

Nephrology Ethics Forum

Exploring Ethical, Moral, and Legal Issues Related to Kidney Diseases

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AJKD Ethics Editor

Shared Decision-Making in Dialysis: The New RPA/ASN Guideline on Appropriate Initiation and Withdrawal of Treatment

Case Presentation

AN 87-YEAR-OLD man with chronic renal failure from hypertensive nephrosclerosis (serum creatinine level, 3.0 mg/dL), complicated by anemia and chronic severe bilateral lymphedema of his legs, was admitted to an outside hospital in septic shock from pneumonia.

The patient developed acute renal failure superimposed on his chronic renal failure and was transferred to the university hospital for dialysis and further treatment. At the university hospital, the patient was found to also have complete heart block, upper gastrointestinal bleeding, cholesterol emboli, deep venous thrombophlebitis of his right leg, cellulitis of his left leg, and severe malnutrition with a serum albumin level of 1.8 mg/dL. The patient was treated for these problems and received dialysis for uremic encephalopathy. After further evaluation, it was clear that the patient would need a permanent pacemaker as well as chronic dialysis.

A study of the history of the patient and his caregiver found that the patient had marked functional impairment. The caregiver assisted the patient with bathing and prepared his meals. Because of the lymphedema in his legs, he was



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unable to walk without difficulty. The patient spent most of his time in a chair reading or watching television. Because the patient valued his independence, he begged the caregiver never to let him be placed in a nursing home.

The nephrologist discussed the options for end-stage renal disease (ESRD) treatment with the patient. Peritoneal dialysis was not an option because the patient had a large ventral hernia. With further discussion, it became clear that the patient, who was aware of his numerous medical problems, was strongly motivated to start dialysis. The patient explained that his wife had Alzheimer's disease and had been in a nursing home for a number of years. The couple had no

children. Even though the patient had not been physically capable of visiting his wife for several years, the patient felt responsible for her. He

INDEX WORDS: *Medical ethics; withholding dialysis; withdrawing dialysis; acute renal failure (ARF); chronic renal failure (CRF); prognosis; palliative care; clinical practice guideline.*

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wanted dialysis so that he could live and continue to oversee his wife's care. He said without question, "We need to do it (dialysis)." When asked how he would get back and forth for hemodialysis, the patient commented that his caregiver would make all the arrangements and handle his transportation. The nephrologist concluded that the patient clearly had decision-making capacity but did not seem to understand the complexity of his medical problems and the difficulties that would be involved in thrice-weekly dialysis. It also appeared that, having worked in an accounting office for a large company, the patient was used to making decisions and having them followed.

With the patient's permission, the nephrologist contacted the caregiver. The caregiver, a family friend who was an aging woman with rheumatoid arthritis, did not think she could transport the patient to hemodialysis treatments. Furthermore, she noted that the patient had difficulty dealing with end-of-life issues. She recounted that, although his wife was elderly, frail, essentially bedridden, and had advanced Alzheimer's disease, the patient had requested cardiopulmonary resuscitation for his wife in the event of cardiac arrest.

The nephrologist decided that the patient needed to hear the concerns of the caregiver. With the patient's consent, a patient care conference was organized in which the patient, the caregiver, the caregiver's spouse (who was also a close friend of the patient), the primary care team, and the nephrologist all participated. At the beginning of the conference, the primary care physician described the patient's multiple medical problems and the procedures that would be necessary to evaluate and treat them, including upper gastrointestinal endoscopy, insertion of a permanent pacemaker, insertion of an inferior vena cava filter, and creation of a vascular access for hemodialysis. The nephrologist then noted that, considering the patient's functional impairment, malnutrition, multiple medical problems, and age, the patient would not be an appropriate candidate for chronic dialysis. The caregiver commented to the patient how he (the patient) had known

that he was going downhill during the past 6 months and how hard living had been in recent weeks. At this point the nephrologist asked the patient, "What is most important to you?" The patient said, "I want to take care of everything." By this, he meant that he wanted to revise his will so that his caregiver would be well taken care of and that some of his estranged nieces and nephews would be removed from the will. He also wanted to be certain that all financial arrangements were in place for his wife's continuing care, because it appeared that she would survive him. With the promise that these matters would be addressed immediately, the patient agreed that he had too much against him and that a palliative care approach without dialysis or pacemaker insertion would be best.

