



Provided by the author(s) and University of Galway in accordance with publisher policies. Please cite the published version when available.

Title	A qualitative exploration of the factors that influence healthcare decision-making in the management of end stage renal disease in older adults in Ireland.
Author(s)	O'Riordan, Julien
Publication Date	2021-12-10
Publisher	NUI Galway
Item record	http://hdl.handle.net/10379/16989

Downloaded 2024-04-25T18:33:50Z

Some rights reserved. For more information, please see the item record link above.



'A qualitative exploration of the factors that influence healthcare decision-making in the management of end stage renal disease in older adults in Ireland.'

A thesis submitted to the School of Medicine, National University of Ireland, Galway in fulfilment of the requirements for the degree of Medical Doctorate

By

Dr Julien O'Riordan

MB BCh BAO BSc MRCPI MICGP DME



School of Medicine

National University of Ireland Galway

Supervisor: Professor Andrew Smyth

Date: 10 /12/2021

Table of Contents

Abstract	6
Declaration	7
Acknowledgements	8
Dedication.....	9
List of Tables	10
List of Figures	11
List of Abbreviations.....	12
Chapter 1: Introduction:	13
1.1 Chronic Kidney Disease and End Stage Renal Disease	14
1.2 ESRD in Older Patients	14
1.3 Advance Care Planning.....	16
1.4 Shared Decision-Making.....	19
1.5 Health Literacy	21
1.6 End-of-Life Care Planning in Nephrology.....	23
1.7 Supportive / Palliative Care & ESRD.....	24
1.8 End-Stage Renal Disease in Older Adults – the Nephrologist Perspective	25
1.9 End-Stage Renal Disease in Older Adults – the Patient Perspective	30
1.10 Clinical Case	36
1.11 Thesis Aim.....	38
Chapter 2: Methodology.....	41

2.1 Research Design	42
2.2 Data Collection.....	42
2.3 Nephrologist Study	43
2.4 Patient Study.....	45
2.5 Rationale for choosing Thematic Analysis	47
2.6 Thematic Analysis	48
2.7 Trustworthiness of the Data.....	49
2.8 Components of Thematic Analysis	51
<i>Chapter 3: Nephrologist Study</i>	<i>54</i>
3.1 Introduction	55
3.2 Methodology.....	56
3.3. Results	57
Table 1: Characteristics of Nephrologists	58
Table 2: Reasons for choosing Conservative Management	60
Table 3: Evolution of ‘Barriers to Discussion.’	61
Table 4: Suboptimal physician communication skills.....	61
Table 5: Themes and subthemes	62
3.4 Discussion	68
Strengths and Limitations	72
3.5 Conclusion.....	73
<i>Chapter 4: Patient Study.....</i>	<i>74</i>
4.1 Introduction	75

4.2 Methodology.....	76
4.3. Results	78
Table 6: Participant Characteristics	78
Table 7: Limited Patient Understanding of CKD.....	79
Table 8: Disempowerment reflected limited health literacy	79
Figure 1: Project Map: Evolution of themes: Limited delivery of patient centred care.....	80
Table 9: Themes and Subthemes.....	81
4.4 Discussion	90
Strengths and Limitations:	92
4.5 Conclusion.....	94
<i>Chapter 5: Overall Discussion & Conclusion.....</i>	<i>95</i>
5.1 Summary of Key Findings from This Research Work	96
5.2 Key Findings in Context of International Literature.....	102
5.3 Future Directions	107
Communication Skills Training.....	107
Patient Health Literacy.....	108
Renal Supportive Care Services	108
<i>Conclusion.....</i>	<i>109</i>
<i>Appendix I: Outputs Arising From This Work</i>	<i>111</i>
Presentations.....	111
Publications	112
Prizes	112
Permissions & Copyright.....	113

<i>Appendix II: Ethical Approval for Nephrologist Study</i>	<i>114</i>
<i>Appendix II: Ethical Approval for Patient Study</i>	<i>115</i>
<i>Appendix III: Focus Group invitation to Consultant Nephrologists.....</i>	<i>116</i>
<i>Appendix IV: Interview Topic Guide for Nephrologist Study</i>	<i>117</i>
<i>Appendix V: Demographic Data of Consultant Nephrologists</i>	<i>119</i>
<i>Appendix VI: Electronic invitation to Consultant Nephrologists.....</i>	<i>120</i>
<i>Appendix VII: Informed Consent Leaflet for Patient Study.....</i>	<i>121</i>
<i>Appendix VIII: Patient Study-Interview Topic Guide.....</i>	<i>126</i>
<i>Appendix IX: Codebook from Nephrologist & Patient Study: sample</i>	<i>128</i>
<i>Appendix X: Memo: Patient Study, Interview 1</i>	<i>130</i>
<i>References.....</i>	<i>132</i>

Abstract

Background

Older patients with end-stage renal disease (ESRD) are willing participants in advance care planning (ACP) but just over 10% engage in it (1-3), potentially as nephrologists fear such conversations may upset patients (4). Hence the values and wishes of patients are frequently underrepresented during key healthcare decision-making (2, 5, 6).

Objectives

The objective of this thesis is to better understand the care of older patients requiring dialysis in Ireland. First, to explore the approach of nephrologists to managing ESRD in these patients including conservative management, dialysis withdrawal and end of life care. Second, to explore the experience of these patients with dialysis, ACP and their satisfaction with life on dialysis.

Methods

Both studies utilised qualitative interviews and thematic analyses to distil the data addressing the objectives.

Results

Twenty nephrologists working in Ireland and fifteen older dialysis patients participated respectively. Nephrologists tend to avoid end of life care discussion reflecting limited communication skills training, a fear of upsetting patients and time constraints. Additional barriers to ACP included limited understanding of ESRD and dialysis by patients. Patients appeared disempowered, displayed limited health literacy and well-being was compromised by limited ACP. Dialysis appeared to jeopardise their core values.

Conclusion

The participation of nephrologists and older patients with ESRD in ACP and shared decision-making in Ireland is suboptimal. Healthcare decision-making, including dialysis initiation, may not reflect patients' core values. Enhanced patient education and improved communication skills training for clinicians to facilitate shared decision-making and ACP is recommended.

Declaration

This thesis is submitted to National University of Ireland, Galway in accordance with the requirements for the degree of Medical Doctorate in the School of Medicine.

I declare that this thesis is a record of my own work and has not been submitted for any other academic award in this University, or elsewhere. All information sources have been fully acknowledged and referenced.

Parts of this work have appeared in peer-reviewed publications and presentations (Appendix I).

Julien O'Riordan

10 /12/2021

Acknowledgements

I am extremely grateful to the nephrologists who participated in this study and who gave generously of their time and experiences. I greatly appreciate their self-reflection and honesty which I believe will serve to enhance the experiences of both patients and clinicians as they navigate the process of healthcare decision-making.

I am deeply indebted to the patients who participated in this study. I feel privileged to have discussed with them some of their deepest concerns, fears and wishes for the future. Their contribution demonstrates courage, humility and a willingness to enhance patient care for future generations.

I am very grateful to Dr Helen Noble for her unfailing mentorship, guidance, expertise and support throughout this thesis and I look forward to future collaborations.

I sincerely appreciate the advice and guidance provided to me by the members of the Graduate Research Committee, Dr Pauline Kane, Professor Declan Devane, Dr Ronan O’Cuiv and Professor Fidelma Dunne.

I am hugely indebted to Professor Andrew Smyth who, throughout this thesis, has continuously impressed me by his supreme professionalism, knowledge, dedication and kindness.

Finally, this work would never have come to fruition without the support, dedication and sacrifice of my loving family of rowdy and boisterous men.

Dedication

I am dedicating this thesis to the people that we meet as patients, every day.

I would like this body of work to be considered as an acknowledgement of the untold challenges faced by patients and an acknowledgement of their vulnerability when all that is familiar to them is threatened.

List of Tables

Table 1: Nephrologist study: Characteristics of Nephrologists

Table 2: Nephrologist Study: Reasons for choosing conservative management

Table 3: Nephrologist Study: Barriers to Discussion

Table 4: Nephrologist Study: Suboptimal physician communication skills

Table 5: Nephrologists Study: Themes and subthemes

Table 6: Patient Study: Participant Characteristics

Table 7: Patient Study: Limited Patient Understanding of CKD.

Table 8: Patient Study: Disempowerment reflected limited health literacy

Table 19: Patient Study: Themes and Subthemes

List of Figures

Figure 1: Patient Study: Project Map: Evolution of themes: Limited delivery of patient centred care

List of Abbreviations

CKD: Chronic kidney disease

eGFR: estimated glomerular filtration rate

ESRD: end-stage renal disease

US: United States

UK: United Kingdom

ACP: advance care planning

EOL: end of life

EOLC: end of life care

LCC: Low Clearance Clinic

HCP: Health Care Professional

RPA/ASN: Renal Physicians' Association/ American Society of Nephrology

CKM: Conservative Kidney Management

HD: Haemodialysis

CCF: Congestive Cardiac Failure

SDM: Shared Decision Making

Chapter 1: Introduction:

1.1 Chronic Kidney Disease and End Stage Renal Disease

Chronic Kidney Disease (CKD) is defined as the presence of kidney damage (usually detected as urinary albumin excretion of ≥ 30 mg/day or equivalent) or decreased kidney function (defined as estimated glomerular filtration rate [eGFR] < 60 mL/min/1.73 m²) for three or more months, irrespective of the cause (7). Current guidelines recommend an age-neutral approach to chronic kidney disease (CKD) management based upon the level of eGFR and the presence of proteinuria (8). This is essential to ensure that ageism does not directly impact the management of patients with CKD. However, it is essential to be aware of potentially large differences in prognosis and illness trajectory between older and younger individuals with similar levels of eGFR (7). A Low Clearance Clinic (LCC) provides clinical review, treatment refinement, symptom control, dietary advice and education to patients with advancing chronic kidney disease (CKD) (9). End stage renal disease (ESRD) is the most advanced stage of CKD where kidney function has declined to the extent that the kidneys cannot adequately function alone and patients typically require renal replacement therapy (including dialysis or kidney transplantation) (7). Conservative care of ESRD, compared to dialysis, may not achieve the same absolute mortality benefit but frequently achieves similar outcomes (e.g. avoidance of hospitalisation) at lower treatment burden and treatment costs (10). Additionally, previous studies indicate that patients approaching ESRD are willing to forgo significant life expectancy in order to minimise the burden and restriction imposed by dialysis (11).

1.2 ESRD in Older Patients

Older patients, defined as those aged 75 years and over, with ESRD constitute the largest group of patients internationally that commence dialysis on an annual basis (11). A detailed literature review to establish what is currently known about the factors which influence the management of ESRD in older patients was performed. A number of established authors, generally based in the US, Canada and the UK, have considered this area from their various perspectives

including nephrology, palliative medicine and social science. The most informative studies date from 2010, particularly from 2015 and are a mix of both qualitative and quantitative, the latter often assessing quality of life measures.

Many of these patients, particularly those with co-existing ischaemic heart disease, derive little survival benefit from dialysis (12) and those aged >80 years often derive no survival benefit at all (13). Older patients who survive beyond three months from dialysis initiation continue to endure a high symptom burden (14) and any survival benefit from dialysis is frequently offset by more time spent in hospital and a greater likelihood of a medically intensive and hospitalised death (5). Patients with ESRD experience an extremely high burden of symptoms, similar to those symptoms of patients with cancer that are hospitalized in palliative care settings (15-17), and they have extensive and unique palliative care needs, often for years before death (1, 18). However, the majority of patients with ESRD die in acute care facilities, without accessing palliative care services (19, 20).

Based on these observations, an increasing number of studies, particularly in the past five years, explored why such a large proportion of older adults with ESRD commence or receive dialysis therapies at all, considering the significant symptom burden and also having to contend with regular travel to and from dialysis centres (14). These include qualitative interview studies with both patients and nephrologists and quantitative studies which measure quality of life. Studies measuring the success or otherwise of conservative management of ESRD in older adults are limited, possibly reflecting the limited and varied international availability of renal supportive care services.

Patients in receipt of dialysis therapies may experience an absolute survival benefit from dialysis, i.e. prolongation of life, as dialysis may be a life-extending treatment for patients across all age groups. Importantly, early outcomes from dialysis therapies confirms a mortality rate of over 10% within three months of dialysis initiation (21, 22) and high rates of hospitalisation for those who survive beyond three months (5, 21). However, there are significant differences in older adults; US data reports a one year mortality of 41% for those aged ≥ 75 years, compared to 28% for those aged 65-74 years and 17% for those aged 45-64 years (23, 24). European data show similar rates for older

patients, with a probability of survival of 71% at one year and 54% at two years after commencing dialysis (21). Increasing age, high comorbidity (particularly diabetes and ischaemic heart disease) suggest that survival is often poor, with those in receipt of dialysis experiencing a non-significant four month absolute extension in survival (12, 25).

Independent of an absolute survival advantage, key literature reports that these individuals are almost 50% more likely to be hospitalised than those receiving conservative management, so that much of the 'gained time' (survival advantage) is spent in hospital or hospital-like settings (5). This study also showed that older patients receiving dialysis are more likely to die in hospital rather than at home or in a hospice, compared to those receiving conservative management. In addition, only a minority of patients in receipt of dialysis receive specialist palliative care input, even among those patients who withdraw from dialysis and whose death is usually certain (19, 20). Of those who do receive specialist palliative care input, they are more likely to receive it only in the last week of life compared to patients with conservative management (20, 26, 27). This likely reflects suboptimal ACP with these patients so that their preferred place of death and preferences for end of life care, including the timing of dialysis withdrawal, have not been explored with them at all or in a timely manner.

The number of studies examining the ability of nephrologists to communicate with patients about prognosis and end of life care are limited and suggest that communication difficulties contribute to poor levels of ACP. Few studies have examined patient understanding of dialysis and conservative management and currently, we know little of the healthcare preferences of patients.

1.3 Advance Care Planning

Advance Care Planning seeks to help patients to understand their condition, identify goals and prepare for the decisions that may have to be made as the condition progresses over time (28-32). An advance care plan (or Advance Healthcare Plan) enables patients to document their

preferences for future care in the event of them losing the ability to express their own wishes (29, 32).

This is distinct from an Advance Healthcare Directive which is a document legally recognised in Ireland. This document records one's wishes for medical treatment in the event they are unable to make these decisions in the future and serves to inform family, friends and doctors of these wishes (32). It is a legally binding document where one writes down what healthcare treatments they would not like in the future. One can also list what treatments they would like to receive but these are not legally binding. Health professionals are obliged to explain why they did not follow these preferences (32). The experience of advance healthcare directives in the US is that they have failed to improve surrogate decision makers' knowledge of patient preferences and therefore have failed to promote patient autonomy (33). Advance directives have also failed to improve end of life care (34). In this US study educational interventions with physicians led to improved use of patient preferences but these interventions were insufficient to motivate physicians to reduce their use of life sustaining treatments (34).

The Renal Physicians Association (RPA) and the American Society Nephrology (ASN) advocate 'a shared decision-making approach to patient care (thus ensuring that patients' values and preferences play a prominent role in decision-making) and recommend facilitating 'advance care planning to help patients understand their condition, identify their goals and prepare for the decisions that may have to be made as the condition progresses over time' (28). However, internationally few older adults with ESRD are afforded an opportunity to avail of appropriate ACP (1, 2). Consequently, these patients typically have a poor understanding of their prognosis and often experience medically intensive end of life scenarios focused on life prolongation, rather than on quality of life (1, 2, 35).

A study in the US, examining the experience of older patients that initiate dialysis reported uniformly negative experiences (6). Participants felt this decision was made by their clinician; they described limited discussion about the decision to start dialysis; some attempted to engage clinicians

about quality of life and prognosis but had limited success. Participants who described less-engaged decision-making felt powerless and faced challenges reconciling their values with dialysis and felt that their preferences had been overlooked. Participants were also distressed by unexpected outcomes; one participant understood that he would feel better after dialysis and was distressed when it left him feeling weak and without appetite.

Other studies of patients with ESRD (in receipt of either conservative management or dialysis) have shown that patients wanted more information and earlier initiation of ACP (30). Participants felt this information needed to focus more on the individual and how his or her illness and interventions would affect his or her life and relationships and what he or she valued most.

The SONG-HD (Standardised Outcomes in Nephrology-Haemodialysis) initiative highlighted disparities between patients and their healthcare providers in regard to the desired outcomes from dialysis (36). Patients and their care givers rated quality of life measures as the most important outcomes (ability to travel, dialysis free time, dialysis adequacy, dealing with feeling washed out after dialysis) while healthcare providers were more concerned with medical parameters (mortality, hospitalisation, decrease in blood pressure, vascular access complications). These disparities underline the importance of timely and comprehensive ACP and shared decision making (SDM), so that the delivery of care is patient centred rather than dictated by medical and biochemical parameters alone.

In Ireland, members of the general public (as well as public representatives and hospital based healthcare professionals) participated in a number of studies (focus group interviews, telephone interviews and national surveys) during 2007/2008 in an effort to gauge the level of understanding of end of life care and the type of concerns people had in regard to dying and bereavement (37-39). These studies demonstrated that most older adults want to participate in decision making (63%) and end of life care (94%) but that knowledge of ACP is poor (40). The general public (and Irish legislators) are largely unfamiliar with, or have little understanding of, terms associated with end of life care, such as 'do not resuscitate' orders, advance directives, artificial

nutrition and hydration. Information about diagnoses and prognoses are often shared with families instead of patients (particularly older patients) at the end of life (41). While most Irish people wish to die at home, the majority die in hospital (42, 43).

Internationally, as few as 10% of patients with ESRD engage in end of life care planning with their nephrologist (1). Older adults dying of ESRD, when compared with those dying of cancer, are less likely to have engaged in ACP, more likely to have an admission to ICU within two years of dying and are more likely to die in hospital (44). They are also much less likely to be engaged with palliative care services (19, 20). Patients requiring dialysis have complex needs and coupled with the frequency of dialysis sessions; much of their primary care needs are provided by the nephrology services (45). This may result in the provision of fragmentary primary care and indeed, may contribute to delays in patients receiving appropriate and timely referral to specialist palliative care services (46).

1.4 Shared Decision-Making

Shared decision-making is an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences (47). Successful SDM, which incorporates ACP, implies decision-making that is patient centred. To this end, patients must attain an understanding of their illness in the context of their likely prognosis and the likely course of the disease (48, 49). Healthcare professionals (HCP) must explore the various treatment options with patients, including a discussion of the risks and benefits of each option. Therefore, patients should attain an understanding of how individual treatment options are likely to impact on their day-to-day life and therefore permit them to make informed choices. Likewise, HCP should aspire to understand patient values and priorities in order to facilitate healthcare decision-making that reflects and complements the unique values of individual patients. This approach empowers patients to make informed healthcare decisions and ensures the delivery of care meets their specific needs (50).

In the context of ESRD, a survey of older patients reported that most patients wished to (i) understand ESRD, (ii) be involved in medical decision making, (iii) participate in a discussion of prognosis including the likely trajectory of their disease and (iv) engage in end of life care planning (where they expected their clinicians to initiate the discussion in a timely manner to provide the opportunity for patients to plan that phase of life) (1). Despite these wishes, this survey also showed that most, whether or not in receipt of dialysis, had not actually engaged in discussions about end of life care (1). Older patients with ESRD report contrasting experiences of SDM, with many reporting a perceived lack of choice as the most common reason for choosing dialysis (51).

Qualitative interview studies reveal much about the complexities of patient wishes, with significant variations both within and across cultures and geographical regions. A Canadian qualitative interview study of patients with ESRD and a mean age of 64 years, identified hope as central to the process of ACP (52). More information earlier in the course of illness focusing on the impact on daily life, along with empowerment of the patient and enhancing professional and personal relationships, were key factors in sustaining patient ability to hope. Clearly, this assumes that patients and HCP are aware of a diagnosis of progressive CKD and that patients are actively attending nephrology services, where there may be time to provide information, educate and counsel patients appropriately. This contrasts significantly with patients not known to nephrology services or those not recognised or known to have CKD, who present acutely with symptoms of uraemia, low eGFR, acute illness (which often includes delirium or altered level of consciousness) and often leads to emergency initiation of dialysis therapy. Ultimately, well informed patients with ESRD are more likely to retain hope and a sense of control over their lives, even in the context of a life-limiting illness. Older patients with ESRD that chose conservative management, stressed the importance of understanding their condition and care through the proactive provision of information from their treating HCP in nephrology units. Delayed provision and/or omission of key information added to patient anxiety, hindered empowerment and limited their ability to retain a

degree of control over their lives. Therefore, optimising the circumstances and environment for SDM are imperative.

1.5 Health Literacy

Health literacy describes that ability of an individual to access, understand, interpret, and use health-related information to manage and improve health (53). As such, health literacy is a prerequisite for engagement with SDM and is key to empower patients to make healthcare decisions concordant with their values and wishes. Older patients with ESRD, whether in receipt of dialysis or conservative management, are required to manage complex medication regimes, adapt to dietary modifications, attend hospital regularly (outpatient clinics, dialysis unit, etc.) and potentially incorporate the rigors of a dialysis regime into their daily life. These activities require health navigation skills, the ability to gain health knowledge, motivation, and problem-solving abilities, all of which are components of personal health literacy (54, 55).

A health literacy framework, applicable in clinical settings, is composed of functional, interactive and critical levels of health literacy, with the latter reflecting the most advanced stage of literacy (54). *Functional* health literacy reflects one's basic understanding of words and numbers pertaining to one's underlying illness (e.g. understanding the meaning of CKD as persistent reduction in renal function). *Interactive* health literacy refers to one's ability to actively engage with HCP in discussing illness and being able to actively participate in healthcare decision making (e.g. deciding to proceed with dialysis access (e.g. arteriovenous fistula formation)) as the likelihood of requiring haemodialysis is significant). *Critical* health literacy reflects the ability to achieve and express individual decisions concordant with their preferences (e.g. a patient decides to forego dialysis and to focus on best supportive care as they wish to minimise hospital visits and maximise their time at home with their spouse and close family).

Health literacy is associated with many health outcomes and characterized as contributing to disparities in health care (56). Among older adults, the implications of limited health literacy include

lower rates of knowledge of complex diseases, less self-care behaviour (including medication adherence), lower rates of ACP, higher rates of aggressive treatment in the last month of life, higher utilisation of emergency services and higher rates of in-hospital death (57-59). While some may choose to die in hospital, those engaged in end of life care discussion experience fewer in-hospital deaths and improved quality of life, suggesting that more patients would choose to die at home if they were engaged in ACP in a timely fashion (60).

Health literacy among older patients with ESRD is limited (2). For example, one study reported that 67% of patients could not define 'prognosis' and 30% misunderstood 'prognosis' to mean 'diagnosis.' Only 33% understood that 'prognosis' pertained to the future course or outcome of disease and many had misconceptions about dialysis (e.g. 'becoming healthy enough to discontinue dialysis'). Patients experienced dialysis as 'intensive and somewhat invasive' and this was often described as discordant with their preferences' (2). A study of 480 incident patients requiring chronic haemodialysis, with a median age of 62years, identified that 32% had limited health literacy (defined as having a <9th grade reading level using the Rapid Estimate of Adult Literacy in Medicine (REALM) score) and those with limited health literacy were at higher risk of death than those with adequate health literacy (61).

Medical terminology and the use of jargon may itself also impact the ability patients to advocate for access to healthcare. For example, one study reported that only a minority of patients with advanced CKD had correct understanding of the terms 'palliative' (22.2%) and 'hospice care'(17.9%) (19). However, after these terms were appropriately explained to patients, the vast majority felt these services were valuable (87.8%) and should be offered (89.7%). Taken together, this demonstrates how older patients with ESRD and low health literacy are extremely vulnerable (57, 61). Low health literacy carries significant implications including difficulty managing medications, poorer overall health, increased mortality, and less efficient use of health services than the general population (57, 62). A European study, of almost 8,000 people, aged >15 years, across eight countries (including Ireland), reported that older age was associated with increased risk of

limited health literacy (specifically, insufficient' or 'problematic' levels of health literacy), which may be compounded by financial deprivation, limited education and lower socioeconomic class (63).

Limited health literacy is not unique to older patients with ESRD. A US-based study of adults aged >16 years identified 36% of participants had health literacy levels rated as 'basic' or 'below basic'. This suggests that 90 million people are estimated to have basic or below basic literacy skills in the US. Adults aged ≥65 years had lower average health literacy than younger age groups, including the proportion with intermediate and proficient health literacy (64). In Europe, 12% were classified as having insufficient health literacy and 47% as having either insufficient or problematic health literacy (63).

1.6 End-of-Life Care Planning in Nephrology

In the US, limited engagement by nephrologists in end of life care discussion with older patients with ESRD has been explored through qualitative interview studies and surveys (1, 2, 4, 65). As stated previously, most of these patients are not only amenable to end of life care discussion, they want to be involved in medical decision making and *rely* on their nephrologist. However, <10% had experience of end of life care planning within the previous year (1). A little over one third (39%) of nephrologists perceived themselves as 'very well prepared' to discuss and make end of life decisions (65). These nephrologists were more likely to use time-limited trials of dialysis and to stop dialysis in patients with permanent and severe dementia. Nephrologists that were in practice for longer and those that were knowledgeable of the RPA/ASN guidelines, reported greater preparedness to make end of life decisions and reported doing so more often in accordance with such recommendations. Those who felt unprepared cited limited training in palliative care and end of life care discussion as contributory factors. Inadequate communication skills training contributes to a reluctance to engage patients in ACP, including a discussion of prognosis and end of life care (66, 67). Nephrologists fear such discussion will jeopardise their relationship with patients and they are uncomfortable with their ability to predict prognosis. Therefore, nephrologists frequently choose to

avoid such discussions (4, 68). Previous studies highlighted this training gap and called for the inclusion of communication skills in core nephrology training curricula (67). Interestingly, a survey comparing US-based nephrology trainees to their counterparts ten years previously, reported an increasing belief that trainees should learn to provide end of life care, but the perceived quality of teaching had not improved over the ten year period. The most common suggestion from trainees on how to improve their end of life care education was a mandatory palliative medicine rotation. The Royal College of Physicians of Ireland programmes include mandatory communication skills training courses for trainees on both the Basic Specialty Training and Higher Specialty Training schemes, including nephrology, but does not mandate a palliative medicine rotation. Additional training in ACP is also available (69).

