

# Ethical Principles and Processes Guiding Dialysis Decision-Making

Alvin H. Moss

## Summary

When the US Congress created the End-Stage Renal Disease (ESRD) Program in 1972, it gave physicians the responsibility of determining which patients were “appropriate” for dialysis. Congress provided no guidance on who should be selected or how. Only five years later, Dr. Belding Scribner, the father of chronic dialysis, noted that there was a need for a “deselection committee” because virtually all criteria for dialysis patient selection had been slackened, if not abandoned. In 1991, the Institute of Medicine Committee to Study the Medicare ESRD Program recommended the development of a clinical practice guideline because they noted there were “an increasing number of [dialysis] patients with limited survival possibilities and relatively poor quality of life.” In 2000, the Renal Physicians Association and the American Society of Nephrology heeded the Institute of Medicine committee’s recommendation and published *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*. In 2010, prompted by a substantial body of new research evidence, the Renal Physicians Association published a second edition of this clinical practice guideline. This article describes the application of the ethical principles of respect for patient autonomy, beneficence, non-maleficence, justice, and professional integrity, and the ethical process of shared decision-making in making decisions about starting, withholding, continuing, and stopping dialysis with patients and families. It urges examination of medical indications and identifies appropriate limits to shared decision-making when the burdens of dialysis can be predicted to substantially outweigh the benefits.

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## Introduction

When the US Congress established the Medicare End-Stage Renal Disease (ESRD) Program in 1972, it created a major ethical problem—determining which patients are appropriate for dialysis. Two relatively recent cases (1,2) demonstrate the problem still continues to challenge the dialysis community and society. In the two cases, legal opinions conflicted because the nephrologists differed on whether dialysis was medically appropriate treatment for permanently unconscious patients. The second case, in particular, illustrates the difficulty that can occur if nephrologists are not aware of the dialysis clinical practice guideline (3) that reports the ethical consensus in this country that patients with permanent profound neurologic impairment are not appropriate for dialysis. The objectives of this paper are to (1) demonstrate the ethical framework of shared decision-making for reaching decisions about the appropriate use of dialysis in patients with poor prognoses, and (2) identify limits to this framework in particular cases. This paper will not address the ethics of dialysis for noncitizens and for disruptive and nonadherent patients. Papers on these topics have been previously published (4,5).

## Case 1: The Family Requests Continued Dialysis of a Comatose Patient

A middle-aged woman with ESRD from diabetic nephropathy was found unresponsive at home. Emer-

gency Medical Services was called and noted a blood sugar of zero. The patient was treated and hospitalized. Over the next 24 hours, the patient received intensive treatment but did not awaken. After a complete neurologic evaluation, she was diagnosed with coma from prolonged hypoglycemia. Despite communication of the poor prognosis, the daughter, the patient’s healthcare surrogate, continued to request dialysis. After 6 more weeks, the treating nephrologist did not think that dialysis should be continued because of the recommendation published in the February 2000 Renal Physicians Association (RPA) and American Society of Nephrology (ASN) clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, which stated it is appropriate to forgo dialysis in “patients with profound neurologic impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment” (3).

No other nephrologist in the hospital was willing to comply with the daughter’s request. In following the process for conflict resolution in the RPA and ASN guideline, the nephrologist contacted other nephrologists throughout the state. None were willing to accept the patient. The daughter was informed that the dialysis would be stopped because the patient remained in a coma. The daughter contacted an attorney, who sought a court order to force the hospital to continue dialysis. The judge ruled that the hospital

Section of Nephrology,  
West Virginia  
University School of  
Medicine, and Center  
for Health Ethics and  
Law, Robert C. Byrd  
Health Sciences Center,  
West Virginia  
University,  
Morgantown, West  
Virginia

**Correspondence:** Dr.  
Alvin H. Moss, Center  
for Health Ethics and  
Law, West Virginia  
University, PO Box  
9022, Morgantown,  
WV 26506-9022.  
Phone: 304-293-7618;  
Fax: 304-293-7442;  
E-mail: amoss@hsc.  
wvu.edu

“shall no longer be obligated or required to provide dialysis treatment” if, after 1 more week, the family could not find a nephrologist to provide dialysis. The judge was influenced in his ruling by (1) the RPA and ASN clinical practice guideline recommending against dialysis for a person in the patient’s condition, and (2) the fact that there was no other option for dialysis for the patient. At the end of the week, the hospital stopped dialysis, and the patient subsequently died.

