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Council of Nephrology Social Workers

The Journal of Nephrology Social Work

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- Improving Advance Care Planning in Chronic Kidney Disease
- Barriers and Facilitators to Supportive Care for ESRD Dialysis Patients
—A Social Worker's Role
- Clinical Social Work End-Of-Life Survey:
Constructive Work with Patients and Family Members on Advance
Directives and Medical Orders for Life-Sustaining Treatment
- Promoting Kidney Transplant in the Dialysis Setting and Medical Orders
for Life-Sustaining Treatment

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The Journal of Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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*Earn ASWB credit for this article through NKF's Professional Education Resource Center (PERC) at <http://education.kidney.org/JNSW-CE-Program>

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The Journal of Nephrology Social Work is always interested in attracting talented CNSW members to serve as Editorial Board members to help with the planning, solicitation, and review of manuscripts for publication.

If you are interested in submitting your resume for consideration to become a member of the Editorial Board, please contact Teri Browne, PhD, MSW, NSW-C by email (browne@sc.edu) or phone (803.777.6258)

CALL FOR MANUSCRIPTS

The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The JNSW contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

- | | | |
|------------------------|-----------------------------------|----------------------|
| ■ Social Work Outcomes | ■ Sexual Functioning | ■ Professional Roles |
| ■ Kidney Transplant | ■ Aging and Gerontological Issues | ■ Rehabilitation |
| ■ Pediatric Issues | ■ Disaster Preparedness | ■ HIV/AIDS |
| ■ End-of-Life Concerns | ■ Comorbid Illnesses | ■ Quality of Life |
| ■ Sleep Disorders | ■ Home Dialysis Modalities | ■ Ethics |

Please email manuscripts to: jnsw@kidney.org. Questions? Contact Editor Teri Browne, PhD, MSW, NSW-C by email (browne@sc.edu) or phone (803.777.6258).

INSTRUCTIONS FOR AUTHORS

The Journal of Nephrology Social Work (JNSW) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. *JNSW* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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A submitted manuscript should be accompanied by a letter that contains the following language and is signed by each author: "In compliance with the Copyright Revision Act of 1976, effective January 1, 1978, the undersigned author(s) transfers all copyright ownership of the manuscript entitled _____ to *The Journal of Nephrology Social Work* in the event this material is published."

To qualify as an original manuscript, the article or a version of the article must not have been published elsewhere. The author(s) must inform the editor if the manuscript is being reviewed for publication by any other journals. Once accepted for publication by the editor, the author(s) cannot make revisions to the manuscript.

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Research and Review. The *JNSW* welcomes reports of original research on any topic related to renal social work. The editors will also consider manuscripts that document the development of new concepts or that review and update topics in the social sciences that are relevant to professionals working in the field of renal social work.

Reports and Commentary. The *JNSW* welcomes manuscripts that describe innovative and evaluated renal social work education programs, that report on viewpoints pertaining to current issues and controversies in the field, or that provide historical perspectives on renal social work. Commentaries are published with the following disclaimer: "The statements, comments, or opinions expressed in this article are those of the author, who is solely responsible for them, and do not necessarily represent the views of the Council of Nephrology Social Workers or the National Kidney Foundation."

Original Research. Full manuscript format should include: introduction, method, results, and discussion of original research. The method section needs either a declaration of IRB approval or exemption. Length should usually not exceed 15 double-spaced pages, including references.

Clinical/Research Briefs. Abbreviated manuscript format presents clinical practice experience, preliminary research findings (basic or clinical), or professional observations in a shortened report form. Length should usually not exceed six double-spaced pages.

Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

Case Studies. These detailed scenarios should illustrate a patient care situation that benefited from clinical social work intervention. Typically, they should consist of a brief clinical and psychosocial history, and a detailed intervention plan with discussion of recommendations focused toward practical application.

Letters to the Editor. Letters should be restricted to scientific commentary about materials published in the *JNSW* or to topics of general interest to professionals working in the field of renal social work.

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Order of the Manuscript Sections

- | | |
|---------------|--------------------------|
| 1) Title page | 5) Appendices (optional) |
| 2) Abstract | 6) Author note |
| 3) Text | 7) Tables |
| 4) References | 8) Figures with captions |

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the APA style guide for exceptions). The title page should also contain the complete address of the institution at which the work was conducted and the contact information for the primary author. A running head (a shortened version of the manuscript's title) should be set in the upper left-hand corner of the page, in all uppercase letters. Page numbering should begin in the upper right-hand corner of this page. With the exception of the page numbers and running heads, all text on the title page should be centered.

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Author Note. JNSW policy is to include an author note with disclosure information at the end of the article. It should begin on a new page with the words “Author Note” centered at the top of the page. Each paragraph should be indented. Running heads and page numbers should continue from the last appendix. Consult the APA style guide for further details on the structure of an author note.

Authors must include a two-sentence disclosure. The author note should include this disclosure (source of funding, affiliation, credentials) and contact information: “address correspondence to” primary author.

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Improving Advance Care Planning in Chronic Kidney Disease

Mary Beth Callahan, ACSW, LCSW, Dallas Nephrology Associates/Dallas Transplant Institute, Dallas, TX

As the age of dialysis patients increases, it is important to increase attention to advance-care planning (ACP) in the nephrology community. There are numerous ways to accomplish ACP, but it is important to note that having an advance directive (medical power of attorney or living will) does not mean that the clinician has a clear understanding of a patient's perceptions. The goal of this study was to evaluate nephrologists' views of ACP goals-of-care and end-of-life (EOL) discussions and improve ACP in chronic kidney disease (CKD). A needs assessment was created to identify and review barriers and strengths that could inform efforts to increase ACP within a large nephrology practice. A survey of nephrologists from a large practice in Texas regularly seeing patients aged 65 and older (N = 31) was conducted. Two-thirds of nephrologists, compared to 50% of other primary care practitioners (PCPs)/other specialists, feel that it is important to have goals-of-care conversations with patients. Eighty-six percent of the nephrologists had not had a conversation with their own healthcare provider about wishes for care at the end of life, in comparison with 52% of PCPs/other specialists. When nephrologists responded at a higher percentage, 6 out of 7 of those responses were independent from PCPs/other specialists. Nearly three-quarters (74%) of nephrologists thought it was their responsibility to initiate ACP, but also felt that they had not had training for talking to patients and families about ACP. A salient observation is the concern expressed by nephrologists over disagreement between family members and patients, coupled with time constraints and comfort level in discussing goals of care. These factors make licensed and experienced social workers ideal partners to facilitate early and repeated ACP discussions with patients and family members, which lead to greater physician-patient engagement and cost-effective care. By having ongoing ACP conversations with patients and family members prior to late stage CKD, nephrologists could more often achieve the patient- and healthcare-valued outcome of goal-concordant care. Goal-concordant care places the patient's values and wishes at the center of care

INTRODUCTION

Dialysis patients over the age of 65 have substantially higher mortality compared to the general population and Medicare populations with cancer, diabetes, or cardiovascular disease (USRDS, 2018). Many patients with chronic kidney disease (CKD) have complex health scenarios. Quality care at the end of life (EOL) for people with chronic and end-stage kidney disease has long been an area of concern. In 2000, the Renal Physicians Association (RPA) established a clinical practice guideline and toolkit, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, to help guide goals-of-care discussions with CKD stage 4 and 5 patients (RPA, 2000). In 2002, the RPA and American Society of Nephrology (ASN) provided a position statement on "Quality Care at the End of Life" to educate the medical community regarding what constitutes quality care at the end of life (RPA/ASN, 2002). Frail, older patients with CKD have special implications, requiring an age-attuned approach to medical management (Schmidt, 2012).

The Core Curriculum in Nephrology Palliative Care (Moss et al., 2004) guides nephrologists through the components and relevance of renal palliative care with background, definitions, and references, yet this area of practice has had limited implementation. There is increasing awareness that older people with comorbidities may not fare well on dialysis and that comprehensive medical management without dialysis may provide the same or longer length of life (Davison, Tupula, Wasnyluk, Siu, Sinnaraja, & Triscott, 2019). Patient-perceived quality of life, including symptom burden, cognitive and physical function, and satisfaction with care are relevant to goals-of-care discussions.

A needs assessment was created to identify and review barriers and strengths that could inform efforts to increase advance-care planning (ACP) within a large nephrology practice. Initial areas noted as opportunities for improvement included:

1. Definition of ACP
2. Territory—referral to another partner or part of routine care
3. Approaches to ACP
4. Expectations
5. Outcomes [STUDY AIM]

BACKGROUND

ACP with CKD patients is now viewed as a priority in chronic disease management by several national organizations including the Renal Physicians Association (2000), the Coalition for Supportive Care of Kidney Patients (CCKP), and Kidney Disease: Improving Global Outcomes (KDIGO) (Davison et al., 2015).

A consensus classification and staging definition for CKD was published in 2002 by the National Kidney Foundation's Kidney Disease Outcome Quality Initiative (NKF-KDOQI, 2002). There are five stages in this classification, with parameters based on glomerulofiltration rate (GFR) and microalbuminuria. CKD stage 4 is defined as severe loss of kidney function (estimated GFR 15–29 mL/min per 1.73 m²). CKD stage 5 is defined as kidney failure requiring dialysis or transplant for survival. End-stage renal disease (ESRD) is noted with estimated GFR < 15 mL/min per 1.73 m². GFR is also used diagnostically in patients who have received a kidney transplant.

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More CKD stage 4 patients die prior to developing ESRD (8.0 per 100 patient years) than those who develop ESRD (7.7 per 100 patient years) (Sud et al., 2014). Therefore, people with CKD stage 4 with other comorbidities may have a high need for early goals-of-care discussions. These numbers are noteworthy and indicate a need for process improvement in ACP, as the United States Renal Data System (USRDS) reports that CKD in the U.S. general (non-institutionalized) population of people aged 20 and older is more common than diabetes mellitus (DM); an estimated 13.6% of adults have CKD, compared to 12.3% with DM (CDC/NCHS, 2016; USRDS, 2016).

Healthcare costs for patients with CKD now represent 20.1% of all Medicare Parts A, B, and D spending (USRDS, 2017). Further review of this population finds that hospital admissions during the last 90 days of life among Medicare beneficiaries with ESRD has remained steady from 2000–2013 and is between 82–84% of this chronically ill population (USRDS, 2016). Admission to an intensive care unit (ICU) for these beneficiaries has increased from 50% to 63% during this same time period with an average length of hospital stay at 34 days during the last 90 days of life (USRDS, 2016).

Despite its suitability, supportive care has not been widely adopted across nephrology practices in the United States (Cohen, Ruthazer, Moss, & Germain, 2010; Combs, et al., 2015; Crews, et al.; DECIDE Investigators, 2014). Alridge et al. (2016) cite education, implementation, and policy as primary barriers. For the purposes of this project, supportive care in CKD/ESRD is defined as:

- shared decision making
- patient/family meetings to discuss prognosis and treatment choices
- ACP that may or may not include:
 - an out-of-hospital do-not-resuscitate order;
 - referral to hospice;
 - and/or transitional care planning and coordination of care as patients move between levels of care need.

This definition is consistent with recommendations that promote improved quality care at the end of life.