The patient's lawyer was called and informed of the patient's poor condition and the immediate need to revise the patient's will and make financial arrangements for the patient's wife. He saw the patient the same day and helped him get his affairs in order. The patient named his caregiver as his Medical Power of Attorney representative and named her spouse as his successor representative.

The following day the patient had signs of early uremic encephalopathy with multifocal myoclonus. The nephrologist asked the patient whether he had told his caregiver everything she needed to know. The patient had discussed neither his preferences for funeral arrangements with her nor the location of his cemetery lot. The caregiver was summoned and the two had their final discussion. The patient was not religious and did not attend church, but he did want his funeral to be conducted by the Baptist pastor of the church his wife had attended. He declined the opportunity to speak to the pastor or to have prayer. The next day the patient was more uremic and began to have severe pain in his legs. The cause of the pain was wet gangrene of the toes—a result of the cholesterol emboli. He was medicated with a hydromorphone infusion for pain, lorazepam for twitching and agitation, and scopolamine to dry up his bronchial secretions. He died the following morning.

DISCUSSION

Dr Alvin H. Moss (Director, Center for Health Ethics and Law, West Virginia University):

The issues that this case raises—patient selection for dialysis, forgoing dialysis, and palliative care for ESRD patients—have finally achieved legitimacy in the nephrology community. It is worth reviewing the history of these issues.

Recent History

Patient selection for dialysis first became an issue in the 1960s after Scribner invented the shunt, making chronic dialysis possible. In 1972, Medicare called for “a medical review board to screen the appropriateness of (ESRD) patients for the proposed treatment procedures (dialysis and transplantation).”¹ In 1986, Neu and Kjellstrand² reported an increasing frequency of patient withdrawal from dialysis and a significant proportion of dialysis patient deaths attributable to this. In 1991, the Institute of Medicine’s Committee for the Study of the Medicare ESRD Program recommended that the nephrology community in conjunction with patients and bioethicists develop “patient acceptance criteria” for dialysis.³ They recognized that an “increasing number of patients with limited survival possibilities and relatively poor quality of life” were being treated with dialysis and that guidelines would be helpful to assist in dialysis decision-making.

The Institute of Medicine Committee’s call for guidelines went unheeded until 1997. Then, using Institute of Medicine criteria for clinical practice guideline topic selection, the leadership of the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) chose the topic of initiation and discontinuation of dialysis from among 24 proposed topics as the one of highest priority to the nephrology community for new guideline development. They did this because they knew that more than 50,000 chronic dialysis patients die per year in the United States and about 20% of those deaths follow a decision to stop dialysis. The RPA/ASN organized a Working Group with representatives from multiple disciplines and organizations in the dialysis community, kidney patients, family members, internal medicine physicians, a bioethi-

cist, and a public policy expert.* The guideline that was developed by this group was entitled “Shared Decision-Making in the Appropriate Initiation of and Withdrawal From Dialysis” (hereinafter referred to as “the RPA/ASN guideline”) and was published in February 2000.⁴

The RPA/ASN guideline utilizes patient-centered values, evidence-based medicine, and jurisprudence to address withholding and withdrawing dialysis in adult patients with either acute renal failure or ESRD. It provides 9 recommendations (Table 1) that are supported with brief rationales, 25 prognostic tables, and 302 references. This paper will describe the application of the RPA/ASN guideline to the case presentation and refer to the growing literature on renal palliative care.

Shared Decision-Making and Informed Refusal

The first recommendation in the RPA/ASN guideline is that dialysis decisions should be made through the process of shared decision-making. The physician is the expert in diagnosis, prognosis, and treatment options, and the patient is the expert in his or her history, values, and preferences. Together, they should come to agreement on a specific course of action. If the patient lacks decision-making capacity, the physician should make decisions with the patient’s legal agent. The legal agent is the individual named by the patient in an advance directive to make decisions for him or her in the event the patient loses decision-making capacity or, if the patient has not completed an advance directive, the person selected to be the surrogate decision-maker according to state law. The legal agent is to make decisions according to the patient’s values and wishes or, if the patient’s wishes are unknown, the patient’s best interest.