1.7 Supportive / Palliative Care & ESRD

Renal supportive care, encompassing conservative management, is an alternative to dialysis, which seeks to optimise quality of life through the active, responsive and non-dialytic management of ESRD (4, 70, 71). Conservative management of ESRD encompasses active management of the metabolic complications of advanced CKD. This may include (i) optimisation of haemoglobin, using erythropoietin and intravenous or oral iron replacement therapy, to a target haemoglobin 10-12g/dL; (ii) management of metabolic acidosis, using oral sodium bicarbonate therapy (whilst minimising the risk of significant fluid retention and volume overload); (iii) management of CKD mineral bone disease (CKD-MBD), using vitamin D analogues, phosphate binders, etc; and (iv) specialist dietary advice to optimise nutrition and minimise complications such as hyperkalaemia or hyperphosphataemia that may lead to additional symptoms. Routine advance care planning and end of life care planning are key components of comprehensive conservative management of ESRD. This service is best delivered by a multidisciplinary team, which can offer timely review and follow-up of the physical, emotional, spiritual and psychosocial needs of patients and their carers.

Some nephrologists perceive conservative management as an equivalent to 'no care', a perception which likely reflects the variability and often rudimentary nature of local service availability, rather than the underlying ethos of conservative management (4). Internationally, conservative management is less well established than dialysis and there is considerable institutional variability in the quality and capacity of the service to meet the needs of patients in a holistic and timely fashion (10). Dialysis, on the other hand, is readily accessible in most developed countries and the regime ensures regular patient contact with a healthcare professional. For these reasons, some nephrologists may view dialysis as a superior treatment option for ESRD.

1.8 End-Stage Renal Disease in Older Adults – the Nephrologist Perspective

A detailed literature review was completed to identify the international evidence demonstrating how nephrologists manage older patients with ESRD. Databases including PubMed and Google Scholar were searched using the following key words or phrases: (i) 'end stage renal disease older adults dialysis', (ii) 'end stage renal failure older patients dialysis', (iii) 'management of end stage renal disease in older patients'; (iv) 'older patients survival on dialysis'; (v) 'end stage renal disease dialysis conservative management', (vi) 'advance care planning older patients end stage renal disease', (vii) 'nephrologists advance care planning older patients', (viii) 'nephrologists older patients communication', (ix) 'nephrologists older patients dialysis' and (x) 'nephrologist clinical decision-making older adults with ESRD'. Potentially relevant articles were accessed through local library services (NUI Galway) or via supervisors who have additional access to relevant publications.

There is a relative paucity of studies that considered the factors influencing clinical decision making of nephrologists when choosing between conservative management or dialysis therapies for older adults with ESRD. Nephrologists may consider the presence of severe clinical conditions (comorbidity), vascular dementia and a low physical functional status as reasons not to start dialysis. Patient preference was considered a very important factor in one study, thus highlighting the importance of patient education and SDM (72).

A qualitative interview study of US- and UK-based nephrologists reported that the predominant barriers to foregoing or withdrawing dialysis therapy included a lack of training in end of life conversations and expectations for aggressive care (i.e. the provision of or continuation of dialysis) by non-nephrologists and the general public (73). In addition, financial incentives to continue to provide dialysis (particularly in the US) may contribute to decisions to initiate dialysis, while the widespread outpatient conservative management programs in the UK offered nephrologists a viable and appropriate alternative to dialysis for their patients.

A discrete choice experiment (DCE), based in Australia and New Zealand, reported that nephrologists were more likely to recommend dialysis for patients with preserved cognition, lower comorbidity, increased life expectancy (from factors not directly related to ESRD), high quality of life and where patients and family were positively inclined towards dialysis (74). Interestingly, nephrologists themselves aged >65 years were more likely to recommend dialysis for older patients. This study also reported that many nephrologists would be willing to forego twelve months of survival to avoid a substantial reduction in quality of life with dialysis.

Importantly, there were a number of key publications after this thesis work commenced, which further examined clinical decision making of nephrologists in the management of ESRD in older adults (4, 75). A qualitative interview study of 35 nephrologists from 18 centres across 9 states in North America included 20% females, 66% with >10years experience in nephrology and 80% worked at academic medical centres (75). Using the well-established typology of Emanuel and Emanuel (76), they characterised the approach of nephrologists to decision-making and clarified how these approaches related to variation in conservative management discussion with patients (75). *'Paternalists'* strongly identified as patient protectors and, like *'institutionalists'*, viewed the initiation of dialysis as a measure of success. *'Institutionalists'* attributed challenges in discussing or providing conservative management for ESRD to system-level policies and influences (including financial incentives, limited time allotted for appointments, and lack of a common approach to conservative management within the care team). Nephrologists adopting an *'informative approach'*

viewed their role as that of an educator, enabling patient-led decision making, as those nephrologists were more concerned with patient autonomy rather than ensuring patients pursue a specific treatment strategy. *'Informers'* presented treatment options neutrally and accepted patient choices. Nephrologists who acted as *'interpreters'* or *'navigators'* perceived their role to be that of guiding the patients towards a treatment most concordant with their wishes and values, and felt that this approach best achieved shared decision-making.

These authors also explored the willingness of nephrologists to discuss conservative management and end of life care with older patients (4). Over one third of nephrologists (37%) described routinely discussing conservative management and end of life care with patients, and were considered *'early adopters'*. Interestingly, despite an increased awareness of conservative management, most nephrologists did not present conservative management neutrally - i.e. as a legitimate alternative to dialysis (4, 75). In addition, there was little evidence of difference between centres; it appears to be the opinion of the individual nephrologist rather than the centre that influences the likelihood of routinely discussing conservative management and end of life care (4).

Nephrologists struggled to define their role; many viewed treatment selection as their role and often dismissed patient preferences (by viewing patients as being uninformed and not wanting to try therapies) (4). Such nephrologists considered instilling hope in patients as part of their role and used this to justify omitting any discussion of conservative management, as they also felt that many patients *'did better than average on dialysis'* and focussed on salient cases to support this theory. This suggests that individual or anecdotal experience heavily informs the practice of nephrologists, particularly with older patients. Importantly, this does not reflect patient wishes or SDM. In addition, most nephrologists circumvented end of life care conversations and focused on active treatments, thereby somewhat obscuring the potentially terminal nature of ESRD. Barriers to discussing conservative management included a fear of withholding beneficial treatment, prognostic uncertainty, and a reluctance to upset patients or jeopardise their therapeutic relationships. Some nephrologists avoided discussing goals of care and quality of life out of fear of incurring an emotional

backlash from their patients. For example, some nephrologists feared patients would become 'suspicious' if offered conservative management and that they would begin to 'shop around' to gain their preferred treatment, possibly reflecting a fear of litigation on the part of the nephrologist.

Institutional barriers also impeded discussion of conservative management and end of life care (4). These included time constraints, absence of co-ordinated care between relevant disciplines necessary for adequate conservative management or end of life care (e.g. palliative medicine and social work). Many felt the financial incentives favouring dialysis influenced behaviour of colleagues, but were less certain about the implications for their own behaviour. Additionally, a lack of systematic training was seen as a key reason for variation in attitudes and approaches to conservative management, even within a single practice/centre. There is clear division between nephrologists on their views of conservative management, perhaps influenced by their understanding of it or the local availability of necessary services. As such, many equated conservative management with 'no care' and having 'nothing to offer', which directly conflicts with their perceptions of their role. Many experienced moral distress, defined as one perceiving their responsibility to act, but because of institutional constraints, they cannot act in a way consistent with their moral judgments. Those considered 'early adopters' responded to this moral distress proactively and noted that universally offering conservative management relieved moral distress, whereas nephrologists who only sometimes offered conservative management continued to experience significant distress. Taken together, this may pose significant challenges for nephrologists to present conservative management fairly.

Another US-based survey explored the attitude of nephrologists toward prescribing or choosing conservative management for or with older adults (77). This study highlighted a lack of data on the outcomes from conservative management and insufficient knowledge of the characteristics of patients most likely to benefit, as barriers to recommending conservative management. Most reported that they were likely to discuss conservative management with

patients but it was unclear how balanced or fairly that conservative management was presented and how often conservative management was recommended.

A semi-structured qualitative interview study of nephrology HCP in Wales (i.e. doctors and nurses involved in providing haemodialysis) explored perspectives on end of life care discussion and ACP (68). Generally, ACP was neglected and discussions pertaining to end of life were usually triggered by a clinical deterioration and often when the patient was too unwell to actively participate in the discussion. HCP considered these discussions difficult and generally avoided discussing prognosis for fear of upsetting patients as well as the inherent difficulty and uncertainty of accurately estimating prognosis. This is consistent with previous studies highlighting the need for additional formal communication skills training, including communication interventions and clinical rotations in palliative medicine, to improve end of life care for patients with ESRD (66, 67).

A recent publication explored the emotional burden that nephrologists endure when making decisions about treatment of ESRD for or with older adults (78). The decision not to start dialysis can be emotionally burdensome because of the uncertainty about how an individual patient will experience dialysis, if the patient will achieve any benefits and the belief that the alternative to dialysis is premature death. Nephrologists struggled to confront death and many believed that patients did not regret dialysis initiation. Attempts to reduce this burden may be reflected in different decision-making styles - paternalistic, informed, etc. SDM may also relieve some of this emotional burden, whilst preserving patient centred care.

A recent systematic review provides a comprehensive overview of the barriers to ACP in patients with ESRD (79). ACP is typically hindered by lack of training of HCP, administrative complexities, pressures of routine care, patients overestimating life expectancy and when patients, family, and/or clinical staff are reluctant to initiate discussions. ACP is more likely to succeed where organisations include it as part of routine care (potentially reducing the stigma associated with such conversations), when the process is culturally appropriate (taking account of patient perceptions) and when patients are willing to consider death and dying with suitably trained staff.

This is consistent with optimal approaches to conservative management delivered by a collaborative multidisciplinary team, often through a Low Clearance Clinic (80). A UK survey of 71 adult nephrology units, with significant variability in the scale and organisation of units, demonstrated that almost 80% engaged in ACP with patients (10). Important areas where variability was evident included the use of terminology to describe conservative management (i.e. the term 'Conservative Management' used in 46% of units), presence of written guidelines (only 35% of units), dedicated Conservative Kidney Management clinics (23% of units) with staff allocated to the running of these clinics (45%).

In summary, knowledge of the factors which influence the clinical decision-making of nephrologists is limited, but the evidence suggests that inadequate training in discussing prognosis and end of life care is a strong influencer. Much of the available evidence is derived from surveys of nephrologists, with important notable exceptions which predate this thesis work.

1.9 End-Stage Renal Disease in Older Adults – the Patient Perspective

Our understanding of the factors which guide and inform decision-making by patients is also limited. For this literature review, a search of electronic databases including PubMed and Google Scholar was conducted using the following terms/phrases: (i) 'decision-making in older adults/patients with end stage renal disease'; (ii) 'priorities of older adults with end stage renal disease', (iii) 'wishes and values of older adults with end stage renal disease', (iv) 'influences on older patients' decision making in end stage renal disease', (v) 'advance care planning in older adults/patients with end stage renal disease/ on dialysis', (vi) 'end-of-life care in older dialysis patients/ older adults', (vii) 'older patients understanding of haemodialysis', (viii) 'health literacy in older adults with ESRD', (ix) 'priorities of older adults with ESRD', (x) 'what older adults with ESRD consider important' and (xi) 'wishes and values of older adults with ESRD'.

A US-based study, of 31 prevalent dialysis patients aged <65 years, explored their experience of dialysis initiation through semi-structured qualitative interviews (6). Participants uniformly did not

view dialysis initiation as their decision, but rather a decision made by their doctor. None had an understanding of conservative management, most described limited engagement with their nephrologist and a tendency to accept physician recommendations with little discussion. Participants struggled for autonomy, experienced little exploration of their preferences and frequently had their decision to decline dialysis initiation overturned by 'assertive' doctors. Most adopted the 'good patient role' whereby they agreed to the advice and suggestions made by HCP and consequently had little input into medical decision making.

The findings of this qualitative study (6) echo those of an earlier Canadian based survey of patients with advanced CKD (Stage IV and Stage V), including those on dialysis or those awaiting transplant (1). That study found that the majority of patients wished to be involved in medical decision making and wanted to participate in end of life care planning but 52% felt the decision to initiate dialysis was made by a doctor and, importantly, 61% retrospectively regretted their decision to initiate dialysis (1). Almost 80% regarded their nephrologist as their main source of medical information, >90% considered it important to be informed about prognosis (including the provision of detailed medical information and the option to withdraw from dialysis) and 83% considered it important to plan ahead and be prepared in case of death (1). However, participants had poor self-reported knowledge of palliative care options and limited understanding of the likely trajectory of CKD. Less than 10% had engaged in end of life care discussion with their nephrologist in the previous 12 months. Most participants were comfortable discussing end of life issues (with family members and nephrology staff members) and they felt these conversations should be ongoing and in response to changing medical circumstances.

Few studies have explored the impact of dialysis vintage on patient satisfaction with their quality of life on dialysis. Shorter duration on dialysis is associated with better physical quality of life (81). Acceptance of illness, which allows patients to adjust to new situations, is an independent predictor positively correlated with quality of life in all domains, except for social relationships (82).

Levels of acceptance of illness are low to moderate among patients on haemodialysis, which in turn, may influence their perception of dialysis.

The potential impact of comprehensive ACP is demonstrated by a Dutch survey of 28 dialysis units, where just 7.4% (n=1329) of patients regretted their decision to initiate dialysis despite 52.8% describing dialysis initiation as 'sudden' (which was subjective and may differ from the definition of 'sudden' as provided by nephrology HCPs in the Netherlands; dialysis initiation with less than six months of pre-dialysis care, with a catheter or as an inpatient) (83). In that jurisdiction, multidisciplinary pre-dialysis care (including early referral to nephrology, comprehensive pre-dialysis education, SDM and planned start of dialysis, where appropriate) is formally established and operates in line with recommendations from the RPA and the 'Choosing Wisely' campaign in the US (84). Taken together, studies suggest that optimising SDM has the potential to reduce the number of patients who later regret their decision to initiate dialysis (1, 6, 83). A scoping review, including 18 publications from 2000 to 2018, which demonstrates that older adults with advanced CKD desire greater involvement and more information about illness, symptoms and what to expect from treatment, appears to substantiate this impression (85). However, it is important to acknowledge that assessments of regret are made in retrospect and based on additional information that would not have been known at the time of dialysis initiation (e.g. actual symptom burden and impact on quality of life within an individual) and is restricted to those that did sufficiently well with dialysis initiation to survive to make that assessment.

Another Dutch study explored the experiences of SDM among older patients with advanced CKD who chose between conservative care and dialysis (51). Overall, patients appeared satisfied with the SDM process, but those reporting negative experiences were more likely to have chosen dialysis. Patients choosing dialysis felt 'forced' to make a decision and perceived a lack of choice as the main reason for choosing dialysis. Only 55% of those that chose dialysis considered their own opinion more important than that of their family or nephrologist, which contrasts with 90% of patients opting for conservative care. This suggests that patients who are less empowered may not

make treatment decisions which reflect their own priorities and wishes. These patients may not have considered conservative care an acceptable option to them and because of the urgency associated with declining health and/ or declining eGFR, felt 'forced' into agreeing to dialysis because of the absence of a third option. However, nephrologists must attain an understanding of patient wishes and values in order to assist patients to make treatment decisions concordant with their values.

A US-based qualitative study reviewed documentation from the electronic medical records of 851 adults, with a mean age of 75 years, that chose to start dialysis within the US Veterans Health Administration (2000-2011) (86). Three major dynamics relevant to understanding how decisions relating to dialysis were made were identified. First, dialysis was viewed as the 'norm'; when patients expressed a desire to forgo dialysis, this deviation would be viewed as unusual by clinicians and may have led to challenges in readily accepting patient decisions, repeatedly questioning patient decisions over time, concerns on competency/capacity and additional strategies to encourage dialysis initiation. Second, clinicians considered particular patients as not appropriate for dialysis on the basis of specific characteristics and/or expected prognosis, rather than after consideration of the patient's goals and values. Once a clinical decision was made, clinicians were reluctant to revisit them. Importantly, when it was clear that patients would not be starting dialysis, nephrologists often signed off from care and had few recommendations other than referral to hospice care. This suggests an 'all-or-nothing approach' to caring for patients with advanced CKD, where initiation of dialysis served as a powerful default option with few perceived alternatives, creating challenges in presenting conservative management in a balanced way.

This is further highlighted in a qualitative interview study of older adults with ESRD across nine nephrology units in the UK, which demonstrated that patient knowledge of conservative management was influenced by local availability (87). Patients from units with a more established conservative management pathway were more aware, less often believed that dialysis would guarantee longevity and more often had discussed the future with staff. Interestingly, some patients

receiving conservative management reported that they would have dialysis if they became unwell in the future, indicating a conditional and potentially dynamic nature of their decision.

Limited health literacy is common in people with CKD, especially among individuals with low socioeconomic status and non-white ethnicity. It directly impacts on the ability of patients to self-manage and participate in medical decision-making, to access care and the quality of care they receive (88). This systematic review demonstrated much higher levels of health literacy in those individuals that received kidney transplantation. This may reflect selection bias as individuals receive kidney transplants after meeting a clinical threshold, completion of a broad range of investigations and detailed counselling. It may also reflect differing levels of comorbidity or access to appropriate healthcare. Limited health literacy was observed in only 14% of transplant recipients, compared to 25-27% of patients with advanced CKD. Another US-based qualitative interview study explored the attitudes of older dialysis recipients to end of life care (2). Limited health literacy presented a substantial barrier to effective communication and led to older adults committing to an intensive pattern of care, such as dialysis, without adequate information. Despite the significant risk of mortality associated with ESRD, 25% had never considered end of life care preferences and only 13% had discussed end of life preferences with physicians. Patients struggled to understand terminology commonly used in end of life discussion. They displayed poor functional literacy, failed to understand key words (e.g. 'prognosis') and had misconceptions about fundamental aspects of their treatment (e.g. viewing dialysis as a 'cure'). Patients reported that nephrologists frequently used, and perhaps relied on, terms that patients did not adequately understand during discussions. This perhaps reflects the discomfort of nephrologists in having such conversations, as awareness of these gaps may have shortened conversations. These gaps in basic knowledge (poor functional health literacy) may limit patients' capacity to engage in meaningful discussion (poor interactive health literacy) and constrain patients to clarify points of confusion and understand trade-offs associated with different treatment options (limited critical health literacy).

Similarly, most patients considered quality of life to be important, but could not define the concept (2). Patients avoided challenging physicians, concerned that they could harm the clinician–patient relationship and felt they could not push the physician into discussion. In an attempt to minimise family distress, many reserved their most deeply held beliefs about end of life care, and at points of confrontation acquiesced to the wishes of family. Patient expectation from dialysis was often at odds with their direct experience. As such, patients often regretted their decision to initiate dialysis and described it as being discordant with their preferences. This reflects the dynamic nature of the decision to receive dialysis. At the time of initiation, it is difficult to accurately predict how a specific individual will experience dialysis, what symptom burden may be relieved or worsened, and what benefits or drawbacks will become apparent. The same individual may have wanted to proceed with dialysis initially, but seek to revisit their decision based on their direct experience and the availability of additional information. Patients struggled to reconcile their end of life values, had limited opportunities for meaningful end of life discussion with family and HCP (perceiving that nephrologists were reluctant to discuss end of life care) and this generated significant uncertainty about their future care. Previous studies report that older patients with ESRD and low levels of health literacy experience higher mortality and greater utilization of emergency services than those with higher health literacy (61, 89). This may reflect that low health literacy is a significant barrier to end of life discussion, completion of ACP and advance directives. Taken together, this results in higher rates of aggressive treatment in the last month of life and a higher likelihood of hospitalised death (57).

In light of this evidence, concerns have been raised on the validity of the informed consent process for older patients with ESRD who commence and continue to receive dialysis (90). This includes concern about the level of understanding of dialysis by patients – including the inherent burdens and risks as well as an understanding of alternative treatments (such as conservative management). If patients are not adequately informed, consent may be questioned. Central to this process is the ability of the patient to actively and appropriately engage in acute or emergency

decisions on dialysis initiation, when cognitive function may be clouded by acute illness, delirium or the metabolic complications of CKD (such as uraemia). Where possible, this could be addressed through the pivotal roles of appropriate ACP and SDM.

1.10 Clinical Case

These principles are clearly illustrated by the following clinical case (91). An 83-year-old gentleman with a history of ESRD resulting from diabetes mellitus, receiving intermittent haemodialysis (HD) for two years, was admitted to hospital with worsening dyspnoea and dizziness for several weeks. His medical history included type II diabetes mellitus (also complicated by diabetic retinopathy) dependent on insulin for two years, peripheral arterial disease (with previous pedal arterial ulceration), congestive cardiac failure (CCF, with an ejection fraction of 30%) and severe aortic stenosis. Functionally, he was restricted by bilateral osteoarthritis of his hips and knees, frequent episodes of gout, obesity, and exertional dyspnoea. Before this hospitalization, his family described him as jolly, easy going, and sociable. A widower, he lived alone, with his daughter close by who visited two to three times per week. He travelled to dialysis sessions by taxi three times per week and received one hour of home help five days a week. He reported increasing fatigue in the preceding months, which largely confined him to home, except for weekly attendance at mass.

On this occasion, he was admitted with a diagnosis of decompensated CCF. Coronary angiography demonstrated significant triple vessel disease (stenoses of the proximal (70%), middle (50%) and distal (99%) left anterior descending coronary artery and 60% stenosis at the middle left circumflex and proximal right coronary artery). The transaortic pressure gradient was 40 mmHg, consistent with pulmonary hypertension he was scheduled for percutaneous coronary intervention. However, he found the coronary angiography distressing as he struggled to breathe when supine and found the application of pressure to his groin very painful (he subsequently developed a femoral hematoma). Consequently, he was fearful about the proposed percutaneous coronary intervention and had developed trouble sleeping.

Two weeks later, given the complexity of the case, he was discussed at a cardiology and cardiothoracic multidisciplinary meeting. As he was considered high risk for aortic valve replacement and unsuitable for coronary artery bypass grafting, medical management was optimized, including an increase to four weekly HD sessions of 3.5 hours of duration, targeting a reduced dry weight. However, he tolerated this poorly because of intradialytic symptomatic hypoglycemia, hypotension, and leg cramps (limiting fluid removal), and he continued to have interdialytic weight gains of 2.5-3.0kg. Clinically, he remained in CCF and complained of pruritus, persistent anxiety, poor sleep, and nocturnal agitation. He was assessed by liaison psychiatry and reported being constantly on edge, unable to sleep or articulate himself and lacking the concentration to read, a past time he had previously enjoyed. Mild cognitive impairment was noted. He was diagnosed with adjustment disorder and mild anxiety and commenced promethazine 25mg at night.

After two months in hospital, he requested discharge but was advised to remain as an inpatient as his condition was deemed high risk. One week later, on Christmas day, he was permitted day leave but was contacted and requested to return to the hospital early as his serum potassium level was >7 mmol/L. One week later, he was discharged home, and he returned to his usual dialysis regime.

Unfortunately, six weeks later, he was hospitalized with an infected arterial pedal ulcer and gangrene of his right great toe. He refused vascular input as he could not tolerate the pain associated with measurement of his ankle brachial index. Since his previous discharge, his sleep remained poor (initial insomnia and frequent wakening); he remained anxious and continued to experience nocturnal agitation. Consequently, his daughter had begun staying with him at night. Given this presentation, the medical team declared him not for resuscitation in the event of cardiopulmonary arrest and commenced transdermal buprenorphine 10 mcg/hour for control of ischemic limb pain. One week later, during a palliative medicine assessment, for management of pain and pruritus, his respiratory rate was reduced (six per minute) and he was somnolent with frequent myoclonus, consistent with opioid toxicity. The buprenorphine patch was removed, he

responded to intravenous naloxone, and dialysis was arranged to reverse opioid toxicity. However, he tolerated only two hours of dialysis due to symptomatic hypotension. The next day, his level of consciousness improved, but he was in severe pain from an ischemic digit. Therefore, he was commenced on a continuous subcutaneous infusion of alfentanil and increased gabapentin dose. A few hours later, he suddenly became acutely short of breath, his breathing became laboured, and his oxygen saturation decreased to 74%. He died 30 minutes later.

This case highlights many clinical and ethical dilemmas when considering dialysis in older patients with multiple comorbidities. As shown earlier in this chapter, in many cases dialysis does not confer a survival benefit (12) and significantly may not improve quality of life(14). Therefore, the approach *must* differ from younger patients or those with less comorbidity. This gentleman had a prolonged hospitalisation, significant symptom burden, functional decline and rehospitalisation before a decision was made to not escalate his medical care. Despite this significant clinical decline, he continued to receive dialysis and there was no documented discussion on his preferences nor was there a decision to formally withdraw dialysis. Thus, the importance of SDM, the pinnacle of patient-centred care, cannot be overstated. Successful SDM between physician and patient (or a legal representative where patients lack decision-making capacity) implies that physicians understand patient values, goals, and preferences and where patients are afforded the opportunity to understand prognosis and disease trajectory(92). This process should result in a clear statement of goals of care, including circumstances where dialysis withdrawal should be considered (28) (93). If, as physicians we fail in this endeavour, we risk depriving our patients of the opportunity to live as long as possible and die gently(94). In practice, however, SDM is poorly integrated into the clinical care of older patients with ESRD (91).

