

Ethics and Health Policy of Dialyzing a Patient in a Persistent Vegetative State

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Summary

Each year, out-of-hospital cardiac arrests occur in approximately 300,000 Americans. Of these patients, less than 10% survive. Survivors often live with neurologic impairments that neurologists classify as anoxic-ischemic encephalopathy (AIE). Neurologic impairments under AIE can vary widely, each with unique outcomes. According to the American Academy of Neurology Practice Parameter paper, the definition of poor outcome in AIE includes death, persistent vegetative state (PVS), or severe disability requiring full nursing care 6 months after event. In a recent survey, participants deemed an outcome of PVS as “worse than dead.” Lay persons’ assessments of quality of life for those in a PVS provide assistance for surrogate decision-makers who are confronted with the clinical decision-making for a loved one in a PVS, whereas clinical practice guidelines help health care providers to make decisions with patients and/or families. In 2000, the Renal Physicians Association and the American Society of Nephrology published a clinical practice guideline, “Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis.” In 2010, after advances in research, a second edition of the guideline was published. The updated guideline confirmed the recommendation to withhold or withdraw ongoing dialysis in “patients with irreversible, profound neurological impairments such that they lack signs of thought, sensation, purposeful behavior and awareness of self and environment,” such as found in patients with PVS. Here, the authors discuss the applicability of this guideline to patients in a PVS. In addition, they build on the guideline’s conception of shared decision-making and discuss how continued dialysis violates ethical and legal principles of care in patients in a PVS.

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Case

Mr. A. is a 73-year-old man with multiple comorbid conditions. After a recent hospitalization for unknown causes and inpatient rehabilitation, he sustains a cardiac arrest at home in the presence of family. Paramedics intubate Mr. A. and perform cardiopulmonary resuscitation while en route to a nearby community hospital. At the hospital, his providers find him in cardiopulmonary arrest from ventricular fibrillation secondary to a myocardial infarction. Resuscitative efforts require 45 minutes to adequately restore circulation. A left heart catheterization with percutaneous intervention to an occluded coronary artery is performed. Anuric renal failure occurs from acute tubular necrosis soon after and dialysis is initiated. He also has complications of postanoxic encephalopathic seizures, lower gastrointestinal bleeding, and laboratory values consistent with shock-liver. He remains intubated without sedation. At both 24 and 72 hours—off sedation—the patient lacks corneal reflexes and has only extensor motor responses to pain. The neurology consultants diagnose him with severe anoxic brain injury and state in the medical record that the patient has a “poor prognosis.”

Two weeks after arrest, the patient is transferred from the initial hospital to a second hospital at the family’s request. At the new hospital, the pulmonary and critical care team consults the neurology, renal, and palliative care teams to discuss the patient’s care plan. Dialysis and ventilator support are continued. The primary team schedules a family meeting for the next day with palliative care, patient

advocacy, social services, and the patient’s wife and two grown children. The meeting centers on discussing the patient as a person, and the medical providers learn that Mr. A. was an incredibly active and personable individual. Mr. A.’s family asks the medical team to continue “everything” but offers conflicting patient values, stating, “The patient would not wish to live this way [in a vegetative state].” Over the course of the patient’s hospital stay, five family meetings occur. The family members feel that they should not make resuscitation decisions. Although the patient “would not want to live this way,” they feel they could not be the ones to “withdraw” technology. The primary team therefore makes the strong medical recommendation that the patient have an order on the chart of do not resuscitate (DNR) and do not reintubate (DNI) after extubation. The medical team informs the family that they wrote an order of DNR/DNI based on the patient’s values and allowed the family to express any objections. The family vocalizes no objections.

The medical team extubates the patient on the basis of medical criteria; he continues to breathe on his own. Intermittent dialysis is continued. A new nephrologist takes over care of the patient. The patient has been in a vegetative state for 30 days, and the neurology service diagnoses the patient as being in a “persistent vegetative state” (PVS). The primary team removes his temporary dialysis catheter because of concern for a bloodstream infection. At this point in his care, the nephrologist discusses the shared decision-making guideline of “withholding or withdrawing dialysis from a

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person who is not neurologically intact." The family finds it difficult to see dialysis as life support similar to ventilators. The attending nephrologist suggests that it is unethical to continue dialysis in a patient in PVS based on the shared decision-making guideline and discusses this in the context of beneficence and nonmaleficence.

