PERSPECTIVES ON CARE
AT THE CLOSE OF LIFE

Practical Considerations in Dialysis Withdrawal
“To Have That Option Is a Blessing”

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THE PATIENT’S STORY
Mr D was a 78-year-old man with end-stage renal disease (ESRD) from diabetes and hypertensive nephrosclerosis. He had a prior history of multiple episodes of aspiration pneumonia. For the past 2 years Mr D resided in a convalescent home, where he was visited frequently by his daughter, son, and their families. Mr D was transferred from his skilled nursing facility to the university hospital with cough, fever, and hypoxia.

Mr D had had diabetes for 10 years, with repeated hospitalizations for nonketotic hyperosmolar state. Comorbid disorders included vascular dementia, atrial fibrillation, chronic lymphocytic leukemia, emphysema, pleural effusion, colonic diverticulosis, and tubular adenoma. Hemodialysis was begun 30 months prior to his final admission, but he became progressively more lethargic, less verbal, and physically weaker. A formal advance directive was never completed. On several occasions Mr D’s children, and both Dr A, his family practice physician, and Dr E, his nephrologist, had discussed Mr D’s deteriorating condition and the treatment alternatives that were available, including cessation of dialysis. For some time the family disagreed with respect to the goals of treatment. Despite the episodic illnesses, Mr D still seemed to relish eating and clearly enjoyed visits. Nonetheless, the repeated hospitalizations and Mr D’s failure to regain his baseline status after each episode weighed heavily on his children.

By the time of his most recent hospitalization, he was no longer able to eat, and talk turned to a feeding tube and other invasive support. His family painfully deliberated over this course of action and finally agreed to dialysis cessation. Mr D was unable to meaningfully participate in this decision. Five days following his last session, Mr D died in the palliative care unit of the hospital.

PERSPECTIVES
A Perspectives editor interviewed Mr D’s physicians and adult children.

Dr A (the family practice physician): For family members, the decision to stop dialysis is not an easy decision, because they feel responsible for actively doing something that will lead to their father’s death.

Dr E (the nephrologist): There were a couple of hospitalizations where Mr D had deteriorated. We had talked to the family about possibly stopping dialysis at those times, but the daughter felt very uncomfortable. . . . It had been clear to the son that his dad had not been doing well for quite some time.

Mr D’s daughter: It was a terribly hard decision.

Mr D’s son: I would not want my father to die from pneumonia. My understanding of stopping dialysis, which is what we finally did, sounded like the best avenue based on what I heard from Dr A.

Dialysis is a remarkable, life-prolonging therapy, as well as by definition a death-delaying treatment. Approximately 300,000 people currently undergo maintenance hemodialysis.

Cessation of life-support treatment is an appropriate option for situations in which the burdens of therapy substantially outweigh the benefits. Decisions to withdraw dialysis now precede 1 in 4 deaths of patients who have end-stage renal disease. Guidelines have been recently published to assist clinicians in making these complex and emotionally charged determinations, and they include: relying on shared decision making by all participants, obtaining informed consent, estimating the prognosis on dialysis, adopting a systematic approach for conflict resolution of disagreements, honoring advance directives, and ensuring the provision of palliative care. These principles are discussed in relation to an elderly man with dementia whose family decided to terminate maintenance hemodialysis.

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dialysis in the United States, and about 95,000 new patients initiate treatment annually. Approximately 40% of dialysis patients are diabetic, 30% have congestive heart failure and ischemic heart disease, 15% have peripheral vascular disease, and 10% have significant cerebrovascular disease. In 1999, only 9% were free of significant comorbid conditions. More than 65,000 patients with ESRD die annually, and the 23% annual mortality rate reflects the degree to which ESRD affects mainly a severely ill, geriatric population. To put this in perspective, the prevalent ESRD mortality rate is comparable with that of non-Hodgkin lymphoma, and higher than that of human immunodeficiency virus and colorectal and ovarian carcinoma. Expected remaining lifetimes of dialysis patients are only one quarter to one fifth those of the age-matched, general population. From 1995 to 1999, 36,000 (17%) of the incident population deaths were preceded by dialysis withdrawal. Although discontinuation rates vary according to geographical region and the practice at individual clinics, last year in New England, 28% of the deaths followed treatment cessation. Viewed through this lens, once a patient starts dialysis it is incumbent on the physician to engage in advance care planning, discuss the option of dialysis withdrawal, and address other end-of-life issues.

