

Nephrology and Palliative Care Collaboration in the Care of Patients With Advanced Kidney Disease: Results of a Clinician Survey

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Visual Abstract included

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Rationale & Objective: Despite calls for integrating palliative care into chronic kidney disease (CKD) care, uptake remains low. The study aim was to describe clinicians' perceptions of the clinical and research priorities in CKD care and the main barriers to collaboration.

Study Design: This was a descriptive cross-sectional study using an online survey developed by clinicians and researchers as the primary data collection method.

Setting & Participants: Clinicians in nephrology and palliative care departments (N = 195) at an academic health center in Virginia were invited to participate. Of the 48.7% (n = 95) who responded, most were registered nurses (65.3%) in nephrology (80%) with more than 15 years' experience (40%).

Predictors: Factors including discipline (nursing, social work, and physician) and practice area (palliative care or nephrology) were assessed.

Outcomes: Main outcomes of interest included clinicians' perceptions of the role of palliative care, barriers to collaboration, and the top clinical and research priorities for patients with advanced CKD.

Analytic Approach: Survey data were analyzed using SPSS using descriptive statistics.

Results: Respondents reported being comfortable caring for patients near the end of life and endorsed advance care planning and collaboration between nephrology and palliative care teams. However, both rarely happen. Fragmentation, or poor coordination of care, was perceived to be the main barrier to collaboration. Perceptions regarding collaboration facilitation differed; nephrology clinicians identified patient/family education as the most important facilitator while palliative care clinicians identified clinician education as most important. Top clinical priorities differed. Palliative care clinicians reported pain/symptom management as taking priority while nephrology clinicians identified caregiver/family support. Developing interventions to support treatment-related decision making was the top research priority.

Limitations: Results reflect perceptions of about half the clinicians at 1 academic health center.

Conclusions: Additional studies to capture patients' and families' perspectives and examine end-of-life care processes are needed. Results may inform future targeted interventions.

Chronic kidney disease (CKD) is a life-limiting progressive condition affecting between 10% and 13% of the worldwide population and >10% of the US population.^{1,2} It ranks among the 10 leading causes of death in the United States.² There are 5 CKD stages ranging in severity from the least, stage 1, to the most severe, stage 5. Advanced CKD, which includes CKD stage 5 (CKD5) managed without kidney replacement therapy and end-stage kidney disease (ESKD) managed with kidney replacement therapy, affects more than 700,000 people in the United States.²

People living with advanced CKD report myriad distressing symptoms, including pain, fatigue, anorexia, pruritus, anxiety, depression, role changes, social isolation, and financial strain.³⁻⁹ Caregivers also report troubling symptoms such as fatigue, insomnia, depression, anxiety, and social isolation.^{10,11}

In addition to coping with these challenges, patients with advanced CKD and caregivers must contend with numerous treatment-related decisions, including whether to opt for kidney replacement therapy or conservative medical management, choosing among dialysis modalities,

establishing goals of care, and completing advance directives.¹²⁻¹⁶

Experts in palliative care and nephrology have proposed integrating palliative care into CKD care to improve the experience of patients and caregivers living with advanced CKD. Palliative care is a philosophy of care delivered by either a patient's primary team or by palliative care specialists that emphasizes symptom control, goals of care/decision making, and the patient/family unit.¹⁷ It is appropriate at any point along the illness trajectory and may be implemented alongside life-extending therapy. It is intended to reduce the physical, emotional, spiritual, and social burdens borne by patients with life-limiting illness and their families.¹⁸ Specifically, in advanced CKD, palliative care has been associated with improved symptom control and clarity about goals of care.¹⁹

However, despite recommendations, referral rates of patients with advanced CKD to palliative care consultation services remain low and adverse outcomes such as lower quality of life due to poor symptom management and high rates of intensive medical care at or near the end of life persist.²⁰ The purpose of this study was to capture

PLAIN-LANGUAGE SUMMARY

People with advanced kidney disease and their caregivers face many decisions and physical/emotional difficulties. Experts recommended more collaboration between palliative care teams and teams caring for patients with kidney disease. This has proved difficult to achieve. Nurses, social workers, and physicians working in palliative care and kidney disease were surveyed regarding what prevented the expansion of palliative care and what issues in caring for patients with advanced kidney disease need most attention. The study found that both groups value collaboration, but collaboration rarely occurred. Increased education of clinicians and patients/families was suggested to improve coordination. Key areas to address were symptom management and caregiver support.

palliative care and nephrology clinicians' perspectives regarding facilitators and barriers to palliative care/nephrology collaboration in caring for patients with advanced CKD and identify the top research and patient care priorities for both specialties. Study findings may provide direction for future research and support the development of interventions to target the main barriers and address the top priorities identified by clinicians.

METHODS

Study Design

This was a descriptive cross-sectional study using an online survey as the primary source of data collection. Research team members collaborated with survey scientists at the Center for Survey Research (CSR) at the University of Virginia in the development and deployment of the survey.

