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# A Patient (Not) Alone

*Lauren Sydney Flicker*

## ABSTRACT

This case analysis examines questions that arise when an ethically appropriate recommendation initially appears to be in conflict with the legally appropriate recommendation. The case involves a dying, incapacitated octogenarian who had friends who were willing to share her values, but not to make decisions on her behalf. These circumstances put the patient in the unique position of being legally considered a "patient alone," but who was ethically like a patient with surrogates—distinctions that are crucial when making end-of-life decisions under the New York Family Health Care Decisions Act. A strict interpretation of the law initially seemed to be in conflict with an ethically appropriate outcome. By gaining a deeper understanding of the patient from those who cared about her, however, and by considering a broader interpretation of the law, an outcome was reached that worked within the framework of the law and honored the patient's reported values.

## CASE DESCRIPTION

When the request for an ethics consult first came in, it did not appear to be a significantly compli-

cated case. A physician assistant (PA) from the Surgical Intensive Care Unit called to discuss Ms E, an 83-year-old woman who was suffering from an intracranial bleed, and who had been unconscious and on a ventilator in our hospital for more than a week. The next step, the PA reported, was a tracheostomy and a PEG tube (percutaneous endoscopic gastrostomy), and discharge to a nursing home. The PA shared that Ms E had lived alone in the community and had no known family; she did have close friends who were visiting and speaking with the clinical team, but neither friend was willing to act as surrogate decision maker.

As the ethics consultant on call, I spoke with the attending physician, and discussed ways of potentially mitigating the friends' concerns about serving as a decision maker, or, failing that, asking them to provide information about Ms E's values. The team was reminded to not pressure the friends into acting as decision makers, and to contact the medical director's office to act as decision maker for anything requiring explicit consent. Through multiple conversations with Ms E's friends, the team and I learned a great deal about Ms E. We learned that she hated being dependent on anyone; that she made friends easily and "adopted" as her surrogate granddaughters the younger women she met while volunteering. She enjoyed the company of her friends, but rejected their expressed desires to help her when they were concerned about her living alone as she

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grew older. Although her friends were religious and believed that withdrawal of ventilator support would be “killing” Ms E, they also believed that she would not have wanted to live in her current state on a ventilator, and that she never would have wanted to end up in a nursing home. While Ms E’s friends were generous with the information they shared, they were adamant about not serving as decision makers.

With the information about Ms E’s values, and a note in the chart from the neurologist who had seen Ms E, stating that she had a 97 percent probability of dying in the next 30 days, the clinical team felt that extubation was the most appropriate course of action. A roadblock to this clinical assessment was the New York State Family Health Care Decisions Act (FHCDA).<sup>1</sup> Signed into law in 2010, the FHCDA was created to enable family members or close friends to make decisions for patients who had lost decision-making capacity and who did not have an advance directive or healthcare proxy.<sup>2</sup> Among other things, the FHCDA provides procedural guidance for decision making for “patients alone,” and articulates standards for withdrawal or withholding of life-sustaining treatments for these patients. Technically, because she did not have anyone to act as a decision maker, Ms E was legally considered to be a patient alone. Under the FHCDA, discussed in detail below, the clinical standards for removing life-sustaining treatment from a patient alone are seemingly impossible to meet.

Nonetheless, I made a recommendation that, given what we learned about Ms E’s values, withdrawal of ventilator support was *ethically* appropriate if the clinical team felt that Ms E met clinical standards for withdrawal. What was not immediately apparent from a plain reading of the FHCDA, however, was that knowing a patient’s values could significantly impact how one interpreted the clinical standards under the FHCDA.

### LEGAL BACKGROUND

As a society, the United States has struggled for decades with the challenge of how to support a patient’s autonomy, even after that patient loses decision-making capacity. Living wills and healthcare proxies were created so that patients’ voices still could be brought into the room after they could no longer speak for themselves. Although living wills can be prone to misinterpretation, and healthcare agents may, at times, make choices that are contrary to a patient’s previously stated wishes, these two mechanisms have served to promote patients’ au-

tonomy, and to ease the moral distress of families and clinicians when they make choices for noncompetent patients. Most states have mechanisms concerning how to make decisions for patients who lack decision-making capacity and who have no living will or healthcare proxy;<sup>3</sup> these state statutes list a hierarchy of relatives (and sometimes friends) who can make some or all decisions for patients in the event that they lose capacity.<sup>4</sup> There is less uniformity concerning mechanisms that address patients who lack decision-making capacity and who lack potential surrogates. Guidance is sparser still for patients who do not fall neatly into any category—particularly patients like Ms E, who was not quite a patient alone, and not quite a patient with a surrogate.

