

Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Renal Physicians Association
and
American Society of Nephrology

CLINICAL PRACTICE GUIDELINE

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RECOMMENDATION SUMMARY

These recommendations are based on the expert consensus opinion of the RPA/ASN Working Group. They developed a priori analytic frameworks regarding decisions to withhold or withdraw dialysis in patients with acute renal failure and end-stage renal disease. Systematic literature reviews were conducted to address pre-specified questions derived from the frameworks. In most instances, the relevant evidence that was identified was contextual in nature and only provided indirect support to the recommendations. The research evidence, case and statutory law, and ethical principles were used by the Working Group in the formulation of their recommendations.

Recommendation No. 1: Shared Decision-Making

A patient-physician relationship that promotes shared decision-making is recommended for all patients with either ARF or ESRD. Participants in shared decision-making should involve at a minimum the patient and the physician. If a patient lacks decision-making capacity, decisions should involve the legal agent. With the patient's consent, shared decision-making may include family members or friends and other members of the renal care team.

Recommendation No. 2: Informed Consent or Refusal

Physicians should fully inform patients about their diagnosis, prognosis, and all treatment options, including: 1) available dialysis modalities, 2) not starting dialysis and continuing conservative management which should include end-of-life care, 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 consequences of the decision.

Recommendation No. 3: Estimating Prognosis

To facilitate informed decisions about starting dialysis for either ARF or ESRD, discussions should occur with the patient or legal agent about life expectancy and quality of life. Depending upon the circumstances (e.g., availability of nephrologists), a primary care physician or nephrologist who is familiar with prognostic data should conduct these discussions. These discussions should be documented and dated. All patients requiring dialysis should have their chances for survival estimated, with the realization that the ability to predict survival in the individual patient is difficult and imprecise. The estimates should be discussed with the patient or legal agent, patient's family, and among the medical team. For patients with ESRD, these discussions should occur as early as possible in the course of the patient's renal disease and continue as the renal disease progresses. For patients who experience major complications that may substantially reduce survival or quality of life, it is appropriate to discuss and/or reassess treatment goals, including consideration of withdrawing dialysis.

Recommendation No. 4: Conflict Resolution

A systematic approach for conflict resolution is recommended if there is disagreement regarding the benefits of dialysis between the patient or legal agent (and those supporting the patient's position) and a member(s) of the renal care team. Conflicts may also occur within the renal care team or between the renal care team and other health care providers. This approach should review

the shared decision-making process for the following potential sources of conflict: 1) miscommunication or misunderstanding about prognosis, 2) intrapersonal or interpersonal issues, or 3) values. If dialysis is indicated emergently, it should be provided while pursuing conflict resolution, provided the patient or legal agent requests it.

Recommendation No. 5: Advance Directives

The renal care team should attempt to obtain written advance directives from all dialysis patients. These advance directives should be honored.

Recommendation No. 6: Withholding or Withdrawing Dialysis

It is appropriate to withhold or withdraw dialysis for patients with either ARF or ESRD in the following situations:

- Patients with decision-making capacity, who being fully informed and making voluntary choices, refuse dialysis or request 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 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.

Recommendation No. 7: Special Patient Groups

It is reasonable to consider not initiating or withdrawing dialysis for patients with ARF or ESRD who have a terminal illness from a nonrenal cause or whose medical condition precludes the technical process of dialysis.

Recommendation No. 8: Time-Limited Trials

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

Recommendation No. 9: Palliative Care

All patients who decide to forgo dialysis or for whom such a decision is made should be treated with continued palliative care. With the patient's consent, persons with expertise in such care, such as hospice health care professionals, should be involved in managing the medical, psychosocial, and spiritual aspects of end-of-life care for these patients. Patients should be offered the option of dying where they prefer including at home with hospice care. Bereavement support should be offered to patients' families.

NOTE: The complete clinical practice guideline may be obtained from the RPA National Office at: 4701 Randolph Road, Suite 102, Rockville, Maryland 20852; phone: 301-468-3515; fax: 301-468-3511; email: rpa@renalmd.org.