Protection of Human Participants

Study procedures were approved by the University of Virginia's Institutional Review Board (protocol #2221). To ensure participants' confidentiality and alleviate concerns of retaliation for nonparticipation, no supervisors or research team members had access to the list of survey respondents. CSR consultants managed survey data collection, which included tracking participation and contacting nonrespondents with reminders.

Data Collection and Measures

Questionnaire Development

An initial questionnaire draft informed by the study aims, experience of the research team, and expertise of both the clinical and survey researchers was developed, pilot tested, and revised in late fall 2018. The online instruments were programmed in Qualtrics and were tested and debugged by both CSR and study principal investigators.

Questionnaire Description

The questionnaire, entitled Clinician Perspectives on Palliative Care in Kidney Disease, consisted of multiple choice, multiple response, Likert-style, and open-ended free-text response questions. Respondents were first asked about their professional title, area of specialty, years of experience, and specific training. Next, respondents were asked about their level of agreement on a list of statements regarding palliative care and hospice in patients with advanced CKD. Respondents were then asked to share their perspectives on appropriate reasons for referrals of patients with kidney disease to palliative care consultation services and when in the illness trajectory referrals are most beneficial. Last, respondents were asked, based on their experience, to identify the main facilitators, barriers, and outcomes of collaboration between palliative care and nephrology and the most urgent clinical needs and top research priorities in palliative care and nephrology.

Sample

The survey sample was composed of clinicians (nurses, physicians, social workers, dietitians, and chaplains) working in either the nephrology or palliative care departments at an approximately 600-bed academic medical center in the mid-Atlantic region of the United States. The nephrology service consists of 11 dialysis centers serving more than 920 patients from throughout central Virginia and 5 outpatient clinics caring for patients with all kidney diseases, including CKD and acute kidney injury. Annual outpatient visits exceed 15,000 per year.

The multidisciplinary palliative care consultation service sees patients in both the inpatient and ambulatory setting. In 2019, the palliative care team received 1,683 requests for consultation in the inpatient setting and 7,207 in the ambulatory setting. The team conducted just fewer than 10,000 visits during that year. Department coordinators provided an exhaustive list of 195 clinicians' names and work email addresses to the collaborating senior survey analyst at CSR.

Survey Production

An advance informational email from the co-principal investigators (M.M., L.B., and E.A.-R.) was mailed to all clinicians working in palliative care and nephrology (N = 195). The survey launched in April 2019 with an invitation email sent to the entire sample. The invitation email was followed by 2 reminder emails and a final closeout email sent to nonrespondents. Data collection closed at the end of May 2019. No financial incentives for participation were offered.

Survey Response

Of the 195 clinicians invited, 94 (48.2%) completed the questionnaire. As indicated in [Table 1](#), the distribution of survey responses by specialty (93.6% nephrology and 6.4% palliative care) closely reflected the distribution by

Table 1. Survey Respondents by Discipline and Practice Area

	Sample Size	Percent of All Samples	Survey Completions	Percent of All Completions
Nephrology				
MD	28	14.4%	7	7.4%
Advanced practice nurse (APRN, NP, CNS)	4	2.1%	1	1.1%
LPN	23	11.8%	10	10.6%
RN	116	59.5%	62	66.0%
Social worker	12	6.2%	8	8.5%
Total nephrology	183	93.8%	88	93.6%
Palliative care				
MD	5	2.6%	3	3.2%
Advanced practice nurse (APRN, NP, CNS)	3	1.5%	2	2.1%
RN	3	1.5%	1	1.1%
Social worker	1	0.5%	0	0.0%
Total palliative care	12	6.2%	6	6.4%
Total	195	100%	94	100.0%

Abbreviations: APRN, advanced practice registered nurse; CNS, certified nurse specialist; MD, doctor of medicine/physician; LPN, licensed practical nurse; NP, nurse practitioner; RN, registered nurse.

specialty within the sample (93.8% nephrology and 6.2% palliative care). However, rate of response varied by professional type. Social workers participated at the highest rate, with a response rate of 61.5%, followed by registered nurses (RNs; 52.9%). Survey participation was lowest among physicians, who had a combined response rate of 30.3%. Looking at both specialty and professional type, most respondents were RNs working in nephrology, which is reflective of the overall sample distribution.

Data Management and Analysis

CSR was responsible for managing and cleaning the data. All data analysis preparation was carried out using SPSS (IBM, version 25.0). CSR analysts deidentified the data before sending it to the research team and provided ongoing statistical support. Survey data were analyzed using descriptive statistics. Frequencies were organized, reported, and displayed by practice area (palliative care and nephrology) and discipline (physician, advanced practice RN [APRN], nurse, and social worker) to facilitate comparisons.

RESULTS

Survey results were organized into the following categories: experiences caring for patients with advanced CKD, attitudes toward and experiences with palliative care in advanced CKD, main facilitators and barriers to collaboration between palliative care and nephrology, most important clinical priorities for patients with advanced CKD, and top research priorities in advanced CKD.

