

PATIENT AND CAREGIVER EXPERIENCES LIVING WITH  
ADVANCED KIDNEY DISEASE

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## ABSTRACT

**Background:** Advanced chronic kidney disease (ACKD), affects hundreds of thousands of people and their caregivers degrading patient and caregiver quality of life (QOL). Integration of palliative care (PC) into care for people living with ACKD has been suggested as a means to improve the quality of life for patients and their non-professional caregivers. However, relatively little research has examined ACKD patient/caregiver perceptions regarding the role of PC. The specific aims of this study are: (1) Describe patients' and caregivers' experiences with and perceptions of living with ACKD, including symptoms/symptom management, decision-making around disease management choices, and other perceived gaps/challenges in care; and (2) explore ACKD patients' and caregivers' understanding of palliative care and their perspectives regarding what role, if any, palliative care should play in managing ACKD.

**Methods:** This qualitative descriptive study identified concerns of patients with ACKD, and their caregivers related to their health and healthcare. Twenty-four interviews were conducted (twenty-two with patients) with participants purposively sampled from dialysis clinics at the University of Virginia. Data were simultaneously collected and analyzed to create codes and eventually categories and themes. Memo-writing was used to document key decision points.

**Findings:** This qualitative descriptive study identified four themes: (1) ACKD impacts patients physically, emotionally, socially, and economically; (2) Patients use a range of self-management strategies learned through trial and error from other patients and clinicians; (3) Decision-making is complex, often not explicit/elucidated, and ongoing throughout kidney replacement therapy (RRT); and (4) Lack of familiarity with PC,

perceived as unnecessary during illness stability, but potentially useful during exacerbations/periods of decline. Patients do not see need for palliative care services now, but some would see utility if they experienced increased complexity/instability in their clinical condition. In general, patients preferred to access services via their usual team of clinicians.

Conclusion: The findings highlighted the challenges ACKD patients face in living with their disease and the strategies they employ to care for themselves. Patients were not familiar with PC. However, they could envision a role for increased access to PC, particularly if delivered by their nephrology team within their usual care settings.

*Keywords:* Advanced chronic kidney disease (ACKD), palliative care (PC).

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## **Chapter 1: Introduction, Problem, and Significance**

Kidney disease impacts 14.9 percent of adults in the United States alone and has a range of potentially severe implications for individual patients and their family caregivers (United States Kidney Data System, 2020). Kidney disease is classified as acute or chronic. A transient reduction in kidney function characterizes acute kidney injury (AKI). Chronic kidney disease (CKD) is characterized by a persistent and often progressive decline in kidney function caused by a wide variety of underlying conditions (Bargman & Skorecki, 2018). Chronic kidney disease is further classified by severity, with stage 1 representing the most negligible loss of kidney function and stage 5 the greatest (Inker et al., 2014). Those patients who reach CKD stage 5 and start kidney replacement therapy (via dialysis or kidney transplant) have end-stage kidney disease (ESKD). This study will focus on the experiences and concerns of patients and caregivers with CKD stage 5 or ESKD, termed advanced CKD (ACKD).

### **Scope and Nature of Kidney Disease**

Chronic kidney disease is common, with some estimates projecting that over 10% of the US population has some degree of CKD (Bargman & Skorecki, 2018). In older adults, however, the rates are much higher, with approximately 50% of people over 80-years old affected (Weiss et al., 2015). Furthermore, the overall number of people living with CKD is projected to increase, primarily due to an aging population and the increasing burden of chronic diseases, especially hypertension and diabetes mellitus type two, both of which increase the risk of developing CKD (Bargman & Skorecki, 2018; Bowling & Muntner, 2012; Kainz et al., 2015). While the majority of people living with CKD do not progress to stage 5, at any given time, approximately 780,000 people in the

United States are living with end-stage kidney disease, with approximately 131,000 new people beginning dialysis each year (United States Kidney Data System, 2020).

Not only is ACKD relatively common, but those affected experience significant morbidity and mortality. In the United States, kidney disease ranks among the ten leading causes of early death (Saran et al., 2018). Living with ACKD impacts patients and caregivers in numerous ways, including physical and psychological symptoms, quality of life, changing social roles, impact on financial status, and the need for complex decisions about treatment and end-of-life care (Bele et al. 2012; Pugh-Clarke et al., 2017; Pungchompoo et al., 2016; Seah et al., 2015; Sellars et al., 2018; Tong et al., 2014).

Historically, therapy for ACKD consisted of supportive care designed to optimize the patient's ability to cope with the sequelae of their kidney failure (Peitzman, 2007). By the 1960s, however, dialysis and kidney transplant had become relatively accessible treatment options in the United States. Dialysis allows the removal of toxins and management of electrolytes and volume status but requires treatment on an ongoing basis. Kidney transplant involves the implantation of a donor's kidney into the ACKD patient, which requires a major operation and ongoing use of immunosuppressive medications to manage donor kidney rejection. A third option, conservative therapy, is typically conducted by nephrology or primary care clinicians and is distinct from PC.

Conservative therapy focuses on preventing CKD progression, symptom control, and managing psychological, social, and spiritual domains for both patients and caregivers (Murtagh et al., 2016). This approach prioritizes optimizing patients' quality of life rather than maximizing their longevity (Brown et al., 2012). As CKD worsens, patients develop increasingly significant symptoms. By the time affected persons reach



CKD stage 5, they frequently suffer from numerous severe physical symptoms. Typically, symptoms progress insidiously, and as kidney function worsens, the number and severity of complications increase, resulting in an elevated symptom burden (Almutary et al., 2016; Khan et al., 2017). Many patients experience severe pain that can only be poorly controlled (Almutary et al., 2016), and other common physical symptoms in ACKD include fatigue, loss of interest in eating, and pruritus (Almutary et al., 2016). Patients undergoing dialysis may also experience symptoms related to their treatment, such as cramping or post-treatment fatigue (Flythe et al., 2018). Patients describe an interplay between their symptoms in which a cascade of interacting symptoms occurs that gives rise to new symptoms and exacerbates symptoms already present. For example, someone experiencing frequent cramping during dialysis treatments may feel more tired after dialysis, which eventually precipitates depression due to unremitting fatigue (Flythe et al., 2018).

In addition to their physical symptoms, patients reported significant levels of psychological distress. Numerous studies found higher rates of depression and anxiety among ESKD patients when compared to the general population (Hackett & Jardine, 2017; Yoong et al., 2017). Many of the physical symptoms that patients experience are related to the sequelae of their underlying disease, but others are attributable to therapies designed for treating their ACKD. The etiology for increased rates of depression and anxiety in ACKD remains uncertain but is likely multifactorial, encompassing physiological, emotional, and social processes (Hackett & Jardine, 2017).

Living with ACKD involves numerous socioeconomic challenges, including paying for treatment, difficulty maintaining employment while dealing with the demands

of treatment, and adapting to changing interpersonal relationships (Hirth et al., 2008; Roberti et al., 2018). Beyond their physical and psychological symptoms, patients also experience challenges to their well-being in the social, spiritual, and economic domains (Brown et al., 2012). Living with ACKD has been shown to have a variable influence on spirituality, with some people finding that the challenge degrades their sense of spirituality, while others finding the adaptation to their illness spirituality enhancing (Elliott et al., 2012; Reig-Ferrer et al., 2012; Song et al., 2018).

### ***Impact on Patient Quality of Life***

Living with ACKD significantly impacts patient quality of life. Quality of life (QOL) is a well-developed concept, with multiple possible definitions and instruments to assess various aspects of patients' experiences. For example, measures may examine global, physical, and mental aspects of quality of life (Balogun et al., 2017; Bele et al., 2012; Ghiasi et al., 2018; Paraskevi, 2011). In addition to symptoms, numerous other personal, interpersonal, social, health system, and policy level determinants impact QOL. Quality of life is essential in understanding patients' experience living with ACKD because QOL may impact patients' clinical outcomes.

### ***Impact on Caregiver Quality of Life***

Living with ACKD not only creates challenges for patients but can also tremendously influence the health and well-being of people who support them as caregivers. In many forms of advanced chronic illness, family and friends provide significant amounts of uncompensated supportive care (Nakken et al., 2015). Caregivers of people living with ACKD experience significant challenges themselves as they

provide support to their care recipients, sometimes experiencing levels of depression and anxiety similar to those of the ACKD patients they support (Pereira et al., 2017).

Additionally, many caregivers experience profound fatigue and report limiting their usual activities due to the requirements of their caregiving role (Pereira et al., 2017). Caregivers also experience other forms of distress related to their role in navigating the health system and coping with the uncertain trajectory of ACKD (Oyegbile & Brysiewicz, 2017). These factors all interact to potentially reduce caregiver quality of life in ways similar to that experienced by patients.

### **Care Model, Treatment Options, and Decisions**

Since the mid-20th century, rapid development has made multiple forms of dialysis and kidney transplant widely accessible in industrialized countries. This proliferation of complex therapies has meant that patients often rely on multiple clinicians for their care, such as seeing a nephrologist for management of their kidney disease and often a primary care provider for aspects of primary care, as well as medical specialists to manage co-morbid cardiovascular disease, diabetes, and other conditions (Wang et al., 2017). Additionally, ACKD patients frequently interact with nurses, dietitians, social workers, and other care team members. The exact details of the care model are significantly influenced by national health system characteristics and local practice pattern variation (Kurella-Tamura et al., 2014; Roderick et al., 2015; Wong et al., 2016). Patients and caregivers may benefit from significant resources; however, a large health care team may also result in a diffusion of responsibility and uncertainty about the role of the various team members (Tam-Tham et al., 2016).

New types of kidney replacement therapy have altered the course of ACKD for many patients. However, these new treatment options present significant decision-making challenges since not all patients derive equal benefits. For example, older patients with poor functional status and higher co-morbid illness may have poorer mortality outcomes with dialysis compared to conservative therapy (Abdel-Rahman & Holley, 2010). Similarly, another study of older adults found that initiating dialysis for this cohort resulted in impaired quality of life compared to conservative therapy (Chen et al., 2018). It can be complex for clinicians, patients, and caregivers to adequately integrate and communicate about these nuances during decision-making processes regarding the initiation of kidney replacement therapy and advanced care planning (Eneanya et al., 2015; Murray et al., 2009; Sea et al., 2015).

### **Patient-Centered Care**

Contemporaneously with the growing complexity of treatment options, there has been broad recognition of the importance of patient-centered care for the attainment of high-quality health care (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001). Patient-centered care is an approach that aligns medical care with the goals and context of individual patients, rather than assuming that all patients will benefit from the same standardized approach to therapy (Barry & Edgman-Levitan, 2012). Patient-centered care results in improved engagement of patients in their health care, and ultimately, higher levels of patient investment are thought to lead to better patient outcomes (Epstein & Street, 2011). Nephrology experts have recognized the importance of incorporating patient-centered care models into nephrology care (O'Hare et al., 2014). Shared decision-making (SDM), a component of patient-centered care, has been

suggested as a critical area of focus in ACKD care, but success in incorporating SDM into routine care has been variable at best (Davis & Davison, 2017; Eneanya et al., 2015; Ladin et al., 2017).

### **The Role of Palliative Care**

One promising approach has been the increasing integration of PC into nephrology care. Palliative care is a philosophy of care that aims to avoid and reduce suffering for patients living with life-limiting illness and their caregivers through a multi-dimensional approach to care with an emphasis on symptom management, effective communication, and maintaining and improving QOL (World Health Organization [WHO], 2018). Palliative care is incorporated into routine care provided by generalists; for example, during standard nephrology care or by PC specialists, acting either in a consultative role or as a patient's primary team. Many of the complex issues raised by ACKD fall within the realm of PC (Dahlin et al., 2016). Despite recognition of the potential value of PC in ACKD implementation and access to PC services for kidney patients remains limited due to a lack of adequately trained clinicians, as well as misperceptions regarding who is eligible or likely to benefit from PC (Kurella Tamura et al., 2018).

Specialists in nephrology as well as PC have highlighted the need for further research to address gaps in meeting the PC needs of people living with ACKD (Culp et al., 2016; Kane et al., 2013; Kurella Tamura & Meier, 2013; O'Hare et al., 2017). Developing a complete understanding of patient and caregiver perspectives on the experience of living with ACKD is therefore crucial in order to permit the development of PC interventions that are both effective and genuinely patient-centered.

## Summary of the Problem

ACKD is a common and severe medical condition that will continue to affect rising numbers of people for the foreseeable future. Over 100,000 people are newly diagnosed each year in the United States alone. Patients living with ACKD as well as their caregivers experience significant physical, emotional, and social burdens, which detract from their health and well-being. To date, practice models have failed to redress patients adequately. Caregiver needs that result in poorly managed symptoms, unmitigated patient and caregiver stress, medical care that is not aligned with patient goals, and higher levels of treatment burden for patients—all contribute to excessive healthcare expenditures via inappropriate resource utilization. Furthermore, in some situations, these factors also lead to increased morbidity and premature mortality.

To address the current gaps in healthcare and improve patient and caregiver experience, experts and national leaders in nephrology and PC have proposed integrating PC into routine care for patients with ACKD earlier in the course of their illness, rather than only at the end of their life. While researchers and clinicians have responded to these demands, patients', and caregivers' perspectives, however, are largely absent, as research agendas were directed by expert opinion and institutional funding priorities. To date, the vast majority of studies have focused on a particular question or issue that researchers decided to examine versus a more patient/caregiver-directed approach (Affinito & Louie, 2018; Cervantes, Jones, et al., 2017; Houben et al., 2014; Walker et al., 2015). Additionally, the experiences and concerns of patients and caregivers are often examined in isolation from each other, despite their interrelated nature (Morton et al., 2010; Tong et al., 2014).

Consequently, little is known regarding patient and caregiver perspectives on the most urgent issues, which research questions are most pressing, and what role PC could and should play in managing ACKD. Without this crucial knowledge, researchers and clinicians cannot deliver patient-centered care. This study aimed to describe the concerns and experiences of ACKD patients and their caregivers across physical, emotional, social, and spiritual domains. In keeping with guidance to enhance the availability and integration of PC into nephrology care, the study also sought to explore patient and caregiver perspectives regarding PC services.

### **Specific Aims**

The specific aims of the study were:

Aim 1): Describe patients' and caregivers' experiences with and perceptions of the experience of living with ACKD, including symptoms/symptom management, decision-making around disease management choices, and other perceived gaps/challenges in care.

Aim 2): Explore ACKD patients' and caregivers' understanding of palliative care and their perspectives regarding what role, if any, palliative care should play in managing ACKD.

## Chapter 2: Literature Review

Because of its exploratory and descriptive nature, this study did not employ an *a-priori* conceptual framework for analysis (Sandelowski, 2000). Nevertheless, previous research has identified several concepts that were likely germane to this project (Polit & Beck, 2017). Relevant concepts included ACKD, PC, quality of life, and patient-centered care. This review describes ACKD and then transitions to analyze how kidney disease impacts patients and their caregivers (seen from physical, psychological, social, and spiritual perspectives). The following section describes PC and its potential impact to improve patients' quality of life and their therapeutic outcomes. The review concludes with an overview of the role of QOL and patient-centered care in assessing and improving the quality of treatment for patients with ACKD.

### Advanced Chronic Kidney Disease

The kidney system comprises the kidneys, the ureters, and the bladder (Morton et al., 2019). The essential component of the kidney is the nephron, composed of two key elements: the glomerulus (a group of capillaries that perform filtration) and the kidney tubule, where electrolytes and water are recovered after filtration (Perlman & Heung, 2019). The kidneys perform multiple essential regulatory and hormonal functions. The regulatory functions control fluid and electrolyte balance and acid-base balance. The hormonal functions control red blood cell formation, blood pressure, and Vitamin D activation. (Barrett et al., 2019).

Acute kidney injury (AKI) is an abrupt reduction in kidney function that occurs within a seven-day period, while chronic kidney disease (CKD) is kidney dysfunction that persists for more than three months (Kellum et al., 2012; Inker et al., 2014). Chronic



kidney disease results from a broad range of underlying pathophysiological processes, which share the common result of impaired function across all aspects of kidney physiology (Bargman & Skorecki, 2018). The most common preventable causes of CKD, accounting for more than 90% of cases globally, include diabetic nephropathy, kidney disease associated with hypertension, diseases of the glomeruli and tubules, and autosomal dominant polycystic kidney disease (Bargman & Skorecki, 2018).

Kidney function is commonly described in terms of glomerular filtration rate (GFR), which is the rate of blood flow filtered through the glomeruli per minute (Martin, 2017). Technical challenges make a direct measurement of glomerular filtration impractical in clinical practice. Therefore, estimated glomerular filtration (eGFR), derived via various equations, is the typical means of staging CKD (Bargman & Skorecki, 2018). Kidney Disease: Improving Global Outcomes (KDIGO) has promulgated a five-stage categorization system based on GFR ranging from G1 (normal) to G5 (kidney failure) (Inker et al., 2014). Stages range from Stage 1 (CKD1), showing a normal or above normal eGFR greater than or equal to 90 ml/min per 1.73m<sup>2</sup> but with abnormal urinary protein secretion, to Stage 5 (CKD5), which is defined as an eGFR of less than 15 ml/min per 1.73m<sup>2</sup> (Bargman & Skorecki, 2018). Once patients begin receiving kidney replacement therapy (dialysis or transplant), they are described as having end-stage kidney disease (ESKD) (Floege et al., 2010).

### ***Epidemiology and Disease Trajectory***

Chronic kidney disease is common, afflicting over 800 million people globally (Kovesdy, 2022). More than 10% of the United States population has been diagnosed with chronic kidney disease (Bargman & Skorecki, 2018). The prevalence in older adults

is considerably higher. By age 80, based on United States samples, up to half of the population will have some degree of CKD (McCullough et al., 2019). In the United States rates of CKD plateaued in the early 2000s, although members of some minoritized groups continue to experience increasing rates (Zhang, 2022).

Less than five percent of those diagnosed with CKD will progress to CKD5. However, even this small percentage means hundreds of thousands of people are experiencing ACKD (Johnston, 2016). In the United States in 2019 nearly 135,000 received a new diagnosis of ESKD (Johansen et al., 2022). This was 2.7 percent higher from 2018 and 15.8 percent higher than in 2009 (Johansen et al., 2022). However, the adjusted incidence decreased over the past decade with a decrease from 431 per million population to 386 per million population (Johansen et al., 2022).

Advanced chronic kidney disease is life-limiting, with mortality rates higher than for those suffering from many types of cancer, stroke, or congestive heart failure (Grubbs, 2018). For example, women with ESKD between the ages of 65 and 74 experience 211 deaths per 1,000 patient-years compared to 73 deaths per 1,000 patient-years for all types of cancer. Men over the age of 75 on dialysis experience a mortality rate of 338 deaths per 1,000 patient years for all types of cancer. This same population experiences a mortality rate of 338 deaths per 1,000 patient-years compared to 210 deaths per 1,000 patient-years for those in the same cohort who experienced an acute myocardial infarction (Saran et al., 2018). Notably, most people living with CKD will die from a problem other than CKD, most commonly cardiovascular disease, although CKD often results in complications or exacerbation of these other health issues (Murtagh et al., 2008).

Illness trajectories have been proposed as helpful ways to frame the progression of life-threatening illnesses. Historically, there have been four commonly identified trajectories: sudden death, which could potentially occur for a myriad of reasons at any time; a brief time of rapid failure, as often seen in cancer; reduced function over a long period with episodic exacerbations, as frequently occurs in advanced organ failure; and a gradual long-term decline, as occurs in dementia (Murray et al., 2005). Thinking in terms of trajectories can help anticipate both the timeframe of expected disease progression, as well as the variable services needs throughout the illness, which can be helpful to clinicians, researchers, and patients (Lunney et al., 2003; Murray et al., 2005).

