

# Ethics Roundtable: The Case of the Surrogate Versus the Living Will

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LK is a 68-year-old female veteran with oxygen-dependent chronic bronchitis who presented to the VA medical center after a ground-level fall. There was head, neck, and left chest pain on arrival and severe hypoxia with room air saturation of 73%. Her oxygenation improved with supplementation with oxygen via nasal cannula. She underwent a traumatic work-up that demonstrated a comminuted cervical odontoid fracture, a sternal fracture, and left-sided third and fourth rib fractures.

During the evaluation, her saturations declined, and an ABG demonstrated critical hypercapnia. Non-invasive ventilation (BiPAP) was initiated. On admission to the ICU, she declined further, became unresponsive, and required emergent intubation. Her son was contacted, who consented to intubation as a life-saving measure. She subsequently suffered a rapid decline with worsening oxygenation requiring increased positive end-expiratory pressure and oxygen concentration. She experienced severe hemodynamic instability requiring high-dose vasopressors.

The following morning her status remained critical. Her husband visited and was very emotional and tearful. He stated that “If she dies, I will die. Do everything you can to keep her alive.” The husband had a recent stroke and demonstrated difficulty retaining information, asking the same questions repeatedly. He did not appear to grasp the gravity of the situation and needed repeated re-orienting that LK was critically ill. He reiterated frequently, “you have to keep her alive; she can’t die.” In discussions with the trauma team, her husband stated that “anything possible to keep her alive” was within goals of care, including long-term ventilator dependence, artificial nutrition via permanent feeding tube, and foreseeable life at a long-term care facility. The patient’s grandson, who reported having some medical experience, concurred.

The following day, records were received from the VA, which included an advanced directive stating that LK did not want any life-sustaining treatments. The document stated LK did not want “artificial nutrition, artificial hydration, invasive or non-invasive ventilation, blood products, or dialysis.” In addition, it asserted there should be no transfers to the hospital

or ICU except for comfort, and no attempts at CPR. A narrative addendum by her primary physician asserted: “Patient states her husband disagrees with her decision for DNR, and it is important to her that this is documented. States she watched her mother die on life support and does not want this for herself. The patient is adamant that she does not want any life-saving attempts and states, ‘when it is my time to go, let me go, I don’t want anybody doing anything.’” The document also appointed the patient’s husband as her surrogate.

Given that LK was critically ill and currently being entirely supported by artificial means, the medical team felt that they were not abiding by the patient’s wishes. Additionally, given the husband’s cognitive deficits, they did not feel that he was an appropriate surrogate.

The son was approached with the advanced directive; he stated, “I was afraid she wrote that down somewhere.” The son accepted the news and seemed to process the information regarding his mother’s illness appropriately, and expressed a desire to act in her best interest. The team felt the son was the most appropriate surrogate, but the husband protested, emphasizing his priority as surrogate decision-maker. An ethics consult was requested.

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## Trauma Surgeon Perspective

*Keelin F. Roche, MD, MPH*

As trauma surgeons, our goal is often the preservation of life at any cost. When a patient presents in extremis, as many trauma patients do, this is our primary objective. There are, however, a few instances where a discussion can immediately be undertaken regarding quality-of-life over life-saving measures. These are typically situations when questions of futility arise, such as transtentorial gunshot wounds or extensive surface area second and third-degree burns. In these instances, when it is immediately apparent that survival is nearly impossible, our focus will switch to the comfort of the loved ones in this trying time. However, when there is any hope of a meaningful recovery, most trauma surgeons will do whatever it takes to persist in that goal. In this case, I see the surgeon's actions during her impending respiratory arrest as entirely just.

