Stopping Dialysis of an Incompetent Patient Over the Family's Objection: Is It Ever Ethical and Legal?1

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ABSTRACT

Decisions to stop dialysis or other life-sustaining treatments for incompetent patients are among the most difficult ethical problems faced by physicians and families. This observation is verified by the large number of court cases (1)—some of which involve dialysis (2)—and the increasing frequency of ethics consultations concerning these decisions (3,4). Theoretically, decision making in these cases should be straightforward. If the patient has provided an oral or written advance directive, the expressed wishes of the patient are to be followed to respect the patient’s right to self-determination (5). For patients who had not provided an advance directive, a surrogate decision maker is to be selected as stipulated by state law (6) or medical tradition. Decisions are then to be made with this surrogate on the basis of what the patient would choose if competent to do so (substituted judgment) or, if the patient’s views about treatment are unknown, the patient’s best interests (4).

When physicians look to family members as surrogate decision makers, they do so on the presumption that the family best represents the patient’s interests. This presumption may not always be correct. We present a case in which the family’s request for dialysis was contrary to the patient’s known wishes and to the treating physician’s assessment of the patient’s best interests. In this case, the nephrologist overrode the family request and ended dialysis treatment. This case illustrates that there are limits to family authority as surrogate decision makers and instructs us that nephrologists, as advocates for the patient, may sometimes be obliged to challenge and at times even override family requests for dialysis.

CASE REPORT

A 68-yr-old woman was taken to the emergency room of a university hospital by her daughter, her only living relative. The woman had progressive weakness and lethargy for several days. Her past medical history was significant for a previous myocardial infarction and numerous chronic illnesses, including Type II diabetes mellitus, atrial fibrillation, congestive heart failure, peripheral vascular disease, chronic obstructive pulmonary disease necessitating home oxygen therapy, diabetic glomerulosclerosis (serum creatinine on admission was 240 μmol/L), and

Key Words: Advance directives, dialysis decisions, legal liability, ethics committees, surrogate decision making

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1046-6673/0411-1879$03.00/0
Journal of the American Society of Nephrology
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Journal of the American Society of Nephrology
1879
severe aortic stenosis. On several occasions, she had refused aortic valve replacement surgery and other medical interventions. More significantly, during those clinic visits, she had indicated to both her family physician and to her daughter that she would not want to be kept alive with life-sustaining measures.

In the emergency department, the patient was tachypneic, cyanotic, hemodynamically unstable, and barely conscious. At the daughter’s request—and without consultation with the patient’s primary-care physician—the woman was admitted to the medical intensive care unit for treatment of septic shock and pulmonary edema. The patient was intubated, and therapy with vasoressors and inotropic agents was begun. Broad-spectrum antibiotics were started, and two gangrenous, infected toes were amputated. With echocardiography, her ejection fraction was estimated to be 25% and her transaortic gradient was 80 to 90 mm/Hg. She was fed via a gastrostomy tube.

One week after admission, the patient was unable to follow commands or communicate but did respond to pain. Despite repeated attempts, she could not be weaned from the ventilator. During that time, she also developed acute oliguric renal failure superimposed on her chronic renal failure. Peritoneal dialysis was begun.

Three weeks after admission, there was no improvement in her neurologic status. She still required dialysis, mechanical ventilation, and tube feeding. A cardiologist judged the patient’s aortic stenosis to be too severe for amelioration by valvuloplasty. A cardiothoracic surgeon, believing she could not survive surgery, declined to operate.

After a month of intensive care, the medical team concluded that further intensive treatment would not offer the patient any reasonable prospects for recovery. They spoke to the daughter, recommended discontinuation of life-sustaining measures, and asked her for consent to change to a comfort care plan for her mother. The daughter refused.