In 2014, the Institute of Medicine (IOM) called for “universal health professional and clinician education and training in the core principles and practices of palliative care: skilled communication about what matters most to patients and their families and how the healthcare system can help achieve those goals” (IOM; Committee on Approaching Death, 2014). Professionals and clinicians include physicians, nurses, social workers, and others. The Project on Death in America (PDIA) launched many projects that begin to illustrate the contribution of social work in palliative and end-of-life care (Walsh-Burke & Csikai, 2005).

In chronic disease management, particularly kidney disease, early and repeated conversations about treatment choices are indicated as the progression of the disease can lead to uremic symptoms which can bring confusion and fatigue (Germain, Davison & Moss, 2011; Germain, Tamura & Davison, 2011; IOM, 2014; Quill & Abernethy, 2013). These factors often decrease the patient’s cognition, and thus, may decrease their decision-making capacity. Additionally, better quality of life, enhanced family outcomes, and reduced overall costs have been noted when early discussions regarding goals of care have taken place (Bernacki & Block, 2014;). As stated earlier, the benefit of early ACP in nephrology has been documented, yet implementation is slow (Holley, et al., 2003; Moss, et al., 2004; Moss, 2010; O’Hare, Armistead, Shrag, Diamond, & Moss, 2014).

ACP Medicare Current Procedural Terminology (CPT) billing codes became available in January 2016. To explore utilization of this benefit, a 2016 national physician survey was commissioned by The John A. Hartford, Cambia Health and California Health Care Foundations to obtain physicians’ experiences with billing Medicare for ACP conversation(s) with their patients, as well as the motivations for and barriers to having these conversations. From this survey, the majority of practicing physicians reported no prior training in end-of-life communication with patients (John A. Hartford Foundation, Cambia Health Foundation, & California Health Care Foundation, 2016). Eighty-nine percent of the 746 physician respondents reported that having a conversation about ACP was extremely or very important. Of the respondents, 66% supported the Medicare benefit that reimburses providers for this conversation, but 86% had not had a conversation about ACP nor billed Medicare for it. Those with training about end-of-life issues and who had a formal system in place reported being more likely to both have these conversations and find them rewarding rather than challenging—but two thirds stated they lacked a formal system for assessing a patient’s end-of-life care concerns.

ACP has many approaches. Some that are widely accepted include:

1. Serious Illness Care Project (SICP)
2. Vital Talk
3. PREPARE™
4. Priming
5. Social Worker-Aided Palliative Care Intervention
6. Improving communication to achieve goal-concordant care

The Serious Illness Care Program (SICP) was created by a team of palliative care experts at Ariadne Labs (Bernacki et al., 2015). Ariadne Labs’ mission is to improve healthcare delivery through creation of scalable tools, such as the SICP. SICP is a system-level intervention centered on structured questions (*The Serious Illness Conversation Guide*) that have been

developed from best practices in basic palliative care. This framework helps clinicians explore topics to gain a better understanding of what is important to the patient in discussing goals of care (Bernacki et al., 2015).

Vital Talk (<https://www.capc.org/collaborations/vitaltalk/>) comes from a nonprofit organization (Center to Advance Palliative Care) with a mission to offer a communication skills training system. The aim is to help practicing clinicians who care for seriously ill patients and their families gain communication skills. The underlying premise is that training is critical to eliciting patient values and to discussing goals of care.

PREPARE™ (for your care) is a patient-facing website (<https://prepareforyourcare.org>) that includes ACP tools without clinician- or system-level interventions (Sudore, Boscardin, Feuz, McMahon, Katen, & Barnes, 2017). Research showed that easy-to-use ACP tools, without clinician and/or system-level interventions, can increase planning documentation at least 25%.

Priming, the idea of a patient-specific pre-conversation communication (priming intervention), may be helpful in discussing goals of care with patients who have serious illness(es). Priming was also studied in a 1990s randomized trial with the objective of improving end-of-life decision making and reducing the frequency of a prolonged process of dying (Curtis et al., 2018; The SUPPORT Principal Investigators, 1995; Teno, Fisher, Hamel, Coppola, & Dawson, 2002).

Social Worker-Aided Palliative Care Intervention is an approach similar to priming. A pilot randomized clinical trial (O'Donnell, Schafer, & Stevenson, 2018) appearing in *JAMA Cardiology* studied if routine initiation of goals-of-care discussions by a palliative care social worker bridging inpatient to outpatient care could facilitate greater patient-physician engagement. Another study by Kalisiak, Hansen, Newell, & Mills (2017) concluded that Licensed Clinical Social Workers (LCSWs) and Registered Nurses (RNs) could provide substantive ACP within team-based care. Stein, Christ, and Cagel (2017) surveyed over 700 palliative care social workers and found that 96% of respondents conducted ACP discussions and 68% documented planning discussions. As noted in this study, licensed and experienced social workers were facilitating, conducting, and leading ACP.

Improving communication to achieve goal-concordant care—High-quality communication has been shown to be essential in improving serious illness care and supporting goal-concordant care (Sanders, Curtis, & Tulskey, 2018). Goal-concordant care occurs when a clinician has communicated in a manner in which patient care follows patient preferences. Three suggested indicators to measure goal-concordant care are: 1) the timing and setting of the serious illness communication; 2) the patient's (or surrogate's) experience with care; and 3) bereavement surveys of caregivers about their perception of goal-concordant care at the end of life.

METHOD

A needs assessment was completed with nephrologists in 2018 to better understand the current state of ACP in nephrology practice and to more clearly identify strengths and barriers to expanding its implementation within a large nephrology practice.

The Cambia survey (John A. Hartford Foundation, Cambia Health Foundation, & California Health Care Foundation, 2016) polled 736 physicians in 2016. This survey, "Physicians' Views Toward Advance-Care Planning and End-of-Life Care," was administered to internists/PCPs, oncologists, pulmonologists, and cardiologists, because these physicians treat conditions linked to the top three causes of death in the U.S.: 1) heart disease; 2) cancer; and 3) chronic lower respiratory disease (CDC/NCHS, 2016).

Since nephrologists have not been widely included in these types of ACP studies and they also provide care to a large number of seriously ill patients over age 65 (USRDS, 2016) within the last 12 months of life (Foote et al., 2012), understanding nephrologists' perspectives is essential to improving ACP with CKD patients. Therefore, a large nephrology practice was surveyed with data comparison to the larger Cambia survey.

IMPLEMENTATION

1. The survey of 89 nephrologists used for this study was adapted as stated above (John A. Hartford Foundation, Cambia Health Foundation, & California Health Care Foundation, 2016). In December 2017, this initial survey was reviewed by the nephrology corporation's administration. The recommendation was to reduce the number of questions from 35 items to 21 items. The goal in reducing the number of questions was to keep the response time under 2 minutes in order to increase the response rate. This is consistent with literature that supports survey burden as a reason for non-response (Cunningham et al., 2015). Review of the literature shows that response rates for large-scale surveys conducted with various medical practitioners have steadily declined from 2000–2012 (Klabunde, Willis, & Casalino, 2013; Wiebe, Kaczorowski, & MacKay, 2012).
2. The Google Forms survey was approved by Dallas Nephrology Associates (DNA) and emailed to all of their 89 nephrologists on three dates in February and March 2018.
3. Response rate from the Google Forms survey was 35%. This rate is consistent with other non-incentivized physician surveys (Cunningham et al., 2015; Weiner, 2008). James, Ziegenfuss, Tilburt, Harris, and Beebe (2011) found support for the efficacy of prepaid cash incentives to optimize response rates for physician surveys. Incentives were credited for that study exceeding the goal of a 50% response rate. Since there was no funding for this project, monetary incentives were not used.

4. Results of the finalized survey of DNA (“Physicians’ Views Toward Advance-Care Planning and End-of-Life Care”) were compared with the Cambia responses using Fisher’s Exact Test of Independence since the number of responses was relatively low (< 1000). Fisher’s exact test and the Chi-Square test of independence check for statistically significant difference. To evaluate the results of the Fisher’s Test we used the p value ≤ 0.05 to test for 95% probability of statistical significance (McDonald, 2014).
5. Defining Null Hypothesis and Alternate Hypothesis:
 - i. Null Hypothesis: The responses from the Cambia specialty physicians and DNA nephrologists are independent (occurrence of one does not affect the probability of occurrence of the other).
 - ii. Alternate Hypothesis: The responses from the physicians surveyed by Cambia and DNA nephrologists have some relationship.
 - iii. A small p -value (≤ 0.05) indicates a very strong evidence against the null hypothesis defined above.
 - iv. A large p -value (> 0.05) indicates weak evidence against the null hypothesis; therefore, we accept the null hypothesis, i.e., there is not a relationship.
6. Survey questions (see **Appendix A**). The finalized survey has 21 questions which is a subset of the Cambia survey.

RESULTS

After tests of difference were completed, two-thirds of DNA compared to one-half PCPs/other specialists surveyed (Cambia survey) felt that it was important to have goals-of-care discussions with patients.

Eighty-six percent of nephrologists had not had a conversation with their own healthcare providers about wishes for care at the end of life, in comparison with 52 percent of PCPs/other specialists (Cambia survey). When the nephrologists responded at a higher percentage, 6 out of 7 of those responses were independent from PCPs/other specialists (Cambia survey) (**Table 1**). Three-quarters (74%) of nephrologists thought it was their responsibility to initiate ACP. Interestingly, three-quarters (74%) of nephrologists also felt that they had not had training for talking to patients and families about ACP.

Table 1.	Dependent	Independent
Nephrologists <i>More important</i> Questions: 6, 7, 8, 9, 13, 17, 21	1	6
Nephrologists <i>Less important</i> Questions: 1, 2, 3, 4, 5, 10, 11, 12, 14, 15, 16, 18, 19, 20	7	7

Other independent responses from nephrologists, indicating issues that they feel *more* strongly about, include:

- perceptions that talking to patients about goals of care and end-of-life wishes is important to reducing unnecessary or unwanted hospitalizations at the end of life
- helping patients and family members be more satisfied with their care
- goals-of-care discussions could increase the number of patients who receive hospice care
- common barriers to having conversations about ACP by physicians are time and comfort

Both groups of respondents (DNA/Cambia) noted that conversations about end-of-life care can be more challenging than rewarding (**Figure 1**). Both identified a perception of responsibility to initiate a conversation about ACP (**Figure 2**). Thus, perception of responsibility does not seem to be a barrier to providing these conversations. However, knowledge of documentation required for Medicare billing is low in both groups, and thus notes an area for improvement (**Figure 3**).

Figures 1–3 relate nephrologists' responses from the survey:

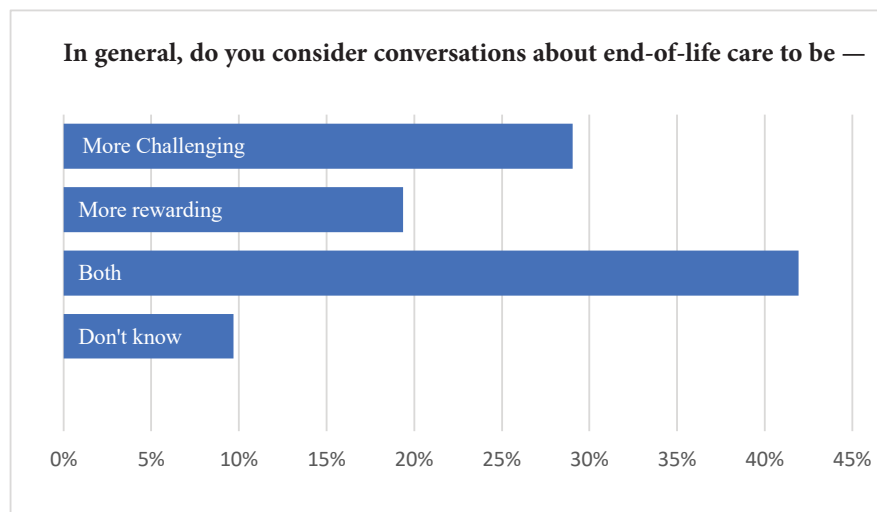


Figure 1.

