Health Care Decision-Making Among Older Patients with Advanced Chronic Kidney Disease and Their Carepartners: Advance Care Planning Preferences, Perceptions, and Experiences

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Abbreviations

ACP: Advance Care Planning

ADLs: Activities for Daily Living

CKD: Chronic Kidney Disease

CMS: Centers for Medicare and Medicaid Services

DART: Decision-Aid for Renal Therapy

GFR: Glomerular Filtration Rate

IADLs: Instrumental Activities for Daily Living

PC-ACP: Patient-Centered Advance Care Planning

Funding and Acknowledgements

This project was funded by the National Center for Advancing Translational Sciences, National Institutes of Health, Award Number KL2TR002545 (PI: Keren Ladin). The content of this thesis is solely the responsibility of the author and does not represent the official views of the NIH.

I would like to thank Dr. Keren Ladin, my thesis chair, for her outstanding guidance over my past three years in the Research on Ethics, Aging, and Community Health (REACH) Lab, and for granting me the opportunity to write this thesis. Thank you to Dr. Susan Koch-Weser for joining this project as my thesis reader and for her invaluable feedback and expertise as I have completed this project. Thank you also to Dr. Renuka Pandya for her leadership of the research team during data collection, and Dr. Shalini Tendulkar for her support and guidance during the thesis writing process this year. I would also like to acknowledge Dr. Daniel Weiner, Dr. John Wong, and Dr. Satia Marotta for their roles in research design and draft feedback. Lastly, I would like to express my gratitude to the patients and carepartners who participated in this study, as well as their clinicians who supported our research efforts.

Abstract

Patient-centered advance care planning (PC-ACP) improves the shared decision-making process among patients with advanced chronic kidney disease (CKD) and their carepartners, particularly regarding end-of-life care decisions. However, limited research has examined the actual end-of-life decision-making experiences of older patients with advanced CKD and their carepartners. This thesis investigates this population's ACP preferences, perceptions, and experiences through quantitative survey analysis. Surveys were conducted with 31 patients over the age of 70 and diagnosed with advanced CKD stage 4 or 5, at two clinical sites in the Boston area. Patients were asked to self-identify a carepartner (the person with whom they discuss important matters relating to their health care) to participate in the study alongside them, and 11 carepartners completed surveys.

Most patients (64%) had a written advance directive and a designated substitute decision maker (81%), and patients generally reported high trust and positive perceptions of their clinicians' judgments. However, few (16%) had actually discussed their preferences for life-sustaining treatment and end-of-life care with their nephrologist, and according to a set of quality indicators, few patients confirmed discussing components reflective of high quality PC-ACP. Nearly all patients and carepartners preferred comfort care over delay of death in situations of a stroke or heart attack (84% of patients and 73% of carepartners) or dementia (81% of patients and 73% of carepartners), but few patients (16%) had discussed these values and goals with their clinicians, nor had they discussed issues of decision-making capacity and consent to care (7%). Patients and carepartners generally agreed about goals of care, advance directives, and experiences with clinicians, though carepartners were more likely to report that they had experienced several discussion components reflective of high-quality PC-ACP.

Advanced CKD patients often believed that clinicians understood their end-of-life wishes, despite reporting that they had not engaged in key ACP conversations that would make those wishes known. Improving clinical communication about ACP may result in end-of-life treatment decisions that better align with patient goals. In addition, the implications of better end-of-life decision-making discussions could be a reduced emotional burden on carepartners, as well as improved bereavement outcomes among survivors. This thesis provides insights to achieving these goals by underscoring the need for PC-ACP among the advanced CKD population of patients and carepartners and discussing several ways that this can be accomplished through clinical and policy recommendations.

Introduction

Advanced Chronic Kidney Disease Among Older Patients

Older patients with advanced chronic kidney disease (CKD) and their carepartners face unique challenges when making health care decisions. This investigation into their preferences, perceptions, and experiences with advance care planning (ACP) aims to illuminate ways to improve their decision-making process regarding their health care and treatment plans. Advanced CKD is characterized by loss of kidney function, and almost a third (32.2%) of adults over age 60 in the United States have CKD, with these older patients belonging to the fastest growing age group with the disease (Saran et al., 2019). When CKD progresses to kidney failure, dialysis or transplantation become necessary to replace renal function, and the majority of these end-stage patients receive hemodialysis (63.1%), with a smaller proportion living with a functioning kidney transplant (29.6%) and the smallest proportion receiving peritoneal dialysis (7.0%) as treatment (Saran et al., 2019). Although kidney transplantation results in a significantly lower mortality risk than other treatments, older patients are often not good candidates for transplantation and do not receive kidney transplants as often as their younger counterparts (Saran et al., 2019; Panduranga et al., 2007). Therefore, these older patients often must decide between higher-intensity dialysis modalities and lower-intensity conservative management, which focuses on quality of life and symptom control, rather than replacement of renal function or extension of life (Chandna et al., 2011). This decision is time sensitive due to the relatively unpredictable trajectory of advanced CKD that often includes cognitive decline, the significant time and energy commitment needed if a patient chooses dialysis, and the clinical shift “from curing to caring” if a patient chooses conservative management instead (Berger et al., 2016; Van Biesen et al., 2004).

Though most older patients with advanced CKD go on to start dialysis, recent studies have shown that for patients with high comorbidity burdens, dialysis may not provide a significant survival benefit (Parvez et al., 2016). However, not all nephrologists discuss conservative management with advanced CKD patients as part of their usual care, and the timing of these discussions varies among providers (Ladin et al., 2018a). In addition, about a third (35.4%) of patients receive little or no nephrology care prior to kidney failure, leaving them in a critical position regarding the emergency decision to begin dialysis (Saran et al., 2019). Due to the illness trajectory of advanced CKD as a progressive decline in function marked by unpredictable complications that can be life-threatening, it is crucial to discuss renal replacement therapy (such as dialysis) before it is medically necessary, through the ACP process (Davison & Torgunrud, 2007; Sellars et al., 2018).

Advance Care Planning

Illness severity and comorbid conditions may impact the ability of older adults with advanced CKD to make choices and engage in treatment, particularly in the setting of acute medical events that require urgent treatment decisions (Berger et al., 2016; Davidson & Torgunrud, 2007; Kurella et al., 2005). ACP can preserve patient autonomy by ensuring that patient values, goals, and preferences for care are communicated to clinicians before the development of incapacity or the need for emergent decision-making (Sudore et al., 2017). Advance care plans can be recorded in written advance directives, such as living wills, do-not-hospitalize orders, and durable powers of attorney for health care. Completing these documents is one key component of patient-centered ACP (PC-ACP), which should also involve an ongoing discussion of treatment options and patient preferences within the patient-family-clinician triad,

as well as standardized documentation and organizational mechanisms to ensure clear access to a patient's advance care plans (Sinuff et al., 2015). These components are interconnected and each contributes to high quality PC-ACP, as summarized in Figure 1.

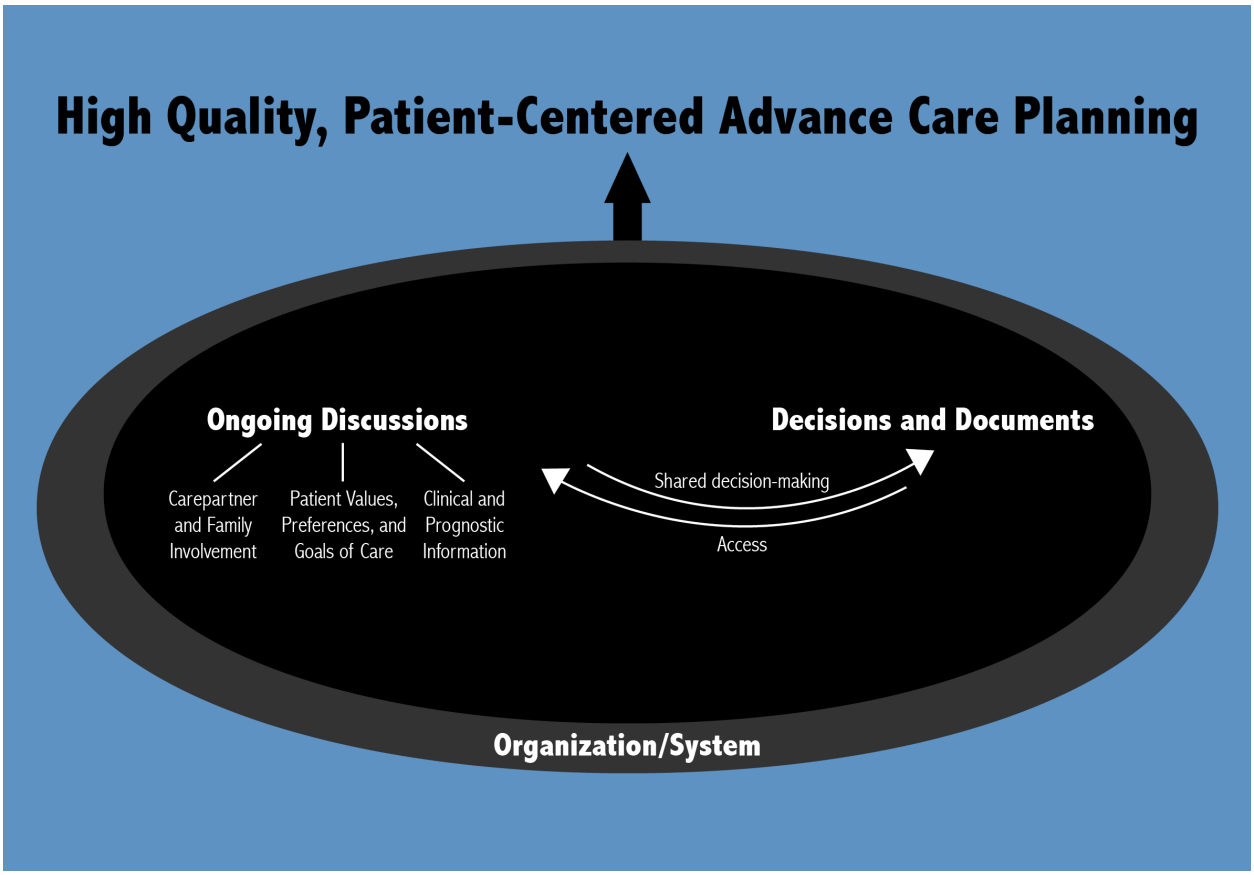

Figure 1. Interconnected components of high quality PC-ACP. Adapted from Sinuff et al.'s (2015) ACP quality indicators.

