

## Integrating Advance Care Planning Within the Psychosocial Care of Nephrology Patients

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*Persons with end-stage kidney disease (ESKD) are at increased risk for multiple health complications, including increased hospitalizations and shortened life expectancy. These health risks elevate the urgency to complete an advance directive (AD), allowing patients to express their wishes if they are unable to because of limited capacity. Dialysis social workers are well-positioned to skillfully lead these conversations and respond to emotional distress, family conflict and pain, and symptom burden that many persons with ESKD experience. This paper outlines a framework for dialysis social workers to assess the wishes of patients in the event of worsening health and offers suggestions for interventions when patients and family members experience distress related to serious illness and advance care planning (ACP).*

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### INTRODUCTION

People with chronic kidney disease (CKD) typically suffer a cascade of comorbid conditions with an intensity that can have a significant impact on their quality of life. After dialysis has been initiated, there is a higher incidence of heart disease, strokes, and dementia. In addition, patients on dialysis are more likely to be hospitalized and for longer; use intensive care units and experience higher treatment intensity than people with other types of end-stage diseases or organ failure (Schmidt, 2017; Wachterman et al., 2017); and have higher mortality rates (USRDS, 2017)—life expectancy is one-third of the general population (USRDS, 2017). High symptom burden, the complexity of (ESKD), and higher resource utilization contribute to a greater urgency to understand the person's wishes and goals before a crisis, through the process of advance care planning (ACP). ACP has been defined as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness” (Sudore et al., 2018). However, the process of ACP often becomes reduced to the completion of an advance directive (AD), a living will, or healthcare proxy, followed by a check mark for completion. At its best, ACP is a dynamic process that focuses on goals of care and shared decision-making—involving patient, family, and provider—and addresses healthcare decisions within a holistic perspective that focuses on quality of life.

The 1990 Patient Self Determination Act (GovTrack.us, 2020) requires healthcare entities to inform patients of their right to execute an AD, but dialysis facilities were not included in the requirement. In 2008, the Code of Federal Regulations (CFR) update explicitly required dialysis facilities to inform patients of their rights to execute an AD and to discontinue treatment (Federal Register, 2008). That change brought honoring the values and wishes regarding serious illness and end-of-life care for patients with ESKD to the forefront. The CFR update required dialysis facility staff to reassess unstable patients monthly, “...with extended or frequent hospitalizations; marked deterioration in health; significant change in psychosocial needs; concurrent poor nutritional status, unmanaged anemia and inadequate dialysis” (Federal Register, 2008). The CFR regulations make the requirements of dialysis facilities, but do not address how to conduct ACP.

Social workers, given their education in assessment, engagement, intervention, and evaluation of individuals, families, groups, and communities, and considering the CFR requirement for a social worker to assess and intervene regarding psychosocial care of patients with ESKD, are well positioned to not only meet this requirement, but to be a value-added team member who can contribute to the quality of life of persons with ESKD. This paper will address how nephrology social workers can contribute to ACP. We present a model for integrating ACP within psychosocial care that is provided to people with CKD/ESKD and who are on dialysis. We argue that ACP is an opportunity for psychosocial interaction that is thoughtful, personal, at times intimate and therapeutic, and consistent with best practice of nephrology social work.

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### *A Model for Integrating Advance Care Planning Within Nephrology Psychosocial Care*

Ideally, ACP begins upstream, well before a patient starts dialysis (Sudore et al., 2018). Disease progression can bring changes in perspectives and preferences, so subsequent review of ACPs is important when there is a change in health status, hospitalization, or when a provider answers “yes” to the question, “Would you be surprised if this patient died in the next year?” (Mandel, Bernacki, & Block, 2017). A combination of both early and serial conversations allows time for providers to help patients and family members grasp the complexity of ESKD, renal replacement therapy options, and the psychosocial impact of life on dialysis. ACP can help a person explore questions such as, “Under what conditions would you want, or not want, aggressive treatment?” This is especially important given that research findings suggest as many as 61% of dialysis patients regret the decision to start dialysis (Davison, 2010). Patients have reported that they would be willing to lose as much as seven months of life expectancy in order to decrease time in the hospital, and lose as many as 15 months of life expectancy if it meant they could travel more (Morton, Tong, Howard, Snelling, & Webster, 2010). Half of patients on dialysis say they want to die at home (Phillips, MacNab, & Loewen, 2018), although hospice, a service that helps patients die at home, is vastly underutilized in the ESKD population (Murray, Arko, Chen, Gilbertson, & Moss, 2006). Medicare beneficiaries who are on dialysis can receive hospice only if they agree to forego dialysis, if a hospice agrees to pay for the treatments, or if the patient qualifies for hospice from a diagnosis other than ESKD (Grubbs, 2018; Kurella Tamura, Goldstein, & Pérez-Stable, 2010). Unfortunately, most patients state that their healthcare providers have not invited discussions about these issues (Axelsson, Klang, Lundh Hagelin, Jacobson, & Gleissman, 2015; Finkelstein et al., 2008; Phillips et al., 2018).