Experiences Caring for Patients With Advanced CKD

Nearly all nephrology clinicians (almost 99%) indicated feeling comfortable caring for patients with advanced CKD

at or near the end of life, with most agreeing that they have been adequately prepared to manage common symptoms. Compared with nephrologists, palliative care clinicians reported relatively less agreement that they had received adequate training (87.5% vs 60.0%) in managing common symptoms specific to kidney disease.

Respondents uniformly endorsed including conservative management of advanced CKD as a treatment option (91.2%) and incorporating advance care planning (91.2%) and goals-of-care discussions (94.6%) into routine care of patients with CKD. Most nephrologists and APRNs (87.5%) reported feeling comfortable initiating prognostic discussions. Additionally, respondents were asked to rate their comfort level regarding assisting patients with advance directives. Among the groups, nurses were the least comfortable discussing advance directives.

Although there was widespread agreement regarding the importance of goals-of-care discussions, which include sharing prognostic information, palliative care clinicians were less likely to agree or strongly agree with the statement that nephrologists should discuss conservative management with all patients with advanced CKD (83.3% vs 40%).

Knowledge About, Attitudes Toward, and Experiences With Palliative Care in Advanced CKD

Of note, responses related to actual practice patterns and experiences appear to contradict responses to knowledge and attitude survey items. For instance, respondents acknowledged the importance of advance care planning discussions. They also agreed that palliative care differs from hospice, is appropriate at any stage of CKD, and is associated with positive outcomes, such as improved patient outcomes (76.5%), more efficient care (77.6%), reduced referring providers' workload burden (51.2%),

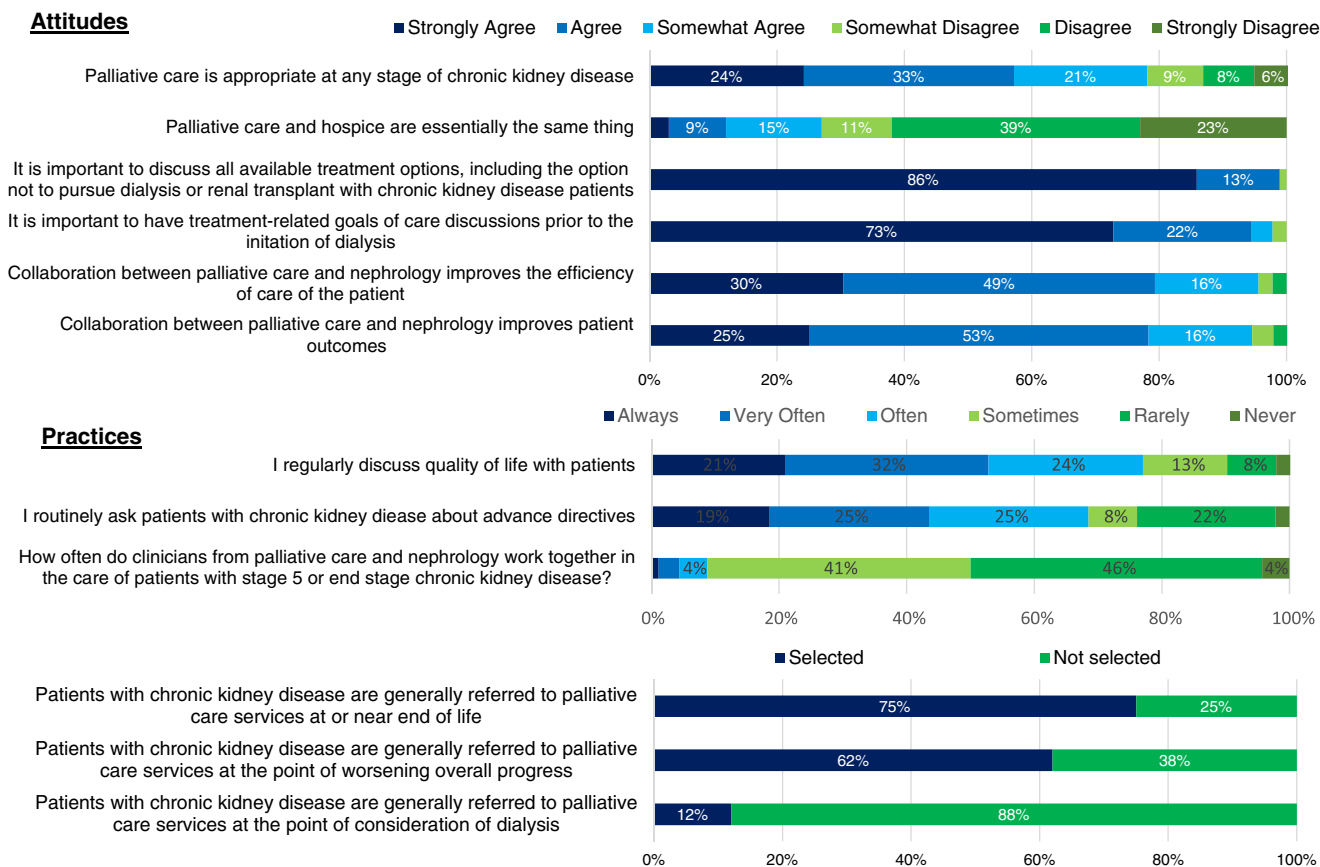


Figure 1. Clinician attitudes versus practices.