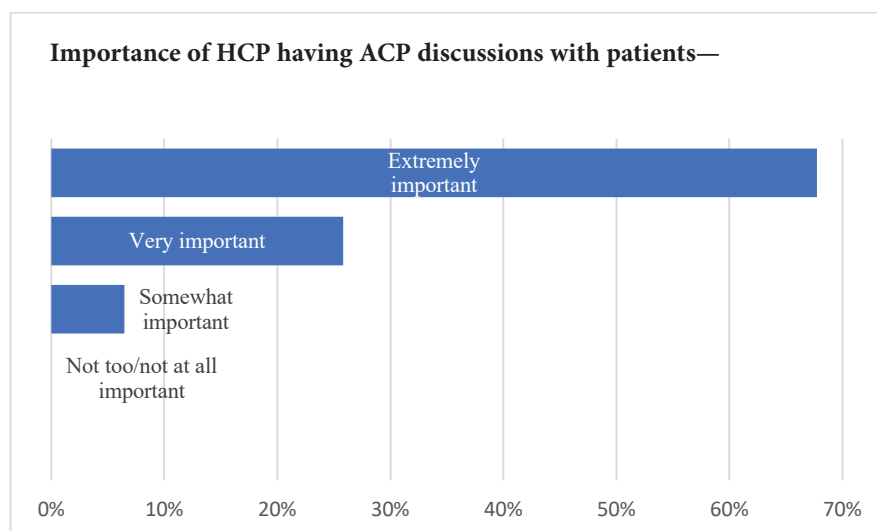
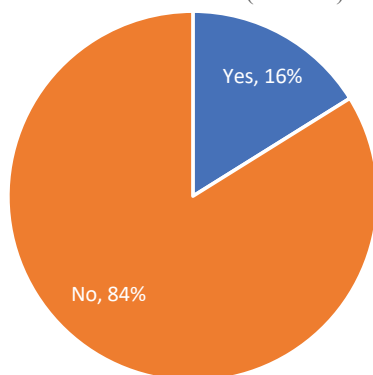


Figure 2.

HCP = healthcare professional

Figure 3.

Do you understand the documentation requirements to bill Medicare? (for ACP)



DISCUSSION

ACP discussions can be difficult because the clinician is often concerned that by talking about serious illness or future care, hope or trust may be diminished. There are numerous ways to accomplish ACP, but it is important to note that having an advance directive (medical power of attorney or living will) does not mean that the clinician has a clear understanding of a patient's perceptions. Listening and asking relevant questions to understand the patient's desire for knowledge (and how much), patient perception of quality of life, how they want to live at the end of life, concerns about treatment now and in the future, life goals, and unfinished business are important for the treating physician to understand in order to define treatment goals that align with patient values. With this information, the patient becomes an active participant in the shared decision-making process.

While kidney disease teams are encouraged to discuss realistic expectations of quality of life related to starting a life-sustaining treatment (dialysis), surveys suggest that many providers find it difficult to have this discussion and feel ill-prepared. Add to this situation that social workers are most often not a part of CKD care, and it creates an opportunity for improvement. Masters'-prepared social workers are in each dialysis setting across the country, but by the time a patient reaches the dialysis social worker, an access (fistula, graft or catheter) has been placed to begin dialysis. Prognosis and patient-perceived quality of life on dialysis have not been explored prior to surgery. With this information, many may have chosen medical management without dialysis. Goals-of-care discussions are often *infrequent, limited, and late* (ILL) (Bernacki et al., 2015).

Kidney transplant recipients continue to have CKD even after transplant. Therefore, kidney transplant teams also have opportunities, often not captured, to address patient quality of life and goals of care. Decisions about how to manage declining transplant function or comorbidities, including cancer, are very relevant to this population who often feel that transplant is a cure rather than a treatment option for kidney failure.

STUDY LIMITATIONS

- Size of sample—the results are based on a comparison to just one other survey of physician specialists. Analysis of larger sample sizes is necessary for more generalizable findings.
- Response rates were fairly low (but consistent with physicians' response rates). Therefore, the sample may be biased.
- Some responses may not be accurately interpreted as facilitators of barriers. For example, we need clearer associations between understanding of how to bill Medicare for ACP and the degree to which this may be a strength or barrier.

CONCLUSIONS AND RECOMMENDATIONS

The purpose of the overall project was to improve ACP within nephrology through a short needs assessment, and to explore how CKD and ESRD patients might receive earlier and repeated goals-of-care discussions, especially as they approach life-changing treatment options. The survey provided important insights into the strengths and barriers to ACP within nephrology when compared to the Cambia responses. As noted in the literature, goal-concordant care requires measuring more than the structural context of care (policy and procedures). Goal-concordant care places the patient's values and wishes at the center of care.

Goals-of-care discussions, palliative care, and symptom management are clinical priorities for CKD patients (Davison, 2001). The decision to start dialysis or have medical management without dialysis is a difficult choice, made even more difficult if the patient and family do not understand the implications of beginning dialysis with multiple comorbidities and advanced age.

A review of survey results with nephrologists indicates opportunities for improvement. Common barriers to physicians having conversations about ACP are time and comfort. These barriers may be ameliorated with team-based approaches to ACP, including licensed, clinical social workers having early and repeated ACP discussions with patients and family members, which lead to greater physician-patient engagement and cost-effective care that is concordant with patient goals (goal-concordant care).

Through the previously related needs assessment and additional training, Dallas Nephrology Associates moved forward with several changes to improve goals-of-care discussions and ACP:

1. Providers are being trained through the Serious Illness Care Project (SICP).
2. The practice has registered for membership with the Center to Advance Palliative Care (CAPC), which provides training in many areas of communication, including delivering serious news, and ACP for all employees.
3. The practice is working with the Pathways Project Collaborative Learning to initiate evidence-based recommendations designed to improve supportive care delivery for patients with kidney disease using the IHI framework of using small tests of change.
4. The practice has designated two new positions to coordinate improvement in goals-of-care discussions: Supportive Care Team Program Manager and Director, Supportive Care Team.

FUTURE RESEARCH

As noted, there are many opportunities to improve goals-of-care discussions early and often for people with CKD. The scope of this project is limited to CKD but End-Stage Renal Disease Seamless Care Organizations (ESCOs) are also looking at providing ACP earlier and repeatedly. Defining impact in an outpatient setting is still being developed but there is potential to define upstream outcomes regarding quality of life, anxiety, and depression that matter to patients and their families. The imperative is to align treatment with the patient's goals of care early, through a process of multiple discussions over time that help a patient manage chronic illness.

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Appendix A.

Survey Question	p-Value	Interpretation (p-value < = 0.05)	DNA More	Comparison Value
1. How often do you talk to patients 65 and older about issues related to advance-care planning or end-of-life care?	0.00012	There is a relationship between responses.	Less	At least once/week
2. Have you had any training on talking with patients and families about advance-care planning?	2.07E-11	There is a relationship between responses.	Less	Yes
3. Have you ever had a conversation with your own doctor or healthcare provider about your wishes for your care at the end of your life?	0.000108	There is a relationship between responses.	Less	Yes
4. In your opinion, how important is it that healthcare providers have these conversations with patients?	0.3683	The responses are independent.	Less	Extremely/ very important
5. Here are some potential outcomes of advance-care planning, goals of care and end-of-life wishes. For you personally, how important is each of these as a reason to talk with your patients about these issues? [You would be better able to honor your patient's values and wishes.]	0.01101	There is a relationship between responses.	Less	Extremely/ very important
6. Here are some potential outcomes of advance-care planning, goals of care and end-of-life wishes. For you personally, how important is each of these as a reason to talk with your patients about these issues? [It could reduce unnecessary or unwanted hospitalization at the end of life.]	0.06102	The responses are independent.	More	Extremely/ very important
7. Here are some potential outcomes of advance-care planning, goals of care and end-of-life wishes. For you personally, how important is each of these as a reason to talk with your patients about these issues? [Patients and family members may be more satisfied with their care.]	0.0932	The responses are independent.	More	Extremely/very important

Continued

8. Here are some potential outcomes of advance-care planning, goals of care and end-of-life wishes. For you personally, how important is each of these as a reason to talk with your patients about these issues? [It could save healthcare costs.]	0.1661	The responses are independent.	More	Extremely/very important
9. Here are some potential outcomes of advance-care planning, goals of care and end-of-life wishes. For you personally, how important is each of these as a reason to talk with your patients about these issues? [It could increase the number of patients who receive hospice care.]	0.09803	The responses are independent.	More	Extremely/very important
10. Have you had an advance-care planning conversation and billed Medicare for it in 2017?	0.7875	The responses are independent.	Less	Yes
11. Do you understand the documentation requirements to bill Medicare? Assumption: This question was framed slightly differently in the two data sets: In the physicians data [Cambia survey] the question is: "Do you bill under Medicare fee-for-service, or not?" In the nephrologists data [DNA survey] the question is: "Do you understand the documentation requirements to bill Medicare?"	$< 2.2e-16$	There is a relationship between responses.	Less	Yes & Question is: 33. Do you bill under Medicare fee-for-service, or not?
12. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If "yes": [You don't have time with everything else on your plate.]	0.8131	The responses are independent.	Less	Frequently/ Sometimes
13. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If "yes": [There's disagreement between family members and the patient.]	0.006899	There is a relationship between responses.	More	Frequently/ Sometimes
14. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If "yes": [You're not sure the time is right.]	0.5315	The responses are independent.	Less	Frequently/ Sometimes

Continued

15. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If “yes”: [It might be an uncomfortable conversation.]	0.3796	The responses are independent.	Less	Frequently/ Sometimes
16. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If “yes”: [You don't want a patient to feel that you are giving up on them.]	0.369	The responses are independent.	Less	Frequently/ Sometimes
17. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If “yes”: [You don't want a patient to give up hope.]	0.587	The responses are independent.	More	Frequently/ Sometimes
18. Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes? If “yes”: [You may be unsure what is culturally appropriate for the patient.]	0.6113	The responses are independent.	Less	Frequently/ Sometimes
19. During conversations about end-of-life care, how often do you feel unsure of what to say?	0.004775	There is a relationship between responses.	Less	Frequently/ Sometimes
20. In general, do you consider conversations about end-of-life care to be more or less challenging?	6.69E-08	There is a relationship between responses.	Less	Frequently/ Sometimes

Continued

<p>21. In general, whose responsibility should it be to initiate advance-care planning with patients: Assumption given slightly different response options: Here are the response options for physicians' data set [Cambia survey]: A. My responsibility B. The patient or family's responsibility C. Another doctor's responsibility D. A different type of healthcare provider, like a nurse or social worker's responsibility</p> <p>For the nephrologists' data set, the response options are [DNA survey]: A. My responsibility B. The patient or family's responsibility C. Another doctor's responsibility D. Another healthcare provider's responsibility, like a nurse or social worker E. A different type of healthcare provider, like a nurse or social worker</p> <p>Given the similarities, we combined the options D and E in the nephrologists data [DNA survey] and compared it with option D in the physicians' data [Cambia survey] set.</p>	0.06175	The responses are independent.	More	Combined options D and E in the nephrologists' data [DNA] and compared it with option D in the physicians data [Cambia] set.
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DNA = Dallas Nephrology Associates

Appendix B.

