al. 2011; Kane et al. 2013). Palliative care provides the opportunity to support people with ESKD in a variety of areas including symptom control, advance care planning supporting end of life discussions and decision making about future care, the provision of psychosocial support, and education to both the patient and their family/carer (Da Silva-Gane & Farrington 2014; Kane et al. 2013; Wasylynuk & Davison 2015).

Both renal policy and expert opinion in the field of renal palliative care have indicated the groups of patients with ESKD who would benefit from palliative care. People with ESKD who would most benefit from the integration of palliative care have been defined as: those choosing not to dialyse who instead opt to be managed conservatively for whom the aim of care is to optimise quality of life and planning for the end of life, those who are considering withdrawing from dialysis, and those
patients who are ‘deteriorating despite dialysis’ (Da Silva-Gane & Farrington 2014; DOH 2009; Kane et al. 2013). This is represented in Figure 1 below:

Figure 1: The End of Life Care Framework for End-Stage Kidney Disease.

(Adapted from the “End of Life Care in Advanced Kidney Disease - A Framework for Implementation, DOH 2009).

Conservative management for some patients with ESKD is now an established treatment option in many renal units; it aims is to provide comprehensive care including complete management of increasing uraemic symptoms, pain management, advanced care planning, and psychological support of both the patient and their family (Jassal et al. 2011). Conservatively managed patients are more likely to have access to palliative care services and less likely to be admitted to or die in hospital than patients who are receiving renal replacement therapy (Hussain et al. 2013).
Those patients who are ‘deteriorating despite dialysis’, include patients who begin dialysis in good health but over time become symptomatic and less able to tolerate the burden of dialysis because of increasing comorbidities, frailty or current medical events such as a new diagnosis of a stroke or cancer and in which management may shift from life-extending to care focused on quality of life, symptom control and planning for the end of life. This group also includes patients who have chronic progressive conditions which have caused renal failure, such as poorly controlled diabetes; although dialysis is started the prognosis is poor, and an approach to care requiring the integration of palliative care should commence alongside dialysis. Access to the same level of supportive and palliative care should be offered to these patients alongside joint working with palliative care services. The illness trajectory of declining patient health associated with these current medical events, and/or functional decline signal a need to reassess the goals of care. In order to prepare patients and their families for the transitions associated with this ‘deterioration despite dialysis’ the goals and limitations of care should be reassessed and discussed; these discussions are most effective when the patient, family and healthcare professional recognise the change and agree on the plan of care (Douglas 2014; Fassett et al. 2011, Grubbs et al. 2014; Koncicki & Schell 2016). For patients who are ‘deteriorating despite dialysis’, the decision may also be made to stop dialysis, often referred to as ‘dialysis withdrawal’, following which death often results in days or weeks (Da Silva-Gane & Farrington 2014; DOH 2009; Kane et al. 2013).

Grubbs et al. (2014) suggest that standard dialysis may be inconsistent with the goals of care for many patients with ESKD who are perceived to be in the last year of life, outlining that a palliative approach to dialysis care which focuses on aligning patient treatment with patients’ informed preferences may be more applicable. The
domains of this palliative approach include eliciting the patients’ goals for care (physical, psychological and spiritual), symptom management and caregiver support. Grubbs et al. (2014) defined this palliative approach to dialysis care as the transition from a conventional disease orientated focus on dialysis as rehabilitative to an approach prioritising comfort and aligned to patient preferences and goals of care to ameliorate symptoms, suffering and improve the quality of life.

Palliative care in ESKD is particularly important in the context of conservative management, withdrawal from dialysis and also for those patients ‘deteriorating despite dialysis’. Advanced care planning and end of life decisions overarch these pathways. However, the provision of palliative care to patients with ESKD is appropriate at any stage of their illness trajectory and is not limited to those patients with advanced disease or those approaching the end of life. Indeed, it is recommended that aspects of palliative care such as advance care planning which supports end of life discussions and decision-making about future care, should start when patients reach ESKD and are being informed about treatment options, however, the evidence suggests that this does not always occur (Davison 2012; Davison et al. 2014; Douglas 2014; Fassett et al. 2011; NHS Kidney Care 2012).

There is no clear pathway to palliative care in ESKD and considerable variation exists, however, several authors have suggested that at a minimum those patients perceived to be in the last twelve months of their life would benefit from increased palliative and supportive care (Da Silva-Gane et al. 2013; Douglas 2014; Koncicki & Schell 2016). Understanding the transitions experienced by patients with ESKD and the identification of those patients who would benefit from the integration of palliative care alongside their nephrology care is important to ensure that they are best supported through the illness trajectory to the end of life.
1.7. Understanding the end of life trajectories in end-stage kidney disease

Illness trajectories are illustrated by a specific shape, representing a pattern of events that can be mapped over the course or duration of a disease. As a concept, illness trajectories are well established in end of life care particularly in relation to the pattern of functional stability and functional decline towards death (Glaser & Strauss 1968; Lunney et al. 2003; Teno et al. 2001). Four trajectories have been identified: sudden death, terminal illness, organ failure and frailty. Each trajectory differs in its length and gradient of functional decline (Lunney et al. 2003).

Understanding the trajectory of illness for people with end-stage kidney disease (ESKD) is a crucial component in relation to care and management. These trajectories provide information on the anticipated course of the illness, identifying potential critical points in a patient’s illness and may provide helpful markers for clinicians to assist them in planning care, including end of life care. The illness trajectory for people with ESKD is variable and can be influenced by whether the decision is made to commence dialysis or not, functional status, age, and the presence of co-morbidities (Douglas 2014; Fassett et al. 2011). For some people who opt for dialysis, a trajectory similar to sudden illness with an acute event such as an infection or cardiac arrest, or a trajectory with progressive subtle declines and partial recovery, such as in chronic organ failure can prevail (Murtagh et al. 2008; Murtagh et al. 2004; Schell et al. 2013). For people with ESKD who elect for conservative management, it has been suggested that the trajectories include: those who die a typical uraemic death, those who follow another death trajectory due to comorbidities e.g. heart failure, those where the cause of death is unclear, and that some patients may follow a trajectory of prolonged dwindling associated with frailty (Noble et al. 2010). However, Murtagh et al. (2011a) undertook a study which included a small sample of seventy-five older patients (mean age of 80.7
years) with ESKD treated conservatively to determine the functional trajectory in the last year of life. The findings suggested that the functional status of this patient group was maintained until late in the course of the illness until a few months before death, and then was followed by a rapid decline towards death. This contrasted with the previously described trajectory of chronic organ failure but is limited due to the small sample size and more research is warranted.

The increasing evidence relating to illness trajectories has advanced the understanding of functional trajectories in the last year of life. Gaps remain in relation to understanding the trajectory to death in ESKD, meaning that prognostication is more difficult, making prediction and anticipation of the end of life care more challenging (Thomas & Noble 2007; Traue & Ross 2005). Whilst an increasing knowledge of these trajectories assist healthcare professionals to recognise physical indications and symptoms at various stages of the illness trajectory facilitating awareness and anticipation of the end of life, these trajectories do not address how people with ESKD experience and adapt to the transitions associated with these trajectories to death. Understanding these transitions within the illness trajectory of ESKD is important in order to support people through the illness trajectory and provide appropriate care.

1.8. Rationale for the research

As the palliative care needs of people with kidney disease have become more evident, there has been an increasing need for health care professionals to understand the trajectories to death of those patients whose are ‘deteriorating despite dialysis’ and those who make a decision to forego dialysis and opt for conservative management of their kidney disease. It is equally important for healthcare professionals to understand how people with ESKD experience and
adapt to the transitions associated with these illness trajectories as they approach the end of life. Understanding these transitions provides the opportunity to support patients and families, not only in their physical health but also with the psychosocial dimensions that accompany ESKD, enabling opportunities to facilitate more skilled and appropriate interventions to address preferences for care and end of life care decisions.

1.8.1. Aims of the research study

The purpose of this study was to explore the transitions experienced by people with ESKD as they approached the end of their lives and to develop a substantive theory which accounted for and explained the process of transition and how people with ESKD made sense of this.

Research Questions:

- What are the transitions experienced by people with ESKD as they approach the end of their lives?
- How do people with ESKD make sense of these transitions?
- What factors influence their experience of these transitions?

1.9. Summary of the chapter

This chapter has provided an overview of the background and rationale for the study. The purpose of the study has been outlined and the research questions presented. The literature review undertaken to identify the current state of scientific knowledge relating to renal palliative care and transitions in palliative care is presented in the next chapter.
CHAPTER 2
THE LITERATURE REVIEW

2.1. Introduction

This chapter presents an overview of the research and scholarly literature surrounding palliative care for people with end-stage kidney disease (ESKD); it also reviews the empirical literature relating to the experience of transitions to palliative and end of life care in other life-limiting illnesses. The literature review aimed to determine the existent knowledge, to examine the empirical evidence and to assess the need for further investigation. The search strategy, scope and results of the literature review are presented and discussed in this section. As it was impossible at the start of the study to predict how the emergent theory would relate to the existing knowledge and understanding, specific literature reviewed and used as a source of data once the emergent theory was grounded sufficiently in a core category is discussed as part of the presentation of the findings and discussion in subsequent chapters.

2.2. Selection criteria and literature search

An initial literature review was undertaken in March 2010. In keeping with the grounded theory method, this literature review involved consideration of a broad range of issues surrounding the research topic. The aim was to identify the empirical studies, systematic reviews and narrative reviews relating to palliative care for end-stage renal disease, and the experience of transitions to palliative and end of life care. The literature review was subsequently revisited in June 2014, October 2015 and September 2016.
2.2.1. Search methods

The following databases were searched to obtain relevant literature: Medline, CINAHL, British Nursing Index, Embase, Cochrane Library and PsychINFO. The foundations of palliative care began in the 1960's with the work of Dame Cicely Saunders who is credited as the founder of the modern hospice and palliative care movement. With this in mind, I felt it appropriate to search databases from 1960 onwards. All databases were searched up to and including September 2016.

The following search strategy was utilised for the review, using the following text and keywords:

End-stage renal disease OR end-stage renal failure OR end-stage kidney disease, OR stage 5 chronic kidney disease OR stage 5 CKD, or advanced kidney disease, chronic renal failure; chronic kidney failure. These were used singularly in each database and then combined using Boolean operators with the text words and phrases: conservative management, palliative care, end of life care, terminal care, supportive care, illness trajectory, transition, patient experience, patient understanding. The MeSH term “palliative care” was used with the other terms entered into the database searches as keywords.

The initial search did not reveal any research articles exploring transition in ESKD. It was decided to broaden the search target to include empirical literature relating to transitions experienced by people with life-limiting illnesses approaching the end of their lives in an attempt to illuminate the experiences in other illnesses and draw comparisons to ESKD to inform the current study. The above search was therefore repeated, but the keywords for kidney disease were replaced with the key words for chronic illness OR, chronic disease OR life-limiting illness OR life-threatening illness OR cancer OR heart failure OR chronic obstructive pulmonary disease.
The word transition was also used as a key word in the search strategy and was used singularly in each database and then combined with the key words for kidney disease, chronic illness OR palliative care used earlier in the search strategy and the text words and phrase: end of life, illness trajectory, patient experience and illness progression using Boolean operators.

The reference lists of all studies obtained, reviews and journal articles were also reviewed for secondary references which had not been obtained from the literature searches.

2.2.2. Inclusion and exclusion criteria

Studies were included if they were published in peer-reviewed journals and included empirical articles, systematic reviews or narrative reviews. Articles were included if they related to an adult population (those 18 years of age or older) with a diagnosis of end-stage kidney disease or life-limiting illness. Articles were limited to those published in English to prevent cultural and linguistic bias in translation. Studies which described the experience of patients undergoing renal replacement therapy (RRT), those receiving conservative/supportive care management or studies where patients were contemplating or had discontinuing dialysis were included. Studies exploring renal transplantation were excluded from the review as they had a functioning kidney. The review included studies which used both quantitative and qualitative research methodologies.

2.2.3. Search results

The literature review demonstrated that the research exploring palliative care in ESKD had developed recently with many of the research studies identified in the review having been undertaken over the last decade. Most of these papers
originated from the United Kingdom, North America and Northern Europe. In total fifty-two articles were included in the literature review, these consisted of five systematic reviews, twenty-four quantitative studies and nineteen qualitative studies, one mixed methods study and three reviews. Forty-one articles explored palliative care in ESKD, two of these articles summarised the evidence for a palliative care approach in ESKD, four were systematic reviews and thirty-five studies examined aspects of palliative care in ESKD. Eleven articles explored the palliative and end of life transitions experienced in people with life-limiting illness were also identified and included in the review. These are outlined in the diagram below:

**Figure 2: Literature Search Results**
2.3 Palliative care for people with end-stage kidney disease

The current literature review identified two review articles (one systematic and one narrative) which evaluated and summarised the recent empirical evidence supporting the palliative care approach for people with ESKD (Crawford et al. 2014; Kane et al. 2013). These provided valuable insight into the existing status of the research pertaining to palliative care in ESKD, acknowledging the limitations of the methodologies and gaps in the recent research in this field. These reviews were therefore considered important in providing context to the current literature review undertaken for this study.

Crawford et al. (2014) systematic review examined the quantity, quality and accessibility of the recent empirical literature over a two-year period from September 2009 to August 2011, with the aim of identifying empirical research articles, systematic reviews and narrative literature reviews that were directly relevant to adults with ESKD and contributed to the evidence-based implementation of a palliative care approach. All peer-reviewed research relating to ESKD were included alongside terms relevant to palliative care.

Of the studies identified in the review by Crawford et al. (2014) most (90%) used quantitative research methodologies, with a majority (80%) using prospective or retrospective observational research designs, conducted in a single centre and consisting of small sample sizes which did not allow for identification of the causal variable. Only one study identified was a randomised controlled trial. Fourteen literature reviews were also identified and included in the review undertaken by Crawford et al. (2014), however, only one of these was a systematic review. Patients receiving active care were well reported in the literature, but there were limited studies which considered conservatively managed patients with only eight articles.
identified. The reviewers also highlighted difficulties in determining whether the included articles focused on patients with ESKD in which death was judged to be imminent or reflected the wider principles of a palliative care approach for people with ESKD. The studies identified predominantly focused on physical and psychological symptoms and multidimensional quality of life (QoL). There was a paucity of research which explored the palliative care experience, communication or meaning of the illness from the perspective of people living with ESKD. Crawford et al. (2014) concluded that the research was dominated by observational studies that did not identify the direction of effect and were, therefore, poor foundations for clinical decision making. However, they also acknowledged that the research literature supporting a palliative care approach in ESKD was expanding and recommended that further identification of the many factors that need to be considered when adopting a palliative approach to care in ESKD could be achieved from consideration of the larger literature on palliative care in other diseases.

Kane et al. (2013), recognising the significant symptom burden, comorbidities and the complexity in relation to the decision to commence or forego dialysis, summarised the evidence for a palliative care approach for ESKD. The authors again commented on the absence of prospective randomised controlled trials, the few limited observational studies to guide practice and the limited population-based studies available to inform the decision for conservative management compared to management with dialysis. However, Kane et al. (2013) acknowledged that research investigating patients who opt for a conservative approach rather than dialysis for the management of their ESKD had started to emerge. There was also an increasing recognition of the importance of research being undertaken into the palliative care needs of people with ESKD and an acknowledgement that this research should
include the preferences and priorities of patients to ensure they were provided with the best care in relation to their palliative and supportive care needs.

The reviews by Crawford et al. (2014) and Kane et al. (2013) both highlighted limitations in the existing research literature and the importance of future research being undertaken which considered the patient’s experience, understanding and priorities in relation to their illness and palliative care. It is the patient perception and experience of palliative care, and the transitions they experience as they approach the end of life that forms the basis of the current study. The critique and synthesis of the existing empirical research literature undertaken for the current study are presented in the subsequent sections included in this chapter.

2.3.1. Prognosis, symptom burden and quality of life for patients with end-stage kidney disease managed with or without dialysis

Two systematic reviews were identified in the literature review (O'Connor & Kumar 2012; Murtagh et al. 2007b). O'Connor and Kumar (2012) examined prognosis, symptom burden and quality of life (QoL) in patients with kidney disease managed conservatively; the systematic review by Murtagh et al. (2007b) explored the symptom burden in dialysis patients. A total of eighteen research studies which explored prognosis, symptom burden and QoL were also identified as part of the current literature review, all of these studies used quantitative methods. Of these eighteen studies, thirteen were included in the systematic review conducted by O'Connor and Kumar (2012). The findings from the two systematic reviews and additional five studies identified in the literature review undertaken for the current study are presented.
2.3.1.1. Prognosis

The systematic review undertaken by O’Connor and Kumar (2012) summarised the research evidence for the studies undertaken prior to March 2011 which examined the prognosis, symptom burden and quality of life (QoL) of people with ESKD who were conservatively managed. Thirteen studies were included in the systematic review; all used quantitative methods. Of the thirteen studies, seven of the studies investigated prognosis (Carson et al. 2009; Chandna et al. 2011; Ellam et al. 2009; Joly et al. 2003; Murtagh et al. 2007a; Smith et al. 2003; Wong et al. 2007). The remaining six studies considered symptom burden and quality of life (QoL) and are discussed in the next section. All seven studies examining prognosis in ESKD used a cohort design, and four of these were prospective studies (Carson et al. 2009; Joly et al. 2003; Smith et al. 2003; Wong et al. 2007). The survival analysis of patients managed conservatively was compared with a sample of patients who were receiving dialysis in five of the seven studies (Carson et al. 2009; Chandna et al. 2011; Joly et al. 2003; Murtagh et al. 2007a; Smith et al. 2003).

O’Connor and Kumar (2012) systematic review results found that in studies of prognosis, conservative management resulted in survival of at least six months, (with a range of 6.3 to 23.4 months). One study in their review suggested that patients who were conservatively managed who were known to a nephrologist before reaching stage 5 chronic kidney disease (CKD) survived longer than those presenting with stage 5 CKD with a median 32 months versus 15 months respectively, although this was not statistically significant (Ellam et al. 2009). The median survival for patients which was measured from when the eGFR <15mmol/l was 21 months. Patients who were managed conservatively tended to be older, be more functionally impaired and have more co-morbidities. Similar survival results for patients managed conservatively were reported in the study by Wong et al. (2007).
survival from the decision not to commence dialysis to death was 23.4 months for patients in this study.

In relation to whether dialysis prolonged survival compared to conservative management (CM) in older people, the findings of the systematic review were mixed. Joly et al. (2003) conducted a single centre cohort study of a sample of 146 older people who opted for dialysis or conservative management. The study found a significant difference in survival for dialysis patients with a median survival of 28.9 months compared to 8.9 months for those patients managed conservatively. However, there was a much lower incidence of diabetes in the dialysis patient group. In contrast, Smith et al. (2003) found that median survival for those patients recommended for conservative care who chose dialysis was not significantly longer than those treated conservatively when adjusted for comorbidities. Smith et al. (2003) concluded that for high-risk dependent patients with renal failure the decision to undergo dialysis had little impact on their survival. The multi-centre study by Murtagh et al. (2007a) which examined survival for elderly patients with stage 5 CKD treated with dialysis compared with those who chose not to have dialysis reported that those patients managed without dialysis had a one-year and two-year survival (measured from first reaching stage 5 CKD) of 68% and 47% respectively. This was worse than those who chose dialysis whose one-year and two-year survival was 84% and 76% respectively. However, when patients with more than one comorbidity or ischaemic heart disease were analysed, the survival benefit of dialysis disappeared.

Similarly, Chandna et al. (2011) compared survival in elderly patients with stage 5 CKD who were managed conservatively or with dialysis and reported that dialysis patients had a mean survival of 67.1 months compared to 21.2 months (p<0.001) in conservatively managed patients. After adjustment for age and comorbidities, this
survival benefit was no longer statistically significant. In contrast, Carson et al. (2009) study of patients over 70 years old found statistically significant survival rates for patients receiving dialysis over those CM patients. However, the additional days of life gained were spent in the hospital, on dialysis or travelling to treatment which emphasises the importance of considering QoL and patient priorities alongside analysing survival benefits for the different treatment modalities in ESKD.

The systematic review by O'Connor and Kumar (2012) concluded that any survival benefits from dialysis decreased with the existence of comorbidities, particularly ischaemic heart disease. Limitations identified by O’Connor and Kumar (2012) included the significant variability in relation to inclusion criteria, as well as different starting points for the measurement of survival which contributed to some of the variability in the reported survival data.

Three further studies which examined survival in patients who had opted for conservative management (CM) or renal replacement therapy (RRT) were identified as part of the current literature review. These studies had all been undertaken since the systematic review by O'Connor and Kumar (2012) was published.

Da Silva-Gane et al. (2012) examined survival and QoL for conservatively managed patients compared to those receiving dialysis (the findings regarding QoL are discussed in the next section; the results pertaining to survival are presented here).

The CM and dialysis groups differed with respect to age, performance status and comorbidities; those in the CM group were significantly older, had more co-morbidities and were more likely to be dependent which meant that the unadjusted survival demonstrated major differences. However, when adjusted for these factors, survival in the dialysis group was 43.3 months compared to 30.1 months in the CM group, meaning the survival gap narrowed to 13.2 months, 10.7 months of which
equated to time spent attending dialysis, supporting the previous findings in the study by Carson et al. (2009).

Hussain et al. (2013) conducted a retrospective, observational study to compare the survival of 441 patients with ESKD who were 70 years of age or older and receiving dialysis or CM. In this study, as in previous studies, the patients in the CM group were older, more likely to have comorbidities and a poorer performance status. Unlike some of the previous survival studies, the starting point for calculating survival in each group for this study was clearly defined, time zero was taken as the time the patient's estimated glomerular filtration rate (eGFR) was <20ml/min, <15mls/min and <12mls/min. The study found that survival was better in the dialysis versus the conservative management group when measured at all three eGFR points, with a survival benefit with dialysis of 2.4 years. However, when factors influencing survival were stratified for both groups independently, dialysis failed to show a survival advantage over CM for patients aged 80 years and older, or for patients with a World Health Organisation (WHO) Performance score of 3 or more. There was also a significant reduction effect on dialysis survival in patients who had a high Comorbidity Index Score. The limitations of this study included the retrospective nature of the study drawn from one renal unit in the United Kingdom and the assessment of performance status which was limited to calculating the WHO score rather than the Karnofsky Index which would have been more accurately determined retrospectively. The study findings would have been enhanced by determining survival from the predicted point of dialysis initiation in the CM group which would have enabled direct comparison of the two treatment modalities. Despite these limitations, the study represented the largest study to date comparing outcomes in older patients with ESKD choosing between dialysis and conservative management.
In a recent single centre cohort study carried out in the Netherlands, Verberne et al. (2016) explored survival in a sample of 311 patients, who were ≥ 70 years of age at the time they opted for CM or dialysis for advanced kidney disease. The findings outlined that patients who chose CM were older (mean 83 years versus 76 years, P<0.001) and that the comorbidity scores did not differ significantly between both groups. The median survival of those patients choosing dialysis was higher than those choosing CM from the time of modality choice. However, the survival advantage of patients choosing dialysis was no longer observed in patients aged ≥80 years old, corroborating with the findings in the study by Hussain et al. (2013). The survival advantage was also substantially reduced in patients ≥70 years old with cardiovascular comorbidities.

In summary, the findings from the systematic reviews and research studies included in this literature review have contributed to a growing evidence base in relation to the survival outcomes for older people receiving dialysis or conservative management for ESKD. The findings from these studies have demonstrated that for some patients there may be little survival benefit from commencing dialysis, particularly for those who are older (>80 years) or who have significant comorbidities, and for these patients conservative management offers an alternative. There is also some limited evidence that while there may be some survival benefit for older patients opting for dialysis, this survival gain may be spent in the hospital, having treatment and travelling for treatment. Several methodological limitations were identified in the systematic review (O’Connor & Kumar 2012) and the three subsequent studies identified (Da Silva-Gane et al. 2012; Hussain et al. 2013; Verberne et al. 2016). These included the retrospective nature of many of the studies, often with small participant samples, the varied starting points for the measurement of survival and, with the exception of one study
(Murtagh et al. 2007a) all the studies were undertaken in single renal centres, and a majority of these centres were in the United Kingdom. It can be argued that a further limitation in the survival outcome studies undertaken to date has been the limited consideration of quality of life (QoL) particularly the qualitative aspects of QoL and the patient perspective within these studies; this is a vital consideration given the apparent limited benefit associated with dialysis in some patients. Despite these limitations, the prognostic information provided by the findings of these studies are useful for clinicians caring for patients with ESKD who are supporting patients in treatment decisions and discussions concerning illness trajectories.

2.3.1.2. Prevalence of symptoms and quality of life

The systematic review by Murtagh et al. (2007b) reported the prevalence of symptoms experienced by people with end-stage kidney disease (ESKD) who were receiving dialysis. Fifty-nine studies were identified, all reported the symptoms experienced by patients receiving dialysis, with the exception of one study which explored symptoms in patients discontinuing dialysis. None of the studies identified reported the prevalence of symptoms in patients managed conservatively. The review concluded that patients receiving dialysis experience multiple symptoms which include: pain, fatigue, pruritus, anorexia, dyspnoea, and constipation. The evidence for patients withdrawing from dialysis was more limited but implied that they also experienced a high symptom burden. The review recommended the need for greater recognition of and research into the prevalence, cause and management of symptoms in patients with ESKD.

In contrast, O'Connor and Kumar (2012) in their systematic reported six studies investigating the symptom burden and quality of life (QoL) of patients receiving conservative management for ESKD (DeBiase et al. 2008; Murphy et al. 2009;
Murtagh et al. 2007c; Murtagh et al. 2010; Saini et al. 2006; Yong et al. 2009). Three of these studies compared the symptom profile and symptom burden in patients managed conservatively (Murphy et al. 2009; Murtagh et al. 2007c; Murtagh et al. 2010). A further two studies compared symptoms and QoL in patients receiving dialysis and CM (DeBiase et al. 2008; Yong et al. 2009). The study by Saini et al. (2006) investigated symptoms and QoL in patients being conservatively managed with a comparison group of patients with advanced cancer.

The studies undertaken by Murtagh et al. (2007c) and Murphy et al. (2009) both reported the prevalence, severity and total symptom burden in patients with ESKD managed conservatively. The most common symptoms reported were fatigue, pruritus, oedema, dyspnoea, pain, poor appetite, dry mouth, poor concentration and muscle cramps. The mean of the symptoms reported was 11.8 and 6.8 respectively.

In a later longitudinal study undertaken across three renal units, Murtagh et al. (2010) evaluated the prevalence of symptoms in the last month of life for people with ESKD managed without dialysis. Similar symptoms were reported to those in the previous studies, but in this study, the mean of symptoms reported was 16.6. The authors concluded that the significant prevalence of symptoms experienced in this patient population increased as they approach the end of their lives and indicated the palliative needs of patients with ESKD may be similar to those with advanced cancer. This emphasised the importance of the recognition and appropriate management of symptoms. A comparison of the prevalence of symptoms in the last month of life for participants in this study with those findings previously reported in the advanced cancer populations concluded that ESKD patients managed conservatively had physical and psychological symptom burdens in the last month of life which were similar or greater than cancer patients. This correlated with the finding from an earlier study by Saini et al. (2006) which
compared the symptom prevalence and burden in a small sample of conservatively managed patients with terminally ill cancer patients and reported the median number of symptoms in CM patients was comparable to the cancer patients (17 versus 15 respectively).

The studies evaluating quality of life for patients with ESKD reported in the review by O'Connor and Kumar (2012) found that QoL in conservatively managed patients was comparable to that of patients on dialysis. De Biase et al. (2008) concluded that although conservatively managed patients had worse adjusted physical health, there was no difference in mental health score between those receiving CM versus dialysis patients. Similarly, Yong et al. (2009) in their study comparing dialysis and conservatively managed patients also found that despite being older and having increased co-morbidities and poorer functional status, QoL was similar in both groups highlighting that in older patients, with poor functional status, it remains unclear whether dialysis initiation impacts life satisfaction.

O'Connor and Kumar (2012) concluded that conservatively managed patients experienced a high symptom burden and that the findings relating to QoL were limited and preliminary. It was difficult to compare studies across studies as the patients may have been at different stages of renal deterioration which may have accounted for the wide range in the prevalence of symptoms. The authors recommended that further research studies were needed which compared the symptoms of age-matched dialysis patients with a cohort of conservatively managed patients. I would suggest that another limitation in these studies was that the symptom and QoL assessment instruments varied between studies thus making a comparison more difficult.
Three further studies were also identified in the current literature review; these had been undertaken following the systematic review by O'Connor and Kumar (2012). The study by Da Silva-Gane et al. (2012) explored survival (reported in the previous section on prognosis) and QoL in a larger sample of elderly patients who had opted either for dialysis or CM. Patients were followed up every three months for up to three years. Correlating with findings from previous studies, those patients opting for CM were older, more dependent and had higher comorbidities than those opting for dialysis. While conservatively managed patients had poorer physical health, and higher levels of anxiety, mental health, depression symptoms and global satisfaction with life were similar in both groups of patients. Importantly, patients who initiated dialysis experienced a decrease in global satisfaction with life score which did not subsequently recover and were not seen in the conservatively managed patients suggesting the negative impact of dialysis on QoL.

Murtagh et al. (2011b) conducted a prospective cohort study of symptoms and patient health-related concerns over time and toward death in a sample of patients with stage 5 CKD who were conservatively managed. The study took place in three renal units in the United Kingdom. The cross-sectional analysis of symptom data collected at study entry had previously been published (Murtagh et al. 2007c), as had symptoms in the month before death (Murtagh et al. 2010). This study reported the longitudinal analyses. The Memorial Symptom Assessment Scale–Short Form and core Palliative Care Outcome Scale. Average (using mean scores over time) and individual (using individual scores over time, with visual graphical analysis) were used to map the trajectories. Seventy-four patients took part in the study (mean age 81 years of age). The study findings outlined that average trajectories showed moderate symptom distress and health-related concerns, with a marked increase in the last 2 months of life. Visual graphical analysis enabled stable, increasing, or
fluctuant individual trajectories in symptoms to be identified. The proportion following these trajectories varied between outcome measures; regarding symptoms, 50% followed a stable pattern, 24% increased, and 21% fluctuated compared with 26%, 57%, and 21%, respectively, for health-related concerns. The study concluded that in the 2 months before death, patients reported a sharp increase in symptom distress and health-related concerns.

A key strength of this study was the longitudinal design which enabled data analysis to map and understand the trajectories of individual participants within the study population. This provided discrete trajectory groupings for individual trajectories, which meant they had more relevance to the clinical context.

More recently, Almutary *et al.* (2016) conducted a cross-sectional, comparative study of people with stage 4 and 5 chronic kidney disease (CKD) who were receiving dialysis or CM for their illness to examine which patients had the greatest symptom burden. A convenience sample of 436 people with CKD was recruited; 329 (75.5%) were receiving dialysis and 107 (25%) were being conservatively managed. Data on reported symptoms were collected using the CKD Symptom Burden Index (CKD-SBI) which measured the prevalence, severity, distress and frequency of 32 symptoms. The results demonstrated that participants reported an average of 13 symptoms, with fatigue and pain being the most common and burdensome. Haemodialysis, older age and being female were independently associated with greater symptom burden in this study. The study concluded that in CKD symptom burden is better understood when capturing the multidimensional aspects of a range of physical and psychological symptoms.

In summary, the current literature demonstrates that patients with ESKD experience a multiplicity of symptoms and these symptoms constitute a considerable burden for
patients regardless of whether they opt for dialysis or are conservatively management. There is also some evidence to support an increase in the prevalence and severity of symptoms in the last months of life. The studies reviewed considered symptom burden in older people with ESKD (mean age of participants was >65 years), and the findings of these studies suggested that for older patients and those with high co-morbidities, dialysis may not offer improvements in symptoms or a survival benefit. This emphasises the importance of considering survival against symptom burden and ensuring that QoL is a fundamental measure of outcomes. The findings also support the need for the application of the tenets of palliative care at an early phase in the management of ESKD, facilitating care that focuses on effective identification and management of physical and psychosocial symptoms and improves QoL. Understanding the likely prognosis, symptom prevalence, burden and severity can help health professionals in their conversations with patients about treatment choices and as they attempt to determine when the end of life is approaching in order to support care for patients. The quantitative survival and symptom data from the studies identified in the current literature review need to be considered alongside the qualitative study data which incorporates the patients' experience of the illness trajectory, the impact of the symptom burden on their daily lives and the transitions they experience as their illness progresses in order to enable the delivery of care tailored to the specific health needs and provide support to these patients in relation to their priorities.

2.3.2 Patient understanding of the illness trajectory and preferences for end of life care in end-stage kidney disease

The previous section outlined the significant symptom burden experienced by patients with end-stage kidney disease (ESKD) regardless of treatment modality
and highlighted the increasing recognition that dialysis may not improve survival, symptom burden or improve quality of life (QoL) in some patients, particularly those who are older with poor functional status or high co-morbidities and that, for these patients, conservative management pathways offer an alternative to dialysis. Communication of prognosis and discussions relating to planning for future death are clearly essential elements of the care of patients with ESKD, and patient understanding of these illness trajectories may affect the treatment decisions they make throughout their illness and at the end of life. The literature review identified seven studies which explored the patient’s perspective of their illness trajectory or their preferences in relation to the end of life care. Five of these studies used a quantitative approach (Collins & Lehane 2013; Davison et al. 2014; Davison 2010; Janssen et al. 2013; Weiner 2010). One study used a mixed methods approach (Da Silva-Gane & Farrington 2014) and one study used a qualitative approach (Schell et al. 2012).

A qualitative study explored how nephrologists and older patients discussed and understood the prognosis and course of the illness trajectory associated with end-stage kidney disease (Schell et al. 2012). Focus groups and interviews were conducted with eleven nephrologists and twenty-nine patients, all over the age of 65 years who were being conservatively managed (n=11) or who were receiving dialysis (n=18). Semi-structured interviews were undertaken with both the nephrologists and patients to explore how the course of the kidney disease was discussed and how it was understood by patients. Thematic analysis revealed six themes (three for patients and three for nephrologists). These themes were categorised according to the challenges patients and nephrologists encountered at each stage of the trajectory. The patient identified themes included: being shocked by their diagnosis, uncertain how their illness will progress, and lacking preparation
to live with dialysis. For nephrologists, the themes identified were: the struggle to explain illness complexity, managing a disease over which they had little control, and avoiding discussions of the future. The study findings highlighted how discussions and understanding of the trajectory of kidney disease are challenging for both patients and nephrologists. Patients experience strong emotions, beginning at diagnosis and continuing throughout their disease trajectory, most patients in the study had not discussed prognosis with their physician. Because these conversations were not taking place patients tended to focus on their current functioning without adequate preparation for what might happen in the future. Although nephrologists recognised that patients often were uninformed about their illness, they often responded by tailoring the information given, rather than addressing patient’s emotions. The progression of their illness was typically communicated through laboratory tests, nephrologists focused on giving this medical information and avoiding discussions about prognosis. Nephrologists outlined how they tended to engage in prognosis and end of life discussions with patients during an acute event rather than when patients were considered stable, which is arguably the wrong time for an end of life discussions as the patient would be less able to contribute fully and vulnerable at this time.

The patients’ perception of their illness trajectory and their experience of discussing future end of life care with the renal team were also reported in the findings of six studies which explored the attitudes, preferences and expectations in relation to end of life care for patients (Collins & Lehrane 2013; Da Silva-Gane & Farrington 2014; Davison et al. 2014; Davison 2010; Janssen et al. 2013; Weiner 2010).

Davison (2010) reported the end of life preferences of patients with stage 4 or 5 chronic kidney disease (CKD) treated at one renal centre in Canada. The study findings highlighted that most patients felt they were well informed about their illness
and prognosis, however, only 17.9% thought their health would deteriorate over the next 12 months and 29.7% reporting that their health would improve. Participants reported they thought about their future health and they were comfortable talking about end of life issues with family and renal staff. Although 50% of participants wanted to have these discussions with the nephrologist and a further 20% with the nephrology nurse, less than 10% of participants indicated that their nephrologist had discussed prognosis or end of life care with them. Patients were asked about preferences for life-sustaining treatments, with regards to resuscitation in the event of a cardiac arrest; 39% of patients wanted to be resuscitated whilst 19% were unsure. However, 82% of participants stated that they would not want a course of treatment which extended life at the expense of prolonging pain and discomfort. A majority of participants (85%) responded that it was important for them to be informed of treatment options, including withdrawal from dialysis, planning for their future death and having their physical symptoms managed by the renal team. The end of life issues they most wanted more information about were those relating to what to expect clinically as death approached, palliative and hospice care, and symptom management. The study identified gaps between the current end of life care practice and the patients’ preferences regarding end of life care. The study findings were similar to those reported in another study by Weiner (2010) which aimed to understand the end of life communications which took place with dialysis patients. The findings of this survey also found that over 50% of the patients with ESKD had not talked about end of life care with the dialysis team whilst more than 75% wanted to do so.

In another study from the Netherlands, Janssen et al. (2013) measured the quality of end of life communication and preferences for life-sustaining treatments in a sample of clinically stable dialysis patients. The quality of communication about the
end of life was found to be poor, only 30% of nephrologists and patients reported discussing cardiopulmonary resuscitation (CPR) and ventilation. However, most patients were able to articulate their preferences, with most patients wanting CPR and admission to critical care if they deteriorated (82.5% and 81% respectively).

Similar findings were reported by Collins and Lehane (2013) in a survey to ascertain the perspective of death, dying and advance care planning in a small sample of older Irish patients who were on dialysis. Most patients were over 70 years of age (78%). A majority of participants were comfortable talking about death and had thought about their future death. In relation to advanced care planning 60% of patients wanted honest discussions with their renal team if they were perceived to have less than six months left to live and over 50% of respondents wanted medical interventions to keep them alive as long as possible if they were dying.

Da Silva-Gane and Farrington (2014) explored the attitudes and perceptions regarding future end of life care planning in patients who were receiving dialysis. Patients receiving haemodialysis were asked to complete the questionnaire, only patients who could complete the questionnaire without an interpreter were eligible. A total of 240 patients completed the questionnaire, a response rate of 75%. Respondents were white European (79%) with a mean age of 67 years and many of the respondents had severe co-morbidities (43%). The findings from the questionnaire found that 88% of respondents would value discussions about future options when their health deteriorated, however, few patients responded that they had given consideration to the type of future treatments they may or may not find acceptable. The vast majority of patients (83%) responded that they would want to be admitted to critical care in the event of a dramatic deterioration in their condition and would wish for everything possible to be done. Likewise, most patients expressed a wish for resuscitation (78%) which was considerably higher than that
reported in the study by Davison (2010). Those who expressed a wish to forego attempts to resuscitate were older and had a higher symptom burden, and were less likely to feel that dialysis had benefited them or had helped them achieve their life goals. Attitudes to having a personalised end of life care plan were generally positive (59%), however, support for this was more evident in the younger patients surveyed i.e. those <60 years of age.

As part of this study twenty patients were also interviewed, all had a poor prognosis (assessed by the response to the surprise question). The mean age of the participants was 68 years and the mean length of time on dialysis was six years. Sixteen patients had severe co-morbidities. Three main themes were identified from these interviews: ‘Living one day at a time’, participants did not see themselves as terminally unwell and appeared to assume that dialysis would keep them alive indefinitely, their focus was on the challenge of day to day living. ‘Complex relationship’ with dialysis; in general participants had negative views about the impact of dialysis. However, this was confounded by the role of dialysis as life-giving and prolonging, which had become a normal part of their life, they were willing to endure the consequences of dialysis and its burdens in return for staying alive. ‘The words are important’ related to the fact that participants had not discussed end of life issues except in the context of wills and funeral arrangements. There was some confusion over the meaning of advanced care planning, but once participants understood this concept, the majority felt this may be potentially beneficial. Da Silva-Gane and Farrington (2014) concluded that the patients’ main focus appeared to be about holding on to what they had, rather than addressing future care needs. The study findings were similar to those reported in the study by Schell et al. (2012) who identified that, in the absence of having had discussions about likely illness...
trajectory and future end of life care plans, the patients focused on their current functioning without planning for what might happen in the future.

In another study, Davison et al. (2014) undertook a cross-sectional interview-based survey of ESKD patients’ attitudes and knowledge regarding palliative and hospice care. The sample consisted of 436 patients with ESKD who were receiving dialysis or being managed conservatively. Only 22.2% and 17.9% of patients respectively had an understanding of palliative and hospice care. Most of the patients with a knowledge of palliative and hospice care had negative perceptions regarding these aspects of care; the source of the patients' knowledge was not generally via interactions with health care professionals. Those with an accurate knowledge of palliative and hospice care were twelve times more likely to be white and to have gained this knowledge from personal family experience. Of interest, the study findings outlined that when palliative and hospice care was described to patients a vast majority (87.8% and 89.7% respectively) felt that these services were valuable and should be offered to patients with ESKD. The study concluded that there needed to be more extensive education for patients with ESKD about palliative and hospice care and the benefits these services could offer.

In summary, the literature review identified a small number of studies which have explored ESKD patients’ understanding of their prognosis and end of life preferences. One study explored the understanding of palliative care in patients who were being managed conservatively. Most of the studies reviewed included quantitative surveys of relatively small patient samples, drawn from single renal units in European and North America. The findings of these studies suggest that communication of prognosis and discussions relating to future end of life care appear to be lacking in the routine care of patients with kidney disease, despite the patient reports of being comfortable discussing future end of life care plans and
indeed expressing that they would want these discussions with the renal teams caring for them. The quantitative nature of most of these studies did not provide the in-depth exploration of the patients’ perceptions and preferences which a qualitative design would have facilitated. The majority of patients in the studies were older patients receiving dialysis (over 65 years) who did not appear to appreciate the palliative nature of their illness and the likelihood of a deterioration in their condition in the near future which may explain the considerable number of participants expressing a desire for life-sustaining interventions in the event of deterioration. The study findings highlight the importance of the integration of a palliative care approach which emphasises honest communication of prognosis and end of life care planning at an early stage and throughout the patient’s illness trajectory.

2.3.3. Factors Influencing the decision to commence or forego dialysis

For each individual patient, the decision to commence or forego dialysis is complex. Decisions include those relating to whether to commence dialysis or to opt for conservative management or, for patients ‘deteriorating despite dialysis’, the decision may include consideration of stopping dialysis. Prognosis, symptom burden and anticipated quality of life all play a part alongside patient preferences in the decision to forego dialysis. Over the last decade, there have been a small but increasing number of studies which have explored the factors influencing patients’ decision making in relation to opting to forego dialysis. There is an increasing awareness in the literature of the need to investigate patient preferences and decision making as part of this process. The literature review identified one narrative review (Moustakas et al. 2012) and seven empirical studies which explored the factors influencing ESKD patients’ decisions to opt for dialysis or conservative management of their illness. The seven studies identified consisted of six qualitative
Moustakas et al. (2012) undertook a narrative review of the peer-reviewed research literature to identify the challenges and needs of older people with chronic kidney disease (CKD) choosing supportive care. The literature was reviewed from 1995 to 2011 and identified twelve studies; these included quantitative and qualitative studies which explored a variety of issues relating to the needs of older people with ESKD managed conservatively including survival, symptoms burden, information and education provision, and patient preference. Three themes were identified from the review: ‘shared decision making’, ‘quality of life’ and ‘the role of educational resources’. The literature generally showed consensus for shared decision making between the patient, family and health professionals but varying levels of input into these decisions, with nephrologists having a greater input. The review also highlighted that quality of life (QoL) was a major factor associated with choices of supportive care and the discontinuation of dialysis but that discussions about QoL with patients with kidney disease were not always evident. Moustakas et al. (2012) suggested that the complexities and the individual nuance of people with kidney disease facing the decision to dialyse or not required a strong relationship between the physician and patient who relied on the health care team to provide enough information and the right information at the right time. Even though there was agreement that shared decision making was important, the literature identified little discussion around supportive care and end of life care, but there was a consensus from the authors that this was changing.

The study undertaken by Ashby et al. (2005) was the first to examine the reasons why patients chose not to commence dialysis or withdraw from dialysis treatment.
Grounded theory methodology was used with semi-structured interviews undertaken with patients to understand their perspective of the reasons for and issues surrounding their decisions to forego or stop dialysis. The authors stated that the initial sample size was estimated to be fifty-two participants, although no rationale was provided for how the estimate of the required sample size had been made. However, the study outlined that due to issues with recruitment which included impaired cognition and deterioration in condition, only sixteen participants were recruited. The participants were divided into three groups: four participants who had withdrawn from dialysis, seven participants who had decided not to commence dialysis, and five spouses of these patients, although no rationale was given as to why the spouses of the patients were included in the study sample.

Three themes were articulated in the report, these were: ‘poor quality of life’, ‘desire not to be a burden’, and ‘doctor-patient issues: prognostic uncertainty and a sense of abandonment’. For the participants who made the decision to withdraw from dialysis, it was clear that this decision was made within the context of a declining health. Participants had spent some time contemplating this decision, only discussing this with family and health care professionals once they were clear that this was what they wanted; the rationale for this was that they did not want to upset their family or that withdrawal would be viewed as akin to suicide. In contrast to this, those participants who had decided not to commence dialysis made this decision with their family and were clear they did not want to commence such a demanding treatment and disrupt their lives.

This desire not to be a burden was articulated by both patient participant groups but was especially evident in those patients who decided not to commence dialysis. Those deciding not to commence dialysis were older, all being over 77 years of age, tended to view dying as a natural course that they would rather take than burdening
their families and were also less willing to make the necessary lifestyle changes associated with dialysis. The authors outlined that age was a significant factor that could impact on the decision with older participants feeling that dialysis would be a waste of resources and impact negatively on their quality of life. The desire not to be a burden and the personal experience of a deteriorating quality of life were crucial elements in the decision to stop or decline dialysis. Participants prominently expressed two aspects of the doctor-patient interaction: prognostic uncertainty meant that participants felt angry if they outlived their prognosis, participants also expressed a desire for death to come quickly and feared a painful death. Feeling abandoned by the healthcare team as they felt they had little follow-up was expressed by those who had decided not to commence dialysis. The study concluded that an open and proactive approach to end of life issues was required. The limitations of the study included the small sample consisting of patients and carers who were at different stages of their illness trajectory, those who had decided to discontinue dialysis and those who had expressed a desire not to commence dialysis when it was needed. While there was also a lack of depth in relation to how patients made these complex decisions and what support they required from health care professionals until death, the study findings offered new knowledge in relation to why patients chose to forego or withdraw from dialysis which had not previously been explored.