and increased job satisfaction (63.9%). Furthermore, nephrologists agreed that they have received adequate training in palliative care. However, more than half the nephrology clinicians reported that palliative care and nephrology rarely or never collaborate and when they do, it is nearly always at or near the end of life. Clinicians cite assisting with withdrawal of care as the most common reason for palliative care referral. Palliative care clinicians report help with hospice and pain and symptom management as the 2 most common reasons for referral, with withdrawal of care a close third (Fig 1).

Respondents were asked to identify the main barriers to collaboration between palliative care and nephrology. Fragmentation of patient care (65% of respondents), reluctance of patients and families to discuss prognosis, palliative care or hospice (49%), and having providers at different locations (39%) were the top 3 barriers to collaboration. For the purposes of this study, fragmentation of care was defined as poor communication and coordination of care among the various teams and providers involved in the care of patients with advanced CKD.

Differences by specialty were observed, with 50% of palliative care clinicians compared with just 22% of nephrology clinicians identifying nephrologists' reluctance to refer patients as a significant barrier to collaboration. However, clinicians from nephrology cited patient and

family reluctance as a major impediment to palliative care referral. This was consistent with other survey items in which clinicians from nephrology agreed that patients and families have a very limited understanding of palliative care and hospice (84.7% agree or strongly agree); do not wish to discuss prognosis, palliative care, or hospice (69.4% at least somewhat agree); and may lose hope if clinicians introduce palliative care (Fig 2).

Similarly, there were differences based on profession, with physician (MD)/APRN respondents reporting fragmentation of care as a barrier at higher rates than other groups. RNs/licensed practical nurses and social workers were more likely than MDs/APRNs to consider reluctance of patients/families to discuss referral to palliative care as a barrier to collaboration (Fig 3).

Respondents were also asked to identify the most important facilitators of collaboration between nephrology and palliative care clinicians in the care of patients with advanced CKD. Overall, the top 3 factors that respondents indicated would enhance collaboration were patient and family education, clinician education, and onsite availability (geographic proximity) of palliative care. Opinions regarding relevant facilitators varied by specialty and professional role.

Palliative care clinicians cited clinician education (83%) as the most important facilitator, with relationships among

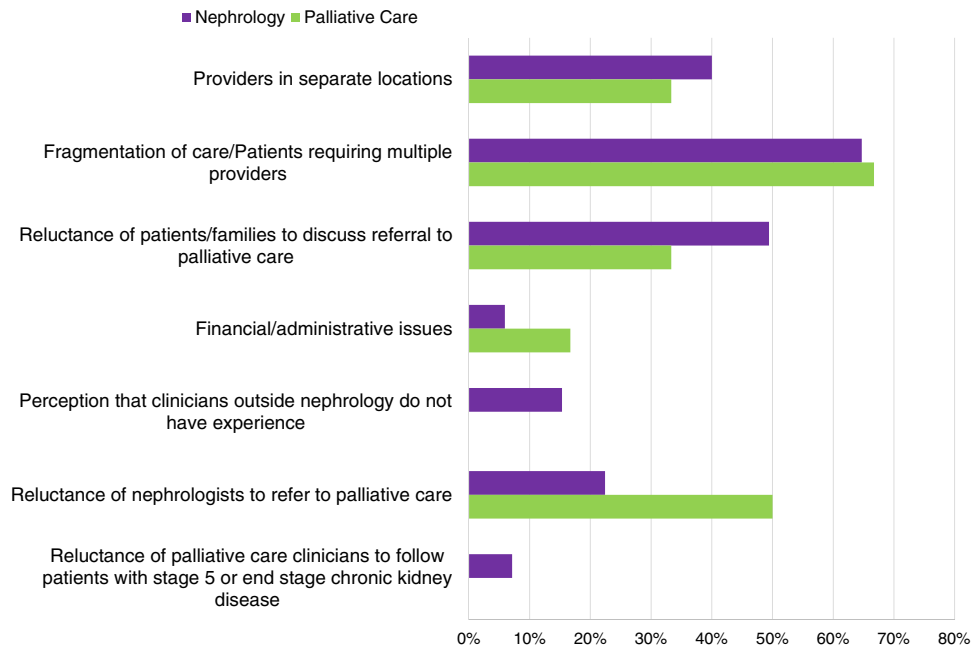


Figure 2. Barriers to collaboration by specialty.

clinicians second (67%). Administrative support, geographic proximity, and patient and family education lagged far behind, with only 16.7% of palliative care respondents endorsing each. However, clinicians in nephrology identified patient and family education as the most important facilitator (69%), followed by clinician education and geographic proximity (Fig 4).

