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Unintended Consequence of Jesse's Law in Arizona Critical Care Medicine

Adrienne Lee Jones-Adamczyk, RN, MSN, ACNP-BC, ACHPN, HEC-C

Patricia Ann Mayer, MD, MS, HEC-C

Banner Gateway Medical Center
Gilbert, AZ USA

Abstract

Jesse's Law, passed in Arizona as a reaction to a surrogate acting against the interests of a specific patient, now prevents intensivists and surrogates who are acting appropriately from discontinuing unwanted interventions in dying hospice patients. The law prohibits statutory surrogates from authorizing discontinuance of artificial nutrition and hydration unless they can present "clear and convincing evidence" to a court that the patient would agree. This law is causing undue harm to hospice patients at end of life by delaying withdrawal of unwanted medical interventions, interfering with accepted and established surrogate decision-making precepts, and negating informed consent because surrogates are unaware that artificial nutrition and hydration cannot be easily discontinued after initiation. The authors offer a case example followed by an ethical analysis of this presumably unintended consequence of the law.

Abbreviations

- ANH: artificial nutrition and hydration
- ICU: intensive care unit
- LST: life sustaining treatment
- PVS: persistent vegetative state
- SDM: surrogate decision maker
- TBI: traumatic brain injury

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We present a composite but common case demonstrating an unfortunate result of Jesse's Law affecting intensivists and their patients who are at end of life. We follow with a short history and discussion of the ethical implications of the law.

Case Report: An 88 y/o widowed woman was admitted to an intensive care unit (ICU) in Arizona in respiratory failure after driving

herself to the local emergency department. By the time her family was reached, she was intubated, on dialysis, and had a feeding tube placed for artificial nutrition and hydration (ANH).

Over the next several days, she worsened and developed multi-organ failure. In conversations with the family, the intensivist elucidated that the patient lived alone and generally declined to complain or seek medical help. The family relayed she was a

third-generation Arizonan who had grown up on the family ranch, where she still lived. She'd often told her family: "When my time comes, it comes; don't keep me alive on machines and tied to tubes. If I'm on my way out, just take me home and let me go." Like many patients, she lacked written advanced directives, but her extended family as her surrogates agreed "her time had come." They requested removal of all tubes and machines and discharge to the ranch with hospice services and family in attendance. As the orders were being written, the nurse asked the intensivist: "What about Jesse's law? We can't just take the feeding tube out and stop the feeding." The nurse was correct. This makes little sense for our patient.

How and why did Arizona get here?

In May of 2007, 36-year-old Jesse Ramirez and his wife were involved in a rollover car crash reportedly caused by a heated argument between the two. Jesse suffered a severe traumatic brain injury (TBI) and was in a coma. Ten days later, his wife, as his statutory surrogate, chose to move him to hospice and discontinue his ANH. Jesse's siblings filed suit, contending that his wife did not have his best interests at heart given their severe marital discord. The Arizona court ruled in favor of Jesse's siblings, and his tube feedings were continued. He moved from hospice to rehab and later regained some function including the ability to recognize and interact with his family (1). Jesse's law, prohibiting surrogates from discontinuing ANH, was passed in 2008 as a reaction to this unfortunate case.

Jesse's Law states: "There is a rebuttable presumption that a patient who does not have a valid living will, power of attorney or other health care directive has directed the patient's health care providers to provide the patient with food and fluid to the degree that is sufficient to sustain life, including, if necessary, through a medically invasive

procedure... and ... that provision is in the patient's best interests." (2) The law, therefore, allows only a legally appointed medical power of attorney or a court-appointed guardian *but not a statutory surrogate* to discontinue ANH for non-medical reasons. The law listed no exceptions, which meant the critical care team could not discontinue our patient's feeding tube unless her surrogate decision makers (SDMs) obtained permission from a court.

How does Jesse's law align with the national evolution of patient rights at end-of-life? It doesn't.