Survey results with significant differences between DNA and Cambia Surveys	<i>p</i> -value	DNA	Cambia
Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about end-of-life wishes: [Don't have time with everything else on your plate.]	0.8131	64%	66%
Had an ACP conversation and billed Medicare for it (2017).	0.7875	9%	13%
Think about your patients 65 and older with a serious illness. What has gotten in the way of talking to them about end-of-life wishes: [You may be unsure what is culturally appropriate for the patient.]	0.6113	42%	43%
Think about your patients 65 and older with a serious illness. What has gotten in the way of talking to them about end-of-life wishes: [You don't want a patient to give up hope.]	0.587	49%	46%
Think about your patients 65 and older with a serious illness. What has gotten in the way of talking to them about end-of-life wishes: [Not sure the time is right.]	0.5315	48%	60%
Think about your patients 65 and older with a serious illness. What has gotten in the way of talking to them about end-of-life wishes: [It might be an uncomfortable conversation.]	0.369	36%	51%
Think about your patients 65 and older with a serious illness. What has gotten in the way of talking to them about end-of-life wishes: [You don't want a patient to feel that you are giving up on them.]	0.369	42%	48%
Importance of HCP having goals-of-care discussions with patients.	0.3683	94%	89%
Goals-of-care discussions could save healthcare costs	0.1661	74%	63%
Goals-of-care discussions could increase the number of patients who receive hospice care.	0.09803	77%	57%
Goals-of-care discussions may help patients and family members be more satisfied with care.	0.0932	84%	81%
Goals-of-care discussions could reduce unnecessary or unwanted hospitalization at the end of life.	0.06102	94%	87%

DNA = Dallas Nephrology Associates

Barriers and Facilitators to Supportive Care for ESRD Dialysis Patients— A Social Worker's Role*

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Despite efforts to increase supportive care for patients on dialysis, many barriers continue to exist. This study surveyed dialysis facility staff to examine the barriers and facilitators related to providing supportive care to patients on dialysis. This qualitative analysis revealed five barriers: 1) lack of integrated, holistic teams; 2) practitioner beliefs; 3) perceptions of social work competence; 4) time and workload; and 5) lack of clarity regarding palliative care versus hospice and interpreting Medicare benefits. The analysis also revealed four facilitators related to providing supportive care: 1) integrated, holistic teams, including family involvement; 2) collaboration across care teams; 3) communication and compassion; and 4) formal or regular mechanisms for the review of advance-care plans. Based on the professional ethics code, social workers can play a role in bolstering their own teams' capacity to integrate supportive-care practices. Further, using their advocacy skills, social workers can lead efforts to ensure that they and their colleagues have appropriate training and competence in supportive care. Finally, social workers, with their knowledge of community resources, can help foster innovative collaboration between dialysis organizations and palliative care and hospice organizations, in spite of current regulatory and financial barriers.

BACKGROUND

Persons with end-stage renal disease (ESRD) on dialysis are widely underserved in the palliative care and hospice communities, despite significant symptom burden, increased mortality and in some cases, desire to receive less medical care and more quality of life (Davison & Torgunrud, 2007; Moss, 2017; Weiner, 2010). The term *supportive care* is used here in favor of end-of-life (EOL) or palliative care, as it encompasses a broader definition that includes, but is not limited to, advance-care planning (ACP) and EOL discussions early in disease prognosis (Cohen, Moss, Weisbord, & Germain, 2006; Davison et al., 2015). Supportive-care discussions and planning benefit patients and their families by improving well-being, reducing anxiety and depression levels, improving overall mood, and by providing a context in which to discuss the patient's prognosis and options for care, as well as to express their emotions (Lautrette et al., 2007; Perry, 2005). Additionally, ACP and supportive-care discussions have been shown to yield more realistic patient and family expectations of outcomes (Lautrette et al., 2007). In nursing home dialysis patients, these tools reduce hospitalizations, intensive care unit stays, and inpatient death (Tamura, Montez-Rath, Hall, Katz, & O'Hare, 2017). Several studies have found that patients may prioritize quality of life over prolonged life (Kane, Vinen & Murtagh, 2013; Mortan et al., 2012), yet providers are not accurate in predicting their patients' priorities (Harrison et al., 2019; Ramer et al., 2018), making it important that providers actually ask about, and then document, their patients' priorities.

Despite the long-acknowledged need for and benefit of supportive, palliative care for kidney patients, many barriers impede its provision. In a survey of a dialysis facility's staff, Culp, Lupu, Arenella, Armistead, and Moss (2016) reported that dialysis staff identified their greatest palliative care needs as: 1) bereavement care; 2) spiritual support; 3) EOL discussions and planning among healthcare providers, patients, and families; 4) pain management; and 5) caregiver support of family. The same study reported that providers were unaware of existing resources related to these areas. Barriers to providing palliative care were identified as: 1) no formal mechanism to identify high-risk patients; 2) patients' reluctance to discuss; 3) no policy related to EOL care; 4) no formal assessment of patients nearing EOL; and 5) no formal goal setting or plan of care for EOL. Respondents reported they wanted guidelines (but were unaware of existing guidelines), supportive-care consultations, and more education for staff and doctors. Less than 5% of respondents felt they were currently provided high-quality supportive or EOL care (Culp, Lupu, Arenella, Armistead, & Moss, 2016).

Other researchers have reported similar barriers to ACP and supportive-care discussions, including feeling ill-prepared to address these conversations due to a lack of education about appropriate language and timing (Ceccarelli, Caster, & Haras, 2008; Haras, Astroth, Woith, & Kossman, 2015), as well as time constraints (Ceskowski et al., 2017). Additional reported barriers include challenges with prognostication (Ceskowski et al., 2008), patient and family unwillingness (Ceskowski et al., 2017; Wasyllynku & Davison, 2014), and patient and family misconceptions (Ceskowski et al., 2017; Wasyllynku & Davison, 2014) or lack of understanding of prognosis (Mandel, Bernacki, & Block, 2016).

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Given their extensive training in engagement, assessment, intervention, and evaluation skills for individuals, families, groups, organizations, and communities, social workers—who are required in dialysis facilities by federal regulation—are well positioned to help address the area of supportive care for patients, families, and staff. To empower social workers at dialysis facilities to effectively intervene and improve the delivery of supportive care at their facilities, a full understanding of the impediments to its implementation is important. To more fully describe dialysis center staff perception of the issues involved in implementing supportive kidney care, we analyzed open-ended comments to a national survey of dialysis center staffs. We asked the question, “What themes about the barriers and facilitators to providing supportive care for persons with ESRD on dialysis emerge from dialysis center staffs’ own descriptions of their experiences?”

METHOD

This article is based on an analysis of the open-ended comments within a survey conducted in 2013 by the Coalition for Supportive Care of Kidney Patients (CSCCKP). CSCCKP members are individuals and organizations working together to transform the culture of kidney patient care to integrate patient-centered, supportive-care approaches and practices (CSCCKP, 2017). Coalition members include renal clinicians, dialysis center staff, hospice and supportive-care providers, patients and family members, policy makers, educators, attorneys, and other experts in their fields. As part of a needs assessment process to develop a strategic plan, the Coalition surveyed dialysis center personnel and kidney health professionals to determine their perceptions about the adequacy of current supportive care, barriers to providing it, and suggestions for improving it for kidney patients. Quantitative results have been reported elsewhere (Culp, Lupu, Arenella, Armistead, & Moss, 2016). This article analyzes the open-ended responses and comments in the survey.

The questionnaire consisted of 16 questions that gathered information on each participant’s healthcare discipline; how well the supportive-care needs of patients/families were met at respondents’ dialysis centers; and perceived barriers to and knowledge of currently available supportive-care resources. Question format included multiple choice and ratings on five-point scales. At multiple points in the survey, respondents were given the opportunity to enter free text to explain their answers. This article analyzes those free-text responses. The questionnaire was administered online through a direct web link to a SurveyMonkey platform. Health professionals from kidney dialysis centers and members of the Renal Physicians Association (RPA) were invited to respond between July and September 2013. The 18 national ESRD Network organizations, serving all U.S. dialysis centers, distributed the survey link via their communication channels, potentially reaching more than 6,000 dialysis providers. Responses were received from every ESRD Network region. The survey link was also disseminated by the RPA to its member email list, which consists of more than 3,500 physicians, physician assistants (PAs), advanced

nurse practitioners (NPs), and practice managers. Participation in the study was voluntary and anonymous.

We analyzed the optional, open-ended responses respondents provided to the following multiple-choice questions:

- What specific interventions are available at your dialysis center?
- What do you believe are barriers to providing high-quality palliative and end-of-life care in YOUR dialysis center?
- What do you believe would help eliminate the barriers to providing high-quality palliative and end-of-life care?
- What ONE change would most improve palliative care in your center?
- What could the Coalition for Supportive Care of Kidney Patients (CSCCKP) provide that would be helpful to your dialysis center?
- This is what we [the respondent] do well that we could share with other dialysis centers:

Respondents included medical directors, nurse practitioners (NPs), physician assistants (PAs), social workers (SWs), registered nurses (RNs), licensed practical nurses, dialysis technicians (DTs), dietitians (RDs), and administrators. A total of 487 respondents completed the survey. Social workers made up the largest group ($n = 199$; 40.9%), followed by nurses ($n = 146$; 30%), dialysis center administrators ($n = 95$; 19.5%), nephrologists ($n = 41$; 8.4%), and nurse practitioners/PAs ($n = 6$, 1.2%). A total of 275 open-ended responses were analyzed.

Data Analysis

Two researchers (one an Assistant Professor of Social Work, DSW, LCSW, and the other an MSW student) reviewed the qualitative survey responses and analyzed the data using a grounded theory approach and constant comparative analysis (Padgett, 2016). The researchers independently read the data multiple times to gain a holistic view of the responses. Qualitative survey responses were uploaded into Microsoft Excel for data analysis, including the question, response, and profession of the respondent, allowing researchers to sort responses by question and by profession. Using an inductive approach, researchers open coded each response in an additional column and kept a list of notes and questions. Researchers regularly met to discuss codes to develop a provisional list of codes. Each response was then re-examined and re-coded, and both researchers met regularly to gain consensus on emerging themes and subthemes until no new themes emerged.

RESULTS

Two overarching themes emerged from the data. The first, “barriers to providing supportive care,” was the most frequently cited response, with a total of 175 responses relating to barriers to or needs for palliative care for dialysis patients. The second theme, labeled “positive practices related to palliative care for dialysis patients,” consisted of 51 responses. The rest of the responses were either mixed (21) or not applicable (28). Quotations are used to illustrate examples of themes that emerged.

