Advance Care Planning in CKD/ESRD: An Evolving Process

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Summary
Advance care planning was historically considered to be simply the completion of a proxy (health care surrogate designation) or instruction (living will) directive that resulted from a conversation between a patient and his or her physician. We now know that advance care planning is a much more comprehensive and dynamic patient-centered process used by patients and families to strengthen relationships, achieve control over medical care, prepare for death, and clarify goals of care. Some advance directives, notably designated health care proxy documents, remain appropriate expressions of advance care planning. Moreover, although physician orders, such as do-not-resuscitate orders and Physician Orders for Life-Sustaining Treatment, may not be strictly defined as advance directives, their completion, when appropriate, is an integral component of advance care planning. The changing health circumstances and illness trajectory characteristic of ESRD mandate that advance care planning discussions adapt to a patient’s situation and therefore must be readdressed at appropriate times and intervals. The options of withholding and withdrawing dialysis add ESRD-specific issues to advance care planning in this population and are events each nephrologist will at some time confront. Advance care planning is important throughout the spectrum of ESRD and is a part of nephrology practice that can be rewarding to nephrologists and beneficial to patients and their families.

Introduction
Historically, advance care planning was considered a finite exercise in which a patient completed a written document or documents after a conversation with his or her physician. The documents consisted of a proxy directive (the person designated as the decision-maker if the patient was not capable of making his or her own decisions about ongoing care and interventions) and instruction directives of various sorts, such as general wishes about care at the end of life, or specific directives or living wills concerning interventions the patient would or would not accept (for example, cardiopulmonary resuscitation [CPR] and prolonged ventilation). Many health care providers celebrated the passage of the Patient Self-Determination Act by the U.S. Congress in 1990, believing that mandated dissemination of information on advance directives would lead most patients to complete them. However, widespread adoption of written advance directives failed to materialize; then and now, only about a third of any group has completed some form of written advance directive.

Many people, including those undergoing dialysis, do not complete written advance directives because the fundamental assumptions about advance directives and advance care planning were flawed. Dialysis patients have taught us that discussions about end-of-life issues occur among patients and families, not between patients and physicians (1). Moreover, it is not what we can endure (interventions) but rather how we live and expect to keep living that guides our decision-making about end-of-life care (2). In addition, many patients, families, and providers realized that completing an advance directive did not ensure that it was followed. Moreover, all medical contingencies cannot be anticipated and addressed in a written advance directive (3).

Advance care planning, therefore, is more appropriately viewed as a process (rather than a single act) that is evolving within a changing health care environment and within changing health conditions of individual patients. This review focuses on the contemporary views of advance care planning within the context of an historical perspective, specifically as the advance care planning process involves those with CKD and ESRD, their families, and their health care providers.

Contemporary Advance Care Planning in CKD and ESRD
Many issues influence the contemporary view and application of advance care planning and advance directives (Table 1). Patients and families use advance care planning not only to prepare for death and identify surrogate decision-makers but also to achieve control over medical situations, relieve burdens on loved ones, and strengthen relationships (4). As pointed out by Davison and Torgunrud, advance care planning by dialysis patients is a relational patient-centered process that focuses on broader goals of care and serves as a guide to facilitate discussions.
among patients, their families, and their health care providers (5).

However, a dichotomy persists about the purpose of advance care planning: Is the goal an exploration of the patient’s overall goals of care and relative limits for intervention, or does the completion of specific written advance directives remain the ultimate goal? Moreover, because not all contingencies can be anticipated in sophisticated medical environments, shouldn’t the primary goal of advance care planning be the preparation of patients and families for decision-making when circumstances warrant (6)? The timing of advance care planning discussions also influences the success of the process and in part depends on patients’ and families’ readiness to engage in the process (7). Complicating advance care planning is the fact that in order to make informed decisions about medical care, prognosis must be discussed, a topic physicians are reluctant to broach. Thus, advance care planning requires repeated meetings and assessments. An additional complication for patients with ESRD is the impaired cognitive capacity in many such patients (8), which limits their ability to make informed decisions and places additional burden on their health care surrogates. The effect of decision-making on health care surrogates has more recently been recognized as a barrier to advance care planning that warrants consideration (9).