1.11 Thesis Aim

Overall, the literature demonstrates that older adults with ESRD have limited understanding of dialysis and alternative treatment options, including conservative management. The extent of

conservative management varies significantly between centres, which impacts the perspective of nephrologists and other HCP in presenting it as a viable therapeutic option to patients with ESRD. This is despite the fact that the survival benefit from dialysis in older adults may be limited, the symptom burden may be significant and no survival benefit has been demonstrated for adults aged >80yrs. The engagement by nephrologists in ACP with older adults with ESRD is limited, potentially out of fears in discussing prognosis and that end of life care will upset patients and jeopardise their therapeutic relationship. Importantly, a significant proportion of older patients receiving dialysis, subsequently regret their decision to initiate dialysis and many felt it was not their decision to initiate dialysis, nor have they been involved in ACP. This may be related to limited health literacy and poor understanding of important terminology and concepts. Our understanding of what older adults with ESRD value and consider important is limited, with the potential for significant differences and variations across cultures and regions. The evidence suggests that most older patients wish to participate in medical decision-making and end of life care discussion, with a heavy reliance on their treating nephrologist. Taken together, this evidence may have implications for the SDM process, optimal patient centred care, patient health literacy, engagement with ACP (including end of life care planning) and the development of renal supportive care services including conservative management of ESRD in Ireland.

Therefore, there are significant gaps in our knowledge and understanding of older patients with ESRD in Ireland. These gaps will be addressed through two distinct bodies of qualitative research work based on thematic analysis. First, a study of nephrologists was performed to explore their perspective on managing ESRD in older patients (including decision on initiation of dialysis vs. conservative management) and their perspective on ACP and end of life care (Chapter 3). Second, a study of older patients receiving haemodialysis was performed to explore their understanding of dialysis and the factors which influenced their decision to commence dialysis, their values and wishes (including end of life care) and their engagement in ACP (Chapter 4).

Specific areas of interest include:

- (i) Clarifying why nephrologists recommend dialysis for older patients
- (ii) Understanding the perspective of nephrologists on dialysis and conservative management for older adults with ESRD
- (iii) Understanding how nephrologists weigh the risks and benefits of therapeutic options for older adults with ESRD
- (iv) Exploring how nephrologists perceive or structure conservative management services at their centre and any associated challenges
- (v) Describing the level of engagement in ACP between older patients and nephrologists in the context of the international literature
- (vi) Exploring if older recipients of dialysis want to discuss prognosis and end of life care
- (vii) Understanding what older recipients of dialysis value and consider important
- (viii) Exploring the level of understanding of ESRD, dialysis and conservative management by older recipients of dialysis in Ireland.

Chapter 2: Methodology

2.1 Research Design

This research work lends itself to a qualitative study design. The two groups of interest, nephrologists and older adults with ESRD receiving dialysis, were studied separately. Each study seeks to explore the factors which influence decision making when considering the treatment options for the management of ESRD, namely dialysis vs. conservative management.

Successful SDM implies that the nephrologist is familiar with the clinical history of the patient and understands the implications of ESRD on the overall health, well-being and quality of life of that individual. The patient relies on the clinical information provided by the nephrologist and other HCP in order to make a decision about which treatment plan is most acceptable and best aligns with their wishes and values. In order to understand this decision making process and the complexities involved, qualitative interviews were conducted with nephrologists and older dialysis recipients until thematic saturation was achieved. This approach, using semi structured interviews, was considered most likely to generate rich data, as it allowed participants to speak freely whilst the interview topic guide ensured consistency of approach from one interview to the next, thereby adding to the credibility of the data. The interviewer sought clarification, as required, during the interviews, which can be considered a form of 'member checking'. A single interviewer was used across both studies, placing the researcher appropriately to compare and contrast the perspectives of both groups. Both studies, 'Nephrologist Study' and 'Patient Study' received ethical approval, without the need for any amendments, from the Galway Research Ethics Committee in advance of conducting any study specific activity (Appendix II).

2.2 Data Collection

All data for this thesis were gathered using scheduled semi-structured qualitative interviews, which were conducted and electronically recorded by the researcher. One focus group was conducted with five local nephrologists and all other interviews were conducted one to one. Interviews with nephrologists were conducted by telephone and recorded electronically; all patient

interviews were conducted face-to-face and recorded electronically. Data analysis was conducted within the framework of thematic analysis, enabling the researcher to identify, analyse, organise, describe and report patterns (themes) found. The researcher conducted all interviews and so brought some initial thoughts and impressions to this first step of thematic analysis, familiarisation with the data. Repeated 'active' reading of interview transcripts facilitated the search for meanings and patterns. Repeated listening to recorded interviews during the transcription process also facilitated familiarisation with the data. Cross coding of the all interview transcripts was completed by additional researchers, independent of the primary researcher, to ensure analytical rigour. Divergent or contrasting themes were sought and consensus reached through discussion.

2.3 Nephrologist Study

A key study objective was to gain insight into the perceptions of nephrologists throughout Ireland at multiple different clinical sites, both public and private. Study participants were recruited from the online register of consultant nephrologists at the Irish Kidney Association as of September 2017. The supervisor of this thesis and consultant nephrologist, contributed the names of additional consultant nephrologists in Ireland at the time of study recruitment who did not appear on the register. This resulted in a total of 37 eligible nephrologists, excluding the supervisor of this work.

A focus group, comprised of five local nephrologists formed the initial stage of the 'Nephrologist Study'. Potential participants were recruited from the local clinical site by electronic invitation (email) which introduced the researcher (as a specialist registrar in palliative medicine) and contained: (i) study objectives, (ii) rationale for conducting the focus group, (iii) potential number of participants and (iv) likely duration of the focus group interview (Appendix III). Confidentiality outside the focus group was guaranteed. All invited participants agreed to participate with a return email confirming participation as evidence of written informed consent. Participants conveyed their availability by email and a date was selected which suited all five participants.

The focus group was planned based on review of literature, requirements and consultation with senior researchers with considerable experience in conducting focus groups interviews in order to optimise the circumstances for both the participants and the interviewer/researcher. The objective of the focus group was to test the acceptability, scope and relevance of the interview topic guide (Appendix IV). Participants provided demographic details prior to commencing the interview (Appendix V). Refreshments were provided for the duration of the interview. The focus group opened with the interviewer reiterating study objectives and reassured participants that confidentiality would be preserved. The interview was recorded using three electronic devices, with two devices used as back up to a digital recorder.

The interviewer posed a question to the group and clarification was provided as sought by the participants. Sufficient time was allowed to ensure all participants had the opportunity to provide a response, whilst also ensuring that no participant felt pressurised to contribute as they may have introduced unnecessary bias (e.g. feeling the need to say something).

The remaining 32 eligible, non-local, nephrologists received an electronic invitation (email) similar to those provided to focus group participants (Appendix VI). Where email addresses were not available on the Irish Kidney Association website, the administration staff at the relevant nephrology department were contacted by telephone and/or email. Where prospective participants failed to respond to the initial invitation, an electronic invitation was sent two months later. Prospective participants who did not respond to a second electronic invitation received a third invitation six weeks later. No further invitations were offered after the third attempt.

The interviewer, phoned the interviewee, nephrologist, at the appointed time. Telephone interviews were conducted in a pre-booked room in the Clinical Science Institute (CSI), NUI Galway. This ensured good telephone coverage and the absence of interruptions while interviews were conducted over loudspeaker. Confidentiality was also preserved in this way. Interviews conducted outside usual working hours were conducted in the study of the interviewer's residence, ensuring no interruptions and preserving confidentiality.

Telephone interviews were recorded using a call recorder app in addition to a digital recorder and voice recorder on a deactivated telephone. Interviews were transcribed, verbatim, by the interviewer, within 48 hours of completion. At this stage, electronic recordings were deleted and transcripts were saved on a password protected laptop stored in a locked cabinet at the CSI.

The interview topic guide ensured a semi-structured interview (Appendix IV). Interviewees were encouraged to speak freely within the framework of the interview topic guide. Clarification was requested, as required. At the conclusion, participants were asked if they felt any relevant areas had been omitted. The interview transcript was not provided to participants after completion of their interview. The interviewer was satisfied that adequate clarification, when deemed necessary, had been provided during the interview process and secondly, the interviewer did not wish to impose further on participants' time of which they had given freely.

Analysis of the focus group and individual interviews occurred concurrently with conduct of interviews. Nvivo Pro 11 Software was utilised to facilitate primary electronic coding and the formation of hierarchical codes (95). Cross reading of alternate transcripts by two experienced qualitative co-researchers ensured analytical rigour.

2.4 Patient Study

This study sought to recruit patients that had commenced haemodialysis when aged 70 years or over and who were in receipt of haemodialysis for a minimum of six weeks. Participants were initially recruited from the Merlin Park Haemodialysis Unit, Galway, but to ensure gender balance, additional ethical approval was obtained (December 2019) to extend the study to include eligible patients attending the Wellstone Clinic, Galway. Exclusion criteria included patients with a documented history of cognitive impairment or patients with delirium and or cognitive impairment as suggested by the 4AT screening tool (96) completed at the time of recruitment.

The interviewer and supervisor met by appointment with the Clinical Nurse Managers (CNM) of each of the Haemodialysis Units (in August 2019 for Merlin Park and December 2019 for

Wellstone Unit). The study objectives, design and method of data collection was presented and discussed; both Clinical Nurse Managers were very enthusiastic and readily agreed to becoming a site for study recruitment, supported by the local treating Consultant Nephrologists.

In both units, prospective participants meeting the inclusion criteria, were identified by the relevant CNM, who provided the researcher with the relevant dialysis schedules. The interviewer presented herself to the CNM in the appropriate unit at times when prospective participants were in receipt of dialysis. Participants agreed to be interviewed during their dialysis sessions as this was felt the least intrusive approach. Additionally, it was considered that some patients might welcome a discussion to occupy some of the time they spent on dialysis.

Prospective participants were initially approached by a dialysis clinical nurse who was briefed by the researcher about the study and the implications for prospective participants. All approached patients agreed to meet with the researcher, who introduced herself as a doctor usually working in palliative care but who was at this time, engaged in research with a supervisor who is a local treating nephrologist, familiar to many of the patients. The objectives of the study were outlined and each patient was provided with a written information leaflet (Appendix VII). Prospective participants were offered to arrange the interview at a future time, but all agreed to conduct the interview at the time of first meeting the researcher. Detailed written informed consent was obtained from each participant and witnessed by a dialysis nurse.

The interview topic guide was formulated following a review of the literature and expert discussion (researcher, supervisor and senior co-researchers) prior to interviewing participants (Appendix VIII). Each interview was conducted with the curtains drawn around the treatment area. The treating nurse was assured that interruptions should continue, as dictated by clinical need. The interview was recorded using three digital voice recorders. Questions were posed, clarification provided, as required, and repetition provided in the case of participants with impaired hearing.

Within the semi-structured interview, participants were encouraged to speak freely. All were offered the opportunity to withdraw following completion of the interview or withdrawal at a later

date. Questions pertaining to prognosis and end of life care were broached delicately and several minutes into the interview process, unless this topic was raised by the participant sooner.

All interviews were transcribed verbatim by the researcher within 48 hours of the interview and the electronic recording was deleted. The transcripts were uploaded to Nvivo Pro 11 Software package where electronic coding was recorded (95). Nvivo Pro 11 facilitated the creation of hierarchical coding, memos and maps and the analysis was stored on a password protected laptop in a locked cabinet at the CSI. Similar to the 'Nephrologist Study', cross coding of alternate transcripts by experienced co-researchers ensured analytical rigour. Data analysis was concurrent with interviewing.

2.5 Rationale for choosing Thematic Analysis

There are multiple established analytical approaches to qualitative data. *Narrative analysis* elicits the meaning of experiences as expressed stories of individuals. It involves focussing on specific elements of the data which include, but are not limited to, how the story is structured, what functions the story serves, what is the substance of the story, and how the story is performed (97). *Phenomenology* helps us to understand the meaning of people's lived experience and these studies explore what people experienced and focuses on their experience of a phenomena (98). *Grounded theory* sets out to discover or construct theory from data in the field, systematically obtained and analysed using comparative analysis (99). *Ethnography* is used to describe and interpret a cultural or social group. It aims to provide rich, holistic insight into people's views and actions, as well as the nature (that is, sights, sounds) of the location they inhabit, through the collection of detailed observations and interviews. The aim is to 'get inside' the way each group of people sees the world (100). *Case study* is a research method common in social science. It is based on an in-depth investigation of a single individual, group, or event. Case studies may be descriptive or explanatory (101). *Thematic analysis* is a qualitative research method that can be widely used across a range of

epistemologies and research questions. It is a method for identifying, analysing, organizing, describing, and reporting themes found within a data set (102).

Thematic analysis was considered the most appropriate approach for the following reasons:

(i) Inductive thematic analysis facilitates the emergence of new themes and subthemes which was considered desirable in an area with a limited evidence base. Inductive thematic analysis also limits any potential bias which may be associated with analysing data using predefined themes as is the approach in deductive thematic analysis.

(ii) While this study is concerned with participant experiences, these experiences are not limited to any one particular phenomenon or phenomena.

(iii) This study recruited two particular groups of individuals, nephrologists and older adults receiving haemodialysis. One of the study objectives was to recruit participants until thematic saturation was reached thereby ensuring the study sample was representative of wider populations (nephrologists and older dialysis recipients).

(iv) The researcher is a novice qualitative researcher. Experienced qualitative researchers consider thematic analysis a foundational method for qualitative analysis, as it provides core skills for conducting many other forms of qualitative analysis (102).

2.6 Thematic Analysis

Thematic analysis is a method for identifying, analysing, organising, describing and reporting patterns (themes) found within a data set (102). It provides a rich and detailed yet complex account of the data, is an accessible and flexible research tool and is not wed to any pre-existing theoretical framework (102, 103). It is argued that thematic analysis is a useful tool for examining the perspectives of different study participants, highlighting similarities and differences and generating unanticipated insights; hence it's applicability to this study. Thematic analysis forces the researcher to adopt a well-structured approach to handling the data, thus producing a clear and organised summary of the key features of the data set (104).

The flexibility of thematic analysis can lead to inconsistency and a lack of coherence when developing themes derived from the research data (105). Therefore, consistency and cohesion is promoted by making explicit an epistemological position that can coherently underpin the study's empirical claims. A theme is defined as an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole (106). Themes bring together components or fragments of ideas or experiences which often are meaningless when viewed alone (107).

Thematic analysis can be an essentialist or realist method (103). Realist method of approach reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society. The researcher studied published literature and books written by experienced qualitative researchers (102, 103, 108). Two experienced and published qualitative researchers also acted as mentors during the process of data collection and analysis. The researcher employed inductive thematic analysis so that the evolution of themes is data driven (102) rather than a deductive approach where the researcher begins with a theory, develops a hypothesis and then collects and analyses the data to test that hypothesis (103). Neither approach is superior but the inductive approach allows for the generation of new theories from the data, considered desirable given the limited evidence base in the literature.

2.7 Trustworthiness of the Data

The researcher conducted, recorded and transcribed all qualitative interviews from both studies. All collected data was treated in the same manner as all interviews were initially coded manually and then electronically using Nvivo Pro 11 Software (95). The primary codes were further analysed leading to a hierarchal coding system with the evolution of themes and subthemes.

The 'trustworthiness' of qualitative data is comparable to the reliability and validity of quantitative data (103). Trustworthiness of the data can be considered in terms of the credibility,

transferability, dependability and confirmability of the data (109). Credibility refers to the 'fit' between the respondent views and the researcher's representation of them (110). Credibility can be enhanced by 'member checking' whereby the findings and interpretations are checked with the participant(s) (109). The researcher engaged in 'member checking' during the interview process in both studies to clarify statements/answers provided, as required. It was felt that asking participants to read the interview transcripts later would have been excessively onerous, who had already generously given of their time. Cross coding of the data by two senior co-researchers also enhanced the credibility of the data.

Transferability refers to the generalizability of the inquiry (110). The researcher considered the findings of this study in the context of the existing literature and both studies substantiate the existing evidence, while also adding new knowledge to this area. The researcher also provides a thick description of the results of each study thereby enabling the reader to judge the transferability of the findings themselves (109).

Dependability of the analytical process is evident in the logic, traceability and clarity of the process (110). Nvivo Pro 11 software displays clearly the rationale underlying the coding process, the nodal hierarchy, and the evolution of themes and subthemes (95). 'Memos' and 'spider diagrams', both components of Nvivo Pro 11 Software, also contribute to the dependability of the analytical process. Cross coding of transcripts and review of the analytical process by senior co-researchers can be considered an audit of the analytical process which further enhances the dependability of the analytical process. Confirmability implies that interpretations and findings are clearly derived from the data (110). Confirmability is attained when credibility, transferability and dependability have been achieved as outlined above (109).

2.8 Components of Thematic Analysis

Familiarisation with the data

One becomes familiar with the data through immersion. Experts recommend that researchers read through the entire data set at least once before initiating the process of coding (102). This allows the researcher freedom to formulate initial ideas, impressions and detect patterns before the rigorous process of primary coding begins. To preserve 'trustworthiness', researchers must remain true to the original accounts and be aware of their own beliefs, values, and experiences which may potentially influence their interpretation of the raw data and thus misrepresent the findings (111). In addition to maintaining self-awareness, cross-reading of transcripts by co-researchers and member checking during interviews enhanced the credibility of the data analysis. Data collection was concurrent with data analysis. This is a recognised practice during thematic analysis and allows the researcher to reflect and reconsider impressions during subsequent phases of the study (109).

Generating initial codes

This begins once the researcher is familiar with the raw data and has a general idea about the ideas contained within. Coding attempts to put a structure on the unstructured raw data. Coding involves reflecting on the data, interacting with it and thinking about it until we understand what is 'being said' (112). During the process of initial coding, the entire text of the data is given full and equal attention and divided or 'clunked' into data segments. Data segments contain interesting aspects of the data and these may form the basis of themes within the data set. 'Labels' are attached to these data segments and these 'labels' are indexed as they relate to a theme, an idea or issue. For example, the following quote from a patient

'Yeah, yeah. Who would want to be resuscitated like to be still in pain, especially at this stage of my life like ,you know if you were younger you'd have say some hope of recovery but I mean , now

there's no hope, you know, it's not feasible.' demonstrates patient acceptance of the concept of death.

Codes should be quite explicit ensuring that they are not interchangeable or that they do not become redundant (113). In this regard, an excessive number of codes becomes counterproductive to the goal of attaining clarity through organising and interpreting the data (104). Sections of the text may be coded numerous times under different codes (114). Hierarchal coding develops with progressive analysis and is very useful in the evolution of global themes. Hierarchal codes capture broad themes and provide an overview while codes lower in the hierarchy reflect different aspects of that theme. It is important that accounts which depart from the dominant analysis are not excluded (102).

The approach to coding must be consistent and employ a defined approach (102). Initially, descriptive coding is employed, which provide little inference beyond what is contained in the data but does allows the researcher to 'get a feel' for the data and to initiate the analytical process (108). These descriptive, low inference codes effectively summarise the data and form the basis for latter higher order coding (115). At that stage, the researcher devised a codebook, i.e. a list of codes with definitions (Appendix IX), which facilitated keeping track of how codes are being used, ensuring consistency and trustworthiness of the analytical approach.

Analytical coding further develops the interpretation of the data and it is central to the qualitative inquiry (108). It encourages the researcher to question the data, which facilitates the evolution of concepts and theories, which emerge inductively from the data. Higher order codes are more interpretative and require a degree of inference. This second-level coding is thus more inferential and organises the data into more meaningful units or pattern codes. Therefore, a pattern code is a more abstract concept that brings together less abstract and more descriptive codes. In this way, broad higher order codes evolve which provide an overview of emerging themes and subthemes.

The researcher's approach to data analysis reflects that of Miles and Huberman (111), including data reduction, data display, drawing and verifying conclusions. Data reduction seeks to reduce the amount of raw data without losing important information. It is a continuous process achieved through segmenting and summarising data, coding and using memos to identify emergent patterns and themes (115). Conceptualising the data through the development of abstract concepts is the final stage of data reduction.

Data display facilitates the organisation, compression and assembly of data throughout the process (115). The researcher's use of Nvivo Pro 11 Software demonstrates how the data was organised, compressed and assembled through the evolution and development of a hierarchal nodal system (95). Project maps were also integral as they facilitated the evolution of themes and abstract concepts by visually enabling the researcher to examine and test possible associations and relationships between aspects of the data. Drawing and verifying conclusions occurs in tandem with data analysis (106). While concepts and ideas may occur early, they are often ill-formed and vague. The use of memos assists ongoing analysis and the further development and conceptualisation of these ideas or themes (98)(Appendix X).

The researcher used Nvivo Pro 11 Software, available from NUI Galway, to organise and store raw data while also recording the hierarchal coding system (95). Nvivo Pro 11 Software facilitated the visualisation of the analytical progress and allowed large amounts of data to be organised and categorised. However the software is not capable of, nor was used, to analyse, conceptualise or theorise data (104). The researcher engaged in self learning using published books, articles and online tutorials provided, by Nvivo, to attain the necessary skills (102, 103, 108, 114), with appropriate oversight from supervisors. The researcher also used memos during the analytical process, which enabled the recording of ideas, impressions, potential associations, questions and other thoughts during coding. The researcher utilised the electronic memo available within Nvivo Pro 11 software, later and during more advanced stages of analysis (Appendix X).

Chapter 3: Nephrologist Study

Published as: O'Riordan J, Noble H, Kane PM, Smyth A. Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study. *BMJ Support Palliat Care*. 2020 Dec;10(4):e39. doi: 10.1136/bmjspcare-2018-001759. PMID: 31239255.

3.1 Introduction

Older adults, aged >75 years, constitute the largest patient group who commence dialysis for end-stage renal disease (ESRD) annually (11). Many experience a high symptom burden from both ESRD and dialysis, while also contending with travel to and from dialysis centres (14). For many, the coexistence of ischaemic heart disease precludes significant survival benefits from dialysis (12). Over 10% of older adults die within three months of dialysis initiation (21, 22) and older adults also have high rates of hospitalisation (22). As such, the survival benefits of dialysis are frequently offset by more time in hospital and a greater likelihood of a medicalised and hospitalised death (5).

Conservative management seeks to optimise quality of life through the active and non-dialytic management of symptoms associated with ESRD, and is best delivered by a collaborative multidisciplinary team through a low clearance clinic (LCC) (80). A Low Clearance Clinic provides clinical review, treatment refinement, symptom control, dietary advice and education to patients with advancing CKD (9). However, the availability and delivery of conservative management varies significantly between nephrology units (4, 10, 87). Renal staff are ideally placed to assist older patients to make informed decisions about treatment options, but need appropriate supports (10) as nephrologists may struggle to define their role in advance care planning (ACP), avoid end of life discussion (for fear of jeopardising relationships with patients) or equate conservative management with 'no care' (4).

As the decision to initiate dialysis is not straightforward, the Renal Physicians Association and the American Society of Nephrology advocate 'a shared decision making approach ensuring that patients' values and preferences play a prominent role' (116). They recommend facilitating advance care planning to help patients understand their condition, identify their goals and prepare for the decisions that may have to be made as the condition progresses over time.' An advance care plan thus enables patients to document their preferences for future care in the event of them losing the ability to express their own wishes (29). However, few older adults with ESRD are afforded an opportunity to avail of appropriate ACP (1, 2, 117, 118). Consequently, these patients typically have

a poor understanding of their prognosis (35, 48) and often experience medically intensive end of life scenarios focused on life prolongation, rather than on quality of life (49).

In Ireland, while most older adults want to participate in decision-making (63%) and end of life care (94%), knowledge of ACP is poor (40). In addition, although most Irish people wish to die at home, the majority die in hospital (42, 43). Initiatives, supported by the Irish Hospice Foundation, have increased ACP in long-term care settings with formal documentation of care plans, reducing inappropriate transfers to acute hospital settings (119). The 'Think Ahead programme' promotes awareness of ACP and serves as an accessible and detailed record of individual care preferences (120). Our study seeks to establish the practices of nephrologists in Ireland, and to compare them with those in the US (4). In our study, we also identify additional barriers to conservative management in older adults and explore the difficulties encountered by nephrologists when discussing prognosis, dialysis withdrawal and end of life care.

3.2 Methodology

Detailed methodology for this study was provided in Chapter 2. In brief, this qualitative study used semi-structured interviews. Initial development of the interview topic guide was informed by a literature review of the management of ESRD in older patients and patient-centred care, undertaken by the researcher and independently reviewed by the supervisor and two senior co-researchers. All interviews were conducted by a single researcher. Initially, five nephrologists participated in a face-to-face focus group to (1) ensure the interview questions were both acceptable and relevant; (2) ensure the interview topic guide was comprehensive; and (3) gauge participants comfort with discussing end of life. No refinement of the interview topic guide was required after the focus group exercise. Subsequently, all other nephrologists working in hospitals throughout Ireland between September 2017 and February 2018 were invited, by email, to participate in a recorded telephone interview. Electronic written consent was provided by return email. Prior to the interview, nephrologists were asked to reflect on: (i) factors influencing their

choice of conservative management or dialysis for older adults with ESRD; (ii) understanding of patient priorities for care; (iii) factors prompting consideration of dialysis.

3.3. Results

All interviews were conducted between September 2017 and February 2018. Interviewing ceased once thematic saturation had been reached. Five local nephrologists were electronically invited to participate in the focus group interview and all agreed by return email. After completion of the focus group interview a further 32 nephrologists were invited to participate in individual telephone interviews. 18 nephrologists confirmed their willingness to participate by return email on receipt of the first electronic invitation and 15 nephrologists ultimately participated in the telephone interview. It is presumed that workload prohibited the remaining three nephrologists from completing the telephone interview. Each nephrologist was electronically provided with a selection of time slots to conduct a telephone interview. 80% of interviews were conducted during the working day, 9-5pm and the remaining 20% (four interviews) were conducted outside of usual working hours at the request of the individual nephrologist.

Overall, 37 nephrologists were invited to participate; 23 consented and 20 completed the focus group or interview (54% response rate). Non-responders did not differ significantly from responders (Table 1). Five nephrologists participated in a face-to-face focus group and 15 nephrologists completed individual telephone interviews (mean duration 22 min).