Similar findings were outlined in a study exploring the factors taken into account by older patients with ESKD when deciding to commence or decline dialysis (Visser et al. 2009). In-depth interviews were conducted with fourteen patients, all over the age of 65 years, who had made the decision to commence or decline dialysis. The reasons participants gave for declining dialysis included their age (those who declined dialysis were older), the perceived loss of autonomy associated with being
on dialysis, distance to attend dialysis and a reluctance to think about the future. In contrast, those opting for dialysis reported that they had done so because they were not prepared to face the end of their life, and felt they had no other choice or had caregiving responsibilities. The finding suggested that the decision to opt for or forego dialysis may not necessarily be based on the perceived effectiveness of treatment but more on personal beliefs and the perceived impact of dialysis on their life.

In a practitioner research study, naturally occurring consultations occurring with thirty patients cared for by a renal supportive care team explored the reasons why patients had opted not to commence dialysis (Noble 2009). Over half of the participants (57%) believed they had made an autonomous decision about opting out of dialysis; this decision was based on the arduous nature of dialysis, the difficulties of getting to the hospital three times a week for treatment and their experience of other people on dialysis who had died. Some participants were unsure whether dialysis would extend their lives or hasten death whilst others believed there was no option but to refuse dialysis as they would not benefit and dialysis would ultimately cause their death (23%). Other participants described how they had chosen medication over dialysis, believing that either would lead to the same outcome. The age of the participants in this study ranged from 65-91 years with the mean age being 78 years, many of the participants had significant co-morbidities. Before this study, little was known about those patients with ESKD who decided to forgo dialysis and opt for conservative management of their illness. Although choices around decision making relating to forgoing dialysis was not a primary aim of this study the findings provided important preliminary insight.

Another study published three years later used the same methodology and reported similar results (Johnston & Noble 2012). Participants reported age (mean age of
participants was 86 years) and having to travel to the hospital three times a week as reasons for opting for non-dialysis management of their ESKD. Others cited feeling well without dialysis and not wanting to upset the status quo or burden their loved ones. In contrast to the previous study findings reported by Noble (2009) in this study, patient choice appeared to be more focused on personal preferences, and participants appeared more empowered by their choices rather than implying the 'no option' articulated previously. However, the methodology used in this study offered significant bias; all participants interviewed had been attending the clinic for over seven months at the time of the study and established a therapeutic relationship with the team over that time.

Morton et al. (2012) utilised discrete choice experiments to examined characteristics of dialysis and trade-offs patients were willing to make in choosing dialysis over conservative management (CM). Patients were more likely to choose dialysis over CM if dialysis involved increased life expectancy, they were able to dialysis during the day or evening rather than the day only, and if subsidised transport was available. In this study, the patient’s age did not significantly affect the preference for dialysis or CM. Patients were more likely not to choose dialysis if an increase in the number of hospital visits was required and if there were more restrictions on their ability to travel. Patients were willing to trade off seven months of life expectancy to reduce the number of required hospital visits and 15 months of life expectancy to increase their ability to travel. The limitation of this study’s methodology related to data being collected on stated preferences, meaning views expressed were hypothetical and the actual choices made may have differed. This highlights the need for patient preferences to be discussed and included in all consultations about treatment options as decisions may change over time.
However, the findings do help provide clinicians with insight into the issues patients consider important to their lives when evaluating the impact of treatment options.

Two recent studies explored the knowledge and understanding of treatment options and the reasons for treatment choices of older people with ESKD. In the first study Moustakas et al. (2015) using a case study methodology, undertook semi-structured interviews and medical case notes analysis for six patients with ESKD who had chosen supportive care (conservative management) of their illness. The interviews facilitated the exploration of topics surrounding the conservative management of ESKD. Case notes were searched for all notations relating to ESKD treatment options. Transcripts were thematically analysed to enable themes to be extracted from the interviews. Four overarching themes emerged from the data analysis, these were: ‘dialysis information but not supportive care information’, ‘no to hospital dialysis and yes to living at home’, ‘importance of partners and family’, and ‘maintaining independence’. Participants perceived they had been given information on dialysis and the effects of this on their lives but had limited recollection of the information provided regarding the conservative management of their illness. One of the major reasons for choosing CM was the information participants had received about dialysis which led to the perception of suffering associated with dialysis and the participants’ belief that their quality of life would deteriorate if they commenced dialysis. Having chosen to decline dialysis, participants were unaware of the future illness trajectory associated with CM and were optimistic in their time frames of living a few more years at home with their families. Participants also explained that going to the hospital would be time-consuming and take away time that could be spent with their families or undertaking other activities they enjoyed in life. The common concerns expressed by participants related to not having to change what they did on a daily basis, not having to adjust their life to incorporate a medical treatment.
such as dialysis into it and remaining independent. The medical case notes review revealed infrequent and non-systematic documentation of the information given concerning supportive care and prognosis. The study concluded that older people were focused on living their remaining time at home without the disturbance of dialysis, hospital visits and other issues associated with dialysis. They wanted to preserve their quality of life, which for them meant staying at home and living day to day with their families.

In the second study, Tonkin-Crine et al. (2015) conducted a multi-centre study exploring the experiences of older people (defined as those 75 years or old) who had opted for conservative management or dialysis. Forty-two participants were recruited from nine renal units across the United Kingdom (4-6 from each unit) and included those receiving dialysis, those opting for dialysis which had not yet commenced and those who were managed conservatively. Semi-structured interviews were undertaken with participants to explore their knowledge and understanding of treatment options and the reasons for their choices.

Four themes emerged from the thematic analysis of the interview transcripts: ‘patient’s understanding of the management of kidney disease’, ‘patient’s perception of their own illness’, ‘patient’s experience of making a management decision about their illness’, and ‘patients’ experience of revised management decisions’. All patients had an understanding of dialysis, but the understanding of conservative management varied between each unit dependent on the maturity of the conservative management pathway. Most patients believed they had no symptoms from their kidney disease, associating any symptoms they did have to their age or other comorbidities. This lack of symptoms appeared to be interpreted by patients as an indicator of their condition not being serious. There were contrasting views about the potential benefits of dialysis; some dialysis and pre-dialysis patients
believed dialysis would extend their lives, however, in those units with an established conservative management pathway, conservative patients believed that dialysis did not guarantee increased survival and believed they would have a better quality of life without dialysis. Some participants thought they were too old for dialysis or worried about being a burden to their families. Transport to the dialysis unit again featured as a major concern and a reason stated by some patients who had chosen not to commence dialysis. For patients who had revised their decisions from conservative to dialysis, this decision appeared to be linked to participants having had little or no discussion about their likely illness trajectory or dying. Those conservatively managed patients in units with well-established pathways were more likely to have had these discussions with staff although most participants reported they had not discussed the future illness trajectory. Reported limitations included recruiting frail elderly patients which limited the generalisation of the findings. Tonkin-Crine et al. (2015) concluded that older people who had chosen different treatment options had contrasting beliefs about the benefits and outcomes of dialysis and that further research was required to increase the evidence base relating to conservative management to support older people with ESKD and to facilitate shared decision making.

In summary, the findings from the qualitative studies included in the current literature review consisted of small samples of patients but produced rich data in relation to their experiences. A limitation of these studies was the study methods, with no study utilising a longitudinal design which meant perceptions relating to treatment decisions were examined at one point in time. The findings from these studies did provide insight into the factors considered important by patients when deciding to commence or forego dialysis, highlighting the complexities and ongoing nature of the decision-making process for patients. Whilst the findings demonstrated that
patients held contrasting views over whether dialysis would extend their lives, the
decisions to commence or forego dialysis were often not based on longevity but
rather on patient preference, and the perceived acceptability of the impact of dialysis
on the on their quality of life. Understanding the factors which influence patients’
decisions to commence or decline dialysis provides a greater appreciation of the
patients’ perceptions of and priorities in relation to their illness, particularly in those
patients who are older, and is important in relation to the provision of care. A greater
understanding offers the opportunity to tailor care to meet the patients’ multifaceted
needs, and better support their care through to the end of their lives.

2.3.4. The experience of patients living with end-stage kidney disease who are
approaching the end of life

The literature review did not identify any studies that directly explored the
experience of transitions for people with end-stage kidney disease (ESKD)
approaching the end of their lives. However, the best evidence that patients
experienced ‘transitions’ were gained from the small number of qualitative studies
and one thematic synthesis exploring the experience and meaning of the illness for
patients living with ESKD who were approaching the end of their lives (Axelsson et

A study describing the meaning of being severely ill living with haemodialysis when
nearing the end of life was undertaken by Axelsson et al. (2012a). A qualitative
longitudinal approach was used and interviews were undertaken with eight patients.
Patients were aged between 66 to 86 years, with a median age of 78 years and had
been receiving dialysis between fifteen months to seven years at the start of the
study. Recruited patients had been assessed as being severely ill by the renal team
caring for them, this assessment was based on the presence of comorbidities,
malnutrition and other complications (unspecified in the study). In-depth interviews were conducted, with patients over a twelve-month period with a total of 31 interviews taking place, there was no attrition due to death during the study period.

Thematic analysis of the interview data revealed three themes and eleven subthemes. The three themes identified were: ‘being subordinate to the deteriorating body’, ‘a changing outlook on life’ and ‘striving for upheld dignity’. ‘Being subordinate to the deteriorating body’ included articulating feeling that fatigue was taking over life, interpretations of a deteriorating body with the recognition of changes and symptoms, and the associated meaning of these for individuals which was often associated with being old, an increasing dependency on other and being trapped by the processes associated with dialysis. ‘The changing outlook on life’ was associated with having to give up plans and the acceptance of a changed life, adjustments and lowering of expectations, and individual’s reflections on the meaning of life on dialysis. In ‘striving for upheld dignity’ participants struggled to uphold dignity losing control on a life with illness and strived to maintain a sense of self. The findings illuminated the physical, psychosocial and existential dimensions of suffering experienced by participants in this study. Axelsson et al. (2012a) concluded that living with haemodialysis when nearing the end of life meant facing progressive losses, threats and uncertainty due to the consequences of a deteriorating health.

As part of the ongoing study intended to increase the understanding and knowledge of end of life issues in severely ill patients with ESKD living on dialysis, Axelsson et al. (2012b) analysed the interview data collected from the in-depth interviews undertaken with the patients who participated in their previous study (Axelsson et al. 2012a) in order to gain a deeper understanding of the thoughts and feelings relating to death and dying. The findings illustrated that the patients’ feelings about
death and dying were complex, and fluctuated both during and between interviews as existential issues and needs were intertwined with their experiences. Three themes and ten subthemes were identified from the qualitative content analysis: ‘being aware that death may be near’, ‘adapting to approaching death’ and ‘being alone with existential thoughts’. ‘Being aware that death may be near’ included being reminded of death and dying by the deteriorating body, their worsening condition and the death of other patients. The awareness that death may be near appeared to be based on these inferences rather than the communication they had had from the health care professionals (HCP) caring for them. ‘Adapting to approaching death’ included looking on death as a natural process and preparing for death as well as repressing thoughts about death and dying. Whilst ‘being alone with existential thoughts’ included wanting to avoid being a burden to the family, and participants’ consideration of dialysis withdrawal as a possibility in the future. Although the sample size was small in this study, limiting the transferability of these findings to similar contexts, the longitudinal approach increased the possibility of identifying changes over time and increased understanding of the patients’ experiences, meaning and the illumination of the existential issues described.

In contrast, the lived experience of older people receiving conservative management (CM) for chronic kidney disease (CKD) was explored in the qualitative phenomenological study by Llewellyn et al. (2014). A purposive sample of nineteen patients receiving CM was recruited from four renal units; these patients were of an older age (ranging from 73 to 94 years) and all had several comorbidities and had been receiving CM for an average of 21 months at the time of the interview. An in-depth interview was undertaken with each participant to explore their perception and experience of their illness from diagnosis to the time they chose CM, their current thoughts about CM and their thoughts about the future. Participants were asked
about their experience of symptoms, how their illness felt day to day and how it affected their lives.

Given the phenomenological perspective of the study, an emphasis was given to the personal meaning and values underlying participants’ behaviours and choices as part of the analysis of the interview data. The findings described that following the shock of diagnosis there was a period of relative stability. Although participants were aware the illness was life threatening, their kidney disease became another illness amongst many. Bad days were described as periods when their illness became disruptive, destabilising participants’ routine and forcing them to reflect on the future. Thoughts of the future were reflected upon within the context of advancing age and comorbidities, with CKD being viewed as just another possibility for an inevitable and relatively near death. Despite knowing their CKD was progressive, participants struggled to imagine what decline might feel like or when it might come and so most participants saw little point in thinking about the future, preferring to see themselves in the present where their illness was stable. This was reinforced by the participants’ relative lack of symptoms from their illness at the time of the interview or them attributing symptoms to other comorbidities, meaning CKD remained abstract to them and bound by medical tests. Participants’ framed their illness as old age, and this influenced their acceptance of the illness. The apparent relative stability of the participants’ CKD at the time of the interview may have influenced their perspective on their illness and is, therefore, a limitation of this study’s findings alongside the cross-sectional approach which provided narratives of participants’ experience at only one point in time rather than spanning their illness trajectory and experience.

Tong et al. (2014) conducted a thematic synthesis of the qualitative studies relating to the patient and caregiver perspective of end of life care in chronic kidney disease.
(CKD). Selection criteria for the review included qualitative studies that explored the experience of adults over the age of 18 on the illness trajectory within the context of end of life care, defined as palliative care, advance care planning, conservative management, withdrawal from dialysis and end of life decisions. Twenty-six research articles involving over 711 patients and 178 caregivers were identified; this included non-dialysis dependent, haemodialysis, peritoneal dialysis, unspecified modalities, and conservatively managed patients. In relation to the qualitative methodology of these studies, 16 reported the patient selection criteria, theoretical saturation was defined as achieved in 9 of the studies and researcher triangulation was reported in 16 of the studies.

The thematic synthesis of these studies revealed five main themes: ‘invasive suffering’, ‘personal vulnerability’, ‘relational responsibility’, ‘negotiating existential tensions’, and ‘preparedness’. Physical deterioration and emotional frailty encompassed the themes of invasive suffering and personal vulnerability. The personal vulnerability also consisted of the subthemes of the imminence of death, misunderstanding and judgement, autonomy and dignity, medical abandonment, and trust and safety. Patients and their caregivers reported feelings of being frustrated by the lack of follow-up by physicians after discontinuing dialysis or choosing not to dialyse and this highlighted the importance of a good rapport with physicians when addressing end of life issues. Relational responsibility included concerns of being a burden and protecting others from grief. Preparedness included subthemes of shared decision making, decisional clarity, and information. Patients also reported being reluctant to ask for information to inform their end of life decisions for fear of being misunderstood or perceived as wanting to discontinue dialysis. As the thematic synthesis also encompassed two studies which included patients with all stages of CKD in the participant samples the themes revealed from
the review were reflective of a wide range of patient perspectives at various stages in their illness trajectory and not necessarily just indicative of those patients with advanced illness approaching the end of their lives.

In summary, whilst these studies did not specifically focus on the experience of transition for people with ESKD as they approach the end of their lives the study findings do provide important insight into the experience of living with ESKD and suggest that people with ESKD may make many transitions within their disease trajectory which involves re-evaluation and adaptation to the changes imposed by their illness.

2.4. The transitions experienced by people with cancer and other life-limiting Illness who are approaching the end of life

Given the paucity of research exploring the experience of transition for people with end-stage kidney disease (ESKD) approaching the end of life, it was considered important to examine and include the research studies exploring the transitional experiences for other patient populations with life-limiting illnesses as they approached the end of their lives and consider the relevance of these research findings to ESKD. The literature review identified one systematic review and a scoping review which explored the transition to palliative care in cancer and chronic illness. Nine qualitative studies were also identified, a majority of these studies explored the experience of transition for patients with cancer and included three studies which compared the transitions experienced in cancer patients with heart failure (HF) or chronic obstructive pulmonary disease (COPD). One study explored transitions in patients with HF, and one explored transitions in patients with COPD.
Marsella (2009) undertook a review to explore the transitions to palliative care; in this review, the transition to palliative care was defined as the transition from ‘curative care to comfort care’ (Marsella 2009:186). As this was a scoping review, it examined a broad range of research in relation to palliative care, including studies with many methodologies but did not assess the quality of these studies. Twenty-eight studies published from 1997 to 2007 were evaluated and considered relevant to the review, however, only two qualitative studies included in the review explored the patients’ perspective of transition to palliative care (Larkin et al. 2007a; Ronaldson & Devery 2001). The majority of the studies evaluated changes in a care setting and community care provision in the last month of life. Three key components which complicate the transition to palliative care in cancer patients were identified: the intrinsic nature of transition, the timing of the transition, and the lack of information surrounding the transition.

In a systematic review, Gardiner et al. (2011) undertook a thematic synthesis of the qualitative research exploring the transition from curative care (defined as care focused on cure or chronic disease management) to palliative care. The review included twelve studies all undertaken in the United Kingdom, a majority of these studies focused on the experience of patients with cancer, with only two studies exploring the experience of patients with heart failure. Four main themes were identified: patient and carer experiences of transition, recognition and identification of the transition phase and criteria for making the transition, optimising and improving transition, and defining/conceptualising transition. The findings of the review suggested that there was little known about this potentially complex transition. The review outlined that there was an important role for the providers of generalist palliative care and that the palliative care approach should be integrated earlier in the illness trajectory to improve the experience of and care for patients.
making the transition. The evidence provided in the review by Gardiner et al. (2011) was drawn from a small number of studies; most of these studies had small sample sizes, and the majority included cancer patients where the trajectory to palliative care is more predictable and the experience of transitions to palliative care for cancer patients may not be representative of other chronic illnesses including ESKD.

2.4.1. The experience of palliative and end of life care transitions in cancer

Four qualitative studies explored the experience of transition to palliative care for patients with a cancer diagnosis (Duggleby et al. 2010; Dalgaard et al. 2010; Larkin et al. 2007a; Ronaldson & Devery 2001).

A study by Larkin et al. (2007a) used a phenomenological approach to explore the transition towards the end of life in palliative care and the meaning for a group of advanced cancer patients whom it was expected would progress to terminal care in the next six to twelve months. Interviews were undertaken with one hundred patients recruited from inpatient palliative care services across six European countries. Four themes described the shifting complexity of the illness, the emotional response to transition and the role of the role of palliative care services in relation to supportive care, these were: Lived body, lived space, lived time and lived others. Participants described a variety of intense emotional reactions experienced when faced with the challenge of transitioning into palliative care which included, limited knowledge of the purpose of transfer to palliative care, uncertainty about who instigated the transfer, and limited involvement in decision making, often due to rapidly increasing symptom burden. In effect, the reality of the situation was not so much in the process (as would be expected from transition), but more a sense of stasis, as they rationalised past experiences with their present situation. Transition was recognised
as a confusing time for patients due to mixed messages, poor communication and
uncertainty. The overall essential of the phenomenon was described as ‘living
transiently in the shadow of death’ (Larkin et al. 2007a:76).

The study concluded that whilst the successful merging of the curative-palliative
interface was beneficial for patients the concept of transition in palliative care
warranted further investigation and raised concerns that transition concepts fail to
capture the palliative care experience fully. The transition experience towards end
of life in palliative care for individuals in this study was framed around patients who
had been admitted to an inpatient palliative care unit; the experience and meaning
described in the findings described the response to this transfer of care reflecting a
narrow focus of the experience of transition from curative to palliative care rather
than the wider palliative care experience associated with an advancing illness.
Whilst this may be applicable to advanced cancer patients, for individuals with a
diagnosis other than cancer, living with a chronic illness such as end-stage kidney
disease, there may be no clear curative- palliative interface as described in this
study, nor may they have accessed specialist palliative care services.

Ronaldson and Devery (2001) also explored the experience of cancer patients who
had recently been referred to palliative care services and included the perspectives
of nurses who were involved directly in the care of patients undergoing the transition
to palliative care services. Interviews were conducted with a small sample of
patients and nurses. Similar to the study by Larkin et al. (2007a), the study focused
on the experience of the transition from curative to palliative care, with key themes
identified as: pace and timing of the transition, fear and misunderstanding, accepting
palliative care, and information provision. The findings illustrated that the transition
for terminally ill cancer patients from curative to palliative care was a major clinical
challenge, being more than a physical process and involved the individual’s
passage from one set of hope to another as patients are faced with their own mortality and there is a shifting focus of care.

Dalgaard *et al.* (2010) explored how transitions to palliative care were experienced by patients with haematological malignancies who were not receiving palliative care services. Two transitions were identified: *the transition from curative treatment to early palliative care* and *the transition to late palliative care*. The transition from curative to early palliative care occurred when the patient was considered incurable, and treatment was considered to be aimed at control. However, this was not specifically communicated to the patients who were instead encouraged to hope and fight. The study identified that the unpredictability of some haematological malignancies and some of the barriers inherent in the practice of health professionals within this field could postpone the identification of transitions to palliative care. This resulted in a transition to palliative care at a late phase with little opportunity for patients to make informed choices. Dalgaard *et al.* (2010:90) conceptualised their analysis as ‘lost in loneliness’ as patients continued with treatment, and were excluded from channelling their hope in a different direction which emphasised the importance of recognising the transitions in the phases of illness and the honest communication of these to patients.

In contrast, Duggleby *et al.* (2010) conducted a grounded theory study to explore how older patients with advanced cancer and families experience transition and how they adapt to these. Multiple perspectives of the transition experience were sought to gain a holistic picture of the transition experience. The study sample consisted of six patients who were all receiving palliative home care service, ten bereaved caregivers and twelve palliative health care professionals. The data analysis revealed four overlapping themes reflecting the transition: *environmental changes, relationships and roles, physical and mental health, and daily activities of living*. The
substantive theory which emerged from the data analysis was described as ‘navigating unknown waters’ (Duggleby et al. 2010:4). Sub-processes included in this emergent theory emphasised how palliative patients and caregivers adapted to the multiple transitions they experienced with their advancing illness, these were: coming to terms with the situation, connecting with others and redefining normal. Multiple complex transitions were experienced and resulted in anxiety, uncertainty as well as including processes of increased awareness. The finding highlighted the need to address these transitions in order to improve palliative care.

2.4.2. Comparison of the experience of transition to palliative and end of life care for people with cancer and other chronic illness

Several studies were identified which examined the experience of transition to palliative and end of life care in patients with other chronic illness. Three studies compared the transitions of patients with advanced cancer with those experienced by patients with other chronic illnesses which included chronic obstructive pulmonary disease (COPD) and heart failure (HF), (Murray et al. 2007; O’Leary et al. 2009; Reinke et al. 2008). A further two studies considered these transitions from the perspective of those with heart failure (Waterworth & Jorgensen 2010) and chronic obstructive pulmonary disease (Pinnock et al. 2011). The studies all used qualitative, longitudinal methodologies to explore the experiences of transition over time in these patient groups.

Reinke et al. (2008) explored the experience of transitions to palliative and end of life care for patients with cancer and chronic pulmonary disease (COPD). This qualitative longitudinal study used grounded theory methodology to examine patients’ perceptions of the experiences of key transitions in the context of living with their advanced illness, COPD or cancer. The study sample consisted of fifty-
five patients, and planned to interview patients over the period of a year, however, there was high attrition with 31 patients having died within the first six months meaning most patients were interviewed on only one occasion. The findings identified themes common to both groups and some themes that were illness specific. Themes common to both groups included: new treatments, no more treatment and the transition from curative to palliative care. Other themes were specific to the COPD group and included: functional limitations, and the initiation of oxygen. For cancer patients, the unique theme included: improvement from illness with patients describing how they hoped to improve from their illness which was not expressed by the COPD patients.

Reinke et al. (2008) suggested important differences in transitions between these two groups and that these transitions often involved more than one time transition. These transitions were different for different individuals, covering a range of issues including changes in therapeutic options but also changes in symptoms, quality of life and functional status. The trajectories of illness at the end of life suggest there may be different experiences of transition over the course of the illness and towards the end of life for patients with cancer and other chronic illnesses and thus different care needs.

The studies by Murray et al. (2007) and O'Leary et al. (2009) compared the experience of transition for patients with advanced cancer and advanced heart failure. Murray et al. (2007) conducted a longitudinal study interviewing patients with heart failure and cancer over an 18-month period. All patients were receiving palliative care for their illness. The study outlined distinct differences between the two patient groups in relation to the social, psychological and spiritual end of life trajectories. Lung cancer patients reported particular distress at key transition points including after treatment when they returned to their old life, at relapse/disease
progression and at the terminal phase, when patients expressed overwhelming uncertainty. In lung cancer patients, the social trajectories mirrored the physical decline in function whilst the psychological and spiritual well-being decreased together at key stages in the disease trajectory. In patients with advanced heart failure, the social and psychological decline tracked the physical decline. Similar findings were reported by O’Leary et al. (2009) who found that both lung cancer and heart failure patients had a similar symptom burden. Both patient groups had unanswered questions which differed between the two patient groups. Cancer patients were concerned with their prognosis and how much time they had left whilst heart failure patients were concerned with what course their illness would take in the future. In both studies, a palliative transition point was described for cancer patients, but for heart failure patients this was rarely clear cut.

A multi-perspective study of the perspectives of people with severe chronic obstructive pulmonary disease (COPD), their informal carers and healthcare professionals as their illness progressed was conducted by Pinnock et al. (2011) to inform the provision of care for people living and dying with COPD. Patients were identified by the teams caring for them using the ‘would you be surprised if the patient died in the next 12 months?’ question. Interviews with patients with COPD, their carers and healthcare professionals (identified by the patient) were conducted over an 18-month period; over half the patients who participated in the study died during the period. Two main themes were identified: acceptance of COPD as a way of life, and the story of COPD. Patients with COPD and their carers adapted to and accepted the debilitating symptoms of a life-limiting illness. The prognostic uncertainty associated with advanced COPD contributed to the difficulty in managing the end stage of the illness, with patients describing a chaos narrative of their illness which was indistinguishable from their life story, with no clear beginning
and an unanticipated end with regards to the end of their lives. Pinnock et al. (2011) concluded that identifying a time point or transition to palliative care had little resonance for people with COPD or their physicians and actually detracted from an early phased introduction of supportive care for COPD patients.

Waterworth and Jorgensen (2010) also used a longitudinal approach to explore the experience of twenty-five older people with advanced heart failure and their transition from independence to dependence as they approached the end of their lives. Interviews were undertaken with patients over a year, with an average of three interviews being undertaken with each individual. The themes which emerged reflected participants’ experiences of living with an advanced life-limiting illness and also their life in general as they got older. Themes identified included acknowledging endings and losses which included consideration of future losses. Uncertainty was identified as a theme relating to how to manage each day and how they would manage in the future, it included the fear of becoming dependent on others and included contemplating death. Good care at the end of life was an important expectation for participants as they made the transition to the end of their lives and illustrated the importance of trust in the healthcare professionals involved in their care.

A common theme identified by both Waterworth and Jorgensen (2010), and Pinnock et al. (2011) were the acknowledgement of endings, losses and acceptance of the debilitating symptoms of a life-limiting illness. The experiences described in both these studies illustrated the complexity of transitions for these two patient groups and that transition for these patients was not a linear process but an overlapping process.
In summary, most of the studies consisted of small samples sizes, with the majority of participants already receiving palliative care services at the commencement of the studies; this may have influenced their experience of the transitions as they approached the end of their lives and limit the generalizability of the findings given that many people living with life-limiting illness will not be known to palliative care services. The literature exploring the experience of transition in cancer patients compared to patients with other life limiting illnesses suggest that the experience of transition to palliative and end of life care is experienced differently depending on the illness. Those exploring transition in cancer patients tended to focus on the transition at one point of the illness and emphasised the shifting process from curative to palliative care, often for patients who were referred to or transferred to specialist palliative care services. The studies which compared transitions in cancer patients (where the transition to palliative care is more easily defined), with those transitions experienced in patients with other life-limiting illness, suggest that the experience of these transitions may differ. The transitional experience for patients with ESKD who are approaching the end of their lives may also be very different than that outlined for cancer patients and other life-limiting illnesses.

The studies reviewed provided insight into how the patients experience the transitions they encounter as they approach the end of their lives and how they adapt to these transitions. The available literature suggests that the prognostic uncertainty associated with life-limiting illness contributes to the difficulty of recognising and actively managing the end stage of the illness trajectory. The difficulty of identifying a time point or indeed, that for some illnesses, there is no defined time point for this transition to palliative care suggests that careful assessment of possible palliative care needs should take place early in the illness trajectory and be revisited at key disease milestones along the patient journey.
These milestones may vary for patients depending upon their underlying condition and therefore need to be considered for each illness in conjunction with the likely illness trajectory. Key milestones for people with ESKD could include, but are not limited to, the decision to commence or forego dialysis in favour of being managed conservatively, or the decision to discontinue dialysis due to illness progression and/or the burden of treatment, the development of new symptoms, critical events such as admission to hospital with infections or diagnosis of secondary illness such as cancer. These milestones all offer health care professionals the opportunity to discuss future plans including palliative and end of life care and emphasise the importance of examining the experiences of transition for people with ESKD as they approach the end of life given the prognostic uncertainty and difficulties of when or indeed if a time point for transition to palliative care is appropriate.

2.5. Summary of the chapter

This literature review has examined the existing studies relating to palliative and end of life care for people with ESKD. The review has demonstrated that research in the field of renal palliative care has advanced over the last decade with an increasing number of studies having been undertaken which have provided insight into the disease trajectory, survival and management of the illness. The studies have emphasised that palliative care can be a critical component of care whether dialysis or conservative management is chosen. There is an increasing evidence base from studies reporting survival of older people with ESKD opting for dialysis or those choosing to be managed conservatively. A number of studies have reported patient-related outcomes such as symptom burden and quality of life. A small number of studies have also explored the patients’ understanding of their prognosis and end of life preferences as well as the factors that influence decision making for patients.
when choosing to commence or forego dialysis; a few studies have explored the patient's experience of living with ESKD as they approach the end of life.

The findings from this literature review have several potential implications in relation to the transitions experienced by patients with ESKD as they approach the end of life. Chick and Meleis (1986) highlighted that in order for transition to occur an awareness of change is a prerequisite. This means that communication of the illness trajectory and the likely outcomes of treatment options is essential for patients in relation to the transitional process. The patient’s understanding of the illness trajectory and treatment outcomes may influence their decisions about treatment choices, including their choices around end of life care and may act as barriers or facilitators within the context of transition for people with ESKD.

The review identified the paucity of research exploring the experience of transitions for people with ESKD as they approached the end of their lives. The research literature surrounding the experience of transition within the context of other life-limiting illness and palliative care was also reviewed. These studies outlined the changing face of the illness experience that manifests itself as people lived with an advancing illness and approached the end of life; the relevance of these study findings within the context of transition for people with ESKD was considered. Research which explores the experience of transition from the perspective of people with ESKD was considered important to facilitate an increased understanding of their experiences. A greater understanding may help health care professionals to be better able to anticipate the challenges the patient has to confront as well as ensure care meets their needs as they approach the end of their lives. This informs the justification for the current research study.
At the time of undertaking this research study, no previous research studies were identified exploring the transitions experienced by people with ESKD as they approached the end of their lives. Following completion of the data collection for this study, the literature review was updated and the small number of more recent studies exploring the experience of people with ESKD were identified and included in the final literature review. The next chapter presents transition as the theoretical framework for this study. It explores the definition of transition and how the concept of transition relates to the associated health-illness trajectories and palliative care.
CHAPTER 3
TRANSITION: THE THEORETICAL FRAMEWORK

3.1. Introduction

Theoretical frameworks are critical in deductive studies where the theoretical framework must be very specific. However, they are also important in exploratory studies. A theoretical framework consists of concepts and together with their definitions and reference to the literature, existing theory. The theoretical framework aims to demonstrate an understanding of the theories and concepts that are relevant to the research study and relate to the broader areas of knowledge which are of interest to the research topic (Green 2014). This chapter explores transition as a theoretical framework for this study by examining the concept of transition within the social and health-illness field. It explores the definition of transition, the existing transition theories, the development and conceptualisation of transition within the health-illness literature and examines the relevance of the concept to chronic life-limiting illness including end-stage kidney disease (ESKD) and palliative care.

3.2. Definitions of transitions

Transition as a concept has evolved in the social sciences and health disciplines including nursing over the last three decades. The types of transition discussed in the literature have focused on developmental, situational, health-illness and organisational transitions (Schumacher & Meleis 1994). Transition has been defined as ‘a passage or movement from one state to another’ (Webster’s Dictionary 1971:324).
Transitional definitions vary according to the disciplinary focus. Within the health-illness literature, transition is consistently used to describe people’s responses during a passage of change, involving the movement from one situation to another or an alteration in health and social circumstances. It connotes the psychosocial processes involved in adapting to the change event or disruption and incorporates a time of inner reorientation and transformation (Chick & Meleis 1986; Kralik 2002; Kralik et al. 2006a; Schumacher & Meleis 1994).

A common definition of transition cited in the health literature is:

‘A passage from one life phase, condition, or status to another… transition refers to both the process and outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation. Defining characteristics of transition include process, disconnectedness, perception and patterns of response’ (Chick & Meleis 1986:239-240, added emphasis).

Inherent in this definition is a process which suggests movement, phases, sequences, and a time span; it involves both the disruption that the transition causes and the person’s responses to this interference. Perhaps the most pervasive characteristic of transition is disconnectedness associated with the disruption of the linkages on which the person’s feelings of security depend and the loss of familiar points of reference. Perception has to do with the meaning of the transition for the individual and how the person experiences the threat to self-concept during the transition. Finally, patterns of response relate to the behaviours, both observable and non-observable during the process of transition, these can be positive or dysfunctional in their manifestation.
3.3. Existing theories of transition

The concept of transition has a long history in a variety of disciplines, particularly anthropology. Anthropologically studies have described transition in terms of the change relating to social rituals, often around key life events such as birth, marriage, and death (Van Gennep 1960). The earliest conceptualisation of transition has been attributed to the work of Van Gennep (1960:2), who defined transition as ‘rites of passage throughout the life course’. According to the ‘rite of passage’ framework proposed by Van Gennep’s (1960), people move through life stages in three distinct phases. Any transition begins with a pre-liminal period, followed by a liminal period, and concludes with a post-liminal period. The pre-liminal rites, the rites of separation, are characterised by a period of separation from the ordinary or previous social life which may occur through the use of customs or taboos. Liminal rites, rites of transition, refer to the customs and the rituals of the individual when they are in a liminal state, perhaps feeling confused and alienated, in a state of limbo. This phase has also been referred to as 'no man’s land' (Draper 2003:63). During the liminal period, the individual exists in a state in which their past life is left behind, but the future state has yet to emerge. Lastly, post-liminal rites, rites of incorporation, occur when the individual is brought back to society and takes up a new status or is re-incorporated into society. The liminal period is structurally and physically invisible, and the liminal persona is a transitional being, the process of becoming initiated into a very different state of life (Van Gennep 1960).

A three-phase model was also proposed by Bridges (2001). The model consisted of an ‘ending’, then a ‘beginning’, and an important ‘neutral zone’, which represented an empty or fallow time in between. Bridges (2001) suggested that transitions follow a time span and commence from the first signs of anticipation, perception or
demonstration of change, then proceed through a period of instability, confusion, and distress, before eventually leading to a calming period of stability.

Later conceptualisation of transition in the health and illness literature importantly incorporated the individual’s response to a disrupted or new social reality, a process of adaptation, and mastery of a new sense of self. An expanded typology was subsequently posited wherein transitions occur during periods of instability. A period of instability may be developmental for example from adolescence to adulthood, situational for example in bereavement, or may relate to the health and illness transitions associated with the process of becoming ill, being diagnosed, recovery, or adapting to a chronic illness (Chick & Meleis 1986; Kralik 2002; Meleis et al. 2000; Schumacher & Meleis 1994).

The theoretical development of transition within the context of health and illness continued to emerge through the work of Meleis and colleagues following the introduction of the concept by Meleis in 1975 (Chick & Meleis 1986; Meleis 1975; Meleis et al. 2000; Schumacher & Meleis 1994). Chick and Meleis (1986) developed a health and illness model of transition which was further explored and conceptualised by Meleis et al. (2000) who proposed a middle-range theory for nursing. The theory conceptualised transition within three key aspects: the nature, the conditions, and the response to transition.

1. **The nature of the transition.** This included the type, pattern, and properties of the transition.

2. **Transition conditions.** This incorporated the facilitators and inhibitors within the transition which may include the meaning, cultural beliefs, attitudes, and the knowledge/expectations of those individuals undergoing the transition.
3. **Patterns of response.** This included process indicators and outcomes indicators. Process indicators were described in terms of feeling connected, interacting, being situated, and developing confidence and coping. Outcome indicators included the mastery of the new skills needed to manage the transition.

The models by Bridges (2001), Chick and Meleis (1985), Meleis *et al.* (2000) and Van Gennep (1960) shared a common assumption that transition was linear and uni-directional. These models suggested that the three phases were somehow distinct and sequential, with start and finish points and readily separated for examination.

Following empirical studies examining the transitional experience in chronic illness, Kralik (2002:146) conceptualised transition as ‘the quest for ordinariness’, and proposed a model of transition in chronic illness defining this as a process which incorporated four interrelated phases: ‘familiar life, the ending, limbo, and becoming ordinary’ (Kralik 2002; Kralik *et al.* 2006b). The phases described in Kralik’s model of transition share some similarities with the ‘the ending’, ‘neutral zone’, and ‘new beginnings’, described in the model by Bridges (2001), and the ‘pre-liminal’, ‘liminal’ and ‘post-liminal’ rites of Van Gennep’s model (1960). However, in contrast to these previous models, Kralik *et al.* (2006b) proposed that individuals with a chronic illness move through these four phases, as well as often moving back and forth between these stages as they encounter ongoing disruption and accommodate changes into their lives as part of the continuing process of living with their illness. This model of transition is depicted diagrammatically to demonstrate how the phases are interrelated and to emphasise the movement through and within these phases as part of the transitional process associated with living with a chronic illness (Kralik 2002; Kralik *et al.* 2006b).
The model outlined that transition occurred when a person’s current reality was disrupted as a result of an illness causing a forced or chosen change that results in the need to construct a new reality. The transition experience was the movement, meaning and learning people made through a disruptive life event so they could continue to live with a coherent and continuing sense of self. A key part of this transition process was the re-orientation and redefinition that people went through to incorporate changed circumstances that the illness caused into their lives (Kralik et al. 2006b). In contrast to the previous models of transition, this model demonstrated the complex and convoluted nature of the transition process which accompanied chronic illness, and that those people in transition went back and forth as part of the transitional process as they tried to accommodate the changes. For people with chronic illness, the model also highlighted that the transitions experienced were multiple and ongoing as part of the illness trajectory.
The work undertaken by Kralik and her colleagues outlined the psychosocial transitions associated with chronic illness and, as such the body in transition was not incorporated into this model (Kralik 2002; Kralik *et al.* 2006b). It is not overtly obvious what role the physical manifestations of chronic illness play in relation to the experience of transition within this model. However, the symptoms and the associated disabilities and limitations imposed by a chronic illness trajectory will inevitably play a significant part in the individual’s awareness of illness, their experience, and the process of transition. The manifestation of physical symptoms would also promote the cycle associated with ongoing transitions as part of the illness trajectory.

Regardless of the philosophical backgrounds of the existing models of transition, there are many similarities between them. The elements common to all these models are:

- A disconnection from previous connections and support, often described as an ending, separation or change.
- An absence of familiar reference points.
- An emergence of new needs, accompanied by the inability to meet old needs in previously accustomed ways.
- An incongruence between former sets of roles, expectations, and identity markers, and those that prevail with the new situation.

In summary, all the transitional models demonstrate that transition is more than just change, it encompasses the process that people go through to incorporate a change or disruption into their lives. The models describe how transition occurs when a person’s current reality is disrupted causing a forced or chosen change that results in the need to construct a new reality. It can only occur if the individual is aware of
the changes that are taking place, acknowledging that a prior way of living/being has ended, or a current reality is under threat and that change needs to occur before the transition process can begin. This is followed by engagement, where the person is immersed in the transition process and undertakes activities such as seeking information and support, identifying new ways of living and making sense of the circumstances. This phase can also be a time of uncertainty and confusion for individuals with the models often referring to this as a period of ‘limbo’ or ‘betwixt and between’ (Bridges 2001; Chick & Meleis 1986; Kralik et al. 2010; Kralik et al. 2006b; Kralik 2002; Meleis et al. 2000; Van Gennep 1960). The transition models indicate that the transitional process involves transformation or alteration, whether it is incorporating, integrating or adapting to the consequences of the illness and that transition involves a process of inner-reorientation as the person learns to adapt and incorporate the new circumstances into their lives. Kralik (2010) suggests that transition in chronic illness needs to be considered at all these levels in order to take a holistic approach to the person.

An overwhelming characteristic of all the transition models is the assumption that people are eventually able to make the transition required to incorporate the changes into their lives. There is a clear emphasis on transition as a positive process of growth and renewal. Indeed, a successful transition is one where feelings of distress are subsequently replaced with ‘new beginnings’, ‘a sense of well-being’, and ‘mastery’ of the change event. The completion of a transition implies the person has reached a period of stability relative to that which has gone before. Even if overall, by comparison with the pre-transition state, the changes seem to be more detrimental than incremental, this does not mean that the transition outcome cannot be a positive one (Bridges 2001; Chick & Meleis 1986; Kralik et al. 2010; Meleis et al. 2000). While Kralik (2002) also acknowledged the re-establishment of stability
as part of the transition process, defining this as ‘becoming ordinary’, in contrast to the previous models Kralik (2002) also made reference to the temporality of this stability given the ongoing nature of the chronic illness trajectory.

3.4. The conceptualisation of transition in the health-illness research literature

The models of transition described by Van Gennep (1960), Bridges (2001), Chick and Meleis (1986), Meleis et al. (2000), and Kralik (2002) all offer frameworks for the study of the transition process within the health and illness setting. Meleis et al. (2000:27) stated that transition theory would benefit from research endeavours that ‘were directed towards defining the diversities and complexities in transition experiences through research with diverse populations in diverse types and patterns of transition’. Although there is evidence of such research occurring in the health and illness literature (Davies 2005; Jarrett 2000; Lowes et al. 2005; Walker 2001; Wilkins & Woodgate 2006), research exploring the experience of transition in chronic illness and palliative care is limited. This section examines the development and conceptualisation of the experience of transition within the qualitative research literature relating to chronic and life-limiting illness. The application of the existing transition models within this literature and an analysis of how these models are substantiated or challenged within these research studies is also presented.

Van Gennep’s (1960) three phase framework of transition has subsequently influenced thinking in the health and illness literature and has been used to examine the transition experience of individuals facing critical or life-limiting illness. Studies undertaken have included patients with chronic kidney disease (CKD) and their associated transition to life on dialysis, and those living with cancer, human immunodeficiency virus (HIV), and chronic kidney disease (Bruce et al. 2014; Martin-McDonald & Biernoff 2002; Molzahn et al. 2008).
Further understanding of the transition process as it related to illness was outlined by Martin-McDonald and Biernoff (2002) who used a collective case study design and narrative methodology to explore the conceptual, and empirical application of the rites of passage model in a group of patients who became dialysis dependent. The study sample consisted of ten participants aged between 22 to 68 years old who had recently commenced haemodialysis, or peritoneal dialysis. Participants were interviewed on three consecutive occasions about how they came to be on dialysis and what the experience of commencing dialysis had been like for them. The first interview focused on the participants telling their stories. The second interview took place 2-3 weeks later and focused on probing participants further about their experiences to gain clarity, elaboration, and meaning. The third interview took place 2-3 weeks after the second interview; at these interviews, participants reviewed a written transcript of their story for the purpose of validating its accuracy.

The findings illuminated the three stages of the ‘rites of passage’ as previously described by Van Gennep (1960). The first stage ‘separation’, involved the movement from non-dialysis to a dialysis-dependent status. ‘Liminality’, involved the process of starting dialysis and included the paradox of living with life and death in a tangible way because of the participants' perceived view of the role that dialysis played in life over death. In this stage, participants described the struggle between needing dialysis and not wanting the trauma and disruption dialysis also caused which corresponded with the description of the liminal period being the “betwixt and between” stage outlined in the model by Van Gennep (1960). Participants associated this stage with a feeling of powerlessness and an overwhelming feeling of being 'damned if you do or don't' in relation to commencing dialysis. The final stage of 'reincorporation' related to dialysis as an ongoing treatment and involved participants re-entering society on a new basis, with the acknowledgement of
different interactive patterns, roles, and responsibilities brought on by being dialysis dependent and acceptance of their lives on dialysis. The study findings demonstrated that each stage of the ‘rites of passage’ were evident in the participants’ narratives describing their experience of the commencement of dialysis.

The study concluded that commencing dialysis was an initiation that delineates the transition from one social state to another. Although the data analysis in this study supported the ‘rites of passage’ model, there were several limitations relating to this study. The small sample size, drawn from one research site in Australia meant that the findings were not generalisable to the wider dialysis population as a whole. The study investigated the experience of participants who had recently initiated dialysis and therefore explored the transition experience concerning one aspect of the illness transition, at one point in time, defining the transition as having a defined beginning, separation, and ending or ‘reincorporation’. However, for people on dialysis ‘reincorporation’ is not time limiting; instead, there is an ongoing transitional process associated with living with the effects of dialysis treatment for this chronic illness. Despite these limitations, the study finding facilitated a greater awareness of the consequences of participants’ choices, their experiences and the suffering associated with the liminal stage of dialysis initiation.

Other researchers have also used Van Gennep’s (1960) ‘rites of passage’ framework to explore individuals’ responses to the transitions associated with life-limiting illness. Molzahn et al. (2008) explored how people with chronic kidney disease (CKD) who were receiving dialysis described their experience of living between the promise of treatment and prolonged life, and the threat of death. A qualitative study was undertaken using secondary data and was guided by Van Genneps (1960) framework, with particular reference to liminality. Eleven narratives
from people with CKD receiving dialysis at one centre in Canada were analysed. The analysis outlined a number of liminal spaces which included: being both independent and dependent, having simultaneous restrictions and freedoms, feeling alone and connected, and being worse off or better off.