Barriers to providing supportive care

Five themes emerged relating to barriers to providing supportive care, including: *lack of integrated, holistic teams; practitioner beliefs; perceptions of social work competence; time and workload barriers; and lack of clarity regarding palliative care versus hospice and interpreting Medicare benefits.*

Lack of integrated, holistic teams

A number of respondents expressed concern regarding the effects of “fractionation of care,” “territoriality,” and a lack of interdisciplinary involvement with supportive care, not just within the dialysis facility, but also with external partners, such as hospice and palliative services. Some stated that supportive care was rarely spoken of in team meetings. One individual explained, “[the] physician wants to meet with patient and family alone without team members involved.” This is juxtaposed with another respondent who stated, “As the social worker, I am the only one providing any EOL information. It is not supported by the physician or other staff members.”

Some respondents spoke of a lack of a holistic approach to care, emphasizing the compartmentalization and discontinuity between dialysis care and other care teams. When asked what were the barriers to care, one nurse stated, “We are responsible for the dialysis and needs of the dialysis [patient]. After a referral is made and the [patient] is on hospice, then hospice should cover pain management and EOL issues. This is not our area and should not be put upon us. Everything we do has to be dialysis related according to CMS. We are not the patient's PCP.” Another respondent echoed this notion: “We are not hospice nurses, [if] we wanted to work in hospice, I would change my field.”

Practitioner beliefs

Practitioner beliefs about religion, personal economic prerogatives, and negative beliefs about supportive care were identified as a barrier that often undermines providing supportive care. One individual stated, “I recently had an MD forbid me to refer a patient to hospice ‘because they will give him narcotics, his blood pressure will drop, and then we will never get any fluid off.’ This is a patient who is clearly in a terminal decline and family has considered stopping treatment.” Some respondents explicitly outlined their beliefs, such as one who stated, “I don't believe a patient on hospice care should be allowed to continue with dialysis.”

Perceptions of social work competence

Many respondents identified the social worker as the professional responsible for addressing the emotional needs of the patient and family regarding supportive care. However, several respondents (both social workers and other professionals) indicated it was outside of the social worker's expertise. One social worker stated, “As a social worker, I sometimes feel that ‘EOL’ is out of my scope of practice. When you talk about ADs [advance directives], I feel underqualified to discuss ‘legal’ issues with patients. To me, a living will or AD is a legal document, and I lack qualifications as a legal expert to complete those.”

Time and workload barriers

The inability of social workers to demonstrate expertise in the supportive needs of patients may be explained by workload and time barriers. In fact, social workers referred to time barriers in a total of 16 separate responses. When asked what changes need to be made to improve care, a social worker responded, “Having more time as a social worker to handle psychosocial issues, rather than such a focus on insurance, billing, and Medicare documentation demands.” Other professionals also echoed that time and workload restraints were barriers to supportive care.

Lack of clarity regarding palliative care versus hospice and interpreting Medicare benefits

A number of responses seemed to indicate a commonly held misconception wherein palliative care is treated as being synonymous with hospice care. Respondents articulated how this leads to care being denied, especially when there are misunderstandings about when a dialysis patient qualifies for hospice or palliative care. One individual noted, “In last 12 months, we have made three referrals to hospice, and two of them were denied for still being on dialysis. All three of them have since passed way.” Another respondent stated, “Most of my patients want hospice care and wish to continue home therapy. This is great, as long as the hospice diagnosis isn't ESRD. I've had to educate hospice [staff] on this and how it's allowable by Medicare.”

Many respondents illustrated the lack of clarity regarding whether Medicare was more concerned with treatment compliance and achieving quality metrics, rather than patient-centered supportive care for kidney patients, recognizing that the initiatives seem to conflict with each other. “With all of the Medicare guidelines of missed treatments, fistula rates, etc. it is really the dialysis center's job to problem solve how they get to every treatment, stay every minute, etc. It is a little bit of a conflict.” Another illustrated, “When palliative care is in place, I would think that the patient's choice to miss treatment would be supported, as dialysis becomes a comfort measure.” Respondents expressed desire for more education to address these issues for staff, patients, and hospices, though time and funding were identified as major barriers in doing so.

Facilitators Related to Palliative Care

Four subthemes emerged from the 51 positive responses related to palliative care: *integrated holistic care teams, including family involvement; collaboration across care teams; communication and compassion; and formal or regular mechanisms for the review of advance-care plans.*

Integrated holistic care teams, including family involvement

Positive responses related to palliative care included descriptions of an integrated, holistic team approach to care, in which multiple disciplines meet to discuss patient care options. One individual described in detail a high level of integration: “The social worker will meet with the patient and discuss options and provide educational materials regarding EOL to find out what the patient wants. We then set up a family meeting where the team (nephrologist, NP, RN, social worker), the patient, and desired family members meet and discuss the patient’s wishes regarding EOL.” Respondents also identified their involvement with family and friends while engaging in supportive care as a practice that should be shared. Some facilities have face-to-face meetings with patients and families to discuss discontinuation of dialysis. One respondent stated, “The core team gets very involved with speaking with the family, when we feel the patient is getting to a point where their quality of life becomes suspect. This includes the FA [Facilitator Administrator], SW, RD, RNCM [Registered Nurse Case Manager], and MD.”

Collaboration across care teams

Respondents also highlighted the importance of collaborating with other healthcare providers, specifically palliative care and hospice providers. One respondent noted the decision to include the palliative care team in dialysis staff meetings, and another expressed desire to have hospice staff visit and offer practical training. A respondent at a veterans hospital illustrated how the collaboration with palliative care teams is helpful by stating, “Our patients are frequently hospitalized here on site so we continue to dialyze them while they are in-patient, and [we] collaborate closely with the in-patient palliative care team to offer quality EOL support to patients and families. This is also helpful to dialysis staff in that they get closure with the patient and family at EOL and also have a better understanding of when it’s time to withdraw from dialysis.”

Communication and compassion

Respondents consistently identified that a positive practice for palliative care was a high degree of frequent, early, and open communication about supportive care, as well as communication that was compassionate. Respondents discussed how they started discussions at onset of dialysis, discussed code scenarios, and often involved family members and friends.

Compassionate communication was also identified as a positive practice. One respondent illustrated this type of communication by stating, “The thing I see the most is how much each staff member truly cares for the patients. Each tech and nurse plays their part to the fullest extent. All patients need to feel love and acceptance, and that is something we already do on a daily basis.”

Formal or regular mechanisms to review advance-care plans

Formal or regular mechanisms to review advanced directives (AD) and Do Not Resuscitate (DNR) orders emerged as useful positive practices to engage in supportive care. One individual noted, “We review and provide AD planning with every new patient within the first 30 days and complete an addendum to care with specific directions for patient/family wishes and expectations. DNRs are reviewed with each requesting patient on a monthly basis to allow the patient to change the option as needed.”

DISCUSSION

Previous studies have surveyed dialysis facility practitioners, but quantitative reports do not convey the full texture and range of respondents’ experiences as expressed in open-ended comments. The prior research has not explored the nuances of the difficulties of front-line practitioners in the field as expressed in their own words, and when given an opportunity to reply to an open-ended question. This analysis provides the insight that many practitioners express willingness to engage in supportive care for patients with kidney disease but encounter significant barriers to positive practices of supportive care.

Integrated, holistic care was identified as both a barrier and facilitator to providing supportive care of kidney patients. When providers only focus on the kidneys, not the person as a whole, they become limited in their ability to provide supportive care. Dialysis facilities are required to employ multiple disciplines, including social workers, as described in the Conditions for Coverage (2008), but numerous comments suggested that full integration of social workers and true interdisciplinary care often doesn’t occur in practice. This finding suggests that if teams want to be successful in implementing supportive care, the entire team needs to work together. Social workers are given guidance in the National Association of Social Workers (NASW) Code of Ethics (2017) Standard 2.01 regarding involvement in interdisciplinary teams: “Social workers who are members of an interdisciplinary team should participate in and contribute to decisions that affect the well-being of clients by drawing on the perspectives, values, and experiences of the social work profession. Professional and ethical obligations of the interdisciplinary team as a whole and of its individual members should be clearly established.”

Frequent, early, and open communication about supportive care, as well as compassionate communication, were identified as tools to address the supportive needs of patients with ESRD. However, this analysis revealed that many dialysis social workers do not feel competent or have time to address the supportive needs of patients with kidney disease, in part due to workload. Likewise, in many cases, the provider’s beliefs regarding the needs of patients at the EOL were in direct opposition to supportive-care practices, which was affirmed in some of the open-ended responses, such as one that stated “I don’t believe a patient on hospice should get dialysis.”

Similar to Culp, Lupu, Arenella, Armistead, and Moss' (2016) quantitative analysis, having a formal mechanism to review advance-care plans was also identified as a tool to increase supportive care. The challenge of adhering to a formal mechanism to review advance-care plans could be overcome if more members of the dialysis team engaged in supportive care conversations. Moreover, increased understanding of the distinctions between hospice and palliative care and interpreting the Medicare benefit could provide patients with meaningful information for ACPs. Increasing active collaboration—not just patient referrals—between dialysis center staff and local palliative care and hospice teams could foster this improved understanding.

This study has two primary limitations. First, respondents were self-selected; only those persons who chose to fill out the survey as well as provide comments, are represented. In addition, the nature of the survey's short responses limited researchers from gathering full context through probing and dialogue.

This analysis contains several practice implications for social workers. First, social workers should assess how their integrated team functions, and how the facility is connected to outside systems, such as hospice and palliative care, and formally review ACP processes in a way that goes beyond typical "checkbox" methods and that includes a high degree of compassionate communication. Second, recognizing that many teams lack an integrated approach, social workers should refer to the NASW Code of Ethics' (NASW, 2017) emphasis on the social worker's role in care teams. Social workers, trained in a systems approach, are well-positioned to be leaders in community outreach to local hospice and palliative care organizations. Third, if the team lacks clarity in understanding the difference between hospice and palliative care and in interpreting the Medicare benefit, social workers should take advantage of free resources, such as those of the Coalition for Supportive Care of Kidney Patients (CCKP, 2017), and share the information with the dialysis team. Social workers can lead efforts to strengthen active collaboration with local palliative care and hospice teams. Finally, social workers should advocate for their profession by making efforts to achieve the highest-level social work degree (NASW, 2017). Help team members understand that an MSW education goes well beyond insurance, transportation, and referral. Social workers need to highlight social work's unique training in diversity, self-awareness and bias, and ethical decision-making, as well as their theory and skills training in engagement, assessment, intervention, and evaluation of individuals, families, groups, organizations, and community systems (Council on Social Work Education, 2017). The training and skill of the MSW not only helps dialysis facilities better meet the Conditions for Coverage (CfC) for psychosocial care but provides dialysis facilities with a valuable resource in supporting the care of patients with kidney disease.

Research implications

Future researchers should consider a deeper dive into the role of dialysis social workers in the supportive care of kidney patients. In particular, researchers should explore how social workers' training and education align with current MSW practices in dialysis facilities and investigate how social workers can be a resource in providing supportive care to kidney patients. Researchers should also consider exploring how dialysis teams providing supportive care to kidney patients use the role of a social worker, focusing on best practices and skill development. Finally, researchers should explore outcomes related to social worker involvement in supportive care of kidney patients, including patient outcomes, such as hospitalization, preferred place of death, as well as implications for social worker time and workload, etc.