New York State’s answer to the challenging questions of decision making for patients without capacity is the FHCDA.<sup>5</sup> As stated above, the FHCDA, signed into law in 2010, was created to enable family members or close friends to make decisions for patients who had lost decision-making capacity and who did not have an advance directive or healthcare proxy.<sup>6</sup> In addition to providing procedural guidance for decision making for patients alone, the FHCDA outlines a hierarchy of surrogates for patients who have friends and family who are willing to act as decision makers, and articulates standards for withdrawing or withholding life-sustaining treatments for patients with surrogates and for patients alone.

Per the FHCDA, if a patient has a surrogate, life-sustaining treatment may only be withdrawn or withheld if the treatment would be an “extraordinary burden” on the patient, and two physicians determine that the patient would die within six months with or without the treatment, *or* the treatment would be so painful or burdensome that it would “reasonably be deemed inhumane” *and* the patient has an “irreversible or incurable condition.”<sup>7</sup> This may appear, at first blush, to be a challenging standard to meet, but the FHCDA leaves substantial room for patients’ values to be honored, even if those values have not been explicitly written down in an advance directive. The “extraordinary burden” criterion can typically be met if surrogates can articulate what they believe the patient would want and they believe that it would violate the patient’s values to pursue treatment.

If a patient has no surrogate to act as decision maker, the bar for withholding or withdrawing treatment is substantially higher. For this group of patients, life-sustaining treatment may only be withdrawn or withheld via court order, or if two physi-

cians determine that the patient will die “imminently” with or without that treatment *and* “the provision of the treatment *would violate accepted medical standards*” (emphasis added).<sup>8</sup> The statute does not define “imminently.”

Under the strictest interpretation of this statute—these criteria, particularly the clause that life-sustaining treatment can only be withdrawn or withheld if the treatment “would violate accepted medical standards”—it is nearly impossible for clinicians to remove life-sustaining treatment from a patient alone. Even without the second clause, the guidelines in the statute remain both incredibly stringent and incredibly ambiguous. The word “imminently,” undefined in the statute, is so vague that different interpretations of the definition could yield wildly different results. The *Oxford English Dictionary* unhelpfully defines “imminent” as “of an event, etc. (almost always of evil or danger): Impending threateningly, hanging over one’s head; ready to befall or overtake one; close at hand in its incidence; coming on shortly.”<sup>9</sup> Some may interpret, “imminently dying” as hours or days, when others might interpret it as weeks or months, “although pervasive in the hospice and palliative care literature, ‘imminence’ of death is rarely defined.”<sup>10</sup> The definition chosen by institutional policy, or in the absence of such a policy, chosen by a physician’s own value set, could have drastic implications for how the FHCDA is interpreted.

The FHCDA sorts patients into categories based on who they have, or do not have, to serve as a decision maker. The law does not provide guidance for situations when a patient does not fit neatly into one category or the other. If a patient has friends or family who are willing to provide insight into that patient’s values, but who are unwilling to act as a decision maker, the patient cannot fit squarely into a FHCDA box. Ms E was a prime example of this. The unique factors surrounding Ms E—the presence of friends who were not willing to act as decision makers, but who knew her intimately and were able to provide significant information about her values and what they believed she would have wanted for herself—made her an ill fit with the FHCDA. She was not quite a patient with a surrogate decision maker, but she was not quite a patient alone. Ethically, she looked more like a patient with a surrogate, but in the strictest legal sense she was a patient alone. In order to be legally compliant, but to act ethically by honoring the patient’s reported wishes, the FHCDA could not have been interpreted in its strictest sense. For a patient like Ms E, two methods could have been utilized to find the bal-

ance between what was legally appropriate and what was ethically appropriate. The first would be to broadly interpret the word “imminently,” and the second would be to use the patient’s narrative to interpret what was and what was not a violation of accepted medical standards.

## THE ETHICS IN THE LAW

There are many clinical situations that are extralegal—circumstances when the law provides no guidance, and clinicians must instead seek guidance from hospital policy, professional association guidelines, or use their own judgment. It is rarer, although certainly not unheard of, for a statute or common law to directly apply to a clinical situation, but for the strictest interpretation of the law to be in conflict with what is ethically appropriate. These situations are challenging for all of the parties involved, but particularly for the ethicist, who is asked to give guidance on ethically appropriate options, but who must also acknowledge the law as a boundary to those options.