Shared Decision-Making

PC-ACP involves shared decision-making, which is a framework that describes a collaborative partnership between a clinician, a patient, and sometimes a patient's loved ones in making health care decisions and striving for the best outcomes according to the patient's preferences, values, and goals (Charles, Gafni, & Whelan, 1997; Hain & Sandy, 2013). This process encourages open dialogue that aims to align medical evidence and best practices with a

patient's unique needs, while building a patient-clinician relationship of trust and honesty (Hain & Sandy, 2013). The idea behind shared decision-making is that power is balanced when each player in the decision-making process shares information and partners to reach consensus, with mutual respect underlying the discussions (Charles, Gafni, & Whelan, 1997; Hain & Sandy, 2013).

Shared decision-making is of particular importance for patients with chronic diseases, such as advanced CKD. For these patients, the patient-clinician relationship is likely long-term, with many iterative decisions needing to be made over time (Charles, Gafni, & Whelan, 1997). These decisions need to be continuously monitored and potentially revised, which requires honesty and open communication from both sides of the clinical encounter (Charles, Gafni, & Whelan, 1997). Specifically for advanced CKD patients, whose treatment (i.e. dialysis) is often life-altering, shared decision-making can provide the foundation necessary to maximize success of the chosen treatment path by increasing patient engagement in the process and thus better aligning the decision with the patient's wishes and expectations (Hain & Sandy, 2013).

However, despite evidence supporting shared decision-making as beneficial to both clinical outcomes and patient satisfaction, not all nephrologists effectively engage in a shared decision-making process (Ladin et al., 2018b). An interview study of nephrologists characterized the different approaches of nephrologists to shared decision-making into four categories of clinician: paternalist, institutionalist, interpretive (navigator), and informative (patient-led) (Ladin et al., 2018b). These groups differed in their priorities in patient interactions and definitions of success, with paternalists and institutionalists prioritizing dialysis initiation, while interpretive and informative clinicians emphasized patient engagement and alignment of patient values with their treatment (Ladin et al., 2018b). More specifically, the paternalist approach

emphasized active treatment and protection of patient health, and the institutionalist approach was shaped by the norms and culture of a specific practice (Ladin et al., 2018b). Among those who prioritized engaging patients in their own treatment, interpretive clinicians processed patient input to guide them toward the optimal option, whereas the informative approach was most focused on patient education and autonomy (Ladin et al., 2018b). Notably, the only clinicians who mentioned discussion of conservative management with their advanced CKD patients were those categorized as interpretive or informative (Ladin et al., 2018b). The interpretive approach was demonstrated as most effective in achieving shared decision-making, since these clinicians focused on providing their patients with all the information and guidance needed to "steer" them toward a decision, after patients were given explicit opportunities to clarify their preferences, values, and goals for care (Ladin et al., 2018b). This clarification is crucial to PC-ACP, in order for patients to receive the best possible end-of-life care for their unique situations and expectations.

Patient-Centered Advance Care Planning

PC-ACP reflects the shared decision-making approach and requires a series of iterative discussions between patients, families, and clinicians to identify values and priorities in end-of-life decision-making (Davison & Torgunrud, 2007; Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Prioritizing ACP discussions is increasingly encouraged as evidence suggests that written advance directives alone might have limited efficacy, for reasons such as the complexity and quantity of decisions to be made, as well as patients sometimes changing their mind as their situations and preferences evolve (McMahan et al., 2013). Patients may be best served by identifying their values and engaging their loved ones to foster a shared understanding

of their desires among their families, decision-making surrogates, and clinicians (Briggs et al., 2004; McMahan et al., 2013; Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014).

Sinuff et al. (2015) developed a conceptual framework with four main categories relating to high quality PC-ACP: pre-hospitalization ACP, goals of care discussion, documentation, and organization or system. Within each of these categories, a multidisciplinary expert panel established several quality indicators and ranked them according to importance based on a review of the literature and several rounds of panel review to achieve consensus (Sinuff et al., 2015). The pre-hospitalization ACP category included high importance quality indicators such as discussion of patient preferences for life-sustaining treatment with their clinician, family, and substitute decision maker (Sinuff et al., 2015). ACP quality indicators including prognostic discussion and explanation of the outcomes, benefits, and burdens or risks of life-sustaining treatment, as well as of comfort care, were included in the goals of care discussion category (Sinuff et al., 2015). The documentation category indicators included written documentation in the patient's medical record of goals of care and ACP conversation outcomes, as well as completion of legal documents such as advance directives (Sinuff et al., 2015). Important organizational mechanisms in the systems-level category included up-to-date access to written advance directives and goals of care within the health care system, as well as policies, resources, and procedures to ensure that the clinical staff were attaining and maintaining ACP facilitation skills (Sinuff et al., 2015). These ACP quality indicators were adapted for use as survey questions in the present study.

As Sinuff et al.'s (2015) ACP quality indicator rankings demonstrated, ACP discussions necessarily include prognostic information, but clinicians are often reluctant to discuss prognosis with advanced CKD patients, and few validated tools exist to assist in risk prediction and

prognosis (Holley, 2012; Tangri et al., 2016). The need for honest discussion of diagnosis and prognosis is not always met for advanced CKD patients due to provider hesitance and fear of distressing the patient (Ladin et al., 2018a). However, timely prognosis discussions between patients and clinicians are associated with less emotional distress, better ACP outcomes, and enhanced patient hope (Davison & Simpson, 2006). In addition, most CKD patients express a strong desire to know about their diagnosis early in the disease, and early discussion can help mitigate emotions and clarify key information related to diagnosis, prognosis, and management before decision-making is urgent (Nunes et al., 2016).

Benefits of Advance Care Planning Among Advanced CKD Patients

PC-ACP has many benefits for advanced CKD patients, as well as for their carepartners and clinicians, relating to health outcomes as well as satisfaction with care. A systematic review of complex ACP interventions found that they positively impact end-of-life care in older adults by reducing hospitalizations, increasing utilization of hospice services, increasing compliance with patients' wishes, and increasing patient satisfaction with care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Among older adults with chronic diseases, PC-ACP promotes and improves shared decision-making (Briggs et al., 2014). PC-ACP also increases patient and family satisfaction, reduces decisional conflict (uncertainty when making a choice), and improves family bereavement outcomes (Briggs et al., 2014; Detering et al., 2010). Specifically among the advanced CKD population, PC-ACP also increases patient-carepartner congruence in decision-making and is associated with an increase in the number of patients who withdraw from dialysis (Kirchhoff et al., 2012; Song et al., 2015). The finding of ACP increasing withdrawal from dialysis is notable because advanced CKD patients frequently receive high intensity

treatment (i.e. dialysis, surgery, intensive care unit) in the last month of life, which often contradicts the patient preference for end-of-life care (Wong, Kreuter, & O'Hare, 2012).

Advance Care Planning Experiences of Advanced CKD Patients

Despite the importance of PC-ACP for older patients with advanced CKD and findings that most patients desire engagement in these discussions, ACP within this patient group rarely occurs until near death and often focuses heavily on written advance directives rather than iterative, holistic discussions (Hines et al., 1999; Holley et al., 1997; Luckett et al., 2014; Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Likely related to the low rates of ACP engagement among advanced CKD patients, many express regret about starting dialysis and a lack of understanding regarding palliative care (Hines et al., 1999; Davison, 2010). In fact, advanced CKD patients experience high intensity end-of-life care at higher rates compared to patients with similarly complex conditions, such as cancer (Wachterman et al., 2017). With the increasing recognition of the importance of ACP discussions, Centers for Medicare and Medicaid Services (CMS) began reimbursing clinicians for this activity in 2016, though early utilization rates are low (CMS, 2017; Belanger et al., 2019).

Qualitative studies show that ACP discussions with advanced CKD patients need to be more normalized, occur earlier in the disease progression, and be further tailored to each individual patient (Bristowe et al., 2015; Goff et al., 2015). Interviews with patients have also emphasized the potential for closer patient-nephrologist relationships to improve ACP engagement and satisfaction in the context of a shared decision-making approach (Goff et al., 2015). If approached properly, ACP can prepare patients and their loved ones as they approach

the end of life by clarifying goals of care and limits for intervention (Holley, 2005; Holley, 2012).

Patient and Carepartner Communication

Communication between patients and carepartners often plays a crucial role in health care decision-making for the population of older patients with advanced CKD. Patients report having ACP-like end-of-life care discussions with their family more often than with their doctors; thus, examining patient and carepartner communication is key to better understanding this population's ACP needs and desires (Hines et al., 1999). Further, many patients who are not having these conversations with their family (or other carepartners) and providers wish that they were (Holley, 2005; Hines et al., 1999). This suggests the existence of barriers that prevent patients who wish to discuss their health care preferences from actually engaging in these discussions within the patient-family-clinician context.

Carepartners who bear some or all of the decision-making responsibility, or worry that they might in the future, can face significant negative emotional burdens and effects such as stress, guilt, and doubt (Wendler & Rid, 2011). Given that advanced CKD is often accompanied by cognitive decline in the patient, proxy decision-making by carepartners is a particularly common occurrence (Drew et al., 2017; Tong et al., 2014). Optimizing communication between patients and carepartners, with the facilitation and support of providers, can lift some of this burden and ensure that all members of the decision-making process have clarity on the patient's values, expectations, and preferences (Holley, 2012; Wendler & Rid, 2011). However, barriers such as health literacy constraints may hinder optimal communication between patients, carepartners, and clinicians, especially for underserved populations (Ladin et al., 2018c).

Health Literacy Considerations in Advance Care Planning

Reaching underserved populations and patients with low health literacy are important considerations in improving the framework for PC-ACP, as this patient-centered process can provide an opportunity to overcome some of the barriers faced by these patient groups. However, limited health literacy can also impede ACP discussions, especially since end-of-life terminology can be misunderstood by patients or carepartners, potentially leading to care that may conflict with patient preferences (Ladin et al., 2018c). Thus, it is of the utmost importance that ACP discussions are as approachable as possible for people with diverse health literacy levels, and that preferences are appropriately documented through written advance directives that are made accessible in the medical record system. Further, since advanced CKD is associated with an increased risk in cognitive decline, which may likely lower health literacy, examining health literacy issues as they relate to these patients' ACP experiences is highly important (Drew et al., 2017).

Many people in the U.S. have limited health literacy, which can be defined as being below a 9th grade reading level and/or having difficulty understanding basic health information, and this presents a significant barrier to patient-clinician communication and decision-making (Cavanaugh et al., 2010). As a result, low health literacy is associated with an increased mortality rate and other poor clinical outcomes related to increased morbidity, intermediate disease markers, and general health status for patients with advanced CKD (Cavanaugh et al., 2010; DeWalt et al., 2004). In contrast, increased health literacy is associated with increased patient activation, which typically leads to better health outcomes and lower costs (Greene et al., 2015). Thus, improving health literacy and communication methods for patients with limited health literacy has the potential to significantly improve clinical outcomes and even save lives. In

addition, limited health literacy has been shown to be associated with underserved populations of minority race, low socioeconomic status, and low education level; thus, addressing health literacy issues can play a role in closing health disparities and improving outcomes for all (Green et al., 2011; Cavanaugh et al., 2010).

