



Online article and related content  
current as of May 15, 2009.

## Practical Considerations in Dialysis Withdrawal: "To Have That Option Is a Blessing"

Lewis M. Cohen; Michael J. Germain; David M. Poppel

JAMA. 2003;289(16):2113-2119 (doi:10.1001/jama.289.16.2113)

<http://jama.ama-assn.org/cgi/content/full/289/16/2113>

Correction

[Contact me if this article is corrected.](#)

Citations

[This article has been cited 28 times.](#)  
[Contact me when this article is cited.](#)

Topic collections

Patient-Physician Relationship/ Care; End-of-life Care/ Palliative Medicine; Renal Diseases; Acute Renal Failure; Dialysis; Perspectives on Care at the Close of Life  
[Contact me when new articles are published in these topic areas.](#)

Subscribe

<http://jama.com/subscribe>

Permissions

[permissions@ama-assn.org](mailto:permissions@ama-assn.org)  
<http://pubs.ama-assn.org/misc/permissions.dtl>

Email Alerts

<http://jamaarchives.com/alerts>

Reprints/E-prints

[reprints@ama-assn.org](mailto:reprints@ama-assn.org)

# Practical Considerations in Dialysis Withdrawal

## "To Have That Option Is a Blessing"

Lewis M. Cohen, MD

Michael J. Germain, MD

David M. Poppel, MD

### 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, be-*

*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.*

JAMA. 2003;289:2113-2119

www.jama.com

*cause 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

**Author Affiliations:** Departments of Psychiatry (Dr Cohen), and Medicine (Drs Germain and Poppel), Baystate Medical Center, Springfield, and Western New England Renal and Transplantation Associates, West Springfield (Drs Germain and Poppel), Mass.

**Corresponding Author and Reprints:** Lewis M. Cohen, MD, Baystate Medical Center, 759 Chestnut St, S2669, Springfield, MA 01199 (e-mail: lewis.cohen@bhs.org).

**Perspectives on Care at the Close of Life** is produced and edited at the University of California, San Francisco, by Stephen J. McPhee, MD, Michael W. Rabow, MD, and Steven Z. Pantilat, MD; Amy J. Markowitz, JD, is managing editor.

**Perspectives on Care at the Close of Life Section Editor:** Margaret A. Winker, MD, Deputy Editor, JAMA.

dialysis in the United States, and about 95 000 new patients initiate treatment annually.<sup>1</sup> 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.<sup>2-4</sup> 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.<sup>5</sup> 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.<sup>6-9</sup> Expected remaining lifetimes of dialysis patients are only one quarter to one fifth those of the age-matched, general population.<sup>1</sup> From 1995 to 1999, 36 000 (17%) of the incident population deaths were preceded by dialysis withdrawal.<sup>1</sup> 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.<sup>10</sup> 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.<sup>11-13</sup> First, they caught the attention of philosophers, theologians, and medical professors, and they provided substantial challenge for the nascent field of bioethics.<sup>14</sup> 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.<sup>15</sup> 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<sup>16</sup> 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.<sup>17,18</sup>

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 stan-

dards more critically.<sup>19-21</sup> 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.<sup>22</sup> A series of articles then analyzed the attitudes and practices of nephrologists in the initiation and the withdrawal of dialysis.<sup>23-27</sup> 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.<sup>28</sup> Canadian nephrologists reported withholding treatment in about 25% of referred patients.<sup>29</sup> 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.<sup>30,31</sup>

## 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.<sup>32-35</sup> 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.*

The earliest phase of the process requires the physician to sensitively broach basic end-of-life issues and to clarify goals of treatment. **BOX 1** outlines steps that we have found can be helpful for the patient and family in the early stages. Ongoing discussions should include the following, which are based on the Society of Nephrology and Renal Physicians Association's 9 tenets:

**1. Shared Decision Making.** According to the retrospective literature on dialysis discontinuation decisions, nearly half the patients lack the capacity to speak for themselves, because of dementia or other organic brain syndromes.<sup>16</sup> Even older patients who are mentally competent often defer to younger relatives and staff to help make these difficult decisions. As in the present case, family members frequently become the primary decision makers.<sup>36</sup> If the physician and family wait until the individual is too sick to participate in discussions, the default decision may be to provide aggressive care to the end; this is often futile, against the patient's values, and associated with needless suffering.<sup>37</sup> As in the present case, families can feel that the burden of arriving at a determination is almost too great for them to tolerate; they need to be helped to reach an appropriate decision.