More recently, researchers have examined how kidney disease might be accounted for within the illness trajectory perspective, suggesting that the experience of people with ACKD may be heterogeneous compared to many other diseases. In contrast to many other conditions in which most patients follow a particular trajectory, ACKD patients are distributed across all four categories of illness trajectory. In kidney disease, some patients ultimately succumb to sudden death, while others, such as those withdrawing from dialysis, experience a brief, rapid decline. Other patients on dialysis, who are treated conservatively, may experience a gradual decline, sometimes with episodic exacerbations (Murtagh et al., 2008).

## **Treatment**

Historically, therapy for kidney disease consisted mainly of supportive care that included prescribed diets, changes in activity and climate, skincare, and sometimes herbal treatments to treat symptoms related to CKD, where patients' risk of mortality was linked mainly to the underlying pathology of their kidney disease (Peitzman, 2007). However,

with the advent of the artificial kidney technology in the 1940s, treatment for ACKD changed tremendously. The first successful kidney transplant in 1954 represented the advent of another potential treatment option for patients with CKD5 (Peitzman, 2007). Dialysis had become a relatively accessible therapy for patients in the United States by the 1960s (O'Connor & Kumar, 2012; Peitzman, 2007). Indeed, dialysis had become the standard of care for most patients with ACKD in the United States, with rates rising consistently through the 1990s (Burrows et al., 2017).

Patients with CKD5 have several treatment options. Currently, the early stages of CKD therapy focus on treatment for the underlying etiology, decreasing proteinuria if present, managing co-morbidities impacting kidney function, such as diabetes or hypertension, and managing complications related to kidney disease, such as anemia and electrolyte abnormalities (Abboud & Henrich, 2010). Therapies that target the underlying cause of a particular patient's CKD and therapies to slow CKD progression are employed throughout the illness. However, once patients reach the CKD5 stage, they are often treated with kidney replacement therapies (kidney transplant, peritoneal dialysis, hemodialysis) to manage symptoms and improve mortality. Many CKD5 patients who opt for kidney replacement therapy such as dialysis or transplant are then termed ESKD. In contrast, other CKD5 patients pursue conservative treatment, focusing on maintaining quality of life rather than longevity while limiting kidney disease progression (Brown et al., 2012; Murphy, Murtagh, et al., 2009).

The most common treatment option offered to patients with CKD5 is dialysis. The term dialysis encompasses two types of procedures: hemodialysis, and peritoneal dialysis, which use distinctly different processes to achieve the same outcome of

removing toxins, balancing electrolytes, and acid/base status, while also removing excess fluid volume from the patients' bloodstream (Winterbottom et al., 2014). A kidney transplant may be an option for candidates who meet complex criteria assessing surgical, medical, and social factors (Segall et al., 2016). This option offers improved mortality rates for those who qualify, compared to lifetime dialysis therapy (Patzner et al., 2016). Kidney transplant involves the surgical implantation of a kidney from a carefully matched living or deceased donor, followed by lifelong immunosuppression to prevent immunologic rejection of the donor organ (Lerma et al., 2019). The resurgence of conservative treatment is relatively recent, and its implementation remains heterogeneous across health systems (Okamoto et al., 2015). Conservative therapy focuses on preventing the progression of the underlying disease process and treating the symptoms and physiological derangements of CKD5 without dialysis or transplantation (O'Connor & Kumar, 2012).

### **Patient Experience**

People living with CKD5/ESKD typically undergo a very high symptom burden in all domains of the human experience. These can be broadly categorized as either the "physical" or "non-physical" aspects of CKD5 symptoms.

#### ***Physical Aspects***

Physical symptoms of ACKD are a result of impaired kidney function leading to increased levels of metabolic waste products in the bloodstream, retention of sodium and water resulting in edema and rising blood pressure, development of metabolic acidosis, electrolyte derangement, anemia, and musculoskeletal deterioration (Sattar, 2011). Other significant complications include anemia due to decreased production of erythropoietin in

the kidney, hyperphosphatemia, and secondary hyperparathyroidism resulting in increased bone fragility (Sattar, 2011). Besides the challenges presented by their kidney disease, patients experience high levels of co-morbid illness. For example, 70% of those aged 65 years or older who start dialysis, suffer from one or more other illnesses, with diabetes and heart disease being the two most common (Kane et al., 2013).

As CKD progresses, so does kidney dysfunction, causing a wide range of troubling symptoms, including shortness of breath, fatigue, pain, edema, pruritus, sleep disturbance, drowsiness, muscle cramps, and anorexia (Almutary et al., 2016; Amro et al., 2014; Brown et al., 2015; Ducharlet et al., 2018; Gamondi et al., 2013; Kwok et al., 2016; Murtagh et al., 2007; Murtagh, Addington-Hall, & Higginson, 2007; Song et al., 2018; Yong et al., 2009). Furthermore, patients report that symptoms are often poorly controlled and increase in severity over time. Patients consistently reported that many of their symptoms are bothersome and often poorly controlled (Amro et al., 2014; Cervantes et al., 2018; Flythe et al., 2018). In fact, at end-of-life, ESKD patients' symptoms are comparable to those of people dying from cancer (Wachterman et al., 2017). Correlation with quality-of-life measures indicates that poorly controlled symptoms degrade patients' overall quality of life (Amro et al., 2014; Song, 2016; Song et al., 2018).

### ***Non-Physical Aspects***

Not only are ACDK patients subject to high levels of physical symptoms, but they also experience debilitating levels of non-physical symptoms, both psychologically and in other domains, including such detriments as diminished social standing, economic insecurity, need for increased support from others, and other significant adjustments (Brown et al., 2012).

### **Psychological Symptoms**

Psychological symptoms are highly prevalent. Studies have repeatedly found higher rates of depression and anxiety among ESKD patients compared to the general population (Hackett & Jardine, 2017; Yoong et al., 2017). Sleep-related problems, either excessive drowsiness or disrupted sleep, are also commonly reported (Cervantes et al., 2018; Murtagh et al., 2007). Other reported psychological symptoms include changes in concentration and increased sadness or irritability (Almutary et al., 2016; Murtagh et al., 2007).

Many of the physical symptoms that patients experience are related to the sequelae of their underlying disease or their respective therapies. At the same time, the etiology for increased rates of depression and anxiety in ACKD remains uncertain but is likely multifactorial, encompassing physiological, emotional, and social processes (Hackett & Jardine, 2017).

### **Spirituality**

Spiritual well-being is an essential aspect of PC and has also been studied in ACKD. Spirituality has been described as “a personal search for meaning and purpose in life that may or may not encompass religion” (Reig-Ferrer et al., 2012, p. 731). Importantly spirituality has been shown to have implications for ACKD patients’ perception of their health, well-being, and quality of life (Reig-Ferrer et al., 2012). The impact of living with ACKD on spiritual wellness is variable, with some studies reporting low levels while others demonstrated improvement over time (Elliott et al., 2012; Reig-Ferrer et al., 2012; Song et al., 2018). Studies of nephrology clinicians have demonstrated that, while many are open to the idea of providing spiritual care or support, they lack

adequate training to confidently address this patient concern (Egan et al., 2014; Egan et al., 2015).

### **Social Conditions**

Beyond physical and non-physical symptoms, people living with ACKD experience numerous psychosocial challenges related to their illness, including obtaining regular transportation to treatment sessions, mobility issues, housing stability, and coping with the time burden of attending regular dialysis sessions, among others (Chan et al., 2016; Cormier et al., 2012; Davison & Jhangri, 2013; White & McDonnell, 2014).

Evidence suggests that factors such as food insecurity, socioeconomic status (SES), and insurance coverage impact the risk of developing ACKD and CKD outcomes (Banerjee et al., 2017; Nicholas et al., 2015). In one study of patients with ESKD in the United States, 29% reported not taking their medications as prescribed due to the cost of prescriptions (Hirth et al., 2008). Many patients report difficulty maintaining employment during treatment which may, in turn, lead to loss of income and health insurance (Roberti et al., 2018). Numerous studies have consistently demonstrated relationships between lower SES and poorer clinical outcomes (Dodd et al., 2018).

Discrimination based on race or ethnicity is an important psychosocial stressor for many patients (Brondolo et al., 2010). Racial and ethnic disparities are well documented among patients with CKD and those receiving PC across multiple outcomes (Arenella, 2016; Chuang et al., 2017; Crews et al., 2014; Desai et al., 2019; Gramling et al., 2019; Nicholas et al., 2013; Worster et al., 2018). Migrants living with ACKD who do not have legal residency status may be excluded from or unable to attain insurance coverage,



which adds another significant barrier to accessing clinical care (Cervantes et al., 2018; Cervantes, Fischer, et al., 2017; Chernin et al., 2012; Hacker et al., 2015).

Older people living with ACKD represent another population facing unique challenges. Aging is a complex process created through the interplay of physical, spiritual, social, and psychological processes, creating a highly individualized experience (Whitbourne & Whitbourne, 2017). Older adults are more likely to be frail or have lower functional status than people with ACKD (Berger et al., 2016). These factors may impact their treatment decisions and also increase the risk of poorer outcomes related to their disease. In one United States study, 18.7% of people starting dialysis did not have good functional status at baseline and over a year afterwards. This finding predicted one-year mortality (Shah et al., 2018). Older adults sometimes face unique challenges in reaching alignment between their own treatment goals and those of their families or clinicians who may offer recommendations that conflict with their own goals (Tong et al., 2014; Winterbottom et al., 2016).

### **Caregiver Experience**

Shockingly, caregivers of people living with ACKD frequently experience symptoms comparable to those experienced by the people they care for. Informal caregivers are a crucial source of support for many people with chronic diseases (Nakken et al., 2015), which is also true in ACKD (Pereira et al., 2017). This role places significant demands on caregivers who have the potential to impact them physically, psychologically, and socially (Pereira et al., 2017). These challenges are highly individualized and may fluctuate throughout the care recipient's illness (Nakken et al., 2015).

### *Physical Symptoms*

Compared to studies regarding patient symptoms, significantly less evidence exists regarding the impact of caregiving in ACKD on physical symptoms or health. Caregivers, like ACKD patients, may experience profound fatigue and report limiting their day-to-day activities due to the demands of their caregiving role (Pereira et al., 2017). Caregivers' level of caring burden impacts their perceived physical well-being. Studies have demonstrated inverse relationships between a higher level of caregiver burden and a lower level of self-assessed health (Affinito & Louie, 2018).

### *Non-Physical Symptoms*

Caregivers' levels of depression and anxiety are similar to those of the ACKD patients they support (Pereira et al., 2017). Many caregivers also report levels of sleep disruption comparable to those of ACKD patients. One study found that 88% of caregiver respondents had a poor sleep experience (Avşar et al., 2015). Caregivers may feel that their caregiver role becomes all-consuming or supplants most of their other life roles (Ebadi et al., 2018). The caregiving experience may create a sense of distress and sometimes contribute to social isolation (Hoang et al., 2018; Walker et al., 2015). Caregivers often perceive a lack of adequate social support (Pereira et al., 2017), as well as experience significant stress related to navigating the health system and coping with the uncertain trajectory of ACKD (Oyegbile & Brysiewicz, 2017). Caregivers experience sequelae related to their care recipient's chosen kidney management modality, including coping with unexpected complications, challenges in arranging for routine travel, and evolution in interpersonal relationships (De Rosenroll et al., 2013). One study found that caregivers of patients treated with transplants had lower caregiver burdens than those

caring for patients treated with hemodialysis (Avşar et al., 2015). Living with ACKD may also cause or increase stress within interpersonal relationships, which can impact both parties' well-being (Cukor et al., 2007).

Caregivers are also often subject to the same or similar socioeconomic stressors that impact patients, such as loss of income due to treatment burden, which can result in loss of health insurance or low-quality health insurance (Mashayekhi et al., 2015; Roberti et al., 2018). The cumulative impact of these factors has been described as caregiver burden, and elevated levels of caregiver burden have been shown to correlate with lower caregiver quality of life (Celik et al., 2012; Farzi et al., 2019; Kang et al., 2019).

### **Quality of Life in ACKD**

Quality of life is a patient-reported outcome that is influenced by the impact of multiple domains of well-being (physical well-being, non-physical well-being, functional capacity) ("Quality of life," n.d.). The interplay of the physical, psychological, spiritual, and social elements outlined above creates a person's perception of their QOL. A person's capacity to be active, perform daily-life activities, and fulfill roles that are important to them in society or within interpersonal relationships are all critical elements in shaping their QOL (Boudreau & Dubé, 2014).

### ***Patient Quality of Life***

There has been a longstanding acknowledgment of the importance of addressing quality of life for those living with ACKD; however, there is no consensus regarding how to achieve this most effectively (Kavalieratos et al., 2016; Moss & Davison, 2015). Research examining the quality of life for ACKD patients shows that many respondents experience low levels of quality of life (Amro et al., 2014; Bele et al., 2012; Lowney et

al., 2015). A wide range of factors influences the quality of life for patients. Symptoms play an important role, with elevated symptoms generally related to lower quality of life (Amro et al., 2014; Lowney et al., 2015; Schick-Makaroff et al., 2018). Patients' coping strategies (spirituality, resignation, distraction) also seem to influence their quality of life, but a lack of outcome consistency prevents recommending particular approaches (Davison & Jhangri, 2013; Schick-Makaroff et al., 2018). An individual patient's health beliefs may also impact their quality of life. For example, an internal locus of control was associated with a higher QOL in a sample of ESKD patients (Paraskevi, 2011).

While ACKD patients experienced overall low QOL levels, there is some evidence of age stratified variability. A systematic review in a limited number of studies, specifically focused on quality of life in older adults with ESKD, found that this potentially vulnerable group often had an equal or better overall and mental quality of life compared to younger ESKD patients (Balogun et al., 2017). Another review comparing the experience of patients on dialysis with those receiving conservative management found comparable QOL, again in a limited sample of studies, none of which reported on United States based samples (Song, 2016).

### ***Caregiver Quality of Life***

There has been less examination of the QOL experience of caregivers caring for those with ACKD. A longitudinal study of caregivers of patients treated with peritoneal dialysis found increasing levels of caregiver burden with an associated decline in quality of life over a one-year follow-up period (Kang et al., 2019). In another cross-sectional study, 62% of caregivers had low physical quality of life scores, while 70.4% scored low on the mental quality of life assessment (Celik et al., 2012). A recent systematic review

and meta-analysis did not identify consistently effective interventions to improve caregiver quality of life measures (Kavalieratos et al., 2016).

### **Patient-Centered Care**

The importance of patient-centered care to the attainment of high-quality healthcare is broadly recognized, generally within healthcare and specifically in ACKD (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001; O'Hare et al., 2014). Patient-centered care aims to shape medical care in ways that are adapted to align with the particular goals and circumstances of a specific patient (Barry & Edgman-Levitan, 2012; Constand et al., 2014). The primary means of achieving patient-centered care is through the substantive engagement of patients in shaping decisions regarding their care (Constand et al., 2014).

Shared decision-making (SDM) is a crucial component of patient-centered care that portends significant relevance to the care of patients with ACKD. The National Academy of Medicine's *Crossing the Quality Chasm* report highlighted strengthening the capacity for shared decision-making to enhance health care quality (Institute of Medicine (US) Committee on Quality of Health Care in America, 2001). Shared decision-making involves engaging patients in their clinical care by eliciting and prioritizing their preferences and values regarding treatment options (Charles et al., 1999; Frosch & Kaplan, 1999). This process can occur in various ways depending on contextual, patient, and clinician factors (Kashaf et al., 2017). Decision-making is a prominent component of patient-centered care for those living with ACKD (Ladin et al., 2018; Reid et al., 2016; Tong et al., 2014). While SDM has been recognized as a vital area of focus in ACKD

care, success in incorporating SDM into routine care, however, has been variable at best (Davis & Davison, 2017; Eneanya et al., 2015; Ladin et al., 2017).

Patients and caregivers face numerous decisions such as whether to pursue conservative or kidney replacement therapy, what type of dialysis to choose (in-center versus home, hemodialysis versus peritoneal dialysis), and choices about advanced care planning (assigning power of attorney, choosing to complete do not resuscitate [DNR] or physician orders for life-sustaining treatment [POLST], as well as choices about discontinuing dialysis) (Davis & Davison, 2017; Hickman et al., 2017; Ladin et al., 2017; Lim et al., 2016; Schmidt et al., 2015). These choices feature prominently in the work of living with or caring for someone experiencing ACKD and often represent fundamental interactions between patients and clinicians. Decisions about whether to pursue conservative management or kidney replacement therapy and advanced care planning are illustrative of the range of factors involved in making decisions for the ACKD patient population.

### **Decision-Making Regarding Treatment Modality**

There is evidence that patients with multiple disease processes aged 75 or older may not experience longer life or better quality of life with dialysis than without (Brown et al., 2015; Moss, 2017). Nevertheless, many clinicians and patients have the impression that not starting dialysis means by necessity impending death for the patient, thereby complicating the decision-making process. Worsening CKD symptoms can be a reason to start dialysis. However, dialysis may be associated with new symptoms that are difficult to anticipate prospectively (Almutary et al., 2016). Socioeconomic burdens and concerns about cost and insurance often impact patients and caregivers' treatment decisions and

access to care, but clinicians often have limited knowledge regarding these issues (Morton et al., 2016; Thompson et al., 2008; Walker et al., 2016). These variables can create significant challenges in achieving optimal decision-making at the patient, clinician, healthcare system, and societal levels.

### *Patient and Caregiver Factors*

Knowledge about CKD patient and caregiver experiences and perceptions regarding the treatment modality decision-making process consists mainly of qualitative studies and survey data. An older systematic review of studies regarding patient decision-making in CKD concluded that, in general, these decisions were challenging for patients, often representing a source of internal distress. Little evidence was available regarding interventions to improve the quality of decisions (Murray et al., 2009). Four factors identified by patients within the aggregated studies as necessary to their decisions were: relationships with others, protecting their status quo/well-being, maintaining control of their lives, and examining the tradeoffs of their decisions (Murray et al., 2009). The theme of maintenance of QOL and well-being was also cited by Australian participants who reported a desire to maintain a sense of routine and normalcy as they transitioned to conservative management (Hoffman et al., 2017). The impact of interpersonal relationships was cited repeatedly in qualitative studies. Many patients found it challenging to balance their preferences regarding treatment decisions with those of their family or informal caregivers. Patients often reported discordance between their desires and those of their supporters, with patients typically preferring conservative treatment and caregivers (often family members) preferring active treatment (Ladin et al., 2017; Sellars et al., 2018).

Another key interpersonal interaction that impacted patients' decision-making was their relationship with their clinicians, especially their nephrologists. Many descriptions of these interactions were fraught. Some patients reported a desire to be a 'good patient' as an essential aspect of this relationship (Ladin et al., 2017). There was a consistent desire to receive clear communication regarding their prognosis and treatment options (Gilman et al., 2017; Hoffman et al., 2017; Ladin et al., 2017). However, even when patients received a significant amount of information, they could not always translate this information into a meaningful understanding of the implications of each of their possible choices (Winterbottom et al., 2014).

Despite the consistent emphasis they placed on autonomy and informed decision-making, many patients reported a sense of receiving relatively little information to inform their decision about selecting between kidney replacement therapies. Patients often perceived that they had no choice regarding starting dialysis since the alternative was a rapid death (Ladin et al., 2017; Song et al., 2013; Winterbottom et al., 2014). Many patients, almost 70% in one study, reported no discussion regarding the potential hazards and complications of kidney replacement therapy, perhaps aligned with the perception that there was no choice to be made (Song et al., 2013). Nearly one-third of some patients in that same study believed that their doctor had decided to begin dialysis for them (Song et al., 2013). In another study, participants reported the experience of struggling to maintain a sense of autonomy (Sellars et al., 2018). Others described having their preferences dismissed or overridden by family members or clinicians (Ladin et al., 2017; Sellars et al., 2018). Participants in another study reported that the choice to begin



dialysis represented a form of loss that they perceived as undermining their self-efficacy (Lovell et al., 2017).