Moving beyond basic health literacy, previous research with the population of elderly dialysis patients revealed that many of these patients have a limited understanding of end-of-life terminology, presenting a barrier to adequate communication between patients and clinicians (Ladin et al., 2018c). Factors relating to and resulting from misunderstanding of this terminology include nephrologists' reluctance to discuss end-of-life, discordance between dialysis expectations and lived experiences, difficulty reconciling end-of-life values with their future care, and conformity to social expectations regarding end-of-life care (Ladin et al., 2018c). These form a barrier to health communication that could result in commitment to a treatment plan that misaligns with patient values and preferences (Ladin et al., 2018c). Therefore, addressing not only general health literacy issues but also specifically issues around end-of-life terminology is crucial to improving ACP among the population of advanced CKD patients.

Limitations of Previous Literature

Several gaps and limitations exist in the current literature related to health care decision-making and ACP among older patients with advanced CKD. Although almost a third of adults over age 60 have CKD, their end-of-life experiences have been understudied compared to patients with other high-mortality diseases (Saran et al., 2019; Wachterman et al., 2017). Several studies investigate the patient-clinician or patient-family relationships in the context of end-of-life care and decision-making, but there is a gap in the literature regarding the patient-family-

clinician triad in ACP for advanced CKD and the unique dynamics of this relational context. Patient and carepartner preferences, perceptions, and experiences of ACP for advanced CKD have also not often been directly compared through parallel survey design. In addition, many existing studies highlight patterns of shortcomings in the system of care for these patients, but not many studies describe evidence-based solutions on how best to educate advanced CKD patients about their treatment options in the context of ACP (Harwood & Clark, 2013; O'Hare et al., 2017; Tong et al., 2014; Tong et al., 2015).

Recent studies with advanced CKD patients, carepartners, and clinicians have demonstrated several gaps in knowledge and areas for further research. In particular, comfort care and conservative management discussions remain relatively unstudied areas, especially in regard to their implications for workflow and patient satisfaction (Ladin et al., 2018a; O'Hare et al., 2017). There remains room to better understand the advanced CKD patient population's values, goals, and preferences for care, and the extent to which these are currently addressed by clinicians and the advanced CKD healthcare system (O'Hare et al., 2017). Lastly, carepartner experiences, burdens, and roles also present room for further study (O'Hare et al., 2017; Bristowe et al., 2015; Sellars et al., 2018). The present research aims to address these gaps and limitations through analysis of advanced CKD patient and carepartner parallel surveys to explore their ACP preferences, perceptions, and experiences and place these findings in the context of the patient-family-clinician triad to propose evidence-based ACP recommendations.

Research Aims

PC-ACP helps to align treatments to patient preferences, reduce the emotional burden on carepartners, and improve bereavement outcomes among survivors. Strategies to encourage and improve ACP for older patients with CKD are needed. To develop strategies, the present research examines quantitative survey data collected from patients and carepartners about their ACP preferences, perceptions, and experiences to describe interactions and discussions between patients, carepartners, and clinicians. Our findings clarify how to improve ACP and end-of-life care by better aligning treatments to patient preferences, values, and goals, as well as reducing the emotional burden on carepartners and increasing mutual understanding of patient needs and wishes within the patient-family-clinician triad.

Methods

A cross-sectional survey of CKD patients and their caregivers was implemented in 2017-2018, at two clinical sites in the Greater Boston Area. The research team consisted of undergraduate and post-doctoral members of the REACH Lab, which is led by Dr. Keren Ladin at Tufts University. Primary data analysis was conducted to assess the ACP preferences, perceptions, and experiences of older patients with advanced CKD and their carepartners.

The baseline surveys analyzed for this thesis were part of the Decision-Aid for Renal Therapy (DART) Pilot Trial, which received Tufts Health Sciences Campus Institutional Review Board (IRB) approval on 1/18/2017 (IRB # 12345). The St. Elizabeth's Medical Center IRB also granted permission to conduct the study there in addition to at Tufts Medical Center, on 7/25/2017 (IRB # CR003).

Measurement Tool

For purposes of this thesis, only the baseline surveys of the DART Pilot Trial were analyzed, and the relevant portions of the patient and carepartner surveys are included in Appendices A and B, respectively. Characteristics of patients were determined by self-reported demographics, medical record review, and the Kidney Disease Quality of Life (KDQOL-36) questionnaire and scoring program, which assessed the effects and burdens of kidney disease on quality of life (Hays et al., 1994). Patients self-reported their ability to perform Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs), to assess independence and functional disability (Spector & Fleishman, 1998). The remainder of the survey included questions to assess patients' understanding of advance directives and participation in ACP, followed by the administration of the Quality of Patient-Clinician

Communication about End-of-Life Care scale (Cronbach's alpha 0.81) (Curtis, Patrick, Caldwell, Greenlee, & Collier, 1999). Developed in patients with advanced AIDS, the four-question instrument assessed communication between patients and clinicians by asking patients about their perceptions of their clinicians' level of understanding and care for them and their preferences (Curtis et al., 1999). This communication quality scale was validated against patient-clinician concordance on advance directives and treatment preferences, as well as Rubin et al.'s (1993) measure of patient satisfaction (Curtis et al., 1999). High quality assessments of communication were correlated with the clinician knowing that the patient had an advance directive ($c^2 = 4.95$; $P = 0.03$), and the communication scale also had a significant positive correlation with the previously validated measure of overall patient satisfaction with care ($r^2 = 0.76$, $p < 0.0001$) (Curtis et al., 1999). This instrument has been cited by over 100 studies that explore end-of-life care for patients with a wide range of conditions beyond AIDS.

After Curtis et al.'s (1999) communication quality scale, cultural sensitivity questions assessed how strongly patients felt that their clinicians understood their values and respected their backgrounds (Saha, Arbelaez, & Cooper, 2003). To assess patient and carepartner experiences of ACP, questions were adapted and listed according to Sinuff et al.'s (2015) ranking of ACP quality indicators. Lastly, to assess patient and carepartner goals of care, Song's (2004) Statement of Treatment Preferences was adapted such that patients and carepartners independently answered whether in two hypothetical scenarios: 1) a sudden stroke or heart attack, and 2) development of dementia, they would prefer either life-sustaining treatment (including dialysis) that delays death, or comfort care.

Participant Screening

At two hospital-based nephrology clinics in the Greater Boston area, electronic health records were used to screen for eligible patients — English-speaking, age 70 years or older adults with advanced CKD (stages 4 or 5, GFR between 15-30, and non-dialysis), with a greater than 15% risk of developing kidney failure according to the Kidney Failure Risk Equation (Tangri et al., 2016). In addition to these criteria, factors such as frequency of nephrology clinic visits, out-of-state residency, and nephrologist recommendation for participation were considered.

Enrolled patients were asked to identify a primary carepartner with whom they discussed "important matters," as defined by the General Social Survey (GSS) social network questions, and who would be most likely to engage in the health care decision-making process alongside the patient (Burt, 1984). During survey implementation, these individuals were referred to as "caregivers," but post-study stakeholder meetings emphasized a shift in language to "carepartners." The language of "caregivers" was cited as potentially misguiding and limiting patients to identifying only those individuals who were involved in providing assistance with other aspects of care, whereas the language of "carepartners" was deemed as more inclusive of anyone the patient turned to when making decisions, even if the patient was relatively autonomous. Carepartners also did not need to be related to the patient-participants, though they were often family members. The identified individuals did not need to live with or near the patient-participants, as the protocol allowed for carepartner phone interviews if necessary. Often, in cases where the patient-participant had identified a healthcare proxy or surrogate decision maker, the

carepartner was that person. These carepartners were approached and consented with patient and carepartner permission.

Participant Recruitment

Patients and carepartners were approached via mail, phone, and then in-person in the nephrology clinics to obtain signed consent, after they were screened for eligibility. Before patients were approached in-person, they were informed of the study via the recruitment letter and phone call, and their clinician was informed and consulted for appropriateness of the participant before they were formally consented. During the patient's initial recruitment meeting, they were asked to identify a carepartner, if possible. The patient (and possible carepartner) were then provided with informed consent forms and verbal information about the study, as well as given the opportunity to ask questions or take extra time to consider their participation.

Data Collection

For the patient participants, study team members read the survey aloud and provided a printed copy, along with visual aids to assist patients who may have had visual or cognitive impairment. Carepartners typically completed their own surveys in writing, usually in the same room. If a survey was left incomplete, it was completed either via phone or at a following visit shortly after. Patients and carepartners were both compensated for their participation.

Data Analysis

A REDCap database was used for storage and organization of survey responses, with patient and carepartner data assigned to the same anonymous participant ID. To determine the

frequency and proportion of responses, descriptive analyses were performed on survey data using SPSS, version 25. For Curtis et al.'s (1999) Quality of Patient-Clinician Communication about End-of-Life Care scale scoring, answers of "No," "Probably yes," and "Definitely yes" were scored as 1, 2, and 3, respectively, yielding a range from 4 to 12 when summing the four questions, with higher scores suggesting better interactions about the quality of end-of-life communications. Relevant sections of the baseline surveys were extracted and organized by participant groups: patients without carepartners, patients with carepartners, and carepartners.

Results

Sample Enrollment and Characteristics

Of 89 patients approached for participation in nephrology clinics (n = 29) and via mail (n = 60), 15 patients consented in the clinic and 18 consented following mailed recruitment letters for a total of 33 consented patients and 11 consented carepartners (37% patient consent rate). Ultimately, 42 participants (31 patients, 11 carepartners) completed surveys. Mean patient age was 79 ± 6.5 years; 67% were men; and 77% completed high school (Table 1). Average estimated glomerular filtration rate (eGFR) was 20 ± 4.9 ml/min/1.73m^2 (Table 1). All patients had difficulty with 1 or more IADLs, and 13% of patients had difficulty with 1 or more ADLs (Table 1).