Decision making is a consensus-building process, and it is grounded in a dialogue among the patient proxy, other close family members, physicians, and immediate caregivers. This process is well described by the American College of Physicians-American Society of Internal Medicine End-of-Life Consensus Panel.<sup>38</sup>

**2. Informed Consent or Refusal.** As Mr D's son suspected, it is important to appreciate the relationship between competence, depression, and death-accelerating decisions.<sup>39-41</sup> Assessment of competence in the context of severe medical illness can be difficult, but standards include the ability to make a consistent choice, an understanding and appreciation of the alternatives and consequences, and the ability to reason rationally about the decision.<sup>42</sup> Depression can interfere with decision-making capacity, and it should be suspected and ruled out in any patient who refuses medical treatment.<sup>43</sup> Although it is essential to identify depression, it is equally important to avoid conflating incompetency and psychiatric illness.<sup>44</sup> Psychiatric investigators are actively attempting to reconceptualize depression in the context of terminal situations,<sup>44</sup> and they are exploring related concepts, such as dignity, boredom, and hopelessness.<sup>45-47</sup> The prevalence of comorbid major depression in patients who withdraw from dialysis is likely comparable with that of the overall ESRD population.<sup>48</sup> In rare instances, patient requests to stop dialysis have been justifiably refused or postponed while treatment was provided for affective disorders or psychoses.<sup>40-51</sup> Patients with marginal competence should be included in negotiations that take place between family and staff.

**3. Estimating Prognosis.** The prognosis of patients with renal failure can be estimated, according to tables and references in the American Society of Nephrology and Renal

### Box 1. Considerations for Dialysis Withdrawal

1. Identify patient who may benefit from withdrawal, including those with
  - Very limited estimated prognosis
  - Poor quality of life
  - Pain unresponsive to treatment
  - Progressive untreatable disease, eg, cancer, dementia, acquired immunodeficiency syndrome, peripheral vascular disease, congestive heart failure
  - Inability or unwillingness to tolerate further dialysis, or
  - Dialysis is technically difficult or impossible
2. Discuss goals of care with patient and family
3. Discuss quality of life on dialysis with patient and/or family
4. Discuss possible symptoms and their palliation
5. Clarify that dialysis withdrawal is an option
6. Reassure that it can result in a peaceful death and discuss usual course
7. Allow time for discussion
8. Make recommendations to withdraw dialysis and request family's assent
9. Provide assurance that the decision is reversible

Physicians Association guidelines, by attending to such factors as comorbid disorders, age, nutrition, and functional status.<sup>32,33</sup> 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.<sup>52</sup> 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.<sup>53</sup>

### 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-*

**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*.<sup>52</sup>

eral days, when he wasn't really getting any better, they made the decision to stop dialysis.

**4. Conflict Resolution.** In families, it is not uncommon for there to be disagreement and conflict. On some occasions, the adult child or relative who has been most emotionally and geographically distant from the patient, possibly feeling unprepared for the end or lacking gradual preparation that those closer to the patient may have felt, arrives at the clinic or hospital and vociferously objects to withdrawal of dialysis.<sup>54</sup> The family member may feel guilty for having neglected the patient and may want to make up for it by advocating aggressive treatment.

The American Society of Nephrology and Renal Physicians Association guidelines present a systematic approach to conflict, as well as a reliance on ethics consultations. Gentle, but firm, diplomacy on the part of the nephrologist is necessary and helpful. Taking time to more fully acknowledge suffering will allow most families to achieve unanimity in support of the patient's decision. Suffering is a key concept in these decisions, and Cassell<sup>55</sup> has eloquently described how both loved ones and staff can cultivate the necessary empathic attentiveness and nondiscursive thinking to recognize its presence.