Of note, when compared with physicians, nurses and social workers ranked education of patients and families about palliative care as the most important facilitator of collaboration. However, support from local leadership/administrators and relationships

among clinicians were more often identified as important facilitators by MDs and social workers than by their nurse colleagues (Fig 5).

Most Important Clinical Priorities for Patients With Advanced CKD

Overall, respondents identified caregiver/family support, pain and symptom management, and advance care planning discussions as all being important supportive/palliative needs in advanced CKD. However, there were differences by specialty and profession in ranking of these clinical priorities. Specifically, clinicians in nephrology

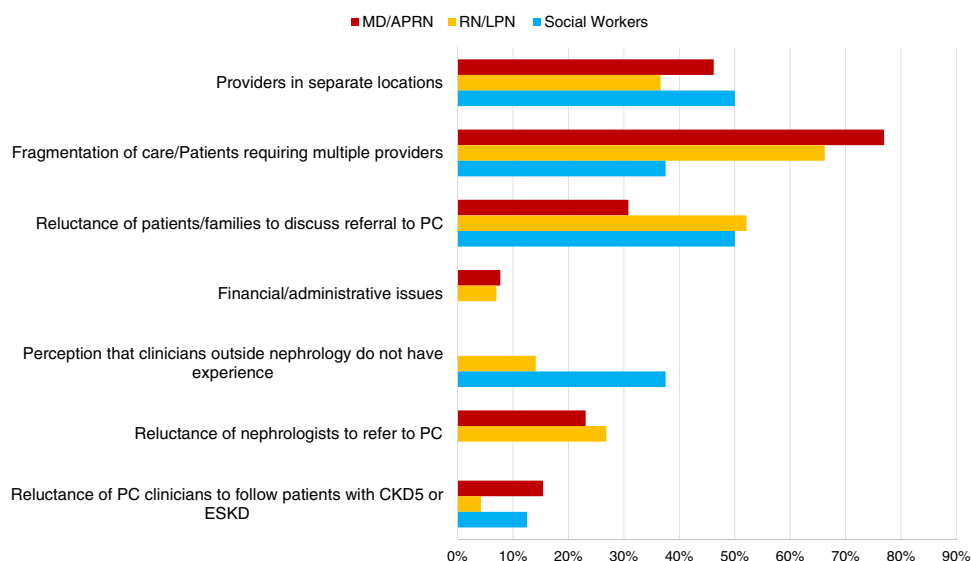


Figure 3. Barriers to collaboration by discipline. Abbreviations: APRN, advance practice RNs; CKD5, chronic kidney disease stage 5; ESKD, end-stage kidney disease; LPN, licensed practical nurse; MD, doctor of medicine/physician; PC, palliative care; RN, registered nurse.

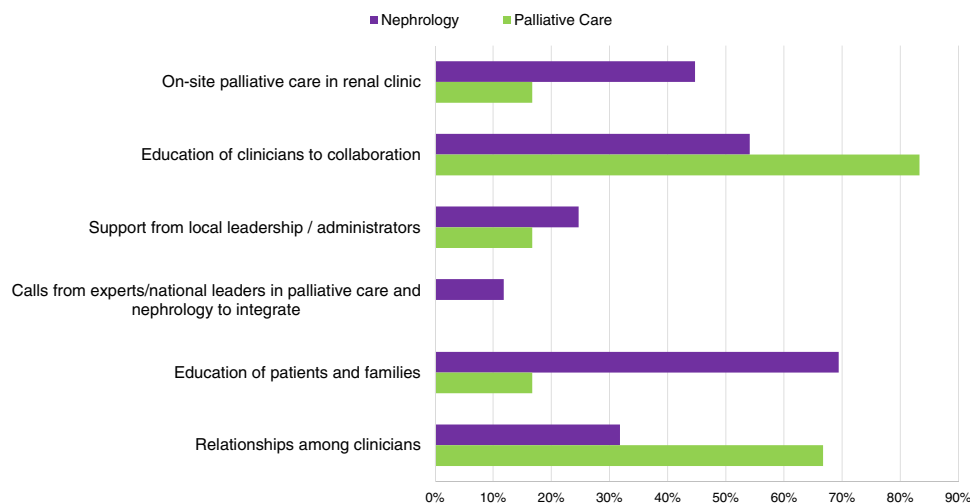


Figure 4. Facilitators to collaboration by specialty.

indicated that caregiver and family support was the most important care need while palliative care clinicians selected pain/symptom management and advance care planning discussions equally as the most important care needs (Fig 6).

Similarly, nurses and social workers identified caregiver/family support as the most important palliative or supportive care need for patients with advanced CKD. An equally high percentage of social workers also identified pain/symptom management as important. In contrast, physicians unanimously rated advance care planning discussions as the most important care need (Fig 7).