When we transition from life preservation to an emphasis on quality of life differs in each patient interaction and from one provider to the next. Given that we often deal with life-altering diagnoses and prolonged hospital courses, we often play the long game, especially in young, previously healthy patients. Elderly trauma patients, typically defined as over age 65, often have a much more complicated recovery which prompts a discussion regarding goals of care early in their hospital course for most trauma surgeons. Maxwell et al. from Vanderbilt has published extensively on the impact of frailty and trauma outcomes.<sup>1</sup> Frailty is defined as a syndrome of reduced strength, endurance, and physiologic function, taking into account several factors, including age, comorbidities, cognition, and function. The authors have shown significant increases in post-injury mortality and decreased mobility in frail trauma patients. Over half of those who meet the criteria to be called frail had not returned to home 6 months or even 1 year post-injury. Overall outcomes can be quite variable and depend significantly on the patients' pre-injury functional status. The description of this patient suggests she was frail pre-injury. All this is to say that even without a clearly outlined advanced directive, this patient represents someone in whom an early conversation regarding goals of care would have been necessary. Most of us in trauma surgery uniquely understand that there are fates far worse than death and insist on frank discussions and early clarifications of goals.

Unfortunately, it is relatively rare to have such a clear advanced directive in writing in the world of trauma surgery. The burden of disease secondary to trauma tends to be woefully unexpected. When we have a clear picture of the patient's goals, this informs and shapes the conversations with families. In this patient's instance, I would say the goals are apparent, but the logistics are somewhat muddled with the appointment of the patient's spouse as surrogate. Although patients do ultimately bear the responsibility of making an appropriate choice for their surrogate, I would wonder if, in this situation, she understood she had alternate choices (i.e., her son or grandson)? It seems clear from the description that her spouse fails to

meet the requirements of surrogacy given his difficulty in retaining information, repetitive questioning, and failure to comprehend the gravity of her situation. It seems likely that the surrogacy designation preceded the recent stroke, which may have impacted his cognition. Although the patient bears the responsibility of choosing an appropriate surrogate, it will often fall on the trauma team to determine the appropriateness in the moment, given the unexpected nature of the trauma.

Much like capacity, the "appropriateness" of a surrogate often depends upon the gravity of the decisions being made. Given that, in this instance, the trauma team is considering a withdrawal of life-sustaining measures, as is the patient's wishes from her advanced directive, the bar for "appropriateness" of any surrogate is very high. The patient's spouse fails to meet this bar, and thus it depends on the trauma team to find the next most appropriate surrogate. The son appears to meet this, given that, although he disagrees with the patient's expressed wishes, he wants to act in accordance with them.

Our job as trauma surgeons is to save a life when possible, but when that is not possible, or the means to get there are not within a patient's expressed goals, then our job is to advocate for that patient. There are times when this is in distinct contrast to the family's wishes, but our duty is to the patient. We can take the actions necessary to meet in a middle ground but had that not been possible here, the trauma team would have still have needed to act following the patient's advanced directive and potentially withdrawn care against their wishes. It is always better for all parties to meet on common ground, and thankfully, in this situation, the patient's son was able to bridge that gap. It is an honor to serve patients and families in crisis, but with that service comes great responsibility and sometimes the necessity to make the most difficult choices. We do that while being as informed as possible, and the patient's advanced directive gives them a voice amid deafening silence. We must respect that voice.

## Ethics Perspective

*Matt Stolick, PhD*

This is a situation in which we should honor a clear advance directive and physician addendum. The ethical issue is primarily one of how to respond to an unfit surrogate, especially when the surrogate is a spouse. The problem is that her husband-surrogate and son do not want to honor her advance directive and multiple clear and memorable expressions of her desire to forego life-sustaining treatments in a situation just like this one.

Initially, this patient had a fall and sustained severe injuries, including several fractures. She was taken to the VA medical center, apparently the residence of her advance directive. However, the advance directive is unavailable in the emergency room and initially unavailable in the ICU. This lack of availability of the advance directive is troubling for 2 reasons. First, because it results in several violations of this patient's advance directive. Medical acts of violation include the initiation of

non-invasive ventilation (BiPAP) and then intubation. In her advance directive, she states that she did not want this done! She said no “artificial nutrition, artificial hydration, *invasive or non-invasive ventilation*, blood products, or dialysis.” (emphasis added) She also directed that there should be no transfers to the hospital or ICU, except for comfort care. Second, the advance directive is located in this very same VA medical center. If the advance directive were located in some other hospital, then the fact that the advance directive was unavailable during intake and admission of this patient would be easier to understand (I assume this advance directive is in hard/paper copy, another major problem in our age of electronic medical records). If the advance directive would have been available upon the arrival and admission of this patient, then the strong moral argument based on respect for autonomy would say that she should not have even been taken to the ICU.