HISTORICAL AND BIOETHICAL ROOTS OF DIALYSIS DISCONTINUATION

Genesis of Dialysis

When dialysis first became available, the limited number of hemodialysis machines and a scarcity of trained personnel made the selection of who would receive this life-saving treatment a contentious problem. Publicity about the “God committees,” which were instituted to make allocation decisions, had 2 major consequences. First, they caught the attention of philosophers, theologians, and medical professors, and they provided substantial challenge for the nascent field of bioethics. Second, the public’s reaction to rationing of medical resources resulted in passage of the 1972 ESRD amendment to the Social Security Act, providing government subsidy for dialysis. Consequently, the population of patients with ESRD receiving dialysis has grown steadily, and care has been accommodated by private for-profit, as well as nonprofit and hospital-based centers.

Dialysis Discontinuation

In 1986, a seminal article by Neu and Kjellstrand fomented a heated national discussion with the report that 23% of deaths among patients at a large regional dialysis center in Minnesota followed discontinuation of dialysis. For many nephrologists the data confirmed their own practice, for some they were a revelation, and for others they were an outrage. The principles of autonomy and self-determination, and the right to refuse therapy, combined to force professionals in the renal community to examine their practices and standards more critically. In 1991, the Institute of Medicine suggested developing clinical practice guidelines to evaluate patients for whom the burdens of renal replacement therapy substantially outweigh the benefits. A series of articles then analyzed the attitudes and practices of nephrologists in the initiation and the withdrawal of dialysis. A study of US nephrologists found that almost 90% had withheld dialysis at least once in the preceding year, and more than 30% had done so as many as 6 times or more. Canadian nephrologists reported withholding treatment in about 25% of referred patients. In 1990, the US Health Care Financing Administration made a subtle, but significant, change to the death certificate form used by ESRD providers; “withdrawal of dialysis” was no longer listed as a potential cause of death. Instead, it appeared in a separate list of more neutral questions that inquired as to whether renal replacement therapy was discontinued prior to death and the reasons for withdrawal. The choices for the latter included: acute medical-surgical complications, inanition, and access or transplant failure. Cessation of dialysis is now recognized as an appropriate treatment option.

GUIDELINES FOR WITHHOLDING AND WITHDRAWING DIALYSIS

After a laborious process that included a comprehensive literature search, evidence critique, and peer review, the American Society of Nephrology and Renal Physicians Association have published practice guidelines for withholding and withdrawing dialysis. The guidelines (available at: http://www.renalmd.org) have 9 tenets, and begin with a patient-physician relationship that promotes shared decision making. The chronological trajectory of the decision-making process entails preparatory psychological consideration and planning, followed by the decision to terminate dialysis, and then further efforts directed at achieving a “good” death.

Preparatory Psychological Considerations and Planning

MR D’S DAUGHTER: We really wanted some kind of affirmation that stopping dialysis was what my father wanted, but we could never really get that from him (because of his dementia) . . . It wasn’t likely that we were going to get anything very meaningful at the point he was hospitalized.

MR D’S SON: We never got a durable power of attorney signed. Initially, I knew that he was depressed. It was one of those things that I was putting off because I didn’t want to get an answer that I couldn’t trust . . . [I was] biased by my reluctance to let him go—and take responsibility. Dr A was as unmanipulative and unaggressive as you can be and still [able to] get the information across. He created an image, a very favorable image, of what Dad’s death would be like if we stopped dialysis. He sort of planted that a couple of times in our brains, not saying, “I think you should do this.” In a sense we were lucky. To have that option is a blessing.
Physicians Association guidelines, by attending to such factors as comorbid disorders, age, nutrition, and functional status.1,2 The current quality of life and the likely impact of dialysis should be discussed with the patient and family, as well as the expected experience if dialysis is withheld or withdrawn. Patients with poor quality of life can be identified by tools routinely used in dialysis units, such as the Quality of Life Questionnaire for patients undergoing dialysis treatment.22 Dialysis withdrawal should be openly discussed as an option for patients with intolerable symptoms that do not respond to maximal medical management, patients who have run out of options for dialysis access, those who are not tolerating treatment, or those who have severe neurological impairment. Based on this information, the patient and family may decide to not initiate dialysis, or to withdraw treatment if already started. Again, it is critical that decision making be a shared process. Physicians must sensitively afford patients and families time to incorporate new and upsetting information.33

### Decision to Terminate Dialysis

**MR D’S DAUGHTER:** When he went into the hospital, they did an examination that determined he was having difficulty swallowing his food. Because he was aspirating, he kept getting pneumonia. So, they stopped feeding him, and at that point we realized we had to make some kind of decision... We didn’t want to tube feed him... My brother and I felt there was no point in taking away the last thing that he had—which was eating.

