

Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Clinical Practice Guideline

Second Edition



RPA

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About the Renal Physicians Association

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Recommendation Summary

To develop their recommendations, the RPA Working Group used a priori analytic frameworks regarding decisions to withhold or withdraw dialysis in adult and pediatric patients with AKI, CKD, and ESRD. Systematic literature reviews were conducted to address pre-specified questions derived from the frameworks. The research evidence, case and statutory law, and ethical principles were used by the Working Group in the formulation of their recommendations.

Adult Patients

Establishing a Shared Decision-Making Relationship

Recommendation No. 1

Develop a physician-patient relationship for shared decision-making.

Shared decision-making is the recognized preferred model for medical decision-making because it addresses the ethical need to fully inform patients about the risks and benefits of treatments, as well as the need to ensure that patients' values and preferences play a prominent role. Because of the number and complexity of decisions involved in treating kidney failure, a shared decision-making relationship is particularly important for patients with acute kidney injury (AKI); stage 4 and 5 chronic kidney disease (CKD); and stage 5 CKD requiring dialysis end-stage renal disease (ESRD). Participants in shared decision-making should involve at a minimum the patient and the physician. In addition, patients should identify and include a person who could serve as their decision-maker in the event they lose decision-making capacity. If a patient lacks decision-making capacity, decisions should involve the person legally authorized to make health care decisions on behalf of the incapacitated patient. This person is often (though not always) a family member and will be called "the legal agent" in the remainder of this document (see **Section 10: Glossary** for a full description). With the patient's consent, shared decision-making may include family members or friends and other members of the health care team.



Informing Patients

Recommendation No. 2

Fully inform AKI, stage 4 and 5 CKD, and ESRD patients about their diagnosis, prognosis, and all treatment options.

In the setting of critical illness many patients with CKD will require urgent dialysis and the vast majority of patients with AKI will have multiple medical problems, in addition to kidney failure. The concept of shared decision-making necessitates a multidisciplinary approach including nephrologists, intensivists, and others as appropriate and decisions about acute renal replacement therapy should be made in the context of other life-sustaining treatments. For example, a decision to withhold dialysis in a patient agreeing to and receiving multiple other forms of life-sustaining therapy could represent discordant treatment in the same way that offering dialysis to a patient who has decided to forgo other forms of life-sustaining therapy might be inappropriate. Intensive care physicians need to be included in shared decision-making for kidney patients in the intensive care unit (ICU).

Recommendation Summary

For ESRD patients, the shared decision-making options include: 1) available dialysis modalities and kidney transplantation if applicable; 2) not starting dialysis and continuing medical management; 3) a time-limited trial of dialysis, and 4) stopping dialysis and receiving end-of-life care. Choices among options should be made by patients or, if patients lack decision-making capacity, their designated legal agents. Their decisions should be informed and voluntary. The renal care team, in conjunction with the primary care physician, should insure that the patient or legal agent understands the benefits and burdens of dialysis and the consequences of not starting or stopping dialysis. Research studies have identified a population of chronic kidney disease patients for whom the prognosis is particularly poor. This population has been found to include patients with two or more of the following characteristics: 1) elderly (defined by research studies identifying poor outcomes in patients who are age 75 years and older); 2) patients with high comorbidity scores (e.g., modified Charlson Comorbidity Index score of 8 or greater); 3) marked functional impairment (e.g., Karnofsky Performance Status Scale score of less than 40); and 4) severe chronic malnutrition (e.g., serum albumin level less than 2.5 g/dL using the bromeresol green method). Patients in this population should be informed that dialysis may not confer a survival advantage or improve functional status over medical management without dialysis and that dialysis entails significant burdens that may detract from their quality of life.

Recommendation No. 3

Give all patients with AKI, stage 5 CKD, or ESRD an estimate of prognosis specific to their overall condition.

To facilitate informed decisions about starting dialysis for AKI, stage 5 CKD, or ESRD, all patients should have their prognosis estimated and discussed, with the realization that the ability to predict survival in the individual patient is limited. Depending on the setting, a primary care physician, intensivist, or nephrologist who is familiar with estimating and communicating prognosis should conduct these discussions (see **Recommendation No. 10** for communication strategies). For patients with ESRD, the “surprise” question “Would I be surprised if this patient died in the next year?” can be used together with known risk factors for poor prognosis: age, comorbidities, severe malnutrition, and poor functional status. For patients with stage 5 CKD pre-dialysis, the estimate of prognosis should be discussed with the patient or legal agent, patient’s family, and among the medical team members to develop a consensus on the goals of care and whether dialysis or active medical management without dialysis should be used to best achieve these goals. These discussions should occur as early as possible in the course of the patient’s kidney disease and continue as the kidney disease progresses. For ESRD patients on dialysis who experience major complications that may substantially reduce survival or quality of life, it is appropriate to reassess treatment goals, including consideration of withdrawal from dialysis.

Facilitating Advance Care Planning

Recommendation No. 4

Institute advance care planning.

The purpose of advance care planning is to help the patient understand his/her condition, identify his/her goals for care, and prepare for the decisions that may have to be made as the condition progresses over time. For chronic dialysis patients, the interdisciplinary renal care team should encourage patient-family discussion and advance care planning and include advance care planning in the overall plan of care for each individual patient (see **Section 10: Glossary** for definition of renal care team). The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be strongly encouraged while they have capacity to talk to their legal agents to ensure that the legal agent knows the patient's wishes and agrees to make decisions according to these wishes.