Interestingly, despite experiences that seemed to suggest significant variability in the quality of their decision-making experiences, patients reported that they were generally content with their treatment choices. In one survey, 58% reported their QOL as good or better (Gilman et al., 2017). In the same study, only seven percent of respondents expressed remorse regarding their decision to start dialysis to manage their ACKD (Gilman et al., 2017).

Caregivers reported experiencing difficulty in transitioning to their new caring role (Hoffman et al., 2017). In one caregiver-focused study, participants framed their caregiving work as patient- and health system-directed. In their patient-directed work, they encouraged and supported their patient in various ways (De Rosenroll et al., 2013). Caregiving work oriented toward the healthcare system involved serving as a conduit to represent the interests and perspectives of their patient to healthcare professionals (De Rosenroll et al., 2013).

### ***Clinician Factors***

A mix of factors can impact clinicians' ability to communicate effectively with patients regarding treatment decisions. For example, while patients with ACKD are often intensely interested in their prognosis, nephrologists report that prognostication is challenging and consequently often avoid discussing a given patient's likely trajectory (Schell et al., 2012). Variability in experience and training can impact the discussion of treatment options. For example, some clinicians may have limited training or exposure to conservative care, making it more difficult to effectively discuss this option with their

patients (Tonkin-Crine et al., 2015). One study found that a cohort of patients who had opted for conservative management essentially felt that they had made their choice in defiance of their nephrologists rather than with their support (Seah et al., 2015). Ethical concerns about withdrawing life-sustaining treatment may impact some clinicians' treatment decisions. In conventional nephrology care systems, there may not be a venue to effectively resolve conflicts about treatment decisions, either those between clinicians and patients or amongst clinicians, which is likely to result in degraded decision quality (Bublitz et al., 2017). In a Brazilian study that sampled nephrologists, over 40% of respondents would not want to discontinue dialysis, were it requested by a competent patient (Tavares et al., 2018).

### ***Health System Factors***

There is significant variation in treatment decisions made between various national health systems, as well as internationally. Older adults in some regions of the United States (regions with greater concentrations of medical specialists and acute care hospital beds, metropolitan zip codes, and higher proportions of impoverished people) are much more likely to dialyze or receive other aggressive care at the end of life than in other regions (O'Hare et al., 2010). An extensive secondary data analysis demonstrated that patients outside the Department of Veterans Affairs (VA) tended to be started on dialysis sooner in their disease process than those in the VA system (Yu et al., 2015). In this study, practice differences were most evident for two patients with the lowest life expectancy and the oldest age (Yu et al., 2015). Another example of system-level variation is the variation in patient reports of having received information regarding conservative management as an option for managing their ACKD. In one survey, only

35% of patients reported discussing conservative treatment (Gilman et al., 2017). Another study, which examined patient experiences across multiple nephrology departments in the United Kingdom, found significant variability between departments in terms of discussion of conservative management, with those programs with established conservative management pathways providing the most detailed information to patients (Tonkin-Crine et al., 2015).

A study conducted with United States nephrologists found that some believed that health policy factors, such as perceived differentials in reimbursement for advanced care planning versus traditional clinical care, contributed to a lack of discussion of conservative care with patients (Grubbs, O’Riordan, et al., 2017). This practice variation often suggests inadequate evidence to guide treatment decisions or the impact of incentives or pressures unrelated to clinical decision-making.

### ***Societal Factors***

Examining choices about kidney replacement therapy for older adults demonstrates significant variability in choices. In the United States, most patients with CKD5 will undergo dialysis, with some estimates showing that even among those over age 85, more than 50% would be dialyzed (Wong et al., 2016). The number of adults initiating dialysis stabilized in the early 2000s, and the overall incidence of CKD5 does not appear to be rising in the United States (Burrows et al., 2017; Rosansky & Clark, 2013). However, the number of older adults commencing dialysis is higher relative to members of other age groups, consistent with the higher prevalence of CKD among older individuals (Rosansky et al., 2017). Similarly, rates of kidney transplantation are

increasing among older adults as well, without an associated decline in post-surgical outcomes for patients (McAdams-DeMarco et al., 2014).

In Europe, and particularly in the UK, conservative treatment plays an increasing but still evolving role for a subset of patients who are unlikely to benefit from kidney replacement therapy in terms of mortality or QOL (Roderick et al., 2015). In the United States, conservative treatment tends to be more of a consideration for patients perceived to be otherwise approaching death and is overall less accessible compared to Europe (Kurella Tamura et al., 2018). There is evidence, however, that those patients who opted not to undergo dialysis were more likely to receive less aggressive treatment and have fewer hospitalizations than those undergoing dialysis in the weeks and months prior to their death (Wong et al., 2014).

### **Decision-Making Regarding Advanced Care Planning**

Another critical aspect of decision-making for patients with ACKD is planning for end-of-life care. Advanced care planning (ACP) is an umbrella term that encompasses discussing and documenting patients' desires and goals for their medical care at the end of life (Brinkman-Stoppelenburg et al., 2014). The product of ACP can vary depending on the patient and their context. Examples of ACP output can include Do-Not-Resuscitate (DNR) orders, written advanced directives, and Physician Orders for Life-Sustaining Treatment (POLST) forms (Brinkman-Stoppelenburg et al., 2014; MacKenzie et al., 2017). These documents are intended to produce a description of patient desires regarding the use of end-of-life interventions, such as the use of cardiopulmonary resuscitation, mechanical ventilation, and the designation of alternate decision makers. Alternatively, patients can specify these choices (Lim et al., 2016). While ACP may

result in a formal document, the ultimate objective of ACP should not be to formalize a document but rather to ensure congruence in understanding a particular patient's goals between the patient, their informal caregivers, and their treatment team in understanding that particular patient's end-of-life goals.

Given the high morbidity and mortality of ESKD, these issues are highly relevant to this population. Compared to peers with cancer, patients with ESKD were less likely to have completed ACP by the end of their lives and were more likely to receive high-intensity interventions immediately before their death (Wachterman et al., 2017). Significant regional variation in the intensity of care suggests that this intensity is influenced by factors beyond medical necessity, which means shared decision-making, including ACP, becomes even more critical (Nicholas et al., 2011; O'Hare et al., 2010).

Patients and caregivers report interest in conducting ACP discussions with their providers (Goff et al., 2015; Holley & Davison, 2015). However, patients and caregivers perceive that these discussions happen with less frequency and clarity from medical providers regarding patients' clinical condition than patients desire (Bristowe et al., 2015; Goff et al., 2015; Lim et al., 2016; Sellars et al., 2018). Patients and caregivers frequently find that they have conflicting opinions regarding what goals of care are appropriate, which can further complicate the ACP process (Luckett et al., 2014). ACP can also be personally challenging for patients as they attempt to clarify their values and face mortality (Sellars et al., 2018).

Health care providers concur with patients' and caregivers' perceptions that ACP is often not optimally implemented (Luckett et al., 2017). Some clinicians report avoiding ACP due to a perceived lack of time and uncertainty regarding patients' receptivity to

ACP discussions (Yee et al., 2011). Other barriers include the complexity of patients' clinical situations, care fragmentation when distributed among several specialties, and uncertainty about which health care team member is responsible for facilitating ACP (Luckett et al., 2017; O'Hare et al., 2016).

This examination of the role of patient-centered care in treating those living with ACKD illustrates that implementing patient-centered care is critical and incomplete. Improved processes to help patients and caregivers better understand their treatment options and engage in meaningful dialogue with their clinicians need to be refined and utilized. A vital aspect of this process will be to understand further patients' and caregivers' perspectives and priorities in all aspects of ACKD management.

### **Palliative Care**

Palliative care (PC) which emphasizes the assessment and management of symptoms, communication with patients and their families regarding prognosis, decisions regarding treatment and to help clarify their goals in managing their illness, and support with non-physical aspects of illness including emotional, spiritual, and social impacts (Ghosh et al., 2015). The purpose of PC is to reduce the burdens (physical, emotional, spiritual, and social) experienced by patients and families undergoing life-limiting illnesses (WHO, 2018).

From its origins in the UK in the 1960s, PC has become increasingly important in the care of patients with complex or advanced illnesses in light of the increasing expansion of services, from academic medical centers into many community settings (Kavalieratos et al., 2016; Penrod et al., 2006). PC typically involves an interdisciplinary approach to care and can be employed during curative therapy at any point in the

patient's life course or comfort-oriented care at the end of life (Dahlin et al., 2016).

Palliative care may be delivered by a specialist specifically consulted for PC services or by a generalist or sub-specialist clinicians (Hobson et al., 2011; Pask et al., 2018; Wee, 2013). Due to the complex and multifaceted manner in which CKD5/ESKD impacts patients and their caregivers, PC's multidisciplinary and comprehensive approach has much to offer (Kelley & Morrison, 2015; Wee, 2013).

### ***PC and Patient Outcomes***

PC involvement has been demonstrated to improve patient outcomes for patients with severe, complex illnesses of various types in terms of quality of life, symptom control, family satisfaction with care, and cost (Kavalieratos et al., 2016; Moens et al., 2014; Zimmermann et al., 2008). Researchers have reported that CKD5/ESKD patients share similar PC and responses to PC consultation to those experienced by patients with advanced cancer, progressive neurological disease, and other forms of similar serious illness (Grubbs, Tuot, et al., 2017; Moens et al., 2014). There is ample evidence that PC improves patient outcomes across multiple conditions (Grubbs, O'Riordan, et al., 2017). For example, one observational study assessed ESKD patients' symptoms before and after inpatient PC consultation and reported reductions in nausea and anxiety (Grubbs, O'Riordan, et al., 2017). Other work with ESKD patients has shown that receiving PC services led to improved outcomes in terms of symptom control and clarity regarding goals of care (Kurella Tamura & Cohen, 2010; Moss & Armistead, 2013; Rak et al., 2017). Patients receiving conservative care have also benefitted from PC services, with evidence supporting improved symptoms management for this cohort (Douglas et al., 2010)

### ***Barriers to PC Uptake in ACKD***

Experts in PC and CKD have advocated for increasing the availability of PC for CKD5/ESKD patients based on the available evidence (Fung et al., 2016; Grubbs, Tuot, et al., 2017; Kurella Tamura et al., 2018; O'Hare et al., 2017). Despite the evidence of improved outcomes for patients receiving PC and expert recommendation to increase the availability of PC services, the uptake of PC for patients living with ESKD has been slow and many patients have limited or no access to or familiarity with PC services (Desai et al., 2019; Kalbfleisch et al., 2015; Kimmel et al., 2013; Norris et al., 2017). People living with ACKD often have frequent contact with healthcare clinicians but have lower quality end-of-life care compared to persons with cancer or dementia, a contrast which appears to be at least partially due to lower levels of PC consultation and advanced care planning among people with ESKD (Wachterman et al., 2016). Few patients with CKD5/ESKD receive PC consultation as part of their treatment plan (Chen et al., 2018; Glare, 2013; Hobson et al., 2011). Compared with cancer patients, people with ESKD tend to be referred to PC later in the course of their illness, during an acute exacerbation of the disease, and with lower functional status (Bostwick et al., 2017). Palliative care's delayed or limited involvement in ACKD management can be examined at the patient/caregiver, clinician, and healthcare system levels.

### ***Patient and Caregiver Factors***

Both patients and caregivers may have an incorrect or incomplete understanding of PC, equating PC with the end-of-life stage or discontinuation of dialysis rather than a component of comprehensive ongoing care (Maddalena et al., 2017). Patient and caregiver personal characteristics (including personality, life experience, coping



strategies, communication patterns) may all interact to either promote or impede PC engagement (Pask et al., 2018). Patients may adopt a future-oriented outlook and avoid reflecting on their current health status, resulting in deferred engagement with PC (Schell et al., 2012). Conflict or communication between patients/caregivers and health care team members may impair PC uptake (Pask et al., 2018).

### ***Clinician Factors***

The most prominent factor impeding PC implementation at a clinician level seems to be a self-perceived lack of education regarding PC practices. Despite recognizing patients' needs, few kidney care providers report having the necessary resources to provide appropriate PC to their patients (Culp et al., 2016). This theme is present across studies in various nations with widely different health care systems (Grubbs, Tuot, et al., 2017; O'Riordan et al., 2019; Pommer et al., 2019). Surveys of nephrology fellows in the United States have found that many felt the need for increased PC exposure during their training (Combs et al., 2015; Shah et al., 2014). Similarly, a sample of Canadian primary care physicians identified a lack of training and access to resources as barriers to implementing conservative management strategies for ACKD patients in their practices (Tam-Tham et al., 2016).

Multiple studies demonstrated an implicit perception among many clinicians that involving PC was the equivalent of withdrawing care or at least opting for conservative management (Bull et al., 2014; Ladin et al., 2018; van Biesen et al., 2015). Consistent with this perspective, some clinicians perceived starting PC discussions as potentially undermining patients' hope for the future (Fung et al., 2016; Ladin et al., 2018). A related

concern cited across multiple studies was a fear that patients might be angered or alarmed by discussions regarding prognosis (Ladin et al., 2018; Schell et al., 2012).

### ***Health System Factors***

A qualitative study involving United States and United Kingdom nephrologists highlighted the influence of health system factors. Physicians in the United States described a lack of access to well-developed outpatient PC resources and financial incentives to provide dialysis to patients. In contrast, U.K. physicians described a contrasting set of systemic factors in which they have no financial incentive to offer one management strategy over another and have access to a robust conservative management resource (Grubbs, Tuot, et al., 2017). Organizational decisions, such as utilizing higher ratios of patients to nurses, often to reduce costs, may degrade opportunities for end-of-life or PC discussions (Moran, 2018).

Burnout, characterized by emotional exhaustion, depersonalization, and diminished personal accomplishment, has received increasing recognition as a problem experienced by many nephrology nurses and physicians (Pawlowicz & Nowicki, 2019; Topbaş et al., 2019). While individual clinicians' manifest burnout, many of the factors shown to contribute to higher rates of burnout, such as low job satisfaction, a sense of inadequate role preparation, and excessive workload are significantly influenced by structural decisions made by healthcare system leaders (Karakoc et al., 2016; Pawlowicz & Nowicki, 2019). Burnout may degrade patient interactions and impede PC or end-of-life discussions (Moran, 2018; Pawlowicz & Nowicki, 2019).

## Summary

Most research to date on PC in CKD5/ESKD has been focused on physical symptoms and advanced care planning, often from the perspective of patients and nephrologists, with little attention to the experiences of patients' family members (Cervantes, Jones, et al., 2017; Grubbs, Tuot, et al., 2017; Morton et al., 2016; Yong et al., 2009). Even studies incorporating caregiver perspectives tended to focus on physical and psychological symptoms. Despite evidence that socioeconomic factors such as insurance status, income, and access to care impact outcomes for patients with kidney disease, research on PC needs in ACKD have given less attention to the broader challenges experienced by patients and their families, such as financial or logistical burdens, which might be amenable to intervention through nephrology or PC-based case management (Hall, 2018; Karamanidou et al., 2014; Morton et al., 2010; Musso et al., 2015; Tong et al., 2014). Based on reviews of the currently available evidence, recommendations have been made to focus future research efforts on eliciting the most significant concerns of patients and their caregivers (Kane et al., 2013; O'Hare et al., 2017).

In summary, the four fundamental concepts for this study were ACKD, PC, quality of life, and patient-centered care. Advanced CKD is an important and relatively common disease that profoundly impacts patients and their caregivers physically, psychologically, socially, and spiritually. Palliative care takes a multi-dimensional approach to care that incorporates attention to all of these aspects and thus has significant potential for improving the QOL for patients and caregivers. Palliative care also has the potential to enhance patient-centered care, especially by amplifying shared decision-

making among patients, caregivers, and clinicians throughout the trajectory of ACKD. This literature review highlighted the importance of understanding the perspectives of people living with ACKD and their caregivers and the limitations of what is currently understood. Clarifying and advancing this understanding is critical for making care more patient-centered and improving outcomes for ACKD patients.

## **Chapter 3: Methods and Procedures**

### **Study Design**

The study employed a qualitative descriptive research design. The study's specific aims were to describe the primary concerns of patients with ACKD, and their caregivers related to ACKD care, to describe patient and caregiver experiences with PC, and their perceptions regarding if and how PC services could contribute to their disease management and wellbeing. Qualitative description is an appropriate method to gain a granular and multi-dimensional description of the experiences and perspectives of individuals living with a particular condition (Marshall & Rossman, 2006; Miles et al., 2014; Sandelowski, 2000). Qualitative description involves explaining a particular set of events closely connected to the data without resorting to higher-level abstraction, as might be found in other qualitative approaches (Sandelowski, 2000).

### **Setting**

Patients were recruited from University of Virginia Health System dialysis centers. The University of Virginia Health System is located in central Virginia with 11 dialysis clinics located within 90 miles of the primary health system campus. Access to the dialysis clinics was facilitated by committee member Dr. Emaad Abdel-Rahman, who, as a member of the Division of Nephrology and as the medical director of the dialysis center provided introductions to key staff members. Access to the dialysis clinics was also advanced by committee co-chair Dr. Maureen Metzger, who had conducted previous studies in the same centers and guided patient recruitment and coordination with dialysis center staff.

The University of Virginia Health System Division of Nephrology annually sees approximately 2,000 outpatients with CKD, including those receiving conservative management for CKD5. Of these patients, 975 people receive dialysis. Among this group, adult patients ranged in age from 19 to 95 years-old, with a median age of 63.7. In terms of race, 50.8% of dialysis patients were described as Black, 39.7% as White, 0.7% as Asian, 3.7% as Native American, and the remainder as “other”/unavailable. Female patients comprised 42% of dialysis patients, males made up 52.6%, and the remainder were listed as “sex” or “gender,” presumably due to categorization error or non-response (Abdel-Rahman, 2018).

### **Sampling Plan**

This study was initiated with a plan to employ maximum variation sampling. Ample evidence demonstrates variable outcomes for patients with ACKD is related to age, race/ethnicity, and management strategy differences. Similar patterns are evident in PC as well. In order to account for variable experiences related to individual identities or clinical characteristics, the study employed maximum variation sampling. Maximum variation is a sampling strategy in which pre-determined characteristics are identified as likely to differentiate participants’ experiences. Based on a review of the literature, critical criteria include CKD5/ESKD management strategies (dialysis and conservative management), age, gender, rural/urban residence, and race (Banerjee et al., 2017; Cervantes, Jones, et al., 2017; Kalbfleisch et al., 2015; Kamal et al., 2017; Kimmel et al., 2013; National Hospice and Palliative Care Organization, 2018; Norris et al., 2017). Subsequently, participants were selected for maximal variation based on these criteria (Creswell & Poth, 2018).

The study focused on adult patients and caregivers because of the significant differences between pediatric and adult concerns and experiences. In order to maximize participation, individuals were not excluded if the other member of their dyad did not participate. For this study, a caregiver denotes any individual playing a significant role in helping them manage their CKD5/ESKD. This included family members, friends, or other non-professional caregivers who provide support to the patient. This caregiver definition was intentionally broad to provide as complete as possible range of experiences for analysis.

### ***Inclusion and Exclusion Criteria***

Study participants included adults over 18 who had been diagnosed with CKD5/ESKD and their caregivers were aged 18 or older. Inclusion criteria for patients included:

1. Adult over age 18.
2. Diagnosis of CKD5/ESKD.
3. Ability to participate in the interview in English.

Inclusion criteria for caregivers included:

1. Adult over age 18.
2. Self-identify or identified by the patient as a caregiver for a patient with a diagnosis of CKD5/ESKD
3. Ability to participate in the interview in English.

Participants were not excluded if they did not have a caregiver, or if their caregiver did not participate. Caregivers or patients diagnosed with moderate to severe dementia or other cognitive disorders that preclude effective participation would have

been excluded from participation. However, no patients or caregivers were excluded for not meeting this or any other inclusion criteria.