In the face of initial objections by some family members to the notion of stopping dialysis unless the medical team declares the patient dead, the nephrologist agrees to place another dialysis catheter and perform dialysis only if it is a time-limited trial. Before the beginning of the time-limited trial for dialysis, the patient becomes bradycardic and then asystolic after a limited period of worsening pulmonary function, possibly from aspiration. The family is calm and at peace when they arrive to see the patient dead.

Introduction

In 2000, the Renal Physicians Association and the American Society of Nephrology published a clinical practice guideline, "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis," to help nephrologists, patients, and families make decisions concerning initiating and withdrawing dialysis (1). The guideline was updated in 2010 (2) incorporating new research on the benefits and burdens of dialysis in patients with specific comorbid conditions; better decision-making quality in patients with AKI, CKD, and ESRD; and practical strategies for nephrologists to implement the guideline (3). Not all nephrologists are aware of the shared decision-making guideline, and of those who are aware, about half use it to help guide clinical decision-making (4). The 2010 guideline provides recommendations for patients with irreversible, profound neurologic impairment, terminal illness, medical conditions that preclude the technical process of dialysis (*i.e.*, advanced dementia or profound hypotension), and age >75 years with specific comorbid conditions and functional decline that would likely lead patients to have no survival benefit from dialysis. The ethical principles of beneficence and nonmaleficence support these recommendations because in certain situations dialysis does not offer a reasonable expectation of net clinical benefit. We discuss how the patient in this case met the criteria to forgo dialysis in patients with "irreversible, profound neurologic impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment," as described in the shared decision-making guideline. Furthermore, we discuss how the process of shared decision-making uniquely applies in this case. Finally, we address how inconsistency in the use of the shared decision-making guideline creates ethical tension between health care providers and between health care providers and families and results in unclear standards of care.

Background

The American Academy of Neurology practice parameter paper defines poor neurologic outcome after cardiac arrest as "death, persistent unconsciousness or vegetative state, or severe disability requiring full nursing care after 6 months" (5). This paper is particularly concerned with one poor outcome, namely the vegetative state, and how it influences the decision to perform or continue dialysis. The Glasgow Outcomes Scale defines vegetative state as a condition in which the patient is "awake but not aware; does

not interact in any cognitive way with the environment; does not fixate or follow with eyes . . ." (5). PVS cannot be diagnosed unless the patient is in a vegetative state for >1 month (6,7).

The predictors of poor neurologic outcome include myoclonic status epilepticus on day 1 after arrest; absence of specific somatosensory evoked nerve potentials within 3 days of the arrest; elevation in a blood marker, serum neuron-specific enolase, to >33 $\mu\text{g/L}$ within 3 days of the arrest; or absence of pupillary or corneal reflexes or motor responses other than extensor within first 3 days after arrest. To avoid withdrawal of life support in patients who have a plausible chance of recovery, these predictors should have a near-zero rate of false-positives for determining poor prognosis, which they do (false-positive rates of 0%–0.7%) (8). For an accurate neurologic examination to be performed, a patient's electrolytes and metabolic profile should be near normal; therefore, the use of dialysis may be necessary in some cases involving AKI, and then reassessment of continuation of dialysis should be completed. Late recovery after traumatic, anoxic, or hemorrhagic long-lasting vegetative state is significantly associated with younger age and is more frequent in traumatic brain injury than in anoxic or hemorrhagic brain injury (9,10).

Although the data regarding cardiopulmonary resuscitation and neurologic outcomes are better understood, what has not, until recently, been studied is whether the public ascribes different importance to the types of "life" of those in altered states of cognition. Gray *et al.* did three experiments with 201 participants of diverse backgrounds and found that laypeople consider PVS "more dead than dead" and that "early death was better than being in PVS." They found that higher religiosity correlated with a stronger belief that a PVS is more dead than dead (11). A likely explanation for this is the belief in the afterlife. The stronger a patient's belief in religion, the more strongly the patient believes that "life" will continue after he or she dies in this world but not if left in a PVS. While Mr. A.'s family never explicitly informed us of his beliefs in afterlife, it is reasonable to consider that a continued life in a PVS would be a "life worse than death," based on the family's information that their loved one "would not want to live this way."

