

## 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.*

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### 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; Wasylynku & Davison, 2014), and patient and family misconceptions (Ceskowski et al., 2017; Wasylynku & 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.

## Author Note

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