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FAST FACTS AND CONCEPTS #207

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Background Historically, stopping dialysis was considered by many to be a form of suicide. However, it is now a widely accepted practice in most countries, with broad ethical and legal consensus that dialysis can be stopped when it is no longer achieving a meaningful goal for the patient. In fact, ~25% of deaths of dialysis patients in North America occur after its cessation. This Fast Fact reviews key issues pertaining to the decision to stop chronic dialysis; *Fast Fact* #208 will discuss the care of patients after it is stopped.

Why dialysis is stopped The goal of dialysis is not only to prolong life by providing renal replacement therapy, but to maintain a patient's quality of life at an acceptable level (see *Fast Fact* #163). Discussions to stop dialysis usually occur when:

- Dialysis is no longer serving to substantially prolong life or is only prolonging a patient's death (e.g., a patient dying from advanced cancer or sepsis with multiorgan system failure).
- The burdens of dialysis and its complications outweigh its life-prolonging benefits to a patient (e.g., a patient with progressive frailty who is becoming bedbound, a patient with severe cognitive failure). In these scenarios dialysis is likely to prolong life but is not helping to restore a patient to an acceptable level of quality of life as assessed by the patient or her/his surrogate decision maker.

Demographics The demographics of dialysis withdrawal have been studied at length. Patient characteristics associated with withdrawal are older age, female, white race, longer duration of dialysis, higher educational level, living alone, severe pain, and comorbidity (with chronic or progressive diseases). Ethnic differences have been observed, with African Americans and Hispanics being less likely to stop dialysis than European Americans. Reported prevalence levels of patient decision-making capacity at the time of withdrawal vary considerably with estimates ranging from 37% to 80%, suggesting cognitive failure drives many of these decisions. Nephrologists rate cognitive and physical functional status as the most important factors for their decision-making around stopping dialysis, and 93% of North American nephrologists report a willingness to honor a patient's request to stop, even if they have a personal preference to continue. Internationally, practices vary tremendously, with much lower rates of dialysis cessation in Japan compared to North America, for instance.

Responding to a request to stop dialysis For patients who are otherwise dying, counsel about terminal care issues surrounding dialysis withdrawal (see *Fast Fact* #208). For patients not otherwise close to death, explore reasons for withdrawal, especially for treatable factors that might contribute to the desire to withdraw dialysis. For patients whose desire to stop dialysis is being driven by factors that are potentially ameliorable, clinicians should make sure that the decision to stop dialysis is fully informed, including the possibility that some concerns could be addressed. These include:

- Inadequately treated depression, anxiety, pain, and other physical or psychological symptoms (including spiritual and existential suffering)
- Dissatisfaction or difficulties with dialysis itself (e.g., modality, time commitment, or setting of treatment)
- Inadequate social support, or concerns with being a burden to loved ones.

Offer to evaluate and treat these concerns; consider a time-limited trial to see if a patient's quality of life can be improved. However, once a clinician feels a patient or surrogate is making a fully informed choice that is consistent with a patient's values and goals, that decision should be honored. Proactively address any concerns patients may voice about the ethics of withdrawal.

Broaching dialysis withdrawal Clinicians who are concerned continuing dialysis is no longer benefitting a patient due the reasons described above should broach discontinuation with the patient and family. This discussion should occur as part of a larger goals-of-care conversation which addresses prognosis (see Fast Fact #191), patient/family assessment of quality of life, and establishes realistic care goals. Dialysis should be discussed as part of an overall medical plan and framed as how it can or cannot address the care goals. "Dialysis will likely make your mother live longer. However – given everything that has been happening – it is not going to improve her strength, memory, or ability to take care of herself. Based on what you've told me about your mother and what is important for her, I would recommend stopping the dialysis as it is only serving to maintain her in a state she would find unacceptable."

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