All questions posed to the focus group appeared acceptable including those pertaining to individual clinical decision making and management of end of life scenarios. The duration of the focus group interview was 35 minutes. More vocal group members tended to respond first. Collegiality was evident between the participants, all engaged and appeared eager to contribute. At the conclusion of the interview, the interviewer asked participants if any relevant areas/topics had been omitted. Analysis of the focus group interview confirmed that the interview topic guide was

sufficiently comprehensive to gather the desired data so no amendments to the topic guide were considered necessary prior to conducting the telephone interviews.

Nephrologists who participated in the individual telephone interviews appeared comfortable during the interview process. Two interviewees were inclined towards short responses while all other participants were generally discursive in their answers. None of the interviewees suggested augmenting the interview topic guide.

Ninety per cent (n=18) of the nephrologists who participated (focus group participants and telephone interview participants) worked solely in a clinical environment; 90% (n=18) had over 10 years' experience in nephrology and 70% (n=14) had completed fellowships in the US (Table 1). All had local access to palliative care services, but only 25% (n=5) had a designated LCC at their site.

Variable		Responder, n(%)	Non-responders, n(%)
Gender	Male	12(60)	11(65)
	Female	8(40)	6(35)
Years since medical school graduation	<15	2(10)	Unknown
	15-20	3(15)	Unknown
	20-30	13(65)	Unknown
	>30	2(10)	Unknown
Nationality	Irish	19(95)	17(100)
	Other	1(5)	0(0)
International fellowships*	USA	14(70)	Unknown
	Canada	1(5)	Unknown
	UK	7(35)	Unknown
	Australia	3(15)	Unknown
Healthcare setting of clinical practice	Public	13(65)	14(82)
	Private	0(0)	1(6)
	Mixed	7(35)	2(12)
Designated Low Clearance Clinic		5(25)	7(40)
Access to local palliative care services		20(100)	17(100)

Table 1: Characteristics of Nephrologists

*Nephrologists may have completed more than one international fellowship during training.

The process of analytical coding led to the emergence of themes and subthemes. Higher levels of analytical coding allowed descriptive codes to evolve into pattern codes which are more abstract concepts that bring together less abstract and more descriptive codes (110). In this way, hierarchal coding develops with the evolution of broad higher order codes providing an overview and detailed lower order codes allowing for distinctions to be made within and between cases (99). A pattern code of reasons for choosing conservative management was identified from descriptive codes and generated a hierarchal coding network (Table 2). Similarly, the concept of 'Barriers to Discussion' evolves from pattern codes and initial descriptive codes (Table 3) and 'suboptimal physician communication skills' is composed of descriptive codes as illustrated below (Table 4).

Pattern Code	Reasons for choosing Conservative Management
Descriptive Codes	Well -resourced service
	Terminal illness
	Significant cognitive impairment
	Severe psychiatric illness
	Dialysis technically not possible
	Patient choice
	No perceived benefit from dialysis
	Lack of social support
	Impaired quality of life
	Impaired decision making capacity
	Effective communication between patient and doctor
	Distance from dialysis unit
	Dependence
	Co-morbidity
	Burden and limitations of dialysis
	Age
Advanced malignancy	
Higher Order Codes	Reasons for choosing conservative management
	Nephrologists' perceptions of patients' priorities
	Nephrologists' experience of Palliative Care
	End of life care
	Doctor patient relationship
	Discussing death, dying and prognosis
	Dialysis withdrawal
	Dialysis initiation
	Barriers to Palliative Care referral
	Barriers to Conservative management
	Barriers to Discussion (of prognosis and end of life care) with patients
	Advance care planning

Table 2: Reasons for choosing Conservative Management

Barriers to discussion (of prognosis and end of life care) with patients	Variable clinical practice among service providers
	Unrealistic family and patient expectations
	Practical barriers
	Limited patient education
	Physician's desire to preserve hope
	Perceived patient denial, reluctance to engage
	Fear of causing distress to patient
	Ready availability of dialysis
	Clinical uncertainty regarding prognosis
	Suboptimal physician communication skills (see Table 5)

Table 3: Evolution of 'Barriers to Discussion.'

Pattern code	Suboptimal physician communication skills
Descriptive codes	Limited communication skills training
	Limited consideration of patients' priorities
	Avoid discussion of prognosis, death to minimise patient distress
	Unable to acknowledge limitations of dialysis

Table 4: Suboptimal physician communication skills

The following themes and subthemes were identified using the analytical processes discussed above and in Chapter 2 Methodology (Table 5)

Theme	Barriers to Advance Care Planning
Subthemes	Nephrologists’ reluctance to distress patients Nephrologists’ desire to instil hope in patients Limited communication skills training Nephrologists’ disillusionment with conservative management
Theme	Barriers to shared decision-making
Subthemes	Patients’ limited understanding of ESRD and dialysis Failing to elicit patients’ preferences and their priorities for their care Nephrologists’ perceptions of dialysis as a ‘safety net.’
Themes	Avoidance of End Of Life Planning
Subthemes	Time constraints Nephrologists’ reticence towards end- of-life planning Inadequate training in end-of-life planning

Table 5: Themes and subthemes

Theme 1: Barriers to Advance Care Planning

Subtheme 1.1: Nephrologists’ reluctance to distress patients

Nephrologists frequently avoided discussing prognosis and end of life care with patients due to a fear of upsetting patients and jeopardising the doctor–patient relationship. Most nephrologists offered dialysis to older patients who presented acutely with advanced kidney failure to preserve hope of a recovery. One nephrologist portrayed dialysis as a life-saving therapy to patients in an effort to instil hope and compensate for the limited time available to communicate adequately with patients.

Participant Quote: ‘Partly because we think we will upset the patients and partly because we like to portray that dialysis is great and will save your life. And partly because we’re always so busy and you don’t have the time to sit down and discuss these things.’(Participant 6)

Another nephrologist reported that colleagues disapproved of engaging patients in any discussion about prognosis.

Participant Quote: ‘...with my own patients I do [discuss prognosis] but the problem is that a lot of the patients belong to colleagues who don’t approve of that and don’t approve of sort of having any discussion whatsoever.’(Participant 5)

Nephrologists did not routinely discuss dialysis withdrawal with patients or the circumstances when it might or should be considered. They feared such conversations would distress patients and their families, who may perceive dialysis withdrawal as the withdrawal of ‘life-saving therapy.’ Twenty-five per cent assumed that patients would not want to engage in end of life planning. They felt that patients would view such a discussion negatively and that it was the responsibility of the nephrologist to ‘keep a brave face on things’ (Participant 4) and to avoid a discussion which would cause patients ‘mental anguish’ (Participant 17). End of life discussions involved family members rather than patients as nephrologists feared patients would feel they had ‘given up on them’ (Participant 12) and that their relationship with patients would be damaged.

Participant Quote: And I think you often wonder then do you possibly change how the patient might feel about how you are treating them, does the patient now think they are about to die and that you have given up on them so I think there is a little bit of that as well.(Participant 12)

Subtheme 1.2: Nephrologists' desire to instil hope in patients

Despite the limitations of dialysis in older patients, most nephrologists dialysed older patients presenting acutely to maximise the chances of a recovery. Three nephrologists justified dialysis in older patients by referencing salient patients whose prognosis on dialysis had exceeded expectation. The desire to preserve hope mirrors their reluctance to upset patients by discussing prognosis and end of life.

Participant Quote: ‘...we tend to not talk about prognosis... the statistics all say [survival on dialysis] is much, much worse than that.... our living experience is different....I don’t think we trust the statistics because what we are experiencing is very different...(Participant 14)’

Subtheme 1.3: Limited communication skills training

In addition to fear of upsetting patients, almost half perceived palliative medicine as integral to the delivery of conservative management in order to optimise ACP and symptom control. Some felt that nephrologists lacked the necessary communication skills to present conservative management as a valid and acceptable treatment option to suitable older patients.

Participant Quote: ‘...I think the barriers [to conservative management] would be maybe communication and I think if you express it in the right way to the patient or families, it’s not necessarily an inferior treatment at all in the right person, you know what I mean, in fact it’s probably a better treatment but you don’t want the patient or family to feel that you are not doing everything that should be done...So you need to be able to have experience in having these conversations...(Participant 13)’

Subtheme 1.4: Nephrologists’ disillusionment with conservative management

Five nephrologists, working across three clinical sites, had access to a designated LCC. Some nephrologists operated an ad hoc LCC with no additional resources. Four nephrologists were disillusioned with conservative management at their respective clinical sites and compared it with ‘no care’; they alluded to a sense of moral distress as they equated it to ‘giving up’ on patients. Conservative management was considered poorly resourced and poorly developed by most nephrologists and many did not regard it as a legitimate treatment option for patients.

Participant Quote: ‘... I don’t think it [conservative management] is adequately resourced in Ireland...It’s really synonymous with little or no care and what tends to happen, is that, although the decision may be made early that someone is going for conservative pathway really when the chips are down to offer them a change of mind at a late stage and go for dialysis...(Participant 7)’

Theme 2: Barriers to shared decision-making

Subtheme 2.1: Patients' limited understanding of ESRD and dialysis

Eighty per cent of nephrologists felt that patients had a limited understanding of ESRD and their treatment options. Despite this, most nephrologists acceded to patient requests for dialysis despite their clinical reservations about their suitability for dialysis.

Participant Quote: '...we tend to offer dialysis to anyone who wants it and who is physically able for it...so anyone who wants it and they have support and they have said that they want to go ahead with it...(Participant 16)'

Nephrologists attributed patients' unrealistic expectations of dialysis to a poor understanding of dialysis and what it entailed. They felt that some patients later regret their decision to commence dialysis and that as nephrologists they needed to be clearer with patients about the limitations of dialysis.

Participant Quote: 'If a patient isn't well informed about what they're facing into going into dialysis, they often think it's going to be a lot easier than we think it's going to be. So you know we probably do need to be much clearer in terms of the outcomes...(Participant 2)'

Subtheme 2.2: Failing to elicit patients' preferences and priorities for their care

Nephrologists frequently made assumptions about patient wishes and as a result often neglected to discuss prognosis and end of life care with patients.

Participant Quote: 'I think we overly simplify that [patients' priorities] and I think we can be guilty of assuming what it is of importance to people...(Participant 8)'

Similarly, nephrologists did not routinely discuss dialysis withdrawal or present it to patients as an acceptable and legitimate treatment option. Three nephrologists described patients who viewed continuing dialysis as their religious obligation despite struggling with it. Erringly, some

patients compared dialysis withdrawal with suicide or euthanasia and felt to withdraw would cause their families and doctors to feel disappointed.

Participant Quote: 'A lot of our elderly people feel that there is a stigma to [dialysis withdrawal]....it's a kind of a quasi-suicide and all the religious connotationsso they will not accede to that. (Participant 4)'

Subtheme 2.3: Nephrologists' perception of dialysis as a 'safety net'

Nephrologists viewed dialysis as a 'safety net' which ensured regular contact between older adults and medical care, via the haemodialysis unit. This differed from patients receiving conservative management, who, in the absence of a designated LCC, may not be reviewed for months. Such service deficits caused feelings of abandonment, helplessness and disillusionment among nephrologists and caused some of them to encourage patients, otherwise suited to conservative management, to commence dialysis thus ensuring regular follow-up.

Participant Quote: '...if they're coming to dialysis I'm in a position to see these guys two or three times per week so I'm going to be in a position to act more promptly, if and when significant symptoms emerge or there's a significant chance of them worsening. So it's a bit of a safety net...if they opt for conservative care I'm not really sure what happens to them...I don't know exactly who is going to look after them...(Participant 2)'

Theme 3: Avoidance of end-of-life planning

Subtheme 3.1: Time constraints

Nephrologists did not routinely explore patient preferences for end of life care and repeated hospital admissions were often necessary to prompt such conversations. Lack of dedicated time was identified as a significant barrier.

Participant Quote: ‘...to discuss stuff like end of life planning, your will, all that kind of stuff. You know I just don’t have the time to do that and I would imagine most of us don’t because we’re already doing 3–4 clinics a week...(2)’

Subtheme 3.2: Nephrologists’ reticence towards end of life planning

These discussions were often prompted by imminent death and occurred for the first time very close to the time of death. In the context of dialysis withdrawal or where a patient was being discharged home to die, these conversations were frequently had with family members rather than the patient.

Participant Quote: ‘I’d say no, I’d say I do that (discussing end of life care) badly I would say...until they end up being admitted and the usual pressure of having something documented in their notes in the event of an acute event otherwise I think I do that badly, I think advance care planning on that is not well done, so I don’t think I’m very good at having those discussions...(Participant 12)’

Nephrologists recognised this omission in patient care and expressed concern that they were not providing patient-centred care, with some impact on patient outcomes.

Participant Quote: ‘...we did a brief review amongst our patients that have died over the last year or two....in the over 75 s...., the majority of those patients still died in hospital ... we are expecting these patients to die and to die soon, they are dying in a kind of an acute, emergency type setting which is, you know very unsatisfactory...(Participant 2)’

Subtheme 3.3: Inadequate training in end of life planning

Many nephrologists felt they lacked the necessary skills and experience to communicate effectively with patients about dying and they perceived this as a barrier to engaging patients in end of life planning.

Participant Quote: ‘... it’s an uncomfortable discussion ...it really depends on the individual clinician, on how good their emotional intelligence is and also their comfort level in having these discussions

with people and tackling potentially difficult family members...and having the skill set and experience to deal with that, I think that's a massive barrier.(Participant 11)'

Most nephrologists perceived palliative care physicians as best placed to discuss end of life and some felt nephrologists lacked the necessary training to do so.

Participant Quote: '...because I think nephrologists in busy clinics are not always the best people to discuss these things (end of life), to be honest with you I don't know if we have the best training so sometimes it is good for them to meet a Palliative Care physician in advance, you probably have more time and you are more empathic than we are (laugh) I'm sorry! More comfortable around having those conversations.(Participant 13)'

Additionally, three nephrologists reported communication difficulties and poor engagement with end of life care among some nephrology trainees.

3.4 Discussion

This study provides valuable new insights into why nephrologists are poor at engaging in ACP and in particular, why they avoid discussing prognosis, dialysis withdrawal and end of life care with older adults with ESRD. Nephrologists were concerned that discussing these sensitive and emotive issues may upset patients. Interestingly, this means that many patients have a limited understanding of their condition and treatment options which affords them little opportunity to participate in a shared decision-making process. Nephrologists remarked on the absence of formal communication skills training and many lacked confidence in their ability to manage patient reactions to these discussions and feared they would damage the doctor–patient relationship, as seen in previous studies also (68) (121).

Time constraints and prognostic uncertainty were additional barriers to engaging in ACP in this study. Nephrologists struggled to acknowledge the limitations of dialysis to patients. Dialysis withdrawal was not routinely considered and nephrologists generally avoided end of life discussion until death was imminent. Many nephrologists were disillusioned with conservative management as

they equated it with '*death*' and '*giving up*'. They struggled to define their role in the conservative management service, felt they had little to offer and that it was poorly resourced to meet patient needs. Many nephrologists felt palliative medicine was fundamental to the delivery of conservative management given their clinical expertise in symptom management and communication. These findings are of international relevance as they provide novel insights into this area and expand on the findings of work undertaken elsewhere (4).

Prognostic uncertainty among nephrologists in Ireland resulted in many avoiding this discussion with patients, consistent with previous international reports (4). Some nephrologists were even discouraged by colleagues from discussing prognosis with patients, leading to inconsistent approaches to patient care. In our study, prognostic uncertainty in the acute setting meant that most nephrologists offered dialysis to older adults and avoided discussing prognosis to minimise patient distress. Our study also found that, for many nephrologists, this fear was compounded by a lack of confidence in their ability to discuss emotive aspects of care with patients, serving as a significant barrier to their engagement in ACP. Well-informed patients are more likely to establish realistic goals and live according to their values and wishes thus retaining a sense of power over their life and maintaining hope, even in the context of a life-limiting illness (1, 52). Therefore, this finding has considerable implications for the provision of patient care in nephrology.

Similar to the US (4), nephrologists in our study based their decision to offer dialysis on their experience of salient patients who had exceeded their life expectancy on dialysis, rather than the evidence which suggests a limited benefit of dialysis for these patients (12). Nephrologists in our study even portrayed dialysis as life-saving therapy in order to circumvent any discussion of prognosis and end of life. Internationally, efforts to enhance SDM and ACP are evident (122). The implementation of ACP has been linked to both a greater likelihood of dying at home or in a nursing home as well as ensuring sufficient control of symptoms (119, 123). Hence, discussion and exploration of mandatory ACP should be encouraged in consultation with patients and carers as

guidelines and policy are developed. The provision of specific training to physicians to ensure they feel confident with the process should also be considered (124).

Conservative management

Conservative management was considered an inferior therapeutic option, 'synonymous with little or no care' by many nephrologists, both in our study and in the literature, and they equated it with 'imminent death', which they perceived as belying their desire to instil hope in patients (4). However, in our study nephrologists were disillusioned with conservative management and morally distressed by the deficits in existing services; particularly inadequate resources, lack of clinical expertise and timely follow-up. Rather than 'abandon' their patients to conservative management (vs. the 'safety net' of dialysis), many nephrologists used the deficits in the service as a rationale for choosing dialysis in older patients, despite their suitability for conservative management. These findings reflect previous studies where nephrologists did not routinely discuss conservative management and actively promoted dialysis (86, 125).

Previous studies report that the survival advantage from dialysis in patients >75 years is significantly reduced by comorbidity, particularly ischaemic heart disease (12), and the survival advantage is lost in patients >80 years (126). Older patients choosing conservative management often maintain their quality of life (14), experience lower rates of hospitalisation and are significantly more likely to die at home or in a hospice than those receiving dialysis (5). As most patients with ESRD prioritise symptom control over life-prolonging therapy and would prefer dying at home or in a hospice, conservative management should not be considered an inferior option as it enables patients to fulfil their wishes (1). Our study highlights major deficits in the existing conservative management service mandating urgent resource investment and service development to create a viable alternative to dialysis for older patients and their treating nephrologists.

Communication

In our study, deficits in communication training and limited clinical experience of conservative management and end of life care provision emerged as contributory factors to poor engagement in ACP. Many nephrologists recognised the need for formal communication skills training, particularly for end of life care, consistent with the perception of nephrologists internationally (65, 67). The Royal College of Physicians of Ireland currently includes mandatory communication training courses for trainees on both the Basic Specialty Training and Higher Specialty Training schemes, including nephrology (69). Training in ACP is also available. However, in our study many nephrologists felt trainees avoided end of life care planning and lacked the ability to communicate with patients about dying. Furthermore, nephrologists perceived palliative medicine physicians as better equipped to initiate discussions around ACP. Nephrologists cannot delegate all of these discussions to palliative medicine and a greater emphasis on training (such as a rotation in palliative medicine as part of nephrology training) should be considered (65, 67, 127).

Most nephrologists acknowledged that older patients had limited understanding of CKD and associated treatment options. Yet, many facilitated poorly informed patients to choose dialysis, despite clinical reservations. Importantly, many nephrologists felt that some patients regretted their decision to commence dialysis, consistent with previous studies (where >60% of patients regretted their decision (1)). Patients want to be seen 'in the context of their personal lives' by healthcare professionals and an understanding of their illness, including prognosis and end of life, is critical to empower them and foster realistic expectations (2, 52). Older patients with ESRD report a willingness to engage in ACP, including end of life planning, and they expect their healthcare providers to initiate these discussions (1, 128). A previous study reported that 80% of patients relied on their nephrologist for medical information, yet 90% of patients revealed that their nephrologist had not discussed prognosis with them (1). Nephrologists in our study were concerned that discussing prognosis would have a deleterious effect, despite this evidence to the contrary (1, 2). In our study, end of life discussions were frequently prompted by an acute clinical deterioration, rather

than in a planned outpatient setting, when patients are more likely to be well enough to actively participate. Many nephrologists assumed patients would not want to participate and elected to speak with family members, reflecting poor patient engagement in end of life planning (1). This potentially deprives patients of the opportunity to better understand their condition and make choices accordingly.

Strengths and Limitations

The main strength of this study is that a sufficient number of nephrologists were interviewed to achieve thematic saturation and identify themes that represent the view of nephrologists around the country. Although the overall response rate was 54%, nephrologists were included from a range of units and locations around the country. Therefore, the views expressed likely reflect average national practice. In addition, individual telephone interviews permitted nephrologists to speak openly about their experiences while preserving their anonymity (in that their views were not directly disclosed to colleagues), outside of the interview setting. Whilst this was different for the focus group of local nephrologists, participants did speak freely and openly. The data was analysed in accordance with the framework of thematic analysis ensuring the credibility, transferability, dependability and confirmability of the findings; trustworthiness of the data (103). A consistent and defined approach was adopted to coding and the transcripts were analysed by two senior qualitative researchers to ensure consensus of data analysis and theme evolution.

The main limitation is that we cannot comment on the practice of non-responders. Non-responders may have been deterred if they felt their participation would result in their clinical practice being judged unfavourably or otherwise. However, the profile of responders is consistent with the national profile of nephrologists in Ireland, and we achieved thematic saturation, such that the overall results would be unlikely to differ significantly with increased participation. Non-verbal

communication, such as facial expressions and gestures, was not captured during the recorded telephone interviews and hence may have compromised the results to some extent

3.5 Conclusion

This study corroborates previous findings (4) in that most nephrologists did not routinely consider conservative management as a legitimate treatment option for older adults with ESRD. Nephrologists struggle with prognostic uncertainty and frequently circumvent end of life discussions for fear of upsetting patients. This study establishes the similarities between the practices and perceptions of nephrologists in Ireland and in the US, highlighting the international significance of our findings. Additionally, our study identifies important barriers experienced by nephrologists in initiating ACP with older adults including the absence of formal communication skills training (in discussing prognosis, dialysis withdrawal, ACP and end of life care preferences) time constraints and limited clinical experience in managing end of life situations. Deficits in conservative management in Ireland precluded many nephrologists from considering it as an acceptable treatment option. This study has important implications for policy makers and the training requirements for current nephrologists in training. More resources are urgently required for conservative management to ensure it becomes a viable treatment option for patients and their treating nephrologists.

Chapter 4: Patient Study

O’Riordan J, Kane PM, Noble H, Smyth A. Advance care planning in older dialysis patients: health care literacy qualitative study. *BMJ Support Palliat Care*. 2021 Oct 11:bmjpcare-2021-003398. doi: 10.1136/bmjpcare-2021-003398. Epub ahead of print. PMID: 34635544.

4.1 Introduction

As outlined in Chapter 3, international evidence shows that older adults (>75 years) account for 25% of patients initiating dialysis every year (129, 130) but for many the survival advantage conferred by dialysis is substantially reduced by comorbidity (21, 129) particularly, ischaemic heart disease (12). Furthermore, dialysis contributes to an already significant symptom burden leading many patients to perceive little benefit on their quality of life (14). Additionally, older dialysis recipients are 50% more likely to die in hospital, rather than at home or in a hospice, compared to patients receiving conservative management for ESRD (5, 49).

The RPA/ASN advocate incorporating ACP as a routine component of the delivery of patient care (9, 116). Older patients with ESRD are willing participants in ACP but just over 10% are engaged in this process (1, 87). The fear of nephrologists of upsetting patients, limited communication skills training and time constraints are recognised barriers to engaging patients in ACP (4, 65, 116, 131). Low health literacy among older patients may also limit engagement in end of life care discussion and increase the likelihood of aggressive treatment at end of life and hospitalised death (57, 132). In this regard, older patients are a particularly vulnerable group (133).

Improving patient health literacy supports patient engagement and empowers patients to participate in a SDM process (54). In previous studies, almost 80% of patients relied on their nephrologist for medical information and 35% wanted their nephrologist to make medical decisions in the event of becoming incapacitated (1). However, >90% of patients had not discussed prognosis and/or been engaged in EOLC discussion by their nephrologist (1).

Nephrologists do not routinely discuss prognosis, dialysis withdrawal and EOLC with patients (4, 131). In Ireland, most older adults want to participate in healthcare decision-making (63%) and EOLC discussion (94%), but knowledge of ACP is poor (42). Most Irish people wish to die at home, but the majority die in hospital (40, 42, 43). In this context, the objectives of this study were to explore: (i) the understanding of older dialysis recipients of haemodialysis; (ii) engagement in end of life care planning; and (iii) satisfaction with life on haemodialysis.

4.2 Methodology

Detailed methodology for this study is provided in Chapter 2. In brief, the objectives of this study were to explore older dialysis patients' understanding and experience of haemodialysis, to explore their engagement in end of life care planning and their satisfaction with life on haemodialysis. Methods are reported in accordance with the COREQ framework (134). The researcher conducted all interviews, is a specialist in palliative medicine and has led and published qualitative research previously. She had no prior relationship with participants and presented herself as a researcher with clinical expertise in palliative medicine.

This descriptive qualitative interview study employed thematic analysis and engaged in purposeful sampling of older patients attending two haemodialysis units in Ireland (108). Eligible patients were identified from a list of all patients registered to receive in-centre haemodialysis at Merlin Park Hospital. Patients with documented cognitive impairment were excluded as per our eligibility criteria. All other patients that initiated haemodialysis over the age of 70 years and in receipt of HD for a minimum of six weeks were considered eligible for invitation to study participation.

Patients were recruited from the Merlin Park HD unit as they appeared on the HD register and until it was clear that further recruitment at this site could introduce a potential bias relating to gender imbalance. At this point female patients, fulfilling the above criteria, were specifically sought from the Wellstone HD unit patient cohort. Patients were approached as they appeared on the HD patient register.