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Clinical Social Work End-Of-Life Survey: Constructive Work with Patients and Family Members on Advance Directives and Medical Orders for Life-Sustaining Treatment

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This article identifies how clinical social workers in medical-surgical, mental health, and nephrology settings at Walter Reed National Military Medical Center (WRNMMC) and the End-Stage Renal Disease (ESRD) Network 5 Mid-Atlantic Renal Coalition assist nephrologists and other physicians in overcoming barriers to end-of-life (EOL) care planning, particularly in patients with end-stage renal disease (ESRD) or acute kidney injury (AKI). To assess differences in practice patterns, an anonymous survey was administered to determine whether social workers were comfortable having EOL care discussions with their patients, and to also assess if these social workers were able to assist the physicians with EOL care planning. Findings showed that social workers identified multiple barriers to discussing EOL care planning. Participants also identified the most important conversations to have when discussing EOL care planning with their patients.

INTRODUCTION

There is a great need for advance-care planning (ACP), and palliative and hospice care in our health system. As the United States population ages, there is a growing number of people who could benefit from these services. Currently there are 90 million people in America with a serious illness and this number is predicted to double by 2040 (Morrison, Augustin, Souvanna, & Meier; The Center to Advance Palliative Care, 2011). Educating patients and their families about advance directives and the benefits of palliative and hospice care is strongly advised.

This is urgently needed in kidney disease care. Although hospice use appears to be growing for end-stage renal disease (ESRD) patients, it is usually used for only a short time (USRDS, 2013), and only 24% of eligible ESRD patients are referred to hospice (Gravaren, 2015). We previously surveyed nephrologists who were associated with a single training program ($n = 93$; 61% response rate) and asked them what they saw as the barriers to referring patients to hospice (Table 1). Six percent cited a lack of available hospice resources in their region; 27% said referral and end-of-life (EOL) discussions were too time consuming; and 69% felt patients had misconceptions about end-of-life (EOL) care. Encouragingly, 92% of these nephrologists felt comfortable having EOL care discussions with their patients (Ceckowski, Little, Merighi, Browne, & Yuan, 2017).

Patients who were approached by a healthcare professional and had a discussion on EOL care planning spent much less time in the hospital, particularly in the ICU (Curtis, 2004; Holden et al., 2015). Furthermore, Medicare now provides payment for such conversations (Gawande, 2016). Previous research suggests that social workers who have their own advance directive are more likely to discuss completing an advance directive with their patients (Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996). In 2012, only 7% of patients who

were seriously ill had an EOL care conversation with their doctor, compared to 60% who had that same discussion with their social worker (The Conversation Project & The Institute for Healthcare Improvement, 2015; Grubbs et al., 2014).

Table 1. Nephrology Survey 2015:
Barriers to EOL Discussions in ESRD Patients
(Ceckowski, Little, Merighi, Browne, & Yuan, 2017)

Predominant Barriers

- Time-consuming nature of discussions (27%)
- Difficulty in determining prognosis for < 6-month survival (35%)
- Patient (63%) and family (71%) unwillingness
- Patient (69%) and family (73%) misconceptions
- Lack of palliative care (12%) and hospice (6%) resources

Nephrologist Survey Summary

- Anonymous, online, cross sectional survey of 93 nephrologists associated with Walter Reed National Military Medical Center (WRNMMC) program since 1987 (including 75 graduated fellows). All contacted by email or fax
- 61% response rate, 95% of whom were in active practice
- 65% in practice > 10 years
- 92% were comfortable discussing EOL care, with no significant difference between those > 10 years in practice and those 10 years or less.
- 31% felt they under-referred
- 57% would refer more patients if dialysis/ultrafiltration could be done in hospice.

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Discussing EOL care with patients can be very difficult for clinical social workers, especially if they lack training or have not experienced a major life changing event themselves (Gutheil & Heyman, 2011; Perry et al., 1996). However, it is also known that patients strongly desire to have EOL care discussions with their care providers (Curtis, 2004; Davison, 2010). In order to have EOL care discussions, it is recommended that scheduled time be set aside for the social worker to sit down with the patient and the family, and that the resources required to complete advance directives (ADs) are available at the hospital, the dialysis center, or the mental health clinic. Unfortunately, some regions lack these resources due to funding priorities (Barnato et al., 2007).

In 2011, *America's Care of Serious Illness: A State-by-State Report Card on Palliative Care in Our Nation's Hospitals* noted that there has been a 138% increase in palliative programs in hospital settings since 2000, and that 92% of Americans would consider taking part in a palliative care program for themselves or their families if they had a serious illness (Morrison et al., 2011). Hospice is a major part of the continuum of care in palliative care programs. Based on a 2011 needs survey of patients and family members (Table 2), Morrison et al. (2011) identified areas in hospice care that could be improved. Many patients still experience pain and shortness of breath in the last few days of their life. Many patients fear pain, and pain management is one factor of ACP that needs improvement. Also, in keeping with the goal of "continuum of care," hospice should offer grief and loss counseling for the patient's family (CMS, 2017), yet only about 33% reported receiving this benefit. Furthermore, 33% stated that they were discharged from the hospital with no follow-up care, which appears to be a complete breakdown of ACP. Holley and Davidson (2015) sum this up by stating that ACP:

...can enhance communication among patients and care providers ensuring that EOL care wishes are known, reduce unwanted and aggressive treatments at the EOL, improve patient and family/loved one satisfaction with care, and reduce stress, anxiety and depression in surviving relatives.
(p. 345)

STUDY AIM

The aim of this study was to describe how clinical social workers in medical-surgical, mental health, and nephrology settings assist nephrologists and other physicians in overcoming barriers to EOL care planning, particularly in patients with ESRD or acute kidney injury (AKI).

METHOD

We surveyed 221 clinical social workers at the Department of Social Work at Walter Reed National Military Medical Center (WRNMMC) and the ESRD Network 5 Mid-Atlantic Renal Coalition regarding EOL care. We distributed by email a 49-item anonymous online survey using SurveyMonkey® (<http://www.surveymonkey.com>) from October 20 to November 22, 2016 (survey available for review upon request).

No personal identification information was collected, no IP Addresses were retained, and respondents were allowed to complete as little or as much of the survey as desired. The survey could only be completed once. Additionally, no email addresses were disclosed to the authors; all were sent through an office administrator at WRNMMC.

Table 2. Results from Hospice Needs Survey

Patients Reported	People Living with Serious Illness Experience
25%	Inadequate treatment of pain
25%	Inadequate treatment for shortness of breath
33%	Inadequate emotional support
33%	No education about how to treat pain and other symptoms following discharge from the hospital
33%	Not provided with arrangements for follow-up care after being discharged from the hospital
(Morrison et al., 2011)	

Social workers were asked about clinical caseloads, number of patients who died in a given year, and where these patients died (e.g., hospice, home, hospital, nursing home). They were asked how many of these deaths were surprising or unexpected. Respondents were asked if they were trained in EOL care planning, and to also assess their own comfort with advance directives and medical orders for life-sustaining treatment (MOLST) discussions with patients and family members. Questions were also asked to assess whether having an advance directive for one's self increased respondents' comfort in completing advance directives for their patients. Respondents were asked if they experienced a significant event in their own lives that prompted their utilization of a personal advance directive (e.g., family death), or if they experienced completing advance directives with their patients' families. Lastly, respondents were also asked about the level of importance they placed on specific patient conversations addressing barriers to EOL care.

Table 3. WRNMMC and ESRD Network 5 Social Work Survey: Description of Respondents and Caseload**Social Work Respondents (*n* = 84)**

	CMSSW <i>n</i> = 11	CMHSW <i>n</i> = 6	CNSW <i>n</i> = 67
Years of Practice (Mean)	25	19	19
SW with their own AD/MOLST (%)	36%	50%	35%
SW personally experienced a significant EOL event (%)	55%	67%	48%
SW EOL training received (Median hrs)	11–20	11–20	6–10
Patients in caseload (Median)	1–20	21–45	> 100
SW assisted a Family Member in AD/MOLST (%)	64%	83%	46%
Patients with AD/MOLST in their chart (Median %)*	1–25%	1–25%	26–50%
Deaths that were surprising or unexpected (Median % in last year)*	None	1–10%	1–10%
Died in hospice (Median %)*	11–25%	1–10%	1–10%
Died at home (Median %)*	1–10%	1–10%	1–10%
Died in the hospital (Median %)*	26–50%	1–10%	26–50%
Died in nursing home (Median %)*	None	None	1–10%

***Excluding respondents who indicated “unsure.”**

AD = advance directive; CMSSW = clinical medical surgical social workers; CMHSW = clinical mental health social workers; CNSW = clinical nephrology social workers; ESRD = end-stage renal disease; MOLST = medical orders for life-sustaining treatment; WRNMMC = Walter Reed National Military Medical Center.

Data are presented descriptively as percentages, medians, and means. Comparisons were performed using the Fisher Exact test, with significance threshold set at $p < 0.05$. The WRNMMC Institutional Review Board (IRB) approved this study [Reference #875078, Project #16-00562].

RESULTS

Eighty-four clinical social workers completed the survey (38% response), summarized in **Table 3**. Eighty percent identified as clinical nephrology social workers (CNSW), 13% as clinical medical surgical social workers (CMSSW), and 7% as clinical mental health social workers (CMHSW).

The mean number of years in practice for CMSSWs was 25, 19 for CMHSWs, and 19 for CNSWs. The median caseload for CMSSWs was 1–20, for CMHSW 21–45, and > 100 patients for CNSWs. The mean number of hours EOL care training was 11–20 hours for CMSSWs and CMHSWs and 6–10 for CNSWs. There was no statistical relationship between training hours

and number of years in the field as a clinical social worker.

Social workers did not think it was too time consuming to discuss AD/MOLST with their patients. Interestingly enough, respondents indicated it was too time consuming for them to complete their own ADs/MOLSTs. Approximately 36% of CMSSWs and CNSWs filled out an AD/MOLST for themselves, and 50% of CMHSWs reported having completed them. In fact, 88% of social workers discussed AD with their patients, but only 28% of social workers reported that they discussed this topic as a team with their physicians. Fifty-three percent of respondents thought that patients were willing to engage in EOL discussions, and 39% reported that family members were willing to engage in this topic. Twenty-eight percent of social workers reported feeling unsure if family members were willing to engage in AD/MOLST conversations and 33% stated that family members were *unwilling* to discuss this topic.

Overall 39% of respondents had completed their own AD/MOLST. Those who reported they had personally experienced a significant life changing event with regard to EOL care (51% overall) *were no more likely* to have completed their own AD/MOLST vs. those who had not (39% vs. 31%; $p = 0.49$). Social workers with their own AD/MOLST were significantly more likely to have assisted a family member with an AD/MOLST than social workers without a completed AD/MOLST (80% vs. 49%; $p = 0.015$). However, social workers with their own AD/MOLST were no more likely to discuss EOL issues with patients than those who did not have their own AD/MOLST (90% vs. 87%; $p = 1.0$). Of those with an AD/MOLST, 33% reported that > 50% of their patients had an AD/MOLST vs. 30% for social workers without ($p = 0.80$).