Multiple issues have been identified as barriers to ACP conversations. First, a large number of nephrologists report that they have not had training on how to initiate discussions about choices (Schell, Green, Tulskey, & Arnold, 2013) and may not be comfortable having ACP conversations (Bristowe et al., 2014; Davison, 2010). **Social workers bring important skills that can help providers develop comfort with seemingly difficult conversations.** Second, many people on dialysis do not consider themselves to have a progressive disease, though Phillips et al. (2018) found that 84% of stage 5 CKD patients want to be informed of prognosis and 80% of stage 5 CKD patients would like to be informed of all of their treatment options, including withdrawal of dialysis. **Patient advocacy by social workers can improve the frequency of important conversations.** Davison and Torgunrud (2007) found that patients expect these conversations to come from their physician. Third, in a survey of dialysis facility staff, most reported being unaware of predictive algorithms or guidelines to help establish prognosis and assist in predicting

disease trajectory (Culp, Lupu, Arenella, Armistead, & Moss, 2015). **Social workers can initiate in-service education about how team members can incorporate guidelines into their assessments of and interactions with patients.**

While most patients with ESKD report talking about end-of-life with family members, Phillips et al. (2018) found that 34.6% of ESKD patients would like to have this discussion with a social worker, and 36.8% would like to have it with a family doctor. Moreover, in a systematic review of social work involvement in ACP (beyond ESKD), Wang, Chan, and Chow (2018) found that up to 90% of social workers report being involved in ACP discussions with patients and that social workers are confident about their ability to have these discussions. Social work involvement in ACP has many positive outcomes including: increased patient discussions with providers about ADs (including physician order for life-sustaining treatment (POLST)), living wills and documentation, and decreased likelihood of receiving care incongruent with their values (Wang et al., 2018). In a survey of dialysis facility staff, social workers were the most knowledgeable professional group about Coalition for Supportive Care of Kidney Patients (CCKP) resources (Culp et al., 2015).

A framework for conducting serial conversations, titled “Sample Language for Serious Illness Conversations Under Several Health Scenarios and Triggers,” was developed by Mandel et al. (2017). Schmidt (2017) has identified challenges in the transitions of ESKD. We have adapted the framework and the challenges for application to social work-initiated ACP conversations. To begin, the consideration of **four questions that can guide practice** are germane to social work practice in a dialysis unit and can advise effective ACP.

- **When should ACP conversations be initiated?**

1) Before, during, or after treatment? 2) At regular intervals (e.g., quarterly, biannually?) or only after an acute event (e.g., access difficulty, hospitalization)? Consideration of patient self-determination is important; patients may a) want to either not extend the time spent at the dialysis unit by arranging a meeting outside of treatment, or have transportation challenges that make flexibility impossible, or b) be unable or unwilling to have a conversation while they are receiving treatment. Moreover, patient choice is an important principle to uphold.

- **Where should ACP conversations occur?** What is available on the unit? Is there a quiet, private space? How are the patient care areas arranged? Is privacy and confidentiality possible? ACP conversations that occur during treatment may be maximally efficient but minimally private, and there also may be distractions from treatment-related symptoms (e.g., blood pressure crises, leg cramps).

- **Who initiates ACP conversations?** ACP can be addressed by any member of the team. When social workers introduce the topic, they can discuss both the medical and psychosocial impacts of the disease and treatment. Documenting the outcomes and helping other team members understand the patient's decisions, fears and worries can direct more effective interdisciplinary care.
- **What is ACP content?** Suggestions include: patient understanding of their illness; informational preferences (How do they like to receive information and how much?); perceptions of prognosis (Social workers will not be giving out medical information, but can address the complications of multimorbidity which contribute to uncertainty); goals (e.g., medical, personal, social, whole-life goals); fears and worries (e.g., medical, emotional, psychosocial); sources of strength and coping (What has worked in other stressful situations?); tolerance (What is acceptable or critical (or tolerable?); limitations (What tradeoffs could/would you be willing to make?); and family issues and involvement (How is your family understanding and dealing with your illness and treatment?; How involved are family members?). All of this is grounded in a psychosocial assessment, which can be enhanced by discussion of overall goals for life and for medical care (Anderson, Aldous, & Lupu, 2018; Mandel et al., 2017).