Table 1: Sample Characteristics

Patient Characteristics	All Patients [No. (%)] n = 31	Patients without carepartners [No. (%)] n = 20	Patients with carepartners [No. (%)] n = 11
Age, mean (SD), years	79 ± 6.5	77 ± 6.2	79 ± 7.0
Gender			
Male	21 (68)	13 (65)	8 (73)
Female	10 (32)	7 (35)	3 (27)
Race			
White	24 (77)	14 (70)	10 (91)
Black or African American	4 (13)	4 (20)	0 (0)
Asian	1 (3.2)	0 (0)	1 (9)
Native American or Alaskan Native	1 (3.2)	1 (5)	0 (0)
Other	2 (6.5)	2 (10)	0 (0)
Marital Status			
Married or living with partner	16 (52)	9 (45)	7 (64)
Unmarried	15 (48)	11 55)	4 (36)
Annual Household Income			
< $25,000	5 (16)	3 (15)	2 (18)
$25,000-$50,000	7 (23)	3 (15)	4 (36)
> $50,000	15 (48)	10 (50)	5 (45)
Not specified	5 (16)	5 (25)	0 (0)
Completed High School	24 (77)	16 (80)	8 (73)
Difficulty with 1 or more ADL	4 (13)	1 (5)	3 (27)
Difficulty with 1 or more IADL	31 (100)	20 (100)	11 (100)
eGFR, mean (SD)	20 ± 4.9	21 ± 5.0	18 ± 4.0
KDQOL-36: Effects of Kidney Disease, mean (SD)	86 ± 15	88 ± 15	82 ± 13
KDQOL-36: Burden of Kidney Disease, mean (SD)	77 ± 25	80 ± 24	71 ± 27

Knowledge and Completion of Advance Directives

First, patients and carepartners were asked about their knowledge and completion of advance directives, as well as their participation in ACP discussions within clinical and familial settings. Nearly half (48%) of patients reported knowing what an "advance directive" was (Table 2). After being provided a definition, 65% of patients stated that they had an advance directive (Table 2). Most patients (81%) had designated a substitute decision maker in writing, and 58% of patients had discussed their preferences for life-sustaining treatments, such as dialysis, with this substitute decision maker (Table 2). However, far fewer patients (16%) said they had discussed their preferences for life-sustaining treatments with their nephrologist, and 19% of patients stated that they had discussed these preferences with other health care clinicians (i.e. a nurse, social worker, or spiritual carer) (Table 2). In general, within patients-carepartner pairs, carepartners appeared more likely than patients to say that they or the patient had discussed the patient's advance directives, including preferences for life-sustaining treatments, with their nephrologist or other health care professionals (Table 2).

Table 2: Advance Directives

	Patients [No. (%)] n = 31		Patients without carepartners [No. (%)] n = 20		Patients with carepartners [No. (%)] n = 11		Carepartners [No. (%)] n = 11	
	Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
Do you know what an advance directive is?	15 (48)	15 (48)	10 (50)	9 (45)	5 (45)	6 (55)	-	-
Do you/your loved one have an advance directive?	20 (65)	10 (32)	13 (65)	6 (30)	7 (64)	4 (36)	4 (36)	5 (45)
Discussed preferences for life-sustaining treatments with substitute decision maker?	18 (58)	11 (23)	14 (70)	4 (20)	4 (36)	7 (64)	6 (55)	3 (27)
Discussed preferences for medically appropriate life-sustaining treatments with nephrologist?	5 (16)	26 (84)	4 (20)	16 (80)	1 (9)	10 (91)	5 (45)	5 (45)
Discussed preferences for medically appropriate life-sustaining treatments with other health care professionals (i.e. nurse social worker and spiritual carer)?	6 (19)	24 (77)	5 (25)	14 (70)	1 (9)	10 (91)	5 (45)	3 (27)
Formally designated in writing (using appropriate legal documentation) someone to be the substitute decision maker?	25 (81)	6 (19)	16 (80)	4 (20)	9 (82)	2 (18)	7 (64)	3 (27)

Patient Expectations, Beliefs, and Trust in Clinicians

Patients were asked about their own perceptions of their clinicians in this section of the survey. Most patients (87%) said that they had someone (their primary care provider, nephrologist, or another clinician) whom they considered their personal health care provider (Table 3). Patients reported a mean trust level of 9.1 ± 2.1 on a scale from 0 to 10 when assessing this clinician's judgments about their medical care, though the strong ceiling effect on this data point limits its accuracy (Table 3). Despite this reported high level of trust, 37% of patients rated conversations with this clinician about their preferences for care as "poor" or "fair" (Table 3).

The mean score for the Quality of Patient-Clinician Communication About End-of-Life Care scale was 10 ± 1.6, out of a total possible score of 12 (Table 3). According to the questions within this scale, less than half of patients (40%) felt that their clinician "definitely" knew the kinds of treatment they would want if they became too sick to speak for themselves (Table 3). More patients (68%) said that their doctor "definitely" cared about them (Table 3). A similar majority (68%) of patients felt that their doctor listened to them in these discussions, and 77% felt that their doctor gave them sufficient attention (Table 3). In a set of questions concerning cultural sensitivity, 61% said that they "strongly agreed" that their doctor understood their background and values, and 87% "strongly disagreed" that their doctor lacked respect for them and the way they lived their lives (Table 3).

Table 3: Patient Expectations, Beliefs, and Trust in Clinicians

	Patients [No. (%)] n = 31				
	Yes	No			
Do you have someone you think of as your personal health care clinician?	27 (87)	3 (10)			
How much do you trust your personal health care clinician's judgments about your medical care? (Scale from 0 to 10) (M (SD))	9.1 ± 2.1				
Quality of Patient-Clinician Communication about End-of-Life Care Scale (Score from 4 to 12; Higher scores associated with better interactions) (M (SD))	10 ± 1.6				
Communication Scale Sub-Questions: 1. Do you think that your clinician knows the kinds of treatment you would want if you got too sick to speak for yourself?	Definitely Yes	Probably Yes	No		
	12 (40)	16 (50)	3 (10)		
2. When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor cares about you as a person?	21 (68)	10 (32)	0 (0)		
3. When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor listens to what you say?	21 (68)	10 (32)	0 (0)		
4. When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor gives you enough of his or her attention?	24 (77)	6 (19)	1 (3)		
Patient rating of the overall quality of discussions with their clinician about the kinds of treatment they would want if they became too sick to speak for themselves (n = 27)	Poor	Fair	Good	Very Good	Excellent
	4 (15)	6 (22)	5 (19)	6 (22)	6 (22)
Cultural Sensitivity: 1. I feel that my doctor understands my background and values.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	
	19 (61)	8 (26)	2 (6.5)	2 (6.5)	
2. I often feel as if my doctor looks down on me and the way I live my life.	0 (0)	1 (3)	3 (10)	27 (87)	

Patient Experiences with Clinicians According to ACP Quality Indicators

In this section of the survey, patient's ACP experiences were assessed according to Sinuff et al.'s (2015) ACP quality indicators. Few (26%) patients had engaged in discussions about prognosis, with only 16% of patients having discussed the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments (Table 4). Still fewer (10%) patients had been involved in discussions around comfort care (Table 4). Only 23% of patients noted being helped with accessing legal documents to communicate their advance care plans, and just 6.5% of patients and their families recalled being offered the opportunity to discuss issues around capacity and consent with regard to ACP (Table 4).

Only 16% of patients recalled having been asked by a clinician about what was important to them, such as values or spiritual beliefs as they consider health care decisions, and about half (45%) of patients indicated that they were given the opportunity to express their fears or concerns (Table 4). A minority (39%) of patients indicated that they were given the opportunity for clarification questions, and less than half (42%) of patients indicated that they had been informed that they could change their mind regarding goals of care decision-making (Table 4).

Most questions about patient experiences with clinicians were answered similarly among patients and their carepartners, but carepartners were more likely to say that a clinician had offered to arrange a family meeting, and more likely to say that they had been asked by a clinician about prior discussions or written documents about the use of life-sustaining treatment (Table 4). Carepartners were also more likely to say that their loved one had been offered support from the allied health care team, and more likely to say that a clinician had provided them and their loved one with "goals of care discussion" information to review prior to an appointment (Table 4).

Table 4: Patient Experiences with Clinicians According to ACP Quality Indicators

Has a member of the health care team talked to you and/or your substitute decision maker about…	Patients [No. (%)] n = 31		Patients without carepartners [No. (%)] n = 20		Patients with carepartners [No. (%)] n = 11		Carepartners [No. (%)] n = 11	
	Yes	No	Yes	No	Yes	No	Yes	No
Your/your loved one's prognosis?	8 (26)	22 (71)	5 (25)	14 (70)	3 (27)	8 (73)	1 (9)	9 (82)
The outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments?	5 (16)	26 (84)	4 (20)	16 (80)	1 (9)	10 (91)	3 (27)	7 (64)
The outcomes, benefits, and burdens of focusing on comfort care as the goal of your treatment?	3 (10)	28 (90)	2 (10)	18 (90)	1 (9)	10 (91)	4 (36)	6 (55)
Arranging a time when you, your substitute decision maker, and/or your family can meet with the doctor to discuss your treatment options and plans?	6 (19)	24 (77)	4 (20)	15 (75)	2 (18)	9 (82)	6 (55)	4 (36)
Whether you had prior discussions or have written documents about use of life-sustaining treatments?	5 (16)	24 (77)	4 (20)	14 (70)	1 (9)	10 (91)	7 (64)	2 (18)
What is important to you/your loved one (such as values, spiritual beliefs, and/or other practices) in considering health care decisions at this stage of your life?	5 (16)	25 (81)	4 (20)	15 (70)	1 (9)	10 (91)	4 (36)	5 (46)
Your fears or concerns?	14 (45)	16 (52)	11 (55)	8 (40)	3 (27)	8 (73)	6 (55)	2 (18)
Whether you had any questions or needed things clarified regarding your overall goals of care?	12 (39)	17 (55)	7 (35)	11 (55)	5 (45)	6 (55)	5 (46)	4 (36)
What treatments you/your loved one prefer to have or not have if you/they develop a life-threatening illness?	6 (19)	24 (77)	5 (25)	14 (70)	1 (9)	10 (91)	3 (27)	4 (36)
Information that you/your loved one may change your/their mind regarding decisions around the goals of care?	13 (42)	16 (52)	10 (50)	8 (40)	3 (27)	8 (73)	4 (40)	3 (30)
Have you and your family been offered an opportunity to discuss with members of your health care team issues around capacity and consent with regard to advance care planning? Specifically, what actions would take place in the event that you lose capacity to consent to care?	2 (6.5)	26 (84)	2 (10)	15 (75)	0 (0)	11 (100)	3 (27)	5 (46)
Have you and your family been offered support from the allied health care team (e.g. spiritual carers, social workers, and clinical nurse specialists) as needed?	2 (6.5)	29 (94)	2 (10)	18 (90)	0 (0)	11 (100)	6 (55)	5 (46)
Has a member of your health care team provided you and/or your family with information about "goals of care discussion" to look at before conversations	3 (10)	26 (84)	3 (15)	15 (75)	0 (0)	11 (100)	4 (36)	5 (46)

with the doctor?								
Has a member of your/your loved one's health care team helped you and/or your family access legal documents to communicate your/your loved one's Advance Care Plans?	7 (23)	24 (77)	5 (25)	15 (75)	2 (18)	9 (82)	3 (27)	8 (73)

Patient and Carepartner Goals of Care

Lastly, patients and carepartners described their goals of care in two hypothetical scenarios: a stroke or heart attack, or the development of dementia. For both scenarios, the majority (84% and 81%, respectively) of patients preferred a focus on comfort care over life-prolonging treatment (Table 5). None of the carepartners preferred delaying death for the patient in either scenario, although some (44% and 22%, respectively) reported uncertainty (Table 5). Comparing patient and carepartner responses, they almost all agreed on focusing on comfort as the preferred approach, with the exception of two patients preferring life-prolonging treatment in the first scenario when their carepartners preferred otherwise or were unsure (Table 5).