The RPA/ASN guideline Working Group realized that there was a potential tension between an evidence-based approach that leads to a particular recommendation for a particular group of patients (eg, those who are terminally ill from cancer) and a normative approach that addresses what should be done for a specific patient with a unique set of values. The Working Group recom-

*Alvin H. Moss, MD, was the Chair of this Working Group.

Table 1. 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 (ARF) and end-stage renal disease (ESRD). Systematic literature reviews were conducted to address prespecified questions derived from the frameworks. In most instances, the relevant evidence that was identified was contextual in nature and provided only indirect support to the recommendations. Research evidence, case and statutory law, and ethical principles were used by the Working Group to formulate its 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 ensure 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 (eg, availability of nephrologist), 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 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.

mended that neither the outcomes for a particular group of patients nor the preferences of an individual patient should be ignored. They urged that nephrologists strike a balance between the two as they engage patients in the process of reaching shared decisions.

In the presented case, the patient had decision-making capacity, and his initial inclination was to start dialysis because he felt responsible for the continuing care of his wife. Neither the nephrologist nor the primary care physician thought that chronic dialysis was appropriate for this patient, and they recommended against it. Because of the patient's reliance on his caregiver, the nephrologist thought that the caregiver should participate in the shared decision-making process and, with the patient's consent, a patient care conference was held.

In this case, options for the patient's ESRD included hemodialysis, a time-limited trial of hemodialysis, and withholding dialysis with the provision of palliative care. After a thorough discussion, the patient agreed to the palliative care approach. He did so with the understanding that those things that were most important to him would be respected. He wanted to revise his will and make financial arrangements for the future care of his wife. The patient's decision to refuse dialysis was facilitated by disclosure of his medical condition, including predicted life expectancy and anticipated quality of life. The nephrologist was able to provide prognostic information to the patient with ease because of the prognostic tables in the RPA/ASN guideline.

Estimating Prognosis

The recommendation in the RPA/ASN guideline to estimate prognosis using an evidence-based medicine approach follows the recommendation on informed consent that says that nephrologists should "fully inform" patients about their condition, including their prognosis. The evidence in the RPA/ASN guideline was identified by a systematic search of the medical literature and then graded. Most of the prognostic evidence received the highest grade and was from inception cohort studies (either multiple or single large representative studies) with more than 80% follow-up and/or validated models from such studies.

Based on the review of the medical literature

presented in the RPA/ASN guideline, age, nutritional status, and functional status were all found to be powerful predictors of prognosis. Being an 87-year-old white male, the patient in the case presentation had an expected 1.7 years of remaining life. Based on a serum albumin of 1.8 g/dL, the patient had less than a 50% chance of survival for 1 year and less than a 28% chance of survival for 18 months. Based on his severely impaired functional status, the patient's relative risk of death was 3.46 times that of a dialysis patient with normal functional status.

One weakness of the RPA/ASN guideline is that there is no reliable way to combine prognostic estimates from separate conditions into an overall prognostic estimate. In addition, not all prognostic factors are taken into account, so that the prognostic estimates for this patient did not factor in his sepsis, complete heart block, gastrointestinal bleeding, cholesterol emboli, wet gangrene, deep venous thrombophlebitis, and chronic lymphedema. Taken together, all of these medical problems could reliably be estimated to have a poor prognosis. In this setting, the risks of dialysis would appear to outweigh the benefits substantially. The goal of the patient care conference was to discuss with the patient his predicted outcome based on the medical evidence and ascertain his values and goals for treatment. In the end, an accommodation was reached that was satisfactory to both the patient and the treating health care team.

Withholding or Withdrawing Dialysis

The RPA/ASN guideline recommends that it is appropriate to withhold or withdraw dialysis for patients with either acute renal failure 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 but 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 neuro-

logical impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.