Most Important Research Priorities

All respondents identified developing interventions to prepare patients and families for treatment-related decision making as the top research priority. Other priorities

included developing interventions for patients who opt for conservative CKD management (ie, not dialysis or transplantation) and interventions to improve end-of-life care. Of note, clinicians in nephrology included improving processes of care or care delivery as a research priority; palliative care clinicians did not.

DISCUSSION

Palliative care and nephrology clinicians from all disciplinary backgrounds endorse palliative care for patients with advanced CKD. Nephrology clinicians associated collaboration with palliative care with positive outcomes, such as improved patient care and greater personal job satisfaction. This aligns with recommendations to incorporate palliative care in the care of patients with advanced CKD and reflects prior research demonstrating improvement in outcomes associated with palliative care use.^{21,22}

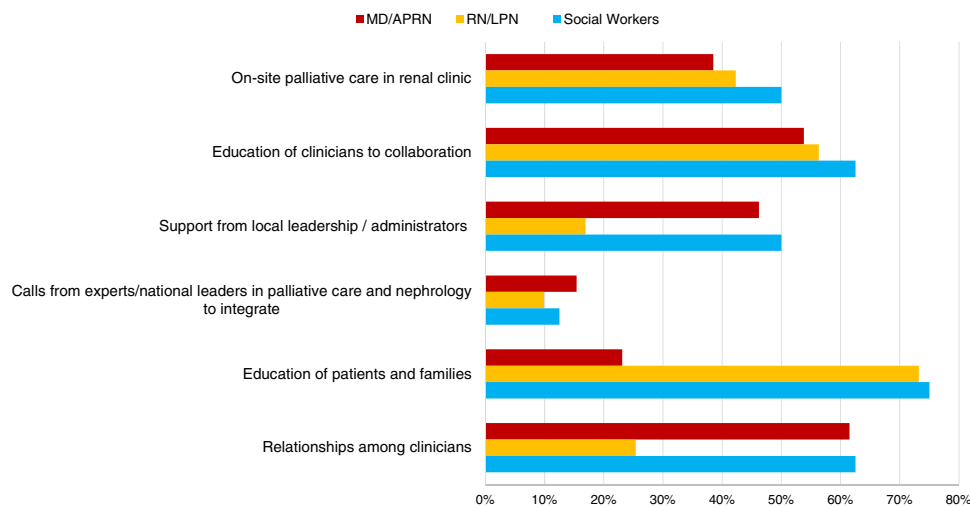


Figure 5. Facilitators to collaboration by discipline. Abbreviations: APRN, advance practice nurse; LPN, licensed practical nurse; MD, doctor of medicine/physician; RN, registered nurse.

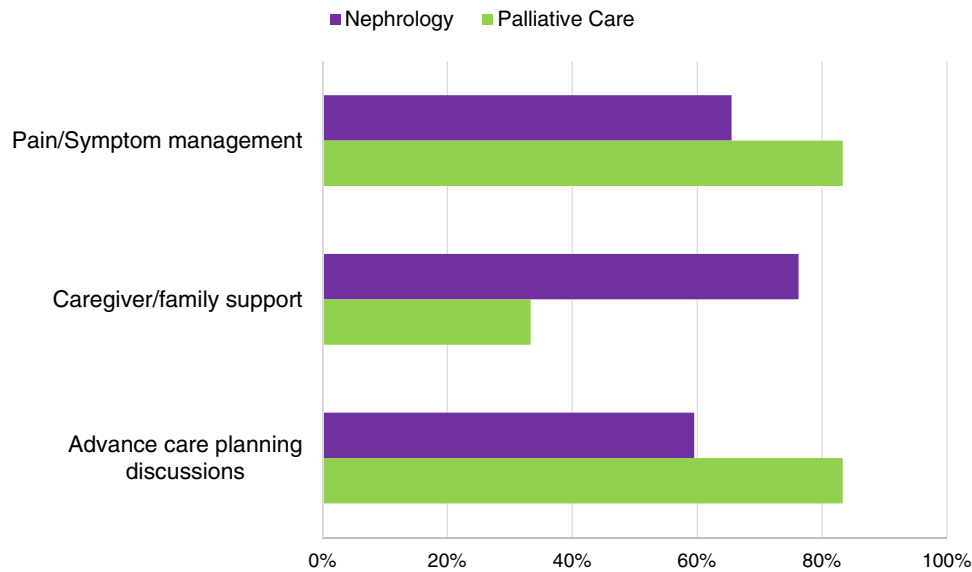


Figure 6. Most important palliative care needs of patients with advanced chronic kidney disease by specialty.

In contrast to previous studies, nearly all our study respondents reported that they were comfortable managing patients with CKD5/ESKD at or near the end of life and were adequately trained in managing the usual symptoms.²³⁻²⁵ Similarly, most MDs and midlevel providers reported feeling comfortable initiating conversations about prognosis and quality of life. Nearly all clinicians agreed that patients with advanced CKD should have advance care planning discussions as part of routine care. However, nurses were less comfortable than colleagues from other disciplines in assisting patients and

families in completing advance directives. This may be because at the study institution, social workers, physicians, and APRNs receive more formal training in advance directives than do nurses. Most clinicians were also able to distinguish between hospice and palliative care, agreeing that palliative care was appropriate at any point in the illness trajectory. These findings may reflect enhanced exposure to palliative care during clinical education, through continuing education, or the presence of a well-established palliative care consultation service at their institution.

