

Caring for Organs or for Patients? Ethical Concerns about the Uniform Anatomical Gift Act (2006)

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In 2006, the National Conference of Commissioners on Uniform State Laws rewrote the Uniform Anatomical Gift Act. To overcome the problem of family members prohibiting organ donation from their deceased loved ones even when a donor card existed, the commissioners modified the act to prevent end-of-life care from precluding organ donation. An unintended consequence of the new wording creates the potential for end-of-life care that prioritizes care of the potential donor organs over care and comfort of the dying person. The commissioners have now revised the act, but the original version has already been legislated in many states, with

others poised to follow. To protect dying patients' wishes about their end-of-life care, states that have legislated or are considering the original act must replace it with the revised version. A long-term and important ethical precept must stand: Care of dying patients takes precedence over organs. Another laudable goal must be promoted as well: Organ donation is an important part of end-of-life care.

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A man has a stroke and has irreversible brain injury, but he is not brain dead. The family want to honor his wishes to "not be kept alive on machines if there is no hope," something he put into an advance directive. However, he designated himself as a donor on his driver's license. The physician wants to discuss what to do next, and how to prioritize care, but he is stopped by a new state law, modeled after the new Uniform Anatomical Gift Act (2006). The law states that, because the patient is an organ donor, his end-of-life care must be managed in a way to promote donation, even if it compromises comforting care. His do-not-resuscitate order is reversed, and he is resuscitated when he becomes hypotensive and loses pulse. Mechanical ventilation, blood sampling, and other critical care are continued. The physician cannot discuss options, because according to the Organ Procurement Organization, the family does not have the option not to donate. Therefore, any decisions regarding terminating critical care are vetoed per statute. Twelve hours later, the patient is taken to the operating room, life-sustaining treatments are removed, he dies, and his organs are procured.

This is a true story. We believe it represents an unintended consequence of new language incorporated into the Uniform Anatomical Gift Act (2006).

THE UNIFORM ANATOMICAL GIFT ACT

Recently, the National Conference of Commissioners on Uniform State Laws (NCCUSL) made important and needed revisions to the Uniform Anatomical Gift Act (2006) (1), the key model statute used by every state as the

legal foundation for organ and tissue donation. In the process of making needed changes, however, they created model legislation containing serious ethical problems. In the model act, the NCCUSL urged state legislatures to create a law that gave organ donation priority over a person's advance directive regarding their end-of-life care and physician orders for life-sustaining treatment (2, 3). The prioritization was ethically improper and will probably be counterproductive to the Commissioners' laudable intent, which was to increase the number of organ donors. Eighteen states have already adopted the statute, 3 have had it passed by at least 1 house of the state legislature, and another 9 have introduced it into their legislatures for action (Table 1). After the Uniform Anatomical Gift Act (2006) was challenged by ethicists (4), the NCCUSL amended the offending section with ethically more acceptable language (Table 2). Despite these changes, ethically suspect laws are already in place. Whether they are changed remains to be seen.

The story of the Uniform Anatomical Gift Act (2006) and the last-minute attempt to modify it provides important insights into controversies surrounding organ donation and end-of-life care. In this article, we outline the reason for updating the act; the ethical concerns involved; and what we can learn from the failure of expert, ethical, and well-meaning people to recognize an important and long-standing ethical boundary. We raise this issue out of a concern that the desire for donor organs has become so fervent that obvious ethical transgressions were overlooked in the effort to improve the process.

The Uniform Anatomical Gift Act needed to be updated. First written in 1968 and revised in 1987 (5), the 1987 model statute was adopted by only 25 states (1), leaving the United States without a national standard. It also needed to be clearer and stronger regarding an individual's decision to donate his or her organs after death, especially in protecting patients' wishes to donate their organs against the wishes of others. The authors of the 2006 version achieved those goals.

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Unfortunately, the original Section 21 in the 2006 version did more. In aiming to prevent advance directives from precluding organ donation, it prioritized the donation of organs over the patient's other end-of-life wishes, as well as physician orders for limitation of life-sustaining treatments. As originally written, Section 21 could have been used to *prevent* provision of routine end-of-life care by patients' bedside physicians, nurses, and allied health professionals in the interest of organ preservation. The proposal (1) stated:

If a prospective donor has a declaration or advance health-care directive, *measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor*, unless the declaration expressly provides to the contrary [emphasis added].

UNINTENDED CONSEQUENCES OF THE UNIFORM ANATOMICAL GIFT ACT (2006)

This statement and the commentary that followed assume that someone wishing to be a donor has prioritized organ donation over other end-of-life management considerations (such as decisions to decline endotracheal intubation, cardiopulmonary resuscitation, and mechanical ventilation). The assumption that would-be organ donors want to prioritize donation over routine palliative care lacks empirical support. There is no evidence that persons prioritize organ donation above (or below, for that matter) other end-of-life care. This assumption also contrasts with a broad literature regarding patients' desires to have their preferences for end-of-life care followed (6). The wording of Section 21 permitted a patient with respiratory failure after a neurologic event to have unwanted intubation "to ensure the medical suitability of an organ for transplantation" even if the patient had an advance directive to the contrary, because "... therapy may not be withheld or withdrawn from the prospective donor, unless the declaration expressly provides to the contrary" (1).