**DR A:** The family focused on what they saw as his one main element of quality of life—his enjoyment of eating. It was a nurturing interaction if they could stay and feed him. After sev-
Patients often prefer to express their terminal care preferences to their loved ones. Values-based directives (“Under what conditions would living be unacceptable to you?”) are more useful than treatment-based directives (“Do you want cardiopulmonary resuscitation?”). Physicians should inquire as to whether patients and loved ones are aware that withdrawal is an option (“Under what circumstances, if any, would you want to stop dialysis?”). This is an important issue to address directly. Most patients and families are concerned that discontinuation not be a long and painful process. Reassurance can be offered that dialysis withdrawal generally results in a peaceful and pain-free death, and the average duration from the last day of cessation until death is 8 days. The decision is easier if it is clear that medical staff are committed to keeping the patient comfortable and will remain involved until the end.

Effective communication skills are needed to have effective discussions. The clinician needs to actively listen and give time for replies and questions. Finally, patients and families should not feel unduly pressured. It can be helpful to let the caregivers know that this is a medical recommendation and that the physician is, with their consent, primarily responsible for the decision.

Religious beliefs need to be elicited and considered in arriving at withdrawal decisions. For example, Roman Catholicism clearly distinguishes between cessation of life-support and suicide; consultations with knowledgeable priests or chaplains can be very comforting for patients and caregivers. On the other hand, Orthodox Judaism does not condone any decisions that shorten life expectancy, and dialysis cessation is not considered to be an option. Ethnic factors are important, and studies have consistently documented that African American patients are about half as likely as whites to stop dialysis. In some Asian cultures, the elderly are held in such high esteem that it would be unthinkable to discuss such issues directly with older patients, but it may be possible instead to do so with their children.

6. Withholding or Withdrawing Dialysis. Once the decision to withdraw dialysis is made, the action phase outlined in Box 2 begins. The physician has a responsibility to provide the patient with the most comfortable death possible. Referral to hospice or a palliative care consultation service should be offered. If desired, plans can be arranged that allow the patient to die at home.

Physicians can rely on general palliative care principles with specific adjustments for renal failure. For example, myoclonic jerks are common in ESRD and they increase in the dying patient, but they also may be successfully managed with benzodiazepines. Intravenous fluids, hyperalimentation, and tube feedings should be stopped in order to avoid fluid overload. Families should be educated that this is the most humane and comfortable course, but that if patients are hungry or thirsty they can be allowed to eat or drink whatever they want. A common concern is that the patient will become edematous and dyspneic.

Box 2. Dialysis Withdrawal Check List

1. Once a decision has been made to withdraw from dialysis, outline a plan with the patient and family and encourage the patient to review his or her advance directive for any changes the patient may wish to make, such as issuing a do not resuscitate order
2. Make sure no treatable condition or symptom motivates withdrawal. Rule out treatable depression or undue social or family pressures
3. Offer spiritual or religious support
4. Discuss preferred site of death (home, nursing home, hospital, in-patient hospice), persons desired to be present, and funeral arrangements
5. Stop nonpalliative medications and order palliative medications and other measures as needed for pain, nausea, agitation, myoclonus, pruritus, and dyspnea
6. Discuss with patient and family contingencies for final hours of the patient’s life, including not calling emergency medical services when patient experiences cardiopulmonary arrest
7. Reinforce continued availability of physician
8. Assess and aid family’s coping and grieving and inform family about bereavement services

*Based in part on Recommendations to the Field.

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tion about the continued availability of ultra filtration (removal of fluid by the dialysis machine without solute removal) will allay anxiety; however, in practice this procedure is infrequently needed and almost all dyspnea can be relieved by judicious use of opioids. Although the principles of palliative care and medication use are similar to those for nondialysis patients, certain drugs need to be avoided (eg, meperidine), or require dosage adjustment (eg, morphine).

Box 3 provides a general approach to symptoms management for patients dying of end-stage renal disease based on my clinical experiences.

7 and 8. Special Groups and Time Trials. In the American Society of Nephrology and Renal Physicians Association Guidelines, special groups refers to certain situations in which it is reasonable to consider either not initiating dialysis or stopping treatment. These would include comorbid terminal illnesses that reduce life expectancy to 6 months or less, such as widely metastatic carcinomas, or situations in which patients are permanently unable to purposefully relate to others. In such cases, time-limited trials of dialysis may be offered for a specified period, eg, 1 to 3 months. At the end of such a period, if the burdens of dialysis appear to outweigh its benefits, the decision may be reached to withdraw treatment in a planned manner.

Palliative Care During Dialysis Withdrawal

Mr D’s Daughter: I knew that with kidney failure you just keep sleeping. I expected it to be a little more drawn out, but I guess he was a lot closer to death than I was willing to understand...

Mr D’s Son: The last couple of days of his life were quite elegant. He became very peaceful. He had been in a very agitated state while he was ill. The final few days were really quite serene. He would have his eyes open and look at us once in a while. . . . It was hard to say how much he saw of us and knew of us. The last night, my sister and daughter and I were there tending to him. He liked having his face wiped with a warm washcloth. . . . My daughter rubbed his head. . . . His eyes were open, but it looked like he was looking into the fourth dimension or something. In a strange way, the whole issue of taking care of my father was an incredible bringing together of the family. It was very good for my relationship with my sister. Even though I dreaded it for years, the whole thing has turned out to be an emotional watershed.