The advance directive (living will or durable power of attorney for health care decisions) should demand respect. This single, incredibly significant, treatment-dictating document represents the uncomfortable conversation this patient had the courage to have. There was likely considerable conflict and criticism to be endured from her husband. Nevertheless, she persisted and completed not only an advance directive but also impressed upon her primary care physician to make an addendum to her chart, insisting on abiding by her advance directive against the likely interference of her husband. She planned ahead and spared others the burden of making this decision for her so that before she was in a situation such as this one, her advance directive would dictate to her surrogate the goals of her health care.

We are told that the son of this patient was contacted and gave consent to this intubation. This is, on the face of it, a very weak sort of consent. Consent implies that he was given sufficient information about the decision to intubate, understood the short-term and long-term costs and benefits of doing so, and a recommendation from the health care team. Perhaps this all happened over the phone in this initial contact with the son. Also, asking the son to intubate this patient risks the son rejecting intubation. If the son refused to consent to the intubation, the healthcare team would have likely intubated her regardless to save this woman’s life, especially without the advance directive. I wonder why they did not instead inform the son that they had already intubated his mother to save her life, an emergency action, and urge him to come to the hospital where he could be better informed about the situation.

Now the patient’s husband arrives. He is “very emotional and tearful.” The primary statement of his perspective is: “If she dies, I will die. Do everything you can to keep her alive,” a statement he reiterated frequently. In *what* it says and *how* it is said, this statement provides enough evidence that he is not a good surrogate for this patient. By definition, a surrogate decision-maker decides for another, where the decision is to be made as that person would have made it, were they able to decide for themselves. This husband-surrogate believes that *he himself* is facing death. As he thinks he will die if his wife dies, he is desperate and willing to do anything at all to keep her, and

therefore himself, alive. The problem with his acting as a surrogate for this patient is because his decision is supposed to be made as his wife would have wanted, but he is deciding for what he wants.

In addition to not deciding as the patient would want him to decide, there are 3 other reasons why this surrogate-husband is failing to meet the qualifications of his role as a surrogate. Beauchamp and Childress explain that there are 4 qualifications that should be satisfied by all surrogate decision-makers.<sup>2</sup> If a surrogate decision-maker fails to demonstrate any one of these necessary qualifications, then the decision can be justifiably overridden. The 4 qualifications:

1. Ability to make reasoned judgments (competence)
2. Adequate knowledge and information
3. Emotional stability
4. A commitment to the incompetent patient’s interests, free of conflicts and free of controlling influences by those who might not act in the patient’s best interests.<sup>2</sup>

This husband/surrogate fails to demonstrate all 4 of these qualifications! Again, he does not meet the fourth qualification. His commitment is not to his wife’s interests but his own interests. He is himself conflicted and being controlled by his desperate desire to keep his wife alive to keep himself alive. He does not meet the first qualification. He is unable to make a reasoned judgment but is acting and deciding according to his passions, fears, and intense emotions. He does not meet the second qualification, adequate information, and understanding, especially regarding the moral and legal power of his wife’s advance directive and the prognosis for his wife. Also, the husband recently had a stroke and has shown difficulty retaining information, such as in asking the same questions repeatedly. He did not appear to grasp the gravity of the situation and needed repeated re-orienting that his wife was critically ill. Furthermore, he does not meet the third qualification, as he is clearly emotionally unstable.

It is puzzling why this husband was appointed a surrogate, given his obvious lack of acceptance of the advance directive of his wife. I assume that in the signing of whatever document we are calling the “advance directive,” in this case, the husband was there, and it was seen as a basic act of respect and fidelity to name him as the decision-maker for her. The problem is the obvious unresolved lack of acceptance he harbors for what his wife has directed. When named as a surrogate, he should be made aware of what this means, and by agreeing to be surrogate, he agrees to act as a surrogate when the time came, abiding by the directives of his wife.

