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Discomfort as a Catalyst: An Ethical Analysis of Donation after Cardiac Death in a Patient with Locked-In Syndrome

Bethany Bruno and Margot M. Eves

ABSTRACT

Donation after cardiac death (DCD) traditionally occurs in two patient populations: (1) those who do not meet neurological death criteria but who have suffered severe neurological damage, and (2) those who are fully alert and awake but are dependent on machines. This case highlights the unique dilemma when a patient falls between these two populations—conscious and cognitively intact, but completely paralyzed except for limited eye movement, afflicted by what the medical community refers to as locked-in syndrome. Prompted by the treatment team's discomfort, an ethics consultant examined whether the team was obligated to discuss a decision to donate with the patient, who was a registered organ donor. This article shows how, in determining whether or not to talk to the patient or family during end-of-life decision making, the weight assigned to the various ethical concerns in the case—the patient's condition, the decision to be made, and the family's agreement or disagreement regarding the patient's wishes—can "swing the pendulum" of ethical analysis in dif-

ferent ways. The comfort of the patient must be accorded the highest priority, as well as the needs of the patient's family. This case study highlights the nuanced contextual factors necessary to guide a treatment team's approach to DCD for a patient with uncertain decision-making capacity.

INTRODUCTION

In the United States, society strongly emphasizes the rights and privileges of the individual, with respect for patients' autonomy often held as paramount against other *prima facie* ethical principles. In this vein, healthcare professionals follow the voluntary decisions of patients who have decision-making capacity, or the decisions of surrogates who are acting in accordance with an incapacitated patient's wishes. However, this dichotomy is not always distinct, prompting the question of how to approach medical decision making when a patient's decision-making capacity remains unclear and the stakes are high, such as at the end of life. The emotional difficulty surrounding these situations affects discussions of beneficence and non-maleficence, depending on the patient's views, cognitive ability, and current emotional state; such discussion might even be harmful to the patient. Nevertheless, when a family requests that healthcare providers not share a patient's

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diagnosis with the patient—which is common in some cultures—healthcare professionals the U.S. are often uncomfortable with the idea of not talking to patients about their care, even when patients indicate that such discussions are unwanted. This article explores a case in which healthcare professionals felt such discomfort and were unsure whether to discuss withdrawal of treatment and organ donation after cardiac death (DCD) with a patient who had locked-in syndrome that was complicated by additional stroke impact and subsequent questionable cognitive ability.

CASE DESCRIPTION

Mr. Smith (not his real name) was a 62-year-old man with a history of heart failure who was admitted for difficulty breathing and seizure-like activity. Shortly after admission, he suffered a severe cardio-embolic stroke affecting the pons, midbrain, bilateral cerebellum, and left thalamus. Despite immediate intervention, emergent intra-arterial therapy failed to avert significant ischemic damage. At the time of the ethics consult, Mr. Smith had been diagnosed with locked-in syndrome; in locked-in syndrome, a patient is conscious and cognitively intact but completely paralyzed except for blinking and vertical eye movements. Since locked-in syndrome typically results from isolated pontine strokes,¹ it was possible that the patient had more deficits than just those traditionally seen in classic locked-in syndrome. Mr. Smith's condition limited a thorough evaluation of his understanding, especially given that sometimes he was awake and responsive but at other times he was unarousable, in a coma-like state. Given his extensive stroke burden, his condition was not expected to improve.

Mr. Smith had a large, highly involved family. His three daughters served as his surrogate decision makers, with the eldest acting as the primary spokesperson for the family. Worried about the diagnosis of heart failure, the patient had discussed his wishes with his children when he was conscious, and all of the children were confident that he would not want to live in a locked-in state, even though they said that they preferred that he try. During one of the patient's conscious intervals, his daughter confirmed her understanding of his wishes with him. A do-not-resuscitate (DNR) order was put in place until the decision to withdraw treatment was officially

made during a family meeting, with the patient's daughters, multiple grandchildren, two sisters, and brother attending.