**5. Advance Directives and Advanced Care Planning.** Physicians should discuss these with patients and family members and then document the goals of care, an obvious necessity before beginning dialysis when the patient is physically and mentally stable, and necessary again at regular intervals during the course of treatment as circumstances change.<sup>56</sup>

Patients often prefer to express their terminal care preferences to their loved ones.<sup>56,57</sup> Values-based directives ("Under what conditions would living be unacceptable to you?") are more useful than treatment-based directives ("Do you want cardiopulmonary resuscitation?"),<sup>58,59</sup> and 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.<sup>60</sup> 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.<sup>50,51</sup> 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.<sup>61-63</sup> 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 assent, 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.<sup>64</sup> 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.<sup>63</sup> Ethnic factors are important, and studies have consistently documented that African American patients are about half as likely as whites to stop dialysis.<sup>65</sup> 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.<sup>66,67</sup>

**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.<sup>68</sup> 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.<sup>69-71</sup> 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. Informa-

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.<sup>72</sup> 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).<sup>69,71</sup> 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?<sup>74</sup>

#### Box 3. End-Stage Renal Disease End-of-Life Symptom Management

1. Pain: Manage according to World Health Organization (WHO) guidelines,<sup>73</sup> with analgesic agents by mouth, by the WHO ladder, around the clock
  - Morphine effective, but leads to build up of neuroactive metabolites
  - Fentanyl or hydromorphone present no metabolism issues
  - Meperidine contraindicated
2. Myoclonic jerks: Treat with benzodiazepines, eg, lorazepam
3. Hunger and thirst: Allow full diet if desired
4. Dyspnea: Opioids and ultrafiltration if necessary to avoid pulmonary edema
5. Excessive secretions (ie, "pulmonary rattle"): Scopolamine and glycopyrrolate

In 1995, my associates and I published the first of 2 prospective research investigations into the clinical phenomenology of dying following discontinuation of dialysis.<sup>75</sup> We differentiated between "good" and "bad" deaths. These were quantified by delineating and summing 3 domains in the Baystate Quality of Dying Score<sup>76</sup>: duration, pain and suffering, and psychosocial factors.

The second investigation involved 131 cases of dialysis cessation.<sup>50,51</sup> 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 bad 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.<sup>50</sup> 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

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."<sup>77</sup> 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.

**Funding/Support:** The Perspectives on Care at the Close of Life section is made possible by a grant from the Robert Wood Johnson Foundation. The Renal Palliative Care Initiative was funded through the Providing Excellence in End of Life Care Program of the Robert Wood Johnson Foundation.

**Other Resources:** For a list of relevant Web sites, see the JAMA Web site at <http://www.jama.com>.

**Acknowledgment:** We thank the staff of the Renal Palliative Care Initiative for their example in addressing the end-of-life issues of this population. Baystate Health System, the Western New England Renal Associates, and the dialysis and transplantation staff at our Fresenius Medical Care, Inc, units have been consistently generous in providing time and support for the project.