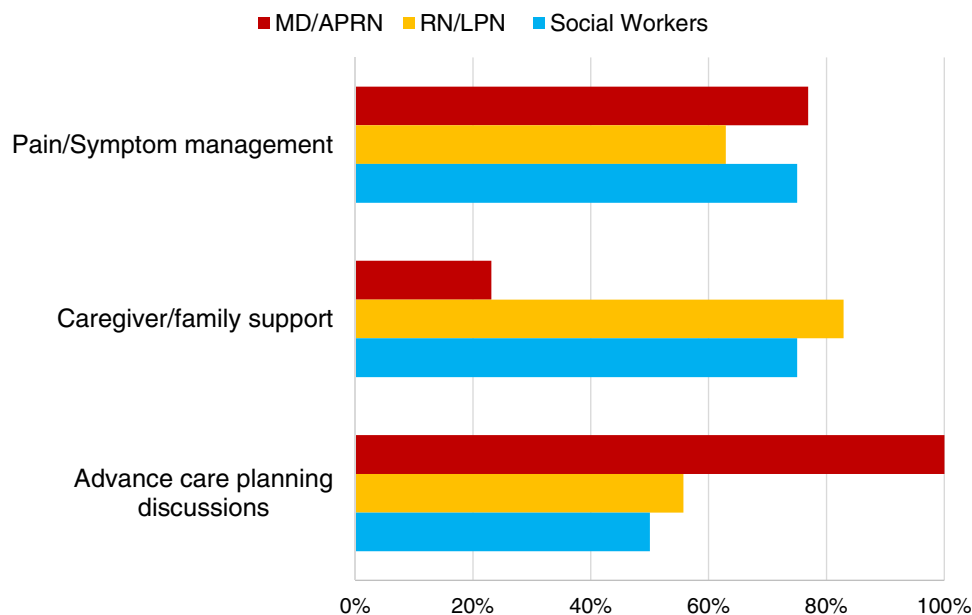


Figure 7. Most important palliative care needs of patients with advanced chronic kidney disease by discipline. Abbreviations: APRN, advance practice nurse; LPN, licensed practical nurse; MD, doctor of medicine/physician; RN, registered nurse.

However, interestingly, there was an apparent disconnect between nephrology clinicians' attitudes toward palliative care and reported behavior. For example, most clinicians endorsed palliative care at any point along the illness trajectory and only a small percentage of nephrology clinicians agreed that palliative care and hospice are essentially the same. However, the top reasons for palliative care consultation included withdrawal of care and transition to hospice, and clinicians reported that most palliative care consultations occurred at or near the end of life. Similarly, referral rates remain very low. In 2019, only 7 of the more than 7,000 palliative care referrals in the ambulatory setting came from nephrology clinicians (3 from physicians and 4 from nurse practitioners). These findings are more consistent with those reported by other investigators.²⁶⁻²⁸

The primary barrier to collaboration cited by respondents from nephrology and palliative care was the fragmentation or poor coordination of care. Fragmentation of care has been recognized as a particular challenge for patients with advanced CKD, who often have comorbid conditions requiring complex care regimens and coordinating appointments and follow-up with multiple providers.⁶

Also similar to prior work, nephrology clinicians perceived that patients and families are reluctant to engage in discussions about palliative care, hospice, or advance care planning and that introducing those topics would cause patients and families to lose hope.²⁷⁻²⁹ Given this perception, it is not surprising that palliative care clinicians in this study considered nephrologists' reluctance to engage palliative care to be a major hurdle in collaboration.

Interestingly, palliative care clinicians were less likely than nephrology clinicians to agree that nephrologists should routinely be discussing conservative management as an option with all patients with advanced kidney disease. Because we did not ask respondents to elaborate, we do not know whether this is because palliative care clinicians believe this topic is best addressed by specially trained palliative care clinicians or some other rationale prompted this response. In light of this, it makes sense that respondents suggested that educating clinicians, patients, and families about palliative care may facilitate collaboration between palliative care and nephrology.

Physicians and APRNs rated advance care planning discussions as the most pressing clinical need for patients with CKD5/ESKD. Meanwhile, nurses and social workers identified caregiver support as the most pressing clinical need. This may be because nurses and social workers interact more regularly with patients' family members and are therefore more aware of the impact of caring for a loved one with advanced CKD.