The first situation applies in this case. “Informed refusal” of care is both ethical and legal. The ethical principles supporting the patient’s refusal of treatment are respect for patient autonomy, beneficence, and nonmaleficence. Patients with decision-making capacity also have the legal right under state law and federal statute (eg, Patient Self-Determination Act) to refuse medically indicated treatment. However, the renal care team is well advised to ensure due diligence in such cases. The toolkit in the RPA/ASN guideline includes a “Withdrawal From Dialysis Checklist” that prompts the team to consider screening the patient for depression, referring the patient for professional counseling, and addressing potentially reversible factors that might lead the patient to change his or her mind.

It is important to emphasize that decisions to initiate dialysis for patients with acute renal failure are distinct from those for patients with ESRD. This case highlights those distinctions. The patient was supported with acute dialysis while undergoing a work-up to establish the extent of his disease and the possibility of recovery. This support allowed data gathering and time for discussion to optimize the shared decision-making regarding chronic dialysis.

Palliative Care Paradigm

For all patients who decide to forgo dialysis or for whom such a decision is made, the RPA/ASN guideline recommends that they be treated with “continued palliative care.” The word *continued* is used advisedly in the guideline. The Working Group believed that all ESRD patients should be treated with palliative care throughout their chronic illness. Palliative care includes pain and symptom management, attention to psychosocial and spiritual concerns, and identification of what matters most to the dying patient. The Working Group’s expectation was that nephrologists would become more expert at palliative care with their chronically ill patients. The guideline recommends that, with the dying patient’s consent, persons with palliative care expertise such as hospice professionals should be involved in the patient’s end-of-life management. Patients should be offered the option of dying in the setting of

their preference, including the home, if possible. Bereavement support should be offered to families.

The emphasis in the RPA/ASN guideline on palliative care was antedated by a 1997 RPA and ASN position statement on “Quality Care at the End of Life.”⁵ This position statement recommends that nephrologists, nephrology nurses, and renal social workers obtain education and skills in the principles of palliative medicine. It also recommends that, once a decision is made to forgo dialysis, the renal care team should refer the patient to a hospice or provide a hospice-like approach to patient care.

There have also been several recent articles describing how a hospice approach might be implemented in the setting of dialysis withdrawal.⁶⁻⁸ These articles document that many dialysis patients are currently not receiving optimal palliative care and are dying in unnecessary distress due to inadequately treated pain, agitation, myoclonus, and dyspnea. The following is a brief summary of palliative care strategies for patients who have discontinued dialysis.

Palliative Care Strategies

Once an ESRD patient makes a decision to forgo dialysis, a fairly predictable course of events is set in motion that requires careful palliative care. Patients die an average of 8 to 12 days after stopping dialysis.^{2,9} Without management of oral and intravenous fluids, fluid overload and pulmonary edema can occur. If death is anticipated in a matter of hours, supplemental oxygen therapy and an opioid is indicated to relieve the dyspnea associated with fluid overload. If death is believed to be a matter of days away, ultrafiltration without dialysis can relieve symptoms. Patients progressively develop uremia that may be manifested by agitation, nausea, hiccoughs, restless legs, myoclonic jerks, pain, delirium, seizures, and eventually loss of consciousness.⁷

Although the benefits of nonpharmacologic measures (such as mouth swabs, lip balm, positioning, back rubs, and fans) should not be underestimated, appropriate use of pharmacology is the cornerstone of palliative medicine.⁵ Haloperidol is the drug of choice for delirium, and it may also be helpful for agitation and nausea. Clonazepam and lorazepam are usually helpful for rest-

less legs and myoclonic jerks. Lorazepam and phenytoin both can control seizures secondary to uremia—a late manifestation of uremic encephalopathy that occurs in less than 10% of patients after dialysis withdrawal.⁶

After dialysis is discontinued, pain is present in almost half of patients during the last 24 hours of life.⁷ In managing severe pain in ESRD patients with opioids, toxic metabolites may accumulate. Administering meperidine in untreated renal failure may lead to the accumulation of normeperidine, which can cause mental status changes and seizures. For this reason, the use of meperidine in renal failure patients is contraindicated. Giving morphine can lead to the accumulation of two active metabolites: morphine-3-glucuronide (associated with hyperalgesia and myoclonus) and morphine-6-glucuronide (associated with respiratory depression and nausea). Hence, morphine should not be used for more than a few days in ESRD patients.