Building on the previous work by Molzahn et al. (2008), Bruce et al. (2014) used narrative inquiry within a constructivist paradigm and conducted semi-structured in-depth interviews with 32 individuals living with life-limiting illnesses which included cancer, human immunodeficiency virus (HIV) and chronic kidney disease (CKD). Participants were asked to take part in four interviews over a three-year period. One participant withdrew from the study after the first interview and five participants, all with CKD, died during the study. During the interviews, participants were asked about their experience of living with their illness, how they made sense of having their illness, whether anything had changed since their last interview, and how their illness had influenced their values and priorities. The findings described the overarching theme of “pervasive liminality” (Molzahn et al. 2008:18); this suggested that living with a life-threatening illness produced complex and paradoxical experiences which did not easily fit into familiar categories of experience. However, the sample in this study consisted of people with very different illnesses and illness trajectories which may have influenced the experience of transition.

In the studies by Martin-McDonald and Biernoff (2002), Molzahn et al. (2008), and Bruce et al. (2014), the experience of individuals undergoing the transitions associated with life-threatening or life-limiting illnesses were examined using Van Gennep (1960) ‘rites of passage’ framework. The greatest congruence with the rites of passage framework was reflected in the study by Martin-McDonald and Biernoff (2002), which explored individuals’ experience pre-dialysis and post-dialysis initiation, meaning that transition was studied at one point in the illness trajectory of
individuals with chronic kidney disease. All three studies described the 'betwixt and between' liminal period as a time when individuals had shed their old identities but had not yet incorporated a new way of being and re-defined their self-identity. However, in the studies by Molzahn et al. (2008) and Bruce et al. (2014) liminality was differentiated from the notion of liminality as an 'in between' phase as outlined in the multiphase process described in Van Gennep's framework. Instead, both these studies described liminality within the context of being overlapping and fluctuating, rather than being part of a process with a defined beginning and end point, thus the findings of both studies refuted the suggestion of a definitive beginning and end as proposed in Van Gennep’s model (1960).

The assumption that transition is a linear process with a defined beginning and end point have been further debated and challenged in the qualitative research investigating the experience of transition in chronic illness. These studies included participants with a variety of chronic illnesses including rheumatoid arthritis, cancer and people recovering from a stroke (Adili et al. 2013; Elmberger et al. 2002; Hilton 2002, Kralik 2002; Kralik et al. 2006c; Paterson 2001; Shaul 1997).

Paterson (2001) undertook a meta-synthesis of 292 qualitative research studies which challenged the assumption of a single linear trajectory in relation to living with a chronic illness. She proposed that living with a chronic illness consisted of an ongoing transitional and transformational process involving movement in many directions, and described this as a shifting perspective model of chronic illness. This challenged the notion of a linear transition as outlined in the models of transition by Van Gennep (1960) and Bridges (2001).

A qualitative study explored the transitions experienced by women with rheumatoid arthritis (Shaul 1997). Interviews were undertaken with thirty women who had had
the illness for less than fifteen years and had experienced two or more changes in function indicative of illness progression alongside a transition in their health status over the last three years. The transition theory outlined by Chick and Meleis (1986) provided a framework for the study. The results demonstrated exemplars of the transitioning process in the participants’ descriptions of how they recognised and learned to live with rheumatoid arthritis. Overlapping and recurring stages of transition were described and the themes identified were: 'becoming aware', 'getting care', 'learning to live with it', and 'mastery'. The transition process began with the awareness that change was occurring, this awareness was linked to the presentation of symptoms relating to the illness. Learning to live with the illness was synonymous with 'disconnectedness', defined in this study as a period of withdrawn from activities, social relationships and work due to the limitations of the illness. The transition continued in an unpredictable manner, very much like the course of rheumatoid arthritis. It was characterised as a time of uncertainty, of learning and a time of establishing new patterns for individuals that eventually led to a sense of control or mastery over their lives as they gained knowledge and awareness of the illness and how to live with it. The participants described how, as they progressed through the transitions of their illness, they gained a sense of 'connectedness' and 'stability'. Although this stability may last for weeks or even years, it was not a final state for participants in this study. For participants, 'outcomes', as described by Chick and Meleis (1986) were not clear events as there was no identifiable end point at which the participants' illness transition was complete. The study findings did provide a preliminary understanding of the transition process that occurred in chronic illness and how this process was an ongoing one, as people with rheumatoid arthritis typically experienced a number of exacerbations and remissions in the course of their illness.
In a study exploring men’s experience of how cancer affected their everyday lives, Elmberger et al. (2002) utilised the concept of transition and an interpretative, descriptive study design, to describe the experience of eight men with blood born malignancies. The findings of the study identified central themes around changes in one’s self-image as a man and as a parent. Subthemes included: ‘gaining control’, ‘balancing emotions’, ‘subjective well-being’, ‘being open with/ not open with family’, and ‘the challenge of family life and family well-being’. The findings also claimed that individuals processed or mastered the changing sense of identity and family relations caused by the illness trajectory through this process of transition. The time span following diagnosis influenced the process of transition with the disruptive events experienced as a result of cancer. There was increasing suffering when the altered sense of self was initially difficult to reconcile to, but this was ameliorated during the reclaiming or re-orientating process that occurred during the transition. The study concluded that men with cancer commenced the health-illness transition at diagnosis and that the transitional period lasted for several years beyond diagnosis as the illness was incorporated into their lives, describing the experience of transition as occurring in a spiral movement.

Similarly, Hilton (2002) undertook a study to explore the experience of transition in a small purposive sample of five elderly women survivors of a stroke. Data gathered from interviews with the participants were thematically analysed. The study identified overarching themes of ‘transition with transformation’, to describe the transition from ‘abled’ to ‘disabled’ as a consequence of the stroke. Five subthemes identified included: ‘deterioration and decline’, ‘loss and helplessness’, ‘regret’, ‘uncertainty and anxiety about the future’, and ‘resilience’. Alongside these subthemes were an additional six interwoven themes identified as: ‘dawning awareness of self as disabled’, ‘life and suffering through loss’, ‘quest for self and
embodiment of disabled’, ‘adaptation to change’, ‘existential re-establishment of self’, and ‘reconciliation and re-engagement’. The study concluded that participants experienced numerous transitions as a result of the stroke which affected how they perceived themselves and their lives and underwent a process of transformation as they sought new roles, identified coping strategies and reconciled with the limitations which the stroke imposed.

The meta-synthesis conducted by Paterson (2001) and the qualitative studies undertaken by Shaul (1997), Elmberger et al. (2002) and Hilton (2002) highlighted that the transitional process was unique, being neither time-bound nor linear in nature and that the duration and outcomes were different for each person. The studies suggested that while many life transitions may have a definitive beginning and end, the transitions experienced by people with chronic illness may be ongoing, as their health fluctuates or their illness progresses.

Building on the concept of transition as a non-linear process in chronic illness Kralik (2002) used participatory research methods and feminist research principles to explore the transitions experienced by midlife women living with a chronic illness. Correspondence was selected as the method of data generation as it was perceived that letter writing would be less intrusive than one to one interviews when researching over a prolonged period of time and would facilitate the reflective process. Data were collected over a period of a year with a sample of 81 women who were living with a chronic illness. It was thematically analysed to provide storied accounts. A subset of participants was actively involved in developing the constructs and themes by offering validation, clarification, and interpretation.

Two major themes emerged: ‘extraordinariness’, which represented the phase of turmoil and distress that occurred when the women first experienced their chronic
illness; and ‘ordinariness’, which occurred over time as the women made the transition of incorporating chronic illness into their lives. The transition from extraordinariness to ordinariness and sometimes back again affected the stability of the daily lives. The theme of extraordinariness included two major constructs: ‘how quickly life changes’ and ‘confronting life with a chronic illness’. How quickly life changes described women’s experiences of discovering they had a chronic illness. Confronting life with a chronic illness described women’s feelings of alienation from familiar life and loss of control over life circumstances. The theme of ordinariness included two major constructs: ‘the illness experience as transforming’ and ‘reconstructing life with illness’. The illness experience as transforming represented the many changes and dynamic state of living with a chronic illness which led to an increased self-awareness and the seeking of empowerment. Reconstructing life with illness represented the process of learning, making choices and identifying the changes that were needed to accommodate the illness into their lives. The achievement of ordinariness enabled the participants to regain a sense of balance and control over their lives again.

The findings revealed that when first confronted with a chronic illness, these individuals appeared to move through a complex trajectory that involved an ‘extraordinary’ phase of turmoil and distress through to an ordinary phase which involved incorporating chronic illness into their lives. The process of transition was found to be non-linear and potentially recurring. Kralik (2002) proposed that the transitions that occur after forced changes, such as the changes associated with chronic illness, where one’s reality and one’s sense of self is threatened and disrupted, is a more intricate and convoluted process with forward and backwards movement. This means that it may be counterproductive to place timespans on the transitional experiences of people with chronic illness as these transitions do not
always follow chronological trajectories. Kralik (2002) concluded transition was a passage during which people redefine their sense of self and redevelop their identity in response to life events such as chronic illness. She also proposed that understanding illness transitions offer a framework that enabled healthcare professionals to move beyond the bio-medically orientated concepts of healthcare practice and facilitate a holistic approach to the provision of care.

The strengths of Kralik’s (2002) study design included a large number of participants who took part in the study and the creative method of data collection which took place over the period of a year. Having participants actively contribute to the process of data analysis and thematic development added to the credibility of the finding. A potential weakness of this study related to the fact that participants self-identified themselves as living with a chronic illness; this raises questions about the applicability of the findings but does remain true to the feminist perspective of the study.

Kralik et al. (2006c) and more recently Adili et al. (2013) built on the earlier work on transition in chronic illness carried out by Kralik (2002). Kralik et al. (2006c) conducted a longitudinal study of twelve men and twenty-five women living with chronic illness. Analysis of the data revealed three themes which further contributed to the understanding of the transitional process. Three themes were identified as: ‘construction of illness in the illness experience’, ‘reconciling and reconstructing’, and ‘connecting with other’. The study findings also found that resilience played an important part in the transitional process for these patients. The study concluded that the transitional process resulted in resilience engendering a strong sense of worth, ability to learn from the experience and the capacity to adapt, describing this process as one of moving on, in which the reconstruction of a valued self-identity was essential.
Adili et al. (2013) explored the transitional experience of older women recently diagnosed with diabetes and examined how they learnt to live with their illness. Data were collected over the period of a year. The study supported the findings of Kralik (2002), concluding that individuals diagnosed with a chronic illness experience ‘extraordinariness’ for extended periods of time as they experience disrupted daily lives and have to accommodate changes in their lives, eventually learning to master the illness. This study and the previous empirical studies undertaken by Kralik (2002) and Kralik et al. (2006c) characterised transition in chronic illness as ‘a process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to disruptive life events’ (Kralik et al. 2006c:321).

In summary, the qualitative research literature has explored transition in a variety of chronic illnesses including cancer, stroke, rheumatoid arthritis, human immunodeficiency virus (HIV) and chronic kidney disease (CKD), at various stages in the illness trajectory including becoming unwell and starting treatment, recovery and adapting to chronic illness. Some studies examined a person’s transition at a particular point in time in the illness trajectory, while others used longitudinal methods to explore the experience of transition and therefore provided a greater breadth of that experience over a period of time. All of the studies consisted of small samples drawn from single centres, with the exception of Kralik (2002). The findings of all the studies supported the notion of identifiable critical points associated with the process of transition, such as the diagnosis of an illness or initiation of treatment; however, sometimes these were less evident and subtle, as in the case of living with a life-limiting illness (Bruce et al. 2014; Kralik 2002, Kralik et al. 2006c,).

The notion of transition as a linear process was not supported by many of the authors in the studies who instead highlighted that for people with chronic illness the process of transition was often complex, with individuals experiencing multiple,
ongoing transitions due to the nature of the illness trajectory. The studies provided little or no discussion with regards to people who did not experience transition due to being unable to adapt and integrate the illness into their lives. Instead, the studies implied that stability was achieved but this fluctuated in chronic illness and as such seldom had a clearly defined end point. The studies demonstrated that the transitions associated with chronic illness could be erratic and unpredictable and required constant adjustment.

The experience of chronic illness created much overt as well as some subtle changes to a person’s life, changes which included relationships, life priorities, and changes in physical, emotional and social wellbeing. People with chronic illness experienced these changes in many ways often described in terms of loss, loss of control, independence, familiar lifestyle, meaning, and of purpose, and associated uncertainty. A consistent finding throughout the research literature was the challenge to self-identity that occurred during the transitional processes experienced by individuals with chronic illness. The changes that occurred as a consequence of a chronic illness caused significant disruption to the individual’s sense of self. The transition process involved restructuring the way one defined oneself by adjusting responses, behaviours, and attitudes to ever changing life situations (Elmberger et al. 2002; Hilton 2002; Kralik 2002; Kralik et al. 2006c; Martin-McDonald & Biernoff 2002; Shaul 1997).

3.5. Transition and its relevance to other theoretical concepts

It is apparent that the concept of transition is closely linked to the concept of self-identity. The reference to the reconstruction of self-identity in the research literature examining transition in chronic illness shares similarities with the earlier work which focused on the notion of restructuring meaning in illness (Bury 1982). The
sociological study by Bury (1982) argued that the impact of living with a long-term condition was so significant it completely changes individuals lives, not only clinically but the entire context of their lives. Bury (1982) described the impact of living with a long-term condition to constitute 'biographical disruption', wherein the condition completely disrupts what individuals previously considered to be their 'normal identity'. Through qualitative interviews conducted with individuals recently diagnosed with rheumatoid arthritis Bury (1982) explored how people dealt with and acknowledged their condition. Specifically, Bury (1982) argued that being diagnosed with a long-term condition had three key impacts on the individual. Firstly, individuals had an awareness of symptoms which led to seeking clinical intervention. The illness or condition changed how people viewed themselves because they were now 'sick', and there was 'disruption' which indicated the new limitation the condition had placed on the individual's everyday, taken for granted life.

More recently, 'biographical disruption' has been critiqued by Williams (2000) who questioned the relevance of the term for the diverse group of people living with a long-term condition. Williams (2000) outlined that biographical disruption did not take account of the issues of timing and context, norms and expectations and how these may affect how individuals perceive their long-term conditions. Furthermore, chronic, life-limiting illnesses are unlikely to be cured; individuals must adapt to living with their illness and the changes experienced throughout their lives. Biographical disruption was therefore excluded as an appropriate theoretical framework given the purpose of the current study was to explore transition for people with end-stage kidney disease who were approaching the end of their lives.
3.6. Transition theory and its relevance to palliative care

The notion of transition is implicit in many palliative care related studies insofar as they explore the palliative care experience from the perspective of disruption, trajectories, change, adjustment, and adaptation. However, literature that explicitly addresses transition within the context of palliative care is limited. Much of the existing literature has focused on the transition from ‘curative to palliative care’ or the change in location of care which includes, for example, the transition from hospital to hospice care and the transition associated with referral to specialist palliative care services. For individuals living with a chronic, life-limiting illness the transition from ‘curative to palliative care’ is not a concept which necessarily serves to highlight the experience of the transitions associated with an illness trajectory which may not have a definitive point at which it transitions from ‘cure to palliative’ or which involving accessing specialist palliative care services.

Given the above considerations, defining the concept of transition in relation to palliative care for people with chronic illness including end-stage kidney disease remains a challenge. It goes further than the place of care; it also relates to the meaning of life/role changes, perceptions of treatment and likelihood of death. However, it has been suggested that understanding the concept of transition for people with chronic illness approaching the end of their lives is necessary for facilitating good end of life care (Gardiner et al. 2011).

Other authors have questioned the appropriateness of transition as a concept relating to the palliative care experience. Larkin et al. (2007a) study of palliative care patients’ experience of transition suggested a gap between current definitions of transition and their expression of the palliative care experience and suggested that ‘transience’ appeared to offer a better definition. Following on from their study
findings, Larkin et al. (2007b) undertook a qualitative conceptual analysis of transience using two case examples, interview data, and the literature. Thirty-one papers relating to transience were identified; the analysis and synthesis of the literature outlined transience as a fragile emotional state associated with sadness and feelings of pain which could lead to the sudden realisation that nothing is truly permanent. A theoretical definition of transience relative to palliative care was formulated as 'transience depicts a fragile emotional state relating to sudden change, exhibited as a feeling of stasis' (Larkin et al. 2007b:91). The defining attributes include in transience were described as fragility, powerlessness, impermanence, time, span, uncertainty and separation.

The conceptual evaluation of transience in relation to palliative care concluded that transience had particular resonance for palliative care and suggested that this was more meaningful for palliative care than the current conceptualisation of transition as a process towards resolution (Larkin et al. 2007b). However, the definition of transience proposed by Larkin et al. (2007b) isn’t necessarily reflective of the experience of palliative care per se for many patients who are approaching the end of their lives. Transience as a nascent concept remains strongly encapsulated within the framework of transition, and as such, its use as a theoretical framework did not support the investigation of transition for people with end-stage kidney disease who were approaching the end their lives.

3.7. Using transition as a theoretical framework to explore the experience of people with end-stage kidney disease approaching the end of life

Meleis and Trangenstein (1994) suggested that when a disease process occurs over time, with a movement towards greater complexity in the disease and illness experience, and changes that create more disruptions in the person’s life, it may be
useful to consider it within a transition framework. There have been some research studies undertaken using transitional theory as a framework for examining the experience of people living with long-term conditions; these have included studies exploring transition for people with kidney disease (Bruce et al. 2014; Martin-McDonald & Biernoff 2002; Molzahn et al. 2008). However, what has arguably been neglected is the process and experience of transition particularly for people with end-stage kidney disease (ESKD) as their illness progresses and they approach the end of life. It is this transitional process and experience that is the focus of the present study, aimed at describing the main issues of importance to people with ESKD as they approach the end of their lives, the transitions they encounter as their illness progresses and how they make sense of this. It would, therefore, seem appropriate in the present study to explore patients’ experiences as they approach the end of their lives using transition as a framework. Using transition as a theoretical framework facilitates the incorporation of transition as a process involving both the disruptions the transition creates and the person’s responses to the experience.

3.8. Summary of the chapter

This chapter has examined the existing theories of transition, how transition has been conceptualised in the literature and applied in the research with reference to chronic illness and palliative care. It has been suggested that transition theory can be an effective way to understand complex adaptations that people undergo as they manage the health-illness transitions, particularly chronic illness. The literature suggests that understanding transition involves exploring the person’s responses to a passage of circumstances and events that demand life adjustment. Shifting the focus of the disease as an event to the experiences of the people who have the
disease and the responses of people during these transitions provides the opportunity to gain a better understanding of the nature of the experience as a whole. The model of transition described by Kralik (2002) was chosen as a framework for the current study as it most accurately reflects the transitional process for people with chronic illness, conceptualising this as a convoluted, ongoing process; this has been supported by the qualitative research literature. Using a transitional framework meant it was possible to develop an understanding of the experience of the process of transition for people with ESKD as they approached the end of their life.
CHAPTER 4
METHODOLOGY AND METHODS

4.1. Introduction

This chapter provides an overview of the methodology and the methods employed for this research study. The chapter begins by revisiting the aims and objectives of the study; this is followed by a summary of the chosen research methodology, a qualitative approach using a constructivist grounded theory perspective. The antecedents of grounded theory, its philosophical and theoretical underpinnings, alongside its key tenets are presented. Emphasis is placed on why constructivist grounded theory, as delineated by Charmaz (2006) was chosen as a methodology framework for the facilitation of inquiry in this study. The chapter also outlines the study design, recruitment strategies, participant inclusion and exclusion criteria, data collection, data analysis, ethical considerations and the criteria used to ensure rigour.

4.2. The aims and objectives of the study

This study was designed to explore the transitions experienced by people with end-stage kidney disease (ESKD) as they approached the end of their lives and to develop a substantive theory which accounted for and explained the process of transition and how people with ESKD made sense of this.

4.3. The study design

A qualitative approach set within a constructivist paradigm provided the general orientation for the work. The methodological approach used to explore the transitions experienced by people living with ESKD as they approached the end of
their lives in this study was constructivist grounded theory. This research design reflected the research aims, questions, and epistemological understanding appropriate to this study; this is discussed in the following section alongside the decision making and rationale for the choices relating to the research study design.

4.3.1. A Qualitative Approach

Qualitative research is based on the belief that human realities are complex and that their experiences are significant (Charmaz 2006; Denzin & Lincoln 2005). Qualitative research involves broadly stated questions about human experience and realities. These are studied through sustained contact with people in the natural settings, producing rich, descriptive data that attempts to interpret the studied phenomena in terms of the meaning people bring to them and helps to understand those persons’ experience (Denzin & Lincoln 2005; Munhall 2012).

Morgan and Smircich (1980) argue that the suitability of a research method derives from the nature of the social phenomena to be explored. The purpose of this study was to explore the experience of people living with ESKD as they approached the end of their lives. Investigating palliative and end of life care issues is known to be methodologically and ethically challenging (Addington-Hall 2002; Aoun & Kristjanson 2005). Given the purpose of this study, a qualitative approach was deemed the most appropriate to explicate the phenomena from the perspective of the participants experiencing it and to uncover the participants’ perception of their world rather than to study the phenomena in another manner. It enabled the exploration of the complex and important issues related to the phenomena and allowed me to explore the meaning people with ESKD ascribed to the transitions they experienced as they approached the final stage of their illness trajectory. This approach also enabled the importance of context and process in relation to the
transitions encountered to be addressed, facilitating the identification of how these took place and who was involved.

4.3.2. Consideration of the research paradigm

Understanding the research paradigm is the first and most crucial step in any researcher’s journey (Creswell 2009; Denzin & Lincoln 2005; Guba & Lincoln 2005). A paradigm may be viewed as a set of 'basic beliefs' or 'worldview' which guide the investigation (Denzin & Lincoln 2005; Guba & Lincoln 2005). Denzin and Lincoln (2005) describe four main interpretive paradigms within qualitative research: positivist and post-positivist, critical, constructivist, and feminist. In this study, the constructivist paradigm was considered the most appropriate to address the research question and achieve the aims of the study.

A constructivist research paradigm assumes a relativist ontological position of multiple social realities. Epistemologically, constructivism is subjective, recognising there are different views of ‘reality’ in terms of what constitutes knowledge and the mutual creation of that knowledge. The participant and the researcher co-create understanding and aim towards an interpretive understanding of the phenomenon in relation to the meaning participants bring to them. (Charmaz 2006:187; Denzin & Lincoln 2005:24).

In order to access the participants’ perspectives of the transitions they experienced as they approached the end of their lives it is argued that the constructivist paradigm is best suited for this research study, noting it is also appropriate for developing areas of inquiry where further exploratory research is required (Charmaz 2000; Denzin & Lincoln 2005; Schwandt 2001). I, therefore, concluded that the qualitative
approach located within the constructivist paradigm was most appropriate for this study.

4.4. Why constructivist grounded theory?

Having decided to adopt a qualitative approach, I undertook a comparative analysis of the major qualitative traditions to ensure the most appropriate form of qualitative research methodology was selected for the purpose of this study. This analysis included the consideration of three main qualitative methodological approaches: grounded theory, phenomenology, and ethnography.

A primary function of grounded theory is to generate an explanatory model for human experiences and processes that are grounded in the data (Eaves 2001). In this way, grounded theory methodology attempts to inductively filter issues of importance for particular groups of people, creating meaning about those issues through the analysis and modelling of theory (Burck 2005; McCann & Clark 2003; Glaser 1978). As the current study aimed to explicate the transitions experienced by people with ESKD as they approach the end of their lives and develop a substantive theory which described how they made sense of these transitions, grounded theory was deemed an appropriate research methodology. A summary of the antecedents and tenets of grounded theory and the rationale for the decision to utilise constructivist grounded theory set are presented.

4.4.1. The antecedents and tenets of grounded theory

In order to have a greater understanding of grounded theory methodology, it was important to consider the antecedents of this approach, the philosophical and theoretical underpinnings and the key tenets of grounded theory. The antecedents
of grounded theory methodology originated in the social sciences, and in particular symbolic interactionism. As a result, the traditions of sociology and social psychology have been especially influenced by the development of grounded theory (Charmaz 2006). The origins of grounded theory date to the mid-1960’s when the sociologists Barney Glaser and Anselm Strauss conducted a study of the awareness of dying (Glaser & Strauss 1965). Two years later they published their seminal work ‘the Discovery of Grounded Theory’ (Glaser & Strauss 1967), which described the methodology they developed while undertaking the ‘awareness of dying’ study’. The methodological approach they developed provided a systematic method of discovering theory from data involving inductive processes. The approach developed as a response to positivist thinker’s belief that qualitative research was unscientific because it rejected controlled experiments and appeared to be based on interpretation (Hood 2007). The grounded theory methodology subsequently became one of the most commonly used and widely recognised approaches to qualitative research (Birk & Mills 2011; Morse 2009). Its popularity lay in that the approach agreed with the positivist epistemological view as it was systematic, replicable and rigorous (Charmaz 2008; Bryant & Charmaz 2007) and also incorporated the symbolic interactionist view which endorsed ‘human reflection, choice, and action’ (Charmaz 2008:515).

The aim of grounded theory has been defined as ‘the discovery of theory from data systematically obtained from social research’ (Glaser & Strauss 1967:2). This inductive research approach and the substantive theory that develops in a grounded theory study is grounded in and emerges from the data. Grounded theory is also explicitly emergent; ‘initial decisions for the theoretical collection of data are based on general perspectives rather than preconceived theoretical frameworks’ (Glaser & Strauss, 1967:65). This means that in a grounded theory study, the theory is
'discovered'; it emerges and is constructed from data obtained in the 'real world' rather than from rigidly predefined hypothesis, concepts and existing theory.

Grounded theory is considered to be a rigorous approach as it outlines a systematic process and key steps for how to gather, collect and analyse the data using the information that emerges from the data itself, rather than forcing preconceived ideas onto the coding and subsequent analysis (Glaser & Strauss 1967). The main tenets delineated by the grounded theory approach include theoretical sampling, the constant comparison method, coding and categorising, memo writing and theory generation, all of which occur simultaneously throughout the research process (Higginbottom & Lauridsen 2014; Jeon 2004). The constant comparative technique is a distinguishing feature of grounded theory analysis during which examples of the phenomena identified by participants are coded then compared and contrasted throughout the data collection phase of the study (Glaser & Strauss 1967). Key issues raised by the participants are followed up in subsequent research interviews (Glaser & Strauss 1967). Unstructured, open interviews are used to gather the data, to ensure that the participants’ subjective views are allowed to emerge; this means that the resulting theory is grounded in the data and discovered, rather than being preconceived by the researcher (Glaser & Strauss 1967; Charmaz 2006). Thus, grounded theory provides a rigorous method of analysis and offers a way of constructing a theory from data gained in the field. Indeed, I considered the ‘groundedness’ and the inductive nature of grounded theory particularly appealing as a methodological approach for the present study as it allowed participation action, and interaction to be captured.

Over time, both Glaser and Strauss developed a separate perspective on grounded theory methodology, Glaser (1978) is associated with classical or Glaserian grounded theory and Strauss and Corbin (1990) are associated with Straussian
grounded theory. Despite this, there are several similarities between the grounded theory work of Glaser and Strauss which include: theoretical sensitivity, theoretical sampling, constant comparison analysis, coding and theoretical memos (Glaser 1978; Strauss & Corbin 1990). Both versions of grounded theory adhere to the same basic research processes of gathering data, coding, comparing, categorising, theoretically sampling, developing a core category and generating a theory (Walker & Myrick 2006).

The methodological approaches to grounded theory described in the works of Glaser and Strauss (1967), Glaser (1978), and Strauss and Corbin (1990) further evolved and developed within the socio-political and academic context with the key constructivist perspective being presented in the works of Charmaz (2006, 2000) and Clarke (2005).

4.4.2. The Key tenets of constructivist grounded theory

Charmaz’s version of constructivist grounded theory considered the classic statements of grounded theory but ‘re-examined them through the methodological lens of the present century’ (Charmaz 2006: xii). In this way, constructivist grounded theory retained the rigour and tools of the classical grounded theory methods, but not the positivist assumptions of the traditional grounded theory approach (Charmaz 2006).

Instead constructivist grounded theory:

‘assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed, and aims towards an interpretive understanding of subjects’ meanings’ (Charmaz 2006:270).
The key tenets of constructivist grounded theory as outlined by Charmaz (2006) are described below:

**Constructivist Grounded Theory**

- Constructivist epistemological assumptions include the researcher’s perspective (p55).
- Theoretical sensitivity emergence is accessed via the researcher who is not a ‘distant observer’ (p178).
- Methods are flexible and thus emergent to access the unanticipated and facilitate the creative process of coding (42).
- Initial coding remains open to ‘exploring whatever theoretical possibilities we can discern in the data’ (p47).
- Theoretical coding ‘clarify and sharpen analysis but avoid imposing a forced framework on them’ (p66)
- The end product of constructivist grounded theory is not predetermined ‘the finished work is a construction’ (p1)

One of the reasons for selecting constructivist grounded theory, as outlined by Charmaz (2006) was because philosophically it was located within the constructivist paradigm in contrast to the in grounded theory approaches stipulated by Glaser (1978), and Strauss and Corbin (1990). Charmaz (2008) maintains that the constructivist version of grounded theory draws its emergent nature from the researcher, arguing that the grounded theories researchers construct through the methods proposed by Glaser and Strauss are undoubtedly influenced by the researcher’s ‘past and present involvements and interactions with people, perspectives and research practices’ (Charmaz 2006:10). In reality, what the researcher brings to the data influences what they see within it; the researchers
cannot separate themselves entirely from their research or achieve complete objectivity.

The constructivist grounded theory approach takes into account that the researcher is not ‘neutral’ in the study (Clarke 2005; Charmaz 2006; Wertz et al. 2011), arguing that the researcher’s perspective directs their attention but does not determine the research. Unlike the views held by Glaser (1978) who outlined that the researcher can and should remove themselves from the influence of their disciplines and the conditions of their research, constructivists aim to make their influences explicit. In the present study, I selected the research topic and brought my own interest in palliative and end of life care for people with end-stage kidney (ESKD) to the area of study. The research area was likely to involve a range of subjective experiences including personal emotions and interactions with others. As a nurse trained in palliative care, I believed that access to personal subjective accounts was vital to exploring the diverse issues associated with the transitions experienced by people with ESKD as they approached the end of their lives. The grounded theory approach, set within the constructivist paradigm in this study, fostered an open and sympathetic approach to understanding the participants’ experiences. In keeping with the constructivist grounded theory approach, I considered myself embedded in the research process rather than a ‘distant observer’ of an empirical phenomenon. I was a part of the knowledge gained from the investigation, and in this way, reality was co-created by myself as the researcher and the participants; the theoretical renderings from the study offered ‘an interpretive portrayal of the studied world, not an exact picture of it’ (Charmaz 2006:10).

Charmaz (2006) asserts that as constructivist grounded theory methodology retains the rigorous systematic processes involved in generating grounded theory, it fosters a qualitative methodology that has its own integrity and makes it possible to
distinguish between one’s own pre-conceptions and genuinely new insights as revealed by the inductive research approach. Adopting a constructivist grounded theory approach in the current study provided a structured framework for undertaking the study but alongside this open-endedness and adaptability were provided by this methodology. Since analysis and data collection proceeded simultaneously, ideas could be followed up as they were created.

Further justification for the selection of grounded theory as a methodology for this study was derived from the assumption that grounded theory makes its greatest contribution in areas where little research has been previously undertaken or little is known about a subject or phenomena (Burck 2005; Glaser 1998; McCann & Clark 2003). Furthermore, it has been suggested that grounded theory is the most suitable method when the aim is to learn ‘how people manage their lives in the context of existing or potential health challenges’ (Schreiber & Stern 2001: xvii). The review of the literature presented in chapter two demonstrated that the transitions experienced by people living with end-stage kidney disease (ESKD) as they approach the end of their lives were understudied and that the illness trajectory meant people with ESKD often lived with their illness and a declining health for substantial periods of time, which added further validity to the choice of grounded theory methodology for this study.

4.4.3. Consideration of other qualitative methodologies

In considering the most appropriate methodology for the study the applicability of adopting phenomenology or ethnography, both qualitative inductive approaches were considered. These are discussed in the following section, and their limitations as possible methodological choices for the study are outlined.
4.4.3.1. Ethnography

The foundations of ethnography lie in the field of anthropology. Ethnographic studies observe, question and listen to participants to uncover what is going on. The researcher’s approach is that of a stranger attempting to understand taken for granted meanings for members of the culture of interest to gain ‘inside knowledge of it’ (Hammersley & Atkinson 1995:8). A key method adopted in ethnographic research is participant observation, which is drawn from the perception that in order to fully understand a particular group of people, the researcher is required to observe and participate in the everyday activities of these people over a period of time. Other methods include in-depth interviews and the use of fieldwork diaries (Hammersley & Atkinson 1995). Alongside this, the researcher’s personal views and experiences about the research area are considered significant and may become part of the data.

Having considered the main tenets of ethnography with reference to my research study I chose not to adopt it as a methodological approach. This decision was based on the following considerations. Firstly, ethnography focuses on shared values and meanings that participants hold within it are taken for granted (Hammersley & Atkinson 1995), using this approach would fail to capture the individual personal transitions experienced by people with ESKD as they approached the end of their lives. Participant observation is also a key method within any ethnographic study; however, it would be difficult to observe the transitions experienced by people with ESKD. For these reasons, ethnography, with its focus on the cultural meaning would not have been a suitable methodology to address the research questions within this study.
4.4.3.2. Phenomenology

Creswell (2009:12) states that using phenomenology 'human experiences are examined through the detailed descriptions of the people being studied'. Phenomenology aims to explore individual phenomena with the purpose of describing the essence of the lived experience (Schwandt 2001). Two main schools of phenomenology exist, descriptive phenomenology and hermeneutic phenomenology (Maggs-Rapport 2001). A descriptive phenomenological approach excludes the researcher’s understanding of the phenomena being studied, via a process of ‘bracketing’ (Crotty 2003). In contrast, hermeneutic phenomenology shares several similarities with constructivist grounded theory; it is located in a constructivist paradigm, the researcher’s worldview is also taken into account in the analysis of the phenomena and it uses open, in-depth interviews to gather data.

Particular consideration was given to phenomenology as a choice of research methodology for this study. However, it was decided that the phenomenological approach would not fit the purpose of the current research study which aimed to explore the transitions experienced by people with ESKD who were approaching the end of their lives, and the wider remit of the study which aimed to develop a substantive theory to explain this phenomenon. Although a phenomenological approach, with its focus on experience, would have set out a rich description and gained an insight into the 'lived experience' of the individuals studied it would not have provided the context and process in relation to these transitions nor would it have assisted in the development of a substantive theory. Phenomenology was therefore not adopted as a research methodology.
4.4.4. Summary

In summary, I concluded that constructivist grounded theory provided an appropriate ontology for the current research study and deemed this to be the most suitable qualitative research methodology for this study which sought to understand the experience of people with ESKD approaching the end of their lives; where the emphasis was on people with ESKD as distinct individuals and the world as they experienced it. It provided a flexible methodology that enabled the transitions experienced by people with ESKD to be explored as they approached the end of their lives. It acknowledged the central role of the researcher in the analysis process and development of the theory which facilitated an emergent approach to the data. As a strategy for inquiry in this study, constructivist grounded theory also provided a structure in relation to the procedures undertaken during data collection and analysis; these are discussed later in the chapter.

4.5. The research setting

The study took place in a large renal unit in England. The centre provided comprehensive renal services based at a University teaching hospital and two satellite units accommodated at the District General Hospitals. Services were provided to a catchment area of over one million people. The demographics of the catchment population consisted of an increasingly ageing population, particularly those over 80 years of age and were mainly Caucasian, with black and ethnic minority groups accounting for less than 3.5% of the population.
4.6. Recruitment to the study

The study sample consisted of people with ESKD. The renal multidisciplinary team initially identified potential participants whom they perceived to be approaching the end of their lives and who met the study inclusion criteria outlined below.

4.6.1. Inclusion and exclusion criteria

The inclusion and exclusion used in this study are outlined below:

Table 2: Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
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<tbody>
<tr>
<td>Patients who were over 18 years of age</td>
</tr>
<tr>
<td>Patients with Stage 5 Chronic Kidney Disease, regardless of the treatment modality they may be receiving</td>
</tr>
<tr>
<td>Perceived by the renal multi-disciplinary team (MDT) to be in the final stages of their illness trajectory and deemed to have a prognosis of less than 12 months which included:</td>
</tr>
<tr>
<td>Patients who were on dialysis (haemodialysis or peritoneal) who had a poor prognosis often due to co-morbidities</td>
</tr>
<tr>
<td>Patients being managed conservatively</td>
</tr>
<tr>
<td>Able to speak English</td>
</tr>
<tr>
<td>Able to give informed and voluntary consent to participate about in the research study</td>
</tr>
<tr>
<td>Able to understand and sign the consent form</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients who were under 18 years of age</td>
</tr>
<tr>
<td>Patients who were cognitively impaired</td>
</tr>
<tr>
<td>Unable to give free and informed consent</td>
</tr>
<tr>
<td>Unable to speak English</td>
</tr>
<tr>
<td>Unable to read and sign the consent form</td>
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As this study aimed to explore the experience of transition for people with ESKD as they approached the end of their lives, the process of these transitions and the changes the participants had to adjust to and accommodate into their lives, the study criteria did not make exclusions based on the treatment modalities participants were receiving at the time of the study. The exclusion of participants who could not speak English was a limitation in the study sample, as the perspective and experience of all people with ESKD are important in gaining a better understanding of their experience in the latter stages of their illness trajectory as they progress to the end of their lives. Given the limited funding available to the researcher it was not possible for the research to employ an interpreter to interview non-English speaking patients as part of the study.

4.6.2. The recruitment process

4.6.2.1. Gaining access to the research setting

In order to gain access to the research setting, the first step was to make contact with the clinical lead for renal services at the acute trust. Following an initial telephone discussion, a face to face meeting with the clinical lead was arranged in order for me to discuss the research study and gain his permission and support required in relation to the National Research Ethics Service application and local Research and Development Committee (R&D) approval processes.

4.6.2.2. Recruiting participants

I attended the renal multidisciplinary team (MDT) meetings chaired by the clinical lead at the acute trust prior to ethical approval being granted and then twice monthly when all approval was in place, and I was ready to commence data collection. The
aim of attending the meetings was to discuss the study with the wider renal team of medical, nursing and therapy staff. Members of the renal team were invited to identify patients they felt were in the final stages of their illness trajectory; those they perceived were in the last 6-12 months of their lives and who met the study inclusion criteria. Given that prognostication is a very inexact science, predicting the end of life in patients with advanced ESKD is often difficult. Previous authors have suggested that the simplest tool for predicting the end of life in this patient group is the surprise question ‘would you be surprised if the patient died in the next 12 months?’ (Da-Silva Gane et al. 2013; Moss et al. 2008; Pang et al. 2011). I discussed the application of this question as a tool to facilitate the identification of appropriate potential participants for the study with the renal team as they reviewed patients on their clinical databases and discussed patients at the renal MDT meetings.

All potential participants were identified by the consultant responsible for their care and confirmed as appropriate by other members of the renal MDT present at the meeting. The team also confirmed that all the potential participants, regardless of treatment modality, were aware that their illness was progressing and that they were in the end stages of their illness. The renal team then agreed that they would discuss the study with the patient when they next attended the clinic, the dialysis unit or were visited at home by a member of the renal MDT. In this way, potential participants were identified and screened against the inclusion and exclusion criteria by a member of the renal MDT involved in their care. It was a member of the renal MDT known to the patient who initially made contact and approached the patient about the study, provided a brief description of the study and gained verbal consent for myself as the researcher to contact them. All potential participants were given a copy of the participant information sheet (Appendix 1). This introduced myself as
the researcher, explained the study, and clearly outlined that participation was voluntary and they were under absolutely no obligation to participate and that any refusal would in no way compromise their care in the future.

My initial contact with the potential participants was predominantly by telephone or on some occasions this took place in the clinic if I had already been informed by the renal team that they had discussed the study with the potential participant who had agreed to meet with me when they attended hospital on a given date. During this initial contact, I discussed the study in more detail and answered any initial questions that potential participants had. One participant contacted me directly about taking part in the research following an initial discussion they had had with the renal team about the study. The date and time of the interview, as well as the location for the interview to take place, were decided and agreed by the participants. Written consent was taken from the participants prior to the interview commencing. Although none of the participants approached refused to participate, three participants deteriorated during the time that lapsed between the initial contact and the date arranged for the interview and it was therefore not possible to undertake the interview with them. A total of twelve participants were interviewed in this study, the demographic details including age, sex, duration of illness, treatment modality and co-morbidities are presented in the findings in chapter five.

4.6.2.3. Issues relating to the recruitment of participants

Once I had gained all ethical approvals required for the study, the challenge remained in gaining access to potential participants. Despite the enthusiasm from the renal consultants during my discussions with them concerning the purpose of the study and access to potential participants for the study, the recruitment process was initially very slow. There were a number of issues regarding access to the study
side by means of the nursing staff, despite having ethical approval in place. Gaining research access to participants initially proved to be a time-consuming and a potentially sensitive process and raised interesting questions as to who is the gatekeeper to patient access.

Although potential participants had already been identified by the consultants who had discussed the study with the patient, there often appeared to be reluctance on the part of some of the renal nursing team to then provide the details of participants, this was despite assurances that the study already had ethical approval and that potential participants had been identified by the renal consultants. I found that several of the nurses on the renal unit, whom I had been directed to by the consultants, would not provide the patient details, often agreeing to do so but then saying they had ‘forgotten’ or had ‘been too busy’. They were very cautious to proceed with assisting in the recruitment process without permission in writing from the Chief Nurse at the acute trust.

The power of gatekeepers to grant or deny research access to participants perceived to be vulnerable has been cited by several authors (Witham et al. 2015; White et al. 2008). Health care professionals often feel that in their caregiving role they need to protect patients from the perceived burden of taking part in research, without actually involving patients in the decision-making process and thus denying them their own autonomy in relation to these decisions. As access was dependent upon an agreed process of recruitment, as the researcher I felt I had little control over this and was initially concerned about the speed of recruitment. Negotiation was a critical skill in taking this forward; I contacted the clinical lead who confirmed that he personally had provided the names of patients with whom he had discussed the study and who had agreed to take part, having then asked the nurses to provide me with the details. I was provided with the names of two senior renal nurses, one
in the satellite renal unit and another who had recently been appointed to coordinate
the care of patients being managed conservatively. I subsequently met both nurses;
they were experienced renal nurses, confident in relation to their communication
and knowledge surrounding their individual patients and very willing to identify and
approach potential participants from their caseloads; they both played key roles in
access to potential participants for the study going forward.

Participant attrition was also an issue. Three participants who agreed to take part
and had an interview date set up then deteriorated and became too unwell to
participate.

4.7. Data Collection

Data collection consisted of an unstructured interview conducted with the
participants. A demographic form was also completed with each participant prior to
the commencement of the interview; this included the participants’ age, sex, marital
status, duration of illness, current treatment and any co-morbidities. Data were
collected between October 2013 and March 2014. Throughout the duration of data
collection, field notes and memos were also recorded. This section outlines the
process of conducting the qualitative unstructured interviews, the choice of the
interview setting, details relating to the format of questions and how a rapport was
established with participants prior to and throughout the interview process.

4.7.1. The qualitative interview process

4.7.1.1. The interview setting

Given the sensitivity of the research topic and the potential that interviewees may
become distressed during the interview, it was imperative that participants felt
comfortable, both physically and emotionally, with the location of the interview. The location for the interview was therefore chosen by the participant. Ten participants opted to have the interview at their home. The remaining two patients chose to be interviewed when they attended the renal department; a room was made available to ensure that privacy during the interview process was maintained. All interviews were digitally tape recorded. Participants were made aware as part of the consent process and prior to the interview that this would be audiotaped and the audiotape equipment was placed in clear view of the participants before the start of the interview.

4.7.1.2. Establishing rapport

It has been argued that establishing rapport in the interview setting is crucial to the quality of information emerging from the data. Charmaz (2006:25) states ‘the interviewer is there to listen, to observe with sensitivity, and to encourage the person to respond’. The interview is about the collaboration between the researcher and the participant, the establishment of this individual to individual dialogue in order to understand rather than explain (Hiller & Diluzio 2004).

In an attempt to establish a good rapport with the study participants the following steps were taken. Although the interviews were undertaken outside of work time, I was keen to ensure I did not dress too casually. I wanted to create an air of informality but also wanted to appear professional in my presentation as I was conscious I was a nurse working in the local health economy and would be considered as such by the participants. Prior to the commencement of the interview, I provided the participants with background information about myself explaining that I was a nurse, having spent much of my career working in the fields of cancer and palliative care. I felt it was important to explain to them that I was not a renal nurse.
but had experience of working with renal patients and other patients with non-cancer life-limiting illness within the context of helping them manage their symptoms and palliative care issues. I also made it clear that although I had discussed the study with the renal team who were supportive of me undertaking the study with their patients, I was not affiliated with the renal team or involved in their care in any way. It was emphasised that the purpose of the interview was for me, as the researcher, to listen to their experiences and this would be conducted in an informal manner. All participants were given the opportunity to raise any queries they had about the study and answer any questions prior to commencing the interview. This sharing of information about my background and the purpose of the interview seemed to serve as an icebreaker; I observed that often the participant’s body language appeared more relaxed and they appeared more comfortable in my presence following this disclosure of information, and this eased the transition into the interview.

4.7.1.3. Conducting the qualitative unstructured interviews

Unstructured interviews were considered the most appropriate method of data collection for the study. The unstructured interview offers a way to explore peoples’ lives and the context in which they make decisions, yielding ‘thick descriptions of their lives’ (Hesse-Biber & Leavy 2006:740). The use of the unstructured interview technique enabled me to explore the complex topics raised in the study which included living with a deteriorating health, functional decline, issues relating to prognosis and the end of life. Using unstructured interviews also ensured that the theory generated was not forced, it enabled ideas to emerge that had not been predetermined by the researcher (Berg 2009; Denzin & Lincoln 2005, Esterberg 2002; Warren & Karner 2005).
An acknowledged way of commencing a qualitative interview is to ask ‘Tell me about …’ (Morse 1995:147). In this study, I opened the interview by inviting participants to recount their experiences of their illness by asking them to ‘tell me about your experience of living with your illness?’. This facilitated the initial interview dialogue; participants were able to tell their stories which started to give meaning to their illness experience. Some participants started their story from a point prior to the initial diagnosis when they had become unwell and sought medical advice, for others their story started with them recounting their first visit to see the renal team. This part of the participant story was often long, it enabled me to gain insight into their stories and gave meaning to their experiences later particularly in relation to the decision-making processes as their illness progressed.