Ninety-five percent of social workers surveyed either strongly agreed or agreed that it was their responsibility to discuss EOL care with their patients, and 98% strongly agreed/agreed that physicians have a responsibility to help patients at EOL to prepare for death. However, when asked if their physicians discussed EOL care with patients and family members, only 42% of respondents said these conversations were occurring.

Overall, respondents reported a total of 1,152 deaths in one year (an average of 15 patients per social worker annually). This suggests respondents were quite experienced in encountering EOL issues. A majority of social workers indicated that among all the patients who died in a year, the deaths were not considered “surprising” or unanticipated. In our survey, it appears that patients were more likely to die in the hospital rather than at home, and most were not enrolled in hospice prior to death (Table 3).

As seen in **Supplement 1**, social workers in our survey reported the most important lesson(s) they learned about addressing EOL care situations in their practice. One social worker thought it very helpful to bring up the discussion with their patients to find out if there were any changes to their decision about having a “do not resuscitate” (DNR) order in their medical record. One social worker also felt that the process should be started by the physician, and that once a treatment process has begun, it is often difficult to change it without being awkward or intrusive. Lim et al. (2016) found there was a barrier to ACP if the physician was not available to initiate the process. It may be that a social worker should work more closely with the physician during the initial visit with the patient. In our survey, we found that physicians, indeed, do not appear comfortable discussing hospice insurance benefits with their patients, a task that has always been handled by the social worker in many institutions.

Clinical social workers “strongly agreed” / “agreed” (77%) that palliative care resources were readily available in their area, as was local hospice care (89%). They “strongly agreed” / “agreed” that EOL care was indicated for their patients (79%), and that EOL-care discussions were not too time-consuming with their patient population (62%). They also observed that while reluctance to discuss EOL issues among patients (24%) and family members (32%) was low, they were likely to have misconceptions about EOL care.

Social Workers’ Discussions with Patients and Families

Discussing AD or MOLST with the patient before serious complications arise is preferred (Perry et al., 1996). Many social workers in a clinic or in a hospital setting engage in healthcare proxy discussions when: a) it is mandatory or company policy; b) initiated by healthcare providers only after the patient’s health begins to decline; or c) the patient initiates the process (Perry et al., 1996). In our survey, social worker respondents ranked 15 conversations (Table 4) they could have with their patients as being “very important” to “very unimportant.” Sitting down with the patient and asking them to discuss this difficult topic was seen as very important.

Empowering the patient and his/her family is a goal for social workers (Van Dorn, Scheyett, Swanson, & Swartz, 2010). Asking the patient what they understand about their diagnosis after the physician discussed it with them was also seen as an important in assessing the patient’s health literacy. Alleviating confusion and doubt has been shown to improve overall health outcomes (Peace & Phillips, 2015).

When asked if their patients had an AD, 33% of CMSSWs surveyed did not know, but 67% thought that 1–50% of their patients had completed one. Fifty percent of CMHSWs also thought that 1–50% of their patients had an AD filled out. CNSWs reported a higher percentage of their patients as having an AD, a median of 26–50%. CNSWs often use AD completion as a quality measure in the patient’s yearly Quality Assessment Performance Improvement (QAPI) plan, which may account for the larger percentage. Often, the discussion of EOL care occurs but the patient may wish to fill out their AD at a later date. In our survey, 94% of CNSWs had a conversation about AD/MOLST with their patients, whereas 70% CMSSWs and 50% CMHSWs reported having had this discussion. The relatively low percentage of CMHSWs who had completed an AD/MOLST with their patients was somewhat surprising. However, the sample of CMHSWs in this study was low. In the Commonwealth of Virginia, key stakeholders have committed to making ADs as one of the “legal tools into routine mental health care” throughout the state (Kemp, Zelle, & Richard, 2015). Through the legislative process, Virginia has taken the lead on this issue nationwide over other states. Interested readers are encouraged to access the Virginia Hospital and Healthcare Association (www.VHHA.com) website for their open-access Supplemental Mental Health Advance Directive.

Lim et al. (2016) found a significant positive correlation between social workers having their own personal AD and their inclination to have a conversation with their patients about AD. However, in our study, social workers with and without ADs did not differ in terms of their likelihood to discuss EOL with patients. In our study, 39% of social workers had a fully executed AD/MOLST, and those who did were significantly more likely to have assisted their own family member in completing one. However, social workers without their own AD/MOLST were no less likely to discuss EOL issues with their patients and had similar completion rates among their patients.

In our study, social workers felt that patient and family members both had misconceptions about EOL care. Nephrologists surveyed in our previous study (**Table 1**) stated that patients (63%) and families (71%) had an unwillingness to discuss EOL issues, and that patients (69%) and families (73%) also had misconceptions about EOL discussions. In one study comparing African Americans to non-African Americans with regard to not trusting the healthcare system, the greater the lack of trust, the greater the decline in effective communication and healthcare compliance (Watkins et al., 2012). If African American patients were in any way suspicious of the healthcare system or had a lack of trust in it, this led to an overall sense of powerlessness when discussing EOL care and their AD. Above all, patients and their families want honesty and caring words in the conversation. This may be the first time a patient has sat down with a provider to discuss AD issues. The physician and the social worker should do all they can to make this a meaningful and empathic experience for every patient.

In The Conversation Project's booklet entitled *Your Conversation Starter Kit by the Institute for Healthcare Improvement* (The Conversation Project and The Institute for Healthcare

Improvement, 2015), the discussion first allows the patient to collect their thoughts so that they can then ultimately reach out to their friends and family with a clear goal. It was noted in Conversation Project data that 90% believed it was important to talk about EOL care planning, but that only 27% actually did so. Eighty percent said they thought it was vital to talk to their doctor about their wishes for medical treatment at the EOL, but only 7% actually had that conversation.

Our respondents ranked the importance of certain conversations that they could have with their patients in discussing EOL care planning (**Table 4**).

We also observed some ambivalence on the part of the social workers with regard to seven of the survey questions (**Table 5**). The respondents "neither agreed nor disagreed" with these statements with some frequency—and thus the responses fell within the "neutral range." These findings were unexpected, especially in view of the questions that the social workers indicated as very important to have with their patients (**Table 5**).

Table 4. WRNMMC and ESRD Network 5 Social Work Survey: Top-Ranking Conversation Questions

Social Workers were asked to rate the level of importance for each of the following patient conversations that address potential barriers to EOL care:

Asking if...	Very Important/ Somewhat Important Discussions (%)
Patients wish to discuss what is most important to them in the last phase of their life?	94%
Patients wish to put their end-of-life care wishes in writing?	90%
Patients have discussed end-of-life care with their family members?	91%
Patients have a plan for where they want and do not want to receive end-of-life care (e.g., home, hospice, nursing home, hospital, etc.)?	91%
Patients want to discuss life milestones (e.g., birthdays, anniversaries, celebrations) that they would like to try to be present for before they die?	91%
Patients have a plan for the kind of treatments they want or do not want during end-of-life care (e.g., pain control, nutrition supplements, intravenous fluids, etc.)?	90%
Patients wish to discuss changing their mind about end-of-life care in the event their circumstances change?	89%
Patients know about their diagnosis(es)?	88%
Patients know about their prognosis?	85%
Patients have disagreements with family members about their decisions for end-of-life care?	86%
Patients wish to make decisions about end-of-life care while meeting with you?	85%
Patients have problems regarding family finances/property, responsibilities, or personal/professional relationships?	76%
Patients are ready to discuss shifting the focus from curative care to comfort care?	76%
Patients want to rehearse the conversation they would like to have with their doctor about end-of-life care?	72%

To support the physician, the clinical social worker should be able to guide the patient through these difficult conversations surrounding EOL care. Yet we see that in one question, “I, together with the physicians with whom I work, discuss Advance Directives or MOLST with our patients as a team,” respondents seem ambivalent. A substantial percentage of the social workers rated this statement as “neither agree nor disagree.” It may be that the social worker is able to have this conversation fully with the patient, but not “as a team” with the physician. Moreover,

for the survey questions, “Most of the physicians with whom I work discuss end-of-life care with their patients” and “Most of the physicians with whom I work discuss end-of-life care with the patient’s family,” we also see a substantial percentage of the social workers state that they “neither agree nor disagree” with the statement.

Table 5. WRNMMC and ESRD Network 5 Social Work Survey: Ambivalence on the Part of the Social Worker

	Mean Likert response (1.67–2.33 indicates neutral area)	% responding “Neither Agree nor Disagree” to the statement
Patients are unwilling to engage in end-of-life discussions.	1.7	23%
Family member(s) are unwilling to engage in end-of-life discussions.	1.9	24%
Most of the physicians with whom I work discuss end-of-life care with their patients.	2	17%
Most of the physicians with whom I work discuss end-of-life care with the patient’s family.	2	20%
I, together with the physicians with whom I work, discuss Advance Directives or MOLST with our patients as a team.	1.8	21%
I discuss insurance benefits for palliative care with my patients.	2	18%
I discuss insurance benefits for hospice care with my patients.	2.1	12%
It is my understanding that it is difficult to accurately determine if a patient’s prognosis for survival is less than 6 months.	2	26%

IMPLICATIONS FOR SOCIAL WORK

Social workers responding to our survey indicated that the physicians with whom they work do not feel comfortable discussing insurance benefits for hospice care (68%) or for palliative care (63%) with patients. A prior study showed that family/internal medicine physicians were nearly 9 times more likely to make EOL referrals than other doctors, and that physicians comfortable discussing EOL care were nearly 7 times more likely to refer (Kogan, Brumber, Wilber, & Euguidenos, 2012).

Lim et al. (2016) showed that not only are social workers more willing to assist patients in filling out an AD/MOLST if they have filled out their own, but those patients whose peers discussed filling out an advance directive were also more likely to complete an AD/MOLST. This is an important topic, one that may have not been discussed in much detail in the past in the literature. In an interdisciplinary and multisystemic approach to patient care, it may be important to consider whether the patient's peers have completed ADs/MOLSTs and how this might affect the patient's actions. Social workers should work with their team to increase the number of patients with an AD/MOLST and who enroll in hospice. Social workers also need more conversations with their physicians about this topic. Further research on this topic is needed, especially on the effects on social work resilience to frequent patient deaths.

CONCLUSION

ACP provides many of the answers the healthcare worker and the patient are seeking to help resolve dilemmas with EOL preparation. ACP enables the patient to put in writing their wishes in the form of a living will and to designate a surrogate in the form of a healthcare power of attorney. ACP can clarify goals of care, including cardiopulmonary resuscitation; intubation/ventilatory support; feeding tube placement; and pain management. If completed in advance, all of these conversations can transpire while the patient is lucid and has capacity, and they are being conducted at a deliberate and calm pace. One goal that is repeatedly cited is permitting maximization of the patient's quality of life (Lim et al., 2016).

Recently, the Centers for Medicare and Medicaid Services (CMS) has approved a payment process for physicians and other healthcare providers who discuss ACP with patients and families. This is a breakthrough moment, and the hope is that healthcare providers will begin these conversations with their patients earlier in the care planning process. More patients are being referred to hospice, but they continue to be referred too late in the overall disease process, with most patients dying within two weeks of entering the hospice program and overall less than 45% dying while enrolled in hospice (Peres, 2016). Further research is needed to better understand why physicians do not discuss EOL care planning with all their patients with a poor prognosis. Most patients wish to die in their own home, and yet nationwide there are more patients dying in the hospital setting (Davison, 2010; Peres, 2016; Teno et al., 2013).