A dialysis clinical nurse sought initial consent from the patient to be approached by the researcher. Patients receiving in-centre haemodialysis for at least six weeks and aged >70yrs at the time of dialysis initiation were eligible and recruited in person. No patients withdrew or declined participation, the latter possibly reflecting a desire to help pass the time on haemodialysis. Study recruitment continued alongside data analysis (of completed interviews) and recruitment ceased once data saturation was achieved. Patients with documented cognitive impairment and delirium

were excluded. All participants were screened for delirium and cognitive impairment, using the 4AT screening tool (4'A's Test; Arousal, Attention, Abbreviated Mental Test-4, Acute change) (96). This tool provides basic cognitive testing, aimed at detecting moderate-severe cognitive impairment, alongside assessment for delirium. Eligible patients received a detailed explanation of the study and provided written informed consent. The Australian Karnofsky Performance Scale (AKPS) assesses patient's ability to perform tasks relating to self-care, work and activity and this was recorded for each participant (135). Interviews took place during haemodialysis in order to minimise intrusions on participant time and with due regard for participant privacy. Dialysis nurses attended to participants during the interview, as required, but these interruptions were brief and minimal. Otherwise, no non-participants were present during the interview.

A literature review, conducted by the researcher, informed the interview topic guide which was also reviewed by co-researchers and supervisor prior to study commencement. Electronic audio recording of face-to-face interviews occurred. All participants were offered the opportunity to withdraw from the study without negative implications for their clinical care.

Interviews were transcribed verbatim, anonymised and imported into Nvivo Pro 11 Software for further analysis (95). Immersion facilitated familiarisation with the data and line-by-line coding facilitated identification of meaningful segments of data which were then coded. Data was analysed inductively for emergent themes, rather than predefined themes, and further thematic analysis resulted in a hierarchical system of coding (108). Cross-coding of alternate scripts was performed by two experienced data coders ensuring analytical rigour. Emerging themes and subthemes were developed further through discussion with co-researchers until consensus was reached. Divergent or contrasting reports were sought and resolved through discussion. Thematic maps facilitated visualisation of the relationship between themes and further refinement generated global themes (108). Repeat interviews were considered unnecessary. Participants were numbered from 1-15 and quotations illustrating themes are attributed to participants in this way. Transcripts were not returned to participants as this was considered excessively onerous. Thematic saturation was

reached following completion of 15 patient interviews (136). Ethical approval was obtained (C.A.2007) from the Clinical Research Ethics Committee Merlin Park Hospital Galway.

4.3. Results

Interviews were conducted between September 2019 and February 2020. Interviewing ceased once thematic saturation was reached. A total of 15 patient interviews were conducted. The mean patient age at interview was 83.3 years (standard deviation 6.1 years) (Table 6). The mean interview duration was 33.3 minutes. In general, there were few interruptions during the interview process so that participants were interviewed alone. Clarification was frequently sought by the interviewer to ensure that she had understood the participant correctly. One participant requested that the interview be concluded early due to tiredness. Otherwise all participants completed the interview. No participant withdrew their participation. All participants engaged enthusiastically and many appeared to enjoy the process.

Characteristic		Estimate
Gender	Male n (%)	8 (54%)
	Female n (%)	7 (46%)
Age at interview, (Mean (Standard Deviation))		83.3 (6.1) years
Age commencing Haemodialysis, (Mean (Standard Deviation))		79.3 (6.8) years
Duration of Haemodialysis, (Mean (Standard Deviation))		4.4 (3.1) years
Aetiology of ESRD	Diabetic nephropathy	7 (46%)
	Hypertensive nephropathy	2 (13%)
	Obstructive uropathy	3 (20%)
	Malignancy	1 (6%)
	Unknown	2 (13%)

Table 6: Participant Characteristics

As in Chapter 3, raw data was reduced and distilled into descriptive codes which further contribute to the evolution of the pattern code; limited patient understanding of CKD (Table 7). Pattern codes were analysed further to develop a hierarchal coding network global themes including the impact of disempowerment on limited health literacy (Table 8).

Pattern Code	Limited Patient Understanding of CKD
Descriptive Codes	Rudimentary understanding of CKD
	Understanding of CKD influenced by nursing background of patient
	Patients don't recall receiving education about CKD from Nephrology or GP
	Nephrology team did not discuss prognosis with them
	Patients don't know what questions to ask
	Patients don't grasp the gravity of ESRD
	Limitations of information booklets
	Unaware of conservative management as an alternative to dialysis
	Patients' lived experience of CKD defines it for them

Table 7: Limited Patient Understanding of CKD.

Global theme	Disempowerment reflected limited health literacy
Pattern codes	Limited patient understanding of dialysis and conservative management
	Limited exploration of the goals of dialysis therapy
	Perception that decision to initiate dialysis was made by a doctor
	Participants vulnerable to unreliable sources of information
	Awareness of knowledge deficits- reluctant to ask questions
	Deferred healthcare decision-making to healthcare professionals

Table 8: Disempowerment reflected limited health literacy

Project maps were also used to facilitate the evolution of themes and abstract concepts by visually enabling the researcher examine and test possible associations and relationships between aspects of the data (Figure 1).

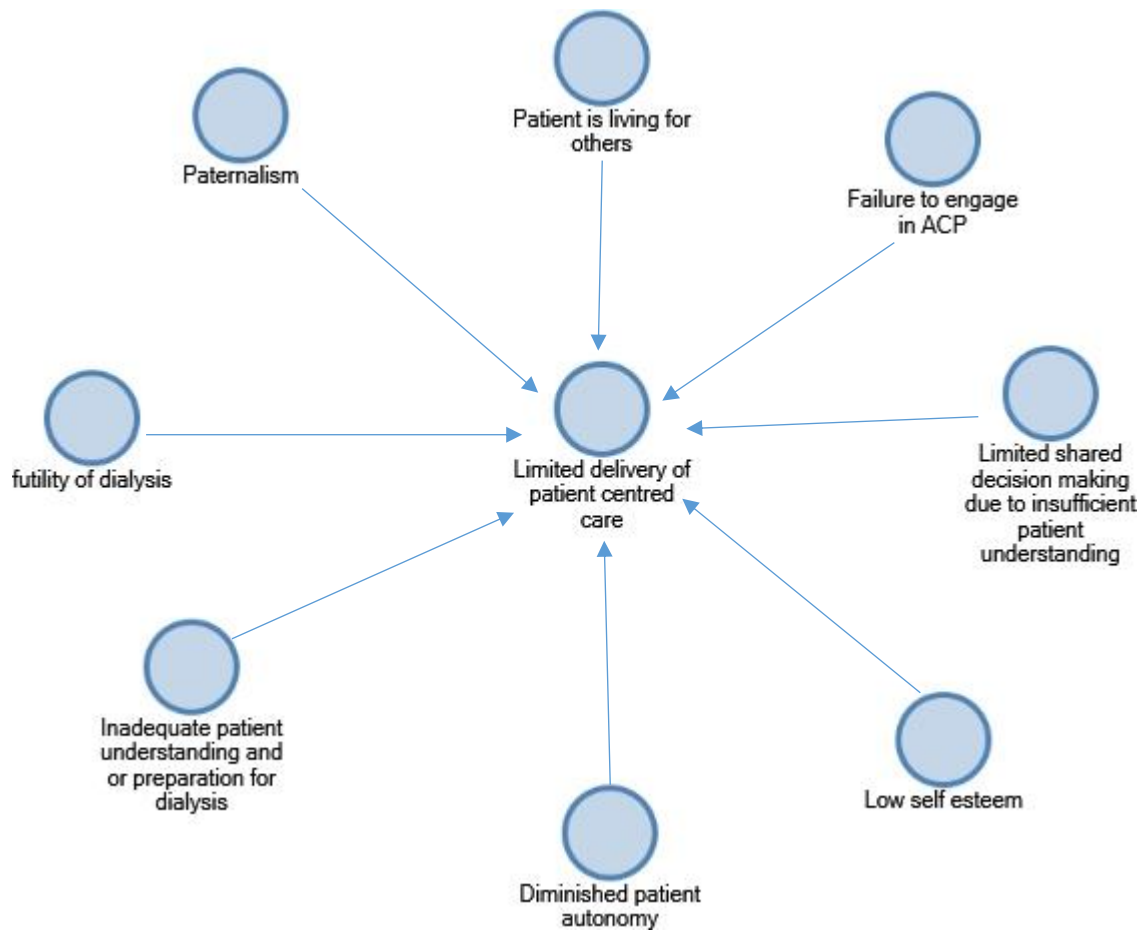


Figure 1: Project Map: Evolution of themes: Limited delivery of patient centred care

The global themes which emerged from the data included disempowerment reflected limited health literacy; poor ACP compromised participant well-being; haemodialysis compromised participants' core values (Table 9).

Theme	Disempowerment reflected limited health literacy
Subthemes	Limited participant understanding of dialysis Participants exhibited poor health literacy Participant suffering reflected limited patient empowerment
Theme	Poor Advance Care Planning compromised participant well-being
Subthemes	Missed opportunities for timely dialysis withdrawal Poor participant support for EOLC planning Participant discord in defining their priorities
Theme	Dialysis compromised participants' core values
Subthemes	Escalating symptom burden on dialysis Spiritual distress Compromised autonomy

Table 9: Themes and Subthemes

Theme 1: Disempowerment reflected limited health literacy:

Participants had a limited understanding of dialysis. Limitations in health literacy restricted their ability to intervene when ongoing dialysis therapy appeared to threaten their fundamental values and priorities. Their continued endurance of dialysis contributed to their suffering.

Subtheme 1.1: Limited participant understanding of dialysis:

Most participants, including those who had spent several years on dialysis, demonstrated a limited understanding of dialysis and of why they commenced dialysis. Participants who commenced dialysis acutely often had no recollection of the events. They did not remember discussing dialysis as a treatment option or once the acute phase passed, whether they wished to continue with dialysis.

Interviewer: ' And do you remember at any stage asking questions about dialysis?

Participant Quote : I didn't ask any questions ... they wheeled me down for dialysis and I just went along and that was it you know.

Interviewer: And did you know at that stage the commitment that was involved? That it would be three times a week?

Participant Quote : I didn't, I hadn't a clue.' (Participant 8)

Most believed that dialysis was the only treatment option available to them and understood that it was necessary to keep them alive. One participant was familiar with the term 'conservative management' and two recalled reading the information booklets provided. All perceived that the decision to initiate dialysis was made by either their nephrology team or their GP, rather than themselves. Participants were vulnerable to misinformation from unreliable sources, including family members and people who had an opinion of dialysis rather than any specialist knowledge or experience of it. Participants relied on other dialysis patients for information. Some participants, who struggled with their own understanding of dialysis, advised fellow patients.

Participant Quote: '...there's another fellah used to come in here along with me for dialysis ... he called me here [HD unit] one day and he said 'what do you think this [dialysis] is doing for us?' ' what do you think it's doing, 'I said, it's keeping us alive?' and he said ' do you think it's doing any good?' and I said ' I do, every time I come in they take fluid off me' and only for they do 'I said, 'I'd be a lot worse.'(Participant 9)

Subtheme 1.2: Participants exhibited poor health literacy.

Participants with concerns were reluctant to ask questions pertaining to optimal daily fluid intake and time sensitive issues (e.g. EOLC planning). Over half of participants wanted to know their prognosis if it was six months or less but none had discussed prognosis or EOLC with clinicians.

Participant Quote: 'I didn't ask too many questions about it (dialysis), the little I know about it is that ... the lips get very dry you know and I'm not sure if I'm drinking too much or too little.

Interviewer: And is that a question you could ask the nurses or the doctors in here [dialysis unit]?

Participant Quote: No, no no.' (emphatic) (Participant 6)

Participants perceived their own knowledge deficits and utilised them to justify placing their trust in clinicians rather than engage in discussion. Others perceived themselves as 'ignorant' and appeared too embarrassed to ask questions. Participants viewed nephrologists as busy professionals and they were reluctant to impinge on their time further by asking questions.

Participant Quote: 'Well I wasn't going to go asking him any questions after that...Because I was ignorant you see.

Interviewer: But why do you think you were ignorant

Participant Quote: Because I didn't understand why he was putting me on [dialysis] for the extra hours, I thought it was fluid you see....'(Participant 9)

Others questioned their entitlement to participate in key healthcare decisions, such as dialysis withdrawal, believing that such decisions were best left to clinicians to decide.

Interviewer: 'Have you ever imagined a situation where you might feel you wouldn't want to continue dialysis?

Participant Quote: Well I'll wait til the doctor tells me that, oh yeah transplant.

Interviewer: No well not transplant. Have you ever felt 'if such and such happened then I would just want to stop the dialysis?'

Participant Quote: Is that up to me now I wonder?Is that up to me?(laugh) No, no I wouldn't, I'll let the hospital decide that.'(Participant 7)

Many participants adopted a passive role in regard to healthcare decision-making. This approach compounded poor levels of health literacy and jeopardised opportunities for patient-centred care.

Interviewer: 'So are you happy for your doctors to make the decisions say when it comes to your healthcare? Are you happy to let those decisions to the doctors?

Participant Quote: Oh yeah definitely yeah.

Interviewer: You trust them?

Participant Quote: Yeah, because I know nothing about medicine or anything. '(Participant 6)

Subtheme 1.3: Participant suffering reflected limited patient empowerment:

All participants ably defined their values and priorities yet many endured a remarkable level of physical, spiritual and emotional suffering without expectation that things should be better. Almost half felt no better after commencing dialysis and many contended with increasingly complex comorbidities. Even when the continuation of dialysis threatened their fundamental values and beliefs (loss of meaning in life, loss of enjoyment and control over one's life), their attitude was one of perseverance and gratitude that they were still alive, rather than questioning the merits of continued dialysis. Among participants, there seemed little exploration of the goals of dialysis therapy beyond sustaining life. Remarkably, for many, dialysis appeared to jeopardise their values rather than preserve them.

Participant Quote: 'I know, kind of, you're not free anymore. You have to come in here [dialysis unit] and do what you're told, taking tablets and then get on the machine...it makes you feel that you are more or less belong to the people of... I shouldn't say it like that...that you belong to the people of the XX [name of haemodialysis unit]...that's where I'll be for the rest of my life.' (Participant 1)

Theme 2: Poor Advance Care Planning compromised participant well-being

None of the participants had discussed prognosis or end of life care (EOLC) with a clinician and many appeared isolated in relation to EOLC planning and key healthcare decisions (e.g. dialysis withdrawal). Many were conflicted about their preferences for care as they sought to balance their innate desires with expectations of their family. There were three important subthemes identified.

Subtheme 2.1: Missed opportunities for timely dialysis withdrawal:

Most participants were unaware that dialysis withdrawal was an acceptable treatment option. Yet, almost half of participants had contemplated discontinuing dialysis demonstrating significant levels of patient distress. Many felt they required the approval of a clinician before they

could consider stopping dialysis. None had discussed dialysis withdrawal or EOLC with a clinician.

Participants appeared to resign themselves to continued dialysis even if conflicted with their wishes.

Interviewer: And if you thought your time [life expectancy] was in the order of a few months would you consider stopping dialysis yourself?

Participant Quote: 'Yes if the doctor thought it was ok to [do so]...' (Participant 1)

One participant viewed dialysis withdrawal as an act of suicide and thus felt precluded from considering it. Others experienced a sense of religious obligation to continue, despite struggling.

Participant Quote: '...it's kind of more of a suicide wouldn't you think?

Interviewer: Why do you think that?

Participant Quote: Well you decide you're giving it [dialysis] up and you know you have only a couple of weeks then until you're gone, so like what's the difference between going out and jumping in the river and doing that?...that's my understanding of it you know.' (Participant 14)

Subtheme 2.2: Poor participant support for End of Life Care Planning:

Many participants did not have the opportunity for EOLC planning. None recalled discussing prognosis, dialysis withdrawal or EOLC with a clinician, yet all had contemplated EOL. Some perceived that doctors avoided 'difficult conversations' because they did not want to upset patients. Most expected clinicians to discuss EOLC once when their prognosis was six months or less and correlated spiritual, financial and practical preparation for death with the likelihood of being at peace at EOL. Others did not perceive EOLC planning as the responsibility of their nephrology team.

Participant Quote: 'Well, I'm sure that I'd know if my time was getting short. I would depend on them [doctors] to tell me.

Interviewer: Would you want them [doctors] to tell you?

Participant Quote: Ah yeah.

Interviewer: What would you see as the importance of that?

Participant Quote: I'd like to know what the future holds.' (Participant 2)

Many participants sought to protect their family and so avoided discussing EOLC with them. Some worried about who would care for them at end of life and others had financial concerns.

Interviewer: 'What do you find hardest about life at the moment?'

Participant Quote: [Long pause]...not saving enough money ...for my funeral...[laugh]

Interviewer: That's a big worry?! And aside from that say?'

Participant Quote: Aside, well I suppose if someone will bury me, aside from that, I don't worry about anything...'(Participant 3)

Some reported that their families had actively discouraged any discussion of EOL, leading to further isolation and a diminished prospect of dying in accordance with their wishes.

Interviewer: Have you discussed that with your family, [the involvement of] palliative care?'

Participant Quote: I haven't actually, no, they don't want to even hear about it you know, or hear about end of life kind of, they don't want to listen to me there, yeah.' (Participant 14)

Subtheme 2.3: Participant discord in defining their priorities:

Participants struggled to reconcile their values and wishes with their desire to protect family. Many struggled to find meaning in their life, but perceived benefit for family in persisting with dialysis and this contributed to external discord. One participant regretted his decision to commence dialysis almost immediately and recalled his son's influence.

Interviewer: 'Did you feel you could say no to dialysis?'

Participant Quote: I did yeah.

Interviewer: You did, ok. What stopped you from saying 'no' to dialysis?'

Participant Quote: Well my son was there with me the day the doctor was there and he kind of advised me to have dialysis.' (Participant 11)

One participant, who had commenced dialysis acutely, wanted to discontinue it once she regained decision-making capacity, but her family persuaded her to continue. A decade later and her family refuse to discuss the circumstances of her acute initiation of dialysis.

Participant Quote: '...I was on dialysis and I was unaware of my surroundings and then when I was [aware], came back to myself, I didn't want to be on it then. There was one particular lady and my daughter who used to have to kind of persuade me, I'd only want to stay about 15 minutes [on dialysis] ...' (Participant 14)

Participants alluded to a sense of having felt compelled to accept dialysis as they understood from clinicians that the only alternative was to die.

Interviewer : 'Did they ask you did you want dialysis?'

Participant Quote: Oh they did, they did, they said to me 'you'll have to go on dialysis if you want to live, kind of...' (Participant 9)

Another participant recalled how the necessity of dialysis was emphasised further when she was told that she would die *and suffer* if she did not continue dialysis.

Participant Quote: 'I remember saying it to one of the nurses there at the time, ah... if I didn't come into, for my dialysis for a week, and she said, 'you would be dead and you would have a very painful death.' (Participant 12)

Many participants had contemplated stopping dialysis but simultaneously, questioned their readiness to die. Limited opportunity/support for open discussion, with both clinicians and family members, seemed to compound this internal discord. Many feared such discussion would upset family members, some families discouraged such discussion and other participants, through social isolation, simply had no one to discuss their concerns with.

Participant Quote: 'I mean I even think to myself I wish I could give this [dialysis] up but then my husband said to me 'well if you give it up, probably you will die! I don't want to leave my husband, my family...so I'm putting up with it ([tearful].)' (Participant 15)

Theme 3 : Dialysis compromised participant core values

Participants did not appear to have explored the goals of dialysis therapy beyond sustaining life. Participants persevered with dialysis even when doing so compromised their core values. Three important subthemes were identified.

Subtheme 3.1: Escalating symptom burden on dialysis:

Participants struggled with the time lost to the rigours of the dialysis regime and when coupled with post dialysis fatigue, most disregarded dialysis days as opportunities for living. Many alluded to the burden of co-morbidities which evolved in complexity over time. Progressive digital ischaemia and the necessity of amputation contributed significantly to distress and symptom burden.

Participant Quote: 'twas gangrene...I've lost the foot now and two toes... it's not looking good you know...

Interviewer: Do you get pain?

Participant: Oh pain, yeah...most of the time, so ...the pain more times than not.

Interviewer: And does that affect your sleep, the pain?

Participant: Ah it would yeah.' (Participant 4)

Others continued to undergo investigation for potentially serious conditions and endured the inherent anxiety. Some reported a deterioration in their quality of life on dialysis, feeling 'down' a lot of the time and unable to cope with additional stressors.

Subtheme 3.2: Spiritual distress

Most participants described features of spiritual distress. Many alluded to a loss of control over their life and a diminishing purpose in life. Others recognised they were living for the benefit of others and this conflicted with their innate desire to discontinue dialysis. None understood that

dialysis withdrawal was a legitimate option. Many derived no enjoyment from life and felt they had nothing to look forward to.

Participant Quote: '... it's [dialysis] really a sentence. I wouldn't say that to anybody else now, it is a sentence really. If I didn't have the two boys and I didn't have my husband I probably wouldn't bother coming here.

Interviewer: You would stop dialysis?

Participant Quote: Yes.

Interviewer: So you are living for them?

Participant Quote: I'm living for them, yeah, yeah, I am . But there would be nothing to live for if they weren't there, I wouldn't be bothered living for myself...' (Participant 15)

Subtheme 3.3: Compromised autonomy

All participants valued autonomy in determining the structure of their day, independence in self-care, social activities and driving. The rigours of the dialysis regime dictated much of the structure of their life. Post-dialysis fatigue coupled with a significant symptom burden limited opportunities for social engagement. Those who had lost their permit to drive, due to declining health, alluded to a sense of loss. Many were distressed by their increasing dependence on others, the restriction of their social activities and their struggle to stay abreast of affairs in their local community. For some, the haemodialysis unit had become their social connection.

Participant Quote: ' ...when I started dialysis it was good because we come in in the taxi three times a week and just away, get out really...

Interviewer: You got out of the house?

Participant Quote: Yeah.' (Participant 3)

4.4 Discussion

This study provides us with valuable new insights into the experiences and perceptions of older patients in receipt of haemodialysis, while reinforcing findings from international studies (6, 36, 137, 138). We highlight the importance of careful consideration of both the benefits and risks associated with haemodialysis in older patients, who often have multiple and complex comorbidity. This study highlights a necessity to enhance patient literacy to facilitate patient empowerment, which in turn enables patients to participate in shared decision-making and advance care planning.

Participant empowerment and health literacy:

In our study, most participants demonstrated a limited understanding of haemodialysis. None had discussed prognosis, dialysis withdrawal or EOLC with their clinicians, similar to previous studies (1, 6, 137, 138). All perceived that the decision to initiate dialysis was made by a doctor and some alluded to coercion from family members. Participants resigned themselves to dialysis because they believed they would die otherwise and, as such, did not perceive they had a choice, reflecting similar patient groups internationally (6, 137).

Our study provides new insights. Participants were reluctant to ask pertinent questions of clinicians and considered their limited knowledge, occasionally perceived as 'ignorance', as reasons to avoid rather than ask questions. They frequently entrusted key healthcare decisions to clinicians who may not have been familiar with all of their wishes. Indeed for many, dialysis appeared to compromise core values rather than embody them. Hence our study provides novel insights which demonstrate how limited health literacy actually perpetuates poor health literacy and that dialysis, prescribed as a life sustaining therapy, frequently jeopardised core values.

Participants understood words and numbers (e.g. declining eGFR reflected deteriorating kidney function, representative of functional literacy), but few displayed more advanced levels of health literacy. Interactive literacy refers to clinician-patient communication and active patient engagement (2). Almost half of our participants had concerns pertaining to EOLC but none had

engaged in EOLC discussion with clinicians. Critical literacy reflects patient ability to make decisions concordant with their preferences, but many of our participants felt their life on dialysis did not reflect their core values and had contemplated discontinuing dialysis due to overwhelming physical, emotional and spiritual distress (2, 6). However none felt sufficiently empowered to discuss this with a clinician.

Shared decision-making, a fundamental component of informed consent, dictates that patients must attain an understanding of their illness, in the context of its likely short- and long-term impacts on their daily life (50). Thus, health literacy is critical to empower patients to participate in this process. Providing opportunities for patients to learn terminology and discuss EOLC preferences enhances health literacy (2). In this study, most patients misunderstood terms commonly used in EOL discussions (e.g. 'prognosis', 'quality of life' and 'hospice care'). They experienced limited opportunities for engagement with nephrologists which restricted their ability to clarify points of confusion and understand trade-offs associated with their treatment options. Information booklets proved of limited benefit; studies show those with limited health literacy are more likely to interpret words literally, confuse meanings, skip key words and tire quickly (139). By explaining prognosis and treatment options, clinicians improve health literacy and may then tailor the conversation to outcomes most important to each patient through a shared decision making approach (140). Nephrologists should be offered appropriate training in this regard (4, 131).

Advance care planning and patient preferences

Patients are not routinely engaged in ACP, despite clinical guidance which prioritise this aspect of care (4, 116, 131). Barriers include fear of jeopardising the doctor-patient relationship by discussing prognosis and EOLC, limited communication skills training and time constraints (4, 131).

All participants were at significant risk of sudden death, yet none had discussed prognosis, dialysis withdrawal or EOLC with a clinician. Participants overestimated their prognosis, many would have considered dialysis withdrawal if approved by a clinician and most wished to die at home.

Participants ably articulated their priorities and values, but many felt their current life did not reflect them. Many experienced either diminished or no control over their life, many were spiritually distressed and struggled to enjoy life. They persevered with dialysis even though, by prolonging life, this appeared to threaten their values and have greater impacts on their quality of life. This perseverance likely reflects limited patient empowerment and therefore missed opportunities for EOLC planning.

ACP gives patients the opportunity, in advance, to outline what scenarios are acceptable and those that are not (29). In our context, ACP seeks to normalise death and dialysis withdrawal by providing a forum for discussion, thereby minimising isolation and discord. Successful ACP guards against treatments which are discordant with patient wishes and by documenting patient expressed wishes, a shared understanding (between patient and clinician) protects patients from coercion by family members. ACP empowers patients to make healthcare decisions consistent with their values and ultimately seeks to optimise patient-centred care (141). Clinicians who successfully navigate such discussions with patients are more likely to incorporate SDM into routine clinical practice (4).