### ***Recruitment***

The study was reviewed and approved by the University of Virginia Institutional Review Board for Health Sciences Research (see Appendix F). Site approval was also obtained from the University of Virginia Health System (see Appendix A). The study was introduced to key staff members at multiple UVA dialysis sites either in-person or via email by me. I incorporated study flyers as a tool to help communicate the pertinent information (see Appendix C).

Recruitment activities for the study were undertaken between March 2020 and August 2022. Based on experience gained during a pilot study, recruitment was conducted by multiple methods, including the distribution of recruitment posters to dialysis clinics, distribution of study information to potentially eligible patients by clinical personnel, and distribution of study information to potentially eligible patients by study personnel at dialysis centers. In order to promote informed consent, all recruitment advertising materials provided a brief description of the study and the participant's role. Patient participants who completed an interview were asked whether they had a caregiver who would be interested in participating in the study. Potential participants who expressed interest in the study were screened for inclusion criteria and given an opportunity to ask questions about the study and the implications of their participation.

Those respondents who agreed to be interviewed were provided a written study consent form to review, sign, and return before scheduling their interview (see Appendix B). Signed consent forms were obtained prior to conducting interviews. During



recruitment, 51 potential participants expressed interest in the study and were given a consent form to review and return. Of those, 34 ultimately completed and returned a consent form. Ten individuals consented but were not interviewed, three did not respond to multiple inquiries about scheduling their interview, one was too busy to schedule when contacted, and the remaining individuals provided incomplete or inaccurate contact information (e.g., partial address or out-of-service phone number) that precluded follow-up. Demographic or clinical data was not obtained prior to patient interviews. Therefore, an analysis of differences between individuals who were not interested in participation, interested individuals who ultimately did not complete an interview, and eventual full-fledged participants in the study, is not possible. A total of 24 participants completed interviews, of which 22 were patients and two were caregiver participants.

As recruitment methods evolved, the physical organization of the dialysis units and the actual recruitment process made purposive sampling unachievable. Recruitment was conducted via speaking with potential participants passing through the dialysis unit lobby or through referrals of interested patients from unit staff members. Given this format, it proved impossible to screen potential target participants in a prospective manner. Instead, all interested persons were contacted and offered the opportunity to enroll in the study if they met the eligibility criteria.

Additionally, as recruitment continued, I made the decision, in consultation with the committee co-chairs, to limit recruitment to patients receiving in-center hemodialysis. This change was made for two reasons. First, it became clear that due to the smaller proportions of patients engaged in treatment modalities other than in-center hemodialysis, it would be difficult to appropriately sample people who were treated via other modalities

simply because fewer possible participants were available. Second, accessing patients for recruitment who were engaged in either conservative management or home modalities (peritoneal or hemodialysis) proved to be more logistically difficult due to the lower frequency of contact these patients had with dialysis centers or nephrology clinics, which limited opportunities for recruitment. Despite these limitations, the previously identified criteria were tracked, and the study sample appears proportionate to available data for UVA Health System ACKD patients.

### **Procedures**

Procedures were developed and implemented in order to minimize the burden of involvement for study participants while simultaneously obtaining adequate amounts of high-quality data. Steps were taken throughout the research process to protect participants' privacy and respect their autonomy regarding study involvement.

### ***Data Collection***

The primary data source for the study were semi-structured interviews conducted by me. Interviews were digitally recorded and transcribed verbatim. One of the 24 interviews was not recorded due to technical issues. The material from that interview was transcribed from memory immediately after the interview concluded. Interviews were conducted at a time convenient for participants. They ranged from approximately 20 minutes to 75 minutes, averaging about an hour, and were adjusted to participants' interests and needs. Initially, participants were offered a choice between being interviewed in person or by telephone. However, as the COVID-19 pandemic evolved, interviews were transitioned exclusively to telephone-based to reduce exposure risks for participants.

Interviews had a conversational style and proceeded from more general topics to more specific and emotional topics, in a laddered fashion, based on participants' feedback and participation (Price, 2002). Opening interview questions were framed to elicit participant concerns as broadly as possible with probes available to follow up, clarify, and elicit more profound responses. The interview guide for the study was developed to provide a framework to direct the interview in addressing the study questions. The researcher created the guide with input from content experts in nephrology and PC, as well as researchers with expertise in qualitative research methods.

The guide was piloted with the study's target population. Prior to initiating the current study a pilot study was conducted to elicit input from patient participants. During the pilot study, participant feedback regarding the experience of being interviewed using the guide and the question content was used to revise the interview questions and process. The interview guide was iteratively revised based on developing themes and aspects of research questions that were not adequately illuminated during early interviews.

Data collection and analysis were conducted contemporaneously, with analysis beginning from the completion of initial interviews and continuing until saturation was judged to have been achieved. Saturation is a concept developed initially within grounded theory research, which has been adopted by qualitative research broadly (Malterud et al., 2016). For this study, saturation was judged by determining that new findings were no longer arising from interviews, that appropriate negative cases were identified for analysis, and that ongoing coding was no longer providing additional insight regarding the study aims (Bradshaw et al., 2017; Morse et al., 2002). Memos were used to capture study processes and decision-making throughout the research process.

A medical record review was conducted in order to better contextualize participant experiences. A data collection form was developed to guide electronic medical record (EMR) data abstraction. Key data include patient comorbidities, the presence or absence of PC involvement, and nephrology or primary care notes regarding PC concerns (e.g. prognosis, decision-making, pain/symptom management, advanced care planning). No patient identifiers were abstracted to protect participants' privacy.

### ***Human Subject Protection***

Risks of participation in the study included participants experiencing fatigue or emotional distress from answering questions during the interview, and breach of confidentiality during the study process.

### ***Informed Consent***

The University of Virginia Institutional Review Board for Health Sciences Research (IRB-HSR) reviewed and approved the study protocol and consent process before recruitment. All recruitment materials emphasized that study participation was voluntary and would not impact participants' clinical care. Patients' clinicians were involved in recruitment, but in a passive manner by which they made potentially eligible patients aware of the study. I provided follow-up information without playing a clinical role. Similarly, I conducted the interviews while not being involved in participants' clinical care, and participants were reminded that they would remain anonymous to reduce any concerns regarding a need to alter their responses to avoid impacting their clinician relationships. All potential participants were allowed to review the written consent form with me and ask questions before deciding whether to participate.

### ***Protections Against Risk***

Participants were informed during the consent process and again at the start of the interview that if they became fatigued, distressed, or wanted to discontinue or suspend their interview at any point, they were free to do so. No participants opted to do so once the interview process began (one opted to reschedule for a more convenient time). No participants reported any physical or emotional distress at any point. The minimum necessary identifying data was collected, and all participant data were deidentified as soon as practicable during the study process to limit the risk of inadvertent disclosure. No known data leaks occurred during the study.

### ***Potential Benefits of the Proposed Research to the Subject or Others***

Several participants reflected at the end of their interview that they had appreciated the opportunity to reflect on their experiences living with ACKD. However, during the recruitment and informed consent processes, prospective participants were informed that they were not expected to derive a direct benefit from their participation.

### ***Data Management***

The audio recordings were transcribed verbatim by a university-approved transcription service or a research team member. Recordings were stored on a secure university-operated and maintained storage drive until transcription was completed. Following verbatim transcription, interview transcripts were reviewed for accuracy against the original recording and revised as necessary. Following verification, the audio files were deleted to protect patient anonymity. Transcripts were uploaded to Dedoose, a data management system for analysis (Dedoose, 2021). Any identifying content was redacted from the transcript.

## **Data Analysis**

Data analysis of both qualitative and quantitative data was conducted throughout the data collection process. Throughout the study results of preliminary analysis were used to inform ongoing data collection efforts.

### ***Qualitative Data Analysis***

Data analysis was conducted following data collection using qualitative content analysis to code data systematically and identify significant themes present within the data (Marshall & Rossman, 2006; Saldaña, 2016). Interviews were analyzed using qualitative content analysis to elucidate themes and patterns across and within interviews. This analysis involved an iterative process of repeatedly reviewing the interview data while recording thoughts and responses to the data and identifying areas that require further examination (Miles et al., 2014).

As data analysis was conducted, the data were examined for themes and commonalities within individual participant interviews and between participants. Each interview transcript was read in total. Following the initial reading, I examined the transcript line by line to code interview content. As data collection progressed, initial codes were revised, and previously coded transcripts were re-coded based on subsequent coding iterations. As codes were developed, they were aggregated into categories and subcategories.

As analysis progressed, key findings were used to create matrices to enhance analysis (Miles et al., 2014). Matrices were utilized to depict data and to examine patterns visually. Ultimately, this process permitted the promulgation of themes that, supported by specific statements from study participants, illustrate participants' answers to the

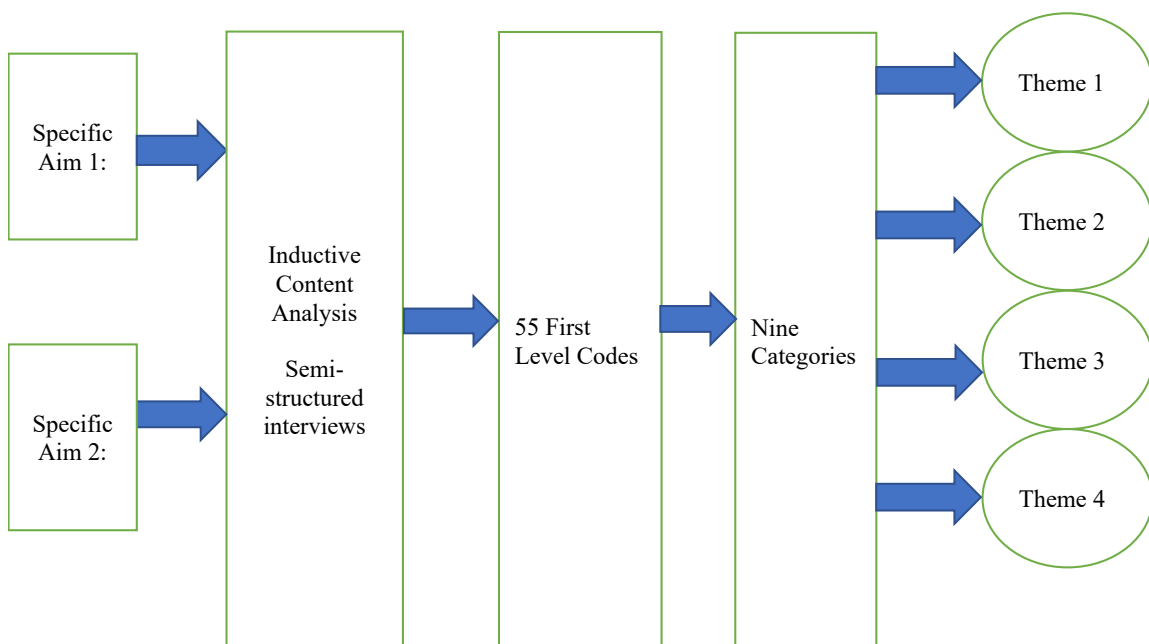
overarching research questions (Miles et al., 2014). Throughout the analysis, memo writing was used to document my perspectives and decisions regarding the analytical process (Lincoln & Guba, 1985).

### ***Maintenance of Rigor***

Qualitative research presents unique challenges in maintaining and assessing research rigor. The credibility, transferability, confirmability, and dependability framework were the basis for rigor in this study (Lincoln & Guba, 1985). In order to maximize credibility, clear delineation was maintained between the study researcher's role and clinicians who may refer patients to the study.

**Figure 3.1**

### *Analytic Trail*



Patients were assured at each step in their recruitment that their participation was voluntary and unrelated to their clinical care. Their anonymity was also emphasized to ascertain that participants understood I would not report their statements to their clinicians. I did not provide clinical commentary or input regarding participants' experiences and focused on the value and importance of hearing what participants had to say. Other strategies to enhance credibility included memo writing, purposive sampling, and continuing data collection until thematic saturation was achieved. Using matrices to visually link themes to underlying evidence enhanced credibility (and confirmability) (Averill, 2002). Finally, member checking was performed by presenting potential findings identified in early interviews to later interview participants to confirm or refute their credibility (Creswell & Poth, 2018).

Transferability was addressed by developing and reporting thorough descriptions of study participants and the study setting. Sampling based on key characteristics influencing the experience of living with CKD5/ESKD further contributed to transferability. Strategies to improve confirmability included the creation of an audit trail through memo writing to document researcher thought processes and decisions taken throughout the study process. Additionally, I regularly consulted with the committee co-chairs, and parallel coding was performed on an ongoing basis.

### ***Quantitative Data Analysis***

Participant data were abstracted from the University of Virginia Health System EMR and patients' self-reported demographic data and analyzed in Microsoft Excel to report descriptive statistics regarding relevant variables such as age, gender, race,



ethnicity, medical comorbidities, and whether or not the patient received formal PC services (Microsoft Corporation, 2022).

## **Chapter 4: Findings**

In this chapter, sample demographic and clinical characteristics are described. Four themes, three addressing Specific Aim 1 and one addressing Specific Aim 2 have been used to organize the study findings. For Specific Aim 1, these themes include: (1) ACKD impacts patients physically, emotionally, socially, and economically; (2) patients use various self-management strategies learned through trial and error from other patients and clinicians; and (3) decision-making is complex, often not explicit/elucidated, and ongoing throughout RRT. Specific Aim 2 was addressed by one theme: 1) Lack of familiarity with PC, perceived as unnecessary during illness stability, but potentially useful during exacerbations/periods of decline.

### **Sample size**

The final sample size was 24. The sample size includes two caregivers and 22 patient participants.

### **Patient Participants**

Table 4.1 shows that 22 patients were interviewed for the study. Patient participants' ages ranged from 34 to 82 years-old, with a median age of 54.5. The majority (64%) were female, Black (50%), living in a rural area (68%), with a range of dialysis treatment from three weeks to 27 years with a median of three years of treatment. Years of education completed ranged from seven to 18 years, with a median of 12 years.

**Table 4.1***Patient Participant Characteristics*

Variable		N (%)
Total number of participants		22
Age	Range	34–82 years
	Median	54.5 years
Sex	Female	15 (68%)
	Male	7 (32%)
Race	Black	11 (50%)
	White	10 (45%)
Residence	Rural	15 (68%)
	Suburban	4 (18%)
	Urban	3 (14%)
Education	Range	7–18 years
	Median	12 years
Dialysis experience	Range	0–27 years
	Median	3 years

**Caregiver Participants**

Two caregivers completed interviews. Both were women in their 50s: one White, one Asian American; one living in a suburban area and the other in a rural community; one completed 16 years of education, and the other completed 18 years of education. Caregiver recruitment was low compared to patient response, and I did not meet the initial goal of recruiting 20 caregiver participants. Out of a total of 22 patient interviews, four (18%) reported not having anyone who served as a caregiver; in three (14%) early interviews I forgot to ask for a caregiver nomination; seven (32%) patients provided caregiver nominations, but despite follow-up contacts these caregivers did not ultimately complete an interview; three (14%) patients reported that their caregivers were too busy to participate; three (14%) patients reported that their primary caregivers were uncomfortable being interviewed and could not identify an alternative caregiver to

participate; and two (9%) patients nominated their caregivers and interviews with them were completed. Additionally, two patients who expressed interest in participating in the study nominated caregivers, but the follow-up to consent/schedule both patients and caregivers was unsuccessful (see Table 4.2).

Seven patient participants provided caregiver nominations, but these caregivers did not ultimately complete an interview. This occurred in a range of ways. Two patients agreed to share information with caregivers who did not contact the study's investigator, and three patients agreed to check with caregivers or provide the study investigator's contact information to caregivers. However, I was not able to successfully contact the patient/caregiver to follow up. One caregiver requested a consent form but did not return it and neither responded to follow-up email/calls, and one caregiver requested a consent form, returned it but did not answer at the time of the scheduled interview or respond to follow-up calls.

In addition to nominations from patient participants, contacts were made with caregivers during recruitment visits to dialysis centers at Waynesboro, Orange, and Page. No potential caregivers were identified during visits at the Kidney Center, Zion Crossroads, or Culpeper sites. Caregivers were contacted about the study while they were at the site, and in case they were receptive to learning more about the study when given information. Several individuals agreed to take a flyer to review, but no one expressed interest in enrolling immediately. None of these contacts yielded any additional participants. The number of potential participants contacted in this manner was limited due to restrictions on site access implemented as part of the COVID-19 infection control efforts.

Recognizing low caregiver recruitment as an issue, I consulted with the committee co-chairs regarding caregiver recruitment throughout the recruitment process and incorporated their feedback into the recruitment process. As the study progressed, I performed a brief literature search for examples of caregiver recruitment in other studies focused on patients with ACKD and identified seven studies. I consulted with the committee co-chairs regarding caregiver recruitment specifically throughout the recruitment process and incorporated their feedback into the recruitment process. Two of these studies initially contacted patients and then asked them to nominate caregivers (Low et al., 2014; Sass et al., 2020); four recruited caregivers by contacting them directly, either with clinical staff or based on nominations by clinical staff (DePasquale et al., 2019; Hoffman et al., 2017; Noble et al., 2013; Sousa et al., 2022). One did not report their recruitment strategy (Gutman et al., 2022).

Three studies reported reasons that potential caregiver participants mentioned for declining to participate (DePasquale et al., 2019; Low et al., 2014; Sousa et al., 2022). Common reasons included inability to attend scheduled focus group meetings, being too busy, or being too distressed. Some patients declined to nominate caregivers, and in some cases no reason for non-participation was provided. Four studies did not report how many people were approached without consenting to participate (Low et al., 2014; Hoffman et al., 2017; Noble et al., 2013; Sass et al., 2020).

**Table 4.2***Study Participants' Caregiver Recruitment Outcomes*

ID	Response	Details
1	No caregiver	Did not identify anyone as having caregiver role for him to nominate.
2	Too busy	Felt caregivers were too busy to participate, declined to nominate.
3	Not requested	Interviewer forgot to ask.
4	Unable to schedule	Agreed to share poster/invite with sibling, no response from sibling.
5	Not requested	Interviewer forgot to ask.
7	Not requested	Interviewer forgot to ask.
11	Participated	Referred to family member who participated.
14	No caregiver	No recent contact with caregiver nominees, declined to nominate.
16	Unable to schedule	Agreed to share poster/invite with sibling, no response from sibling.
18	Unable to schedule	Agreed to check with family, but unable to contact to follow up.
20	Unable to schedule	Spouse requested consent, not returned to date, no response to follow up call.
21	Unable to schedule	Caregiver consented, missed interview, no response to calls x2.
24	Declined	Declined to nominate, indicated family are "not big talkers."
25	Participated	Referred to family member who participated.
28	Too busy	Declined to nominate, candidates all very busy.
29	No caregiver	No caregiver to nominate.
30	Unable to schedule	Caregiver requested consent, no response to email and f/u call.
31	Unable to schedule	Nominated spouse but unable to contact x2 calls.
32	Too busy	Patient checked with immediate family, but all too busy.
34	Declined	Spouse does not enjoy talking so declined to refer.
35	No caregiver	Tries to limit family/friend involvement in his healthcare.

In summary, caregiver recruitment was much lower than anticipated. In comparing my recruitment strategies to those employed in similar studies, the strategy of contacting caregivers through patients is very typical and historically successful. I did not identify any information regarding the impact of the COVID-19 pandemic on caregiver recruitment. However, it seems likely that this impacted study recruitment both in terms of access to caregivers, which was reduced due to infection control restrictions at sites,

and potentially in terms of patient/caregiver perception of the ability to make time for activities such as research, given the overall higher levels of stress/demands.

### **Participant Demographics**

Sample participants' age ranged from 34–82 years-old at the time of their interview, with a median age of 54.5. Fourteen (64%) interviewees were female, and nine (41%) were Black, which is generally comparable with UVA Division of Nephrology dialysis patients as a whole (Abdel-Rahman, 2018). Fourteen (64%) participants lived in rural communities, with seven of the UVA Health Systems dialysis units located in rural areas. By comparison, the adjusted national prevalence of ESKD in 2018 was 5854.8 per million for Black patients and 1703.8 per million for White patients (United States Kidney Data System, 2020). Prevalence by age was distributed from 890.6 for ages 18–44, 4157.3 for ages 45–64, and 7401.6 per million for ages 65–74 (United States Kidney Data System, 2020). Years of experience utilizing hemodialysis for kidney replacement therapy ranged from less than one year to 27 years, with a median of three years.