Hydromorphone, fentanyl, and possibly methadone are better choices for treatment of severe pain in ESRD patients. Hydromorphone and fentanyl have active metabolites, but their role in neuroexcitation remains largely conjectural. Methadone has no known active metabolite, but it has a longer and sometimes-unpredictable half-life that can make dosing more difficult.⁶ The patient in the presented case had his pain, agitation, and myoclonus well-controlled with an hydromorphone infusion and lorazepam injections.

Relief of physical symptoms is an important first step; however, family and spiritual concerns are often what is most important to patients. In the case presented, the patient was not interested in prayer or talking to a minister, but he was interested in making financial arrangements for his wife's continuing care. He also wanted to revise his will to reward his caregiver who had been helpful to him and to remove family members who had not helped. Providing for his wife and handling his finances well had given his life meaning and value. Helping him in his final hours with these tasks met his deepest spiritual needs. Based on an article by Lo et al,¹⁰ the RPA/ASN guideline suggests that the following questions help patients identify their spiritual concerns:

- As you think about the future, what is most important to you (what matters the most to you)?
- Is faith important to you in this illness?
- Would you like to explore religious matters with someone?
- What do you still want to accomplish during this life?
- What might be left undone if you were to die today?
- What is your understanding about what happens to you after you die?
- Given that your time is limited, what legacy do you want to leave to your family?

Ideally, addressing patients' spiritual concerns is a part of continued palliative care that begins long before the end of life. However, most dialysis units are not adequately staffed or trained to address these concerns in a timely and effective manner.

CONCLUSION

This paper and the new RPA/ASN guideline address the ethically charged question that has remained unanswered since the inception of the Medicare ESRD program, “*Who* should be dialyzed?” They also provide answers to two related questions, “*How* should this be decided?” and “If ESRD patients decide to forgo dialysis, how should they be treated?” The goal of the RPA/ASN guideline is that the recommended process of shared decision-making will result in respectful, compassionate treatment for the thousands of ESRD patients who decide to forgo dialysis each year.

QUESTIONS/ANSWERS

Dr David Z. Levine (Ethics Forum Editor; Professor of Medicine, Division of Nephrology, Ottawa Hospital, University of Ottawa): In the acute case you presented, the caring nephrologist spent an enormous amount of time with the patient, his caregiver, and the primary care team. Many will be concerned about how they can find such time in their frenetic dialysis units, while others may not feel that such effort is warranted. Has the RPA/ASN Working Group

considered how to provide incentives to make this model of devoted care more common?

Dr Moss: I think that the most tangible incentive to providing the type of care described is the physician's personal satisfaction that comes from offering compassionate care during an extremely trying time for patients and families. As I talk to other nephrologists, they tell me that providing excellent end-of-life care is the thing that they have found to be the most rewarding aspect of their work. Not only do the patients benefit, but also families will remember and appreciate their loved one's end-of-life care for years afterward.

In fact, my time with this case amounted to 1 hour a day for several consecutive days. I believe that my knowledge of the RPA/ASN guideline allowed me to work effectively and efficiently with the patient, caregiver, and health care team. Particularly helpful were the recommendations regarding palliative care and the toolkit, which included "Questions to Guide Discussions of End-of-Life Issues" and the "Preparation for Dying Checklist." Because of these resources, I knew what the issues were and what I needed to ask. My encouragement to practicing nephrologists would be to become familiar with the new guideline and use the resources in the toolkit.

Dr David Mendelssohn (St. Michael's Hospital and University of Toronto): I think that the most controversial recommendation in the new guideline is the requirement of complete disclosure of prognosis in every patient. How can we be certain that complete disclosure of prognosis will be the best policy? There is no evidence to support this approach. It may disturb patients, and it is not current practice.