We suggest that ACP is an important and enduring element of psychosocial re-evaluation and intervention. Five distinct phases of the disease trajectory that signal the need for revisiting patients' goals of care and **five specific challenges** inform the transitions. Each phase has significant psychosocial issues. Complex healthcare decisions are complicated further by contextual issues (e.g., housing, family stressors, financial issues) that may change over time.

- **Pre-dialysis:** First, it is important to determine if social workers can meet patients before dialysis begins. Has the progression of CKD/ESKD been sudden or gradual? How has the person prepared? Have they received any dialysis education? What challenges are anticipated (e.g., work, transportation)? Patients may indicate that they have previously completed an AD, healthcare proxy (HCP), or living will, and state, "I signed the form," believing that completion is sufficient (Miller, 2015). This affords an opportunity to underscore that one conversation is not enough because perspectives may shift and need reconsideration as needs change.
- **Dialysis initiation:** Does the patient understand his/her diagnosis, i.e. the meaning of needing dialysis? Does the patient understand the rigidity of the schedule and the implications of missing treatment? What arrangements need to be made to accommodate dialysis? What life changes are causing distress?

- **Post-hospitalization or with functional decline:** What changes have occurred? (Has this influenced your way of thinking about your goals of care?) What new stressors have emerged? This event may create feelings of uncertainty about the future. Re-evaluate concrete needs for assistance. What new needs occurred throughout the hospitalization or with the decline? Is additional caregiving needed? Is placement in a care facility necessary? Was an AD, a living will, or health care proxy (HCP) invoked? Are changes to these documents needed to uphold wishes in the future?
- **After access failure/access procedure:** Has this crisis changed perspectives or perceptions?
- **Withdrawal consideration:** Is there understanding that withdrawal from dialysis will end in death? Is hospice admission a consideration? Has a POLST/MOLST/POST (physician order for life-sustaining treatment/medical order for life-sustaining treatment/physician order for scope of treatment) been completed? What are the family's needs as the end of life nears? Preparatory grieving can be addressed.

*Adapted from: Mandel et al., 2017; Schmidt, 2017.*

The challenges inherent in the transition from chronic to end-stage kidney disease have been documented by Schmidt (2017). We suggest that these challenges are a part of each phase of the trajectory of this disease and can be assessed as part of ACP re-evaluations. In addition, the assessment of fears and concerns, goals, sources of strength and coping, and family well-being are important to assess at each phase. We suggest that social workers consider **assessment of the following items**, which can address the challenges and natural support of the patient.

- **Status of CKD/ESKD:** Understanding of CKD/ESKD, as well as comorbid conditions, symptom burden, prognosis, and complications.
- **Psychosocial issues:** Cognitive ability, willingness, or capacity to adhere to treatment regimens, and awareness of the outcomes of nonadherence; family and social support, their influence and involvement.
- **Requirements of dialysis:** Access surgery and maintenance; logistics of scheduling, transportation; consideration of transplantation; payment issues; medication management; independence/dependence and the need for caregiving.
- **Burdens:** Symptoms, physical, emotional, financial, existential, spiritual, logistical, and vocational, as well as family issues.
- **Fears and concerns:** Is there anything that worries you?

- **Goals of care:** What goals do you have for your health or yourself?
- **Sources of strength and coping:** What gives you strength? How do you cope?
- **Sources of meaning and purpose in life:** What gives your life meaning and purpose?

*Adapted from: Mandel et al., 2017; Schmidt, 2017.*

While ACP and assessment of goals, fears, and strengths will likely create therapeutic healing, social workers are also skilled in treating emotional and existential distress related to serious illness and disease progression. Social workers can provide brief, short-term interventions to patients and family members who may be struggling with pain and symptoms related to ESKD, anxiety about health conditions, family conflict over decision-making, and anticipatory grief related to ESKD. Depending on what emerges in ACP, the following **interventions** may be considered:

- Mindfulness meditations
- Deep breathing exercises
- Relaxation techniques
- Problem-solving counseling
- Assertive communication training
- Family counseling
- Worry management planning
- Sleep hygiene exercises
- Anticipatory grief support

*(Hunter, Goodie, Oordt, & Dobmeyer, 2009).*

## CONCLUSION

Social workers in dialysis facilities are well-suited to engage in ACP, given their training in engagement, assessment, evaluation of and interventions with individuals, families, groups, and communities. Despite the clear presentation of morbidity and mortality following the initiation of dialysis, a key issue to consider is that dialysis patients often do not identify as having a progressive health condition and this may create a barrier to addressing ACP (Phillips et al., 2018). This framework provides a softer approach that may provide entrée without generating resistance and yield considered thought about choice-making. Conversations about goals-of-care and the serial reconsideration of the experience of dialysis and its influence on the patient's healthcare wishes can yield meaningful and important conversations that facilitate person-centered care and dignity as death nears. ACP is an important element in the quality of psychosocial nephrology care.

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