Table 5: Patient and Carepartner Goals of Care

Stroke or Heart Attack	**All Patients [No. (%)] (n = 31)**	**Patients without carepartners [No. (%)] (n = 20)**	**Patients with carepartners [No. (%)] (n = 11)**	**Carepartners [No. (%)] (n = 9)**
The goals of care should be focused on delaying death.	2 (6)	1 (5)	1 (9)	0 (0)
The goals of care should be focused on comfort and peace.	26 (84)	18 (90)	8 (73)	5 (56)
I am not sure.	3 (10)	1 (5)	2 (18)	4 (44)
Dementia				
The goals of care should be focused on delaying death.	1 (3)	0 (0)	1 (9)	0 (0)
The goals of care should be focused on comfort and peace.	25 (81)	17 (85)	8 (73)	7 (77.8)
I am not sure.	5 (16)	3 (15)	2 (18)	2 (22.2)

Discussion

Among older adults with advanced CKD, most believed that their clinicians (nephrologists) knew what treatment they would want, even though very few patients recalled actually having had conversations with their clinicians about these preferences. Their levels of trust and perceived quality of communication with their clinicians were high, which is consistent with findings for patients with other complex chronic diseases (Curtis et al., 1999). However, despite their confidence in their clinicians, most patients reported communication experiences that did not satisfy PC-ACP quality indicators (Sinuff et al., 2015). Specifically, most were not asked about their values, fears, or concerns, or whether they had any clarifying questions. Most had not discussed the possibilities of changing their mind or losing the ability to consent to care, and few were offered support from the allied health care team or helped by their clinician to complete written advance directives. This discrepancy between perceptions and experiences demonstrates the unmet potential for PC-ACP to better engage this patient population, and several clinical and policy-level implications of this will be discussed.

Our findings aligned with previous evidence in showing that most patients desired ACP engagement, but rarely experienced it (Holley, 2012). When it did occur, it was often overly focused on written advance directives rather than iterative discussions, and prior evidence demonstrates that even this document-driven form of ACP often does not occur until the very end of life for advanced CKD patients (Hines et al., 1999; Holley et al., 1997; Luckett et al., 2014; Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). This lack of actual engagement in key components of ACP, as demonstrated by our findings and prior studies, likely plays a role in patients' occasional regret after starting dialysis (Davison, 2010; Holley et al., 1997; Luckett et al., 2014; Sinuff et al., 2015). This regret could likely be avoided in some cases

if clinicians made sure to include conservative management discussions in their standard ACP process (Ladin et al., 2018a). In addition, clinicians should make clear to patients that they can change their mind, and our finding that fewer than half of patients were aware that they could shift their decision emphasizes the importance of this clarification. The self-reported patient perceptions of clinicians in our study demonstrate the trust that advanced CKD patients hold in their clinicians. However, the strong discrepancy between these positive perceptions by patients and their following lack of actual ACP experiences with clinicians highlights the need to improve communication efforts to prevent patient regret and improve understanding of all their end-of-life care options. The sensitive nature of advanced CKD and the life-altering health care decisions involved necessitates this demonstrated high level of trust, but patient trust must be matched by clinician facilitation of shared decision-making and PC-ACP (Berger et al., 2016; Charles, Gafni, & Whelan, 1997). Furthermore, this strong trust and the high esteem that patients in our study held for their clinicians should show that these patients are open to increased engagement with their clinicians and encourage nephrologists to center these patients in ongoing ACP discussions.

Lack of Clinician-Initiated Discussion of Prognosis

Clinicians play an important role in PC-ACP, and this role includes facilitating a discussion of prognosis with the patient and their family and guiding them through understanding and processing this crucial, yet often difficult information. These clinician-led conversations are shown to improve ACP outcomes and reduce emotional distress (Davison & Simpson, 2006). However, few patients reported discussing their prognosis with their clinicians, despite evidence that patients want to know their prognosis even when the predicted outcomes are not desirable (Ladin et al., 2016). This is consistent with previous findings indicating that

clinicians are often reluctant to discuss prognosis with advanced CKD patients, in part because they lack CKD-specific validated tools to assist them in providing effective and compassionate guidance to an individual's estimated life expectancy (Couchoud et al., 2016; Holley, 2012). Future research should investigate this reluctance in CKD care, as in other advanced diseases, including advanced cancer, discussion of prognosis is associated with more realistic patient expectations and has not been shown to harm the patient's emotional well-being or the patient-clinician relationship (Enzinger, Zhang, Schrag, & Prigerson, 2015). In fact, the shared decision-making approach emphasizes that open communication of information, including prognosis, is crucial to building a strong patient-clinician relationship with foundations of trust and honesty (Charles, Gafni, & Whelan, 1997).

Patient-Family Discussions and the Patient-Family-Clinician Triad

Our findings also demonstrate that some patients who have not engaged in ACP discussions with their clinicians may still be having similar conversations with their loved ones. In terms of advance directives, more patients had formally designated a surrogate decision maker than had completed a written advance directive. Moving beyond written documents, most patients had discussed the use of life-sustaining treatment with their surrogate decision maker (often a family member), whereas only a small minority of patients reported having these discussions with a doctor. This finding matches existing evidence that ACP-related discussions occur most often in the patient-family context rather than between patients and clinicians, though most patients desire these conversations to occur in both these contexts (Holley, 2005; Hines et al., 1999). Yet, PC-ACP has been demonstrated to be most effective when clinicians promote shared decision-making with the patient and their family, and effective PC-ACP and shared decision-making improves patient and family satisfaction and reduces decisional conflict

(Holley, 2005; Briggs et al., 2004; Detering et al., 2010). Therefore, clinicians should accept the role of introducing PC-ACP into the patient-family-clinician triad, with emphasis on bringing to light conversations that the patient and family may likely already have had about their values and goals in regard to end-of-life care. Clinicians can then guide the patient and their loved ones through clarifying the implications of these values and goals in terms of preferences for life-sustaining treatment, in an environment of mutual respect and understanding, where each member of the triad has the patient's best interests in mind.

Among advanced CKD patients, PC-ACP is associated with an increased number of patients who withdraw from dialysis — a finding that likely demonstrates how PC-ACP can increase patient knowledge of alternatives to dialysis and improve congruence of care with patient wishes, as most of these patients prefer comfort care over dialysis (Kirchhoff et al., 2012). For carepartners, PC-ACP discussions can lower their decision-making burden if the patient loses the capacity to make treatment decisions for themselves. In a systematic review of the effect of making treatment decisions for an incapacitated adult on surrogate decision makers, at least one-third experienced negative emotional burdens, which were often substantial and long lasting (Wendler & Rid, 2011). When clinicians engage in these discussions and facilitate positive communication between the patient-family-clinician triad to ensure that surrogate decision makers feel confident in knowing which treatment is consistent with the patients' preferences, this can reduce the emotional burden on surrogate decision makers (Holley, 2012; Wendler & Rid, 2011).

Our findings also demonstrate that patients and their carepartners do not always agree and may remember discussions with clinicians differently. One reason for the patient-carepartner discrepancies may be limited health literacy relating to end-of-life and disease-specific

terminology, which is a significant barrier to communication with clinicians and can lead to a more intensive care plan than a patient may actually want (Ladin et al., 2017). However, PC-ACP has been demonstrated to increase patient-carepartner congruence in decision-making (Song et al., 2015). This reinforces the need for clinicians to engage patients and their families together in PC-ACP conversations, as improved shared decision-making efforts by the clinician could increase patients' understanding of their disease and care options as well as improve concordance and help all members of the patient-family-clinician triad have a mutual understanding of the patients' preferences and treatment path.

Comfort Care vs. Delay of Death

Lastly, when presented with specific scenarios where longer life would be associated with substantial negative impacts on quality of life, the present study shows that nearly all patients and carepartners expressed a preference for focusing on comfort over delaying death as a care goal. This is consistent with previous research demonstrating that patients most often desire comfort care at the end of life and prefer to not die in a hospital, and evidence shows that patients who experience appropriate ACP are more likely to receive comfort care in alignment with these wishes (Silveira, Kim, & Langa, 2010). For advanced CKD patients, the choice to pursue comfort care in place of dialysis is highly sensitive and requires thorough education and open communication between a patient and their clinician. Most of these patients go on dialysis, despite evidence that may not support an increased life expectancy with that higher intensity treatment path (Parvez et al., 2016). One reason for this is likely that it is not always standard practice to discuss comfort care or conservative management with advanced CKD patients, or these discussions may not occur early enough in the illness trajectory to accurately assess a patient's preferences and allow them sufficient time to ponder their choice (Ladin et al., 2018a).

Thus, the integration of PC-ACP into usual care for older patients with advanced CKD and their carepartners presents an important opportunity to delineate a patient's goals, values, and preferences in order to best tailor and align their future care.

Implications and Recommendations for the Future

Clinical Implications

Our findings present implications for how clinical care can improve to better address the ACP needs of the advanced CKD patient population and their carepartners. First, clinicians must recognize the high level of trust that their patients hold in the clinician's judgments and acknowledge that this patient trust does not necessarily mean that the clinician actually does know what a patient wants for their health care. However, the demonstrated trust of these patients in their nephrologists should be encouraging to these clinicians, with the implication that patients would likely listen to and consider their clinicians' judgments during ACP discussions. Yet, these discussions do not appear to be happening according to a PC-ACP framework. Our findings highlighted discrepancies between patients' optimistic perceptions of their clinician's understanding and the clinical realities that most of the patients had no recollection of experiencing many of the key components of effective PC-ACP. These vital components of PC-ACP include, according to the shared decision-making framework and Sinuff et al.'s (2015) ACP quality indicators: early initiation and frequent revisiting of ACP discussions; involvement of family; compassionate guidance to understanding prognosis; explanation and discussion of the benefits and burdens (or risks) of all care and treatment options, including conservative management; exploration of patient preferences, values, and goals; explicit opportunities to ask questions, express fears or concerns, or change one's mind; written documentation of advance

care plans; and organizational commitment to making these up-to-date written documents easily accessible and securely stored in the medical records system. Each of these components must be clearly articulated so that the patient and their family or carepartner can be fully engaged in the process. Particularly with the last component relating to documentation and storage, it is crucial that clinical institutions standardize the location of ACP documentation in electronic health records and ensure that clinicians are trained in how to properly complete, sign, and store these documents. Standardization of storage mechanisms and training of the entire interdisciplinary health care team could help avoid existing issues relating to variation within and between clinical practices that hinder transferability of ACP documentation, such as between an outpatient and an inpatient setting (Wilson et al., 2013). Improved storage and training would streamline the PC-ACP process and ensure that important decisions made during these discussions are not lost or forgotten as a patient moves through the healthcare system.