Ms E’s case seemed at first to be a prime example of a stark conflict between ethics and the law. Several factors indicated that withdrawal of life-sustaining treatment was the ethically appropriate choice. Even though Ms E’s friends believed that withdrawal of a ventilator was a moral wrong, they still clearly articulated that Ms E would not have wanted to be burdened by a ventilator or to have her death unnecessarily prolonged. Additionally, the judgment of the clinical team was that Ms E would never regain consciousness. Because her friends were unwilling to act as decision makers, Ms E was, in the strictest legal sense, a patient alone, and therefore her treatment needed to be held to the standards set forth by the FHCDA—standards that seemed to make withdrawal of life-sustaining treatment all but impossible for a patient alone.

The strictest legal interpretation is certainly not the *only* interpretation of a statute, and is often not the most appropriate interpretation of a law. The language of the FHCDA, or more specifically the language omitted from the FHCDA, indicates that the FHCDA is not intended to be interpreted in the strictest sense. Statutes are rife with definitions. Legislation at the state and federal level often includes a subsection for definitions to explicitly spell out how words should be interpreted, so that the law may be applied uniformly. The FHCDA has such a section. It defines commonly used words such as “adult,”<sup>11</sup> “attending physician,”<sup>12</sup> and “hospital,”<sup>13</sup> to ensure that these words will be consistently interpreted by

all who read and use the FHCDA. That the drafters of the FHCDA did not include the word “imminently” in the definitions section of the statute is a significant indicator that the legislators understood that there are multiple ways to define this word, and that perhaps it is not in a patient’s best interest to provide a strict definition. The statute, as it currently reads, not only invites, but requires, physicians to use their own clinical judgment. Perhaps, then, the FHCDA is not as stringent as it first seems. And perhaps the lack of definition of the word “imminently” is not frustratingly vague, but instead purposefully open to interpretation, to allow clinical judgment and to best serve the individual patient.

The factors surrounding Ms E’s case encouraged a broad interpretation of the word “imminently.” Physicians believed that she would die in hours or days without the ventilator, or in days, weeks, or (least likely) months with the ventilator. A strict interpretation of the requirement that a patient would “die imminently with or without treatment” might indicate that the patient would need to die in hours or days with or without the treatment.

Perhaps if we had known nothing about Ms E, about the woman that she was, the life that she had lived, and the independence she valued—perhaps if she had been truly a patient alone—we would have been inclined to apply that strict interpretation of “imminently.” But we did have this information about Ms E. Throughout her hospital stay, Ms E’s friends painted a picture of the woman she had been, and the choices they believed she would have made if she had been able to speak for herself. Her friends made it clear that “progressing” to a tracheotomy and PEG placement, with discharge to a nursing home, would not have been acceptable to her. The middle ground—keeping Ms E ventilated on the floor until she passed—would also have been contrary to Ms E’s values, as described by her friends.

Based on what her friends shared with us, it was unlikely that Ms E would have appreciated the few extra weeks she might have gained on the ventilator. All of the clinicians on the team agreed that she was a very sick woman, who was actively dying. These factors: the clinical picture, combined with the portrait painted by her friends, supported an interpretation of “imminently” that was less severe, and more in line with what all of the parties believed Ms E would have wanted.

Ms E’s case also suggested that the second clause concerning withdrawal of life-sustaining treatment from a patient alone—the clause stating that such treatment could be withdrawn from a patient alone only when the provision of the treatment would vio-

late medical standards—should not have been interpreted in the strictest possible sense. Stating that life-sustaining treatment may only be withdrawn if continuing treatment “would violate accepted medical standards” can certainly, at first blush, seem like a nearly impossible standard to meet, and a standard that could only be interpreted narrowly.

Yet there was a way to interpret this that left room to incorporate the patient’s narrative, if and when that patient’s narrative was known. It may not have violated accepted medical standards to have left a patient on a ventilator who was not clearly physically suffering, who was never expected to regain consciousness, and who was expected to die in weeks to months. It would be, however, a violation of medical, ethical, and legal standards to violate a patient’s autonomy by continuing to treat her against her wishes. Ms E did not have a written advance directive to give her a voice, nor was she able to tell us during her hospitalization that she would not want to be sustained by a ventilator or a tracheostomy.