Those rights, including withdrawing and withholding life-sustaining treatment (LST), date to 1976 with the Karen Ann Quinlan case (3). Karen Ann suffered an anoxic brain injury following a respiratory arrest and was subsequently determined to be in a persistent vegetative state (PVS). When months passed without improvement, her family requested the discontinuation of her ventilator based on their belief that Karen Ann would not want her life prolonged in her current condition. The hospital and her treating physicians initially denied this request fearing accusations of murder. The case eventually reached the New Jersey Supreme Court, which allowed removal of the ventilator and set two groundbreaking precedents. First, the Court determined that families are appropriate SDMs for incapacitated patients. Second, the Court determined patients and SDMs do have the right to refuse LST (4). The second major case, that of Nancy Cruzan, began in 1990. (3) This young woman's parents as her SDMs also requested withdrawal of LST, but in this case, the LST was her feeding tube. Nancy was also in a PVS after a car accident but did not need a ventilator; she had been kept alive through ANH alone. Nancy's case was the first withdrawal of ANH to be heard by the US Supreme Court. Although the ruling was multifaceted, it did allow withdrawal of the

feeding tube, and Nancy died eight years after her accident once her ANH was discontinued (5).

These landmark cases clearly established SDMs as appropriate medical decision-makers for incapacitated patients and empowered them to withhold or withdraw medical treatments, including ANH (3). Along with this power, SDMs have the obligation to make decisions according to accepted criteria, namely 1) the wishes of the patient 2) if patient wishes are unknown, then SDMs are to use substituted judgment, that is, to make the decision they believe the patient would make if she were able to speak for herself or 3) in the absence of the first two, SDMs are to act in the patient's best interest (2,6).

Jesse's law in Arizona creates an exception to these precedents. Although Arizona allows withholding or withdrawing other LST by SDMs (including ICU treatments), it does not allow for the withdrawal of ANH, even when the SDM has clear knowledge of the patient's wishes (2). Jesse's law specifically presumes that a patient receiving ANH who lacks advance directives wants - in all cases - to prolong life and continue ANH indefinitely without regard to prognosis, quality of life, or verbalized preferences as told to SDMs (2). This includes the patient described in our case, who clearly would not have wanted continued ANH as she was dying.

Jesse's law, with its lack of exceptions, therefore, causes undue harm at the end of life for dying Arizona patients because it makes assumptions about patient wishes and conflicts with patient autonomy. The law focuses on ANH when the real problem in Jesse's case was an SDM who was clearly not acting in his best interests. Although young patients with brain injuries like Jesse may recover over time, our terminally ill patient could not; yet the law prohibited the ICU team from removing (withdrawing) her feeding tube.

Indeed, withholding and withdrawing LST have long been considered ethically equivalent. (3,7,8,9). McGee (7) reports stopping (withdrawing) ANH is akin to an omission (withholding). The accepted ethical premise is that omissions do not cause death; actions do. Therefore stopping ANH is no more a cause of death than not starting ANH would be. Similarly, Beauchamp and Childress (8), the founders of principles in modern medical ethics, assert no morally relevant difference between ANH and other types of LST types. They add the "right to refuse treatment should not be contingent on the type of treatment" offered. The American Academy of Neurology agrees and openly opposes legislation that presumes to know a patient's wishes regarding ANH and/or limits the ability of patients to declare their preferences, including through discussions with SDMs (9). Current ethical consensus supports an appropriately acting SDM (not the case with Jesse's wife) to authorize withholding or withdrawing ANH as well as to make any other medical decision a surrogate would make.

Unfortunately, Jesse's law interferes with both autonomy and the informed consent process in Arizona for dying patients. Respect for autonomy allows patients (or their SDMs) to accept or reject recommended medical treatments that affect their bodies.