The leading research priority for all respondents was the development of interventions to prepare patients and caregivers for treatment-related decision making. This is consistent with recent emphasis by experts in chronic

illness, including kidney disease, on shared decision making and disease-specific advance care planning and research examining the effectiveness of interventions to support decision making for patients with advanced CKD.^{30,31} Other priorities included interventions to improve care for patients who opt for conservative management, improve end-of-life care for patients with advanced CKD, and support informal caregivers.^{21,32-34}

All studies have limitations. The survey was conducted in 1 academic health system in the mid-Atlantic region of the United States with a well-established palliative care consultation service. We achieved a response rate just <50%, with response rates substantially lower among physicians. There is no way to know if respondents accurately represent the views of nonresponders at the University of Virginia or clinicians across the country. Also, there were marked differences in subgroup sizes (eg, many more nurses than non-nurses and many more clinicians from nephrology than palliative care), which diminished our ability to detect statistically significant differences between groups. Furthermore, patients and family caregivers were not surveyed so their perspectives on palliative care remain unknown.

Despite the limitations, the study has some notable strengths and implications for research, education, and practice. The main strength of the study is the rigor with which the survey was developed and deployed. Clinician researchers from palliative care, nephrology, medicine, and nursing worked closely with survey scientists in survey development, pilot testing, and deployment. Similarly, survey question domains were consistent with topics deemed priorities by national leaders in palliative care and nephrology. In addition, inviting providers from various professions working in palliative care and nephrology facilitated analysis among groups. Last, although the study was conducted in 1 academic health system, the 11 dialysis centers that are a part of the health system serve a relatively geographically diverse patient population.

Survey results have implications for research, education, and practice. The survey could easily be modified and administered to clinicians in other areas of the United States or abroad. In addition, effective collaboration between researchers and clinicians is crucial to any clinical study's success. An understanding of clinicians' top research and clinical priorities likely improves our chances of both targeting pressing needs of the population and increasing clinician buy-in. We are currently engaged in a multisite pragmatic trial of a communication intervention designed to prepare dialysis patients and their surrogates for decision making in advanced illness, one of the priorities identified by the survey respondents.

Of course, patient and family buy-in is necessary too. A next logical step before intervention development therefore is eliciting patients' and caregivers' perspectives. One of the graduate student research assistants on the study has obtained institutional review board approval for a qualitative study describing patients and caregivers' experiences

with palliative care and perspectives on the role of palliative care in the care of patients with advanced CKD.

Other potential directions for research include developing interventions to manage troubling symptoms in patients receiving dialysis and those who opt for conservative management and to support caregivers who contribute substantively to the overall care of patients with advanced CKD, potentially at the expense of their own well-being.

Survey results also indicate that education about palliative care, how to incorporate principles of primary palliative care into the management of patients with advanced CKD, and when to refer patients for specialty palliative care services may be beneficial. Clinicians indicated that patients and families would benefit from information as well. Results of the study described may provide information on what types of information patients and caregivers need and want.

Last, clinical leaders could consider ways in which they can address current barriers at their institutions. For example, at some institutions (such as ours), palliative care services are primarily “housed” in oncology departments on the main health care campus. However, many dialysis patients receive dialysis at remote clinics, some as much as 2 or more hours away. The geographic separation certainly poses a challenge. Providing palliative care consultations remotely using telehealth is one option that may be beneficial. Similarly, often when patients are hospitalized, nephrologists are in a consulting role rather than an attending role and therefore unable to refer patients for palliative care consultations. Examining how current structures of care impede collaboration is warranted.

In summary, this survey provided an opportunity to meaningfully engage the clinicians providing direct care to one of our most vulnerable patient populations, those with advanced CKD. Armed with an increased understanding of clinicians’ perceptions of what matters most in the care of those patients, we feel empowered to move toward our collective goal of improving the patient and caregiver experience in advanced CKD. It is our hope that other clinicians and researchers will feel encouraged as well.

ARTICLE INFORMATION

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Should palliative care be integrated into advanced chronic kidney disease care?

Kidney
Medicine



University of
Virginia
Single Center



Descriptive
cross-sectional
study



Online
questionnaire



Clinicians
in nephrology &
palliative care



April to May
2019



Questionnaire title:
'Clinician Perspectives on
Palliative care in Kidney Disease'



94/195 (48.2%)
Completion rate



93.6%
Of responses were from
Nephrology

% respondents by profession



61.5%
Social workers



52.9%
Registered nurses



30.3%
Physicians

Main questionnaire findings



MDs and NPs (Nurse Practitioners) felt comfortable initiating conversations about quality of life



Nurses were less comfortable than other disciplines in starting discussions about quality of life (perhaps due to lack of training)



Most clinicians only obtain palliative care services at or near end-of-life



Primary barriers for collaboration between nephrology and palliative care included fragmentation of care and limited care coordination

Conclusion: Survey results showed that nephrology clinicians from all disciplinary backgrounds endorse palliative care for patient with advanced chronic kidney disease but experience barriers in implementation.

Reference: Metzger M, Yoder J, Fitzgibbon K et al. Nephrology and palliative care collaboration in the care of patients with advanced kidney disease: results of a clinical survey. *Kidney Medicine*, 2021.

Visual Abstract by Hector M. Madariaga, MD

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