The medical team was troubled by the daughter’s response and consulted the hospital ethics committee. The ethics committee conducted a series of meetings. At one of these, three close friends of the patient attended along with the daughter. These friends described the patient as “independent and feisty.” They stated that the patient had told them that she did not like doctors or hospitals and also noted that she had repeatedly expressed to them that she would not want to be kept alive by machines. The ethics committee contacted the patient’s family physician who confirmed the statements of the close friends about the patient’s wishes. Although the daughter did not deny that these were her mother’s views, she persisted in her unwillingness to agree to the physician’s recommendations. She said, “I do not want to give up on my mom. I’m not ready to lose her yet.” She also stated that she did not want to be responsible for determining the time of her mother’s death or for causing it in any way.

The ethics committee agreed that the ethically appropriate treatment for this dying patient was comfort care and concurred with the medical team’s recommendation to withdraw aggressive interventions, including mechanical ventilation and dialysis. Furthermore, it recommended counseling for the daughter. That counseling was undertaken by both social workers and the hospital chaplain. From the counseling, it was learned that the daughter was overwhelmed by her mother’s terminal condition. It was also learned that the mother-daughter relationship had been strained and that the daughter now felt guilty about the tensions that had marred their relationship. Further, the daughter lacked a social support system to help her through the wrenching ordeal of her mother’s dying. In fact, the very prospect of making treatment decisions for her mother that might hasten her mother’s death intensified her anguish.

The intensive care unit physicians negotiated an accord with the daughter in which the patient was to be transferred to a private room on a regular medical floor where mechanical ventilation, tube feeding, and peritoneal dialysis were to be continued. A new attending physician, who thought such measures were inappropriate, again raised the issue of their withdrawal. The daughter remained adamantly opposed. The physician then sought an opinion from hospital legal counsel who advised that stopping life-prolonging treatment against the daughter’s wishes might result in litigation. The physician, concerned about possible legal liability, continued mechanical ventilation and dialysis.

After several more weeks of treatment, the patient’s dialysis catheter became nonfunctional. Dialysis had to be stopped. Despite the daughter’s request, the nephrologist refused to replace the catheter. He offered her the option of having her mother’s treatment transferred to physicians at another hospital, but she declined the offer, saying that she doubted that other physicians would dialyze her mother if the present physicians would not. The patient died 10 days later with her daughter still unhappy about the nephrologist’s decision to terminate dialysis treatment but resigned to it. In the 12 months since her mother’s death, the daughter has not initiated legal action against the hospital or the physicians.

DISCUSSION

In cases in which the patient has not provided an advance directive, it is usual practice for physicians
to turn to the incompetent patient’s family for direction regarding decisions to start, continue, or withdraw life-sustaining treatment. Commenting on the Wanglie case, Angell wrote, “[This is] the most sensitive and workable approach” (7). Moreover, she noted, “...a system in which life-sustaining treatment is discontinued over the objections of those who love the patient, on a case-by-case basis, would be callous.” For Angell, the most important aspect of the dispute between the physicians and the family over the continuation of life-sustaining mechanical ventilation for the permanently unconscious 87 year-old Mrs. Wanglie was not what should be decided, but who should decide. Angell applauded the court’s resolution regarding decisions to start, continue, or withdraw life-sustaining treatment for the incompetent patient’s family has an intimate understanding of the patient’s medical attitudes and general world view and therefore is in the best position to know the motives and considerations that would control the patient’s medical decisions” (8).

Studies show that nephrologists follow this practice. They turn to families for treatment choices and honor those choices, even when they judge that such therapy is not appropriate. For example, in a survey of nephrologists, Singer et al. found that for an incompetent patient whose wishes were unknown, fewer than 1% of nephrologists (1 of 115) would follow their medical judgment and stop dialysis if the family disagreed with this action (9). In that study, 82% stated that they would continue dialysis in this situation; the other 18% said that they would exercise another option, such as seeking legal guidance, discussing the matter further with the family, or consulting an ethics committee. Another study found that 17% of 318 dialysis unit medical directors would, if requested, start dialysis on a permanently unconscious patient who develops renal failure (10). Those who would do so indicated that, although they also thought dialysis of permanently unconscious patients was inappropriate, they would provide it, if the family requested, because of fear of legal liability.