In this whole case, the surrogate decision makers are the major obstacle to respecting the clearly autonomous wishes of this patient. However, there is a powerful and strongly justified assumption of family members as first on the list of surrogates in a *prima facie* way (family are surrogates unless some reason for disqualifying them). Beauchamp and Childress explore 4 main classes of decision makers used in cases of withholding and terminating treatment for incompetent

patients: families, physicians and other health care professionals, institutional committees (including ethics committee), and courts. They explain that “wide agreement exists that the patient’s closest family member is the first choice as a surrogate.”<sup>2</sup> This does not mean, however, that a family member’s decision as surrogate cannot be justifiably overridden. “Even the patient’s closest family members sometimes make unacceptable decisions, and the authority of the family is not final or ultimate.”<sup>2</sup>

Given that this is an advance directive that clearly applies to this situation, the moral principle of respect for autonomy is strongest among all principles involved in this case. This is a situation in which the advance directive should guide decision-making. The wishes of this patient in this advance directive should be the focus of our discussions with this surrogate-husband as well as the son or grandson, the other possible surrogates in this situation. If the surrogate refuses to abide by the advance directive, then he has the burden of giving good reasons for doing so. The surrogate has to explain how continued treatment would be in this patient’s best interests, in the short and long term, and not how continued treatment is in *his own* perceived best interests. He should be encouraged to acknowledge the meaning of a “surrogate” as well as the basic respect his wife is due. This discussion will get us into talking about the poor prognosis, pain and suffering to be experienced by this patient, perhaps reminding the husband that this is basically the same sort of death that his wife said she had witnessed watching her mother die on life support and said she did not want for herself.

The ultimate challenge from pulling back, providing comfort care and allowing this patient to die is the inability of this husband (son, grandson, family) to let go. The health care team should help him do so here, acting as agents of this patient, who we must now imagine pleading to us now, in her words: ‘when it is my time to go, let me go, I don’t want anybody doing anything’.

## Spiritual Care Perspective

Scott Boyles, MDiv

As healthcare professionals, spiritual care providers adhere to a code of ethics that guides the provision of appropriate spiritual care. Respecting patient autonomy is a high ethical priority. Spiritual care providers have a role in helping a patient articulate their goals of care. In a safe space, the patient is encouraged to clearly and freely share what they want to happen, “curative, rehabilitative, life-prolonging, or comfort focused” care without judgment.<sup>3</sup> The advance directive codifies the patient’s wishes, and is the primary expression of the patient’s autonomy when they can no longer articulate them. These wishes are essential to helping the inter-disciplinary team provide the care the patient has already made clear they desire.

In this case, LK had already expressed her desires vis-à-vis goals of care, even before her fall. In her written advanced directive, LK makes it very clear what her wishes were in the

event that she could no longer articulate them. She even noted her husband’s disagreement with her perspective and addresses it in her advance directive, apparently to ensure his adherence to them. It is curious that her advance directive was not consulted until what appears to be the third day of her care. In the meantime, LK was transferred to the ICU, intubated with consent from her son, and her husband directed the team to do “anything possible to keep her alive,” all items addressed (and refused) by LK in her advance directive. Perhaps the current question of replacing the named surrogate could have been avoided by consulting the advance directive when LK first began receiving care.

In terms of the question at hand, “Can the named surrogate be replaced?,” patient autonomy is still key. LK named her husband as surrogate, even knowing that he disagreed with her. A decision to replace him should not be treated lightly. The husband’s heartfelt reactions to his wife’s healthcare crisis: “You have to keep her alive, she can’t die,” and “If she dies, I will die. Do everything you can to keep her alive,” suggest deep emotions that not only indicate concern for the patient but for himself as well. What lies beneath these gut-wrenching statements are meaningful and important to explore to better understand the husband’s perspective as it relates to his role as surrogate.