## REFERENCES

1. US Renal Data System. *USRDS 2002 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*. Bethesda, Md: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2002.
2. Shidler NR, Peterson RA, Kimmel PL. Quality of life and psychological relationships in patient with chronic renal insufficiency. *Am J Kidney Dis*. 1998;32:557-566.
3. Valderrabano F, Jofre R, Lopez-Gomez JM. Quality of life in end-stage renal disease patients. *Am J Kidney Dis*. 2001;38:443-464.
4. Merkus MP, Jager KJ, Dekker FW, de Haan RJ, Boeschoten EW, Krediet RT. Physical symptoms and quality of life in patient on chronic dialysis: results of the Netherlands cooperative study on adequacy of dialysis (NECOSAD). *Nephrol Dial Transplant*. 1999;14:1163-1170.
5. United States Renal Data System 1999 Annual Report, excerpts. *Am J Kidney Dis*. 1999;34:S1-S176.
6. Weisbord SD, Carmody SS, Bruns FJ, Chang CH, Zeidel ML, Arnold RM. The prevalence, severity and physician recognition of symptoms in hemodialysis patients [abstract]. *J Am Soc Nephrol*. 2002;13:706A.
7. Weisbord SD, Carmody SS, Bruns FJ, Rotondi AJ, Cohen LM, Zeidel ML, Arnold RM. Symptom burden, quality-of-life, advance care planning, and the potential value of palliative care in severely ill hemodialysis patients. *Nephrol Dial Transplant*. In press.
8. US Renal Data System. *USRDS 2001 Annual Data Report*. Bethesda, Md: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2001.
9. Ries LA, Eisner MP, Kosary CL, eds. *SEER Cancer Statistics Review, 1973-1999*. Bethesda, Md: National Cancer Institute, 2002. Available at: [http://seer.cancer.gov/csr/1973\\_1999/](http://seer.cancer.gov/csr/1973_1999/). Accessibility verified March 24, 2003.
10. ESRD Network of New England. *2001 Annual Report to the Centers for Medicare and Medicaid Services*. New Haven, Conn: Tyco Printers; July 2002:60-63.
11. Alexander S. They decide who lives, who dies. *Life Magazine*. 1962:102-125.
12. Darrah JB. Moment in history: the committee. *ASAIO Trans*. 1987;33:791-793.
13. Rabetoy CP, Cohen LM. Integrating palliative care into dialysis treatment: an American perspective. *EDTNA/ERCA Psychosocial Handbook*. In press.
14. Cummings NB. Ethical and Legal considerations in end-stage renal disease. In: Schrier RW, ed. *Diseases of the Kidney and Urinary Tract*. Vol 3, 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2001:3007-3044.
15. McBride P. The development of hemodialysis. In: Nissenson AR, Fine RN, Gentile DE, eds. *Clinical Dialysis*. 2nd ed. Norwalk, Conn: Appleton & Lang; 1990: 20.
16. Neu S, Kjellstrand CM. Stopping long-term dialysis: an empirical study of withdrawal of life-supporting treatment. *N Engl J Med*. 1986;314:14-20.
17. Dessner GH. Stopping long-term dialysis [letter]. *N Engl J Med*. 1986;314: 1449.
18. Fisher SH, Curry E, Batuman V. Stopping long-term dialysis [letter]. *N Engl J Med*. 1986;314:1449-1450.
19. Friedman EA. Withdrawal of therapy. *ASAIO Trans*. 1987;33:794-805.
20. Lowance DC. Withdrawal from dialysis: an ethical perspective. *Kidney Int*. 1988; 34:124-135.
21. Lowance DC. Factors and guidelines to be considered in offering treatment to patients with end-stage renal disease: a personal opinion. *Am J Kidney Dis*. 1993; 21:679-683.
22. Rettig RA, Levinsky NG, ed. *Kidney Failure and the Federal Government*. Washington, DC: Committee for the Study of the Medicare ESRD Program, Division of Health Care Services, Institute of Medicine, National Academy Press; 1991.
23. Holley JL, Foulks CJ, Moss AH. Nephrologists' reported attitudes about factors influencing recommendation to initiate or withdraw dialysis. *J Am Soc Nephrol*. 1991;1:1284-1288.
24. Moss AH, Stocking CB, Sachs GA, Siegler M. Variation in the attitudes of dialysis unit medical directors toward decisions to withhold and withdraw dialysis. *J Am Soc Nephrol*. 1993;4:229-234.
25. Sekkarie MA, Moss AH. Withholding and withdrawing dialysis: the role of physician specialty and education and patient functional status. *Am J Kidney Dis*. 1998; 31:464-472.
26. Eiser AR. Withdrawal from dialysis: the role of autonomy and community-based values. *Am J Kidney Dis*. 1996;27:451-457.
27. Singer PA. The End-Stage Renal Disease Network of New England: nephrologists' experience with and attitudes towards decisions to forego dialysis. *J Am Soc Nephrol*. 1992;2:1235-1240.
28. Singer PA. Nephrologists' experience with and attitudes towards decisions to forego dialysis. *J Am Soc Nephrol*. 1992;2:1235-1240.
29. Hirsch DJ, West ML, Cohen AD, Jindal KK. Experience with not offering dialysis to patients with a poor prognosis. *Am J Kidney Dis*. 1994;23:463-466.
30. Cotler M, Ganzini L, Cohen M. Resolution and ambivalence. *Hastings Cent Rep*. 2000;30:24-25.
31. Cohen LM. Suicide, hastening death, and psychiatry. *Arch Intern Med*. 1998; 158:1973-1976.
32. National Kidney Foundation. *Initiation or Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team*. New York, NY: National Kidney Foundation; 1996.
33. *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis: Clinical Practice Guideline: 2*. Washington, DC: Renal Physicians Association and American Society of Nephrology; 2000.
34. Galla J. Clinical practice guideline on shared decision-making in the appropriate initiation and withdrawal from dialysis. *J Am Soc Nephrol*. 2000;11:1340-1342.
35. Moss AH, for the RPA and ASN Working Group. A new clinical practice guideline on initiation and withdrawal of dialysis that makes explicit the role of palliative medicine. *J Palliat Med*. 2000;3:253-260.
36. Woods A, Berzoff J, Cohen LM, et al. The family perspective of end-of-life care in end-stage renal disease: the role of the social worker. *J Nephrol Social Work*. 1999;19:9-21.
37. Davison SN. Quality end-of-life care in dialysis units. *Semin Dial*. 2002;15: 41-44.
38. Karlawish JHT, Quilla T, Meier DE. A consensus-based approach to providing palliative care to patients who lack decision-making capacity. *Ann Intern Med*. 1999; 130:835-840.