The ethical justification for honoring family decisions about dialysis is the belief that the family is most likely to know what the patient, if able to speak to the situation, would have wanted. The family, however, has no moral authority to make medical decisions for the patient independent of the patient’s wishes or best interests. As the President’s Commission for the Study of Ethical Problems in Medicine stated: “Decisions made by others on patients’ behalf should, when possible, attempt to replicate the ones patients would make if they were capable of doing so. When this is not feasible, decisions by surrogates on behalf of patients must protect the patients’ best interests” (11). A similar presumption underlies the legal basis for involving families in decision making for incompetent patients (12).

Studies have documented, however, that the decisions family members would make for the patient frequently fail to reflect the choices the patients themselves would make (13–15). Families, these studies show, consistently chose life-sustaining treatments for the patients more often than patients did. Given these findings, physicians ought not to indiscriminately comply with family decisions about dialysis or other life-sustaining treatments. Before doing so, they must assure themselves that the family fully understands the patient’s condition and that, given the situation, the family’s treatment requests are in agreement with the patient’s known wishes or best interests.

In the case presented here, the patient’s friends and family physician indicated that the patient would not have wanted life-sustaining treatment, an assertion that was not disputed by the patient’s daughter. By asking for treatment contrary to what her mother would have wanted, the daughter breached her fiduciary duty as a surrogate decision maker to replicate as closely as possible the choice her mother herself would have made. Therefore, she was no longer the best person to be making treatment decisions with the doctors for her mother.

Furthermore, the continuation of aggressive medical interventions such as mechanical ventilation and dialysis were not in the patient’s best interests. The patient’s intractable congestive heart failure from severe aortic stenosis could not be corrected. She was beyond any realistic expectation of recovery. Continuing medical interventions functioned not as therapies to reverse or ease her condition, but as means only to prolong her pain and suffering and postpone her dying. The attending physician and the nephrologist both thought it was inappropriate in such circumstances to continue this treatment. The daughter herself admitted that she would not want such measures if she were in her mother’s condition.

On what basis, then, should the physicians honor the daughter’s plea for continued ventilation and dialysis? These served, it seemed, only to assuage the daughter’s guilt by allowing her to believe that she was doing everything possible for her mother. Psychotherapy may be of value to a distraught family member, but subjecting a dying patient to mechanical ventilation and dialysis to alleviate the guilt of a grieving family member is not warranted. In Kant’s categorical imperative, the dignity of every human precludes an individual from being used as a means
to someone else's end (16). Mitigating the emotional distress of the daughter does not justify prolonging the mother's agony.

Despite hospital legal counsel's advice to continue whatever life-sustaining treatments the daughter wanted, when the peritoneal dialysis catheter became obstructed, the nephrologist refused to replace it and to reinstitute dialysis. In making this decision, he took the attorney's recommendation as well as those he had received from other physicians and the ethics consultants as factors to be weighed in determining what duty he owed to his patient. He was aware that hospital attorneys sometimes view their role as limited to lessening potential financial exposure of their clients—hospitals. Concern for and commitment to the best interests of the patient, in such instances, often receive only secondary attention (1). He also knew that courts that have examined the issue have found that there is no legal obligation for physicians to participate in medical treatment contrary to their conscience. As one of us has noted elsewhere (17), in Brophy v. New England Sinai Hospital, the Supreme Judicial Court of Massachusetts upheld the right of a hospital and its physicians to refuse to participate in an act that violated their ethical principles. The ruling said that there is nothing in the law "which would justify compelling medical professionals . . . to take active measures which are contrary to their view of their ethical duty toward their patients" (18).

Similarly, the Virginia Legislature recently enacted the Health Care Decisions Act, the pertinent part of which reads "Nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate" (19).

Further, in cases in which life-sustaining treatment not desired by the patient or judged not in the patient's best interests has been withdrawn from incompetent patients, the courts have consistently found that physicians participating in such cases have been free from civil or criminal sanctions (1). Weir and Gostin, commenting on these cases, note that "many, perhaps most, of these clinical cases ended up in court because the physicians were anxious about what the Quinlan court called "the brooding presence of . . . possible liability" "(1). Physician concern about that liability prompted Meisel to describe seven legal myths about terminating life-sustaining treatment, including three that are relevant to this case: (1) that anything that is not specifically permitted by law is prohibited; (2) that it is permissible to withhold treatment, but once started, it must be continued; and (3) that termination of life support requires going to court (20). He noted that physician ignorance or misinformation about the law is dangerous. Physicians who are unaware of the limits of their knowledge are likely, contrary to their own medical judgment, to continue treatments that are detrimental to their patients' welfare.