Many of these factors become barriers to advance care planning and may serve as excuses to avoid planning by nephrologists and dialysis unit care providers. The clinical practice guideline Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis makes 10 evidence-based recommendations about starting and stopping dialysis (10). Recommendation 4 addresses advance care planning and suggests that it should be incorporated into the overall care plan for each dialysis patient (10). As others have suggested, the central role of advance care planning is most reasonably viewed as a way for patients and their designated decision-makers to prepare for future decision-making and to explore the life goals serving as the foundation for a patient’s choices about medical care.

**Useful Advance Directives**

Despite the general failure of advance directives, some useful advance directives remain. Do-not-resuscitate (DNR) orders and Physician Orders for Life-Sustaining Treatment (POLST), or the equivalent, are actual physician orders and therefore not strictly defined as advance directives (which are documents completed by a patient with capacity; surrogates cannot complete advance directives). However, DNR forms typically require the competent patient’s signature, as do many POLST forms. Thus, these orders may be considered “hybrid” advance directives: physician orders with direct evidence of patient participation via signature.

These are useful written documents whose completion should be encouraged by dialysis patients when possible. Dialysis patients’ survival after in-hospital CPR is no better than that of other hospitalized patients and is slightly worse at 6 months, with only 3% survival (11). Overall survival after inpatient CPR remains low, generally 10%–15% (12). Thus, DNR orders are useful documents whose completion should be encouraged. Dialysis units have an ethical obligation to honor DNR requests by patients (10). Tools to aid in the discussion and completion of these directives are available at the Kidney End-of-Life Coalition website for use by dialysis units (13). Informed consent is required to refuse or accept a DNR order, and it is incumbent upon nephrologists and other dialysis care providers engaged in advance care planning with patients and their families to provide information on CPR outcomes. Additionally, the risks of CPR (rib and sternal fractures, which can result in pain, suffering, pneumonia, and prolonged ventilation) should be reviewed, along with possible outcomes of successful CPR (persistent vegetative state). Communication about CPR is a skill that can be learned by nephrologists in order to aid patients and families in making informed decisions (10).

The national POLST paradigm was developed as a standardized advance care planning document to be completed by health care providers and patients or surrogate decision-makers (14). It is accepted in states and areas where

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### Table 1. Characteristics of contemporary advance care planning

<table>
<thead>
<tr>
<th>General goals</th>
<th>To facilitate discussions among patients, families, and health care providers</th>
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<tbody>
<tr>
<td></td>
<td>To prepare for death</td>
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<td></td>
<td>To identify and educate surrogate decision-makers</td>
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<td>To harmonize decision-making between patients and surrogates</td>
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<td>To achieve control over medical care</td>
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<td>To relieve burdens on loved ones</td>
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<td>To strengthen relationships</td>
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<td>To clarify goals of care</td>
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<td>To prepare for in-the-moment decision-making</td>
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<td>Specific goals</td>
<td>To complete a health care proxy or health care power-of-attorney form</td>
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<td>Timing of discussions</td>
<td>When considering renal replacement therapy</td>
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<td></td>
<td>With sentinel events</td>
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<td></td>
<td>Whenever issues are raised by patients and/or families</td>
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<td></td>
<td>If the answer to the “surprise” question is “no”</td>
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<td>As part of the routine care plan</td>
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DNR, do-not-resuscitate; POLST, Physician Orders for Life-Sustaining Treatment. Adapted from references 1–4 and 9.
Surrogate Decision-Makers

A recent systematic review of the literature addressing the effects of treatment decision-making by surrogates found at least a third of surrogates experienced a negative emotional burden as a result of making treatment decisions (9). Stress, guilt over the decisions made, and doubt about whether the right decisions were made were negative effects described by surrogates. For many surrogates, these negative emotional effects persisted for months or even years (9). When surrogates feel confident in their understanding of what the patient would choose if he or she were able to make decisions, surrogates feel less stress and anxiety (9). In such instances, therefore, a patient-completed advance directive was beneficial to surrogates asked to make medical decisions.

However, in some situations, surrogate stress was created when dissonance occurred between what a patient had expressed as a treatment wish and what a surrogate felt was in the best interest of the patient at the time. Sehgal et al. examined surrogate decision-making among dialysis patients and their proxies and found that although patients generally felt comfortable leaving decision-making to their surrogates, surrogates preferred more specific instructions be provided by patients (19). Clearly, poor communication among patients, surrogates, and health care providers exacerbates the emotional burden on surrogates. Thus, shared decision-making and good communication among all involved is required for successful advance care planning. Nephrologists and dialysis health care providers can facilitate advance care planning and encourage communication among patients and their decision-makers, but they must be aware of the need to readdress end-of-life issues throughout a patient’s life with ESRD. Again, advance care planning is a process and is best included as an integral component of a patient’s overall care plan that is reviewed periodically.