An interview guide was developed to provide prompts during the interview (Appendix 2). The structure of the questions included in the interview guide was developed based on the principles outlined by Patton (2002) who suggested that good questions in qualitative interviews should be open-ended, neutral, sensitive and clear to the interviewee, and based on behaviours or experience, opinion and values, on feelings, knowledge and sensory experience. The content of the interview guide was developed following a review of the literature relating to palliative care, end of life care and transitional research (previously presented in chapter 2). Several authors have proposed that the experience of transition can be explored through discussions about ‘critical events’ (Meleis et al. 2000; Kralik 2002). In the current study, critical events were explored with participants by asking them to reflect on incidents when their health had changed, the nature of these changes, their perception of these incidents and the associated meaning they ascribed to them. The interview guide was peer reviewed by patient members of the patient
experience committee at my own hospital, but the interview guide was not peer reviewed by palliative care or ESKD patients.

The flexibility of using unstructured interviews was a major appeal in this study, the adaptability and seeing the reaction of the participants enabled me, as the researcher to probe individual responses thus facilitating the collection of rich data. Gordon (1980) described two types of probing, recapitulation and silence probes, both of which were used in the current study. The recapitulation probe takes the participant back to the beginning of the described experience and often results in new details being recounted. The value of the recapitulation probe, when used in this study, is demonstrated in the excerpt below. The example is taken from an interview in which the participant had earlier mentioned that he felt isolated from people.

**Researcher:** ‘I think you said before that you felt quite isolated from people. Could you tell me a little more about that?’

**Participant:** ‘Yes, that’s right, I did say that. It’s like I don’t have anything in common with people anymore, my friends, I no longer share that world. Um, my life is so different from my friends’ lives. We used to be so close, go out, had things to talk about, but I don’t think that anymore’.

The silence probe gave participants time to think and let them finish what they wanted to say. As an experienced palliative care nurse I found it easy to use both these probes as had often used these in my clinical practice when assessing patients, I felt comfortable with the silences, being able to hold these, enabling patients to gather their thoughts and continue the interview at their own pace.

The first three interviews were less focused; I relied more on the interview guide for prompts during these interviews. However, as this was a grounded theory study, data collection and analysis were undertaken simultaneously. As the interview
process progressed and interviews were conducted with other participants, I used prompts and tentative categories identified in the earlier interviews and initial data analysis to explore these tentative codes and categories in more depth with subsequent participants. I also became more comfortable allowing participants to lead the interviews and discuss their experience in their own way, enabling them to tell their story, even if this often meant that they diverged off into other aspects of their lives. Sometimes this did not appear immediately relevant to the study questions but letting them describe their experience at their own pace and using prompts in a subtle way enabled me to gain a greater understanding of the meanings participants associated with their experiences.

Given the sensitive nature of the research topic, I was keen to ensure that whilst participants were given the opportunity to have their voice heard and take part in the study they were not harmed by the interview process. Being sensitive to and responding to the participants was my priority during the process of interviewing. I remained vigilant throughout the interview process to verbal and non-verbal cues that may indicate that participants were becoming distressed or fatigued by the interview process and questioning. Throughout the interview process, I reminded participants they could stop at any time and regularly checked they were able and willing to continue the interview.

4.7.2. Field notes

Throughout the process of data collection, field notes were kept. These recorded the setting of the interview, non-verbal communication, mannerisms, body language and behaviour observed during the interview. These field notes were written immediately after the interviews had finished while they were still fresh in my mind. The field notes were used to record observations and reflections on the interview process.
process itself and the data; they also contributed to the reflexive approach to the ongoing analytical process. I found that the recording and later review of these field notes was particularly relevant to this study and assisted me with the noting of salient points from the interview and emotions that had emerged, and helped me gauge participants’ responses to questions as well as facilitating my own reflection on my emotions during the interview process. An example of a field note extract is provided in Appendix 3.

4.8. Data Management

Participant interviews, the field notes, and memos were all sources of data in this study. The literature was also recognised as a source of data and contributed to the understandings and analysis relating to the studied phenomenon which was the transitions experienced by people with end-stage kidney disease as they approached the end of their lives.

4.8.1. Transcribing the Interviews

All participants completed and signed the consent form before the commencement of the interviews, and the consent process outlined that the interviews would be tape recorded. Taped interviews were transcribed verbatim by me as soon as possible after the interview had taken place. I made the decision to transcribe all the interviews myself so that I did not risk missing something important by having them transcribed for me. Esterberg (2002) endorses the researcher undertaking the transcriptions as it enables the identification of the emotional pitch of the participants, identification of how the silences and pauses are used, and early identification of the repetition of words and phrases. Although transcribing the tapes myself was time-consuming, it afforded me the opportunity to get close to the data.
and provided me with a greater understanding and depth of knowledge of these interviews due to the repeated listening of these tapes during the transcription. Field notes and memos were also transcribed in preparation for analysis.

4.8.2. Consideration of using a qualitative software programme to manage the data

On commencement of the research process, I did consider the feasibility of using a qualitative software programme to assist in the data management and analysis of the data obtained from the qualitative unstructured interviews. Prior to the data collecting phase of this study, I undertook NVivo training, and although the software was used for the initial management of data, it was not used for the ongoing data analysis process. The software was new to me, and I struggled with the technical aspects of the software. I initially tried to use the software to assist in the line by line coding, but I found it impacted negatively on my ability to analyse the data and did not facilitate original thought and interpretation. I achieved a greater familiarity with the interview data through the manual processes, reading and re-reading of the transcripts, re-listening to the audiotaped interviews, making memos and using pen and paper to make diagrams. This helped with the thought process and moving the theorising forward.

4.9. Data Analysis

Data collection, data analysis, and conceptual theorising occurred simultaneously and continued until the theory emerged from this analysis. Data analysis was undertaken using the constructivist grounded theory processes described by Charmaz (2006) as a guiding framework. This framework for data analysis is outlined diagrammatically below:
While the process of conducting analysis suggests a step by step procedure to follow, Charmaz (2006) warns that this must be tempered by the need not to stifle the creative process. Analysis of the study data began with coding the interview transcripts, undertaken as soon as possible after each interview. The process of coding consisted of three phases: initial coding, focused coding and theoretical coding. The subsequent development of concepts and theorising in order for the theoretical model to emerge had several phases as increasingly abstract ideas were developed from the participants’ own words, meanings and actions.

4.9.1. Initial Coding

Initial coding is the first step in the coding process during which the aim is to ‘remain open to exploring the data’ (Charmaz 2006:47). During initial coding, each interview transcript was analysed line by line, breaking the data down to discreet incidents,
events, actions, and interactions. Each line was labelled to note when participants had raised key terms such as ‘getting on with things’ or ‘deciding what to do’. The label represented what was important about what had been said, and this enabled the beginning of the conceptualisation of ideas. An example of the line by line coding from an interview extract is provided in Appendix 4.

The line by line coding revealed codes which originated from the participants’ own words (in vivo coding). Starting with the words of participants helped me stay close to the data, and provided a way of viewing their experiences, from their perspectives. In this way, the analysis of the data used codes which originated from the data and indicated the participants’ perspective, using the language of the participants. The in vivo codes which originated from the data afforded an important check on the significance of the codes to participants’ specific meaning and experiences, these codes acted as symbolic markers of the participants’ own language and conveyed the meaning for them during the initial analysis.

Charmaz (2006:136) outlines that ‘if you can focus your coding on analysing actions you have ready grist for seeing sequences and making connections’. When reviewing the interview transcripts and undertaking the line by line coding I tried to adopt the strategy of coding for ‘actions’ rather than themes as a method for moving away from static topics and into enacted processes. To achieve this, during the process of conducting the line by line coding I also coded for gerunds (words ending in ‘ing’), these gerunds indicate process as opposed to themes, for example, ‘feeling alone’ was a gerund from the early analysis of the data.

Some codes were both in vivo and gerunds, an example of a code that was both in vivo and a gerund which emerged from the line by line coding was ‘living here and now’, which was used to indicate how participants coped with the deterioration in
their health and the uncertainty of the future. In this way, coding for gerunds enabled the sense of action that was part of how the participants adjusted as their illness progressed to be retained during coding.

A variety of in vivo and gerund codes emerged in the line by line coding. Examples of the in vivo and gerunds which emerged from the line by line coding are presented below:

<table>
<thead>
<tr>
<th>Codes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>In Vivo</td>
<td>right decision, relationships, family roles, good and bad days, big decisions, support, independent, everyday decisions, control, put it together, personality, responsibility, understanding.</td>
</tr>
<tr>
<td>Gerund</td>
<td>knowing, discussing things, thinking aloud, accepting, getting on with it, not knowing, looking forward, being realistic, feeling guilty; holding my own, being determined; not giving up, living each day, enduring decisions, negotiating, compromising, being present focused.</td>
</tr>
</tbody>
</table>

The initial line by line coding facilitated the process of data analysis ensuring that the data analysis which emerged was grounded in the participants’ accounts and limited the likelihood of superimposing my own preconceive ideas and views on the data (Charmaz 2006). Through the initial line by line coding the gaps emerged in the data and the need to develop the properties of the categories provided leads that were pursued in the ongoing data collection. During each episode of initial coding, the categories were further developed, their properties and dimensions were more fully described, this led to some categories being collapsed and others were expanded upon into further categories.
4.9.2. Focused Coding

Charmaz (2006:57) defines focused coding as 'using the most significant or frequent earlier codes to sift through large amounts of data'. It is the next step in the process of coding and is more directed, selective and conceptual than the initial line by line coding process. Undertaking focused coding involved the process of extracting the most frequently used key codes from the initial coding and grouping them together. Focused coding meant that the data were viewed across the interviews, the memos, and the field notes. For example, in relation to the initial code ‘knowing’, I examined all the sources of data to see how each participant articulated this experience. This helped to further develop the code of ‘knowing’. I was drawn to look at what led to participants ‘knowing’, the effect of this ‘knowing’ and the way participants responded to this including the support systems and the strategies they adopted and relied upon to accommodate this ‘knowing’ into their lives. After analysis and coding as part of this stage of focused coding, I was able to develop the initial provisional code of ‘knowing’ into the category of ‘knowing without clarity or confirmation’, as the analysis developed to conceptualise participants experience of this process.

Ongoing comparative analysis and conceptualisation undertaken during the process of focused coding resulted in amendments to the initial coding. For example, an earlier category of ‘controlling involvement’ was later developed into ‘continuing to be involved in ongoing decision making about care’, which became part of the subcategory ‘negotiating and compromising on involvement in ongoing decision making about care’. This was in recognition that the process of transition for participants as their health deteriorated and they approached the end of their lives related to how decisions were made, how they made sense of these decisions and
the acceptability of these decisions, which was influenced by how involved they felt they were in the decision-making process rather than 'controlling' these decisions.

4.9.3. Theoretical Coding

The process of theoretical coding involved examining the relationships between the categories in the data. As part of this coding process, I analysed the focused codes and specified the relationships between the categories, integrating and organising them into the major categories and the development of the core category. As the data collection continued, new categories were compared with other examples of the same category to fully describe and challenge interpretations and thus improve the explanatory power (Strauss and Corbin 1990). This was achieved through the application of the constant comparative method outlined below.

4.9.4. Constant comparative analysis

The constant comparative analysis is central to the analysis of data in a grounded theory study. It enables the ideas generated by the data analysis and the emerging theory to be constantly compared with the data to 'check that the ideas are well grounded in the data' (Gibbs 2002:240). Constant comparative analysis enables the accuracy of the initial evidence to be checked, to fully describe concepts and categories, to improve the descriptive power of categories so as to make generalisations, to specify a concept, to analyse, and to verify and generate theory (Glaser & Strauss 1967; Holton 2007).

Each participant interview was coded and as more interviewed were undertaken, the data coded similarly were compared and descriptions of the codes were made, delineating some earlier codes and developing others into categories. I continuously
revisited the data and the words of the participants, using the previous data and the
analysis to influence future data collection and analysis as part of this comparative
process. Data collection became more focused as the study continued, but the
constant comparison of the data continued, building the categories by comparing
new codes with existing codes. The emerging categories were also compared to
more data as well as comparing the emerging categories to each other. Charmaz
(2006:179) states 'making comparisons between data, codes and categories
advance your conceptual understanding because you define analytic properties of
your categories'.

This process of constant comparison was applied on an ongoing basis throughout
the data collection and analysis process, as I compared and contrasted concepts
which emerged from the data which were relevant to the transitions experienced by
the participants as they approached the end of their lives and explored how they
made sense of these changes. Alongside this, I wrote memos to capture my
interpretations and record my reflections of the analysis process (memo writing is
discussed in more details in the next section). I returned to these memos and my
field notes comparing these to interviews as I coded and continued to code the data
and as the process of theorising continued. Charmaz (2006:135) explains that:

'when you theorise, you reach down to fundamentals, up to abstractions and
probe into experience. The content of theorising cuts to the core of studied life
and poses new questions about it'.

Sorting the categories which emerged from the process of coding, diagramming and
integrating the memos was an interconnected process which took place throughout
the research process and was strategies required for refining the theoretical links
as the theory emerged.
4.9.5. Theoretical Memos

An integral part of the development of grounded theory is memo writing. Memos are used to note the reflections that have taken place concerning the data and to compile questions in order to build further upon and explore ideas (Charmaz 2006). Through memoing, the researcher stops and analyses their ideas about the codes and emerging categories. In this study, my thoughts and feelings on key issues were recorded in my memos.

Memo writing was an ongoing process and was critical to the development of the data collection process. I undertook writing memos throughout the data collection process in this study. During early data analysis, these memos explained the properties and dimensions of the categories; they became more theoretical in nature as the analysis proceeded. In this way, I was able to capture the similarities and differences in the data. My thoughts and feelings in relation to what I was seeing in the data, the similarities, differences and connections were all captured and explored through memo writing.

Ongoing memo writing in the study enabled me to analyse ideas as they arose, and challenge my own preconceived ideas in comparison to those emerging from the data. This enabled me to stay grounded in what was going on from the participants’ perspective, enabling an open, candid account of the codes and categories which were emerging. Memo writing, undertaken throughout the interviewing, transcribing, coding, and writing process, provided an opportunity to step outside the coding process and further explore the ideas identified during the analytic process. An example of a theoretical memo written during the data analysis process is shown in Appendix 5.
4.9.6. Diagramming

Diagramming is a technique advocated by some grounded theorists for use in the facilitation of the data analysis process (Charmaz 2006). Throughout the data collection and analysis process, a series of visual diagrams were collated by myself to help me visualise and explore the relationships between codes and categories. Diagramming helped with the interpretation of the emerging data and to discover potential links within and between the categories. Appendix 6 illustrates an example of a diagram collated during the data analysis in this study.

4.9.7. The literature as a source of data

A further source of data for this study was the literature and documents relevant to the field of study. Glaser and Strauss (1967) recommends that when discovering grounded theory, no previous research is reviewed prior to data collection. In this way, the analysis is not influenced by existing literature and thus remains open to fresh insights and avoids what has been termed as received theory (Glaser 1978; Glaser & Strauss 1967). In contrast, Charmaz (2006) encourages the use of acquired knowledge from the literature during all phases of the research process, maintaining that literature should be used both before and during the study to stimulate theoretical sensitivity, questioning and to direct theoretical sampling. I completed the literature review initially to set out the broad parameters of the area of research. Having completed most of the analysis, I then revisited and reviewed the literature on three further occasions. By doing this, I remained open to new ideas and so minimised its influence on me (Charmaz, 2006). In adopting this process, I was able to clarify the contribution of this study to the field of transition and the experience of people with ESKD approaching the end of their lives.
4.9.8. Theoretical sampling

In grounded theory studies, theoretical sampling is a key element of conducting the study and forms part of the process of theoretical saturation. It differs from the initial sampling in a research study when the criteria for the study participants are defined prior to commencing the data collection (inclusion and exclusion criteria for the sample have been outlined in section 4.5). Charmaz (2006:96) describes theoretical sampling as ‘seeking pertinent data to develop the emerging theory’ and notes that its purpose is ‘to elaborate and refine the categories constituting the theories’.

In this study, the process of theoretical sampling was undertaken. However, this process was not straightforward. The recruitment strategy for this study and the problems initially experienced with recruitment meant it was not possible to directly select participants for their views on transition; however, the inclusion of participants with ESKD regardless of treatment modality meant that a broad range of participants were accessed who varied in terms of characteristics.

Charmaz (2006) suggests that when questions arise from the data and when gaps are identified, the researcher should seek answers to the questions to close the gaps. A way of achieving this is to return to the research participants, or by seeking this information from other research participants. In the current study, participants were interviewed on one occasion; it would have proven difficult and posed additional ethical issues to undertake follow-up interviews with the participants to allow for theoretical sampling and conceptual issues to be explored. However, I did use theoretical sampling as a means of refining the categories that were emerging, and to develop these further in the study. This was achieved by noting initial categories identified in the interviews with participants in the earlier analysis and including these in subsequent interviews to facilitate their development and
saturation (Charmaz 2006). For example, a category I identified early in the data analysis process related to the participants’ interactions with health care professionals. In the analysis of the first interview, the participant referred to her experience of an interaction she had with several health care professionals and how she felt she was not being listened to. Theoretical sampling mandated that I check my ideas against the empirical realities within the data, moving between the category and the data (Charmaz 2006). Therefore, in my subsequent interviews with participants, I explored participants’ interactions with health care professionals and questioned them directly about aspects of their experience.

4.9.9. Theoretical saturation

Prior to commencement of the study, it was anticipated that approximately 15-20 participants would be required to yield in-depth data and establish credibility, thoroughness, and rigour. However, in this study, as in other grounded theory studies, it was difficult to determine a sample size at the start of the study as data collection continued until the data no longer revealed any new theoretical insights, or new properties of the core categories and theoretical saturation was achieved.

According to several authors, in qualitative studies the notion of saturation of categories supersedes that of sample size, meaning the samples for some studies may be quite small but still fulfil the requirements of the study itself; the richness of the data coming from the detailed descriptions and analysis of these rather than the volume of data produced determines the sample size (Charmaz 2006; Cutcliffe 2000; Higginbottom 2004; Puddephatt 2006; Sandelowski 1995). In the current study, despite the small sample, I noted that by interview twelve no new issues were emerging and I judged that theoretical saturation had been achieved. Throughout the analysis field notes and memos were recorded of my reflections on whether new
properties of the category were emerging so I could identify when no new issues were emerging, and saturation had been achieved.

4.9.10. Reflexivity

Reflexivity has been conceptualised and defined in many ways, but it often refers to the generalised practice in which researchers strive to make their influences on the research explicit (Mruck & Mey 2007; Guba & Lincoln 2005; Cutcliffe 2003; Pillow 2003; Finlay 2002). A key tenet of constructivist grounded theory is that researchers must adopt a reflexive approach and consider their contribution to the theory (Charmaz 2006; Gentle et al. 2014; Mallory 2001; Neill 2006). Consistent with the constructivist grounded theory approach, it was important to ensure that I was transparent about the subjective approach taken and the interpretations I made throughout the research process. While reflexivity is essential in any grounded theory study, in this study which involved people with advanced disease who were nearing the end of their lives reflexivity regarding the positioning of myself as the researcher was particularly significant as the participants represented a vulnerable group; critical reflexivity was therefore essential with regards to my presence and accountability in the research, but also in relation to the use of my prior experiences and knowledge (Clarke 2005).

Reflexivity started from the onset of the research process and pertained to my understanding and acknowledgement of my own values, beliefs and attitudes within the research process and how these may have influenced the study. Nagy Hesse-Biber (2007:326) outlined that reflexivity starts with the researcher asking the following questions ‘how does who I am impact on the research process and what shapes the questions I chose to study and my approach to studying them?’. Reflexivity involved me asking myself these questions, reflecting inwards on my own
experiences and perceptions of reality. My personal and professional experiences were all acknowledged as I brought to the research my own view of the world which included my views on palliative care for life-limiting illness including ESKD, my own experiences of this, of research processes, and palliative and end of life care research.

The research method I chose for this study strongly reflected my personal affinity with qualitative research approaches, in that I believe that individuals are themselves agents in conducting and defining their own realities and recognise there is no one truth. From a personal perspective, the work was informed by my experience as a palliative care nurse but also as a relative of a family member who lived with ESKD. I had previously worked as a palliative care nurse for many years, providing care for people who had a variety of end-stage, life-limiting illness including ESKD, in a variety of setting including acute hospitals, primary care, and specialist palliative care units. In more recent years I had been involved in the development and commissioning of service models for palliative care across all care settings which included specific service models in relation to palliative care. This experience meant I had a high degree of familiarity with providing palliative and end of life care across all care settings and specialities and was very comfortable discussing the issues associated with the end of life with people. This familiarity presented a potential risk in relation to assumptions I might make and that I might take for granted aspects of the process that the participants were engaged in during the research.

The methods of constructivist grounded theory are considered to be 'neutral', but by contrast, the researcher is not; the researcher plays a key role in the coding process by identifying relevant data (Charmaz, 2006). By using a constructivist approach, I was also able to reflect upon and consider my role in the process of gathering the
data in terms of coding, interview questions, and analysis. In this study, while the participant was the key informant, I posed the questions and identified specific areas to be explored. Consequently, my role was not neutral but rather my perspective was integral to the analysis process and emerging data; this is articulated by Charmaz (2006:178) as ‘researchers are part of what they study, not separate from it’. I recognised that the interview was an interactive relationship between myself as the research interviewer and the participants and that the theory which emerged from the study was itself a construction developed by myself as the researcher and the participants (Charmaz, 2005).

During the course of the study, I repeated considered the notion of ‘giving voice to the participants from their own perspectives’ (Clarke 2005:15). This was something I reflected on throughout the study when interpreting and presenting the data to ensure that I presented this in a way that ensured that the participants perspective was presented rather than presenting the data in a way that suited my own purposes. In presenting the data, I wanted to ensure that a sense of the individual participants and their accounts retained a degree of visibility in the text, ensuring that the reader was able to make connections with both the study findings and the data that these arose from. This also provided a way of demonstrating the value I placed on the participants’ contributions and by keeping their words intact in the process of analysis, their presence was maintained throughout the process (Mills et al. 2006).

Qualitative research studies are often criticised for their lack of objectivity and potential for researcher bias. Researcher bias was acknowledged by myself as the researcher in this study and I was cognizant of how I, as the researcher influenced the inquiry. By adopting a reflexive stance I sought to mediate the potential for this bias, scrutinising my experiences, decisions and interpretations, ensuring these
were transparent and explicit throughout the research process. By using reflexivity in this study it offered me a methodological basis for enhancing the objectivity of the study finding.

4.9.11. Theoretical sensitivity as a form of reflexivity

Several researchers have highlighted the congruence of reflexivity with grounded theory and the ways in which aspects of reflexivity are already inherent in grounded theory, especially according to the constructivist approach. Hall and Callery (2001:263) suggest that ‘reflexivity already exists in grounded theory research since theoretical sensitivity emphasises the reflective use of self in the process of development of research questions and doing analysis’. Theoretical sensitivity relates to the grounded theory practices of bringing the researchers background to bear on the study (Glaser 1978); it is the researcher’s experience, understanding, knowledge, and skill which fosters the development of the categories. Theoretical sensitivity allows the researcher to develop a theory that is grounded, conceptually dense and well-integrated (Strauss & Corbin 1990). Glaser believed that theoretical sensitivity could be attained through immersion in the data, line by line comparison, memo by memo, and code by code (Glaser 1978).

Theoretical sensitivity was achieved in this study by using the constant comparative method throughout the data collection process and a thorough review of the literature. Theoretical sensitivity was enhanced through the constant comparison method by assisting me to think about the concepts, categories, and their properties during the data collection via the interviews with participants, data analysis and memo writing which occurred simultaneously during the cyclical research process (Jeon 2004).
4.10. Ethical consideration and challenges

4.10.1. Ethics Committee Review

The study was submitted to National Research Ethics Service (NRES) in December 2013 for ethical consideration and approval. The initial feedback from the Committee was that they would be content to give a favourable ethical opinion of the research, subject to the following:

- Provide the committee with an independent peer review.
- The interview guide contains a specific question relating to participants’ palliative care experience.
- Provide the Committee with the correspondence from the Acute Hospital Trust confirming they were happy to be the lead NHS R&D.
- The Patient Information Sheet be revised to include:
  - Make it clear that the study is about the experience of living with End Stage Renal Disease.
  - The title should include the wording ‘palliative care’.
  - An introductory paragraph introducing the researcher be included.

Following these amendments being made, ethical approval was granted in May 2013 and a formal letter offering a favourable opinion for the research project was provided (Appendix 7). Gardiner et al. (2011) have described how palliative care research is susceptible to ethical committee challenge linked to the association that patients might make to particular terminology. In this study, the Ethics Committee specified that all paperwork must make clear reference to palliative care so that the highest level of transparency of the purpose of the study could be afforded to participants. I was conscious that use of the wording ‘palliative care’ may not be a term easily comprehended by potential participants. However, during my initial
contact with potential participants to discuss the study with them, several clearly articulated their understanding of the term making comments such as ‘palliative care, well, that’s about dying isn’t it’.

The request for an independent peer review was problematic; it was difficult to identify someone who fulfilled the requirements set out by the Committee as the review had to be carried out by an academic in the field of palliative care whom I had no affiliation to which limited the potential reviewers I could approach. With support from my supervisor, an appropriate academic was finally identified to undertake this review and provide a critique of the proposed research study and a favourable response was given following this peer review process.

Following NRES ethical approval, ethical approval was granted by the Research and Development Committee at the acute NHS Trust where the study would take place. The University Ethics Committee also granted approval for the study. As I worked in a neighbouring Trust within the same locality as the study site, the Research and Development department at the acute NHS Trust confirmed that I did not need an honorary contract or a Disclosure and Barring Service (DBS) clearance prior to being able to access the research site. I was granted a letter of access to the acute NHS Trust which provided me with access to potential participants at the Trust for a period of one year.

In this study the ethical principles of respect for autonomy, non-maleficence, and beneficence (Beauchamp & Childress 2013) guided the study design and the ethical processes implemented within the study in relation to the process of consent, maintaining anonymity and confidentiality, and protecting participants from harm and distress during the interview process.
4.10.2. Respect for autonomy

Undertaking research in a palliative care setting requires sensitivity as patients are often highly vulnerable, both physically and psychologically. Although undertaking research with patients who are approaching the end of life raises ethical issues, it should not be assumed that people nearing the end of their lives will not want to engage in research. It has been suggested that rather than arguing whether certain groups should be included in research studies, it is more ethical to ask whether it is justifiable to leave certain groups out and exclude them from research (Bradburn & Maher 2005; Gillies & Alldred 2002). Within the context of palliative care, several authors have highlighted that preventing vulnerable people from being recruited into a study is denying them the basic right to autonomy, the right to decide for themselves whether or not to participate; it also exposes them to the risk of marginalisation (Dean & McClement 2002; Gysel et al. 2008; Kendall et al. 2007; Stevens et al. 2003).

There is evidence within the current literature that not only is research among vulnerable populations unlikely to result in harm, there is also often benefits to be gained by participation which can have a cathartic effect for respondents by them sharing their experience (Barnett 2001; Casarett & Karlawish 2001; Gysel et al. 2008; McFartick et al. 2006). Indeed, in this study, once I gained access to potential participants, they were keen to take part in the study despite having explained to them that there would be no direct benefits to themselves by agreeing to participate. Several participants expressed that they had found the process of being interviewed useful to them. It had enabled them to discuss things they had not discussed previously, expressing that as I was a stranger, not connected to their care in any way, they could just 'say what they were thinking' and did not have to 'worry about offending or upsetting me'. Others expressed that they hoped that what they had
told me had been helpful to my study and they hoped that telling their story would help other people in some small way. Other studies have also demonstrated that despite there being no benefit to the individual, patients perceived as ‘vulnerable’ have a willingness to participate in research with the hope of the potential to benefit others (Alexander 2010).

4.10.3. The process of seeking informed consent

The ethical principle of respect for autonomy underpins the notion of informed consent. The decision to take part in a study should be taken voluntarily, in the complete knowledge of what the implications would be for the participant and that those agreeing to take part should not feel compelled to do so (Green & Thorgood 2004). In this study, individuals were enabled to make an informed decision in several ways. Each participant was given a Patient Information Sheet (PIS) setting out the purpose of the study, the reasons for being invited to participate, the reassurance that they were not obliged to participate, and that opting not to take part in the study would not affect any aspect of their current or future provision of health care. Those invited to participate were also given time to consider whether or not to take part, which also enabled them to discuss the study with others prior to making a decision. A contact telephone number was provided should they require any additional information and was included in the PTS given to each potential participant (Appendix 1). Prior to formally commencing the interviews, the consent form was discussed, and participants were invited to raise any concerns about the study. The consent form confirmed agreement to participate, indicating that they had read and understood the patient information sheet and understood that the interview would be audiotaped but all information would be kept securely and participant identifiable information would be anonymised (Appendix 8).
4.10.4. Principles of non-maleficence

All researchers must ensure that 'the dignity, rights and wellbeing of the participants must be the primary consideration of any research study' (the Research Governance Framework for Health and Social Care, Department of Health 2005b:11). The ethical principal of 'non-maleficence; first, do no harm' was the paramount consideration for me throughout the research process. I was conscious that the topic of the experience of transitions for people with ESKD who were approaching the end of their lives might raise potentially distressing and sensitive issues. Specific steps were taken in the development of the study design and implementation process to ensure that participants were protected from harm at all times.

Several steps were adopted to protect the participants during the study. Initial contact with potential participants was made by the renal team involved in the participant’s care. In acting as an independent gatekeeper, the renal staff provided prospective participants with the initial information about the study and obtained agreement for me to contact them to discuss the research in more detail. As these gatekeepers were involved in caring for the individual patient participant, they had a good understanding of the participant’s current condition and suitability for the initial contact with myself. As the potential participant already had a relationship with the renal team, it was perceived that it would be easier for them to decline any further discussion regarding participation in the study. Additionally, as part of the consent process participants were reminded of their right to withdraw from the study at any time which included during the interview itself, that provision of health care would not be compromised and that the information they shared would remain confidential. Following the interview, participants were offered the opportunity to receive a summary of the interview, but all declined.
I had previously undertaken a research study with cancer patients who were in the end stages of their illness and had experience of the potential for participants to become distressed during the interview. I was alert to the possibility of this happening with participants in the current study and was vigilant throughout the interview to observe for both verbal and non-verbal cues that the participant may be finding the interview tiring or distressing. I regularly checked and confirmed with participants that they were happy to continue the interview, reminding them they could call a stop to it at any time. Although I had anticipated that participants might become distressed during the interview, this did not occur during the interviews carried out as part of this study. However, as part of the planning process and ethics submission for this study I had already considered what action I would take had this happened in the interview. If a participant had become distressed during the interview, I would have stopped the interview, offered immediate support and contacted a member of the renal multi-disciplinary team who cared for the patient to ensure ongoing support was available following the interview, including access to counselling support if this was required. At the end of each interview, I conducted a debrief with the participant, part of this included summarising the interview, answering any questions they had, and seeking assurance that there was no one they wanted me to contact following the interview.

4.10.5. Participant confidentiality and anonymity

All participants were assured anonymity and confidentiality prior to the commencement of the interview. This was explained to each participant, and I also outlined that the only exception to this would be if, as part of the interview they divulged that they or someone else was at significant risk of harm. In such an instance, I would, as a nurse have been bound by my own professional body, the
Nursing and Midwifery Council (NMC) and I would have acted in accordance with this code which specifies that I must:

'put the interests of people using or needing nursing first....... make their care and safety your main concern and make sure their dignity is preserved, and their needs are met, assessed and responded to' (NMC 2015:4).

The confidentiality of the participants was also assured when documenting the findings of the research. All interview transcriptions were stored on an NHS encrypted computer during data analysis, and tape recordings were destroyed following this transcription. All research data were kept in a locked cupboard in my NHS work office. The transcripts were given an identifying number, and names or other identifying features were removed, with participants allocated a pseudonym. The location of the acute NHS Trust which served as the recruitment site was also anonymised to maintain confidentiality.

4.11. Ensuring rigour in this grounded theory study

Qualitative research has been criticised for being overly subjective and not open to scrutiny. This has led to considerable debate within the field of qualitative research concerning the most appropriate criteria and terms to adopt when evaluating such studies (Charmaz 2006; Hutchinson & Wilson 2001; Lincoln & Guba 2005; Morse & Richards 2002; Sandelowski 1993). There are a variety of frameworks and criteria for assessing rigour in qualitative studies. Hutchinson and Wilson (2001) purport that researchers using grounded theory methods must ensure that the issues of believability and rigour in their research are addressed outlining that a quality grounded theory has codes that fit the data and the practice areas for which it is derived. Having considered which framework to use to guide the evaluation, I chose
Hutchinson and Wilson (2001) framework to address the issues of rigour in this study. The framework consists of three criteria: credibility, auditability, and fittingness. The rigour of this study is now discussed with reference to the three criteria.

4.11.1. Credibility

Credibility denotes the trustworthiness of the entire research process. According to Charmaz (2006), credibility is concerned with whether the results are plausible in terms of the data presented, the analysis, the evidence presented or claims made and the breadth of data gathered.

The research presented familiarity with the research topic through the presentation of the literature review relating to ESKD, end of life transitions, and transitional theory. The study presented new insight into the transitions experienced by people with ESKD as they approach the end of their lives and how they make sense of this. This was discussed with reference to the existing research and the implications in relation to this study took into account the existing literature and alongside the new findings in the study. The study sample consisted of people with ESKD deemed to be approaching the end of their lives who were receiving dialysis or conservative care, had a variety of co-morbidities and a varied duration of illness; this provided a broad perspective.

Twelve in-depth qualitative interviews were undertaken with participants with ESKD during data collection. To facilitate depth to the data, I conducted the interviews in a location which suited the participants; typically, this was their homes. The interviews lasted on average around sixty-ninety minutes, and so facilitated a relatively lengthy interview with sufficient time to explore areas of relevance to the
participants, covering a broad range of topics. In order to gauge the depth of the data gathered, the preliminary codes and categories were discussed on an ongoing basis with my supervisor to discuss the emerging categories.

Charmaz (2006) points to the assessment of the breadth and depth of the data and whether the categories are saturated, thus meaning that the fullness of the studied experience is represented. This was demonstrated in the current study in a number of ways. Firstly, by the end of the data collection period, no new issues regarding the research topic were being raised in the interviews and theoretical saturation was deemed to have been achieved, this was despite the small sample size. The process of constant comparison was also employed to compare different categories as they emerged throughout the data collection and analysis process. Lastly, the emerging data in the study were considered against existing literature on ESKD, end of life care and transitions; this enabled me to draw upon key concepts within the existing research and build upon these existing studies.

The issue of transferability was also examined with respect to this study. A study that uses a sample size that is too small may have unique and particular findings such that its qualitative transferability becomes questionable, and group differences may not be detected when they actually exist. Despite the small sample size in this study, the study sample provided in-depth data, achieved theoretical saturation and identified theoretical ideas that merit further exploration (these are discussed in the recommendations section). In order to assess the extent to which the study may be true of people in other settings, I returned to the literature within the research area again during the discussion of the research findings.
4.11.2. Auditability

Auditability relates to the extent to which future research would yield similar results if the same methods were applied. It relates to the consistency of findings, meaning that another researcher could clearly follow the trial used to analysis the data, they could follow the decision making and thought processes used in the study and develop a comparable conclusion (Chiovitti & Piran 2003; Sandelowski 1986). The steps taken throughout the data collection and analysis process have been clearly described to facilitate the readers understanding of the criteria I used to formulate my thinking and detail how and why the participants in the study were chosen. I kept a research journal throughout the research study to record field notes, memos, and reflections of my observations during the interview and analysis process. Examples of memos, field notes, diagramming and coding are provided for the reader in the presentation of the data analysis process.

4.11.3. Fittingness

Fittingness indicates whether the findings of a study are meaningful and applicable to readers in terms of their experiences and whether the findings are a reflection of the life experiences being explored. This can be achieved by checking the data collected for fit by providing feedback to participants; this is referred to as member checking (Guba & Lincoln 2005). In this study, at the end of each interview, the key issues raised by the participant were summarised verbally by myself and fed back to the participant to check that my understanding of their perspective was correct. In this way, participants were afforded the opportunity to amend or add to my summary.

Chiovitti and Piran (2003), advised that fittingness can be accomplished by delineating the scope of the study in terms of the sample, setting and level of theory
by describing how the current literature relates to each category which emerges in the generation of the theory in a study. In the present study, this is explored in the discussion in chapter 6, when categories are compared with the existing knowledge, theory, and research.

4.12. Summary of the chapter

This chapter has provided a discussion on constructivist grounded theory and the rationale for its choice as the methodology for the study. The design of the study, the strategies employed with regards to the recruitment of participants, data collection, data management and data analysis have been discussed, alongside the ethical principles applied and challenges relevant to the study. The research methods employed in the study were in accordance with the constructivist grounded theory approach which also provided the structure to guide the process of analysis (Charmaz, 2006). The procedures which were taken to ensure the rigour and the credibility of the study are presented, taking into account the debates within qualitative research. The next chapter presents the findings of the research study, the categories, and theoretical insights which emerged from the data analysis. The substantive theory which developed from the analysis is also presented.
CHAPTER 5
THE FINDINGS

5.1. Introduction

This chapter presents the findings from the study. Following the principles of constructivist grounded theory (Charmaz 2006) the core category, categories and sub-categories within these are identified. Constructs in this study emerged from the constant comparison analysis and conceptualisation of the data derived from the twelve patient participant interviews. Data analysis was a complex process; data were constantly visited and re-visited during the data collection and analysis as the categories emerged, ensuring the findings of the study were clearly grounded in the data.

A summary of the participants' demographic information is presented. This is followed by the presentation of the core category and the three interrelated conceptual categories and their sub-categories which emerged from the data and form the basis of the emergent theory. An overview of the substantive theory which emerged from the integration of the categories is presented; the relationship between the conceptual categories is examined and made explicit in relation to the construct of this theory.

Throughout the presentation of the findings exemplar participant quotes, theoretical notes and memos are used to provide rich descriptions and to contextualise the categories emerging from the data analysis. The participants' quotes have been anonymised and pseudonyms used. Relevant literature was interwoven into the findings thus contributing to the process of the evolving grounded theory. In addition, the literature was also used to help clarify ideas, to make comparisons, to further theoretical discussion, and show how and where this work fits or extends relevant
literature' (Charmaz 2006:167). A more extensive engagement with the literature, a deeper analysis and interpretation is presented as part of the discussion in chapter six.

5.2. Demographics of participants

Basic demographic information consisting of the participants' age, sex, marital status, duration of illness (as defined by the individual), current treatment and any comorbidities were collected before the interview commenced. Interviews were undertaken with twelve people who had end-stage kidney disease (ESKD) who met the inclusion criteria outlined for the study. Written consent was obtained from each participant prior to the commencement of the interview. The demographic details of the twelve participants are shown below:

Table 3: Demographics of the Participants in the Study

<table>
<thead>
<tr>
<th>Name *</th>
<th>Gender (M/F)</th>
<th>Age</th>
<th>Treatment Modality</th>
<th>Duration of Illness Co-morbidities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jack</td>
<td>M</td>
<td>73</td>
<td>Conservative (unable to have dialysis)</td>
<td>3 Cardiac, Diabetes</td>
</tr>
<tr>
<td>Dorothy Alan</td>
<td>F</td>
<td>81</td>
<td>Dialysis</td>
<td>4 Cardiac</td>
</tr>
<tr>
<td>Alan</td>
<td>M</td>
<td>89</td>
<td>Conservative</td>
<td>2 Nil</td>
</tr>
<tr>
<td>Rebecca</td>
<td>F</td>
<td>85</td>
<td>Conservative</td>
<td>4 Cancer</td>
</tr>
<tr>
<td>Gladys Jane</td>
<td>F</td>
<td>81</td>
<td>Conservative</td>
<td>2 Nil</td>
</tr>
<tr>
<td>Jane</td>
<td>F</td>
<td>73</td>
<td>Conservative</td>
<td>1 Diabetes</td>
</tr>
<tr>
<td>Leonard Norman</td>
<td>M</td>
<td>73</td>
<td>Dialysis</td>
<td>4 Cancer</td>
</tr>
<tr>
<td>Irene</td>
<td>M</td>
<td>63</td>
<td>Dialysis</td>
<td>10 Cardiac</td>
</tr>
<tr>
<td>Angela John</td>
<td>F</td>
<td>86</td>
<td>Conservative</td>
<td>3 Diabetes</td>
</tr>
<tr>
<td>Amanda</td>
<td>F</td>
<td>67</td>
<td>Dialysis</td>
<td>4 Nil</td>
</tr>
</tbody>
</table>

(*All names used were pseudonyms to ensure anonymity was maintained for study participants)

The study sample consisted of seven females and five male participants; six were married, four were widowed, and two were single. All participants were of white British, Irish or European ethnic origin. The mean age of participant was 77.5 years
(range 63-89 years). The duration of the time since diagnosis was defined by the participants and often articulated in relation to the time they had been under the care of the renal team at the acute NHS Trust. The duration of the illness was not confirmed by the researcher as I did not access the participants’ medical notes or seek clarification from the renal team. Of the twelve participants in this study, two articulated that they had been unable to have haemodialysis due to the extent of their underlying comorbidities, however, one of these participants had been offered peritoneal dialysis and had refused this. This meant that a total of eleven of the twelve participants had been offered renal replacement therapy (RRT), whether haemodialysis or peritoneal dialysis and seven of these participants had declined RTT and chosen conservative management of their ESKD; four participants were receiving dialysis at the time of being interviewed. Participants receiving dialysis were experiencing increasing difficulties undertaking treatment.

5.3. Core category, categories and subcategories.

Three categories and the subcategories within these emerged from the data. These categories were: striving to maintain autonomy and control in decision making, managing uncertainty: knowing without clarity or confirmation, and the importance of virtues in transitioning through the illness. The core category which emerged from the analysis in this grounded theory study was conceptualised as restructuring reality. The emergent categories, subcategories, and core category are represented below:
5.4. Category 1: Striving to maintain autonomy and control in decision-making

*Striving to maintain a sense of autonomy and control in decision making* throughout the illness trajectory was identified as a category from the data analysis. Decisions described by participants as significant and requiring their explicit involvement were those decisions which influenced how they lived their remaining life; these commenced earlier in the illness trajectory and continued as their illness deteriorated and they recognised that they were limited in relation to the time they had left. Three subcategories were identified relating to the category of *striving to maintain autonomy and control in decision making*, these subcategories appeared crucial to the participants’ perceptions of their quality of remaining life and influenced...
the transitional experience for participants as their illness had progressed and their health had deteriorated. The three subcategories were: factors influencing initial treatment decisions making, negotiating and compromising on involvement in ongoing decision making about care, and planning for the end of life.

5.4.1. Factors influencing initial treatment decision making

The first sub-category which related to the category striving to maintain autonomy and control in decision making was: factors influencing initial treatment decision making. Exercising autonomy and having a perceived sense of control by actively participating in decision making was considered important by participants. This commenced earlier in the illness when participants had to make choices relating to whether to commence renal replacement therapy (RRT) or opt to be conservatively managed for their ESKD. As their illness progressed, participants reflected on the treatment decisions they had made earlier in their illness in an attempt to evaluate the impact of these decisions on their lives.

In this study, seven of the participants had chosen to be managed conservatively despite being offered renal replacement therapy (RRT). These participants described how they felt that they had been given the information and support to make these decisions, but it had been ‘down to them’ to make the final decision about treatment and they felt that they had made the best decision for them. This is illustrated in the following quotation from a participant, Angela who had been offered dialysis but had made the decision to managed conservatively for her ESKD:

‘No, I did say I didn’t want treatment. You know, having to go up to the hospital all the time at my age, no, I didn’t want to be like that, you know on dialysis. I didn’t want anything like that! I told them that when the nurse came to see me and talk to me over that. We went through it all, but I told her ‘that’s not for me that. No, I’ll just carry on doing what I’m doing, carry on like that and hope I don’t get any problems, well, not for a while anyhow’, that’s what I told her.’
For Angela, the decision to forego dialysis was influenced by her thoughts of ‘having to go up to the hospital all the time at my age’, she preferred to refrain from treatment opting to address any problems with her illness as they arose. The need for repeated attendance at the hospital and making reference to one’s age were frequently articulated as factors considered by participants in relation to their decisions about commencing or foregoing dialysis.

The interplay between other aspects of the participants’ lives which they deemed important and the influence of these on their decision making relating to treatment options emerged from the analysis of the participant narratives. Another participant also recalled the discussion she had about her treatment options and how she had made her decision to forego dialysis as Jane explained:

‘Yes, I couldn’t have dialysis, not the one in your vein, you know. Well, that one was out anyway, I’ve hardly any veins for the dialysis. He did tell me that, my own doctor when he said about it. And the other one, there’s another dialysis………..oh, what’s it called? You know, it’s something you do at night, it goes in your tummy. But, um, ……..the one for the night thing, um, there’s no one to do it or anything for me, you know, I wouldn’t have been able to stay at home anymore, I’d have to leave my home, and I didn’t want to do that’.  

For Jane, the available dialysis treatment was unacceptable to her as it would have meant having to sacrifice her independence and impacted on her perceived quality of life as it would also have meant she had to give up living in her own home. For participants, there was not a pre-requisite for treatment at any cost. Rather, as part of the decision-making around treatment options participants reflected on the information and discussions they had with health care professionals about these options and considered these alongside other aspects of their lives which were important to them. Their decisions were often based on the consideration of what they were willing to ‘accept’ and the ‘compromises’ they were willing to
accommodate into their lives rather than any perceived potential benefits or increased longevity from treatment.