This would be an opportunity for the spiritual care provider on the team to encourage the husband to share about his relationship with his wife and what her death will mean to him in practical terms. An important aspect of spiritual care is allowing the care recipient to feel heard, that their opinion is important and acknowledged. Doing so may provide an atmosphere in which LK’s wishes can be presented to the husband again and a collaboration between the husband and his wife’s wishes can be achieved. This may not be possible due to the husband’s apparent cognitive deficits due to his recent stroke. In that case it may make sense to seriously consider Lk’s son as surrogate in place of the husband.

When considering the son, skepticism arises concerning his appropriateness as an alternate surrogate. This is the same son who “consented to intubation as a life-saving measure” for LK, while apparently knowing this was against her wishes. His knowledge of her desires is evident in the comment, “I was afraid she wrote that down somewhere.” This expands the quandary about who would be the appropriate surrogate. The designated surrogate wants everything medically possible done for his wife in direct contradiction to her wishes, and at the same time does not fully understand the critical nature of his wife’s health. The alternate surrogate also contradicted LK’s wishes. Neither of them seem to be an ideal candidate, but perhaps together they can be. Bringing both the husband and the son (and perhaps the grandson too) together may provide a solution to the surrogate question. This will give them all an opportunity to share about who LK is to each of them, their love for her, and her love for them. With this as a foundation presenting her wishes again may bring them to a point of solidarity where they can all 3 make decisions together that reflect LK’s wishes. This would allow the team to receive clear

direction from a collaborative surrogate in agreement to carry out the patient's wishes.

## Physician Perspective

Gregory T Carter, MD, MS

This is a challenging situation. In my view, the ethical concerns are really driven by the husband's reaction to this scenario. He has had his own health issues with a recent stroke. The stroke has created some cognitive issues that may be clouding his judgment and he now appears to be in "panic mode". His statement that "If she dies, I will die. Do everything you can to keep her alive" really reflects a very skewed viewpoint of the situation in his mind and shows that he is not really processing things appropriately. Of course, he does not want to lose his beloved wife. However, her health is so poor, she would not likely be able to do much caregiving herself. That assumes she survives this situation, which is certainly not a given here considering the severity of her condition, even with a full court press on her care plan.

Fortunately, the hospital was able to obtain records, including a very thorough and clear advanced directive. LK's advance directive states that she did not want any life-sustaining treatments, specifically outlining not to use "artificial nutrition, artificial hydration, invasive or non-invasive ventilation, blood products, or dialysis." Moreover, the husband's comments that "you have to keep her alive, she can't die" further illustrate his lack of insight into his wife's medical condition. Was it not for the husband's panic and cry for help, this would be a very different situation?

The husband would normally be the appropriate surrogate in this scenario. Employing the typical hierarchy would dictate that. However, it would normally also be the case that surrogate decision makers would always consider any directives the patient articulated when competent. The surrogate is expected to have "substituted judgment", implying that they know the patient intimately enough to best carry out the course they think the patient would have chosen. This also implies that the surrogate himself be of sound mind and capable of making rational decisions, in his wife's best interest. You can make a strong argument that this would not appear to be the case here.

I concur completely with the team's opinion that the son is the most appropriate surrogate. It is not clear in my mind that the husband has the functional capacity or competence to function at a surrogate decision maker for his wife. He does not appear to be mentally able to provide an informed health care decision. He is making decisions based upon a fear of his own personal situation, rather than his wife.

I believe that these circumstances support the team to use the son as the surrogate decision-maker. The son could also be a key player in helping to convince his father that he is not making appropriate, rational choices. Nonetheless, if the husband continues to strongly object, he may have some legal recourse and the ethics committee may need input from hospital's legal team.