In accordance with hospital and organ procurement organization (OPO) policy, the OPO was notified of the patient's status prior to the family meeting, so the OPO might ask about donation after the conclusion of the end-of-life discussion. Before the OPO spoke to the family, they asked the healthcare team about organ donation. The patient was a registered organ donor and had previously spoken with his family about his desire to donate. However, caregivers and the OPO expressed discomfort about proceeding with DCD for a patient who appeared to be locked-in and therefore potentially cognitively intact.

An ethics consult was requested to address several concerns before the family meeting, including whether it would be beneficial to revisit the daughter's discussion with the patient, whether the team was obligated to review the decision to donate with the patient, and how to ensure the patient's comfort and minimize distress should the team proceed with DCD. From these concerns stemmed larger questions regarding when to talk with the patient versus the family when there is a question of capacity, what organ donor registration means, and what kind of experience we owe patients at the end of their lives.

DISCUSSION

Initial Discomfort

The thought of being trapped in one's own body, completely dependent on others and with limited ability to communicate with the outside world, often provokes a gut-wrenching reaction. For many, the thought of others making decisions about your care, including whether you live or die, without your input, is even worse. Tragic stories such as that of Rom Houben, who was inaccurately diagnosed as being in a persistent vegetative state for more than 20 years, lend further credence to this fear, and although Houben's story is extreme, reports suggest that the rate of misdiagnosis in disorders of consciousness is as high as 40 percent.²

Given these statistics, it is not difficult to understand why the medical team was uncomfortable with the thought of withdrawing life-sustaining treatment and carrying out DCD with-

out Mr. Smith's explicit consent. Even the OPO, which is generally prodonation, remained hesitant. Regardless of the difficulty in communication, if there was any chance that the patient was "in there," was there an ethical obligation to ask him what he wanted? Alternatively, was it ethically appropriate to rely on surrogate decision makers in this situation?

The Question of Consciousness

Intrinsic to this discomfort, and perhaps this case's most unique dilemma, is the question of consciousness and its significance. As reflected in the literature, discussions of treatment withdrawal and DCD, in general, occur in two distinct patient populations: (1) those who are not brain dead but who have suffered severe neurological damage and remain in an unconscious or minimally conscious state, and (2) those who are fully alert and awake but severely disabled and dependent on machines. In the first population, the patient must have previously provided consent by registering as an organ donor or the family must provide consent for treatment withdrawal and DCD. In the second population, the patient chooses to have life-sustaining measures withdrawn, thereby ending his or her life and subsequently donating an organ or organs. The latter situation is significantly rarer, with only several case reports published. In the U.S., these have primarily included patients with amyotrophic lateral sclerosis (ALS), commonly referred to as Lou Gehrig's disease.³ There is at least one report from the Netherlands of DCD after euthanasia in a locked-in patient.⁴ In these cases, the patients explicitly requested to end their lives through either discontinuation of life support or euthanasia and to subsequently donate their organs via DCD.

The case of Mr. Smith lies between these two extremes, and prompts the question of whether to talk to a patient or a patient's family when the patient's decision-making capacity remains unclear. Ultimately, the answer to this question is situation dependent, as the patient's condition, the decision to be made, and the family's agreement or disagreement regarding the patient's wishes may "swing the pendulum" of ethical analysis in different ways. As the gravity of the decision to be made increases, so does the drive to ascertain the patient's exact wishes; however, more difficult decisions necessitate a greater level of capacity on the part of the pa-

tient, which the patient's condition may, unfortunately, limit. Thus, in situations when a patient's capacity to make a decision is questionable, ethicists must weigh the value of getting the patient's input against the likelihood that he or she will be able to provide an informed decision. Whether there is consensus within the patient's family may tip the balance, for if there is widespread, unresolvable disagreement about what the patient would want, it may be worth at least trying to ask the patient directly, despite the question of capacity and, if necessary, over any objections by family members.