The renal care team should attempt to obtain written advance directives from all dialysis patients. Where legally accepted, Physician Orders for Life-Sustaining Treatment (POLST) or similar state-specific forms, also should be completed as part of the advance care planning process. At a minimum, each dialysis patient should be asked to designate a legal agent in a state-specific advance directive. Advance directives should be honored by dialysis centers, nephrologists, and other nephrology clinicians except possibly in situations in which the advance directive requests treatment contrary to the standard of care (see **Recommendation No. 8** on conflict resolution).



Making a Decision to Not Initiate or to Discontinue Dialysis

Recommendation No. 5*

If appropriate, forgo (withhold initiating or withdraw ongoing) dialysis for patients with AKI, CKD, or ESRD in certain, well-defined situations.

These situations include the following:

- Patients with decision-making capacity, who being fully informed and making voluntary choices, refuse dialysis or request that dialysis be discontinued.
- Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis in an oral or written advance directive.
- Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis or request that it be discontinued.
- Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.

*Medical management incorporating palliative care is an integral part of the decision to forgo dialysis in AKI, CKD, or ESRD, and attention to patient comfort and quality of life while dying should be addressed directly or managed by palliative care consultation and referral to a hospice program (see **Recommendation No. 9** on palliative care services).

Recommendation Summary

Recommendation No. 6

Consider forgoing dialysis for AKI, CKD, or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely.

Included in these categories of patients are the following:

- Those whose medical condition precludes the technical process of dialysis because the patient is unable to cooperate (e.g., advanced dementia patient who pulls out dialysis needles) or because the patient's condition is too unstable (e.g., profound hypotension).
- Those who have a terminal illness from non-renal causes (acknowledging that some in this condition may perceive benefit from and choose to undergo dialysis).
- Those with stage 5 CKD older than age 75 years who meet two or more of the following statistically significant very poor prognosis criteria (see **Recommendations No. 2 and 3**): 1) clinicians' response of "No, I would not be surprised" to the surprise question; 2) high comorbidity score; 3) significantly impaired functional status (e.g., Karnofsky Performance Status score less than 40); and 4) severe chronic malnutrition (i.e., serum albumin less than 2.5 g/dL using the bromocresol green method).

Resolving Conflicts about What Dialysis Decisions to Make

Recommendation No. 7

Consider a time-limited trial of dialysis for patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis.

If a time-limited trial of dialysis is conducted, the nephrologist, the patient, the patient's legal agent, and the patient's family (with the patient's permission to participate in decision-making) should agree in advance on the length of the trial and parameters to be assessed during and at the completion of the time-limited trial to determine whether dialysis has benefited the patient and whether dialysis should be continued.

Recommendation No. 8

Establish a systematic due process approach for conflict resolution if there is disagreement about what decision should be made with regard to dialysis.

Conflicts may occur between the patient/legal agent and the renal care team about whether dialysis will benefit the patient. Conflicts also may occur within the renal care team or between the renal care team and other health care providers. In sitting down and talking with the patient/legal agent, the nephrologist should try to understand their views, provide data to support his/her recommendation, and correct misunderstandings. In the process of shared decision-making, the following potential sources of conflict have been recognized: 1) miscommunication or misunderstanding about prognosis; 2) intrapersonal or interpersonal issues; or 3) special values. If dialysis is indicated emergently, it should be provided while pursuing conflict resolution, provided the patient or legal agent requests it.

Providing Effective Palliative Care

Recommendation No. 9

To improve patient-centered outcomes, offer palliative care services and interventions to all AKI, CKD, and ESRD patients who suffer from burdens of their disease.

Palliative care services are appropriate for people who chose to undergo or remain on dialysis and for those who choose not to start or to discontinue dialysis. With the patient's consent, a multi-professional team with expertise in renal palliative care, including nephrology professionals, family or community-based professionals, and specialist hospice or palliative care providers, should be involved in managing the physical, psychological, social, and spiritual aspects of treatment for these patients, including end-of-life care. Physical and psychological symptoms should be routinely and regularly assessed and actively managed. The professionals providing treatment should be trained in assessing and managing symptoms and in advanced communication skills. Patients should be offered the option of dying where they prefer, including at home with hospice care, provided there is sufficient and appropriate support to enable this option. Support also should be offered to patients' families, including bereavement support where appropriate. Dialysis patients for whom the goals of care are primarily comfort should have quality measures distinct from patients for whom the goals are aggressive therapy with optimization of functional capacity.

Recommendation No. 10

Use a systematic approach to communicate about diagnosis, prognosis, treatment options, and goals of care.

Good communication improves patients' adjustment to illness, increases adherence to treatment, and results in higher patient and family satisfaction with care. Patients appreciate sensitive delivery of information about their prognosis and the ability to balance reality while maintaining hope. In communicating with patients, the critical task for clinicians is to integrate complicated biomedical facts and conditions with emotional, social, and spiritual realities that are equally complex but not well described in the language of medicine. This information must be communicated in a way that patients, legal agents, and families can understand and use to reach informed decisions about dialysis and transplantation options. Patients' decisions should be based on an accurate understanding of their condition and the pros and cons of treatment options. To facilitate effective communication, reliance upon a multidisciplinary approach including nephrologists, intensivists, and others as appropriate is warranted. Decisions about acute renal replacement therapy in AKI should be made in the context of other life-sustaining treatments. Intensive care physicians should be included in shared decision-making for kidney patients in the ICU to facilitate discussions on global disease or injury prognosis. Fellowship programs should incorporate training to help nephrologists develop effective, empathetic communication skills, which are essential in caring for this patient population.