Illness Trajectories in CKD and ESRD

The concept of illness trajectories is an established issue in palliative medicine and was described over a decade ago as a pattern of functional decline to death observed in individuals with various illnesses (20). Initially, three distinct patterns were outlined: sudden death, steady decline followed by an expected death, and a pattern of underlying decline upon which episodes of acute deterioration were followed by some functional recovery, although usually the recovery did not reach the previous level of functional status (Figure 1). Understanding the illness trajectory allows providers, patients, and families to plan for health care needs and interventions over the course of a chronic illness and provides a framework for the dying process. Review of U.S. Medicare claims data and interviews with elderly people led to refinement of illness trajectories and the addition of trajectories for dementia and frailty (21). Additionally, the pattern of steady decline punctuated by episodes of acute exacerbation with some recovery was labeled as the trajectory characterizing those with organ failure (21).

Models for the organ failure illness trajectory have included chronic pulmonary disease, heart failure, and, more recently, stroke and diabetes mellitus (22). Although ESRD has never been a model for illness trajectory, this pattern of organ failure is observed in many patients undergoing long-term dialysis (23). Acute declines are common among dialysis patients experiencing hospitalizations for acute myocardial infarction, limb amputation, bacteremic episodes associated with central venous catheter infections, or hip fractures. These episodes or sentinel events generally affect a patient’s functional status, from which some improvement may be observed; however, often slight but perceptible greater impairment in functional status occurs.
Nephrologists and other dialysis providers should acknowledge these sentinel events and this pattern of illness trajectory because each episode provides an opportunity to readdress the patient’s goals of care and, thus, his or her wishes for ongoing and future care. Because advance care planning is a process and not an isolated event, and because sentinel events and illness trajectories affect a patient’s health status and quality of life, wishes for future care should be readdressed and discussed in light of the patient’s new clinical status.

Recently, Murtagh et al. described the functional trajectory in 75 elderly patients with stage 5 CKD who were treated conservatively (without dialysis) (24). Of note, they found a distinct trajectory (Figure 1) in which functional status remained stable until the last month of life and then steeply declined (24). Additional study of illness trajectories in patients with CKD and ESRD would be helpful to plan for end-of-life care and to identify opportunities for ongoing advance care planning among patients and families.

**Prognosis in ESRD**

Implicit in patterns of illness trajectories and advance care planning is some consideration of prognosis. Patients must be informed about their prognosis in order to make informed decisions about the kinds of care and interventions they prefer. However, despite the inherent importance of prognosis in medical decision-making, few validated tools exist to aid in disease-specific prognostication (25). Moreover, physicians and patients tend to overestimate survival, and many patients and health care providers are reluctant to discuss prognosis. The reluctance to discuss prognosis is often based on a lack of confidence in predicting prognosis, a fear of abolishing hope, and discomfort with such discussions. However, because estimating prognosis is a vital component to decision-making about starting and stopping dialysis, it is recommended that each patient with CKD be given an estimate of his or her prognosis when renal replacement therapy is being discussed (10). Observational cohort studies and large multicenter studies of survival have identified mortality risk factors in dialysis patients. These include low serum albumin, poor functional status, comorbid conditions (especially ischemic heart disease, cancer, peripheral vascular disease, dementia, and diabetes mellitus), patient age, and the “surprise” question (answering “no” to the question, “Would I be surprised if this patient died within the next 6 months?”) (26–32). An online calculator (http://touchcalc.com/calculators/sq) combines the “surprise” question with other risk factors to provide a patient-specific prognosis for survival in hemodialysis patients (33). Although exact prognosis for an individual patient may be unclear, such prognostic tools can facilitate advance care planning by patients and families.

Interestingly, we have little information on whether patients with ESRD and CKD want specific information on prognosis. One Canadian study of 100 CKD clinic attendees found that 97% wanted extensive information on prognosis in order to plan and understand anticipated life changes (34). Most of these survey participants were white. A study of 153 more ethnically diverse in-center hemodialysis patients found only 51% of patients desired specific information on prognosis (35). As with wishes for medical interventions at the end of life, ethnic differences among populations may account for these disparate results; still, additional information on the benefits and risks of providing relatively specific information on prognosis would be welcome. Dialysis care providers can learn communication skills to help them in discussions of these intimate and potentially emotionally difficult topics (10).