In the future, when asked the question of who has an AD, the number of patients can and should be higher than our survey suggests. ADs/MOLSTs are powerful documents that allow for patients' input for future care. They are ethical and empowering tools for the patient, family, physician, healthcare team, and the institution(s) providing care. Considerable patient, family, and systemic barriers exist, and many social workers noted that there were considerable misconceptions among patients and family members about EOL care planning. Additional efforts are needed to overcome familial and structural barriers to facilitate timely referral to EOL care services. We believe social workers in any setting can serve as pivotal interdisciplinary healthcare team members to increase the use of ADs/MOLSTs. Social workers who use ADs/MOLSTs can empower patients to make the best decisions about their healthcare and can also help the healthcare team best carry out each patient's wishes.

RESOURCES

Social workers in our survey made it a point to ask for resources to further discuss EOL care planning with their patients. Below is a list of a few resources used in writing this article:

- *Your Conversation Starter Kit: When It Comes to End-of-Life Care, Talking Matters*
https://theconversationproject.org/wp-content/uploads/2015/09/TCP_StarterKit_Final.pdf
- The GoWish game
<http://www.gowish.org/>
- Conversations for Life
<http://www.conversationsforlife.co.uk/>
- Mental Health Supplement to Advance Directive form
<https://www.inova.org/patient-and-visitor-information/making-healthcare--decisions/mental-health-supplement>
- America's Care of Serious Illness
<https://www.capc.org/report-card>
- Medicare Hospice Benefits
<https://www.medicare.gov/pubs/pdf/02154-medicare-hospice-benefits.pdf>

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Supplement 1. Social Workers' EOL Lessons

Please tell us the most important lesson(s) you have learned about addressing end-of-life care situations in your clinical practice.

“Be Proactive. Have visual resources handy.”

“Patients usually come from the hospital with a DNR (do not resuscitate) but have no idea what that is. Patients need to be educated better by hospital staff.”

“Patients generally are hesitant to discuss, or they have documents addressing their choices. Others will not discuss.”

“MDs in nephrology do not address end-of-life care in dialysis units, most of these discussions occur in hospitals by attending physicians.”

“I bring up the discussion often, but I find that when it comes up; patients don't wish to discuss it, as if discussing it will bring on death.”

“To question patients about any changes they wish to make, such as revising a DNR, and their feeling about advanced (sic) directives.”

“I try to be very unbiased. I see AD [advanced directives] as a present to [a] patient and to their family. I do discuss that there are free options in our state to get [a] healthcare decision maker [sic] and living will. [I] Also discuss personality of families matters and [remember] that all children are equal.”

“Doctors need to be honest with patients and families, and they need to speak in terminology that is simple and comprehensive. It is important to ensure that the entire clinical/core team is on the same page with one another, as well as the patient and his/her family.”

“I think the most important lesson I learned is that people often wait on their medical provider to signal that it's time to end treatment. Families find it difficult to stop a love[d] one's treatment once its begun, no matter how cumbersome the process becomes.”

“I found it is important to have an honest, open conversation about end-of-life care. It is helpful to give patients written and verbal information about end-of-life care and including ways to discuss the matter with family and friends.”

“Understanding the cultural difference[s] when talking to patients about end-of-life care and respecting the patient's choice not to discuss.”

“Patient's wishes need to be documented with legally supported documentation. However, many patient's (sic), even in end-of-life care (dialysis), are uncomfortable thinking/speaking about these wishes. Patients also don't understand the importance of legal documentation for end-of-life. Patients think, ‘My kids know what I want,’ or, ‘It doesn't matter,’ or, ‘Someone else will take care of it.’”

“Medical team and social work must be on the same page.”

“Worked with hospice for 11 years. Everyone is going to die at some point in time, and we need to accept this. We have some control over how we want the last part of our life to look like (except in unexpected deaths). I feel strongly that these discussions are very helpful in how we grieve. Not having the discussion leaves a lot of questions that can't be answered ‘after the fact.’ I met a man once who said it all... ‘[I] never wanted to meet you (hospice), but now that I need you, I'm damned glad you're here.’”

“Brings peace to people.”

“Be sensitive to patient's and family's position/feelings when addressing this issue.”

“Each conversation is custom-crafted with and for each person, even if the basic ingredients of an end-of-life conversation are the same, and, done well, each end-result will be a customized package designed to meet each person's needs and wishes.”

“End-of-life questions are not addressed that much.”

“Never assume that patients know that it's an option not to continue dialysis.”

“Listen to the patient and family member[s] and let them tell how and when it is important to them.”

“To take the opportunity or the ‘teachable moment’ when another patient dies or experiences a near-death event.”

“I do not have enough resources or do not know where to get resources to help with discussions. An example would be some literature they can take home to their families.”

“Patient and family need to make decisions together.”

“Physicians seem to ignore that this is a guaranteed part of the life cycle process, and it is as much their responsibility to acknowledge this as it is the rest of the team's.”

“The courage of people when facing end-of-life issues.”

“Follow [the] patient[’s] lead and respect their wishes.”

“It's best to meet with the patient and any of their loved ones the patient's decisions will impact.”

“Mothers always want heroic measures. Patients often do not really care how their end-of-life circumstance affects their family.”

“It is never too early to start planning.”

“That life review is very important and the idea that if circumstances or prognosis (sic) change, their decision can change. I've also learned that fear and mistrust of the medical system can be formidable barriers to planning.”

“Trust your own judgement.”

“While working in ICU, I learned that patients do not know what full code means, and they need to be asked direct, clear questions about allowing the dying process vs. being brought back to life, especially in cases of anticipated terminal illness tx (sic). Also, to discuss patients' spiritual beliefs, as this is important to process as they are dying, normalizing traditional vs. non-traditional spirituality.”

“Education and forms.”

Practice Note: Promoting Kidney Transplant in the Dialysis Setting

Hannah Graves, LMSW, Piedmont Transplant, Atlanta, GA

Helping patients get kidney transplants is an important task for dialysis social workers. I began working as a dialysis social worker less than three years ago, and in that time was successful in helping 13 of my patients get a kidney transplant, and 15 other patients get listed for a transplant. This practice note examines how I accomplished these outcomes and provides readers with some suggestions to help dialysis patients get kidney transplants.

Importantly, my best practices are based on a team approach—one person alone cannot successfully improve kidney transplant rates in a unit. A patient has to have the desire for transplant, a transplant champion has to make a referral that is supported by the patient's nephrologist, and the patient's clinical team has to educate and encourage patients to help them successfully receive a transplant.

Being new to dialysis allowed me to approach kidney transplantation as one might approach the first day of school—get the basics by asking those with experience. I spoke with patients and professionals in the transplant community about the trials and tribulations related to getting a transplant. I then sought experts in the community to come to my dialysis clinic to offer their expertise in the form of “lobby days.” In my transplant community, those experts are from local transplant centers and the Georgia Transplant Foundation. The representatives from these organizations set up in our lobby and met patients as they left treatment or entered the clinic for dialysis.

These professional connections allowed me to form partnerships, obtain materials, and create a fun and colorful bulletin board to break down the transplant process in an easy-to-understand format (**Image 1**). I also created a resource table in the lobby set out materials from the transplant centers, Georgia Transplant Foundation, the National Kidney Foundation, and my ESRD Network (**Image 2**). By walking the path of learning with my patients, I was able to establish a process that works for me, my dialysis care team, and most importantly, my patients.

Image 1. Transplant bulletin board in the lobby of the dialysis center

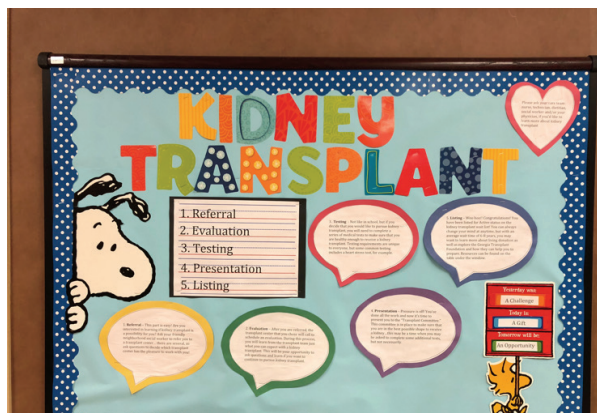


Image 2. Transplant resource table in the lobby



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Once a patient receives this education about transplantation and makes a decision about getting a transplant and which transplant center they would like to work with, I set to work helping them get listed. My process begins with completing a referral form, gathering the needed information, and sending it to a transplant center. I then notify patients that the referral has been sent and that they should be expecting a call to schedule the evaluation. From this point, it can take several weeks to several months for a patient to be evaluated for transplant. During this time, I make an effort to be encouraging, ask questions about the patient's perceptions of the process, and offer assistance with the coordination of scheduling and attending requested testing.

Many times, the patient may get discouraged by the "hoop jumping" that the transplant center is making them do in order to be listed for transplant. This is an important time to offer assistance, provide education and encouragement, and demonstrate how easy follow-up can be by doing so yourself. So many times, misunderstandings and miscommunication can delay a patient being listed, so if follow-up is a part of the

process, then delays can be minimized. If all goes well, the patient is then listed for kidney transplant. In my community, the average wait time for a deceased donor is 6–8 years. Once the patient is listed, I then begin a conversation with them and provide education on living donors, and also explore listing them at other transplant centers outside of our community. For example, the University of Alabama at Birmingham is three hours from our clinic and pulls from a different organ donor pool than Georgia. These next steps may or may not be productive for the listed dialysis patient, but they are important next actions in the process.

Not only does it take a village to get a patient a kidney transplant, a successful one also lifts up the entire group. Nothing can provide greater encouragement than to see a patient receive a transplant. It is like watching a metamorphosis to see a person who is dependent on dialysis to survive no longer need such treatment because they were able to get a new start with a transplant. I can honestly say that the transplant process that I have worked to develop with my team is what sustained me in a challenging career as a dialysis social worker.



People are waiting for a chance at a better life. The kidney transplant waiting list is getting longer, and in response, the National Kidney Foundation (NKF) has developed THE BIG ASK: THE BIG GIVE. This initiative educates and raises awareness about living kidney donation and transplantation among kidney patients, their families, and friends.

THE BIG ASK

For people with kidney disease, asking someone to consider donating a kidney can seem impossible. Many won't get a transplant because they don't know how to ask or are uncomfortable with asking. NKF provides suggestions and tips on how to start a conversation about the possibility of donation.

THE BIG GIVE

The decision about whether to donate a kidney can be daunting. People considering living donation have many questions about what's involved. NKF offers factual, unbiased information addressing common concerns, and support in making the decision.

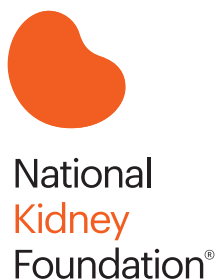


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NKF Cares Help Line—Trained professionals answer questions and provide confidential, one-on-one support to patients, families, and potential donors. Hours: Monday–Friday, 9:00am–5:00pm EST (English/Spanish). 844.2BIGASK (844.224.4275); bigask@kidney.org.

www.kidney.org/livingdonation—NKF's website provides information for kidney patients and potential donors.

#BigAskBigGive



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