

Commentary

End-of-Life Care and Organ Donation: Rethinking Legislative Separation

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Abstract

Reflections on Claire O’Callaghan and Brendan Parent’s article “Withdrawal of Life-Sustaining Treatment and Organ Donation After Circulatory Death: Consequences of Legislative Separation.”

Keywords: Donation after circulatory determination of death (DCD); End-of-Life; Organ donation; Uniform Anatomical Gift Act; Withdrawal of life-sustaining treatment (WLST)

We keep the wall between us as we go.
To each the boulders that have fallen to each.
--Robert Frost, “Mending Wall”¹

A distinctive feature of organized transplant medicine has been the bifurcation of clinical roles that entail caring for potential organ donors at the end of life (EOL) and caring for potential transplant recipients. This division of responsibility, commonly understood as an ethical safeguard protecting potential donors’ welfare, stems from widespread appreciation that their interests may conflict with those of patients in need of a transplant. Thus, the American Medical Association’s Council on Ethical and Judicial Affairs urges physicians engaged in transplantation to “[e]nsure that” members of the transplant team are not involved in decisions about withdrawal of treatment or the determination of death.² Additionally, the Council’s guidance calls on physicians to “encourage health care institutions to distinguish the roles of health care professionals who solicit or coordinate organ transplantation from those who provide care at the time of death.”³ In this issue of *The Journal of Law, Medicine & Ethics*, Claire O’Callaghan and Brendan Parent show that the *separation of decision structures* shaping EOL care and organ donation cuts more broadly and deeply than references to the *division of clinical labor* might suggest. Typically, decisions about the use of life-sustaining treatments (LSTs) are governed by state Health Care Decisions Acts (HCDAs), while organ donation is governed by Anatomical Gift Acts (AGAs).⁴ The two sets of choices are not only treated distinctly as a matter of law; they are addressed in different sections of the state code.

O’Callaghan and Parent surmise that this disconnect is the result of a “decoupling” strategy, similar to the aforementioned decoupling of clinical roles, intended to ensure that patients’ goals of care with respect to LSTs are not compromised by the potential for organ

donation.⁵ That rationale resonates with public apprehensions about intrusive or unduly aggressive organ retrieval.⁶ Without historical investigation, it is less clear why state legislators or members of the Uniform Law Commission opted to treat health-care decisions and anatomical gifts as separate policy domains. Hospital personnel such as in-house counsel and intensive care unit (ICU) staff may notice that the next of kin recognized in a state AGA do not perfectly track the default hierarchy of substitute decision-makers in the same jurisdiction’s HCDA. Yet this absence of alignment may be a consequence of customary divides between fields of legal specialization and disconnected, organic, legislative initiatives, rather than deliberate decoupling based on some unifying theory. Within such a heterogeneous and at times ambiguous legislative environment, tensions between patients’ health care advanced directives and donation authorization “may be handled differently by different clinicians, OPOs [organ procurement organizations], or institutional agreements.”⁷ Regardless of these arrangements’ origins, the Authors elucidate realistic case scenarios in which current policies and practices, particularly those aiming to preserve opportunities for donation, seem as likely to frustrate patients’ values and wishes as to advance them.⁸

The crux of the problem is that fully honoring an incapacitated patient’s prior wishes with respect to EOL care may not be compatible with fully honoring the same individual’s prior wish to be an organ donor. The reason for this is that EOL care options and possibilities for organ donation are not independent physiologically, much as we may try to disaggregate them procedurally. Choices related to the use and withdrawal of LSTs, such as the timing and location of withdrawal, will affect organ viability for transplantation, whether or not transplant considerations inform the discussion. Conversely, techniques that could optimize organs for clinical use, such as transporting a dying patient from a community hospital to a better-equipped donor center, are likely to affect EOL experiences and may only be practicable if HCDA-compliant advance directives are suspended. Decoupling EOL