Policy Implications

Clinical interventions and improvements are most effective when they have the backing of systemic, policy-level change. It is an important step that CMS now offers reimbursement to clinicians who engage in ACP discussions, though early data show minimal ACP reimbursement claim rates by nephrologists (Belanger et al., 2019). This suggests that structural barriers to ACP still exist, one of which may be the relatively low financial incentive offered by the CMS reimbursement (Belanger et al., 2019). Additionally, documentation barriers may exist, particularly when the PC-ACP discussions are somewhat informal and spread apart, and health literacy issues may also limit engagement in these discussions (Belanger et al., 2019; Ladin et al., 2017). Reimbursement may thus not be sufficient to incentivize nephrologists to begin these

challenging conversations and to document these discussions in a patient's medical records, but it could serve as one important step to addressing the social, professional, and structural barriers to patient-clinician communication of end-of-life preferences.

In order for national level change, such as the CMS reimbursement, to reach its potential, individual institutions must first buy in to the mission to increase and improve PC-ACP facilitation. To begin, institutions can better educate future and current health care providers on PC-ACP and shared decision-making, and these processes should be integrated into standardized medical curriculum as necessary elements of a positive patient interaction and relationship. Components of ACP that have proved particular difficulty, such as discussion of prognosis, merit special attention in medical training. Clinicians should know that patients desire this information and learn how to effectively and compassionately facilitate these prognostic discussions such that a patient and their family can be provided with all the knowledge necessary to make the best decision for their unique situation.

Clinicians should also be trained to interact effectively with families and carepartners, especially if they are in a specialty such as nephrology where they frequently engage with these non-patient actors. Issues of capacity to engage in the decision-making process and to consent to care must be addressed from an institutional standpoint, so that clinicians know how to best proceed and can communicate this information to the patient and carepartner, preferably before the event of incapacity. In addition, a shift away from emphasis on high intensity treatment programs (i.e. dialysis) for older advanced CKD patients and a focus on educating clinicians on conservative management and comfort care could lead to better alignment of care with patient wishes and values for the end of life. As previously discussed, clinicians as well as the entire health care team should be trained in proper completion and storage of ACP documentation,

potentially with standardization across institutions in regard to location of ACP documents in the electronic health records system. Lastly, institutions should prioritize communication and discussion of federal policy-level changes such as the CMS reimbursement, so that all clinicians are aware of these opportunities and of the broader push for an improved PC-ACP landscape.

Strengths and Limitations of the Study

The strengths of this study were that the survey included a wide and comprehensive range of questions that assessed both perceptions and experiences regarding ACP, and that patient and carepartner responses were directly compared. In addition, the method of individual, one-on-one surveys allowed for clarifications to be made when necessary and for the patients to go at their own pace, possibly reducing the potential for inaccurate responses and increasing patient comfort with the study.

The population was limited to older adults with advanced CKD not receiving dialysis who were able to complete study surveys, limiting generalizability to higher functioning older adults. Additionally, both the patient and carepartner samples were fairly small. Further, all participants lived in the greater Boston area, and most of the surveyed patients were white men, thereby limiting generalizability to the broader, diverse population. A larger sample size with greater diversity could have the power to possibly detect disparities and incongruences that our current sample could not demonstrate. Recall bias could also have skewed results, as many of the questions asked patients and carepartners to recall previous events and experiences. In addition, the measure of trust (a self-reported trust score from 0 to 10) had a strong ceiling effect, and future studies should consider alternative ways to measure patient trust in clinicians, possibly with an extended scale or with non-numeric options. In general, further research is warranted to

extend the findings of this study to the wider and more diverse population of older adults with advanced CKD.

Conclusion

Our findings show that patients' perceptions of their clinicians' understanding of their treatment wishes often do not align with the completion of key PC-ACP steps in actual discussions with clinicians about their end-of-life goals, values, and preferences. Most patients and carepartners preferred comfort care over delaying death in different end-stage disease scenarios, and applying this to advanced CKD demonstrates the necessity of thorough PC-ACP discussions that align patient preferences with treatment to improve quality of life, better satisfy patient and carepartner wishes, improve concordance between patients and carepartners, and reduce emotional distress for all parties involved.

Clinicians should work to better incorporate key PC-ACP components, such as communicating prognosis, engaging patients and families in shared decision-making, and facilitating completion and proper storage of ACP documentation. Further, PC-ACP discussions should occur in the context of the patient-family-clinician triad, especially since these conversations often already occur in the patient-family context. Clinicians should work to understand the values and background of the patient and their family and guide them to achieve consensus on the treatment path forward, as this dyad may have differences in their perceptions of clinical interactions. With improved facilitation of PC-ACP, all members of the patient-family-clinician triad can achieve a mutual understanding of the patient's preferences, values, and goals of care.

Institutional and policy-level change should also play a role in improving the PC-ACP landscape and ultimately establishing a system where patients feel engaged in their health and receive care that aligns with their preferences, values, and goals. These systems-level recommendations include further reimbursement for PC-ACP, improved education and training

to help clinicians act as effective facilitators, and standardized documentation and storage procedures. Achieving the goal of an improved PC-ACP landscape has potential to improve advanced CKD patient and carepartner quality of life and satisfaction with their care.

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Appendix A: Patient Surveys

Participant ID#:

Interviewer:
Date: ____ ____/____ ____/____ ____

Start time:

Stop time:

Interviewer Script:

Thank you for participating in this study being conducted by researchers at Tufts University and Tufts University Medical School. It is important that your opinions be heard.

During this interview, we will ask you to think about your experiences making decisions about treatments for kidney disease or helping others who face these decisions. We are interested in learning more about the conversations that you have regarding treatment selection (or guiding others with treatment choices), and regarding advance care planning. We are interested in your opinions about the timing of these conversations, who should be engaged in the process, and what type of information would be helpful in discussing these decisions in a clinical setting.

The results will be used to help us understand how people make decisions about initiating dialysis and advance care planning, what aspects of the decision-making process could be improved, and how the experience of receiving dialysis impacts patients and their families.

We would like to assure you that your responses are confidential.
Information that identifies you will not be shared with anyone.

Thank you for your valued input.

Confidential

Advance directives_patient

Record ID _____

These questions are to be completed by the patient only.

Do you know what an advance directive is?
- ◯ Yes
- ◯ No
- ◯ I'm not sure

Do you have an advance directive?
- ◯ Yes
- ◯ No
- ◯ I'm not sure

If you do not have an advance directive, why? (choose one)
- ◯ Doesn't apply; I have an advance directive
- ◯ I don't know what an advance directive is
- ◯ I never thought about signing one
- ◯ I don't need it because I'm in good health
- ◯ I don't need it because my family knows my wishes
- ◯ I don't need it because my doctor knows my wishes
- ◯ Some other reason

What type of advance directive do you have?
- ☐ Living will
- ☐ Durable power of attorney for health care/Health care power of attorney/Health care proxy
- ☐ Other
- ☐ Unknown

What type of advance directive do you have? _____

When did you complete your advance directive? (What month)
- ◯ January
- ◯ February
- ◯ March
- ◯ April
- ◯ May
- ◯ June
- ◯ July
- ◯ August
- ◯ September
- ◯ October
- ◯ November
- ◯ December
- ◯ I don't know

When did you complete your advance directive? (What year?) _____
(Year advance directive completed/signed (e.g. 2016); if unknown, enter "unknown")

Who has access to your advance directive? (can check multiple)
- ☐ My family
- ☐ My friends
- ☐ My lawyer(s)
- ☐ My doctor(s)
- ☐ Clergy
- ☐ Other

Confidential

These questions concern advance care planning. Please answer at baseline and 3-month follow up only.

	Yes	No	I don't know	Refused
Have you discussed your preferences for using or not using life-sustaining treatments with your substitute decision maker (a person who makes health care decisions on your behalf)?	○	○	○	○
Has your doctor talked to you and or a family member about your prognosis, or indicated how much time you have to live?	○	○	○	○
Have you and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with your family doctor or other doctor?	○	○	○	○
Have you discussed your preferences for using or not using medically appropriate life-sustaining treatments with other family members?	○	○	○	○
Have you formally designated in writing (using appropriate legal documentation) someone you trust to be your substitute decision maker concerning medical treatment decisions in the event you are not able to do so? In case of power of attorney it should be related to health care.	○	○	○	○
Did a member of your health care team offer to arrange a time when you and your family could meet with the doctor to discuss the use of medically appropriate life-sustaining treatments they would want or not want in the event that your physical health deteriorates?	○	○	○	○

Confidential

Do you have an advance directive or living will, or have you indicated in some other way (for example, verbally, through a video, and so on) the medical treatments you would want or not want in the event that you are unable to communicate for yourself as a result of a life-threatening health problem?	○	○	○	○
Have you and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with other health care professionals (i.e. nurse social worker and spiritual carer)	○	○	○	○

Confidential

Clinical info_patient

Record ID _____

(PATIENT ONLY) The following questions should be asked of the patient.

Who do you live with? (can check multiple)
- ☐ Spouse/partner
- ☐ Children
- ☐ Other relatives
- ☐ Friends
- ☐ Roommate(s)
- ☐ No one
- ☐ Other
- ☐ Unknown

What is/are the cause(s) of your kidney disease? (can check multiple)
- ☐ Diabetes
- ☐ Hypertension
- ☐ Glomerulonephritis
- ☐ Polycystic or other inherited kidney disease
- ☐ Obstructions (kidney stone, tumor or enlarged prostate gland in men)
- ☐ Other
- ☐ Unknown

Have you ever attended a dialysis options/education class?
- ○ Yes
- ○ No
- ○ Unknown

The questions below are to be determined by reviewing the patient's medical chart.