Dr Moss: Your question is a particularly important one. Contrary to what you suggest, there is evidence that the vast majority of dialysis patients,^{11,12} like other patients,^{13,14} do want to be informed and participate in decision-making. Only a minority of older dialysis patients are satisfied with being informed about their condition without participating in decision-making.¹² The concern of the RPA/ASN Working Group that drafted the guideline—and please remember that the Working Group was composed of people from multiple disciplines, including nursing and social work—was that many patients and families agree to start dialysis with little or no under-

standing that there is an extremely low likelihood of benefit. The Working Group felt that not to inform patients and families constituted a form of deception. In my experience as an ethics consultant, I have learned that patients and families assume that, if the physician is willing to provide a procedure or treatment in response to their request, then it must be beneficial. Otherwise, why would the physician offer it?

At this time, when informed consent is the ethical and legal norm, the issue is less focused on whether the patient should be informed and more focused on *how* the physician should inform the patient. The nephrologist needs to find out how much patients understand about their kidney failure, how serious they believe it to be, and how much they want to know about it. If the patient does not want to be involved in the decision-making, then the physician needs to ask the patient whom the patient wants to be involved. Ultimately, someone representing the patient needs to know the prognosis. Otherwise, there cannot be true, shared decision-making. In discussing whether to start dialysis, nephrologists can be compassionate and disclose enough to let patients know that there is not a realistic expectation of long-term survival. They can provide hope that medical therapy without dialysis can make the patient's remaining days or weeks comfortable, that the nephrologist will not abandon the patient, and that whatever the patient reasonably wants to accomplish before death can be worked on. As Carl Kjellstrand wrote in an editorial in *JAMA* regarding advance directives and end-of-life care, "We (physicians) need to be more open to the patient and more realistic about what we can or cannot do. . . physicians need to teach themselves to recognize better the shadow line between prolonging life and prolonging dying and to understand that death should be a human act of dignity and not a prolonged mechanical failure that can be fixed with even more technology."¹⁵

Dr John F. Seely (Ottawa Hospital and University of Ottawa): How do we ensure that patients who decide to discontinue dialysis are able to complete any "unfinished business" before death, whether that is legal, financial, family, emotional, or spiritual?

Dr Moss: The answer to your question has to do with good advance care planning. This should be initiated shortly after patients begin dialysis and then continued throughout their course of dialysis. Recommendation #5 in the RPA/ASN guideline has to do with advance directives, and the recommendation contains suggested steps for implementing advance care planning. These steps include questions that patients are to be asked once or twice a year, such as, “If you become too sick to make decisions for yourself, whom do you want to make decisions for you?” and “Under what circumstances, if any, would you want to stop dialysis?” In the toolkit of the RPA/ASN guideline, there are also additional questions useful in guiding end-of-life discussions. I agree that, if we waited until dialysis is stopped and the patient has only a matter of days to live, there may not be enough time to address important life closure issues. That is the reason why the RPA/ASN guideline recommends “palliative care throughout (the patient’s) illness which includes management of pain and other symptoms, attention to psychosocial and spiritual concerns, and identification of what matters most to the patient in the dying process.”⁴

Dr Mark Goldstein (St. Michael’s Hospital and the University of Toronto): The guideline seems to emphasize respecting the wishes of patients that want dialysis. Did the Working Group also address the case of patients who wish to forgo dialysis?

Dr Moss: Yes, recommendation #9 talks about palliative care for those who forgo dialysis and includes not only those who stop dialysis, but also those who choose not to start it. Recommendation #6 covers withholding as well as withdrawing dialysis.

Dr Jeffrey Zaltzman (St. Michael’s Hospital and the University of Toronto): Is it ever appropriate to tell patients or family that dialysis is futile, that is, clearly not medically indicated?

Dr Moss: The Working Group discussed the issue of futility a great deal; however, the word *futility* does not appear in the guideline. Clearly, communication is key in circumstances in which the patient or family requests dialysis that the nephrologist does not think should be provided. If the nephrologist believes, based on the medical literature and his or her experience, that the

burdens of dialysis substantially outweigh the benefits, then he or she is obliged to communicate this information to patients and families. If a conflict occurs, then the RPA/ASN guideline recommends a systematic process for conflict resolution. The RPA/ASN Working Group had patient representatives who voiced the concerns of patients and families in such situations. The Working Group endorsed the overriding principle of shared decision-making; they thought that being candid about prognosis and doing time-limited trials as needed would be a better approach than using futility as a medical trump card to justify unilateral decisions.