### Case 2: Court-ordered Dialysis of a Patient in a Persistent Vegetative State

In January 2008, a 73-year-old man, Ruben Betancourt, developed anoxic encephalopathy after surgery. He was subsequently diagnosed to be in a persistent vegetative state and discharged. In July 2008, he was readmitted to Trinitas Regional Medical Center with a diagnosis of renal failure. At this point, he had been in a persistent vegetative state for over 6 months. The patient was also ventilator dependent and received nutrition via feeding tube. In the Superior Court of New Jersey decision of March 4, 2009, in regard to *Betancourt v. Trinitas Regional Medical Hospital*, Judge Malone wrote that the treating nephrologist, who was either unaware of the RPA and ASN guideline or else chose to ignore it, indicated that dialysis treatment was “appropriate” for Mr. Betancourt, who had ESRD. In apparent disagreement with the nephrologist, the hospital advised the Betancourt family that life support should be discontinued. The court granted the guardianship application of the patient’s daughter, Jacqueline Betancourt, and noted that the decision to continue or terminate life support, such as dialysis, is outside the role of the court. As a result, Trinitas Regional Medical Center remained under a previously issued court order to dialyze Mr. Betancourt. The patient lived for 10 months while on dialysis, in a persistent vegetative state, and for 7 of those months, the hospital was under a court order to provide dialysis. The patient died while still receiving dialysis in May 2009.

### The Professional Responsibility to Determine Patients Appropriate for Dialysis

The judge in the Betancourt case observed that it is not the role of the court to determine when dialysis is appropriate. When the US Congress created the ESRD program in 1972, it gave physicians the responsibility to determine which patients were “appropriate” for dialysis but did not define “appropriate” in the legislation. Hence, Congress provided no guidance to nephrologists on who should be selected for dialysis or how. By 1977, only 5 years after Congress passed the Social Security Amendments, which created the Medicare ESRD program, Dr. Belding Scribner, the father of chronic hemodialysis, noted that there was a need for a “deselection committee” because virtually all criteria for dialysis patient selection had been slackened, if not abandoned, and many ESRD patients who would not previously have been accepted as dialysis candidates were on treatment (6). A decade later, the first report of the U.S. Renal Data System documented the progressively greater acceptance rate of patients onto dialysis (7), and subsequent reports showed that the sharp rise in the number of dialysis patients could be explained, in part, by the inclu-

sion of patients who had poor prognoses (8). In less than a decade, a major ethical question for the dialysis community, “Who should be dialyzed?” had morphed into “Who should **not** be dialyzed?” (6,9).

In 1991, the Institute of Medicine Committee for the Study of the Medicare ESRD stated that the Medicare ESRD Program included “an increasing number of patients with limited survival possibilities and relatively poor quality of life” and noted the need for a clinical practice guideline “for evaluating patients for whom the burdens of renal replacement therapy may substantially outweigh the benefits” (10). Agreeing with Congress, the Institute of Medicine Medicare ESRD Committee wrote that nephrologists have a “professional responsibility to deal with the issues of initiation and termination of [dialysis] treatment.” Just a year earlier, another Institute of Medicine committee, the Committee on Clinical Practice Guidelines, had defined clinical practice guidelines as “systematically developed statements to assist practitioner and patient decisions about *appropriate* healthcare for specific clinical circumstances” (emphasis added) (11). The clinical practice guideline committee recognized that the concept of “appropriate” care was crucial to their definition and explicitly defined it as care in which the expected health benefits (increased life expectancy; better functional status; and reduced morbidity, pain, and anxiety) exceed the negative consequences by a sufficiently wide margin that the procedure is worth doing (11).

The RPA and ASN heeded the Institute of Medicine Medicare ESRD Program Committee’s recommendation and published the Shared Decision-Making guideline, whose goal was to provide clinicians, patients, and families with the most current evidence about the benefits and burdens of dialysis for patients with diverse conditions, and practical strategies to help clinicians implement the guideline recommendations for patients with acute kidney injury and ESRD. In 2010, prompted by a substantial body of new research evidence on dialysis decision-making and outcomes of dialysis in different patient populations, especially patients 75 years of age and older with multiple comorbid conditions, the RPA published a second edition of this guideline (12).