Insurance provider
- ○ Medicare
- ○ Medicaid
- ○ Private
- ○ VA
- ○ Uninsured
- ○ Other
- ○ Unknown

Does patient have history of or currently have diabetes?
- ○ Yes
- ○ No
- ○ Unknown

Does patient have history of or currently have coronary heart disease?
- ○ Yes
- ○ No
- ○ Unknown

Does patient have history of or currently have peripheral vascular disease?
- ○ Yes
- ○ No
- ○ Unknown

Does patient have history of or currently have cancer?
- ○ Yes
- ○ No
- ○ Unknown

Confidential

Cause(s) of patient's kidney disease (from chart)

- ☐ Diabetes
- ☐ Hypertension
- ☐ Glomerulonephritis
- ☐ Polycystic or other inherited kidney disease
- ☐ Obstructions (kidney stone, tumor, or enlarged prostate gland in men)
- ☐ Other
- ☐ Unknown

(Causes of patient's CKD as determined from medical record)

Does patient have dialysis access in place?

- ◯ Yes
- ◯ No
- ◯ Unknown

Is dialysis access functional?

- ◯ Yes
- ◯ No
- ◯ Unknown

What date was dialysis access placed? _____

Hemoglobin value _____
(most recent hemoglobin value)

Serum Albumin _____
(most recent serum albumin value (listed in Chem-Other))

Serum Calcium _____
(most recent serum calcium value)

Serum Phosphate/Serum Phosphorus value _____
(most recent Serum Phosphate/Serum Phosphorus value)

Serum Bicarbonate/CO2 _____
(most recent serum bicarbonate value (listed in Chem-Panels))

Confidential

Katz ADL_patient

Record ID _____

(PATIENT ONLY) For each of the six activities below, select the description that best matches your ability to complete the task.

Bathing	○ Bathes self completely or needs help bathing only a single part of the body such as the back, genital area or disabled extremity. ○ Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
Dressing	○ Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes. ○ Needs help with dressing self or needs to be completely dressed.
Toileting	○ Goes to toilet, gets on and off, arranges clothes, cleans genital area without help. ○ Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
Transferring	○ Moves in and out of bed or chair unassisted. Mechanical transfer aids are accepted. ○ Needs help in moving from bed to chair or requires a complete transfer.
Continence	○ Exercises complete self control over urination and defecation. ○ Is partially or totally incontinent of bowel or bladder.
Feeding	○ Gets food from plate into mouth without help. Preparation of food may be done by another person. ○ Needs partial or total help with feeding or requires parenteral feeding.
ADL total points	_____

Confidential

Lawton-Brody IADL_patient

Record ID _____

(PATIENT ONLY) For each category, select the item description that most closely resembles the patient's highest function level.

Ability to Use Telephone	◯ Operates telephone on own initiative-looks up and dials numbers, etc. ◯ Dials a few well-known numbers ◯ Answers telephone but does not dial ◯ Does not use telephone at all
Shopping	◯ Takes care of all shopping needs independently ◯ Shops independently for small purchases ◯ Needs to be accompanied on any shopping trip ◯ Completely unable to shop
Food Preparation	◯ prepares, and serves adequate meals independently ◯ Prepares adequate meals if supplied with ingredients ◯ serves and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet ◯ Needs to have meals prepared and served
Laundry	◯ Does personal laundry completely ◯ Launders small items-rinses stockings, etc. ◯ All laundry must be done by others
Housekeeping	◯ Maintains house alone or with occasional assistance (e.g. "heavy work domestic help") ◯ Performs light daily tasks such as dish washing, bed making ◯ Performs light daily tasks but cannot maintain acceptable level of cleanliness ◯ Needs help with all home maintenance tasks ◯ Does not participate in any housekeeping tasks
Mode of Transportation	◯ Travels independently on public transportation or drives own car ◯ Arranges own travel via taxi, but does not otherwise use public transportation ◯ Travels on public transportation when accompanied by another ◯ Travel limited to taxi or automobile with assistance of another ◯ Does not travel at all
Responsibility for Own Medications	◯ Is responsible for taking medication in correct dosages at correct time ◯ Takes responsibility if medication is prepared in advance in separate dosage ◯ Is not capable of dispensing own medication

Confidential

Ability to Handle Finances	○ Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income ○ Manages day-to-day purchases, but needs help with banking, major purchases, etc. ○ Incapable of handling money
Total score	_____

Confidential

Please think about how effective your kidney medication/dialysis has been. On a scale from 0 to 10, where 0 means completely ineffective and 10 means completely effective, how effective would you say your kidney medication/dialysis has been?	◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 ◯ Don't know ◯ Refused
Who first raised the idea of starting dialysis?	◯ Me ◯ Health care provider ◯ Don't know ◯ Refused
A personal health care provider is the health care provider who knows you best. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician assistant. Do you have someone you think of as your personal health care provider?	◯ Yes ◯ No ◯ Don't know ◯ Refused
On a scale from zero to 10, where 0 means do not trust at all and 10 means trust completely, how much do you trust your personal health care provider's judgments about your medical care?	◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 ◯ Don't know ◯ Refused
(If baseline survey) During the past 12 months, how many times have you been hospitalized overnight or longer? (If 3-month or 6-month follow-up): How many times have you been hospitalized overnight or longer since our last interview?	_____
Do you think that your clinician knows the kinds of treatment you would want if you got too sick to speak for yourself?	◯ No ◯ Probably yes ◯ Definitely yes
When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor cares about you as a person?	◯ No ◯ Probably yes ◯ Definitely yes
When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor listens to what you say?	◯ No ◯ Probably yes ◯ Definitely yes
When you are talking with your doctor about the kinds of treatment you want if you get very sick, do you feel that your doctor gives you enough of his or her attention?	◯ No ◯ Probably yes ◯ Definitely yes
I feel that my doctor understands my background and values.	◯ Strongly agree ◯ Somewhat agree ◯ Somewhat disagree ◯ Strongly disagree
How would you rate the overall quality of the discussions you've had with your doctor/clinician about the kinds of treatment you would want if you got too sick to speak for yourself?	◯ Poor ◯ Fair ◯ Good ◯ Very good ◯ Excellent
I often feel as if my doctor looks down on me and the way I live my life.	◯ Strongly agree ◯ Somewhat agree ◯ Somewhat disagree ◯ Strongly disagree
Who have you designated to be your substitute decision maker (e.g. Spouse, Adult Child, etc. Do not write a person's name.)?	_____ (Who has the patient identified as their SDM (e.g., spouse, adult child, friend, relative, etc. Not a name))

This set of questions has to do with goals of care discussion. Please answer at baseline and 6-month follow up only.

	Yes	No	I don't know	Refused
Has a member of the health care team talked to you and/or your substitute decision maker about your prognosis, or indicated how much time you have to live?	○	○	○	○
Has a member of your health care team talked to you and/or your substitute decision maker about the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments?	○	○	○	○
Has a member of your health care team talked to you and/or your substitute decision maker about the outcomes, benefits, and burdens of focusing on comfort care as the goal of your treatment? (For example, speaking to you about palliative care or treating symptoms like pain without trying to cure or control your underlying illness).	○	○	○	○
Has a member of your health care team offered to arrange a time when you, your substitute decision maker, and/or your family can meet with the doctor to discuss your treatment options and plans?	○	○	○	○
Has a member of your health care team asked if you or your substitute decision maker had prior discussions or has written documents about use of life-sustaining treatments?	○	○	○	○

Confidential

Has a member of your health care team asked you, your substitute decision maker, and/or your family about what is important to you/them (such as values, spiritual beliefs, and/or other practices) as you/they consider health care decisions at this stage of your life?	○	○	○	○
Has a member of your health care team given you the opportunity to express your fears or discuss what concerns you?	○	○	○	○
Has a member of your health care team asked you and/or your family if you/they had any questions or needed things clarified regarding your overall goals of care?	○	○	○	○
Has a member of your health care team asked you about what treatments you prefer to have or not have if you develop a life-threatening illness?	○	○	○	○
Have you been informed that you may change your mind regarding decisions around the goals of care?	○	○	○	○
Have you and your family been offered an opportunity to discuss with members of your health care team issues around capacity and consent with regard to advance care planning? Specifically, what actions would take place in the event that you lose capacity to consent to care?	○	○	○	○
Have you and your family been offered support from the allied health care team (e.g. spiritual carers, social workers, and clinical nurse specialists) as needed?	○	○	○	○

Confidential

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Has a member of your health care team provided you and/or your family with information about "goals of care discussion" to look at before conversations with the doctor?	○	○	○	○

Has a member of your health care team helped you and/or your family access legal documents to communicate your Advance Care Plans?

○ Yes ○ No ○ I don't know
○ Refused

Confidential

Goals of care_patient

Record ID _____

These questions are to be completed by the patient only.

You suffer from a severe stroke or heart attack. You are very seriously ill and your mind is no longer sound. For example, you do not know what is going on and you cannot speak for yourself. The doctors and nurses believe that you are unlikely to recover and that continuing life-sustaining treatment, including dialysis, is no longer helpful to you. The costs and burdens of life-sustaining treatment are now very high. Your doctor is asking your family member (or health care agent) what goals of care should be. What should the goals of care be focused on?

- ◯ The goals of care should be focused on delaying my death. I want to continue life-sustaining treatment.
- ◯ The goals of care should be focused on my comfort and peace. I do not want life sustaining treatment, including dialysis. Instead, I want treatment to make me as comfortable as possible and would like my family and faith community to pray for me.
- ◯ I am not sure.

You develop advanced dementia, and you can no longer be yourself. For example, you are not aware of your feelings, not able to make decisions, and not able to recognize other persons, including your loved ones. Your dementia is no longer responding to treatment. Your doctor is asking your family member (health care agent) what goals of care should be. What should the goals of care be focused on?

- ◯ The goals of care should be focused on delaying my death. I want to continue life-sustaining treatment.
- ◯ The goals of care should be focused on my comfort and peace. I do not want life-sustaining treatment, including dialysis. Instead, I want treatment to make me as comfortable as possible and would like my family and faith community to pray for me.
- ◯ I am not sure.

Confidential

Demographic info_patient

Record ID _____

These questions are to be completed by the patient only.

What is the highest grade or year of school you completed?

- ◯ No formal education
- ◯ Grade 1
- ◯ Grade 2
- ◯ Grade 3
- ◯ Grade 4
- ◯ Grade 5 (Elementary school)
- ◯ Grade 6
- ◯ Grade 7
- ◯ Grade 8 (Middle school)
- ◯ Grade 9
- ◯ Grade 10
- ◯ Grade 11 (Some high school)
- ◯ Grade 12 or GED (High school graduate)
- ◯ Grade 13
- ◯ Grade 14 (Some college or technical school)
- ◯ Grade 15
- ◯ Grade 16 (College graduate)
- ◯ Grade 17 or more (Postgraduate)
- ◯ Don't know
- ◯ Refuse

What is the year of your birth?