When the original version of the Uniform Anatomical Gift Act (2006) became law, patients were put at risk. To be sure, a person's advance directive could avoid this conflict by stating not only which specific treatments are not wanted but also *specifying the priority* of organ donation and end-of-life care. This has the advantage of providing caregivers with explicit first-person instructions. However, those with a donor card who fail to prioritize their wishes will have their advance directive for withholding or withdrawing life support nullified.

The original version of the Uniform Anatomical Gift Act (2006) created an unwanted and improper intrusion into the physician's care of dying patients because, if enacted by states, it legislates the countermanding of a physician's orders by other personnel, namely organ procurement coordinators, who are not licensed to prescribe for or provide medical care for living individuals. A national ini-

Key Summary Points

The Uniform Anatomical Gift Act (2006) is improved, but it prioritizes organ donation over end-of-life care concerns. This is ethically wrong.

The original Uniform Anatomical Gift Act (2006) has been legislated in many states.

A revised Uniform Anatomical Gift Act (2006) corrects the concerns but has not been introduced into most legislation.

Health professionals should urge states to adopt the revised Uniform Anatomical Gift Act (2006).

Promoters of organ donation should include more end-of-life and critical care professionals in their organizations.

tiative is under way to increase use of physician orders for life-sustaining treatment to promote appropriate end-of-life care (2, 3). Physician orders for life-sustaining treatment are not patient wishes; they are a physician's order set. Physicians' orders have a protected status in a health care organization, and rightly so. Imagine the potential for harm if physicians' orders were construed merely as suggestions that could be ignored in the service of broader social purposes. Sometimes physicians do improperly write orders that have the effect of precluding organ donation. But, ignoring physicians' orders regarding end-of-life care is not the best method to rectify physicians' errors or increase trust between intensive care unit caregivers and organ procurement professionals.

Evidence indicates that people have clear opinions on their end-of-life care, including not only preferences for interventions, such as palliative medications, but also organ donation (7). However, individuals rarely record their priorities in their advance directives. Regrettably, no one, when asked for consent to donate (which often occurs at a state motor vehicle license office), is also asked whether the organ donation should nullify their preferences regarding end-of-life care. In this setting, the argument that organ donor consent should take precedence over all other end-of-life care issues is at least dubious, possibly against the patient's wishes, and definitely uninformed. Acting on such uninformed consent is ethically and perhaps legally improper (because of a lack of evidence that people understand this issue when consent is obtained). And yet, it happens. The Uniform Anatomical Gift Act (2006) took advantage of this broad, uninformed consent and undefined prioritization to indeed make donation take priority over other end-of-life care considerations.

The original version of the Uniform Anatomical Gift Act (2006) is unethical in another way. Because it vetoed certain routine end-of-life orders written by physicians, the

Table 1. Status of the Uniform Anatomical Gift Act (2006) in the United States, as of August 2007*

Enacted	Passed 1 or Both Legislatures and Are Awaiting Governor's Signature	Introduced into Legislature, Action Pending
Arizona†	California	District of Columbia
Arkansas	North Carolina	New Jersey
Colorado†	Texas	New York
Idaho		U.S. Virgin Islands
Indiana		Alabama
Iowa†		Alaska
Kansas		Maine
Minnesota†		Missouri
Montana		Washington
Nevada†		
New Mexico		
North Dakota		
Oregon†		
Rhode Island‡		
South Dakota		
Tennessee†		
Utah		
Virginia		

* Information from the National Conference of Commissioners on Uniform State Laws, August 2007. Accessed at www.nccusl.org/update/uniformact_factsheets/uniformacts-fs-uaga.asp on 22 October 2007.

† These states enacted the revised Uniform Anatomical Gift Act (2006).

‡ Section 21 was omitted.

2006 act can subordinate care of the patient to care of the organ. Priority care for organs makes sense for individuals who already have been determined to be dead according to neurologic criteria, but not when patients are still alive. There is a clear proscription against transplantation personnel caring for potential donors because of the conflict of interest. The 2006 act codifies exactly this behavior. There is no question that the best policy for patients who are alive in intensive care units is continued care by the critical care professionals rather than organ procurement organization representatives or transplantation physicians. After patient death, the latter 2 may take control.

Finally, this inversion of priorities may be counterproductive to the goal of increasing organ availability. A known barrier to obtaining consent for organ donation from individuals is the fear that the consent will lead to poor critical care because decisions might be based on what is best for organs rather than what is best for the patient (8, 9). Put bluntly, people are afraid that their doctors (critical care or otherwise) will stop appropriate care to “get at” their organs. The original version of the Uniform Anatomical Gift Act (2006) seemed to codify this improper behavior.