Dr Lori Adler (Operations Director, Geriatric Program, Toronto Rehabilitation Institute): Several of the examples you discussed involved elderly patients. Do elderly patients have the deck stacked against them in decisions regarding the withdrawal of dialysis? Please comment on this and issues related specifically to the care of the elderly.

Dr Moss: The elderly are those on dialysis who have the highest frequency of making decisions to withdraw from dialysis, but they are also those who have the fastest growth in treatment rate. In the United States, the majority of new patients starting dialysis are over the age of 65. So, age-discrimination does not appear to be a major factor. It is true that much of the prognostic data are not favorable for the elderly. For example, there are a number of studies quoted in the RPA/ASN guideline indicating that the risk of death increases 2% to 4% for each additional year of life. But, if you ask me, “Do you have some elderly patients who are doing very well on dialysis and who would rate their quality of life as a 10 out of 10?” The answer is “Yes.” So, the nephrologist needs to consider all factors, not just age, and discuss the benefits and risks of dialysis and engage patients in individual shared decision-making. The elderly will often choose dialysis for a year or two or until a major complication occurs, such as a massive stroke or heart attack or peripheral vascular disease requiring amputation. At this point they might decide that their quality of life is no longer satisfactory and decide to stop dialysis. The challenge of caring for elderly dialysis patients is to determine how to best optimize their quality of life.

Professor Bernard Dickens (Faculty of Law, University of Toronto): Is “decision-making capacity” the same for accepting and rejecting dialysis or can capacity be asymmetrical, calibrated to the significance and implications of the options for the patient?

Dr Moss: The latter is true. Some patients may possess sufficient understanding and reasoning ability to make easy decisions but not more difficult ones that require more knowledge and complex levels of reasoning. The decision to start dialysis is not controversial if the nephrologist recommends it and the family, as well as the patient with limited capacity, agrees. One would want to have a higher level of capacity on the part of the ESRD patient to accept his or her decision to reject dialysis because of the very serious implications of the decision. If the patient lacks sufficient capacity to make such a decision, then the nephrologist will need to talk to the patient’s medical power of attorney representative or health care surrogate, depending on the law in the state or province where the patient resides.

Dr Mendelssohn: Would it not be optimal for the renal team to acquire the expertise to provide palliative care rather than rely on a Palliative Care Team that may result in discontinuous care?

Dr Moss: Yes, it would be the ideal for nephrologists and other members of the renal care team to start palliative care from the first day that patients with renal disease come under their care. However, there is a shortage of nephrologists in Canada, just as there is in the United States. There are not enough of us to go around, especially when we are talking about home visits at the end of life that can be quite time-consuming and could be made by members of a hospice team. We can work as a team with hospice professionals. Nephrologists can become more knowledgeable about palliative care and remain involved but also get the help of others who are more skilled at psychosocial and spiritual aspects of care.

Dr Sara Davison (Ottawa Hospital and the University of Ottawa): In your experience, how receptive are nephrologists to the concept of initiating palliative care concurrently with the initiation of hemodialysis in elderly patients with significant comorbidity? I think it is very impor-

tant, but my experience has been that physicians are reluctant to discuss palliative care issues even in this patient group.

Dr Moss: I agree with you. The principles of palliative medicine have not been routinely incorporated into the practice of nephrology. This failure is due in part to a lack of education about a palliative care approach to the ESRD patient. The American Medical Association’s Education for Physicians on End-of-Life Care (EPEC) is an excellent program to teach physicians how to provide palliative care. The ESRD Working Group of the Robert Wood Johnson Foundation’s program, “Promoting Excellence in End-of-Life Care,” is modifying the EPEC curriculum for specific use by nephrologists. However, even before the education can occur, the attitudes of nephrologists need to change to recognize that palliative care is important to patients and therefore something they need to learn how to provide. I believe nephrologists’ attitudes will change as the culture in the United States and Canada continues to place more of an emphasis on the quality of the dying experience.