39. Sullivan MD, Youngner SJ. Depression, competence, and the right to refuse lifesaving medical treatment. *Am J Psychiatry*. 1994;151:971-978.
40. Cohen LM, Steinberg MD, Hails KC, Dobscha SK, Fischel SV. The psychiatric evaluation of death-hastening requests: lessons from dialysis discontinuation. *Psychosomatics*. 2000;41:195-203.
41. Leeman CP. Depression and the right to die. *Gen Hosp Psychiatry*. 1999;21:112-115.
42. Zaubler TS. The unexamined death is not worth dying. *Psychosomatics*. 2000;41:193-194.
43. Beck DA, Koenig HG, Beck JS. Depression. *Clin Geriatr Med*. 1998;14:765-786.
44. Chochinov HM, Wilson KG, Enns M, Lander S. Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgments. *Am J Psychiatry*. 1994;151:537-540.
45. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000;284:2907-2911.
46. Shuster JL, Breitbart W, Chochinov HM, for the Ad Hoc Committee on End-of-Life Care of the Academy of Psychosomatic Medicine. Psychiatric aspects of excellent end-of-life care. *Psychosomatics*. 1999;40:1-4.
47. Chochinov HM. Dignity-conserving care: a new model for palliative care. *JAMA*. 2002;287:2253-2260.
48. Cohen LM, Dobscha SK, Hails KC, Morris JE, Pekow PS, Chochinov HM. Depression and suicidal ideation in patients who discontinue the life-support treatment of dialysis. *Psychosom Med*. 2002;64:889-896.
49. Levy NB, Cohen LM. Central and peripheral nervous systems in uremia. In: Massry SG, Glasscock R, eds. *Textbook of Nephrology*. 4th ed. Philadelphia, Pa: Williams & Wilkins; 2001:1279-1282.
50. Cohen LM, Germain M, Poppel DM, Woods A, Kjellstrand CM. Dialysis discontinuation and palliative care. *Am J Kidney Dis*. 2000;36:140-144.
51. Cohen LM, Germain M, Poppel DM, Pekow PS, Woods A, Kjellstrand CM. Dying well after discontinuing the life-support treatment of dialysis. *Arch Intern Med*. 2000;160:2513-2518.
52. End-Stage Renal Disease Workgroup. *Recommendations to the Field*. Available at: <http://www.promotingexcellence.org/esrd>. Accessed April 3, 2003.
53. Levinson W, Cohen MS, Brady D, Duffy FD. To change or not to change: "sounds like you have a dilemma." *Ann Intern Med*. 2001;135:386-390.
54. Cohen LM, Germain M, Brennan M. End-stage renal disease and discontinuation of dialysis. In: Morrison RS, Meier DE, Capello CF, eds. *Geriatric Palliative Care*. London, England: Oxford University Press; 2003:192-202.
55. Cassel EJ. Diagnosing suffering: a perspective. *Ann Intern Med*. 1999;131:531-534.
56. Holley JL, Stackiewicz L, Dacko C, Rault R. Factors influencing dialysis patients' completion of advance directives. *Am J Kidney Dis*. 1997;30:356-360.
57. Holley JL, Hines SC, Glover JJ, Babrow AS, Badzek LA, Moss AH. Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. *Am J Kidney Dis*. 1999;33:688-693.
58. Singer PA. Advance care planning in dialysis. *Am J Kidney Dis*. 1999;33:980-991.
59. Fried TR, Bradley EH, Towle VR, Allore H. Understanding the treatment preferences of seriously ill patients. *N Engl J Med*. 2002;346:1061-1066.