Nevertheless, ethicists should be wary of their motivation in asking patients with questionable capacity for their input. Honest reflection of motives must be made; in this case, ethicists must ask themselves whether asking the patient would be based on a sincere belief that the patient could provide a meaningful answer, or a desire to "check a box" and/or provide reassurance that the right course of action has been taken. This may not be possible to determine, but ethicists should, in any case, ask themselves these questions, and if they are primarily "checking a box," and this may do harm, they should consider omitting this step. Further, despite ethicists' best intentions, asking the patient for input can backfire. For example, if the patient fails to understand or cannot communicate, the discussion may contribute to the patient's frustration and angst, possibly causing psychological or emotional harm; or, if the patient makes statements contrary to his or her previously stated wishes, there is the additional challenge of trying to determine which stated wishes should be followed. Even though U.S. society places a strong emphasis on patients' autonomy, efforts should be made to avoid demanding a patient's input without a full consideration of the situation.

Ethical Analysis

In this context, the ethicist determined that the most ethically appropriate option was to forgo revisiting the conversation about withdrawing treatment with Mr. Smith. Given his waxing and waning responsiveness and the severity of his stroke beyond that of the typical locked-in patient, Mr. Smith's ability to comprehend the choices to be made remained unclear, even after the medical team's best assessment. Additionally, his large family was tightly knit

and appeared to react appropriately to their situation. They clearly applied the substituted judgment standard, honoring their understanding of the patient's wishes as they noted his desire not to live this way, despite their preference that he try to do so. These factors increased the ethicist's and the treatment team's comfort in relying on Mr. Smith's family members to make decisions; the ethicist's and team's comfort was further strengthened because the patient's daughter had discussed the patient's condition with him over the weekend. Given the difficulty of ascertaining the patient's ability to process information, the agreement among family members regarding what the patient's wishes were, and the conversation between the patient and his daughter that confirmed those wishes, the potential emotional harms of discussing end-of-life decisions outweighed the potential autonomy benefits of directly addressing the patient.

Similarly, from an ethical perspective, it was not necessary to review the decision to be an organ donor directly with Mr. Smith. Although the patient's condition was relatively uncommon, there is no substantive ethical difference in candidacy for DCD between a patient with locked-in syndrome and other potential DCD donors, such as a patient with ALS who is cognitively intact and desirous to discontinue life-sustaining support, or an unconscious or minimally conscious patient. Mr. Smith had previously chosen to register as an organ donor and had spoken with his family about his desire to be an organ donor, further indicating that donation was a value of his and was consistent with his wishes. To question his decision would be to hold him to a higher standard than that expected of other organ donors, whose donor registration would be respected without the corroboration of family members.

Although there remains variation in practice among OPOs, the 1987 amendment to the Uniform Anatomical Gift Act requires that a patient's donor registration be honored even when the family disagrees, out of respect for the patient's autonomy.⁵ Furthermore, although individuals may change their donor status and choose not to donate at any time, to ask Mr. Smith in his state of questionable capacity about whether he would like to donate might have caused additional ambiguity or confusion if he then stated contradictory wishes. Putting all of this together, it was ethically supportable, and seemed preferable, to honor Mr. Smith's previ-

ously stated wishes by following the standard DCD process.

Although it was not ethically obligatory to confirm the decision to donate with Mr. Smith, the treatment team considered whether it would be reassuring to share with him that it would follow his wishes. Many patients and families find meaning and comfort in knowing that their loss will save others' lives through organ donation.⁶ During these deliberations, the team discussed the uncertainty of DCD, as the process does not guarantee a patient's ability to donate. In order to proceed with the donation, the patient's heart must naturally stop within 60 minutes after life-sustaining support is withdrawn, to optimize the organs' viability for transplantation. Ultimately, this information was not shared with Mr. Smith, given concerns about his ability to understand and the emotional impact such a conversation might have on him. These are emotionally difficult topics that may be exacerbated by the potential for inadequate understanding of the information and the risk of conflating the questions of withdrawing treatment and donating organs. Depending on a patient's views, cognitive ability, and current emotional state, such discussion could even be cruel. It is unclear whether Mr. Smith's family discussed these plans with him. In retrospect, a better approach might have been to explore the family's thoughts on whether Mr. Smith would have found such knowledge reassuring, meaningful, or comforting, and, if they did, for the ethicist to support the family through the conversation. Without such family input, however, the potential comfort and other emotional benefits were not worth the risk of potential distress and other emotional harms.