Regular review of patient satisfaction with dialysis by clinicians is essential to ensure that dialysis, prescribed as a life prolonging therapy, is not inadvertently prolonging patient suffering. Salient events such as medical decompensations, whether or not culminating in hospital admission or escalation of care, should prompt a review of the goals of care. In our study, dialysis appeared to compromise the core values of many, rather than embody them. Our study also highlights the importance of normalising death so that patients feel empowered to make decisions concordant with their values.

Strengths and Limitations:

A key strength of our study was the choice of qualitative design, using standardised methodologies and best practice, to ensure consistency, validity and analytical rigour (including cross coding of transcripts by two senior qualitative researchers). Participants had the opportunity to

speak freely and openly about their experiences and feelings while preserving their anonymity. All participants were offered to choose their preferred time and location for the interview and all were content to conduct the interviews in the haemodialysis unit during treatments. We had a high rate of completion of interviews, with only one participant terminating the interview early due to fatigue. Haemodialysis recipients are often quite comfortable and familiar with the haemodialysis environment and may have been more relaxed in that setting than in an alternative hospital or university location. In addition, interviews were conducted during times when the treating nephrologists were not present in the haemodialysis units, further facilitating study participants in speaking freely. This was enhanced by the fact that the key researcher for this work is not directly involved in providing haemodialysis or other nephrology based care to any of the patient cohort. Therefore, there would be no conflict of interest for interactions between study participants and the researcher and less likelihood of underreporting of concerns.

Although our study was conducted in a single region with only two haemodialysis centres, the centres represent the only haemodialysis units in our catchment area and therefore treat all patients that require haemodialysis. In addition, there was a very high consent rate (100%) amongst patients identified as suitable for the study. It is possible that there was an inherent selection bias in the participants included, as the dialysis staff may have inadvertently selected patients most like to meaningfully engage with the researcher on the topic, and therefore not represent the views of the entire dialysis cohort aged >70 years. However, it is likely that some patients excluded by the dialysis staff may not have fulfilled all of our eligibility criteria (e.g. cognitive impairment), and the potential impact of this bias is small. All participants in this study were of white Caucasian ethnicity and participants' religious denomination was not sought. In the absence of cultural diversity, this may limit the generalizability of the study findings. However, these findings are likely to be highly representative of older adults receiving haemodialysis in the West of Ireland and likely to be relevant to other regions of our country and beyond to similar cultures. Participant accounts are subject to recall bias and their perspectives are open to change. However, our study reflects the findings of

international studies and interviewing continued until thematic saturation was reached, therefore minimising the likelihood inaccuracies.

4.5 Conclusion

This study provides us with new insights into the experience of older adults in receipt of dialysis and reinforces the findings of previous international studies. We elicit participant priorities and highlight the limited levels of health literacy among this cohort. We demonstrate how poor health literacy limits patient empowerment and restricts their participation in SDM and ACP. This has significant implications for the validity of the informed consent process prior to dialysis initiation.

Policy recommendations include communication skills training for nephrology HCPs and consideration of the incorporation of a rotation in palliative medicine into the core curriculum for Higher Specialist Training in nephrology. Renal supportive care services, including the provision of conservative management of ESRD, require further development in order to provide an alternative option to dialysis for older adults.

Chapter 5: Overall Discussion & Conclusion

5.1 Summary of Key Findings from This Research Work

Since the inception of haemodialysis in the 1960s, access to dialysis has improved exponentially (in the developed world) such that the availability of haemodialysis is largely unrestricted. The benefit of dialysis therapy in older patients with ESRD is often dramatically different to that seen in younger patients, who are more likely to be candidates for renal transplantation. Similarly, younger patients are more likely, across Ireland, to be candidates for and successful with peritoneal dialysis, which affords patients greater flexibility than in-centre haemodialysis. In other jurisdictions, there is much greater availability of programs for ‘assisted peritoneal dialysis’ which is often highly utilised by older patients, who may be more likely to require support for the home-based peritoneal dialysis, which requires dexterity, visual acuity, hand-eye coordination (for connecting peritoneal dialysis catheters to machines or bags of peritoneal dialysate fluid) and strength (to lift fluid bags ranging from two to ten kilograms). Therefore, for many older patients with advancing CKD or ESKD, the decision to initiate renal replacement therapy is restricted to haemodialysis only, and complicates decision-making (116). The proposed benefit of prolongation of life must be balanced by the impact of haemodialysis on overall physical, emotional and spiritual well-being.

Nephrologists in our study did not routinely discuss prognosis and dying with older patients with ESRD; therefore dialysis withdrawal was not routinely presented as a future option to older patients considering dialysis initiation. Older patients have significant life experience, including bereavement and individually, are coping with at least one significant morbidity (CKD) and associated complications. It would seem likely that these patients have, at some stage, considered their own mortality. Yet, most nephrologists alluded to an inherent discomfort in discussing prognosis and dying and so many avoided the discussion altogether. A key challenge in this area is our lack of ability to predict prognosis accurately.

Patients perceived clinician tendency to avoid difficult conversations and their attempts to buoy patients up. However, most patients expected their nephrologist to initiate end of life care

discussion once their prognosis was considered to be of the order of six months or less. This disparity between patients and nephrologists compromised older patients' opportunity to prepare for the only certainty in life, death.

Clinicians are trained to postpone death. Well-established ethical principles (beneficence, nonmaleficence, autonomy and justice) guide the delivery of patient care and these principles pay homage to the fact that we will all eventually die. Therefore, at some point it will be appropriate to offer patients the opportunity to discuss their death and to afford them the opportunity to plan this phase of their life in accordance with their core values. ACP encompasses end of life care planning and as with other aspects of HCP training, specific training on how to conduct ACP is essential.

Nephrologists concerns about engaging patients in end of life care discussion (upsetting patients, jeopardising doctor-patient relationship) and believing that patients don't want to engage in such discussion, are unfounded in the literature (1, 6, 52). They are heavily influenced by anecdote and personal experience, which are likely to be impacted by recall bias.

Patients relied on their nephrologists to assist them with healthcare decision-making but the approach outlined above deprived them of this opportunity. The avoidance of end of life care planning by nephrologists likely reflected their assumptions about patient attitudes to dying. Older patients, by virtue of their age are resilient. Their values, beliefs and attitudes to dying are informed by a lived experience, stretching over many decades. End of life care planning should be considered a natural process which seeks to honour and reflect the complexity and wealth of the life lived, such is its importance.

Nephrologists appeared to prioritise the preservation of life above the quality of life. This may reflect clinical training which traditionally focussed on life prolongation and clinical institutions typically report patient outcomes in terms of 'survival to discharge' vs. 'in-hospital deaths.'

Nephrologists may have feared medico-legal repercussions if all available therapies, including dialysis, were not offered to older patients with ESRD who appeared to be clinically deteriorating.

Some nephrologists believed the decision to initiate dialysis belonged to the patient, irrespective of any clinical misgivings they may have had about the appropriateness of dialysis for the individual patient. A patient who chooses dialysis is not making an autonomous decision, unless they are fully informed. This implies that if choosing dialysis, one has considered and discounted the alternatives, including best supportive care, one understands the likely impact of dialysis on daily life in the short and long term, quality of life and length of life (90). This did not appear to be the case with many of our patients.

Successful shared decision-making, (as discussed in Chapter 1) ensures patients are empowered to make treatment decisions concordant with their wishes and that their clinician (who has acquired an understanding of these wishes) guides them in this process (142). Successful SDM therefore optimises the circumstances for patient centred care and ensures the validity of the informed consent process (50). Communication difficulties impeded this process. While most patients relied on their nephrologist to address end of life care planning in a timely fashion, some nephrologists expected patients to broach the topic. Patients also alluded to pertinent questions (concerning dialysis regime, daily fluid intake) which they had not asked their nephrologist, suggesting suboptimal communication between patients and their treating HCP.

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (2). Our patients identified valid concerns, but, appeared unable to question HCPs because of feelings of embarrassment, low self-esteem, lacking the necessary vocabulary to formulate questions and not recognising the validity of their questions. Some participants had commenced haemodialysis during periods of acute illness that could exacerbate the metabolic complications of CKD and lead to delirium or altered levels of consciousness. Such individuals were distressed by unanswered questions pertaining to that period, but none recalled having questioned their nephrologist. They may not have been comfortable in having such conversations with their spouses or family members.

Clearly, clinicians were mistaken to assume that patients had no concerns if they didn't ask questions.

Patient understanding of haemodialysis was largely informed by their own personal experience. One participant alluded to the tubes entering and leaving his body, but admitted to little understanding of the process of dialysis. He assumed that it must be doing him 'some good' if the doctors had prescribed it and suggests an inherent trust in his HCPs. All understood that dialysis was necessary to keep them alive, but none appeared to have considered the goals of dialysis beyond sustaining life. One participant appeared shocked when the prospect of discontinuing dialysis if struggling was mentioned; his response alluded to a religious obligation to continue haemodialysis until death and another perceived dialysis withdrawal as 'suicide.' None of our patients were aware of dialysis withdrawal as a valid and acceptable treatment option. These findings suggest inadequate levels of participant health literacy and suboptimal SDM.

Nephrologists were distressed by and had insight into the consequences of inadequate ACP and end of life care planning for older patients. One nephrologist alluded to a clinical audit which explored the place of death of older patients receiving haemodialysis that showed the majority of patients had died in hospital, reflecting an intensive end of life scenario for patients whose prognosis was already considered poor. Some nephrologists alluded to inadequate training in end of life care discussion as a barrier to engaging with patients about dying, echoing the findings of other studies (67). Some perceived that palliative care physicians were better trained, were more empathic and had more time to engage with patients and so referred patients to palliative care for end of life care planning. Time constraints were alluded to as a barrier by many. When older patients presented acutely in fulminant renal failure, time constraints coupled with prognostic uncertainty resulted in acute haemodialysis initiation becoming the default option for most rather than best supportive care.

Renal supportive care, including conservative management of ESRD, was offered in 20% of the clinical institutions of the interviewed nephrologists. For most, it was an ad hoc service largely

reliant on the perseverance and good will of busy nephrologists and clinical nurse specialists who delivered the service through established CKD clinics and reviewed patients acutely when required. However, most nephrologists were not resourced to provide a designated renal supportive care service ensuring regular patient review, adequate symptom control and multi-disciplinary input.

Nephrologists alluded to the disparity between renal supportive care services in Ireland and those more established services across the UK. Some were so disillusioned with the service available in Ireland that they offered older patients, ideally suited to renal supportive care, haemodialysis in an attempt to alleviate symptoms and ensure regular patient contact. Our findings suggest that nephrologists tended to assume what was of importance to patients rather than asking them explicitly. If nephrologists did not understand what was of importance to older patients, because of inadequate ACP, how can healthcare decision-making reflect patient wishes and values?

All of our patients alluded to the burden of haemodialysis (time lost to travel and time spent on dialysis, dialysis regime dictating the structure of their week, physical and psychological symptom burden associated with dialysis). Some enjoyed active lifestyles on their non-dialysis days and for them, the inherent burden of haemodialysis appeared to be justified. However, many displayed features of spiritual distress (loss of control over their life, diminishing purpose, living for the benefit of others). For many, their current life did not reflect their core values (autonomy and independence in activities of daily living, social connection).

Haemodialysis was not responsible for the spiritual distress experienced by participants but rather a marker of serious morbidity. None of the patients were listed for renal transplantation; all, by virtue of ESRD, were at significant risk of sudden death. Their chance of surviving a cardiac arrest was poor and their chances of making a meaningful recovery even less (living independently, socially connected with a purpose in life). All participants understood dialysis was necessary to keep them alive. Dialysis relieved dyspnoea for some who had presented with severe shortness of breath prior to initiation. However, patients contended with other symptoms, not relieved by dialysis. Digital ischaemia was progressive and many were undergoing digital amputation; others were diagnosed

with additional life-limiting conditions while on haemodialysis; others were undergoing investigation for new and serious conditions and some worried about existing serious comorbidities. Some felt their quality of life had deteriorated since commencing haemodialysis.

In this study, the mean dialysis vintage was 4.4 years (standard deviation 3.1 years). This has the potential to introduce survivor bias, although the standard deviation of dialysis vintage was large and the dialysis vintage ranged from 0.1 to 10 years. Patients with much shorter survival times after commencing dialysis therapy are therefore under represented as it is well established that there are mortality rates of up to 10% at three months and 50% at two years (14, 21). Given the high mortality in the immediate period following dialysis initiation (often reflecting high acuity of comorbidity and complexity that precludes continued haemodialysis), research into recipients of chronic haemodialysis, focuses on those that survive beyond the first six to twelve weeks, meeting the definition of 'prevalent' dialysis patient. Our eligibility criteria were in line with that standard. In addition, patients soon after dialysis initiation may perceive less changes in their quality of life with the initiation of HD. In this period, patients may have transient cognitive impairment, secondary to the metabolic complications of advanced CKD, which would limit their ability to meaningfully engage in our study. Finally, some patients may choose to withdraw from haemodialysis after a small number of treatments. Such patients, are likely to feel empowered to make such decisions and may also be well supported by their family in this regard. It is likely such patients retain a sense of control over their lives and consequently may report less spiritual distress than longer term recipients of haemodialysis, as represented in the Patient Study. Finally, a subset of patients that receive haemodialysis for less than three months, may recover sufficient renal function to discontinue dialysis and survive with residual CKD. Those patients would not reflect the cohort of interest for our study.

Older patients with ESRD must understand that dialysis is not a 'magic bullet', as one nephrologist described. Haemodialysis may offer an absolute survival benefit to some patients, but this may not be acceptable to patients if dialysis does not alleviate their symptom burden. Clinicians

must understand patients' core values before advising dialysis initiation. Similarly, dialysis withdrawal must be routinely presented to older patients as an acceptable option, such that patients understand that there is an 'escape route' if life with dialysis becomes overwhelming.

Clinicians must normalise death and dialysis withdrawal in order to avoid prolonging patient distress. Patients alluded to a profound sense of discord (both internal and external) and existential distress as they struggled to reconcile their desire to discontinue dialysis with not being ready to die and the wishes of their family to continue dialysis. In the absence of adequate ACP, participants appeared isolated and many appeared to be seeking permission to die. Avoidance of end of life care discussion detracts from the normalisation of dying and exposes patients to unnecessary distress.

5.2 Key Findings in Context of International Literature

Nephrologist Study

Our findings align most closely with studies in the US. Renal supportive care services, including conservative management of ESRD in the US are less well developed than other western countries such as the UK. A consistent finding from both studies comprising this thesis is that renal supportive care services in Ireland are also suboptimal. By comparing and contrasting the findings of this thesis to studies from the US, Canada and Europe, it provides some indication of what advances are required in Ireland in order to provide a renal supportive care service which inspires confidence in both clinicians and patients.

It is important to note that ACP including end of life care planning among older patients with ESRD, is limited internationally. Most nephrologists did not routinely engage older patients with ESRD in ACP and end of life care discussion, similar to both US and European studies (1, 2, 4, 68, 137). Those who provided conservative management of ESRD to older patients seemed more likely to discuss the future with patients; this reflects similar work in the US where such nephrologists were considered 'early adopters' (4). Similarly these nephrologists appeared more positive about conservative management, despite a lack of designated resources and appeared to adopt this

approach into their routine practice. Studies in the US demonstrate that early adopters used routine discussion of conservative management as a method of alleviating their own feelings of moral distress associated with treatment decisions for older patients with ESRD.

The emotional burden associated with decision-making about dialysis in older patients was evident among nephrologists and reflects perceptions of colleagues in the US (4, 78) and the UK (68, 73). Specific challenges in this regard pertain to uncertainty about how a patient will do with dialysis, believing that the alternative is death and nephrologists' discomfort confronting death. Previous studies highlight the perception of conservative management as equating with 'no care' (4); some of the nephrologists included in our study alluded to this degree of disillusionment and the absence of any such service at their institution and consequently, were reluctant to prescribe conservative management. This contrasts with the availability of renal supportive care clinics across the UK, albeit with variability between nephrology units in terms of the service provided (10).

Nephrologists alluded to communication difficulties and time constraints as barriers to ACP and end of life care discussion. Specifically, some mentioned inadequate communication skills training, similar to studies in the US (65, 67) and in the UK (68, 73), despite more widespread availability of renal supportive care services in the latter. Specific deficits included a lack of training in end of life care discussion as a barrier to foregoing or withdrawing dialysis (73).

Patient Study

All patients perceived that the decision to initiate dialysis was made by a clinician. Most did not feel they had a choice as they understood the alternative to be death. Similar patient perspectives have been reported in studies from the US (1, 6). Most of our patients wanted to participate in end of life care planning but none had discussed this with a clinician. Similar findings are evident in studies conducted in the US and Canada, where older patients with ESRD have not discussed end of life care despite wanting to participate (1, 2, 6, 143). All of our patients had considered end of life care preferences, which differs from some studies in the US where up to 25%

of older dialysis patients had never considered it (2). In addition, our patients alluded to clinicians being uncomfortable discussing death and so avoided discussion altogether. Some felt that end of life care was not the responsibility of the nephrology team; these findings echo similar studies in the US where older dialysis patients perceived that nephrologists considered end of life care irrelevant (2).

Limited health literacy among older patients in receipt of dialysis has been demonstrated in recent studies, including limited understanding of basic terms such as 'prognosis', 'quality of life' and 'becoming healthy enough to discontinue dialysis' (2, 6, 61). Most of our patients had a limited understanding of dialysis at the time of commencement and this persisted in those that were in receipt of dialysis for several years. These findings are corroborated by studies in the US and UK (23, 120).

All of our patients perceived that the decision to commence haemodialysis was made by a doctor and most understood that without dialysis they would die and so felt they had little choice but to agree to dialysis, corroborating previous studies (1, 6). None of our patients were aware that dialysis withdrawal was a legitimate option and none of them had discussed end of life care with a nephrologist. This is quite remarkable as previous reports identified a proportion of participants rather than all (15, 23). Perhaps some of our patients did not recognise, identify or recall discussions on end of life care with clinicians. Alternatively, nephrologists may have used vague terminology when discussing 'prognosis' and 'dying', in an attempt to minimise patient distress, and this confused patients such that they did not realise they were discussing death. It may also reflect limited understanding of commonly used terminology in end of life discussions, as reported previously (2, 6).

Patients appeared reluctant to question their clinicians even if it pertained to time sensitive issues (e.g. end of life care preferences) or relevant and specific topics (e.g. daily fluid intake). Not engaging in discussion on fluid intake seems remarkable considering haemodialysis sessions generally commence with patients being weighed, identification of fluid gain, setting of target

ultrafiltration and sessions end with patient weight to determine progress. Perhaps these conversations take place with other staff within haemodialysis units (e.g. nursing staff) rather than with clinicians directly. The lack of discussion of end of life in particular reflects similar findings in the US where patients conformed to the 'good patient role' and avoided challenging clinicians or pushing them into discussions for fear of damaging the doctor-patient relationship (2, 6). Similarly patients attempted to protect their families by avoiding end of life care discussion, thereby isolating themselves (2).

Our patients did not appear to have considered the goals of dialysis therapy, beyond sustaining life. For many, dialysis appeared to compromise core values (diminished autonomy and control over one's life, loss of purpose, loss of enjoyment) and many appeared spiritually distressed. Studies in the US reported similar experiences among older patients who felt dialysis was discordant with their preferences (2, 6).

Currently, a lack of robust evidence regarding the comparative effectiveness of dialysis and conservative management in the frail older person with multiple health problems compounds the complexity of decision-making in this area. The findings of this thesis suggest that prognostic uncertainty inclines nephrologists to guide patients towards dialysis and in turn, patients perceive dialysis as the only option available to them, believing that the alternative is death. In order to best understand the perspectives of both clinicians and patients, qualitative methodologies were employed in this thesis. The work highlights what older adults in receipt of dialysis patients consider important; quality of life, retaining control over one's life, preserving one's identity, feeling at peace, well-being of family and for the majority, being informed about their future and being afforded the opportunity to participate in EOLC planning in a timely manner. However, patients as well as their nephrologists, must understand the implications, including any trade-offs, of their healthcare decisions. In this regard, quantitative studies, demonstrating the outcomes from conservative management, including impacts on survival, quality of life and symptom burden in older patients are urgently required.

The Conservative Kidney Management Assessment of Practice Patterns Study (CKMAPPS) arose from the need to optimise the delivery of high quality conservative management of ESRD in the UK (144). CKMAPPS demonstrates how a mixed methods approach was utilized to explore the perspectives of patients, nephrology staff and general practitioners, through qualitative interviews, and how those findings assisted the interpretation of a quantitative national survey of nephrology units, which demonstrated considerable variability in the conservative management services. This led to the Prepare for Kidney Care study, a randomized controlled trial, where patients aged >65 years with stage 5 CKD are randomised to 'preparation for responsive management of ESRD' or 'preparation for RRT'(145). Although powered to detect a positive 0.345 difference in quality-adjusted life years between arms, this trial also takes a realist approach with a range of person-centred secondary outcomes and embedded qualitative research. This study, by virtue of its design, acknowledges the value of a mixed methods approach and the mutual benefit of combining qualitative and quantitative approaches to answer a complex research question.

5.3 Future Directions

The findings of this work indicate suboptimal SDM between clinicians and older patients with ESRD. Some consequences of inadequate ACP and end of life care planning are evident in the experiences reported by our patients and the concerns of nephrologists about upsetting patients appear to be largely unfounded. Time constraints as a barrier to ACP likely reflect both clinician factors and institutional factors, but should not be a barrier to ACP and SDM in appropriate healthcare settings. The recommendations detailed below are inspired by the findings of this thesis.

Communication Skills Training

Communication skills training for clinicians is critical to equip them with the confidence, vocabulary and skill to engage their patients in SDM without fear of emotional backlash from patients (67). Equally, patients need to be prepared for such conversations and evidence based interventions are currently in use to facilitate the process of ACP. VitalTalk and ACP Decision, two evidence-based interventions form the basis of ACP-PEACE study (146). VitalTalk, aimed at clinicians, utilises small group sessions using role play with trained actors portraying patients through which clinicians learn effective delivery of serious news, prognosis discussion and early and late goals of care conversations. Previous studies demonstrated benefit from short (45-60minute) training modules designed to facilitate clinician discussion of prognosis and goals of care (147). ACP Decisions Videos, aimed at patients, uses short video decision aids to address the most common issues facing older patients with serious illness. The ACP Decisions videos have been shown to increase knowledge, decision certainty and the stability of preferences over time and to better inform the way that patients choose healthcare interventions towards the end of life (132, 148).

Another possibility to enhance communication skills among nephrology trainees is to incorporate a clinical rotation in palliative medicine as part of the core curriculum in higher specialist training in nephrology as has been previously mooted in the US (67). Studies suggest that exposure

to advance care planning discussion is a key determinant of how likely nephrology trainees are to initiate a discussion of goals of care (149).

Patient Health Literacy

Limited health literacy, defined as insufficient and problematic health literacy, affects many and may be compounded by financial deprivation, low social status, low education or older age, suggesting the presence of a social gradient (63). The literature is limited on how best to improve health literacy, which remains a significant global challenge. It is likely that enhanced SDM will better empower patients to challenge clinicians if they feel their current treatment regime threatens their wishes and values. Regular clinician review of patient satisfaction on dialysis will also help safe guard against prolonged burdensome treatments.

Clinical nurse specialists play a vital role as an accessible point of contact with specialist hospital services for patients in the community. For patients in receipt of in-centre haemodialysis, as studied here, they also have regular contact (two to four times per week) with nurses and other HCP based in haemodialysis units. This presents unique opportunities (and challenges) for patients and HCP to better understand patient preferences and also to better understand each other's point of view. This environment also frequently identifies patients who appear to be struggling on dialysis. However, to date, this has not yet led to improvements in SDM or triggering end of life care discussions. There is particular scope for haemodialysis unit staff to enhance contextually appropriate patient health literacy and to advocate for patients as part of multidisciplinary care.

Renal Supportive Care Services

The findings from our nephrologists unequivocally demonstrates an urgent need to develop renal supportive care services, including conservative management of ESRD, in Ireland. The UK provides us with a well-established model of care and many of the participating nephrologists had worked in renal supportive care services abroad. The formal establishment of such a service

nationally will ensure a legitimate alternative to dialysis for both patients and clinicians; it will help forge relationships with specialist palliative care services. Joint renal/palliative care clinics will satisfy mutual learning needs and ensure a coordinated package of care for service users as well as providing a rich learning environment for clinicians in training. Previous studies demonstrated economic benefit, where the cost of in-centre dialysis compared favourably with the cost of delivering conservative management of ESRD (150).

Conclusion

This thesis contributes new knowledge to patient care in Ireland and as discussed above, corroborates the findings of previous international studies of managing ESRD in older adults. The Nephrologist Study identifies important barriers experienced in Ireland in initiating ACP with older adults including the absence of formal communication skills training (in discussing prognosis, dialysis withdrawal, ACP and end of life care preferences), time constraints and limited clinical experience in managing end of life situations. Deficits in conservative management in Ireland precluded many nephrologists from considering it as an acceptable treatment option. The work also corroborates previous findings that most nephrologists (i) do not routinely consider conservative management as a legitimate treatment option for older adults with ESRD and (ii) struggle with prognostic uncertainty and frequently circumvent end of life discussion for fear of upsetting patients. This work establishes similarities between the practices and perceptions of nephrologists in Ireland and in the US, highlighting the international significance of our findings.

The Patient Study provides us with new insights into the experience of older dialysis patients and reinforces the findings of previous international studies. This study highlights limited health literacy and limited empowerment, reflecting suboptimal SDM and ACP. In this context, we demonstrate how healthcare decision-making may jeopardise the core values of patients. These

findings have significant implications for the validity of the informed consent for dialysis and the delivery of patient centred care.

Policy recommendations include improved communication skills training for clinicians to enhance patient participation in SDM and to help clinicians guide patients towards decisions most concordant with their values. Improvements in patient education are also recommended in order to enhance patient health literacy and optimise the conditions for patient centred care. More resources are urgently required for the development of renal supportive care services, including conservative management of ESRD to ensure it becomes a viable treatment option for patients and their treating nephrologists.