A patient’s values don’t always come in a neat, legally recognizable package. Having a patient’s wishes explicitly stated in a legal document, or through the patient’s own voice, can reassure a clinical team that they are honoring the patient’s values, but advance directives are not always a clear roadmap to what a patient would want in a specific clinical instance. And sometimes, even without an advance directive or the patient’s voice, her or his values can be known and applied to the clinical circumstance. We will never know with 100 percent certainty that Ms E would have rejected being sustained by mechanical means. The independent statements of Ms E’s friends, however, who believed that withdrawal of life-sustaining treatment was murder, but that Ms E would have not wanted to be kept alive via mechanical ventilation, should have carried significant weight. This knowledge of Ms E’s values, of the woman she was, and the life she believed was worth living, were strong indicators that it would have violated her autonomy to continue treatment. Since violating a patient’s autonomy is against medical standards, continuing to provide life-sustaining treatment to a woman who would not have wanted it, even if that woman is technically a “patient alone,” would have been a violation of medical standards.

## RECOMMENDATIONS

In the chart, I recommended that, given the information we had about Ms E, that if Ms E’s friends

felt that her values were consistent with extubation, and her clinicians believed that she would die imminently with or without ventilator support, then it would be ethically permissible to seek administrative consent for extubation. The note further suggested that the clinical team continue to engage Ms E's friends to provide information about Ms E and her values, and that while the door should be left open for them to change their minds about acting as decision makers, they should not be pressured to do so.

### CONCLUSION

Ms E lived for a week post extubation. A priest friend, whom we had not been able to reach initially, arrived days after Ms E had been extubated and validated the team's action by verifying that extubation and comfort care were consistent with what Ms E would have wanted; that she never would have wanted to remain on the ventilator, and that she certainly would not have wanted a tracheotomy or a PEG, or to be discharged to a nursing home.

The FHCDA appears to be a strict law that prevents withdrawal of life-sustaining treatment from patients who have no surrogate decision maker.<sup>14</sup> Upon further analysis, however, the law is not as black and white as it may first appear. By not defining "imminently," the drafters of the FHCDA were arguably leaving room for clinical judgment, and for the narrative of each patient to play a role in clarifying what "imminently" might mean. The highest bar set by the FHCDA—stating that life-sustaining treatment can only be withdrawn from a patient alone if providing that treatment would be a violation of medical standards—is also less stringent than it first appears, but only when a patient's values are known. Knowing this information, and having an idea of who the patient is and what she or he would have deemed a good life, allows the clinical team to permit a patient to die in a manner than can be deemed consistent with the law.

Occasions arise when it may initially appear that following the letter of the law would require physicians to act in a way that may be ethically inappropriate. There are times when this conflict may be real and unavoidable. In many circumstances, however, particularly a circumstance such as this, knowing the patient's narrative, as well as considering what the law does *not* say, allow for a path that allows the clinical team to follow the law without abandoning the patient's values or what is ethically appropriate.

### PRIVACY

Features of this case have been altered to de-identify the case and protect privacy. Informed consent was not obtained, as the patient is deceased and has no family.

### CONFLICTS OF INTEREST

The author has no conflicts of interest to disclose.

### NOTES

1. Laws of 2010, adding N.Y. Public Health Law Article 29-CC, The Family Health Care Decisions Act, chap. 8.

2. T. Miller, "New York Adopts Broad Changes To Law on Treatment Decisions," *New York Law Journal* (2010): 58.

3. American Bar Association, "Default Surrogate Consent Laws," [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_default\\_surrogate\\_consent\\_statutes.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf).

4. *Ibid.*

5. The Family Health Care Decisions Act, see note 1 above.

6. Miller, see note 2 above.

7. The Family Health Care Decisions Act, §2994-d.5.

8. *Ibid.*

9. "Imminent," *OED Online*, 2015, <http://www.oed.com/view/Entry/91904>, n. 1.

10. T.W. Kirk et al., "National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary On the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients," *Journal of Pain and Symptom Management* 39, no. 5 (2010).

11. The Family Health Care Decisions Act, see note 1 above, §2994-a.1

12. *Ibid.*, §2994-a.2

13. *Ibid.*, §2994-a.18

14. Several months after Ms E's hospital admission and subsequent death, the New York State Legislature passed an Amendment to the New York Family Health Care Decision Act. (The Family Health Care Decisions Act, Amd. §2994-g.5(c)). This amendment creates a path to hospice for incapacitated patients who do not have a surrogate, by allowing an ethics review committee (ERC) to apply the standard used for withholding or withdrawing life-sustaining treatment from an incapacitated patient with a surrogate, to hospice enrollment for an incapacitated patient without a surrogate. While this new amendment may assist some patients alone who are eligible for hospice, whose values are known, it will not impact those incapacitated patients alone who are not eligible for hospice, whether or not their values are known. Ultimately, this amendment wasn't there to serve Ms E and her values—nor not clear that she would have been considered eligible for hospice—and it is not available for patients like Ms E who live in states with laws that are closer to the FHCDA prior to this amendment.