For one participant, a decision regarding treatment had been negated by his poor health status and advanced stages of his co-morbidities meaning that dialysis had not been an option. Despite this, he still emphasised how he felt he had very much been involved in the discussions about this decision and understood the reason for the decision being made. This is illustrated by Jack’s explanation:

‘I mean, basically, they can’t do anything else. I couldn’t have a transplant, I couldn’t have dialysis, Dr X explained all that to me, with what’s wrong with me and all that. So, um, all it is keep, well, looking after me, that’s it. I mean there’s not just one thing going on. I mean I can’t walk, that’s my diabetes, that’s the top and bottom of it, and I’d get too out of breath, because of the heart and the kidneys’.

The existence of co-morbidities had been an important consideration for other participants in the decision-making process as they contemplated whether dialysis would improve their overall health or perceived quality of life. Participants used terms such as ‘there’s not just one thing wrong with me’, ‘I’ve got so much going on with me’, and, ‘then there’s the cancer’, to emphasise that decisions regarding treatment were not just influenced by the diagnosis of ESKD. In making the decision participants weighed up the potential benefits they perceived dialysis afforded which included the possibility of prolongation of life against the impact of co-morbidities which would remain unchanged with or without dialysis. Another participant, John, described how he had been offered the option of dialysis but had decided to be managed conservatively.

‘I think really they suggested dialysis but I, I didn’t want that. It’s a difficult one when you know that if you have it, you might live a little bit longer………But, well, I refused because of my age and because it’s my legs and back you see, the dialysis wouldn’t be a big help to me really. I’m 88 now, so, as I said, I’m well, I don’t know, I’m as well as I can be regarding, um, how I am. When we went into it, it was my own decision, and I said, “no, I think I’m alright as I am”.'
I mean it’s not going to help my legs is it, it’s not going to make me better, I’m still going to die’. No, I’ve had a good life’.

For John, the decision not to have dialysis had again been multi-factorial as he considered his age, his co-morbidities and his current quality of life. His narrative also illustrated that his decision was influenced by an acknowledgement that the dialysis would not change the outcome in relation to his death. This futility of treatment’ was highlighted by other participants as a contributing factor influencing their decision making concerning the acceptability of treatment for their ESKD; choosing dialysis did not change the overall outcome for them and was therefore not the major factor in their considerations when deciding on treatment options. This is illustrated in the following extract by Rebecca, when she described her decision not to commence dialysis:

‘I just didn’t want it... it’s not for me because what happens, you still die at the end, so you might as well choose.... the choice you’ve made’.

The futility of treatment was also expressed by those participants who had previously opted for dialysis treatment describing this as ‘dialysis or no dialysis the outcome is still death’. They recognised that the dialysis was life-prolonging, but that life on dialysis still meant a limited prognosis as illustrated by a participant, Norman, in the following extract:

‘When they told, me I had the kidney problem, they told me I wouldn’t be able to go on the transplant list, so, well............so that was it, dialysis or nothing for me! I wasn’t ready for nothing, that wasn’t something I thought about, I mean, not having the dialysis would have been me giving up, wouldn’t it? So, that was it, it was dialysis. I’m not daft, I know that in the end, well, dialysis or no dialysis I’m still going to die from this but that was the only decision I could make at the time. Would I do it different now, I’m not sure, I did what I did and I’m living with that now’.

Norman perceived that not choosing dialysis would have meant accepting that he was going to die and at the time this was not something he could contemplate. As
Norman reflected on these decisions years later as his illness had progressed, he now resigned himself to the outcome of his illness regardless of dialysis. Participants receiving dialysis in the current study did not regret the decision to commence dialysis; rather they felt it was a decision they had made which they now lived with the consequences of. This finding contrasts with the findings of a previous study by Davison (2010) who found that 60% of patients who started dialysis later regretted the decision to commence dialysis.

The present study finding highlighted that participants’ decisions to commence or forego dialysis were often less based on the perceived longevity that might accompany dialysis and related more to participants’ perceived quality of life, personal preferences, and what compromises they were willing to make. Those participants who chose to forego dialysis also tended to be older. These findings support those of previous studies which explored the factors associated with patients’ decisions to commence or forego dialysis. In previous studies, the reasons for refusing dialysis included: the arduous nature of dialysis, having to attend hospital three times weekly for treatment, and patients with ESKD perceiving they were too old (Johnston & Noble 2012; Noble 2009; Visser et al. 2009). In contrast to the previous studies, participants in the current study also consistently outlined that the presence of comorbidities played a significant contribution to their decision making to forego dialysis.

As their health deteriorated, participants had reflected on the decisions they had made earlier in their illness trajectory to commence or forego dialysis. They re-evaluated these decisions and the impact of them on their lives using terms such as ‘I don’t seem to have suffered from the decisions I’ve made’, ‘I’m still here’, and ‘I think I’ve done okay” when reflecting on these treatment choices. While participants considered that these decisions had been made autonomously and very much theirs
to own, they had been made in discussion with and the support of their families. Often, later in their illness trajectory participants sought re-confirmation from the health care team caring for them that these decisions had been the right one for them. This was demonstrated by one participant Rebecca who had been diagnosed over four years earlier with ESKD:

‘Yes, it’s entirely a personal choice and … I talked it over with my son. He obviously said to me ‘mum, it’s your decision, it’s your life’ he said, ‘but whatever you do, we’re behind you’. He said, ‘we’ll agree with whatever you do; it’s what you want’. And… I’ve got one sister, she’s down south but I talked it over with her, and so, knowing me, she thought I was doing the right thing…..so and then Dr X said ‘I think you’ve made the right decision’ and, er, ……..everyone thought, thought I’d done right, then I felt alright…..But it is a big decision to make, when you know you could go on it. When you could live a little longer. But then, knowing I’ve got cancer …….Um, well………..well for me it was the softer thing, you know. I could live my life as I wanted, sort of thing’.

In summary, participants felt that they exercised personal autonomy in making the decisions about whether to commence or forego dialysis and be conservatively managed but felt they were supported by family and health care professionals in this process. Their decisions were influenced by factors which included the participant’s perception of their age in relation to the appropriateness of commencing dialysis, their comorbidities, perceived quality of life and personal preferences. Decision making was often based on the consideration of what participants were willing to tolerate concerning the disruption to their lives and the compromises they were willing to accommodate into their lives as a consequence of dialysis rather than any perceived potential benefits from treatment. The futility of treatment was also highlighted by participants as a factor in the treatment decision making as they often perceived that choosing dialysis did not change the overall outcome of their illness trajectory and was therefore not a key factor for a majority of participants when deciding on treatment options. Despite the time that had lapsed since these treatment decisions first being made, as their illness progressed
participants reflected on these decisions and sought reassurance from other as well as reassuring themselves that they had made the right decision.

5.4.2. Negotiating and compromising on involvement in ongoing decision making about care

The second sub-category that related to striving to maintain autonomy and control in decision making, was negotiating and compromising on involvement in ongoing decision making about care. Participants continued to strive to make autonomous decisions relating to their health and life throughout their disease trajectory. There was an emphasis on remaining involved in the decision-making process relating to ongoing care. This involvement was particularly significant as their condition deteriorated and they recognised that they were limited in relation to the time and energy they had left. This focused their decision making on the allocation of both time and energy for priority activities they wanted to undertake. There were numerous decisions that participants had to negotiate and compromise on regarding daily life and on-going care as their illness progressed.

Decision making which enabled participants to remain at home despite their deteriorating physical health and functioning was particularly important to them as they struggled to maintain a sense of autonomy and control in decisions relating to this aspect of their care. Many had had to make significant compromises and accommodate changes in their lives which they previously would have found unacceptable in order to achieve their goal of remaining in their own homes. These compromises often involved relying on others to achieve these goals; this is illustrated by the following extract from a participant Jane:

‘I so wanted to be at home; I had to really push for that. They weren’t keen to let me go. They told me I wouldn’t be able to get out of bed; I can’t move you
see and because I live on my own, they said it wouldn't be safe me sitting in the chair on my own until the carers came in. When I came out of hospital they told me the hours the carers come in, but it didn't suit the meals; it was no good at all, but I wanted to be at home. So, my brother comes to give me my breakfast, then they come in and give me a top up. Then they do dinner ........and empty my catheter bag......... Then they come in at 3 o'clock, you see, teatime for them is 3 o'clock. That's ridiculous, that's what I told them. I said, 'I'm used to having my tea at 6 o'clock', but now I have it at 3 o'clock! But at least I'm at home'.

For Jane making choices which enabled her to live with her illness as it progressed were important to her and her illness experience. She maintained a sense of control and involvement in relation to decision making; her perceived independence was not defined by her level of physical disability but rather in her ability to continue to make decisions about her care.

Participants frequently evaluated the acceptability of the medical advice and care given to them; how this aligned with their daily lifestyle and activities was significant to them. Restrictions placed on participants which they perceived had not paid adequate consideration to the impact of these on their lives were often challenged. Participants used terms such as 'unable to tolerate', 'unacceptable to me' and 'it's me that has to live with it' when reflecting on this. One participant, Gladys, described how the renal team had put her on a low sodium diet and the impact of this for her:

'When I saw the renal doctor up at the hospital, he talked about putting me on this low sodium diet because I'd not been doing great. He gave me all this information that told me all about it, what you can have, what you can't, that sort of thing. That's all very fine, but when I started to try to stick to it, it was too much. I couldn't have this, and I couldn't have that................I just couldn't tolerate that. It was silly! I already had trouble with me appetite anyway; I didn't eat much. But this meant I couldn't eat any of the things I liked. I'd be eating nothing if I'd stuck to that. So, I told my own doctor.....I said to him 'I'm not having this, they can forget it'. So, we decided that it could stop'.

Despite the medical team’s intention of improving her symptoms, Gladys found that she was unwilling to ‘tolerate’ the restrictions imposed by this as it did not fit her lifestyle or improve the quality of her life. Involvement in decisions relating to
ongoing care often meant participants negotiating with the health care professionals involved in their care to reach an agreement on the acceptability of these plans of care.

The rights of patients to make decisions and choose treatment according to their own values and goals, and the responsibility of health care professionals to respect this has long been affirmed (Bartholome 1992; Beauchamp & Childress 2013). However, participants often felt that when they decided not to adhere to the medical advice given this earned them the label of being non-compliant. This is demonstrated in the following data extract from a participant, Rebecca who said:

“Well, it wasn’t long ago my legs had got really bad, and a different doctor came and wanted me to go in [to the hospital], she said, ‘go and get some investigations into your feet’. But I’ve suffered with bad circulation all my life, and I said, ‘no’. With the kidney problem, what could they do? She said, ‘well we can’t help you, unless you go in and find out what’s causing it, ..........we can’t help you unless you go in’. I said, ‘I’m very sorry, I know it’s against you, you’re wanting to send me in, but I don’t want to go, I’m not going’. She wasn’t listening to what I was saying. Well, I’ve never set eyes on any of them since’.

Challenging the decision of the health care professional was uncomfortable for Rebecca who described this as ‘going against’ the doctor’s request but demonstrated that she perceived a lack of involvement in decision making, being excluded from the process and not listened to. It also showed that by challenging the doctor’s decision she felt frustrated by her opinions not being listened to and abandoned, having had no further interactions with the doctor or team at her local health centre. Rebecca’s preference was to remain in control of decision making particularly when the information she received did not fit with her life.

Rebecca’s experience resonated with other participants in the study, who had all experienced feelings of frustration about their ability to be involved in decision-making at some time during their illness. However, unlike Rebecca, for the other
participants, control of the decision itself was less important for these individuals than being involved in the decision-making process itself. As their health deteriorated participants’ perception of involvement in decision making related less to whether they actually made the decisions and were more concerned with the health care professionals approached, how health care professionals shared information and how decision making was managed. This is illustrated in the following extract from a participant, Alan, whose health had deteriorated and who was struggling to remain independent:

“When I got out of the hospital, I really wasn’t good at all. I was so weak you see, and I just couldn’t get up, not really. I’d always been okay before, I mean I’d looked after my wife when she had dementia, I’d not had any help or that. The district nurse came in to do my injection; she could see how weak I was. She said, ‘now Alan, I think you ought to have someone come in, to help you out, get you up and that’. You know to check I was alright. Anyway, we decided she’d get in touch with social services, …So she did, and now they come in and help me wash and that, check I’m alright and eating, and I’ve got this [pendant alarm] so if I fall they’ll know that. They’ve put something outside for the key so they can get in. So, that’s all very good’.

Although Alan had struggled to maintain his independence, as his illness progressed, the perceived control over decision making was less critical than the involvement in the decision making itself.

Participants continued to feel engaged and involved in decisions regarding their care when a health professional they trusted had explained the rationale for the decisions, and they understood the explanation. Participants used terms such as ‘we’re trying’ or ‘we’ve decided’ to articulate this and implied that they very much viewed decision making as a partnership with these trusted health care professionals. Another participant, Jack, articulates this when he described his relationship with the consultant responsible for his care:

‘I can ask him things, and he’ll tell me anything, anything you want to know. He lets me know what’s going on; he explains things, what’s happening with my
blood tests. He listens to what’s been happening, tells me what’ll help. At the moment we’re trying the Aranesp injections more often, I’ve felt better since we made that change. I trust him implicitly; what he tells me I’ll do.

Jack felt very much involved in the decision making regarding his care. He trusted the renal consultant and felt involved in his care using the term ‘we’re’ to describe how the decisions were shared by himself and his renal team. As the illness progressed, there was a transition in relation to participants’ perceived desire for control over decision making to one which participants perceived very much as shared decision making. This contrasted with the autonomy and control over decisions expressed by participants when they reflected on the treatment decisions made earlier in their disease trajectory which they very much felt they owned. However, the involvement in decision making did contribute to the sense of still having some control and enabled participants to maintain a sense of competence and influence in relation to ongoing care decisions.

As the illness progressed participants strived to retain involvement in decisions made about their care, with control being perceived as less important than it had been earlier in their illness trajectory. Participating in decision-making about ongoing care, involved a process of negotiation in relation to the acceptability of care options and significant compromises, but feeling listened to and included in the process, with health professionals they trusted enabled participants to continue to feel they exercised a degree of personal autonomy despite an increasing physical dependency.

5.4.3. Planning for the end of life

Striving to maintain autonomy and control in decision making included the subcategory: planning for the end of life. This planning focused on the practical
elements associated with arrangements after death. Participants felt they had to sort things out and tie up all the ‘loose ends’ for their families so they would not have to concern themselves with this after their death. While some participants had not yet made plans, they articulated that this was something they did want to do. They expressed how they felt a ‘responsibility’ and ‘duty’ to ensure that they had made and discussed these plans with their family and friends. This is demonstrated in the following extract for a participant, Rebecca, who describes how she had persisted with having the discussion with her son about her death:

‘I’ve sorted out my funeral, my will, all that sort of thing. I wanted to leave everything in apple pie order for my son. It was hard at first getting him to talk, to listen to what I want, what I needed to do. It hit him hard when his dad died you see, and he didn’t want to go there. I tried to talk to him, he didn’t want to at first, I had to keep at him. In the end, I had to say to him ‘look we need to talk about this, it was a mess when dad died and it’s worse now, there’s the house to sort out and everything. He listened in the end’.

It was important to Rebecca to leave things in ‘apple pie order’, to ease the burden for her family after her death by having already prepared for a future when she would not be around. For many participants, planning in this way meant addressing activities that centred on very practical arrangements such as the funeral, sorting out wills and the financial aspects of death which needed to be organised rather than decision making relating to the transition to the end of life care itself. These findings correlate with those from a study conducted utilising secondary data analysis from fourteen interviews undertaken with patients with chronic kidney disease. The study found that participants focused on the practical problems of funerals and finances in an attempt to ease the burden of these tasks following their death for their loved ones and defined this as the theme ‘preparing for death while living life’ (Molzahn et al. 2012:21).
Having to make decisions about foregoing treatment, procedures and place of death were considered by participants to be significant end of life decisions. However, only one participant had had any discussion about these topics, she very much wanted to remain in control of all aspects of her life and death and actively pursued these discussions with her consultant. Rebecca explained this:

'I just ask him, and he’ll say to you ‘do you really want to know?’ and if I say yes then he tells you. He said to me, that now... Well, because I’m not having dialysis if I collapse they won’t bring me back........you know, revive me........I said to him ‘Good, why would I want that!’. I think he probably thinks I’m awful, I’m always like that, but that’s me'.

Although participants were concerned about the decisions they may have to make about care at the end of their life, many of them did not perceive that these decisions relating to the future needed to be addressed in the present. Participants used terms such as ‘I might have some big decisions to make’, and ‘I’ll have some tough things to think about’, to reflect that these end of life decisions may have to be made in the future. The following extract by John illustrates this:

‘Um, will I have to say if I want to be resuscitated or anything like that, you know. Um, I haven’t really talked about it, but I do know, I do know! Will I be able to stay in my home or will I have to go in a home, those sort of things, they’re big things to have to think about really? I do think about these things sometimes........ but I’ve not really talked about it. But when it gets to that stage I’m sure that Dr X will tell me when the time is right because I’m pretty sure I’ve told him I’d want to know'.

The trajectory to the end of life and perceived ‘big decisions’ associated with this were difficult for John to contemplate in the present but were clearly a concern to him for the future. He had not made any decisions relating to the end of his life itself or discussed with health professionals, family or friends what he might want in the future but felt assured that his medical team would raise these with him ‘when the time was right’. The postponement of these decisions until a ‘later time’ in the illness...
trajectory was articulated by participants in the study despite them acknowledging that their death was likely in the near future.

The relationships that participants had developed with health care professionals over the duration of their illness trajectory were remarkably important to them when thinking about end of life issues. Participants had expectations that these relationships would continue as their condition deteriorated and were assured that the renal team would continue to be responsive. They anticipated that the renal team would have these end of life discussions with them when the ‘time was right’ using terms such as ‘I trust Dr X, he’ll tell me when it gets to that’ or ‘Nurse X is always on the end of the phone if I get bad’. Whilst participants had strived to retain a sense of autonomy and control throughout their illness, when reflecting on the end of life care decisions they may have to make they preferred to relinquish some of this control to health care professional in whom they trusted. In contemplating these decisions, there was a move away from feeling they owned the decision, as illustrated earlier in their disease trajectory when participants made decisions about treatment choices, to partnership in decision making as the disease progressed. There was a disparity between the expectations of participants in relation to the assumption that health care professionals would raise these issues with them at the appropriate time and the reality that participants had been identified by their renal team as potential study participants because they were perceived to be in the end stages of their illness trajectory, having a perceived prognosis of less than 12 months.
5.5. Category 2: Managing Uncertainty: Knowing without clarity or confirmation

Managing uncertainty was identified as a category in this study and was associated with the uncertainty participants experienced when contemplating the time they had left and what the end of their life would be like. The existential knowledge that time was short and that they were nearing the end of their lives was articulated by all participants in the study. They knew that their condition would deteriorate further but did not know when this would happen, how it would happen and what to expect. Managing this uncertainty was defined as knowing without clarity or confirmation and illustrated in the three sub-categories: knowing you will die but not knowing when, vigilantly observing for changes, and knowing you will die but not knowing how.

5.5.1. Knowing you will die but not knowing when

The first subcategory which related to managing uncertainty: knowing without clarity or confirmation was defined as knowing you will die but not knowing when. Participants understood that ESKD was a life-limiting illness; they were conscious of the possibility of further deterioration in their condition, the likelihood of dying in the near future and acknowledged the uncertainty of not knowing when this would be. For participants, managing this uncertainty meant questioning when further progression would occur and how it would unfold. Participants conceded that their day to day reality consisted of questions and unknowns about their future, this was articulated in phrases such as: 'not knowing', ‘thinking about the future and how long it will go on for', and ‘waiting and wondering’.
Participants echoed the notion of uncertainty associated with the likelihood of illness progression. Rebecca, who had been treated conservatively for over four years described the uncertainty associated with the illness trajectory as:

‘And I’m still here….not sure for how much longer, but….well, that’s the only thing……..you keep wondering how much longer you’re going on, you know. I don’t know….I’ve had it explained to me, how it goes, you know…….. but still, no-one can tell me how long I’ve got, when it will be. I’m waiting, waiting to see’.

Rebecca’s description reinforced the uncertainty associated with knowing what will happen but not knowing when as she ‘wondered’ and ‘waited’ for her condition to deteriorate. Inherent in Rebecca’s narrative of the uncertainty surrounding the illness trajectory were the notions of direction, movement, and unpredictability which were all associated with time. Participants found themselves questioning when progression would occur and how it would unfold meaning that the not knowing direction was alternatively a knowing without clarity or confirmation. This resonates with the ‘intangible reality’ used to describe the experience of uncertainty in a study exploring the experience of living with the uncertainty associated with life-limiting illness. This ‘intangible reality’ described the uncertainty as ‘being experienced or existing in a fact that is not definite or clear, being elusive, vague and unable to be touched or grasped’ (McGonigal-Kenney 2011:127).

The prospect of dying was a persistent but not an overwhelming presence in the lives of the participants describing this as being ‘in the back of your mind’ and ‘always present’. Although it did not pervade their existence, it never completely disappeared. Amanda illustrated this saying:

‘It’s not like I’m always thinking about it, but it’s there, you know, it’s going to be …..well, you know it’s there, you know dying……you know, and so it goes on….I mean I carry on that’s it, what else can you do’.
Amanda described that although this uncertainty was present, it did not consume her or how she lived her remaining life. Participants instead acknowledged the uncertainty and strived to find ways to incorporate the unknowns into their lives. According to Meleis et al. (2000), a possible indicator that transition is occurring is that the person feels connected to and is interacting with their situation, confronting the issues and/or the people around them and gaining an understanding of how to live and be in their altered world. In the present study participants revised their plans for living based on the possibility or probability of their death in the near future, they felt that often the only choices they had were in continuing to live and adopt a particular attitude towards living and dying. For many participants, this attitude was portrayed as an essential optimism by them, acknowledging their deterioration and the finitude of their illness participants expressed how they lived ‘here and now’ and did not worry too much about the future.

For other participants focusing on the ‘here and now’ enabled them to cope with the prognostic uncertainty; thinking about the future meant facing death which they felt they had little control over and increased the anxiety and uncertainty for them. The following extract by one participant, Norman, who was receiving dialysis but having increasing complications making it difficult to tolerate the treatment illustrates this:

‘Um, well obviously I’m, I’m…I have got fears, you know issues. I know that I’ve not got that long to go, that one day I won’t be around anymore, but I try to block that out, I push it into the background, it’s easier that way. Each day I live………live, you know. I think to myself, well, like it might be me last because that’s good, better that way, because you can control things better. I can’t think too far ahead anymore, that’s too much, and there’s just no point to that, it won’t help doing that. The worst thing would be being on my own. I’m not scared of dying, but like I said before I know I’m getting worse, I can feel it. But I don’t know how long it’s going to be, so I just carry on day after day’.

Although he acknowledged the reality of his situation, for Norman, thinking about the future and what might happen was ‘too much’, and as a consequence, he was
guarded in relation to how much he allowed himself to talk about the future and the time he had left. As such he actively sought to suppress thoughts and feelings of uncertainty. This was not perceived as denial but rather his way of coping, enabling the feelings of uncertainty to be less overwhelming and allowing him to carry on living his remaining life.

In summary, knowing you will die but not knowing when this would happen was identified by all the participants and impacted on how they perceived their remaining lives. In managing this uncertainty, the participants questioned when progression would occur and how it would unfold. Adjusting to this uncertainty included the participants’ changing their perspective on living, accommodating this uncertainty into their daily lives meant they did not let their thoughts and feeling of uncertainty about the future illness trajectory overwhelm their lives.

5.5.2. Vigilantly monitoring for changes

The second sub-category which emerged from the data and related to the category of managing uncertainty: knowing without clarity or confirmation was described as: vigilantly monitoring for changes. Waiting for death and not knowing when this would happen, was a source of lingering uncertainty that varied in intensity, timing and content, presenting itself in several ways in the participants' daily lives. There was often a focused sensitivity associated with contemplating when death might happen which manifested itself by participants being vigilant for changes in their condition that may represent a deterioration and progression of their illness. Participants tried to visualise what further deterioration would look like and evaluate how their illness was progressing, looking for signs of deterioration attributed to their kidney disease. This was illustrated by one participant, John, who described this uncertainty saying:
'It looks much, much the same, the blood tests, that is……….., I'm holding my own I think, I think that's what Dr X said, you know. So, this is the problem……. I don’t know how long things will go on for, you know, we don't know what happens. It's not easy, that's all, I suppose, but that's it, you just wonder don't you, but things seem okay at the moment, the blood tests and that '.

For John not knowing ‘how long things will go on for’ meant he struggled to assimilate the prognostic uncertainty of his illness alongside the physiological markers of his illness and the discussions held with the renal team. There was a disparity between these physiological markers and the psychosocial processes of the illness trajectory as he grappled with this uncertainty and tried to make sense of his current reality, framing his illness around these tangible physiological markers whilst also scrutinizing the conversations held with his consultant looking for inferences within these discussions which indicated the status of his illness.

Vigilantly monitoring for changes often meant participants observed for any changes in their health and attempted to determine the meaning of these changes. Participants described being quick to detect or respond to any change in health status, often initially attributing any change to be an indication of deterioration due to their ESKD, whether it was or not. At these times ‘uncertainty’ would move from being in the background to being in the foreground as participants worried that any symptom represented a permanent deterioration in their illness, and questioned whether this represented a new milestone in relation to the disease progression and the trajectory to the end of life. This is illustrated by one participant who recalled how a recent episode of illness prompted him to question whether this represented deterioration in his illness, making him reflect on what the future might hold and the changes he may be faced with as his health deteriorated, Jack explained:

‘Just after Christmas, neither of us [wife and participant] weren’t very well, we had a tummy bug, and our daughter, of course, had been over. Well, we were just taken poorly quite quickly. … well it just, well it did upset me a bit to think to myself ‘what's happening? Is this it?’ And it got me to thinking I might have to
go into a home, that sort of thing. It’s always at the back of your mind, especially 
with the kidney problem. I don’t get depressed about it, but you just think, 
because I’ve had the illness for a long time, but that was the first time I was took 
to bed, but anyhow I got over it, didn’t I. Anyway, I’m still here to tell the tale’.

For many participants, the presentation of a new symptom would prompt them to 
contemplate whether this was related to the kidney disease, represented new 
symptomology and as such deterioration in their condition. This is illustrated by John 
when he described a recent acute episode of pain:

'Whenever I have anything wrong, like when I had pain a few days ago, it just 
came on very quickly, um, in my back and then it went to my front and, well, I 
didn’t know if it was to do with my kidneys. Whenever there’s anything wrong, 
you always just wonder if this is it……if it’s getting worse, you know. Anyhow, it 
passed off so it’s alright, I’d probably just pulled a muscle, but it makes you think 
don’t it, I mean, I know that one day I won’t be around, that’s it, I know that’.

The onset of a new symptom or illness episode prompted participants to consider 
the meaning of this in relation to their ESKD. Such episodes forced them to attend 
to their illness, as they reflected on what these symptoms represented and what 
they might face in the future. Although these concerns ebbed and flowed, they 
remained a constant in the lives of the participants. The knowledge that their 
condition would deteriorate was meaningful in relation to participants’ perception of 
the changes in their bodies, describing this as ‘greater awareness’, ‘looking more 
closely’ and ‘alert to the possibility that something might happen’. Participants were 
cautious not to overlook any symptom in case it was important and represented a 
new milestone in relation to the progression and deterioration in their illness 
trajectory.

The present study findings contrast those from a previous study of patients with 
ESKD managed conservatively (Llewellyn et al. 2014). Llewellyn et al. (2014) found 
that patients attributed symptoms to other co-morbidities rather than considering 
any symptoms to be indicative of ESKD which meant ESKD remained abstract and
was woven into the overall narrative of long-term illness. In comparison, in the
current study, despite participants having other comorbidities and regardless of
treatment modality, participants framed the presentation of any symptom within the
context of ESKD.

In summary, managing the uncertainty associated with *knowing without clarity or
confirmation* meant that participants vigilantly observed for changes in their health.
They monitored for symptoms and tried to determine the meaning of any new
symptoms and illness behaviours in relation to whether these changes were
indicative of illness progression and the trajectory toward the end of life.

5.5.3. Knowing you will die but not knowing how

*Knowing you will die but not knowing how* was the final sub-category within the
category managing uncertainty. Participants openly talked about dying as a
consequence of ESKD. They had considered the possibility of their death as they
anticipated their future. Participants were aware that this would happen sometime
soon and as already discussed they lived with the uncertainty associated with not
knowing exactly how long they had left to live. For participants, death was seen as
a part of life, they reflected that bad things happen all the time using the words
‘people get ill’, ‘people have accidents’, ‘anyone could step under a bus’. Many
participants had also already experienced the death of loved ones. Although
thinking about death was difficult the participants reconciled to themselves that it
was just a part of life. This was articulated by Angela when she explained her
thoughts about death:

*I know that it’s going to get worse, well, it’s not going to get better is it! I know
there’s only one conclusion to all this. So, obviously, I think about death, of
course, I do, it’s inevitable at my age. No, you’ve got to go some time haven’t,
it’s not like I can keep going on forever. For me it’s about knowing I’ve got the
kidney problem, I live with that, but, ......well, for me it's like this, I can see the ending where I suppose for a lot of people they cannot. But I can't complain, I mean I'm 86, you've got to go some time, I know that. No, I can't complain, I've had a good innings.........I feel well, I'm not suffering or ought like that, I'm well looked after here'.

For Angela having ESKD meant she ‘could see an ending’ which other people without such an illness possibly couldn’t. Having ESKD had required her to contemplate the reality of living with this illness and what this meant for her future and the end of her life. The ‘inevitability’ of death was influenced by her recognition of the finitude of her illness, accompanied by her perception of the impact of her age on the likelihood of death. In this study the association between dying and ageing resounded with most participants; many of whom were in their eighties, as they described how they had reconciled the terminal nature of their illness and considered that they had already ‘outlived their time’. This resonates with the findings of the previous studies by Ashby et al. (2005), Axelsson et al. (2012a, 2012b) and Llewellyn et al. (2014) who all reported that older patients with kidney disease often tended to see dying as a natural course of ageing and illness.

The notion of having already ‘outlived their time’ was also reflected by the younger participants who had often lived with significant co-morbidities for many years prior to or as well as the renal disease and thus felt they had lived beyond their time. The narrative by Leonard, who had had a previous transplant, had subsequently started dialysis and later been diagnosed with a lymphoma from the long term immuno-suppressants articulated this by saying:

‘Well, by rights I shouldn’t be here when I think of everything that’s happened with me...Recently, I was so unwell I developed pneumonia and subsequent to that I developed septicaemia........I’ve had the last rites twice, that’s how bad it got. It all sounds very poetic, but I think I’ve been lucky’.
Although there was an acknowledgement of the finitude of their illness, participants did not articulate that they were ready to die, only rather that they knew that it was inevitable. Reflecting on end of life issues meant an appraisal of the possibility of their death in the near future. Whilst participants expressed they were not afraid of death itself, when they contemplated what the end of their life would be like they were apprehensive and uncertain about the process of dying and what they could expect during that phase of their illness trajectory. One participant, John illustrates this saying:

'I mean, I know it’s, I know it’s ……I mean we’re talking about, about the end……..the end, aren't we. Well, you've got to accept it, haven't you? We all have to accept, don't we? It's not that, I mean, I know I'm going to die soon. It's just, well, I mean ….What will happen in the end?'.

For participants, there were concerns that the process of dying would mean they would suffer symptoms. The participants were relatively stable with regards to symptoms at the time of being interviewed describing the main symptoms to be a lack of appetite and fatigue. A few participants were experiencing some pain from chronic conditions such as arthritis, but this was not associated with their ESKD. Despite this, participants believed they would experience pain when they were dying, which is demonstrated in the following extract from a participant, John who described:

'Will it be painful? I mean …..What will happen? Is it going to be painful, you know or do they inject you? Will I die in pain?……., it's that sort of thing that worries me'.

Similarly, other participants expressed the belief that they would be in pain at the end of their lives and were concerned that this would not be controlled. Few participants had had conversations with the health professionals involved in their care about what might happen at the end of life and what they could expect in
relation to the management of the symptoms they may experience, other participants were confused by discussions that had taken place. A participant, Jane, described her interpretation of a conversation that had taken place with her doctor; she believed that during this conversation she had been told that when her renal function deteriorated to a certain level, she would die in pain.

'...the kidney problem, well it's gone to 14 now, you know the kidney test. But I don't know how, they, they just said...... they said I would go. You know, in something like when it's about 10. I don't know if that's what it is but, um, and that it would be very, very painful then! You know, that, that I'll be in pain at the end and that upsets me'.

Despite articulating that they were not afraid of death itself participants consistently expressed fears about the process of dying and the uncertainty of knowing they would die soon but not knowing how or what the process would be like. In the absence of apparent discussions and information from those health professionals caring for them, they had contemplated the end of their life, how this would be and associated this with being in pain and questioned whether symptoms could be controlled in the final stages of their illness. This is captured in the extract from Jane, as she reflected on the prospect of her death:

'We all wonder about the unknown, don't we? We do......you know......because no-ones comes back to say that was alright [laugh]. I know what I want, I'm kind of working it through, I really hope I can stay here until the end, I mean, I've lived here for 50 years, I don't want to leave, no, no. ..........But I live on my own, I don't know...... So you hope that it'll be alright, the pain and that they'll be able to help with that'.

Previous research evidence supports the significant symptom burden (including pain) experienced by patients with ESKD and that the prevalence and severity of symptoms increase in the last months of life (O'Connor & Kumar 2012; Murtagh et al. 2010). The current study findings identify that the perceived symptom burden at
the end of life created significant uncertainty for participants when contemplating the end of their lives.

In summary, managing uncertainty in relation to the process of dying was a common theme for participants in this study as they contemplated their future and the possibility of their death. Participants acknowledged that they would die at some stage in the future often reconciling this with ageing and the experience of having lived with ESKD for some time. Participants were anxious about the process of dying and in particular whether symptoms would be controlled at the end of their lives. This was exacerbated by the seeming lack of discussion and lack of information regarding what to expect at the end of their lives from the health care professionals involved in their care and meant participants again lived with the uncertainty of knowing without clarity or confirmation in relation to the process of dying.

5.6. Category 3: The Importance of personal virtues in transitioning through the illness

The experience of transition for people with ESKD and their ability to adjust to these transitions within the context of their illness trajectory centred on certain demonstrated personal characteristics which participants already possessed or had acquired over the duration of their illness. In this study, personal characteristics referred to the unique features individual patients portrayed in response to a deteriorating health as a consequence of their progressive illness. These qualities had an inherent morality to them and so were defined as personal virtues and conceptualised within the category: the importance of personal virtues in transitioning through the illness. Four key virtues emerged from the data and were defined in the sub-categories: gratitude, acceptance, being present-focused, and courage and determination.
5.6.1. Gratitude

The first sub-category within the category of the importance of personal virtues in transitioning through the illness was gratitude. Gratitude was a personal characteristic consistently identified in the data with all participants expressing gratitude in one form or another. This gratitude was expressed in a variety of ways by participants; being grateful for the time they had, the quality and duration of the life they had lived despite their illness, and as an appreciation for the care and support they had received throughout their illness trajectory.

Participants reflected on the lives they had lived, the time that had elapsed since they were first diagnosed with ESKD and the life they had had since. Many participants described how they considered that they had had a ‘good life’ and had lived longer with their illness than they had expected. They felt fortunate for the perceived additional time they had and what this time had enabled them to achieve in their lives. Participants used terms such as ‘I’ve been lucky’, ‘I’ve had a good life’, and ‘I’ve been fortunate’ as expressions of gratitude when they contemplated their lives. This was articulated by Dorothy who said:

‘I’ve been lucky really. I’ve had a good life, and I’ve had a good innings really. I’ve lasted longer than I thought I would have done, it’s been over four years now since I was first diagnosed. That’s my great-granddaughter over there [referring to a photograph], I didn’t think I’d see her get to what she has, you know. She wasn’t even born when I found out I had the kidney problem so… so, you know, I’m grateful for the time I’ve had, it’s……lucky I’ve seen her’.

Dorothy was grateful for the time she had and perceived she had had a good life which had extended beyond her illness diagnosis and enabled her to continue to be involved with her family and see them develop and grow. The expression of gratitude for both the life lived, and the possibility of the life that remained was expressed by many participants. Participants perceived that their lives had been
lived in the best way they could, and emulated a feeling of pride in the life they had lived.

Participants frequently made reference to people who they considered worse off than themselves. They articulated that they had been fortunate particularly when they compared their lives to those of others they perceived were less fortunate than themselves, this included other people who had been diagnosed with a serious illness or had had their lives cut short. Rebecca describes this by saying:

‘I can’t grumble really, I’ve had a good innings. It’s no good grumbling when you think of all those boys who have been cut down in Afghanistan; my grandson’s been their twice you know. No, I’ve been lucky to get as far as I have, I can’t grumble, I’ve had a good life...I mean, there’s always someone worse off than yourself isn’t there’

Rebecca was grateful for the life she had and the duration of her life. She compared the longevity of her life with others whose lives had been cut short and considered she had been ‘lucky’ compared to them. Similarly, another participant, Leonard, explained how fortunate he felt his life had been despite having ESKD alongside a diagnosis of cancer. Despite the limitations ESKD imposed on his life he still considered his life privileged when he compared the experience of his illness with that of others he had encountered during his illness trajectory.

‘No, I mean, I’m grateful for the life I’ve had. I’m not saying it’s been easy, but even when you’re ill, there’s always someone worse off than yourself isn’t there. It’s easy to feel down, but then you only have to look around to realise how lucky you are. You only have to look around you when you’re in the hospital to see that. And that helps, helps you take stock of things. So many people are worse off than me, and have no-one’.

Despite their illness often being accompanied by other significant comorbidities participants described themselves as ‘lucky’ and did not take things for granted when they reflected on their illness experience compared to others they felt to be worse off. A qualitative study of hope in eleven patients with a life-limiting illness
which included patients with heart failure, cancer, and respiratory disease also found that participants frequently described the notion of being fortunate compared to others worse off than themselves when reflecting on their illness and their future (Schaufel et al. 2011).

Gratitude was also expressed regarding the care and support participants had received from others, such as family, close friends and health care professionals. These relationships were paramount to participants and had strengthened throughout their illness trajectory. Many participants described how they would not have been able to cope as well as they had without this support. One participant, Norman described this saying:

‘She’s been there for me. God knows, every day when she’s come I’ve moaned and groaned about how I am. I want to give her something back when I go, make sure I’ve left her something. She knows what I’m going through. I’ve been blessed a lot, and I do count my blessings. I’ve lived longer than I thought I would, probably than I should, and I think part of that is down to her’.

The notion of gratitude was often articulated by participants as ‘counting one’s blessings’ when they reflected back on their illness, their lives and the support they had received from friends and family. Alongside this, participants repeatedly spoke of the appreciation they felt for friends and family, and how they wanted to show this gratitude and thank them by leaving something behind for their loved ones after they had died. This appreciation was also directed to health care professionals who participants' felt had supported and cared for them throughout their illness trajectory. Participants often described these health professionals using terms such as ‘they’ve been marvellous’, ‘they’ve really looked after me’ and ‘they’ve supported me and my family’.

In summary, gratitude was a personal virtue frequently demonstrated by participants. It meant an appreciation for the little things previously taken for granted,
expressions of ‘feeling lucky’ when they compared their fortune to others and appreciation for the care and support they received.

5.6.2. Acceptance

Acceptance was the second sub-category within the category the importance of personal virtues in transitioning through the illness. Acceptance was a recurrent theme emerging from the data. The ability to ‘accept’ the changes imposed by a deteriorating health and a progressive illness on their lives frequently emerged from the data. Participants used terms such as ‘I’ve accepted it’ and ‘I’m getting on with it’, when describing how they had adapted to the many changes caused by the illness and a deteriorating health, this was articulated by Irene who said:

'It’s difficult, but I think I’ve accepted it, my illness that is and what it means for me. It’s not been easy, but I have, I mean, I have accepted this'.

Many participants had lived knowing they had ESKD for several years alongside other significant co-morbidities and this appeared to have afforded them the opportunity to reflect on how to live with their illness and to adjust as the illness progressed. This is illustrated in the following extract from one participant, Rebecca who had lived with ESKD for over four years, during which time she had also been diagnosed with breast cancer. She said:

'Well, I’ve got it, chronic kidney disease, that’s what they call it and I’ve got to see it out to the end! But I wouldn’t wish it on anyone else, it’s not nice, but then again there is nothing we can do. But it’s um....... anyway, you know you can survive with it, well I think I’ve proved that. I find ways to deal with it as it gets worse'.

Rebecca had resigned herself to her illness and the inevitable outcome of this describing how she had to ‘see it out to the end’. Despite being reconciled to her illness and the prospect of a further deterioration in her health, she also articulated
how she would continue to find ways to adjust as her illness progressed. The existential knowledge that they would not live much longer was constantly brought into focus by participants in relation to the physical and psychological adjustments they had undergone and those they anticipated they would have to face in the future as their illness progressed. However, despite this, none of the participants expressed they were ready to give up or wanted to die, instead indicating an acceptance of their illness and accompanying deteriorating health. Reconciling oneself to the illness and incorporating it into one’s life was a part of acceptance.

Acceptance, for participants in this study also involved ‘putting things into perspective’. Most participants had a realistic view of their situation, their illness, and declining health. They described having ‘put things into perspective’, in acknowledgement that their lives were changed and they were no longer able to do the things they used to do. ‘Putting things into perspective’ meant re-evaluating life, accepting the changes and constraints caused by the illness, and not dwelling too much on what was no longer possible. This often involved acknowledging the physical limitations imposed on them by a declining physical function as their illness progressed, as demonstrated in the following extract from a participant Amanda, who said:

’I’ve accepted what I cannot do, as well as what I can still do. As I’ve got more unwell, well, I’ve put things into perspective, things that used to be important to me, well they just aren’t anymore. It’s no good fretting over things that just cannot be. I have a different attitude towards life now, I’ve had to, you have to get on with it, there’s nothing else to it’.

The notion of putting things into perspective and the acceptance of the limitations imposed by a deteriorating health was further echoed by other participants, for example Leonard, who described this as:
“I can still manage. I surprised myself and Joanie [wife] sometimes. I’ve had a good life....so all I can say is..........um, I’ve accepted that I’m as good as can be expected. I don’t set out to do things anymore, if I can't do it, I don’t do it. I know my limitations’.

According to Meleis et al. (2000) transition occurs when the person feels located or situated so they can reflect and interact, and develop increasing confidence in their capacity to live with the adjustments they must make. This correlates with the experience of transition for participants in the current study who accepted a changed life as a consequence of their illness and had adjusted to a new way of living within these changes.

Acceptance was an ongoing process, and for some participants, it was sometimes a difficult process as their illness progressed and the consequences of this, both physical and psychological manifested themselves. For participants, living with ESKD meant having to accept a changed life, participants talked about ‘you have to accept the situation’, ‘you have to deal with it’, but this acceptance was not a linear process, and acceptance waxed and waned as the illness progressed. This is illustrated in the following extract from a participant Jack:

“I think I’ve come to terms with my illness. I get it. I know what it means, and I know what’s going to happen sooner or later. I mean, I know I’m going to die in the end, that’s inevitable, you can't live forever, and I’m getting on a bit now [laugh].... I’ve accepted that. But that doesn’t mean I’ve come to terms with everything about the illness and what’s happening to me, not all the time..... It's not that easy. There’s still things that get to me, you know, I have bad days when it gets on top of me’.

Although Jack described how he had ‘come to terms’ with his illness, recognising that his life was finite, acceptance of the consequences and outcome of the illness were not all encompassing. There was a variability to this acceptance which was frequently articulated by participants. Another participant, Jane described this saying:
'Most of the time I'm alright, you get on with it, don't you. I've accepted that I can't change things, they are what they are, and that's how things are now. I do the best I can and get on with it. I think I do alright, I'm happy here at home but well, you get your down days, you get your up days. You're only human'.

The personal virtue of ‘acceptance’ demonstrated by participants as their illness progressed resonates with the ‘becoming ordinary’ phase in the process of transition described by Kralik (2002). During the process of transition Kralik (2002) described how people experienced a changing pattern of being and doing which incorporated new ways of living, with life being lived in a way that provided a sense of coherence. Acceptance within the process of transition for participants in the current study was also not a linear process, acceptance waxed and waned in a similar way to the process of transition described by Kralik (2002).

5.6.3. Being Present Focused

The third sub-category within the category the importance of personal virtues in transitioning through the illness was categorised as: being present focused. For participants living with ESKD experiencing the transitions associated with a deteriorating health meant they had intentionally re-orientated to maintaining a focus on the present. Being grounded in the present participants described how they strived to live their lives the best they could and tried to remain positive by remaining ‘present focused’ and not concerning themselves too much thinking about the future, often describing this as living in the ‘here and now’.

Being present focused meant living day to day rather than worrying about the future. Participants used terms such as ‘I just take things as they come, I take each day as it happens’, and ‘I don't plan too far ahead’ to emphasise how they had orientated themselves in the present. This was illustrated in the following extract from one of the participants, Leonard who stated:
'I just take things as they come now. I used to plan; I was always planning but well, as I've got worse, you know, more tired and stuff, well, and it made me think. There are some things I just cannot influence, I have no control over, sort of thing. So now, I concentrate on the now, what I have to do today and maybe tomorrow, but I don’t think too far ahead. I take it one day at a time'.

Leonard had changed his attitude to how he lived, choosing to concentrate on what he was doing from one day to the next rather than making long term plans. Remaining grounded in the present involved living each day at a time and not projecting too far into the future. By not projecting too far into the future participants chose not to worry too much about things that had not yet happened. As one participant, Jane articulated:

'I don’t tend to worry too much anymore, you know, about what might happen, I don’t worry about stuff until it happens. You don’t know what’s going to happen tomorrow so what’s the point of worrying about it now, if you do that then you just get all wound up, and that’s no good, worrying yourself about things that haven’t even happened yet. That doesn’t mean I don’t know what’s going to happen; I’ve already said I know that I’m going to die from this but thinking too far ahead, well, that’s not going to change nothing is it'.