Dr Levine: Dr Moss, could you please clarify for us one aspect of recommendation # 7 in the publication relating to the special group of patients who have a terminal illness from a nonrenal cause and who are not expected to survive more than 6 months? The guideline says it is reasonable not to initiate dialysis. Firstly, is the implication that the nephrologist might not even speak with the patient or surrogate about the rationale for withholding dialysis? Secondly, it seems to me that this is somewhat contrary to the spirit of entering into a partnership with a patient and sharing the patient’s values. Certainly, there is a palliative care aspect of good dialysis in these remaining months for some patients.

Dr Moss: Good question. If you look at the wording for the RPA/ASN guideline recommendation #6 about withholding and withdrawing life-sustaining treatment, it says, “It is appropriate to withhold or withdrawal dialysis. . .” and then specifies 4 situations. For the patients with terminal disease from a nonrenal cause, the RPA/ASN guideline recommendation #7 states, “It is reasonable to consider not initiating or withdrawing dialysis. . .” The Working Group made a much less strong recommendation there than it

did with regard to withholding and withdrawing life-sustaining treatment. So, if the patient has a terminal illness, is not doing well, and is experiencing significant pain and suffering, the nephrologist could make a strong argument not to start dialysis. However, you are right that the spirit of the guideline is shared decision-making. So, after all options are thoroughly discussed, if the patient says, "I really want to undergo dialysis," and the renal care team thinks dialysis is possible, then dialysis should be started. Careful and thorough advance care planning is even more necessary in these cases. It will be important to know under what circumstances the patient would want to stop dialysis or not to undergo other life support interventions. The guideline does not foreclose the possibility of a patient with metastatic disease requesting and receiving dialysis for a few months until some life goal is achieved.

REFERENCES

1. United States Congress: Public Law No. 92-603, § 299I, October 30, 1972
2. Neu S, Kjellstrand CM: Stopping long-term dialysis: An empirical study of withdrawal of life-supporting treatment. *N Engl J Med* 314:14-20, 1986
3. Cassel CK, Moss AH, Rettig RA, Lewinsky NG: Ethical issues, in Rettig RA, Lewinsky NG (eds): *Kidney Failure and the Federal Government*. Washington, DC, National Academy Press, 1991, pp 51-61
4. Renal Physicians Association and American Society of Nephrology: *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. Clinical Practice Guideline Number 2. Rockville, MD, RPA, 2000
5. Renal Physicians Association, American Society of Nephrology: *RPA/ASN Position on Quality Care at the End of Life*. Adopted April 14, 1997.
6. Neely KJ, Roxel DM: Palliative care/hospice and the withdrawal of dialysis. *J Pall Med* 3:57-67, 2000
7. Cohen LM, Germain M, Poppel DM, Woods A, Kjellstrand CM: Dialysis discontinuation and palliative care. *Am J Kidney Dis* 36:140-144, 2000
8. DeValasco R, Dinwiddie L: Management of the patient with ESRD after withdrawal from dialysis. *ANNA J* 25:611-614, 1998
9. Sekkarie MA, Moss AH: Withholding and withdrawing dialysis: The role of physician specialty and education and patient functional status. *Am J Kidney Dis* 31:464-472, 1998
10. Lo B, Quill T, Tulsy J: Discussing palliative care with patients. *Ann Intern Med* 130:744-749, 1999
11. Holley JL, Finucane TE, Moss AH: Dialysis patients' attitudes about cardiopulmonary resuscitation and stopping dialysis. *Am J Nephrol* 9:245-251, 1989
12. Hines SC, Moss AH, Badzek L: Being involved or just being informed: Communication preferences of seriously ill, older adults. *Communication Quarterly* 45:268-281, 1997
13. Nease RF Jr, Brooks WB: Patient desire for information and decision making in health care decisions: The Autonomy Preference Index and the Health Opinion Survey. *J Gen Intern Med* 10:593-600, 1995
14. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, Bilodeau B, Watson P, Mueller B: Information needs and decisional preferences in woman with breast cancer *JAMA* 277:1485-1492, 1997
15. Kjellstrand CM: Who should decide about your death? *JAMA* 267:103-104, 1992