We know of at least 1 organ procurement organization representative who told a physician he could not discuss prognosis and end-of-life treatment options with a patient's family because the patient had a donor designation on his driver's license “and withdrawing treatment is not an option.” The representative had the concern that the family would choose to withdraw life-sustaining treatments after the discussion and nullify the donor's intent to donate. Families cannot revoke a person's documented deci-

sion to be an organ donor. But the notion that the veto power implicitly created by the new act might be misused to prevent physicians from discussing options concerning prognosis and treatment can only *increase* distrust of the organ donation process.

LESSONS LEARNED

Of course, organ and tissue donation should occur whenever possible as part of quality end-of-life care. If organ donation cannot occur because of patient wishes for specific end-of-life care, it should sadden us. But we may take consolation in the fact that tissues—eyes, skin, bones, ligaments, heart valves, and blood vessels—can be donated and still save many lives. For some, that will have to do. For others, organ donation may be a higher priority, and they might want to adjust their care in order to achieve that goal. But of course, sound public policy would require us to ask them.

Those who do want to donate should do 1 of 3 things: 1) Put this decision into their advance directive; 2) notify their local organ procurement organization to enter them into their donor registry; or 3) for states that have legislation to support it, designate themselves as a donor when they obtain their driver's license. In addition, for the people who wish to prioritize organ donation over routine end-of-life care, this should be indicated in their advance directive.

What should happen? First, we must protect patients. States that haven't introduced the Uniform Anatomical Gift Act (2006) should introduce the amended version. States that have introduced the original version should

Table 2. Changes to Text of Section 21

Original wording of Section 21

- b) If a prospective donor has a declaration or advance health-care directive, *measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor*, unless the declaration expressly provides to the contrary [emphasis added].

Revised wording of Section 21

- b) If a prospective donor has a declaration or advance health-care directive and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, an agent acting under the prospective donor's declaration or directive, or, if none or the agent is not reasonably available, another person authorized by law other than this [act] to make health-care decisions on behalf of the prospective donor, shall act for the donor to resolve the conflict. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under Section 9. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.

abandon it in favor of the revision. Finally, states that have already enacted the original version must amend the law with the new Section 21 as soon as possible to protect their citizens. It is important that our laws reflect our intention to provide outstanding end-of-life care as a priority and that organ donation should not trump that intention.

Second, there are some important lessons to be learned. It is likely that most of the time, critical care professionals can satisfy patient wishes concerning both how they die and their desire to donate organs, particularly given the widespread availability of donation after cardiac death. It is a mistake to think that prioritizing 1 over the other is likely to foster both. We are pleased that, for the first time, wording has been added to the revised Uniform Anatomical Gift Act (2006) reflecting the important notion that organ donation should not adversely affect palliative care in a significant way. There is a sort of “dual universe” that exists at the bedside of dying patients who also want to be organ donors. On the one hand, critical care professionals want to provide quality end-of-life care. On the other, procurement coordinators try to promote organ donation activities that can save lives. In the real world, these goals can be seen as competing interests and can raise suspicions that undermine trust. The revised wording helps to resolve the ambiguity and misperceptions.

Third, NCCUSL and other organ donation groups must broaden representation to include end-of-life caregivers. Neither NCCUSL nor organ procurement organizations are insensitive to the terminally ill or their families. Of course, they too want to promote quality end-of-life care. But the NCCUSL drafting committee, which seems to have had no representation by end-of-life care experts, disregarded important ethical concerns. We believe that their membership reflects, and perhaps promotes, the same sort of dichotomy that exists at the bedside, as well as the “let’s increase donation” mindset that led to this misguided section. In the future, those concerned with organ donation must work closely with those involved with end-of-life care to create laws and public policies that avoid oversights and unanticipated concerns about that care. We, like the Institute of Medicine (10), urge expanded membership in all organ donation policy discussions.

Fourth, organ donation is an end-of-life care issue. People choose to donate at least in part because they want saving lives to be part of their legacy. New organ donor collaboratives recognize this and are aimed at critical care professionals who are integral to the process. We applaud this partnership. Perhaps it is time to stop promoting organ donation by using a “we need your organs” strategy. Instead, the story of the Uniform Anatomical Gift Act (2006) suggests the wisdom of a strategy that includes end-of-life caregivers and says, “After you die, organ donation can add to a legacy you and your family can treasure.” Great end-of-life care is a necessary foundation to promote trust that may overcome long-existing anxieties some have toward organ donation.

CONCLUSION

Should organ donation trump end-of-life care? If we know this is the patient’s wish, then yes. In other situations, we think not. Donor registry permission should emerge as an authoritative voice regarding patient wishes only *after* end-of-life care decisions have been resolved. If done in this order, no change in donor registries is required. The revised Uniform Anatomical Gift Act (2006) makes this point. We advocate that for people who do enter into a registry, they receive communication (perhaps a pamphlet) regarding what their designation means and how to make modifications to their decision. This would address concerns that the current process does not provide *informed* consent. But this recommendation should not distract from our main point: In a situation where the priority is not known, we should always err on the side of taking care of patients before organs.

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