9. Palliative Care. Although there is a growing awareness that patients benefit from palliative care throughout the spectrum of life-threatening illness, dialysis discontinuation is clearly a circumstance that calls for a maximal palliative approach. The following 4 questions may be helpful in shaping the management strategy.

1. Am I reducing the patient’s physical and psychological suffering?

2. Am I maximizing the patient’s sense of control?

3. Am I decreasing the strain on the family?

4. Am I facilitating the patient’s chance to spend meaningful time with his or her family, particularly at home?

In 1995, my associates and I published the first of 2 prospective research investigations into the clinical phenomenology of dying following discontinuation of dialysis. We differentiated between “good” and “bad” deaths. These were quantified by delineating and summing 3 domains in the Baystate Quality of Dying Score: duration, pain and suffering, and psychosocial factors.

The second investigation involved 131 cases of dialysis cessation. The research team at each site completed the Baystate Quality of Dying Score, and an additional category was added for the “very good” deaths, which had the highest scores. According to this measure, 15% of the subjects were judged to have had good deaths, 38% had good deaths, and 46% had very good deaths. Caregivers and loved ones reported that nearly half (42%) of the sample had pain during their last 24 hours of life. Delirium and dementia were more frequent than depression; at referral, more than half of the sample was somnolent or comatose, and within a few hours less than one third of the patients could be meaningfully interviewed. This may have been an artifact of the study design, which involved referral after the decision to stop dialysis had already been made, but it certainly reflected the severity of illness at the time of dialysis termination.

Mr D is representative of the dialysis discontinuation population in that he was an elderly man with diabetes, who was unable to participate in the decision because of dementia and who had a peaceful death, with family members present, within a few days of his last dialysis session. Although Mr D’s children agonized over the decision, their reflections suggest that they successfully accommodated to the dialysis cessation. The family appears to have appreciated the physicians’ patience, and the deft manner in which information was provided. Both Drs E and A were sensitive to the family’s benchmark of quality of life, and they waited...
CONSIDERATIONS IN DIALYSIS WITHDRAWAL

until the patient could no longer enjoy eating before revisiting the option of discontinuation.

CONCLUSION

Each year, more than 10,000 deaths in the United States are preceded by decisions to withdraw from dialysis. Mr D is illustrative of many individuals who no longer retain the capacity to meaningfully speak up on their own behalf. Our knowledge about dialysis discontinuation is largely based on retrospective data that is sprinkled with a couple of modest prospective investigations. Research is needed that will longitudinally follow a diverse sample of dialysis patients through the course of their illness, and monitor with validated instruments the psychosocial and physical factors that are likely to predict whether dialysis is stopped prior to death, including whether depression or uncontrolled pain contributes to these decisions, and whether improved management alters the choices of patients and families. Research also is needed to better describe the process by which patients die, and to devise a strategy that fully integrates the advances of palliative care into the practice of dialysis. Until these investigations are accomplished, the American Society of Nephrology and Renal Physicians Association guidelines offer the best opportunity for us to make correct determinations. Dame Cicely Saunders, the founder of the hospice movement, once said, “How people die remains in the memories of those who live on.” One can only hope that there will be many more families like that of Mr D’s, who look back on a death and are satisfied that it was a fitting and merciful ending to a loved one’s life.

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REFERENCES


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Other Sources

**Promoting Excellence in End-of-Life Care**
http://www.promotingexcellence.org

The End-Stage-Renal Disease Workgroup report for this organization which is committed to improving end-of-life care.

**Aging with Dignity**
http://www.agingwithdignity.org

Five Wishes—advance directive is available to view on and order from this site.

**US Renal Data Systems Database**
http://www.USRDS.org

This Web site provides yearly data reports of the end-stage renal disease population in the United States.

**Renal Physicians Association**
http://www.renalmd.org

Renal Physicians Association/American Society of Nephrology guidelines and position statements on palliative care and dialysis withdrawal are available on this Web site.

**National Kidney Foundation**
http://www.kidney.org

Initiation or Withdrawal of Dialysis in End-Stage Renal-Disease Guidelines are available on this Web site.

**Cleveland Clinic Acute Renal Failure Mortality Calculator**
http://www.bio.ri.ccf.org/arf

This site allows calculation of mortality for a patient with renal failure using various models.

**American Medical Association: Education for Physicians in End-of-Life Care**
http://www.epec.net

The EPEC Project provides educational materials designed to educate all US physicians on the essential clinical competencies required to provide quality end-of-life care.