For Jane, being present focused did not mean denying the reality of her illness, there was a recognition from her of what her illness meant with regards to her future, the thoughts of the future were ever present but by refocusing on the present and the ‘here and now’, these thoughts did not consume her everyday reality. Hovering between living in the present and worrying about the future, participants opted to focus on living in the present. They acknowledged the future, the difficult situations they may have to go through including further deterioration in their health and death but did not let this consume them and chose to be present-focused and expressed an optimism despite the progression of the illness. Hopes for the future were articulated in relation to care they would receive as they deteriorated and the hopes that they would be able to remain at home.
This optimism was also reflected as an essential hope by planning for the short term and setting short term goals to achieve rather than worrying about the future. Participants tried to enjoy the good parts of their lives and expressed hope for remaining good times during the time they had left, expressing hopes for the present or near future. John articulated his hopes for the short term which he wanted to achieve:

‘The grandchildren will be forty in February next year. The family’s planning a big party, we’ll all be getting together, the whole family. It will be good to meet up with everyone, all of us together. I just hope I can make it, you know, I hope I’m feeling well enough to go’.

In summary, the personal virtue of ‘being present focused’ whilst not a moral virtue per se was a virtue demonstrated by participants and meant they had reconciled their lives and the changes associated with living with a progressing illness. Being ‘present focused’ participants lived in the here and now, they did not dwell too much on things that were no longer possible, but intentionally focusing on living each day as well as they could. This did not mean they had given up on the future; they still maintained hope in relation to future short term goals and the enjoyment of good moments in their remaining lives.

5.6.4. Courage and determination

The last sub-category within the category the importance of personal virtues in transitioning through the illness was courage and determination. The personal virtues of courage frequently emerged from the data. It was apparent that an inner strength of character or self-determination was a quality held by participants in this study which helped them accommodate the many adjustments and challenges faced during their illness trajectory.
Participants did not speak directly of being courageous when describing how they had lived with ESKD and the adjustments they had made as a consequence of their progressive decline in health. However, an inner strength and sense of courage were clearly evident from the data analysis. Terms such as ‘you’ve got to be strong’, ‘It’s hard, but you have to tell yourself to push on’ and ‘you just have to keep going’ reflected this inner strength and courage. Dorothy described this as:

‘I know I’m not like I used to be, but I’m still the same person up here [pointing to head]. I’m not going to change there, whatever happens. It’s what you have to do unless you’re going to let yourself go and give in. You find the strength, up here [pointing to head], even if it’s the only thing you have. You find new ways…...the determination……you can’t just let yourself go, give up and everything. Well, you might as well be gone if you do that’.

Dorothy acknowledged that the physical limitations imposed by her illness prevented her from being the person she used to be physically, however, her strength of character and sense of self, endured as her health deteriorated and she continued to challenge herself to carry on. The notion of a strength to persevere and endure was also echoed in the data from other participants as illustrated in the following data extract from another participant, Leonard:

‘What I mean, but……………um, there’s a line in an old Scottish song that goes like this, ‘High Lord, going to keep right on to the end of the road’. And that’s literally what I’m doing. I’m keeping going. It’s not always easy, problems crop up, new things to deal with, I’ve had a few stops in the hospital over the last few months which are never good, but I’ll keep on going. That’s what I’ve always done so I’m not likely to change at the end am I?’.

For Leonard, his courage and his determination were also grounded in a realistic appraisal of his current reality and future. His determination helped him to perpetuate the ongoing resilience needed for the current and future transitions. Similarly, another participant, Rebecca, whilst realistic about her illness and prognosis demonstrated this inner strength and determination to adapt to the ongoing challenges she faced as her health declined describing this as:
‘I suppose I’m doing it my way. I’ve told them if they want to play anything at my funeral, they can get up and sing ‘I did it my way’. [laugh]"

For other participants, their courage was driven by the desire to protect their families and loved ones from the effects the illness was having on them. Participants described how they kept going for their families, so their families would not worry about them, challenging themselves despite their illness limitations to achieve this. Amanda articulated this as:

‘I try to be strong and help myself and get on with it. I know that we are all different, but it helps if you can get on with it……It eases it for other people if you do, other people don’t worry the same. If people come and see me sitting in the chair they don’t know what it’s like but they think I’m okay, that’s just the way it’s got to be. You want to protect them, I know it’s silly, their grown up, they know what’s going on, but I’m still their mum, that’s my job’.

For participants managing their lives with a declining health was an on-going struggle and posed persistent threats to maintaining their courage and determination. Courage was not limitless; fear and frustration could still take over at any time, and this highlighted the role that interpersonal forces played in this. In the process of meeting the challenge of their illness participants learnt and continued to learn how to address their fears and move beyond them, courageous in the acceptance of their illness. As Amanda articulated:

‘You get your ups and downs. On a bad day, it's hard, you sit here and think, what's it the point, why keep going? I remember one time I refused to go up to the hospital when they came to collect me. I said, ‘No, I’m not going, I don’t care’. I’d had enough. They phoned me from the hospital, and I went in the next day. You have to go on, don't you? I mean, pick yourself up, give yourself a talking to, or sometimes my husband gives me the talking to [laugh] and then you find it in yourself to carry on. Like I said you get your downs, days when it’s all, you know, a bit much. But then you’re better again, for a while anyway’.

The participants’ strength to endure through their illness increased and decreased in intensity as their illness progressed. Although participants described how it was sometimes difficult to see through the bad days, their determination did drive them
on. Implicit in this determination was the impact that support from family and friends had on the participants.

To summarise, in this study the personal virtues of gratitude, acceptance, being present-focused, and courage and determination assisted participants with the many adjustments, both physical and psychological that they encountered as their illness progressed. There was an altruistic humility associated with the expression of these characteristic with the participants describing an appreciation for small things previously taken for granted, an acceptance of their illness and death, living day to day and setting short term goals. These characteristics fluctuated, during the many challenges and transitions they faced as the illness progressed, but for participants in this study, helped them to continue to adjust and carry on.

5.7. Core Category: Restructuring Reality

The ongoing changes experienced by participants with ESKD as they approached the end of their lives and the associated transitions accompanying these changes was conceptualised as restructuring reality. Restructuring reality represented the dynamic process which was experienced by participants as they attempted to adapt to the physical, psychosocial and existential consequences of a progressive illness and accommodate these into their remaining lives, whilst acknowledging that their lives were now very different and the remaining time they had left was short.

Restructuring reality incorporated adjusting to loss, which for participants in this study involved looking back on their past lives whilst contemplating what the future held and was conceptualised as living with loss. Participants paradoxically reflected on the lives they had lived, the things they had achieved and the losses they had faced, while contemplating what the future held, the anticipated losses they would
endure as a consequence of illness progression, and the associated probability of
death in the near future. Many participants had already experienced the death of
significant others in their lives, having lost a partner or having suffered the loss of
friends and family members often due to illness. As participants considered their
past and acknowledged the losses in their lives, there was a recognition that their
current reality was temporal. This is demonstrated in the following extract from a
participant, Dorothy:

‘I’ve been on my own for a quite some time now, I’ve got used to that, my
husband passed away eight years ago, he had pneumonia and was gone just
like that,[clicking her fingers]. It was really quick. ‘I’ve lost so many people in my
life; nothing lasts forever does it. My sister and her husband used to live next
door. They’ve both gone now; there’s a young couple who live there now. It’s
sad really, so many of my family and friends are dying or have died haven’t they.
I don’t think there are any of my school friends left. Um, um. I’m one of the only
ones left now…..So, I think I’ve done okay, but you know at my age, the thought
of dying, it’s going to be there. Well, when your times up……there’s nothing
more to say’.

Dorothy recognised her own finitude which she attributed, in part to her advancing
age. For Dorothy, the losses she had faced in relation to significant people in her
life had been multiple; whilst there was an intrinsic sadness in recollecting these
losses there was also the recognition that death was a part of living. Living with loss
meant that death was seen as inevitable and was reconciled with a life lived. The
notion that ‘nothing lasts forever’ emerged from the narratives of many participants
in the study as they recalled those friends and family who had died and the likelihood
of their own death in the future. Participants used terms such as ‘well, what do you
expect at my age’, you have to die at some point’ and ‘you know you can’t go on
forever’.

Reflecting on the past and future losses by participants reinforced the temporality of
their lives and resulted in the acknowledgement of the impermanence of their
current reality given the changes they had already experienced due to their illness
trajectory and those changes anticipated as they approached the end of their lives. This acknowledgement of the impermanence of their lives was an important part of the transition process for participants inferring an awareness and understanding of their current situation and anticipated future. The importance of acknowledging endings and losses has previously been identified as an important aspect of the transition associated with progressive illness. Waterson and Jorgenson (2010), explored the transition from independence to dependence and sometimes death in a sample of older people with heart failure, and reported the multiple and ongoing experiences of those losses associated with a deteriorating health. The study also explored the participants' perception of the future loss associated with death, which participants often associated with their age and reflected this positively.

*Living with loss* included participants' contemplating the impact their death would have on their friends and families and the losses they would endure as a consequence of this. This is illustrated in the following extract from a participant, Irene when she thought about her own death and leaving her husband:

‘He knows me so well, he’s my best friend, he knows what I’m going through, I mean, we’ve cried together, we’ve been together so long, we’ve got old together, but I know we’re not going to get much older together now, not me anyway. The thought of that, I just thought well, we’d be that old couple, sitting in front of the TV, talking about old times. But that’s not going to happen now, is it. In a way it’s frustrating really, you work hard all your life, you plan for when you get older don’t you….. how it will be, what you’ll do, but well that’s not to be now. I know he’ll be okay, I just hope, you know, he’s not too lonely’.

Irene expressed frustration associated with the realisation that her future was different from how she had anticipated it would be. Whilst she conceded that her future was now significantly shorter and greatly altered from the one she had envisaged, acknowledging the loss of this future was accompanied by the concern for her husband following her death, and how he would cope with this loss.
This notion of concern for loved ones and how they would cope when they were no longer around was echoed by other participants in the study, being a common theme expressed by participants as they contemplated and lived with loss. Participants used terms such as ‘I’ll be leaving him on his own’, and ‘we’ve always been there for each other’ when they spoke about this. Another participant Jack stated:

‘We’ve been together 53 years, that’s a long time, we’ve had a good marriage, we’ve had three lovely children and have eight grandchildren. Yes, we’ve been through a lot together, but we’ve rarely had a day apart in that time, except when one of us had been in the hospital. One of us had to go first, we know that it’ll be me, won’t it! She’ll be alright without me, she has the kids, our son’s only five minutes away and he’ll make sure she’s okay he’s told me that. But still I just worry, I’ll be going before her, I’ve always been there for her, she’s been there for me too, it’s just ……well, I feel this sense of guilt that I’m leaving her behind’.

For Jack, while acknowledging and living with the anticipated future losses he also reminisced on the achievements in his life including his relationship, accomplishments as a husband, father and grandfather. He acknowledged that his life would end, but he reassured himself that his family would cope without him, but he expressed a sense of ‘guilt’ in relation to his partner who would be left behind following his death.

This notion of ‘guilt’ at leaving loved ones behind to cope on their own was also echoed by other participants in the study. Amanda expressed a similar sense of guilt when she contemplated her own death:

‘I mean, the kids, they’re grown up now, it’s not like they need me like they did when they were little, but I’m still they’re mum, they still come to me with their problems. And my daughter, well, she’s a single mum you know……….we help out as much as we can, but she’ll be on her own. I won’t be there to help out, look after the grandchildren …It’s that sort of thing that gets to you, you know, that you won’t be able to help, John [husband], he’ll still do his best to help out, though, they’ll help each other out’.

Whilst participants felt a sense of ‘guilt’ when they contemplated their death and the loved ones who would be left behind. There was also an anticipation that their
families and friends would be able to cope without them following their death as they adjusted to living with their own loss. Despite the future loss their families would endure as a result of their death, there was an optimism expressed by many participants that their families and friends would support each other and adjust to this. This was articulated by participants when they used a phrase such as ‘I know he’ll be okay when I’m gone’, ‘they’ll help each other out’, and ‘the kids will help out’ to describe how their families would cope following their death.

Living with loss involved participants evaluating their lives as a consequence of previous, current and future losses. This life review included looking back on the past as well as contemplating the future, reminiscing about achievements as well as reflecting on the losses they had already endured and accommodated into their lives. In contemplating the future, there was recognition of future losses, a frustration associated with the realisation by participants that the reality of their imminent future was often different from that they had envisaged and an associated guilt when they thought about those loved ones they would leave behind following their death. There was also an acknowledgement that loss was an inevitable part of life, which they reconciled was to be expected at their age. Living with loss was incorporated into the process of restructuring reality experienced by participants as they established a greater awareness and understanding of their current situation and their future as they approached the end of their life.

All participants in this study emphasised the importance of relationships with family and friends and the changing nature of these throughout the illness trajectory. As participants’ physical status had declined family members and friends had taken on a more visible role as informal caregivers. However, the changes in relationships extended beyond the assistance provided with the provision of physical care and included the psychosocial aspects of relationships, highlighting the strengths and
weaknesses of these personal relationships alongside the transitions associated with a deteriorating health.

Participants frequently described how their spouse, sibling and sometimes children had adopted a caregiver’s role as they had become more physically dependent. One participant, Irene, described how her niece had stepped into the caregiver’s role and how this enabled her to remain at home:

‘She’s good you know, she comes round twice a day without fail to check in on me. It must be tiring for her you know, day in and day out. She comes even when she’s not well herself. She gives me my pills, my painkillers and insulin and checks my blood sugar’s okay. She rings me in the day as well, from work you see to make sure I’m okay. She’s a proper little nurse these days; I’d struggle without her’.

Similarly, another participant explained the changing nature of his relationship with his wife in relation to the increasing role she had played in providing and monitoring his care as his illness had become more debilitating. Leonard articulated this as:

‘Joanie [wife] has never been a nurse, but, well she’s learnt lots over the time I’ve been ill, especially as I’ve needed more help. She’s been there through it all; it’s a part of her like it is me. She knows as much as them, she really does! She does my dressings, helps me take my tablets……..things like that. We’ve been together such a long time that she just knows me, she knows when something is up. She’s been so strong throughout my illness. Recently I’ve had 2 TIA’s [transient ischaemic attacks] over the last couple of months; I was on the phone one morning, and I just felt… I just went flat, you know. Joanie never even fussed she just dialled 999, she was calm as you like and just got on with it. I was in the renal unit then for about 10 days, I made a concerted effort, I mean, to take all my medication and get out of the hospital, get back home to her, that’s better than buying Joanie a bunch of flowers’.

Leonard’s wife had cared for him over an extended period of time and had learnt the skills to take on many aspects of his care. Although it might be expected that family members might take on an increasing role in care as a loved one deteriorated, Leonard’s narrative demonstrated his confidence and trust in his wife’s ability to recognise and intervene to changes in his condition. He described how ‘strong’ she
had been, and his description accentuated his admiration for her and the way she coped with his illness. It also outlined the importance he placed on his role as a husband and the perceived sense of duty he felt on his part to continue to live with his illness and ‘get back home to her’.

Whilst participants placed a high value on the support provided by family and friends in relation to assisting with daily activities and care, the changing nature of relationships with family and friends stretched beyond these physical aspects of care. Participants made reference to the significant emotional support provided by family and friends as participants approached the end of life, they felt indebted to family and close friends for the support provided. This is illustrated in the following extract from a participant, Norman who describes the support provided to him by his close friend:

‘She’s been so faithful.........despite having her own family to look after she still gives loads of her time. She gets me things, you know what I mean. She’s the one that’s kept me going, without her I’d have given up a long time ago. I’m lucky I’ve still got Joanne as my friend, I mean, she’s seen me at my worst, cried with me, we’ve been friends since we were in school. She knows what I’m going through, she understands, she knows I’m just sounding off and just want to get things out of my system. I don’t think I’d have lasted as long as I have without her being with me’.

Norman’s narrative demonstrated the value he placed on his friendship and the support she had given him throughout his illness. For him, the emotional support gained from his friendship had sustained him through his illness trajectory describing her as ‘the one that’s kept me going’. This emotional support was important to participants, all of whom spoke of someone, whether this was a spouse, sibling, child, nephew, niece or friend that helped sustain them through their illness trajectory using terms such as ‘she’s my constant’, ‘he keeps me going’, ‘she gets me through the bad days’ and ‘I can rely on them’, to emphasise the importance of
this emotional support. Participants often spoke with pride and respect when reflecting on the support provided by family and friends.

Often the relationship with family members and close friends had strengthened as the participant's illness had deteriorated, being illustrated by quotes such as 'we’re closer now', 'we understand each other more', and 'we never used to be this close'. The reestablishment of close family bonds and strengthening of close relationships was viewed as a positive consequence of their illness trajectory. This is illustrated by one participant, Jane who explained:

‘With my husband dying I was very, very low, for, oh, a long time. We’d been married for fifty years and um………I didn’t, I didn’t know what to do because I was here on my own. But my brother started coming around a bit more. Then I got ill, and now my brother comes in three times a day, morning, noon and night he’s here. He comes and feeds me, both of us…… [referring to her dog]. Well, I don’t know really, we weren’t close for many years but now, well, now we’re closer, I couldn’t do without him, I’m on my own here, he keeps me going, jollies me along, you know….’. 

Despite describing their relationship as ‘not close for many years’, over the course of her illness Jane’s relationship with her brother had strengthened, with him undertaking a key role in relation to her physical care but was also her main source of emotional support.

Whilst relationships with family and close friends were strengthened and augmented as the participants’ illness progressed, for some participants other previously important relationships diminished in significance as their health deteriorated. As their illness had progressed some participants described how they had experienced a disconnect from others, expressing this as a lack of desire for interactions with other people previously perceived as important. This was illustrated in the following extract from a participant, Gladys:
'I used to go down the social club, see my friends, catch up, that sort of thing. I used to like to go out for a drive in the country. I couldn’t drive myself anymore but even when my friends offer to take me, I, well, I can’t be bothered. I could go, it’s just I don’t want to. I’m not lonely or depressed or anything like that, it’s just well, I’ve deliberately distanced myself, I just don’t have the same inclination, to be around people like I used to……. Gosh, that sounds dreadful, they’re good people, I still talk to my friends on the phone, they’d come round if I wanted them to but I’m okay as I am’.

Despite articulating that she would still be able to maintain social contact if she wanted to, Gladys described how she had made a conscious choice to limit these interactions emphasising that she felt neither ‘lonely’ or ‘depressed’ but no longer had the desire for the previous level of social contact. This social withdrawal and disconnect described by some participants appeared to be a psychological adjustment to a deteriorating health described by participants as ‘a conscious withdrawal’, and a ‘deliberate distancing’ and were independent of the limitation imposed by the physical deterioration and restrictions associated with their illness.

For other participants, this disconnect from others was a consequence of no longer sharing the same social world. For these participants, they had lived with their illness for a substantial amount of time and as their illness had progressed they had become more isolated from friends. One participant Norman said:

'I’ve gone from a man who used to like socialising to being quite, well, lonely really. I don’t have anything else to talk to them about now except my illness, and they’ve heard that before. They don’t understand what it’s like for me, and I don’t have much to talk about anymore but what’s happening to me. I don’t really have the opportunity anymore, and I’m quite isolated except when Joanne [close friend] comes around. When I’d be, talking to my friends, well they’d heard it before. They’ve got their own problems; they don’t want to hear about my kidney problems all the time do they. I don’t want to burden them with that. I know I go on, and on but well, Joanne doesn’t mind that, I don’t know what I’d do if she didn’t pop round’.

Norman described how, as his illness progressed he had limited his social contact. He felt he had a narrow focus of conversation other than his illness and did not want to ‘burden’ friends by constantly discussing his illness so had withdrawn from these
friends, but this had left him feeling ‘isolated’ and ‘lonely’. Other participants used terms such as ‘they don’t really understand’, ‘they look and think I’m alright’ and ‘we don’t have the same things to talk about any more’ when describing how they had limited their social contact with previous friends as they had progressed along their illness trajectory; they felt they no longer shared the same perspectives.

Restructuring reality incorporated the transitions associated with the changing nature of relationships as participants’ health declined and they approached the end of life. As participants’ health deteriorated a greater emphasis was placed on the role undertaken by family members and close friends in relation to informal caregiving. The changing nature of relationships with friend and family experienced by participants as the illness trajectory progressed also served to emphasise the strengths and weaknesses of personal relationships with some gaining greater importance. Other relationships faded in significance with some participants describing a ‘conscious’ and ‘deliberate’ social withdrawal whilst for other participants their relationships with friends diminished as participants no longer shared the same social realm.

Many of the participants in the study had lived with kidney disease for some time, often alongside other co-morbidities such as diabetes, cardiac disease and respiratory disease. As their illness had progressed there had been an associated decline in their physical function which, despite other comorbidities, participants attributed to the ESKD, often framing this alongside older age. Participants experienced an increasing inability to carrying out everyday activities as their physical function declined and they struggled to make the psychological adjustments they had to incorporate this into their lives as their independence was eroded.
For many participants, their mobility was now severely restricted due to fatigue and increasing frailty; this decline in physical function affected the participants’ ability to carry out everyday activities as well as previous activities of interest. Participants found it increasingly difficult or were no longer able to undertake simple tasks which they had previously taken for granted, this included activities of daily living and simple household activities. Participants used phrases such as ‘I can’t do the things I used to do’, ‘I keep having to stop’, and ‘I’m so slow these days’ to describe activity limitations they faced. This is illustrated in the following extract from one participant, Alan:

’No, I’d not had to give in sort of thing, I’d managed. No, it’s the last few months, maybe a bit longer……… I can’t do much now before my legs go and I have to sit down. I potter round indoors, but I can’t get out any more like I used to. I’ve really slowed down; even little jobs make me tired really quickly. I suppose at my age and with this renal problem and all, it’s to be expected. I’m okay if I take it slow and don’t do much’.

Alan’s physical function had declined over a short time period, and he was now no longer able to do simple tasks without considerable effort. He associated these changes with his advancing illness but also implied that this was linked to his age and was to be expected. Similar findings were outlined in the study of patients receiving dialysis who were approaching the end of life (Axelsson et al. 2012a). In this study, physical decline was framed within the context of old age and articulated as ‘being subordinate to the deteriorating body’ (Axelsson et al. 2012a:47).

In the present study participants frequently described how, as their physical function had declined activities became more arduous and outlined the emotional impact which accompanied these changes. As another participant, Irene explained:

’My legs aren’t what they used to be. I run out of steam really quickly these days. I get tired doing even the simplest things. I cannot tell you how long it takes me to do things, simple things……. It’s frustrating; I have to keep sitting down, it’s getting ridiculous!’.
Participants emphasised the ‘frustration’ associated with struggling to undertake simple tasks previously taken for granted but which were now often impossible to undertake due to the restrictions imposed by their deteriorating health. This is emphasised in the quotation from another participant Gladys:

“I just don’t have the energy I had before. I find I start something, something as simple as a spot of tidying up and then I have to sit down. I cannot keep going like I used to that’s for sure. It’s terribly frustrating... I sit here, it’s so frustrating because I just don’t have the energy anymore. I say to myself ‘come on Gladys, get on with it’, but I can’t hurry, I have to stop, I’m so slow’.

Despite trying to push herself to continue with household activities Gladys acknowledged that she was now unable to do this anymore. Some participants described how they often had to break down tasks into smaller ones or find alternative ways to carry out these activities as they tried to adapt to this decline in physical function. This is illustrated in the following extract from a participant, Dorothy:

‘When I do anything, even simple things, it takes me so much longer, you know, making a bite to eat, for example, it takes time……. I have to stop all the time and rest, and well, that’s why it takes me so long. But I’ve got a chair in the kitchen now so I can sit down and take my time. But then after making the food there was a problem because my legs aren’t what they were it’s difficult to carry the food through so I’ve got this, well, it’s like a walking frame with wheels on it and a shelf sort of thing so I can take the food on it; my grandson found it for me on his computer. I don’t care how long it takes me, I’m trying my best to carry on doing things for myself’.

For Dorothy, making changes to enable her to be able to undertake routine daily activities was important to her as her health deteriorated and she attempted to maintain a sense of independence and control even if this was over seemingly small and simple tasks.

Other participants had relinquished some tasks completely as they adapted to the decline in physical function and the increased dependency associated with this.
Participants had re-evaluated what was important to them, what things they considered it was essential for them to do and what things they were willing to compromise on and relinquish or delegate to someone else. This is highlighted in the following extract from one participant, Angela:

'I didn't want to have to have help coming in but, well, I couldn’t keep going the way I was, you know, trying to convince myself I could still do things like I used to. I just don’t have the energy anymore. It was all just getting on top of me, I had to let go of something. So at least this way I can manage now, she does the housework stuff and I can concentrate on looking after myself. Does that make sense?'

Angela had re-evaluated what things she had to do, what things she was able to give up and the activities she could get help with to enable her to preserve her energy. Although this had been difficult for her she also acknowledged that in order for her to be able to continue to be independent at home she had to ‘let go’ and relinquish some control over her life and accept that she needed help with daily tasks. Participants used terms such as ‘there’s just some things I cannot do’, ‘I had to think well, what’s really important’ and ‘I’ve had to compromise on what’s possible’ when describing how they had adapted to their declining physical health. For many participants whilst adapting to functional decline involved a degree of ‘letting go’ of those things that were not possible it also included making the best of what was still possible this was articulated by John who said:

‘There are some things I just cannot do anymore, to try would just be stupid! I couldn’t get in the garden or anything anymore, because I’m very bad really getting about; it’s my legs you see. So, it’s just getting out in the garden really.........I miss getting out. We’ve got a lovely garden, I wish I could get out, just to potter really, you know. But I can still look out at it. I sit here and watch the birds on that tree there. And she [wife] gives me chores to do, I wipe the dishes, peel the vegetables and set the table. She keeps me busy....... I’m still under the thumb [laugh].'

John acknowledged the loss of activities he used to enjoy as a consequence of his
increased physical dependence, but he still took pleasure from reflecting on the things he had previously enjoyed. Despite being unable to undertake tasks around the house as he had previously done, he still gained satisfaction from feeling that he still had a role to play, having found new ways to busy himself and participate in daily activities.

The ability to continue to participate and contribute actively in life, all be it in an altered, or new roles were valued by participants particularly as their physical function declined. Adjusting to the physical limitations imposed by a deteriorating health and accommodating these into one’s life required participants to redefine priorities and compromise in order to enable them to retain a sense of independence and usefulness, often substituting activities that were no longer possible with other interests and activities which maintained a sense of meaningfulness contribution.

The increasing dependency was a source of frustration, serving as a constant reminder to some participants that time was limited. As a consequence, some participants were unable to adjust to the deterioration in their physical function, the losses and restrictions now imposed by the illness, meaning they were unable to accommodate these changes into their lives, as illustrated in the quotation from Norman:

‘I used to be out at the allotment, growing my own veg, pottering about and all that. It used to help me keep my diet and fluids down, but, now I’m not so good, see there’s nothing else to do. I’m sitting down, drinking tea, feeling sorry for myself. Then I’ll have another cup of tea and what have you... Oh, it’s horrible, of course, that means you put on more fluid and especially with my heart, that’s no good. Watching yourself being able to do less and less, well, it just reminds you that things are only going one way aren’t they’.

Knowing that he could not do the things he valued and enjoyed in the past prompted the realisation for Norman that his life was becoming increasingly restricted. The loss of independence as a result of his deteriorating health was a constant reminder
to him that time was running out. Although many participants had adjusted to their declining physical function and health, the threat of the further loss of independence as their illness progressed was a constant for participants as they contemplated the future.

The tangible decline in physical function was a cause of frustration for participants. Many participants had reflected on this decline in physical function, having reconsidered the things which were important to them and what things they were willing to give up. In order for participants to continue to feel a sense of independence, they had to adapt to this functional decline. Restructuring reality in the face of a declining physical function and increased dependence involved a degree of ‘letting go’ of those things that were not possible and relinquishing some control over aspects of their lives. It also included making the best of what was still possible and continuing to contribute to their care and family responsibilities in different ways which enabled them to maintain a sense of purpose and usefulness.

5.8. The substantive theory of restructuring reality during transition for people with end-stage kidney disease approaching the end of life

In this study, the substantive theory which described the transitions experienced by people with ESKD and how they made sense of these was conceptualised as ‘the restructuring of reality during transition for people with ESKD approaching the end of life’. The tentative theory integrated the multiple transitions people with ESKD experience as they approach the end of life, living with the loss and functional decline associated with an advancing illness. It acknowledged the certainty of death alongside the uncertainties associated with living whilst dying and was accompanied by a more profound awareness of themselves and the re-evaluation of what and who was important to them. In making sense of these transitions and
accommodating them into their lives participants strived to maintain autonomy and control through involvement in decision making throughout the illness trajectory towards death. Personal qualities inherent in the individuals' being helped them to navigate the transitions associated with this trajectory by them restructuring their reality which shaped their remaining lives.

5.9. Summary of Chapter

This chapter has presented the core category and the three dynamic, interrelated conceptual categories which form the basis of the emergent theory. Each category has been reported separately, and extracts of raw data were used to supplement the text, adding human insight and dimension to the analysis. The theory which emerged in this study described as *restructuring reality during transition for people with ESKD approaching the end of life*, has also been presented and the relationship between the core category and the three other conceptual categories in relation to the construction of the emergent theory has been examined.

In the next chapter, this emergent theory and its underpinning assumptions will be considered and compared against the existing transition theory. The findings of the study will also be discussed in relation to the research questions and the existing literature.
CHAPTER 6
DISCUSSION, RECOMMENDATIONS AND CONCLUSION

6.1. Introduction

This chapter presents a discussion of the findings. The aim of this study was to explore the transitions experienced by people with end-stage kidney disease (ESKD) as they approached the end of their lives and to develop a substantive theory that accounted for and explained the process and how people made sense of this. The research questions were: what are the transitions experienced by people with ESKD as they approach the end of their lives? how do people with ESKD make sense of these transitions? and what factors influence their experience of these transitions? Following a constructivist grounded theory (CGT) approach the discussion in this chapter is a synthesis of the research findings, the relevant literature and my own interpretive perspectives (Charmaz 2006). The prior theoretical work is acknowledged and the discussion locates this study within the relevant transitional theory and positions the new substantive theory in relation to these existent theories thus demonstrating where the work fits or extends the existing literature and theories. The findings of the study are discussed in relation to the strengths and limitations of the study. Finally, the chapter concludes with a discussion of the recommendations for clinical practice, education, and future research and a concluding summary.

6.2. The substantive theory of restructuring reality during transition for people with end-stage kidney disease as they approach the end of life

The constructivist grounded theory methodology and use of transition as a theoretical framework for the study resulted in an increased understanding of the
transitions experienced by people with ESKD as they approached the end of life. The theory presented as part of this study was based on the analysis and interpretations of the participant descriptions.

The substantive theory of *restructuring reality during transition for people with ESKD* described the experience of people with ESKD as they approached the end stages of their illness trajectory. The theory thus differs from the existing transition theories associated with chronic illness as it is contextually situated in the experience of people with ESKD who are nearing the end of life. The previous transitional theory has explored transitions for people with chronic illness but not those approaching the end of life (Kralik et al. 2010; Kralik et al. 2006c; Kralik 2002; Meleis et al. 2000).

The existing transitions literature on palliative and end of life care has predominantly focused on the transitions associated with the location of care at the end of life or those patients already receiving specialist palliative care services rather than the transitions associated with living whilst dying from ESKD which was the focus of the current study (Duggleby et al. 2010; Larkin et al. 2007a; Murray et al. 2007; Ronaldson & Devery 2001).

Conceptually, *restructuring reality during transition* differs from the existent theories as it situates the transitions associated with a declining physical function and increased dependence for people with ESKD approaching the end of life alongside the relationship aspects within the experience and emphasises involvement and control in decision making within the transitional process.

The findings revealed the context, process, perception and patterns of response to the transitions experienced by people with ESKD and resulted in the theorising of this phenomenon conceptualising this as *the restructuring of reality*. The types of transition, key transition points experienced by the participants within their illness
trajectory and the responses to these changes which contributed to the process of *restructuring reality for people with ESKD as they approach the end of life* are outlined in the diagram below. Alongside this, the facilitators and inhibitors to these transitions are also illustrated.

**Figure 6: Restructuring Reality: Points of transition, facilitating and inhibiting factors and patterns of response for people with ESKD**

6.2.1. The context of transition

Within the context of this study, patients with ESKD experienced a multitude of physical, psychological, roles and responsibilities, activities of daily living, and social and relationship transitions across the illness trajectory to the end of life. The transition points for participants who were approaching the end of their lives were
interrelated, overlapping and constantly interacting. These included the previous transitions associated with ESKD, present and anticipated future transitions, all of which were interwoven into the process of restructuring reality. The transition points and the subsequent restructuring of reality as a consequence of these transitions was a fluid process, incorporating the many changes in the participants’ physical health, function, daily activities, independence, relationships, and sense of self as they approached the end of life. The transition points and adjustments to these were also influenced by a variety of factors which emerged from the data analysis.

The transition points in the participants’ illness trajectory were often disruptive and characterised by uncertainty, frustration, and disturbance in the patients’ prior views of themselves. To accommodate the outcomes of these transitions into their remaining lives patients had to acknowledge these changes and the associated losses that had occurred, were occurring and would occur in the future to enable them to restructure their reality within the context of these changes.

The transition points to the end of life often began much earlier in the illness trajectory at the point of diagnosis and initial treatment decision making when the realisation of their situation made participants question their own mortality. These initial transitions and the changes made to one’s life as a consequence of the diagnosis and treatment choices made remained with patients long after these changes had been integrated into their lives. For many participants, it was only after prolonged periods that the realities of living with ESKD, and the outcomes of the initial decisions and treatment choices were really appreciated, reflected upon and questioned. The starting point for many of the present transitions for people with ESKD began with participants re-focusing on these past transitions, the previous sense of self and realities which had now been left behind. Reflecting on these
previous transitions contributed to the process of adjusting to the present transitions as participants attempted to negotiate and integrate these into their lives.

A change in physical health and functional status often signified a key transition point for participants with ESKD in this study. These changes may be subtle, sometimes transient but were often ongoing and cumulative. They included increased fatigue, reduced appetite and increased fragility which meant participants were no longer able to function as they previously had done. The changes associated with a decline in physical health and function prompted other key transition points for participants in their illness trajectory. These included the associated transition point from independence to dependence which often resulted in a change in roles both for the participant and family, social withdrawal, and the additional provision of care to meet the participant’s daily care needs and help facilitate them remaining at home.

The physical and functional transitions experienced by participants often acted as a catalyst for participants to review the wider current and future transition points within the context of their illness trajectory and led to the realisation of an altered sense of self and of their own death in the future. Death became a stronger threat than it had been and participants started to think about preparing for death and at the same time continued to try to live in the present. This represented a key transition point as participants oscillated between their present life situation and the reality of their future. Living on the threshold to the future unknowns was a significant transition point for participants in relation to the elements of their illness and projecting the transitions they would face in the future associated with a further decline in their health, the considerations of place of care when this happened and contemplating the end of life care decisions. *Restructuring reality* enabled participants to continue
to live in the present whilst being cognizant of the uncertainties associated with their future.

6.2.2. The process of transition

The transitions experienced and the resulting disruption to the participants were dealt with and integrated into their lives through the process of restructuring reality. Restructuring reality meant living with the loss and the possibility of dying through a process of revisiting one's plans for living in the present, attempting to make sense of events and learning to live in a changed reality. There was a recognition by participants of the temporality and impermanence of their reality as their health deteriorated and they approached the end of their lives. Participants had to perpetually restructure their current reality and expectations in relation to the future as a consequence of the ongoing changes imposed on them as their illness progressed and their health declined. This contrasts with the previous theories of transition which outlined transition as a linear process with a distinct beginning and ending (Bridges 2004; Van Gennep 1960). Whilst the concept of transition having definitive beginnings and endings might be applicable much earlier in the illness trajectory of ESKD when decisions are made to commence or forego dialysis, in this study, it did not represent the transitions experienced by participants with ESKD as they approached the end of life. The tentative theory of restructuring reality is portrayed in this study as an ongoing, continuously changing process as health declines, with transitions often occurring simultaneously, being associated with new or recurring losses which required on-going adjustments and the restructuring of reality but did not always result in a new or prolonged period of stability. This supports the previous transition theories of Kralik et al. (2010; 2006b) and Meleis et al. (2000) which depict transitions as motional, creating movement and flow in the
lives of those living the experience and which does not always follow a chronological trajectory.

The emerging overall process by which people with ESKD responded to these transitions was defined as \textit{restricting reality during transition for people with ESKD as they approach the end of life}. The process encompassed the way participants came to know and understand the transitional experiences. It also related to how participants adjusted to these physical and psychosocial losses encountered during their illness trajectory in order to assimilate and accommodate the changes.

\subsection*{6.2.3. Perception and patterns of response to transition}

Participants strived to maintain a sense of control as they navigated the process of transition, this included continuing to be involved in decision making relating to their ongoing care and plans for their death. However, as their health deteriorated, participants were willing to relinquish some of the control over decision-making. Patients coped with a deteriorating health by managing awareness and restructuring their reality to one in which they could continue to live in and retain a sense of control and individuality, reconfirming their identity through continuing activities they enjoyed or substituting these so they still felt competent and useful.

Restructuring reality occurred through a changing definition of what was important and when to worry. Participants re-evaluated what was important to them, choosing to live in the \textit{'here and now'} and normalised their experience within the context of their age and the reality that \textit{'nothing lasts forever'}. Coming to terms with their situation, and connecting with others including trusted healthcare professionals,
were important factors for participants as they negotiated these transitions and the disruption associated with these.

Participants drew on innate personal characteristics to help them accommodate the changes they experienced into their lives and live with the uncertainties associated with their illness progression to death, meaning over the duration of their illness participants had been able to restructure their reality, reframing this in response to these transitions, reflecting on what things were still important to them, and this enabled them to achieve a continued sense of control over their lives and continued involvement in their care.

6.3. Situating the substantive theory and study findings within the context of the existing literature

Some of the assumptions inherent in the substantive theory of restructuring reality during transition and the conceptual categories that underpin this are supported and/or challenged by the existing literature. Each conceptual category within the emergent theory will be examined to make it explicit how the assumptions underpinning each category are embedded in the pre-existing literature. The contribution that has been made to the knowledge base of transition will also be outlined.

6.3.1. Reconstructing Reality

The existing transitional theories outline that awareness is a core prerequisite for transition to take place (Kralik et al. 2010; Kralik et al 2006b; Bridges 2004; Selder 1989). In this study, there was an awareness by all participants that their health was declining, their current reality was grounded in the knowledge that they were
approaching the end of their lives and the probability of their own death in the near future. This awareness had not always been confirmed by the healthcare teams involved in their care as the end of life discussions had not taken place for most patients.

Although all participants acknowledged that the time they had left was short, ‘endings’ for participants in this study were not always related to the thought of death but were associated with the multiple losses in their lives which had occurred, were occurring or those they anticipated would occur in the future. An important part of the transitional experience for participants in this study, as they attempted to adjust to these changes, was the recognition that their current reality was very different due to these losses and the changes they had had to accommodate into their lives as part of their illness trajectory. Participants dealt with approaching the end of their lives by managing awareness of their situation and adjusting to this through the process of restructing reality.

Restructuring reality meant living with the losses associated with health deterioration, physical function decline and the associated loss of independence. This included the process of revisiting one's plans for living in a reality based on the uncertainty of when their health would deteriorate further and the possibility of death in the near future. As part of revisiting these plans, participants had to face the realities of their future which included facing loss and in so doing they chose to maximise the present. In an attempt to maximise the present participants focused on living ‘here and now’, focusing on current function and what they were still able to achieve rather than dwelling too much on what would happen in the future. The importance of the daily routine and being able to accomplish tasks and feel productive was important to participants; they employed strategies to maintain activities and complete tasks. Although many participants could not perform the
tasks they used to they still found satisfaction from the activities they were still able
to undertake or modified how and what they did so they continued to feel useful
even if in a small way and that they were still able to contribute. Similarly, Dobratz
(2002; 2011) investigated the characteristics of ‘self-becoming’ with individuals who
were aware of their impending death and also described how participants adjusted
their expectations as physical functions declined and adapted by accentuating and
cherishing the few remaining functions they had left.

Acknowledging endings and losses had been articulated as a key theme in previous
research exploring transition in people with advanced life-limiting illness. Waterworth
and Jorgensen (2010) study of the transition from independence to
dependence and death for older people with heart failure identified that when
thinking about losses and the future participants expressed a sense of
hopelessness about this with nothing to look forward to; losses could be multiple
and ongoing in relation to both relationships and social support networks and this
was often reflected by participants as a readiness to die. In the present study,
hopelessness was not expressed by participants. Although a quintessential sadness
was expressed in relation to the losses experienced and anticipated, death was
accepted as a part of living and participants acknowledged that for them ‘nothing
lasts forever’. Participants conceded that their lives would end soon but none of
them expressed a desire or readiness to die. Instead, they coped with the
knowledge of their own finitude by managing the awareness of this and re-framing
their hopes.

In this study restructuring reality included living with loss and ‘looking back on the
past whilst contemplating the future’. Individuals reflected on the past and their life
achievements, the time they had had since becoming ill and what they had still
managed to achieve despite their illness helped participants maintain hope for their
remaining future in relation to short-term goals, expressed as an essential optimism. ‘Looking back on the past whilst contemplating the future’ is comparable to the findings from a study of palliative care patients with cancer who were being cared for by a community palliative care team which found that reminiscing on who they once were compared to who they were now was helpful for patients in coming to terms with their situation and in helping them to retain hope (Duggleby et al. 2010).

The constant change that facilitated these transitions for participants nearing the end of their lives was challenging. Progressive illness forced participants to re-evaluate what was important to them, compromising and making changes in their lives that they may not have chosen if the illness had not been present or which they might previously have deemed unacceptable. Often it also included relinquishing control over the decision making related to some aspects of their lives. This meant participants had to change the meaning and focus of their lives in order to facilitate these illness transitions, conceding that they would have to make the most of the time that they had left and found ways to re-think their illness, how it would affect them as it progressed and how they were going to manage the changes they would face. This change in perspective is very much in line with the theories of adjustment to chronic illness which stress the importance of people sometimes having to change their world views to cope with the onset of chronic illness. As Sharpe and Curran (2006:1159) noted;

‘meaningfulness occurs when the new event is integrated into one’s life scheme either by changing pre-existing beliefs to accommodate the event or by changing the meaning of the event so that it is congruent with helpful pre-existing beliefs’.
In this study as the illness progressed participants experienced other transitions associated with changes in their relationships with family, friends and wider social interactions including those with health care professionals. These changes stretched beyond the relationship changes associated with an increasing physical dependency which required family members to undertake caregiving roles. Many participants found that existing close relationships were reinforced and previous family ties which had lapsed were re-established and consolidated as the illness progressed. Changing relationships included social withdrawal, this was often driven by a lack of desire for or the usual connection with people other than family and close friends or as a result of no longer sharing the same social world. This social withdrawal was not necessarily associated with the decline in their physical function. Some participants who were very physically incapacitated by their illness described how they still maintained meaningful social interactions despite these limitations. This withdrawal appeared to be associated with a psychological process and adjustment to the likelihood of death in the near future. This contrasts with the previous research findings by Murray et al. (2007). In their study of the experience and needs of people with advanced lung cancer or heart failure, they found that social and psychological decline tended to be linked to a physical decline in function. As the disease progressed and physical limitations increased, participants experienced a decreased sense of well-being and their world tended to diminish to family and then self.

Many participants perceived that at their age illness was a part of the ageing trajectory and something that was anticipated and accepted as a consequence of the ageing process. Throughout the narrative accounts in this study participants talked about getting older, and articulated what age and illness meant to them. Decisions were often influenced by participants’ perception of their age, the
significance they placed on the presence of other co-morbidities and the duration of time since the diagnosis of ESKD, all of which contributed to their experience of the process of transition. Often the older participants expressed how had they been ten years younger their decisions regarding dialysis treatment may have been different.

The importance of age in the life course at which a person becomes ill and the impact of this on the illness perspective was a central theme in this study and is supported by previous studies of people with ESKD (Ashby et al. 2005; Llewellyn et al. 2014; Low et al. 2014). The current study findings build upon these previous studies which also framed peoples’ perception of their illness and treatment decision within the context of ageing. Llewellyn et al. (2014) in their study of continuity in older people with late stage chronic kidney disease who had declined dialysis described how illness emerged as something inevitable, being perceived as relating to the gradual wearing out of the body. Age was also a significant reason for renal abatement in the study by Ashby et al. (2005) with older people expressing that dialysis would adversely affect their quality of life. Low et al. (2014) study of the experience of close carers of people with stage 5 chronic kidney disease who were conservatively managed concluded that conservative management is organised around the discourse of natural ageing where later life is seen to be defined by decline and eventual death. The participants in the present study included participants having dialysis as well as those being conservatively managed and all participants related the experience of transition to ageing. Associating their experiences with ageing meant that participants normalised their experiences as being a part of the ageing process; this influenced the decisions that participants made about treatment and it also influenced their perception of other aspects of living, including their viewpoint on their approaching
death, their feelings on loss, on their functional decline and their acceptance of their illness experience. Consequently, the individuals' perception of ageing contributed to how they adjusted to the transitions they encountered as they approached the end of life and the process of how they restructured their reality.

6.3.2. Striving to maintain autonomy and control in decision-making

Striving to maintain autonomy and control in decision making during the transitions experienced by participants throughout the illness trajectory emerged as an important factor in relation to both the process of these transitions and how participants negotiated and made sense of these transitions as their health deteriorated. Beauchamp and Childress (2013) described how illness can threaten autonomy and control, outlining that the need for information and control can differ over a period of adjustment. In the present study involvement in decision making occurred on a continuum; the level of involvement that participants desired and were able to achieve engagement in changed throughout the duration of their illness and as a consequence of the transitions they encountered and had incorporated into their lives as their illness had progressed and their health had deteriorated.

6.3.2.1. Factors influencing initial treatment decision making

Shared decision making is a process of communication by which physicians and patients agree on a specific course of action based on a common understanding of the patient’s treatment goals, taking into account the benefits and harms of the treatment options, the likelihood of achieving the outcomes that are most important to individual patients and the support that will be provided (Davison et al. 2015; Elwyn et al. 2012). With reference to chronic kidney disease (CKD), a shared decision-making approach is endorsed to achieve better health outcomes and
greater patient satisfaction, being particularly relevant before the initiation of dialysis when patients should understand the benefits, burdens, and alternatives to dialysis (Davison et al. 2015; Germain, Davison & Moss 2011; Moustakas et al. 2012).