## Legal Perspective (note 1)

Eddy R. Smith, JD, CEPA

### *Patient's Right to Control Her Body and Medical Care*

The US Supreme Court has declared that every person has a Due Process Clause liberty interest in refusing unwanted medical treatment (note 2). "[T]he Constitution supports a right to reject life-sustaining medical treatment as a function of the fundamental right to bodily integrity under the Due Process Clause." (note 3) States have echoed the public policy that "every person has the fundamental and inherent right to die naturally with as much dignity as circumstances permit and to accept, refuse, withdraw from, or otherwise control decisions relating to the rendering of the person's own medical care, specifically including palliative care and the use of extraordinary procedures and treatment." (note 4)

### *Advance Directives*

State laws allow individuals to declare their end-of-life medical care wishes prospectively through "advance directives" (living wills, health care powers of attorney, advance care plans, and the like) in case they later are unable to communicate their wishes. Such legal structures "affect[] a fundamental right: personal autonomy, which includes the ability to make one's own decisions about health care." (note 5) If a patient cannot make and communicate her wishes and the medical providers have determined that the predicates to the advance directive have been satisfied, the advance directive speaks for the patient.

Beyond giving health care directions, an individual executing an advance directive may appoint someone (an attorney-in-fact, agent, or surrogate) to make health care decisions when the principal is unable to do so for herself. The surrogate stands in the shoes of the patient and generally may make any decisions the patient could have made if competent to do so. Statutes provide legal protections for health care surrogates making decisions for the patient and medical providers relying upon the decisions and directions of a surrogate, including those made based on the terms of an advance directive (note 6).

### *Practical Limits to Protection of Patient Wishes When Chosen Surrogate Does Not Agree*

One overarching practical reality is that family members can sue medical providers, but documents cannot. For some medical providers, that is the only reality that matters. (Once, after handing to my father's nurse his health care power of attorney naming me as his agent, I tried to give the nurse my father's living will. The nurse indicated that the medical facility did not need the living will, because "if you're named as agent, we follow your directions.") Understanding this dynamic, I tell clients that the most important choice they make in their health care documents is whom to name as agent/surrogate, because

that person can either support and defend the patient's wishes or undermine them.

Nonetheless, the law requires a health care surrogate/agent to comply with the patient's wishes, however expressed, and legal protections for medical providers are conditioned upon honoring patient self-determination (note 7). What are medical providers to do when the patient's surrogate advocates for a course of treatment that conflicts with the patient's advance directive?

State statutory frameworks can guide LK's medical care providers:

(b) [A] health care provider or institution providing care to a patient shall [] (1) [c]omply with *an individual instruction of the patient* and with a *reasonable* interpretation of that instruction made by a person then authorized to make health care decisions for the patient; and [] (2) [c]omply with a health care decision for the patient made by a person then authorized to make health care decisions for the patient to the same extent as if the decision had been made by the patient while having capacity (note 8).

Thus, the surrogate may make decisions only to the extent that the patient's wishes are unknown and through "reasonable" interpretations of the patient's known wishes.

The 2008 Cardoza case illustrates how firmly medical care providers must seek to uphold patients' wishes:

In *Cardoza v. USC. University Hospital*, . . . [h]ealth care providers complied with decisions of an appointed health care agent, a son of the patient, to continue aggressive interventions for his mother. But the agent's sister, and patient's daughter, brought a lawsuit alleging that providers failed to comply with her mother's advance directive. Since the surrogate had no authority to contravene instructions and preferences memorialized in the advance directive, the court held that the hospital could not have complied with the surrogate's decisions "in good faith." Therefore, the court held that the hospital was not entitled to immunity (note 9).

### Legal Recommendation

The medical providers should refuse to follow LK's husband's directions. Beyond the questions of his emotional and mental capacity, the advance directive gives clear indication of LK's wishes, including her accurate prediction that her husband would refuse to follow her instructions. Failure to honor LK's wishes could cause adverse legal consequences.

LK's medical providers have 3 viable options:

1. Deem LK's husband "unavailable" and appoint the son as an alternate surrogate (if the jurisdiction so allows pursuant to something like the Tennessee Health Care Decisions Act) (note 10). While the providers would be on reasonable legal ground making this determination under the circumstances, it does leave the door open to litigation by LK's husband. The providers should prevail in any such litigation, but all litigation is painful.