Moving Shared Decision-Making Forward in Dialysis Care

Mr. A. never completed an advance directive or participated in any type of advance care planning with his primary care provider. The shared decision-making guideline suggests that nephrologists should participate in shared decision-making and advance care planning with their patients in earlier stages of the disease process. As data suggest, advance care planning across the country often does not occur (12). Although up to 35% of patients with CKD have an advance directive (13), advance care planning on a broader scale is becoming more important (14).

Mr. A.'s inability to complete a written advance directive does not alter the standards that his health care provider must hold his surrogates to when making decisions on his behalf. Those standards include the patient's previously expressed wishes, substituted judgment, and best interest. The first standard favors the patient's voice and

Table 1. Situations in which it is ethically appropriate to withhold or withdraw dialysis

- Patients with decision-making capacity who, being fully informed and making voluntary choices, refuse dialysis or request that dialysis therapy be discontinued
- Patients who no longer possess decision-making capacity who previously have indicated refusal of dialysis therapy in an oral or written advance directive
- Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis therapy or request that it be discontinued
- Patients with irreversible profound neurologic impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment

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asks whether the patient left any explicit wishes or preferences for the surrogate or treatment team. When these instructions are unavailable, the health care providers in conjunction with the surrogate decision-maker should ensure that decision-making follows the substituted judgment standard. This requires that surrogates make inferences from patients' past behaviors, goals, and values to the current decision. When neither of the above is available, the surrogate should make decisions that promote the patient's best interest, decisions that "promote and protect the patient's health-related and other interests" (15).

Surrogates often have a difficult time adhering to the patient's previously expressed wishes. For example, Kuehlmeier *et al.* found that the majority of surrogates overrode PVS patients' known wishes of "not wanting to live this way" (16). The surrogates provided three primary reasons: the caregiver's expectation that the patient might improve, the caregiver's definition of what constitutes a life-sustaining treatment (*i.e.*, artificial nutrition versus artificial respiration or, in this case, dialysis versus artificial respiration), and a sense of moral obligation not to harm the patient or cause suffering. All three of the above reasons were present in the family of Mr. A.

In Mr. A.'s case, a substituted judgment was possible with the course of action suggested by the medical team. As Kon points out, decision-making is a continuum with "patient- or agent-driven decision making [at one end], with physician-driven decision making . . . [at the other]. In the middle there are many possible approaches" (17). The shared decision-making guideline involves situations across this spectrum also. In informed nondissent shared decision-making, "the physician, guided by the patient's values, determines the best course of action and fully informs the patient [or surrogate decision-maker]. The patient [or decision-maker] may either remain silent, thereby allowing the physician's decision to stand, or veto the decision" (17). Therefore, in the case of the DNR/DNI order for Mr. A., it was apparent that an informed nondissent method was what the patient's surrogates sought.

This is different in the case of dialysis in an elderly patient who is in a PVS from nontraumatic brain injury because the intervention is not clinically indicated and practice parameters exist. The decision-making in this case is primarily physician-driven instead. Education of family members regarding the goals of dialysis is of paramount importance. The immediate goal of dialysis is to help in accurate neurologic prognosis, and the long-term goal of dialysis—to allow for

patient interaction with the world—is key for surrogate understanding of medical decision-making. This then translates into a time-limited trial if the goal is for interaction with the world and prognosis for return to this type of interaction is unlikely and becomes less likely with time. Thus, in the case of Mr. A., the nephrologist stated to the family that it is not appropriate to continue indefinite dialysis on a patient in a PVS as stated in the shared decision-making guideline, and he agreed to further dialysis only if a time-limited trial were established with discontinuation at the end of the trial if Mr. A. remained in a PVS.