A shared decision-making process with regards to these initial treatment decisions and ongoing care decisions in relation to some aspects of care emerged from the analysis of the data. In this study participants articulated that they had been involved in the decisions to commence or forego dialysis. Although they felt they had been supported by the renal team and had often involved family members in the discussions ultimately the decision had been one they had made. The decisions made reflected individual understanding of the choices within the context of their overall experience of illness. There was an emphasis on the personal nature of decision making based on their perception of their present life, relationships and anticipation of the future, all of which were incorporated into the decision making to pursue certain treatment options or to refuse treatment.

Llewelyn et al. (2014) study focused on the embodied and lived experience of older people with ESKD who had declined dialysis, the study included how participants constructed treatment modalities and approached treatment choices. The findings of their study outlined that participants thought that dialysis would be too disruptive, robbing them of their freedom and instead they chose the continuity of their current life offered by the conservative management option. Participants viewed dialysis as a treatment that both gave the option of life and at the same time took it away due to the time spent receiving treatment and the recovery period; when contemplating dialysis participants ‘did not want to risk losing time in the present for the promise of a future gain of life’ (Llewelyn et al. 2014: 52). In the current study participants’ decisions were also driven by a desire to maintain the current state of self, wanting to maintain as normal a routine as possible thus preserving a daily way of life. This
was particularly important to those participants who chose to forego dialysis and be managed conservatively who wanted to avoid the disruption that treatment may cause to their way of living.

Although participants made reference to a perceived potential increased life expectancy from dialysis, longevity did not feature as an important consideration for those patients who chose to forego dialysis. However, participants who had opted for conservative management described their decisions as having been influenced by the ‘futility of treatment’: participants felt that with or without dialysis they would still die, as dialysis was not curative and at best life prolonging. This contrasts with the findings of previous studies which explored factors that influenced patients with ESKD decisions to commence or forego dialysis (Ashby et al. 2005; Johnston & Noble 2012; Llewelyn et al. 2014; Morton et al. 2010; Tonkin-Crine et al. 2015; Visser et al. 2009). The current findings may, in part be due to the characteristics of the participants in this study who had a declining health and were deemed to be approaching the end of their lives. Previous studies included patient samples who had not yet made the decision (Morton et al. 2010), those who had recently made the decision to be managed conservatively (Johnston & Noble 2012), or those conservatively managed participants who were perceived to have relatively stable disease at the time of interview (Llewelyn et al. 2014). The retrospective nature of the current study meant it was not possible to determine if participants held these views at the time they made the initial decision to opt for conservative management or whether this developed and was influenced by their deteriorating health. Prospective longitudinal studies would enable the assumptions about these decisions to be explored over the course of the illness trajectory.
6.3.2.2. Negotiating and compromising on involvement in ongoing decision making

The importance of autonomy and control in decision making for participants shifted in response to the transitions experienced as their health deteriorated and illness progressed. When considering decision making relating to daily activities participants were willing to compromise many more aspects of care which they previously would not have contemplated in order to achieve goals that were acceptable to them. The importance of control diminished as participants’ health declined and they became more dependent. Participants often became more concerned about their involvement in the decision making process rather than who actually made the decision. This shift meant participants moved from a position of describing how they felt they had made the decision regarding initial treatment options to a model of decision making which emphasised continuing involvement but where control over who made the decision itself becoming less important than being provided with the information and feeling they were involved in the process. This meant that even if participants didn't believe that they had controlled a decision they may still perceive they had been sufficiently involved in the decision making process as long as the outcome was still palatable to them.

Autonomy has been described as being on a continuum, with the point at which actions are more understood and less controlled by others being the point at which intentional actions are substantially autonomous as opposed to fully autonomous (Dalinis 2005). This was particularly evident when participants had had to compromise and accept help with care at home. Often this decision was made by a health care professional or family member, however, participants articulated how they felt they had been involved in the process and understood that this was the
only way that they would be enabled to remain in their home as their health deteriorated.

As their health deteriorated participants placed a greater emphasis on negotiating and compromising on decisions made in conjunction with health care professionals they trusted who were prepared to listen and understand their perspective. This meant participants felt informed by and confident enough in those caring for them that they were willing to relinquish control of decisions related to some aspects of their care. High levels of trust, the amount of experience with the disease and interactions with health care are associated with shared decision making (Kraetschmer et al. 2004, Say et al. 2006). The interactions and trusting relationships participants had with the renal health care professionals had developed over their illness, the level of trust in other health care professionals involved in their care was less evident in the findings of the study. Trust is based upon the extent to which others (health care professionals) are able to assist in times of need and distress and is related to hope, perseverance, and empathy (Karnilowicz 2011). Trusting the expertise, views, and advice of the healthcare professionals in this study facilitated the individual’s sense of choice and awareness, however, when participants were not confident in the health care professional or they felt that their opinions and concerns were not being listened to then controlling decisions became a means of obtaining control of the process.

6.3.2.3. Planning for the end of life

Shared decision making with health care professionals also provides the most favourable conditions for decision making with regards to palliative care, with the evidence demonstrating that shared decision-making, is also preferred by patients as they approach the end of life (Belanger et al. 2014; Belanger et al. 2011; Wilson
et al. 2013). In the current study participants acknowledged the inevitability of their own death. Some participants had already addressed the practicalities of dying such as preparing a will and funeral arrangements, whilst others were contemplating making these arrangements. Participants had also contemplated some of the other decisions they may have to make in the future such as foregoing treatment, decisions relating to the place of care when their health deteriorated and those relating to the end of life. They all indicated that they would want to be involved in these decisions. However, the participants' expectations were that the discussions relating to their end of life care would be initiated by the renal team. Whilst participants felt that it was important to address end of life issues they did not perceive that there was an immediate necessity to have the end of life care discussions in the present, reassured that health professionals would discuss this with them when it was appropriate. They were frequently willing to relinquish control over end of life decisions to these trusted health care professionals who they anticipated would have the discussions with them when ‘the time was right’. Consequently, very few participants had had discussions with health care professionals about the end of life and their care at the end of life.

Wilson et al. (2013) advocate a ‘decision ecology’ model of autonomy and decision making for palliative care patients. This model acknowledges the wider social context, individual narratives and emphasises trust between health professionals and patients in supporting decision making towards the end of life. The model supports autonomy not just at the level of wider decisions around care choice but also at the level of everyday care. Given the findings of the present study, exploring the implementation of such a model warrants further investigation as to the implications and benefits for people with ESKD.
Moustakas et al. (2012) identified shared decision making and the relationship with the renal team as important aspects of care in their review of the literature exploring the needs of older people who were conservatively managed for ESKD. Davison (2010) in the study of end of life preferences for patients with ESKD reported that patients wanted communication from the renal team about their prognosis and future care including discussions relating to planning for future death, although 90% of patients had not had any discussion with the team despite over half of participants relying on the renal team for emotional support which included finding hope and meaning in their lives. Similarly, Collins and Lehane (2013) and Da Silva-Gane and Farrington (2014) explored patient perspective and preferences relating to palliative and end of life care in patients with ESKD and reported that patients wanted honest communication about future care options when their health deteriorated. These studies all explored preferences for future end of life decision making in patients receiving dialysis and in whom the current health status was not specified, meaning many may have been stable at the time of their preferences being sought and as such may differ from the participant sample in the present study. In the current study participants were receiving dialysis or being conservatively managed and all participants had been identified by the renal team for recruitment into the study because they had a deteriorating health and were deemed to be in the last year of life. Despite the possible differences in the sample, the present study findings reflected those of the previous studies; participants still expected the renal team would have the end of life discussions with them and the majority reported that healthcare professionals, including the renal team, had not talked to them about how much time they had left and few participants had completed any sort of advanced directives. This raises important considerations in relation to autonomy, decision making and the timings of the end of life decision-making discussions.
This study demonstrated a disparity in relation to the expectations of participants surrounding the assumptions that health care professionals would raise end of life care planning with them ‘when the time was right’, and the reality that these participants had been identified by their renal team as appropriate participants for the researcher to approach for the study because they had a deteriorating health and were thought to be in the end stages of their illness trajectory approaching the end of their lives. Indeed, participants had consented to take part in a study exploring palliative care, they were able to articulate what palliative care meant and talked very candidly during the interviews about knowing that they would die in the near future.

Policy initiatives have underpinned the importance of the integration of palliative care earlier in the illness trajectory for people with life-limiting illnesses including those people with ESKD and outlined the recommendations that patients should receive timely evaluation of their prognosis, information choices and for those near the end of their life a jointly agreed palliative care plan built around their individual needs and preferences (National End of Life Programme 2012; NICE 2011; Department of Health 2009, Department of Health 2005a). These policy recommendations do not appear to have been integrated into the care of participants in the current study. End of life care discussions and advanced care planning throughout the illness trajectory had not taken place, this was despite the renal team having anticipated that the patients were in the end phase of their illness and approaching the end of their lives as part of the identification of participants by them to be interviewed as part of the study. Another recent study also showed that people with ESKD receiving dialysis reported a lack of opportunity to discuss their future, particularly if their health deteriorated with health care professionals and that these discussions rarely took place although
patients desired them to (Bristowe et al. 2015). The current study findings and those of Bristowe et al. (2015) support the previous policy recommendations to normalise discussions about preferences and priorities early in the illness trajectory and the implementation of advanced care planning for people with ESKD by the renal team.

Whilst end of life discussions can be challenging for healthcare professionals, the tendency to delay these conversations may present a barrier that impedes the individual from taking part in decision-making (Belanger et al. 2011). In a recent study, Bull et al. (2014) undertook a small survey to determine the perceptions that renal health care professionals had about the role of palliative care in the management of chronic kidney disease. The findings showed that whilst renal healthcare professionals supported discussion of end of life care early in the patient's illness at pre-dialysis to enable clearer decision making alongside discussions of treatment options, they also considered the patient's own request to receive information was an important consideration in determining the timing of these discussions. The study findings revealed that healthcare professionals' beliefs, values, and knowledge of palliative care influenced their end of life care decisions. Health care professionals were not interviewed as part of the current research study so it is not possible to ascertain why these discussions had not taken place. However, what is clear is that the study participants trusted the renal team caring for them, they wanted these discussions to take place and this would indicate that the renal team was best placed to have these discussions and support participants through the decision-making associated with planning their end of life care.

In summary, many of the previous studies pertaining to decision making and ESKD focused largely on decision making relating to treatment decisions and had a
particular emphasis on dialysis patients and shared care decision making. In the current study, the process of decision making, and the factors influencing this have been explored from the patient’s perspective across the illness trajectory for participants who were receiving dialysis or conservative management. The findings emphasised the importance that contributing in decision making played for participants, both during the transitions they had already experienced throughout their illness trajectory and those they anticipated they would have to negotiate in the future. Alongside this was the expectations that these discussions would be led by the renal healthcare professionals caring for them. Decision making for these participants with ESKD was complex and dynamic, evolving over time and towards the end of life.

6.3.3. Managing Uncertainty: Knowing without clarity or confirmation

Uncertainty has been described as a key feature within the transitions associated with complex life events (Kralik et al. 2010; Kralik et al. 2006a; Meleis et al. 2000) and has been identified as a common experience for people living with chronic illness (Bailey et al. 2010; Bailey et al. 2007; Mishel 1999; Morrow 2010, Penrod 2007).

Previous research studies exploring transition in life-limiting illness have described uncertainty within the context of the transitions experienced, with the experience of uncertainty often varying depending on the patient’s primary illness. In cancer patients, this uncertainty often centred on prognosis and how much time they had left (Murray et al. 2007; O’Leary et al. 2009). While for patients with a non-cancer diagnosis, the uncertainty was often associated more with the illness trajectory itself rather than the longevity of their remaining life; patients were more concerned about the course their illness would take in the future and the impact this would have in
relation to a decline in physical function, how they would manage day to day, and how they would manage in the future (Murray et al. 2007; O'Leary et al. 2009; Waterworth & Jorgensen 2010). Uncertainty has also emerged as a theme in studies exploring the experiences of living with ESKD and dialysis. With reference to ESKD, Molzahn et al. (2008) undertook a secondary analysis of the narratives of eleven people who were undergoing dialysis for ESKD, uncertainty was expressed within the narratives as a new and uncertain normal associated with a life lived on dialysis. The experience of uncertainty was described within the context of liminal experiences to explain the disruption caused by dialysis and included living/not living, independence/dependence, normal/not normal and being alone/connected. Axelsson et al. (2012a) also described the experience of uncertainty for people living with haemodialysis who were nearing the end of life expressing this as the ‘shared borderland between living and dying’ associated with the suffering due to increasing impediments and consequences of a deteriorating body and the uncertainty associated with the existential thoughts and feelings of being aware that death was near.

In the current study managing uncertainty emerged as participants lived with the knowns (certainties) and unknowns (uncertainties) associated with their illness trajectory, the awareness of their own finitude, accompanied by the possibility of death in the near future and the dying process itself. In the present study, living with the certainties and uncertainties associated with a deteriorating health and the inevitable outcome was conceptualised as knowing without clarity or confirmation. Although participants were cognizant that they were living with the certainty of death, they also expressed a concurrent sense of uncertainty about the ‘when’ and ‘how’ associated with the uncertainty of the illness trajectory and the process of dying; this invoked a corresponding sense of anxiety, with questions being articulated around
the circumstances of dying and concerns for those who would be left behind to carry on after their death. For participants, certainty and uncertainty were interwoven into the transitional experience of living with ESKD, co-existing situationally and existentially as their illness progressed.

Whilst illness trajectories provide physiological markers of illness, the anticipated course of the illness and the decline in a person’s functional capacity, Strauss and Corbin (1990) argue that trajectories of illness are also strongly linked to the ill person’s perception of events. In the present study participants knew that the end of their life was approaching and whilst knowing this was accompanied by a degree of certainty, it opened participants up to the uncertainties of living whilst progressing to death. Knowing created ways of being; acknowledging the finitude of their illness meant that their current reality now included the expectation that their health would deteriorate further and that the future would be short. Unknowns involved the reality of knowing what direction their illness was taking but not the timescale or what to expect, meaning participants found it difficult to anticipate what further decline would look like. Although participants sought to adjust and locate themselves within the prognostic uncertainty inherent in their illness trajectory, the day to day reality of their illness and the prospect of further deterioration and death brought a closer sense of awareness; participants questioned how and when further deterioration would unfold. This increased awareness was manifested with participants as vigilantly observing for changes which may indicate a deterioration in their health and indicate ‘is this it?’

The findings in this study show a notable degree of convergence with the previous literature pertaining to uncertainty in chronic illness. Mishel (1988; 1999) in her seminal work and development of the mid-range theory of uncertainty in chronic illness proposed that ‘vigilance’ was a coping mechanism used by persons
experiencing uncertainty in illness. Likewise, studies exploring uncertainty in chronic illness populations corroborate with the current study findings describing an increasing awareness, being alert to and anticipating changes in condition which may indicate changes in the illness trajectory (Bunker 2007; Farcus 2012, Morrow 2010,).

In Morrow’s (2010) phenomenological study exploring uncertainty amongst people with advanced heart failure, the core concept of ‘vigilantly anticipating’ was defined and described as ‘guardedly speculating and envisioning what lay ahead’ (Morrow 2010:320) as participants described how they felt unsure about what lay ahead and carefully watched the changes in their illness. A more recent study highlighted that uncertainty was also common in patients with advanced illness, included patients with ESKD (Etkind et al. 2016). The study found that factors affecting how people responded to uncertainty included information needs, engagement with healthcare professionals and a focus on the present day versus the future. Uncertainty influenced patients’ engagement with their illness, preferences and future care priorities and how this uncertainty was managed could lead to poor patient outcomes.

Uncertainty for participants in the current study also focused on the present day versus the future care priorities including the process of dying itself. As they considered the future and the process of dying participants envisaged the symptoms they may experience as they entered the end phase of their lives, whether these would be controlled and whether they would be able to continue to be cared for in the place of their choice. For many participants in this study concerns centred around ‘will it be painful’?. Llewellyn et al. (2014) study of participants who were being conservatively managed for ESKD reported that they also expressed concerns about what to expect at the end of life, and whether their death would be
accompanied by pain. Davison (2010) in her study exploring the end of life preferences in patients receiving dialysis, highlighted that although participants were not yet necessarily at the end of their lives, the end of life issues patients wanted more knowledge about were: what to expect clinically near the end of life, palliative care services, and symptom management. Given that people dying with ESKD experience a high symptom burden often comparable to the symptom burden experienced by cancer patients as they approach the end of life (O’Connor & Kumar 2012) the integration of a palliative care approach aimed at facilitating these end of life discussions with patients earlier in their illness trajectory would offer the opportunity to help manage the uncertainty as their illness progresses and provide reassurance around these end of life issues which should surely be the prerequisite for the model of renal palliative care, particularly for older people, with co-morbidities and in whom dialysis may offer no significant gains in either longevity or quality of life.

6.3.4. The importance of personal virtues in transitioning through the Illness

Lebacqz (1985:279) defined virtues associated with the threats of illness as ‘qualities of excellence in response to the stresses of pain, discomfort, physical limitations, loss of autonomy, vulnerability and loss of self’. This definition implying that virtues are not just character traits but more specifically are responses to situations. Participants in the present study exhibited personal characteristics in response to the transitions experienced throughout their illness trajectory. These were defined in the analysis of the findings as personal virtues and described the qualities that they drew on or had developed in order to endure the physical and psychosocial burden associated with their illness. These personal virtues included gratitude, acceptance, being present-focused, and courage and determination.
Recent literature has also emphasised the role of psychological traits, virtues and character strengths, whether momentary states or enduring traits and the contribution of these to the well-being, the adaptation and the adjustment to chronic illness (Kim et al. 2016; Sirois 2014).

The previous research has suggested that chronically ill people face enduring physical and mental burdens which forces them to draw upon personal and moral resources in the face of continuing adversity (Campbell & Swift 2002; Dekker et al. 2005).

Campbell and Swift (2002) investigated patients’ perspectives of the role of a person’s character in chronic illness and suggested that patients valued qualities such as courage or perseverance, maintenance of self-respect, acceptance, and the ability to maintain good relationships with others. The study used patient narratives to highlight the possible virtues relevant to chronic illness, characterising these as the qualities of the ‘virtuous patient’. A small number of patients with ESKD were included in the study sample, all of whom were receiving dialysis and were considered to have stable disease at the time of being interviewed. The qualities valued by these individuals included bearing endurance or perseverance, a sense of reality, awareness of own finitude, acceptance-acquiescence, and gratitude-hope (Campbell & Swift 2002). Participants in the current study were receiving dialysis or conservative management and were considered to have advanced illness approaching the end of life, despite these differences the personal virtues which emerged from the analysis reflected those described in the study by Campbell and Swift (2002).

Acceptance of the changes and illness trajectory consistently emerged from the participant narratives in the current study. The ability to ‘accept’ the changes
associated with their illness, how these impacted on their current reality and the anticipated changes they perceived they would face in the future as their illness progressed resonated through the contextual categories and the emerging theory. Acceptance was not a passive process for participants in the study, it did not imply compliance or unassertiveness on their part, rather this acceptance implied the participants’ perspective as one where they had realistically appraised their situation, had a realistic picture of their current condition and the restrictions imposed on them by their illness and declining health and the associated inevitability of their own death in the near future. This was often expressed by participants as having ‘put things into perspective’ again resonating with the virtues of acceptance and sense of reality described in the study by Campbell and Swift (2002).

Participants strived to live their lives the best they could, remaining present focused and tried not to concern themselves too much thinking about the future, often describing this as living in the ‘here and now’. This helped them adjust to and accept the uncertainty associated with their current reality and future. Being present focused and living in ‘the here and now’ represented an attitudinal value or virtue in relation to the characteristics participants demonstrated in the approach they adopted whilst continuing to live with their illness. Morrow (2010) in her study of the lived experience of feeling unsure in a sample of ten patients with chronic heart failure described ‘moments of acquiescence’ to illustrate the patients’ experiences of accepting and ‘going with the flow’. These ‘moments of acquiescence’ illuminated the patients’ experiences of choosing to accept what they already knew about their illness as well as the unknown in relation to the future illness trajectory describing this as accepting ‘what is and is not all at once’ (Morrow 2010:320). The moments of acquiescence described in the study by Morrow (2010) resonate with the findings of ‘living in the here and now’ described in the present study.
Studies have suggested that when people with a chronic or terminal condition reach a stage of acceptance, they are able to appraise their current situation more easily and think of ways to cope or make adjustments (Bova 2001, Mistry & Simpson 2013). These studies suggest that people ‘accept’ that they will experience losses and that some of these losses cannot be compensated for; they consequently assess if they have the necessary resources to overcome the problem. In the present study, the personal virtues of acceptance and the associated sense of realism demonstrated by participants appeared to positively affect how they coped with the threats posed by their illness. This is not to suggest that virtues are coping strategies in themselves, rather it suggests they were important factors associated with the process of transition for the participants in this study. Dekker et al. (2005) suggest that virtues are ‘prior to’ and therefore help to determine coping strategies, they are moral qualities that help to characterise coping in the context of chronic illness.

Campbell and Swift (2002) suggested that there is a dynamic interrelationship between the threats and challenges caused by the illness and the core virtues. This dynamic interrelationship was evident in the current study, illustrating the significance of these virtues within the experience of the transitions associated with a deteriorating health in people with ESKD approaching the end of their lives. The virtues demonstrated by participants shaped and influenced their responses, facilitating the process of ‘restructuring of reality’, as they adapted and accommodated the physical and psychosocial transitions experienced into their remaining lives.

It is not clear in this study whether these virtues developed as a consequence of the illness or already existed and were drawn upon by participants in order to face the challenge of the transitions experienced as their illness had progressed. However,
important questions arise in relation to the influence of personal virtues and the role they play in the transitional experience of people with ESKD approaching the end of their lives. How participants might be supported to develop or strengthen such virtues requires further investigation and consideration by health care professionals involved in the support and on-going care of this patient population.

6.4. Strengths and limitations of the study

The key strengths and limitations of the study are outlined in the following section.

6.4.1. Strengths of the study

A key strength of this study is that it extends knowledge, providing new insight and a deeper awareness of the transitional experiences for people with ESKD as they approach the end of their lives through the conceptual rendering of the data and the development of a substantive theory. The substantive theory has been articulated as *restructuring reality during transition for people with ESKD as they approach the end of life*. This tentative theory furthers the understanding of the experience of the transitions associated with the end of life illness trajectory for people with ESKD. This theory could be useful for advancing strategies for supporting people through the transitions faced as their illness progresses and they approach the end of life.

Another major strength of the study was the enthusiasm of the participants and their genuine willingness to share their stories. I was initially concerned about the difficulties that may have been associated with interviewing participants given the sensitive nature of the research and the problematic recruitment process associated with the ‘gatekeeping’ by members of the renal nursing team which made initial recruitment difficult. However, once access to participants had been gained they were eager to share their stories, speaking with honesty and candour about their
experience, and the uncertainties associated with their declining health. Whilst acknowledging the likelihood of their own death in the near future, participants also articulated their hopes for the future including the end of their lives. This enabled rich data to be generated from their narratives despite the small sample size, and a deeper understanding of the transitions experienced during the trajectory to end of life for people with ESKD to be gained. I was humbled by their sharing of their intimate thoughts and feelings about their lives, and the limited time they had left.

6.4.2. Limitations of the Study.

Several potential limitations were identified which related to the methodological considerations of the study. In order to make these limitations transparent and open to critique, these are now discussed.

The sample size in this study was small, consisting of twelve people with ESKD. It was initially intended that 15-20 participants would be recruited into the study to enable theoretical saturation. Whilst the small number of participants in the study could be considered a limitation of the work, Charmaz (2006:18) outlined that ‘the ultimate quality and credibility of the work lies with the richness, depth, suitability and sufficiency of the data’. In the study interviews continued to be undertaken until no new issues emerged; the data generated from the analysis of the interviews with participants provided rich and in-depth data regarding the transitions experienced and how these were accommodated into their lives, contributing to a greater understanding of the studied phenomenon.

The findings from this research were drawn from interviews with participants with ESKD recruited from one large renal centre in England. Participants who were unable to speak English and provide written consent were excluded. All participants
were British, or European Caucasians and although they were representative of the population in this geographical area they would not necessarily be representative of the ESKD population in the United Kingdom as a whole (Gilg et al. 2014). Ethnicity, religion, and socioeconomic characteristics may shape the patient’s perspective of end of life care. It is, therefore, conceivable that experiences could be different for people cared for in renal units in other geographical locations and cultural context. The issues associated with ‘gatekeeping’ by some renal staff during recruitment may also have meant that the participants who agreed to take part represented those who were more comfortable discussing their thoughts about dying. Indeed, although participants were not receiving palliative care all expressed a knowledge of what this was and were able to articulate their thoughts about the end of life.

This study lies firmly within the interpretive tradition ‘as the analysis was contextually situated in time, place, culture, and situation’ (Charmaz 2006:131). Qualitative research makes no claim to generalizability; qualitative approaches recognise there is no single interpretive truth and that qualitative research approaches investigate ‘the real world of the participant and so can provide important insight and knowledge’ (Denzin & Lincoln 2005:8). Therefore, the findings of this study cannot be representative of the transitions experienced by all people with ESKD but they do deepen the understanding of the transitions experienced and provide valuable insights for those who care for people with ESKD who are approaching the end of life. The findings may be applied to other clinical context and be relevant to clinicians who treat people with advanced, life-limiting-illness but given the limitations described, the findings may not be transferable to different cultural and religious settings.

This study did not therefore seek the views of other stakeholders, such as the partners of the patients with ESKD or the views of health professionals and this
could be seen as a limiting factor to the study. The aim of this study was to focus specifically on and explore the transitional experiences of people with ESKD as they approached the end of life from their perspectives. However, the value of seeking the perspectives of partners/significant others and health care professionals is acknowledged as it would add further dimensions to understanding transitions.

A final limitation of the study is that interview data were collected at only one point in time. Transitions occur over time and a longitudinal approach would have enabled the experience of these transitions and the participant’s response to this to be explored throughout the illness trajectory.

6.5. Recommendations from the study findings

A number of recommendations are proposed from the findings of the study. These recommendations relate to clinical practice, education and further research in the area of renal palliative care and transition.

6.5.1. Recommendations for clinical practice

It has been over seven years since the publication of the ‘End of Life Care in Advanced Kidney Disease: A Framework for Implementation’, a policy which aimed to improve the palliative and end of life care for people with kidney disease (Department of Health 2009). Considerable progress has been made with regards to renal palliative care over the time period since the publication of this document, and the integration of palliative care alongside renal care for people with ESKD regardless of treatment modality is widely acknowledged as beneficial. Despite the increased evidence base for palliative and supportive care in ESKD, there is still more that needs to be done to improve and embed the principles of palliative care
alongside renal care for people with ESKD who are approaching the end of their lives.

The analysis and interpretation of the present study findings outlined the transitions experienced by people with ESKD as they approached the end of their lives. These transitions were overlapping and ongoing and were defined within the substantive theory of *restricting reality*. The study findings also identified opportunities for a palliative care approach to meet the needs participants articulated and to facilitate the process of transition. The findings highlight several recommendations for clinical practice which are outlined and discussed.

6.5.1.1. **Using the substantive theory as a framework to support people with ESKD who are approaching the end of life.**

Theories provide frameworks for understanding complex situations such as the process and response to transitions associated with ESKD as people approach the end of life; in this study, this was conceptualised within the substantive theory of *restricting reality during transition for people with ESKD*.

Recognising these transitions provides an opportunity to understand the patient’s experience in a different way and may be useful to healthcare professionals by providing an opportunity to support patients and their families, not only in their physical health but with the psychosocial dimensions that accompany this life-limiting illness.

Working with this substantive theory as a framework could help healthcare professionals identify the many transitions in the patient’s health which could be a prompt for exploring the meaning of these changes with the patient and may afford an opportunity to discuss the likely prognosis and future illness trajectory with the
patient. These discussions can then be revisited with new or changing transitions as the patient’s health deteriorates and they approach the end of life.

The substantive theory may also provide a useful approach in the development of intervention strategies to reduce the uncertainties, anxiety, and frustration experienced by people with ESKD as a result of the transitions associated with the progression to the end of life. For example, healthcare professionals involved in the care and support of people with ESKD approaching the end of life may focus on helping patients search for meaning through life review (reminiscing) and re-evaluating priorities so patients are still able to feel a sense of satisfaction in relation to the things they have achieved in their life or can still achieve and do. These can be used as strategies to help people adjust to the changes they are experiencing as they approach the end of life.

6.5.1.2. Discussing palliative care services

Renal healthcare professionals may argue that they now routinely engage in conversations with their patients and their families regarding the availability of palliative care services, however, this is not always supported by the literature (Davison et al. 2014) and in the present study although participants were able to articulate what palliative care was none had had any contact or discussions about this with the renal team. Renal healthcare professionals must engage in conversations with patients and their families regarding the availability of palliative care services, framing these conversations and providing information in relation to what these services can provide so that patients can understand in unequivocal terms the services they can access and the value these can add to their care at all stages of their illness trajectory but particularly as they approach the end of life.
6.5.1.3. Advanced care planning and shared decision-making

Both the ‘End of life care in advanced kidney disease framework’ (Department of Health 2009) and the ‘End of life care: conservative kidney management and withdrawal from dialysis guideline’ (UK Renal Association 2014) both advocate advanced care planning (ACP) for patients with a recognised end of life care need which includes those conservatively managed and those deteriorating despite dialysis. However, the findings of the current study and other recent studies suggest there is still variability in the practice of undertaking such conversations about patient preferences, priorities, and end of life care with people with ESKD (Bristowe et al. 2015; Davison et al. 2015; Davison et al. 2014; Douglas et al. 2014; Koncicki & Schell 2015; Wasylynuk & Davison. 2016). Healthcare professionals caring for people with ESKD should implement advanced care planning as an approach to help support the initiation of discussions with people and their families about future care preferences including end of life care earlier in the illness trajectory. ACP should be in place for all patients in whom the renal team would not be surprised if they died in the next year.

Once identified, patients’ preferences for care should be routinely written to ensure patients receive the care they want regardless of the care location. Goals of care may change over time so advanced care planning should be an iterative process re-visited over time. A greater understanding of the transitions experienced by people with ESKD as they approach the end of life as outlined in the findings of the present study can assist healthcare professionals by providing prompts for when to re-visit the goals of care.

Advanced care planning should extend to the role patients prefer to play in care decision making. This should be re-evaluated throughout the illness trajectory with
shared decision making taking place when planning care which should extend to
disease progression and end of life care decisions.

6.5.1.4. Shifting the focus of care

People with ESKD are increasingly elderly, frail and have comorbidities. A care-
focused approach needs to be incorporated alongside the disease focus regardless
of treatment modality, to enable identification of those who are deteriorating and to
facilitate an improvement in communication about preferences and future care.
The recently published National Institute for Health and Care Excellence guideline
for people with multimorbidity makes recommendations for the clinical assessment
and management of people with multimorbidity, with multimorbidity being defined
as two or more long-term conditions (NICE 2016). The guideline aims to maximise
the care of adults with multimorbidity by reducing treatment burden, unplanned care,
and improve the quality of life by promoting shared decision making based on the
priorities of the individual person in terms of treatment, health priorities, lifestyle, and
goals. A key principle implicit in the guideline is that patients have the right to be
involved in discussions and make informed decisions about their care. The guideline
recommends that people with multimorbidity have an agreed individualised
management plan, developed in conjunction with the patients which will include the
goals and plans for future care, who is responsible for coordinating care, and how
the plan is to be communicated to everyone involved in the patient’s care.
This multimorbidity guideline (NICE 2016) has particular relevance to people with
ESKD and the transitions they encounter as they approach the end of life.
Implementing this guidance in renal services will facilitate the care-focused
approach required for many people with ESKD who are frail and have additional
comorbidities. Appropriate patients will have an individualised management plan
and goals of present and future care documented which can be reviewed during and following transitions. The guideline shares many similarities with the previous End of Life Care Strategy policy document (DOH 2009) and Renal Association Guidelines (2014) in that it outlines communication of who is responsible for care coordination which echoes the key worker recommendation of the previous policy documents and guidance; it also outlines that the plan should be communicated to all involved in the care. As this guidance is not speciality specific and recommended for all patients with multimorbidity it will be implemented earlier in the illness trajectory, and aid in the personalisation of the present and future care decisions including those related to stopping or withholding treatment.

6.5.1.5. Integrating renal and palliative care approaches

The trusted relationships developed with the renal team by participants throughout the duration of their illness means that they may be best placed to support people with ESKD through the transitions as they approach the end of life. Patients with kidney disease expect the renal healthcare professionals to guide them through the final stages of their illness meaning renal healthcare professionals must have the confidence and skills to support their patients through the transitions experienced. Due to their relationships with patients the renal team, if knowledgeable about the transition process are in an excellent position to provide understanding guidance and help navigate the patient through these transitions.

Adopting and implementing aspects of the palliative care approach within the patients' management plan earlier in the illness trajectory will benefit patients with ESKD. A shared care approach to palliative and renal care will enable patients and their families to benefit from both team's expertise. The integrated palliative care
approach needs to extend to primary care, renal and palliative care services working collaboratively to ensure patients are supported and their on-going needs are met.

### 6.5.2 Recommendations for education

The findings of this study demonstrated that although participants acknowledged their illness was life-limiting most had not had discussions about their illness trajectory and future end of life care decision making with health care professionals. Despite this, their expectations were that the renal team would have these discussions with them ‘when the time was right’. The study findings support previous recommendations outlining the need for increased education and training for all healthcare professionals involved in the provision of care to people with ESKD and their families (Bristowe et al. 2015; Davison et al. 2015; Goff et al. 2015). Renal healthcare professionals need specific training to address the needs and preferences of their patients given the complexities of treatment and the challenges of prognostication in ESKD. This will enhance renal healthcare professionals’ confidence in their ability to have difficult conversations with patients concerning treatment choices, help them support patients to manage the uncertainties associated with the illness trajectory and the transitions experienced including those transitions to the end of life, and enable the expectations by patients that the renal team will facilitate these discussions to be achieved. This education is needed to enable the patient, family, and healthcare professional to gain a greater appreciation of the relevance and benefits of palliative care and improves the integration of palliative care and nephrology care.

Specific education should focus on and address:
Advanced care planning (ACP) is considered a critical component of high-quality kidney care with the ability to improve both the lives and deaths of patients with ESKD. Unfortunately, ACP has still not yet been embedded into the routine care of these patients, often because members of the renal team feel they lack the skills and confidence to undertake these conversations (Davison et al. 2015; Goff et al. 2015; Wasylynuk & Davison 2016). Effective ACP communication can be taught and practiced. By providing renal healthcare professionals with the techniques and strategies to enhance their communication skills and a framework to help facilitate these conversations they can become confident and competent in this aspect of care.

Communication skills training should be provided to all nephrology healthcare professionals involved in the care of patients and families with ESKD. There are already established and effective models of communication skills training available both within the oncology and palliative care settings e.g. Sage and Thyme Training which have been delivered to nephrology teams and evaluated successfully (NHS Kidney Care 2012). Renal-specific advanced communication training programmes aimed at improving ACP for renal patients have also been piloted and positively evaluated (Bristowe et al. 2014).

Palliative care training should be an essential component of continuing medical education within the field of nephrology and be a core competency for all members of the renal multidisciplinary team.

There should be systems in place which enable the delivery of experiential learning alongside formal training programmes through collaborative working and establishment of jointly funded renal/palliative care posts or rotational posts between renal and palliative care to enable sharing of both specialities expert knowledge.
6.5.3 Recommendations for further research

This study has added to the small but growing body of research which has explored the understanding of the illness trajectory, end of life care preferences and the experiences of people with ESKD as they approach the end of life. It has also added to the research exploring the factors that influence decision making earlier in the illness trajectory when patients decide to commence or forego dialysis. In addition, the study has highlighted the importance participants attribute to being able to continue to contribute to decision making throughout the illness trajectory.

Similarly, the study has also contributed to the research knowledge relating to transitional theory in palliative care describing this from the perspective of people with ESKD. In this study, people with ESKD experienced multiple physical and psychosocial transitions as they approached the end of their lives. Previous transitions research had focused predominantly on cancer patients, those already accessing palliative care services and the transition from curative to palliative care which are not always relevant to many people with other life-limiting illnesses; these transitions were not evident from the analysis of the data in this study. The transitions experienced were often more subtle for people with ESKD as they approached the end of life.

The substantive theory presented in this study provides a foundation for future research. Considerations for future studies should include:

- The current study sample consisted of white British people which is not necessarily representative of patients with ESKD across the United Kingdom. The application of the substantive theory ‘restructuring reality’ requires further research to be undertaken to explore this in a wider ethnic and socio-demographic population of patients, to gain a greater understanding of the
phenomenon and experiences of transitions for this wider patient group with ESKD.

- Further research is also needed to determine if the experiences and process of transition described in this study and defined as ‘restructuring reality’ were unique to individuals with ESKD or are shared with other individuals with a life-limiting illness who are approaching the end of life.

- Given the findings of the present and previous studies which highlighted that people with ESKD want to have discussions about future end of life care and issues, there needs to be further research which explores interventions that would best facilitate palliative care discussions in this patient population. Further research which focuses on open communication and shared decision making throughout the illness trajectory of people with ESKD are required to ensure that the most effective implementation of processes that facilitate this communication and ongoing decision making to meet the needs of individual patients are in place.

- There remains considerable variability with regards to the provision of the palliative care approach for people with kidney disease; some renal services in the United Kingdom have strong links and multidisciplinary workings with palliative care services, some have renal palliative care nurses which interface and bridge both renal and palliative care services. Research which examines models of renal palliative care provision should be undertaken to determine the most effective models which meet the needs of all patients and families with ESKD and support them through the illness trajectory and transitions experienced as they approach the end of life.

- Studies using a longitudinal design should be undertaken. This would enable the exploration of the experience and adjustment to transitions over the course of the illness trajectory to the end of life for people with ESKD. Further
understanding and identification of these transitions and the priorities for patients over time as their illness progressed would facilitate and guide the end of life approach and delivery of future care for people with ESKD during these transitions.

- The substantive theory of ‘restructuring reality’ needs to be further explored within a wider context which includes the perspectives of partners/significant others and health care professionals caring for people living with ESKD. This will enable a deeper understanding of the experience and impact of these transitions on those close to and caring for the patient, this will provide an additional dimension to the experience of transition and the process of ‘restructuring reality’ which accompanies these transitions as people adjust to the changes associated with approaching the end of life. It will also enable the identification of the facilitators and inhibitors to these transitions from both the family/carers and health professionals’ perspective. Undertaking this research would add to the overall understanding of the phenomenon of ‘restructuring reality during transition for people with ESKD in relation to fostering resilience for people living ESKD and identifies strategies to enhance the development of resilience in this patient population.

6.6 Conclusion

In this study constructivist grounded theory was used to develop a substantive theory from the empirical data obtained from the analysis and interpretation of the interviews undertaken with people with ESKD. This substantive theory was conceptualised as ‘the restructuring of reality’. The process of ‘restructuring reality’ demonstrated that people with ESKD experienced multiple transitions as their illness progressed and they neared the end of life. For participants, these transitions
included acknowledging losses, living with functional decline, shifting roles and changing relationships which were accompanied by a more profound awareness of themselves and the people who were important to them. Making sense of these losses involved striving to maintain autonomy and control in decision making throughout the illness trajectory and the transitions which accompanied this, acknowledging the certainty of death alongside the uncertainty associated with not knowing when or how this would occur. The personal virtues demonstrated by participants helped them to manage the uncertainty associated with the illness trajectory and the transitional experiences and shaped how they lived their remaining lives as they approached death.

The findings in this study have addressed a gap in the literature relating to the nature and experience of transitions for people with ESKD as they approach the end of life. The tentative theory adds to the knowledge of transitions experienced by this patient group, it provides a potential framework for future research and may provide a useful approach to the development of interventions and strategies to diminish the issues experienced by people with ESKD during the illness trajectory to end of life.
REFERENCES.


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APPENDIX 1

PARTICIPANT INFORMATION SHEET

(Version: DClin.02 – dated: 06/04/2013)

The experience of palliative care for people living with end-stage renal disease.

My name is Kara Blackwell, I am a registered nurse with many years’ experience working in palliative care services providing care and support to people who have cancer and other life limiting illnesses including renal disease. I am also a part-time student on the Doctorate in Clinical Practice at the University of Surrey.

I am undertaking this study as part of the Doctorate in Clinical Practice. The study is being conducted to gain a greater understanding of the experience of living with end-stage renal disease and the issues that are important from the perspective of the patient, throughout the illness.

You are being invited to take part in this study because you are living with end-stage renal disease.

Before you decide if you would like to take part in the study, it is important that you understand what will be involved and why the research is being done. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like further information.

What is the purpose of the study?

The purpose of this study is to explore what it is like to live with end stage renal disease and gain your experience of the care you have received at different stages of your illness including your experience and feelings about “critical events” in your illness. Examples of critical events would be when you became more unwell or when you had to make decisions around changing aspects of your treatment and care. Health care professionals need to learn more about the experience of people living with this disease to understand what it is like for people as they have to deal with
different aspects of their illness and treatment so we can better help other persons in similar situations.

Why have I been invited to take part?

You are being invited to take part in the study because you are living with renal disease.

Do I have to take part?

No, you do not have to take part. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. Your participation is voluntary, and you may withdraw from the study for any reason, at any time, without penalty of any sort. It will not affect your care in any way. You may refuse to answer any individual question if you wish.

What will happen if I do decide to take part?

If you agree to participate, the researcher, an experienced nurse will visit you in your home or in hospital, whichever you would prefer and at a time when it is convenient for you. You will be asked to answer questions about yourself (age etc.) Then you will be asked about your experiences living with your illness and the care you have received. Your answers to these questions will be audio taped with your permission. The form and questions will take about 60-90 minutes.

What are the risks or disadvantages of taking part in the study?

Answering the questions may be tiring or upsetting. You do not have to answer any questions you don’t want to. You can stop the interview at any time you want. If you get tired, don’t feel well or become upset, you can take a break at any time or end the interview. If you wish I will contact a member of staff in the team who looks after you or your family.

What are the benefits of taking part in the study?

It is unlikely that taking part in this study will benefit you directly, although some people have found they benefited from talking about their illness with a nurse. However, what you say may help others. The information will be used by health care professionals to provide better care for people in similar situations.
Will all the information remain confidentiality?

If you decide to take part in the study your confidentiality, anonymity and privacy will be maintained at all times. The only exception to this will be if, as part of the interview you divulge that you or someone else are at significant risk of harm. In this instance the researcher, who is a nurse, would act in accordance with guidance from the Nursing and Midwifery Council (NMC) in relation to raising and escalating concerns (NMC 2008).

All data will be kept by the researcher in a study file that will be locked in her office. The information will only be used for research purposes. Your answers will be written down on a form, it will not have your name on it. The tape recording will be transcribed and then destroyed, your name will not be on any of the information. Your name will not appear in any report. All information from this study will be reported in a group format for conferences and publications so no one can identify you. Although direct quotations will be used in reporting the results of this study, they will be presented in such a way as no one can identify you. Your name will not be used and all identifying information will be removed from any report or publication.

All data will be stored securely and destroyed 10 years following completion of the study, as per the University of Surrey’s research requirements.

What will happen to the results?

Copies of the results will be available, along with the rest of the project, on completion of the project. I will be happy to provide you with an information sheet outlining the key findings at the end of the study if you would like a copy. You can also contact me by telephone or email at any time.

Who can be conducted for further information and to answer any questions?

Thank you for taking the time to read the information sheet. If you require any further information or have any questions about this research then please feel free to contact me at any time on the contact details provided below.

This study has been reviewed and granted a favourable opinion by the National Research Ethics Service (NRES) Committee West Midlands-Staffordshire, the Research and Development Department at the Hospital and the University of Surrey Ethics Committee.

Principal Investigator: Kara Blackwell

Deputy Director of Nursing
Academic Supervisors: Prof. S. Faithfull (s.faithfull@surrey.ac.uk).

Prof. A. Gallagher (a.gallagher@surrey.ac.uk).

If you have any complaints about the researcher following your interview please feel free to raise these with the researcher’s academic supervisors who can be contacted via the University at the following address:

Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey
Guildford
GU2 7TE
APPENDIX 2

Interview Guide

Open ended questions to prompt discussion

1. This study is about people’s experience of living with end stage renal disease and palliative care, tell me about your experience of living with this illness?

2. Who have you discussed your illness and current treatment with?

3. How do you feel about your illness and the care you are currently receiving?

4. Tell me about a “critical event” in your illness, for example, when you became more unwell or when you had to make decisions around changing aspects of your treatment and care?
   - Who was involved/helped support you when you had to make these decisions?
   - How did this feel at this time?

5. What are the most important things/main issues for you in relation to your illness and treatment?

6. Do you have concerns about decisions that you might have to make about your care in the near future?
   - Who have you discussed these concerns with?

7. Can you tell me about any experience you have had in relation to palliative care?
APPENDIX 3: Field Note Extract.

<table>
<thead>
<tr>
<th>Field Notes. Interview 4 – Jane (pseudonym)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I arrived to conduct the interview with Jane. I telephoned her when I was outside the house, as she had previously told me to and we had arranged when I spoke to her. There was a key safe and she explained how to assess this to get into the house. When I entered the home she called me to come into the room on the left. On entering the room I found a lady who was bedbound and had a micro-environment set up in her lounge with hoist, hospital bed, overlay mattress etc. All that she required was easily accessible from her bed. I was struck by how isolated and vulnerable she appeared. She lived alone and had carers who came in 4 times daily. At first, I questioned to myself whether I should be there conducting the interview, however, she gestured me over and was keen that I pulled up a chair so we could start the interview. We went through the consent process and then started the interview.</td>
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<tr>
<td>I was an experienced palliative care nurse, used to interactions with people with advanced illness, but during the initial part of the interview I was taken aback by my own level of paternalism which I felt towards Jane; I related this to her physical vulnerability and sense of isolation I felt for her, I had almost not wanted to start the interview initially. Although she was frail and quiet spoken, as we started talking it was evident that Jane was confident in what she was saying and articulated her thoughts and feelings as part of telling her story very clearly. Initially, there were several long pauses, which I interrupted by asking Jane if she was alright or did she want to stop, to which she responded very firmly, that she was just thinking things through, and of course she was alright. I noted that, not long after the interview had commenced her telephone started to ring, I immediately again asked if she would like to terminate the interview, but she said no, that she was enjoying the conversation and would get rid of the caller, at which point she quickly dismissed the caller (a family member) saying she was busy being interviewed by the lady she’d told them about.</td>
</tr>
<tr>
<td>As the interview continued I realised my first impressions of Jane were unfounded. Whilst she was physically vulnerable, she was very spirited and very much in control of her situation and indeed the interview. I was struck by the level of clarity she articulated in relation to her understanding of her illness, her experience and how she gave meaning and insight to her illness and what she perceived the future held for her, which she was very matter of fact about. I was also struck by how determined she was</td>
</tr>
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</table>
to manage the circumstances caused by her illness as much as she could despite the difficulties she had faced and anticipated she would face.