### Shared Decision-making as the Ethical Process for the Guideline

First recognized in 1982 by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research as the “ideal” model for patient-physician relationships, shared decision-making is the recommended model for dialysis decision-making because it addresses the ethical need to fully inform patients about the risks and benefits of treatments, as well as the need to ensure that patients’ values and preferences play a prominent role (13). The President’s Commission recognized boundaries or limits to the process, however, noting, “Informed consent does not mean that patients can insist upon anything they want.” Rather, the commission explained that patients only have a choice among medically accepted and available options that are believed to have a chance of promoting the patient’s welfare. The following year, the President’s Commission repeated the limitation it

had previously stated for shared decision-making. The commission observed that allowing patients the ethical and legal authority to exercise their negative right to abstain from some or all medical treatment does not grant them a positive right to particular treatments. The commission noted that the care provided by health care professionals is generally limited to professional standards and medically acceptable treatment options. The President's Commission also noted that there is no ethically relevant difference between not starting a life-sustaining treatment such as dialysis and stopping it. This position provides the ethical justification for time-limited trials of dialysis. If the benefit of a life-sustaining treatment is uncertain, the commission recommended starting a time-limited trial of the treatment and then stopping it if the anticipated benefit does not occur (14).

Aware of the President's Commission's work, the drafters of the Shared Decision-Making guideline recommended that shared decision-making be used to make dialysis decisions. Much like the President's Commission publications, the Shared Decision-Making guideline placed limits on the shared decision-making process. These limits were set to protect the rights of patients and the professional integrity of health care professionals. In the ethical framework of shared decision-making, the patient has the right to refuse dialysis even if the renal care team disagrees with the patient's decision and wants the patient to undergo dialysis. Similarly, the renal care team has the right to refuse to offer dialysis when the expected benefits do not justify the risks. Recognizing that there are circumstances in which patients and renal care teams might disagree about decisions to start, continue, or stop dialysis, this guideline provides recommendations for how to resolve such conflicts, including the use of time-limited trials and ethics consultation.

### Ethical Principles and the Process of Dialysis Decision-making

The recommendations of the second edition of the Shared Decision-Making guideline have been previously summarized (12). The domains and recommendations have been based on what has been described as the four-topic approach to ethical analysis: medical indications, patient preferences, quality of life, and contextual features (15). It provides a structured approach to identifying, analyzing, and resolving ethical issues in clinical medicine. **This approach uses the ethical principles of respect for patient autonomy, beneficence, nonmaleficence, justice, and professional integrity**, but realizes that these principles may conflict in individual cases and, therefore, "that clinicians need a straightforward method of sorting out the pertinent facts and values of any case into an orderly pattern that facilitates discussion and resolution of ethical problems."

Examining **medical indications** requires a consideration of the patient's diagnoses, overall medical condition, prognosis, and treatment options. Medical indications reflect the ethical principles of beneficence and nonmaleficence because the decisions based on medical indications must be guided by the ethical duty to benefit patients and do them no harm. Professional integrity requires physicians to

refrain from providing dialysis when it is not medically indicated, that is, the burdens of treatment substantially outweigh the benefits. In circumstances in which dialysis is not medically indicated, a patient or family preference to receive dialysis does not justify its provision.

A third case, in which dialysis is not medically indicated, can help to clarify this approach. The family of a 91-year-old woman residing in a nursing home with advanced dementia, ischemic cardiomyopathy, severe malnutrition (serum albumin is 2.1g/dl), poor functional status (she is nonambulatory and unable to sit independently), and stage 5 chronic kidney disease asks that an arteriovenous fistula be inserted and that she be started on dialysis when she becomes uremic. The family reports that their goal is for the patient to improve her functional status once she starts dialysis. Research data show that, for this patient, dialysis is very unlikely to confer a survival advantage (16), death is much more likely than survival to start dialysis (17), and the family's goal of improved functional status after initiation of dialysis is extremely unlikely to be achieved. In a study of 3702 nursing home residents starting dialysis, not one was reported to have improved functional status; at 1 year, 87% had died or declined in functional status and only 13% had maintained their predialysis functional status (18,19). If the patient were to live to start dialysis, her predicted 6-month survival is 12% and 12-month survival is essentially nil (20,21). Germain and colleagues have noted that a time-limited trial of dialysis is appropriate only if there is a reasonable chance it will provide a net benefit to the patient and achieve the patient's and/or family's goals (22). Because the body of medical evidence as applied to this patient indicates that (1) the burdens of dialysis strongly outweigh the benefits, and (2) the family's goal for dialysis is not achievable, the nephrologist should decline to refer the patient for arteriovenous fistula insertion and recommend active medical management without dialysis.

