

Patient-centered practices in organ donation

Christopher P. Michetti 

Inova Fairfax Medical Campus, Falls Church,
Virginia

Correspondence

Christopher P. Michetti

Email: christopher.michetti@inova.org

The opportunity for a critically ill patient to be an organ donor depends on a complex interplay of factors (the Donation Process), one of which is the treating medical team's perspective of the importance and priority of donation during end-of-life care. Medical providers frequently are hesitant to administer treatments to preserve organ function in patients whose death is imminent for fear of invoking a conflict of interest. The basis of the perceived conflict is that organ donation is a process done for the sole benefit of organ transplant recipients and not for the donor, and therefore care directed toward donation prior to death is not for the donor patient's benefit. In this report, it is argued that the Donation Process is indeed a patient-centered process for the potential organ donor and that organ donation serves the donor's best interests. In addition, key elements of the Donation Process are described.

KEYWORDS

critical care/intensive care management, editorial/personal viewpoint, education, physician education

A 49-year-old man lies in an intensive care unit bed, comatose. He sustained a severe traumatic brain injury and was unconscious at the scene where he was intubated before transport to the trauma center. Imaging confirms what his clinical exam portends: a devastating injury from which he is unlikely to recover. After 3 days, despite maximal medical therapy, he has recalcitrant intracranial hypertension. His family remains at his bedside, hoping. He develops progressive organ dysfunction, hypovolemia, and hypotension from diabetes insipidus.

The critical care fellow suggests a fluid bolus and vasopressin infusion. The supervising physician declines to initiate more intensive measures, indicating that his injury is nonsurvivable and discussions about comfort care measures are planned for the morning. The fellow counters that without this support, organ failure may ensue and he could be ineligible to donate his organs. The attending rebukes, "That won't change the outcome, and you can't think about donation before he's even dead." By morning it is clear that herniation has occurred, and the patient is pronounced dead by neurological criteria. His wife points out that her husband often talked about wanting to donate his organs when he died—could he do that now? The organ procurement organization (OPO) is notified and reviews his case, but they determine that he is not suitable for donation; his organ dysfunction is too advanced.

Unfortunately, this is a common scenario. Up to one quarter of potential organ donors are lost due to inattention to standard physiologic goals when death by neurologic criteria is imminent.¹ Conversely, a practice of aggressive management in such patients increases the number of organ donors as well as the number of organs recovered for transplantation.²⁻⁴ In one study over an 8-year period, aggressive management resulted in an 82% increase in donors and an 87% decrease in donors lost to hemodynamic collapse.³ In the case presented here, under the premise of avoiding a conflict of interest attention was not given to the possibility that this person could be an organ donor. Or that he *wanted to be* a donor. After all, isn't organ donation something that happens *after* death? How can we try to save a person's life yet simultaneously plan for their death? Is planning for organ donation admitting defeat? Or worse, is it an abrogation of our duty to this patient's care?

These questions are challenging, but become less so when viewed through a patient-centered perspective. According to the Institute of Medicine, patient-centered care is "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions."⁵ Organ donation, which hinges on a patient's own affirmation (or that of a surrogate on their behalf) to donate his or her own organs after death, is therefore integral to patient-centered care. Donation is

Abbreviation: OPO, organ procurement organization

the fulfillment, if medically possible, of a choice made by a person based on their "preferences, needs, and values." Consequently, the "Donation Process" centers on facilitating this wish of the donor.

The Donation Process involves all of the things that health care professionals do—or don't do—that affect the ability of the patient to be a successful organ donor if they or their surrogate so chooses, and if they die in the hospital. It includes decisions about if, how, where, and when a patient is treated and resuscitated and how those decisions align with a patient's wishes for their treatment at the end of life. It includes the timeliness with which the OPO is notified, their subsequent activities, and the interaction between hospital and OPO personnel. Importantly, it involves how a patient's family is treated, the quality of communication with them, and the degree of trust engendered. The components of the process require attention and management whether or not the patient actually dies or wants to be a donor, because they must be performed in advance of those determinations to permit the option of donation later should that choice be made. Similar to how preventable medical errors may occur, where multiple seemingly unrelated factors in a complex system interact to culminate in a negative outcome,⁶ various acts and omissions during the course of a critically ill patient's care must play out in a certain way to allow a positive outcome for donation. The strategy of "begin with the end in mind"⁷ succinctly summarizes the approach needed for an optimal Donation Process.

There are several influences on this process, and significant among them is the attitude of the physicians treating the potential donor. Components of the process may be carefully coordinated, delayed, directly counteracted, or ignored outright depending on a physician's perception of the importance of organ donation in general or to their patients. For example, if one takes the approach of the attending physician in our opening scenario, contemplating treatments directed at preserving organ function for the potential of donation is not only a low priority, but possibly contraindicated in the patient whose imminent death is almost certain, because it would not save his life. Also, the attending physician indicates that attention to donation is not beneficial for this person while the patient is alive, presumably because the physician considers transplant recipients as the sole beneficiaries of donation.