Throughout the process, the ethicist and the treatment team remained attentive to the emotional needs of Mr. Smith's family. His youngest daughter was pregnant and appeared to be emotionally fragile in the setting of changing hormones, losing her father, and knowing her baby would never have a chance to meet his or her grandfather. Although these concerns were not relevant to the ethical analysis, they appropriately influenced the course of care. The team was careful to not prolong the end-of-life and donation processes, as each day waiting heightened the family's stress. At the same time, it was vital to ensure that the team's thought process and ethical analyses were not clouded by bias stemming from recognition of the national or-

gan shortage and their desire to promote organ donation.

In considering DCD for Mr. Smith, the team also raised questions about how to perform DCD in a manner that would ensure the patient's comfort and support his family. Following the institution's DCD protocol, Mr. Smith was transported to the operating room for implementation of comfort measures and withdrawal of life-sustaining measures, with his family accompanying him. The patient received all of the same comfort measures that would have been administered to any other patient in the intensive care unit (ICU) for whom life-sustaining treatment was withdrawn. The patient's comfort and preemptive pain management measures were accorded top priority, and the palliative medicine team ensured that Mr. Smith was sufficiently sedated and did not experience any distress, given that he had been intermittently alert and awake. Unfortunately, in that it precluded fully carrying out his wishes to donate his organs, Mr. Smith's heart did not stop within the requisite 60 minutes, and he was immediately taken back to the ICU to die peacefully, still with family by his side. Similar procedures should be followed in future cases regardless of the patient's level of consciousness.

Implications for Organ Donation Policy

Intrinsic to this ethics consult were questions of what organ donor registration means and how to assure a patient's comfort in the setting of DCD. With respect to the former, organ donor registration in the U.S. typically occurs at a state department of motor vehicles, but may also take place via online enrollment. However, these practices may limit an individual's autonomy by failing to assess the person's decision-making capacity, to ensure voluntary decision making that is free from external pressure, and to provide sufficient information about the risks and benefits of donation, to ensure an informed medical decision.⁷ Despite this, in the U.S., society and the healthcare profession accept organ donor registration as a reflection of an individual's true wishes, and laws require that a patient's recorded wishes be followed.⁸ Nevertheless, recognition of these limitations gave this treatment team pause in considering Mr. Smith, given the possibility, however remote, of potentially revisiting the decision to donate with him—an opportunity that is never available to

donors who meet death by neurological criteria, and is rarely available to DCD donors. For the previously discussed reasons, this avenue was ultimately not followed, but the question did highlight the failures of our organ donor registration system. Although solving this problem is outside the scope of this article, if all individuals who completed organ donation registrations did so with voluntary, informed consent, with full decision-making capacity, there would be no need to question an individual's donor registration status, whether nonresponsive or awake.

CONCLUSION

Mr. Smith was afflicted by locked-in syndrome and had questionable cognition and waxing and waning of consciousness. His case demonstrates the need for a careful balance between respect for autonomy and beneficence. Although not discussing the patient's wishes with him initially elicited discomfort among team members, further analysis indicated that it was not ethically obligatory to review his decision to donate, but rather that it was ethically supportable to honor his previously stated wishes by following the standard DCD process. In future cases, the question of whether to talk to a patient or a family when a patient's decision-making capacity is unclear may differ depending on the patient's condition, the decision to be made, and the family's agreement or disagreement regarding the patient's wishes. This case demonstrates the importance of access to a robust and trusted ethics consultation service and a treatment team's willingness to pause for reflection on and assurance of the ethical supportability of an organ donation plan. It also highlights the benefit of having pre-emptive discussions and an advanced directive to facilitate end-of-life care that aligns with a patient's wishes.

BLINDING OF THE CASE

Details of the case have been altered to protect the privacy of the patient's family members.

NOTES

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5. Uniform Law Commission, National Conference of Commissioners on Uniform State Laws, "Anatomical Gift Act (2006)," [http://www.uniformlaws.org/ActSummary.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://www.uniformlaws.org/ActSummary.aspx?title=Anatomical%20Gift%20Act%20(2006))

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8. Uniform Law Commission, National Conference of Commissioners on Uniform State Laws, "Anatomical Gift Act (2006)," see note 6 above.