Appendix I: Outputs Arising From This Work

Presentations

'Nephrologist Study'- 'Do we understand each other? Advance care planning in older patients with end stage renal disease: A qualitative nephrologist interview study.'

Presented at:

- **Irish Association of Palliative Care Research and Education Seminar February 7th 2019**
Winner of best research and winner of best oral presentation.
Awarded the **Mary Redmond Medal** and education bursary worth 1000 euro.
- **Accepted for oral presentation at the Irish Renal Society April 2019**
- **UK Kidney week 2019/ Renal Association and British Renal Society June 4th 2019**

'Patient Study' – Health literacy and advance care planning in older dialysis patients: A qualitative interview study.

Presented at:

- **Irish Association of Palliative Care Research and Education Seminar May 13th 2021**
Winner best research and best oral presentation
Awarded the opportunity to be considered for publication in BMJ Supportive & Palliative Care and education bursary worth 1000 euro.
- Palliative medicine journal club, Galway Hospice Foundation, August 2020
- Renal journal club, Galway University Hospital and Saolta Hospital Group, September 2020

Publications

O'Riordan J, Kane PM, Noble H, Beatty S, Mannion E, Murtagh C, Harnett I, Smyth A. When Less Is More: Optimizing Care for Elderly Patients Failing to Thrive on Dialysis. *J Pain Symptom Manage*. 2018 Apr;55(4):1241-1245. doi: 10.1016/j.jpainsymman.2017.12.475. Epub 2017 Dec 14. PMID: 29248567

O'Riordan J, Noble H, Kane PM, Smyth A. Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study. *BMJ Support Palliat Care*. 2020 Dec;10(4):e39. doi: 10.1136/bmjspcare-2018-001759. Epub 2019 Jun 25. PMID: 31239255

O'Riordan J, Kane PM, Noble H, Smyth A. 'Advance care planning in older dialysis patients: health care literacy qualitative study.' *BMJ Support Palliat Care*.2021. *In Press*

Prizes

2019: **Irish Association of Palliative Care Research and Education Seminar** February 7th 2019

Winner of **best research** and winner of **best oral presentation**.

Awarded the **Mary Redmond Medal** and **education bursary**.

2021: **Irish Association of Palliative Care Research and Education Seminar** May 13th 2021

Winner **best research** and winner of **best oral presentation**.

Awarded an opportunity to be **considered for publication in BMJ Supportive & Palliative Care** and **education bursary**.

Permissions & Copyright

O'Riordan J, Kane PM, Noble H, Beatty S, Mannion E, Murtagh C, Harnett I, Smyth A. When Less Is More: Optimizing Care for Elderly Patients Failing to Thrive on Dialysis. *J Pain Symptom Manage*. 2018 Apr;55(4):1241-1245. doi: 10.1016/j.jpainsymman.2017.12.475. Epub 2017 Dec 14. PMID: 29248567

- This article was published in the *Journal of Pain and Symptom Management*, Vol 55, O'Riordan J, Kane PM, Noble H, Beatty S, Mannion E, Murtagh C, Harnett I, Smyth A. When Less Is More: Optimizing Care for Elderly Patients Failing to Thrive on Dialysis. 1241-1245. Copyright Elsevier 2018.

O'Riordan J, Noble H, Kane PM, Smyth A. Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study. *BMJ Support Palliat Care*. 2020 Dec;10(4):e39. doi: 10.1136/bmjspcare-2018-001759. Epub 2019 Jun 25. PMID: 31239255

- This article was published in the *BMJ Supportive and Palliative Care*, Vol 10, O'Riordan J, Noble H, Kane PM, Smyth A. Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study. Copyright BMJ Journals.

O'Riordan J, Kane PM, Noble H, Smyth A. 'Advance care planning in older dialysis patients: health care literacy qualitative study.' *BMJ Support Palliat Care*.2021. *In Press*

Appendix II: Ethical Approval for Nephrologist Study

Clinical Research Ethics Committee

Room 59

1st Floor

Merlin Park Hospital

Galway

12th May 2017

Dr Julien O’Riordan

Specialist Registrar Palliative Medicine

22 Renmore Crescent

Renmore

Galway

Ref C.A 1734- ‘A qualitative analysis of the factors which influencing nephrologists’ clinical decision making regarding the choice between Renal Replacement Therapy and Conservative Management in patients over 75 years of age with End Stage Renal Disease (ESRD).’

Dear Dr O’Riordan

The Chairman’s decision to approve the above project was ratified at the Clinical Research Ethics Committee on Wednesday 10th May, 2017.

Yours sincerely

Professor B Gerard Loftus

Chairman Clinical Research ethics Committee

Appendix II: Ethical Approval for Patient Study

Clinical Research Ethics Committee

Room 59

1st Floor

Merlin Park Hospital

Galway

22nd June 2018

Dr Julien O’Riordan

Specialist Registrar Palliative Medicine

23 Glenside

Newtown

Annacotty

Co.Limerick

V94 Y9P4

Ref C.A 2007- ‘A qualitative analysis of the perspectives of elderly patients with End Stage Renal Disease in a pre- dialysis and haemodialysis setting.’

Dear Dr O’Riordan

I have considered and reviewed the above submission, and I am happy to confirm Chairman’s approval to proceed.

Yours sincerely

Professor B Gerard Loftus

Chairman Clinical Research ethics Committee

Appendix III: Focus Group invitation to Consultant Nephrologists

Dear Dr

I hope all is good with you.

I would be very grateful if you would be happy to participate in a focus group interview with the other local consultant nephrologists.

The aim of this focus group is to examine the factors which influence Nephrologists' clinical decision making when choosing between RRT and conservative management in a population of patients over 75 years with ESRD. Following this I plan to invite all consultant nephrologists in the Republic of Ireland to participate in a telephone interview focusing on this area. The focus group will provide reassurance that I am covering all relevant areas of this topic and that the questions are acceptable. I will ensure your confidentiality outside of the focus group interview and I recently received ethical approval to proceed with the study.

I understand Friday mornings between 8-9am may be the best time slot to avail of? Please let me know what dates might suit you over the next six weeks.

Please let me know if you have any other questions or concerns.

Many thanks

Best wishes

Julien O'Riordan MB BCh BSO BSc MRCPI MICGP DME

Supervisor: Dr Andrew Smyth Consultant Nephrologist/General Physician & Postdoctoral Researcher

Dept : Nephrology & HRB Clinical Research Facility Galway

Appendix IV: Interview Topic Guide for Nephrologist Study

Q1 What factors **influence your choice of either RRT or Conservative Management** for patients 75 years and over in the following two groups; a) known to you eg. from Renal out patients? b) who present acutely with end stage renal failure of unknown duration? ie. crashlander / ED

Q2 How do you proceed/ manage the situation if you are concerned that the patient may lack **decision making capacity?** (due to cognitive impairment, uraemia, acutely unwell)

Q3 In general, what do you **hope to achieve by offering RRT to patients 75 yrs** and over? Eg in terms of improving or maintaining their QOL? improving life expectancy ?

Q4 How often do you **discuss the course of ESRD, symptomatology and prognosis** with patients 75yrs and older? Their families? In what situations might you not?

Q5 How often do you **discuss the impact of RRT (PD/HD) on daily life** with the patients aged 75 yrs of age and older? In what situations might you not?

Q6 From your experience of patients over 75 years with ESRD, what do you think are their **main priorities** are? (eg quality of life, not burdening family, maintaining independence). **List in order of priority**

Q7 In regard to patients over 75 years with ESRD (following either a Conservative Management pathway or in receipt of RRT), if you feel they are unlikely to be alive in one year, how often do you **discuss prognosis, end of life care and mode of dying with them?** With their family? **Barriers to this discussion?**

Q8 When **might you consider withdrawing RRT** in patients who have commenced it at 75yrs and older? How do you **manage them following withdrawal?**

Q9 How often do you **discuss conservative management** as a treatment option for patients with ESRD over 75 years of age? (never, rarely, occasionally, frequently, always)

How do you **explain 'Conservative Management'** to the patient and do you feel comfortable discussing it?

Q10 Palliative Care and ESRD

How **often do you refer patients over 75 years** with ESRD, on Conservative Management or in receipt of RRT to Palliative Care? Symptom control? End of life care?

How do you **present Palliative Care to** patients? What do you **understand the role of Palliative Care** in this population? **Barriers** to referral?

Appendix V: Demographic Data of Consultant Nephrologists

Q1 Female/ male

Q2 Number of years qualified from Medical School:

Please tick the relevant category.

<15 years _ 15-20 years_ 20-30 years_ >30 years _

Q3 Nationality

Q4 If you underwent post graduate nephrology training outside Ireland please enter the location(s) of same.

Q5 Your Healthcare Setting

Please circle the relevant option.

Public

Private

Mixed Public and Private

Q6 Is there a low clearance clinic at your Healthcare facility: Yes/ No

Q7 Is there a Palliative Care service at your Healthcare facility: Yes/ No

Appendix VI: Electronic invitation to Consultant Nephrologists

Dear Dr

I am an Spr in Palliative Medicine in Galway University Hospital. I am interested in identifying the factors which influence Consultant Nephrologists to offer either RRT or Conservative Management to patients with end stage renal disease aged 75 years and over.

I am inviting all Consultant Nephrologists in the Republic to participate in a telephone interview with me. The interview will take no more than twenty minutes. The data will be recorded, transcribed and anonymised by myself. Below is a list of areas I will cover during the interview:

- (i) Factors influencing your choice of conservative vs RRT management for elderly patients with ESRD
- (ii) Factors prompting dialysis withdrawal
- (iii) Your understanding of patients' priorities for their care
- (iv) Discussion of prognosis and end of life care with patients
- (v) Palliative Care referral, barriers to same

I would be extremely grateful if you were happy to participate in this study. I will contact you if you would like to provide me with contact details. Would any of the following dates suit you?

Wed Oct 18th from 4pm onwards/ Thurs Oct 19th between 9:30 - 2pm/ Fri Oct 20th anytime/ Wed Oct 25th any time after 2:30pm/ Thurs Oct 26th anytime

If any evening suits you that is fine with me also.

Many thanks for your time

Yours sincerely

Julien O'Riordan MB BCh BAO BSC MRCPI MICGP DME

Supervisor: Dr Andrew Smyth Consultant Nephrologist/General Physician & Postdoctoral Researcher

Dept : Nephrology & HRB Clinical Research Facility Galway

Appendix VII: Informed Consent Leaflet for Patient Study

Perspectives of Patients on Renal Disease Patient Information Leaflet and Informed Consent Form

Principal Investigator: Dr Julien O’Riordan

Academic Supervisor: Prof Andrew Smyth

You are invited to take part in a research study to understand the perspectives of patients with kidney disease and the treatments that you receive. Before making your decision, it is important that you understand why the research is being done and what it will involve for you. This sheet details important information on the study that you will need to consider. Please take your time to read through this carefully and discuss it with your family, friends and doctor, if you wish. Do not hesitate to ask the study doctor if you need any further information or clarification.

Introduction

Kidney disease is becoming more common, and it affects an increasing number of people in Ireland, particularly an increasing number of older people. In order to best provide treatments to patients with kidney disease and to ensure that patients have a more satisfying healthcare experience, it is important that we understand people in Ireland with kidney disease to find out about experiences of living with kidney disease, treatments received, expectations in the future and future wishes. In this research project, we hope to speak with patients attending the Nephrology Services at Galway University Hospitals who are aged 75 years and over with kidney disease.

We are not evaluating the effects of any tests, treatments or medications at part of this study.

Instead, we wish to interview you to talk about your experiences with kidney disease.

Why have I been chosen?

You have been invited to participate in this study as you are over 75 years of age and are attending the Nephrology Services at Galway University Hospitals. Professor Andrew Smyth, Consultant Nephrologist at Galway University Hospitals is supervising this project. Approximately 30 patients will be involved in the study, all in Galway.

Do I have to take part?

Your participation in this study is entirely voluntary and you should feel under no pressure to consent. Refusing and/or withdrawing from the study is permitted at any time and you are not obliged to provide a reason. The decision to either refuse to enrol or to withdraw from the study will have no consequence on your present or future care.

Is there any financial benefit for me if I take part?

There is no financial compensation to you as a participant in this study.

What happens if I decide to take part?

If you decide to participate, Dr Julien O’Riordan will organise to meet with you for an interview at a time and date that suits you during your dialysis session in the Haemodialysis Unit in Merlin Park Hospital.

The interview will take between 20 and 40 minutes and we will discuss your experience with kidney disease, treatments and future expectations. The duration of the interview will be determined by you and you are free to stop the interview at any time.

The interview will be audio recorded using a Dictaphone and an electronic recorder as back up. As soon as possible after the interview, the recording will be typed up, and any mention of your name or other identifiable information will be removed. Once the typed interview is finalised, the recordings from both the Dictaphone and electronic recorded will be deleted. The typed interviews will be kept in a password protected file on a password protected, encrypted computer and will not be traceable to you.

Are there any risks involved?

There are no risks involved in being part of this study as we are conducting an interview to discuss your personal experiences of kidney disease.

What are the potential benefits for me?

Your participation in the study may not result in any direct health benefits to you. However, this study hopes to identify the perspectives, thoughts and opinions of patients with kidney disease attending the Galway Nephrology services and will help with the care and options available to

current and future patients with kidney disease. The findings may also influence the way patients with kidney disease are cared for in other parts of Ireland or other countries.

Will my taking part be confidential?

All information collected about you during the study will be kept strictly confidential and will only be seen by the research team. Once you consent to participate, you will be assigned a unique study number that will be used on your recordings and typed up report of your interview. You will not be identifiable on any final study reports, and all audio recordings of your interview will be deleted once the typed up reports are finalised. You will also not be identifiable on any presentations or publications from this research, as your comments will be combined with the other participants in the research project.

The information from your interview (your personal data) will be typed up into a final report that will not contain your name or other identifiable information. You have the right to review the report to ensure that it is accurate and you have the right to request changes to the information if you believe that it is not correct. You also have the right to request the deletion of your personal data.

Who will have access to my data?

Any paper records, including copies of this consent form, will be stored in a locked filing cabinet in a secure location at the HRB Clinical Research Facility on the grounds of University Hospital Galway.

Access to these paper records will be restricted to Dr O’Riordan and Prof Smyth. All electronic reports will be kept in password-protected files, on password-protected encrypted computers. These reports will be available to Dr O’Riordan and Prof Smyth at NUI Galway / Saolta.

Your reports may also be sent to our two research collaborators – Dr Helen Noble and Dr Pauline Kane. Neither Dr Noble and Dr Kane will receive any data that will identify you as an individual, and both are doctors who will keep the data confidential. They will help us in the analysis of the reports and they will delete all copies of reports that they received, once the analysis is completed. Dr O’Riordan will retain copies of the anonymised typed reports, in electronic format, to complete the analysis and report the findings at national or international meetings, through publications and for

the completion of a postgraduate research degree thesis at NUI Galway. These reports and any paper copies will be retained for a maximum of 3 years from the date of your consent and will be destroyed by Dr O’Riordan and/or Prof Smyth.

Where can I get further information on Data Protection and GDPR?

If you have any concerns or questions about any personal data you believe or know that NUI Galway or Saolta holds about you related to this study, please contact Dr Julien O’Riordan or Prof Andrew Smyth via the reception at the HRB Clinical Research Facility Galway on 091-494369.

You can also contact the following Data Protection Officers:

1. NUI Galway Data Protection Officer – dataprotection@nuigalway.ie
2. HSE West Deputy Data Protection Officer – ddpo.west@hse.ie or 091-776819

In the event that you wish to make a complaint about how your personal data is being processed by us or how your complaint has been handled, you have the right to lodge a complaint directly with the Data Protection Commission at the Office of the Data Protection Commissioner, Canal House, Station Road, Portarlinton, Co. Laois, R32 AP23 or on 0761-104800 or LoCall 1890252231 or info@dataprotection.ie

Who is organising the study?

Prof Andrew Smyth and Dr Julien O’Riordan are the investigators leading this study. No funding has been obtained to complete this study.

Who has reviewed the study?

The Galway University Hospitals Ethics Committee has reviewed and approved this study, to ensure that your rights as a participant are protected.

What happens if I have any questions, concerns or complaints regarding the study?

If you have any concerns, questions or complaints about the study, please contact Dr Julien O’Riordan or Prof Andrew Smyth via the reception at the HRB Clinical Research Facility Galway on 091-494369.

Appendix VIII: Patient Study-Interview Topic Guide

Understanding of CKD and impact on daily life.

Tell me, what do you understand by the term chronic kidney disease? Do you remember receiving any information about CKD? If so, who gave you that information? (doctor, nurse, relative)

Did you feel you had a **good understanding of chronic kidney disease before starting dialysis?**

Have you considered how chronic kidney disease might affect you in the future? Have you discussed this with your kidney doctor? With your family?

Before starting dialysis, had **CKD been affecting you in your day to day life?** If so, can you tell me how?

Since starting dialysis have those symptoms changed?

Dialysis:

Why did you start dialysis? Was it your decision? Did you feel it was your decision? Of not, your doctors' or your family's decision?

Did you feel under pressure to choose dialysis? If so, from whom?

Did you feel you had a **realistic understanding of dialysis** before you started? What do you believe dialysis is doing for you?

Had you any fears about starting dialysis? If so, can you describe them?(eg in terms of frequency, duration on dialysis, transport issues, burden on family/carers, post dialysis fatigue, dizziness)

What do you find are the **most difficult things about dialysis?**

Has dialysis changed your life and if so, in what way?

Can you identify any benefits of dialysis? (improved symptoms of ESRD, relationships with patients, staff of haemodialysis unit)

Do you or have you **ever regretted starting dialysis?**

Do your family/ doctors/ renal nurses know how you feel about dialysis? Who are you most likely to discuss this with?

Do you know how your family/ carer feels about you being on dialysis?

Has anyone ever discussed a situation with you where you might **stop dialysis?** Have you ever considered a situation where you might choose to stop dialysis?

What is your understanding of the role of dialysis in your situation?

Were any alternatives to dialysis presented to you; **conservative management?** How were they described to you? Why did you not choose this alternative?

When you started dialysis what did you expect it would do for you? (relieve symptom burden, improve bloods, unrelated)

Given your experience of dialysis to date, how does it match your expectation of it?

(frequency of RRT, duration on RRT, transport issues, less available for other things on dialysis days, burden on family/ carers, post dialysis fatigue, dizziness, social aspect to RRT, etc)

Did you expect to feel better or worse than you feel now?

Do you feel you were given **sufficient information about dialysis before starting** it? Who was the best source of that information? (doctor, CNS, family, friends, other patients, internet)

What are the good aspects of being on dialysis? (company, routine, friends in unit, support of nursing staff)

Can you describe a **good day to me? A bad day?**

****Explore:** Tell me what makes you feel good about yourself? What is important to you in your life?

Priorities for care

What are the most important things, your expectations of, the doctors and nurses caring for you can do for you? What are your priorities in regard to your healthcare now and in the future?

Do you think your doctors and nurses are aware of these wishes?

Dialysis withdrawal

Has anyone ever discussed a situation where you might come off dialysis? Have you ever considered a situation where you might choose to stop dialysis?

End of life planning

Have you ever thought about dying? Has anyone ever spoke to you about dying and what your wishes might be for that part of your life?

Do your doctors and nurses talk to you about dying? If not, why do you think that is?

Appendix IX: Codebook from Nephrologist & Patient Study: sample

Advance care planning helps patients understand their condition, identify their goals and prepare for the decisions that may have to be made as the condition progresses over time.

An *advance care plan* enables patients to document their preferences for future care in the event of them losing the ability to express their own wishes.

Burden of dialysis refers to the physical, psychological and social demands experienced by dialysis recipients by virtue of being on dialysis and which may adversely affect their well-being.

A *valuable service* is accessible, provides support, well organised, provides continuity of care and provides education to the service users.

Shared decision-making is the process whereby clinicians understand what is of most important to patients and patients attain a level of health literacy which allows them to make healthcare decisions which are concordant with their core values.

Comorbidities are co-existing significant health problems in addition to the underlying condition which has caused ESRD.

Conservative management of end stage kidney disease seeks to optimise quality of life through the active and non-dialytic management of symptoms of ESRD, and is best delivered by a collaborative multidisciplinary team in a low clearance clinic .

A *low clearance clinic* provides clinical review, treatment refinement, symptom control, dietary advice and education to patients with advancing chronic kidney disease.

Terminal illness is a life limiting condition.

End of life care involves treatment, care and support for people who are nearing the end of their life.

Dialysis withdrawal is the discontinuation of maintenance dialysis

Prognosis is an opinion, based on medical experience, of the likely course of a medical condition and the likely outcome of a situation.

Barriers to dialysis withdrawal relate to factors which make the withdrawal of dialysis for a particular patient or group of patients challenging. It relates to patient factors, clinician factors, family and societal factors.

Barriers to conservative management of ESRD relate to the factors which make the decision to choose and deliver conservative management of ESRD more challenging.

Barriers to palliative care referral relates to the factors which make referral to specialist palliative care services challenging. It pertains to clinician factors, patient and family factors as well as accessibility to the service.

Spiritual distress can be defined as “the impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, and/or a power greater than oneself.

Appendix X: Memo: Patient Study, Interview 1

Loss of autonomy: A feeling that one belongs to the dialysis unit, having no control over your life or death, that doctors are controlling her life.

Patients' lack of understanding of dialysis can lead to anger at oneself for agreeing to dialysis, judging oneself as being 'silly' for agreeing to it

Lack of understanding causes fear in patients eg 'all these tubes and things'

In the absence of adequate formal education about **dialysis patients are vulnerable** to receiving misinformation from sources in the community.

Patients' reluctance to complain belies their true feelings and sufferings unless specifically enquired about. Their expressed emotions often conflict with their statements. This patient believes she doesn't have the right to complain!

Why are people reluctant complain? Don't want to disrespect doctors, to be alive should be enough, knowing there are others 'worse off than me', should be grateful to God that she is alive.

Isolation of dialysis recipients: because of the dialysis commitment, recovery from dialysis and co morbidity, erosion of independence with declining health eg. loss of driver's licence.

Grief reaction, sense of loss: declining independence, loss of former life. The enormity of adjusting one's life to dialysis is distressing and often not acceptable to patients

Persistent symptoms of CKD eg nausea, dyspnoea

Spiritual distress: loss of meaning in life

Priorities in life: having control, sense of personal achievement, engaging with nature, having things to do, being part of a community, socially connected and informed, being creative, family, independence, able to drive, going to Mass, shopping, to feel at peace when she dies, to be a good person, relationships in HD with staff

Frightened to stop dialysis: The symptoms prior to commencing dialysis serve as a deterrent to dialysis withdrawal along with the fear of dying; not being able to remain alive rather than the process of dying.

Implications of **failing to normalise dialysis withdrawal** as an option for patients: Dialysis withdrawal not a choice but a consequence of being too unwell to attend HD.

Futility of dialysis: Severe physical restrictions, spiritual distress,

Paternalism: Renal team deciding she was for dialysis, GP withdrawing her licence to drive?

Acceptance of the inevitability of dying

EOLC planning: unfamiliarity with renal team members, failure of team to broach EOLC with patient.

She sees it as something 'cheeky' if she were to broach 'dying' with doctors, hence not 'routine or acceptable'.

Importance of predicting death: Wants to know a few months in advance that she is likely to die to allow her to prepare. Also she would consider dialysis withdrawal at this stage if her doctor thought it was reasonable.

Patients don't understand that to not have dialysis is an option! They see no option other than dialysis. Hence dialysis is presented to them as the only option , conservative management is not discussed.

Quality of life has deteriorated on dialysis

Not **looking forward to anything in life**, as in interview 4.

References

1. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010;5(2):195-204.
2. Ladin K, Buttafarro K, Hahn E, Koch-Weser S, Weiner DE. "End-of-Life Care? I'm not Going to Worry About That Yet." Health Literacy Gaps and End-of-Life Planning Among Elderly Dialysis Patients. *Gerontologist*. 2018;58(2):290-9.
3. Amro OW, Ramasamy M, Strom JA, Weiner DE, Jaber BL. Nephrologist-Facilitated Advance Care Planning for Hemodialysis Patients: A Quality Improvement Project. *Am J Kidney Dis*. 2016;68(1):103-9.
4. Ladin K, Pandya R, Kannam A, Loke R, Oskoui T, Perrone RD, et al. Discussing Conservative Management With Older Patients With CKD: An Interview Study of Nephrologists. *Am J Kidney Dis*. 2018;71(5):627-35.
5. Carson RC, Juszczak M, Davenport A, Burns A. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol*. 2009;4(10):1611-9.
6. Ladin K, Lin N, Hahn E, Zhang G, Koch-Weser S, Weiner DE. Engagement in decision-making and patient satisfaction: a qualitative study of older patients' perceptions of dialysis initiation and modality decisions. *Nephrol Dial Transplant*. 2017;32(8):1394-401.
7. Levey AS, de Jong PE, Coresh J, El Nahas M, Astor BC, Matsushita K, et al. The definition, classification, and prognosis of chronic kidney disease: a KDIGO Controversies Conference report. *Kidney Int*. 2011;80(1):17-28.
8. Summary of Recommendation Statements. *Kidney Int Suppl* (2011). 2013;3(1):5-14.
9. Trust NHaSC. Information for patients attending the supportive low clearance clinic. In: Trust NHaSC, editor. http://www.northerntrusthscinet/pdf/Information_for_patients_with_kidney_disease_attending_Supportive_Low_Clearance_Clinicpdf2019 Accessed.
10. Okamoto I, Tonkin-Crine S, Rayner H, Murtagh FE, Farrington K, Caskey F, et al. Conservative care for ESRD in the United Kingdom: a national survey. *Clin J Am Soc Nephrol*. 2015;10(1):120-6.
11. Hole B, Tonkin-Crine S, Caskey FJ, Roderick P. Treatment of End-stage Kidney Failure without Renal Replacement Therapy. *Semin Dial*. 2016;29(6):491-506.
12. Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant*. 2007;22(7):1955-62.
13. Martínez Echevers Y, Toapanta Gaibor NG, Nava Pérez N, Barbosa Martin F, Montes Delgado R, Guerrero Riscos M. Survival of patients ≥ 70 years with advanced chronic kidney disease: Dialysis vs. conservative care. *Nefrologia*. 2016;36(3):283-91.
14. Da Silva-Gane M, Wellsted D, Greenshields H, Norton S, Chandna SM, Farrington K. Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. *Clin J Am Soc Nephrol*. 2012;7(12):2002-9.
15. Saini T, Murtagh FE, Dupont PJ, McKinnon PM, Hatfield P, Saunders Y. Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. *Palliat Med*. 2006;20(6):631-6.
16. Murtagh FE, Addington-Hall JM, Donohoe P, Higginson IJ. Symptom management in patients with established renal failure managed without dialysis. *EDTNA ERCA J*. 2006;32(2):93-8.
17. Lowney AC, Myles HT, Bristowe K, Lowney EL, Shepherd K, Murphy M, et al. Understanding What Influences the Health-Related Quality of Life of Hemodialysis Patients: A Collaborative Study in England and Ireland. *J Pain Symptom Manage*. 2015;50(6):778-85.
18. Davison SN, Jhangri GS. Existential and supportive care needs among patients with chronic kidney disease. *J Pain Symptom Manage*. 2010;40(6):838-43.