**Stopping Dialysis**

Unique to dialysis patients is the ability to control one’s death by withdrawing from dialysis. Depending on the population examined, up to 40% of dialysis patients may die from stopping dialysis (27). However, few dialysis patients include dialysis withdrawal as a topic in advance care planning discussions with families and loved ones (36). Perhaps because dialysis becomes a usual and routine part of an ESRD patient’s life, it is viewed differently from other end-of-life interventions, such as CPR, intubation.
and ventilation, or placement of feeding tubes for nutritional support (3,36). The frequency with which dialysis patients in the United States withdraw from dialysis has contributed to the comfort nephrologists feel in addressing end-of-life issues with dialysis patients and their families and has probably influenced the acceptance of advance directives, such as DNR orders, by dialysis units (37). Of note, an evidence-based clinical practice guideline addressing these aspects of nephrologic care exists to guide nephrologists and dialysis units (10). As with most aspects of end-of-life care and advance care planning, ESRD patients expect health care providers to raise issues of medical interventions in order to allow patients and their loved ones to discuss advance care planning (1). The option of withdrawing from dialysis is an appropriate topic to be discussed by nephrologists and dialysis care providers whenever a patient or family member mentions it and when patients suffer irreversible, profound neurologic impairment (10).

Withholding Dialysis

Advance care planning in patients with CKD may also consider initiating or choosing not to begin renal replacement therapy. As with decisions to stop dialysis, forgoing dialysis may ethically be considered in patients with a very poor prognosis or those in whom dialysis cannot be safely provided (10). Some would suggest that the “default” position for such patients should be supportive care and that dialysis be initiated only if a compelling reason exists (and probably in a time-limited trial fashion) (10). Evidence suggests that elderly CKD patients with poor functional status, significant comorbidity, and malnutrition generally have a poor prognosis; nearly 50% die within a year of beginning dialysis (38,39). Increasingly, advance care planning among all patients with CKD includes the option of conservative (no dialysis) treatment, in which the focus is on life quality and symptom management (38,39). Patients and families can consider such options only if they are informed of them by their health care providers during discussions of advance care planning.

Dialysis Unit and Nephrologist Responsibilities to Provide Advance Care Planning

Shared decision-making is an overall goal in the care of all patients (10). Because dialysis is a government-provided health care benefit in the United States, dialysis units and nephrologists operate under conditions of coverage in their provision of renal replacement therapy to those with ESRD. The patient care provision of the Conditions for Coverage for ESRD Facilities includes the statement that a patient “be informed of his or her right to execute advance directives, and the facility’s policy regarding advance directives.” Thus, dialysis units are obligated to provide their patients with information on their policies about advance directives (e.g., DNR orders or POLST where applicable) and to offer the patients an opportunity to complete an advance directive. Physicians have an ethical obligation to participate in shared decision-making with patients and families, and a large part of a physician’s role in that process is to provide the information required by patients and families to make informed decisions (40). Thus, physicians and dialysis units should offer information on prognosis and options to withdraw from dialysis as well as provide opportunities to complete written advance directives. By incorporating advance care planning in the overall care plan for each patient, dialysis units can ensure these issues are addressed on a regular basis. Toolkits and guidelines are available to assist in this process (10,13). Ongoing study of the decision-making process, including qualitative tools, may identify more effective instruments and methods for advance care planning among patients with ESRD and their families and health care providers (41,42).

Conclusions

For most dialysis patients, the quality of their lives determines their acceptance or rejection of medical interventions to prolong life. Because the quality of their lives changes, their goals for care and treatment change. Thus, advance care planning is a dynamic process and not a single event resulting from one conversation. Contempor ary advance care planning primarily occurs between patients and families, who expect health care providers to raise the issues and therefore prompt discussions. The general goals of advance care planning are broad and may or may not lead to completion of written advance directives. Nephrologists and dialysis providers are obligated to address advance care planning under conditions for coverage and are ethically bound to honor patients’ requests. Some discussion of prognosis is implicit in informed decision-making and thus should be included among topics covered in education about renal replacement therapy. Awareness of illness trajectories and answering “no” to the question, “Would I be surprised if this patient died within the next 6 months?” should alert nephrologists to the appropriateness of advance care planning for individual patients. For nephrologists uncomfortable with this aspect of ESRD care, the clinical practice guideline Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis is an invaluable tool (10). Advance care planning is an integral part of ESRD care and should be included in the overall care plan of each dialysis patient.

References