Withholding and Withdrawing Dialysis in Severely Neurologically Injured Patients

Recommendation 5 of the shared decision-making guideline states that it is ethically appropriate to forgo dialysis in "patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment" (see Table 1) (2). In the setting of PVS despite dialysis, no benefit can be ascribed to dialysis continuation, only burdens. In a patient who "would not want to live this way [PVS]", dialysis would not improve the neurologic outcome further. When a new nephrologist took over care following diagnosis of a PVS, it was appropriate to then insist on a time-limited trial rather than indefinite continuation of dialysis. As shared decision-making recommendations 8 and 9 clarify, time-limited trials are initiated with the understanding that dialysis will be withdrawn at the end of the trial if clinical improvement does not occur (2). In this case, if the patient's neurologic status did not recover from PVS, dialysis would be withdrawn. Upon starting a time-limited trial, the patient, family, and all health care providers must be clear on the goals of treatment, assessment of outcomes, and duration of trial (18).

Choice itself can be misleading when physicians give options to patients and their family members that are not real options. Blinderman *et al.* suggest that when physicians offer resuscitation in a patient in a PVS, they are inadvertently offering a procedure that the health care team knows is ineffective at improving the state the patient is already in (19,20). The family clearly stated that the patient "would not wish to live this way" but also, in multiple meetings, state that they should not have to be the ones to make "these decisions" for their loved one because it means "choosing death." The intensive care

unit team, after obtaining a thorough history through a series of family meetings about the type of person the patient was and his values before arrest, realize that the family is asking for less choice.

Furthermore, the idea that to obtain consent from a patient or family a health care provider must offer *all* treatment options available to patient or family is absurd. Providers only need to offer medically indicated options. As others have pointed out, this understanding of informed consent creates a “false choice” for patients or families and can be deceptive (21,22). Under these situations, providers ask patients or families to reject or accept interventions that are not medically reasonable (*i.e.*, options that fail to offer a realistic expectation of net clinical benefit to the patient) (23,24). The medical team taking care of Mr. A. has a professional responsibility to exercise clinical judgment—as provided by the shared decision-making guideline—to guide his family in decision-making that makes clinical sense and does not present them with choices that are not real choices. The family was overwhelmed and asking for guidance. They stated that their loved one “did not wish to live this way.” Although the shared decision-making guideline is not a mandate, it helps validate the medical team’s decision to set a time-limited trial for dialysis.

Inconsistent Care Violates Ethical and Legal Principles

Although it is important to know that the shared decision-making guideline provides a tool for conflict resolution in situations such as those of Mr. A. and the ethical appropriateness of withholding/withdrawing dialysis, what actually happens in real practice creates a unique setting of care. Sixty-one percent of nephrologists are aware of the guideline, and half of those who are aware of the practice guideline use it to help them make clinical decisions (4). A lack of knowledge or understanding of the ethics behind health care guidelines is prime for producing a practice pattern that not only creates confusion for the family on what the recommendation from the medical team is but also leads to a confusing standard of medical care for the community.

Two recent court cases show this confusing standard of care. The shared decision-making guideline is expert opinion that stands up in a court of law as standard of care when appropriately used. The standard of care is determined by the standard that would be exercised by the reasonably prudent medical professional (25). In a West Virginia case, a surrogate wished to continue dialysis in a patient in PVS (26). A nephrologist followed the shared decision-making guideline regarding discontinuation of dialysis in this patient and cited doing so. All other nephrologists in the hospital concurred with the decision. Therefore, they were considered to be following the standard of care for their medical practice. They also followed due diligence to find another nephrologist who would practice differently in line with surrogate wishes. No accepting nephrologist was found in the state, which furthered the case that there was no nephrologist available who practiced outside of the shared decision-making guideline. This strengthened the case for standard of care, and the court ruled in favor of discontinuation of dialysis.