**Table 4.3**

#### *Participant Demographics*

Characteristic	Patient Participants	UVA Dialysis Patients
Median Years HD	3	
Average Years HD	6.53	
Min. Years HD	0	
Max. Years HD	27	
Median Age	54.5	63.7
Max. Age	82	95
Min. Age	34	19
Female	14 (64%)	42%
Male	8 (36%)	52.6%
Black	9 (41%)	50.8%

White	10 (45%)	39.7%
Rural	14 (64%)	
Suburban	3 (14%)	
Urban	3 (14%)	

### Participant Chart Review

Patient participants University of Virginia Health System EPIC charts were reviewed to provide additional context to qualitative findings. Out of 20 patient participants records for 19 were located within the University of Virginia Health System EPIC system. Participants were documented to have a median of **five** co-morbid conditions, most commonly hypertension (n = 19), diabetes mellitus type two (n = 10), and congestive heart failure (n = nine). No evidence of palliative care consultation or follow up was found for **any** participants.

Nephrology notes for one patient and primary care notes for nine patients were present in University of Virginia Health System EPIC. During the review no patients had discussions regarding ACKD prognosis, RRT decision-making, or advanced care planning documented in EPIC. One patient had an advanced directive scanned into EPIC. Documentation regarding pain assessment and management was identified for one respondent with their primary care provider (PCP). No documentation regarding ACKD symptoms assessment and management was found for any participants and regarding RRT symptom assessment and management for two participants, one with their PCP and one with nephrology team. A total of six participants received psychological or psychiatric screening or treatment, all from their primary care team. Five participants had documented discussions regarding social support and resources, all with their PCP.



## **Qualitative Findings**

Qualitative findings are reported below organized by the specific aim that the findings address. Themes identified during data analysis are listed and linked to supporting statements from participants.

### ***Specific Aim One:***

Describe patients' and caregivers' experiences with and perceptions of the experience of living with ACKD including symptom/s management, decision-making around disease management choices, and other perceived gaps/challenges in care.

The three themes addressing Specific Aim One are: Theme One: ACKD impacts patients physically, emotionally, socially, and economically; Theme Two: Patients use a range of self-management strategies learned through trial and error from other patients and clinicians; and Theme Three: Decision-making is complex, often not explicit/elucidated, and ongoing throughout RRT. Themes two and three are further divided into several sub-themes which illuminate specific aspects of the overarching theme.

### ***Theme One: ACKD Impacts Patients Physically, Emotionally, Socially, and Economically***

Consistent with prior studies, patient and caregiver participants described experiencing various impacts across multiple life domains due to ACKD, including physical, emotional, social, and economic. These impacts were often profoundly felt by participants and required significant adaptation and coping strategies. Participants described being affected by ACKD and the experience and the logistical demands of participating in kidney replacement therapy as part of their treatment.

### **Physical Impacts of ACKD.**

Distinguishing between symptoms caused directly by ACKD versus those that were a consequence of the treatment of ACKD, particularly RRT such as hemodialysis, can be challenging. For example, it may be impossible to tease out what portion of a patient's post-dialysis fatigue is driven by electrolyte shifts and ultrafiltration related to the dialysis treatment itself, and what portion results from anemia of CKD specifically. In terms of the individual patient experience, this distinction is not ultimately useful for most patients to make. Several participants related that they had frequent symptoms, some of which were exacerbated by attending dialysis:

Everything's changed. It changed my whole life, you know. The days that I [a]in't on dialysis I'm recovering from the days where I just took dialysis 'cause you get sick after you take the dialysis and then you're sick really through the next day. You'd start feeling better the following day and you have to do dialysis again, so it takes away your complete life. You stay sick to the stomach a lot. ... My legs hurt me all the time. I stay sick to the stomach. I get a headache a lot. Your body's just ill, sickly. Some people tolerate it better than others. That's the reason why I don't like to complain 'cause a lot of people do better than me and there's a lot of people worse than me, you know. (ID 4)

Yeah, it takes a lot out of you. You know, the nurse practitioner at dialysis says that it's kind of comparable to going to the gym and working out for four hours, so usually after dialysis I have to come home and take a long nap and I don't know if it depends on how much weight they pull from me, but sometimes I just

like sleep until I have to get up the next morning, you know ... And then that turns a four-hour dialysis session to pretty much the next day. (ID 11)

Other participants reported essentially no symptoms related to either their ACKD or RRT or symptom improvement.

I go to dialysis three days a week and I try to watch my diet and you know, we don't eat out hardly at all and that's about it. We take walks. ... I used to do Zumba and Aqua Zumba, so I did that twice a week ... I volunteered at the hospital. (ID 25)

I don't be in no pain, and I thank God for that. I don't be in pain. I wake up normal. I go to bed. Now, my appetite is very good, and you know, it just—and then I guess like I told you—I'm thinking about getting up every other day. You know, when you go where you don't have to get out—like I go to my—I had to go in. I feel good if I ain't got to go and that day I get me some rest. (ID 5)

For some participants, the severity of their ACKD symptoms was what prompted the decision to initiate hemodialysis.

Because I actually started dialysis[,] which I had went I want to say almost six months before and had my arm, my fistula done because we knew it was coming and they wanted to have it prepared so it would grow and it would be good, so

that happened like six months before I actually started but when I actually started dialysis I like thought I had pneumonia or something cause I couldn't breathe. I had fluid, really bad fluid. I'm telling you I was taking my last breath I believed because I couldn't catch my breath. (ID 18)

Another patient participant noted that they experienced fairly minimal symptoms before starting hemodialysis. They also described their post-treatment symptoms as relatively minor compared to the experience of the previously quoted interviewee.

Before I started dialysis I was—my legs were starting to swell but now I don't have any problem with that since I started dialysis. (ID 28)

Many participants described a sense that their physical symptoms and level of function evolved over time, often experiencing gradual declines and loss of abilities they had taken for granted earlier in life.

When I first started dialysis, some days like in the evenings—me and my girlfriend, we would walk, you know. Me and her would take a walk sometimes 'cause we were on a diet thing. We haven't done that for a lot of years, you know, and I don't think I can do it now. I just don't, you know. If I push myself, I probably could but I don't try to. I feel like I've went through a lot. (ID 18)

Some participants felt that gaining experience on dialysis had allowed them to adapt to the treatment experience and that over time they experienced less treatment related symptoms.

I don't feel nothing 'cause I'm not a young one. I've been doing it so long it don't affect me like everybody else. After 26 years I'd say I'm used to it. My nurse has nothing left to do. They do all to me that they can do. ... I take care of myself. I do what I can. I'm by myself a lot. I've gotta get fed. But you're supposed to. (ID 29).

I would say probably within the first year of dialysis trying to figure it out it tends to be a little rough 'cause they say like, you know, when you have use of your kidneys you can like get rid of the fluid and stuff and you don't really notice it but they'll say like, if you go to dialysis three days out of the week, ... it's kind of like trying to do everything from that time that the kidneys would have done within those times during those days and they try to get it done in three and a half hours so it's kind of putting stress on your body, so I figure probably in that first year you're really just trying to get used to all of it ... so I'd say like six months to about a year or so it's just like you just try to get accustomed to it so you know, you have all that fluid on, especially if you're not, you know, careful with your fluids and you know, they're pulling it all off at once you're just leaving out of there kind of hunched over like, and you go to bed and you're just sitting like this—you're just knocked out. Your electrolytes gotta reshift 'cause it's all shifted

from dialysis and then it's like your body's got to recuperate from all that was taken off so you're just kind of out of it and you just go to bed. (ID 35)

Physical symptoms both as a consequence of ACKD and treatment for ACKD play a major role in the experience of patient participants living with ACKD. Participants described variable symptoms which evolved over time and which, for many, took a significant amount of time and effort to manage or recover from.

**Emotional Impacts of ACKD.** In other studies patients living with ACKD described emotional and psychological experiences related to their disease (Hackett & Jardine, 2017; Yoong et al., 2017). This was the case for participants in this study as well. Participants related to a range of emotional experiences:

“A little stressful. It kind of makes me a little sad that I got sick.” (ID 24)

It bothers me emotionally sometimes too, but I try not to let it bother me 'cause I know I got to go do the kidney dialysis. I know that's what keeps me alive, so I try not to let that bother me. Just get up, you know, get up and go on 'cause I know that's what keeps me alive, so I try not to let it bother me. (ID 14)

For some participants their ACKD diagnosis meant confronting their mortality in a way that was upsetting:

Well, I try not to think about it but sometimes you get really depressed thinking about dying, you know. That is in the back of your head, but I try not to think about it. I'm saved. I believe in the Lord. I leave it up to Him, you know, but I do get depressed about that sometimes because I'm still young, you know. And I don't have grandkids yet. My youngest son is still in college. There's a lot of life events that I still want to do, you know, things I haven't ever done. (ID 18)

Navigating difficulties encountered during the treatment process was another source of stress for participants:

It's been emotional. I mean, you know, leaving and having to go to the hospital a couple of times after work. ... I've had several occasions where I had to get stuck three or four times in the same day and it causes bruising and it can be stressful, you know. I mean, I think it's more the consistency of the technicians that I'm experiencing. They have a lot of turnover at dialysis. It's stressful, I have no doubt about that. You know, it's having to go to the Vascular Center I think three times now. One time was just to get another catheter put in but the other times it was my fistula had to be worked on so it's constant stress and anxiety, you know. (ID 31)

In addition to managing their physical symptoms some patients found that physical changes related to dialysis impacted their self-image:

I've got a catheter in my chest so I can't get that one wet so in the summertime no swimming, showering is limited. I don't know, it's just like I've got a catheter in my chest, and I've got a fistula in my arm and like I'm self-conscious about wearing like shirts with - sleeveless shirts, so it kind of affects me all the way around. (ID 30)

Participants described diverse ways in which ACKD impacted them emotionally ranging from a sense of sadness to confrontation with their own mortality.

**Social Impacts of ACKD.** Many participants described experiencing changes in multiple social roles as a result of living with ACKD. Often this meant giving up roles that had filled previously or having to adapt or adjust their roles relative to what they had been able to perform prior to their ACKD diagnosis and treatment:

“You depend on everybody else. It's a different life. I've never depended on anybody for anything, you know. But now I really can't do a whole lot of nothing, you know. I can barely walk. I can't walk far. I can't stand no longer than a minute.” (ID 4)

Several participants described concerns about loss of independence or the need to rely more heavily on others around them. While this was realized for some, such as in the quote above, other participants came to realize that they were able to maintain much of their autonomy despite their treatments.



Actually, I wasn't even gonna do dialysis, you know, cause I thought I was gonna die so I was just like, well I'm not gonna do it cause I didn't want to be a burden on people. ... I just thought I would be too dependent on everyone, and I wasn't gonna have my self-dependence [*sic*] ... But for the most part I do have my self-dependence [*sic*] and I cherish that, which everybody does. You know, nobody wants to be a burden on anyone. Especially these days, everybody is so busy working and trying to make their own living and have their own homes and families to take care of, you know. (ID 18)

Other interviewees described a more intermediate impact, for example finding that the time required to complete their dialysis treatments required that they adjust their role within their family or adapt occasional activities such as travel:

I was watching my grandkids every day and so now I pretty much watch them on Tuesdays and Thursdays because by the time I get out of dialysis and take a nap, you know, it's mid-day so they have to find somebody else to watch the kids on Mondays, Wednesdays, and Fridays now. (ID 28)

I don't feel like doing anything after [dialysis]. I mean, I don't know about men, but women have a certain amount of things you have to do every day, so I still do a certain amount of things, but I don't make anything a priority that day except dialysis. That's my priority. (ID 18)

I would say that pretty much like planning like vacations or being away for more than a couple days at a time is like you can't really do that because you have to have dialysis every other day. (ID 30)

You just kind of have to schedule yourself around your dialysis. I have took it—the social worker has arranged for me to take it before at different places and you know, you just gotta kind of work yourself around it, the schedule. (ID 20)

Some participants felt relatively little social impact from their ACKD diagnosis:

I mean, it boils down to living and I guess, I can't think of the word for it, the joy of living and the joy of existing and if you want the joy of living you've got to—I don't think you've got to, but you've got to deal with what dialysis does for you. ... Throughout my dialysis I have a drink or two. ... Not that I got too carried away on it either. But that's part of being around people, I can have a drink with other people. Some people I've been knowing for 10 years and still don't know that I'm on dialysis. I don't take my dialysis—when I leave there, I leave it at the dialysis center. I don't take all that baggage home with me when I'm out and about on the streets. (ID 16)

Patient participants described a range of social impacts as a result of their ACKD diagnosis and treatment. Some experienced a profound reduction in their autonomy that related to their illness, while others found that they were able to adapt their roles to maintain them within the new restrictions imposed by their diagnosis.

**Economic Impacts of ACKD.** Participant patients described ACKD impacting them economically. Patients found their ability to earn income limited by the symptoms of their disease as well as the demands of treatment.

Well, what's most depressing is I can't work. I've always worked since I was 14 and I don't know if I could work now, you know, but when I first went on dialysis, I feel like I could have worked some, you know, maybe, but you can't really find anyone to work with you just so many days a week or certain hours.  
(ID 18)

I was working before I got on dialysis, and I just pretty much got fired due to surgery to start dialysis, for the fistula in my arm. They gave me time off which was okay and then I had a return date to come back and was just going through a lot with the health stuff. I came back maybe a few days late because I forgot the date and then when I got back, they were pretty much saying they let me go because I didn't come back on the return date. (ID 30)

I do landscaping and grass cutting but I mean, it was tough last year because every time I looked, I was either having a surgery or having that catheter put in or, you know, going to the emergency room for bleeding. It just couldn't really do much last year so hopefully, you know, this year I've been able to do a little more.  
(ID 31)

In addition to the challenges of maintaining employment while navigating ACKD, employment could also have negative consequences for some social programs, which was an added consideration.

I mean, some people can work, and they don't take their Disability and some people work and they may take your Disability too. So my husband has a good job, he does well for our family, and I was scared I would lose my Disability which I need. Financially, I need it, you know. (ID 18)

In addition to employment considerations, there were financial costs associated with treatment. Some patients discovered they had no significant out of pocket cost:

“My insurance is handling it” (ID 24).

Other participants faced costs not covered by insurance:

“Well, you know it costs a lot to do dialysis, you know. My situation is my deductible was like \$7,000.00, Medicaid Advantage Plan so I'm paying like \$150.00 a month to repay those deductibles. It's been expensive, yeah” (ID 31).

Other participants explained their costs further:

I'm glad they put me in there because the case worker that helps out ... she helped me a ton with getting assistance from UVA, helping me out with the cost and you know, she helped me fill out a lot of things to try to help get some extra support. Just with me being on Disability and make a little too much to get a lot of assistance, so I can't really get any help with rides or anything of that nature because I make too much money and the only way to get that kind of help is to be on Medicaid and I make too much to be on Medicaid, and then she helped me get financial assistance through UVA and then she also helped me with getting one of my medicines for free, the phosphorus finders, so she was a big help. (ID 28)

She's on Medicare and she also has a supplemental health insurance and so dialysis as far as I've seen is pretty expensive but I believe that she is supposed to be paying something like \$1,000.00 a month which we can't afford so she sends them a check of like \$25.00 a month and then at some point it gets turned over to a collection agency and then she's paying them \$25.00 a month also because her Social Security is like \$1,200.00 a month and so I don't know very many people on Social Security or otherwise who would be able to afford \$1,000.00 a month to pay for dialysis. (ID 42)

Transportation to treatments was a specific concern for participants:

“But the struggle is getting there for him, and I imagine there are a lot of single, non-driving dialysis patients and that is worrisome because if they can’t get to dialysis that could be a life-threatening issue.” (ID 17)

Participants described increased difficulty finding or maintaining employment due to their ACKD diagnosis, but also experienced challenges such as limited insurance coverage and uncertainty about eligibility criteria for social services programs, all of which amplified the economic impact of ACKD for them.

***Theme Two: Patients Use a Range of Self-Management Strategies Learned through Trial and Error, from Other Patients, and Clinicians***

Study participants described a wide range of ways that ACKD impacted their lives. In the same way, they described a wide range of strategies that they have developed to mitigate these impacts. Patients frequently interface with their medical teams regarding various aspects of their ACKD experience. However, they consistently describe the necessity of learning skills to care for themselves and adapt to the reality of living day to day with ACKD. These self-management strategies clustered around three major areas: nutrition, fluid, and physical activity.

**Nutrition.** Advanced chronic kidney disease has significant nutritional implications for patients. Patients’ dietary intake can significantly impact their levels of electrolytes, such as potassium and phosphate, due to decreased kidney clearance. In turn, excess elevations in potassium and phosphate can cause both life-threatening acute and long-term complications, therefore these are frequent areas of focus in terms of lab monitoring and discussions with the treatment team (Piccoli et al., 2020). Patients are

particularly urged to restrict their intake of potassium and phosphorus (Piccoli et al., 2020). In addition to electrolyte status, patients may also receive feedback regarding their protein levels on lab work, specifically albumin, which is used as a marker for malnutrition (Zha & Qian, 2017).

Some patient participants described experiencing significant stress and even fear regarding how to navigate these new dietary requirements:

When I was in the hospital and started dialysis, the nutrition lady comes in there and tells you all these foods you cannot eat anything of, you know, like tomatoes, bananas, potatoes. You've gotta really watch your potassium, you know, which is very important because if you get too much it can give you a heart attack. You could die. So when I first came home, I was scared to eat. ... [My doctor] told me that one of the guys that did dialysis, his wife was making tomato juice and said he kept tasting it. You know, just tasting it to see if it was where it needed to be, and he ended up having a heart attack and dying from tasting, and that never left my mind. (ID 18)

Other participants found that they did not need to make substantial dietary changes at all, as disclosed by the following participant, who stated:

“Well, the eating pattern hasn't really changed much for me.” (ID 30)

However, many patient participants reported that the ‘kidney diet’ that was recommended to them often required significant changes from their usual eating patterns:

Everything that I used to eat that was healthy, but everything I loved is too high in potassium or phosphorus now for me to eat. ... I immersed myself in the diet first and I realized how awful it was and that I could not survive like that. Just I couldn't. To me it was just pulled chicken and white rice and I just couldn't do it. First of all, I don't really care for chicken, and I don't care for rice. 90% of the foods that I can eat I don't like. (ID 36)

This discovery often resulted in a sense of conflict for patients who found that the guidance they received was contradictory or did not fit well with their overall life situation.

Because it would be like, “Don't eat peanut butter,” and then on your emergency plan it was like, “Eat peanut butter and jelly sandwiches.” It's like, do I eat it, do I not? It was so confusing, the food part, but after being there and learning things I've learned, everyone is different. (ID 18)

I just went on with things, ... I didn't watch my diet that much cause I would buy fast foods on the way home from dialysis and of course, that's not good for me, but anyhow, I was tired of cooking. Oh, dear. (ID 25)



Others described a process of exploration and adaptation in order adjust their eating patterns to align more closely with the nutritional recommendations from their medical team. For some, this took the form of adopting an active approach to their eating and learning new patterns:

I started reading through labels because they list the ingredients and stuff. The only thing that you have to be careful with is there is some stuff that has naturally occurring phosphorus, so like milk and chocolate and stuff like that—it's not listed on the label but there is phosphorus in it. So there are some things you've just got to know, but the biggest thing you can do is avoid preserved foods like hot dogs, bologna, some frozen stuff will have stuff in there. It's weird. It's even in Gold Peak sweet tea, which I don't understand why it's in there because there's Pure Leaf, which uses citric acid whereas Gold Peak uses phosphoric acid. (ID 21)

Another approach reported by some patient participants was one of creating a balance between their usual eating patterns and the medical nutritional recommendations. Some patients described a process of growing their self-knowledge and learning about their physical limitations in the setting of new levels of kidney function.