For all medically indicated treatment, the **preferences of the patient**, based on the patient's own values and personal assessment of benefits and burdens, are ethically relevant. In every clinical case, the following questions must be raised: What are the patient's goals? Has the patient been provided sufficient information? Does the patient comprehend? Is the patient consenting voluntarily? If the patient lacks decision-making capacity, nephrologists must ask, "Who has the authority to decide on behalf of this patient?" The patient preferences topic reflects the ethical principle of respect for autonomy because providers of care, family members, and others have an ethical duty to accept the decisions regarding medically indicated treatment made by patients with decision-making capacity, and, in the absence of capacity, to follow state law and formulate decisions with patients' appropriate legal agents that respect patients' wishes, or, if the wishes are unknown, patients' best interests. In practice, patients with decision-making capacity who request dialysis almost always receive it either on a time-limited trial, if the patient's prognosis is particularly poor, or on a chronic basis. The usual reason why dialysis is not provided to a patient who requests it is if the dialysis is not technically feasible. As long as dialysis is technically feasible (two of the



biggest barriers to feasibility are inability to maintain a dialysis access and profound hypotension), in most cases, dialysis *per se* is not futile. If dialysis can be performed, it is likely to improve survival in acute kidney injury and ESRD patients *if* their lives will not be limited by other comorbidities. Dialysis can be said to be physiologically futile, however, if the patient cannot tolerate the dialysis process or if dialysis will not prevent the patient's imminent death (23).

Any injury or illness threatens persons with actual or potential reduced **quality of life**, manifested in the signs and symptoms of their disease. The object of all medical intervention is to restore, maintain, or improve quality of life. The patient is the best judge of his/her quality of life, and his/her view should be respected. This topic is based on the ethical principle of beneficence and respect for autonomy.

Physicians undertake the care of patients with the intent and the duty to make all reasonable efforts to help them. The topics of medical indications, patient preferences, and quality of life bring out these essential features of the case. Yet every medical case is embedded in a larger context of persons, institutions, and financial and social arrangements. Patient care is influenced, positively or negatively, by the possibilities and the constraints of that context. There are psychologic, financial, legal, scientific, educational, and spiritual **contextual features**. They may be crucially important to the understanding and resolution of the case. The topic of contextual features allows consideration of the ethical principle of justice, that is, attention to the effect on the welfare of parties other than the patient and the equitable distribution of burdens or benefits arising from treatment decisions among the parties and within institutions.

As in the three cases presented in this paper, conflict about whether dialysis should be provided most often occurs regarding patients who lack decision-making capacity. The Shared Decision-Making guideline recommends against dialysis in certain well defined situations. Chief among them is when patients have irreversible, profound neurologic impairment so that they are permanently unable to relate purposefully to others. This recommendation is consistent with observations of the Institute of Medicine Medicare ESRD Program Committee that prolongation of life with dialysis may not always be a benefit that outweighs all burdens and that virtually all nephrologists agree that dialysis treatment is not always the best choice for every ESRD patient (10). The Institute of Medicine committee cited theologians who noted that death is part of the human condition and that attempts to forestall death with life-sustaining technology may result in "grotesque and fragmented existences" without any potential for human interaction (24,25).

## Conclusion

Using well established ethical principles and processes, the ethical framework of shared decision-making assists nephrologists to reach agreement on a major ethical question of the ESRD program: "Who should be dialyzed?" The recommendations are far-reaching and potentially establish a model for other life-sustaining technologies. Commentators have remarked that answering this question requires an understanding of our common humanity.

## Disclosures

None.

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