In the second instance, the Betancourt case, the nephrologist was either unaware or ignored the shared decision-making

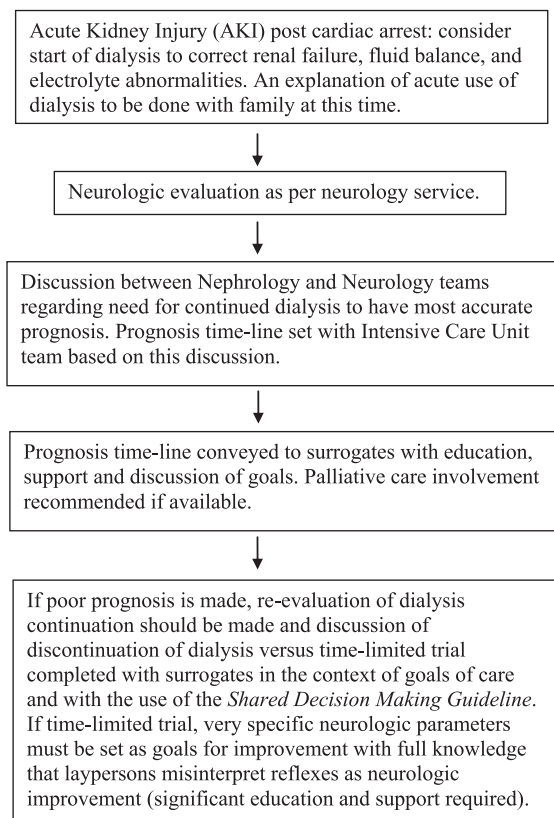


Figure 1. | Flow chart of decision-making regarding dialysis and poor neurologic prognosis, specifically vegetative states.

guideline and thus started and continued dialysis in a 73-year-old man who was in a PVS state for over 6 months in the hospital (27). When the hospital tried to discontinue dialysis and artificial life support, they did not cite the shared decision-making guideline or make an adequate argument regarding reasoning behind discontinuation of dialysis. Therefore, no case was made on standard of care and the court ruled in favor of the patient’s surrogate (28).

Thus, even if the shared decision-making guideline suggests a certain standard of care, what is being noted in the field and pointed out by Justice Perley is that “professional prudence is defined by actual or accepted practice within a profession, rather than theories about what ‘should’ have been done” (29). While physicians may decide that medical interventions are no longer clinically indicated (*e.g.*, dialysis in the setting of a noncognitive patient), many of the providers still continue dialysis. As Thaddeus Pope has rightly pointed out, in “the medical futility context, this is a problem. . . . Since, legally speaking, actions speak louder than words, clinicians are creating the very standard of care that they do not want to comply with” (30). Physicians can still find resolution in these complex cases. Practicing physicians who are often providers of end-of-life care need to be consistent in what they offer. Justice requires it. To accomplish this goal, developing hospital protocols that respond to patients in PVS who have renal failure will go a long way toward resolution. Ultimately, in cases like that of Mr. A., the best solution is a preventive one.

Conclusion

Mr. A. had a high mortality index at onset of cardiac arrest and his neurologic prognosis was poor. After a month of being in a vegetative state, the chances of his having a life that the family deemed acceptable for and by the patient based on his previous life was unlikely. There was an enormous sense of loss of a vibrant patriarch by the family. Although the false-positive rates for the neurologic prognostic factors used was near zero (8), the family and the medical team still had extremely difficult emotional discussions. Of utmost importance was the surrogates' understanding of their loved one's values that he "would not want to live this way." In this case, informed nondissent was useful for DNR/DNI orders for Mr. A. but not appropriate for withdrawal of dialysis. The shared decision-making guideline created consensus practice parameters that guide physicians in appropriate care of patients in PVS. Education of surrogates on the reason dialysis is no longer appropriate in a patient in PVS followed by conflict resolution using a time-limited trial with set goals is appropriate. Lack of knowledge of the shared decision-making guideline by nephrologists creates variability in practice, which, in turn, leads to injustices in care. To prevent family and caregiver turmoil in future similar cases, it is appropriate and recommended that hospital-based protocols for patients with renal failure in a PVS be implemented on the basis of the shared decision-making guideline (Figure 1).

Disclosures

J.L. received speakers fees from Asercare (a hospice company) and CEU Concepts (a continuing education company). S.G. reports consultant services for Bondurant Mixson & Elmore LLP in 2012 and <4% share in two Davita dialysis units.

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