You know, and I'm learning more about myself too, about what I'm capable of physically. You know, I don't eat like I used to obviously because well, huh, the diabetic diet and the nephrology diet is awful. And the sad thing is, everything

that I used to eat that was healthy, but I loved is too high in potassium or phosphorus now for me to eat. So I'm learning because I'm hard-headed. I'm stubborn. But I can eat those things. I just can't eat a lot of them, so instead of buying the 40-pound watermelon, get one of the sliced watermelons, cut it in half, eat a little bit and make sure my girlfriend eats the rest of it. You know that sort of thing. You know, a little bit of avocado is not gonna kill me. (ID 36)

Other participants framed the process more closely in terms of experimentation, using the physiological feedback they received from their dialysis center testing to monitor their body's response to a different nutritional strategy, and based off of education received from their treatment team.

I immersed myself in the diet first and I realized how awful it was and that I could not survive like that. ... so I started experimenting and on MyChart ... so when they do my blood tests for dialysis, I have access to those. ... And they set them up so that there's a bar beneath and there's, you know, a yellow and then there's a gray area and then there's another yellow, which I assumed and was correct that the gray area is the normal area, so as long as the numbers stayed in the normal area, I'm doing good. The closer to the middle I got the better I was doing. So through process of elimination with that I paid as close attention to my blood work as they did and then I was paying attention to my blood sugar and my blood pressure and my diet and what I was adding to my diet slowly and keep in mind, I've got all the paperwork that shows, you know, these are the really bad

potassium and phosphorus, and these are the medium and these are the okay. So I went through all of that and tried to figure out what my happy medium could be.

(ID 36)

I think the main thing is really, you know, making sure you don't have too much fluid on and also making sure you don't have too much phosphorus and potassium and stuff like that too, but I feel like that's a lot easier to maintain than, you know—cause it's like, you know, I can still eat potatoes but I just don't eat as much so afterwards you still feel like you still have some semblance of a normal lifestyle cause you're not, you know, taking off everything that you normally would eat if you had healthy kidneys so you still have something there, so it's not like you totally have to cut it all out and then it's just like you have to figure out what can you eat, but you just have to moderate certain things. (ID 35)

In addition to avoiding or limiting certain foods participants noted that introducing and timing food could impact their symptoms after their dialysis treatment.

I usually do come home from dialysis, and I usually fix my breakfast. The first thing I do is eat. It feels like—I know one of the fellows that used to go there. He had done it for 30 years and he told me, “If you eat protein afterwards it helps you,” and he was right. Eat a little bit [of] protein, like I usually fry an egg or, you know, something like that. He used to take a peanut butter and jelly sandwich with him. As soon as he was done with dialysis, he would eat that, and it helped him feel better. (ID 18)

**Fluid.** Fluid management was another major issue discussed by patient participants. Many patients with ACKD experience decreased kidney water clearance which can lead to retained fluid (See & Polkinghorne, 2020). This fluid retention can cause elevated blood pressure and the development of edema both pulmonary and peripheral, among other consequences. Patients being treated with in-center hemodialysis typically undergo treatment three days per week. An estimated dry weight is recorded by their treatment team, which reflects their estimated weight when they are euvolemic. Then before each treatment session patients weigh themselves and the discordance between the dry weight and their actual weight is assumed to be excess fluid which should be removed during the treatment (See & Polkinghorne, 2020). Many patients described the challenge of reducing their fluid intake from their usual baseline as one of the most challenging parts of adapting to in-center hemodialysis as part of their ACKD treatment.

So really just trying not to—that was one of the hardest things for me to get used to because I drank probably about a gallon of water a day at least before and now I can drink something like two quarts for two days of total liquid and now obviously that would be to maintain but obviously I get over that a little bit, but I try to. I'm also a chugger. I don't like to just sip drinks. I like to—if I'm gonna pour myself a soda I want to drink it right away—that's the best it ever could be, right out of that refrigerator. (ID 21)

It was more the fluid intake that was the toughest part. Like I drink [] a lot of water. That was kind of my thing, especially like, you know, you're doing exercises. I play a lot of basketball so it's kind of one of those things when they say, "You gotta cut back on your fluids," and I was like, "What?" So that took a lot, but I've worked on it and it's working out so far, so that was the toughest part with the fluid intake. (ID 35)

Overtime, participants reported learning to better recognize cues and coordinate with dialysis staff regarding their fluid status.

Sometimes you don't even know you have that much fluid on you and then like certain things can happen. ... You might have to make an emergency trip to the hospital and they've got to like figure out how much fluid is really on your body that needs to be like pulled and find your actual dry weight, so after a while it was like—probably, like it was years ago but it was like the blood pressure was up but I felt fine and then come to find out I had so much fluid still on and they didn't know—they thought it was like the dry weight and I had like maybe like a kilo and a half still on that nobody even knew about and I had to go to UVA and they had to pull it off to find my actual dry weight so yeah, then after they took that off I was fine but it was just crazy. It can be tough if you don't have that fluid intake regulated cause if you don't it will cause so many problems and you don't even know anything about it. (ID 35)

As time goes by and just dealing with it day after day and going to dialysis like three days a week, you learn as you go so you learn how your body feels like when your blood pressure drops, when you're in fluid overload. Like you learn your body as you go, so it's like—how do I put it? And just being older too and just asking questions in dialysis like, “What are you doing? What are you giving me?” ... I mean, of course when I first get in there and my blood pressure is higher, I feel different than when I leave and the blood pressure drops due to when they pull the fluid off, so I kind of try not to plan too much afterwards cause I'll be trying to get some rest to get my energy back up. (ID 30)

Some patients found that increasing their use of ice provided a way to have the experience of quenching their thirst while reducing their total volume of fluid intake in a given period of time.

I might try to buy like the smallest or like if they have like a large drink, I keep the thought that I'm not gonna drink that much, just enough and like if I'm still thirsty I just have the ice out of it and I keep the fluid but keep the drink in the cup. You know how that is, you have like the ice, and you might have tea or something in there? You just like put the ice in it and just get the ice and then you just spit the drink back out into the cut, so you don't be drinking. ... So like ice is your best friend. It's like for every dialysis patient, ice is your best friend. (ID 35)

Patients also reported that navigating fluid management during dialysis treatment required their input and awareness. They found that they needed to monitor their physical experiences and provide feedback to staff members when they experienced symptoms, like cramping, that suggested a need to modify their treatment target or machine settings:

No, I can go to the dialysis and be seen and if sometimes if my leg gets to hurting and I'm hurting some kind of bad I have to tell them to take me off the seat and they'll do that, but they can't do it too many times 'cause they want to get that fluid off. (ID 14)

**Physical Activity.** In addition to confronting challenges with navigating self-management of their nutrition and fluid status, many patients reported that they have had to make adaptations in their physical activity in response to symptoms of ACKD and also due to post-treatment symptoms related to hemodialysis. Many patients emphasized that their goal was to continue to remain active at a level as close to their pre-ACKD status as possible.

Like the doctor told me, he said, "As difficult as it is, don't let it get you. You get it." And I believe in God and so I just keep on doing what I was doing ... I just go with—I try not to think about it. ... I try not to think about it, and I just keep doing what I was doing before I knew I had kidney disease. I just keep on doing what I was doing. You know, I tried to walk. I came out of my apartment and go

to the store and do things I really don't even think about my disease. I just go and do what I gotta do and come on back home. (ID 5)

Despite this goal, many participants described experiencing symptoms that forced them to modify or reduce their activity levels in a way that was notable and impactful for them:

“I don't know, I've always been before, even when I was diabetic, I was always very, very active and athletic. I used to do a lot of mountain biking and road cycling and I don't know if I'll be able to ever do that again.” (ID 11)

Some participants reported that over the counter supplements were helpful with reducing their physical symptoms:

“I tried all the little things. I take my little, little um vitamins and stuff, little aids, and stuff like that. That helps a little bit with a little strength but it's not gonna overpower mother nature.” (ID 16)

Participants frequently reported the need to rest after their hemodialysis treatment due to an experience of profound fatigue:



“I have to rest up. Sometimes I come home, sit for a little bit, get there take a nap, get up and feel somewhat better and then I go to bed a short time later ... Usually by the next day I’m mostly better.” (ID 24)

Another reported:

Uh huh, and so I usually do that and then I go feed and then after that I usually rest until supper. I just sit around or lay around. Sometimes I take a nap but most the time I can’t even take a nap, but I will rest and just watch TV or lay around or something on dialysis days. When I first started, I would do things on dialysis days, you know. I would do extra things on dialysis days but as the years have run on it gets harder and I just don’t push myself like I did. (ID 18)

Many participants found that pacing their activities and enlisting support from caregivers to complete certain tasks was helpful in balancing their energy levels and activities of daily living. For example, one participant described how he divided the task of bringing his grocery shopping in from his vehicle to his home with his home health aide:

“Then sometimes I’ll leave it in the car, and she’ll go dig it out for me. Just depends on what it is, like meats and stuff that can’t be left in there I’ll try to get that in here and get it put away, so if I leave it in the car a lot of times, she’ll get it for me.” (ID 14)

Another participant described his strategy of timing activities around his dialysis schedule in order to take optimize his energy levels:

“I actively avoid trying to go out on Sundays. ... for the most part I just tend to do stuff on Monday, Wednesday, Friday, Saturday.” (ID 21)

Participants described a range of self-management strategies for navigating the challenges of adapting to the nutrition, fluid, and activity changes required to successfully live with ACKD. They utilized education and support from kidney professionals and lay caregivers in developing their strategies, but many ultimately found they needed to rely on internal resources and adapt input from others to fit with their specific circumstances and priorities.

***Theme Three: Decision-Making is Complex, Often not Explicit/Elucidated, and Ongoing Throughout RRT***

Patients living with ACKD frequently face complex decisions as they start kidney replacement therapy. An added factor impacting this decision-making process is that for many patients these decisions happen under urgent circumstances, with clinicians informing patients that deferring or delaying RRT would be life-threatening. Because of this urgency, patient participants often did not perceive a decision happening at all:

I went to the doctor. You check in, they check your blood and tell you, you know, I was hesitating, and I had put it off and put it off. He was right on me. He said, “It’ s time for it.” I had put it off about a month. Finally he told me, “You better

come on in,” and that was it. You know, you’re in denial and I didn’t realize how important that was, until I got involved talking with him. ... I thought I could make it with the pills without the whole process, you know, but it didn’t work like that. ... The doctor told me that dialysis was the way to go. ... It had to happen. I didn’t realize how important it was [u]ntil I really got involved. When [my doctor] called me in and we went ahead to start the procedure just how quickly he started, you know, when they started the dialysis. He said, “Listen, you’re in more trouble - it’s more serious than you think it is.” I didn’t know how serious a problem I had until I got involved in it, you know, in the hospital. (ID 2)

I knew my function was getting lower, but I didn’t—so this happened at the height of the pandemic and everything and I thought I had COVID. I was having trouble breathing. I was very lethargic. I had pain all over. The only thing I didn’t have was a fever, and so I was trying to figure out what this could be, you know, taking Tylenol just trying to treat it like a common cold. Well, it obviously was not a common cold and my neighbor saw me sitting outside and she was like, “Oh, we’re going to UVA.” And so she literally put me in the back of her car, drove me to UVA. I checked in and I had 2% kidney function at the time. ... At that point they were just like, “We’re doing this.” Cause it was basically life-saving preventative measures at that point. It was no longer a “here are your options, what do you want to do?” It was like, “This is what we’re doing. It’s the treatment you need.” I mean, obviously you have to okay it, but I mean like they were saying, “This is literally what we’re gonna have to do.” ... It was a

discussion - it was never like, “Okay, you may not need to go on dialysis.” It was always a matter of when, but honestly the last time I had seen [their nephrologist] was October of 2019 and so just over that next year things just went downhill and so it kind of all happened at once, so there was never - like for example, the fistula that I have now—it was put in December after I had already been on dialysis for a month just because like I had no time. I should have planned better, and I didn’t. (ID 21)

Some participants described having a clear decision point and a process of weighing their choices regarding starting treatment and deciding on an RRT modality:

Well, he told me I needed treatment, and I talked it over with my family doctor and I said I don’t want to go on it. He said he thinks it’s best for me to go ahead. ... ‘Cause I didn’t want it three days a week. Oh, Lord. The doctor and the children pushing me. ... [Her friends] would just say I wouldn’t do it; I wouldn’t do it. ... I thought about it, and I prayed about it and talked to the children about it. That’s what made me get on the machine. ... I talked to my family. They wanted me to live longer. ... [Y]ou know, they wanted me here with them. I don’t like needles and I didn’t start it. I didn’t want to get up early in [the] morning and I didn’t want to start that, and it was a lot of things I didn’t want to do. ... I didn’t even ask for another kidney. At my age I didn’t know if I had to go through all that trouble and the trouble I have been through, it would have done alright. (ID 32)

I went up to a [creatinine of] three and then to a five and then to an eight and it went to a 13 and in a short period of time, short period of time—within months. And he sat me down and he said, “You’re either going to have a transplant or go on dialysis.” Now, that’s when I woke up. Because he hadn’t shared that with me all those 11 years [of previous monitoring]. I was just going along. Okay, I’m keeping this disease at bay, everything’s stable so I don’t need to do anything, so as far as making a decision I didn’t have to do anything, just keep living, just keep living. Only when he sat me down and told me, “Your condition is worsening and you’re gonna have to make a decision.” There one or two choices, actually three choices. The third choice is do nothing but of course I wasn’t gonna do that, but the two real choices were either get on the transplant list or go on dialysis, ‘cause he said, “You’re getting very close to where you’re getting to stage four.” So as far as decision-making, up to 11 years I really didn’t have to make any major decisions. (ID 1)

I can do dialysis at the place, I can do home dialysis, or I could do the one in the stomach ... Yeah, they offered it to me but with my husband working, like I said, it’s just one of them scary issues. Not that we couldn’t have worked ourselves through it and managed it, but no. We weren’t ready for that either. I’ve asked him and no. It’s a scary thing. If we did something wrong, you know, what do you do? You know, kind of thing and I don’t really understand the one that they said about going in the belly. I don’t quite understand that one. I don’t know if it

would be a good thing for me or, you know. I know that the one for home is out of the question. (ID 34)

You know, like I said, it was my choice to go on dialysis. She recommended that it probably was best over-all for me to have a little bit better energy and also, you know, I was excited about the home dialysis. I didn't know that was an option, but it didn't work out. That would have been a good thing that I could kind of control my time a little better by doing it at home because you can—I could do it overnight in eight hours and do it again the next day. It sounded great. ... We had looked at it and my wife is still working and the dynamics—I had a daughter that was staying here that was working from home, but you know, now that I know what's all involved, I don't know if that would have been a good thing. I guess, you know, some people do it and it probably could work but I'd have to have a care partner that would be here when I was doing dialysis, so I think maybe that be something I look at in the future but right now everybody's working and it's nothing you should be doing by yourself I don't think. I'd have to have somebody here to monitor what's going on. ... "I always have the option to go back to that but right now I'm going to the dialysis center. My wife and everybody's still working so I wouldn't have anybody to actually be here to help if something went wrong. I live in a rural area so it's not convenient to do right now. (ID 31)

After their initial RRT choice patient participants continue to reevaluate their options and may face new decision points regarding RRT.

“Like if it’s my goal to do dialysis at home it’s so uncertain because there’s a lot that I have to learn and you know, after my brain injury I’m hoping that I will be able to learn everything, so that’s a big uncertainty. I had a psychoanalytical evaluation at UVA to determine the extent of my brain injury and they said, “Yeah, well you definitely have a brain injury,” because of my memory loss and I think if I can’t remember everything then I will never be able to dialyze at home, you know. I’ll have to always have somebody do it for me and so it’s pretty far from being certain even though I know in order for me to go back to work full-time that’s what I will have to do but there’s uncertainty there which means my goal of going back to work is uncertain, you know. (ID 11)

Actually I started out—the first kidney transplant in ‘93 after two weeks I rejected and then started on dialysis, then I waited about 15 months, in ‘94, late ‘94, and tried a second transplant, but the second transplant I got on a waiting list because I didn’t want to involve family members again because remember the first was my brother who did the first one. So I got a cadaver kidney on the second one, but the same thing happened. But what happened though, it changed my whole attitude towards dialysis, okay, and the reason for that is here I am—I looked at it and I said, “What are my options now?” Okay, number one, I can’t—I could try for a third transplant but it’s not likely because I’ve had two failed ones and for pretty much the same reason and for the same period, two weeks out. So that was out. So then I said, “Well, I don’t want to do nothing because if I do nothing, I’m

gonna die cause I need some kind of treatment.” So the only option that was left on the table was dialysis, so my attitude towards dialysis changed drastically because remember when I first looked at the option back when I was looking at the options, dialysis I felt was a temporary fix but, in my case, now it’s got to be a permanent fix cause I don’t have any other options. So I went into dialysis totally different, and I think it helped me. It was a blessing in disguise because the fact that I had lost two transplants and the only option on the table was dialysis. I said, “I’m gonna make the best out of this option that I have, so I’m gonna set out to be the very best dialysis I can be. Now I am now, I’m in my mid-30’s okay. A bunch more mature, I don’t feel like I’m invincible now as opposed to when I was 22 and then you remember it was a hit-[or]-miss type thing, right, taking the blood pressure medicine and changing my diet and all that. I was regimented to say, “I’m gonna stick with this. I’m gonna be totally compliant.” (ID 1)

In addition to decisions about RRT modality patients faced other related decisions, such as decisions about establishing vascular accesses or management of co-morbidities.

They’re wanting me to go get a fistula but I’m not ready. I just see, and I understand the complications that can come from this and even my heart doctor has told me, “You need to get a fistula.” Okay, that’s fine and dandy but I’m not ready. My psyche says, “No, not yet.” I’ve watched too many problems and I’m not saying that I’m gonna have that problem, but I’ve watched others that have it



have their issues. I'm not ready for that. I'm not ready for that. ... Well, I've watched other patients where one has to get it particularly done this way ... They do their dialysis and get, you know, taken off the machine when they're done and they sit there and bleed and they bleed and they bleed, and I've even watched patients go to the hospital because they can't get it to stop. ... You know, and then they keep telling me, you know, if I get an infection from this one that I have, you know, it's bad news for me, but I'm getting there. I'm getting—I'm more stepping forward than I am stepping back. ... You get to do different things. Don't take me wrong. I bathe, you know, I get that, but when I get a fistula I can take a shower, you know. That's not a, you know, that's a bonus but it's not a 'yippie-ki-yay' kind of thing, you know what I mean? You know what I mean? ... You know, that's not why I want to do the fistula is because, oh, wow, I can go take a bath or oh, wow, I can go take a shower. (ID 34)

With the blood pressure medications. That's the one that stands out to me because like I had to—this is like, because it was just like crazy about the blood pressure and then we find out that it was fluid and then they just tried a whole bunch of blood pressure medications but it made my blood pressure drop like too low so one of the things we figured out is that if we cut back on the blood pressure medication and basically say well, before treatment if you didn't take it the day of—like before the treatment, cause I have one that's twice a day so if I don't take one during the day and then go on treatment then, then it works, then the blood pressure works out better so it won't drop all the way like super low, so that's one

of those things that stands out to me, was the blood pressure medication. Because of all that it went to like three—it might have been like three or four blood pressure medications and now it's just one. ... Yeah, 'cause we was just working it out from there. Like she would work on it. ... she's a nurse practitioner but she was helping me out with that a lot, so that's the one that stands out to me cause she was really helping me out with it... It took a little while 'cause we were still trying to figure out why it was doing that but once we got it figured out it was fine. So I have to credit her for that. (ID 35)

### **Specific Aim Two**

Explore ACKD patients' and caregivers' understanding of palliative care and their perspectives regarding what role, if any, palliative care should play in the management of ACKD.