60. Holley JL, Hines SC, Glover JJ, Babrow AS, Badzek LA, Moss AH. Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. *Am J Kidney Dis*. 1999;33:688-693.
61. Robert Buckman. *How to Break Bad News*. Baltimore, Md: Johns Hopkins Press; 1992.
62. Coulehan JL, Platt FW, Egener B, et al. "Let me see if I have that right . . .": words that help build empathy. *Ann Intern Med*. 2001;135:221-227.
63. Quill TE. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." *JAMA*. 2000;284:2502-2507.
64. Kaye M. Religious aspects of stopping treatment. In: Kjellstrand CM, Dossetor JB, eds. *Ethical Problems in Dialysis and Transplantation*. Dordrecht, the Netherlands: Kluwer Academic Publishers; 1992:117-125.
65. Leggat JE Jr, Swartz RD, Port FK. Withdrawal from dialysis: a review with emphasis on the black experience. *Adv Ren Replace Ther*. 1997;4:22-29.
66. Crawley LM, Marshall PA, Lo B, Koenig BA, for the End-of-Life Care Consensus Panel. Strategies for culturally effective end-of-life care. *Ann Intern Med*. 2002;136:673-679.
67. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "you got to go where he lives." *JAMA*. 2001;286:2993-3001.
68. Jansen LA, Sulmasy DP. Sedation, alimentation, hydration, and equivocation: careful conversations about care at the end of life. *Ann Intern Med*. 2002;136:845-849.
69. Cohen LM, Reiter G, Poppel M, Germain M. Renal Palliative Care. In: Addington-Hall J, Higginson I, eds. *Oxford Textbook of Palliative Care for Non-Cancer Patients*. London, England: Oxford University Press; 2001:103-113.
70. Cohen LM, Germain MJ. Palliative and Supportive Care. In: Brady H, Wilcox C, eds. *Therapy of Nephrology and Hypertension: A Companion to Brenner's The Kidney*. 2nd ed. Orlando, Fla: Harcourt; 2003:753-756.
71. Cohen LM, Germain MJ, Tessier EG. Neuropsychiatric complications and psychopharmacology of end-stage renal disease. In: Brady H, Wilcox C, eds. *Therapy of Nephrology and Hypertension: A Companion to Brenner's The Kidney*. 2nd ed. Orlando, Fla: Harcourt; 2003:731-746.
72. Cohen LM: Renal disease. In: Wise M, Rundell JR, eds. *Textbook of Consultation-Liaison Psychiatry: Psychiatry in the Medically Ill*, 2nd ed: Washington, DC: American Psychiatric Press; 2002:537-562.
73. World Health Organization. *Cancer Pain Relief*. Geneva, Switzerland: World Health Organization; 1996.
74. Meier DE, Morrison RS. Autonomy reconsidered. *N Engl J Med*. 2002;346:1087-1089.
75. Cohen LM, McCue J, Germain M, Kjellstrand C. Dialysis discontinuation: a "good" death? *Arch Intern Med*. 1995;155:42-47.
76. Cohen LM, Poppel DM, Cohen GM, Reiter GS. A very good death: measuring quality of dying in end-stage renal disease. *J Palliat Med*. 2001;4:167-172.
77. Saunders C. Pain and impending death. In: Wall PD, Melzack R, eds. *Textbook of Pain*. New York, NY: Churchill Livingstone; 1989:624-631.

## 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.