_____
(Enter year (e.g. 2016); Don't know; or Refused)

Are you currently married or living with a partner?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Refused

Are you separated, divorced, widowed, or have you never been married?

- ◯ No
- ◯ Separated
- ◯ Divorced
- ◯ Widowed
- ◯ Never married
- ◯ Don't know
- ◯ Refused

Are you Hispanic or Latino?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Refused

Which one or more of the following would you say represents your race?

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Native American or Alaskan Native
- ☐ Other
- ☐ Don't know
- ☐ Refused

Confidential

Thinking about you and any other members of your household, what is your combined annual household income, meaning the total pre-tax income from all sources in 2015?

- ◯ Less than $25,000
- ◯ Between $25,000 and $49,999
- ◯ Between $50,000 and $74,999
- ◯ Between $75,000 and $99,999
- ◯ More than $100,000

Do you identify as male or female?

- ◯ Male
- ◯ Female
- ◯ Don't know
- ◯ Refused

Confidential

KDQOL-36_patient

Record ID _____

These questions are to be completed by the patient only.

In general, would you say your health is: [Mark an X in the one box that best describes your answer.]

- ◯ Excellent
- ◯ Very good
- ◯ Good
- ◯ Fair
- ◯ Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? [Mark an X in a box on each line.]

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	◯	◯	◯
Climbing several flights of stairs	◯	◯	◯

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
Accomplished less than you would like	◯	◯
Were limited in the kind of work or other activities	◯	◯

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
Accomplished less than you would like	◯	◯
Didn't do work or other activities as carefully as usual	◯	◯

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ◯ Not at all
- ◯ A little bit
- ◯ Moderately
- ◯ Quite a bit
- ◯ Extremely

Confidential

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
Did you have a lot of energy?	◯	◯	◯	◯	◯	◯
Have you felt downhearted and blue?	◯	◯	◯	◯	◯	◯

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
My kidney disease interferes too much with my life	◯	◯	◯	◯	◯
Too much of my time is spent dealing with my kidney disease	◯	◯	◯	◯	◯
I feel frustrated dealing with my kidney disease	◯	◯	◯	◯	◯
I feel like a burden on my family	◯	◯	◯	◯	◯

During the past 4 weeks, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
Soreness in your muscles?	◯	◯	◯	◯	◯
Chest pain?	◯	◯	◯	◯	◯
Cramps?	◯	◯	◯	◯	◯
Itchy skin?	◯	◯	◯	◯	◯
Dry skin?	◯	◯	◯	◯	◯
Shortness of breath?	◯	◯	◯	◯	◯
Faintness or dizziness?	◯	◯	◯	◯	◯
Lack of appetite?	◯	◯	◯	◯	◯
Washed out or drained?	◯	◯	◯	◯	◯
Numbness in hands or feet?	◯	◯	◯	◯	◯

Confidential

Nausea or upset stomach?	○	○	○	○	○
(Hemodialysis patient only) Problems with your access site?	○	○	○	○	○
(Peritoneal dialysis patient only) Problems with your catheter site?	○	○	○	○	○

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
Fluid restriction?	○	○	○	○	○
Dietary restriction?	○	○	○	○	○
Your ability to work around the house?	○	○	○	○	○
Your ability to travel?	○	○	○	○	○
Being dependent on doctors and other medical staff?	○	○	○	○	○
Stress or worries caused by kidney disease?	○	○	○	○	○
Your sex life?	○	○	○	○	○
Your personal appearance?	○	○	○	○	○

Appendix B: Carepartner Surveys

Participant ID#: _____

Interviewer: _____
Date: ____ ____/____ ____/____ ____

Start time:
_____

Stop time:
_____

Interviewer Script:

Thank you for participating in this study being conducted by researchers at Tufts University and Tufts University Medical School. It is important that your opinions be heard.

During this interview, we will ask you to think about your experiences making decisions about treatments for kidney disease or helping others who face these decisions. We are interested in learning more about the conversations that you have regarding treatment selection (or guiding others with treatment choices), and regarding advance care planning. We are interested in your opinions about the timing of these conversations, who should be engaged in the process, and what type of information would be helpful in discussing these decisions in a clinical setting.

The results will be used to help us understand how people make decisions about initiating dialysis and advance care planning, what aspects of the decision-making process could be improved, and how the experience of receiving dialysis impacts patients and their families.

We would like to assure you that your responses are confidential.
Information that identifies you will not be shared with anyone.

Thank you for your valued input.

Confidential

First Assessment_caregiver

Record ID _____

(CAREGIVER ONLY) These questions are to be answered by the caregiver only.
This set of questions has to do with Advance Care Planning. Please answer this set of questions at baseline and 3-month follow-up surveys only.

	Yes	No	I don't know	Refused
Did your loved one discuss his/her preferences for using or not using life-sustaining treatments with you or with their substitute decision maker (SDM)?	○	○	○	○
Did the doctor talk to your loved one and/or you about prognosis or indicated how much time your loved one has left to live?	○	○	○	○
Did your loved one and/or you discuss their preferences for using or not using medically appropriate life-sustaining treatments with your loved one's family doctor or other doctor?	○	○	○	○
Did your loved one formally designate, in writing, someone who they trust to be their SDM concerning medical treatment decisions in the event they are not able to do so (using appropriate legal documentation depending on jurisdiction). In case of power of attorney, it should be related to health care.	○	○	○	○

Confidential

Did a member of the health care team offer to arrange a time with your loved one and you could meet with the doctor to discuss the use of medically appropriate life-sustaining treatments they would want, or not want, in the event your loved one's physical health deteriorates.	○	○	○	○
Does your loved one have an advance directive or living will or indicated in some other way (verbal, video, and so on) the medical treatments they would want (or not want) in the event they are unable to communicate for themselves as a result of a life-threatening health problem?	○	○	○	○
Have you and/or your loved one discussed their preferences for using or not using medically appropriate life-sustaining treatments with other health care professional (i.e. nurse, social worker, and spiritual carer).	○	○	○	○

Has a member of your loved one's health care team helped you and/or your family access legal documents to communicate your loved one's Advance Care Plans? ○ Yes ○ No

Who did your loved one designate as their substitute decision maker (e.g. Spouse, Adult Child, etc. Do not write a person's name.)? _____ (Indicate who designated as SDM (e.g. spouse, adult child, etc. Not a name).)

Confidential

This set of questions has to do with goals of care discussion. Please answer this set of questions at baseline and 6-month follow-up surveys only.

	Yes	No	I don't know	Refused
Has a member of the health care team talked to your loved one and/or SDM about prognosis or indicated in some way how much time s/he has left to live?	○	○	○	○
Has a member of the health care team talked to your loved one and/or SDM about the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments?	○	○	○	○
Has a member of the health care team talked to your loved one and/or SDM about the outcomes, benefits, and burdens of focusing on comfort care as the goal of the patient's treatment (e.g., palliative care or treating symptoms like pain without trying to cure or control their underlying illness).	○	○	○	○
Has a member of the health care team offered to arrange a time when your loved one/SDM and/or you can meet with the doctor to discuss the treatment options and plans?	○	○	○	○
Has a member of the health care team asked if your loved one or SDM had prior discussions or has written documents about the use of life-sustaining treatments?	○	○	○	○
Has a member of the health care team asked your loved one/SDM and /or you about what is important to them as they consider health care decisions at this stage of your loved one's life (i.e., values, spiritual beliefs, and other practices).	○	○	○	○

Confidential

Has a member of the health care team given your loved one the opportunity to express his/her fears or discuss what concerns him/her?	○	○	○	○
Has a member of the health care team given you the opportunity to express your fears or discuss what concerns you?	○	○	○	○
Has a member of the health care team asked your loved one and/or you if they had any questions or needed things clarified regarding your loved one's overall goals of care?	○	○	○	○
Has a member of the health care team asked your loved one what treatments s/he prefers to have or not have if they develop a life-threatening illness?	○	○	○	○
Has a member of the health care team asked you what treatments your loved one prefers to have or not have if they develop a life-threatening illness?	○	○	○	○
Has your loved one been informed that they may change their minds regarding their decisions around goals of care?	○	○	○	○
Have you been informed that your loved one may change their minds regarding their decisions around goals of care?	○	○	○	○
Have your loved one and you been offered an opportunity to discuss with members of the health care team issues around capacity and consent with regard to advance care planning (ACP); specifically what actions would take place in the possible event of losing capacity to consent to care?	○	○	○	○

Confidential

Have your loved one and you been offered support from the allied health care team (e.g., spiritual care, social work, and clinical nurse specialist) as needed?	○	○	○	○
Has a member of the health care team provided your loved one and/or you with information about goals of care discussion to look at before conversations with the doctor?	○	○	○	○

Has a member of the health care team helped your loved one and/or you access legal documents to communicate your loved one's Advance Care Plans?

○ Yes ○ No ○ I don't know
○ Refused

DART RCT Baseline-Caregiver

This set of questions is aimed at identifying the goals of medical care for your loved one under two different scenarios.

Scenario 1:

Imagine……

Your loved one develops cancer that spreads throughout his/her body or suffers from a severe stroke or heart attack. Your loved one is very seriously ill and his or her mind is no longer sound. For example, your loved one does not know what is going on and he or she cannot speak for him-/herself. The doctors and nurses believe that your loved one is unlikely to recover and that continuing life-sustaining treatment, including dialysis, is not likely to help him or her improve from the illness. The costs and burdens of life-sustaining treatment are now very high. Your loved one's doctor is asking you as the health care agent for his/her what goals of care should be.

What should the goals of care be focused on? In other words, what would your loved one want?

- The goals of care should be focused on delaying my loved one's death. My loved one would want to continue life-sustaining treatment, like a breathing machine, CPR, and dialysis.
- The goals of care should be focused on my loved one's comfort and peace. My loved one would not want life-sustaining treatment, like a breathing machine, CPR, and dialysis. Instead, he/she would want treatment to make him/her as comfortable as possible
- I am not sure.

Scenario 2:

Imagine……

Your loved one develops advanced dementia, and he or she can no longer be him/herself. For example, your loved one is not aware of his or her feelings, not able to make decisions, and not able to recognize other persons, including you and other family members. His/her dementia is no longer responding to treatment. His/her doctor is asking you as the health care agent for him/her what goals of care should be.

What should the goals of care be focused on? In other words, what would your loved one want?

- The goals of care should be focused on delaying my loved one's death. My loved one would want to continue life-sustaining treatment, like a breathing machine, CPR, and dialysis.
- The goals of care should be focused on my loved one's comfort and peace. My loved one would not want life-sustaining treatment, like a breathing machine, CPR, and dialysis. Instead, he/she would want treatment to make him/her as comfortable as possible
- I am not sure.