This is likely the "right" answer, but perhaps not the safest.

2. Ask a court to replace the husband as surrogate (note 11). This would be safer than the first option because the court would decide whether LK's husband could remain as LK's advocate and, if not, who should take his place, but the process could take time and expend significant resources to resolve the issues.
3. Offer to transfer LK to a facility that can follow LK's husband's directions, if one can be found (note 12). This likely would be the safest option, which will be all that matters to some providers, but simply "kicks the can down the road," as another provider would be faced with the same issues.

### Social Work Perspective

Angela Eastridge, MSW

End-of-life care planning was important to LK and she took the necessary steps to make her choices known. She informed her family of her wishes, she communicated her wishes and concerns with her primary care doctor, and she executed an advance directive. However, when the time came for LK's directives to be carried out, her wishes were jeopardized because she had appointed her spouse as her healthcare surrogate, knowing he was not in agreement with her choices.

The surrogate's primary responsibility is to reach decisions that the patient would have made if able.<sup>4</sup> Most individuals, like LK, choose someone who is closely related to them. However, surrogates frequently make treatment decisions that are not in agreement with the patient's wishes. In a situation such as this, the healthcare team is left to reconcile these differences. The voice and rights of a patient who lacks decision-making capacity must not be minimized or ignored. Standard 1.14 of the National Association of Social Workers Code of Ethics states that social workers take reasonable steps to safeguard the interests and the rights of those patients who lack decision-making capacity.<sup>5</sup>

In many cases, the healthcare team does not know the patient's preferences for end-of-life care. However, in this scenario, LK's preferences were documented in her advance directive. An advance directive is defined as "a person's verbal or written expression or instructions about his or her wishes, preferences, or plans for future medical treatment or health care if he/she becomes unable to communicate."<sup>6</sup> LK made it clear, both verbally and in writing, that she did not want life-sustaining measures. The social worker should promote the patient's right to self-determination and clinicians should regard advance directives as the full extension of a patient's autonomy who once possessed decision-making capacity.<sup>7</sup>

The healthcare team can certainly empathize with LK's husband. He is in the difficult position of having to make critical decisions for his wife while confronting the real possibility of her death. Research in decision psychology suggests

that strong emotions can impair how individuals process and reason information.<sup>8</sup> Additionally, decisions about life support require surrogates to consider that they may need to “let go” of their loved one. Some surrogates may make treatment choices contrary to the patient’s values and wishes to avoid the negative feelings caused by the death of a loved one. While it is the goal of the social worker and the healthcare team to minimize the emotional pain of the spouse and family, the social worker must remain committed to the patient and promote their well-being and make their interests primary.

Because the healthcare team is aware of LK’s wishes for end-of-life care, the social worker should recommend that the healthcare team honor her autonomy by allowing her preferences to take precedence over the decisions of her husband. The social worker would support any legal process that was available to remove the spouse from his role as a surrogate if necessary.

While patients bear responsibility for the decisions they make about advance care planning, healthcare providers can provide education and guidance to patients that will enable them to make better-informed decisions. Few patients discuss end-of-life issues with their healthcare team although most would welcome such discussions and most want their physician to initiate those conversations. Healthcare providers can help patients articulate their specific wishes about interventions such as artificial hydration and nutrition, mechanical ventilation, and the level of quality of life that they would wish to avoid.<sup>9</sup>

The appointment of a healthcare surrogate is a decision that can have serious implications for patients who lose decision-making capacity. In this case, the appointment of the healthcare surrogate was perhaps the most significant factor in creating this dilemma.

Patients are often advised to appoint a trustworthy relative or close friend who knows them well and is willing to carry out their wishes. However, research suggests that approximately one-third of the time surrogates make decisions that are different than what the patient would have made for themselves. The best predictor of a surrogate’s ultimate decision is based not upon what the patient would have wanted, but what decision the surrogate would make for themselves based on their own preferences and values. Based on this evidence, patients should be directed to have conversations with potential healthcare surrogates not just about their preferences and values but also the preferences and values of the potential appointee. Consequently, healthcare providers should consider these dynamics when offering guidance to patients regarding this aspect of advance care planning to increase the likelihood of the patient’s wishes being followed.