19. Murray AM, Arko C, Chen SC, Gilbertson DT, Moss AH. Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol*. 2006;1(6):1248-55.
20. Redahan L, Brady B, Smyth A, Higgins S, Wall C. The use of palliative care services amongst end-stage kidney disease patients in an Irish tertiary referral centre. *Clin Kidney J*. 2013;6(6):604-8.
21. 2011 EERAR. ERA EDTA Registry Annual Report 2011. Amsterdam Academic Medical Centre, Department of Medical Informatics: Amsterdam Academic Medical Centre, Department of Medical Informatics; 2011.
22. Chan KE, Maddux FW, Tolckoff-Rubin N, Karumanchi SA, Thadhani R, Hakim RM. Early outcomes among those initiating chronic dialysis in the United States. *Clin J Am Soc Nephrol*. 2011;6(11):2642-9.
23. Vandecasteele SJ, Kurella Tamura M. A patient-centered vision of care for ESRD: dialysis as a bridging treatment or as a final destination? *J Am Soc Nephrol*. 2014;25(8):1647-51.
24. Berger JR, Hedayati SS. Renal replacement therapy in the elderly population. *Clin J Am Soc Nephrol*. 2012;7(6):1039-46.
25. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant*. 2011;26(5):1608-14.
26. Morton RL, Webster AC, McGeechan K, Howard K, Murtagh FE, Gray NA, et al. Conservative Management and End-of-Life Care in an Australian Cohort with ESRD. *Clin J Am Soc Nephrol*. 2016;11(12):2195-203.
27. Smith C, Da Silva-Gane M, Chandna S, Warwicker P, Greenwood R, Farrington K. Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract*. 2003;95(2):c40-6.
28. Galla JH. Clinical practice guideline on shared decision-making in the appropriate initiation of and withdrawal from dialysis. The Renal Physicians Association and the American Society of Nephrology. *J Am Soc Nephrol*. 2000;11(7):1340-2.
29. Irish Hospice Foundation I. , IHF Perspectives 4:A perspectives on advance care planning for end-of-life care, Dublin. 2016 ed. <http://hospicefoundation.ie/wp-content/uploads/2016/06/IHF-Perspective-4-A-Perspective-on-Advance-Care-Plamnnng-for-end-of-life.pdf>(Accessed 12/03/2019): Irish Hospice Foundation; 2016.
30. Davison SN. Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clin J Am Soc Nephrol*. 2006;1(5):1023-8.
31. Davison SN. Quality end-of-life care in dialysis units. *Semin Dial*. 2002;15(1):41-4.
32. Advance Care Planning and Advance Healthcare Directives [Internet]. Irish Hospice Foundation.
33. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep*. 2004;34(2):30-42.
34. Hanson LC, Tulsy JA, Danis M. Can clinical interventions change care at the end of life? *Ann Intern Med*. 1997;126(5):381-8.
35. Wachterman MW, Marcantonio ER, Davis RB, Cohen RA, Waikar SS, Phillips RS, et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Intern Med*. 2013;173(13):1206-14.
36. Evangelidis N, Craig JC, Tong A, Investigators SECa. STANDARDISED OUTCOMES IN NEPHROLOGY-HAEMODIALYSIS (SONG-HD): USING THE DELPHI METHOD TO GAIN CONSENSUS ON CORE OUTCOMES FOR HAEMODIALYSIS TRIALS. *J Ren Care*. 2015;41(4):211-2.
37. McCarthy J LM, Weafer J, Dooley D. Conversations with the Irish public about death and dying. *Studies: An Irish Quarterly Review*. 2009;98(392):457-72.
38. Weafer J MJ, Loughrey M. Exploring death and dying: The views of the Irish public. <http://hospicefoundation.ie/publications/reports/>: Irish Hospice Foundation; 2009.
39. McCarthy J, Weafer J, Loughrey M. Irish views on death and dying: a national survey. *J Med Ethics*. 2010;36(8):454-8.

40. McCarthy J DM, Dooley D, Campbell L, Smith D, O'Neill C, Quinlan C, Weafer J. The complete framework for end-of-life care. Ireland. In: Ireland RCoS, editor. <http://epubsrcsiie/gprep/1>. Ireland 2010.
41. Quinlan C QR, O'Neill C. Perspectives and Experiences of Patient Autonomy at End of Life; A qualitative study with patients, family and friends. www.sfh.ie: Irish Hospice Foundation; 2012.
42. JA W. The Irish Hospice Foundation: Irish attitudes to death, dying and bereavement 2004-2014.: Irish Hospice Foundation; 2014.
43. McKeown K HT, Twomey S. The culture of end-of-life care in hospitals in Ireland, Report 4. Irish Hospice Foundation Dublin: Irish Hospice Foundation- Hospice friendly hospitals; 2010.
44. O'Hare AM, Szarka J, McFarland LV, Taylor JS, Sudore RL, Trivedi R, et al. Provider Perspectives on Advance Care Planning for Patients with Kidney Disease: Whose Job Is It Anyway? *Clin J Am Soc Nephrol*. 2016;11(5):855-66.
45. Ahmed S, Mendu ML. The Value of Primary Care Provider Involvement in the Care of Kidney Failure Patients on Dialysis: Finding the Balance. *Clin J Am Soc Nephrol*. 2020;15(4):450-2.
46. Wang V, Diamantidis CJ, Wylie J, Greer RC. Minding the gap and overlap: a literature review of fragmentation of primary care for chronic dialysis patients. *BMC Nephrol*. 2017;18(1):274.
47. Morton RL, Snelling P, Webster AC, Rose J, Masterson R, Johnson DW, et al. Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. *CMAJ*. 2012;184(5):E277-83.
48. Hussain JA, Flemming K, Murtagh FE, Johnson MJ. Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research. *Clin J Am Soc Nephrol*. 2015;10(7):1201-15.
49. Wong SP, Kreuter W, O'Hare AM. Treatment intensity at the end of life in older adults receiving long-term dialysis. *Arch Intern Med*. 2012;172(8):661-3; discussion 3-4.
50. Shared decision-making [Internet]. NICE. 2020 Accessed.
51. Verberne WR, Konijn WS, Prantl K, Dijkers J, Roskam MT, van Delden JJM, et al. Older patients' experiences with a shared decision-making process on choosing dialysis or conservative care for advanced chronic kidney disease: a survey study. *BMC Nephrol*. 2019;20(1):264.
52. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ*. 2006;333(7574):886.
53. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80.
54. Nutbeam D. The evolving concept of health literacy. *Soc Sci Med*. 2008;67(12):2072-8.
55. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav*. 2007;31 Suppl 1:S19-26.
56. Literacy IoMUCoH. Health Literacy: A Prescription to End Confusion. 2004.
57. Volandes AE, Paasche-Orlow M, Gillick MR, Cook EF, Shaykevich S, Abbo ED, et al. Health literacy not race predicts end-of-life care preferences. *J Palliat Med*. 2008;11(5):754-62.
58. Dewalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP. Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med*. 2004;19(12):1228-39.
59. Osborn CY, Paasche-Orlow MK, Davis TC, Wolf MS. Health literacy: an overlooked factor in understanding HIV health disparities. *Am J Prev Med*. 2007;33(5):374-8.
60. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.
61. Cavanaugh KL, Wingard RL, Hakim RM, Eden S, Shintani A, Wallston KA, et al. Low health literacy associates with increased mortality in ESRD. *J Am Soc Nephrol*. 2010;21(11):1979-85.
62. Kutner M GE, Jin Y, Paulsen C. The Health literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. Washington DC. National Centre for Education Statistics, US Department of Education, 2006: NATIONAL Centre for Education Statistics, US Department of Education; 2003 , published 2006 NCES 483.

63. Sørensen K, Pelikan JM, Röthlin F, Ganahl K, Slonska Z, Doyle G, et al. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *Eur J Public Health*. 2015;25(6):1053-8.
64. Kutner M GE, Jin Y, Paulsen C. The Health literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. Washington DC. National Centre for Education Statistics, US Department of Education, 2006: NAational Centre for Education Statistics, US Department of Education; 2003 , published 2006.
65. Davison SN, Jhangri GS, Holley JL, Moss AH. Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol*. 2006;1(6):1256-62.
66. Eneanya ND, Goff SL, Martinez T, Gutierrez N, Klingensmith J, Griffith JL, et al. Shared decision-making in end-stage renal disease: a protocol for a multi-center study of a communication intervention to improve end-of-life care for dialysis patients. *BMC Palliat Care*. 2015;14:30.
67. Combs SA, Culp S, Matlock DD, Kutner JS, Holley JL, Moss AH. Update on end-of-life care training during nephrology fellowship: a cross-sectional national survey of fellows. *Am J Kidney Dis*. 2015;65(2):233-9.
68. Lazenby S, Edwards A, Samuriwo R, Riley S, Murray MA, Carson-Stevens A. End-of-life care decisions for haemodialysis patients - 'We only tend to have that discussion with them when they start deteriorating'. *Health Expect*. 2017;20(2):260-73.
69. Royal College of Physicians of Ireland R. RCPI training curriculum. www.rcpi.ie/training/basic-specialist-training/higher-specialist-training; RCPI; Accessed 11/03/2019.
70. National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) NIOH, NIH. Conservative Management for kidney failure <https://www.niddk.nih.gov/health-information/kidney/kidney-disease/kidney-failure/conservtaive-management>.: National Institutes of Health, NIH.; Accessed 12/03/2019 [
71. Ren Q, Shi Q, Ma T, Wang J, Li Q, Li X. Quality of life, symptoms, and sleep quality of elderly with end-stage renal disease receiving conservative management: a systematic review. *Health Qual Life Outcomes*. 2019;17(1):78.
72. van de Luijngaarden MW, Noordzij M, van Biesen W, Couchoud C, Cancarini G, Bos WJ, et al. Conservative care in Europe--nephrologists' experience with the decision not to start renal replacement therapy. *Nephrol Dial Transplant*. 2013;28(10):2604-12.
73. Grubbs V, Tuot DS, Powe NR, O'Donoghue D, Chesla CA. System-Level Barriers and Facilitators for Foregoing or Withdrawing Dialysis: A Qualitative Study of Nephrologists in the United States and England. *Am J Kidney Dis*. 2017;70(5):602-10.
74. Foote C, Morton RL, Jardine M, Gallagher M, Brown M, Howard K, et al. Considerations of Nephrologists when Suggesting Dialysis in Elderly patients with Renal failure (CONSIDER): a discrete choice experiment. *Nephrol Dial Transplant*. 2014;29(12):2302-9.
75. Ladin K, Pandya R, Perrone RD, Meyer KB, Kannam A, Loke R, et al. Characterizing Approaches to Dialysis Decision Making with Older Adults: A Qualitative Study of Nephrologists. *Clin J Am Soc Nephrol*. 2018;13(8):1188-96.
76. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267(16):2221-6.
77. Parvez S, Abdel-Kader K, Pankratz VS, Song MK, Unruh M. Provider Knowledge, Attitudes, and Practices Surrounding Conservative Management for Patients with Advanced CKD. *Clin J Am Soc Nephrol*. 2016;11(5):812-20.
78. Wachterman MW, Leveille T, Keating NL, Simon SR, Waikar SS, Bokhour B. Nephrologists' emotional burden regarding decision-making about dialysis initiation in older adults: a qualitative study. *BMC Nephrol*. 2019;20(1):385.
79. O'Halloran P, Noble H, Norwood K, Maxwell P, Shields J, Fogarty D, et al. Advance Care Planning With Patients Who Have End-Stage Kidney Disease: A Systematic Realist Review. *J Pain Symptom Manage*. 2018;56(5):795-807.e18.

80. National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) NIOH, NIH. Conservative Management for kidney failure <https://www.niddk.nih.gov/health-information/kidney/kidney-disease/kidney-failure/conservative-management>.: National Institutes of Health, NIH.; 2019 [
81. Bohlke M, Nunes DL, Marini SS, Kitamura C, Andrade M, Von-Gysel MP. Predictors of quality of life among patients on dialysis in southern Brazil. *Sao Paulo Med J.* 2008;126(5):252-6.
82. Jankowska-Polanska B, Uchmanowicz I, Wysocka A, Uchmanowicz B, Lomper K, Fal AM. Factors affecting the quality of life of chronic dialysis patients. *Eur J Public Health.* 2017;27(2):262-7.
83. Berkhout-Byrne N, Gaasbeek A, Mallat MJK, Rabelink TJ, Mooijaart SP, Dekker FW, et al. Regret about the decision to start dialysis: a cross-sectional Dutch national survey. *Neth J Med.* 2017;75(6):225-34.
84. Williams AW, Dwyer AC, Eddy AA, Fink JC, Jaber BL, Linas SL, et al. Critical and honest conversations: the evidence behind the "Choosing Wisely" campaign recommendations by the American Society of Nephrology. *Clin J Am Soc Nephrol.* 2012;7(10):1664-72.
85. Raj R, Thiruvengadam S, Ahuja KDK, Frandsen M, Jose M. Discussions during shared decision-making in older adults with advanced renal disease: a scoping review. *BMJ Open.* 2019;9(11):e031427.
86. Wong SP, Vig EK, Taylor JS, Burrows NR, Liu CF, Williams DE, et al. Timing of Initiation of Maintenance Dialysis: A Qualitative Analysis of the Electronic Medical Records of a National Cohort of Patients From the Department of Veterans Affairs. *JAMA Intern Med.* 2016;176(2):228-35.
87. Tonkin-Crine S, Okamoto I, Leydon GM, Murtagh FE, Farrington K, Caskey F, et al. Understanding by older patients of dialysis and conservative management for chronic kidney failure. *Am J Kidney Dis.* 2015;65(3):443-50.
88. Taylor DM, Fraser SDS, Bradley JA, Bradley C, Draper H, Metcalfe W, et al. A Systematic Review of the Prevalence and Associations of Limited Health Literacy in CKD. *Clin J Am Soc Nephrol.* 2017;12(7):1070-84.
89. Green JA, Mor MK, Shields AM, Sevick MA, Arnold RM, Palevsky PM, et al. Associations of health literacy with dialysis adherence and health resource utilization in patients receiving maintenance hemodialysis. *Am J Kidney Dis.* 2013;62(1):73-80.
90. Brennan F, Stewart C, Burgess H, Davison SN, Moss AH, Murtagh FEM, et al. Time to Improve Informed Consent for Dialysis: An International Perspective. *Clin J Am Soc Nephrol.* 2017;12(6):1001-9.
91. O'Riordan J, Kane PM, Noble H, Beatty S, Mannion E, Murtagh C, et al. When Less Is More: Optimizing Care for Elderly Patients Failing to Thrive on Dialysis. *J Pain Symptom Manage.* 2018;55(4):1241-5.
92. O'Hare AM, Armistead N, Schrag WL, Diamond L, Moss AH. Patient-centered care: an opportunity to accomplish the "Three Aims" of the National Quality Strategy in the Medicare ESRD program. *Clin J Am Soc Nephrol.* 2014;9(12):2189-94.
93. Schmidt RJ, Moss AH. Dying on dialysis: the case for a dignified withdrawal. *Clin J Am Soc Nephrol.* 2014;9(1):174-80.
94. Byock I. *The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life.* Group AP, editor. United States of America 2013.
95. Nvivo. Nvivo Pro 11 Qualitative Data Analysis Computer Software programme. Pro 11 ed. QSR International: QSR International; Dec 2015.
96. Tiegies Z, Maclullich AMJ, Anand A, Brookes C, Cassarino M, O'connor M, et al. Diagnostic accuracy of the 4AT for delirium detection in older adults: systematic review and meta-analysis. *Age Ageing.* 2020.
97. Allen M. *The SAGE Encyclopedia of Communication Research.* Allen M, editor: SAGE Publication. Inc; 2017.
98. Norlyk A, Harder I. What makes a phenomenological study phenomenological? An analysis of peer-reviewed empirical nursing studies. *Qual Health Res.* 2010;20(3):420-31.

99. Chun Tie Y, Birks M, Francis K. Grounded theory research: A design framework for novice researchers. *SAGE Open Med.* 2019;7:2050312118822927.
100. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ.* 2008;337:a1020.
101. Halperin I. Case Studies in Exercise and Sport Sciences: A Powerful Tool to Bridge the Science-Practice Gap. *Int J Sports Physiol Perform.* 2018:1-9.
102. Braun Virginia CV. Using thematic analysis in psychology. *Qualitative Research in Psychology.* 2006;3(2):77-101.
103. Nowell LS NJ, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods.* 2017;16:1-13.
104. Nigel K. Using templates in the thematic analysis of text. *Essential guide to Qualitative Methods in Organizational Research: Sage; 2004.* p. 256-70.
105. Holloway I TL. The Status of Method: Flexibility, Consistency and Coherence. *Qualitative Research.* 2003;3(3):345-57.
106. DeSantis L, Ugarriza DN. The concept of theme as used in qualitative nursing research. *West J Nurs Res.* 2000;22(3):351-72.
107. Aronson J. A Pragmatic View of Thematic Analysis. *The Qualitative Report.* 1995;2(1):1-3.
108. JW C. *Qualitative Inquiry and Research Design; Choosing Among Five Approaches.* Third ed: SAGE Publications; 2013.
109. Lincoln YS GE. *Naturalistic Inquiry.* First ed: SAGE; 1985.
110. Tobin GA BC. Methodological Rigour within a Qualitative Framework. *Journal of Advanced Nursing.* 2004;48(4):388-96.
111. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res.* 2007;17(10):1372-80.
112. Morse Janice RL. *Read Me First for a User's Guide to Qualitative Methods.* third ed. USA: SAGE Publications Inc; 2012.
113. J A-S. Thematic networks: An analytical tool for Qualitative Research. *Qualitative Research.* 2001;1(3):385-485.
114. Jackson Kristi BP. *Qualitative Data Analysis with Nvivo.* Second ed: Sage.
115. Miles MB HA, Saldana J. *Qualitative Data Analysis: A methods sourcebook.* Third ed. Los Angeles: SAGE Publications Inc.; 2014.
116. Association TR. Clinical practice guidelines for the initiation, management and withdrawal of renal replacement therapy. In: Association TR, editor. <http://www.renalorg/guidelines>: The Renal Association; 2014.
117. Tavares N, Jarrett N, Hunt K, Wilkinson T. Palliative and end-of-life care conversations in COPD: a systematic literature review. *ERJ Open Res.* 2017;3(2).
118. Jameson K HA. Multilevel barriers to advance care planning: Perspectives of healthcare providers, patients and families. *BMJ Supportive and Palliative Care.* 2015:A12.3-A3.
119. Cornally N, McGlade C, Weathers E, Daly E, Fitzgerald C, O'Caoimh R, et al. Evaluating the systematic implementation of the 'Let Me Decide' advance care planning programme in long term care through focus groups: staff perspectives. *BMC Palliat Care.* 2015;14:55.
120. Dunphy EJ, Conlon SC, O'Brien SA, Loughrey E, O'Shea BJ. End-of-life planning with frail patients attending general practice: an exploratory prospective cross-sectional study. *Br J Gen Pract.* 2016;66(650):e661-6.
121. Salat H, Javier A, Siew ED, Figueroa R, Lipworth L, Kabagambe E, et al. Nephrology Provider Prognostic Perceptions and Care Delivered to Older Adults with Advanced Kidney Disease. *Clin J Am Soc Nephrol.* 2017;12(11):1762-70.
122. Brown EA, Bekker HL, Davison SN, Koffman J, Schell JO. Supportive Care: Communication Strategies to Improve Cultural Competence in Shared Decision Making. *Clin J Am Soc Nephrol.* 2016;11(10):1902-8.

123. Dixon J, King D, Knapp M. Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. *BMJ Support Palliat Care*. 2019;9(3):316-25.
124. Framework NGS. The National Gold Standards Framework (GSF) Centre in end of life care. <http://goldstandardsframework.org.uk/info@gsfcentre.co.uk>: Gold Standards Framework; 2019 Accessed.
125. Kaufman SR, Shim JK, Russ AJ. Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci*. 2006;61(4):S175-84.
126. Verberne WR, Geers AB, Jellema WT, Vincent HH, van Delden JJ, Bos WJ. Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis. *Clin J Am Soc Nephrol*. 2016;11(4):633-40.
127. van Biesen W, van de Luijtgarden MW, Brown EA, Michel JP, van Munster BC, Jager KJ, et al. Nephrologists' perceptions regarding dialysis withdrawal and palliative care in Europe: lessons from a European Renal Best Practice survey. *Nephrol Dial Transplant*. 2015;30(12):1951-8.
128. Davison SN, Kromm SK, Currie GR. Patient and health professional preferences for organ allocation and procurement, end-of-life care and organization of care for patients with chronic kidney disease using a discrete choice experiment. *Nephrol Dial Transplant*. 2010;25(7):2334-41.
129. System URD. US Renal Data System Annual Report 2019: Epidemiology of Kidney Disease in the United States, Executive Summary. http://www.usrds.org/2019/view/USRDS_2019_ES_final.pdf.: US Renal Data System; 2019.
130. Gilg J, Caskey F, Fogarty D. UK Renal Registry 18th Annual Report: Chapter 1 UK Renal Replacement Therapy Incidence in 2014: National and Centre-specific Analyses. *Nephron*. 2016;132 Suppl 1:9-40.
131. O'Riordan J, Noble H, Kane PM, Smyth A. Advance care plan barriers in older patients with end-stage renal disease: a qualitative nephrologist interview study. *BMJ Support Palliat Care*. 2020;10(4):e39.
132. Volandes AE, Barry MJ, Chang Y, Paasche-Orlow MK. Improving decision making at the end of life with video images. *Med Decis Making*. 2010;30(1):29-34.
133. Schell JO, Green JA, Tulsy JA, Arnold RM. Communication skills training for dialysis decision-making and end-of-life care in nephrology. *Clin J Am Soc Nephrol*. 2013;8(4):675-80.
134. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-57.
135. Abernethy AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliat Care*. 2005;4:7.
136. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893-907.
137. Schell JO, Patel UD, Steinhauser KE, Ammarell N, Tulsy JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis*. 2012;59(4):495-503.
138. Hines SC BL, Moss AH. Informed Consent Among Chronically ill Elderly: Assessing its (in)adequacy and predictors. *Journal of Applied Communication Research*. 2009;25(3):151-69.
139. Subramanian A, Doak C, Doak LG. Treatment of patients with literacy issues. *Am Fam Physician*. 2006;74(9):1626, 9.
140. Melhado L, Bushy A. Exploring uncertainty in advance care planning in African Americans: does low health literacy influence decision making preference at end of life. *Am J Hosp Palliat Care*. 2011;28(7):495-500.
141. Sudore RL, Heyland DK, Lum HD, Rietjens JAC, Korff IJ, Ritchie CS, et al. Outcomes That Define Successful Advance Care Planning: A Delphi Panel Consensus. *J Pain Symptom Manage*. 2018;55(2):245-55.e8.

142. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681-92.
143. Davison SN, Jhangri GS, Koffman J. Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. *BMJ Support Palliat Care*. 2016;6(1):66-74.
144. Roderick P, Rayner H, Tonkin-Crine S, Okamoto I, Eyles C, Leydon G, et al. A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure. 2015.
145. Murphy E, Burns A, Murtagh FEM, Rooshenas L, Caskey FJ. The Prepare for Kidney Care Study: prepare for renal dialysis versus responsive management in advanced chronic kidney disease. *Nephrol Dial Transplant*. 2021;36(6):975-82.
146. Lakin JR, Brannen EN, Tulskey JA, Paasche-Orlow MK, Lindvall C, Chang Y, et al. Advance Care Planning: Promoting Effective and Aligned Communication in the Elderly (ACP-PEACE): the study protocol for a pragmatic stepped-wedge trial of older patients with cancer. *BMJ Open*. 2020;10(7):e040999.
147. Zehm A, Lindvall C, Parks K, Schaefer K, Chittenden E. Prognosis, Communication, and Advance Care Planning in Heart Failure: A Module for Students, Residents, Fellows, and Practicing Clinicians. *MedEdPORTAL*. 2017;13:10596.
148. Deep KS, Hunter A, Murphy K, Volandes A. "It helps me see with my heart": how video informs patients' rationale for decisions about future care in advanced dementia. *Patient Educ Couns*. 2010;81(2):229-34.
149. Nair D, El-Sourady M, Bonnet K, Schlundt DG, Fanning JB, Karlekar MB. Barriers and Facilitators to Discussing Goals of Care among Nephrology Trainees: A Qualitative Analysis and Novel Educational Intervention. *J Palliat Med*. 2020;23(8):1045-51.
150. Phair G, Agus A, Normand C, Brazil K, Burns A, Roderick P, et al. Healthcare use, costs and quality of life in patients with end-stage kidney disease receiving conservative management: results from a multi-centre observational study (PACKS). *Palliat Med*. 2018;32(8):1401-9.