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and donation decisions (even if one considers this to be the most prudent approach) does not merely disaggregate the choices; they must be prioritized sequentially or reconciled in some other way. Notably, tensions between EOL and donation preferences can be explained and analyzed in terms of patients' individual commitments, which come into conflict in particular circumstances, *without reference* to the interests of third parties such as loved ones at the bedside and transplant candidates. Ideally, people who would prefer not to have every possibly life-prolonging physiological support, but also hope to donate their organs, might give surrogate healthcare decision-makers a clear indication of how these objectives should be balanced or reconciled. In reality, few patients are likely to have considered what current implementations of donation after circulatory determination of death (DCD) may encompass when completing advance directives or agreeing to donation.⁹

The challenges illustrated by O'Callaghan and Parent have become more salient in recent years as a result of two closely-related developments. One driver is the expansion of DCD, in absolute terms and relative to donation after death determined by neurological criteria, with newer outcomes data and refinements in techniques for identifying organs suitable for transplant.¹⁰ A second factor, supporting the increased use of DCD, is greater understanding of how the conditions of organ donation and preservation affect transplant outcomes and can be manipulated to improve these outcomes.¹¹ Prospective donors generally are not well-positioned to specify how they would want evolving organ recovery techniques to be utilized at some unknown future time, even if there were a mechanism for registering their preferences. Hence, normative choices relating to the integration of LSTs and DCD are likely to continue arising around potential donors who are hospitalized, near the end of life, and no longer able to process these questions themselves. After surveying existing sources of guidance and their limitations, O'Callaghan and Parent gesture to several possible structural reforms that may ease stresses on patients, loved ones, clinicians, and institutions while "ensur[ing] that patient-donors' values and preferences are sufficiently respected."¹² Fittingly, the authors identify roles for diverse stakeholders in more closely and deliberately integrating EOL care and donation decision-making, highlighting the potential value of additional inquiry and input in the pursuit of this objective.¹³

In responding to the call to revisit present arrangements, members of the public, including policymakers, will be pressed to think attentively about what values and interests we are seeking to uphold, as well as what harms we are seeking to mitigate. In medical ethics literature, this task was prefigured by criticism of changes made to the Uniform Anatomical Gift Act in 2006, which were tempered in another update the following year. Whereas the 2006 version of the model act leaned heavily toward maintaining the possibility of donation in the face of incongruous or unknown patient wishes about withdrawal of LSTs and donation, the 2007 amendment aimed for something approximating a state of "equipoise."¹⁴ That equipoise, extended over time to enable the review of documents, donor assessment, and approaching family members about donation, has become today's potentially distressing "limbo period."¹⁵ The technical feasibility of employing LSTs for the purpose of clarifying whether individual patients should remain on LSTs to facilitate organ donation presents a vexing challenge of distinguishing due process from undue burden. Values that many of us are likely to consider important in the balance include *patients' own goals and preferences* (insofar as these can be discerned), *patients' physical comfort, respect for their relationships of trust with substitute decision-makers, and clinicians' ability to*

*perform their roles with ethical integrity.*¹⁶ Additional, policy-level considerations may include *public confidence in healthcare systems* and the relative merits of *standardization* and *harmonization* versus *responsiveness to differences in local circumstances* and *flexibility for creative adaptation*.

This kind of wayfinding exercise offers an opportunity to evaluate (judiciously) prevailing assumptions in the field of solid organ transplantation. For example, we might consider whether it makes sense for clinicians in the circle of care, with appropriate preparation, to have a more central part in conversations about DCD with surrogate decision-makers than is usually the case now. If key questions concern how antemortem measures may or may not fit into a patient's schema of values or vision of a good death, the patient's attending physician could plausibly be better positioned to explore these questions than are OPO staff.¹⁷ Partitions and air gaps can safeguard cherished values and interests, or hinder their realization. O'Callaghan and Parent have provided substantial reason to think that, in some circumstances, the current contours of decision separation are setting up, rather than averting, conflicts over the use of LSTs and harms at the end of life. That apprehension makes this an opportune juncture to ask if we are maintaining the right kinds of boundaries in the right places.

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