In this case, the treating nephrologist concluded that the patient's medical status had deteriorated to the point that further aggressive measures were not warranted. Much the same as the cardiologist and the cardiac surgeon had determined that, although it was technically possible to attempt valvuloplasty or valve replacement, neither action was medically justifiable, the nephrologist determined that inserting a new peritoneal dialysis catheter and restarting dialysis were not appropriate.

Although it is psychologically easier to refuse to replace an obstructed peritoneal dialysis catheter than to terminate ongoing dialysis, the same ethical and legal principles ground withholding and withdrawing a treatment (5, 21). With dialysis, as in any other therapy, two things are required to justify its use: (1) a physician's assessment that there is an expected benefit from the intervention and (2) the patient's consent (or known desire) for that benefit. In cases such as this, when both are absent—despite family demands for its use—continued dialysis is not ethically or legally required.

PROCEDURAL CONCERNS IN STOPPING DIALYSIS OVER THE FAMILY'S OBJECTION

Stopping dialysis over the objection of a patient's family is unsettling. It is hoped such decisions need not be made very often. When they must, the nephrologist should proceed in a thorough and careful manner. Such decisions should be made openly and focused clearly on the patient's wishes or best interests. At a minimum, they should only be reached after the following have occurred: extended conversation with the family; the agreement of other members of the dialysis team; the concurrence of an ethics committee (if available); a detailed note in the patient's medical record documenting all of the factors relevant to the decision; and an attempt to transfer the patient's care if the family wishes it.

In conversation with the family, it is often helpful to ask them why they request the treatment. The family response may help identify a misunderstanding about the patient's diagnosis or prognosis that can be resolved with further explanation. It also might reveal psychological or social problems that need to be addressed independent of treatment decisions for the patient.

In such cases, an ethics committee review of the case may help to clarify and resolve the issue. As demonstrated by this case, ethics committee consultation may assist physicians by bringing to light the patient's expressed treatment preferences and by
facilitating communication among those with involvement or interest in the patient’s care. Also, ethics committee consultation allows for nonadversarial exploration of the options available in the case. Moreover, if the ethics committee finds that the treating physician’s recommendation is within the range of acceptable options, the committee can serve to reassure the physician of the appropriateness of his or her decision.

If the case comes to the difficult point of the physician refusing a family’s request for dialysis, the family should be given the option of an attempt to transfer the patient to another physician’s care. This recommendation is grounded, not in ethics, but in the law. State laws require that physicians make a reasonable effort to transfer patients if they cannot, in good conscience, follow the wishes of the patient’s surrogate (19.22–24). Our experience has been that if one physician refuses to comply with a family’s request for aggressive treatment for a patient with a very poor prognosis, then all will, and transfer will not be possible.

CONCLUSION

If, after the completion of the procedure described above—conversation, consultation, documentation, and an unsuccessful attempt to transfer—the family persists in requesting dialysis that the patient would not have wanted, the nephrologist has an ethical obligation and a legal right to refuse the family’s request. In such cases, the nephrologist should indicate to the family that he or she understands what they want and explain, “I am sorry, but we don’t do that here.” As nephrologists, we say this not because we lack compassion or respect for the family; such an action, as in this case, relieves the family of the burden of the decision to stop dialysis. We say this because as physicians our primary responsibility is to the patient. This commitment is and remains to respect the patient’s wishes and to be of benefit and do no harm.

ACKNOWLEDGMENTS

The authors thank Sandra A. Price, J.D., Mark Siegler, M.D., and Bruce D. Weinstein, Ph.D., for their helpful suggestions regarding an earlier draft of this manuscript and Cynthia F. Jamison for secretarial assistance.

REFERENCES