About a half hour into the interview her carers arrived to change her and get her lunch, again I asked if she wanted to stop the interview, she again said no and insisted I have a cup of tea and wait so we could continue the interview. The interview continued after for over an hour. Jane appeared genuinely excited by the opportunity to share her experience with me. I could see that she was thinking through the answers to my probes and working through her story as she told it. This gave me a real insight of the struggle she had had to remain “independent” and involved in the decisions related to her care, particularly when it had come to decisions to enable her to stay in her own home and how she had overcome the barriers she had encountered. Having completed the interview I reflected on this when I arrived back at my office. Despite my initial apprehension at undertaking the interview, the interview with Jane was one of the best so far in relation to the dialogue and flow of conversation. It had been a privilege for the opportunity to share an understanding of her experience and “world”, which provided valuable insight and was very rewarding to me to have been able to do this.
# APPENDIX 4: Interview -Line by Line Coding

<table>
<thead>
<tr>
<th>Interview</th>
<th>Line by line codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>R: Who did you discuss that with?</td>
<td>Decision making</td>
</tr>
<tr>
<td>P3: Well, at the beginning, I didn’t………, well I didn’t want dialysis, because… from here you have to go to XXX hospital to start with three times a week.</td>
<td>Getting to hospital</td>
</tr>
<tr>
<td>R: That’s right</td>
<td></td>
</tr>
<tr>
<td>P3: I don’t like those buses you go in….I’m not a good traveller, and I think the time you’ve been there and come back, back to an empty house……. I’d rather just carry on as I am………………………………. Yes, because it takes out your whole day, and from what I’ve heard from patients who have had it, it's very tiring, they usually collapse on the bed when they come home and have a good sleep, you know.</td>
<td>Practicalities of having treatment</td>
</tr>
<tr>
<td>R: Did you discuss having dialysis?</td>
<td>Travelling</td>
</tr>
<tr>
<td>P3: Well, when, er, not at the time I was diagnosed, I didn’t……….But I used to go to the hospital, to collect the injections……and I had to go to the dialysis ward to get them. And I was standing there waiting to get the injections, looking round at them all laying on the beds and having it and I thought, “no, that’s not for me!”.</td>
<td>Disruption to life</td>
</tr>
<tr>
<td>R: So dialysis wasn’t for you?</td>
<td>Perceived effects</td>
</tr>
<tr>
<td>P3: It’s just, em…..I just didn’t want it. Dr X has really been very good, he really made sure I made my mind up, but, er…….it wasn’t his persuasion in any way</td>
<td>Loosing the whole day</td>
</tr>
<tr>
<td>R: He let you decide?</td>
<td>Symptoms of treatment</td>
</tr>
<tr>
<td>P: Yes, yes, he’s been absolutely fantastic, marvellous with me……and, er, I don’t mind going to him, mostly you dread going but it’s, he’s never like that. We can have a bit of a joke about it, you know.</td>
<td>Feeling supported</td>
</tr>
<tr>
<td>R: I see</td>
<td>Making own decisions</td>
</tr>
<tr>
<td>P3: Yes, em, he’s been very good, I feel he’s got me through really, you know.</td>
<td>Not influenced</td>
</tr>
<tr>
<td>R: Got you through?</td>
<td>Support and praise</td>
</tr>
<tr>
<td>P3: Oh yeah, he has………and June’s [renal Nurse] very good when she comes, you know, telling me what’s what. No, em, it’s a difficult situation, er, it was a difficult decision to make, but I felt, well everyone thought I’d made the right one… Dr X felt I’d made the right one. You know, several times I went back</td>
<td>relationship with renal team</td>
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<tr>
<td></td>
<td>Not apprehensive when seen</td>
</tr>
<tr>
<td></td>
<td>humour</td>
</tr>
<tr>
<td></td>
<td>support from renal team</td>
</tr>
<tr>
<td></td>
<td>supported decision, advice and information</td>
</tr>
<tr>
<td></td>
<td>confirming decisions</td>
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<tr>
<td></td>
<td>querying decision</td>
</tr>
<tr>
<td></td>
<td>control of decision</td>
</tr>
</tbody>
</table>
and he, you know, said “have you changed your mind?” And I said, “no, and I won’t change my mind”. …..When I’ve made up my mind that’s it! I said, “I just didn’t want it….it’s not for me because what happens, you still die at the end, so you might as well choose….the choice you’ve made”. Yeah, it’s entirely a personal choice and er, I’ve talked it over with my son. He obviously said to me ‘mum, it’s your decision, it’s your life’ he said ‘but whatever you do it’s, er, we’re behind you’. He said ‘we’ll agree with whatever you do, it’s what you want’. And…er, I’ve got one sister, she’s down south but I talked it over with her, and so, knowing me, she thought I was doing the right thing…..so and then Dr X said ‘I think you’ve made the right decision’ and, er, ……..everyone thought, thought I’d done right, then I felt alright, but it is a big decision to make, when you know you could go on it, when you could live a little longer. But then, knowing I’ve got the cancer ……..Um, well…….., well for me it was the softer thing, you know. I could live my life as I wanted, sort of thing. And I’m still here….not sure for how much longer, but….well, that’s the only thing with saying you won’t have dialysis……….you keep wondering how much longer you’re going on, you know. I don’t know….I’ve had it explained to me, how it goes, you know and er, different things I can get. June’s explained, you know and that I can get help with it…..you feel that you’ve got a lifeline.

R: They are a lifeline?

P3: Oh yeah, I feel supported, I know I’ve got them at the end of the phone, a lifeline….I know I can’t see them all the while but at the same time, I can, if I pick the phone up, they’ve always come back to me and helped me with advice. I can speak to them, definitely. I never speak to the GP as you can never get an appointment

R: Gosh

R: Yes, it’s hopeless. But between June and Dr X, I manage, you know. I saw Dr X about three weeks ago, won’t see him now for a little…cannot remember when…and, er, you just keep going…..do the best you can. They’re there if I need them.

R: They’re a support for you?

P3: Yes, it’s there, that’s right. As long as that’s there, I know if I go off, they’ll get back to me. The District nurses come into inject me and I know if I am in trouble I can phone them, they’d come as well, so, all in all, I’d rather do what I’m doing.

R: How do you feel about your illness and your care?

Option to change mind determination
Control of choices how you die
Autonomy
Your life-controlling it
Family support
Seeking confirmation for decision made
People to talk things through
Getting decision

Big decision
Living longer
Other illnesses to consider
Living way wants
How much time left??
Consequences of decisions
Wondering
Expectations about illness pathway
Information expectations
Renal team=lifeline
Backup support

Health care support centres around hospital
Getting the advice and support
Available and responsive accessibility

Frequent contact
Timeliness of reviews
Doing the best you can

Trusts renal team to support
Secondary care support
accessibility
P3: You know, I'm lucky, I've had that the two illnesses nearly as long, I've not been in and had a big operation or anything.

R: So you've not had to go into hospital?

P3: No, I've not had to give in sort of thing, I've managed. I can't do a lot, I can't do much before my legs go and I have to sit down, you know. No, it's the last few months, 6 months, you know, I've had to give in. I've had to give me care up and then, of course, you're confined to four walls...

R: You're confined?

P3: Yes, there's not much I can do...my son comes to take me to the hospital if he can get in...[laugh] And, er, he does the shopping for me, changes my bed, that sort of thing. The rest of the family...grandchildren, great grandchildren, I don't see them enough, they're King's Lynn way, and I don't see them, but they keep bringing me photographs to show me how much older they've got [laugh]. Like my grandson there. Yes, it's er, I like to see them but, that's the only thing, to see them.....grow up.

R: Um

P3: I didn't think I'd see them get to what they have, you know watch them grow up more...so I'm glad for tha, you know

R: Gosh, yes

P3: So, you know, it's.....lucky I have seen him. Well [sigh]...... you'll find people worse off than me. It's ur......you get your up days, and you get your down days, be expected really.

R: Yes,

P3: It's frustration more than anything, then you think, it's not, you get your down days because you feel ill, but it's also because you can't do the things you want to do.

R: Right

P3: I've just had to get somebody in, and she comes and does the hoovering for me and cleans the bathroom and that because I can't get down now, I can't well, put my tights on, that in itself is a marathon, nobody would believe the way I do it [laugh] I do it with my walking stick.

[P3 and R laugh]
P3: It's the only way I can get them on......I've ruined a good many pairs but I manage it with my walking stick. The doctor once said, well, I had really itching legs, I think it's because of the kidney problem, your skin goes very dry on me legs and he said ur, he'd get the carers to come in a put the cream, E45 on. I said I don't want the carers coming in [laugh]. He said 'why?' and I said 'because I don't want to, I'll do it myself'. And he said 'how are you going to do that?' You can't get down'. I said 'if you leave me for 24 hours I'll have worked it out'. And I got a big spatula and I bound it with cloth and then get that soaked in the E45 and then you can't go wrong with it.

R: Right.

P3: Yes, it's what you, that's what you've got to do unless you're going to just give up, find new ways to get on......it's about independence.............if you're just going, well you can't give up, and let everyone do everything, you might as well be gone. You know, you can do things for yourself.

You know it makes life a lot easier, it's em, I'm not trying to be a good one or anything like that, but some people want help but,.......I think you've got to find a way, you can do it if you sit long enough and think, work it out sort of thing.

[P3 and R laugh]

P3: Yes, you have to make changes........ I do all sorts of silly things. People would laugh at me if they knew half the things I did, but I get through with it. I don't want to give up, you know...

R: You don't want to give up?

P3: No, I think I've done it, you know, 'Look at me', I don't think I've done so bad, I've had it for 2 years, it was just a nasty blow, that, you know and you know, my blood pressure was so high, I never got sent to the right person and then it was too late, it's too late now..........when I went there, if I'd been sent there earlier, I might not have got like this, so bad with my kidney, you know. They are a good thing, pain killers but they can be deadly can't they. I can't have anything that's got anti-inflammatories in them now, in it now, you know, it's um, you've got to, it's another thing you've got to stop and think about, not taking that because then that it. It's, er, you know, I think I've done alright up til now.

R: So what's the most important thing for you at the moment?

P3 what I don't want is to go into hospital. I'd rather get in touch with XX hospital than my own GP though because we don't get on, because twice he's wanted me to go into hospital and I wouldn't go.

Making adjustments to limitations
Symptoms
Striving to still do things
Determination to carry on
Working it out
Determined
Innovating to remain able to do things
Not giving in,
Changing how do things
Hanging on to independence
Not giving in/up
Still trying to be independent

Reflecting on how to live life with illness
Finding a way
Working things out

Reconciling with change
Maintaining independence in new ways
Not giving up

Reflecting on time lived with illness
Wondering if things could have been different
Finding a meaning for why happened
Other health issues
Thinking things through because of illness
Reassurance about things are going Still thinking doing alright

Experience of getting support when unwell
Challenging advice that doesn't fit values
R: You wouldn't go?

P3: I told him it’s my body and I’m going to do what I want with it [laugh] I’ve mucked about with hospitals enough in my life, I’ve had, what do you call it, injections into my spine, before this, before the kidney problem started. I’ve had all sorts of things and nothing gets to it, the pain from arthritis, you’ve got it haven’t you, it’s worse now as I can’t take the same pain killers because of this. But, um, he wanted me to go in when I had that bad diarrhoea, he thought I might be dehydrated but I said right, I’ll drink more, I was determined I’m not going in, I’m not going in.

R: Right

P3: If you go in at my age, with my problems, that’s when you pick all the germs up, I mean…………. Well, it wasn’t long ago my legs had got really bad and a different doctor came and wanted me to go in [to hospital], she said go and get some investigations into your feet, but I’ve suffered with bad circulation all my life, and I said ‘no’, with the kidney problem what could they do. She said, ‘well we can’t help you, unless you go in and find out what’s causing it, ………we can’t help you unless you go in’. I said ‘I’m very sorry, I know it’s against you, you’re wanting to send me in but I don’t want to go, I’m not going’. She wasn’t listening to what I was saying. Well, I’ve never set eyes on any of them since’

R:Um

P3: They won’t ever cure it but they can help’, I don’t see, some people say go to hospital but I don’t see, not if I can help it.

R: It seems very important to you,?

P3: Yes it is, I’m going to do my best to stay out despite their pressure to go in. Well, at the moment, as I say, I’m managing, it’s not like I’m in terrible pain or anything, so I’m very grateful. My mind is still clear, I and while it is……….well, I want to do what I want to do. There may come a time when I’ll have to, but until then I’ll do what I’m going to do. I know it’s not always the right thing but so far I haven’t suffered…

R: It’s the right thing for you?

P3: No, so far I haven’t suffered from the decisions I’ve made so, only that I can’t get to sleep with my legs, but it could be worse, you never know do you, I know things are worse, but I’m getting on with it, I find a way, I carry on, it’s getting worse and I’ve had to alter things but………. Yes, I suppose I’m doing it my way. I’ve told them if they want to play anything at

| Controlling others involved in care |
| Taking action to try to help oneself |
| Previous illness experiences |
| Lots of things happened symptoms |
| Negotiating alternatives |
| Challenging when outcomes not congruent |
| Determination |
| Reference to age within experiences |
| Lack of continuity of relationships |
| Difficulties ascertaining self |
| Not taking the advice |
| Expectations from others |
| Controlling health care professionals views |
| Not being listened to |
| Feeling let down by some support |
| Outcomes of care important consideration |
| Managing Symptoms |
| Able to make decisions |
| Acknowledging that things might change |
| Reflecting on when she hasn’t taken the advice given and implications |
| Not suffered as a consequence |
| Acknowledging that things getting worse and may need to change |
| Making others aware |
| Impact of previous loss family |
| Retaining sense of who you are |
my funeral, they can get up and sing 'I did it my way'.

[laugh]
I’m always making a joke of it, You’ve got, You’ve got to face it……………..my son has come round now, at first he couldn’t take it and he lost his dad when he was thirty and he never really got over that and er, I’ve been on my own so I’ve had to get hard, you know if you want to live a life. I keep bright and cheerful, sort of thing, but it’s still, it’s always there, I’m living with it but I’m not just living with the one thing. My son said ‘I don’t think there’s anything else you can get, is there’, and I said ‘no, it’s getting that way’. It’s um, he said he just doesn’t know why I got so much and I don’t either but I can’t do anything about it. I nursed me husband, I thought he’d be here to look after me but he could go on so, he was only 56 and that’s no age, so, no, you, you just get on with it.

No, it’s………… well, I just worry about my son, he could go up and spend time with his family but he stays around for me. He says ‘oh mum’.

R: You are his mum.

R: Yes, someone else said that to me. He didn’t use to be able to talk about it………………you know. He knew I wasn’t having dialysis but he couldn’t talk about, about, you know,……….. me dying. But it was important to me, I’ve sorted out my funeral, my will, all that sort of thing. I wanted to leave everything in apple pie order for my son. It was hard at first getting him to talk, to listen to what I want, what I needed to do. It hit him hard when his dad died you see and he didn’t want to go there. I tried to talk to him, he didn’t want to at first, I had to keep at him. In the end, I had to say to him ‘look we need to talk about this. It was a mess when dad died and it’s worse now, there’s the house to sort out and everything listened in the end’. But he will now, have a bit of a joke sort of thing and it makes life a lot easier if you can just have a joke about it. I said, people probably think it’s the wrong thing to do, that you shouldn’t joke about dying but it gets me through. I’ve always been one who’d see the funny side and that gets me through and I’m sorry but if other people can’t put up with that, well I’m putting up with a lot more so they’ll have to put up with that.

| Planning for end, making sure communicated to family |
| Humour                                           |
| Impact on family, losses                         |
| Trying to be positive                            |
| Living with many things that are wrong           |
| Family concerns                                  |
| Questioning why things happen                    |
| Life doesn’t turn out like expected              |
| Personal impact of previous loss                 |
| Getting on with it                               |
| Concerns for family                              |
| Wanting to prepare family                        |
| Concerns for family                              |
| Supporting family                                |
| Concerns for family                              |
| Practical aspects of dying                       |
| Supporting family                                |
| Acknowledging death                              |
| Seeking engagement from family                   |
| Getting them talking                             |
| Previous loss                                    |
| Controlling what wants/going to happen           |
| Working through important issues                 |
| Humour                                           |
| Able to have conversations with family           |
| Using humour to talk about death                 |
| Seeing the funny side                            |
| Finding ways to get through.                     |

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APPENDIX 5: Example of Theoretical Memo

**Memo (24/02/2014)**

Participants’ decision making as their illness progressed appears to be heavily influenced by their experience of decision making earlier in their illness trajectory, often participants reflected on these prior decisions and the outcome and impact of these when they discussed the later decisions they had made or those they perceived they would make in the future. Being in control of decision making in relation to care seemed important to participants earlier in their illness; this focus of ‘control’ and ‘involvement’ changed as the illness progressed. There appeared to be a declining continuum in relation to participants’ desire for control over decision making as their health deteriorated but ‘involvement’, even in the late stages of illness remained a consistent category identified from the analysis of the interview data. This was also influenced by the interactions and relationships with health care professionals and participants.

Often, as participants’ health deteriorated they ended up in a process of negotiating their continued involvement in decision making. Continuing to maintain a sense of involvement in decision making appeared to be an important concept to participants in relation to them navigating the transitions associated with their advancing illness in a positive way. When participants described being involved in decision making and having their concerns/wishes listened to and acknowledged, the decision-making process and experience was described positively. There was a perceived exchange of information between the health care professional and the participant. There was also an implied relationship and trust with these health care professionals which appeared to lead to collaborative decisions. When participants felt involved in decisions, regardless of the outcome of the decision itself, participants articulated this as positive experience and were able to rationalise the outcome, even if the outcome of the decision was not what the participant would have chosen or wanted initially; with an emphasis on an increasing acceptance of the need to compromise when making care decisions. Involvement played a part in their acceptance of the changes they were experiencing due to their deteriorating health and facilitated a sense of retained autonomy.

Negative feelings such as frustration resulted when participants had struggled to be heard, excluded or marginalized from decision making when they had not been provided with information and the process of decision making and rationale for this had been unclear to them. In these circumstances participants lacked confidence in the health care professional involved, it is not clear if this is because they were not being involved in the decision making or whether this was expressed as a result of the lack of involvement and information provision. However, gaining control again became important in these instances were involvement was lacking.

When participants believe they are involved in decisions relating to transitions in care this was influenced heavily by their prior experiences in decision making, control, and involvement in this, relationships, information giving, being listened to and acknowledged, participants were willing to relinquish control and replace this with collaborative/joint working or even relinquish decision making completely to those they trusted.

Further considerations:
• Relationships, trust and impact on decision-making
• Collaboration in decisions, what does this look like?
• Positive and negative factors in decision making relating to ongoing care
• How do participants negotiate and compromise in relation to deciding?
APPENDIX 6: Diagramming

Diagrams were used when working through the data collection and analysis process to help visualise what was going on and the linkages of the spoken words. This diagram helped me explore how participants responded to the loss of independence and the links other codes and categories which were emerging during data analysis.
APPENDIX 7

Health Research Authority
National Research Ethics Service

Dear Miss Blackwell

Study title: A study of the experience of transitions to palliative care of people who are living with End Stage Renal Disease (ESRD).

REC reference: 13/WM/0111

IRAS project ID: 92618

Thank you for your letter of 13 April 2013, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator.

Confirmation of ethical opinion

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

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

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

Where an NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:
Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

**Feedback**

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.

Further information is available at National Research Ethics Service website > After Review

**13/WM/0111 Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at [http://www.hra.nhs.uk/hra-training/](http://www.hra.nhs.uk/hra-training/)

With the Committee’s best wishes for the success of this project. Yours sincerely

[Signature]

Email: nrescommittee.westmidlands-staffordshire@nhs.net

**Enclosures:** List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers”
Attendance at Sub-Committee of the REC meeting
on 14 May 2013

Committee Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Present</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Jackie-Anne Kilding</td>
<td>Community Paediatrician</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Dr Kathryn Kinmond</td>
<td>Senior Lecturer</td>
<td>Yes</td>
<td>Chair</td>
</tr>
</tbody>
</table>
CONSENT FORM
Version 2 06/04/2013

Title of Project: The experience of palliative care for people living with end-stage renal disease.

Name of Researcher: Kara Blackwell

Please initial box

1. I confirm that I have read and understood the information sheet dated 06/04/2013 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I give consent for the interview to be audio taped.

4. I understand that direct quotations will be used in reporting the results of this study but that these will be presented in such a way that I will not be identifiable.

5. I understand that relevant sections of my data collected during the study may be looked at by responsible individuals involved in the research or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

6. I agree to take part in the above study.

Name of Patient Date Signature
________________________ ____________________________ __________

Name of Researcher Date Signature
________________________ ____________________________ __________
APPENDIX 9

Overview of the Integration of my Knowledge, Research, and Practice

1.0 Introduction

This paper provides an overview of the integration of knowledge, research and practice within the context of the Doctorate in Clinical Practice Programme. It outlines how the taught elements of the programme have underpinned the research project and how I integrated this new knowledge within my existing knowledge of palliative care for non-malignant life-limiting illnesses and utilised this within the research study. Within this paper, the taught modules, interactions with professional, clinical and academic colleagues, as well as the reading, reflection and thinking I undertook personally throughout this process will be discussed in relation to how they have contributed to the overall experience of my learning and the acquisition of knowledge.

2.0 The Doctorate in Clinical Practice.

The six taught elements within the Doctorate Programme followed on from each other over the first 2 years of the 4-year programme. My personal aims and objectives for the taught elements of the programme were to understand and gain a greater theoretical knowledge and understanding across all the aspects of the module enabling me to grow both academically and professionally by completing the stipulated assignments and applying the new learning within my area of clinical practice. These taught elements and the knowledge and learning gained from this and the integration of this knowledge and learning within the research project is represented below:
The taught modules undertaken, a summary of my personal learning and growth from undertaking these and the applications in relation to my clinical practice and the research I subsequently completed are outlined in the next section.
2.1 Introduction to Doctoral Studies.

This initial module set the scene for the 4-year study programme. It outlined the expectations in relation to the core competencies that the programme aimed to develop and the expectations of studying at a doctoral level. The module was supported by an e-learning facility to enable in line discussion with other student colleagues and lecturers. This was my first experience of using an e-learning function which I found interesting. The module encouraged students to start to think, even at this early stage about their area of interest for the research thesis so as to begin to formulate ideas and have an open dialogue with academic and clinical colleagues in the healthcare settings about these preliminary ideas. This helped me define the area of interest but at this stage, this was not narrowed down to a defined research topic.

2.2 Communities in Practice Module

This module explored the development of professional knowledge; it considered the historical, cultural and political influences within this. There was an exploration of the links between the philosophy of science and knowledge.

Application to Research and Clinical Practice.

This enabled me to better understand how learning and knowledge are best advanced in current practice. I found this module useful in relation enabling me to reflect on my learning and development needs and this formative work was the first step assisting me to gain a greater sense of where I was starting from in relation to my research journey.
2.3 Policy Politics and Power.

The first taught module undertaken was Policy, Power and Politics, as part of this module a policy review was undertaken and submitted. I chose to review the “End of Life Care Strategy: Promoting high-quality care for all adults at the end of life (Department of Health 2008). The publication of this policy represented a marked shift in government policy in relation to addressing end of life care for all people living with a life-limiting illness and was aligned with the increasing public awareness and demand for choice, to be cared for and die in one’s home (if this is one’s choice) and a commitment to lead improvements in access to end of life care and to increase peoples’ choice at the end of their lives.

Application to Research and Clinical Practice.

The policy review enabled me to develop a wider understand of the political agendas driving policies in health care and those crucial factors which influence the development. This greater awareness of policy development and policy drivers enabled me to better influence changes within clinical practice, being more confident and aware of the policy/evidence base behind this. Following this module the knowledge gained was particularly useful to a piece of work I undertook following the Trust that I worked in at the time becoming an Integrated Care Organisation. I chaired the Group undertaking the transformation project looking at the implementation of “Improvement of End of Life Care for People in Nursing Home” which was undertaken in the two boroughs where we provided community nursing and palliative care nursing and the knowledge gained from this review certainly helped my confidence in engaging with key stakeholders across primary, secondary and the private sector.
The policy review and analysis of this as part of this assignment were also a key element of the development of the research proposal in relation to the background and context of the research project exploring the experience of transition to palliative care for people with End Stage Renal Disease (ESRD).

2.4 Advanced Research Methods

This module provided comprehensive, in-depth training on a range of qualitative and quantitative research methodologies and the module was fundamental in advancing skills that would underpin my research project.

As part of the Advanced Research Methods assignment, I had to research approaches for the compulsory research scenarios provided and then critically analyse the methodological approaches taken and justify the rationale for the research design, data collection methods, sampling and ethical issues. As one of these scenarios relating to researching a “good death,” I was able to gain a greater understanding of the ethical issues which would apply to my own area of research interest, palliative care. These included undertaking research in vulnerable patient populations, professional gatekeeping which was proven to be a particular barrier for me as a researcher when I did undertake my research study, and recruitment in relation to the palliative care population.

Application to Research and Clinical Practice

I gained a great deal of knowledge in relation to qualitative research methodologies which was particularly useful when I came to contemplate and critique the various methodologies and identify the one best suited to my identified research topic later in the progression of the doctorate programme.
2.5 Leadership in healthcare organisations

This module has been instrumental in developing my leadership awareness, changing my attitudes to leadership and challenging me to evaluate my own insight into my leadership styles and behaviour. As part of the written assessment for this module, I had to undertake a critical reflection on a leadership issue in my own area of practice. This involved exploring the relationship between leader and follower and how this is enacted in my own organisation.

Implications for research and Clinical Practice.

The critical reflection and the theory explored as part of this module further advanced my knowledge and interest in this area and prompted me to reflect on how my leadership might impact on those I lead and manage around me. I feel that as a consequence of this module I have grown as a leader and in relation to the greater insight I now have of my own behaviour on others.

2.5 Service Evaluation

This module enabled me to increase my awareness and understanding of the range and use of quantitative methods and mixed methods as I used these to undertaking a service evaluation of a Hospital Specialist Palliative Care Team (HSPCT). Undertaking an evaluation of the HSPCT service provision using Donabidian’s model (1980) as a framework for the service evaluation increased my understanding of how to evaluate and demonstrate the outcomes in relation to benefits gained for key stakeholders accessing the service.
**Application to Research and Clinical Practice.**

The service evaluation designed as part of this module was subsequently used in my area of clinical practice to evaluate the HSPCT I managed. It contributed to the development of future work in relation to the ongoing evaluation of specialist services and the development of Performance Scorecards for these services to evaluate and demonstrate the quality of service provision. During the development and implementation of the service evaluation module my skills in relation to multidisciplinary team working, communication, negotiation, and leadership developed which were beneficial in my professional practice. The completion of this services evaluation also helped facilitate greater understanding in relation to my research proposal and undertaking the research study relating to the experience of transitions to palliative care.

**3.0 Summary of Integration of Knowledge. Research and Practice**

In summary, the knowledge gained through the completion of this academic programme, the academic support, discussions with peer students and clinical colleagues has helped me develop both academically and also in my professional clinical and leadership role. The taught modules undertaken as part of the doctorate programme, accompanied by the supervisory sessions provided me with direction throughout this doctoral journey. Alongside this, it has enabled me to develop and utilise the skills more effectively in relation to undertaking critical analysis, developing as a critical thinker and in extending a deeper understanding of phenomena through the exploration, dialogue and challenge acquired during this academic programme. I have a greater arsenal of skills and tools to draw on to undertake transformation work, lead on change projects integrating research
findings and data analysis into the reports and business cases I prepare as part of my role.

Undertaking the Doctorate in Clinical Practice has also provided me with a unique opportunity to extend my knowledge in relation to all aspects relating to the planning and implementation of research within the clinical setting. It has enabled me to develop further as a researcher, all be it, still an inexperienced researcher. It has provided me with a deep insight into the process and added significantly to the previous limited experience I had which was gained when I undertook my Master’s Degree much earlier in my career. The academic work undertaken during the Doctorate of Clinical Practice has developed my awareness of the factors which influence and hinder the completion of good quality research in palliative care. Furthermore, I consider that, undertaking the doctorate has made me a much more confident practitioner as well as having added to my knowledge and confidence as a senior nurse leader working in an ever changing and particularly challenging NHS. I have been able to share many of the skills and knowledge I have gained and have used it to inspire and motivate others within my professional sphere to undertake academic activities and research.

These key points in relation to the integration of my knowledge, research and practice for myself having undertaken the Doctorate in Clinical Practice can be summarised as:

- Development of a higher level of knowledge and skills in relation to qualitative and quantitative research design, data collection techniques and analysis.

- Personal development as a more analytical and critical thinker, which has enabled me to have the ability and confidence to undertake a research study at this academic level within my field of clinical expertise.
• The appreciation of the benefits of more extensive and in-depth discussions with academic supervisors and other peers, both on the doctorate programme or within other academic institutions affiliated with the Acute Hospital Trusts I have worked

• A greater understanding of the many research methodologies, and the ability to evaluate the appropriateness of these in relation to the research being undertaken.

• A greater appreciation of the ethical considerations inherent in undertaking research with vulnerable patients within the NHS.

• A greater understanding and appreciation for the knowledge and skills I have both as a senior clinician, senior leader and novice researcher in the NHS.

4.0 Conclusion

Overall I consider that I have effectively integrated my knowledge, research, and practice which benefits the care I deliver and the teams I lead within my current role. I believe that although the Doctorate in Clinical Practice has challenged me in many ways I have grown as an individual and as a health care professional as a result of having completed this programme of study.
APPENDIX 10

RESEARCH LOG

1.0 Introduction

This research log represents a summary of the development of my research skills over the four years of Doctoral study. It provides a record of my personal development throughout my research journey and is supported by supervisory feedback, ethics approval meetings, and annual reviews.

2.0 Learning Needs Analysis

I started the doctorate programme with a small amount of personal experience of having previously undertaken a research study as part of a Masters in Science (MSc) which I completed in 2000. As part of the MSc programme, I completed a qualitative research study exploring psychosexual issues for people with advanced cancer. At the time of commencing the Doctorate programme I was still practicing clinically within the field of palliative care and was working closely with the academic Palliative Care Department affiliated to the acute NHS Trust in which I worked, I was an active member of a Research Project Advisory Group undertaking a systematic review to understand the place of death for non-malignant conditions.

On commencement of the Doctorate programme a learning needs analysis was completed by undertaking a strengths, weaknesses, opportunities and threats [SWOT] analysis which enabled me to explore my motivations for undertaking doctoral studies, assess the extent of my existing research knowledge and highlight the areas that I needed to focus on in relation to my personal development as part of this research journey.
Table 1: SWOT Analysis.

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Opportunities</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Passionate about improving clinical care</td>
<td>• To carry out a substantive piece of research</td>
</tr>
<tr>
<td>• Effective professionals networks and peer support</td>
<td>• Writing for publication- have not yet done this</td>
</tr>
<tr>
<td>• Experience of undertaking research at MSc level</td>
<td>• Academic support</td>
</tr>
<tr>
<td>• Effectively critically evaluate information</td>
<td>• Peer support</td>
</tr>
<tr>
<td>• Experience of audit in practice to drive practice development</td>
<td>• Level of skill around critical analysis but these need to be further at doctoral level</td>
</tr>
<tr>
<td>• Team player, supportive of others</td>
<td>• Use of software to manage data analysis</td>
</tr>
<tr>
<td>• About to work inter-professionally</td>
<td>• Develop improved skills writing at a higher academic level.</td>
</tr>
<tr>
<td></td>
<td>• Ideas of research topic area but not yet clearly defined</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Weaknesses</th>
<th>Threats</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Time management</td>
<td>• Organisational pressures impacting on study time</td>
</tr>
<tr>
<td>• Limited in depth understanding of research methodologies, methods and data analysis</td>
<td>• Study leave for undertaking the research study</td>
</tr>
<tr>
<td>• Limited experience of undertaking research</td>
<td>• Achieving a workable work/ study/ life balance that enables me to achieve goals within designated timescales</td>
</tr>
</tbody>
</table>

**Action Plan to address Knowledge Gaps**

Following the completion of the SWOT analysis which identified some key areas of concern and knowledge gaps, I developed a personal development plan to try to address some of these knowledge and skill gaps as outlined below.
Table 2: Action Plan to develop knowledge gaps.

<table>
<thead>
<tr>
<th>Knowledge &amp; Skills Development</th>
<th>Action Plan</th>
</tr>
</thead>
</table>
| Development of study skills required for Doctoral-level study | • Complete and maintain reflective researcher log  
• Access and read appropriate supporting literature  
• Continue to attend and contribute to Research Advisory Group in own Organisation  
• Identify work based supervisor/support  
• Access academic supervisor |
| Time and Project management skills | • Discussion with line manager regarding access to study leave  
• Access literature to support planning of Ph.D. studies: Dunleavy, P (2003) Authoring Ph.D.: how to plan, draft, write and finish a doctoral thesis or dissertation  
• Attend relevant study skills seminars  
• Planned time management to enable ring-fenced study time |
| Critical reading ability /critical analysis skills | • Attend appropriate seminars  
• Library access and familiarity with key resources  
• Advanced Research module within taught element of doctorate programme |
| Greater understanding of advanced research methodologies | • Modules within the taught elements of Doctorate Programme  
• Regular reading, review of research with particular reference to research methodologies, critically explore these  
• Expand depth and scope of literature read |
| Presentation and academic writing skills | • Supervision sessions and feedback on written work submitted  
• Continue to undertake regular teaching in speciality area  
• Attend and present at Palliative Care Seminars internally and externally to my organisation |
3.0 Key Aspects of Research Journey and Challenges

This section will present an outline of the key aspects of my research journey, the key challenges, and significant events which occurred whilst undertaking the research study.

3.1 Topic review

At the start of the doctorate programme the focus of the research project was in its early phase. I knew the broad topic of interest; palliative care in non-malignant disease but had not developed this further. It took me considerably longer than I initially anticipated to refine this and develop the research question. Initially, although it was clear to me what it was I was looking to investigate my initial interpretation of this lacked clarity and I struggled to articulate this clearly. The research question was formulated following involvement in a systematic review during which I had several conversations with palliative care colleagues, some of which had a special interest in renal disease. These conversations focused my mind in relation to the research topic I was interested in; knowing more about the patient’s experience of transitions, not just in relation to place of care but also the psychosocial aspects involved in the transition to palliative care, and how this applies to non-malignancy. I had a particular interest in renal palliative care, this had developed from previous work undertaken with a large renal centre working alongside them to support the implementation of the Liverpool Care Pathway in 2002.

Literature reviews were conducted to understand in more detail the issues associated with renal palliative care and the experience of this stage of the illness trajectory for patients. These initial literature searches were supported by library
staff at several institutions including the University of Surrey and Kings College London and from research articles considered of interest to me provided by my academic supervisor and academic/clinical palliative care colleagues.

3.2 The Research Proposal

Having completed the first outline of my research project in 2010, this required much further work which was completed over the following 6 months. I initially struggled with deciding on a research methodology, having decided that qualitative methodology was best suited I initially went down the route of case study before a meeting with my academic supervisors helped me clarify that grounded theory would be a better and more suitable methodology. The development of the research proposal was lengthier than originally planned due to work based issues having changed roles.

3.3 Methodological Considerations

I already had a particular interest in qualitative research methodologies having previously undertaken a phenomenological study for my MSc in Palliative Care. My research topic was best suited to qualitative methods. However, as I read more about qualitative methodologies I became particularly interested in the grounded theory methodology considering this to be the best fit for my study, allowing for rich, in-depth data and the generation of a theory to explain the process and experience of transition.

3.4 The Process of Ethical Approval

The process of ethics approval was particularly challenging in this study. Having submitted the ethics paperwork via the Integrated Research Application System (IRAS) I attended the NHS Research Ethics Committee meeting in December 2012.
The fact that this was a study exploring palliative care was of particular concern to them in relation to the process of informed consent and protection from distress. Although I was able to talk through this and articulate how this would be managed, the initial feedback requested minor alterations to the Participant Information Sheet and other supporting documentation but also stipulated that in order to achieve a favourable ethics opinion I had to have the research proposal peer reviewed by an academic who was an expert in the field to provide assurance around scientific merit. This was despite my academic supervisors, one a Professor in Cancer Care and the other Professor in Ethics and Care having agreed this study and signed off the ethics application paperwork. Identifying someone that would be considered suitable in relation to their request was time-consuming and delayed the final ethics approval by some months. This was my first experience of this process as the research previously undertaken for my MSc had only required liaison with local ethics committees which had been much less stressful, and frustrating despite the previous study also addressing the needs of a palliative care population of patients. Having achieved a favourable opinion at national level the process of obtaining Research and Development (R&D) and University Ethics approval was uncomplicated and granted in a relatively short timescale.

3.5 Recruitment

Prior to ethics approval being confirmed, I did contact the Clinical Lead for Renal Medicine at the Trust where I had applied for local ethics to undertake the study. He arranged for me to meet with him, he was very enthusiastic and certain they would be able to identify potential participants for me to approach about the study. Following ethics approval, I attended the renal multi-disciplinary team (MDT) meetings to discuss the study and elicit their help in relation to recruitment. Despite this, recruitment of participants was a challenge for me throughout the study. Data
collection commenced in September 2013, I had initially anticipated that given the enthusiasm of the team I would soon be recruiting. However, recruitment continued until the end of March 2014 and was very slow. Despite clinicians identifying potential participants from their clinical database and requesting that this was discussed with patients by the nursing team, there was a degree of gatekeeping with the nurses often wanting permission from the Chief Nurse for the Trust prior to approaching participants. This was despite explaining that the study had been granted approval from the Research and Development Department within the Trust. However, just when I was about to despair I was introduced to two senior nurses who were very amenable, proactively identified and discussed with patients who I could then approach. Three participants who agreed to take part did have to withdraw as they became very unwell prior to the interview and as such it was inappropriate to continue.

3.6 Data Collection

Having struggled to get to this point this was the most enjoyable and rewarding part of the research journey. I was able to use my nursing palliative care skills to easily establish a rapport with participants, put them at ease and which encouraged them to share their stories. Throughout the interviews I was struck by their honesty and courage as they talked, often for what they expressed as the first time about their concerns in relation to their progressing illness, dying and the care of their family members. I was keen to transcribe the interviews myself as a way of becoming more familiar with the data, to identify the emergent categories and theory and to really enable me to listen and understand the participants’ stories and experiences.
3.7 Annual reviews

I have completed four annual reviews reflecting my progress with the taught module assignments and the research study. These have been used to inform my research log. The annual summary enabled me to reflect and compare my progress against the doctorate programme objectives and personal objectives and review the achievements and the difficulties encountered.

3.8 Training

As well as the taught modules I have attended training on the software data management system NVivo and also had to complete the Good Clinical Practice (GCP) program which was a stipulation for the Research and Development Committee in the acute Trust where study participants were recruited.

3.9 Support from Others

Completing the reflective research log has made me aware of the support and networking with others that has taken place as part of the completion of my research. This networking has stretched beyond various academic and professional boundaries and has had a positive impact on my development and the progress of my project. This has been achieved through attendance and networking at national conferences and leadership meetings, discussions with peers from other healthcare disciplines both locally and nationally, discussions with my academic supervisor, academic colleagues, and conversations with patients and their carers in the clinical area of practice. Colleagues in palliative care were particularly supportive in the early stages of the development of the research project.

3.10 Supervision
Supervision has been a valuable support for me throughout my research project. In the initial stages, I was slow to take up and utilise this supervision but this has become increasingly important over the duration of the study. I have had the same principal academic supervisor throughout my doctorate programme my second supervisor changed earlier on in the research programme due to retirement but has remained consistent since. Feedback from the supervisory sessions has helped me to develop my research project, explore suggestions made and enabled me to be more confident in undertaking the study itself. As I moved out of the South East of England and relocated to the West Midlands accessing supervision became more difficult but was achieved via telephone conference calls and Skype, with occasional face to face supervision sessions. A summary of key supervisory sessions is outlined in Table 3.

Table 3: Summary of Key Supervision Sessions

<table>
<thead>
<tr>
<th>Date</th>
<th>Discussion points</th>
<th>Action points</th>
</tr>
</thead>
</table>
| November 2009 | Discussion of possible topic areas in relation to renal disease and palliative care  
Explored possible theoretical bases of transition and how this might help frame a qualitative study  
Links to taught elements e.g policy, service evaluation | • Read qualitative work in relation to treatment decisions and moving into palliative care  
• Discuss with clinical leads the importance and relevance of work in relation to existing studies  
• Write 2 pages summary of ideas |
| March 2010   | Discussed need to book regular supervision, joint supervision sessions with both supervisors  
Explore research question: Do certain groups make this transition and if so how does it differ  
Case study methodology as a framework | • Write first part of literature review  
• Send draft Easter  
• Organise telephone tutorial for feedback  
• Dates for supervision over next 6 months. |
<table>
<thead>
<tr>
<th>Month</th>
<th>Event</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 2010</td>
<td>Discussion of taught assignments</td>
<td>• Plan to complete these in timeframe  &lt;br&gt;• Work on draft research proposal</td>
</tr>
<tr>
<td>February 2011</td>
<td>Feedback on Proposal  &lt;br&gt;Discussion on research methodology  &lt;br&gt;Planning for project</td>
<td>• Take out case study and explore grounded theory methodology  &lt;br&gt;• Make clear introduction and clinical relevance</td>
</tr>
<tr>
<td>June 2011</td>
<td>Annual Review  &lt;br&gt;Completed and passed all taught elements of Doctorate Programme  &lt;br&gt;Slow progress due to work related issues and time to revise proposal</td>
<td>• Need to progress with Ethics paperwork and approval  &lt;br&gt;• Write draft methodology</td>
</tr>
<tr>
<td>January 2012</td>
<td>Temporary Withdrawal 4 months</td>
<td>Data for ethics committee  &lt;br&gt;Arrange further supervision following this</td>
</tr>
<tr>
<td>December 2012</td>
<td>Submission of NRES Ethics</td>
<td>Professor Young identified and to be approached to undertake a review of the proposal.</td>
</tr>
<tr>
<td>March 2013</td>
<td>Identification of who to approach in relation to Ethics Committee</td>
<td>Labels for ethics committee  &lt;br&gt;Arrange further supervision following this</td>
</tr>
<tr>
<td>May 2013</td>
<td>Academic peer review of proposal</td>
<td>Letter of endorsement for the study from academic expert as per stipulation by Ethics Committee</td>
</tr>
<tr>
<td>May 2013</td>
<td>Condition of favourable opinion</td>
<td>• Ethics approval finally was given</td>
</tr>
<tr>
<td>June 2013</td>
<td>Discussed R&amp;D submission and University Ethics Approval Process</td>
<td>• R&amp;D request completion of GCP training so need to book this  &lt;br&gt;• Submit University paperwork and R&amp;D submission by end of June</td>
</tr>
<tr>
<td>July 2013</td>
<td>Annual Review</td>
<td>• Delays caused by Ethics process and request for peer review prior to granting approval</td>
</tr>
<tr>
<td>September 2013</td>
<td>Recruitment of participants</td>
<td>• Feedback from meeting with Lead Clinician  &lt;br&gt;• Attendance at Renal Multidisciplinary meeting</td>
</tr>
<tr>
<td>Month</td>
<td>Task Description</td>
<td></td>
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<td>-----------</td>
<td>----------------------------------------------------------------------------------</td>
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</tr>
</tbody>
</table>
| November 2013 | Recruitment of patients to the study  
Engagement by senior nursing staff |
|           | • Contact Chief Nurse at Acute Trust to request help with addressing nurses concerns that she agree to them helping facilitate recruitment  
• Initial themes from first few interviews discussed |
| December 2013 | Review of Literature                                                                 |
|           | • Amend based on feedback from supervision sessions and written  
• Restructuring of Introductory chapter and what sections should be included in this.  
• Theoretical framework to follow on from the literature review.  
• Consider recent literature relating to End of Life Care Pathway. |
| January 2014 | Methods Chapter                                                                       |
|           | • Continue to develop this |
| April 2014  | Discussion of initial chapters and findings                                           |
|           | • Require much more work in relation to depth of analysis  
• Continue analysis  
• Work on developing higher level themes and how these emerged and use reflections from field notes  
• Read more about ethical issues |
| July 2014   | Review of Findings Chapter                                                            |
|           | • Review changes and complete  
• Proofread and correct typos  
• Send remaining categories within the findings by end of August  
• Discussion previous literature review, include transitions research in chronic illness  
• Discussions relating to examiner |
| August 2014 | Review of Findings Chapter                                                            |
|           | • Amend based on Feedback  
• Professor Faithfull identified external examiner and liaising  
• Examination Form sent to Professor |
3.11 Challenges

The main challenges other than the ones already mentioned in relation to the research study related to the difficulties achieving a balance between my professional role at work, academic work, and personal life. I have had several role changes, one of which included relocating my whole family to the West Midlands. Although I struggle with time keeping I have always previously been able to meet deadlines, including academic deadlines, however, in a senior post in a very challenging NHS this has become increasingly difficult and caused a great deal of stress for me.

4.0 Summary of the Research Log

There has been an increasing interest in palliative care for non-malignant diseases over the last decade. Despite this, the experience of the transition to palliative care for patient populations with chronic illnesses has remained unclear and under-researched. Many patients still do not have access to palliative care services during
the end stages of their lives. This study has been valuable in contributing to the knowledge base of the experience of people with End Stage Renal Disease approaching the end of their lives. This study has enabled me to expand my understanding of both this area of research and also my skills as a researcher and develop a deeper understanding of the issues and challenges associated with undertaking research particularly when it relates to palliative care.