#### ***Theme Four: Lack of familiarity with PC, perceived as unnecessary during illness stability, but potentially useful during exacerbations/periods of decline.***

Patients were not familiar with PC, especially outside of EOL care. Patients do not see need for PC services now, but some would see utility if they experienced increased complexity/instability in their clinical condition. In general, patients preferred to access services via their usual team of clinicians.

A majority of patients reported that they were not familiar with PC and had not had experience with PC specialists either personally or generally.

“I'm not sure what that is. ... I haven't heard of that.” (ID 24)

“No, I’m not familiar with that at all.” (ID 11)

“I’ve heard of it, but I don’t know what it is.” (ID 25)

Some participants associated PC with hospice or end of life care:

“I’ve heard it. Like hospice type care but not PC in relation to kidney disease. ...

You know, I always confuse palliative care with end-of-life care.” (ID 3)

“Yes, I’ve heard of it. ... For me it’s been mainly with terminally ill family members and that type of thing. Its comfort care I guess and then follow-up care.” (ID 17)

Several participants felt they would not benefit from additional PC services at this point because they felt well and were clinically stable:

“Not really necessary. ... I think I have what I needed already.” (ID 24)

I have resources for [areas addressed by palliative care] and like I said, I don’t have any problem with anything. I’m just happy the way I am now and like I said, I don’t be in no pain. I get up normal. Everything with me is just normal. The only way I know I got a kidney problem is ‘cause I have to go to dialysis. Other than that, I’m fine. (ID 5)

Several interviewees observed that while they did not see a current need for PC services, they could envision future situations in which access to additional PC resources could be valuable for them or their family member.

It doesn't bother her at all and so—but I could see in the future maybe as she would, you know, either physically or mentally deteriorate, I think that would be—absolutely that would be something I would need some help, you know, guiding because I wouldn't necessarily know. Okay, is she having, you know, onset of dementia or is this something that's kidney related—is it because, you know, she didn't get her dialysis today or is she argumentative with me because she—is it something kidney related or is it just that she's getting old and crotchety, you know? (ID 42)

So maybe if I did have multiple issues that would be helpful, but I just feel like right now I'm not interested in that, and I don't feel like I need it. ... I'm not saying that in the future, you know, if my health, you know, gets worse and I have issues I may need extra help. (ID 18)

It's just for me, like at dialysis right now I pretty much have something similar to that so I mean, like that's like once a week so we have discussions about certain things and when the kidney doctor comes in every now and then, you know, with the lab work and stuff, if I have anything to say to him, you know, I can speak to him then. But the social worker and the dietician, I speak with them pretty much

like—definitely the dietician, like almost—like I go \_\_\_\_\_ and if she's in there, I talk to her pretty much every time. So anything else that I need I can speak with the social worker about it. Pretty much everybody is real cool, just everybody there in general, you know, like the technicians and the nurses and everybody else, you know, so if there's anything like that, you know, yeah. But I do think it's a good idea. I mean, like if I need something a little more in detail like that, I figure I would try it out but right now, for what it is right now, everything's pretty steady with that, with what's going on right now. It sounds like a good idea though but I'm okay with what I have right now. (ID 35)

Participants often felt their care team was already active in terms addressing multiple dimensions of PC:

Well, we have that now. Our doctor does that ... you tell your doctor if you're hurting. You tell your doctor if you're sleeping every day and you're sick at your stomach or had any falls or, you know. ... Nausea, vomiting, or diarrhea. They ask us that every day so it's addressed, and any falls. Any pain anywhere and any other problems going on anywhere. They ask you that every day. (ID 4)

The doctors who are involved that I'm associated with have all given me good advice and laid out options and what I need to do and things like that, so I've felt pretty informed. (ID 28)

Some participants suggested that enhanced resources to address patients' emotional experiences and needs could be a useful addition to the current services provided.

That would help everybody. It wouldn't help just one or two of us. That would be widespread and I ... believe more people would stay in dialysis. I believe more people would take the dialysis. I don't think so many people would give up. You know, there ain't nobody to encourage nothing. (ID 4)

I can see where other people aren't as strong as me and might need that kind of help but as for me, I'm pretty strong and I'm not gonna let myself get too down or discouraged, so for me that really wouldn't be helpful or needed. (ID 28)

Patients tended to see their "usual team," either their nephrology team or their PCP, as their clinical care coordinators and relied on them for recommendations about where and when to seek other health care services.

I try to do everything through one program. I don't try to have my stuff all spread around through different facilities. My doctor, my dialysis doctor, my main doctor, he's my urologist, he's my all-around physician, general physician. I try to keep everything in-house. Everything goes through him. I tell him first what's going on and then they give me a referral outside of dialysis to what branch I need

to. Any procedures that need to be done, they call back to dialysis and check and see if it's okay with them, then when they okay it then I get it done. (ID 16)

Once a month Dr. \_\_\_\_\_ or Dr. \_\_\_\_\_'s there, but they'll sit down and go over with me what's got to be done. You know, they'll tell you what's got to be done and I have found that they usually send me to the very best doctor that they can as a referral. I mean, I've got complete trust in them and the choices that they make and if I have a question, you know, they're answered for me, and the decision is just made right there. (ID 20)

I just feel like probably we could just benefit from a regular physician cause doctors cope with other things too, like you could have—I mean it just causes other things, like the tiredness part and like being weak and stuff like this. Some issues they can't help with. ... I can't remember exactly what it was, but I went to dialysis, and I talked to them about it and their response to that is that I would have to make an appointment with my family doctor to deal with that, so I feel like I have to explain my issues more than one time. ... and plus if a doctor was there that did that it would be like they would know what your kidney issues and whatever and pull up your lab work and everything while you're there and they could pretty much give you a response there and they could call you in medications or whatever you need, rather than making another appointment. (ID 30)

Participants generally had no knowledge or only incomplete knowledge of PC. Many indicated that their current health care team already performed at least some aspects of PC services. Interviewees generally did not see an immediate need for additional access to PC services. However, several of them indicated that if their health status changed, they could envision benefiting from access to expanded PC service.



## Chapter 5: Discussion

This chapter reviews the critical study findings in the context of prior research and existing studies, and the particular strengths and limitations of this study are described. Finally, the implications of the study findings for future research, practice, education, and policy are discussed. Participants in this study overall approximated the demographic characteristics of other persons within the UVA Health System dialysis clinics. They were also broadly similar to those reported for national samples of dialysis patients.

### **Participants Described a Multi-Faceted Set of Impacts Related to Their ACKD and RRT**

The experiences described by study participants were similar to those reported in prior studies. Many interviewees described high levels of fatigue and other physical symptoms related to ACKD and RRT. In addition to physical challenges, patients pointed out that treatment was, at times, emotionally burdensome. For example, most participants described some health crisis or acute illness associated with starting dialysis, often a source of stress. Facing the severity of their illness and changing functional status were other sources of emotional distress.

Participants highlighted other challenges, including the need to adapt their social roles and responsibilities. These adaptations were required either because of physical symptoms experienced due to dialysis treatment or because of logistical issues, such as the need to attend dialysis treatment at specified times.

Participants also described the economic impact of ACKD in several areas. Many participants found it challenging to maintain employment. This was due to the symptom

burden of their illness and the time commitments required to attend treatment and participate in other aspects of their care, such as attending clinician's appointments. Finally, multiple patients reported relatively high financial costs as an area of concern. Patients with dual Medicare and Medicaid eligibility reported that this combination of coverage minimized their treatment-related costs (although they still faced financial challenges in other areas). However, several patients who were solely Medicare beneficiaries had high out-of-pocket costs that were financially burdensome.

In addition to employment challenges, many participants described the difficulty of accessing reliable transportation as a high-priority issue. This likely reflects the primarily suburban and rural nature of the participants' domicile location. Many of these communities would be very car-dependent, and several persons could not drive in general or experienced difficulty driving after treatment. This represented some difficulty even in situations where insurance-funded transportation was available. Participants reported that this mode of transportation was often not reliable enough to depend on for treatment, or flexible enough when schedule adjustments were needed.

### **Perception of Decision-Making Regarding RRT**

Consistent with national statistics, many respondents described the experience of initiating dialysis in response to the onset of acute symptoms, which were not mitigated by medical management. Participants consistently reported their perception that there was effectively no decision to be made for them regarding dialysis initiation because the alternative was death. A smaller group of participants reported less urgent starts, which they negotiated with their nephrologists on an outpatient basis. However, these patients also typically understood their options as dialysis initiation or impending demise. No

participants reported a discussion of conservative management. The lack of discussion of conservative management may reflect the age and health status of participants, who were younger than individuals for whom strong evidence of benefit from conservative management exists (Rosansky et al., 2017).

### **Patients Were Not Familiar with or in Contact with PC Services**

Study participants did not see themselves as currently needing PC but thought some resources could be potentially helpful in the future. The majority of participants, however, were not familiar with PC. Among those who recognized the term, it was exclusively associated with end-of-life care. This is common and consistent with findings from prior studies (Chen et al., 2018).

None of the interviewees felt that they currently required additional PC services. Many patients felt that their usual care team (nephrology or primary care) already provided an adequate level of PC-type services, making further access unnecessary. Another significant portion of respondents indicated that they viewed themselves as relatively clinically stable and did not currently require augmented PC. However, they indicated that they could see those services' potential value and role if their condition became more unstable or complicated.

Overall, participants reported good access to resources for managing physical symptoms, frequently assessed by medical and dialysis center staff. Participants indicated more limited access to resources for emotional and psychological burdens of ACKD. They suggested that adding additional resources in this area could be helpful.

### **Patients Preferred Care Coordination via the Primary Team and Access to Services via Their Usual Means of Care**

Interviewees described high levels of contact with the healthcare system through their dialysis treatments and other sources of care, which required significant portions of their time and frequent travel/access to transportation. They also described coordinating care among multiple clinical teams. Several participants highlighted the value of accessing more comprehensive “one-stop shopping” for services, including expanded access to primary care through their dialysis center.

This suggests that improving access to PC services might be most effective by incorporating enhanced services into existing nephrology teams rather than focusing on referral or access to a freestanding autonomous PC service. Many participants reflected on the fact that their nephrology clinicians were already addressing specific aspects of the PC role, particularly those related to the decision-making and management of physical symptoms. This again could suggest the potential value of enhancing the capacity for nephrology teams to provide higher intensity PC services rather than focusing on specialty PC clinicians.

In summary, participants reported experiences broadly aligned with extant literature regarding treatment burdens and experiences. This group’s particular concern was transportation issues reflecting their rural and suburban communities. Patients typically saw themselves as clinically stable, with adequate support through their current treatment teams (especially nephrology/dialysis centers), and therefore not currently requiring PC services, despite endorsing significant physical, emotional, social, and financial stressors related to their illness and treatment that might be amenable to PC

interventions. However, after learning about PC, multiple participants felt that access to enhanced PC resources would likely be helpful if their condition decompensated or they experienced more complex illnesses. Many participants experienced significant time and logistical burdens related to involvement with and coordination between multiple care teams and frequent dialysis session attendance. Several participants highlighted the value of accessing services through their dialysis centers, pointing out that they already attended the centers regularly and felt comfortable with the staff.

### **Study Limitations**

Limitations of the study include that it is conducted within one University Health System within an academic setting, which might present different incentives and pressures and clinical practice patterns compared to a private practice clinical setting. Another limitation was my inability to successfully recruit an adequate number of caregiver participants. Finally, a significant limitation that will need to be addressed in future studies is the exclusion of people not comfortable interviewing in English, especially persons whose preferred language is Spanish. Available evidence suggests that Latinx persons living with ESKD, who represent a significant and growing proportion of ESKD patients, likely have unique concerns and preferences for care that will require exploration in future studies (Cervantes et al., 2018; Cervantes, Jones, et al., 2017; Cervantes, Linas, et al., 2016; Cervantes, Zoucha, & Jones, 2016).

### **Practice Implications**

Patient feedback indicated that access to PC services was potentially valuable, notably in case patients experienced increased complexity or growing instability in their health. However, patient participants did not perceive themselves currently as needing PC

intervention at this point in their illness trajectory, even when they reported physical, emotional, social, or economic distress that might be amenable to PC intervention.

This is consistent with prior work which found that patients tended to underreport symptoms because they found that reporting often did not result in effective treatment (Feldman et al., 2013). Patients also often indicated that they looked to their nephrology or primary care teams for guidance regarding when to seek specialty consultation. The unstated implication was that if they needed PC input their regular clinicians would let them know and arrange a referral. However, rates of PC referral for patients with ESKD within this particular health system are known to be low, consistent with the experience of ESKD patients generally (Abdel-Rahman et al., 2021). For example, less than 60 percent of terminally ill ESKD patients received PC consultations and among those who were not acutely dying but opted to discontinue dialysis only 34 percent received PC consultation (Abdel-Rahman et al., 2021). This indicates that there is definite room to improve access to PC for ESKD patients, despite participants general consensus that they did not see an immediate personal need for PC involvement.

Participants indicated that their nephrology teams had already incorporated some aspects of PC. This was most evident in terms of physical symptom assessment and decision-making regarding treatment options. Participants also reported support with navigating social and economic impacts of ESKD. However, despite reported support for managing economic sequelae of ESKD, multiple participants did report that gaps remained. Participants described facing financial consequences from ESKD due to changes in employment, changes in social roles resulting in reallocation of tasks to others with resultant implications in time and financial burdens, and burdensome levels of out-

of-pocket cost despite having insurance coverage. At least one interviewee highlighted class related impacts because the physical demands of their 'blue collar' work were not compatible with their new health status (ID 16).

Socioeconomic status has been shown in previous research to be a risk factor for development of ESKD, which suggests that patients with ESKD may be at increased risk for economic harms and complications related to financial impact of ESKD (Nicholas et al., 2015). The burden of limited employment and resultant financial difficulties is also consistent with the experiences of patient participants in other studies (Roberti, J. et al., 2018). Assessing and addressing financial stress has the potential to improve outcomes for ESKD patients by improving ability to participate in treatment and manage stress related to financial insufficiency.

Interviewees did not specifically reference experiences of racial discrimination in their interviews. However, structural racism and inequities related to race are well described in regard to both CKD and palliative care (Chuang et al., 2017; Mohottige et al., 2021; Worster et al., 2018). Organizational level clinical interventions have been proposed as a means to improve health equity and further development and implementation is warranted (Mohottige et al., 2021).

Transportation was a concern identified by multiple participants, particularly those residing in rural areas. Participants highlighted having difficulty at times following through on treatment recommendations because of transportation issues. Consistent attendance at dialysis was also sometimes imperiled by transportation issues. This is consistent with other studies in which transportation access impacts treatment, especially for persons living in rural communities (Park & Kear, 2017). Incorporating transportation

needs assessment and identifying relevant resources may be important for ESKD patients in rural communities.

A potential area for improvement that patients identified was access to support for the emotional/psychological burdens experienced due to their illness. Several participants also described an interest in having more opportunities to engage with fellow patients in more substantive ways for mutual learning and support. This could suggest a means to address the gap in care for emotional support that would be relatively low-intensity in terms of resources (compared to adding large numbers of mental health clinicians, higher-intensity screening, and more aggressive referral to existing mental health services).

Participants often described that dialysis initiation was the only option available to them, which would support the value of ongoing work to improve shared decision-making around dialysis initiation and access to conservative management for patients with ACKD. They also described a high level of treatment burden and a preference to coordinate their care through the nephrology team. This combination of factors suggests that practice models that focus on enhancing the capacity of existing teams to provide high-quality and intensity of PC services or provide access to PC consultation at a dialysis center would be preferable for patients compared to trying to increase referrals to or consultations with a specialist PC center or service.

### **Research Implications**

Given the feedback from patients that their nephrology teams already addressed multiple aspects of PC services, future research to examine the operationalization of these activities in clinical practice would be helpful for informing interventions to enhance or



augment extant services. Further exploration of patients' emotional experiences and the relative value of possible interventions would also be helpful. Understanding nephrology clinicians' awareness and intent around these roles could allow targeted interventions to enhance and expand their capacity to meet patients' needs. Participants' experiences with starting RRT support ongoing research regarding this aspect of ACKD care.

The economic impact of living with ESKD is a known concern from past research. Financial toxicity has been identified as an important concept relevant to people living with cancer (de Souza et al., 2017). Future research to characterize and identify financial toxicity related to ESKD care may be a useful paradigm. Additionally, research examining the transportation needs and experiences of ESKD patients may be useful in further characterizing the gaps faced by patients and identifying potential intervention targets.

Another area for future research suggested by participant input is examining novel models of care delivery for ESKD patients. Participants expressed interest avoiding increased treatment burden and, in the potential, to access resources like primary care within their dialysis center. Fragmentation of primary care has been recognized as a challenge for ESKD patients (Wang et al., 2017). One potential solution proposed has been the integration of primary care services into dialysis centers, which participant input would support examining further (Hynes et al., 2019).

### **Education Implications**

Patients reported little awareness of PC as a potential resource. Those who were familiar with PC associated it with end-of-life care. This common finding among patients and caregivers opens up the potential role for enhanced education of communities in

general and particularly of patients with serious chronic illness and their caregivers about PC. This aspect also highlights the value of further education for nephrology clinicians about the potential role of connecting their patients with PC earlier in the illness trajectory. This finding is aligned with research in which PC and nephrology clinicians suggested that improved education around PC roles and services was needed for both patients and clinicians (Metzger et al., 2021)

### **Policy Implications**

Participants identified challenges related to costs of care and loss of income related to ESKD. Transportation issues were also a concern, despite transportation services already being incorporated into Medicaid benefits. Both of these issues are potential targets for policy interventions either at the insurance payer level or via reforms to government benefits programs at the federal and state levels.

Whenever a new clinical initiative is considered—for example, interventions targeted at enhancing capacity and delivery of PC services by primary nephrology teams, the potential exists for clinicians to be saddled with new demands or targets without adequate logistical resources to address those demands effectively. Participants already noted that dialysis and clinical staff faced significant demands on their time and were at times challenged to meet their existing responsibilities. Therefore, any move to increase services will require policy changes at both the institutional and patient levels to ensure that interventions are supported in a way that permits the delivery of high-value services rather than merely checking another box.

Specific policy interventions to address concerns regarding emotional support identified by participants could include funding for screening and treatment of emotional

or psychological problems related to ACKD, including the addition of dedicated clinicians to allow the inculcation of higher-intensity mental health services to nephrology units. Since nephrology social workers are already heavily burdened with case management responsibilities and typically already managing multiple priorities, it is not reasonable to expect additional responsibilities for emotional assessment and support could be added onto their existing responsibilities.

### **Conclusion**

Study participants indicated little familiarity or experience with dedicated PC services. They reported that their nephrology teams provided several aspects of PC, including assessing and managing physical symptoms and support with complex medical decision-making. They did identify support with navigating the emotional/psychological burdens of ACKD as a potential gap to be addressed. Participants did not feel they required additional PC services at this time. However, many indicated that they could envision future situations in which enhanced PC services might be beneficial. Respondents already experience a significant treatment burden related to the frequency and duration of medical appointments and dialysis treatments. Additionally, they preferred to coordinate their care through their nephrologists. Given participants' responses, future clinical, research, education, and policy efforts to enhance access to PC should focus on understanding current practices and enhancing the technical and logistical capacity of nephrology teams to deliver higher-intensity and quality PC services in the context of dialysis centers, where patients are already receiving regular treatment and care.

## APPENDIX A: CONSENT DOCUMENT

IRB-HSR# 22163: Patient and Caregiver Concerns in Advanced Chronic Kidney Disease: A Qualitative Study

### Consent of an Adult to Be in a Research Study

In this form "you" means a person 18 years of age or older who is being asked to volunteer to participate in this study.

#### What is the purpose of this form?

This form will provide you with information about this research study. You do not have to be in the study if you do not want to. You should have all your questions answered before you agree to be in this study.