"Every person being of adult years and sound mind has the right to determine what shall be done with his own body"(10). Respect for autonomy includes a requirement of informed consent. In Arizona, SDMs who consent to ANH do not then have the authority to withdraw consent unless they go to court to present "clear and convincing evidence" that the patient would refuse ANH (2). Few SDMs are aware of this when ANH is started, fewer still have the time or energy for a court appearance when faced with a dying loved one. And since informed consent requires the SDM to have "adequate and truthful information about the risk versus

benefits and understand the treatment goals", we posit consent is often not obtained regarding ANH for patients such as ours (6). An informed consent conversation for ANH includes at least three key points (6,11):

- 1) ANH is a medical treatment and not a basic intervention...for all patients;
- 2) ANH provides uncertain benefits for many diagnoses and has considerable risks and discomfort;
- 3) ANH is not a comfort measure since symptoms associated with not eating or drinking can be palliated and generally resolve within a short period of time.

We add that, in Arizona, the ANH informed consent conversation with surrogates ought to specify that permission for ANH cannot be withdrawn (without court intervention) once given.

ANH is rarely indicated for patients with a terminal illness at end-of-life. It carries significant risks, including bleeding, infection, aspiration, and the use of physical or chemical restraints to prevent a patient from dislodging the required tubes. There is no evidence that ANH at the end of life leads to improved survival or quality of life; it is rarely beneficial and often harmful (7,11). And yet, Jesse's law makes no easy provisions for such patients.

Our patient wanted to die unencumbered by medical interventions including her feeding tube, but the ICU team could not accommodate that request under current Arizona law. So, what choices remain for our patient, her surrogates and the ICU team? The team can leave the feeding tube in place, or the surrogates can try and convince a court to allow its removal, spending time in court instead of with their loved one.

We assert that Jesse's law, with its lack of exceptions for patients such as ours, creates undue distress and barriers for intensivists and surrogates attempting to honor patient wishes and end ANH appropriately in dying patients. Jesse's law should have addressed unreasonable surrogates instead of preventing

all surrogates from taking an action that is often in the best interest of a loved one.

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References

1. Grado G. (2011, October 8). *Crash survivor's case spurs new state law*. East Valley Tribune. Retrieved September 15, 2022, from https://www.eastvalleytribune.com/local/crash-survivor-s-case-spurs-new-state-law/article_486772f1-4bd0-59e3-b24f-073bbce7b543.html AZ HB2823.
2. AZ HB2823. Fifty-fifth Legislature 1st Regular. (2021, May 24). LegiScan. Retrieved November 07, 2022, from <https://legiscan.com/AZ/bill/HB2823/2021>
3. Fine RL. From Quinlan to Schiavo: medical, ethical, and legal issues in severe brain injury. *Proc (Bayl Univ Med Cent)*. 2005 Oct;18(4):303-10. [[CrossRef](#)] [[PubMed](#)]
4. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (NJ 1976)
5. *Cruzan v. Director, Missouri Department of Health*, 110 S. Ct. 2841 (1990), 19 Fla. St. U. L. Rev. 209 (1991).
6. Shah P, Thornton I, Turrin D, Hipskind J. (2022, June 11). *Informed Consent*. Stat Pearls. Retrieved November 8, 2022, from <https://www.ncbi.nlm.nih.gov/books/NBK430827/>
7. McGee A. Does withdrawing life-sustaining treatment cause death or allow the patient to die? *Med Law Rev*. 2014 Winter;22(1):26-47. [[CrossRef](#)] [[PubMed](#)]
8. Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*. 8th ed. New York, NY: Oxford University Press; 2019: 165-166.

9. Bacon D, Williams MA, Gordon J. Position statement on laws and regulations concerning life-sustaining treatment, including artificial nutrition and hydration, for patients lacking decision-making capacity. *Neurology*. 2007 Apr 3;68(14):1097-100. [\[CrossRef\]](#) [\[PubMed\]](#)
10. *Schloendorff v. New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (N.Y. 1914).
11. Casarett D, Kapo J, Caplan A. Appropriate use of artificial nutrition and hydration—fundamental principles and recommendations. *N Engl J Med*. 2005 Dec 15;353(24):2607-12. [\[CrossRef\]](#) [\[PubMed\]](#)