In making this unilateral decision, the attending is also making several assumptions on behalf of the patient, including that (1) the only relevant outcome to consider is life or death; (2) the patient prefers a dying process that excludes any treatments whose purpose is not to save his life; (3) the patient does not have specific wishes for being an organ donor and would therefore leave it to the medical team to decide if this option should be considered, and when; (4) the patient prefers end-of-life care that prioritizes minimal intervention over care that includes more active measures that could preserve organ function for donation; (5) considering organ donation prior to the patient's death is not in the patient's best interests, and by extension, that such consideration is only in transplant recipients' interests; (6) the patient's family, acting as his surrogates, would decline the opportunity for donation if it required planning prior to his death; (7) he would not want to offer his family the possibility of

comfort that may result from knowing that in death he saved the lives of one or more other people, if achieving that outcome meant receiving care during life that would prolong the dying process or cause his family any immediate bereavement; and (8) all of these donation-related activities could not be done in a way that preserves his dignity or the medical team's compassion for his family.

At the heart of these assumptions is the perception that the Donation Process is centered exclusively on the potential organ recipients. And if that is true, then acting on a dying patient to improve a potential recipient's chances of obtaining an organ transplant presents a conflict of interest. But is this accurate? Although transplantation is the ultimate goal of the broader organ donation system, I would assert that the Donation Process has as much to do with the donor's own best interests. Patients have a right to autonomy: to be self-determining with regard to their medical wishes. In the United States, the Patient Self-Determination Act of 1990⁸ outlines a person's right to document their medical wishes in advance and for them to be honored as valid when patients lack the capacity to otherwise express them. As health professionals, our duty to our patients' medical directives does not cease upon death if one of those directives is to facilitate organ donation. This wish is often intimately tied to a patient's values and beliefs in ways that other medical decisions are not. It is, in a way, an individual's decision about what happens to other people as much as it is a decision for one's own treatment. Yet individuals have a justified expectation that such directives will be carried out after they die. Patients who wish to be organ donors put their trust in the medical system to bring that wish to fruition. During life they benefit from the comfort of their perceived assurance that

TABLE 1 Components of the organ donation process: patient factors

Eligibility	Determined exclusively by the OPO Based on current medical condition, medical history, and age
Desire	Documented by the patient through first person authorization, such as in a donor registry, driver's license, or advance directive First person authorization becomes active upon death, is legally binding, and irrevocable Determined by surrogates when patient's wishes are unknown or undocumented. Must be determined prior to actions or inactions that could threaten organ suitability for donation
Suitability	Having sufficient function and viability to allow transplantation Influenced by acute medical events occurring prior to death, including prehospital and admission Threatened by hypoperfusion, ischemia, hypoxemia, and metabolic abnormalities Ultimately determined by the OPO and transplant center, but optimized by the medical team until eligibility and desire are determined

OPO, organ procurement organization.

our Donation Process is set up to do just that. But the process may not work unless it begins early enough, that is, as soon as the possibility of death is recognized.

In hospitals with a donation-supportive culture, it is recognized that there exists no distinction in priority of the wish to be a donor from any other autonomous medical decision, such as agreeing to an operation for colon cancer or a cardiac catheterization for a myocardial infarction. Medically and legally, the wish to be a donor is not subordinate to other end-of-life medical decisions.⁹ But sometimes caregivers' fear of conflicting interests¹⁰ (prioritizing recipients' interests over those of the donor patient) results in subordination of the donation directive. This fear perpetuates the narrow view that anything done for the purpose of organ donation is done solely for the benefit of transplant recipients. From this perspective, interventions to preserve organ function in potential donors serve only others' best interests. However, if a patient's autonomous wish is to donate, preserving that option for them (as the fellow in the opening vignette attempted) is fully aligned with their own best interests and honors the donors' directive. When organs are recovered and then judged unsuitable for transplantation, there is no recipient. Was the attempt on the donor's behalf not worth it? Was the donor's intent not heroic?

Nevertheless, a dilemma still exists. The process of donation requires advanced planning to determine three patient-centered factors: eligibility, desire, and suitability to donate (Table 1). Responsibility for the first two usually rests with the OPO. The third,

suitability, requires good organ function and is the responsibility of the medical treatment team. This means avoiding ischemia and hypoxemia, which may arise when supportive treatments are limited or withdrawn (often in the name of "futility") or to quell the family's concern that these treatments are only prolonging their loved one's suffering prior to an inevitable death. Patients rarely realize that their desire to be an organ donor and their desire to forego certain treatments at the end of life are often mutually exclusive. The need to preserve organ perfusion and oxygenation for donation often requires the very measures that will prolong life when death is desired, such as vasopressors and active ventilatory management. What should one do in such a precarious situation?