Please read this form carefully. If you want to be in the study, you will need to sign this form. You will be given a copy of this form.

#### Who is funding this study?

This study is funded by an internal grant from the University of Virginia, a dissertation grant from the Southern Nursing Research Society, and a grant from the American Association of Nurse Practitioners Grant Program.

#### Key Information About This Research Study

<b>Principal Investigator:</b>	Randy Jones, PhD, RN, FAAN University of Virginia School of Nursing 225 Jeanette Lancaster Way University of Virginia, Charlottesville, VA 22903. Telephone: (434) 924-0125

You are being asked to take part in a research study. You do not have to take part in this study. You should only agree to take part in this study after reading this consent form and discussing it with the study team. You may also discuss this with your family, friends, health care providers or others before you make a decision.

#### What problem is this study trying to solve?

The purpose of the study is to better understand what issues and concerns are most important to patients living with serious kidney problems/chronic kidney disease stage 5 (CKD5)/end-stage renal disease (ESRD) and their caregivers. We also want to hear about what role, if any, palliative care, a special team focused on symptom management, communication, and goal setting, has or should have in caring for patients with serious kidney problems/chronic kidney

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disease stage 5 (CKD5)/ESRD. You are being asked to be in the study because you have a diagnosis of chronic kidney disease stage 5 (CKD5)/end-stage renal disease (ESRD) or because you are a caregiver for someone who does.

**Why would you want to take part in this study?**

You will not be helped by being in this study, but the information gained by doing this study may help others in the future.

**Why would you NOT want to take part in this study?**

You might not want to take part in this study because you would need to complete an interview and you may become fatigued or distressed from answering questions during the interview. If you are a person with serious kidney problems/chronic kidney disease stage 5 (CKD5)/end-stage renal disease (ESRD) your University of Virginia medical records will be reviewed as part of this study and you might prefer not to have researchers review your records.

**What will I have to do if I take part in this study?**

If you take part in this study you will:

- If you choose to participate in this study you will be interviewed by a research nurse and asked a series of questions about your experiences.
- You will be interviewed in person or by telephone, at a time that you choose.
- Your interview will be recorded on a digital audio recorder.
- If you are participating as a patient, researchers will review your University of Virginia medical records to supplement the information you provide during your interview.

**What will happen if you are in the study?**

**Study procedures**

- If you agree to be in this study, you will sign this consent form before any study related procedures take place.
- You will schedule a time for an in person or telephone interview that is convenient for you.
- You will be interviewed by a research nurse and asked a series of questions about your experiences with kidney disease and your opinions about palliative care.
- You may skip any question that makes you uncomfortable and you can stop the interview/survey at any time.
- Your interview will be recorded in order to allow study of your answers.
- If you are a person living with kidney disease your University of Virginia medical records will be reviewed to add more background after your interview.

**How long will this study take?**

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Your participation in this study will require *one interview at a time you choose*. This visit will last about one to one and a half hour.

### **What are the risks of being in this study?**

You may become fatigued during the interview or distressed from answering questions.

#### **Risks of Videotaping/Audio taping:**

Your interview will be digitally audio recorded for transcription and analysis. We will not collect any identifying information during the interview in order to protect your privacy. We will delete the electronic recording of your interview once a written transcript is created, usually within 30 days of your interview.

### **Could you be helped by being in this study?**

You will not benefit from being in this study. However, the information researchers get from this study may help others in the future.

### **What are your other choices if you do not join this study?**

You do not have to be in this study to be treated for your illness or condition. You can get the usual treatment even if you choose not to be in this study.

### **Will you be paid for being in this study?**

You will be paid \$30 for enrolling in this study by *gift card*. You should get your payment about 30 days after completing your consent form.

### **Will being in this study cost you any money?**

You will be responsible for any telephone charges for receiving an incoming telephone call if you schedule a phone interview.

You will be responsible for the cost of travel to come to any study visit and for any parking costs.

### **What if you are hurt in this study?**

If you are hurt as a result of being in this study, there are no plans to pay you for medical expenses, lost wages, disability, or discomfort. The charges for any medical treatment you receive will be billed to your insurance. You will be responsible for any amount your insurance does not cover. You do not give up any legal rights, such as seeking compensation for injury, by signing this form.

### **What happens if you leave the study early?**

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You can change your mind about being in the study any time. You can agree to be in the study now and change your mind later. If you decide to stop, please tell us right away. You do not have to be in this study to get services you can normally get at the University of Virginia.

### **How will your personal information be shared?**

The UVA researchers are asking for your permission to gather, use and share information about you for this study. If you decide not to give your permission, you cannot be in this study, but you can continue to receive regular medical care at UVA.

Information obtained from you during this study may be used in future research. Your information may be shared with other researchers inside or outside of the University of Virginia. They will not be sent with information that could identify you such as name, address or phone number.

### **If you sign this form, we may collect any or all of the following information about you:**

- Personal information such as name, address and date of birth
- Social Security number ONLY IF you are being paid to be in this study
- Your health information if required for this study. This may include a review of your medical records and test results from before, during and after the study from any of your doctors or health care providers. This may include mental health care records, substance abuse records, and/or HIV/AIDS records.

### **Who will see your private information?**

- The researchers to make sure they can conduct the study the right way, observe the effects of the study and understand its results
- People or groups that oversee the study to make sure it is done correctly
- The sponsor(s) of this study, and the people or groups it hires to help perform or review this research
- Insurance companies or other organizations that may need the information in order to pay your medical bills or other costs of your participation in the study
- Tax reporting offices (if you are paid for being in the study)
- People who evaluate study results, which can include sponsors and other companies that make the drug or device being studied, researchers at other sites conducting the same study, and government agencies that provide oversight such as the Food and Drug Administration (FDA) if the study is regulated by the FDA.
- If you tell us that someone is hurting you, or that you might hurt yourself or someone else, the law may require us to let people in authority know so they can protect you and others.

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Some of the people outside of UVa who will see your information may not have to follow the same privacy laws that we follow. They may release your information to others, and it may no longer be protected by those laws.

The information collected from you might be published in a medical journal. This would be done in a way that protects your privacy. No one will be able to find out from the article that you were in the study.

**What if you sign the form but then decide you don't want your private information shared?**

You can change your mind at any time. Your permission does not end unless you cancel it. To cancel it, please send a letter to the researchers listed on this form. Then you will no longer be in the study.

**Please contact the Principal Investigator listed earlier in this form to:**

- Obtain more information about the study
- Ask a question about the study procedures or treatments
- Report an illness, injury, or other problem (you may also need to tell your regular doctors)
- Leave the study before it is finished
- Express a concern about the study

Principal Investigator: Randy Jones, PhD, RN, FAAN  
University of Virginia School of Nursing  
225 Jeanette Lancaster Way, Charlottesville, VA 22903.  
Telephone: (434)-924-0125

**What if you have a concern about this study?**

You may also report a concern about this study or ask questions about your rights as a research subject by contacting the Institutional Review Board listed below.

University of Virginia Institutional Review Board for Health Sciences Research  
PO Box 800483, Charlottesville, Virginia 22908, Telephone: 434-924-9634

When you call or write about a concern, please give as much information as you can. Include the name of the study leader, the IRB-HSR Number (at the top of this form), and details about the problem. This will help officials look into your concern. When reporting a concern, you do not have to give your name.



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## Signatures

### What does your signature mean?

Before you sign this form, please ask questions about any part of this study that is not clear to you. Your signature below means that you have received this information and all your questions have been answered. If you sign the form it means that you agree to join the study. You will receive a copy of this signed document.

### Consent From Adult

\_\_\_\_\_  
PARTICIPANT  
(SIGNATURE)

\_\_\_\_\_  
PARTICIPANT  
(PRINT)

\_\_\_\_\_  
DATE

**To be completed by participant if 18 years of age or older.**

### Person Obtaining Consent

By signing below you confirm that you have fully explained this study to the potential subject, allowed them time to read the consent or have the consent read to them, and have answered all their questions.

\_\_\_\_\_  
PERSON OBTAINING CONSENT  
(SIGNATURE)

\_\_\_\_\_  
PERSON OBTAINING CONSENT  
(PRINT)

\_\_\_\_\_  
DATE

### Signature of Impartial Witness

**If this consent form is read to the subject because the subject is blind or illiterate, an impartial witness not affiliated with the research or study doctor must be present for the consenting process and sign the following statement. The subject may place an X on the Participant Signature line above.**

I agree the information in this informed consent form was presented orally in my presence to the **identified individual(s)** who has had the opportunity to ask any questions he/she had about the study. I also agree that the **identified individual(s)** freely gave their informed consent to participate in this trial.

\_\_\_\_\_  
IMPARTIAL WITNESS  
(SIGNATURE)

\_\_\_\_\_  
IMPARTIAL WITNESS  
(PRINT)

\_\_\_\_\_  
DATE

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**APPENDIX B: RECRUITMENT FLYER**

## **Patient and Caregiver Experiences Living with Advanced Kidney Disease Study**

The University of Virginia School of Nursing seeks adults 18 years-old or older living with chronic kidney disease stage 5, or end stage kidney disease, for a research study. The purpose of the study is to understand what issues and concerns are most important to them related to living with kidney disease.

The study involves participation in one telephone interview. Flexible interview times available. Interviews are estimated to last 60-90 minutes. Participants will receive a \$30 gift card in appreciation of their time.

For more information please contact: Jonathan Yoder, MSN, RN  
Phone: 434-207-2234 Email: [jdy4gd@virginia.edu](mailto:jdy4gd@virginia.edu)  
IRB HSR # 22163  
Principal Investigator: Maureen Metzger, PhD, RN

**UVA SCHOOL OF NURSING**

## APPENDIX C: INTERVIEW GUIDE

### Patient and Caregiver Concerns in ACKD Interview Guide

1. I would like to start with a few general questions about you. These allow us to give a general sense of who we talked to in our interviews, but your information will not be reported in a way that you could be recognized. We also know that sometimes people with different backgrounds have different experiences or outcomes in the healthcare system, which is what makes these questions important to review. What is your age? What is your gender? What is your race/ethnicity? How far did you go in school? Would you say that you live in a rural, urban, or suburban community? When did you start dialysis?
2. When was the first time you (or patient's name) were told you have a kidney problem? How did you learn that your kidneys were failing?
3. Tell me about your current day-to-day experience living with kidney disease (or caring for [patient's name] while they are living with kidney disease).
4. How has having (or [patient's name] having) kidney disease changed your life?
5. What about kidney disease bothers you (or [patient's name]) most?
  - a. If only mention physical symptoms probe: Sometimes our physical health impacts our emotions. How is your mood given your health (or caregiving) situation?
  - b. If no spontaneous discussion of social dynamics: People often experience changes in relationships, changes in finances, changes in roles, and so on, related to kidney disease. Have those types of changes been a challenge for you (or [patient's name])?
6. How do you manage in terms of these challenges? What resources or people currently help with managing these concerns?
  - c. If uncertain: Sometimes people get help in different ways from family members, friends, other patients, health care professionals, social services programs, faith communities, and so on.
7. We are very interested in learning more about how people make choices or decisions about managing their kidney disease.
  - d. What types of decisions have you (or [patient's name]) had to make related to kidney disease?
  - e. Who was involved in decision-making?
  - f. What resources were helpful?

- g. What other resources would have been useful to you and [patient's name]?
- h. Are there any other decisions that were important or challenging (repeat question series 7 b–e until to other major decisions elicited)?

Probe: If do not mention dialysis versus other strategies (conservative management, transplant): I noticed you did not include making a choice about dialysis. Why is that?

- 8. Which of these resources have been helpful? How?
- 9. Are there gaps or problems related to your (or [patient's name]) kidney disease that you feel are not being addressed?
- 10. When you look into the future how do you see things going in terms of your (or [patient's name]) kidney problems? Do you anticipate things continuing as they are, getting better, getting worse?
- 11. What concerns you the most about the future?
- 12. Some people have suggested that something called palliative care (PC) may be helpful to people with kidney disease. Have you heard of palliative care?
  - i. If yes: From whom?
- 13. If I asked you to describe or explain palliative care, what would you say? There are no right or wrong answers, I am just interested in your thoughts.
- 14. Has anyone ever suggested that you (or [patient's name]) see PC? Who?
- 15. A. If seen by PC:
  - j. Did you (or [patient's name]) have a one-time appointment or are you (or [patient's name]) continuing to work with PC?
  - k. What has working with PC been like?
  - l. What did PC do or what are they doing?
  - m. Can you say more about your experiences with PC? How were they useful or not useful? Did/does having PC involved in your (or [patient's name]) care make a difference for you? If so, how?

- B. If referral discussed but not seen by PC:
- n. Why did you (or patient's name) decide not to meet with someone from the PC team?
  - o. Can you imagine a situation or problem that might lead you (or [patient's name]) to work with PC?
- C. If not offered referral or seen by PC: Some common reasons for involving the PC team include helping with making decisions, pain, and symptom management, and giving patients and families information and support.
- p. Do you see a role for the PC team in the care of your (or patient's name) kidney's failing? If so, can you say more about that? If not, why not?
16. What has your experience been living with kidney disease during the pandemic?
- q. Have your experiences with the pandemic made you think differently about your health?
  - r. About the future?
17. There are lots of people that are interested in how to take better care of people living with kidney disease, such as nurses, doctors, social workers, researchers, and policy makers. What you like them to know about how that could be done?
18. Because this is research, we will share what we learn with people who work with patients living with kidney disease and researchers. Is there anything that you feel is important for us to know or point out that was not covered in the interview?
19. Could you recommend a family member, friend, or other person who has been a help to you in some way, providing emotional support, helping with meals, with rides, with medicine, that I could call to see if they would want to be interviewed about their perspective on these questions?

Examples of possible general probe questions:

Anything else? Tell me more about that? What makes you say that? How did you feel about that?

Can you say more about what made that significant? Can you say more about what that means?

## APPENDIX D: CHART AUDIT FORM

Study ID			
Active co-morbid conditions (Based on most progress notes)			
Palliative care consult ever?			
Followed by palliative care for two or more visits ever?			
<i>(Based on HPI, assessment, plan and/or orders in progress note)</i>	Nephrology	Primary care	Other
Discussion of ACKD prognosis			
Discussion of RRT decision-making			
Discussion of advanced care planning			
Pain assessment/management			
ACKD symptom assessment/management			
RRT symptom assessment/management			
Psychological/psychiatric assessment/management			
Social support assessment/referral			

## Appendix E: IRB Approval

ASSURANCE FORM  
University of Virginia  
Institutional Review Board for Health Sciences Research  
HIPAA Privacy Board

<b>IRB – HSR # 22163</b>		
Event:  Approval New Protocol - Expedited	Type: Protocol	Sponsor(s):  University of Virginia Sponsor Protocol #:  <hr style="border: 0.5px solid black;"/> Principal Investigator: Maureen Metzger,  PhD, RN
Title: Patient and Caregiver Concerns in Advanced Chronic Kidney Disease: A Qualitative Study		
Assurance: Federal Wide Assurance (FWA)#: 00006183 UVa IRB #1 Registration IRB#00000447		
Certification of IRB Review:  The IRB-HSR/HIPAA Privacy Board abides by 21CFR50, 21CFR56, 45CFR46, 45CFR160, 45CFR164, 32CFR219 and ICH guidelines as compatible with FDA and DHHS regulations. This activity has been reviewed in accordance with these regulations.		
Event Date: 02/12/20 Protocol Expiration Date: 02/11/21 Number of Subjects: 40 Protocol: 02/05/20		
UVA Site Only Study-Application 02/05/20 Study-Data Security Plan 02/10/20		
Current Status: Open to enrollment		

Consent Version Dates:

Adult 02/05/20

Committee Members (did not vote): Randy Jones

Comments: The IRB determined the protocol met the criteria for approval per the federal regulations and was approved. It is open to enrollment.

The purpose of this study is to describe concerns and experiences of advanced chronic kidney disease (ACKD) patients and their caregivers across physical, emotional, social, and spiritual domains.

The study will involve and interview and medical record review. There is no outside sponsor for this study.

N=40 Ages= 18 years of age and greater

The following documents are on file with this protocol:



1. Clinical personnel script
2. Eligibility review script
3. Interview guide 01-03-2020

This study is not regulated by the FDA as it does not involve research on a drug, biologic or device. No vulnerable populations to be enrolled.

No additional committee approvals are required.

No compensation

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REGULATORY INFORMATION:

The IRB determined this protocol met the criteria of minimal risk.

Category #5: Research involving materials (data, documents, records, or specimens) that have been collected solely for non-research purposes (such as medical treatment and/or diagnosis).

Category #7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Written consent will be obtained for this study.

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PLEASE REMEMBER:

\* If an outside sponsor is providing funding or supplies, you must contact the SOM Grants and Contracts Office/ OSP regarding the need for a contract and letter of indemnification. If it is determined that either of these documents is required, participants cannot be enrolled until these documents are complete.

\* You must notify the IRB of any new personnel working on the protocol PRIOR to them beginning work.

- \* You must obtain IRB approval prior to implementing any changes to the approved protocol or consent form except in an emergency, if necessary to safeguard the well-being of currently enrolled subjects.
- \* If you are obtaining consent from subjects, prisoners are not allowed to be enrolled in this study unless the IRB-HSR previously approved the enrollment of prisoners. If one of your subjects becomes a prisoner after they are enrolled in the protocol, you must notify the IRB immediately.
- \* You must notify the IRB-HSR office within 30 days of the closure of this study.
  
- \* You are required to submit either an IRB Status Report or an IRB Update Form to the IRB-HSR at least once a year.

The IRB-HSR official noted below certifies that the information provided above is correct and that, as required, future reviews will be performed, and certification will be provided.

Name: Amy E. Blackman, MSN, RN, CCRC  Title: Member, Institutional Review Board for Health Sciences Research  Phone: 434-924-9634      Fax: 434-924-2932	Name and Address of Institution: IRB for Health Sciences Research University of Virginia, PO Box 800483 Charlottesville, VA 22908
	<b>OR</b>
	IRB for Health Sciences Research One Morton Drive, Suite 400 Charlottesville, VA 22903
Approval: Approved by Amy E. Blackman, MSN, RN, CCRC From IP Address: 128.143.229.234	Date: 02/12/20 at 12:31 PM

## APPENDIX F: FINAL CODE LIST

### *ACKD patient response*

ACKD symptom management  
 CKD diagnosis experience  
 CKD diagnosis story  
 Coping strategies for ACKD physical symptoms  
 Decision making  
 Future concerns  
 Future goals  
 Patient attitude/outlook  
 Self-management strategies

### *ACKD symptoms/impacts*

ACKD physical symptoms  
 Emotional impact of ACKD  
 Impact of non-RRT CKD treatment  
 Prognosis  
 Psychological impact of ACKD  
 Social impact of ACKD  
 Socioeconomic impact of ACKD/RRT  
 Spiritual impact of ACKD  
 COVID experiences

### *Caregivers*

Dialysis technician caregiver  
 Dietician caregiver  
 Family caregivers  
 For profit versus not-for-profit dialysis providers  
 Friend caregiver  
 Nurse caregiver  
 Other lay caregiver  
 Other professional caregiver  
 Physician caregiver  
 Social worker caregiver  
 Unspecified dialysis staff caregiver

Interdisciplinary care  
 Message for professionals

### *Palliative care*

Heard of PC?  
 PC experience?  
 PC referral?  
 PC role actual?  
 PC role recommended?

PC suggested?  
Patient definition/understanding of PC  
Perception of need for PC

***RRT***

RRT decision resource persons  
Coping strategies for physical symptoms of RRT  
Experience of RRT  
Experience of care coordination  
Non-physical impacts of RRT  
Physical impact of treatment  
RRT Clinician patient power dynamics  
RRT decision making  
RRT self-management other than physical symptoms  
RRT start perception of choice?  
RRT symptom management  
Starting RRT process

***Resources***

Family support (other than caregiving)  
Social services support  
Transportation

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