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## Notes

1. The following is provided for academic purposes only. Nothing herein constitutes, or may be relied upon as, legal advice to any person.
2. See *Cruzan v. Director, Missouri Department of Health*. 497 US 261, 110 S. Ct. 2841, 111 L. Ed. 2d 224, 1990 US LEXIS 3301, 58 USLW 4916, \*15. Publication June 25, 1990. See *Cruzan v. Dir.*, Mo. Dept’t of Health, 497 US 261 (1990).
3. *Blouin v. Spitzer*. 356 F.3d 348, 2004 US App. LEXIS 1477, \*25 (2d Cir). Publication February 2, 2004. See legal discussion in Baumrucker SJ, Gersch H, Holland H, et al. Ethics roundtable: autonomy and delusion. *Am. J. Hospice & Palliative Med*, April 2021. *Blouin v. Spitzer*, 356 F.3d 348 (2nd Cir. 2004); See Baumrucker SJ, Gersch H, Holland H, et al. Ethics roundtable: autonomy and delusion. *Am J Hospice & Palliative Med*, April 2021.
4. TENN. CODE ANN. § 32-11-102. TENN. CODE ANN. § 32-11-102.
5. *Nina McKey v. Nat’l Healthcare Corp.*, 2008 Tenn. App. LEXIS 477 at \*9 (citing *Cabany v. Mayfield Rehab. & Special Care Ctr.*, 2007 Tenn. App. LEXIS 696, 2007 WL 3445550 at \*5). *Nina McKey v. Nat’l Healthcorp.*, No. M2007-02341-COA-R3-CV, 2008 Tenn. App. LEXIS 477, at \*9 (Tenn. Ct. App. Aug. 15, 2008); *Cabany v. Mayfield Rehab. & Special Care Ctr.*, No. M2006-00594-COA-R3-CV, 2007 Tenn. App. LEXIS 696, at \*5 (Tenn. Ct. App. Nov. 15, 2007).
6. See, e.g. TENN. CODE ANN. §§ 32-11-110; 34-6-208; 68-11-1810. See e.g. TENN CODE ANN. §§ 32-11-110, 34-6-208, 68-11-1810.
7. See, e.g. TENN. CODE ANN. §§ 34-6-205, 34-6-208(b)(2), 68-11-1803(e), 68-11-1806(d), 68-11-1807(a).
8. TENN. CODE ANN. § 68-11-1808 (emphasis added).
9. Pope TM. Clinicians may not administer life-sustaining treatment without consent: civil, criminal, and disciplinary sanctions. *J Health & Biomed L*. 2013;9:213, \*285, citing *Cardoza v. USC Univ. Hosp.*, No. B195092, 2008 WL 3413312, 14-15 (Cal. Ct. App. 2008). Pope TM. Clinicians may not administer life-sustaining treatment without consent: civil, criminal, and disciplinary sanctions. *J Health & Biomed L*. 2013;9:213, 285.
10. See TENN. CODE ANN. § 68-11-1806(b).
11. “A surrogate is the patient’s agent and, as such, must act according to the patient’s instructions, known preferences, and best interests. When a surrogate exceeds the scope of her authority, she can and should be replaced.” Pope TM. Health law and bioethics: pressing issues and changing times: surrogate selection: an increasingly viable, but limited, solution to intractable futility disputes. *St Louis U J Health L & Pol’y* 2010;3:183, \*189. Pope TM. Health law and bioethics: pressing issues and changing times: surrogate selection: an increasingly viable, but limited, solution to intractable futility disputes. *St Louis U J Health L & Pol’y* 2010;3:183, 189 (“A surrogate is the patient’s agent and, as such, must act according to the patient’s instructions, known preferences, and best interests. When a surrogate exceeds the scope of her authority, she can and should be replaced.”).
12. See, e.g. TENN. CODE ANN. §§ 32-11-108, 34-6-214, 68-11-1808.

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