This dilemma can be addressed by determining the patient's wishes on the matter, to the degree they can be determined. This usually requires involvement of OPO professionals, who will speak with the patient's family or surrogate to arrive at a suitable outcome from the patient's perspective, based on the patient's values. Early involvement of the OPO is just one of many hospital and OPO-related factors that contribute to the Donation Process (Table 2). When patients have already expressed their donation intention, such as through first person authorization (Table 1), OPO staff have a solid foundation on which to build their relationship with families and discuss the patients' wishes. The conversation may then shift from speculation on what the patient would have wanted to how their known wishes can be honored. Ideally, donation wishes would

TABLE 2 Components of the organ donation process: hospital and OPO factors

Hospital policies and practices	<p>Policies in place for determination of death; organ, tissue, and eye donation; donation after determination of death by neurologic criteria; donation after determination of death by circulatory criteria</p> <p>Organ donation committee or council</p> <p>Fostering a donation-supportive hospital culture</p>
Hospital-OPO collaboration	<p>Memorandum of understanding or other written agreement with OPO</p> <p>Shared educational activities about donation</p> <p>Bidirectional feedback</p> <p>Engaging leaders and donation "champions"</p>
Practitioner knowledge, attitude, skill	<p>Practitioners' level of support of the donation mission</p> <p>Practitioners' clinical competence in donation practices and procedures</p> <p>Use of clinical triggers for OPO notification</p> <p>Meeting with OPO staff ("huddle") to discuss potential donors</p>
Death declaration	<p>Death declared based on neurologic criteria (brain death) or circulatory criteria</p> <p>Performed by medical providers based on standard medical practices, local statutes, and national guidelines</p> <p>Documented meticulously and using a standard form</p>
Donor management	<p>Necessary for donors after death by neurologic criteria and often guided by the OPO, sometimes in collaboration with intensivists</p> <p>For donors after death by circulatory criteria, management remains with the medical team until death is pronounced</p>
Organ recovery	<p>Performed by the recovery team in the operating room</p> <p>Always occurs after declaration of death</p>

OPO, organ procurement organization.

be documented in advance directives in the same manner as other end-of-life care choices, thus relieving the family of the decision-making burden and reducing the ambivalence experienced by some physicians about providing care directed at donation in a nonsurvivable patient. Nevertheless, ensuring that the option of donation is offered to all eligible patients and their families is a patient-centered approach directed at discovering and honoring patients' wishes, in addition to being one of the Centers for Medicare and Medicaid Services conditions of participation.¹¹

The consideration of comfort measures by a patient's family imposes a sense of urgency to discover the patient's donation wishes and also an obligation to continue full medical treatment until that determination is made.⁹ This is a critical mandate. After all, a patient's wish to donate could not be honored if the health care team permitted ischemia, because this act of omission decreases the chances of successful donation. This would be a contradiction of the patient's request to be a donor. If the patient has chosen not to donate, then treatment limitations may be appropriate; however, according to the revised Uniform Anatomical Gift Act,⁹ those limitations cannot be enacted until a decision about donation is determined. Maintenance of life-sustaining treatments to preserve the option of donation serves the best interests of those who wish to be donors, provided it does not present a risk of harm or a diminution of their dignity. The patient-centered focus on honoring the potential donor's wishes eliminates any potential conflict of interest or ethical dilemma that may arise when such practices are viewed as being only for the transplant recipients' benefit. This practice in fact has legal support in the United States⁹ as well as the United Kingdom.¹² However it is not only a legal requirement but also excellent end-of-life medical care.

Physicians should also recognize the importance of timely declaration of death by neurologic criteria (brain death), soon after its clinical signs are apparent. This benefits both patients and their families. Earlier declaration of brain death facilitates earlier donation-centered management by the OPO, should the patient be an organ donor. This in turn is associated with a greater number of organs suitable for transplant for each donor.¹³ But appropriate declaration of death is necessary regardless of a patient's intent to donate his or her organs. For example, families may opt for comfort care measures in patients who are neurologically devastated but in whom brain death has not yet been determined. If the patient is deemed ineligible for donation, medical providers may forego the detailed examination for brain death and institute comfort measures instead, reasoning that formal brain death declaration is not necessary in nondonors. This practice should be strongly discouraged; it would not be medically or ethically appropriate to go through the motions of withdrawal of "life-sustaining" treatments in a patient who has already died, merely because the examination to determine death has not been performed. Perhaps even more concerning is the potential for burdening the family with the decision to stop treatments, and the guilt that may go along with that decision, when they could have been reassured that the patient already died of their own disease.

Health care professionals who feel conflicted about providing ongoing medical care to a patient whose death is imminent for the

purpose of preserving the patient's suitability for donation need not look past their patient's room to the transplant center for justification. They only need to ask, "Is this what my patient would want?" And then they should attempt to answer that question before withholding vital measures that are sustaining organ function. The fact that donation happens to ultimately benefit transplant recipients is surely a wonderful outcome. But when it comes to our duty as health care providers to the patient right in front of us, this is not necessarily as relevant. We must achieve expertise in the Donation Process as part of normal end-of-life care for the benefit of *our* patients, *their* wishes, and *their* legacy. It is a patient-centered process, and the patient at the center of it is the donor.

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ORCID

Christopher P. Michetti  <https://orcid.org/0000-0002-3744-0603>

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